Public Health England

Protecting and improving the nation's health

National End of Life Care Intelligence Network

Current research

End of life care research area:

Organisational and supporting processes

Summary research

No	Summary Research Aim	Organisation
6	To understand the barriers and facilitators to implementing advance care planning in practice.	Royal Berkshire NHS Foundation Trust
12	Identify factors involved in the decision-making process involved for adults who subsequently die within three days of admission to hospital.	University of Cambridge
15	Understanding the complex discourses that influence care delivery in end of life care in the acute sector and the influence of mainstream media on discursive practice.	Northumbria University
17	To explore how sedation is used in palliative care and develop a normative understanding of this practice.	Northumbria Healthcare NHS Foundation Trust and
21	Systematic review of interventions relating to drug treatments for symptoms and other issues pertinent to the end of life and of evaluations relating to the benefits of types of palliative care services.	University College London
22	To examine decisions made within a hospital multidisciplinary team about artificial nutrition for individuals at risk of lacking decision-making capacity.	Department of Public Health and Primary Care, University of Cambridge
27	Understanding why adult patients known to palliative care (or referred during admission) present to the emergency department.	Barts Health NHS
30	To develop and pilot a systematic approach to the early identification, assessment and support of informal carers of people who are approaching the end of their lives.	Marie Curie Hospice, Edinburgh
42	Exploring the use of clinically assisted hydration in dying patients.	St Richard's Hospice
43	Study of clinically assisted hydration (vs mouth care) at the end of life in cancer patients.	Royal Surrey County Hospital NHS Foundation Trust
49	To explore the implementation process of a project aimed at delivering integrated palliative care to people in the community.	University of Kent
51	1. Systematic review of published guidance, policy and evidence related to palliative care service design and delivery for Children and Young People (CYP) with life-limiting illness. 2. Exploration of stakeholder experience and expectations of palliative care services for CYP.	Warwick Medical School, University of Warwick
53	Multiple systematic reviews of symptom management, organisation of support for carers, evidence support for policy and decision making.	The University of Bath
55	Cochrane Systematic review of the impact of morphine, fentanyl, oxycodone or codeine on patient consciousness, appetite and thirst to treat cancer.	Cochrane pain, Palliative and Supportive Care Group
58	To develop a new Cancer Carer Medicines Management intervention and to test its feasibility, acceptability and efficiency.	Faculty of Health Sciences, University of Southampton
62	A feasibility study to inform the design of a randomised controlled trial to identify the most clinically and cost effective length of anticoagulation with low molecular weight heparin in the treatment of Cancer Associated Thrombosis (ALICAT).	Cardiff University

No	Summary Research Aim	Organisation
64	Fragmatic: a randomised controlled trial to evaluate whether daily Dalteparin impacts on overall survival in lung cancer patients.	Cardiff University
68	Prognosis prediction using palliative prognostic index for hospice patients. To externally validate the tool in a multi-centre setting.	EllenorLions Hospice
73	To investigate the use, benefits and risk of blended 'real food' diet in children and young people with complex enteral feeding needs.	Helen and Douglas House Hospices for Children and Young Adults, Coventry and Warwickshire PCT Foundation Trust, Nottingham Children's Hospital, Cardiff University Hospital of Wales, Newcastle Childrens Hospital
75	Invasive Neurodestructive Procedures in Cancer pain pilot study exploring the role of cordotomy in the management of mesothelioma-related pain.	Bangor University
79	To test the reliability of proxy symptom assessments of elderly patients dying in hospital, comparing assessments by named nurse, informal care giver and patient.	Marie Curie Hospice, Solihull
82	To assess the effectiveness of indwelling drainage catheters for the management of ascites in advanced cirrhosis.	Brighton and Sussex University Hospitals NHS Trust
86	Efficacy of Trans-dermal Nitrate in reducing the severity of terminal lung secretions in patients dying from end stage malignancy.	St Raphael's Hospice
94	Advanced care planning for children, frameworks to categorise children with life-limiting conditions, transitional care for young people.	University of Birmingham
97	Improving experiences of palliative care for older people, their carers and staff in the emergency department using Experience-based Co-design.	Florence Nightingale Faculty of Nursing and Midwifery
103	To map the geographical location of healthcare services in South London and visualise how variation in place of death is related to the location of services.	Cicely Saunders Institute, King's College London
104	CLAHRC South London – Palliative and end of life care theme – Project 1 - Geographical accessibility to healthcare facilities and place of death in South London.	Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation. King's College London
108	Identify factors most associated with variation in hospital use in the last 12 months of life.	Nuffield Trust
110	To assess the contribution that data linkage could make to understanding patterns of care at the end of life, focusing on patients with bowel and blood cancers.	University of York and Hull York Medical School
115	Chemical compatibility of drugs administered by continuous subcutaneous infusion for end of life care (ChemdEL).	Marie Curie Palliative Care Institute Liverpool
116	To measure hydration in advanced cancer patients using bioelectrical impedance vector analysis (BIVA) in order to determine the relationship between symptoms, biochemistry, and performance status.	Marie Curie Palliative Care Institute Liverpool
122	To provide evidence based guidance for recruitment to studies needed for the effective care and management of children with life limiting conditions and life threatening illnesses.	Louis Dundas Centre for Children's Palliative Care, University College London

