Core Health Outcomes In Childhood Epilepsy (CHOICE study): Selection of a Core Outcome Set (COS)

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Introduction

Rolandic epilepsy, also known as benign epilepsy with centro-temporal spikes (BECTS), is the most common type of childhood epilepsy.

Seizure freedom is frequently reported as the most common outcome to measure. Yet, it is important to consider sideeffects of antiepileptic drugs and the impact these have on a child's life.

The aim of this work 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.¹²

Methods

Identify candidate outcomes from literature 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 as 3 stakeholder groups. 52 outcomés were rated in Round 2 after 4 outcomes were suggested by participants in Round 1.

Ratify COS

Step 1

Step 2

Step 3

• 15 people (2 young people, 4 parents and 9 professionals) from the Delphi survey participated part in a face-to-facé consensus meeting

We used COMET (Core Outcome Measures in Effectiveness Trials) initiative 10 guidance

Results

In the Delphi, participants

to 9 (critical) whether an

rated from 1 (not important)

outcome was important for

displayed in the consensus

2). Outcomes that did not

reach our **pre-defined**

on in the meeting.

meeting as pie charts (figure

consensus definition (figure

39 outcomes were ratified

for inclusion in the COS which

can be grouped in to 10 overall

1) were discussed & voted

inclusion in the COS. The

Delphi results were

Seizure freedom

Seizures

Family functioning

Family life

Cognition Speech & Language

> Social functioning Ability to join in

> > activities with others

Rolandic

Sleep

Time spent asleep at

night

Epilepsy

Core Outcome Set (39 outcomes, 10

Domains)

Global Quality of Life

Overall quality of life

Mental health Fears of having a seizure

Conclusions

Behaviour

Behavioural

concerns

Physical functioning

Manual ability: fine

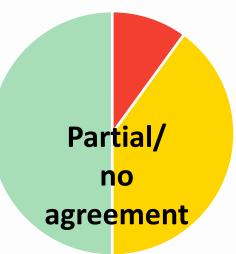
motor

consensus **Adverse events**

>70% voted not important (1-3) across all 3 stakeholders ■ Not important ■ Important ■ Critical

Fig. 1 Pre-defined

<70% voted important (7-9) across all 3 stakeholders



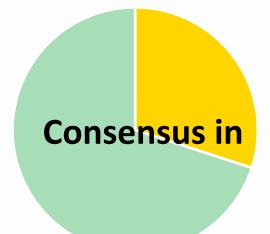
Stakeholder

Stakeholder

Consensus out

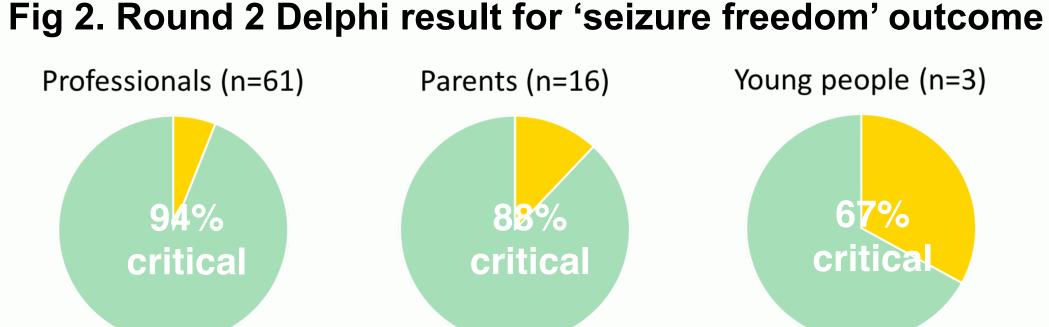
■ Not important ■ Important ■ Critical Stakeholder

>70% voted important (7-9) across all 3 stakeholders



Not important - Important - Critical

domains (bold words).



Young people (n=3) ■ Not important ■ Important ■ Critical

We have produced the first COS for evaluative research in rolandic epilepsy. The findings may be generaliseable to other common childhood epilepsies. We will review ways to measure the outcomes in the COS with guidance 11

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■ Not important ■ Important ■ Critical





■ Not important ■ Important ■ Critical





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References & Affiliations

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⁶ Edge Hill University, UK ⁷ Bangor University, UK

⁸ University of Liverpool, UK ⁹ Evelina London Children's Hospital & King's College London, UK ⁰ Williamson, P. et al. The COMET Initiative: http://www.comet-initiative.org ¹¹ Mokkink, L. B. et al. (2010). The COSMIN checklist for assessing the methodological quality

of studies on measurement properties of health status measurement instruments: an international Delphi study. Quality of life research 19.4: 539-549. ¹² Morris, C. et al (2017). Core Health Outcomes in Childhood Epilepsy (CHOICE): protocol for the selection of a core outcomes set. Trials, 18(1), p572.

