Maternal, Newborn and Infant Clinical Outcome Review Programme

MBRRACE-UK
Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK

# Saving Lives, Improving Mothers' Care

## Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2013–15

December 2017

UNIVERSITY OF OXFORD
HQIP Healthcare Quality Improvement Partnership
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Sands Stillbirth & neonatal death charity
NHS Bradford Teaching Hospitals NHS Foundation Trust
npeu National Perinatal Epidemiology Unit

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# Foreword

It is impossible to read a report of this nature, including details of the women affected, and not feel a pressing need to act. We owe it to the 359 motherless children, and countless other family members and friends of the women whose deaths are reported here, to do all we can to try to prevent women from dying in the future.

It is clear that the needs of our maternity population are multiple, changing and complex. Women are entering pregnancy with more pre-existing problems, including both significant mental and physical health disorders, as well as complex social challenges. These additional problems inevitably lead to more difficult pregnancies, unless care is carefully coordinated across relevant teams - including all of the teams with the required expertise of caring for pregnant women with specific conditions.

After women have given birth, planning for care at the transition from secondary to primary care, and between maternity and community teams, is vitally important to ensure women remain in the best health possible in the postnatal period and beyond. It is also clear that planning ahead, and anticipating risks in future pregnancies, can make a substantial positive difference in ensuring a healthy mum and baby compared with a difficult pregnancy, as a consequence of which some mothers and babies may die.

Maintaining seamless care across primary and secondary care teams pre-pregnancy, during pregnancy and after pregnancy is thus more important than ever. The General Practitioner (GP) takes a holistic view of a woman's care across the whole of her reproductive lifespan, but can only do so in conjunction with appropriate specialists, and if communication between teams is rapid, reliable and appropriate.

Women also need to be aware of how best to optimise their health before they become pregnant. Many pregnancies, although wanted, are unplanned, and we must all take every opportunity to discuss both planning for pregnancy as well as contraception with any woman of reproductive age who has a known health problem. Making sure that before any pregnancy, her health is the best it can be, with medications which are safest for her and her baby, will prevent women and babies from dying in the future.

This is a responsibility for us all, GP, midwife, physician, obstetrician, nurse specialist, surgeon or health visitor. We cannot all be experts in all areas of care, however we must know the limitations of our expertise and know when and how to seek appropriate expert advice and be sure it will be given in a timely way. Only then can we make a difference.

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# Key messages
## from the report 2017

MBRRACE-UK
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In 2013-15 **8.8 women** per 100,000 died during pregnancy or up to six weeks after giving birth or the end of pregnancy.

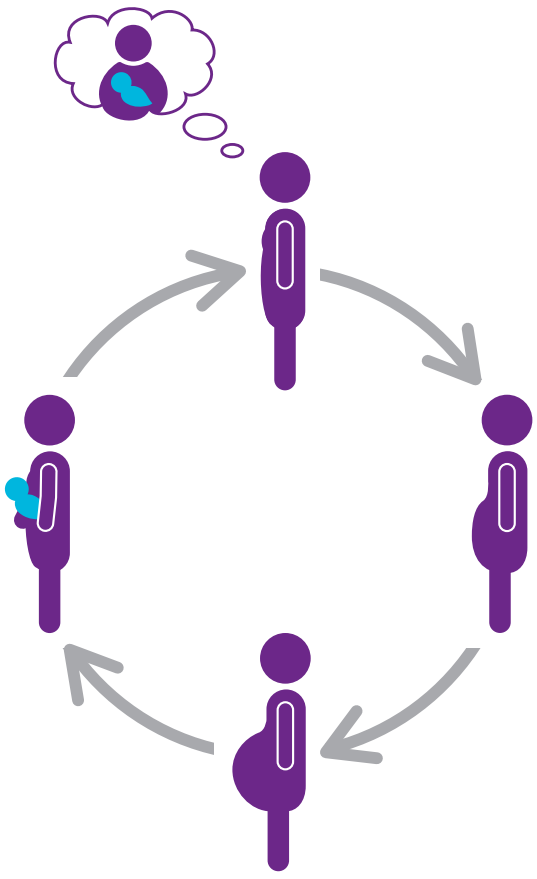
**Two thirds of women who died** had pre-existing physical or mental health problems.

## Forward planning works

For women with physical and mental health problems:

Before pregnancy, plan contraception as well as the safest medication

Do not stop medication in early or later pregnancy without consulting a specialist



Take account of changes which occur in the postpartum period and change medication accordingly. Plan for contraception as well as the next pregnancy

Think about special medication considerations around the time of labour and birth

# Executive Summary

## Introduction

It is imperative that we continue to learn from the deaths of women during and after pregnancy. This report, the fourth 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 2013 and 2015 in the UK. In addition, it also includes Confidential Enquiries into the care of women who died between 2013 and 2015 in the UK and Republic of Ireland from neurological conditions, other medical and surgical conditions, sepsis, anaesthetic complications, haemorrhage and amniotic fluid embolism, as well as Confidential Enquiries into the care of women with morbidity due to uncontrolled epilepsy in pregnancy and those with severe postpartum mental illness.

Surveillance information is included for 556 women who died during or up to one year after the end of pregnancy between 2013 and 2015. The care of 124 women who died and 46 with severe morbidity was reviewed in depth for the Confidential Enquiry chapters.

## Methods

Maternal deaths are reported to MBRRACE-UK or to Maternal Death Enquiry (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 national records. 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. The care of each woman is then assessed by one or two obstetricians, midwives, pathologists, anaesthetists and other specialist assessors as required, including 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 surveillance data.

## Causes and trends

There was no change in the overall maternal death rate in the UK between 2010–12 and 2013–15, which is now 8.76 per 100,000 maternities (95% CI 7.59 – 10.05). This suggests that further actions are urgently needed to continue to reduce maternal deaths in the UK, and to achieve a reduction in maternal deaths by 50% by 2030 in England. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals**

There has been a significant 23% decrease in indirect maternal mortality since 2010–12 (95% CI 1–40%), primarily due to a decrease in influenza deaths and deaths from indirect causes of maternal sepsis. Cardiac disease remains the leading cause of indirect maternal death during or up to six weeks after the end of pregnancy with a rate of 2.34 per 100,000 maternities (95% CI 1.76–3.06).

Maternal deaths from direct causes are unchanged with no significant change in the rates between 2010–12 and 2013–15. Thrombosis and thromboembolism remain the leading cause of direct maternal death during or up to six weeks after the end of pregnancy. There is a potentially concerning, although non-significant, 99% increase in maternal deaths from haemorrhage (95% CI 4% decrease-392% increase). This is due to a small increase in the number of deaths of women with abnormal placentation.

Maternal suicide is the third largest cause of direct maternal deaths occurring during or within 42 days of the end of pregnancy. However, it remains the leading cause of direct deaths occurring during pregnancy or up to a year after the end of pregnancy, with 1 in 7 women who die in the period between 6 weeks and one year after pregnancy dying by suicide.

Assessors judged that 35% of women who died, 4% of women with severe morbidity from epilepsy and 26% of women with severe mental illness had good care. However, improvements in care may have made a difference to the outcome for 41% of women who died, 52% of women with epilepsy and 26% of women with severe mental illness.

# Key areas for action

## Improving overall care

High level actions are needed to ensure that it is seen as the responsibility of all health professionals to facilitate opportunistic pre- and post-pregnancy counselling and appropriate framing of the advice when women with pre-existing conditions attend any appointment, and that resources for pre- and post-pregnancy counselling are provided, together with open access to specialist contraceptive services. **ACTION: Policy makers, health professionals**

Since women attend maternity services during pregnancy, funding streams should facilitate the offer and delivery of influenza immunisation in maternity services as part of antenatal care, rather than in primary care. **ACTION: Policy makers, service planners/commissioner**s

All units are required to have escalation policies for periods of high activity. These policies should include a plan to obtain more and senior obstetric and anaesthetic assistance as well as considering midwifery staffing and diverting activity. Local review reports submitted to MBRRACE-UK should include a full assessment of staffing-workload balance issues if these were felt to be a contributory factor. **ACTION: Service planners/commissioners, service managers, health professionals**

## Improving care of women with epilepsy

Women with epilepsy should be provided, before conception, with verbal and written information on prenatal screening and its implications, the risks of self-discontinuation of anti-epileptic drugs and the effects of seizures and anti-epileptics on the fetus and on the pregnancy, breastfeeding and contraception. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Obstetric teams should take urgent action when pregnant women with a current or past diagnosis of epilepsy have discontinued anti-epileptic drugs without specialist advice. Urgent attempts should be made by all clinicians involved in care to offer the woman immediate access to an appropriately trained professional (e.g. neurologist/epilepsy specialist nurse or midwife) to review her medication and prescribe anti-epileptic drugs if appropriate. **ACTION: Health professionals**

Postpartum safety advice and strategies should be part of the antenatal and postnatal discussions with the mother alongside discussion of breastfeeding, seizure deterioration and anti-epileptic drug intake. **ACTION: Health professionals**

## Improving care of women with stroke

Pregnancy should not alter the investigation and treatment of a woman presenting with a stroke. **ACTION: Service planners/commissioners, service managers, health professionals**

Neurological examination including assessment for neck stiffness and fundoscopy is mandatory for all women with new onset headaches or headaches with atypical features, particularly focal symptoms. **ACTION: Health professionals**

A lack of an immediately available critical care bed must not be a reason for refusing admission for patients requiring urgent neurosurgery. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

## Improving care of women with mental health problems

Women with any past history of psychotic disorder, even where not diagnosed as postpartum psychosis or bipolar disorder, should be regarded as at elevated risk in future postpartum periods and should be referred to mental health services in pregnancy to receive an individualised assessment of risk. **ACTION: Service planners/commissioners, service managers, health professionals**

Following recovery, it is the responsibility of the treating mental health team to ensure that all women experiencing postpartum psychosis receive a clear explanation of future risk, including the availability of risk minimisation strategies, and the need for re-referral during subsequent pregnancies and that this is shared with other relevant health professionals. **ACTION: Health professionals**

It is the responsibility of mental health services to ensure that a late pregnancy and early postnatal care plan is completed, jointly with the woman, usually at 28–32 weeks of pregnancy. Where the plan includes decisions about medication management, it should be completed, or overseen, by a psychiatrist. **ACTION: Health professionals**

Statutory health organisations should consider routine monitoring of the proportion of women and babies who are unnecessarily separated when the mother is admitted to psychiatric care. **ACTION: Policy makers**

## Improving care of women with medical and general surgical disorders

In pregnant or postpartum women with complex medical problems involving multiple specialities, the responsible consultant obstetrician or physician must show clear leadership and be responsible for coordinating care and liaising with anaesthetists, midwives, other physicians and obstetricians and all other professionals who need to be involved in the care of these women. **ACTION: Health professionals**

Pregnancy should not be viewed as a contraindication to surgery in the presence of malignancy or progressive symptoms or conditions at high risk of progression or exacerbation in pregnancy. **ACTION: Health professionals**

Women with multiple and complex problems may require additional care following discharge from hospital after birth and there is a need for senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians and all relevant colleagues. **ACTION: Service planners/commissioners, service managers, health professionals**

## Improving prevention and care of sepsis

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. **ACTION: Service managers, health professionals**

When assessing a woman who is unwell, consider her clinical condition in addition to her MEOWS score. **ACTION: Health professionals**

Consideration should be given to 'declaring sepsis', analogous to activation of the major obstetric haemorrhage protocol, to ensure the relevant members of the multidisciplinary team are informed, aware and act. **ACTION: Service managers, health professionals**

Women should be advised, within 24 hours of giving birth, of the symptoms and signs of conditions, including sepsis, that may threaten their lives and require them to access emergency treatment. **ACTION: Service planners/commissioners, service managers, health professionals**

## Improving anaesthetic care

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. **ACTION: Health professionals**

In cases of massive obstetric haemorrhage women must be adequately resuscitated and bleeding stopped prior to extubation following general anaesthesia. Evidence of adequate resuscitation should be sought prior to extubation. **ACTION: Health professionals**

Aortocaval compression should be suspected in any supine pregnant woman who develops severe hypotension after induction of anaesthesia, even if some lateral tilt has been applied. If there is a delay in delivery, putting the woman into the left lateral position may be the only option if other manoeuvres fail or if the woman has refractory severe hypotension. **ACTION: Health professionals**

The choice of endotracheal tube for pregnant women should start at size 7.0mm and proceed to smaller tube selections if needed (size 6.0mm and 5.0mm). It is recommended that all resuscitation carts used in maternity units should include endotracheal tubes no larger than 7.0mm and include smaller sizes such as 6.0mm and 5.0mm. **ACTION: Service managers, health professionals**

## Improving prevention and care of haemorrhage and amniotic fluid embolism

Haemorrhage should be considered when classic signs of hypovolaemia are present (tachycardia and/or agitation and the late sign of hypotension) even in the absence of revealed bleeding. **ACTION: Health professionals**

Misoprostol should always be used with extreme caution for women with late intrauterine fetal death, especially in the presence of a uterine scar. In these women, particularly those with a scar, dinoprostone may be more appropriate. **ACTION: Health professionals**

Recurrent bleeding, pain or agitation should be seen as 'red flags' in women with placenta accreta and women should be advised to remain in hospital. **ACTION: Health professionals**

There is a need for consideration of how competence in abdominal hysterectomy can be achieved for obstetricians in training, and how these skills can be maintained at consultant level, e.g. through simulation training. **ACTION: Policy makers, professional organisations, health professionals**

# Conclusions

It is striking that across these disparate complications, and amongst both women who died and those who survive but have severe morbidity, one recurring dominant theme emerges. There remain multiple opportunities to reduce women's risk of complications in pregnancy through early and forward planning of the care of women with known pre-existing medical and mental health problems. Provision of appropriate advice and optimisation of medication prior to pregnancy, referral early in pregnancy for the appropriate specialist advice and planning of antenatal, intrapartum and postnatal care, and effective postnatal provision of advice concerning risks and planning for future pregnancies are the key improvements needed to prevent women dying or having severe complications in the future.

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# Glossary of terms

| | |
|---|---|
| **AED** | Anti-Epileptic Drug |
| **AFE** | Amniotic Fluid Embolism |
| **ALSO** | Advanced Life Support in Obstetrics |
| **ATSM** | Advanced Training Skills Modules |
| **BMI** | Body mass index |
| **BP** | Blood pressure |
| **BUMPS** | Better Use of Medicines in Pregnancy |
| **CEMD** | Confidential Enquiries into Maternal Deaths |
| **CEMM** | Confidential Enquiries into Maternal Morbidity |
| **CI** | Confidence interval |
| **CMACE** | Centre for Maternal and Child Enquiries |
| **CPR** | Cardiopulmonary resuscitation |
| **CT** | Computerised Tomography |
| **DIC** | Disseminated intravascular coagulation |
| **DNA** | Did Not Attend |
| **DS** | Dissociative Seizures |
| **ECMO** | Extracorporeal membrane oxygenation |
| **EWS** | Early warning scores |
| **FAST** | Focussed Assessment with Sonography in Trauma |
| **FE** | Focal Epilepsy |
| **GCS** | Glasgow Coma Score |
| **GP** | General practitioner |
| **HELLP** | Haemolysis, Elevated Liver enzymes, Low Platelet count |
| **HES** | Hospital Episode Statistics |
| **HQIP** | Healthcare Quality Improvement Partnership |
| **HSE** | Health Service Executive |
| **ICD** | International Classification of Diseases |
| **IGE** | Idiopathic Generalised Epilepsy |
| **ILAE** | International League Against Epilepsy |
| **IMD** | Index of Multiple Deprivation |
| **IOL** | Induction Of Labour |
| **MBRRACE-UK** | Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK |
| **MDE** | Maternal Death Enquiry |
| **MEOWS** | Modified Early Obstetric Warning Score |
| **MHRA** | Medicines and Healthcare products Regulatory Agency |
| **MMR** | Maternal mortality ratio |
| **mMOET** | Managing Medical and Obstetric Emergencies and Trauma |
| **MNI-CORP** | Maternal Newborn and Infant Clinical Outcome Review Programme |
| **MRSA** | Methicillin-resistant Staphylococcus Aureus |
| **NAP6** | Royal College of Anaesthetists 6th National Audit Project |
| **NEAD** | Non-Epileptic Attack Disorder |
| **NHS** | National Health Service |
| **NICE** | National Institute for Health and Care Excellence |
| **NIMACH** | Northern Ireland Maternal and Child Health |
| **NMPA** | National Maternal and Perinatal Audit |
| **PCR** | Protein Creatinine Ratio |
| **PEA** | Pulseless electrical activity |
| **PEFR** | Peak expiratory flow rate |
| **PPH** | Postpartum Haemorrhage |
| **PROMPT** | Practical Obstetric Multi-Professional Training |
| **RCOG** | Royal College of Obstetricians and Gynaecologists |
| **RR** | Risk ratio |
| **RRR** | Ratio of relative risks |
| **SBAR** | Situation Background Assessment Recommendation tool |
| **SI** | Serious Incident |
| **SIGN** | Scottish Intercollegiate Guidelines Network |
| **SLE** | Systemic lupus erythematosus |
| **SUDEP** | Sudden unexpected death in epilepsy |
| **SVD** | Spontaneous Vaginal Delivery |
| **TTP** | Thrombotic thrombocytopenic purpura |
| **UKOSS** | UK Obstetric Surveillance System |
| **UE** | Unclassified Epilepsy |
| **VBAC** | Vaginal birth after caesarean section |

# Contents

# 1. Introduction and methodology

Marian Knight

## 1.1 The 2017 Saving Lives, Improving Mothers' Care report

The value of reviewing the care of women with severe morbidity during or shortly after pregnancy in addition to those who die is now well-recognised. In this report we present the results of two morbidity enquiries, into the care of women with uncontrolled epilepsy and into the care of women with significant postpartum mental illness. Both identify a number of new messages to improve care not previously identified from enquiries into maternal deaths. Particularly valuably, these Enquiries identified clear examples where excellent proactive management led to good outcomes in second and subsequent pregnancies, illustrating the effect of the exemplary care that can be provided in maternity and perinatal mental health services in the UK.

Both conditions are ones which confer significant risk in future pregnancies, and perhaps the clearest message to take forward is the need to recognise and manage this risk pro-actively. In the case of women with uncontrolled epilepsy, pre-pregnancy counselling, appropriate contraceptive advice and optimisation of medication and seizure control prior to any subsequent pregnancy will go a long way to improving outcomes for these women. The themes identified in relation to women with severe postpartum mental illness are very similar. Perhaps the area of greatest opportunity is the counselling of women concerning risk, and management of risk, immediately following their recovery from a pregnancy-related psychotic episode. This is an opportunity for improvement within perinatal mental health services as well as general psychiatric services and maternity services.

This fourth maternal report from the MBRRACE-UK collaboration is the first to begin to repeat the three-year cycle of topic-based Confidential Enquiry reports. A number of messages for care were identified during the course of the reviews of the care of women who died between 2013 and 2015 which also featured in the 2014 and later reports. In order to avoid unnecessary repetition, readers are referred back to the relevant recommendations in previous reports, as detailed background supporting information has not been reiterated in order to keep this report as succinct as possible.

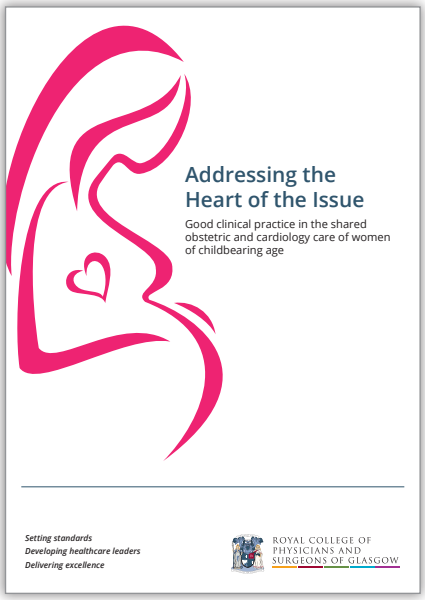
This is the first of the new style annual MBRRACE-UK maternal reports that has not shown a continuing decrease in the overall maternal mortality rate since the last report. Whilst the increase is not statistically significant, it is worth noting a small but worrying increase in the number of women dying from haemorrhage in relation to abnormally invasive placentation. The association between prior caesarean birth and placenta praevia, accreta, increta and percreta is well established (Fitzpatrick, Sellers et al. 2012), and the rising incidence of caesarean birth is also clear (Betran, Ye et al. 2016). These women's deaths provide an impetus towards efforts to investigate the drivers of rising intervention rates as well as towards improvement in management of women with known abnormally invasive placentation. They also emphasise the importance of the 2018 MBRRACE-UK morbidity enquiry, investigating the care of women with severe haemorrhage who survive, as their deaths clearly form the tip of the iceberg of disease.

This is the first MBRRACE-UK maternal report to show a statistically significantly decreasing trend in indirect maternal deaths when considering rolling triennial rates since 2003. One of the most marked observations is the dramatic decrease in the rates of maternal death from sepsis due to indirect causes, not only due to a decrease in influenza-related maternal deaths, but also due to a decrease in maternal deaths from causes such as pneumonia and meningitis. Raised awareness of sepsis in the UK and Ireland, through the work of organisations such as the UK Sepsis Trust, may have played a part in this change. The need for similar awareness and recognition on a global scale has led to the new Global Maternal Sepsis Awareness campaign and Global Obstetric Surveillance Study from the WHO (*http://srhr.org/sepsis/*), and it is to be hoped that similar decreases in maternal and newborn deaths to those seen in the UK will result. This raised awareness of sepsis can perhaps provide a model for raising awareness of other disorders, such as cardiac disease, epilepsy and mental health disorders, that we will need to have to meet the Government ambition of a halving of maternal deaths by 2030 in England (Department of Health 2015) and similar decreases in the Republic of Ireland and the other nations of the UK.

## 1.2 Actions following the release of the 2014, 2015 and 2016 reports

We would like to draw readers' attention to a number of key initiatives following the release of previous reports. This is not a comprehensive list and there are many other local, regional and national initiatives ongoing not captured here.

The 2015 report highlighted the critical importance of maternal mental health. A series of open access e-learning modules on perinatal mental health produced by Health Education England in conjunction with the Royal College of General Practitioners, the Institute of Health Visiting and the Department of Health are now available at *http://www.e-lfh.org.uk/programmes/perinatal-mental-health/open-access-perinatal-mental-health-sessions/*. In 2017 the new Scottish Managed Clinical Network for Perinatal Mental Health was launched to identify gaps in provision of perinatal mental health care in Scotland and further promote improvements in local services (*https://news.gov.scot/news/mental-health-for-new-mums*).

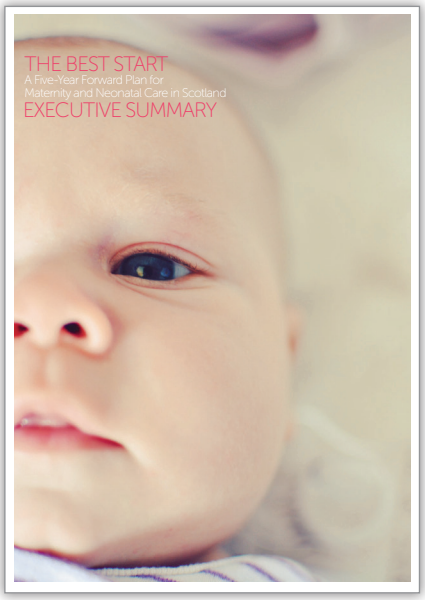



The Royal College of Physicians and Surgeons of Glasgow has developed a set of standards for the care of women with cardiac disease in pregnancy. These are available from: *https://rcpsg.ac.uk/media/news/1808/addressing-the-heart-of-the-issue.pdf*.

Two updated green-top guidelines have been released by the RCOG with direct relevance to topics covered in the 2014 and 2017 reports. These cover prevention and management of post-partum haemorrhage (Green-top Guideline No. 52) (Royal College of Obstetricians and Gynaecologists 2016a) and blood transfusion in obstetrics (Green-top Guideline 47) (Royal College of Obstetricians and Gynaecologists 2015). Following the release of the 2014 report, the Institute of Obstetricians and Gynaecologists in conjunction with the Health Service Executive in Ireland have produced a new guideline on bacterial infections specific to pregnancy (Institute of Obstetricians and Gynaecologists and National Clinical Programme in Obstetrics and Gynaecology 2015), and this year produced a guideline on bereavement care following maternal death in a hospital setting (Institute of Obstetricians and Gynaecologists and National Clinical Programme in Obstetrics and Gynaecology 2017). Both are available at *https://www.rcpi.ie/faculties/obstetricians-and-gynaecologists/national-clinical-guidelines-in-obstetrics-and-gynaecology/*.

Further to the release of the new RCOG Green-top Guideline on Epilepsy in Pregnancy (*https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68/*) (Royal College of Obstetricians and Gynaecologists 2016b), this year a new RCM i-learn module on epilepsy in pregnancy has been released. The module 'aims to develop knowledge and understanding of epilepsy, its treatment and management and improve midwives' confidence in supporting pregnant women and their relatives more effectively as part of a wider multidisciplinary team' and is available free for RCM members at *http://www.ilearn.rcm.org.uk/enrol/index.php?id=391*. The International League Against Epilepsy (ILAE) has also developed a website with specific simple suggestions on management of epilepsy and use of anti-epileptic drugs for women as well as different groups of health professionals (obstetricians and midwives, neurologists, epilepsy specialist nurses and epileptologists, pharmacists, emergency physicians, GPs and commissioners) (*http://ilaebritish.org.uk/epilepsy-and-women*).

The next steps guidance to achieve the Government ambition of a halving of maternal deaths by 2030 in England, published in October 2016 (available at *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/560491/Safer_Maternity_Care_ action_plan.pdf*), cites the evidence from the 2015 report concerning the importance of addressing maternal mental health. The guidance also highlights continued reporting to MBRRACE-UK as a key action for hospitals (Maternity Safety Programme Team Department of Health 2016). Evidence from the 2014 and 2015 reports was used to inform the recent Five-Year Forward Plan for Maternity and Neonatal Care in Scotland (The Scottish Government 2017), focussing particularly on actions to improve multiprofessional working, notably for women with multiple care needs, and improving communication at the interface between primary and secondary care.





The new national maternity strategy in Ireland 'Creating a better future together–National Maternity Strategy 2016–2026' (*http://health.gov.ie/wp-content/uploads/2016/01/Final-version-27.01.16.pdf*) used evidence from the 2014 report to develop a number of actions, particularly in relation to developing a clear process for communication in the event of clinical deterioration of mother or baby (Department of Health (Ireland) 2017)

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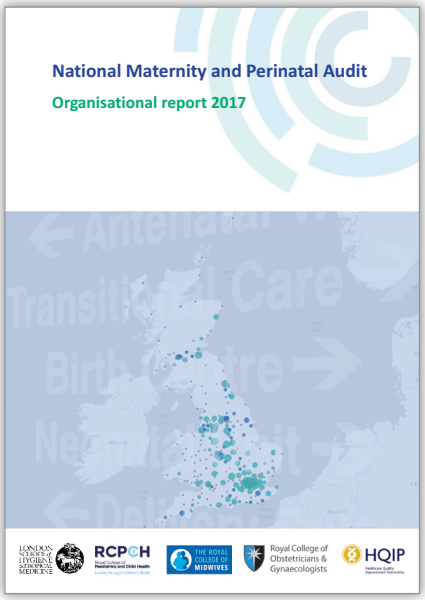



The new National Maternity and Perinatal Audit has investigated a number of recommendations from recent MBRRACE-UK reports in its recently published first organisational report (NMPA Project Team 2017). The report adds important evidence to that of this Enquiry concerning service organisation for women with medical and mental health co-morbidities. For example, it identified that only 18% of obstetric units had a joint obstetric cardiac clinic, with the units in England that did have a joint clinic being largely concentrated in London. Only two units in Scotland and one unit in Wales had a joint clinic. The report also noted variation in access to echocardiography–although 96% of obstetric units had on-site echocardiography available, only 37% had 24-hour access. This highlights the importance of ongoing actions to address the following recommendations from the 2016 report:

**Lack of co-location of obstetric and cardiac services jeopardises interdisciplinary working and communication. Measures such as joint obstetric cardiac clinics, multidisciplinary care plans, copying letters to the woman and all clinicians involved in her care, as well as staff from all specialties writing in the woman's hand held notes may mitigate against the inherent risk of inadequate communication between specialists (Knight, Nair et al. 2016).**

**All consultant led maternity units should have ready access to an ECG machine and someone who can interpret ECGs. Similarly, echocardiography, performed by a competent practitioner, should be available 7 Days a week (NHS England 2013).**

## 1.3 Topics covered in MBRRACE-UK maternal reports 2014–17

The programme now requires the production of annual CEMD reports. Reports were previously produced on a triennial basis, because the number of maternal deaths from individual causes is small, and three years' worth of data is required to identify consistent lessons learned for future care and to maintain anonymity and confidentiality. Clearly the need to undertake annual reporting does not change this requirement, therefore, each topic-specific chapter which appeared in the previous triennial report now appears in an annual report once every three years on a cyclical basis, alongside a surveillance chapter reporting three years of statistical data. All causes of maternal death have now been covered once in this three-year cycle; this report is the first of the next three-year cycle:

- **2014 report:** Surveillance data on maternal deaths from 2009–12. Confidential Enquiry reports on severe morbidity from and deaths from sepsis, deaths from haemorrhage, amniotic fluid embolism (AFE), anaesthesia, neurological, respiratory, endocrine and other indirect causes.
- **2015 report:** Surveillance data on maternal deaths from 2011–13. Confidential Enquiry reports on deaths from psychiatric causes, deaths due to thrombosis and thromboembolism, malignancy, homicides and late deaths
- **2016 report:** Surveillance data on maternal deaths from 2012–14. Confidential Enquiry reports on deaths and severe morbidity from cardiac causes, deaths from pre-eclampsia and eclampsia and related causes and deaths in early pregnancy, messages for critical care.
- **2017 (this report):** Surveillance data on maternal deaths from 2013–15. Confidential Enquiry reports on severe morbidity from and deaths from epilepsy, deaths from haemorrhage, amniotic fluid embolism (AFE), anaesthesia, stroke, respiratory, endocrine and other indirect causes, severe morbidity from psychosis.

Alongside the Confidential Enquiries into maternal deaths we also conduct enquiries into maternal morbidity topics, which can be proposed by anyone. Proposals for topics are accepted annually between October and December. Further details are available at *https://www.npeu.ox.ac.uk/mbrrace-uk/topics*.

## 1.4 The MBRRACE-UK Confidential Enquiries into Maternal Deaths and Morbidity Methods

### Maternal Deaths

The methods for the Confidential Enquiry into maternal deaths remain unchanged, and readers are therefore referred to the 2016 report (Knight, Nair et al. 2016) for a full description of the methods (*https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202016%20-%20website.pdf*).

### 1.4.1 Maternal Morbidity

Women are identified for the Confidential Enquiries into Maternal Morbidity in different ways according to the topic. The women with severe epilepsy were identified from an existing UKOSS study, which identified women with severe epilepsy fulfilling the criteria in Box 1.1 between October 2015 and March 2017.

**Box 1.1: Box 1.1: Case definition used in the UKOSS severe epilepsy in pregnancy study**

Any pregnant woman in the UK who fulfils at least one of the following criteria:

- A woman with epilepsy who dies during pregnancy or up to day 42 postpartum, where the cause of death is directly attributed to the consequences of epilepsy, including Sudden Unexpected Death in Epilepsy (SUDEP)*.
- A woman with epilepsy who is admitted to hospital as an inpatient for management of generalised tonic-clonic seizures during pregnancy or the postpartum period.
- All women being treated with ≥3 anti-epileptic drugs simultaneously at any point during their pregnancy.

*These women were not included in the morbidity Confidential Enquiry

All surviving women notified nationally were used as the sampling frame. A geographically representative sample of 32 women was drawn at random from this group. A full set of medical records was requested from each hospital concerned. The records then underwent expert assessment in exactly the same way as the records of the women who died. Consent was requested from women in Northern Ireland to participate, since legislation does not exist to allow inclusion of their data without consent. Hospitals provided only 23 of 32 requested sets of records; the care of these 23 women is described in Chapter 3.

