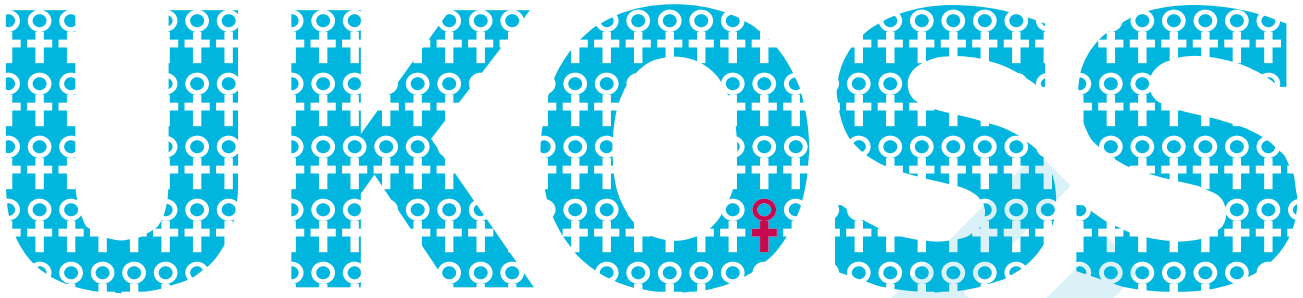


ID Number:



UK Obstetric Surveillance System

Myeloproliferative Disorders Study 01/10

Data Collection Form - CASE

Please report any woman delivering on or after 1st January 2010
and before 1st January 2013.

Case Definition:

All pregnant women identified as having:

- Either** a myeloproliferative disorder (essential thrombocythaemia, polycythaemia vera, myelofibrosis), diagnosed by a consultant haematologist according to WHO guidelines
- Or** a thrombocytosis (platelet count persistently greater than $600 \times 10^9/l$ on two consecutive occasions)
- Or** an erythrocytosis (haemoglobin persistently greater than 16.5g/dl in the absence of bleeding or sepsis)

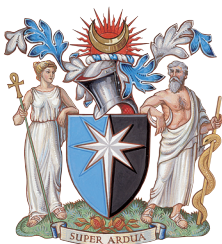
Please return the completed form to:

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

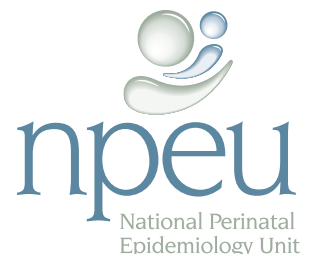
Fax: 01865 289701

Phone: 01865 289714

Case reported in: _____



Royal College of
Obstetricians and
Gynaecologists



*For guidance please see back cover

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

 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

current

never gave up prior to pregnancy

gave up during pregnancy

Section 2: Previous Obstetric History

2.1 Gravity

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 previous pregnancy problems?^{2*}

Yes No

If Yes, please specify _____

Section 3

Section 3a: Previous Medical History

Please indicate whether any of the following were present:

3a.1 Essential hypertension

Yes No

3a.2 Hyperlipidaemia

Yes No Not known

3a.3 Diabetes mellitus

Yes No

If Yes, please state type

Type 1 Type 2 Not known

3a.4 Thrombophilia^{3*}

Yes No Not known

If Yes, please specify details _____

3a.5 Did this woman have any thromboembolic events prior to the current pregnancy?

Yes No

If Yes, please give dates of event(s)

Event 1 / /

Event 2 / /

3a.6 Did this woman have any haemorrhagic events prior to the current pregnancy?

Yes No

If Yes,

Please specify site

Was a transfusion required?

Yes No

Yes No

Yes No

3a.7 History of peripheral vascular disease

Yes No

3a.8 History of ischaemic heart disease (include angiography/angioplasty)

Yes No

3a.9 Did the woman have any other pre-existing medical problems?^{4*}

Yes No

If Yes, please give details _____

Section 3b: Diagnosis of MPD

3b.1 What type of myeloproliferative disorder does the woman have?

- Essential thrombocythaemia
- Polycythaemia vera
- Myelofibrosis
- Thrombocytosis
- Erythrocytosis

3b.2 Date of Diagnosis

/ /

3b.3 Please give details of full blood counts taken 6 weeks apart

	Blood Count 1	Blood Count 2
Date	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
WCC	<input type="text"/> <input type="text"/> . <input type="text"/>	<input type="text"/> <input type="text"/> . <input type="text"/>
Neut	<input type="text"/> . <input type="text"/>	<input type="text"/> . <input type="text"/>
HB	<input type="text"/> <input type="text"/> . <input type="text"/>	<input type="text"/> <input type="text"/> . <input type="text"/>
HCT/PCV (%)	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
MCV	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>
Plt	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

3b.4 Please indicate whether any of the following therapies were used

Drug name	Prior to pregnancy	During pregnancy	Max dose	Date Stopped
Aspirin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/>	
LMW Heparin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/>	
Interferon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/>	
Hydroxyurea/ Hydroxycarbamide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
Anagrelide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>

3b.5 Was the woman seen by a haematologist?

