



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:

Person-centred coordinated care

Summary research

No	Summary Research Aim	Organisation
1	Qualitative study to explore palliative care needs and experiences of black and minority ethnic (BME) groups in Kent.	University of Greenwich
10	Understanding complexity, patient experience and organisational behaviour for long-term life-limiting conditions at end of life.	Faculty of Health Sciences, University of Southampton
13	Investigating the views of people with incurable lung cancer and advanced chronic obstructive pulmonary disease, their lay and professional carers.	University of Cambridge
14	Primary care study investigating community care pathways at the end of life.	University of Cambridge
18	The characteristics, needs, experiences and outcomes of patients diagnosed with lung cancer on emergency admission to hospital.	University of Nottingham
24	Exploration of end of life care for frail older people in an acute hospital setting, with a particular focus on whether care differed for patients with and without dementia.	University of Nottingham
32	Exploring the Lived Experience of People with Cancer and Advanced Disease.	Chelsea & Westminster NHS Foundation Trust
34	The experiences and multi-dimensional needs of people with major stroke.	University of Edinburgh
37	Spirituality as a proxy for religion in hospice care.	Goldsmiths, University of London
45	Observational study of care home residents' preferred place of care/preferred place of death.	Royal Surrey County Hospital NHS Foundation Trust
57	FLAME is a clinical trial testing whether future care planning is acceptable, feasible and deliverable to patients with advanced heart disease caused by heart failure, valvular heart disease and coronary heart disease.	NHS Lothian, Edinburgh Royal Infirmary
63	A qualitative study to evaluate the experiences of patients living with cancer associated thrombosis (PELICAN).	Cardiff University
70	A palliative care approach for people with advanced heart failure: recognition of need, transitions in care and impact on patients, family carers and clinicians.	Hull York Medical School
87	The barriers and enablers to access to palliative care for people with chronic obstructive pulmonary disease (COPD).	Birmingham St Marys Hospice
88	The effectiveness of the Patient Dignity Question on improving person-centred care for people with palliative needs being cared for in an acute hospital setting.	University of Nottingham
92	To explore the dynamic physical, psychosocial, existential and information needs of patients living and dying with advanced liver disease and their lay and professional carers.	University of Edinburgh
96	To examine how people with advanced cancer use coping strategies to regain or maintain psychological wellbeing.	Lancaster University
100	Developing and clinimetrically testing a palliative screening tool for Parkinson's disease.	Hull York Medical School
101	Understanding the felt meaning of the relationship between self and cancer during post-treatment cancer survivorship.	St Luke's Hospice

No	Summary Research Aim	Organisation
106	Exploring appropriate and inappropriate prescribing at end of life for people with Dementia.	Hull York Medical School, University of Hull
109	Comparison of hospital utilisation in the last 12 months of life by ethnic group.	Nuffield Trust
129	ACCESSCare: Advanced Cancer Care Equality Strategy for Sexual Minorities – improving the care of lesbian, gay, bisexual and/or trans* people facing the later stages of a life-limiting illness.	King's College London
130	Exploring variation in care at the end of life: The Last Outing: exploring end of life experiences and care needs in the lives of older lesbian, gay, bisexual and trans people.	University of Nottingham / Marie Curie Research
140	Using action research to improve end of life care for prisoners.	Lancaster University
141	To investigate the use of metaphors by members of different stakeholder groups regarding their experiences, attitudes and expectations of end of life care.	Lancaster University
142	To develop a support garment for people with ascites.	Lancaster University
143	To provide new evidence on the trajectory of health and social care needs and preferences (and whether these change) of patients with advanced chronic obstructive pulmonary disease (COPD) and their informal carers, to inform clinical practice.	University of Cambridge (in collaboration with King's College London, RAND Europe, Cambridgeshire University Hospitals' NHS Foundation Trust, Cambridgeshire Community Services, & University of Manchester)
151	Evaluation of the clinical and cost-effectiveness of Short-term Integrated Palliative Care Services (SIPC) to OPTimise CARE for people with advanced long-term Neurological conditions.	Cicely Saunders Institute, King's College London
153	To use qualitative and quantitative data from multiple sources to develop a feasible and acceptable intervention to improve care for those with advanced dementia who are approaching death and to test the new model in practice.	Marie Curie Palliative Care Research Department, University College London

Full research

No 1

Study Aim
To examine end of life practices among black and minority ethnic (BME) groups in Kent and to explore their experiences of palliative care and identification of unmet need.