Women with psychosis and a known history of either bipolar disorder or a previous episode of puerperal psychosis were identified through different sources in the four UK nations. In England, women with psychosis were identified through data linkage carried out by NHS Digital. This involved linkage of Hospital Episode Statistics (HES) data for mental health service inpatient discharges with a diagnosis of psychosis to HES maternity data. In Wales and Northern Ireland women were identified through treating psychiatrists; as with the epilepsy study, in Northern Ireland consent was obtained from women for inclusion of their records in the Confidential Enquiry. No women from Scotland were able to be included since, following the investigation of several sources of data, none proved suitable. At that stage, there was insufficient time remaining for the Enquiry to identify women through treating psychiatrists.

# 2. Maternal Mortality in the UK 2012–14: Surveillance and Epidemiology

Manisha Nair and Marian Knight

## 2.1 Key points

There was no change in the overall maternal death rate in the UK between 2010–12 and 2013–15, which suggests that further actions are urgently needed to achieve a reduction of maternal deaths by 50% by 2030. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals**

There has been a significant decrease in indirect maternal mortality since 2010–12, primarily due to a decrease in influenza deaths, and deaths from indirect causes of maternal sepsis. Cardiac disease remains the leading cause of indirect maternal death during or up to six weeks after the end of pregnancy.

Maternal deaths from direct causes are unchanged with no significant change in the rates between 2010–12 and 2013–15. Thrombosis and thromboembolism remain the leading cause of direct maternal death during or up to six weeks after the end of pregnancy. There is a potentially concerning, although non-significant, increase in maternal deaths from haemorrhage.

Maternal suicide is the third largest cause of direct maternal deaths occurring during or within 42 days of the end of pregnancy. However, it remains the leading cause of direct deaths occurring within a year after the end of pregnancy.

Only 68% of local clinicians' reports were returned for women who died in 2015. These reports are essential to allow MBRRACE-UK assessors to fully take account of any local factors impacting on care, and should be returned in a timely manner. **ACTION: All health professionals**

## 2.2 Causes and trends

Overall, 240 women died in 2013–15 during or within 42 days of the end of pregnancy in the UK. The deaths of 38 women were classified as coincidental. Thus in this triennium 202 women died from direct and indirect causes among 2,305,920 maternities, a maternal death rate of 8.76 per 100,000 maternities (95% CI 7.59–10.05). This is comparable to the rate of 8.54 per 100,000 maternities (95% CI 7.40–9.81) in 2012–14. Direct and indirect maternal deaths are classified using ICD-MM (World Health Organisation 2012). As in the previous reports, information on deaths from the Republic of Ireland is not included in this chapter and therefore rates and numbers presented here are comparable with all previous UK reports.

Table 2.1 and Figure 2.1 show rolling three-yearly maternal death rates since 2003 using ICD-MM. There was an overall 37% decrease (95% CI 25% to 48%) in maternal death rates between 2003–05 and 2013–15 (rate ratio (RR) 0.63, 95% CI 0.52–0.75; p=0.002 for trend in rolling rates over time). The direct maternal death rate has decreased by 44% since 2003–05 with a RR of 0.56 (95% CI 0.43–0.74, p=0.004) and there was a 31% decrease in the rate of indirect maternal deaths (RR 0.69, 95% CI 0.53 to 0.88, p=0.034).

The rates of overall mortality and direct maternal death in the 2013–15 triennium were not significantly different from the rates in 2010–12 (RR for overall mortality = 0.87, 95% CI = 0.71 to 1.05, p=0.065; RR for direct deaths = 1.03, 95% CI = 0.76 to 1.40, p=0.422). However the indirect maternal death rate was significantly lower in 2013–15 than 2010–12 (RR = 0.77, 95% CI = 0.60 to 0.99, p=0.034).

Detailed analysis showed that the decrease in indirect maternal deaths was once again primarily due to a decrease in deaths due to influenza (RR 0.08, 95% CI 0.01–0.61 when comparing 2013–15 with 2010–12; p=0.0017) and other indirect causes of sepsis (RR 0.15, 95% CI 0.03–0.49; p=0.0002). In this triennium there was only one death from influenza, one death from pneumococcal meningitis, one from pneumonia and one as a result of Clostridium difficile infection. Although, as noted in the 2016 report, there has been a low level of influenza activity, this highlights the potential impact of increasing immu-

nisation rates in pregnancy, and raised awareness of, and actions to treat, sepsis from sources outside the genital tract, both highlighted in the 2014 report (Knight, Kenyon et al. 2014). Immunisation against seasonal influenza must remain a public health priority (Knight, Kenyon et al. 2014), particularly in light of high levels of influenza H3 infection observed in 2017 in Australia (Australian Government Department of Health 2017).

The plateauing of the triennial rates of direct and indirect maternal deaths since 2011–13 highlights the challenge of achieving the Government ambition of reducing maternal deaths in England by 50% by 2030 (Department of Health 2015).

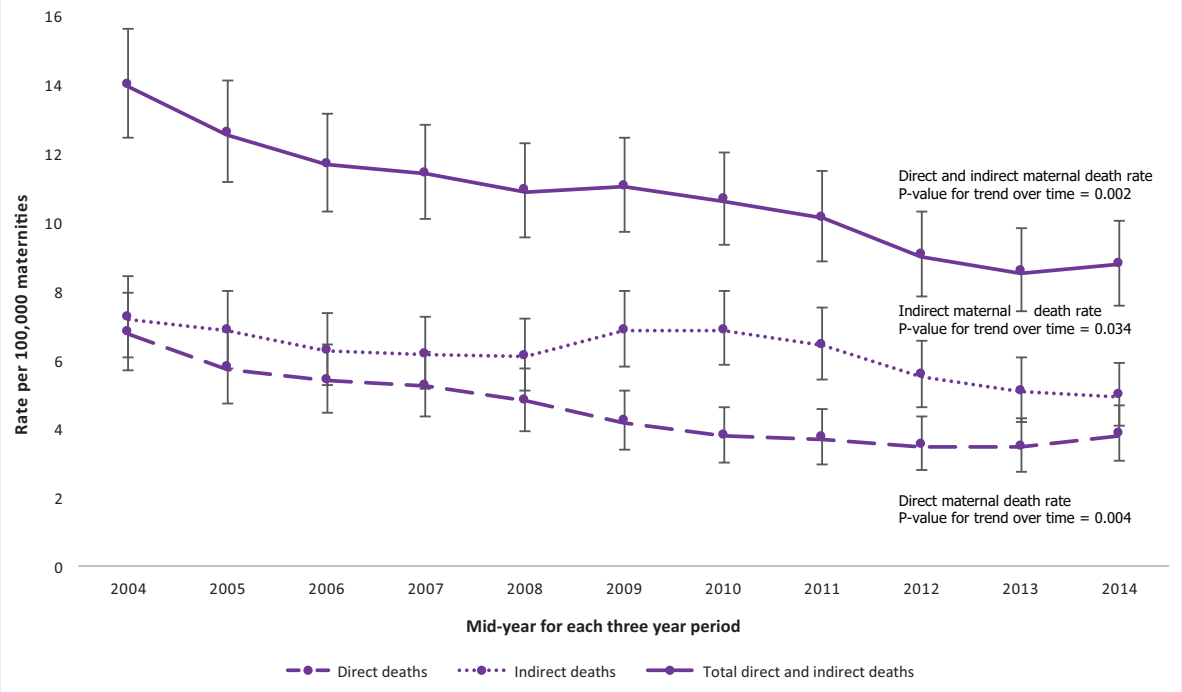
Triennial rates are shown in Table 2.2 and Figure 2.2.

**Table 2.1: Table 2.1: Rolling three-year average direct and indirect maternal mortality rates per 100,000 maternities, deaths classified using ICD-MM; UK 2003–15**

| 3-year period | Total UK maternities | Direct deaths | | | Indirect deaths | | | Total Direct and Indirect deaths | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI |
| 2003–05 | 2 114 004 | 143 | 6.76 | 5.70–7.97 | 152 | 7.19 | 6.09–8.43 | 295 | 13.95 | 12.45–15.64 |
| 2004–06 | 2 165 909 | 124 | 5.73 | 4.76–6.83 | 148 | 6.83 | 5.78–8.03 | 272 | 12.56 | 11.15–14.14 |
| 2005–07 | 2 220 979 | 120 | 5.40 | 4.48–6.46 | 139 | 6.26 | 5.26–7.39 | 259 | 11.66 | 10.32–13.17 |
| 2006–08 | 2 291 493 | 120 | 5.24 | 4.34–6.26 | 141 | 6.15 | 5.18–7.26 | 261 | 11.39 | 10.09–12.86 |
| 2007–09 | 2 331 835 | 112 | 4.80 | 3.95–5.78 | 142 | 6.09 | 5.13–7.18 | 254 | 10.89 | 9.59 -12.32 |
| 2008–10 | 2 366 082 | 99 | 4.18 | 3.40–5.09 | 162 | 6.85 | 5.83–7.99 | 261 | 11.03 | 9.73–12.45 |
| 2009–11 | 2 379 014 | 90 | 3.78 | 3.04–4.65 | 163 | 6.85 | 5.84–7.99 | 253 | 10.63 | 9.36–12.03 |
| 2010–12 | 2 401 624 | 89 | 3.71 | 2.98–4.56 | 154 | 6.41 | 5.44–7.51 | 243 | 10.12 | 8.89–11.47 |
| 2011–13 | 2 373 213 | 83 | 3.50 | 2.79–4.34 | 131 | 5.52 | 4.62–6.55 | 214 | 9.02 | 7.85–10.31 |
| 2012–14 | 2 341 745 | 81 | 3.46 | 2.75–4.30 | 119 | 5.08 | 4.21–6.08 | 200 | 8.54 | 7.40–9.81 |
| 2013–15 | 2 305 920 | 88 | 3.82 | 3.06–4.70 | 114 | 4.94 | 4.08–5.94 | 202 | 8.76 | 7.59–10.05 |

Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

**Figure 2.1: Direct and indirect maternal mortality rates per 100,000 maternities using ICD-MM and Previous UK classification systems; rolling three year average rates 2003–2015**



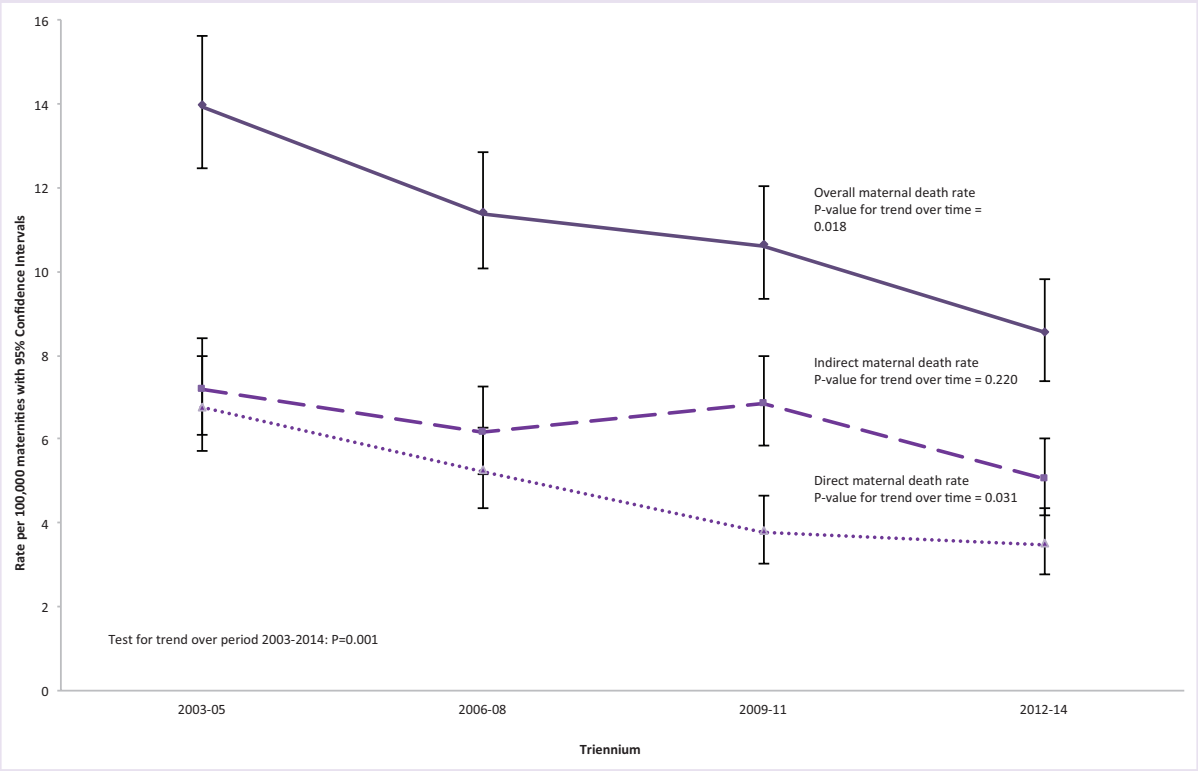

Sources: CMACE, MBRRACE-UK

**Table 2.2: Direct and Indirect maternal deaths and mortality rates per 100,000 maternities by triennium, UK using ICD-MM; UK 2003–14**

| Triennium | Direct deaths recorded | | | Indirect deaths recorded | | | Total Direct and Indirect deaths recorded | | |
|---|---|---|---|---|---|---|---|---|---|
| | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI |
| 2003–05 | 143 | 6.76 | 5.70–7.97 | 152 | 7.19 | 6.09–8.43 | 295 | 13.95 | 12.45–15.64 |
| 2006–08 | 120 | 5.24 | 4.34–6.26 | 141 | 6.15 | 5.18–7.26 | 261 | 11.39 | 10.09–12.86 |
| 2009–11 | 90 | 3.78 | 3.04–4.65 | 163 | 6.85 | 5.84–7.99 | 253 | 10.63 | 9.36–12.03 |
| 2012–14 | 81 | 3.46 | 2.75–4.30 | 119 | 5.08 | 4.21–6.08 | 200 | 8.54 | 7.40–9.81 |

Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

**Figure 2.2: Direct and Indirect maternal mortality rates per 100,000 maternities; UK: 2003–2014 (using ICD-MM)**

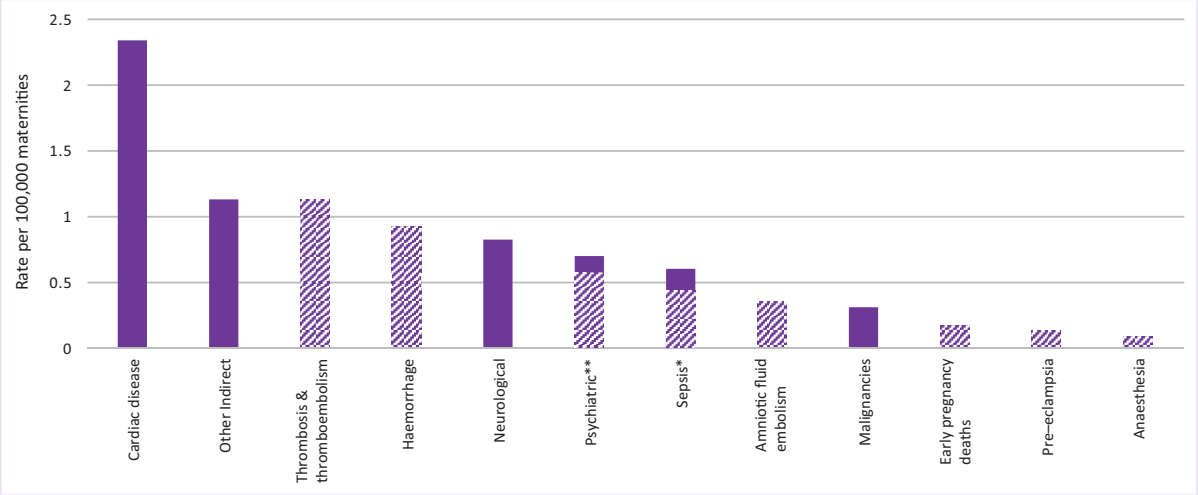



Sources: CMACE, MBRRACE-UK

## Deaths due to individual causes

Maternal deaths by cause are shown in Tables 2.3 and 2.4, and Figure 2.3. Rolling three year rates for individual causes are presented for five overlapping triennial reporting periods (2009–11, 2010–12, 2011–13, 2012–14 and 2013–15) (Table 2.3 and Figure 2.3) and for non-overlapping triennial periods between 1985–7 and 2012–14 (Table 2.4). Since there has not been a complete triennium since the previous report, Table 2.4 is the same as included in the 2016 report; deaths by suicide have been included amongst indirect deaths in Table 2.4 to allow for comparability to earlier years. Three-year rolling rates for causes of death classified according to ICD-MM sub-groups are presented in Table 2.5.

## Figure 2.3: Maternal mortality by cause 2013–15




Hatched bars show direct causes of death, solid bars indicate indirect causes of death;
*Rate for direct sepsis (genital tract sepsis and other pregnancy related infections) is shown in hatched and rate for indirect sepsis (influenza, pneumonia, others) in solid bar
**Rate for suicides (direct) is shown in hatched and rate for indirect psychiatric causes (drugs/alcohol) in solid bar
Source: MBRRACE-UK

## Table 2.3: Maternal mortality rates by cause, per 100,000 maternities, 2009 to 2015

| Cause of death | 2009–11 | | | 2010–12 | | | 2011–13 | | | 2012–14 | | | 2013–15 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI |
| **All Direct and Indirect deaths** | 253 | 10.63 | 9.36–12.03 | 243 | 10.12 | 8.89–11.47 | 214 | 9.02 | 7.85–10.31 | 200 | 8.54 | 7.40–9.81 | 202 | 8.76 | 7.59–10.05 |
| **Direct deaths** | | | | | | | | | | | | | | | |
| Pregnancy related infections - Sepsis* | 16 | 0.67 | 0.38–1.09 | 13 | 0.54 | 0.29–0.93 | 8 | 0.34 | 0.15–0.66 | 7 | 0.29 | 0.12–0.61 | 10 | 0.43 | 0.21–0.79 |
| Pre-eclampsia and eclampsia | 10 | 0.42 | 0.20–0.77 | 9 | 0.38 | 0.18–0.71 | 6 | 0.25 | 0.09–0.55 | 2 | 0.08 | 0.01–0.31 | 3 | 0.13 | 0.03–0.38 |
| Thrombosis and thromboembolism | 30 | 1.26 | 0.85–1.80 | 26 | 1.08 | 0.71–1.59 | 24 | 1.01 | 0.65–1.50 | 20 | 0.85 | 0.52–1.32 | 26 | 1.13 | 0.74–1.65 |
| Amniotic fluid embolism | 7 | 0.29 | 0.12–0.61 | 8 | 0.33 | 0.14–0.66 | 10 | 0.42 | 0.20–0.78 | 16 | 0.68 | 0.39–1.11 | 8 | 0.35 | 0.15–0.68 |
| Early pregnancy deaths | 4 | 0.17 | 0.05–0.43 | 8 | 0.33 | 0.14–0.66 | 6 | 0.25 | 0.09–0.55 | 7 | 0.29 | 0.12–0.61 | 4 | 0.17 | 0.05–0.44 |
| Haemorrhage | 14 | 0.59 | 0.32–0.99 | 11 | 0.46 | 0.23–0.82 | 13 | 0.55 | 0.29–0.94 | 13 | 0.56 | 0.29–0.95 | 21 | 0.91 | 0.56–1.39 |
| Anaesthesia | 3 | 0.12 | 0.03–0.37 | 4 | 0.17 | 0.05–0.43 | 3 | 0.13 | 0.03–0.37 | 2 | 0.09 | 0.01–0.31 | 2 | 0.09 | 0.01–0.31 |
| Psychiatric causes - Suicides | 6 | 0.25 | 0.09–0.55 | 10 | 0.42 | 0.20–0.77 | 13 | 0.55 | 0.29–0.94 | 14 | 0.60 | 0.33–1.00 | 12 | 0.52 | 0.27–0.91 |
| Unascertained - direct | - | - | - | - | - | - | - | - | - | - | - | - | 2 | 0.09 | 0.01–0.31 |
| All Direct | 90 | 3.78 | 3.04–4.65 | 89 | 3.71 | 2.98–4.56 | 83 | 3.50 | 2.79–4.34 | 81 | 3.46 | 2.75–4.30 | 88 | 3.82 | 3.06–4.70 |
| **Indirect** | | | | | | | | | | | | | | | |
| Cardiac disease | 51 | 2.14 | 1.60–2.82 | 54 | 2.25 | 1.69–2.93 | 49 | 2.06 | 1.53–2.73 | 51 | 2.18 | 1.62–2.86 | 54 | 2.34 | 1.76–3.06 |
| Indirect Sepsis - Influenza | 27 | 1.13 | 0.75–1.65 | 13 | 0.54 | 0.29–0.93 | 9 | 0.38 | 0.17–0.72 | 1 | 0.04 | 0.001–0.24 | 1 | 0.04 | 0.001–0.24 |
| Indirect Sepsis–Pneumonia/ others | 15 | 0.63 | 0.35–1.04 | 21 | 0.87 | 0.54–1.34 | 20 | 0.84 | 0.52–1.30 | 14 | 0.60 | 0.33–1.00 | 3 | 0.13 | 0.03–0.38 |
| Other Indirect causes | 29 | 1.22 | 0.82–1.75 | 26 | 1.08 | 0.71–1.59 | 22 | 0.93 | 0.58–1.40 | 23 | 0.98 | 0.62–1.47 | 26 | 1.13 | 0.74–1.65 |
| Indirect neurological conditions | 30 | 1.26 | 0.85–1.80 | 31 | 1.29 | 0.88–1.83 | 24 | 1.01 | 0.65–1.5 | 22 | 0.94 | 0.59–1.42 | 19 | 0.82 | 0.49–1.29 |
| Psychiatric causes–Drugs/alcohol/others | 7 | 0.29 | 0.12–0.61 | 6 | 0.25 | 0.09–0.54 | 6 | 0.25 | 0.09–0.55 | 4 | 0.17 | 0.05–0.44 | 4 | 0.17 | 0.05–0.44 |
| Indirect malignancies | 4 | 0.17 | 0.05–0.45 | 3 | 0.13 | 0.03–0.37 | 1 | 0.04 | 0.001–0.24 | 4 | 0.17 | 0.05–0.44 | 7 | 0.30 | 0.12–0.63 |
| All Indirect | 163 | 6.85 | 5.84–7.99 | 154 | 6.41 | 5.44–7.51 | 131 | 5.52 | 4.62–6.55 | 119 | 5.08 | 4.21–6.08 | 114 | 4.94 | 4.08–5.94 |
| **Coincidental** | | | | | | | | | | | | | | | |
| Homicide | 7 | 0.29 | 0.12–0.61 | 10 | 0.42 | 0.20–0.77 | 8 | 0.34 | 0.15–0.66 | 9 | 0.38 | 0.18–0.73 | 9 | 0.39 | 0.18–0.74 |
| Other coincidental | 16 | 0.67 | 0.38–1.09 | 16 | 0.67 | 0.38–1.08 | 18 | 0.76 | 0.45–1.20 | 32 | 1.37 | 0.94–1.93 | 29 | 1.26 | 0.84–1.81 |
| All coincidental | 23 | 0.98 | 0.61–1.45 | 26 | 1.08 | 0.71–1.59 | 26 | 1.10 | 0.72–1.61 | 41 | 1.75 | 1.26–2.38 | 38 | 1.65 | 1.17–2.26 |
| **Late deaths** | 325 | 13.66 | 12.22–15.33 | 313 | 13.03 | 11.63–14.56 | 335 | 14.12 | 12.64–15.71 | 323 | 13.79 | 12.33–15.38 | 326 | 14.14 | 12.64–15.76 |

*Genital/ urinary tract sepsis deaths, including early pregnancy deaths as a result of genital/ urinary tract sepsis. Other deaths from infectious causes are classified under indirect causes.

Source: MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency.

## Table 2.4: UK Maternal deaths and mortality rates per 100,000 maternities by cause 1985–2014 (Maternal deaths by suicide classified as indirect for comparability)

| Cause of death | Numbers | | | | | | | | | | Rates per 100,000 maternities | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1985–87 | 1988–90 | 1991–93 | 1994–96 | 1997–99 | 2000–02 | 2003–05 | 2006–08 | 2009–11 | 2012–14 | 1985–87 | 1988–90 | 1991–93 | 1994–96 | 1997–99 | 2000–02 | 2003–05 | 2006–08 | 2009–11 | 2012–14 |
| All Direct and Indirect deaths | 223 | 238 | 228 | 268 | 242 | 261 | 295 | 261 | 253 | 200 | 9.83 | 10.08 | 9.85 | 12.19 | 11.4 | 13.07 | 13.95 | 11.39 | 10.63 | 8.54 |
| Direct deaths | | | | | | | | | | | | | | | | | | | | |
| Sepsis* | 9 | 17 | 15 | 16 | 18 | 13 | 18 | 26 | 16 | 7 | 0.40 | 0.72 | 0.65 | 0.73 | 0.85 | 0.65 | 0.85 | 1.13 | 0.63 | 0.29 |
| Pre-eclampsia and eclampsia | 27 | 27 | 20 | 20 | 16 | 14 | 18 | 19 | 10 | 2 | 1.19 | 1.14 | 0.86 | 0.91 | 0.75 | 0.70 | 0.85 | 0.83 | 0.42 | 0.08 |
| Thrombosis and thromboembolism | 32 | 33 | 35 | 48 | 35 | 30 | 41 | 18 | 30 | 20 | 1.41 | 1.40 | 1.51 | 2.18 | 1.65 | 1.50 | 1.94 | 0.79 | 1.26 | 0.85 |
| Amniotic fluid embolism | 9 | 11 | 10 | 17 | 8 | 5 | 17 | 13 | 7 | 16 | 0.40 | 0.47 | 0.43 | 0.77 | 0.38 | 0.25 | 0.80 | 0.57 | 0.29 | 0.68 |
| Early pregnancy deaths | 16 | 24 | 17 | 15 | 17 | 15 | 14 | 11 | 4 | 7 | 0.71 | 1.02 | 0.73 | 0.68 | 0.80 | 0.75 | 0.66 | 0.48 | 0.17 | 0.29 |
| Haemorrhage | 10 | 22 | 15 | 12 | 7 | 17 | 14 | 9 | 14 | 13 | 0.44 | 0.93 | 0.65 | 0.55 | 0.33 | 0.85 | 0.66 | 0.39 | 0.59 | 0.56 |
| Anaesthesia | 6 | 4 | 8 | 1 | 3 | 6 | 6 | 7 | 3 | 2 | 0.26 | 0.17 | 0.35 | 0.05 | 0.14 | 0.30 | 0.28 | 0.31 | 0.12 | 0.09 |
| Other Direct‡ | 27 | 17 | 14 | 7 | 7 | 8 | 4 | 4 | - | - | 1.19 | 0.72 | 0.60 | 0.32 | 0.33 | 0.40 | 0.19 | 0.17 | - | - |
| All direct | 139 | 145 | 128 | 134 | 106 | 106 | 132 | 107 | 82 | 67 | 6.13 | 6.14 | 5.53 | 6.10 | 4.99 | 5.31 | 6.24 | 4.67 | 3.49 | 2.84 |
| Indirect deaths | | | | | | | | | | | | | | | | | | | | |
| Cardiac disease | 23 | 18 | 37 | 39 | 35 | 44 | 48 | 53 | 51 | 51 | 1.01 | 0.76 | 1.60 | 1.77 | 1.65 | 2.20 | 2.27 | 2.31 | 2.14 | 2.18 |
| Other Indirect causes | 43 | 45 | 38 | 39 | 41 | 50 | 50 | 49 | 72 | 38 | 1.90 | 1.91 | 1.64 | 1.77 | 1.93 | 2.50 | 2.37 | 2.14 | 3.03 | 1.62 |
| Indirect neurological conditions | 19 | 30 | 25 | 47 | 34 | 40 | 37 | 36 | 30 | 22 | 0.84 | 1.27 | 1.08 | 2.14 | 1.60 | 2.00 | 1.75 | 1.57 | 1.26 | 0.94 |
| Psychiatric causes | † | † | † | 9 | 15 | 16 | 18 | 13 | 13 | 18 | † | † | † | 0.41 | 0.71 | 0.80 | 0.85 | 0.57 | 0.55 | 0.77 |
| Indirect malignancies | † | † | † | † | 11 | 5 | 10 | 3 | 4 | 4 | † | † | † | † | 0.52 | 0.25 | 0.47 | 0.13 | 0.17 | 0.17 |
| All Indirect | 84 | 93 | 100 | 134 | 136 | 155 | 163 | 154 | 170 | 133 | 3.70 | 3.94 | 4.32 | 6.10 | 6.40 | 7.76 | 7.71 | 6.59 | 7.15 | 5.68 |
| Coincidental | 26 | 39 | 46 | 36 | 29 | 36 | 55 | 50 | 22 | 41 | 1.15 | 1.65 | 1.99 | 1.64 | 1.37 | 1.80 | 2.60 | 2.18 | 0.98 | 1.75 |

*Including early pregnancy deaths as a result of sepsis

‡Acute fatty liver and genital tract trauma; included with pre-eclampsia and eclampsia and haemorrhage respectively from 2009 onwards

†Deaths from these causes not included in reports from earlier years

Sources: CMACE, MBRRACE-UK

**Table 2.5: Maternal mortality rates by cause using ICD-MM group classification, per 100,000 maternities, 2009 to 2015**

| Cause of death | 2009–11 | | | 2010–12 | | | 2011–13 | | | 2012–14 | | | 2013–15 | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI | n | Rate | 95% CI |
| **Direct causes** | | | | | | | | | | | | | | | |
| Group 1: Pregnancy with abortive outcome | 4 | 0.17 | 0.05–0.43 | 8 | 0.33 | 0.14–0.66 | 6 | 0.25 | 0.09–0.55 | 7 | 0.29 | 0.12–0.62 | 4 | 0.17 | 0.05–0.44 |
| Group 2: Hypertensive disorders | 10 | 0.42 | 0.20–0.77 | 9 | 0.38 | 0.18–0.71 | 6 | 0.25 | 0.09–0.55 | 2 | 0.08 | 0.01–0.31 | 3 | 0.13 | 0.03–0.38 |
| Group 3: Obstetric Haemorrhage | 14 | 0.59 | 0.32–0.99 | 11 | 0.46 | 0.23–0.82 | 13 | 0.55 | 0.29–0.94 | 13 | 0.56 | 0.29–0.95 | 21 | 0.91 | 0.56–1.39 |
| Group 4: Pregnancy-related infection | 16 | 0.67 | 0.38–1.09 | 13 | 0.54 | 0.29–0.93 | 8 | 0.34 | 0.15–0.66 | 7 | 0.29 | 0.12–0.61 | 10 | 0.43 | 0.21–0.79 |
| Group 5: Other obstetric complications | 43 | 1.81 | 1.31–2.43 | 44 | 1.83 | 1.33–2.46 | 47 | 1.98 | 1.46–2.63 | 50 | 2.14 | 1.58–2.81 | 48 | 2.08 | 1.53–2.76 |
| Group 6: Unanticipated complications of management | 3 | 0.12 | 0.03–0.37 | 4 | 0.17 | 0.05–0.43 | 3 | 0.13 | 0.03–0.37 | 2 | 0.09 | 0.01–0.31 | 2 | 0.09 | 0.01–0.31 |
| **Indirect causes** | | | | | | | | | | | | | | | |
| Group 7: Non-obstetric complications | 163 | 6.85 | 5.84–7.99 | 154 | 6.41 | 5.44–7.51 | 131 | 5.52 | 4.62–6.55 | 119 | 5.08 | 4.21–6.08 | 114 | 4.94 | 4.08–5.94 |
| Group 8: Unknown/undetermined | 0 | 0 | - | 0 | 0 | - | 0 | 0 | - | 0 | 0 | - | 0 | 0 | - |
| **Coincidental causes** | | | | | | | | | | | | | | | |
| Group 9: Coincidental causes | 23 | 0.98 | 0.61–1.45 | 26 | 1.08 | 0.71–1.59 | 26 | 1.10 | 0.72–1.61 | 41 | 1.75 | 1.26–2.38 | 38 | 1.65 | 1.17–2.26 |

Source: MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency.

