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 x10^9/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

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

1.2 Ethnic group* (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 ☐
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 previous pregnancy problems?*
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
If Yes, please state type
Type 1 ☐ Type 2 ☐ Not known

3a.4 Thrombophilia*
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 DD/MM/YYYY
Event 2 DD/MM/YYYY

3a.6 Did this woman have any haemorrhagic events prior to the current pregnancy?
Yes ☐ No ☐
If Yes, please specify site

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?*
Yes ☐ No ☐
If Yes, please give details ________________________________

*For guidance please see back cover
**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

<table>
<thead>
<tr>
<th>Date</th>
<th>Blood Count 1</th>
<th>Blood Count 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD/MM/YYYY</td>
<td>DD/MM/YYYY</td>
</tr>
<tr>
<td>WCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neut</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HB</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HCT/PCV (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plt</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Drug name</th>
<th>Prior to pregnancy</th>
<th>During pregnancy</th>
<th>Max dose</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspirin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LMW Heparin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interferon</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hydroxyurea/ Hydroxycarbamide</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anagrelide</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**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

*For guidance please see back cover*
Section 4: This Pregnancy

4.1 Final Estimated Date of Delivery (EDD)*

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?*
   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 □□□□ 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 urgencyd*

   Indication for caesarean section

   Method of anaesthesia: Regional □ General anaesthetic □

*For guidance please see back cover
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?  
Yes ☐  No ☐  
If Yes, please specify ________________________________  

6a.3 Was a thrombophilia diagnosed during or after this pregnancy?  
Yes ☐  No ☐  Not tested ☐  
If Yes, please specify diagnosis ________________________________  

6a.4 Did the woman die?  
Yes ☐  No ☐  
If Yes, please specify date of death DD/MM/YYYY  
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  
DD/MM/YYYY HH:mm  

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?  
Yes ☐  No ☐  
If Yes, please specify ________________________________  

6b.8 Did this infant die?  
Yes ☐  No ☐  
If Yes, please specify date of death DD/MM/YYYY  
What was the primary cause of death as stated on the death certificate?  
(Please state if not known.) ________________________________  

*For guidance please see back cover
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

DD/MM/YY

You may find it useful in the case of queries to keep a copy of this form.

*For guidance please see back cover
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