MBRRACE-UK Confidential Survey

Guidelines for Perinatal and Infant Death data entry

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The MBRRACE-UK data collection has been approved by the Review of Central Returns Steering Committee (ROCR) – ROCR/OR/2187/001MAND
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1. Introduction

These guidelines are designed to provide you with a basic overview of how to use the MBRRACE-UK website to record perinatal deaths. We have attempted to make the website as easy to use and compatible as possible, and any difficulties we hope will be answered by consulting this guide. If you have unresolved difficulties with entering data on the website, please contact MBRRACE-UK.

2. Web browser information

To ensure high security, this web form must be used on computers that have internet browser software which is considered an appropriate standard. This web form is designed to work on:

- Internet Explorer (version 9 onwards)
- Firefox (version 5.0 onwards)
- Safari (version 5.0 onwards)
- Chrome (version 12.0)

For computers running older versions of Internet Explorer (7 & 8) we have provided a Chrome Frame plugin from Google that you will have to install the first time you use the form. If it is required, you will be prompted to install the Chrome Frame browser plugin the first time you use the MBRRACE-UK website. You will only need to do this once and may need to restart your system. If you have problems installing the plugin, please email us with the contact details for your IT department.

Please note that if you try to use the web form on older browsers without using the plugin it will not work properly. Please do not run this web form on browsers older than and including Internet Explorer 6 as this will not have the appropriate security features.

Some web browsers remember (“cache”) data and autocomplete or predictively type in data for you. This may include patient identifiable information. In order to preserve patient confidentiality we would discourage you from using this feature and politely request that you disable it by turning autocomplete “off” in your browser’s ‘options’ tab.
3. Logging in for the first time

The MBRRACE-UK website is located at [www.mbrrace.ox.ac.uk](http://www.mbrrace.ox.ac.uk)

You will arrive at the login screen, where you will be asked to enter the user details that have been sent to your registered email address.

- When logging in for the first time, users will need to request a new activation code.

- This code will be sent to the user’s registered email address.

- Use this code as a single use authentication code, and change this upon registering.

- This can also be done if you forget your password
4. The home page

Once you have logged in, you will come to the home screen. You are able to check project news and updates, as well as accessing the data entry form.

- To enter data, click on the **Perinatal and Infant Death** tab
- Then click on the pink button, titled ‘**Perinatal and Infant Death data entry**’

You will then come to the following screen:

From this screen you have two options. You can **start a new case**, or **search for an existing case**.
5. Starting a new case

- To start entering a new case, select the hospital you wish to enter data for.
- Then click ‘Start a new case’
- Each new case will be assigned a **Case ID**. Take a note of this number so you can search for the case easily in future.

6. Searching for an existing case

To search for an existing case that you have already entered or started to enter, you can use the following options under the **Search Criteria** heading:

Either:

- NHS/CHI number

Or:

- Family name/surname
- **and** Date of birth

Or:

- The **MBRRACE Case ID**, which will be assigned for each case.

Click on the ‘Search’ button.

The results will appear on the right hand side. You can then click ‘Edit this form’ to review and modify the information that has already been entered.
7. Before moving on – Notification and Woman’s details

The first section of the form you will see is **1 Notification and Woman’s details**.

You are now able to enter data into the form.

You will be asked to enter basic identifying information about the woman. If this is a case that has already been entered, and you have searched for it using the search feature, these details will already be filled out. If it is a new case, you can start adding the data required.

- Enter data into the boxes provided, or for an existing case, check to see if they are correct
- Click on ‘Confirm, save and continue’ to save work and move onto the **next section**
- If you do not have all the details, you can click on ‘Partial save and continue’
- Take note of the **Case ID** for future reference
8. Sections of the form

There are six sections you are required to fill out. These are:

1. **Notification and Woman’s details**
   - 1.1 Woman’s identifiers
   - 1.2 Woman’s details

2. **Woman’s health**
   - 2.1 Woman’s health

3. **Previous pregnancies**
   - 3.1 Previous pregnancies
   - 3.2 Obstetric history

