We welcome enquiries about any aspects of our work which may be of interest to you.

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INTRODUCTION

Welcome to this tri-annual report of the Department of Palliative Care and Policy in Guy’s, King’s and St. Thomas’ School of Medicine, at King’s College London. We have chosen to report three years’ activity in this document in order to give a clearer picture of progress and connections in the different elements of our work.

Palliative care and hospice services have grown rapidly across the globe, and can now be found in over a hundred countries. However, despite this growth, research progress has struggled to keep pace with needs of patients and families in terms of discovering better treatments and ways of providing quality services. The research community faces many different barriers – the challenges of conducting research among very ill patients and distressed families, the lack of dedicated streams of funding, and a nihilism on the part of some clinicians, ethics committees and organisational bodies that views the whole topic as “too difficult” to research. We are, therefore, proud of our achievements to date, and are grateful to those funders that have invested in this topic. We would like to thank the Department of Health, particularly Regional NHS Research and Development strands which (when in existence) invested in research in palliative care, the charities including The Cicely Saunders Foundation, Macmillan Cancer Relief, Marie Curie Cancer Care, Cancer Research UK, The Diana Princess of Wales Memorial Fund, Help the Hospices, The Multiple Sclerosis Society, British Heart Foundation, Stroke Association, MND Association, The Nuffield Trust, The Florian Foundation and Department of Health USA and others for having the vision to support this area.

I would also like to thank those organisations which have collaborated with us, from within King’s College London, throughout the United Kingdom and many other countries. They have brought skills and expertise which greatly benefited the programmes and have begun to pave the way for multi-professional research. Similarly, we are grateful for the interactions with the MSc and PhD students within the department. Both programmes attract highly motivated, skilled and knowledgeable individuals from a diverse range of backgrounds, including medical, nursing, psycho-social and therapeutic professions and from different countries. Their projects and interactions have helped us to broaden our vision, and students have undertaken original and high quality work, which is now moving to publication. They enable us to strengthen our external links for wider future collaboration.

Due to the challenges to research in our topic you will see that some of the elements of our research is dedicated towards methodological development – advancing ways to evaluate complex interventions using the MRC Framework, to examine the needs of ethnic groups, to investigate preferences into place of care, as well as developments in methods in measuring quality of care and palliative outcomes, and techniques in systematic literature reviewing.

There are many individuals to thank in the preparation of this report, but, in particular I would like to thank those individuals with whom we closely collaborate, our Head of Division, Professor Alan McGregor, and the Head of the School of Medicine, Professor Gwyn Williams, the Acting Principal, Professor Barry Ife, and the Vice Principal, Professor Graham Catto for their support. I also thank the members of the department who have all contributed to the production of this research through their research activities, and in particular, Bimpe Akinwunmi, Dr. Rachel Burman, Jenni Burt and Dr. Richard Harding for being the team that pulled the report together for the department.

Finally, we thank those patients, families, practitioners and colleagues across all areas who have participated with us in generating this research, which we hope will serve to improve the care of patients and families and inform the delivery of high quality palliative care services.

Professor Irene Higginson BMedSci BMBS FFPHM PhD
HEAD OF DEPARTMENT
1.0 OVERVIEW

The Department of Palliative Care and Policy at King’s College London was founded in 1996 as a new academic department in the School of Medicine. It has grown from one founding Professor and two research staff in 1996, to 30 staff and an annual research grant income of around £1m in 2003. It has seen the internal and external promotion and development of several staff. In 2003, the department was joined by Professor Lynne Turner-Stokes, The Herbert Dunhill Professor of Rehabilitation, and her team.

A major strength of the Department of Palliative Care and Policy is the great diversity of expertise brought to our research programme by the academic and clinical staff. Members of the Department have backgrounds in clinical medicine, nursing, public health, sociology, health services research, epidemiology, anthropology and psychology, which together generate a dynamic and stimulating research environment.

The Department’s research programmes provide comprehensive coverage of the key issues in supportive and palliative care. Ranging from health service to clinical research, our work is united by the aim to improve understanding, practice and organisation in supportive and palliative care in order to discover ways to improve care and treatment for those affected by progressive illness. Each year staff in the department publish an average of around 40 research papers in peer review journals, 10 book chapters, and often one or two books. We run a multi-professional MSc programme attended by a diverse range of international palliative care practitioners, and contribute to undergraduate medical teaching. Throughout the course of the year the department has many requests for overseas visitors, although only around 2 or 3 can be accommodated. Senior staff are invited to lecture in all continents of the globe, although only a very limited number of invitations can be accepted.

Since 2000, the Department has been awarded over 50 grants for the conduct of international, national and local research, representing £6 million of research income. A full list of all grants can be found in Section 2.6, page 72.

Within this report, we present our research programmes within five major subject strands. These are:

- Measuring and improving services
- Non-cancer care
- Improving assessment and treatment: clinically based research
- Researching dying in society
- Academic rehabilitation

Of course, many of these areas are interlinked, and issues raised by research in one strand frequently elicit insights and developments in another. This report provides an overview of the development of each of our research areas over the last three years, the members of staff working within them, and the particular projects in progress and completed. It also highlights our work in education, both undergraduate and postgraduate, and our clinical links across London.
1.1 Profiles of Professors and Administrative Team

**Professor Irene J Higginson**
Irene Higginson qualified in medicine from Nottingham University and has worked in wide ranging medical and university positions, including radiotherapy and oncology, in-patient and home hospice care, the Department of Health (England), and various universities. She began working in palliative care in the late 1980s and her PhD was on the development of the Support Team Assessment Schedule, one of the first measurement scales in palliative care. Before joining King’s she was Senior Lecturer/Consultant at the London School of Hygiene and Tropical Medicine and Director of Research and Development at Kensington & Chelsea and Westminster Health Authority. She is Head of Department of Palliative Care and Policy, has active research programmes, leads the MSc in Palliative Care, and plays an active role in the clinical service, including on-call. She has served on a number of external committees and journals – she chaired the National Council for Hospice and Specialist Palliative Care Quality Committee (1996 – 2001). In April 2002 she became Dean of Graduate Studies in the School of Medicine, overseeing the quality of PhD and MSc programmes. In June 2002 she took up the post of Scientific Director of The Cicely Saunders Foundation, to lead the development of an international centre of research in palliative care.

Her research interests and publications are in the following areas: quality of life and outcome measurements, evaluation of palliative care especially of new services and interventions, epidemiology, clinical audit, effectiveness, psychosocial factors and care, symptom assessment, cachexia/anorexia, and elderly care.

**Professor Julia Addington-Hall**
Julia is a social scientist, and has been involved in palliative care research since the mid-80’s. She co-led the Regional Study of Care for the Dying, the largest UK study of care for the dying to date. Her current research interests include palliative care for non-cancer patients particularly those with heart failure, depression in palliative care patients, and improving care for the dying in the NHS. She is Chair of the UK Palliative Care Research Society, an editor of the journal ‘Palliative Medicine’, and a member of the National Cancer Research Institute Palliative Care Development Group. Joining the department as a senior lecturer Julia was internally promoted to a Personal Chair in Palliative Care Research and Policy. Sadly, Julia left the department at end of February 2004 to take up an exciting new Chair in End-of-Life Care in the School of Nursing and Midwifery at the University of Southampton. We wish her well, and no doubt will continue links and collaboration.

**Professor Lynne Turner-Stokes**
Lynne Turner-Stokes was educated at Bedales School (1966-1973), Oxford University (1973-6) and University College Hospital (1976-9). She qualified in Medicine in 1979 and spent the next decade training in general medicine and rheumatology. A DM thesis (undertaken 1985-8 on the immune response to influenza in systemic lupus erythematosus) confirmed her view that she never wished to look another lymphocyte in the eye and she returned to clinical medicine with a desire to concentrate on the more human aspects of chronic disease. After accrediting in Rheumatology and Rehabilitation in 1992, she was appointed as consultant to set up a new Regional Rehabilitation Unit (RRU) at Northwick Park Hospital in Harrow.
The RRU provides a tertiary specialist rehabilitation services for younger adult patients with severe complex disabilities, mainly resulting from acquired brain injury. Over the last decade, Lynne and her 5 consultant colleagues have built up a co-ordinated network of specialist rehabilitation services across North-West Thames, serving patients and their families both in hospital and in the community. Within this network, the RRU acts as a central focus for research and training for all professionals involved in rehabilitation and has a national and international reputation as a leading service in the field of neurological rehabilitation.

Lynne was appointed to the Herbert Dunhill Chair of Rehabilitation at KCL in 2001, with a view to developing a two-site academic department of rehabilitation between KCL and Northwick Park. Academic Rehabilitation joined forces with the Department of Palliative Care and Policy in 2003. Her particular research interests include the development 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.

In addition to her clinical and academic work, Lynne has a major interest in the development of NHS policy to improve rehabilitation services in the NHS. She is currently the Deputy Chair of the External Reference Group of the National Service Framework for Long Term Conditions. In this role 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.

Dr. Nora Donaldson
Nora has worked on sequential methods and on survival analysis, with particular emphasis on cancer studies. Most of her work on this front has been done in collaboration with Professor John Whitehead at the University of Reading and Professor Max Parmar, Director of the Cancer Division at the MRC. Nora has been actively involved in the design of clinical trials conducted by the MRC and the Danish Breast Cancer Group, as well as collaborative work with statisticians and oncologists of the MRC and the National Cancer Institute (Bethesda, MD). Nora has also collaborated extensively with teams at Stanford University and University of Salamanca, among others. Motivated by her collaboration with the department of Palliative Care and the Institute of Psychiatry, her research interests are now in the evaluation of quality of life and is particularly concerned with the problems posed by the longitudinal and multivariate nature of this constructs. She is also interested in the audit and evaluation of health care in general.

Nora has diverse experience in statistical consultancy and in managing statistical services centres in large university hospitals. She has been the head of the Clinical Research Statistics Unit of King’s College Hospital-NHS TRUST for the last five years and is now managing the statistical services for the Lewisham Hospital NHS Trust, within the R&D Directorate. During this time, Nora has also been honorary Senior Lecturer in the GKT School of Medicine and the Institute of Psychiatry, working very closely with the departments of Palliative Care, Rheumatology, Medical Engineering and Biostatistics. She was awarded Chartered Statistician status by the Royal Statistical Society in 2002 and has been ex-officio member of the Research & Ethics Committee for the last five years.
Nora’s extensive teaching experience includes advanced undergraduate and postgraduate teaching and lecturing for specialists and non-specialists from various disciplines. She has taught at King’s College London, Stanford University, University of Maryland, American University, Universidad del Valle (Colombia), among others. She has been visiting lecturer and external examiner at the Universidad de Salamanca (Spain) and a Senior Research Fellow for a project funded by the MRC to evaluate sequential methods in the design and analysis of cancer clinical trials. Nora teaches Medical Statistics, Multivariate Analysis and Time Series Analysis for several MSc. Programs and provides statistical supervision to many MSc and PhD students.

**Bimpe Akinwunmi**
Bimpe is a qualified secretary/administrator and previously worked in various multi-professional organisations, with a particular preference to the academic environment. She joined the department in 1997 having worked at St John’s Institute of Dermatology, St Thomas’ Hospital. Bimpe is PA to the Deputy Head of Department

**Jo Clark**
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 Kings 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.
Maggie Johnson
Maggie is the Department Administrator and supports the MSc in Palliative Care. She has a degree in Economics from the University of East Anglia and a range of IT, teaching and secretarial qualifications. She has had an 18 year career in teaching having taught 8 to 60 year olds in primary, secondary and tertiary education and having covered a wide range of subjects, mostly pertinently IT and Administration. More recently she has been the education administrator at St Christopher’s Hospice and moved to her current position in early 2002.

Jennifer Lunan
Jenny is Professor Higginson’s PA and is usually the first point of contact for Professor Higginson. She is a qualified EN and is an Associate Member of AMSPAR. Following her AMSPAR course she worked as an Administrative / College Secretary in the Health Centre at University College, London, where she worked for the College GP practice and for the Consultant Psychiatrist. Following that she worked as PA / Laboratory Secretary to a Consultant Histopathologist and Consultant Biochemist in the ICRF Clinical Oncology Unit based at Guy’s Hospital. Jenny joined the department in July 1998.
2.0 RESEARCH ACTIVITY

2.1 Measuring and improving services

2.1.1 Background and overview
Palliative care is a relatively new field, and robust evaluations have been limited. In the past, such evaluations have also been weakened by inappropriate or insensitive measures of benefit, such as the outcome of care and quality of life. To set standards of care we need both appropriate tools to measure quality of life, outcomes and evidence about the most effective models of care.

The Department has been active in developing measures both for use during care, (e.g. the Palliative Outcome Scale – POS), and afterwards through the views of informal carers’ experiences of services (the ‘VOICES’ questionnaire: Views of Informal Carers – Evaluation of Services). These tools have been further refined during the last three years. To inform future delivery of services we have conducted systematic literature reviews, often as a result of winning NHS Research and Development Grants, and have evaluated individual services. We are also involved in a substantial programme of research and development work on palliative care within primary care.

Research topics within ‘measuring and improving services’ include:
• Quality of life measurement
• Services for carers
• Palliative day care
• Palliative care within primary care
• Palliative care within cancer care

2.1.2 ACADEMIC STAFF PROFILES

Fiona Aspinal
Fiona trained as a Registered General Nurse and has several years’ clinical experience working in palliative care and elderly care settings. She has a BA (Hons) in Social Policy and an MA in Public Administration and Public Policy where her interests included complementary therapies, health policy and citizen/user participation in decision-making. Since April 2000, she worked on the PROMOTE project which aims to develop methods of monitoring service quality and identifying mechanisms of feedback to decision-makers.

Stephen Barclay (Honorary)
Dr Stephen Barclay joined the Department as an Honorary Senior Research Associate in 2002, having collaborated with Professor Julia Addington-Hall and Cathy Shipman previously. He works as a General Practitioner in Cambridge, where he is also Honorary Consultant Physician in Palliative Medicine at the Cambridge hospice and Macmillan Research Fellow in the Department of Public Health and Primary Care. His research focuses on Palliative Care in the Primary Care setting. His MD thesis, entitled “General Practitioner provision of Palliative Care” is due to be completed shortly, and is supervised by Professor Julia Addington-Hall and Professor Chris Todd (Manchester).
Dr. Teresa Beynon
Teresa has been a Consultant in Palliative Medicine at Guys’ and St. Thomas’ NHS Hospital Trust since January 1996, with academic leadership from Professor Higginson and close links to the clinical department at Kings College Hospital. She completed an M.D. thesis on the topic of developing education in palliative care for primary health care professionals in 2003 and is part of the evaluation team reviewing the impact of district nurse education, funded by the Department of health and based at Kings College. She is part of the South London Research Group and has supervised research registrars in training. Research interests include evaluating educational programmes, clinical development of a topical gel and management of bowel obstruction. The department has also been involved in a successful European Union bid to develop IT systems for Palliative Care services with the Trusts corporate development department, now led by fellow Consultant Dr. Tom Bozek.

Jenni Burt
Jenni has a BA(Hons) in Biological Anthropology from the University of Cambridge, and an MSc in Public Health from the London School of Hygiene and Tropical Medicine. Prior to coming into research, she worked for a number of different health-related voluntary organisations. Previously based in the Department of General Practice at King’s, Jenni’s research projects included the use of NHS Direct in relation to deprivation, and an evaluation of the integration of NHS Direct with GP out-of-hours services. She is now researching the provision of palliative care within primary care. Her major work is a research and development project, funded by the King’s Fund, aimed at enhancing primary care support to dying people and their carers across London. Jenni is also involved in the national evaluation of the Department of Health funded education and support programme for District Nurses in the principles and practice of palliative care, leading on a survey of 5,000 bereaved carers.
Dr. Elizabeth Davies
Elizabeth is Honorary Lecturer and Consultant in Public Health Medicine. Her public health training to date has included public health practice in health authorities, academic departments, the Department of Health and NICE with an emphasis on work on the implementation of the Calman-Hine report. Before this she completed a PhD in Medicine studying the quality of life of patients with malignant cerebral glioma and co-ordinated the development of Royal College guidelines for good practice in the care of these patients. Her research interests are health services research in cancer and neurology, including the area of palliative care and in guideline development and implementation. Current projects include a systematic review of communication, information and support for patients with malignant cerebral glioma, primary research in rehabilitation and information needs of these patients, patient illness behaviour and GP management of colorectal cancer symptoms and evaluation of NICE guidance. In 2003 she won a Harkness Fellowship to study ways to improve cancer care in the UK and USA. In 2004 she returned to the UK and took up a Clinical Senior Lecturer post at King’s College London working within the Thames Cancer Registry.

