

## Engagement Report

### Topic details

<b>Title of policy or policy statement:</b>	Treatment of iron overload for transfused and non-transfused patients with chronic inherited anaemias (all ages)
<b>Programme of Care:</b>	Blood and Infection
<b>Clinical Reference Group:</b>	Haemoglobinopathies
<b>URN:</b>	2109

### 1. Summary

This report summarises the feedback NHS England received from engagement during the development of this policy proposition, and how this feedback has been considered. The policy proposition went out to stakeholder engagement between 30<sup>th</sup> March to 13<sup>th</sup> April 2022. There were 3 responses.

### 2. Background

This clinical commissioning policy proposition recommends a revision of the published Clinical Commissioning Policy '*Treatment of iron overload for transfused and non-transfused patients with chronic inherited anaemias*' to extend the treatment combinations available. The clinical policy proposition was developed through conducting an externally conducted evidence review and by a Policy Working Group (PWG) consisting of haematology experts, patient representatives, a public health specialist and a specialist commissioner for NHS England.

This proposed policy is for use in people with chronic inherited anaemias who are at risk of iron overload due to their need for repeated transfusions. The treatment may also be required for patients with non-transfusion dependent iron overload that occurs due to increased gastrointestinal iron absorption. These two proposed combination therapies will offer alternative treatment options for patients who are unable to achieve negative iron balance despite adherence to optimal doses of monotherapy or those who are unable to tolerate the currently commissioned iron chelation therapies outlined in the afore mentioned existing policy.

### 3. Engagement

NHS England has a duty under Section 13Q of the NHS Act 2006 (as amended) to 'make arrangements' to involve the public in commissioning. Full guidance is available in the Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning. In addition, NHS England has a legal duty to promote equality under the Equality Act (2010) and reduce health inequalities under the Health and Social Care Act (2012).

The policy proposition was sent for stakeholder testing for 2 weeks from 30<sup>th</sup> March to 13<sup>th</sup> April 2022. The comments have then been shared with the Policy Working Group to enable full consideration of feedback and to support a decision on whether any changes to the proposition might be recommended.

Respondents were asked the following questions:

- Do you support the proposition for the treatment of iron overload for transfused and non-transfused patients with chronic inherited anaemias to be available through routine commissioning/not for routine commissioning based on the evidence review and within the criteria set out in this document?
- Do you believe that there is any additional information that we should have considered in the evidence review? If so, please give brief details.
- Do you believe that there are any potential positive and/or negative impacts on patient care as a result of making this treatment option available? If so, please give details.
- Do you have any further comments on the proposition? If Yes, please describe below, in no more than 500 words, any further comments on the proposed changes to the document as part of this initial 'sense check'.
- Please declare any conflict of interests relating to this document or service area.
- Do you support the Equality and Health Inequalities Impact Assessment?

A 13Q assessment has been completed following stakeholder testing. (delete the not applicable paragraphs)

The Programme of Care has decided that the proposition offers a clear and positive impact on patient treatment, by potentially making a new treatment available which widens the range of treatment options without disrupting current care or limiting patient choice, and therefore further public consultation was not required. This decision has been assured by the Patient Public Voice Advisory Group.

#### 4. Engagement Results

Three responses were received: all from clinicians and one from an individual.

All respondents supported the policy proposition and deemed that it would have positive impacts upon patients.

In line with the 13Q assessment it was deemed that further public consultation was not required.

#### 5. How has feedback been considered?

Responses to engagement have been reviewed by the Policy Working Group and the Blood and Infection PoC. The following themes were raised during engagement:

Keys themes in feedback	NHS England Response
<b>Relevant Evidence</b>	
Suggestion to include clinical trials on the proposed drugs, some patients are more sensitive to deferral than others.	PWG to comment.
<b>Impact Assessment</b>	
Access to these combination regimens will significantly improve the clinical management of patients with iron	Noted.

overload who are unable to be treated with the approved so far regimens. As a result this will also be cost effective as the risk of complications from sub-optimally treated iron overload such as endocrinopathies and heart disease as well as the risk of morbidity associated with the toxicity of current regimens will be potentially substantially reduced.	
Suggestion to ensure the National Haemoglobinopathy Register will capture these regimens so longitudinal data can be collected.	Outlined in audit requirements in the policy proposition document.
<b>Changes/addition to policy</b>	
No changes	Noted

**6. Has anything been changed in the policy proposition as a result of the stakeholder testing and consultation?**

No changes have been made to the policy proposition based on the engagement response.

**7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final policy proposition?**

No.