

**Maternal, Newborn and  
Infant Clinical Outcome  
Review Programme**



## **Saving Lives, Improving Mothers' Care**

Lessons learned to inform maternity care from the  
UK and Ireland Confidential Enquiries into Maternal  
Deaths and Morbidity 2014–16



November 2018



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UK and Ireland Confidential Enquiries into Maternal  
Deaths and Morbidity 2014–16

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November 2018



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# Foreword

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Since the first of the maternal confidential enquiry reports produced by the MBRRACE-UK collaboration, user and support groups have been involved in producing a lay summary of the report results. Whilst drafting the lay summary of report this year, we were struck by three important messages for health professionals and policy makers that were apparent from the case reviews covering both physical and mental health:

Firstly, it is essential for doctors, midwives and allied health professionals to challenge assumptions, both their own and those of others. This includes an assumption that symptoms relate to normal pregnancy even where they are concerning and persistent, hence leading to delay in diagnosis, or an assumption that some women have simply too many or complex problems to be helped, or a default assumption that stopping medication is appropriate in pregnancy without considering the benefits and risks to the mother.

Secondly, we could quite clearly see the value of continuity of care and shared record keeping, particularly that provided by midwives and GPs - ensuring women are able to be heard and develop trusting and supportive relationships with health professionals to disclose and discuss their concerns, enabling women to receive the right specialist care with appropriate communication between different hospital and community services, and rapid referral when it is needed.

Thirdly, it was very evident that there needs to be a major emphasis on training for non-specialists in the management of pregnant and postpartum women - whether this be training for liaison, crisis and home treatment mental health teams on the specific features of perinatal mental illness, or medical and surgical teams on treatment of pregnant women with comorbidities.

It is striking that there are two areas where we seem to be making little impact. Research is urgently needed to understand why black women are five times more likely and Asian women twice as likely to die compared to white women. More research is needed to understand the specific causes of the deaths of women from these ethnic groups. Yet again in this report it has been noted that maternal mortality is increasingly a problem for women with multiple vulnerabilities. Specifically, it highlights yet again that a number of women died by suicide after a pregnancy or postnatal loss, or after removal of their infant into care. For some women, pre-existing mental health conditions were exacerbated when their child was removed, and it is essential that care for the mother increases rather than decreases in these circumstances. On too many occasions the mother was forgotten once services were appropriately reassured that her child was safe.

Each of our organisations values the ability to contribute to developing the lay summary and associated infographics. The key messages are used not only to help empower and inform women and families, but as a focus for dissemination activities and to open conversations with policy makers and politicians to drive further improvements in care. We urge all readers to do the same with this main report.

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# Key messages

## from the report 2018



In 2014-16 **9.8 women** per 100,000 died during pregnancy or up to six weeks after childbirth or the end of pregnancy.

Most women who died had multiple health problems or other vulnerabilities.



### Balancing choices:

Always consider individual **benefits** and **risks** when making decisions about pregnancy

#### Things to think about:

Many medicines are **safe** during pregnancy

Continuing medication or preventing illness with vaccination may be the best way to keep both mother and baby healthy - ask a specialist

Black and Asian women have a higher risk of dying in pregnancy

White women		8/100,000
Asian women	<b>2x</b>	15/100,000
Black women	<b>5x</b>	40/100,000

Be body aware - some symptoms are normal in pregnancy but know the **red flags** and always seek specialist advice if symptoms persist

Older women are at greater risk of dying

Aged 20-24		7/100,000
Aged 35-39	<b>2x</b>	14/100,000
Aged 40 or over	<b>3x</b>	22/100,000

Overweight or obese women are at higher risk of blood clots including in early pregnancy

# Executive Summary

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## Introduction

This report, the fifth 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 2014 and 2016 in the UK. In addition, it also includes Confidential Enquiries into the care of women who died between 2014 and 2016 in the UK and Ireland from mental health conditions, thrombosis and thromboembolism, malignancy and homicide, as well as morbidity Confidential Enquiries into the care of women with major obstetric haemorrhage.

Surveillance information is included for 545 women who died during or up to one year after the end of pregnancy between 2014 and 2016. The care of 247 women who died and 34 with severe morbidity from major obstetric haemorrhage was reviewed in depth for the Confidential Enquiry chapters.

## Methods

Maternal deaths are reported to MBRRACE-UK, NIMACH or to MDE Ireland by the staff caring for the women concerned, or through other sources including coroners, procurators fiscal and media reports. In addition, identification of deaths is cross-checked with records from the Office for National Statistics and National Records of Scotland. Full medical records are obtained for all women who die as well as those identified for the Confidential Enquiry into Maternal Morbidity, and anonymised prior to undergoing confidential review. The anonymous records are reviewed by a pathologist, together with an obstetrician or physician as required to establish a woman's cause of death. 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 statistically non-significant increase in the overall maternal death rate in the UK between 2011–13 and 2014–16, which suggests that implementation of the recommendations of these reports is urgently needed to achieve a reduction in maternal deaths. Assessors judged that 28% of women who died and 12% of women surviving with major obstetric haemorrhage had good care. However, improvements in care may have made a difference to the outcome for 37% of women who died and 74% of women with major obstetric haemorrhage who survived. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals.**

Maternal deaths from direct causes are unchanged with no significant change in the rates between 2011–13 and 2014–16. Thrombosis and thromboembolism remain the leading cause of direct maternal death during or up to six weeks after the end of pregnancy.

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, with a mortality rate of 2.8 per 100,000 maternities (95% CI 2.2–3.5).



## Key areas for action

### Improving overall care

There is a five-fold difference in maternal mortality rates amongst women from Black ethnic backgrounds and an almost two-fold difference amongst women from Asian Ethnic backgrounds compared to white women. Urgent action is needed to address these disparities. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals.**

There is an urgent need to establish pathways for release of mental health records with the Chief Medical Officers and Departments of Health of Ireland and the four UK nations to MBRRACE-UK. **ACTION: Policy makers.**

There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, and during and after pregnancy. **ACTION: Policy makers, professional organisations.**

Decisions on continuing, stopping or changing medication in pregnancy should be made only after careful review of the benefits and risks of doing so, to both mother and infant. **ACTION: Professional organisations, all health professionals.**

### Improving care of women with haemorrhage

Women who have had a previous caesarean section who also have either placenta praevia or an anterior placenta underlying the old caesarean section scar at 32 weeks of gestation are at increased risk of placenta accreta and should be managed as if they have placenta accreta, with appropriate preparations for surgery made. **ACTION: Service planners/commissioners, service managers, health professionals.**

Any woman with suspected placenta praevia accreta should be reviewed by a consultant obstetrician and consultant anaesthetist in the antenatal period. The different risks and treatment options should have been discussed and a plan agreed. The plan should always be followed especially in the event of an emergency delivery. **ACTION: Service planners/commissioners, service managers, health professionals.**

Any woman going to theatre electively with suspected placenta praevia accreta should be attended by a consultant obstetrician and anaesthetist. If the delivery is unexpected, out-of-hours consultant obstetric and anaesthetic staff should be alerted and attend as soon as possible. **ACTION: Service managers, health professionals.**

Young women are vulnerable to pressure sores and care should be taken of pressure points in the obstetric population as well as other populations. **ACTION: Service managers, health professionals.**

### Improving prevention and treatment of thrombosis and thromboembolism

There is clear evidence that doctors and midwives find existing scoring systems for thromboembolic risk difficult to apply in practice. There is an urgent need for development of a tool to make the current risk assessment system simpler and more reproducible. **ACTION: Professional organisations, service planners/commissioners, service managers, health professionals.**

If women need thromboprophylaxis as soon as they become pregnant there should be clear pathways for them to access prescriptions and support to ensure compliance. **ACTION: Service planners/commissioners, service managers, health professionals.**

Women with a high BMI should be given information about the symptoms of VTE. **ACTION: Service planners/commissioners, service managers, health professionals.**

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. Risk assessment should be repeated if the woman is admitted to hospital for any reason or develops other intercurrent problems. Risk assessment should be repeated again intrapartum or immediately postpartum. **ACTION: Service managers, health professionals.**

Reassessment of VTE risk after miscarriage or ectopic pregnancy to consider whether thromboprophylaxis is required is as important as reassessment of risk after giving birth. **ACTION: Service managers, health professionals.**



## Improving care of women with mental health problems

Liaison, crisis and home treatment staff should have specific training, at induction and continuing professional development, in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women. Formal links should be made with local specialist perinatal mental health services to facilitate training. **ACTION: Service planners/commissioners, service managers, health professionals.**

Mental health services should work to minimise barriers to care for women in pregnancy and the postnatal period, recognising the need for lowered thresholds and direct access for maternity and primary care professionals. **ACTION: Service planners/commissioners, service managers, health professionals.**

Assessments should always include a review of previous history and always take into account the findings of recent presentations and escalating patterns of symptoms, their severity and any associated abnormal behaviour. **ACTION: Service managers, health professionals.**

Women should receive continuity of mental health care. Where more than one mental health team is involved, there should be a clearly identified individual who co-ordinates care. **ACTION: Service planners/commissioners, service managers, health professionals.**

In women facing multiple adversity, changes in frequency or nature of presentations may reflect worsening mental state or the emergence of new complications (such as alcohol or substance misuse or interpersonal violence), and should prompt renewed attempts at engagement, diagnosis and care co-ordination. **ACTION: Service managers, health professionals.**

New expressions or acts of violent self-harm, or new and persistent expressions of incompetency as a mother or estrangement from the infant are 'red flag' symptoms and should always be regarded seriously. **ACTION: Health professionals.**

## Improving care of women from vulnerable groups

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. **ACTION: Health professionals.**

Services should develop or adapt clear protocols and methods for sharing information, both within and between agencies, about people at risk of, experiencing, or perpetrating domestic violence and abuse. This is even more important with increasing use of electronic records to ensure all agencies involved in a woman's care are aware of her risk of domestic abuse. This would be further facilitated by support for the intra-operability of systems to support information sharing through electronic records. **ACTION: Service planners/commissioners, service managers, health professionals, police and safeguarding (social care) professionals.**

Women with complex and multiple 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. **ACTION: Service planners/commissioners, service managers, health professionals.**

The postnatal care plan for women with complex and multiple problems 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.**

## Improving care of women with malignancy

Repeated presentation with pain and/or pain requiring opiates should be considered a 'red flag' and warrant a thorough assessment of the woman to establish the cause. **ACTION: Health professionals.**

If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus. In such instances, a discussion of potential risks and benefits with the woman should be used to determine the most appropriate pathway of investigation. **ACTION: Service planners/commissioners, service managers, health professionals.**

For women with cancer, advice on postponement of pregnancy should be individualised and based on treatment needs and prognosis over time. Most women with breast cancer should wait at least two years after treatment, which is when the risk of breast cancer recurrence is highest. **ACTION: Service planners/commissioners, service managers, health professionals.**

Thrombosis, particularly migratory or in an unusual location, should be fully investigated as it may be a presenting sign of cancer in pregnancy or postpartum. **ACTION: Health professionals.**

Pregnant and postpartum women presenting to the emergency department with medical problems should be discussed with a member of the maternity medical team. **ACTION: Service managers, health professionals.**

All pregnant or postpartum women who are diagnosed with cancer should have the possibility of an underlying familial syndrome considered, particularly, but not only hereditary non-polyposis colorectal cancer, with appropriate investigations, including tumour testing, performed and family testing offered as appropriate. **ACTION: Service planners/commissioners, service managers, health professionals.**

## Conclusions

The themes of 'too much, too soon' and 'too little too late' represent the extremes of maternity care at which we need to focus to improve maternal health globally, and 'too little, too late' is clearly represented amongst the messages to improve care identified in this report. We see 'too little, too late' in the care of women with mental health problems, particularly thinking about the benefits that could be obtained by early identification of risk and putting in place postnatal review and monitoring strategies to allow early detection and treatment of potential relapse. There is very clear evidence of 'too little, too late' in the care of vulnerable women, particularly those who misuse drugs and alcohol, and in prevention of thromboembolism. The review of the care of women who survived severe haemorrhage reflects 'too little, too late' when recognition that a woman is bleeding is delayed. The almost five-fold higher mortality rate amongst black women compared with white women requires urgent explanation and hence development of actions to address this. There is a clear place for engaging further with third sector organisations to address advocacy and support needs for ethnic minority women as well as further research on the underlying causes of disparity.

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# Glossary of terms

<b>AFE</b>	Amniotic Fluid Embolism	<b>ICD</b>	International Classification of Diseases
<b>AIP</b>	Abnormally Invasive Placenta	<b>ICD-MM</b>	International Classification of Diseases – Maternal Mortality
<b>ALSO</b>	Advanced Life Support in Obstetrics	<b>IHP+</b>	Health Partnership and related initiatives
<b>BMI</b>	Body mass index	<b>IMD</b>	Index of Multiple Deprivation
<b>BP</b>	Blood pressure	<b>IOL</b>	Induction Of Labour
<b>CEMD</b>	Confidential Enquiries into Maternal Deaths	<b>IVF</b>	In vitro fertilisation
<b>CEMM</b>	Confidential Enquiries into Maternal Morbidity	<b>LMWH</b>	Low molecular weight heparin
<b>CI</b>	Confidence interval	<b>MBRRACE-UK</b>	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
<b>CMACE</b>	Centre for Maternal and Child Enquiries	<b>MBU</b>	Mother and Baby Unit
<b>CPAP</b>	Continuous positive airway pressure	<b>MDE</b>	Maternal Death Enquiry
<b>CPN</b>	Community psychiatric nurse	<b>MEMo</b>	Medical Emergencies in Obstetrics
<b>CRHT</b>	Crisis resolution and home treatment	<b>MEOWS</b>	Modified Early Obstetric Warning Score
<b>CT</b>	Computerised Tomography	<b>MMR</b>	Maternal mortality ratio
<b>CTPA</b>	Computerised tomography pulmonary angiogram	<b>mMOET</b>	Managing Medical and Obstetric Emergencies and Trauma
<b>DIC</b>	Disseminated intravascular coagulation	<b>MNI-CORP</b>	Maternal Newborn and Infant Clinical Outcome Review Programme
<b>DNA</b>	Deoxyribonucleic acid	<b>NHS</b>	National Health Service
<b>DVT</b>	Deep venous thrombosis	<b>NICE</b>	National Institute for Health and Care Excellence
<b>ECMO</b>	Extracorporeal membrane oxygenation	<b>NIMACH</b>	Northern Ireland Maternal and Child Health
<b>ECT</b>	Electroconvulsive therapy	<b>NMPA</b>	National Maternal and Perinatal Audit
<b>EWS</b>	Early warning scores	<b>PE</b>	Pulmonary embolism
<b>FAST</b>	Focussed Assessment with Sonography in Trauma	<b>PMCT</b>	Post mortem Computerised Tomography
<b>GCS</b>	Glasgow Coma Score	<b>PPH</b>	Postpartum Haemorrhage
<b>GP</b>	General practitioner	<b>PVA</b>	Polyvinyl alcohol
<b>HELLP</b>	Haemolysis, Elevated Liver enzymes, Low Platelet count		
<b>HES</b>	Hospital Episode Statistics		
<b>HQIP</b>	Healthcare Quality Improvement Partnership		
<b>HSE</b>	Health Service Executive		

## Key to colour coding

Vignettes concerning the care of women who died are described in blue boxes

Vignettes concerning the care of women who had severe morbidity but survived are described in purple boxes

**Recommendations are presented in green boxes.**

The majority of recommendations arise from existing national guidelines or previous reports and these are cited alongside the recommendation. Where no citation is given, the recommendation is based on improvements in care noted by MBRRACE reviewers for which there is no current national guidance. The recommendations identified by MBRRACE reviewers as the most frequently needed improvements are highlighted in the key messages section at the start of each chapter. The specific individuals or professional groups who need to take action are indicated alongside the key messages, where appropriate.

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# 1. Introduction and methodology

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Marian Knight

## 1.1 The 2018 Saving Lives, Improving Mothers' Care report

The 2016 Lancet series on maternal health (The Lancet Maternal Health Series study group 2016) highlighted the themes of 'too much, too soon' and 'too little too late' representing the extremes of maternity care on which we need to focus to improve maternal health globally. It is striking that both are evident in the messages identified in this report. We see 'too little, too late' in the care of women with mental health problems, particularly thinking about the benefits that could be derived by early identification of risk and putting in place postnatal review and monitoring strategies to allow early detection and treatment of potential relapse. There is very clear evidence of 'too little, too late' in the care of vulnerable women, particularly those who misuse drugs and alcohol; on several occasions healthcare staff were unable to see beyond the women's substance misuse problems to identify additional underlying illness.

The theme of 'too little, too late' is also reflected amongst the messages for prevention of thrombosis and thromboembolism. Whilst in both the UK and Ireland we have very detailed guidelines about assessment of women's risk and prescription of thromboprophylaxis at different stages of pregnancy and the postpartum period (Royal College of Obstetricians and Gynaecologists 2015a, Royal College of Obstetricians and Gynaecologists 2015b, Institute of Obstetricians and Gynaecologists Royal College of Physicians of Ireland, HSE Clinical Care Programme in Obstetrics and Gynaecology et al. 2016), there is confusion around their application. The guidelines are clearly being interpreted variably in different hospitals and by different clinicians, with the result that women are not necessarily getting the thromboprophylaxis they need, or for too short a time (too little) or after a delay (too late). The challenge remains of how to ensure women with risk factors very early in pregnancy can access thromboprophylaxis; a substantial proportion of deaths from thromboembolism continue to occur in the first trimester before women have accessed either their GP or maternity care. This emphasises the importance of ongoing public health interventions to address risk factors such as obesity and smoking, and further consideration of the impact of rising maternal age.

It is encouraging, however, that 'too little, too late' in the care of women with malignancy was a much less prominent theme in this report compared with the 2015 report (Knight, Tuffnell et al. 2015); there was evidence that women received appropriate treatment, particularly chemotherapy, and it was not being delayed simply because women were pregnant or postpartum.

'Too much, too soon' is, in contrast, a possible issue when considering severe maternal haemorrhage. This report includes a confidential enquiry into the care of women with major obstetric haemorrhage, all of whom survived. The majority of the women reviewed had haemorrhage in relation to a complication of caesarean section, either because of abnormally invasive placentation, linked to a previous caesarean birth, or because of complicated angle tears which occurred at caesarean section undertaken in the late stages of labour. 'Too much, too soon' was also evident in some of the other causes of haemorrhage, for example several women had haemorrhage following uterine hyperstimulation. Additional evidence of 'too much, too soon' was seen when examining fluid replacement during and after haemorrhage; over-replacement with crystalloids led to the development of pulmonary oedema in several women. However, 'too little, too late' was more evident in these women's care. On many occasions the fact that women were bleeding was not recognised, often due to concealed bleeding which was apparent from deteriorating vital signs but these were missed, indicating an ongoing need to improve identification of deterioration through physiological measures. Perhaps most concerning on the theme of 'too little, too late' is the fact that young, previously healthy women are left with pressure sores after management of their haemorrhage due to lack of consideration of the need to manage pressure points.

Once again the Enquiry did not identify any disparity in maternal mortality rates between women born in the UK and those born in other countries, which is an encouraging reflection of universal health care free at the point of access. However, there still remains a large disparity between the maternal mortality rate of women of white ethnicity compared to women from black and Asian ethnic groups. The almost five-fold higher mortality rate amongst black women compared with white women requires urgent explanation and action. Previous research has suggested that this inequality of outcome may be partly explained by gestational diabetes during their current pregnancy, medical comorbidities, previous pregnancy prob-

lems and inadequate use of antenatal care, all of which could provide an initial focus for action to reduce this inequality (Nair, Knight et al. 2016). Nevertheless there is a clear place for engaging further with third sector organisations to address advocacy and support needs for ethnic minority women as well as further research on the underlying causes of these disparities.

## 1.2 Actions following the release of the 2014-2017 reports



A major announcement in England made after the 2017 report (Knight, Nair et al. 2017) went to press was the introduction of maternal medicine networks (Department of Health 2017). The vision to develop 12 regional maternal medicine networks, and funding to train the required medical professionals was developed directly on the basis of recommendations from the maternal Enquiry reports. Alongside the announcement of the networks, funding was announced to train 12 consultant physicians as obstetric physicians to work alongside obstetricians specialising in maternal medicine to deliver the essential multi-disciplinary care needed to begin to address the improvements in care needed for pregnant and postpartum women with medical co-morbidities.

Linked to the need to improve care for women with pre-existing or new onset medical conditions, and the increasing recognition of 'human factors' underlying many maternal deaths, an evaluation of a new multi-disciplinary simulation-based training programme designed to address Medical Emergencies in Obstetrics (MEMO) (Lavelle, Abthorpe et al. 2018), specifically designed to address the recommendations of the 2014 report (Knight, Kenyon et al. 2014), showed that

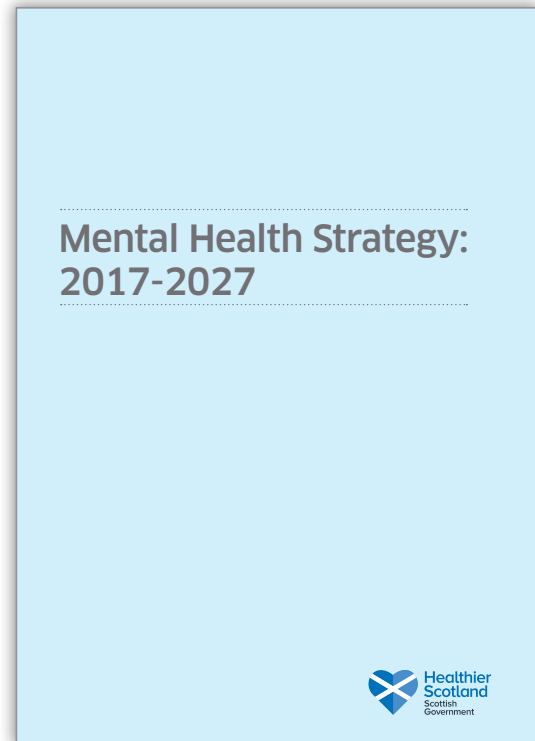
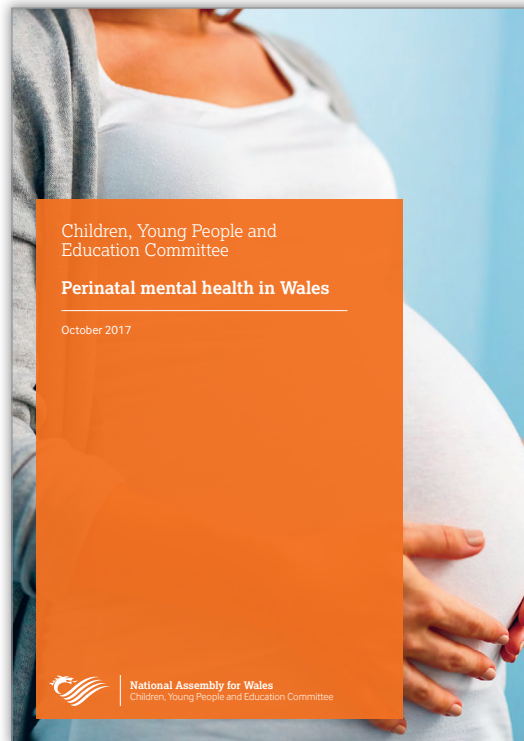
the training improved the participants' management of medical deterioration in pregnancy as well as their awareness of human

factors. In a similar development, the Managing Medical and Obstetric Emergencies and Trauma (mMOET) course has been renamed to highlight the need to address medical emergencies together with the trauma components of the course (Advanced Life Support Group 2016).

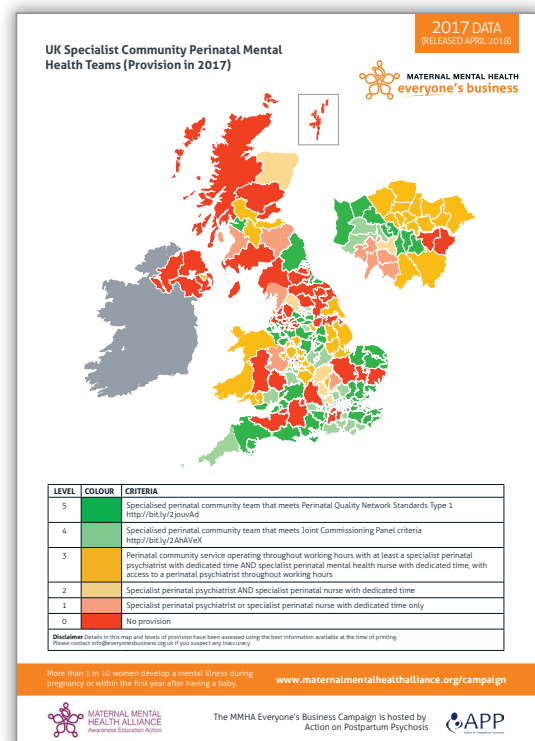
In November 2017 the Health Service Executive in the Republic of Ireland launched a new model of care for perinatal mental health services, including for the first time plans for an inpatient mother and baby unit, a facility not previously available to women in Ireland (Health Service Executive 2017). The new planned service includes specialist perinatal mental health services aligned with maternity networks across the whole country. The importance of access to specialist perinatal mental health services for women for both prevention and treatment of mental health problems in pregnancy and the postpartum period has repeatedly been highlighted in these reports (Knight, Tuffnell et al. 2015, Knight, Nair et al. 2017), and is reiterated once again in chapter 5.



The Scottish Government also committed to funding the introduction of a Managed Clinical Network to improve the recognition and treatment of perinatal mental health problems in its 2017 Mental Health Strategy (The Scottish Government 2017).



In response to a report from the National Assembly for Wales (Children Young People and Education Committee 2017), the Welsh Government has also agreed to further support the development of perinatal mental health services in Wales, in particular recognising the need for a new Mother and Baby Unit in southern Wales (Gething 2018). Alongside these reports, the Maternal Mental Health Alliance has updated its mapping exercise, which shows that gaps still exist in the provision of perinatal mental health services with more action still needed (Maternal Mental Health Alliance 2017). Other reviews have highlighted the need for an inpatient mother and baby unit in Northern Ireland (The Regulation and Quality Improvement Authority 2017). The Perinatal Mental Health Care Pathway for Northern Ireland was revised in July 2017.



### 1.3 Topics covered in MBRRACE-UK maternal reports 2014-18

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 second of the next three-year cycle:

- **2014 report:** Surveillance data on maternal deaths from 2009-12. Confidential Enquiry reports on severe morbidity 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 report:** Surveillance data on maternal deaths from 2013-15. Confidential Enquiry reports on severe morbidity from psychosis, severe morbidity and deaths from epilepsy, deaths from haemorrhage, amniotic fluid embolism (AFE), anaesthesia, stroke, respiratory, endocrine and other indirect causes.
- **2018 (this report):** Surveillance data on maternal deaths from 2014-16. Confidential Enquiry reports on deaths from psychiatric causes, deaths due to thrombosis and thromboembolism, malignancy and homicides, and morbidity from major obstetric haemorrhage.

