

Cancer, Palliative and End of Life Care
Research Projects 2012

This brochure contains details of our recently completed and on-going work in the fields of cancer survivorship and end of life care. For further information please visit www.southampton.ac.uk/cpele for more details on each of the projects listed, and where relevant obtain a copy of the final report.

Cancer, Palliative and End of Life Care Research Group

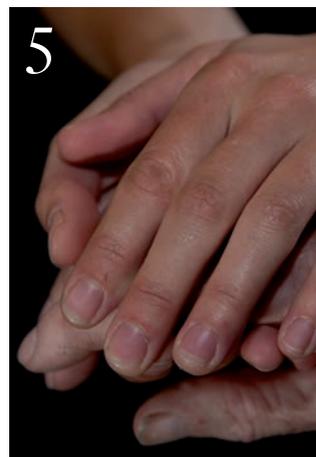
We are a thriving and diverse community of researchers, clinicians, educators and students working together to transform care and improve outcomes for individuals affected by cancer, other life-limiting conditions, and those at the end of life. Our diversity of skills, perspectives and methodological expertise attracts international multidisciplinary research collaborations and enables us to ask the right questions to generate theory, influence policy and change practice.

Cancer survivorship

As a leader in cancer survivorship research and host to the Macmillan Survivorship Research Group we use a range of methods to explore how people present with the symptoms of cancer, how they deal with those symptoms and how they manage day to day life. The needs of carers and older people are a particular focus. We develop and test a range of interventions that address physical, social, emotional consequences and help people manage using approaches like on-line self-management tools and coaching.

Palliative and end of life care

Our research informs new approaches to symptom management for a range of conditions, identifies and responds to the support needs of carers and those experiencing bereavement, tackles the ethical and logistical dilemmas surrounding organ donation and uses innovative methodologies to investigate choice at end of life. As the home of the VOICES questionnaire and developers of the methodology for the first Department of Health end of life care survey, we are at the heart of improvements to the quality of services that support people approaching the end of their lives.





Pictured clockwise

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Identifying symptoms that predict lung cancer

Recently completed projects

Early diagnosis

Developing research to improve Early Lung Cancer Diagnosis

The fellowship involved two strands of work. The first strand developed a symptoms, risks and comorbidities questionnaire (IPCARD) for use in future prospective studies to obtain predictive values of symptoms for lung cancer diagnosis. The second strand explored communication about early symptoms with the aim of developing symptom elicitation interventions for integration into Clinical Decision Support Aids (CDSAs).

Project Team
Brindle L

Funder
Research Councils UK Fellowship (2005 – 2011)

Treatment

Understanding the unknown: a case study approach to explore patients, carers and health care professionals; experiences of cancer of unknown primary site

Cancer of Unknown Primary (CUP) has a particularly poor prognosis, with less than one in ten patients diagnosed with CUP surviving for five years or more. Very little is known about the experience of living with CUP. This study used a case study approach to explore patients', carers' and health care professionals' experiences of CUP. Up to 25 patients with CUP were interviewed and invited to nominate two health professionals and one lay person who they felt had been most involved or affected by their illness, who were also interviewed. The findings from these interviews shaped the second stage: nominal groups with patients, family members and health care professionals to inform practical recommendations about how to improve the support of CUP patients.

Project Team
Addington-Hall J, Richardson A, Wagland R, Foster R, Davis C (Southampton University Hospital Trust), Boyland L (Oakhaven Hospice Trust), Symons J (Cancer of Unknown Primary Foundation - Jo's friends)

Funder
Dimpleby Cancer Care

www.southampton.ac.uk/healthsciences/research/projects/Understanding_the_unknown.page?

End of Life

I'm just in the shadow to keep an eye - an investigation to understand need for support in family members of people having chemotherapy

There is a growing recognition that family carers have unmet needs that impact on their experience of supporting, and ability to support, a family member through chemotherapy. As more treatment is delivered within day care it is imperative this gap in current knowledge is addressed. Not surprisingly supporting family caregivers was a top priority identified in the Macmillan Listening study.