No	Summary Research Aim	Organisation
131	To establish whether oral ketamine given in addition to best standard pain management, improves neuropathic cancer pain compared to best standard pain management alone.	Marie Curie Research
132	Controlling symptoms in the last year of life.	Marie Curie Research and University of Manchester
133	The overall aim of the study was to elicit the accounts of family carers who had witnessed the dying at home of an older person.	Marie Curie Research International Observatory on End of Life Care, Lancaster University, UK
134	To scope experience, attitudes and views of critical care staff regarding feasibility of transferring patients home to die and develop clinical guidance.	University of Southampton
135	The purpose of this study is to test the reliability of and validate a clinical needs assessment tool for people with interstitial lung disease (ILD). This will help identify palliative needs and those patients who need referral to specialist palliative care services. Symptom control in the last year of life.	Marie Curie Research
136	Family carers' perceptions of their educational needs when providing end of life care: a systematic review of qualitative research.	Department of Health Sciences, University of York
137	A two-year research study to explore the specific challenges of involving volunteers in palliative care roles which require direct contact with patients or their families and how these can be met.	The Institute for Volunteering Research (at NCVO) and the International Observatory on End of Life Care (at Lancaster University)
138	The use, impact on patient and family wellbeing, and understanding of the role, of volunteers to support end of life care.	Marie Curie Palliative Care Research Department, UCL Division of Psychiatry
145	Identifying community based chronic heart failure patients in the last year of life.	NHS Lothian, Edinburgh Royal Infirmary
146	Identifying acute coronary syndrome patients approaching end of life.	NHS Lothian, Edinburgh Royal Infirmary
147	To identify barriers for people with end stage liver disease and their close family members to access good quality end of life care and to identify cost-effective ways of enabling service improvements in a single locality.	Marie Curie Palliative Care research Department (UCL) & Royal Free London NHS Foundation Trust

Full research

No 6

Study Aim
To understand the barriers and facilitators to implementing advance care planning in practice.

Methodology
An explanatory systematic review of implementation studies using normalisation process theory.

More information
From this study further work will be undertaken investigating treatment escalation plans.

Organisation
Royal Berkshire NHS Foundation Trust

Contact (Name and Email address only)
Susi Lund, susi.lund@royalberkshire.nhs.uk

Research is:	Single centre
Research project is funded:	As part of post doctoral fellowship
Research project cover:	England - South

No 12

Study Aim

Hospital admissions close to the end of life are often viewed as inappropriate and avoidable and have been little studied. The decision processes involved are often complex, involving patients, lay carers and professionals from numerous sectors. This study seeks to identify factors involved in the decision-making process involved for adults who subsequently die within three days of admission.

The research questions are:

1. How are decisions that result in admissions at the end of life made in practice?
2. How do healthcare professionals view end of life hospital admissions?
3. What do patients, carers and practitioners think can or should be different in decision-making around admissions to hospital at end of life?
4. How does current practice compare with policy?

Methodology

Retrospective study at two hospitals. 'Clusters' focused on a patient with cancer, chronic obstructive pulmonary disease or dementia, who had died within 3 days of admission. Semi-structured interviews were held with: Up to five community and hospital healthcare professionals involved in the admission within a few days of the death. One next of kin interviewed 3 to 6 months after the death.

To date 17 patient clusters have totalled 57 interviews.

Organisation

University of Cambridge

Contact (Name and Email address only)

Dr Stephen Barclay, sigb2@medschl.cam.ac.uk; Sarah Hoare, seh91@medschl.cam.ac.uk

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

No 15

Study Aim
To contribute to professional understanding of the contextual conditions necessary for optimal end of life care in the acute sector. Objectives: 1. To explore what are the emerging, competing and overlapping discourses that influence end of life care. 2. To consider the influence and impact of mainstream media on discursive practice in end of life care. 3.To explore how tools (apparatus) emerge and are embedded in end of life care in the acute sector. 4. To explore how these discourses shape end of life care practice.

Methodology
Foucauldian Discourse Analysis.

More information
This is the final year of my doctoral studies.

Organisation
Northumbria University

Contact (Name and Email address only)
Joanne Atkinson, Joanne.atkinson@northumbria.ac.uk

Research is:	Single centre
Research project is funded:	Professional Doctoral Studies
Research project cover:	Newcastle upon Tyne;England - North

No 17

Study Aim

To explore how sedation is used in palliative care and develop a normative understanding of this practice.

Methodology

This was ethnographic research and methods included participant observation and in-depth qualitative interviewing. The four principle objectives of this research study were:

1. To understand and describe how 'sedation' is defined in the literature and in practice.
2. To understand how the practice of sedation reflects thoughts about its indications, the intentions behind it and attitudes towards it.
3. To develop a normative understanding of the practice of sedation.
4. To examine how sedation relates to the broader aims of palliative care.

More information

This research was completed as part of a PhD in June 2013. Publications are in progress, but to date presentations have been posters and an oral presentation at the PCC 2012.

Organisation

Northumbria Healthcare NHS Foundation Trust and Marie Curie Hospice Newcastle

Contact details

Katie Frew, katie.frew@nhct.nhs.uk

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

No 21

Study Aim
I am a systematic reviewer involved in the generation of Cochrane and other reviews relating to palliative care. I work as part of a team on reviewing interventions relating to drug treatments for symptoms and other issues pertinent to the end of life, such as anxiety, depression, constipation and delirium. I also explore evaluations relating to the benefits of types of palliative care services such as those that involve Chaplins or volunteers.

Methodology
Systematic review methods to evaluate both quantitative and qualitative evidence.

