**The relation between practice that is consistent with NICE guideline 142 recommendations and waiting times within Autism Spectrum Disorder diagnostic services**

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**Abstract**

**Background:** This study explores the extent to which recommendations from the National Institute of Health and Care Excellence (NICE) 142 guidelines, section 9.2 (relating to identification, assessment and diagnosis) reflected existing routine clinical practice in Autism Spectrum Disorder (ASD) diagnosing services in Scotland; and whether there was a significant relation between routine practice which more closely reflected these recommendations and waiting times.

**Method:** A cross-sectional, retrospective case note analysis of recently diagnosed adults, in eight ASD services across Scotland.

**Results:** The study found that the existing practice of the participating services was consistent with 14 (maximum number) of the included recommendations in at least half of cases analysed (range 37-70 cases) and was not related to increased total waiting time for diagnosis.

**Conclusion:** The results, based only on the included recommendations, suggest that the section 9.2 recommendations can be integrated into clinical practice in Scotland with relative ease and that it is unlikely to have a negative impact on waiting times.

**Key words:** Clinical Guidelines, wait times, diagnosis, Autism Spectrum Disorder, NICE

**Introduction**

Timely diagnosis of Autism Spectrum Disorder (ASD) can help facilitate access to appropriate support for the individual and carers (Goin & Myers, 2004), however, there are high levels of dissatisfaction with the diagnostic process in terms of the time it takes to diagnose, the diagnostic process itself and post diagnostic support for both children (Crane, Chester, Goddard, Henry, & Hill, 2015) and adults (Jones, Goddard, Hill, Henry, & Crane, 2014). Two recent studies suggest that diagnostic practices, and the time taken to diagnose ASD in adults, vary widely across the UK (Jones et al., 2014; Lowenstein & Sutton, 2013) indicating a need for a more standardised and equitable approach.

Clinical guidelines aim to reduce service variations in the provision and quality of care (e.g. National Institute of Clinical Excellence [NICE[[1]](#footnote-1)], 2012) and to improve the patient and carer experience and clinical outcomes by providing practitioners with an impartial structured summary and evaluation of the evidence base. NICE guidelines, while developed for use in England and Wales, are recognised and used internationally (NICE International, 2014). While organisations such as NICE are not without their critics (e.g. see Pearson & Rawlins, 2005), reviews of the impact of such guidelines suggest that they can be associated with a range of improved patient outcomes in health, such as better mental health and lower levels of post-natal depression compared with normal care (MacArthur et al., 2003) as well as having benefits for professionals and organisations, such as improved staff and patient satisfaction (see Bazian for an overview, 2005). Bazian (2005, p274), however, conducted a systematic review of research in this area and concluded that ‘guidelines can work but often don’t.’

One significant reason why clinical guidelines may not work is a lack of practitioner adherence to them. Research with practitioners working with a range of physical (e.g. Johansson, Pilhammar, Khalaf, & Willman, 2008) and mental health conditions (e.g. Currin et al., 2007), has found adherence to guidelines to be relatively low and to vary both within the same patient population (Goldma, Healy, Florence, Simpson, & Milner, 2003) and between different diagnostic groups within the same clinical practice (Van Fenema, Van Der Wee, Bauer, Witte, & Zitman, 2012). A number of barriers to adherence have been identified including limited practitioner awareness of guidelines which are relevant to their practice; a lack of consensus about how the terminology used in guidelines should be interpreted (e.g. Gyani, Shafran, & Rose, 2012; Rhodes, Genders, Owen, O'Hanlon, & Brown, 2010); insufficient training for professionals in their use and resistance to what are seen as prescriptive processes which conflict with clinical decision-making (Hirsch, 2003).

One of the common features that is shared by guidelines that have been successfully integrated into practice is that they are seen as making the process quicker and easier. Clinicians may, therefore, be unlikely to implement guidelines if they consider them to be introducing an additional time-consuming step in the process of providing care (Bazian, 2005) or require additional staff resources (Rhodes et al., 2010). These concerns are particularly pertinent in the context of a focus on reducing waiting times across the National Health Service in the UK (Department of Health [DOH], 2013; Scottish Government, 2011) and clinicians may be particularly reluctant to introduce guidelines which they feel may negatively impact on waiting times. It is, therefore, important to establish if practice that is consistent with guidelines is related to increased waiting times. Research has also indicated that guidelines that are successfully implemented reflect routine practice for the clinical group being targeted (Bazian, 2005).

In 2012 NICE developed guidelines on the identification, diagnosis and management of ASD in adults. Prior to their development no equivalent evidence base guidance existed for clinicians working in adult ASD services in Scotland, although guidance was available in relation to children (NICE, 2011; Scottish Intercollegiate Guidelines Network, 2007), and it was unknown to what extent the recommendations reflected existing practice there. The research reviewed above suggests that the NICE (2012) guideline had a greater chance of being routinely implemented in practice if it reflected existing practice and was not considered to increase waiting times.

