NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HST PROGRAMME

Equality impact assessment – Scoping

HST Givosiran for treating acute hepatic porphyria

Batch 72

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?

It was highlighted that:

- the use of haem arginate and liver transplantation (listed as comparators in the scope) may not be acceptable forms of treatment for Jehovah's Witnesses;
- acute hepatic porphyria mainly effects young women;
- some people, especially those with disabilities, may find it more difficult to travel to treatment centres to receive treatment.
- 2. What is the preliminary view as to what extent these potential equality issues need addressing by the Committee?

The potential for comparators to be an unacceptable treatment option for some people based on religious beliefs will be fully considered by the committee.

Issues related to differences in prevalence or incidence of a disease cannot be addressed in a highly specialised technology evaluation.

It is expected that the travel requirements to specialist centres will be similar to those currently required for haem arginate, which is the most common treatment for this population in current practice. 3. Has any change to the draft scope been agreed to highlight potential equality issues?

No.

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

No. It is expected that the patient and carer organisations currently included on the stakeholder list will be able to provide the relevant insight into the equality issues highlighted.