

Clinical Practice Snapshot

Anorectal Malformations

FINAL VERSION, 230531

1. General

1.1. Please update the common data elements. (*Changes might have occurred in patient status/hospital or treatment/genetics/diagnosis, etc.*)

- I have changed nothing (0) [Radio button, single selection]
- I have added previously unknown information (1)

2. Type of malformation

2.1. *If Rare or complex disease is not anorectal malformation (CDE)*, type of anorectal malformation

- Perineal fistula
- Rectourethral fistula (undetermined type)
- Rectourethral fistula, bulbar type
- Rectourethral fistula, prostatic type
- Rectovesical fistula (bladderneck fistula)
- Vestibular fistula
- Cloacal malformation
- No fistula
- Anal stenosis
- Pouch colon
- Rectal atresia
- Rectal stenosis
- Rectovaginal fistula
- H-type fistula
- Not determined or unknown
- Other → *if selected other, a text box [string] will appear*

3. Patient characteristics

3.1. Was this patient referred from another clinic?

- No, this patient was first seen in this clinic (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

3.1.1. *If yes*, what was this patient referred for?

- Surgery only (1) [Radio button, single selection]
- Second opinion (2)
- As part of a collaboration (3)
- Transfer of all care to a specialized center (4)
- Other (4) *if selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

3.1.2. *If yes*, was this patient referred from another country?

- No, from a clinic within the same country (0) [Radio button, single selection]

- Yes (1)
- Unknown / no information in medical file (99)

3.1.2.1. *If no or yes, what is the name [string] of the clinic this patient was referred from?*

4. Diagnostics and associated abnormalities

4.1. Has an ultrasound of the kidneys and bladder been performed?

- No or not yet (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.1.1. *If no, why not?*

[Checkbox, multiple selection]

- It is planned and has not taken place yet (1)
- No indication (2)
- Other (3) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

4.1.2. *If yes, date first ultrasound: [date format]*

- *Must be after date of birth; calculate and show age (days) of patient at time of ultrasound*

4.1.3. *If yes, were any abnormalities found on this first ultrasound of the kidneys and bladder?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.1.3.1. *If yes, what abnormalities were found during this ultrasound of the kidneys and bladder?*

[Checkbox, multiple selection]

- Hydronephrosis (1)
- Dysplastic / hypoplastic kidney (2)
- Renal agenesis / absent kidney (3)
- Horseshoe kidney (4)
- Ectopic kidney (5)
- Renal cyst(s) (6)
- Duplicated collecting system (7)
- Mega-ureter (12)
- Other (11) *If selected other, a text box [string] will appear*

4.1.3.1.1. *If any, which kidney is affected?*

[Radio button, single selection]

- Left (1)
- Right (2)
- Both (3)
- Unknown / no information in medical file (99)

4.2. Has a voiding cystourethrogram (VCUG) been performed?

- No or not yet (0) *If selected, 'why not' options of 2.1.1 will appear* [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.2.1. *If yes, date first VCUG: [date format]*

- *Must be after date of birth; calculate and show age (weeks) of patient at time of VCUG*

4.2.2. *If yes, was vesicourethral reflux diagnosed during this first VCUG?*

- No (0) [Radio button, single selection]
- Yes (1) *If selected, 'left' or 'right' will appear, then grade 1-5 options will appear*
- Unknown / no information in medical file (99)

