



Clinical Practice Snapshot

Bladder exstrophy

DRAFT VERSION, 240821

Specify diagnosis

Exstrophy-epispadias complex

- Isolated epispadias **Classic bladder exstrophy** Exstrophy variants Cloacal exstrophy

1. Please update the common data elements. (*Changes might have occurred in patient status/hospital or treatment/genetics/diagnostics etc.*) [Radio button, one selection]

- I have changed nothing
 I have added (previously unknown) information

2. Primary diagnosis [Checkbox, multiple selection]

- a. Which diagnostics were performed after initial diagnosis [Checkbox, multiple selection]
- X-ray of pelvis
 Ultrasound of the kidneys
 Culture bladder plate
 Creatinine measurements of child (at least 72 hours after birth)
 Other diagnostics/imaging
 Unknown
- (If 'X-ray of pelvis', answer question 2b)
(If 'Ultrasound of the kidneys', answer question 2c
(If 'Culture bladder plate' answer question 2d)
(If 'Creatinine measurements', answer question 2e, 2f and 2g)
(If 'Other diagnostics/imaging', answer question 2i and 2j)*
- b. Date x-ray of pelvis [Date, dd/mm/yy format; at/after DoB]
- c. Date ultrasound of kidneys [Date, dd/mm/yy format; at/after DoB]
- d. Date culture bladder plate [Date, dd/mm/yy format; at/after DoB]
- e. Date first creatinine measurement of child (first creatinine measurement of child, be aware that first creatinine measurements within 72h of birth might represent creatinine values of the mother) [Date, dd/mm/yy format; at/after DoB]
- f. First creatinine value of child (first creatinine measurement of child, be aware that first creatinine measurements within 72h of birth might represent creatinine values of the mother). [Numeric, 1 decimal]
- g. Unit creatine value [Radio button, one selection]
- mmol/L
 μmol/L
 mg/dL
 Other creatinine unit
 Unknown
- (If 'Other creatinine unit', answer question 2h)*
- h. Other creatinine unit [String]
- i. Date other diagnostics/imaging [Date, dd/mm/yy format; at/after DoB]
- j. Specification other diagnostics/imaging [String]

- k. Initial wound coverage before primary closure [Checkbox, multiple selection]
 No coverage
 Diaper
 Wet gauze
 Other wound coverage
 Unknown
(If 'Other wound coverage', answer question 2l)
- l. Other wound coverage [String]

3. Primary surgery

- a. Was primary closure surgery performed? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 3c)
(If 'No', answer question 3b)
- b. Reason no primary closure surgery? [String]
- c. Was primary surgery performed at the Health Care Provider for which you are registering this patient? [Radio button, one selection]
 Yes No Unknown
(If 'No', answer question 3d)
- d. Where was the primary surgery performed? [String]
- e. Was the primary closure surgery performed in a multi stage repair? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer Topic 4)
- f. Date of primary surgery [Date, dd/mm/yy format; at/after DoB]
- g. Procedure performed at primary surgery [Checkbox, multiple selection]
 Primary closure only
 Primary closure with osteotomy
 Symphysis approximation without osteotomy
 Bladder neck reconstruction
 Epispadias reconstruction
 Ureteral reimplant
 Inguinal hernia repair
 Umbilicus reconstruction
 Genital mobilization in female
 Introitus plasty
 Soft in-tissue mobilization (Kelly procedure)
 Unknown
 Other primary surgical procedure
(If 'Primary closure with osteotomy', answer question 3h and 3i)
(If 'Bladder neck reconstruction', answer question 3j and 3k)
(If 'Ureteral implant', answer question 3l)
(If 'Other', answer question 3m)
- h. Which type of osteotomy was performed? [Radio button, one selection]
 Anterior
 Lateral
 Posterior
 Combined lateral and posterior
 Unknown
- i. The osteotomy was performed [Radio button, one selection]
 Unilateral Bilateral Unknown
- j. Type of bladder neck reconstruction [String]
- k. Was the bladder neck reconstruction performed to achieve urine continence?
 Yes No Unknown
- l. Which type of ureteral reimplant was performed? [Radio button, one selection]
 Right Left Bilateral Unknown
- m. Specification other primary surgical procedure [String]
- n. Type of immobilization after primary closure [Radio button, one selection]

- None
- Mermaid
- Cast
- Bryant's traction
- Other type of immobilization
- Unknown

(If 'Other type of immobilization', answer question 3o)

