

Systematic review of tools to measure outcomes for young children with autism spectrum disorder

Helen McConachie,^{1*} Jeremy R Parr,² Magdalena Glod,¹ Jennifer Hanratty,³ Nuala Livingstone,³ Inalegwu P Oono,¹ Shannon Robalino,¹ Gillian Baird,⁴ Bryony Beresford,⁵ Tony Charman,⁶ Deborah Garland,⁷ Jonathan Green,⁸ Paul Gringras,⁴ Glenys Jones,⁹ James Law,¹ Ann S Le Couteur,¹ Geraldine Macdonald,³ Elaine M McColl,¹ Christopher Morris,¹⁰ Jacqueline Rodgers,² Emily Simonoff,⁶ Caroline B Terwee¹¹ and Katrina Williams¹²

¹Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

²Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK

³School of Sociology, Social Policy and Social Work, Queen's University Belfast, Belfast, Northern Ireland, UK

⁴Guy's and St Thomas' NHS Foundation Trust, London, UK

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

⁶Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

⁷National Autistic Society North East Autism Resource Centre, Newcastle upon Tyne, UK

⁸Institute of Brain, Behaviour and Mental Health, University of Manchester, Manchester, UK

⁹School of Education, University of Birmingham, Birmingham, UK

¹⁰PenCRU, Child Health Group, University of Exeter Medical School, University of Exeter, Exeter, UK

¹¹Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

¹²University of Melbourne, Royal Children's Hospital and Murdoch Childrens Research Institute, Melbourne, Australia

*Corresponding author

Declared competing interests of authors: Ann S Le Couteur is one of the authors of the Autism Diagnostic Interview but receives no royalties; Elaine M McColl is a member of the NIHR Journals Library Editorial Group.

Published June 2015

DOI: 10.3310/hta19410

Plain English summary

Review of tools for autism spectrum disorder in children

Health Technology Assessment 2015; Vol. 19: No. 41

DOI: 10.3310/hta19410

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

Plain English summary

The MeASURe (Measurement in Autism Spectrum disorder Under Review) project aimed to find the best tools, such as tests and questionnaires, to measure the progress of children with autism up to the age of 6 years.

First, we asked people what they thought it was important to measure. Parents, and children and adults with autism, told us that happiness, anxiety and sensory overload were most important. Health and education staff said they needed tools to measure areas of difficulty. This was because these are important when deciding whether a child has autism, and in finding out what things help them.

Next we found all of the published studies that tracked the progress of children with autism, to find out what tools researchers had used. Between them, these studies used 131 tools, so we then looked for studies that told us how good these tools were when used with children with autism.

We found tools that could be used to monitor some aspects of the progress of young children with autism but not all. There was little or no evidence about whether tools that describe children's social participation and well-being are useful for children with autism. We found good evidence for the usefulness of a small number of tools that measure autism characteristics and behaviour problems. When we showed these to parents and professionals at a Discussion Day, they pointed out flaws, such as unclear wording and crowded presentation of questionnaires.

New research is needed to improve this situation. Valued outcomes to assess include social communication skills, well-being and quality of family life.

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 5.116

Health Technology Assessment is indexed in MEDLINE, CINAHL, EMBASE, The Cochrane Library and the ISI Science Citation Index.

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 HTA archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hta. 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 Technology Assessment* journal

Reports are published in *Health Technology Assessment* (HTA) if (1) they have resulted from work for the HTA programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Reviews in *Health Technology Assessment* are termed 'systematic' when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

HTA programme

The HTA programme, part of the National Institute for Health Research (NIHR), was set up in 1993. It produces high-quality research information on the effectiveness, costs and broader impact of health technologies for those who use, manage and provide care in the NHS. 'Health technologies' are broadly defined as all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care.

The journal is indexed in NHS Evidence via its abstracts included in MEDLINE and its Technology Assessment Reports inform National Institute for Health and Care Excellence (NICE) guidance. HTA research is also an important source of evidence for National Screening Committee (NSC) policy decisions.

For more information about the HTA programme please visit the website: <http://www.nets.nihr.ac.uk/programmes/hta>

This report

The research reported in this issue of the journal was funded by the HTA programme as project number 11/22/03. The contractual start date was in June 2012. The draft report began editorial review in April 2014 and was accepted for publication in July 2014. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft 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 HTA 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 HTA programme or the Department of Health.

© Queen's Printer and Controller of HMSO 2015. This work was produced by McConachie *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).

Editor-in-Chief of *Health Technology Assessment* and NIHR Journals Library

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 McColl 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 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 Professor of Child Health Research, UCL Institute of Child Health, 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