Maternal, Newborn and Infant Clinical Outcome Review Programme



# Saving Lives, Improving Mothers' Care

Surveillance of maternal deaths in the UK 2011-13 and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-13



#### December 2015

















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Maternal Deaths and Morbidity 2009-13

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### **Foreword**

I very much welcome this first MBRRACE-UK report to focus on the psychiatric causes of maternal deaths. The UK was the first country in the world to quantify and examine in detail the reasons why women with mental disorders die in pregnancy and in the postnatal period. Over almost two decades the lessons learned have made stark reading and I commend the work of the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity in bringing the continuing harsh reality of the risks associated with mental disorders to women in the perinatal period to our attention. This new report covers a period of five years where 161 mothers died from psychiatric causes.

The report highlights that care for women before, during and after pregnancy must be seamless across the professions, disciplines and agencies that support and work with women during this period of immense vulnerability. Maternity services, primary care and mental health services need to work together and share information about relevant mental health history to ensure that women receive the appropriate care they need on the basis of an informed risk assessment of their mental health needs. A very clear message in this report is the urgent need to improve training of all the relevant professional groups about perinatal mental illness, and particularly the speed with which women's illness can progress. Crisis and home treatment mental health teams need to address the identified gaps in training regarding the particular distinctive features and risks of perinatal mental illness. Women continue to face huge variation in access to specialist perinatal mental health services (community and in-patient) across unacceptably large areas of the UK despite the evidence that these services may reduce the risk of women dying.

Looking at maternal deaths beyond solely mental health, the predominant theme is that many women who die have multiple morbidities, as well as complex social factors, substance misuse and domestic abuse. Women from vulnerable populations still have a disproportionate risk of dying prematurely, possibly as a result of the multiple health and social challenges they face. This report provides a number of examples of 'tunnel vision' in our clinical thinking – increasing evidence of clinical subspecialisation and an inability to view the woman in a holistic manner and provide for her needs appropriately and effectively. Across the four nations of the UK, the Royal College of Psychiatrists endeavours to work closely with partner organisations and departments of health to promote the well-being of pregnant and postnatal women and to close the gaps in service provision; the College of Psychiatrists in Ireland undertakes a similar role. The College supports the work of the Maternal Mental Health Alliance by working closely with the Royal Colleges of Midwives and Obstetricians and Gynaecologists to improve training and education of all professionals who work with women during this time.

The clear message to us all, whether doctor, midwife, nurse, manager, allied health or social care professional, service planner or policymaker, must be that we need to practice and embed the patient centred care that we all preach. This means providing the kind of care that takes into account the entirety of the woman's health and social needs before, during and after pregnancy. Women remain at high risk throughout the first year after giving birth of death due to mental illness. Therefore, the mental health support and care we provide must be as comprehensive, safe and effective as the physical health care women receive in pregnancy. The need for parity of esteem has never been so self-evident.

**Professor Sir Simon Wessely** 

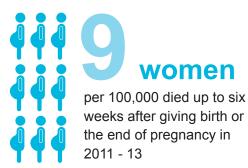
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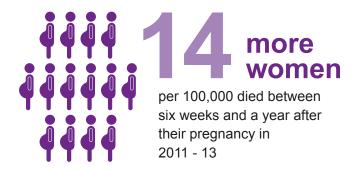
President of the Royal College of Psychiatrists

# Key messages

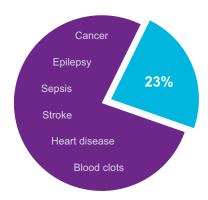


from the report 2015





#### Mental health matters

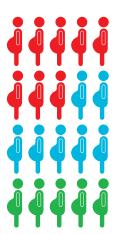


Almost a quarter of women who died between six weeks and one year after pregnancy died from mental-health related causes



1 in 7 women died by Suicide

# Specialist perinatal mental health care matters\*



If the women who died by suicide became ill today:

- 40% would not be able to get any specialist perinatal mental health care.
- Only 25% would get the highest standard of care.

