ID Number:

UKOSS

UK Obstetric Surveillance System

Severe Epilepsy in Pregnancy Study 03/15

Data Collection Form - CASE

Please report any woman delivering between 01/10/2015 and 30/09/2016.

Case Definition:

EITHER:

Death of a woman with epilepsy during pregnancy or up to day 42 after delivery, where the cause of death is directly attributed to the consequences of epilepsy, including SUDEP;

OR

Admission to hospital for management of generalised tonic-clonic seizures during pregnancy or the post-partum period (if presenting to healthcare services);

OR

Any woman being treated with 3 or more antiepileptic drugs simultaneously during pregnancy.

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

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 **Does the woman drink alcohol?** Yes ☐ No ☐

If Yes, is there known alcohol dependence? Yes ☐ No ☐

1.9 **Does the woman use recreational drugs?** Yes ☐ No ☐

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: _____

*For guidance please see back cover

Section 3:

Section 3a: Previous Medical History

3a.1 Did the woman have epilepsy before the current pregnancy? Yes ☐ No ☐

3a.2 When was the diagnosis of epilepsy made? D D / M M / Y Y

3a.3 Was there a precipitating cause for the woman's epilepsy? Yes ☐ No ☐ Not known ☐

If Yes, please specify: _____

3a.4 Before this pregnancy, has the woman been admitted to hospital for epilepsy? *(Excluding attendance to A&E, outpatients)* Yes ☐ No ☐

3a.5 What type of seizures does the woman have? Tonic-clonic seizures ☐ Other ☐

3a.6 When did the most recent seizure occur before pregnancy? >0 - 3 months ☐ >3 - 6 months ☐ >6 - 12 months ☐ >12 months ☐ **OR** tick if not known ☐

3a.7 How many seizures did the woman have in the 12 months before this pregnancy?

Number: ☐☐ *(enter zero if none)* **OR** tick if not known ☐

3a.8 Did the woman have any other previous or pre-existing medical problems:[3*] Yes ☐ No ☐

If Yes, please specify: _____

3a.9 Has management of the women's epilepsy been reviewed in a specialist neurology service? Yes ☐ No ☐

If Yes, Before, but NOT during pregnancy ☐ During previous pregnancy, not current ☐ In current pregnancy ☐

Section 3b: Medication and pregnancy

3b.1 Did the woman take high dose pre-pregnancy folic acid (5 mg)? Yes ☐ No ☐

3b.2 Did the woman take vitamin K during the pregnancy? Yes ☐ No ☐

3b.3 Please list all antiepileptic medications taken by the woman and any corresponding changes in dose: *(Please enter **I (increased dose)**, **D (decreased dose)**, **X (stopped)** or **NC (no change)***

Medicine	Prepregnancy[#]	Antenatal	Postnatal

[#] *up to12 months before*

3b.4 Was the woman prescribed any other regular medications? Yes ☐ No ☐

If Yes, please list all other regular medications prescribed? (Excluding analgesia and medications in labour) _____

*For guidance please see back cover

Section 4: This Pregnancy

4.1 **What is the agreed 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 this a planned pregnancy?** Yes ☐ No ☐

4.4 **When was the antenatal booking assessment performed?** D D / M M / Y Y

4.5 **Was the plan for midwifery led care throughout pregnancy?** Yes ☐ No ☐

If No, please specify the lead clinician:

Maternal Medicine Secondary Centre ☐ Maternal Medicine Tertiary Centre ☐

General Obstetric Consultant ☐ General Practitioner ☐

4.6 **Which groups of clinicians managed the woman's pregnancy?**

Please indicate which and when the woman was reviewed by ticking the relevant box below

Clinician	Pre-pregnancy	Antenatal	Intrapartum
Maternal Medicine Secondary Centre	☐	☐	☐
Maternal Medicine Tertiary Centre	☐	☐	☐
General Obstetric Consultant	☐	☐	☐
Specialist Midwife (epilepsy)	☐	☐	☐
Midwife	☐	☐	☐
Consultant Neurologist	☐	☐	☐
Epilepsy Nurse Specialist	☐	☐	☐
Consultant Anaesthetist	☐	☐	☐
Other – please specify	_____	_____	_____

4.7 **Did the management plan for pregnancy include an outline of care for epilepsy for the following:**

Antenatal period: Yes ☐ No ☐

Intrapartum period: Yes ☐ No ☐

Post pregnancy, including medication: Yes ☐ No ☐

Postpartum contraception: Yes ☐ No ☐

Future pregnancies: Yes ☐ No ☐

4.8 **Was the risk of a change in seizure pattern discussed?** Yes ☐ No ☐ Not known ☐

4.9 **Was the risk of SUDEP discussed?** Yes ☐ No ☐ Not known ☐

4.10 **Were fetal abnormalities identified during the woman's antenatal care?** Yes ☐ No ☐

If Yes, please specify: _____

4.11 **Was a fetal cardiac ultrasound performed?** Yes ☐ No ☐

4.12 **Did the woman have seizures during pregnancy and before admission for delivery?** Yes ☐ No ☐

If Yes, did the seizures occur out of hospital? Yes ☐ No ☐

Was the woman admitted to hospital? Yes ☐ No ☐

Were the seizures: Status epilepticus ☐ Tonic-clonic ☐ **OR** Other ☐

How many seizures did the woman have in total? ☐☐

4.13 **Were there other problems in this pregnancy?** Yes ☐ No ☐

If Yes, please specify: _____

*For guidance please see back cover

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

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

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 **What were the planned and final places of birth?**

	Planned birth place	Final birth place
Standalone midwifery unit	☐	☐
Alongside midwifery unit	☐	☐
Consultant led unit; midwifery care	☐	☐
Consultant led unit; consultant care	☐	☐
Home	☐	☐
Other	☐	☐

5.5 **Was delivery induced?** Yes ☐ No ☐

If Yes, please state indication: _____

Was vaginal prostaglandin used? Yes ☐ No ☐

5.6 **Did the woman labour?** Yes ☐ No ☐

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

5.7 **Was an oxytocin infusion used during labour?** Yes ☐ No ☐

5.8 **Which methods of pain relief were used in labour or delivery?**

Oral analgesia ☐ Intramuscular analgesia ☐ Inhalational *(Eg. Entonox)* ☐

Regional analgesia/ anaesthesia ☐ PCA ☐

5.9 **Did the woman have seizures during labour or delivery?** Yes ☐ No ☐

If Yes, were these: Status epilepticus ☐ Tonic-clonic ☐ **OR** Other ☐

How many seizures did the woman have in total? ☐☐

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

If Yes,

Grade of urgency[5]* ☐

Indication for caesarean section _____

Method of anaesthesia Regional ☐ General ☐

*For guidance please see back cover

Section 6: Outcomes

Section 6a: Woman

6a.1 Was the woman admitted to ITU or level 3 care? Yes ☐ No ☐

If Yes, duration of stay: ☐☐ *days*

OR Tick if woman is still in ITU or level 3 care: ☐

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 ☐ Operative vaginal ☐ 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 the infant have a congenital anomaly? Yes ☐ No ☐

If Yes, please specify: _____

6b.10 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) _____

*For guidance please see back cover

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

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,
Exchange transfusion