

## Which questionnaire is best for assessing health and quality of life in children with neurodisability?

***Patient Reported Outcome Measures (PROMs) are short questionnaires, completed by the person being treated, to assess their health at a single point in time.***

### What did we find?

- We found 35 PROMs that aim to measure health or health related quality of life in children. 12 of these PROMs were tested in children with neurodisability.
- The most common conditions in which these 12 PROMs were tested were cerebral palsy, epilepsy, ADHD, autism and traumatic brain injury.
- The ***Pediatric Quality of Life (PedsQL)*** and ***Child Health Questionnaire (CHQ)*** were tested more than any other PROM but evidence from studies suggests that neither are strong measures.
- We found that the PROM with the most evidence for being a good measure of health in children with neurodisability was one called ***DISABKIDS***.
- ***KIDSCREEN*** and ***Child Health Utility (CHU-9D)*** were also found to be better than others however they had not been tested enough in children with neurodisability.
- There was not enough evidence to find out overall how well PROMs work in children with neurodisability, especially for assessing meaningful changes in health.



### Why did we do this review?

Patient Reported Outcome Measures (PROMs) are used to assess health and changes in health in the NHS. Bringing together PROM scores for groups of patients provides a way of seeing whether services, treatments and therapies are improving health outcomes over time. It is vital therefore that PROMs are tested well and are an accurate way of measuring health outcomes.

We wanted to find all the studies that tested the use of PROMs in children, and identify which PROMs work best for children with neurodisability.

### How did we do this review?

The research was a systematic review. This brings together the results of all studies addressing the same research question.

First we identified all the currently available PROMs that could be used to measure child health and wellbeing. Then we reviewed all the studies that tested the PROMs in children. Next we looked at the evidence from studies that tested these PROMs specifically in groups of children with neurodisability conditions.

## Quality of the research and cautionary notes

The studies we found varied in quality, with newer studies reported more completely and of better quality than older studies.

Overall, there was not enough evidence to find out how well PROMs work in children with neurodisability especially in assessing meaningful changes in health. Even the questionnaires that were found to work best in groups of children with neurodisability - **DISABKIDS**, **KIDSCREEN** and **Child Health Utility (CHU-9D)** - have not been tested thoroughly enough.

None of the existing PROMs assess all the key areas of health identified by young people with neurodisability, parents and clinicians. These key areas include communication, emotional wellbeing, pain, sleep, mobility, self-care, independence, mental health, community and social life, behaviour, toileting and safety.

## What next?

This work shows that the PROMs we found need to be tested more in children with neurodisability, particularly to find out what changes in the scores from the PROMs means about changes to their health.

The fact that none of the existing PROMs assess all of the key areas of health as identified by the children, parents and clinicians means that a new questionnaire could be warranted. However, it would be useful to research whether PROMs that only measure one or two outcomes (e.g. pain or sleep) are acceptable to children with neurodisability and their parents before starting the development of a new PROM.



## Contact details and further information about the published paper:

The PenCLAHRC EST is part of Evidence Synthesis and Modelling for Health Improvement (ESMI), at the University of Exeter Medical School. Further information about this research is available on the University of Exeter Medical School website: <http://medicine.exeter.ac.uk/esmi/workstreams/>

This work was carried out in collaboration with the Peninsula Cerebra Research Unit (PenCRU). Some of the text is taken from the PenCRU research summary:

<http://www.pencru.org/media/universityofexeter/medicalschoo/subsites/pencru/PLSPROMSinND.pdf>

The full version of the systematic review of these findings is published in Health Services and Delivery Research. You can access the paper here: <http://dx.doi.org/10.3310/hsdr02150>

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