In 2016-18, 217 women died during or up to six weeks after pregnancy, from causes associated with their pregnancy, among 2,235,159 women giving birth in the UK. 9.7 women per 100,000 died during pregnancy or up to six weeks after childbirth or the end of pregnancy.

We need to talk about SUDEP
Act on:

- Night-time seizures
- Uncontrolled seizures
- Ineffective treatment

A constellation of biases
566 women died during or up to a year after pregnancy in the UK and Ireland

Systemic Biases due to pregnancy, health and other issues prevent women with complex and multiple problems receiving the care they need

Epilepsy and stroke 13%
Cardiac disease 23%
Blood clots 15%
Mental health conditions 13%
Sepsis 11%
Bleeding 9%
Other physical conditions 7%
Cancer 3%
Pre-eclampsia 2%
Other 4%
Introduction

This report, the seventh MBRRACE-UK annual report of the Confidential Enquiry into Maternal Deaths and Morbidity, includes surveillance data on women who died during or up to one year after pregnancy between 2016 and 2018 in the UK. In addition, it also includes Confidential Enquiries into the care of women who died between 2016 and 2018 in the UK and Ireland from epilepsy and stroke, general medical and surgical disorders, anaesthetic causes, haemorrhage, amniotic fluid embolism and sepsis.

The report also includes a Morbidity Confidential Enquiry into the care of women with pulmonary embolism.

Surveillance information is included for 547 women who died during or up to one year after the end of pregnancy between 2016 and 2018. The care of 34 women with pulmonary embolism was reviewed in depth for the Confidential Enquiry chapter.

This report can be read as a single document; each chapter is also designed to be read as a standalone report as, although the whole report is relevant to maternity staff, service providers and policy-makers, there are specific clinicians and service providers for whom only single chapters are pertinent. There are seven different chapters which may be read independently, the topics covered are: 1. Surveillance of maternal deaths 2. Neurological conditions 3. Medical and general surgical disorders 4. Anaesthesia 5. Morbidity from pulmonary embolism 6. Haemorrhage and amniotic fluid embolism 7. Sepsis.

Methods

Maternal deaths are reported to MBRRACE-UK, NIMACH or to MDE Ireland by the staff caring for the women concerned, or through other sources including coroners, procurators fiscal and media reports. In addition, identification of deaths is cross-checked with records from the Office for National Statistics, Information Services Division Scotland and National Records of Scotland. Full medical records are obtained for all women who die as well as those identified for the Confidential Enquiry into Maternal Morbidity, and anonymised prior to undergoing confidential review. The anonymous records are reviewed by a pathologist, together with an obstetrician or physician as required to establish a woman’s cause of death. Each woman’s care is examined by between ten and fifteen multidisciplinary expert reviewers and assessed against current guidelines and standards (such as that produced by NICE or relevant Royal Colleges and other professional organisations). Subsequently the expert reviews of each woman’s care are examined by a multidisciplinary writing group to enable the main themes for learning to be drawn out for the MBRRACE-UK report. These recommendations for future care are presented here, alongside a surveillance chapter reporting three years of UK statistical surveillance data.

NOTE: Relevant actions are addressed to all health professionals as silo working leading to compromised care is a recurring theme identified in these enquiries. Some actions may be more pertinent to specific professional groups than others but all should nonetheless be reviewed for relevance to practice by each group.

Causes and trends

There was a statistically non-significant increase in the overall maternal death rate in the UK between 2013-15 and 2016-18 which suggests that continued focus on implementation of the recommendations of these reports is needed to achieve a reduction in maternal deaths. Assessors judged that 29% of women who died had good care. However, improvements in care which may have made a difference to the outcome were identified for 51% of women who died. ACTION: Policy makers, service planners/commissioners, service managers, all health professionals

There remains a more than four-fold difference in maternal mortality rates amongst women from Black ethnic backgrounds and an almost two-fold difference amongst women from Asian ethnic backgrounds compared to white women, emphasising the need for a continued focus on action to address these disparities. ACTION: Policy makers, service planners/commissioners, service managers, all health professionals

Eight percent of the women who died during or up to a year after pregnancy in the UK in 2016-18 were at severe and multiple disadvantage. The main elements of multiple disadvantage were a mental health diagnosis, substance use and domestic abuse.

