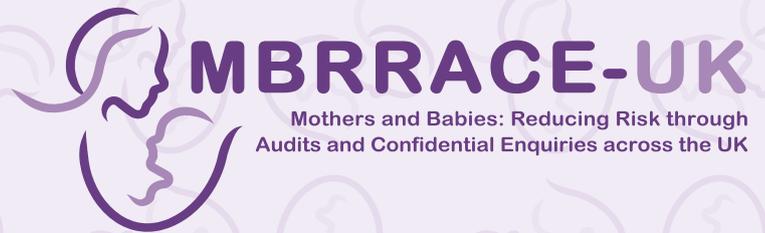


# Maternal, Newborn and Infant Clinical Outcome Review Programme



## Saving Lives, Improving Mothers' Care

Lessons learned to inform maternity care from the UK  
and Ireland Confidential Enquiries into Maternal Deaths  
and Morbidity 2017-19



November 2021



# 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 2017-19

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November 2021

# Funding

The Maternal, Newborn and Infant Clinical Outcome Review Programme, delivered by MBRRACE-UK, is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data. HQIP holds the contract to commission, manage, and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The Maternal, Newborn and Infant Clinical Outcome Review Programme is funded by NHS England, NHS Wales, the Health and Social Care division of the Scottish government, The Northern Ireland Department of Health, and the States of Jersey, Guernsey, and the Isle of Man [www.hqip.org.uk/national-programmes](http://www.hqip.org.uk/national-programmes).

**Design by:** Sarah Chamberlain and Andy Kirk

**Cover Artist:** Tana West

**Printed by:** BCQ

**This report should be cited as:**

Knight M, Bunch K, Tuffnell D, Patel R, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2021.

**ISBN:** 978-1-8383678-9-3

**Individual chapters from this report should be cited using the format of the following example for chapter 4:**

Cantwell R, Cairns A, Bunch K and Knight M on behalf of the MBRRACE-UK mental health chapter-writing group. Improving mental health care and care for women with multiple adversity. In Knight M, Bunch K, Tuffnell D, Patel R, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2021: p34-51.

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# Foreword

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As we write this foreword, the Birthrights inquiry into Racial Injustice in Maternity Care is analysing evidence from hundreds of Black, Brown and mixed ethnicity women and birthing people about their experiences and the impacts of systemic racism on their care. Emerging themes, backed up by testimony from healthcare professionals, include feeling unsafe, their concerns being ignored or dismissed, denial of pain relief due to racial stereotypes, and pervasive microaggressions causing harm or distress.

This MBRRACE-UK report shows yet again the stark disparity in maternal mortality rates between women from Black and Asian aggregated ethnic groups and White women – more than four times higher for Black women, two times higher for mixed ethnicity women and almost twice as high for Asian women. Apart from a slight drop in the maternal mortality rate for Black women, this bleak picture has not changed in over a decade.

We remain deeply concerned that Black and Brown people's basic human rights to safety, dignity, respect and equality in pregnancy and childbirth are not being protected, respected or upheld.

Our inquiry has also heard how previous life experiences – racist attitudes, microaggressions, dismissal of concerns, breakdown of trust – can affect interactions with maternity services. This report cannot capture the impact of this prior experience, but it must be recognised and better understood.

Although we cannot hear the voices of the women whose deaths are examined in this MBRRACE-UK Confidential Enquiry, it is clear that basic human rights are still challenged at many levels. Women do not receive essential contraceptive and pre-pregnancy advice because of structural and cultural biases. The fact of women's pregnancy still leads to investigations such as x-rays, as well as essential medications, being withheld because of a culture focusing entirely on potential risk, rather than benefit. Gaps in postnatal care are stark. It is also very evident how other factors – socioeconomic deprivation, language difficulties, mental health problems, obesity, domestic abuse – combine to increase the impact of the structural and cultural biases women experience simply because they are, have been, or might become, pregnant.

Birthrights began our inquiry recognising that systemic racism exists in society as a whole – so it must also impact maternity care. We must also understand the systemic, multi-layered discrimination against pregnant women and birthing people which prevents them receiving the best care before, during and after pregnancy and which may result in the ultimate tragedy of a maternal death. These facts are not new and action is long overdue.

We must all play a part in the solution – whether through advocacy, recognising the impacts of our own bias, validating a mother's experiences and concerns, or simply being the one person to listen and act.