Organisation
University College London

Contact details
Bridget Candy, b.candy@ucl.ac.uk

Research is:	Multi centre
Research project is funded:	Mainly from Marie Curie Cancer Care
Research project cover:	My search is for evidence internationally as well as locally

No 22

Study Aim
This study examines decisions about artificial nutrition for individuals at risk of lacking decision-making capacity made within a hospital multidisciplinary team. The key research questions are: 1. How many individuals lacked decision-making capacity at the time of referral? 2. How are decisions made concerning artificial nutrition for individuals at risk of lacking decision-making capacity? 3. What are the key decision-making factors?

Methodology
An examination of hospital records over a one year period, and a 3 month non-participant observation of the multidisciplinary team.

Organisation
Department of Public Health and Primary Care, University of Cambridge

Contact details
Dr. Gemma Clarke, gcc29@medschl.cam.ac.uk

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

No 27

Study Aim

Why do adult patients known to palliative care (or referred during admission) present to the emergency department?

1. What are the clinical and demographic characteristics of such patients?
2. What are the perspectives of such patients?

Methodology

Observational, prospective service evaluation consisting of 2 phases:

1. Review of the emergency department documentation (and subsequent medical notes if admitted).
2. Qualitative phase including patient case studies.

More information

The aim of the project is to collect quantitative demographic and clinical information about patients known to palliative care that present to the ED. A select group of patients will then be asked to participate in the second phase, which will involve case studies.

Organisation

Barts Health NHS

Contact details

Dr Emilie Green, emilie.green@doctors.org.uk

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

No 30

Study Aim
To develop and pilot a systematic approach to the early identification, assessment and support of informal carers of people who are approaching the end of their lives. Objective 1: To develop a preliminary model of carer identification, assessment, support and referral. Objective 2: To pilot and evaluate the intervention in four contrasting general practices.

Methodology
Qualitative feasibility study.

More information
The needs of carers continue to go unrecognised yet their role is often significant. We are hoping this feasibility study will be the first phase of a complex intervention.

Organisation
Marie Curie Hospice, Edinburgh

Contact details
Dr Emma Carduff, emma.carduff@ed.ac.uk

Research is:	Single centre
Research project is funded:	Dimbleby Marie Cure Cancer Care
Research project cover:	Scotland

No 42

Study Aim
Feasibility study - exploring use of clinically assisted hydration in dying patients.

Methodology
Cluster randomised study.

More information
We are just at the point of becoming a 'research active' hospice and are just signing up for this study, which will be our first.

Organisation
St Richard's Hospice

Contact details
Dr Nicola Wilderspin, NWilderspin@strichards.org.uk

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

No 43

Study Aim
Feasibility study of clinically assisted hydration (vs mouth care) at the end of life in cancer patients. Aim: can definitive study be done?

Methodology
Cluster randomised controlled trial.

More information
Funded by RfPB.

Organisation
Royal Surrey County Hospital NHS Foundation Trust

Contact details
Dr Andrew Davies, adavies12@nhs.net

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

No 49

Study Aim
The aim of my study is to explore the implementation process of a project aimed at delivering integrated palliative care to people in the community. The focus of the study is primarily at the stakeholder level, looking at the strategies used to implement the project and what influenced the process. It also will look at patient and carer outcomes to explore how the degree of implementation is linked to outcomes.

Methodology
Mixed methods study using interviews, survey, document review, audit data, observations, and focus group.

Organisation
University of Kent

Contact details
Laura Holdsworth, L.M.Holdsworth@kent.ac.uk

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

No 51

Study Aim

Palliative care for children and young people (CYP); What, when, how?

Background:
Current definitions of palliative care for CYP are broad and non-specific, which provides practical challenges for patients and families, the healthcare professionals caring for them, and those responsible for commissioning services. Palliative care services for CYP around the UK differ between regions, with multiple statutory and voluntary providers involved. The future development of high quality, standardised palliative care services which serve CYP with life-limiting illness and their families, presents a huge challenge for the NHS.

Research questions:
1. How do current definitions of palliative care services for CYP concord with service delivery, policy and guidance in the UK?
2. What is the current evidence base for practice and policy related to palliative care service delivery for CYP?
3. What are the experiences and preferences of CYP, and/or their relatives or carers, in relation to the delivery of palliative care services?
4. What are the facilitators and barriers to the delivery of palliative care for CYP, and how might these be overcome?
5. What should an integrated model of palliative care for CYP look like?

Methodology

Design: Systematic review. Qualitative interview study.
Intended benefits: Palliative care and care planning in partnership with patients and families allows identification of preferences, better outcomes for families, and can avoid costly hospital admissions. CYP with life-limiting conditions, many of which are highly complex, represent an important population for consideration by the NHS. This in-depth investigation in to the design and delivery of palliative care services for CYP and development of a model of care will ultimately provide benefit for patients requiring those services, and their families. The outcomes will contribute to the improvement of integrated care, are highly relevant to the NHS, social care and third sector providers of palliative care for CYP, and to those providing palliative care in primary and secondary care sectors.

More information

The project has been funded as part of the NIHR Call for research for children and young people with long term conditions.

Organisation

Warwick Medical School, University of Warwick

Contact details

Dr Sarah Mitchell, S.Mitchell6@nhs.net

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

No 53

Study Aim
Multiple research projects in systematic review and meta-analysis within the Cochrane Collaboration as Co-ordinating Editor of the Pain, Palliative and Supportive Care Cochrane Review Group. Specifically: Titles on aspects of symptom management, organisation of care, support for carers. Evidence support for policy and decision making.

Methodology
Systematic Review.

Organisation
The University of Bath

Contact details
Professor Christopher Eccleston, c.eccleston@bath.ac.uk

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

No 55

Study Aim
Impact of morphine, fentanyl, oxycodone or codeine one patient consciousness, appetite and thirst to treat cancer. Cochrane Systematic review.