Cardiac disease remains the largest single cause of indirect maternal deaths. Neurological causes (epilepsy and stroke) are the second most common indirect cause of maternal death, and the third commonest cause of death overall. There has been a statistically significant increase in maternal mortality due to Sudden Unexpected Death in Epilepsy (SUDEP).

Maternal deaths from direct causes are unchanged with no significant change in the rates between 2013-15 and 2016-18. Thrombosis and thromboembolism remains the leading cause of direct maternal death during or up to six weeks after the end of pregnancy. Maternal suicide remains the leading cause of direct deaths occurring within a year after the end of pregnancy.
Key messages to improve care

The majority of recommendations which MBRRACE-UK assessors have identified to improve care are drawn directly from existing guidance or reports and denote areas where implementation of existing guidance needs strengthening. In a small number of instances, actions are needed for which national guidelines are not available, and these are presented separately here for clarity.

New recommendations to improve care

For professional organisations:

1. Develop guidance to ensure SUDEP awareness, risk assessment and risk minimisation is standard care for women with epilepsy before, during and after pregnancy and ensure this is embedded in pathways of care. [ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians].
2. Develop guidance to indicate the need for definitive radiological diagnosis in women who have an inconclusive VQ scan [ACTION: Royal Colleges of Physicians, Radiologists, Obstetricians and Gynaecologists].
3. Produce guidance on which bedside tests should be used for assessment of coagulation and the required training to perform and interpret those tests [ACTION: Royal Colleges of Anaesthetists, Obstetricians and Gynaecologists, Physicians].
4. Establish a mechanism to disseminate the learning from this report, not only to maternity staff, but more widely to GPs, emergency department practitioners, physicians and surgeons [ACTION: Academy of Medical Royal Colleges].

For policy makers, service planners/commissioners and service managers:

5. Develop clear standards of care for joint maternity and neurology services, which allow for: early referral in pregnancy, particularly if pregnancy is unplanned, to optimise anti-epileptic drug regimens; rapid referral for neurology review if women have worsening epilepsy symptoms; pathways for immediate advice for junior staff out of hours; postnatal review to ensure anti-epileptic drug doses are appropriately adjusted [ACTION: NHSE/I and equivalents in the devolved nations and Ireland].
6. Ensure each regional maternal medicine network has a pathway to enable women to access their designated epilepsy care team within a maximum of two weeks. [ACTION: Maternal Medicine Networks and equivalent structures in Ireland and the devolved nations].
7. Ensure all maternity units have access to an epilepsy team [ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards].
8. Establish pathways to facilitate rapid specialist stroke care for women with stroke diagnosed in inpatient maternity settings [ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards].
9. Provide specialist multidisciplinary care for pregnant women who have had bariatric surgery by a team who have expertise in bariatric disorders [ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards].
10. Use the scenarios identified from review of the care of women who died for ‘skills and drills’ training [ACTION: Hospitals/Trusts/Health Boards].
11. Ensure early senior involvement in the care of women with extremely preterm prelabour rupture of membranes and a full explanation of the risks and benefits of continuing the pregnancy. This should include discussion of termination of pregnancy [ACTION: Hospitals/Trusts/Health Boards].

For health professionals:

12. Regard nocturnal seizures as a ‘red flag’ indicating women with epilepsy need urgent referral to an epilepsy service or obstetric physician [ACTION: All Health Professionals].
13. Ensure that women on prophylactic and treatment dose anticoagulation have a structured management plan to guide practitioners during the antenatal, intrapartum and postpartum period [ACTION: All Health Professionals].
14. Ensure at least one senior clinician takes a ‘helicopter view’ of the management of a woman with major obstetric haemorrhage to coordinate all aspects of care [ACTION: All Health Professionals].
15. Ensure that the response to obstetric haemorrhage is tailored to the proportionate blood loss as a percentage of circulating blood volume based on a woman’s body weight [ACTION: All Health Professionals].
16. Do not perform controlled cord traction if there are no signs of placental separation (blood loss and lengthening of the cord) and take steps to manage the placenta as retained [ACTION: All Health Professionals].
17. Be aware that signs of uterine inversion include pain when attempting to deliver the placenta, a rapid deterioration of maternal condition and a loss of fundal height without delivery of the placenta [ACTION: All Health Professionals].
Recommendations identified from existing guidance requiring improved implementation

Maternity Networks should work with their member organisations and professional groups to support all relevant healthcare professionals to deliver care for pregnant women in line with these recommendations. Original source of each recommendation indicated in brackets.

Care of women with neurological complications

Women with epilepsy taking antiepileptic drugs who become unexpectedly pregnant should be able to discuss therapy with an epilepsy specialist on an urgent basis. It is never recommended to stop or change antiepileptic drugs abruptly without an informed discussion [RCOG green-top guideline 68] ACTION: All Health Professionals, Service Managers.

Pregnant women who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English, may not make full use of antenatal care services. This may be because of unfamiliarity with the health service or because they find it hard to communicate with healthcare staff. Healthcare professionals should help support these women’s uptake of antenatal care services by: using a variety of means to communicate with women; telling women about antenatal care services and how to use them; undertaking training in the specific needs of women in these groups [NICE guideline CG110] ACTION: All Health Professionals.

Offer antihypertensive treatment to pregnant women who have chronic hypertension and who are not already on treatment if they have: sustained systolic blood pressure of 140 mmHg or higher; or sustained diastolic blood pressure of 90 mmHg or higher [NICE Guideline NG133] ACTION: All Health Professionals.

Care of women with medical and general surgical disorders

Women with pre-existing medical conditions should have pre-pregnancy counselling by doctors with experience of managing their disorder in pregnancy [Saving Lives, Improving Mothers’ Care 2014] ACTION: All Health Professionals, Service Managers.

Services providing care to pregnant women should be able to offer all appropriate methods of contraception, including long-acting reversible contraception, to women before they are discharged from the service [Faculty of Sexual and Reproductive Health Guideline Contraception After Pregnancy] ACTION: All Health Professionals, Service Managers.

Women admitted with sickle cell crisis should be looked after by the multidisciplinary team, involving obstetricians, midwives, haematologists and anaesthetists [RCOG green-top guideline 61] ACTION: All Health Professionals, Service Managers.

Critical care support can be initiated in a variety of settings. Critical care outreach nurses can work in partnership with midwives to provide care before transfer to the critical care unit. Delay caused by bed pressures in a critical care unit is not a reason to postpone critical care [Saving Lives, Improving Mothers’ Care 2016] ACTION: All Health Professionals, Service Managers.

Anaesthetic Care

Pregnant women with complex needs or a complex medical history should have timely antenatal multi-disciplinary planning, and an experienced obstetric anaesthetist should contribute to the planning [Saving Lives, Improving Mothers’ Care 2019] ACTION: All Health Professionals, Service Managers.

Prompt action and good communication within and between teams are crucial when dealing with sudden unexpected catastrophes, especially when the diagnosis is not immediately clear [Saving Lives, Improving Mothers’ Care 2014] ACTION: All Health Professionals, Service Managers.

In sudden onset severe maternal shock e.g. anaphylaxis, the presence of a pulse may be an unreliable indicator of adequate cardiac output. In the absence of a recordable blood pressure or other indicator of cardiac output, the early initiation of external cardiac compressions may be life-saving [Saving Lives, Improving Mothers’ Care 2017] ACTION: All Health Professionals, Service Managers.

Pregnant or postpartum women recovering from anaesthesia require the same standard of postoperative monitoring, including documentation, as non-obstetric patients [Saving Lives, Improving Mothers’ Care 2014] ACTION: All Health Professionals, Service Managers.
Prevention and treatment of thromboembolism

There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply consistently in practice. There is a need for development of a tool to make the current risk assessment system simpler and more reproducible [Saving Lives, Improving Mothers’ Care 2018] ACTION: NHSE/I and equivalents in the devolved nations and Ireland. Audits should be conducted not only to assess whether thromboembolism risk assessment was performed, but also whether the calculated risk score was correct [Saving Lives, Improving Mothers’ Care 2018] ACTION: All Health Professionals, Service Managers.

Reassessment of VTE risk after miscarriage or ectopic pregnancy to consider whether thromboprophylaxis is required is as important as reassessment of risk after giving birth [RCOG Green-top guideline 37a] ACTION: All Health Professionals.

Thrombolysis or surgical embolectomy should be considered for pregnant women with high-risk PE [ESC Guidelines for the diagnosis and management of acute pulmonary embolism 2019] ACTION: All Health Professionals.

