ID Number:

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

Exomphalos

Data Collection Form

Details of treatment up to 28 days following surgery/decision for non-operative treatment

Infants presenting on or after 1st March 2014 and before the 1st March 2015

Exclude:

All infants with gastroschisis

Case Definition:

Any live-born infant with herniation of abdominal content through the umbilical ring, the contents being covered by a membrane. This membrane may have been ruptured at the time of delivery.

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. If codes or examples are required, some lists (not exhaustive) are included on the back page of the form.
5. Tick the boxes as appropriate. If you require any additional space to answer a question please use the space provided in section 8.
6. Please complete all dates in the format DD/MM/YY, and all times using the 24hr clock e.g. 18:37
7. **If you do not know the answers to some questions, please indicate this in section 8.**
8. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 8 to describe the problem.

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?** Y Y Y Y

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 **Ethnic group[1]***

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

If Yes, please specify _____

1.5 **Is there any family history of exomphalos or related conditions including syndromes?** Yes ☐ No ☐

If Yes, please specify _____

1.6 **Gestational age at birth** *(completed weeks)*

1.7 **Gender** male ☐ female ☐ indeterminate ☐

1.8 **Birthweight** g

1.9 **What was the planned mode of delivery prior to the onset of labour?** Vaginal ☐ Caesarean ☐

If Caesarean was planned, what was the indication _____

1.10 **What was the mode of delivery?** Spontaneous vaginal ☐ Ventouse ☐ Forceps ☐
Breech ☐ Pre-labour caesarean section ☐ Caesarean section after onset of labour ☐

1.11 **Was exomphalos suspected antenatally?** Yes ☐ No ☐

If Yes, at what gestational age was it first suspected weeks

1.12 **Was the mother offered amniocentesis and/or CVS?** Yes ☐ No ☐

If Yes, did the mother refuse these tests? Yes ☐ No ☐

If No, please tick all that were performed and give details of results Amniocentesis ☐ CVS ☐

Results: _____

1.13 **Were any other anomalies detected antenatally?** Yes ☐ No ☐

If Yes, please specify _____

1.14 **Was a syndrome suspected?** Yes ☐ No ☐

If Yes, please specify _____

1.15 **Did the mother receive prenatal surgical counselling?** Yes ☐ No ☐

Section 2: Initial Presentation and Management

2.1 **Age in days at first presentation to your hospital** days

2.2 **What was the date of presentation?** D D / M M / Y Y

2.3 **Was the infant transferred from another hospital?** Yes ☐ No ☐

If Yes, please specify where the infant was born? _____

2.4 **Was the defect size at the level of the abdominal wall measured/estimated?** Yes ☐ No ☐

If Yes, what was the diameter? cm

2.5 **Was the maximum width of the sac measured/estimated?** Yes ☐ No ☐

If Yes, what was the diameter? cm

2.6 **Was the liver in the sac?** Yes ☐ No ☐

2.7 **Was the sac ruptured?** Yes ☐ No ☐

If Yes, when was the sac known to have ruptured?
Before delivery ☐ During delivery ☐ After delivery ☐ Time not known ☐

2.8 **Apart from exomphalos, were there any other anomalies detected on clinical examination?** Yes ☐ No ☐

If Yes, please specify all _____

2.9 **Was the infant commenced on antibiotics in the first 48 hours of life?** Yes ☐ No ☐

If Yes, please complete the table below:

Agent	Route of administration	Indication	Duration (days)

2.10 **Were any imaging investigations undertaken on the infant?** Yes ☐ No ☐

If Yes, please indicate all that apply:

Investigation			Date	Describe any abnormalities detected
Ultrasound KUB	Yes ☐	No ☐	D D / M M / Y Y	
Ultrasound Head	Yes ☐	No ☐	D D / M M / Y Y	
Ultrasound Spine	Yes ☐	No ☐	D D / M M / Y Y	
Echo	Yes ☐	No ☐	D D / M M / Y Y	
MRI Head	Yes ☐	No ☐	D D / M M / Y Y	
UGI Contrast	Yes ☐	No ☐	D D / M M / Y Y	
Other	Yes ☐	No ☐	D D / M M / Y Y	

