

Engagement report for specialist services for haemophilia and related bleeding disorders (adults and children)

18 March 2024 Version 1.0

Topic details

Programme of Care	Blood and Infection
Clinical Reference Group	Specialised Blood Disorders
Unique Reference Number (URN)	

1. Summary

This report summarises the feedback NHS England received from engagement during the development of this service specification, and how this feedback has been considered.

The stakeholder testing period was open for 3 weeks from Monday 5 February until Friday 25 February. In total 10 responses were received however 1 of these was inadvertently a duplicate; 1 of the duplicates was removed from responses, therefore 9 unique responses were received. Responses were received from a range of individuals and organisations; most were positive and supportive of the new service specification.

2. Background

This service specification has been developed by a Specification Working Group (SWG) made up of clinicians from across the UK, plus a range of specialities (medical consultants, physiotherapy, psychology, nursing, social work), and patient representatives from the leading national patient charity and an individual patient with extensive advocacy and lived experience in the field. In addition, the SWG included specialists with paediatric haemophilia care and called upon other experts for contributions and sense-checking material. The SWG was chaired by the National Speciality Adviser for Specialised Blood Disorders. All members of the SWG made significant contributions to the specification and challenged the content at multiple points. Consensus was reached at all points, usually following discussion and sometimes a compromise.

3. Engagement Results

3.1 Stakeholder Testing

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 service specification was sent for stakeholder testing for **3 weeks** from 5 to 25 February 2024. The comments have then been shared with the Specification Working Group to enable full consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

Respondents were asked the following questions:

- What are your thoughts on the proposed updates to the service specification for specialist services for haemophilia and related bleeding disorders (adults and children)?
- What are your thoughts on the extent to which the specification supports the development and delivery of high quality, safe and effective specialist services for haemophilia and related bleeding disorders (adults and children)?
- Do you think that this updated specification supports the development and delivery of high quality, safe and effective specialist services for haemophilia and related bleeding disorders (adults and children)?
- Is there any additional information we should have considered as part of this process or which you feel we have omitted?

3.2 Stakeholder testing results and summary of participants

Respondent by type	
Clinician or clinical centre	2
Devolved Nation, Health Service	1
Patient organisation (responses from same)	2
Pharmaceutical company	3
Professional organisation	1

Responses were strongly supportive of the revised service specification. Usefully, some respondents highlighted specific points of clarity, or issues which they felt should be addressed in more detail. Several questions were not answered by all respondents.

8 respondents supported the accompanying equality and health inequalities impact assessment (EHIA) and 1 respondent did not support it. The respondent who did not support the EHIA provided a narrative to highlight specific points, which have in turn been addressed by the SWG.

A 13Q assessment has been completed following stakeholder testing.

3.3 Public consultation

Not applicable. Following the stakeholder consultation, the SWG awaits advice from the Patient and Public Voice Assurance Group (PPVAG) on whether a public consultation would be useful and desirable.

3.4 Public consultation results and summary of participants

Not applicable, no public consultation has been undertaken and the SWG awaits advice from PPVAG on whether a public consultation would be useful and desirable.

4 How has feedback been considered

Responses to engagement have been reviewed by the Specification Working Group and the Blood and Infection Programme of Care (POC). The following themes were raised during engagement:

Engagement activity theme identified in eg stakeholder testing, public consultation	Keys themes in feedback	NHS England response
	Relevant Evidence	
Stakeholder testing	None identified	No response required
	Impact Assessment	
Stakeholder testing	Nothing raised	No response required
	Current patient pathway	
Stakeholder testing	One minor point raised	Small amendment to the pathway description to reflect a less common but important route to access care
	Potential impact on equality and health inequalities	
Stakeholder testing	One respondent raised a number of points	The points raised were useful but most related to a specific dimension of care (medicines) and not necessarily the service specification. On balance the SWG opted not to make any amendments to the EHIA
	Changes/addition to policy	
Stakeholder testing	Various, relatively minor, points of clarity or correction	A few minor changes were made to the

5 Has anything changed in the service specification as a result of the stakeholder testing and consultation?

The following change(s) based on the engagement responses has (have) been made to the service specification:

This is a new, revised, service specification. Following stakeholder testing only a few minor changes were made, some of which were stylistic and others were simple points of clarification or corrections. See stakeholder testing appendix for details.

6 Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification?

None, but note that a public consultation has not been undertaken and the SWG awaits advice from PPVAG as to whether a public consultation would be useful and desirable.

7 What are the next steps including how interested stakeholders will be kept informed of progress?

The SWG requests the POC to assure and approve the SWG responses stakeholders who did respond to the stakeholder consultation.

The SWG requests the POC to approve the decision to await advice from the PPVAG before deciding whether to proceed with a public consultation.

When the Specification is published, irrespective of whether a public consultation is undertaken, all registered stakeholders will be formally notified when the revised specification is published. Some of the most important stakeholders are members of the SWG and the CRG and these connections will be used passively and actively to keep interested parties and the wider patient community informed.