

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	170094P
Policy Title	Trientine for Wilson disease
Lead Commissioner	██████████
Clinical Reference Group	Metabolic Clinical Reference Group
Which stakeholders were contacted to be involved in policy development?	<ol style="list-style-type: none"> 1. Royal College of Physicians 2. Royal College of paediatrics and child health 3. Metabolic CRG and its registered stakeholders 4. Adult neurosciences CRG and its registered stakeholders 5. Paediatric medicine CRG and its registered stakeholders 6. Hepatobiliary and pancreas CRG and its registered stakeholders 7. British Association for the Study of the Liver 8. British Society of Paediatric Gastroenterology, Hepatology and Nutrition 9. Wilson Disease Association 10. British Liver Trust 11. British Inherited Metabolic Disease Group 12. Association of British Neurology 13. British Paediatric Neurology Association 14. Rare disease UK 15. Metabolic Support UK 16. Genetic Alliance UK 17. Institute of Psychiatry 18. Royal College of Psychiatrists
Identify the relevant Royal College or Professional Society to the policy and indicate how	<p>Royal College of Physicians Royal College of Paediatrics and Child Health These organisations were contacted by email</p>

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>
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 being kept informed of progress with	Stakeholders will be emailed and advised of the Policy Working Group responses

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