- 4.3. Have urodynamic studies (UDS) been performed?
- No or not yet (0) *If selected, 'why not' options of 2.1.1 will appear* [Radio button, single selection]
 - Yes (1)
 - Unknown / no information in medical file (99)
- 4.3.1. *If yes, date first UDS:* [date format]
- Must be after date of birth; calculate and show age (weeks) of patient at time of UDS*
- 4.3.2. *If yes, were any abnormalities found on this first UDS?*
- No (0) [Radio button, single selection]
 - Yes, neurogenic bladder (1)
 - Yes, other (77) *If selected other, a text box [string] will appear*
 - Unknown / no information in medical file (99)
- 4.4. Has a cystoscopy been performed?
- No or not yet (0) *If selected, 'why not' options of 2.1.1 will appear* [Radio button, single selection]
 - Yes (1)
 - Unknown / no information in medical file (99)
- 4.4.1. *If yes, date first cystoscopy:* [date format]
- Must be after date of birth; calculate and show age (weeks) of patient at time of cystoscopy*
- 4.4.2. *If yes, were any abnormalities found on this first cystoscopy?*
- No (0) [Radio button, single selection]
 - Yes (1)
 - Unknown / no information in medical file (99)
- 4.4.2.1. *If yes, what abnormalities were found on this first cystoscopy?* [Checkbox, multiple selection]
- Bladder trabeculation (1)
 - Ectopic ureter (2)
 - Posterior urethral valves (3)
 - Urethral stricture (4)
 - Other (77) *If selected other, a text box [string] will appear*
- 4.5. (IF FEMALE) Has a vaginoscopy been performed?
- No or not yet (0) *If selected, 'why not' options of 2.1.1 will appear* [Radio button, single selection]
 - Yes (1)
 - Unknown / no information in medical file (99)
- 4.5.1. *If yes, date first vaginoscopy:* [date format]
- Must be after date of birth; calculate and show age (weeks) of patient at time of vaginoscopy*
- 4.5.2. *If yes, were any abnormalities found on this first vaginoscopy?*
- No (0) [Radio button, single selection]
 - Yes (1)
 - Unknown / no information in medical file (99)
- 4.5.2.1. *If yes, what abnormalities were found on this first vaginoscopy?*
- Hydrocolpos (1) [Checkbox, multiple selection]
 - Vaginal septum (2)
 - Vaginal atresia (3)
 - Mullerian remnants / vaginal agenesis (4)

- Other (77) *If selected other, a text box [string] will appear*

4.6. Has an X-ray of the spine and/or sacrum been performed?

- No or not yet (0) *If selected, 'why not' of 2.1.1 options will appear* [Radio button, single selection]
- Yes (1)
- Unknown (99)

4.6.1. *If yes, date first X-ray of the spine and/or sacrum:* [date format]

- *Must be after date of birth; calculate and show age (weeks) of patient at time of X-ray*

4.6.2. *If yes, were any abnormalities found during this first X-ray of the spine and/or sacrum?*

- No (0) [Checkbox, multiple selection]
- Vertebral malformations (e.g., hemivertebrae, butterfly vertebrae, supernumerary vertebrae, fusion of vertebrae) (1)
- Spinal malformations (e.g., scoliosis, kyphosis, lordosis, absence or fusion of spine) (2)
- Costal malformations (e.g., cervical ribs, accessory ribs, absence or fusion of ribs) (3)
- Sacral malformations (e.g., complete or partial coccygeal agenesis, hemisacrum, sacral hypoplasia, partial sacral agenesis, complete sacral agenesis, fused sacral vertebrae) (5)
- Other (4) *If selected other, a text box [string] will appear*
- Unknown / no information in medical file (99)

4.6.2.1. *If vertebral* → show all options listed with checkbox

4.6.2.2. *If spinal* → show all options listed with checkbox

4.6.2.3. *If costal* → show all options listed with checkbox

4.6.2.4. *If sacral* → show all options listed with checkbox

4.6.2.5. *If any except No, is there need for (orthopedic / neurologic) follow-up?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.7. Has an ultrasound of the spine been performed?

- No or not yet (0) *If selected, 'why not' options will appear* [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.7.1. *If yes, date first ultrasound of the spine:* [date format]

- *Must be after date of birth; calculate and show age (weeks) of patient at time of ultrasound*

4.7.2. *If yes, were any abnormalities found during this first ultrasound of the spine? (Other than those found on the X-ray, if applicable)*

- No (0) [Checkbox, multiple selection]
- Tethered cord (1)
- Terminal filum lipoma (2)
- Syrinx (3)
- Presacral mass (4)
- Spinal dysraphism/spina bifida (5)
- Caudal regression syndrome (7)
- Other (6) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

4.7.2.1. *If any except No, is there need for neurological or neurosurgical follow-up (including referral)?*

- No (0) [Radio button, single selection]
- Yes (1)

- Unknown / no information in medical file (99)

4.7.2.2. *If any except No, did the patient undergo any neurosurgical intervention(s)?*

- No (0) [Radio button, single selection]
- Yes (1) *If selected a text box to enter [date] will appear.*
- Unknown / no information in medical file (99)

4.8. Has an MRI of the spine and/or pelvis been performed?

- No or not yet (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.8.1. *If no, why not?*

[Checkbox, multiple selection]

- It is planned and has not taken place yet (1)
- No indication (e.g., ultrasound was normal) (2)
- Other (77) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

