Sickle Cell Disease in Pregnancy
Study 02/10

Data Collection Form - CASE

Please report women delivering on or after 1st February 2010
and before 1st February 2011

Case Definition:
Include women with:

Either homozygous sickle cell disease
Or compound heterozygous conditions of HbS with HbC, D, E, O-Arab or Beta thalassaemia (ie HbSC, HbSD, HbSE, HbS0-Arab, HbSBeta+thalassaemia and HbSBetathalassaemia

EXCLUDE:

Women with sickle cell trait

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

Case reported in: __________________________
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  current  gave up during pregnancy

1.8 Sickle genotype (tick only one)

HbSS  HbSE  HbSC  HbS0-Arab  HbSD  HbSβ+thalassaemia  HbSβ0thalassaemia

*For guidance please see back cover
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: Previous Medical History

Please indicate whether any of the following were present prior to pregnancy:

3.1 Essential hypertension
   Yes ☐ No ☐
3.2 Renal impairment
   Yes ☐ No ☐
3.3 Stroke or TIA
   Yes ☐ No ☐
3.4 Pulmonary hypertension
   Yes ☐ No ☐
3.5 Venous thromboembolism
   Yes ☐ No ☐
3.6 Known uterine fibroids
   Yes ☐ No ☐
3.7 Other pre-existing medical problem
   Yes ☐ No ☐
   If Yes, please specify ______________________________________

Section 4: This Pregnancy

Section 4a: Initial Booking Data

4a.1 Final Estimated Date of Delivery (EDD)**
   D D / M M / Y Y

4a.2 Was this pregnancy a multiple pregnancy?
   Yes ☐ No ☐
   If Yes, specify number of fetuses

4a.3 What was the haemoglobin at booking?
   g/dl

4a.4 What was the creatinine level at booking?
   μmol/l

Section 4b: Antenatal complications during the current pregnancy**

4b.1 Did the woman have any painful crises?
   Yes ☐ No ☐
   If Yes, please give:
   Number of mild crises
   Number of moderate crises
   Number of severe crises
   Number of extremely severe crises

*For guidance please see back cover
4b.2 Did the woman have an acute chest syndrome? Yes ☐ No ☐
If Yes, did it require a transfusion? Yes ☐ No ☐

4b.3 Did the woman have a gestational hypertensive disorder? Yes ☐ No ☐
If Yes, was this (please tick all that apply)
- Pregnancy induced hypertension ☐
- Pre-eclampsia ☐
- Eclampsia ☐

4b.4 Did the woman have any renal insufficiency? Yes ☐ No ☐
If Yes, please give peak creatinine level ☐ ☐ µmol/l

4b.5 Did the woman have a urinary tract infection? Yes ☐ No ☐

4b.6 Did the woman have an antepartum haemorrhage? Yes ☐ No ☐

4b.7 Did the woman have acute anaemia? Yes ☐ No ☐
If Yes, please state lowest Hb level ☐ ☐ g/dl
Did the woman receive a blood transfusion for this episode? Yes ☐ No ☐

4b.8 Did the woman have a DVT or pulmonary embolism? Yes ☐ No ☐

4b.9 Were there any other problems in this pregnancy? Yes ☐ No ☐
If Yes, please specify ________________________________

Section 4c: Antenatal medication and management

4c.1 Was the woman prescribed any of the following?

<table>
<thead>
<tr>
<th>Drug</th>
<th>Yes</th>
<th>No</th>
<th>Date prescribed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspirin</td>
<td>☐</td>
<td>☐</td>
<td>D M Y YMD</td>
</tr>
<tr>
<td>Heparin</td>
<td>☐</td>
<td>☐</td>
<td>D M Y YMD</td>
</tr>
<tr>
<td>Penicillin V</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Anthypertensives</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
</tbody>
</table>

4c.2 Did the woman have any antenatal blood transfusions? Yes ☐ No ☐ Refused ☐
If Yes, please complete table

