ID Number:

UKOSS

UK Obstetric Surveillance System

Antithrombin/Protein C deficiency

Study 05/19

Data Collection Form - CASE

Please report any woman delivering on or after the 1st June 2019 and before 30th June 2020

Case Definition:

Antithrombin (AT) Deficiency:

Any pregnant woman with known antithrombin deficiency and found to have an antithrombin level below the lower limit of normal for their local hospital reference laboratory.

Protein C (PC) Deficiency:

Any pregnant woman with known protein C deficiency and found to have a protein C level below the lower limit of normal for their local hospital reference laboratory.

CASE

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

Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.
2. Fill in the form using the information available in the woman's case notes.
3. If the woman has received secondary mental health care (prior to or during her current pregnancy) please consult with the woman's most recent psychiatric team to complete this form. If you are unable to contact a psychiatrist involved in the woman's care please contact the UKOSS administrator and provide details of the mental health team she was receiving care from.
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 you do not know the answers to some questions, please indicate this in section 7
8. 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.
9. If you do not know the answers to some questions, please indicate this in section 7.
10. If you encounter any problems with completing the form please contact the UKOSS coordinator or use the space in section 10 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 Was the woman in paid employment at booking? Yes ☐ No ☐

If Yes, what is her occupation? _____

If No, what is her partner's occupation *(if any)*? _____

1.4 Height at booking: ☐☐☐ *cm*

1.5 Weight at booking: ☐☐☐.☐ *kg*

1.6 What is the woman's smoking status?

Never ☐ Current ☐ Gave up prior to pregnancy ☐ Gave up during pregnancy ☐

Section 2: Previous Obstetric History

2.1 Gravidity

Number of completed pregnancies beyond 24 weeks: ☐☐

Did this woman have any pregnancies which ended at less than 24 weeks? Yes ☐ No ☐

If Yes, please specify number ☐☐

and give gestations at which they ended _____

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

If Yes, please specify: _____

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Section 3: Medical History

3.1 Was the woman known to have AT /PC deficiency prior to pregnancy? Yes ☐ No ☐

If Yes, when was AT/ PC deficiency diagnosed? Y Y Y Y

3.2 What is this woman's lowest known recorded AT/PC level?

Lowest known level	Laboratory normal range
AT ☐☐ %	
PC ☐☐☐ IU/dL	

3.3 Was AT/ PC level checked during this (index) pregnancy? Yes ☐ No ☐

If Yes, please complete below

Level during pregnancy	Date measured	Laboratory normal range
AT ☐☐ %	D D / M M / Y Y	
PC ☐☐☐ IU/dL	D D / M M / Y Y	

3.4 Has the woman had genetic testing to identify a specific mutation associated with AT/PC deficiency? Yes ☐ No ☐

If Yes, please specify mutation identified _____

3.5 Has this woman had a previous venous thromboembolism (VTE)? Yes ☐ No ☐

If Yes, please indicate date of occurrence, site of thrombosis and associated factors of each event below.

	Event 1	Event 2	Event 3
Date	D D / M M / Y Y	D D / M M / Y Y	D D / M M / Y Y
Site of thrombosis	_____	_____	_____
Associated factors (tick one)			
Provoked: Surgery	☐	☐	☐
Immobilisation	☐	☐	☐
Cancer	☐	☐	☐
COCP	☐	☐	☐
Pregnancy	☐	☐	☐
Long-haul flight	☐	☐	☐
Other *(please specify)* _____ _____	☐	☐	☐
Minimally Provoked: Dehydration	☐	☐	☐
Short-haul flight	☐	☐	☐
COCP >1yr	☐	☐	☐
Other *(please specify)* _____ _____	☐	☐	☐
Unprovoked:	☐	☐	☐

3.6 **Was the woman on long term anticoagulation (including aspirin) for AT/ PC deficiency immediately prior to this (index) pregnancy?** Yes ☐ No ☐

If Yes, please specify treatment _____ and daily dose _____

3.7 **Does the woman have a known first degree family history of AT/PC deficiency?** Yes ☐ No ☐

If Yes, have any of these affected relatives had VTE? Yes ☐ No ☐

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

If Yes, please give details: _____

Section 4: This (Index) 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 anticoagulation started during the pregnancy (do not include women who continued anticoagulation started prior to pregnancy)?** Yes ☐ No ☐

