

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

MBRRACE-UK has been appointed by the Healthcare Quality Improvement Programme to run the national Maternal, Newborn and Infant Clinical Outcome Review Programme. MBRRACE-UK will continue the national programme of surveillance of maternal deaths, stillbirth and infant deaths and carry out a programme of confidential enquiries into maternal deaths, serious maternal morbidity, stillbirths, infant morbidity and mortality.

The aim of MBRRACE-UK is to provide robust information to support the delivery of safe, equitable, high quality, patient-centred maternal, newborn and infant health services.

Welcome to our latest update

Since we started work in June 2012 we have been evaluating the legacy data left at the close of CMACE (our predecessors); establishing the new processes to collect surveillance data, in particular addressing the requirement to move from the old paper based system to using electronic data capture; setting in place new arrangements for the confidential enquiries of maternal deaths and serious morbidity; establishing a new programme of confidential enquiry panels into perinatal and infant morbidity and mortality; and underpinning these activities by obtaining the appropriate regulatory approvals.

We appreciate the challenge that the move to electronic data capture may present for some users of the new data collection system. With the level, extent and detail of information we will be collecting security considerations are paramount. Older versions of browsers used to access the internet do not provide sufficient security and the data collection system will not run properly. Details of the requirements necessary to run new MBRRACE-UK web-based data collection system can be found at: www.npeu.ox.ac.uk/mbrrace-uk/itspec

We would like to take this opportunity to thank all the staff in Units who have been waiting for the launch of the web-based data collection system. The development of this system has been a huge undertaking in a very short space of time and we appreciate the frustration this has caused for those of you waiting to use it to notify us of your cases. Thank you for your patience.

More information about all our activities is available on our website at: www.npeu.ox.ac.uk/mbrrace-uk









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Update on the Perinatal Surveillance and Confidential Enquiry Programme

Where are we now?

The web-based perinatal data collection system

This has now reached its final version following extensive internal and external testing and is available to registered users at all registered hospitals across the UK. We have gone to great lengths to design a system which is user-friendly and fit for purpose, collecting data that is useful and accurate. However no system is perfect and we would welcome your comments and suggestions on the experience of using it. This will allow us to improve the system over the coming months. You can contact us by email and phone: email: mbrrace-uk@npeu.ox.ac.uk

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We look forward to hearing from you.

The UK stillbirth rate is a priority for further investigation (see graph below)



We have changed the coding system for perinatal deaths – Why?

Previous coding using systems used for UK perinatal data collection were designed to identify broad groups of deaths but left many, especially stillbirths, unclassified. We therefore wanted to use a system that was able to record more detail about the influences on any particular death and which would allow better international comparison. After much discussion and advice we chose CODAC.

CODAC (Cause Of Death and Associated Conditions)¹ system has been used widely around the world. The CODAC system uses a hierarchical tree of potential causes to code the underlying cause of death. When entering data about a death you will see that it asks you to identify the main cause of death and associated factors at three levels. Of course it will take a little time for everyone to get used to CODAC and so we are also asking you to record what was on the death / stillbirth certificate or in the notes so that we can evaluate the use of this new coding system. If we do find any problems, we will let you know.

1. Froen JF, Pinar H,Flenady V, Bahrin S, Bahrin S, et al. Causes of death and associated conditions (Codac) – a utilitarian approach to the classification of perinatal deaths. BMC Pregnancy and Childbirth 2009 9:22.

The CODAC classification system

The CODAC classification system – coding underlying cause of death

The first level used by CODAC is shown 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. Further information is available in the user guide on our website (https://www.npeu.ox.ac.uk/mbrrace-uk). We have included examples of coding for common causes of neonatal death to help explain how CODAC works. There is also a helpful search engine included in the data collection pages to help you generate these codes.

What's next?

Confidential Enquiries

The work of MBRRACE-UK also encompasses a rolling programme of confidential enquiries investigating varies aspects of perinatal morbidity and mortality.

The chosen topic for 2013 is congenital diaphragmatic hernia. The process for the selection of a topic for 2014 has just been completed and will focus on unexplained stillbirth at term. The process to choose the topic for 2015 will begin this autumn and will be flagged in a future newsletter.

Congenital diaphragmatic hernia remains an extremely challenging condition with regard to management. The enquiry process will focus on the care pathway and will begin with a consensus process to identify the key elements of good care from diagnosis to discharge / death. Whilst some more detailed aspects of management may remain controversial we anticipate that there will be sufficient consensus to allow the suitability of existing network pathways to be tested from the perspective of families.

After the consensus process is complete a number of panels will be established with members from each English region, Scotland, Northern Ireland and Wales. Standardisation across panels will be carried out and between 60 and 80 cases will be reviewed. Stratification will be used to ensure that cases sampled reflect a range of outcomes as well as geographical representation. We will keep you updated with our progress on the website and in future newsletters.



Update on the Maternal Surveillance and Confidential Enquiry Programme

Where are we now?

We are extremely pleased to have been working with the relevant Royal Colleges and specialist societies to recruit a number of expert assessors ready to undertake the confidential case reviews of the maternal deaths which have occurred since 2009. Teams of obstetric, anaesthetic, midwifery, pathology and psychiatric assessors are in place to review all cases, with some cases additionally reviewed by specialist physicians, general practitioners, intensive care and emergency medicine specialists. Further details of the appointed assessors will be available on the MBRRACE-UK website after their appointments have been ratified by the MBRRACE-UK Independent Advisory Group.

What's next?

New confidential enquiries into severe maternal morbidity

The morbidity theme for the 2014 report is maternal sepsis, and we have begun to identify a sample of 30 cases from across the UK of women who survived septic shock during or after pregnancy, selected randomly from the cases reported in the UKOSS maternal sepsis study. We will undertake a confidential case review of these cases, and hence will be collecting anonymised case notes and clinicians' reports, to be assessed by the same groups of expert assessors who review the maternal deaths. This work will be advised by a specially recruited group of experts in maternal sepsis.

Data collection

We estimate there are now over 400 maternal deaths UK-wide for which we need to collect surveillance information, fully anonymised copies of case-notes, post-mortem reports and clinicians' reports before we can commence the confidential enquiry process. We really value your help in collecting this information. On transfer of the legacy data for deaths from January 2009 onwards we received complete data on fewer than 100 maternal deaths, and partial data on about 120 cases. There are also 40 cases for which we have a case identification number but insufficient information to enable us to identify the woman and/or the hospital where the death occurred. Charlotte McClymont and her team will therefore be checking cases with all centres to ensure that we have records for them all.

There have also been over 150 new cases reported and we are collecting the relevant information on these cases. Changes to information security and data protection processes require us to collect all paper-based information in an anonymised format; hence all case-notes must be anonymised before return to the MBRRACE office. Unfortunately this means that the return of data has been slower than anticipated; we have to date received case notes for fewer than 20 of the outstanding cases. We are working with the regulatory authorities to investigate a one-off solution for collection of the legacy data, since we need to begin the confidential enquiry process very shortly in order to produce the surveillance and confidential enquiry report in 2014. Any delay in returning data risks delaying the report.

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.