The proposed research aims to:

- Elaborate on and clarify experiences of family members supporting relatives through a course of chemotherapy
- Conceptualise their need for information and support across the course of chemotherapy
- Understand factors that impact on perceived confidence to support the patient
- Identify potentially feasible and acceptable interventions for family members to be tested in future

Project Team

Ream E (King's College London), Finnegan-John J (King's College London), Foster R, Fuller G, Oakley C (King's College London) Richardson A

Funder

Macmillan Cancer Support

Men as carers in multiple sclerosis: identifying their support needs and preferences

Multiple sclerosis affects twice as many women as men but little is known about the experiences and needs of men who care for women at the end of life. The aim of this research was to identify the support needs and preferences for support of male carers caring for women with multiple sclerosis with palliative and end of life care needs. The project was conducted in three stages: first, 30 men caring for women with severe MS have been invited to tell their stories about how they are living and coping with caring to learn from them what support would be useful and how they would prefer to receive such support. We also invited up to 10 bereaved men with experience of caring for a person with MS to tell their stories.

To broaden the range of experiences, we also explored men's stories of caring posted on UK internet sites. Second, we developed a questionnaire based on the findings of the men's stories to test with up to 150 men to establish the validity of the findings. Finally, we invited MS patients, male caregivers and health professionals to meetings to consider the findings, to make practical recommendations for improving support for men caring for people with MS, and to discuss future research priorities.

Project Team

Addington-Hall J, Sibley A, Payne S (Lancaster University)

Funder

MS Society

Communication pathways surrounding people with cancer: who is involved, how do they communicate, and how do patients understand and manage this?

People with advanced cancer and palliative care needs are at the centre of this research project of up to 25 case studies, aiming to look in great detail at the communication pathways surrounding people with advanced cancer. It is known that the communication surrounding people with advanced cancer can be particularly complex, as they may undergo a variety of care provision, treatments, and monitoring in different geographical locations, involving many different health and social care professionals. This research aims to discover the extent of patient's activity, or role, in aiding the flow of communication between the various locations and professionals, and any strategies they may use to self-manage and/or coordinate their care-and health-related communication.

Project Team

Jarrett N, Porter K, Addington-Hall J, Corner J, Duke S, Davis C, Lathlean J

Funder

Dimbleby Cancer Care

Variations in out of hours end of life care in primary care organisations in England and Scotland

Details of study available on request.

Project Team

Addington-Hall J, Lattimer V (University of East Anglia), Brailsford S, Gerard K, Salisbury C (University of Bristol), Heaney D (University of Aberdeen), Todd C (University of Manchester), Bennett M (University of Leeds), Moore M (University of Southampton), Brien S, England H, Cotterell P

Funder

National Institute of Health Research (SDO)

Transitions between services at the end of life

Health professionals and families believe that there is often a mismatch between the services received and the experience that older adult patients would choose. Movement between places of care may not always be in the best interest of the patient or favour the best outcomes.

Our proposed study will examine the reality underlying these beliefs, in a study of transitions – or movement between places of care- in the twelve months before death. Our proposed study is three parts and is focused on people who died with stroke, heart failure or lung cancer. The first part will examine how often and when older people with these diagnoses move between places of care in the last year of life. To do this, we will analyse linked hospital and death statistics for England. In the second part, we will look at the human stories behind the statistics we calculated in the first part. Interviews with patients and bereaved carers will tell us what transitions meant for the patients and their families. In the final part of the study, we will interview people who commission and provide services. Summaries of the patients' and carers' views from the second part will be used to stimulate discussion and give insights into the pressures faced by the people who can influence the transitions.

