ID Number:

UKOSS

UK Obstetric Surveillance System

Single intrauterine fetal death in monochorionic twins study (Single Twin Demise)

Study 04/16

Data Collection Form - CASE

Case Definition:

Please report any woman in the UK with a monochorionic twin pregnancy presenting between 1st July 2016 and 30th June 2017 with single twin demise after the first trimester dating scan, defined as:

a) Monochorionic twin pregnancy – chorionicity confirmed at first trimester scan (<14 weeks) due to ultrasonic absence of the lambda sign (an echogenic V-shaped chorionic projection of tissue in dichorionic placentation).

AND

b) Single intrauterine fetal death – intrauterine death of one twin (including spontaneous single twin demise or selective feticide) after the first trimester dating scan performed between 10-14 weeks.

Exclude: Higher order multiple pregnancies where multifetal pregnancy reduction has taken place.

Please denote the dead twin as TWIN B and the alive twin as TWIN A throughout, regardless of birth order.

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 National Perinatal Epidemiology Unit

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: 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 (if any) occupation:

_____

1.4 Height at booking: ☐☐☐ *cm*

1.5 Weight at booking: ☐☐☐.☐ *kg*

1.6 Smoking status:

never ☐ gave up prior to pregnancy ☐

current ☐ gave up during pregnancy ☐

*For guidance please see back cover

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 Does this woman have any history of previous preterm birth? Yes ☐ No ☐

If Yes, please specify number of pregnancies resulting in preterm birth: ☐

and gestation at delivery of each: _____

2.3 Have any of this woman's children died in the neonatal period (up to 28 days of age)? Yes ☐ No ☐

If Yes, please specify gestation at delivery/age at death of all babies who died if known:

_____

2.4 Did the women have a previous history of multiple pregnancy? Yes ☐ No ☐

If Yes, please give details: _____

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

If Yes, please specify: _____

Section 3: Previous Medical History

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

If Yes, please give details: _____

Section 4a: This Pregnancy

4a.1 Final Estimated Date of Delivery (EDD):[4]* D D / M M / Y Y

4a.2 Was this a confirmed monochorionic pregnancy? Yes ☐ No ☐

If No, **this pregnancy is not eligible for this UKOSS survey** ☐

If Yes, how was monochorionicity confirmed: USS ☐ Other ☐

If Other, please specify: _____

4a.3 What date was single twin demise diagnosed? D D / M M / Y Y

4a.4 Was the single twin demise: *(please tick one)* Spontaneous ☐ **OR** Iatrogenic (feticide) ☐

If Iatrogenic, please give the indication: _____

4a.5 Was this an assisted conception pregnancy? Yes ☐ No ☐

If Yes, please specify the type of artificial reproductive technique (e.g. IVF, ICSI, clomiphene):

_____

*For guidance please see back cover

Section 4b: Pregnancy complications

4b.1 Was twin to twin transfusion syndrome diagnosed? Yes ☐ No ☐

If Yes, what was the date of diagnosis? D D / M M / Y Y

What was the Quintero stage[5] at diagnosis? ☐

Was Twin B (died) donor or recipient *(please tick one)* Donor ☐ **OR** Recipient ☐

4b.2 Was selective IUGR noted (>20% difference in estimated fetal weights or birthweights)? Yes ☐ No ☐

If Yes, what date was this diagnosed? D D / M M / Y Y

What was the greatest estimated disparity in fetal weights? ☐☐ %

Please give the estimated fetal weights at this assessment Twin A: ☐☐☐☐ *g*

Twin B: ☐☐☐☐ *g*

Were any Doppler abnormalities[6] noted?

If Yes, please state which vessel and for which twin in the following table:

	TWIN A	TWIN B
Umbilical artery	Yes ☐ No ☐	Yes ☐ No ☐
Middle cerebral artery	Yes ☐ No ☐	Yes ☐ No ☐
Ductus venosus	Yes ☐ No ☐	Yes ☐ No ☐

4b.3 Were any chromosomal or structural anomalies identified in either twin? Yes ☐ No ☐

If Yes, please complete the table below to show anomalies present in each twin and method of diagnosis (e.g. amniocentesis, ultrasound) and date of diagnosis. If no anomalies in one twin, please state none.

