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: ________________________________
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:

<table>
<thead>
<tr>
<th>Investigation</th>
<th>Yes</th>
<th>No</th>
<th>Date</th>
<th>Any Abnormalities Detected*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ultrasound</strong></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Renal Tract</td>
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</tr>
<tr>
<td>Spine</td>
<td></td>
<td></td>
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<tr>
<td>Echo</td>
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<tr>
<td><strong>Plain X-ray</strong></td>
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<td>If Yes, was there gas:</td>
</tr>
<tr>
<td>Prone cross-table lateral</td>
<td></td>
<td></td>
<td></td>
<td>below the coccyx [ ]</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>above the coccyx [ ]</td>
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<tr>
<td>CXR</td>
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<tr>
<td>AXR</td>
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<tr>
<td>Whole Spine</td>
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<td></td>
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<tr>
<td>Lumbo sacral AP only</td>
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<tr>
<td><strong>Micturating Cystourethrogram</strong></td>
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<td></td>
<td>If Yes, what type of contrast study was performed?</td>
</tr>
<tr>
<td>Contrasting Study (E.g. distal loopogram)</td>
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<tr>
<td>Other, imaging please specify</td>
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</tr>
</tbody>
</table>

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? ____________

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
   - Dilatation/calibration of anus
   - Peña Stimulation
   - Manual Evacuation/washout
   - Formation of a stoma
   - Examination under Anaesthesia
   - Definitive correction of anorectal atresia or stenosis
   - 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? ____________
   (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
   - Central Venous Line Insertion
   - Urethral catheterisation
   - Cystoscopy
   - Vaginoscopy
   - Endoscopy of the distal colon
   - Formation of a Stoma
   - 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 M Y YMD  

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

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### 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 M Y YMD  

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 M Y YMD
### 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
- [ ] Rectovesical fistula
- [ ] Imperforate anus without fistula
- [ ] Prostatic rectourethral fistula
- [ ] Funnel Anus
- [ ] Cloaca
- [ ] Rectal atresia/stenosis
- [ ] Pouch Colon
- [ ] 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

<table>
<thead>
<tr>
<th>Type of Anomaly</th>
<th>Yes</th>
<th>No</th>
<th>If Yes, please give details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal column/cord</td>
<td></td>
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<tr>
<td>Sacrum</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Limb</td>
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<td></td>
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<tr>
<td>Cardiac</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renal tract/Genital</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal (incl. OA)</td>
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<td></td>
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<tr>
<td>Genetic including aneuploidy</td>
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<tr>
<td>Other named syndromes/associations, <em>please specify</em></td>
<td></td>
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<tr>
<td>Other structural, <em>please specify</em></td>
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</tbody>
</table>
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:

<table>
<thead>
<tr>
<th>Date of Surgery</th>
<th>Details of Further Surgical Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>D D M M Y Y</td>
<td></td>
</tr>
<tr>
<td>D D M M Y Y</td>
<td></td>
</tr>
<tr>
<td>D D M M Y Y</td>
<td></td>
</tr>
</tbody>
</table>

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 ☐ ☐ ☐ ☐

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: ☐ ☐ ☐ ☐

9.3 Did the infant/child die?
   Yes ☐ No ☐
   If Yes, please give date of death: ☐ ☐ ☐ ☐
   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
   ☐ ☐ ☐ ☐
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