#### It's OK to tell

The mind changes as well as the body during and after pregnancy.

#### Women who report:

- New thoughts of violent self harm
- Sudden onset or rapidly worsening mental symptoms
- Persistent feelings of estrangement from their baby

need urgent referral to a specialist perinatal mental health team

<sup>\*</sup>Mapping data from the Maternal Mental Health Alliance (http://everyonesbusiness.org.uk)

## **Executive Summary**

#### Introduction

The UK Confidential Enquiry into Maternal Deaths (CEMD) has represented a gold standard internationally for detailed investigation and improvement in maternity care for over 60 years. It recognises the importance of learning from every woman's death, during or after pregnancy, not only for the staff and services involved in caring for her, but for the family and friends she leaves behind. This, the second of the Confidential Enquiry into Maternal Deaths annual reports produced by the MBRRACE-UK collaboration, includes data on surveillance of maternal deaths between 2011 and 2013. It also includes Confidential Enquiries for women who died between 2009 and 2013 focusing on lessons on maternal mental health and substance abuse, thrombosis and thromboembolism, caring for women with cancer in pregnancy or postpartum, homicide and domestic abuse, and improvements identified from investigation of the care of women who died between six weeks and one year after the end of pregnancy. In collaboration with MDE Ireland, the report also includes Confidential Enquiries into the deaths of women from these causes in Ireland. Each topic-specific Confidential Enquiry chapter now appears in an annual report once every three years on a cyclical basis.

Surveillance information is included for 575 women who died during or up to one year after the end of pregnancy between 2011 and 2013. The care of 248 women was reviewed in depth for the Confidential Enquiry chapters.

#### Methods

Maternal deaths are reported to MBRRACE-UK 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 and National Records of Scotland. Full medical records are obtained of all women who die and anonymised prior to undergoing confidential review. The anonymous records are reviewed by a pathologist and clinical epidemiologist, together with an obstetrician or physician as required to establish a woman's cause of death. The care of each woman is then assessed by two obstetricians, two midwives, two pathologists, one or two anaesthetists and other specialist assessors as required, including pairs of psychiatrists, general practitioners, physicians, emergency medicine specialists and intensive care experts. Each woman's care is thus examined by between ten and fifteen expert reviewers. 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 data.

#### **Key areas for action**

# For Policy-makers, Service Planners and Commissioners, Public Health and Professional Organisations

Perinatal mental health clinical networks should be established to develop local services and clear pathways of care to prevent care being fragmented and uncoordinated. Networks should always include specialist addictions services.

Pregnant and postnatal women who are substance misusers often have complex social and mental health issues and these women need access to assertive outreach care from specialist addictions and specialist mental health services.

Liaison, crisis and home treatment mental health teams require additional support and education in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women.

There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, and during and after pregnancy.

Policy makers and service planners should ensure that there are no barriers in place that prevent clinicians seeking directly the advice and/or involvement of experts in other specialties for women with multiple morbidities, particularly on discharge from maternity care.

Multi-agency local reviews of all women who die from a mental health-related cause at any stage during pregnancy and the first postnatal year should be carried out and should involve all the services that cared for the woman. Similar reviews should be considered for women with complex or multiple morbidities.

#### For Medical Directors, Clinical Directors, Heads of Midwifery and Clinical Service Managers

Good communication between primary care, mental health and maternity services is critical to good quality care for women with mental ill health, in particular:

- At booking there should be a routine enquiry about a current or past history of mental health problems, which should cover the full range of mental health issues and not just depression.
- Maternity services should ensure that the GP is made aware of a woman's pregnancy and enquire of the GP about the woman's past mental health history.

Mental Health Services should publicise the findings of this report and its procedures widely among mental health staff in order to highlight the messages directly relevant to improving care for pregnant and postpartum women with mental health problems.

All pregnant and postnatal women presenting to the Emergency Department with medical problems should be discussed with a member of the maternity medical team. This should ensure appropriate investigations and treatments for pulmonary embolism are not withheld and prophylaxis is prescribed where appropriate.

