ID Number:

British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)

Posterior Urethral Valves

Children presenting on or after 1st October 2014 and before 1st October 2015

Data Collection Form

Case Definition:

The eligible cases will be all children in the UK with either an antenatal diagnosis of possible PUV, or newly-diagnosed PUV, confirmed on imaging or cystoscopy, presenting during the study period, irrespective of age at presentation.

Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.
2. Fill in the form using the information available in the infant's case notes.
3. Tick the boxes as appropriate. If you require any additional space to answer a question please use the space provided in section 7.
4. Please complete all dates in the format DD/MM/YY, and all times using the 24hr clock e.g. 18:37
5. **If you do not know the answers to some questions, please indicate this in section 7.**
6. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 7.

Please return the completed form to:

BAPS-CASS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 617775
Phone: 01865 289714

Case reported in: _____

National Perinatal Epidemiology Unit

Section 1: Presentation

1.1 **Date of presentation** D D / M M / Y Y

1.2 **Age at presentation** *(years/months or days)* Y Y / M M ***OR*** D D

1.3 **Did the child present postnatally in the first year of life?** Yes ☐ No ☐

If Yes, how did the child present *(tick all that apply)*

Incidental finding on investigation of antenatal hydronephrosis ☐

Symptomatic with UTI / Renal Impairment ☐

1.4 **Did the patient present after a year of age?** Yes ☐ No ☐

If Yes, tick all the symptoms at presentation

UTI ☐ Renal impairment ☐ Incontinence ☐ Other ☐

If Other, please give details _____

1.5 **Is PUV an isolated abnormality in this child?** Yes ☐ No ☐

If No, please give details of associated abnormalities

_____

Section 2: Antenatal/Birth data (if available)

2.1 **What was the mother's year of birth?** ☐☐☐☐ Not known ☐

2.2 **Please give the first alphabetical part of mother's postcode**
(e.g. OX for Oxfordshire, EH for Edinburgh, L for Liverpool) ☐☐

2.3 **What is the child's Ethnic group[1]*** ☐☐

2.4 **Gestational age at birth** *(completed weeks)* ☐☐ Not known ☐

2.5 **Gender** Male ☐ Indeterminate ☐

2.6 **Birthweight** ☐☐☐☐ g

2.7 **Is there a family history of PUV?** Yes ☐ No ☐

2.8 **Was congenital bladder outlet obstruction suspected antenatally?**
Yes ☐ No ☐ Not known ☐

If Yes, what date was it first suspected? D D / M M / Y Y

What antenatal findings were present? Please indicate in the table below

Feature	**Present** *(please tick)*	**If present on the left, give max diameter**	**If present on the right, give max diameter**	**Gestational age first noted**
Megacystis	☐			
Key-hole sign	☐			
Oligo/anhydramnios	☐			
Hydroureter	Left ☐ Right ☐			
Hydronephrosis	Left ☐ Right ☐			

*For guidance please see back cover

Feature	Present *(please tick)*	If present on the left, give max diameter	If present on the right, give max diameter	Gestational age first noted
Kidney dysplasis				
Echogenic cortex	Left ☐ Right ☐			
Cortical thinning	Left ☐ Right ☐			
Cortical cysts	Left ☐ Right ☐			
Urinary ascites	☐			

Was any antenatal intervention performed? Yes ☐ No ☐

If Yes, please complete table below

Procedure	Performed? *(please tick)*	Date first performed	Result
Amniocentesis	☐	D D / M M / Y Y	Karyotype _____ B2microglobulin _____
Fetal bladder aspiration	☐	D D / M M / Y Y	Sodium _____ Potassium _____ B2microglobulin _____ Bladder decompression _____
Fetal Vesicoamniotic shunt	☐	D D / M M / Y Y	Bladder decompression _____

Were there any complications of the intervention? Yes ☐ No ☐

If Yes, please give details _____

Section 3: Initial Investigations and Management

3.1 Did the child have an initial ultrasound at the tertiary centre? Yes ☐ No ☐

If Yes, was the child catheterised at the time of the ultrasound? Yes ☐ No ☐

What date was this performed? D D / M M / Y Y

Was the bladder? *(please tick one)* Large ☐ Normal size ☐ Small ☐

Please indicate other findings in the table below

Feature	Present *(please tick)*	If present or present on the left, give max measurement (mm)	If present on the right, give max measurement (mm)
Thick–walled Bladder	☐		
Hydroureter	Left ☐ Right ☐		
Hydronephrosis	Left ☐ Right ☐		
Parenchyma abnormality			
Thinned	Left ☐ Right ☐		
Poor cortico-medulary differentiation (CMD)	Left ☐ Right ☐		
Cysts	Left ☐ Right ☐		
Urinoma	☐		