## Direct deaths

Thrombosis and thromboembolism continue to be the leading cause of direct deaths occurring within 42 days of the end of pregnancy, followed by deaths due to obstetric haemorrhage and deaths by suicide (Figure 2.3). The maternal death rate from pre-eclampsia and eclampsia continues to be low. There was no statistically significant change in the rate of direct maternal deaths from any cause between 2009 and 2015, although the near doubling in the maternal death rate from haemorrhage between 2010–12 and 2013–15 is of potential concern (RR 1.99, 95% CI 0.96–4.92). This is discussed further in Chapter 8.

## Indirect deaths

As noted above, there was a statistically significant decrease in the rates of indirect maternal death between 2010–12 and 2013–15, mainly due to a decrease in the rate of deaths from influenza and other indirect causes of sepsis. However, deaths due to indirect causes still remain the major proportion (56%) of maternal deaths in the UK. As in previous reports, cardiac disease remains the largest single cause of indirect maternal deaths (Figure 2.3). There was no significant change in the maternal mortality rate from cardiac disease between 2010–12 and 2013–15 (p=0.833).

There was a 36% decrease in the rate of deaths due to neurological causes in 2013–15 compared with 2010–12, but this decrease is not statistically significant (p=0.113). An in-depth review of the care of the women who died from neurological causes in 2013–15 is presented in Chapter 3.

## International comparison

For international comparison, data from the 2016 report is presented in Table 2.6 to highlight the maternal mortality ratios estimated for the UK using routinely reported data. The rate estimate from routine sources of data is much lower (about half) than the actual rates as identified through the UK CEMD, which uses multiple sources of death identification. New figures are not presented, as there has not been a complete triennium since these ratios were calculated.

**Table 2.6: Maternal mortality ratios* per 100,000 live births, UK: 1985–2014**

| Triennium | No. of deaths identified through death certificates | Maternal mortality ratio | 95% CI | Denominator number of live births |
|---|---|---|---|---|
| 1985–87 | 174 | 7.67 | 6.61–8.90 | 2,268,766 |
| 1988–90 | 171 | 7.24 | 6.24–8.42 | 2,360,309 |
| 1991–93 | 150 | 6.48 | 5.52–7.60 | 2,315,204 |
| 1994–96 | 158 | 7.19 | 6.15–8.40 | 2,197,640 |
| 1997–99 | 128 | 6.03 | 5.70–7.17 | 2,123,614 |
| 2000–02 | 136 | 6.81 | 5.76–8.05 | 1,997,472 |
| 2003–05 | 149 | 7.05 | 6.00–8.27 | 2,114,004 |
| 2006–08 | 155 | 6.76 | 5.78–7.92 | 2,291,493 |
| 2009–11 | 134 | 5.57 | 4.67–6.60 | 2,405,251 |
| 2012–14 | 110 | 4.65 | 3.82–5.60 | 2,368,125 |

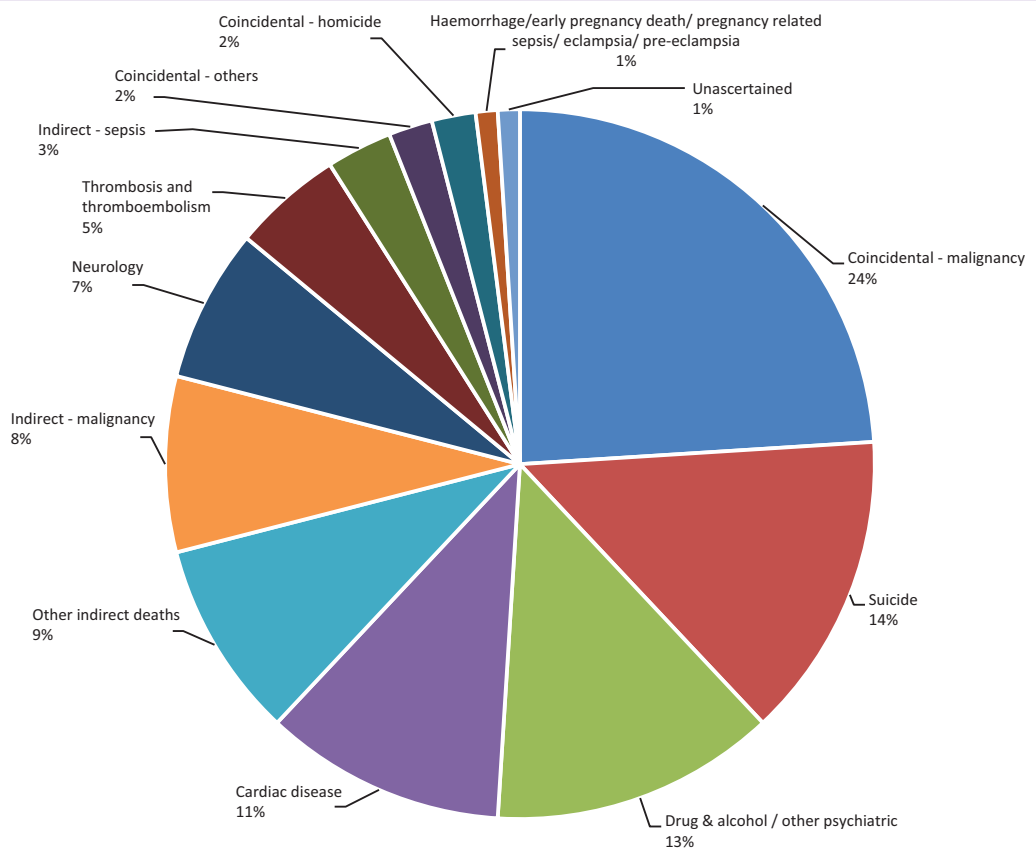
Source: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

*Note that this table reports the Maternal Mortality Ratio and not the rate as elsewhere in the report

## Women who died between six weeks and one year after the end of pregnancy

In the triennium 2013–15, 326 women died between six weeks and one year after the end of pregnancy, representing a mortality rate of 14.1 per 100,000 maternities (95% CI 12.6–15.8), comparable to the last triennium. Their causes of death are shown in Figure 2.4. Maternal suicides continue to be the leading cause of direct deaths occurring between six weeks and one year after the end of pregnancy.

**Figure 2.4: Causes of death amongst women who died between six weeks and one year after the end of pregnancy, UK 2013–15**




## 2.3 The characteristics of women who died 2013–15

### The women and babies

Of the 202 women who died from direct and indirect causes during or up to 42 days after the end of their pregnancy in 2013–15, a quarter (51 women) were still pregnant at the time of their death and 59% of these women were ≤20 weeks' gestation (Table 2.7). Fifteen (7%) women had a pregnancy loss at ≤20 weeks' gestation and for 3 women we did not have information about the gestational age at delivery or infant outcome. The remaining 133 women gave birth to a total of 140 infants, 109 (78%) survived, 31 died (20 stillborn and 11 neonatal deaths). The 202 women who died left behind a further 250 children, thus a total of 359 motherless children remain. The majority of women who gave birth did so in hospital (78%); 15% of women gave birth in an emergency department or an ambulance, and 4% at home (Table 2.8). In this triennium 93 of the women who died were delivered by caesarean section, 38% of these were performed perimortem. A total of 36 babies were born by perimortem caesarean section of which half were born after 32 weeks of gestation. Eight out of the 18 babies born after 32 weeks' gestation survived (5 were stillborn and 5 died in the neonatal period) and six out of the remaining 18 born at 32 weeks or less survived (8 were stillborn and 4 died in the neonatal period). Thus 39% of the total 36 babies delivered by perimortem caesarean section survived (36% were stillborn and 25% died in the neonatal period).

**Table 2.7: Table 2.7: Timing of maternal deaths in relation to pregnancy 2013–15**

| Time period of deaths in the pregnancy care pathway | Direct (n=88) Frequency (%) | Indirect (n=114) Frequency (%) | Total (n=202) Frequency (%) |
|---|---|---|---|
| Antenatal period | | | |
| *≤20 weeks* | 11 (13) | 19 (17) | 30 (15) |
| *>20 weeks* | 5 (6) | 16 (14) | 21 (10) |
| Postnatal on day of delivery | 28 (32) | 27 (24) | 55 (27) |
| Postnatal 1–41 days after delivery | 44 (50) | 52 (46) | 96 (48) |

**Table 2.8: Place of delivery amongst women >20 weeks' gestation who died after delivery 2013–15**

| Place of delivery (for women who had a childbirth) | Direct (n=62) Frequency (%) | Indirect (n=74) Frequency (%) | Total (n=136) Frequency (%) |
|---|---|---|---|
| Home | 4 (6) | 1 (1) | 5 (4) |
| Hospital (except Emergency Department) | 50 (81) | 56 (76) | 106 (78) |
| Emergency Department or ambulance | 8 (13) | 13 (18) | 21 (15) |
| Not known | 0 (0) | 4 (5) | 4 (3) |

## Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2013–15 are shown in Table 2.9. The proportion of women who did not have information recorded on whether they were subject to domestic abuse before or during pregnancy has increased to 60%, higher than the figure of 40% reported in 2016 (Knight, Nair et al. 2016). The following key message from the 2015 report needs to be reiterated:

**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.**

**NICE Antenatal care guideline CG62 (National Institute for Health and Care Excellence 2008a)**

The rates of maternal mortality varied by age, socioeconomic status and ethnic background of the women, which are known to be independently associated with an increased risk of maternal death in the UK (Nair, Kurinczuk et al. 2015, Nair, Knight et al. 2016). The rate of maternal mortality was higher amongst older women, those living in the most deprived areas and amongst women from particular ethnic minority groups (Table 2.10). In contrast to the 2016 report, there was a statistically significant difference between women living in the most deprived areas and those living in the least deprived areas in this triennium. As noted in the 2016 report, denominator figures for the specific ethnic groups are no longer in the public domain and permissions processes and charges levied by NHS Digital render them unobtainable; instead aggregate rates using larger ethnicity groupings are presented in Tables 2.10 and 2.11. Comparable to the previous reports, the risk of maternal death in 2013–15 was significantly higher among women from Black ethnic minority backgrounds compared with White women (RR 4.28; 95% CI 2.65 to 6.69). With the exception of a marginally significant increase in the relative risk of maternal death in the fourth IMD quintile in this triennium compared with 2010–12, the estimated ratios of relative risk (RRR) of maternal death in the different age, socioeconomic and ethnic groups did not show any statistically significant differences (Table 2.11). This suggests that there was no significant change in the inequality gaps across these time-periods.

Slightly less than a quarter of women who died in 2013–15 (24%) were born outside the UK; 44% of these women were not UK citizens. Overall 12% of the women who died were not UK citizens. Women who died who were born abroad had arrived in the UK a median of 3 years before they died (range 3 months to 22 years), and 79% were from Asia (mainly Pakistan and Bangladesh) and Africa (mainly Nigeria, Somalia and Democratic Republic of Congo), 13% from Eastern Europe (mostly from Poland) and the remainder from other parts of Europe, North America and the Caribbean. Table 2.12 shows the rates of death amongst women born in selected countries with the highest number of deaths. Similar to the previous triennium, there was no statistically significant difference in maternal death rate between women born in the UK and those born outside the UK in 2013–15. However, women born in certain specific countries had a significantly higher risk of death compared to women born in the UK (Table 2.12). Of the 24 women who were not UK citizens and born outside the UK, 3 were refugees (13%), 7 were visitors (29%) and 14 (58%) had another status, including wife of UK resident.

## Table 2.9: The socio-demographic characteristics of women who died 2013–15

| Characteristics | Direct (n=88)% Frequency (%) | Indirect (n=114) Frequency (%) | Total (n=202) Frequency (%) |
|---|---|---|---|
| Socio-demographic | | | |
| Age (years) | | | |
| *<20* | 2 (2) | 6 (5) | 8 (4) |
| *20–24* | 6 (7) | 18 (16) | 24 (12) |
| *25–29* | 17 (19) | 28 (25) | 45 (22) |
| *30–34* | 27 (31) | 28 (25) | 55 (27) |
| *35–39* | 23 (26) | 28 (25) | 51 (25) |
| *≥ 40* | 13 (15) | 6 (5) | 19 (9) |
| Parity | | | |
| *0* | 29 (33) | 40 (35) | 69 (34) |
| *1 to 2* | 42 (48) | 52 (46) | 94 (47) |
| *≥3* | 14 (16) | 18 (16) | 32 (16) |
| *Missing* | 3 (3) | 4 (4) | 7 (3) |
| UK citizen | | | |
| *Yes* | 72 (82) | 96 (84) | 168 (83) |
| *No* | 13 (15) | 12 (11) | 25 (12) |
| *Missing* | 3 (3) | 6 (5) | 9 (4) |
| Ethnicity | | | |
| *White European* | 54 (61) | 83 (73) | 137 (68) |
| *Indian* | 1 (1) | 2 (2) | 3 (1) |
| *Pakistani* | 8 (9) | 5 (4) | 13 (6) |
| *Bangladeshi* | 1 (1) | 3 (3) | 4 (2) |
| *Other Asian* | 2 (2) | 1 (1) | 3 (1) |
| *Black Caribbean* | 5 (6) | 3 (3) | 8 (4) |
| *Black African* | 10 (11) | 9 (8) | 19 (9) |
| *Others/ Mixed* | 6 (7) | 5 (4) | 11 (5) |
| *Missing* | 1 (1) | 3 (3) | 4 (2) |
| Woman's region of birth | | | |
| *United Kingdom* | 56 (64) | 78 (68) | 134 (66) |
| *Eastern Europe* | 2 (2) | 4 (4) | 6 (3) |
| *Western Europe* | 1 (1) | 1 (1) | 2 (1) |
| *Asia* | 9 (10) | 10 (9) | 19 (9) |
| *Africa* | 8 (9) | 11 (10) | 19 (9) |
| *Australia and North America* | 2 (2) | 0 (0) | 2 (1) |
| *Missing* | 10 (11) | 10 (9) | 20 (10) |
| Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence) | | | |
| *First quintile (Least deprived)* | 5 (6) | 8 (7) | 13 (6) |
| *Second quintile* | 7 (8) | 11 (10) | 18 (9) |
| *Third quintile* | 11 (13) | 20 (18) | 31 (15) |
| *Fourth quintile* | 20 (23) | 28 (25) | 48 (24) |
| *Fifth quintile (Most deprived)* | 25 (28) | 31 (27) | 56 (28) |
| *Missing* | 20 (23) | 16 (14) | 36 (18) |
| Socioeconomic status (Occupational classification) | | | |
| *Employed (Either woman or partner)* | 53 (60) | 65 (57) | 118 (58) |
| *Unemployed (Both)* | 11 (13) | 9 (8) | 20 (10) |
| *Missing* | 24 (27) | 40 (35) | 64 (32) |
| Able to speak/understand English | | | |
| *Yes* | 79 (90) | 108 (95) | 187 (93) |
| *No* | 9 (10) | 3 (3) | 12 (6) |
| *Missing* | 0 (0) | 3 (3) | 3 (1) |
| Living arrangements | | | |
| *With partner* | 56 (64) | 77 (68) | 133 (66) |
| *Living alone* | 11 (13) | 15 (13) | 26 (13) |
| *With parents/extended family* | 13 (15) | 13 (11) | 26 (13) |
| *Others* | 3 (3) | 3 (3) | 6 (3) |
| *Missing* | 5 (6) | 6 (5) | 11 (5) |
| Domestic abuse (prior to pregnancy/ during pregnancy) | | | |
| *Yes* | 5 (6) | 4 (4) | 9 (4) |
| *No* | 31 (35) | 41 (36) | 72 (36) |
| *Missing* | 52 (59) | 69 (61) | 121 (60) |
| Known to social services | | | |
| *Yes* | 14 (16) | 14 (12) | 28 (14) |
| *No* | 72 (82) | 94 (82) | 166 (82) |
| *Missing* | 2 (2) | 6 (5) | 8 (4) |

## Table 2.10: Maternal mortality rates amongst different population groups 2013–15

| | Total maternities 2012–14 | Total deaths | Rate per 100,000 maternities | 95% CI | Relative risk (RR) | 95% CI |
|---|---|---|---|---|---|---|
| Age (years) | | | | | | |
| *<20* | 88,846 | 8 | 9.00 | 3.89 to 17.74 | 1.41 | 0.55 to 3.25 |
| *20–24* | 376,968 | 24 | 6.37 | 4.08 to 9.47 | 1 (Ref) | - |
| *25–29* | 652,426 | 45 | 6.90 | 5.03 to 9.23 | 1.08 | 0.65 to 1.86 |
| *30–34* | 712,524 | 55 | 7.72 | 5.82 to 10.05 | 1.21 | 0.74 to 2.05 |
| *35–39* | 380,872 | 51 | 13.39 | 9.97 to 17.61 | 2.10 | 1.27 to 3.57 |
| *≥ 40* | 94,198 | 19 | 20.17 | 12.14 to 31.5 | 3.17 | 1.64 to 6.03 |
| IMD Quintiles (England only) | | | | | | |
| *I (Least deprived/*highest 20%) | 280,943 | 11 | 3.92 | 1.95 to 7.01 | 1 (Ref) | |
| *II* | 305,341 | 13 | 4.26 | 2.27 to 7.28 | 1.09 | 0.45 to 2.68 |
| *III* | 352,761 | 26 | 7.37 | 4.81 to10.8 | 1.88 | 0.90 to 4.22 |
| *IV* | 428,041 | 45 | 10.51 | 7.67 to 14.07 | 2.69 | 1.37 to 5.76 |
| *V (Most deprived/*lowest 20%) | 520,239 | 48 | 9.23 | 6.80 to 12.23 | 2.36 | 1.21 to 5.03 |
| Ethnic group (England only) | | | | | | |
| *White (inc. not known)* | 1,535,033 | 101 | 6.58 | 5.36 to 7.99 | 1 (Ref) | - |
| *Asian* | 203,888 | 22 | 10.79 | 6.76 to 16.34 | 1.64 | 0.98 to 2.62 |
| *Black* | 88,743 | 25 | 28.17 | 18.23 to 41.6 | 4.28 | 2.65 to 6.69 |
| *Chinese/ others* | 73,736 | 3 | 4.07 | 0.83 to 11.89 | 0.62 | 0.13 to 1.86 |
| *Mixed* | 30,254 | 3 | 9.92 | 2.04 to 28.98 | 1.51 | 0.31 to 4.53 |

## Table 2.11: Comparing the relative risk of maternal death among different population groups between 2010–12 and 2013–15

| | 2010–12 | | 2013–15 | | Ratio of the relative risks (RRR) (comparing 2013–15 with 2010–12) | 95% CI | P-value |
|---|---|---|---|---|---|---|---|
| | Relative risk (RR) | 95% CI | Relative risk (RR) | 95% C | | | |
| Age (years) | | | | | | | |
| *<20* | 1.16 | 0.51 to 2.42 | 1.41 | 0.55 to 3.25 | 1.22 | 0.37 to 3.96 | 0.746 |
| *20–24* | 1 (Ref) | - | 1 (Ref) | - | - | - | - |
| *25–29* | 1.28 | 0.81 to 2.04 | 1.08 | 0.65 to 1.86 | 0.84 | 0.42 to 1.69 | 0.635 |
| *30–34* | 1.44 | 0.93 to 2.27 | 1.21 | 0.74 to 2.05 | 0.84 | 0.43 to 1.65 | 0.614 |
| *35–39* | 1.93 | 1.21 to 3.12 | 2.10 | 1.27 to 3.57 | 1.09 | 0.54 to 2.19 | 0.813 |
| *≥ 40* | 3.51 | 1.96 to 6.23 | 3.17 | 1.64 to 6.03 | 0.90 | 0.38 to 2.16 | 0.818 |
| IMD Quintiles (England only) | | | | | | | |
| *I (Least deprived/ highest 20%)* | 1 (Ref) | - | 1 (Ref) | - | - | - | - |
| *II* | 0.94 | 0.53 to 1.66 | 1.09 | 0.45 to 2.68 | 1.16 | 0.40 to 3.34 | 0.784 |
| *III* | 0.87 | 0.50 to 1.52 | 1.88 | 0.90 to 4.22 | 2.16 | 0.83 to 5.59 | 0.112 |
| *IV* | 1.12 | 0.68 to 1.88 | 2.69 | 1.37 to 5.76 | 2.40 | 1.00 to 5.78 | 0.050 |
| *V (Most deprived/ lowest 20%)* | 1.32 | 0.83 to 2.14 | 2.36 | 1.21 to 5.03 | 1.78 | 0.76 to 4.20 | 0.183 |
| Ethnic group (England only) | | | | | | | |
| *White (inc. not known)* | 1 (Ref) | - | 1 (Ref) | - | - | - | - |
| *Asian* | 1.66 | 1.09 to 2.46 | 1.64 | 0.98 to 2.62 | 0.98 | 0.52 to 1.87 | 0.970 |
| *Black* | 3.03 | 1.93 to 4.59 | 4.28 | 2.65 to 6.69 | 1.41 | 0.74 to 2.66 | 0.158 |
| *Chinese/ others* | 0.99 | 0.36 to 2.22 | 0.62 | 0.13 to 1.86 | 0.62 | 0.12 to 3.13 | 0.569 |
| *Mixed* | 0.38 | 0.01 to 2.13 | 1.51 | 0.31 to 4.53 | 3.97 | 0.19 to 79.6 | 0.366 |

**Table 2.12: Maternal mortality rates according to mother's country of birth (selected countries)**

| Woman's country of birth | Maternities 2013–15 | Total Deaths | Rate per 100,000 maternities | 95% CI | Relative risk (RR) | 95% CI |
|---|---|---|---|---|---|---|
| UK | 1,722,806 | 134 | 7.78 | 6.52 to 9.21 | 1 (Ref) | - |
| Outside UK | 583,114 | 48 | 8.23 | 6.07 to 10.91 | 1.06 | 0.74 to 1.48 |
| Specific countries | | | | | | |
| *Bangladesh* | 23741 | 3 | 12.64 | 2.61 to 36.9 | 1.62 | 0.33 to 4.85 |
| *Pakistan* | 56013 | 10 | 17.85 | 8.56 to 32.8 | 2.30 | 1.08 to 4.35 |
| *Jamaica* | 5716 | 4 | 69.9 | 19.1 to 179.1 | 8.99 | 2.41 to 23.6 |
| *Nigeria* | 22241 | 3 | 13.5 | 2.78 to 39.4 | 1.73 | 0.35 to 5.17 |
| *Poland* | 74052 | 3 | 4.1 | 0.84 to 11.84 | 0.52 | 0.11 to 1.55 |

## Medical and pregnancy-related characteristics

Studies have shown that 66% of the increased risk of maternal death in the UK could be attributed to medical comorbidities (Nair, Knight et al. 2016). More than two-thirds (68%) of the women who died in 2013–15 were known to have pre-existing medical problems (Table 2.13), 16% were known to have pre-existing mental health problems and 8% had pre-existing cardiac problems. More than a third (34%) of the women who died in this triennium were obese and 19% were overweight (Table 2.13).

The pregnancy-related characteristics of the women who died in 2013–15 are shown in Table 2.14.

**Table 2.13: Selected medical conditions and characteristics identified amongst women who died 2013–15**

| Medical condition/characteristic | Direct (n=88) Frequency (%) | Indirect (n=114) Frequency (%) | Total (n=202) Frequency (%) |
|---|---|---|---|
| Body mass index (BMI) (Kg/m$^2$) | | | |
| *<18* | 1 (1) | 6 (5) | 7 (3) |
| *18–24* | 26 (30) | 35 (31) | 61 (30) |
| *25–29* | 21 (24) | 18 (16) | 39 (19) |
| *≥ 30* | 30 (34) | 38 (33) | 68 (34) |
| *Missing* | 10 (11) | 17 (15) | 27 (13) |
| Mental health problems or psychiatric disorders | | | |
| *Yes* | 16 (18) | 17 (15) | 33 (16) |
| *No* | 70 (80) | 93 (82) | 163 (81) |
| *Missing* | 2 (2) | 4 (4) | 6 (3) |
| Pre-existing cardiac problems | | | |
| *Yes* | 3 (3) | 14 (12) | 17 (8) |
| *No* | 83 (94) | 96 (84) | 179 (89) |
| *Missing* | 2 (2) | 4 (4) | 6 (3) |
| Any pre-existing medical problem (excluding obesity) | | | |
| *Yes* | 55 (63) | 83 (73) | 138 (68) |
| *No* | 31 (35) | 27 (24) | 58 (29) |
| *Missing* | 2 (2) | 4 (4) | 6 (3) |

**Table 2.14: Pregnancy-related characteristics of the women who died 2013–15**

| Characteristics | Direct (n=88) Frequency (%) | Indirect (n=114) Frequency (%) | Total (n=202) Frequency (%) |
|---|---|---|---|
| Pregnancy known to be as a result of assisted reproductive techniques | | | |
| *Yes* | 5 (6) | 1 (1) | 6 (3) |
| *No* | 81 (92) | 108 (95) | 189 (94) |
| *Missing* | 2 (2) | 5 (4) | 7 (3) |
| Multiple pregnancy | | | |
| *Yes* | 5 (6) | 3 (3) | 8 (4) |
| *No* | 83 (94) | 105 (92) | 188 (93) |
| *Missing* | 0 (0) | 6 (5) | 6 (3) |
| Previous caesarean section | | | |
| *Yes* | 24 (27) | 21 (18) | 45 (22) |
| *No* | 61 (69) | 88 (77) | 149 (74) |
| *Missing* | 3 (3) | 5 (4) | 8 (4) |
| Previous caesarean numbers (among women who had a previous caesarean section) | | | |
| *1* | 13 (54) | 16 (76) | 29 (64) |
| ≥2 | 11 (46) | 5 (24) | 16 (36) |

## Other characteristics of women who died

Both substance misuse and inadequate utilisation of antenatal care services have been shown to be independently associated with increased risk of maternal death in the UK (Nair, Kurinczuk et al. 2015, Nair, Knight et al. 2016). The prevalence of these risk factors among women who died in 2013–15 did not differ from that noted in the previous reports (Table 2.15) and use of recommended antenatal care still remains low. Less than a third (30%) of women who received antenatal care, received the recommended level of care according to NICE antenatal care guidelines (booking at 10 weeks or less and no routine antenatal visits missed) (National Institute for Health and Care Excellence 2008a).

### Table 2.15: Other characteristics of women who died 2013–15

| Characteristics | Direct (n=88) Frequency (%) | Indirect (n=114) Frequency (%) | Total (n=202) Frequency (%) |
|---|---|---|---|
| Smoking | | | |
| *Smoker* | 18 (20) | 26 (23) | 44 (22) |
| *Non-smoker* | 63 (72) | 73 (64) | 136 (67) |
| *Missing* | 7 (8) | 15 (13) | 22 (11) |
| Substance user | | | |
| *Yes* | 9 (10) | 8 (7) | 17 (8) |
| *No* | 78 (89) | 101 (89) | 179 (89) |
| *Missing* | 1 (1) | 5 (4) | 6 (3) |
| Received any antenatal care* | | | |
| *Yes* | 75 (85) | 101 (89) | 176 (87) |
| *No* | 13 (15) | 11 (10) | 24 (12) |
| *Missing* | 0 (0) | 2 (2) | 2 (1) |
| Gestational age at booking (among women who received any antenatal care) (weeks) | | | |
| *≤10* | 27 (36) | 43 (43) | 70 (40) |
| *11–12* | 30 (40) | 35 (35) | 65 (37) |
| *>12* | 17 (23) | 19 (19) | 36 (20) |
| *Missing* | 1 (1) | 4 (4) | 5 (3) |
| Received recommended antenatal care† (among women who received any antenatal care) | | | |
| *Yes* | 18 (24) | 35 (35) | 53 (30) |
| *No* | 56 (75) | 61 (60) | 117 (66) |
| *Missing* | 1 (1) | 5 (5) | 6 (3) |
| Received a minimum level of antenatal care† (among women who received any antenatal care) | | | |
| *Yes* | 55 (73) | 72 (71) | 127 (72) |
| *No* | 19 (25) | 21 (21) | 40 (23) |
| *Missing* | 1 (1) | 8 (8) | 9 (5) |

*Includes 7 women who died in early pregnancy.

†NICE recommended antenatal care: booked at 10 weeks or less and no antenatal visits missed. Minimum level of care: booked at less than 13 weeks and 3 or fewer antenatal visits missed.

## Classification of quality of care

This section includes information on women who died between 2013 and 2015 and are included in the Confidential Enquiry chapters of this report (including 31 women who died between six weeks and a year after the end of pregnancy and women from the Republic of Ireland). Table 2.16 shows the classification of care as agreed by the assessors for 124 women whose case notes were available with sufficient information for an in-depth review. Among these women 35% were assessed to have received good care, but detailed assessment showed that for another 41% improvements in care may have made a difference to their outcome.

**Table 2.16: Classification of care received by women who died and for whom case notes were available for an in-depth review and are included in the Confidential Enquiry chapters, UK and Ireland (2013–15)**

| Classification of care received | (n=124)* Number (%) |
|---|---|
| Good care | 44 (35) |
| Improvements to care which would have made no difference to outcome | 29 (23) |
| Improvements to care which may have made a difference to outcome | 51 (41) |

*includes only women whose case notes were available with sufficient information for an in-depth review

## Local clinicians' reports

There was an increase in the proportion of reports received from local clinicians of those requested for the Confidential Enquiry from 18% in 2012 to 65% in 2014. However, there has been only a small increase in 2015 to 68%. Local clinicians' reports are absolutely essential to allow MBRRACE-UK assessors to take full account of any local factors impacting on care, and we urge clinicians to return these in a timely manner. Proportions for different specialty groups are listed in table 2.17.

**Table 2.17: Percentages of local clinicians' reports received for women who died in 2015**

| Specialty group | Percentage of reports requested that were received |
|---|---|
| Obstetricians | 66 |
| Anaesthetists | 78 |
| Midwives | 65 |
| Critical Care Clinicians | 70 |
| Emergency Medicine Specialists | 65 |
| GPs | 72 |
| Physicians | 66 |
| Psychiatrists | 44 |
| *Total* | 68 |

**All health professionals should return MBRRACE-UK local clinicians reports when requested. They are essential to identify local factors impacting on care.**

# 2.4 The women who survived

## Women with severe epilepsy

A national cohort study was undertaken through the UK Obstetric Surveillance System between October 2015 and March 2017, identifying all pregnant women with severe epilepsy. As described in section 1.4, 23 women were included in the Confidential Enquiry. The characteristics of the women who survived and were selected for inclusion in the Confidential Enquiry into Maternal Morbidity are shown in Table 2.18.

**Table 2.18: Characteristics of women with severe epilepsy who survived**

| Characteristics | Total (n=23) Frequency (%) |
|---|---|
| Age | |
| *<25* | 4 (17) |
| *25–34* | 14 (61) |
| *≥35* | 5 (22) |
| Parity | |
| *0* | 9 (39) |
| *≥1* | 13 (57) |
| *Missing* | 1 (4) |
| Ethnicity | |
| *White European* | 20 (87) |
| *Other* | 2 (9) |
| *Missing* | 1 (4) |
| Socioeconomic status (Occupational classification) | |
| *Employed (Either woman or partner)* | 13 (57) |
| *Unemployed (Both)* | 3 (13) |
| *Missing* | 7 (30) |
| Smoking | |
| *Smoker* | 4 (17) |
| *Non-smoker* | 19 (83) |
| Substance misuse | |
| *Yes* | 2 (9) |
| *No* | 20 (87) |
| *Missing* | 1 (4) |
| Body mass index (BMI) (kg/m$^2$) | |
| *<18* | 0 (0) |
| *18–24* | 9 (39) |
| *25–29* | 6 (26) |
| *≥30* | 6 (26) |
| *Missing* | 2 (9) |
| Any pre-existing medical or mental health problem in addition to epilepsy (excluding obesity) | |
| *Yes* | 6 (26) |
| *No* | 15 (65) |
| *Missing* | 2 (9) |

Four of the six women reported to have a pre-existing problem had mental health problems and two had another medical problem in addition to their epilepsy

## Women with psychosis

As noted in section 1.4, women with psychosis were identified through a variety of sources and we do not have overall numbers to provide an incidence estimate. Previous research suggests an estimated incidence of 1 case per 1000 births (Harlow, Vitonis et al. 2007), with an approximately 200-fold increase in incidence amongst women with a previous psychiatric admission. As noted in section 1.4, 23 women were included in the Confidential Enquiry into Maternal Morbidity, and the results of this Confidential Enquiry are included in Chapter 4. Characteristics of the women are included in Table 2.19.

