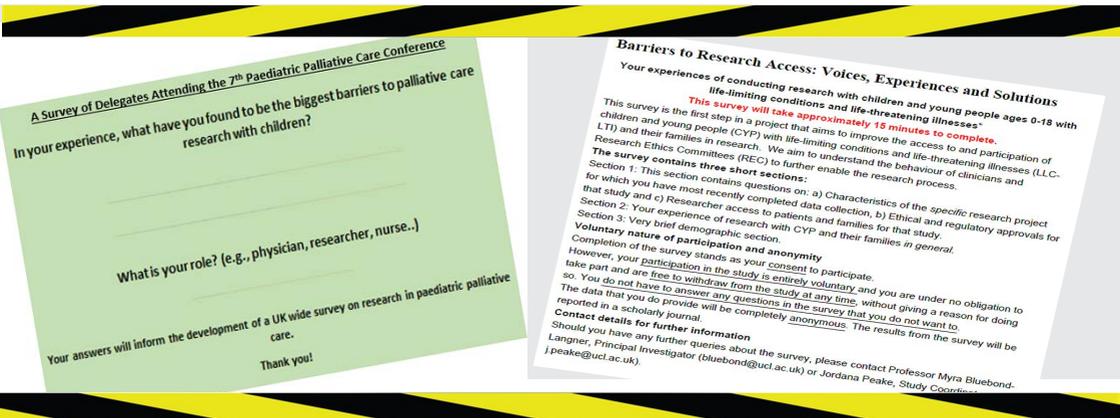


CLAHRCBITE

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 7th 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?'

Key barriers identified by palliative care clinicians;

Responses were received from 76 out of approximately 80 researchers and clinicians who were in the room on the last day of the conference. Four key barriers were identified in the data:

Table 1. Summary of barriers to conducting research identified from survey responses.

| Barrier | Exemplar quotes | Number of delegates mentioning barrier (n=76) |
|--|--|---|
| Time and other resources | 'Lack of protected time or accessible funding to develop research projects to a fundable stage' 'Lack of protected time or accessible funding to develop research projects to a fundable stage. Difficulty establishing academic-clinical partnerships – we're still in silos!' | 43 |
| Clinician's attitudes towards research | 'No academic niche – it doesn't fit with my university's priorities' 'Influencing the research agenda/priorities. Influencing organisational leaders of the importance/value of research in practice in voluntary sector – building research capacity by embedding researchers in teams... Small numbers issues – more collaboration across teams/areas to develop critical mass' | 31 |
| Clinician's perceptions of patients and their families | 'Clinician's willingness to involve families in what can be perceived as an extra burden. Also time; we know some of these families on their journey may be short and rushed' 'Concerns re overburdening families at a very sensitive time.' | 29 |
| Ethical approval processes | 'Nightmare of ethical approval' 'Ethics committees who are scared of PPC + dying!' | 24 |

Four key barriers identified by palliative care clinicians;

1. Time and resources: Clinicians already have high workloads and limited time, so prioritising research is challenging.
2. Clinician's attitudes to research: Clinicians noted a lack of experience and confidence in conducting research, and received little support to do so.
3. Clinicians' perceptions of patients and families: A paternalistic approach was noted, with clinicians afraid of burdening or 'upsetting' families.
4. Ethical approval process: Both clinicians and researchers found the ethical approval process challenging and restrictive.

Preliminary findings from the survey of chief investigators:

Chief investigators (CIs) for National Institute of Health Research portfolio studies involving CYP with LLC/LTI and their families were invited to complete an anonymous, web-based questionnaire, including both open and closed-ended questions. Sixty-one CIs participated in the survey; three key barriers to research were identified, alongside four potential solutions:

Three key barriers identified by CIs

- Ethical and regulatory approval: Many CIs found the application and research approval process complex and lengthy, typically taking more than six months to complete.
- Access to patients and families via clinicians: CIs noted variability in the willingness of clinicians to invite participants into CIs studies.
- Funding: Funding was the biggest barrier identified by CIs, particularly for those employed in clinical, rather than research focused, positions.

Four CI-proposed solutions to identified barriers

- Ensuring a well-considered methodology with broad inclusion criteria
- Attending REC/R&D meetings and seeking advice prior to submission
- Involving CYP and families and clinicians in research planning
- Embedding researchers into clinical teams

What's next?

Barriers to research with CYP with LLC/LTI and their families continue to exist. Ongoing research within BRAVES currently focuses on exploring REC responses to research proposals involving CYP with LLC/LTIs, and the perspectives of REC members who evaluate paediatric palliative care research proposals.

Find out More

A call for increased paediatric palliative care research: Identifying barriers.

Palliative Medicine 2016 Dec; 30(10):979-980. Epub 2016 May 13.

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A call for increased paediatric palliative care research: Identifying barriers.

Podcast hosted by Palliative Medicine, May 2016

<http://journals.sagepub.com/doi/suppl/10.1177/0269216316648087>

Research barriers in children and young people with life-limiting conditions: a survey

BMJ Supportive & Palliative Care 2018;0:1–7.

[doi:10.1136/bmjspcare-2018-001521](https://doi.org/10.1136/bmjspcare-2018-001521)

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Increasing participation of children and young people with life limiting conditions and life threatening illnesses in qualitative research

https://clahrc-norththames.nihr.ac.uk/methods_theme/increasing_participation_cyp