

Survived so What? Identifying Priorities for Research with Children and Families Post-Paediatric Intensive Care Unit

Manning et al. (2018)
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For which topic were research priorities identified?

paediatric Intensive Care Unit survivors

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

The involvement of patients and the public in the development, implementation and evaluation of health care services and research is recognized to have tangible benefits in relation to effectiveness and credibility. However, despite >96% of children and young people surviving critical illness or injury, there is a paucity of published reports demonstrating their contribution to informing the priorities for aftercare services and outcomes research.

What was the objective?

to identify the service and research priorities for paediatric Intensive Care Unit survivors with children and young people, their families and other stakeholders

What was the outcome?

a list of 4 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

meeting

How were the priorities for research identified exactly?

Step 1: meetings: to evaluate PICU experiences and to identify priorities, meetings held separately for parents and health professionals and CYP who included PICU survivors, PICU survivor siblings and other children who had experienced health services, participants were asked to discuss the questions: How can the needs of CYP and families be better supported/ addressed? What should future projects/research focus on?

Which stakeholders took part?

CYP who had experienced a critical illness/injury, their parents and carer, siblings and other family members, health professionals, service managers and commissioners. Participants: 24 participants: 8 CYP aged 7-15 years (3 PICU survivors, 2 PICU survivor siblings, 3 who had engaged with health services), 6 parents and carers (including 5 parents/carers of PICU survivors), 8 health professionals, a commissioner, a service manager.

How were stakeholders recruited?

A purposive sampling approach was used: Eight CYP participants, and their families, from 'The SCETCH Project' were invited via postal mail to attend the consultation event. Other stakeholders, such as professionals, were invited to attend via local and regional email distribution lists. All invitees were requested to disseminate the invitation to other potentially interested parties.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.