E02/S(HSS)b

2013/14 NHS STANDARD CONTRACT
BLADDER EXSTROPHY SERVICE (CHILDREN)

PARTICULARS, SCHEDULE 2- THE SERVICES, A- SERVICE SPECIFICATIONS

Service Specification No.	E02/S(HSS)b
Service	Bladder Exstrophy Service (Children)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

2. Scope

2.1 Aims and objectives of service

This service provides for the management of children with bladder exstrophy, primary epispadias, cloacal exstrophy and all variants.The exstrophy-epispadias complex represents one of the most severe birth defects localised to the lower abdomen and genitalia. It affects the bony pelvis, the urinary tract, the appearance and function of the external genitalia and in the most severe forms affects also the bowel. The conditions within the bladder exstrophy spectrum are compatible with life, but require constant expert health care and support from birth to adult life.

The service is strengthened by its holistic approach to care with a team that includes dedicated psychologists, clinical nurse specialists, nephrology, urodynamics and a specialist paediatric urology ward.

The goals of exstrophy reconstruction are:

- anatomic reconstruction of the bladder/urethra, bony pelvis, abdominal wall and external genitalia
- creation of urinary continence with preservation of renal function
- healthy psychological adjustment and adaptation to the condition throughout life
- support during adolescence.

There are different surgical approaches to repair the exstrophy, which require different techniques and different timing for surgery. The two designated centres have different, but well accepted surgical methodology.

The Great Ormond Street Hospital for Children NHS Trust (GOSH) team performs an early reconstruction in the first days of life. The Central Manchester University Hospitals NHS Foundation Trust (CMUHFT) exstrophy team has developed over the years a Delayed Exstrophy Reconstruction (DER) which is generally performed around 3 months of age. In both units further reconstruction is performed in males around the age of 1 year using different surgical techniques to reconstruct the penis. GOSH undertake additional significant reconstruction to both sexes around age 1 year when the bladder neck is reconfigured in both sexes.

With both approaches, further surgical treatment to aid continence is sometimes necessary in both male and female patients, and involves bladder outlet procedures, usually between 4 and 7 years of age.

In due course, the intention and hope is that the children will gain fully controlled volitional urethral voiding. Sometimes this will not be achieved, but dryness and healthy kidneys can be achieved virtually always by augmentation of the bladder combined with some form of catheterising stoma being constructed in the abdominal wall. Urethral catheterisation can be difficult to negotiate following bladder exstrophy repair and the better, easier and safer option is using intermittent catheterisation through the abdominal (the Mitrofanoff principle).

Frequent hospital visits are necessary for the child's upper urinary tract to be assessed, and there are often complications such as urinary infection which may bring children back into hospital. A referral to clinical psychology can also be made at any stage in the child's medical pathway.

Service should have dedicated "one-stop" bladder exstrophy outpatient clinics. This multi-disciplinary approach ensures that families can meat the entire exstrophy team accessing the radiology service at the main time. This aspect of the service is particularly important for families travelling a long distance to attend the hospital appointments. Additional clinical nurse specialist (CNS) home support is provided if required.

There are many other significant problems which can affect the patient during childhood and adolescent years. These include surgery for penile concerns as well as specific complications which can affect the urinary tract. For example, the o-ongoing problems of urinary reconstruction sometimes mean that patients may later develop bladder stones and require further surgery for these. In females, it is quite common (30%) to develop stenosis of the vaginal introitus which could require surgical intervention at puberty or sometimes even before that. Many girls benefit from further surgical reconstruction of the genitalia in late childhood or in early puberty. Pregnancy in a woman born with this condition can often lead to uterine prolapse and procidentia, which can also require specialist surgery.

In boys with bladder exstrophy and epispadias, the penis is reconstructed in the first 18 months of life. The penis in these conditions is shorter and fatter than normal penises.

Sometimes the external aspect of the penis can be lengthened by subsequent surgery either during childhood or at puberty. Such operations are significant procedures, necessitating a surgical/urological team able to deal with these complex procedures. During their children's development, the parents have the burden of coping with their child's urinary

incontinence including whether continence can ever be achieved. There are also the later sexual appearance function anxieties particularly in boys. During the life of bladder exstrophy patients who have there are almost always special educational and psychosocial support needs because of the urinary incontinence, abnormal genitalia and the frequent admissions which most children have as a result of complications or because of the regular investigations.

The impact of bladder exstrophy-epispadias therefore necessitates an integrated model of psychosocial support.

