Pregnancy in women with stage 5 Chronic Kidney Disease (chronic renal failure)
Study 01/12

Data Collection Form - CASE

Please report any woman delivering on or after 1st February 2012 and before 1st January 2014.

Case Definition:

Please report any pregnant woman with stage 5 Chronic Kidney Disease (chronic renal failure). This would usually include any pregnant woman in one of the following groups:

- A woman with an estimated glomerular filtration rate (eGFR) <15mls/min/1.73m² pre-pregnancy
- A woman receiving peritoneal or haemodialysis at conception
- A woman with a serum creatinine >300µmol/l pre-pregnancy
- A woman with a serum creatinine >250µmol/l on two or more occasions during pregnancy
- A woman commenced on peritoneal or haemodialysis to treat chronic kidney disease during this pregnancy

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: ___________________________
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? 

   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 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 (including kidney problems during previous pregnancies)?2* Yes No

   If Yes, please specify: 

*For guidance please see back cover
Section 3: Previous Medical History

3.1 What was the underlying disease or condition causing chronic kidney disease?

3.2 Has this woman received a renal transplant?  
Yes ☐  No ☐  
If Yes, what was the date of the most recent transplant?  
[ ] [ ] [ ] [ ]

3.3 Has this woman previously received dialysis?  
Yes ☐  No ☐  
If Yes, on what date was dialysis first commenced?  
[ ] [ ] [ ] [ ]
Was this during a previous pregnancy?  
Yes ☐  No ☐
What was the indication for starting dialysis? ________________________________
What were the following values when dialysis was commenced?

<table>
<thead>
<tr>
<th>Value</th>
<th>Unit</th>
<th>Date</th>
<th>Not Recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>K+</td>
<td>mmol/l</td>
<td>[ ] [ ] [ ]</td>
<td>☐</td>
</tr>
<tr>
<td>Urea</td>
<td>mmol/l</td>
<td>[ ] [ ] [ ]</td>
<td>☐</td>
</tr>
<tr>
<td>Creatinine</td>
<td>µmol/l</td>
<td>[ ] [ ] [ ]</td>
<td>☐</td>
</tr>
<tr>
<td>Bicarbonate</td>
<td>mmol/l</td>
<td>[ ] [ ] [ ]</td>
<td>☐</td>
</tr>
</tbody>
</table>

Was there proteinuria prior to pregnancy?  
Yes ☐  No ☐
If Yes, what was the Albumin/Creatinine Ratio (ACR) _______  OR  Protein/Creatinine Ratio (PCR) _______

3.4 What were the following values prior to pregnancy?

<table>
<thead>
<tr>
<th>Value</th>
<th>Unit</th>
<th>Not Recorded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volume of urine per 24h</td>
<td>ml</td>
<td>☐</td>
</tr>
<tr>
<td>Most recent diastolic BP</td>
<td>mmHg</td>
<td>☐</td>
</tr>
<tr>
<td>Most recent serum creatinine</td>
<td>µmol/l</td>
<td>☐</td>
</tr>
<tr>
<td>eGFR</td>
<td>mls/min/1.73m²</td>
<td>☐</td>
</tr>
</tbody>
</table>

3.5 Did the woman have any other pre-existing medical problems? Yes ☐  No ☐
If Yes, please give details: ________________________________

*For guidance please see back cover
**Section 4: This Pregnancy**

**Section 4a: Antenatal care and management**

4a.1 Final Estimated Date of Delivery (EDD)**

4a.2 Was antenatal care undertaken in the usual hospital for this woman’s area of residence?

- **Yes** ☐
- **No** ☐

  If **No**, please indicate below reasons for care at a different hospital *(tick all that apply)*

  - Referred to a tertiary centre because of underlying medical condition ☐
  - Patient preference ☐
  - Other ☐

  If **Other**, please specify: __________________________

4a.3 Was this a multiple pregnancy?

- **Yes** ☐
- **No** ☐

  If **Yes**, please specify number of fetuses:

4a.4 Did this woman conceive while taking ACE inhibitors (e.g. captopril)?

- **Yes** ☐
- **No** ☐

4a.5 Did this woman receive Erythrocyte Stimulating Agents (ESA)/Erythropoetin (EPO)?

- **Yes** ☐
- **No** ☐

  If **Yes**, please give agent and maximum dose: (e.g. aranesp, micera)

<table>
<thead>
<tr>
<th>Agent</th>
<th>Dose</th>
<th>Frequency</th>
</tr>
</thead>
</table>

4a.6 Did the woman receive intravenous iron during pregnancy?

