UKOSS

UK Obstetric Surveillance System

Endocrine related neoplasia syndromes in pregnancy 01/26

Data Collection Form - CASE

Please report any woman delivering on or after the 01/10/2026 and before 01/10/2028

Case Definition:

Any woman with a genetic diagnosis of multiple endocrine neoplasia type 1 (MEN1 caused by an inherited pathogenic variant in the MEN1 gene), multiple endocrine neoplasia type 2 or type 3 (MEN2/3 caused by inherited pathogenic variants in the RET gene) or Von Hippel Lindau syndrome (VHL caused by inherited pathogenic variants in the VHL gene)

Case ID Number: | | | | | | | |

Sample CASE

Royal College of Obstetricians and Gynaecologists

Bringing to life the best in women's health care

Please return the completed form to:

ukoss@npeu.ox.ac.uk

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

Phone: 01865 617764 / 617774

Reporting Month: _____

Reporting Hospital: _____

NPEU

Nuffield Department of Women's & Reproductive Health

University of Oxford

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 for your own reference on the 'UKOSS - Reported cases' document.
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.

CASE Sample

*For guidance please see back cover

Section 1: Woman's details

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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 **Vaping status** never ☐ gave up prior to pregnancy ☐ current ☐ gave up during pregnancy ☐

Section 2: Previous Obstetric History

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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 problem[2]*** Yes ☐ No ☐

If Yes, please specify: _____

2.3 **Was the woman under the care of an endocrinologist or genetics specialist for her genetic condition before or during pregnancy?** Yes ☐ No ☐

2.4 **Did the woman have any of the following during any previous pregnancy?** *(tick all that apply)*

Hypercalcemia ☐ Hypertension ☐ Pre-eclampsia ☐

Gestational diabetes ☐ None of the above ☐

2.5 **Was the woman taking any medication related to her genetic diagnosis in a previous pregnancy?** Yes ☐ No ☐

If Yes, please specify: _____

2.6 **Were there any complications for the baby during or after delivery in the previous pregnancy?** Yes ☐ No ☐

If Yes, please specify: _____

Sample

*For guidance please see back cover

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Section 3: Medical History

Please complete the section relevant to the woman's genetic diagnosis (MEN1, MEN2/3 or VHL)

Section 3a: MEN1

3a.1 Does the woman have MEN1? Yes ☐ No ☐

If Yes, go to 3a.2 **If No,** go to 3b.1

3a.2 What year was the genetic diagnosis of MEN1? Y Y Y Y

3a.3 Did the woman develop any of the following complications prior to pregnancy?

	Yes or No	If Yes, has the woman had surgery
Hyperparathyroidism	Yes ☐ No ☐	Yes ☐ No ☐
Pancreatic neuroendocrine tumour	Yes ☐ No ☐	Yes ☐ No ☐
Pituitary adenoma	Yes ☐ No ☐	Yes ☐ No ☐
Adrenal tumour	Yes ☐ No ☐	Yes ☐ No ☐
Thymic or bronchial neuroendocrine tumour	Yes ☐ No ☐	Yes ☐ No ☐

3a.4 Diagnosis and tests during this pregnancy.

Please complete the highest values known of the test results during pregnancy in the table below.

Please enter NK if not known or ND if test not done.

Test	During pregnancy	Date	Reference range applicable to that centre
Corrected calcium		D D / M M / Y Y	
Parathyroid hormone		D D / M M / Y Y	
Prolactin		D D / M M / Y Y	
IGF-1		D D / M M / Y Y	
Vitamin D		D D / M M / Y Y	
Gastrin		D D / M M / Y Y	
MRI pancreas – size of pancreatic neuro-endocrine tumour identified	_____ mm	D D / M M / Y Y	N/A
MRI pituitary – size of any pituitary tumour(s) identified	_____ mm	D D / M M / Y Y	N/A

3a.5 Did the woman have any other pre-existing medical problems?[3*] Yes ☐ No ☐

If Yes, please specify: _____

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3a.6 **Was the woman taking any of the following medications prior to pregnancy?** *please tick all that apply*

Medication	Yes
Alphacalcidol	☐
Belzutifan	☐
Bromocriptine	☐
Calcium supplements	☐
Cabergoline	☐
Cholecalciferol (Vitamin D)	☐
Cinacalcet	☐
Fludrocortisone	☐
Hydrocortisone	☐
Lanreotide	☐
Thyroxine	☐
None of the above	☐

Please go to Section 4

Section 3b: MEN2/3

3b.1 **Does the woman have MEN2/3?** Yes ☐ No ☐

If Yes, go to 3b.2 **If No,** go to 3c.1

3b.2 **What year was the genetic diagnosis of MEN2/3?** Y Y Y Y

3b.3 **Which of the following complications has the woman developed:**

	Yes or No	If Yes, has the woman had surgery
Risk-reducing thyroidectomy following genetic diagnosis of MEN2/3	Yes ☐ No ☐	N/A
Medullary thyroid cancer	Yes ☐ No ☐	N/A
Pheochromocytoma	Yes ☐ No ☐	Yes ☐ No ☐
If Yes, unilateral (on one adrenal gland only)	Yes ☐ No ☐	
OR bilateral (on both adrenal glands)	Yes ☐ No ☐	
Primary hyperparathyroidism	Yes ☐ No ☐	Yes ☐ No ☐

Sample

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3b.4 Diagnosis and tests during this pregnancy.

