

BARRIERS TO RESEARCH ACCESS: VOICES, EXPERIENCES AND SOLUTIONS.

THE BRAVES PROJECT.

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AIMS:

BRAVES is a programme of research aiming (1) to explore the barriers to conducting research with children and young people (CYP) with life-limiting conditions and life-threatening illnesses (LLC/LTI) (2) to develop solutions for overcoming these barriers.

4 WORK PACKAGES:

**Work package 1:
SYSTEMATIC
REVIEW**

**Work package 2:
BARRIERS TO
RESEARCH**

**Work package 3:
SOLUTIONS**

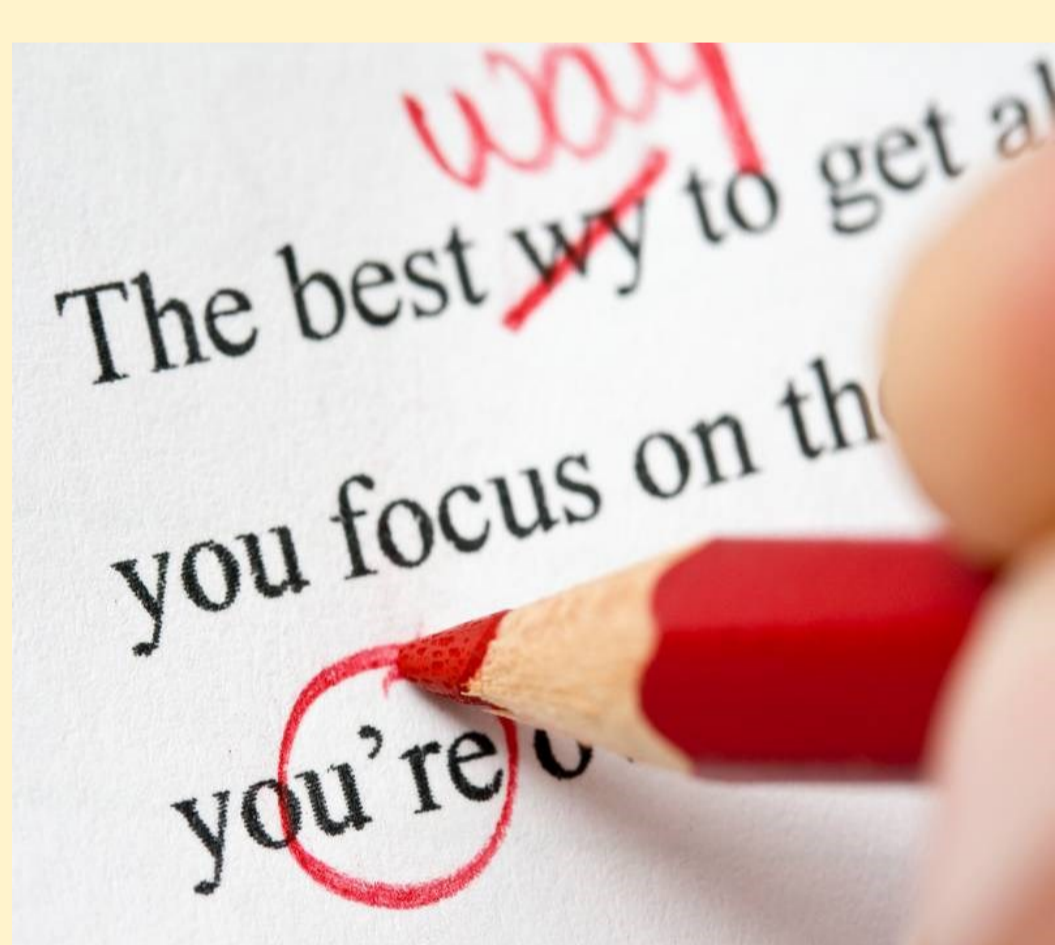
**Work package 4:
DOCUMENT
ANALYSIS**

KEY FINDING:

Recruitment strategies and recruitment results are not consistently reported in research with CYP with LLC/LTI.

