ID Number:

UKOSS

UK Obstetric Surveillance System

Pregnancy in Women with Cystic Fibrosis Study 03/15

Data Collection Form - CASE

Please report any woman delivering on or after 1st March 2015 and before 1st March 2017.

Case Definition:

All pregnant women with a diagnosis of cystic fibrosis confirmed by CF mutation genotyping either prior to or during the current pregnancy who are booked for antenatal care in a UK obstetric unit

Please return the completed form to:

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

Fax: 01865 617775
Phone: 01865 289714

Case reported in: _____

Royal College of Obstetricians and Gynaecologists
Bringing to life the best in women's health care

npeu National Perinatal Epidemiology Unit

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 Y Y Y Y

1.2 Ethnic group:[1]* *(enter code, please see back cover for guidance)* ☐☐

1.3 Marital status: single ☐ married ☐ cohabiting ☐

1.4 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:

_____

1.5 Height at booking: ☐☐☐ *cm*

1.6 Weight at booking: ☐☐☐.☐ *kg*

1.7 Smoking status: never ☐ gave up prior to pregnancy ☐

current ☐ gave up during pregnancy ☐

*For guidance please see back cover

Section 2: Previous Obstetric History

2.1 Gravidity

Number of completed pregnancies beyond 24 weeks: ☐☐

Number of live births ☐☐

Number of stillbirths ☐☐

Number of terminations ☐☐

Please state number performed for:

Medical advice/maternal health ☐☐

Fetal abnormality ☐☐

Other indication ☐☐

Please give date of delivery of the most recent completed pregnancy beyond 24 weeks: D D / M M / Y Y

Number of pregnancies less than 24 weeks ☐☐

Number of miscarriages ☐☐

Number of terminations of pregnancy ☐☐

Please state number performed for:

Medical advice/maternal health ☐☐

Fetal abnormality ☐☐

Other indication ☐☐

Number of ectopic pregnancies ☐☐

Please give the end date of the most recent pregnancy less than 24 weeks: D D / M M / Y Y

If no previous pregnancies, *please go to section 3*

2.2 Did the woman have any other previous pregnancy problems?[2]* Yes ☐ No ☐

If Yes, please specify: _____

Section 3: Previous Medical History

3.1 Age at diagnosis with CF At birth ☐ ***OR*** Months ☐☐ Years ☐☐

3.2 Does the woman have genetically diagnosed CF? Yes ☐ No ☐

If Yes, is the mutation known? Yes ☐ No ☐

If Yes, What was the genotype?

F508/F508 ☐

F508/other ☐

Other/other ☐

3.3 What is the CF status of the father of the baby?

Affected ☐ Known carrier ☐ Unaffected ☐ Not known ☐

3.4 Was the FEV1 prior to pregnancy recorded? Yes ☐ No ☐

If Yes, what was the last recorded FEV1 prior to the start of the pregnancy (volume in ml/or percentage) ☐☐☐☐ mls ***or*** ☐☐ %

What date was this recorded? D D / M M / Y Y

*For guidance please see back cover

3.5 **Did the woman have any of the following prior to this pregnancy?** Yes ☐ No ☐

If Yes, Please tick all that apply

- Pancreatic insufficiency ☐
- CF-related diabetes ☐
- Cholestatic liver disease ☐
- Asthma/bronchiectasis ☐
- Pulmonary hypertension ☐
- Heart transplant ☐
- Lung transplant ☐

3.6 **Did the woman have any other pre-existing medical conditions?[3]*** Yes ☐ No ☐

If Yes, please give details _____

3.7 **Did the woman seek pre-pregnancy counselling?** Yes ☐ No ☐ Not known ☐

Section 4: This Pregnancy

4.1 **Final Estimated Date of Delivery (EDD):[4]*** D D / M M / Y Y

4.2 **Was this a multiple pregnancy?** Yes ☐ No ☐

If Yes, please specify number of fetuses: ☐

4.3 **What was the first recorded FEV1 during this pregnancy?** ☐☐☐☐ mls ***or*** ☐☐ %

What date was this recorded? D D / M M / Y Y

4.4 **What was the last recorded FEV1 during this pregnancy?** ☐☐☐☐ mls ***or*** ☐☐ %

What date was this recorded? D D / M M / Y Y

4.5 **Please list medications at booking** _____

_____

_____

_____

_____

4.6 **Did the woman require IV antibiotics during this pregnancy for a CF-related infection?** Yes ☐ No ☐

If Yes, how may separate courses were required (include any current course)? ☐☐

4.7 **Did the woman develop any of the following?** Yes ☐ No ☐

If Yes, *tick all that apply* Gestational diabetes ☐ Obstetric cholestasis ☐ Pre-eclampsia

