



Public Health
England

Protecting and improving the nation's health

National End of Life Care Intelligence Network

Current evidence

End of life care research area:

**Engaged, informed individuals and
carers**

Summary research

No	Summary Research Aim	Organisation
2	Clinical trial of self management of analgesia and related treatments at end of life.	University of Leeds
7	Barriers to tissue donation: what cognitive and emotional associations do bereaved family members bring to the multi tissue and corneal request interview?	Faculty of Health Sciences, University of Southampton
19	Does the Respecting Choices advance care planning programme improve quality of life and symptoms of patients with advanced cancer.	Lancaster University, University of Nottingham
20	To develop and pilot a training programme for volunteers and support workers who help carers providing home based end of life care. To develop a resource pack for carers.	University of Nottingham
23	To explore the implementation of advance care planning (ACP) in community care settings.	University of Nottingham
25	To test the effectiveness of the Family's Voice diary for improving communication between family and health professionals in a hospital setting.	North Tees and Hartlepool NHS Foundation Trust
28	A study of the potential of new communications media for facilitating the work of the hospice and to better understand its impact on the social relationships of patients with family, friends and neighbours.	University College London and Hospice of St Francis Berkhamsted
35	Understanding the challenges faced by clinicians in initiating conversations about end of life care.	University of Exeter Medical School
36	Religion and belief: integrated or not concepts in end of life care.	Goldsmiths, University of London
38	Concepts of mental capacity as it relates to assisted dying.	The Royal Marsden NHS Foundation Trust
44	An observational study exploring concordance between patients and their carers with regard to end of life care choices.	Royal Surrey County Hospital NHS Foundation Trust
46	Observational ethnographic study exploring compassion in end of life care.	University of Bradford
48	To document how 'choice' is mobilised in end of life care and how this is reflected in people's everyday experiences towards the end of life.	University of Cambridge
50	Comparing the effectiveness of palliative care for elderly people in long term care facilities in Europe.	International Observatory on End of Life Care, Lancaster University
52	To investigate the impact of end of life care decision-making on bereaved parents of children and young people with life-limiting conditions.	Birmingham Children's Hospital, Birmingham
60	Co-Care project: to develop and implement a system of community-based volunteer-led support for family caregivers caring for a relative or friend with palliative and/or end of life care needs at home.	Faculty of Health Sciences, University of Southampton
61	To explore the feasibility of family caregivers administering subcutaneous medications for symptom control for palliative care patients dying at home.	Trinity Hospice, London

No	Summary Research Aim	Organisation
72	Understanding and responding to those bereaved through their family members' substance use.	University of Bath - Centre for Death and Society, Department of Social and Policy Sciences
80	To investigate the content, timing and format of support that's required by family carers at patient discharge from acute care at end of life.	University of Manchester (as part of NIHR CLAHRC Greater Manchester)
84	Can health promoting messages be assimilated by first degree relatives of patients with advanced breast and colorectal cancer?	Marie Curie Hospice West Midlands
90	To explore the holistic, psychological, physical and developmental needs of young adults with the purpose of enhancing their quality of life.	University of Nottingham
91	To look at how people prepare for funeral costs and the role of the state in supporting those who struggle to pay for a funeral.	University of Bath
95	To seek views from relatives or friends of those who have recently died, about their experiences at the end of life.	The End of Life Partnership
98	The Cheshire Living Well, Dying Well Public Health Programme: multiple projects to improve health and wellbeing by supporting a change in knowledge, attitude and behaviour towards life, age, death and loss.	The End of Life Partnership
105	To understand how working as a hospice volunteer with people at the end of life in the community affects volunteers' experiences and their attitudes towards death and dying?	Lancaster University
107	Promoting lifestyle behaviour change in hospital patients: development of an evidence-based psychological intervention.	Marie Curie Cancer Care
112	Supporting staff and people at end of life and their families in making decisions relating to CPR in the context of their religious beliefs.	Jewish Care
117	To develop, implement and evaluate a volunteer support service for care of the dying within a University Hospital Trust.	Marie Curie Palliative Care Institute Liverpool
118	Comparative study of the socio-politics, demography and care practises of the elderly approaching the end of life in Germany and England.	Oxford Institute of Population Ageing, UK and Department of Sociology, LMU Munich, Germany
119	Study into the involvement of residents with dementia in a residential home for people with intellectual disability and dementia.	University of Kent
120	Exploring how teenagers, diagnosed with leukaemia, their families and health care professionals' experience participation in decision making regarding care and treatment.	Louis Dundas Centre for Children's Palliative Care, University College London
121	To understand decision making for children with a high risk brain tumour and inform the development of evidence based guidance.	Louis Dundas Centre for Children's Palliative Care, University College London