**Sandra Igwe**

Co-Chair  
Inquiry on Racial Injustice  
in Maternity Care



**Amy Gibbs**

Chief Executive  
Birthrights

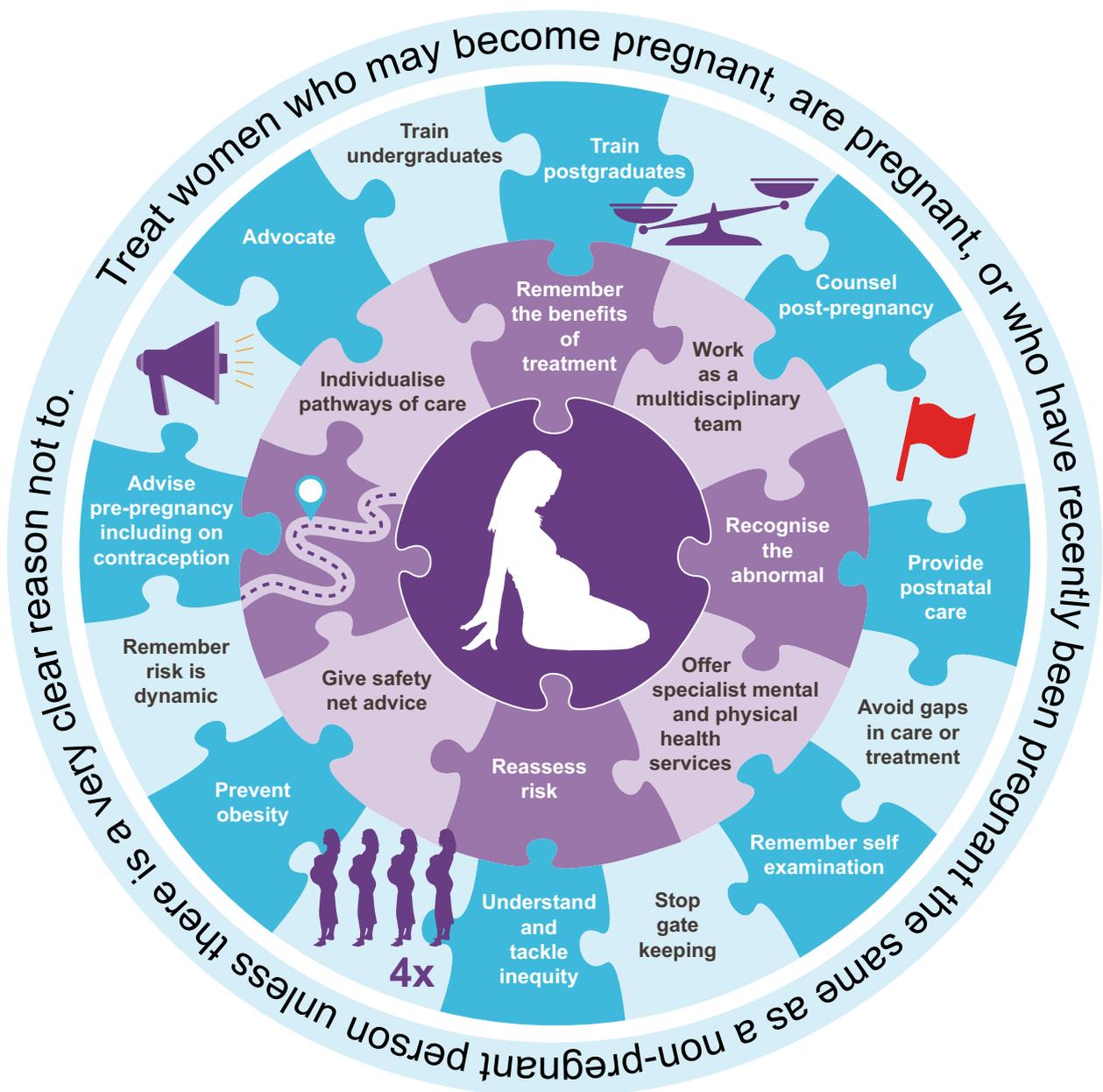


# Key messages from the report 2021

In 2017-19, **191 women died** during or up to six weeks after the end of pregnancy, from causes associated with their pregnancy, among 2,173,810 women giving birth in the UK.

**8.8 women** per 100,000 died during pregnancy or up to six weeks after childbirth or the end of pregnancy. There is no statistically significant difference in maternal mortality compared to 2010-12.

## Preventing maternal deaths - we are all part of the solution



# Executive Summary

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## Introduction

This report, the eighth 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 2017 and 2019 in the UK. In addition, it also includes Confidential Enquiries into the care of women who died between 2017 and 2019 in the UK and Ireland from mental health-related causes, venous thromboembolism, homicide and malignancy.

The report also includes a Morbidity Confidential Enquiry into the care of women who gave birth aged over 45 years. Surveillance information is included for 495 women who died during or up to one year after the end of pregnancy between 2017 and 2019. The care of 37 women who gave birth aged over 45 years was reviewed in depth for the Confidential Enquiry chapter.

This report can be read as a single document; each chapter is also designed to be read as a standalone report as, although the whole report is relevant to maternity staff, service providers and policy-makers, there are specific clinicians and service providers for whom only single chapters are pertinent. There are seven different chapters which may be read independently, the topics covered are: 1. Surveillance of maternal deaths 2. Older maternal age (morbidity enquiry) 3. Mental health and multiple adversity 4. Malignancy 5. Venous thromboembolism.

## Methods

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

**IMPORTANT NOTE: Relevant actions are addressed to all health professionals involved in the care of women who are pregnant, have recently been pregnant or likely to become pregnant in the future** as silo working leading to compromised care is a recurring theme identified in these enquiries. *The phrasing 'All Health Professionals' is used for brevity but should be taken to mean the groups noted above.* Some actions may be more pertinent to specific professional groups than others but all should nonetheless be reviewed for relevance to practice by each group.

## Causes and trends

There was a statistically non-significant decrease in the overall maternal death rate in the UK between 2014-16 and 2017-19 which suggests that continued focus on implementation of the recommendations of these reports is needed to achieve a reduction in maternal deaths. Assessors judged that 17% of women who died had good care. However, improvements in care which may have made a difference to the outcome were identified for 37% of women who died. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals**

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

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

Cardiac disease remains the largest single cause of maternal deaths. Neurological causes (epilepsy and stroke) are the second most common cause of maternal death.

There was a statistically non-significant decrease in maternal death rates from direct causes between 2014-16 and 2017-19. Thrombosis and thromboembolism remains the leading cause of direct maternal death during or up to six weeks after the end of pregnancy. Maternal suicide remains the leading cause of direct deaths occurring within a year after the end of pregnancy.

## Key messages to improve care

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

## New recommendations to improve care

### For professional organisations:

1. Collate recommendations from relevant guidelines into a single definitive source of guidance on the care for older women in pregnancy, including both women planning assisted reproduction and those who conceive spontaneously **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians]**.
2. Develop guidance on single embryo transfer for older women undergoing in vitro fertilisation, particularly in the context of medical co-morbidities **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians, British Fertility Society]**.
3. Ensure that postgraduate medical and surgical curricula include training in the need for contraceptive advice to women of reproductive age and how to ensure that it is provided and pre-pregnancy planning to women of reproductive age with medical problems such as cancer **[ACTION: Academy of Medical Royal Colleges]**.
4. Develop clear guidance on imaging in pregnancy, including for both diagnosis and staging **[ACTION: Royal Colleges of Radiologists, Obstetricians and Gynaecologists, Physicians]**.

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

5. Ensure there are clear and explicit pathways into specialist perinatal mental health care, which take into account all other aspects of perinatal mental health provision, including specialist roles within midwifery and obstetric services, in order to avoid any confusion over roles and responsibilities **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.
6. Ensure perinatal mental health services do not exclude patients on the basis of diagnosis, where they would ordinarily be seen by general adult mental health teams **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.
7. Ensure specialist services have the capacity to assess and manage all women who require secondary care mental health services, and be able to adjust for the altered (generally lowered) thresholds for assessment in the perinatal period **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.
8. Ensure local incident review teams are multidisciplinary in composition and that investigations are carried out across organisational structures where indicated **[ACTION: Hospitals/Trusts/Health Boards]**.
9. Develop a mechanism to ensure all VTE risk assessment tools used for pregnant and postpartum women are consistent with national guidance **[ACTION: NHSE/I and equivalents in the devolved nations and Ireland]**.

### For health professionals:

10. Do not delay consultant appointments and evidence-based effective preventive interventions such as aspirin pending the results of investigations such as prenatal diagnosis **[ACTION: All Health Professionals]**.
11. Recognise that 'post-pregnancy' counselling is as important as pre-pregnancy counselling for future pregnancies and for joining up obstetric and medical care to optimise a woman's long-term health **[ACTION: All Health Professionals]**.
12. Consider previous history, pattern of symptom development and ongoing stressors when assessing immediate risk and management of women with mental health symptoms. Plans should address immediate, short-term and long-term risk **[ACTION: All Health Professionals]**.
13. If psychotropic medication has been discontinued in advance of, or during, pregnancy, ensure women have an early postnatal review to determine whether they should recommence medication **[ACTION: All Health Professionals]**.
14. Where a woman with severe postnatal illness has previously responded well to treatment then there should be an expectation of a good recovery from subsequent postpartum episodes. Ensure that it is recognised that discharge from inpatient care before recovery is achieved is likely to be associated with continued risk **[ACTION: All Health Professionals]**.
15. While relatives provide invaluable support to the woman, complementing the care provided by universal and specialist services, they should not be given responsibilities beyond their capabilities or be expected to act as a substitute for an effective mental health response **[ACTION: All Health Professionals]**.