Table 2.19: Characteristics of women with psychosis who survived

| Characteristics | Total (n=23) Frequency (%) |
|---|---|
| Age | |
| *<25* | 3 (13) |
| *25–34* | 14 (61) |
| *≥35* | 6 (26) |
| Parity | |
| *0* | 9 (39) |
| *≥1* | 14 (61) |
| Ethnicity | |
| *White European* | 14 (61) |
| *Other* | 8 (35) |
| *Missing* | 1 (4) |
| Socioeconomic status (Occupational classification) | |
| *Employed (Either woman or partner)* | 18 (78) |
| *Unemployed (Both)* | 2 (9) |
| *Missing* | 3 (13) |
| Body mass index (BMI) (kg/m$^2$) | |
| *<18* | 0 (0) |
| *18–24* | 9 (39) |
| *25–29* | 6 (26) |
| *≥30* | 8 (35) |
| Any pre-existing medical problem (excluding obesity) | |
| *Yes* | 6 (26) |
| *No* | 17 (74) |

Only one out of the 23 women smoked during pregnancy, none misused substances or alcohol

# 3. Lessons on epilepsy and stroke

Andrew Kelso, Adrian Wills and Marian Knight on behalf of the MBRRACE-UK neurology chapter-writing group

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## 3.1 Key messages

All women with epilepsy should be provided with the information they need prior to conception. This includes verbal and written information on prenatal screening and its implications, the risks of self-discontinuation of anti-epileptic drugs and the effects of seizures and anti-epileptics on the fetus and on the pregnancy, breastfeeding and contraception. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Obstetric teams should take urgent action when pregnant women with a current or past diagnosis of epilepsy have discontinued anti-epileptic drugs without specialist advice. Urgent attempts should be made by all clinicians involved in care to offer the woman immediate access to an appropriately trained professional (e.g. neurologist/epilepsy specialist nurse or midwife) to review her medication and prescribe AEDs if appropriate. **ACTION: Health professionals**

GPs, secondary care providers and commissioners should work together to ensure that women with epilepsy have access to appropriately specialised care, before, during, and after pregnancy. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Pregnant women with epilepsy often face additional physical, mental health or social problems. As with all women with these types of problems additional effort should be taken to ensure they have access to the care they need. This should take into account interpersonal dynamics which may be challenging, provide properly trained interpreters where necessary, and link up with agencies outside the health service (including prisons, probation services, police forces, and social services). **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Postpartum safety advice and strategies should be part of the antenatal and postnatal discussions with the mother alongside breastfeeding, seizure deterioration and AED intake. **ACTION: Health professionals**

Pregnancy should not alter the investigation and treatment of a woman presenting with a stroke. **ACTION: Service planners/commissioners, service managers, health professionals**

Neurological examination including assessment for neck stiffness and fundoscopy is mandatory for all women with new onset headaches or headache with atypical features, particularly focal symptoms. **ACTION: Health professionals**

A change in mental state and new seizures should lead to prompt neurological assessment. **ACTION: Health professionals**

A lack of an immediately available critical care bed must not be a reason for refusing admission for patients requiring urgent neurosurgery. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

## 3.2 Caring for women with epilepsy

### Introduction

Epilepsy remains the commonest serious neurological disease, and every year there are an estimated 2500 pregnancies in the UK in women with epilepsy (UK and Ireland Epilepsy and Pregnancy Register 2016). There remain concerns regarding the incidence of Sudden Unexplained Death in Epilepsy

(SUDEP) in pregnancy, and that it may be higher than population estimates suggest (Edey, Moran et al. 2014). Previous Confidential Enquiries have suggested that significant improvements in care are necessary to reduce mortality. This chapter reviews the care of the women with epilepsy who died during or in the one year after pregnancy between 2013 and 2015. Using a similar methodology, it also reviews the care of 23 women with uncontrolled epilepsy during pregnancy who did not die, sampled from the United Kingdom Obstetric Surveillance System (UKOSS) study of uncontrolled epilepsy.

## The women who died

In 2013–2015, eight women with epilepsy died during pregnancy or in the immediate post-partum period, and five women died between six weeks and one year after delivery; the death of one woman in the late postpartum period was considered pregnancy-related and her care was reviewed for the purposes of this chapter. The details of the care of the women reviewed are summarised in Table 3.1. In all of them, improvements in care were identified, and these may have influenced the outcome for seven women. The commonest cause of death was Sudden Unexplained Death in Epilepsy (SUDEP). One woman drowned in the bath.

**Table 3.1: Summary of the care of the women with epilepsy who died 2013–2015 and whose care was reviewed (n=9)**

| Cause of death | SUDEP | Drowning | SUDEP | SUDEP | SUDEP | SUDEP | SUDEP | SUDEP | SUDEP |
|---|---|---|---|---|---|---|---|---|---|
| Timing of death | 2nd trimester | Late postpartum | 2nd trimester | Early postpartum | 2nd trimester | 3rd trimester | 1st trimester | 3rd trimester | 3rd trimester |
| Improvements in care identified which may have changed outcome? | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes |
| Medication | None (previously on SVP) | LEV | None | None | None | LTG | None (previously on SVP) | CLB | LEV, LTG |
| Pre-conception counselling | No | Yes | No | Yes | No | Yes | Yes | Yes | Unclear |
| Specialist review during pregnancy? | No | No | No | No | No | Yes | Yes | Yes | Yes |
| Was epilepsy controlled pre-pregnancy? | Not known | No | No | No | No | No | No | No | No |

SVP–sodium valproate; LEV–Levetiracetam; LTG–lamotrigine; CLB–clobazam

## Previous recommendations

The care of women who died from epilepsy was last reviewed in 2014, when the following high-level recommendations were made:

**Pre-conception counselling for women with epilepsy is widely advised, but is not always delivered effectively and should be robustly offered in all care settings on an opportunistic basis (National Institute for Health and Care Excellence 2012)**

**All antenatal services should identify a liaison epilepsy nurse to integrate into their routine antenatal service (Knight, Kenyon et al. 2014)**

**All women with a possible new diagnosis of epilepsy should be seen promptly by a specialist in epilepsy and the care of pregnant women with epilepsy should be shared between an epilepsy specialist or obstetric physician and an obstetrician (National Institute for Health and Care Excellence 2012)**

**Pregnant or recently pregnant women with epilepsy should never be accommodated in single rooms (National Institute for Health and Care Excellence 2012)**

**SUDEP remains the major cause of death in pregnant or postpartum women with epilepsy, and further research is required to inform risk reduction strategies (Knight, Kenyon et al. 2014)**

**Multi-agency evidence based operational guidance is urgently required to standardise and improve the care of pregnant women with epilepsy (Knight, Kenyon et al. 2014)**

The information contained in Table 3.1 emphasises that these recommendations deserve reiteration. Nevertheless, since the last report on epilepsy in pregnancy, a number of actions have occurred. The Royal College of Obstetricians and Gynaecologists have published a comprehensive guideline on epilepsy in pregnancy (Royal College of Obstetricians and Gynaecologists 2016b), which was expedited in response to the 2014 report. A UK-based group of key stakeholders have discussed the issues surrounding epilepsy and pregnancy, and have recommended a series of changes in epilepsy care necessary to reduce death (Leach, Smith et al. 2017). The Empire trial (the only randomised controlled trial of AED monitoring in pregnancy) has finished recruiting, and the results are in draft. These can be viewed as early signs of progress.

That women are still dying without seeing an epilepsy specialist during their pregnancy is perhaps not surprising. Changes in practice prompted by the 2014 report would not have taken effect until at least 2015, which is the third year covered by this review. This 2017 report confirms that women who die miss out on effective pre-conception counselling and do not have ready access to specialist care during their pregnancy. What is worse is that they can be easily identified pre-pregnancy, as they all (bar one on whom we had no pre-pregnancy epilepsy information) had uncontrolled seizures. As in previous reviews, there is still evidence of a lack of ownership for the care of women with epilepsy, fragmented services and inefficient or poor communication.

However, there are a number of encouraging observations. Although the mortality rate is not statistically significantly different, there have been fewer deaths due to epilepsy than in previous years (eight during pregnancy or up to 42 days postpartum in this three year period (0.32 per 100,000 maternities, 95% CI 0.14–0.63), compared with fourteen in the last review covering four years (0.40 per 100,000 maternities, 95% CI 0.22–0.68)). There was some evidence of exemplary practice in extremely challenging situations. Two women died despite receiving highly specialised and diligent epilepsy care during their pregnancy, highlighting the mortality associated with epilepsy, even when care is optimised.

## New themes as foci for improvement

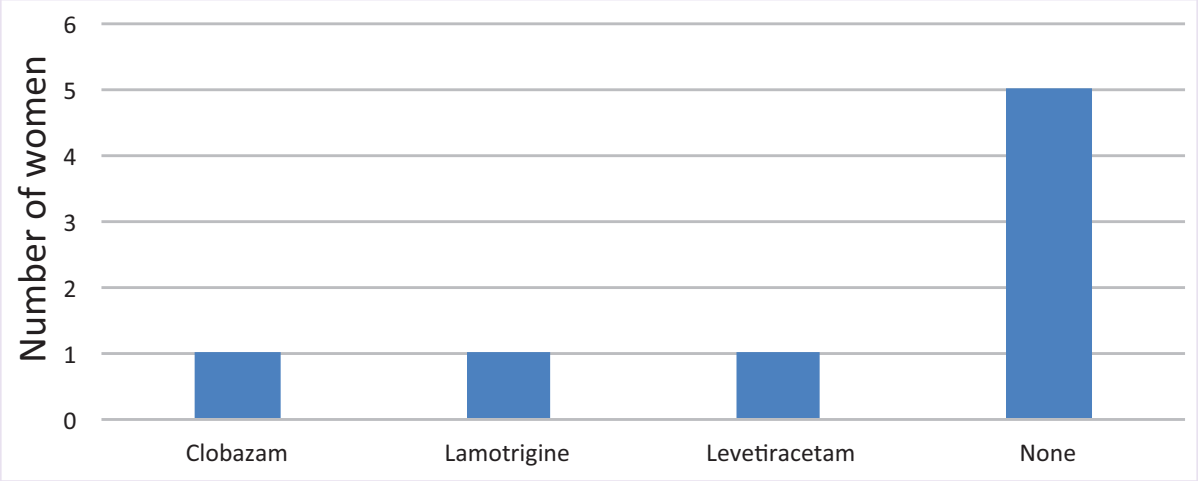
### Anti-epileptic drug-taking behaviours

A woman with epilepsy had recently moved to the United Kingdom from Eastern Europe, where she had been told by a neurologist to stop her sodium valproate shortly after becoming pregnant. She could not speak English well. The GP recognised that she was not taking medication. She was not referred to epilepsy services, and despite several contacts with her GP, midwife and obstetrician, she did not restart any medication. She died from SUDEP in the third trimester of pregnancy.

An historical association between use of lamotrigine and maternal death seemed less likely in the 2014 MBRRACE report, which indicated that women who died were treated with a range of antiepileptic drugs (AEDs) (Knight, Kenyon et al. 2014). This 2017 report suggests a different association–women with epilepsy are dying because they are taking no AEDs during pregnancy (Figure 3.1). Two women stopped their AED on the advice of a medical professional (neurologist in another country; GP in United Kingdom). Three women made their own decision to stop medication, one of them following consultation with their Epilepsy nurse. Two women who stopped medication had previously been prescribed sodium valproate. All of the women saw a series of clinicians (including midwives, obstetricians, GPs), many of whom noted the absence of an AED, but did not take action to restart them (either by writing a prescription or by arranging urgent specialist review). Whilst people with epilepsy are encouraged to be their own advocates and to make decisions about their own health, the chapter writing group were not convinced that these women had access to the full breadth of information about risks available, and their concerns were not fully explored.

**Obstetric teams should take urgent action when pregnant women with a current or past diagnosis of epilepsy have discontinued anti-epileptic drugs without specialist advice. Urgent attempts should be made by all clinicians involved in care to offer the woman immediate access to an appropriately trained professional (e.g. neurologist/epilepsy specialist nurse or midwife) to review her medication and prescribe AEDs if appropriate. All women with epilepsy should be provided with the information they need prior to conception.**

**Figure 3.1: Antiepileptic drugs (AEDs) used by women who died, 2013–2015**




Note one woman was prescribed both lamotrigine and levetiracetam

## Inadequate medical knowledge

A woman was told to stop her Levetiracetam by a GP due to early pregnancy. She was advised to restart it but did not attend her follow up appointment and this recommendation was not followed up. She registered at a different GP practice during pregnancy, and her new GP did not make efforts to establish her epilepsy treatment. She died of SUDEP in the second trimester of pregnancy.

Two women died because they were given the wrong advice from their doctor regarding AEDs in pregnancy. In one case, the advice was obtained from a neurologist practicing outside the UK and Ireland, but in another the advice was from a local GP. Epilepsy care is increasingly specialised, and even more so in women of childbearing age, and urgent referral to a neurologist or epilepsy specialist is needed to get appropriate advice. Access to epilepsy specialists should be facilitated across networks of care as a minimum.

**GPs, secondary care providers and commissioners should work together to ensure that women with epilepsy have access to appropriately specialised care, before, during, and after pregnancy.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

**Access to epilepsy specialists should be facilitated across networks of care as a minimum.**

## Care of highly vulnerable women

A woman with learning disability lived with her partner and had reported for some years that she was seizure free on no medication. She frequently missed appointments and had been lost to neurological follow up. Pregnancy care was similarly patchy and intermittent. She had no formal carer or social support. She died of SUDEP in the second trimester of pregnancy. During review, it became apparent that she had been having seizures during sleep for years, misattributed by her partner as nightmares. Opportunities to intervene were missed.

Four women who died had socially complex lives or were vulnerable. Sociobiological factors associated with death in these women included poor English language skills, forensic issues (including some obstetric care in prison), domestic violence, contact with social services, older children in care, and learning disability. Traditional models of care may be inadequate for these women. For instance, DNA policies where women are discharged from either epilepsy or obstetric services following missed appointments may not take into account the significant challenges some women face, where even the apparently simple task of attending an important appointment is unachievable on some days.

**Pregnant women with epilepsy often face additional physical, mental health or social problems. As with all women with these types of problems additional effort should be taken to ensure they have access to the care they need. This should take into account interpersonal dynamics which may be challenging, provide properly trained interpreters where necessary, and link up with agencies outside the health service (including prisons, probation services, police forces, and social services).**

## Patient education and engagement

A woman with idiopathic generalised epilepsy had been highly resistant to multiple AEDs, and following extensive counselling with her epilepsy team, had decided to stop all of her AEDs other than clobazam prior to pregnancy. She received highly tailored joint care from epilepsy specialists and obstetricians/midwives during her pregnancy and appropriate risk assessments were made throughout. She was an equal partner in her care. She nevertheless died from SUDEP in the third trimester of pregnancy reflecting the high-risk nature of pregnancy in women with uncontrolled epilepsy.

Health care is increasingly attempting to become more patient-centred, and women are appropriately encouraged to be equal partners in their own health care. That women are increasingly confident in making their own healthcare decisions may be reflected in our observations in this report about AEDs. However, patient-centred health care is insufficient if it operates in isolation from informed support. Obstetric and epilepsy services increasingly take women's choice into account, but this should not stop them from having difficult discussions with women, particularly when they are taking potentially high risk decisions.

The jobs of doctors, nurses and midwives are becoming less directive and more facilitative. We have to ensure that we are skilled in signposting women to the information they need in the present and for the future, including providing that information where necessary, or ensuring that women have access to it (Royal College of Obstetricians and Gynaecologists 2016b). Where women take a course of action that clinicians feel is potentially high risk, those clinicians should be confident in challenging those decisions, within an atmosphere of trust and mutual respect. Management of long-term medical conditions in pregnancy should place the woman at the centre of every decision, and ensure that she has access to all appropriate information to help her make those decisions. Where women do not have capacity, this should be recognised at an early stage, appropriate steps taken to safeguard the woman and decision-making processes clarified.

## The women who survived

As well as reviewing the care of women who died, in this report the care of women with epilepsy in pregnancy who did not die was also reviewed. The care of twenty-three women with uncontrolled epilepsy in pregnancy was examined, and the details are summarised in Table 3.2. Whilst 12 women were identified where an improvement may have made a difference to their outcome, and care of most of the other women could have been improved with no definite effect on outcome, there were multiple examples of good practice. These included:

- Joint obstetric and epilepsy clinics
- Shared record keeping
- Shared decision making between women and the teams caring for them
- Protocols for management of epilepsy in pregnancy

However, despite these examples, a number of areas for improvement were also observed. In common with the care of women who died, these included a need for effective communication, co-ordinated care and adequate specialist review during pregnancy. These reviews show that a need for improvements in care is not limited to the women who died, and (as previously suspected) reflect a wider need for appropriate systems and knowledge to care for women with epilepsy during pregnancy.

**Table 3.2: The care of women with severe uncontrolled epilepsy who survived.**

| Diagnosis | AEDs used | Improvements in care identified which may have changed outcome? | Epilepsy risk advice | Birth plan | Postnatal contraceptive advice | Baby care | Mode of delivery | UK Epilepsy and Pregnancy register |
|---|---|---|---|---|---|---|---|---|
| DS | None | Yes | Yes | No | No | No | IOL | Yes |
| UE | LEV | No | No | No | No | No | SVD | No |
| UE | None | No | Yes | No | No | No | SVD | No |
| UE | LEV; LTG | Yes | No | No | No | No | SVD | No |
| IGE | SVP; TPM | No | Yes | Yes | Yes | Yes | IOL | Yes |
| FE | LEV; CBZ | No | Yes | No | Yes | Yes | IOL | No |
| FE | LTG; CLN | Yes | Yes | No | Yes | Yes | SVD | No |
| FE | LTG; CBZ; GBP | Yes | No | No | No | No | IOL | No |
| UE | LTG | No | Yes | Yes | Yes | No | SVD | No |
| UE | LTG | No | Yes | No | Yes | No | IOL | No |
| UE | LTG | Yes | No | No | No | No | CS | No |
| Other | None | No | No | No | No | No | IOL | No |
| UE | None | No | No | No | No | No | SVD | No |
| DS and UE | Unclear | Yes | No | No | No | No | CS | No |
| UE | LTG; LEV | Yes | Yes | No | No | No | IOL | No |
| UE | LTG; LEV | No | No | No | No | No | IOL | No |
| FE | LEV | Yes | Yes | Yes | Yes | Yes | SVD | No |
| UE | SVP | No | Yes | No | Yes | No | SVD | Yes |
| DS and UE | None | No | Yes | No | No | Yes | IOL | Yes |
| DS | LTG | Yes | No | No | No | No | IOL | No |
| UE | LTG; CBZ; LEV; CLB | Yes | No | No | No | No | IOL | No |
| UE | LEV; DPH | Yes | Yes | No | No | No | IOL | No |
| IGE | SVP; LEV; CLN | Yes | Yes | Yes | Yes | No | IOL | Yes |

DS–dissociative seizures; FE–Focal Epilepsy; IGE–Idiopathic Generalised Epilepsy; UE–Unclassified Epilepsy; CBZ–carbamazepine; CLB–clobazam; CLN–clonazepam; DPH–phenytoin; GPB–gabapentin; LEV–levetiracetam; LTG–lamotrigine; SVP–sodium valproate; TPM–topiramate; CS–caesarean section; IOL–Induction of labour; SVD–spontaneous vaginal delivery

## Syndromic diagnosis

A young woman with epilepsy was managed throughout pregnancy by an epilepsy nurse specialist. There was no evidence of a syndromic diagnosis in either her obstetric notes or in the epilepsy nurse specialist letters. She had both focal and tonic-clonic seizures throughout pregnancy and was treated with an atypical combination of four anti-epileptic drugs. Side effects prevented further dose escalation, but the rationale for the choice of drugs and details of previous treatment were unclear. The nurse specialist appeared to have little consultant support. The woman was induced preterm because of unstable epilepsy. She was kept in hospital for 72 hours postnatally, supervised by her partner and mother. She had no postnatal discussion of future risk, breastfeeding, or postnatal drug doses.

Syndromic diagnosis of epilepsy was unclear for most women. This is important: without defining the epilepsy syndrome properly and transparently, it is not possible to reliably prescribe the most effective AED(s) at the lowest effective dose. This is complex, and may not be achievable by many general neurology services nationally at present. However, it reflects a significant deficiency of care and a focus for service development in future.

A woman with temporal lobe epilepsy was under the care of a consultant neurologist and epilepsy nurse specialist. Risk assessment was incorrect as her ongoing focal seizures were not fully appreciated by either her consultant or epilepsy nurse specialist. It was unclear whether the decision not to increase the dose of levetiracetam or add in a second agent was fully discussed with her. She had a generalised tonic-clonic seizure at the end of the pregnancy, and managing her focal seizures differently may have prevented this. Her main co-morbidity was a severe puerperal psychotic depression. Neurological contributors to this - the possible contribution of post-ictal psychosis and levetiracetam - were not considered.

Understanding the implications of active epilepsy in terms of seizure recurrence risk is important. This woman's incorrect initial risk assessment led to low risk care, with missed opportunities to improve her outcome and potentially to prevent severity of postnatal psychiatric problems. The assessment of risk involves consideration of multiple factors, including duration and severity of epilepsy, frequency and type of seizures, and impact of epilepsy on the mother, and should be undertaken by a specialist (Royal College of Obstetricians and Gynaecologists 2016b). Women who have remained seizure-free for at least 10 years (with the last 5 years off AEDs) and those with a childhood epilepsy syndrome who have reached adulthood seizure- and treatment-free can be considered no longer to have epilepsy and can be managed as low-risk provided there are no other risk factors (Royal College of Obstetricians and Gynaecologists 2016b).

**The diagnosis of epilepsy and epileptiform seizures should be made by a medical practitioner with expertise in epilepsy, usually a neurologist.**

**Women with epilepsy, their families and healthcare professionals should be aware of the different types of epilepsy and their presentation to assess the specific risks to the mother and baby.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

A woman had a firm diagnosis of non-epileptic attack disorder (also called non-epileptic seizures, psychogenic seizures, pseudoseizures, or dissociative seizures) made by a consultant neurologist in 2010 when epilepsy was excluded. During her pregnancy in 2015, her epilepsy nurse was still unprepared to exclude epilepsy fully, and this led to confusion with the obstetric team. There was good communication and early referrals between the obstetric team, the epilepsy nurse, and obstetric anaesthetic team. However, the obstetric team and obstetric anaesthetists did not appreciate that she did not have epilepsy and therefore provided advice as if she did. Her labour was induced because of 'unstable epilepsy', when in fact she had unstable non-epileptic seizures.

This woman's diagnosis of non-epileptic attack disorder (NEAD) was not recognised or accepted by the teams caring for her, despite a clear diagnosis from a neurologist. It was notable that several women whose care was reviewed for the purposes of this enquiry had non-epileptic attack disorder, either alone or co-existing with epilepsy, which was not recognised. In many instances this led to use of escalating doses and combinations of anti-epileptic drugs and consequent unnecessary fetal exposure. Non-epileptic attack disorder is an important part of the differential diagnosis of drug-resistant seizures (Reuber, Baker et al. 2004, Royal College of Obstetricians and Gynaecologists 2016b), and requires multidisciplinary management with access to psychological or psychiatric services. This further emphasises the importance of correct syndromic diagnosis in all women with seizures during pregnancy.

**Inappropriate medical intervention, including AED administration and iatrogenic early delivery, should be avoided when there is a firm diagnosis of non-epileptic attack disorder.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

Where epilepsy, obstetric and other teams worked together, outcomes for women were good. There was clear evidence that good epilepsy care can be provided in challenging circumstances provided services are available and willing to re-prioritise.

A teenager with a complex syndrome and uncontrolled seizures was transitioning from paediatric to adult neurology at the time of her pregnancy. Throughout her pregnancy there was active communication between epilepsy and obstetric services with close management of her anti-epileptic medication. Labour was induced at term and she had an uneventful recovery postnatally after receiving appropriate safety advice.

## Birth plan

A woman who had been seizure free for five years was referred in early pregnancy as high risk and seen in the Maternal Medicine clinic at 14 weeks. She was seen regularly by both obstetrician and epilepsy nurse specialist but there was no evidence of joint appointments. Her birth plan did not consider epilepsy. She had a single seizure during early labour, thought to be triggered by pain and/or sleep deprivation. Prior to discharge she received appropriate advice regarding driving and medication but no safety advice re baby care or discussion of postnatal risk or implications for future pregnancies.

An epilepsy specific birth plan may have prevented her seizure during early labour, through consideration of management of both her pain and sleep deprivation. A birth plan which takes into account epilepsy and its management in the intra and immediate postpartum period can be life-saving (Royal College of Obstetricians and Gynaecologists 2016b). Only four women included in this review had discussions leading to a birth plan that properly took their epilepsy into account.

### Epilepsy risk advice

Specific advice about the effects of epilepsy on pregnancy and vice versa was lacking from the care of ten women. This potentially exposes them to unnecessary risk and may indicate a lack of adequate education and care.

**Women with epilepsy should be provided with verbal and written information on prenatal screening and its implications, the risks of self-discontinuation of AEDs and the effects of seizures and AEDs on the fetus and on the pregnancy, breastfeeding and contraception.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

### Contraception

Use of contraception in epilepsy is complicated by the differing effects of AEDs on hormonal contraception, and is important because of the risks of major congenital malformations associated with exposure to AEDs in utero. Fewer than half of the women whose care was reviewed here (10 of 23) were offered the opportunity to discuss contraception following their pregnancy.

**Women with epilepsy should be offered effective contraception to avoid unplanned pregnancies.**

**The risks of contraceptive failure and the short- and long-term adverse effects of each contraceptive method should be carefully explained to the woman. Effective contraception is extremely important with regard to stabilisation of epilepsy and planning of pregnancy to optimise outcomes.**

**Women taking enzyme-inducing AEDs (carbamazepine, phenytoin, phenobarbital, primidone, oxcarbazepine, topiramate and eslicarbazepine) should be counselled about the risk of failure with some hormonal contraceptives.**

**All methods of contraception may be offered to women taking non-enzyme-inducing AEDs (e.g. sodium valproate, levetiracetam, gabapentin, vigabatrin, tiagabine and pregabalin).**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

### Baby care

Very few women with epilepsy received advice on safe baby care. The care of neonates and infants by women with epilepsy requires specific guidance. Simple precautions taken by women with uncontrolled epilepsy (such as carrying the baby securely fastened in a car seat) can be highly effective in reducing the risk to the baby and also maternal anxiety. Services should have systems in place to ensure that all women receive this guidance.

**Postpartum safety advice and strategies should be part of the antenatal and postnatal discussions with the mother alongside breastfeeding, seizure deterioration and AED intake.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

### Epilepsy and Pregnancy Registers

The UK Epilepsy and Pregnancy Register, along with other international pregnancy registers, has transformed our understanding of the effects of AEDs in pregnancy, and has allowed us to give increasingly specific advice to women about the effects of AEDs in pregnancy. Despite this, there is incomplete registration of pregnancies, and in this review, less than a quarter of women were specifically directed towards the register or asked for permission for their clinician to register their pregnancy. Better registration of epilepsy and pregnancy will undoubtedly improve understanding of the effects of AEDs (particularly newer drugs, for which pregnancy information is uniformly sparse). Services should have systems in place to direct women to the register.

**All pregnant women with epilepsy should be provided with information about the UK Epilepsy and Pregnancy Register and invited to register.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

A woman with known juvenile myoclonic epilepsy had seizures which were well controlled outside pregnancy but had shown deterioration in a previous pregnancy. She was correctly identified as high risk. There was very good communication between all members of her neurology, GP, midwifery and obstetric teams throughout pregnancy. There was a joint epilepsy antenatal clinic in place. All appropriate advice and risk discussions happened. Her antiepileptic drugs were manipulated properly leading to improved seizure control. She received appropriate advice to reduce the dosages after delivery. Exemplary care led to a good pregnancy outcome for both her and her baby.

The RCOG Green Top Guidance is very clear on the areas of care described here (birth planning, risk and safety advice, contraception, advice for baby care and epilepsy registers) (Royal College of Obstetricians and Gynaecologists 2016b). Health care providers should ensure that they have effective systems in place to provide women with epilepsy these basic care needs, to reduce their risk and minimize potential harm.

### Mode of Delivery

It is notable that of the women whose care was reviewed, 13 had labour induced either hormonally or with a manual sweep of membranes. Whilst there may be very good reasons for this, it was not possible to study this systematically in this review. Further study of the UKOSS data will undoubtedly lead to further insights into this high rate of induction. Several of the women were offered induction of labour because of their epilepsy *per se*, in contradiction to the advice provided by RCOG (Royal College of Obstetricians and Gynaecologists 2016b). Further investigation of the reasons underlying clinicians' decisions to recommend induction is needed.

**The diagnosis of epilepsy per se is not an indication for planned caesarean section or induction of labour.**

**RCOG Green-top guideline 68 Epilepsy in Pregnancy (Royal College of Obstetricians and Gynaecologists 2016b)**

## 3.3 Messages for stroke care

### Summary of the key findings 2013–15

Alongside epilepsy, stroke represents the other major neurological cause of maternal death in the UK. In the UK and Ireland in 2013–15 there were 12 women who died from intracranial haemorrhage during or up to six weeks after pregnancy, 7 from subarachnoid haemorrhage and 5 from intracerebral haemorrhage. This represents an overall maternal mortality rate directly due to intracranial haemorrhage of 0.48

per 100,000 maternities (95% CI 0.25 to 0.84 per 100,000 maternities). Note that this does not include women who died from intracranial haemorrhage following pre-eclampsia; improvements to their care were considered in the pre-eclampsia chapter in the 2016 report (Knight, Nair et al. 2016). Notably, no women died from thrombotic stroke during pregnancy or up to six weeks after pregnancy in this period.

A further 16 women died from stroke between six weeks and one year after the end of pregnancy; the care of 8 of these women was reviewed for the purposes of this section, thus the care of a total of 20 women was reviewed.

## Recurring themes

Although in general the care of women with intracranial haemorrhage was good, with no improvements identified for 60% of women, a number of areas of care were identified, noted in the 2014 report, which can still be further improved.

### Neurological examination

A pregnant woman presented with headache, neck stiffness and vomiting in the second trimester of pregnancy. No neurological examination was documented. The medical team did not appear to appreciate the significance of her meningism and she was presumed to have hyperemesis gravidarum. She subsequently died from the complications of her intracranial haemorrhage and hydrocephalus.

This woman illustrates the importance of key recommendations made in the 2014 and 2015 reports:

**Neurological examination including assessment for neck stiffness is mandatory in all new onset headaches or headache with atypical features, particularly focal symptoms. (Knight, Kenyon et al. 2014)**

**Neurological examination including fundoscopy is mandatory in all women with new onset headaches or headache with atypical symptoms (Knight, Tuffnell et al. 2015)**

It is important to note that hyperemesis gravidarum should only be diagnosed if onset is in the first trimester and other causes of nausea and vomiting have been excluded (Royal College of Obstetricians and Gynaecologists 2016c).

### Delayed diagnosis

A postpartum woman presented with a three-month history of altered behaviour and seizures. She was referred to the psychiatric team but there was no neurology involvement. She died from a catastrophic intracranial haemorrhage complicating a vasculopathy. She did not have a postmortem examination so the precise aetiology of her vascular disease was never established.

A change in mental state and new seizures should lead to prompt neurological assessment. Current NICE guidelines (National Institute for Health and Care Excellence 2015a) recommend that GPs consider urgent (within two weeks) neuro-imaging via direct access in adults with progressive sub-acute loss of neurological function, as in this woman. The importance of postmortem examination is a recurring message of these enquiries, not only to establish the exact cause of a woman's death, but also in order to identify diseases which may have significance for living relatives.

A pregnant woman presented with headache and severe breathlessness due to pulmonary oedema. In view of her severe respiratory symptoms, the importance of her headache was not appreciated by the medical team. Her stress related cardiomyopathy, Takutsobo (broken heart) syndrome, was secondary to subarachnoid haemorrhage. She died from the neurological complications of her subarachnoid haemorrhage.