If Yes, what date was treatment started? D D / M M / Y Y

What medication was first used? _____

What dose was first used? _____

4.4 **Were there any concerns over anticoagulant compliance?** Yes ☐ No ☐

4.5 **Did the woman have any side effect symptoms that were attributed to AT/ PC deficiency treatment** *(e.g. rash)***?** Yes ☐ No ☐

4.6 **During pregnancy, were anti-Xa levels monitored?** Yes ☐ No ☐

If Yes, what was the planned schedule for checking the anti-Xa levels? *(please tick one)*

Fortnightly ☐ Monthly ☐ Once per trimester ☐ Other ☐

If Other, please specify: _____

4.7 **Was the woman recieving a daily dose of heparin/ LMWH during pregnancy?** Yes ☐ No ☐

If Yes, what was the highest daily dose of heparin/ LMWH that the woman received during pregnancy?

Name of Drug _____ Daily dose _____

For how long did the woman receive this dose? ☐☐ *weeks*

4.8 **During pregnancy, how many times was the heparin dose changed?** ☐☐

What daily heparin/ LMWH dose was prescribed at:

	Drug Name	Dose
Booking		
12 weeks		
20 weeks		
20 weeks		

4.9 **Did the woman have a suspected or confirmed VTE during this pregnancy?** Yes ☐ No ☐

If Yes, please provide date D D / M M / Y Y and site of thrombosis _____

Was she thrombolysed? Yes ☐ No ☐

4.10 **Did the woman have pre-eclampsia/HELLP?** Yes ☐ No ☐

4.11 **Did she have any other pregnancy problems?** Yes ☐ No ☐

If Yes, please specify: _____

Section 5: Delivery of this (Index) Pregnancy

5.1 **Is the 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 _____

5.2 **Did she have a miscarriage/late fetal loss?** Yes ☐ No ☐

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

5.3 **Did the woman have a termination of pregnancy?** Yes ☐ No ☐

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

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

If Yes, was this spontaneous or induced? *(If induced, please provide reasons)*

_____

5.5 **Did the woman have a Caesarean section?** Yes ☐ No ☐

If Yes, please state:

Grade of urgency:[5]* ☐

Indication for caesarean section: _____

5.6 **What anaesthesia did the woman receive?** *(Please tick one)*

General anaesthetic ☐ Regional anaesthesia ☐

If General anaesthesia was used, please give indication _____

5.7 **When was the last dose of anticoagulation given before delivery of the baby?** D D / M M / Y Y h h : m m (24hr)

5.8 **What was the estimated blood loss at delivery?** ☐☐☐☐ *mls*

5.9 **Did the woman receive treatment with antithrombin concentrate during labour?** Yes ☐ No ☐

If Yes, when was this given? D D / M M / Y Y h h : m m (24hr)

What was the indication? _____

What dose was prescribed? _____

5.10 **When was the first dose of anticoagulation given after delivery of the infant?** D D / M M / Y Y h h : m m (24hr)

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Section 6: Outcomes

Section 6a: Woman

6a.1 What was the plan for postnatal anticoagulation? _____

6a.2 Did the woman have a VTE post-partum? Yes ☐ No ☐

If Yes, please provide date and site of thrombosis _____

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

If Yes, state the primary cause *(e.g. placental abruption/ uterine atony)*

_____

Were blood components used? Yes ☐ No ☐

6a.3 Did the woman have a placental abruption? Yes ☐ No ☐

6a.4 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 6e: 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 ☐ Forceps ☐ Vaginal Breech ☐

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

6b.3 Birthweight: ☐☐☐☐ *g*

6b.4 Was there Intra-uterine growth restriction? Yes ☐ No ☐

If Yes, when was this identified D D / M M / Y Y

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

6b.6 Apgar 5 min ☐☐ 10 min ☐☐

6b.7 Did the infant require admission to the neonatal unit/ SCBU? Yes ☐ No ☐

6b.8 Did any major infant complications occur? Yes ☐ No ☐

If Yes, please specify: _____

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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Section 7: Further information

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

Section 8: Your details

8.1 **Name of UKOSS representative 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.

CASE

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:

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
Placenta praevia
Gestational diabetes
Significant placental abruption
Post-partum haemorrhage requiring transfusion

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

Cardiac disease (congenital or acquired)
Renal disease
Endocrine disorders e.g. diabetes, 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