

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Scoping

Exagamglogene autotemcel for treating transfusion-dependent beta-thalassaemia

Batch 89

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

1. Have any potential equality issues been identified during the scoping process (draft scope consultation and scoping workshop discussion), and, if so, what are they?

Consultees have raised several health inequalities issues related to beta thalassaemia:

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.

2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?

NICE considers appraisal technologies within their marketing authorisation for the whole population including those from different ethnic and genetic backgrounds. Stakeholders will have an opportunity to submit evidence on health inequalities, such as the impact of historical inequality and injustice and unmet need related to access to current treatment, as part of the technology appraisal and the committee will consider the impact of recommendations on people protected characteristics in conjunction with [the principles that guide the development of NICE guidance and standards](#) including the aim to reduce health inequalities. However, please note:

1. Issues related to differences in prevalence or incidence of a disease or a reduced life expectancy for one particular protected group cannot be addressed in a technology appraisal.
2. The committee must follow the processes and methods set out in the [NICE health technology evaluation manual](#) and are unable to divert from these methods and processes for individual evaluations or they will risk introducing further inequalities.
3. The committee may ask for more information from clinical experts about pre-treatment / conditioning with drugs that may affect fertility. Any costs of fertility preservation should be included in the modelling.

3. Has any change to the draft scope been agreed to highlight potential equality issues?

No; it was already included the background section of the scope.

4. Have any additional stakeholders related to potential equality issues been identified during the scoping process, and, if so, have changes to the matrix been made?

No

Approved by Associate Director (name): Jasdeep Hayre

Date: 25/04/2023