Methodology
Systematic review methodology.

More information
Completed and published on the Cochrane Library May 2014.

Organisation
Cochrane pain, Palliative and Supportive Care Group

Contact details
Anna Hobson, anna.hobson@ndcn.ox.ac.uk

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

No 58

Study Aim
Our aim is to develop a new Cancer Carer Medicines Management intervention and to test its feasibility, acceptability and efficacy to improve carers' knowledge, beliefs, skills and self-efficacy for pain medicines management, decrease carer strain and improve mood state.

Methodology
This study is a Phase I-II feasibility study, funded by Dimbleby Marie Curie, is being conducted (2013-2015) We have completed a rapid appraisal of research on interventions for carer management of end of life pain medicines; developed and refined of the intervention through user collaboration; and undertaken a feasibility trial involving nurses and carers in two sites.

More information
Further details can be found on the study website www.southampton.ac.uk/cpelc/research/ccmm.page

Organisation
Faculty of Health Sciences, University of Southampton

Contact details
Professor Sue Latter, sml@southampton.ac.uk

Research is:	Multi centre
Research project is funded:	National
Research project cover:	England - South, Wales

No 62

Study Aim
HTA Project: 10/145/01 - A feasibility study to inform the design of a randomised controlled trial to identify the most clinically and cost effective length of Anticoagulation with Low molecular weight heparin in the treatment of Cancer Associated Thrombosis (ALICAT). A mixed methods feasibility study to explore the willingness of patients with advanced cancer to be randomised into an RCT evaluating the treatment of cancer associated thrombosis for 6 months or 12 months.

Methodology
Mixed methods: Randomised control trial Online web survey. Qualitative interviews. Focus groups. Health economic analysis.

More information
This was a themed call by the HTA.

Organisation
Cardiff University

Contact details
Simon Noble, simon.noble@wales.nhs.uk

Research is:	Multi centre
Research project is funded:	HTA Project:10/145/01
Research project cover:	England - Midlands and East, Wales

No 64

Study Aim
Fragmatic: a randomised controlled trial to evaluate whether daily dalteparin impacts on overall survival in lung cancer patients.

Methodology
Clinical Randomised Controlled Trial.

More information
We have completed recruitment of 2200 patients across 130 clinical sites.

Organisation
Cardiff University

Contact details
Simon Noble, simon.noble@wales.nhs.uk

Research is:	Multi centre
Research project is funded:	Cancer Research UK
Research project cover:	England - North, Midlands and East, South, London, Scotland, Wales, Ireland

No 68

Study Aim
Prognosis prediction using Palliative prognostic index in hospice patients. To externally validate the tool, in a multi-centre setting.

Methodology
Observational.

Organisation
EllenorLions Hospice

Contact details
Sivakumar Subramaniam, drsivaks@aol.com

Research is:	Multi centre
Research project is funded:	Non funded
Research project cover:	England - South

No 73

Study Aim
To investigate the use, benefits and risk of blended 'real food' diet in children and young people with complex enteral feeding needs (project in development, funding sought).

Methodology
Review and mixed approaches.

More information
A multi-site supra regional project.

Organisation
Helen and Douglas House Hospices for Children and Young Adults, Coventry and Warwickshire PCT Foundation Trust, Nottingham Children's Hospital, Cardiff University Hospital of Wales, Newcastle Childrens Hospital

Contact details
Professor Jane Coad - jane.coad@coventry.ac.uk OR Dr Susie Lapwood, slapwood@helenanddouglas.org.uk

Research is:	Multi centre
Research project is funded:	Not funded as yet
Research project cover:	Supra-regional: West Midlands, Nottinghamshire, Thames Valley, Cardiff and Newcastle

No 75

Study Aim
The INPIC pilot study (Invasive Neurodestructive Procedures in Cancer pain): The role of cordotomy in the management of mesothelioma-related pain.

Methodology
Systematic review service survey Consensus methods National intervention registry set-up.

More information
This project has concluded and is in the dissemination phase. A national intervention registry for percutaneous cervical cordotomy is underway and should report on the first 100 cases soon.

Organisation
Bangor University

Contact details
Dr Marlise Poolman, m.poolman@bangor.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	England - North, Midlands and East, South, London, Scotland, Wales

No 79

Study Aim

Title: Reliability of proxy symptom assessments of elderly patients dying in hospital.

Aims: A prospective symptom assessment comparison by named nurse (HCP) and informal caregiver (ICG) with that of patient (>64 yrs) dying on an acute hospital ward. To determine the most reliable proxy, which symptoms are assessed accurately and when proxy assessment should be interpreted cautiously.

Methodology

Methods: 50 triads of terminally ill patient, ICG and HCP on medical wards of an acute general hospital. Assessments were made by each respondent within a 24 hour period, using the patient and caregiver versions of the palliative outcome scale (POS) and the palliative outcome scale for symptoms (POS-S). Demographic data on the 3 groups were collected. Analysis used weighted kappa statistics to generate levels of agreement between proxy and patient.

Organisation

Marie Curie Hospice, Solihull

Contact details

Chantal Meystre, Chantal.Meystre@mariecurie.org.uk

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

No 82

Study Aim
To assess the effectiveness of indwelling drainage catheters for the management of ascites in advanced cirrhosis.

Methodology
Feasibility RCT.

More information
Currently in process of gaining ethical approval.