Yes No

If Yes, please give name of hospital where the woman was seen and the name of the haematologist if known (*Please state if not known*)

3b.6 Does the woman have a JAK2 V617F mutation?

Yes No Not screened

Section 3c: Family history

3c.1 Is there a family history of a myeloproliferative disorder, familial thrombocytosis or erythrocytosis?

Yes No Not known

3c.2 Is there a family history of premature cardiovascular disease? (MI/Angina or TIA/stroke in a male relative less than 55 years or a female less than 65 years)

Yes No Not known

Section 4: This Pregnancy

4.1 Final Estimated Date of Delivery (EDD)^{5*}

/ /

4.2 Was this a multiple pregnancy?

Yes No

If Yes, please specify number of fetuses

4.3 Were there any other problems in this pregnancy?^{2*}

Yes No

If Yes, please specify _____

4.4 What was the woman's blood pressure at booking?

Systolic Diastolic

4.5 Was eclampsia/pre-eclampsia diagnosed in this pregnancy?

Yes No

4.6 What was the highest recorded blood pressure this pregnancy?

Systolic

Date / /

Diastolic

Date / /

Section 5: Delivery

5.1 Did this woman have a miscarriage?

Yes No

If Yes, please specify date

/ /

5.2 Did this woman have a termination of pregnancy?

Yes No

If Yes, please specify date

/ /

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 Was delivery by caesarean section?

Yes No

If Yes, please state:

Grade of urgency^{6*}

Indication for caesarean section _____

Method of anaesthesia:

Regional General anaesthetic

Section 6: Outcomes

Section 6a: Woman

6a.1 Was the woman admitted to ITU?

Yes No

If Yes, duration of stay

 days

Or Tick if woman is still in ITU

Or Tick if woman was transferred to another hospital

6a.2 Did any other major maternal morbidity occur?^{7*}

Yes No

If Yes, please specify _____

6a.3 Was a thrombophilia diagnosed during or after this pregnancy?^{3*}

Yes No Not tested

If Yes, please specify diagnosis _____

6a.4 Did the woman 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.) _____

Was a post mortem examination undertaken?

Yes No

If Yes, did the examination confirm the diagnosis?

Yes No Not known

Section 6b: 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 Lift-out forceps Rotational forceps Breech Pre-labour caesarean section Caesarean section after onset of labour

6b.3 Birthweight

 g

6b.4 Was the infant stillborn?

Yes No

If Yes, please go to section 7.

6b.5 5 min Apgar

6b.6 Was the infant admitted to the neonatal unit?

Yes No

6b.7 Did any other major infant complications occur?^{8*}

Yes No

If Yes, please specify _____

6b.8 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.) _____

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:

3 or more miscarriages up to 12 weeks
Mid trimester loss 12-24 weeks
Late pregnancy loss after 24 weeks
Amniocentesis
Amniotic fluid embolism
Baby with a major congenital abnormality
Eclampsia
Gestational diabetes
Massive Haemorrhage
Hyperemesis requiring admission
Infant requiring intensive care
Neonatal death
Placenta praevia
Placental abruption
Post-partum haemorrhage requiring transfusion
Pre-eclampsia (hypertension and proteinuria)
Premature rupture of membranes
Preterm birth (24-37/40)
Puerperal psychosis
Severe infection e.g. pyelonephritis
Stillbirth
Stroke or TIA
Surgical procedure in pregnancy

3. Disorders with associated thrombophilia, including:

Anticardiolipin antibodies
Antiphospholipid syndrome
Antithrombin deficiency
Factor V Leiden
Gross varicose veins
Inflammatory disorders e.g. inflammatory bowel disease
Lupus anticoagulant

Other medical disorders e.g. nephrotic syndrome, cardiac disease
Paraplegia
Protein C deficiency
Protein S deficiency
Prothrombin gene variant
Sickle cell disease

4. Previous or pre-existing maternal medical problems, including :

Cardiac disease (congenital or acquired)
Diabetes
Epilepsy
Endocrine disorders e.g. hypo or hyperthyroidism
Essential hypertension
Haematological disorders
Inflammatory disorders e.g. inflammatory bowel disease
Psychiatric disorders
Renal disease
Polycystic Kidney Disease

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:

Adult respiratory distress syndrome
Cardiac arrest
Cerebrovascular accident
Disseminated intravascular coagulopathy
HELLP
Mendelson's syndrome
Persistent vegetative state
Renal failure
Required ventilation
Septicaemia
Thrombosis – arterial
Thrombosis - venous
Haemorrhage

8. Infant complications, including:

Chronic lung disease
Exchange transfusion
Intraventricular haemorrhage
Jaundice requiring phototherapy
Major congenital anomaly
Necrotising enterocolitis
Neonatal encephalopathy
Respiratory distress syndrome
Severe infection e.g. septicaemia, meningitis