No	Summary Research Aim	Organisation
144	To developing a relevant and acceptable educational intervention for informal carers of patients with breathlessness in advanced disease.	University of Cambridge (in collaboration with King's College London, RAND Europe, Cambridgeshire University Hospitals' NHS Foundation Trust, Cambridgeshire Community Services, & University of Manchester)
152	Exploring the most important parts of care in the last year of life, how experiences are influenced by age, what support young adults and families need and the challenges that exist for health and social care professionals.	Lead site: University College London Hospitals

Full research

No 2

Study Aim

The Academic Unit of Palliative Care, University of Leeds, hosts a number of funded research projects. These include an NIHR Programme Grant on improving management of pain from advanced cancer in the community (IMPACCT) and an NIHR HTA clinical trial of self management of analgesia and related treatments at end of life (SMARTE). We are an EAPC collaborating centre for European research projects.

Methodology

Systematic reviews, interviews, database analyses, observational studies, randomised controlled trial.

Organisation

University of Leeds

Contact details

Professor Mike Bennett, m.i.bennett@leeds.ac.uk

Research is:	Multi centre
Research project is funded:	National
Research project cover:	England - North

No 7

Study Aim

Barriers to tissue donation: what cognitive and emotional associations do bereaved family members bring to the multi tissue and corneal request interview?

Methodology

Qualitative methods.

More information

This was funded as a NIHR Post Doc Fellowship and is part of a 10 year programme of research into end of life decision making in organ and tissue donation.

Organisation

Faculty of Health Sciences, University of Southampton

Contact details

Dr Tracy Long-Sutehall, T.Long@soton.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	England

No 19

Study Aim

Does the Respecting Choices advance care planning programme improve quality of life and symptoms of patients with advanced cancer.

Methodology

A phase III multicentre cluster randomised clinical trial.

More information

This is the first multi country RCT of an advance care planning intervention. It is a five year study, from 2013-2018. As well as the UK, it involves the Netherlands (study leaders); Belgium; Slovenia, Denmark and Italy.

Organisation

Lancaster University, University of Nottingham

Contact details

Professor Sheila Payne, s.a.payne@lancaster.ac.uk; Professor Jane Seymour, jane.seymour@nottingham.ac.uk

Research is:	Multi centre
Research project is funded:	EUFP7
Research project cover:	Six countries including the UK

No 20

Study Aim

To develop and pilot a training programme for volunteers and support workers who help carers providing home based end of life care. The programme will use the domains of an evidence based carer support need assessment tool (CSNAT) as a framework. To develop a resource pack for carers, (including the CSNAT tool) to enable them to identify and prioritise areas of need and facilitate discussion in each individual case of what support is most appropriate.

Methodology

Participatory action research employing qualitative methods of data collection, bibliographic review and secondary analysis techniques. Action research emphasises collaborative working in gaining practical knowledge.

More information

The training programme has been piloted with three different groups, and revised in the light of evaluative comments. It is currently being assessed by a group of critical readers. The resource pack has been developed and is integrated into the training programme.

Organisation

University of Nottingham

Contact details

Professor Jane Seymour, jane.seymour@nottingham.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	England - Midlands and East

No 23

Study Aim

Care and communication between health professionals and patients affected by severe or chronic illness in community care settings (just completed). The purpose of the study was to explore the implementation of advance care planning (ACP) in community care settings through investigation of how patients, carers and professionals negotiate the initiation of ACP and the outcomes of discussion and planning for end of life care in terms of how closely the preferences which patients express are subsequently realised.

Methodology

Qualitative study involving 2 workstreams:

1. Longitudinal case studies involving up to 6 month follow up of sets of patients, carers and nominated health professionals and review of medical records.
2. A series of single interviews with health professionals.

Organisation

University of Nottingham

Contact details

Kristian Pollock, kristian.pollock@nottingham.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	England - Midlands and East

No 25

Study Aim

This research follows on from a previous project (McEvoy et al 2012, Smith et al 2012) which developed these ideas in one NHS trust (North Tees & Hartlepool Foundation Trust). This new project aims to test the effectiveness of the Family's Voice in other NHS hospitals within (primarily) the Northern Strategic Clinical Networks NHS England and interested trusts across the NHS. It will also include some nursing homes and a hospice. Its purpose is to introduce a 'Family's Voice' diary for the family/friends of those patients who are dying in hospital. The diary is intended to improve communication between family and health professionals by inviting and encouraging them to document their observations concerning the quality of care provided to the patient and themselves during end of life care. The principal question being asked is: To what extent can the successful implementation of the Family's Voice, developed in one trust, be replicated in other hospital NHS trusts, nursing homes and a hospice?

