

MBRRACE-UK and the UK-wide national Maternal, Newborn and Infant Clinical Outcome Review Programme – an update

The Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) is one of a number of programmes of quality review overseen by the Healthcare Quality Improvement Partnership (HQIP). In June 2012, HQIP appointed MBRRACE-UK (Mothers and Babies – Reducing Risk through Audits and Confidential Enquiries across the UK) to run the national MNI-CORP. The MBRRACE-UK data collection system for the UK-wide national surveillance of stillbirths, infant deaths and maternal deaths went live during April 2013.

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The Maternal, Newborn and Infant Clinical Outcome Review Programme (MNI-CORP) originated in 1993, although the formal review of maternal deaths began much earlier in 1952. Over time it has been run by different organisations, including CESDI (Confidential Enquiry into Stillbirths and Deaths in Infancy) and most recently CMACE (Centre for Maternal and Child Enquiries). The oversight of the work has been the responsibility of different sections of the Department of Health (DH) during this period. In 2010, at the end of the previous contract period, the DH commenced a new tendering process for the work. The timing of this decision coincided with the peak of the financial crisis and great change within the DH; these were probably significant factors that led to:

- A need to reduce significantly the budget allocated to this activity.
- Significant delays in choosing a new provider.

It was in June 2012 that the Healthcare Quality Improvement Partnership (HQIP) appointed MBRRACE-UK (Mothers and Babies – Reducing Risk through Audits and Confidential Enquiries across the UK) to run the national MNI-CORP. MBRRACE-UK is a collaboration comprising members from the following organisations:

- National Perinatal Epidemiology Unit (NPEU) at Oxford University
- University of Leicester
- University of Liverpool

- University of Birmingham
- University College London
- Imperial College London
- Sands, the stillbirth and neonatal death charity
- General practitioner input.

Picking up the reins

Data collection led by CMACE ended on 31 March 2011. With the appointment of the MBRRACE-UK team to lead this process, work commenced immediately to put in place a new data collection system that took advantage of modern IT opportunities and was also able to help deal with some of the challenges resulting from a much reduced budget. At present, the data collection system (described in more detail below) should be considered as a ‘work in progress’ as time constraints have meant that the focus has been on recommencing comprehensive good quality data collection. Once this has been achieved it will be possible to increase the sophistication of the system, not only in terms of the dataset but also in terms of data quality, as well as allowing potential interaction with individual clinicians and families.

During the provider changeover, although data continued to be requested from Trusts, completeness and quality of the data submitted showed great variation and the extent to which the data for 2010, 2011 and 2012 can be analysed and published with confidence, is unclear. This is primarily an issue for the perinatal data

Keywords

perinatal mortality; stillbirth; neonatal mortality; prematurity; congenital anomaly

Key points

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1. There is a new system for reporting perinatal deaths in the UK.
2. It is vital that users ensure that the data they enter are both accurate and complete.
3. There will be an annual confidential enquiry run across the UK on a topic selected from those submitted as part of an open call.

as the small number of maternal deaths means that it is feasible to ensure data completeness and quality retrospectively.

Launch of the new MBRRACE-UK surveillance data collection system

The MBRRACE-UK (www.npeu.ox.ac.uk/mbrance-uk) data collection system for the UK-wide national surveillance of stillbirths and infant deaths was opened for external testing at the end of March 2013 and went live during April 2013. The launch was staggered so that not all hospitals tried to commence data entry on the same day.

MBRRACE-UK will be collecting information about:

- *Late fetal loss*: any baby delivered showing no signs of life between 22⁺⁰ and 23⁺⁶ weeks' gestation.
- *Termination of pregnancy*: terminations that resulted in the ending of a pregnancy in an NHS hospital after 22⁺⁰ weeks' gestation.
- *Stillbirth*: any baby delivered showing no signs of life after 24⁺⁰ weeks' gestation.
- *Neonatal death*: any death of a live born baby (at any stage of gestation) occurring before 28 completed days after birth.
- *Post-neonatal death*: any death of an infant from 28 days' old, up to the age of one year, who was never discharged from the neonatal unit before death.
- *Maternal death*: all maternal deaths occurring during pregnancy and up to one year after completion of the pregnancy.

During 2013 there will be development of systems for collection of information about all other post-neonatal deaths. This will be carried out in conjunction with Child Death Overview Panels, who already have such systems in place (see below).

