This is a pre-print version of the paper which was subsequently published as:

McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A.L., & Irvine, L. (2015). The relationship between waiting times and 'adherence' to the SIGN 98 guideline in Autism Spectrum Disorder diagnostic services in Scotland. Autism. Early view. DOI: 10.1177/1362361315586136

The relationship between waiting times and 'adherence' to the SIGN 98 guideline in Autism Spectrum Disorder diagnostic services in Scotland

Karen McKenzie, Kirsty Forsyth, Anne O'Hare, Iain McClure, Marion Rutherford, Aja Murray, Linda Irvine

Abstract

Objectives: To explore the extent to which the SIGN 98 guidelines that focus on the assessment and diagnosis of Autism Spectrum Disorder (ASD) were adhered to in child ASD diagnostic services in Scotland; and whether there was a significant relationship between routine practice which more closely reflected these recommendations (increased adherence) and increased waiting times.

Design: Retrospective, cross-sectional case note analysis

Setting: Eight child ASD diagnostic services across Scotland.

Participants: Data were included from 80 child case notes which met the inclusion criteria that the individual had received a diagnosis of ASD and had been diagnosed by the participating service within the past 24 months.

Main outcome measures: Adherence (the extent to which the routine clinical practice of the service, recorded within the case notes, was consistent with SIGN 98 guideline assessment and diagnosis recommendations) ranged from a possible 0 (no adherence) to 19 (full adherence). Total wait for diagnosis was from referral to diagnosis being shared.

Results: Overall, 17/22 of the recommendations were adhered to in over 50 of the 80 included cases and in 70 or more cases for 11/22 of the recommendations, with a mean adherence score of 16 (SD = 1.9). No significant correlation was found between adherence and total wait time for untransformed ((r = .15, p =. 32) or transformed data (r =.12, p =. 20).

Conclusions: The results indicated that, in general, the assessment and diagnostic practices of the participating child ASD diagnostic services were consistent with the relevant SIGN 98 guideline recommendations. Increased adherence to the 19 included recommendations was not significantly related to increased total waiting times, indicating that the SIGN 98 recommendations have generally been integrated into practice, without a resultant increase in patient waits.

Introduction

Autism Spectrum Disorder (ASD) is a lifelong developmental disorder, with estimated prevalence rates in both children and adults (Baron-Cohen et al., 2009; Yates and Le Couteur, 2012) of approximately 1%. Individuals with ASD represent a heterogeneous group, making diagnosis challenging, but all have difficulties with social interaction and communication and restrictive, repetitive behaviours, interests or activities which have been present since early childhood (American Psychiatric Association [APA], 2013). By definition the individual's difficulties must restrict and impair daily functioning (APA, 2013) but ASD can also be associated with additional negative consequences for diagnosed individuals and their families (Reed and Osborne, 2013), including financial, emotional and behavioural challenges (Al-Qabandi et al., 2011). It is recognised that there are variations

in practice within (Lowenstein and Sutton, 2013) and between countries (Lauriston, 2013; Moh and Magiati, 2012) in the assessment and diagnosis of ASD and that this can result in differences in waiting time for diagnosis, age of the individual at diagnosis, parental stress, and satisfaction with the process (see Moh and Magiati, 2012 for an overview).

The facilitation of a more consistent and evidence based approach to health care interventions was one of the key aims of the Scottish Intercollegiate Guidelines Network (SIGN) when it was set up in 1993 (Miller, 2002). Since that time, a number of SIGN guidelines have been developed, including in relation to ASD in children and young people (SIGN, 2002). SIGN guidelines are recognised internationally (e.g. Lauriston, 2013; Moh and Magiati, 2012) and used for audit and benchmarking purposes both in the UK and abroad (Stride et al., 2007). Such clinical guidelines can facilitate effective decision making and transparent and equitable services (McClure and Le Couteur, 2007). Initially SIGN adopted the position that the implementation of SIGN guidelines into practice was the responsibility of health boards (Miller, 2002). The more recent position is to support implementation through approaches such as awareness raising and developing resources and tools to support implementation (SIGN, 2013). This change perhaps reflects the recognition that

there is wide variation in the extent to which SIGN guidelines are adopted in practice (e.g. Clement and Dempster, 2004) and the multiple, interacting factors that can impact on implementation (Livesey and Noon, 2007). Research on the use of SIGN guidelines in practice in different health specialties has found outcomes ranging from limited adherence (Merrylees et al., 1999), through no significant change (Kerr et al., 2005), to increasing compliance with SIGN guidelines over time (Ogundipe et al., 2008). Studies have also found improvement in record keeping following publication of SIGN (Campbell et al., 2000; Williams et al., 2002).