Maria Dunckley
Maria has a BSc in Psychology from Goldsmith’s College, University of London and an MSc in Health Psychology from the University of Southampton. She previously worked for the Imperial Cancer Research Fund in Edinburgh looking at psychosocial issues associated with genetic testing. She joined the department in April 2001 to work on PROMOTE, which aims to develop methods on monitoring service quality and identifying mechanisms of feedback to decision-makers. Maria left the department in 2003 to work for the Picker Institute, Oxford.
Dr. Marjolein Gysels
Marjolein Gysels completed an MA at the University of Ghent in Belgium and received a PhD in anthropology at the University of Amsterdam in 1996. She has carried out research in D.R. Congo on Swahili and oral literature. She worked for the TANESA project on AIDS in Tanzania on female infertility, and for the Medical Research Council (UK) Programme on AIDS in Uganda on commercial sex work. At King’s College London, she collaborated on the Project to Improve Management of Terminal Illness (PROMOTE), and she wrote the systematic reviews for the Research Evidence Manual which has recently been published as part of the NICE Guidance for supportive and palliative care services for those affected by cancer.

Dr. Richard Harding
Richard originally read social anthropology and conducted field work in the Netherlands, followed by a Masters in Social Policy & Social Work Studies at the LSE. His PhD supervised by Professor Higginson and Professor Todd (Manchester) addressed informal carers in palliative care. The thesis and subsequent papers appraised current evidence, undertook qualitative developmental work, and then designed and evaluated a short-term group intervention that aimed to provide peer support and multi-professional information across two home palliative care services. His clinical experience includes HIV and palliative care management, acute adult health hospital social work and community care management. He also designs and delivers community-based groupwork focused on behavioural change. His academic interests in palliative care are informal carers, HIV, palliative care provision in Africa, and evaluation methods. His broader interests are in behavioural interventions and HIV prevention. His current work is focused on palliative care in Sub-Saharan Africa.
**Tariq Saleem**
Tariq has a degree in psychology and a MSc in health psychology from the University of London. He joined the department in April 2003 to work on a study developing VOICES (Views of Informal Carers - Evaluation of Services questionnaire) for use in a population-based survey of experiences of people who die from stroke and their families, from the perspective of bereaved relatives. Issues in translating this questionnaire into South Asian languages were addressed. Currently he has a leading role in research for a new center for palliative care in neurology looking at appropriate ways to measure outcomes and quality of life in progressive neurological conditions. In the past he has worked in the departments of oncology, hematology and neurology. Research areas have included cancer screening, sickle cell & thalassemia counseling, bilingual health advocacy services, men's health: predictors of testicular self-examination by extending the theory of planned behaviour with masculinity, conducting cognitive and motor movement assessments in people with motor movement disorders, and the anxiety/worry process.

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**Cathy Shipman**
Cathy is a Senior Research Fellow at the Department of Palliative Care & Policy, King's College London. She is also a Development Consultant at the King's Fund in primary palliative care. She has worked in health services research and evaluation for many years including studies of PCG/T development, out of hours care, learning disability, health needs assessment, mental health promotion and unemployment and health. Over the past few years she has worked principally in primary palliative care including an evaluation of the Macmillan GP Facilitator Programme in Palliative Care. She is currently working on the evaluation of Department of Health funded Education and Support Programme for District and Community nurses in palliative care. She has also undertaken a repeat study of PCTs work on cancer and palliative care for Macmillan Cancer Relief. Other current work includes supporting a primary palliative care project working with PCTs across London for the King’s Fund and supporting the development of a primary palliative care strategy in Cambridgeshire.

**Additional Contributors**
We would also like to acknowledge the valuable contribution of the following former members of staff in the department to research undertaken during the period covered in this report:

- Dr. Jayne Chidgey
- Uta Drescher
- Dr. Danielle Goodwin
- Dr. Rhidian Hughes
- Alison Pearce
- Dr. Meera Rajeskarar
2.1.3 RESEARCH UNDERTAKEN 2000 - 2003

PROMOTE: A project designed to develop tools to improve care
Fiona Aspinal, Maria Dunckley, Rhidian Hughes, Marjolein Gysels, Julia Addington-Hall, Irene J Higginson et. al.

The PROMOTE project aimed to further validate and refine the POS and VOICES measures. The project reviewed and revised the content of both tools, providing a stronger theoretical and user-led basis for the assessments. A user guide for POS was published (Aspinal, Hughes, Higginson et al. 2003 – Report) and two translated versions (Urdu and Punjabi) were developed (Dunckley, Hughes, Addington-Hall et al. 2003). Research tested the ways in which the tool crossed cultural boundaries. Work on VOICES has led to the publication of a systematic literature review identifying the best ways to measure satisfaction, relevant to the VOICES questionnaire (Aspinal, Addington-Hall, Hughes et al. 2003). Preferred methods for using the questionnaire amongst the ethnic minority populations were investigated both as part of PROMOTE and as part of a related study developing a stroke-specific version of VOICES.

Quality of Life: More person centred measures
Irene J Higginson, Julia Addington-Hall, Nora Donaldson, Lalit Kalra et. al.

Professor Irene Higginson, with colleagues at King’s (including Professor Julia Addington-Hall, Dr. Nora Donaldson and Professor Lalit Kalra (Stroke Medicine, King’s College London), published a series of articles on quality of life measurement in the British Medical Journal (Addington-Hall and Kalra 2001; Carr, Gibson and Robinson 2001; Carr and Higginson 2001; Higginson and Carr 2001; Farsides and Dunlop 2001). These were compiled with additional work to form a book, published by BMA books (Carr, Higginson and Robinson 2003). This academic review appraises what is meant by quality of life, existing measures and reviews new concepts that seek to make quality of life and outcome measures more patient focused. It explores the concept of response shift, whereby patients and professionals change their perceptions as a result of experience or coping. This normal human response has not been previously accounted for in quality of life assessment. The book describes ways that this can be included in future assessment. The revised POS tool attempts to begin to take account of changes in perceptions, by including open questions, where the patients lead the assessment. However, further questions remain about how to analyse this data.

Analysis of palliative care outcomes in three European Countries
Irene J Higginson and Massimo Costantini (Genoa, Italy)

As part of an European Community funded grant, jointly held with Farsides (Centre for Medical Law and Ethics, King’s College London) and others, Higginson and Costantini set out to explore palliative care outcomes as collected in multicentre studies in England, Ireland and Italy. Each study collected data using the Support Team Assessment Schedule – a precursor of the Palliative Outcome Scale. The results showed that in every country, four components were important in determining communication (Higginson and Costantini 2002). Higginson and Costantini also assessed prognosis estimates, and showed how a range is preferable to a single estimate. This was the first article published in the new web based journal – BMC Palliative Care (Higginson and Costantini 2002).

Figure. Main inter-relationships between domains affecting quality of life and communication between patient and family: results from pooled data in three countries found in the multivariable logistic analysis. (Beta is a measure of the strength of the association and estimates the coefficient of the equation. R² is the proportion of variance explained by the model).

Development and evaluation of the 90-minute group, a new model of improved support for carers
Richard Harding, Alison Pearce, Irene J Higginson

Despite the high level of need, which may exceed that of patients, the provision of services for carers is at best patchy and unevaluated. Dr. Richard Harding, Alison Pearce and Professor Irene Higginson’s original programme of research has made a significant contribution to the field of informal care research using the MRC Framework for developing and evaluating complex interventions. Our outputs from a collaboration of Camden and Islington palliative care service and St. Christopher's Hospice home care, have:

• Systematically reviewed the current evidence for specific models of support for carers (Harding and Higginson 2003)
• Using a qualitative methodology, explored the barriers that carers create and perceive in meeting their own needs, defining a previously unrecognised concept of ambivalence (Harding and Higginson 2001). Using these results we have proposed a set of service guidelines for effective support
• Designed an original intervention formulated for the research evidence, the “90-minute group” – avoiding the use of the terms “support” and “carer” and emphasising the short amount of time (Harding, Leam, Pearce et al. 2002)
• Evaluated the intervention comparing in two clusters carers attending the group with those not in attendance. Our findings identified the nature of individuals who find a group most beneficial and make recommendations with respect to design, content, delivery, uptake, and evaluation methods
• Reported subsequent analysis of the impact of patient status on carer psychological status and made recommendations on delivering balanced provision for both.

These findings from our research have now been rolled out and have initiated service funding and development for carers’ interventions beyond our study centres. In addition, Professor Higginson has applied some of the methodology in the evaluation of carer support of patients with dementia (Woods, Wills, Higginson et al. 2003). The results are informing future studies, including methods to evaluate new services and the development of services for patients with MS.

The first multicentre evaluation of palliative day care
Irene J Higginson et. al.

Despite its rapid expansion, hospice day care has never been rigorously evaluated. A questionnaire survey of all day care units in the London Region identified a wide range of services (Higginson, Hearn, Myers et al 2000). From these the investigators – Higginson, Goodwin, Normand, and Douglas (these last two individuals from London School of Hygiene and Tropical Medicine), and Naysmith and Myers (Pembridge Palliative Care Service and Amesbury (Chichester) identified six units, representing different more medical or social models of support, for a comparative evaluation. A multiprofessional project group was established with representatives from all units. All units collected data over two years on newly referred patients to palliative day care and a comparison group, following individuals until discharge or death. The results show that patients attending day care report that they like it, and describe the main benefits as “getting out” and “meeting others” (Higginson and Goodwin 2001; Goodwin, Higginson, Myers et al. 2002; Goodwin, Higginson, Myers et al. 2003). However, there was little change on traditional quality of life measures. We are currently analysing whether there are differences in quality of life and data from the sixth unit (in Chichester), which was last to be established and where in addition to a concurrent comparison group of patients not receiving day care, we have collected information about patients before day care was available (before group). An economic evaluation has been included assessing the cost of day care and whether it substitutes or supplements existing services.
Palliative Care within Primary Care
Evaluation of the Macmillan GP Facilitator Programme
Cathy Shipman and Julia Addington-Hall

Professor Julia Addington-Hall and Cathy Shipman were commissioned by Macmillan Cancer Relief to conduct a national evaluation of their Macmillan GP Facilitator Programme, in which GPs with some expertise and specific interest in palliative care are given dedicated time to provide peer support in palliative care for colleagues. The evaluation included elements of both formative and summative evaluation, and has produced a number of findings. Firstly, the evaluation found evidence that GP facilitators improved awareness of some palliative care services amongst GPs, and enhanced communication between primary and specialist palliative care services. This is particularly important to enable primary health care professionals, who provide most palliative care within the community, to seek support and advice both for patients and carers and themselves when necessary to enable patients to remain at home for as long as possible (Shipman, Addington-Hall, Thompson et al. 2003; Shipman, Thompson, Pearce et al. 2001). This evaluation also found that GPs work in differing ways with specialist colleagues (Shipman, Addington-Hall, Barclay et al. 2002). Most of the GPs interviewed preferred to use specialist colleagues as a resource, while some preferred to hand over care entirely and some seldom used specialist support or advice. Specialist providers need to be aware of such patterns of working, which are not necessarily fixed, to enable optimum collaborative support to be provided to patients and carers in the community (Shipman, Addington-Hall, Barclay et al. 2002). The evaluation also found that most GPs wanted education in palliative care for non-cancer patients, but more of those from inner city areas wanted education in the basics of palliative care (Shipman, Addington-Hall, Barclay et al. 2001). Out of hours care in the community was also an area of concern for GPs and District Nurses with the change in GP out of hours arrangements. Few GPs reported routinely handing over information about patients to Co-operatives or Deputising Services which meant little was known if the patient or carer made a call for help. Most GPs and District Nurses wanted 24-hour availability of specialist palliative care support (Shipman, Addington-Hall, Barclay et al. 2000).

McGill Quality of Life assessments of patients at first and third interview, showing no significant different between patients who received day care and a comparison group. [Key to box plots: the figure shows box-plot of median value (bar), 75% and 25% quartile of values (box), maximum values (whiskers), outlier values (I) and extreme values (*), high scores indicate better quality of life].

Macmillan Cancer Relief commissioned a study of palliative and cancer care service development and commissioning with Primary Care Groups and Trust in 2000. This study found that cancer and particularly palliative care not a high priority when the Cancer Plan was published in the Autumn of 2000 (Shipman, Pearl, Addington-Hall et al. 2001). The transition to PCT status and other central priorities such as National Service Frameworks (NSFs), were limiting the amount of time and resources that could be allocated. Most PCG/Ts had some form of cancer lead post and some involvement in planning and commissioning cancer services, although many were still commissioning services through the old Health Authorities.

The above PCT survey has been repeated during 2003/4 with funding from Macmillan Cancer Relief. The aim was to identify PCT progress in service development and commissioning, current priorities, achievements and obstacles to success and to compare activity with the first study.

Cathy Shipman is also working with a colleague in the department (Stephen Barclay) to support the development of a primary palliative care strategy across Cambridgeshire.

Palliative Care in Primary Care across London
Jennifer Burt, Cathy Shipman, Julia Addington-Hall, Patrick White and Irene J Higginson

Another major study is also taking place with five PCTs across London to support palliative care in primary care. Currently, there is a lack of information about the range of palliative care need in primary care, preferred ways and effective means of meeting that need, and available resources across the interface between primary and secondary care. The project, funded by The King’s Fund, aims to develop the capacity of PCTs in London to commission palliative care in a way that reduces inequalities and enhances patient and family care. This large scale needs assessment is using a range of methods to investigate the views of GPs, District and community nurses, specialist palliative care providers, PCT staff, patients and carers to identify key issues in the provision of care, resource needs, and preferred service developments.

Evaluating the National Palliative Care Education and Support Programme for District and Community Nurses funded by the Department of Health
Cathy Shipman, Jennifer Burt, Julia Addington Hall, Alison Richardson, Emma Ream and Teresa Beynon

The department was commissioned by the Department of Health to conduct a national evaluation of the education in the principles and practice of palliative care being provided to District Nursing teams across the country, by Cancer Networks and funded by the Department of Health. This evaluation is a complex piece of work involving before and after surveys of District Nurses, GPs and bereaved carers (using the VOICES questionnaire) to measure any change in scores resulting from current educational programmes. Qualitative work within the evaluation comprises exploring the experience of and provision of palliative care education to identify perceptions of best practice that will inform future programme development. The study has recently been extended beyond its original focus on cancer patients to include an assessment of the impact of the educational programme on older patients who die from conditions other than cancer.

Palliative Care within Cancer Care

Systematic reviews
Marjolein Gysels, Irene Higginson, Elizabeth Davies et. al.

In the area of systematic reviews, Professor Irene Higginson, Dr. Marjolein Gysels, Professor Alison Richardson (School of Nursing, King’s College London), Dr. Elizabeth Davies and colleagues have developed considerable expertise over past years. The group:

• Were commissioned to provide the evidence on the effectiveness of palliative, psychological and person-centred care for the Department of Health

Clinical Outcomes Guidance in to national guidance for cancer for the care of patients with breast cancer, lung cancer, colorectal cancer and neurological cancer. This led to publications on individual topics such as palliative care (Hearn and Higginson 1998), information giving (McPherson and Higginson 2001), as well as inclusion in Department of Health Guidance for policy makers and funders of services. In addition, Davies and Higginson have undertaken a systematic review of communication, information and support for patients with malignant cerebral glioma and the care for their relatives (Davies and Higginson 2003).

• Won a competitive grant from the Welsh Office

to undertake a systematic literature review into the effectiveness of different models of specialist palliative care

- by Professor Irene Higginson, in collaboration with Professor Finlay and colleagues at the University of Wales. The group has published the first comprehensive evidence indicating the effectiveness of hospital-based palliative care teams and the full review, including the first meta-analysis, demonstrating both quantitative and qualitative benefits from specialist palliative care multi-professional teams and hospital based teams, has been published in the Journal of Pain and Symptom Management (Higginson, Finlay, Goodwin et al. 2002; Finlay, Higginson, Goodwin et al. 2002; Goodwin, Higginson, Edwards et al. 2002; Finlay, Higginson, Goodwin et al. 2003).

