

Consultation Report

Topic details

Title of policy or policy statement:	Infliximab for refractory or progressive neurosarcoidosis (adults and post-pubescent children)
Programme of Care:	Trauma
Clinical Reference Group:	Neurosciences
URN:	1817

1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the policy proposition.

2. Background

Neurosarcoidosis is an uncommon but potentially serious manifestation of sarcoidosis, characterised by the presence of lumps caused by clusters of inflammatory cells. While the cranial nerves are most commonly affected, it can also affect other nervous system tissues such as the meninges, brain parenchyma, spinal cord, peripheral nerve and muscle. A specific subgroup of neurosarcoidosis involves the brain parenchyma, which can cause tissue destruction, and this is the group of patients who are likely to benefit from infliximab as it can prevent this tissue destruction.

Most patients with sarcoidosis do not require treatment and often make a full recovery. Around one third of people with sarcoidosis have more serious disease requiring treatment with steroids and drugs that suppress the immune system. In the group of patients with the invasive parenchymal form, these treatments have been shown to be ineffective.

This policy proposition considers whether infliximab should be added as a treatment for patients with neurosarcoidosis affecting the brain parenchyma in whom high dose steroids and other oral immunosuppressants have failed.

This policy proposition is for routine commissioning and has been subject to stakeholder testing and public consultation in line with standard methods.

3. Publication of consultation

The policy proposition was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 30 days from 1st November to 30th November 2019. Consultation comments have then been shared with the Policy Working Group to enable full consideration of feedback and to support a decision on whether any changes to the policy might be recommended.

Respondents were asked the following consultation questions:

- Has all the relevant evidence been taken into account?
- Does the impact assessment fairly reflect the likely activity, budget and service impact? If not, what is inaccurate?
- Does the policy proposition accurately describe the current patient pathway that patients experience? If not, what is different?
- Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that have been described?
- Are there any changes or additions you think need to be made to this document, and why?

4. Results of consultation

There were ten respondents to the public consultation – 5 from individual clinicians not responding on behalf of an organisation, 1 non-profit provider, 1 from the Association of British Neurology, 1 from the British Thoracic Society and one on behalf of an NHS hospital.

Each of these respondents fully supported the draft policy proposition. 3 of the respondents commented that access to this treatment would reduce inequality and health inequality.

One of the respondents commented that the impact assessment was excessive and too prescriptive.

5. How have consultation responses been considered?

Responses have been carefully considered and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity
- Level 2: Issue has already been considered by the CRG in its development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the CRG in its work programme and as part of the next iteration of the document
- Level 4: Falls outside of the scope of the specification and NHS England's direct commissioning responsibility.

One response was considered level 2. The rest of the comments were endorsing the proposition.

6. Has anything been changed in the policy as a result of the consultation?

There have been no changes as a result of the consultation. Respondents endorsed the policy.

7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final policy proposal?

There are no remaining concerns outstanding following the consultation.