Methodology
Qualitative in depth interviews and focus groups.

More information
Data collection is currently underway and we hope to complete the project in March 2015.

Organisation
University of Greenwich

Contact details
Dr David M Smith, sd50@gre.ac.uk; Dr Carlos Moreno Leguizamon C.J.Moreno@greenwich.ac.uk

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

No 10

Study Aim

I lead the Complexity, Patient Experience and Organisational Behaviour research programme in NIHR Wessex CLAHRC. This focuses on experiences of long-term life-limiting conditions at end of life.

Methodology

We will use systematic reviews, qualitative research methods, participatory co-design, survey methods, agent based modelling, systems dynamic modelling, and cluster randomised trials. This work is underpinned by Normalization Process Theory and Burden of Treatment Theory.

Organisation

Faculty of Health Sciences, University of Southampton

Contact details

Carl May, c.r.may@soton.ac.uk

Research is:	Multi centre
Research project is funded:	NIHR CLAHRC Wessex
Research project cover:	England - South

No 13

Study Aim

A study of people with incurable lung cancer and advanced chronic obstructive pulmonary disease, their lay and professional carers, investigating their views of:

1. The existence and nature of their transition (if any) from chronic illness to palliative and end of life care.
2. Their care, support and information needs at this stage of illness.
3. The aspects of care they regard as key markers of high quality care at this stage of illness.

Methodology

Lung cancer patients are recruited from hospital clinics, with COPD patients from the same GP practice. Clusters consist of: lung cancer patient, their lay supporter and nurse; COPD patient, their lay supporter and nurse; a GP who knows both patients. Ten complete and four partial clusters recruited. Semi-structured interviews with each cluster member, supported by the use of PICTOR charts.

More information

Data collection and analysis are now complete. There are significant differences and similarities in the support needs of lung cancer and COPD patients that are of great relevance to national end of life care policy.

Organisation

University of Cambridge

Contact details

Dr Stephen Barclay, sigb2@medschl.cam.ac.uk

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

No 14

Study Aim

The CAPE study investigates palliative and end of life care in primary care, with three main research questions:

1. For whom is home death 'good'.
2. For whom is home death not 'good'.
3. What is needed to optimise both of these options to provide best care according to the needs of the patient.

Methodology

Multi-method four phase study.

Phase 1: Characterising pathways of care provision in the last twelve months of life. Summarising care received by 400 deceased patients (20 patients from 20 practices) by extracting data from GP and District Nurse records.

Phase 2: Case discussion groups in 10 participating practices, generating greater information of five patients in each practice.

Phase 3: GP, District Nurse and bereaved carer interviews in 10 participating practices concerning one cancer and one non-cancer deceased patient.

Phase 4: Developing a toolkit to optimise care based on the first three phases.

More information

Phases 1 and 2 now complete: a unique dataset on primary care end of life care provision for 400 patients in the last 6 months of their lives.

Phase 3 will be complete by April 2015.

Organisation

University of Cambridge

Contact details

Dr Stephen Barclay, sigb2@medschl.cam.ac.uk

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

No 18

Study Aim

What are the characteristics, needs, experiences and outcomes of patients diagnosed with lung cancer on emergency admission to hospital?

Methodology

This is a single centre study with quantitative and qualitative work packages (WP).

WP1 gathers basic details about all patients diagnosed with lung cancer during a 12 month period, focusing on demographics, diagnostic and treatment pathways and selected outcomes.

WP2 obtains information from those patients DFEA or, when unable, their carers, about their holistic needs and experiences, using the Sheffield Profile for Assessment and Referral to Care questionnaire and selected questions from the National Cancer Patient Experience Survey. WP3 uses in-depth qualitative interviews with patients and carers to obtain detailed accounts of their symptoms, help seeking behaviours prior to admission and subsequent experiences of care.

More information

We have papers under review.

