Global PaedSurg Data Collection Form: English

During which month did the patient present to your hospital?
Please select the month that the patient presented to your hospital for the first time with this congenital anomaly. For example, if a baby was born with gastroschisis on the 29th September and presented to your hospital on the 1st October you should select October.

Has consent been provided to include this patient in the study?
Yes / No / Patient consent is not required for this study at my institution

> If no, which condition did the patient present with*? Oesophageal atresia / Congenital diaphragmatic hernia / Intestinal atresia / Gastroschisis / Exomphalos / Omphalocele / Anorectal malformation / Hirschsprung's Disease*. Please select all the conditions that the patient presented with. Do not select a condition which the patient has already received surgical treatment for previously.

---------- Demographics ----------

1. Gestational age at birth: _____
Number of weeks from the first day of the women's last menstrual cycle until birth. Round up or down to the nearest week.

2. Age at presentation (in hours): _____ We understand this information may be difficult to obtain - please be as accurate as you can. Please round to the nearest hour. This number may be very large for patients who have a delayed presentation - please still enter it. For neonates born within your centre please enter 0. Enter unknown if unknown.

3. Gender: *Male / Female/ Ambiguous/ Unknown*

4. Weight at presentation: _____ In kilograms (kg) on the day of presentation. Please provide a value to 1 decimal place.

5. Does the patient have another anomaly in addition to the study condition?
Yes, Cardiovascular, Yes, Respiratory, Yes: Gastrointestinal, Yes: Neurological, Yes: Genito-urinary, Yes: Musculoskeletal, Yes: Down syndrome, Yes: Beckwith-Wiedemann syndrome, Yes: Cystic fibrosis, Yes: Chromosomal, Yes: Other, No
Select all that apply. Include all anomalies diagnosed at any stage up until 30-days post primary intervention or 30-days following presentation for those who didn't receive an intervention. If you suspect an associated anomaly, but it has yet to be diagnosed, select 'other'.

6. Distance from the patient's home to your hospital: _____
In kilometres (km). Please round to the nearest kilometre. Please enter 0 if born in your hospital.

---------- Antenatal Care and Delivery ----------

7. Antenatal ultrasound undertaken?
Yes: study condition diagnosed, Yes: problem identified but study condition not diagnosed, Yes: no problem identified, No

> If the condition was diagnosed antenatally, at what gestational age? _____
> Please round up to the nearest week. If the patient has more than one study condition, please note the gestational age at which one or more of the conditions was first diagnosed.

8. Mode of transport to hospital:
Ambulance, Other transport provided by the health service, Patient's own transport, Born within the hospital

> Where did the patient present from? *Home / Community Clinic / General Practice / District Hospital / Other / Unknown*
> District hospital includes: secondary level healthcare, provincial hospital, general hospital, general mission hospital or regional hospital. It has general anaesthesia and can provide general surgical care. If other, please specify:

9. Type of delivery:
Vaginal (spontaneous), Vaginal (induced), Caesarean section (elective), Caesarean section (urgent/non-elective), Unknown
Vaginal delivery includes those requiring forceps and ventouse.

---------- Clinical Condition and Patient Care ----------

10. Was the patient septic on arrival? *Yes/ No*
Sepsis is SIRS (Systemic Inflammatory Response Syndrome) with a suspected or confirmed bacterial, viral, or fungal cause. SIRS is a response to a stimulus, which results in two or more of the following: temperature > 38.5°C or < 36°C, tachycardia*, bradycardia* in children < 1 year old, tachypnoea*, leukopenia or leucocytosis*, hyperglycaemia*, altered mental status, hyperlactaemia*, increased central capillary refill time >2 seconds. *Variables are defined as values outside the normal range for age. Arrival is the time of birth for neonates born at your hospital.

> If yes, were appropriate antibiotics administered? *Yes: within 1 hour of arrival, Yes: within the first day of arrival, No*

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Appropriate antibiotics are defined as either broad spectrum covering gram negative, gram positive and anaerobic bacteria OR antibiotics that are the standard empirical treatment for that condition according to local guidelines OR are based on sensitivities provided by a microbiology sample.

11. Was the patient hypovolaemic on arrival? *Yes/ No*
Criteria for diagnosis include at least one of the following: prolonged central capillary refill time > 2 seconds, *tachycardia, mottled skin, *reduced urine output, cyanosis, impaired consciousness, *hypotension. *Variables are defined as values outside the normal range for age.

