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### **A national study to investigate the clinical use of standardised instruments in autism spectrum disorder assessment of children and adults in Scotland**

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**Title:** A national study to investigate the clinical use of standardised instruments in autism spectrum disorder assessment of children and adults in Scotland

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## **Abstract**

*Background:* There are few large scale studies about the nature and extent of the actual use of standardised assessments for Autism Spectrum Disorder diagnosis in clinical practice. This study compares and contrasts practice in diagnostic services for both adults and children.

*Method:* We conducted an analysis of retrospective case notes from 150 cases (70 adult, 80 children) assessed for Autism Spectrum Disorder by 16 diagnostic services.

*Results:* We found differences between adult and child services in staff training and use of standardised assessment during diagnosis. All child services had staff trained in and regularly using standardised assessments. Most adult services had staff trained in using instruments but only half used them regularly. Administration of standardised ASD assessments was ten times more likely in children than in adults (OR = 10.1; CI = 4.24, 24.0). Child services selected the ADOS as the standardised tool and Adult services selected the DISCO, with very little overlap. Decisions to administer standardised tools were not based on case complexity but rather the same process was applied to all referrals within a service. The three recommended components of assessment (clinical history, clinical observation and contextual information) were included for the majority of cases, although clinical observation was more frequently used with children than with adults.

*Conclusions:* Based on the findings, we suggest a need for a wider range of appropriate assessments for use with adults, particularly those with an intellectual disability and for further research into the reasons behind the choices clinicians make during the assessment process. For child services in Scotland, there is a need for more training in use of current diagnostic interviews. Clinicians did not vary tools used based on complexity, suggesting that this is a notion still to be clearly defined and operationalised in clinical decision making about the use of standardised assessments.

*Key words:* Autism Spectrum Disorder; Children; Adults; Assessment

## Highlights

- All child and most adult services had at least one clinician trained to use a standardised ASD assessment.
- Administration of standardised ASD diagnostic assessments was ten times more likely in children than in adults.
- ADOS was used almost exclusively by child services and DISCO was used in adult services. Other recommended tools were rarely or never used.
- The concept of case complexity remains undefined and this did not influence clinical decisions over administering standardised tools or not.
- Three recommended components of assessment (clinical history, clinical observation and contextual information) were used in most cases.

## 1. Introduction

There is no single diagnostic measure for Autism Spectrum Disorder (ASD). Experienced clinicians observe core symptoms and interpret information from a range of sources, with consideration of age, intellectual ability and co-existing conditions (Matson et al., 2012). Standardised instruments structure this information gathering, making it more reliable and consistent between cases (De Bildt et al., 2004).

The components of a 'gold-standard' ASD diagnosis and the usefulness of standardised instruments for this task are much debated and only limited guidance exists for clinicians in terms of assessment processes and tools. Charman and Gotham (2013) summarise the commonly recommended standardised ASD diagnostic instruments for clinical history and observational assessments for adults and children. These are: the ADOS (Autism Diagnostic Observation Schedule, Lord et al., 2000); ADI-R (The Autism Diagnostic Interview-Revised, Lord, Rutter, & Le Couteur, 1994) and The Developmental, Dimensional and Diagnostic Interview (Skuse et al., 2004). The DISCO (Diagnosis of Social and Communication Disorder Schedule, Leekam, Libby, Wing, Gould, & Taylor, 2002) is recommended for use in complex cases for adults (NICE 142, 2012). For the purpose of this paper, screening instruments such as the M-CHAT (Kleinman, Robins, Ventola, Pandey, Boorstein, Esser, & Barton, 2008) are not included and there was no reported use in our clinical sample of children aged between 0-5 years (n=23/70). Diagnosing clinicians are advised to consider using autism specific standardised instruments as part of a more comprehensive assessment for children and young people but not in every case (Scottish Intercollegiate Guidelines Network [SIGN], 2007; National Institute for Health and Care Excellence [NICE], 2011) and in more complex cases for adults with and without a learning disability (NICE, 2012).