Organisation
Brighton and Sussex University Hospitals NHS Trust

Contact details
Dr Louise Mason, louise.mason@bsuh.nhs.uk

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

No 86

Study Aim
Efficacy of Trans-dermal Nitrate in reducing the severity of terminal lung secretions in patients dying from end stage malignancy.

Methodology
RCT pilot; Double blinded, placebo controlled.

More information
I am entering the final stages of my pilot research.

Organisation
St Raphael's Hospice

Contact details
Dr Marie Joseph, mariejoseph@straphaels.org.uk

Research is:	Single centre
Research project is funded:	Hospice
Research project cover:	England - South, London, Ireland

No 94

Study Aim
No 'Live' projects, but involved in advanced care planning for children, developing frameworks to categorise children with life-limiting conditions for service mapping etc. Also have a special interest in transitional care for young people.

Methodology
Mixed methods.

Organisation
University of Birmingham

Contact details
Dr Karen Shaw, k.l.shaw@bham.ac.uk

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

No 97

Study Aim
Title: Improving experiences of palliative care for older people, their carers and staff in the Emergency Department (ED) using Experience-based Co-design. Aim: To identify the defining moments of the shared experiences of palliative care in the ED for those providing and receiving it. To draw the groups together to work in partnership to redesign those aspects causing the greatest barriers to high quality palliative care provision, and positive care experiences.

Methodology
Participatory action research, specifically experience-based co-design.

More information
This project is currently still in progress but by January I will have completed all practical elements and will be writing up the thesis.

Organisation
Florence Nightingale Faculty of Nursing and Midwifery

Contact details
Rebecca Blackwell, Rebecca.blackwell@kcl.ac.uk

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

No 103

Study Aim
CLAHRC. A key aim is to map the geographical location of healthcare services in South London and visualise how variation in place of death is related to the location of services. http://www.csi.kcl.ac.uk/nihrclahrc.html

Methodology

Organisation
Cicely Saunders Institute, King's College London

Contact details
Dr Gao Wei, wei.gao@kcl.ac.uk

Research project cover:	England - London

No 104

Study Aim
To investigate the relationship between geographic accessibility to end of life care facilities and services and place of death in South London.

Methodology
Routine death registration data, healthcare facilities data and GIS/Statistical packages.

Organisation
Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation. King's College London

Contact details
Clare Pearson, clare.pearson@kcl.ac.uk

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

No 108

Study Aim
What factors are most associated with variation in hospital use in the last 12 months of life? This analysis will explore the relative importance of patient level or system level variables in influencing observed hospital use. The aim is to develop a better understanding of where changes in the care systems are more likely to lead to changes in the use of hospital care at the end of life.

Methodology
Multivariate regression analysis of hospital use for a cohort of 1.2 million people that died between 2009-12 in England.

Organisation
Nuffield Trust

Contact details
Martin Bardsley, martin.bardsley@nuffieldtrust.org.uk; Theo Georghiou, theo.georghiou@nuffieldtrust.org.uk

Research is:	Multi centre
Research project is funded:	Nuffield Trust funding the work
Research project cover:	England - North, Midlands and East, South, London

No 110

Study Aim

The project set out to assess the contribution that data linkage could make to understanding patterns of care at the end of life, focusing on patients with two forms of cancer, bowel and blood cancers, for which the research team had access to national data. Specific objectives were:

1. To establish an individual-level linked data record covering the final year of life for people dying with and of colorectal and haematological cancers in England in a single year (2008).
2. To include in this record routine information recorded from death registration; inpatient and outpatient NHS hospital activity and cancer registration.
3. For a subset of these individuals, to incorporate information recorded as part of primary care data entries within the Clinical Practice Research Data link (CPRD) that relate to palliative care provision.
4. To describe the patterns of place of death.
5. To explore factors associated with the place of death, including features of the disease, socio-demographic circumstances and organisation of care.
6. To summarise the patterns of care received, including, where possible, recorded contacts with specialist palliative care service.

Methodology

Individual level data linkage, descriptive analyses of care patterns, multiple variable regression analyses to examine factors associated with place of death.

Organisation

University of York and Hull York Medical School

Contact details

Steven Oliver, steven.oliver@hyms.ac.uk

Research is:	Single centre
Research project is funded:	Charity - Marie Cure Cancer Care
Research project cover:	England - North, Midlands and East, South, London

No 115

Study Aim
Chemical compatibility of drugs administered by continuous subcutaneous infusion for end of life care (ChemdEL). The aims of this study are: 1. To identify the most common combination of drugs used in continuous subcutaneous infusion driver. 2. To test the chemical compatibility of the most common combinations of drugs used in continuous subcutaneous infusion driver.

Methodology
Survey and Delphi to identify common combinations Chemical analysis at QC lab.

Organisation
Marie Curie Palliative Care Institute Liverpool

Contact details
andman99@liverpool.ac.uk; stephen.mason@liverpool.ac.uk

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

No 116

Study Aim
This study aims to measure hydration in advanced cancer patients using bioelectrical impedance vector analysis (BIVA) in order to determine the relationship between symptoms, biochemistry, and performance status.

Methodology
Observational longitudinal cohort study.

Organisation
Marie Curie Palliative Care Institute Liverpool

Contact details
a.c.nwosu@liverpool.ac.uk; stephen.mason@liverpool.ac.uk

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

No 122

Study Aim

Purpose: To provide evidence based guidance for recruitment to studies needed for the effective care and management of children with life limiting conditions and life threatening illnesses. This mixed methods project will explore the impact and effectiveness of recruitment practices from the perspective of children and young people, their families, researchers and health care professionals over the course of illness (e.g. diagnosis, deterioration, death and bereavement).

