UKOSS

UK Obstetric Surveillance System

Pregnancy in women with known cardiomyopathy Study 02/21

Data Collection Form - CASE

Please report all pregnant women whose pregnancy ends on or after 1st June 2021 and before 31st May 2024

Case Definition:

Any pregnant woman with an established diagnosis of cardiomyopathy prior to pregnancy (including dilated cardiomyopathy, hypertrophic cardiomyopathy, previous peripartum cardiomyopathy and arrhythmogenic right ventricular cardiomyopathy (ARVC)).

Case ID Number: | | | | | | |

Royal College of Obstetricians and Gynaecologists

Bringing to life the best in women's health care

Please return the completed form to:

ukoss@npeu.ox.ac.uk

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

Phone: 01865 617764 / 617774

Reporting Period: _____

Reporting Hospital: _____

NPEU

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 table provided 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 ☐

Section 2: Previous Obstetric History

2.1 Gravidity

Number of previous completed pregnancies beyond 24 weeks ☐☐

Number of previous 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 _____

*For guidance please see back cover

Section 3: Previous Medical History

3.1 Did the woman have a prior pregnancy complicated by peripartum cardiomyopathy (PPCM)? Yes ☐ No ☐

If Yes,

What was the date of first diagnosis? D D / M M / Y Y

What was the lowest ejection fraction (EF) on echocardiogram in that pregnancy? ☐☐☐ **%** or tick if not known ☐

What was the pro-BNP (pro- beta natriuretic peptide) in that pregnancy?

☐☐ pg/mL or tick if not known ☐

Was the pregnancy a twin/multifetal pregnancy? Yes ☐ No ☐ Not known ☐

Was a diagnosis of pre-eclampsia made in that pregnancy? Yes ☐ No ☐ Not known ☐

Was a diagnosis of gestational hypertension made in that pregnancy?

Yes ☐ No ☐ Not known ☐

Was the diagnosis made antenatally? Yes ☐ No ☐

If Yes, at what gestation? ☐☐ weeks ***OR*** tick if not known ☐

Was the diagnosis made postnatally? Yes ☐ No ☐

If Yes, how many weeks postnatally? ☐☐ weeks ***OR*** tick if not known ☐

Did the women receive bromocriptine for management of PPCM?

Yes ☐ No ☐ Not known ☐

3.2 Did the woman have a known history of hypertrophic cardiomyopathy (HCM)? Yes ☐ No ☐

If Yes,

What was the most recent septal wall thickness on echocardiography prior to pregnancy? ☐☐ mm ***OR*** tick if not known ☐

Was there documented left ventricular outflow tract obstruction?

Yes ☐ No ☐ Not known ☐

Had the woman undergone septal myectomy prior to pregnancy?

Yes ☐ No ☐ Not known ☐

3.3 Did the woman have arrhythmogenic right ventricular cardiomyopathy (ARVC)?

Yes ☐ No ☐

3.4 Did the woman have dilated cardiomyopathy (DCM)? Yes ☐ No ☐

3.5 Did the woman have any other cardiomyopathy not specified above? Yes ☐ No ☐

If Yes, please specify _____

3.6 Was the woman receiving ongoing cardiology review prior to pregnancy?

Yes ☐ No ☐ Not known ☐

3.7 Did the woman receive documented pre-pregnancy counselling?

Yes ☐ No ☐ Not documented ☐

3.8 Did the woman have any other pre-existing medical problems?[3]*

If Yes, please give details _____

3.9 **What was the woman's New York Heart class prior to pregnancy[4]*?** *(please tick one)*

I ☐ II ☐ III ☐ IV ☐

3.10 **Was the woman prescribed any of the following types of medication prior to pregnancy?** *(tick all that apply)*

Beta-blockers (e.g Bisoprolol/Atenolol) ☐
Diuretics (e.g Frusemide) ☐
Angiotensin receptor inhibitors (e.g Losartan, Candesartan) ☐
Angiotensin converting enzyme blockers (e.g Enalapril/Captopril) ☐
Anticoagulants (e.g warfarin, low molecular weight heparin (e.g dalteparin), Rivaroxaban) ☐

If she was prescribed an anticoagulant, please specify which _____

_____

Section 4: This Pregnancy

4.1 **Final Estimated Date of Delivery (EDD)[5]*** D D / M M / Y Y

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

If Yes, specify number of fetuses ☐

4.3 **Were any of the following signs of heart failure noted at booking?** *(tick all that apply)*

Shortness of breath ☐ Tachycardia (defined as resting heart rate > 100bpm) ☐
Peripheral oedema ☐ Chest pain ☐ None of these ☐

4.4 **Did any of the following complications occur during pregnancy?** Yes ☐ No ☐

If Yes, tick all that apply and indicate date and type if applicable

	Tick if Yes	Date	Type/location
Arrhythmia	☐	D D / M M / Y Y	_____
Heart Failure	☐	D D / M M / Y Y	N/A
Thrombosis	☐	D D / M M / Y Y	_____
Stroke/TIA	☐	D D / M M / Y Y	_____

4.5 **Was the woman admitted to hospital during pregnancy for any other reason?** Yes ☐ No ☐

If Yes, please specify reason for admission _____

Regarding the mother's pattern of care during pregnancy

4.6 **Which of following best describes the pattern of care this woman received in pregnancy?** *(please tick one)*

