

European Pediatric Surgical Audit - 2027



* = required, ** = required by validation

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Patient data

Patient identification

Only include patients for whom the primary surgical procedure was performed in your hospital. - Redo surgeries should not be entered here. - Only patients aged 18 years or younger are eligible for registration - Exception: For malrotation, non-operative patients should be entered as well.

Hospital *	☐ UMC Groningen	☐ AMC
	☐ VU Medisch Centrum Amsterdam	☐ LUMC
	☐ UMCU	☐ Erasmus Medisch Centrum Rotterdam
	☐ St. Radboud Nijmegen	☐ Academisch Ziekenhuis Maastricht
	☐ Antoni van Leeuwenhoek, Amsterdam	☐ Amsterdam UMC
	☐ Rigshospitalet, Hillerød	☐ Hannover Medical School
	☐ Helsinki University Hospital, Helsinki	☐ Karolinska University Hospital, Stockholm
	☐ Universitätsmedizin Mannheim	☐ Oslo University Hospital
	☐ Skåne University Hospital	☐ Universitaire Ziekenhuizen Leuven
	☐ A.O. SS. Antonio e Biagio e Cesare Arrigo di Alessandria	☐ Spitalul Clinic de Urgenta pentru Copii "Louis Turcanu" Timisoara
	☐ Ospedale Pediatrico Bambino Gesù	☐ National Institute of Children's Diseases, NUDCH
	☐ Regina Margherita Children's Hospital, Torino	☐ Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Milano
	☐ N. I. Pirogov, Sofia	☐ Children's University Hospital Latvia
	☐ Hospital Sant Joan de Déu	☐ Hospital Universitario La Paz
	☐ Kepler University Hospital Linz	☐ Universitair Ziekenhuis Gent
	☐ University Children's Hospital Belgrade	☐ Hacettepe University
	☐ Southampton Children's Hospital	☐ University Medical Center Hamburg-Eppendorf
	☐ Universitätsklinikum Leipzig	☐ Universitätsklinikum Frankfurt
	☐ University Hospital Wrocław	☐ Universitätsklinikum Bonn
	☐ Odense University Hospital	☐ Motol University Hospital Czech Republic
	☐ University Medical Centre Ljubljana	☐ Hospital of Lithuanian University of Health Sciences Kauno klinikos
	☐ DEMO	
Patient number as documented in the patient's chart at the healthcare facility *		
Country idcode	☐ the Netherlands	☐ Germany
	☐ Belgium	☐ Sweden
	☐ Other/Unknown/no idcode	
Social security number		

Name details

Initials *	
Prefix	
Surname **	

Personal data

Date of birth *		
Sex *	☐ Male	☐ Female
	☐ Undetermined	☐ Foetus (unknown)
Country of residence *		
Postal code **		
Date of death		
Cause of death	☐ Due to anomaly	☐ Due to comorbidity
	☐ Other	

Enter the pseudonyms as provided by ZorgTTP

Pseudonym-MRN	
Pseudonym-C	
Pseudonym-RGG	
Pseudonym-NGG	
Pseudonym-sNGG	
Pseudonym-GG	
Pseudonym-NGGV	
Pseudonym-sNGGV	

Prenatal data

Prenatal diagnostics

Prenatal ultrasound	☐ No	☐ Yes	☐ Unknown
Prenatal MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected diagnosis	☐ No	☐ Yes	☐ Unknown
Prenatal genetic testing	☐ No	☐ Yes	☐ Unknown

Type of prenatal genetic testing

Karyotyping	☐ No	☐ Yes	☐ Unknown
Microarray	☐ No	☐ Yes	☐ Unknown
Whole Exome Sequencing (WES)	☐ No	☐ Yes	☐ Unknown
Whole Genome Sequencing	☐ No	☐ Yes	☐ Unknown
Unknown	☐ No	☐ Yes	☐ Unknown
Prenatal genetic abnormality diagnosed?	☐ No	☐ Yes	☐ Unknown
Prenatal suspect diagnosis (weeks)	☐		
	☐ Unknown		

Prenatal anomalies on prenatal ultrasound

Polyhydramnios	☐ No	☐ Yes	☐ Unknown
Prenatally suspected cardiac anomalies	☐ No	☐ Yes	☐ Unknown
Prenatally suspected gastrointestinal anomalies.	☐ No	☐ Yes	☐ Unknown
Prenatally suspected anomalies of the central nervous system.	☐ No	☐ Yes	☐ Unknown
Prenatally suspected limb anomalies	☐ No	☐ Yes	☐ Unknown
Prenatally suspected urogenital anomalies	☐ No	☐ Yes	☐ Unknown
Prenatally suspected other anomalies	☐ No	☐ Yes	☐ Unknown

Prenatal anomalies on MRI

Prenatal anomalies on MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected cardiac anomalies on MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected urogenital anomalies on MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected other anomalies on MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected gastrointestinal anomalies on MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected anomalies of the central nervous system on MRI	☐ No	☐ Yes	☐ Unknown
Prenatally suspected limb anomalies on MRI	☐ No	☐ Yes	☐ Unknown

Perinatal data

Perinatal information

Place of delivery	☐ Home	☐ Regional hospital
	☐ Pediatric surgical center	☐ Unknown
Type of delivery	☐ Vaginal	☐ Elective cesarean section
	☐ Emergency cesarean section	☐ Unknown
Gestational age (weeks)	☐	
	☐ Unknown	
Gestational age (days)	☐	
	☐ Unknown	
Birth weight (grams) *	☐	
	☐ Unknown	

Malformation

Add a malformation ('create'), e.g.: * Anorectal malformation * Hirschsprung's disease * Congenital diaphragmatic hernia (Bochdalek) * Omphalocele * Esophageal atresia * Gastroschisis * Malrotation * Necrotizing enterocolitis (NEC) If a child has more than one malformation, add ('create') multiple malformations.

Anorectal malformation

Type of malformation

Age at onset **	☐ Antenatal	☐ At birth
	☐ Date (to be specified below)	☐ Undetermined
Date of onset **		
Age at diagnosis **	☐ Antenatal	☐ At birth
	☐ Date (to be specified below)	☐ Undetermined
Date of diagnosis **		
Date of admission tertiary paediatric surgical centre *		

Diagnostics

Type of anorectal malformation *	☐ Perineal fistula	☐ Rectourethral fistula
	☐ Rectobladderneck fistula	☐ Vestibular fistula
	☐ Persistent cloaca	☐ Imperforate anus without fistula
	☐ Rare type	
Type of rectourethral fistula	☐ Bulbar	☐ Prostatic
Rare type	☐ Anterior ectopic syndrome	☐ Urogenital sinus
	☐ Cloacal extrophy	☐ Rectal atresia
	☐ Rectal stenosis	☐ Rectovaginal fistula
	☐ H fistula	☐ Pouch colon
	☐ Other	

Diagnosed spinal cord anomalies

X-ray lumbosacral vertebrae **	☐ Not performed	☐ Normal
	☐ Abnormal	
Lumbosacral vertebrae	☐ Partial/complete lumbosacral agenesis	☐ Hemisacrum or scimitar sacrum
	☐ Asymmetric sacrum	☐ Posterior sacral extension
	☐ Agenesis of os coccyx	☐ Sacrum underdevelopment
Sacral ratio AP		
Sacral ratio LAT		
Ultrasound spinal cord	☐ Not performed	☐ Normal
	☐ Abnormal	
MRI lumbosacral vertebrae	☐ Not performed	☐ Normal
	☐ Abnormal	

Spinalcord malformations

Low conus medullaris	☐ No	☐ Yes	☐ Unknown
Thickened filum terminale	☐ No	☐ Yes	☐ Unknown
Intraspinal lipoma	☐ No	☐ Yes	☐ Unknown
Tethered cord	☐ No	☐ Yes	☐ Unknown
Stenosis of dural sack	☐ No	☐ Yes	☐ Unknown
Narowed spinal canal	☐ No	☐ Yes	☐ Unknown
Other spinal cord anomalies	☐ No	☐ Yes	☐ Unknown

Diagnosed UG anomalies

Pelvic MRI	☐ Performed	☐ Not performed
Ultrasound urogenital tract	☐ Not performed ☐ Abnormal	☐ Normal
Voiding cysto-urethrography	☐ Not performed ☐ Abnormal	☐ Normal
Renography (DTPA-, MAG 3-, DMSA-scan) **	☐ Not performed ☐ Abnormal	☐ Normal
Urodynamic assesment	☐ Not performed ☐ Abnormal	☐ Normal

Diagnosed urologic anomalies

Unilateral renal agenesis	☐ No	☐ Yes	☐ Unknown
Vesicoureteral reflux	☐ No	☐ Yes	☐ Unknown
Neurogenic bladder	☐ No	☐ Yes	☐ Unknown
Renal dysplasia	☐ No	☐ Yes	☐ Unknown
Renal ectopia	☐ No	☐ Yes	☐ Unknown
Megaureter	☐ No	☐ Yes	☐ Unknown
Ectopic ureter	☐ No	☐ Yes	☐ Unknown
Hydronephrosis	☐ No	☐ Yes	☐ Unknown
Obstruction of distal ureter	☐ No	☐ Yes	☐ Unknown
Other urologic anomalies	☐ No	☐ Yes	☐ Unknown
Classification of vesicoureteral reflux	☐ Grade I	☐ Grade II	
	☐ Grade III	☐ Grade IV	
	☐ Grade V		
Diagnosed genital malformations	☐ No	☐ Yes	☐ Unknown

Type of genital malformation

Vaginal agenesis	☐ No	☐ Yes	☐ Unknown
Vaginal duplication/septum	☐ No	☐ Yes	☐ Unknown
Bicornuate uterus/uterus duplex	☐ No	☐ Yes	☐ Unknown
Mullerian remnants/atresia uterus	☐ No	☐ Yes	☐ Unknown
Hydrocolpos	☐ No	☐ Yes	☐ Unknown
Cryptorchism one sided	☐ No	☐ Yes	☐ Unknown
Cryptorchism two sided	☐ No	☐ Yes	☐ Unknown
Hypospadia	☐ No	☐ Yes	☐ Unknown
Other genital malformation	☐ No	☐ Yes	☐ Unknown
Other UG anomalies			
Chromosomal investigation postpartum **	☐ Not performed ☐ Abnormal	☐ Normal	

Diagnosed cardiac, bone and GI anomalies

Diagnosed anomalies of the bones	☐ No	☐ Yes	☐ Unknown
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Bone anomalies

Hemivertebrae	☐ No	☐ Yes	☐ Unknown
Agenesis thoracic vertebrae	☐ No	☐ Yes	☐ Unknown
Scoliosis	☐ No	☐ Yes	☐ Unknown
Limb deformities	☐ No	☐ Yes	☐ Unknown
Other bone anomalies	☐ No	☐ Yes	☐ Unknown
Diagnosed gastrointestinal or cardiac anomalies	☐ No	☐ Yes	☐ Unknown

Gastrointestinal or cardiac anomalies

Esophageal atresia	☐ No	☐ Yes	☐ Unknown
Duodenal atresia	☐ No	☐ Yes	☐ Unknown
VSD / ASD	☐ No	☐ Yes	☐ Unknown
Fallot Tetralogy	☐ No	☐ Yes	☐ Unknown
Coarctatio aortae	☐ No	☐ Yes	☐ Unknown
Patent ductus arteriosus	☐ No	☐ Yes	☐ Unknown
Other GI / cardiac anomalies	☐ No	☐ Yes	☐ Unknown

Surgery

Temporary enterostomy *	☐ No	☐ Yes	☐ Unknown
Date temporary enterostomy *			
Location temporary enterostomy	☐ Transverse colon	☐ Sigmoid	
	☐ Ileum	☐ Colon descendens	
	☐ Jejunum	☐ Colon ascendens	
Type of temporary enterostomy *	☐ Single end enterostomy	☐ Loop enterostomy	
	☐ Split enterostomy		
Complications enterostomy *	☐ No	☐ Yes	☐ Unknown

Type of complication

Infection	☐ No	☐ Yes	☐ Unknown
Stomal prolapse	☐ No	☐ Yes	☐ Unknown
Stomal stenosis	☐ No	☐ Yes	☐ Unknown
Other	☐ No	☐ Yes	☐ Unknown
Patient died before definitive repair?	☐ No	☐ Yes	

Patient has died before definitive repair? If yes, go to 'Patientdata' to register the date of death.