If yes, was an intravenous fluid bolus given? *Yes: within 1 hour of arrival, Yes: on the first day of arrival, No*
If yes, how much intravenous fluid was given? *10 - 20mls/ kg, above 20mls/ kg*
If less than 10mls/ kg was given please select 'no' for the question asking if intravenous fluid was given.

12. Was the patient hypothermic on arrival? *Yes/ No*
Defined as < 36.5 degrees Celsius core temperature. Arrival is the time of birth for neonates born at your hospital.

If yes, was the patient warmed on arrival to within a normal temperature range? *Yes/ No*
Only select yes if warming was commenced within 1 hour of arrival. Arrival is the time of birth for neonates born at your hospital.

13. Did the patient receive central venous access?
Yes: umbilical catheter, Yes: peripherally inserted central catheter (PICC), Yes: percutaneously inserted central line with ultrasound guidance, Yes: surgically placed central line (open insertion), No
Please select all that the patient received within 30-days of primary intervention or 30-days of presentation if no intervention was undertaken.

If yes, did the patient acquire central line sepsis? *Yes: diagnosed clinically, Yes: confirmed on microbiology, No*
Within 30-days of primary intervention or 30-days of presentation if no intervention was undertaken.

14. Time from arrival at your hospital to primary intervention in hours (enter 0 if no intervention was undertaken):_____
Primary intervention for each condition is defined as: **Oesophageal atresia**; surgery, either temporising or definitive, to manage the oesophageal atresia and/ or tracheo-oesophageal fistula. **Congenital diaphragmatic hernia**; surgery to reduce the hernia and close the defect. **Intestinal atresia**; surgery, either temporising or definitive, to manage the obstruction including stoma formation and primary anastomosis. **Gastroschisis**; any procedure to either cover or reduce the bowel and/ or close the defect. This includes application of a silo (regardless of whether or not they go on to require surgery). It excludes initial covering of the bowel in a plastic covering (bag or cling film) prior to intervention. **Exomphalos**; surgery or application of topical treatment to the sac in patients managed conservatively (regardless of whether or not they go on to require surgery). **Hirschsprung's disease**; surgery, either temporising or definitive, or rectal/ distal bowel irrigation, laxatives or digital stimulation in patients managed conservatively. This does not include pre-operative washouts in patients planned to have surgery. **Anorectal malformation**; surgery, either temporising or definitive, or anal/ fistula dilatation in patients with a low anorectal malformation managed conservatively.

15. American Society of Anaesthesiologists (ASA) Score at the time of primary intervention:
1. Healthy person, 2. Mild systemic disease, 3. Severe systemic disease, 4. Severe systemic disease that is a constant threat to life, 5. A moribund patient who is not expected to survive without the operation, Not applicable - no intervention

16. What type of anaesthesia was used for the primary intervention?
General anaesthesia with endotracheal tube, General anaesthesia with laryngeal airway, Ketamine anaesthesia, Spinal/ caudal anaesthesia, Local anaesthesia only, No anaesthesia/ just analgesia, No anaesthesia/ no analgesia, Not applicable: no surgery or intervention undertaken.

17. Who undertook the anaesthetic for the primary intervention?
Anaesthetic doctor, Anaesthetic nurse, Medical officer, Surgeon, Other healthcare professional, No anaesthetic undertaken
If more than one of these personnel were present please select the most senior.

18. Who undertook the primary intervention?
Paediatric surgeon (or junior with paediatric surgeon assisting/ in the room), General surgeon (or junior with paediatric surgeon assisting/ in the room), Junior doctor, medical officer or other (without a paediatric or general surgeon assisting/ in the room), Trainee surgeon (without a paediatric or general surgeon assisting or in the room), Not applicable - no surgery or primary intervention undertaken.

19. Was a Surgical Safety Checklist used at the time of primary intervention?
Yes, No: but it was available, No: it was not available, Not applicable: a conservative primary intervention was undertaken, Not applicable: no surgery or primary intervention undertaken

20. Total duration of antibiotics following primary intervention _____
In days (including the day of surgery and the day antibiotics were stopped. Include intravenous and oral antibiotics).