The bladder exstrophy service has the following primary objectives:

- anatomic reconstruction of the bladder, abdominal wall and genitalia;
- creation of urinary continence (preferably volitional voiding);
- the preservation of renal function;
- the eventual development of functional and cosmetically acceptable genitalia;
- healthy psychological adjustment and adaptation to the condition throughout life.

A key aim of the service into the future is to support the development and regular benchmarking of comparable outcome measures for exstrophy treatment in the UK and, in the longer term, internationally. The intention of this is to develop a practical way of assessing both surgical outcomes and key indicators around continence and psychological outcomes for these children. The service has developed a clear care pathway for children presenting with exstrophy and has built strong links with adolescent services. The service will continue to develop this work in the future.

2.2 Service description/care pathway

The team is led by paediatric urology consultants supported by high-quality staff with experience in bladder exstrophy with the case mix. The service should be provided in a children's teaching hospital with all support services and specialties available. In particular, strong working relationships should exist with neonatology, nephrology, and radiology and paediatric surgery. The clinical team provides antenatal counselling for parents of babies diagnosed on prenatal ultrasound with bladder exstrophy or cloacal exstrophy. Parents are invited to come to the unit and meet the staff who will care for their child in due course.

The service should have close links to urodynamics able to offer a comprehensive range of diagnostics. Clinical nurse specialists are also available to prepare the patient and family for surgery, and they also teach techniques of intermittent

catheterisation to ensure proper bladder emptying and perform urodynamic studies to assess the function of the lower urinary tract in patients with exstrophy and other abnormalities of the bladder.

The service must have intensive care provision with dedicated paediatric and neonatal intensive care units. The Paediatric Urology Unit should be staffed by nurses skilled in the management of patients who have received major lower urinary tract reconstruction. There should be on-site paediatric radiological and nephrological services.

During these early years there are almost always special educational and psychosocial support needs because of the urinary incontinence, abnormal genitalia and the frequent admissions which most children have as a result of complications or because of the regular investigations. To support families through this the services should have dedicated senior psychologist support specialising in exstrophy. Services hold multi-disciplinary meetings including mortality and morbidity meeting to ensure that complications are discussed. Where appropriate any risk or incidents are reported to the Surgery Clinical Unit Board through the governance reporting structure.

At CMUHFT, the first operation is performed around age three months. This operation closes the bladder and abdominal wall, so that the bladder is inside the body and in the correct position. After the operation, urine will drain from the urinary tract through a number of catheters (plastic tubes) placed in the bladder and kidneys. All children undergo anterior pelvic osteotomy to facilitate successful closure. All children have an epidural local anaesthetic block. Post-op, the children go to intensive care for ongoing epidural pain relief and occasionally ventilation. They are usually able to go to the ward or if they go to the High Dependency Unit (HDU) they will normally return to the ward after 36 hours.

At GOSH, the initial surgery compromises of a bladder and abdominal wall repair. This operation closes the bladder and abdominal wall, so that the bladder is inside the body and in the correct position. After the operation, urine will drain from the urinary tract through a number of catheters (plastic tubes) placed in the bladder and kidneys. Post-op children may go to intensive care if they require sedation and ventilation to reduce unnecessary movement during the initial healing. However, a number of children will go directly to urology ward without requiring intensive care (ICU).

The full bladder exstrophy pathways are attached in appendix 1 and 2.

Exstrophy multi-disciplinary team (MDT):

- paediatric urologists providing surgical services
- clinical nurse specialist
- clinical psychologist
- dedicated bladder exstrophy anaesthetist
- paediatric orthopaedic consultant
- adolescent gynaecologist

- adult urologist
- obstetrician.

The management of childhood issues has evolved considerably in the last 10 years as the children have become adolescents and eventually adults and the service needs to offer a holistic approach for the children as they move through adolescence, into puberty and onto adult life. Services need to link directly to both urological and gynaecological services. Service should have a transition protocol for patients to ensure that they are offered seamless support around issues that may arise as part of the medical pathway such as vaginal dilatation and sexual health aspects.

Days/hours of operation:

- theatre lists in theatres run Monday to Friday with emergency lists running weekday afternoons and out of hours.
- ward: 24/7
- outpatients & urodynamics: Monday to Friday 0900 – 1700
- specific bladder exstrophy paediatric, adolescent, young adult and adult clinics
- biofeedback sessions.

