ID Number:
Date of Diagnosis :
Date of Definitive Surgery :

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

BAPS-CASS Hirschsprung's Disease

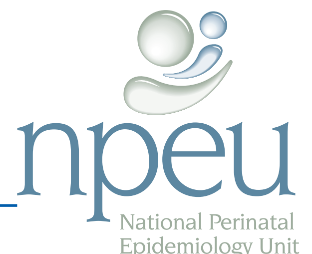
Data Collection Form - OUTCOMES AT 1 YEAR SINCE DIAGNOSIS

SAMPLE CASE

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: ______________________



Instructions

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

Section 1:

1.1 What date was the child last seen? DD/MM/YY

1.2 Has definitive surgery been performed? Yes ☐ No ☐

If Yes, what was the date of definitive surgery? DD/MM/YY

Now please go to section 2.

If No, why was definitive surgery not performed? *(please tick only one)*

Planned staged procedure – pull-through still awaited ☐

Planned end stoma – no pull-through planned ☐

Please state reason for planned end stoma ____________

Now please go to section 3.

Section 2: Bowel Function Since Definitive Surgery

2.1 What is the child's current stool frequency? 2 or less per week ☐ 3-6 per week ☐ 1-2 per day ☐ 3-6 per day ☐ 6-10 per day ☐ > 10 per day ☐

2.2 Has medication for constipation been prescribed? Yes ☐ No ☐

If Yes, please tick all applicable medications:

Medication		
Stool softener	☐	Date last administered DD/MM/YY
Stimulant laxatives	☐	Date last administered DD/MM/YY
Enemas	☐	Date last administered DD/MM/YY

2.3 Were post-operative bowel washouts required? Yes ☐ No ☐

If Yes, what was the date of the last washout? DD/MM/YY

2.4 Has anti-propulsive medication (e.g loperamide) been prescribed? Yes ☐ No ☐

If Yes, when was it last administered? DD/MM/YY

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

If Yes, when were they last administered? DD/MM/YY

Please tick all medications used: Cycled antibiotics ☐ Prebiotics ☐ Probiotics ☐

SAMPLE CASE

2.6 Has this child had any episodes of suspected post-operative enterocolitis? Yes ☐ No ☐

(Defined by intention-to-treat with a requirement for bowel rest, rectal washouts and intravenous antibiotics)

If Yes, please indicate:

Number of episodes ☐☐

Number of re-admissions ☐☐

Section 3: Further Investigation and Management

3.1 Have rectal biopsies been performed post diagnosis? Yes ☐ No ☐

Date	Method *(please tick)*	Result *(please tick all that apply)*
D D / M M / Y Y	Suction ☐ Punch ☐ Full-thickness ☐	Ganglionic ☐ Aganglionic ☐ Enterocolitis ☐ Inadequate ☐
D D / M M / Y Y	Suction ☐ Punch ☐ Full-thickness ☐	Ganglionic ☐ Aganglionic ☐ Enterocolitis ☐ Inadequate ☐

3.2 Have anal dilatations been performed? Yes ☐ No ☐

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

3.3 Was anorectal manometry performed post diagnosis? Yes ☐ No ☐

3.4 Was a staged pull-through originally planned/performed? Yes ☐ No ☐

If Yes, has the **original** stoma been closed? Yes ☐ No ☐

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

Were there any stoma complications requiring revision prior to formal closure? Yes ☐ No ☐

If Yes, please give details: ____________________

3.5 Was another enterostomy formed after definitive surgery? Yes ☐ No ☐ Not applicable ☐

If Yes, please indicate site: Ileum ☐ Colon ☐

Indication for stoma: *(please tick one only)*

Enterocolitis ☐

Outlet obstruction ☐

Anastomotic leak ☐

Perianal excoriation ☐

Other ____________________

Were there any complications requiring revision of new enterostomy? Yes ☐ No ☐

If Yes, please give details: ____________________

SAMPLE CASE

3.6 Has revisional surgery been performed? Yes ☐ No ☐ Not applicable ☐

If Yes, please give date of surgery? D D / M M / Y Y

What revisional surgery was undertaken?

Posterior myectomy/myotomy ☐

Redo Pull-through ☐

Other ________________

If redo pull-through, please indicate technique:

Soave-Boley ☐

Swenson's ☐

Duhamel ☐

Other ________________

3.7 Has the child had any further operations not described above? Yes ☐ No ☐

If Yes, please give details of any further operations performed over the 12 months since diagnosis.

Date	Details of procedure	Indication for procedure
D D / M M / Y Y		
D D / M M / Y Y		
D D / M M / Y Y		

3.8 Did this 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 if not known)*

____

____

____

3.9 Please add any other relevant information below

____

____

____

____

____

Section 4:

Name of person completing the form ________________

Designation ________________

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.

SAMPLE CASE