It has been argued that a thorough clinical history alongside an astute clinical examination can be an excellent alternative to standardised assessments (Carpenter, 2012). However, research based on application of DSM – IV diagnostic criteria (American Psychiatric Association 1994) highlights that there can be low levels of diagnostic agreement between expert clinicians without the use of standardised instruments (Williams, Atkins, & Soles, 2009) and that a combination of two or more standardised assessments can increase reliability of diagnosis in children (e.g. Kim & Lord, 2012). Staff training in the use of screening tools has been shown to increase expertise and

diagnostic agreement in paediatric practice (Swanson et al., 2014). It is recommended in the National Autism Plan for Children [NAPC] (Le Couteur, Baird, & Mills, 2003) that in child services, at least one clinician in each area should be trained in one of the current diagnostic interviews and that staff should be trained in one of the currently recommended assessment tools, which could include observational tools. It remains unclear, however, how widespread the staff training in standardised diagnostic instruments is.

Evidence-based clinical guidelines recommend that experienced clinicians should make ASD diagnoses using all three components of assessment: information from a clinical history; clinical diagnostic observation and contextual assessment, i.e., the individual's presentation in real life settings (SIGN, 2007; NICE, 2011; NICE, 2012). The latter can be addressed by direct observation outside the clinical context, or questionnaires completed by informants observing the individual in different contexts.

There has been limited research exploring the extent to which clinicians pragmatically balance the recommendations relating to use of standardised assessment within a context of scarce clinical resources and a need for efficiency (Matson et al., 2012).

In child services, earlier studies indicated that standardised instruments are used in 33-61% of cases (Martin, Bibby, Mudford, & Eikeseth, 2003; Williams et al., 2009; Palmer, Ketteridge, Parr, Baird, & Le Couteur, 2010). Two recent studies found that the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) was used in around half of cases and that its use was more likely with older children and in more complex cases (Hathorn, Alateeqi, Graham, & O'Hare, 2014; Rzepecka, McKenzie, McClure, & Murphy, 2012).

Very few studies have reported clinician views about practice in ASD diagnostic assessment. In a survey of 116 practitioners from child and adult services (Rogers, Goddard, Hill, Henry, & Crane, 2015), 75% found standardised instruments to be very or quite helpful. Only 4% found them to be unhelpful. In their study of reported rather than actual use, the ADOS and the DISCO were the most commonly used tools across all services, with 63% reportedly using ADOS and 33% using the DISCO. How this differed across child and adult services was not reported.

In recognition of the importance of the clinician perspective on selection and use of standardised instruments, our research team carried out focus groups with staff (n=95) from all 16 participating services. Findings reported in Rutherford et al. (submitted) identify challenges and

solutions to reducing the wait for diagnostic assessment. All child services viewed the ADOS positively and suggested that even when not using it, familiarity with the structure informs assessment practice. Child teams reported feeling well trained and confident in diagnostic assessment, whereas in adult services there was variability between well established and newer teams. Several less experienced participants reported taking on ASD diagnosis despite not having had enough relevant training only because no other service would take this role on. More experienced adult teams reported confidence that clinical judgement exceeds that of such tools and were less motivated to use them clinically even if trained.

There have, however, been no studies of the actual use of standardised instruments in clinical practice with children and there are no studies in adult services. The present study, therefore aimed to identify, from a sample of Scottish child and adult ASD diagnostic services, (1) the number of services with at least one clinician trained in the use of a standardised instrument for ASD diagnostic assessment, (2) the extent to which standardised instruments are used in practice, and (3) the extent to which diagnostic decisions take account of the recommended components of assessment (clinical history, clinical observation and contextual information).

## **2. Methods**

Study approval was granted by the Caldicott Guardian and the research and development departments of the participating services.

### *2.1 Design*

A quantitative cross-sectional analysis of case notes of 150 cases (70 adult and 80 child) from 16 ASD diagnostic services which represented the 14 Health Board areas across Scotland.

### *2.2 Sample of services*

Sixteen services (eight adult, eight child) that routinely diagnosed ASD were randomly selected from a sample of 68 services (15 adult, 53 child) across Scotland from private and public

sectors, using a proportionate stratified random sampling method. The final sample was representative of the Scottish population in terms of 'urban' and 'rural' classification and deprivation category (see McKenzie et al., 2015).

