



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:

Health and care professionals committed to partnership working

Summary research

No	Summary Research Aim	Organisation
3	Development of a clinical scoring system to support making for admission of children and young people to a paediatric intensive care unit.	University of York
8	The experiences, attitudes, population characteristics and practice of transferring patients in critical care home to die.	Faculty of Health Sciences, University of Southampton
11	How senior health care professionals recognise dying and engage patients and families to negotiate key decisions.	Heatherwood and Wexham Park NHS Foundation Trust
16	Evaluation of the progress and impact of a data sharing project in end of life care (Cambridgeshire EPaCCS).	University of Cambridge
26	Evaluation of a palliative care education intervention to improve and sustain participants' confidence and professional development in palliative care and translation to care delivery.	Princess Alice Hospice
31	Qualitative interviews with GPs, consultants, senior hospital and community nurses, chaplains and other allied health professionals that have experienced bereavement to explore the meaning of leadership in end of life care.	Chelsea & Westminster NHS Foundation Trust
33	Survey to develop a toolkit (CHOICE) to support staff in care homes in caring for patients at the end of life.	Chelsea & Westminster NHS Foundation Trust
40	To explore doctors' (non-specialist in palliative care) experiences of the Liverpool Care Pathway in hospital practice.	Central and North West London NHS Foundation Trust
41	To explore the learning needs of junior trainees in relation to end of life care and media attention.	Central and North West London NHS Foundation Trust
54	Literature search to develop a database of end of life care publications with type of evidence and linked where possible to the Priorities of Care.	Cochrane pain, Palliative and Supportive Care Group
59	OACC provides systematic and comprehensive outcome measurement and assessment of patients' concerns and quality improvement through capture and feedback of outcomes data.	Cicely Saunders Institute, King's College London
65	Fatigue in advanced cancer.	St George's NHS Trust
66	To describe the quality of life experienced by patients with stage 5 chronic kidney disease treated conservatively and to assess whether SF-36 is a useful tool in this population.	London North West Healthcare NHS Trust
67	What do health professionals and those important to the dying person consider to be elements of care that can be decided using a shared decision making process?	Mersey Deanery
69	Our team's interests include breathlessness and we will be devising a project shortly.	Cambridge University Hospitals NHS Foundation Trust
74	Exploring the triggers for holistic assessment for chronic obstructive pulmonary disease (COPD) patients and their carers.	Pilgrims Hospices in East Kent
76	Doctors' experiences of using the Liverpool Care Pathway in an acute hospital setting.	Palliative Medicine Trainee at West Midlands Deanery

No	Summary Research Aim	Organisation
77	To explore the effect of a pre-existing medical identity on the experience of training and working as an integrative psychotherapist and the effect of psychotherapy training on medical practice.	Marie Curie Hospice, Solihull
78	To determine the survival of patients referred to a UK hospital palliative care team and to identify prognostic factors.	Marie Curie Hospice, Solihull
99	The experience, attitudes, and views of critical care health care professionals regarding the feasibility of transferring critical care patients home to die.	University of Southampton, Faculty of Health Sciences
111	Assessing the impact of an end of life care educational programme for the care staff of a nursing home for people with dementia the end of life.	Jewish Care
114	To assess how the Gold Standards Framework quality improvement training programme for primary care teams, Going for Gold, improves outcomes in end of life care.	The Gold Standards Framework Centre CIC
126	Establishing an improved evidence base for care, during these final hours or days, across a range of conditions.	Marie Curie Research
127	To examine factors associated with place of care and place of death in patients with haematological malignancies.	Marie Curie Research; Epidemiology and Cancer Statistics Group, University of York; Leukaemia and Lymphoma Research
128	To determine how best to include individuals near to death in research on EoL care by identifying solutions and developing best practice guidance on processes of consent adults lacking capacity.	Marie Curie Cancer Care UK
139	Initiating end of life care in stroke: clinical decision-making around prognosis.	Bangor University
148	To develop and evaluate the feasibility of a short-term integrated palliative care service for frail older people in community settings delivered through integrated working between specialist palliative care and primary care teams.	King's College London
154	To assess how the Gold Standards Framework quality improvement training programme for care homes improves outcomes in end of life care.	The Gold Standards Framework Centre CIC
155	To assess how the Gold Standards Framework quality improvement training programmes for acute and community hospitals improves outcomes in end of life care.	The Gold Standards Framework Centre CIC

Full research

No 3

Study Aim
Children and young people with life-limiting conditions (LLC) and hospital admissions to paediatric intensive care units (PICU) in England; the development of a clinical scoring system.

