



UK Obstetric Surveillance System

Adrenal Tumours in Pregnancy Study 01/11

Data Collection Form - CASE

Please report any woman delivering on or after 1st March 2011 and before 1st March 2012.

Case Definition:

All pregnant women with a functioning adrenal neuroendocrine tumour (as defined below), including women diagnosed pre-pregnancy who have not undergone surgery to remove the tumour.

Phaeochromocytoma – Neuroendocrine adrenal tumour that secretes catecholamines (stress hormones) these include dopamine, nor-adrenaline, adrenaline, metadrenaline and normetadrenaline.

Cushing's Syndrome – Adrenal cortex tumour that secretes excessive amounts of cortisol.

Conn's Syndrome – Adrenal cortex adenoma that secretes excessive amounts of aldosterone.

Please return the completed form to:

UKOSS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF



Royal College of
Obstetricians and
Gynaecologists

Fax: 01865 617775
Phone: 01865 289714
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:^{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

Section 2: Previous Obstetric History

- 2.1 Gravity**
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

2.3 Did the woman have pre-eclampsia in a previous pregnancy? Yes No

If Yes, please give:

Number of deliveries < 34 weeks in which the woman had pre-eclampsia:

Number of deliveries 34-37 weeks in which the woman had pre-eclampsia:

2.4 Was the tumour diagnosed during or following a previous pregnancy?

During Following Neither

Section 3: Diagnosis of Adrenal Tumour

3.1 Date of diagnosis: / /

3.2 What was the diagnosis? (Please tick one only)

Phaeochromocytoma

Cushing's syndrome

Conn's syndrome

3.3 What were the symptoms at first presentation of the tumour? (Please tick all that apply)

Headache Palpitations Sweating Pregnancy induced hypertension

Pre-eclampsia Cardiac failure Stroke Other

If Other, please give details: _____

3.4 Is the tumour associated with any of the following genetic conditions? Yes No

If Yes, please indicate which genetic mutation: (Please tick one only)

Von Hippel Lindau

MEN 2

Neurofibromatosis 1

Succinate dehydrogenase mutation

3.5 Does a 1st degree relative have any of the following? Yes No

If Yes, please tick all that apply:

Hypertension

Endocrine tumour

Genetic condition as detailed in Q3.4

3.6 Has an endocrinologist confirmed the diagnosis? Yes No

If Yes, please give name of endocrinologist and hospital where the woman was seen:

3.7 Did the woman have any other pre-existing medical problem^{3*} Yes No

If Yes, please give details: _____

Section 4: This Pregnancy

4.1 Final Estimated Date of Delivery (EDD):^{4*} / /

4.2 Was this a multiple pregnancy? Yes No

If Yes, please specify number of fetuses:

4.3 Was any medication prescribed?

Yes No

If Yes, please complete table below: *(Please tick all that apply)*

Medication	Pre-conception	1st Trimester	2nd Trimester	3rd Trimester
Phaeochromocytoma				
Phenoxybenzamine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Propranolol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Labetalol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cushing's Syndrome				
Metyrapone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mitotane	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aminoglutethimide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ketoconazole	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amiloride	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conn's Syndrome				
Spirolactone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eplerenone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amiloride	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For all tumour types				
Other <i>(Please specify)</i>	_____			

4.4 Hormone values during this pregnancy: *(Please enter R (raised), N (normal), L (low) or X (not measured) for all that apply to the type of tumour diagnosed)*

	Pre-conception	1st Trimester	2nd Trimester	3rd Trimester
Phaeochromocytoma				
Plasma Metadrenaline				
Plasma Normetadrenaline				
Plasma Noradrenaline				
Plasma Adrenaline				
24hr urinary Adrenaline				
24hr Urinary Noradrenaline				
24hr Urinary Dopamine				
24hr Urinary Normetadrenaline				
24hr Urinary Metadrenaline				
Cushing's Syndrome				
Plasma ACTH				
09:00 Plasma Cortisol				
24hr Urinary Cortisol				

*For guidance please see back cover

	Pre-conception	1st Trimester	2nd Trimester	3rd Trimester
Conn's Syndrome				
Plasma Potassium				
Plasma Renin Activity				
Serum Aldosterone				
Renin/Aldosterone ratio				

- 4.5 Did the woman have a 75g glucose tolerance test?** Yes No
If Yes, please give date of test: DD / MM / YY
 And specify glucose levels
 Glucose at 0 minutes (mmol/L): .
 Glucose at 120 minutes (mmol/L): .

- 4.6 Was an abdominal ultrasound performed to measure the tumour during this pregnancy?** Yes No
If Yes, what was the date of the first scan? DD / MM / YY
 Was the tumour Intra-adrenal Extra-adrenal
 What was the first recorded size of the tumour? Length: cm Height: cm
 Did the tumour increase in size in this pregnancy? Yes No

4.7 What were the highest blood pressure values recorded during this pregnancy?

	Booking	1st Trimester	2nd Trimester	3rd Trimester
Systolic BP				
Diastolic BP				

- 4.8 Did the woman have significant proteinuria?** Yes No
If Yes, please give maximum proteinuria (one measurement only) + g/24hr
 PCR
4.9 Did the woman have an adrenalectomy? Yes No
If Yes, please give date of surgery: DD / MM / YY
 Was the surgery: Unilateral **OR** Bilateral
 Was the surgery done laproscopically? Yes No Not known
 What was the diagnosis on histology? _____
4.10 What was the planned mode of delivery? Vaginal **OR** C-section?
4.11 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: DD / MM / YY
5.2 Did this woman have a termination of pregnancy? Yes No
If Yes, please specify date: DD / MM / YY

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 (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 If the woman had a c-section, did she have a wound infection or dehiscence? Yes No Not Applicable

6a.3 Did any other major maternal morbidity occur?^{6*} Yes No

If Yes, please specify: _____

6a.4 Did the woman die? Yes No

If Yes, please specify date and time of death / / :

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 / / :

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 Sex of infant Male Female Indeterminate

6b.4 Birthweight g

6b.5 Did the infant have a congenital anomaly?

Yes No

If Yes, please give details : _____

6b.6 Was the infant stillborn?

Yes No

If Yes, please go to section 7.

6b.7 5 min Apgar

6b.8 Was the infant admitted to the neonatal unit?

Yes No

6b.9 Was the cord blood pH measured?

Yes No

If Yes, what was the umbilical arterial pH?

.

What was the umbilical vein pH?

.

6b.10 Did any other major infant complications occur?^{7*}

Yes No

If Yes, please specify: _____

6b.11 Did this infant die?

Yes No

If Yes, please specify date and time 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.

*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, 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. HIV 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