



Which questionnaires are best to assess the health-related quality of life in children with epilepsy?

Key points of the study

- Health-related quality of life is how someone feels about their daily life and wellbeing. It is a term that covers many things including emotional, social and physical aspects of health. It is an important focus for research in childhood epilepsy because of the medical, social, and psychological complications of seizures and epilepsy medications. Structured questionnaires are used to measure health-related quality of life.
- A systematic review brings together all of the evidence to help answer a specific research question. We conducted a systematic review to find and evaluate all of the questionnaires that exist to measure health-related quality of life in children with epilepsy.
- We identified 11 questionnaires that measure health-related quality of life specifically for children with epilepsy. Some questionnaires are for a child to complete and others are designed for either a child and/or parent to complete. We found 27 research studies that had evaluated the 11 questionnaires and assessed how 'robust' the measurement is.
- Our review recommends two leading questionnaires with more robust evidence of better measurement properties: The Quality of Life in Childhood Epilepsy questionnaire (called "QoLCE-55" for short) which is for parents to complete, and the Health-related Quality of Life Measure for Children with Epilepsy questionnaire (called "CHEQoL" for short) which is for both the child and parent to complete.
- It is also important to consider what the specific content of a questionnaire is and whether it measures things that are important to children with epilepsy and their families.

1. Who did the study and why?

- The study was led by a team of researchers and health professionals mainly from King's College London and the University of Exeter Medical School.
- The research is part of the [Core Health Outcomes in Childhood Epilepsy \(CHOICE\) Study](#), which is itself part of a research programme called '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 National Institute for Health Research (NIHR) funds this research.
- *Why?*
Health-related quality of life is important to measure in childhood epilepsy research. This is done by using structured questionnaires. We wanted to bring together all of the evidence there is about these questionnaires so that we could recommend the 'best' questionnaires to use in epilepsy research.

2. What did we do?

- We undertook a **systematic review**. A systematic review is an un-biased, in-depth method for answering a particular research question. It brings together all of the results from previously published research. Our research question was to find out *"which questionnaires are best to assess the health-related quality of life in children with epilepsy are good?"*
- For a questionnaire to be considered '**good**' it needs to meet standard criteria across a range of **measurement properties**.

There are a number of different measurement properties, including validity and reliability:

- **validity** is how well a questionnaire measures what it aims to assess
- **reliability** is whether the questionnaire measures consistently each time it is completed

How did we search for evidence?

- We searched online libraries that catalogue published research papers looking for questionnaires that measure health-related quality of life in children with epilepsy.
- Then we looked for studies that tested the measurement properties of the questionnaires in children with epilepsy. We included questionnaires that were evaluated in children with epilepsy aged 5-16 years old.

How did we judge the measurement properties?

- We noted descriptive characteristics of each questionnaire, such as whether it is completed by a child and/or parent.

- We recorded details about the measurement properties of questionnaires that was reported in the research papers.
- We used a standard recognised method for assessing how well a study was done to check the quality of the research studies.
- We summarised all of this evidence so that we could make recommendations.

3. What did we find?

- We found 11 questionnaires that measure health-related quality of life in children with epilepsy. We found 27 published research papers that had tested the 11 questionnaires.
- The quality of the research about the questionnaires was variable. More recently published studies reported their methods more fully.
- No questionnaire had been tested across all of the measurement properties that we examined.
- There were two leading questionnaires from the review that had more high-quality evidence:
 - **The Quality of Life in Childhood Epilepsy (QoLCE-55)** is for parents of children with epilepsy aged 4-18 years to complete. It has 55 questions.
 - **The Health-related Quality of Life Measure for Children with Epilepsy (CHEQoL)** is for children and for parents of children aged 6-15 years with epilepsy to complete. It has 25 questions.

How are these findings useful?

- This review highlights the strengths and limitations of current questionnaires that measure health-related quality of life for children with epilepsy.

4. What's next?

- It is important to consider what aspects of health a questionnaire measures. It is also important that the questionnaire is acceptable to young people with epilepsy and their families.

- Recently we proposed a top 10 most important outcomes for children with epilepsy: seizures, sleep, social functioning, mental health, cognition, physical functioning, behaviour, adverse events, family life and global quality of life. These outcomes were rated as important to measure in research about childhood epilepsy by young people with epilepsy and their families and clinicians ([Click here to read a plain English summary of how we decided the top 10 outcomes](#)).
- We are looking to see the extent that the questionnaires we identified measure these important aspects of health.

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