Aims and Objectives:

1. To investigate recruitment processes across a range of studies of children and young people (CYP) with life-limiting conditions (LLC) and life-threatening illnesses (LTI), and from the perspective of four stakeholder groups in order to identify strategies to improve recruitment and participation in future studies. Specifically, the objectives are: a) To describe how recruitment discussions between families (bereaved and non-bereaved) and recruiters or researchers are conducted, and how information is communicated during these encounters, b) To describe the experiences, views and support needs of families, recruiters and researchers in relation to study recruitment, c) To explore the views of potential recruiters and eligible families who decline to be involved in the studies, d) To explore the impact of recruitment practices on recruitment rate, potential bias in the sample and study findings, and relevant stakeholders (participants, recruiters and researchers), e) To assess sample bias due to non-invitation and non-participation of eligible families.

2. To provide a body of evidence for the research community to assist in: a) The design of studies, b) Applications to Research Ethics Committees, c) Reporting of recruitment in publications and conference presentations.

Methodology

Preliminary work:

a) We will conduct a systematic review of the literature to provide an overview of current invitation and recruitment practices of recently published research with children and young people with life-limiting conditions and life-threatening illnesses and their families. We focus on how practices impact recruitment and retention rates.

b) We will also conduct a national survey among principle investigators involved with research studies listed on the NIHR Portfolio, focusing on their perceptions and experiences of research. BRAVES project work: This will be a mixed methods project involving several work-streams.

Work-stream 1. The first work-stream involves the collection and analysis of qualitative and quantitative recruitment data from different study types, including qualitative and quantitative studies. Recruitment data will be compared (a) within each of the studies, (b) across the different studies, and (c) with published data from studies of recruitment to different study types.

Other work-streams:

Other work-streams will involve national surveys of:

1.Knowledge and attitudes of health care professionals, involved in research with CYP with LLC and LLI.

2. CYP with LLC and LLI and their parents with regard to the recruitment of CYP with LLC and LTI to different study types. 3.Societal views on recruitment of CYP with LLC and LTI and their families to research.

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:	Very early stages, currently working on a grant proposal to obtain external national funding.
Research project cover:	UK

No 131

Study Aim
Ketamine has been used anecdotally for the treatment of neuropathic pain in cancer, for approximately 20 years. However, to date, there has been limited evidence to support this due to a lack of robust clinical trials. The aim of the study is to assess if oral ketamine is useful in the treatment of neuropathic cancer pain.

Methodology
Design: A randomised, double blind trial of oral ketamine versus placebo. Following a period where current analgesia is optimised, patients will then be randomised (1:1) ratio to receive either ketamine or placebo. The trial will last for up to 6 weeks. 214 patients will be recruited to each arm. Population: Adult patients with neuropathic cancer pain. Intervention: Patients will receive oral ketamine and the dose will be titrated as per analgesic effect in consideration of any side-effects. Comparator: Patients will receive a placebo. Outcome: The primary outcome is assessment of neuropathic pain.

Organisation
Marie Curie Research

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Research is:	Multi centre
Research project is funded:	Cancer Research UK and Marie Curie
Research project cover:	UK

No 132

Study Aim

Controlling symptoms in the last year of life.

The aim of this study was to evaluate the feasibility and acceptability of a 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).

Professor Alex Molassiotis and Dr Janelle Yorke, 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.

Methodology

This was a non-blinded randomised controlled feasibility trial comprising of two groups: intervention group receiving respiratory distress symptom intervention and control group. The intervention was delivered in 2 hourly sessions delivered one week apart and a follow-up telephone call. Assessments were conducted at baseline, week 4 and week 12.

More information

The study has now completed is due to report. We have submitted a proposal for funding to NIHR Research for patient Benefit, January 2015 call.

Organisation

Marie Curie Research and University of Manchester

Contact details

Professor Alex Molasiotis, alex.molasiotis@polyu.edu.hk and Dr Janelle Yorke, Janelle.Yorke@manchester.ac.uk

Research is:	Multi centre
Research project cover:	Manchester and Liverpool

No 133

Study Aim

The overall aim of the study was to elicit the accounts of family carers who had witnessed the dying at home of an older person.

Professor Sheila Payne, Unpacking the home: family carers reflections on dying at home.

Methodology

Data in this qualitative study were collected through semi-structured interviews with 59 bereaved family members; participants were recruited via GP practices in the North West and South West of England. Two types of data analysis were undertaken; a cross-sectional thematic analysis using the principles of grounded theory, and a narrative analysis of a subset of 30 transcripts. A final phase of integration was then undertaken to offer insights from the findings and a critique of policies.

More information

Policy recommendations about support for family carers caring for dying older people at home:

• There needs to be a radical review of the way in which personal social care is provided, which includes the recruitment, training and support of care staff.

• The extent to which carers are affected by the dying process is individualised and can therefore be hard to anticipate; however, the needs of bereaved carers should be assessed properly.

• Training, monitoring and supervision are particularly important for staff working in home settings because of the invisibility of what goes on there.

Organisation

Marie Curie Research International Observatory on End of Life Care, Lancaster University, UK

Contact details

Professor Sheila Payne, s.a.payne@lancaster.ac.uk

Research is:	Multi centre
Research project is funded:	June 2011-May 2013
Research project cover:	South West and North West England

No 134

Study Aim

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

The study aimed to scope the experience, attitudes, and views of critical care health care professionals regarding the feasibility of transferring critical care patients home to die. The objectives for the study were to:

1. Investigate current experience of, practices related to, and views towards transferring critical care patients home to die.
2. Identify factors that enable or challenge service providers to transfer patients in this care setting home to die.
3. Scope the size and characteristics of the potential 'transferring patients home to die' critical care population.
4. Explore factors that might influence the feasibility of transferring critical care patients' home to die, including resources and infrastructure required.
5. Make recommendations on models of care/service specifications in this area.

