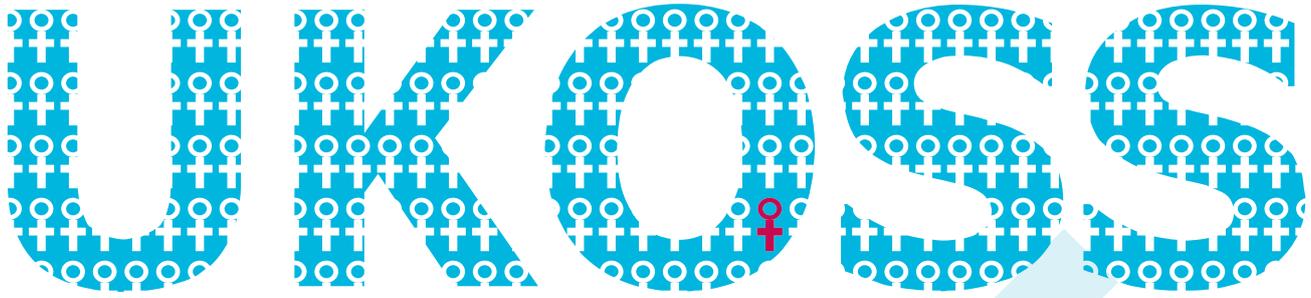


ID Number:



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 2022

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.



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:
- 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: _____

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immobilisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
COCP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long-haul flight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Minimally Provoked: Dehydration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Short-haul flight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
COCP >1yr	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unprovoked:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- 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*}** / /
- 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? / /
- 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 receiving 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 | _____ | _____ |

- 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*}** / /
- 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? / /
- 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 receiving 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 | _____ | _____ |
| 28 weeks | _____ | _____ |

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 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: 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

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

What was the primary cause of death as stated on the death certificate?

(Please state if not known) _____

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