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/mbrance-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/mbrance-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 major obstetric haemorrhage were identified from an existing UKOSS study of massive transfusion in major obstetric haemorrhage, which identified women fulfilling the criteria in Box 1.1 between July 2012 and June 2013 (Green, Knight et al. 2016).

#### **Box 1.1: Case definition used in the UKOSS massive transfusion for major obstetric haemorrhage study**

Any pregnant woman of 20 weeks gestation or more identified as having 8 or more units of RBC transfusion (excluding cell salvage) within a 24 hour period.

All surviving women notified nationally were used as the sampling frame. A geographically representative sample of 40 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 34 of 40 requested sets of records; the care of these 34 women is described in Chapter 3.



## 2. Maternal Mortality in the UK 2014–16: Surveillance and Epidemiology

Kathryn Bunch and Marian Knight

### 2.1 Key points

There was a statistically non-significant increase in the overall maternal death rate in the UK between 2011-13 and 2014-16, which suggests that implementation of the recommendations of these reports is urgently needed to achieve a reduction in maternal deaths. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals.**

There is a five-fold difference in maternal mortality rates amongst women from black ethnic backgrounds and an almost two-fold difference amongst women from Asian Ethnic backgrounds compared to white women. Urgent action is needed to address these disparities. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals.**

Maternal deaths from direct causes are unchanged with no significant change in the rates between 2011-13 and 2014-16. Thrombosis and thromboembolism remain the leading cause of direct maternal death during or up to six weeks after the end of pregnancy.

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.

For almost one fifth of women who died in 2016, there was no evidence they had been asked about a history of mental health problems. Eliciting any relevant history is essential to ensure appropriate proactive management of risk of mental health problems. **ACTION: All health professionals.**

### 2.2 Causes and trends

Overall, 259 women died in 2014-16 during or within 42 days of the end of pregnancy in the UK. The deaths of 34 women were classified as coincidental. Thus in this triennium 225 women died from direct and indirect causes, classified using ICD-MM (World Health Organisation 2012), among 2,301,628 maternities, a maternal death rate of 9.78 per 100,000 maternities (95% CI 8.54 – 11.14). This compares to the rate of 8.76 per 100,000 maternities (95% CI 7.59 – 10.05) in 2013-15. As in previous MBRRACE-UK maternal 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 remains an overall decrease in maternal death rates between 2003-05 and 2014-16 (rate ratio (RR) 0.70, 95% CI 0.59-0.84;  $p=0.002$  for trend in rolling rates over time). The direct maternal death rate has decreased by 37% since 2003-05 with a RR of 0.63 (95% CI 0.48-0.82,  $p=0.009$ ) and there was a 23% decrease in the rate of indirect maternal deaths (RR 0.77, 95% CI 0.60 to 0.98,  $p=0.018$ ).

However, the rates of overall mortality, direct and indirect maternal death in the 2014-16 triennium were not significantly different from the rates in 2011-13, the immediately preceding triennium (RR for overall mortality = 1.08, 95% CI = 0.90 to 1.31,  $p=0.398$ ; RR for direct deaths = 1.22, 95% CI = 0.90 to 1.65; RR for indirect deaths = 1.00, 95% CI = 0.78 to 1.29,  $p=0.998$ ).

All cause-specific rates have seen a statistically non-significant increase over the past few years, with overall maternal death rates now on a par with those in 2010-12, indirect maternal death rates on a par with 2011-13 and direct maternal death rates on a par with 2008-10. Detailed analysis shows that the changes in rates are due to small increases in numbers of women dying from most causes of death, both direct and indirect, none of which are individually statistically significant. The nadir in the overall UK maternal mortality rate was observed in 2012-14, and this highlights further the challenge of achieving the Government ambition of reducing maternal deaths in England by 50% by 2025 (Department of Health 2017).

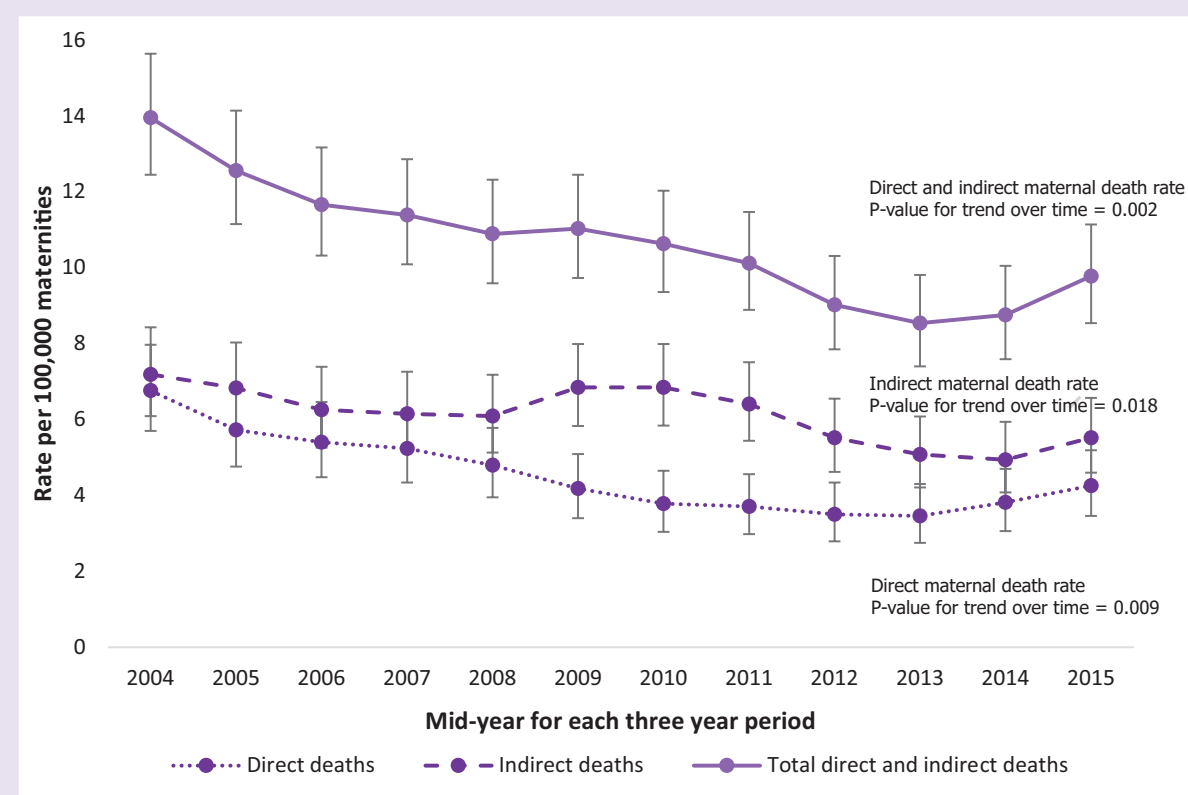
Triennial rates are shown in Table 2.2 and Figure 2.2. A comparison of figures 2.1 and 2.2 clearly shows the benefit of annual monitoring and presentation of rolling three-year rates.

**Table 2.1: Rolling three-year average direct and indirect maternal mortality rates per 100,000 maternities, deaths classified using ICD-MM; UK 2003–16**

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
2014–16	2 301 628	98	4.26	3.46–5.19	127	5.52	4.60–6.57	225	9.78	8.54–11.14

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 2003–2016**



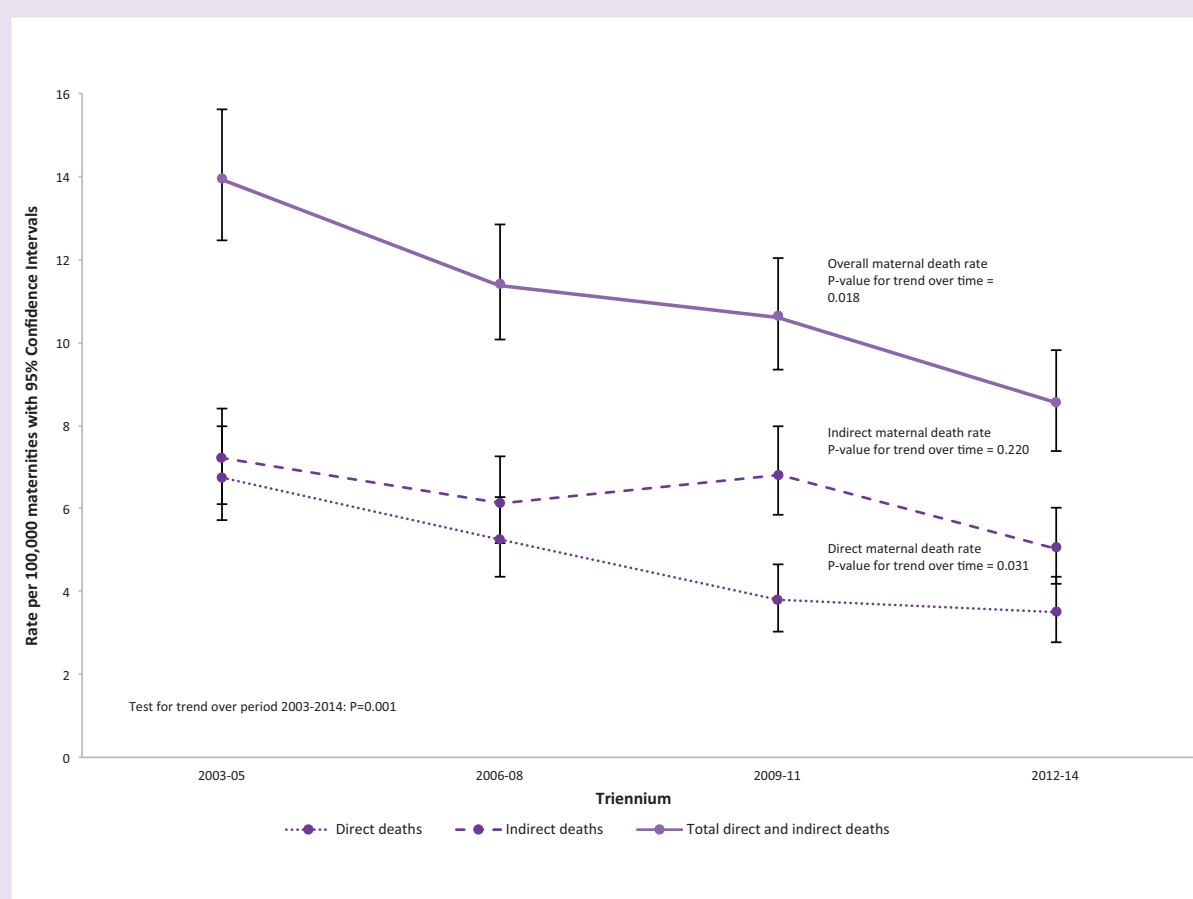
Sources: CMACE, MBRRACE-UK

**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)**

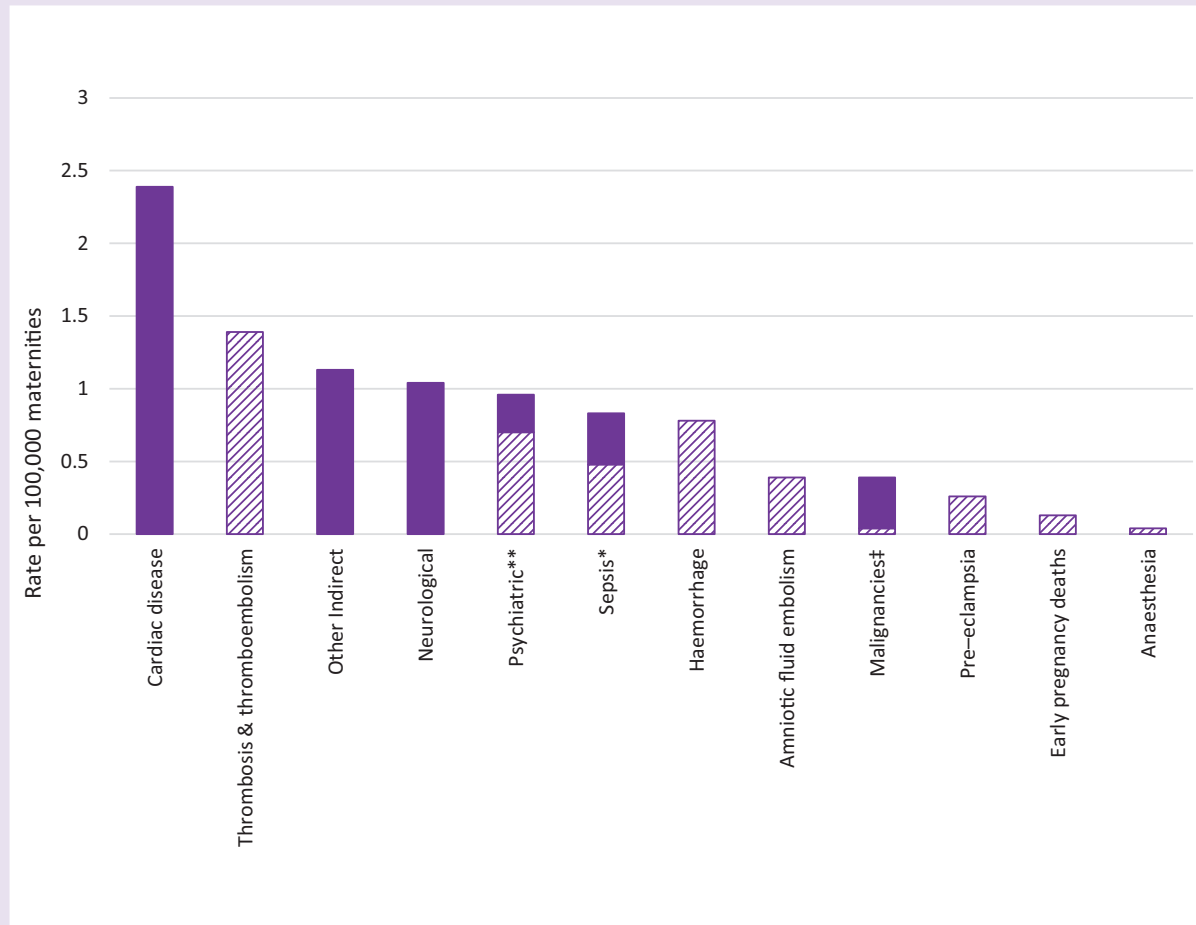


Sources: CMACE, MBRRACE-UK

## 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 (2010-12, 2011-13, 2012-14, 2013-15 and 2014-16) (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 and 2017 reports; 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 2014-16**



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

‡Rate for direct malignancies (choriocarcinoma) shown in hatched and rate for indirect malignancies (breast/ovary/cervix) in solid bar

Source: MBRRACE-UK

**Table 2.3: Maternal mortality rates by cause, per 100,000 maternities, 2010 to 2016**

Cause of death	2010-12			2011-13			2012-14			2013-15			2014-16		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
<b>All Direct and Indirect deaths</b>	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	225	9.78	8.54-11.14
<b>Direct deaths</b>															
Pregnancy related infections - Sepsis*	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	11	0.48	0.24-0.86
Pre-eclampsia and eclampsia	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	6	0.26	0.10-0.57
Thrombosis and thromboembolism	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	32	1.39	0.95-1.96
Amniotic fluid embolism	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	9	0.39	0.18-0.74
Early pregnancy deaths	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	3	0.13	0.03-0.38
Haemorrhage	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	18	0.78	0.46-1.24
Anaesthesia	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	1	0.04	0.001-0.24
Psychiatric causes - Suicides	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	16	0.70	0.40-1.13
Malignancy - direct													1	0.04	0.001-0.24
Unascertained - direct	-	-	-	-	-	-	-	-	-	2	0.09	0.01-0.31	1	0.04	0.001-0.24
<b>All Direct</b>	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	98	4.26	3.46-5.19
<b>Indirect</b>															
Cardiac disease	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	55	2.39	1.80-3.11
Indirect Sepsis - Influenza	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	2	0.09	0.01-0.31
Indirect Sepsis-Pneumonia/ others	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	6	0.26	0.10-0.57
Other Indirect causes	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	26	1.13	0.74-1.66
Indirect neurological conditions	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	24	1.04	0.67-1.55
Psychiatric causes-Drugs/alcohol/others	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	6	0.26	0.10-0.57
Indirect malignancies	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	8	0.35	0.15-0.69
<b>All Indirect</b>	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	127	5.52	4.60-6.57
<b>Coincidental</b>															
Homicide	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	10	0.43	0.21-0.80
Other coincidental	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	24	1.04	0.67-1.55
All coincidental	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	34	1.48	1.02-2.06
<b>Late deaths</b>	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	286	12.43	11.03-13.95

\*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, National Records 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, 2010 to 2016**

Cause of death	2010-12			2011-13			2012-14			2013-15			2014-16		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
<b>Direct causes</b>															
Group 1: Pregnancy with abortive outcome	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	3	0.13	0.03-0.38
Group 2: Hypertensive disorders	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	6	0.26	0.10-0.57
Group 3: Obstetric Haemorrhage	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	18	0.78	0.46-1.24
Group 4: Pregnancy-related infection	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	11	0.48	0.24-0.86
Group 5: Other obstetric complications	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	59	2.56	1.95-3.31
Group 6: Unanticipated complications of management	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	1	0.04	0.001-0.24
<b>Indirect causes</b>															
Group 7: Non-obstetric complications	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	127	5.52	4.60-6.57
Group 8: Unknown/undetermined	0	0	-	0	0	-	0	0	-	0	0	-	0	-	-
<b>Coincidental causes</b>															
Group 9: Coincidental causes	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	34	1.48	1.02-2.06

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



## Direct deaths

There was no statistically significant change in the rate of direct maternal deaths from any cause between 2009 and 2016. 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 mortality rate from thrombosis and thromboembolism is now the same as it was in 1985-87, possibly reflecting the increased prevalence of risk factors for VTE in the UK maternity population, emphasising the importance of the messages outlined in chapter 4. Maternal death rates from suicide remain unchanged; these women's deaths are reviewed in detail in chapter 5. The rate of maternal mortality from haemorrhage is not significantly different from the rate in 2011-13 (RR 1.43, 95% CI 0.70-2.91), but in the absence of a decrease in rate the messages identified in chapter 3 for improving care for women with haemorrhage remain pertinent. The maternal death rate from pre-eclampsia and eclampsia continues to be low but there is no evidence of an ongoing decrease in the mortality rate.

## Indirect deaths

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 has been no change in the maternal mortality rate from cardiac disease since enhanced case ascertainment was introduced (RR 1.05, 95% CI 0.71-1.55 when comparing 2003-05 with 2014-16). Cardiac disease will be a focus of the 2019 report.

## Coincidental deaths

Most women's deaths from malignancy during or after pregnancy are classified as coincidental deaths, however, when all causes of malignancy are considered together, the overall pregnancy-related mortality rate is 4.4 per 100,000 maternities (95% CI 3.6-5.4; 102 women died between 2014-16 from malignancy). Many messages for improving their care have been identified and these are considered in chapter 7. Women who are murdered are also considered within the group of coincidental deaths. Ten women were murdered during or up to six weeks after pregnancy in the UK in 2014-16, all by a partner or former partner. This equates to a mortality rate of 0.43 per 100,000 maternities (95% CI 0.21-0.80), which is very similar to the mortality rate from direct causes of maternal sepsis. Identifying and preventing domestic violence, as discussed in chapter 6, is essential to prevent these women's deaths.

## 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

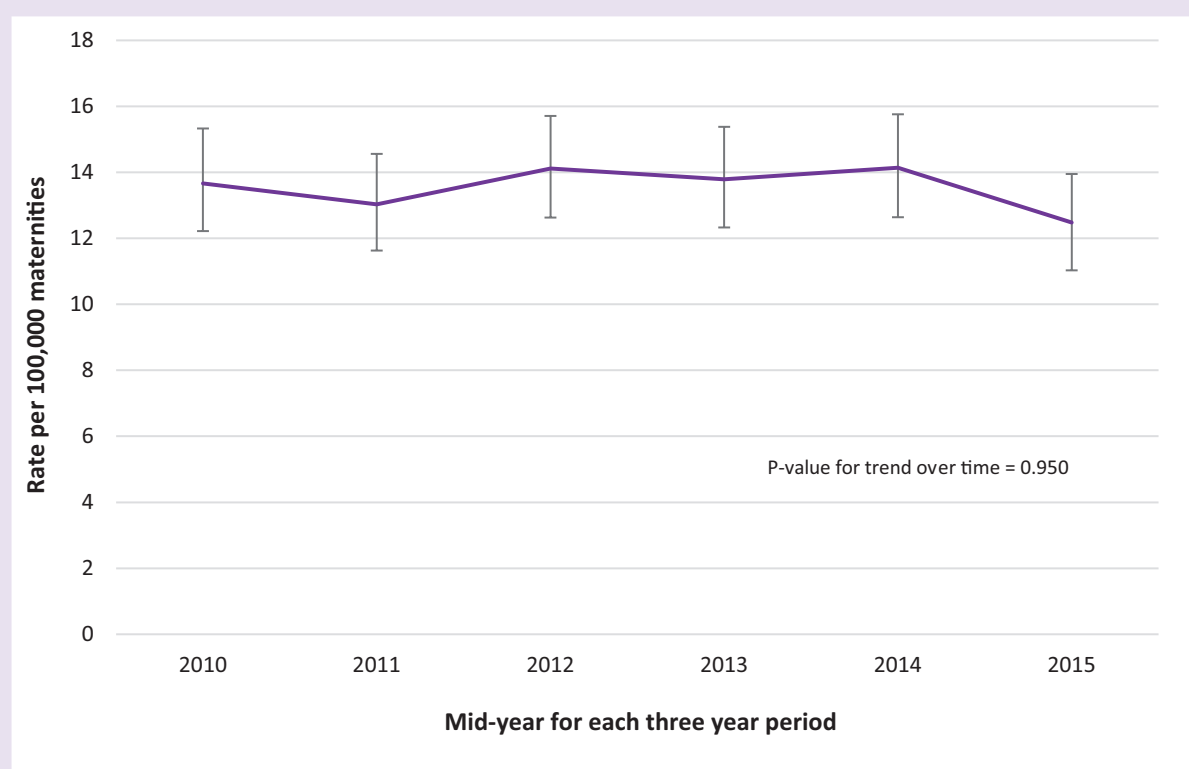
Source: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

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

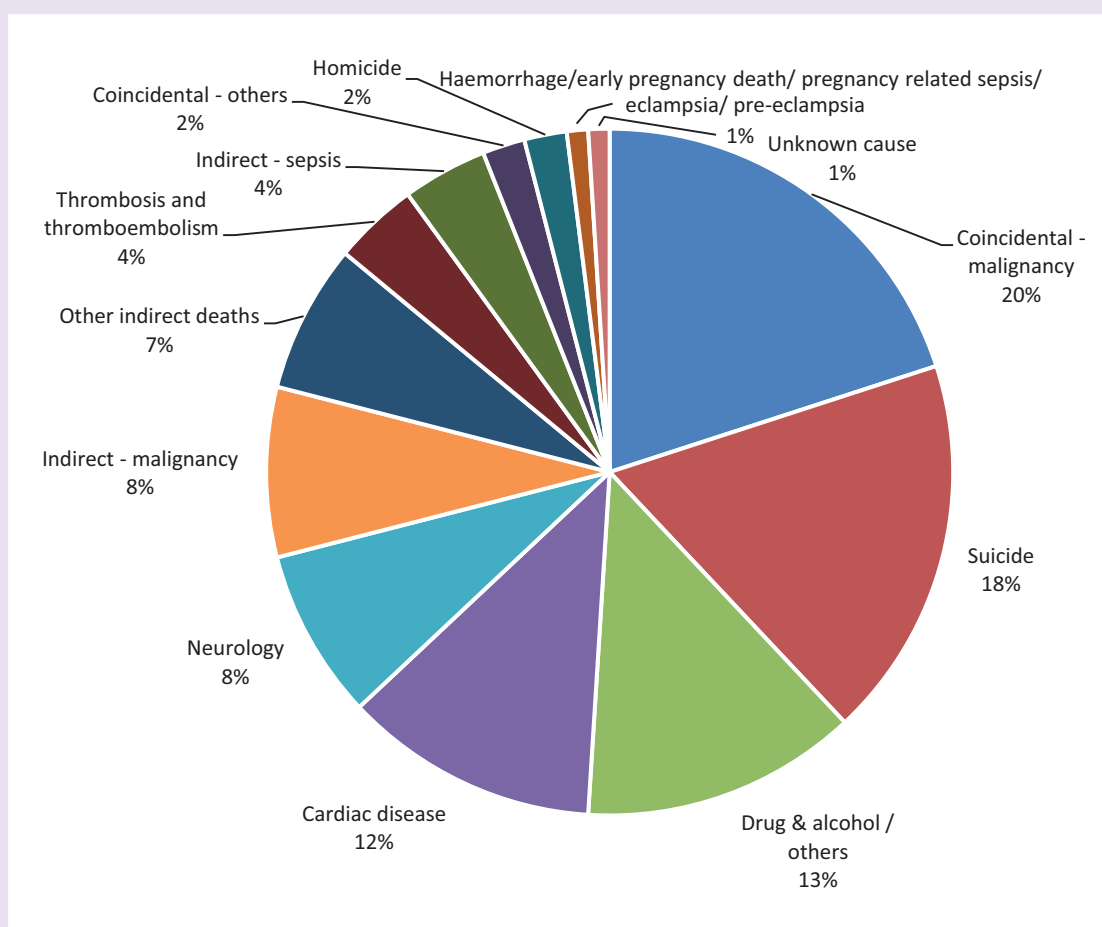
## Women who died between six weeks and one year after the end of pregnancy

In the triennium 2014-16, 286 women died between six weeks and one year after the end of pregnancy, representing a mortality rate of 12.4 per 100,000 maternities (95% CI 11.0 – 14.0). This represents a non-significant 12% reduction compared with 2011-13 (RR 0.88, 95% CI 0.75-1.03). Rolling rates of late deaths are shown in figure 2.4 and causes of late death in Figure 2.5. 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: Pregnancy-related maternal mortality rates six weeks to one year after the end of pregnancy, UK, 2009-2016**



**Figure 2.5: Causes of death amongst women who died between six weeks and one year after the end of pregnancy, UK 2014-16**



## 2.3 The characteristics of women who died 2014-16

### The women and babies

Of the 225 women who died from direct and indirect causes during or up to 42 days after the end of their pregnancy in 2014-16, 28% (64 women) were still pregnant at the time of their death and of these women 63% were  $\leq 20$  weeks' gestation (Table 2.7). Twelve (5%) women had a pregnancy loss at  $\leq 20$  weeks' gestation. The remaining 149 women gave birth to a total of 158 infants, 114 (72%) survived, 44 died (31 babies were stillborn and 13 died in the neonatal period). The 225 women who died left behind a further 254 children, thus a total of 368 motherless children remain. The majority of women who gave birth did so in hospital (81%); 16% of women gave birth in an emergency department or an ambulance, and 3% at home (Table 2.8). In this triennium 106 of the women who died were delivered by caesarean section, 42% of these were performed perimortem as part of attempted resuscitation. A total of 46 babies were born by perimortem caesarean section of which 21 (46%) were born after 32 weeks of gestation. Nine out of the 21 babies born after 32 weeks' gestation survived (8 were stillborn and 4 died in the neonatal period) and three out of the remaining 25 born at 32 weeks or less survived (16 were stillborn and 6 died in the neonatal period). Thus 26% of the total 46 babies delivered by perimortem caesarean section survived (52% were stillborn and 22% died in the neonatal period).