Referred to a tertiary centre for an opinion but care continued in local hospital ☐
Care transferred to a tertiary centre which took over the remainder of the pregnancy ☐
Tertiary centre care throughout ☐

*For guidance please see back cover

4.7 **Did the woman have echocardiography performed during pregnancy?** Yes ☐ No ☐

If Yes, please complete details below (continue in section 7 if necessary)

Date	Estimated left ventricular ejection fraction (%)	Tick if not recorded
D D / M M / Y Y		☐
D D / M M / Y Y		☐
D D / M M / Y Y		☐

4.8 **Did the woman have a fetal echocardiogram?** Yes ☐ No ☐

4.9 **Was the fetus affected by cardiac disease?** Yes ☐ No ☐ Unclear ☐

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

If Yes to 5.1 or 5.2, please 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 from your hospital? Yes ☐ No ☐

If No, please indicate name of hospital providing future care

_____

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

If No, please indicate name of delivery hospital, then *go to section 7*.

_____

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

If Yes, please state indication _____

Was vaginal prostaglandin used? Yes ☐ No ☐

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

5.6 **Did the woman have a caesarean section?** Yes ☐ No ☐

If Yes, please state:

Grade of urgency[6]* ☐

Indication for caesarean section _____

Method of anaesthesia: CSE ☐ Spinal ☐ Epidural ☐ General anaesthetic ☐

If general anaesthesia was used please give indication _____

5.7 **Did the woman have any of the following invasive monitoring during labour or delivery?** *(tick all that apply)*

Arterial Line ☐ Central Line (e.g neck line) ☐ No invasive monitoring ☐

5.8 **What was the estimated blood loss at delivery?** ☐☐☐☐ mls

5.9 Were any of the following medications used in the third stage of labour or to treat postpartum haemorrhage? Yes ☐ No ☐

If Yes, tick all that apply and indicate dose and route if appropriate

	Tick if Yes	Dose	Route
Syntocinon	☐		
Carbetocin	☐		
Syntometrine	☐		
Ergometrine	☐		
Misoprostol	☐		
Carbeprost	☐		

Section 6: Outcomes

Section 6a: Woman

6a.1 Was the woman admitted to ITU Level 3 critical care? Yes ☐ No ☐

If Yes, please specify

Duration of stay ☐☐ days

Or Tick if woman is still in Level 3 critical care ☐

Or Tick if woman was transferred to another hospital ☐

6a.2 Was the woman admitted to HDU Level 2 critical care? Yes ☐ No ☐

If Yes, was this: *(please tick one)* Obstetric HDU ☐ Other HDU ☐

Duration of stay ☐☐ days

Or Tick if woman is still in HDU Level 2 critical care ☐

Or Tick if woman was transferred to another hospital ☐

6a.3 Did the woman have any of the following complications after delivery? Yes ☐ No ☐

If Yes, tick all that apply and indicate dose and route if appropriate

	Tick if Yes	Date	Type/location
Arrhythmia	☐	D D / M M / Y Y	
Heart Failure	☐	D D / M M / Y Y	N/A
Thrombosis	☐	D D / M M / Y Y	
Stroke/TIA	☐	D D / M M / Y Y	

6a.4 Did any other major maternal morbidity occur?[7]* Yes ☐ No ☐

If Yes, please specify _____

6a.5 Did the woman initiate breastfeeding? Yes ☐ No ☐ Unsure ☐

6a.6 **Were any of the following medications prescribed following delivery?** *(tick all that apply)*

Beta-blocker ☐ Angiotensin Receptor-inhibitor ☐ Diuretics ☐

Angiotensin Receptor Blocker ☐ Bromocriptine ☐ None of these ☐

6a.7 **Was an echocardiogram performed after delivery and prior to discharge?** Yes ☐ No ☐

If Yes, what was the estimated ejection fraction? ☐☐☐ **%** ***OR*** tick if not known ☐

6a.8 **Was medical thromboprophylaxis given postpartum?** Yes ☐ No ☐

If Yes, for how long postpartum was it planned to be given? ☐☐ days

6a.9 **Was the woman given contraceptive advice prior to discharge?** Yes ☐ No ☐

If Yes, was contraception provided? Yes ☐ No ☐

If Yes, please specify type of contraception provided _____

6a.10 **What date was the woman discharged after giving birth?** D D / M M / Y Y

6a.11 **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) _____

Was a post mortem examination undertaken? Yes ☐ No ☐

If Yes, did the examination confirm the certified cause of death?

Yes ☐ No ☐ 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 ☐ Ventouse ☐

Forceps ☐ Breech ☐

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 ☐

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

If Yes, please specify _____

6b.9 **Did this infant die?** Yes ☐ No ☐

*For guidance please see back cover

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

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

Section 8:

Name of person completing the form _____

Designation _____

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.

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
HIV

4. New York Heart Classification:

Grade 1- No limitation physical activity
Grade 2 Slight limitation of physical activity
Grade 3 Marked limitation of physical activity
Grade 4 Unable to carry out any physical activity without discomfort.

5. Estimated date of delivery (EDD):

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

6. 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

7. Major maternal medical complications, including:

Persistent vegetative state
Cardiac arrest
Cerebrovascular accident
Adult respiratory distress syndrome
Disseminated intravascular coagulopathy
HELLP
Pulmonary oedema
Secondary infection e.g.pneumonia
Renal failure
Thrombotic event
Septicaemia
Required ventilation

8. 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