Methodology
This is a research project which will utilise data linkage and quantitative data analysis techniques to exploit routinely collected NHS datasets to develop a clinical scoring system that will assist with making decisions about the appropriateness of admitting a child with LLC to a PICU.

Organisation
University of York

Contact details
Dr Lorna Fraser, lorna.fraser@york.ac.uk

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

No 8

Study Aim

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

Methodology

Mixed methods.

More information

This is the most recent study in a programme of work looking at dying in critical care environments.

Organisation

Faculty of Health Sciences, University of Southampton

Contact details

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

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

No 11

Study Aim

How senior health care professionals recognise dying and engage patients and families to negotiate key decisions to improve the patient and carer experience. Participatory action-research explored as a means to develop clinical practice. <http://www.bath.ac.uk/cdas/people/students/joanne-wilson/>

Methodology

Participatory action research.

Organisation

Heatherwood and Wexham Park NHS Foundation Trust

Contact details

Jo Wilson, jo.wilson@hwph-tr.nhs.uk

Research is:	Single centre
Research project is funded:	Personal study - PhD
Research project cover:	Acute Hospital

No 16

Study Aim

Prepared to Share is an evaluation and research study accompanying the Cambridgeshire and Peterborough Clinical Commissioning Group Project on Data Sharing in End of Life Care (the Cambridgeshire EPaCCS). The service development project started in July 2012 and went live in Feb 2014. The study (2013-2015) aims to evaluate the project progress and its impact, while positioning the evaluation in research on broader questions on attitudes to data sharing, Electronic Palliative Care Co-ordination Systems (EPaCCS) and implementation of health information technology (HIT).

Methodology

Mixed methods study: survey to GPs and Practice Managers; interviews with a broad range of stakeholders (GPs, patients, carers, hospital and hospice staff, district nurses, practice managers, commissioners, etc.); observations; document analysis; analysis of Dashboard data (routine data on use of the service).

Organisation

University of Cambridge

Contact details

Dr Mila Petrova, mp686@medschl.cam.ac.uk

Research is:	Single centre
Research project is funded:	National funding schemes with local contribution and management: Health Innovation and Education Cluster funding administered by Cambridge University Health Partners and NIHR CLAHRC for East of England
Research project cover:	England - Midlands and East

No 26

Study Aim

Can a palliative care education intervention improve and sustain participants' confidence and professional development in palliative care and does this translate to care delivery?

Methodology

Survey and semi-structured interview of sub-sample.

More information

Currently collecting data with the aim of study completion the end of 2015.

Organisation

Princess Alice Hospice

Contact details

Liz Reed, lizreed@pah.org.uk

Research is:	Multi centre
Research project is funded:	Local
Research project cover:	England - Midlands and East, London, Scotland, Ireland

No 31

Study Aim

The study funded through an NIHR CLAHRC Fellowship is exploring the meaning of leadership in end of life care outside the specialist setting.

Methodology

Focus group with people who have experienced bereavement. Interviews with GPs, Consultants, Senior hospital and community nurses, Chaplains and other Allied Health Professionals.

Organisation

Chelsea & Westminster NHS Foundation Trust

Contact details

Dr Barry Quinn, barry.quinn@chelwest.nhs.uk

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

No 33

Study Aim

Part of a research group working with the University of Surrey to develop a toolkit (CHOICE) to support staff in care homes in caring for patients at the end of life.
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Methodology

Focus groups. Questionnaires.

Organisation

Chelsea & Westminster NHS Foundation Trust
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Contact details

Dr Barry Quinn, barry.quinn@chelwest.nhs.uk
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Research is:	Multi centre
Research project is funded:	Local
Research project cover:	England - South

No 40

Study Aim

To understand doctors experiences of the LCP in practice - non-specialists in Palliative Care in hospitals.

Methodology

Qualitative.

More information

I am supervising a masters student to complete this project.

Organisation

Central and North West London NHS Foundation Trust

Contact details

Sarah Yardley, sarahyardley@nhs.net

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

No 41

Study Aim

Junior trainees learning needs in relation to end of life care and media attention.