	Anomaly present	Method of diagnosis
TWIN A		
TWIN B		

4b.4 Was amniodrainage performed? Yes ☐ No ☐

If Yes, which sac was drained? Twin A ☐ **OR** Twin B ☐

4b.5 Were any other antenatal interventions performed? Yes ☐ No ☐

If Yes, please state intervention: _____

And date performed: D D / M M / Y Y

4b.6 Was an antenatal ultrasound performed to look for neurological damage? Yes ☐ No ☐

If Yes, please give date: D D / M M / Y Y

Please specify findings: _____

4b.7 Was an antenatal MRI performed to look for neurological damage? Yes ☐ No ☐

If Yes, please give date: D D / M M / Y Y

Please specify findings: _____

4b.8 Were there any other problems in this pregnancy?[2] 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 D / M M / Y Y

and cause (if known): _____

5.2 **Did this woman have a termination of pregnancy?** Yes ☐ No ☐

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

and reason (if known): _____

If Yes to 5.1 or 5.2, please go to 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 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:[7]* ☐

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 **Did any other major maternal morbidity occur?[8]*** Yes ☐ No ☐

If Yes, please specify: _____

6a.3 **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) _____

*For guidance please see back cover

Section 6b: Infant B (Twin B dead)

NB: Please denote twin B as dead twin (or the first to die when both have died) and twin A as alive twin (or second to die) regardless of birth order.

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 or Forceps ☐ Breech ☐
Pre-labour caesarean section ☐ Caesarean section after onset of labour ☐

6b.3 Birthweight: ☐☐☐☐ *g*

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

6b.5 Were there any abnormal features noted at external examination? Yes ☐ No ☐

If Yes, please describe*:* _____

6b.6 Was a stillbirth certificate completed (i.e. for births >24 weeks)? Yes ☐ No ☐

If Yes, what was the primary cause of death as stated on the death certificate?

_____

6b.7 Was a post mortem examination undertaken? Yes ☐ No ☐

If Yes, did the examination confirm the certified cause of death/diagnosis? Yes ☐ No ☐
Not known ☐

If No, what was the stated cause of death? _____

Section 6c: Infant A (Twin A alive)

6c.1 Date and time of delivery: D D / M M / Y Y h h : m m (24hr)

6c.2 Mode of delivery: Spontaneous vaginal ☐ Ventouse or Forceps ☐ Breech ☐
Pre-labour caesarean section ☐ Caesarean section after onset of labour ☐

6c.3 Birthweight: ☐☐☐☐ *g*

6c.4 Sex of infant: Male ☐ Female ☐ Indeterminate ☐

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

If Yes, please specify date of death: D D / M M / Y Y

Was this: *(please tick one):* Prior to labour ☐ **OR** During labour ☐

What was the presumed cause of death? _____

Please now go to section 7 if the infant was stillborn.

6c.6 5 min Apgar ☐☐

6c.7 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

If Yes, please state reason for admission: _____

6c.8 Did any other major infant complications occur?[9]* Yes ☐ No ☐

If Yes, please specify: _____

6c.9 Was there any ultrasound or MRI evidence of neurological damage in the surviving twin postnatally? Yes ☐ No ☐ Not known ☐

If Yes, please give details i.e. date of imaging, type of imaging, type of abnormality:

_____

*For guidance please see back cover

6c.10 Were there any abnormal neurological signs noted in the neonatal period prior to discharge? Yes ☐ No ☐ Not known ☐

If Yes, please specify: _____

6c.11 Did this infant die in the neonatal period? 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) _____

Was a post mortem examination undertaken? Yes ☐ No ☐

If Yes, did the examination confirm the certified cause of death/diagnosis? Yes ☐ No ☐ Not known ☐

If No, what was the stated cause of death? _____

6c.12 Has this infant been discharged from your hospital? Yes ☐ No ☐

If Yes, was this to: Home ☐ Another hospital ☐

What was the date of discharge from your hospital: D D / M M / Y Y

Was there any planned imaging in the surviving twin or planned follow-up after discharge? Yes ☐ No ☐ Not known ☐

If Yes, please specify what imaging was planned: _____

Please specify timing of any planned follow-up visit: _____

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: D D / M M / Y Y

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. Twin to twin transfusion syndrome, please state which twin donor and which twin recipient and then state Quintero stage:

Stage I.	Poly/Oligohydramnios with bladder of the Doner still visible
Stage II.	Bladder of the Doner not visible
Stage III.	Presence of either AEDFV in the UA, reverse flow in the DV, or pulsatile UV in either twin
Stage IV.	Hydrops in either twin
Stage V.	Demise of one or both twins

6. Doppler abnormalities:

UMBILICAL ARTERY DOPPLER – pulsatility index (PI) or resistance index (RI)>95th centile, absent end diastolic flow, reversed end-diastolic flow

MIDDLE CEREBRAL ARTERY DOPPLER – PI<5th centile or >95th centile, absent end diastolic flow, MCA peak systolic velocity (PSV) >95th centile

DUCTUS VENOSUS – absent a wave, reversed a wave, peak velocity index for veins (PVIV) >95th centile

7. 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

8. 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

9. 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