

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

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Registration date 08/09/2025	Overall study status Ongoing	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 08/09/2025	Condition category 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

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
Dr Emma Chapman, E.J.Chapman@leeds.ac.uk

Contact information

Type(s)
Principal investigator

Contact name
Prof Lucy Ziegler

ORCID ID
<https://orcid.org/0000-0001-9563-5014>

Contact details
Academic Unit of Palliative Care
Leeds Institute of Health Sciences
University of Leeds
Level 10
Worsley Building
Clarendon Way
Leeds
United Kingdom
LS2 9NL
-
l.e.ziegler@leeds.ac.uk

Type(s)
Public, Scientific

Contact name
Dr Emma Chapman

ORCID ID
<https://orcid.org/0000-0003-2859-2020>

Contact details

Academic Unit of Palliative Care
Leeds Institute of Health Sciences
University of Leeds
Level 10
Worsley Building
Clarendon Way
Leeds
United Kingdom
LS2 9NL
+44 1133430863
e.j.chapman@leeds.ac.uk

Additional identifiers

Integrated Research Application System (IRAS)
334486

Central Portfolio Management System (CPMS)
58619

National Institute for Health and Care Research (NIHR)
159019

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

Study type(s)

Other

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(s)

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.

Key secondary outcome(s)

There are no secondary outcome measures

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

Healthy volunteers allowed

No

Age group

Mixed

Lower age limit

14 years

Sex

All

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**

United Kingdom

England

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
Bradford
United Kingdom
BD3 9LE

Study participating centre

University of Leeds
Academic Unit of Palliative Care,
Worsley Building, Clarendon Way
Leeds
United Kingdom
LS2 9NL

Sponsor information

Organisation
University of Leeds

ROR
<https://ror.org/024mrx33>

Funder(s)

Funder type
Government

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

Results and Publications

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?
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
Study website			24/07/2025	No	No