4. **This pregnancy**
   - 4.1 Booking
   - 4.2 Antenatal care provision

5. **Delivery and outcomes**
   - 5.1 Delivery and outcomes summary

6. **Check and complete form**
   - 6.1 Add clinicians
   - 6.2 Check and close form

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1. This section asks for basic information about the woman (e.g. name, address, demographic information, NHS and hospital identification)

2. Enter data about pre-existing medical conditions, smoking status and breath CO levels, and information about alcohol and drug use

3. Add information about previous pregnancies and obstetric history here (including outcomes and complications)

4. Add antenatal booking details such as type of antenatal care provision (intended and actual), the woman’s height and weight, EDD, place of delivery

5. There are four parts to this section, allowing you to add details of (A) labour and delivery, (B) baby/fetus outcomes, (C) cause of death, and (D) post-mortem.

6. This section allows you to add details of clinicians involved.

You can also check the form to see if there are any errors or missing data.
9. Finding your place

- The index page allows you to access different sections of the form for editing. You can close and expand each section of the form using this menu.
- The ‘Jump to section’ button at the bottom of the page allows you to quickly access other parts of the form.

Using these headings to navigate through the form will automatically save work in progress. However, it is worth continually saving work to make sure data is not lost.

10. Saving work in progress

- At the end of each section, there is a ‘Save and continue’ button. Once you have finished a section click this button to avoid losing data.
- You can click ‘Save ‘as is’’ at the bottom of the page to save uncompleted forms.
11. Entering data

Incorrect answers

The form will let you know if information has been entered incorrectly.

- When an appropriate value is added in the boxes, the text will show up in **green**.

- Unusual values (e.g. higher than expected alcohol consumption) will show up in **yellow**.

- When an incorrect value is added, the text will show up in **red** along with an explanation. This will also happen if dubious or unlikely values are added (e.g. adding a person’s weight in as 1000kg).

Unknown answers

Questions that have a drop down list will have an option to select ‘unknown’ if you do not know the answer. For questions that require you to enter data manually (i.e. type it in yourself rather than choose from a drop-down list), you can click the grey (X) on the left-hand side of the box if the answer is not known:

It will then turn black with a check (✓):

You are able to click this box again if you gain the information at a later date.
Entering data continued...

Dates and measurements

Some questions ask for a specific date (e.g. the woman’s date of birth). When you click in the box, a calendar will appear and you can choose the specific date from here. Alternatively, you can enter the date manually using the format DD/MM/YYYY (e.g. 01/01/1979).

- Click in the box and choose the year, month and date
- Alternatively, enter the date using the format DD/MM/YYYY (e.g. 01/01/1979)
- For questions about height and weight, please use metric measurements (centimetres, kilograms, grams) rather than imperial (pounds, ounces, feet, inches).

Entering specific places

Some questions ask you to enter a specific place (normally a medical facility). These questions are Intended place of delivery at booking (in section 4.1), Intended place of delivery at onset of labour (section 4.2) and Actual place of delivery (also in section 4.2).

- Where it asks for place of delivery, type in the first few letters of the place.
- Options will appear in the drop-down list below the box.
12. Entering medical conditions

Some sections will ask for information about medical conditions, and use specific classification systems for illnesses and causes of death – either the WHO International Classification of Disease (ICD-10) or Causes of Death and Associated Conditions (CODAC). These sections are:

2.1 Woman’s health (ICD-10) *(Did the woman have any pre-existing medical conditions?)*

3.2 Obstetric history (CODAC) *(Did the woman have any previous pregnancy complications?)*

5.1C Cause of death (CODAC)

These sections allow you to search for specific conditions using words or parts of a word. For example, if you were searching for ‘Diabetes’, typing in a few letters of the word (‘diabe’) will produce all conditions that contain this term. It also allows you to add multiple conditions if necessary. For more information on the CODAC system, please see the Appendix (p.15).