McEvoy M, Pugh E, Blenkinsopp J (2012) Communication diary to aid care at the end of life. Nursing Times Vol 108 No 17. Smith S, Pugh E, McEvoy M,. (2012) Involving families in end of life care. Nursing Management July; 19 (4):16-22. NEQOS (2012) End of Life Carers Diaries. An analysis of quantitative data June 2012 North East Quality Observatory Systems. By Martin Wood Renaissance Research.

Methodology

The research methodology is mixed method using a 'Family's Voice' diary in 'real time' recording scores and comments. The analysis will consist of descriptive and correlative analysis plus content analysis from the free text. The testing of the diary will include 11 acute hospitals, 10 nursing homes and one hospice.

Organisation

North Tees and Hartlepool NHS Foundation Trust

Contact details

Mel McEvoy, mel.mcevoy@nth.nhs.uk; Mr John Blenkinsopp, Dr Eileen Scott

Research is:	Multi centre
Research project is funded:	Local
Research project cover:	England - North, Midlands and East, South

No 28

Study Aim

1. A study of the potential of new communications media for facilitating the work of the hospice.
2. Researching a better understanding of the impact of new communication media on the social relationships of patients with family, friends and neighbours.

Methodology

Ethnographic and interviews.

More information

The report for the first project may be found at www.ucl.ac.uk/anthropology/people/academic_staff/d_miller/mil-28
The work is a collaboration with Kimberley McLaughlin of the Hospice of St Francis Berkhamsted.

Organisation

University College London and Hospice of St Francis Berkhamsted

Contact details

Daniel Miller, d.miller@ucl.ac.uk; Kimberley McLaughlin, kimberley.mclaughlin@stfrancis.org.uk

Research is:	Single centre
Research project is funded:	European Research Council
Research project cover:	England - South

No 35

Study Aim

The challenges faced by clinicians in initiating conversations about end of life care. Our study undertook a micro-level approach to this topic and centred on the specific aspects of end of life conversations that clinicians experience as difficult or challenging.

Methodology

Fifteen interviews one to one were undertaken with senior hospital doctors (13 consultants and 2 Specialist Registrar grade) to elicit their experiences of discussing care with patients nearing the end of life. The sample included Palliative medicine, Care of the Elderly, Oncology, Neurology and Surgical doctors which enabled exploration of a range of views from individuals in different specialities. The interviews were recorded and transcribe verbatim and were analysed qualitatively using the principle of constant comparison, underpinned by grounded theory methods.

More information

Barriers and Facilitators identified lack of time/enough time included for example in outpatient clinics and this compared between the Hospice and on the ward where Palliative medicine consultants felt they were able to have more time to have conversations as they were able to develop more of a relationship as the person would be staying for an average of eight days.

Organisation

University of Exeter Medical School

Contact details

Dr Kerry Jones, k.s.jones@exeter.ac.uk

Research is:	Single centre
Research project is funded:	Local
Research project cover:	South West

No 36

Study Aim

Religion and belief: integrated or not concepts in end of life care.

Methodology

Triangulation - Qualitative Research Project.

More information

Forthcoming published results early 2015.

Organisation

Goldsmiths, University of London

Contact details

Panagiotis Pentaris, p.pentaris@gold.ac.uk

Research is:	Multi centre
Research project is funded:	International
Research project cover:	England - North, Midlands and East, South, London

No 38

Study Aim

My PhD thesis is looking at concepts of mental capacity as it relates to assisted dying.

Methodology

Grounded theory.

Organisation

The Royal Marsden NHS Foundation Trust

Contact details

Annabel Price, ap806@medschl.cam.ac.uk

Research is:	Multi centre
Research project is funded:	Local
Research project cover:	England and Wales

No 44

Study Aim

An observational study of concordance between patients and their carers with regard to end of life care choices.
Aim: do patients/their carers agree?

Methodology

Observational study (quantitative; questionnaire; paired observations).

More information

Recruitment almost completed.