21. Did the patient receive a blood transfusion?
Yes: not cross-matched, Yes: cross-matched, No: not required, No: it was required but not available.
Within 30-days of primary intervention or 30-days of presentation if no intervention was undertaken.

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22. Did the patient require ventilation? *Yes: and it was given, Yes: but it was not available, No*
Within 30-days of primary intervention or 30-days of presentation if no intervention was undertaken. Please include all types of ventilation.

If yes, for how long did the patient remain on ventilation?
In days (include all days on ventilation within 30-days of primary intervention or 30-days of presentation if no intervention was undertaken).

23. Time to first enteral feed (post-primary intervention): _____
In days (include the day of primary intervention and the day of first enteral feed in the calculation). Enter 0 if enteral feeds were not commenced. Enter 999 if feeds were not stopped, for example in patients with Hirschsprung's Disease managed conservatively. Include all types of enteral feeding - oral, nasogastric, gastrostomy and other.

24. Time to full enteral feeds (post-primary intervention): _____
In days (enter 0 if the patient died before reaching full enteral feeds or 30 if the patient had not reached full enteral feeds at 30-days post primary intervention or 30-days following admission in patients who did not receive a primary intervention). Include all types of enteral feeding - oral, nasogastric, gastrostomy and other.

25. Did the patient require parenteral nutrition?
Yes and it was given, Yes and it was sometimes available but less than required, Yes but it was not available, No

If yes, for how long did the patient receive parenteral nutrition?
In days. Include all days that the patient received parenteral nutrition (any volume) up until 30-days post primary intervention or 30-days following presentation in patients who do not receive an intervention.

---------- Outcomes ----------

26. Did the patient survive to discharge? *Yes/ No*
Select yes if the patient was still alive in your hospital 30-days after primary intervention or 30-days after presentation in patients who do not receive a primary intervention.

If the patient was discharged prior, were they still alive at 30-days following primary intervention?
Yes, No, Not followed-up after discharge, Followed-up but not until 30-days post primary intervention
This can include all reliable communication with the patient/ patient's family including in person, via telephone and other.

If no, cause of death? *Sepsis, Aspiration pneumonia, Respiratory failure, Cardiac failure, Malnutrition, Electrolyte disturbance, Haemorrhage, Lack of intravenous access, Hypoglycaemia, Recurrent tracheo-oesophageal fistula, Recurrent diaphragmatic hernia, Anastomotic leak, Ischaemic bowel, Ruptured exomphalos sac, Enterocolitis, Other*. If other, please specify

27. Duration of hospital stay (days): _____
Please include the day of admission and the day of discharge in your calculation. For example, if a patient presented on 1st October and was discharged on the 5th October, their duration of hospital stay would be 5 days. If the patient died, please record the number of days from admission to death. Only include the duration of the primary admission, not subsequent admissions if the patient re-presented.

28. Did the patient have a surgical site infection? *Yes, No, Not applicable, no surgical wound*
This is defined as including one or more of the following within 30-days of surgery: 1) purulent drainage from the superficial or deep (fascia or muscle) incision, but not within the organ/ space component of the surgical site OR 2) at least two of: pain or tenderness; localised swelling; redness; heat; fever; AND the incision is opened deliberately to manage infection, spontaneously dehisces or the clinician diagnoses a SSI (negative culture swab excludes this criterion) OR 3) there is an abscess within the wound (clinically or radiologically detected).

29. Did the patient have a full thickness wound dehiscence? *Yes, No, Not applicable - no surgical wound.*
This is defined as all layers of the wound opening within 30-days of surgery.

30. Did the patient require a further unplanned intervention? *Yes - percutaneous intervention, Yes - surgical intervention, No, Not applicable - no primary intervention undertaken.* Within 30-days of primary intervention. This does not include routine reduction and closure of the defect in neonates with gastroschisis receiving a preformed silo.

31. Was the patient followed up at 30-days post primary surgery or intervention to assess for complications?
Yes: reviewed in person, Yes: via telephone consultation, Yes: via other means, Yes: still an in-patient at 30-days, No: data is based on in-patient observations only, No: follow-up was done, but prior to 30-days

32. If the patient had a complication, when was it diagnosed? *During the primary admission, As an emergency re-attender, At routine follow-up as an out-patient, Not applicable, no complications*

What study condition does this patient have? *Oesophageal atresia, Congenital diaphragmatic hernia, Intestinal atresia, Gastroschisis, Exomphalos/ Omphalocele, Anorectal malformation, Hirschsprung's Disease*
If the patient has presented for the first time with more than one of these conditions please select all that apply. If the patient presented on this occasion with one of these conditions, but previously had another condition managed then only select the condition they are presenting with on this occasion and enter that they have another anomaly in the demographics section above. For example, if the patient presents at 2-months with Hirschsprung's disease, but previously had a duodenal atresia repair please select Hirschsprung's disease here (not intestinal atresia) and tick in the section above that they have another gastrointestinal anomaly.

