ID Number:

UKOSS

UK Obstetric Surveillance System

Pregnancy following bone marrow transplantation
Study 02/20

Data Collection Form - CASE

Please report all women who give birth or whose pregnancy ends between 01/01/2020 and 31/12/2022

Case Definition:

Please report any woman who has a pregnancy following bone marrow transplantation, with or without total body irradiation. Please report all women with a pregnancy, irrespective of the pregnancy outcome (e.g. miscarriage, termination, stillbirth, live birth).

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.
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.

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 **BMI at booking:** ☐☐.☐

1.8 **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

3.1 **Bone marrow transplant details**

What year was the most recent bone marrow transplant undertaken? Y Y Y Y

In which centre did the woman receive the transplant? _____

Did the woman receive total body irradiation? Yes ☐ No ☐ Not known ☐

If Yes, please state dose of irradiation ☐☐ ***or*** tick if not known ☐

3.2 **What was the indication for bone marrow transplant** *(please tick one)***?**

Acute lymphoblastic leukaemia ☐ Acute myeloid leukaemia ☐ Lymphoma ☐

Aplastic anaemia ☐ Non-malignant haematology *(eg sickle cell)* ☐

Immunodeficiency ☐ Other ☐ **If Other,** please specify: _____

3.3 **Did the woman receive pre-pregnancy medical advice?** Yes ☐ No ☐ Not known ☐

If Yes, from whom? *(please tick all that apply)*

Maternal fetal specialist obstetrician ☐ General obstetrician ☐ Obstetric physician ☐

Haematologist or oncologist or cancer care nurse ☐ Other ☐

If Other, please specify: _____

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

Cardiac function impaired — Yes ☐ No ☐

Renal function impaired — Yes ☐ No ☐

Lung function impaired — Yes ☐ No ☐

Hypertension — Yes ☐ No ☐

Hypothyroidism — Yes ☐ No ☐

Ovarian failure — Yes ☐ No ☐

Other — Yes ☐ No ☐

If Other, please specify: _____

Section 4:

Section 4a: This pregnancy

4a.1 Type of conception

Was this a natural conception? Yes ☐ No ☐ Not known ☐

Was this an IVF/ICSI pregnancy? Yes ☐ No ☐ Not known ☐

If Yes, did she use own eggs or donor eggs? Own ☐ Donor ☐

If Yes, did she receive treatment in the UK or overseas? UK ☐ Overseas ☐

Please give name of clinic if known: _____

4a.2 Was this a multiple pregnancy? Yes ☐ No ☐

If Yes, please specify number of fetuses ☐☐

4a.3 What was the final Estimated Date of Delivery (EDD)?[4]* D D / M M / Y Y

Section 4b: Antenatal care

4b.1 What specialties were involved in the woman's care during the antenatal period? *(please tick all that apply)*

Obstetrician ☐ Maternal fetal specialist service ☐ Preterm birth specialist service ☐

Obstetric physician ☐ Anaesthetist ☐ Neonatologist ☐

Oncologist or cancer care nurse ☐ Haematologist ☐ Other ☐

If Other, please specify: _____

4b.2 Investigations

Did the woman have an echocardiogram in pregnancy? Yes ☐ No ☐

Were serial growth scans performed? Yes ☐ No ☐

4b.3 Medication

Was the woman taking any regular medications during pregnancy? *(please tick all that apply)*

Prophylactic antibiotic eg penicillin ☐ Aspirin 75 or 150 mg daily ☐

Low molecular weight heparin ☐ Iron supplementation (ferrous sulphate/ fumarate) ☐

Hormone replacement therapy ☐ Other ☐

If Other, (please specify drug, frequency and dose) _____

4b.4 Were there other problems in this pregnancy?[2]* Yes ☐ No ☐

If Yes, please specify: _____

Section 4c: Preterm birth surveillance

4c.1 Was this woman assessed in a high-risk preterm birth prevention service?

