

Engagement Report for Service Specifications

Unique Reference Number	1662
Policy Title	Inherited White Matter Disorders Diagnostic and Management Service (IWMD) (All Ages)
Accountable Commissioner	
Clinical Reference Group	Paediatric Neurosciences
Which stakeholders were contacted to be involved in service specification development?	<ul style="list-style-type: none"> • Paediatric Neurosciences Clinical Reference Group (CRG) Members and Stakeholders • Adult Neurosciences CRG - Members and Stakeholders • Metabolic CRG Members and Stakeholder • Paediatric Neurosciences Spina Bifida Specification Working Group; • British Society for Neuroradiology • Metabolic Support UK (for Children Living with Metabolic Disease (was CLIMB) • Krabbe UK disease support group (was Saving Babies UK) • UK LSD Collaborative group • Cats Foundation • MLD Family Association • The MPS Society • Alex the Leukodystrophy Charity • British Inherited Metabolic Disease Group • British Dietetic Association • Royal College of Nursing • British Paediatric Neurosciences Association (BPNA) • Association of British Neurologists (ABN)

<p>Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved</p>	<ul style="list-style-type: none"> • British Paediatric Neurosciences Association • Association of British Neurologists <p>The BPNA is represented on the Specification Working Group and members of the BPNA have been involved by successive Presidents of the association since NHS England started work on this specification.</p> <p>Both the BPNA and the ABN were involved recently in considering and approving the proposal to extend the age scope of the specification from children only to all ages. To support this, they were sent the draft specification and the proposal to change the service to includes adults from the adult neurologists at [x] provider to extend the age range covered by the specification.</p> <p>Both the BPNA and the ABN received the specification as part of stakeholder testing.</p> <p>Stakeholder testing took place in September 2018.</p>
<p>Which stakeholders have actually been involved?</p>	<p>Seven responses were received in total from:</p> <ul style="list-style-type: none"> • Private individual 1. • Clinician, x provider. • Private individual 2. • Private individual 3. • Member of the Association of British Neurologists, (ABN) Neurogenetics Advisory Group. • Senior member of the British Paediatric Neurosciences Association. • Stakeholder Group member.
<p>Explain reason if there is any difference from previous question</p>	<p>Some consultees did not response to the consultation invite.</p>
<p>Identify any particular stakeholder organisations that may be key to the specification development that you have approached that have yet to be engaged. Indicate why?</p>	<p>Not applicable (N/A)</p>

<p>How have stakeholders been involved? What engagement methods have been used?</p>	<p>There are representatives from the Paediatric Neurosciences CRG, Adult Neurosciences CRG, Metabolic CRG, the BPNA and a number of stakeholder groups on the Specification Working Group.</p>
<p>What has happened or changed as a result of their input?</p>	<p>Comments were collated into a draft report, circulated to and considered by the members of the NHS England Paediatric Neurosciences IWMD Specification Working Group ‘the SWG’, including NHS England commissioners.</p> <p>A number of additions and changes have been made to the specification as part of an iterative development process as follows:</p> <ol style="list-style-type: none"> 1. One of the responses suggested that the SWG should seek to understand the successes and lessons learned from establishing the referral and communication route between referring and receiving units for the Children’s Epilepsy Specialised Service (CESS). A teleconference was convened with a CESS receiving unit clinical lead who had set up the service in that unit and members of the IWMD SWG to share learning. As a result, a number of key principles were established for how the IWMD service should engage with referrers and all key partners in the system who manage IWMD patient care, including district general hospitals, tertiary neurology units and the IWMD Lead Centres. New wording was added to the specification which includes the following: ‘Each patient who is discussed by the virtual or face to face MDT will/should have a named clinician in all key parts of their network of care so that all are aware of the patient’s referral, diagnosis and care plan’. 2. A teleconference also took place between the Clinical Co-Chair of the NHS England Women and Children Programme of Care (PoC) Board and the SWG regarding: networked communication with referrers and providers in all key parts of the care pathway; ensuring that the service adds value and does not increase cost unnecessarily, such as repeating tests; that there should be a clear education and training role for service providers with all key parts of the system and that service providers should set out clear referral pathways and guidelines. 3. A follow-on phone call also took place with a representative from the stakeholder group Metabolic Support UK (MSUK)

	<p>who is a member of the specification working group, and it was agreed to add the following wording to the specification: 'the IWMD Lead Centre diagnosing specialist will signpost patients and their families/carers to relevant support groups and provide information on the patient's condition'.</p>
<p>How are stakeholders being kept informed of progress with specification development as a result of their input?</p>	<p>Outcomes will be shared with all as part of the public consultation.</p>
<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>As five of the stakeholders considered six weeks to be appropriate, and one recommended 12 weeks, the W&C PoC Board will be asked to determine the length of public consultation that should be undertaken.</p>