ID Number:

UKOSS

UK Obstetric Surveillance System

Fontan in pregnancy

Study 01/19

Data Collection Form - CASE

Please report any woman delivering on or after the 01/01/19 and before 31/05/22

Case Definition:

All women with prior Fontan repair who have a pregnancy, regardless of outcome.

Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.
2. Fill in the form using the information available in the woman's case notes.
3. If the woman has received secondary mental health care (prior to or during her current pregnancy) please consult with the woman's most recent psychiatric team to complete this form. If you are unable to contact a psychiatrist involved in the woman's care please contact the UKOSS administrator and provide details of the mental health team she was receiving care from.
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 you do not know the answers to some questions, please indicate this in section 7
8. 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.
9. If you do not know the answers to some questions, please indicate this in section 7.
10. If you encounter any problems with completing the form please contact the UKOSS coordinator or use the space in section 10 to describe the problem.

Royal College of Obstetricians and Gynaecologists

Bringing to life the best in women's health care

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: _____

NPEU

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 **What is the woman's smoking status?**

Never ☐ Current ☐ Gave up prior to pregnancy ☐ Gave up during pregnancy ☐

Section 2: Previous Obstetric History

2.1 **Gravidity**

Number of completed pregnancies beyond 24 weeks: ☐☐

Number of pregnancies less than 24 weeks: ☐☐

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

Please note you may find it helpful to consult with the woman's cardiologist/obstetric physician/ maternal medicine specialist for completion of this section

3.1 **What was the underlying defect that led to Fontan repair?** *(please tick one)*

Tricuspid Atresia ☐ Pulmonary atresia with intact ventricular septum ☐

Hypoplastic left heart ☐ Double inlet ventricle ☐ Not known ☐ Other ☐

If Other, please specify _____

3.2 **When was the repair first performed?** D D / M M / Y Y

3.3 **What type of Fontan repair was performed?** *(please tick one)*

AP Fontan ☐ Lateral Tunnel Fontan ☐ TCPC Fontan ☐ Other ☐

If Other, please specify _____

3.4 **What was the woman's functional class prior to pregnancy?** *(please tick one)*

NYHA I ☐ NYHA II ☐ NYHA III ☐ NYHA IV ☐

3.5 **Did the Fontan repair still have a fenestration?** Yes ☐ No ☐ Not known ☐

3.6 Did the woman have any of the following complications prior to her current pregnancy? *(please tick all that apply)*

	Outside of pregnancy	In a previous pregnancy
Heart failure	☐	☐
Arrhythmia (atrial or ventricular)	☐	☐
DVT	☐	☐
Pulmonary embolism	☐	☐
Stroke	☐	☐
Antepartum haemorrhage	N/A	☐

3.7 Was the woman prescribed any form of anticoagulation immediately prior to this pregnancy? *(please tick one)*

Aspirin ☐ LMWH prophylactic dose ☐ LWMH treatment dose ☐ Warfarin ☐ None ☐

Novel oral anticoagulants (NOACs) ☐ Other ☐ **If Other,** please specify _____

3.8 What was the woman's ventricular function prior to pregnancy? *(please tick one)*

Normal ☐ Mild impairment ☐ Moderate impairment ☐ Severe impairment ☐

3.9 Did the woman have liver fibrosis on ultrasound scan? Yes ☐ No ☐ Not known ☐

3.10 What was the woman's oxygen saturation prior to pregnancy? ☐☐ % or tick if not known ☐

3.11 Did the woman receive pre-pregnancy counselling? Yes ☐ No ☐ Not known ☐

3.12 Did the woman have exercise testing prior to pregnancy? Yes ☐ No ☐ Not known ☐

3.13 Was the woman prescribed any other cardiac medications prior to pregnancy? *(please tick all that apply)* None ☐ Beta blockers ☐ Diuretics ☐ Other ☐

If Other, please specify _____

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

If Yes, please give details: _____

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 Was this pregnancy a spontaneous conception? Yes ☐ No ☐

4.4 How was pregnancy managed with regard to antiplatelet agents or anticoagulants (please indicate one option only and date commenced)?

	Date commenced
Aspirin Only	D D / M M / Y Y
Aspirin and LMWH prophylactic dose	D D / M M / Y Y
LMWH prophylactic dose only	D D / M M / Y Y
LMWH treatment dose	D D / M M / Y Y
LMWH treatment dose and Aspirin	D D / M M / Y Y
Warfarin	D D / M M / Y Y

4.5 **Did the woman have monitoring of Factor Xa levels or INR checks?**

Yes ☐ No ☐ Not applicable (not on heparin or warfarin) ☐

4.6 **Did the woman have any of the following complications during pregnancy (tick all that apply and indicate management used)?**

Complication		Management - tick all that apply	Date first occurred
Heart failure	☐	Betablocker ☐ Diuretics ☐ Bedrest ☐	D D / M M / Y Y
Arrhythmia-Atrial or Ventricular	☐	Betablockers ☐ Cardioversion ☐ Other antiarrhythmic agents ☐	D D / M M / Y Y
Thrombosis or Thrombotic Stroke	☐	LMWH ☐ Thrombolysis ☐	D D / M M / Y Y
Antepartum Haemorrhage	☐	Stopped Aspirin ☐ Stopped other anticoagulants ☐	D D / M M / Y Y
Liver Dysfunction	☐	N/A	D D / M M / Y Y

4.7 **Did the woman have a fetal echocardiogram in pregnancy?** Yes ☐ No ☐

If Yes, how many? ☐☐

4.8 **How many scans did the woman have other than her dating scan and anomaly scan?** *(If none, please enter zero)* ☐☐

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

If Yes, please specify: _____

4.10 **Please describe the pattern of antenatal care this woman received** *(please tick one)*

Midwife Led ☐ Consultant Led Care ☐ Joint Care with Cardiologist in combined clinic ☐

Joint Care with Cardiologist in different clinic located on the same site ☐

Joint Care with Cardiologist in different clinic located on a different site ☐

Care transferred to tertiary centre ☐

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

What type of termination of pregnancy did she have? Medical ☐ Surgical ☐

If surgical, where was this carried out (please tick one)?

The women's local hospital ☐ A specialist centre ☐

If Yes to 5.1 or 5.2, please go to 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 Did the woman have an individualised cardiac/obstetric/anaesthetic care plan for the management of labour? Yes ☐ No ☐

5.5 What was the planned mode of delivery? *(please tick one)* Vaginal ☐ Caesarean section ☐

5.6 Was delivery induced? Yes ☐ No ☐

If Yes, please state indication: _____

Was vaginal prostaglandin used? Yes ☐ No ☐

5.7 Did the woman labour? Yes ☐ No ☐

If Yes, was the labour augmented? Yes ☐ No ☐

Did the woman have an epidural? Yes ☐ No ☐

Did the woman have an imposed shortened second stage?
Yes ☐ No ☐ Not applicable (did not reach second stage) ☐

Was there active management of the third stage of labour?
Yes ☐ No ☐ Not applicable (did not reach third stage) ☐

If Yes, which uterotonic was used? _____

5.8 Was delivery by caesarean section? Yes ☐ No ☐

If Yes, please state:

Grade of urgency:[5]* ☐

Indication for caesarean section: _____

Method of anaesthesia: Regional ☐ General anaesthetic ☐

Did this differ to the planned method of anaesthesia? Yes ☐ No ☐

5.9 Did the woman stop anticoagulation prior to delivery?
Yes ☐ No ☐ Not applicable (not on anticoagulation) ☐

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

5.11 Did the woman have a PPH? (Blood loss ≥500ml) Yes ☐ No ☐

If Yes, which of the following managements were used *(please tick all that apply)*

Manual compression ☐ Syntocinon bolus dose ☐ Syntometrine ☐

Syntocinon infusion ☐ Haemobate ☐ Ergometrine ☐ Misoprostol ☐

Intrauterine balloon ☐ Brace sutures ☐ Other ☐

If Other, please specify _____

5.12 Which of the following best describes how postpartum thromboprophylaxis/anticoagulation was managed? *(please tick one)*

LMWH prophylactic dose only ☐ LMWH treatment dose ☐

LMWH treatment dose initially then Warfarin commenced ☐ Other ☐

If Other, please specify _____

5.13 What was the planned duration of thromboprophylaxis/anticoagulation? *(please tick one)*

10days ☐ 6 weeks ☐ Ongoing (Indefinite) ☐ Other ☐

If Other, please specify _____

5.14 Did the woman have echocardiography prior to discharge or up until 3 months postpartum?

Yes ☐ No ☐ Planned but not yet carried out ☐

If Yes, what was the ventricular function as assessed by Echo *(please tick one)*?

Normal ☐ Mild impairment ☐ Moderate impairment ☐ Severe impairment ☐

5.15 Was the woman advised about contraception prior to discharge? Yes ☐ No ☐

If Yes, was she discharged with any contraceptive methods *(please tick one)*?

Oral contraceptive ☐ Copper coil fitted ☐ Mirena fitted ☐ Nexplanon fitted ☐

Depo administered ☐ None ☐

Local systems do not allow hospital supply of postnatal contraception ☐

Section 6: Outcomes

Section 6a: Woman

6a.1 Did the woman receive level 2 critical care (on HTU, obstetric ward or elsewhere)? Yes ☐ No ☐

6a.2 Did the woman receive level 3 critical care (on ITU or elsewhere)? Yes ☐ No ☐

If Yes, duration of stay: ☐☐ *days*

OR Tick if woman is still in ITU (critical care level 3): ☐

OR Tick if woman was transferred to another hospital: ☐

6a.3 Did any other major maternal morbidity occur?[6]* Yes ☐ No ☐

If Yes, please specify: _____

6a.4 Was the woman readmitted to hospital following delivery? Yes ☐ No ☐

If Yes, please state indication for readmission: _____

Where was she readmitted? (please tick one) Obstetric unit ☐ Cardiology ward ☐ Other ☐

6a.5 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 ☐ Vaginal 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 ☐

If Yes, please specify indication _____

6b.8 Did the infant have a congenital heart defect? Yes ☐ No ☐

6b.9 Did any major infant complications occur?[7]* Yes ☐ No ☐

If Yes, please specify _____

6b.10 Did this infant die? Yes ☐ No ☐

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: Further information

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

Section 8: Your details

8.1 Name of UKOSS representative 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.

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. 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, meningitis
Exchange transfusion