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: ____________________
Section 1: Presentation

1.1 Date of presentation D D M M Y Y M D

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*

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 M D

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

<table>
<thead>
<tr>
<th>Feature</th>
<th>Present (please tick)</th>
<th>If present on the left, give max diameter</th>
<th>If present on the right, give max diameter</th>
<th>Gestational age first noted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Megacystis</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Key-hole sign</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oligo/anhydramnios</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hydroureter</td>
<td>Left ☐ Right ☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hydronephrosis</td>
<td>Left ☐ Right ☐</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*For guidance please see back cover
### Section 3: Initial Investigations and Management

#### 3.1 Did the child have an initial ultrasound at the tertiary centre?

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

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

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

Please indicate other findings in the table below

<table>
<thead>
<tr>
<th>Feature</th>
<th>Present (please tick)</th>
<th>If present on the left, give max measurement (mm)</th>
<th>If present on the right, give max measurement (mm)</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Thick–walled Bladder</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Parenchyma abnormality</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thinned</td>
<td>Left ☐ Right ☐</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Cysts</td>
<td>Left ☐ Right ☐</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urinoma</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Was any antenatal intervention performed?  
Yes ☐ No ☐

If Yes, please complete table below

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Performed? (please tick)</th>
<th>Date first performed</th>
<th>Result</th>
</tr>
</thead>
</table>
| Amniocentesis                  | ☐                        | /D D M M Y YMD       | Karyotype ☐
|                               |                          |                      | B2microglobulin ☐ |
| Fetal bladder aspiration       | ☐                        | /D D M M Y YMD       | Sodium ☐
|                               |                          |                      | Potassium ☐
|                               |                          |                      | B2microglobulin ☐
|                               |                          |                      | Bladder decompression |
| Fetal Vesicoamniotic shunt     | ☐                        | /D D M M Y YMD       | Bladder decompression |

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

If Yes, please give details ____________________________
3.2 Did the child have an initial micturating cystourethrogram (MCUG)?
   If Yes, what date was this performed?  
   Was PUV suggested?  
   Was the bladder? (please tick one)  
   Did the bladder have any of the following? (tick all that apply)  
   Was there left-sided vesicoureteric reflux (VUR)? (tick one only)  
   Was there right-sided vesicoureteric reflux (VUR)? (tick one only)  
   Was the urethra? (tick one only)  

3.3 Did the child have bladder catheterisation?  
   If Yes, was this? (tick one only)  

3.4 Was the child polyuric (>4mls/kg/hr)?  
   If Yes, what date did this first start?  
   Date resolved?  
   Tick if not resolved  

3.5 What was the child’s height (or length) at referral?  

3.6 Was the creatinine measured after referral?  
   If Yes, please complete table below:  
   *Plateau defined as steady state post diuresis recovery  

Section 4: Initial and Definitive Surgery

4.1 Did the child have surgery?  
   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)  

4.3 What was the indication for surgery? (tick all that apply)  
   If Other, please specify  

If Other, please specify
4.4 What was the date of initial surgery?

4.5 Was a cystoscopy performed?
   If Yes, what date was this performed?
   Was the diagnosis of PUV confirmed?

4.6 Was valve ablation performed?
   If Yes,
     On what date was this?
     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)

4.7 Was a bladder neck incision performed?
   If Yes, where? (describe position as per 12 hr clock)

4.8 Was a post-op urethral catheter placed?
   If Yes, please give date removed or tick if still in place

4.9 Were any other surgical procedures performed during the initial surgery (e.g. percutaneous drainage of urinoma, stenting of ureters)?
   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?

If Yes, please give details in the table below:

<table>
<thead>
<tr>
<th>Date of Surgery</th>
<th>Details of Further Surgical Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>D M Y YMD</td>
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</tr>
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<td></td>
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<td></td>
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5.4 Was the creatinine measured at around 1 month post-surgery/treatment?

If Yes, please give result

- [ ] Yes
- [ ] No

Date of measurement

<table>
<thead>
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And child’s height/length if different from Q3.5

<table>
<thead>
<tr>
<th>Height/length</th>
</tr>
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<tbody>
<tr>
<td>cms</td>
</tr>
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</table>

5.5 Has the child developed end-stage renal failure?

If Yes, what date was it diagnosed?

- [ ] Yes
- [ ] No

Has the child had a kidney transplant?

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?

If Yes, was the bladder? (please tick one)

- [ ] Large
- [ ] Normal size
- [ ] Small

Please indicate other findings in the table below

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Section 6: Urinary tract infections

6.1 Has the child ever had UTIs (before and/or after diagnosis)?

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

<table>
<thead>
<tr>
<th>Date</th>
<th>Symptoms e.g. Fever, Vomiting, Smelly urine, Dysuria, Abdo pain</th>
<th>Urine culture If Yes, state organism grown below</th>
<th>Admitted?</th>
<th>Antibiotic used and route of administration (PO/IV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>D D M M YYYY</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
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<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
<td>D D M M YYYY</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
<td>Yes ☐ No ☐</td>
</tr>
</tbody>
</table>

6.2 Has the child received prophylactic antibiotics?

  If Yes, what was the most recent antibiotic __________________________

  Dose used __________________________

  What date was this started? D D M M YYYY

6.3 Has the child had a circumcision?

  If Yes, date of operation D D M M YYYY

  Indication for surgery

  Prophylaxis ☐ Religious ☐ Other ☐

  If Other, please specify __________________________

Section 7: Outcomes / Other information

7.1 Has the child been discharged home?

  If Yes, please specify date of discharge D D M M YYYY

7.2 Has the child been discharged to another hospital?

  If Yes, please give name of hospital __________________________

  Name of responsible clinician __________________________

  Date of transfer D D M M YYYY

7.3 Did the child die?

  If Yes, please give date of death D D M M YYYY

  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)

  In-hospital produced information leaflets ☐

  Contact details for support groups ☐

  Information leaflets for support groups ☐
Section 9:

9.1 Name of person completing the form

9.2 Designation

9.3 Today's date

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