

This is a repository copy of *Informing the NHS Outcomes Framework:evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting.*

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/80851/>

Version: Published Version

Article:

Morris, Christopher, Janssens, Astrid, Allard, Amanda et al. (12 more authors) (2014) Informing the NHS Outcomes Framework:evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting. Health Services and Delivery Research. ISSN 2050-4357

<https://doi.org/10.3310/hsdr02150>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting

Christopher Morris,^{1*} Astrid Janssens,¹
Amanda Allard,² Joanne Thompson Coon,¹
Valerie Shilling,¹ Richard Tomlinson,³ Jane Williams,⁴
Andrew Fellowes,² Morwenna Rogers,¹ Karen Allen,¹
Bryony Beresford,⁵ Colin Green,¹ Crispin Jenkinson,⁶
Alan Tennant⁷ and Stuart Logan¹

¹University of Exeter Medical School, University of Exeter, Exeter, UK

²Council for Disabled Children, National Children's Bureau, London, UK

³Department of Child Health, Royal Devon and Exeter NHS Foundation Trust, Exeter, UK

⁴Department of Child Health and Paediatrics, Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust, Nottingham, UK

⁵Social Policy Research Unit, University of York, York, UK

⁶Department of Public Health, University of Oxford, Oxford, UK

⁷Department of Rehabilitation Medicine, University of Leeds, Leeds, UK

*Corresponding author

Declared competing interests of authors: none

Published May 2014

DOI: 10.3310/hsdr02150

Plain English summary

Informing the NHS Outcomes Framework

Health Services and Delivery Research 2014; Vol. 2: No. 15

DOI: 10.3310/hsdr02150

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain English summary

This research sought agreement on what children and young people with neurodisability want from their health care, and what clinicians are aiming to achieve. We spoke to 54 children and young people with neurodisability, and to an unrelated group of 53 parents in focus groups and interviews. We also engaged with over 200 health professionals in several rounds of an online survey. A small group of 15 young people, parents and professionals who had participated in the research then met to rank the most important outcomes. The key health outcomes were agreed as communication, emotional well-being, pain, mobility, independence/self-care, worry/mental health, social activities and sleep. Parents of children with learning disability also rated behaviour, toileting and safety as important. NHS performance is increasingly being judged using questionnaires called patient-reported outcome measures, or PROMs. Therefore, we assessed whether or not the key outcomes we identified could be measured reliably using existing PROM questionnaires. No PROM was found to be entirely satisfactory in scientific terms but some showed potential. Few PROMs had been tested specifically with children and young people affected by neurodisability. Young people and parents reacted unfavourably to examples of the questionnaires we showed them in our research. Agreement between parents and young people's responses to these questionnaires is generally not reliable. However, the views of parents are crucial, particularly for children who cannot respond themselves. Further consultation with young people, families and professionals is warranted to support using PROMs to measure NHS outcomes. Research to test potential PROMs with different age groups and conditions would be valuable.

Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nihredit@southampton.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the *Health Services and Delivery Research* journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: www.netssc.ac.uk/hsdr/

This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its proceeding programmes as project number 10/2002/16. The contractual start date was in February 2012. The final report began editorial review in June 2013 and was accepted for publication in October 2013. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2014. This work was produced by Morris *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Health Services and Delivery Research Editor-in-Chief

Professor Ray Fitzpatrick Professor of Public Health and Primary Care, University of Oxford, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley Director, NIHR Evaluation, Trials and Studies and Director of the HTA Programme, UK

NIHR Journals Library Editors

Professor Ken Stein Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

Professor Aileen Clarke Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Peter Davidson Director of NETSCC, HTA, UK

Ms Tara Lamont Scientific Advisor, NETSCC, UK

Professor Elaine McCall Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Professor of Health Sciences Research, Faculty of Education, University of Winchester, UK

Professor Jane Norman Professor of Maternal and Fetal Health, University of Edinburgh, UK

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts Professorial Research Associate, University College London, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: nihredit@southampton.ac.uk