### 2.2.1 Participants

All participating child services were provided through multi-disciplinary teams (MDTs), averaging 5.2 MDT members per service (range 3-9 members) and comprised four Child and Adolescent Mental Health services (CAMHS), three Child Development Centres (CDCs) or equivalent, and one joint service. In adult services, five had MDT involvement; averaging 2.7 MDT members (range 1-7 members). The adult sample comprised three ID Services, two Adult Mental Health services and three services that only accepted referrals for ASD diagnosis.

### 2.3 Data collection and analysis

In order to establish the level of use of standardised instruments for each participating service, a *Service Configuration* tool to gather information about each service and an *Individual Data Collection* form to audit case notes were developed by the research team based on previous research and evidence-based guidelines (see McKenzie et al., 2015). A range of demographic and clinical details were recorded from case notes including additional diagnoses, such as Intellectual Disability (ID) (McKenzie et al., 2015; Rutherford et al., 2016). To increase inter-rater reliability, the team developed an accompanying *Operational Definitions* document. Descriptive statistics were used to address the aims of the study.

## 3. Results

The service configuration tool data is summarised in Tables 1 and 2.

**Table 1**

Service configuration: child services



<b>Child services</b>	<b>Type of service and Urban/Rural Classification</b>	<b>Type of assessment</b>	<b>Number of staff in the diagnosing team</b>	<b>Professions represented in the wider team undertaking assessment contributing to the diagnosis</b>	<b>Range of experience in ASD diagnosis (years)</b>	<b>Estimated number of referrals per year</b>
Service 1	General CAMHS <i>Urban</i>	Multi-disciplinary Assessment	3	Child & Adolescent Psychiatrist, Clinical Psychologist, Specialist Nurse, OT, SLT, Social Worker, Family Therapist, Play Therapist & Psychotherapist	5-10	missing
Service 2	General CAMHS <i>Urban/Rural</i>	Multi-disciplinary Assessment	3	Child & Adolescent Psychiatrist, Clinical Psychologist, Specialist Nurse, OT & Child Psychotherapist	Over 20	60-72
Service 3	Specialist CAMHS <i>Urban</i>	Multi-disciplinary Assessment	4	Child & Adolescent Psychiatrist, Clinical Psychologist, Specialist Nurse, Community MH Worker, Educational Psychologist, General Psychiatrist, OT, Paediatrician & SLT	10-20	132
Service 4	General CDC and CAMHS <i>Urban/Rural</i>	Multi-disciplinary Assessment	3	Child & Adolescent Psychiatrist, Paediatrician, SLT	10-20	72
Service 5	Specialist CAMHS <i>Urban</i>	Multi-disciplinary Assessment	6 or more	Child & Adolescent Psychiatrist, Clinical Psychologist, Specialist Nurse, OT & SLT	10-20	missing
Service 6	Specialist CDC <i>Urban</i>	Multi-disciplinary Assessment	4	OT, Paediatrician & SLT	5-10	180
Service 7	General CDC <i>Rural</i>	Multi-disciplinary Assessment	4	Child & Adolescent Psychiatrist, Clinical Psychologist, Educational Psychologist, OT, Paediatrician, SLT, Education & Nursery Nurse	10-20	24
Service 8	General CDC <i>Urban</i>	Multi-disciplinary Assessment	6 or more	Educational Psychologist, Paediatrician, SLT & Social Worker	10-20	60

\*NB these are estimates

**Table 2**

Service configuration: adult services

<b>Adult Services</b>	<b>Type of service and Urban/Rural Classification</b>	<b>Type of assessment</b>	<b>Number of staff in the diagnosing team</b>	<b>Professions represented in the wider team undertaking assessment contributing to the diagnosis</b>	<b>Range of experience in ASD diagnosis (years)</b>	<b>Estimated number of referrals per year</b>
Service 1	Specialist ID <i>Urban</i>	Multi-disciplinary assessment	6 or more	Clinical Psychologist, Specialist Nurse, General Psychiatrist, OT, Physio, SLT, Dietician & Community Nurse	10-20	12-24

