

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1861
Policy Title	Ustekinumab for refractory Crohn's disease in pre-pubescent children
Clinical Reference Group	Paediatric Medicine
Which stakeholders were contacted to be involved in policy development?	<p>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:</p> <ul style="list-style-type: none"> • Clinical Reference Group (CRG); and • Registered stakeholders for the CRG. <p>After a review of the Clinical Reference Group Stakeholder List the following organisations were identified as 'missing' and were contacted and invited to take part in stakeholder testing: Crohn's and Colitis UK (CCUK), Circa, British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN), Royal College of Paediatrics and Child Health (RCPCH), ECCO and Janssen.</p>
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	BSPGHAN members are on the PWG and BSPGHAN and RCPCH were included in stakeholder testing.
Which stakeholders have actually been involved?	Policy working group members and CRG stakeholders. In addition, all the stakeholders identified 'missing' from the list (see above) were invited to take part in stakeholder testing.
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	None.

<p>yet to be engaged. Indicate why?</p>	
<p>How have stakeholders been involved? What engagement methods have been used?</p>	<p>Stakeholders have been involved in the policy working group.</p> <p>The draft policy proposition was distributed to stakeholders via email for a period of 2 weeks of stakeholder testing between 9th to 23rd August 2019, in preparation for public consultation.</p> <p>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. There were 6 respondents including: 1 professional societies, 1 Charity, 2 individuals and 2 providers.</p>
<p>What has happened or changed as a result of their input?</p>	<p>No changes have been made to the draft policy proposition as a result of stakeholder feedback.</p> <p>6 people/organisations responded. Out of the 6 responses received, 4 supported the proposal based on the evidence; however, one of the 4 respondents commented that whilst the evidence of its use in children is limited the reported study has been encouraging and would like to see NHS England commission the treatment.</p> <p>The respondents stated several papers which in their opinion supported a routine commissioning position. The papers have been reviewed by the Public Health Lead. The papers have either already been included in the evidence review or are deemed outside of the PICO. In addition, one further study was also suggested but is unpublished and therefore outside the parameters of the evidence review. However, the abstract was reviewed by the Public Health Lead and only 25% of the study population appear to be pre-pubescent. Therefore, it is not possible to ascertain what the outcomes were for pre-pubescent children or by disease severity.</p>
<p>How are stakeholders being kept informed of progress with policy development as a result of their input?</p>	<p>All stakeholders (including CRG members and registered stakeholders) will be notified when the draft policy proposition goes out to public consultation and will be kept informed of the policy's progress through NHS England's consultation process and portal website.</p>
<p>What level of wider public consultation is recommended by the</p>	<p>The CRG recommends public consultation for 30 days.</p>

CRG for the NPOC Board to agree as a result of stakeholder involvement?	
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