

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1709 ID018
Policy Title	Vonicog alfa for treating von Willebrand disease
Accountable Commissioner	Will Horsley
Clinical Lead	Michael Laffan
Clinical Reference Group	Specialised Blood Disorders
Which stakeholders were contacted to be involved in policy development?	<p>A policy working group was established in line with NHS England's standard methods.</p> <p>The draft policy proposition was sent to the following groups for comment:</p> <ul style="list-style-type: none"> • Specialised Blood Disorders Clinical Reference Group (CRG); and • Registered stakeholders for the Specialised Blood Disorders CRG
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	All of the relevant Royal Colleges and professional societies were invited to take part in stakeholder testing.
Which stakeholders have actually been involved?	Specialised Blood Disorders CRG and registered stakeholders. 3 responses were received from stakeholders. This included 2 pharmaceutical companies and 1 non-profit professional
Explain reason if there is any difference from previous question	Not all organisations commented on the documents.
Identify any particular stakeholder	None, the main patient and carer representative organisations were involved throughout the development of the draft policy proposition

organisations that may be key to the policy development that you have approached that have yet to be engaged. Indicate why?	
How have stakeholders been involved? What engagement methods have been used?	<p>Policy working group meeting and subsequent contact for policy development</p> <p>The draft policy proposition was distributed to stakeholders via email for a period of two weeks of stakeholder testing, in preparation for public consultation.</p> <p>Stakeholders were asked to submit their responses via email, using a standard response and in line with NHS England's standard processes for developing clinical commissioning policies.</p>
What has happened or changed as a result of their input?	<p>Comments were submitted by 3 stakeholders and these have been reviewed by the policy working group. Amendments were made to the documents where appropriate following consideration by the PWG. The amendments included:</p> <ul style="list-style-type: none"> • Clarification about prior use of desmopressin and tranexamic acid (the original text stated previous treatments included 'desmopressin and tranexamic acid', we have reworded to 'desmopressin with or without tranexamic acid') • Reworded the treatment pathway section, including minor tweaks to wording, and using a more balanced description of the disadvantages of plasma based products
How are stakeholders being kept informed of progress with policy development as a result of their input?	<p>All stakeholders (including CRG members and registered stakeholders) will be notified when the draft policy proposition goes out to public consultation and will be kept informed of the policy's progress through NHS England's consultation portal website</p>
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	<p>Of the 4 stakeholder responses:</p> <ul style="list-style-type: none"> • 2 (of which 1 was a 'no comment' response from an individual, and the other was a comparator company unhappy with the description of plasma-based products) suggested the longer period of up to 12 weeks was used • 1 (the company for vonicog) suggested up to 6 weeks • The other made no suggestion. <p>The consensus of the PWG was that 6 weeks should be used.</p>