Accessing and using the system

Because of the need to have a new robust system for data collection in place soon after the awarding of the contract, it was necessary to make some initial strategic decisions in terms of how the process would run. Access to the MBRRACE-UK data collection system would initially be limited to a handful of individuals in each Trust who would be responsible for data entry. Maternity services, neonatal units and children's hospitals across England, Wales and Scotland were contacted and the relevant heads of midwifery and clinical directors asked to identify those individuals who would be responsible for registering

cases from their Trust into the MBRRACE-UK data collection system. Many Trusts have focussed this activity on risk management staff, at least for the time being.

The new arrangements involve electronic data collection using a newly developed secure, web-based data entry application. The need to comply with NHS data security requirements has meant that only relatively up-to-date web browsers are compatible with the system. Details of the requirements have been sent to all those who will be involved in data entry during this first year.

In coming years, subject to contract, it is hoped that access and responsibility for data entry is widened to individual consultants. There is also exploration of the possibility for parents to 'sign off' data entered into the system about their baby, if they so wish.

Separate local arrangements are being made by NIMACH (Northern Ireland Maternal and Child Health) in Northern Ireland and in north east England for data entry during 2013 – these areas have existing centralised arrangements for collecting such data.

The data entry system was opened in April 2013 and, because user names and passwords were issued to all Trusts, it is hoped that information about deaths occurring from then on will be entered in a timely fashion. Deaths that occurred between 1 January 2013 and the launch of the new system should now be entered.

Medical notes are often removed from clinical areas once a death has occurred. For this reason, paper copies of the data collection system are being made available to assist units in gathering the relevant information about each case. These paper copies should be retained by the relevant clinical service and either destroyed or filed in the notes, once the details of the case have been entered electronically on to the MBRRACE-UK system. The paper copies must not be posted to MBRRACE-UK since they will contain personal identifiers alongside clinical information and such action would represent a serious breach of the Data Protection Act.

Advantages of the electronic data collection system

Staff in individual units will be able to see which cases have already been notified – this will save duplicate notifications and effort. Once information about an

individual case has been successfully entered into the system, a copy of the data will be able available for printing for inclusion in the medical notes. The project is working to ensure that data required by Child Death Overview Panels (CDOPs) is captured by the MBRRACE-UK system so that the completion of two separate forms becomes unnecessary. To support local audit and review, it is planned that functionality will be added to the MBRRACE-UK data collection system during 2013/14 that will allow individual units to download information about their own cases. This will help in checking that all eligible cases have been notified and will act as a central information source for units about all of their deaths.

What is different?

In terms of data collection, the switch to a web-based system has provided opportunity to review the data that is collected about each death and also to employ some more modern and sophisticated classification systems – in particular, the opportunity to classify perinatal and neonatal deaths using the CODAC and ReCoDe systems^{1,2}. The hierarchical structure of these systems is easily dealt with using multiple drop-down lists; the system also has a search facility for particular terms.

Maternal past medical history is also coded directly into ICD-10. Entered terms produce a range of options to choose from, which then code directly to ICD-10 (**FIGURE 1**). Certain 'contentious areas' have been focussed on, eg data collection on births at, or after, 22 weeks' gestation has been restored but in addition, detailed information about signs of life immediately after birth are sought.

Arrangements for confidential enquiries

In addition to national surveillance, MBRRACE-UK has also been commissioned to conduct confidential enquiries on a rolling programme of topic-specific maternal, stillbirth and infant mortality and morbidity cases. Congenital diaphragmatic hernia (CDH) has been selected as the first perinatal topic for confidential review due to the severity of the condition and the range of outcomes which result. During 2013 confidential enquiries will be carried out that will focus on the quality of care provided along the

whole of the care pathway, from diagnosis to discharge. Around 80 cases of CDH will be selected from a study conducted jointly through the UK Obstetric Surveillance System (UKOSS: www.npeu.ox.ac.uk/ukoss), the British Association of Paediatric Surgeons Congenital Anomalies Surveillance System (BAPS-CASS: www.npeu.ox.ac.uk/baps-cass) and the British Isles Network of Congenital Anomaly Registers (BINOCAR: www.binocar.org/). The cases will be identified as a stratified random sample; it will be ensured that all potential outcomes of CDH are represented in the review sample. These enquiries will be carried out as panel reviews. The process of recruiting relevant specialists to be part of the review process will begin shortly. It is envisaged that these individuals will be identified with the assistance of relevant Royal Colleges and professional associations.