Date of ARM repair *			
Surgical procedure ARM repair *	☐ Anoplasty	☐ PSARP - without abdominal phase	
	☐ PSARP - with abdominal phase	☐ ASARP	
	☐ PSARVUP / TUM	☐ None, definite enterostomy	
	☐ Other		
Enterostomy during ARM repair	☐ No	☐ Yes	☐ Unknown
Abdominal approach ARM repair	☐ Laparotomy assisted	☐ Laparoscopy assisted	
	☐ Only transanal		
Date of closure			
Date enterostomy closure *			
Date of discharge			

Complications

Complications of surgical repair (within 30 days of surgery) *	☐ No	☐ Yes	☐ Unknown
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Type of complication

Wound infection (grade 3-4) *	☐ No	☐ Yes	☐ Unknown
Wound dehiscence *	☐ No	☐ Yes	☐ Unknown

Anal stenosis (< H10 at age 6 months) *	☐ No	☐ Yes	☐ Unknown
Persistenter / recurrent fistula *	☐ No	☐ Yes	☐ Unknown
Urethral injury *	☐ No	☐ Yes	☐ Unknown
Other complications *	☐ No	☐ Yes	☐ Unknown
Reintervention due to complications *	☐ No	☐ Yes	☐ Unknown
Date of reintervention *			
Death (within 30 days of surgery) *	☐ No	☐ Yes	☐ Unknown

Patient has died within 30 days after surgery? If yes, go to 'Patientdata' to register the date of death.

Hirschsprung's disease

Family history

Age at onset **	☐ Antenatal	☐ At birth	
	☐ Date (to be specified below)	☐ Undetermined	
Date of onset **			
Age at diagnosis **	☐ Antenatal	☐ At birth	
	☐ Date (to be specified below)	☐ Undetermined	
Date of diagnosis **			
Relevant family history	☐ No	☐ Yes	☐ Unknown

Family history

Waardenburg syndrome	☐ No	☐ Yes	☐ Unknown
MEN II A, II B	☐ No	☐ Yes	☐ Unknown
Neonatal mortality of unknown abdominal cause	☐ No	☐ Yes	☐ Unknown
Other	☐ No	☐ Yes	☐ Unknown

Diagnostics

Date of admission tertiary paediatric surgical centre *	
Date of consult paediatric surgeon **	
Date of presenting symptoms **	

Presenting symptoms

Abdominal distension	☐ No	☐ Yes	☐ Unknown
First meconium stool *	☐ < 24 hours	☐ 24-48 hours	
	☐ > 48 hours	☐ Unknown	
Bilious vomiting	☐ No	☐ Yes	☐ Unknown
Enterocolitis	☐ No	☐ Yes	☐ Unknown
Signs of bowel perforation	☐ No	☐ Yes	☐ Unknown
Constipation	☐ No	☐ Yes	☐ Unknown
Poor feeding/failure to thrive	☐ No	☐ Yes	☐ Unknown

Diagnostics

Biopsy method	☐ Rectal suction biopsy	☐ Full-thickness biopsy	
	☐ Both (Rectal suction biopsy & Full-thickness biopsy)	☐ Not performed	
Number of samples collected			
Date of biopsy			
Date of histological confirmation of HSCR			
Staining method used for biopsy: Hematoxylin & eosin	☐ No	☐ Yes	☐ Unknown
Staining method used for biopsy: Calretinin	☐ No	☐ Yes	☐ Unknown

Staining method used for biopsy: Acetylcholinesterase	☐ No	☐ Yes	☐ Unknown
Staining method used for biopsy: other	☐ No	☐ Yes	☐ Unknown
Abdominal X-ray	☐ Not performed		☐ Performed
Results suspected for Hirschprung's disease?	☐ No	☐ Yes	☐ Unknown
Preoperative contrast enema	☐ No	☐ Yes	☐ Unknown
Suspected extent of aganglionosis	☐ Rectosigmoid		☐ Long segment colon
	☐ Total colon		☐ Total colon and distal ileum
	☐ Total colon and complete / nearly complete small bowel		
Date of contrast enema			
Preoperative malnutrition screening.	☐ No	☐ Yes	☐ Unknown
Growth deviation	☐ No	☐ Yes	☐ Unknown
Targeted pre-operative nutritional support.	☐ No	☐ Yes	☐ Unknown
Results suspected for Hirschprung's disease?	☐ No	☐ Yes	☐ Unknown
Anorectal manometry *	☐ Not performed		☐ Performed
Results suspected for Hirschprung's disease?	☐ No	☐ Yes	☐ Unknown
Rectal suction biopsies *	☐ Not performed		☐ Performed
Results suspected for Hirschprung's disease?	☐ No	☐ Yes	☐ Unknown
Full thickness biopsies *	☐ Not performed		☐ Performed
Results suspected for Hirschprung's disease?	☐ No	☐ Yes	☐ Unknown

Associated congenital disorders

Other disorders	☐ No	☐ Yes	☐ Unknown
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Associated anomalies			
Family history of HSCR	☐ No	☐ Yes	☐ Unknown
Intestinal anomalies	☐ No	☐ Yes	☐ Unknown
Cardiovascular anomalies	☐ No	☐ Yes	☐ Unknown
Pulmonary anomalies	☐ No	☐ Yes	☐ Unknown
Neurologic anomalies	☐ No	☐ Yes	☐ Unknown
Urogenital anomalies	☐ No	☐ Yes	☐ Unknown
Other anomalies	☐ No	☐ Yes	☐ Unknown
Genetic consultation offered	☐ No	☐ Yes	☐ Unknown
Genetic testing performed	☐ No	☐ Yes	☐ Unknown
RET gene testing performed	☐ No	☐ Yes	☐ Unknown
Chromosomal/genetic abnormalities identified	☐ No	☐ Yes	☐ Unknown
MEN2A	☐ No	☐ Yes	☐ Unknown
Down's syndrome	☐ No	☐ Yes	☐ Unknown
Waardenburg syndrome	☐ No	☐ Yes	☐ Unknown
Mowat-Wilson syndrome	☐ No	☐ Yes	☐ Unknown
Cartilage-hair hypoplasia	☐ No	☐ Yes	☐ Unknown
Other	☐ No	☐ Yes	☐ Unknown
Please specify			

Surgery

Preoperative management

Preoperative irrigations	☐ No	☐ Yes	☐ Unknown
Frequency of rectal irrigations per day			

IV antibiotics administered	☐ No	☐ Yes	☐ Unknown
Preoperative stoma formation	☐ No	☐ Yes	☐ Unknown
Primary treatment *	☐ Rectal washouts ☐ Temporary enterostomy		
	☐ Rectal washouts + temporary enterostomy		
Level of stoma	☐ Ileostomy ☐ Colostomy		
Date of stoma formation *			
Were biopsies taken during stoma formation?	☐ No	☐ Yes	☐ Unknown
Indication for stoma formation	☐ Failure of irrigation Hirschsprung´s associated enterocolitis ☐ (HAEC) unresponsive to conservative treatment		
	☐ Perforation	☐ Other	
Type of temporary enterostomy *	☐ Single end enterostomy ☐ Loop enterostomy		
	☐ Split enterostomy		
Patient died before definitive repair?	☐ No ☐ Yes		

Patient has died before definitive repair? If yes, go to 'Patientdata' to register the date of death.

Definitive repair with continuity restoration

Type of surgical procedure	☐ Primary pull-through ☐ Staged pull-through (stoma first)		
	☐ Definitive enterostomy		
Sub-type of definitive surgery	☐ Soave-like TERPT ☐ Swenson-like TERPT		
	☐ Duhamel ☐ Other		
Length of cuff (in cm)			
Planned surgical approach	☐ Laparotomy (open) ☐ Laparoscopic		
	☐ Laparoscopic assisted transanal ☐ Only transanal		
Conversion to laparotomy	☐ No	☐ Yes	☐ Unknown
Date of definitive surgery *			
Intraoperative "mapping" biopsies taken	☐ No	☐ Yes	☐ Unknown
Extent of bowel resection	☐ Rectosigmoid ☐ Colon transversum		
	☐ Colon ascendens ☐ Total colon		
	☐ Total colon and distal ileum ☐ Total colon and total/near complete small bowel		
	☐ Colon descendens		
How many centimeters proximal to the first normal biopsy was the transection performed?			
Transanal dissection commences...cm above the anorectal line			
Date enterostomy closure *			

Intraoperative complications

Bleeding requiring transfusion	☐ No	☐ Yes	☐ Unknown
Iatrogenic injury to bowel	☐ No	☐ Yes	☐ Unknown
Ureteric injury	☐ No	☐ Yes	☐ Unknown
Bladder injury	☐ No	☐ Yes	☐ Unknown
Pelvic nerve injury	☐ No	☐ Yes	☐ Unknown
Anesthesia related adverse events	☐ No	☐ Yes	☐ Unknown
Other	☐ No	☐ Yes	☐ Unknown
Surgical technique *	☐ Transanal endorectal pull through (Soave Like) ☐ Transanal endorectal pull through (Swenson Like)		
	☐ Duhamel	☐ None, definite enterostomy	
	☐ Other		
Approach elective reconstruction	☐ Laparotomy assisted ☐ Laparoscopy assisted		
	☐ Only transanal		
Resected specimen	☐ Rectosigmoid ☐ Long segment colon		
	☐ Total colon ☐ Total colon and distal ileum		
	☐ Total colon and complete / nearly complete small bowel		
Pathology: proximal resection side normal *	☐ No	☐ Yes	☐ Unknown

Enterostomy performed during surgical repair **	☐ No	☐ Yes	☐ Unknown
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End of primary hospitalization

Complications within 30 days

Complications of surgical repair, 30 days postop	☐ No	☐ Yes	☐ Unknown
Anal stenosis (< H10 at age 6 months) **	☐ No	☐ Yes	☐ Unknown
Woundinfection **	☐ No	☐ Yes	☐ Unknown
Wound infection - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Anastomotic leakage/insufficiency **	☐ No	☐ Yes	☐ Unknown
Anastomotic leakage/insufficiency - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Perianal excoriation **	☐ No	☐ Yes	☐ Unknown
Perianal excoriation - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Anastomotic stricture **	☐ No	☐ Yes	☐ Unknown
Anastomotic stenosis - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Enterostomy complications **	☐ No	☐ Yes	☐ Unknown
Urologic complications **	☐ No	☐ Yes	☐ Unknown
Urologic complications - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
HAEC **	☐ No	☐ Yes	☐ Unknown
HAEC - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Other **	☐ No	☐ Yes	☐ Unknown
Other - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		

HAEC criteria present:

Abdominal distension **	☐ No	☐ Yes	☐ Unknown
Explosive emptying after rectal examination **	☐ No	☐ Yes	☐ Unknown
Obstructive symptoms **	☐ No	☐ Yes	☐ Unknown
Abnormal C-reactive protein **	☐ No	☐ Yes	☐ Unknown
Abnormal White Blood Cell count **	☐ No	☐ Yes	☐ Unknown
Dilated bowel loops on X-ray **	☐ No	☐ Yes	☐ Unknown
Air-fluid levels on X-ray **	☐ No	☐ Yes	☐ Unknown
Features of toxic megacolon on X-ray **	☐ No	☐ Yes	☐ Unknown
Sepsis **	☐ No	☐ Yes	☐ Unknown
Signs of impending septic shock **	☐ No	☐ Yes	☐ Unknown

Altered general condition **	☐ No	☐ Yes	☐ Unknown
Peritoneal signs **	☐ No	☐ Yes	☐ Unknown
Altered mentation **	☐ No	☐ Yes	☐ Unknown
Pneumoperitoneum on X-Ray **	☐ No	☐ Yes	☐ Unknown

Surgical (re-)interventions within 30 days postoperative

Reoperations performed **	☐ No	☐ Yes
Anastomosis revision **	☐ No	☐ Yes
Stoma **	☐ No	☐ Yes
Date of creation stoma **		
Examination under anesthesia **	☐ No	☐ Yes
Dilatation **	☐ No	☐ Yes

Discharge

Unplanned reoperation(< 30 days) *	☐ None	☐ Relaparotomy
	☐ Other surgery	
Date reoperation *		
Date of discharge of hospitalization		
Death (within 30 days after surgery) **	☐ No	☐ Yes
		☐ Unknown

Patient has died within 30 days after surgery? If yes, go to 'Patientdata' to register the date of death.

Cause of death	☐ HAEC	☐ An associated anomaly
	☐ Due to HSCR	☐ Other
Enterostomy at discharge	☐ No	☐ Yes

1 Year Post Operative

If any of the following was already recorded at end of primary hospitalization, do not register it again here. This section should cover events occurring between 30 days and 1 year postoperatively.

Has the patient died?	☐ No	☐ Yes	☐ Unknown
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Patient has died within 1 year after surgery? If yes, go to 'Patientdata' to register the date of death.

