ISRCTN75964234 https://doi.org/10.1186/ISRCTN75964234

Helping optimise primary care support during transition from children's hospice care

Submission date 24/07/2025	**Recruitment status** Recruiting
Registration date 08/09/2025	**Overall study status** Ongoing
Last Edited 08/09/2025	**Condition category** Other

☐ Prospectively registered
☒ Protocol
☐ Statistical analysis plan
☐ Results
☐ Individual participant data
☒ Record updated in last year

Plain English summary of protocol

Background and study aims

There are over 86,000 children and young people in England living with conditions that will shorten their lives. Many of these young people are supported by children's hospices. In the past, children's hospices often continued to care for young people into adulthood. But this is no longer possible because more young people are living longer and the number of people needing care is growing. Now, as they become adults, young people must move from children's hospice care to adult healthcare services. Although access to palliative care is now a human right in the UK, young people often do not receive the same level of care as children or older adults. General Practitioners (GPs) play a key role in providing good care at the end of life, but most are not involved in helping young people move from children's to adult services. This study aims to develop a set of resources, called a toolbox, to help GPs become more involved in supporting young people with life-limiting conditions during this transition.

Who can participate?

Young people aged 14 years or older with a life-limiting condition who have used children's hospice services and are approaching, going through, or have recently gone through the move to adult services can take part. Parents or carers of these young people can also take part, including those whose child has died in the last five years. Healthcare professionals, including GPs and hospice staff who support young people during this transition, can also participate.

What does the study involve?

Participants will be invited to take part in interviews to share their experiences and views. These interviews will help the research team understand what information GPs need and how best to support them. Young people, families, GPs, and hospice staff will work together to co-design the toolbox. The toolbox will include resources for patients, GPs, and children's hospices. The study will also test how well the toolbox works in real-life settings with a group of 24 young people who are currently moving from children's to adult services.

What are the possible benefits and risks of participating?

There is no payment for taking part. Participation will be a valuable and much appreciated addition to improving care. We hope what we learn will improve the experience of young people and families in the future. Taking part will give participants the opportunity for their views and experiences to be heard. It is possible that talking about experiences may be upsetting. If this happens, we will make some suggestions who the participant might like to talk with about this. If during an interview or workshop a participant tells us about something that makes us think someone is at risk of serious harm, we will contact an appropriate person for support

Where is the study run from?
University of Leeds (UK)

When is the study starting and how long is it expected to run for?
September 2024 to August 2027

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

Who is the main contact?
Prof. Lucy Ziegler, l.e.ziegler@leeds.ac.uk
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Contact information

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Principal Investigator

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Additional identifiers

EudraCT/CTIS number
Nil known

IRAS number
334486

ClinicalTrials.gov number
Nil known

Secondary identifying numbers
CPMS 58619, NIHR159019

Study information

Scientific Title
Helping Optimise Primary Care Support During Transition from Children’s Hospice Care

Acronym
HOPSCOTCH

Study objectives
HOPSCOTCH aims to develop a toolbox of resources, with modules for patients, primary care and children’s hospices, to enhance the involvement of GP practices in the care of young people with life-limiting conditions particularly during transition from children's hospice care.

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 02/07/2025, Wales REC 3 (Castlebridge 4, 15-19 Cowbridge Road East, Cardiff, CF14 4XW, United Kingdom; +44 2922 940963; Wales.REC3@wales.nhs.uk), ref: 25/WA/0181

Study design
Observational qualitative

Primary study design
Observational

Secondary study design
Qualitative study

Study setting(s)
GP practice, Hospice

Study type(s)
Other

Participant information sheet
See study outputs table

Health condition(s) or problem(s) studied
Primary care support during transition from children’s hospice care

Interventions
The HOPSCOTCH study comprises three workstreams (WS), using an adapted Experience-Based Co-Design (EBCD) approach to develop and assess a primary care intervention supporting transitions from children’s to adult hospice services.

WS1: Young People and Family Perspectives

WS1 explores transition experiences from the viewpoint of young people and their families /carers. Eighteen participants will be recruited from 12 partner children’s hospices, representing three transition stages: pre-, during, and post-transition.

Part 1: Participants will engage in in-depth, audio-recorded interviews (up to 90 minutes), conducted in-person or via Microsoft Teams/telephone. Interviews follow a narrative and semi-structured format, focusing on primary care’s role. Demographic data will be collected via anonymised forms.
Part 2: Interviewees will be invited to a feedback workshop (online or in-person), using a ‘catalyst film’ derived from interview recordings to prompt emotional mapping discussions. Participants will identify and prioritise 4–5 key areas for improvement.
Part 3: Selected participants will join a joint co-design event with healthcare professionals.
Part 4: Volunteers may participate in small online co-development sessions to refine intervention components.

WS2: Healthcare Professional Perspectives

WS2 gathers insights from 18 clinicians: six each from general practice, adult palliative care, and paediatric palliative care.

Part 1: Interviews (up to 60 minutes) will explore transition processes, primary care engagement, and training needs. Conducted via Teams, telephone, or in-person, recordings will be transcribed and anonymised.
Part 2: A feedback workshop will present findings and the catalyst film from WS1. Documentary analysis of non-identifiable transition documents will support discussion. Participants will prioritise 4–5 feasible improvement areas.

Part 3: Professionals will join young people and families in a joint co-design event.
Part 4: Clinicians may join small co-development sessions to refine specific intervention elements.

WS3: Feasibility Testing

WS3 will assess the feasibility of implementing the HOPSCOTCH intervention in clinical practice. Details will be submitted in a future ethics application.

