NHS England

Engagement Report for Service Specifications

Unique Reference Number	1708
Specification Title	Intestinal Failure (Adults)
Lead Commissioner	Andy Hughes
Clinical Reference Group	Specialised Colorectal
Which stakeholders were contacted to be involved in service specification development?	Patient Organisations, patients, providers, commissioners and 195 members of the Specialised Colorectal Clinical Reference Group (CRG) Stakeholder Group
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved	The following groups are represented on the CRG and have been fully engaged in the development of the service specification: British Association of Parenteral and Enteral Nutrition (BAPEN) British Pharmaceutical Nutrition Group (BPNG) British Intestinal Failure Alliance (BIFA) National Nurses Nutrition Group (NNNG) The Parenteral & Enteral Nutrition Group (PENG)

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Which stakeholders have actually been involved?	Patients on Intravenous and Naso-gastric Nutrition Therapy (PINNT) 22 patients participated in two focus groups held at the national centres and 96 people responded to a subsequent patient survey which picked up on key themes from focus groups. In addition, around 200 colleagues attended four regional clinical workshops. This included clinical & managerial professionals from 15 providers across London, 16 providers in the North, 17 providers in the South and 16 providers in the Midlands and East. Moreover, 10 commissioners from the 4 regions participated.
Explain reason if there is any difference from previous question	Not applicable
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?	No particular stakeholder groups have been identified as difficult to engage with.
How have stakeholders been involved? What engagement methods have been used?	Patient Voice representatives are included on keys working groups and have supported activities to engage with patients. The engagement methods are a Clinical Working Group, Provider, Commissioner and patient focus groups and a patient survey (online & telephone). In addition, updates and newsletters have been sent to the CRG members and the CRG stakeholder group.
What has happened or changed as a result of their input?	Need to sum up the changes to the service spec once completed by TB and GC
How are stakeholders	Regular updates are sent out to the IF review Working Groups and CRG stakeholders. We have heavily promoted stakeholder registration, and the number of registered stakeholders has

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being kept informed of progress with specification development as a result of their input?	doubled over the past three months.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	The CRG recommends a 30 day consultation for the service specification. This is prior to the formal consultation that will take place relating to the next phase of market analysis and agreeing a procurement intervention.

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Stakeholder/CRG Feedback

Organisation Responding	Feedback Received	SWG response	Resulting Action
Stakeholder workshops	Ensure that network-based relationship between providers is an essential key element of the future commissioned model of IF services	Agree – will strengthen this element	Additional paragraph added in to Section 2 entitled "Networks of Care"
Stakeholder workshops	Consider if the IF surgical procedures needs to be counted per surgeon or per unit and the minimum numbers of long term HPN patients for HPN Centres. Establish clear evidence base on how the recommended minimum number of HPN and IF surgical procedures were identified	The Clinical Working Group considered counting the procedure by surgeon; however, as most IF surgical cases are complex the norm is for 2 surgeons undertake them. Consequently, the group decided that a minimum per centre was more appropriate and also consistent	No amendments to Specification

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		with published national guidance (ASGBI 2010) . A minimum for long term HPN patients is already included in Annex A2 serial D2. There is currently no specific clear evidence for the minimum numbers for IF; however, there is evidence that frequency and volumes improves outcomes. The current numbers were set on clinical consensus. Going forward this will be reviewed using the IF registry outcomes data when complications and surgical outcomes at all units will be measured consistently	
Stakeholder workshops	Consider if HPN or Integrated Centres can be provided by a network of providers rather than	Commissioners will consider any	No amendments to Specification

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	individual providers with co-located services	viable proposal for networking. The Specification describes the principles of network arrangements.	
Stakeholder workshops	Consider how HPN needs of palliative care patients will be managed by HPN/Integrated centres. Will they be managed in IF Centre or in DGHs with outreach or remote consultation/input from a specialist IF centre	Management will either be at an Integrated or Home PN Centre or a facilitated remote discharge. Responsibility remains with the Integrated/Home PN Centre	Added sentence to the relevant palliative care bullet point in section 2
Stakeholder workshops	Tariff and appropriate future coding and funding needs to be an integral part of the review	This is not the remit of the Service Specification; however, this is a key workstream within the wider service review. The outputs will be confirmed in the prior to the procurement phase	No amendments to Specification
Stakeholder workshops	Consider the question regarding support to develop inspiring new centres particularly in the areas where	Agree that this process should	A comment has been added to