Information should be clearly displayed in waiting areas and other suitable places about the support on offer for those affected by domestic violence and abuse. This should include information about relevant local and national helplines. These details should be provided in booking information and hand-held maternity notes.

#### For Doctors, Midwives and Allied Health Professionals

The following are 'red flag' signs for severe maternal mental illness and require urgent senior psychiatric assessment:

- Recent significant change in mental state or emergence of new symptoms,
- New thoughts or acts of violent self-harm.
- New and persistent expressions of incompetency as a mother or estrangement from the infant.

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. This should be repeated intrapartum or immediately postpartum and if the woman is admitted to hospital or develops other intercurrent problems.

Treat cancer the same in pregnancy as in non-pregnant women. Treating cancer does not usually require early delivery.

Staff in antenatal, postnatal, reproductive care, sexual health, alcohol or drug misuse, mental health, children's and vulnerable adults' services should ask all women whether they have experienced domestic violence and abuse. Women should be given the opportunity to disclose domestic abuse in an environment in which they feel secure.

#### Causes and trends

Overall there has been a statistically significant decrease in the maternal death rate between 2009-12 and 2011-13 in the UK. Maternal death rates from direct causes continue to decrease, but indirect maternal death rates remain high with no significant change in the rate since 2003. **Coordinated action across a wide range of health services is required to address this problem**.

There were no deaths from influenza in 2012 and 2013, which also contributed to the decrease in the overall rate of maternal death in 2011-13. This is mainly due to a low level of influenza activity in 2012 and 2013 (compared to 2009 and 2010) rather than an increase in the uptake of vaccination among pregnant women. Increasing immunisation rates in pregnancy against seasonal influenza must remain a public health priority.

Thrombosis and thromboembolism remains the leading cause of direct maternal death and cardiac disease the leading cause of indirect maternal deaths. Almost a quarter of maternal deaths occurring between six weeks and one year after the end of pregnancy were due to psychiatric causes.

Access to and uptake of antenatal care remains an issue amongst women who died. Only a third of women who died received the nationally recommended level of antenatal care.

#### Key topic-specific messages for care

#### Lessons on maternal mental health

The following are 'red flag' signs for severe maternal illness and require urgent senior psychiatric assessment:

- Recent significant change in mental state or emergence of new symptoms,
- New thoughts or acts of violent self-harm,
- New and persistent expressions of incompetency as a mother or estrangement from the infant.

Admission to a mother and baby unit should always be considered where a woman has any of the following:

- rapidly changing mental state,
- suicidal ideation (particularly of a violent nature),
- pervasive guilt or hopelessness,
- significant estrangement from the infant,
- new or persistent beliefs of inadequacy as a mother,
- evidence of psychosis.

Mental health assessments should always include a review of previous history and take into account the findings of recent presentations and escalating patterns of abnormal behaviour.

Loss of a child, either by miscarriage, stillbirth, neonatal death or by the child being taken into care increases vulnerability to mental illness for the mother and she should receive additional monitoring and support.

Partners and other family members may require explanation and education regarding maternal mental illness and its accompanying risks.

Investigations into deaths from psychiatric causes at any stage during pregnancy and the first postnatal year should be carried out and should be multi-agency and include all the services involved in caring for the woman.

#### Prevention and treatment of thrombosis and thromboembolism

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. This should be repeated intrapartum or immediately postpartum and if the woman is admitted to hospital or develops other intercurrent problems.

Prescription for the entire postnatal course of low molecular weight heparin (LMWH) should be issued in secondary care.

Predictive tools for pulmonary embolism used outside pregnancy to determine the need for radiological investigation, such as the Wells score, are not validated for and should not be used in pregnancy.

Pregnant and postnatal women presenting to the Emergency Department with medical problems should be discussed with a member of the maternity medical team. This should ensure appropriate investigations and treatments for pulmonary embolism are not withheld and prophylaxis is prescribed where appropriate.