Organisation

University of Nottingham

Contact details

Andrew Wilcock, andrew.wilcock@nottingham.ac.uk; Jane Seymour, jane.seymour@nottingham.ac.uk

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

No 24

Study Aim

Caring for frail or seriously ill older people on acute hospital wards. The study explored end of life care for frail older people in an acute hospital setting, with a particular focus on whether care differed for patients with and without dementia.

Methodology

Qualitative study involving extensive ward observation, interviews with ward staff and bereaved carers, review of medical records of deceased patients, construction of patient cases.

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 32

Study Aim

The Project of Sense Making as Part of Illness: Exploring the Lived Experience of People with Cancer and Advanced Disease. Doctoral Thesis. King's College, London.

Methodology

In depth interviews using a phenomenological approach.

Organisation

Chelsea & Westminster NHS Foundation Trust

Contact details

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

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

No 34

Study Aim

Understanding the experiences and multi-dimensional needs of people with major stroke. Aim: to understand if there are any unmet needs for palliative care in patients with severe stroke, and how to improve the quality of their life and dying.

Methodology

Mixed methods. Primarily serial in-depth qualitative interviews with patients, their family carers, and their key health and social care professionals over the twelve months following the stroke.

Organisation

University of Edinburgh

Contact details

Marilyn Kendall, Marilyn.Kendall@ed.ac.uk

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

No 37

Study Aim
Spirituality as a proxy for religion in hospice care.

Methodology
Qualitative Interviewing.

Organisation
Goldsmiths, University of London

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

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

No 45

Study Aim

Observational study of care home residents' preferred place of care/preferred place of death.

Methodology

Observational study (quantitative; questionnaire).

More information

Study in set up.

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
Research project cover:	England - South, London

No 57

Study Aim

FLAME is a clinical trial testing whether future care planning is acceptable, feasible and deliverable to patients with advanced heart disease caused by heart failure, valvular heart disease and coronary heart disease.

Methodology

The patient, and their nominated informal carer, are offered 'extra supportive care' from a consultant cardiologist and specialist cardiac nurse for a period of 12 weeks following discharge from hospital. This extra supportive also includes three 1 hour interviews at 6 weekly intervals during which the patient and their family are able to discuss a broad range of topics about their condition, their treatment and their expectations for the future. The patient and family members develop a joint care plan with the research team which includes what they will do if their health condition worsens at some point in the future. Various questionnaires are being used to assess the impact of the extra care on the quality of life of patients and their family.

More information

There has been a great deal of interest in the study from the cardiology, palliative care and general medicine community. While it is a relatively small trial, it addresses a very important issue and the findings will represent the first attempt to use a randomised trial approach for end of life care in acute cardiology patients. Baseline findings and detailed design of the study can be found in Denvir et al, BMJ Open. 2014 Jul 14;4(7):e005021. doi: 10.1136/bmjopen-2014-005021

Organisation

NHS Lothian, Edinburgh Royal Infirmary

Contact details

Dr Martin Denvir, martin.denvir@ed.ac.uk

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

No 63

Study Aim

A qualitative study to evaluate the experiences of patients living with cancer associated thrombosis (PELICAN).

Methodology

Qualitative interviews with framework analysis.

Organisation

Cardiff University

Contact details

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

Research is:	Multi centre
Research project is funded:	Pharma Investigator Initiated Research Project
Research project cover:	UK, France, Germany, Spain, Saudi, Jordan, Kuwait, Canada

No 70

Study Aim

A palliative care approach for people with advanced heart failure: recognition of need, transitions in care and impact on patients, family carers and clinicians.

Methodology

Mixed methods: systematic literature review; secondary analysis of contemporaneous collected data from a national GP database (CPRD); qualitative data (patients, family carers and health care professionals and focus groups with health care professionals).

Organisation

Hull York Medical School

Contact details

Dr Amy Gadoud, amy.gadoud@hyms.ac.uk

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

No 87

Study Aim

What are the barriers and enablers to access to palliative care for people with chronic obstructive pulmonary disease (COPD).

Methodology

Mixed methods. Focus groups with Respiratory teams an GP/DN, recruited on twitter and conducted online. Followed by survey recruited from twitter.

More information

Still current not yet published.

