NICE National Institute for Health and Care Excellence

NHS England

Engagement Report for Specialised Commissioning Policies

Unique Reference Number and NICE ID	1696 ID004
Policy Title	Cholic acid and chenodeoxycholic acid for treating inborn errors in primary bile acid synthesis
Accountable Commissioner	Joan Ward
Clinical Lead	Richard Thompson
Clinical Reference Group	Metabolic
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: •.Metabolic CRG and registered stakeholders
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 are registered stakeholders of the Metabolic CRG.
Which stakeholders have actually been involved?	Metabolic CRG and registered stakeholders
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?	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?	There were 2 responses to stakeholder testing which have been reviewed by the policy working group. No changes were made as a result of the stakeholder comments received on the documents. Some comments did not require action (such as positive comments on the documents), and some comments were outside of the remit of the work (such as payment arrangements for lab tests). Comments of note included: • Comments on the lack of evidence for cholic acid as a *second* line treatment (no change made because this is as a result of the documents suggesting chenodeoxycholic acid should be tried first, before cholic acid) • Comments suggesting the effectiveness criteria should be consistent across all treatments (no change made because the treatments and the subpopulations can be associated with differing outcomes for patients. This therefore requires different effectiveness criteria). • Comments suggesting that effectiveness should be demonstrated by slowed progression of disease (no change made because the PWG considered that effectiveness should be measured by improvement or stabilisation of disease)
How are stakeholders being kept informed of progress with policy	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

development as 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 4 week consultation period was stated in the responses. .