NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH TECHNOLOGY APPRAISAL PROGRAMME

Equality impact assessment – Guidance development

STA Iptacopan for treating paroxysmal nocturnal haemoglobinuria [ID6176]

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

Final draft guidance

(when no draft guidance was issued)

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

Potential equality issues raised during scoping were:

- Inequalities if different recommendations are made for pregnant people and children.
- Pegcetacoplan is administered with subcutaneous injection, which may impact people who find it difficult or may not be able to self-administer pegcetacoplan. This may include people with dexterity, visual or cognitive disabilities.

The committee considered all protected characteristics during its decision-making and recommendations are made according to the marketing authorisation. It acknowledged the benefits of iptacopan having an oral mode of administration.

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?

The company highlighted that all treatments for paroxysmal nocturnal haemoglobinuria are either with intravenous infusion or subcutaneous injection, which could disadvantage people with needle phobia. Also, subcutaneous infusions may be unsuitable for people who are obese due to absorption issues and for people with dexterity, visual or cognitive disabilities because of difficulties with self-administering treatment.

The committee considered that the points raised are not equality issues in relation to iptacopan and noted that iptacopan is an oral treatment.

A clinical expert submission highlighted that iptacopan is not advised during pregnancy. Also, that people under the age of 18 are not included in the iptacopan clinical trials.

The committee agreed that healthcare professionals should follow the guidance about pregnancy in the summary of product characteristics. The committee can only recommend a treatment in line with its marketing authorisation.

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 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. Iptacopan is recommended within its full marketing authorisation.	

5.	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?
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 final draft guidance, and, if so, where?
Yes, section 3.17.	

Approved by Associate Director (name): Jasdeep Hayre

Date: 9 May 2024