

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

Congenital Diaphragmatic Hernia Data Collection Form

Data Collection Form - CASE

Case Definition:

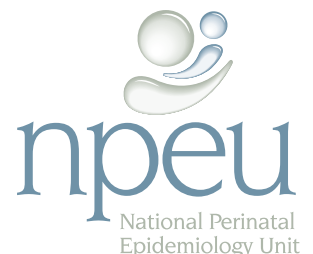
Any live-born infant with a congenital diaphragmatic hernia, defined as a developmental defect of the diaphragm present at birth allowing herniation of abdominal contents into the chest. Infants with defects occurring in any position (e.g. postero-lateral, central) should be included.

Please return the completed form to:

BAPS-CASS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF

Fax: 01865 289701
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 in section 7.
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 7.
7. If you encounter any problems with completing the form please contact the Study Administrator or use the space in section 7 to describe the problem.

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

Section 1: Antenatal data

- 1.1 Was CDH suspected antenatally?** Yes No
If Yes, at what gestational age? weeks
- 1.2 Which feature suggested the diagnosis? (please tick all that apply)**
- Stomach/bowel in chest
- Liver herniation
- Other
- If Other, please specify _____
- 1.3 Was polyhydramnios present antenatally?** Yes No
- 1.4 Was the Lung Head Ratio (LHR) measured?** Yes No
- If Yes,
- What was the lowest LHR? .
- What date was this measured? //
- 1.5 Was fetal therapy undertaken?** Yes No
- If Yes,
- Was FETO balloon tracheal occlusion undertaken? Yes No
- If Yes, please state
- Date of occlusion //
- Date and time of balloon retrieval // :^{24hr}
- Were antenatal corticosteroids administered? Yes No
- If Yes, please state
- Date of first course //
- Number of courses given
- 1.6 What was the mother's year of birth?**
- 1.7 Please give the first alphabetical part of mother's postcode (e.g. OX for Oxfordshire, EH for Edinburgh, L for Liverpool)**
- 1.8 Was this a multiple pregnancy?** Yes No
- If Yes,
- How many fetuses?
- Did any of the other fetuses have CDH? Yes No
- 1.9 Was there a family history of CDH?** Yes No
- If Yes, please state which relative(s): _____
- 1.10 Was the surgical team involved in the antenatal planning of care?** Yes No
- 1.11 Was a member of the surgical team involved in the antenatal counselling of the parents?** Yes No

Section 2: Birth data

- 2.1 What was the mode of delivery?**
- Vaginal delivery
- Pre-labour caesarean section
- Caesarean section after onset of labour
- 2.2 Ethnic Group^{1*}**

*For guidance please see inside front cover

- 2.3 What was the gestational age at birth? (*completed weeks*)
- 2.4 What is the sex of the infant? Male Female Indeterminate
- 2.5 What was the birth weight? g
- 2.6 What was the head circumference? . cm
- 2.7 What was the 5min Apgar score?
- 2.8 Was surfactant given at birth? Yes No
- 2.9 Was the infant transferred from another hospital after delivery? Yes No

If Yes, please specify

Hospital infant was born in: _____

Date of transfer

/ /

- 2.10 Were there any other anomalies confirmed or suspected? Yes No

If Yes, please complete table below:

Anomaly	Suspected antenatally (Tick if yes)	Diagnosed postnatally (Tick if yes)
	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>

Section 3: Pre-Operative Investigations and Management

- 3.1 Was a chest X-Ray performed? Yes No
- 3.2 Which side was the hernia defect? Left Right Bilateral
- 3.3 Was an echocardiogram performed pre-operatively? Yes No
- 3.4 Was any ventilatory support used prior to surgery? Yes No

If Yes, please indicate strategies used prior to surgery and the order of use:

	Tick if used	Indicate order of use (1,2,3 etc)
Conventional mode ventilation	<input type="checkbox"/>	<input type="text"/>
High frequency oscillation	<input type="checkbox"/>	<input type="text"/>
ECMO	<input type="checkbox"/>	<input type="text"/>
Liquid	<input type="checkbox"/>	<input type="text"/>
Nasal CPAP	<input type="checkbox"/>	<input type="text"/>

- 3.5 Were inotropes used? Yes No

If Yes, please list agents used:

- 3.6 Were pulmonary vasodilators used? Yes No

If Yes, please indicate agents used (*tick all that apply*)

- Nitric oxide
- Sildenafil
- Other

If Other, please specify _____

Section 4: Operation details

4.1 Was an operation performed? Yes No

If No

Please indicate why not _____

Then go to section 5

If Yes, please continue

4.2 What was the date of operation? DD / MM / YY

4.3 What was the type of hernia? Posterolateral Central

Anteromedial Agenesis

4.4 Was ECMO used peri-operatively? Yes No

If Yes, for how many days was it used?

4.5 Was any other peri-operative ventilation technique used? Yes No

If Yes, was it

Conventional mode ventilation

High frequency oscillation

For how many days was the infant ventilated post-operatively?

4.6 What surgical techniques were used? (tick all that apply)

Primary diaphragm repair Yes No

If Yes, please specify suture material _____

Patch repair Yes No

If Yes, please specify patch material _____

Abdominal wall patch (abdominoplasty) Yes No

If Yes, please specify patch material _____

Chest drain deployed Yes No

Minimally invasive surgery Yes No

Fundoplication Yes No

Other Yes No

If Yes, please specify _____

4.7 Was malrotation treated during the same surgical procedure? Yes No

Section 5: Morbidity during primary admission

Please indicate if any of the following were present.

- 5.1 Chylothorax** Yes No
If Yes, how was this managed?
TPN Yes No
Octreotide Yes No
Other Yes No
If Other, please specify _____
- 5.2 Recurrent hernia** Yes No
If Yes, please specify
Method of repair _____
Date of repair / /
- 5.3 Neurological sequelae (CNS dysfunction)** Yes No
If Yes, please specify problem _____
- 5.4 Pneumothorax** Yes No
If Yes, was this Pre-operative Post-operative Both
- 5.5 Other morbidity** Yes No
If Yes, please specify _____

Section 6: Outcomes

A: Hospital Discharge

- 6a.1 Has the infant been transferred to another hospital?** Yes No
If Yes, please give
Name of hospital _____
Date of transfer / /
Responsible clinician _____
- 6a.2 Has the infant been discharged home?** Yes No
If Yes, please give
Date of discharge / /
Was the baby discharged home on oxygen? Yes No
- 6a.3 Was a neonatal hearing screen undertaken before discharge/ transfer?** Yes No
If Yes, what was the result? No impairment Other
If Other, please specify _____
- 6a.4 Did this infant die?** Yes No
If Yes,
What was the date of death? / /
What was the principle cause of death as stated of the Death Certificate?

SAMPLE
CASE