



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 31/12/2021

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).

Case ID Number:

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@npeu.ox.ac.uk

UKOSS

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

Phone: 01865 617764 / 617774

Reporting Month: _____

Reporting Hospital: _____



NPEU

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 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?
- 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*} / /

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
and date measured

cm

/ /

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

/ /

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:

/ /

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:

/ /

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

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: / / : ^{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 / /

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: / /

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?

Therapy

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

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:

/ /

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
Mendelson'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