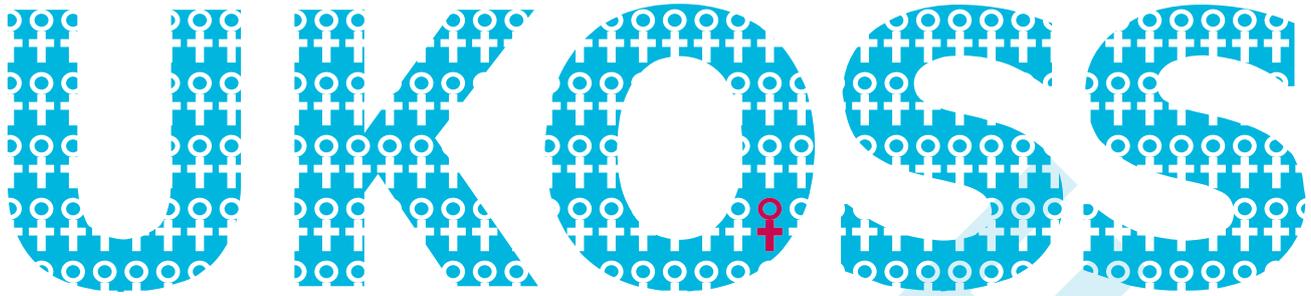


ID Number:



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

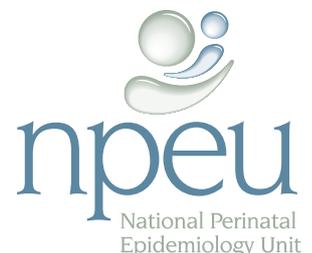


Royal College of
Obstetricians
and Gynaecologists

Bringing to life the best
in women's health care

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.

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 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: / /

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: / /

If no previous pregnancies, please go to section 3

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

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?

/ /

*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*} DD / MM / YY

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? DD / MM / YY

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

What date was this recorded? DD / MM / YY

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 many 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? DD / MM / YY

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 _____

Section 5: Delivery

5.1 Did this woman have a miscarriage?

Yes No

If Yes, please specify date

DD / MM / YY

5.2 Did this woman have a termination of pregnancy?

Yes No

If Yes, please specify date

DD / MM / YY

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?

DD / MM / YY

What was the date of discharge from HDU?

DD / MM / YY

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 / YY

What was the date of discharge from ITU?

DD / MM / YY

OR Tick if woman is still in ITU OR Tick if woman was transferred to another hospital

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

/ / :

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 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

/ / :

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

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
Mendelson'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