Takutsubo cardiomyopathy is also known as acute stress-induced cardiomyopathy and apical ballooning syndrome. The word 'Takotsubo' means 'octopus pot' in Japanese, as the left ventricle of the heart changes into a similar shape. The condition is usually temporary and reversible, but it is important the underlying cause is established. In this instance, the significance of the woman's headache was not appreciated. Whilst headaches are common, Box 3.1 illustrates red flag symptoms which should prompt clinician concern and women to seek advice urgently.

**Box 3.1: 'Red Flag' headache symptoms which should prompt clinician concern and women to obtain urgent advice from their doctor or midwife**

- Headache of sudden onset, described as the 'worst ever'
- Headaches with additional symptoms not usually experienced–neck stiffness, fever, weakness, double vision, drowsiness, seizures
- A headache that takes longer to resolve than usual or persists longer than 48 hours

### Delayed transfer

A postpartum woman presented with sudden headache and collapse (GCS 10/15). Her care was discussed with the neurosurgery registrar who noted that there were no available critical care beds at the regional neuroscience centre and therefore a decision was made not to transfer her. The decision not to transfer was revised some hours later following consultant to consultant discussion. However, by the time of transfer to the Regional Neuroscience Centre she had deteriorated (GCS 3/15) and she subsequently died from her intracerebral haemorrhage.

The Society for British Neurological Surgeons care quality statement (The Society of British Neurological Surgeons 2015) states that, "admission to a regional neurosurgical unit for life-saving, emergency surgery should never be delayed" and that "neurosurgical units should not refuse admission to patients requiring emergency surgery from their catchment population. The lack of critical care beds must not be a reason for refusing admission for patients requiring urgent surgery." Earlier transfer of this woman's care, and/or earlier consultant-to-consultant communication may have proved life-saving. The following messages from 2014 can be reiterated:

**Pregnancy should not alter the standard of care for stroke. (Knight, Kenyon et al. 2014)**

**All women, pregnant or not, should be admitted to a Hyperacute Stroke Unit. (National Institute for Health and Care Excellence 2008b)**

### Communication

A woman was re-admitted to an obstetric unit on two occasions post-delivery because of poorly controlled blood pressure. She was treated with labetalol but it was not re-prescribed by her GP after discharge and there is no record that the woman attended for planned weekly blood pressure checks after discharge from community midwifery care. She had a catastrophic intracranial bleed from ruptured cerebral aneurysm several days later.

It is not a new message that hospital-GP communication is important. In this instance it is not clear whether the woman or her GP was made aware of the importance of monitoring and good blood pressure control for her wellbeing.

**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 (Knight, Tuffnell et al. 2015).**

## 3.4 Conclusions

In general, care for women with stroke was good. However, there remains a need for substantial improvements in the care of women with epilepsy; structured, multidisciplinary timely review and forward planning for intrapartum and postpartum care may prevent the majority of women's deaths. The morbidity study also identified the need for many improvements in care to reduce risks of poor outcomes for women with epilepsy and their babies. Efforts to improve care of women with epilepsy are underway, but it will take at least five years before the results of any interventions can be measured. Women with long-term conditions such as epilepsy need our help to understand what their options are, and appropriate advocacy needs to be provided for those that struggle to engage with health services.

**Table 3.3: Classification of care received by women who died from neurological causes and for whom case notes were available for an in-depth review, UK and Ireland, 2013–15**

| Classification of care received | Women who died from epilepsy Number (%) N=9 | Women with uncontrolled epilepsy who survived Number (%) N=23 | Women who died from intracranial haemorrhage Number (%) N=20 |
|---|---|---|---|
| Good care | 2 (22) | 1 (4) | 12 (60) |
| Improvements to care which would have made no difference to outcome | 0 (0) | 10 (43) | 3 (15) |
| Improvements to care which may have made a difference to outcome | 7 (78) | 12 (52) | 5 (25) |

# 4. Caring for women with psychosis

Roch Cantwell, Ron Gray and Marian Knight on behalf of the MBRRACE-UK psychosis chapter-writing group

Chapter writing group members: Anita Banerjee, Kathryn Bunch, Malcolm Griffiths, Fiona Hanrahan, Marian Knight, Janine Lynch, Laura Magee, Judy Shakespeare, Katherine Stanley, Thomas van den Akker

## 4.1 Key messages

Women with any past history of psychotic disorder, even where not diagnosed as postpartum psychosis or bipolar disorder, should be regarded as at elevated risk in future postpartum periods and should be referred to mental health services in pregnancy to receive an individualised assessment of risk. **ACTION: Service planners/commissioners, service managers, health professionals**

Women with a family history of postpartum major mental illness should be monitored by maternity and primary care services for any change in mental state in late pregnancy and the early postpartum. Where the woman herself is currently unwell in pregnancy or has had previous postpartum mood destabilisation, she should be referred to mental health services as soon as possible in pregnancy to receive an individualised assessment of risk. **ACTION: Service planners/commissioners, service managers, health professionals**

Following recovery, it is the responsibility of the treating mental health team to ensure that all women experiencing postpartum psychosis receive a clear explanation of future risk, including the availability of risk minimisation strategies, and the need for re-referral during subsequent pregnancies and that this is shared with other relevant health professionals. **ACTION: Health professionals**

It is the responsibility of mental health services to ensure that a late pregnancy and early postnatal care plan is completed, jointly with the woman, usually at 28–32 weeks of pregnancy. Where the plan includes decisions about medication management, it should be completed, or overseen, by a psychiatrist. **ACTION: Health professionals**

Where there is diagnostic uncertainty requiring physical health investigation by obstetric and/or medical specialists, there should be close liaison between, and regular review by, senior medical staff from obstetrics, medicine and psychiatry. **ACTION: Health professionals**

Statutory health organisations should consider routine monitoring of the proportion of women and babies who are unnecessarily separated when the mother is admitted to psychiatric care. **ACTION: Policy makers**

With the woman's consent, families should be made aware at an early stage of the benefits of joint mother-infant admission. **ACTION: Health professionals**

Valproate should not be used in the management of psychiatric disorder in women of childbearing potential. If there are exceptional reasons for use, then it should only be prescribed in conjunction with long-acting reversible contraception, and with clear documentation of informed consent. The MHRA toolkit is recommended for this purpose. **ACTION: Health professionals**

## 4.2 Background

This report provides the first opportunity to review the care of those women who developed significant postpartum mental illness, and then recovered. A significant proportion of the women had identifiable factors in their medical history which placed them at high postpartum risk (previous postpartum psychosis, bipolar disorder or other psychotic disorder). Many lessons from this review echo those raised in maternal death enquiries but some are new.

## 4.3 Women with severe mental illness

For the purposes of this chapter, the aim was to review care of women with psychosis and a known history of either bipolar disorder or a previous episode of puerperal psychosis. The methods to identify these women are described in section 1.4. In total, a sample of 32 potentially eligible women were identified through NHS Digital in England, however, on further enquiry, 12 of the women identified (38%) either did not have any mental health problems or had not had a birth in the previous year, and were thus erroneously identified in the NHS Digital data. Their records were not retrieved for review. Following review of the full records of the remaining 20 women identified, it was evident that some had experienced only their first psychotic episode (i.e. they did not have a known history of either bipolar disorder or a previous episode of puerperal psychosis). Nevertheless, assessors identified important messages on reviewing their care, and therefore they were included in this analysis. The care of a further three women from Wales and Northern Ireland was reviewed, thus for the purposes of this chapter, the care of 23 women was reviewed.

Postpartum psychosis affects 1–2 per 1,000 women after childbirth, with the majority of those affected having an onset within the first three postnatal months. However, where a woman has a past history of postpartum psychosis or bipolar disorder, her risk rises to 25%-50%. If there is, in addition, a first degree relative with either disorder, the risk for the woman is even higher (Kendell, Chalmers et al. 1987).

## 4.4 Overview of care and lessons to be learned echoing those raised in maternal death enquiries

### Early identification of risk

#### Risk at booking

As in the maternal death enquiries, we found evidence of incomplete booking proformas, with mental health risk factors either not asked about or not recorded. In one instance, although the GP referral letter clearly provided information on past significant mental ill health, the booking form recorded no problems. Even where problems were identified in pregnancy or the early postpartum period, this did not always lead to timely referral to specialist services.

**At a woman's first contact with services in pregnancy and the postnatal period, ask about:**

- **any past or present severe mental illness**
- **past or present treatment by a specialist mental health service, including inpatient care**
- **any severe perinatal mental illness in a first-degree relative (mother, sister or daughter).**

**Refer to a secondary mental health service (preferably a specialist perinatal mental health service) for assessment and treatment, all women who:**

- **have or are suspected to have severe mental illness**
- **have any history of severe mental illness (during pregnancy or the postnatal period or at any other time).**

**Ensure that the woman's GP knows about the referral.**

**NICE guideline CG192: Antenatal and postnatal mental health (National Institute for Health and Care Excellence 2014)**

## Risk in the early postpartum period

A young woman developed postpartum psychosis within days of delivery. She had no evident high-risk features but her change in mental state was noted at the time of her discharge from the postnatal wards. She had had a traumatic delivery with significant blood loss. Her community midwife made an urgent referral to perinatal mental health services at 7 days but the following day she self-presented to the Emergency Department with disturbed sleep and behaviour, and thoughts of killing herself, her husband and baby. A junior psychiatrist diagnosed 'anxiety state' and discharged her with hypnotic medication. She represented on the 14th postnatal day and was seen by a liaison nurse who elicited symptoms of psychotic illness but repeated the earlier conclusion of an anxiety state. When she represented for a third time the significance of her symptoms were recognised and she was admitted and treated.

This woman's significant early postpartum change in mental state was downplayed, with symptoms not recognised as heralding severe mental illness. There is also further evidence that assessments by junior staff failed to take into account the particular risk she faced in the immediate postpartum period.

**Early postpartum significant change in mental state, or emergence of new symptoms, is a 'red flag' which should prompt further assessment (Knight, Tuffnell et al. 2015)**

**There should be an expectation of early consultant perinatal psychiatrist involvement in the assessment and management of high-risk women and of women exhibiting sudden alterations in mental state in late pregnancy or the early puerperium (Knight, Tuffnell et al. 2015)**

## Timeliness of mental health service responses

Mental health services have a responsibility to respond in a timely fashion when a woman is becoming acutely unwell. This is particularly important where a woman may be in an environment which is not designed to meet her mental health needs.

A woman became unwell during her maternity admission while in labour. The on call mental health team was contacted on the evening of admission. Despite becoming increasingly psychotic with distressing delusional beliefs that her baby was dead, she was not reviewed by a mental health nurse for over 16 hours. She then waited in labour suite for a further 8 hours before being seen by a psychiatrist, who initially suggested she remain there until the following day. By the early hours of the subsequent morning she had become so disturbed that she required urgent admission, at which point she was judged "too unwell" to go to a mother and baby unit.

The mental health team response could clearly be improved. Maternity units are rarely appropriate environments to manage acutely disturbed, psychotic women. There should be clear pathways of referral and response, known to all staff, which take into account the likelihood of early postpartum rapid deterioration and timescales appropriate to acute maternity care.

**Managers and senior healthcare professionals responsible for perinatal mental health services (including those working in maternity and primary care services) should ensure that:**

- **there are clearly specified care pathways so that all primary and secondary healthcare professionals involved in the care of women during pregnancy and the postnatal period know how to access assessment and treatment**

- **staff have supervision and training, covering mental health problems, assessment methods and referral routes, to allow them to follow the care pathways.**

**If a woman has sudden onset of symptoms suggesting postpartum psychosis, refer her to a secondary mental health service (preferably a specialist perinatal mental health service) for immediate assessment (within 4 hours of referral).**

**NICE guideline CG192: Antenatal and postnatal mental health (National Institute for Health and Care Excellence 2014)**

**Psychiatric services should have priority care pathways for pregnant and postpartum women which will include a rapid response time for women in late pregnancy and the first 6 weeks following delivery (Lewis, Cantwell et al. 2011)**

## Use of interpreters

Previous reports have repeatedly commented on the need to ensure that family members are not used as interpreters. In one instance, a woman whose first language was not English became acutely unwell two days after delivery. While her care from maternity and mental health staff was appropriate, family members were used as interpreters and, once external interpreters were involved, it became clear that she was more symptomatic than previously thought.

**Women should always have the opportunity of being seen alone and, where there are language barriers, family or friends should not be used as interpreters.**

**NICE Guideline CG110 Pregnancy and Complex Social Factors (National Institute for Health and Care Excellence 2010)**

## Mental capacity

The 2009–2013 Enquiry into Maternal Deaths referred to the need to ensure that women with physical health difficulties have the capacity to made decisions regarding their treatment, particularly when that may mean refusing or not adhering to treatment (Knight, Nair et al. 2016). This theme is again evident here.

A woman with a prior history of postpartum psychosis became mentally unwell following a further delivery. She required continuing treatment for hyperthyroidism but refused to take appropriate medication, and also significantly reduced the dose of prophylactic antipsychotic medication. No assessment of her capacity to make these decisions about her medical care was undertaken.

Maternity and general medical/surgical services should have an awareness of mental capacity legislation, an understanding of the differences in application of mental capacity and mental health legislation, and skills in making an initial assessment of capacity. If in doubt, mental health services will be able to advise on application of mental health legislation.

**All healthcare staff have a duty to ensure that patients have the mental capacity to make decisions regarding their physical and mental health care. Where there is doubt, an assessment of capacity should be undertaken (Knight, Tuffnell et al. 2015)**

## 4.5 New messages for care

### Narrow interpretation of risk

A woman developed postpartum psychosis at the time of her delivery, requiring admission to hospital on the first postpartum day. Her past history of psychotic depression had been noted at booking and maternity services appropriately sought advice from mental health. The advice given was that there was no need for mental health assessment if she was currently well. Consequently, no plan was in place for her management and there was significant delay in accessing psychiatric help when she became acutely unwell.

This woman's care illustrates the dangers of narrow interpretation of risk, with failure to recognise that all women with a previous history of psychotic illness should be regarded as at elevated risk, and require an individualised assessment of that risk by mental health services.

For another woman, her family history combined with her own personal history of non-psychotic postnatal depression, should have alerted staff to the risk she faced.

A woman, who was pregnant with her second child, had a previous history of postnatal depression, requiring six months of antidepressant treatment in primary care. Her own mother had a history of postnatal depression after ***her*** first pregnancy, and postpartum psychosis after her second. The woman developed significant depressive symptoms within weeks of giving birth, with accompanying suicidal ideation. She was only referred to mental health services some months later, after a significant overdose. She had overvalued (probably delusional) beliefs of incompetence as a mother, distressing imagery of harm to her children, and strong suicidal ideation and planning. She was eventually admitted to inpatient care.

This woman's experience illustrates the need for a more sophisticated and individualised approach to assessing risk, particularly where the pattern of occurrence of this woman's illness mirrored that of her mother.

**If there is a family history of postpartum psychosis or bipolar disorder, maternity and primary care services should be alert for change in mental state in late pregnancy and the early postpartum and, if present, should refer for urgent psychiatric assessment.**

**Referral for specialist psychiatric assessment in pregnancy should be considered for women with current mood disorder of mild or moderate severity who have a first-degree relative with a history of bipolar disorder or postpartum psychosis.**

**Any past history of psychosis should prompt psychiatric referral and assessment in pregnancy.**

**Box 4.1: Amber flags which should prompt heightened awareness of change in mental state**

- Women with any past history of psychotic disorder, even where not diagnosed as postpartum psychosis or bipolar disorder, should be regarded as at elevated risk in future postpartum periods and should be referred to mental health services in pregnancy to receive an individualised assessment of risk and development of a postpartum plan
- Women with a family history of postpartum major mental illness should be closely monitored by maternity and primary care services in late pregnancy and the early postpartum period. Where they themselves are currently unwell in pregnancy or have had previous postpartum mood destabilisation, they should be referred to mental health services as soon as possible in pregnancy to receive an individualised assessment of risk and development of a management plan

The personal and familial pattern of occurrence and re-occurrence of postpartum mood disorder should inform risk minimisation strategies.

## Forward planning for future risk

### Counselling on future risk

Previous enquiries have reported a need to identify those at increased risk. Where a woman has had an episode of postpartum psychosis, then her risk of recurrence following a future pregnancy is markedly increased. Several women, who had had a postpartum psychosis, received no advice about risk in future postpartum periods, or any discussion of ways to mitigate that risk. In some instances, although a discussion of risk occurred, the level of risk was underestimated or misattributed. This is despite the fact that for a number of these women, care had been provided by specialist perinatal mental health services.

A young woman developed postpartum psychosis after the birth of her first child, requiring admission within three weeks of childbirth. She had had a traumatic delivery with significant blood loss. The perinatal mental health team assessed her and she was admitted to a mother and baby unit. She received good inpatient care and was appropriately followed up by specialist services. At the point of discharge from care, her illness was explained to her as being due to her traumatic delivery, and her risk therefore less marked. It was suggested that she could be seen in future pregnancies at her request or "should further problems arise". There was no recorded discussion of risk minimisation strategies.

A woman was admitted within three weeks of childbirth with postpartum psychosis. Her diagnosis, and appropriate management, was delayed because of misattribution to personality factors. On recovery she requested discussion of future risk herself. While her increased risk was explained to her, no mention was made of prophylactic interventions. This was also true during a subsequent pregnancy three years later.

**Following recovery, it is the responsibility of the treating mental health team to ensure that all women experiencing postpartum psychosis receive a clear explanation of future risk, including the availability of risk minimisation strategies, and the need for re-referral during subsequent pregnancies and that this is shared with other relevant health professionals.**

### Completing the late pregnancy and early postpartum care plan

All women who are at high risk of postpartum major mental illness should have a written plan for their management, including risk reduction strategies, which is shared with all professionals involved in the woman's care, and with the woman herself. Mental health services (ideally specialist perinatal mental health services) should take responsibility for ensuring this is completed.

> An older woman was identified at booking as having had a previous psychotic illness. Mental health services were contacted but said they did not need to see her if she did not have current symptoms. No plan was made for her late pregnancy management and she became unwell during labour.

For some women responsibility was given to non-medical professionals for the plan's completion. This was problematic where complex medication decisions were required.

> A woman with a previous history of non-affective psychosis, and who was taking a combination of antidepressant, antipsychotic and anxiolytic medications, was seen by perinatal mental health services, but responsibility for completing the care plan was given to a specialist midwife. She was subsequently discharged from specialist care prior to delivery. There was confusion over her medications in late pregnancy and in the postnatal period she remained off all medication. She relapsed within three months of delivery.

**It is the responsibility of mental health services to ensure that a late pregnancy and early postnatal care plan is completed, jointly with the woman, usually at 28–32 weeks of pregnancy. Where the plan includes decisions on medication management, it should be completed by, or confirmed with, a psychiatrist.**

## Care follows the woman

Discontinuity of mental health care has been a theme in previous reports. However, this morbidity enquiry illustrates a number of additional instances where difficulties at the interface between services have led to impairments in care.

### Links with neonatal and special care baby units

Where a woman requires inpatient mental health care, and her baby requires specialist neonatal care, it should be the responsibility of both mental health and maternity services to ensure that NICU/SCBU is informed of the woman's admission to a psychiatric ward or mother and baby unit, and visits to the baby are appropriately facilitated. This may be challenging if a woman has been detained under mental health legislation but is important both for the mother-baby relationship and long-term health.

> A woman with a past history of postpartum psychosis became unwell again within two weeks of delivery. She was admitted to a general psychiatry ward, discharged, then readmitted again to general psychiatry and transferred to a regional mother and baby unit. During part of this time her baby was admitted to a neonatal unit and there were difficulties maintaining contact between mother and child.

**Maternity and mental health services have a duty to ensure that, where a baby requires inpatient neonatal care and the mother requires inpatient psychiatric care, neonatal services are informed of the mother's admission and visits to the baby are appropriately facilitated.**

### Continuity of maternity care

Women who require regional Mother and Baby Unit (MBU) admission antenatally may have to transfer maternity care to a closer service. Where this occurs, it is the responsibility of the mental health team to ensure that links are also maintained with her local maternity team, so that there is no discontinuity of pregnancy/early postpartum maternity care.

A woman with a past history of postpartum psychosis required admission to an MBU late in a subsequent pregnancy. She remained on the MBU to delivery and was readmitted directly from the postnatal wards again for a further three weeks after delivery. There was some discontinuity of maternity care given her admission to the regional MBU and there was a lack of communication with local midwifery services regarding her ongoing care.

**Mental health and maternity services have a duty to ensure that, where a woman requires inpatient mental health care, links are maintained with her local maternity service and GP and both are involved in discharge planning, where relevant.**

### Joint management of diagnostic overshadowing

For a number of women there was diagnostic uncertainty, particularly in the early stages of evolution of their psychotic disorder, where it was necessary to rule out underlying organic causes of symptom presentation. It is well recognised that postpartum psychosis can present with confusion and a rapidly changing mental state, mimicking delirium. Joint management can be challenging, particularly as maternity, acute medical and mental health services are often not co-located. There is a risk of sequential, rather than joint, assessment and management.

A woman booked late in her second pregnancy and was subsequently admitted to maternity care in the third trimester with symptoms consistent with acute confusion. She was medically investigated with CT head, lumbar puncture and appropriate bloods, and treated for suspected infection. She was delivered by caesarean section on the following day because of fetal tachycardia. Postnatally she remained confused and intermittently unresponsive. She was referred to psychiatric liaison services and was felt to have a primary mental health diagnosis. Six days later she was transferred to an MBU where she commenced anti-psychotic medication for the first time. She was readmitted to maternity care via the emergency department three days later with hypertension and unresponsiveness. She was treated symptomatically for pre-eclampsia and further investigated to rule out other underlying disorder. She returned to the MBU after 9 days and completed her treatment there.

Although there was appropriate investigation to rule out an underlying organic disorder in this woman, there was sequential rather than joint management, leading to delay in recognising her lack of ability to consent to physical health care, and delay in instigating symptomatic treatment of her psychotic symptoms. Furthermore, her management was largely provided by junior staff, with little evidence of psychiatric, obstetric or medical consultant overview.

For a second woman, care was more integrated, leading to better co-ordination of care and no delay in instigating symptomatic treatment.

A woman became unwell within two days of the birth of her fourth child. She had been discharged from the postnatal ward on the day after delivery but readmitted within a day following assessment by her community midwife who had become concerned that she was acting strangely and refusing to eat or drink. On return to the maternity unit obstetric staff promptly assessed her. They sought early advice from the perinatal mental health team who saw her on the same day. She had a medical review and early investigation to rule out organic factors. In the face of mental state deterioration, she was transferred to an MBU, where she made a rapid recovery.

This woman's care was more co-ordinated, with evidence of rapid involvement of appropriate staff, leading to rapid appropriate treatment and early recovery.

**Where there is diagnostic uncertainty requiring physical health investigation by obstetric and/or medical specialists, there should be close liaison between, and regular review by, senior medical staff from obstetrics, medicine and psychiatry. Treatment with antipsychotic medication should not be delayed while investigations are undertaken.**

## Inpatient care

### Consideration of MBU care

Although joint admission of mother and baby is overwhelmingly recognised as best practice, there were a number of admissions where this does not appear to have been considered. In a number of other instances, women were first admitted to a general adult ward, or sometimes to a maternity ward, because no MBU bed was available.

A woman had a history of postpartum psychosis with onset during labour. On that occasion, she had a prolonged admission over several months, resulting in her losing custody of her child. She was appropriately referred for specialist assessment in her current pregnancy but there was no recorded discussion of options for MBU care if admission were to be required. She became unwell again within a fortnight of delivery, resulting in a further prolonged admission to general psychiatry, with only limited access to her children.

For this woman, the stakes were particularly high given her previous loss of custody due to prolonged illness. It could be argued that, as her first episode had such an early onset, prophylactic admission to an MBU should have formed part of the late pregnancy and early postnatal care plan.

The recommendation in favour of joint admission has appeared repeatedly over a number of reports following reviews of maternal deaths. The fact that it was a very strong theme identified in this review of women with severe psychiatric morbidity suggests separation of mother and infant may be more widespread than previously thought, but there are no routinely available data to monitor this. Early separation of mother and infant can have very long-lasting consequences. There is a need for monitoring and reporting where joint admission does not occur so that barriers to effective care can be identified and removed.

**Statutory health organisations should consider routine monitoring of the proportion of women and babies who are unnecessarily separated when the mother is admitted to psychiatric care.**

### Family engagement with MBU care

On two occasions family members expressed concern at potential transfer to an MBU. In both these instances, the woman had been admitted to a local general psychiatry ward initially. Families seemed reluctant, once alternative infant care arrangements were already made, to see transfer to an MBU as therapeutic, rather seeing it as disruptive for both mother and baby.

> A woman with pre-existing bipolar disorder was seen by perinatal mental health services in pregnancy and a plan put in place for her postnatal management. Unfortunately, she became unwell within the first postnatal week. She was initially admitted to the postnatal wards, then transferred to a general psychiatry ward as no MBU beds were available. Although an MBU bed was then identified, her transfer was delayed as family members expressed concern at a further change in where she would be treated.

The 2015 MBRRACE-UK report identified the need to educate families with regard to the nature of perinatal mental disorder (Knight, Tuffnell et al. 2015). We extend this here to recommend that families are made aware at an early stage of the benefits of joint mother-infant admission, particularly where a woman has been identified in pregnancy as at high risk of postpartum relapse.

**With the woman's consent, families should be made aware at an early stage of the benefits of joint mother-infant admission.**

### Early discharge and readmission

> A woman with a past history of postpartum psychosis was assessed by perinatal psychiatry in pregnancy and a plan was put in place for her postnatal management. She developed symptoms within 48 hours of delivery and was admitted to a maternity ward. Her symptoms appeared to settle rapidly and she was discharged to mental health crisis services. However her symptoms re-emerged and she was admitted two weeks later, under Mental Health Act provisions, to a general psychiatry ward. Again, her symptoms appeared to resolve quickly and she was discharged within two weeks. There was rapid deterioration in the community and she eventually required readmission, and then transfer to an MBU, where she remained for two months. She subsequently made a full recovery.

The natural history of postpartum psychosis is often one of fluctuating symptoms and transient improvements. General services may not be as familiar with this pattern and assume recovery too quickly. It is also important to test out recovery from inpatient care in a gradual fashion, for example with increasing duration of home leave, given that the added responsibilities and change in role have the potential to act as triggers to relapse.

**Treating teams should be aware of fluctuating symptom patterns in postpartum psychosis, and tailor management accordingly.**

## Specific prescribing issues

There were a number of issues concerning prescribing practice which emerged from this enquiry.

### Prescribing in pregnancy and breastfeeding

Particularly where late pregnancy/early postnatal care plans were not in place, there were examples of confusion over prescribing issues in pregnancy and breastfeeding, with lack of consistency of advice from different professionals. With a few notable exceptions, most drugs are not incompatible with pregnancy or breastfeeding but women should be able to access consistent, evidence-based advice, in oral and written forms, in order to be able to make informed choices. Excellent professional and patient resources on medicines in pregnancy, and professional resources on medicines in breastfeeding, exist and should be routinely used. There is a need to develop patient-focussed resources about medicines in breastfeeding.

**Box 4.2: Evidence based prescribing resources in pregnancy and breastfeeding**

***Pregnancy–for professionals***

- Toxbase (www.toxbase.org)

***Pregnancy–for women and families***

- Better Use of Medicines in Pregnancy (BUMPS) (www.medicinesinpregnancy.org)

***Breastfeeding–for professionals***

- LactMed (https://toxnet.nlm.nih.gov/newtoxnet/lactmed.htm)

### Prescribing progesterone

A woman who had a prior history of postnatal depression, and a family history of postpartum psychosis, developed sleep disturbance in late pregnancy and early onset depressive symptoms postnatally, later evolving into a postpartum psychosis. She was commenced on progesterone immediately after delivery. There was no clear obstetric reason for this and it appears to have been prescribed for mental health reasons.

There is no evidence that progesterone improves mood, or is effective prophylaxis or treatment for psychiatric disorder. Indeed, there is evidence that it may worsen mood.

**Progesterone should not be used in the management of depressed mood.**

### Prescribing valproate

The harmful effects of valproate on the fetus are well documented. In general, it is recommended that valproate should not be prescribed, for the purposes of managing psychiatric disorder, to women of childbearing potential. While there may be exceptional reasons for considering the use of valproate, in such circumstances there should be clear documentation of a discussion of risks and use of long-acting reversible contraception for the duration of prescribing.

A woman with a history of postpartum psychosis became unwell again shortly after the birth of her second child. During her MBU admission, her medication was altered to valproate. Although there may have been good reason to consider its use, there was no documented discussion of risks or contraception, and at discharge she was advised only that her husband should use barrier methods to reduce the risk of illness recurrence in relation to future pregnancies.

**Valproate should not be used in the management of psychiatric disorders in women of child-bearing potential. If there are exceptional reasons for use, then it should only be prescribed in conjunction with long-acting reversible contraception, and with clear documentation of informed consent. The MHRA toolkit is recommended for this purpose (https://www.gov.uk/government/publications/toolkit-on-the-risks-of-valproate-medicines-in-female-patients).**

### Active long-term management

This review provided an opportunity to examine longer-term care of women who had a previous child-bearing-related mental illness. In a small number of women, there was evidence of a failure to actively manage symptoms and an apparent acceptance of a degree of disability and functional impairment, which denied the women the opportunity to make the best recovery possible. This would be a deficit in care in any circumstance, but is particularly distressing where women have to care not only for their own health, but also are responsible for the care and development of their new baby and often other children.

A woman with a prior diagnosis of psychotic disorder was seen in pregnancy by general and perinatal mental health services. In the postnatal period she had worsening persecutory symptoms and her antipsychotic medication was altered. Some 10 months after delivery, her care was transferred to a different general psychiatry team due to change of address. She was seen at approximately 3–4 month intervals but it is striking that, despite her description of continuing symptoms causing distress and impairment of functioning, she was offered no further changes in management, or any attempt made to optimise her pharmacological management, over the course of the subsequent two years of records available to the Enquiry. This was despite her need to care for three children.

## 4.6 Good care

### Examples of individual excellence in care

There were a number of examples of individual practice that reflect the lengths to which practitioners will go to ensure the safety and welfare of their patients.

A young woman with a history of depression became acutely unwell 5 days after delivery. Her community midwife, noticing her disturbed mental state at a routine visit, arranged an urgent psychiatric assessment and remained with her for several hours until she was admitted to hospital. She made a full recovery.

### Forward planning works

There were also examples of good team practice where women, whose care had not been well managed in an earlier pregnancy, received early intervention and risk minimisation in a subsequent pregnancy, due to appropriate identification of risk and referral to specialist services.

A woman developed a postpartum depressive psychosis requiring MBU admission approximately six months after the birth of her first child. Her developing depressive and psychotic symptoms were under-recognised and she had strong ideas of suicide and infanticide by the time of her referral to mental health services. Her inpatient care was good and, on discharge, a well-recorded discussion took place about risk in future pregnancies and the need to seek psychiatric referral. In a subsequent pregnancy two years later she was appropriately referred to specialist services. A plan was put in place for her late pregnancy and early postpartum management, and she did not relapse acutely.

## 4.7 Conclusions

This review of the care of women with significant postpartum mental illness has identified a number of key areas in which care can be improved to prevent significant illness as well as mortality in the future. Improvements in care were noted for almost three-quarters of women, although these were only thought to be related to outcome in a quarter (Table 4.1). Particularly pertinent are recognition of risk and forward planning of future risk. Where risk was recognised and managed appropriately with early recognition and treatment of deteriorating mental health in women with previous severe postpartum illness, there was clear evidence of a lesser severity of symptoms and quicker resolution. This should be the gold standard we aspire to for all such women.

