ID Number:

British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS)

Anorectal Malformation (ARM)

Infants or children presenting on or after 1st October 2015 and before 1st October 2016

Data Collection Form

Case Definition:

All children in the UK with imperforate anus or absence or narrowing of the communication canal between the rectum and anus with or without fistula to neighbouring organs, **newly diagnosed during the study period, irrespective of age at presentation or any additional anomalies.**

Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.
2. Fill in the form using the information available in the infant's case notes.
3. Tick the boxes as appropriate. If you require any additional space to answer a question please use the space provided in section 10.
4. Please complete all dates in the format DD/MM/YY, and all times using the 24hr clock e.g. 18:37
5. **If you do not know the answers to some questions, please indicate this in section 10.**
6. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 10.

Please return the completed form to:

BAPS-CASS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 617775
Phone: 01865 289714

Case reported in: _____

National Perinatal Epidemiology Unit

Section 1: Antenatal/Birth data

1.1 **What was the mother's year of birth?** ☐☐☐☐ Not known ☐

1.2 **Please give the first alphabetical part of mother's postcode**
(E.g. OX for Oxfordshire, EH for Edinburgh, L for Liverpool) ☐☐

1.3 **What is the infant/child's Ethnic group*** ☐☐

1.4 **Has the mother ever had a pregnancy where the fetus has been diagnosed with either ARM, another structural anomaly, a chromosomal anomaly or malformation syndrome?** Yes ☐ No ☐

If Yes, please give details: _____

1.5 **Is there any family history of ARM or related conditions, including syndromes and associations?** Yes ☐ No ☐

If Yes, please give details including relation to this infant/child:

_____

Please continue in Section 10 if necessary.

1.6 **Did the mother receive any fertility treatment to assist with the conception of this pregnancy?** Yes ☐ No ☐ Not known ☐

If Yes, please give details: _____

1.7 **Gestational age at birth** *(completed weeks)* ☐☐ *weeks* Not known ☐

1.8 **Gender** Female ☐ Male ☐ Indeterminate ☐

1.9 **Birthweight** ☐☐☐☐ *g*

1.10 **Was ARM suspected antenatally?** Yes ☐ No ☐

If Yes, at what gestational age was it first suspected? *(completed weeks)* ☐☐

If Yes, please document sonographic abnormalities noted:

Dilated Rectum Yes ☐ No ☐ Not known ☐

Hydrocolpus Yes ☐ No ☐ Not known ☐

Others *(please list)* _____

_____

Please continue in Section 10 if necessary.

If Yes, did the mother receive prenatal surgical counselling? Yes ☐ No ☐

Section 2: Initial Investigations and Management

2.1 **What was the infant/child's age at first presentation to your hospital?**
(If diagnosed antenatally and inborn, please record '0') ☐☐ *years* ☐☐ *months* ☐☐ *days*

2.2 **What was the date of first presentation to your hospital?** D D / M M / Y Y

2.3 **Was the infant/child transferred as an inpatient from another hospital?** Yes ☐ No ☐

If Yes, please specify which hospital: _____

Date of Transfer: D D / M M / Y Y

2.4 **What was the date of diagnosis?** D D / M M / Y Y

*For guidance please see back cover

2.5 **Was the infant/child more than 24 hours old at the time of diagnosis?** Yes ☐ No ☐ Not known ☐

2.6 **Was the infant/child discharged home after birth before diagnosis?** Yes ☐ No ☐

2.7 **Who first suspected an anorectal abnormality in this infant/child?** *(please only tick one)*

Parent ☐ Midwife ☐
Health Visitor ☐ GP ☐
Paediatrician ☐ Paediatric Surgical Team ☐
Other ☐ please specify: _____ Not known ☐

2.8 **Were any imaging investigations undertaken on this infant/child?** Yes ☐ No ☐

If Yes, please indicate all that apply:

Investigation	Yes	No	Date	Any Abnormalities Detected[#]
Ultrasound				
Renal Tract	☐	☐	D D / M M / Y Y	
Spine	☐	☐	D D / M M / Y Y	
Echo	☐	☐	D D / M M / Y Y	
Plain X-ray				
Prone cross-table lateral	☐	☐	D D / M M / Y Y	**If Yes**, was there gas: below the coccyx ☐ above the coccyx ☐
CXR	☐	☐	D D / M M / Y Y	
AXR	☐	☐	D D / M M / Y Y	
Whole Spine	☐	☐	D D / M M / Y Y	
Lumbo sacral AP only	☐	☐	D D / M M / Y Y	
Micturating Cystourethrogram	☐	☐	D D / M M / Y Y	
Contrast study *(E.g. distal loopogram)*	☐	☐	D D / M M / Y Y	**If Yes**, what was type of contrast study was performed? _____ What was the result? _____
Other, imaging *please specify*	☐	☐	D D / M M / Y Y	_____