Service 2	Specialist ASD Service <i>Urban/Rural</i>	Single practitioner assessment	1	General Psychiatrist	5-10	10
Service 3	Specialist MH <i>Urban</i>	Not stated	6 or more	Specialist Nurse, General Psychiatrist, OT, SLT & another psychiatrist	5-10	20-30
Service 4	Specialist ID <i>Urban/rural</i>	Single profession assessment	2	Specialist Nurse & Charge Nurse	5-10	12
Service 5	Specialist ASD Service <i>Urban</i>	Multi-disciplinary assessment	3	Psychologist, nurse & Psychological Consultant	Over 20	25
Service 6	General ID <i>Urban</i>	Single practitioner assessment	6 or more	Clinical Psychologist, Trainee (not specified) & an Assistant (not specified)	10-20	missing
Service 7	General MH <i>Urban</i>	Single practitioner assessment	6 or more	Clinical Psychologist	5-10	4/5
Service 8	Specialist ASD Service <i>Urban</i>	Multi-disciplinary assessment	2	Specialist Nurse, General Psychiatrist, SLT, CPN & CLDN	Over 20	120

### 3.1 Training in the use of standardised instruments

In all child services there were staff trained in and regularly using one of the three recommended standardised instruments for clinical history or observation, mainly ADOS. In Adult services 7/8 had staff trained in standardised instruments, mainly DISCO, but only 4/8 services had staff regularly using these.

#### 3.1.1 Use of standardised instruments in practice

Table 3 illustrates the number of cases for which a recommended standardised assessment was used to aid diagnosis. As there was little variation within services in the use of standardised instruments (i.e., either they were used or they were not used in particular services across the sample), it was not possible to conduct any statistical analyses for individual assessments. However, a  $\chi^2$  test showed a difference in the frequencies of receiving one or more standardised instruments between children and adults,  $\chi^2(1) = 30.6$ ,  $p < .001$ . Children were found to be 10 times more likely to be administered a standardised instrument than adults (odds ratio = 10.1; CI = 4.24, 24.0).

**Table 3**

The number of cases for which a standardised assessment was used to aid diagnosis.

	Observational Tools		Interview Tools		Self report Tools		Contextual Assessment Tools					
	ADOS-G	ADI-R	DISCO	3DI	RAADS-R	AAA	GARS (Parent : Teacher)	GADS	SRS (Parent : Teacher)	KADI		
72/80 children were assessed using one or more standardised instruments												
Total number of times instrument were used ( <i>n</i> =83)	69	0	0	0	N/A	N/A	1	0	6	5	2	N/A
Number of cases involving one instrument ( <i>n</i> = 67)	64	0	0	0	N/A	N/A	1	0	2	0	0	N/A
Number of cases involving two instruments ( <i>n</i> =7)	3	0	0	0	N/A	N/A	0	0	4	3	0	N/A
	4	0	0	0	N/A	N/A	0	0	4	0	0	N/A
Number of cases involving three instruments ( <i>n</i> = 2)	2	0	0	0	N/A	N/A	0	0	0	2	2	N/A
Number of child services who used these instruments	8	0	0	0	N/A	N/A	1	0	2	1	1	N/A
33/70 adults were assessed using one or more standardised instruments												
Total number of times instruments were used ( <i>n</i> =34)	2	0	20	0	7	3	N/A	N/A	N/A	N/A	N/A	2
Number of cases involving one instrument ( <i>n</i> =32/33)	2	0	20	0	6	3	N/A	N/A	N/A	N/A	N/A	1
Number of case involving two instruments ( <i>n</i> =1/33)	0	0	0	0	1	0	N/A	N/A	N/A	N/A	N/A	1
Number of adult services who used these instruments	2	0	3	0	3	2	N/A	N/A	N/A	N/A	N/A	1

ADOS-G: Autism Diagnostic Observation Schedule –Generic (Lord et al., 2000); ADI-R: Autism Diagnostic Interview-Revised (Lord, Rutter, & Le Couteur, 1994); DISCO: Diagnosis of Social and Communication Disorder Schedule (Leekam, Libby, Wing, Gould, & Taylor, 2002); 3di: Developmental, Dimensional and Diagnostic Interview (Skuse et al., 2004); RAADS-R: Ritvo Autism Asperger Diagnostic Scale – Revised (Ritvo et al., 2011); AAA: Adult Asperger Assessment (Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005); GARS: Gilliam Autism Rating Scale (Gilliam, 2006); GADS: Gilliam Asperger's Disorder Scale (Gilliam, 2001); SRS: Social Responsiveness Scale (Constantino, 2005); KADI: Krug Asperger's Disorder Index (Krug & Arick, 2003).

