Peninsula Cerebra Research Unit
PenCRU Childhood Disability Research

Research Summary

# Questionnaires assessing children's health and quality of life: which one to use?

This research summary was written by PenCRU and members of the PenCRU Family Faculty

## Key findings

- Patient Reported Outcome Measures (PROMs) assess a patient's health at a single point in time, and are collected through short, self-completed questionnaires.
- Bringing together PROM scores for groups of patients provides a way to assess whether services, treatment and therapies are improving their health outcomes.
- We found 35 PROMs that aim to measure health or health-related quality of life for children.
- We identified 90 research studies for 21 of these questionnaires, where the measurement properties had been tested using English language versions in general populations.
- None of the questionnaires had been tested for all the necessary measurement properties, and there was little evidence that these questionnaires are robust to measure change in health.

## Who carried out this research and why?

The study was led by the team at Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School.

The National Institute for Health Research funded the research. This is the Government organisation that funds health related research in the UK.

Patient Reported Outcome Measures (PROMs) are short, self-completed questionnaires used to assess a patient's health at a single point in time. Responses to questions produce a score indicating better or worse health. Bringing together PROM scores provides one way to assess whether services, treatments and therapies are improving their health outcomes.

PROMs are used in research, clinical audits and as routine outcome indicators in the NHS. It is important to be very clear exactly which aspects of health are being measured. It is also vital that that the measures are robust for the purpose.

This study was part of a project examining health outcomes for children with neurodisability. The research was necessary to check which aspects of health are assessed by existing PROMs, and update whether there is evidence they work as expected when used with children generally.

There are a number of ways to check how good a measurement is. Examples of relevant and required 'measurement properties' include:

- *Validity* is whether the questionnaire measures what it says it does;
- *Proxy reliability* is whether scores from parent's proxy responses are the same as from children;
- *Test-retest reliability* is whether scores remain the same after a period of time, when no change has occurred during that period;
- *Responsiveness* examines how much scores change when health improves or gets worse.

## What did we do?

This type of research is called a systematic review. Systematic reviews bring together the results of all studies addressing the same research question. The aim is to provide a comprehensive and impartial summary of research evidence on a topic.

### How did we search for evidence?

We searched online libraries that catalogue published research papers. In the first stage we looked for PROMs that could be used for children with any neurodisability condition. In the second stage we looked for research studies that had examined measurement properties of these previously identified PROMs in a general population.

### How did we compare PROMs?

Characteristics of each PROM were catalogued, such as the target age group, number of questions, time to complete etc. We examined all the individual questions to identify which aspects of health each PROM assesses. We mapped these aspects of health using a classification system produce by the World Health Organization.

### How did we judge the measurement properties?

There are standard criteria for assessing whether any PROM score is likely to be valid and reliable. There are also standards for judging how well the research was done and reported. We applied these criteria to appraise both the evidence itself and the quality of the evidence.

## What did we find?

We found 35 PROMs that cover different age ranges and ask about various aspects of health. Different versions for both child self-report and parent report are available for some PROMs.

Some questions focus on functioning, asking about activities a child can or does do; other questions focus on wellbeing, asking how the child feels about a particular aspect of their health. Most PROMs include questions about social function, asking about social and community activities.

The questions and response options are formatted in various ways. Some use smiley faces or other illustrations, and others just words. Questionnaires vary in length; some are brief, others take 15-20 minutes or longer to complete.

When we looked for evidence from research that had tested how good the measurements were, we found 90 studies for 21 of the PROMs. These were research studies evaluating only English language versions of the selected questionnaires in a general population sample.

The quality of the research we looked at was variable. In general, recent studies were reported more completely than older ones and were judged to be of higher quality methods.

None of the PROMs had been tested on all the relevant measurement properties. PROMs that had more and higher quality evidence in support of their measurement properties were:

- Child Health & Illness Profile (CHIP)
- Healthy Pathways
- KIDSCREEN
- Multidimensional Student Life Satisfaction Scale (MSLSS)

The research we looked at suggests that scores from child and parent reports are not reliable. This is particularly the case for aspects of health that cannot be seen, such as emotional wellbeing. Therefore both child and parent responses should be gathered whenever possible.

Little is known about how well any of the PROMs measure change in general populations. Studies of responsiveness are more often done with children with specific conditions, and we did not include these in this part of the review.

## How are the findings useful?

There is keen interest to improve health outcomes for children, so we need ways to measure whether their health has improved.

The technical information about PROMs included in this review helps our understanding of the strengths and limitations of these assessments.

The information about what aspects of health are assessed by different PROMs is useful to help choose an outcome measure for specific purposes, such as the target of a therapy.

The information about measurement properties of particular PROMs will help in the selection of outcome measures that are likely to produce a robust measurement that is valid and reliable.

## What next?

The findings from this review provide a foundation for examining measurement properties of PROMs for use in other conditions.

In a later stage of this project we examined the evidence from studies that tested PROMs in groups of children with neurodisability conditions such as cerebral palsy, epilepsy etc. This work could be repeated for other conditions, using the work reported in this paper as a starting point.

## Who reviewed our research?

This study is published as two papers in a journal called Value in Health. Before the journal accepted the study to be published it asked independent experts to look at the papers and decide whether the research had been done properly and whether it was important.

**The full papers are published in the journal Value in Health and free accessible via these links:**

**http://www.valueinhealthjournal.com/article/S1098-3015(14)04792-5/pdf**

**http://www.valueinhealthjournal.com/article/S1098-3015(15)00013-3/pdf**

**or contact Astrid Janssens at a.janssens@exeter.ac.uk**

The team that carried out the research are: Astrid Janssens, Morwenna Rogers, Jo Thompson Coon, Karen Allen, Colin Green, Crispin Jenkinson, Alan Tennant, Stuart Logan and Chris Morris, with support from four parent members from the PenCRU Family Faculty.

Astrid, Morwenna, Jo, Karen, Colin, Chris and Stuart are all part of the Peninsula Cerebra Research Unit and or the NIHR Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC) at the University of Exeter Medical School. Crispin is head of the Health Services Research Unit at the University of Oxford and Alan is member of the Psychometric Laboratory for Health Sciences at the University of Leeds.

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