ID Number:

Date of surgery:

Date of Transfer to Your Hospital:

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

Meconium Ileus in Association with Cystic Fibrosis

Data Collection Form - OUTCOMES AT ONE YEAR

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 7.
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 7.**
6. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 7.

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: Outcomes

1.1 **What date was the child last seen in your hospital?** D D / M M / Y Y

1.2 **Was the child discharged to another hospital?** Yes ☐ No ☐

If Yes, please give name of hospital _____

Name of responsible consultant at other hospital _____

Date of transfer D D / M M / Y Y

1.3 **Has the child been discharged home?** Yes ☐ No ☐

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

Section 2: Cystic fibrosis

2.1 **Has the diagnosis of Cystic Fibrosis been confirmed?** Yes ☐ No ☐

If Yes, was DNA testing performed? Yes ☐ No ☐

If Yes, what was the genotype? F508/F508 ☐ F508/other ☐ Other/other ☐

Was a sweat test performed? Yes ☐ No ☐

If Yes, did the result confirm the diagnosis of Cystic Fibrosis? Yes ☐ No ☐

Is the child under the care of a dedicated Cystic Fibrosis team? Yes ☐ No ☐

Section 3: Feeding

3.1 **Did the child ever require TPN?** Yes ☐ No ☐

If Yes, are they still receiving TPN? Yes ☐ No ☐

If No, for how many days in total did the child receive

Full TPN ☐☐ Partial TPN ☐☐ Supplementary to full enteral feeds ☐☐

3.2 **Is the child fully enterally fed now?** Yes ☐ No ☐

If Yes, is this *(tick one only)*

Oral ☐ Via NG tube or gastrostomy ☐ Via NJ tube or jejunostomy ☐

3.3 **What is the last recorded weight of the child?** ☐☐.☐ kg D D / M M / Y Y

3.4 **What is the last recorded height of the child?** ☐☐ cm D D / M M / Y Y

3.5 **Has the child had cholestasis?** Yes ☐ No ☐

3.6 **Has the child had IFALD (Intestinal Failure Associated Liver Disease)?** Yes ☐ No ☐

Section 4: Bowel function

4.1 **Has anti-propulsive medication been prescribed e.g. loperamide, erythromycin etc.?** Yes ☐ No ☐

If Yes, please provide details?

Agent	Dose	Dose units	Date last administered
			D D / M M / Y Y
			D D / M M / Y Y

4.2 Has treatment for bacterial overgrowth been prescribed? Yes ☐ No ☐

If Yes, what date was it last administered? D D / M M / Y Y

Please tick all medications used

Cycled antibiotics ☐

Probiotics e.g. lactobacillus acidophilus, bifidobacterium bifidum ☐

4.3 Has the child required treatment for DIOS (distal intestinal obstruction syndrome)? Yes ☐ No ☐

If Yes, how was the diagnosis confirmed? *(tick all that apply)*

Abdominal mass ☐ USS ☐ AXR ☐ Contrast enema ☐ Other ☐

If Other, please give details _____

How was it treated? *(tick all that apply)*

Nil by mouth, NG tube and IV fluids ☐ Oral/NG N-acetylcysteine ☐ Oral/NG gastrografin ☐

Oral/NG Klean Prep ☐ Therapeutic contrast enema ☐ Surgery ☐ Other ☐

If Other, please give details _____

4.4 Has the child required treatment for adhesive bowel obstruction? Yes ☐ No ☐

If Yes, what treatment was used? *(tick all that apply)*

Conservative management – "drip and suck" ☐ Surgery – adhesiolysis ☐

Surgery – bowel resection ☐ Other ☐

If Other, please give details _____

4.5 Has the child required treatment for constipation? Yes ☐ No ☐

If Yes, please give details of all treatment given _____

_____

Section 5: Stoma

5.1 Did the child have a stoma? Yes ☐ No ☐

If No, *please go to Section 6*

5.2 Were there any stomal complications? Yes ☐ No ☐

If Yes, (*tick all that apply)*

Prolapse ☐ Retraction ☐ Stenosis/outlet obstruction ☐

Parastomal hernia ☐ Parastomal fistula ☐ Other ☐

If Other, please give details _____

5.3 Were there any functional stomal complications? Yes ☐ No ☐

If Yes, tick all that apply

Stercoral Obstruction ☐ High stoma losses > 20ml/kg ☐ Other ☐

If Other, please give details _____

5.4 Has the stoma been closed? Yes ☐ No ☐

If Yes, what was the date of stoma closure D D / M M / Y Y

What is the stool frequency? *(tick one only)* 2 or less per week ☐ 3 - 6 per week ☐

1 - 2 per day ☐ 3 - 6 per day ☐ 6 - 9 per day ☐ > 10 per day ☐

5.5 **Did the child require a second stoma to be formed after closure of the first stoma?** Yes ☐ No ☐

If Yes, what was the indication? *(tick all that apply)* Leak ☐ Stenosis ☐ Other ☐

If Other, please give details _____

Section 6: Other Outcomes

6.1 **Did the child require any other surgical procedures other than those listed above?** Yes ☐ No ☐

If Yes, please give details in the table below

Date	Details	Complications *(If no complications please state none)*
D D / M M / Y Y		
D D / M M / Y Y		
D D / M M / Y Y		

6.2 **Has the child had any lung infections in the last year?** Yes ☐ No ☐

If Yes, was the causative organism cultured? Yes ☐ No ☐

If Yes, please give details of the cultured organism _____

6.3 **Has the child been assessed for pancreatic insufficiency (faecal elastase)?** Yes ☐ No ☐

If Yes, does the child have pancreatic insufficiency? Yes ☐ No ☐

Section 7:

7.1 **Did the child die?** Yes ☐ No ☐

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

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

_____

7.2 **Please add any other relevant information**

_____

_____

_____

_____

_____

_____

Section 8:

8.1 **Name of person completing the form** _____

8.2 **Designation** _____

8.3 **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.