ID Number:

Date of surgery:

Date of Transfer to Your Hospital:

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

Exomphalos

Data Collection Form - OUTCOMES AT ONE YEAR

NB for the purposes of this Data Collection Form, 28 days refers to 28 days from the date of first surgical intervention, (or decision for non-operative management) and one-year refers to 1 year from this first date

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 child'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 2.
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 2.**
6. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 2.

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 Has the child been discharged home? Yes ☐ No ☐

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

1.2 Has the 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

1.3 Have any surgical procedures been undertaken since initial management (first closure attempt or non-operative therapy)?* Yes ☐ No ☐

If Yes, please complete the dates and indications below

Date	Procedure	Indication	Management/ Complications
D D / M M / Y Y			
D D / M M / Y Y			
D D / M M / Y Y			

**Please include all procedures including those carried out by other specialties*

Please continue in Section 2 if necessary

1.4 Has the child been re-admitted after initial discharge? Yes ☐ No ☐

If Yes, please give details

Date re-admitted	Date discharged	Indication	Complications
D D / M M / Y Y	D D / M M / Y Y		
D D / M M / Y Y	D D / M M / Y Y		
D D / M M / Y Y	D D / M M / Y Y		

Please continue in Section 2 if necessary

1.5 Did the child receive respiratory support *(ie CPAP/ BiPAP / High flow nasal cannula O2** / nasal cannula oxygen)* **beyond 28 days?** Yes ☐ No ☐

If Yes, please give details below.
If used for more than one discrete time period please record on a separate line.

Mode	Date commenced	Still using Yes or No	If No, Date discontinued
	D D / M M / Y Y	Y ☐ N ☐	D D / M M / Y Y
	D D / M M / Y Y	Y ☐ N ☐	D D / M M / Y Y
	D D / M M / Y Y	Y ☐ N ☐	D D / M M / Y Y

*Please continue in Section 2 if necessary **Eg Vapotherm/ Optiflow*

1.6 Did the child require a tracheostomy? Yes ☐ No ☐

If Yes, is this still present? Yes ☐ No ☐

If No, what date was this removed D D / M M / Y Y

1.7 Did the child receive parenteral nutrition (PN) after 28 days? Yes ☐ No ☐

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

If No, what date was this stopped D D / M M / Y Y

1.8 Was the child fully orally fed at 28 days? Yes ☐ No ☐

If Yes, has this child remained fully orally fed until 1yr? Yes ☐ No ☐

If No, to either of these, please indicate any modes of nutrition used
eg NG, NJ, gastrostomy/ feeding jejunostomy

Mode	Date commenced	Still using Yes or No	If No, Date discontinued
	D D / M M / Y Y	Y ☐ N ☐	D D / M M / Y Y
	D D / M M / Y Y	Y ☐ N ☐	D D / M M / Y Y
	D D / M M / Y Y	Y ☐ N ☐	D D / M M / Y Y

Please continue in Section 2 if necessary

1.9 How many days in total has this child spent on an intensive care unit by one year? ☐☐☐

1.10 Was the child treated with antibiotics beyond 28 days for proven or suspected infection? Yes ☐ No ☐

If Yes, please give the details below *(If agent used more than once, please add as a separate episode)*

Agent(s) used	Route	Indication	Positive blood cultures? Yes or No	Date Started	Date Stopped
			Y ☐ N ☐	D D / M M / Y Y	D D / M M / Y Y
			Y ☐ N ☐	D D / M M / Y Y	D D / M M / Y Y
			Y ☐ N ☐	D D / M M / Y Y	D D / M M / Y Y

Please continue in Section 2 if necessary

1.11 Was the child conservatively managed initially? Yes ☐ No ☐

If Yes, did any complications occur after 28 days? *eg sac leak/ damage* Yes ☐ No ☐

If Yes, please give the details below

Complication	Date occured	Management	Outcome
	D D / M M / Y Y		
	D D / M M / Y Y		
	D D / M M / Y Y		

Please continue in Section 2 if necessary

Was the sac covered with dressings initially? Yes ☐ No ☐

If Yes, have dressings ceased to be used? Yes ☐ No ☐

If Yes, please give date of discontinuation D D / M M / Y Y

Has the defect achieved full epithelialisation? Yes ☐ No ☐

If Yes, when did this occur? D D / M M / Y Y

Has the child had a fascial closure (including bridging the fascial defect using a patch)? Yes ☐ No ☐

If No, has a time of closure been suggested? Yes ☐ No ☐

If Yes, Please state the age this is planned *(ie 18m, 2 yrs)* _____

Please state the rationale for this timing or state if not known *(ie, when rolling over, out of nappies etc)* _____

1.12 **How many Peripherally Inserted Central Catheters (PICC) lines or Central Venous lines (CVL) has this child had inserted(by one year)?** *(If zero, please indicate zero)* PICC ☐☐ CVL ☐☐

1.13 **Did the child have any other morbidity not documented above?*** Yes ☐ No ☐

If Yes, please give details _____

**Eg neurological or neurosensory impairment, ongoing problems with hypoglycaemia etc*

1.14 **Was the child ever diagnosed with a syndrome or genetic anomaly?** Yes ☐ No ☐

If Yes, what was the nature of this? _____

1.15 **Has the child received outpatient physiotherapy before one year?** Yes ☐ No ☐

1.16 **How many times has the child attended outpatients in the last year?**
(<u>any speciality</u> in the tertiary centre) (If zero, please indicate zero). ☐☐

1.17 **What is the child's latest recorded;**

Weight ☐☐.☐ kg

Date measured D D / M M / Y Y

Length/ height ☐☐ cms

Date measured D D / M M / Y Y

1.18 **Did the 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)*

_____

Did the child have a postmortem? Yes ☐ No ☐

If Yes, what was the cause of death from the post mortem?

_____

Section 2: Please add any other relevant information below

_____

_____

_____

_____

_____

_____

_____

_____

Section 3:

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

3.2 **Designation** _____

3.3 **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.