16. Women with substance misuse are often more vulnerable and at greater risk of relapse in the postnatal period, even if they have shown improvement in pregnancy. Ensure they are reviewed for re-engagement in the early postpartum period where they have been involved with addictions services in the immediate preconception period or during pregnancy **[ACTION: All Health Professionals]**.
17. Ensure symptoms of possible cancer are followed up postnatally **[ACTION: All Health Professionals]**.
18. Ensure that assessment of adherence to administration forms part of the antenatal or postnatal assessment of women prescribed low molecular weight heparin **[ACTION: All Health Professionals]**.

## Recommendations identified from existing guidance requiring improved implementation

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

### Care of older mothers

Guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women [*Saving Lives, Improving Mothers' Care 2019*] **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians, British Fertility Society]**.

Women who have a major risk factor [including age>40] should be referred for serial ultrasound measurement of fetal size and assessment of wellbeing with umbilical artery Doppler from 26–28 weeks of pregnancy [*RCOG Green-top guideline 31*] **[ACTION: All Health Professionals]**.

Advise pregnant women at high risk of pre-eclampsia, or with more than one moderate risk factor for pre-eclampsia to take 75–150 mg of aspirin daily from 12 weeks until the birth of the baby [*NICE NG 133 Hypertension in pregnancy*] **[ACTION: All Health Professionals]**.

Offer testing for gestational diabetes to women with BMI above 30 kg/m<sup>2</sup> at booking, previous macrosomic baby weighing 4.5 kg or more, previous gestational diabetes, family history of diabetes (first-degree relative with diabetes) or an ethnicity with a high prevalence of diabetes [*NICE Guideline NG3 Diabetes in pregnancy*] **[ACTION: All Health Professionals]**.

[In the event of preterm birth before 27 weeks of gestation] management of labour, birth and the immediate neonatal period should reflect the wishes and values of the mother and her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals. [*Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation. A BAPM Framework for Practice*] **[ACTION: All Health Professionals]**.

When treating women with antihypertensive medication during the postnatal period, use medicines that are taken once daily when possible [*NICE NG 133 Hypertension in pregnancy*] **[ACTION: All Health Professionals]**.

After childbirth, effective contraception should be discussed and offered prior to discharge from maternity services [*Guidance on the provision of contraception by maternity services after childbirth during the COVID-19 pandemic*] **[ACTION: All Health Professionals]**.

### Care of women with mental health problems and multiple adversity

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 [*Saving Lives, Improving Mothers' Care 2015*] **[ACTION: All Health Professionals]**.

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 [*Saving Lives, Improving Mothers' Care 2018*] **[ACTION: Hospitals/Trusts/Health Boards, All Health Professionals]**.

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. [*Saving Lives, Improving Mothers' Care 2015*] **[ACTION: All Health Professionals]**.

Regard women with any past history of psychotic disorder as at elevated risk and requiring individualised assessment of risk. [*Saving Lives, Improving Mothers' Care 2017*] **[ACTION: All Health Professionals]**.

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 [*Saving Lives, Improving Mothers' Care 2015*] **[ACTION: All 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 *[Saving Lives, Improving Mothers' Care 2018]* **[ACTION: All Health Professionals]**.

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 *[Saving Lives, Improving Mothers' Care 2018]* **[ACTION: Hospitals/Trusts/Health Boards]**.

Ask the woman about domestic abuse in a kind, sensitive manner at the first antenatal (booking) appointment, or at the earliest opportunity when she is alone. Ensure that there is an opportunity to have a private, one-to-one discussion. *[NICE Antenatal care guideline NG201]* **[ACTION: All Health Professionals]**.

## Care of women with cancer

For women with cancer, advice on postponement of pregnancy should be individualised and based on treatment needs and prognosis over time. *[RCOG Green-top guideline 12]* **[ACTION: All Health Professionals]**.

Guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of co-morbidities such as cardiac disease and cancer *[Saving Lives, Improving Mothers' Care 2019]* **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians, British Fertility Society]**.

Ensure early senior involvement of the maternal medicine team for any pregnant or postpartum woman admitted with [concerning symptoms of medical illness in pregnancy], whatever her gestation and wherever in the hospital she receives care *[MBRRACE-UK Rapid report 2021]* **[ACTION: All Health Professionals]**.

Care should be taken of pressure points in the obstetric population as well as other populations *[Saving Lives, Improving Mothers' Care 2018]* **[ACTION: All Health Professionals]**.

Investigate and treat pregnant and postpartum women the same as non-pregnant women unless there is a clear reason not to *[Multiple MBRRACE-UK Reports]* **[ACTION: All Health Professionals]**.

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for women if, on examination, the appearance of their cervix is consistent with cervical cancer *[NICE NG12]* **[ACTION: All Health Professionals]**.

Face to face treatment may be preferable when: the patient has complex clinical needs, you need to examine the patient, it's hard to ensure, by remote means, that patients have all the information they want and need about treatment options *[GMC guidance on remote consultations]* **[ACTION: All Health Professionals]**.

