ISRCTN90752212 https://doi.org/10.1186/ISRCTN90752212

Testing a case-mix classification in palliative care

Submission date
28/02/2017

Recruitment status
No longer recruiting

Registration date
02/03/2017

Overall study status
Completed

Last Edited
09/07/2024

Condition category
Other

[_] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
In England, the hospice movement has provided a model of good palliative (end of life) care for those with advanced progressive (worsening) disease. However, the care offered around the country can differ greatly. Older people or those with non-cancerous conditions, for instance, are less likely to receive palliative care. There are also major geographical variations in NHS provision often resulting in a mismatch between the palliative care needs of a patient/family, the resources provided to meet those needs, and patient health outcomes achieved. Casemix classifications provide the health care sector with a consistent method of classifying types of patients, their treatment and associated costs. The aim of this study is to follow participants being treated at a range of different places in order to develop a casemix classification for palliative care will enable these inequities in provision to be addressed.

Who can participate?
Adults who are receiving specialist palliative care across inpatient (hospice and hospital), community and outpatient settings, and their family carers.

What does the study involve?
Participants and their family carers are followed by the research team for up to 12 months. Patient participants and their family carers provide data on their symptoms and concerns, whether these are addressed, and other important background information. They also provide inofmration about how they previously used services. The study also includes a post-bereavement survey to family carers where appropriate, to identify symptoms and concerns immediately prior to death, and also family support needs after death. Clinicians collect data about the patient participants including background and health information, episode start and end data, case-mix variables (such as phase of illness, functional status and problem severity), alongside information on patient-level resource use in specialist palliative care settings. These data are linked to patient participant data, encrypted and transferred to the central database and analysed to understand how to better match patient-level resource use to needs.

What are the possible benefits and risks of participating?
Participants will benefit from improved matching of resources to needs at an individual level. There are no notable risks involved with participating.

Where is the study run from?
Inpatient, community and outpatient settings throughout England (UK)

When is the study starting and how long is it expected to run for?
February 2016 to September 2018

Who is funding the study?
National Institute for Health Research (UK)

Who is the main contact?
Dr Fliss Murtagh
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Contact information

Type(s)
Public

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Additional identifiers

Protocol serial number
31205

Study information

Scientific Title
C-CHANGE Workstream 4: Testing a case-mix classification in palliative care (cohort study)

Acronym
C-CHANGE

Study objectives

The aim of this study is to prospectively validate a case-mix classification (a system to group people into classes that are homogeneous in their resource use) for palliative care (previously developed) over time and across the range of complexity, conditions and settings.

Ethics approval required
Old ethics approval format

Ethics approval(s)
London –Bromley Research Ethics Committee, 05/09/2016, ref: 16/LO/1021

Study design
Observational; Design type: Cohort study

Primary study design
Observational

Study type(s)
Treatment

Health condition(s) or problem(s) studied
Specialty: Cancer, Primary sub-specialty: Palliative and Supportive Care; UKCRC code/ Disease: Other/ Ill-defined and unknown causes of mortality

Interventions
Patient participants will provide data on their symptoms and concerns, whether these are addressed and other key demographics and social variables. They will also provide retrospective data on their use of services. Family carers will complete data about their own circumstances including their basic demographic information, distress measured by distress thermometer, caregiver burden using the Zarit Caregiver Burden Inventory (6-item version) and questionnaires regarding the patient where the patient is too unwell to complete (e.g., SF-12v2 and Pall-CSRI). These data will be collected from patients and (separately) their main family carers using a combination of face-to-face/telephone contacts and postal questionnaires according to participants' preferences at start, phase change, and end of episodes of care. Where phase exceeds 4 weeks, data items will be captured as for phase change.