**Table 2.7: Timing of maternal deaths in relation to pregnancy 2014-16**

Time period of deaths in the pregnancy care pathway	Direct (n=98) Frequency (%)	Indirect (n=127) Frequency (%)	Total (n=225) Frequency (%)
Antenatal period			
≤20 weeks	15 (15)	25 (20)	40 (18)
>20 weeks	7 (7)	17 (13)	24 (11)
Postnatal on day of delivery	29 (30)	28 (22)	57 (25)
Postnatal 1–41 days after delivery	47 (48)	57 (45)	104 (46)

**Table 2.8: Place of birth amongst women >20 weeks' gestation who died after birth 2014-16**

Place of birth (for women who had a childbirth)	Direct (n=68) Frequency (%)	Indirect (n=81) Frequency (%)	Total (n=149) Frequency (%)
Home	2(3)	2 (2)	4 (3)
Hospital (except Emergency Department)	58 (85)	62 (77)	120 (81)
Emergency Department or ambulance	8 (12)	16 (20)	24 (16)
Not known	0 (0)	1 (1)	1 (1)

## Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2014-16 are shown in Table 2.9. The proportion of women who did not have information on whether they were subject to domestic abuse before or during pregnancy was 36%. Domestic abuse is considered further in chapter 6.

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). There remain statistically significant differences in the maternal mortality rates between women living in the most deprived areas and those living in the least deprived areas. As noted in the 2016 report, we are no longer able to obtain denominator figures for the specific ethnic groups, instead aggregate rates using larger ethnicity groupings are presented in Tables 2.10 and 2.11. The risk of maternal death in 2014-16 is yet again significantly almost five-fold higher among women from black ethnic minority backgrounds compared with white women (RR 4.93; 95% CI 3.27 to 7.26). Women from Asian backgrounds are also at higher risk than white women (RR 1.81, 95% CI 1.16 to 2.73). There were significant increases in the relative risk of maternal death in the third and fourth IMD quintiles in this triennium compared with 2011-13, otherwise 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 the inequality gaps remain. Further research is needed to fully understand the reasons for these disparities and hence to develop actions to address them.

A quarter of women who died in 2014-16 (24%) were born outside the UK; 42% of these women were not UK citizens. Overall 11% of the women who died were not UK citizens. Women who died who were born abroad and who were not UK citizens had arrived in the UK a median of 3.5 years before they died (range 3 months to 18 years). Women who died who were born abroad were from Asia (32%, mainly Pakistan and India) and Africa (37%, mainly Nigeria, Eritrea, Sierra Leone and South Africa), Eastern Europe (16%, mostly from the Czech Republic, Poland and Romania) with the remainder from other parts of Europe, 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 2014-16. 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 were born outside the UK, 3 were refugees/asylum seekers (13%), 6 (25%) were recently arrived wives of UK residents, 6 were EU citizens (25%) and 9 (38%) had another or unknown status.

It is also of note that 16% of women who died were known to social services, highlighting further the vulnerability of many women who died.

**Table 2.9: The socio-demographic characteristics of women who died 2014-16**

Characteristics	Direct (n=98) Frequency (%)	Indirect (n=127) Frequency (%)	Total (n=225) Frequency (%)
<b>Age (years)</b>			
<20	3 (3)	6 (5)	9 (4)
20–24	9 (9)	17 (13)	26 (12)
25–29	20 (20)	33 (26)	53 (24)
30–34	25 (26)	35 (28)	60 (27)
35–39	29 (30)	27 (21)	56 (25)
≥ 40	12(12)	9 (7)	21 (9)
<b>Parity</b>			
0	35 (36)	44 (35)	79 (35)
1 to 2	42 (43)	56 (44)	98 (44)
≥3	14 (14)	18 (14)	32 (14)
Missing	7 (7)	9 (7)	16 (7)
<b>UK citizen</b>			
Yes	77 (79)	106 (83)	183 (81)
No	11 (11)	13 (10)	24 (11)
Missing	10 (10)	8 (6)	18 (8)
<b>Ethnicity</b>			
White European	63 (64)	83 (65)	146 (65)
Indian	3 (3)	7 (6)	10 (4)
Pakistani	6 (6)	8 (6)	14 (6)
Bangladeshi	1 (1)	2 (2)	3 (1)
Other Asian	4 (4)	0 (0)	4 (2)
Black Caribbean	6(6)	2 (2)	8 (4)
Black African	6 (6)	17 (13)	23 (10)
Others/ Mixed	5 (5)	6 (5)	11 (5)
Missing	4 (4)	2 (2)	6 (3)
<b>Woman's region of birth</b>			
United Kingdom	59 (60)	83 (65)	142 (63)
Eastern Europe	7 (7)	2 (2)	9 (4)
Western Europe	1 (1)	1 (1)	2 (1)
Asia	9 (9)	9 (7)	18 (8)
Africa	4 (4)	17 (13)	21 (9)
Australia and North America	0 (0)	1 (1)	1 (0)
Central & South America & Caribbean	5 (5)	1 (1)	6 (3)
Missing	13 (13)	13 (10)	26 (12)
<b>Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)</b>			
First quintile (Least deprived)	4 (4)	6 (5)	10 (4)
Second quintile	5 (5)	15 (12)	20 (9)
Third quintile	15 (15)	23 (18)	38 (17)
Fourth quintile	25 (26)	29 (23)	54 (24)
Fifth quintile (Most deprived)	24 (24)	38 (30)	62 (28)
Missing	25 (26)	16 (13)	41 (18)
<b>Socioeconomic status (Occupational classification)</b>			
Employed (Either woman or partner)	58 (59)	67 (53)	125 (56)
Unemployed (Both)	20 (20)	24 (19)	44 (20)
Missing	20 (20)	36 (28)	56 (25)
<b>Able to speak/understand English</b>			
Yes	91 (93)	124 (98)	215 (96)
No	7 (7)	0 (0)	7 (3)
Missing	0 (0)	3 (2)	3 (1)
<b>Living arrangements</b>			
With partner	72 (73)	90 (71)	162 (72)
Living alone	9 (9)	19 (15)	28 (12)
With parents/extended family	9 (9)	11 (9)	20 (9)
Others	1 (1)	1 (1)	2 (1)
Missing	7 (7)	6 (5)	13 (6)
<b>Domestic abuse (prior to pregnancy/ during pregnancy)</b>			
Yes	10 (10)	8 (6)	18 (8)
No	52 (53)	73 (57)	125(56)
Missing	36 (37)	46 (36)	82 (36)
<b>Known to social services</b>			
Yes	16 (16)	21 (17)	37 (16)
No	78 (80)	101 (80)	179 (80)
Missing	4 (4)	5(4)	9 (4)

**Table 2.10: Maternal mortality rates amongst different population groups 2014–16**

	Total maternities 2014-16	Total deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
Age (years)						
<20	81,185	9	11.1	5.07 to 21.04	1.53	0.63 to 3.36
20–24	357,941	26	7.26	4.74 to 10.64	1 (Ref)	-
25–29	651,355	53	8.14	6.10 to 10.64	1.12	0.69 to 1.87
30–34	720,962	60	8.32	6.35 to 10.71	1.15	0.71 to 1.89
35–39	395,374	56	14.16	10.70 to 18.39	1.95	1.20 to 3.24
≥ 40	94,723	21	22.17	13.72 to 33.89	3.05	1.63 to 5.64
IMD Quintiles (England only)						
<i>I (Least deprived/highest 20%)</i>	276162	9	3.26	1.49 to 6.19	1 (Ref)	-
<i>II</i>	306896	17	5.54	3.23 to 8.87	1.70	0.72 to 4.33
<i>III</i>	349005	35	10.03	6.99 to 13.95	3.08	1.45 to 7.28
<i>IV</i>	422310	50	11.84	8.79 to 15.61	3.63	1.77 to 8.40
<i>V (Most deprived/lowest 20%)</i>	510542	54	10.58	7.95 to 13.80	3.25	1.59 to 7.48
Ethnic group (England only)						
<i>White (inc. not known)</i>	1,529,881	123	8.04	6.68 to 9.59	1 (Ref)	-
<i>Asian</i>	199,661	29	14.52	9.73 to 20.86	1.81	1.16 to 2.73
<i>Black</i>	85,735	34	39.66	27.47 to 55.41	4.93	3.27 to 7.26
<i>Chinese/ others</i>	75,235	4	5.32	1.45 to 13.61	0.66	0.18 to 1.74
<i>Mixed</i>	30,639	5	16.32	5.30 to 38.08	2.03	0.65 to 4.87

**Table 2.11: Comparing the relative risk of maternal death among different population groups between 2011-13 and 2014-16**

	2011-13		2014-16		Ratio of the relative risks (RRR) (comparing 2014-16 with 2011-13)	95% CI	P-value
	Relative risk (RR)	95% CI	Relative risk (RR)	95% C			
Age (years)							
<20	1.33	0.51 to 3.08	1.53	0.63 to 3.36	1.15	0.34 to 3.93	0.823
20–24	1 (Ref)	-	1 (Ref)	-	-	-	-
25–29	1.40	0.84 to 2.41	1.12	0.69 to 1.87	0.80	0.39 to 1.65	0.547
30–34	1.67	1.02 to 2.82	1.15	0.71 to 1.89	0.69	0.34 to 1.39	0.301
35–39	2.53	1.52 to 4.33	1.95	1.20 to 3.24	0.77	0.37 to 1.59	0.480
≥ 40	3.69	1.90 to 7.09	3.05	1.63 to 5.64	0.83	0.33 to 2.04	0.680
IMD Quintiles (England only)							
<i>I (Least deprived/highest 20%)</i>	1 (Ref)	-	1 (Ref)	-	-	-	-
<i>II</i>	0.89	0.47 to 1.71	1.70	0.72 to 4.33	1.91	0.63 to 5.77	0.251
<i>III</i>	0.77	0.40 to 1.47	3.08	1.45 to 7.28	4.00	1.42 to 11.28	0.009
<i>IV</i>	1.35	0.79 to 2.35	3.63	1.77 to 8.40	2.69	1.04 to 6.96	0.041
<i>V (Most deprived/lowest 20%)</i>	1.44	0.87 to 2.46	3.25	1.59 to 7.48	2.26	0.89 to 5.73	0.087
Ethnic group (England only)							
<i>White (inc. not known)</i>	1 (Ref)	-	1 (Ref)	-	-	-	-
<i>Asian</i>	1.64	1.04 to 2.50	1.81	1.16 to 2.73	1.10	0.60 to 2.04	0.752
<i>Black</i>	3.46	2.17 to 5.31	4.93	3.27 to 7.26	1.42	0.78 to 2.59	0.247
<i>Chinese/ others</i>	0.55	0.11 to 1.65	0.66	0.18 to 1.74	1.20	0.21 to 7.02	0.840
<i>Mixed</i>	0.43	0.01 to 2.43	2.03	0.65 to 4.87	4.72	0.25 to 88.00	0.298

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

Woman's country of birth	Maternities 2014-16	Total Deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
UK	1,695,266*	142	8.38	7.06 to 9.87	1 (Ref)	-
Outside UK	606,362*	57	9.40	7.12 to 12.18	1.12	0.81 to 1.54
Specific countries						
<i>Eritrea</i>	3241 <sup>‡</sup>	3	92.56	19.09 to 270.27	11.05	2.25 to 32.96
<i>India</i>	42687 <sup>‡</sup>	3	7.03	1.45 to 20.54	0.84	0.17 to 2.50
<i>Jamaica</i>	5300 <sup>‡</sup>	3	56.60	11.67 to 165.33	6.76	1.38 to 20.15
<i>Nigeria</i>	21476 <sup>‡</sup>	7	32.59	13.11 to 67.15	3.89	1.54 to 8.22
<i>Pakistan</i>	54379 <sup>‡</sup>	8	14.71	6.35 to 28.99	1.76	0.74 to 3.56

<sup>#</sup>Country of birth not recorded for 26 women who died

<sup>\*</sup>Estimates based on proportions of births to UK and non-UK born mothers applied to number of maternities

<sup>‡</sup>Estimates based on ratio of maternities to births applied to number of births recorded to mothers born in stated country

## 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 2014-16 were known to have pre-existing medical problems (Table 2.13), 24% were known to have pre-existing mental health problems and 8% had pre-existing cardiac problems. Notably, however, for women who died in 2016, for 19% it was reported to be unknown whether they had previous or pre-existing mental health problems, despite the identification of this being a key recommendation in 2015 (Knight, Tuffnell et al. 2015), reiterated again in chapter 5. More than a third (37%) of the women who died in this triennium were obese and 20% were overweight (Table 2.13).

The pregnancy-related characteristics of the women who died in 2014-16 are shown in Table 2.14.

**Table 2.13: Selected medical conditions and characteristics identified amongst women who died 2014-16**

Medical condition/characteristic	Direct (n=98) Frequency (%)	Indirect (n=127) Frequency (%)	Total (n=225) Frequency (%)
Body mass index (BMI) (Kg/m <sup>2</sup> )			
<18	0 (0)	3 (2)	3 (1)
18–24	28 (29)	38 (30)	66 (29)
25–29	26 (27)	19 (15)	45 (20)
≥ 30	34 (35)	50 (39)	84 (37)
Missing	10 (10)	17 (13)	27 (12)
Mental health problems or psychiatric disorders			
Yes	24 (24)	31 (24)	55 (24)
No	67 (68)	83 (65)	150 (67)
Missing	7 (7)	13 (10)	20 (9)
Pre-existing cardiac problems			
Yes	4 (4)	13 (10)	17 (8)
No	90 (92)	112 (88)	202 (90)
Missing	4 (4)	2 (2)	6 (3)
Any pre-existing medical problem (excluding obesity)			
Yes	60 (61)	94 (74)	154 (68)
No	34 (35)	31 (24)	65 (29)
Missing	4 (4)	2 (2)	6 (3)



**Table 2.14: Pregnancy-related characteristics of the women who died 2014-16**

Characteristics	Direct (n=98) Frequency (%)	Indirect (n=127) Frequency (%)	Total (n=225) Frequency (%)
Pregnancy known to be as a result of assisted reproductive techniques			
Yes	4 (4)	4 (3)	8 (4)
No	92 (94)	120 (94)	212 (94)
Missing	2 (2)	3 (2)	5 (2)
Multiple pregnancy			
Yes	6 (6)	4 (3)	10 (4)
No	92 (94)	123 (97)	215 (93)
Previous caesarean section			
Yes	25 (26)	20 (16)	45 (20)
No	69 (70)	102 (80)	171 (76)
Missing	4 (4)	5 (4)	9 (4)
Previous caesarean numbers (among women who had a previous caesarean section)			
1	15 (60)	18 (90)	33 (73)
≥2	10 (40)	2 (10)	12 (27)

### Other characteristics of women who died

Inadequate utilisation of antenatal care services and substance misuse have been shown to be 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 2014-16 did not differ from that noted in the previous reports (Table 2.15) and use of recommended antenatal care still remains low. Just over a quarter (26%) 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 2017).

**Table 2.15: Other characteristics of women who died in 2014-16**

Characteristics	Direct (n=98) Frequency (%)	Indirect (n=127) Frequency (%)	Total (n=225) Frequency (%)
Smoking			
<i>Smoker</i>	25 (26)	34 (27)	59 (26)
<i>Non-smoker</i>	62 (63)	80 (63)	142(63)
<i>Missing</i>	11 (11)	13 (10)	24 (11)
Substance user			
<i>Yes</i>	11 (11)	16 (13)	27 (12)
<i>No</i>	85 (87)	108 (85)	193 (86)
<i>Missing</i>	2 (2)	3 (2)	5 (2)
Received any antenatal care*			
<i>Yes</i>	86 (88)	112 (88)	198 (88)
<i>No</i>	12 (12)	15 (12)	27 (12)
Gestational age at booking (among women who received any antenatal care)			
<i>≤10</i>	28 (33)	45 (40)	73 (37)
<i>11–12</i>	35 (41)	41 (37)	76 (38)
<i>&gt;12</i>	22 (26)	23 (21)	45 (23)
<i>Missing</i>	1 (1)	3 (3)	4 (2)
Received <i>recommended</i> antenatal care <sup>†</sup> (among women who received any antenatal care)			
<i>Yes</i>	19 (22)	33 (29)	52 (26)
<i>No</i>	65 (76)	75 (67)	140 (71)
<i>Missing</i>	2 (2)	4 (4)	6 (3)
Received a minimum level of antenatal care <sup>†</sup> (among women who received any antenatal care)			
<i>Yes</i>	61 (71)	78 (70)	139 (70)
<i>No</i>	22 (26)	26 (23)	48 (24)
<i>Missing</i>	3 (3)	8 (7)	11 (6)

\*Includes 3 women who died in early pregnancy.

<sup>†</sup>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 2014 and 2016 and are included in the confidential enquiry chapters of this report (including 128 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 233 women whose case notes were available with sufficient information for an in-depth review. Among these women 28% were assessed to have received good care, but detailed assessment showed that for another 38% 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 (2014-16)**

Classification of care received	(n=225)* Number (%)
Good care	63 (28)
Improvements to care which would have made no difference to outcome	77 (34)
Improvements to care which may have made a difference to outcome	85 (38)

\*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 68% in 2015. There has been an encouraging further increase to 77% in 2016, with GPs showing the highest proportionate return rate at 87% (Table 2.17). Local clinicians' reports are absolutely essential to allow MBRRACE-UK assessors to fully take account of any local factors impacting on care, and we urge clinicians to return these in a timely manner.

**Table 2.17: Percentages of local clinicians' reports received for women who died in 2016**

Specialty group	Percentage of reports requested that were received
Obstetricians	73
Anaesthetists	76
Midwives	72
Critical Care Clinicians	81
Emergency Medicine Specialists	65
GPs	87
Physicians	78
Psychiatrists	77
<i>Total</i>	77

## 2.4 The women who survived

### Women who survived after major obstetric haemorrhage and massive transfusion

A national cohort study was undertaken through the UK Obstetric Surveillance System between July 2012 and June 2013, identifying all pregnant women at  $\geq 20$  weeks of gestation receiving  $\geq 8$  units of red blood cells within 24 hours of giving birth (Green, Knight et al. 2016). As described in section 1.4, 34 women were included in the morbidity 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. It is worth noting that, in contrast to the women who died, fewer of these women were overweight or obese and only a minority had pre-existing medical or mental health problems.

**Table 2.18: Characteristics of women who survived after major obstetric haemorrhage**

Characteristics	Total (n=34) Frequency (%)
Age	
<25	3 (9)
25–34	16(47)
$\geq 35$	15 (44)
Parity	
0	14(41)
$\geq 1$	20 (59)
Previous caesarean section	
Yes	16 (47)
No	18 (53)
Previous caesarean numbers (among women who had a previous caesarean section)	
1	5 (31)
$\geq 2$	11 (69)
Ethnicity	
White European	20 (59)
Other	14 (41)
Socioeconomic status (Occupational classification)	
Employed (Either woman or partner)	30 (88)
Unemployed (Both)	3 (9)
Missing	1 (3)
Smoking	
Smoker	4 (12)
Non-smoker	30 (88)
Body mass index (BMI) (kg/m <sup>2</sup> )	
<18	2 (6)
18–24	19 (56)
25–29	7 (21)
$\geq 30$	6 (18)
Any pre-existing medical or mental health problem (excluding obesity)	
Yes	5 (15)
No	29 (85)

# 3. Messages for prevention and treatment of morbidity from major obstetric haemorrhage

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## 3.1 Key messages

Recognition of bleeding remains important. Caesarean section in advanced labour is associated with a risk of uterine angle extensions which can be difficult to control and which can cause concealed bleeding post operatively. **ACTION: Health professionals.**

Always exclude each of the four Ts (tone, tissue, trauma and thrombin) when assessing any woman with ongoing bleeding. **ACTION: Health professionals.**

Women who have had a previous caesarean section who also have either placenta praevia or an anterior placenta underlying the old caesarean section scar at 32 weeks of gestation are at increased risk of placenta accreta and should be managed as if they have placenta accreta, with appropriate preparations for surgery made. **ACTION: Service planners/commissioners, service managers, health professionals.**

Any woman with suspected placenta praevia accreta should be reviewed by a consultant obstetrician and consultant anaesthetist in the antenatal period. The different risks and treatment options should have been discussed and a plan agreed. **ACTION: Service planners/commissioners, service managers, health professionals.**

Any woman going to theatre electively with suspected placenta praevia accreta should be attended by a consultant obstetrician and anaesthetist. If the delivery is unexpected, out-of-hours consultant obstetric and anaesthetic staff should be alerted and attend as soon as possible. **ACTION: Service managers, health professionals.**

Documentation of fluid balance is part of the protocol for monitoring and investigation in major PPH; care must be taken to avoid over-replacement as well as under-replacement. **ACTION: Health professionals.**

Young women are vulnerable to pressure sores and care should be taken of pressure points in the obstetric population as well as other populations. **ACTION: Service managers, health professionals.**

## 3.2 Background

Rates of postpartum haemorrhage are known to be increasing in high resource settings (Knight, Callaghan et al. 2009), and alongside this a near-doubling of the maternal death rate from haemorrhage was identified in 2013-15 (Knight, Nair et al. 2017). This was almost entirely due to an increase in the numbers of women dying from haemorrhage in association with abnormally invasive/morbidly adherent placentation (AIP) – placenta accreta, increta or percreta. There is no evidence of any change in this trend from the figures identified in this report; the maternal mortality rate from haemorrhage in the UK remains at 0.78 per 100,000 maternities. As noted in chapter 1, the women whose care was examined here were a stratified random sample of all women of 20 weeks or more gestation who were transfused 8 or more

units of red cells in the UK between July 2012 and June 2013 (Green, Knight et al. 2016). They are thus representative of all women who survived following a massive transfusion in association with obstetric haemorrhage in the UK.

### 3.3 The women who survived

The care of thirty-four women was reviewed for the purposes of this chapter. The causes of these women's haemorrhages exhibit two clear themes: abnormally invasive placentation (13 women) and trauma (uterine and vaginal tears in 11 women) (Table 3.1). Haemorrhage in relation to infection or atony was also identified in 8 women whose care was examined for the purposes of this chapter. It is striking how similar the causes of these women's haemorrhage are to the causes of women's deaths from haemorrhage as described in chapter 8 of the 2017 report (Knight, Nair et al. 2017), with the exception that trauma – uterine or vaginal tears – appears to be associated with a greater proportion of haemorrhage morbidity.

**Table 3.1: Direct deaths by type of obstetric haemorrhage 2013-15 and causes of haemorrhage morbidity 2012-13**

Cause of death/haemorrhage	Women who died UK and Ireland 2013-15	Women who survived UK 2012-13
<b>Placental Abruption</b>	3	0
<b>Placenta Praevia/accreta</b>	9 (8 with accreta/increta/percreta)	13** (13 with accreta/increta/percreta)
<b>Atony alone</b>	7 (5 post caesarean birth)	4 (4 post caesarean birth)
<b>Delayed manual removal of placenta</b>	2	1
<b>Genital Tract Trauma</b>	1	11
<b>AFE</b>	9	1
<b>Infection</b>	0*	4
<b>TOTAL</b>	31	34

\*Note that the deaths of women which were thought to be due primarily due to infection are considered in the sepsis chapter

\*\*One women with AIP had a uterine rupture as a consequence

Although only four women had solely atonic haemorrhage, atony was also a feature in six of the women who had genital tract trauma, three of whom gave birth by caesarean section. Amongst the women with genital tract trauma, six of the tears occurred at caesarean section, of which four were diagnosed late, four followed spontaneous vaginal birth, of which one was associated with excessive misoprostol, and one followed forceps birth. Of note the woman who survived an amniotic fluid embolism also had excessive uterotonic doses.



## 3.4 Overview of care and lessons to be learned

### Recognition of haemorrhage

A woman underwent a caesarean section in the late evening at 9cm dilation for failure to progress following spontaneous onset of labour. Immediately after giving birth she had a large postpartum haemorrhage which was recognised to be due to complex broad ligament trauma and atony. The major haemorrhage protocol was immediately activated and general anaesthesia was induced. A consultant obstetrician arrived 8 minutes after the major haemorrhage call was made. The woman bled three litres within the first hour after her caesarean and a further consultant was called and arrived to assist 50 minutes after the major haemorrhage call. Her haemorrhage was eventually controlled with the assistance of a third obstetrician/gynaecologist and a vascular surgeon who repaired a torn uterine artery. Her uterus was preserved. She bled in total 6 litres and was transfused 10 units of red cells as well as FFP and platelets, all of which arrived promptly on request. She made an uneventful recovery.

This woman's haemorrhage was recognised early, the major haemorrhage protocol was appropriately followed and early involvement of senior staff from different specialties led to control of her bleeding and her eventual uneventful recovery. It was encouraging to note that amongst all the women examined, in contrast to the women who died and whose care was reviewed in the 2017 report (Knight, Nair et al. 2017), the haemorrhage was generally recognised at an earlier stage. There were thus less profound delays in their management and this was clearly a factor in their ultimate recovery. Note, however, that all women whose care was examined for the purposes of this chapter had been transfused at least eight units of red cells, and there were many opportunities where management could have been different or more timely, leading to earlier resolution of their bleeding.

In eight women, staff were slow to recognise the significant haemorrhage. This was particularly evident when women were being cared for on postnatal wards or in recovery; in theatre haemorrhage was generally better recognised and acted on more quickly.

A woman undergoing a trial of labour after caesarean section progressed slowly and her labour was augmented with syntocinon. She failed to progress and underwent caesarean section. At operation she bled 2 litres and was noted to have an abnormal thin and vascular lower segment. She re-bled in recovery, became hypotensive, and after a 15 minute delay was returned to theatre for an examination under anaesthesia and insertion of an intrauterine balloon. Her blood loss was now over 4 litres and she was transferred to intensive care. She lost a further 600ml via an abdominal drain and therefore returned to theatre a second time at which time a broad ligament haematoma was identified and she had diathermy to bleeding points. Her estimated blood loss was now 6 litres. She had a further bleed in intensive care and following a CT scan which showed intra-abdominal bleeding returned to theatre for a second relaparotomy at which time her damaged uterine artery was identified by a non-obstetric surgeon and ligated.

Assessors felt that a laparotomy on first return to theatre may have identified this woman's intra-abdominal bleeding earlier, but particularly that the significance of her hypotension in recovery was not recognised. The following recommendation was made in both 2014 and 2017 and remains relevant here.

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) (Recommendation in both 2014 and 2017).

## Identification of trauma

In eight of the women whose care was reviewed, haemorrhage was caused by either a uterine or cervical/vaginal tear which was not initially recognised. Examination under anaesthetic plays an important role in excluding both trauma and retained tissue as the cause in any women with a major haemorrhage – but both causes should always be looked for.

