



2021 surveillance of autism (NICE guidelines CG128, CG142 and CG170)

Surveillance report

Published: 14 June 2021

www.nice.org.uk

Contents

Surveillance decision	3
Reasons for the decision	4
Overview of 2021 surveillance methods	9
Evidence considered in surveillance	10
Ongoing research	10
Intelligence gathered during surveillance	12
Equalities	19
Overall decision	20

Surveillance decision

We received a large volume of comments during consultation about implementing some of the recommendations in the guidelines highlighting that service capacity issues are affecting implementation. We are aware of several initiatives in progress to address these service capacity issues including work by NHS England and NHS Improvement (NHSE&I).

During this surveillance review we did not identify scientific evidence that suggested guideline recommendations do not represent best practice therefore we will not update the following guidelines on autism at this time:

- [Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) (NICE guideline CG128)
- [Autism spectrum disorder in adults: diagnosis and management](#) (NICE guideline CG142)
- [Autism spectrum disorder in under 19s: support and management](#) (NICE guideline CG170)

Due to the number of initiatives underway that may impact on future service delivery, we will use a living surveillance model to monitor their progress and review their impact on the autism guidelines on an ongoing basis. This includes assessing the impact of the following when they publish in line with the surveillance process for [reacting to events](#):

- NHSE&I early findings report on differentiated pathways
- The [Department of Health and Social Care \(DHSC\) and Department for Education Review of the National Autism Strategy 'Think Autism'](#)
- The [Re-ASCed \(A Realist Evaluation of Autism ServiCe Delivery\) study](#)
- [International Classification of Diseases 11th Revision \(ICD-11\)](#), following full adoption in January 2022
- Fifteen ongoing trials identified during surveillance listed in the [ongoing research section](#) of this report.

Additionally, we will make the following amendments to refresh the guidelines:

- amend the language used in the recommendations that describe autistic people and the signs of autism spectrum disorder (ASD)
- make an editorial amendment to the NICE guideline on autism in under 19s: identification and diagnosis, highlighting the existing recommendation, to be aware that underdiagnosis in females can be an issue
- add a recommendation to the NICE guideline on autism spectrum disorder in under 19s: support and management, about assessing and providing support for feeding difficulties, including restrictive diets
- add the wording 'consider using melatonin' to recommendation 1.7.7 in the NICE guideline on autism spectrum disorder in under 19s: support and management, about managing insomnia.

Reasons for the decision

We considered new evidence from published literature, policies, guidelines, topic experts, patient groups and stakeholders and we did not identify any that suggested guideline recommendations do not currently represent best practice.

Service delivery

We received a strong signal from topic experts and stakeholders that there are problems implementing recommendations because of service capacity issues. These issues were also reported in the government's autism self-assessment framework, which reviews progress in implementing the autism strategy. The DHSC and Department for Education are currently carrying out a review of the 2014 autism strategy 'Think Autism' and the revised strategy is expected to support the NHS Long Term Plan, which includes initiatives to improve outcomes in autistic people. We will monitor the review and assess its impact on recommendations when it publishes. We will discuss the implementation issues highlighted with NICE's implementation team.

One stakeholder responded that they thought the surveillance review had misinterpreted the policy context in light of new work by NHSE&I and other organisations. We received stakeholder comments from 2 charities: Autistica and the National Autistic Society and we had discussions with NHSE&I, whose role is to support the NHS to deliver improved care. The stakeholders and NHSE&I expressed concern that recommendations are 'at odds' with autism pathway improvements NHSE&I are currently developing to address NHS Long

Term Plan objectives, and they thought this may cause confusion for commissioners. NHSE&I highlighted 2 projects relevant to their work:

- [The SHAPE project: mapping and evaluating Specialist Autism Team service models](#)
- [Re-ASCed \(A Realist Evaluation of Autism Service Delivery\)](#)

The SHAPE study published post-consultation of this review, at which point we assessed the findings against recommendations in the NICE guideline on autism spectrum disorder in adults: diagnosis and management. The study reported improvements in mental health for people attending Specialist Autism Team (SAT) services that combine diagnostic and support services. These results are broadly supportive of [recommendations 1.1.13 and 1.1.14](#), which recommend the formation of SATs and outline their key functions, including delivering and coordinating diagnostic services, interventions and other support services. The Re-ASCed study is ongoing, and we will assess its impact on the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis when it publishes. We did not identify any other evidence relating to the current work by NHSE&I or their collaborators during surveillance. We will monitor the impact of these outputs on recommendations within the NICE autism guidelines in a timely manner.

Language

A number of stakeholders commented that the language used in the guidelines and surveillance review was ableist, medicalised and misconceptualised ASD. We will make the following editorial amendments to address this:

- In all guidelines we will replace 'people with autism' with 'autistic people', which is in line with the [NICE style guide](#).
- In the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis, where it is appropriate to do so, we will use 'features suggesting possible autism' in line with the language used in ICD-11 instead of 'signs and symptoms' of autism, when referring to suspected presentations of autism.
- In the NICE guideline on autism spectrum disorder in adults: diagnosis and management, we will add the phrase 'behaviour that challenges' in place of 'challenging behaviour' because it is more appropriately person-centred and consistent with other NICE guidelines.

- We will provide a link to [making decisions about your care](#) from the recommendations sections of all 3 guidelines as this describes how NICE recommendations can help with shared decision making.

Melatonin

We identified evidence for the effectiveness of melatonin for insomnia in autistic children and noted it is licensed for use with this group as described by the British National Formulary for Children (BNFc). Additionally, [recommendation 1.11.2 in the NICE guideline on challenging behaviour and learning disabilities](#) recommends 'consider melatonin for sleep problems.' We asked stakeholders as part of this consultation 'do you think it is appropriate for [recommendation 1.7.7 in the NICE guideline on autism spectrum disorder in under 19s: support and management](#) to be amended to include: 'If medication is needed to aid sleep, consider melatonin?' Twelve stakeholders responded and agreed with this proposal but cautioned that this should only be after non-pharmacological strategies have been tried. Current recommendations accommodate this approach. Recommendation 1.7.7 recommends do not use a pharmacological intervention to aid sleep unless a sleep plan has failed, and sleep problems are having a negative impact.

We will add 'consider melatonin' to recommendation 1.7.7 and remove the research recommendation on managing sleep problems, as this update now addresses that issue.

Autism Spectrum Quotient – 10 items

During the development of the surveillance review, topic experts and patient groups highlighted issues with the validity of the Autism Spectrum Quotient – 10 items (AQ-10) screening tool. We identified a study ([Ashwood et al. 2016](#)) that reported a 64% false negative rate in adults with suspected ASD. We consulted with stakeholders about how they used the AQ-10 in order to check the interpretation of [recommendation 1.2.3 in the NICE guideline on autism spectrum disorder in adults: diagnosis and management](#), which recommends that the AQ-10 can be considered for screening adults without a moderate or severe learning disability, and if they score above 6, or autism is suspected based on clinical judgement, to refer for assessment. Stakeholders confirmed that, in line with the current recommendation, they would not use the AQ-10 alone to screen for autism. Stakeholders also said that the AQ-10 can be unreliable. Based on these findings we will not amend recommendation 1.2.3 at this time as further research is required. However, we have flagged AQ-10 reliability and validity as an area to look for evidence at the next surveillance review timepoint.

We will highlight [research recommendation 1 in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) about training professionals to recognise the features of possible autism to the National Institute for Health Research (NIHR) as an area where research is needed. We will also promote this research recommendation via NICE's social media channels.

Outside of this surveillance review an article ([Waldren et al. 2021](#)) was brought to our attention that reported that the cut-off point of above 6 (i.e. 7) in recommendation 1.2.3 was incorrect. The authors suggested that the correct cut-off point should be 6 or above (i.e. 6) as reported in [Allison et al. 2012](#), which informed the development of recommendation 1.2.3. We have confirmed that this is an error that we will correct.

Mental health

Several topic experts and patient groups noted that autistic people are frequently admitted for inpatient psychiatric care. Five stakeholders also made comments about inadequate mental health provision and indicated that recommendations about mental health in all 3 guidelines could be improved.

A number of stakeholders highlighted the work of [NHS England's Transforming care programme](#), and provided prevalence evidence that used data from the programme's [Assuring transformation dataset](#). This programme aims to reduce hospitalisations and institutionalisation of autistic people and those with learning disabilities. Whilst we acknowledge the dataset does show an upward trend in mental psychiatric admissions for this group, we did not identify any studies from the programme that we could assess for impact on recommendations. During surveillance we identified policy reports that reported this issue, for example the [Parliamentary Joint Select Committee report on the detention of young people with learning disabilities and/or autism](#). We also identified initiatives in the NHS Long Term Plan designed to address this issue. However, we did not identify any evidence to indicate that NICE recommendations, no longer represent best practice, but rather services have not been able to achieve recommended best practice.

Impact of COVID-19

We asked stakeholders about the impact of COVID-19 on services and received responses from 19 stakeholders across the 3 consultations. Stakeholders highlighted that there is uncertainty over the risks and benefits of telepsychiatry, telemedicine and virtual consultations; and that personal protective equipment acted as a barrier to

communication. We did not identify any evidence about these issues during surveillance, but we expect that this evidence will emerge in the near future, and we will consider any necessary changes at the appropriate time.

A number of stakeholders highlighted that uncertainty associated with the pandemic was impacting autistic people's mental health, an issue compounded by reduced access to services. We plan to look at all the mental health guidelines in NICE's portfolio together in order to explore the implications of system drivers, including the impact of COVID-19 on service delivery and on our recommendations.

For further details and a summary of all evidence identified in surveillance, see [appendix A](#).

Overview of 2021 surveillance methods

NICE's surveillance team checked whether recommendations in the following guidelines remain up to date:

- [Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) (NICE guideline CG128)
- [Autism spectrum disorder in adults: diagnosis and management](#) (NICE guideline CG142)
- [Autism spectrum disorder in under 19s: support and management](#) (NICE guideline CG170)

The surveillance process consisted of:

- Feedback from topic experts and patient groups via a questionnaire.
- A search for new or updated Cochrane reviews and national policy.
- Consideration of evidence from previous surveillance.
- Examining related NICE guidance and quality standards and NIHR signals.
- A search for ongoing research.
- Examining the NICE event tracker for relevant ongoing and published events.
- Literature searches to identify relevant evidence.
- Assessing the new evidence against current recommendations to determine whether or not to update sections of the guideline, or the whole guideline.
- Consulting with stakeholders on the proposal not to update the guidelines.
- Considering comments received during consultation and making any necessary changes to the proposal.

For further details about the process and the possible update decisions that are available, see [ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual](#).

Evidence considered in surveillance

Search and selection strategy

We searched for new evidence related to the 3 NICE guidelines on autism in children and adults.

We found 191 studies in a search for systematic reviews, randomised controlled trials and diagnostic studies published between 27 January 2016 and 1 November 2019.

We also included:

- 5 relevant studies from a total of 166 identified by topic experts
- 4 studies from previous surveillance reviews to provide a context for new studies identified (on therapeutic horseback riding, use of atomoxetine, use of guanfacine and parent training versus parent education)
- 1 study considered during development of the NICE guideline on autism spectrum disorder in children: support and management to provide context for new studies identified (on parent-mediated social communication treatment [PACT]).
- 2 studies identified in comments received during consultation on this review.

From all sources, we considered 203 studies to be relevant to the guidelines.

See [appendix A](#) for details of all evidence considered, and references.

Selecting relevant studies

Diagnostic studies were only eligible for inclusion if they met the criteria set by the original guideline development group of at least 80% sensitivity and specificity. There were no specific inclusion criteria for randomised controlled trials or systematic reviews.

Ongoing research

We checked for relevant ongoing research; of the ongoing studies identified, 15 were assessed as having the potential to change recommendations. Therefore, we plan to

regularly check whether these studies have published results and evaluate the impact of the results on current recommendations as soon as possible following publication. These studies are:

- [ComAlong Toddler - Parental course to help the child to communicate](#)
- [Improving autistic children's social communication with parents in everyday settings](#)
- [ADIE to prevent development of anxiety disorders in autism](#)
- [An investigation of the frequency of social communication problems among adults admitted to acute mental health wards](#)
- [Sleeping Sound with Autism Spectrum Disorder \(ASD\)](#)
- [Managing repetitive behaviours parent group study](#)
- [A primary school research study to establish whether Social Stories can improve social and emotional health in children with autism spectrum disorder](#)
- [A trial of sensory integration therapy versus usual care for sensory processing difficulties in autism spectrum disorder in children](#)
- [Reducing suicidality in autism-spectrum patients using dialectical behaviour therapy](#)
- [An evaluation of LEGO-based therapy in school for children with autism](#)
- [A trial of Acceptance and Commitment Therapy for caregivers](#)
- [The Secret Agent Society: Operation Regulation intervention - transdiagnostic trial](#)
- [Behavioural and cognitive behavioural therapy for obsessive compulsive disorder \(OCD\) in individuals with autism spectrum disorder \(ASD\)](#)
- [Pivotal Response Treatment for autism spectrum disorder \(ASD\)](#)
- [Re-ASCed \(A Realist Evaluation of Autism ServiCe Delivery\) - highlighted by a stakeholder during consultation; see \[reasons for the decision\]\(#\).](#)

Intelligence gathered during surveillance

Views of topic experts and patient groups

We considered the views of topic experts who were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty. For this surveillance review, topic experts completed a questionnaire about developments in evidence, policy and services related to the guidelines.

We sent questionnaires to 26 topic experts and 4 patient groups. We received responses from 13 topic experts and 3 patient groups.

Topic experts comprised: a consultant child and adolescent psychologist; a consultant speech and language therapist; a consultant in paediatric neurodisability; a professor of clinical child psychology; a professor of adult and child psychology; a social care provider with a special interest in autism and behaviour that challenges; a nurse consultant with special interest in learning disabilities, autism and behaviour that challenges; an autism lead practitioner; a GP with special interest in autism and ADHD; an improvement manager with special interest in autism, learning disabilities and mental health in children and young people; an occupational therapist specialising in neurodisability; a child and adolescent psychiatrist and a consultant psychiatrist.

Patient group responses were received from the National Autistic Society, Autistica and the National Autistic Taskforce. Topic experts and patient groups raised the issue of the validity of AQ-10 as a screening tool, discussed in [reasons for the decision](#). They also highlighted several areas where lack of service capacity was acting as a barrier to the implementation of guideline recommendations, discussed in [implementation issues](#). Topic experts and patient groups highlighted that people with protected characteristics need specific consideration when providing autism services. This is discussed in [equalities](#).

Views of stakeholders

Because this surveillance proposal was to not update the guidelines, we consulted with stakeholders. In total 31 stakeholder organisations commented on the 3 consultations: 11 charities, 8 NHS organisations, 5 professional groups (including 3 royal colleges), 4 commercial organisations and 3 research organisations.

Twenty-one organisations responded to the consultation for the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis: 9 charities, 4 NHS organisations, 4 professional organisations (including 2 royal colleges), 2 commercial organisations and 2 research organisations. Five agreed with the proposal to not update the guideline, 14 disagreed and the remainder did not respond or were undecided.

Twenty-two organisations responded to the consultation for the NICE guideline on autism spectrum disorder in adults: diagnosis and management: 9 charities, 5 NHS organisations, 4 professional organisations (including 2 royal colleges), 2 commercial organisations and 2 research organisations. Six agreed with the proposal to not update the guideline, 14 disagreed and the remainder did not respond or had no comment.

Twenty-seven organisations responded to the consultation for the NICE guideline on autism spectrum disorder in under 19s: support and management: 11 charities, 5 NHS organisations, 5 professional organisations (including 3 royal colleges), 4 commercial organisations and 2 research organisations. Four agreed with the proposal to not update the guideline, 16 disagreed and the remainder did not respond or were undecided.

Areas for which stakeholders provided evidence included the following:

- Four stakeholders commented about interventions that use an applied behaviour analysis (ABA) approach. Three noted that there was new evidence for the effectiveness of ABA and that it should be explicitly recommended by the NICE guideline on autism spectrum disorder in under 19s: support and management. One piece of evidence about ABA ([Dixon et al. 2019](#)) met the inclusion criteria for the surveillance review and has been added to the section about ABA in [appendix A](#). The study findings support [recommendation 1.3.1](#) to consider a specific social communication intervention. Several other papers were provided but they either did not meet the surveillance review inclusion criteria, or they had already been identified and assessed as part of the surveillance review and were not considered to have an impact on existing recommendations. Two stakeholders commented that the [NICE guideline on challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#), recommends ABA. It was noted that similar to autism guidelines, this guideline accommodates ABA-based approaches but also makes a [research recommendation about ABA](#) because the evidence is equivocal. One stakeholder commented that ABA has the potential to cause harm and a 'do not use' recommendation should be added to the NICE guideline on autism spectrum disorder in adults: diagnosis and management. We did not find any evidence during surveillance that indicated ABA causes harm.
- One stakeholder commented that recommendations in the NICE guidelines on autism spectrum disorder in adults: diagnosis and management and autism spectrum disorder in under 19s: support and management should be aligned with the [World Health Organisation's International Classification of Functioning, Disability and Health \(ICF\) core sets](#) for ASD and provided evidence about the ICF. The evidence did not meet inclusion criteria. We did not find any evidence about ICF during surveillance that met inclusion criteria, but we have flagged it as an area of interest for which to look for evidence at the next surveillance review timepoint.

- Two stakeholders commented that there was new evidence for parenting programmes, provided evidence, and felt that recommendations in the NICE guidelines on autism spectrum disorder in under 19s: recognition, referral and diagnosis and autism spectrum disorder in under 19s: support and management should be updated in light of this. The evidence provided had either already been identified during surveillance or did not meet inclusion criteria. New evidence for parent- and carer-mediated interventions identified during surveillance supported the content in recommendations 1.4.6 to 1.4.9 in the NICE guideline on autism spectrum disorder in under 19s support and management, so an update in this area is not recommended. We also identified a number of ongoing studies about parenting interventions that we will track and assess the impact of their results on recommendations, when they publish.
- Three stakeholders highlighted increased prevalence of joint hypermobility or Ehlers-Danos syndrome (EDS) in autistic people and suggested that this should be added to the lists of co-occurring conditions in the NICE guidelines on autism spectrum disorder in under 19s: recognition, referral and diagnosis and autism spectrum disorder in adults: diagnosis and management. We did not identify any evidence that met the inclusion criteria for this review however, we will add EDS to the issues log as an area to look for evidence in UK populations at the next surveillance review. A 2016 surveillance review of the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis resulted in ADHD being added to the list of co-existing conditions based on around 20-times higher increase risk of ADHD in autistic people. For the other potential risk factors, the committee considered the evidence to be 'insufficient'.
- Four stakeholders commented that recommendations could be improved for autistic people with eating disorders or restrictive diets. Recommendation 1.5.15 in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis, contains information on assessing for co-existing eating disorders. Recommendation 1.1.9 in the NICE guideline on autism spectrum disorder in adults: diagnosis and management, contains information on offering advice about the benefits of a healthy diet.

