



## Research Summary

# Prioritising health outcomes for children and young people with neurodisability

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

## Key findings

- Young people with neurodisability, parent carers and health professionals worked together to prioritise the most important aspects of health for children/young people with neurodisability.
- A core set of outcomes were: communication, emotional wellbeing, pain, sleep, mobility, self-care, independence, mental health, community and social life, behaviour, toileting and safety.
- Patient Reported Outcome Measures (PROMs) are short, self-completed questionnaires used to assess a patient's health at a single point in time.
- Available PROMs measure some relevant aspects of health, but no PROM captures all the key domains prioritised as for children and young people with neurodisability.
- Further research could examine how to measure each aspect of health using PROMs.

## 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.

Health services are increasingly focused on measuring and monitoring outcomes, particularly those that reflect patients' priorities. To be meaningful, outcomes measured should be valued by patients and carers, be consistent with what health professionals seek to achieve, and be able to be measured robustly.

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 that the aspects of health being measured match the outcomes that families and health professionals think are most important.

This study was the final part of a major project examining health outcomes for children with neurodisability. The aims were to seek a shared vision between families and clinicians regarding key aspects of health, and then to appraise which PROMs could be used to assess them.

## What did we do?

In the earlier stages of the research we asked [families' views](#) on which health outcomes they thought were important, and we asked [health professionals](#) which outcomes they target and are most important for the NHS to improve. We also examined all the currently available [PROMs for measuring children's health](#) to see which aspects of health they measured.

These research activities produced a list of 33 aspects of health. Prioritisation was required in order to reduce this to a smaller core set of the more important aspects of health.

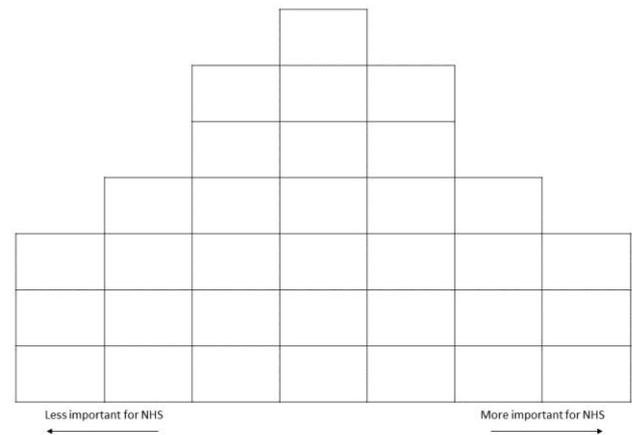
## Who took part?

We invited a representative group of people who had taken part in earlier stages of the research. Fifteen people participated in the prioritisation meeting: 3 young people, (one with autism, two with neuromuscular conditions who were wheelchair users), 5 parent carers of children with various complex conditions including one or more of cerebral palsy, autism, epilepsy, learning difficulties, and 7 health professionals: two paediatricians, physiotherapist, occupational therapist, nurse, paediatric surgeon, and a child and adolescent psychiatrist.

## How were aspects of health prioritised?

We split the participants into two groups, each with a mix of clinician and family representatives. The 33 aspects of health were represented on laminated cards, with an illustration. Participants were directed to work collectively in their groups to order the 33 cards on a grid with 33 boxes.

The column boxes on the right side of the grid were for those aspects of health that they felt should be more important for the NHS to focus on. The left side column boxes were labelled as 'less important', though not unimportant.



## How was the final choice made?

To bring together a core set of health outcomes we identified (i) higher priority aspects of health from the stakeholder meeting, (ii) aspects of health more valued by young people and parents in the qualitative study, (iii) aspects of health targeted by professionals in the surveys. Finally, we examined whether these aspects of health can be assessed for children with neurodisability using currently available PROMs.

## What did we find?

The groups engaged well and completed the task. The picture (below) shows the completed grid positions for one of the groups. The two groups didn't decide on exactly the same order, but both groups ranked communication and emotional wellbeing in the far right-hand column giving them the highest level of importance.

Shared priorities were communication, emotional wellbeing, pain, sleep, mobility, self-care, independence, mental health, and social activities. In addition, behaviour, toileting, and safety are important for parent carers and also targeted by health professionals.



None of the PROMs we found assesses all the prioritised aspects of health for children with neurodisability. Some of the existing PROMs do assess some of them, but not always in ways that are appropriate. For instance, some PROMs ask about mobility in terms of walking and running, but not about mobility generally, which might include using a wheelchair.

### How are the findings useful?

The research findings provide an incremental step towards a shared vision between families and clinicians for a core set of more important health outcomes for children with neurodisability.

Health services should now focus collectively on improving these priority aspects of health. So, the findings are important to clinicians, managers and also those responsible for commissioning services in the NHS.

A single PROM assessing the key aspects of health that could be applied across paediatric neurodisability remains to be developed.

The methods we used are relevant to the COMET (Core Outcome Measures for Evaluative Trials) Initiative. COMET is seeking ways to engage patients, carers and clinicians to agree core outcome sets for conditions. Then, to encourage researchers to all measure the core outcomes in the same way. This will improve the efficiency of research as results can be compared easily.

### What next?

Future research could appraise PROMs that specifically measure the prioritised aspects of health. This would inform how each of the outcome areas can best be measured.

The prioritisation activity could be repeated with other groups to see how consistent the priorities are across groups. The key aspects of health may vary for children with specific conditions.

### Who reviewed our research?

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

The full paper is published in the journal **Health and Quality of Life Outcomes** and free accessible: <http://www.hqlo.com/content/13/1/87> for further information contact [penclu@exeter.ac.uk](mailto:penclu@exeter.ac.uk)

The team that carried out the research are: Chris Morris, Astrid Janssens, Val Shilling, Amanda Allard, Andrew Fellowes, Richard Tomlinson, Jane Williams, Jo Thompson Coon, Morwenna Rogers, Bryony Beresford, Colin Green, Crispin Jenkinson, Alan Tennant, Stuart Logan, with four members from the PenCRU Family Faculty.

Chris, Astrid, Val, Jo, Morwenna, Colin, 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. Amanda and Andrew both work at the Council for Disabled Children. Richard is a Consultant Paediatrician in Exeter, and Jane is a Consultant Paediatrician in Nottingham. Bryony leads the children and families team at the Social Policy Research Unit. 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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