

Tools and outcome measures for monitoring autism spectrum disorder

Introduction

The aim of the HTA programme is to ensure that high quality research information on the effectiveness, costs and broader impact of health technologies is produced in the most efficient way for those who use, manage, provide care in or develop policy for the NHS. Topics for research are identified and prioritised to meet the needs of the NHS. Health technology assessment forms a substantial portfolio of work within the National Institute for Health Research and each year about fifty new studies are commissioned to help answer questions of direct importance to the NHS. The studies include both primary research and evidence synthesis.

Question

What is the validity of tools and outcome measures used in measuring and monitoring autism spectrum disorder (ASD); and how well do these reflect and measure issues of importance for patients and carers?

- 1 Technology:** Tools for measuring and monitoring aspects of autism (excluding diagnosis).
- 2 Patient group:** Children with autism spectrum disorder up to about 6 years old.
- 3 Setting:** Any appropriate setting.
- 4 Control or comparator treatment:** n/a
- 5 Design:** A systematic review of qualitative and quantitative tools and outcome measures used in the assessment and monitoring of children with ASD. The validity of the tools and their sensitivity to change should be assessed, as well as their importance to carers. These findings should inform a discussion about the appropriate choice of tools and identify those elements that appear to be most robust and could best inform the future development of a suite of tools for use in research into the effectiveness of interventions for ASD but potentially also for use in clinical practice.
- 6 Important outcomes:** Findings of the systematic reviews, suitability of tools for use in monitoring patients, and research recommendations.

Information for potential applicants:

Autistic spectrum disorder encompasses a wide variety of behavioural and communicative problems. In the UK there are over half a million people with autism - around 1 in 100 people. Yet, it often remains unrecognised and undiagnosed until or after late preschool age. The initial presentation can be to a wide range of professionals in primary care, education or social services. ASD-specific diagnostic instruments may be used to supplement the process of clinical observation, as part of the diagnostic assessment. A wide number of different rating instruments have been developed and some have not been validated. . It would be desirable to have a suite of validated tools with standardised outcome measures for use in clinical practice in the NHS as well as for use in research.