Women should be offered a choice of LMWH or oral anticoagulant for postnatal therapy after discussion about the need for regular blood tests for monitoring of warfarin, particularly during the first 10 days of treatment [RCOG Green-top guideline 37b] ACTION: All Health Professionals.

Women should be advised that neither heparin (unfractionated or LMWH) nor warfarin is contraindicated in breastfeeding [RCOG Green-top guideline 37b] ACTION: All Health Professionals.

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Postnatal review for women who develop VTE during pregnancy or the puerperium should, whenever possible, be at an obstetric medicine clinic or a joint obstetric haematology clinic [RCOG Green-top guideline 37b] ACTION: All Health Professionals.

Care of women with haemorrhage or amniotic fluid embolism

Haemorrhage (which might be concealed) should be considered when classic signs of hypovolaemia are present (tachycardia and/or agitation with hypotension often a late sign) even in the absence of revealed bleeding [RCOG Green-top guideline 52] ACTION: All Health Professionals.

When there has been a massive haemorrhage and the bleeding is ongoing, or there are clinical concerns, then a massive haemorrhage call should be activated [RCOG Green-top guideline 52] ACTION: Service Managers, All Health Professionals.

In major PPH (blood loss greater than 1000 ml) and ongoing haemorrhage or clinical shock monitor temperature every 15 minutes [RCOG Green-top guideline 52]. ACTION: All Health Professionals.

One member of the team should be assigned the task of recording events, fluids, drugs, blood and components transfused, and vital signs [RCOG Green-top guideline 52] ACTION: Service managers, All Health Professionals.

Resort to hysterectomy sooner rather than later (especially in cases of placenta accreta or uterine rupture) [RCOG Green-top guideline 52] ACTION: All Health Professionals.

Coagulation factors should be administered promptly after multidisciplinary discussion in accordance with the principles in RCOG Green-top Guideline 52. ACTION: All Health Professionals

Prevention and treatment of infection

Offer influenza vaccine to pregnant women at any stage of pregnancy (first, second or third trimesters) [Immunisation against infectious disease: the green book 2019] ACTION: All Health Professionals.

Provide the woman with an interpreter (who may be a link worker or advocate and should not be a member of the woman’s family, her legal guardian or her partner) who can communicate with her in her preferred language. When giving spoken information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly [NICE Guideline CG110] ACTION: Service managers, All Health Professionals.

“Think Sepsis” at an early stage when presented with an unwell pregnant or recently pregnant woman, take the appropriate observations and act on them [Saving Lives, Improving Mothers’ Care 2014] ACTION: All Health Professionals.

In the postnatal period health professionals must perform and record a full set of physiological vital signs, pulse, blood pressure, temperature and respiratory rate, in any woman with symptoms or signs of ill health [RCOG Green-top guideline 64b] ACTION: All Health Professionals.

Midwives and others carrying out postnatal checks in the community should have a thermometer to enable them to check the temperature of women who are unwell [Saving Lives, Improving Mothers’ Care 2017] ACTION: All Health Professionals.

When assessing a woman who is unwell consider her condition in addition to her MEOWS score [Saving Lives, Improving Mothers’ Care 2017] ACTION: All Health Professionals.
Conclusions

Almost three quarters of women who died during pregnancy or up to six weeks after pregnancy in 2016-18 had a pre-existing physical or mental health condition. We have no similar information on the overall proportion of pregnant women with pre-existing physical or mental health conditions and cannot therefore quantify the absolute risk of maternal mortality in these women. It is likely there is a hidden disparity in maternal mortality rates between women with pre-existing health conditions and those without.

This report has identified a concerning rise in the number of women who are dying from Sudden Unexplained Death in Epilepsy (SUDEP). One of the major findings when reviewing the care of these women was the low proportion whose medications were optimised either before or during pregnancy. Clear and rapid pathways of access to neurology and/or epilepsy teams with expertise in caring for women before and during pregnancy need to be established. Repeatedly it was identified that women with both epilepsy and other conditions were stopping medicines, either of their own volition or on the advice of a health professional, or receiving inappropriate medications, simply because they were pregnant. The conversation has changed and it is now recognised that disparity in maternal mortality simply because of a woman’s ethnicity is unacceptable. The conversation now also has to encompass the recognition that it is equally unacceptable for women with pre-existing medical conditions such as epilepsy to receive a lower standard of care simply because they are pregnant.