

Engagement Report for Specialised Commissioning Policies

Unique Reference Number and NICE ID	1813 ID012
Policy Title	Canakinumab for treating periodic fever syndromes TRAPS, HIDS/MKD and FMF (ages 2 and older)
Clinical Reference Group	Specialised Immunology and Allergy Services
Which stakeholders were contacted to be involved in policy development?	<p>A policy working group (PWG) 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"> • Allergy and Immunology CRG and registered stakeholders • Specialised Rheumatology CRG and registered stakeholders • Adult Rheumatology CRG and registered stakeholders • Dermatology CRG and registered stakeholders list • Paediatric Medicine CRG and registered stakeholders list • Specialised Pain CRG and registered stakeholders • British Association for Immunology • BPAIIG (British Paediatric Allergy, Immunity and Infection Group) • BSPAR- British society of paediatric and adolescent rheumatology for RCPCH • Royal College of Pathologists • Royal College of Physicians • British Association of Dermatologists • Rare Autoinflammatory group UK
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.

<p>Which stakeholders have actually been involved?</p>	<p>6 responses were received from stakeholders, including 2 individual clinicians. Rare Autoinflammatory Conditions Community – UK Birmingham Women’s and Children’s Hospital NHS Foundation Trust Specialised Rheumatology CRG Primary Immunodeficiency UK</p>
<p>Explain reason if there is any difference from previous question</p>	<p>Not all organisations commented on the documents.</p>
<p>Identify any particular stakeholder organisations that may be key to the policy development that you have approached that have yet to be engaged. Indicate why?</p>	<p>None, the main patient and carer representative organisations were involved throughout the development of the draft policy proposition</p>
<p>How have stakeholders been involved? What engagement methods have been used?</p>	<p>PWG meeting and subsequent contact for policy development The draft policy proposition was distributed to stakeholders via email for a period of two weeks of stakeholder testing, in preparation for public consultation. 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>
<p>What has happened or changed as a result of their input?</p>	<p>Comments were submitted by 6 stakeholders and these have been reviewed by the policy working group. No amendments were made to the documents following consideration by the PWG.</p>
<p>How are stakeholders being kept informed of progress with policy development as a result of their input?</p>	<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>
<p>What level of wider public</p>	<p>It is proposed that highly specialised products will go for period of public consultation for four weeks.</p>

<p>consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?</p>	
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