A woman underwent induction of labour after a spontaneous rupture of membranes with meconium staining at term. She gave birth after a 12 hour labour with an apparent delay between delivery of the baby's head and body, although it is unclear whether any manoeuvres were performed. Thirty minutes after she gave birth, she had a two litre postpartum haemorrhage presumed to be due to uterine atony. A massive obstetric haemorrhage call was made, she received uterotonics and was taken to theatre within 20 minutes for examination under anaesthetic. The consultant obstetrician was alerted but did not attend. The woman left theatre after two hours, but within 30 minutes had a further bleed of one litre. She returned to theatre and the consultant attended and identified high vaginal and cervical tears which took a further two hours to repair. She was transferred by ambulance to a level 2 critical care unit.

In this instance it is unclear whether a systematic assessment of each of the four main causes of bleeding (Box 3.1) were undertaken during the woman's initial two hour theatre episode.

### Box 3.1: Causes of postpartum haemorrhage (Royal College of Obstetricians and Gynaecologists 2016)

**Tone** - abnormalities of uterine contraction

**Tissue** - retained products of conception, abnormally invasive placenta

**Trauma** - genital tract injury

**Thrombin** - abnormalities of coagulation

High vaginal and cervical tears can occur after spontaneous as well as assisted vaginal birth, as the above vignette shows. The other frequent trauma seen in the cases reviewed related to angle tears at caesarean sections especially when carried out in the late first or second stage.

A woman underwent a post-dates induction of labour. A caesarean section for fetal distress was carried out when she was 9cm dilated. In recovery she was noted to be bleeding. The consultant attended immediately; at relaparotomy the bleeding left angle tear to the uterus was repaired. The woman recovered uneventfully after her 8 unit transfusion and level 2 critical care.

Even though this woman's angle tear was not diagnosed at the initial caesarean section, her postpartum haemorrhage was diagnosed promptly in recovery, the consultant attended promptly, examined the woman appropriately and her haemorrhage was rapidly treated.

At caesarean section in advanced labour the lower segment is ballooned out and the tissues are oedematous and friable. This, combined with sometimes difficult manipulation to deliver the impacted fetal head makes the risk of a tear greater, and if rotation of the uterus has not been recognised or corrected the angle tear can extend into the broad ligament. Four of five women who had caesarean sections in advanced labour had troublesome angle extensions and broad ligament haematomas.

**Caesarean section in advanced labour is associated with a risk of uterine angle extensions which can cause concealed bleeding post operatively and bleeding which can be difficult to control.**

**Always exclude each of the four Ts (tone, tissue, trauma and thrombin) when assessing any woman with ongoing bleeding.**

**Consultants should attend second stage caesarean sections until trainees have been signed off with OSATS (Royal College of Obstetricians and Gynaecologists 2009).**

**A multidisciplinary team involving senior members of staff should be summoned to attend to women with major PPH (blood loss of more than 1000 ml) and ongoing bleeding or clinical shock. (Royal College of Obstetricians and Gynaecologists 2016).**

**The consultant obstetrician should attend in person when there is a PPH of more than 1500 ml where the haemorrhage is continuing (Royal College of Obstetricians and Gynaecologists 2009).**

Some women with bleeding due to trauma were managed inappropriately with intrauterine balloons.

A woman undergoing a trial of labour after caesarean section underwent an unsuccessful trial of operative vaginal delivery in theatre after delay in second stage. A right angle extension was noted at caesarean section. The registrar made an appropriately early call for help. The consultant attended after a recorded 1200ml of blood loss, repaired the tear and placed an intrauterine balloon. Signs of the woman's ongoing concealed haemorrhage were not noticed until several hours later, when she returned to theatre. She underwent interventional radiological management of an inaccessible bleeding vessel. In total she lost over 15 litres of blood and received more than 20 units of red cells along with other blood products.

It was unclear that this woman was ever truly haemodynamically stable after her initial tear was repaired. In this instance the insertion of the intrauterine balloon provided false reassurance that her haemorrhage was under control as she was not bleeding vaginally. Signs of her ongoing bleeding were missed.

**Intrauterine balloon tamponade is an appropriate first-line 'surgical' intervention for most women where uterine atony is the only or main cause of haemorrhage (Royal College of Obstetricians and Gynaecologists 2016).**

## Abnormally invasive placentation

Thirteen of the women whose care was reviewed for the purposes of this chapter had morbidly adherent placentae – placenta accreta, increta or percreta. There are two aspects to caring for women at risk of accreta: the first requires antenatal diagnosis, the second relates to the care peri-delivery, and both are particularly important given the observed increase in the number of women dying from haemorrhage associated with abnormally invasive placenta (Knight, Nair et al. 2017), and current trends in caesarean birth (Betran, Ye et al. 2016), a recognised risk factor for abnormal placentation. Assessors noted huge variation in diagnosis and planning of care, from no recognition or anticipation of accreta, to late recognition. Some women, despite placenta accreta being anticipated, had no imaging.

## Diagnosis

A woman with three previous caesarean births was noted to have a major placenta praevia at 24 weeks. At the same scan a fetal anomaly was noted and thereafter attention focussed solely on care and delivery planning for the fetus. The woman's very high risk of placenta accreta was never considered. At delivery, the placenta was adherent and the baby was delivered with difficulty after 20 minutes and following conversion to general anaesthesia. The placenta was eventually removed piecemeal, but the woman had further bleeding in recovery and returned to theatre. Brace sutures did not control the haemorrhage and she had a hysterectomy. She was cared for overnight in intensive care. She recovered physically but continued to have mental health problems after her traumatic delivery.

The risk factors for abnormally invasive placentation, most notably previous caesarean section, but also including IVF pregnancy, other uterine surgery and endometrial ablation, are well known (Fitzpatrick, Sellers et al. 2012). In four women the diagnosis of placenta accreta was not considered despite clear risk factors. The proportion of women with risk factors continues to grow and awareness of these factors will become increasingly important. Risk recognition allows for full multidisciplinary planning.

**All women require follow-up imaging if the placenta covers or overlaps the cervical os at 20 weeks of gestation.**

**Women with a previous caesarean section require a higher index of suspicion as there are two problems to exclude: placenta praevia and placenta accreta. If the placenta lies anteriorly and reaches the cervical os at 20 weeks, a follow-up scan can help identify if it is implanted into the caesarean section scar.**

**Women who have had a previous caesarean section who also have either placenta praevia or an anterior placenta underlying the old caesarean section scar at 32 weeks of gestation are at increased risk of placenta accreta and should be managed as if they have placenta accreta, with appropriate preparations for surgery made.**

**(Royal College of Obstetricians and Gynaecologists 2011a)**

## Planning of care for women with suspected placenta accreta

A woman with a major placenta praevia accreta had a large antepartum haemorrhage in the second trimester. She was managed conservatively and a multidisciplinary team made detailed plans for her delivery in the event of a future bleed in line with the suspected placenta accreta care bundle. However, when she had a further bleed in the early third trimester she was delivered by caesarean section without any of the plans being followed and with little preparation. She was tachycardic at the start of the procedure but the significance of this was not recognised and the procedure commenced with a junior anaesthetist under epidural anaesthesia with one small intravenous line. The procedure was converted to general anaesthesia after difficult surgery. She lost over 12 litres of blood in less than two hours.

Some women at high risk of accreta underwent appropriate imaging and delivery was planned well. However, in some instances, as this woman's care illustrates, the need for an emergency delivery had been anticipated and detailed and appropriate plans made which were not followed in the acute situation.

**Any woman with suspected placenta praevia accreta should be reviewed by a consultant obstetrician in the antenatal period. The different risks and treatment options should have been discussed and a plan agreed, which should be reflected clearly in the consent form. This should include the anticipated skin and uterine incisions and whether conservative management of the placenta or proceeding straight to hysterectomy is preferred in the situation where accreta is confirmed at surgery. Additional possible interventions in the case of massive haemorrhage should also be discussed, including cell salvage and interventional radiology when available.**

**The care bundle for suspected placenta accreta should be applied in all cases where there is a placenta praevia and a previous caesarean section or an anterior placenta underlying the old caesarean scar.**

**Any woman going to theatre electively with suspected placenta praevia accreta should be attended by a consultant obstetrician and anaesthetist. If the delivery is unexpected, out-of-hours consultant obstetric and anaesthetic staff should be alerted and attend as soon as possible.**

**(Royal College of Obstetricians and Gynaecologists 2011a)**

Whilst there was anaesthetist involvement in the planning of some women's care, reviewers noted in particular that where plans were made antenatally, anaesthetists were often not involved. RCOG guidance states that "The choice of anaesthetic technique for caesarean sections for placenta praevia and suspected placenta accreta must be made by the anaesthetist conducting the procedure. There is insufficient evidence to support one technique over another", and, as noted above, that consultant anaesthetists should be present when any woman with suspected placenta praevia accreta goes to theatre (Royal College of Obstetricians and Gynaecologists 2011a). It follows therefore that consultant anaesthetist review should always take place in the antenatal period as part of multidisciplinary planning.

The following are the basic elements of the care bundle for women where placenta praevia accreta is suspected following antenatal imaging and MDT discussion (Paterson-Brown and Singh 2010):

- Consultant obstetrician planned and directly supervising delivery
- Consultant obstetric anaesthetist planned and directly supervising anaesthetic at delivery
- Blood and blood products available on site
- Multidisciplinary involvement in pre-op planning
- Discussion and consent includes possible intervention (such as hysterectomy, leaving placenta in situ, cell salvage and interventional radiology)
- Local availability of level 2 critical care bed

Following the plans made, particularly ensuring consultant presence, is even more important when a woman presents out of hours with bleeding and is therefore at higher risk of complications.

## Hysterectomy

A woman with multiple previous caesarean births was noted to have a placenta which covered the cervical os at her 20 week scan and was booked for a scan at 32 weeks. She was admitted with a major haemorrhage at 31 weeks and after a 2 litre blood loss the decision was made by her consultant to deliver her. At caesarean section her placenta was removed piecemeal with the assistance of a second consultant. An intrauterine balloon was inserted and she left theatre after an estimated 6 litre blood loss. One hour later her estimated blood loss was 11 litres and therefore she returned to theatre for a hysterectomy. She recovered after 5 days in intensive care.

The placenta accreta bundle clearly describes the importance of advance discussion of possible hysterectomy. The majority of women with abnormally invasive placentation whose care was reviewed here underwent hysterectomy. It was difficult for the assessors to comment on the timing of proceeding to hysterectomy in ten of these women, without more information about the woman's wishes, and consent

issues, but clinically it was often, as illustrated in the vignette above, a decision taken late after litres of blood loss, massive transfusions, and returns to theatre. In two women who had cardiac arrests, the decision to perform a hysterectomy was taken promptly.

## Uterine hyperstimulation

Three women had major haemorrhage in the context of hyperstimulation. One woman who was undergoing induction of labour after an intrauterine death received an inappropriate dose of misoprostol, another woman had a precipitate labour after induction with a long-acting Dinoprostone and the third had her labour augmented with oxytocin after an antepartum haemorrhage and laboured very rapidly with hyperstimulation. Antepartum haemorrhage alone is a known risk factor for rapid labour and any stimulation should be done extremely carefully.

**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).**

**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 (Knight, Nair et al. 2017).**

**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).**

## Delayed removal of placenta

Two women, whose care was reviewed in the 2017 report (Knight, Nair et al. 2017) died from concealed haemorrhage when removal of a retained placenta was delayed. This theme was also evident amongst the women who survived.

A woman was induced following an intrauterine death in association with infection. She gave birth rapidly but her placenta was retained. Despite revealed bleeding, she was not taken to theatre for a manual placental removal until four hours later. The consultant obstetrician was not called until she had lost an estimated three litres of blood. Conservative measures to control her haemorrhage with prostaglandins and tranexamic acid were successful and she was discharged six days later.

**Once a retained placenta is diagnosed obstetric review and transfer to theatre should be expedited and careful recording of observations should be performed, with consideration that a persistent loss can become significant, concealed bleeding can be marked and deterioration is likely (Knight, Nair et al. 2017).**

This woman's care also illustrates another recurrent theme identified by reviewers, who noted that junior staff were sometimes slow to call for help when women were deteriorating in the context of severe bleeding which failed to respond to first-line measures.



**Concerns should be escalated to a senior doctor or midwife if a woman deteriorates, and there should be a named senior doctor in charge of ongoing care (Knight, Kenyon et al. 2014).**

**Deterioration includes adverse changes in physiological vital signs even in the absence of change in the woman's clinical demeanor or obvious revealed blood loss.**

## The tamponade test

A woman in spontaneous labour underwent an emergency caesarean birth for fetal distress. In recovery 50 minutes later she was noted to have a PPH which was managed with uterotonics, but after a further 30 minutes blood loss had reached 2 litres. She was taken to theatre for an examination under anaesthesia and a small piece of retained placenta was removed. An intrauterine balloon was inserted and she went to recovery at which point the consultant was informed about her 3 litre blood loss. She continued to bleed so returned to theatre for a second time. The consultant obstetrician performed a laparotomy and inserted a brace suture. She was admitted to the intensive care unit overnight but made a full recovery and was discharged home.

In this instance the woman was managed appropriately up until the insertion of the intrauterine balloon. At this stage, a 'Tamponade test' could have revealed whether the intrauterine balloon was effectively controlling her haemorrhage, and indicated the need for immediate laparotomy. This would have led to earlier cessation of her haemorrhage and potentially prevented her intensive care unit admission.

**If pharmacological measures fail to control the haemorrhage, initiate surgical haemostasis sooner rather than later. Intrauterine balloon tamponade is an appropriate first-line 'surgical' intervention for most women where uterine atony is the only or main cause of haemorrhage. A 'positive test' (control of PPH following inflation of the balloon) indicates that laparotomy is not required, whereas a 'negative test' (continued PPH following inflation of the balloon) is an indication to proceed to laparotomy. ...Hysterectomy should not be delayed until the woman is in extremis.**

**RCOG Green-top guideline 52 (Royal College of Obstetricians and Gynaecologists 2011b).**

## Infection and bleeding risk

Four women had major haemorrhage when they were clearly septic. In all these women, the sepsis was thought to be a contributing factor to the severity of their haemorrhage, and the importance of sepsis as a risk factor for haemorrhage should not be forgotten – it may lead either to uterine atony or to disseminated intravascular coagulation (Royal College of Obstetricians and Gynaecologists 2016).

A woman presented in labour 48 hours after spontaneous rupture of membranes clearly septic. A sepsis bundle was started and she was rapidly delivered by caesarean section, at which she lost 1.5 litres of blood. She bled a further 1000ml over the next 12 hours but her coagulopathy was appropriately managed by a multidisciplinary senior team and she made an uneventful recovery.

This woman's care illustrates the benefit of early recognition of the sepsis underlying her haemorrhage and careful management of the resulting coagulopathy by an experienced senior multidisciplinary team.

## Fluid balance

Careful attention to fluid balance in women with pre-eclampsia has eliminated pulmonary oedema as a cause of maternal death in women with hypertensive disorders in the UK and Ireland over recent years. It is therefore concerning that several of the women whose care was examined in this chapter developed pulmonary oedema as a consequence of the fluids they received to manage their haemorrhage. Consideration of over-replacement is as important as consideration of under-replacement. Over replacement with crystalloid and/or colloid could worsen any developing coagulopathy and be counter-productive. Fluid management requires skilled senior input. If fluid replacement is needed blood and blood products should be sourced with speed to avoid over reliance on crystalloids to support the cardiovascular system. It is important to continually reassess the signs of the woman's intravascular volume status during intravenous fluid resuscitation and to frequently monitor fluid balance.

A woman with a BMI of 21kg/m<sup>2</sup> gave birth rapidly after an antepartum haemorrhage and hyperstimulation after augmentation. She bled a total of 4 litres following a third degree tear. She received 10 units of red cells, 10 units of FFP, 2 units of cryoprecipitate and a unit of platelets. Her fluid balance was poorly recorded and although she also received crystalloids, the volumes are unclear. She developed pulmonary oedema, requiring CPAP followed by a two day stay in intensive care.

**Documentation of fluid balance is part of the protocol for monitoring and investigation in major PPH (Royal College of Obstetricians and Gynaecologists 2016).**

## Pressure sores

A young woman with a major placenta praevia percreta had an unplanned early delivery after an antepartum haemorrhage. Difficult surgery involving the bladder took several hours – it was more than two hours before a consultant gynaecologist and urologist were called to assist. She subsequently developed pressure sores on both buttocks.

Two women whose care was examined here developed pressure sores. It is disappointing that in this instance despite there being multiple points where improvements could have been made in this woman's care these were not recognised by the obstetric team.

**Young women are vulnerable to pressure sores and care should be taken of pressure points in the obstetric population as well as other populations.**

## 3.5 Pathological review

Fifteen of the women reviewed for the purposes of this chapter had an emergency hysterectomy, total or subtotal. Although it is assumed that all the resected uteri were submitted to histopathology laboratories for analysis, only nine pathology reports were available for this qualitative review of their pathology and correlation with the clinical circumstances.

The quality features assessed included: the clinical information presented to the pathologist on the request form, the extent of sampling of the uterus, the microscopic data and the diagnostic conclusions in the reports. These were compared with the full medical records as supplied to MBRRACE.

The positive pathologies found in the hysterectomies were placenta praevia, placenta accreta/percreta, retained placenta, thrombosed vessels, and uterine rupture. No cases had had uterine artery embolisation with PVA particles. There was only one placental pathology report.

Most of the reports were of good quality and addressed the clinically known or suspected pathologies, mainly to confirm them. Uterine atony has no specific histopathological features, so unsurprisingly the reports in these instances were non-specific, yet they usefully included significant 'negatives' such as absence of amniotic squames in the uterine vessels and absence of retained placental material.

The detail of clinical information presented varied from complete (i.e. number of previous caesarean sections, known placenta praevia or accreta etc) to merely 'massive obstetric haemorrhage' with no clinical clues. Placenta accreta was identified pathologically in one case where there was no clinical mention of it. However, in another, where placenta praevia and percreta were both evident at surgery, only the praevia was stated on the request form, and the pathologist therefore did not address the percreta aspect. Finally, in one case of clinical placenta praevia and previous Caesarean section, neither facts were mentioned on the request form, and the pathology report was therefore unfocussed and non-specific as the pathologist had no pertinent information to guide examination.

**To assist the pathologist to obtain the maximum useful information, inclusion of the following information concerning significant features with the pathology request is essential: present and previous caesarean sections and their number, location of the placenta in the uterus, suspected placenta accreta/percreta or retained placenta, uterine rupture, uterine artery embolisation.**

**Where possible, the placenta should accompany the uterus to the laboratory to enable the most complete report possible.**

While the (usually subtotal) hysterectomy will have been for uncontrolled obstetric haemorrhage and so should concentrate on finding reasons for the haemorrhage, it is also important to remember the need, if the patient survives, of reporting the nature of the mucosa at the inferior margin; if this is endometrial, then there is a risk of endometrial neoplasia at the top of the cervical stump. This information will be particularly pertinent to women's future care.

## 3.6 Conclusions

This confidential enquiry into maternal morbidity from haemorrhage identified improvements in care for almost 90% of women; in 74% this would have made a difference to their outcome (Table 3.2). The enquiry has highlighted several themes which were also recognised in the reviews of maternal deaths, but importantly has identified new messages relating to the care of women with abnormal placentation and genital tract trauma. There is a clear need to recognise women who are at risk of abnormal placentation and plan appropriately for their delivery care, ensuring that plans are enacted when women are admitted in an emergency. The risk of uterine angle tears following caesarean section in advanced labour needs to be recognised, and there should be greater awareness of the possibility of concealed haemorrhage in relation to genital tract trauma in all its forms. In the context of rising caesarean section rates, taking forward these messages for care is essential to prevent escalating frequency of both major obstetric haemorrhage and maternal death.

**Table 3.2: Classification of care received by women who survived major obstetric haemorrhage, UK, 2012-13**

Classification of care received	Women with major obstetric haemorrhage Number (%) N=34
Good care	4 (12)
Improvements to care which would have made no difference to outcome	5 (15)
Improvements to care which may have made a difference to outcome	25 (74)

## 4. Lessons for prevention and treatment of thrombosis and thromboembolism

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### 4.1 Key messages

There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply in practice. There is an urgent need for development of a tool to make the current risk assessment system simpler and more reproducible. **ACTION: Professional organisations, service planners/commissioners, service managers, health professionals.**

Audits should be conducted not only to assess whether thromboembolism risk assessment was performed, but also whether the calculated risk score was correct. **ACTION: Service managers, health professionals.**

All women should undergo a documented assessment of risk factors for venous thromboembolism in early pregnancy or pre-pregnancy. Risk assessment should be repeated if the woman is admitted to hospital for any reason or develops other intercurrent problems. Risk assessment should be repeated again intrapartum or immediately postpartum. **ACTION: Service managers, health professionals.**

Reassessment of VTE risk after miscarriage or ectopic pregnancy to consider whether thromboprophylaxis is required is as important as reassessment of risk after giving birth. **ACTION: Service managers, health professionals.**

If women need thromboprophylaxis as soon as they become pregnant there should be clear pathways for them to access prescriptions and support to ensure compliance. **ACTION: Service planners/commissioners, service managers, health professionals.**

Women with a high BMI should be given information about the symptoms of VTE. **ACTION: Service planners/commissioners, service managers, health professionals.**

Women with a BMI  $\geq 40$ kg/m<sup>2</sup> score 2 points on the RCOG guideline for thromboprophylaxis in pregnancy and therefore all need postnatal thromboprophylaxis regardless of mode of delivery. **ACTION: Service managers, health professionals.**

Prescriptions for the entire postnatal course of low molecular weight heparin should be issued in secondary care. This will help ensure that women receive the full course without the need to visit their GP to obtain another prescription. **ACTION: Service planners/commissioners, service managers, health professionals.**

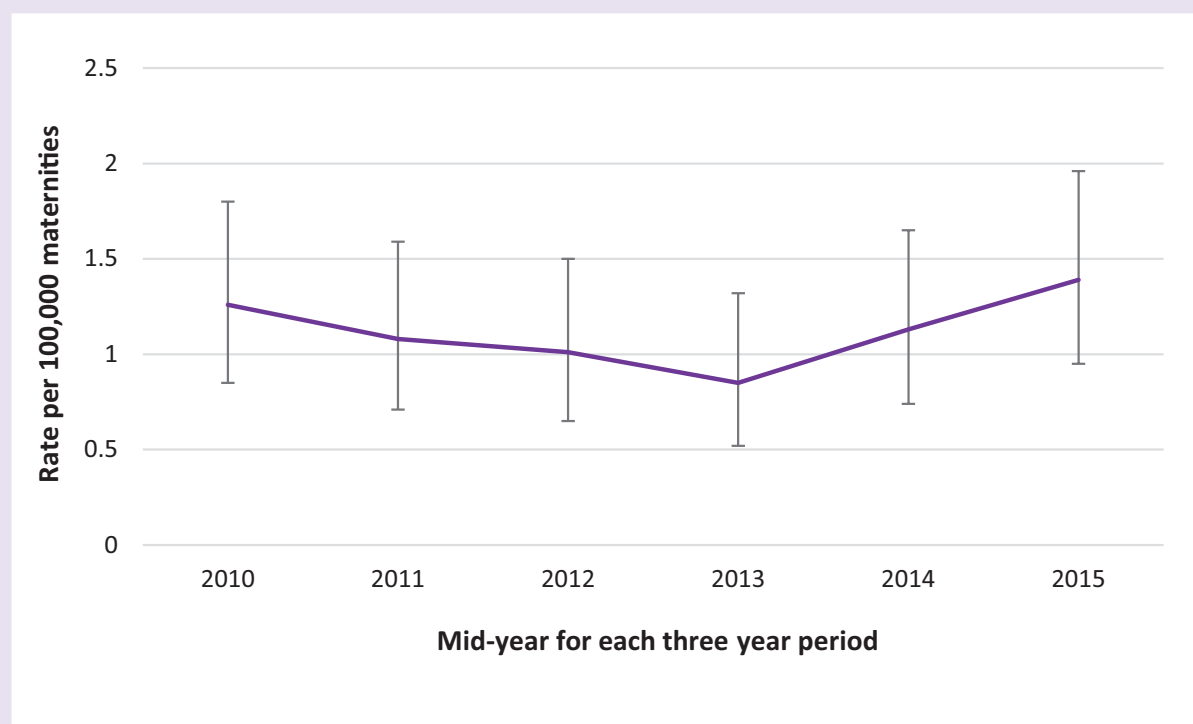
## 4.2 Background

Venous thromboembolism (VTE) remains the leading cause of direct maternal death, with no evidence of a consistent decrease in mortality over the past 20 years. This is despite detailed guidance for both prevention and treatment of thromboembolic disease from the Royal College of Obstetricians and Gynaecologists, most recently updated in 2015, and the Institute of Obstetricians and Gynaecologists, updated in 2016, leading to the wider use of thromboprophylaxis (Royal College of Obstetricians and Gynaecologists 2015a, Royal College of Obstetricians and Gynaecologists 2015b, Institute of Obstetricians and Gynaecologists Royal College of Physicians of Ireland, HSE Clinical Care Programme in Obstetrics and Gynaecology et al. 2016). Alongside the changes in guidelines, the maternity population as well as interventions are changing. Women giving birth are now older, with more risk factors for thromboembolic disease such as obesity. More interventions such as caesarean section are undertaken, also placing women at higher risk of VTE. Thus it is likely that VTE in association with pregnancy will become an even greater problem without careful attention to prevention.

## 4.3 The women who died

There were 39 women who died from venous thromboembolism in the UK and Ireland between 2014 and 2016. Thirty women died from pulmonary embolism and two women died from venous sinus thrombosis during pregnancy or up to 6 weeks after pregnancy. The care of five women who died between six weeks and six months after pregnancy were reviewed for the purposes of this chapter, but the deaths of two women which occurred more than 6 months after they gave birth were thought to be unlikely to be related to pregnancy, thus the care of 37 women was reviewed for the purposes of this chapter. The maternal mortality from venous thromboembolism during pregnancy or up to six weeks after the end of pregnancy in the UK was 1.39 per 100,000 maternities in 2014-2016 (95% CI 0.95-1.96) compared to 1.01 per 100,000 in 2011-2013 (95% CI 0.65-1.50). There has been no significant change in mortality due to venous thromboembolic disease since 2009 ( $p=0.664$ ) (Figure 4.1).

Figure 4.1: Maternal mortality from venous thromboembolism, 3 year rolling rates UK 2009-16



Of the 35 women who died from pulmonary embolism 12 collapsed antenatally, three following a first trimester pregnancy loss, and 20 postnatally. Of the 20 women who collapsed postnatally 14 had been delivered by caesarean section and 6 had vaginal births. Of the 12 who collapsed antenatally 6 deaths were in the first trimester, 2 were in the second trimester and 4 were in the third trimester.