Methodology

The study was carried out in 3 phases and used mixed methods.

Phase 1 - 6 focus groups carried out with: i) health care professionals from critical care, ii) health care professionals from community services, and iii) members of a patient and public forum and explored experiences of, and views and attitudes toward, transferring patients home to die from critical care settings. Following this a web-based survey was sent to lead consultants and nurses working in 409 critical care and high care units across the UK i) to establish level of transfer activity in UK ii) to identify how many critical care staff had direct experience of organising a transfer home from their unit, and iii) determine what attitudes, views and concerns. Individual telephone interviews were held with 21 doctors and nurses who had been actively involved in transfer/s, or had been involved in discussions about the possibility of transferring a patient home to die with the aim of identifying the practical issues that needed to be considered when providing this type of service.

Phase 2 - audit of medical records of 7,844 patients who were inpatients in 7 critical and high care units at two hospitals in the South of England over a one year period. The audit identified the number of patients who died on the units, and of these, how many patients (if certain criteria applied) could potentially have been offered the option of transfer home to die.

Phase 3 - a national Stakeholder Event of 85 representatives from professional organisations, critical and community care health care professionals, patients and relatives.

More information

This research culminated in the development of guidance to help clinical teams working with patients and their families to explore the potential to take someone home to die. The guidance was developed from the survey of critical care staff. 36% of those surveyed had some experience of transfer and the majority agreed it was a good idea in principal. The focus groups and interviews confirmed health professionals were very positive but highlighted several challenges. These included the needs of patients for particular types of care, responsiveness and availability of community services and uncertainty over how long the period would be between time withdrawal of treatment and to time of death – which could be anything from a few minutes to a few days. At the moment the transfer of patients home to die happens relatively infrequently. It is a complex and highly time dependent process.

The research confirmed healthcare professionals are committed to helping patients in critical care die at home, if this is their place of choice. Working with health professionals from critical care and community services across the UK a guideline has been developed that can help teams make decision about possible options for care at end of life and put the necessary arrangements in place for those whose last wish is to die at home.

See weblink for final report and links to papers published from the study:
http://www.southampton.ac.uk/healthsciences/research/projects/an_investigation_about_transferring_patients_in_critical_care_home.page?#overview

Organisation

University of Southampton

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Research is:	Multi centre
Research project is funded:	Marie Curie Cancer Care
Research project cover:	UK

No 135

Study Aim

To validate the Needs Assessment Tool-progressive Disease (NAT: PD) for use in people with Interstitial Lung Diseases (ILD).

Symptom control in the last year of life.

Professor Miriam Johnson, The adaptation and validation of an assessment tool to identify the palliative care needs of people with irreversible idiopathic interstitial lung disease for use in every day clinical practice.

Methodology

This is a psychometric testing and validation of a needs assessment tool (Face and content validity; inter-rater and test-retest reliability; construct validity).

Method - This is a three stage project:

Stage 1. Face validity testing of the NAT:PD-ILD and identification of barriers and facilitators to implementation.

A qualitative approach using focus groups (FG) with patients, carers and clinicians to review each aspect of the adapted NAT:PD-ILD for relevance and appropriateness. FG facilitators (N=2) will use the NAT:PD-ILD as a guide and at the end, we will compare and analyse the consensus regarding any necessary changes. The FG will be audio-recorded and transcribed. Cognitive mapping (Nvivo) will be used for clinicians FG and the Expert Group (the research team, a patient and a carer representative, two clinicians, one representative of each site – Hull, London and Manchester) will review and discuss the final changes of the tool.

Stage 2. Inter-rater and test-retest reliability.

This stage have two main steps:

1. Make videos. Ten videos will be made by clinicians from respiratory teams with ILD patients and carers, using the NAT:PD-ILD as a guide for the consult. The recorded consultations will last 15-20 minutes each to make the consultation as real as possible.

2. View the videos. Clinicians from all three sites (N=50) will be recruited to view 2 or 3 video consultations. A total of 100 viewings will be expected for reliable assessment of the NAT:PD-ILD inter-rater and test-retest.

For inter-rater and test-retest reliability, will use Cohen's Kappa statistic and Weighted kappa.

Stage 3. Construct validity.

Sixty-five participants will be recruited through the ILD clinics to do a consultation with ILD clinicians, based on NAT:PD-ILD tool. At the end of this consult, participants will be invited to fill "St George's Respiratory Questionnaire-IPF (SGRQ-I)" and the carers "Carer Strain Index" and "Carer Support Needs Assessment Tool". These questionnaires will allow the content validity, comparing the tools with Kendall's Tau-b correlation coefficient.

Dissemination conference.

A dissemination conference including clinicians and experts will take place to report the work completed on the NAT:PD-ILD in the general context of education and raising awareness of palliative care issues in ILD. Speakers will be members of the research team.

Organisation
Marie Curie Research

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Research is:	Multi centre
Research project is funded:	Marie Curie Cancer Care
Research project cover:	Hull and East Yorkshire

No 136

Study Aim
A systematic review of research papers exploring family carers' perceptions of their education needs when providing care at the end of life. The review included 35 research papers, reporting on the experiences of over 900 carers. The findings show that throughout the illness trajectory there were ways in which information and education were provided that facilitated carers in their caring role and others which acted as barriers. Commonly, carers experienced both as a patient's illness progressed.