Organisation

Royal Surrey County Hospital NHS Foundation Trust

Contact details

Dr Andrew Davies, adavies12@nhs.net

Research is:	Multi centre
Research project is funded:	Departmental research fund (soft money)
Research project cover:	England - South

No 46

Study Aim

Exploring compassion in end of life care.

Methodology

Qualitative - observational ethnographic.

Organisation

University of Bradford

Contact details

Laura Middleton-Green, L.Middleton-green@bradford.ac.uk

Research is:	Single centre
Research project is funded:	PhD project
Research project cover:	England - North

No 48

Study Aim

To document how 'choice' is mobilised in end of life care (translated from policy to practice) and how this is reflected in people's everyday experiences towards the end of life. For example, how are documents, like the Preferred Priorities for Care, used in healthcare? What is important to people in their last year of life?

Methodology

Ethnography of policy, healthcare practice, and people's everyday lives towards the end of life. In addition to analysing policy documents, interviewing policy-makers and healthcare professionals, I focused on the experiences of those who are the subject of end of life care policy and is based on long-term interaction with 10 people (up to 14 months), often in their own homes and involving their daily routines and family; this is supplemented by an additional 43 in-depth interviews and observations of support groups.

More information

The full PhD, entitled Planning for death? An ethnographic study of choice and English end of life care, can be accessed at www.repository.cam.ac.uk/handle/1810/245560

Organisation

University of Cambridge

Contact details

Erica Borgstrom, eb442@cam.ac.uk; dr.borgstrom@gmail.com

Research is:	Multi centre
Research project is funded:	NIHR CLAHRC project
Research project cover:	England - Midlands and East

No 50

Study Aim

PACE: Comparing the effectiveness of palliative care for elderly people in long term care facilities in Europe.

1. To map and classify existing palliative care systems in long term care facilities in terms of structures, organisations and policies for palliative care, across Europe.
2. To compare effectiveness of health care systems with and without formal palliative care structures in long term care facilities in six EU countries (BE, UK, IT, FI, PL, NL) in terms of patient and family outcomes representative cross-sectional study of deaths (STUDY I).
3. To compare the impact of a health service intervention 'Route to Success' aimed to improve the quality of palliative care in long term care facilities with traditional care (as control) in long term care facilities in Europe, on patient, family and staff outcomes and on cost-effectiveness.

Methodology

Programme of research:

1. Mapping of palliative care development in long-term care facilities.
2. Retrospective survey of deaths in long-term care facilities across 6 countries.
3. Cluster randomised controlled trial.

Organisation

International Observatory on End of Life Care, Lancaster University

Contact details

Katherine Froggatt, k.froggatt@lancaster.ac.uk

Research is:	Multi centre
Research project is funded:	EUFP7
Research project cover:	Europe; England - North, Midlands and East, South, London

No 52

Study Aim

We have received funding from the Birmingham Children's Hospital Research Foundation to complete the following project.

Aim:

To investigate the impact of end of life care decision-making, including the Advance Care Planning (ACP) process, on bereaved parents of children and young people (CYP) with life-limiting conditions (LLC) who die in the Paediatric Intensive Care Unit (PICU).

Objectives:

1. To explore and describe the experiences and perspectives of bereaved parents regarding the end of life care decision-making process on PICU.
2. To identify the facilitators and barriers to the end of life care decision-making process, including ACP, for CYP with life-limiting conditions, from the perspective of bereaved parents.
3. To explore and describe the benefits and risks of the ACP process for CYP with life-limiting conditions as perceived by bereaved parents.

Methodology

This study will provide an in-depth qualitative interview investigation into the experiences of parents around end of life decision-making in the PICU, and the impact of these experiences. Insights from the study will provide valuable information and a human perspective that will contribute to improving care for others in the same situation in the future.

Organisation

Birmingham Children's Hospital, Birmingham

Contact details

Dr Adrian Plunkett, Adrian.Plunkett@bch.nhs.uk; Dr Sarah Mitchell, S.Mitchell6@nhs.net

Research is:	Single centre
Research project is funded:	Local
Research project cover:	England - Midlands and East

No 60

Study Aim

Community-based volunteer-led support for family caregivers caring for a relative or friend with palliative and/or end of life care needs at home (Co-Care). The aim of the Co-Care project is to develop and implement a system of community-based volunteer-led support for family caregivers caring for a relative or friend with palliative and/or end of life care needs at home.

