

Stakeholder Engagement Report for Service Specifications

Reference	E09/S(HSS)/tba Specification
Title	Service specification for a new model of service for Rare Hereditary Neuropathies for children and young people
Accountable Commissioner	Bernie Stocks
Lead Clinical Reference Group	Paediatric Neurosciences
Collaborating Clinical Reference Groups	

Which stakeholders were contacted to be involved in the specification development?	<p>Key leads from the Paediatric Neurosciences Clinical Reference Group (CRG), and a Policy Working Group consisting of clinical leads from a number of trusts in England.</p> <p>Stakeholder engagement involved the document being shared with the Strategic Clinical Networks, the registered stakeholder of the Paediatric Neurosciences CRG, and with the following stakeholder organisations: Save Babies UK, Climb, CMT United Kingdom, Muscular Dystrophy UK, the MS Trust and the National Muscular Sclerosis Society.</p>
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<p>Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved</p>	<p>A member of the British Paediatric Neurology Association supported the development of the specification.</p>
<p>Which stakeholders have actually been involved? State reason for any difference from previous questions</p>	<p>Key leads from the Paediatric Neurosciences Clinical Reference Group (CRG) and the Policy Working Group.</p>
<p>Identify any particular stakeholder organisations that may be key to the specification development that have been difficult to engage. Indicate why they have been difficult to engage</p>	<p>The key stakeholder organisations have commented.</p>
<p>How have the stakeholders been involved? What engagement methods have been used?</p>	
<p>The draft specification was shared with the Paediatric Neurosciences CRG and in November 2015, the specification for the new model of care was circulated to stakeholders for comment to determine whether any amendments were required on the basis of stakeholder opinion.</p> <p>There was one response, which was from the [x] clinical laboratory service enquiring about any proposed changes to the existing local clinical laboratory services - no changes are proposed. Rather, the RHN service will add value to the current patient pathway by interpreting test results and creating a bespoke treatment package for patients, some of which can be delivered locally if this is appropriate to the severity of the child.</p>	
<p>What has happened or changed as a result of their input?</p>	<p>The response was considered by the members of the CRG Policy Working Group and this issue was clarified in the specification.</p>

<p>How have stakeholders been informed of progress with the specification development as a result of their input?</p>	<p>This engagement report, along with the updated policy proposition will be circulated as part of the public consultation. Stakeholders will be notified and invited to comment further.</p>
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<p>What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?</p>	<p>Public consultation for a period of 30 days.</p>
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FOR PUBLIC CONSULTATION ONLY