Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1853
Policy Title	Rituximab for Refractory Systemic Lupus Erythematosus (SLE) in Adults and Post-Pubertal Children
Lead Commissioner	Jackie Parr
Clinical Reference Group	Specialised Rheumatology
Which stakeholders were contacted to be involved in policy development?	A policy working group was established in line with NHS England's standard methods. The draft policy proposition was sent to the following groups for comment: • Clinical Reference Group (CRG); and • Registered stakeholders for the 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. 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 & Paediatric Pharmacists Group Royal College of Physicians The Royal College of Surgeons of Edinburgh The Society & College of Radiographers UK Clinical Pharmacy Association
Which stakeholders have actually been involved?	Specialised Rheumatology Clinical Reference Group and a number of registered stakeholders. the main patient and carer representative organisations were involved throughout the development of the draft policy proposition. including: British Liver Trust

	DDD/C3G Renal Support Group UK – Rare Disease UK Ehlers Danlos Support UK Genetic Alliance UK Lupus UK Primary Immunodeficiency UK Rare Autoinflammatory Conditions' Community - UK Scleroderma & Raynaud's UK (SRUK) Vasculitis UK
Explain reason if there is any difference from previous question	Not all registered stakeholders responded to the testing.
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?	None, the main patient and carer representative organisations were involved throughout the development of the draft policy proposition. including: British Liver Trust DDD/C3G Renal Support Group UK – Rare Disease UK Ehlers Danlos Support UK Genetic Alliance UK Lupus UK Primary Immunodeficiency UK Rare Autoinflammatory Conditions' Community - UK Scleroderma & Raynaud's UK (SRUK) Vasculitis UK
How have stakeholders been involved? What engagement methods have been used?	None, the main patient and carer representative organisations were involved throughout the development of the draft policy proposition. The draft policy proposition was distributed to stakeholders via email for a period of three 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. Policy working group meeting and subsequent contact for policy development
What has happened or changed as a result of their input?	Responses were submitted by 19 stakeholders. These included: 1 response from a national charity patient organisation 2 responses from drug companies 1 response from a professional society

	13 responses from individual clinicians 1 response from a non-clinical CRG member 1 response from a non-clinical professional • All respondents but one supported the policy proposition in providing access to older children and adults • It should be noted all clinicians, including the professional society, and lead pharmacist strongly supported use of Rituximab in pre-pubertal 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. • Clarification was added that the registration of children commenced on Rituximab should use a modified data set, similar to BILAG-BR. • Amendments were made to clarify off label use in other similar conditions, dosing and use as a re-treatment. 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. 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.
How are stakeholders being kept informed of progress with policy development as a result of their input?	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.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	30 days