Methodology

We are currently at the stage of programme development, consisting of 4 interlinked projects: Scoping study of relevant evidence (Project 1). Survey of community-based volunteer-led initiatives for family caregivers providing palliative and/or end of life care (Project 2). Linked stakeholder focus groups and workshops to underpin decisions about the proposed complex model of support; linked focus groups & workshops with stakeholders to map channels of communication with high risk caregivers (Project 3). Critical dialogue on implementation science priorities and practices to underpin implementation design and build capacity (Project 4).

Organisation

Faculty of Health Sciences, University of Southampton

Contact details

Dr Christopher Bailey, C.D.Bailey@soton.ac.uk

Research is:	Multi centre
Research project is funded:	National
Research project cover:	England - Midlands and East, South, London

No 61

Study Aim

To explore the feasibility of family caregivers administering subcutaneous medications for symptom control for palliative care patients dying at home.

Methodology

Mixed methods - questionnaire survey of healthcare professionals, using closed and open ended questions; semi-structured interviews with bereaved caregivers for palliative care patients who died at home.

Organisation

Trinity Hospice, London

Contact details

Dr Barbara Sheehy-Skeffington, sheehysb@hotmail.com

Research is:	Single centre
Research project is funded:	No funding provided. Part of MSc studies.
Research project cover:	England - London

No 72

Study Aim

Understanding and responding to those bereaved through their family members' substance use.

Methodology

100 Qualitative interviews with individuals and couples bereaved through substance use; 6 focus groups with 40 practitioners and bereaved people; a working group of 12 practitioners and bereaved people.

More information

More info at: www.bath.ac.uk/cdas/research/understanding-those-bereaved-through-substance-misuse/

Organisation

University of Bath - Centre for Death and Society, Department of Social and Policy Sciences

Contact details

Dr Christine Valentine, c.a.valentine@bath.ac.uk

Research is:	Multi centre
Research project is funded:	National
Research project cover:	England - mainly South West; Scotland

No 80

Study Aim

Supporting carers to enable patient discharge at end of life.

Aims:

1. To investigate the content, timing and format of support that's required by family carers at patient discharge from acute care at end of life.
2. To use findings to adapt an evidence-based carer support needs assessment tool to the acute care setting and integrate it into a pathway to facilitate timely and appropriate patient discharge.

Methodology

Qualitative.

Organisation

University of Manchester (as part of NIHR CLAHRC Greater Manchester)

Contact details

Prof. Gunn Grande, Gunn.Grande@manchester.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	England - North

No 84

Study Aim

Ethics of Health promotion in Palliative care: Can health promoting messages be assimilated by first degree relatives of patients with advanced breast and colorectal cancer?

Methodology

In depth qualitative interviewing.

More information

Patient, and their first degree relatives are being interviewed. Interviews and Focus groups with palliative care clinicians, general practitioners and healthcare professionals, have just received been a favourable ethical opinion and will proceed soon. The PhD student is Dr Nicky Baker, nicky.baker@mariecurie.org.uk

Organisation

Marie Curie Hospice West Midlands

Contact details

Kathy Armour, Kathy.armour@mariecurie.org.uk

Research is:	Single centre
Research project is funded:	BMA
Research project cover:	England - Midlands and East

No 90

Study Aim

The study aims to provide a clear understanding of the clinical problems of young adults being cared for by Children's Hospices Association Scotland with the purpose of enhancing their quality of life. In the study we take clinical problems to mean the holistic, psychological, physical and developmental needs of young adults and their families due to the inseparable impact of one on the other.

Methodology

Qualitative longitudinal study.

Organisation

University of Nottingham

Contact details

Professor Bridget Johnston, Bridget.Johnston@nottingham.ac.uk

Research is:	Multi centre
Research project is funded:	Local
Research project cover:	Scotland

No 91

Study Aim

I have just finished two projects on funeral costs. The studies aimed to look at how people prepare for funeral costs and the role of the state in supporting those who struggle to pay for a funeral.

Methodology

Both studies were small qualitative studies, c40-60 participants each.

Organisation

University of Bath

Contact details

Dr Kate Woodthorpe, k.v.woodthorpe@bath.ac.uk

Research is:	Single centre
Research project is funded:	Commercial funder
Research project cover:	England - South

No 95

Study Aim

To seek views from relatives or friends of those who have recently died, about their experiences at the end of life.

Methodology

Interviews/questionnaires/surveys.

More information

This has been commissioned to help inform local CCG and hospice commissioning priorities.