• Won the contract from the Department of Health
to review the evidence of service configurations in supportive and palliative care for cancer patients, which was commissioned by the National Institute of Clinical Excellence (NICE) (Professor Irene Higginson, Dr. Marjolein Gysels and Professor Alison Richardson, Professor of Cancer and Palliative Care Nursing, King’s College London). This is an extensive high profile project which reviews the evidence for all components of palliative and supportive care in cancer. The evidence is leading to the national guidance on supportive and palliative care in cancer, which will determine which services are funded.
Since October 2001 the group has worked on the Research Evidence Manual (Gysels, Higginson, Rajasekaran et al. 2003) to back the recommendations which are currently being developed for the NICE Guidance on Palliative and Supportive Care for Patients with Cancer. This Guidance focuses on the configuration of services a Won the contract from the Department of Health to review the evidence of nd the ways in which they can best be designed and delivered. The Research Evidence Manual comprises systematic literature reviews covering twelve different topics, as each of these contribute to the holistic understanding of palliative care:

- Co-ordination of care
- User involvement in planning, delivering and evaluating services
- Face-to-face communication
- Information
- Psychological support
- Social support services
- Spiritual support services
- General palliative care services, incorporating care of dying patients
- Specialist palliative care services
- Specialist palliative day care services
- Rehabilitation services: Complementary therapy services
- Care for families and carers, including bereavement care

The Guidance for Supportive and Palliative Care for Adults with Cancer was published in March 2004 with a press launch. A link to the Research Evidence Manual can be found via our web site at www.kcl.ac.uk/palliative and copies of the document can be obtained from the NHS Response line 0870 1555455.

Other systematic reviews which focus on a particular aspects of these areas have been presented at conferences and written or are in preparation (Gysels and Higginson 2003; Gysels, Higginson and Richardson 2003; Harding and Higginson 2003). These include communication training for health professionals who care for patients with cancer and a comparison of video and interactive multimedia technology as formats for patient education in cancer care.

As direct evidence on service delivery was sometimes difficult to retrieve or even not present at all, it was necessary to go beyond the traditional high grade evidence of the randomised controlled trial. Some topic areas contained almost exclusively qualitative evidence, on topics such as spiritual care, user involvement or bereavement care. In the future we would seek to undertake qualitative reviews in these areas. This also requires the development of qualitative systematic review methodologies and appropriate grading systems, which the Institute would be well placed to develop. Evidence about gaps in the research knowledge is presented within the guidance and has been submitted to the new National Cancer Research Institute.

Systematic literature reviews of hospital palliative care team effectiveness
Source: Higginson et al. J Pain and Symptom Management 2002; 23(2): 96-106

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Supporting informal carers in palliative care: The 90 Minute Group

Palliative care aims to support families and carers throughout the illness and into bereavement. Carers’ needs are wide ranging, encompassing the primary needs of information and psychological/emotional support, as well as finance, fatigue, respite, relationship counselling, practical support and education e.g. lifting and handling. Despite evidence suggesting that the needs of carers may exceed those of the patient, there have been few carer-specific interventions in palliative care. Using the MRC framework for intervention development and testing, the Carers’ Study aimed to design and evaluate a short-term group intervention for informal carers of patients attending home palliative care. The sequential stages of the study reviewed the existing evidence, explored barriers to professional intervention sand service uptake, modelled the intervention, and used an outcome evaluation design to compare carer outcomes to a comparison group. The study was collaboration between the academic department of Palliative Care and Policy, St Christopher’s Hospice and the Palliative Care Centre, Camden and Islington Community NHS Trust. The project steering group consisted of academics and clinicians across palliative nursing, medicine and social work.

Stage 1: Appraising the evidence. The systematic literature review of carers’ interventions studies in cancer and palliative care found only 6 published evaluations of carer-specific interventions. Although groupwork was the favoured model of intervention, no (quasi) experimental evaluation of groups for carers were identified. In general, the evidence suffered from a lack of robust methods of development and testing.

Stage 2: Maximising acceptability and uptake. Although a reluctance to accept professional help had been noted in the literature, the reasons for this were unclear. Our qualitative study generated a central concept of ambivalence among carers, and this operated in relation to their role and identity, taking a break from attending the patient that they so strongly needed, and to accessing professional support. A subsequent analysis of our quantitative data found that patient pain and psychological distress were associated with carer psychological problems and poor coping. Our recommendations were that interventions should be time limited, should address patients’ needs before carers needs can be met, should respect existing coping strategies, should avoid use of the term “carer”, and should ensure legitimacy in requesting the carer to leave the patient.

Stage 3: Modelling the intervention. The intervention was modelled from the evidence for need and effectiveness from the systematic review and the findings from the qualitative investigation. The design process was facilitated across research and clinical staff. The “90 Minute Group” aimed to provide support and information for a maximum of 12 carers over 6 weeks, and a sitting and transport service were provided. Special emphasis was placed on the recruitment process and materials, a with a strong pro-active effort made by facilitators to ensure ease of acceptance and attendance. Multi-professional teaching, based on informal question-and-answer sessions, were combined with peer exchange managed by a single constant facilitator.

Stage 4: Testing the intervention. 73 carers entered an observational quasi-experimental evaluation, comparing outcomes between those who accepted and declined the intervention. Multivariate regression analysis was hampered by the expected challenges of attrition. However, uptake at 25% was directly comparable to similar cancer population interventions, and qualitative data reported high levels of support and coping gains from attendees. Peer support and exchange of ideas and the opportunity to gain multi-professional guidance in an informal space were particularly valued.
2.1.5
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2.2 Non-cancer care

2.2.1 Background and overview
Little attention has been paid to the needs of people who die from causes other than cancer. In 2001 Addington-Hall and Higginson (editors) published with Oxford University Press the first major textbook to examine palliative care for non-cancer patients in detail. This book brought together evidence about the problems of patients with different primary diagnoses and their families and identified gaps in knowledge.

Before services can be extended to include non-cancer patients more information is needed about individual’s specific needs and solutions to problems need to be tested and demonstrated. Therefore programmes of work have been established and are being further developed for circulatory and respiratory conditions (heart failure, COPD and stroke), neurological conditions (MS, MND and Parkinson’s disease) and other non-cancer conditions.

2.2.2 ACADEMIC STAFF PROFILES

Dr. Rachel Burman
Rachel qualified in medicine in 1988 and became a consultant in palliative care in 1997. She is working part time with the palliative care team at King’s College Hospital NHS Trust and is an honorary senior lecturer in the Department of Palliative Care and Policy. She worked in neurology and cardiology before entering a career in palliative care. This has left a commitment to the palliative care needs of patients with a non-malignant diagnosis and she is currently 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 Human Rights Act and healthcare provision.
Dr. Karen Lowton
Karen worked as an intensive care nurse and a research sister for a number of years before taking up a Research Fellow post in the Department of Palliative Care and Policy and completing a PhD entitled Living with cystic fibrosis: perceptions of health and risks of treatment. The research measured perceptions of quality of life amongst adults with cystic fibrosis and their family carer by using the SF-36 health status questionnaire, and compared these measurements to how staff at a specialist CF centre estimated patients’ quality of life. Qualitative interviews with patients and their family members explored how adults managed disclosure of the disease to others, and their perceptions of the risks of current and future treatment and care. Other research work includes investigating the impact and management of bereaved children at Primary and Secondary schools in England. Karen has recently begun work on a project that attempts to capture relatives’ experiences of care given to family members who have died from cystic fibrosis and is currently conducting interviews with bereaved relatives across the country. The Cicely Saunders Foundation has provided funds to enable the research to be completed. Karen also contributes to the MSc in Palliative Care run by the Department. Karen was recently promoted to a lectureship post in the School of Nursing at King’s College London and continues to hold an Honorary Research Fellow post in the Department of Palliative Care and Policy.

Angie Rogers
Angie completed a BA (Hons) in Social Science and an MSc in Sociology with Special Reference to Medicine at Royal Holloway and Bedford New College. Her first research position was as a research assistant at West Berks Health Authority on an evaluation of local drugs services and an HIV/AIDS school-based health education initiative. Angie joined the Department of Epidemiology and Public Health at University College, London and worked on a study of adolescent health in Camden and Islington Health Authority. She joined the Department of Palliative Care and Policy in September 1997 working on a study investigating the need for palliative care among stroke patients and then a cohort study of heart failure patients. Her research interests include qualitative research methods, health and social inequalities and ethnicity and health. Currently Angie holds an ESRC case studentship to study for her PhD at Royal Holloway University of London.
Anu Sinha
Anu has a BA(Hons) in Psychology and Media from the University of Leeds, and an MSc from Brunel University in Applied Psychology. Anu’s previous employment experience has involved working with adults with learning disabilities, and most recently on a rehabilitation ward for people recovering from acquired brain injury. She worked in a psychiatric unit for the elderly within Leeds Community & Mental Health Services NHS Trust, where she also conducted research with carers and health professionals working with people with dementia. Anu joined the department in November 2001 to work on the BUILD project, an action research project that seeks to reshape health and social care services through building user involvement with people with Motor Neurone Disease, their carers and family members. In March 2002 she also joined the PROMOTE team.

Bella Vivat
Bella studied medicine for 3 years in the 1980s and later took a BSc in IT, following which she studied at Edinburgh University for an MSc and then a PhD in Science and Technology Studies. Bella is currently completing her PhD, which is an ethnographic study of the spiritual aspects of care in a Catholic hospice in the West of Scotland.

Bella is especially interested in philosophies of knowledge and the relationship between beliefs, knowledges and practices in science, technology and medicine, including challenges to established, dominant understandings of these and the drawing of distinctions between lay and expert people. These thoughts frame Bella’s interest in various understandings of health and medicine and, in particular, in the spiritual aspects of health care.

In March 2003 Bella joined the Department as Research Fellow on a project, funded by the MS Society, to develop and evaluate a flagship neurology and palliative care service for people with MS.

Additional Contributors
We would also like to acknowledge the valuable contribution of the following former members of staff in the department to research undertaken during the period covered in this report:

Dr. David Gruenwald (Visiting Fellow from the US)
Saffron Karlsen
Anne McCoy
2.2.3 RESEARCH UNDERTAKEN 2000 - 2003

Multiple Sclerosis: development and evaluation of flagship service
Bella Vivat, Polly Edmonds, Rachel Burman, Eli Silber, Irene J Higginson

Dr. Polly Edmonds, Professor Irene Higginson, Dr. Rachel Burman, Dr. Eli Silber and Bella Vivat have won this major grant from the MS Society to develop and evaluate a new model of care. In 2003 the project undertook a needs assessment to more clearly identify what services currently exist for patients with MND and MS, what patients, carers and healthcare professionals working with these patients feel is important and whether patients are able to access appropriate services. Following this a new team has been established, based at the King’s Neurosciences centre and working closely with the hospital palliative care team. The new team will identify patients with MS and MND that might have palliative care needs, in order to undertake specialist assessment, to collaborate with existing services to improve access to non hospital-based services and to undertake appropriate education of healthcare professionals, patients and carers. As the service is new and innovative, it will be evaluated using a before and after design plus a comparison between fast track and standard referral times.

The BUILD project, to test and compare two models of user involvement for patients with MND.
Anu Sinha, Rhidian Hughes, Irene J Higginson, Nigel Leigh

This project co-led by Professors Higginson and Leigh (Institute of Neurology, Institute of Psychiatry) is designed to improve care using feedback from users to remodel services. Our study compares the effects of user involvement through the standard format of a group with a virtual forum on the internet (Down, Sinha, Hughes et al. 2002; Hughes, Down, Sinha et al. 2003). The report of the pilot work is due for publication by J oseph Rowntree and has been shortlisted for a BUPA award for clinical excellence for improving communication and services in care. However, we do not know the long term effects of the virtual forum or how it will roll out to patients with other neurological conditions and, if successful, we wish to take this work forward as part of our emerging Centre for Palliative Neurology.

HIV/AIDS
Richard Harding, Irene J Higginson

Professor Irene Higginson has been providing expert advice to the Department of Health and Human Services, USA on the development and evaluation of palliative care for people with HIV/AIDS during the past four years. In December 2000 she co-organised (with J oseph O’Neill, Director, Office of National AIDS Policy, The White House, Washington DC, USA) a conference at the Royal Society of Medicine on Palliative Care in the Age of HIV/AIDS, which reviewed current evidence on care and disease trends and patient needs. Several keynote speakers from the UK and USA were involved, including Professor Easterbrook, Professor of HIV/Genito-Urinary Medicine at King’s College London. The proceedings, edited by Dr Robin Fox and Professor Irene Higginson, were published in 2001 as an entire issue of the Journal of the Royal Society of Medicine (Journal of the Royal Society of Medicine, Issue 94). Professor Higginson is also co-investigator, with colleagues at Columbia University, New York, on an evaluation of six new models of palliative care for people with HIV/AIDS. The project is now in its fourth year and the next two years will see completion of data collection, final analysis and full reporting.

Following a research fellowship offered to Dr. Richard Harding and Professor Irene Higginson from the US Department of Health Washington DC and Columbia University Mailman School of Public Health, a body of evidence appraisal has been produced on the effectiveness of palliative care in HIV/AIDS patient management (Harding, Stewart, Marconi et al. 2003). The role, and continuing need, for palliation has been identified in the changing HIV epidemiology, and a further analysis of the evidence has identified the barriers and inequalities in the provision of and access to palliative care in HIV/AIDS. The findings are also feeding into the work on HIV/AIDS palliative care in Africa.

Heart Failure
Angie Rogers, Anne McCoy, J ulia Addington-Hall, Polly Edmonds, Simon Gibbs

Heart failure research was mainly focused on testing new treatments and evaluating methods to help heart failure patients comply with dietary and other restrictions to prevent hospitalisations. The experiences of patients living with heart failure has received less attention, and the needs of those who die even less - despite prognosis being similar to that of patients with metastatic colo-rectal cancer. Angie Rogers, Anne McCoy, Professor J ulia Addington-Hall, Dr. Polly Edmonds, and Dr. Simon Gibbs (Imperial College) conducted a prospective cohort study (funded by the British Heart Foundation) of patients with severe heart failure. Components included:

• an in-depth qualitative study of patients’ experience of living with severe heart failure. Findings have included novel insights into the informational needs of these patients and the barriers they experience in seeking information, as well as into their experience and understanding of their symptoms and drug therapy.

• semi-structured interviews with 200 heart failure patients following their discharge from hospital, and with their nominated informal carers. We
have found that the functional status and symptoms of patients with severe heart failure are as bad as in metastatic lung cancer, and up to 60% of these patients have uncontrolled symptoms of fatigue and breathlessness. A significant minority experience pain, but almost none were taking analgesia. A third were depressed - and those reporting a poor quality of life, difficulty in getting information from health professionals, and severe symptoms were most likely to be depressed. Few were receiving any help with depression. Many patients are dissatisfied with the information they have received, and with communication with health professionals. Many informal carers reported being overwhelmed by the patient’s needs.

**Stroke**  
Angie Rogers, Julia Addington-Hall et al.

Despite high levels of mortality and morbidity the palliative care needs of stroke patients have received little attention. Angie Rogers, Julia Addington-Hall, Pandora Pound (KCL Public Health) and Professor Lalit Kalra (Professor of Stroke Medicine, King’s College London) have used qualitative research methods to study in depth the experiences of patients who died from stroke and their families, to investigate whether dying stroke patients could be identified. Methods included non-participant observation on an acute stroke unit, and in-depth interviews with the families of dying stroke patients and with health professionals (interviews with patients were not possible because they were usually unconscious). The findings showed that dying stroke patients could be identified by health professionals, highlighted the complexities involved in decision-making about these patients’ futures (in particular, whether they should receive artificial nutrition), and described how these patients received little attention between decisions being made to withdraw or withhold active treatments and the patient ‘actively dying’ (Rogers 2001).

The qualitative methods used in this study allowed dying from stroke to be investigated in depth, but were not intended to be representative of all patients who die from stroke. The NHS Research and Development Programme have therefore funded the development of a stroke-specific version of VOICES (informed by the findings of the earlier study, as well as interviews with health professionals and others) and its use in a forthcoming population-based survey to describe the experiences of people who die from a stroke at home, in care homes and in hospitals. The findings will be used to inform the development and evaluation of appropriate education for health professionals working with these patients, and of novel interventions.

**COPD**  
Helena Elkington, Patrick White, Julia Addington-Hall, Polly Edmonds

With Dr. Patrick White and Helena Elkington (Department of General Practice, King’s College London) Professor Julia Addington-Hall and Dr. Polly Edmonds have investigated the needs of COPD patients from the perspective of bereaved relatives, using both qualitative and quantitative research methods. A COPD-specific version of VOICES has been developed, and is available for use in further studies investigating the complex needs of these patients, and testing the effectiveness of novel interventions. Clinical links are being developed with the King’s Breathing for Life/COPD team. This will enable opportunities for developing and evaluating palliative care interventions and the impact of decision making at the end of life.

