ID Number:

UKOSS

UK Obstetric Surveillance System

HELLP Syndrome
Study 02/11

Data Collection Form - CASE

Please report any woman presenting on or after the 1st June 2011 and before 1st June 2012.

Case Definition:

All pregnant women identified as having HELLP syndrome defined as **NEW ONSET** of the following:

1. **Elevated liver enzymes**, defined as:
   Serum aspartate aminotransferase (AST) ≥70 iu/L
   OR
   Gamma-glutamyltransferase (γ-GT) ≥70 iu/L
   OR
   Alanine aminotransferase (ALT) ≥70 iu/L
   AND
2. **Low platelets**, defined as platelet count < 100 x10^9/l
   AND
3. **EITHER**
   Haemolysis, defined by abnormal peripheral blood smear or serum lactate Dehydrogenase (LDH) levels ≥600 iu/L or total bilirubin ≥20.5 µmol/l
   OR
   Hypertension, defined as a systolic blood pressure ≥ 140 mmHg or a diastolic blood pressure ≥ 90 mmHg
   OR
   Proteinuria, defined as 1+ (0.3 g/l) or more on dipstick testing, a protein: creatinine ratio of 30 mg/mmol or more on a random sample, or a urine protein excretion of 300 mg or more per 24 hours

Royal College of Obstetricians and Gynaecologists

Please return the completed form to:

UKOSS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 617775
Phone: 01865 289714

Case reported in: _____

npeu National Perinatal Epidemiology Unit

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 and weight at booking: ☐☐☐ *cm* AND ☐☐☐.☐ *kg*

1.6 Smoking status: never ☐ gave up prior to pregnancy ☐
current ☐ 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 What was the date of delivery/termination/miscarriage in the most recent previous pregnancy: D D / M M / Y Y

2.3 Please indicate if any of the following were present in previous pregnancies: *(Please tick all that apply)*

Pregnancy induced hypertension (PIH) ☐ Pre-eclampsia ☐ Eclampsia ☐
HELLP syndrome ☐ Gestational diabetes ☐

2.4 Did the woman have any other previous pregnancy problems?[2]* Yes ☐ No ☐

If Yes, please specify: _____

*For guidance please see back cover

Section 3: Previous Medical History

3.1 **Did the woman have essential hypertension at booking or prior to pregnancy?** Yes ☐ No ☐

If Yes, was she receiving anti-hypertensive medication at booking or prior to pregnancy? Yes ☐ No ☐

3.2 **Does the women have pre-existing diabetes mellitus?** Type 1 ☐ Type 2 ☐ Neither ☐

3.3 **Did the women have any other previous or pre-existing medical problems?[3]*** Yes ☐ No ☐

If Yes, please specify: _____

Section 4:

Section 4a: This Pregnancy

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

4a.2 **Was this a multiple pregnancy?** Yes ☐ No ☐

If Yes, please specify number of fetuses: ☐

4a.3 **Date of booking:** D D / M M / Y Y

4a.4 **What was the platelet count at booking?** ☐☐☐ *x10⁹/L*

4a.5 **Was the woman diagnosed with any of the following in this pregnancy?**

	Yes	No	Date of diagnosis
Pregnancy induced hypertension (PIH)	☐	☐	D D / M M / Y Y
Pre-eclampsia	☐	☐	D D / M M / Y Y
Eclampsia	☐	☐	D D / M M / Y Y
Gestational diabetes	☐	☐	D D / M M / Y Y

4a.6 **What were the levels of the following in this pregnancy or tick if not recorded:**

	Tick if booking level not recorded	Level at booking	Tick if highest level not recorded	Highest Level	Date of highest level recorded
Systolic BP (mmHg)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
Diastolic BP (mmHg)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
Proteinuria *(please indicate units)*	☐	_____	☐	_____	D D / M M / Y Y

4a.7 **Were there any other problems in this pregnancy?[2]*** Yes ☐ No ☐

If Yes, please specify: _____

*For guidance please see back cover

Section 4b: Diagnosis and management of HELLP syndrome

4b.1 Date and time of diagnosis of HELLP syndrome: D D / M M / Y Y h h : m m (24hr)