Organisation

The End of Life Partnership

Contact details

Lynne Partington, l-partington@eolp.org.uk

Research is:	Single centre
Research project is funded:	Local
Research project cover:	England - North West

No 98

Study Aim

The Cheshire Living Well, Dying Well Public Health Programme aims to improve health and wellbeing by supporting a change in knowledge, attitude and behaviour towards life, age, death and loss. The Cheshire Living Well, Dying Well Programme is part of the Public Health and Wellbeing Department of The End of Life Partnership. The EoLP is working together to transform 'End of Life Experience and Care'. The mission statement of The End of Life Partnership is to lead educate and facilitate excellence and best practice in palliative and end of life care; and to influence and enable our communities to live and die well, supported by the health, social and voluntary workforce. The EoLP is a charitable collaborative that works across Cheshire East and Cheshire West and Chester local authority areas as well as linking into the Strategic Clinical Networks in Merseyside and Greater Manchester. There are five dedicated departments: Public Health and Wellbeing, Research and Evaluation, Service Development, Education and Practice Development, Business Support and Technology. The work of The EoLP is shaped, overseen and monitored by key local stakeholders from a wide range of organisations.

Methodology

Numerous projects and interventions being evaluated therefore mixed methodology.

More information

We are collating evidence for a number of initiatives, projects and interventions from across the Programmes within the organisation.

Organisation

The End of Life Partnership

Contact details

Rachel Zammit, r-zammit@eolp.org.uk

Research is:	Single centre
Research project is funded:	Local
Research project cover:	England - North

No 105

Study Aim

Research question: How does community hospice volunteering with people at the end of life impact on volunteers in relation to their experiences and their attitudes to death?

Methodology

This qualitative study will interview 15-20 adult volunteers, who are visiting patients at the end of their lives in their own communities, recruited from independent hospices that provide community volunteer support. A narrative approach will be used, encouraging participants to tell their story about being a volunteer with a focus on their experiences, training and support. The interviews will be audio taped and transcribed. The data will be analysed using narrative analysis that looks for storylines that run through the main interview.

More information

This project is part of my PhD in Palliative Care with Lancaster University and is in the final year.

Organisation

Lancaster University

Contact details

Barbara Gale, barbara.gale@stnh.org.uk
Dr Amanda Bingley, a.bingley@lancaster.ac.uk
Prof Carol Thomas, c.thomas@lancaster.ac.uk

Research is:	Multi centre
Research project is funded:	Jointly with the researcher, her own hospice and funding from Hospice UK
Research project cover:	England - Midlands and East, London

No 107

Study Aim

Lucy Gate, Charlotte Warren-Gash, Angela Bartley, Adrian Tookman, Alison Rodger, Alex Clarke. Promoting lifestyle behaviour change in hospital patients: development of an evidence-based psychological intervention. BMJ Open. Submitted for publication. 2014

Methodology

More information

This is about delivering a public health agenda in an Acute Trust It IS NOT an end of life project but gives an important question that a public health message can be delivered in the setting of an Acute Trust. The learning from this is relevant for end of life and hospice care where a teachable moment can be exploited to deliver a public health message.

Organisation

Marie Curie Cancer Care

Contact details

Dr Adrian Tookman, adrian.tookman@mariecurie.org.uk

Research is:	Single centre
Research project is funded:	Local
Research project cover:	England - London

No 112

Study Aim

We are exploring the opportunity to have a better understanding of supporting staff and people at end of life and their families in making decisions relating to CPR in the context of their religious beliefs.

Methodology

Not yet decided.

More information

This is at very early stages.

Organisation

Jewish Care

Contact details

Gaby Wills, gwills@jcare.org

Research is:	Multi centre
Research project is funded:	Currently exploring with a number of funding organisations
Research project cover:	England - London

No 117

Study Aim

The aim of the project as is to develop, implement and evaluate a care of the dying volunteer support service within a University Hospital Trust.

Methodology

Mixed Methods evaluation of a complex intervention.

Organisation

Marie Curie Palliative Care Institute Liverpool

Contact details

stephen.mason@liverpool.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	England - North

No 118

Study Aim

Researching the Elderly Approaching end of life: Socio-Politics, Demography and Care Practises Life expectancies and age at death are increasing in Germany (Lehr 2007) and England (Leeson 2014) and more people die in extreme old age. Yet, longevity comes with a price. In the course of the demographic change people not only live longer, but die longer, partially due to more easily treated but not curable diseases. Therefore research on the end of life is important, because the demographic change does not only demand a renegotiation of ageing (see Denninger et al 2010), but also a renegotiation of dying.