Discharge criteria & planning including any transition arrangements

A dedicated discharge liaison nurse arranges support/care at home to be provided by local paediatric community nurses or, if appropriate health visitors and continence nurses following all major surgical procedures. Discharge after this type of procedure is deemed safe after the child and family have received education and training for catheters and wounds, and support is organised for care at home.

Preparation for transition to adult services is commenced at approximately 14 years of age when appropriate. Children are generally considered appropriate for transition if their current treatment plan is completed, they have no outstanding procedures to be performed and they are not under current psychological counselling. Transition is a joint process with clinical and support teams at University College London Hospitals NHS Foundation Trust (UCLH) and Central Manchester University Hospitals NHS Foundation Trust (CMUHFT).

2.3 Population covered

This service covers patients registered with an English General Practitioner, resident in Scotland, resident in the European Union and eligible for treatment in the NHS under reciprocal arrangements. Patients from Wales and Northern Ireland are not part of this commissioned service and the Trust must have separate arrangements in place for patients from these and other non EU referrers.

2.4 Any acceptance and exclusion criteria

Every effort is maintained to promote equal access to the service regardless of culture, disability, gender sensitive issues or where patients live. The service has a duty to co-operate with the commissioner in undertaking Equality Impact . Assessments as a requirement of race, gender, sexual orientation, religion and disability equality legislation. Referrals will be accepted from colleagues in secondary care. Local consultants in England should refer only to the designated supraregional centres.A shared care protocols is available. There are no exclusion criteria for appropriate referrals within the exstrophy spectrum.

2.5 Interdependencies with other services

There has been a sustained focus on developing whole systems care for bladder exstrophy patients who will inevitably need continuing care into adolescence and adulthood. Transition process is a joint process with clinical and support teams at UCLH and CMUHFT.Where exstrophy is diagnosed antenatally parents can be reviewed as part of their ante natal care. The team meets the families as part of their antenatal care at the adult side of the trust in conjunction with the dedicated obstetric team.

Collaboration with other units

Services have in place links with adult services to ensure smooth adolescent transition. Great Ormond Street Hospital for Children NHS Trust is linked with adolescent and adult services at UCLH. CMUHFT is as described above working closely with consultants in the adult services.

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

4. Key Service Outcomes

Outcomes

- Audit of surgical outcomes and patient/parent satisfaction are on-going. This will audit neonatal care and subsequent care at 6 months, 3 years and 6 years
- Audit information will be shared on a yearly basis with commissioners and British Association of Paediatric Urologists (BAPU)
- Clinical governance requirements – trust's clinical governance procedures to be followed. Any Serious Untoward Incidents (SUIs) to be notified to NHS

England (NHSE) in accordance with the Contract.

Governance

Service should have in place systems for collecting data corporately on serious incidents, and for multidisciplinary review.

Membership of registry/trials - a national dataset is agreed and must be collected for the service.

5. Location of Provider Premises

Central Manchester University Hospitals NHS Foundation Trust, Manchester.

Great Ormond Street Hospital for Children NHS Trust, London

Appendix 1 - Central Manchester and Manchester Children's University Hospitals care pathway

All patients follow the first part of the pathway

Pathway Event		Procedure/Assessment/Investigation	Planned Timescale	Additional Activities
1.	**Situation A: antenatal diagnosis (50%)**	Referral from obstetrician to consultant paediatric urologist a) telephone contact of nurse specialist with parents b) antenatal consultation (outpatient appointment): • consultant urologist, 45 mins • psychologist 60 mins • nurse specialist 60 mins c) second consultation if necessary d) communication – letter/phone call to District General Hospital (DGH)/primary care If diagnosed antenatally families given antenatal consultation leaflet.	Antenatal	When baby is born all families get a copy of the urology nursing service leaflet
2.	**Situation B: No antenatal diagnosis (50%)**	a) Referral to RMCH urology team (urgent referral by phone usually) b) Nurse specialist contacts the referring hospital nursing team and speaks to parents c) If Classic Bladder Exstrophy, baby transferred when mother ready to be transferred with the baby. If Cloacal Exstrophy, baby transferred as soon as possible – treated as a clinical urgency, possibly requiring theatre. d) Communication – letter/phone call to DGH/Primary Care If diagnosed post-natally a welcome letter is faxed to the maternity unit		When baby is born all families get a copy of the urology nursing service leaflet