Cause of death	☐ HAEC	☐ An associated anomaly
	☐ Due to HSCR	☐ Other
Specify other:		

Patient characteristics

Weight (in kg), 1 year postop	
Length (in cm), 1 year postop	
Date of examination	
Parenteral nutrition	☐ No
	☐ Yes
	☐ Unknown

Complications 1st year

Residual aganglionosis	☐ No	☐ Yes	☐ Unknown
Residual aganglionosis - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Radiological suspicion	☐ No	☐ Yes	
Histological confirmation.	☐ No	☐ Yes	
Woundinfection	☐ No	☐ Yes	☐ Unknown
Wound infection - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Anastomotic stricture	☐ No	☐ Yes	☐ Unknown

Anastomotic stenosis - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Cuff stricture	☐ No	☐ Yes ☐ Unknown
Anastomotic leakage/insufficiency	☐ No	☐ Yes ☐ Unknown
Anastomotic leakage/insufficiency - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Perianal excoriation	☐ No	☐ Yes ☐ Unknown
Perianal excoriation - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Urologic complications	☐ No	☐ Yes ☐ Unknown
Urologic complications - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
HAEC	☐ No	☐ Yes ☐ Unknown
HAEC- Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Number of episodes within the first year		

HAEC criteria present:

Abdominal distension	☐ No	☐ Yes ☐ Unknown
Explosive emptying after rectal examination	☐ No	☐ Yes ☐ Unknown
Obstructive symptoms	☐ No	☐ Yes ☐ Unknown
Abnormal C-reactive protein	☐ No	☐ Yes ☐ Unknown
Abnormal White Blood Cell count	☐ No	☐ Yes ☐ Unknown
Dilated bowel loops on X-ray	☐ No	☐ Yes ☐ Unknown
Air-fluid levels on X-ray	☐ No	☐ Yes ☐ Unknown
Features of toxic megacolon on X-ray	☐ No	☐ Yes ☐ Unknown
Sepsis	☐ No	☐ Yes ☐ Unknown
Signs of impending septic shock	☐ No	☐ Yes ☐ Unknown
Altered general condition	☐ No	☐ Yes ☐ Unknown
Peritoneal signs	☐ No	☐ Yes ☐ Unknown
Altered mentation	☐ No	☐ Yes ☐ Unknown
Pneumoperitoneum on X-Ray	☐ No	☐ Yes ☐ Unknown

Surgical (re-)interventions

Coloanal anastomosis calibration to assess for strictures	☐ No	☐ Yes
Date of coloanal anastomosis calibration		
Stricture confirmed?	☐ No	☐ Yes
Redo pull-through performed	☐ No	☐ Yes
Date redo pull-through performed		
Other reoperations performed	☐ No	☐ Yes
Anastomosis revision	☐ No	☐ Yes
Stoma formation	☐ No	☐ Yes
Date of creation stoma		
Repeat rectal biopsy	☐ No	☐ Yes
Examination under anesthesia	☐ No	☐ Yes
Serial dilatations	☐ No	☐ Yes

Non-surgical diagnostics/procedures

Ultrasound screening for Congenital Anomalies of the Kidney and Urinary Tract (CAKUT)	☐ No	☐ Yes
Contrast enema	☐ No	☐ Yes
Anorectal manometry	☐ No	☐ Yes
Colonic manometry	☐ No	☐ Yes
Endorectal ultrasound	☐ No	☐ Yes
Botulinum toxin injections	☐ No	☐ Yes
Performed under general anesthesia	☐ No	☐ Yes
Calprotectin measured	☐ No	☐ Yes

Functional outcomes

Constipation	☐ No	☐ Yes
Oral laxatives	☐ No	☐ Yes
Bulking agents	☐ No	☐ Yes
Advice for dietary changes by dietician	☐ No	☐ Yes
Enemas	☐ No	☐ Yes
Biofeedback therapy	☐ No	☐ Yes
Physical therapy	☐ No	☐ Yes

5 Year Post Operative

If any of the following was already recorded at end of primary hospitalization and 1 year Post operative, do not register it again here. This section should cover events occurring between 1 year and 5 years postoperatively.

Has the patient died?	☐ No	☐ Yes	☐ Unknown
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Patient has died within 1 year after surgery? If yes, go to 'Patientdata' to register the date of death.

Cause of death	☐ HAEC	☐ An associated anomaly
	☐ Due to HSCR	☐ Other
Specify other:		

Patient characteristics

Weight (in kg), 5 year postop	
Length (in cm), 5 year postop	
Date of examination	
Parenteral nutrition	☐ No ☐ Yes ☐ Unknown

Complications 5th year

Residual aganglionosis	☐ No		☐ Yes	☐ Unknown
Residual aganglionosis - Clavien-Madadi	☐ Ia		☐ Ib	
	☐ II		☐ IIIa	
	☐ IIIb		☐ IV	
	☐ V			
Radiological suspicion	☐ No		☐ Yes	
Histological confirmation	☐ No		☐ Yes	
Woundinfection	☐ No		☐ Yes	☐ Unknown
Wound infection - Clavien-Madadi	☐ Ia		☐ Ib	
	☐ II		☐ IIIa	
	☐ IIIb		☐ IV	
	☐ V			
Anastomotic stricture	☐ No		☐ Yes	☐ Unknown
Anastomotic stricture - Clavien-Madadi	☐ Ia		☐ Ib	
	☐ II		☐ IIIa	
	☐ IIIb		☐ IV	
	☐ V			
Cuff stricture	☐ No		☐ Yes	☐ Unknown

Anastomotic leakage/insufficiency	☐ No	☐ Yes	☐ Unknown
Anastomotic leakage/insufficiency - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Perianal excoriation	☐ No	☐ Yes	☐ Unknown
Perianal excoriation - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Urologic complications	☐ No	☐ Yes	☐ Unknown
Urologic complications - Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
HAEC	☐ No	☐ Yes	☐ Unknown
HAEC- Clavien-Madadi	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Number of episodes within the first 5 years			

Surgical (re-)interventions

Coloanal anastomosis calibration to assess for strictures	☐ No	☐ Yes
Date of coloanal anastomosis calibration		
Redo pull-through performed	☐ No	☐ Yes
Date redo pull-through performed		
Other reoperations performed	☐ No	☐ Yes
Anastomosis revision	☐ No	☐ Yes
Stoma formation	☐ No	☐ Yes
Date of creation stoma		
Repeat rectal biopsy	☐ No	☐ Yes
Examination under anesthesia	☐ No	☐ Yes
Serial dilatations	☐ No	☐ Yes

Non-surgical diagnostics/procedures

Contrast enema	☐ No	☐ Yes
Anorectal manometry	☐ No	☐ Yes
Colonic manometry	☐ No	☐ Yes
Endorectal ultrasound	☐ No	☐ Yes
Botulinum toxin injections	☐ No	☐ Yes
Performed under general anesthesia	☐ No	☐ Yes
Calprotectin measured	☐ No	☐ Yes

Functional outcomes

Bowel Function Score		
Constipation	☐ No	☐ Yes
Oral laxatives	☐ No	☐ Yes
Bulking agents	☐ No	☐ Yes
Advice for dietary changes by dietician	☐ No	☐ Yes
Enemas	☐ No	☐ Yes
Biofeedback therapy	☐ No	☐ Yes
Physical therapy	☐ No	☐ Yes
Fecal incontinence	☐ No	☐ Yes

Grade of incontinence	☐ Occasionally ☐ Constant, with social problems	☐ Every day, but without social problems
Loperamide or similar	☐ No	☐ Yes
Advice for dietary changes by dietician	☐ No	☐ Yes
Bulking agents	☐ No	☐ Yes
Enemas	☐ No	☐ Yes
Biofeedback therapy	☐ No	☐ Yes
Physical therapy	☐ No	☐ Yes
Urinary incontinence	☐ No	☐ Yes

Congenital diaphragmatic hernia

Diagnosis

Age at onset **	☐ Antenatal ☐ Date (to be specified below)	☐ At birth ☐ Undetermined
Date of onset **		
Age at diagnosis **	☐ Antenatal ☐ Date (to be specified below)	☐ At birth ☐ Undetermined
Date of diagnosis **		
Date of admission tertiary paediatric surgical centre *		
Antenatal steroids	☐ No ☐ Yes	☐ Unknown
Familial predisposition	☐ No ☐ Yes	☐ Unknown
Side of defect *	☐ Left ☐ Both sides	☐ Right
Type of hernia **	☐ Bochdalek ☐ Eventration	☐ Morgagni
Postnatal diagnosis	☐ <6 hours postpartum ☐ ≥24 hours postpartum	☐ 6-24 hours postpartum

Additional anomalies

Initial clinical symptoms

Pulmonal hypertension	☐ No ☐ Yes ☐ Unknown
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Anomalies detected by prenatal ultrasound

Stomach in thorax	☐ No ☐ Yes	☐ Unknown
Liver in thorax	☐ No ☐ Yes	☐ Unknown
Congenital cardiac anomalies	☐ No ☐ Yes	☐ Unknown
Foetoscopic endoluminal tracheal occlusion	☐ No ☐ Yes	☐ Unknown
Observed to expected lung to head ratio	☐ Smaller than 25% ☐ Larger than 40%	☐ 25% - 40% ☐ Unknown

Associated congenital anomalies

Cardial	☐ No ☐ Yes	☐ Unknown
Omphalocele	☐ No ☐ Yes	☐ Unknown
Pulmonary	☐ No ☐ Yes	☐ Unknown
Other associated anomalies	☐ No ☐ Yes	☐ Unknown

Ventilation

Mechanical ventilation	☐ No ☐ Yes
Initial mode of ventilation	☐ Conventional ☐ Unknown ☐ High frequency oscillation

Date of start mechanical ventilation *	
Date extubation	
(Preoperative) pneumothorax	☐ No ☐ Yes ☐ Unknown

ECMO

Transfer to ECMO centre *	☐ Yes ☐ No ☐ No, already in ECMO center
Date of transfer to ECMO centre *	
ECMO treatment *	☐ arteriovenous ☐ venovenous ☐ no ECMO treatment
Need for reconstruction of vessels at decannulation?	☐ No ☐ Yes
Technique	☐ Ligation ☐ Reconstruction
Startdate ECMO *	
Stopdate ECMO *	

Surgery

Patient died before definitive repair?	☐ No ☐ Yes
--	--

Patient has died before definitive repair? If yes, go to 'Patientdata' to register the date of death.

Date of surgery *	
Surgical approach	☐ Abdominal ☐ Thoracic
Surgical technique	☐ Open ☐ Scopic
Abdominal approach	☐ Median laparotomy ☐ Subcostal incision ☐ Transverse laparotomy
Conversion	☐ No ☐ Yes ☐ Unknown
Size of anomaly	☐ Boston scale A (<1/4) ☐ Boston scale B (1/4-1/2) ☐ Boston scale C (1/2-3/4) ☐ Boston scale D (>3/4)
Hernial sac	☐ No ☐ Yes ☐ Unknown
Closure of the defect	☐ Primary ☐ Patch ☐ Primary with Onlay patch
Material	☐ PTFE ☐ Permacol ☐ Surgisis ☐ Stratice ☐ Other
Resection pulmonary sequestration	☐ No ☐ Yes ☐ Unknown
Nonrotation procedure (in case of malrotation)	☐ No ☐ Yes ☐ Unknown
Closure of the abdominal wall *	☐ Primary ☐ Patch ☐ Silo ☐ Only skin closure
Date removal patch/silo and closure abdominal wall	
Chesttube	☐ No ☐ Yes ☐ Unknown

Complications

Complications during first admission *	☐ No ☐ Yes ☐ Unknown
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Type of complication

Postoperative bleeding **	☐ No ☐ Yes ☐ Unknown
Surgical wound dehiscence **	☐ No ☐ Yes ☐ Unknown
Bowel obstruction / ileus **	☐ No ☐ Yes ☐ Unknown
Sepsis *	☐ No ☐ Yes ☐ Unknown
Bleeding *	☐ No ☐ Yes ☐ Unknown
DIC *	☐ No ☐ Yes ☐ Unknown
Cerebral bleeding *	☐ No ☐ Yes ☐ Unknown
Convulsions *	☐ No ☐ Yes ☐ Unknown
Brain death *	☐ No ☐ Yes ☐ Unknown

BPD *	☐ No	☐ Yes	☐ Unknown
Pneumonia *	☐ No	☐ Yes	☐ Unknown
Chylothorax **	☐ No	☐ Yes	☐ Unknown
Pneumothorax *	☐ No	☐ Yes	☐ Unknown
Lung bleeding *	☐ No	☐ Yes	☐ Unknown
Circulatory arrest *	☐ No	☐ Yes	☐ Unknown
Arythmia *	☐ No	☐ Yes	☐ Unknown
Hypotensia *	☐ No	☐ Yes	☐ Unknown
Catheter-related thrombosis **	☐ No	☐ Yes	☐ Unknown
Wound infection *	☐ No	☐ Yes	☐ Unknown
Renal failure *	☐ No	☐ Yes	☐ Unknown
Metabolic disorders *	☐ No	☐ Yes	☐ Unknown
Gastroesophageal reflux (GER) *	☐ No	☐ Yes	☐ Unknown
GER treatment *	☐ Medication		☐ Surgical
	☐ Both medication and surgical		
Serothorax	☐ No	☐ Yes	☐ Unknown
Postoperative chest tube	☐ No	☐ Yes	☐ Unknown
Duration chest tube (days)			
Recurrence CDH (within 1 year) *	☐ No	☐ Yes	☐ Unknown
Redo surgery and other surgical interventions (within 1 year) *	☐ No	☐ Yes	☐ Unknown

Type of redo surgery

Select type of redo surgery. Multiple types are possible

Gastrostomy	☐ No	☐ Yes	☐ Unknown
Laparotomy for bowel obstruction / ileus	☐ No	☐ Yes	☐ Unknown
Anti-reflux surgery	☐ No	☐ Yes	☐ Unknown
Correction recurrence CDH	☐ No	☐ Yes	☐ Unknown
Repair incisional hernia	☐ No	☐ Yes	☐ Unknown
Other	☐ No	☐ Yes	☐ Unknown
Date of redo surgery *			
Death after first admission *	☐ No	☐ Yes	☐ Unknown

Patient has died after first admission? If yes, go to 'Patientdata' to register the date of death.