- o. Specification other type of immobilization [String]
- p. Type of drainage after primary closure [Checkbox, multiple choice]
 No (specific) drainage
 Suprapubic catheter
 1 ureteral splint
 2 ureteral splints
 Transurethral catheter
 Wound drain
 Other type of drainage
 Unknown
(If 'Suprapubic catheter', answer question 3q)
(If '1 ureteral splint', answer question 3r and 3s)
(If '2 ureteral splints', answer question 3t)
(If 'Transurethral catheter', answer question 3y)
(If 'Wound drain', answer question 3z)
(If 'Other type of drainage', answer question 3aa and 3bb)
- q. Removal date suprapubic catheter [Date, dd/mm/yy format; at/after Date surgery]
- r. Position ureteral splint [Radio button, one selection]
 Left kidney Right kidney Unknown
- s. Removal date 1 ureteral splint [Date, dd/mm/yy format; at/after Date surgery]
- t. Were the two ureteral splints removed at the same time? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 3u)
(If 'No', answer question 3v, 3w and 3x)
- u. Removal date of the 2 ureteral splints [Date, dd/mm/yy format; at/after Date surgery]
- v. Which ureteral splint was removed first?
 Left kidney Right kidney Unknown
- w. Removal date left ureteral splint [Date, dd/mm/yy format; at/after Date surgery]
- x. Removal date right ureteral splint [Date, dd/mm/yy format; at/after Date surgery]
- y. Removal date transurethral catheter [Date, dd/mm/yy format; at/after Date surgery]
- z. Removal date wound drain [Date, dd/mm/yy format; at/after Date surgery]
- aa. Specification other type of drainage [String]
- bb. Removal date other type of drainage [Date, dd/mm/yy format; at/after Date surgery]
- cc. Was treatment with prophylactic antibiotics started after primary closure? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 3dd)
- dd. Type of prophylactic antibiotics [Radio button, one selection]
 Trimethoprim
 Nitrofurantoin
 Amoxicillin
 Amoxicillin clavulanic acid
 Other type of prophylactic antibiotics
 Unknown

(If 'Other type of antibiotics, answer question 3ee)
ee. Specification other type of antibiotics [String]

4. Additional interventions (multi stage repair)
Which additional interventions were performed? [Checkbox, multiple selection]

- a. None
 Bladder neck reconstruction
 Epispadias reconstruction
 Ureteral reimplant
 Inguinal hernia repair
 Umbilicus reconstruction
 Genital mobilization in female
 Introitus plasty
 Soft in-tissue mobilization (Kelly procedure)
 Unknown
 Other additional surgical procedure (If 'Bladder neck reconstruction', answer question 4b and 4c)

(If 'Ureteral implant', answer question 4d)

(If 'Other', answer question 4e)

(If not 'None', a date field will appear per performed additional intervention)

b. Type of bladder neck reconstruction [String]

c. Was the bladder neck reconstruction performed to achieve urine continence? [Radio button, one selection]
 Yes No Unknown

d. Which type of ureteral reimplant was performed? [Radio button, one selection]
 Right Left Bilateral Unknown

e. Specification other additional surgical procedure [String]

f. Date additional intervention (one per performed additional intervention) [Date, dd/mm/yy format; at/after Date of primary surgery]

5. Reoperation (for complications) within two years of the start date of treatment (see comment at top of the Clinical Practice Snapshot):

a. Total number of reoperations (performed in this and other HCPs) [Numeric (integer)]

(Depending on the number of reoperations, questions 5c-5e will appear that many times, with a maximum of 10 reoperations)

(If 'Number of reoperations' > 0, answer question 5b)

b. Number of reoperations performed at another HCP [Numeric (integer)]

c. Indication reoperation [Check box, multiple selection]

- Failed bladder closure
 Urethral stricture
 Cystolithiasis (bladder stones)
 Urethral fistula
 Other
 Unknown

(If 'Other', answer question 5d)

d. Specification other reason reoperation [String]

e. Date of reoperation: [Date, dd/mm/yy format; at/after Date 1st surg]

6. Was Clean Intermittent Catheterisation (CIC) started in the first two years of life (before the age of 2)?

a. Was early CIC performed? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 6b)

b. Date early CIC [Date, dd/mm/yy format; at/after DoB]

7. Specialists involved/Multidisciplinary team

- a. Which specialists were consulted in the treatment of this patient / who are involved in the multidisciplinary team? [Checkbox, multiple selection]
- Nurse specialist
 - Pediatric psychologist
 - Social worker
 - Orthopedist
 - Paediatric urologist/surgeon
 - Paediatric nephrologist
 - Endocrinologist
 - Other expert
 - Unknown
- (If 'Other expert', answer question 7b)*
- b. Specification other expert [String]
-

