



2021 exceptional surveillance of autism spectrum disorder in under 19s: support and management (NICE guideline CG170)

Surveillance report

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Surveillance decision

We propose to make an amendment to the [section on interventions for coexisting problems in the NICE guideline on autism spectrum disorder in under 19s: support and management](#). The update will add a recommendation on assessing and providing support for feeding difficulties, including restrictive diets.

Exceptional surveillance review summary

Reason for considering this area

In March 2021, we received an enquiry in which concerns were raised that the NICE guidelines on autism do not appropriately cover the issue of restrictive diets and the potential for nutritional deficiencies in autistic children. The inquirer suggested that monitoring autistic children for nutritional deficiencies, including regular blood tests, could prevent serious nutritional consequences, such as blindness.

Methods

To review the impact of this query on NICE guidance we took the following approach:

- Considered the evidence used to develop the NICE guideline on autism spectrum disorder in under 19s: support and management.
- Assessed the enquiry against the current recommendations.
- Sought the views of topic experts.

It was concluded that full updated literature searches were not needed because the information we obtained was enough to establish whether an amendment to the guideline was needed.

For further information, see [ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual](#).

Surveillance proposal

How the guideline was developed

The current NICE guideline has a section on interventions for coexisting problems but this does not include recommendations for restricted diets.

At the time of guideline development, the committee were aware that feeding difficulties, such as restricted diets, are common in autism. The committee also understood the distress caused to families by eating problems which can occasionally result in severe nutritional deficiencies. An evidence review was undertaken to evaluate the clinical and cost effectiveness of interventions aimed at coexisting problems (including feeding difficulties) for autistic children. However, there was no evidence on feeding difficulties, including restrictive diets, and the committee therefore did not develop any recommendations.

However, the section on autism diagnostic assessment for children and young people in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis has a recommendation that states: 'consider whether the child or young person may have any of the following as a coexisting condition, and if suspected carry out appropriate assessments and referrals: feeding problems, including restricted diets' [other conditions removed for brevity here]. At the time of guideline development there was no evidence for eating disorders such as restricted diets, but the committee were aware that healthcare professionals have raised the possibility of eating disorders, and the committee felt this was a coexisting condition that should be systematically looked for in children with autism.

New intelligence

An enquirer was concerned that NICE do not appropriately cover the issue of restrictive diets and the potential for nutritional deficiencies in autism spectrum disorders in children. They provided personal accounts of 2 autistic children who subsequently became blind as a result of nutritional deficiencies that seem to be caused by restrictive diets. As such, they suggested that monitoring autistic children for nutritional deficiencies, including regular blood tests, could prevent serious nutritional consequences in autistic children.

Previous surveillance

In 2021, the 3 NICE guidelines on autism underwent a surveillance review to check if the recommendations were current. While the decision was not to update the guidelines at this time, the review acknowledged the impact of service capacity issues on implementing some of the recommendations and highlighted that we plan to assess the impact of several pieces of ongoing work that address service delivery when they publish.

With regards to diet and nutrition, 4 stakeholders commented that recommendations could be improved for autistic people with eating disorders or restrictive diets. However, surveillance of the NICE guideline on autism spectrum disorder in under 19s: support and management, only identified 1 relevant randomised controlled trial (RCT) ([Sharp et al. 2019](#)) from a search for diagnostic studies, systematic reviews and RCTs published between 27 January 2016 and 1 November 2019. The RCT compared 'Managing Eating Aversions and Limited variety' (MEAL) plan with parent education. MEAL Plan provided parents with nutrition education and meal strategies to expand a child's diet. The comparator, parent education, provided information about autism without guidance on nutrition, meal structure, or diet. The study reported superiority for MEAL Plan on the Clinical Global Impression - Improvement scale, the Brief Autism Mealtime Behaviors Inventory and for grams of food consumed at 16 weeks' follow-up. The study was not deemed to impact the guideline due to the small sample size (n=38). It was concluded that the results should be replicated in larger studies before an impact on current recommendations can be considered.

Topic experts

A total of 9 topic experts who had previously participated in the development of NICE's 3 autism guidelines were contacted for their views.

First round of feedback

Initially views were sought on amending the section on interventions for coexisting problems in the NICE guideline on autism spectrum disorder in under 19s: support and management to include a new recommendation to reflect the content on eating disorders in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis. The proposed wording was as follows.

Interventions for feeding problems, including restricted diets

'Assess for any feeding or nutritional problems, including restricted diets; monitor and refer if needed.'

A total of 6 experts responded. Experts included a consultant child and adolescent psychologist, a consultant in paediatric neurodisability, an autism lead practitioner, and a speech and language therapist.

All experts agreed with the proposal to add a subsection on feeding problems, including restricted diets, into the section on interventions for coexisting problems. The comments received confirmed that restrictive diets are an important issue in autistic children and can often be lifelong, therefore this is a valuable addition to the guideline.

However, feedback was received around wording of the recommendation to ensure it was clear and helpful in practice. One expert suggested that the word 'growth' be included. This was added as it was felt to be an important feature of assessing the impact of feeding issues.

Another expert suggested that the wording: 'for further investigations and evidence-based intervention(s) if needed' was added. The expert went on to say that they were concerned about affected individuals and their families who are not being referred for access to well informed and experienced professionals including dietitians, nutritionists and psychologists, about to provide evidence-based support in the treatment and management of restrictive diets. This was not included in the recommendation as it was considered that investigations are part of the process of assessment and monitoring. 'Evidence-based interventions' could not be added to the recommendation due to a lack of sufficient evidence on such interventions (see [previous surveillance in 2016](#) and the [2021 surveillance](#)). It is also expected that referrals are only made to qualified healthcare professionals, in line with recommendations on the [general principles of care](#).

Second round of feedback

Internal NICE reflection on the seriousness of the enquiry subsequently resulted in a reconsideration of the editorial approach that would be suitable. In this instance it was considered important to add an additional sentence to highlight to clinicians the risk of nutritional deficiencies and possible need for regular blood tests. This goes beyond the content of the recommendation on coexisting conditions in the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis. However, given that severe nutritional deficiencies represent a potential safety issue, it was felt to be a suitable

approach to take but important to ratify with topic experts once more.

As such views were then sought with the same group of experts on adding the following recommendation wording into the section on interventions for coexisting problems.

Interventions for feeding problems, including restricted diets

'Be aware that feeding problems, including restricted diets can result in nutritional deficiencies that may have serious consequences.'

'Assess for any feeding, growth or nutritional problems, including restricted diets. Monitor and refer if needed. As part of a full nutritional assessment and monitoring, blood tests to check for nutritional deficiencies may be required.'

Six topic experts responded, and all agreed with the additional wording.

Similar concerns were raised and addressed as described above. In addition, 1 topic expert raised a concern around who would implement the recommendation. Details of who should implement recommendations in the NICE guideline are provided in the [recommendations on general principles of care](#).

Another topic expert commented that a balanced approach to monitoring needs to be achieved as autistic children can find blood tests highly stressful. This detail was not added to the recommendation as the NICE guideline already includes recommendations, which highlight making adjustments to the processes and delivery of care to minimise any negative impact. NICE also has [making decisions about your care](#), which covers shared decision-making and includes advice on health and care professionals working together with patients, their families and carers to help them choose tests, treatments, management or support packages that work best for them. In addition, NICE is developing a [guideline on shared decision making](#).

Equalities

No equalities issues were identified during the surveillance process.

Overall decision

We propose to make an amendment to the section on interventions for coexisting problems in 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.

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