Discharge

Transfer from ECMO centre *	☐ No	☐ Yes	☐ Unknown
Date of transfer from ECMO centre *			
Date of discharge *			
Discharge to	☐ Pediatric surgical center		☐ Periferal hospital
	☐ Home		☐ Other
Weight at time of discharge (grams) *			

At time of discharge

Additional oxygen	☐ No	☐ Yes	☐ Unknown
Tube feeding	☐ No	☐ Yes	☐ Unknown
Antireflux medication	☐ No	☐ Yes	☐ Unknown

Omphalocele

Diagnostics and treatment I

Age at onset **	☐ Antenatal		☐ At birth
	☐ Date (to be specified below)		☐ Undetermined

Date of onset **			
Age at diagnosis **	☐ Antenatal	☐ At birth	
	☐ Date (to be specified below)	☐ Undetermined	
Date of diagnosis **			
Date of admission tertiary paediatric surgical centre *			

Prenatal diagnostics (20 weeks)

Diameter abdominal wall defect (cm)	
Abdomen diameter (cm)	
Circumference cele (cm)	

At time of birth

Rupture of omhalocele sac	☐ No	☐ Yes	
Stomach included	☐ No	☐ Yes	
Liver included	☐ No	☐ Yes	
Type of omphalocele (Giant=> 5cm)	☐ Normal	☐ Giant	
Date start enteral feeding			
Date full enteral feeding			
Ultrasound kidney	☐ No	☐ Yes	☐ Unknown

Conclusion ultrasound kidney

Enlarged pyelum	☐ No	☐ Yes	☐ Unknown
Cysts	☐ No	☐ Yes	☐ Unknown
Abnormal location kidney	☐ No	☐ Yes	☐ Unknown
Renal agenesis	☐ No	☐ Yes	☐ Unknown
Other anomalies	☐ No	☐ Yes	☐ Unknown
Ultrasound heart and aortic arch	☐ No	☐ Yes	☐ Unknown

Conclusion ultrasound heart

Ventricular septal defect	☐ No	☐ Yes	☐ Unknown
Atrial septal defect	☐ No	☐ Yes	☐ Unknown
Fallot tetralogy	☐ No	☐ Yes	☐ Unknown
Patent ductus arteriosus	☐ No	☐ Yes	☐ Unknown
Other anomalies	☐ No	☐ Yes	☐ Unknown

Conclusion ultrasound aorta

Right side descending aorta	☐ No	☐ Yes	☐ Unknown
Other anomalies	☐ No	☐ Yes	☐ Unknown
DNA diagnostics	☐ No	☐ Yes	☐ Unknown
Conclusion DNA diagnostics	☐ No abnormalities	☐ Full trisomies (x, 13, 18, 21)	
	☐ Deletions (13q, 17q, 16q24)	☐ Single gene disorders	
	☐ Other genetic abnormalities		
Genetic counseling *	☐ No	☐ Yes	☐ Unknown
Conclusion genetic counseling	☐ Normal	☐ Syndromal	☐ Other

Additional defects

Gastrointestinal defects	☐ No	☐ Yes	☐ Unknown
Other defects	☐ No	☐ Yes	☐ Unknown

Diagnostics and treatment II

Respiratory failure

Oxygen	☐ No	☐ Yes
Ventilator	☐ No	☐ Yes

Duration of mechanical ventilation		
Lung hypoplasia	☐ No	☐ Yes
Suspension of omphalocele	☐ No	☐ Yes
Type of surface cover	☐ Dry (only bandage) ☐ Wound dressing	☐ Flammazine ☐ Other
Complication of suspension	☐ No	☐ Yes (omphalitus)
Surgical treatment *	☐ No	☐ Yes
Type of treatment (surgical) *	☐ Primary closure ☐ Delayed closure	☐ Staged closure
Discharge before surgical procedure?	☐ No	☐ Yes

Herniated organs

Small bowel	☐ No	☐ Yes	☐ Unknown
Colon	☐ No	☐ Yes	☐ Unknown
Stomach	☐ No	☐ Yes	☐ Unknown
Liver	☐ No	☐ Yes	☐ Unknown
Gondads	☐ No	☐ Yes	☐ Unknown
Bladder	☐ No	☐ Yes	☐ Unknown
Malrotation	☐ No	☐ Yes	
Non rotation treatment	☐ No	☐ Yes	
Appendectomy	☐ No	☐ Yes	

Discharge

Date of discharge

If the patient died during the initial hospital admission, please enter the date of death.

Discharge to	☐ Pediatric surgical center	☐ Periferal hospital
	☐ Home	☐ Other

If the patient died during hospital admission please choose other.

Death during hospital admission or within 30 days after surgery	☐ No	☐ Yes	☐ Unknown
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Patient has died within 30 days after surgery? If yes, go to 'Patientdata' to register the date of death.

Re admission	☐ No	☐ Yes
Date of readmission		
Urgency of readmission	☐ Elective surgery	☐ Acute surgery

Reason of readmission

Wound infection	☐ No	☐ Yes
Wound dehiscence	☐ No	☐ Yes
Parenteral feeding	☐ No	☐ Yes
Other reasons	☐ No	☐ Yes

Omphalocele procedure

Procedure

Date of surgery *		
Closure skin	☐ No	☐ Yes
Closure abdominal wall	☐ (Primary) Closure ☐ Silo ☐ Plasty	☐ Open ☐ Patch ☐ Plasty and patch
Operative complications	☐ No	☐ Yes

Type of operative complication

Bleeding	☐ No	☐ Yes
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Bowel perforation	☐ No	☐ Yes
Other	☐ No	☐ Yes
Postoperative complications	☐ No	☐ Yes

Type of postoperative complication

Abdominal compartment syndrome	☐ No	☐ Yes
Respiratory failure (mechanical ventilation)	☐ No	☐ Yes
Respiratory tract infection	☐ No	☐ Yes
Wound dehiscence	☐ No	☐ Yes
Renal failure	☐ No	☐ Yes
Bowel obstruction / ileus	☐ No	☐ Yes
Line sepsis	☐ No	☐ Yes
Gastro oesophageal reflux	☐ No	☐ Yes
Other	☐ No	☐ Yes

Discharge

Discharge

Was the patient discharged after surgery?	☐ No	☐ Yes
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Date of discharge	
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If the patient died during the initial hospital admission, please enter the date of death.

Discharge to	☐ Pediatric surgical center	☐ Periferal hospital
	☐ Home	☐ Other

If the patient died during hospital admission please choose other.

Death during hospital admission or within 30 days after surgery	☐ No	☐ Yes	☐ Unknown
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Patient has died during hospital admission or within 30 days after surgery? If yes, go to 'Patientdata' to register the date of death.

Readmission (within the first year)	☐ No	☐ Yes
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Date of readmission	
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Reason of readmission

Elective surgery	☐ No	☐ Yes
Acute surgery	☐ No	☐ Yes
Wound infection	☐ No	☐ Yes
Wound dehiscence	☐ No	☐ Yes
Parenteral feeding	☐ No	☐ Yes
Other reasons	☐ No	☐ Yes

Esophageal atresia

Diagnostics for EA

Onset and admission

Age at onset **	☐ Antenatal	☐ At birth
	☐ Date (to be specified below)	☐ Undetermined

Date of onset **	
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Age at diagnosis **	☐ Antenatal	☐ At birth
	☐ Date (to be specified below)	☐ Undetermined

Date of diagnosis **	
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Date of admission tertiary paediatric surgical centre *	
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Discharge before primary repair? **	☐ No	☐ Yes	☐ Unknown
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Date of admission for primary repair **	
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Diagnostic testing

Suction tube *	☐ No	☐ Yes	☐ Unknown
X-ray of thorax/abdomen with nasoesophageal tube in situ	☐ No	☐ Yes	☐ Unknown
X-ray of thorax/abdomen with contrast	☐ No	☐ Yes	☐ Unknown

Gross classification

Classification of esophageal atresia *	☐ A	☐ B
	☐ C	☐ D
	☐ E	

Tracheobronchoscopy

Tracheobronchoscopy performed? **	☐ No	☐ Yes	☐ Unknown
Date of tracheobronchoscopy *			
Sedation during tracheobronchoscopy? **	☐ Spontaneously breathing	☐ Fully sedated	
	☐ Unknown		
Location lower fistula **	☐ Carina	☐ Above the carina	
	☐ Unknown		
Tracheomalacia on first tracheobronchoscopy? **	☐ No	☐ Yes	☐ Unknown
Other abnormalities on first tracheobronchoscopy? **	☐ No	☐ Yes	☐ Unknown

Associated anomalies

Cardiac anomalies and anomalies of the large vessels

Echocardiography **	☐ No	☐ Yes	
	☐ Done in other hospital	☐ Unknown	
Date of echocardiography **	☐		
	☐ Unknown		
Cardiac anomalies or anomalies of the large vessels diagnosed? **	☐ No	☐ Yes	☐ Unknown

Diagnosed cardiac anomalies

Ventricular septal defect	☐ No	☐ Yes	☐ Unknown
Atrial septal defect	☐ No	☐ Yes	☐ Unknown
Tetralogy of Fallot	☐ No	☐ Yes	☐ Unknown
Patent ductus arteriosus	☐ No	☐ Yes	☐ Unknown
Other cardiac anomalies	☐ No	☐ Yes	☐ Unknown

Diagnosed vessel anomalies

Right side descending aorta	☐ No	☐ Yes	☐ Unknown
Coarctatio aortae	☐ No	☐ Yes	☐ Unknown
Other anomalies of the large vessels	☐ No	☐ Yes	☐ Unknown

Cardiac interventions

Cardiac interventions?	☐ No	☐ Yes	☐ Unknown
Date of first cardiac intervention			

Renal anomalies

Ultrasound of kidneys performed? **	☐ No	☐ Yes
	☐ Done in other hospital	☐ Unknown
Date of kidney ultrasound **	☐	
	☐ Unknown	

Renal anomalies diagnosed? **	☐ No	☐ Yes	☐ Unknown
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Diagnosed renal anomalies

Enlarged pyelum	☐ No	☐ Yes	☐ Unknown
Renal cysts	☐ No	☐ Yes	☐ Unknown
Abnormal location of the kidney	☐ No	☐ Yes	☐ Unknown
Renal agenesis	☐ No	☐ Yes	☐ Unknown
Duplicature	☐ No	☐ Yes	☐ Unknown
Other renal anomalies	☐ No	☐ Yes	☐ Unknown

Other VACTERL anomalies

Anorectal malformation? **	☐ No anorectal malformation	☐ Anus atresia/imperforate anus without fistula	
	☐ Perineal fistula	☐ Rectourethral fistula	
	☐ Rectobladderneck fistula	☐ Vestibular fistula	
	☐ Persistent cloaca	☐ Other	
Vertebral anomalies **	☐ No	☐ Yes	☐ Unknown
Limb anomalies **	☐ No	☐ Yes	☐ Unknown

Genetics and DNA

Genetic counseling during primary hospital stay **	☐ No	☐ Yes	☐ Unknown
DNA diagnostics performed within the first year? **	☐ No	☐ Yes	☐ Unknown
Conclusion DNA diagnostics	☐ No abnormalities	☐ Full trisomies (x, 13, 18, 21)	
	☐ Deletions (13q, 17q, 16q24)	☐ Single gene disorders	
	☐ Other genetic abnormalities		
Syndrome associated with EA? **	☐ No associated syndrome	☐ VACTERL association	
	☐ CHARGE syndrome	☐ Trisomy 21 (Down)	
	☐ Other		

Other anomalies

Laryngeal anomalies? **	☐ No	☐ Yes	☐ Unknown
Laryngotracheoesophageal cleft	☐ No	☐ Yes	☐ Unknown
Neurologic anomalies? **	☐ No	☐ Yes	☐ Unknown
Pulmonary anomalies? **	☐ No	☐ Yes	☐ Unknown
Other intestinal anomalies? **	☐ No	☐ Yes	☐ Unknown
Duodenal atresia	☐ No	☐ Yes	☐ Unknown
Abdominal wall defects? **	☐ No	☐ Yes	☐ Unknown
Genital anomalies? **	☐ No	☐ Yes	☐ Unknown
Any other congenital anomalies? **	☐ No	☐ Yes	☐ Unknown

Surgery

Previous attempt at esophageal anastomosis (only if in other hospital) **	☐ No	☐ Yes	☐ Unknown
Did the patient die before the continuity repair? **	☐ No	☐ Yes	
Did the patient die due to (complications related to) the esophageal atresia?	☐ No	☐ Yes	☐ Unknown

Patient has died before definitive repair? If yes, go to 'Patientdata' to register the date of death.

Primary repair

Date of esophageal reconstruction *			
Type of repair **	☐ Primary anastomosis	☐ Delayed primary anastomosis	
	☐ Secondary anastomosis		

Type of secondary anastomosis **	☐ Gastric pull-up	☐ Gastric sleeve
	☐ Jejunal interposition	☐ Colonic interposition
Location of tracheoesophageal fistula *	☐ Proximal	☐ Distal
	☐ Proximal and distal	
Fistula closure approach	☐ Cervical	☐ Thoracoscopy
	☐ Thoracotomy	☐ Endoscopic

Traction

Was traction performed? **	☐ No	☐ Yes	☐ Unknown
Traction method	☐ External	☐ Internal	
	☐ Kimura	☐ Other	
	☐ Unknown		
Number of traction surgeries	☐		
	☐ Unknown		
Peroperative tracheobronchoscopy *	☐ No	☐ Yes, no abnormalities	
	☐ Yes, tracheomalacia	☐ Yes, extra fistula	
	☐ Yes, extra fistula and tracheomalacia	☐ Yes, other abnormalities	

Gastrostomy

Gastrostomy *	☐ No	☐ Yes	☐ Unknown
Date of gastrostomy *			

Esophageal repair: surgical details

Intended and initiated surgical approach *	☐ Thoracotomy		☐ Thoracoscopy
Conversion *	☐ No	☐ Yes	☐ Unknown
Surgical approach	☐ Posterolateral, classic		☐ Posterolateral, muscle sparing
	☐ Unknown		
Intercostal or rib resection	☐ Intercostal		☐ Rib resection
	☐ Unknown		
Pleural approach	☐ Extrapleural		☐ Intrapleural
	☐ Thorascopy with conversion		☐ Unknown
Transection azygos vein	☐ No	☐ Yes	☐ Unknown
Suture method used for anastomosis	☐ Interrupted sutures		☐ Running sutures
	☐ Combination		
Transanastomotic tube left during surgery	☐ No	☐ Yes	☐ Unknown
Type of surgery *	☐ Primary anastomosis		☐ Esophageal traction technique
	☐ Jejunum interposition		☐ Colon interposition
	☐ Gastric pull-up		☐ Gastric sleeve

Traction

Date of start traction *			
Thoracic tube left during surgery	☐ No	☐ Yes	☐ Unknown
Number of days of transanastomotic tube *			

Intraoperative complications

Were there any intraoperative complications? **	☐ No	☐ Yes	☐ Unknown
Tube complications	☐ No	☐ Yes	☐ Unknown
Tube complications - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Bleeding	☐ No	☐ Yes	☐ Unknown
Bleeding - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		

Blood transfusion **	☐ No	☐ Yes	☐ Unknown
Iatrogenic damage	☐ No	☐ Yes	☐ Unknown
Iatrogenic nerve damage	☐ No	☐ Yes	☐ Unknown
Nerve damage - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Iatrogenic tracheal damage	☐ No	☐ Yes	☐ Unknown
Tracheal damage - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Iatrogenic airway/lung damage	☐ No	☐ Yes	☐ Unknown
Airway/lung damage - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Iatrogenic major vessel damage	☐ No	☐ Yes	☐ Unknown
Major vessels - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Other iatrogenic damage	☐ No	☐ Yes	☐ Unknown
Other - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Hemodynamic complications	☐ No	☐ Yes	☐ Unknown
Hemodynamic complications - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Pulmonary complications	☐ No	☐ Yes	☐ Unknown
Pulmonary complications - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Other intraoperative complications	☐ No	☐ Yes	☐ Unknown
Other intraoperative complications - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		

End of primary hospitalization

Ventilation

Preoperative intubation	☐ No	☐ Yes	☐ Unknown
Mode of ventilation	☐ Conventional	☐ High frequency oscillation	
	☐ Unknown		
Date of preoperative intubation			
Preoperative extubation or extubation on date of surgery?	☐ No	☐ Yes	☐ Unknown
Date of preoperative extubation			
Respiratory support after preoperative extubation?	☐ No	☐ Yes	☐ Unknown
Postoperative intubation (not if the patient was only intubated during surgery)	☐ No	☐ Yes	☐ Unknown
Mode of ventilation	☐ Conventional	☐ High frequency oscillation	
	☐ Unknown		
Date of postoperative intubation			
Date of postoperative extubation			

Respiratory support after postoperative extubation?	☐ No	☐ Yes	☐ Unknown
Reintubation	☐ No	☐ Yes	☐ Unknown
Day of last extubation			

Mortality

Death before discharge *	☐ No	☐ Yes	☐ Unknown
Did the patient die due to (complications related to) the esophageal atresia?	☐ No	☐ Yes	☐ Unknown

Patient has died before discharge? If yes, go to 'Patientdata' to register the date of death.

Discharge

Date of discharge *			
Destination of discharge	☐ Home	☐ Regional hospital	
	☐ Center with pediatric surgical unit	☐ Other care facility	
	☐ Unknown		
Anti-reflux medications at discharge	☐ No	☐ Yes	☐ Unknown
Reason for starting anti-reflux meds	☐ Standard of care		☐ Symptomatic
	☐ Both		☐ Unknown

30-day complications

30-day complications *	☐ No	☐ Yes	☐ Unknown
Anastomotic leakage *	☐ No	☐ Yes	☐ Unknown
Symptoms of leakage? *	☐ No	☐ Yes	☐ Unknown
Radiologic proof of leakage? *	☐ No	☐ Yes	☐ Unknown
Anastomotic leakage - Clavien-Madadi *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
Redo continuity repair within 30 days? *	☐ No reoperation was performed		☐ Reanastomosis of the esophagus
	☐ Gastric pull-up		☐ Gastric sleeve
	☐ Jejunal interposition		☐ Colonic interposition
Date of redo continuity repair *			
Postoperative infections	☐ No	☐ Yes	☐ Unknown
Wound infection	☐ No	☐ Yes	☐ Unknown
Wound infection - Clavien-Madadi *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
Pneumonia	☐ No	☐ Yes	☐ Unknown
Pneumonia - Clavien-Madadi *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
UTI	☐ No	☐ Yes	☐ Unknown
UTI - Clavien-Madadi *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
Line sepsis	☐ No	☐ Yes	☐ Unknown
Line sepsis - Clavien-Madadi *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
Infection of other known source	☐ No	☐ Yes	☐ Unknown
Infection of other known source - Clavien-Madadi *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		

Infection of unknown origin	☐ No	☐ Yes	☐ Unknown
Infection of unknown origin - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Chylothorax **	☐ No	☐ Yes	☐ Unknown
Chylothorax - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Other 30-day complications **	☐ No	☐ Yes	☐ Unknown
Other 30-day complications - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		

One-year follow-up

One-year complications

One-year complications (between 30 days and one year postop) **	☐ No	☐ Yes	☐ Unknown
Complication of the esophageal anastomosis? **	☐ No	☐ Yes	☐ Unknown
Anastomotic complication - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Redo continuity repair within one year? *	☐ No reoperation was performed	☐ Reanastomosis of the esophagus	
	☐ Gastric pull-up	☐ Gastric sleeve	
	☐ Jejunal interposition	☐ Colonic interposition	
Date of redo continuity repair			
Anastomotic stricture **	☐ No	☐ Yes	☐ Unknown
Anastomotic stricture - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Date of first dilatation			
Technique of dilatation	☐ Bougienage	☐ Balloon	
Additional treatments during dilatation procedure	☐ No	☐ Yes	☐ Unknown
Number of dilatations during the first year *			
Recurrent fistula **	☐ No	☐ Yes	☐ Unknown
Recurrent fistula - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Date recurrent fistula repair			
Location recurrent fistula	☐ Proximal	☐ Distal	
	☐ Proximal and distal		
Recurrent fistula closure approach	☐ Cervical	☐ Thoracoscopy	
	☐ Thoracotomy	☐ Endoscopic	
Gastroesophageal reflux disease **	☐ No	☐ Yes	☐ Unknown
Gastroesophageal reflux disease - Clavien-Madadi **	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Anti-reflux medication	☐ No	☐ Yes	☐ Unknown
Anti-reflux procedure *	☐ No	☐ Yes	☐ Unknown
Date of anti-reflux procedure			

Type of anti-reflux procedure	☐ Nissen, laparotomy ☐ Thal, laparotomy ☐ Other, laparotomy	☐ Nissen, laparoscopy ☐ Thal, laparoscopy ☐ Other, laparoscopy
Redo anti-reflux procedure during first year	☐ No ☐ Yes ☐ Unknown	
Date of redo anti-reflux procedure		
Type of redo anti-reflux procedure	☐ Nissen, laparotomy ☐ Thal, laparotomy ☐ Other, laparotomy	☐ Nissen, laparoscopy ☐ Thal, laparoscopy ☐ Other, laparoscopy
Frequency of cyanotic episodes (ALTE / Dying spells) **	☐ Never/rare ☐ Once per week or less ☐ At least once per day	☐ Once per month or less ☐ 2-6 times per week
Tracheomalacia (postoperative) **	☐ No ☐ Yes ☐ Unknown	
Tracheomalacia - Clavien-Madadi * **	☐ Ia ☐ II ☐ IIIb ☐ V	☐ Ib ☐ IIIa ☐ IV
Surgery for tracheomalacia *	☐ No ☐ Yes, posterior tracheopexy	☐ Yes, aortopexy ☐ Yes, other procedure
Date of anti-tracheomalacia procedure		
Surgical approach of anti-tracheomalacia procedure	☐ Thoracotomy ☐ Thoracoscopy, converted to thoracotomy	☐ Thoracoscopy ☐ Sternotomy
Vocal cord paresis or paralysis that developed after surgery **	☐ No ☐ Yes ☐ Unknown	
Vocal cord paresis - Clavien-Madadi * **	☐ Ia ☐ II ☐ IIIb ☐ V	☐ Ib ☐ IIIa ☐ IV
Unilateral or bilateral	☐ Unilateral ☐ Bilateral	

Surgeries and readmissions

Other surgeries during the first year **	☐ No ☐ Yes ☐ Unknown
Total number of surgeries during the first year **	
Readmission for other reasons than reoperation	☐ No ☐ Yes ☐ Unknown
Total number of admissions during the first year **	

Feeding

Start enteral feeding (tube)	
Start oral feeding	☐ ☐ Oral feeding not started at 1 year
Full oral feeding	☐ ☐ Full oral feeding not achieved at 1 year
Oral feeding issues / Oral aversion at one year **	☐ No ☐ Yes ☐ Unknown
Need for feeding supplements	☐ No ☐ Yes ☐ Unknown
Visit SLT specialist	☐ No ☐ Yes ☐ Unknown

Growth and ability to maintain weight

Weight at 1 year (in g) **	☐ ☐ Unknown
Date of weight measurement	
Length at 1 year (in cm) **	☐ ☐ Unknown
Date of length measurement	

Mortality

Mortality at 1 year **	☐ No ☐ Yes
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Did the patient die due to (complications related to) the esophageal atresia?	☐ No	☐ Yes	☐ Unknown
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Patient has died due to (complications related to) the esophageal atresia? If yes, go to 'Patientdata' to register the date of death.