Organisation

Birmingham St Marys Hospice

Contact details

Sharon Hudson, Sharonfhudson@gmail.com

Research is:	Multi centre
Research project is funded:	NIHR funded MRES
Research project cover:	UK

No 88

Study Aim

The aim of this study is to explore the effectiveness of the Patient Dignity Question on improving person-centred care for people with palliative needs being cared for in an acute hospital setting.

Methodology

Mixed method before and after design. Data was collected using standard outcome measures; collection of standard demographic measures qualitative interviews.

Organisation

University of Nottingham

Contact details

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

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

No 92

Study Aim

Study title: Living, dying and caring in advanced liver disease: the challenge of uncertainty.

Study aim: To broaden our understanding of the experience of living and dying with advanced liver disease. Specifically, to explore the dynamic physical, psychosocial, existential and information needs of patients and their lay and professional carers, and to review their use of health, social and voluntary services.

Methodology

Qualitative, multi-perspective, serial in-depth interviews with patients, lay carers and healthcare professionals.

Organisation

University of Edinburgh

Contact details

Barbara Kimbell, b.kimbell@sms.ed.ac.uk

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

No 96

Study Aim

To examine how people with advanced cancer use coping strategies to regain or maintain psychological wellbeing.

Methodology

Qualitative, face to face interviews with patients and family carers.

More information

Study recently completed - in dissemination phase.

Organisation

Lancaster University

Contact details

Catherine Walshe, c.walshe@lancaster.ac.uk

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

No 100

Study Aim

PhD research project titled: Palliative care for Parkinson's disease: developing a needs assessment tool. This project has developed and clinimetrically tested a palliative screening tool for Parkinson's disease (PD). Data collection and analysis is complete, thesis being completed ahead of submission for publications.

Methodology

Mixed methodology. 4 phase project consisting of:

1. Systematic review and synthesis of qualitative literature.
2. Primary qualitative study.
3. Adaptation of a palliative tool for use in PD.
4. Clinimetric testing.

Organisation

Hull York Medical School

Contact details

Dr Edward Richfield, edward.richfield@hyms.ac.uk

Research is:	Single centre
Research project is funded:	Research fellowship grant, Dunhill Medical Trust
Research project cover:	England - North

No 101

Study Aim

What is the felt meaning of the relationship between self and cancer during post-treatment cancer survivorship. Building an understanding of variations and changes from a perspective of embodied cognition.

Methodology

Hermeneutic phenomenology.

More information

Research funded by St. Luke's (Cheshire) Hospice and part of DProf at Bournemouth University.

Organisation

St Luke's Hospice

Contact details

Kathleen Vandenberghe, Kathleen_Vandenberghe@stlukes-hospice.co.uk

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

No 106

Study Aim

My PhD project will aim to identify which drugs may be inappropriate to prescribe to people with dementia at the end of their life and to explore the barriers to withdrawing medications with health professionals and relatives of people with advanced dementia.

Methodology

A Delphi study will seek consensus on appropriate and inappropriate prescribing at end of life using panel of expert clinicians specialising in dementia and end of life care from across the UK. The second part of the study will explore, by interview, the views of health professionals about withdrawing the medications identified as inappropriate in the Delphi study. In addition, focus groups with relatives of people with advanced dementia will explore the circumstances under which withdrawal of medications would be acceptable to them through the use of a series of scenarios to be discussed as a group.

Organisation

Hull York Medical School, University of Hull

Contact details

Debbie Hukins, hydh7@hyms.ac.uk

Research is:	
Research project is funded:	Scholarship for PhD
Research project cover:	England - North

No 109

Study Aim

Differences in hospital use at the end of life by ethnic group.

Methodology

Comparison of hospital utilisation in the last 12 months of life by ethnic group - standardising for a range of potentially confounding variables at person and health system level.

Organisation

Nuffield Trust

Contact details

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

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

No 129

Study Aim

Aim: to improve demand for and supply of palliative care for people who identify as lesbian, gay, bisexual and/or trans* and are in the later stages of a life-limiting illness.

Research has shown that people who identify as lesbian, gay, bisexual and/or trans*, and their significant others, may not receive the care they need when facing a life-limiting illness, despite an increased risk of certain cancers (Harding et al, 2012 (<http://online.liebertpub.com/doi/pdf/10.1089/jpm.2011.0279>)).