4.8.2. *If yes, date first MRI of the spine and/or pelvis: [date format]*

- *Must be after date of birth; calculate and show age (weeks) of patient at time of MRI*

4.8.3. *If yes, what section was investigated on the MRI?*

[Radio button, single selection]

- The complete spine (0)
- Only the pelvis/sacrum and coccyx (1)
- Unknown / no information in medical file (99)

4.8.4. *If yes, were any abnormalities found during this first MRI of the spine and/or pelvis? (Other than those found on the X-ray, if applicable)*

- No (0) [Checkbox, multiple selection]
- Tethered cord (1)
- (Filum terminale) Lipoma (2)
- Syrinx (3)
- Presacral mass (4)
- Spinal dysraphism/spina bifida (5)
- Caudal regression syndrome (7)
- Other (6) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

4.8.4.1. *If any except No, is there need for neurological or neurosurgical follow-up (including referral)?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.8.4.2. *If any except No, did the patient undergo any neurosurgical intervention(s)?*

- No (0) [Radio button, single selection]
- Yes (1) *If selected a text box to enter [date] will appear.*
- Unknown / no information in medical file (99)

4.9. Has an echocardiogram (ultrasound of the heart) been performed?

- No or not yet (0) *If selected, 'why not' options will appear* [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.9.1. *If yes, date first echocardiogram: [date format]*

- *Must be after date of birth; calculate and show age (days) of patient at time of echocardiogram*

4.9.2. *If yes, were any abnormalities found during this first echocardiogram?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.9.2.1. *If yes, what abnormalities were found during this first echocardiogram?*

- Open / patent foramen ovale (7) [Checkbox, multiple selection]
- Atrial septal defect (other than above) (2)
- Persistent ductus arteriosus / open duct of Botalli (1)
- Ventricular septal defect (3)
- Pulmonary valve stenosis (8)
- Pulmonary hypertension (4)
- Bilateral / persistent left superior vena cava (5)
- Tetralogy of Fallot (9)
- Coarctation of the aorta (10)
- Other (6) *If selected other, a text box [string] will appear.*

4.9.2.2. *If yes, is there need for cardiological follow-up (including referral)?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

4.9.2.3. *If yes, did the patient undergo any cardiosurgical intervention(s)?*

- No (0) [Radio button, single selection]
- Yes (1) *If selected a text box to enter [date] will appear.*
- Unknown / no information in medical file (99)

4.10. What other associated abnormalities not previously mentioned have been found?

- None (0) [Radio button, single selection]
- Tracheoesophageal abnormalities (e.g. tracheoesophageal fistula, esophageal atresia) (1)
- Cardiac abnormalities (e.g. atrial septal defect, ventricular septal defect, pulmonary valve stenosis, bilateral superior vena cava) (8)
- Gastrointestinal abnormalities (e.g. duodenal atresia, intestinal malrotation, Hirschsprung's disease, inguinal hernia) (2)
- Renal/urological abnormalities (e.g. hydronephrosis, posterior urethral valves, megaureter, vesicourethral reflux, neurogenic bladder) (3)
- Genital abnormalities (e.g. cryptorchidism, hypospadias, penoscrotal transposition, vaginal atresia, hydrocolpos, bicornuate uterus) (4)
- Limb abnormalities (e.g. radial dysplasia, hypoplastic thumb, polydactyly, syndactyly, congenital dysplasia of the hip) (5)
- Vertebral/sacral abnormalities (e.g. hemivertebrae, butterfly vertebrae, hemisacrum, coccygeal agenesis) (9)
- Spinal malformations (e.g., tethered cord, terminal filum lipoma, syrinx, presacral mass, caudal regression syndrome) (10)
- Craniofacial abnormalities (e.g. cleft lip, cleft palate, hearing impairment) (6)
- Other (7) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

[Checkbox, multiple selection]

4.10.1. *If tracheoesophageal abnormalities, what abnormality?*

- Esophageal agenesis (Vogt 1) (1)
- Esophageal atresia *without* tracheoesophageal fistula (pure atresia; Gross A / Vogt 2) (2)
- Esophageal atresia *with* proximal tracheoesophageal fistula (Gross B, Vogt 3A) (3)
- Esophageal atresia *with* distal tracheoesophageal fistula (Gross C / Vogt 3B) (4)

