

Within the UK, 32 out of every 10,000 children are living with a life-limiting condition or life-threatening illness (LLC/ LTI).



Research, from genetic studies to drug trials is vital to improving care for these children and their families, but the inclusion of this vulnerable population into research studies has been difficult.

[Barriers to Research Access: Voices, Experiences, and Solutions](#) (BRAVES) is a CLAHRC study focusing on improving access and participation in research for children and young people with LLC/LTI and their families.

A [new BITE](#) – a postcard “need to know” summary of our published research – shares the perceptions of clinicians and research leaders on their perceptions of the barriers preventing children and their families becoming involved in research.

The BRAVES team surveyed palliative care clinicians, often “gatekeepers” to children and their families getting involved in research asking them

***‘In your experience, what have you found to be the biggest barriers to palliative care research with children?’***

We also consulted Chief Investigators (CIs) – leaders of NIHR research studies involving CYP with LLC/LTI and their families. CI’s were invited to complete an anonymous, web-based questionnaire and three key barriers to research were emerged, alongside four potential solutions.

CLAHRC North Thames  
September 2018

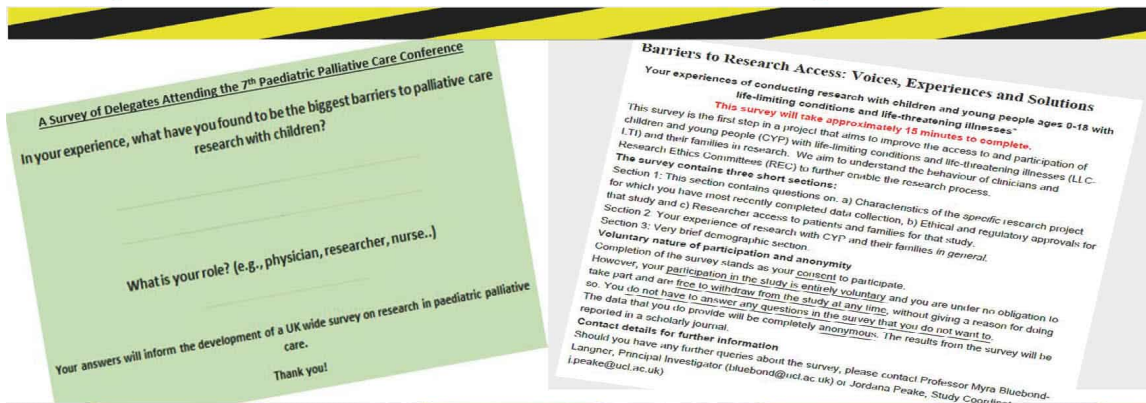


National Institute for  
Health Research

# CLAHRCBITE

Brokering Innovation Through Evidence

**Barriers to Research Access: Voices, Experiences, and Solutions (BRAVES)  
Reports from Palliative Care Clinicians and Chief Investigators**



**Within the UK, 32 out of every 10,000 children are living with a life-limiting condition or life-threatening illness (LLC/LTI).**

Further research, from genetic studies to drug trials to studies exploring care and treatment experiences and preferences, is needed to ensure that these children and their families receive the best care possible.

However, inclusion of this vulnerable population into research studies has been difficult. Though barriers to research with children and young people (CYP) with LLC/LTI undoubtedly exist, prior studies exploring the experiences of key stakeholders in the research process and their proposed solutions to these barriers are limited.

## What was the aim of the project?

The BRAVES project focuses on improving access and participation in research for children and young people with LLC/LTI and their families. The study explores the perspectives of key stakeholders through five work packages:

1. A systematic review exploring recruitment practices in research with CYP with LLC/LTIs
2. A survey of palliative care clinicians' perceptions of barriers to research with children (The CARDIFF survey)
3. A national survey of chief investigators' experiences conducting studies involving CYP with LLC/LTIs
4. An analysis of documents for studies of CYP with LLC/LTI submitted for research ethics committee (REC) review
5. Interviews exploring REC member experiences of reviewing research involving CYP with LLC/LTIs

## What we found

**Highlights from the survey of palliative care clinicians;**

Delegates from the 7<sup>th</sup> Paediatric Palliative Care Conference (Cardiff) were asked to respond to the question 'In your experience, what have you found to be the biggest barriers to palliative care research with children?'

This research is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care North Thames (CLAHRC North Thames).

