**CHILDREN AND YOUNG PEOPLE SUPPORT RESEARCH WITHOUT PRIOR CONSENT IN LIFE THREATENING SITUATIONS: A QUALITATIVE STUDY**

**Kerry Woolfall**[[1]](#footnote-1)**, Louise Roper**1**, Frances Sherratt1, Paul McNamara**5**, Richard Appleton**[[2]](#footnote-2)**, Esther Crawley**[[3]](#footnote-3)**, Angus Dawson**[[4]](#footnote-4)**, Lucy Frith**1**, Carrol Gamble**[[5]](#footnote-5)**, Bridget Young**1**.**

**Background and aims**

Variations from informed consent (known as deferred consent or research without prior consent - RWPC) enable paediatric critical care research to proceed by allowing consent to be sought *after* a child has received an investigational intervention. The first trials conducted in this setting show high levels of recruitment, yet children and young people (CYP) were rarely involved in recruitment discussions, often because they were too young or too poorly [1](#_ENREF_1). We aimed to explore CYP’s views on RWPC and identify methods of involving them in decisions about their participation in critical care research.

**· Methods**

In-depth qualitative interview study involving 14 CYP (aged 7 to 15 years) with chronic health conditions and experience of paediatric emergency care treatment in the 12 months prior to interview.

**· Results**

CYP were keen to be included in critical care research without prior consent if doctors viewed the trial intervention to be safe and of potential benefit to participants and others. **All CYP felt that they have the right to be informed and have a say about their participation in a trial as soon as they had recovered. CYP suggest methods** to help practitioners and parents facilitate RWPC discussions with children, including videos, cartoons, websites and leaflets.

**· Conclusions:**

**CYP support research without prior consent in life threatening situations and provide examples of how multimedia resources could be used to engage and involve children in decisions about participation in research when they have recovered.**

Word count: 240

Author details:

Presenting author: Kerry Woolfall, Department of Psychological Sciences, Institute of Psychology, Health & Society, University of Liverpool, Liverpool, UK woolfall@liverpool.ac.uk

Louise Roper, Department of Psychological Sciences, Institute of Psychology, Health & Society, University of Liverpool, Liverpool, UK louise22@liverpool.ac.uk

Frances Sherratt, Department of Psychological Sciences, Institute of Psychology, Health & Society, University of Liverpool, Liverpool, UK, Sherratt@liverpool.ac.uk

Paul McNamara, Department of Child Health, Institute of Translational Medicine, University of Liverpool, Liverpool, UK mcnamp@liverpool.ac.uk

Richard Appleton, Neurology Department, Alder Hey Children’s Hospital, Liverpool, UK Richard.Appleton@alderhey.nhs.uk

Esther Crawley, School of Social & Community Medicine, University of Bristol, Bristol, UK Esther.Crawley@bristol.ac.uk

Angus Dawson, School of Public Health, University of Sydney, Sydney, Australia Angus.Dawson@sydney.edu.au

Lucy Frith, Department of Health Service Research, Institute of Psychology, Health & Society, University of Liverpool, Liverpool, UK frith@liverpool.ac.uk

Carrol Gamble, Department of Biostatistics, Institute of Translational Medicine, University of Liverpool, Liverpool, UK carrolp@liverpool.ac.uk

Bridget Young, Department of Psychological Sciences, Institute of Psychology, Health & Society, University of Liverpool, Liverpool, UK byoung@liverpool.ac.uk

1. The University of Liverpool, Institute of Psychology, Health & Society [↑](#footnote-ref-1)
2. Alder Hey Children’s Hospital [↑](#footnote-ref-2)
3. University of Bristol [↑](#footnote-ref-3)
4. University of Sydney [↑](#footnote-ref-4)
5. The University of Liverpool, Institute of Translational Medicine [↑](#footnote-ref-5)