The current change among dying trajectories generates new orders of knowledge, places and spaces, as well as practises and care. In Germany these processes of transformation take place without adequate research. As only a few elderly die where, when and how as they would have wished, the highly emotional public debates about scandals in elderly care homes, living wills and Assisted Dying/Euthanasia demonstrate the urgency of empirical research. Nonetheless, German research foundations support research on ageing that focusses mainly on successful ageing, a concept that idealises healthy, active and mobile elderly helpfully contributing to society after retirement.

Research on old age, illness and dying remains marginalised, although the dying process inevitably plays a very important part of ageing. The task of this research agenda will be to place the demographic change within a broader understanding, eschewing any sense of old age, illness and dying as a burden on society or posing a threat to the individual.

The primary research questions therefore concern basic information about the elderly who are approaching the end of life: Socio-Politics: What are the current issues facing the elderly approaching the end of their lives? Demography: Where do the elderly live at the end of their lives? Care practises: How do they approach this stage?

These basic research questions form three subprojects, which are framed as follows. The research is comparative both historically and internationally covering the past 15 years. The research focuses on Germany and the United Kingdom, which have been selected because these countries are facing the same demographic transition. Yet, the different social and political backgrounds and the differing assisted suicide regulations will offer more information on how social structures affect the elderly reaching the final life stage. The different welfare state models of these countries (conservative vs. liberal) vary in quality, influence the social needs of their citizens, and determine via different legal situations the security of old age and the situation in which they die. Moreover, the secondary data analyses can be collected relatively easily through the already existent data bases in Great Britain (NEoLCIN) and Germany (SHARE and Base I and II).

Methodology

For each subproject there is a different methodological approach:

1. Sociopolitics: Discourse analysis.
2. Demography: Demographic statistics.
3. Practises and care: Focussed ethnography.

Organisation

Oxford Institute of Population Ageing, UK and Department of Sociology, LMU Munich, Germany

Contact details

Tina Weber, tina.weber@ageing.ox.ac.uk, tina.weber@soziologie.uni-muenchen.de

Research is:	Single centre
Research project is funded:	Submitting the project proposal to a German Foundation.
Research project cover:	England and Germany

No 119

Study Aim

Study into the involvement of residents with dementia in a residential home for people with intellectual disability and dementia.

Methodology

Assessment via scales - with residents and staff.

More information

This is ongoing and should be completed by January 2015.

Organisation

University of Kent

Contact details

Dr David Oliver, drdjoliver@gmail.com

Research is:	Single centre
Research project is funded:	Local
Research project cover:	England - South

No 120

Study Aim

This project seeks to understand how teenagers, families and health care professionals' experience participation in decision making regarding care and treatment. It focuses on young people aged 13-19 years diagnosed with leukaemia receiving their care and treatment in a tertiary hospital the UK. The primary objective is to understand the complex process of decision making that takes place among health care professionals, families and young people independently, and together, when decisions regarding the young person's care and treatment need to be made. Specifically the project will delineate the role of the young person in decision making as understood in principle and manifest in practice. The results of the study will be used to inform the development of evidence-based guidelines for the role of young people, parents and health care professionals in decision-making regarding care and treatment.

Methodology

The research will use qualitative methodology, participant observation and semi-structured interviews, as well as document and medical record review. Participant observation includes both audio recording and the taking of field notes in a variety of settings such as, clinical consultations, multidisciplinary team meetings and informal bedside, home or corridor chats. These observations will provide a real time account of decision making with teenagers, families and the clinical team. The keeping of field notes in addition to audio recordings allows for a complete account of the context, including aspects that the tape recordings cannot capture, with consistent data being noted in each setting (Emerson, Fretz & Shaw, 2007). Towards the end of the research all participants will be invited to participate in an open ended, one-to-one, semi-structured interview to discuss their experiences in more depth. Clinicians, parents, young people and any other guardians or family members present during the course of the decision making process will be invited. It is through these audio-recorded interviews and the informal chats before and after observations, that we will be able to understand how each party understands participation in principle. Interviews will be transcribed verbatim.

Organisation

Louis Dundas Centre for Children's Palliative Care, University College London

Contact details

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Research is:	Multi centre
Research project is funded:	National
Research project cover:	England - London

No 121

Study Aim

This project seeks to understand decision making for children with a high risk brain tumour - a tumour with a very poor prognosis (median survival < 2 years).