Two-year follow-up

Multidisciplinary team

Multidisciplinary team **	☐ No	☐ Yes	☐ Unknown
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Two-year complications

Two-year complications (between one year and two years postop) **	☐ No	☐ Yes	☐ Unknown
Complication of the esophageal anastomosis? **	☐ No	☐ Yes	☐ Unknown
Anastomotic complication - Clavien-Madadi *	☐ Ia ☐ Ib ☐ II ☐ IIIa ☐ IIIb ☐ IV ☐ V		
Redo continuity repair within two years *	☐ No reoperation was performed ☐ Reanastomosis of the esophagus ☐ Gastric pull-up ☐ Gastric sleeve ☐ Jejunal interposition ☐ Colonic interposition		
Date of redo continuity repair			
Anastomotic stricture **	☐ No	☐ Yes	☐ Unknown
Anastomotic stricture - Clavien-Madadi *	☐ Ia ☐ Ib ☐ II ☐ IIIa ☐ IIIb ☐ IV ☐ V		
Date of first dilatation			
Technique of dilatation	☐ Bougienage ☐ Balloon		
Additional treatments during dilatation procedure	☐ No	☐ Yes	☐ Unknown
Number of dilatations during the second year *			
Recurrent fistula during the second year **	☐ No	☐ Yes	☐ Unknown
Recurrent fistula - Clavien-Madadi *	☐ Ia ☐ Ib ☐ II ☐ IIIa ☐ IIIb ☐ IV ☐ V		
Date recurrent fistula repair			
Location recurrent fistula	☐ Proximal ☐ Distal ☐ Proximal and distal		
Recurrent fistula closure approach	☐ Cervical ☐ Thoracoscopy ☐ Thoracotomy ☐ Endoscopic		
Gastroesophageal reflux disease **	☐ No	☐ Yes	☐ Unknown
Gastroesophageal reflux disease - Clavien-Madadi **	☐ Ia ☐ Ib ☐ II ☐ IIIa ☐ IIIb ☐ IV ☐ V		
Anti-reflux medication	☐ No	☐ Yes	☐ Unknown
Anti-reflux procedure *	☐ No	☐ Yes	☐ Unknown
Date of anti-reflux procedure			
Type of anti-reflux procedure	☐ Nissen, laparotomy ☐ Nissen, laparoscopy ☐ Thal, laparotomy ☐ Thal, laparoscopy ☐ Other, laparotomy ☐ Other, laparoscopy		
Redo anti-reflux procedure during first year	☐ No	☐ Yes	☐ Unknown
Date of redo anti-reflux procedure			

Type of redo anti-reflux procedure	☐ Nissen, laparotomy ☐ Thal, laparotomy ☐ Other, laparotomy	☐ Nissen, laparoscopy ☐ Thal, laparoscopy ☐ Other, laparoscopy
Frequency of cyanotic episodes (ALTE / Dying spells) **	☐ Never/rare ☐ Once per week or less ☐ At least once per day	☐ Once per month or less ☐ 2-6 times per week
Tracheomalacia **	☐ No ☐ Yes ☐ Unknown	
Tracheomalacia - Clavien-Madadi * **	☐ Ia ☐ II ☐ IIIb ☐ V	☐ Ib ☐ IIIa ☐ IV
Surgery for tracheomalacia *	☐ No ☐ Yes, posterior tracheopexy	☐ Yes, aortopexy ☐ Yes, other procedure
Date of anti-tracheomalacia procedure		
Surgical approach of anti-tracheomalacia procedure	☐ Thoracotomy ☐ Thoracoscopy, converted to thoracotomy	☐ Thoracoscopy ☐ Sternotomy

Surgeries and readmissions

Other surgeries during the second year **	☐ No ☐ Yes ☐ Unknown
Total number of surgeries during the second year **	
Readmission for other reasons than reoperation	☐ No ☐ Yes ☐ Unknown
Total number of admissions during the second year **	

Feeding

Oral feeding issues / Oral aversion at two years **	☐ No ☐ Yes ☐ Unknown
Difficulties in swallowing / Dysphagia **	☐ No ☐ Yes ☐ Unknown
Visit SLT specialist	☐ No ☐ Yes ☐ Unknown
Need for tube feeding	☐ No ☐ Yes ☐ Unknown
Full oral feeding	☐ ☐ Full oral feeding not achieved after 2 years
Need for feeding supplements	☐ No ☐ Yes ☐ Unknown

Growth and ability to maintain weight

Weight at 2 years (in g) **	☐ ☐ Unknown
Date of weight measurement	
Length at 2 year (in cm) **	☐ ☐ Unknown
Date of length measurement	

Other EA-associated morbidity

Oesophagitis **	☐ No ☐ Yes ☐ Unknown
Number of acute lower respiratory infections **	☐ ☐ No acute lower respiratory infections ☐ Unknown
Chronic respiratory complications or symptoms **	☐ No ☐ Yes ☐ Unknown
Musculoskeletal sequelae **	☐ No ☐ Yes ☐ Unknown
Chronic use of medications	☐ No ☐ Yes ☐ Unknown

Mortality

Mortality at 2 year **	☐ No ☐ Yes
Did the patient die due to (complications related to) the esophageal atresia?	☐ No ☐ Yes ☐ Unknown

Patient has died due to (complications related to) the esophageal atresia? If yes, go to 'Patientdata' to register the date of death.

Complications

Complications

Diagnosis anastomotic leakage *	☐ Clinical symptoms	☐ Contrast study
Anastomotic stenosis (during first admission) *	☐ No ☐ Yes	☐ Unknown
Tracheomalacia *	☐ No ☐ Yes	☐ Unknown
Diagnosis tracheomalacia *	☐ Clinical symptoms	☐ Bronchoscopy
Other complications *	☐ No ☐ Yes	☐ Unknown

Other complications

Cardiac complications *	☐ No ☐ Yes	☐ Unknown
Pulmonary complications *	☐ No ☐ Yes	☐ Unknown
Urogenital complications *	☐ No ☐ Yes	☐ Unknown
Gastrointestinal complications *	☐ No ☐ Yes	☐ Unknown
Other complications *	☐ No ☐ Yes	☐ Unknown

Redo surgery first admission

Redo surgery during first admission *	☐ No ☐ Yes	☐ Unknown
Date of redo surgery *		

Type of surgery

Anastomotic dilatation *	☐ No ☐ Yes	☐ Unknown
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Discharge

Re-admission *	☐ No	☐ Yes	☐ Unknown
Reason of re-admission *	☐ Stenosis	☐ ALTE	
	☐ Gastro esophageal reflux	☐ Pulmonal	
	☐ Cardial	☐ Other	

Redo surgery first year

Redo surgery first year *	☐ No ☐ Yes	☐ Unknown
Date of redo surgery *		

Type of surgery

Anastomotic dilatation (secondary) *	☐ No	☐ Yes	☐ Unknown
Technique of dilatation (secondary) *	☐ Dilatation with tube		☐ Dilatation during gastroscopy
	☐ Radiological balloon dilatation		

Complications redo surgery

Complications after redo surgery *	☐ No ☐ Yes	☐ Unknown
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Type of complication

Pneumonia (secondary) *	☐ No	☐ Yes	☐ Unknown
Anastomotic leakage (secondary) *	☐ No	☐ Yes	☐ Unknown
Diagnosis anastomotic leakage (secondary) *	☐ Clinical symptoms		☐ Contrast study
Gastro-esophageal reflux (secondary) *	☐ No	☐ Yes	☐ Unknown
Diagnosis gastro-esophageal reflux (secondary) *	☐ Clinical symptoms		☐ Contrast study
	☐ 24 h pH measurement		

Anastomotic stenosis (secondary) *	☐ No	☐ Yes	☐ Unknown
Tracheomalacia (secondary) *	☐ No	☐ Yes	☐ Unknown
Other complications (secondary) *	☐ No	☐ Yes	☐ Unknown

Other complications

Cardiac complications *	☐ No	☐ Yes	☐ Unknown
Pulmonary complications *	☐ No	☐ Yes	☐ Unknown
Urogenital complications *	☐ No	☐ Yes	☐ Unknown
Gastrointestinal complications *	☐ No	☐ Yes	☐ Unknown
Other complications *	☐ No	☐ Yes	☐ Unknown

Gastroschisis

Diagnostics and treatment

Age at onset **	☐ Antenatal	☐ At birth
	☐ Date (to be specified below)	☐ Undetermined
Date of onset **		
Age at diagnosis **	☐ Antenatal	☐ At birth
	☐ Date (to be specified below)	☐ Undetermined
Date of diagnosis **		
Date of admission tertiary paediatric surgical centre *		

Pre repair size of defect

AP diameter (mm)	
LR diameter (mm)	

Bowel injury score

Matting	☐ None	☐ Moderate	☐ Severe
Necrosis	☐ Absent	☐ Focal	☐ Diffuse
Atresia	☐ Absent	☐ Suspected	
	☐ Present	☐ Unknown	
Preoperative perforation	☐ No	☐ Yes	
Volvulus	☐ No	☐ Yes	☐ Unknown
Other	☐ No	☐ Yes	☐ Unknown

Other abnormalities and defects

DNA diagnostics	☐ No	☐ Yes	☐ Unknown
Conclusion DNA diagnostics	☐ No abnormalities		☐ Full trisomies (x, 13, 18, 21)
	☐ Deletions (13q, 17q, 16q24)		☐ Single gene disorders
	☐ Other genetic abnormalities		
Other defects	☐ No	☐ Yes	☐ Unknown

Other defects

Cardiac defects	☐ No	☐ Yes	☐ Unknown
Defects kidney	☐ No	☐ Yes	☐ Unknown
Testicular defects	☐ No	☐ Yes	☐ Unknown
Other defects	☐ No	☐ Yes	☐ Unknown
If other, describe			
Surgery *	☐ No	☐ Yes	

Surgery

Patient died before definitive repair?	☐ No	☐ Yes
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Patient has died before definitive repair? If yes, go to 'Patientdata' to register the date of death.

Type of repair	☐ Primary closure, sedation (Bianchi)	☐ Primary closure, general anaesthesia
	☐ Closure with patch	☐ Closure with silo
	☐ Closure with silo, then patch	☐ Closure with silo, general anaesthesia
Date of repair *		
Size of silo		
Duration of silo (days)		
Malrotation	☐ No	☐ Yes ☐ Unknown
Non rotation treatment	☐ No	☐ Yes
Appendectomy	☐ No	☐ Yes

Herniated organs

Small bowel	☐ No	☐ Yes
Colon	☐ No	☐ Yes
Stomach	☐ No	☐ Yes
Liver	☐ No	☐ Yes
Gonads	☐ No	☐ Yes
Bladder	☐ No	☐ Yes
Perioperative antibiotics	☐ No	☐ Yes
Peroperative complications	☐ No	☐ Yes

Peroperative complications

Bleeding	☐ No	☐ Yes
Bleeding - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Bowel perforation	☐ No	☐ Yes
Bowel perforation - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Other	☐ No	☐ Yes
Other intraoperative complications - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Postoperative complications **	☐ No	☐ Yes

Type of postoperative complication

Respiratory failure (mechanical ventilation)	☐ No	☐ Yes
Respiratory failure (mechanical ventilation) - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Respiratory tract infection	☐ No	☐ Yes
Respiratory tract infection - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Wound dehiscence	☐ No	☐ Yes
Wound dehiscence - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Wound/patch infection	☐ No	☐ Yes
Wound/patch infection - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	

Renal failure	☐ No	☐ Yes
Renal failure - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Bowel obstruction / ileus	☐ No	☐ Yes
Bowel obstruction / ileus - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Line sepsis *	☐ No	☐ Yes
Line sepsis - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Gastro oesophageal reflux	☐ No	☐ Yes
Gastro oesophageal reflux - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Abdominal compartment syndrome	☐ No	☐ Yes
Abdominal compartment syndrome - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Other	☐ No	☐ Yes
Other postoperative complications - Clavien-Madadi	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	

Discharge

Date start enteral feeding	
Date full enteral feeding **	

Discharge

Date of discharge	
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If the patient died during the initial hospital admission, please enter the date of death.

Discharge to	☐ Pediatric surgical center	☐ Periferal hospital
	☐ Home	☐ Other

If the patient died during hospital admission please choose other.

Death during hospital admission or within 30 days after surgery	☐ No	☐ Yes	☐ Unknown
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Patient has died during hospital admission or within 30 days after surgery? If yes, go to 'Patientdata' to register the date of death.

Readmission (within the first year)	☐ No	☐ Yes
Date of readmission		

Reason of readmission

Acute surgery	☐ No	☐ Yes
Elective surgery	☐ No	☐ Yes
Wound infection	☐ No	☐ Yes
Wound dehiscence	☐ No	☐ Yes
Parenteral feeding	☐ No	☐ Yes
Other reasons	☐ No	☐ Yes

Biliary atresia

Diagnosis and surgery

Age at onset **	☐ Antenatal ☐ Date (to be specified below)	☐ At birth ☐ Undetermined
Date of onset **		
Age at diagnosis **	☐ Antenatal ☐ Date (to be specified below)	☐ At birth ☐ Undetermined
Date of diagnosis **		
Date of admission tertiary paediatric surgical centre *		
Patient died before definitive repair?	☐ No	☐ Yes
<i>Patient has died before definitive repair? If yes, go to 'Patientdata' to register the date of death.</i>		
Kasai procedure *	☐ No	☐ Yes ☐ Unknown
Date Kasai procedure *		
Type of biliary atresia	☐ Isolated biliary atresia ☐ Cystic biliary atresia (CBA) ☐ Biliary atresia with splenic malformation (BASM)	

1-year follow up

Clearance of jaundice < 6 months *	☐ No	☐ Yes	☐ Unknown
Screening OLT within the first year *	☐ No	☐ Yes	☐ Unknown
Liver transplantation (OLT) *	☐ No	☐ Yes	☐ Unknown
Date of liver transplantation			
Death	☐ No	☐ Yes	☐ Unknown

Patient has died? If the answer is yes, go to 'Patientdata' to register the date of death.