3.	**First admission for Classic Bladder Exstrophy**	a) Admission at RMCH ALOS 3 days (2 – 4 days) b) Baby assessed by urology and orthopaedic team • consultant paed urologist – 45–60 mins • consultant paed orthopaedic surgeon -30 mins • consultant anaesthetist -15 mins • nurse specialist - 60 mins minimum • clinical psychology - 60 mins minimum c) Pathology tests - urgent FBC and U's and E's, d) Radiology - ultrasound upper renal tract, e) ECHO – consultant cardiologist – 15 mins f) Medical illustrations - photos g) Baby discharged home h) Discharge letter to GP/DGH		We are in the process of developing a leaflet that provides information on the whole service and what to expect around surgery, this will be given out to parents prior to their baby's first operation.
4.	**Home visits by nurse specialist plus periodic communication with GP and health visitor**			
5.	**Second admission for pre-op assessment**	a) Admission to RMCH – ALOS 2 days b) Pathology tests- FBC and U's and E's, Blood cross match. Urine culture. c) Radiology • CT scan pelvis • US Hips d) Consultant paed urology consultation and consent for surgery - 20 mins e) Consultant paed orthopaedic consultation and consent for surgery 20 mins f) Clinical psychology consultation – 1 hour g) Nurse specialist 30 mins h) Discharge letter to GP/DGH	At 6 weeks-3 months of age	

6.	**Third admission for surgery**	a) RMCH admission – ALOS 18 days (2 to 3 weeks) b) Theatres – 2 – 3 sessions • 2 consultant urologists • 1 consultant orthopaedic • 1 consultant anaesthetist • External Pelvic Fixator • Theatre staffing c) Pain team heavily involved in the post-op (48 hours of epidural) d) 1 day in ICU e) 2 days in HDU f) 2-3 weeks in the ward (cubicle) g) Demanding nursing care – • 3 times/day dressing • once/week blood test • 3 times/week urine test) h) Daily review by consultant urologist. – 10 mins per day i) Multiple daily reviews by nurse specialist- j) 2/ week k) consultant orthopaedic review 10 mins per visit l) Weekly review by clinical psychologist – 60 minutes per visit m) Pathology tests n) US renal tract before discharged home o) Discharge letter to GP/DGH		
7.	**Nurse specialist in contact by phone with health visitor and community children's nursing / district nursing teams**			
8.	**Nurse specialist home visit(s) with primary care team.**			
9.	**Out-patient review**	a) MDT clinic – o Consultant Paed Urologist – 30 mins o Nurse Specialist – 30 mins o Clinical Psychologist - 30 mins b) OPD costs	2 weeks after surgery (para 6) above or at anytime if necessary	

		c) OPD letter to GP/DGH/Primary Care Team		
10.	**Fourth admission**	Admission to RMCH - ALOS 3 days (2 to 5 days) Consultant orthopaedic consultation and removal of external fixator – 20 mins Consultant urology consultation and removal of catheters – 10 mins daily Nurse Specialist multiple daily reviews – 60 mins Pathology & Radiology tests – Ultrasound of renal tract and urine culture f) Patient discharged home g) Discharge letter to GP/DGH	6 weeks after surgery	
11.	**Out-patient review**	a) MDT clinic o Consultant paed urologist – 30 mins o Nurse specialist – 30 mins o Clinical psychologist – 30 mins b) OPD costs c) OPD letter to GP/DGH and primary care team	In 2-3 weeks following admission (para 10)	
12.	**OPD for Orthopaedic Surgeon**	a) Consultant orthopaedic surgeon – 20 mins b) OPD costs c) Radiology – Plain x-rays d) OPD letter to GP/DGH		
13.	**If patient doing well, OPD consultations**	a) MDT clinic • Consultant Paed Urologist – 30 mins • Nurse Specialist- 30 mins • Clinical Psychologist – 30 mins b) OPD costs c) Radiology – Ultrasound renal tract d) OPD letter to GP and Primary Care Team	After 6 months	
14.	**At 1 year of age – In patient admission**	a) Admission to RMCH – ALOS 2 days (1 to 3 days) b) Radiology - ultrasound renal tract and DMSA c) Pathology tests - U's and E's d) Theatre - Examination under anaesthesia and assessment of bladder capacity (1 hour) • consultant urologist • consultant anaesthetist	1 year of age	