<table>
<thead>
<tr>
<th>Date</th>
<th>Indication</th>
<th>Top-up/Manual exchange/Automated exchange</th>
</tr>
</thead>
<tbody>
<tr>
<td>D M Y YMD</td>
<td></td>
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<tr>
<td>D M Y YMD</td>
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<td>D M Y YMD</td>
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</tbody>
</table>

*For guidance please see back cover
### Section 5: Delivery

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did this woman have a miscarriage?</td>
<td></td>
<td></td>
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<tr>
<td>If Yes, please specify date</td>
<td></td>
<td></td>
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<tr>
<td>Did this woman have a termination of pregnancy?</td>
<td></td>
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<tr>
<td>If Yes, please specify date</td>
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<td></td>
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<tr>
<td>Is this woman still undelivered?</td>
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<tr>
<td>If Yes, will she be receiving the rest of her antenatal care from your hospital?</td>
<td></td>
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<tr>
<td>If No, please indicate name of hospital providing future care</td>
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<td></td>
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<tr>
<td>Will she be delivered at your hospital?</td>
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<tr>
<td>If No, please indicate name of delivery hospital, then go to Section 7</td>
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<tr>
<td>Was delivery induced?</td>
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<td></td>
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<tr>
<td>If Yes, please state indication</td>
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<tr>
<td>Was delivery by Caesarean section?</td>
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<tr>
<td>If Yes, please state:</td>
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<td></td>
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<tr>
<td>Grade of urgency*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indication for caesarean section</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Method of anaesthesia:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General anaesthetic</td>
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</tbody>
</table>
Section 6: Outcomes

Section 6a: Woman

6a.1 Was the woman admitted to ITU/HDU? Yes ☐ No ☐
  If Yes, duration of stay ☐ days
  Or Tick if woman is still in ITU/HDU ☐
  Or Tick if woman was transferred to another hospital ☐

6a.2 Did the woman have a postpartum haemorrhage?* Yes ☐ No ☐
  If Yes, what was the estimated blood loss? ☐ mls

6a.3 Did the woman have a post-natal DVT? Yes ☐ No ☐ Not known ☐

6a.4 Did the woman have a post-natal pulmonary embolism? Yes ☐ No ☐ Not known ☐

6a.5 Did the woman have a pain crisis within 6 weeks of delivery? Yes ☐ No ☐ Not known ☐

6a.6 Did any other major maternal complications occur?* Yes ☐ No ☐
  If Yes, please specify ________________________________

6a.7 Did the woman die? Yes ☐ No ☐
  If Yes, please specify date of death D / M / Y M D Y
  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: 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 / M / Y M D Y : h m

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 Was the infant still alive at 7 days? Yes ☐ No ☐ Not known ☐

*For guidance please see back cover
Section 7:
Please use this space to enter any other information you feel may be important

________________________________________________________________________
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Section 8:

8.1 Name of person completing the form

8.2 Designation

8.3 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:**
   - 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 – intra-uterine death after 24 weeks
   - Stroke or TIA
   - Surgical procedure in pregnancy

3. **Estimated date of delivery (EDD):**
   Use the best estimate (ultrasound scan or date of last menstrual period) based on a 40 week gestation

4. **Antenatal events**
   - Painful crisis: typical sickle-related bone pain of sufficient severity to require opiate analgesia
   - Mild crisis - may or may not have required pain medication, but did not prevent normal daily activities
   - Moderate crisis - required medications and caused significant changes in daily activities
   - Severe crisis - required attendance at hospital
   - Extremely severe crises - admitted to hospital
   - Acute chest syndrome: pulmonary symptoms and signs associated with a new pulmonary infiltrate on chest X-ray
   - Renal insufficiency – 20% increase in baseline creatinine or glomerular filtration rate <60ml/min
   - Urinary tract infection: urinary symptoms with positive urine culture, asymptomatic bacteruria and pyelonephritis
   - Antepartum haemorrhage
   - Acute anaemia – 30% decrease in baseline haemoglobin

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. **Postpartum haemorrhage**
   Estimated loss of 500ml or more during or following delivery or loss of 1000ml or more with caesarean delivery.

7. **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

8. **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