Gastroschisis:

33. Type of gastroschisis:
Simple, Complex: associated with atresia, Complex: associated with necrosis, Complex: associated with perforation, Complex: associated with closing gastroschisis
Select all that apply.

34. Primary intervention: *Primary closure in the operating room (OR), Primary closure at the cotside (Bianchi technique), Staged closure using a preformed silo, Staged closure using an Alexis Wound Retractor and Protector, Staged closure using a surgical silo (including improvised silo), Other method, No intervention undertaken*

If other, please specify _____

Method of defect closure: *Fascia and skin closed with sutures, Just skin closed with sutures: fascia left open, Umbilical cord sutured over the defect: fascia left open, Sutureless closure with skin edges opposed and dressing applied, Dressing applied: defect left open to close by secondary intention, Other, Patient died before the defect was closed*

If other, please specify _____

On what day following admission was abdominal wall closure achieved? _____
In days. Please include the first day of admission and the day of closure in the calculation. For example, for a neonate admitted with gastroschisis on 2nd October who had the defect closed on 4th October, please insert 3 days.

Did the neonate have any of these complications within 30-days of primary intervention?
Ischemic bowel, Abdominal compartment syndrome (ACS), Necrotising enterocolitis, None of these
Select all that apply. ACS is defined as respiratory insufficiency secondary to compromised tidal volumes, decreased urine output caused by falling renal perfusion or any other organ dysfunction caused by increased intra-abdominal pressure.

If the patient has ACS, was the abdomen re-opened? *Yes/ No*

Anorectal malformation (ARM):

33. Type of anorectal malformation (Krickenbeck classification): *Low ARM: Perineal (cutaneous) fistula, High ARM: Rectourethral fistula (bulbar), High ARM: Rectourethral fistula (prostatic), High ARM: Rectovesical fistula, High ARM: Vestibular fistula, High ARM: Cloaca, High ARM: No fistula, High ARM: Type unknown at present, Rare variant: Pouch colon, Rare variant: Rectal atresia/ stenosis, Rare variant: Rectovaginal fistula, Rare variant: H fistula, Other*

34. Did the neonate have pre-operative bowel perforation? *Yes, No*

35. What was the primary intervention undertaken?
Fistula dilation: no surgery, Loop sigmoid colostomy, Divided sigmoid colostomy, Loop transverse colostomy, Divided transverse colostomy, Other stoma, Anoplasty, Posterior sagittal anorectoplasty (PSARP), Abdominosacroperineal pull-through, Abdominoperineal pull-through, Laparoscopic-assisted pull-through, Palliative care, Other
Select all that apply

If other, please specify _____

If primary anorectal reconstruction was undertaken, was a Peña stimulator or equivalent used to identify the position of the muscle complex intra-operatively? *Yes, no: equipment was not available, no: the equipment was available but not used*
Peña stimulator: Muscle locating stimulator commonly used to identify the anal sphincter muscles whilst undertaking a PSARP for patients with ARM.

Did the patient have any of the following complications within 30-days of surgery?
For each of the below answer: *Yes, No, Not applicable*

- *Electrolyte disturbance*
- *High output stoma (over 20mls/kg/day)*
- *Stoma prolapse/ retraction/ herniation*
- *Peri-stoma skin breakdown (or perianal if primary reconstructive surgery undertaken without a covering stoma)*
- *Anal stenosis in those undergoing primary anorectal reconstruction without covering stoma.*

What is the plan for future management?
No further operative management, Anoplasty/ pull-through planned at your hospital, Anoplasty/ pull-through planned at another hospital, Stoma closure planned at your hospital, Stoma closure planned at another hospital, Other
Please tick all that apply

If other, please specify _____

Oesophageal atresia (OA) +/- Tracheo-Oesophageal Fistula (TOF):

33. Type of OA +/- TOF (Gross classification): *A, B, C, D, E*
A: without a fistula, B: proximal TOF, distal OA, C: distal TOF with proximal OA, D: proximal and distal TOF, E: H-type TOF without OA.

34. Long or short gap? *Long, Short, Unknown*
Long gap OA: A gap of 4 vertebral bodies or more. Anatomically cases either have no TOF or a gap of over 4 vertebral bodies following division of the distal fistula making primary repair unfeasible. Short OA: A gap of less than 4 vertebral bodies. Primary anastomosis typically feasible.

35. Pneumonia at presentation? *Yes: diagnosed clinically, Yes: diagnosed radiologically, Yes: other means of diagnosis, No: patient born in the study centre, No: patients born outside the study centre but no evidence of pneumonia on arrival*
Pneumonia is defined as lung inflammation typically caused by bacterial or viral infection, in which the air sacs fill with pus and may become solid.

36. Primary intervention: *TOF ligation, Oesophageal anastomosis, Oesophagostomy, Gastrostomy, Ligation of the distal oesophagus, Gastro-oesophageal disconnection, Foker technique, Fundoplication, Other (please specify), Palliative care*
Select all that apply. If other, please specify _____

If the patient had a primary oesophageal anastomosis, was a post-operative oesophagogram undertaken? *Yes, No.* At any stage.

If yes, routine or clinically indicated? *Routine Clinically indicated*

If yes, when? _____ Number of days after primary surgery

If yes, what was the result? *Leak, No leak*

For patients diagnosed with a leak radiologically, was it associated with clinical symptoms? *Yes, No*

Time to first oral feed post-operatively _____
In days. Please include the day of surgery and the first day of oral feeds in the calculation. Enter 0 if oral feeds were not commenced within 30-days of primary intervention. Do not include other types of enteral feeding such as nasogastric or gastrostomy feeding.

Time to full oral feeds _____
In days (enter 0 if the patient died before reaching full oral feeds or 30 if the patient had not reached full oral feeds at 30-days post primary intervention). Do not include other types of enteral feeding such as nasogastric or gastrostomy feeding.

For patient's not receiving a primary oesophageal anastomosis, at what age is definitive surgery planned? _____
In months (enter unknown if not planned or enter not applicable if primary anastomosis was undertaken).

For patient's not receiving a primary oesophageal anastomosis, what is the future planned procedure?
Gap assessment, Primary oesophageal anastomosis if possible, Gastric pull-up, Jejunal interposition, Colonic interposition, Not applicable: primary anastomosis undertaken, Other, Unknown. Select all that apply

If other, please specify _____

If the patient had surgery, what was the approach? *Thoracotomy muscle cutting, Thoracotomy muscle splitting, Thoracoscopy, Laparotomy, Laparoscopy, Limited local incision, Other.* During primary surgery

If other, please specify _____

If thoracoscopic or laparoscopic, was the surgery converted to open? *Yes, No*

Did the patient have a condition specific complication within 30-days of primary intervention? *Pneumonia, Mediastinitis, Pneumothorax, Chylothorax, Haemothorax, Anastomotic leak, Anastomotic stricture, Recurrent TOF, Other, None*
Select all that apply.

If other, please specify _____

Did the patient have tracheomalacia? *Yes: diagnosed clinically, Yes: diagnosed on bronchoscopy, Yes: diagnosed on CT Yes: diagnosed on bronchogram, Yes: other method of diagnosis, No*

If yes, was an intervention undertaken? *Yes: aortopexy, Yes: tracheostomy, Yes: tracheal stent, Yes: supportive management (oxygen +/- ventilation) only, Yes: other treatment, No*

If other, please specify _____

Congenital Diaphragmatic Hernia (CDH):

33. Type of CDH: *Left posteriolateral (Bochdalek), Right posteriolateral (Bochdalek), Bilateral posteriolateral (Bochdalek), Central, Anterior (Morgagni), Other*

If other, please specify _____

Type of Bochdalek CDH (CDH Study Group Classification): *A, B, C, D, Other (specify), Unknown*
Defect A: smallest defect, usually "intramuscular" defect with >90% of the hemi-diaphragm present; this defect involves < 10% of the circumference of the chest wall. Defect B: 50-75% hemi-diaphragm present; this defect involves < 50% of the chest wall. Defect C: < 50% hemi-diaphragm present; this defect involves >50% of the chest wall. Defect D: largest defect (previously known as "agenesis"); complete or near complete absence of the diaphragm with < 10% hemi-diaphragm present; this defect involves >90% of the chest wall. Surgically, it is an absent posterior rim beyond the spine, absent posterior-lateral rim, and an anterior/anterior-medial rim which is miniscule. As it is truly unusual to have zero tissue at all, this is the CDHSG member consensus. "D" defects should all require a patch (or muscle flap) for repair.

If bilateral, what was the type of Bochdalek hernia on the left: *A, B, C, D, Other, Unknown*

If bilateral, what was the type of Bochdalek hernia on the right: *A, B, C, D, Other, Unknown*

If other, please specify_____

34. If antenatally diagnosed, what was the lung-to-head ratio (LHR)? _____ Enter zero if not undertaken/ not known.

35. Was foetal tracheal occlusion (FETO) undertaken? *Yes, No*

If yes, at what gestational age was it inserted? _____, unknown.

If yes, at was gestational age was it removed? _____, at birth, unknown.

36. Liver position? *Chest, Abdomen, Unknown*

37. Did the patient have pulmonary hypertension (at any stage)? *Yes: diagnosed clinically, Yes: diagnosis confirmed on echocardiography, Yes: other method of confirming diagnosis, No, Unknown*
Persistent pulmonary hypertension of the newborn (PPHN) is defined as the failure of the normal circulatory transition that occurs after birth. It is a syndrome characterised by marked pulmonary hypertension that causes hypoxemia secondary to right-to-left extrapulmonary shunting of deoxygenated blood. It should be suspected whenever the level of hypoxemia is out of proportion to the level of pulmonary disease. Echocardiography plays a major role in screening and assisting in making the diagnosis of PPHN.

If yes, treatment given? *Nitric oxide, Prostacyclin, Alprostadil, Milrinone, Other, None: not required, None: required but not available.*

If other, please specify?_____

38. Did the patient receive extracorporeal membrane oxygenation (ECMO)? *Yes, No*

If yes, for how long? _____
In days. Include the day the patient went onto ECMO and the day they were taken off in the calculation.

39. Primary intervention: *Primary repair (absorbable sutures), Primary repair (non-absorbable sutures), Patch repair, Palliation, Discharged with planned elective repair, Other*

If patch repair, material used? *Permacol, PTFE, Alloderm, Dacron, Mesh plug, Muscle flap, Surgisis, Other*
If other, please specify _____

Other procedures undertaken at the same time? *Chest drain insertion, Abdominal wall patch, Fundoplication, Correction of malrotation, Appendicectomy, Other (specify), None*
Select all that apply. If other, please specify _____

Surgical approach: *Laparotomy, Laparoscopy, Thoracotomy, Thoracoscopy, Other (please specify)*

If laparoscopic or thoracoscopic, was the surgery converted to open? *Yes/No*

If other, please specify _____

Condition specific complication within 30-days of primary surgery? *Air leak (not just redundant space in the pleural cavity which is common), Chylothorax, Recurrence, Adhesional obstruction, Other, None.* Select all that apply.

If other, please specify _____

Intestinal Atresia:

33. Type of intestinal atresia: *Duodenal, Jejuno-ileal, Colonic*

34. Classification of duodenal or colonic atresia: *1,2,3,4*
1) intraluminal web with continuity of the muscular layer, 2) atretic segment without a mesenteric defect, 3) atretic segment with mesenteric defect, 4) multiple atresias = string of sausages appearance.

Classification of jejuno-ileal atresia: *1,2,3a,3b,4*
1) intraluminal web with continuity of the muscular layer, 2) atretic segment without a mesenteric defect, 3a) atretic segment with mesenteric defect, 3b) apple-peel (bowel wrapped around a single artery), 4) multiple atresias = string of sausages appearance.

35. Primary intervention for duodenal atresia:
Duodenoduodenostomy, Duodenojenunostomy, Web excision only, Palliation, Other

If other, please specify: _____

Surgical approach: *Laparotomy, Laparoscopy, Endoscopy, Other*

Conversion to open procedure? *Yes/ No*

Type of anastomosis: *Kimura's diamond shape, Side-to-side, End-to-end*

Primary intervention for jejuno-ileal and colonic atresia: *Primary anastomosis, Bowel resection, Division of web only, Loop stoma, Divided stoma, Bishop-Koop stoma, Santulli stoma, Palliation, Other.* Select all that apply.

If bowel was excised, what was the total length of bowel excised _____
In centimetres (cm). Enter 0 if unknown.

Surgical approach: *Laparotomy, Laparoscopy, Endoscopy, Other*

Conversion to open procedure? *Yes, No*

Was the distal bowel flushed to check for patency? *Yes, No*

If the patient underwent surgery, did they have a condition specific complication within 30-days of primary intervention:
Anastomotic leak, Anastomotic stenosis, Short-gut, Missed additional atresia, Adhesive bowel obstruction, Stoma prolapse, Stoma retraction, Parastomal hernia, Parastomal skin breakdown, Other
Select all that apply. For the purposes of this study short gut is defined as more than 50% of the small intestine excised (when short bowel syndrome can occur).

If other, please specify _____

Exomphalos:

33. Type of Exomphalos? *Major, Minor*
Major: >50% of the liver in the exomphalos sac and abdominal wall defect >5cm. Minor: Infants with defects less than 5cm.

34. Hypoglycaemic on arrival? *Yes, No, Blood glucose not measured*
Hypoglycaemia is defined as a blood glucose level below 4 mmol/L (72mg/dL).

35. Primary intervention: *Primary operative closure, Staged closure, Conservative management*

If the patient had a staged closure, what was the time from primary intervention to closure _____
In days. Please include the day of the primary intervention and the day of closure in the calculation. Enter 30 if still not closed at 30-days after primary intervention.

If conservative management, was a topical treatment applied to the exomphalos sac?
Yes: silver sulfadiazine, Yes: betadine, Yes: honey, Yes: merbromide tannage, Yes: other, no

If other, please specify _____

If conservative management was undertaken, what is the plan for future management?
No further surgery planned, Delayed closure at this hospital, Delayed closure at another hospital, Other

If other, please specify _____

36. Did the patient had a ruptured sac? *Yes, No*

Hirschsprung's disease:

33. Time to first passage of meconium after birth: *Less than 24 hours, 24-48 hours, Over 48 hours, Unknown*

34. Features at presentation:
Abdominal distension, Bilious vomiting, Non-bilious vomiting, Poor feeding, Suspected enterocolitis, Perforation, Other
Select all that apply.

35. Source of diagnosis of Hirschsprung's disease:
Genetic, Mucosal biopsy, Full thickness biopsy, Anorectal manometry, Barium enema, Not confirmed: suspected only, Other

If on biopsy, what was the method of histology staining:
Hemotoxilin and Eosin (H&E), Acetylcholinesterase, Calretinin, Other
Select all that apply. If other, please specify _____

36. Length of aganglionosis:
Rectal, Sigmoid, Descending colon, Transverse colon, Ascending colon, Small bowel, Unknown at present

37. Primary intervention: *Conservative: no treatment, Conservative: digital stimulation and laxatives, Conservative: regular rectal washouts/ enemas, Failed conservative management followed by a stoma during the same hospital admission, Primary stoma (with or without pre-operative washouts or enemas prior to a planned stoma placement), Primary pull-through (Swenson), Primary pull-through (Duhamel), Primary pull-through (Soave), Primary pull-through (Other), Transanal posterior anorectal myectomy, Palliative care, Other*

If primary pull-through was undertaken, did the patient have a covering stoma? *Yes, No*

Was it laparoscopic assisted? *Yes, No*

Did the patient have any condition specific complications within 30-days of primary intervention?
Hirschsprung's associated enterocolitis (HAEC), Electrolyte disturbance, High stoma output (over 20mls/kg/day), Stoma prolapse/ retraction/ herniation, Peri-stoma skin breakdown (or perianal if primary pull-through was undertaken without a covering stoma), Anal stenosis, Post-operative obstruction, Anastomotic leak (if primary pull-through was undertaken without a covering stoma), Other
Select all that apply. HAEC is defined as inflammation of the small and or large bowel in patient's born with Hirschsprung's disease. If the patient was managed conservatively, please tick if they developed enterocolitis within 30-days of presentation.

What is the plan for future management? *No further surgery planned, Anorectal pull-through at your hospital, Anorectal pull-through at a different hospital, Stoma closure, Other, Unknown*