If Other, please specify: _____

Section 3: Management of the Sac

3.1 **Did the infant have bowel reduction and cord ligation on unit without attending theatre?** Yes ☐ No ☐

If Yes, *please go to section 5*

If No, *please continue*

Non-Operative Therapy

3.2 **Did the infant have non-operative therapy?** Yes ☐ No ☐

If No, *please go to section 4*

3.3 **What was the indication?** *(tick one only)*

Consultant's routine practice in viscero-abdominal disproportion ☐
Infant unfit for surgery ☐
Concern about comorbidities ☐
Other ☐

If Other, please specify: _____

3.4 **Were any dressings applied to the sac?** Yes ☐ No ☐

If Yes, please give details of any dressing applied: _____

What date were dressings stopped altogether? D D / M M / Y Y

3.5 **Were any topical therapies applied to the sac/ skin?** Yes ☐ No ☐

If Yes, please give details of any topical therapies: _____

What date were topical therapies stopped altogether? D D / M M / Y Y

3.6 **Were silver levels measured in the infant?** Yes ☐ No ☐

If Yes, what was the highest recorded level ☐☐ mg/L ***OR*** ☐☐ nmol/L

3.7 **Was there any evidence of sac damage or leak during non-operative therapy?** Yes ☐ No ☐

If Yes, did the infant require surgery because of this? Yes ☐ No ☐

3.8 **Was the infant discharged home or transferred before full epithelialisation?** Yes ☐ No ☐

3.9 **How long did the defect take to completely epithelialise?** ☐☐ weeks

Not epithelialised yet ☐

3.10 **Were elastic compression devices used on the abdomen?** Yes ☐ No ☐

Section 4: Surgical Management

4.1 **Did the infant have surgery?** Yes ☐ No ☐

If Yes, *please specify date:* D D / M M / Y Y

If No, *please go to Section 5*

4.2 **Please specify the sequence of operative procedures, including all those attempted at first closure** *(tick all that apply)*

Procedure	Attempted	Successful	Unsuccessful	Please indicate the order in which procedures were attempted (1,2,3 etc)	Please indicate the date when procedures were attempted
Closure of fascia	☐	☐	☐ Reason: _____		
Silo Formation	☐	☐	☐ Reason: _____		
Bridging of fascia with a patch	☐	☐	☐ Reason: _____		
Skin closure without fascial closure	☐	☐	☐ Reason: _____		

4.3 Was a silo used? Yes ☐ No ☐

If Yes, was the sac removed? Yes ☐ No ☐

What materials were used to construct the silo? _____

Was controlled reduction, (silo tucking) undertaken? Yes ☐ No ☐

If Yes, were there any adverse sequelae? Yes ☐ No ☐

If Yes, please give details: _____

Was this silo operatively revised at any point? Yes ☐ No ☐

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

What was the indication? _____

What materials were used to construct the revised silo? _____

What date was the silo removed? D D / M M / Y Y

4.4 Was a patch used? Yes ☐ No ☐

If Yes, what material was used for the patch? _____

Was there a plan to remove this at a later date? Yes ☐ No ☐

Was skin apposed over the patch? Yes ☐ No ☐

4.5 Were any additional procedures performed at the time of the initial operation? *(tick all that apply)* Yes ☐ No ☐

Placement of a tunnelled central venous line ☐ Correction of malrotation ☐

Appendicectomy ☐ Other ☐

If Other, please specify: _____

4.6 Did any intra-operative surgical complications occur? Yes ☐ No ☐

If Yes, please specify: _____

4.7 Did the infant receive monitoring for abdominal compartment syndrome? Yes ☐ No ☐

If Yes, please specify what monitoring method was used _____

4.8 Was vacuum assisted therapy used at any point? Yes ☐ No ☐

If Yes, what was the duration? ☐☐ days

Section 5: Ongoing Management

5.1 Did the infant develop infection or receive intravenous, oral or topical antimicrobials during their stay for prophylaxis or treatment of proven or suspected infection (including antifungals)? Yes ☐ No ☐

