

# Psychologists report an error in the NICE guidelines for autism

March 18 2021

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Reporting in the *Lancet Psychiatry* today, psychologists at the University of Bath highlight that a widely used technique for autism screening is being misused, which may have prevented many people from receiving

an autism diagnosis over the past decade.

When individuals with suspected [autism](#) are assessed by a GP, a decision to refer them to a specialist for diagnosis is informed by using the Autism Spectrum Quotient. This ten-point scale, known as the 'AQ-10', is an internationally used technique, whereby individuals agree or disagree with statements such as 'I find it difficult to work out people's intentions'. The maximum score is ten, and higher scores represent more autistic traits.

A score of six or above on this scale should signal that an individual needs to be referred to a specialist psychologist or psychiatrist. However, through this new research, psychologists have uncovered that for almost ten years the NICE guidelines have incorrectly been recommending a score of 'more than 6 out of 10'. This error may have consequently prevented people who scored '6' from receiving proper support.

The Bath team were surprised to discover this error, and closely analysed the original research about the autism screening tool in comparison with the NICE guidance. They found that the NICE Guideline Development Group had considered, but rejected, a cut-off score for diagnosis of seven or above ( $\geq 7$ ). In their *Lancet* article, they conclude that the NICE recommendation of a score "more than 6 out of 10" is an error.

The researchers say that the use of an inappropriately high cut-off score makes this autism screening tool less sensitive, and therefore less accurate. Because it is so widely used among GPs and other healthcare professionals, this issue will be contributing to missed autism referrals, diagnoses, and opportunities for intervention and support. Although clinicians are not solely reliant on AQ-10 scores to make referrals, it factors into their decision-making process. As the NICE AQ-10 guidelines have been in place for almost a decade, the consequences of this mistake will be considerable.

Until the erroneous guidelines are corrected by NICE, the psychologists are calling for an urgent review into this matter, so that pending diagnoses are not missed and that any errors in previous screening can be rectified. In their paper, they recommend that clinicians and researchers use the cut-off score of "6 or above" ( $\geq 6$ ) instead of NICE's "more than 6 out of 10" ( $\geq 7$ ) to inform their work.

Dr. Punit Shah, Associate Professor of Psychology at the University of Bath and the GW4 Neurodevelopmental Neurodiversity Network, explained: "This is a worrying finding as cut-off scores on screening tools underpin their accuracy. Although a difference of 1-point might not seem huge, a 1-point increased cut-off score on a 10-point scale is substantial and makes the instrument less psychologically sensitive. This means that many people going to their GPs who genuinely have autism—perhaps scoring 6 on the scale—are currently less likely to be referred to specialists for full diagnostic assessment. Diagnosis is of course crucial: without a diagnosis, people have less access to appropriate interventions and support, even certain benefits.

"It is impossible to put a number on exactly how many people will have been affected by this, but it is well known that delayed referrals and late diagnoses of autism have negative consequences for the mental health and wellbeing of autistic people and their families. We urgently need to do all we can to raise awareness of this issue, among GPs and other clinicians, while the NICE guidelines are corrected. NHS waiting times for autism assessments are already far too long and these flaws in screening procedures will be compounding this issue."

Lucy Waldren, lead author of the article also of the Department of Psychology at Bath, suggests the findings have implications for autism and psychiatry research. She says: "Our examination of the literature has discovered that the erroneous NICE guidelines have caused major confusion amongst researchers on which cut-off scores to use. We have

found several examples of the incorrect value being applied. Participants in studies have also been inappropriately excluded based on their scores. And, even when the correct value was used, it has been incorrectly attributed to the NICE guidance. If researchers have followed the incorrect NICE guidelines and used the AQ-10 incorrectly in their studies, they may need to reanalyse and republish, or even consider retracting their findings."

**More information:** *Lancet Psychiatry* (2021). [DOI: 10.1016/S2215-0366\(21\)00065-1](https://doi.org/10.1016/S2215-0366(21)00065-1) , [www.thelancet.com/journals/lan.../21\)00065-1/fulltext](http://www.thelancet.com/journals/lan.../21)00065-1/fulltext)

Provided by University of Bath

Citation: Psychologists report an error in the NICE guidelines for autism (2021, March 18) retrieved 11 March 2023 from <https://medicalxpress.com/news/2021-03-psychologists-error-nice-guidelines-autism.html>

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