Morris et al. Trials 2015, 16(Suppl 1):O4
http://www.trialsjournal.com/content/16/S1/O4

TRIALS

ORAL PRESENTATION Open Access

Towards a shared vision for measureable and meaningful health outcomes for children and young people with neurodisability: qualitative research, Delphi survey, systematic review, and stakeholder prioritisation

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From The 4th Meeting of the Core Outcome Measures in Effectiveness Trials (COMET) Initiative
Rome, Italy. 19-20 November 2014

Objective

To seek a shared vision between families and clinicians regarding key aspects of health as outcomes, beyond mortality and morbidity, for children and young people with neurodisability. To appraise the appropriateness and measurement properties of multidimensional patient reported outcome measures (PROMs) to assess the outcome domains.

Methods

Relevant outcomes were identified from (i) qualitative research with children and young people with neurodisability and parent carers, (ii) Delphi survey with health professionals, and (iii) systematic review of PROMs. The International Classification of Functioning Disability and Health provided a common language to code aspects of health. A stakeholder group participated in a prioritisation Q-sort task. Participants 54 children and young people with neurodisability and 53 parent carers participated in either focus groups or interviews; 262 multidisciplinary health professionals took part in one or more rounds of a Delphi survey. 15 stakeholders participated in a consensus meeting: 3 young people, 5 parent carers, and 7 multidisciplinary health professionals.

Results

The qualitative study and Delphi survey suggested a range of aspects of health that are important to service users and targeted by health professionals. There was partial but not complete overlap. Key outcome areas prioritised were: communication, emotional wellbeing, pain, sleep, mobility, self-care, independence, mental health, social activities; behaviour, toileting, and safety were also important to many parents. No single multidimensional PROM was identified that captured all the key aspects of health. Evidence was lacking of one or more measurement properties for all candidate PROMs in children and young people with neurodisability, and especially for preference-based measures.

Conclusions

This research proposes a core suite of outcome domains for children and young people with neurodisability that can be used to assess health services routinely and in trials. Further work is required to produce a single PROM to measure these outcomes efficiently across neurodisability.

Acknowledgements

This study was part of research funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research programme (Project 10/2002/16). The views and opinions expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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Published: 29 May 2015

doi:10.1186/1745-6215-16-S1-O4
Cite this article as: Morris *et al.*: Towards a shared vision for measureable and meaningful health outcomes for children and young people with neurodisability: qualitative research, Delphi survey, systematic review, and stakeholder prioritisation. *Trials* 2015 **16**(Suppl 1):O4.