



UK Obstetric Surveillance System

Congenital Diaphragmatic Hernia Cases Study 02/09

Data Collection Form - CASE

Please report any woman delivering between 1st April 2009 and 31st March 2010.

Case Definition:

Any pregnant woman with a fetus affected by a congenital diaphragmatic hernia.

Please return the completed form to:

UKOSS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF



Royal College of
Obstetricians and
Gynaecologists

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 woman's name on the Clinician's Section of the blue card retained in the UKOSS folder.
3. Fill in the form using the information available in the woman'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 codes or examples are required, some lists (not exhaustive) are included on the back page of the form.
7. If the woman has not yet delivered, please complete the form as far as you are able, excluding delivery and outcome information, and return to the UKOSS Administrator. We will send these sections again for you to complete two weeks after the woman's expected date of delivery.
8. **If you do not know the answers to some questions, please indicate this in section 7.**
9. If you encounter any problems with completing the form please contact the UKOSS Administrator or use the space in section 7 to describe the problem.

Section 1: Woman's details

- 1.1 Year of birth**
- 1.2 Ethnic group^{1*}** (enter code, please see back cover for guidance)
- 1.3 First letters of postcode e.g. OX for Oxfordshire, EH for Edinburgh**
- 1.4 Marital status** single married cohabiting
- 1.5 Was the woman in paid employment at booking?** Yes No
If Yes, what is her occupation _____
If No, what is her partner's (if any) occupation _____
- 1.6 Height at booking (cm)**
- 1.7 Weight at booking (kg)**
- 1.8 Smoking status** never gave up prior to pregnancy
current gave up during pregnancy

Section 2: Previous Obstetric History

- 2.1 Gravity**
Number of completed pregnancies 24 weeks and beyond
Number of pregnancies less than 24 weeks
- If no previous pregnancies, please go to section 3**
- 2.2 Did the woman have any previous pregnancy problems?^{2*}** Yes No
If Yes, please specify _____
- 2.3 Previous infant with congenital diaphragmatic hernia?** Yes No
- 2.4 Any other previous infant with a structural or chromosomal anomaly?** Yes No
If Yes, please specify anomaly _____

*For guidance please see back cover

Section 3: Previous Medical History

3.1 Were there any previous or pre-existing medical problems?^{3*}

Yes No

If Yes, please specify _____

Section 4a: This Pregnancy

4a.1 Final Estimated Date of Delivery (EDD)^{4*}

/ /

4a.2 Was this pregnancy a multiple pregnancy?

Yes No

If Yes, please specify number of fetuses

4a.3 Were there problems in this pregnancy?^{2*}

Yes No

If Yes, please specify _____

4a.4 Was any regular medication received in early pregnancy?

Yes No

If Yes, please specify medications used _____

4a.5 Was the woman first booked for antenatal care at a different hospital? Yes No

If Yes, please give

Date of referral to your hospital

/ /

And name of booking unit for antenatal care _____

4a.6 Was this woman booked for delivery at a different hospital?

Yes No

If Yes, please give name of booking unit for delivery _____

Section 4b: Diagnosis of Diaphragmatic Hernia

4b.1 Date of Diagnosis

/ /

4b.2 Was an ultrasound diagnosis made?

Yes No

Isolated congenital diaphragmatic hernia

Congenital diaphragmatic hernia with other abnormality

Please specify additional abnormalities _____

Other anomaly

Please specify _____

4b.3 Which side was the hernia defect?

Left Right Bilateral

4b.4 Was there mediastinal shift?

Yes No

If Yes, was it Mild Moderate Severe

4b.5 Contents of hernia (please tick if contained)

Stomach

Bowel

Liver

Kidney

Other

If Other, please specify _____

4b.6 Was the lung volume formally assessed?

Yes No

If Yes,

Was Ultrasound Lung Head Ratio measured?

Yes No

If Yes, please give result

.

Was an MRI performed

Yes No

If Yes, please give result _____

4b.7 Did the woman have antenatal karyotyping?

Yes No

If Yes, please indicate

The method used

amniocentesis CVS FBS

And give date of test

//

And result _____

4b.8 Did the woman have polyhydramnios?

Yes No

If Yes, what date was this first diagnosed?

//

4b.9 Was any antenatal treatment given?

Yes No

If Yes, please specify treatment and date given

Treatment	Date
	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>

Section 4c: Antenatal Management

4c.1 Was the fetus treated with laryngeal balloon occlusion?

Yes No

If Yes, please indicate

Date when balloon was inserted

//

And date when the balloon was removed

//

Was this part of the FETO trial?

Yes No

4c.2 Were antenatal steroids used?

Yes No

If Yes, please indicate

Date of first course

//

And number of courses given

4c.3 Please indicate whether any of the following were performed and the frequency with which they were performed

Biophysical profile Yes No Every weeks

CTG Yes No Every weeks

Growth scan Yes No Every weeks

Umbilical artery doppler Yes No Every weeks

4c.4 Was the surgical team involved in the antenatal planning of care?

Yes No

4c.5 Was a member of the surgical team involved in the antenatal counselling of the parents?