RECOMMENDATIONS:

TO IMPROVE THE GENERALIZABILITY OF RESULTS, LET'S CORRECT REPORTING!



KEY FINDINGS:

Barriers to conducting research with CYP with LLC/LTI include:



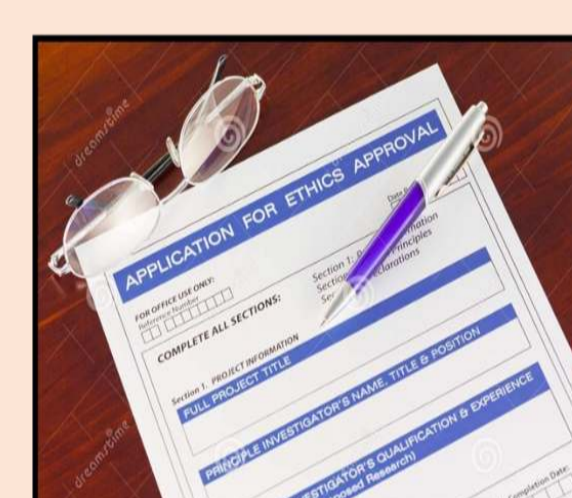
Time & funding



Clinician's attitudes towards research



Clinician gatekeeping



Ethical approval processes

KEY FINDINGS:

Solutions for overcoming barriers to research include:

- Having a well thought-out methodology with broad inclusion criteria
- Involving CYP, their families and their clinicians early in the research process
- Seeking advice from others who have been through the ethical and regulatory approval processes
- Embedding researchers in clinical teams.

KEY FINDINGS:

Researchers were more likely to receive a favourable opinion if they attended the Research Ethics Committee (REC) meeting where their research was being reviewed.

A favourable review was never given if the research team were not present at the meeting.

**RECOMMENDATIONS
GO TO THE REC MEETING!**



"Quick, let's make the decision before everyone else shows up!"

Review Article



The under reporting of recruitment strategies in research with children with life-threatening illnesses: A systematic review

Hudson BF, Oostendorp LJ, Candy B, Vickerstaff V, Jones L, Lakhanpaul M, Vickerstaff V, Jones L, Bluebond-Langner M, Stone P.

The under reporting of recruitment strategies in research with children with life-threatening illnesses: a systematic review. Palliat Med. [Internet], 2017 May;31(5):419-36.

Available from: doi: 10.1177/0269216316663856



Research Letter



A call for increased paediatric palliative care research: Identifying barriers

Beecham E, Hudson BF, Oostendorp L, Candy B, Jones L, Vickerstaff V, Lakhanpaul M, Stone P, Chambers L, Hall D, Hall K, Ganeshamoorthy T, Comac M, Bluebond-Langner M.

A call for increased paediatric palliative care research: Identifying barriers. Palliat Med. [Internet], 2016 Dec;30(10):979-80.

Available from: doi: 10.1177/0269216316664807



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

Jordana Natalie Peake,¹ Emma Beecham,^{1,2} Linda J M Oostendorp,^{1,2} Briony F Hudson,^{2,3} Patrick Stone,² Louise Jones,² Monica Lakhanpaul,⁴ Myra Bluebond-Langner¹

Peake JN, Beecham E, Oostendorp LJ, Hudson BF, Stone P, Jones L, Lakhanpaul M, Bluebond-Langner M.

Research barriers in children and young people with life-limiting conditions: a survey. BMJ Support Palliat Care. [Internet], 2018 Jul 31;

Available from: doi: 10.1136/bmjspcare-2018-001521



Challenges in receiving research ethics committee approval for studies involving children and young people with life-limiting conditions and life-threatening illnesses: An analysis of research ethics committee minutes and correspondence with principal investigators

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