**Cystic Fibrosis**  
Karen Lowton, Irene J Higginson

Currently, research on cystic fibrosis tends to focus on future potential treatments such as gene therapy, rather than describing how care is actually experienced at the end of life. In her PhD thesis Dr. Karen Lowton explored issues related to quality of life for people with CF. Through a grant from The Cicely Saunders Foundation, Karen Lowton and Irene Higginson have begun an exploratory project to describe and understand families’ experiences of end-of-life care, both to provide a resource for other families and to enable health services to improve the care they currently offer.
2.2.4
IN FOCUS

Developing and evaluating a palliative care service for people affected by MS

In 2002 the Multiple Sclerosis Society awarded the Department over £300,000 for research into palliative care and MS. This research is the first of its kind, and comprises two phases, following the steps of the Medical Research Council (MRC) Framework for the evaluation of complex interventions. The first phase of the study – service design/modelling – is now complete, and has resulted in a flagship neurology and palliative care service at King’s College Hospital. The second phase of the study – service evaluation – will begin as soon as the service is fully established. This framework was originally used by Higginson and Harding to develop and evaluate the support group for carers.

Studies in recent years have shown that people with MS may be able to benefit from palliative care, through its attention to pain and symptom control issues and provision of psychological, social and spiritual support. Dr Polly Edmonds, the lead investigator, says: “We want to develop models of good practice to influence the development of similar services across the UK and worldwide.”

The first phase of the study began in March 2003 and was completed at the end of 2003. Between March and August 2003 semi-structured interviews were conducted with 23 people with MS and 17 carers in Southeast London, and 12 focus groups and 4 individual interviews were conducted with HCPs working in MS, rehabilitation or palliative care across Southeast England. These interactions were taped and transcribed and a content analysis performed.

The main preoccupations of people with MS were their experiences of loss, relating to mobility, independence, and personal relationships, while a few had specific concerns regarding pain, medication, non-specialist care, and end-of-life issues. Others, particularly informal carers, were troubled by:

• quality of inpatient care
• continuity and co-ordination of care
• lack of information, and
• the sense that they had constantly to fight for the services and benefits which they received.

C05 (wife with MS, UNDS 27): Everything is compartmentalised. The carers, the health centres, the GPs, the MS nurses, and the hospitals. It’s all these groups... and there’s no intermix! There’s no thread in between anything.

C06 (deceased husband with MS): I would have liked more assistance with what was going to happen at the end... I would have liked more information... to know what to expect.

C08 (husband with MS, UNDS 45): On a practical level it’s been hard, still having to fight for everything.

HCPs identified issues relating to:
• resources
• continuity of care
• provision and access to services
• rehabilitation goals
• unpredictability of the disease process
• specific physical and psychological problems, and the end-of-life, specifically terminal care and decision-making.

On the basis of these findings, together with literature reviews, the service was designed to include a palliative care consultant, a clinical nurse specialist, a psychosocial worker, and a service co-ordinator, whose role will include collating information and providing an information resource.

The service was formally launched on 30 January 2004 and is expected to be fully established by June 2004. At this point the evaluation study will begin.

The service will complement rather than duplicate the work of existing services
• provide a quality palliative care multiprofessional assessment and diagnosis for the individual
• provide specialist welfare benefits advice and bereavement support as appropriate
• liaise and act as a catalyst with local services, both primary care and specialist teams
• enable crisis prevention
• develop education and support to primary and secondary care to improve co-ordination and quality of care
• inform future research initiatives
• provide descriptions of a model(s) of good practice that might be generalisable for the UK and worldwide

The evaluation will aim to:
• describe the referral patterns and activity of the service;
• describe the experiences and views of the service of people with MS who have been referred to it and the experiences and views of those informally involved in their care.
• identify those aspects of the service which are most useful to people with MS, those informally involved in their care and health care professionals.

Dr Eli Silber, Consultant Neurologist at King’s College Hospital, part of the project team
2.2.5 PUBLICATIONS

PAPERS IN SCIENTIFIC JOURNALS

2001


**HIGGINSON IJ, O’Neill J.** Conclusions from the meeting (Palliative care in the age of HIV/AIDS. Papers and recommendations from a US/UK meeting). J journal of the Royal Society of Medicine 2001;94:496-498


**LOWTON K, HIGGINSON I, SHIPMAN C.** Evaluation of an intervention to reduce the impact of childhood bereavement at school. Journal of Interprofessional Care 2001;15:397-398


2002


**LOWTON K.** Can we provide effective palliative care for adults with cystic fibrosis? European Journal of Palliative Care 2002;9:142-144


2003

**EDMONDS P, ROGERS A.** ‘If only someone had told me ...’ A review of the care of patients dying in hospital. Clinical Medicine 2003;3:149-152

**LOWTON K.** ‘Double or quits’: perceptions and management of organ transplantation by adults with cystic fibrosis. Social Science and Medicine 2003;56:1355-1367


2004


PUBLICATIONS IN OTHER JOURNALS

2002


RESEARCH LETTERS

2001


2003

CONFERENCE PRESENTATIONS

2001


2002


2003
BOOKS

2001

BOOK CHAPTERS

2001


2003

2004

REPORTS

2001


2002

2003


2004
LOWTON K, HIGGINSON IJ, Thomas J, Jones C, Kraus F, Monroe B. Supporting bereaved students in primary and secondary schools. King’s College London and National Council for Hospice and Specialist Palliative Care Services. 2004
2.3 Improving Assessment and Treatment: Clinically based Research

2.3.1 Background and overview

Focused clinical research seeks to discover more effective ways to prevent and treat pain, symptoms and other problems experienced by patients and families towards the end of life. This is achieved through epidemiological studies of cause, natural history and associated factors of symptoms and problems; clinical trials evaluating new treatments; systematic literature reviews and the establishment of programme units of collaboration with other medical specialties for specific conditions or symptoms where therapies for symptom relief and palliative care have thus far been little developed. The group focuses on symptoms and problems that have been neglected in the past.

Areas of particular focus within our clinical research include:
- Pain
- Depression
- Fatigue
- Breathlessness

2.3.2 ACADEMIC STAFF PROFILES

Dr. Lara Alloway
Lara studied medicine at the University of Southampton, qualifying in 1995. Following which she worked in hospital general medicine, gaining membership of the Royal College of Physicians of London in 1998. Since then she has worked in palliative medicine. In 2000 Lara joined the South Thames Specialist Registrar Training Scheme and have worked in posts incorporating hospice, community and hospital palliative care. As part of her training Lara joined the department in March 2003 in order to pursue her research interest: the symptomatic treatment of breathlessness. She is currently setting up a project comparing morphine preparations in the treatment of breathlessness in cancer patients. Lara is also developing and validating a symptom module for the Palliative care Outcome Scale.

Jo Armes
Jo is a qualified nurse who has gained clinical and research experience in the cancer and palliative care setting over the past 10 years. Jo has a BSc in Nursing Studies and an MSc in Research and Evaluation for Professional Practice. Much of her recent research experience has been gained in conducting qualitative studies, including an assessment of the needs of people with HIV/AIDS for palliative care, and an examination of the factors influencing place of death. She was awarded a CR UK Nursing Fellowship to undertake a PhD, which is now nearing completion. This assesses the effectiveness of a brief psycho-educational intervention in improving cancer-related fatigue by means of a randomised trial.
Dr. Sara Booth
Sara became interested in palliative medicine when she was a student and worked at St Christopher’s Hospice as an auxiliary nurse. After graduating however, she pursued anaesthetics to registrar level (Oxford Radcliffe Hospitals) and then returned to train in palliative medicine gaining experience in psychiatry before starting palliative medicine at St Christopher’s. After St Christopher’s Sarah returned to Oxford to become Senior Registrar at Sir Michael Sobell House and then started a hospital palliative care service at the John Radcliffe Hospital. She then completed one year’s full-time research as an NHS R&D fellow before starting as Macmillan Consultant in Palliative Medicine at Addenbrookes Hospital, Cambridge in 1998. Sara is now collaborating with the department on modelling a breathlessness service on a Sainsbury’s family charities grant.

Dr. Polly Edmonds
Polly is a consultant in Palliative Medicine at King’s College Hospital NHS Trust and honorary senior lecturer in the Department of Palliative Care and Policy, King’s College London. She qualified from St Mary’s Hospital Medical School, and trained in General Medicine, Medical Oncology and Palliative Medicine. She is closely involved in the undergraduate curriculum at Guy’s King’s and St Thomas’ School of Medicine, and her research interests include palliative care for non-cancer patients.

Dr. Jean Potter
Jean completed her general medical training and became a Specialist Registrar in Clinical Oncology. Realising that she was more interested in the palliative care aspects of the job, she changed speciality and joined the North Thames training scheme in Palliative Medicine. She is sandwiching her clinical training around a PhD, which assesses the prevalence, pain qualities and treatment of neuropathic pain experienced by people with malignant and non-malignant conditions.

Additional Contributors
We would also like to acknowledge the valuable contribution of the following former member of staff in the department to research undertaken during the period covered in this report:

Julie Hearn – Honorary Research Fellow
2.3.3 RESEARCH UNDERTAKEN 2000 - 2003

Pain
Julie Hearn, Jean Potter, Irene Higginson and Lynne Turner-Stokes

Julie Hearn and Professor Irene Higginson conducted systematic reviews on the general prevalence of pain. Then, following funding from Mrs Coco Markus for a clinical PhD Fellowship, Dr. Jean Potter (a physician PhD student) and Professor Higginson developed the reviews and conducted a longitudinal study of neuropathic pain’s natural history and comparing the treatment outcomes between diabetic neuropathy and neuropathic pain in cancer. Recruitment and follow up to this epidemiological study was successful, 85% of potential interviews were conducted in both patient groups. The method of identifying patients with neuropathic pain proved successful (Potter, Higginson, Scadding et al. 2003). The work demonstrated the validity of a screening tool - the Leeds Assessment of Neuropathic Symptoms and Signs (LANSS). Five hundred and sixty two patients were surveyed, and the prevalence of neuropathic pain in the groups of outpatients were similar (pain 21-23%, neuropathic pain 8-10%). Compared to expert opinion the sensitivity and specificity of the LANSS were 79-82% and 98-100%. Seventy percent of patients with neuropathic pain rated it as severe. Further analysis is tracking the change in pain experience over time and the treatment outcomes.

Pain is a common sequel to neurological damage. Unfortunately, many patients with neurological conditions also have cognitive and/or communicative deficits which prevent them from describing their symptoms and alerting staff to their suffering. Professor Lynne Turner-Stokes and her team have explored a variety of methods to quantify pain in patients who are unable to use standard questionnaires, pain scales and the other usual tools which clinical staff use to quantify pain. The AbilityQ is a pre-screening questionnaire which tests the individual’s ability to complete a questionnaire accurately before they put pen to paper, and also helps the investigator to define the types of help which they might need to complete the questionnaire accurately (Turner-Stokes and Rusconi 2003). The Scales of Pain Intensity (SPIN) is a simplified graphic form of visual analogues scale which allows the investigator to explore pain with patients who are profoundly dysphasic or cognitively impaired. Professor Turner-Stokes has also conducted a randomised trial to evaluate cognitive behavioural pain management programmes, and to show that group therapy can be as effective as individual therapy (Turner-Stokes, Erkeller-Yuksel, Miles et al. 2003).

Bisphosphonates in Malignant Disease
Polly Edmonds et al.

In addition to researching individual symptoms we are interested in assessing new treatments that may benefit several symptoms. Dr. Polly Edmonds and colleagues have recently completed a systematic review, funded by Heath Technology Assessment programme of the NHS Research and Development, of the role of bisphosphonates in malignant disease (Ross, Saunders, Edmonds et al. 2003). This has demonstrated the efficacy of bisphosphonates in reducing the skeletal morbidity associated with bone metastases and in the treatment of malignant hypercalcaemia. An economic evaluation suggested that the use of bisphosphonates for these clinical indications is cost effective. There are few studies assessing the role of bisphosphonates in the adjuvant setting (to delay the development of bony metastatic disease); early analysis suggests that bisphosphonates may have a role in this setting, but the results of current studies are awaited before firm conclusions can be drawn.
**Depression**
Julia Addington-Hall, Matthew Hotopf, Lynne Turner-Stokes et al.

Professor Julia Addington-Hall and Dr. Matthew Hotopf (Clinical Reader, Institute of Psychiatry, King’s College London) have conducted systematic reviews of the prevalence of, risk factors for, and treatment of depression in palliative care patients (Hotopf, Chidgey, Addington-Hall et al. 2002; Lan Ly, Chidgey, Addington-Hall et al. 2002).

Professor Lynne Turner-Stokes has reviewed the evidence base for the treatment of depression following stroke, leading to the development of clinical guidelines (Turner-Stokes and Hassan 2002; Turner-Stokes and Hassan 2002) which now need testing in practice.

**Fatigue**
Jo Armes, Julia Addington-Hall, Matthew Hotopf, Alison Richardson

Fatigue is a common symptom in palliative care patients and is particularly difficult to treat. Jo Armes (a nurse PhD student funded by Cancer Research UK), Professor Julia Addington-Hall, Dr. Matthew Hotopf (Institute of Psychiatry, King’s College London) and Professor Alison Richardson (School of Nursing, King’s College London) have developed an innovative psycho-educational intervention based on a theoretical model developed following an extensive literature review. They are currently testing its efficacy via a randomised controlled trial which will also provide new information on the causes and correlates of fatigue in this population. Jo Armes, Mei Krishnasamy (Australia) and Professor Irene Higginson have also just completed the first major textbook on Fatigue in Cancer, published by Oxford University Press in 2004.

**Breathlessness**
Polly Edmonds, Irene Higginson

Breathlessness (or dyspnoea) is the most common severely distressing symptom after pain among patients with progressive cancer, heart failure, respiratory failure and many other terminal conditions. Our research to date has shown that it affects around 70% of patients with advanced cancer and is severe in over a quarter. It is more common among patients who have disease in the lung, or those with muscle weakness, affecting the capacity to breathe. It increases in severity as death approaches (Edmonds, Higginson, Altmann et al. 2000). In many countries, the three conditions where breathlessness is most problematic – heart failure, lung cancer and chronic lung disease – are the most common causes of mortality and morbidity.

Following a major five-year programme grant from The Cicely Saunders Foundation we are about to embark on the Improving Breathlessness Programme, a major collaborative research programme that seeks solutions to breathlessness.

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The prevalence of depression, results of a systematic review
2.3.4
IN FOCUS

Summary of Systematic Review of the role of Bisphosphonates in Metastatic Disease

J R Ross, Y Saunders, PM Edmonds, S Patel, D Wonderling, C Normand, K Broadley.
Funded by the NHS R&D HTA Programme

Aims and Methods
This systematic review was conducted to identify evidence for the role of bisphosphonates in malignancy for the treatment of hypercalcaemia, prevention of skeletal morbidity and use in the adjuvant setting. An economic review of the literature and modelling of cost effectiveness was also undertaken. The review was conducted using methodology outlined by the Cochrane Collaboration.

Results
Acute hypercalcaemia of malignancy - bisphosphonates normalised serum calcium in >70% of patients within 2-6 days. Pamidronate was more effective than control, etidronate, mithramycin and low-dose clodronate but equal to high dose clodronate in achieving normocalcaemia. Pamidronate prolonged the median time to relapse compared with clodronate or etidronate.

Prevention of skeletal morbidity - bisphosphonates compared to placebo significantly reduced the odds ratio (OR) for fractures (OR [95% CI] vertebral 0.69 [0.57-0.84], non-vertebral 0.65 [0.54-0.79], combined 0.65 [0.55-0.78]), radiotherapy 0.67 [0.57-0.79] and hypercalcaemia 0.54 [0.36-0.81], but not orthopaedic surgery 0.70 [0.46-1.05] or spinal cord compression 0.71 [0.47-1.08]. Bisphosphonates significantly increased time to first skeletal related event (SRE) but did not effect survival. Subanalyses suggest that most evidence support the use of intravenous aminobisphosphonates.

Adjuvant setting - Clodronate, given to patients with primary operable breast cancer and no metastatic disease, significantly reduced the number of patients developing bone metastases. This benefit was not maintained once regular administration had been discontinued. Two trials reported significant survival advantages in the treated groups.

Economic Modelling - for acute hypercalcaemia, drugs with the longest cumulative duration of normocalcaemia were most cost effective. For skeletal morbidity, Markov models estimated that the overall cost of bisphosphonates therapy to prevent a skeletal related event was £250 and £1500 per event for patients with breast cancer and multiple myeloma respectively.

Conclusion
High dose aminobisphosphonates are more effective for the treatment of acute hypercalcaemia and delay time to relapse. Bisphosphonates significantly reduce SREs and delay time to SRE in patients with bony metastatic disease but do not effect survival. Benefit is demonstrated after admission for 6-12 months and the greatest body of evidence supports the use of intravenous aminobisphosphonates. Further evidence is required to support use in the adjuvant setting.