The aims of the present paper were, therefore, to explore:

1. the extent to which the section 9.2 recommendations of the NICE (2012) guidelines which relate to case identification, assessment and diagnosis, reflected existing routine clinical practice in ASD diagnosing services in Scotland.
2. whether there was a significant relation between routine practice which more closely reflects the recommendations of the NICE (2012) guideline and increased waiting times.

**Method**

Ethical approval for the study was received from the Caldicott Guardian and the Research and Development Departments of the participating services.

*Design*

The study design was a cross-sectional, retrospective case note study of adult ASD diagnostic services in Scotland.

*Participating services*

Eight services participated. These were identified using proportionate stratified random sampling from a potential pool of 15 adult ASD diagnostic services in Scotland, and invited to participate. Stratification was based on the Scottish Government definition of urban/rural classification i.e. those services classified as ‘urban’ were contacted in order determined by the random sampling until the required number agreed to participate and the same process was repeated with those services classified as ‘rural.’ Of these, three were Intellectual Disability services, two were Adult Mental Health services and three were specialist ASD services. Five of the services had multi-disciplinary team input with an overall average of 2.75 members per service (range 1-7 members). Three of the services were in ‘large urban areas’, four in ‘other urban areas’ and one in an ‘accessible rural area.’ All services assessed at least ten individuals per year.

*Participants*

Case notes were included in the study if the individual had received a diagnosis of ASD from the participating service in the prior 24 months (inclusive of Autism, Asperger’s Disorder, Autism Spectrum Condition, Autistic Spectrum Disorder). Seventy case notes were included from the eight services, with 5 services providing 10 cases each, 1 providing 11 cases and 1 each providing 4 and 5 cases. The participants comprised 43 males, 24 females, 1 person who was transgender and 2 for whom gender was not stated. The average age at referral was 31.2 years (SD = 11, range 17 - 55.5 years) and average age at diagnosis was 31.7 years (SD = 10.9, range = 17.7 - 56.3 years). The diagnoses given were: Autism Spectrum Disorder = 23, Autism= 15 (including two diagnoses of Atypical Autism) and Asperger’s Syndrome = 32.

*Measures*

Information on the extent to which existing practice was consistent with the section of the NICE (2012) guideline which related to ‘identification and assessment’ (section 9.2) was collected as part of a wider project which utilised data collection tools which comprised an Individual Data Collection Form and a Service Configuration Tool. These were developed for the research and were reviewed by five professionals who were external to the project team and who had expertise in the assessment and diagnosis of ASD. The tools were also piloted with a number of case notes before being finalised for use in the research. Copies are available from the research team.

Information on practice relevant to the NICE (2012) guideline was gathered systematically from the case notes, using the above measures, by the research team, who were independent of the participating services. The recommendations from section 9.2 of the NICE (2012) guideline were operationalized as short statements which could be coded as ‘Yes’, ‘No’, ‘Not applicable’ or ‘Unknown’ (see Table 1). Recommendations were omitted where it would not be possible to determine if the guideline would be applicable from the information available in the case notes e.g. where the clinician was recommended to ‘consider’ a particular course of action if appropriate, or where the recommendation would only be applicable to a subgroup of clients, such as those without an intellectual disability. This resulted in 14 recommendations being included in the analysis. ‘Recommended practice’ was conceptualised as the extent to which the pre-existing routine clinical practice of the service, as reflected within the case notes, was consistent with section 9.2 of the NICE guideline recommendations. In addition, total wait for diagnosis from referral to diagnosis being shared with the individual and/or appropriate other (e.g. parent/carer) was calculated based on dates recorded within the case notes. As the data were collected retrospectively during a time period that preceded the publication of the NICE (2012) guideline, the resulting information reflected clinical practice and waiting times, prior to formal implementation of the guideline.

*Analysis*

We tabulated the numbers of individual cases in which each guideline was carried out in practice. We estimated the extent to which clinical practice for a given case reflected these recommendations by creating a sum score across all the items, with a possible minimum score of 0 (no practice consistent with the recommendations) and maximum of 14 (all practice consistent with the recommendations). The analyses focussed only on the 14 items that were applicable to all the cases involved in the current study, in order to provide a fair comparison across cases. Total scores were missing for 28 participants for whom data were missing on one or more of the 14 individual items comprising this sum. We evaluated the association between this sum score and the duration of the diagnostic process using all cases irrespective of whether they had missing recommended practice scores or not and dealt with missing data using maximum likelihood (ML) estimation. A limitation of using ML estimation to deal with missingness is that it is assumes that data are missing at random (MAR). The MAR assumption was not empirically testable and may not hold e.g. if low recommended practice scores were more likely to be missing because these same cases were also documented with less care. If MAR does not hold, parameter estimates may be biased. Duration of diagnostic process was estimated as the time (in days) between an individual being referred and an individual being told of their diagnosis. Both the wait times and diagnostic durations variable exhibited substantial non-normality and were skewed in the opposite directions. We, therefore, transformed both to normality using a rankit inverse normal transformation prior to analysis (e.g. see Bishara & Hittner, 2012). We then computed the Pearson’s correlation between the ‘recommended practice’ variable and the total duration of the diagnostic process.