Despite the potential and reported benefits of clinical guidelines, they are subject to some criticisms. These include the static nature of guidelines, which are unable to be updated quickly, failure to reflect the complexity and heterogeneity of individuals, particularly those with comorbid conditions, and limited ability to take a holistic account of the person and the impact of his/her condition on wider quality of life (Clement and Dempster, 2004; Sleeman et al., 2010). There are also concerns that while consensus methods can be subject to bias (Campbell et al., 2000), a reliance on evidence based practice in guidelines may unintentionally result in a focus on areas that can be more easily

measured (Mesibov and Shea, 2011). Such concerns may manifest in clinical practice in failure to implement guidelines.

Campbell et al (2000) argue that the main barrier to implementation of guidelines is the time required by individuals and organisations to change practice. Staff may perceive that aspects of the guidelines, such as increased recording, may be perceived as taking staff time away from patient contact. Service time constraints have been identified by a number of other researchers as a barrier to guideline implementation (Currin et al., 2007; Toner et al., 2010). This is perhaps unsurprising in a context where there is a focus on reducing waiting times to access NHS services across the UK (Department of Health [DOH], 2013; Scottish Government, 2011). Unsurprisingly, clinicians are more likely to adopt guidelines if they perceive that they will make the process quicker (Ltd, 2005). Services, therefore, have to strike a difficult balance between providing an efficient service that produces waiting times within government targets and a quality service that is consistent with practice guidelines. Despite the conclusion of many authors that regular audit, with feedback to services, is required in order to facilitate the implementation of guidelines into practice (Clement and Dempster, 2004; Kerr et al., 2005; Livesey and Noon, 2007; Stride et

al., 2007), there has been a dearth of research examining the impact that adherence to guidelines has on waiting times.

The present study, therefore aimed to explore:

a) the extent to which the sections of SIGN 98 (SIGN, 2007) that focus on the assessment and diagnosis of ASD were adhered to in child ASD diagnostic services in Scotland;
b) whether there is a significant relationship between routine practice which more closely reflects the recommendations of the SIGN 98 (SIGN, 2007) guideline (conceptualised as increased adherence) and increased waiting times.

Method

Ethical approval

The study received approval from the Caldicott Guardian and the Research and Development Departments of the participating health services.

Design

The design was a retrospective, cross-sectional case note analysis of child ASD diagnostic services.

Participating services

There was no up to date list of diagnostic services at the time the study took place, therefore, a sampling frame was generated from a broad range of sources inclusive of: the National Autistic Society's UK-wide Autism Services Directory Website, the NHS Education for Scotland Directory, Information Services Division, Health Networks, Education Networks, Voluntary Sector, Scottish Government, eSAY (the statistics project of the Scottish Consortium for Learning Disability), and a comprehensive web search. A telephone survey was then conducted to ascertain which services conducted diagnostic assessment of individuals with ASD. This resulted in a list of 64 child services, of which 53 routinely (i.e., more than 10 per year) assessed for ASD. Of the 53 services, 23 were Child and Adolescent Mental Health Services (CAMHS), 15 were Child Development Centres or equivalent, and 15 were specialist ASD or communication teams. The research used proportionate stratified random sampling. In order to select the final participating services,each was categorised as being 'urban' or 'rural,' based on the Scottish Government's 6-fold classification. From these

categories, a random sample was conducted and the sampled services (n=8) were invited to participate.

Participants

The inclusion criteria for the case notes were that the individual concerned had received a diagnosis of ASD from the participating service and was one of the 10 most recent cases where the individual had received a diagnosis of ASD. As the study took place before the publication of the DSM V (APA, 2013), diagnosis of ASD was inclusive of Autism, Asperger's Disorder, and Autism Spectrum Condition, as well as Autistic Spectrum Disorder. Twenty two children were also recorded as having an intellectual disability. Eighty case notes were obtained from the eight services.

