Engagement Report for Service Specifications

Unique Reference Number	1653
Specification Title	Complex Gynaecology/ Female Urology: Genito-Urinary Tract Fistulae (Girls and Women aged 16 and above)
Lead Commissioner	Bernie Stocks
Clinical Reference Group	Specialised Women's CRG
Which stakeholders were contacted to be involved in service specification development?	• UVF Specification Working Group including three patient representatives • Three previous patients of the service • The British Association of Urological Surgeons (BAUS) • Specialised Women's CRG members and stakeholders
Identify the relevant Royal College or Professional Society to the specification and indicate how they have been involved	The British Association of Urological Surgeons (BAUS) – a representative of which is on the specification working group and has been involved in the development of the specification.

Which stakeholders have actually been involved?	The eight respondees to the stakeholder testing were: • A member of the BAUS who is also a Specification Working Group member • Two of the Specification Working Group Patient and Public Voice representatives, one of whom was a recipient of the service • One person from the stakeholder list of the Specialised Women's Clinical Reference Group (JH) • Two patients who have previously received surgery at a specialist unit having being referred by their GP • Two current providers of the service (The Hillingdon and University Hospitals of Leicester).
Explain reason if there is any difference from previous question	If the stakeholders responded to the call for comments, these were included in this document.
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?	None
How have stakeholders been involved? What engagement methods have been used?	NHS England email sent 8 December 2017 noting the opening of the two week's stakeholder testing with a close date of 22 December 2017 and telephone calls made to a number of patients whose names had been put forward to ask them to participate – some of whom gave verbal comments and supported these with email or paper responses.
What has happened or changed as a result of their input?	Suggestions have been taken into account where this was within the scope of the Specification Working Group's responsibilities. Additional actions will be undertaken at the relevant stage of provider qualification if the proposed revised specification is approved for implementaiton.

How are stakeholders being kept informed of progress with specification development as a result of their input?	This engagement outcomes report will be shared with the Specification Working Group for comment and whether any amendments need to be made to the specification and then with the Specialised Women's CRG and the Women and Children Programme of Care Board. Stakeholders will receive an email noting the changes that have been made.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	Public consultation is planned for the end of January 2018 together with a wider package of new/revised Complex Gynaecology specifications.

BS as at 16 01 18 as at 19.38 amended 30 01 18 13.18

UVF Stakeholder/CRG Feedback

	Organisation Responding	Feedback Received	SWG response	Resulting Action
a	b	c	d	e
1	Specification working Group PPV member #1	i) The scope is clear ii) Pathway - from the initial referral through to the necessary follow-up patients require the care pathway provides a systematic flow for the patient's journey. The 'one stop' clinic is also beneficial for patients in that it provides a seamless journey, and avoids having to make numerous visits involving time and cost. From the NHS point of view – there is less impact on resources such as clinic times, staff and the inherent costs this involves. iii) Clinical Dependencies: No changes necessary here – all looks excellent. I had earlier in the process voiced some concern at the provision of psychological	• No action required. • No action required. • No action required.	• No action required. • No action required. • No action required.

		support for these patients particularly so as they are able to access support with health professionals specifically experienced in dealing with patients suffering incontinence and similar conditions locally which has now been appropriately addressed namely looking at support from clinical nurse specialists. iv) No further comment necessary – I am happy to say it will be a welcome addition to specialised services in the improved provision of care for women experiencing fistulae. v) I am a Patient Representative on the Specialised Women's CRG and have been involved in the development of this particular specification.	• No action required. • No action required.	• No action required. • No action required
2	Specification working Group PPV member #2, and previous patient #1	i) I am happy with the proposed draft. The following recommendations I feel would help support patients in line with the other comments already made. ii) In my experience the community nurses caring for me after I had been diagnosed with a fistula were not trained to insert catheters. Although the community nurses were the only emergency number I	• No action required. • The Specification Working Group have reviewed the wording in the specification and do not consider that there is more that can be added in regarding the local	• No action required. • The Specification Working Group will address this as part of implementation planning when the revised service specification is being

		was given. On visiting the house a couple of nurses could not inset a catheter as they said they hadn't received training and could insert a catheter but refused to do it on the grounds that I had just had an operation and didn't want to do any damage. A catheter passport or direct access to the local urology ward would help, including who is suitable/not suitable to re insert the catheter and info on my problem.	management of catheters as such, although the suggestion of direct access to local urology wards will be pursued and this may also be included in the discharge letter to the GP, copied to the patient so that the patient is aware they can approach their local hospital urology team to access staff who may be suitable to re-insert the catheter.	implemented following the provider qualification process and the Specialised Women's Clinical Reference Group will receive update reports on progress.
		iii) I really found it difficult to find information on my condition and what to expect with it and – a leaflet or website would really help and reduce patients distress and help explain things to community nurses etc.	• The Specification Working Group agreed to include the weblinks in the specification to the BAUS patient information leaflets on UVF and VVF. - weblinks added onto page 10 of the specification.	• The Specification Working Group will address this as part of implementation planning when the revised service specification is being implemented following the provider qualification process and the Specialised Women's Clinical Reference Group will receive update reports on progress.

