NICE National Institute for Health and Care Excellence

NHS England

Engagement Report for Specialised Commissioning Policies

Unique Reference Number and NICE ID	1745 ID009
Policy Title	Telotristat for treating carcinoid syndrome diarrhoea
Accountable Commissioner	Barry O'Neill
Clinical Lead	Martyn Caplin
Clinical Reference Group	Specialised Endocrinology
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: • Specialised Endocrinology Clinical Reference Group registered stakeholders
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	The following Royal Colleges and professional societies were invited to take part in stakeholder testing. British Society of Gastroenterology Royal College of Physicians The Pituitary Foundation Royal Association for Deaf people British Psychological Society Royal College of Radiologists Royal College of Surgeons
Which stakeholders have actually been involved?	3 responses were received from stakeholders, including 1 individual clinician. NET patient foundation (NPF) Ipsen Ltd
Explain reason if there is any	Not all organisations commented on the documents.

difference from previous question	
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, the main patient and carer representative organisations were involved throughout the development of the draft policy proposition
How have stakeholders been involved? What engagement methods have been used?	Policy working group meeting and subsequent contact for policy development The draft policy proposition was distributed to stakeholders via email for a period of two weeks of stakeholder testing, 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?	During the development of the policy, the policy working group expressed concern at the decision made by Clinical Panel to change the policy to not for routine commissioning. 1 letter was sent to NICE from the Clinical Lead, and 3 other letters from the company, NPF and UKINETS. All the letters urged the Clinical Panel to reconsider their decision. The letters were directed to NHS England who responded directly to the authors. During the stakeholder testing phase specifically, comments were submitted by 3 stakeholders and these have been reviewed by the policy working group. The comments referred to evidence that was not included in the original evidence review. No changes will be made to the evidence review document because this evidence was not available in a peer reviewed journal at the time of writing the clinical evidence review. However, it was noted that the additional evidence will be reviewed by the PHE lead and an additional evidence form completed to assess materiality.
How are stakeholders being kept informed of progress with policy development as	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 portal website

a result of their input?	
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	A 2 month consultation period has been suggested.