Yes ☐ No ☐ Not available ☐

4c.2 Did she have a uterine anomaly identified? Yes ☐ No ☐ Not known ☐

If Yes, please describe: _____

4c.3 Did she undergo transvaginal cervical length scans? Yes ☐ No ☐

If Yes, please specify shortest cervical length measurement ☐☐☐ *cm*

and date measured D D / M M / Y Y

4c.4 Did she receive any preterm birth prevention interventions? Yes ☐ No ☐

If Yes, please specify type of intervention: *(please tick all that apply)*

- Progesterone supplementation ☐
- "Arabin" cervical pessary ☐
- Cervical cerclage:
  - Vaginal low "Macdonald" ☐
  - Vaginal high "Shirodkar" ☐
  - Abdominal open pre-pregnancy ☐
  - Abdominal open during pregnancy ☐
  - Laparoscopic abdominal pre-pregnancy ☐

Was intervention elective or in response to cervical shortening? _____

Date of first intervention D D / M M / Y Y

4c.5 Were corticosteroids administered for fetal lung maturation? Yes ☐ No ☐

Section 5: Pregnancy outcome

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

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

If Yes to 5.1, please go to sections 6a, 7 and 8

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 5.2, please go to sections 6a, 7 and 8

5.3 Is this woman still undelivered? Yes ☐ No ☐

If Yes, will she receive the rest of her antenatal care from your hospital? Yes ☐ No ☐

If not your hospital, please give name of hospital providing future care:

_____

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

If not your hospital, please give name of delivery hospital

_____

If Yes to 5.3, please go to sections 6a, 7 and 8

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 ☐

If Yes, date and time of labour onset D D / M M / Y Y h h : m m (24hr)

Augmentation? Yes ☐ No ☐

5.6 Was delivery by caesarean section? Yes ☐ No ☐

If Yes, please state grade of urgency: ☐

Indication for caesarean section: _____

Method of anesthesia Regional ☐ General ☐

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

5.8 Did the woman receive blood products? *(tick all that apply)*

Yes – donated blood ☐ Yes – cell salvage blood ☐ No ☐

If Yes, was the blood irradiated? Yes ☐ No ☐ Not known ☐

Section 6: Outcomes

Section 6a: Woman

6a.1 Was the woman admitted to ITU (critical care level 3)? 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.2 Did any other major maternal morbidity occur?[6*] Yes ☐ No ☐

6a.3 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/diagnosis?

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 Did the infant have any congenital anomalies? Yes ☐ No ☐

If Yes, please specify: _____

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

If Yes, was this? Antenatal ☐ Intrapartum ☐

If Yes, *please go to section 7*

6b.7 5 min Apgar ☐☐

6b.8 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

If Yes, what was the indication? _____

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

If Yes, please specify _____

6b.10 Was breastfeeding initiated? Yes ☐ No ☐

6b.11 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:

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

_____

_____

Section 8:

8.1 What is the name and unit of the most recent lead haematologist, present or past:

Name: _____

Unit: _____

8.2 Name of person completing the form: _____

8.3 Designation: _____

8.4 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.

Section 9: Haematology Details

Please complete as much of the following sections as you are able to, in consultation with the woman's clinical haematologist if necessary

Diagnosis

9.1 What was the underlying condition leading to bone marrow transplant?

_____

9.2 What year was this condition diagnosed? Y Y Y Y

Therapy

9.3 What year did the woman undergo first bone marrow transplantation and what was her age at transplant? Y Y Y Y

9.4 Pubertal status at transplant:

Pre-pubertal ☐ Peri -pubertal ☐ Post-puberty ☐ Not known ☐

Had she started periods by the time of transplant? Yes ☐ No ☐

9.5 What conditioning treatment did the woman undergo prior to transplant?

_____

Did this include total body irradiation? Yes ☐ No ☐

9.6 Did she have GVHD (graft-versus-host disease)? Yes ☐ No ☐

If Yes, grade? ☐☐

Which organ(s) were affected? Liver ☐ Skin ☐ Gut ☐ Other ☐

If Other, please specify: _____

Section 10:

10.1 Name of person completing the haematology form:

_____

10.2 Designation: _____

10.3 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
Pre-eclampsia
Eclampsia
3 or more miscarriages
Prolonged premature rupture of membranes (PPROM)
Preterm birth (24-37 weeks gestation)
Mid trimester loss (<24 weeks gestation)
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:

Neutropenic sepsis
Heart failure
Pancytopenia
Cardiomyopathy
Uncontrolled emesis
Spontaneous preterm delivery
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:

Fetal growth restriction (EFW or AC <3rd gestation specific centile)
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