		• consultant radiologist • theatre team e) Post op – consultant urologist consultation – 20 mins f) Nurse specialist consultation 30 mins g) Discharge letter to GP		
15.	**If patient doing well, out-patient consultations –**	MDT clinic – • Consultant paed urologist – 30 mins • Nurse Specialist – 30 mins • Clinical Psychologist – 30 mins b) OPD costs c) Radiology – Ultrasound OPD letter to GP and primary care team	2 per year	
16.	**OPD review – Orthopaedics**	a) Consultant orthopaedic surgeon – 20 mins b) OPD costs c) OPD letter to GP and primary care team	Annually	
17.	**At 3 year of age In patient admission**	Admission to RMCH – 2 days (1 to 3 days) Radiology – Ultrasound renal tract, some have DMSAs 50 % of patients c) Pathology tests - U's and E's Theatres - Examination under anaesthesia and assessment of bladder capacity - consultant urologist - consultant anaesthetist - theatre team Consultant urologist consultation – 20 mins Nurse specialist consultation – 60 mins Nurse specialist home visit to discuss toilet training, support family – 1 day Discharge letter to GP and primary care team		
18.	**If patient doing well, outpatient consultations**	a) MDT clinic - consultant urologist- 30 mins - nurse specialist – 30 mins - clinical psychologist – 30 mins b) Radiology – ultrasound on urinary tract c) OPD costs d) OPD letter to GP and primary care team	1..,./ per year	

Bladder Exstrophy – Continuation of Care Pathway

The Following procedures will take place for some patients each year. For those on the Pathway above it is estimated that patients will require the following on a yearly basis.

Pathway Event		Procedure/Assessment/Investigation	Planned Timescale	Additional Activities
1.	**At 5 years of age, if patient still incontinent – inpatient admission**	a) Admission to RMCH – ALOS 2 days (2 to 3 days) b) Radiology – ultrasound renal tract, +/- DMSA c) Pathology tests – U's and E's d) Theatre – examination under anaesthesia and assessment of bladder capacity (1 hour) • consultant urologist • consultant anaesthetist • theatre team Out-patient consultation whilst an inpatient, re the choice of available treatments (bladder neck repair if good BC, bladder augmentation and bladder neck repair/closure + continent diversion if poor BC, urinary diversion) • consultant urologist – 60 mins • nurse specialist – 30 mins on ward • followed by multiple home visits (2 as a baseline x I day each visit due to travel & the consultation) • If decision involves catheterisation then school visits are made pre-operatively • clinical psychologist – 60 mins • OPD costs f) Nurse specialist home visit g) Discharge letter to GP and primary care team If Intermittent self-catheterisation (ISC) is indicated families are given the information DVD produced by Royal Manchester Children's Hospital (RMCH) and the Astratech booklets If Augment with Mitrofonoff is indicated families are given a copy of the information DVD and the "Me and my Mitrofonoff" booklet produced by RMCH. If schools need to be involved in ISC or any other continence aspect a collaborative agreement is developed as part of the patient information package and copies given to school. Information leaflet of tightening of a stoma given to patients who have had a stoma	5 years of age	

		created		
2.	**Orthopaedic OPD review**	a) Consultant orthopaedic surgeon – 20 mins b) OPD costs c) OPD letter to GP and primary care team		

3.	**In patient admission for continent surgery**	Admission to RMCH – ALOS 2 to 3 weeks Pathology Tests - FBC and U's and E's, Blood cross match. Urine culture c) Theatre sessions – 2 sessions - 2 consultant urologist - consultant anaesthetist - theatre team d) Radiology – ultrasound on renal tract before discharging patient home with catheters e) Weekly out-patient review whilst an inpatient f) Nurse specialist regular telephone contact with the family and community nursing teams – 60 mins for all the calls g) Discharge letter to GP and primary care team		
4.	**Re-admission for removal of catheters and continent training**	a) Admission to RMCH – 1 week b) Commencement of continent training by nurse specialist, multiple daily reviews = 2 hours per day c) Radiology – post op ultrasound d) Discharge letter to GP and primary care team If catheterisation has been taught then home visit by nurse specialist 1 week following discharge and contact with school as above. If bladder neck repair (no catheterisation) nurse specialist makes contact with school	6 weeks after surgery	
5.	**Outpatient review**	a) MDT clinic - consultant urologist- 20 mins - nurse specialist – 20 mins - clinical psychologist – 20 mins b) OPD costs c) OPD letter to GP and primary care team	After 6 weeks	

