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Equitable palliative care in the community through primary care

Submission date
22/07/2025

Recruitment status
Recruiting

Registration date
01/08/2025

Overall study status
Ongoing

Last Edited
24/06/2026

Condition category
Other

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol

Background and study aims
Palliative care and end-of-life care aim to improve the quality of life for people with any serious illness who can't be cured in the last years, months, weeks, or days of their lives. In England, almost one-quarter of people who could benefit from palliative and end-of-life care do not receive it. People who live in the most deprived areas are least likely to receive palliative and end-of-life care. Primary care includes general practices, community nursing and pharmacies. These are the first places that people go to for healthcare and treatment in the community. Primary care provides most palliative and end-of-life care to people at home and in care homes, but this is very variable. In England, primary care services are working more closely with specialist services, such as hospices or NHS specialist palliative care teams, in "Integrated Neighbourhood Teams". Integration could improve palliative and end-of-life care and reduce inequities and inequalities, but research is urgently needed to understand how this works best, when, where and for whom. This research will investigate how, when, where and for whom an integrated approach can improve palliative and end-of-life care for patients and their family members and carers, especially for patients living in very deprived areas. This research will increase understanding about what is most important to patients with palliative care needs and /or at the end of life, and their family members or carers, including people living in very deprived areas. It will also help us to understand how services can best work together to improve palliative and end-of-life care. The information will be provided to patients, family members, carers, and professionals, and will inform recommendations to the NHS about what resources are required for people, especially from the most deprived areas, to experience much fairer palliative and end-of-life care in the future.

Who can participate?
Patients in receipt of palliative care and their carers, health professionals working with patients in receipt of palliative care, and commissioners and palliative care leads

What does the study involve?
This study will be carried out in four parts:
1. Understanding patient experiences: This includes interviews with patients and carers, reviewing their medical records, and running a survey to understand their preferences.
2. Evaluating care models: Health professionals will take part in interviews and focus groups to

help refine and test ideas for better care delivery.
3. Testing the impact: A computer model will be used to see how the new care approach might affect healthcare resources, quality of care, and fairness.
4. Planning for real-world use: Two workshops with experts and public representatives will identify what's needed to successfully put the new approach into practice.

What are the possible benefits and risks of participating?
The information collected through participation in the study may not directly benefit the care that the patient currently receives. However, it may help to improve palliative and end-of-life care for patients living in similar communities with high levels of deprivation in the future.

There are no specific risks associated with taking part in the study. However, participants may experience some inconvenience due to the time required to participate in an interview or complete an online questionnaire.

Where is the study run from?
University of Leeds, UK

When is the study starting and how long is it expected to run for?
February 2025 to February 2028

Who is funding the study?
National Institute for Health and Care Research (NIHR), UK

Who is the main contact?
Ms Jacqueline Birtwistle, j.birtwistle@leeds.ac.uk

Contact information

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Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
354755

Central Portfolio Management System (CPMS)
69730

National Institute for Health and Care Research (NIHR)
162177

Study information

Scientific Title
Equitable palliative care in the community through primary care (EPIC-PC): a realist study to propose a new integrated neighbourhood team approach to palliative and end of life care

Acronym
EPIC-PC

Study objectives
What are the key contexts, resources and components required for an integrated approach to palliative and end of life care to deliver improved and more equitable outcomes for patients and carers?

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 20/08/2025, East of Scotland Research Ethics Service REC 2 (Tayside medical Science Centre (TASC), Residency Block, Level 3, Ninewells Hospital & Medical School, Dundee, DD1 9SY, United Kingdom; -; tay.eosres@nhs.scot), ref: 25/ES/0066

Primary study design
Observational

Study design
Realist evaluation methodology with mixed methods

Study type(s)
Quality of life, Treatment

Health condition(s) or problem(s) studied
Palliative and end of life care

Interventions
A multi-perspective mixed-methods study will be conducted with patients, caregivers, and health professionals, focusing on socioeconomic deprivation. This study will be structured into four work packages (WPs):
1. The study will include (i) qualitative interviews with patients receiving palliative care and their family members/carers, (ii) a review of primary care case notes for these patients, and (iii) a broader survey utilising discrete choice experiment methods to gather comprehensive data on patient perspectives.
2. A realist evaluation of integrated palliative and end-of-life care service delivery models, involving (1) theory-refining interviews and (2) theory-consolidating focus groups with health professionals. Realist analysis will bring together data from WPs 1&2, leading to a proposed integrated approach to palliative and end-of-life care
3. Dynamic simulation modelling will be used to assess the impact of the integrated approach on healthcare resource needs, care quality, and inequalities.
4. Two expert stakeholder workshops, with professionals and PPIE involvement, will identify key enablers for the successful implementation of the proposed integrated approach in practice.

Intervention Type
Mixed

Primary outcome(s)
To improve access to and experience of palliative care for patients living in areas of socioeconomic deprivation, the following data will be measured using realist methods:
1. The experiences of people (patients with palliative care needs, carers, health professionals) of access to palliative care in the community in the North and North East of England will be captured through conversational interviews
2. Patient and carer priorities for future care via case note reviews detailing patients' service use (e.g., types and frequency of services accessed, health professionals consulted) will be assessed through a national cross-sectional Discrete Choice Experiment (DCE) survey

Key secondary outcome(s)
1. Resource use and cost data will be measured using dynamic simulation modelling developed based on current provision of palliative care in the community (e.g. service use).
2. A second model will be developed that predicts resource use and cost of a proposed integrated approach of the provision of palliative and end-of-life care in the community.

Completion date
01/02/2028

Eligibility

Key inclusion criteria
1. Patients in receipt of palliative care and their carers
2. Health professionals working with patients in receipt of palliative care
3. Commissioners and palliative care leads

Participant type(s)
Carer, Health professional, Patient

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 Years

Upper age limit
110 Years

Sex
All

Total final enrolment
0

Key exclusion criteria
Patients and Carers:
1. Adults with advanced serious illness who are unable to participate in a conversational interview for any reason related to their condition
2. Adults with advanced serious illness who are unable to provide informed consent for any reason related to their condition (for example, becoming too unwell or approaching the end of life)
3. Children and young people aged < 18 years
4. Carers and/or family members who have not been invited to take part by the patient participant

Health professionals:
This is a community-based study, so it excludes participants who work exclusively in hospital trusts

Date of first enrolment
01/11/2025

Date of final enrolment
01/12/2027

Locations

Countries of recruitment

United Kingdom

England

Study participating centre
Academic Unit of Palliative Care
Worsley Building
Clarendon Way
University of Leeds
Leeds
England
LS2 9JT

Sponsor information

Organisation
University of Leeds

ROR
https://ror.org/024mrxd33

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care 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 available from the corresponding author on reasonable request.
J.Birtwistle@leeds.ac.uk

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		22/06/2026	24/06/2026	Yes	No
Protocol file	version 1.4	23/06/2025	23/07/2025	No	No
Protocol file	version 1.6	26/08/2025	11/11/2025	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes