

**Title:** Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of Autism Spectrum Disorder in adults and children

**Author 1: (corresponding author)**

Marion Rutherford<sup>a, b, \*</sup>, Karen McKenzie<sup>c</sup>, Kirsty Forsyth<sup>a</sup>, Deborah McCartney<sup>a</sup>, Anne O'Hare<sup>d</sup>, Iain McClure<sup>e, d</sup> and Linda Irvine<sup>f</sup>

<sup>a</sup>Queen Margaret University, School of Health Sciences, Edinburgh, United Kingdom

<sup>b</sup>NHS Lothian Speech and Language Therapy Department, Edinburgh, United Kingdom

<sup>c</sup>Faculty of Health and Life Sciences, Northumbria University, Newcastle-Upon-Tyne

<sup>d</sup>Salvesen Mindroom Centre, Child Life & Health, School of Clinical Sciences, University of Edinburgh, United Kingdom

<sup>e</sup>School of Clinical Sciences, University of Edinburgh, United Kingdom

<sup>d</sup>NHS Lothian, Child and Adolescent Psychiatry, Edenhall Hospital, Musselburgh, United Kingdom

<sup>f</sup>NHS Lothian Headquarters, Edinburgh, United Kingdom

**\*Corresponding author:** Marion Rutherford, School of Health Sciences, Queen Margaret University, Edinburgh, Scotland, United Kingdom, EH21 6UU, Tel: +44 (0)131 474 0000, Fax: +44 (0)131 474 0001, Email: [mrutherford@qmu.ac.uk](mailto:mrutherford@qmu.ac.uk)

**Email addresses:** Marion Rutherford: [mrutherford@qmu.ac.uk](mailto:mrutherford@qmu.ac.uk), Dr Karen McKenzie:

[k.mckenzie@northumbria.ac.uk](mailto:k.mckenzie@northumbria.ac.uk), Professor Kirsty Forsyth: [kforsyth@qmu.ac.uk](mailto:kforsyth@qmu.ac.uk), Deborah McCartney:

[dmccartney@qmu.ac.uk](mailto:dmccartney@qmu.ac.uk), Dr Anne O'Hare: [aohare@ed.ac.uk](mailto:aohare@ed.ac.uk), Dr Iain McClure:

[imcclure@staffmail.ed.ac.uk](mailto:imcclure@staffmail.ed.ac.uk), Linda Irvine: [linda.irvine@nhslothian.scot.nhs.uk](mailto:linda.irvine@nhslothian.scot.nhs.uk)

## **Abstract**

*Background:* This paper reports on the development of child and adult Action Plans for Autism Spectrum Disorder to address the problem of delayed diagnosis and lengthy waiting times. Evidence used in the development of action plans was gathered from a sequential mixed methods study to further understand the reasons for the long waiting time and potential solutions. This is the first published investigation, from the perspective of diagnosing professional teams, of the reasons for delays, which also generates solutions.

*Methods:* Ninety five clinicians from 8 child and 8 adult services attended 16 focus groups to explore clinicians' views on a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines. During focus groups, quantitative data were fed back, used to frame discussions and facilitate solution focused action planning with each service. Sixteen local action plans were synthesised to create an ASD Action Plan for children and an ASD Action Plan for adults.

*Results:* Key solutions are proposed to support the reduction of the wait for diagnostic assessment, through reducing non-attendance rates, reducing inappropriate referrals, developing efficient working and communication and improving the effectiveness of care pathways. These are presented in actions plans for use by clinical teams.

*Conclusion:* The first step in addressing the clinical challenge of increased wait for diagnostic assessment of ASD is understanding the complex and multi-factorial reasons for delays. The action plans developed here through systematic enquiry and synthesis may provide clinical diagnostic teams with evidence based guidance on common challenges and solutions to guide future quality improvement programmes. Future research to evaluate whether using Action Plans leads to a reduction in waiting times would be of value.

*Key words:* Focus groups; Autism spectrum disorder; diagnostic assessment; wait times

## **Highlights**

- This study develops our understanding of the reasons for delay in assessment and diagnosis of autism spectrum disorders, based on triangulation of clinical data from quantitative analysis and qualitative data from a large focus group sample.
- The study offers translation of research evidence into practical application in the form of action plans for ASD services.
- The paper presents an Action Plan for child diagnostic teams to improve efficiency and quality of the diagnostic assessment process.
- The paper presents an Action Plan for adult diagnostic teams to improve efficiency and quality of the diagnostic assessment process.

## 1. Introduction

The international dilemma of increasing demand for assessment of Autism Spectrum Disorder (ASD) (Baio, 2012), together with the lengthy duration of the diagnostic assessment process (Matson, Beighley & Turygin, 2012) can lead to delayed diagnosis and dissatisfaction with services (Crane, Chester, Goddard, Henry & Hill, 2016; Moh & Magiati, 2012). Clinical guidelines advise health professionals on components of a quality diagnostic assessment (National Institute of Clinical Excellence [NICE], 2011; NICE, 2012; Scottish Intercollegiate Guidelines Network [SIGN], 2007). There is, however, little evidence based guidance for clinicians which offers ways of improving efficiency and reducing the wait for diagnosis of ASD, while adhering to clinical guidelines (McClure, Mackay, Mamdani & McCaughey, 2010).

Pathways for diagnostic assessment have discrete stages (Le Couteur, Baird & Mills, 2003a; NICE, 2015) and there is evidence of the benefits of investigating solutions aimed at improving efficiency at each stage (Radnor, Holweg & Waring, 2012). In the United Kingdom (UK) the recommended timescale for diagnostic assessment of children is no longer than 119 days (17 weeks) from referral for ASD assessment to diagnosis being shared (Le Couteur et al., 2003a), however, only some child services meet this standard (Palmer, 2011). Currently, no recommended standard is in place for adults in the UK. In Scotland, although adherence to evidence based clinical guidelines is high and is unrelated to waiting times (McKenzie et al., 2015a, 2016) there is currently a long wait for diagnosis of ASD (McKenzie et al., 2015b), with 74% of child and 59% of adult services exceeding the 119 day standard.

Only limited research exists about the factors that may impact on waiting times for ASD diagnosis and this suggests that these differ for adults and children. Having more information about children prior to diagnosis was associated with shorter assessment durations. In adults, the presence of risk factors for ASD (e.g. intellectual disability) was associated with a shorter wait between referral and first appointment; however, it was also associated with a longer assessment duration and greater number of contacts (McKenzie et al., 2015b).

More effective solutions to reducing waits arise when clinicians are consulted and included in a multi-faceted process of change (Melton, Forsyth & Freeth, 2012). Quality improvement science offers methods and frameworks to support the adoption of evidence based practice (Meyers, Durlak & Wandersman, 2012) and audit feedback, critical reflection and action planning are considered useful strategies in the planning stage of practice change (Vachon et al., 2015). Despite the value placed

on partnership working between researchers and practitioners to facilitate improved evidence based practice (Pentland et al., 2011), the perspectives of clinicians working with individuals with ASD are rarely reported (Rogers, Goddard, Hill, Henry & Crane, 2015). In order to try to address this, we engaged in active dialogue with clinicians for the purpose of developing a deeper understanding of waiting times and to explore possible practical solutions to support local, evidence based service improvement. We used a mixed method approach, now commonly applied in healthcare research, which has potential for rigorous, methodologically sound studies leading to valid outcomes (Creswell, Klassen, Plano Clark & Smith, 2011). The integration of quantitative findings from phase 1 of our study (McKenzie et al., 2015a) with qualitative research methods (Silverman, 2010), using focus groups, facilitated the gathering of rich data about the complexities of ASD clinical practice (Carbone, Behl, Azor & Murphy, 2010). Action planning has been identified as an important step in ensuring that evidence gathered from clinical data is used to enable practice change (Husk, 2008). Through this approach we hoped to meet the objectives of our inquiry, while ensuring strong relevance to clinical practice (Lingard, Albert & Levinson, 2008). The research adopted a social constructivist epistemological stance i.e. that our perceived reality is shaped by our culture and society (Lit & Shek 2002). From this perspective we attempted to understand, interpret and locate the 'meaning' of the results in the social and clinical context and community of practice within which the participants worked.

### *1.1 Objectives*

- To explore the reasons clinicians give to explain long wait times for diagnosis for ASD.
- To identify clinicians' views on the challenges and solutions to a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines.
- To develop collaborative action plans for improving the efficiency and quality of the process of ASD diagnosis in child and adult services.

## **2. Methods**

### *2.1 Ethical approval*

The Caldicott Guardian and the research and development departments of the participating services granted approval for this study.

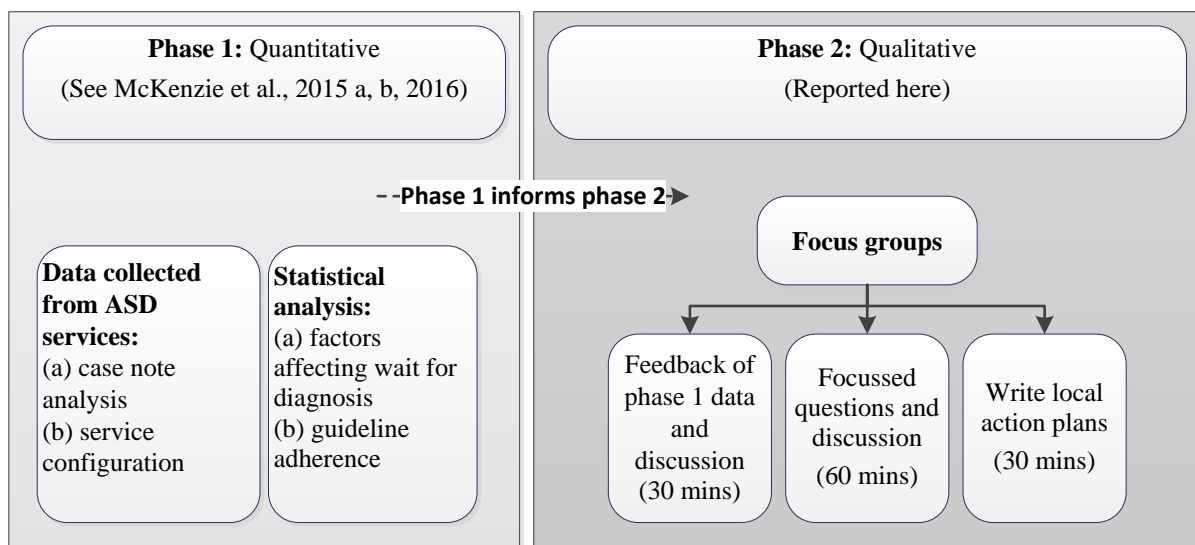
## 2.2 Context for the study

The study was part of the Scottish national Autism ACHIEVE Alliance study in which 16 (8 child and 8 adult) ASD diagnostic services participated and provided case note data on recently diagnosed individuals. Details of the services and methodology used to gather and analyse the quantitative data from the case notes are provided in McKenzie et al. (2015b). All sixteen services providing quantitative data were invited to participate in local focus groups.

## 2.3 Design

The study employed a sequential mixed methods design (Creswell et al., 2011), see Figure 1.

**Fig. 1.** Phase 1 and 2 of a sequential mixed methods study.



The quantitative data analysis (McKenzie et al 2015a, 2015b, 2016) preceded and informed the qualitative phase of the study and formed the basis of individualised feedback to the participating services as part of the focus groups. Two stages of qualitative analysis were applied. Firstly, during the focus group, key points were incorporated into a collaborative local action plan to reduce waits (and maintain or improve quality). Secondly, data from all the focus groups were triangulated and

synthesised, leading to the development of an Action Plan for Child services and an Action Plan for Adult services.

## 2.4 Participants

Services (n=16) were selected originally through proportionate stratified randomised sampling and were therefore a nationally representative Scottish sample (McKenzie et al., 2015b). Ninety five participants, from these services took part in the focus groups (see Tables 1 and 2). These were members of clinical diagnostic teams or community based colleagues contributing to diagnostic pathways. An average of seven professionals per group participated in the child services' focus groups (range 4-10), with the most commonly represented professions being Clinical Psychology, Speech and Language Therapy (SALT), and Paediatricians. An average of six professionals (range 1-9) participated in the adult services' focus groups, with the most commonly represented professions being Clinical Psychology, Nursing, Psychiatry and SALT. There were 61 female and 24 male participants and the range of years of experience in ASD diagnosis amongst clinicians (excluding students and trainees) was between 5 and over 20 years.

**Table 1.** Participants from Child ASD Diagnostic Services

Child Services	Assessment Type	Type of service	Number of participants	Gender of participants		Professional Roles of those who attended
				Male	Female	
Service 1	Multi-disciplinary	Other	5	2	3	1x psychiatrist, 1x Nurse, 1x OT, 2x clinical psychologist
Service 2	Multi-disciplinary	General	10	2	8	1x Team Lead, 1x Principle Clinical Psychologist, 1x Trainee Ed Psychologist, 2x Staff Nurse, 5x Clinical Psychologist
Service 3	Multi-disciplinary	Specialist	6	0	6	1x Consultant Child & Adolescent Psychiatrist, 1x Paediatrician, 1x OT, 1x Clinical Psychologist, 2 x Senior SALT
Service 4	Multi-disciplinary	General	6	1	5	1x Psychiatrist, 1x Educational Psychologist, 2x SALT, 2x Paediatrician,
Service 5	Multi-disciplinary	Specialist	7	0	7	1x Specialist Nurse, 1x Medical Student, 1x Consultant Paediatrician, 2x Clinical Psychologist, , 2x Principle SALT
Service 6	Multi-disciplinary	Specialist	5	0	5	1x SALT, 1x Educational Psychologist, 1x Community Paediatrician, 1x OT, 1x Consultant
Service 7	Multi-disciplinary	General	4	0	4	1x SALT, 1x Clinical Psychologist, 2x Consultant Paediatrician,
Service 8	Multi-disciplinary	General	4	0	4	1x Community Paediatrician, 1x, Specialist Doctor, 2x SALT,

Total	47	5	42
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**Table 2.** Participants from Adult ASD Diagnostic Services

Adult Services	Assessment Type	Type of service	Number of participants	Gender of participants		Professional Roles of those who attended
				Male	Female	
Service 1	Multi-disciplinary	General	7	2	5	1x Specialist SALT, 1x Psychiatrist, 2x Senior Nurses, 1x Lead Dietician, 1x Consultant Clinical Psychologist, 1x Occupational Therapist (OT)
Service 2	Single practitioner	Specialist within general service	1	0	1	1x Consultant Psychiatrist,
Service 3	Not Stated	Specialist	7	3	4	1x OT, 1x Specialist SALT, 1x Consultant Psychiatrist, 1x Senior Lecturer, 3x Nurses
Service 4	Not Stated	Specialist team within general service	6	4	2	2x Senior Nurses, 1x Consultant Clinical Psychologist, 2 x Psychiatrists, 1xSALT
Service 5	Multi-disciplinary	Specialist	3	2	1	2x Clinical Psychologists, 1x Nurse,
Service 6	Single practitioner	General	7	4	3	5x senior clinical psychologists, 2x assistant psychologist
Service 7	Single practitioner	General	9	1	8	1x Consultant Clinical Psychologist, 1x Trainee Clinical Psychologist, 1x Consultant Clinical Psychiatrist, 6x Clinical Psychologist
Service 8	Multi-disciplinary	Specialist	8	3	5	1x Consultant Psychiatrist, 4 x Community Nurses, 1x Lead SALT, 1x Consultant Psychiatrist; 1x Student Nurse,
Total			48	19	29	

### 2.5 Data collection

Data were collected via focus groups. Each focus group was hosted locally by the participating services and was approximately two hours long. They were led by two researcher facilitators, with a high level of clinical experience in working with individuals with ASD and previous experience in group interviewing. One member of the team facilitated group discussion while the other took notes on flip charts visible to all. All group interviews were digitally audio recorded in preparation for data analysis. Participating staff gave written consent for recording, use and storage of data. The focus groups were semi-structured and consisted of the following three components:

a) Quantitative data were shared with services, with regard to their own service and in comparison with the average results for the other participating child or adult services. Participants



were supported to discuss this feedback in the context of possible reasons for the issues raised, the impact on waiting times for diagnosis of ASD and possible solutions (if appropriate). The variables about which the services received feedback included; *estimated rates of non-attendance and diagnosis; actual duration of each stage of the assessment process (range: 14 days to 1942 days across services); number of client contacts per case between referral and diagnosis; components involved in the entire diagnostic process from referral to receiving the diagnosis and percentage adherence to guidelines.*

b) Key focus group questions were common to all groups and were followed by locally individualised questions related to the quantitative findings (see Table 3). This was a solution-focused discussion, concentrating on changes which would be possible within current resources.

c) Group reflection, based on the preceding discussion, was used to develop local action plans to reduce waiting times. This included solutions to service specific issues and maintenance points. The completed action plans were written up and subsequently shared with each service.