**Results**

*Recommended practice*

The extent to which the different section 9.2 NICE 142 guideline recommendations were applicable and applied to clinical cases in practice are provided in Table 1. Table 2 provides the descriptive statistics for the transformed and untransformed data for ‘recommended practice’ and waiting time. The mean score for ‘recommended practice’ across participants was 11.9 (SD = 1.4). The correlation between the raw (untransformed) scores and wait times variables suggested that there was no significant association between the extent to which clinical practice for a given case reflected the recommendations and the duration of the diagnostic process for that individual (*r* =-.10, *p* = .50) . The correlation between the two variables transformed to normality was also small and non-significant (*r* = -.08, *p* = .58). As clustering only inflates statistical significance, we did not proceed to correct standard errors for clustering by services.

 [Insert table 1 about here]

 [Insert table 2 about here]

**Discussion**

It is frequently considered that a significant barrier to the successful implementation of guidelines is clinician resistance to them, and this may contribute to the gap between the production of evidence based research and its translation into clinical practice, through, for example, clinical guidelines (Cooksey & Cooksey, 2006). The present study, however, found that the included NICE (2012) section 9.2 recommendations were generally consistent with existing clinical practice in many respects, with services using the 14 recommended practices (which were applicable to all cases), in at least half of the cases analysed. The mean score of 11.9 (SD = 1.4) out of a possible maximum of 14 also indicated practice that was generally consistent with the recommendations. This is encouraging, in light of research which indicates that a common factor in successfully implemented guidelines is that they reflect routine practice for the clinical group being targeted (Bazian, 2005). While the reasons why particular recommendations were not reflected in practice are unknown, the pattern of responses suggests that this may occur in single practitioner services (where it would not be possible to have team based or multi-professional assessment) and where the practice is influenced by whether the individual has an intellectual disability or not. For example, the involvement of a family member or carer may be more likely where the individual has an intellectual disability.

While the present study found relatively high levels of practice that was consistent with the NICE (2012) guideline, suggesting that resistance to formal implementation of the guideline would be likely to be low, one potential contributing factor to any such resistance could be the concern that implementation could result in increased waiting times. There is a significant focus within health services on waiting times and the extent of the wait is an important indicator of service quality (e.g. DOH, 2013). Importantly, the present study found that there was no significant relation between practice that was consistent with the section 9.2 included recommendations of the NICE (2012) guideline and total waiting time for diagnosis. This suggests that clinicians could implement the included recommendations in this section of the guideline without concern that it will impact negatively on waiting time for diagnosis.

*Limitations*

While the study reports on a representative sample of the national population in Scotland, the number of case notes included was restricted by the time constraints of the study, in that we wished the sample to reflect recent clinical practice prior to the introduction of the NICE (2012) guideline. As such the number of individuals who had received a positive diagnosis of ASD was necessarily limited. Some recommendations were excluded from the analyses, such as those that required the clinician to ‘consider’ a particular course of action, because it was not possible for the research team to determine whether a particular recommendation was appropriate or not from the information in the case notes. The inclusion of all of the recommendations may have resulted in different levels of ‘recommended practice’ and a different impact on waiting times. Better recording in the case notes of the reasons why components of the guideline were or were not implemented would allow this limitation to be addressed in future research.

In addition, the study was unable to identify the clinical complexity of the diagnosed individuals included in the study. Variations in clinical complexity are likely to impact on the assessment process and related total waiting time for diagnosis. In order to control for this potentially confounding factor to some extent, only those recommendations which were recorded as being applicable to all participants, were included in the analysis examining the relation between ‘recommended practice’ and total waiting times. For this reason, some of the recommendations which would not be applicable to all individuals and which may be indicative of greater clinical complexity were excluded from the analyses e.g. risk assessment of potential harm to others/self- harm.

**Implications**

The study found that existing practice in ASD diagnostic services in Scotland was generally consistent with that recommended in section 9.2 of the NICE (2012) guideline. In addition, greater concordance between the existing practice and those recommendations which were relevant to all included cases sampled was not found to be related to increased total waiting time for diagnosis. The results, based only on the included recommendations, suggest that the section 9.2 recommendations can be integrated into clinical practice in Scotland with relative ease and that it is unlikely to have a negative impact on waiting times.