The ACCESSCare project has been designed to address this inequity through:

1. The development and dissemination of evidence-based mass media resources with the LGB and/or T communities to increase the demand for appropriate end of life care.
2. The improvement of supply of appropriate end of life care through development of training resources for integration within existing end of life care curricula for health care professionals.

Methodology

The ACCESSCare project is undertaking in depth qualitative interviews to explore the experiences of people who identify as lesbian, gay, bisexual and or trans* and are facing the later stages of a life limiting illness.

Recruitment is through referral from local clinical teams across London, and through self-referral in response to media and poster adverts across the UK. Recruitment will continue until September 2015.

The findings from the previous literature and the qualitative interviews will be used to shape the mass media resources for the LGB and/or T communities, as well as training for health care professionals.

More information

<http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/living/access/index.aspx>

Organisation

King's College London

Contact details

Dr Katherine Bristowe, accesscare@kcl.ac.uk

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

No 130

Study Aim

1. To identify particular needs and preferences salient to sexual/gender orientation relating to EoLC (End of Life Care) as identified by LGBT (lesbian, gay, bisexual and transgender) elders.
2. To examine ways in which sexual/gender orientation may impact on experiences of EoLC for LGBT elders.
3. To explore LGBT elders' familial and friendship networks and the ways in which these personal networks may influence later life experiences towards and at end of life.
4. To identify recommendations for good practice in EoLC issues addressing issues for LGBT elders.

Methodology

A mixed methods study with three phases.

1. Survey (n = 237) of older LGBT people's (aged 60 and over) experiences and needs in relation to EoLC across the UK (England, Wales, Scotland and Northern Ireland).

The survey includes sets of closed questions (with some spaces for participants to add further detail if they wish to) to explore: perceptions of the importance/influence of sexual orientation/gender identity in the participant's life generally, in their experiences of health and social care and relating to thinking about /planning for end of life care.

2. In-depth interviews with a sub-sample of the survey respondents (n = 60) to examine issues highlighted from the survey. Themes addressed in the interviews include: attitudes and beliefs about EoLC issues, concerns and/or experiences of caring or receiving care at end of life, needs for information and support. The interview will incorporate 'eco-maps' - a participatory visual technique to map out and prompt discussions about respondents' supportive networks.

3. A public engagement workshop to feedback findings and to collaboratively develop recommendations to contribute to outcomes of the study.

More information

The project is now complete with an end date for a final report to be submitted to the funders by March 2015.

We have already been commissioned to feed our findings into national consultations currently underway, which are seeking to improve end of life care:

- Government review of choice in end of life care
- CQC (Care Quality Commission) 'Inequalities and Variations in Provision of End of Life Care' themed programme.

We had funding to be part of the 2014 Economic and Social Research Council Festival of Social Sciences and held an event in Nottingham, 4 November 2014:

Ageing and care for older LGBT people: Screening of critically acclaimed Documentary Gen Silent, which explores real-life issues facing older LGBT people in later life and towards the end of life. This was followed by a Q&A discussion panel after the film to explore the UK context of issues raised in the documentary.

We have presented findings from the project at numerous conferences and Dr Almack is presenting at forthcoming conferences in 2015 including:

- International Association of Gerontology and Geriatrics 8th European Congress, Dublin. Symposium on LGBT ageing co-convoked by Dr Kathryn Almack, University of Nottingham and Professor Gloria Gutman, Simon Fraser University, Canada.
- Queer Kinship and Relationships International Conference. Zalesie, Masuria, Poland.

The team are also working on a series of publications.

Organisation

University of Nottingham / Marie Curie Research

Contact details

Dr Kathryn Almack, k.almack@nottingham.ac.uk

Research is:	Single centre
Research project is funded:	Marie Curie Cancer Care Research Programme 2012-14
Research project cover:	UK

No 140

Study Aim

The study 'Both sides of the fence: using action research to improve end of life care for prisoners' aims to devise a transferable model of integrated palliative and end of life care, that involves prison staff, specialist palliative care practitioners and primary care staff, to ensure the delivery of high quality care for prisoners.

