Engagement Report for Service Specifications

Unique Reference Number	URN
Specification Title	Hand and Upper Limb Transplant Service
Lead Commissioner	Nicola Symes
Clinical Reference Group	Complex Rehabilitation and Disability
Which stakeholders were contacted to be involved in service specification development?	Service Provider – Leeds Teaching Hospital NHS Trust NHS Blood and Transplant Rehabilitation and Prosthetic Service Representatives Public Health England Quality Surveillance Team, NHS England Patient Representative
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved	

Which stakeholders have actually been involved?	Service Provider – Leeds Teaching Hospital NHS Trust NHS Blood and Transplant Rehabilitation and Prosthetic Service Representatives Public Health England Quality Surveillance Team, NHS England Patient Representative
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?	Not applicable
How have stakeholders been involved? What engagement methods have been used?	Stakeholders have been involved within the service specification working group. A specific ‘upper limb loss’ care pathway meeting was held to discuss the links with the prosthetic and rehabilitation services.
What has happened or changed as a result of their input?	
How are stakeholders being kept informed of	Those stakeholders on the working group are being kept advised of progress of the service specification.

progress with specification development as a result of their input?	The engagement report will be shared with the Complex Rehabilitation and Disability CRG for information.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	Four week public consultation

Stakeholder/CRG Feedback

Organisation Responding	Feedback Received	SWG response	Resulting Action
NHS England – Patient Experience Team	**On page 3 there is the paragraph** Patients should be offered written information to help them to make informed decisions about their healthcare, at appropriate points within the assessment process, and should be given appropriate time and space to consider all the information and the implications of transplantation. **I think there needs to be consideration to change from "written information" to information provided in a format that is accessible to the patient and carer/families. (I'm thinking about the Accessible Information Standard and not everyone can access written information)**	Comment noted and agreed	The sentence has been revised to reflect the suggested wording.
NHS England - specialised	My understanding is that Oxford will be acting as a subsite for this activity and there is no mention of this or description of how the pathway would work for this element (e.g. what the expectation would be of who would do which elements of the pathway.) Could it be clarified what elements of rehabilitation would be done within the transplant centre and what would be done locally	This response is outside of the scope of the stakeholder testing question. The transplant centre will provide rehabilitation whist	No change required.

	for the patient. (E.g. would the post-acute phase hand physio / rehab be CCG based / local trust etc.?)	the patient is an inpatient. The provision of ongoing rehabilitation will be discussed on an individual basis to meet patient need and in discussion with their local team.	No change required.
	No mention of coding or payment approach especially how payment would be organised post the initial surgery.	This response is outside of the scope of the stakeholder testing question and will be discussed with the respondent directly.	No change required.
	What numbers are expected? The change in demographic section is not correct as there isn't a service currently so it would be unmet need that should be scoped	There is a service in place at present (February 2016), the demographic section is considered accurate.	No change required.

Individual	I'm not sure where the transplant service will be based. Is this a national or a regional service?	This is stated in provider lead section. There is one national provider due to the highly specialised and low volume nature of this service.	No change required.
Individual - Non Profit Professional	No	Noted	No change required.
The British Association of Prosthetists and Orthotists (BAPO)	BAPO are concerned that this document does not mention the term 'prosthetist' – the HCPC registered professional who's role it is to lead assessment, prescription, fitting, supply and review of prosthetic limbs. The term 'prosthetic specialists' (section 2.2) is too vague and implies that this role could be done by more than one staff group which is not the case. 'Prosthetist' should be clearly stated. Similarly section 2.1 states that there should be 'evaluation' of the patients 'use and benefit of prosthetic limbs'. BAPO suggest this was most appropriately be conducted with direct consultation with the patients named prosthetist. It is also of concern that this specification mentions that the donor will be offered a prosthetic limb (section 2.2). BAPO's understanding of the procedure is that the donor is deceased and will therefore not require a functional prosthesis.	The working group noted the comment, slight rewording agreed specifying consultants with experience of amputee rehabilitation and experienced prosthetists. Yes, although the donor is deceased a non-functional cosmetic limb is provided to the donor out of respect and dignity for the organ	The sentence has been revised to reflect the suggested wording. No change required.

		donor and their family. This has been subject to previous discussion and agreement with NHSBT.	
Individual	In relation with the “Exclusion criteria: congenital limb anomalies”: It is clear that “the aim of the service is to provide hand and upper limb transplantation to reconstruct an absent upper limb or hand, lost as result of trauma or infection. Hand and upper limb transplantation would, ordinarily, only be offered to those for whom current reconstructive techniques or prostheses are unsuitable or unsatisfactory. With the overall aim being to improve functional capacity and quality of life.” My question is if there is any assessment being done in the case of congenital limb anomalies to consider limb amputation. And in this case, which would be the options of such patients to be included in the evaluation process to benefit from transplantation in the case no other reconstructive techniques or prostheses would be a successful treatment?	The working group noted that at present this is out of scope of the clinical commissioning policy and therefore not included in the specification. Current evidence is that patients with congenital abnormalities do not have the required neurological pathways established for successful transplantation.	No action.
Individual - Patient Ambassador	As in my previous response, I understand that rehabilitation therapies will be based on NICE Guidelines and would just like to ensure that the importance of using this as a ‘guideline’ is important, as I believe that it is imperative that rehabilitation therapies should not be limited in HAUL and that access to rehabilitation therapies should be continued until such time that	The working group agree the importance of rehabilitation.	No action

