

Clinical Practice Snapshot

Posterior Urethral Valves

FINAL VERSION, 231010

1. Please update the common data elements. (*Changes might have occurred in patient status/hospital or treatment/genetics/diagnostics etc.*)
 - I have changed nothing [Radio button, one selection]
 - I have added (previously unknown) information

2. 1st surgical procedure performed to resect the valves: (*Should be performed in **this** HCP*)
 - a. Date: [Date, dd/mm/yy format; at/after DoB]
 - b. Procedure:
 - Cold knife Hot knife [Radio button, one selection]
 - Unknown Other [If selected "Other", a text box [string] will appear.]

3. 2nd surgical procedure performed to check for and, if applicable, resect valve remnants: (*Should be performed in **this** HCP*)
 - a. Was there a control cystoscopy performed?
 - Yes No Unknown [Radio button, one selection]
 - (if yes, answer question 2b and 2c)
 - b. Date first checkup cystoscopy: [Date, dd/mm/yy format; at/after Date of 1st Surgery]
 - c. Was there a re-excision performed during the first control cystoscopy?
 - Yes No [Radio button, one selection]
 - d. Surgical and/or requiring general anesthesia: [Tick-box, multiple selection]
 - Reresection Date [Date, dd/mm/yy format; at/after DoB]
 - Vesicostomy Date [Date, dd/mm/yy format; at/after DoB]
 - Open ureterostomies Date [Date, dd/mm/yy format; at/after DoB]
 - Anti reflux surgery Date [Date, dd/mm/yy format; at/after DoB]
 - Ureterectomy Date [Date, dd/mm/yy format; at/after DoB]
 - Nephrectomy Date [Date, dd/mm/yy format; at/after DoB]
 - Catheterisable stoma Date [Date, dd/mm/yy format; at/after DoB]
 - Bladder augment Date [Date, dd/mm/yy format; at/after DoB]
 - Transplantation Date [Date, dd/mm/yy format; at/after DoB]
 - Otis urethrotomy and/or urethral dilatations Date [Date, dd/mm/yy format; at/after DoB]
 - Suprapubic catheter Date [Date, dd/mm/yy format; at/after DoB]
 - Botuline toxine (Botox[®]) injections Date [Date, dd/mm/yy format; at/after DoB]
 - Hyaluronic Acid/Dextranome (Deflux[®]) injections Date [Date, dd/mm/yy format; at/after DoB]
 - Other [If selected, a text box [string] will appear.] Date [Date, dd/mm/yy format; at/after DoB]
 - No additional interventions

(If any selected, it's asked how many of these procedures are performed and up to 5 procedures can be entered)

e. Non-surgical or not requiring general anaesthesia:

- Clean Intermittent Catheterisation (CIC) Date [Date, dd/mm/yy format; at/after DoB]
- Percutaneous Tibial Nerve Stimulation (PTNS) Date [Date, dd/mm/yy format; at/after DoB]
- Other [If selected, a text box [string] will appear.] Date [Date, dd/mm/yy format; at/after DoB]
- No additional interventions

(If any selected, it's asked how many of these procedures are performed and up to 5 procedures can be entered)

4. Renal function renography MAG-3 / DMSA:

a. Performed (If multiple renographies were performed, please answer this question for the first one):

- Yes, MAG-3 No [Radio button, one selection]
- Yes, DMSA Unknown

(if yes, answer questions 4b, 4c, and 4d)

b. Date first function renography: [Date, dd/mm/yy format; at/after DoB]

c. Left function during first renography (in %): [Numeric (Integer)]

d. Right function during first renography (in %): [Autocomplete with Numeric (Integer)=100-Left]

5. First micturition cystourethrography (MCG) vesico-ureteric reflux (VUR) before surgery:

a. Performed:

- Yes No Unknown [Radio button, one selection]
- (if yes, answer questions 5b, 5c and 5d)

b. Date first MCG VUR: [Date, dd/mm/yy format; at/after DoB]

c. VUR present left during first MCG VUR:

- Yes No Unknown [Radio button, one selection]

d. VUR present right during first MCG VUR:

- Yes No Unknown [Radio button, one selection]

6. Lowest creatinine:

a. Creatinine measurements (if applicable, if patient is on dialysis or transplantation: Were creatinine measurements performed prior to the start of dialysis or transplantation?)

- Yes No Unknown [Radio button, one selection]
- (if yes, answer questions 6b, 6c, 6d and 6e)

b. Lowest creatinine value ($\mu\text{mol/l}$) at or before surgery: [Numeric (Integer)]

c. Date lowest creatinine was measured at or before surgery: [Date, dd/mm/yy format; at/after DoB]

d. Creatinine value ($\mu\text{mol/l}$) at approximately one year of age:

(if the patient underwent surgery after one year of age, please use the measurement approximately one year after surgery) [Numeric (Integer)]

e. Date creatinine was measured at approximately one year of age: [Date, dd/mm/yy format; at/after DoB]

(if the patient underwent surgery after one year of age, please use the measurement approximately one year after surgery)

7. Last follow up date (The last follow up date is the last moment of (telephone) contact with the treating doctor or nurse practitioner for (issues relating to) this diagnosis.):

 [Date, dd/mm/yy format; at/after DoB]



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