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	there are gaps in the service provision, unmet population needs or difficult geography	allow for new or existing centres to develop expertise. This would need to be within the network arrangements	the network paragraph already added (see above)
Stakeholder workshops	To include DGHs/ hospitals non-commissioned for IF centres into the commissioned model of care and the requirements to support patients in DGHs, provide fast access to specialist expertise and provide outreach service in DGHs into the Service Specification and the final commissioned model of care.	. The service specification describes the core model of IF and PN services. Providers can consider network arrangements that suit local needs	Already accounted for in network comments already made
Stakeholder workshops	There should be allowance made for patient choice and clinical needs to enable patient to be referred outside of the usual network of providers with equal degree of efficiency. Model should allow for patients to be referred to a different HPN/ Integrated IF Centre unit outside of the hub/spoke.	Agree. Once IF centres are designated patients can be referred to any designated centre. The location of treatment long term would need to take account of the host centres ability to support that if it is not within its network.	Sentence added to Section 2
Stakeholder workshops	A more blended network model of care delivery and referrals should be considered for some of the areas	Commissioners	No amendments made to

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	and shared with other areas who may then also wish to consider it.	will consider different network models as long as they can demonstrate deliver of the service specification.	Specification
Stakeholder workshops	Consider networks spanning across more than one commissioning geography, particularly in the South East and London.	This consultation is prior to the formal procurement intervention which will describe the areas to be served	Already referenced in network additions
Stakeholder workshops	Consider if the IF network will need to fit into STP boundaries	STP footprints are designed to cover an agreed commissioning area linked to multiple Local Authority and CCG commissioning responsibilities for a large number of services. IF networks will not necessarily coincide with these footprints.	No amendments made to Specification
Stakeholder	Consider if we can direct ambulances to take patient	Given the rarity of	No amendments

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workshops	to the right centre the first time rather than going from centre to centre- like it is done in trauma networks	emergency IF admissions where the patient is unable to get him/herself to hospital by their own transport, this is not required.	made to Specification
Stakeholder workshops	Consider specifying and developing external networking linkages eg transplant centres and small bowel centres.	Do not recognise the entity of "small bowel centres". Transplantation and linkages with transplant centres is already included in the Specification	No amendments made to Specification
Stakeholder workshops	To consider development and implementing appropriate standards and training to meet the training needs	Agree. However, this is a work stream to be considered in the future.	No amendments made to Specification
Stakeholder workshops	To develop a proposal for a timeline for providers to become compliant with the standards that enables them to work towards the more ambitious goals at a realistic pace.	Agree in principle but detail will be part of the procurement intervention phase	Added sentence in Section 4.2
Stakeholder workshops	To develop criteria for outreach services and consider how to best incorporate into the service specification	This is part of the network issues already addressed	No amendments made to Specification
Stakeholder workshops	Consider practical proposal on centralised referral system management for each of the network and for standardising the referral documentation, clinical	The matter of centralised referral management	No amendments made to Specification

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	information and requirements across the country.	within each network will be for the individual networks to organise after commissioning. With regard for nationwide documentation, protocols etc, the CWG agrees that this is important and will need to be considered in due course.	
Stakeholder workshops	Consider specifying framework/process for patient repatriation developed with the clinical and public health input.	This is dealt with adequately in the Specification. The CWG does not feel additional detail is required	No amendments made to Specification
Stakeholder workshops	To require clinicians to be involved in data reporting into BANS to enable the IF community and commissioners to have a good data suitable for clinical audit and performance monitoring	IF registry data entry is mandatory and already dealt with in the Specification.	No amendments made to Specification
Stakeholder workshops	Pass the request to develop BANS database further to make it more user friendly to enter and extract information to the BANS team.	The CWG's response is that the IF registry is only just starting to be more widely used. There may	No amendments made to Specification

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		well be some changes required in due course, but this is not a matter for the Specification. The comment has been shared with registry host.	
Stakeholder workshops	Consider developing or identify responsible team to develop clinical and performance audit including roles, responsibilities, timescales and what type of information (by whom, how frequently in what way) will be shared with IF providers	The requirement for designated centres to participate in audit is already included in the service specification. The further development of performance metrics will be for networks to consider. Commissioners would support national working by centres on these areas after centres have been commissioned. It is not for the Specification to be proscriptive on	No amendments made to Specification