Methodology

Qualitative.

More information

I am supervising a masters student in this project.

Organisation

Central and North West London NHS Foundation Trust

Contact details

Sarah Yardley, sarahyardley@nhs.net

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

No 54

Study Aim

Database of publications in end of life care.

Methodology

Detailed search of main databases - Medline, Embase and Cochrane Library. Assembled into a database and annotated with type of evidence and linked where possible to the Priorities of care.

More information

Due to complete in spring 2015 and will be available online.

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:	Not restricted geographically

No 59

Study Aim

Introduction:

Patient-reported outcome measurement are considered the best way to actively engage patients in assessing the care they are receiving. This Outcome Assessment and Complexity Collaborative (OACC) intends to fill the gap in palliative care outcome measurement in England to help demonstrate and improve the quality of palliative care services.

Aim and objectives of proposed collaborative:

This project aims to transform palliative care for patients and families in South East London by implementing routine outcome measurement to systematically inform and improve quality of palliative care services. OACC provides systematic and comprehensive outcome measurement and assessment of patients' concerns and quality improvement through capture and feedback of outcomes data.

Our specific objectives are to:

1. Agree and refine suitable outcome measures for routine use in palliative care.
2. Develop and implement staff training to support the implementation of these outcome measures.
3. Integrate health information technology to establish practicable and workable ways of capturing and processing data and delivering outputs.
4. Collect pre-defined outcomes on all palliative care patients: a) in the acute sector, across four hospital sites, b) in the community sector, across community palliative care teams, c) in the inpatient hospice setting.
5. Provide regular feedback of results to these teams, using Quality Improvement Facilitators, in order to directly improve patient and family care.

Methodology

This is a service development and implementation project, with embedded research which uses mixed methods to determine and explore which components of the implementation of outcome measures into palliative care work and how/why components work or don't work.

Organisation

Cicely Saunders Institute, King's College London

Contact details

Dr Fliss Murtagh, fliss.murtagh@kcl.ac.uk

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

No 65

Study Aim

Proposal only as part of HTA call - fatigue in advanced cancer.

Methodology

RCT.

More information

Under review for funding only. No currently funded projects.

Organisation

St George's NHS Trust

Contact details

Ollie Minton, ominton@sgul.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 66

Study Aim

The aim of my research project is to describe the quality of life (QoL) experienced by patients with stage 5 chronic kidney disease treated conservatively (without dialysis) as measured using the SF-36 instrument, its change over time, and its relationship to symptoms and other demographic and clinical factors. A second aim is to assess whether SF-36 is a useful tool in this population.

Methodology

This is a secondary data analysis. The primary data were collected prospectively and longitudinally (by Dr F Murtagh) from patients with stage 5 CKD who had opted for conservative management in one of 3 UK renal units. Data consisted of self-completed questionnaires covering symptoms and other concerns, demographic and clinical data. QoL was assessed using the SF-36 tool. In the current study, some psychometric properties of SF-36 in this unique population are being explored. Changes in QoL over time are described and quantified, and interpreted in the context of clinical meaningfulness. Correlations between QoL, symptoms and other concerns are also being explored.

More information

This is undertaken as part of MSc in Palliative Care (King's College London).

Organisation

London North West Healthcare NHS Trust

Contact details

Dr Gilli Erez, erezgilli@gmail.com

Research is:	Single centre
Research project is funded:	Privately funded as part of MSc
Research project cover:	England - London

No 67

Study Aim

What do health professionals and those important to the dying person consider to be elements of care that can be decided using a shared decision making process?

Methodology

Qualitative semi structured interviews.

More information

In preliminary phase.

Organisation

Mersey Deanery

Contact details

Andrew Khodabukus, andrew.khodabukus@nhs.net

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

No 69

Study Aim

I have just (1 month ago) started an academic clinical fellowship at ST3 level in palliative care, I will be starting my first research project in the next few months. Our team's interests include breathlessness and we will be devising a project shortly.

Methodology

Unsure yet - possibly mixed methods to include both qualitative and quantitative data.

Organisation

Cambridge University Hospitals NHS Foundation Trust

Contact details

Chloe Chin, chloe.chin@addenbrookes.nhs.uk

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

No 74

Study Aim

Chronic Obstructive Pulmonary Disease (COPD) PhD project. This study explored what the triggers for holistic assessment are for COPD patients and their carers. The findings have now been written up and published in a peer reviewed journal and presented at conferences. Further publication potentially to follow.

