Engagement Report

Topic details

Title of policy or policy statement:	Rituximab and eculizumab for the prevention and management of delayed haemolytic transfusion reactions and hyperhaemolysis in patients with haemoglobinopathies
Programme of Care:	Blood & Infection
Clinical Reference Group:	Haemoglobinopathies
URN:	1821

1. Summary

This report summarises the feedback we received from engagement during the development of this policy proposition, and how this feedback has been considered.

No responses were received from stakeholders following the two week period of stakeholder testing.

2. Background

This policy proposition has been developed by a Policy Working Group made up of clinicians from Haematology services and Patient & Public Voice representation, in line with NHS England's standard methods.

A final decision as to whether Rituximab and Eculizumab will be routinely commissioned will be made by NHS England following a recommendation from the Clinical Priorities Advisory Group. The proposal is: Rituximab and Eculizumab is recommended to be available as a treatment option through routine commissioning for delayed haemolytic transfusion reactions and hyperhaemolysis in patients with haemoglobinopathies within the criteria set out in the document.

The draft policy proposition was sent to the following groups for comment:

- Haemoglobinopathy Clinical Reference Group (CRG); and
- Registered stakeholders for the CRG

In addition, the CRG stakeholder list was reviewed to identify and capture any missing key stakeholders from the list to ensure complete representation.

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 two weeks from the 18th September to the 30th September 2019. There were no comments received following the process; this has been shared with the Policy Working Group to enable full consideration on this outcome.

Respondents were asked the following questions:

- Do you support the proposition for Rituximab and Eculizumab to be available for the prevention and management of Delayed Haemolytic Transfusion Reactions and Hyperhaemolysis in patients with haemoglobinopathies through 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 for this policy proposition.

The Programme of Care has determined that the proposition offers a clear and positive impact on patient treatment, by potentially making this treatment available.

This will provide alternative treatment options, without disrupting current care or limiting patient choice. Therefore, it was considered that further public consultation was not required for this policy. This decision has been approved and assured by the Patient Public Voice Advisory Group (PPVAG).

4. Engagement Results

Following the consultation process undertaken, there were no responses received from stakeholders for this policy.

In line with the 13Q assessment it was deemed that further public consultation would not be required as the proposal presents no material change and is designed to provide increased access to additional treatment for patients with the most severe conditions and is therefore of considerable benefit to the patient population. This decision has been approved and assured by the Patient Public Voice Advisory Group (PPVAG), noting the policy impacts on a relatively small number of patients and the opportunity to comment on these proposals has been offered during Stakeholder Testing, with Patient and Public Voice involvement in the Policy Working Group and the Haemoglobinopathies Clinical Reference Group.

5. How has feedback been considered?

Not applicable - No responses to the stakeholder testing were received.

Keys themes in feedback	NHS England Response
Relevant Evidence	
Impact Assessment	
Current Patient Pathway	
Potential impact on equality and health inequalities	
Changes/addition to policy	

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

Not applicable.

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

Not applicable.