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		how these matters should be managed.	
Stakeholder workshops	Consider feedback about the inclusion of Blueteq form reference into the service specification	Noted and accepted	Changed reference to Blueteq to prior notification system
Stakeholder workshops	Take into account the anticipated service growth and likely fast expansion in the palliative care patients for market analysis and service planning.	The impact assessment report takes account of expected growth factors.	No amendments made to Specification
Stakeholder workshops	Consider more detailed discussions with paediatric IF services about transition planning and develop best practice recommendations.	It has been agreed with NHSE that at present this Service Specification is not going to address transition from Paediatric IF but this should be a future topic for designated centres to address	No amendments made to Specification
Stakeholder workshops	Consider palliative patients as a separate group in the service specification due to unique features and needs of this group.	This is already the case in the Specification	No amendments made to Specification
Stakeholder workshops	Consider if patients on enteral feeding need/can be included.	It is recognised that there are patients on enteral feeding with	No amendments made to Specification

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		complex care needs very similar to PN patients. The CWG understands that this is controversial and the matter has been debated many times. However, the consensus is that patients who can be fed by normal enteral means (i.e. not by fistuloclycis or enteroclycis) do not, by definition, have IF. Their care is therefore specifically excluded in this Service Specification.	
Stakeholder workshops	Consider the issue with 28 days PN requirements and how inappropriate PN prescription will be identified/managed.	The entry into specialised IF care will be assessed by Integrated or Home PN Centres. All patients receiving PN for	No amendments made to Specification

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		>28 days will be flagged and therefore, any patients being inappropriately managed will be excluded.	
Stakeholder workshops	Consider how the requirement for dedicated ward area can be implemented in practice and who/how will be monitoring the compliance with the requirements	This is very difficult, as each commissioned centre will have different arrangements. If there is clear breach of the concept of a "dedicated ward area" then that should become obvious, especially through patient feedback. Commissioners recognise there are different ways of delivering this requirement.	No amendments made to Specification
Stakeholder workshops	Consider development of more detailed recommended staff to patient ratios for other professional groups and co-location requirements	The purpose of the service model is to describe core national requirements. How	No amendments made to Specification

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		these are operationalised will vary and will take account of wider service and staffing resources. However, there is work in progressive with the national groups (NNNG, BDA, BPNG) to consider this matter further	
Stakeholder workshops	Consider requirements for out of hours staff cover and recommended levels	It is explicit in the Specification that there must be robust arrangements for out of hours care provision. It is not for the Specification to be proscriptive as to how each unit should deliver this.	No amendments made to Specification
Stakeholder workshops	Consider how staff competencies can be managed	This is not a matter for this Service Specification, although the CWG recognises that	No amendments made to Specification

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		competency assessment and management is very important, and again a matter that will be considered with the national professional groups	
Stakeholder workshops	Need to consider development of more MDT specific requirements or best practice guidance perhaps with other stakeholder groups	MDT working is already in the Specification. How these work within Centres and networks will evolve after commissioning.	No amendments made to Specification
Stakeholder workshops	Consider cross regional networking solutions and take into account actual patient flows and the reasons for them when conducting market analysis and service configuration	Agreed. Already addressed earlier in this document and will be considered as the procurement intervention phase foes forward	No amendments made to Specification
Patients / carers	Strong support for ensuring that there is access to specialist, high quality care when required.	This is already the case in the Specification	No amendments made to Specification
Patients /	75% patients who responded to the survey expressed	This may be the	No amendments

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carers	support for travelling further in order to access specialist support, when required	case for Type 2 patients; however, it is envisaged that type 3 patients should be able to access quality care closer to home. The aim is this will be achieved through the use of networks leading to an increase in quality and standardisation	made to Specification
Patients / carers	Many patients mentioned problems with communications / collaboration between hospitals (ie ability to move up or down the system as needs changed, which should be addressed by a more effective network model.	This is already the case in the Specification	No amendments made to Specification
Patients / carers	Several patients raised concerns about access to specialist nursing in order to access self care training & line management , and expedite hospital discharge	This should be covered under the network arrangements	No amendments made to Specification
Patients / carers	Access to psychological support was a common theme from patients. Given the complex and life changing nature of this long term condition, patients wanted better access to support them with the	This is already the case in the Specification	No amendments made to Specification

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	psychological issues of adjusting to life without normal nutrition.		

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