Methodology

21 patients and nine carers were recruited for interview to describe their experiences of holistic assessment and to explore the concept of triggers to facilitate this.

Organisation

Pilgrims Hospices in East Kent

Contact details

Dr Declan Cawley, Declan.cawley@pilgrimshospices.org

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

No 76

Study Aim

Working title:

'How do doctors experiences of the Liverpool Care Pathway influence their understanding and conceptualisation of its purpose? A qualitative exploration of views within an acute hospital'.

Aim of the research:

To gain a greater depth of understanding of doctors' experiences of using the LCP in an acute hospital setting and to link these experiences, and other factors, to the doctors' perceptions and conceptualisation of the LCP.

Methodology

Qualitative Research. Semi-structured interviews with doctors. Thematic analysis.

More information

Justification of relevance. Although the LCP has now been formally withdrawn from clinical practice in the UK the value of this research is not lessened, indeed rather it is essential at this point of flux in end of life care provision that well conducted research is undertaken.

Organisation

Palliative Medicine Trainee at West Midlands Deanery

Contact details

Dr Sharon Twigger, sharon.twigger@nhs.net

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

No 77

Study Aim

Background:

Medical identity is formed intrapsychically and intrapersonally during training. Maintaining empathy in students and doctors in senior years is challenging. Empathy loss and use of defences may cause stress and isolation. Palliative care doctors become involved with patients and relatives more than other specialties. Integration of psychotherapy theory with medical knowledge has demonstrable benefits.

1,2 Aims:

To explore the effect of a pre-existing medical identity on the experience of training and working as an integrative psychotherapist and the effect of psychotherapy training on medical practice.

Methodology

Methods: Interpretative Phenomenological Analysis (IPA) explores daily events given meaning. The hermeneutic uses reflection and cyclical bracketing allowing preconceptions to rise to consciousness. As analysis arises from within the text, it is a robust method for working with identity. IPA has an ideographic base so the method supports small sample size research. Four medical consultants who also worked as integrative therapists, (2 palliative medicine, 1 haematology, 1 diabetes and endocrinology) gave 90 minute semi-structured interviews. Ethical code and confidentiality followed the practice of UKCP. Interviews transcribed with prosodic information were analysed line by line demonstrating emergent patterns. Data coding linked themes into super-ordinate groups. Supervision and collegial interaction encouraged reflexivity.

More information

It is closed now.

Organisation

Marie Curie Hospice, Solihull

Contact details

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

Research is:	Single centre
Research project is funded:	None
Research project cover:	England - North, Midlands and East, South, London

No 78

Study Aim

Background: Predicting the survival of terminally ill patients accurately is important as it facilitates clinical decision making and may avoid patients choosing invasive, active treatments and thereby a hospital death.

Aim: To determine the survival of patients referred to a UK hospital palliative care team and to identify prognostic factors.

Methodology

Methods: Consecutive patients referred to the hospital palliative care team were assessed and discussed at a weekly multi-disciplinary meeting. Demographic data, diagnostic information, Karnofsky performance score (KPS), clinical prediction of survival (CPS) and length of time between admission to hospital and clinical assessment were recorded and later compared with actual survival.

Organisation

Marie Curie Hospice, Solihull

Contact details

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

Research is:	Single centre
Research project is funded:	None
Research project cover:	England - Midlands and East

No 99

Study Aim

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

Qualitative (focus groups, interviews) and quantitative (survey, audit).

Organisation

University of Southampton, Faculty of Health Sciences

Contact details

Anne-Sophie Darlington, a.darlington@soton.ac.uk

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

No 111

Study Aim

The study carried out 2009 - 2012 looked at improving the areas below through an educational programme regarding end of life care for the care staff of a nursing home for people with dementia. Particularly: the end of life experience/quality of life of the person with dementia at end of life, the experience and quality of life of their relative, the quality of life and stress levels of staff providing the care.

Methodology

The Study used quantitative measures of quality of life and stress as well as qualitative data gained through semi structured interviews with relatives and staff and a small number of residents who were able to participate.

