

Appendix One – Stakeholder/CRG Feedback

	Organisation Responding	Feedback Received	PWG response	Resulting Action
1	Royal College of Physicians	The Royal College of Physicians supported the comments made below by the British Society of Gastroenterology	NA	No change to the policy is required
2	British Society of Gastroenterology	<p>We didn't receive any feedback or comments from the Liver Section committee members.</p> <p>My only concern (mentioned below) related to Section 9: "As part of this policy proposition, specialist centres will be recognised based upon the availability of Consultant expertise in Wilson disease, hepatological, neurological (movement disorder expertise) and metabolic disorders."</p> <p>There are currently no formally accredited Wilson's Disease centres. It is not made explicit how specialist prescribing centres will be selected – particularly if expertise in Wilson's Disease is listed distinctly from hepatological expertise as the sentence currently reads.</p> <p>Do they envisage a</p>	<p>PWG understands that a proposal will be made to NHS England to develop a service specification for Wilson Disease.</p> <p>There is no</p>	No change to the policy is required

		<p>minimum number of Wilson's cases per site? Or would there be a formal procurement exercise for sites to be selected against a published service specification?</p>	<p>intention to undertake a formal provider selection process at this time, centres that meet the criteria set out in the policy will be identified as part of the commissioning plan for this policy</p>	
3	Chair of Paediatric Medicine Clinical reference Group	<p>There is a BASL (British Association of the Study of the Liver) paediatric working group reviewing this drug in Wilson disease with who I am in contact.</p> <p>Can I ensure the children's representatives on this WG have seen this please?</p>	<p>BASL have confirmed that they are happy with the draft policy and that this includes the paediatric aspects.</p> <p>The PWG has paediatric representation and its membership overlaps BASL</p>	No change to the policy is required
4	Association of British Neurologists	<p>There is an unresolved issue regarding the best treatment choice for patients who are deteriorating neurologically while on treatment with penicillamine or trientine. There is limited / controversial evidence for the use of zinc in this setting.</p> <p>However, we note that all 3 treatments are recommended by NICE, so this gives options for this scenario</p>	<p>The PWG are cognisant of the complexities of treating this cohort of patients and the limited evidence in relation to the use of zinc.</p> <p>NICE have not made any formal recommendations in relation to Wilson disease. NICE undertook the evidence</p>	No change to the policy is required

			reviews for this policy on behalf of NHS England. The proposed policy is based on the evidence.	
5	Member of Metabolic Clinical Reference Group	Supported the 4 week consultation period	Noted	No change to the policy is required
6	British Association for the Study of the Liver	BASL welcomes and fully endorses the draft policy. We have no further comments to add.	Noted	No change to the policy is required
7	Wilson Disease Support Group-UK	Wilson Disease Support Group-UK endorse this policy	Noted	No change to the policy is required