### 3.3 Assessment of each key component of ASD diagnostic assessment

**Table 4**

Combination of components of ASD diagnostic assessment used for adults and children, with and without an ID.

	<b>Clinical history</b>	<b>Clinical history and contextual information</b>	<b>Clinical history and clinical observation</b>	<b>Clinical history, clinical observation, and contextual information</b>
Components	1 component only	2 components only	2 components only	all 3 components
Number of cases	Number	Number	Number	Number
All Adults (n =70)	4	18	7	41*
Adults with ID (n = 26)	3	11	1	11
Adults without ID (n = 43)	1	7	6	29
All Children (n = 80)	1	1	10*	68
Children with ID (n = 19)	0	0	3	16
Children without ID (n = 61)	1	1	4	44
Overall total (all adults and children)	5	19	17	109

\*1/70 adult case from component 3 was missing and it was unknown whether they had an ID.

\*11/80 child cases from components 2 and 3 were missing from the child data and it was unknown whether they had an ID.

Table 4 illustrates the extent to which one, two or three key components of ASD diagnostic assessment were included in each case. Three components were used in the majority of cases (109/150). We again used a  $X^2$  to test for differences between adults and children. A significant result was found, suggesting that adults and children differ in the range of assessments they tend to receive,  $X^2(3) = 23.7, p < .001$ . In order to determine where these differences lie, we followed the approach described by Sharpe (2015) and examined the standardised residual values for each combination shown in Table 4 (i.e. a z-score measuring the difference between what was observed and what would be expected if there was no true difference between adults and children; Agresti, 2007, p. 38). These were calculated using the formula:

$$\text{standardised residual} = (\text{observed} - \text{expected}) / \sqrt{\text{residual cell variance}}$$

For the four combinations shown in Table 4, absolute values of the residuals were found to be 1.5, 4.5, 0.5, and 3.6. As these are z-scores, any value greater than 2 is likely to reflect a significant difference. Significant differences were found to lie between the frequencies of adults and children receiving an assessment containing only clinical history and contextual information, and between the

frequencies of adults and children receiving all three components. Taken together, this may suggest that adults are more likely than children to be assessed and diagnosed without clinical observations.

#### **4. Discussion**

Our study aimed to explore some aspects of the process of ASD diagnostic services in Scotland. The recommendations that diagnosis is made by experienced clinicians, based on information reported and observed from three main components was largely adhered to, with diagnosis being made on the basis of clinical history alone in only five cases. Findings would suggest that clinicians have recognised the limitations of diagnosis from one component alone and the most common combinations of assessment were clinical history together with contextual information or these two with the addition of observation. Clinical observations are used more frequently with children than adults.

We found that all participating child services had at least one clinician trained in and using a standardised assessment tool; seven adult services had staff trained, but only 4 services regularly used them. Findings indicate that adult services largely adhere to Le Couteur's recommendation for child services (2003) that at least one clinician in each service should be trained in a diagnostic interview tool (either ADI-R or DISCO) but that child services opted for training in an observational tools instead (ADOS).

Despite the recognition of the importance in training in the use of standardised instruments for improving the competency of staff, some services may have difficulty providing this because of the availability and cost (McEwen et al., 2015) or because of the time required to administer the assessments in practice (Charman & Baird, 2002). Focus groups with the adult services sampled here (Rutherford et al., submitted) did not identify specific challenges in accessing training in standardised instruments and expressed the intention to seek further training to address gaps. They did however report that the time required administering the DISCO reduced its use. Both child and adult services could consider training in ADI-R; for child services this could address the lack of use of standardised clinical history/interview tools (0/80) and for adult services it might be administered in less time than the DISCO. Although standardised tools may not be recommended in every case, training in these tools can enhance practice. It is recognised that gathering a clinical history can be a challenge in adult cases (NICE, 2011), and therefore

adult services could consider further training and use of observational tools, such as ADOS, which was only used in 2/70 adult cases.

