## NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

### HealthTech evaluation programme

## Equality impact assessment: Guidance development

# GID-HTE10056 Digital therapy for chronic tic disorders and Tourette Syndrome: Early value assessment

The impact on equality has been assessed during this evaluation according to the principles of the <u>NICE Equality scheme</u>.

### Draft guidance consultation

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

The committee considered the potential equality issues that were identified during scoping. Key issues included:

- Digitally enabled technologies for tic disorders and Tourette syndrome are accessed via a mobile phone, tablet, or computer. People will need regular access to a device with internet access to use the technologies. Additional support and resources may be needed for people who are unfamiliar with digital technologies or do not have access to smart devices or the internet.
- Digitally enabled therapy may not be accessible to all socio-economic groups. Additional support and resources may also be needed for people with visual or hearing impairments, cognitive impairment, problems with manual dexterity, learning disabilities or who have difficulty reading or understanding health-related information in English. People's ethnic, religious, and cultural backgrounds may affect their views of digital health technologies. Healthcare professionals should discuss the language and cultural content of the technologies with people before use.
- In the UK, Tourette Syndrome is identified in 1 per 100 school children. The mean age of onset for tic disorders is approximately 5 years, although it can be lower in up to 40% of patients. Typically, the severity of tic disorders worsens between 10 and 12 years of age and improves naturally during adolescence and early adulthood. Tic disorders manifest more often in boys than girls with a ratio between 3:1 and 4:1. People with tic disorders, particularly when the illness is more severe, will experience serious social issues such as extensive stigma, public avoidance and discrimination.

• Most participants in at least one of the ORBIT studies (the UK study) were White. Clinical experts explained that it reflects the cohort of people with chronic tic disorders and Tourette syndrome in UK NHS clinics.

Age, sex, disability, race and religion are protected characteristics under the Equality Act (2010). The committee acknowledged that access to digital therapies may not be improved for those who are unable to get a diagnosis or cannot engage with a digital intervention due to a lack of accessibility, unavailability of internet connection or lack of experience with computers or smartphones and alternative treatment options should continue to be available. The committee suggested that steps should be taken to minimise these risks.

2. Have any other potential equality issues been highlighted in the company's submission, or patient and carer organisation questionnaires, and, if so, how has the committee addressed these?

No further equality issues were highlighted.

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

No other potential equality issues or considerations were identified by the committee.

**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?

People who are less comfortable or skilled at using digital technologies may be less willing to use one for managing tics. Additional support may also be needed for people with additional accessibility needs or who have problems with manual dexterity, vision, or who have cognitive impairment and an alternative treatment option may be more appropriate. The draft guidance addresses the equality issues in section 3.17 - 3.20.

**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?

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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?

The equality considerations are discussed in sections 3.17–3.20 of the guidance.

**7.** Have the committee's considerations of equality issues been described in the medical technology consultation document, and, if so, where?

Yes, these have been described in section 3.17 to 3.20 of the draft guidance. Patient considerations are also discussed in sections 3.15 to 3.16 of the draft guidance.

### Early value assessment guidance document

1. Have any additional potential equality issues been raised during the consultation, and, if so, how has the committee addressed these?

The committee noted that care pathways currently vary across the UK and some areas lack established and commissioned pathways. This makes it difficult for people living in areas without local services to access specialist tertiary services. They are discussed in section 3.17 of the final guidance.

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?

Yes. Only ORBIT is recommended in the final guidance because Neupulse is currently still in development and awaiting appropriate regulatory approval. However, ORBIT is designed to be age-appropriate for children and young people aged 9 to 17 years, as well as their parents or carers, and has only been studied in this population. Neupulse is suitable for adults, as well as children and young people aged 12 and over. Accessing diagnosis and treatment for adults with tic disorders is extremely challenging.

3. If the recommendations have changed after consultation, 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. Only ORBIT is recommended in the final guidance, but there is no adverse impact on people with disabilities.

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?

The committee acknowledged that there is a lack of treatment options for adults, including digital therapies, and notes that further development and evidence generation would help address this unmet need. They are discussed in section 3.18 of the final guidance.

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

Yes, these have been described in section 3.17 to 3.21 of the final guidance. Patient considerations are also discussed in sections 3.15 to 3.16 of the final guidance.

#### Approved by Associate Director: E. Eaton Turner

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