

## Engagement Report for Clinical Commissioning Policies

<b>Unique Reference Number</b>	1610
<b>Policy Title</b>	Trientine for Wilson disease
<b>Lead Commissioner</b>	Joan Ward
<b>Clinical Reference Group</b>	Metabolic Clinical Reference Group
Which stakeholders were contacted to be involved in policy development?	<ol style="list-style-type: none"> <li>1. Royal College of Physicians</li> <li>2. Royal College of paediatrics and child health</li> <li>3. Metabolic CRG and its registered stakeholders</li> <li>4. Adult neurosciences CRG and its registered stakeholders</li> <li>5. Paediatric medicine CRG and its registered stakeholders</li> <li>6. Hepatobiliary and pancreas CRG and its registered stakeholders</li> <li>7. British Association for the Study of the Liver</li> <li>8. British Society of Paediatric Gastroenterology, Hepatology and Nutrition</li> <li>9. Wilson Disease Support Group-UK(WSDG-UK)</li> <li>10. British Liver Trust</li> <li>11. British Inherited Metabolic Disease Group</li> <li>12. Association of British Neurology</li> <li>13. British Paediatric Neurology Association</li> <li>14. Rare disease UK</li> <li>15. Metabolic Support UK</li> <li>16. Genetic Alliance UK</li> <li>17. Institute of Psychiatry</li> <li>18. Royal College of Psychiatrists</li> </ol>
Identify the relevant Royal College or Professional	<p>Royal College of Physicians</p> <p>Royal College of Paediatrics and Child Health</p> <p>These organisations were contacted by email</p>

Society to the policy and indicate how they have been involved	
Which stakeholders have actually been involved?	<p>Responses were received from</p> <p>Royal College of Physicians</p> <p>British Society of Gastroenterology</p> <p>Association of British Neurologists</p> <p>Member of Metabolic CRG</p> <p>Paediatric Medicine Clinical Reference Group</p> <p>British Association for the Study of the Liver</p> <p>Wilson Disease Support Group-UK</p>
Explain reason if there is any difference from previous question	<p>The Royal College of Physicians forwarded the stakeholder consultation to the British Society of Gastroenterology.</p> <p>There were no other responses than those listed above.</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?	
How have stakeholders been involved? What engagement methods have been used?	Stakeholders were emailed and asked to respond by this method
What has happened or changed as a result of their input?	There have been no changes to the policy
How are stakeholders	Stakeholders will be emailed and advised of the Policy Working Group responses

being kept informed of 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?	4 weeks