

Engagement Report for Service Specifications

Unique Reference Number	170125S	
Specification Title	Haemoglobinopathies: Haemoglobinopathy Coordinating Centres	
Clinical Reference Group	Specialised Haemoglobinopathies CRG	
Which stakeholders were contacted to be involved in service specification development?		All registered stakeholders with the Specialised Haemoglobinopathies CRG, CRG members, including PPV members, as per the SHT specification
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved		
Which stakeholders have actually been involved?		CRG clinical and PPV members CRG Stakeholders
Explain reason if there is any difference from previous question		Range of engagement activities undertaken giving people the opportunity to participate in addition to the testing Stakeholder decision to participate in stakeholder feedback
Identify any particular stakeholder organisations that may be key to the specification development that you have approached that have yet to be engaged. Indicate		None

why?	
How have stakeholders been involved? What engagement methods have been used?	Stakeholders have been engaged through a number of approaches including stakeholder updates, on-line questionnaires, regional meetings, teleconferences, WebEx presentations and by piggy-backing onto planned event, such as those organised by the Sickle Cell Disease Society
What has happened or changed as a result of their input?	Changes have been made to the service specification in response to comments received
How are stakeholders being kept informed of progress with specification development as a result of their input?	Stakeholder updates will be sent out, indicating feedback received and what has changed as a result
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	The proposed changes to the service did not trigger 13Q. This was approved by PPVAG. However, in order to gain as much feedback and engagement as possible, a 60-day engagement phase was conducted. A report summarising the points raised during this process is included with this report.