6.	**If patient doing well, outpatient consultations**	a) MDT clinic - consultant urologist – 30 mins - nurse specialist – 30 mins - clinical psychologist – 30 mins b) Radiology – ultrasound of renal tract c) OPD Costs d) OPD letter to GP and primary care team In addition to the above the following is likely to occur: unplanned interventions for recurrent urinary tract infections, increasing dilatation of upper urinary tract, formation of bladder stones, stenosis of the stoma. Nursing and psychological support for patient and family usually necessary. Community team and school need support from RMCH in the majority of the cases (frequent contacts with both medical and nursing staff).	After 6 months	* at any stage if parents are concerned about managing difficult questions or challenging social situations relating to their child's condition they are given the managing curiosity and questions booklet produced by RMCH. At all ages families receive a copy of our annual newsletter
	Transition 13 years plus	Patients given a "preparing to transfer to adult urology services" leaflet. Patients readiness to move to adult services is monitored using a transition checklist which patients can have a copy of if they wish, and will automatically be given a copy of when they are discharged The "4 boys" and "4 girls" leaflets are given out with parental consent from 13 years upwards. In some cases we provide parents with these booklets at an earlier stage so that they can familiarise themselves with the information prior to their child's sex education classes at school.		

Appendix 2 -GOSH care pathway

1. Pre-Birth	**Antenatal diagnosis and counselling**
Day 2	Birth and referral / transfer to GOSH Investigation: Blood screen, Xmatch 1 unit, renal ultrasound Closure: Day 1-3 Bladder closure without osteotomies Epidural anaesthesia and return to ward (PC) 5 day admission to NICU for sedation/ventilation (IM ad PGD) Duration of admission 5 – 14 days. Post op: Ureteric catheters for 1 week Urethral stent for 10-14 days Renal ultrasound before discharge
3 months	EUA cystoscopy at 3 months Assess bladder capacity, urethra and suitability for next step Second ultrasound =/- cystogram
2. KELLY OPERATION	
1 year	**6 to 18 months** Work up: Ultrasound, blood screen and Xmatch 2 units Operation: 3 to 6 hours Ureteric reimplantation Full penile/clitoral and pelvic floor mobilisation Bladder neck reconstruction Urethral reconstruction Sphincter reconstruction Penile/clitoral reconstruction Umbilical reconstruction Post operative: Admission 8-14 days Ureteric catheters 7 days Urethral stent 10-14 days Suprapubic 3-4 weeks Readmission/patient hotel: After 3-4 weeks for clamp and release of suprapubic catheter

	Renal ultrasound CNS assessment Removal of catheter Failure to void: Ultrasound, further EUA/cystoscopy/urethral dilatation Replace Suprapubic Start CIC Ureteric/renal dilatation: MAG 3 renogram EUA/cystoscopy/urethral dilatation
1-2 years	Follow up: Outpatients 3 months for the first year CNS assessment and renal ultrasound before each outpatients
FEMALE PATIENTS FROM 2 YEARS	
2 years	Assessment Review continence by CNS and consultant appointment with renal ultrasound every 6-12 months
3 years	Continent EUA and cysto-vaginoscopy 1-2 years after the Kelly procedure
5 years	Incontinent: CNS review 5 years old start biofeedback 4 day visits per patient to see CNS/use equipment Work up to bladder reconstruction if still wet Revert to continent follow up if dry Reconstruction: Ileocystoplasty Bladder neck reconstruction/closure Mitrofanoff formation 8 – 14 day admission Readmit/patient hotel at 1 month to learn CIC of Mitrofanoff Regular cystoplasty follow up.EUA to assess vagina before puberty
10 years	Transfer to adolescent services at UCLH after puberty
MALE PATIENTS FROM 2 YEARS With hypospadiac urethral opening after Kelly procedure	
2 years	Assessment Review continence by CNS and consultant appointment with renal ultrasound every 6-12 months
Continent:	
	Urethral reconstruction in 2 stages*
3 years	Admission for EUA cystoscopy 1-2 years after Kelly procedure

3-12 years	Observe regularly (1-2 yearly with CNS and consultant review)

Puberty	Transfer to adolescent services at UCLH after puberty
Incontinent:	
	Regular review in OPD with prior CNS assessment and renal ultrasound every 6 - 12 months
2- 5 years	Urethral reconstruction before 5 years in 2 stages
5 years	Still wet try biofeedback at 5 years 4 sessions for 1- 2days with CNS Dry – revert to continent follow up
5 years	Still wet try trial of BHCG stimulation,3 bolus injections over 3 weeks CNS assessment of continence and renal ultrasound before and after stimulation Dry – revert to continent follow up Consider reconstruction if still incontinent Psychologist review Ileocystoplasty Bladder neck reconstruction/closure Mitrofanoff formation 8 – 14 day admission Readmit/patient hotel at 1 month to learn CIC of Mitrofanoff Regular cystoplasty follow up