Measures

Information on adherence to the section of SIGN 98 (SIGN, 2007) which focused on assessment and diagnosis was collected using two data collection tools: an Individual Data Collection Form and a Service Configuration Tool. These tools were developed for the research and were reviewed by five independent professionals who had expertise in the

assessment and diagnosis of ASD, as well as being piloted with a number of case notes prior to use.

Information on adherence to the relevant aspects of the SIGN 98 guideline was gathered from the case notes and the service configuration tool by research team members, who were unconnected with the participating services. The recommendations were operationalized as short statements which could be coded as 'Yes', 'No', 'Not applicable' or 'Unknown' (see Table 1). Where it was not possible for the researchers to determine if the guideline was applicable from the case note information e.g. if the guideline was only to be applied 'if relevant,' the particular recommendation was omitted. Adherence 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 the relevant sections of the SIGN 98 guideline recommendations. Waiting time was conceptualised as the total wait for diagnosis from referral to diagnosis being shared with the individual and/or appropriate other (e.g. parent/carer). The duration of this diagnostic process was calculated based on the dates recorded within the case notes.

Analysis

We evaluated the degree to which participating services adhered to the SIGN 98 guideline by examining the frequencies of cases for which the guideline was adhered to, not adhered to, not applicable or for which information on guideline adherence was missing. We then computed the Pearson's correlation between guideline adherence and duration of diagnostic process. A guideline adherence score was computed for each case, which was the sum of all relevant items of the SIGN 98 guideline. Three items were excluded from this analysis because these were not relevant to all cases. These were: Occupational therapy assessments were considered (if relevant); Physiotherapy assessments were considered (if relevant); Advice on diet and food intake was sought (if individual displayed significant food selectivity, dysfunctional feeding behaviour, or restricted diet which were producing adverse symptoms).

Guideline adherence scores thus had a possible range from 0 (no guidelines were adhered to) to 19 (all guidelines were adhered to). The mean adherence score in the sample was 16.0 (SD=1.86) and scores ranged from 11 to 19. Eight cases (10%) had missing adherence scores due to having missing scores on one or more of the individual items. Missing data were dealt with using full information maximum likelihood estimation. Diagnostic duration was computed as the time in days between referral and diagnosis being

shared. This variable showed high levels of skew (2.39) and was, therefore, transformed to normality using a Rankit Inverse Normal (RIN) transformation. This successfully dealt with the skewness.

Results

The frequency with which each SIGN guideline was adhered to is reported in Table 1. Descriptive statistics for the adherence scores and diagnostic durations are provided in Table 2. The mean adherence score was relatively high at 16 given that the scores could range from 0 to 19 and it showed little variation around this value (SD= 1.9). In contrast, the raw diagnostic duration variable showed a large amount of variation.

[Insert table 1 here]

Association between SIGN adherence and diagnostic duration

The Pearson's correlation between adherence scores and the transformed diagnostic duration was r=.12 (p=.20). This was slightly larger than the correlation with the raw diagnostic durations (r=.15, p=.32). Neither correlation was statistically significant.

[Insert table 2 here]

Discussion

The assessment and diagnostic practices for ASD have been found to vary both within the UK (Lowenstein and Sutton, 2013) and between different countries (Lauritsen, 2013; Moh and Magiati, 2012), with resultant differences in the experiences of children and their families (Moh and Magiati, 2012). SIGN guidelines explicitly aim to bring increased standardisation, equity and quality to health care provision and the SIGN 98 (SIGN, 2007) guidelines for children and young people with ASD are no different. Research suggests that an important barrier to implementation may be the perception that the implementation of some guidelines are incompatible with service time constraints and thus will have a negative impact on waiting times (e.g. Campbell et al., 2000; Currin et al., 2007, Toner et al., 2010). It is suggested that such perceptions may lead to reduced guideline adherence. The present study examined the extent to which eight child ASD diagnostic services adhered to selected SIGN 98 (SIGN, 2007) guidelines relating to assessment and diagnosis. The results indicated that adherence was generally high overall, with 17/22 of the

recommendations being adhered to in over 50 of the 80 included cases and in 70 or more cases for 11/22 of the of the recommendations. Similarly the mean adherence score for the participants was 16 (out of a possible 19), with a small standard deviation of 1.9. Given that wide variation in the extent to which guidelines are adhered to has been reported previously, this result is encouraging and indicates that the practice in relation to assessment and diagnosis of ASD in children was consistent with recommended practice in the majority of the included case-notes. As one of the case note inclusion criteria was that the case file was one of the 10 most recent cases where the individual had received a diagnosis of ASD, this also suggests that the results reflect recent practice.