Research Aims:

Primary aim: To inform the development of evidence based guidance which will assist parents, children and clinicians in decision making regarding care treatment and research participation in relation to paediatric high risk brain tumours.

Secondary aims: To provide a robust description and analysis of decision making for children with high risk brain tumours over the entire course of the illness with attention to the views, perspectives and actions of parents, children and clinicians.

Research Objectives:

1. Document the decision making process. Follow children, parents and clinicians from diagnosis with a high risk brain tumour over the entire course of the illness. Capture the voices of children, parents and clinicians as decisions are made throughout the course of the illness. Collect multiple types of data from several sources: including verbatim transcripts and notes from MDT meetings, family consultations with clinicians, open-ended, semi-structured interviews, informal conversations and interactions with all stakeholders as well as medical records and materials given to or accessed by parents and children.
2. Analyse the decision making process and develop a conceptual model. Describe the role of children, parents and clinicians in decision making over the course of the illness. Track what and when parents are told about their child's prognosis. Assess parents' views of their child's prognosis at various points in the illness. Document parents' understandings of the purpose and efficacy of treatments for high risk brain tumours. Construct a natural history for high risk brain tumours, identifying turning points for both parents and clinicians. Identify disease related changes in children's, parents' and clinicians' views of themselves in interaction and determine the impact of these on relationships. Determine parents', children's and clinicians' goals in deciding upon a particular course of care or treatment. Determine basic precepts or principles- pragmatic, ethical, etc.-upon which children, parents and clinicians rely in decision making. Track parents' and clinicians' assessment of the balance of anticipated benefits versus pain, discomfort or other burdens when decisions are taken.
3. Develop specific guidance from our research findings. Conduct participatory workshops for parents, children and clinicians involved in the study to review study results. Combine the findings of research with feedback from parents, children and clinicians to formulate guidance for those caring for, treating and diagnosed with a high risk paediatric brain tumour.

Methodology

This is an ethnographic longitudinal prospective study using participant observation, semi-structured interviews and document review.

Organisation

Louis Dundas Centre for Children's Palliative Care, University College London

Contact details

Professor Myra Bluebond-Langner, bluebond@ucl.ac.uk

Research is:	Multi centre
Research project is funded:	National
Research project cover:	England - London

No 144

Study Aim

The Learning about Breathlessness study (LaB) has two key aims:

Primary aim - to develop an evidence-based educational intervention for informal carers of patients with breathlessness in advanced disease.

Secondary aim - identification of referrer-relevant outcomes for a future RCT to test the effectiveness of the intervention.

Methodology

Four stage study:

Stage 1 (Identifying carer needs and preferences): qualitative interviews with breathless patients (with advanced COPD or cancer) and their carers to identify carers' educational needs and intervention preferences, synthesised with our systematic review findings.

Stage 2 (Identifying evidence-based intervention content with clinical experts): clinical expert workshops to review Stage 1 findings and develop evidence-based intervention content and potential delivery-modes.

Stage 3 (Intervention co-development with informal carers): informal carer workshops to co-develop the intervention based on Stage 1-2 findings to ensure relevance and accessibility.

Stage 4 (Identification of referrer-relevant outcomes): on-line survey of potential intervention referrers (clinicians) to identify outcomes to measure in a future RCT of the intervention.

More information

The Learning about Breathlessness study (LaB) is the operational title for a study funded by Dimpleby Cancer Care (01/02/2014–31/01/2016).

Formal title: Developing a relevant and acceptable educational intervention for informal carers of patients with with breathlessness in advanced disease.

Organisation

University of Cambridge (in collaboration with King's College London, RAND Europe, Cambridgeshire University Hospitals' NHS Foundation Trust, Cambridgeshire Community Services, & University of Manchester)

Contact details

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Research is:	Single centre
Research project is funded:	National
Research project cover:	East of England and South London plus national stakeholders

No 152

Study Aim

When cure is not likely: What do young adults with cancer (aged 16-40 years) and their families need and how can it best be delivered?

Methodology

Multiple methods study for complex interventions using realistic evaluation:

1. Analysing available information - detailed synthesis of the literature.
2. Interviews with patients, families and professionals – to gather subjective experience.
3. Scenario workshops with families and professionals - to generate new thinking and potential solutions to problems raised.
4. Expert Panel. We will present our findings and recommendations to a panel of professional experts for further refinement.
5. Make recommendations for practice.

Organisation

Lead site: University College London Hospitals

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Research is:	Multi centre
Research project is funded:	National
Research project cover:	England