4.8 **What was the woman's last recorded weight prior to delivery or was this not recorded?** ☐☐☐.☐ *kg* Not recorded ☐

What date was this recorded? D D / M M / Y Y

4.9 **Did the woman require artificial feeding (NG, NJ or PEG) at any time during this pregnancy or immediately postpartum?** Yes ☐ No ☐

4.10 **Were there any other problems in this pregnancy?[2]*** Yes ☐ No ☐

If Yes, please specify _____

*For guidance please see back cover

Section 5: Delivery

5.1 **Did this woman have a miscarriage?** Yes ☐ No ☐

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

5.2 **Did this woman have a termination of pregnancy?** Yes ☐ No ☐

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

Was this for: *(please tick one)*

Medical advice/maternal health ☐

Fetal abnormality ☐

Other indication ☐

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 the name of the hospital providing future care

_____

Will she be delivered at your hospital? Yes ☐ No ☐

If No, please indicate the name of delivery hospital, then *go to Section 7*

_____

5.4 **Was delivery induced?** Yes ☐ No ☐

If Yes, please state indication _____

5.5 **Did the woman labour?** Yes ☐ No ☐

5.6 **Was delivery by caesarean section?** Yes ☐ No ☐

If Yes, please state:

Grade of urgency[5]* ☐

Indication for caesarean section _____

Method of anaesthesia Regional ☐ General ☐

Section 6: Outcomes
Section 6a: Woman

6a.1 **Was the woman admitted to HDU (level 2 care)?** Yes ☐ No ☐

If Yes, what was the date of admission to HDU? D D / M M / Y Y

What was the date of discharge from HDU? D D / M M / Y Y

OR Tick if woman is still in HDU ☐

OR Tick if woman was transferred to another hospital ☐

6a.2 **Was the woman admitted to ITU (level 3 care)?** Yes ☐ No ☐

If Yes, what was the date of admission to ITU? D D / M M / Y Y

What was the date of discharge from ITU? D D / M M / Y Y

OR Tick if woman is still in ITU ☐

OR Tick if woman was transferred to another hospital ☐

*For guidance please see back cover

6a.3 Was the woman ventilated? Yes ☐ No ☐

If Yes, was this Invasive ☐ Non-invasive ☐

6a.4 Did the woman require any other organ support (e.g. renal dialysis, inotropes)? Yes ☐ No ☐

If Yes, please specify support required

_____

6a.5 Did any other major maternal morbidity occur?[6]* Yes ☐ No ☐

If Yes, please specify: _____

6a.6 Did the woman die? Yes ☐ No ☐

If Yes, please specify date and time of death D D / M M / Y Y h h : m m (24hr)

What was the primary cause of death as stated on the death certificate?
(Please state if not known.) _____

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 D D / M M / Y Y h h : m m (24hr)

6b.2 Mode of delivery Spontaneous vaginal cephalic ☐ Spontaneous vaginal breech ☐
Ventouse ☐ Non-rotational forceps ☐ Rotational forceps ☐
Pre-labour caesarean section ☐ Caesarean section after onset of labour ☐

6b.3 Birthweight ☐☐☐☐ *g*

6b.4 Sex of infant Male ☐ Female ☐ Indeterminate ☐

6b.5 Was the infant stillborn? Yes ☐ No ☐

If Yes, *please go to section 7*.

6b.6 5 min Apgar ☐☐

6b.7 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

If Yes, duration of stay ☐☐ *days*

OR Tick if still in neonatal unit ☐

OR Tick if admitted to another hospital ☐

6b.8 Did any other major infant complications occur?[7]* Yes ☐ No ☐

If Yes, please specify: _____

6b.9 Did this infant die? Yes ☐ No ☐

If Yes, please specify date and time of death D D / M M / Y Y h h : m m (24hr)

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 7:

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

Section 8:

8.1 Name of person completing the form: _____

8.2 Designation: _____

8.3 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.

*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:

Thrombotic event
Amniotic fluid embolism
Eclampsia
3 or more miscarriages
Preterm birth or mid trimester loss
Neonatal death
Stillbirth
Baby with a major congenital abnormality
Small for gestational age (SGA) infant
Large for gestational age (LGA) infant
Infant requiring intensive care
Puerperal psychosis
Placenta praevia
Gestational diabetes
Significant placental abruption
Post-partum haemorrhage requiring transfusion
Surgical procedure in pregnancy
Hyperemesis requiring admission
Dehydration requiring admission
Ovarian hyperstimulation syndrome
Severe infection e.g. pyelonephritis

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

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
Autoimmune diseases
Cancer

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
HELLP
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,
Exchange transfusion