3.2 Did the child have an initial micturating cystourethrogram (MCUG) Yes ☐ No ☐

If Yes, what date was this performed? D D / M M / Y Y

Was PUV suggested? Yes ☐ No ☐ Not diagnostic ☐

Was the bladder? *(please tick one)* Large ☐ Normal size ☐ Small ☐

Did the bladder have any of the following? *(tick all that apply)*

Trabeculation ☐ Diverticuli ☐ Distorted shape ☐

Was there left-sided vesicoureteric reflux (VUR)? *(tick one only)*

None ☐ Non-dilated ☐ Dilated ☐

Was there right-sided vesicoureteric reflux (VUR)? *(tick one only)*

None ☐ Non-dilated ☐ Dilated ☐

Was the urethra? *(tick one only)* Normal ☐ Dilated ☐

3.3 Did the child have bladder catheterisation? Yes ☐ No ☐

If Yes, was this? *(tick one only)* Suprapubic ☐ Urethral ☐

3.4 Was the child polyuric (>4mls/kg/hr)? Yes ☐ No ☐

If Yes, what date did this first start? D D / M M / Y Y Date resolved? D D / M M / Y Y

Tick if not resolved ☐

3.5 What was the child's height (or length) at referral? ☐☐ cms

3.6 Was the creatinine measured after referral? Yes ☐ No ☐

If Yes, please complete table below:

	Result	Height (length) cm if different from Q3.5	Date
Highest creatinine pre-surgery/treatment	µmols/l		D D / M M / Y Y
Plateau* creatinine pre-surgery/treatment	µmols/l		D D / M M / Y Y
Plateau* urine osmolality	mOsm/kg		D D / M M / Y Y

*Plateau defined as steady state post diuresis recovery

Section 4: Initial and Definitive Surgery

4.1 Did the child have surgery? Yes ☐ No ☐

If No, state reason for not having surgery e.g death

_____

If No, *please go to Section 5*

4.2 Type of initial surgery *(tick one only)*

Cystoscopy and incision PUV ☐ Vesicostomy ☐

Ureterostomy ☐ Pyelostomy ☐ Placement of suprapubic catheter (SPC) ☐

Nephrostomy ☐ Drainage intra-abdominal collection ☐ Other ☐

If Other, please specify _____

4.3 What was the indication for surgery? *(tick all that apply)*

Ready for PUV incision ☐ Too small for primary valve ablation ☐

Persistent poor upper tract drainage ☐ Urinoma ☐ Ascites ☐ Other

If Other, please specify _____

4.4 What was the date of initial surgery? D D / M M / Y Y

4.5 Was a cystoscopy performed? Yes ☐ No ☐

If Yes, what date was this performed? D D / M M / Y Y

Was the diagnosis of PUV confirmed? Yes ☐ No ☐

4.6 Was valve ablation performed? Yes ☐ No ☐

If Yes,

On what date was this? D D / M M / Y Y

What were the findings *(tick one only)*

a. Supra-sphincteric obstruction (True PUV)

i. Extensive membrane ☐

ii. Complete membrane ☐

iii. Extensive bilateral leaflets ☐

iv. Right leaflet large ☐

v. Left leaflet large ☐

b. Infra-sphincteric obstruction (Cobbs Collar) ☐

c. Anterior urethral obstruction (Syrinx) ☐

What incisions were made *(please tick all that apply)*?

i. 5 o'clock ☐

ii. 7 o'clock ☐

iii. 12 o'clock ☐

iv. Other ☐

If Other, please specify (describe positions as per 12 hr clock)

_____

Was a bladder neck incision performed? Yes ☐ No ☐

If Yes, where? (describe position as per 12 hr clock)

_____

Was a post-op urethral catheter placed? Yes ☐ No ☐

If Yes, please give date removed D D / M M / Y Y or tick if still in place ☐

4.7 Was a subsequent vesicostomy performed? Yes ☐ No ☐

If Yes, what date was this performed? D D / M M / Y Y

What was the indication for vesicostomy? _____

What was the bladder wall thickness? ☐☐ mm

4.8 Was a subsequent ureterostomy performed? Yes ☐ No ☐

If Yes, what date was this performed? D D / M M / Y Y

What was the indication for ureterostomy? _____

What was the ureter appearance? *(please describe)* _____

_____

4.9 Were any other surgical procedures performed during the initial surgery (e.g. percutaneous drainage of urinoma, stenting of ureters)? Yes ☐ No ☐