2.9 **Was the sacral ratio calculated?** Yes ☐ No ☐ Not known ☐

If Yes, what was the result? _____

2.10 **Was there spontaneous meconium passage in the first 24 hours of life?** Yes ☐ No ☐ Not known ☐

2.11 **Was there meconium in the urine prior to the first surgical intervention?** Yes ☐ No ☐ Not known ☐

[#]Please state if none

Section 3: Initial Surgical Management

3.1 Has this infant/child had a surgical procedure (including EUA)? Yes ☐ No ☐

If No, was this because:
- Patient died prior to surgical management ☐
- Plan for conservative management ☐
- Plan for future surgery ☐
- Other ☐

If Other, please specify reason: _____

*If the child did not have a surgical procedure, **please go to Section 6**, otherwise **continue below***

3.2 What was the date of first surgical procedure? D D / M M / Y Y

3.3 Which of the following were performed at the first surgical intervention for management of the ARM? *(Please tick all that apply)*

- Examination under Anaesthesia ☐
- Peña Stimulation ☐
- Formation of a stoma ☐
- Definitive correction of anorectal atresia or stenosis ☐
- Dilatation/calibration of anus ☐
- Manual Evacuation/washout ☐
- Examination under Anaesthesia ☐
- Other ☐

If Other, please specify reason: _____

3.4 Were any other procedures performed at the same time as the first surgical intervention for the ARM?
(E.g. ligation of trachea-oesophageal fistula etc.) Yes ☐ No ☐

If Yes, please state all additional procedures performed at the same time:

_____

Section 4: Definitive Surgical Management

4.1 Has the infant/child had definitive surgical correction of their ARM? Yes ☐ No ☐

If No, ***please go to Section 6***

If Yes, what was the date? D D / M M / Y Y

(If this was undertaken at the first surgical intervention, please enter the same date as in 3.2)

4.2 Were any of the following performed prior to, or during, the definitive surgical correction of the ARM?
(Please tick all that apply. If none, tick 'none of the above')

- Bowel Preparation ☐
- Urethral catheterisation ☐
- Vaginoscopy ☐
- Formation of a Stoma ☐
- Central Venous Line Insertion ☐
- Cystoscopy ☐
- Endoscopy of the distal colon ☐
- None of the above ☐

4.3 Were any other procedures performed at the same time as definitive surgical correction not mentioned previously? Yes ☐ No ☐

If Yes, please give details: _____

Please continue in Section 10 if necessary.

4.4 Did the child have an anoplasty? Yes ☐ No ☐

If Yes, please describe: *(e.g. V-Y plasty, cut-back etc.)*

_____

If No, which definite procedure was performed?

Trans-anal proctoplasty (TAP) ☐
Posterior Saggital Ano-rectoplasty (PSARP) ☐
Anterior Saggital Ano-rectoplasty (ASARP) ☐
Other ☐

If Other, please specify: _____

_____

4.5 Was abdominal mobilisation of the bowel undertaken? Yes ☐ No ☐

If Yes, was this: open ☐ **OR** laparoscopic ☐

4.6 On what date did enteral feeds commence following definite surgical correction? D D / M M / Y Y

4.7 How many days post-operative TPN did the child receive?
(If Zero, please record 0) ☐☐☐

Section 5: Stoma Information

5.1 Has this infant/child had a stoma? Yes ☐ No ☐

If No, ***please go to Section 6***, otherwise continue below

5.2 What was the date of formation? D D / M M / Y Y

5.3 Why was a stoma formed in this patient?

Formed as part of a planned staged surgical approach ☐
Performed as an emergency ☐
Other reason ☐

If Other, please specify reason: _____

5.4 Was the stoma a:

Loop stoma ☐
Single ended stoma ☐
Divided stoma (separate stoma and mucous fistula) ☐

5.5 Was the stoma in the:

Small Intestine ☐
Transverse colon ☐
Descending colon/sigmoid junction ☐
Other ☐

If Other, please specify site: _____

5.6 Has the stoma been closed? Yes ☐ No ☐

If Yes, please indicate the date of closure: D D / M M / Y Y

Section 6: Definitive Diagnosis

6.1 Has the final anatomical classification of this infant/child's anorectal atresia or stenosis been established? *(Please only tick one)* Yes ☐ No ☐

If Yes, was this: pre-operatively ☐ intra-operatively ☐ At post-mortem ☐

What was the final anatomical classification?