4b.2 Please indicate which of the following signs/symptoms were noted prior to or at diagnosis:

Right upper abdominal quadrant or epigastric pain ☐ Nausea/vomiting ☐

Headache ☐ Visual changes ☐ Other ☐

If Other please specify: _____

4b.3 Please record the blood levels of the following at diagnosis and at their minimum level or tick if not recorded:

Marker	Tick if diagnosis level not recorded	Level at diagnosis	Tick if lowest level not recorded	Lowest recorded level	Date lowest level recorded
Platelet count (x10⁹/L)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
Glucose (mmol/L)	☐	☐☐.☐	☐	☐☐.☐	D D / M M / Y Y
Haemoglobin (g/dL)	☐	☐☐.☐	☐	☐☐.☐	D D / M M / Y Y
Blood gases - pH	☐	☐.☐☐	☐	☐.☐☐	D D / M M / Y Y

4b.4 Please record the blood levels of the following at diagnosis and at their maximum level or tick if not recorded:

Marker	Tick if diagnosis level not recorded	Level at diagnosis	Tick if highest level not recorded	Highest recorded level	Date highest level recorded
AST (iu/L)	☐	☐☐☐☐	☐	☐☐☐☐	D D / M M / Y Y
ALT (iu/L)	☐	☐☐☐☐	☐	☐☐☐☐	D D / M M / Y Y
γ-GT (iu/L)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
LDH (iu/L)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
Total bilirubin (µmol/l)	☐	☐☐.☐	☐	☐☐.☐	D D / M M / Y Y
Creatinine (µmol/l)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
White cell count (x10⁹/L)	☐	☐☐.☐	☐	☐☐.☐	D D / M M / Y Y
PT (sec)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
APTT (sec)	☐	☐☐☐	☐	☐☐☐	D D / M M / Y Y
Blood gases – base excess (mEq/L)	☐	- ☐☐.☐	☐	- ☐☐.☐	D D / M M / Y Y

4b.5 Was a peripheral blood smear performed? Yes ☐ No ☐

If Yes, was there evidence of haemolysis (fragmented or contracted red cells) Yes ☐ No ☐

4b.6 Was diagnosis of HELLP syndrome: antepartum ☐ intrapartum ☐ postpartum ☐

If antepartum, was the planned management immediately following diagnosis:

Immediate delivery ☐ delivery within 48 hours ☐

expectant/conservative (prolonging pregnancy >48 hours) ☐

*For guidance please see back cover

4b.7 Was the woman given corticosteroids? Yes ☐ No ☐

If Yes, please specify:

Agent	Dose	Units	Indication	Date started
				D D / M M / Y Y

4b.8 Was any antihypertensive medication commenced/continued in this pregnancy (antenatally or postnatally)? Yes ☐ No ☐

If Yes, please specify:

Name of drug	Date treatment started
	D D / M M / Y Y
	D D / M M / Y Y

4b.9 Were any of the following treatments commenced/continued in this pregnancy (antenatally or postnatally)?

	Yes	No	Date treatment started
Magnesium sulphate	☐	☐	D D / M M / Y Y
Aspirin	☐	☐	D D / M M / Y Y

4b.10 Was any other medication commenced/continued in this pregnancy (antenatally or postnatally)? Yes ☐ No ☐

If Yes, please specify:

Name of medication	Indication	Date treatment started
		D D / M M / Y Y
		D D / M M / Y Y

4b.11 Did the women refuse blood products? Yes ☐ No ☐

If No, were blood products given? Yes ☐ No ☐

4b.12 Were any of the following used for thromboprophylaxis? *(please tick all that apply)*

	Antenatally	Postnatally
TED Stockings	☐	☐
Low molecular weight heparin	☐	☐

4b.13 Did the woman develop any overt clinical signs of coagulopathy (non-obstetric bleeding)? E.g. petechiae, haematuria, bleeding gums Yes ☐ No ☐

If Yes, please specify: _____

Section 5: Delivery

5.1 Did this woman have a miscarriage? Yes ☐ No ☐

If Yes, please specify date: D D / M M / Y Y

5.2 Did this woman have a termination of pregnancy? Yes ☐ No ☐

If Yes, please specify date: D D / M M / Y Y

*For guidance please see back cover

5.3 **Is this woman still undelivered?** Yes ☐ No ☐

If Yes, 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 **Did the woman labour?** Yes ☐ No ☐

5.6 **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 (critical care level 3) or obstetric 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 require ventilation?** Yes ☐ No ☐

6a.3 **Did the woman require haemodialysis?** Yes ☐ No ☐

If Yes, for how long was she dialysed? ☐☐ *days*

6a.4 **Did the woman have hepatic encephalopathy** Yes ☐ No ☐

6a.5 **Was the woman transferred to a liver unit?** Yes ☐ No ☐

6a.6 **Did any other major maternal morbidity occur?[6]*** Yes ☐ No ☐

If Yes, please specify: _____

6a.7 **Has the woman been discharged from hospital?** Yes ☐ No ☐

If Yes, what was the date of the woman's discharge from hospital? D D / M M / Y Y

Was the woman readmitted after discharge? Yes ☐ No ☐ Not known ☐

If Yes, what was the reason for readmission? _____

6a.8 **Did the woman die?** Yes ☐ No ☐

If Yes, please specify date and time of death D D / M M / Y Y h h : m m (24hr)

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 ☐

*For guidance please see back cover

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 D / M M / Y Y h h : m m (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 Sex of infant: Male ☐ Female ☐ Indeterminate ☐

6b.5 Was the infant stillborn? Yes ☐ No ☐

If Yes, *please go to section 7.*

6b.6 5 min Apgar ☐☐

6b.7 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

6b.8 Did any other major infant complications occur?[7]* Yes ☐ No ☐

If Yes, please specify: _____

6b.9 Did this infant die? Yes ☐ No ☐

If Yes, please specify date and time of death D D / M M / Y Y h h : m m (24hr)

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: D D / M M / Y Y

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, for example:

3 or more miscarriages
Acute fatty liver
Amniotic fluid embolism
Ante-partum haemorrhage requiring transfusion
Baby with major congenital problem
Hyperemesis requiring admission
IUGR/small for gestational age
Neonatal death
Placenta praevia
Placental abruption
Placenta accreta/percreta/increta
Post-partum haemorrhage requiring transfusion
Preterm birth or mid-trimester loss
Severe infection (e.g. pyelonephritis)
Stillbirth (IUD)
Surgical procedure in pregnancy
Significant antepartum haemorrhage
Thrombotic event (DVT/Pulmonary embolus/ Stroke)

3. Previous or pre-existing maternal medical problems, for example:

Auto-immune disease
Cancer
Cardiac disease (congenital or acquired)
Epilepsy
Endocrine disorders, e.g.Hypo or hyperthyroidism,
Haematological disorders e.g. sickle cell disease, diagnosed thrombophilia
Inflammatory disorders e.g. Inflammatory bowel disease
Psychiatric disorders
Renal disease
Thrombotic event (pulmonary embolism)
Coagulopathy
Polycystic ovary disease

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, for example:

Adult respiratory distress syndrome
Cardiac arrest
Cerebrovascular accident/intercranial haemorrhage
Convulsions – not diagnosed as eclampsia
Disseminated intravascular coagulopathy (DIC)
Deranged clotting – not DIC
Multiple organ failure
Persistent vegetative state/anoxic/hypoxic brain injury
Pulmonary oedema
Septicaemia/septic shock
Thrombotic event

7. Infant complications, for example:

Chronic lung disease
Exchange transfusion
Intraventricular haemorrhage
Major congenital anomaly
Multiorgan failure
Necrotising enterocolitis
Neonatal encephalopathy/HIE/birth asphyxia
Respiratory distress syndrome/Ventilated/ Pneumothorax/Chest effusions/Haemothorax
Severe infection e.g. septicaemia, meningitis
Severe jaundice requiring phototherapy