

Engagement Report for Service Specifications	
<b>Unique Reference Number</b>	1643 1641
<b>Specification Title</b>	Small bowel transplantation service (Paediatrics) Small bowel transplantation service (Adults)
<b>Lead Commissioner</b>	Sarah Watson
<b>Clinical Reference Group</b>	Paediatric Medicine CRG Hepatobiliary and Pancreas CRG
Which stakeholders were contacted to be involved in service specification development?	Members of the Paediatric Medicine CRG and its stakeholders Members of the Hepatobiliary CRG and its stakeholders  NHS BT's Multi-visceral and Composite Tissue Advisory Group
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved	The Royal College of Physicians has commented on the service specification
Which stakeholders have actually been involved?	As above
Explain reason if there is any difference from previous question	Not applicable
Identify any particular stakeholder organisations	NHS BT as commissioners of organ donation and allocation services.

that may be key to the specification development that you have approached that have yet to be engaged. Indicate why?	
How have stakeholders been involved? What engagement methods have been used?	Discussion and circulation of the specification for comment and consideration at expert meetings.
What has happened or changed as a result of their input?	<p>CRG members have either made changes to the specification to reflect the comments and suggestions proposed or responded to the stakeholders to answer specific questions or comment further.</p> <p>The original specification was written some time ago so there was some updating of references and data. From the patient groups there was a greater drawing out of issues focussing on patient experience.</p> <p>The service specification describes the service broadly as published by the NSCT prior to April 2013 with a greater focus on outcomes not related to mortality, the ongoing management of patients and the arrangement for transition from paediatric services to adult services. When the specifications were first written transition services were not needed.</p>
How are stakeholders being kept informed of progress with specification development as a result of their input?	The Multi-visceral and Composite Tissue Advisory Group take the issue as an agenda item. Otherwise communication is mostly through email. Some phone calls have been held with the provider units.
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 public consultation in line with the recommended level of consultation for all HSS.

## Stakeholder/CRG Feedback



Organisation Responding	Feedback Received	SWG response	Resulting Action
Paediatric CRG member	<p>I have focussed on the paediatric specification which looks like a well written document. With respect to transition I would suggest that patients and families should have the opportunity to meet a clinician from the adult team in a supported manner prior to transfer and this need to be clear in both adult and paediatric documents.</p> <p>To meet the key outcome targets the team needs a professional with appropriate training and expertise (from social work or similar background) to be able to address requirements of the common assessment framework. Many families will require this support because of the serious impact of caring for a child with intestinal failure on parent's ability to work and to care for other children especially when care is provided at a long distance from home.</p> <p>While this work can be undertaken by specialist nurses in my experience it is much more effectively and cost effectively done by someone with a family support or social care training.</p>	<p>Agreed</p> <p>The specification includes the statement that <i>the routes to access social services and other support services will be offered to those patients requiring them</i></p> <p>We recognise that such support is important for patients and families but stating a more explicit requirement is outside of the scope of the specification</p>	<p>Added in clarity about this requirement in both specifications (P3)</p> <p>No action</p>
Paediatric CRG member	The specification alludes only to cover a surgical assessment	The pathway covers both and the specification is certainly intended to cover a multidisciplinary patient assessment.	The wording under the assessment paragraph has been changed to balance the focus on medical and surgical patient management

<p>Alder Hey Children's NHS Foundation Trust</p>	<p>It talks about how the management of the patient's immunosuppression will be by the transplant centre. Is it worth highlighting that this may well be the case but information needs to be shared with the referrer +/- the child's DGH in case they are admitted there? Sometimes it can be difficult to establish what the regimen/monitoring requirements are because we don't have access to information from the transplant centre. Maybe too much detail to include in the scope of this document?</p> <p>The section 'Key Service Outcomes' states: All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work, play specialists and CAMHS services within nationally defined access standards.</p> <p>Where are the pharmacists in this list?</p> <p>Later in the same section it talks in more detail about medicines management for this group - but actually this reads like it is a standard rather than a specialist (i.e. paediatric gastro) pharmacy service.</p> <p>All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:</p> <ul style="list-style-type: none"> <li>• ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability</li> <li>• ensure that staff handling medicines have the competency and skills needed for children and young people's medicines management</li> <li>• ensure that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.</li> </ul>	<p>The specification states that <i>The provider is required to copy all correspondence with patients and between consultants to the patient's GP.</i></p> <p>This list is included in NHS England's standard agreed <i>Provision of services to children</i> specification appendix and if not subject to edit as part of this process</p> <p>A paediatric pharmacist would be a member of the nutritional care team in experienced IF/Rehabilitation/Intestinal transplant centre.</p> <p>This list is included in NHS England's standard agreed Provision of services to children specification appendix and if not subject to edit as part of this process</p>	<p>The specification has been edited to include and clarify this requirement</p> <p>No changes made</p> <p>Added in nutritional care team to extended MDT membership</p> <p>No changes made</p>
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Royal College of Physicians	This is an appropriate set of specifications that are already being met through the national referral system to the 2 adult centres. SO the answer is Yes but we cannot comment for paediatrics.	Noted	No changes made
Consultant Oxford University Hospitals NHS Trust	Comments on adult spec only:  page.3, para 2: Humoral rejection is not well defined page 6, para 6, final word "intestine"- Patients with intestinal failure with a poor quality of life on parenteral nutrition.	Additional paragraph on humoral rejection added to both adult and paediatric service specificaitons.  Patients with irreversible intestinal failure are included in the eligible patient population.	No changes made to the specification  No changes made to the specification