**Table 4.1: Classification of care received by women who had psychosis and survived and were included in the Confidential Enquiry into Maternal Morbidity, UK**

| Classification of care received | (n=23) Number (%) |
|---|---|
| Good care | 6 (26) |
| Improvements to care which would have made no difference to outcome | 11 (48) |
| Improvements to care which may have made a difference to outcome | 6 (26) |

# 5. Lessons for the care of women with medical and general surgical disorders

Marian Knight and Catherine Nelson-Piercy on behalf of the medical and surgical chapter-writing group

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## 5.1 Key messages

High level actions are needed to ensure that it is seen as the responsibility of all health professionals to facilitate opportunistic pre-pregnancy counselling and appropriate framing of the advice when women with pre-existing conditions attend any appointment, and that resources for pre- and post-pregnancy counselling are provided, together with open access to specialist contraceptive services. **ACTION: Policy makers, health professionals**

Women with pre-existing medical conditions should have pre-pregnancy counselling by doctors with experience of managing their disorder in pregnancy. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Research into the most effective way to encourage obese women to normalise their weight before conception to reduce the risk associated with obesity in pregnancy should be supported. **ACTION: Policy makers**

In pregnant or postpartum women with complex medical problems involving multiple specialities, the responsible consultant obstetrician or physician must show clear leadership and be responsible for coordinating care and liaising with anaesthetists, midwives, other physicians and obstetricians and all other professionals who need to be involved in the care of these women. **ACTION: Health professionals**

When a woman is transferred to level 3 / intensive care, daily consultant obstetric and physician involvement must remain to ensure continuity of care, even if only in a supportive role, until such time that the woman is ready to be repatriated to the maternity unit. **ACTION: Health professionals**

Pregnancy should not be viewed as a contraindication to surgery in the presence of malignancy or progressive symptoms or conditions at high risk of progression or exacerbation in pregnancy. **ACTION: Health professionals**

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 the delivery of critical care. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Women with multiple and complex problems may require additional care following discharge from hospital after birth and there is a need for senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians and all relevant colleagues. **ACTION: Service planners/commissioners, service managers, health professionals**

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 general practitioner to arrange. **ACTION: Service planners/commissioners, service managers, health professionals**

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. **ACTION: Service managers, health professionals**

## 5.2 Background

Deaths from underlying physical and mental health causes continue to represent the majority of maternal deaths in the UK and Ireland. This chapter examines in detail the care of women who died from medical disorders, with the exception of women who died from cardiac disease, which was considered in 2016 (Knight, Nair et al. 2016), malignancy, which was considered in 2015 (Knight, Tuffnell et al. 2015), neurological disease, which is considered in Chapter 3 of this report, and sepsis, which is considered in Chapter 6. Additionally, this chapter considers deaths of women who required general surgical care (as opposed to obstetric/gynaecological surgery), and as such also contains messages for general surgeons.

The assessors noted particularly, once again, the need for co-ordinated, multidisciplinary care, pre-pregnancy, during pregnancy and after pregnancy to prevent future deaths of women with co-existing disease.

## 5.3 Summary of the key findings 2009–13

In the UK and Ireland there were 26 women who died during pregnancy or up to 42 days after pregnancy from other indirect causes between 2013 and 15. This represents an overall mortality rate of 1.13 (95% CI 0.74–1.65). The care of a further 15 women who died between 42 days and a year after pregnancy was reviewed for the purposes of this chapter. Additionally, the care of two women whose cause of death remains unascertained, but which was thought to be directly related to pregnancy, is considered here. Sixteen women died between 42 days and one year after pregnancy from other indirect causes but their records were not available for detailed review. Thus, overall, the care of 43 women was reviewed for the purposes of this chapter (Table 5.1).

**Table 5.1: Causes of death amongst women whose care was assessed for the purposes of this chapter, UK and Ireland, 2013–15**

| Cause of death | Number of women (%) (n=43) |
|---|---|
| Arterial aneurysm | 10 (23) |
| Respiratory | 9 (21) |
| Connective tissue disorder | 6 (14) |
| Haematological | 7 (16) |
| Endocrine | 2 (5) |
| Pancreatitis | 2 (5) |
| Other | 2 (5) |
| Unascertained | 5 (12) |

## 5.4 Overview of care and lessons to be learned

### Recurring themes

The need for pre-pregnancy counselling was highlighted in the 2014 report (Knight, Kenyon et al. 2014). Assessors reviewing the care of the women who died from medical disorders in 2013–15 once again noted the need for more effective pre- or post-pregnancy counselling of women with pre-existing conditions and effective contraception. It was clear that many professionals caring for women did not consider it their responsibility to counsel them concerning the risks of pregnancy, nor to provide contraception or contraceptive advice, and on some occasions had not even considered the possibility that a woman of reproductive age might become pregnant. In some instances when pre-pregnancy counselling had apparently been undertaken it was not clear that women truly understood the degree of risk to their health that pregnancy posed. Several women at high risk had undergone one or more previous high-risk pregnancies and still had not received adequate post-pregnancy advice regarding contraception or the risk of future pregnancies.

A multiparous woman had known severe lung disease. Prior to her current pregnancy, she had been seen regularly by her respiratory physician who had noted a significant decline in her respiratory function, but had put this down to a concurrent chest infection. Despite a previous complicated pregnancy, there

is no evidence from her records that the possibility of further pregnancy was ever considered by her physician and associated risks discussed. She asked for transfer to a different physician as she felt she was not being listened to. She presented repeatedly during her pregnancy and at every stage her deteriorating lung function was underestimated with no clear co-ordination of care. She was delivered in the third trimester due to deteriorating lung function but deteriorated again in the postnatal period and died.

**Women with pre-existing medical conditions should have pre-pregnancy counselling by doctors with experience of managing their disorder in pregnancy (Knight, Kenyon et al. 2014).**

**It is the responsibility of all professionals involved in the care of women of reproductive age with co-existing medical problems, whatever their professional background and medical specialty, to provide pre- or post-pregnancy advice and contraception.**

**High level actions are needed to ensure that it is seen as the responsibility of all health professionals to facilitate opportunistic counselling and appropriate framing of the advice when women attend any appointment, and that resources for pre- and post-pregnancy counselling are provided, together with open access to specialist contraceptive services.**

**Clinicians should refer to the relevant current Faculty of Sexual and Reproductive Health guidelines, including the UK Medical Eligibility Criteria for Contraceptive Use (UKMEC), when making a clinical judgment on safe and appropriate methods of contraception for a woman after pregnancy. (Faculty of Sexual and Reproductive Healthcare 2017)**

A woman with a complex medical condition was known to be at high risk for potential anaesthetic complications and was referred appropriately for anaesthetic assessment in her local unit. However, a fetal anomaly was identified and her care was transferred to a tertiary unit. Once the diagnosis was made, her care was focused entirely on the fetal needs, and her own issues were overlooked. She had challenges with communication and understanding and these were not recognised at the tertiary unit. Despite being booked for elective caesarean delivery she never had an anaesthetic assessment and this led to concerns when she was admitted as an emergency in early labour. She collapsed and died shortly after delivery from a complication of her medical condition.

The challenges of delivering good quality antenatal care for a woman with a complex medical condition become greater when delivery is planned in a different unit to her antenatal care. Although this did not contribute to this woman's death, it clearly impacted on the care she received. This is a recurring issue, since no single individual considers they are the lead for a woman's care when a fetal abnormality is identified, and delivery planned in the tertiary unit. The important leadership role for the consultant obstetrician in the care of women with sepsis is highlighted in current guidance (Royal College of Obstetricians and Gynaecologists 2012b), and was highlighted in the 2014 report (Knight, Kenyon et al. 2014). It is clear that, in a similar manner, women with complex medical problems need a consultant to take a clear leadership role.

**In pregnant or postpartum women with complex medical problems involving multiple specialities, the responsible consultant obstetrician or physician must show clear leadership and be responsible for coordinating care and liaising with anaesthetists, midwives, other physicians and obstetricians and all other professionals who need to be involved in the care of these women.**

**When a woman is transferred to level 3 / intensive care, daily consultant obstetric and physician involvement must remain to ensure continuity of care, even if only in a supportive role, until such time that the woman is ready to be repatriated to the maternity unit.**

**Adapted from RCOG Green-top guideline 64b (Royal College of Obstetricians and Gynaecologists 2012b)**

## Arterial aneurysms

Ten women died from spontaneous intra-abdominal bleeding, nine had a ruptured splenic artery aneurysm. In most instances this was an unheralded event and women had no clear risk factors other than pregnancy, although two women were known to have portal hypertension in association with liver disease, a recognised risk factor for splenic artery aneurysm rupture. Neither of these women had apparently received pre-pregnancy advice about the risks of pregnancy.

A young multiparous woman had a normal birth at term and complained of epigastric pain shortly after delivery. Over the next ten days she re-presented three times with similar symptoms to her GP, Emergency Department and midwife. Investigations at the time were normal apart from marked anaemia. The evening after seeing her midwife she collapsed and had a pulseless electrical activity arrest. The ambulance transfer took over 30 minutes during which time she received no effective resuscitation. On arrival in the Emergency Department a Focused Assessment with Sonography in Trauma (FAST) scan revealed free fluid in her abdomen, nevertheless she was thrombolysed for presumed pulmonary embolism. Although the correct diagnosis was subsequently made following visible abdominal distension, transfer to theatre was delayed and she died from her coagulopathic haemorrhage.

In retrospect, this woman had several clear herald bleeds, which were potential opportunities to make the diagnosis, particularly in light of her falling haemoglobin. She had obvious free fluid in her abdomen on Focused Assessment with Sonography in Trauma (FAST) scan, which also suggested the diagnosis. Although pulmonary embolism is an important cause of collapse during pregnancy and postpartum, the differential diagnosis includes bleeding, and a FAST scan is an important modality to investigate this, particularly in the presence of anaemia. Similar messages were identified in the care of women with ectopic pregnancy in the 2016 report (Knight, Nair et al. 2016).

**Women of reproductive age presenting to the Emergency Department collapsed, in whom a pulmonary embolism is suspected, should have a Focused Assessment with Sonography in Trauma (FAST) scan to exclude intra-abdominal bleeding … especially in the presence of anaemia (Knight, Nair et al. 2016).**

Similarly, the importance of rapid transport to hospital in this scenario to allow for effective resuscitation has been previously emphasised. Four of the women who died from splenic artery aneurysm had delayed transfer to hospital with ineffective attempts at resuscitation.

**Women of reproductive age who present in the community in a state of shock and/or collapse with no obvious cause should be transferred to a hospital Emergency Department without delay for urgent assessment and treatment (Knight, Nair et al. 2016).**

**Paramedic services should review protocols for the management in the community of the collapsed/shocked woman of reproductive age (Knight, Nair et al. 2016).**

An extremely obese woman with a previous history of venous thromboembolism collapsed at home in the third trimester and was appropriately rapidly transferred to hospital. She underwent exemplary resuscitation and perimortem caesarean section within four minutes. At the time of the perimortem caesarean section, three litres of blood was found in her abdomen, but the team still considered pulmonary embolism the most likely cause of her collapse. A crash call was made to the surgical team, who took over 30 minutes to arrive and on arrival considered that they were unable to assess the woman's abdomen adequately because of the transverse suprapubic incision made for the perimortem caesarean section. They did not extend the incision and therefore did not explore her abdomen adequately. She died shortly afterwards.

Very reasonably this woman's collapse was initially attributed to massive PE on account of her risk factors for venous thromboembolism - past history, morbid obesity and pregnancy. However, the documentation suggests that this was still thought to be the cause of her collapse despite the presence of three litres of blood in the abdomen. Spontaneous intra-abdominal bleeding of that extent would be an unlikely consequence of massive PE. There was no clinical evidence of disseminated intravascular coagulopathy documented in the caesarean section note. There was no other documentation stating that she was bleeding spontaneously from other sites.

Splenic artery rupture is rare, but it has a recognised association with pregnancy (van Rijn, Ten Raa et al. 2017). There needs to be heightened awareness of this potential diagnosis in pregnant women presenting acutely with intra-abdominal bleeding of non-obstetric origin. The upper abdomen must be examined and an appropriate incision to achieve this must be made; a transverse suprapubic incision can be extended if necessary.

Concealed haemorrhage should be considered in women who present with hypotension, tachycardia or agitation. As described in Chapter 8, women who died from haemorrhage due to obstetric causes also presented with signs that indicated concealed bleeding which were not identified.

## Respiratory

Nine women died from respiratory causes, including two from cystic fibrosis, two from asthma, two from other known lung diseases, two from non-specific respiratory failure, and one from acute airway obstruction. Five of these women died more than 42 days after the end of pregnancy. As previously noted in the 2014 report, undiagnosed pulmonary hypertension was a feature in some of the women with known lung disease.

**Women with severe lung disease require screening for pulmonary hypertension prior to pregnancy (Knight, Kenyon et al. 2014)**

It has been noted repeatedly in this Enquiry that pregnant women should be treated the same as non-pregnant women unless there is a clear reason not to. This applies equally to surgical procedures as well as medical treatment.

A woman with a stenosed airway was scheduled for surgery to treat this, but this was cancelled in view of her pregnancy. She died of acute airway obstruction in mid-pregnancy.

**Pregnancy should not be viewed as a contraindication to surgery in the presence of malignancy or progressive symptoms or conditions at high risk of progression or exacerbation in pregnancy.**

A young woman with a chronic severe respiratory condition and multiple co-morbidities died in pregnancy following deterioration due to influenza. She had been invited by her GP practice to attend for influenza vaccination but had not attended.

As noted in chapter 6, the need to make additional appointments is a barrier to women receiving influenza vaccination.

**Since women attend maternity services during pregnancy, funding streams should facilitate the offer and delivery of influenza immunisation in maternity services as part of antenatal care, rather than in primary care.**

Both women who died from asthma were smokers. In one instance a woman requested frequent repeat prescriptions of her bronchodilators (reliever) in pregnancy, but despite efforts by her general practice to contact her, she did not recognise the importance of continuing her inhaled steroids (preventer).

## Haematology

A young woman with a known history of thrombotic thrombocytopenic purpura presented in the first trimester with a history of feeling unwell, nausea and vomiting and haematuria. She was transferred from her local hospital rapidly to a tertiary hospital, under the care of the haematologists. Her hospital course was one of progressive decline despite plasma exchange and blood products. She was not reviewed by an obstetrician for 24 hours. She was critically ill but this was not recognised. She was not seen by an outreach team, critical care specialist or anaesthetist until she had had a cardiac arrest on the ward from which she could not be resuscitated.

Two women died from thrombotic thrombocytopenic purpura (TTP) and one from an acute sickle cell crisis. The severity of the illness of none of these women was recognised, highlighting the importance, once again, of multidisciplinary expert care.

Four women died from haemophagocytic lymphohistiocytosis (HLH), all of whom were from ethnic minorities. Haemophagocytic lymphohistiocytosis (HLH) is a syndrome of uncontrolled immune activation with increasing incidence (Schram and Berliner 2015). In adults it is often associated with malignancy (most commonly lymphoma or leukaemia), infection (most commonly EBV) and autoimmune disorders. Many reported cases are on immunosuppressive therapy. It presents with fever, splenomegaly, cytopenias, hypertriglyceridaemia, hypofibrinogenaemia, markedly raised ferritin and haemophagocytosis is demonstrated in the bone marrow, spleen or lymph nodes.

It is important that clinicians are aware of this potentially fatal disease to ensure timely diagnosis and treatment. It is almost universally fatal without treatment and treatment involves immunosuppression (steroids and calcineurin inhibitors), etoposide based chemotherapy, alemtuzumab (an anti CD52 monoclonal antibody) and bone marrow transplant.

## Connective tissue disorders

Six women died from connective tissue disorders, two of whom died more than 42 days after the end of pregnancy.

> A woman with a recent onset severe connective tissue disorder underwent IVF without any evidence that she received pre-pregnancy advice about her condition and the risks of pregnancy. After booking she was referred appropriately to an obstetric physician who explained the high risk of continuing her pregnancy and counselled termination. She elected to continue with the pregnancy but her condition deteriorated and she died in the postpartum period after intensive therapy.

Because of her specific high-risk condition, this woman should have been counselled to avoid pregnancy for five years after her initial diagnosis, but there is no evidence that her rheumatologist was aware of this. Connective tissue disorders are frequently associated with reduced fertility but it is important that fertility treatments should not be offered without expert counselling about the risks of pregnancy.

> A woman booked with a haemoglobin of 90 g/L. Initial tests of ferritin, B12 and folate were reported to be normal. Her anaemia progressed during pregnancy despite oral iron but was not further investigated. She became breathless in the second trimester. In her third trimester she was noted to be tachycardic. She had a normal delivery but became unwell immediately afterwards and was suspected to have sepsis. However, no evidence of infection was found and she was discharged on day four. She presented repeatedly to her GP and the Emergency Department over the next few weeks with persistent lethargy and a cough. She was noted still to be anaemic. Shortly before her death she presented again to a different GP with oedematous legs and was referred to hospital. On admission the woman was diagnosed to have a pericardial effusion, cardiac valve disease and SLE. Her condition deteriorated with respiratory failure and she died a few days later.

This woman exhibited many of the features of connective tissue disease in pregnancy. She had a persistent anaemia which was not investigated and may have indicated her new onset illness. Her illness flared immediately postpartum, which is common in connective tissue disorders. There was a lack of a lead professional after delivery and poor communication and handover to her GP. She presented repeatedly to different practitioners in the postpartum period, no-one recognised this as a 'red flag' and no-one recognised how ill she was until she was in extremis.

## Liver

One woman died in the postnatal period from liver disease. She had abnormal liver function tests in pregnancy but this was not followed up and the abnormal result was not communicated to her GP.

One size does not fit all in postnatal care. As highlighted in the recent Chief Medical Officer for England's report 'The health of the 51%' there is an urgent need for robust evidence on how to provide appropriately tailored postnatal care (Davies 2015). The importance of a good handover of care to the GP was highlighted in the 2015 report (Knight, Tuffnell et al. 2015).

**Women with multiple and complex problems require additional care following discharge from hospital after birth and there is a need for senior review prior to discharge, with a clear plan for the postnatal period. This review should include input from obstetricians 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 general practitioner 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.**

**(Knight, Tuffnell et al. 2015)**

## Endocrine

One woman died from Addison's disease and one from diabetic ketoacidosis, both more than 42 days after the end of pregnancy. Importantly, and in contrast to previous triennia, there were no deaths of women with diabetes during pregnancy or postpartum from hypoglycaemia. However, both women who died had multiple and complex problems, and yet both received less, rather than more postnatal care. Both would have benefitted from a detailed postnatal care plan as highlighted above. Neither had any postnatal follow-up by their endocrine team.

## Pancreatitis

Two women died from pancreatitis more than 42 days after the end of their pregnancy. In both instances admission to critical care was delayed. The 2016 recommendation is reiterated in the sepsis chapter and bears repeating here.

**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 (Knight, Nair et al. 2016).**

These women, as well as the woman who died from TTP illustrate the importance of declaring 'critical care' to ensure the relevant members of the multidisciplinary team are informed and aware.

## Obesity

A woman with a BMI of 50 needed early delivery due to fetal compromise. Delivery was delayed due to problems getting an appropriate theatre table. Intraoperatively her regional block was not adequate and so was converted to a general anaesthetic. Her caesarean section was reportedly difficult with the procedure taking almost two hours. Post-operatively she was reluctant to mobilise but this was attributed to her obesity. Over the next three days she was oliguric and tachycardic, although her observations were not correctly recorded on the MEOWS chart. She reported increasing pain, which was attributed to difficulty with bladder emptying. No-one recognized the signs of sepsis. A CT was considered to rule out urinary tract injury but there was a delay in the investigation being requested and then a greater delay in performing the CT because the radiologist was reluctant due to the woman's size. The scan was initially reported incorrectly, and when correctly reported was not acted on by the general surgical team until the next day despite an indication of bowel perforation. She died from faecal peritonitis following perforated colonic pseudo-obstruction.

This woman died from her Ogilvie's syndrome following elective caesarean section. At several points her care was clearly compromised by her morbid obesity. Forty-two percent of the women whose care was reviewed in this chapter were noted to be obese; reviewers noted several instances where the care of morbidly obese women was delayed due to a lack of equipment, or a reluctance to operate due to the likely challenges. Similarly in several instances there were clear technical difficulties–anaesthetic, operative or radiological - solely due to a woman's body habitus. Difficulties in radiological investigations were also noted amongst women whose care was examined in other chapters of this report, notably the women who died from placenta accreta.

As the proportions of women who are obese, or morbidly obese, in pregnancy continue to rise, such problems are likely to become ever more frequent. A lack of equipment was noted in the UKOSS study of extreme obesity in pregnancy in 2010 (Knight, Kurinczuk et al. 2010), together with the high proportion of women delivered by caesarean section. However, it is unclear how widely women of reproductive age are aware of the risks and challenges of obesity in pregnancy (Heslehurst, Simpson et al. 2008).

**Reducing BMI and optimising control of medical conditions results in improved fertility, reduced risk of miscarriage and improved pregnancy outcomes.**

**Research into the most effective way to encourage obese women to normalise their weight before conception to reduce the risk associated with obesity in pregnancy should be supported.**

**Women with pre-existing medical conditions should have pre-pregnancy counselling by doctors with experience of managing their disorder in pregnancy (Knight, Kenyon et al. 2014). This includes women with extreme morbid obesity.**

### Unascertained

Despite both pathological and clinical review, the exact cause of the deaths of five women could not be established. Two women collapsed during pregnancy with symptoms which may have indicated either an anaesthetic cause, an anaphylactic reaction, or a possible amniotic fluid embolism and were therefore considered to be direct deaths. Three women's deaths were considered to be indirect deaths, with the assessors unable to determine whether they died from a cardiac cause, with other causes including sepsis remaining a possibility, but with insufficient evidence to clearly indicate one single cause of death.

## 5.5 Conclusions

Improvements to care which may have made a difference to outcome were noted for almost a quarter of the women whose care was reviewed in this chapter (Table 5.2). Nevertheless, in many instances, it was clear that the most important areas where care could be improved were either before a woman became pregnant–better pre-pregnancy advice and access to appropriate contraception–or after pregnancy–better handover of care in the postnatal period, a clear postnatal care plan and tailored postnatal care including contraceptive advice. Perhaps the clearest message to improve care for these women is to recognise that it is the responsibility of all professionals involved in the care of women of reproductive age with co-existing medical problems, including obesity, whatever their professional background and medical specialty, to provide pre- or post-pregnancy advice and contraception. Clinicians without the necessary expertise to provide such counselling should refer women for specialised pre-pregnancy and/or antenatal services.

**Table 5.2: Classification of care received by women who died from other indirect causes and for whom case notes were available for an in-depth review, UK and Ireland, 2013–15**

| Classification of care received | Number (%) N=43 |
|---|---|
| Good care | 15 (35) |
| Improvements to care which would have made no difference to outcome | 17 (40) |
| Improvements to care which may have made a difference to outcome | 11 (26) |

# 6. Messages for the prevention and treatment of sepsis

Marian Knight, Derek Tuffnell and Jenny Kurinczuk on behalf of the sepsis chapter-writing group

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## 6.1 Key messages

Since women attend maternity services during pregnancy, funding streams should facilitate the offer and delivery of influenza immunisation in maternity services as part of antenatal care, rather than in primary care. **ACTION: Policy makers, service planners/commissioners**

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. **ACTION: Service managers, health professionals**

When assessing a woman who is unwell, consider her clinical condition in addition to her MEOWS score. **ACTION: Health professionals**

The key actions for diagnosis and management of sepsis are:

- Timely recognition
- Fast administration of intravenous antibiotics
- Quick involvement of experts - senior review is essential

**ACTION: Health professionals**

Consideration should be given to 'declaring sepsis', analogous to activation of the major obstetric haemorrhage protocol, to ensure the relevant members of the multidisciplinary team are informed, aware and act. **ACTION: Service managers, health professionals**

It is important to recognise that chronic illness and immunosuppression are risk factors for sepsis. For women with chronic illness or who are immunosuppressed there should be a lower threshold for admission, the administration of appropriate antibiotics and supportive therapy, as well as input from senior clinicians. **ACTION: Health professionals**

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. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Women should be advised, within 24 hours of giving birth, of the symptoms and signs of conditions, including sepsis, that may threaten their lives and require them to access emergency treatment. **ACTION: Service planners/commissioners, service managers, health professionals**

## 6.2 Background

The last report that investigated the care of women with sepsis covered the four-year period of 2009 to 2012. That report encouraged clinicians to think about sepsis in terms of primary recognition and management as well as a heightened awareness of the possibility of sepsis (Knight, Kenyon et al. 2014). Since the report has been published, there has been significant work focused in sepsis with the 'Surviving Sepsis Campaign' (Rhodes, Evans et al. 2017) and NICE guidance (National Institute for Health and

Care Excellence 2016) to try and ensure consideration, prompt recognition and treatment of sepsis. The UK Sepsis Trust has developed six specific clinical toolkits applicable to pregnant and postpartum women presenting at all levels of the health service (UK Sepsis Trust 2016)(*http://sepsistrust.org/clinical-toolkit/*).

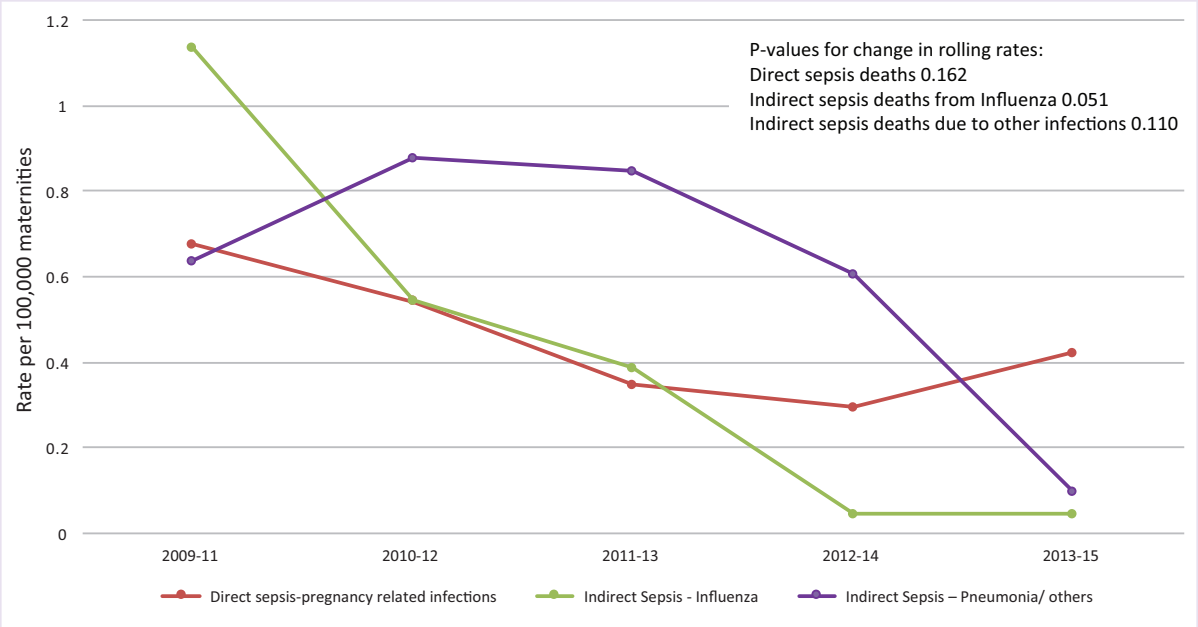
In the 2014 report a substantial number of women died following infection with influenza and there was encouragement to adopt widespread influenza vaccination in pregnancy. As noted in the 2016 report, there has been a significant reduction in the number of women dying from influenza, although this may be because of different circulating strains rather than because of improvements in vaccination and/or treatment. Nevertheless, women are still dying from a vaccine preventable disease, and embedding the messages around influenza vaccination and treatment remains essential to prevent deaths as well as in preparation for any future pandemic.

It is important to note that a new international definition of maternal sepsis has been developed by the WHO (World Health Organisation 2017). This describes maternal sepsis as "a life-threatening condition defined as organ dysfunction resulting from infection during pregnancy, childbirth, post-abortion, or postpartum period." The women considered here all meet this new definition.

## 6.3 Summary of the key findings 2013–15

In the UK and Ireland there were 24 women who died from sepsis between 2013–15, defined in its widest sense as a death from a primary infective cause. Ten of these women died more than 42 days after the end of pregnancy (late deaths). This represents a maternal mortality rate from sepsis during or up to six weeks after pregnancy of 0.56 per 100,000 maternities (95% CI 0.31 to 0.94 per 100,000 maternities). This is in contrast to the 71 women who died during or up to six weeks after pregnancy between 2009 and 2012, an overall mortality rate of 2.04 per 100,000 maternities (95% CI 1.60–2.58) (Figure 6.1). Seven women died from genital tract sepsis in 2013 to 2015, sustaining the trend of a low maternal mortality rate from genital tract sepsis (0.28 per 100,000 maternities, 95% CI 0.11 to 0.58 per 100,000 maternities). Four women died due to urinary tract sepsis or wound infections following caesarean section, there were thus eleven direct maternal deaths due to sepsis, one of which occurred late, between six weeks and one year after the end of pregnancy. Only one woman died in this triennium from influenza. There were twelve women who died from other causes of infection, nine of whom died between six weeks and one year after the end of pregnancy.

**Figure 6.1: Maternal mortality rate due to sepsis per 100,000 maternities, UK 2009–15**



## Women Who Died from Genital Tract and Other Direct Causes of Sepsis

Seven women died from genital tract sepsis. In two women the cause was postnatal Group A Streptococcus after normal birth. There was a woman with mid trimester chorioamnionitis with an unproven organism, one with chorioamnionitis at term, and three women with sepsis post caesarean section. In one the organism was E Coli and in two no clear organism was identified. Thus one of the deaths was a mid-trimester birth, three were following normal birth and three were following caesarean section.

There were five further deaths from direct causes of sepsis, one of which occurred more than six weeks after the end of pregnancy. Two women died from caesarean section wound infections, one of which was due to MRSA PVL. Two women died from urinary sepsis and a further woman died shortly after birth from E coli with a presumed urinary cause.

## Sepsis Due To Other Causes

### Influenza

The difference in virulence of circulating influenza strains in the period from 2013 to 2015 probably explains why only one woman died from influenza which was confirmed to be H1N1.

### Other Causes

One woman died from pneumococcal meningitis, one from pneumonia and one from a Clostridium difficile infection in the 6 weeks postnatally.

Between six weeks and one year after the end of pregnancy, two women died from pneumonia, two from meningitis (one pneumococcal and one meningococcal), two from other cerebral infections and three from other infective causes.

The deaths of five of these women were considered unrelated to pregnancy and were not reviewed for the purposes of this chapter.

# 6.4 Overview of care and lessons to be learned

## Recurring themes

### Influenza

> A previously healthy woman in the early third trimester of pregnancy was admitted with a respiratory illness during the peak of the influenza season. Neither her GP nor the hospital team considered the diagnosis of influenza. It was not considered until a week into her admission by which time she was receiving intensive respiratory support on the critical care unit. Antiviral medication was not commenced empirically but only following a positive tracheal aspirate which confirmed H1N1, almost two weeks after the start of her illness. She continued to deteriorate despite ECMO and died. She had not been immunised. It was unclear whether immunisation had been offered.

Although there has been not been an influenza pandemic since 2009–10, staff caring for pregnant women should remain aware of the possibility of influenza infection, particularly during peak seasonal periods (usually January). The difference in infectivity and virulence of circulating influenza strains in the period from 2013 to 2015 is probably the major main reason why only one woman died from influenza. A second woman, considered in Chapter 5, died following deterioration of her chronic respiratory condition exacerbated by influenza infection. Their deaths highlight the continued importance of several recommendations from the 2014 report.

**Department of Health/RCOG Guideline on the investigation and management of pregnant women with seasonal or pandemic flu should be followed (Department of Health and the Royal College of Obstetricians and Gynaecologists 2009)**

**Early neuraminidase inhibitor treatment should be instigated for pregnant women with symptoms consistent with influenza, in line with national guidance (Department of Health and the Royal College of Obstetricians and Gynaecologists 2009)**

**The benefits of influenza vaccination to pregnant women should be promoted and pregnant women at any stage of pregnancy should be offered vaccination against seasonal and pandemic influenza with inactivated vaccine (Public Health England 2014)**

As observed in the death of the woman with cystic fibrosis following influenza discussed in chapter 5, local policies and practices with regards to influenza immunisation may be a barrier to women receiving influenza vaccine. Immunisation rates in pregnancy still remain lower than other at risk population groups (44.9% in England, 58.6% in Northern Ireland, 49.3% in Scotland and 76.8% in Wales) (Health Protection Scotland 2017, Public Health Agency 2017, Public Health England 2017, Public Health Wales 2017). Systems that require women to make a separate appointment at their general practice at specific times to obtain influenza vaccination may act as a deterrent, in contrast to vaccination at routine antenatal appointments. Influenza vaccination provision in antenatal clinics is very variable, due to a variety of barriers including payment pathways, service commissioning arrangements, and training requirements for midwives or maternity care assistants. Staff attitudes and staff immunisation rates are also known to influence immunisation rates in pregnancy (Wilson, Paterson et al. 2015).

