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
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* (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

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

Section 2: Previous Obstetric History

2.1 Gravidity

   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?*

   If Yes, please specify

2.3 Previous infant with congenital diaphragmatic hernia?

2.4 Any other previous infant with a structural or chromosomal anomaly?

   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?*

   Yes ☐  No ☐

   If Yes, please specify ________________________________

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**Section 4a: This Pregnancy**

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

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?*

   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

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**Section 4b: Diagnosis of Diaphragmatic Hernia**

4b.1 Date of Diagnosis

4b.2 Was an ultrasound diagnosis made?

   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 ________________________________

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*For guidance please see back cover
4b.6 Was the lung volume formally assessed?  
If Yes,  
Was Ultrasound Lung Head Ratio measured?  
If Yes, please give result  
Was an MRI performed  
If Yes, please give result

4b.7 Did the woman have antenatal karyotyping?  
If Yes, please indicate  
The method used  
And give date of test  
And result

4b.8 Did the woman have polyhydramnios?  
If Yes, what date was this first diagnosed?

4b.9 Was any antenatal treatment given?  
If Yes, please specify treatment and date given

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Date</th>
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<tbody>
<tr>
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</table>

Section 4c: Antenatal Management
4c.1 Was the fetus treated with laryngeal balloon occlusion?  
If Yes, please indicate  
Date when balloon was inserted  
And date when the balloon was removed  
Was this part of the FETO trial?

4c.2Were antenatal steroids used?  
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

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Yes</th>
<th>No</th>
<th>Every weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biophysical profile</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>CTG</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Growth scan</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Umbilical artery doppler</td>
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</table>

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

*For guidance please see back cover*
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 urgency5*  
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

6b.2 Mode of delivery

<table>
<thead>
<tr>
<th>Choice</th>
<th>□</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spontaneous vaginal</td>
<td></td>
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<tr>
<td>Ventouse</td>
<td></td>
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<tr>
<td>Lift-out forceps</td>
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<tr>
<td>Rotational forceps</td>
<td></td>
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<tr>
<td>Breech</td>
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<tr>
<td>Pre-labour caesarean section</td>
<td></td>
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<tr>
<td>Caesarean section after onset of labour</td>
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</tbody>
</table>

6b.3 Sex of infant

<table>
<thead>
<tr>
<th>Choice</th>
<th>□</th>
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<tbody>
<tr>
<td>Male</td>
<td></td>
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<tr>
<td>Female</td>
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</table>

6b.4 Birthweight

<table>
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<tr>
<th>Number</th>
<th>g</th>
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</table>

6b.5 Was the infant stillborn?

<table>
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<tr>
<th>Choice</th>
<th>□</th>
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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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</tbody>
</table>

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?

<table>
<thead>
<tr>
<th>Choice</th>
<th>□</th>
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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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</table>

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?

<table>
<thead>
<tr>
<th>Choice</th>
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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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</table>

If Yes, was it

Isolated □

With other associated abnormalities /genetic syndromes □

Please specify additional abnormalities ____________________________

6b.9 Did a surgical repair take place

<table>
<thead>
<tr>
<th>Choice</th>
<th>□</th>
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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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</table>

If No, please state why not (if known) ____________________________

6b.10 Did any other major infant complications occur?*

<table>
<thead>
<tr>
<th>Choice</th>
<th>□</th>
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<tbody>
<tr>
<td>Yes</td>
<td></td>
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<tr>
<td>No</td>
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</table>

If Yes, please specify ____________________________

6b.11 Did this infant die?

<table>
<thead>
<tr>
<th>Choice</th>
<th>□</th>
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<tbody>
<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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If Yes, please specify date of death

/ /D M Y YMD

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

(please state if not known) ____________________________________________

*For guidance please see back cover
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