

MBRRACE-UK Topic Proposal Form

Guidance on completing each section of this form is provided in the form of prompt questions. *These are not intended to be comprehensive* but to allow an opportunity to provide the MBRRACE-UK programme team and their Independent Advisory Group with an overview of the rationale supporting your proposal.

Completed forms should be submitted electronically to mbrrace-uk@npeu.ox.ac.uk by 31st December 2014.

Topic Title	Status epilepticus/uncontrolled epilepsy in pregnancy
Name of Proposer	
Organisation	
Email Address	

1. Overview of the Proposed Topic
Provide a summary of the essential features of the proposed topic; including aims, objectives, and opportunities for quality improvement if this topic is selected.
<p>Maximum response 200 words</p> <p>The most recent confidential enquiry report (2009-2012) highlighted the fact that the rate of maternal death from epilepsy was unchanged from 2006-8, and the maternal death rate was now higher than the rate of death from hypertensive disorders in pregnancy. The majority of women died from SUDEP; two died from drowning. Themes identified included a lack of pre-pregnancy advice and failure to refer for and/or receive specialist care during pregnancy. Some women stopped their medication in early pregnancy. However, there were only 14 women who died. The aim of this confidential enquiry would be to review the care of women with uncontrolled epilepsy, defined as admission to hospital for management of uncontrolled epilepsy and/or status epilepticus in pregnancy. This would provide the opportunity for a more detailed and extensive review of care in order to identify additional points on the care pathway in which the quality of care could be improved.</p>

<p>2. Background Information</p>
<p>2.1 Background and clinical context of the proposed topic. Include incidence / prevalence of the condition(s), its impact on the patient and family / carers; and its impact on the NHS and / or social care organisations.</p>
<p>Maximum response 250 words.</p> <p>As noted above the most recent confidential enquiry report highlighted the fact that the rate of maternal death from epilepsy was unchanged from 2006-8, and the maternal death rate was now higher than the rate of death from hypertensive disorders in pregnancy. The maternal death rate from epilepsy was 0.5 per 100,000 maternities. The majority of women died from SUDEP; two died from drowning. We do not currently have any UK data on the incidence of status epilepticus in pregnancy; data from the EURAP registry reports 21 cases of status epilepticus in pregnancy amongst 3,806 pregnancies of 3,451 women with epilepsy (1). Uncontrolled epilepsy clearly has a major impact on both women and their families as well as NHS resources. The messages for care identified from reviews of maternal deaths do not appear to have changed over several years which suggests further initiatives, including potentially a morbidity confidential enquiry, are needed to improve care.</p>
<p>2.2 Relevant data. Are you aware of any other work on this topic? How will this study enhance or add to the body of work that has already been completed?</p>
<p>Maximum response 250 words.</p> <p>See response above. This would clearly add to existing confidential enquiry data, and would complement the EMPIRE study which investigated anti-epileptic drug management strategies in pregnancy but closed early. Results of this study are awaited. A UKOSS study of uncontrolled epilepsy has been proposed as part of the forward programme of work of the Policy Research Unit in Maternal Health and Care, but a decision on whether this will proceed has not yet been taken.</p>
<p>2.3 Standards and guidelines. Are there any current standards relating to this topic. Please give details of any such measures existing for the care areas that can be assessed in this study. These might include, QoFs, CQUINS, NICE Quality Standards, QIPP activities etc.</p>
<p>Maximum response 250 words.</p> <p>There are both SIGN and NICE guidelines on the management of epilepsy. The next version of the SIGN guidelines will have an expanded section on pregnancy (due for release Jan/Feb 2015), but there are no specific guidelines on the management of epilepsy in pregnancy.</p>
<p>2.4 Alignment with health policy direction. How does the project sit with current policies and political direction? How does it relate to current topics in the public arena? Is public interest formalised within recognised organisations?</p>
<p>Maximum response 250 words</p> <p>The 2014 confidential enquiry report called for the development of guidelines into the management of epilepsy in pregnancy. Depending on the timing of the guideline development process, this confidential enquiry might be aligned to add important information to aid guideline development.</p>
<p>2.5 Key stakeholders. Which groups constitute the key stakeholders for this topic?</p>
<p>Please list.</p> <p>Royal College of Obstetricians and Gynaecologists, Royal College of Midwives, Association of British Neurologists, Royal Colleges of Physicians,</p>

Royal College of General Practitioners,
Epilepsy Action,
Epilepsy Society,
Epilepsy Bereaved

3. Any other information you would like to add

Please add any further information you think would be useful in the assessment of your topic proposal. This may include the potential risks associated with this proposal.

Maximum response 250 words.

Reference

1. Battino D, Tomson T, Bonizzoni E, Craig J, Lindhout D, Sabers A, et al. Seizure control and treatment changes in pregnancy: observations from the EURAP epilepsy pregnancy registry. *Epilepsia*. 2013;54(9):1621-7.

The Maternal, Newborn and Infant Clinical Outcome Review programme, delivered by MBRRACE-UK, is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social care division of the Scottish Government, the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS), the States of Jersey, Guernsey, and the Isle of Man.

September 2014