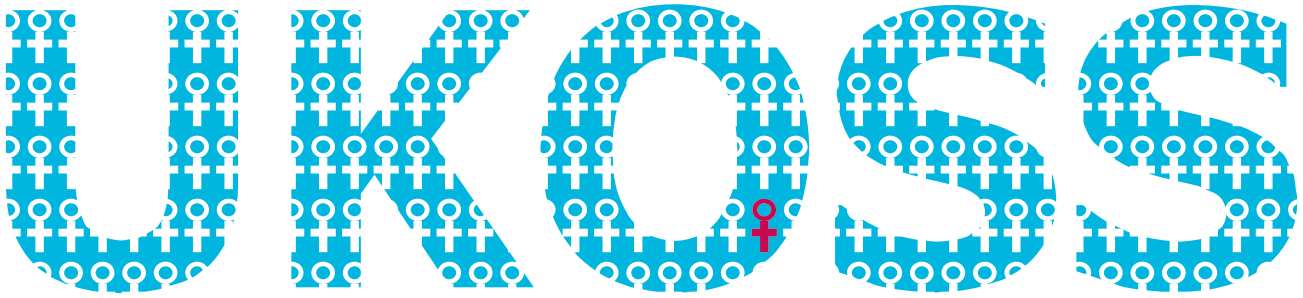


ID Number:



UK Obstetric Surveillance System

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 HbSBeta⁰thalassaemia)

EXCLUDE:

Women with sickle cell trait

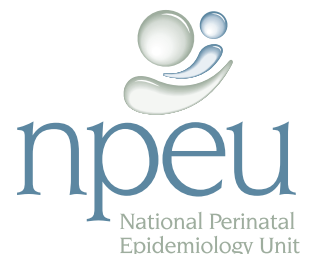
Please return the completed form to:

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

 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

never gave up prior to pregnancy
current gave up during pregnancy

1.8 Sickle genotype (tick only one)

HbSS HbSE
HbSC HbS0-Arab
HbSD HbS β ⁺thalassaemia
HbS β ⁰thalassaemia

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?^{2*}

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)^{3*}

/ /

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?

$\mu\text{mol/l}$

Section 4b: Antenatal complications during the current pregnancy^{4*}

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 | <input type="checkbox"/> |
| Pre-eclampsia | <input type="checkbox"/> |
| Eclampsia | <input type="checkbox"/> |
- 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?

	Yes	No	Date prescribed
Aspirin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
Heparin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>
Penicillin V	<input type="checkbox"/>	<input type="checkbox"/>	
Antihypertensives	<input type="checkbox"/>	<input type="checkbox"/>	

4c.2 Did the woman have any antenatal blood transfusions? Yes No Refused

If Yes, please complete table

Date	Indication	Top-up/ Manual exchange/ Automated exchange
<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"/>	_____	_____
<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	_____	_____
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<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"/>	_____	_____

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 _____

5.5 Was delivery by Caesarean section?

Yes No

If Yes, please state:

Grade of urgency^{5*}

Indication for caesarean section _____

Method of anaesthesia:

Regional

General anaesthetic

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?^{6*}** 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?^{7*}** Yes No
If Yes, please specify _____
- 6a.7 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 Was the infant still alive at 7 days?** Yes No Not known

6b.9 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 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
Mendelson'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