Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1832 ID019
Policy Title	Mercaptamine hydrochloride for treating corneal cystine crystal deposits caused by cystinosis
Clinical Reference Group	Renal Services and Specialised Ear and Ophthalmology Clinical Reference Groups
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: • Clinical Reference Groups (CRG); and • Registered stakeholders for the CRGs
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	All of the relevant Royal Colleges and professional societies were invited to take part in stakeholder testing.
Which stakeholders have actually been involved?	Specialised Ear and Ophthalmology and Renal Services Clinical Reference Groups. 2 responses were received from stakeholders. This included a response from a patient organisation and a response from an individual clinician.
Explain reason if there is any difference from previous question	Not all organisations commented on the documents.
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	Policy working group meeting and subsequent contact for policy development.

involved? What engagement methods have been used?	2 patient groups were included as members of the PWG, Metabolic Support UK and Cystinosis Foundation UK. These patient groups were therefore able to input into the development of the policy proposition from the outset. Prior to the proposition being issued to stakeholders the Marketing authorisation holder Recordati Rare Diseases, (formerly Orphan Europe) met with the PWG and NICE and had the opportunity to discuss the evidence and subsequently were able to comment on the draft policy proposition. The draft policy proposition was distributed to CRG stakeholders via email for a period of three weeks of stakeholder testing. 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?	Responses were submitted by 2 registered stakeholders. However, the responses only indicated the desired level of consultation and no comments about the documents were received. No amendments were made to the documents as a result of stakeholder testing. Recordati Rare Diseases offered advice on the following and updates were made to the policy or impact reports: 1. Confirmation of patient numbers 2. Longer-term complications of cystine crystal deposits, i.e. corneal neovascularisation, various forms of keratopathies which leads to visual impairment 3. Access to homecare 4. Clarification of room temperature storage of product in contrast to the unlicensed eye drops which require refrigeration after each use
How are stakeholders being kept informed of progress with policy development as a result of their input?	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
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	2 respondents suggested up to 12 weeks consultation to include some additional proactive engagement activities during the live consultation period. However no further detail or suggestions were made on the issues for proactive engagement and the limited response suggests that a consultation of longer than 4 weeks is not required. It is therefore recommended at 4 weeks public consultation take place.