Recommendations that were adhered to in fewer cases tended to reflect situations where the recommendation was to be followed 'if relevant'. As it was frequently impossible for the independent researcher to ascertain from the case notes if the recommendation would have been relevant or not, these were often coded as 'unknown'. Studies have consistently reported difficulty in auditing adherence to guidelines due to the inadequacy of the available records and paperwork (Kerr et al., 2005; Williams et al., 2002). Given the growing need for health professionals to demonstrate competence in both audit and evidence based practice (Craig et al., 2010), clinicians may, in future, more clearly document

the reasons for their decision. This will be of particular value in cases where the implementation of a recommendation is based on clinical judgement of the relevance to a particular individual. There were also two additional recommendations that were adhered to less frequently, which could be considered to have been relevant to all individuals being assessed. Firstly: 'A comprehensive evaluation of speech and language and communication skills was conducted by a Speech and Language Therapist (SLT) with ASD training', which was adhered to in only half of the cases. This may reflect the fact that not all of the participating services had a SLT as part of their diagnostic team. It may also be that if an individual is verbal it may be considered that a communication assessment is not required. Secondly: 'The individual was considered for an assessment of intellectual, neuropsychological and adaptive functioning', which was adhered to in only 26/80 cases. This is perhaps concerning, given the high comorbidity of ASD with intellectual disability (Matson and Shoemaker, 2009) and may suggest that some children with an intellectual disability are not being identified by ASD diagnostic services. This finding may reflect the fact that intellectual and neuropsychological assessment can only be undertaken by appropriately trained and qualified applied psychologists, such as clinical or educational psychologists (British Psychology Society, 2000), who again may not be members of the

diagnostic team. In addition, there is debate amongst psychologists about the relevance and appropriateness of intellectual assessment of children (Elliot, 2000) which may act as an additional barrier to implementation. This suggests a need to ensure that diagnosing services have ready access to all professions who are needed to contribute to the ASD assessment and diagnostic process. In general, however, the results indicated that the practice of the child ASD diagnostic services was consistent with the included SIGN 98 recommendations.

The second aim of the study was to explore whether increased adherence to SIGN 98 was associated with increased total waiting time from referral to sharing the diagnosis. No significant relationship was found, indicating that providing a diagnostic service that is consistent with good practice guidelines does not impact negatively on waiting times. This is important, given that the length of patient wait is an important NHS quality indicator (DOH, 2013, Scottish Government, 2011).

Limitations

The study had a number of limitations and the results must be considered in this context. While it is encouraging that levels of adherence were relatively high, the relatively low variance in adherence limits the scope to detect significant associations between adherence and waiting times. It may be that the reason that no significant association was found is because adherence is generally consistently quite high to begin with. Similarly, while the study reflected practice in a representative national population sample in Scotland, the sample size was constrained by the number of case notes available that met the inclusion criteria of the study. It was not possible to identify and directly take account of the clinical complexity of the included individuals, despite this being a factor that would be thought likely to impact on the assessment duration. An attempt was made to control for variations in clinical complexity by only including those recommendations that were applicable to all individuals. The exclusion of three recommendations from the waiting time analysis, on this basis, may however, also have impacted on the results. All three excluded recommendations required assessment by, or consultation with, other health professionals, which would be likely to increase assessment duration, and in turn, total waiting time.

Conclusion

The results indicated that, in general, the assessment and diagnostic practices of the participating child ASD diagnostic services were consistent with the relevant SIGN 98 guideline recommendations. Increased adherence to those guidelines that were applicable to all cases was not significantly related to increased total waiting times, indicating that the SIGN 98 recommendations have generally been integrated into practice, without a resultant increase in patient waits.

Acknowledgments

We would like to acknowledge Ciara Catchpole (CC) and Tess Johnston (TJ) who gathered data for this study. This publication was supported by a grant from The Scottish Government. Its content is solely the responsibility of the authors and does not necessarily represent the official views of the Scottish Government.

