NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HIGHLY SPECIALISED TECHNOLOGIES EVALUATION PROGRAMME

Equality impact assessment – Scoping

HST
Lumasiran for treating primary hyperoxaluria type 1 ID3765

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?
• PH1 is an autosomal recessive disorder, therefore cultures in which consanguineous marriage is common are disproportionately affected • UK incidence and prevalence disproportionately higher in ethnic minorities including those of Pakistani and other south Asian origin • Ease of access for patients from all areas of the country to attend specialist centres for metabolic kidney stone disease • Inequality risk as some people who have symptoms of primary hyperoxaluria but are not referred for assessment to a specialist centre because of distance or inadequate referral pathways.

2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?
• Issues related to differences in prevalence or incidence of a disease cannot be addressed in a highly specialised technology evaluation. Stakeholders can submit evidence on differing diagnosis timeliness, outcomes and quality of life between different populations. • The committee will be made aware of issues related to ease of access in relation to people with metabolic kidney stone disease.

3.	Has any change to the draft scope been agreed to highlight potential equality issues?
No changes have been made.	

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 additional stakeholders have been identified.	

Approved by Associate Director (name): Jasdeep Hayre

Date: 10 May 2021