- Look for the option to ‘Add condition’, or ‘Add cause…’. In some instances you may have to answer a filter question, e.g. ‘Did the woman have any pre-existing medical conditions?’ (2.1)
- On the new screen that pops up, enter your search term or part of the term.
- You may wish to use more than one term (e.g. *heart* and *valve*). If so, tick the box to include all terms. Otherwise the search will include items that contain either term.
- Select condition from the drop-down list in the box below
- You will be asked for one primary cause of death and additional associated conditions if necessary. If both the Death Certificate and Post Mortem are available, please use the Post Mortem when recording the cause of death.
13. Finishing the form and Logging out

Before finishing the form, you will be asked to check through the data to rectify any mistakes. This is in section 6.1 “Check and close the case”.

- Click on the heading “Check and close the case”
- Then click “Check all sections”
- Errors will show up in the list on the right-hand side
- You can jump to the relevant section by clicking on the text in pink.

Leaving the form is simple. The ‘Logout’ button can be found in the top-right corner of the page. If the form has been inactive for some time, you will be logged out automatically. You may lose unsaved data if this happens. You can also leave the form by clicking the ‘Perinatal and Infant Death’ heading at the top of the page.

To ensure confidentiality, and to avoid losing unsaved data, please log out of the website if you have to leave your computer station unattended.

- The ‘Logout’ button is located in the top-right corner of the page.
- When leaving the site, you will be reminded to make sure your data is saved.
14. Accessing FAQ’s

Frequently Asked Questions (FAQ’s) are available on the website.

You can either click the **blue** button at the top of the form (under the heading ‘Perinatal and Infant Death Form’) for general queries.

Alternatively, you can hover the cursor over the **black question mark** for information specific to that question.

FAQ’s will be continuously updated the more the site is used.

To provide feedback or for more information, please click the ‘**contact us**’ button on the home page.
Appendix: Causes of Death and Associated Conditions (CODAC)

Please note that this section is for information only. When you enter data, the MBRRACE-UK website will generate these codes for you using the search facility explained in section 12 above.

Coding Cause of Death using the CODAC system of classification

The most appropriate and up-date classification system has been chosen to record the causes of perinatal deaths and associated maternal conditions for the MBRRACE-UK data collection: this is the CODAC (Causes of Death and Associated Conditions) system. The authors state that “....the CODAC classification has benefited from being discussed and developed over an extended time period by a diverse group of experts, being independently tested in several populations by different groups of coders, and amended according to user feedback prior to publication”¹. The intention of the creation of the CODAC system is to improve the management of information related to the causes of perinatal death, associated conditions, which will hopefully, enable comparisons and detailed study of common clinical scenarios¹.

The CODAC system uses a hierarchical tree of potential causes to code the underlying cause of death. In addition, up to 2 further codes for associated conditions can be generated if required. Each code is 3 digits long, with each digit representing one of each of the three levels of the hierarchy of the classification system. The conditions in each level are numbered 0..1..2..3 and so on. So, for example, the main causes of death in Level I, are listed below:

Main causes of death – Level I

0  Infection
1  Neonatal
2  Intrapartum
3  Congenital Anomaly
4  Fetal
5  Cord
6  Placenta
7  Maternal
8  Unknown
9  Termination

At level II each of these causes is sub-divided and allocated a code 0..1..2..3, this occurs again at level III.

Figure 1 below gives several examples of how conditions are coded using the 3 levels of coding and figure 2 illustrates how the associated conditions are coded.
Fig 1. CODAC Coding Examples

Example 1 – Necrotizing enterocolitis

CODAC code 141
Example 2 – Unspecified congenital anomaly of the central nervous system

CODAC code 310

**LEVEL I**
- 0 Infection
- 1 Neonatal
- 2 Intrapartum
- 3 Congenital anomaly
- 4 Fetal
- 5 Cord
- 6 Placenta
- 7 Maternal
- 8 Unknown
- 9 Termination

**LEVEL II**
- 0 Unspecified or other
  - 1 Central nervous system
    - 2 Cardiovascular and lymphatic vessels
    - 3 Genito-urinary
    - 4 Skeletal
    - 5 Respiratory and diaphragm
    - 6 Gastro-intestinal tract
    - 7 Trisomies
    - 8 Aneuploidies / structural chromosomal abnormalities - other
    - 9 Amniotic banding