Summary statistics from pooled analysis at fixed time points for effect of bisphosphonates on skeletal morbidity end points, specifically radiotherapy, non-vertebral fractures, orthopaedic surgery and hypercalcaemia in patients with metastatic bone disease.


<table>
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<th>Months of treatment</th>
<th>Number of studies</th>
<th>Number of patients</th>
<th>Odds ratio (95% CI)</th>
<th>P Value</th>
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<tr>
<td>Non-vertebral fractures</td>
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### 2.3.5 PUBLICATIONS

#### PAPERS IN SCIENTIFIC JOURNALS

**2001**


**2002**


**2003**

**ARMES PJ, ADDINGTON-HALL J M.** Perspectives on symptom control in patients receiving community palliative care. Palliative Medicine 2003;17:608-615

**BOOTH S.** Wade R. The role of oxygen and air in the palliation of breathlessness associated with advanced cancer. Jourimum of the Royal Society of Medicine 2003;96:215-218

**EDMONDS P, ROGERS A.** ‘If only someone had told me ...’ A review of the care of patients dying in hospital. Clinical Medicine 2003;3:149-152

**POTTER J, Hami F, Bryan T, Quigley C.** Symptoms in 400 patients referred to palliative care services: prevalence and patterns. Palliative Medicine 2003;17:310-314


**2004**


**EDMONDS P.** Organization of palliative care services. Medicine 2004;32:2-3


#### PUBLICATIONS IN OTHER JOURNALS

**2001**

Fyvie J, **EDMONDS P.** Transfer of pain management to the home and outpatient setting. Future Prescriber 2001;Jan/Feb:19-21

**2002**


#### RESEARCH LETTERS

**2003**

**EDMONDS P, Lucas C, on behalf of the South London Palliative Care Research Group.** A trial that failed because of poor recruitment. Palliative Medicine 2003;17:557.

#### CONFERENCE PRESENTATIONS

**2001**

**ARMES J.** Using meta-ethnography to synthesize qualitative studies. Palliative Medicine 2001;15:526-527

**ARMES J, ADDINGTON-HALL J M.** A qualitative study of the factors influencing the assessment and management of symptoms in the community. Palliative Medicine 2001;15:537-538


Swann D, **EDMONDS P, Davis C, ANDREWS V, THOMPSON M.** A pilot study to assess the value of breathlessness descriptors as aids to diagnosis in people with advanced cancer. Pall Med 2001;15:544
**BOOKS**

2004


**BOOK CHAPTERS**

2001


2002


2003


2004


**REPORTS**

2001


2003


2004

2.4 Researching Dying in Society

2.4.1 BACKGROUND

The increase of cancer and other progressive illness as a cause of death in our society poses new problems for health professionals, for health care spending, and for society as a whole. In future years there will be a keener debate over such questions of ways to meet the growing cultural diversity in our society, of euthanasia, advance directives, and location of dying, together with the economic, social, psychological, spiritual and ethical implications of these trends.

The Department has been developing this strand of research over the last three years. Key areas of work currently include:
- Ethnicity
- Older people
- Preferences for home deaths
- Advance directives
- Palliative care in Developing Countries

2.4.2 ACADEMIC STAFF PROFILES

Dr. Heidi Hill
Heidi graduated in 1997 with a BSc in Human Biology from King's College London and then began work in the Respiratory Medicine & Allergy Department at Guy's Hospital from where she obtained her PhD in Vascular Physiology. Whilst writing her thesis Heidi worked as an editor for a health media company where she researched and wrote articles for the national press on healthcare provision including maternity services and infertility treatments. Heidi joined the Department of Palliative Care & Policy in November 2001 and she undertook systematic literature reviews into a number of issues related to providing good care for the dying, including: the effectiveness of advanced directives and DNR orders in determining a ‘good death’, and effective methods of providing symptom control.

Jonathan Koffman
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 has involved health services research for Parkside Health Authority and Kensington & Chelsea and Westminster Health Authority. Jonathan is now the Course Co-ordinator for the multi-professional MSc in Palliative Care. His research interests include the palliative care needs of black and minority ethnic groups, social exclusion at the end of life and palliative care education. He has published in the following areas: mental health, homelessness, the elderly, HIV/AIDS, palliative care, public health services research, and education. He is working towards a PhD exploring the influence of ethnicity and culture on coping with advanced cancer in Caribbean and native-born white United Kingdom patients.
Revd. Prebendary Peter Speck (Honorary)

Peter Speck started his career as a scientist gaining a degree in zoology and biochemistry from the University of Wales at Bangor (1964) before doing his theology degrees at Birmingham. He was ordained into the Anglican priesthood in the Church of Wales and served in parish of Rhosddu, Wrexham.

Full-time work in the National Health Service started with his appointment in 1972 as a whole-time Hospital Chaplain to the United Sheffield Hospitals later becoming Senior Chaplain at the Northern General Hospital. In 1979, he became whole-time senior chaplain to the Royal Free Hospital, London and Honorary Senior Lecturer in medical ethics at the Royal Free School of Medicine. During his period at the Royal Free, he was also Visiting Tutor to the Tavistock Clinic and Institute of Human Relations, London.

In 1995, Peter was appointed as Trust Chaplaincy Team Leader to Southampton University Hospitals NHS Trust. Member of the Local Research Ethics Committee, and Co-Chair of the Clinical Ethics Committee. He was also Visiting Lecturer and Examiner for MSc in Palliative Care at Southampton University and at King’s College, London. For many years was member of editorial board of the international (indexed) journal “Palliative Medicine” Editorial Board member for NICE guidance for supportive care in palliative care. (published March 2004)

Peter ‘retired’ from whole time chaplaincy in Sept. 2002. Peter’s main research interest is in belief systems and whether they are influential in outcome from serious illness and life crises. In addition to his association with Kings College London, he has collaborated closely with Professor Michael King, Dept. of Academic Psychiatry at Royal Free Hospital, London and with Professor Peter Coleman, Psychology Dept. Southampton University. Several peer reviewed papers published and a Templeton Exemplary Papers award for innovative research in religion and medicine 1996.

He is the author of several books on pastoral care and chapters in books relating to pastoral care in health care and palliative medicine. Peter’s long involvement nationally and inter-nationally in this subject area has included lecturing on aspects of palliative care, ethics and spirituality in many countries around the world, and on the MSc course at King’s. Peter is currently a Visiting Fellow (Faculty of Medicine) Southampton University and Hon Senior Research Fellow at King’s College London, (Dept. of Palliative Care & Policy.)

Additional Contributors

We would also like to acknowledge the valuable contribution of the following former member of staff in the department to research undertaken during the period covered in this report:

Dr. Christine McPherson
Cultural and ethnic issues
Jonathan Koffman and Irene J Higginson.

People from minority ethnic backgrounds currently represent approximately 7.9 per cent of the population in the United Kingdom. Although there is a significant lack of data about people from minority ethnic communities, the available data confirms that some groups experience disproportionate disadvantage across the board. They are frequently concentrated in deprived areas and suffer all the problems that affect other people in these areas. But people from minority ethnic communities also suffer the consequences of overt and inadvertent racial discrimination - individual and institutional - and an inadequate recognition and understanding of other complexities they may experience, for example barriers like language, cultural and religious differences.

Although evidence of poor health among black and minority ethnic communities and the inadequate services to address it are not new, until recently very little attention had focused on people with advanced disease and their families. Redressing this issue is important, since a greater understanding of the health and social needs of different ethnic communities at the end of life may lead to improvements in health of patients and post-bereavement outcomes in family members, further justified by the growing number of older people within these communities who will experience advanced disease. The Department of Palliative Care & Policy has therefore focused attention on the local Caribbean population during the past five years and has also in the process of evaluating a community-based palliative care pathway to improve the up-take of specialist palliative care services among diverse communities living in Brent and Harrow.

Older people
Elizabeth Davies, Irene J Higginson

Older people form a further vulnerable group whose needs have often been neglected in the past. Dr. Elizabeth Davies and Professor Irene Higginson have embarked on an evidence-based review commissioned by the World Health Organisation (WHO) on the needs of older people in palliative care, and how these may be met. Professor Irene Higginson and Dr. Elizabeth Davies are leading, on behalf of the European Association for Palliative Care, an international project team of experts with multidisciplinary backgrounds, including individuals from geriatric and palliative medicine. The work will result in WHO guidance, from the European Office of WHO, for policy makers and governments which will be published in 2004, supported by the Floriani Foundation. Two short documents, Palliative Care: The Solid Facts and Better Palliative Care for Older People will be published by the WHO in 2004. The documents highlight the need for cross European studies, to better understand the palliative care experience and effective treatments and care in different contexts, which we expect the WHO to feed into EC Funding streams.
Preferences for and trends in home death
Irene J Higginson, Barbara Gomez

Understanding trends can help to indicate areas for investigation. The department holds data on all death registrations from cancer in England and Wales from 1985 to 1999 inclusive, obtained from the Office of National Statistics (ONS). Preliminary analysis of this data set identified that home death was independently less likely in older people, in women, in those who suffered cancers other than colorectal and lung, and those who lived in deprived areas of the country. However, the analysis also identified that there were wide variations between geographical areas in the proportions of people who died at home – ranging from as much as 70 to less than 10% of cancer deaths at home (using five year average data) (Higginson, Astin and Dolan 1998; Higginson, Jarman, Astin et al. 1999).

To understand this further, we are conducting a series of systematic literature reviews. The first review investigated preferences for place of care and identified that home is a strong preference, being present in between 50 and 80% of patients and a slightly lower proportion of families and professionals. Various factors affect a preference, including prior experience, expectations and a positive or negative view of home and hospital care (Higginson and Sen-Gupta 2000). The Cicely Saunders Foundation explored these preferences further through a national telephone survey of 1000 people of priorities and preferences for end of life care. When respondents were asked where they would like to be cared for if they were dying there was an overwhelming preference for home care, with hospice coming second (56% and 24% respectively). This was consistent across regions and all age groups, except that residents in the area of London and those age 65 years and over had slightly lower home preferences of just under 50%. There is a stark contrast between preferences of where people said they wanted to be cared for and where they actually die, both for people with cancer and other causes (Higginson 2003).

Place of cancer death for children and young adults in England and Wales, 1995-99 (n=3,197) Source: Higginson and Thompson, BMJ
Advance Directives
Heidi Hill, Julia Addington-Hall

Dr. Heidi Hill and Professor Julia Addington-Hall have conducted a systematic review of whether advance care planning - including living wills and advance directives - have a significant effect on the number and type of medical interventions in the last days of life, or on other aspects of patient experience. This forms part of a programme of work with the Nuffield Trust on Dying in the NHS, which Professor Addington-Hall is leading.

Palliative Care in Developing Countries
Richard Harding, Irene J Higginson et. al.

Palliative care is important not only in developed, but also developing and resource-poor communities. The research of the Institute will focus on providing cost effective methods of treatment and solutions, such as simple drugs, that will work in poor as well as affluent countries. Initially, we will focus on care in Africa. This is partly in response to the White House, USA, initiative to provide $15 billion for care and treatment for people with HIV/AIDS in Africa. Fifteen percent of this money will be spent on palliative care and Professor Irene Higginson has already been involved in a keynote meeting at the White House, which agreed the role of palliative care in this initiative. As part of this, Dr. Richard Harding and Professor Irene Higginson, together with colleagues in the USA (O’Neill and Marconi) undertook a survey of HIV/AIDS end-of-life care in sub-Saharan Africa. This collaboration with the White House National Office of AIDS policy is the first body of evidence on current practice priorities and challenges to the provision of palliative care in Africa. The findings from the study have provided a framework for this current funding interest in care in Africa, specifically:

• Describing current models
• Comparing service aims and disease groups and stages
• Identifying components of palliation
• Presenting challenges to pain relief
• Identifying the role of advocacy for palliative care
• Describing structural and governmental support for palliative care
• Presenting priorities for future provision

This initiative was accompanied by a research grant from the Diana Princess of Wales Memorial Fund (Dr. Richard Harding and Professor Irene Higginson) to appraise palliative care services in Africa in terms of sustainability, patient outcomes, community models, and integration into existing health systems. A further collaboration with a hospice in Africa has investigated pain prevalence and measurement.
2.4.4
IN FOCUS

Comparing the experience of advanced disease between black Caribbeans and white patients

Over the last five years we have been exploring the experience of advanced disease, and specifically cancer, among the local black Caribbean community. Jonathan Koffman and Professor Irene Higginson analysed family members or close friends reports of 50 first-generation black Caribbean and 50 native-born white United Kingdom relatives or dependants who lived in Lambeth, Southwark and Lewisham. The findings revealed a mixed picture where a number of unmet needs were identified. Poorer access to specialist palliative care services were evidenced among black Caribbean patients, as well instances of less satisfactory care, especially in the community (Koffman & Higginson 2001). Other areas explored included the different outcomes of religious faith among patients at the end of life and family or close friends who cared for them (Koffman & Higginson 2002); patient’s and families’ attitudes to euthanasia and timeliness of death (Higginson & Koffman 2003); the experience of cancer-related symptoms and their management, where higher levels of symptom-related distress were reported among black Caribbean patients (see figure 1) (Koffman, Higginson & Donaldson 2003); family or close friends accounts of caring for a relative or dependant with advanced disease (Koffman & Higginson 2003); the preferences and actual location of patients’ death, including their involvement in decisions as to where in where they died (Koffman & Higginson 2004); and the different outcomes of bereavement among relatives and close friends of deceased patients (Koffman, Higginson & Donaldson 2004).

Jonathan Koffman, Professor Irene Higginson, Dr Myfanwy Morgan and Dr Polly Edmonds have taken this research further to explore the lived experience of advanced cancer among the Caribbean community using qualitative methods. Face-to-face interviews were conducted during 2001-2003 with 30 black Caribbean and 20 native-born white with advanced cancer in their homes and in hospital settings. We also interviewed the spouses of six Caribbean and six white cancer patients who died during the course of study.

The data from this study has helped us better understand the different meanings of advanced cancer between black Caribbean and white patients, and what aspects of the illness they most troubled them, and this affected their everyday lives. We also have a greater understanding of how patients coped with their illness. Patients explained how family, friends and the local community helped them. They also spoke about the care offered by health care professionals in hospitals and the community. More Caribbean than white patients discussed the meaning of religious faith and spirituality in helping them understand their illness and cope with its uncertainties.

Cancer also affected the lives of family members from both communities. Spouses discussed how their lives had changed as their husband or wife’s cancer had progressed, and how this caused great distress. They also shared how they had coped, sometimes relying on the support of other close family members and the community, and sometimes on health care professionals. As with the Caribbean patients, more spouses from this community discussed their religious faith and spirituality as being helpful in understanding the illness and cope with it.

Whilst it is clear from our findings that there were sometimes differences between black Caribbean and white patients with advanced cancer and their relatives, we also observed important variations within the two cultures, suggesting taking these two communities at face value may reduce them to cultural stereo-types.

Symptom severity in advanced cancer assessed in two ethnic groups by interviews with bereaved family members and friends
(Source: Journal of the Royal Society of Medicine 2003;96:10-16)
2.4.5 PUBLICATIONS

PUBLICATIONS IN SCIENTIFIC JOURNALS

2001


2002
HIGGINSON IJ. US and UK horizons in palliative care. European Jourmal of Palliative Care 2001;8:40

KOFFMAN J. Rituals surrounding death and dying within the black Caribbean community. Palliative Care Today 2001;10:7-8

PUBLICATIONS IN OTHER JOURNALS

2001
HIGGINSON I. US and UK horizons in palliative care. European Jourmal of Palliative Care 2001;8:40

RESEARCH LETTERS

2001
KOFFMAN J. Alcohol abuse – common or garden? British Jourmal of General Practice 2001;51:408-409

CONFERENCE PRESENTATIONS

2001


McPHERSON CJ, ADDINGTON-HALL J M. How do memories of a significant other’s experience change during the bereavement period? British Psychological Society Centenary Annual Conference, Glasgow. 2001
2002
KOFFMAN J. Quality assurance for cancer patients and their families: turning vision into reality. 2nd International Seminar on Cancer Nursing of the Foundation for the Promotion of Cancer Research, Tokyo, Japan. March 2002


KOFFMAN J, HIGGINSON IJ. A comparison of informal caregivers’ experiences of tending black Caribbean and white dependents with advanced disease. 2nd Congress of the Research Network of the European Association of Palliative Care, Lyon, France. May 2002

MCPherson C, ADDINGTON-HALL J. How do proxies’ perceptions of patients’ pain, anxiety and depression change during the bereavement period? Journal of Palliative Care 2002;18:245-246

BOOK CHAPTERS

2001


2003


2004


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2003
2.5 Rehabilitation

2.5.1 Background and overview

The interface between rehabilitation and palliative care in progressive neurological conditions such as multiple sclerosis, motor neurone disease or severe brain injury is frequently difficult to define due to the variable or very slow progressive nature of the condition. Many patients would benefit from a more collaborative approach. Bringing together academic rehabilitation and palliative care will help to underpin the objectives of extending palliative care to patients and families according to need, wherever they are and whatever their condition.