		iv) There were no patient support groups or anyone I could find to share my experience or see some light at the end of the tunnel who had recovered from fistula. I would be really happy to participate with this and be a 'recovered from fistula supportee'. Feeling isolated added to the difficulty of the condition.	• The Specification Working Group agreed to review current provision of support for patients at each of the centres and see if there could be any joint approach, taking into account this offer.	• No further action required.
		v) Could some guidance be given to maternity units about catheter care on discharge? I was sent home after a week of having my son with a catheter 'secured' on my leg by a loose tubigrip and the tubing just dangling not anchored by a clip on my stomach. It was really painful and impossible to move around. Until my sister researched it and I asked the local urology nurse. The timescale of a week of seeing a specialist about catheter care was too long.	• The Specification Working Group noted this point and will review advice to local maternity units on catheter care.	• To be discussed following public consultation responses.
		vi) I had my initial tests done locally but my test results were not looked at by the team at [xxxx] before my initial consultation as the Urology	• Noted – the specification already addresses this point via the MDT for non-urgent repairs, plus	• No further action required

		team meeting was in the afternoon and my appointment was that morning.	additional wording has been added for urgent referrals to the Specification, Page 2, Section 2.1 'it is the aim that the referral will first be reviewed by the MDT, the patient will then be seen as an urgent case and the repair carried out before the tissues become unsuitable for repair'.	
		vii) I think the pathway looks good and feel I really benefited from having centralised expertise, thank you for putting together this pathway and listening to my comments.	• Noted – no action required	• No further action required
3	Previous patient #2	i) In xxxx I was diagnosed with cancer of the womb and consequently had a full hysterectomy. Before I was able to move onto radiotherapy, I was told the bladder problems I had suffered from after surgery were due to a vesico-vaginal fistula, and that radiotherapy could not proceed. I realised very quickly that [my local] medical staff had little or no experience with this condition which	• The specification working group noted this comment. This point will be resolved via the provider selection process on the basis of numbers and expertise.	• No action required at this stage as this will be addressed through the provider qualification process.

		made me feel very frightened, insecure and distrustful. (in a previous telephone conversation with this patient, she noted that the local clinician noted that they had done 'only one before'.		
		ii) I discussed the situation with my GP and she suggested that I be referred to the Warrell Unit at St Mary's Manchester, where Dr Fiona Reid was an expert. From my first visit, I felt I had found the right place to tackle my problem. Dr Reid made me feel safe and that she would be able to put things right. Reading through the specification you sent me, I realise that the medical staff followed the procedures set down. I am extremely grateful to Dr Reid and the Warrell Unit.	• The Specification Working Group noted this comment.	• No further action other than to note that this will be addressed through the provider qualification process.
		iii) [I am concerned about the] exclusions on page 5 about patients with cancer	• The Specification Working Group noted this comment. It is proposed to clarify this point on the Specification/ Page 5/ Exclusions and the wording has been changed from: 'Patients with gynaecological	• The proposed new wording was agreed.

			cancer, whose care is covered in the relevant cancer service specifications; to: 'Patients with gynaecological cancer, whose care is covered in the relevant cancer service specifications until the cancer is resolved after which time the patient's GP may make the referral to the service.' This was subsequently changed to: 'Vesicovaginal and urethrovaginal fistula that are the result of active new or recurrent cancer requiring further cancer treatment:'.	
4	Previous patient #3	viii)The scope is clear. ix) The care pathway and clinical dependencies are clear. x) Centralisation of services is an excellent idea. I would stress the importance of providing a catheter passport and psychological support and advice on patient groups as I never had these and wish I had. I am on a bladder cancer support forum and a few women have had	• No action required • No action required • The comment that the Catheter passport is a good idea was noted by the Specification Working Group.	• No action required. • No action required. • No action required.

		fistulae. All believe they are alone and that successful repair depends on finding an experienced doctor somewhere in Europe. Someone sought treatment in Belgium. Centralising this service would help women realise they are not alone and that specialists are available to help them. xi) Whereas the pathway looks clear during the hospital stay, it's essential to work with district/community nurses once the patient is discharged. The patient can feel alone and isolated once home and the mention of fistula (or neobladder) to community nurses tends to draw a blank.	• The Specification Working Group noted this comment and that some patients and possibly also GPs are not aware of the service currently on offer in England and therefore propose to review the communication to support this revised specification if it is approved, including the review of options such as adding information to i) the NHS Choices website/ (I have a urinary fistula webpage/ list of national centres); ii) liaison with the RCGP's Education Team and iii) the Royal College of Obstetricians and Gynaecologists (RCOG)	• It was agreed that the Specification Working Group will discuss communication options with NHS Choices, the Royal College of General Practitioner's Education Committee the Royal College of Obstetricians and Gynaecologists, and with BAUS and BSUG regarding wording on their websites.

