

**CLINICAL PRIORITIES ADVISORY GROUP  
06 and 07 November 2018**

<b>Agenda Item No</b>	
<b>National Programme</b>	Internal Medicine and Women and Children's
<b>Clinical Reference Group</b>	Hepatobiliary and Pancreas / Paediatric Medicine
<b>URN</b>	170096S / 170097S

Title (Insert Service Specification title in full)	
Small bowel transplantation service (adults) Small bowel transplantation service (paediatrics)	
<b>Actions Requested</b>	1. Support the adoption of the service specification propositions
	2. Consider their relative priority

Proposition
To recommend the adoption of the revised service specifications for the paediatric and adult small bowel highly specialised services. The specifications include amendments to clarify the transition pathway between the paediatric and adult services. When the service was first started transition between the centres was not a consideration. The other change of note in the specifications is clarification of the responsibility for long term follow up and management of patients.

Clinical Panel recommendation
Not Applicable

The committee is asked to receive the following assurance:	
1.	The Head of Clinical Effectiveness confirms the proposals have completed the appropriate sequence of governance steps and includes where necessary an: Evidence Review; Clinical Panel Report.
2.	The Head of Acute Programmes confirms the proposals are supported by an: Impact Assessment; Stakeholder Engagement Report; Consultation Report; Equality Impact and Assessment Report; Service Specification Proposition. The relevant National Programme of Care Board has approved these reports.
3.	The Director of Finance (Specialised Commissioning) confirms that the impact assessment has reasonably estimated a) the incremental cost and b) the budget impact of the proposal.
4.	The Operational Delivery Director (Specialised Commissioning) confirms that the service and operational impacts have been completed.

5.	The Director of Nursing (Specialised Commissioning) confirms that the proposed quality indicators have been adequately defined.
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<b>The following documents are included (others available on request):</b>
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1.	Service Specification Propositions
2.	Consultation Report
3.	Evidence Summary - Not Applicable
4.	Clinical Panel Report - Not Applicable
5.	Equality Impact and Assessment Report

<b>The Benefits of the Proposition</b>
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No	Metric	Summary of benefit (where applicable)
1.	Survival	
2.	Progression free survival	
3.	Mobility	
4.	Self-care	
5.	Usual activities	
6.	Pain	
7.	Anxiety / Depression	
8.	Replacement of more toxic treatment	
9.	Dependency on care giver / supporting independence	
10.	Safety	
11.	Delivery of intervention	

<b>Considerations from review by the Rare Disease Advisory Group (RDAG)</b>
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RDAG supported the service specification for the small bowel transplantation service (adults).
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**Pharmaceutical considerations**

Not applicable.

**Considerations from review by National Programme of Care****PoC Board support:**

The proposal was discussed with the Women and Children's and Internal Medicine Programme of Care Boards in September 2018 and was signed off virtually on 5<sup>th</sup> October 2018.

**Benefit of Service Specification:**

The service specifications describe the service as currently provided plus updates to reflect the NHS England policy on ongoing immunosuppression.

The intervention is delivered in one of the four designated specialist centres for intestinal transplantation in the UK. Services are subject to continuous cumulative sum control chart quality monitoring.

Extracts from NHS Blood and Transplant (NHSBT) data, routinely collected from transplant units shows that the majority of adult patients return to self-caring status, and children to educational activities, whilst requiring regular medical follow-up.

Pain management is a key issue in many adult patients with intestinal failure, and progressive reduction of pain medication is a postoperative challenge, often requiring careful management over an extended period.

The replacement of long-term parenteral nutrition with intestinal transplantation is associated with improvement in quality of life and a reduction in the complications associated with parenteral nutrition, including recurrent IV line sepsis, thrombosis of major veins and cholestatic liver disease.

The service when established was funded to provide 1 year follow up for patients. The specification changes that responsibility to be clear the paediatric transplant centres need to support transition to an adult service and all should have lifelong clinical responsibility for patient management. The specifications detail the requirements to ensure patients follow a planned transition pathway. These transition pathways have been developed in the last 2 years supported by funding from Specialised Commissioning.

**Implementation timescale:**

There are amendments to trust data flows and contracts which could be implemented with the appropriate transfer of resources by April 2019.