Methodology

This study uses participatory action research in a three-phased design; the research is taking place in one Category C prison that has a high population of older and disabled prisoners.

Phase 1 is a detailed situational analysis of current practice to ascertain the nature of end of life care provision in the prison, in which data are collected through interviews and focus groups with prison officers, prison healthcare staff, other prison staff and prisoners, as well as healthcare staff from outside the prison. A small number of case studies are also being undertaken, each centred on a prisoner who is approaching the end of his life.

Phase 2 consists of action cycles, in which staff from both inside and outside the prison work together to identify changes that would improve end of life care; these changes are then implemented using a cyclical process of review, planning, action and evaluation. In Phase 3, key stakeholders from prisons, specialist palliative care and primary care will be brought together with policy makers in two 'deliberative panels' to discuss the findings of the research and ensure that they have a wide impact across the prison service.

Organisation

Lancaster University

Contact details

Dr Mary Turner, j.m.turner@lancaster.ac.uk

Research is:	Single centre
Research project is funded:	Funded by Marie Curie Cancer Care
Research project cover:	North West England

No 141

Study Aim

'Metaphor in End of Life Care'. The aim of this project is to investigate the use of metaphor in the experience of end of life care in the UK. We have studied the metaphors used by members of different stakeholder groups (patients, unpaid family carers and healthcare professionals) in a 1.5-million-word corpus consisting of interviews and contributions to online forums. We have addressed the following research questions:

1. How do members of different stakeholder groups (health professionals, patients and unpaid family carers) use metaphor to talk about their experiences, attitudes and expectations of end of life care (e.g. palliative treatment, preparations for dying, etc.)?

2. What does the use of metaphor by these stakeholder groups suggest about (a) the experiences and needs of the members of these groups and their mutual relationships, and (b) the nature of metaphor as a linguistic and cognitive phenomenon? For more information, see the project website: <http://ucrel.lancs.ac.uk/melc/>

Methodology

The method we have employed to identify and analyse metaphor in our data is both qualitative and quantitative. Our approach includes the exploitation of an online semantic annotation tool developed by a member of the team, which has enabled us to identify metaphorical expressions more systematically than is possible with other methods for the study of metaphor in large data sets.

Organisation

Lancaster University

Contact details

Professor Elena Semino; e.semino@lancaster.ac.uk

Research is:	Single centre
Research project is funded:	National, UK Economic and Social Research Council (ESRC)
Research project cover:	UK

No 142

Study Aim

SUPPORTED is a study where an abdominal binder is being developed following primary research by Dr Nancy Preston. The binder would be used a support garment for people with ascites. Ascites is the build-up of large volumes of fluid in the abdomen (about 5 litres) which requires drainage every few weeks. It can occur as a result of advanced cancer, liver disease and hearth failure. The binder is aimed at improving comfort for patients and may also delay the re-accumulation of fluid following drainage as a result of increased lymphatic pressure. This will build upon the findings from using another binder which whilst increased intra-abdominal pressure and provided support to patients was felt to be too shallow and too warm. The new garment uses lighter material and has been developed specifically for this purpose so is longer and prevents it rising up.

Methodology

An observation study is starting this year where patients will see how easy it is to apply the binder and wear it. We are recruiting up 10 participants. Feedback will then be used inform a larger randomised controlled trial.

Organisation

Lancaster University

Contact details

Dr Nancy Preston n.j.preston@lancaster.ac.uk

Research is:	Single centre
Research project is funded:	Part of Lancaster University Impact Fund
Research project cover:	Preston Area

No 143

Study Aim

The Living with Breathlessness study programme (LWB) aims to inform new framework for care and support in advanced chronic obstructive pulmonary disease (COPD) based on recognition of the slow relentless progression of non-malignant disease and its effect on patients and carers. To inform this this study will provide new evidence on the trajectory of health and social care needs and preferences (and whether these change) of these patients, and their carers.

It will report variation in the experience and outcome of care in advanced COPD in relation to:

1. Changing physical, psychological and social support needs of patients and informal carers from patients', carers' and health care professionals' perspectives.
2. Care preferences (places and sources of care).
3. barriers and facilitators to health care professionals' ability to meet needs.
4. Stakeholder-developed recommendations for clinical practice.