In general, for women with breast cancer, early delivery to avoid delays in chemotherapy should not be recommended. For women diagnosed with breast cancer in the third trimester, the risk-benefit is likely to favour both mother and baby if a woman can receive at least two cycles of chemotherapy prior to a term (39-40 week) birth *[Saving Lives, Improving Mothers' Care 2019]* **[ACTION: All Health Professionals]**.

## Prevention and treatment of thromboembolism

Women with previous VTE should be offered pre-pregnancy counselling and a prospective management plan for thromboprophylaxis in pregnancy made. Those who become pregnant before receiving such counselling should be referred at the earliest opportunity in pregnancy to a clinician with expertise in thrombosis in pregnancy *[Green-top guideline 37a]* **[ACTION: All Health Professionals]**.

There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply consistently in practice. There is a need for development of a tool to make the current risk assessment system simpler and more reproducible *[Saving Lives, Improving Mothers' Care 2018]* **[ACTION: NHSE/I and equivalents in the devolved nations and Ireland]**.

Ensure that women on prophylactic and treatment dose anticoagulation have a structured management plan to guide practitioners during the antenatal, intrapartum and post-natal period *[Saving Lives, Improving Mothers' Care 2020]* **[ACTION: Hospitals/Trusts/Health Boards]**.

Ensure that a consultant reviews and prioritises women prescribed prophylactic and treatment dose anticoagulation waiting for induction of labour in order to reduce the time women are not receiving low molecular weight heparin *[Saving Lives, Improving Mothers' Care 2020]* **[ACTION: Hospitals/Trusts/Health Boards]**.

It is recommended that anticoagulation with unfractionated heparin, including a weight-adjusted bolus injection, be initiated without delay in patients with high-risk pulmonary embolism. Systemic thrombolytic therapy is recommended for high-risk pulmonary embolism **[ACTION: All Health Professionals]**.

## Conclusions

The recurring theme identified in all chapters in this report revolves around risk and the fact that risk is not static, but dynamic. There is a need for recognition of the role that pre- and post-pregnancy actions can have in significantly decreasing risk, and, conversely, the additional risk women are placed under during pregnancy by clinician behaviours which focus on concerns over a woman's pregnancy rather than concerns over a woman herself. This emphasises again the need for care pre-pregnancy, during pregnancy and after pregnancy by the multidisciplinary team skilled in pregnancy medicine.

This report includes a morbidity enquiry into the care of women giving birth at aged 45 or over, which illustrates many of the complexities of intersecting risk and risk perception. Pregnancy at advanced maternal age is known to be associated with higher rates of maternal mortality, as these reports illustrate very clearly, higher rates of pregnancy loss and other pregnancy complications, and yet the average age at first childbirth continues to increase. Very few women planning pregnancy at an advanced maternal age had a clearly documented discussion over the potential health impacts to them or their unborn child.

The UK Government Health and Social Care Committee rated progress against the ambition in England to reduce maternal mortality by 50% by 2025 as inadequate. Beginning to address these wider cultural and structural biases affecting women's care on the basis of their pregnancy or the potential to become pregnant is fundamental to the prevention of maternal mortality in the UK and Ireland. These issues intersect with other biases women experience due to their ethnicity, socioeconomic status, co-morbidities, language, disability or social complexity. Addressing these structural biases must start with early medical, midwifery and nursing education and form a fundamental part of any wider women's health strategy. We are all part of the solution.

# Acknowledgements

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It is with grateful thanks that the MBRRACE-UK collaboration would like to acknowledge the contribution of the many healthcare professionals and staff from the health service and other organisations who were involved in the notification of maternal deaths, the provision of data and the assessment of individual deaths in both the UK and Ireland. Without the generous contribution of their time and expertise it would not have been possible to produce this report. It is only through this collaborative effort that it has been possible to conduct this confidential enquiry and to continue the UK tradition of national self-audit to improve care for women, babies and their families in the future. We would particularly like to thank all MBRRACE-UK Lead Reporters and other staff in Trusts and Health Boards across the UK and Ireland who provided the information about women who died to enable the enquiry to be conducted.

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## 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 with the character M in the corner **M**

The majority of recommendations arise from existing national guidelines or previous reports and the source of these recommendations are cited within green boxes. Example:

**Existing guidance requiring improved implementation is presented in green boxes**

**NICE 2345**

Recommendations based on improvements in care noted by MBRRACE reviewers for which there is no current national guidance and which has not been noted in previous guidance or reports are shown in purple boxes. Example:

**New recommendations are presented in purple boxes with the character N in the corner.**

**N**

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.