Please complete the highest values known of the test results during pregnancy in the table below.

Please enter NK if not known or ND if test not done.

Test	During pregnancy	Date	Reference range applicable to that centre
Corrected calcium		D D / M M / Y Y	
Parathyroid hormone		D D / M M / Y Y	
Plasma normetanephrine		D D / M M / Y Y	
Plasma metanephrine		D D / M M / Y Y	
Urinary normetanephrine		D D / M M / Y Y	
Urinary metanephrine		D D / M M / Y Y	
Calcitonin		D D / M M / Y Y	
T4		D D / M M / Y Y	
T3		D D / M M / Y Y	
TSH		D D / M M / Y Y	
MRI adrenals – size of any adrenal nodule(s) identified	____ mm	D D / M M / Y Y	N/A

3b.5 Did the woman have any other pre-existing medical problems?[3*] Yes ☐ No ☐

If Yes, please specify: _____

3b.6 Was the woman taking any of the following medications prior to pregnancy? *please tick all that apply*

Medication	Yes
Alphacalcidol	☐
Belzutifan	☐
Bromocriptine	☐
Calcium supplements	☐
Cabergoline	☐
Cholecalciferol (Vitamin D)	☐
Cinacalcet	☐
Fludrocortisone	☐
Hydrocortisone	☐
Lanreotide	☐
Thyroxine	☐
None of the above	☐

Please go to Section 4

Sample

Section 3c: VHL

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3c.1 Does the woman have VHL? Yes ☐ No ☐

If Yes, go to 3c.2 **If No,** go to Section 4

3c.2 What year was the genetic diagnosis of VHL? Y Y Y Y

3c.3 Which of the following complications has the woman developed:

	Yes or No	If Yes, has the woman had surgery
Pheochromocytoma	Yes ☐ No ☐	Yes ☐ No ☐
If Yes, unilateral (on one adrenal gland only)	Yes ☐ No ☐	
OR bilateral (on both adrenal glands)	Yes ☐ No ☐	
Renal cell carcinoma	Yes ☐ No ☐	Yes ☐ No ☐
If Yes, unilateral	Yes ☐ No ☐	
OR bilateral	Yes ☐ No ☐	
Pancreatic neuroendocrine tumour	Yes ☐ No ☐	Yes ☐ No ☐
Cerebellar hemangioblastoma	Yes ☐ No ☐	Yes ☐ No ☐
Spinal hemangioblastoma	Yes ☐ No ☐	Yes ☐ No ☐
Retinal angioma	Yes ☐ No ☐	N/A

3c.4 Diagnosis and tests during this pregnancy.

Please complete the highest values known of the test results during pregnancy in the table below.

Please enter NK if not known or ND if test not done.

Test	During pregnancy	Date	Reference range applicable to that centre
Plasma normetanephrine		D D / M M / Y Y	
Plasma metanephrine		D D / M M / Y Y	
Urinary normetanephrine		D D / M M / Y Y	
Urinary metanephrine		D D / M M / Y Y	
Kidney imaging (US/CS/MRI) – size of any kidney tumour(s) identified	_____ mm	D D / M M / Y Y	N/A
MRI spine – size of any spinal hemangioblastoma(s) identified	_____ mm	D D / M M / Y Y	N/A
MRI head – size of any cerebella hemangioblastoma(s) identified	_____ mm	D D / M M / Y Y	N/A
MRI pancreas – size of any pancreatic neuroendocrine tumour(s) identified	_____ mm	D D / M M / Y Y	N/A
MRI adrenals – size of any adrenal nodule(s) identified	_____ mm	D D / M M / Y Y	N/A

3c.5 Did the woman have any other pre-existing medical problems?[3*] Yes ☐ No ☐

If Yes, please specify: _____

Sample

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3c.6 **Was the woman taking any of the following medications prior to pregnancy?** *please tick all that apply*

Medication	Yes
Alphacalcidol	☐
Belzutifan	☐
Bromocriptine	☐
Calcium supplements	☐
Cabergoline	☐
Cholecalciferol (Vitamin D)	☐
Cinacalcet	☐
Fludrocortisone	☐
Hydrocortisone	☐
Lanreotide	☐
Thyroxine	☐
None of the above	☐