**Table 3.** Focus group questions

Questions	Examples of tailored sub questions for questions 1-3 for individual services included
Q1. In what ways could your service increase capacity for ASD diagnostic assessment within existing resources?	<p>What can be done to reduce the number who are assessed but not diagnosed with ASD?</p> <p>What do you think would be a successful way of reducing the wait for first appointment?</p> <p>How can you avoid duplication of contextual information gathered prior to 1st assessment appointment?</p>
Q2. How can you ensure a good standard of practice and robust and accurate diagnosis?	<p>What are the key features that allow a good quality, robust and accurate diagnosis?</p> <p>What is your rationale for choosing not to use recommended standardised assessments?</p>
Q3. What are your needs in relation to knowledge, skills and training?	<p>Are there any specific gaps in knowledge, skills or training that would benefit your service, to increase capacity and deliver a robust diagnosis?</p> <p>How can/ do you ensure your service adherence to quality standards/ indicators is over 80%?</p>
<p><b>Let's review the solutions you have suggested (see flip chart) please pick out those which you feel are the most achievable for you now so that we can explore them in further detail to make an action plan.</b></p>	

### 2.5.1 Data sources

The data were: the recordings; notes taken during the groups, additional field notes and tape based notes made with specific consideration of the research aims.

### *2.5.2 Data analysis*

Thematic analysis (Vaismoradi, Turunen & Bondas, 2013) was used to analyse and interpret the data using tape based analysis (Onwuegbuzie, Dickinson, Leech & Zoran, 2009). This is a recognised method of focusing transcription and analysis specifically on the key phenomenon of interest, in which an analyst listens to the focus group recording and creates an abridged transcript. Themes were then identified and coded for each group, using an analysis team, to provide greater transparency (Ward, Furber, Tierney & Swallow, 2013). Recurring themes were noted and discussion across adult and child analysis teams took place to support consistent analysis and recording of themes. Services were offered the opportunity to review the action plans for accuracy.

Comprehensive coding was then undertaken, in relation to the key themes which were identified in the focus groups and action plans in relation to the research aims: a) reducing the wait for diagnosis (through increasing efficiency and capacity) and b) ensuring a good quality diagnostic process with good adherence to clinical guidelines.

Data from the transcripts and local action plans were then reviewed systematically to identify solutions within each theme. Relationships between themes for both child and adult services were identified through diagrams and debriefing (Creswell & Miller, 2000). Findings were synthesized into two aggregated action plans; one for child and one for adult services (see tables 4 and 5)

## **3. Results**

The study involved 95 focus group participants from a nationally representative sample of 16 services. Participants were professionals working with children and adults with ASD. Overall, the child services comprised larger, multi-disciplinary teams, which had undertaken extensive ASD specific training and had been established for longer than the adult services. All child services were multi-disciplinary and three had multi-agency partner representation from Education and Health Visiting colleagues. Four of the adult groups were multi-disciplinary, two contained only Psychologists, one service was largely nurse led and one service was provided by a single practitioner. No multi-agency partnerships were reported.

Focus group data reported here, concentrates on the synthesis of thematic analysis and local action plans to present solutions generated by participants in relation to efficiency and quality.

### 3.1 Action Plans

Local action plans (n=16) generated by focus group participants centred on potential changes to improve efficiency and quality that could be made within existing resources and within a reasonable timescale. Data from local plans and thematic analysis were synthesised to form aggregated Action Plans for child and adult services tailored to the needs of each group (see tables 4 and 5).

**Table 4.** Aggregated Action Plan for child services

Stage of process	Issue	Identified Solution
At all stages	Care pathways	<p>Develop, implement and maintain a clear, written, multi-agency diagnostic pathway for pre-school and school aged children which adheres to standards set (both locally and nationally).</p> <p>Develop protocols, practice tools and guidance for each stage in the pathway.</p> <p>Have flexibility within the pathway, so different children have different combinations of assessments dependent on need; for example only doing school observations/ cognitive assessment where this information cannot be gathered without a visit.</p>
Pre-referral	Referrer knowledge	<p>Provide training for referrers on:</p> <ul style="list-style-type: none"> <li>• Signs and symptoms</li> <li>• When to refer</li> <li>• Recognising ASD in girls</li> <li>• Differential diagnoses, such as attachment disorders</li> </ul> <p>Provide training for referrers on local systems:</p> <ul style="list-style-type: none"> <li>• How to refer</li> <li>• Awareness of local pathway</li> </ul> <p>Develop a system to flag up children who are at risk and the health visitor's role in monitoring.</p>
	Limited information pre-referral	<p>Collectively decide on use of triage and/or screening tools to gather relevant information to discern whether there is a need to go on to next stage of pathway or not.</p> <p>Provide guidance about information needed pre-referral.</p>
Referral to first appointment	Engaging families	<p>Provide information to families prior to first appointment about the clinic and what will be discussed.</p> <p>Create leaflets and guidance for families about stages of assessment, including an ADOS (Autism Diagnostic Assessment Schedule) information leaflet.</p>
	Collecting contextual information	<p>Design/ develop a tool and pack for education colleagues about contextual assessment, observation and reporting to inform the diagnostic assessment process.</p> <p>Use a systematic approach to gather contextual information in advance of appointment.</p>

	Reducing wait for first appointment	<p>Review staffing distribution and skill mix to create more appointments within current resources.</p> <p>Use multi-agency case discussion panels to improve the efficiency and quality of assessment and to direct children to the correct route from the start (i.e. a local staged assessment model).</p>
Duration of assessment	Reducing number of contacts	Complete the diagnostic assessment in 1-2 clinic appointments.
Diagnosis to sharing diagnosis and after	Efficient communication of diagnosis	<p>Provide feedback to families on same day as diagnostic assessment (where possible).</p> <p>Develop standardised report writing protocols.</p>
	Post diagnosis support	<p>Use the ADOS assessment to highlight areas of difficulty and develop support strategies for the individual.</p> <p>Have a post diagnostic meeting with families.</p> <p>Develop a post-diagnostic pack for families.</p> <p>Make links between health, education and voluntary sector agencies who provide support and intervention.</p>