# Glossary of terms

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<b>AFE</b>	Amniotic Fluid Embolism	<b>MBU</b>	Mother and Baby Unit
<b>BAPM</b>	British Association of Perinatal Medicine	<b>MDE</b>	Maternal Death Enquiry
<b>BMI</b>	Body Mass Index	<b>MMC</b>	Maternal Medicine Centres
<b>BP</b>	Blood pressure	<b>MRI</b>	Magnetic Resonance Imaging
<b>BTS</b>	British Thoracic Society	<b>NCAPOP</b>	National Clinical Audit and Patient Outcomes Programme
<b>CEMD</b>	Confidential Enquiries into Maternal Deaths	<b>NHS</b>	National Health Service
<b>CEMM</b>	Confidential Enquiries into Maternal Morbidity	<b>NICE</b>	National Institute for Health and Care Excellence
<b>CI</b>	Confidence interval	<b>NIMACH</b>	Northern Ireland Maternal and Child Health
<b>CMACE</b>	Centre for Maternal and Child Enquiries	<b>NMPA</b>	National Maternal and Perinatal Audit
<b>COVID-19</b>	Coronavirus disease 2019	<b>PE</b>	Pulmonary embolism
<b>CT</b>	Computerised Tomography	<b>PHE</b>	Public Health England
<b>CTPA</b>	Computerised Tomography Pulmonary Angiogram	<b>PTE</b>	Pulmonary thromboembolism
<b>DOAC</b>	Direct Oral Anticoagulant	<b>RCM</b>	Royal college of Midwives
<b>DVT</b>	Deep venous thrombosis	<b>RCOG</b>	Royal College of Obstetricians and Gynaecologists
<b>ERS</b>	European Respiratory Society	<b>RCP</b>	Royal College of Physicians
<b>ESC</b>	European Society for Cardiology	<b>RCPATH</b>	Royal College of Pathologists
<b>FSRH</b>	Faculty of Sexual and Reproductive Health	<b>RQIA</b>	Regulation and Quality Improvement Authority
<b>GP</b>	General practitioner	<b>RR</b>	Rate ratio
<b>GLOSS</b>	Global Maternal Sepsis Study	<b>RRR</b>	Ratio of relative risks
<b>GMC</b>	General Medical Council	<b>SARS-CoV-2</b>	Severe Acute Respiratory Syndrome Coronavirus 2
<b>HQIP</b>	Healthcare Quality Improvement Partnership	<b>SIGN</b>	Scottish Intercollegiate Guidelines Network
<b>HSE</b>	Health Service Executive	<b>SUDEP</b>	Sudden unexpected death in epilepsy
<b>ICD</b>	International Classification of Diseases	<b>TB</b>	Tuberculosis
<b>ICD-MM</b>	International Classification of Diseases – Maternal Mortality	<b>UK MEC</b>	UK Medical Eligibility Criteria
<b>IMD</b>	Index of Multiple Deprivation	<b>VQ</b>	Ventilation-perfusion
<b>IVF</b>	In vitro fertilisation	<b>VTE</b>	Venous thromboembolism
<b>LARC</b>	Long-acting reversible contraception	<b>WHO</b>	World Health Organisation
<b>LMWH</b>	Low molecular weight heparin		
<b>MBRRACE-UK</b>	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK		

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# 1. Introduction and methodology

Marian Knight

## 1.1 The 2021 Saving Lives, Improving Mothers' Care report

As with many activities over the last year, the work of the MBRRACE-UK team and assessors moved entirely online from March 2020. All MBRRACE-UK staff were required to work from home, reporting staff in NHS hospitals switched to providing information almost entirely electronically, assessors continued to undertake assessments alongside extremely pressured NHS work, and all chapter writing meetings were conducted virtually. In addition, over the period in which the work for this 2021 report was being conducted, the MBRRACE-UK team and assessors produced two additional rapid reports on SARS-CoV-2 associated maternal deaths to ensure messages for care were translated rapidly into practice. This report must therefore start with heartfelt thanks to all those who have contributed and enabled its production despite these challenges.

The recurring theme identified in all chapters in this report revolves around risk and the fact that risk is not static, but dynamic. Perhaps most disappointing is the lack of recognition of the role that pre- and post-pregnancy actions can have in significantly decreasing risk, and, conversely, the additional risk women are placed under during pregnancy by clinician behaviours which focus on concerns over a woman's pregnancy rather than concerns over a woman herself. As the WRISK project (<https://wrisk.org/>) has clearly identified in their analysis of risk-based messages in the UK media (Marshall et al. 2021), women make reproductive health decisions and behaviours in the context of cumulative anxiety-provoking messages which associate risk with almost any food, drink, medication or underlying health condition. Clinicians are subject to the same environmental influences, potentially enhancing their focus on pregnancy concerns to the detriment of women's health. This emphasises again the need for care pre-pregnancy, during pregnancy and after pregnancy by the multidisciplinary team skilled in pregnancy medicine.