If Yes, please specify operation _____

Section 5: Early morbidity (up to 28 days post initial surgery / treatment)

5.1 Please tick those that occurred None ☐ Bleeding ☐ Wound infection ☐ UTI ☐

5.2 Did the child have pulmonary hypoplasia? Yes ☐ No ☐

5.3 Were any further surgical procedures required in the first 28 days post surgery/treatment? Yes ☐ No ☐

If Yes, please give details in the table below:

Date of Surgery	Details of Further Surgical Procedure
D D / M M / Y Y	
D D / M M / Y Y	
D D / M M / Y Y	

5.4 Was the creatinine measured at around 1 month post-surgery/treatment? Yes ☐ No ☐

If Yes, please give result ☐☐ µmols/l

Date of measurement D D / M M / Y Y

And child's height/length if different from Q3.5 ☐☐ cms

5.5 Has the child developed end-stage renal failure? Yes ☐ No ☐

If Yes, what date was it diagnosed? D D / M M / Y Y

Has the child had a kidney transplant? Yes ☐ No ☐

If Yes, was this a living related (LRD) ☐ or cadaveric donation ☐

If No, is the child receiving? Peritoneal dialysis ☐ Haemodialysis ☐

5.6 Did the child have a post treatment ultrasound? Yes ☐ No ☐

If Yes, was the bladder? *(please tick one)* Large ☐ Normal size ☐ Small ☐

Please indicate other findings in the table below

Feature	Present *(please tick)*	If present or present on the left, give max measurement (mm)	If present on the right, give max measurement (mm)
Thick–walled Bladder	☐		
Hydroureter	Left ☐ Right ☐		
Hydronephrosis	Left ☐ Right ☐		
Parenchyma abnormality			
Thinned	Left ☐ Right ☐		
Poor cortico-medulary differentiation (CMD)	Left ☐ Right ☐		
Cysts	Left ☐ Right ☐		
Urinoma	☐		

Section 6: Urinary tract infections

6.1 Has the child ever had UTIs (before and/or after diagnosis)? Yes ☐ No ☐

If Yes, please give details of confirmed UTIs in the table below:

Date	Symptoms e.g. Fever, Vomiting, Smelly urine, Dysuria, Abdo pain	Urine culture If Yes, state organism grown below	Admitted?	Antibiotic used and route of administration (PO/IV)
D D / M M / Y Y		Yes ☐ No ☐	Yes ☐ No ☐	
D D / M M / Y Y		Yes ☐ No ☐	Yes ☐ No ☐	
D D / M M / Y Y		Yes ☐ No ☐	Yes ☐ No ☐	

6.2 Has the child received prophylactic antibiotics? Yes ☐ No ☐

If Yes, what was the most recent antibiotic _____

Dose used _____

What date was this started? D D / M M / Y Y

6.3 Has the child had a circumcision? Yes ☐ No ☐

If Yes, date of operation D D / M M / Y Y

Indication for surgery Prophylaxis ☐ Religious ☐ Other ☐

If Other, please specify _____

Section 7: Outcomes / Other information

7.1 Has the child been discharged home? Yes ☐ No ☐

If Yes, please specify date of discharge D D / M M / Y Y

7.2 Has the child been discharged to another hospital? Yes ☐ No ☐

If Yes, please give name of hospital _____

Name of responsible clinician _____

Date of transfer D D / M M / Y Y

7.3 Did the child die? Yes ☐ No ☐

If Yes, please give date of death D D / M M / Y Y

Cause of death as stated on the death certificate (please state of not known)

_____

7.4 Were the parents given any of the following? *(tick all that apply)* Yes ☐ No ☐

In-hospital produced information leaflets ☐

Contact details for support groups ☐

Information leaflets for support groups ☐

Section 8: Comments

8.1 Please add any other relevant information

Section 9:

9.1 Name of person completing the form _____

9.2 Designation _____

9.3 Today's date D D / M M / Y Y

You may find it useful in the case of queries to keep a copy of this form.

Definitions

UK Census Coding for ethnic group

WHITE
- 01. British
- 02. Irish
- 03. Any other white background

MIXED
- 04. White and black Caribbean
- 05. White and black African
- 06. White and Asian
- 07. Any other mixed background

ASIAN OR ASIAN BRITISH
- 08. Indian
- 09. Pakistani
- 10. Bangladeshi
- 11. Any other Asian background

BLACK OR BLACK BRITISH
- 12. Caribbean
- 13. African
- 14. Any other black background

CHINESE OR OTHER ETHNIC GROUP
- 15. Chinese
- 16. Any other ethnic group