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: ________________________
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.

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Section 1: Woman’s details

1.1 Year of birth

1.2 Ethnic group:* (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:

| Date of delivery (DD/MM/YYYY): |  |

2.2 **Did the woman have any other previous pregnancy problems?**

*Yes* ☐  *No* ☐

If *Yes*, please specify:

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**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?**

If *Yes*, what was the last recorded FEV1 prior to the start of the pregnancy

- (volume in ml/or percentage)

- mls ☐  % ☐

What date was this recorded?

| Date recorded (DD/MM/YYYY): |  |

*For guidance please see back cover*
### Section 4: This Pregnancy

4.1 **Final Estimated Date of Delivery (EDD):**

4.2 **Was this a multiple pregnancy?**

4.3 **What was the first recorded FEV1 during this pregnancy?**

4.4 **What was the last recorded FEV1 during this pregnancy?**

4.5 **Please list medications at booking**

4.6 **Did the woman require IV antibiotics during this pregnancy for a CF-related infection?**

4.7 **Did the woman develop any of the following?**

4.8 **What was the woman’s last recorded weight prior to delivery or was this not recorded?**

4.9 **Did the woman require artificial feeding (NG, NJ or PEG) at any time during this pregnancy or immediately postpartum?**

4.10 **Were there any other problems in this pregnancy?**

*For guidance please see back cover*
**Section 5: Delivery**

5.1 Did this woman have a miscarriage?  
   Yes ☐ No ☐
   If Yes, please specify date
   [DD MM YYYY]

5.2 Did this woman have a termination of pregnancy?  
   Yes ☐ No ☐
   If Yes, please specify date
   [DD MM YYYY]
   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 the 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*  
   - Indication for caesarean section
   - Method of anaesthesia
   Regional ☐ General ☐

*For guidance please see back cover

**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?  
   [DD MM YYYY]
   What was the date of discharge from HDU?  
   [DD MM YYYY]
   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?  
   [DD MM YYYY]
   What was the date of discharge from ITU?  
   [DD MM YYYY]
   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?  
Yes [ ]  No [ ]
If Yes, please specify:

6a.6 Did the woman die?  
Yes [ ]  No [ ]
If Yes, please specify date and time of death
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

6b.2 Mode of delivery

6b.3 Birthweight

6b.4 Sex of infant

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
OR Tick if still in neonatal unit
OR Tick if admitted to another hospital

6b.8 Did any other major infant complications occur?  
Yes [ ]  No [ ]
If Yes, please specify:

6b.9 Did this infant die?  
Yes [ ]  No [ ]
If Yes, please specify date and time 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 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: ____________ ____________ ____________

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