This report includes a morbidity enquiry into the care of women giving birth at aged 45 or over, which illustrates many of the complexities of intersecting risk and risk perception. Pregnancy at advanced maternal age is known to be associated with higher rates of maternal mortality, as these reports illustrate very clearly, higher rates of pregnancy loss and other pregnancy complications, and yet the average age at first childbirth continues to increase. Very few women planning pregnancy at an advanced maternal age had a clearly documented discussion over the potential health impacts to them or their unborn child. It is concerning that pregnancy at older age becomes more of a societal norm, coming as it does with an increased likelihood of entering pregnancy with pre-existing co-morbidities, as the cultural bias against appropriate use of medication in pregnancy appears only to increase.

This report is being finalised in the week that the Health and Social Care Committee in the UK published its report on progress against the ambition in England to reduce maternal mortality by 50% by 2025 (Health and Social Care Committee 2021a). Progress was rated as inadequate. Beginning to address these wider cultural and structural biases affecting women's care on the basis of their pregnancy or the potential to become pregnant, which, as highlighted in the 2020 report, intersect with other biases women experience due to their ethnicity, socioeconomic status, co-morbidities, language, disability or social complexity is fundamental to the prevention of maternal mortality in the UK and Ireland. This must start with early medical, midwifery and nursing education and form a fundamental part of any wider women's health strategy.

## 1.2 Actions following the release of the 2014-2020 reports

Although this report sees a welcome small decrease in the maternal mortality rate for women from Black, Asian and Mixed ethnic groups, there is still no substantive change in the disparity in mortality rates between women from Black ethnic groups and those from White ethnic groups, or between women from Asian ethnic groups and those from White ethnic groups. Actions as a consequence of these disparities remain ever more important. The disparity in Black women's outcomes as well as experiences was highlighted by Channel 4 in a documentary "the Black Maternity Scandal" in March 2021, leading to further parliamentary round table discussions with the Woman and Equalities Select Committee on how to reduce the disparity. A Maternity Inequalities Oversight Forum, established by the Department of Health and Social Care, has continued to meet regularly. NHS England and NHS Improvement have developed Equity and Equality Guidance for Local Maternity Systems ([www.england.nhs.uk/publication/equity-and-equality-guidance-for-local-maternity-systems/](http://www.england.nhs.uk/publication/equity-and-equality-guidance-for-local-maternity-systems/)) and asked Local Maternity Systems to coproduce Equity and Equality Action Plans by 28 February 2022. In



addition, the RCOG Race Equality Taskforce has continued to work together with the Fivexmore campaign to drive change and change attitudes. Their ‘five steps for health professionals’ can be found at <https://www.rcog.org.uk/globalassets/documents/news/campaigns-and-opinions/racial-equality-taskforce/poster-five-steps-for-healthcare-professionals.pdf>.

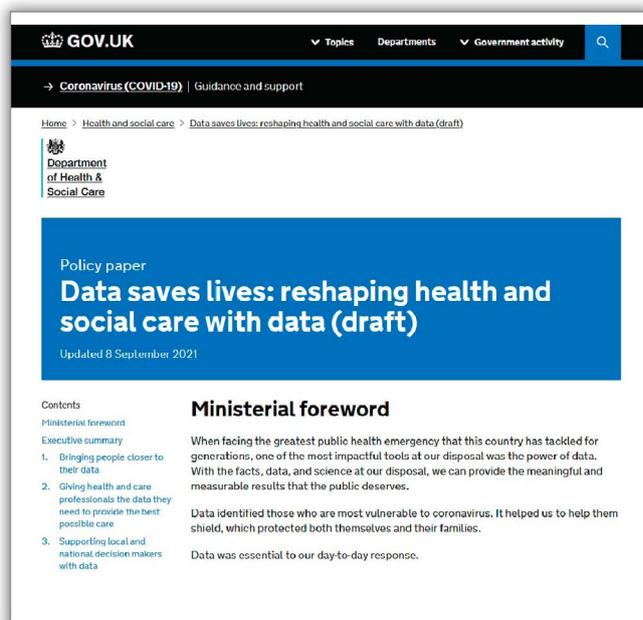
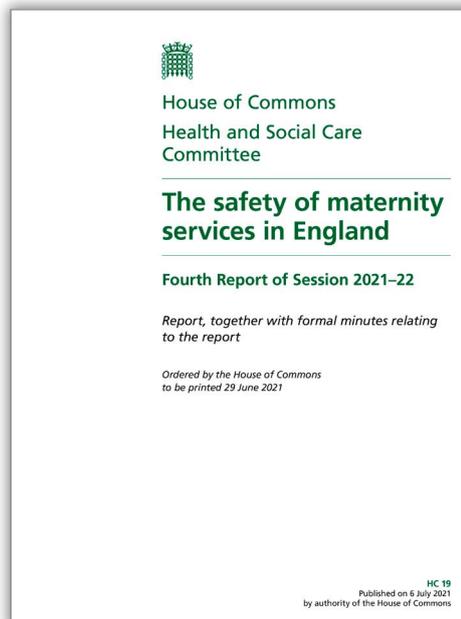


As a direct consequence of the disparity in maternal mortality between women from Black, Asian and Mixed ethnicity groups and White women, the charity Birthrights is conducting an investigation into Racial injustice in maternity care, with a specific focus on which fundamental human rights are in jeopardy, to add a wider lens to the factors underlying this inequality (<https://www.birthrights.org.uk/campaigns-research/racial-injustice/>).