Methodology
Synthesis of qualitative research using meta-ethnography.

Organisation
Department of Health Sciences, University of York

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Dr Kate Fleming, kate.flemming@york.ac.uk

Research is:	Single centre
Research project is funded:	Dimbleby Marie Curie Cancer Care Research Fund

No 137

Study Aim

The aim of the research was to identify how good practice in the involvement of volunteers in palliative care services which require direct contact with patients or their families can enable organisations to meet the challenges they face. Within this aim there were three specific objectives:

1. To identify good practice in the involvement, support and management of volunteers who provide direct patient and family support within palliative care.
2. To explore the impact of volunteers and volunteering on palliative care and the clinical outcomes for patients.
3. To identify ways of improving palliative care through the involvement of volunteers.

Methodology

The project included a narrative literature review (Morris et al, 2012 - http://eapcnet.wordpress.com/2013/05/24/researching-volunteering-in-hospices/); a survey of volunteer managers (n=191 of 290 UK adult palliative care organisations that involve volunteers, 67% response rate); and eleven in-depth organisational case studies selected through purposive diversity sampling criteria and involving 205 interviewees through in-depth primarily individual interviews with staff, volunteers, patients and relatives. The study began in 2012 and concluded in 2014. Survey data was subjected to descriptive and frequency analysis in SPSS 20. Case study data was transcribed and uploaded to Nvivo 10 and subject to systematic 'code and retrieve' analysis within and across cases.

Organisation

The Institute for Volunteering Research (at NCVO) and the International Observatory on End of Life Care (at Lancaster University)

Contact details

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Research is:	Multi centre
Research project is funded:	Dimbleby Cancer Care and Marie Curie Cancer Care Research Fund
Research project cover:	England

No 138

Study Aim

The use of volunteers to support end of life care.

How volunteers may improve end of life care: an evidence synthesis of qualitative and quantitative research and survey of current practice.

1. To collate and critique the international evidence on whether involving volunteers in the provision of palliative care makes a difference to patient and family wellbeing.
2. To collate and critique the qualitative evidence on the role of the volunteer, to undertake a thematic synthesis to explore how the role of the volunteer with direct contact with palliative care patients is understood by volunteers, patients, their families and staff.
3. To undertake a survey to describe current involvement of volunteers with direct patient/family contact in UK palliative care services.

Methodology

This study involved:

1. A narrative systematic review of qualitative and quantitative research.
2. A thematic synthesis of qualitative studies.
3. Cross-sectional surveys.

Organisation

Marie Curie Palliative Care Research Department, UCL Division of Psychiatry

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Research is:	Single centre
Research project is funded:	Dimbleby Marie Curie Cancer Care Research Fund grant DCMC-RF-11-02
Research project cover:	International literature and UK-wide surveys

No 145

Study Aim

To assess the clinical utility of the Gold Standards Framework Prognostic Indicator Guide (GSF) and the Seattle Heart Failure Model (SHF) to identify patients with chronic heart failure (CHF) in the last year of life.

Methodology

An observational cohort study of 138 community based ambulatory patients with New York Heart Association (NYHA) class III and IV CHF managed by a specialist heart failure nursing team followed up for 12 months from enrolment following baseline assessment using the Gold Standards Framework and the Seattle Heart Failure Prognostic Score.

More information

Neither the GSF nor the SHF accurately predicted which patients were in the last year of life. The poor prognostic ability of these models highlights one of the barriers to providing timely palliative care in CHF.

See published article : Haga et al, Heart

Organisation

NHS Lothian, Edinburgh Royal Infirmary

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

No 146

Study Aim

Identify patients with acute coronary syndrome (ACS) who survive hospitalisation and, at the time of hospital discharge, have an estimated prognosis of less than 12 months and who may therefore benefit from end of life care.

Methodology

172 unselected consecutive patients with confirmed ACS were assessed using the Gold Standards Framework (GSF) and the GRACE score at discharge and then followed up for 12 months for mortality and hospitalisation.

More information

GSF criteria identified 40 (23%) patients potentially suitable for end of life care while GRACE identified 32 (19%) patients with ≥ 10% risk of death within 6 months. Patients meeting GSF criteria were 3 times more likely to die during follow-up and the GRACE score was highly predictive of 12 month mortality. Each tool or a combination could be used to identify patients with ACS who have limited prognosis and who may benefit from end of life care.

Further details can be found in the published manuscript: Fenning et al, PLoS One. 2012;7(4):e35536. doi: 10.1371/journal.pone.0035536

Organisation

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

No 147

Study Aim
Liver disease is the third largest cause of premature death in the United Kingdom. The recent Lancet Commission report on improving liver care acknowledges the importance of both primary care and hospital services in providing high quality care for people with liver disease, but it does not directly address care issues that affect those who are dying of liver disease. At present, this care is poor and more studies are needed to understand how end of life (EoL) care for this group of patients can be improved.

Methodology
Rapid Participatory Appraisal – mixed methods incorporating case note audit, qualitative methods and health economics.

More information
Final stages of collecting data with patients and close family members. Data synthesis still ongoing.

Organisation
Marie Curie Palliative Care research Department (UCL) & Royal Free London NHS Foundation Trust

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Research is:	Single centre
Research project is funded:	Funding for the Research Department provided by Marie Curie Cancer Care.
Research project cover:	London (North)