# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

#### **EQUALITY IMPACT ASSESSMENT**

# Vitamin B12 deficiency in over 16s: diagnosis and management

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

#### Age

Stakeholders commented that including age (especially in people aged 65 and over) as a risk factor and recommending an initial diagnostic test for anyone with at least 1 risk factor and 1 symptom or sign would create a huge resource impact without leading to a significant increase in identifying people with vitamin B12 deficiency. The committee discussed increasing age again and agreed that the factors associated with this are already covered in other symptoms, signs and risk factors. These include diets low in vitamin B12, cognitive difficulties such as difficulty concentrating or short-term memory loss (sometimes described as 'brain fog') which can be symptoms of delirium or dementia.

#### Disability

A stakeholder noted that people with a learning disability and some autistic people may not be able to articulate their response to pain in the expected way. Recommendations to help healthcare professionals and the people using services manage in these situations are covered in other NICE guidance including the NICE guidelines on <a href="Patient experience in adult NHS services">Patient experience in adult NHS services</a>, <a href="Shared decision making">Shared decision making</a> and <a href="Decision-making">Decision-making</a> and <a href="making">mental capacity</a>. The guideline cross refers to those guidelines.

A stakeholder raised the issue of diagnostic overshadowing. This occurs when the symptoms of physical ill health are mistakenly either attributed to a mental health or behavioural problem or considered inherent to the person's learning disability or autism diagnosis. People with a learning disability or autism have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different and not obvious. Their presentation may be different from that of people without a learning disability or autism. Recommendations to help healthcare professionals and the people

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using services manage in these situations are covered in other NICE guidance including the NICE guidelines on <u>Patient experience in adult NHS services</u>, <u>Shared decision making</u> and <u>Decision-making and mental capacity</u>. This guideline cross refers to those guidelines. There is also a <u>NICE guideline on Learning disabilities and behaviour that challenges</u> that gives recommendations on communication needs.

A stakeholder noted to pay attention to healthcare passports. Some people with a learning disability and some autistic people may have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. It was advised that the person or their accompanying carer should be asked if they have one of these. Recommendations to help healthcare professionals and the people using services manage in these situations are covered in other NICE guidance including the NICE guidelines on <a href="Patient experience">Patient experience in adult NHS services</a>, <a href="Shared decision making">Shared decision making</a> and <a href="Decision-making">Decision-making</a> and <a href="making and mental capacity">Decision-making</a> and <a href="making and mental

A stakeholder noted that injections may be a problem for people with sensory issues. The committee noted this is a wider issue than vitamin B12 deficiency. The <a href="NICE guideline on Shared decision making">NICE guideline on Shared decision making</a> covers recommendations on ways for healthcare professionals and people using services to work together. Both are linked to in this guideline. The <a href="NICE guideline on Patient experience">NICE guideline on Patient experience</a> in adult <a href="NHS services">NHS services</a> recommends listening to and discussing any fears or concerns the patient has.

#### Pregnancy and maternity

Stakeholders noted that total B12 test results are only affected during pregnancy, possibly the last trimester of pregnancy and not during breastfeeding. The committee had made a recommendation to use active B12 during pregnancy and breastfeeding for the draft consultation. They agreed to take out breastfeeding from the recommendations related to this.

#### Race

A stakeholder commented that the incidence of autoimmune disease in Black and Asian populations may be an additional risk factor to consider as patients are likely to have more than one autoimmune condition. Autoimmune conditions are already listed as a risk factor in the section on when to recognise vitamin B12 deficiency, and therefore these people should be captured.

Stakeholders suggested tentative guidance on cutoffs should be provided to avoid misinterpretation. Pathology laboratories do not currently provide reference ranges for people of Black ethnicity. The studies highlighting the cutoffs were done from one laboratory and the committee agreed that while this laboratory covers a population representative of the UK as a whole, further studies would be needed to suggest what the cutoffs should be. Revisiting the

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recommendation that vitamin B12 replacement should be considered if the person's reference range is indeterminate the committee agreed this could be seen as treating people with black ethnicity differently. Therefore they updated the recommendation so that it only raised awareness that people with Black ethnicity may have a higher reference range for serum vitamin B12 concentrations than people of White or Asian ethnicity. They also made a research recommendation covering this.

#### Sex

A stakeholder commented that current data indicates that vitamin B12 deficiency, including pernicious anaemia, is more common in women, as are autoimmune conditions in general. The experiences of women seeking a diagnosis for their symptoms reported in studies illustrates frequent dismissal of symptoms such as fatigue by healthcare professionals, and attribution to lifestyle and women's health issues, such as menopause. Similar experiences are noted when ineffective symptom control is reported. Autoimmune conditions were included as a risk factor in the consultation version along with listing autoimmune conditions as a risk factor. Vitamin B12 deficiency, including pernicious anaemia was not listed. The guideline links to the <a href="NICE guideline on Patient experience in adult NHS services">NICE guideline on Patient experience in adult NHS services</a> which covers recommendations on knowing the patient as an individual, listening to patient concerns and tailoring healthcare services for each patient.

#### Socio-economic factors

A stakeholder commented on the risk factors recommendations and suggested including people with limited financial resources in the risk factor related to people who find it difficult to buy or prepare food. The committee agreed this was important to included. They also agreed it would be better in a separate comment and added one that states 'in people who find it difficult to obtain or afford foods rich in vitamin B12 (for example, people on low income)'.

Other definable characteristics (these are examples):

A stakeholder suggested making reference to the importance of communication. This includes trying to understand the person being cared for, checking with the person themselves, their family member or carer, using simple, clear language, avoiding medical terms and 'jargon' wherever possible. Although not stated in the comment the committee were aware that this could affect anyone whose first language is not English which could include refugees, asylum seekers and migrant workers. Further detail on communication and treating people as individuals is covered by a cross reference in the guideline to other NICE guidance including the NICE guidelines on <a href="Patient experience in adult NHS services">Patient experience in adult NHS services</a>, <a href="Shared decision making">Shared decision making</a> and <a href="Decision-making">Decision-making</a> and <a href="making">mental capacity</a>. This guideline cross refers to those guidelines. There is also a <a href="NICE">NICE</a>

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guideline on Learning disabilities and behaviour that challenges that gives recommendations on communication needs.
4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?
None of the changes to recommendations are thought to make it more difficult for a specific group to access services.
4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?
None of the changes to recommendations are thought to have an adverse impact on people with disabilities.
4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in question 4.2, or otherwise fulfil NICE's obligations to advance equality?
None of the changes to recommendations are thought to make it more difficult for a specific group to access services.

4.5 Have the Committee's considerations of equality issues been described in the final guideline, and, if so, where?

These issues are discussed in the Committee's discussion and interpretation of the evidence sections of relevant evidence reports.

Updated by Developer: Carlos Sharpin

Date: 11 December 2023

Approved by NICE quality assurance lead: Rupert Franklin

Date: 04 March 2024