**Table 4 (continued).** Aggregated Action Plan for child services

<b>Stage of process</b>	<b>Issue</b>	<b>Identified Solution</b>
Quality	Consistency and equity	Develop an ASD assessment pack for use by all professionals involved in ASD diagnosis to ensure consistency.
	Training and development	<p>Establish ADOS peer review and consensus rating cycle locally.</p> <p>Have more staff trained in standardised assessment tools, e.g. ADOS.</p> <p>Review training needs of the Multi-Disciplinary team and develop an explicit plan for succession planning and training needs (e.g. ADOS), to be shared and agreed with management.</p> <p>New staff to attend specialist clinics to observe and develop skills and confidence, and possibly 'buddy up' with other staff for learning.</p> <p>Timetable regular CPD (Continuing Professional Development) sessions for the team to review service development needs and to follow through on planning cycle.</p> <p>Have a national forum or group to share experiences and knowledge, involving professionals and individuals and their families.</p>
Quality	Planning resources to meet service needs	<p>Review service configuration and skill mix to accommodate demand within resources available (e.g. making extra clinic time).</p> <p>Ensure a core group of staff have dedicated ASD time in their job plan.</p> <p>Develop and maintain links with multi-agency and multi-disciplinary partners (e.g. SALT, Occupational Therapists, Paediatricians, Psychologists, Psychiatrists, Social work, Education and Voluntary Sector) for input into diagnosis and relevant intervention.</p> <p>Make efficient use of admin support to free up the diagnostic team.</p> <p>Ensure the diagnostic team have shared skills for core aspects of ASD assessment to avoid over-dependence on one person.</p>
	Evaluation of service	<p>Audit and evaluate aspects of services in relation to standards and guidelines. Conduct a parent satisfaction audit.</p> <p>Maintain or develop efficient systems of collecting information about referrals, waiting times and outcomes to support audit and self-evaluation.</p> <p>Develop and implement a guidelines checklist for each case file.</p> <p>Participate in research and generate research practice within clinical teams.</p> <p>Collect and share statistical information with service managers and Health Boards (referral rate, capacity and anticipated effect on level of resource needed).</p> <p>Investigate and review screening tools available (e.g. GARS, SRS, SCQ).</p> <p>Have someone to lead/champion change within the service.</p> <p>Foster good communication and relationships within the team.</p>

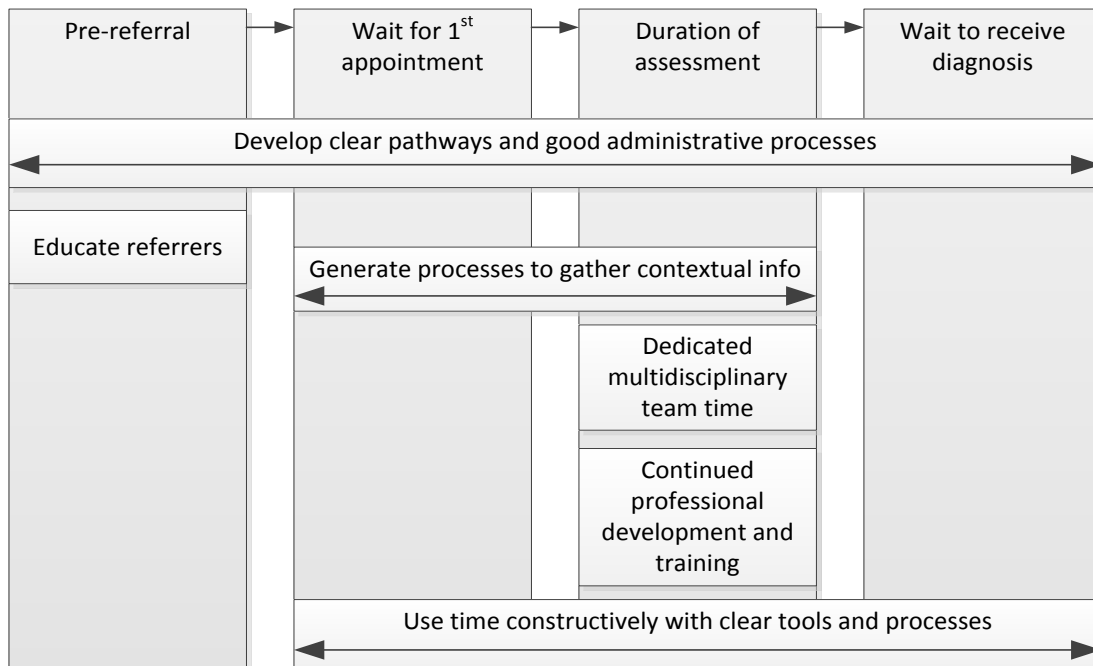
**Table 5.** Aggregated Action Plan for adult services

Stage of process	Issue	Identified Solution
At all stages	Care pathways	<p>Develop and use a clear pathway for the ASD assessment process, detailing the pathway from referral to sharing diagnosis.</p> <p>Implement diagnostic pathway to inform assessment process, e.g. appropriate assessments to use in particular situations, minimum number of required appointments and their purpose.</p> <p>Make the referral and diagnostic pathway available to referrers.</p> <p>Set time targets for completion of any stage of the diagnostic assessment process from referral to sharing diagnosis.</p> <p>Ensure there is adequate administrative support.</p>
Pre-referral	Inappropriate referrals	<p>Provide information about indicators of ASD to referrers and potential referrers.</p> <p>Ensure submission of screening tools with referrals.</p> <p>Provide basic 'ASD awareness' training to referrers.</p>
	Limited information pre-referral	<p>Develop proformas for individual, family (if appropriate) or referrers to complete and submit with referral form.</p>
Referral to first appointment	High non-attendance rate	<p>Have a system for pre-empting non-attendances (e.g. opt in letters, phone calls etc.).</p> <p>Reduce number of inappropriate referrals (see above).</p> <p>Provide service in local area where possible, e.g. initial home visit.</p> <p>Where appropriate enlist support of carer or support worker to facilitate attendance, e.g. where individual has an intellectual disability.</p>
	Reducing wait for first appointment	<p>Have identified ASD diagnosis appointments to slot referrals into.</p> <p>Make appointments immediately on receipt of referral.</p>
	Constructive use of time to first appointment	<p>Use information provided pre-referral to inform diagnostic process.</p> <p>Develop an abbreviated pathway for those who clearly meet criteria for diagnosis.</p> <p>Use screening tools (if not completed by referrer).</p> <p>Request that individual, family, referrers or others, as appropriate complete proforma requesting relevant developmental and contextual information.</p>
First appointment to diagnosis	Promoting effective multi-disciplinary working	<p>Have dedicated, protected time for regular multi-disciplinary review meetings.</p> <p>Work in conjunction with other diagnostic practitioner(s), with protected and scheduled slots to carry out assessments together.</p> <p>Have a multi-disciplinary assessment.</p> <p>Complete the diagnostic process in one day (if appropriate).</p>

