

## Engagement Report for Clinical Commissioning Policies

<b>Unique Reference Number</b>	1853
<b>Policy Title</b>	Rituximab for refractory Systemic Lupus Erythematosus (SLE) in adults and post-pubescent children
<b>Clinical Reference Group</b>	Specialised Rheumatology
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"> <li>• Clinical Reference Group (CRG); and</li> <li>• Registered stakeholders for the CRG</li> </ul>
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	<p>All of the relevant Royal Colleges and professional societies were invited to take part in stakeholder testing.</p> <p>The Association of the British Pharmaceutical Industry  The British Psychological Society  British Society for Rheumatology  The Royal College of Radiologists  The Institute of Biomedical Science  Neonatal &amp; Paediatric Pharmacists Group  Royal College of Physicians  The Royal College of Surgeons of Edinburgh  The Society &amp; College of Radiographers  UK Clinical Pharmacy Association</p>
Which stakeholders have actually been involved?	<p>Specialised Rheumatology Clinical Reference Group and a number of registered stakeholders.</p> <p>Responses were submitted by 19 stakeholders.</p> <p>These included:</p> <p>1 response from a national charity patient organisation</p>

	<p>2 responses from drug companies</p> <p>1 response from a professional society</p> <p>13 responses from individual clinicians</p> <p>1 response from a non-clinical CRG member</p> <p>1 response from a non-clinical professional</p>
<p>Explain reason if there is any difference from previous question</p>	<p>Not all registered stakeholders responded to the testing.</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>including:</p> <p>British Liver Trust</p> <p>DDD/C3G Renal Support Group UK – Rare Disease UK</p> <p>Ehlers Danlos Support UK</p> <p>Genetic Alliance UK</p> <p>Lupus UK</p> <p>Primary Immunodeficiency UK</p> <p>Rare Autoinflammatory Conditions' Community - UK</p> <p>Scleroderma &amp; Raynaud's UK (SRUK)</p> <p>Vasculitis UK</p>
<p>How have stakeholders been involved? What engagement methods have been used?</p>	<p>The draft policy proposition was distributed to stakeholders via email for a period of three weeks of stakeholder testing, in preparation for public consultation.</p> <p>Stakeholders were asked to submit their responses via email, using a standard response form and in line with NHS England's methods for developing clinical commissioning policies.</p> <p>The Policy Working Group discussed the responses at subsequent contact for policy development</p>
<p>What has happened or changed as a result of their input?</p>	<ul style="list-style-type: none"> <li>• All respondents but one supported the policy proposition in providing access to older children and adults</li> <li>• It should be noted all clinicians, including the professional society, and lead pharmacist strongly supported use of Rituximab in pre-pubescent children as well but this had not secured the support of the Clinical Panel, due to insufficient evidence for this aspect of the policy proposal.</li> <li>• Clarification was added that the registration of children commenced on Rituximab should use a modified data set, similar to BILAG-BR.</li> <li>• Amendments were made to clarify off label use in other similar conditions, dosing and use as a re-treatment.</li> </ul>

	<p>A number of minor amendments were made to the draft documents in order to improve accuracy or clarity. The majority of responses were noted, with no further changes required.</p> <p>A small number of responses fell outside the scope of this policy process, most notably relating to the use of alternative antiCD20 drugs when patients have experienced a reaction to rituximab, and the additional resources required to collect registry data and research.</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 consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?</p>	<p>30 days</p>