Engagement Report for Clinical Commissioning Policies

Unique Reference Number	A03X11
Policy Title	Pasireotide for acromegaly as third-line treatment (adults)
Accountable Commissioner	Debbie Hart
Clinical Reference Group	Specialised Endocrinology CRG
Which stakeholders were contacted to be involved in policy development?	All CRG members and registered stakeholders.
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?	CRG stakeholders identified one additional organisation not already contacted who will be invited to respond to the consultation: the Genetic Alliance.
How have the stakeholders been involved? What engagement methods have been used?	The draft policy proposition and evidence review was circulated to the full membership of the CRG and registered stakeholders 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. Five responses were received – two from pharmaceutical companies, one from a patient organisation, one from a pharmacist and one from a clinician. Two stakeholders supported the policy proposition and evidence review as currently drafted, three did not support a non-routine commissioning position. No new peer reviewed, published evidence was identified. The manufacturer identified a range of unpublished evidence they requested be taken into account and queried elements of the content of the evidence review summary. The manufacturer also raised concerns that NHS England had not followed its prioritisation framework and that it was not the correct authority to consider the balance of risks and benefits when considering clinical effectiveness. The patient organisation raised, through several case studies, the voice of the patient noting that those with uncontrolled acromegaly continue to experience the symptoms and co-morbidities of their condition which have a negative effect on their quality of life. It further noted that, without access to treatment, patients face an increased risk of mortality. The concerns raised regarding non-routine commissioning of pasireotide for acromegaly were: • Lack of choice for patients • Lack of application of the prioritisation framework (compared to Pasireotide for Cushing's disease) • No alternative treatment available for patients who have failed other treatments • A different decision by NHS England, compared with Wales and Scotland • Insufficient clinical debate about where this treatment should sit in the acromegaly pathway 4 out of 5 stakeholders supported a 30-day consultation period. The manufacturer requested 60 days.

What has happened or changed as a result of their input?	The PWG has considered the feedback received. • The points made regarding the application of the prioritisation framework were discounted, as the policy proposition has not yet been considered by CPAG. • The points made regarding unpublished evidence and alignment with Scotland and Wales were discounted as these are outside the remit of the policy development process. • The points made regarding consistency of application of process for this policy were discounted, as these are not relevant to the development of this policy proposition. • The points made regarding involvement of the wider clinical body were considered and have been addressed through stakeholder testing and plans for consultation. Two minor updates were made to the policy proposition: the evidence review and the policy statement.
How are stakeholders being kept informed of progress with policy development as a result of their input?	This engagement report, along with the updated 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 30 days, as supported by the majority of stakeholders.