			re the national service offer available and iv) a ask for a list of centres to be included on the British Association of Urological Surgeons (BAUS) and the British Society of Urogynaecology (BSUG) websites.	
		xii) A catheter passport is an excellent idea. Ms Greenwell asked my views on receiving a weekly phone call from the hospital. That would be great (I did receive weekly phone calls from the urinary diversion nurses following my cystectomy, which were incredibly reassuring). However, I appreciate that resources are tight and this might not be feasible.	• The Specification Working Group noted the patient's comment that a weekly check in phone call from the urinary diversion nurse following surgery was beneficial and appreciated. The current wording in the revised specification is considered to be appropriate: 'for UVF/VVF, the service's CNS/CNP will telephone patients to follow them up one week after discharge and then in the outpatient clinic between one to three weeks following repair, the CNS/CNP will undertake a cystogram	• No action required

			and/ or methyl blue test and will review patients to establish whether the repair wound has healed appropriately.	
5	Mr Christopher Harding, BAUS	I am happy with the specification on behalf of BAUS.	• No action required	• No action required.
6	Mr Alvan Pope, The Hillingdon Hospital Foundation Trust	i) The scope is clear. ii) The pathway and clinical dependencies are not clear as although they talk about acute repairs, I think if this policy is introduced it will all but stop that as realistically a referral to and subsequent surgery in one of just 3 national centres will not occur within 2-3 weeks. That will increase morbidity and most likely the follow-on medico-legal claims that as you know can often be defused by a rapid & successful local repair. iii) We only do small numbers but that doesn't mean we cannot do them successfully. As far as I can remember none of the primary repairs that I have done over the years of VVFs have failed. We would already refer the more complex fistulas to UCLH anyway, ie: chronic post radiation or	• No action required • The Specification Working Group noted this and will take account of the number of centres needed and speed of the patient journey as part of the provider qualification process. • The Specification Working Group noted this comment.	• No action required. • This will be addressed at a later step in the qualification process as per the NHS England process. • This comment will be taken into account as part of the provider qualification process. It is likely that the number of centres will be reduced from the current number based on an assessment of factors including historic activity levels,

		involving the rectum as well. We should give credit for common sense and professionalism - If we consider a case within our range of skills than we should be allowed to manage it, if not we would refer on.		approaches used (abdominal or vaginal) the historic number of repairs versus neobladders, reoperation numbers, and expertise.
7	Mr Jaskarn Rai University Hospitals Leicester	i) The scope is clear. ii) The pathway and clinical dependencies are clear iii) Further comments - Leicester has always offered female fistula repair as a service. We work jointly with our urogynae colleagues. We would continue to offer this service in Leicester. We can do this jointly with Birmingham and Nottingham as we have a close working relationship with the specialist there.	• No action required • No action required • The Specification Working Group noted this comment.	• No action required • No action required • This comment will be taken into account as part of the provider qualification process. It is likely that the number of centres will be reduced based on an assessment of factors such as historic activity levels, approaches used (abdominal or vaginal) the historic number of repairs versus neobladders, reoperation numbers, and expertise.
8	Specialised Women's Clinical Reference Group Stakeholder – Jane Harvey.	i) The scope is clear – although suggest that it commences with a definition.	• The Specification Working Group noted this comment and agreed to add the following wording in Scope, page 1:' which is where urinary fluid	• The Specification Working Group agreed the proposed wording.

			leaks or flows out of the vagina'.	
		ii) The pathway and clinical dependencies are not entirely clear: a. Why are 16 year old girls not included only those girls aged over 16?	• The Specification working group noted that in some places the age of 16 and above is already included but 'over 16' is used in other places – this has been corrected to age 16 and over throughout the document.	• Correction made, no further action required.
		b. Why can't any relevant HCP refer e.g. specialist physios	• The Specification working group noted this comment and added specialist Health care practitioners to the list of referrers.	• Correction made, no further action require
		c. It is not clear what 'VVF symptoms' is:	• This is noted and the additional detail 'fluid leaking or flowing out of the vagina' has been added'.	• Correction made, no further action required.
		iii) Further comments: Typos and corrections		

		• the patient ‘will either asked’ • MDT and several other abbreviations are used prior to explanation • The citations are not consistent re Harvard system e.g. for 2 authors separate by ‘and’ • Not listing authors and et al • RE the below need to tell patients what ‘prepared’ means: You should come prepared to perform a flow rate test and let the nursing staff in outpatients know this is what you are expecting upon your arrival	• Typing error noted should read ‘either be asked’ and correction made. • Errors corrected • Correction made, no further action required. • Correction made, no further action required • This suggestion is noted – it is proposed to add in the following wording: ‘A flow rate test is a special test to measure how fast you pass urine (a maximum urinary flow rate) and entails passing urine into a special funnel which measures electronically how fast your urine is expelled. This simple test will be performed immediately before you see your urologist or Specialist	• Correction made, no further action required. • Correction made, no further action required. • Correction made, no further action required • Correction made, no further action required • Correction made, no further action required.

			Nurse to discuss the results of your X-rays and/or ultrasound scans. To prepare for this test, you should try to come to this appointment in clinic with your bladder comfortably full. If your bladder contains less than 150ml (quarter of a pint), the result of the test may be unsatisfactory. If you have difficulty in keeping a full bladder, please inform the staff as soon as you arrive so that they can help provide you with sufficient fluid to fill up your bladder.	