Methodology

Four linked component studies:

1. Longitudinal Interview Study: an 18-month follow up study of patients with advanced COPD (n=235) and their informal carers (n=115) involving 3-monthly mixed-method semi-structured interviews using flexible methodology to capture changing function, support needs and service-access (including bereavement interviews with informal carers).
2. Barriers and Facilitators Study: longitudinal qualitative interviews with key health care professionals (identified by Longitudinal Interview Study patients) in parallel with the Longitudinal Interview Study, to identify barriers/facilitators for health care professionals in meeting need.
3. Care Preferences Survey: Discrete Choice Experiments (using preference vignettes) within a three-wave longitudinal survey (n=303) to identify change in care preferences in relation to changing need.
4. Stakeholder Study: national stakeholder workshop to consider the suitability, feasibility, and acceptability of recommendations drafted by an expert multi-disciplinary team (based on findings of studies 1-3) and follow up Delphi survey to review and prioritise the revised recommendations.

More information

The Living with Breathlessness study (LWB) is the operational title for a programme of work jointly funded by:
1) Marie Curie Cancer Care [formal title: End of life care in advanced Chronic Obstructive Pulmonary Disease (COPD) - identifying, understanding

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

Dr Morag Farquhar, mcf22@medschl.cam.ac.uk
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Research is:	Multi centre
Research project is funded:	National
Research project cover:	East of England and South London plus national stakeholders

No 151

Study Aim

To determine the effectiveness and cost-effectiveness of Short-term Integrated Palliative Care Services (SIPC) in improving symptoms, selected patient and caregiver reported outcomes and reducing hospital utilisation for people severely affected by long-term neurological conditions (LTNCs).

Methodology

This is a randomised Phase III, fast-track controlled trial. It is a multicentre evaluation of a complex intervention, following the MRC guidance for the development and evaluation of complex interventions.

This study incorporates:

- (i) a set up and feasibility phase to refine recruitment and methods;
- (ii) mapping usual care for patients with LTNCs across the different centres (by prior work collecting information about the services and during the study recording services received at baseline and in the standard care group);
- (iii) a randomised controlled trial of SIPC (the intervention) offered from a MPCT compared to best usual care;
- (iv) a qualitative component, to explore the ways that the SIPC affects patients and caregivers, how the change process may work, how SIPC may be improved and to interpret quantitative results;
- (v) a survey of health professionals; and
- (vi) economic modelling to estimate the NHS and societal resources required for and longer term impacts of SIPC.

Organisation

Cicely Saunders Institute, King's College London

Contact details

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Research is:	Multi centre
Research project is funded:	National
Research project cover:	South London, Brighton and Hove/Sussex, Cardiff, Liverpool and Nottingham

No 153

Study Aim

Developing an intervention to improve end of life care in advanced dementia.

Methodology

A realist approach taking account of contexts across UK to generate an understanding of enablers and barriers to care. Intervention components were derived from qualitative and quantitative sources (reviews of literature and policy documents, workshops, interviews and cohort study) and mapped to underlying theories of whole systems change. National consensus on intervention components was achieved using a RAND/UCLA Appropriateness method. The intervention was implemented in an exploratory naturalistic study and final results are available later in 2015.

More information

The three year programme is completed. Sustainability of the effects of the intervention will be assessed later in 2015. Associated protocol publications

Elliott M, Harrington J, Moore K, Davis S, Kupeli N, Vickerstaff V, Gola A, Candy B, Sampson EL, Jones L. A protocol for an exploratory phase I mixed-methods study of enhanced integrated care for care home residents with advanced dementia: the Compassion Intervention. *BMJ Open*. 2014 Jun 17;4(6):e005661. doi: 10.1136/bmjopen-2014-005661

Jones L, Harrington J, Scott S, Davis S, Lord K, Vickerstaff V, Round J, Candy B, Sampson EL. CoMPASs: IOn programme (Care Of Memory Problems in Advanced Stages of dementia: Improving Our Knowledge): protocol for a mixed methods study. *BMJ Open*. 2012 Nov 27;2(6). pii: e002265. doi: 10.1136/bmjopen-2012-002265.

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