

# Equitable palliative care in the community through primary care

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<b>Registration date</b> 01/08/2025	<b>Overall study status</b> Ongoing	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
<b>Last Edited</b> 31/07/2025	<b>Condition category</b> Other	<input type="checkbox"/> Individual participant data <input checked="" type="checkbox"/> 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](mailto:j.birtwistle@leeds.ac.uk)

### **Study website**

<https://medicinehealth.leeds.ac.uk/directories0/dir-record/research-projects/1908/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>

## **Contact information**

### **Type(s)**

Principal Investigator

### **Contact name**

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**Type(s)**

Public, Scientific

**Contact name**

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## Additional identifiers

**EudraCT/CTIS number**

Nil known

**IRAS number**

354755

**ClinicalTrials.gov number**

Nil known

**Secondary identifying numbers**

CPMS 69730, NIHR162177

## 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)**

Submitted 14/07/2025, 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

## **Study design**

Realist evaluation methodology with mixed methods

## **Primary study design**

Observational

## **Secondary study design**

Realist study

## **Study setting(s)**

Community, GP practice, Home, Hospice, Medical and other records

## **Study type(s)**

Quality of life, Treatment

## **Participant information sheet**

Not available in web format, please use contact details to request a participant information sheet

## **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 measure**

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

### **Secondary outcome measures**

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.

### **Overall study start date**

01/02/2025

### **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)**

Patient, Health professional, Carer

### **Age group**

Mixed

### **Lower age limit**

18 Years

### **Upper age limit**

110 Years

### **Sex**

Both

### **Target number of participants**

90

### **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**

England

United Kingdom

**Study participating centre**

**Academic Unit of Palliative Care**

Worsley Building

Clarendon Way

University of Leeds

Leeds

United Kingdom

LS2 9JT

## **Sponsor information**

**Organisation**

University of Leeds

**Sponsor details**

Governance and Compliance Directorate

The University of Leeds

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+44 (0)113 3437587

[governance-ethics@leeds.ac.uk](mailto:governance-ethics@leeds.ac.uk)

**Sponsor type**

University/education

**Website**

<https://www.leeds.ac.uk>

**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**

**Publication and dissemination plan**

A minimum of six academic papers (and conference presentations) will be produced, including:

- Protocol paper (open access)
- Approaches to PPI in primary care and palliative care research for people from marginalised and minoritised communities
- Findings from qualitative data analysis in WPs 1 and 2
- Results of the Discrete Choice Experiment
- Findings from the realist analysis and development of the program theory/proposal for the integrated neighbourhood approach, detailing what works, when, why, and for whom
- The economic model developed in WP3

Other outputs will include:

- A project website, developed in partnership with the Patient and Family Advisory Panel, featuring information on PPI, accessible resources, and infographics of study findings

- Policy and research briefings summarising key findings and recommendations for future research
- Final project report for the NIHR

**Intention to publish date**

01/02/2029

**Individual participant data (IPD) sharing plan**

The data-sharing plans for the current study are unknown and will be made available at a later date.

**IPD sharing plan summary**

Data sharing statement to be made available at a later date

**Study outputs**

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Protocol file</a>	version 1.4	23/06/2025	23/07/2025	No	No