**LEVEL III**
- 0 Unspecified
  - 1 Anencephaly
  - 2 Craniorachischisis
  - 3 Holoprosencephaly
  - 4 Hydranencephaly
  - 5 Hydrocephalus
  - 6 Microcephaly
  - 7 Other
Example 3 – Placental abruption in a small for gestation placenta

CODAC code 637

**LEVEL I**
- 0 Infection
- 1 Neonatal
- 2 Intrapartum
- 3 Congenital anomaly
- 4 Fetal
- 5 Cord
- 6 **Placenta**
- 7 Maternal
- 8 Unknown
- 9 Termination

**LEVEL II**
- 0 Unspecified or other
- 1 Abnormal implantation, migration or shape
- 2 Villous / vascular mal-development
- **3 Abruption or retro-placental haematoma**
- 4 Infarctions and thrombi
- 5 Circulatory disorder - other non-abruptions
- 6 Neoplastic disorder
- 7 Transfusion and feto-maternal haemorrhage
- 8 Small for gestation placenta

**LEVEL III**
- 0 Unspecified
- 1 In abnormal or scarred uterus
- 2 In apparently normal placenta
- 3 In pre-existing abnormal implantation or shape
- 4 In pre-existing villous mal-development
- 5 In pre-existing infarctions
- 6 In pre-existing circulatory disorders – nos
- **7 In pre-existing small for gestation placenta**
- 8 In pre-existing infection / inflammation of the placenta
- 9 Other
Example 4 – Unexplained stillbirth

CODAC code 861

**LEVEL I**
- 0 Infection
- 1 Neonatal
- 2 Intrapartum
- 3 Congenital anomaly
- 4 Fetal
- 5 Cord
- 6 Placenta
- 7 Maternal
- 8 Unknown
- 9 Termination

**LEVEL II**
- 0 Unspecified or other
- 1 Unknown with no placental PAD nor autopsy
- 2 Unknown with no placental PAD
- 3 Unknown with no autopsy
- 4 Unknown / lacking documentation
- 5 Unknown despite autopsy and placental PAD
- 6 Unexplained despite full evaluation
- 7 Unclassifiable

**LEVEL III**
- 0 Unspecified
- 1 despite documented full evaluation according to guidelines - unexplained stillbirth
- 2 despite documented full evaluation according to guidelines - SIDS Category II
- 3 Other

Cause of death: Unknown (8)/Unexplained despite full evaluation (6)/despite documented full evaluation according to guidelines: unexplained stillbirth (1) = 861 – with no Associated Conditions (AC).

Up to two Associated Conditions can be coded for each cause of death. The following examples illustrate coding of cord knots, eclampsia, one associated maternal condition and one associated perinatal condition:
Fig 2. CODAC Coding Examples – Associated Conditions

Example 5 – AC (cord knot in otherwise uncompromised cord of normal length (unspecified))

CODAC code 511
Example 6 – AC (maternal hypertensive disorder – eclampsia)

CODAC code 711

LEVEL I
0 Infection
1 Neonatal
2 Intrapartum
3 Congenital anomaly
4 Fetal
5 Cord
6 Placenta
7 Maternal
8 Associated perinatal
9 Associated maternal

LEVEL II
0 Unspecified or other
1 Hypertensive disorder
2 Uterus and cervix
3 Diabetes
4 Endocrine - other
5 Anaemia
6 Haematology - other
7 Autoimmune - other
8 Malnutrition
9 Infection

LEVEL III
0 Unspecified
1 Eclampsia
2 HELLP syndrome with or without eclampsia
3 Hypertension / hypertensive crisis - unspecified
4 Hypertension / hypertensive crisis in pregnancy-induced HT / preeclampsia
5 Hypertension / hypertensive crisis in preexisting HT
6 Ehler-Danlos syndrome
7 Pulmonary hypertension - other
8 Other
Example 7 – AC (Associated Perinatal, small for gestational age – clinical diagnosis by ultrasound measures)

**CODAC code 817**
Example 8 – AC (Associated Maternal, maternal characteristics – BMI >40)

CODAC code 962

References: