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

Holly Crudgington¹, Christopher Morris², Colin Dunkley³, Frances Gibbon⁴, Janet Currier⁵, Deborah Roberts⁶, Morwenna Rogers⁷, Lucy Bray⁸, Bernie Carter⁹, Dyfrig Hughesⁱ⁰, Catrin Tudur Smith¹¹, Paula Williamson¹², Paul Gringras¹³ & Deb Pal¹⁴

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 side-effects 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.

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 outcomes were rated in Round 2 after 4 outcomes were suggested by participants in Round 1.

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

We used COMET (Core Outcome Measures in Effectiveness Trials) initiative¹⁰ guidance

Results

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

39 outcomes were ratified for inclusion in the COS which can be grouped in to 10 overall domains (bold words).

Rolandic Epilepsy

Core Outcome Set (39 outcomes, 10 Domains)

Fig 1 Pre-defined consensus

Fig 2. Round 2 Delphi result for ‘seizure freedom’ outcome

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

Conclusions

We have produced the first COS for evaluative research in rolandic epilepsy. The findings may be generalisable to other common childhood epilepsies. We will review ways to measure the outcomes in the COS with guidance¹¹

References & Affiliations

This poster presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (RP-PG-0615-2007). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

NIHR:
£599,500; £513,041; £1,012,500

atum Research as part of the National Institute for Health Research (NIHR) Programme Grants for Applied Research Programme (RP-PG-0615-2007). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.