A sample of 20-25 patients who have experienced at least two transitions of care and family carers will be purposively selected to take part in one or two face-to-face interviews. The interviews will be semi-structured and follow the interview schedule for the patient participants and family carers. Each interviews last 40 minutes, but this will be guided by the participant. In order to provide information on how transitions in care might be better negotiated to improve outcomes and experiences, the interviews will cover these key topics; communication, coordination of care, information and support needs, discharge planning, and experience of transitions. Data from the first five interviews will be analysed and feedback from our Patient and Public Involvement group will be used to refine the interview schedule for subsequent interviews.

Participants and their family carers will be followed to test a case-mix classification longitudinally through transitions between settings (e.g. from home to hospital, from hospice to

home etc.). The study will also include a post bereavement survey to family carers where appropriate, to identify symptoms and concerns immediately prior to death, and also family support needs after death.

Clinicians will collect data about the patient participants on demographic and clinical data, episode start and end data, potential case-mix variables (e.g., phase of illness, functional status and problem severity) alongside information on patient-level resource use in specialist palliative care settings. These data will be linked to patient participant data, encrypted and transferred to the central database and analysed to understand how we can better match patient-level resource use to needs.

Intervention Type
Other

Primary outcome(s)
Cost of the episode of care (and cost per phase and per diem) is captured by i) staff activity matrix at every contact, the Palliative care Resource Use Score (PRUS) at change of phase of illness and at the end of episode, and patient/carer completed inventory of palliative care services received based on the Client Services Receipt Inventory (Pall-CSRI) at end of episodes of care or three monthly whichever is earlier over the telephone.

Key secondary outcome(s))
No secondary outcome measures.

Completion date
30/09/2018

Eligibility

Key inclusion criteria
1. All adult patients (≥18 years) receiving specialist palliative care
2. People with advanced disease, regardless of primary diagnosis
3. Across inpatient (hospice and hospital), community and outpatient settings

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Sex
All

Total final enrolment

309

Key exclusion criteria
1. Patients considered by clinicians too ill to be approached
2. Not receiving specialist palliative care
3. Aged under 18 years

Date of first enrolment
01/11/2016

Date of final enrolment
31/05/2018

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
King's College Hospital
Denmark Hill
London
United Kingdom
SE5 9RS

Study participating centre
Princess Royal University Hospital
Farnborough Common
Orpington
United Kingdom
BR6 8ND

Study participating centre
St Christopher's Hospice
51-59 Lawrie Park Road
London
United Kingdom
SE26 6DZ

Study participating centre

St Joseph’s Hospice
Mare Street
London
United Kingdom
E8 4SA

Study participating centre
Royal Sussex County Hosptial
Eastern Road
Brighton
United Kingdom
BN2 5BE

Study participating centre
Brighton General Hosptial
Elm Grove
Brighton
United Kingdom
BN2 3EW

Study participating centre
Martlets Hospice
Wayfield Avenue
Hove
United Kingdom
BN3 7LW

Study participating centre
Forest Holmes Hospice
Longfleet Road
Poole
United Kingdom
BH15 2JB

Study participating centre
St Catherine’s Hospice
Throxenby Lane
Scarborough
United Kingdom
YO12 5RE

Study participating centre
St Giles Hospice
Fisherwick Road
Whittington
United Kingdom
WS14 9LH

Study participating centre
St Luke’s Hospice
Little Common Lane
Sheffield
United Kingdom
S11 9NE

Study participating centre
Pilgrim Hospices
56 London road
Canterbury
United Kingdom
CT2 8JA

Study participating centre
St Michael's Hospice
Crimple House
Hornbeam Park Avenue
Harrogate
United Kingdom
HG2 8QL

Study participating centre
Harrogate and District NHS Foundation Trust
Lancaster Park Road
Harrogate
United Kingdom
HG2 7SX

Sponsor information

Organisation
King's College London

ROR
https://ror.org/0220mzb33

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are/will be available upon request from Dr Fliss Murtagh (fliss.murtagh@kcl.ac.uk)

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		01/11/2023	09/07/2024	Yes	No
Protocol article	protocol	17/03/2018		Yes	No
HRA research summary			28/06/2023	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes