

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HEALTH TECHNOLOGY APPRAISAL PROGRAMME

### Equality impact assessment – Guidance development

#### STA: Exagamglogene autotemcel for treating transfusion- dependent beta-thalassaemia

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

#### Final draft guidance

(when no draft guidance was issued)

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

The following equalities issues were raised during the scoping process:

1. High prevalence of thalassaemia in people with non-white backgrounds, including from Mediterranean countries like Greece and Turkey, South Asia, Southeast Asia, the Middle East and Africa.
2. Racial discrimination of ethnic minority populations who already face health inequalities, stigmatisation and prejudice and the impact of funding within services and available treatment options for people with beta thalassaemia.
3. Decreased life expectancy and health related quality of life in people of Asian and Southeast Asian origin with the condition compared with those of other ethnic origins.
4. Difficulty accessing donor blood in those of ethnic minority groups due to shortage of ethnically matched blood stocks available and the need for alternative treatments that reduce the need for blood transfusions.
5. How health technology assessment processes and tools may disadvantage people with thalassaemia.
6. People with the condition could be considered disabled under the Equality Act 2010.

7. Treatment with exa-cel may require pre-treatment / conditioning with busulfan (or other drugs) which could affect fertility; this consideration may impact decisions about uptake by groups with protected characteristics.

For each issue, the following considerations were made:

- the committee understood concerns with the high prevalence of beta-thalassaemia for people from specific ethnic minority groups, but it noted this is not an equalities issue that is within the remit of the committee
- the committee considered that decreased life expectancy for people from specific ethnic origins was partially addressed in the model, but it took this into account deliberately
- the committee considered the limited availability of donor blood for people from specific ethnic minority backgrounds as an equalities issue that the availability of exa-cel could address, so it took this into account in its decision-making
- the committee understood that some people with beta-thalassaemia can be considered as disabled under the Equality Act 2010 and it considered this was captured in cost-effectiveness estimates
- the committee noted that the summary of product characteristics for exagamglogene autotemcel identifies that infertility has been observed with myeloablative conditioning (such as busulfan) so fertility preservation options should be considered.

The committee noted the reasonable adjustments that it had made in developing its recommendations. For example, it recognised the potential barriers to generating high-quality evidence because of health inequalities. It also accepted a higher degree of uncertainty in the clinical evidence.

The committee also increased the acceptable ICER with which exa cel would be considered cost effective. The committee considered the equality issues, noting that its recommendations apply to everyone covered by the marketing authorisation indication for exa cel for beta-thalassaemia. It concluded that its recommendations do not have a different impact on people protected by equalities legislation than on the wider population.

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?

No other issues have been raised.

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

No other issues have been identified.

4. Do the 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 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?

No.

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

Yes see section 3.15.

**Approved by Associate Director (name):** Jasdeep Hayre

**Date:** 1 August 2024