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

Treatment (T) / Prophylaxis (P)	Agent (s) used	Indication	Duration (days)

Continue in section 8 if necessary

5.2 **Was the infant ever colonised or infected by a multi-resistant organism?** Yes ☐ No ☐

If Yes, please give details below:

Organism	Site of infection/ colonisation	Infected	Colonised

5.3 **Was invasive ventilatory support used (excluding CPAP)?** Yes ☐ No ☐

If managed non-operatively – total number of days of ventilation ☐☐ days

If managed operatively – number of days of ventilation before surgery ☐☐ days

number of days ventilation after surgery ☐☐ days

5.4 **How many Peripherally Inserted Central Catheters (PICC lines) did the infant have inserted?** ☐☐

5.5 **How many Central Venous Lines did the infant have inserted?** ☐☐

Section 6: Nutrition at 28 days after surgery or 28 days after decision for non-operative management

6.1 **Has the infant ever received parenteral nutrition?** Yes ☐ No ☐

If Yes, was the infant still receiving parenteral nutrition at 28 days? Yes ☐ No ☐

If No, give total number of days on parenteral nutrition ☐☐ days

6.2 **What date was the infant first enterally fed (including tube feeding)?** D D / M M / Y Y

6.3 **Is the infant now fully enterally fed (including tube feeding)?** Yes ☐ No ☐

If Yes, what date were full enteral feeds started? D D / M M / Y Y

6.4 **Did the infant ever receive breast milk (including expressed or donor milk)?** Yes ☐ No ☐

If Yes, was this exclusive? Yes ☐ No ☐

6.5 **Did the infant receive any probiotic therapy?** Yes ☐ No ☐

If Yes, please give details below:

Agent	Route of administration	Duration (hours/days)

6.6 **What was the mode of feeding at 28 days or point of discharge (whichever was sooner)?**

Exclusively oral ☐ Nasogastric plus oral ☐ Exclusively Nasogastric ☐

Nasojejunal plus oral ☐ Exclusively Nasojejunal ☐ Other ☐

If Other, please specify: _____

Section 7: Early Morbidity up to 28 days after surgery or up to 28 days after decision for non-operative management

7.1 Were any further surgical procedures required *(If not included in table 4.2)*? Yes ☐ No ☐

If Yes, please give details 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	

7.2 Did any complications relating to surgical or non-operative therapy occur? Yes ☐ No ☐

If Yes, please tick all that apply:

Abdominal wall hernia (if not intended) ☐

Wound Dehiscence ☐ Abdominal Compartment syndrome ☐

How was Abdominal Compartment syndrome diagnosed? _____

Other ☐

If Other, please specify: _____

7.3 Did the infant have any other morbidity? Yes ☐ No ☐

If Yes, please give details: _____

Section 8: Outcomes/Other information

8.1 Has the infant been discharged home? Yes ☐ No ☐

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

8.2 What was the weight and head circumference of the infant at 28 days or point of discharge (whichever was sooner)?

Weight ☐☐☐☐ g

Head Circumference ☐☐ cm

Date D D / M M / Y Y

8.3 Has the infant been discharged to another hospital? Yes ☐ No ☐

If Yes, please give name of hospital

Name of responsible consultant at transfer hospital _____

Date of transfer D D / M M / Y Y

8.4 Was the infant ever diagnosed with a syndrome or a chromosomal anomaly? Yes ☐ No ☐

If Yes, please give details _____

8.5 Did the infant have a malrotation? Yes ☐ No ☐ Not identified through imaging or surgery ☐

If Yes, was this communicated to parents? Yes ☐ No ☐ Unclear ☐

8.6 Did the infant 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)*

Was a post-mortem performed? Yes ☐ No ☐

Were any additional abnormalities detected? Yes ☐ No ☐

If Yes, please give details

8.7 Please add other relevant information below

Section 9:

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.

Definitions

1. 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