Overall, of the 37 women who died and whose care was reviewed for the purposes of this chapter, 21 women (57%) had a BMI  $\geq 30\text{kg/m}^2$ , a further 6 (16%) had a BMI  $\geq 25\text{kg/m}^2$  but  $<30\text{kg/m}^2$ . BMI was missing for 3 (8%) women. Nine women (24%) smoked, 25 (68%) had either never smoked or given up before pregnancy and smoking status was unknown for 3 (8%). Seven of the 9 women who smoked (78%) were obese (BMI  $\geq 30\text{kg/m}^2$ ). Twenty-six (70%) women were aged under 35 when they died, 7 (19%) were aged 35-39 and 4 were aged 40 or over.

In 69% (22) of the 32 women who died during pregnancy or up to 6 weeks following pregnancy improvements in care may have made a difference to the outcome.

## 4.4 Overview of care and lessons to be learned

### Women at risk in early pregnancy

A worryingly high proportion of women died in the first trimester; seven women died whilst still pregnant and three following a first trimester pregnancy loss. Although three women had a BMI of over  $40\text{kg/m}^2$ , with the highest BMI among the women who died in the first trimester being  $56\text{kg/m}^2$ , none had other or sufficient risk factors for antenatal prophylaxis to be started at diagnosis of pregnancy. Two women were known to have sickle cell trait, but while sickle cell anaemia is a known risk factor for thromboembolism, the evidence is less clear for sickle cell trait, and guidelines vary as to whether it should be considered (Scottish Intercollegiate Guidelines Network 2014, Royal College of Obstetricians and Gynaecologists 2015a). Nevertheless sickle cell trait alone would not have led to antenatal prophylaxis in any guidance.

Importantly risk assessment and thromboprophylaxis (low molecular weight heparin, LMWH) prescription should take place as early as possible. To enable this, service designer/commissioners and local primary and secondary care providers need to work together to ensure efficient and effective care pathways allowing women to receive their LMWH prescription in a timely fashion.

In three women, the importance of other early pregnancy complications and their association with risk of VTE was not recognised.

A woman died after a septic miscarriage. There were delays in emptying her uterus and delays in further surgery despite ongoing sepsis. Thromboprophylaxis was not initiated and she died from a pulmonary embolism, although a number of improvements were also identified in her sepsis care, in particular the need for earlier source control.

This woman's death emphasises the significance of the relationship between sepsis and VTE. Current systemic infection (requiring intravenous antibiotics or admission to hospital) is a recognised risk factor for VTE and guidelines emphasise the importance of ongoing reassessment of risk to take these factors into account

After a woman with known substance dependence had surgical management of an ectopic pregnancy no risk assessment for VTE was carried out. When she presented with shortness of breath and tachycardia the focus was on concern about possible withdrawal symptoms though the cause of her symptoms was the pulmonary embolism from which she died.



Although it is unclear whether women undergoing surgical management of miscarriage and surgical termination of pregnancy are at increased risk of VTE, assessment of VTE risk after any surgical procedure ending pregnancy is as important as assessment postnatally. Any surgical procedure in pregnancy or the puerperium gives a score of 3 in the RCOG guidance (Royal College of Obstetricians and Gynaecologists 2015a), therefore postnatal thromboprophylaxis is indicated. In this instance, this woman should have received 10 days of thromboprophylaxis. In addition, when she presented with her respiratory symptoms and tachycardia, her co-morbid substance misuse distracted from a proper assessment which would have led to diagnosis of her VTE.

**If women need thromboprophylaxis as soon as they become pregnant there should be clear pathways for them to access prescriptions and support to ensure compliance.**

**Reassessment of VTE risk after miscarriage or ectopic pregnancy to consider whether thromboprophylaxis is required is as important as reassessment of risk after giving birth.**

**Any surgical procedure in pregnancy or the puerperium gives a score of 3 in the RCOG thromboprophylaxis guidance, indicating that 10 days of postnatal thromboprophylaxis should be considered (Royal College of Obstetricians and Gynaecologists 2015a).**

## Risk assessment and prescribing thromboprophylaxis

### Consistency of risk assessment

It was apparent from the reviews undertaken that risk assessment is not interpreted consistently. In a number of instances assessors noted that local, simplified versions of national risk assessment scoring frameworks had been produced. These appeared to have significant deviation from national guidance and it was not clear on what basis the simplifications had been made. This inconsistency in risk assessment was noted between units and between clinicians caring for the women who died, but also between MBRRACE assessors reviewing the same woman's care. This shows that there is considerable confusion as to how best to perform risk assessment for whether thromboprophylaxis is required and about the duration of thromboprophylaxis. Although measures are in place to ensure that risk assessment takes place, there is no assessment of the quality and consistency of that assessment. There is a need for ongoing audit of whether that assessment is consistent with guidance as well as whether it is carried out.

**Audits should be conducted not only to assess whether thromboembolism risk assessment was performed, but also whether the calculated risk score was correct.**

A simpler form of risk assessment could also ensure consistency. There seems to be variation as to who performs risk assessment from anaesthetists after a caesarean section to obstetricians and midwives. Whichever professional performs the risk assessment there needs to be consideration of all relevant factors and a clear plan as to the duration of treatment.

A feature assessors noted was that several morbidly obese women did not meet the criteria for antenatal thromboprophylaxis as this was their only risk factor. 8 of the 37 women had a BMI  $\geq 40$ kg/m<sup>2</sup>. Whilst this should lead to postnatal thromboprophylaxis four women were undelivered when they died and not receiving thromboprophylaxis. The RCOG guideline (Royal College of Obstetricians and Gynaecologists 2015a) states that risk is higher with increasing obesity so some degree of individual assessment is required for women with extreme obesity, taking into account other factors such as their mobility status to judge whether they qualify for LMWH. It was not clear that any of these women had been given information about the symptoms of VTE in pregnancy.

**There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply consistently in practice. There is an urgent need for development of a tool to make the current risk assessment system simpler and more reproducible.**

**Women with a high BMI should be given information about the symptoms of VTE.**

**Women with a BMI  $\geq 40\text{kg/m}^2$  score 2 points on the RCOG guideline for thromboprophylaxis in pregnancy and therefore all need postnatal thromboprophylaxis regardless of mode of delivery (Knight, Tuffnell et al. 2015).**

### **Electronic records**

As highlighted above, risk assessment in the first trimester is also important and assessors noted that in some instances where units are using electronic records the GP did not have access to the antenatal records. This makes accurate risk assessment in primary care more difficult.

Difficulty with electronic record systems was reflected in the assessments undertaken for the enquiry as the multiple electronic record systems made reviewing women's care more difficult. Some of the records when converted to documents outside the system became unintelligible. This is likely to generate challenges for external review in many similar situations and is an important consideration which needs to be taken forward as electronic patient records develop and supersede paper records.

**As electronic patient records systems develop, issues of access from outside individual units need to be taken into account, not only for direct patient care but also for external review processes such as the Confidential Enquiries.**

### **Reassessment of risk**

An older woman with a pregnancy as the result of assisted reproductive techniques collapsed immediately after a caesarean section. She had been an inpatient for 10 days prior to the caesarean section with pre-eclampsia but had not been given thromboprophylaxis.

As was highlighted in the care of women who died after first trimester pregnancy losses, risk factors change throughout pregnancy and ongoing risk assessment must continue throughout pregnancy. In this instance, the woman's admission to hospital alone placed her at intermediate risk and antenatal thromboprophylaxis should have been considered. Admission alone increases VTE risk 12 fold (Royal College of Obstetricians and Gynaecologists 2015a). Her pre-eclampsia was a further risk factor which indicated she should have antenatal thromboprophylaxis from 28 weeks gestation.

**Risk assessment for venous thrombosis (VTE) should be undertaken at booking and repeated at any hospital admission, intrapartum or immediately postpartum and before discharge from hospital. (Knight, Tuffnell et al. 2015)**

**Antenatal admission places a woman at intermediate risk of VTE and she should be considered for antenatal thromboprophylaxis (Royal College of Obstetricians and Gynaecologists 2015a).**

## Symptoms/signs of VTE

Four women who died antenatally and two who died postnatally presented with symptoms and signs that were potentially indicative of VTE but appropriate investigation did not happen. In one woman repeated episodes of tachycardia and breathlessness were attributed to anxiety and she had a cardiac arrest a few days later. Two women with leg pain in the first trimester either did not have investigations or were not followed up.

A woman with a BMI of 46kg/m<sup>2</sup> had calf pain and breathlessness at 8 weeks gestation. She attended the emergency department and was given one dose of low molecular weight heparin. However no investigation or follow up of treatment took place. She was seen in primary care with 'anxiety' and managed for a presumed pulled muscle for two weeks. She died a week later from a pulmonary embolism.

The pathway for women with potential signs of VTE to seek medical attention needs to be clear. Midwives seem to tell women to go to the GP, but it is not clear whether women are always aware of the urgency with which they need to be seen and assessed by a medical professional. Women should be advised not to delay and/or local systems should ensure that the pathways for referral are appropriate and rapid. Clinicians also need to be aware that with pulmonary embolism in pregnancy there may be no signs in the legs. This can mean a leg Doppler can be negative, and if clinical suspicion of PE is high, V/Q or CTPA should be undertaken.

A woman was admitted in the third trimester and had leg pain and shortness of breath. She smoked and had a high platelet count. She was seen by a student midwife and junior doctor. The student's midwifery mentor was not present. No investigation of these symptoms and no escalation to senior staff took place. She died from a subsequent massive pulmonary embolism.

If, after review, there is uncertainty about a diagnosis or management plan, then senior review should be sought. In this instance escalation to a senior may have led to detection and treatment of this woman's VTE and prevented her eventual death.

**Individual hospitals should have an agreed protocol for the objective diagnosis of suspected VTE during pregnancy (Royal College of Obstetricians and Gynaecologists 2015b).**

**Management [of life-threatening PE] should involve a multidisciplinary team including senior physicians, obstetricians and radiologists.(Royal College of Obstetricians and Gynaecologists 2015b).**

## Commencing treatment, dose and compliance

A woman with a BMI over 35kg/m<sup>2</sup> was in lithotomy for 90 minutes for suturing of vaginal and cervical tears. She had multiple 'fainting' episodes postnatally that were not investigated until day 44. She was admitted to a medical unit where the diagnosis was considered but they delayed LMWH because of concerns over breastfeeding. A few hours later she collapsed and died.

Thromboprophylaxis should be started as soon as is clinically appropriate after birth. In very high risk women it is possible to give unfractionated heparin around the time of labour and birth as its effect can be reversed quickly. Women who have had a major haemorrhage or surgery for morbidly adherent placenta or with signs of sepsis are at risk for VTE, therefore prolonged delays before thromboprophylaxis is started should be avoided. Physicians need to be aware that breast feeding is not a contraindication to commencing treatment.

Ensuring the appropriate dosage is prescribed is important once the need for thromboprophylaxis has been determined. This enquiry has previously noted that a woman's weight needs to be rechecked in the third trimester but it also needs to be checked postnatally. Women will need to be weighed again to risk assess and ensure the correct dosage is advised.

A woman with a BMI over 40kg/m<sup>2</sup> who smoked heavily needed a six week supply of postnatal thromboprophylaxis. She was only given sufficient for two weeks. She developed a DVT in the postnatal period and was treated with rivaroxaban but died two weeks later. While review of her care shows compliance may have played a role in the failure of treatment, the complete course of LMWH was not supplied from secondary care leading to an interruption of her prophylaxis which should have continued for six weeks.

This was the only instance amongst the women who died of a woman being discharged with an insufficient course of thromboprophylaxis so it does appear that units are now ensuring a full course is provided. However issues with risk assessment meant that in some instances the duration of treatment was shorter than it should have been. Some women also received an inadequate dose for their weight.

**Prescriptions for the entire postnatal course of LMWH should be issued in secondary care. This will help ensure that women receive the full course without the need to visit their GP to obtain another prescription. This also provides a double safety net since the prescription will be checked by a hospital pharmacist, who ensures the correct weight-appropriate dose is dispensed. (Knight, Tuffnell et al. 2015)**

It was difficult in a number of women's records to confirm that there was compliance with thromboprophylaxis or treatment after discharge from hospital. Rivaroxaban was prescribed, as described above, in this woman who required postnatal treatment for at least three months. Use of rivaroxaban is not in current guidance and data about rivaroxaban and breastfeeding are lacking, however, it can be used where women decline LMWH injections. Ensuring women are aware of the importance of postnatal injections or tablets is imperative. This may be assisted by regular enquiries by any health care professional, including community midwives or maternity care assistants as to whether women have any concerns over self-administering their treatment.

### Management of the acute event

A woman with a BMI of over 40kg/m<sup>2</sup> had an emergency caesarean section. She had not had an antenatal VTE risk assessment. Postnatally her risk was incorrectly scored so she had a shortened duration of treatment. She collapsed three weeks postnatally at home and the ambulance crew persisted with resuscitation in the home so she did not leave her home until 53 minutes after the ambulance arrived. At hospital she was given thrombolysis but resuscitation was discontinued after 39 minutes.

If the acute event occurs in the community then early transfer to an acute setting is appropriate as this may allow thrombolysis. From review of the cases there was an impression that more thrombolysis was being performed in the acute setting which is encouraging. However, it is important to remember that after thrombolysis more prolonged resuscitation is appropriate before determining that treatment has not been successful. Nevertheless, there were still instances where thrombolysis was not considered or was inappropriately considered to be contraindicated. Echocardiography can be helpful in the acute phase to assess whether a pulmonary embolus is the diagnosis.

A woman with a BMI of over 40kg/m<sup>2</sup> had some calf pain antenatally that was not investigated. She had a caesarean section. She felt unwell in the hours immediately after surgery but this was not escalated to medical staff. She collapsed five hours later. There were further delays in diagnosis and initiating treatment as senior staff were busy with another woman. However once senior staff were available, bedside echocardiography supported the diagnosis of PE, following which she received thrombolysis. Unfortunately she could not be resuscitated.

**Neither pregnancy, caesarean section delivery or the immediate postpartum state are absolute contraindications to thrombolysis. (Knight, Kenyon et al. 2014)**

### Venous sinus thrombosis

There were two women who died from venous sinus thrombosis (VST), one postnatal and one antenatal. The symptoms of headache were ascribed to other illness despite no real features to support that and the diagnosis of VST was not considered. Neither woman underwent appropriate imaging. Atypical severe headache in pregnancy or postpartum should prompt the involvement of the obstetric medical team and appropriate investigation.

**Brain CT may not diagnose venous sinus thrombosis. CT venography or MR venography is required.**

## 4.5 Conclusions

The overwhelming theme identified in the reviews of the care of the women who died from VTE was inconsistency of risk assessment. This is reflected in the assessment that for two thirds of women, improvements in care were noted that may have made a difference to their outcome (Table 4.1). The inconsistency stemmed from confusion over interpretation of national guidance, local interpretation of national guidance, and a lack of reassessment at points when women's risk changed during pregnancy. There is an urgent need for action to address this. Coupled with this is a need to consider the pathways of care for women in the first trimester who have risk factors for VTE and to ensure that they receive thromboprophylaxis early in pregnancy where appropriate. Raising awareness of the symptoms of VTE among women with a high BMI, in particular, may be needed to prevent women from dying from VTE in early pregnancy.

**Table 4.1: Classification of care received by women who died from thrombosis and thromboembolism, UK and Ireland, 2014-16**

Classification of care received	Women who died from VTE Number (%) N= 37 (including 5 late)
<b>Good care</b>	6 (16)
<b>Improvements to care which would have made no difference to outcome</b>	6 (inc. 2 late)(16)
<b>Improvements to care which may have made a difference to outcome</b>	25 (inc. 3 late)(68)

## 5. Messages for mental health

Roch Cantwell, Esther Youd and Marian Knight on behalf of the MBRRACE-UK mental health chapter-writing group

Chapter writing group members: Kathryn Bunch, Roch Cantwell, Philippa Cox, Bill Fawcett, Linda Ibbetson, Hemali Jayakody, Sara Kenyon, Marian Knight, Rohit Kotnis, Jenny Kurinczuk, Kim Morley, Judy Shakespeare, Derek Tuffnell, Esther Youd

### 5.1 Key messages

There is an urgent need to establish pathways for release of mental health records with the Chief Medical Officers and Departments of Health of Ireland and the four UK nations to MBRRACE-UK. **ACTION: Policy makers**

Liaison, crisis and home treatment staff should have specific training, at induction and continuing professional development, in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women. Formal links should be made with local specialist perinatal mental health services to facilitate training. **ACTION: Service planners/commissioners, service managers, health professionals**

Assessments should always include a review of previous history and always take into account the findings of recent presentations and escalating patterns of symptoms, their severity and any associated abnormal behaviour. **ACTION: Service managers, health professionals**

Decisions on continuing, stopping or changing medication in pregnancy should be made only after careful review of the benefits and risks of doing so, to both mother and infant. **ACTION: Professional organisations, all health professionals**

Women should receive continuity of mental health care. Where more than one mental health team is involved, there should be a clearly identified individual who co-ordinates care. **ACTION: Service planners/commissioners, service managers, health professionals**

In women facing multiple adversity, changes in frequency or nature of presentations may reflect worsening mental state or the emergence of new complications (such as alcohol or substance misuse or interpersonal violence), and should prompt renewed attempts at engagement, diagnosis and care co-ordination. **ACTION: Service managers, health professionals**

New expressions or acts of violent self-harm, or new and persistent expressions of incompetency as a mother or estrangement from the infant are 'red flag' symptoms and should always be regarded seriously. **ACTION: Health professionals**

Self-harm in pregnancy or the early postpartum period is an unusual event, and should always prompt referral for continuing evaluation, ideally by specialist perinatal mental health services. **ACTION: Service planners/commissioners, service managers, health professionals**

Mental health services should work to minimise barriers to care for women in pregnancy and the postnatal period, recognising the need for lowered thresholds and direct access for maternity and primary care professionals. **ACTION: Service planners/commissioners, service managers, health professionals**

### 5.2 Background

The 2015 report was the first to review the care of all women who died by suicide in pregnancy or up to one year postpartum (Knight, Tuffnell et al. 2015); prior to MBRRACE-UK only deaths after 42 days were reviewed if they were notified to the confidential enquiry, whereas the MBRRACE-UK team seeks to identify and review all deaths by suicide up to one year after the end of the pregnancy. Since then, the importance of maternal mental health continues to be increasingly recognised, with announcements of new funding for perinatal mental health services, new perinatal mental health networks (The Scottish Government 2017), and a new model of care for Ireland with respect to specialist perinatal mental health services (Health Service Executive 2017). However, the latest mapping from the Maternal Mental Health Alliance still identifies large gaps in quality perinatal mental health care (Maternal Mental Health Alliance



2017), and women in large parts of both the UK and Ireland have no access to inpatient mother and baby unit care in their area and close to support from family and friends. These gaps in service provision exist despite an estimated 10% of women experiencing a mental health problem during pregnancy or postpartum (National Institute for Health and Care Excellence 2014a). The care of all women who died by suicide during pregnancy or up to one year after pregnancy in 2014-16 in the UK and Ireland was reviewed for the purposes of this chapter, thus the care of all women who died by suicide up to one year after pregnancy has now been reviewed for a continuous period of 8 years.

**Table 5.1: The socio-demographic characteristics of women who died by suicide 2014-16 in the UK and Ireland**

Characteristics	Suicide (n=71) Frequency (%)
<b>Age</b>	
<20	2 (3)
20 – 24	8 (11)
25 – 29	22 (31)
30 – 34	18 (25)
35 – 39	17 (24)
≥ 40	4 (6)
<b>Parity</b>	
Nulliparous	15 (21)
Multiparous	51 (72)
Missing	5 (7)
<b>UK or Irish citizen</b>	
Yes	65 (92)
No	2 (3)
Missing	4 (6)
<b>Ethnicity</b>	
White	61 (86)
Black or other minority ethnic group	7 (10)
Missing	3 (4)
<b>Woman's region of birth</b>	
United Kingdom or Ireland	53 (75)
Remainder of Europe	4 (6)
Outside Europe	4 (6)
Missing	10 (14)
<b>Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)</b>	
First quintile (Least deprived)	8 (11)
Second quintile	6 (9)
Third quintile	8 (11)
Fourth quintile	13 (18)
Fifth quintile (Most deprived)	13 (18)
Missing	15 (21)
<b>Socioeconomic status (Occupational classification)</b>	
Employed (Either woman or partner)	16 (23)
Unemployed (Both)	35 (49)
Missing	21 (30)
<b>Able to speak/understand English</b>	
Yes	68 (96)
No	1 (1)
Missing	2 (3)
<b>Living arrangements</b>	
With partner	49 (69)
Living alone	13 (18)
With parents/extended family	2 (3)
Others	1 (1)
Missing	6 (8)
<b>Domestic abuse (prior to pregnancy/ during pregnancy)</b>	
Yes	17 (24)
No	12 (17)
Missing	42 (59)
<b>Known to social services</b>	
Yes	28 (39)
No	35 (49)
Missing	8 (11)



## 5.3 The women who died

Seventy-one women died by suicide during pregnancy or up to one year after pregnancy in 2014-16 in the UK and Ireland, a mortality rate of 2.9 per 100,000 maternities (95% CI 2.2-3.6). This compares to a rate of 2.3 per 100,000 maternities (95% CI 1.9-2.8) in 2009-13 ( $p=0.210$ ), and a suicide rate of 4.2 per 100,000 (95% CI 3.4-5.1) amongst the general population of women (including pregnant and postpartum women) aged 25-29 in 2016 in the UK (Office for National Statistics 2017). Overall, including the 43 women whose deaths were related to drug and alcohol misuse and who are further discussed in chapter 6, 114 women died from mental health-related causes during or up to one year after pregnancy in the UK and Ireland, a mortality rate of 4.57 per 100,000 maternities (95% CI 3.77-5.48).

### Characteristics

The women who died by suicide had a median age of 30 years, 86% were of white ethnicity and 91% were UK or Irish citizens (Table 5.1). Over two thirds (71%) were multiparous. Twenty-eight women (39%) were known to social services. Almost a quarter (24%) had a known history of domestic abuse, but for 59% complete information was missing. This compares to a known history of domestic abuse for 9% of women who died from other causes, with a similar level of missing information. Eighty-six percent of women who died by suicide received some antenatal care but only 31% of those who received antenatal care received the recommended level of care. One in five (21%) booked at greater than 12 weeks' gestation.

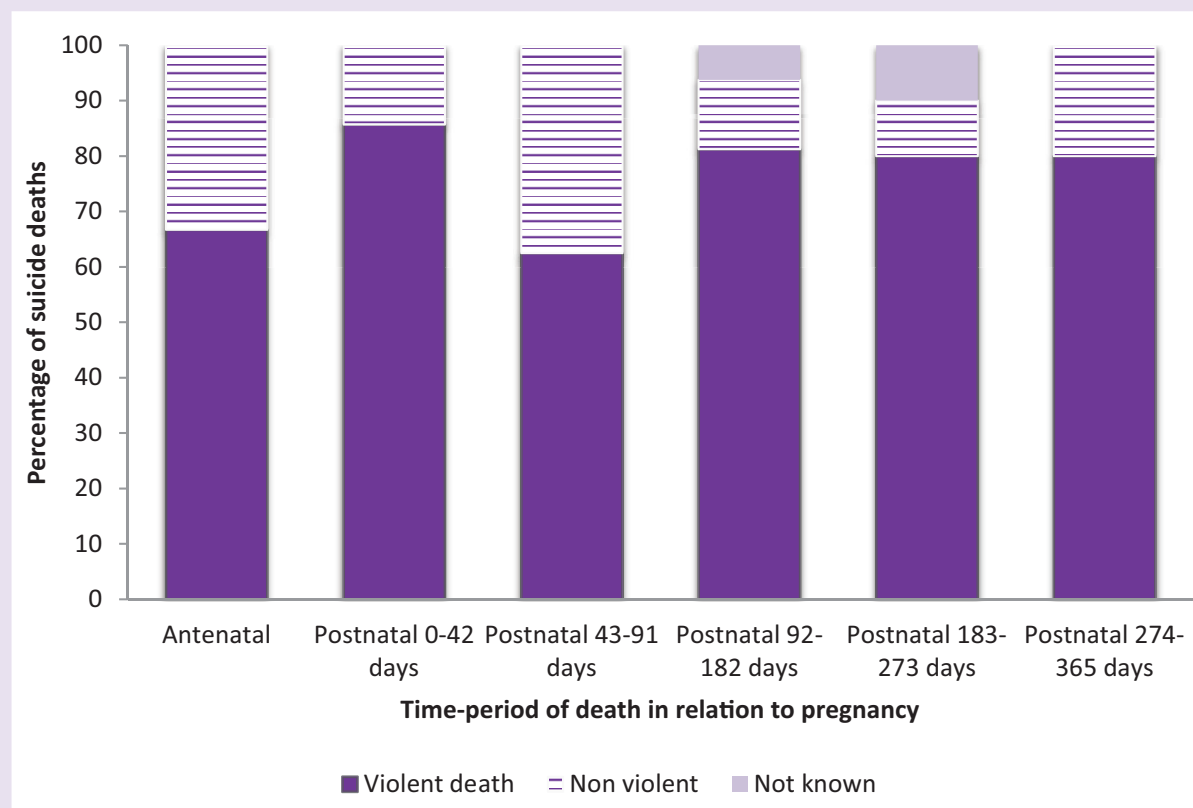
### Timing

Women's deaths were distributed almost evenly across the postnatal period, with only one in eight occurring antenatally (Table 5.2). As reported in previous Enquiry reports, most women died by violent means (Figure 5.1).

**Table 5.2: Timing of the deaths of women who died by suicide in relation to pregnancy, UK and Ireland 2014-16**

Time period of deaths in the pregnancy care pathway	Suicide (n=71) Frequency (%)
Antenatal period	9 (13)
Postnatal 0 to 6 weeks after delivery (0-42 days)	7 (10)
Postnatal more than 6 weeks but less than 3 months after delivery (43-91 days)	8 (11)
Postnatal 3 months or more but less than 6 months after delivery (92-182 days)	17 (24)
Postnatal 6 months or more but less than 9 months after delivery (183-273 days)	20 (28)
Postnatal 9 months or more but less than 12 months after delivery (74-365 days)	10 (14)

**Figure 5.1: Timing of violent suicide deaths in relation to pregnancy, UK and Ireland 2014-16**



P-value for chi-square test for difference in proportion of violent and non-violent deaths across the time period=0.546

## Diagnosis

Attribution of diagnosis presents a challenge for the enquiry, not least because of the almost complete absence of mental health records made available for review. For most women, diagnosis has been inferred indirectly from those given in maternity or primary care records, and/or based on symptom patterns described. Nevertheless, as in the previous report, the most common diagnosis was of recurrent depressive disorder and the majority of women had a prior history of mental ill health at some point in their lives. Notably, very few women had previous psychotic disorder, whether bipolar, postpartum or non-affective.

## 5.4 Overview of care and lessons to be learned

Maternity care and/or primary care records, together with some mental health records, were available for detailed review for 68 of the 71 women who died by suicide.

### Good care

A woman with no past history of mental health contact died by violent means a few weeks after the birth of her first child. She was asked all appropriate questions about her mental health in pregnancy and received good antenatal and postnatal care. She left a suicide note but gave no indication at any point before her death of any mental health concerns.