Co-Design Event and Outputs:
A one-day online co-design event will bring together all stakeholders. The morning session will present findings and facilitate process mapping to develop a logic model. Afternoon sessions will use this model to identify priorities and co-create the HOPSCOTCH toolbox.

Key Outputs:
1. Logic Model: Defines optimal primary care support during transition, outlining roles of young people, families, and professionals.
2. HOPSCOTCH Toolbox Modules:
-Young Person & Family Module: Guidance on engaging with GP teams.
-Primary Care Module: Consultation templates, training links, and engagement strategies.
-Specialist Palliative Care Module: Tools to enhance communication and information flow to primary care.

Intervention Type
Other

Phase
Not Specified

Primary outcome measure
1. Semi-structured interviews will be used to understand and explore the experience of transitioning from children's hospice support, from the perspectives of young people with life limiting conditions and their families.
2. Semi-structured interviews will be used to understand and explore the experience of supporting transition of young people with life limiting conditions and their families, from the perspectives of healthcare professionals working in primary care and adult or children's hospices.
3. Reflexive thematic analysis will be used to draw out key themes from the data and identify opportunities to enhance engagement of general practice in the coordination and delivery of care to young people as they transition from children's hospices.
4. Experience-based co-design (EBCD) inspired methodology will be used to co-design a complex intervention (the HOPSCOTCH toolbox) to facilitate this enhanced engagement.

Secondary outcome measures
There are no secondary outcome measures

Overall study start date
01/09/2024

Completion date
31/08/2027

Eligibility

Key inclusion criteria

Young people:
1. Young person with a life limiting condition
2. Minimum 14 years of age
3. Previous or current user of children’s hospice services
4. The young person must be approaching transition to adult services, in the process of transitioning to adult services or have transitioned to adult services within the last 5 years
5. Capacity (with support if required) to understand information and consent either in written or verbal form
6. Capacity and willingness to take part in a discussion about their experience

Parent or carer:
1. Parent or carer from the same household of a young person with a life limiting condition who is approaching transition to adult services, in the process of transitioning to adult services or has transitioned to adult services within the previous 5 years
2. Minimum 18 years of age
3. Parent or carer of a young person who is a previous or current user of children’s hospice services
4. Family or carers may still participate in the study if their young person has died within the previous 5 years and experienced any of the above stages of transition prior to death
5. Capacity to understand information and consent either in written or verbal form
6. Capacity and willingness to take part in a discussion about their experience

Healthcare professional:
1. Minimum 18 years of age
2. Work in primary care, adult hospice or children's hospice
3. Hospice staff has a role or responsibility in supporting transition
4. Capacity to understand information and consent either in written or verbal form
5. Capacity and willingness to take part in a discussion about their experience

Participant type(s)

Patient, Health professional, Carer, Other

Age group

Mixed

Lower age limit

14 Years

Sex

Both

Target number of participants

36

Key exclusion criteria

Young people:
1. Transition to adult services occurred more than 5 years ago
2. Under 14 years of age

3. Young people who are too unwell (as judged by the healthcare professional making initial contact) will not be approached for interview, but their family members may still participate if they wish to
4. Young people who are unable to participate in a conversational interview for any reason related to their condition will not be approached for interview, but their family members may participate if they wish to

Parent or carer:
1. Transition to adult services occurred more than 5 years ago
2. Unable to provide informed consent

Healthcare professionals:
1. None

Date of first enrolment
01/09/2025

Date of final enrolment
31/08/2026

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
Noah's Ark Children's Hospice
The Ark Byng Road
Barnet
United Kingdom
EN5 4NP

Study participating centre
St Oswalds Hospice
Regent Avenue
Newcastle upon Tyne
United Kingdom
NE3 1EE

Study participating centre
Shooting Star Childrens Hospice
The Avenue
Hampton

United Kingdom
TW12 3RA

Study participating centre
Helen and Douglas House
14a Magdalen Road
Oxford
United Kingdom
OX4 1RW

Study participating centre
East Anglia's Children's Hospices
Church Lane
Milton
Cambridge
United Kingdom
CB24 6AB

Study participating centre
Children's Hospice South West
Little Bridge House
Redlands Road
Fremington
Barnstaple
United Kingdom
EX31 2PZ

Study participating centre
Martin House Hospice
Martin House
Grove Road
Clifford
Wetherby
United Kingdom
LS23 6TX

Study participating centre
St Gemma's Hospice
329 Harrogate Road

Leeds
United Kingdom
LS17 6QD

Study participating centre
Marie Curie Hospice
Maudsley Street
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BD3 9LE

Study participating centre
University of Leeds
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Sponsor type
University/education

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ROR
https://ror.org/024mrxd33

Funder(s)

Funder type
Government

Funder Name
NIHR Evaluation, Trials and Studies Co-ordinating Centre (NETSCC)

Results and Publications

Publication and dissemination plan
Planned publication in a peer-reviewed journal

Intention to publish date

Individual participant data (IPD) sharing plan
The current data sharing plans for this study are unknown and will be 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?
Study website			24/07/2025	No	No
Participant information sheet	Healthcare Professionals version 2.0	01/07/2025	28/07/2025	No	Yes
Participant information sheet	Patient Carers version 2.0	01/07/2025	28/07/2025	No	Yes
Participant information sheet	Young persons version 2.0	01/07/2025	28/07/2025	No	Yes
Participant information sheet	Younger persons version 2.0	01/07/2025	28/07/2025	No	Yes
Protocol file	version 2.0	01/07/2025	28/07/2025	No	No