**Since women attend maternity services during pregnancy, funding streams should facilitate the offer and delivery of influenza immunisation in maternity services as part of antenatal care, rather than in primary care.**

## Think Sepsis

A woman with a large for dates baby was admitted at term in early labour. CTG abnormalities were not recognised and responded to and an intrauterine death occurred. She then developed signs of sepsis and acute kidney injury during labour, which were not promptly recognised. A sepsis bundle was not initiated. After a prolonged second stage she had a massive haemorrhage, developed coagulopathy and died. Although her death was probably multifactorial, sepsis was the underlying cause of her deterioration. Reviewers noted several aspects of her resuscitation that could have been improved. Senior staff were not involved until after her collapse.

After her death it was thought amniotic fluid embolus was implicated, although this was reported as a secondary phenomenon by the pathologist at postmortem. This led to a superficial review of her care, significantly limiting the lessons that should have been learnt from her death. A pathologist, who would have provided a better understanding of the post-mortem findings, was not involved in the review.

As with this woman, although each woman died from a slightly different underlying cause, most still presented with clear signs of sepsis or potential sepsis. Reviewers identified delays in recognition of sepsis and the full completion of the sepsis bundle, including lack of complete observations, a delay in providing prompt antibiotics and measurement of lactate. A number of the women did not have appropriate involvement of senior clinicians and there was a lack of communication between specialities about the need for senior and specialist involvement. There were specific issues around the availability of high dependency or intensive care beds and care whilst awaiting transfer to intensive care. Ultimately source control, ending the pregnancy or hysterectomy may be required to improve the clinical situation. All these messages for care were identified in the 2014 report.

**"Think Sepsis" at an early stage when presented with an unwell pregnant or recently pregnant woman, take the appropriate observations and act on them (Knight, Kenyon et al. 2014)**

**The key actions for diagnosis and management of sepsis are:**

- **Timely recognition**
- **Fast administration of intravenous antibiotics**
- **Quick involvement of experts - senior review is essential (NHS England 2014)**

**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 (National Institute for Health and Care Excellence 2006, Royal College of Obstetricians and Gynaecologists 2012a)**

**Where sepsis is suspected a sepsis care bundle must be applied in a structured and systematic way with urgency. Each maternity unit must have a protocol for which bundle to use and audit its implementation (Royal College of Obstetricians and Gynaecologists 2012a, Royal College of Obstetricians and Gynaecologists 2012b)**

**Where sepsis is present the source should actively be sought with appropriate imaging and consideration given to whether surgical or radiological-guided drainage is required (Royal College of Obstetricians and Gynaecologists 2012b)**

A woman presented three times with loss of fluid in the second trimester and retrospectively it was clear she had ruptured membranes. There was no check of fetal viability. She was admitted unwell with clear signs of sepsis. There was a delay in review and antibiotics were not given for over ninety minutes. Lactate was not checked for three hours. There was no senior involvement and although a critical care clinician reviewed her there was a delay in transfer to the critical care unit. Attempted medical management to end the pregnancy was unsuccessful and there was a further significant delay in emptying her uterus. She deteriorated and died from overwhelming sepsis.

This woman's care also demonstrates that all of the lessons highlighted above are clearly still relevant. Three other women who died had preterm rupture of the membranes and were appropriately managed with prophylactic erythromycin to improve neonatal outcomes following preterm rupture of the membranes (National Institute for Health and Care Excellence 2015b). When these women subsequently developed sepsis there seemed to be a view they were being treated. However, erythromycin, whilst an appropriate prophylactic agent, is not an appropriate antibiotic where treatment is required and broad-spectrum antibiotics are indicated. Source control for uterine infection when a woman is still pregnant involves ending the pregnancy and may require hysterectomy.

A woman with a twin pregnancy had preterm prelabour rupture of the membranes and laboured and delivered quickly. She was pyrexial overnight. She had required transfusion but this had to be stopped because of her raised temperature. Her platelets dropped and this was attributed to HELLP syndrome. She became increasingly unwell and the need for intensive care was recognised. The critical care team accepted her but there was a three-hour delay in transfer to the critical care unit due to bed availability. In that time little or no support or treatment was provided. This seems to have been partly because maternity staff were busy with other women but also because there was a perception that as she had been accepted by the critical care team her care was no longer their responsibility, even though she had not been transferred. She deteriorated rapidly and died.

If a woman is ill enough to need intensive care she needs close observation and support whilst awaiting transfer. The teams did not appreciate the severity of her condition nor communicate the need for continuing treatment. Several previous reports have highlighted that critical care is a management modality not a place and should be provided wherever the woman is located and should not be delayed by bed availability on the critical care unit.

**There should be adequate provision of appropriate critical care support for the management of a pregnant woman who becomes unwell. All consultant led delivery suites must have access to level 2 critical care facilities that are appropriately equipped and staffed by teams of senior obstetricians, anaesthetists and midwives, skilled in looking after seriously ill women especially those with sepsis. Plans should be in place for provision of critical care on delivery units if this is the most appropriate setting for a woman with sepsis to receive care (Knight, Kenyon et al. 2014).**

**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 (Knight, Nair et al. 2016).**

Although it was clear that staff were aware that this woman was severely ill, reviewers felt that more overt communication about her condition may have led to improvements in her care.

**Consideration should be given to 'declaring sepsis', analogous to activation of the major obstetric haemorrhage protocol, to ensure the relevant members of the multidisciplinary team are informed, aware and act.**

## Other messages for care

A woman had an uneventful delivery and was discharged home. She was well at her subsequent three postnatal checks. She collapsed one morning ten days after giving birth, having been well a few hours earlier. Her family immediately called an ambulance which arrived quickly, but by this time she was unresponsive. She was therefore transferred rapidly to the emergency department, where both obstetric and anaesthetic staff were waiting having been alerted en route. She received exemplary resuscitation but nevertheless died from overwhelming Group A streptococcal infection. The subsequent excellent comprehensive review of her care by the local teams included the ambulance service and emergency department clinicians as well as obstetric and midwifery teams.

This woman's care illustrates the devastating speed with which Group A streptococcal infection can progress. She died despite rapid action by both her family and the ambulance service and exemplary clinical care. The teams caring for her nevertheless carried out a comprehensive multi-disciplinary review in order to identify potential improvements in their practice.

Two other women became unwell postnatally in the community.

A woman was unwell with diarrhoea and vomiting on day 7 after a normal birth. Midwives were reassured by her normal MEOWS scores. She was profoundly unwell and when admitted on day 9 had severe sepsis and had a lactate of 8 mmol/L. The cause of her sepsis was Clostridium difficile with pancolitis from which she died.

It is important to recognise that MEOWS scores alone should not be used as the sole measure of assessment and escalation is appropriate if the woman is unwell in the community as well as in hospital. It is also important not to be reassured by a single set of observations plotted on a MEOWS chart; MEOWS scores should be monitored to identify change. It has previously been acknowledged that research is needed to identify evidence-based trigger levels for MEOWS charts, however, trigger levels will never be perfect and it is important that the whole clinical picture is considered. Clinicians should be aware that sepsis can present with hypothermia. The respiratory rate is invaluable in the identification of a woman who is unwell.

**When assessing a woman who is unwell, consider her clinical condition in addition to her MEOWS score.**

In one woman who became unwell in the postnatal period at home the midwives who attended did not undertake her clinical observations. It transpired that community midwives did not carry thermometers. It would seem a minimum requirement that community midwives would have the ability to check the temperature in addition to the blood pressure, pulse and respiratory rate. The new NICE postnatal care guideline (due for publication 2020) must add clarity about when postnatal observations should be performed.

**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.**

Empowering women with information about the presenting features of serious illness requires clinicians to listen to their concerns and act accordingly. In addition, multiple presentations, even in different settings, should be seen as a 'red flag' and careful review, with escalation to senior clinicians is important to ensure appropriate assessment and care. Two of the women who died in the late postnatal period had presented with symptoms multiple times. In one woman the opportunity to make an earlier diagnosis of meningitis was missed. When women are unwell a general medical examination is required, particularly focussing on the symptoms. In a woman with headache a neurological examination should be undertaken.

**Women [should be] advised, within 24 hours of the birth, of the symptoms and signs of conditions that may threaten their lives and require them to access emergency treatment (National Institute for Health and Care Excellence 2015c).**

Three women died from infections with uncommon or emerging organisms. Unusual organisms will present in pregnancy because of the relative immunosuppressed state. The involvement of experts in microbiology and infectious diseases remains key to managing their care. It may be that external advice is needed.

A woman with a history of SLE developed sepsis in the second trimester. The significance of her immunosuppression was not recognised and she deteriorated rapidly and died.

Several women, three of whom whose deaths are considered in Chapter 5, who were immunosuppressed for various reasons or had chronic illnesses, such as diabetes or sickle cell trait, which put them at risk of infection, died from sepsis. Immunosuppression puts a woman at higher risk of rapid deterioration from sepsis and in any woman who is immunocompromised infection should be considered high on the differential diagnosis when they are unwell.

**It is important to recognise that chronic illness and immunosuppression are risk factors for sepsis. For women with chronic illness or who are immunosuppressed there should be a lower threshold for admission, the administration of appropriate antibiotics and supportive therapy, as well as input from senior clinicians.**

## 6.5 Conclusions

It is good news that the number of maternal deaths from sepsis has reduced sharply in the last triennium. Whilst there are still messages to be learned and improvements that can be made (Table 6.1) this represents a significant improvement in outcomes. However, this should not lead to complacency, particularly around influenza but also in terms of the early recognition and treatment of women who may have sepsis.

**Table 6.1: Classification of care received by women who died from sepsis and for whom case notes were available for an in-depth review, UK and Ireland, 2013–15**

| Classification of care received | Number (%) N=19 |
|---|---|
| Good care | 5 (26) |
| Improvements to care which would have made no difference to outcome | 5 (26) |
| Improvements to care which may have made a difference to outcome | 9 (47) |

# 7. Messages for anaesthetic care

James Bamber and Nuala Lucas on behalf of the anaesthesia chapter-writing group

Chapter-writing group members: James Bamber, Kathryn Bunch, David Churchill, Lisa Elliott, Diana Fothergill, Kate Harding, Sara Kenyon, Mike Kinsella, Marian Knight, Jenny Kurinczuk, Denise Lightfoot, Nuala Lucas, Elizabeth McGrady, Manisha Nair, Katharine Stanley, Derek Tuffnell, Thomas van den Akker, Esther Youd.

## 7.1 Key messages

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. **ACTION: Health professionals**

Anaesthetists must continue to be vigilant about the risk of pulmonary aspiration in pregnant women who require general anaesthesia. An individualised risk assessment should be made and appropriate precautions taken. **ACTION: Health professionals**

In cases of massive obstetric haemorrhage women must be adequately resuscitated and bleeding stopped prior to extubation following general anaesthesia. Evidence of adequate resuscitation should be sought prior to extubation. **ACTION: Health professionals**

Aortocaval compression should be suspected in any supine pregnant woman who develops severe hypotension after induction of anaesthesia, even if some lateral tilt has been applied. If there is a delay in delivery, putting the woman into the left lateral position may be the only option if other manoeuvres fail or if the woman has refractory severe hypotension. **ACTION: Health professionals**

In the absence of contraindications such as hypertension, prophylactic vasopressors should be administered to pregnant women who have spinal anaesthesia. **ACTION: Health professionals**

The choice of endotracheal tube for pregnant women should start at size 7.0mm and proceed to smaller tube selections if needed (size 6.0mm and 5.0mm). It is recommended that all resuscitation carts used in maternity units should include endotracheal tubes no larger than 7.0mm and include smaller sizes such as 6.0mm and 5.0mm. **ACTION: Service managers, health professionals**

Pregnant women with complex needs or a complex medical history should have timely antenatal multidisciplinary planning, and an experienced obstetric anaesthetist should contribute to the planning. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

Hospital serious incident reviews should comment on the quality of the documentation i.e. observations and the clinical management, of adverse serious events. The reviews should also comment on whether there was any process for debriefing and support available to staff involved in these very stressful situations. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

## 7.2 Background

The maternal death rate directly in relation to anaesthesia remains reassuringly low despite the background of an increasingly high-risk obstetric population. This reflects well on the standards of anaesthetic practice in the UK. Anaesthetists have a crucial and growing role in promoting and improving safety in maternity units, in addition to specific anaesthetic skills in the provision of care to women who develop complications during pregnancy and delivery. It has been estimated that anaesthetists are involved in the care of 60% of pregnant women, therefore during the period covered by this report anaesthetists will have been involved in the care of approximately 1.4 million women (The Audit Commission 1997). Although the number of deaths directly attributed to anaesthesia is extremely low, the potential for anaesthesia to cause significant morbidity and mortality must never be forgotten.

## 7.3 Summary of the key findings 2009–13

In the UK and Ireland there were 2 women who died directly from complications of anaesthesia between 2013–15, both of whom died during or within 42 days of the end of pregnancy. This represents an overall maternal mortality rate directly due to anaesthesia of 0.08 per 100,000 maternities (95% CI 0.01 to 0.28 per 100,000 maternities). As noted above, this is unchanged from previous triennia.

## 7.4 Overview of care and lessons to be learned

### Lessons from direct anaesthetic deaths

A woman presented with immediate acute bronchospasm followed by severe hypotension and a skin rash after induction of general anaesthesia. Her anaphylaxis was suspected immediately, senior help arrived very quickly and adrenaline was administered promptly. Ventilation through the tracheal tube was impossible and in accordance with good practice the tube was replaced to exclude equipment obstruction as a cause. Although a pulse was felt the woman's blood pressure was not recordable and several doses of adrenaline were given. Resuscitation was successful but she sustained a hypoxic brain injury from which she died.

During a critical event such as anaphylaxis, where the woman has a palpable pulse but profound hypotension, it is appropriate to commence cardiopulmonary resuscitation. However, there is currently no national recommendation for the specific level of hypotension in an adult, which should mandate the initiation of cardiac compressions to support organ perfusion. Anaphylaxis is the focus of the Royal College of Anaesthetists 6th National Audit Project (NAP6) and this topic is likely to be the subject of further scrutiny in the NAP6 Report. Guidance for clinicians about what level of hypotension should mandate the initiation of cardiac compressions is required.

**Trained healthcare staff cannot assess the breathing and pulse sufficiently reliably to confirm cardiac arrest.**

**Delivering chest compressions to a patient with a beating heart is unlikely to cause harm. However, delays in diagnosis of cardiac arrest and starting CPR will adversely affect survival and must be avoided.**

A woman with a small bowel obstruction aspirated during induction of anaesthesia for a combined Category 3 caesarean section and general surgical procedure. Pulmonary aspiration has been identified as a leading cause of airway-related anaesthetic deaths, in most instances associated with identifiable risk factors (Cook TM, Woodall N et al. 2011). A UKOSS study of failed intubation in obstetrics found an incidence of aspiration of 8% associated with failed intubation, compared to 1% in case matched controls (Quinn, Milne et al. 2013). More recently a UK two-year national descriptive study examining pulmonary aspiration during pregnancy and the immediate postpartum period found an overall incidence of only 6.0 per 1,000,000 maternities (95% CI 2.8 to 11.4). In seven out of the nine women aspiration occurred in association with general anaesthesia, representing an estimated incidence of 2.2 cases per 10,000 general anaesthetics (95% CI 0.9 to 4.5)(Knight M, Bogod D et al. 2016). While these figures are reassuring for obstetric anaesthetists, it is imperative to remember that pregnancy is a risk factor for pulmonary aspiration. Obesity is another risk factor that is increasingly present.

Anaesthetists must continue to be vigilant about the possibility of pulmonary aspiration and undertake individualised risk assessment and precautions against pulmonary aspiration in every woman. Precautions should include the use of H2 antagonists and antacids which have been demonstrated in a Cochrane Review to be associated with a decrease in the risk of intragastric pH < 2.5 at intubation when compared with placebo (Paranjothy, Griffiths et al. 2014). The use of a nasogastric tube to empty the stomach is indicated in conditions such as bowel obstruction or ileus. The woman who aspirated did not have a nasogastric tube in place or aspiration of her stomach prior to induction.

Improvements to care were noted in both these women, but for only one was it thought that the improvements identified may have made a difference to the outcome.

## Lessons for anaesthetic care

During the Enquiry process anaesthetic assessors reviewed the anaesthetic care of all women who died. This provides an opportunity for detailed analysis of related factors that may have contributed to their deaths, including the standard of care provided by anaesthetists. This analysis has highlighted important themes for anaesthetic care; many of these themes will be familiar to experienced obstetric anaesthetists and should be used as a focus for teaching and training junior colleagues.

### Recurrent themes

#### *Hypoventilation after extubation*

> A woman had a category 1 caesarean section under general anaesthesia. After delivery she developed uterine atony, which was treated with multiple uterotonics. Prior to extubation she had a tachycardia of 130bpm, and haemoglobin of 64g/L assessed by a point of care testing device. No blood transfusion was given until after extubation. The woman's condition deteriorated post extubation and she was re-anaesthetised one hour later for a hysterectomy but was acidotic, coagulopathic and had a cardiac arrest from which she could not be resuscitated despite having a massive blood transfusion.

The issue of inadequate resuscitation prior to extubation was highlighted in previous reports (Knight, Kenyon et al. 2014) but was once again noted to be a factor in some women's deaths. These women frequently had postpartum haemorrhage but had not been adequately resuscitated prior to extubation. Following extubation, various factors can contribute to rapid depletion of oxygen stores and a reduction in arterial oxygen saturation. It is essential that the complications of postpartum haemorrhage such as metabolic derangement (acid-base and electrolyte), and hypothermia are corrected prior to extubation (Difficult Airway Society Extubation Guidelines, Popat et al. 2012). Extubation of a woman who is underresuscitated is imprudent as she is unlikely to be able to adequately compensate for her metabolic acidosis by increased respiratory effort because of her impaired consciousness and the residual effects of any opioid analgesia that has been given prior to extubation.

In the vignette above the woman may have been extubated because the haemorrhage had been underestimated or the effectiveness of resuscitation had not been assessed using blood lactate and acid base balance measurements. National and international guidelines highlight the importance of measuring serial lactate and bicarbonate levels (Kozek-Langenecker, Afshari et al. 2013) when managing haemorrhage. Persistent abnormal lactate and bicarbonate levels may indicate inadequate resuscitation, but a deteriorating trend may also indicate unrecognised ongoing bleeding.

#### *Supine hypotension*

The alleviation of aortocaval compression by the gravid uterus is another issue highlighted in the previous report and which may have contributed to one woman's death in the current report.

> A morbidly obese woman who had a combined epidural and general anaesthetic became profoundly hypotensive after induction of general anaesthesia and then had a cardiac arrest during a haemorrhage at delivery. It was not evident that manoeuvres were utilised to prevent or minimise the onset of aortocaval compression.

It may be difficult to judge whether uterine displacement has been achieved in the morbidly obese patient.

**Aortocaval compression should be suspected in any supine pregnant woman who develops severe hypotension after induction of anaesthesia, even if some lateral tilt has been applied. If there is a delay in delivery, putting the woman into the left lateral position may be the only option if other manoeuvres fail or if the woman has refractory severe hypotension.**

### *Hypotension during spinal anaesthesia*

Spinal anaesthesia-induced maternal hypotension can occur in up to three quarters of women in the absence of prophylactic measures, causing maternal nausea and vomiting and impaired uteroplacental perfusion leading to fetal acidaemia. The assessors identified several instances where prophylactic vasopressors with spinal anaesthesia were not administered, which may have compromised further the condition of an already ill woman. The Cardiac Arrest in Pregnancy Study (Beckett, Knight et al. 2017) identified that obstetric anaesthesia, predominantly due to a high neuraxial block, was the leading cause of cardiac arrest in pregnant women in the UK, although this remains a rare complication and all women in that study were successfully resuscitated. The use of prophylactic vasopressors is a national recommendation in the NICE caesarean section guideline CG132 (National Institute for Health and Care Excellence 2011) and consensus recommendations on the use of vasopressors during caesarean section were published this year (Kinsella, Carvalho et al. 2017).

**Alpha agonist drugs are the most appropriate agents to treat or prevent hypotension following spinal anaesthesia. Although those with a small amount of beta agonist activity may have the best profile (noradrenaline (norepinephrine), metaraminol), phenylephrine is currently recommended because of the amount of supporting data. Single-dilution techniques, and / or prefilled syringes should be considered.**

**Left lateral uterine displacement and intravenous colloid preloading or crystalloid co-loading, should be used in addition to vasopressors.**

**International consensus statement on the management of hypotension with vasopressors during caesarean section under spinal anaesthesia (Kinsella, Carvalho et al. 2017)**

### *Airway management*

The Obstetric Anaesthetists' Association and the Difficult Airway Society have published guidelines on airway management in obstetrics (Mushambi, Kinsella et al. 2015). These concentrate on provision of general anaesthesia for caesarean section, and the management of failed tracheal intubation. There is an aid to decision making for the latter, as the anaesthetist will either have to waken the woman and provide alternative anaesthesia, or continue the general anaesthetic with an unsecured airway. This aid can also help other health professionals to understand the management decisions made by the anaesthetist.

Although provision of anaesthesia for pregnant women in other situations may be less complex than at caesarean section, a number of the same factors apply with regard to anatomical and physiological changes.

A postnatal woman collapsed and required cardiopulmonary resuscitation, but the anaesthetists concerned had difficulty intubating with a size 7.5mm tracheal tube. The physiological changes of pregnancy include respiratory tract mucosal oedema, and capillary engorgement of nasal, oropharyngeal mucosa and laryngeal tissues, which can all affect the size of the glottic opening. Smaller tubes may be easier to insert, as the view of the larynx during passage of the tube is subjectively better (Asai and Shingu 2004). Insertion of a smaller endotracheal tube is likely to be less traumatic and there is an association between larger tubes and glottic and tracheal damage, particularly in women (Hawkins 1977, Bishop, Weymuller et al. 1984).

**The choice of tracheal tube for pregnant women should start at size 7.0 and proceed to smaller tube selections if needed (size 6.0 and 5.0).**

**Obstetric Anaesthetists' Association and Difficult Airway Society guidelines for the management of difficult and failed tracheal intubation in obstetrics (Mushambi, Kinsella et al. 2015)**

A recent UK national survey of airway training in anaesthetic departments highlighted the widespread variation in the provision, frequency and content of practical airway training outside the operating theatre; in 16% of units there was no provision for workshop-type manikin-based airway training (Lindkaer Jensen, Cook et al. 2016). The authors of this survey suggested it is time for a national and consistent approach to airway training. The difficulties associated with training for general anaesthesia in obstetrics have previously been highlighted (Johnson, Lyons et al. 2000); it would seem timely for a national strategy for airway training in obstetrics to be developed and mandated.

### *Team working, communication and escalation of care*

The best care of pregnant and postpartum women requires health professionals to work and communicate effectively as a team. As in previous reports poor team working, communication or failure to seek the involvement of senior doctors may have adversely affected care of several women who died.

Three main interventions have been identified as having a key role in improving team working: training in the use of systematic processes such as PROMPT (Practical Obstetric Multi-Professional Training), ALSO (Advance Life Support in Obstetrics) and mMOET (Managing Medical and Obstetric Emergencies and Trauma); structured communication utilising tools such as SBAR (Situation, Background, Assessment, Recommendation) to improve the reliability of transferring critical information; and organisational interventions that change work processes and structures so that they support more effective communication (Buljac-Samardzic, Dekker-van Doorn et al. 2010).

A woman became hypotensive and pale very shortly after a forceps delivery. The duty trainee anaesthetist was called to attend to assist with additional intravenous access but was unable to insert a cannula. Fluid resuscitation continued through the single existing large bore cannula and she received three litres of crystalloid over the next hour. Her hypotension persisted and a point of care haemoglobin measurement recorded a haemoglobin of 49g/L. Only at this time was blood ordered, and only one unit of blood was initially given due the woman feeling breathless. Two hours after the anaesthetist first attended, the woman was transferred to the operating theatre for the insertion of a central line for additional intravenous access. The consultant obstetrician was called but could not attend immediately. After several failed attempts at central venous cannulation and at the request of the consultant obstetrician the consultant anaesthetist was called to attend. By the time the consultant anaesthetist arrived the woman had already had a cardiac arrest due to hypovolaemia. The woman died from intra-abdominal bleeding secondary to a ruptured uterus.

In some instances, as illustrated above, an appropriately trained senior or consultant doctor did not see a woman in time to potentially make a difference to the outcome. It is essential that senior colleagues are actively involved when managing complications around the time of delivery. If there are concerns about the condition of a woman, midwives and junior medical staff must be actively encouraged to seek the advice and input of their senior colleagues and senior doctors must attend wherever possible.

### *Planning care of women with complex needs*

**Pregnant women with complex needs or a complex medical history should have antenatal multidisciplinary planning and an experienced obstetric anaesthetist should contribute to the planning.**

The assessors noted several groups of pregnant women in whom there was no evidence of sufficient planning or awareness that planning was required.

***Jehovah's Witnesses***

A woman with refractory antenatal anaemia who was a Jehovah's Witness had no antenatal discussion of what blood products would or would not be acceptable to use, no discussion of how peripartum haemorrhage would be managed or any referral to an anaesthetic clinic.

**All women declining blood transfusion require careful multidisciplinary planning with senior clinician input during pregnancy to minimise anaemia and to manage blood loss. Early use of iron replacement is indicated with, if needed, use of intravenous iron.**

**RCOG Green-top Guideline No. 47 (Royal College of Obstetricians and Gynaecologists 2015)**

**In women who are Jehovah's witnesses absolute clarity about which fractions of blood products are acceptable and which are not is required, and should be formally documented in the antenatal period.**

***Difficult airway***

A woman with a known congenital abnormality of her upper airway and previous history of difficult intubation was not assessed by an anaesthetist until the day before her delivery. She had been referred for anaesthetic review in early pregnancy but this was not followed up until very late in her pregnancy.

**Women predicted to have significant airway difficulties, such that rapid sequence induction would not be suitable, should be referred antenatally for formulation of a specific anaesthetic and obstetric management plan.**

**Obstetric Anaesthetists' Association and Difficult Airway Society guidelines for the management of difficult and failed tracheal intubation in obstetrics (Mushambi, Kinsella et al. 2015)**

***Morbid obesity***

A woman with a BMI of 55kg/m$^2$ and a past history of sepsis and intensive care after a previous caesarean section had an anaesthetic assessment by an anaesthetic registrar. The documented assessment was limited to briefly recorded advice as to when thromboprophylaxis should be withheld prior to an elective caesarean section. There was no documentation of an anaesthetic management plan for delivery.

**Women with a booking BMI ≥30kg/m² should have an informed discussion antenatally about possible intrapartum complications associated with a high BMI, and management strategies considered. This should be documented in the notes.**

**Pregnant women with a booking BMI ≥40kg/m² should have an antenatal consultation with an obstetric anaesthetist, so that potential difficulties with venous access, regional or general anaesthesia can be identified. An anaesthetic management plan for labour and delivery should be discussed and documented in the medical records.**

**Royal College of Anaesthetists Guidelines for the Provision of Anaesthesia Services for an Obstetric Population 2017 (Royal College of Anaesthetists 2017)**

### *Documentation*

Clear documentation including recording of physiological parameters is essential to enable learning from adverse incidents. A consistent finding in case reviews is poor documentation, particularly in the emergency situation. The presence of a nominated scribe to contemporaneously record events can mitigate this problem. In addition a printout of the automatic vital sign readings can also be helpful.

### *Serious Incident (SI) Reviews*

The anaesthetic assessors found that for several local reviews of the care of women who died, there was no anaesthetic representation. The Confidential Enquiry into Maternal Deaths has involved anaesthetists in the review process for most of its history and regards the involvement of anaesthetists as essential. The care of all women who die is reviewed as part of this Enquiry by at least one anaesthetist irrespective of whether the woman has undergone anaesthesia. Local hospital reviews will also benefit from ensuring the participation of anaesthetists in the review process, not only to identify improvements in anaesthetic care, but also to provide valuable insights into other aspects of care such as resuscitation and fluid management. SI reviews may also wish to consider commenting on important, frequently unconsidered aspects such as whether there was any process for debriefing and support available to staff involved in these very stressful situations.

## 7.5 Conclusions

Many of the lessons highlighted in this chapter are not new and have been recognised by previous Confidential Enquiry Reports and existing national guidance. The challenge for the future lies in the implementation of national guidance through increased awareness of best practice by education, training and shared learning from local reviews of serious adverse events and ‘near misses’.

# 8. Messages for care of women with haemorrhage or amniotic fluid embolism

Marian Knight and Sara Paterson-Brown on behalf of the haemorrhage and AFE chapter-writing group

Chapter-writing group members: Kathryn Bunch, Diana Fothergill, Mike Kinsella, Alison Kirkpatrick, Marian Knight, Jenny Kurinczuk, Manisha Nair, Sue Orchard, Roshni Patel, Sara Paterson-Brown, Judy Shakespeare, Derek Tuffnell, Thomas van den Akker, Adrian Yoong,

## 8.1 Key messages

Fluid resuscitation and blood transfusion should not be delayed because of false reassurance from a single haemoglobin result. **ACTION: Health professionals**

Misoprostol should always be used with extreme caution for women with late intrauterine fetal death, especially in the presence of a uterine scar. In these women, particularly those with a scar, dinoprostone may be more appropriate. **ACTION: Health professionals**

Haemorrhage (which might be concealed) should be considered when classic signs of hypovolaemia are present (tachycardia and/or agitation and the late sign of hypotension) even in the absence of revealed bleeding. **ACTION: 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. **ACTION: Service managers, health professionals**

Recurrent bleeding, pain or agitation should be seen as 'red flags' in women with placenta accreta and women should be advised to remain in hospital. **ACTION: Health professionals**

Once a retained placenta is diagnosed obstetric review and transfer to theatre should be expedited and careful recording of observations should be performed as concealed bleeding can be marked and deterioration is likely. **ACTION: Health professionals**

Early recourse to hysterectomy is recommended where bleeding is associated with placenta accreta or uterine rupture or when bleeding continues after an unsuccessful intrauterine balloon. In extremis and/or while waiting for assistance there are measures which can help. These include aortic compression and stepwise uterine artery ligation. **ACTION: Health professionals**

There is a need for consideration of how competence in abdominal hysterectomy can be achieved for obstetricians in training, and how these skills can be maintained at consultant level, e.g. through simulation training. **ACTION: Policy makers, professional organisations, health professionals**

Local review reports submitted to MBRRACE-UK should include a full assessment of staffing-workload balance issues if these were felt to be a contributory factor. All documents used to conduct the local review, e.g. timelines, should be submitted to MBRRACE-UK, irrespective of whether these are required by local providers or commissioners. **ACTION: Policy makers, service planners/commissioners, service managers, health professionals**

All units are required to have escalation policies for periods of high activity. These policies should include a plan to obtain more and senior obstetric and anaesthetic assistance as well as considering midwifery staffing and diverting activity. **ACTION: Service planners/commissioners, service managers, health professionals**

## 8.2 Background

Whilst obstetric haemorrhage remains a leading cause of maternal deaths worldwide, it is now an uncommon cause of death in the UK. Nevertheless, clear improvements to care of women who died from haemorrhage continue to be identified. Several recommendations included in previous reports were once again identified as important and therefore need repeating, in particular in relation to use and overuse of uterotonics. Particularly important to note is the changing pattern of haemorrhage deaths, with more women dying than ever before in association with abnormal placentation. This is perhaps unsurprising in light of the known association with previous caesarean delivery (Fitzpatrick, Sellers et al. 2012) and rising caesarean delivery rates (Betran, Ye et al. 2016).

