

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1696
Policy Title	Cholic acid and chenodeoxycholic acid for treating inborn errors of bile acid synthesis (all ages)
Lead Commissioner	
Clinical Reference Group	Metabolic CRG
Which	Metabolic CRG and stake holders
Which stakeholders were contacted to be involved	Adult Neurosciences CRG
	Paediatric neurosciences CRG
	Hepatobiliary and Pancreas CRG
in policy development?	Paediatric Medicine CRG
development.	Royal College of Physicians
	Royal College Paediatrics and Child Health
	Children's Liver Disease Foundation
	British Liver Trust
	Metabolic Support UK
	British Inherited Metabolic Diseases Group
	Neonatal and Paediatric Pharmacists Group
	British Society for Paediatric Gastroenterology, Hepatology and Nutrition
Identify the relevant Royal	Royal College of Physicians
	Royal College Paediatrics and Child Health
College or Professional	British Inherited Metabolic Diseases Group
Society to the policy and	
	These organisations were contacted by email and asked to
indicate how they have been	respond
involved	

Which	British Inherited Metabolic Diseases Group
stakeholders have actually	Leadiant Biosciences
been involved?	
Explain reason if there is any 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?	
How have stakeholders been involved? What engagement methods have been used?	Stake holders were emailed a copy of the draft policy and evidence reviews and asked to comment.
What has happened or changed as a result of their input?	There have been no changes to the policy following stakeholder consultation.
How are stakeholders being kept informed of progress with policy development as a result of their input?	Stakeholders will receive an electronic response to the points they have raised.
What level of wider public consultation is recommended	One month

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