	the patient shows little or no improvement in outcome or benefit from therapy services.		
British Healthcare Trades Association (BHTA)	• The reference to prosthetic specialist is vague – it should be clear that it would involve a prosthetist with significant upper limb experience.	The working group noted the comment, slight rewording agreed specifying consultants with experience of amputee rehabilitation and experienced prosthetists.	The sentence has been revised to reflect the suggested wording.
	• There is reference to the patient not being successfully fitted with prosthetic limbs – some further clarification here would be useful – there are upper limb prosthetic components which are currently not supplied through NHS England – microprocessor / multi-articulating hands for example – patients should have been given the option to trial these before any hand transplant is considered. It should also be clear that the patient has seen a specialist upper limb prosthetist – a lot of centres only provide the basics in upper limb prosthetics and it should be ensured that the patient has had access to the best options before this surgical outcome is considered.	NHS England can only offer treatments that are commissioned. The provision of prosthesis and prosthetic services are not in the scope of this service specification.	No action required.
	• The document makes reference to "Working closely with rehabilitation and prosthetic specialists as part of a wider upper limb loss care pathway for patients" – section 2.2. We are not aware that any such pathway exists at the minute so access to what this is and how it works needs to be clear (in reference section if nowhere else).	Noted – there is not a formal pathway, but a commitment to work collaboratively. Wording revised.	Wording revised.

	• There is reference to a clinical psychologist being part of the team but a good, clear psychological assessment needs to be part of the inclusion criteria – the psychological impact of a transplantation, which is so visible to the patient and other people, cannot be underestimated. In the original osseo-integration project at Roehampton the psychological impact and assessments were by far the biggest factor in whether or not a patient would be successful on this programme and this will be just as important here. • There is no reference to TMR treatment being tried (targeted muscle reinnervation) before a hand transplant is considered. It is also a surgical technique which involves a lot of time and effort but there is no need for immunosuppressant drugs for users after the surgery. • We presume that this treatment is only going to be considered for patients with below elbow, through wrist or partial hand amputations/limb loss - this is not clear in the document and may set up false expectations with patients who have a higher level of amputation/loss.	Psychological assessment is a core aspect of the patient assessment for suitability for transplantation. TMR is not routinely commissioned and not in scope of this specification. Transplant may be considered for patients with any upper limb loss (above and below elbow).	No action required. No action required. No action required
Leeds Teaching Hospital Trust	2.1 Inclusion criteria = Unsuitable for current prosthesis. Potentially could state previous trial or lack of suitability for prosthesis 2.1 Referral = May require formal re-assessment by their local service Potentially could state formal reassessment by Leeds Prosthetic service	The working group felt current wording was accurate. The working group felt that current wording was accurate. It is not a requirement for	No action required No action required

		patients to receive reassessment by the Leeds prosthetic service. Patients are required to have an assessment by their local service.	
	2.1 Surveillance potentially could add during this period these patients still have prosthetic needs that would be on-going.	Agree – patients may require on going prosthetic needs, and they would remain under the care of their local services as required.	No action required
	3.4 Evidence Base =Reference incomplete as page numbers not included. Located via the internet. We note the article is 20 years old and discussing replanting rather than transplantation. A more recent article we found was Quadrimembral Amputation: A review and perspective on the role of comprosite Tissue Allotransplantation Volume 21 May 2011 page 87-89. This article also takes reference to the original article quoted. (Major replantation versus revision amputation and prosthetic fitting in the upper extremity)	Noted, however, the evidence cited is in line with the associated policy published in 2016. No additional formal evidence review was completed for the associated service specification.	No action required.
Individual – Patient Advocate	No	Noted	No action required

Individual	Section 1.3 I am concerned that this aspect of treatment, i.e. specialised hand transplant centres (which suggests that there will be only a few places in the country that carry out this procedure) will result in a post code lottery. i htink it would help if some consideration of support for those patients and their families who are not close to one of these centres, was inserted. This should not incur excessive expense as the document states below that only about 3 patients a year might be eligible and there is no belief that there will be a large increase in numbers should this process be accepted as clinical practice	There is only one centre commissioned nationally to provide this highly specialised service in the country. All patients nationally will have equal access to the service. The service will work with teams local to the patient and establish shared care arrangements to meet their individual needs.	No action required.
	Referral - in the previous paragraph you say referrals will be made by one of the following and yet here you say the prosthetic dept must be included... this needs clarification	A referral should include an assessment from the local prosthetic service, however, the referral may be made by another team.	No action required.
	Inclusion Criteria - I feel that it is important not to close the door on anyone who asks to be referred just because they don't satisfy the above criteria ...it means chances to learn more about this process may be missed. By all means filter the numbers but always be aware of each individual case's wider context. It smacks of cost control rather than a patient-centred approach.	The working group feel the current criteria is appropriate, and not restrictive.	No action required.

	Assessment - I am glad to see the inclusion of a clinical psychologist. the implications of this procedure extend far beyond the simple physical issues and concerns	Noted	No action required.