

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	170103P
Policy Title	Sapropterin for phenylketonuria
Accountable Commissioner	██████████
Clinical Reference Group	Metabolic
Which stakeholders were contacted to be involved in policy development?	<p>Metabolic CRG and registered stakeholders</p> <p>Paediatric Medicine CRG</p> <p>Paed Neurosciences CRG</p> <p>Royal College of Paediatrics and Child Health</p> <p>Royal College of Physicians</p> <p>Adult neurosciences CRG</p> <p>BIMDG</p> <p>Biomarin</p> <p>NSPKU</p> <p>PHED UP</p> <p>British Dietetic Association (BDA)</p> <p>Metabolic Support UK</p> <p>Genetic Alliance UK</p> <p>Association of British Neurology</p> <p>British Paediatric Neurology Association</p>
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	<p>Royal College of Physicians</p> <p>Royal College of Paediatrics' and Child Health</p> <p>These organisations were emailed and asked to comment on the draft policy proposition.</p>
Which stakeholders	NSPKU

<p>have actually been involved?</p>	<p>PHED UP PHED UP carer British Dietetic Association (BDA) Metabolic Support UK British Inherited Metabolic Diseases Group (BIMDG) Norfolk and Norwich Hospital NHS Trust Individual British Academy of Childhood Disability BioMarin Birmingham Women's and Children's NHS Foundation Trust. Women and Children's Programme of Care Board</p>
<p>Explain reason if there is any difference from previous question</p>	
<p>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?</p>	
<p>How have stakeholders been involved? What engagement methods have been used?</p>	<p>Stakeholders were emailed and asked to respond.</p>
<p>What has happened or changed as a result of their input?</p>	<p>More details about the diet were included. The eligibility criteria were revised to include genetic testing as the standard assessment.</p>
<p>How are stakeholders being kept informed of</p>	<p>Stakeholders will be emailed the response to their comments.</p>

progress with policy 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?	This is an interim policy and will not be subject to public consultation.