

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: [Radio button, one selection]
 - Cold knife Hot knife
 - 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? [Radio button, one selection]
 - Yes No Unknown
 - (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? [Radio button, one selection]
 - Yes No
 - 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. Lowest creatinine value ($\mu\text{mol/l}$) at approximately one year of age: [Numeric (Integer)]

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

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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