ID Number:

UKOSS

UK Obstetric Surveillance System

Cirrhosis in pregnancy

Study 01/17

Data Collection Form - CASE

Case Definition:

Any woman giving birth in the UK between the 1st of June 2017 and 31st of May 2018 identified as having hepatic cirrhosis.

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.
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.

Royal College of Obstetricians and Gynaecologists

Bringing to life the best in women's health care

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

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*

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 this woman's liver function deteriorate during a previous pregnancy?** Yes ☐ No ☐

2.3 **Has this woman ever had any of the following:** *Please tick all that apply*

A pre-term delivery (<37 weeks) ☐ An infant admitted to the neonatal unit ☐

A stillbirth ☐ None of the above ☐

2.4 **Has this woman ever had any of the following in previous pregnancies:**
Please tick all that apply

Pre-eclampsia ☐ HELLP ☐ Obstetric Cholestasis ☐

Acute Fatty Liver of Pregnancy ☐ Gestational diabetes ☐ None of the above ☐

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

If Yes, please specify: _____

Section 3: Previous Medical History

3.1 **When was cirrhosis diagnosed?** D D / M M / Y Y

3.2 **What was the diagnosis of cirrhosis based on:**

a) Liver biopsy: Yes ☐ No ☐

b) CT, MRI or Ultrasound scan: Yes ☐ No ☐

3.3 **Does the woman have portal hypertension:** Yes ☐ No ☐ Not known ☐

If Yes, please give the date of diagnosis D D / M M / Y Y

3.4 **Which underlying liver disease does this woman have** *(please tick one)*:

Autoimmune Hepatitis ☐ Primary Sclerosing Cholangitis ☐ Primary Biliary Cirrhosis ☐

Hepatitis B ☐ Hepatitis C ☐ Portal Vein Thrombosis ☐ Other ☐ Not known ☐

If Other, please specify: _____

3.5 **Did the woman have oesophageal varices before this pregnancy:**

Yes ☐ No ☐ Not known ☐

If Yes, what was the size of the varices at the last pre-pregnancy endoscopy (please tick one):

0 - None ☐ I - Small ☐ II - Medium ☐ III - Large ☐ Not known ☐

3.6 **Has this woman ever had treatment for a variceal bleed:** Yes ☐ No ☐ Not known ☐

If Yes, did she have: Band Ligation: Yes ☐ No ☐ Not known ☐

Injection Sclerotherapy: Yes ☐ No ☐ Not known ☐

3.7 **Has this woman had a liver transplant:** Yes ☐ No ☐

If Yes, please give the year of transplant: Y Y Y Y

3.8 **Does the woman have any history of gallstones:** Yes ☐ No ☐ Not known ☐

3.9 **Has this woman ever had drug induced cholestasis:** Yes ☐ No ☐ Not known ☐

If Yes, please give the name of the drug responsible: _____

3.10 **Does this woman have any other previous / pre-existing medical conditions:** Yes ☐ No ☐

If Yes, please specify: _____

3.11 **Did this woman have pre-pregnancy counselling from a doctor with a specialist knowledge of liver disease in pregnancy:** Yes ☐ No ☐ Not known ☐

Section 4: This Pregnancy

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

4.2 **Was this a multiple pregnancy?** Yes ☐ No ☐

If Yes, please specify number of fetuses: ☐☐

4.3 **Was conception?** Spontaneous ☐ Assisted ☐

4.4 **What was the date of the first (booking) appointment in pregnancy?** D D / M M / Y Y

4.5 **Regarding this woman's medication, were any of the following:** *Please tick all that apply*

	Taken at conception	Stopped prior to conception	Stopped following conception	Started during pregnancy	Never taken
Ursodeoxycholic acid	☐	☐	☐	☐	☐
Steroids	☐	☐	☐	☐	☐
Vitamin K	☐	☐	☐	☐	☐
Immunosuppression (specify which)	☐	☐	☐	☐	☐

If Immunosuppression, please specify which: _____

4.6 **Were any other drugs not listed above taken during pregnancy for underlying liver disease?** Yes ☐ No ☐

If Yes, please list drugs taken _____

4.7 Did this woman have any of the following symptoms during pregnancy:

	Tick all that apply	If Yes, please provide the date first noted in pregnancy
Pruritus	☐	D D / M M / Y Y
Jaundice	☐	D D / M M / Y Y
Ascites	☐	D D / M M / Y Y
Gastrointestinal bleeding	☐	D D / M M / Y Y
Encephalopathy	☐	D D / M M / Y Y
None of the above	☐	

4.8 Were any of the following blood tests abnormal at the time of conception?
Please tick all that apply

Raised ALT?	☐	Low Albumin?	☐
Raised Bilirubin?	☐	Low Sodium?	☐
Raised Bile Acids?	☐	Low Haemaglobin?	☐
Raised Creatinine?	☐	Low Platelets?	☐
Raised Prolonged prothrombin time?	☐	None of the above	☐

4.9 Please give details of the worst levels of the following blood tests during pregnancy

	Worst level	Or tick if not known	Date
ALT		☐	D D / M M / Y Y
Bilirubin		☐	D D / M M / Y Y
Bile Acids		☐	D D / M M / Y Y
Albumin		☐	D D / M M / Y Y
Creatinine		☐	D D / M M / Y Y
Sodium		☐	D D / M M / Y Y
Haemoglobin		☐	D D / M M / Y Y
Platelets		☐	D D / M M / Y Y
Prothrombin time		☐	D D / M M / Y Y

4.10 Please give details of the pre-delivery levels of the following blood tests

	Pre-delivery level	Or tick if not known	Date
ALT		☐	D D / M M / Y Y
Bilirubin		☐	D D / M M / Y Y
Bile Acids		☐	D D / M M / Y Y
Albumin		☐	D D / M M / Y Y
Creatinine		☐	D D / M M / Y Y
Sodium		☐	D D / M M / Y Y
Haemoglobin		☐	D D / M M / Y Y
Platelets		☐	D D / M M / Y Y
Prothrombin time		☐	D D / M M / Y Y

4.11 Did this woman have any of the following pregnancy problems: *Please tick all that apply*

Pre-eclampsia ☐ Pregnancy induced hypertension ☐ HELLP ☐

Cholestasis ☐ AFLP ☐ Gestational diabetes ☐ None of the above ☐

4.12 Did the woman have a post-partum haemorrhage: Yes ☐ No ☐

If Yes, please give estimated blood loss ☐☐☐☐☐ ml

4.13 Did the woman have a diagnostic endoscopy during pregnancy:

Yes ☐ No ☐ Not known ☐

If Yes, did she have varices Yes ☐ No ☐ Not known ☐

If Yes, what was the size of the varices *(please tick one)*:

0 - None ☐ I - Small ☐ II - Medium ☐ III - Large ☐ Not known ☐

Was any treatment given during the procedure? *(please tick one)*

None ☐ Sclerotherapy ☐ Banding ☐ Not known ☐

4.14 Did the woman have a variceal bleed during pregnancy: Yes ☐ No ☐

If Yes, please give date of bleed and treatment (indicate banding/sclerotherapy/octreotide/none)

Date of bleed	Treatment
D D / M M / Y Y	
D D / M M / Y Y	
D D / M M / Y Y	

4.15 Did this woman have a liver ultrasound scan during pregnancy: Yes ☐ No ☐

If Yes, what was the size of the spleen ☐☐ cm

4.16 Did the woman have an episode of encephalopathy during pregnancy: Yes ☐ No ☐

If Yes, what was the grade of encephalopathy:

None ☐ Mild ☐ Moderate ☐ Severe ☐ Coma ☐ Not known ☐

What treatment did she receive? _____

4.17 Did this woman have a liver transplant during the pregnancy: Yes ☐ No ☐

If Yes, please give date D D / M M / Y Y

4.18 Were there any other problems in this pregnancy?[2] 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

and indication: _____

If Yes to 5.1 or 5.2, please go to sections 6a, 7 and 8

*For guidance please see back cover

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 **Did the woman labour?** Yes ☐ No ☐

5.6 **Was delivery by caesarean section?** Yes ☐ No ☐

If Yes, please state:

Grade of urgency:[7]* ☐

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)?** Yes ☐ No ☐

If Yes, duration of stay: ☐☐ *days*

OR Tick if woman is still in ITU (critical care level 3): ☐

OR Tick if woman was transferred to another hospital: ☐

6a.2 **Did any other major maternal morbidity occur?**[6]* Yes ☐ No ☐

If Yes, please specify: _____

6a.3 **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) _____

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 or Forceps ☐ Vaginal 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 meconium staining of the liquor noted at any point prior to delivery? Yes ☐ No ☐

6b.8 Was the umbilical arterial or venous pH measured? Yes ☐ No ☐

If Yes, what was the umbilical arterial pH? ☐.☐☐

What was the umbilical vein pH? ☐.☐☐

6b.9 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

If Yes, what was the indication? _____

6b.10 Did any major infant complications occur?[7]* Yes ☐ No ☐

If Yes, please specify _____

6b.11 Did this infant have a congenital abnormality: Yes ☐ No ☐

If Yes, please give details _____

6b.12 Did this infant die? Yes ☐ No ☐

If Yes, please specify date of death D D / M M / Y Y

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.

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;

Thrombotic event
Amniotic fluid embolism
Eclampsia
3 or more miscarriages
Preterm birth or mid trimester loss
Neonatal death
Stillbirth
Baby with a major congenital abnormality
Small for gestational age (SGA) infant
Large for gestational age (LGA) infant
Infant requiring intensive care
Puerperal psychosis
Placenta praevia
Gestational diabetes
Significant placental abruption
Post-partum haemorrhage requiring transfusion
Surgical procedure in pregnancy
Hyperemesis requiring admission
Dehydration requiring admission
Ovarian hyperstimulation syndrome
Severe infection e.g. pyelonephritis

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

Cardiac disease (congenital or acquired)
Renal disease
Endocrine disorders e.g. hypo or hyperthyroidism
Psychiatric disorders
Haematological disorders e.g. sickle cell disease, diagnosed thrombophilia
Inflammatory disorders e.g. inflammatory bowel disease
Autoimmune diseases
Cancer
HIV

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, 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

7. 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