2.5.2 ACADEMIC STAFF PROFILES

Stephen Ashford
Stephen Ashford qualified as a physiotherapist from Salford University and has worked primarily in neurorehabilitation since, including acute stroke units, rehabilitation units and national centres such as the Royal Hospital for Neurodisability, Putney. Current research is focused on use of Goal Attainment Scaling and other outcomes to assess the effects of rehabilitation in people with complex disabilities. Other recent work has focused on the use of botulinum toxin as an adjunct to physiotherapy intervention for spasticity management in individuals with brain injury. Steve is in the process of registering for a PhD within the department which will examine the need for accurate and appropriate assessment of the shoulder (function, care needs and pain) in hemiplegia.

Diana Jackson
Diana trained as a physiotherapist at Kings College Hospital and subsequently worked in a number of different hospital settings before specialising in neurological rehabilitation. Following an M.Sc. in rehabilitation studies at Southampton University, Diana joined the Regional Rehabilitation Unit at Northwick Park Hospital as a researcher in 1996. Projects since then have included a randomised controlled trial of aerobic exercise training for patients with acquired brain injury and the development of an integrated care pathway for the management of hemiplegic shoulder pain. Diana is nearing the end of a PhD on the assessment of shoulder pain in stroke patients and has gained experience of using both quantitative and qualitative methodologies in the process. She is currently employed as a clinical research fellow working on a Department of Health funded questionnaire study into the needs of carers of adults with acquired brain injury. Findings will contribute to the National Service Framework for Long-term Neurological Conditions.
Joel Sheridan
Joel Sheridan has a first class honours degree in Psychology and German from the University of Kent at Canterbury. He has been at King’s as a psychology research assistant since October 2003, interviewing carers of people with brain injuries. During his degree he spent three months working at the University of Jena (Germany), investigating the effects of panic disorder on cognitive inhibition. After graduating, he worked for a firm of occupational psychologists mainly on the NHS projects, assisting with the provision of development workshops for potential primary care trust chief executives.

Amanda Tadrous
Amanda graduated from The University of Liverpool with a BSc (Hons) in Psychology in 2003. She has a keen interest neuropsychology and has previously carried out research at the Walton Neurorehabilitation Unit designing and evaluating a patient led, disease specific measure of worry and anxiety for brain injury. She joined the department in October 2003 to work on the acquired brain injury carers project – a department of health funded study investigating the experiences of those who care for someone with a brain injury. She is also currently working on a sub-project evaluating a carer-completion version of the Northwick Park Dependency Score.

Heather Williams
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. This project will also form the basis of her MPhil studies.
2.5.3 RESEARCH UNDERTAKEN 2000 - 2003

Outcome measurement

A common strand to much of the recent work is the development of outcome measures with which to assess the effectiveness of rehabilitation intervention, and exploration of the relationship between different measures in current use in the UK. Over 8 years we have built up unique experience in the application, computerisation and statistical handling of outcome data.

Care needs assessment: a new outcome measure for severe disability

Development and evaluation of instruments which may be used to assess dependency on nursing and therapy staff, and importantly to assess the cost-implications - both of providing rehabilitation, and of its impact on reducing the long-term costs of care.

- The Northwick Park Dependency Score (NPDS) - a measure of nursing dependency for use in a hospital rehabilitation ward.
- The Northwick Park Care Needs Assessment (NPCNA) - a generic measure of care needs in the community and thus the cost of continuing care provided by health and social services.
- The Northwick Park Therapy Dependency Score (NPTDS) - is now in development.

FIM+FAM: A common language in disability measurement in the UK?

Professor Turner-Stokes has spear-headed a drive to develop common language outcome measurement for brain injury rehabilitation in the UK, with development of the UK FIM+FAM. In addition to the research and development aspects, the department acts as a centre for co-ordinating training and developing IT systems to assist with data collection.

Complex interventions in the context of brain injury rehabilitation

Integrated Care Pathway development

This area of work involves the development of multi-disciplinary integrated care pathways (ICPs). The ICPs are based on systematic reviews of the published evidence, to manage symptoms in the context of severe brain injury. Their purpose is not only to improve management, but also to form a basis for monitoring and assessment on which to measure the effectiveness of interventions prospectively. ICPs developed and published by the department to date are:

- Management of hemiplegic shoulder pain,
- Management of depression following acquired brain injury
- Use of botulinum toxin in management of spasticity

Evaluation of symptoms in complex disability

Patient with cognitive and communicative deficits following brain injury frequently have difficulty in completing questionnaires or reporting symptoms such as pain and depression. The projects have also involved development and evaluation of several original assessment tools adapted for disabled individuals including:

- The AbilityQ - a screening tool to assessment ability to complete a questionnaire (Turner-Stokes)
- The ShoulderQ - a tool for assessing the timing and severity of shoulder pain in patients with cognitive and language deficits
- The Scale of Pain Intensity (SPIN)
- The Depression Intensity Scale Circles (DISCs)

Evaluation of other complex interventions

In addition to the development of formal care pathways, other evaluations have been conducted to assess the benefits of intervention in the group of patients with severe complex disability, who would be predicted to have poor outcomes in terms of functional recovery. For example:

- To evaluate after care for patients with complex disabilities following discharge from a regional rehabilitation service (funded by the Regional Health Authority)
- A retrospective meta-analysis of pooled trial data to assess functional benefits from botulinum toxin in the management of upper limb spasticity.
Effectiveness of brain injury rehabilitation and Influencing policy

A further major area of work is the demonstration of effectiveness of rehabilitation through systematic review of the literature and the development of evidence-based standards and guidelines. These guidelines play a significant role in influencing policy regarding the provision and quality of rehabilitation services in the UK. In addition, Professor Turner-Stokes’ position as Deputy Chair of the External Reference Group for the NSF in long-term conditions, and as Chair of the Research and Evidence subgroup, has provided a useful platform from which to influence national policy, and to press for further investment in rehabilitation research.

• Initial reviews were undertaken in 1999 where Professor Turner-Stokes led a BSRM working party to identify the evidence for effectiveness in rehabilitation which was then published in a supplement to Clinical Rehabilitation.

• More recently this work has focussed on Cochrane reviews. A review is registered for the effectiveness of multi-disciplinary rehabilitation in rehabilitation of adults with acquired brain injury. This review has been used to underpin the National Guidelines for Rehabilitation in Acquired Brain Injury.

• The guidelines have been developed by a multi-agency working party chairmanship of Prof Turner-Stokes and were published in 2003 by the British Society of Rehabilitation Medicine and the Royal College of Physicians.

• A further area of work has been the gathering and evaluation of the literature to underpin the NSF for long-term conditions, which has also required the development of a new research typology which includes qualitative evaluation of the research as well as categorisation by design.

Users and carer experiences in acquired brain injury and other Long term conditions

Diana Jackson, Joel Sheridan, Amanda Tadrous

Work is recently underway to evaluate the experiences of users and their carers in long-term neurological conditions. This started with a series of systematic reviews undertaken in collaboration with the Social Policy research Unit (SPRU) York, and has progressed to a survey of the experiences of carers for people with brain injuries, which will be compared within collaboration with the Institute of Psychiatry, KCL.

Acquired brain injury can have major impact, not only for the individual, but also for their family and carers. If carers are not adequately supported, family relationships can break down, resulting in morbidity, distress and increased costs to the health and social services. This Department of Health funded questionnaire study aims to find out more about the experiences and needs of these carers. Findings will contribute to the Government’s National Service Framework for Long Term Neurological Conditions and will help to identify what kinds of support may be most helpful for the future. Questionnaires are being sent to carers identified through national voluntary organisations, such as Headway and the Encephalitis Society, and through rehabilitation units. Questions ask about the impairments and levels of dependency of the adult being cared for and about carer health, burden, the stressfulness of caring and quality of life. Respondents are followed up with a telephone interview to clarify any difficult questions and to invite further free comments.

This work is only recently started but publications are expected to arise from it by 2004/5.
2.5.4 PUBLICATIONS

PUBLICATIONS IN SCIENTIFIC JOURNALS

2001

Thornton H, JACKSON D, TURNER-STOKES L. Accuracy of prediction of walking for young stroke patients by use of the FIM. Physiotherapy Research International 2001;6:1-14


2002
ASHFORD S. Serial casting in the new born infant for correction of the soft tissue deformity associated with posterior bowing of the tibia. Physiotherapy 2002;88:148-152


2003


2004


TURNER-STOKES L, Rusconi S. Screening for ability to complete a questionnaire: a preliminary evaluation of the AbilityQ and ShoulderQ for assessing shoulder pain in stroke patients. Clinical Rehabilitation 2003;17:150-157
Rusconi S, Turner-Stokes L. An evaluation of aftercare following discharge from a regional rehabilitation service. Disability and Rehabilitation 2003;25:1281-1288


2004


Conference Presentations

2001


2002


Pautz A, Jackson D, Turner-Stokes L. Screening for ability to complete questionnaires; further development of the AbilityQ. Poster presentation: 13th European Congress of Physical and Rehabilitation Medicine, Brighton. May 2002


2003


Rusconi S, Turner-Stokes L. An audit survey of aftercare following discharge from a specialist in-patient rehabilitation service. International Society for Physical and Rehabilitation Medicine, Prague. May 2003


2004


REPORTS

2002


**TURNER-STOKES, L, WARD AB.** Short guidelines for the use of Botulinum Toxin in the management of spasticity. Clinical Medicine 2002; 2: 128-130

2003

**TURNER-STOKES, L.** Development of Clinical Governance in the UK: its implications for rehabilitation medicine Clinical Medicine, 2003; 3: 135-141


2004


2.6 Research grants received

We are extremely grateful to these organisations who have supported research in the department, mainly through competitively won peer review grants and in some instances commissioned research:

1. British Heart Foundation
2. British Medical Association
3. Cancer Research UK
4. Columbia University/HSRA (USA)
5. Department of Health
6. The Diana, Princess of Wales Memorial Fund
7. Dunhill Medical Trust
8. European Community
9. Fondazione Floriani
10. Foundation Open Society Institute
11. Gulbenkian Foundation
12. Guy's & St. Thomas’ Charitable Foundation
13. International Union Against Cancer
14. Ipsen Limited
15. Joseph Rowntree Foundation
16. King’s Fund
17. King’s Healthcare Trust JCR
18. Macmillan Cancer Relief
19. Motor Neurone Disease Association
20. Multiple Sclerosis Society
21. National Council for Hospice and Specialist Palliative Care Services
22. National Institute for Clinical Excellence (NICE)
23. National Lotteries Charities Board
24. NHS Executive (North Thames Older People’s Programme)
25. NHS Executive London Region
26. NHS Executive South East
27. NHS R & D London Regional Responsive Funding
28. NHS Research and Development, London
29. Pfizer Limited
30. South Thames Executive
31. St. Christopher’s Hospice/Coco Marcus Trust
32. St. Luke’s Hospice
33. Stockport NSH PCT
34. The Cicely Saunders Foundation
35. The Duke Institute on Care at the End of Life
36. The Elizabeth Clark Charitable Trust /Addenbrookes NHS Trust
37. The Human BSE Foundation
38. The Luff Foundation
39. The Nuffield Trust
40. The Rayne Foundation
41. The University of York
42. World Health Organisation

SUMMARY OF GRANTS HELD SINCE 2000

1. The Needs of Patients with Severe Heart Failure for Palliative Care
   British Heart Foundation
   JSR Gibbs, JM Addington-Hall, A Rogers, A Coats
   £176,201.00 (£109,500 KCL)

2. PhD Studentship ‘Outcome Measurement in Palliative Care: critical appraisal, validation and development of the retrospective approach
   King’s Healthcare Trust J CR
   JM Addington-Hall
   £40,310.00

3. Multi-centre evaluation of palliative day care
   NHS Executive (North Thames, Older People’s Programme)
   I Higginson, C Normond, C Myers
   £133,000

4. Palliative care in Europe: Ethics and Communication
   European Community
   C Farsides, IJ Higginson, B Monroe, S Wilkinson, M Costantini, F Foscani, B Zylicz, XG Batiste
   ECU 286,080

5. Care in the last year of life: a comparison of black Afro-Caribbean and white populations of south London
   South Thames Executive
   I Higginson, R Dunlop
   £79,792.00

6. Project to Improve the Management of Terminal Illness (PROMOTE)
   National Lotteries Charities Board
   RJ Dunlop, IJ Higginson, J M Addington-Hall, J M, PM Edmonds
   £555,542.00

7. A joint project to consider the impact of childhood bereavement at school (CANDLE)
   National Council for Hospice and Specialist Palliative Care Services
   C Shipman, J M Addington-Hall, IJ Higginson
   £35,000.00

8. The Coco Markus Clinical Research Fellowship in Palliative Care
   St Christopher's Hospice/ Coco Markus Trust
   IJ Higginson
   £119,988.00
9. Review of evidence for cancer guidance  
The University of York  
IJ Higginson  
£20,000.00

10. London Strategy for Palliative Care  
NHS Executive London Region  
£5,613.00

11. Evaluation of a New Palliative Day Care Service in Chichester  
NHS Executive South East  
IJ Higginson, C Normand, B Amesbury  
£126,907.00

12. The attitudes of older people to death, palliative treatment and hospice care  
NHS Research and Development, London  
JM Addington-Hall  
£122,124.00 (£24,861 KCL)

13. Development of a postal questionnaire for use in a population-based survey of the experiences of people who die from stroke and their families, from the perspective of bereaved relatives  
NHS R&D London Region Responsive Funding  
JM Addington-Hall, L Kalra, A Rogers, N Donaldson  
£74,176.00

14. A randomised controlled trial to evaluate the effectiveness of a brief psycho-educational intervention in reducing the distress associated with cancer-related fatigue - Nursing Research Fellowship  
The Cancer Research Campaign  
PJ Armes, JM Addington-Hall, M Hotopf, A Carr  
£104,160.00

15. Culture, Cancer and Meaning: a qualitative account of the effects of advanced disease in the black Caribbean and white populations of inner London  
Guy's & St. Thomas' Charitable Foundation  
IJ Higginson, M Morgan, PM Edmonds  
£75,906.00

16. Evaluation and Support Center for the End of Life Initiative (HRSA)  
Columbia University / HSRA (USA)  
IJ Higginson  
£51,960.58

17. Strategies for rehabilitation and health education in adults with malignant cerebral glioma  
British Medical Association  
E Davies  
£14,500.00

18. Macmillan Primary Care Research Study for LASER  
Macmillan Cancer Relief  
JM Addington-Hall  
£15,500.00

19. Systematic review of the psychosocial care of patients with malignant cerebral glioma  
British Medical Association  
IJ Higginson, E Davies  
£14,500.00

20. To establish the post of a Research Associate/Fellow  
St. Christopher's Hospice  
IJ Higginson, JM Addington-Hall  
£69,000.00

21. An Experience in Learning  
Gulbenkian Foundation  
IJ Higginson, B Murray  
£10,000.00

22. National Standards and Performance Indicators Project  
National Council for Hospice and Specialist Palliative Care Services  
IJ Higginson, J Koffman  
£16,000.00

23. The Development of Ways to Explore Quality of Palliative Care in the US and the UK  
The Duke Institute on Care at the End of Life  
IJ Higginson  
£30,581.61

24. Development of The Cicely Saunders Foundation  
The Cicely Saunders Foundation  
IJ Higginson  
£14,228.00

25. Better Palliative Care for Older People  
Foundation Open Society Institute  
IJ Higginson  
£14,027.61

26. Research Fellowship in Palliative Care - Danielle Goodwin  
Columbia University  
IJ Higginson  
£15,000.00
27. UICC International Cancer Technology Transfer Fellowship
International Union Against Cancer
Ij Higginson
£1,414.00

28. Care for the Dying and the NHS
The Nuffield Trust
J M Addington-Hall
£14,500.00

29. Improving End of Life Care for Older People
Foundation Floriani
Ij Higginson
£46,348.00

30. Supportive and Palliative Care Guidance
National Institute for Clinical Excellence
Ij Higginson, A Richardson
£208,781.00