Project Team

Addington-Hall J, Lowson E, Hanratty B (University of Liverpool), Holmes L (University of Liverpool), Goldacre M (University of Oxford), Grande G (University of Manchester), Payne S (Lancaster University)

Funder

National Institute of Health Research

Current research projects

Screening/Genetics

Incidental findings (IFs) from genetic tests: exploring the ethical issues and implications for practice

Genetic testing techniques have advanced enormously over the past few decades. It is now possible to examine large portions of a person's genetic code at costs manageable to routine NHS services. As well as diagnosing the cause of specific clinical signs and symptoms, or family histories of disease, such genetic testing will also at times find entirely unexpected, but clinically relevant information about a person, such as a future disease likelihood. This research fellowship aims to gain an empirical and ethical insight into the experiences and attitudes of healthcare users and professionals towards incidental findings (IFs) from genetic testing, using both quantitative and qualitative research methods. This together with an analysis of relevant literature will provide novel insights into the practical and ethical issues surrounding IFs in genetic practice and allow the development of guidance on how practice should evolve as technologies increase the likelihood of IFs.

Project Team

Crawford G

Supervisors

Luccassen A, Foster C, Clancy T

Funder

NIHR fellowship held by Gill Crawford in Faculty of Medicine

Early diagnosis

Symptom prevalence and help seeking in patients at risk of lung cancer: exploratory feasibility study in primary care

The study will explore the help seeking behaviour of patients with symptoms that might indicate early stages of lung cancer, and the factors that might inhibit or promote such help seeking. The study will have two phases. Firstly, primary care patients will be sent a patient-completed questionnaire to record symptoms and epidemiological risk factors. The questionnaire is based upon the IPCARD questionnaire previously developed by Brindle, Corner and Wilson, to identify symptoms indicative of lung cancer. From the questionnaire responses and GPs' notes we will examine the rates, severity and duration of different symptoms reported amongst the patients and their help-seeking behaviour. In the second phase of the study we will interview 45 respondents to explore help seeking intentions of individuals experiencing symptoms potentially indicative of lung cancer, and the factors that may promote or inhibit them from such help seeking behaviour. Administering the questionnaire in this study will also help us to understand the practicality of its use in a primary care population to identify a group who might benefit from GP intervention, which would be developed and evaluated in a future trial.

Project Team

Corner J, Brindle L, Wagland R, Moore M

Funder

Cancer Research UK NAEDI funding stream

Using a participant-completed questionnaire (IPCARD) to identify symptoms that predict lung cancer: A feasibility study

Most of those with lung cancer are diagnosed at a late stage when curative treatment is not possible. Government guidelines recommend referral for chest X-ray if any 1 of 10 possible lung cancer symptoms is unexplained or present for more than 3 weeks. However, these symptoms often have other causes and some are very common. There is a pressing need for information about symptoms that will help GPs distinguish between patients with minor illness or chronic respiratory disease and those who may have lung cancer. The absence of evidence about symptoms reflects the cost and size of the studies required to calculate the likelihood that someone reporting a symptom (or group of symptoms) to their doctor has lung cancer. This research has generated evidence needed to improve earlier detection of lung cancer in 2 ways: i. By refining and validating a patient-completed symptom questionnaire (IPCARD). This will reduce the costs of future large-scale studies. These future studies will identify how likely it is that someone experiencing a particular symptom has lung cancer. ii. By providing preliminary evidence about the predictive value of this questionnaire for lung cancer diagnosis.

Project Team

Brindle L, Wilson S (University of Birmingham), (co-leads)
James E, Clifford S, Parker L (Birmingham), Dowswell G (Birmingham), Corner J.

Funder

National School of Primary Care Research

IPCARD Chest Clinic Study – Early diagnosis of lung cancer

This study will use a self-completion questionnaire (IPCARD) to prospectively and systematically collect symptom, risk and comorbidity data to identify symptoms that can distinguish between lung cancer and non-malignant respiratory disease, and symptoms that predict operable lung cancer. Patients aged ≥ 40 attending 3 lung-shadow clinics before diagnosis will be invited to complete the questionnaire. Diagnoses will be followed up four months following recruitment. Analyses will:

- Identify symptoms that predict LC diagnosis in a population with high rates of respiratory disease (chest clinic population).
- Identify differences between symptoms of operable and inoperable LC.
- Identify symptoms that predict LC in a GP population without chronic respiratory disease (COPD) – case control study.

Outcomes: This study will evaluate the diagnostic value of symptoms for their future inclusion in clinical decision aids in development, prior to evaluation.

