

Consultation Report

Topic details

Title of policy or policy statement:	Small bowel transplantation service (Children and Adults)
Programme of Care:	Internal Medicine
Clinical Reference Group:	Paediatric Medicine and Hepatobiliary and Pancreas
URN:	170096S & 170097S

1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the revised service specifications for the national small bowel transplantation service.

2. Background

Intestinal transplantation is an established therapeutic modality in the management of adult patients with irreversible intestinal failure. It is performed in patients with short bowel syndrome, with multivisceral (several abdominal organs) transplantation reserved for those patients who develop cholestatic liver disease (where bile cannot flow from the liver to the small intestine) from total parenteral nutrition. Primary indications for intestinal transplant include depletion of central venous access sites, multiple episodes of catheter related sepsis, electrolyte disturbance, dehydration, and progressive cholestatic liver failure. Additional indications for intestinal and multivisceral transplant include diffuse porto-mesenteric thrombosis (a blood clot in one of the veins that drains blood from the intestine), malignancies limited to the abdominal compartment, and congenital motility disorders of the intestine.

In children, transplantation should be routinely considered for patients with life threatening complications of bowel (intestinal) failure which may be caused by one of the following conditions:

1. Short bowel syndrome (which occurs after previous bowel operations in which a large amount of bowel has had to be removed) such as gastroschisis (intestines that extend outside of the body), volvulus (twisted intestine) and necrotising enterocolitis (where portions of the bowel tissue die).
2. Motility disorders such as Hirschsprung's disease and intestinal pseudo-obstruction.

3. Mucosal disorders (defective inner lining of the bowel) such as microvillus inclusion disease (causes severe dehydration), and tufting enteropathy (causes life-threatening diarrhoea).

The small bowel and multivisceral transplant service was established in the UK in the early 1990s. The service provides care to patients who either may require or who have received a small bowel transplant. The service is commissioned to provide a comprehensive assessment, transplantation and follow up service to eligible patients who are fit enough to undergo the procedure.

The change to these service specifications clarified the services' responsibility for long term follow up of patients and ensuring appropriate transition of patients from the paediatric services to the adult transplant units. The specifications contained some outdated information so this has been updated. The currently published paediatric specification replicates most of the adult specification and offers little specific information relevant to the paediatric programme. The specifications have been rewritten and should be considered together to ensure consistency whilst providing information specific to the services provided for children and adults.

The service aims to improve the quality and length of life of patients undergoing small bowel or multivisceral transplantation and to ensure outcomes for patients are comparable to the best centres internationally. The number of transplants has fluctuated since the programme was established with up to ■ adult transplants and approximately ■ paediatric transplants carried out each year. Most years there are fewer than 30 patients on the adult and paediatric waiting lists.

3. Publication of consultation

The policy was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 30 days from 23rd August 2018 to 21st September 2018. Consultation comments have then been shared with the Specification Working Group to enable full consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

Respondents were asked the following consultation questions:

- Has all the relevant evidence been taken into account?
- Does the impact assessment fairly reflect the likely activity, budget and service impact? If not, what is inaccurate?
- Does the proposition accurately describe the current patient pathway that patients experience? If not, what is different?
- Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that have been described?
- Are there any changes or additions you think need to be made to this document, and why?

4. Results of consultation

There were two responses to the public consultation, [REDACTED]. Both responses were positive in answering each question in the consultation.

All respondents responded that:

- all relevant evidence had been taken into account in developing the service specifications,
- that the impact assessment fairly reflected the likely activity, budget and service impact to be expected,
- that the service specifications accurately describe the current patient pathway that patients experience,
- there was no potential impact on equality and health inequalities which might arise as a result of the service specifications.

5. How have consultation responses been considered?

Responses have been carefully considered and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity
- Level 2: Issue has already been considered by the CRG in its development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the CRG in its work programme and as part of the next iteration of the document
- Level 4: Falls outside of the scope of the specification and NHS England's direct commissioning responsibility

All responses were noted and none fell into the categories set out.

6. Has anything been changed in the service specification as a result of the consultation?

No.

7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification proposition?

No.