Key differences in the diagnostic pathways and differences in service configuration demand different actions and the plans are intended to inform child and adult services conducting diagnostic assessment of ASD, through provision of frameworks for service improvement. The most commonly

cited solutions across both child and adult services are summarised in Figure 2.

**Fig. 2.** Summary of key solutions generated by focus group participants



Of the services with a written care pathway (n=11/16), areas for improvement were identified; services without a pathway sought to develop one. Pathways commonly identify specific stages (Coghill & Seth, 2015) and different solutions were generated for each pathway stage (see figure 2), matching the quantitative data gathered in phase 1 of the project and reported in McKenzie et al. (2015b). For example, the finding that efficiency could be improved by gathering more information prior to the first appointment, led to a number of services developing proformas for gathering information from referrers at the point of referral.

In analysis of the individual action plans, services identified between 3 and 10 actions in their plans, with an average of 6 in adult services and 7 in child services. In respect of the adult services, two were well established regional services and the identified actions focussed on using their expertise to build capacity in other services, such as securing and making best use dedicated time to build partnerships with other services. Four services had plans linked to the development of a new service, with the need to develop pathways and processes. One service had already developed a pathway and identified actions linked to maintaining successes, evaluating and adapting the pathway.

All of the less well established services, whether general or specialist, included actions related to training and capacity building through skill development.

All of the child services already had pathways in place and many of the planned actions related to embedding these pathways in practice, evaluation and revising where necessary, in order to improve the consistency with which they were applied across the whole health board area. Specific actions included introducing processes and practices to reduce the number of contacts required and to gather information more effectively and efficiently. One service identified the need to have different, more specific pathways for different age groups. Many services also identified the need for strategic actions such as protecting the time allocated for ASD diagnosis, succession planning and capacity building at all levels.

### 3.2 Influencing Factors

The analysis identified a range of factors which might potentially have influenced the clinicians' 'stage of readiness' to accept and implement specific practice change (Abrines-Jaume et al., 2014; Melton, 2010). These are summarised in Table 6 and described below.

**Table 6.** Factors which might potentially influence the clinicians' stage of readiness to accept and implement changes

<b>Subthemes</b>	<b>Components</b>
a) Attitude about the need to reduce the wait for diagnostic assessment	Previous experience of ineffective wait reduction methods Extent to which reducing duration of assessment is seen as a high priority Late recognition or referral of adults High threshold for adult referrals
b) Service configuration	Multi agency practice and roles Completing assessments in 1-2 contacts Flexibility depending on complexity Post diagnostic support – a different or an integrated phase? Configuring services to use transferable skills work across both ID and non ID services
c) Adherence to clinical guidelines	Plans in place Guideline standards not adhered to
d) Use of standardised instruments	Contextual information Clinical history and observation
e) Experience and training	Needs identified



For most of the services the need to reduce duration of assessment was a high priority, *“I think there is a lot of concern about a long wait for assessment... intervention is put on hold, which doesn't feel ethical”*. One child service did not identify strongly with the consensus view, saying, *“some parents want a bit more time to get to grips with the idea”*.

The lack of diagnostic services for adults without ID was highlighted as a particular challenge and the late age of referral for diagnostic assessment in adults was a greater issue than the duration of diagnostic assessment. Newly formed adult services reported that anything was better than the previous situation of no service provision.

All child services worked within a broader multi-agency setting and expected that ASD diagnostic assessment was part of their core work. In three adult services, participants stated a desire for a more multi-disciplinary approach. The participants discussed completing assessments in one or two contacts. Three child services regularly did this, providing that relevant information was collected in advance. One child service was uncertain - *“it's very efficient but it could be a little too brutal [for families]”*. Some services stated that pathways should include flexibility depending on complexity. *“There is the odd occasion when you feel like you're going through the pathway because it's there and it's what you're supposed to do... it feels like you could make the diagnosis in a much shorter time”*. A small number of services identified potential benefits of flexible approaches to assessment, for example, in one child service, direct contextual observations were only undertaken by the clinical team when standardised scores were discrepant between home and school – thus ensuring this was undertaken when most needed and therefore time was used more efficiently.

Services reported good awareness of clinical guidelines, although it was noted that the implementation of some was at times challenging. For example, cognitive assessment, as recommended in SIGN (2007) was rarely conducted in child services. In adult services, some standards that were difficult to achieve included collecting a full developmental history, recommended in NICE (2011) and conducting physical examinations, as recommended in the Scottish Quality Diagnostic Standard which preceded NICE (2011).

Most child and two adult services used indirect methods of gathering contextual information from informants (through standardised instruments or local proformas). *“I think if parents and school are both reporting the same difficulties then it's absolutely fine to go with the report... and if there's a difference of opinion, you really need somebody else to go in and have a look”*. All child services used

standardised diagnostic tools for clinical observation (Rutherford et al., in press), and viewed these positively, *“I think the ADOS really helps”*; *“even if you’re not using ADOS, having done the training, you have that structure in your head”*. In adult services, less experienced participants were keen to be trained in standardised assessment tools to increase diagnostic accuracy. *“I think there’s a heck of a lot of knowledge in our service but people perhaps don’t have the confidence and I think if you put in a standardised tool, you give them that confidence”*. Experienced adult teams felt that once a team becomes highly experienced in diagnosis, the accuracy of their clinical judgement exceeds that of such tools.