- **Yes** ☐
- **No** ☐

  If **Yes**, please give dose and number of doses:

<table>
<thead>
<tr>
<th>Dose</th>
<th>Number</th>
</tr>
</thead>
</table>

4a.7 Did this woman receive any of the following during pregnancy?

- **Yes** ☐
- **No** ☐

  If **Yes**, please tick all that apply

  - Aspirin ☐
  - LMWH (in addition to anticoagulation on dialysis) ☐
  - Unfractionated heparin ☐
  - Vitamin D (cholecalciferol or adcal D3) ☐

**Section 4b: Dialysis therapy**

4b.1 Has this woman received dialysis in this pregnancy?

- **Yes** ☐
- **No** ☐

  If **Yes**, please indicate whether any of the following dialysis therapies were used in this pregnancy *(Please tick all that apply)*

  *If more than one dialysis treatment was given please give dates of changes*

<table>
<thead>
<tr>
<th>Used</th>
<th>Maximum hours per week during pregnancy</th>
<th>Date of change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peritoneal Dialysis</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Haemodialysis</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Nocturnal dialysis</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Haemodiafiltration (Dialysis using individually prescribed replacement fluid)</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

*For guidance please see back cover*
Were there any admissions for dialysis related events?  

If Yes, please tick all that apply:

- Hypotension  [ ]
- Line infection [ ]
- Line not working [ ]
- Fistula or graft clotting [ ]

Please give details of access for dialysis (Please tick all that apply)

<table>
<thead>
<tr>
<th>Used</th>
<th>Date started</th>
<th>Still used</th>
<th>Date ended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Line 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Line 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Line 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fistula</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graft (type of fistula)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4b.2 Please indicate the number of antihypertensive drugs used:

- Prior to pregnancy [ ]
- First trimester (up to 14 weeks) [ ]
- Second trimester (14-28 weeks) [ ]
- Third trimester (after 28 weeks) [ ]

Section 4c: Laboratory results and complications

4c.1 Please record the levels of the following:

<table>
<thead>
<tr>
<th>Highest serum urea (mmol/l)</th>
<th>Lowest serum urea (mmol/l)</th>
<th>Lowest haemoglobin (g/dl)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First trimester (up to 14 weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Second trimester (14-28 weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third trimester (after 28 weeks)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4c.2 Did the woman have a serum creatinine >250µmol/l on two or more occasions in this pregnancy?  

Yes [ ] No [ ]

4c.3 Did the woman have polyhydramnios (Amniotic Fluid Index >20cm) diagnosed at any point in pregnancy?  

Yes [ ] No [ ]

4c.4 Was pre-eclampsia (or superimposed pre-eclampsia) diagnosed in this pregnancy?  

Yes [ ] No [ ]

If Yes – what was:

- Highest systolic blood pressure (mmHg)? [ ]
- Highest diastolic blood pressure (mmHg)? [ ]

4c.5 Were there any 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 M Y YMD

5.2 Did this woman have a termination of pregnancy?  
Yes ☐  No ☐  
If Yes, please specify date:  
☐ ☐ ☐ ☐ /D M Y YMD

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 the 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 Did the woman labour?  
Yes ☐  No ☐

5.6 Was delivery by caesarean section?  
Yes ☐  No ☐  
If Yes, please state:  
Grade of urgency: 6* ☐
Indication for caesarean section:  
Method of anaesthesia:  
Regional ☐  General anaesthetic ☐

**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? 7*  
Yes ☐  No ☐  
If Yes, please specify:  

6a.3 Did the woman die?  
Yes ☐  No ☐  
If Yes, please specify date and time of death  
☐ ☐ ☐ ☐ /D M Y YMD:  
h m mh 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 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](http://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 Birthweight: 

6b.4 Sex of infant:
- Male
- Female
- Indeterminate

6b.5 Was the infant stillborn?
If Yes, please go to section 7.

6b.6 5 min Apgar

6b.7 Was the infant admitted to the neonatal unit?

6b.8 Did any other major infant complications occur?**
If Yes, please specify:

6b.9 Did this infant die?
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
- 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. Definition of pre-eclampsia:
Systolic BP ≥ 140 and/or diastolic BP ≥ 90 and proteinuria ≥ 300mg/24hrs (30mg/mmol Protein creatinine ratio). If hypertension already present - the new onset of proteinuria; if proteinuria already present - the new onset of hypertension; if both hypertension and proteinuria present - the development of one additional clinical or biochemical feature of pre-eclampsia e.g abnormal LFTs)

6. 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

7. 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
- Thrombotic event
- Septicaemia
- Required ventilation

8. 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
- Exchange transfusion