Malrotation

Diagnostics for malrotation

Onset and admission

Date of admission tertiary paediatric surgical centre *			
Age at onset *	☐ Antenatal ☐ Date (to be specified below)	☐ At birth ☐ Undetermined	
Date of onset *			
Age at diagnosis *	☐ Antenatal ☐ Date (to be specified below)	☐ At birth ☐ Undetermined	
Date of onset *			
Symptoms at diagnosis *	☐ No	☐ Yes	☐ Unknown
Incidental finding **	☐ Yes, before surgery ☐ No	☐ Yes, during surgery ☐ Unknown	
Acute intestinal obstruction *	☐ No	☐ Yes	☐ Unknown
Volvolus *	☐ No	☐ Yes	☐ Unknown
Chronic or recurrent abdominal symptoms *	☐ No	☐ Yes	☐ Unknown
Cardiac intervention *	☐ No	☐ Yes	☐ Unknown
Date cardiac intervention *			

Diagnostic testing

Was an upper gastrointestinal contrast study performed? *	☐ No	☐ Yes	☐ Unknown
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Date of upper gastrointestinal contrast study *			
The diagnosis of malrotation was based on: *	☐ Upper gastrointestinal contrast study		☐ Intraoperative findings
	☐ Ultrasound		
Whirlpool sign on ultrasound *	☐ No	☐ Yes	☐ Unknown
Type of malrotation **	☐ Typical		☐ Atypical
Echocardiography *	☐ No	☐ Yes	☐ Unknown
Date of echocardiography *			
Persistent ductus arteriosus *	☐ No	☐ Yes	☐ Unknown
Ventricular septal defect *	☐ No	☐ Yes	☐ Unknown
Atrial septal defect *	☐ No	☐ Yes	☐ Unknown
Tetralogy of Fallot *	☐ No	☐ Yes	☐ Unknown
Right descending aorta *	☐ No	☐ Yes	☐ Unknown
Coarctatio Aortae *	☐ No	☐ Yes	☐ Unknown
Other cardiac anomalies *	☐ No	☐ Yes	☐ Unknown
Ultrasound of the urogenital system *	☐ No	☐ Yes	☐ Unknown
Date of the ultrasound of the urogenital system *			
Cysts *	☐ No	☐ Yes	☐ Unknown
Enlarged pyelum *	☐ No	☐ Yes	☐ Unknown
Abnormal location *	☐ No	☐ Yes	☐ Unknown
Urogenital duplication *	☐ No	☐ Yes	☐ Unknown
Renal agenesis *	☐ No	☐ Yes	☐ Unknown
Other urogenital malformation *	☐ No	☐ Yes	☐ Unknown

Associated anomalies			
Situs inversus *	☐ No	☐ Yes	☐ Unknown
Isomerism *	☐ No	☐ Yes	☐ Unknown
Form of isomerism *	☐ Left isomerism		☐ Right isomerism
Duodenal Atresia *	☐ No	☐ Yes	☐ Unknown
Jejunioileal Atresia *	☐ No	☐ Yes	☐ Unknown
Congenital diaphragmatic hernia *	☐ No	☐ Yes	☐ Unknown
Gastroschisis *	☐ No	☐ Yes	☐ Unknown
Anorectal malformation *	☐ No	☐ Yes	☐ Unknown
Hirschsprung's disease *	☐ No	☐ Yes	☐ Unknown
Other *	☐ No	☐ Yes	☐ Unknown

Treatment			
Management of malrotation *	☐ Surgical management		☐ Non-surgical treatment
Date of primary surgery *			
Prophylactic surgical procedure *	☐ No	☐ Yes	☐ Unknown
Approach of surgical procedure *	☐ Laparoscopy		☐ Laparotomy
	☐ Laparoscopy converted to laparotomy		☐ Unknown
Technique of surgical procedure *	☐ Ladd's procedure		☐ Other
Bowel resection *	☐ No	☐ Yes	☐ Unknown
Jejunum resection *	☐ No	☐ Yes	☐ Unknown
Ileum resection *	☐ No	☐ Yes	☐ Unknown
Terminal ileum resection *	☐ No	☐ Yes	☐ Unknown
Ileocecal valve *	☐ No	☐ Yes	☐ Unknown
Ascending colon *	☐ No	☐ Yes	☐ Unknown
Transverse colon resection *	☐ No	☐ Yes	☐ Unknown
Descending colon resection *	☐ No	☐ Yes	☐ Unknown
Sigmoid colon resection *	☐ No	☐ Yes	☐ Unknown

Length of remaining small bowel (in cm) *	☐ ☐ Unknown
Length of remaining colon (in cm) *	☐ ☐ Unknown
Postoperative parenteral nutrition *	☐ No ☐ Yes ☐ Unknown
Date of start parenteral nutrition *	☐ ☐ Unknown
Parenteral nutrition stop before discharge *	☐ No ☐ Yes ☐ Unknown
Date of stop parenteral nutrition *	☐ ☐ Unknown
Date of discharge *	☐ ☐ Unknown

One-year follow-up (surgical)

Was the patient readmitted? *	☐ No ☐ Yes ☐ Unknown
Date of readmission *	☐ ☐ Unknown

Complications after surgical management

Wound complication *	☐ No ☐ Yes ☐ Unknown
Wound complication - Clavien-Madadi *	☐ Ia ☐ Ib ☐ II ☐ IIIa ☐ IIIb ☐ IV ☐ V
Bowel obstruction/volvulus *	☐ No ☐ Yes ☐ Unknown
Bowel obstruction/volvulus - Clavien-Madadi *	☐ Ia ☐ Ib ☐ II ☐ IIIa ☐ IIIb ☐ IV ☐ V
Management of bowel obstruction/volvulus *	☐ Surgical management ☐ Non-surgical treatment
Date of reoperation *	
Approach of surgical procedure *	☐ Laparoscopy ☐ Laparotomy ☐ Laparoscopy converted to laparotomy ☐ Unknown
Technique of surgical procedure *	☐ Ladd's procedure ☐ Other
Bowel resection *	☐ No ☐ Yes ☐ Unknown
Jejunum resection *	☐ No ☐ Yes ☐ Unknown
Ileum resection *	☐ No ☐ Yes ☐ Unknown
Terminal ileum resection *	☐ No ☐ Yes ☐ Unknown
Ileocecal valve *	☐ No ☐ Yes ☐ Unknown
Ascending colon *	☐ No ☐ Yes ☐ Unknown
Transverse colon resection *	☐ No ☐ Yes ☐ Unknown
Descending colon resection *	☐ No ☐ Yes ☐ Unknown
Sigmoid colon resection *	☐ No ☐ Yes ☐ Unknown
Length of remaining small bowel (in cm) *	☐ ☐ Unknown
Length of remaining colon (in cm) *	☐ ☐ Unknown
Postoperative parenteral nutrition *	☐ No ☐ Yes ☐ Unknown
Date of start parenteral nutrition *	☐ ☐ Unknown
Parenteral nutrition stop before discharge *	☐ No ☐ Yes ☐ Unknown
Date of stop parenteral nutrition *	☐ ☐ Unknown
Other complications *	☐ No ☐ Yes ☐ Unknown

Other complications - Clavien-Madadi *	☐ Ia	☐ Ib
	☐ II	☐ IIIa
	☐ IIIb	☐ IV
	☐ V	
Date of discharge *	☐	
	☐ Unknown	

One-year follow-up (non-surgical)

Bowel obstruction/volvulus *	☐ No	☐ Yes	☐ Unknown
Bowel obstruction/volvulus - Clavien-Madadi *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Management of bowel obstruction/volvulus *	☐ Surgical management	☐ Non-surgical treatment	
Date of readmission *	☐		
	☐ Unknown		
Intraoperative finding: malrotation *	☐ No	☐ Yes	☐ Unknown
Intraoperative finding: bowel obstruction/volvulus *	☐ No	☐ Yes	☐ Unknown
Intraoperative finding: bowel ischemia *	☐ No	☐ Yes	☐ Unknown
Intraoperative finding: other complication *	☐ No	☐ Yes	☐ Unknown
Date of surgery *			
Approach of surgical procedure *	☐ Laparoscopy	☐ Laparotomy	
	☐ Laparoscopy converted to laparotomy	☐ Unknown	
Technique of surgical procedure *	☐ Ladd's procedure	☐ Other	
Bowel resection *	☐ No	☐ Yes	☐ Unknown
Jejunum resection *	☐ No	☐ Yes	☐ Unknown
Ileum resection *	☐ No	☐ Yes	☐ Unknown
Terminal ileum resection *	☐ No	☐ Yes	☐ Unknown
Ileocecal valve *	☐ No	☐ Yes	☐ Unknown
Ascending colon *	☐ No	☐ Yes	☐ Unknown
Transverse colon resection *	☐ No	☐ Yes	☐ Unknown
Descending colon resection *	☐ No	☐ Yes	☐ Unknown
Sigmoid colon resection *	☐ No	☐ Yes	☐ Unknown
Length of remaining small bowel (in cm) *	☐		
	☐ Unknown		
Length of remaining colon (in cm) *	☐		
	☐ Unknown		
Postoperative parenteral nutrition *	☐ No	☐ Yes	☐ Unknown
Date of start parenteral nutrition *	☐		
	☐ Unknown		
Parenteral nutrition stop before discharge *	☐ No	☐ Yes	☐ Unknown
Date of stop parenteral nutrition *	☐		
	☐ Unknown		
Hospital admission *	☐ No	☐ Yes	☐ Unknown
Other complications *	☐ No	☐ Yes	☐ Unknown
Date of discharge *	☐		
	☐ Unknown		

One-year postoperative general

Reoperation or other surgeries *	☐ No	☐ Yes	☐ Unknown
Number of surgeries due to malrotation *			

Number of surgeries due to other causes *			
Parenteral nutrition at 1 year postoperatively *	☐ No	☐ Yes	☐ Unknown
Death during first year *	☐ No	☐ Yes	☐ Unknown
Death related to malrotation *	☐ No	☐ Yes	☐ Unknown

Necrotizing enterocolitis

Diagnostics

Onset and diagnosis/admission

Date at diagnosis	☐		
	☐ Unknown		
Date of admission treating paediatric surgical center *			
Where was the patient referred from?	☐ Another internal department	☐ Another healthcare centre	
	☐ Home		
Date of consult paediatric surgeon *	☐		
	☐ Unknown		
Weight at NEC diagnosis (grams) *			
Type of NEC (Bell's stage) *	☐ 1A	☐ 1B	
	☐ 2A	☐ 2B	
	☐ 3A	☐ 3B	
Umbilical line	☐ No	☐ Yes	☐ Unknown

Feeding

Enteral feeding received prior to NEC diagnosis *	☐ No	☐ Yes	☐ Unknown
Type of enteral feeding *	☐ Mother's own milk	☐ Human donor milk	
	☐ Artificial formula	☐ Combination of human milk and formula	
Enteral feeding received 24 hours prior to NEC diagnosis *	☐ No	☐ Yes	☐ Unknown
Type of enteral feeding *	☐ Mother's own milk	☐ Human donor milk	
	☐ Artificial formula	☐ Combination of human milk and formula	

Diagnostics and disease signs

During the active course of disease, please specify systematic signs

Temperature instability *	☐ Hypothermia (< 36 degrees Celsius)	☐ Normothermia	
	☐ Hyperthermia/fever (> 38.5 degrees Celsius)		
Bradycardia *	☐ No	☐ Yes	☐ Unknown
Metabolic acidosis *	☐ No	☐ Yes	☐ Unknown
Thrombocytopenia *	☐ No	☐ Yes	☐ Unknown
Neutropenia *	☐ No	☐ Yes	☐ Unknown
Hypotension (requiring fluid, vasopressor or inotropic support) *	☐ No	☐ Yes	☐ Unknown
Ventilated prior to NEC diagnosis? *	☐ No	☐ Yes	
Apnea *	☐ No	☐ Yes	☐ Unknown

Please specify abdominal signs, during active course of disease

Gastric retention *	☐ No	☐ Yes	☐ Unknown
Bilious aspirates *	☐ No	☐ Yes	☐ Unknown
Abdominal distension *	☐ No	☐ Yes	☐ Unknown
Abdominal tenderness *	☐ No	☐ Yes	☐ Unknown
Abdominal discoloration *	☐ No	☐ Yes	☐ Unknown
Fecal blood *	☐ No	☐ Yes	☐ Unknown

Signs of peritonitis (requiring fluid, vasopressor or inotropic support) *	☐ No	☐ Yes	☐ Unknown
How were radiographic disease signs assessed? *	☐ X-ray of abdomen	☐ Ultra sound of abdomen	
	☐ Both	☐ None	

Please specify radiographic disease signs, during active course of disease

Intestinal dilation *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Ileus *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Pneumatosis intestinalis *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Ascites *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Portal venous gas *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Pneumoperitoneum *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Fixed bowel loop >24 hours (at repeated X-Ray) *	☐ Yes, on X-ray	☐ Yes, on ultrasound
	☐ Yes, both	☐ No
	☐ Unknown	
Cerebral neonatal ultrasound and/or MRI at NEC diagnosis *	☐ No	☐ Yes, ultrasound
	☐ Yes, MRI	☐ Unknown