The solutions generated varied between teams and were strongly influenced by the experience of the team; more experienced teams tended to have a greater number of areas in which they could share good practice, whilst less experienced teams required more solutions. Regardless of experience, participants valued the opportunity to review practice, *“It’s been really helpful to get time and space to reflect on your practice”*.

#### **4. Discussion**

Clinicians working in ASD diagnostic teams wrestle with the challenge of reducing the length of wait for diagnosis, whilst faced with an increasing number of referrals, resource constraints and the need to meet clinical guideline standards (Rogers et al., 2015). This study has led to the development of practical solutions for ASD services wishing to deliver positive practice change, through improving efficiency and ensuring adherence to clinical guidelines such as NICE (2012) and SIGN (2007), as summarised in the aggregated child and adult action plans.

The collection of the qualitative data collection was informed and enhanced by the prior quantitative analysis (McKenzie et al., 2015b) and likewise, results from the qualitative analysis provide a richer picture than that obtained from quantitative data alone, allowing a more detailed exploration of the factors that clinicians perceive as impacting on waiting times. For example, it is known that simply increasing staffing is not an effective solution for reducing waits (Kaplan & Porter, 2011; Murray & Berwick, 2003) and that limited time and resources and lack of training for staff are commonly cited barriers in health research (Donato, Shane & Hemsley, 2014; Fenikilé, Ellerbeck, Filippi & Daley, 2014). While these issues were also highlighted by all of the participating services, more specific factors were also identified. Three main areas for discussion emerged: efficiency in the

pathway, a quality service and influencing factors. Many challenges and solutions identified in this study are common to other fields of healthcare.

#### *4.1 Efficiency*

Care pathways, are widely used internationally for a range of conditions. They are dynamic and complex interventions, which enhance evidence based practice, efficiency and multi-disciplinary working through their collaborative development (Vanhaecht et al., 2012) and typically include time frames or criteria based progression (Rotter et al., 2011). In common with compelling research evidence (McClure et al., 2010), the majority of ASD services consulted with, agreed on the need to improve efficiency in the diagnostic process, through the use of effective care pathways (NICE, 2011; NICE, 2015).

At the pre-referral stage, adult services highlighted the need to educate referrers to better identify ASD through the use of recommended tools (NICE, 2012), in agreement with recommendations for child services (Oosterling et al., 2010). Training to improve the quality and relevance of referrals (Blank, Peter, Pickvance, Wilford & MacDonald, 2008) and increasing knowledge about the referral processes were also identified as time saving solutions. Although referral management is a commonly cited problem in healthcare, there is still limited good quality evidence about effective solutions (Davies & Elwyn, 2006) and further evaluation of the effectiveness of the identified solutions for ASD services is needed. In common with NICE (2011), the child services specifically raised the need for improved identification of ASD in girls, and both focus group and quantitative analysis suggest that the main delay for females occurs prior to referral (Rutherford et al., 2016).

In common with modern healthcare research (Guy et al., 2012), non-attendance at appointments was a reported challenge in ASD services, with the effect of increasing service costs and waiting times (Gurol-Urganci, De Jongh, Vodopivec-Jamsek, Atun & Car, 2013). A range of factors are known to impact on cancellations and no-shows including: forgetfulness; fear; transport difficulties; inconvenience of time and location; long waiting times and administrative errors (Wilkinson & Daly, 2012). There is some evidence that solutions, such as reminders (Gurol-Urganci et al., 2013) and increasing motivation to attend, such as improving patient information and using patient driven appointment scheduling (Rose, Ross & Horwitz, 2011) can be effective. Focus group participants

suggested locally relevant solutions, which take account of the reasons for non-attendance before implementing solutions, such as having systems to pre-empt non-attendance (opt in letters, phone calls); reducing the number of inappropriate referrals, so that those offered appointments are those who need to be there and are more likely to attend, providing the service as locally as possible and enlisting a support contact to facilitate attendance.

Gathering more information prior to the first appointment is associated with reduced duration of assessment (McKenzie et al., 2015b). The use of informants (such as a parent or teacher) to gather contextual information was more common practice in child services and this was done through both standardised tools and non-standardised proformas. Only two adult services used a consistent approach to information gathering at this stage and no standardised tools for contextual assessment were being used. Staff working in adult services identified that having tools both for families to complete with regard to early history and which allowed contextual information to be gathered would be useful additions to practice. The practice of diagnostic teams making direct observations of individuals in a range of contexts is commendable but less efficient than asking for this information from those with daily involvement. Further development of tools (e.g. Social Responsiveness Scale - Adult, Constantino, 2005) might provide important solutions.

Flexible approaches to assessment were also identified as solutions to improving efficiency. Examples included the clinical team only undertaking direct contextual observations when standardised scores were discrepant between home and school or using an abbreviated assessment pathway for more straightforward cases. The latter is consistent with the recommendation by NICE (2012) that an assessment approach should be based on the complexity of the case, but was not in place in any services at the time of the study.

Developing good multi-disciplinary communication and team working were commonly cited solutions and are known to confer benefits to individuals with ASD and their families (Baker, Day & Salas, 2006; McClure et al., 2010). Practitioners from the child services also suggested the need to create more appointments through reviewing skill mix and distribution of staffing within the multi-disciplinary teams.

Our quantitative analysis of case note data had found that the duration of assessment was shorter when there were fewer separate contacts (or appointments) involved in the process (McKenzie et al., 2015b) and gathering information effectively from other sources is one way to

achieve this. Most, but not all, services were in agreement that it would be a useful aspiration to complete the assessment in 1-2 appointments, except in the most complex cases. This would also reduce the risk of duplication of assessment across repeated contacts.