## 8.3 Summary of the key findings 2009–13

In the UK and Ireland there were 22 women who died from obstetric haemorrhage between 2013–15, one of these women died more than 42 days after the end of pregnancy (Table 8.1). This represents an overall mortality rate of 0.88 (95% CI 0.55 to 1.33). Of note, 9 women died from haemorrhage in association with abnormal placentation, 8 of whom had placenta accreta, increta or percreta.

**Table 8.1: Direct deaths by type of obstetric haemorrhage 1994–2015**

| Time period | Placental Abruption | Placenta Praevia/ accreta | Postpartum haemorrhage | | Total deaths from haemorrhage | Direct haemorrhage death rate per 100,000 maternities | |
|---|---|---|---|---|---|---|---|
| | | | Atony | Genital Tract Trauma | | rate | CI |
| 1994–6 | 4 | 3 | 5 | 5 | 17 | 0.77 | 0.45–1.24 |
| 1997–99 | 3 | 3 | 1 | 2 | 9 | 0.42 | 0.19–0.80 |
| 2000–2 | 3 | 4 | 10 | 1 | 18 | 0.9 | 0.53–1.42 |
| 2003–5 | 2 | 3 | 9 | 3 | 17 | 0.8 | 0.47–1.29 |
| 2006–8 | 2 | 2 | 3 +2 | (0/2) | 9 | 0.39 | 0.18–0.75 |
| 2009–12† | 2 | 1 | 7 | 7 | 17 | 0.49 | 0.29–0.78 |
| 2013–15† | 3 | 9* | 9** | 1 | 22 | 0.88 | 0.55–1.33 |

†Figures for UK and Ireland. All other figures are UK only.
*One placenta praevia alone, 8 accreta/increta/percreta
**5 post caesarean delivery

Nine women died from amniotic fluid embolism, representing a mortality rate of 0.36 (95% CI 0.16 to 0.68). Five of these women were induced; two of whom were induced following an intrauterine death. Five of these nine women belonged to ethnic minority groups (2 Pakistani and 3 Black Caribbean) and one of nine did not understand English. Two-thirds of these women were either overweight or obese (4 overweight, 2 obese).

## 8.4 Overview of care and lessons to be learned

### Obstetric haemorrhage

#### Recurring themes

The assessment of blood loss and identification of the need for replacement of fluids and blood products is key to the management of obstetric haemorrhage.

As has been noted previously (Knight, Kenyon et al. 2014) there were several instances when undue reliance was placed on a single point of care haemoglobin result, without considering the woman's clinical condition as a whole. Three women died from haemorrhage after a point of care haemoglobin test had provided false reassurance. Similarly, five women had ongoing bleeding, the severity of which was not appreciated as no-one calculated the women's total blood loss and observations were frequently lacking, especially in the first hour or two after delivery. Whilst most of these women showed signs of significant haemorrhage (most notably tachycardia and agitation) they were not hypotensive (which is a very late

physiological sign of haemorrhage) until they were in extremis. Concealed haemorrhage may be due to obstetric or non-obstetric causes (discussed further in Chapter 5) but should be considered in women with tachycardia or hypotension and/or agitation. A further two women had abnormal observations charted on a MEOWS or similar chart, but these were not acted upon. There were subsequently extreme difficulties in obtaining vascular access for one of these women. The following recommendations were made in the 2014 report and they continue to be relevant:

**Fluid resuscitation and blood transfusion should not be delayed because of false reassurance from single haemoglobin results. When there is evidence of considerable blood loss and fluid resuscitation has not been commenced or is inadequate, the result shows the haemoglobin concentration from before the bleeding, not what it has been diluted to after fluid resuscitation. Haemoglobin measurements should be repeated regularly during the transfusion process. (United Kingdom Blood Services 2013)**

**Whilst significant haemorrhage may be apparent from observed physiological disturbances young fit pregnant women compensate remarkably well. Whilst a tachycardia commonly develops there can be a paradoxical bradycardia and hypotension is always a very late sign, therefore ongoing bleeding should be acted upon quickly (Thomas and Dixon 2004).**

**Physiological observations including the respiratory rate recorded within a trigger system such as the MEOWS chart should be used to monitor all antenatal and postnatal admissions. However, it is the response to the abnormal score that will affect outcome, not simply its documentation. (Lewis 2007, Maternal Critical Care Working Group 2011)**

**Maternity units should have as part of their major obstetric haemorrhage protocol guidance for achieving intravascular access when access is particularly difficult. The use of intraosseous technology and appropriate staff training should be considered (Knight, Kenyon et al. 2014)**

In addition to the use of intraosseous technology, where venous access is problematic in pregnant women, for example amongst groups of women who have venous damage following chemotherapy or intravenous drug use, the peripherally inserted central venous catheter can be an option (Dowse, Kinsella et al. 2016). This can be particularly valuable when repeated blood sampling is required.

### *Uterine hyperstimulation*

Uterine hyperstimulation following induced labour was frequently identified among the women who died from haemorrhage or amniotic fluid embolism. Seven women who died were over stimulated; four of nine (44%) women who died from AFE and three of 22 (14%) women who died from haemorrhage. The following recommendation was made in the 2014 report and it was clear that this needs to be reiterated.

**Stimulating or augmenting uterine contractions should be done in accordance with current guidance and paying particular attention to avoiding uterine tachysystole or hyperstimulation. (Knight, Kenyon et al. 2014)**

In particular, reviewers noted that excessive doses of misoprostol were used. Five women died following induction of labour after an intrauterine death; all received excessive doses of misoprostol. In addition, two multiparous women were induced and hyperstimulated with prostaglandins. In neither instance was this recognised and treated with tocolytics; both developed AFE and torrential haemorrhage. Any time uterotonics are being used great care should be taken to avoid over stimulating, and the dose should be adjusted according to the individual's response.

A woman presented with an intrauterine death and massive polyhydramnios at 36 weeks. She was given an overdose of misoprostol of 100mcg (the dose should have been 25–50mcg at this gestation according to RCOG guidelines)– six hours after mifepristone. She developed strong contractions, delivered and had a massive haemorrhage from which she died. She was being cared for in a bereavement suite.

This woman's blood loss was underestimated and the coagulation problems that developed should have been managed more aggressively.

**Recommended doses of misoprostol for women with late intrauterine fetal death:**

- **100 micrograms 6-hourly before 26+6 weeks, for up to 24 hours**
- **25–50 micrograms 4-hourly at 27+0 weeks or more, for up to 24 hours**

**The lower dose should be used for women with a previous caesarean section**

**RCOG Green top guideline 55 Late intrauterine fetal death and stillbirth (Royal College of Obstetricians and Gynaecologists 2010)**

**Misoprostol should always be used with extreme caution for women with late intrauterine fetal death, especially in the presence of a uterine scar. In these women, particularly those with a scar, dinoprostone may be more appropriate.**

A multiparous, morbidly obese woman presented with an intrauterine death at 19 weeks gestation. She had grossly excessive dosages of misoprostol (800mcg, 400mcg and 400mcg within 7 hours, rather than 100mcg 6 hourly at this gestation). She had worsening pain, an abnormal early warning score and falling haemoglobin. There was a delay in the recognition of concealed haemorrhage. Her agitation with a pulse of 190bpm was put down to mental health issues. She had a cardiac arrest and at laparotomy there was a ruptured uterus and placenta accreta. Despite resuscitation and hysterectomy she died.

**Haemorrhage (which might be concealed) should be considered when classic signs of hypovolaemia are present (tachycardia and/or agitation and the late sign of hypotension) even in the absence of revealed bleeding.**

**Agitation and anxiety are clinical signs and symptoms not a diagnosis.**

### *Placenta praevia/accreta*

Four of the nine women who died from placenta praevia or accreta died following collapse at home. Three of these women were known to have placenta praevia or accreta and two had had previous bleeding episodes.

A woman with two previous caesarean sections was diagnosed with placenta accreta. She had had three previous admissions with bleeding. A week after discharge she developed pain and bleeding. There was confusion over whether she was to be taken to the local hospital or the unit she had been referred to for her placenta accreta. A perimortem caesarean section was performed in A+E but despite best efforts she died.

**Recurrent bleeding, pain or agitation should be seen as 'red flags' in women with placenta accreta and women should be advised to remain in hospital.**

Of the eight women who died from accreta, three had catastrophic antenatal intraperitoneal bleeding (with uterine rupture in two women), two presented with retained placentas after delivering vaginally, and two presented at caesarean section when the uterus was accessed through the placenta and catastrophic haemorrhage ensued. One woman died from complications of a planned embolization procedure where

the small particles injected must have travelled through an arterio-venous shunt resulting in fatal pulmonary emboli. Such shunts may be more likely with repeat procedures, and should be excluded (especially for repeat procedures) before injecting the largest feasible size of the particles.

### *Major Obstetric Haemorrhage Protocol*

A parous woman was induced with a sustained release prostaglandin. She was rapidly delivered by caesarean section under general anaesthesia following uterine hyperstimulation. She subsequently had an atonic uterus, but her ongoing vaginal blood loss was not monitored after suturing of the uterus. She was extubated while still unstable. When her ongoing blood loss became apparent a massive obstetric haemorrhage was not declared; a consultant obstetrician was not called. She was by this stage in extremis and was unable to be resuscitated after her cardiac arrest.

Declaring a major obstetric haemorrhage will alert staff to the severity of a situation and facilitate senior involvement. Whilst this woman's blood loss was not recognised initially, when it was recognised, triggering the major obstetric haemorrhage protocol would have facilitated more rapid resuscitation, communication with senior staff and provision of appropriate equipment.

**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.**

This woman's care also illustrates the problem of task fixation. In this instance, the junior obstetrician was focussed on suturing the caesarean section wound and did not appreciate the degree of ongoing vaginal bleeding. This also occurred in a woman with vaginal trauma after a forceps delivery. A similar theme was identified in the care of women who were being induced after abruption-related intrauterine death. The staff caring for these women were focussing on achieving a vaginal delivery and again did not appreciate the extent of the concealed abruption and the women's deteriorating condition.

### *Hysterectomy*

Assessors felt that hysterectomy could have been undertaken earlier in the course of haemorrhage for four women. In two of these women, there was clear reluctance on the part of the managing consultant to initiate the decision for hysterectomy. Abdominal hysterectomy is carried out much less frequently in gynaecological practice than previously and this combined with run through training over fewer working hours means that there is now an emerging generation of obstetric consultants who have little personal experience of the procedure. Competence in abdominal hysterectomy is not required for a Certificate of Completion of Training in those trainees who have done exclusively obstetric ATSM modules.

**There is a need for consideration of how competence in abdominal hysterectomy can be achieved for obstetricians in training, and how these skills can be maintained at consultant level, e.g. through simulation training.**

As noted in the 2014 report:

**Early recourse to hysterectomy is recommended where bleeding is associated with placenta accreta or uterine rupture or when bleeding continues after an unsuccessful intrauterine balloon. Hysterectomy should not be delayed until the woman is in extremis or while less definitive procedures with which the surgeon has little experience are attempted.**

**RCOG Green-top guideline 52 (Royal College of Obstetricians and Gynaecologists 2016a)**

**In extremis and/or while waiting for assistance there are measures which can help. These include aortic compression and stepwise uterine artery ligation.**

## New themes

### *Delay in manual removal of placenta*

A woman with a history of drug misuse gave birth 20 minutes after admission but had a retained placenta. There was a 90 minute delay getting to theatre and by this point she was tachycardic. There had been few observations between birth and transfer to theatre. She arrested during anaesthesia. There were difficulties with venous access. The blood loss was underestimated and there were delays in treatment with manual removal. The difficulties were compounded by the fact it was 4am and that there was another woman in theatre, so the registrar and anaesthetist were busy. There was as a consequence little medical input at a crucial time.

Two women died following delayed manual removal of a retained placenta. In both instances, the extent of concealed blood loss was not appreciated, there were inadequate observations recorded between delivery and going to theatre and signs of deterioration were missed. As noted above, and observed among some of the women who died following rupture of splenic and other artery aneurysms, there is a need to consider concealed haemorrhage as a cause of collapse.

**Once a retained placenta is diagnosed obstetric review and transfer to theatre should be expedited and careful recording of observations should be performed as concealed bleeding can be marked and deterioration is likely.**

### *Staffing-workload balance issues*

Assessors noted that compared to cases reviewed in previous MBRRACE-UK reports there was an increasing number of comments in relation to staffing-workload balance issues which had an impact on these women's deaths. There were a number of occasions when obstetric staff were reported to be in theatre or dealing with emergencies elsewhere. However, it was not clear whether this was due to increased reporting because of more complete local clinician reports or more thorough local reviews, or whether this represented a true increase in such pressures. In some instances the assessors were unable to assess the full extent of the staffing-workload balance issues because of limited detail included in the local review reports.

**Local review reports submitted to MBRRACE-UK should include a full assessment of staffing-workload balance issues if these were felt to be a contributory factor. All documents used to conduct the local review, e.g. timelines, should be submitted to MBRRACE-UK, irrespective of whether these are required by local providers or commissioners.**

**All units are required to have escalation policies for periods of high activity. These policies should include a plan to obtain more and senior obstetric and anaesthetic assistance as well as considering midwifery staffing and diverting activity.**

### *Support for staff*

> A woman presented with a massive placental abruption. She was a Jehovah's witness and declined some blood products. There was some confusion about which blood fractions could be given. She died of her haemorrhage after several days of intensive care. The staff involved were clearly very affected by this event. One had a period of long term sickness and one left their job.

This emphasises the importance of considering staff wellbeing and support and the offer of counselling where needed following these events.

**In women who are Jehovah's witnesses absolute clarity about which fractions of blood products are acceptable and which are not is required, and should be formally documented in the antenatal period.**

## Amniotic Fluid Embolism

Many of the messages for care described above amongst the women who died from postpartum haemorrhage were also seen amongst the women who died from AFE. One woman collapsed antenatally. Two women who had intrauterine deaths received excessive doses of misoprostol and collapsed following hyperstimulation, and as noted above, two multiparous women had an AFE after hyperstimulation following prostaglandin. Two women died during established labour following induction; in one of these women the indication for induction was debatable. Two women collapsed after spontaneous rupture of membranes, and two women collapsed immediately postnatally.

Amniotic fluid embolism was thought to be a secondary phenomenon contributing to the deaths of an additional four women.

> A woman presented with an intrauterine death in the late third trimester. She was given misoprostol 100mcg at four hourly intervals. This was well in excess of recommended dosages. Thirty minutes after birth she collapsed and had a cardiac arrest. Despite extensive resuscitation she continued to deteriorate. Interventional radiology was used to try to control bleeding but she was bleeding from splenic injury from the resuscitation.

**Units must be clear that they are using the appropriate dosage of agents for induction of labour. These differ according to gestation and are lower for women with a uterine scar.**

In one woman who collapsed intrapartum, an early decision for perimortem caesarean section was made, however, this was delayed because there was no scalpel on the resuscitation trolley on delivery suite.

**A pre-mounted scalpel blade and two cord clamps should be kept available on the resuscitation trolley to ensure that there are no delays if perimortem caesarean section is necessary (Knight, Kenyon et al. 2014).**

In most instances the women who died from AFE received timely and excellent resuscitation. There was clear evidence that staff were profoundly affected by these women's deaths and there were notable examples of good support for staff.

A woman had a rapid collapse after a forceps birth. Despite appropriate and vigorous resuscitation she died. This was clearly a distressing event for staff. There was evidence of good support for staff from the supervisor of midwives during the night when the woman died and staff were debriefed and offered the option of counselling. This approach is important for staff after such events.

## 8.5 Conclusions

It is disappointing that many of the messages regarding the care of women who died from haemorrhage remain very similar to those reported in 2014 (Knight, Kenyon et al. 2014). Assessors noted improvements in care, which may have made a difference to outcome, in almost 60% of women (Table 8.2). There is thus clear potential for preventing more deaths from haemorrhage and AFE in the future. Of particular concern is the rising rate of maternal death in association with placenta accreta. Maternal deaths represent only the tip of the iceberg and the morbidity associated with abnormal placentation is substantial (Fitzpatrick, Sellers et al. 2014). As the risk factors for placenta accreta, such as previous caesarean delivery, are known to be increasing in the population, the increase in mortality associated with abnormal placentation may simply reflect an increase in the incidence. Maternal morbidity from major haemorrhage will be reviewed in the 2018 report, but there may be a place for a further study of placenta accreta/increta/percreta morbidity to further identify improvements in care.

**Table 8.2: Classification of care received by women who died from haemorrhage or AFE, UK and Ireland, 2013–15**

| Classification of care received | Number (%) N=31 |
|---|---|
| Good care | 10 (32) |
| Improvements to care which would have made no difference to outcome | 3 (10) |
| Improvements to care which may have made a difference to outcome | 18 (58) |

# 9. References


Asai, T. and K. Shingu (2004). Difficulty in advancing a tracheal tube over a fibreoptic bronchoscope: incidence, causes and solutions. Br J Anaesth 92(6): 870-881.

Australian Government Department of Health. (2017). Australian Influenza Surveillance Report and Activity Updates. Retrieved 13/09/2017, 2017, from *http://www.health.gov.au/flureport - current*.

Beckett, V. A., M. Knight and P. Sharpe (2017). The CAPS Study: incidence, management and outcomes of cardiac arrest in pregnancy in the UK: a prospective, descriptive study. BJOG 124(9): 1374-1381.

Betran, A. P., J. Ye, A. B. Moller, J. Zhang, A. M. Gulmezoglu and M. R. Torloni (2016). The Increasing Trend in Caesarean Section Rates: Global, Regional and National Estimates: 1990-2014. PLoS One 11(2): e0148343.

Bishop, M. J., E. A. Weymuller, Jr. and B. R. Fink (1984). Laryngeal effects of prolonged intubation. Anesth Analg 63(3): 335-342.

Buljac-Samardzic, M., C. M. Dekker-van Doorn, J. D. van Wijngaarden and K. P. van Wijk (2010). Interventions to improve team effectiveness: a systematic review. Health Policy 94(3): 183-195.

Cook T.M., N. Woodall, C. Frerk (eds) and on behalf of the Fourth National Audit Project (2011). Major complications of airway management in the UK: results of the Fourth National Audit Project of the Royal College of Anaesthetists and the Difficult Airway Society.

Davies, S. C. (2015). Annual Report of the Chief Medical Officer, 2014, The Health of the 51%: Women. London, Department of Health.

Department of Health. (2015). New ambition to halve rate of stillbirths and infant deaths. Retrieved 27/09/2016, from *https://www.gov.uk/government/news/new-ambition-to-halve-rate-of-stillbirths-and-infant-deaths*.

Department of Health (Ireland) (2017). Creating a better future together – National Maternity Strategy 2016-2026. Dublin, Department of Health.

Department of Health and the Royal College of Obstetricians and Gynaecologists (2009). Pandemic H1N1 2009 Influenza: Clinical management guidelines for pregnancy. London, Department of Health and the Royal College of Obstetricians and Gynaecologists.

Difficult Airway Society Extubation Guidelines, G., M. Popat, V. Mitchell, R. Dravid, A. Patel, C. Swampillai and A. Higgs (2012). Difficult Airway Society Guidelines for the management of tracheal extubation. Anaesthesia 67(3): 318-340.

Dowse, C., S. M. Kinsella and M. J. Scrutton (2016). Peripherally inserted central venous catheters in parturients with poor peripheral venous access: a case report and assessment of potential applications. Eur J Obstet Gynecol Reprod Biol 205: 191-192.

Edey, S., N. Moran and L. Nashef (2014). SUDEP and epilepsy-related mortality in pregnancy. Epilepsia 55(7): e72-74.

Faculty of Sexual and Reproductive Healthcare. (2017). FSRH Guideline Contraception After Pregnancy. from *https://www.fsrh.org/standards-and-guidance/documents/contraception-after-pregnancy-guideline-january-2017/*.

Fitzpatrick, K. E., S. Sellers, P. Spark, J. J. Kurinczuk, P. Brocklehurst and M. Knight (2012). Incidence and Risk Factors for Placenta Accreta/Increta/Percreta in the UK: A National Case-Control Study. Plos One 7(12).

Fitzpatrick, K. E., S. Sellers, P. Spark, J. J. Kurinczuk, P. Brocklehurst and M. Knight (2014). The management and outcomes of placenta accreta, increta, and percreta in the UK: a population-based descriptive study. BJOG 121(1): 62-71.

Harlow, B. L., A. F. Vitonis, P. Sparen, S. Cnattingius, H. Joffe and C. M. Hultman (2007). Incidence of hospitalization for postpartum psychotic and bipolar episodes in women with and without prior prepregnancy or prenatal psychiatric hospitalizations. Arch Gen Psychiatry 64(1): 42-48.

Hawkins, D. B. (1977). Glottic and subglottic stenosis from endotracheal intubation. Laryngoscope 87(3): 339-346.

Health Protection Scotland (2017). HPS Weekly National Influenza Report: Summary of surveillance of influenza and other seasonal respiratory illnesses Week ending 21 May 2017 – week 20.

Heslehurst, N., H. Simpson, et al. (2008). The impact of maternal BMI status on pregnancy outcomes with immediate short-term obstetric resource implications: a meta-analysis. Obes Rev 9(6): 635-683.

Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and National Clinical Programme in Obstetrics and Gynaecology. (2015). Clinical Practice Guideline - Bacterial Infections Specific to Pregnancy. Retrieved 30/10/2017, 2017, from *https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2016/05/29.-Bacterial-Infection-Specific-to-Pregnancy.pdf*.

Institute of Obstetricians and Gynaecologists, Royal College of Physicians of Ireland and National Clinical Programme in Obstetrics and Gynaecology. (2017). Clinical Practice Guideline - Bereavement care following maternal death within a hospital setting. Retrieved 30/10/2017, 2017, from *https://rcpi-live-cdn.s3.amazonaws.com/wp-content/uploads/2015/12/Bereavement-guideline.pdf*.

Johnson, R. V., G. R. Lyons, R. C. Wilson and A. P. Robinson (2000). Training in obstetric general anaesthesia: a vanishing art? Anaesthesia 55(2): 179-183.

Kendell, R. E., J. C. Chalmers and C. Platz (1987). Epidemiology of puerperal psychoses. Br J Psychiatry 150: 662-673.

Kinsella, S., B. Carvalho, et al. (2017). International consensus statement on the management of hypotension with vasopressors during caesarean section under spinal anaesthesia. Anaesthesia [EPub ahear of print].

Knight M, Bogod D, Lucas DN, Quinn A and K. JJ. (2016). Pulmonary aspiration during pregnancy or immediately postpartum in the UK: a two-year national descriptive study. International Journal of Obstetric Anesthesia 26(Supplement 1): S6-S54.

Knight, M., S. Kenyon, P. Brocklehurst, J. Neilson, J. Shakespeare, J. Kurinczuk (Eds.) on behalf of MBRRACE-UK (2014). Saving Lives, Improving Mothers' Care - Lessons learned to inform future maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-12. Oxford, National Perinatal Epidemiology Unit, University of Oxford.

Knight, M., J. Kurinczuk, P. Spark, P. Brocklehurst and on behalf of UKOSS (2010). Extreme Obesity in Pregnancy in the United Kingdom. Obstetrics and Gynecology 115(5): 989-997.

Knight, M., M. Nair, D. Tuffnell, S. Kenyon, J. Shakespeare, P. Brocklehurst, J. Kurinczuk on behalf of MBRRACE-UK., Eds. (2016). Saving Lives, Improving Mothers' Care - Surveillance of maternal deaths in the UK 2012-14 and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2009-14. Oxford, National Perinatal Epidemiology Unit, University of Oxford.

Knight, M., D. Tuffnell, S. Kenyon, J. Shakespeare, R. Gray, J. Kurinczuk (Eds) on behalf of MBRRACE-UK. (2015). 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. Oxford, National Perinatal Epidemiology Unit, University of Oxford.

Kozek-Langenecker, S. A., A. Afshari, et al. (2013). Management of severe perioperative bleeding: guidelines from the European Society of Anaesthesiology. Eur J Anaesthesiol 30(6): 270-382.

Leach, J. P., P. E. Smith, et al. (2017). Epilepsy and Pregnancy: For healthy pregnancies and happy outcomes. Suggestions for service improvements from the Multispecialty UK Epilepsy Mortality Group. Seizure 50: 67-72.

Lewis, G. (Ed)., R. Cantwell, et al. (2011). Saving Mothers' Lives: Reviewing maternal deaths to make motherhood safer: 2006-2008. The Eighth Report of the Confidential Enquiries into Maternal Deaths in the United Kingdom. BJOG 118 Suppl 1: 1-203.

Lindkaer Jensen, N. H., T. M. Cook and F. E. Kelly (2016). A national survey of practical airway training in UK anaesthetic departments. Time for a national policy? Anaesthesia 71(11): 1273-1279.

Maternity Safety Programme Team Department of Health (2016). Safer Maternity Care. Next steps towards the national maternity ambition. London, Department of Health.

Mushambi, M. C., S. M. Kinsella, et al. (2015). Obstetric Anaesthetists' Association and Difficult Airway Society guidelines for the management of difficult and failed tracheal intubation in obstetrics. Anaesthesia 70(11): 1286-1306.

Nair, M., M. Knight and J. J. Kurinczuk (2016). Risk factors and newborn outcomes associated with maternal deaths in the UK from 2009 to 2013: a national case-control study. BJOG 123(10): 1654-1662.

Nair, M., J. J. Kurinczuk, P. Brocklehurst, S. Sellers, G. Lewis and M. Knight (2015). Factors associated with maternal death from direct pregnancy complications: a UK national case-control study. BJOG 122(5): 653-662.

National Institute for Health and Care Excellence. (2006). CG37. Postnatal care: Routine postnatal care of women and their babies. From *http://www.nice.org.uk/guidance/cg37*.

National Institute for Health and Care Excellence. (2008a). CG62: Antenatal care. Retrieved 15/04/2014 from *http://www.nice.org.uk/guidance/cg62*.

National Institute for Health and Care Excellence (2008b). CG68: Diagnosis and initial management of acute stroke and transient ischaemic attack. Retrieved 16/04/2017 from *https://www.nice.org.uk/guidance/cg68*.

National Institute for Health and Care Excellence. (2010). CG110: Pregnancy and complex social factors: A model for service provision for pregnant women with complex social factors. Retrieved 23/07/2015 from *https://www.nice.org.uk/guidance/cg110*.

National Institute for Health and Care Excellence. (2011). CG132: Caesarean section. Retrieved 15/04/2015 from *https://www.nice.org.uk/guidance/cg132*.

National Institute for Health and Care Excellence. (2012). CG137. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. Retrieved 02/07/14 2014, from *http://www.nice.org.uk/guidance/CG137*.

National Institute for Health and Care Excellence. (2014). CG192: Antenatal and postnatal mental health: clinical management and service guidance. Retrieved 15/04/2015 from *https://www.nice.org.uk/guidance/cg192*.

National Institute for Health and Care Excellence. (2015a). NG12: Suspected cancer - recognition and referral. Retrieved 23/07/2015 from *https://www.nice.org.uk/guidance/ng12*.

National Institute for Health and Care Excellence. (2015b). NG25: preterm labour and birth. Retrieved 13/04/2016 from *https://www.nice.org.uk/guidance/ng25*.

National Institute for Health and Care Excellence. (2015c). QS37: Postnatal care. Retrieved 28/09/2016 from *https://www.nice.org.uk/guidance/qs37*.

National Institute for Health and Care Excellence. (2016). NG51: Sepsis: recognition, diagnosis and early management. Retrieved 27/09/2016 from *https://www.nice.org.uk/guidance/ng51*.

NHS England. (2013). NHS Services, Seven Days a Week Forum Summary of Initial Findings. Retrieved 27/09/2016 from *https://www.england.nhs.uk/wp-content/uploads/2013/12/forum-summary-report.pdf*.

NHS England. (2014). Patient Safety Alert: Resources to support the prompt recognition of sepsis and the rapid initiation of treatment. Retrieved 11/09/14 from *http://www.england.nhs.uk/wp-content/uploads/2014/09/psa-sepsis.pdf*.

NMPA Project Team (2017). National Maternity and Perinatal Audit: organisational report 2017. London, RCOG.

Paranjothy, S., J. D. Griffiths, H. K. Broughton, G. M. Gyte, H. C. Brown and J. Thomas (2014). Interventions at caesarean section for reducing the risk of aspiration pneumonitis. Cochrane Database Syst Rev(2): CD004943.

Public Health Agency (2017). Surveillance of Influenza in Northern Ireland 2016 – 2017.

Public Health England. (2014). Immunisation against infectious disease. Retrieved 02/07/14 from *https://www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book*.

Public Health England (2017). Seasonal influenza vaccine uptake in GP patients in England: winter season 2016 to 2017.

Public Health Wales (2017). Seasonal influenza in Wales 2016/17 Annual Report.

Quinn, A. C., D. Milne, M. Columb, H. Gorton and M. Knight (2013). Failed tracheal intubation in obstetric anaesthesia: 2 yr national casecontrol study in the UK. British Journal of Anaesthesia 110(1): 74-80.

Reuber, M., G. A. Baker, R. Gill, D. F. Smith and D. W. Chadwick (2004). Failure to recognize psychogenic nonepileptic seizures may cause death. Neurology 62(5): 834-835.

Rhodes, A., L. E. Evans, et al. (2017). Surviving Sepsis Campaign: International Guidelines for Management of Sepsis and Septic Shock: 2016. Intensive Care Med 43(3): 304-377.

Royal College of Anaesthetists (2017). Guidelines for the Provision of Anaesthesia Services (GPAS): Guidelines for the Provision of Anaesthesia Services for an Obstetric Population 2017.

Royal College of Obstetricians and Gynaecologists (2010). Green-top Guideline 55: Late Intrauterine Fetal Death and Stillbirth.

Royal College of Obstetricians and Gynaecologists (2012a). Green-top Guideline No. 64a. Bacterial Sepsis in Pregnancy. London, RCOG.

Royal College of Obstetricians and Gynaecologists (2012b). Green-top Guideline No. 64b. Bacterial Sepsis following Pregnancy. London, RCOG.

Royal College of Obstetricians and Gynaecologists (2015). Green-top Guideline 47: Blood Transfusions in Obstetrics. London, RCOG

Royal College of Obstetricians and Gynaecologists (2016a). Green-top Guideline 52: Postpartum Haemorrhage, Prevention and Management. London, RCOG

Royal College of Obstetricians and Gynaecologists (2016b). Green-top Guideline 68: Epilepsy in Pregnancy. London, RCOG

Royal College of Obstetricians and Gynaecologists (2016c). Green-top Guideline 69: The Management of Nausea and Vomiting of Pregnancy and Hyperemesis Gravidarum London, RCOG

Schram, A. M. and N. Berliner (2015). How I treat hemophagocytic lymphohistiocytosis in the adult patient. Blood 125(19): 2908-2914.

The Audit Commission (1997). Anaesthesia under examination: the efficiency and effectiveness of anaesthesia and pain relief services in England and Wales. London, The Audit Commission.

The Scottish Government (2017). The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland. Edinburgh, The Scottish Government.

The Society of British Neurological Surgeons (2015). Care quality statement. London, The Society of British Neurological Surgeons.

UK and Ireland Epilepsy and Pregnancy Register. (2016). UK and Ireland Epilepsy and Pregnancy Register. Retrieved 24/08/17 from *http://www.epilepsyandpregnancy.co.uk*.

UK Sepsis Trust. (2016). Maternal sepsis toolkits. Retrieved 28/09/2016 from *http://sepsistrust.org/clinical-toolkit/*.

van Rijn, M. J., S. Ten Raa, J. M. Hendriks and H. J. Verhagen (2017). Visceral aneurysms: Old paradigms, new insights? Best Pract Res Clin Gastroenterol 31(1): 97-104.

Wilson, R. J., P. Paterson, C. Jarrett and H. J. Larson (2015). Understanding factors influencing vaccination acceptance during pregnancy globally: A literature review. Vaccine 33(47): 6420-6429.

World Health Organisation. (2012). The WHO Application of ICD-10 to deaths during pregnancy, childbirth and the puerperium: ICD-MM. Retrieved 07/10/2015 from *http://apps.who.int/iris/bitstream/10665/70929/1/9789241548458_eng.pdf?ua=1*.

World Health Organisation (2017). Statement on Maternal Sepsis. Geneva, World Health Organisation.

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