- Esophageal atresia *with* dual tracheoesophageal fistulas (Gross D / Vogt 3C) (5)
- Tracheoesophageal fistula *without* atresia (H-type fistula / Gross E) (6)
- Tracheomalacia (7)
- Other (77) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

4.10.2. *If cardiac abnormalities, what abnormality?* [Checkbox, multiple selection]

- Open / patent foramen ovale (1)
- Atrial septal defect (other than above) (2)
- Persistent ductus arteriosus / open duct of Botalli (3)
- Ventricular septal defect (4)
- Pulmonary valve stenosis (5)
- Pulmonary hypertension (6)
- Bilateral / persistent left superior vena cava (7)
- Tetralogy of Fallot (8)
- Coarctation of the aorta (9)
- Other (77) *If selected other, a text box [string] will appear.*

4.10.3. *If gastrointestinal abnormalities, what abnormality?* [Checkbox, multiple selection]

- Duodenal atresia (1)
- Intestinal malrotation (2)
- Meckel's diverticulum (3)
- Hirschsprung disease (4)
- Inguinal hernia (5)
- Other (77) *If selected other, a text box [string] will appear*

4.10.4. *If urological abnormalities, what abnormality?* [Checkbox, multiple selection]

- Vesicourethral reflux (1)
- Hydronephrosis (2)
- Dysplastic/hypoplastic kidney (3)
- Renal agenesis / absent kidney (4)
- Horseshoe kidney (5)
- Ectopic kidney (6)
- Renal cysts (7)
- Duplicated collecting system (8)
- Posterior urethral valves (9)
- Ectopic ureter (10)
- Ureter stenosis (11)
- Mega-ureter (12)
- Neurogenic bladder (13)
- Urethral stricture (14)
- Cystocele (15)
- Meatal stenosis (16)
- Other (77) *If selected other, a text box [string] will appear*

4.10.4.1.1. *If (1-7), which side is affected?* [Radio button, single selection]

- Left (1)
- Right (2)
- Both (3)
- Unknown / no information in medical file (99)

4.10.5. *If genital abnormalities AND male, what abnormality?* [Checkbox, multiple selection]

- Cryptorchidism / undescended testes (1)
- Hypospadias (2)
- Epispadias (3)
- Bifid scrotum (4)

- Penoscrotal transposition (5)
- Ambiguous genitalia (6)
- Other (77) *If selected other, a text box [string] will appear*
- Unknown / no information in medical file (99)

4.10.6. *If genital abnormalities AND female, what abnormality?* [Checkbox, multiple selection]

- Hydrocolpos (1)
- Vaginal septum (2)
- Vaginal atresia (3)
- Mullerian remnants / vaginal agenesis (4)
- Bicornuate uterus (5)
- Ambiguous genitalia (6)
- Other (77) *If selected other, a text box [string] will appear*

4.10.7. *If limb abnormalities, what abnormality?* [Checkbox, multiple selection]

- Accessory thumbs (1)
- Congenital absence of hand(s)/finger(s)/thumb(s) (2)
- Radial dysplasia / club hand (3)
- Club foot (4)
- Polydactyly or syndactyly (5)
- Congenital dysplasia of the hip (6)
- Other (7) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

4.10.8. *If vertebral/sacral abnormalities, what abnormality?* [Checkbox, multiple selection]

- Hemivertebrae (1)
- Butterfly vertebrae (2)
- Supernumerary vertebrae (3)
- Fusion of vertebrae (4)
- Complete or partial coccygeal agenesis (5)
- Hemisacrum (6)
- Sacral hypoplasia (7)
- Partial sacral agenesis (8)
- Complete sacral agenesis (9)
- Fused sacral vertebrae (10)
- Other (77) *If selected other, a text box [string] will appear.*

4.10.9. *If spinal abnormalities, what abnormality?* [Checkbox, multiple selection]

- Tethered cord (1)
- Terminal filum lipoma (2)
- Syrinx (3)
- Presacral mass (4)
- Spinal dysraphism / spina bifida (5)
- Caudal regression syndrome (6)
- Other (77) *If selected other, a text box [string] will appear*

4.10.10. *If craniofacial abnormalities, what abnormality?* [Checkbox, multiple selection]

- Cheilo(gnatopalato)schisis (cleft lip / cleft palate) (1)
- Hearing impairment (2)
- Microtia / anotia (small or absent ears) (3)
- Choanal stenosis/atresia (4)
- Other (77) *If selected other, a text box [string] will appear*