Project Team

Brindle L (CI), Shim J (PhD student), George S, Nichols P, Banerjee A

Funder

University of Southampton

SPUTNIK (Solitary Pulmonary nodules) – IPCARD sub study

(IPCARD sub study) – use of IPCARD to distinguish between malignant and non-malignant pulmonary nodules. The feasibility of using IPCARD for the surveillance of those with SPNs will also be examined.

A small proportion of patients with lung cancer present with a solitary pulmonary nodule (SPN) on diagnostic imaging tests. This is an important group of patients because presentation as a SPN represents early disease with high 5 year survival rates following surgical resection. However, not all SPNs are due to lung cancer and the accurate characterisation of SPNs for diagnosis of early stage lung cancer is a diagnostic challenge with significant associated health costs.

Widely adopted clinical guidelines for the subsequent investigation of SPNs recommend serial CT scans to look for subsequent growth with biopsy to confirm diagnosis. UK, National Institute for Health and Clinical Excellence (NICE) guidelines recommend FDG-PET for the assessment of SPN in cases where a biopsy is not possible or has failed. DEC-CT and FDG-PET scans give different information about the SPN. Information from either scan or combined information from both scans may be better in the diagnosis of early stage lung cancer.

Project Team
George S (Sputnik CI), Brindle L (IPCARD study CI)

Funder
HTA

CANDID – Early diagnosis of colorectal/lung cancer

(IPCARD add on study)

The IPCARD questionnaire will be administered prospectively to a primary care population to obtain predictive values for lung cancer diagnosis.

In primary care the key areas of concern for both doctor and patients are delay in diagnosing cancer, getting high risk patients referred first, and keeping investigation to a minimum. There have been few valid studies to assist decision-making in primary care, either to get a patient referred quickly or to assist in making sure an anxious patient is effectively reassured. This study seeks to work out which of the symptoms and examination findings are the most effective in predicting lung or colon cancer. To decide the best clinical information to collect in the study we will interview patients and also get consensus from a group of experts. Then we will recruit 20,000 patients who consult their GP - half with lung symptoms and the other half with low bowel symptoms. Clinical information will be collected using standardised internet based forms. Willing patients will complete lifestyle questionnaires and provide blood or saliva samples (including for genetic analysis). The National Cancer Registry will then be monitored to see which patients develop cancer, and statistical analysis will determine the most important clinical variables that predict cancer. The clinical prediction ‘rules’ or decision aids developed from these studies will then be tested with a further 2000 patients for each condition for validity.

Project Team
Little P (CI), Brindle L (IPCARD sub study lead)

Funder
NSPCR

Treatment

Development and pilot study of an online interactive surgical decision aid for young women newly diagnosed with early stage breast cancer

This pilot study will use age-specific outcome data to formulate a decision aid aimed specifically at young women with early onset breast cancer. The decision aid will provide age relevant information to help women understand treatment choices and outcomes. The decision aid will be developed and piloted in collaboration with the Breast Cancer Care Service User Research Partnership who will support the development and initial evaluation of the system. A subsequent large randomized evaluation study will measure how effective the decision aid is for improving knowledge and in helping women feel informed and comfortable with the decision reached.

Project Team

Eccles D, Foster C, Simmonds P, Altman D, Cutress R, Gerty S, Recio Saucedo A

Funder

NIHR RfPB

Enhancing the role of carers in the outpatient chemotherapy setting

This project is using methods akin to experience based co-design to determine the nature, content and format of an intervention aimed at helping family members of patients having chemotherapy.

Project Team

Ream E (King's College London), Richardson A, Robert G (King's College London), Verity R (King's College London), Oakley C (King's College London)

Funder

Dimbleby Cancer Care

A phase 1-11 feasibility trial of Cancer Carer Medicines Management (CCMM): an educational intervention for carer management of pain medication in cancer patients at end of life

Phase 1 will involve the systematic development of the intervention including a literature review, theoretical framework, and qualitative interviews with health care professionals, patients and carers. In Phase 2, we will conduct a feasibility trial, randomising nurses at two sites (Hampshire and Cardiff), training intervention group nurses in using the intervention with carers, and collecting data on a range of patient and carer outcomes using validated questionnaires and qualitative interviews with carers and nurses to understand experiences of CCMM and of being in the trial. Results will be used to inform the design of a multi-centre randomised trial.

