

Consensus Research Priorities for Paediatric Status Epilepticus: A Delphi Study of Health Consumers, Researchers and Clinicians

Furyk et al. (2018)

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For which topic were research priorities identified?

pediatric status epilepticus

In which location was the research priority setting conducted?

Australia - Australia; Australia - New Zealand

Why was it conducted at all?

Status epilepticus (SE) is a paediatric emergency with significant morbidity and mortality. Recommendations beyond first line care are not based on high quality evidence. Emergency physicians and neurologists are key stakeholders in managing this condition. A collaborative, widely consulted approach to identifying priorities can help direct limited research funds appropriately.

What was the objective?

to identify consensus research priorities in pediatric status epilepticus among experts and health consumers

What was the outcome?

a ranking list of 9 research questions

How long did the research prioritization take?

April 2016 - November 2016

Which methods were used to identify research priorities?

Delphi

How were the priorities for research identified exactly?

Step 1: Delphi round 1: participants were asked to identify research priorities in the field of paediatric status epilepticus that they believed was lacking by asking: Thinking about your experience with paediatric convulsive status epilepticus, what are the most important research questions that need addressing. Step 2: data processing: questions collated into themes, mutually exclusive research questions developed, proposed questions then reviewed and refined, resulting in 37 unique questions in seven categories. Step 3: Delphi round 2: participants were asked to rate 32 questions, 16 questions that did not reach consensus refined. Step 4: Delphi round 3: participants were asked to re-rate

Which stakeholders took part?

Paediatric neurologists, emergency physicians, consumer participants. Delphi round 1: 54 participants. Delphi round 2: 42 participants. Delphi round 3: 44 participants.

How were stakeholders recruited?

Invitation was distributed to paediatric neurologists through the ANZCNS by email. Emergency physicians were invited to participate through site representatives of the PREDICT network. Site representatives at PREDICT sites were asked to nominate interested clinicians, and provide email details, to approximate respondent numbers from neurologists to maintain balance and representation of both groups and inclusion of perspectives of non researchers. Consumer participants: Information regarding the study objectives was distributed through Epilepsy Queensland social media webpages, with an explanatory sheet, and a link to participation in the survey.

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.