5. Surgery and treatments

5.1. Does or did the patient have a stoma/enterostomy? *(If the patient still has a stoma, mark 'yes' for this item. We do not refer to vesicostomies)*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.1.1. *If yes, date stoma construction:* [date format]

- Must be after date of construction; calculate and show age (days) of patient at time of stoma construction*

5.1.2. *If yes, what type of stoma/enterostomy was constructed?*

- Loop stoma (1) [Radio button, single selection]
- Split/divided stoma (2)
- Unknown / no information in medical file (99)

5.1.3. *If yes, where was the stoma/enterostomy placed?*

- Ileum (1) [Radio button, single selection]
- Transverse colon (3)
- Descending or sigmoid colon (4)
- Other (5) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.1.4. Did the formation of the stoma cause any complications? [Checkbox, multiple selection]

- No (0)
- Wound infection (1)
- Wound dehiscence (2)
- High output (3)
- Stomal prolapse (4)
- Leakage (5)
- Stenosis (6)
- Parastomal hernia (7)
- Other (77) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.1.4.1. *If any complication selected, how would you classify selected complication?
If more than one complication selected, show for each complication.*

[Radio button, single selection]

- No need for pharmacological, surgical, endoscopic, or radiological interventions, besides symptomatic treatment (antiemetics, analgesics, diuretics, electrolytes). (1)
- Requiring pharmacological treatment such as antibiotics, blood transfusions, or total parenteral nutrition. (2)
- Requiring surgical, endoscopic, or radiologic intervention. (3)
- Life-threatening requiring intensive care management. (4)
- Patient died. (5)
- Unknown / no information in medical file (99)

5.1.5. *If yes, does the patient still have the stoma?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.1.5.1. *If no, date stoma closure:* [date format]

- Must be after date of birth; calculate and show age (weeks) of patient at time of stoma closure*

5.1.5.2. *If no*, were there any complications related to the closure of the stoma?
[Checkbox, multiple selection]

- No (0)
- Wound infection (1)
- Wound dehiscence (2)
- Anastomotic leak (3)
- Anastomotic stenosis (4)
- Adhesive obstruction (5)
- Other (77) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.1.6. *If yes, does or did the patient have another stoma / enterostomy?*

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.1.6.1. *If yes*, date stoma construction: [date format]

- Must be after date of construction; calculate and show age (days) of patient at time of stoma construction*

5.1.6.2. *If yes*, what type of stoma/enterostomy was constructed?

- Loop stoma (1) [Radio button, single selection]
- Split/divided stoma (2)
- Unknown / no information in medical file (99)

5.1.6.3. *If yes*, where was the stoma/enterostomy placed?

- Ileum (1) [Radio button, single selection]
- Transverse colon (3)
- Descending or sigmoid colon (4)
- Other (5) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.1.6.4. *If yes*, does the patient still have the stoma?

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.1.6.4.1. *If no*, date stoma closure: [date format]

- Must be after date of birth; calculate and show age (weeks) of patient at time of stoma closure*

5.2. Does or did the patient have a vesicostomy or Mitrofanoff stoma?

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.2.1. *If yes*, does the patient still have the vesicostomy or Mitrofanoff stoma?

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.3. Has the patient undergone anorectal reconstructive surgery?

- No or not yet (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

5.3.1. *If no or not yet, why not?*

- Surgery is not necessary / not indicated (0) [Radio button, single selection]
- Surgery is planned and has not taken place yet (1)
- Other interventions (e.g. cardiac surgery) had priority or patient was not fit enough for surgery (2)
- Care of patient was transferred to another center (3)
- Patient died before the planned surgery (4)
- Other (5) *If selected other, a text box [string] will appear.*
-
- Unknown / no information in medical file (99)

5.3.2. *If yes and 1.2 also yes, If Yes (and 1.2 also yes), where was the reconstructive surgery performed?*

- This HCP (1) [Radio button, single selection]
- Other HCP (0) → *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.3.3. *If yes, what type of surgery?*

- Anoplasty (1) [Checkbox, multiple selection]
- Mini-PSARP (i.e. below the levator ani musculature) (2)
- Sphincter-sparing PSARP (10)
- Perineal-sparing PSARP (11)
- Posterior sagittal anorectoplasty (PSARP) (3)
- Anterior sagittal anorectoplasty (ASARP) (4)
- Laparoscopic-assisted anorectoplasty (LAARP) (5)
- Perineal repair with open abdominal repair (laparotomy) (6)
- PSARP with total urogenital mobilization (TUM) (7)
- Posterior sagittal anorectovaginourethroplasty (PSARVUP) (8)
- Other (9) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.3.4. *If yes, date reconstructive surgery: [date format]*