References:

Al-Qabandi M, Gorter JW and Rosenbaum P (2011) Early autism detection: are we ready for routine screening? *Pediatrics* 128(1): e211-e217.

American Psychiatric Association editor (2013) *Diagnostic and Statistical Manual of Mental Disorders*. Fifth Edition ed. London: American Psychiatric Publishing.

Baron-Cohen S, Scott FJ, Allison C, Williams J, Bolton P, Matthews FE and Brayne C (2009) Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry* 194(6): 500-509.

British Psychological Society (2000) Learning disability: Definitions and Contexts. *British Psychological Society*. Leicester.

Campbell H, Bradshaw N, Davidson R, Dean J, Goudie D, Holloway S and Porteous M (2000) Evidence based medicine in practice: lessons from a Scottish clinical genetics project. *Journal of Medical Genetics* 37(9): 684-691.

Clement WA and Dempster JH (2004) Implementation by Scottish otolaryngologists of the Scottish Intercollegiate Guidelines Network document Management of Sore Throats and the Indications for Tonsillectomy: four years on. *The Journal of Laryngology & Otology* 118(5): 357-361.

Craig WL, Green R, El-Ghorr A, James R, Brown K and Twaddle S (2010) S86–Web-based adjuncts to guideline dissemination Novel interventions from the Scottish Intercollegiate Guidelines Network (SIGN). *Otolaryngology-Head and Neck Surgery* 143(1): 57-57.

Currin L, Waller G, Treasure J, Nodder J, Stone C, Yeomans M and Schmidt MD (2007) The use of guidelines for dissemination of "best practice" in primary care of patients with eating disorders. *International Journal of Eating Disorders* 40(5): 476-479.

Department of Health (2013) The Handbook to the NHS Constitution. London: Department of Health.

Elliott JG (2000) The psychological assessment of children with learning difficulties. *British Journal of Special Education* 27(2): 59-66.

Kerr J, Smith R, Gray S, Beard D and Robertson C (2005) An audit of clinical practice in the management of head injured patients following the introduction of the Scottish Intercollegiate Guidelines Network (SIGN) recommendations. *Emergency medicine journal* 22(12): 850-854.

Lauritsen MB (2013) Autism Spectrum Disorders. *European child & adolescent psychiatry* 22(1): 37-42.

Livesey EA and Noon JM (2007) Implementing guidelines: what works. *Archives of disease in childhood-Education & practice edition* 92(5): ep129-ep134.

Lowenstein J and Sutton K (2013) An audit of the processes and tools used in different services across the South-West Region to diagnose Asperger syndrome in adults. *Good Autism Practice (GAP)* 14(1): 80-88.

Ltd B (2005) Do evidence-based guidelines improve the quality of care? *Evidence-Based Healthcare and Public Health* 9(4): 270-275.

Matson JL and Shoemaker M (2009) Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities* 30(6): 1107-1114.

McClure I and Le Couteur A (2007) Evidence-based approaches to autism spectrum disorders. *Child: Care, Health & Development* 33(5): 509-512.

Merrylees C, Taylor TW, Shaw JW, Fraser HW, Dutta D, Ersoy Y and MacWalters RS (1999) CT brain scans after acute stroke: how far are we from meeting the Scottish intercollegiate guidelines network (SIGN) recommendations? Results from the year prior to guideline publication. *Health Bulletin* 57(4):252-256.

Mesibov GB and Shea V (2011) Evidence-based practices and autism. *Autism* 15 (1): 114-133.

Miller J (2002) The Scottish Intercollegiate Guidelines Network (SIGN). *The British Journal of Diabetes & Vascular Disease* 2(1): 47-49.

Moh TA and Magiati I (2012) Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders* 01 6(1): 293-303.

Ogundipe O, Cordina J and Norris C (2008) Description of a chronic heart failure service model and review of pharmacotherapy in a district general hospital in comparison to Scottish Intercollegiate Guideline Network (SIGN) guidelines. *Scottish Medical Journal* 53(3): 28-32.

Reed P and Osborne LA (2013) Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders. *Archives of Disease in Childhood* 97(10): 927-931.

Scottish Government (2011) Patients Rights (Scotland) Act. Edinburgh: HMSO.

Scottish Intercollegiate Guidelines Network (SIGN) (2007) Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. Edinburgh: SIGN 98.

Scottish Intercollegiate Guidelines Network (2013) What is SIGN? Available at: http://sign.ac.uk/about/introduction.html. (accessed 11 December 2013).

Sleeman D, Moss L, Gyftodimos E, Nicolson M and Devereux G (2010) A comparison between clinical decisions made about lung cancer patients and those inherent in the corresponding Scottish Intercollegiate Guidelines Network (SIGN) guideline. *Health Informatics Journal* 16(4): 260-273.

Stride P, Houston A, Ratnapala D and Perron J (2007) International benchmarking of 500 admissions with a fractured hip in Australia using the Standard Audit of Hip Fractures in Europe and the Scottish Intercollegiate Guidelines Network. *Journal of the Royal College of Physicians of Edinburgh* 37(2): 98-102.

Toner R, Snape C, Acton S and Blenkiron P 2010 Do general practitioners adhere to NICE guidelines for depression? Systematic questionnaire survey. *Primary Health Care Research and Development* 04 11(2): 123-131.

Williams A, Lee P and Kerr A (2002) Scottish Intercollegiate Guidelines Network (SIGN) guidelines on tonsillectomy: a three cycle audit of clinical record keeping and adherence to national guidelines. *The Journal of Laryngology & Otology* 116(6): 453-454.

Yates K and Le Couteur A (2012) Diagnosing Autism. *Paediatrics and Child Health* 23(1): 5-10.

Table 1. Adherence (frequency) to the SIGN 98 guideline (those aspects which could be scored).

SIGN 98 Recommendations and Good Practice Points	Yes	No	N/A or ?
The diagnostic assessment included a developmental and family history (or every effort was made to ascertain it)	80	0	0
A medical history and examination was conducted by a medically trained professional	56	24	0
The diagnostic assessment used information drawn from observation	79	1	0
Wider contextual and functional information was obtained regarding the individual's functioning outside the clinic setting	78	2	0
Existing information from all settings was gathered	70	10	0
There was a direct clinical observation/assessment of the individual's social and communication skills	78	2	0
The individual's behaviour/behavioural problems were considered as part of the diagnostic process	79	1	0
A comprehensive evaluation of speech and language and communication skills was conducted by an SLT with ASD training	40	40	0

Assessment of the individual's past and current mental health was conducted	51	26	3
The individual was considered for an assessment of intellectual, neuropsychological and adaptive functioning	26	54	0
Where clinically appropriate, detailed assessment was conducted to accurately identify and manage comorbid problems/coexisting conditions^	54	23	3
Professionals assessed the needs and strengths of each family member and available informal support systems (i.e. support outwith services)	69	11	0
Internationally recognised diagnostic criteria were used	78	2	0
Consideration was given to whether informal support systems needed to be supplemented	77	3	0
The family received copies of the letters sent to the various professionals who were asked to assess their child (i.e. referral letters)	51	28	1
Occupational therapy assessments were considered (if relevant) ^	47	22	11
Physiotherapy assessments were considered (if relevant) ^	13	12	55
Advice on diet and food intake was sought (if individual displayed significant food selectivity, dysfunctional feeding behaviour, or restricted diet which were producing adverse symptoms) ^	17	31	32
At time of diagnosis, the family was given a good quality written report of the outcome of the various assessments and the final diagnosis	74	6	0
Parents were provided with information in an accessible and absorbable form	68	12	0
The information provided related to the individual's particular ASD presentation	76	4	0
Professionals offered parents an opportunity to ask questions when disclosing information about the individual with ASD	79	0	1

Key: ? – It was unclear based on the information available if this recommendation was completed
^ – This recommendation was difficult to analyse due to the difficulty in assessing the relevance for each case note, based on the information available

Table 2. Descriptive statistics for adherence and diagnostic duration.

Variable	N	Mean	SD	Skew	Kurtosis
SIGN adherence score[a]	72	16.00	1.86	-0.71	-0.12
Diagnostic Duration (Days)	80	335.96	317.76	2.39	8.11
RIN transformed Diagnostic Duration	80	0.00	1.00	.00	-0.13

[a]This is a sum of all SIGN items excluding the three which were not applicable to all cases.