While there continue to be important lessons to learn, old and new, there were a few women, including the woman described above, who died in the absence of any prior indication of ill health. There were also examples of good care by staff who went to great lengths to support and treat women. The complexity and severity of the illness of the woman described below posed major challenges for the treating team and it was evident that they strived to achieve a good therapeutic alliance with her and her family.

An older woman died by violent suicide several months after the birth of her child. She had a prior history of anxiety and depression. There were problems with her baby's development, diagnosed in pregnancy, leading to the woman developing more significant depressive disorder. She was well supported by maternity staff and appropriately referred to her specialist perinatal mental health service. She was seen rapidly by a community psychiatric nurse and, within a day, by the consultant. A plan was put in place for her management, including antidepressant medication, close follow up and mother and baby unit admission after delivery. On the mother and baby unit her severe illness presented a challenge to those attempting to form a therapeutic relationship with her. Consideration was given to ECT. Her admission was prolonged and a careful plan was made for gradually increasing time out, with good family involvement, but she took her own life while on leave.

## Repeated recommendations

### Previous history and good communication

Every previous report has highlighted the importance not just of recognising risk where there is prior mental ill health, but also communicating that risk to all professionals involved in the woman's care.

A woman died by hanging four months after giving birth. She had a prior history of depression, eating problems and self-harm, but this was not passed on to maternity services. Maternity services were therefore unaware of a return of her eating difficulties in pregnancy. In the postpartum period she disclosed concerning thoughts about ending her own, and her children's lives but this information was not shared among professionals. She was seen by a range of different professionals but her care was not well co-ordinated, leading to a poor response to worsening mental ill health.

**There is a clear duty on all health professionals to pass on relevant information that may affect the care a woman receives during pregnancy or alter her outcomes.**

**GPs should inform maternity services of any past psychiatric history and maternity services should ensure that the GP is made aware of a woman's pregnancy and enquire of the GP about past psychiatric history (Knight, Tuffnell et al. 2015).**

**If the woman is already known to mental health services, they should be made aware that she is pregnant, and they have the same duty of care to the woman to inform maternity services of any risk she faces.**

## Red Flags

The 2015 Report (Knight, Tuffnell et al. 2015) highlighted a number of clinical scenarios that should act as 'red flags' for professionals. They include (i) recent significant change in mental state or the emergence of new symptoms, (ii) new thoughts or acts of violent self-harm and (iii) new and persistent expressions of incompetency as a mother or estrangement from the infant. This enquiry confirms their importance.

### Box 5.1 'Red Flag' presentations which should prompt urgent senior psychiatric assessment

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

A woman died by hanging several months after the birth of her first child. She had prior treatment for depression, appropriately detected by maternity staff. She reported early postpartum mood lowering and her GP altered her antidepressant treatment and made a referral to mental health. She expressed strong beliefs that her baby deserved a better mother than her, repeating these to the health visitor and mental health team. She described worsening suicidal thoughts of a violent nature but they were described as 'fleeting' by mental health staff. She was accepted for intensive home treatment but died before that commenced.

In addition to demonstrating all three 'red flags', this woman's care also highlighted previous lessons regarding the downgrading of suicide risk through use of shorthand terms such as 'fleeting' or 'impulsive' to equate with lack of intent.

A woman died by hanging several months after the birth of her third child. She had a history of depression with self-harm in the past, which was communicated to maternity services. She had worsening anxiety and depressive symptoms postnatally. On the day she died she contacted her GP to say she had made an attempt on her life. An appointment was made for the following day, by which time she had died.

This woman's presentation starkly demonstrates the need for an urgent response to thoughts or acts of violent self-harm. Making an appointment for review the following day is not appropriate.

**Assessments should always include a review of previous history and always take into account the findings of recent presentations and escalating patterns of symptoms, their severity and any associated abnormal behaviour.**

**New expressions or acts of violent self-harm are 'red flag' symptoms and should always be regarded seriously.**

**New and persistent expressions of incompetency as a mother or estrangement from the infant are 'red flag' symptoms and may be indicators of significant depressive disorder. In some instances, this may reflect psychotic thinking. In the presence of significant illness, such symptoms may be best addressed through inpatient mother and baby care (Knight, Tuffnell et al. 2015).**

### Amber flags and forward planning

The 2017 Psychiatric Morbidity Review (Knight, Nair et al. 2017) highlighted the care of women who had a pre-existing major mental disorder which placed them at risk in future early postpartum periods. A past history of psychosis and significant family history were identified as 'amber flags' and are echoed in this report examining the care of women who died.

A woman died by violent means several months after the birth of her second child. She had experienced depressive disorder after her first delivery, with suicidal thinking, and was later diagnosed with bipolar affective disorder. There was a strong family history of the same illness. In her discharge from mental health services, several months before the index pregnancy, there was no mention of future postpartum risk or risk minimisation strategies. Her past history was elicited by maternity services and she was referred for specialist review. However, there is no record of her being seen by mental health services in pregnancy. She showed evidence of early postpartum recurrence but, despite periods of inpatient treatment, her subsequent care was characterised by limited recognition of significant risk or an appreciation of the importance of her past history in predicting future risk.

This woman did not receive the information she required, after her first pregnancy-related illness, to make an informed choice about risk minimisation strategies and care in future pregnancies. Mental health services did not appreciate the significant risk she was under and the opportunities available for reducing her risk, including recognition of early postpartum change in mental state, the need for close follow up where high risk exists, the importance of ensuring continuity of care and the recognition of, and acting upon, escalating patterns of self-destructive behaviours.

#### **Recommendations – Amber Flags**

**Regard women with any past history of psychotic disorder as at elevated risk and requiring individualised assessment of risk.**

**Closely monitor women with a family history of bipolar disorder or postpartum psychosis and refer if any change in mental state. If they themselves have any mood disorder or history of postpartum mood destabilisation they should have an individualised assessment of risk.**

**Personal and familial patterns of occurrence and re-occurrence should inform risk minimisation strategies (Knight, Nair et al. 2017).**

#### **Recommendations – Forward planning for future risk**

**Following recovery, it is the responsibility of the treating team to ensure that all women experiencing postpartum psychosis receive a clear explanation of:**

- **future risk**
- **the availability of risk minimisation strategies**
- **the need for re-referral during subsequent pregnancies**

#### **Crisis, liaison and home treatment team training**

A mother with no prior history of mental illness presented to her GP with low mood six months after giving birth. She was treated with antidepressants in primary care. One week before her death she presented to the Emergency Department describing low mood with suicidal ideas. She was noted to be slowed in her speech. Her mother had to prevent her from harming herself violently earlier in the day. A consultant psychiatrist advised admission but beds were 'gate-kept' by the crisis resolution/home treatment team, who judged she could be managed at home. She died by hanging shortly afterwards.

While specialist perinatal mental health teams may be aware of the distinctive presentations and risks associated with perinatal mental illness, the enquiries have repeatedly noted that further training is required for other teams managing acute presentations.

**Liaison, crisis and home treatment staff should have specific training, at induction and continuing professional development, in understanding the distinctive features and risks of perinatal mental illness if they are to provide emergency and out-of-hours care for pregnant and postnatal women. Formal links should be made with local specialist perinatal mental health services to facilitate training.**

## Mother and Baby Unit (MBU) availability

As in previous reports, there were a number of examples where emphasis was placed on keeping women out of hospital, even where there were clear indications that admission to a mother and baby unit was needed. At times, it was unclear whether the option of admission had even been considered or broached with the woman and her family. For other women, while there were periods of admission, they were to general psychiatry wards, resulting in separation from the infant and poor engagement with care.

A young woman died by overdose in the months following the birth of her third child. She had significant early life adversity, a family history of significant mental disorder, a prior history of depression and poor physical health. She struggled to cope during pregnancy and developed a steadily worsening depressive disorder in the postnatal period. She was referred to mental health services five weeks after giving birth. She self-harmed, in a medically serious manner, on at least three occasions, and was admitted to general psychiatric inpatient wards at least twice. Her admissions were very brief, terminating in her taking her own discharge, despite evidence of mounting risk. At no point was admission to an MBU suggested. This may have resulted both in improved engagement with care and a more longitudinal approach to her difficulties.

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

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

(Knight, Tuffnell et al. 2015)

## Experience of loss

A number of women died by suicide in the time after a pregnancy or postnatal loss. These included loss through miscarriage, termination, and neonatal or infant death. As in previous reports, suicide also followed removal of the infant into care. For some women, pre-existing mental health difficulties were exacerbated by the loss.

An older woman with longstanding anxiety problems died by violent suicide. She was seen by mental health services in pregnancy with anxiety and depressive symptoms, including thoughts of self-harm. Her difficulties persisted in the postnatal period. She remained under psychiatric care and was commenced on antidepressant medication. Her death occurred within days of the accidental death of her baby.

This woman's death highlights the vulnerability after loss, particularly where there is underlying mental illness.

A woman with a long history of depression and alcohol misuse died a few weeks after the removal of her children into care. Her antidepressants had been discontinued by her GP in the first trimester and she had subsequently self-harmed during pregnancy. In the postnatal period, her behaviour was erratic, with excessive alcohol use. There was little communication between her GP and health visitor concerning her risk at the time of child removal.

This woman, like many others, had multiple psychological and social difficulties, including mental illness and substance misuse. However, the appropriate concern for the children's welfare was not matched by similar attention to her and communication between professionals could have been improved. In this, and other similar examples, there is evidence of professionals compartmentalising their responsibilities. Suicide prevention should be seen as all professionals' responsibility.

**Loss of a child, either by miscarriage, stillbirth and neonatal death or by the child being taken into care increases vulnerability to mental illness for the mother and she should receive additional monitoring and support (Knight, Tuffnell et al. 2015).**

### Partner and family involvement

Previous reports have highlighted the need to avoid placing too great a burden of care on other family members, and the importance of education for partner and family on perinatal mental illness, so they can support women to receive appropriate care.

A woman died by violent means several months after the birth of her child. She had a past history of depression following termination of pregnancy and showed evidence of early postnatal depressive symptoms. She re-presented to her Emergency Department some months later with significant depressive symptoms and a clear attempt at violent suicide on that day. By the time of mental health review several hours later, she denied ongoing suicidal intent (despite acknowledging her intent earlier on) and both she and her partner said they did not want any additional intervention. She was discharged and died the following day.

There are a number of lessons here, including the need for more senior review, or at very least discussion with a senior. There was no attempt to explain to her or her partner the risks she might face in view of her underlying significant mental illness.

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

### Grade of assessor

The 2015 report highlighted the importance of senior review for women experiencing changes in mental state in late pregnancy and the early postpartum (Knight, Tuffnell et al. 2015). For the woman described above, although her presentation was much later, there was still a lack of a more senior view on her care that might have recognised the significant risk she posed to herself.

**There should be an expectation of early consultant 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.**



## Care by multiple teams

Previously, it has been noted that women's care was characterised by discontinuities rather than being well co-ordinated. The nature of mental health service provision sometimes detracted from consistency of care.

A woman with known previous psychotic disorder died within days of the birth of her first child. Her infant died with her. During pregnancy, she was referred to her specialist perinatal mental health team, but they do not appear to have assumed main responsibility either for her care or its co-ordination. She was moved from one adult mental health team to a second in pregnancy, and her early postnatal review, while still on the maternity wards, was carried out by a different team again.

This woman's care highlights the need to minimise alterations to continuity of care during pregnancy and the postnatal period, and the central role that perinatal mental health services should play in overall co-ordination and in direct clinical contact, particularly around the times known to pose greater risk, such as assessments made in the early postpartum period. It is inevitable that other services will become involved in care where there is a need for intensive follow-up or presentation occurs out of normal working hours. As noted already however, this, and previous examples, demonstrate the importance of additional training for those teams in recognising the distinctive presentations and risks associated with the perinatal period.

**Women should receive continuity of mental health care. Where more than one mental health team is involved, there should be a clearly identified individual who co-ordinates care.**

## Extended suicide

As in previous reports, instances of infant or child death were extremely rare, occurring on only two occasions. For one woman, there was very clear evidence of underlying severe mental illness. In the second, there was insufficient information to make a diagnosis in retrospect.

## New messages for care

### Multiple adversities

There appears to have been a shift in the pattern of diagnoses among the women who died by suicide. A significant proportion had evidence of longstanding emotional instability, characterised by early life adversity, multiple social disadvantage, chaotic patterns of engagement and, not infrequently, co-morbid substance misuse. While this group is not new to the enquiry, their prevalence amongst women who die by suicide may have increased; changes in the way information was collected prior to 2009 makes this impossible to assess statistically. The consequences for their care are striking. For a number of women, professionals went out of their way to encourage engagement, but for others, there was a sense of therapeutic pessimism and a failure to enquire as to why the woman might be presenting in such a manner.

A young woman, who herself had a disrupted and inconsistent upbringing, died by violent suicide a few months after the birth of her second child. A GP record of previous depressive disorder was not passed on to maternity services. She denied substance use at booking though it subsequently emerged that she had a long history of prescribed opiate addiction. She found it difficult to engage with maternity services antenatally. She presented repeatedly in pregnancy with physical injury but no one questioned the possibility of domestic abuse. Her behaviour became more erratic in the postnatal period. She left the postnatal wards without informing staff and is reported as being verbally aggressive. Two months after giving birth she took an overdose but refused treatment in the Emergency Department. Within several days her mother had contacted services to say she was suicidal. A referral was made for crisis team involvement but she re-presented the following day having overdosed again. A CPN assessment found 'no mental health issues' despite ongoing suicidal ideas. Her children were subsequently removed from her care. She became homeless and had worsening physical health problems. She was seen by addictions services shortly before her death when her longstanding substance use was identified.

There were a number of very clear warning signs regarding this woman's previous difficulties that were not passed on, or detected, at booking or during her antenatal care. There were missed opportunities for engagement with mental health services. Overall, there was a failure to be curious or question the reasons behind her presentations, whether with physical injury in pregnancy or increasingly chaotic behaviour in the postnatal period. This lack of sensitive enquiry is repeated in the care of several other women. These opportunities presented themselves at times of change in pattern of presentation. While this is recognised in previous recommendations on symptom pattern, it bears modifying here to reflect the complexity seen in vulnerable populations.

**In women facing multiple adversity, changes in frequency or nature of presentations may reflect worsening mental state or the emergence of new complications (such as alcohol or substance misuse or interpersonal violence), and should prompt renewed attempts at engagement, diagnosis and care co-ordination.**

### Judgements based on diagnosis or social circumstances

There was evidence that putative diagnoses or the presence of psychosocial factors resulted in a judgement that risk was lowered. In many circumstances, the presence of impulsivity, substance misuse, or social adversity increases, rather than decreases, risk of self-harm and suicide.

A woman died by violent suicide six months after the birth of her sixth child. Her older children were not in her care and there was a history of significant domestic violence. She had a prior episode of depression, with a serious attempt on her life resulting in hospital admission, some years earlier in the context of her social and family difficulties. A decision was made to remove her child at birth. She had a recurrence of depressive disorder postnatally and was treated by her GP with antidepressants and regular review. She had worsening suicidal thoughts (all with a violent theme) and had to be stopped from acting on these by her partner. Her GP made an urgent referral to mental health services but it took a month for her to be seen. The recorded assessment contained little detail and concluded that she had an adjustment disorder in the context of adverse social stressors. She was discharged from care and died by hanging two days later.

For this woman, a more senior assessment may have recognised her real risk, rather than linking risk to diagnosis and social circumstances.

**While diagnosis and social circumstances should form part of a holistic risk assessment for self-harm and suicide, they should not be used to categorise women into simplified high or low risk groups.**

### Avoidance of care

An older woman developed early onset low mood and pervasive guilty ruminations over her care of her infant. She was appropriately referred to mental health services but disengaged despite significant concerns over her mental health. Five weeks later she had died by violent suicide.

Again, while not an entirely new message, the number of women who avoided, or disengaged from, care in the time leading to their deaths is striking.

A young woman, with no previous history of mental health problems, died by violent suicide some months after the death of her infant from an underlying medical problem. Her GP attempted to maintain regular contact but she avoided face-to-face meetings. She also declined contact with a bereavement counsellor. Her symptoms persisted but were ascribed to bereavement.

**Disengagement from care should be regarded as a potential indicator of worsening mental state. All professionals involved in the woman's care should be informed of non-attendances and assertive follow-up arranged where there is already concern regarding mental state or prior evidence of risk.**

### Self-harm

The 'red flags' noted in the 2015 Enquiry included the need to recognise thoughts or acts of violent self-harm as indicators of significant risk (Knight, Tuffnell et al. 2015). In this triennium, there were a number of women who self-harmed, sometimes by overdose, before going on to die by violent suicide. Acts of self-harm in pregnancy or the early postpartum period are unusual events. For that reason, they should prompt referral to specialist perinatal mental health services for review.

A woman from an immigrant background died by violent suicide mid-pregnancy. She had a one-year history of depressive symptoms treated in primary care, with overdose on one occasion pre-pregnancy. In her first trimester, she presented to the Emergency Department following an overdose, with tablets and alcohol, and lacerations to her wrists. While awaiting assessment she made attempts to strangle herself. A mental health assessment noted possible previous alcohol dependency but no acute mental illness. She was discharged without follow-up. At her booking, one week later, she was referred to perinatal mental health services. They rejected the referral based on the mention of alcohol problems, suggesting referral to addictions services instead. Her GP regarded this as an error and asked that the specialist referral proceed. She took a further overdose, with alcohol and attempted strangulation, a week later. The Emergency Department summary noted ongoing thoughts of ending her life but the mental health assessment categorised her act as 'impulsive'. Three weeks later she died violently.

This woman's care demonstrates the 'in the moment' assessments noted in the 2015 enquiry, where the use of the term 'impulsive' seems to ignore the pattern of escalating self-destructive behaviour and worsening mental state. In addition, two acts of significant self-harm in the second trimester of pregnancy, in a woman with a history of mental ill health, should result in urgent specialist perinatal mental health review. In this instance, the woman had been appropriately referred to specialist perinatal mental health services early in pregnancy but rejected without assessment on inappropriate grounds, despite challenge by the GP. Alcohol problems are not a reason to refuse to see women with serious mental health problems.

**Self-harm in pregnancy or the early postpartum period is an unusual event, and should always prompt referral for continuing evaluation, ideally by specialist perinatal mental health services.**

### Gatekeeping, silo-working and co-ordination of care

It has long been recognised that presentations in pregnancy and the postnatal period require a response that takes into account distinct symptom patterns, rapidity of escalation and need for altered thresholds for referral. In this enquiry, these messages are repeated, but there is also evidence that services tended to work in isolation, sometimes creating barriers to rapid assessment, and did not take an overview of complex presentations requiring clinical leadership and care co-ordination. The previous recommendation on care co-ordination is strengthened here to suggest that specialist perinatal mental health services should take on this responsibility where possible.

A woman died by violent suicide several months after the birth of her second child. She had a prior history of depression and a family history of suicide. She engaged poorly with recommendations (for medication and counselling) to manage low mood in pregnancy, but, despite repeated assessments by maternity staff and her GP, it was felt she did not meet the threshold for referral into secondary care mental health services. Specifically, she did not score highly enough on standardised assessment tools used as part of the referral criteria and not all maternity staff could access direct referral.

There were clear barriers to care for this woman. Over-reliance on pro-forma assessments limited access to secondary care services, and included restrictions on who could refer into services.

A woman died by violent suicide nine months after the birth of her third child. She was known to social services and had a history of anxiety, depression and self-harm. She attended very frequently at her GP practice. During pregnancy, she had multiple maternity admissions with varying physical symptoms. Repeated investigations did not reveal an underlying cause. She had four psychiatric reviews while still an inpatient, coming to differing diagnostic conclusions, and with little evidence of a plan for treatment or care co-ordination. In the first six postnatal weeks, she had three changes of antidepressant. She expressed violent suicidal intent on several occasions. She was seen by a number of different specialist mental health teams, received a variety of diagnoses, and ultimately died while awaiting assessment following an overdose.

A woman died by violent means a few months after the birth of her second child. She had a prior history of severe postpartum mental illness but, despite referral, she was not seen in pregnancy for risk assessment and management. She showed evidence of early postpartum recurrence. She had an escalating pattern of significant self-harm. She was seen by several different mental health teams and was admitted, on three occasions, each time to a different mental health inpatient setting. There was limited co-ordination of care or oversight of the pattern of symptom worsening.

Both these women presented very complex challenges and required senior care co-ordination. There was very limited evidence of joint working across teams to manage their care.

An older woman died by violent suicide almost a year after the birth of her first child. She had a prior history of mental ill health and required intensive post-natal mental health care, including two periods of hospitalisation. There was an extended period where her key worker was on leave and during that time there was no co-ordination with her health visitor despite significant concerns for her mental state.

The woman's care was significantly compromised by discontinuity, although the absence of her key worker was known and could have been planned for.

**Mental health services should work to minimise barriers to care for women in pregnancy and the postnatal period, recognising the need for lowered thresholds and direct access for maternity and primary care professionals.**

**Complex care co-ordination should be led by specialist perinatal mental health services where possible, and ensure continuity when key workers are absent.**

### Psychiatric co-morbidities

The 2017 Morbidity Report highlighted areas where physical health complaints caused diagnostic confusion and led to poor care planning (Knight, Nair et al. 2017). In this enquiry we noted a number of occasions where the woman's care was adversely affected by overshadowing from other psychiatric co-morbidities, which distracted clinicians from recognising developing suicidality.

A woman died by violent suicide a few months after the birth of her child. She had a long history of depressed mood, deliberate self-harm and eating difficulties. This was not fully passed on to maternity services and her worsening eating disorder was not picked up in pregnancy. In the postnatal period she also developed significantly worsening mood with suicidal ideation. She spoke of ending her life and said that she could understand how a mother could also end the lives of her children. The response was a referral to the eating disorder service. They proposed admission to treat her eating disorder and for her children to go into foster care. It subsequently transpired that she was judged to be suitable for home treatment but her children were still removed from her care. She died a few days later.

This woman's care focussed on her eating disorder, which, while clearly requiring treatment, nevertheless overshadowed her worsening depressive and suicidal symptoms. The final act of removal of her children, without providing additional support and risk management for her, was the act that likely led to her death.

**Evidence of suicidal thinking must be acted on, even where the focus of therapy is on another aspect of the woman's care.**

## Care of women in prison

There are a small number of women in this report who were imprisoned at the time of their deaths. Although they had access to psychiatric care, the strictures of prison routine, and lack of anticipation of care needs, caused significant problems for them at a particularly sensitive time.

A woman in her 30s died within a few days of the birth of her child. She had significant polysubstance misuse and her older children were in care. She had a history of overdosing. In pregnancy, she was seen by a prison psychiatrist and was followed up regularly. She repeatedly mentioned thoughts of self-harm, often linked to ongoing child protection procedures, but said that being pregnant was why she did not act on these thoughts. She last had contact with prison mental health services several days before she gave birth. She believed she would be able to remain in hospital with her baby after she gave birth until her baby was removed into care. However, she was moved back to prison without her baby but encouraged to visit daily and to express. Equipment for expressing was not always available to her in prison. On the day she died, she was informed that she could no longer visit her baby, but could express milk. She had no contact with prison psychiatric services in the postnatal period.

For this woman, there was a clearly increased risk in the postnatal period, particularly given the removal of her infant into care. The sudden change of plan by prison services, unavailability of equipment for expressing (a need which should have been anticipated) along with lack of psychiatric review, were likely to increase her sense of loss. In particular, no one asked her about thoughts of self-harm or suicide at a time that she herself had flagged up as more risky, and which is well documented from previous Enquiry reports.

Women who are imprisoned during pregnancy or in the postnatal period face the same range of risks as those in other settings, exacerbated by their particular circumstances, and by the increased risk of separation from their infant.

**Prison staff should be actively engaged in assisting the woman to plan for routine aspects of labour, birth and infant feeding, which may be affected by imprisonment, and should receive additional training on the distinctive features of, and risks associated with, perinatal mental illness.**

## Prescribing issues – de-prescribing

A woman died violently in her third trimester. She had a previous history of anxiety and depression, with depression in a previous postnatal period. She had been prescribed venlafaxine prior to the pregnancy to good effect, but it was stopped on discovering the pregnancy, either by the woman herself or by her GP. No alternative was suggested and there does not appear to have been any specialist service within her area. She developed worsening anxiety, and then depression, with a range of physical complaints, poor coping and suicidal ideation. As her symptoms worsened, she was referred to a low intensity psychological therapies service. She returned to her GP asking to restart her previously effective venlafaxine. It is clear from the consultation notes that her GP was very reluctant to prescribe and placed responsibility for the decision entirely on the woman, documenting an explanation of the risks, but not the benefits, of taking medication. She died a week later on the day she was due to undergo a mental health assessment.

This woman's care reiterates the need to take changes in mental state and thoughts of suicide seriously, particularly in late pregnancy and the early postpartum period. It also reflects the need for access to specialist perinatal mental health service provision in all areas. In addition, there was a focus on preventing possible harm to the fetus which distracted from her own need to receive ongoing care.



**Decisions on continuing, stopping or changing medication in pregnancy should be made only after careful review of the benefits and risks of doing so, to both mother and infant.**

### **Prescribing issues – propranolol**

Two women died by overdose of propranolol during this enquiry period. One was clearly taken with deliberate intent, the second was less certain. Both had a history of anxiety and deliberate self-harm. The indications for prescribing were uncertain. These women's deaths highlight the toxicity associated with beta blockers in overdose and the need for caution, and ongoing monitoring of prescribing and mental state, where these medications are dispensed.

### **Adequacy of mental health record returns**

We have previously reported on the low rate of returns of medical records from mental health services. In the absence of psychiatric records it is often very difficult to assess the quality or frequency of interaction, or the specific disciplines or teams involved in the woman's care. As mentioned at the outset of this chapter, it is also hard to ascribe diagnoses retrospectively.

In the 2015 enquiry, a recommendation was made that mental health services should publicise Enquiry findings to highlight messages pertaining to improving mental health care. This has not resulted in any improvement in the proportion of psychiatric records received. In the current Enquiry period, mental health records were returned for only 29 of 62 women (48%) women who died from mental health disorders and had been in contact with mental health services. The Maternal Deaths Enquiries form one of the four UK National Confidential Enquiries, which also includes the National Confidential Inquiry into Suicides and Homicides. The methodology ensures anonymity and the aim is to improve care. There are thus no reasons to impede access to clinical records for Enquiry staff and assessors. Indeed, co-operating with the Enquiry should be seen as good clinical practice and good corporate governance.

**There is an urgent need to establish pathways for release of mental health records with the Chief Medical Officers and Departments of Health of Ireland and the four UK nations. Records for all women who die during or in the year after pregnancy who have had contact with mental health services should be released directly to MBRRACE-UK from risk/governance departments.**



## 5.5 Messages for pathology

A post mortem was performed in 66 of the 71 women who died by suicide (93%). The methods women used are shown in table 5.3.

**Table 5.3: Method of suicide used by women who died, UK and Ireland 2014-16**

Method	Number of women (%) N=71
Hanging	42 (59)
Drug toxicity	14 (20)
Fall from height	6 (8)
Hit by train	4 (6)
Suicidal stabbing	2 (3)
Unclear	3 (4)

These violent methods are relatively unusual in suicides in women in the general population but more commonly employed in the setting of maternal death. This has been recognised in previous reports. The three women who used an uncertain method included one woman with probable suicidal insulin injection, which can be extremely difficult or impossible to prove at autopsy, one woman for whom the autopsy report was not available, and one woman whose autopsy report was inadequate and the precise cause of her death was difficult to determine.