Section 4: This Pregnancy

4.1 **Final Estimated Date of Birth (EDB)?**[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 **Were there any changes to the pre-pregnancy medications.** *Please indicate if pre-pregnancy medications were continued in pregnancy and if so, whether they were stopped during pregnancy.*

Medication	Continued in pregnancy	Stopped during pregnancy	If stopped, indicate in which trimester medication was stopped
Alphacalcidol	☐	☐	
Belzutifan	☐	☐	
Bromocriptine	☐	☐	
Calcium supplements	☐	☐	
Cabergoline	☐	☐	
Cholecalciferol (Vitamin D)	☐	☐	
Cinacalcet	☐	☐	
Fludrocortisone	☐	☐	
Hydrocortisone	☐	☐	
Lanreotide	☐	☐	
Thyroxine	☐	☐	

Please specify any new medications related to the specific endocrine syndrome that were started in pregnancy:

_____

Sample

4.4 **Did the woman develop any of the following complications during pregnancy?**

Hypercalcemia or hypocalcemia requiring hospital admission — Yes ☐ No ☐

Adrenal crisis (acute episode of hypotensive shock requiring emergency steroid replacement) — Yes ☐ No ☐

A hypertensive disorder of pregnancy — Yes ☐ No ☐

Gestational diabetes — Yes ☐ No ☐

A growth in any existing tumors during pregnancy — Yes ☐ No ☐

If Yes, please provide further details _____

4.5 **Did the woman require surgical intervention other than surgery related to delivery during the pregnancy?** Yes ☐ No ☐

If Yes, please specify: _____

4.6 **Was the woman referred to a maternal medicine clinic?** Yes ☐ No ☐

4.7 **Was this woman offered pre or post implantation genetic testing?**

Yes ☐ No ☐ Unknown ☐

If Yes, please specify: _____

4.8 **Were there any other problems in this pregnancy?**[2*] Yes ☐ No ☐

If Yes, please specify: _____

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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

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

If Yes, will she be receiving the rest of her antenatal care at your hospital? Yes ☐ No ☐ Not known ☐

If No, please indicate the name of the hospital providing future care:

_____

Will she be delivered at your hospital? Yes ☐ No ☐

If No, please indicate the name of delivery hospital, *then go to section 7:*

_____

5.4 **Was induction of labour attempted?** Yes ☐ No ☐

If Yes, please state indication: _____

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

5.6 **Did the woman have a caesarean section?** Yes ☐ No ☐

If Yes, please state:

Grade of urgency[5*] ☐

Indication for caesarean section: _____

Method of anaesthesia: Regional ☐ General anaesthetic ☐

If regional, please state:

Spinal ☐ Epidural ☐ Combined spinal and epidural ☐

5.7 **What was the date and time of childbirth?** D D / M M / Y Y h h : m m (24hr)

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5.8 Mode of birth

Spontaneous vaginal ☐ Ventouse ☐ Forceps ☐ Breech ☐

Pre-labour caesarean section ☐ Caesarean section after onset of labour ☐

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Section 6: Outcomes

Section 6a: Woman

6a.1 Was the woman admitted to ITU (critical care level 2 or 3)? Yes ☐ No ☐

If Yes, please specify:

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 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) _____

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Section 6b: Infant outcomes

If more than one infant, for each additional infant please photocopy the infant section of the form **(before filling it in)** and attach extra sheets) or download extra copies of the form.

6b.1 Birthweight ☐☐☐☐ g

6b.2 Sex of infant Male ☐ Female ☐ Indeterminate ☐

6b.3 Was the infant stillborn? Yes ☐ No ☐

6b.4 5 min Apgar ☐☐

6b.5 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

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

If Yes, please specify details _____

6b.7 Did the infant have any of the following complications post delivery?

Hypocalcemia Yes ☐ No ☐

Hypoglycemia Yes ☐ No ☐

6b.8 Did the infant have genetic testing post-partum? Yes ☐ No ☐

If Yes, please include genetic results if these are known:

_____

6b.9 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) _____

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Sample CASE

Section 7:

Please use this space to enter any other information you feel may be important

CASE Sample

Section 8:

Name of person completing the form _____

Designation _____

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. English, Welsh, Scottish, Northern Irish or British
- 02. Irish
- 03. Gypsy or Irish Traveller
- 04. Roma
- 05. Any other white background

MIXED
- 06. White and black Caribbean
- 07. White and black African
- 08. White and Asian
- 09. Any other mixed or multiple ethnic background

ASIAN OR ASIAN BRITISH
- 10. Indian
- 11. Pakistani
- 12. Bangladeshi
- 13. Chinese
- 14. Any other Asian background

BLACK OR BLACK BRITISH
- 15. Caribbean
- 16. African
- 17. Any other black, black British or Caribbean background

OTHER ETHNIC GROUP
- 18. Arab
- 19. 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 birth (EDB):

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. Need to deliver but no maternal or fetal compromise
4. At time to suit the woman and maternity team

6. Major maternal morbidity, 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

Sample