



## MBRRACE-UK: Delivering the UK-wide Maternal, Newborn and Infant Clinical Outcome Review Programme

### Welcome to Issue 3 of the MBRRACE-UK Newsletter

This issue will focus on the progress made so far with the data collection for the MBRRACE-UK Perinatal Surveillance System and the plans underway for the 2013 Perinatal Confidential Enquiry. In addition there is an update of the outcome of the Confidential Enquiry topic selection and the Confidential Enquiry into Maternal Deaths which is now in progress.

### Where are we now?

The web-based Perinatal Surveillance data collection system was launched at a meeting at Imperial College London on Thursday 11th April. At the time of publication we have:

**165** - Trusts/Health Boards represented  
**1275** - Registered users  
**377** - Users have logged on to the system  
**1075** - Cases entered  
**337** - Cases remain incomplete

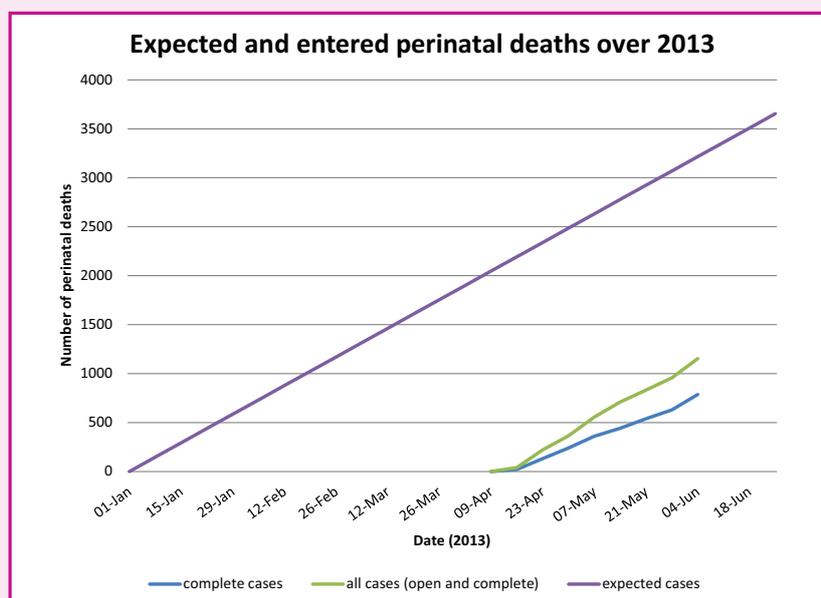
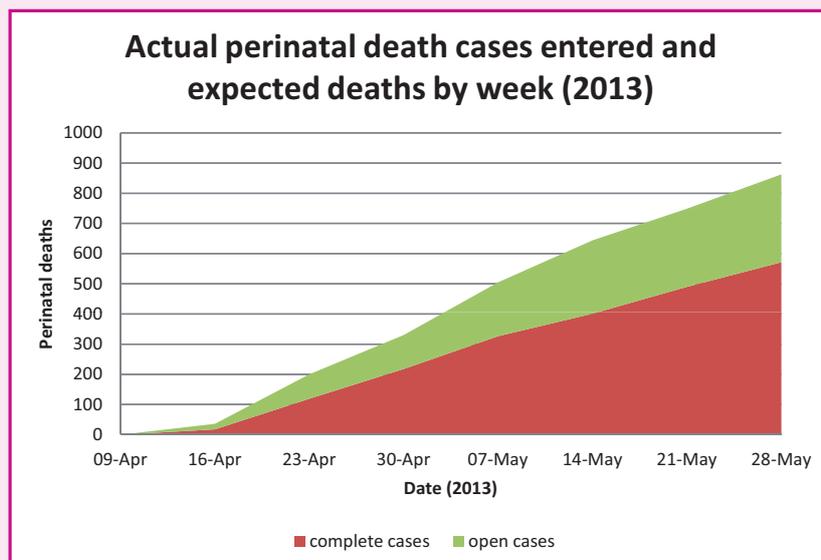
### NEWSFLASH

- Individual copies of completed forms can now be downloaded and printed off for inclusion in clinical notes and to send to your local CDOP/CDR
- Some Units have yet to enter any cases in the MBRRACE-UK system for 2013. If you have not yet started entering cases please can you do so before your backlog of cases becomes unmanageable

Thank you to everyone who has spent many hours recording the data and working through the back-log of cases accumulated over the last few months. Your patience, dedication and hard work are greatly appreciated.

Accurate and timely completion of data are essential in order to meet the reporting timetable. A report on perinatal deaths will be produced each year based on the BIRTHS in the previous chronological year. Data entry up to 31st of March the following year will ensure the capture all neonatal deaths. This will allow us to produce annual reports the following autumn. As timescales will be tight it will be crucial to collect data as close to real-time as possible. As we progress through the year we aim to give individual feedback to Units throughout the year so that there are no last minute surprises.

The graphs below illustrate the current status of data collection and show the predicted number of cases versus the actual data collection to date and the number of completed cases versus those still awaiting completion.



The perinatal team (Dr Pauline Hyman-Taylor and Mrs Janet Hood) will shortly be contacting all registered users by email. To facilitate communication between users and MBRRACE-UK and to allow information to be cascaded down through the clinical teams within each Unit, we will be asking for nominations for an **MBRRACE lead user** within your organisation. We will need to identify a lead user for each Specialty in your Unit for two reasons:

- Validation of deaths registered with ONS (England & Wales), NRS (Scotland) and GRO (Northern Ireland) will be carried out to ensure all stillbirths and neonatal deaths have been notified to MBRRACE-UK. If we identify that a death has apparently been 'missed' the outstanding data will then be requested from the relevant Unit via the lead user.
- The data entered into the system will be reviewed on a monthly basis for accuracy and completeness. We will highlight any data queries and forward a request for amendments to the lead user at each unit. By highlighting discrepancies as soon as possible after data entry we hope they can be rectified quickly and avoid a large backlog.

At the moment some Units have just one individual registered with the MBRRACE-UK system. We would encourage every organisation to ensure they have a number of users registered to ensure 24/7 coverage for MBRRACE-UK.

## Support

The MBRRACE-UK team are working to support our users and answer questions and queries. There is an email support service provided to address any issues arising from entering data into the system

[mbrrace.support@npeu.ox.ac.uk](mailto:mbrrace.support@npeu.ox.ac.uk)

and there are two telephone numbers available:

**University of Oxford (maternal office) 01865 289 715**

**University of Leicester (perinatal office) 0116 252 5425**

If you are encountering problems with data entry into the system please contact us and we will endeavour to help you as quickly as we can.

There are two sources of direct help available to you:

- The 'online data entry guidebook' can be downloaded from the data entry system once you login (<https://www.mbrrace.ox.ac.uk/>) and is also available at: <https://www.npeu.ox.ac.uk/mbrrace-uk> This deals with common user issues relating to logging on, passwords and being unable to progress through the form. There is also an appendix dealing with the coding of cause of death (CODAC).
- The other source of help is the 'Frequently Asked Questions' (FAQ) button on the main perinatal data entry screen; this is updated as issues arise. Details of the system requirements necessary to run the new MBRRACE-UK web-based data collection system can be found at: [www.npeu.ox.ac.uk/mbrrace-uk/itspec](http://www.npeu.ox.ac.uk/mbrrace-uk/itspec)

### Hot tips on coding medical conditions and cause of death

One of the common queries is for help with coding either previous maternal medical conditions or cause of death:

- consider which body system is affected by the condition being coded. For example: cardiovascular, neurological, respiratory etc.
- search under the first 4 or 5 characters e.g. depr for depression
- consider synonyms as a search term

## What's next?

### Progress report on the 2013 Perinatal Confidential Enquiry

The topic chosen for the 2013 perinatal confidential enquiry is congenital diaphragmatic hernia. The Expert Panel has now been identified and will be meeting early in July to begin the process of agreeing a consensus on the key elements of care from diagnosis to discharge / death. This will then be used by the confidential enquiry review panels to evaluate the extent to which these standards of care were achieved in a series of recent cases sampled from across the UK. The review panels will be convened throughout October, November and December and the findings will be reported in mid-2014.



## Topics selected for future confidential enquiries

Twenty-three topics were proposed for future confidential enquiries. Following the three stage HQIP topic selection process the following topics were chosen by the MBRRACE-UK Independent Advisory Group:

### The perinatal/infant morbidity and mortality confidential enquires for 2014:

- Unexpected term antepartum stillbirth of normally formed infants

### The maternal morbidity confidential enquiries for 2014 and 2015:

- Women who are at high risk of major postpartum mental illness in pregnancy (history of bipolar affective disorder or postpartum psychosis) and who subsequently develop a postpartum psychosis requiring psychiatric admission
- Pregnancy in women with artificial heart valves

### A statement from Dr Catherine Calderwood, Chair of the Independent Advisory Group, regarding the selection of confidential enquiry topics:

“We were gratified by the number and quality of topics proposed in this first round of proposals. The choice of the final topics was difficult given the number and range suggested. Following the lengthy selection process the two severe maternal morbidity topics were selected, by the Independent Advisory Group, from those proposed on the basis that they represent the major morbidities underlying the two leading causes of maternal deaths in the period 2000-2008. Both were also considered important for confidential enquiry because of the significance for both conditions of multi-disciplinary, cross-specialty working and issues around choice of medication, medication adherence and dosage monitoring. Confidential enquiries into both conditions were considered likely to provide generalisable messages relevant to other psychiatric and cardiac topics. The stillbirth topic was selected from those proposed as stillbirths overall account for more than 50% of all perinatal deaths and the stillbirth rate in this particular sub-group has not changed substantially for the past decade.”

More information about the confidential enquiry topic selection process can be found at:  
<https://www.npeu.ox.ac.uk/mbrance-uk/topic-proposals>

## Maternal Data Collection and the Confidential Enquiries

### Where are we now?

In view of the large backlog of maternal deaths from January 2009 onwards, we have now received regulatory approval to collect non-anonymised copies of maternal case records until the backlog is dealt with. Charlotte McClymont and her team will be in touch with details of how to send these to us securely. We would be grateful if you can send copies of the notes as soon as they are requested, as the MBRRACE-UK assessors have now been recruited and have begun reviewing cases.



Once again **thank you** for all your hard work so far and your patience in waiting for the new data entry system, it is greatly appreciated. We look forward to working with you over the coming months and will keep you updated with newsletters and postings on the MBRRACE-UK website.



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**MBRRACE-UK Meet the collaborators -**  
**Scan the QR code for more details of the people involved.**