Perineal (Cutaneous) fistula ☐	Recto-vestibular fistula ☐
Bulbar rectourethral fistula ☐	Recto-vaginal fistula ☐
Prostatic rectourethral fistula ☐	Cloaca ☐
Rectovesical fistula ☐	Imperforate anus without fistula ☐
Anal stenosis ☐	Funnel Anus ☐
Rectal atresia/stenosis ☐	Pouch Colon ☐
H fistula ☐	Anterior Anus ☐
	Other ☐

If Other, please specify: _____

6.2 Did this child have a perineal fistula or an anterior anus? Yes ☐ No ☐

If Yes, what was the distance from the opening to the centre of the sphincter muscle? ☐☐ *mm* Not known ☐

What was the calibre of the opening prior to dilatation/correction? *Hegar size* ☐☐ Not known ☐

What proportion of the opening was surrounded by sphincter? ☐☐ % Not known ☐

6.3 Is anorectal atresia or stenosis an isolated abnormality in this infant/child? Yes ☐ No ☐

If No, please give details of associated abnormalities

Type of Anomaly	Yes	No	If Yes, please give details
Spinal column/cord	☐	☐	
Sacrum	☐	☐	
Limb	☐	☐	
Cardiac	☐	☐	
Renal tract/Genital	☐	☐	
Gastrointestinal (incl. OA)	☐	☐	
Genetic including aneuploidy	☐	☐	
Other named syndromes/ associations, *please specify*	☐	☐	
Other structural, *please specify*	☐	☐	

Section 7: Other Management

7.1 **Did the infant/child undergo anal dilatations?** Yes ☐ No ☐

If No, ***please go to Section 8***, otherwise continue below

7.2 **What size Hegar did dilatations start at?** *Hegar size* ☐☐ Not known ☐

7.3 **Was anal dilation used as definitive management for the anorectal atresia or stenosis?** *(i.e. no surgical correction was performed)* Yes ☐ No ☐

If Yes, what date did they commence? D D / M M / Y Y

7.4 **Was anal dilatation used as part of post-operative management?** Yes ☐ No ☐

If Yes, what date did they commence? D D / M M / Y Y

7.5 **Have dilatations finished?** Yes ☐ No ☐ Not known ☐

If Yes, what size Hegar did dilatations finish at? *Hegar size* ☐☐

7.6 **Were the infant/child's primary carers (parents/guardians) trained to perform anal dilatations?** Yes ☐ No ☐

Section 8: Early Morbidity

(28 days post initial surgery or decision for non-operative management)

8.1 **Were any further surgical procedures required in the first 28 days following initial surgery or decision for non-operative management?** Yes ☐ No ☐

If Yes, please give details in the table below:

Date of Surgery	Details of Further Surgical Procedure
D D / M M / Y Y	
D D / M M / Y Y	
D D / M M / Y Y	

Please continue in Section 10 if necessary

8.2 **Did any complications relating to surgical management occur?** Yes ☐ No ☐

If Yes, tick all that apply:

Wound infection requiring antibiotics ☐

Pelvic abscess ☐

Dehiscence of perineal wound ☐

Stoma problem ☐

Please describe: _____

Injury to a viscus *(e.g. bladder/urethra)* ☐

Please give details: _____

Other complication(s) ☐

Please specify: _____

Please continue in Section 10 if necessary

8.3 **Did this infant have any other morbidity?** Yes ☐ No ☐

If Yes, please give details: _____

Please continue in Section 10 if necessary

Section 9: Outcomes

9.1 Has the infant/child been discharged home? Yes ☐ No ☐

If Yes, please specify date of discharge D D / M M / Y Y

9.2 Has the infant/child been discharged to another hospital? Yes ☐ No ☐

If Yes, please give name of hospital: _____

Name of responsible consultant: _____

Date of transfer: D D / M M / Y Y

9.3 Did the infant/child die? Yes ☐ No ☐

If Yes, please give date of death: D D / M M / Y Y

Cause of death as stated on the death certificate (please state of not known):

_____

Section 10: Other information

10.1 Please add any other relevant information

_____

_____

_____

_____

_____

_____

_____

_____

Section 11:

11.1 Name of person completing the form _____

11.2 Designation _____

11.3 Today's date D D / M M / Y Y

You may find it useful in the case of queries to keep a copy of this form.

Definitions

UK Census Coding for ethnic group

WHITE
- 01. British
- 02. Irish
- 03. Any other white background

MIXED
- 04. White and black Caribbean
- 05. White and black African
- 06. White and Asian
- 07. Any other mixed background

ASIAN OR ASIAN BRITISH
- 08. Indian
- 09. Pakistani
- 10. Bangladeshi
- 11. Any other Asian background

BLACK OR BLACK BRITISH
- 12. Caribbean
- 13. African
- 14. Any other black background

CHINESE OR OTHER ETHNIC GROUP
- 15. Chinese
- 16. Any other ethnic group