Confidential enquiries of all maternal deaths from 2009 onwards, together with a rolling programme of topic-specific maternal morbidity cases, are underway. Maternal sepsis has been selected as the maternal morbidity topic for confidential enquiries during 2013, due to its prominence as the leading cause of direct maternal deaths in 2006-2008. About 30 cases of severe maternal sepsis will be identified to undergo confidential case review from the recently completed UKOSS study of sepsis. With the assistance of the relevant Royal Colleges, recruitment of case assessors for the maternal reviews has started; it is anticipated that case reviews will be underway shortly.

The retrospective identification of cases for both sets of confidential enquiries using recently completed studies, will enable rapid identification of cases for these first mortality/morbidity topics. This ability to 'hit the ground running' was important given the short timescales available for this particular round. However, in future years the choice of topics for confidential enquiry will follow the procedure that HQIP has developed for all of the Clinical Outcome Review

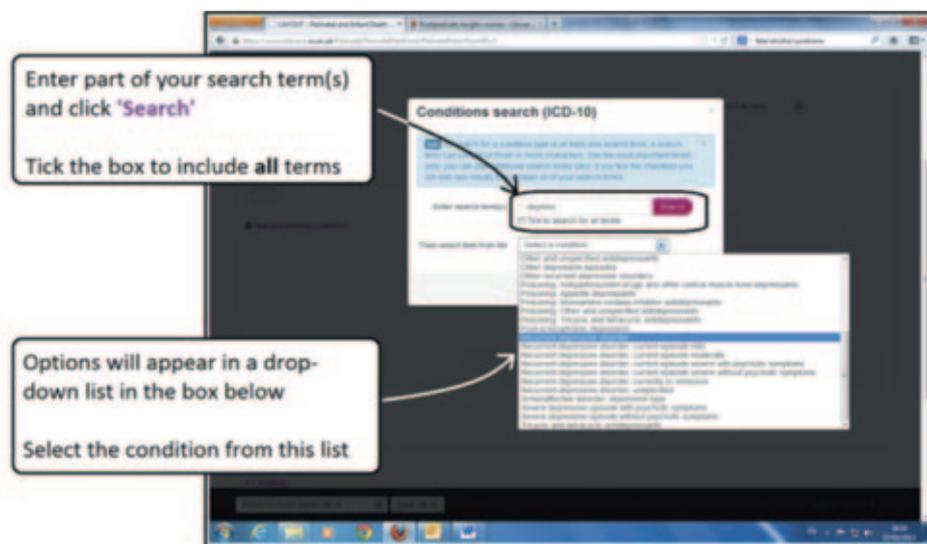


FIGURE 1 A sample screen of drop-down list options: ICD-10 categories/codes in relation to maternal health.

Programmes that it oversees. Towards the end of each year, HQIP will advertise for topic suggestions and these will then be sifted before one is chosen from a shortlist of four by an Independent Advisory Group. This process has just been completed and the topic for the perinatal confidential enquiry in 2014 is unexplained stillbirth at term.

Funding and quality accounts (England)

The MBRRACE-UK system is commissioned by HQIP and jointly funded by the DH (England); the Scottish Government Health Department; NHS Wales; The Department of Health, Social Services and Public Safety Northern Ireland; the Channel Islands; and the Isle of Man.

MBRRACE-UK collects data in England on behalf of the DH. Trusts in England are required to contribute data to MBRRACE-UK in order to fulfil their mandatory obligations both to participate in national confidential enquiries and also to report how they have implemented the recommendations to help improve the quality of patient care.

Keeping in touch

Because of the need to re-establish data

collection as soon as possible, the project focussed very heavily on getting the new data collection system in place in the period after the contract was awarded. As a result, although various means to try and communicate widely about what was taking place were used, the contact was not as regular nor wide ranging as might have been desired and MBRRACE-UK would like to take the opportunity to apologise for this. Now that the new system for data entry is working, albeit with a need for further development, it is intended that more regular communications with all clinical teams interested in the programme will be established.

Further information about the programme is available on the MBRRACE-UK website at: www.npeu.ox.ac.uk/mbrrace-uk. To contact the MBRRACE-UK team, email: mbrrace-uk@npeu.ox.ac.uk or telephone: +44 (0)1865 289715.

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