



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:

Commissioning

Summary research

No	Summary Research Aim	Organisation
4	Quantitative analysis of the numbers and needs of children in Scotland requiring Palliative Care (ChiSP Study).	University of York
5	Quantitative analysis of survival in children and young people in England with life-limiting conditions.	University of York
9	The impact on hospital admissions of frail elderly patients by introducing advance care planning into the highest risk group.	London Northwest Healthcare Trust
29	The C-CHANGE project: The aim is to develop and validate a patient-centred, nationally applicable case-mix classification for adult palliative care provision.	King's College London, Cicely Saunders Institute
39	Evaluating a fatigue management intervention for people in the last year of life.	The Royal Marsden NHS Foundation Trust
47	Evaluation of telemedicine project to support people at home in the last year of life.	University of Bradford
56	Research on the symptom burden and health and social needs of people with advanced dementia at the end of life, and their carers to develop and pilot a complex intervention to improve end of life care.	University College London
71	To study recognition of the need for a palliative approach to care in diseases such as chronic obstructive pulmonary disease (COPD) and dementia, explore patient relevant outcomes of hospitalisations and place of death.	Hull York Medical School
81	To investigate the costs, contributions and economic value of family care giving in end of life cancer care.	University of Manchester (as part of NIHR CLAHRC Greater Manchester)
83	Factors affecting implementation of a Carer Support Needs Assessment Tool in palliative home care.	University of Manchester
85	Economics of end of life care: Using economic outcome measures for assessing benefit in a hospice setting: feasibility, appropriateness and adaptation.	Marie Curie Hospice West Midlands
89	Evaluation of Macmillan Specialist Care at Home.	University of Nottingham
93	To test whether the role of a dedicated supportive care liver nurse specialist can improve the care planning, care co-ordination and quality of life of people living with advanced liver disease in the community.	University of Edinburgh
102	The GUIDE_Care project is a population-based study to describe the variations in place of death and the factors that affect these.	Cicely Saunders Institute, King's College London
113	How effective are UK services for bereaved children and young people?	Childhood Bereavement Network
123	To explore the feasibility and acceptability of an intervention to identify, assess and support unpaid carers, in primary care, who are caring for someone at the end of life.	Marie Curie Cancer Care
124	Living with a person dying from cancer, lung disease or dementia: Health outcomes from a general practice cohort study.	Marie Curie Palliative Care Research Department University College London
125	Impact of palliative care day services on quality of life of patients, carers and families. Quality indicators in palliative care day services.	Marie Curie Cancer Care and Queen's University Belfast

No	Summary Research Aim	Organisation
149	To map pathways of care for end of life care across Greater Manchester, whilst exploring performance in relation to the facilitation of Death in Usual Place of Residence (DIUPR).	University of Manchester (as part of NIHR CLAHRC Greater Manchester)
150	Scoping the cancer-specific learning and development needs of clinical and non-clinical staff working in primary, community and palliative care across the City of Manchester.	University of Manchester (as part of NIHR CLAHRC Greater Manchester)

Full research

No 4

Study Aim

Children in Scotland requiring palliative care: identifying numbers and needs (ChiSP Study).

Methodology

This study aims to use quantitative analyses of routinely collected healthcare statistics and a qualitative literature review to achieve the aims stated below 1.2 Aims (as per tender):

1. The actual number of children and young people with life-limiting or life threatening conditions in Scotland.
2. The number of children and young people with palliative care needs, as well as their ages, any underlying conditions, care needs and geographic locations and ethnicity.
3. The stage of the condition (stable/unstable/deteriorating/dying) of each of these children and young people with palliative care needs.

Organisation

University of York

Contact details

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

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

No 5

Study Aim

Survival in children and young people in England with life-limiting conditions.

Methodology

Quantitative analyses of routinely collected health care data.

More information

This project is funded as part of the Paediatric Palliative Care program of research funded by Martin house Children's Hospice.

Organisation

University of York

Contact details

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

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

No 9

Study Aim

What is the impact on hospital admissions of frail elderly patients by introducing advance care planning into the highest risk group.

Methodology

Control intervention study.

More information

Was supported by the employment of a Darzi Fellow, part-funded by the London Deanery.

Organisation

London Northwest Healthcare Trust

Contact details

Dr Charles Daniels, cdaniels1@nhs.net

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

No 29

Study Aim

The C-CHANGE project: The aim is to develop and validate a patient-centred, nationally applicable case-mix classification for adult palliative care provision, which: i) validly and reliably reflects patient and family needs, ii) captures clinical complexity across different advanced conditions and settings, and iii) enables the delivery of better quality and more efficient care in the last year of life, linked to appropriate outcomes and indicators of quality of care. <http://www.nihr.ac.uk/funding/fundingdetails.htm?postid=2248>

Methodology

This is a programme of research with several different workstreams, in which a variety of quantitative, qualitative and mixed methods are being used.

More information

This work is aligned to the Palliative Care Funding Pilots work.

Organisation

King's College London, Cicely Saunders Institute

Contact details

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

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

No 39

Study Aim

Evaluating a fatigue management intervention for people in the last year of life.

Methodology

Mixed methods.

Organisation

The Royal Marsden NHS Foundation Trust
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Contact details

Theresa Wiseman, theresa.wiseman@rmh.nhs.uk

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

No 47

Study Aim

Gold Line - evaluation of telemedicine project to support people at home in the last year of life.
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Methodology

Qualitative - semi-structured interviews.

Organisation

University of Bradford

Contact details

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

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

No 56

Study Aim

The CoMPASs:IO n (Care Of Memory Problems in the Advanced Stages of dementia: Improving Our knowledge) programme.

Objectives:

To conduct detailed research on the symptom burden and health and social needs of people with advanced dementia at the end of life, and their carers to use this information to develop and pilot a complex intervention to improve end of life care for people with advanced dementia.

Method:

Workstream One (0-12 months) a cohort study of people with advanced dementia and their carers, residing in their own homes and care homes, will provide data on clinical and social needs. This will indicate the potential interventions. We will hold an iterative cycle of workshops and interviews with carers and professional stakeholders. This bottom up approach will define the core components of the intervention, including an understanding of context and mechanisms, and potential outcomes. Workstream Two (9-15 months) we shall refine our intervention, considering adaptation of existing care models. Our intervention, and the team needed, will be described in a manual. We shall consider training and support needs and the costs incurred. Workstream Three (15-36 months) we shall pilot our intervention in one setting to understand how its components influence pathways care, patient and carer outcomes, and assess our training and support programme. We shall check for long term effects, potential for transferability, and describe the cost-effectiveness of its components.

Deliverables:

An in-depth understanding of an intervention to improve care, including economic evidence, to inform health and social care commissioners.

Methodology

Mixed methods, qualitative and quantitative.

Organisation

University College London

Contact details

Elizabeth Sampson, e.sampson@ucl.ac.uk

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

No 71

Study Aim

Previous study used a national GP database, Clinical Practice Research Data link (CPRD) to study recognition of the need for a palliative approach to care in heart failure and cancer. This project will look at other important diseases such as chronic obstructive pulmonary disease (COPD) and dementia. It will further innovate by linking to Office of National Statistics (ONS) Mortality data and Hospital Episode Statistics (HES) data to explore patient relevant outcomes of hospitalisations and place of death. It will explore if there has been any improvement in the last few years as government policy has emphasised palliative care in these conditions. It will look to see if recording the need for palliative care made any difference in terms of people spending less time in hospital and dying outside of hospital such as in their own home. It will explore if there is an association between early recognition of the need for a palliative approach to care for heart failure patients on: 1) place of death? 2) number and length of hospitalisations?

Methodology

Secondary analysis of a large well-validated database of anonymised electronic contemporaneous medical record from UK clinical records (primary care and linked hospital data and death certificate data).

Organisation

Hull York Medical School

Contact details

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

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

No 81

Study Aim

To investigate the costs, contributions and economic value of family care giving in end of life cancer care.

Objectives:

1. To describe carers' demographic characteristics.
2. To determine carers' contribution in terms of time, nature of care and support provided.
3. To characterise the economic and other costs to carers providing end of life cancer care.
4. To investigate the association between carer characteristics and time spent caring, costs to carers and carer wellbeing.
5. To estimate the economic value of end of life care provided by family carers for people with cancer.

Methodology

Quantitative - involving a national survey.

Organisation

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

Contact details

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

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

No 83

Study Aim

What factors affect implementation of a Carer Support Needs Assessment Tool in palliative home care.
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Methodology

Mixed methods study.

Organisation

University of Manchester

Contact details

Gunn Grande, gunn.grande@manchester.ac.uk

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

No 85

Study Aim

Economics of End of Life Care: Using economic outcome measures for assessing benefit in a hospice setting: feasibility, appropriateness and adaptation.

Methodology

Semi-structured qualitative interviews using the Think aloud technique.

More information

Marie Curie Hospice Solihull is the single site for recruitment of patients, their close persons and the healthcare professionals looking after them.

Organisation

Marie Curie Hospice West Midlands

Contact details

Prof Joanna Coast, J.Coast@bham.ac.uk

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

No 89

Study Aim

Evaluation of Macmillan Specialist Care at Home.
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Methodology

Realist evaluation using mixed methods including economic evaluation.

Organisation

University of Nottingham

Contact details

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

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

No 93

Study Aim

Study title: Supportive care in the community for people living with advanced liver disease: a feasibility study.
Study aim: To test whether the role of a dedicated supportive care liver nurse specialist can improve the care planning, care co-ordination and quality of life of people living with advanced liver disease.

Methodology

Serial questionnaires and qualitative interviews with patients, lay carers and care 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 102

Study Aim

GUIDE_Care project <http://www.csi.kcl.ac.uk/guidecare.html>

Methodology

Analyses focusing on different aspects in end of life care have been done on the data for all causes as well as for selected causes of death and subpopulation analysis.

Organisation

Cicely Saunders Institute, King's College London

Contact details

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

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

No 113

Study Aim

How effective are UK services for bereaved children and young people?

Methodology

Pre and post-intervention questionnaires. Focus groups.

Organisation

Childhood Bereavement Network

Contact details

Alison Penny, apenny@ncb.org.uk

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

No 123

Study Aim

A feasibility study of early identification, assessment and support for informal carers in primary care.
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Methodology

Intervention study using qualitative and quantitative pre and post intervention data.

Organisation

Marie Curie Cancer Care

Contact details

Professor Scott Murray, Scott.Murray@ed.ac.uk

Research is:	Single centre
Research project is funded:	Dimbleby and Marie Curie Cancer Care
Research project cover:	Lothian, Scotland

No 124

Study Aim

A retrospective national cohort study of the demographic characteristics, health outcomes and health service use of cohabitants living with terminally ill patients with cancer, chronic obstructive pulmonary disease and dementia.

Methodology

A retrospective national cohort study using The Health Improvement Network (THIN) UK primary care database.

Participants were:

1. Cohabitants aged 60 years or over of people who died with a diagnosis of cancer (lung or colorectal), chronic obstructive pulmonary disease (COPD) or dementia.
2. With an age gap of no greater than 15 years.
3. with at least one year of follow-up before bereavement. Prevalence of cohabitant health outcomes were described in the year before and after bereavement. Random effects Poisson regression was used to calculate incidence rate ratios (IRRs) comparing the dementia and COPD groups with the cancer group. Total sample size of bereaved cohabitants is 13,693.

Organisation

Marie Curie Palliative Care Research Department University College London

Contact details

Dr Liz Sampson, e.sampson@ucl.ac.uk

Research is:	Single centre
Research project is funded:	Marie Curie Cancer Care and Dimpleby Foundation
Research project cover:	UK

No 125

Study Aim

1. Development of a set of quality indicators (QIs) for the assessment of all aspects (structure, process and outcome) of quality of care of Palliative Care Day Services (PCDS).
2. Development and implementation of a toolkit for assessment of QIs in PCDS.

Methodology

QIs will be developed by considering the best available published evidence and by consulting with professionals and service users who are involved in, or have experience of, PCDS. This consultation process will follow a systematic format that has been used previously in the development of QIs for other services (known as the RAND/UCLA method), which includes the following steps:

1. A review of the evidence and presentation of a draft set of QIs.
2. Review of the draft QIs by panels of service users and health care professionals – to consider their appropriateness and comprehensiveness.
3. Identification of appropriate ways of assessing the agreed set of QIs.
4. Production of draft documentation (toolkit) for the routine assessment of the agreed QIs.

Nurses working in PCDS will then implement the toolkit to complete the QIs for a small number of patients. The nurses will provide feedback via data collection forms and a structured interview on the extent to which data associated with each QI:

1. Is collected routinely (including adherence), available, and accessible?
2. Represents a burden of data generation and/or collection (for patients and/or staff)?
3. The toolkit instructions are clearly formulated - for data collection, analysis and presentation?

The toolkit will be modified in response to this feedback in order to produce a final version and accompanying manual. In conjunction with the toolkit, a commentary on the relative burden associated with measuring each indicator will be produced with recommendations for service providers.

More information

A comprehensive toolkit for the assessment of QIs in PCDS will be produced. With the assistance of organisations involved in its development, the toolkit will be promoted to service providers across the UK. This will enable a rigorous approach to the asse

Organisation

Marie Curie Cancer Care and Queen's University Belfast

Contact details

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

No 149

Study Aim

A mapping exercise of the provision of end of life care across Greater Manchester exploring performance in relation to the facilitation of Death in Usual Place of Residence. Beginning with a quantitative investigation of performance across Greater Manchester, followed by a qualitative investigation of the underlying factors affecting performance, in order to develop a range of critical success factors in the delivery of high quality, choice-led end of life care.

Methodology

Mixed methods study.

Organisation

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

Contact details

Prof. Damian Hodgson, damian.hodgson@manchester.ac.uk

Research is:	Multi centre
Research project is funded:	Locally – via NIHR CLAHRC GM
Research project cover:	Greater Manchester

No 150

Study Aim

The study aimed to:

- Increase understanding of the current workforce in primary, community and palliative care services across Manchester who contribute to the care of PABC by illuminating the range of organisations/services, workforce and staff roles involved.
- Understand about the level of awareness, knowledge and skills about cancer/cancer care, the preparation to deliver cancer care (including the factors which form a ‘good’ patient experience), and the learning and development needs of the workforce.
- Analyse the cancer-specific learning opportunities across Manchester, regionally and nationally, and make recommendations to meet the workforce needs.

Methodology

Mixed methods study.

Organisation

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

Contact details

Dr Vanessa Taylor, vanessa.taylor@manchester.ac.uk

Research is:	Multi centre
Research project is funded:	Macmillan (Manchester Cancer Improvement Partnership)
Research project cover:	Manchester