Project Team

Latter S, Hopkinson J (Cardiff University), Richardson A, Duke S, Anstey S (Cardiff University), Bennett M (University of Leeds), Smith P, May C

Funder

Dimbleby Marie Curie Cancer Care



Supporting patients making decisions about surgery

Mapping treatment workload in heart failure

A high treatment workload can be challenging for self-management, particularly at end of life. This is because as capacity dwindles, patients become less able to carry out the treatment tasks required to manage their condition, leading to worsening of symptoms, reduced use of services and poorer quality of life. To better understand the self-management support needs of patients who have Heart Failure, we need to be able to measure workload associated with their treatment. This exploratory longitudinal study seeks to explore the work that patients with heart failure to manage their condition as well as determine whether this ‘work’ can be measured over time. By measuring workload we will be able to foresee periods when a more supportive model of care might be more appropriate.

Project Team

Hunt K, Anton-Solanas I, Richardson A, May, C

Funder

University of Southampton “Annual Adventures in Research” Award

Pilot feasibility randomised trial of a novel non-pharmacological intervention for the management of the respiratory distress symptom cluster (breathlessness, cough, fatigue) in patients with advanced lung cancer

The purpose of this study is to feasibility-test a novel non-pharmacological supportive care intervention designed to promote effective coping and better management of common lung cancer-associated symptoms (respiratory distress symptom cluster i.e. breathlessness, cough, fatigue). The study will provide evidence of the feasibility of the new intervention in the lung cancer population and offer the opportunity of final refinement before being fully tested with a phase III randomised trial.

Project Team

Bailey C, Molassiotis A (University of Manchester)

Funder

Marie Curie Cancer Care

Survivorship

A longitudinal cohort study of joint and muscle aches, pains and stiffness in women with primary breast cancer

Breast cancer affects one in nine UK women and almost two thirds of newly diagnosed women are now likely to survive for at least 20 years. A greater proportion of women with early BC are now receiving adjuvant therapy. The limited research evidence suggests that joint pain may be experienced by three quarters of women following primary BC treatment. Aims of the research are as follows:

- To establish the natural history of joint aches, pains and muscle stiffness (JAPaMS) over time in women being treated for early breast cancer
- to investigate whether and how the prevalence and natural history of JAPaMS differs in women receiving adjuvant therapy for invasive early breast cancer from that in women following treatment for ductal carcinoma in situ (DCIS)
- to explore the impact of JAPaMS on quality of life (QoL) in women with invasive early breast cancer
- to explore their impact on functional ability
- and to undertake an exploratory analysis of how the natural history of JAPaMS differs between adjuvant treatment groups.

Study findings will be used to educate health professionals about the natural history and impact of these under-researched and under-treated symptoms, better equipping them to support patients and enabling them to provide more accurate information to patients to inform treatment decisions. Findings will inform future research into both the causes of JAPaMS in breast cancer and into effective interventions.

Project Team
Addington-Hall J, Fenlon D, Simmonds P, Clough J, Powers C

Funder
Breast Cancer Campaign

CREW (ColoRECTal Wellbeing) cohort: a cohort study to explore recovery of health and well-being following primary treatment of colorectal cancer

This questionnaire study will follow 1000 people with colorectal cancer over a period of two years in the first instance, recruited from 25 centres across the UK, to establish the natural history of the recovery of their health and wellbeing. It will assess how quickly people return to a state of wellbeing after colorectal cancer and measure factors which influence this course of recovery. Outcomes will help inform health care providers about what helps or hinders rapid and effective recovery from cancer, identify who might be at risk of problems in recovery and identify areas for the development of interventions to aid this process.

