Engagement Report for Clinical Commissioning Policies

Unique Reference Number	A13X07
Policy Title	Rituximab for immunoglobulin G4-related disease (IgG4-RD)
Accountable Commissioner	Jon Gulliver
Clinical Reference Group	Specialised Rheumatology
Which stakeholders were contacted to be involved in policy development?	All CRG members and CRG listed stakeholders.
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	Representatives of relevant Royal College or Professional Societies were contacted for Stakeholder Testing as part of the CRG.
Which stakeholders have actually been involved?	All of the key stakeholders listed above were invited to comment.
Explain reason if there is any difference from previous question	Not applicable.

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.
How have the stakeholders been involved? What engagement methods have been used?	The draft policy was circulated to the full membership of the CRG and its registered stakeholders for one week for their views, both to establish whether any amendments to the policy are required, and to understand from their perspective what the key questions to ask at consultation might be. Five responses were received in total: four from CRG members and one from a registered stakeholder, the manufacturer of the drug. <u>Key responses were as follows:</u> (1) Stakeholders either supported or had no comments regarding the 30 day period of public consultation (2) One CRG member suggested that the UKIVAS be used as the national registry for IgG4-RD (3) Another CRG member suggested that Rituximab be used second-line in patients at risk of steroid associated morbidity (4) The stakeholder noted that the trade name with marketing authorisation in the UK/Europe be used for Rituximab (MabThera) (5) The stakeholder also noted the exclusion criteria be amended to include the manufacturer's guidance (Summary of Product Characteristics, SPC) (6) The stakeholder, furthermore, noted that more detail be given regarding the administration of the drug. (7) Lastly, the stakeholder suggested the trade name be used when recording treatmennt in patient files.
What has happened or changed as a result of their input?	The PWG has considered the feedback received. - The PWG believes a new registry should be set up to monitor outcomes for this new disease area, modelled on the British Isles Lupus Assessment Group (BILAG) registry. - Re Rituximab in the treatment pathway, the PWG noted that it proposed - and the Clinical Panel agreed - that Rituximab be used as a third-line treatment. - Re the stakeholder suggestion that the full list of exclusions be taken from the SPC, the PWG felt it to be regular practice for all clinicians to be aware of the SPC before prescribing a drug - Re the stakeholder comment that the trade name be used in patient records, the PWG said this was not regular clinical practice. Three minor amendments were made as a result of the comments provided.
How are stakeholders being kept informed of progress with policy development as a result of their input?	This engagement report, along with the updated policy proposition will be circulated as part of the public consultation. Stakeholders will be notified and invited to comment further.

What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	Public consultation for a period of 30 days as supported by stakeholders.