- Outside of this surveillance review we received a query which raised concerns that the guidelines for autistic children do not appropriately cover the issue of restrictive diets. It was suggested that monitoring autistic children for nutritional deficiencies in cases of severe restricted diets could prevent serious adverse events. To address this, we carried out a separate exceptional surveillance review that investigated restrictive diets in autistic children. Following this exceptional review we will make an editorial amendment to [section 1.7 of the NICE guideline on autism spectrum disorders in under 19s: support and management](#) to add a recommendation on assessing and providing support for feeding difficulties, including restrictive diets.
- NICE have also produced a [guideline on eating disorders: recognition and treatment](#). We will therefore not update recommendations about eating disorders.

Implementation of the guideline

Service capacity issues were highlighted as barriers to implementing recommendations by topic experts, patient groups and stakeholders. Similar concerns were highlighted during previous surveillance reviews.

Capacity issues were thought to impact implementation of recommendations in the following areas:

Diagnosis and assessment

Capacity issues made it difficult to carry out assessments and diagnoses within specified timescales. Concerns were raised that the overall diagnosis process takes too long and that there is underdiagnosis in adults. One stakeholder commented that system capacity rendered the recommendations unimplementable and recommended a tiered or fast track pathway for different complexities of diagnosis. Another stakeholder commented that core assessments that are 'good enough' are required and suggested that NICE recommendations were acting to increase waiting times, with a 'disconnect' between recommendations and current demand and capacity. Six stakeholders highlighted implementation issues, and several that this was acting to increase waiting times for a full diagnostic assessment to more than 3 months recommended by [recommendation 1.5.1 in the NICE guideline on autism in under 19s: diagnosis and assessment](#). This is consistent with intelligence identified during this surveillance timepoint.

We did not however identify any published evidence that suggested recommendations act

to increase waiting times or that reported on the effectiveness of tiered pathways. However, we are aware of several pieces of [ongoing work](#) to address these issues which we will monitor and assess for impact on recommendations when they complete.

Two stakeholders commented that recommendations could be improved by better alignment with ICD-11. We will assess the impact on recommendations of ICD-11 when it is fully implemented in January 2022.

Organisation of services

Lack of capacity acted as a barrier to working with other departments to manage co-existing conditions. A stakeholder commented that while the NICE guideline on autism in under 19s: recognition, referral and diagnosis recommends a broad approach to autism assessment that should encompass neurodevelopmental and mental health assessment, in practice this was not happening.

Topic experts highlighted that transition from children to adult services is often not joined up or planned far enough in advance. The [NICE guideline on autism spectrum disorder in adults: diagnosis and management](#) recommends if children and young people present at the time of transition they should be jointly assessed by adult and children's services. NICE has also published a [guideline on transition from children's to adults' services for young people using health or social care services](#), which makes recommendations to improve the way transition is planned and carried out and which are relevant to the delivery of autism services. NICE has also produced a [quality standard on transition from children's to adults' services](#) based on the guideline that is designed to enable service providers and commissioners to improve quality in areas identified as high priority for improvement.

Concerns were raised about the training and competencies of healthcare staff including specialists, and about the lack of 'autism-friendly' environments in healthcare facilities.

Topic experts noted that there is insufficient community care resulting in inappropriate inpatient admissions.

Autism without learning disability

Topic experts commented that there is insufficient implementation of recommendations with people who have autism but who do not have a learning disability. The [SHAPE study](#)

indicated that this issue is being addressed. The study mapped and evaluated the SAT model of working. It reported that where the SAT model had been adopted it was being used for diagnosis and support of adults without learning disabilities as it was recognised that this group was lacking support.

We discussed planned investment in autism services with NHSE&I who noted that evaluations of new services could inform this surveillance review. However, we did not identify any evidence of this type, and the government reports and policies identified support existing recommendations. We acknowledge that there are concerns around the implementation of some recommendations. We will monitor the progress of the review of the 2014 autism strategy and assess its impact on the guidelines covered by this surveillance review on publication (see the [reasons for the decision](#)).