Project Team
Fenlon D, Chivers-Seymour K, Foster C

Funder
Macmillan Cancer Support (part of Macmillan Programme grant)

On-line survey of issues and problems of cancer survivors

An online survey was conducted using the University's iSurvey software to examine self-efficacy to self-manage cancer and treatment related problems in the 12 months following primary cancer treatment. The survey advertised on and off-line and recruited 182 participants in 4 months.

Project Team
Foster C, Breckons M

Funder
Macmillan Cancer Support (part of Macmillan Programme grant)



Exploring recovery of health and wellbeing

RESTORE Development and testing of on-line intervention to support self-management (fatigue is focus in first instance)

An online intervention has been developed using the University's LifeGuide programme and aims to increase people's confidence to manage cancer related fatigue. Development of the resource has been completed and involved working closely with people affected by cancer. The resource will be now be tested through a randomised controlled trial delivered in a clinical setting.

Project Team

Foster C, Grimmett C, Breckons M, Calman L

Funder

Macmillan Cancer Support (part of Macmillan Programme grant)

Evaluating the introduction of supported self-managed follow-up for people with cancer

This project is evaluating the change of follow up care for patients who have completed their curative treatment for breast, colorectal, and testicular cancer. The service change will lead to clinically suitable patients being offered 'patient triggered follow up' with support for self- management. The overall aim of the evaluation is to explore the effectiveness and productivity of the new PTFU and to compare this with clinic based follow up, based on a range of patient outcomes, including, quality of life, unmet needs, patient activation, use of health services, experience of follow up, and personal costs to patients. The evaluation is also examining staff experiences and the process and impact of this innovation.

Project Team

Simmonds P, Batehup L (Macmillan Cancer Support), Corner J, Gage H (Surrey), Williams P (Surrey), Richardson A, Porter K, Royle G, Cutress R, Wagland R, Winter J, & Davies N. (Macmillan Cancer Support)

Funder

Macmillan Cancer Support

Feasibility study of coaching for cancer survivors

The aims of this study were to:

- Determine the acceptability, feasibility and practicality of implementing life coaching as an intervention for cancer survivors;
- Explore the mechanisms by which coaching brings about personal benefits for individuals, and how it facilitates them to positively address and self-manage problems associated with survivorship and achieve self-defined goals;
- Assess the suitability of data collection process & selected outcome measures.

Findings will be used from this study to inform the design of a randomised controlled trial.

Participants were recruited from local cancer support groups and cancer information centres. Eligibility criteria include: within one year of completion of primary cancer treatment; over 18 years; no metastatic disease; no mental health problems. All participants were offered life coaching as part of a one group pre-test post-test study. The coaching intervention consisted of one face to face and five telephone sessions over three months. Outcomes assessed include quality of life, self-efficacy, goal attainment, social difficulties and psychological distress. Interviews were used to explore the process and outcomes of coaching and experience of trial procedures.

Project Team
Richardson A, Fenlon D, Wagland R

Funder
Internal funding

Feasibility of establishing a cohort of lung cancer patients treated with curative intent to gather patient reported outcomes

There is little research involving lung cancer patients treated with curative intent (CI) to inform service development and optimal timing of supportive interventions for those who have completed treatment. By gathering patient reported outcomes from this group we will understand patterns of recovery and identify appropriate interventions. This pilot will determine the feasibility of establishing a cohort of lung cancer patients treated with CI to gather patient reported outcomes to inform improvements in care and support. Having data on recovery of health and well-being will inform the nature of follow-up care patients receive and help patients make decisions about treatment that will impact on their everyday lives. By establishing a cohort of lung cancer patients treated with CI we will be able to explore a range of factors that influence recovery of health and well-being; including mapping patterns of recurrence, symptoms, identifying unmet needs, support and skills required to manage these.

Project Team
Foster C, Calman L, Richardson A, Baird J

Funder
Roy Castle Foundation

End of Life

An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practices

This three phase mixed methods feasibility and scoping study is the first in the UK to explore the experience and attitudes of Health Care Professionals toward taking patients from critical care units' home to die.