Some clinicians also commented on the time required to complete some standardised assessments (e.g. The Diagnostic Interview for Social and Communication Disorders, Wing, Leekam, Libby, Gould & Larcombe, 2002) and planned to undertake training in other tools such as the Autism diagnostic Observation Schedule (Rutter, DiLavore, Risi, Gotham & Bishop, 2012) and Autism Diagnostic Interview-Revised (Le Couteur, Lord & Rutter, 2003b) which they felt may be quicker to administer. Some experienced clinicians reported confidence in both making diagnoses without the use of any standardised tools, and in applying the diagnostic pathway more flexibly depending on case complexity. Carpenter (2012) also found that experienced clinicians were more confident to diagnose with limited information.

Whilst many teams shared the diagnosis on the day of the appointment, others took information back to formulation meetings before sharing the diagnosis at a later date, thus increasing the overall length of the diagnostic process. This was exacerbated by the time taken to write reports, particularly when there was a lack of administrative support for this. Both report templates and adapting appointment scheduling were identified as solutions to these issues.

#### *4.2 Quality*

Evidence based decision making is commonly recommended in health care but in reality, as well as a dearth of evidence about what works in some fields, there is under-use and delayed adoption of research evidence in practice (Pentland et al., 2014). The “quality” themes raised in this study were consistent with those identified in previous research and included the need for: adherence to clinical guidelines (Pentland et al., 2014); educational strategies to support training and professional development (Groll & Grimshaw, 2003); skill mix and use of staffing resource (Antunes & Moreira, 2013); identifying factors to support change in practice such as having someone to champion the change (Melton, 2012), and service evaluation and audit (Bowling, 2014). Practitioners in this study generated solutions relevant to their own context, thereby potentially increasing the likelihood of successful service improvement. While the suggested solutions have strong face validity and clinical relevance, their implementation is yet to be evaluated.

#### *4.3 Influencing factors.*

Sustaining motivation to change is enhanced by sharing a vision amongst a team (Wiek & Iwaniec, 2014) and the action plans have the potential to help consolidate and operationalise this vision. However a number of factors were identified which seemed likely to influence readiness to accept and implement change. The consensus view was that there was a need to reduce the wait for ASD diagnosis, although the absence of adult services in some geographical areas was seen as a greater priority for change. The services had a range of views about ideal service configuration. The strength of the multi-disciplinary approach in child services was commended, whilst the isolation of some clinicians in adult services was seen as problematic.

There was a strong consensus on the importance of guideline adherence; with areas where this was difficult being identified, for example, the use of cognitive assessments in children or use of physical examination in adults. Overall, child and adult services aspired to have staff trained in and using standardised instruments, but practitioners identified the need for better guidance, in order to use resources more flexibly.

#### *4.4 Implications for policy and practice and research*

Delayed access to health care and waiting lists are commonly reported challenges but there is very little evidence available in relation to solutions for ASD services (McKenzie et al., 2015b) which utilise practitioner views in generating multi-faceted solutions (Melton, 2010). In this study, qualitative approaches, informed by previous quantitative analysis resulted in practitioner generated, collaborative action plans which identified solutions to the complex problem of long waiting times for ASD diagnosis, while protecting service quality. Future research is needed to evaluate the impact of the implementation of these action plans on waiting times in practice.

#### *4.5 Is there an ideal waiting time?*

The majority of services surveyed failed to meet the 119 day standard from referral to diagnosis (McKenzie et al., 2015b). There is a steer from policy makers, driven and informed by individuals with ASD and their families (Scottish Government 2011), to develop sustainable ways to reduce the wait for, and duration of, diagnostic assessment. The majority of focus group participants

from both child and adult services concurred, with only one service explicitly stating that they did not think there was a need to make diagnosis happen more quickly. This service, which worked with children under 5 years of age, expressed that families need time and it is not helpful to rush them. They argued that services in their area provided support based on need rather than diagnosis and, therefore, the argument that diagnosis facilitates better support did not apply in their experience. The aspiration to deliver inclusive support on a needs-led basis is one shared by many (Florian and Spratt 2013), however, no examples could be found where this is in place to the extent that waiting for diagnosis is not an issue for individuals with ASD.

It is unclear if there is an “ideal waiting time” that allows families and individuals with ASD to participate jointly in the process of diagnosis (Rogers et al 2015), and for services to gather the relevant assessment information and deliver good quality, accurate diagnoses. Such an ‘ideal’ is also likely to vary according to the complexity of the individual’s case and individual, family and service variables such as age, access to appropriate support, and family resources. Further research is needed to address these questions in order to help services to both develop flexible and responsive approaches to the needs of individuals and their families and offer a consistent and robust diagnostic process, which is consistent with clinical guidelines. While this may be seen as a difficult balance to achieve, the recent NICE guidelines (NICE 2011; NICE 2012) offers some support clinicians by recommending different approaches for different cases. Our focus group findings suggest that greater flexibility is more likely to occur in more experienced and well established teams which undertake a high volume of diagnostic assessments. The clinicians in such teams were able to articulate the clinical reasoning behind flexible pathways.

## **5. Limitations**

The study had a number of limitations. Firstly, because of the specific research aims, it focused on the views of clinicians, rather than those of parents, carers and individuals with ASD. Future research could gain the perspectives of other stakeholders about measures that are implemented to reduce waiting time for diagnosis. Secondly, while the study included the views of 95 clinicians from a range of services across Scotland, the extent to which their views, identified barriers and solutions are representative of clinicians more widely is unknown. Finally, while the action plans

generated by the participating services have face and clinical validity, there is a need to evaluate the extent to which they reduce waiting times for diagnosis of ASD in practice.

## **6. Conclusion**

The study used systematic enquiry to effectively identify challenges and solutions to achieving the balance between service efficiency and quality, presented in action plans for adult and child services. In summary, services sought to improve efficiency by: further educating referrers about appropriate referrals and information required from them; creating new, or developing existing, pathways; gathering more information prior to first appointment and reducing contacts during the assessment; developing training opportunities and using clear guidance about tools and processes to use at each stage.

## **Conflict of interest**

The authors have no conflict of interests to declare.

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