31. Create a flagship neurology and palliative care service for south London
Multiple Sclerosis Society
P Edmonds, Ij Higginson, E Silber, N Leigh, J Addington-Hall
£309,255.00

32. Evaluation of acceptability and effectiveness of the DOH funded education and support programme for district and community nurses in the principles and practice of palliative care
Department of Health
J Addington-Hall, C Shipman, A Richardson, A Reams
£150,000.00

33. Evaluation of acceptability and effectiveness of the DOH funded education and support programme for district and community nurses in the principles and practice of palliative care: impact on older non-cancer patients
Department of Health
J Addington-Hall, C Shipman, A Richardson, A Reams
£55,860.00

34. Research into Palliative Medicine and Care of Patients with Variant Creutzfeldt-Jakob Disease
The Human BSE Foundation
Dr Emma Jones
£10,000.00

35. Scientific Director: Creation of a research programme
Cicely Saunders Foundation
I Higginson
£195,000.00

36. Research fellowship - Richard Harding
Columbia University
I Higginson
£27,433.00

37. Non-invasive ventilation, quality of life and cognitive function (a pilot study to define primary and secondary outcome measures for future randomised trials).
Motor Neurone Disease Association
J Moxham, N Leigh, L Goldstein and J M Addington-Hall
£78,446.00

38. Enhancing Primary Care Support to Dying People and Carers across London
King's Fund
J M Addington-Hall, Ij Higginson, P White, H Elkington, T Beynon
£50,000.00

39. Palliative Care Pathways Project
St Luke's Hospice
Jonathan Koffman
£8,305.00

40. User Involvement in Motor Neurone Disease
Joseph Rowntree Foundation
Ij Higginson, N Leigh
£19,004.00

41. Stockport VOICES Survey
Stockport NHS PCT
J M Addington-Hall
£5,000.00

42. Macmillan Primary Care Research Project for the London, Anglia and South East Region
Macmillan Cancer Relief
J M Addington-Hall, C Shipman
£20,625

43. Responsive Funding Programme. The health and social service needs of chronic obstructive pulmonary disease (COPD) patients in the last year of life.
NHS Executive London
P White, H Elkington, J M Addington-Hall, R Higgs, C Pettinari, G Cochrane and A Olding.
£82,672.00
44. Evidence Review of Palliative Care in Africa
   Diana Fund
   I Higginson, R Harding
   £18,906.00

45. What are the appropriate services and support to address the palliative care needs of older people
   World Health Organisation
   E Davies, I Higginson
   $3,000.00

46. Improving breathlessness at the end of life: a 5 year programme
   Cicely Saunders Foundation
   IJ Higginson
   £849,367.00

47. Developing a Centre for Palliative Neurology
   King’s College Hospital, Dept of R & D
   IJ Higginson, N Leigh, P Edmonds, L Turner-Stokes, E Choy
   £163,885

48. Establishment of breathlessness service
   S Booth, IJ Higginson
   The Elizabeth Clark Charitable Trust / Addenbrookes NHS Trust
   £120,000

49. Concern and continuity in the care of cancer patients and their carers: a multi-method approach to enlightened management
   M King, A Richardson, L J ones, A Tookman, A J ones, IJ Higginson, C Mason, R Blizard, I Nazareth, S Byford
   £485,000

50. Understanding and improving the quality of end-of-life care for patients dying from end stage renal failure
   Guy’s & St Thomas’ Charitable Foundation
   I Higginson, F Murtagh, J M Addington-Hall, T Beynon, P Edmonds, P Donohoe
   £214,000

51. Acquired Brain Injury - Impact on Carers
   Department of Health
   L Turner-Stokes
   £249,950.00

52. Preparation for the National Service Framework in long term conditions
   Department of Health
   L Turner-Stokes
   £100,053

53. Development & validation of a tool to assess dependency in relation to nursing staff provision in rehabilitation settings
   Dunhill Medical Trust
   L Turner-Stokes
   £109,500.00

54. Development and evaluation of tools to assess shoulder pain in patients with complex disabilities
   Dunhill Medical Trust Research fellowship
   L Turner-Stokes
   £109,500.00

55. Development of the academic department of rehabilitation
   The Rayne Foundation
   L Turner-Stokes
   £50,000.00 per annum

56. Core funding for research programme
   The Luff Foundation (Northwick Park Hospital)
   L Turner-Stokes
   £23,500.00 per annum

57. An RCT of sertraline in the management of depression following brain injury
   Investigator-led grant from Pfizer Ltd (Northwick Park Hospital)
   L Turner-Stokes
   £80,000

58. An open-label study of botulinum toxon in the management of shoulder spasticity
   Investigator-led grant from Ipsen Ltd (Northwick Park Hospital)
   L Turner-Stokes
   £30,000

59. Audit of Professionals’ Assessment and Intervention for Informal Care Givers in Home Palliative Care: Prevalence, Processes and Strategies
   St Christopher’s Hospice
   R Harding
   £5,086.00
2.7 Collaborations

We would like to thank all our collaborators with whom we have worked on many individual projects, programmes, and teaching activities. We value the range of expertise and skills the following inexhaustive list represents:

WITHIN KING’S COLLEGE LONDON
- Cancer Division
- Institute of Psychiatry
- Florence Nightingale School of Nursing and Midwifery
- Centre for Medical Law and Ethics
- Institute of Neurodisability
- Institute of Neurology
- Department of Stroke Medicine
- Department of Respiratory Medicine
- Department of General Practice
- Department of HIV Medicine
- Department of Cardiovascular Medicine
- King’s College Hospital Palliative Care Team

EXTERNAL
- South London Cancer Network
- South London Palliative Care Research Group
- Camden and Islington Palliative Care Team
- St Christopher’s Hospice
- St. Luke’s Hospice, Harrow
- Chichester Hospice
- NCRI Palliative Care Collaborative Study Group
- The Oxford Centre for Enablement
- Addenbrooks Hospital, Cambridge
- National Council for Hospice and Specialist Palliative Care

INTERNATIONAL
- Institute of Cancer Research, Genoa, Italy
- Floriani Foundation, Italy
- HIV/AIDS Bureau, HRSA, USA
- White House Office of National AIDS Policy, USA
- Columbia University, USA
- Duke Institute
- Melbourne University, Australia
- Hospice Africa Uganda
- International Association of Hospice and Palliative Care
- International Scientific Expert Panel of The Cicely Saunders Foundation
Committee work

PROFESSOR IRENE HIGGINSON
Chair
GKT School of Medicine Postgraduate Research
Students Committee
GKT School of Medicine Postgraduate Taught Course
Organisers Committee

Membership
GKT School of Medicine Medical Education Committee
GKT School of Medicine Postgraduate Board of Examiners Committee
Division of Cancer Studies
Graduate School for Health Sciences Executive
GKT School of Medicine Management Board
GKT School of Medicine Management Board Executive
GKT School of Medicine Research Committee
King’s College Hospital Trust Consultants Committee

External
Association of Palliative Medicine Science Committee
Macmillan Cancer Relief Observatory Group
MS Society Palliative Care Development Group
MS Society Science and Development Board
NCRI Palliative Care Study Development Group
Patron of Cancer Black Care and The Dementia Relief Trust

PROFESSOR LYNNE TURNER-STOKES
Chair
NSF External Reference Group (Deputy Chair), Research and Evidence Group (Chair)
BSRM Research and Clinical Standards sub-committee
BSRM/BGS Guideline Development Group: for guidance on the management of depression following acquired brain injury

Membership
BSRM Executive Committee
NPIMR Board of Trustees
NPIMR Executive Council
Institute of Complex Disability: Board of Trustees
Professional Reference Group on the NICE Guideline for MS
RCP/BSRM Joint Specialty Committee for Rehab Medicine
RCP Clinical Effectiveness Forum: Concise Guidance Lead
Referral Guidelines for Management of Spasticity (Sponsored by Allergan)
Royal College of Physicians (Specialist Advisor for the new process of selecting topics for referral to the National Institute for Clinical Excellence [NICE])
MDU Council and Cases Committee
Access to Rehabilitation: Advisory Group to Civil Justice Council
Pan London Neurosciences Network meeting

NWLH: R&D group: lead for multi-professional Health Services Research
NWLH Clinical Governance Committee
Editorial Board: Clinical Rehabilitation

DR. POLLY EDMONDS
School of Medicine
OSCE committee (as year 4 OSCE coordinator)
Year 4 curriculum committee
MPOA sub-block committee
Medical Education Committee

Southeast London Cancer Network
Palliative Care Working Group (chair)
Cancer Network Forum (representing palliative care)
Upper GI Tumour Working Group
Skin Tumour Working Group

KCH
Cancer Committee
Cancer Management Team
Specialist Medicine Care Group Executive Committee

DR. RACHEL BURMAN
Ethics Subject Panel Senate of University of London
Clinical Ethics Committee, St. Christopher’s Hospice
British Institute of Human Rights - Human rights advocate

JONATHAN KOFFMAN
Membership
GKT School of Medicine Postgraduate, Board of Examiners in the Guy’s, King’s and St. Thomas’ School of Medicine
Panel for Medicine Sociology, University of London
King’s College Research Ethics Committee

External
St. Luke’s Hospice, Kenton Grange, Harrow, London – Evaluation of palliative care pathway (Member of Subject Group)
St. Christopher’s Hospice Research Ethics Committee
2.8 International Keynote Lectures

2001

Professor Irene Higginson


Professor Lynne Turner-Stokes


2002

Professor Irene Higginson


Professor Lynne Turner-Stokes


13. Australian Faculty of Rehabilitation Medicine, Brisbane, Australia. May 2002. Management of upper limb spasticity – a place for serial Botulinum Toxin injection?

Jonathan Koffman


Professor Irene Higginson


20. Western Australia Palliative Care Conference. Perth, Western Australia. 22-24 May 2003. 22 May - Keynote: Why should we offer palliative care to non-cancer patients; 23 May - Keynote: Are palliative care teams making a difference?; 24 May - Keynote: Palliative care: issues in an ageing population

Professor Lynne Turner-Stokes


3.0 EDUCATION AND OUTREACH

3.1 Undergraduate Education

Guy’s, King’s and St Thomas’ is now the largest medical school in the UK. In the past, education about palliative care has often been virtually absent from the medical curriculum. Dr. Polly Edmonds, Dr. Rachel Burman and Dr. Claire Sinnott have led the development of the undergraduate medical curriculum in palliative care at the School of Medicine. This is an integrated programme of teaching over the five years of the course, based around the delivery of seminars, symposia and clinical bedside teaching. The teaching has been well evaluated by students, and is now one of the most comprehensive in the world. In addition, Dr. Edmonds is deputy head of year 4 (responsible for the OSCE) in the medical school.

3.2 Postgraduate Education

MSc in Palliative Care

The MSc in Palliative Care is a unique and highly regarded course, designed to train the future leaders in palliative medicine and care. Focussing on evidence-based practice, it teaches research and statistics as well as the evidence for the assessment and management of symptoms, psychological issues, and the development and assessment of services. It includes ethics, spiritual issues, cultural issues and advanced research methods in both qualitative and quantitative designs. The MSc in Palliative Care is distinctive in that it is the only postgraduate programme in the United Kingdom that is truly multi-professional and research-based. To the best of our knowledge there is no other MSc course in Palliative Care outside the UK that can compete with our reputation. The MSc was highlighted during the Quality Assurance Agency visit to the Medical School in March 2000 as being ‘taught very well and assessed’.

A total of 87 students have registered for the course since it commenced in January 1998. The course has also attracted overseas students who bring with them different cultural and policy perspectives on the provision of palliative care. Countries represented have included Iceland, India, Japan, Norway, Philippines, Switzerland, Taiwan and the USA. The number of students from outside the UK, but within the European Community, however, has increased in recent years. So far, nine students have been represented by the following countries: Cyprus, Denmark, Germany, Greece, Holland, Ireland and Italy. As the MSc in Palliative Care continues to gain greater international recognition we anticipate more students from Europe will apply to the course.

In a recent survey (2003) of all former MSc students, 84% stated they believed the experience of attending the course had contributed to their career progress. Many reported they had moved into new posts. Two are now Nurse Consultants in Palliative Care (innovative posts in the discipline). Further, two students are now registered for a PhD. Twenty-five per cent of students surveyed had successfully published research in peer-reviewed journals. In addition, 65% of those surveyed had plans to publish in the near future. Many of these students reported they were making use of core skills acquired during their time at King’s in their work settings. These activities include needs assessment, policy development, education, systematic reviews, quality assurance and clinical audit and the evaluation of services. Qualitative accounts of the added-value of multi-professional learning were very positive. Quotes included: ‘The benefits of learning together were immense - challenged and broadened by views from different disciplines and different countries. Better understanding of issues in team’ and “It gave me a much broader perspective and expanded my vision. It was very exciting facilitating each discipline to learn from each other”.

We hope to build on both ours and our students’ success to date. In the coming years we wish to attract a greater number of students from other relevant disciplines, and from overseas, who care for patients and their families with advanced disease. We also wish to develop new modules focusing on death in society (linked to the proposed programme below) and an e-learning strategy.
<table>
<thead>
<tr>
<th>Name</th>
<th>Research Project Title</th>
<th>Year of graduation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Claudia Bausewein</td>
<td>The German version of the Palliative Care Outcome Scale (POS)</td>
<td>2003</td>
</tr>
<tr>
<td>Dr Ellen Bugge</td>
<td>Which factors influence the process of passing on knowledge in informal settings between the professional and those who know less about the subject?</td>
<td>2003</td>
</tr>
<tr>
<td>Dr Harriet Bush</td>
<td>A pilot study to assess the quality of informed consent given in palliative care research trials by assessing patients understanding of the research trial they have consented to and their experiences of the consent process</td>
<td>2003</td>
</tr>
<tr>
<td>Dr Ian Cairns</td>
<td>Measuring individual quality of life with SEIQoL-DW on hospice admission - is it of any use to nursing staff? A qualitative evaluation</td>
<td>2002</td>
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<tr>
<td>Dr Jane Cowap</td>
<td>Attitudes of local research ethics committees and palliative care researchers to research in palliative care</td>
<td>2002</td>
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<tr>
<td>Dr Veronie Dijkers</td>
<td>Bereavement: a comparison of black Caribbean and white English caregivers of patients with a progressing advanced disease in an inner London Health Authority</td>
<td>2003</td>
</tr>
<tr>
<td>Rachel Edwards</td>
<td>Multiprofessional education: the future of palliative care teaching? A qualitative study exploring the attitudes and experiences of students and tutors on the Master of Science in Palliative Care course at King's College, London</td>
<td>2002</td>
</tr>
<tr>
<td>Jackie Edwards</td>
<td>A descriptive study exploring the concept of fatigue in teenagers ages 13-19 years, five years post treatment for cancer</td>
<td>2002</td>
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<tr>
<td>Louise Exton</td>
<td>A pilot study to investigate steroid myopathy inpatients with advanced cancer</td>
<td>2002</td>
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<tr>
<td>Gail Fitzgerald</td>
<td>Experiences of student nurses in caring for palliative care patients on an acute oncology unit</td>
<td>2002</td>
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<tr>
<td>Dr Petra Flock</td>
<td>A study to determine the effectiveness of Diamorphine gel to control pain of painful pressure ulcers and compare it with placebo: a pilot study</td>
<td>2002</td>
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<tr>
<td>Dr Yoke Ching Foo</td>
<td>Systematic review of cancer-specific quality of life instrument in therapeutic trials involving patients with metastatic disease</td>
<td>2002</td>
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<tr>
<td>Nicky Grundy</td>
<td>The perceived needs of people from black and ethnic minorities requiring palliative care: views and experiences of service providers</td>
<td>2002</td>
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<tr>
<td>Dr Joan Hester</td>
<td>Palliative care needs at a district general hospital: the view of patients, carers and health professionals. A descriptive epidemiological survey</td>
<td>2004</td>
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<tr>
<td>Ros Hinsley</td>
<td>The impact of weight loss on body image in advanced cancer</td>
<td>2004</td>
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<tr>
<td>Dr Elizabeth Horak</td>
<td>Parents' experiences with life limited children. A qualitative study</td>
<td>2002</td>
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<tr>
<td>Dr Kiran Kaur</td>
<td>Assessing the impact of palliative day care services on the quality of life of patients</td>
<td>2002</td>
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<tr>
<td>Aine Legg</td>
<td>An exploration of community nurses’ perception of what spirituality means to them and how they assess spirituality in practice</td>
<td>2003</td>
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<tr>
<td>Dr Anna Lock</td>
<td>The very old who die from cancer: epidemiology and place of death in England and Wales (1995 - 1999)</td>
<td>2004</td>
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<tr>
<td>Name</td>
<td>Research Project Title</td>
<td>Year of graduation</td>
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<tr>
<td>Jacqueline Lunn</td>
<td>An investigation into the desired outcomes of occupational therapists working with people who have advanced cancer</td>
<td>2002</td>
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<tr>
<td>Dr Farida Malik</td>
<td>Systematic review into the quality of research data investigating whether steroids are effective in the control of symptoms and signs associated with the presence of primary or secondary brain tumours and whether steroids are effective in decreasing the tissue oedema associated with the above cases</td>
<td>2003</td>
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<tr>
<td>Susan Morgan</td>
<td>Annual Report – Whittington Hospital NHS Trust</td>
<td>2003</td>
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<tr>
<td>Judy Mulligan</td>
<td>The effectiveness of the respiratory nurse specialists role for people with chronic obstructive pulmonary disease: a systematic review</td>
<td>2004</td>
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<tr>
<td>Ann Muls</td>
<td>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?</td>
<td>2004</td>
</tr>
<tr>
<td>Dr Fliss Murtagh</td>
<td>Evaluation of an ethics history for hospice in-patients to facilitate information-giving and decision-making</td>
<td>2003</td>
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<tr>
<td>Dr Paul Paes</td>
<td>A pilot study to assess the effectiveness of palliative care clinic in improving the quality of life for patients with severe heart failure</td>
<td>2004</td>
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<tr>
<td>Ginette Pilkington</td>
<td>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</td>
<td>2004</td>
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<tr>
<td>Mandy Reynolds</td>
<td>An exploratory study of bereaved grandparents experience of losing a grandchild to a primary central nervous system tumour</td>
<td>2004</td>
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<tr>
<td>Vicky Robinson</td>
<td>How is spiritual care at the end of life understood and practised in the UK? - a critical review of the literature</td>
<td>2003</td>
</tr>
<tr>
<td>Dr Cynthia San Luis</td>
<td>Assessing spirituality in the end of life</td>
<td>2003</td>
</tr>
<tr>
<td>Dr Ildiko Schuller</td>
<td>A needs assessment for adolescent palliative care</td>
<td>2002</td>
</tr>
<tr>
<td>Rachel Taylor</td>
<td>The management of depression and irritability and aggression in people with Huntington’s disease - a systematic review of the literature</td>
<td>2004</td>
</tr>
<tr>
<td>Katherine Thompson</td>
<td>What is the &quot;pain&quot; experienced by patients with heart failure and is there a role for specialist palliative care?</td>
<td>2004</td>
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<tr>
<td>Thora Thorhallsdottir</td>
<td>Caring and uncaring encounters with nurses and health care staff from the perspective of palliative care patients</td>
<td>2002</td>
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<tr>
<td>Dr Tove Vejlgaard</td>
<td>Educational needs in palliative care of doctors and nurses in a Danish county hospital and the related primary care</td>
<td>2002</td>
</tr>
<tr>
<td>Carol Walford</td>
<td>A study to identify the physical and emotional displacement experienced by Kosovar refugees now living in south east London</td>
<td>2002</td>
</tr>
<tr>
<td>Stella Whitehouse</td>
<td>Continuing care provision for palliative care patients</td>
<td>2004</td>
</tr>
<tr>
<td>Poon Wing Hong</td>
<td>The exploration study of experiences of Singapore trained nurses working in the cancer/palliative care services in the United Kingdom</td>
<td>2002</td>
</tr>
</tbody>
</table>
3.3 Policy development, clinical links and involvement in the local community