Other sources of information

We considered all other correspondence received since the guidelines were published. We considered an enquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiance disorder (ODD). During preparation of the guidelines, the developers acknowledged that PDA is not a recognised disorder in the sense that it was not included in the current ICD or DSM, and developed specific advice on how to differentiate between alternative diagnoses with similar features, available in [appendix K of the full guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#). The appendix describes PDA as a particular subgroup of autism that it is characterised by a refusal to comply (demand avoidance) and that such oppositional behaviour can be described as ODD. [Recommendation 1.5.7 in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#) recommends considering ODD as a potential differential diagnosis and whether specific assessments are needed to interpret the autism history and observations.

As ODD is already covered by the guidelines as a potential differential diagnosis and the guideline appendix acknowledges PDA; in the absence of any further evidence about PDA we assessed this enquiry as having no impact on current recommendations.

See [appendix B from all 3 guidelines](#) for full details of stakeholders' comments and our responses.

See [ensuring that published guidelines are current and accurate in developing NICE](#)

[guidelines: the manual](#) for more details on our consultation processes.

Equalities

Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake of specialist services was low among black and minority ethnic groups.

We identified evidence of underdiagnosis in girls and women. Several topic experts also highlighted this issue. Five stakeholders commented on this issue during consultation and suggested it was as a result of increased 'masking' of the signs of ASD by this group, gendered screening and diagnostic tools aimed at 'cisgender males', and a lack of practitioner skills to recognise ASD in this group. While some stakeholders suggested recommendations should be updated to reflect these views, we did not find any evidence for gender-specific diagnostic instruments that may address this issue. We did identify some evidence that high quality diagnostic techniques may address this inequality. Recommendation 1.2.5 in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis, recommends practitioners who suspect autism to be aware of a number of issues including underdiagnosis in girls. We will make an editorial amendment to make underdiagnosis in girls the first bulleted item in this recommendation. This same guideline makes a [research recommendation about training healthcare staff to improve their ASD identification skills](#) particularly with at risk groups including girls. We will highlight this recommendation to the NIHR as an area where research is needed.

Several stakeholders commented that recommendations should take more account of protected characteristics under the Equalities Act and that some may run counter to the need to make reasonable adjustments to accommodate people. We did not find evidence to suggest this is the case and note that the [NICE guidelines on autism spectrum disorder in under 19s: support and management](#) and [autism spectrum disorder in adults: diagnosis and management](#) include sections about person-centred care. Additionally, equality impact assessments are available for the [NICE guidelines on autism spectrum disorder in under 19s: recognition, referral and diagnosis](#), [autism spectrum disorder in adults: diagnosis and management](#) and [autism spectrum disorder in under 19s: support and management](#). We plan to link from all 3 guidelines to [making decisions about your care](#), which describes how NICE recommendations can help with shared decision making.

No new evidence was identified addressing the needs of any other specific groups, a

finding consistent with previous surveillance reviews. Several vulnerable and hard to reach groups were identified in the scopes of the included guidelines and a small amount of evidence for specific subgroups was identified and considered during development of the guidelines. Recommendation 1.1.5 in the NICE guideline on autism spectrum disorder in under 19s: support and management and recommendation 1.8.3 in the NICE guideline on autism spectrum disorder in adults: diagnosis and management give information on promoting and organising care for specific subgroups. In the absence of new evidence, we have concluded that these service organisation recommendations are still valid, and that clinical recommendations about specific healthcare interventions remain applicable to all groups.

Overall decision

We acknowledge concerns around service capacity and the work of NHSE&I to address these issues. We will ensure that published policy and research evidence evaluating new services for autism is assessed for its impact on the autism guidelines as it publishes.

After considering all evidence, topic experts and stakeholder views, and other intelligence on the impact on current recommendations, we decided that no update is necessary at the current time. We will:

- refresh the language used in the recommendations as described in reasons for the decision,
- amend recommendation 1.7.7 in the NICE guideline on autism spectrum disorder in under 19s: support and management to include 'consider melatonin'
- make an editorial amendment to add a recommendation about providing support for feeding difficulties to the NICE guideline on autism spectrum disorder in under 19s: support and management.

ISBN: 978-1-4731-4169-8