More information

The research resulted in a change of care culture and practice and had a direct impact on the experience of end of life/end of life care on all those involved. We are currently exploring further research opportunities to build on this study and expand the learning.

Organisation

Jewish Care

Contact details

Gaby Wills, gwills@jcare.org

Research is:	Single centre
Research project is funded:	King's Fund
Research project cover:	England - London

No 114

Study Aim

To assess how the Gold Standards Framework quality improvement training programme for **primary care teams**, Going for Gold, improves outcomes in end of life care.

Methodology

Multiple methodology. Quantative: comparative before and after evaluations of key outcome measures, comparative audits, after death/discharge analysis, organisational questionnaire, staff surveys. Qualitative: portfolio of evidence and interviews with staff to assess depth of adoption.

More information

GSF has a summary of evaluations in primary care, care homes and hospitals available on the website or on demand. Plus an Evidence Summary (<http://www.goldstandardsframework.org.uk/evidence>) of current independent peer reviewed published or grey literature.

Organisation

The Gold Standards Framework Centre CIC

Contact details

Prof Keri Thomas, Keri.thomas@gsfcentre.co.uk

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

No 126

Study Aim
Establishing an improved evidence base for care, during these final hours or days, across a range of conditions. Professor Jane Seymour, Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life; a prospective community based case study using mixed methods.

Methodology

Organisation
Marie Curie Research

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

No 127

Study Aim

Among patients with haematological malignancies, the study aims to:

1. Examine preferred place of death.
2. Examine factors associated with actual place of death (demographic, diagnostic etc.).
3. Identify changes that could be made to practice to enable patients to die in their preferred place.

Methodology

The study is set within the infrastructure of the Haematological Malignancy Research Network (www.hmrn.org), which registers all patients newly diagnosed with a haematological malignancy across 14 hospitals in the Yorkshire and Humber area. There are two methodological strands to this project:

- 1) Abstraction of over the hospital records of all HMRN patients (registered since this study began in September 2004), that died between 1st September 2011 and 31st August 2012 (n=1132).
- 2) Qualitative interviews with patients, relatives and clinical staff including palliative care and haematology practitioners (n=59).

More information

Data collection has now finished for this study and data analysis and write-up is now in progress.

Organisation

Marie Curie Research; Epidemiology and Cancer Statistics Group, University of York; Leukaemia and Lymphoma Research

Contact details

Dr Debra Howell, debra.howell@york.ac.uk

Research is:	Multi centre
Research project is funded:	Marie Curie Cancer Care
Research project cover:	Fourteen hospitals across Yorkshire and Humberside

No 128

Study Aim

To determine how best to include individuals near to death in research on end of life care by identifying solutions and developing best practice guidance on processes of consent for people with impaired mental capacity.

Methodology

Observational study design using systematic review and consensus methods. The study used three simultaneous research methods of systematic literature appraisal with grey literature survey; Transparent Expert Consultation (TEC) using consensus methods of nominal group to generate recommends and consensus survey to prioritise; and an expert think-tank workshop to explore areas of contention/uncertainty.

More information

MORECare Capacity developed the guidance on processes of consent for adults lacking capacity in research on palliative and end of life care. The guidance is an addendum to the MORECare Statement on best practice solutions to developing and evaluating complex interventions in palliative and end of life care.

Reference: Higginson IJ, Evans CJ, Grande G, et al. Evaluating complex interventions in End of Life Care: the MORECare Statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. BMC Med. 2013; 11 DOI: 10.1186/1741-7015-11-111.

Organisation

Marie Curie Cancer Care UK

Contact details

Dr Catherine Evans, catherine.evans@kcl.ac.uk

Research is:	Single centre
Research project is funded:	Marie Curie Cancer Care UK

No 139

Study Aim

This study aims to address the following research questions:

1. What is/are the trajectories of dying in the acute stroke phase?
2. What are patients' and family members' experiences of the initiation of end of life care within acute stroke?
3. How do clinicians draw on the different types of prognostic, clinical and other information sources used in making decisions about initiating end of life care in acute stroke?

Methodology

The research uses a two-phased, mixed methods design.

Phase 1 is an observational patient tracking study to identify dying trajectories, with interviews of a sub-sample of patients and/or carers and bereaved carers to explore views about the initiation of end of life care.