Please specify findings on ultrasound

Please specify findings on MRI

Intracranial hemorrhage *	☐ No	☐ Yes	☐ Unknown
Most severe 'Papile' grade *	☐ I	☐ II	
	☐ III	☐ IV	
Venous cerebral infarction *	☐ No	☐ Yes	☐ Unknown
Side of lesions *	☐ Unilateral	☐ Bilateral	
Periventricular leucomalacia grade 2 or higher *	☐ No	☐ Yes	☐ Unknown

Associated anomalies

Cardiac and large vessels anomalies

Echocardiography *	☐ No	☐ Yes
	☐ Done in another hospital	☐ Unknown
Date of echocardiography *	☐	
	☐ Unknown	
Major cardiac defects *	☐ No	☐ Yes
	☐ Yes	☐ Unknown
Patent ductus arteriosus *	☐ No	☐ Yes
	☐ Yes	☐ Unknown
Management of PDA *	☐ Medical treatment	☐ Surgical treatment
	☐ Not yet treated at time of NEC diagnosis	
Cardiac interventions *	☐ No	☐ Yes
	☐ Yes	☐ Unknown
Date of first cardiac intervention *	☐	
	☐ Unknown	
Type of cardiac intervention *	☐ Surgical treatment	☐ Percutane cardiac treatment
	☐ Conservative treatment	
Did the patient pass away prior to the cardiac intervention? *	☐ Yes, due to cardiac anomaly	☐ Yes, NEC related
	☐ Yes, reason unknown	☐ No

Indication for surgery

Pneumoperitoneum *	☐ No	☐ Yes
Clinical deterioration despite maximal non-surgical treatment for 24 hours *	☐ No	☐ Yes
Fixed loop for 24 hours *	☐ No	☐ Yes

Surgical intervention

Surgical intervention for NEC *	☐ No	☐ Yes	☐ Unknown
Date of surgical intervention *	☐		
	☐ Unknown		
Time to surgery from diagnosis of NEC (hours) *			
Type of surgical intervention *	☐ Peritoneal drainage		
	☐ Laparotomy		
	☐ Both (drainage as a bridge to surgery/transport)		
Open close procedure *	☐ No	☐ Yes	☐ Unknown
Date of death *	☐		
	☐ Unknown		
Bowel resection *	☐ No	☐ Yes	☐ Unknown
Stoma, primary anastomosis or clip and drop *	☐ Enterostomy/colostomy		
	☐ Primary anastomosis		
	☐ Clip and drop		
	☐ Both (enterostomy/colostomy and primary anastomosis due to multiple resections)		
	☐ Other		
Place of stoma *	☐ Jejunum		
	☐ Ileum		
	☐ Colon ascendens		
	☐ Transvers colon		
	☐ Colon descendens		
	☐ Sigmoid		
Number of anastomoses *			

Which part of the bowel has been removed?

Jejunum *	☐ No	☐ Yes	☐ Unknown
Ileum *	☐ No	☐ Yes	☐ Unknown
Terminal ileum/coecum *	☐ No	☐ Yes	☐ Unknown
Colon ascendens *	☐ No	☐ Yes	☐ Unknown
Transvers colon *	☐ No	☐ Yes	☐ Unknown
Colon descendens *	☐ No	☐ Yes	☐ Unknown
Sigmoid Transverse colon *	☐ No	☐ Yes	☐ Unknown
Sigmoid *	☐ No	☐ Yes	☐ Unknown
Length of small bowel after resection (cm) *			
Length of colon after resection (cm) *			
Was the ileocecal valve resected *	☐ No	☐ Yes	

Location of NEC

Jejunum *	☐ No	☐ Yes	☐ Unknown
Ileum *	☐ No	☐ Yes	☐ Unknown
Terminal ileum/coecum *	☐ No	☐ Yes	☐ Unknown
Colon ascendens *	☐ No	☐ Yes	☐ Unknown
Transvers colon *	☐ No	☐ Yes	☐ Unknown
Colon descendens *	☐ No	☐ Yes	☐ Unknown
Sigmoid *	☐ No	☐ Yes	☐ Unknown
NEC totalis *	☐ No	☐ Yes	☐ Unknown

Secondary laparotomy

A planned second-look laparotomy *	☐ No	☐ Yes	☐ Unknown
Open close procedure *	☐ No	☐ Yes	☐ Unknown

Date of death *	☐ ☐ Unknown		
Bowel resection *	☐ No ☐ Yes ☐ Unknown		
Stoma, primary anastomosis or clip and drop *	☐ Enterostomy/colostomy		☐ Primary anastomosis
	☐ Clip and drop		☐ Both (enterostomy/colostomy and primary anastomosis due to multiple resections)
	☐ Other		
Place of stoma *	☐ Jejunum		☐ Ileum
	☐ Colon ascendens		☐ Transvers colon
	☐ Colon descendens		☐ Sigmoid
Number of anastomoses *			
<i>Which part of the bowel has been removed?</i>			
Jejunum *	☐ No ☐ Yes ☐ Unknown		
Ileum *	☐ No ☐ Yes ☐ Unknown		
Terminal ileum/coecum *	☐ No ☐ Yes ☐ Unknown		
Colon ascendens *	☐ No ☐ Yes ☐ Unknown		
Transvers colon *	☐ No ☐ Yes ☐ Unknown		
Colon descendens *	☐ No ☐ Yes ☐ Unknown		
Sigmoid Transverse colon *	☐ No ☐ Yes ☐ Unknown		
Sigmoid *	☐ No ☐ Yes ☐ Unknown		
Length of small bowel after resection (cm) *			
Length of colon after resection (cm) *			
Was the ileocecal valve resected *	☐ No ☐ Yes		

End of primary hospitalization

Refeeding after NEC diagnosis

Reinitiation of minimal enteral feeding after NEC diagnosis (MEF) *	☐ No ☐ Yes ☐ Unknown		
Date of start MEF *	☐ ☐ Unknown		
Reinitiation enteral feeding after NEC diagnosis *	☐ ☐ Unknown		
Type of enteral feeding after NEC episode *	☐ Mother's own milk		☐ Human donor milk
	☐ Artificial formula		☐ Combination of human milk and formula
If combination, please specify more or less than 50% human *	☐ >50% human		☐ < 50% human
Distal refeeding via mucous fistula before closing the stoma *	☐ No ☐ Yes ☐ Unknown		
Full enteral feeding after NEC diagnosis *	☐ ☐ Unknown		

30 day complications

30 day complications *	☐ No ☐ Yes ☐ Unknown		
Clinical sepsis (not central line associated) *	☐ No ☐ Yes ☐ Unknown		
Clinical sepsis - Clavien Madadi severity score *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
Stoma related complications *	☐ No ☐ Yes ☐ Unknown		
Stoma related complications - Clavien Madadi severity score *	☐ Ia		☐ Ib
	☐ II		☐ IIIa
	☐ IIIb		☐ IV
	☐ V		
High output stoma *	☐ No ☐ Yes ☐ Unknown		
Dermatitis *	☐ No ☐ Yes ☐ Unknown		
Stoma prolapse *	☐ No ☐ Yes ☐ Unknown		

Anastomotic leakage *	☐ No	☐ Yes	☐ Unknown
Anastomotic leakage - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Abdominal compartment syndrome *	☐ No	☐ Yes	☐ Unknown
Abdominal compartment syndrome - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Wound complication (including wound dehiscence and wound infection) *	☐ No	☐ Yes	☐ Unknown
Wound complication - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Fascial dehiscence (Platzbauch) *	☐ No	☐ Yes	☐ Unknown
Fascial dehiscence (Platzbauch) - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Anastomotic stricture *	☐ No	☐ Yes	☐ Unknown
Anastomotic stricture - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Post NEC stenosis *	☐ No	☐ Yes	☐ Unknown
Post NEC stenosis -Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Adhesive bowel obstruction for which surgery is performed *	☐ No	☐ Yes	☐ Unknown
Adhesive bowel obstruction - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		
Central line-associated complications *	☐ No	☐ Yes	☐ Unknown
Central line-associated complications - Clavien Madadi severity score *	☐ Ia	☐ Ib	
	☐ II	☐ IIIa	
	☐ IIIb	☐ IV	
	☐ V		

Discharge

Date of discharge *	☐		
	☐ Unknown		
Destination of discharge *	☐ Home	☐ Regional hospital	
	☐ Center with pediatric surgical unit	☐ Other care facility	
	☐ Unknown		
Diversion to palliative care post-operative *	☐ No	☐ Yes	☐ Unknown
Did the patient die? *	☐ No	☐ Yes	☐ Unknown
Date of death *	☐		
	☐ Unknown		
Did the patient die due to (complications related to) NEC *	☐ No	☐ Yes	☐ Unknown

Enterostomy closure

Has enterostomy closure already taken place? *	☐ No	☐ Yes	☐ Unknown
Date of closure *	☐		
	☐ Unknown		

One-year follow-up

Short bowel syndrome

Presence of short bowel syndrome - associated intestinal failure (Short bowel syndrome - Intestinal failure)? *

☐ No ☐ Yes ☐ Unknown

Enterostomy closure

Has enterostomy closure already taken place? *

☐ No ☐ Yes ☐ Unknown

Date of closure *

☐
☐ Unknown

1 year complications

1 year complications *

☐ No ☐ Yes ☐ Unknown

Clinical sepsis (not central line associated) *

☐ No ☐ Yes ☐ Unknown

Clinical sepsis - Clavien Madadi severity score *

☐ Ia ☐ Ib
☐ II ☐ IIIa
☐ IIIb ☐ IV
☐ V

Stoma related complications *

☐ No ☐ Yes ☐ Unknown

Stoma related complications - Clavien Madadi severity score *

☐ Ia ☐ Ib
☐ II ☐ IIIa
☐ IIIb ☐ IV
☐ V

High output stoma *

☐ No ☐ Yes ☐ Unknown

Dermatitis *

☐ No ☐ Yes ☐ Unknown

Stoma prolapse *

☐ No ☐ Yes ☐ Unknown

Stoma prolapse - Wound complication (including wound dehiscence and wound infection) *

☐ No ☐ Yes ☐ Unknown

Wound complication - Clavien Madadi severity score *

☐ Ia ☐ Ib
☐ II ☐ IIIa
☐ IIIb ☐ IV
☐ V

Anastomotic stricture *

☐ No ☐ Yes ☐ Unknown

Anastomotic stricture - Clavien Madadi severity score *

☐ Ia ☐ Ib
☐ II ☐ IIIa
☐ IIIb ☐ IV
☐ V

Post NEC stenosis *

☐ No ☐ Yes ☐ Unknown

Post NEC stenosis - Clavien Madadi severity score *

☐ Ia ☐ Ib
☐ II ☐ IIIa
☐ IIIb ☐ IV
☐ V

Adhesive bowel obstruction for which surgery is performed *

☐ No ☐ Yes ☐ Unknown

Adhesive bowel obstruction - Clavien Madadi severity score *

☐ Ia ☐ Ib
☐ II ☐ IIIa
☐ IIIb ☐ IV
☐ V

Mortality

Did the patient die? *

☐ No ☐ Yes ☐ Unknown

Date of death *

☐
☐ Unknown

Did the patient die due to (complications related to) NEC *

☐ No ☐ Yes ☐ Unknown

Two-year follow-up

Follow up 2 year

Neurodevelopment within 2 years *	☐ No	☐ Yes	☐ Unknown
Neurodevelopment is monitored using validated scales. *	☐ No	☐ Yes	☐ Unknown
Presence of neurodevelopmental impairment *	☐ No	☐ Yes	☐ Unknown

Please specify the domain(s) in which neurodevelopmental impairment is present

Motor *	☐ No	☐ Yes	☐ Unknown
Cognitive *	☐ No	☐ Yes	☐ Unknown
Sensory *	☐ Hearing loss ☐ Vision loss ☐ Both ☐ No ☐ Unknown		
Developmental *	☐ No	☐ Yes	☐ Unknown

Reoperation

Unplanned NEC-related abdominal reoperation within 2 years *	☐ No	☐ Yes	☐ Unknown
If yes, please specify the number of reoperations. *			
Unplanned NEC-related non-abdominal reoperation within 2 years *	☐ No	☐ Yes	☐ Unknown
If yes, please specify the number of reoperations. *			

Mortality

Did the patient die? *	☐ No	☐ Yes	☐ Unknown
Date of death *	☐ ☐ Unknown		
Did the patient die due to (complications related to) NEC *	☐ No	☐ Yes	☐ Unknown

Enterostomy closure

Has enterostomy closure already taken place? *	☐ No	☐ Yes	☐ Unknown
Date of closure *	☐ ☐ Unknown		