

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Guidance development

STA Fenfluramine for treating seizures associated with Lennox–Gastaut syndrome in people 2 years and over [ID1651]

The impact on equality has been assessed during this appraisal according to the principles of the NICE equality scheme.

Consultation

1. Have the potential equality issues identified during the scoping process been addressed by the committee, and, if so, how?

Yes, during scoping stakeholders noted that it is important to consider the population of people with Lennox-Gastaut seizures living in long term care and/or those with Lennox-Gastaut seizures associated cognitive impairment and/or learning disability and ensure that there are no barriers to access to the available treatments. It was also noted that this target population is likely to have intellectual disabilities and may have difficulty communicating adverse effects and therefore this should be carefully monitored by carers and medical attendants.

The committee noted these issues and was aware of the need for equitable access to fenfluramine should it be recommended. The committee will ensure that any recommendations do not make it more difficult in practice for a specific group (such as people with cognitive impairment) to access the technology compared with other groups.

2. Have any other potential equality issues been raised in the submissions, expert statements or academic report, and, if so, how has the committee addressed these?

A clinical expert considered fenfluramine treatment will be initiated by specialists. But, because adults with LGS may not be under the care of a specialist, they may not have access to new treatments. A patient expert noted that some of the tests potentially required to initiate fenfluramine may be traumatic for people with LGS who have sensory issues.

The committee was aware of the need for equitable access to fenfluramine should it be recommended but noted that access to treatments is an implementation issue that cannot be addressed in a technology appraisal recommendation. It was also aware of monitoring requirements for fenfluramine and noted that these should be considered before initiating fenfluramine treatment.

3. Have any other potential equality issues been identified by the committee, and, if so, how has the committee addressed these?

No

4. Do the preliminary recommendations make it more difficult in practice for a specific group to access the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

5. Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No

6. Are there any recommendations or explanations that the committee could make to remove or alleviate barriers to, or difficulties with,

access identified in questions 4 or 5, or otherwise fulfil NICE's obligations to promote equality?
N/A

7. Have the committee's considerations of equality issues been described in the appraisal consultation document, and, if so, where?
Yes, please see section 3.25

Approved by Associate Director (name): ...Linda Landells.....

Date: 22 January 2024

Second consultation

(when DG issued)

1. Have any additional potential equality issues been raised during the consultation, and, if so, how has the committee addressed these?
<p>Yes, clinical experts noted that fenfluramine is available in other countries so it will lead to an inequality issue if not available in NHS</p> <p>The committee noted that that this is not an equality issue as defined by the Equality Act 2010.</p> <p>A clinical expert also noted that people with strong advocates, who are more likely to be less deprived, may be able to negotiate access via Individual Funding Request (IFR) routes or self-fund, which is inequitable.</p> <p>In accordance with NICE's social value judgement principles, no priority is given based on individuals' income, social class, position in life or social roles in guidance developed for the NHS. NICE's standard approach to economic modelling (the 'reference case') does not compare NHS healthcare with privately funded healthcare.</p>

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 the technology compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

N/A

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?

N/A

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 identified in questions 2 and 3, or otherwise fulfil NICE's obligations to promote equality?

N/A

5. Have the committee's considerations of equality issues been described in the final appraisal determination, and, if so, where?

Yes, please see section 3.27

Approved by Associate Director (name): Lorna Dunning

Date: 24/10/24