Phase 2 uses clinical scenarios in a 'Think aloud exercise', a standard method in decision-making research, to examine prognostic and other information, and cognitive processes that staff use when making judgements or decisions. Participants are also interviewed to explore how they make decisions about initiating end of life care, and the information that they think they use.

Organisation

Bangor University

Contact details

Dr Chris Burton, c.burton@bangor.ac.uk

Research is:	Multi centre
Research project is funded:	Funded by Marie Curie Cancer Care
Research project cover:	North Wales, North West England, West Wales, West Midlands

No 148

Study Aim

People are living longer and dying increasingly with frailty and complex co-morbidities. Many suffer unnecessarily because of limited recognition of palliative care needs, aggressive management and under treatment. Palliative care is advocated for frail older people with non-malignant conditions to improve assessment and treatment, but with little evidence of effectiveness. This study aims to work with NHS staff in a community trust to develop and evaluate a new short-term integrated palliative and supportive care (SIPS) service for frail older people with non-malignant conditions living at home or in a care home and their families. Short-term palliative care could be effective as it relies on existing services with additional support at times of actual or anticipated deterioration in wellbeing.

Methodology

The research methods follow the Medical Research Council guidance for the development and evaluation of complex interventions.

Phase 1a intervention development involves a post-bereavement survey to determine preferences for care and palliative care outcomes by place of death for older people (n=882); and phase 1b a stakeholder consultation with recipients of care and service providers/ commissioners, on the survey findings to develop the intervention and then, an on-line/postal survey on the proposed components and outcomes.

Phase 2 is a feasibility trial to develop procedures for a full randomised controlled trial and refine a model of integrated professional working. Phase 2 involves 52 older people randomised to receive short-term integrated palliative and supportive care (SIPS) or usual care. The primary outcome is symptom burden for five key palliative symptoms (breathlessness, anxiety/depression, constipation, pain and fatigue) from the Integrated Palliative Outcome Scale symptom component (I-POS), secondary outcomes: palliative outcomes (I-POS), survival, attainment of preferred place of death, carer burden (Carer Zarit Burden Interview), and economic evaluation (Client Service Receipt Inventory). Nested qualitative studies examine recipients' experiences of the intervention (patients/carers n=18) and service providers/commissioners experiences of delivering (n=40).

More information

This is a joint study between King's College London and Sussex Community NHS Trust.

Phase 1a and 1b are complete and in write up, phase 2 – comparative feasibility trial- opened in September 2014. Study completion date November 2015. The study is overseen by a: Steering Group comprising the applicants, researchers and invited members; and an Independent Project Advisory Group comprising eight lay members who have worked with us since protocol development through to study implementation and continue into dissemination.

Organisation

King's College London

Contact details

Dr Dr Catherine Evans, catherine.evans@kcl.ac.uk

Research is:	Single centre
Research project is funded:	National
Research project cover:	Brighton & Hove and West Sussex

No 154

Study Aim

To assess how the Gold Standards Framework quality improvement training programme for **care homes** improves outcomes in end of life care.

Methodology

Multiple methodology. Quantative: comparative before and after evaluations of key outcome measures, comparative audits, after death/discharge analysis, organisational questionnaire, staff surveys, feedback from carers/relatives. Qualitative: portfolio of evidence and interviews with staff to assess depth of adoption.

More information

GSF has a summary of Evaluations in care homes available on the website or on demand. Plus an evidence summary (<http://www.goldstandardsframework.org.uk/evidence>) of current independent peer reviewed published or grey literature.

Organisation

The Gold Standards Framework Centre CIC

Contact details

Prof Keri Thomas, Keri.thomas@gsfcentre.co.uk

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

No 155

Study Aim

To assess how the Gold Standards Framework quality improvement training programmes for **acute and community hospitals** improves outcomes in end of life care.

Methodology

Quantative: comparative before and after evaluations of key outcome measures, comparative audits, after death/discharge analysis, organisational questionnaire, staff surveys, feedback from carers/relatives. Qualitative: portfolio of evidence and interviews with staff to assess depth of adoption.

More information

GSF has a summary of evaluations in hospitals available on the website or on demand. Plus an evidence summary (<http://www.goldstandardsframework.org.uk/evidence>) of current independent peer reviewed published or grey literature.

Organisation

The Gold Standards Framework Centre CIC

Contact details

Prof Keri Thomas, Keri.thomas@gsfcentre.co.uk

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