- Must be after date of birth; calculate and show age (weeks) of patient at time reconstructive surgery*

5.3.5. *If yes, were there any complications after the surgery?*

- Wound infection (1) [Checkbox, multiple selection]
- Wound dehiscence (2)
- Rectal / mucosal prolapse (3)
- Recurrent recto-urogenital fistula (4)
- Mislocated rectum / anus (5)
- Anal stricture / stenosis (6)
- Remnant of original fistula (7)
- Insufficient initial reconstruction requiring redo reconstructive surgery (e.g. mislocated anus, breakdown perineal body) (8) *If selected, show options for type [same as 3.2.2] and [date].*
- Neurogenic bladder or urinary retention (9)
- Other (10) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

5.3.5.1. *If any complication except redo selected, how would you classify selected complication?*

If more than one complication selected, show for each complication.

[Radio button, single selection]

- No need for pharmacological, surgical, endoscopic, or radiological interventions, besides symptomatic treatment (antiemetics, analgesics, diuretics, electrolytes). (1)
- Requiring pharmacological treatment such as antibiotics, blood transfusions, or total parenteral nutrition. (2)
- Requiring surgical, endoscopic, or radiologic intervention. (3)
- Life-threatening requiring intensive care management. (4)
- Patient died. (5)
- Unknown / no information in medical file (99)

5.4. Did the patient undergo anal dilatations?

- No (0) [Radio button, single selection]
- Yes, and finished or quit (1)
- Yes, and still ongoing (2)
- Unknown / no information in medical file (99)

5.4.1. *If any 'yes', were any of the dilatations under analgesia or general anesthesia?*

- No (0)
- Yes (1)
- Unknown (99)

5.5. Is the patient treated with any stool regulators (e.g. stool softeners, enemas, oral laxatives)?

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

[Checkbox, multiple selection]

5.5.1. *If yes, with which of the following stool regulators is the patient treated?*

- Stool softener (e.g. macrogol, polyethylene glycol, lactulose, psyllium fibers) (1)
- Oral stimulant/contact laxatives (e.g., senna, bisacodyl) (2)
- Enemas (phosphate, sorbitol/microlax) (3)
- Rectal water irrigation systems (4)
- Other (5) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)

6. Functional outcomes

6.1. Is the patient constipated? (*If the patient is being treated with stool regulators, mark this item as "Yes".*)

- No (0) [Radio button, single selection]
- Yes (1)
- Unknown / no information in medical file (99)

6.2. How often does the patient defecate?

- Less than 3 times a week (1) [Radio button, single selection]
- 3-5 times a week (2)
- 6-8 times a week / 1-2 times a day (3)
- 2-5 times a day (4)
- More than 5 times a day (5)
- More than 10 times a day (6)
- Unknown / no information in medical file (99)

6.3. Does or did the patient have a diaper rash?

- No, never (0) [Radio button, single selection]
- No, not anymore (1)
- Yes, sometimes (2)
- Yes, frequently (3)

- Unknown / no information in medical file (99)

6.4. Is the patient growing well (i.e., gaining weight)?

- No (0)
- Yes (1)
- Unknown / no information in medical file (99)

[Radio button, single selection]

6.5. Is the patient developing well (i.e., mentally and physically)?

- No (0)
- Yes (1)
- Unknown / no information in medical file (99)

[Radio button, single selection]

7. **Research**

7.1. Is the patient participating in any research study? (*Not including this registry or another registry.*)

- No (0)
- Yes (1)
- Unknown / no information in medical file (99)

[Radio button, single selection]

7.1.1. *If yes, what study/studies:* [string]

7.2. Is the patient registered in any other (anorectal malformation) patient registry?

- No (0)
- Yes (1)
- Unknown / no information in medical file (99)

[Radio button, single selection]

7.2.1. *If yes, which one?*

[Checkbox, multiple selection]

- Local or hospital-based registry (1)
- National registry (e.g., CURE-Net, DICA) (2)
- International registry (e.g., ARM-Net) (3)
- Other ERN (e.g. ERNICA) (4)
- Other (5) *If selected other, a text box [string] will appear.*
- Unknown / no information in medical file (99)



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