

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HEALTH TECHNOLOGY APPRAISAL PROGRAMME

### Equality impact assessment – Guidance development

### HST Leniolisib for activated phosphoinositide 3-kinase delta syndrome in people 12 years and over [ID6130]

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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No potential issues were identified during the scoping process.
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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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Stakeholders raised several issues:
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| <ul style="list-style-type: none"><li>• People with APDS from an ethnic minority background may have fewer suitable donors available for HSCT</li><li>• HSCT access may be restricted for some young people with APDS due to the lack of parental consent</li><li>• Currently no licensed treatments available for APDS or UK clinical guidelines. This may lead to sub-optimal and inconsistent use of off-label medicines and variable approaches in managing APDS</li><li>• Variable manifestations may make it challenging to accurately recognise and diagnose APDS, leading to delayed diagnoses with a median delay of 7 years</li></ul> |
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- People with suspected APDS can be referred to up to 6 different clinicians during APDS diagnosis pathway
- Awareness of APDS in the medical community is still low and can compound diagnostic challenges
- Individuals living in areas not served by a specialist immunology service or for groups where referral to specialist services occur less frequently

The committee considered the issues raised. It noted that issues about challenges with diagnosis and management but were not able to address these within the appraisal. It did consider the impact the recommendation may have for people with protected characteristics (including race). It was aware that the use of hematopoietic stem cell transplants was very low in people with APDS aged 12 years and older. So it agreed that this was not a potential equality issue that could be addressed.

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 draft guidance, and, if so, where?
Yes, see section 3.18

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

**Date:** 23/10/2024