Project Team
Richardson A, Coombs M, Long-Sutehall T, Addington-Hall J, Darlington A-S

Funder
Marie Curie Cancer Care

Developing stated preference discrete choice experiments for improving the redesign of patient-led healthcare services

This project will develop and apply Discrete Choice Experiments (DCE) to value aspects of health services and quality of life, particularly for policy-relevant attributes of palliative care programmes and informal care at the end-of-life. The goal is to further DCE methodology related to generalisability, qualitative/mixed methods and econometric analysis.

Project Team
Gerard K, Bolt T

Funder
NIHR Career Development Fellowship

Barriers to tissue and corneal donation

The gap between supply and demand in organ and tissue transplantation continues to be an issue that countries across the world are challenged by.

This study is accessing recorded 'real time' interviews between nurse practitioners and bereaved family members to explore the consent process underpinning multi tissue and eye donation. The aim of this exploratory work is to gain insight into what is happening in this dynamic interaction, what language is used and what information family members seek when making their decision to agree to, or decline, donation.

Project Team
Long-Sutehall T

Funder
NIHR Career Development Fellowship

Anticipatory prescriptions to manage symptoms in last days of life

Details of study available on request.

Project Team
Addington-Hall J, Seymour J (Nottingham)

Funder
Marie Curie Cancer Care



Giving support at the end of life

Case for support: managing suffering at the end of life

This study aims to study how the technology of continuous sedation until death has been reported in the clinical and bio-ethical literature and criteria for decision-making

Some dying people experience symptoms of pain and suffering in the last hours or days of life that do not respond well to conventional therapies. In such circumstances, doctors may give the person sedation so that they go into a coma until death occurs. This practice is known as ‘continuous deep sedation until death’ or as ‘palliative’ or ‘terminal’ sedation among clinicians.

Project Team
Addington-Hall J, Seymour J (Nottingham)

Funder
ESRC

Experiences of cancer patients at end of life, as reported by bereaved relatives using VOICES questionnaire

Over the past 20 years a programme of work has been developed using population-based surveys of deaths to investigate experiences of people at the end of life, as reported by bereaved relatives. Most recently, commissioned by Department of Health (DH) in England to develop methods for national survey, and to refine questionnaire (VOICES) for use to evaluate impact of DH end of life care strategy (VOICES-SF). The method developed and the VOICES-SF were used in 2011 in the first English national survey of bereaved carers conducted by Office of National Statistics.

Project Team
Addington-Hall J

Funder
Not currently funded



ENTRY OF DEATH

Deaths Registration Act 1953

in the		LONDON BOROUGH OF EAL
6	7	8
Cause of death	Signature, description, and residence of informant	When registered

Exploring data on place of death

Managing suffering at the end of life: a study of continuous deep sedation until death’ together with ‘Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life: a prospective community based case study using mixed methods’

The first of these studies is part of the UNBIASED study (UK Netherlands Belgium International Sedation Study), which comprises three linked studies with separate funding sources in the UK, Belgium and the Netherlands. The aims of the study are to explore decision-making surrounding the application of continuous sedation until death in contemporary clinical practice, and to understand the experiences of clinical staff and decedents’ informal care-givers of the use of continuous sedation until death and their perceptions of its contribution to the dying process. The second study has developed out of the first, and is studying the role of nurses in implementing palliative sedation.

Project Team
Addington-Hall J, Seymour J (Nottingham University)

Funder
ESRC and Marie Curie Cancer Care

International Study of Place of Death

An epidemiological study using death certificates and other available data to explore variation in place of death between countries in Europe (Phase 1 – completed) and Europe and beyond (Phase II, 2012 onwards).

Led by
Dr Cohen and Professor Deliens, End-of-life Care Research Group Ghent University & Vrije Universiteit Brussel. Adopted by the Research Network of the European Association of Palliative Care

Project Team
Addington-Hall J. Cohen and Deliens, End-of-life Care Research Group Ghent University & Vrije Universiteit Brussel. Adopted by the Research Network of the European Association of Palliative Care

Funder
Not currently funded



Our diverse community of researchers

Cancer, palliative and end of life care research group

Members of staff associated with this group:

Professor Alison Richardson
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