Strong clinical links have already been established with hospital and community services in a range of specialties. Dr. Polly Edmonds leads the palliative care team at King’s College London, and she and Dr. Rachel Burman are Honorary Senior Lecturers and are an integral part of academic development and management within the Department. In addition, there is a developing clinical collaboration between King’s College Hospital, Guy’s and St Thomas’ Hospitals with a shared on call service (including academic and clinical consultants) across the whole of this area of south London.

All of the above clinicians with academic backgrounds provide links in to clinical services and many of the clinical Professors have an active role in clinical care. There are active clinical programmes with colleagues in pain relief, health care of the elderly, neurology, oncology, as well as palliative care.

Good working links already exist with the South East London Palliative Care Network and local hospices and palliative care services, including St Christopher’s Hospice, Trinity Hospice, and many units in North and South London, as well as with Primary Care Trusts, nursing homes and other local hospitals.
3.4
Art of Dying

Does medicine have a role in care at the end of life? King's College London series on the Art of Dying
This year long symposium ran from the academic year 2002-2003 to bring together scholars from the humanities, clinicians and social scientists to investigate changing perspectives on what constitutes a good death across time and in a variety of cultures. It was co-organised by Professor Barry Ife (Vice Principal), Professor Irene Higginson and Professor Brian Hurwitz (Professor Medicine and the Arts).

Medicine has placed much attention on the beginning of life, and on preventing and treating disease and its effects. When Bevan created the National Health Service he described its objectives as prevention, cure and rehabilitation. He did not mention care of the end of life, although it was implied by the notion of 'cradle to grave' NHS care.

Whereas 100 years ago most people died as a result of an acute, often infectious disease, nowadays most people die as a result of chronic diseases, such as heart failure, stroke, other circulatory diseases, respiratory diseases, cancer, neurological conditions, or dementia. Whilst life expectancy has increased, so also has chronic illness and disability.

There were a total of 21 events, involving over 40 speakers over the whole year. In the first event, on Friday 11 October 2002, Miri Rubin, Lewis Wolpert and Dame Cicely Saunders debated how we could and should prepare for death in the 21st Century. Their debate ranged across the development of hospice and palliative care, historical perspectives on the depiction of death and the wish by some for euthanasia.

In the second, one-day workshop – The Nature of Death, Past, Present and Future – eight interprofessional scholars discussed epidemiological trends of dying, how the causes of death have changed through history, and how clinical practice and medical education has changed in response. This debated attitudes to death in Roman and Greek times, pain in medieval death, the extent to which pathological death has replaced the notion of a natural death, itself now replaced by the concept of a normal death, and about how a nine year project is been transforming the culture of death in America. The relationship of death to contemporary art and the development of a more appropriate curriculum for medical education were also discussed. The workshop ended by looking to the future, reviewing the trends of dying in old age and in general practice. On 24 October, the Right Honourable Lady Justice Hale DBE gave the Fison Memorial Lecture entitled ‘A pretty pass: when is there a right to die?’ This dealt with legal aspects concerned with the end of life.

Flyer: The Art of Dying Symposium, King's College London 2002 - 2003
Other events during the Art of Dying symposium were:

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>2002</td>
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<tr>
<td>Friday 11 October</td>
<td>Matters of Life and Death</td>
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<tr>
<td>Monday 21 October</td>
<td>The Nature of Death</td>
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<tr>
<td>Thursday 24 October</td>
<td>The Fison Memorial Lecture</td>
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<tr>
<td>Friday 15 November</td>
<td>Prognosis and Preparation</td>
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<tr>
<td>November</td>
<td>Dying on Film – a series of films, documentary and fictional which touch on death and dying</td>
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<tr>
<td>2003</td>
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<tr>
<td>January</td>
<td>Dying on Film</td>
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<tr>
<td>Monday 20 January – Sunday 16 February</td>
<td>Helen Storey: Death Dresses</td>
</tr>
<tr>
<td>Tuesday 11 February</td>
<td>Recollecting Dying: Palliative Care for non-Cancer Patients</td>
</tr>
<tr>
<td>Saturday 8 – Sunday 9 February</td>
<td>Music &amp; Death in the Eighteenth Century</td>
</tr>
<tr>
<td>Saturday 22 February</td>
<td>Discourses of Death</td>
</tr>
<tr>
<td>Wednesday 5 March</td>
<td>Medicine and Subjectivity</td>
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<tr>
<td>Wednesday 26 March</td>
<td>Dying Depicted</td>
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<tr>
<td>Sunday 27 April</td>
<td>The Performance of Dying</td>
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<tr>
<td>Friday 16 May</td>
<td>Cancer Tales</td>
</tr>
<tr>
<td>Tuesday 10 June</td>
<td>Death and Dying in Antiquity and the Middle Ages</td>
</tr>
<tr>
<td>Wednesday 2 July</td>
<td>Death and Dying: Legal and Philosophical Reflections</td>
</tr>
</tbody>
</table>

Web page: www.kcl.ac.uk/depsta/humanities/art_of_dying
4.0
The future: The Cicely Saunders Institute of Palliative Care

It is our vision to create an institute of excellence in palliative care at King’s. King’s College London is committed to developing the field of palliative care internationally. The Institute is well placed here for two main reasons. First, the merger of King’s College with the United Medical and Dental Schools of Guy’s and St Thomas’ in 1998 established the College as the largest healthcare education provider in Europe, taking in over 350 medical students in each year. Second, the multifaculty nature of King’s College offers unrivalled opportunities to raise the profile of palliative care to a much wider audience. This will raise awareness and provide a stronger multiprofessional pool of scholars, doctors, nurses and other clinicians who can work in the field.

As a result, The Cicely Saunders Foundation is working with the department and others to establish the Cicely Saunders Institute in purpose built facilities to house collaborative networks, multiprofessional scholars and clinicians, and teaching facilities dedicated to palliative care. The Institute will extend our external and internal collaborations, and bring a more multiprofessional vision to palliative care. It will also bring clinical and non-clinical services together, improving integration between research and practice. To ensure full translational research can be undertaken and that findings are translated into clinical practice, the clinical teams working on palliative care will also be housed within this building.
## Current Members of Department

<table>
<thead>
<tr>
<th>NAME</th>
<th>Position</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROFESSOR IRENE HIGGINSON</td>
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<td>Data Entry Clerk</td>
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<tr>
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<tr>
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<td>Honorary Senior Lecturer/Head, Clinical Research Statistics, KCH NHS Trust</td>
<td><a href="mailto:nora.donaldson@kcl.ac.uk">nora.donaldson@kcl.ac.uk</a></td>
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<td>Senior Research Fellow</td>
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<tr>
<td>DR MARJ OLEIN GYSELS</td>
<td>Departmental Administrator</td>
<td><a href="mailto:marjolein.gysels@kcl.ac.uk">marjolein.gysels@kcl.ac.uk</a></td>
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<tr>
<td>DR RICHARD HARDING</td>
<td>Lecturer</td>
<td><a href="mailto:richard.harding@kcl.ac.uk">richard.harding@kcl.ac.uk</a></td>
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<tr>
<td>DIANA J JACKSON</td>
<td>Senior Clinical Research Fellow</td>
<td><a href="mailto:diana.m.jackson@kcl.ac.uk">diana.m.jackson@kcl.ac.uk</a></td>
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<tr>
<td>MAGGIE J JOHNSON</td>
<td>Departmental Administrator</td>
<td><a href="mailto:maggie.johnson@kcl.ac.uk">maggie.johnson@kcl.ac.uk</a></td>
</tr>
<tr>
<td>J ONATHAN KOFFMAN</td>
<td>Lecturer/MSc Course Co-ordinator</td>
<td><a href="mailto:jennifer.lunan@kcl.ac.uk">jennifer.lunan@kcl.ac.uk</a></td>
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<tr>
<td>JENNIFER LUNAN</td>
<td>PA to Professor Irene Higginson</td>
<td><a href="mailto:julie.payne@kcl.ac.uk">julie.payne@kcl.ac.uk</a></td>
</tr>
<tr>
<td>JULIE PAYNE</td>
<td>Research Fellow</td>
<td><a href="mailto:tariq.saleem@kcl.ac.uk">tariq.saleem@kcl.ac.uk</a></td>
</tr>
<tr>
<td>TARIQ SALEEM</td>
<td>Research Assistant Psychologist</td>
<td><a href="mailto:joel.sheridan@kcl.ac.uk">joel.sheridan@kcl.ac.uk</a></td>
</tr>
<tr>
<td>J OEL SHERIDAN</td>
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<tr>
<td>AMANDA TADROUS</td>
<td>Research Assistant Psychologist</td>
<td><a href="mailto:bella.vivat@kcl.ac.uk">bella.vivat@kcl.ac.uk</a></td>
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<td>BELLA VIVAT</td>
<td>Research Fellow</td>
<td><a href="mailto:heather.williams@nwlh.nhs.uk">heather.williams@nwlh.nhs.uk</a></td>
</tr>
</tbody>
</table>

## Previous Members of the Department (Since 2001)

<table>
<thead>
<tr>
<th>NAME</th>
<th>Position</th>
<th>Year of Departure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professor Jula Addington-Hall</td>
<td>Professor of Palliative Care Research and Policy/Deputy Head of Department</td>
<td>March 2004</td>
</tr>
<tr>
<td>Fiona Aspinal</td>
<td>Research Associate</td>
<td>2003</td>
</tr>
<tr>
<td>Tracy Banton</td>
<td>Secretary/Administrator</td>
<td>2001</td>
</tr>
<tr>
<td>Uta Drescher</td>
<td>Research Associate</td>
<td>2002</td>
</tr>
<tr>
<td>Maria Dunckley</td>
<td>Research Associate</td>
<td>2003</td>
</tr>
<tr>
<td>Danielle Goodwin</td>
<td>Research Associate/PhD Student</td>
<td>2002</td>
</tr>
<tr>
<td>Heidi Hill</td>
<td>Research Associate</td>
<td>2003</td>
</tr>
<tr>
<td>Dr Rhidian Hughes</td>
<td>Senior Research Fellow</td>
<td>January 2004</td>
</tr>
<tr>
<td>Dr Karen Lowton</td>
<td>Research Fellow</td>
<td>2003</td>
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<tr>
<td>Kirsty McCormack</td>
<td>Research Associate</td>
<td>2002</td>
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<tr>
<td>Christine McPherson</td>
<td>PhD Research Student</td>
<td>2002</td>
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<tr>
<td>Brendan Murray</td>
<td>Playright</td>
<td>2003</td>
</tr>
<tr>
<td>Alison Pearce</td>
<td>Research Assistant</td>
<td>2001</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>Dr Meera Rajeskaran</td>
<td>Specialist Registrar</td>
<td>2003</td>
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<tr>
<td>Angie Rogers</td>
<td>Research Associate</td>
<td>2002</td>
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<tr>
<td>Anu Sinha</td>
<td>Research Assistant</td>
<td>2002</td>
</tr>
<tr>
<td>Dr Claire Sinnott</td>
<td>Consultant in Palliative Medicine/Research Associate</td>
<td>2002</td>
</tr>
<tr>
<td>Margaret Thompson</td>
<td>Honorary Senior Lecturer</td>
<td>2002</td>
</tr>
<tr>
<td>Maria Zis</td>
<td>Statistician</td>
<td>2003</td>
</tr>
<tr>
<td></td>
<td>Research Assistant</td>
<td>2002</td>
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</table>
### HONORARY MEMBERS OF STAFF

<table>
<thead>
<tr>
<th>NAME</th>
<th>POSITION IN DEPARTMENT</th>
<th>CURRENT AFFILIATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Stephen Barclay</td>
<td>Honorary Senior Research Fellow</td>
<td>University of Cambridge</td>
</tr>
<tr>
<td>Dr Sarah Booth</td>
<td>Honorary Senior Research Fellow</td>
<td>Addenbrooke's Hospital NHS Trust</td>
</tr>
<tr>
<td>Dr Karen Lowton</td>
<td>Honorary Research Fellow</td>
<td>Nursing and Midwifery, King’s College London</td>
</tr>
<tr>
<td>Revd Peter Speck</td>
<td>Honorary Senior Research Fellow</td>
<td>Chaplain</td>
</tr>
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### VISITING ACADEMICS (2001 - 2004)

<table>
<thead>
<tr>
<th>NAME</th>
<th>COUNTRY</th>
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<tbody>
<tr>
<td>Dr. Gillian Fyles</td>
<td>Canada</td>
</tr>
<tr>
<td>Professor Mary Gray</td>
<td>USA</td>
</tr>
<tr>
<td>Dr David Gruenwald</td>
<td>USA</td>
</tr>
<tr>
<td>Dr Doug Smucker</td>
<td>USA</td>
</tr>
<tr>
<td>Dr Wu Huei Yaw</td>
<td>Singapore</td>
</tr>
<tr>
<td>Dr Angeline Seah</td>
<td>Singapore</td>
</tr>
<tr>
<td>Professor Harvey Chochinov</td>
<td>Canada</td>
</tr>
<tr>
<td>Dr João Paolo Solano</td>
<td>Brazil</td>
</tr>
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</table>