Engagement Report for Clinical Commissioning Policies

Unique Reference Number	F06X05
Policy Title	Intravenous immunoglobulin for acute disseminated encephalomyelitis and autoimmune encephalitis
Accountable Commissioner	Jane Pearson-Moore
Clinical Reference Group	Specialised Immunology and Allergy
Which stakeholders were contacted to be involved in policy development?	Specialised Immunology and Allergy CRG membership Specialised Immunology and Allergy CRG registered stakeholders Neuroscience CRG Association of British Neurologists (ABN) Royal College of Paediatrics and Child Health (RCPCH)
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 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. Eight responses were received in total: five from stakeholders, two from Specialised Immunology and Allergy CRG members, and one Neuroscience CRG member. Key response themes as follows: (1) None of the respondents supported a not routinely commissioned position, all feeling that IVIg was an important treatment option for these patients. (2) Respondents highlighted a range of unpublished evidence and ongoing studies. No missing published evidence was identified. PWG recognised the importance of ongoing trials as these could change the policy outcome when published. (3) Respondents highlighted that the next best alternative treatment of plasma exchange is not widely available, meaning that some patients will be left without access to any treatment, causing inequity of access and inequality of outcome. (4) Respondents pointed out that the proposed commissioning position represented a decommissioning of treatment, as IVIg is currently offered for these patients as a 'grey' indication, and challenged whether there was evidence of ineffectivenes to support this position (5) Additional stakeholders (Association of British Neurologists, Encephalitis Society, British Paediatric Neurology Association, Neurological Alliance, Autoimmune Encephalitis Alliance) have been identified to include in the public consultation. PWG noted that Association of British Neurologists and Autoimmune Encephalitis Alliance were engaged as part of stakeholder testing.
What has happened or changed as a result of their input?	Stakeholders were invited to comment. No updates were made to the policy proposition and evidence review. The issues raised regarding inequity and inequality were captured in the impact assessment and highlighted to the Programme of Care Board. The concerns about ongoing trials and decommissioning without evidence for ineffectiveness are being highlighted to the Programme of Care Board through this engagement report, and the Board cover paper. Additional identified stakeholders will be invited to the public consultation.
How are stakeholders being kept informed of progress with policy development as a result of their input?	This engagement report, along with the 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 the majority of stakeholders.