Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1625
Policy Title	Rituximab for anti-NMDAR autoimmune encephalitis (all ages)
Lead Commissioner	Penelope Gray
Clinical Reference Group	Paediatric Neurosciences
Which stakeholders were contacted to be involved in policy development?	Paediatric Neurosciences CRG members and registered stakeholders Adult Neurosciences CRG members and registered stakeholders Immunology and Allergy CRG members and registered stakeholders
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	Members of British Paediatric Neurology Association (BPNA) are on the paediatric neurosciences CRG President of BPNA was emailed as part of stakeholder testing Encephalitis Society are represented on the Policy Working Group
Which stakeholders have actually been involved?	Paediatric Neurosciences CRG member Paediatric Neuroscience Operational Delivery Networks, United Kingdom Clinical Pharmacy Association (Neurosciences Group) Public Health Medicine Consultant Paediatrician Barts Health NHS Trust Multiple Sclerosis and Neuroimmunology Group of the Association of British Neurologists St Georges University Hospital NHS Foundation Trust London,

	Royal College of Physicians
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 stakeholders been involved? What engagement methods have been used?	Stakeholder response form was sent via the women and children's email to identified CRG members and registered stakeholders with a 14 day response time. This is in line with the NHS England standard operating procedure for policy development
What has happened or changed as a result of their input?	Stakeholders were supportive of the policy and recommended a short consultation period as it could reasonably be expected to be broadly supported. <u>Summary of responses</u> 2 stakeholders raised queries about the place of intravenous immunoglobulin (IVIg) as first line treatment as set out in the policy and particularly how this was consistent with the NHS England position on first line treatment for IVIG for auto-immune encephalitis. In addition 1 stakeholder welcomed the proposal as it consolidates the place of IVIG and plasma exchange. They commented that it would also be useful to outline the place of cyclophosphamide. 1 stakeholder asked for clarity on the rationale for the criteria which means that patients must have failed or not responded to first line treatment by four weeks of treatment initiation as some patients may require more intensive support more rapidly. 1 stakeholder thought that for patients aged 18 years and younger, the infusion could be given in secondary care once initiated by tertiary care. 1 stakeholder asked to extend this policy please to apply to all antibody-mediated auto-immune encephalitis, not just NMDAR.

	1 stakeholder suggested the following amendments: • There should be some latitude around the changes in modified Rankin scale. For instance, if the mRS goes from 5 to 3 after the first-line treatment, the patient may well be considerably disabled and still benefit from rituximab. • We welcome the inclusion of paediatric patients, but note that, in practice, 16 and 17 year olds can be in Paediatric or Adult bed/clinics and some of the 17 year olds may turn 18 in a Paediatric bed/clinic. So, the text needs to recognise this. 1 stakeholder was disappointed that the position is restricted to anti-NMDAR autoimmune encephalitis with no provision detailed to incorporate Rasmussens encephalitis for example or any other autoimmune encephalitides where relapse/need for chronic treatment is much more common 1 stakeholder sought clarification regarding specifics of the time interval criterion between treatments detailed in the document. Individuals interpreted this differently suggesting some ambiguity in the wording. However, overall the content was interpreted that clinicians must decide 4 weeks after treatment initiation or 6 weeks after symptom onset i.e. this would be the earliest time point that rituximab treatment could be considered. Should this be the intended comprehension the timescales would appear as satisfactory. <u>What has changed as a result:</u> The policy working group has reviewed the proposed policy in light of the comments on first line immunotherapy. The scope of the policy is only to set out the commissioning position on the use of rituximab for second line treatment for anti- NMDAR auto-immune encephalitis. It is not intended to cover a wider treatment pathway for auto-immune encephalitis. The policy working group has therefore updated the patient pathway and removed references to first line immunotherapy to reflect this. It is not within the scope of this policy to comment on the place of cyclophosphamide in the treatment pathway. The policy working group have reviewed the evidence and made changes to the definition of the deterioration using the Modified Rankin Scale as a result of comments from stakeholder testing. The clinical evidence review and the practical requirements to deliver first line immunotherapy were considered when setting the criteria for rituximab to be used by four weeks of treatment initiation OR within six weeks of first symptoms. The policy working group consider that this is clear in the proposed policy and no changes have been made to this criterion in light of comments from stakeholder testing. The policy working group support rituximab being initiated and continued in a paediatric tertiary setting. No changes have been

	made the policy in light of comments from stakeholder testing. The policy proposition is based on available evidence for the use of rituximab for auto-immune encephalitis identified through the clinical evidence review. No new or additional evidence has been identified through stakeholder testing. Therefore no changes to the patient cohort or eligibility have been made in light of comments from stakeholder testing. The policy has been amended to reflect that patients aged 16-18 may be treated in a paediatric or adult setting.
How are stakeholders being kept informed of progress with policy development as a result of their input?	• Email confirmation to stakeholders who responded to let them inform them of changes to policy as a result of stakeholder testing • Paediatric Neurosciences CRG informed through regular CRG meetings
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	Four weeks