8. Follow-up

- a. Date Last follow-up in HCP within two years of the start date of treatment (see comment at top of the Clinical Practice Snapshot) [Date, dd/mm/yy format; at/after DoB]
-
- Which additional diagnostics have been performed within two years of the start date of treatment (see comment at top of the Clinical Practice Snapshot)? [Checkbox, multiple selection]
- Video Urodynamic Study (VUDS)
 - Urodynamic Study (UDS)
 - Micturition cystourethrography (MCG)
 - Ultrasound of the kidneys
 - Urine culture
 - Serum creatinine
 - Other additional diagnostics
 - Unknown
- (If 'VUDS', answer question 8b and 8c)*
(If 'UDS', answer question 8d and 8e)
(If 'MCG', answer question 8f and 8g)
(If 'UDS' and/or 'VUDS', answer question 8h and 8i)
(If 'MCG' and/or 'VUDS', answer question 8j, 8l)
(If 'Ultrasound of the kidneys', answer question 8o, 8p, 8r, 8s, 8u, 8w, 8aa and 8bb)
(If 'Urine culture', answer question 8dd and 8ee)
(If 'Serum creatinine', answer question 8ff, 8gg, 8hh, 8jj, 8kk, 8ll)(If 'Other additional diagnostics', answer question 8nn)
- b. Number of VUDS performed in HCP within two years from the start date of treatment [Numeric, integer]
-
- c. Date last VUDS [Date, dd/mm/yy format; at/after DoB]
-
- d. Number of UDS performed in HCP within two years from the start date of treatment [Numeric, integer]
-
- e. Date last UDS [Date, dd/mm/yy format; at/after DoB]
-
- f. Number of MCG performed in HCP within two years from the start date of treatment [Numeric, integer]
-
- g. Date last MCG [Date, dd/mm/yy format; at/after DoB]
-
- h. How much is the bladder capacity (mL)? [Numeric, integer]
-
- i. Is there less compliancy of the bladder (as seen on the (V)UDS)? [Radio button, one selection]
- Yes No Unknown
- j. Vesicoureteral reflux (VUR) present left during MCG [Radio button, one selection]
- Yes No Unknown
- (If 'Yes', answer question 8k)*
- k. Grade VUR [Radio button, one selection]
- 1 2 3 4 5 Unknown
- l. VUR present right during MCG [Radio button, one selection]
- Yes No Unknown
- (If 'Yes', answer question 8m)*

- m. Grade VUR [Radio button, one selection]
 1 2 3 4 5 Unknown
- n. Is there an overactive bladder? [Radio button, one selection]
 Yes No Unknown
- o. Number of ultrasounds of the kidney performed in HCP within two years from the start date of treatment
 [Numeric, integer]
- p. Date last ultrasound of the kidneys [Date, dd/mm/yy format; at/after DoB]
- q. Number of kidneys present [Radio button, one selection]
 1 2 3 Unknown
(If '3', answer question 8t, 8y, 8cc)
- r. Length of left kidney (craniocaudal dimension, in cm)? [Numeric, integer]
- s. Length of right kidney (craniocaudal dimension, in cm)? [Numeric, integer]
- t. Length of third kidney (craniocaudal dimension, in cm)? [Numeric, integer]
- u. Hydronephrosis of left kidney present on last ultrasound of the kidneys within two years from the start date of treatment? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 8v)
- v. Grade hydronephrosis [Radio button, one selection]
 1 2 3 4 Unknown
- w. Hydronephrosis of right kidney present on last ultrasound of the kidneys within two years from the start date of treatment? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 8y)
- x. Grade hydronephrosis [Radio button, one selection]
 1 2 3 4 Unknown
- y. Hydronephrosis of third kidney present on last ultrasound of the kidneys within two years from the start date of treatment? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 8z)
- z. Grade hydronephrosis [Radio button, one selection]
 1 2 3 4 Unknown
- aa. Was debris present in the left kidney on the last ultrasound of the kidneys within two years from the start date of treatment? [Radio button, one selection]
 Yes No Unknown
- bb. Was debris present in the right kidney on the last ultrasound of the kidneys within two years from the start date of treatment? [Radio button, one selection]
 Yes No Unknown
- cc. Was debris present in the third kidney on the last ultrasound of the kidneys within two years from the start date of treatment? [Radio button, one selection]
 Yes No Unknown
- dd. Date last urine culture [Date, dd/mm/yy format; at/after DoB]
- ee. Of all performed urine cultures within two year from the start date of treatment, how many urine cultures were positive? [Radio button, one selection]
 0 1 2-5 >5 Unknown
- ff. Date creatinine value at/around 1 year of age [Date, dd/mm/yy format; at/after DoB]
- gg. Value creatinine measurement at/around 1 year of age [Numeric, 1 decimal]
- hh. Unit creatine value at/around 1 year of age [Radio button, one selection]
 mmol/L
 μmol/L
 mg/dL
 Other creatinine unit
 Unknown
(If 'Other creatinine unit', answer question 8ii)
- ii. Other creatinine unit [String]

-
- jj. Date last creatinine value within two years of the start date of treatment (see comment at top of the Clinical Practice Snapshot) [\[Date, dd/mm/yy format; at/after DoB\]](#)
-
- kk. Value last creatinine measurement within two years of the start date of treatment (see comment at top of the Clinical Practice Snapshot) [\[Numeric, 1 decimal\]](#)
-
- ll. Unit last creatine value [\[Radio button, one selection\]](#)
- mmol/L
- μ mol/L
- mg/dL
- Other creatinine unit
- Unknown
- (If 'Other creatinine unit', answer question 8mm)*
- mm. Other creatinine unit [\[String\]](#)
-
- nn. Specification other additional diagnostics [\[String\]](#)
-
- oo. Which continence materials are used? [\[Check box, multiple selection\]](#)
- No materials (child is continent)
- Normal diapers
- Special continence materials
- Other continence materials
- Unknown
- (If 'Other continence materials', answer question 8pp)*
- pp. Specification other continence materials [\[String\]](#)
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