#### Caring for women with cancer in pregnancy or postpartum

Treat cancer the same in pregnancy as in non-pregnant women:

- If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus.
- Treatment for all women with cancer in pregnancy should be the same as for cancer in non-pregnant women, unless there is specific evidence that to do this would cause harm. The same targets for diagnosis and treatment times should apply in pregnant and postpartum women as for non-pregnant women.
- Early multidisciplinary discussions are needed for all pregnant women with a new diagnosis of cancer as well as newly pregnant women with a previous cancer diagnosis. A named individual should be nominated to coordinate care; this is particularly important when care is provided across multiple centres.
- Neurological examination including fundoscopy is mandatory in all women with new onset headaches or headache with atypical symptoms.

Treating cancer does not usually require early delivery:

latrogenic preterm delivery is associated with cognitive impairment and other long-term sequelae for the infant and should be avoided wherever possible.

#### Learning from homicides and women who experienced domestic abuse

Pregnancy and the puerperium represent periods of higher risk of domestic abuse. Any woman reporting a previous history of domestic abuse should therefore be considered at high risk.

Healthcare professionals need to be alert to the symptoms or signs of domestic abuse and women should be given the opportunity to disclose domestic abuse in an environment in which they feel secure.

All health professionals caring for women should be aware of the pathway of care once domestic abuse is disclosed, and escalate to senior staff if necessary.

Pregnant and postpartum women presenting to the emergency department repeatedly and/or with unusual symptoms should be discussed with a member of the maternity team and the GP should be informed.

A named midwife should take responsibility and provide the majority of antenatal care for pregnant women who experience domestic abuse.

The care of any woman murdered during or up to one year after pregnancy should be subject to multiagency Domestic Homicide Review or equivalent.

#### Messages for the care of women who died between six weeks and a year after pregnancy

Many of the women who died between six weeks and one year after pregnancy had long-standing and multiple morbidities occurring prior to, during and after pregnancy, and they often led socially complex lives.

Care of these women more than six weeks after birth is currently outside the remit/scope of maternity services, however, there is a clear need for co-ordinated care, including actions for maternity services:

- These women require additional care following discharge from hospital after birth and there should be senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians, midwives and all relevant colleagues.
- The postnatal care plan should include the timing of follow up appointments, which should be arranged with the appropriate services before the woman is discharged and not left to the GP to arrange.
- A comprehensive summary by the senior obstetrician of the maternity care episode should be sent to the GP who should be responsible for co-ordinating care after discharge from maternity services.
- Repeated presentation to the GP, community midwife (while still under maternity services) health visitor
  or emergency services should be considered a 'red flag' and warrant a thorough assessment by the
  GP of all of a woman's problems.

Review of a maternal death occurring up to a year after the end of pregnancy should involve all the agencies (including maternity services) who were involved in her care.

There is a need for evidence and practical guidance for the management of women with multiple morbidities and social factors prior to pregnancy, during and after pregnancy.

#### **Conclusions**

Almost a quarter of women who died between six weeks and one year after the end of pregnancy died from psychiatric disorders, and this report has identified a number of key messages to improve the care of women with mental illness. For many women who died, the unique features of perinatal mental illness and its rapid escalation were not recognised by staff in general adult mental health services. This reinforces the need for Perinatal Mental Health Networks and the importance of ensuring that all women have access to expert perinatal mental health care. For staff in maternity services and general practice, awareness of 'red flag' symptoms, as well as the pathways of care will help ensure that women get appropriate referral when they need mental health care. Across all of the topic areas reviewed in this report, there was very clear evidence of fragmented care, gaps in care, and a lack of an individual taking overall responsibility for each woman, which is symptomatic of the increasing division of care into sub-specialties. This was particularly evident postnatally. Every member of healthcare staff has a responsibility to ensure that women have appropriate care, even if it is outside their specialty area, and should take personal responsibility for ensuring she has proper follow-up arranged; a letter to the GP will not suffice.