

# Thanks NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## HIGHLY SPECIALISED TECHNOLOGY EVALUATION PROGRAMME

### Equality impact assessment – Guidance development

#### Lumasiran for treating primary hyperoxaluria type 1

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

#### Consultation

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

Several potential equality issues were identified during scoping:

- Because primary hyperoxaluria type 1 (PH1) is an autosomal recessive condition, it disproportionately affects cultures in which consanguineous marriage is common. Therefore, PH1 is more common in people from certain ethnic minority groups.
- Some people who have symptoms of PH1 may experience inequalities in care because of distance to a specialist centre or inadequate referral pathways.
- It may be difficult for some people with metabolic kidney stone disease to access and attend specialist centres because of where they live.

The committee considered that issues about differences in the prevalence or incidence of a disease and healthcare implementation cannot be addressed in a highly specialised technology evaluation.

2. Have any other potential equality issues been raised in the submissions, expert statements or independent academic report, and, if so, how has the Committee addressed these?

The company submission highlighted that PH1 disproportionately affects young people, their families and caregivers (mainly female). The committee considered that issues about differences in the prevalence or incidence of a disease cannot be addressed in a highly specialised technology evaluation.

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

No other issues were identified.

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?

Not applicable.

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?

Not applicable.

7. Have the Committee's considerations of equality issues been described in the evaluation consultation document, and, if so, where?

See section 3.31 of the ECD.

**Approved by Associate Director:** Richard Diaz

**Date:** 4 May 2022

## Second consultation

(when an ECD issued)

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

A stakeholder commented that the PH1 gene can be found in all people and is not limited to a single ethnic group. So, if lumasiran was recommended then it should be offered to anyone in need of this treatment.

The committee was mindful of its obligations in relation to the Equality Act 2010 and that it can only recommend the use of lumasiran within its marketing authorisation.

1. 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?

Not applicable.

2. 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?

Not applicable.

3. 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?

Not applicable.

4. Have the committee's considerations of equality issues been described in the final appraisal determination, and, if so, where?

See section 3.36 of the ECD.

**Approved by Associate Director (name):** Richard Diaz.....

**Date:** 2 Nov 2022

## Final evaluation document

(when an ECD is issued)

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

No additional potential equality issues were raised during the second consultation.

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?

Not applicable.

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?

Not applicable.

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?

Not applicable.

5. Have the committee's considerations of equality issues been described in the final evaluation document, and, if so, where?
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See section 3.37 of the FED.
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**Approved by Associate Director (name):** ...Richard Diaz.....

**Date:** 13 March 2023