A recent study of reported use of standardised assessments, found that staff reported use of a wider range of tools for diagnostic assessment of ASD across the UK than was found in this study (Rogers et al., 2015). These authors also report that ADI-R was used by 27% of respondents, the 3Di (Skuse et al., 2004) by 9% and the screening tool, The Social Communication Questionnaire (Rutter, Bailey & Lord, 2003) by 28%. However, none of these were in use in our clinical study, showing inconsistent practice between Scotland and the UK services sampled. When comparing their study with ours, a similar proportion of staff reported use of ADOS when compared with actual use in our child group and the DISCO was reportedly the second most commonly used tool – as was the case in this study.

There were differences, in the current study between child and adult services in terms of the frequency that particular standardised assessments were used, with adult services using five different standardised ASD assessments on 34 occasions across the 70 cases, while child services used four different assessments on 83 occasions across the 80 cases. Statistical analysis revealed that children were 10 times more likely to have a standardised assessment administered than adults. It is unclear whether these differences reflect different clinical needs in adult and child services, or whether the difference is explained by the more widely established practice of diagnosing ASD in child services, the greater volume of research evidence with regard to use of standardised assessment in children and the longer availability of relevant clinical guidelines. ASD clinical guidelines for children have been available for longer than adult guidelines, meaning that recommendations regarding the type and use of standardised assessment tools may have been less accessible to adult clinicians. There may be cultural and attitudinal factors affecting value given to standardised instruments, which require further examination (Rutherford et al. submitted).

The publication of NICE 142 guideline in 2012 for adults with ASD is likely to influence training, attitude and practice in relation to using standardised assessments. This may be particularly beneficial for those adult services where multi-disciplinary team (MDT) input was not available. The challenge of managing more complex cases without a MDT may be mitigated by use of standardised instruments.

Furthermore, adult practitioners may feel that the assessments that were available at the time of the study did not fully meet their needs. A criticism of the use of the ADOS and ADI-R for clinical

purposes is that they were primarily designed for valid and reliable recruitment of participants with ASD for research (see Lecavalier et al., 2006), rather than for clinical use. Low specificity is reported for the ADOS in clinical samples of adults with and without an ID (Pugliese et al., 2015; Sappok et al., 2013). The recent updating of the ADOS may address some of these concerns; however, there is a continuing need for a range of standardised assessments that are suitable for use with individuals with ID.

Finally, further research is required to explain the differences between child and adult services and whether findings reflect the use of fewer standardised tools by adult services providers because they may experience fewer cases that they consider to be complex, whether there are cultural differences in practice, or whether some clinicians are more discerning in their use of standardised assessments, using them in situations in which there is greater uncertainty about the diagnosis (NICE, 2011; NICE, 2012). The notion of complexity is still to be clearly defined and operationalised in terms of how it should influence the use of standardised assessments and results indicate that clinicians did not vary tools used based on perceived complexity.

The limitations of this study should be considered when interpreting the findings. Limitations include that the study did not independently confirm the validity of the diagnoses, the quality of the results is influenced by the accuracy of clinical record keeping, and the lack of variability within services in the selection of instruments, which limited potential for statistical analysis. There is limited generalizability to clinicians in solo practice diagnosing ASD due to almost all diagnoses being given in the context of multi-disciplinary teams.

#### 4.1 Implications for practice

This study enabled examination of use of standardised instruments in ASD diagnostic assessment as recommended by recent ASD guidelines, in a nationally representative clinical sample of child and adult services, highlighting areas of strength and areas for practice and research development in an area not well reported. The study found differences between child and adult services in the training and use of standardised assessments, with adult services being less likely to have a practitioner both trained in using such assessments in practice. Results suggest the need for wider training in use of standardised interview (clinical history) tools in child services, as one of the tools available to clinicians (as recommended by Le Couteur 2003) and the need for increased use of clinical observation in adult

services. Further development of tools for indirect contextual assessment in adults is also recommended. To date, little is known about the reasons behind practitioners' choices to use standardised assessments or not. While clinical guidelines identify case complexity as an important factor, to date this concept remains undefined and the extent to which it influences clinical practice is unknown. Findings here suggest that teams tend to use the same tools for all assessments and therefore do not yet select tools based on case features, as recommended in clinical guidelines. Future research is needed to address these issues in order to help services adopt the most efficient and effective diagnostic practices.

### **Conflict of interest**

The authors have no conflicts of interest to report.

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