



Finding out what is most important to measure in research for children with epilepsy

Key Points

- We reviewed published research and made a list of all the ways used to measure effects of epilepsy and whether treatments for epilepsy work. We grouped together any outcomes that are similar.
- Young people with epilepsy, parents and health professionals took part in an online survey. The survey asked them to rate which of the outcomes they thought are most important to measure in child epilepsy research.
- A smaller number of young people with epilepsy, parents and health professionals took part in a meeting to reach agreement about the most important ways to measure as outcomes in research.
- The 38 outcomes we agreed on are proposed as a 'core outcome set' of what should be measured in all child epilepsy research.

1. Who did the study and why?

- This study is part of a large research project called **CASTLE** which stands for 'Changing Agendas on Sleep Treatment and Learning in Epilepsy'. CASTLE is focused on the most common type of childhood epilepsy, which is sometimes called rolandic epilepsy.
- The aim of CASTLE is to help answer the question 'which kind of treatment is best for children with rolandic epilepsy?' It might be best to treat children with medicine or not. We do not know yet. That is why the CASTLE study is important.
- This first part of CASTLE is called the CHOICE (Core Health Outcomes in Childhood Epilepsy) study. The aim of CHOICE was to find out which outcomes are most important to measure in child epilepsy research, with help from young people with epilepsy, their families and health professionals. This work is important because it makes sure child epilepsy research in the future includes outcomes that are important to families. The study was led by a team of researchers and health professionals. The main research site was King's College London with help from researchers and clinicians around England and Wales.

2. What did we do?

STEP 1: Identify Outcomes

- We searched for all published research studies on rolandic epilepsy and listed all the ways that were used to measure the effects of epilepsy
- We listed the outcomes and similar ones were grouped
- The list of the outcomes were put in to an online Delphi survey. A Delphi survey is a process to reach agreement between different groups of people.

STEP 2: Online Delphi survey



Round 1

- We needed the help of (1) young people with epilepsy, (2) their parents and (3) professionals to work out which of the outcomes from the review were most important.
- Participants took part in the Delphi survey as three separate groups and were asked to rate how important each outcome was on a scale of 1 (not important) to 10 (critical).

Not important			Important but not critical			Critical		
1	2	3	4	5	6	7	8	9
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Round 2

- A few weeks later, participants were asked to take part in Round 2 of the survey. They could see their original ratings of the outcomes and the ratings of the other groups.
- Participants could decide whether to keep their rating the same, or to change it to agree more or less with other participants in the groups.

We decided beforehand that only outcomes rated as important (7-9) by more than 70% of the people in all three groups in the survey would automatically be included in the core outcome set.



STEP 3: Face-to-face consensus meeting

- We invited the young people, parents and health professionals who took part in both rounds of the survey to take part in a face-to-face meeting in London.
- The meeting was used to discuss and vote on the outcomes that did not reach agreement in the survey and to confirm the final core outcomes.

3. What did we find?

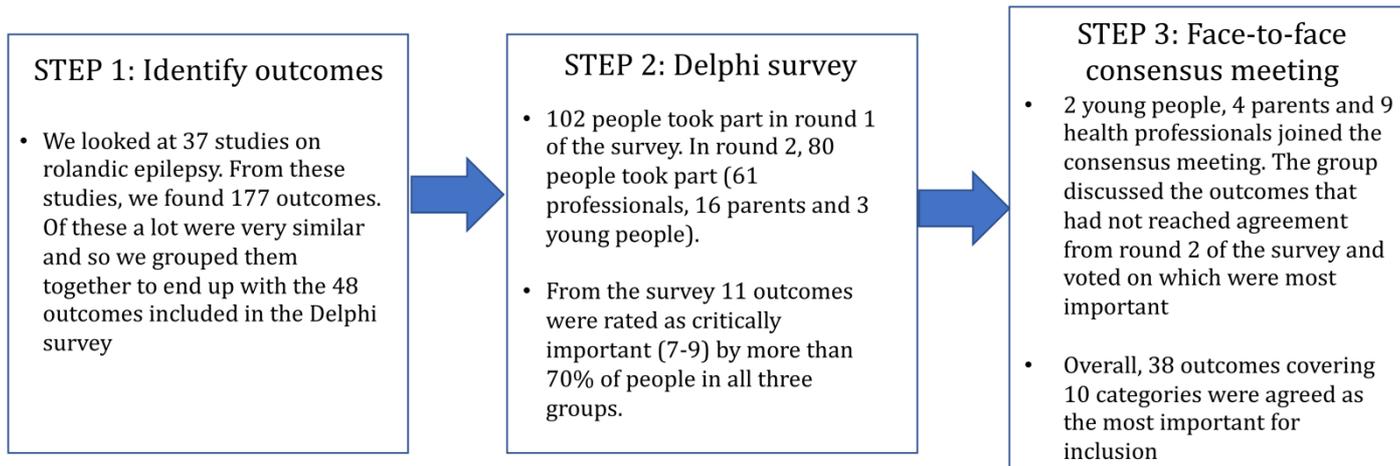


Table: An example of one outcome from each of the 10 categories.

Category	Outcome
Seizures	Seizure freedom
Sleep	Daytime sleepiness
Social functioning	Ability to join in activities with others
Mental Health	Feelings about having epilepsy
Cognition	Learning
Physical functioning	Movement ability, gross motor function
Behaviour	Impulsivity
Adverse events	Adverse events or reactions
Family life	Relationships with parents and siblings
Global quality of life	Global Quality of life

The full list of outcomes can be found on www.castlestudy.org.uk/choice

4. What's next?

This study brought together young people with epilepsy, parents and professionals to reach agreement towards a core set of outcomes to measure in child epilepsy research. We suggest that future studies on treatment for childhood epilepsy take into account the outcomes we suggest.

Further research could focus on:

- ranking the outcomes to try and reduce the number of outcomes to a more 'critical' core outcome set for research. This will make it easier to use in research.
- looking at how to measure the outcomes, such as questionnaires used to measure health related quality of life specifically for children with epilepsy.

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