

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HEALTH TECHNOLOGY APPRAISAL PROGRAMME

### Equality impact assessment – Guidance development

#### STA Exagamglogene autotemcel for treating sickle cell disease in people 12 years and over

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

#### Consultation

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| 1. Have the potential equality issues identified during the scoping process been addressed by the committee, and, if so, how? |
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<p>At the scoping stage, the following equality issues were raised:</p>
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| <ul style="list-style-type: none"><li>• Sickle cell disease mainly affects people from African or African-Caribbean family background.</li><li>• There is a socioeconomic imbalance among people with sickle cell disease.</li></ul> |
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<p>The committee considered the impact the recommendation may have for people with protected characteristics (including race) and the impact on people from socioeconomically deprived backgrounds. It concluded that a reasonable adjustment to account for health inequalities was to adjust its acceptable ICER above the typical maximum threshold.</p>
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| 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? |
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<p>It was highlighted that people with sickle cell disease consider that the condition is not widely understood, including among healthcare</p>
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professionals, which often results in poor hospital care and stigma around seeking pain relief for crises.

It was also highlighted that there is a high unmet need and limited access to new safe, effective treatments for SCD which widens health inequalities for the SCD community.

Stakeholders raised that there is likely to remain an unmet need for a cohort of people, especially those older than the studied age group (12-35 years). They also noted that the required pre-treatment and conditioning with busulfan before exa-cel may affect the fertility of people having exa-cel.

The committee considered these potential issues and was aware that the marketing authorisation did not include a limit on the upper age that people can have exa-cel.

The committee was mindful that most of the equality issues raised were closely related to the health inequalities issues. Alongside these issues, a reasonable adjustment is to increase the acceptable ICER above the typical maximum threshold.

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

No other equalities issues 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?

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?

No.

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

Sections 3.17, 3.18 and 3.20

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

**Date:** 6 March 2024

## Final draft guidance

(when draft guidance issued)

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

Yes. It was highlighted that:

- People of Black African and Caribbean heritage are more likely to experience poverty, discrimination, barriers to accessing healthcare and poorer health outcomes
- The NHS commissioning criteria allows children to receive hematopoietic stem cell transplant (HSCT) using any donor e.g., matched unrelated donors. However, adults can only have HSCT from

a fully matched sibling donor. Only 15% of adults with SCD have an available donor.

- Careful consideration needs to be given to the ethnic, faith and cultural needs/aspects of individuals who are being offered this treatment

The committee was mindful that some of the equality issues raised were closely related to the health inequalities issues. The committee considered the impact the recommendation may have for people with protected characteristics (including race) and the impact on people from socioeconomically deprived backgrounds. It concluded that a reasonable adjustment to account for health inequalities was to adjust its acceptable ICER above the typical maximum threshold.

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?

No.

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?

No.

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?

No.
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5. Have the committee's considerations of equality issues been described in the final draft guidance, and, if so, where?
Yes. See section 3.19, 3.20 and 3.23

**Approved by Associate Director (name):** Lorna Dunning

**Date:** 21/01/2025