Core Health Outcomes In Childhood Epilepsy (CHOICE) study: Development of a Core Outcome Set (COS) using systematic review methods and a Delphi survey consensus

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1. Introduction

Rolandic epilepsy, also known as benign epilepsy with centro-temporal spikes (BECTS), is the most common type of childhood epilepsy. Seizure freedom is most often reported as the primary outcome to measure in research. Yet, it is also important to consider side-effects of interventions and the impact these have on a child’s quality of life.

The aim of this study was to develop a Core Outcome Set (COS) to be used in evaluative research of interventions for children with rolandic epilepsy. Our protocol is published.1

2. Methods

Step 1: Identify candidate outcomes
Step 2: Delphi Survey
Step 3: Ratify COS

In the Delphi, participants rated from 1 (not important) to 9 (critical) whether an outcome was important for inclusion in the COS. Outcomes that did not reach our pre-defined consensus definition (fig 1) were discussed & voted on in the meeting. The Delphi results were displayed in the consensus meeting as pie charts (fig 2).

We used COMET (Core Outcome Measures in Effectiveness Trials) initiative guidance 2

3. Results

Identify candidate outcomes from systematic review
• 339 abstracts were screened and 37 papers were eligible for the review. Verbatim outcomes were recorded
• 48 outcomes were selected for Round 1 of the Delphi

Seek consensus on important domains (Delphi)
• 61 professionals, 16 parents and 3 young people took part fully in a 2 Round Delphi survey as separate Stakeholder groups. 52 outcomes were rated in Round 2 after 4 outcomes were suggested by participants in Round 1

Review consensus and ratify Core Outcome Set
• 15 people (4 parents, 2 children, 9 professionals) from the Delphi survey participated part in a face-to-face consensus meeting.

38 outcomes were ratified for inclusion in the COS which can be grouped into 10 overall domains (bold words)

4. Conclusions

Our methodology was a proportionate and pragmatic approach towards producing a COS for evaluating research on interventions aiming to improve the health of children with RE+. The findings may be generalisable to other common childhood epilepsies. We will review ways to measure the outcomes in the COS with guidance 3

References
4 Global Quality of Life: Mental health Fears of having a seizure
5 >70% voted important (7-9) across all 3 stakeholders
6 <70% voted important (7-9) across all 3 stakeholders
7 >100% voted important (7-9) across all 3 stakeholders
8 Not important, Important, Critical

Fig 1. Pre-defined consensus

Fig 2. Round 2 Delphi result for ‘Fears of having a seizure’ outcome

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Professionals (n=61) Parents (n=16) Young People (n=3)

84% 81% 100%

Not important, Important, Critical

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