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**Conflict of interests**

None

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Table 1

Frequencies of clinical practices reflecting section 5 of NICE 142 guideline

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Guideline no.****(item number)1** | **Description** | **Reflected clinical practice****No. (%)** | **Did not reflect clinical practice****No. (%)** | **Unclear if applicable to case based on information in case notes No. (%)** | **Missing information****No. (%)** |
| 9.2.1.5**(2)** | **Assessment undertaken by professionals who were trained and competent?** | **70 (100)** | **0 (0)** | **0 (0)** | **0 (0)** |
| 9.2.1.5**(3)** | **Assessment was team based** | **42 (60)** | **25 (36)** | **0 (0)** | **3 (4)** |
| 9.2.1.5**(4)** | **Assessment used a range of professions/skills** | **37 (53)** | **27 (39)** | **0 (0)** | **6 (8)** |
| 9.2.1.5(5) | Where possible a family member, partner, carer or other informant was involved | 48 (69) | 5 (7) | 13 (18) | 4 (6) |
| 9.2.1.5**(6)** | **Documentary evidence (such as school reports) of current and past behaviour and early development utilised.** | **40 (57)** | **26 (37)** | **0 (0)** | **4 (6)** |
| 9.2.1.6(7) | Discussion with the person about the purpose of the assessment and how the outcome of the assessment would be fed back to them. | 61(87) | 1(1.5) | 7 (10) | 1(1.5) |
| 9.2.1.7**(8)** | **Difficulties in social interaction were assessed** | **67 (96)** | **2 (3)** | **0 (0)** | **1 (1)** |
| 9.2.1.7**(9)** | **Difficulties in communication were assessed** | **66 (94)** | **2 (3)** | **0 (0)** | **2 (3)** |
| 9.2.1.7**(10)** | **Stereotypic behaviour was assessed.** | **65 (93)** | **3 (4)** | **0 (0)** | **2 (3)** |
| 9.2.1.7**(11)** | **Resistance to change / restricted interests were assessed.** | **65 (93)** | **3 (4)** | **0 (0)** | **2 (3)** |
| 9.2.1.7**(12)** | **Early developmental history was taken.** | **66 (94)** | **0 (0)** | **0 (0)** | **4 (6)** |
| 9.2.1.7**(14)** | **Assessments were conducted on functioning at home, in education or in employment.** | **58 (83)** | **7 (10)** | **0 (0)** | **5 (7)** |
| 9.2.1.7**(15)** | **Assessments were carried out on past and current physical disorders.** | **47 (67)** | **23 (33)** | **0 (0)** | **0 (0)** |
| **9.2.1.7****(16)** | **Assessments were carried out on mental disorders.** | **47 (67)** | **11 (16)** | **0 (0)** | **12 (17)** |
| 9.2.1.7(17) | Assessments were carried out on any other neurodevelopmental conditions. | 0 (0) | 0 (0) | 69 (99) | 1(1) |
| 9.2.1.7**(18)** | **Hyper- and/or hypo-sensory sensitivities were considered.** | **69 (99)** | **1 (1)** | **0 (0)** | **0 (0)** |
| 9.2.1.7**(19)** | **Direct observation was conducted** | **64 (92)** | **5 (7)** | **0 (0)** | **1 (1)** |
| 9.2.1.12(21) | Risk assessment for self-harm was conducted. | 14 (20) | 16 (23) | 17 (24) | 23 (33) |
| 9.2.1.12(22) | Risk assessment of harm to others was conducted. | 10 (14) | 17 (24) | 20 (29) | 23 (33) |
| 9.2.1.13(24) | A care plan was developed | 45 (64) | 12 (17) | 2 (3) | 11 (16) |
| 9.2.1.18(26) | Follow-up appointment was given to discuss the implications of the diagnosis. | 45 (64) | 12 (17) | 2 (3) | 11 (16) |

1 *Items in bold were included in the analyses.*

Table 2

Descriptive Statistics for Analysis Variables

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **N** | **Mean** | **SD** | **Skew** | **Kurtosis** |
| NICE recommended practice scorea | 42 | 11.9 | 1.40 | -1.07 | 2.46 |
| RIN transformed NICE recommended practice scorea | 42 | -.01 | 1.00 | -.14 | -.21 |
| Diagnostic Duration (Days) | 69 | 163.9 | 104.04 | 1.72 | 2.97 |
| RIN transformed Diagnostic Duration | 69 | 0.00 | 1.00 | 0.00 | -.14 |

a *Based on items 2,3,4,6,8,9,10,11,12,14,15,16,18,19 which were applicable to all cases in the dataset.*

1. Now re-named National Institute of Health and Care Excellence [↑](#footnote-ref-1)