In 27 women (39%) the autopsy report was felt to be in need of major improvement by the reviewing pathologist. Pathologists who would not usually undertake maternal death autopsies may find themselves performing these kinds of autopsies where suicide or drug toxicity is suspected and the fact of pregnancy or recent pregnancy may not be known. However, there were often more basic details missing including limited descriptions of injuries or other external findings (including lack of description of a ligature mark or the presence or absence of petechial haemorrhages in cases of hanging), and often poor correlation of findings with the circumstances of death and given cause of death.

Toxicology use and/or interpretation was noted to be in need of improvement in 19 women (28%). Examples include limited toxicology testing (alcohol only), poor quality toxicology reports (levels of drugs not given), for example, in a woman with suspected morphine toxicity, the free and total morphine levels and their ratio was not given which is vital for interpretation of its significance and the interval between administration and death. Additionally there was often limited interpretation of the toxicology findings by the pathologist including the basic question of what effect the drugs or alcohol might have had on the deceased, and no discussion of toxicology findings in the clinicopathological correlation despite their inclusion in the cause of death.

In several instances the class of drug was included in the cause of death but not the specific drug names.

In one instance where the woman died 8 days after admission to hospital, the admission blood samples were not available for testing by the pathologist and therefore the suspicion of a drug-related cause of death from propranolol toxicity was unable to be confirmed.

In two women who died by hanging, an external-only autopsy was performed. There was no internal examination. In both women toxicology was performed but the pathologist's interpretation of the toxicology findings was limited. External-only autopsies, in the absence of post mortem CT scanning, are not recommended by the Royal College of Pathologists on the basis of quality (personal communication from Dr Mike Osborn, Chair of the Royal College of Pathologists Death Investigation Group). Published guidance on the autopsy in cases of suspected suicide from the Royal College of Pathologists is expected in the next year.

In two women in whom an invasive autopsy was performed, the women's brain was not examined. In addition, in one woman where brain pathology was in the given cause of death, the required histological examination of the brain, necessary to reach the given diagnosis, was not performed. Post mortem examination (invasive, by post mortem CT or a combination of both) should include all organs - cases of neurological abnormality (for example frontal lobe pathology) have been encountered where such pathology might have a bearing on the decision making ability of the deceased in taking their own life. This may have direct implications for coroners in coming to a conclusion of suicide or otherwise.

In one woman a post mortem CT (PMCT) was performed in conjunction with an external examination. This is the first example of the use of PMCT seen in MBRRACE-UK maternal death reviews, although as the use of PMCT increases across the UK, it will become more common. In this instance the examination was appropriately carried out in conjunction with an external examination. The combination of external examination with PMCT is in keeping with PMCT guidance from the Royal College of Pathologists. The interpretation of PMCT findings will be dependent on the experience of the reporting radiologist, but in this woman assessors felt interpretation was in keeping with the clinical features. One area of question was the reliability of PMCT in assessing bowel ischaemia/infarction given how challenging this diagnosis is in life with a functioning circulation. It was not stated how soon after death the PMCT was performed or whether contrast or ventilation was used. One additional fact of note was that the CT report did not comment on the pelvic organs, yet the external examination noted a healing lower abdominal scar.

**Recommendation for clinicians:**

**If a pregnant or postpartum woman is admitted with suspected drug toxicity, blood samples from admission should be requested to be retained by the lab so as to be available for detailed toxicology testing if required.**

**Messages for pathologists:**

**Pathologists should take care to describe and document external findings including injuries and findings pertinent to the cause of death.**

**Toxicology should always be performed when women die by suspected suicide, to include a routine screen for known prescribed drugs, drugs of abuse and alcohol.**

**Pathologists and coroners should ensure the quality of toxicology reports is sufficient to enable proper interpretation in the context of the woman's death. Specifically:**

- **Toxicology laboratories should report the levels of drugs detected, along with the levels known to be associated with fatality.**
- **Where morphine is detected, toxicology laboratories should report the free and total morphine levels and their ratio.**

**Specific drugs names should be used in reporting the woman's cause of death, not the class of drugs.**

**Clinico-pathological correlation should draw together the circumstances of a woman's death with the findings at autopsy, with discussion of the significance of toxicology findings and the likely pathological effects.**

**Post mortem examination should involve all organs including the brain.**

**External-only autopsies should not be performed, unless in conjunction with post mortem CT scanning.**

**Post mortem CT scanning (PMCT) should be undertaken in line with Royal College of Pathologists and Royal College of Radiologists guidance and in maternal deaths, care should be taken to ensure comment on the pelvic organs.**

## 5.6 Conclusions

Although a number of examples of good care were identified, assessors felt that in over half of women, improvements in care may have made a difference to their outcomes (Table 5.4). Multiple messages for care were identified which have been described before, perhaps most critically the need to be aware of both red and amber flags in the perinatal period. Alongside this, the need for training of liaison, crisis home treatment and prison mental health teams about the unique features of perinatal mental illness, and particularly the potential for rapid deterioration, is stark. It is notable that very few women who died had acute psychotic illnesses, or a history of such disorders, suggesting these women's illnesses are being recognised and treated. However, the challenge facing both maternity and perinatal mental health services is caring for women with multiple adversities; most of the women who died by suicide faced many difficulties, social, physical and mental. In the light of this theme of women with many complex problems, it is particularly disappointing that the MBRRACE-UK admin team face many barriers when attempting to obtain mental health records for review by the enquiry. This is an urgent area for action.

**Table 5.4: Classification of care received by women who died by suicide, UK and Ireland, 2014-16**

Classification of care received	Women who died by suicide Number (%) N=68*
Good care	10 (15)
Improvements to care which would have made no difference to outcome	21 (31)
Improvements to care which may have made a difference to outcome	37 (54)
*Records were not available for review for 3 women	

## 6. Messages for the care of women from vulnerable groups

Judy Shakespeare, Esther Youd and Marian Knight on behalf of the MBRRACE-UK other psychiatric and homicide chapter-writing group

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### 6.1 Key messages

There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, and during and after pregnancy. **ACTION: Policy makers, professional organisations**

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. **ACTION: Health professionals**

Services should develop or adapt clear protocols and methods for sharing information, both within and between agencies, about people at risk of, experiencing, or perpetrating domestic violence and abuse. This is even more important with increasing use of electronic records to ensure all agencies involved in a woman's care are aware of her risk of domestic abuse. This would be further facilitated by support for the intra-operability of systems to support information sharing through electronic records. **ACTION: Service planners/commissioners, service managers, health professionals, police and safeguarding (social care) professionals**

Consider ways of ensuring that, for each woman who misuses substances:

- progress is tracked through the relevant agencies involved in her care
- notes from the different agencies involved in her care are combined into a single document
- there is a coordinated care plan.

**ACTION: Service planners/commissioners, service managers, health professionals**

Women with complex and multiple 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. **ACTION: Service planners/commissioners, service managers, health professionals**

The postnatal care plan for women with complex and multiple problems 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**

In women facing multiple adversity, changes in frequency or nature of presentations may reflect worsening mental state or the emergence of new complications (such as alcohol or substance misuse or interpersonal violence), and should prompt renewed attempts at engagement, diagnosis and care co-ordination. **ACTION: Service managers, health professionals**

### 6.2 Background

This chapter is focussed on the care of women from vulnerable groups: those who died by homicide as a result of domestic violence, and those who died as a result of drug and alcohol misuse. A recent report on the health and care of vulnerable pregnant women in Europe (Women Political Leaders Global Forum 2018) defines vulnerable pregnant women as "pregnant women who experience a distance in accessing

maternal healthcare, as refugees/ migrants/ ethnic minorities/ second or third generation immigrants, due to problems in speaking the language and/ or understanding the culture, and/ or due to lack of income, housing or social support". In the context of the UK and Ireland, and amongst the women whose deaths were examined for the purposes of this chapter, vulnerability is most often represented by the trio of domestic abuse, mental health problems and drug and alcohol problems. There is often a cycle of families with intergenerational problems. Women frequently have had involvement with the care system when they themselves were children, are victims of child sexual abuse, are known to social services, self-harm, and have depression, anxiety and chronic trauma. Their pregnancy care is commonly characterised by late booking, chaotic behaviours, difficulty keeping appointments and poor engagement with conventionally designed maternity services. Outcomes for children of mothers with these problems are known to be worse than for other children. Health professionals often feel helpless and hopeless about the care of these women, and yet, as a group increasingly represented within these maternal death enquiries, they are a group for whom improvements in care are essential to prevent future deaths. The risk of drug misuse in women is substantially reduced during pregnancy and multiple analyses suggest that this association is largely causal, implying that pregnancy is indeed a strong intrinsic motivator for drug abuse cessation (Kendler, Ohlsson et al. 2017). Pregnancy therefore represents a time of opportunity which should not be ignored.

### 6.3 The women who died

Fourteen women were murdered, all by partner or a former partner, 10 of whom died during pregnancy or up to six weeks after pregnancy. All were reviewed for the purposes of this chapter. Eleven of the 14 women (79%) received some antenatal care, but only 4 of these (36%) received the recommended level of care (booked at 10 weeks or less and no antenatal visits missed). Eight (73%) received the minimum level of care (booked at less than 13 weeks and no more than 3 antenatal visits missed).

Overall, 43 women died in relation to drug and alcohol misuse, 6 during pregnancy or up to six weeks after the end of pregnancy, and the remaining 37 between six weeks and one year after the end of pregnancy. The deaths of thirty-five women who died in relation to drug or alcohol toxicity were reviewed for the purposes of this chapter; 28 were drug-related, 3 alcohol-related, 1 related to both drug and alcohol toxicity and the exact causes were unclear for 3 women. Two women died from cardiac effects of drugs, two from neurological effects of amphetamine and spice respectively; the remaining women died from respiratory causes. Twenty-nine of the 35 women (83%) received some antenatal care, but only 3 of these (10%) received the recommended level of care (booked at 10 weeks or less and no antenatal visits missed). Thirteen (45%) received the minimum level of care (booked at less than 13 weeks and no more than 3 antenatal visits missed).

### 6.4 Overview of care and lessons to be learned

#### Repeated recommendations

##### Homicide and domestic abuse

All of the 14 women who were murdered were killed by a partner or former partner, five had a known history of domestic abuse. In several others there was no evidence women had been asked about domestic abuse, or they had only ever been seen in the presence of their partner and thus had no opportunity to report abuse. One woman who was at high risk repeatedly denied domestic abuse when asked, and no-one investigated further despite multiple presentations with suspicious signs.

Two women were killed by partners with known severe mental health problems. In one instance the woman's partner's problems remained unknown to maternity services. One of these women was never seen alone throughout her pregnancy and there is no evidence she was ever asked about domestic abuse. The second woman denied domestic abuse on questioning but presented multiple times during pregnancy and postpartum with minor injuries and other complaints which were never explained or explored.

As well as being aware of the symptoms and signs of domestic abuse, these women also highlight the importance of being alert to the mental health of partners, which may render these women additionally at risk.

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

**NICE Antenatal care guideline CG62 (National Institute for Health and Care Excellence 2017)**

In another instance, staff reported after a woman's death that they had not been trained to enquire about domestic abuse using the hospital's newly introduced electronic records. Furthermore, it was noted that documentation of domestic abuse was only available to antenatal staff via women's computerised antenatal records and was not shared with other agencies. Computerised prompts help to ensure that all women are asked about domestic abuse, but staff still need training in how to undertake this sensitively and to understand the importance of questioning women alone. It may be helpful to alert women that they will be asked about domestic abuse in the absence of their partner so that it is clear this is normal practice.

As noted in chapter 2, of all the women who died in 2014-16 during or up to six weeks after the end of pregnancy, 8% had a known history of domestic abuse. However, in 64% there was no information about whether they had a history of domestic abuse; it was unclear whether or not they had been asked.

**Services should develop or adapt clear protocols and methods for sharing information, both within and between agencies, about people at risk of, experiencing, or perpetrating domestic violence and abuse (National Institute for Health and Care Excellence 2014b). This is even more important with increasing use of electronic records to ensure all agencies involved in a woman's care are aware of her risk of domestic violence. This would be further facilitated by support for the interoperability of systems to support information sharing through electronic records.**

There were clear examples of exemplary care.

A woman revealed a history of domestic abuse. She attended hospital following another episode of violence. She was appropriately referred to the specialist domestic abuse midwife, and during her pregnancy numerous agencies were involved including community, hospital and social services as well as safeguarding teams. Nevertheless, she remained living with her partner and died following a further episode of violence.

The teams caring for this woman were clearly aware of the pathways of care for women known to be at risk from domestic abuse in their area. Different agencies worked together well but in this instance were unable to prevent the eventual outcome.

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

**NICE Guideline CG110 Pregnancy and complex social factors (National Institute for Health and Care Excellence 2010)**



## Drug and alcohol misuse

### Severe and multiple deprivation (SMD)

Most women who died from drug or alcohol misuse were extremely vulnerable with multiple medical, mental health and social problems, including histories of deliberate self-harm, domestic abuse and children who had been removed. As noted above, the occurrence of the trio of co-morbidities, domestic abuse, mental health problems and drug and alcohol misuse was a strong theme.

A woman died as a result of acute intoxication from alcohol and heroin in the third trimester of pregnancy. She had a long history of drug and alcohol misuse, depression, self-harm and domestic violence. All of her previous children had been taken into care. Social services were aware of these issues. Her pregnancy was unplanned. She had not taken opiates for some years, and had had a successful inpatient alcohol detoxification. At her first antenatal clinic her history of drug and alcohol problems was noted and she was appropriately referred to the child protection midwife and drug and alcohol team. She was subsequently a poor attender at appointments. She appears to have given no indication to any staff about her use of opiates again and her poor attendance at appointments and lack of contact did not alert any one to her situation.

In this instance, as well as many others in this enquiry, this woman's pregnancy was unplanned. Discussing and considering long-acting methods of contraception remains important in all women with chronic conditions, including these particularly vulnerable groups. During pregnancy, multiple professionals were involved in this woman's care but no one person was identified to coordinate her care; a single named professional may have recognised the pattern of deterioration in her substance use.

#### Consider ways of ensuring that, for each woman who misuses substances:

- progress is tracked through the relevant agencies involved in her care
- notes from the different agencies involved in her care are combined into a single document
- there is a coordinated care plan

**Offer the woman a named midwife or doctor who has specialised knowledge of, and experience in, the care of women who misuse substances, and provide a direct-line telephone number for the named midwife or doctor**

**NICE guideline CG110: Pregnancy and complex social factors (National Institute for Health and Care Excellence 2010)**

Guidance is clear that the outcomes of pregnancy for both mother and infant are better for opioid dependent women who enter methadone treatment programmes than for those who do not (Independent expert working group 2017). A recent update to the guideline is clear that the main objective of management is to achieve stability across four domains – pharmacological, social, medical and psychological. As a further protective measure the guideline recommends offering all opiate users in the community access to a take home supply of naloxone with instructions on its use and with training on managing suspected overdoses. Availability of naloxone may have prevented this woman's death from her final overdose.



**Substitute prescribing can occur at any time in pregnancy and carries a lower risk than continuing illicit use. Substitute prescribing has the advantage of allowing engagement and therefore identification of health and social needs, as well as offering the opportunity for brief interventions and advice to improve outcomes.**

**Maintenance opioid treatment, at a dose that stops or minimises illicit use, is most appropriate for ensuring continuity of management of pregnancy and aftercare.**

**Women prescribed controlled drugs must be advised of the availability of take home naloxone.**

**Drug misuse and dependence: UK Guidelines on drug misuse and dependence update (2017). (Independent expert working group 2017)**

### **Complex problems associated with drug and alcohol misuse**

A woman with known chronic alcohol abuse and acute fatty liver did not report her alcohol use to the midwife at booking. She had an uneventful pregnancy. At 28 weeks she had abnormal blood test results that were not noted nor acted upon. Some months after giving birth she reported suicidal thoughts to her GP, but she was not referred. One week before her death she attended the emergency department with a self-induced fracture while she was drunk, but no action was taken, despite her disclosure of alcohol dependence. A week later she died from a massive gastrointestinal bleed.

Evidence of ongoing problems with drug and/or alcohol abuse was often missed postnatally, emphasising the importance of senior involvement with coordinated postnatal care for these women with complex and multiple problems. A copy of the postnatal plan drawn up at discharge should be given to the woman as well as sent electronically to her GP.

**Women with complex and multiple 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 for women with complex and multiple problems 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.**

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

### **Judgements based on medical history**

A woman with known drug and alcohol dependence presented to the Emergency Department with abdominal pain and vomiting a few months after giving birth. She was found to have severe hypokalaemia, but was discharged with oral potassium supplements and oral antiemetics. She collapsed and died shortly after discharge. Her death was thought to be due to a cardiac arrhythmia in relation to metabolic disturbance, secondary to vomiting due to alcohol and drug withdrawal.

In this instance, it appears that this woman's symptoms were downgraded simply because she was a drug and alcohol user. Health professionals may feel helpless and hopeless about caring for these women, but fully investigating and managing their symptoms is as important as for women without their multiple and complex problems. There was frequent evidence of this 'fixation error' where significant symptoms were attributed to facets of women's drug and alcohol dependence. In this instance, the severity of the metabolic disturbance caused by her withdrawal was not recognised. Another woman, considered in the malignancy chapter, had similar symptoms which were consistently attributed to withdrawal, which led to late diagnosis of her cancer.

After a woman with known substance dependence had surgical management of an ectopic pregnancy no risk assessment for VTE was carried out despite clear risk factors. When she presented with shortness of breath and tachycardia the focus was on concern about possible withdrawal symptoms though the cause of her symptoms was the pulmonary embolism from which she died.

At one point this woman, described in the thrombosis chapter, unsuccessfully requested oxygen for her severe breathlessness. Her symptoms were assumed to be drug withdrawal although they did not abate when she was given methadone. She was treated with diazepam and discharged after a day. Her symptoms persisted and when she collapsed she was readmitted to hospital but could not be resuscitated. These issues are clearly reflected amongst women who died by suicide and the following recommendation is reiterated from chapter 5.

**In women facing multiple adversity, changes in frequency or nature of presentations may reflect worsening mental state or the emergence of new complications, and should prompt renewed attempts at engagement, diagnosis and care co-ordination.**

### Co-morbid depressive illness

A multiparous woman with a long history of substance misuse booked late after an unplanned conception. All her previous children were in care. She gave birth uneventfully at term. All postnatal care of her baby on the postnatal ward was supervised, and a court order was made while she was an inpatient for removal of her child to foster care. The woman reported suicidal feelings to staff and was very distressed. She was reviewed by the mental health team on the ward who felt she had capacity and she did not have suicidal intent, but a plan was put in place for follow up once she was discharged. She was visited multiple times by the mental health team up to four weeks post-discharge; visits were continued despite being unable to access her home on several occasions. She was seen and discharged on day 28. There were repeated attempts at contact from the drug liaison team in the following months after birth, but they were unable to engage with her. She died from an overdose a few months later.

Many of the messages for mental health care noted in the previous chapter were echoed here, since co-morbid mental illness was common. However, there were very clear examples of exemplary multi-disciplinary care. This woman's mental health problems were taken seriously by mental health and drug liaison services but she withdrew from engagement with them. On other occasions, however, there was evidence of silo working, which prevented women obtaining appropriate treatment for their mental health problems.

A woman with emotionally unstable personality disorder and a history of drug misuse visited her GP some weeks after birth expressing suicidal thoughts. She was referred urgently to the community mental health team, who assessed her but did not accept her for treatment because she said she was drinking. They discharged her. One month later she died from an overdose.

Many drug and alcohol teams do not have the expertise and/or the remit to manage mental health problems. This community mental health team clearly felt unable or unwilling to manage this woman's mental health problems because of her alcohol dependence. She was thus unable to get the care she needed. Given changes to commissioning pathways and the move in some areas for local authorities to be responsible for addictions services, there is the potential for these gaps in care to become greater.

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

## Opioid prescription

A woman with complex problems including an emotionally unstable personality disorder, diabetes, a gastric band and chronic pain became pregnant despite an implant. She was delivered early because of intrauterine growth retardation and discharged home with a large supply of tramadol for pain relief. A few days after giving birth she died and at postmortem was found to have a fatal level of tramadol and other drugs in her blood.

Two women died with a fatal level of tramadol found at postmortem. In neither instance was it clear whether the overdose was taken with deliberate intent. Both women had, however, been discharged from hospital with a very large supply of the drug. It is increasingly recognised that many people are leaving hospital with opioid tablets they do not need (Makary, Overton et al. 2017), and this may have contributed to these women's deaths. Overprescribing has been identified as a major contributor to the opioid epidemic and it has been suggested that decreasing the default take-home dose or considering non-narcotic alternatives are simple actions to address this (Makary, Overton et al. 2017). Detailed guidance exists on prescribing and deprescribing (Royal College of Anaesthetists Faculty of Pain Medicine 2015).

**Prescription of opioid analgesics postnatally should follow national guidance and consideration given to decreasing the take-home dose or supplying non-narcotic alternatives.**

## Capacity issues

An older woman with alcoholic liver disease and multiple social problems was admitted to a tertiary unit with end stage liver disease after she was found to be 18 weeks pregnant while in police custody. Her mental capacity was assessed by a liaison psychiatrist and found to be inconsistent and fluctuating. Her behaviour was very challenging. She died of multi-organ failure at 20 weeks of pregnancy.

There was no evidence that anyone had considered this woman's contraception needs nor her capacity to make decisions about her contraception or her health care needs.

**All healthcare staff have a duty to ensure that patients have the mental capacity to make decisions regarding their care. Where there is doubt, an assessment of capacity should be undertaken. Further information and guidance on assessing capacity can be found at:**

- [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/348440/OPG603-Health-care-workers-MCA-decisions.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/348440/OPG603-Health-care-workers-MCA-decisions.pdf) (England & Wales);
- <http://www.gov.scot/Resource/Doc/217194/0058194.pdf> (Scotland)

(Knight, Tuffnell et al. 2015)

## 6.5 Messages for pathology

A post mortem examination was conducted for 31 of the 35 women who died in relation to drug and alcohol use. In 4 women no pathology report was available for review, thus the autopsy reports of 27 women were reviewed.

In 13 women the autopsy report was considered to be poor by the reviewing pathologist. Issues included lack of clinico-pathological correlation, lack of histology, lack of toxicology, poor interpretation of toxicology findings, lack of comment on the significance of findings, absence of history or circumstances of death, poor conclusions drawn by the pathologist.

For one woman the cause of death given by the pathologist was considered erroneous by the reviewing pathologists. A natural cause “left ventricular hypertrophy” was given with little evidence to support this and no histology undertaken. On review the death was considered likely to be related to drug toxicity.

Issues relating to toxicology use and interpretation were similar to those encountered when reviewing deaths by suicide (see section 5.5).

For two women the cause of death was unascertained and in both instances this was due to an inadequate pathological examination. There was an assumption that both women died due to drug toxicity and yet this was not proven on toxicology testing.

A woman who was a known substance misuser died in the postpartum period; the pathologist made the assumption that her death was due to a drug overdose. However, the toxicology assessment was incomplete and there was no histology undertaken.

Every opportunity to determine the cause of this woman’s death was missed. The possibility of sudden cardiac death or other potential causes remains undetermined as the appropriate investigations were not undertaken. The death of any young woman requires adequate investigation to make a diagnosis, irrespective of her past medical history. This was not the situation here and the possibility of identifying conditions which may have implications for surviving family members was not considered.

### Messages for pathologists:

**Pathologists should never assume a woman’s death is due to drug toxicity or any other specific cause without clear evidence. They should keep an open mind about the potential causes of death and conduct testing according to the potential differential causes.**

**Pathologists and coroners should ensure the quality of toxicology reports is sufficient to enable proper interpretation in the context of the woman’s death. Specifically:**

- **Toxicology laboratories should report the levels of drugs detected, along with the levels known to be associated with fatality.**
- **Where morphine is detected, toxicology laboratories should report the free and total morphine levels and their ratio.**

**Specific drug names should be used in reporting the woman’s cause of death, not the class of drugs.**

**Clinico-pathological correlation should draw together the circumstances of a woman’s death with the findings at autopsy, with discussion of the significance of toxicology findings and the likely pathological effects.**

## 6.6 Conclusions

All the messages in this chapter are repeated from those identified in 2015 (Knight, Tuffnell et al. 2015); in 53% of women, improvements in care were identified and for 16% those improvements may have made a difference to their outcome. The 2015 report recommended practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, during and after pregnancy (Knight, Tuffnell et al. 2015). This has not happened and yet clearly there remain multiple opportunities to improve care. In the context of major reorganisations of maternity care (The National Maternity Review 2015, The Scottish Government 2017) and new mental health services, ensuring safe and appropriate care for this group of women must be a priority. This may require new research into effective interventions and particularly an effective system of coordinated multidisciplinary care.

**There is a need for practical national guidance for the management of women with multiple morbidities and social factors prior to pregnancy, and during and after pregnancy (Knight, Tuffnell et al. 2015).**

**Table 6.1: Classification of care received by women who died from other psychiatric disorders and homicide, UK, 2014-16**

Classification of care received	Women who died from other psychiatric disorders Number (%) N=35	Women who died by homicide Number (%) N=14
Good care	16 (46)	7 (50)
Improvements to care which would have made no difference to outcome	14 (40)	4 (29)
Improvements to care which may have made a difference to outcome	5 (14)	3 (21)

# 7. Lessons for treatment of malignancy

Marian Knight, Anita Banerjee, Malcolm Griffiths and Adrian Yoong on behalf of the MBRRACE-UK cancer in pregnancy chapter-writing group

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## 7.1 Key messages

Previous cervical smear history may be useful in order to assess the possibility of a neoplastic lesion of the cervix as the cause of antepartum haemorrhage. A speculum examination can be useful to visualise a lower genital tract cause for the haemorrhage. **ACTION: Service managers, health professionals**

Thrombosis, particularly migratory or in an unusual location, should be fully investigated as it may be a presenting sign of cancer in pregnancy or postpartum. **ACTION: Health professionals**

Pregnant and postpartum women presenting to the emergency department with medical problems should be discussed with a member of the maternity medical team. **ACTION: Service managers, health professionals**

Repeated presentation with pain and/or pain requiring opiates should be considered a 'red flag' and warrant a thorough assessment of the woman to establish the cause. **ACTION: Health professionals**

If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus. In such instances, a discussion of potential risks and benefits with the woman should be used to determine the most appropriate pathway of investigation. **ACTION: Service planners/commissioners, service managers, health professionals**

For women with cancer, advice on postponement of pregnancy and contraception should be individualised and based on treatment needs and prognosis over time. Most women with breast cancer should wait at least two years after treatment, which is when the risk of breast cancer recurrence is highest. **ACTION: Service planners/commissioners, service managers, health professionals**

All pregnant or postpartum women who are diagnosed with cancer should have the possibility of an underlying familial syndrome considered, particularly, but not only hereditary non-polyposis colorectal cancer, with appropriate investigations, including tumour testing, performed and family testing offered as appropriate. **ACTION: Service planners/commissioners, service managers, health professionals**

## 7.2 Background

Whilst in the majority of women, the occurrence of cancer is coincidental to pregnancy, that is, it would have arisen irrespective of the woman's pregnancy, it is very clear that the simple fact of a woman with cancer being pregnant can have major implications for the quality of her care. Recent data shows an almost 50% higher age-standardised incidence rate of cancer during pregnancy in comparison to non-pregnant women of reproductive age, possibly relating to more frequent examination and therefore an increased chance of detection (National Cancer Registration and Analysis Service 2018). This further emphasises the importance of high quality cancer care in pregnancy and the postpartum period. Compromises in cancer care received during pregnancy can have major implications on women's future quality of life as well as survival, and for this reason this chapter includes reviews of the care of women who died between six weeks and one year after the end of pregnancy. In this chapter, perhaps more than any other, the distinction between direct, indirect and coincidental maternal deaths becomes irrelevant (van den Akker, Nair et al. 2017); there remain many opportunities to improve care irrespective of the type of cancer from which women died. Alongside this, the rising age of the maternity population, and therefore an expected rising incidence of cancer among pregnant and postpartum women (National Cancer Regis-



tration and Analysis Service 2018), emphasises the ongoing importance of not ignoring these 'coincidental' maternal deaths and learning lessons to improve future diagnosis and management of malignancy in association with pregnancy.