Yes No

Section 5: Delivery

5.1 Did this woman have a miscarriage?

Yes No

If Yes, please specify date

/ /

5.2 Did this woman have a termination of pregnancy?

Yes No

If Yes, please specify date

/ /

If Yes to 5.1. or 5.2, please now complete sections 6a, 7 and 8

5.3 Is this woman still undelivered?

Yes No

If Yes,

Will she be receiving the rest of her antenatal care at your hospital?

Yes No

If No, please indicate name of hospital providing future care

Then go to section 7

If No, please continue

5.4 What was the planned delivery hospital? _____

5.5 Did the woman deliver at the planned delivery hospital?

Yes No

If No, please state why not _____

5.6 Did this woman have pre-labour rupture of membranes?

Yes No

If Yes, please specify date and time

/ / :

5.7 What was the planned mode of delivery?

Vaginal Abdominal

5.8 Was delivery induced?

Yes No

If Yes, please state indication _____

5.9 Did the woman labour?

Yes No

5.10 Was delivery by caesarean section?

Yes No

If Yes, please state

Grade of urgency^{5*} _____

Indication for caesarean section _____

Grade of operator _____

Method of anaesthesia (tick all that apply)

Epidural Single-shot spinal Continuous spinal CSE General

Section 6: Outcomes

Section 6a: Woman

6a.1 Did any other major maternal morbidity occur?^{6*}

Yes No

If Yes, please specify _____

6a.2 Did the woman die?

Yes No

If Yes, please specify

Date of death

/ /

What was the primary cause of death as stated on the death certificate?

(please state if not known) _____

*For guidance please see back cover

Section 6b: Infant 1

NB: If more than one infant, for each additional infant, please photocopy the infant section of the form (**before filling it in**) and attach extra sheet(s) or download additional forms from the website: www.npeu.ox.ac.uk/ukoss

6b.1 Date and time of delivery

/ / : 24hr

6b.2 Mode of delivery

Spontaneous vaginal Ventouse Lift-out forceps Rotational forceps
Breech Pre-labour caesarean section Caesarean section after onset of labour

6b.3 Sex of infant

Male Female

6b.4 Birthweight

g

6b.5 Was the infant stillborn?

Yes No

If Yes, was this

antepartum intrapartum?

Please go to section 7

6b.6 5 min Apgar

6b.7 Was the infant admitted to the neonatal/paediatric surgical unit?

Yes No

If Yes, please specify

Duration of stay (*if known*)

days

Or Tick if infant is still an inpatient

Or Tick if infant was transferred to another hospital

If transferred, please indicate name of hospital _____

6b.8 Was congenital diaphragmatic hernia confirmed postnatally?

Yes No

If Yes, was it

Isolated

With other associated abnormalities /genetic syndromes

Please specify additional abnormalities _____

6b.9 Did a surgical repair take place

Yes No

If No, please state why not (*if known*) _____

6b.10 Did any other major infant complications occur?^{7*}

Yes No

If Yes, please specify _____

6b.11 Did this infant die?

Yes No

If Yes, please specify date of death

/ /

What was the primary cause of death as stated on the death certificate?

(*please state if not known*) _____

Section 7

Please use this space to enter any other information you feel may be important

SAMPLE CASE

Section 8

Name of person completing the form _____

Designation _____

Today's date

D	D	/	M	M	/	Y	Y
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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

2: Previous or current pregnancy problems, including:

Surgical procedure in pregnancy
Hyperemesis requiring admission
Dehydration requiring admission
Thrombotic event
Ovarian hyperstimulation syndrome
Severe infection e.g. pyelonephritis
Pre-eclampsia (hypertension and proteinuria)
Significant antepartum haemorrhage
Gestational diabetes
Placental abruption
Cardiac problems

3: Previous or pre-existing maternal medical problems, including:

Essential hypertension
Cardiac disease (congenital or acquired)
Renal disease
Endocrine disorders e.g. hypo or hyperthyroidism
Psychiatric disorders
Haematological disorders e.g. sickle cell disease, diagnosed thrombophilia
Inflammatory disorders e.g. inflammatory bowel disease
Epilepsy
Diabetes

Autoimmune diseases

Cancer

HIV

4: Estimated date of delivery (EDD): Use the best estimate (ultrasound scan or date of last menstrual period) based on a 40 week gestation

5: RCA/RCOG/CEMACH/CNST Classification for urgency of caesarean section:

1. Immediate threat to life of woman or fetus
2. Maternal or fetal compromise which is not immediately life-threatening
3. Needing early delivery but no maternal or fetal compromise
4. At a time to suit the woman and maternity team

6: Major maternal medical complications, including:

Persistent vegetative state
Cardiac arrest
Cerebrovascular accident
Adult respiratory distress syndrome
Disseminated intravascular coagulopathy
Pulmonary oedema
Mendleson's syndrome
Renal failure
Thrombotic event
Septicaemia
Required ventilation

7: Fetal/infant complications, including:

Respiratory distress syndrome
Intraventricular haemorrhage
Necrotising enterocolitis
Neonatal encephalopathy
Chronic lung disease
Severe jaundice requiring phototherapy
Major congenital anomaly
Severe infection e.g. septicaemia, meningitis
Exchange transfusion