

# BEYOND SEIZURE CONTROL

**Functioning outcomes** are also important to **parents** including learning and cognition, quality of life, independence and participation in everyday life.

*"It's looking at the whole child and how everything impacts"* (FP8)

## A mixed methods study to develop a core outcome set for refractory childhood epilepsy treated with ketogenic diet therapy: Preliminary findings

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### Scoping Review of Outcomes

- Studies of childhood epilepsy treated with ketogenic diet (KD) therapy
- **2663** articles (Jan 2008-Oct 2018)
- **147** met inclusion criteria

### Semi-Structured Interviews

- **21** parents of a child with epilepsy currently or recently treated with KD
- Aim: Explore their experiences of epilepsy treated with KD and views on outcomes
- Content analysis identified all outcomes in transcripts

### Outcome List for Delphi Survey

- Outcomes identified in scoping review and interviews were collated, then grouped into domains according to the COMET taxonomy
- Review and ratification with the Study Advisory Group (parents, KD charity representative and KD dietitian)

## RESULTS

The scoping review identified 921 verbatim outcomes, sorted into 90 unique outcome categories, then classified into 21 domains of the COMET taxonomy. Fig.1 maps the 10 most commonly reported outcomes. Only 52% of outcomes were reported more than once. 59% were measured subjectively and only 13 articles used a validated assessment tool. The list was ratified to 70 outcomes following review with the Study Advisory Group.

When interviewed, parents identified 39 outcomes from the scoping review and 7 new outcomes; parental health and wellbeing, family life, participation in everyday life, parent's confidence with KD, independence, use of rescue medication and seizure duration. Parents shared meaningful insights and reasoning (fig. 2) for their prioritisation of individual outcomes (table 1). Seizure reduction, learning and cognition, AED reduction, quality of life, independence and participation were most often identified as priority outcomes.

## CONCLUSIONS

1. Variability in reported outcomes demonstrates a clear need for a core outcome set for paediatric epilepsy treated with KD therapy (COMET registration #1116).
2. Measured and reported outcomes don't always reflect parents' views on important or priority outcomes

## NEXT STEPS

Parents, professionals, and researchers are participating in a 2-round Delphi survey and consensus meeting to agree priority outcomes. The core outcome set will guide outcome measurement and reporting in future trials and clinical practice.

Fig.1 MAP OF THE 10 MOST COMMONLY REPORTED OUTCOMES IN SCOPING REVIEW

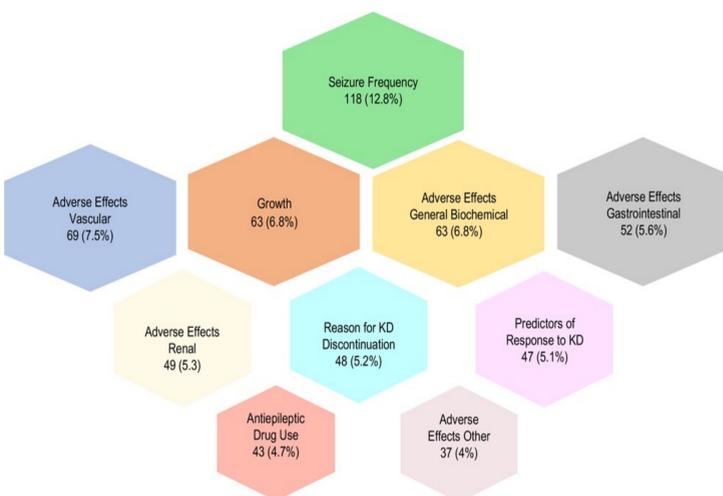


Fig.2 PARENTS VIEWS ON PRIORITY OUTCOMES

"My priority outcome... was definitely seizure control. That was the reason we did it [KD] But I think if we had not seen the benefit on seizures we'd have still stayed on because of the alertness and quality of life....It's looking at the whole child and how everything impact" (FP8)

"Quality of life is my first, I know that. Just him being able to do..just to have the same experiences as others (FP19). As well as quality of life, life experiences too. We're a family who try to get out and about" (partner MP2)

"Definitely the development. Definitely. It means that even if he was still having seizures now but he was able to be in school and they were mainly controlled and he was still being a normal child, then I think that's the most important thing-that they have some sort of normality" (FP9)

"I think seizure freedom was obviously the goal, but I think having the behaviour... and being medication free was also really important. Not everyone gets to that stage but that was a big step for us being medication free" (FP15)

"For him its amazing that he can go to school. He was so fascinated that he will be able to go to school like a regular kid and not study alone. Kids like to be together" (FP5)

"For me progress, just the cognitive ones for me were the biggest... That was worth anything we go through. The seizures are never going to be controlled... but their livable. The cognitive benefits for him were my biggest step forward and that was just amazing" (FP7)

TABLE 1. PRIORITY OUTCOMES IDENTIFIED BY PARENTS

Outcome	N identified
Seizure reduction	6
Learning and cognition	6
Anti-epileptic drug reduction	4
Quality of life (child)	4
Independence	3
Participation	3
Alertness	1
Speech and language	1
Seizure freedom	1
Fatigue	1
Growth	1
Mobility	1
Improved behaviour	1

Ethical approval was granted (London-Surrey REC, 19/LO/1680)

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We extend a big thank you to the parents who participated



Take a picture to download the poster and visit our study webpage