### 7.3 The women who died

One hundred and four women died during or up to one year after pregnancy from malignant disease during 2014-16 in the UK and Ireland. Twenty-six women died during or up to six weeks after the end of pregnancy, a mortality rate of 1.04 per 100,000 maternities (95% CI 0.68-1.53). Of these 26 women, 8 died from breast cancer, 6 from brain or CNS tumours, 5 gastrointestinal tumours, 1 from choriocarcinoma, 4 from tumours in other sites. Two women had an unknown primary. Only nine of these 26 women (35%) had an autopsy, all were coronial or fiscal.

78 women died from cancer between six weeks and one year after the end of pregnancy. Detailed records were available for review of 45 of these women. Of these 45 women, 10 died from a gastrointestinal malignancy, 7 from haematological malignancies, 6 from breast cancer, 5 from cervical cancer, 5 from skin cancers, 4 from brain or CNS tumours, 6 from tumours in other sites. Two women had an unknown primary.

### 7.4 Overview of care and lessons to be learned

Overall reviewers felt that the care of pregnant and postpartum women with cancer who died was substantially improved compared with the care of the women who died between 2009 and 2013 (Knight, Tuffnell et al. 2015). In particular, there was no evidence that chemo or radiotherapy was inappropriately withheld because women were pregnant at the time of their diagnosis. As with the care of the woman described below, the reviewers identified many examples of good care which ensured women maintained a good quality of life despite their terminal disease and supported them to make their own choices about many aspects of their care both during and after pregnancy.

A woman developed aggressive inflammatory breast cancer in the first trimester of pregnancy with metastases. Her chemotherapy and surgery was expedited but unfortunately she did not respond. She deteriorated and was delivered early in the third trimester to allow for radiotherapy. Funding was made available from within the hospital to allow her to be nursed on delivery suite. She had patient-centred multidisciplinary team care, with regular consultant input from obstetrics and gynaecology, oncology (surgical and medical), anaesthesia, neonatology, radiology and palliative care. She remained on the labour ward for palliative care for the next month (near her baby on the neonatal unit) until she died.

#### Recurring themes

Although care after diagnosis in general was felt to have improved, there were still many examples where the fact that a woman was either pregnant or postpartum clearly delayed her diagnosis despite symptoms which were highly suspicious of malignant disease.

#### Delays to diagnosis

##### *Pain requiring opiates*

A woman presented at 15 weeks in pregnancy with severe left sided pelvic pain which was attributed to symphysis pubis dysfunction. She was referred to a physiotherapist and discharged from consultant care. She presented repeatedly with escalating pain (requiring opiates) along with intermittent PV discharge and a swollen left leg. Only at caesarean section was her large pelvic mass diagnosed, at which point the significance of her history of incomplete treatment of cervical intraepithelial neoplasia was recognised. She died from her metastatic cervical cancer shortly afterwards.



This woman exhibited several 'red flags' previously noted by the enquiry, including repeated presentation and severe pain requiring opiates without a clear diagnosis. Four other women had similar long-standing severe pain managed with opioids without recognition of the significance of their other symptoms and leading to a delay in the diagnosis of their malignant disease.

**Repeated presentation with pain and/or pain requiring opiates should be considered a 'red flag' and warrant a thorough assessment of the woman to establish the cause.**

### *Recurrent vaginal bleeding*

Four women had recurrent vaginal bleeding during pregnancy and were subsequently diagnosed with cervical cancer. In one instance, the woman concerned never underwent a speculum examination because of concerns over placenta praevia, and in two others a speculum examination was carried out but on only one occasion. In both women the presence of the cervical tumour was not recognised by the junior doctors concerned. This led to a delay of several weeks in these women's diagnoses. Although the presentation of cervical cancer in pregnancy depends on the stage at diagnosis and lesion size, pregnant women usually present with post-coital bleeding or vaginal discharge (Royal College of Obstetricians and Gynaecologists 2011c). Two of the women reviewed here presented with post-coital bleeding and one with a persistent vaginal discharge. It is important to note that gentle speculum examination can be performed even with placenta praevia to visualise the cervix and check for local causes of bleeding. Two of the women had never had a cervical smear.

A woman who had a previous normal smear a year earlier presented in the third trimester with vaginal bleeding for approximately two weeks. The senior registrar who attended her undertook a speculum examination and recognised a suspicious cervical mass. The registrar made an urgent referral to colposcopy and the woman's advanced tumour was rapidly diagnosed and treated. She received excellent multidisciplinary care and was able to spend time at home with her baby before she died in a hospice a few months later.

Despite a history of a normal smear, this woman was appropriately examined, referred and her cancer diagnosed quickly. Subsequent multidisciplinary team planning allowed her to spend time with her new baby and control of her pain before she died.

**Previous cervical smear history may be useful in order to assess the possibility of a neoplastic lesion of the cervix as the cause of antepartum haemorrhage. A speculum examination can be useful to visualise a lower genital tract cause for the haemorrhage.**

**If the woman presents with a clinically suspicious cervix she should be referred for colposcopic evaluation in line with guidelines from the British Society for Colposcopy and Cervical Pathology.**

**(Royal College of Obstetricians and Gynaecologists 2011c)**

### *Delayed radiological investigations*

A woman presented in the first trimester with an extensive lower limb DVT, breathlessness and haemoptysis. A pericardial effusion was noted on echocardiography. She did not undergo a chest x-ray or CT pulmonary angiogram; her records make reference to the fact that she was 'scared' by a radiologist discussing radiation risks to the fetus. She was treated for presumed pulmonary embolism, but became more symptomatic in the third trimester when she was diagnosed with cardiac tamponade. This was drained percutaneously and she was delivered by caesarean section. Continuing respiratory symptoms post-birth led to a chest x-ray and diagnosis of her malignant pleural effusion. She died shortly afterwards.

MBRRACE-UK reviewers as well as the local team caring for her felt that if this woman had not been pregnant, her lung cancer would have been diagnosed when she first presented with her DVT. She would have undergone a chest x-ray and/or CTPA or perfusion scan which would have resulted in earlier diagnosis and treatment and this may have changed her outcome. It is a recurrent message of these enquiries that investigations which are strongly indicated in the non-pregnant should not be withheld because of concerns about the fetus. In this instance it is not known what advice was given to the woman about the risks of investigation, but guidance is clear that the risks are small (Royal College of Obstetricians and Gynaecologists 2015b).

**Women with suspected PE should be advised that, compared with CTPA, V/Q scanning may carry a slightly increased risk of childhood cancer but is associated with a lower risk of maternal breast cancer; in both situations, the absolute risk is very small (Royal College of Obstetricians and Gynaecologists 2015b).**

**If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant woman, but with caution when there is evidence of specific risks to the fetus. In such instances, a discussion of potential risks and benefits with the woman should be used to determine the most appropriate pathway of investigation (Knight, Tuffnell et al. 2015a).**

### *Thrombosis and assessing VTE risk*

**Malignancy diagnosed within six months of becoming pregnant is an independent risk factor for VTE. RCOG guidance should be followed: antenatal thromboprophylaxis from 28 weeks and postnatal thromboprophylaxis for at least 10 days unless contraindicated, for example if cerebral metastases or blood dyscrasia are present (Royal College of Obstetricians and Gynaecologists 2015).**

This recommendation was made in the 2015 report and reviewers noted that it was particularly pertinent once again as several women developed thromboembolic disease. Three women presented initially with a VTE and it must be remembered that thrombosis, particularly in unusual locations, can be the first presentation of a cancer.

A woman developed an extensive thrombosis in her neck veins two weeks after a caesarean birth. The unusual location was attributed to the fact that she was postpartum. She developed further thrombotic events including DVT and PE but the diagnosis of malignancy was not considered despite review by multiple clinicians from different specialties. The diagnosis was eventually made four months postpartum and she died shortly afterwards.

Two women had Trousseau's syndrome (Varki 2007), presenting with unusual or migratory and multiple thromboses, identified in retrospect to herald their visceral malignancy. In both women the diagnosis was made late. Although reviewers felt that earlier diagnosis would have been unlikely to prevent these women's deaths, more timely diagnosis could have improved their quality of life in their final months.

**Thrombosis, particularly migratory or in an unusual location, should be fully investigated as it may be a presenting sign of cancer in pregnancy or postpartum.**

### *Neurological investigation*

At booking a woman gave a three month history of severe headaches which she described as migraine, causing her to wake at night. These continued through pregnancy until she was admitted to the Emergency Department in her second trimester with falls and loss of consciousness. She was discharged home with no follow-up arranged. Two days later she was admitted in status epilepticus at which time her cerebral metastatic disease was diagnosed. She was treated during pregnancy and gave birth in her third trimester, but her disease progressed rapidly and she died shortly afterwards.

There were several occasions when this woman could have had a full neurological examination and appropriate imaging, which may have led to recognition of her raised intracranial pressure and allowed for earlier treatment. Reviewers also noted opportunities for earlier diagnosis of another woman who died from a primary brain tumour; in this instance she presented with arm weakness in the first trimester with a two month history of headaches. Her GP made a routine neurology referral and she was given an appointment for seven months later. An acute worsening of her symptoms led to the diagnosis of her tumour two months before her appointment date. The importance of a neurological examination, as well as timely referral pathways, has been reiterated repeatedly in these reports.

**Neurological examination including fundoscopy is mandatory in all women with new onset headaches or headache with atypical symptoms.**

### *Making a diagnosis not simply excluding one*

A woman attended the Emergency Department late in her third trimester with breathlessness. She had a respiratory rate of 40 but her chest was noted to be clear. She was investigated for suspected pulmonary embolism but as investigations were negative she was discharged home with a diagnosis of presumed pneumonia. Neither an obstetrician nor a physician were asked to review her. Two days later she represented acutely unwell with suspected cholecystitis and was admitted to the intensive care unit. She was not seen by an obstetrician for a further 36 hours. When consulted, the obstetrician advised laparotomy and caesarean section. Her metastatic liver disease was diagnosed on a pre-operative ultrasound scan.

As has been noted before in MBRRACE-UK reports, for several women who presented with symptoms of breathlessness and pain, investigations were undertaken to rule out pulmonary embolism, and once these proved negative, no further attempt was made to establish a diagnosis. It has also been a repeated message of these reports that pregnant women with medical problems who present to the emergency department should be discussed with the maternity medical team. All pregnant women, particularly ill pregnant women, should be reviewed by a member of the obstetric team, and hospital policies should reflect this.

**Pregnant and postpartum women presenting to the emergency department with medical problems should be discussed with a member of the maternity medical team. (Knight, Tuffnell et al. 2015)**

**A raised respiratory rate, chest pain, persistent tachycardia and orthopnoea are important signs and symptoms which should always be fully investigated. The emphasis should be on making a diagnosis, not simply excluding a diagnosis (Knight, Nair et al. 2016).**

### *Fixation error*

A woman presented repeatedly postnatally with a painful erythematous breast lump. Her symptoms were attributed on each occasion to mastitis despite a classic peau d'orange appearance and axillary lymph nodes. Her metastatic breast cancer was diagnosed when she was referred to the breast clinic for drainage of a presumed axillary abscess.

Many women whose care was examined for the purposes of this chapter had symptoms that were repeatedly attributed to pregnancy and which failed to respond to standard management. Several others were assumed to have infections of various kinds including, as in this woman's case, repeated courses of antibiotics. Two women with spinal metastases were assumed to have spinal tuberculosis and managed as such for several weeks, despite the lack of a tissue diagnosis. In some instances, these symptoms predated pregnancy. Clinicians need to remain aware of other causes of women's symptoms, particularly in the context of repeated presentation and/or failure to respond to treatment.

**Taking a full history and conducting a complete examination is important whatever the route through which a pregnant woman first accesses services (Knight, Tuffnell et al. 2015).**

### *Multidisciplinary team care*

As in previous enquiries, reviewers noted that several women with complex cancers were cared for by multiple teams across multiple sites and there was therefore a lack of multidisciplinary planning which impacted on women's quality of life.

**There should be an early multidisciplinary discussion about the care of any woman with complex medical conditions in pregnancy. This is particularly important if the woman is managed across several centres. A named individual needs to take overall responsibility for coordinating her care (Knight, Tuffnell et al. 2015).**

### *Contraception*

Seven women whose care was reviewed for the purposes of this chapter conceived while receiving chemotherapy, or shortly after completing chemotherapy.

A 35 year-old woman was amenorrhoeic immediately following completion of chemotherapy for triple negative breast cancer. At her six month review the possibility of pregnancy was not considered and contraception was not discussed. When she presented with terminal metastatic disease four months later, she was found to be in the second trimester of pregnancy. She rapidly deteriorated and both she and her baby died.

In this instance, and for most of the other six women who conceived during or shortly after their cancer treatment, there was no evidence that any of the staff caring for them had even considered the possibility of pregnancy in women of reproductive age or thought to discuss contraception. One woman made an

active decision to stop contraception during treatment of her breast cancer, and no-one discussed with her the risks of pregnancy. All clinicians caring for women of reproductive age, whatever their medical specialty, need to be aware of the risks of pregnancy in women with medical co-morbidities, including cancer, and should be able to give appropriate contraceptive advice.

**For women with cancer, advice on postponement of pregnancy should be individualised and based on treatment needs and prognosis over time. Most women with breast cancer should wait at least two years after treatment, which is when the risk of breast cancer recurrence is highest (Royal College of Obstetricians and Gynaecologists 2015c).**

**Non-hormonal methods of contraception are recommended for women wishing to avoid pregnancy after treatment of breast cancer (Royal College of Obstetricians and Gynaecologists 2015c)**

## New messages for care

### *Familial cancer syndromes*

Whilst there was evidence that the possibility of an underlying cancer syndrome had been considered following the diagnoses of breast cancer in the women of reproductive age whose care was reviewed for the purposes of this chapter, there was no evidence in other women that familial cancer syndromes had been considered. In particular, there were several deaths of young women with colorectal cancer when there had been no consideration of the need for testing for Lynch syndrome with the potential importance of the diagnosis for surviving close family members.

A woman presented repeatedly to different locations with shoulder pain, back pain, breathlessness, persistent anaemia and altered bowel habit in the third trimester of pregnancy. These symptoms were attributed to iron deficiency, musculoskeletal pain and acid reflux. PE was considered on two occasions but she was not investigated further. She presented acutely unwell at term at which time liver nodules were identified but thought to be infective in origin. Liver biopsy at caesarean section revealed her metastatic colorectal cancer. She had not received any low molecular weight heparin thromboprophylaxis due to concerns over the possibility of haemorrhage. She collapsed from a massive PE shortly after giving birth and died shortly afterwards.

This woman's care illustrates many of the themes already discussed, including attribution of her symptoms to pregnancy, repeated presentation without a clear diagnosis, and risk of thromboembolism. In addition, however, despite the diagnosis of colorectal cancer in a young woman, no-one considered the possibility of Lynch syndrome (hereditary non-polyposis colorectal cancer or HNPCC) (Lynch, Snyder et al. 2015). Lynch syndrome is one of the most common hereditary colorectal cancer syndromes and is associated with a familial predisposition to cancers, particularly of colorectal and endometrial origin. It is due to an inherited defect in the genes which are involved in DNA mismatch repair and is diagnosed on the basis of family history, tumour pathology and genetic testing. None of the women who died from colorectal cancer in association with pregnancy had the possibility of Lynch syndrome considered; their tumours appear not to have been sent for the relevant genetic testing (for microsatellite instability), nor were their families referred for consideration of screening.

**All pregnant or postpartum women who are diagnosed with cancer should have the possibility of an underlying familial syndrome considered, particularly, but not only hereditary non-polyposis colorectal cancer, with appropriate investigations, including tumour testing, performed and family testing offered as appropriate.**

### **General anaesthesia**

A woman diagnosed with metastatic cancer early in her first pregnancy deteriorated in the third trimester despite chemotherapy. She was known to have spinal metastases and underwent caesarean birth under general anaesthesia. She died a month later.

Three women known to have advanced cancer were delivered by caesarean section under general anaesthesia. In two women, including the one above, this was because they were thought to have spinal metastases. Another was suspected of having raised intracranial pressure. None were delivered in an emergency. Spinal metastases alone are not an indication for general anaesthesia for delivery. For these women, all of whom were in the late stages of their disease, the delivery under general anaesthesia potentially denied the woman and her partner or other members of her family the positive memory of their baby being born despite the mother's terminal cancer.

### **Fluid balance**

A woman with a haematological malignancy and known clotting problems received several units of red cells and at least two litres of crystalloid around the time of her caesarean birth. Her exact fluid balance is unclear as there was no clearly documented fluid balance chart in her records, but she appears to have a positive balance of at least six litres. She deteriorated five hours after giving birth and was noted to have pulmonary oedema. She failed to respond to diuretics and died shortly afterwards.

As noted in chapter 3, careful attention to fluid balance is important, including attention to over-replacement as well as under-replacement.

### **Vulnerability**

A woman known to be a substance misuser with a history of domestic abuse booked late in her pregnancy. She gave birth normally at term and reported on the postnatal ward that she had a breast lump. She was referred to the junior doctor who told her to go and see her GP for a referral to the breast clinic. Three months later she presented to the Emergency Department with chest pain. She was found to have a pleural effusion and 6cm left breast lump with axillary nodes. Advanced breast cancer was confirmed on biopsy and she died shortly afterwards. No local review of her care was undertaken.

Although this woman's drug dependency and lifestyle contributed significantly to her late presentation of breast cancer, nevertheless her death should have merited a local review of care. There was a missed opportunity to treat her after she gave birth when she first complained of a breast lump. This young woman had chaotic life, was known to be a poor attender, and had just had a baby. It was wholly unreasonable to expect her to make an urgent appointment with her GP. This was a situation where delaying discharge while awaiting investigations was justified. The challenges of caring for women with complex and multiple problems, particularly in the postnatal period was highlighted in the 2015 report, and the importance of arranging all appointments before discharge was noted.



Women with complex and multiple 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 for women with complex and multiple problems should include the timing of follow up appointments, which should be arranged with the appropriate services before the women is discharged and not left to the general practitioner to arrange. (Knight, Tuffnell et al. 2015)

## 7.5 Conclusions

The care of women who died from malignancy in pregnancy or during the postpartum period appears to have improved considerably since the last review in 2015 (Knight, Tuffnell et al. 2015). Assessors noted particularly that chemotherapy was rarely inappropriately delayed because of concerns over fetal exposure. Nevertheless, delays simply because women were either pregnant or had recently given birth were still evident, underlining the importance of remaining alert to symptoms which are not normal for pregnancy. For several women undergoing treatment for cancer no-one had considered the possibility that they might become pregnant and had not provided appropriate contraceptive advice, leaving them with the additional difficulty of an unplanned pregnancy. It must be emphasised that provision of contraceptive advice should occur in oncology as well as other medical settings. Alongside provision of high quality care for women, the importance of high quality care for surviving family members must be considered; there remain key missed opportunities to identify familial cancer syndromes which could prevent future death and morbidity in family members.

**Table 7.1: Classification of care received by women who died as a result of malignancy, UK and Ireland, 2014-16**

Classification of care received	Women who died from malignancy Number (%) N=71
Good care	24 (34)
Improvements to care which would have made no difference to outcome	32 (45)
Improvements in care which may have made a difference to outcome	15 (21)



# 8. Key indicators for local audits to assess implementation of recommendations

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Hemali Jayakody and Marian Knight

## 8.1 Background

The reviews of women's care contained within this report have given rise to more than 70 recommendations to change or improve current practice and care for pregnant and postpartum women. Recommendations alone, however, will not drive improvement unless they are implemented and change monitored regularly to see sustained improvement. In order to assist local units to audit their current practice and identify areas for improvement this chapter therefore contains key indicators according to each thematic area which could be used in local audits and surveys.

## 8.2 Identification of indicators

In order to identify the indicators, we developed a simplified framework for assessment of the implementation status of recommendations. The framework was developed using the Donabedian model for the assessment of the quality of care and the International Health Partnership and related initiatives (IHP+) framework adopted by the World Health Organisation for monitoring and evaluation of health system performance (Donabedian 2005, World Health Organisation 2010). From the potential indicators identified using the framework, key output and outcome indicators were selected for regular monitoring based on the main recommendations of each topic-specific chapter. The selection was based on simplicity, availability of information at the local level and measurability. These indicators align where possible with auditable areas specified in Greentop guidelines, the Care Quality Commission inspection framework or devolved nations equivalents and other frequently used standards.

## 8.3 Anticipated local use

The MBRRACE-UK Independent Advisory Group suggest that individual units should audit compliance with at least one indicator from within each theme. This should be undertaken as a quality improvement activity (The King's Fund and The Health Foundation 2017); following initial audit, units should further investigate the care of women for whom the indicator is not met in order to identify changes needed and implement actions to drive improvement. Re-audit after the actions have been implemented is essential.

For ease, where appropriate, suggested denominator and numerator groups are provided to allow calculation of the appropriate percentages.

## 8.4 Key audit indicators

### Prevention and treatment of obstetric haemorrhage

- The percentage of women managed according to the placenta praevia after previous caesarean section care bundle (Paterson-Brown and Singh 2010). *Denominator: total number of women with a placenta praevia following a previous caesarean birth in a specified time period. Numerator: the number of these women meeting all six elements of the care bundle.*
- The percentage of women cared for in maternity settings who developed pressure sores during their hospital stay. *Denominator: total number of women cared for in the unit over a specified time period. Numerator: the number of these women developing pressure sores.*

- The percentage of second stage caesarean sections carried out by trainees that are yet to complete a summative objective structured assessment of technical skills (OSATS) which are attended by a consultant obstetrician. *Denominator: total number of second stage caesarean sections carried out by trainees that have not yet completed a summative OSATS in a specified time period. Numerator: the number of these caesarean sections attended by a consultant obstetrician.*
- The percentage of records of women who have had a major PPH which have accurate documentation of fluid balance. *Denominator: number of women with major PPH in a specified time period. Numerator: the number of these women whose records have an accurate documentation of fluid balance.*

## Prevention and treatment of thrombosis and thromboembolism

- The percentage of women who underwent VTE risk assessment at specified times (pre or early pregnancy, pregnancy, postpartum or at any hospital admission or inter-current problems). *Denominator: number of women cared for in the unit in a specified time period. Numerator: number of these women who underwent a VTE risk assessment at each time point.*
- The percentage of women (pre or early pregnancy, pregnancy, postpartum) who had an accurate assessment score for thromboembolism risk. *Denominator: total number of women cared for in the unit in a specified time period. Numerator: number of these women whose VTE risk assessment score was accurately documented at each time point.*
- The percentage of pregnant and postpartum women with a BMI of 30 kg/m<sup>2</sup> or more who were informed about the symptoms of VTE. *Denominator: total number of women with a BMI of 30 kg/m<sup>2</sup> cared for in the unit in a specified time period. Numerator: number of these women receiving information about the symptoms of VTE.*

## Improving care of women with mental health problems

- The percentage of liaison and crisis resolution and home treatment (CRHT) staff members who have completed training in perinatal mental health within the last two years. *Denominator: total number of liaison and CRHT staff members at a specified time point. Numerator: number of these staff who have completed appropriate training in the previous two years.*
- Availability of a local guideline/policy which specifies an early referral pathway for women with mental health problems identified by maternity services and primary care.
- The percentage of pregnant or postpartum women who received care from mental health services who had a named care co-ordinator. *Denominator: total number of pregnant or postpartum women receiving care from mental health services in a specified time period. Numerator: number of these women who had a named care coordinator.*
- The availability of a local training programme for maternity care professionals on perinatal mental health, including the 'red flag' symptoms/signs.
- The percentage of pregnant women who had complete details about their past mental health history documented. *Denominator: total number of women cared for in the unit in a specified time period. Numerator: number of these women whose mental health history was accurately documented.*
- The percentage of mental health records requested by MBRRACE-UK supplied for the confidential enquiry. *Denominator: number of mental health records requested by MBRRACE-UK in a specified time period. Numerator: number of these records returned to MBRRACE-UK.*

## Improving the care of women from vulnerable groups

- The percentage of women known to be subject to domestic abuse whose data were appropriately shared across all relevant agencies. *Denominator: total number of women known to be subject to domestic abuse in a specified time period. Numerator: number of these women whose information was appropriately shared across all relevant agencies.*
- The percentage of health professionals in maternity services who have been trained on adult safeguarding. *Denominator: total number of staff members at a specified time point. Numerator: number of these staff who have completed appropriate training.*
- The availability of a clear pathway of shared care between perinatal mental health services and specialist addiction services.

- The percentage of women with complex medical and/or social problems who were discharged with a confirmed follow up appointment date. *Denominator: total number of women known to have multiple/complex health and social problems giving birth in a specified time period. Numerator: number of these women discharged with a confirmed follow-up appointment date.*

### Improving treatment of women with malignancy

- The percentage of pregnant women prescribed repeated opiates without a confirmed diagnosis. *Denominator: total number of pregnant women prescribed repeated opiates in a specified time period. Numerator: number of these women without a confirmed diagnosis following appropriate investigation.*
- The percentage of pregnant and postpartum women who were seen within two weeks by specialists for a suspected cancer. *Denominator: total number of pregnant and postpartum women with suspected cancer in a specified time period. Numerator: number of these women seen by specialist services within two weeks.*
- The percentage of women of reproductive age with cancer who received pre-pregnancy counselling and contraception advice. *Denominator: total number of women of reproductive age with cancer in a specified time period. Numerator: number of these women who received pre-pregnancy counselling and contraception advice.*
- The percentage of pregnant and postpartum women presenting to the emergency department seen by a member of the maternity medical team. *Denominator: total number of pregnant and postpartum women presenting to the emergency department in a specified time period. Numerator: number of these women seen by a member of the maternity medical team.*

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