Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1817
Policy Title	Infliximab for neurosarcoidosis
Clinical Reference Group	Neurosciences
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: • Neurosciences and Rheumatology Clinical Reference Groups (CRG); and • Registered stakeholders for the CRGs. In addition, the CRG stakeholder list was reviewed to identify any missing key stakeholders. Sarcoidosis UK were identified and invited to take part in stakeholder testing.
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	Royal College of Physicians, British Psychological Society, British Society of Rehabilitation Medicine, the Royal College of Speech and Language Therapists and UKCPA Neurosciences Pharmacists Group were all included in stakeholder testing.
Which stakeholders have actually been involved?	Policy working group members (including a Patient Public Voice rep, representing Sarcoidosis UK) and CRG stakeholders.
Explain reason if there is any difference from previous question	None.

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?	No other stakeholder groups were identified.
How have stakeholders been involved? What engagement methods have been used?	Stakeholders have been involved in the policy working group. The draft policy proposition was distributed to stakeholders via email for a period of 2 weeks of stakeholder testing between 7th to 23rd August 2019, 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.
What has happened or changed as a result of their input?	Corrected Charity name There were 8 respondents including: 1 Charity, 6 individuals and 1 provider. Of the 8 responses received, 7 stakeholders actively supported the draft policy proposition. Respondents did not support the exclusion criteria for TB and HBV positive patients. However, it is felt that this is outside the scope of the current evidence review and policy and should be subject to a separate preliminary policy proposal so the evidence in the use of infliximab in these patient groups can be considered. In addition, one respondent raised concern based on anecdotal evidence that biosimilars are not as effective as the branded product. There is not yet enough reliable evidence to make a decision as to whether IFX is more effective (better tolerance and efficacy) than infliximab biosimilars, specifically in the population of patients that have progressive/ refractory neurosarcoidosis. Should further research be published in this area than the policy can be updated.
How are stakeholders	All stakeholders (including CRG members and registered stakeholders) will be notified when the draft policy proposition

being kept informed of progress with policy development as a result of their input?	goes out to public consultation and will be kept informed of the policy's progress through NHS England's consultation process and 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?	The CRG recommends public consultation for 30 days.