Evidence from MBRRACE-UK was cited as underpinning several recommendations in the recent Health and Social Care Select Committee Inquiry on the Safety of Maternity Services in England (Health and Social Care Committee 2021b). Evidence from MBRRACE, the Fivexmore campaign and others particularly underpinned the following recommendations:

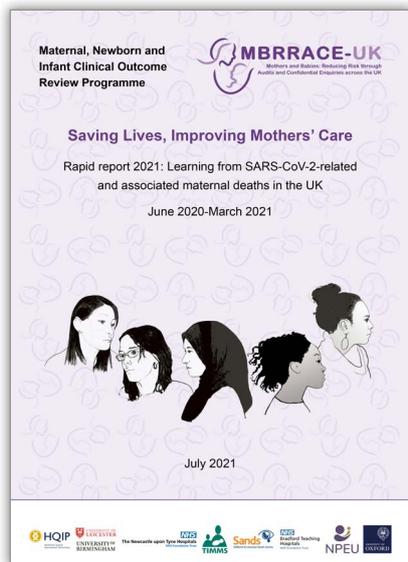
*“Having the right skill set... is crucial for the successful implementation of continuity of carer. We therefore recommend that those involved in delivering this model have received appropriate training and that all professionals are competent and trained in all areas that they work in, particularly in relation to Black mothers where the disparities are the greatest.”*

*“Given the underlying causes of these outcomes for women from Black, Asian and minority ethnic groups relate to a range of issues beyond the remit of the Department, we recommend that the Government as a whole introduce a target to end the disparity in maternal and neonatal outcomes with a clear timeframe for achieving that target. The Department must lead the development of a strategy to achieve this target and should include consultation with mothers from a variety of different backgrounds.”*



Whilst there are still clearly many maternal deaths which could be prevented, the MBRRACE-UK programme was noted as an important case study in the NHSX policy document ‘Data Saves Lives’ (Department of Health and Social Care 2021), highlighting the 2020 report finding of an increase in maternal deaths from SUDEP, and the resulting recommendation that all women should receive risk minimisation advice and ensure that medications were optimised to control seizure frequency (Knight et al. 2020b). The MBRRACE-UK team, working together with the charity SUDEP Action, have been invited to present to several groups, including the All Party Parliamentary Group on Epilepsy, to try to ensure that women’s needs are recognised alongside concerns over fetal wellbeing. It is of concern that current discourse around valproate use remains focussed around fetal risk without the essential focus on ensuring that women receive alternative effective anti-epileptic medication.

Working with the Resuscitation Council, the Obstetric Anaesthetists Association have developed an ‘Obstetric Cardiac Arrest Quick Reference Guide’ addressing several recommendations from these reports regarding modifications required for the resuscitation of pregnant women as well as causes of cardiac arrest to consider. Available at [https://www.oaa-anaes.ac.uk/assets/\\_managed/cms/files/Clinical%20Guidelines/Obstetric%20Cardiac%20Arrest%20QRH%20OAA%20V1%201.pdf](https://www.oaa-anaes.ac.uk/assets/_managed/cms/files/Clinical%20Guidelines/Obstetric%20Cardiac%20Arrest%20QRH%20OAA%20V1%201.pdf).



Throughout the COVID-19 pandemic, the MBRRACE-UK team have continued to work directly with the RCOG/RCM guideline cell to ensure that findings from the ongoing enquiries were rapidly translated into guidelines for practice (Royal College of Obstetricians and Gynaecologists and The Royal College of Midwives 2021). The most recent rapid report into SARS-CoV-2-associated maternal deaths highlighted the lower standard of care which women received simply because they were pregnant or postpartum (Knight et al. 2021), leading to further actions from the Royal Colleges to ensure that this additional inequity was addressed. One of the key messages from these reports has been, and remains ‘treat a pregnant woman as you would a non-pregnant woman unless there is a clear reason not to.’

NHS England has fed back to the MBRRACE-UK team responses to other recommendations in the 2020 report. These responses are included in the Appendix.

### 1.3 Topics covered in MBRRACE-UK maternal reports 2014-2020

Since 2014 the programme has involved 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 twice in two three-year cycles; this report is the second in the third 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 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.
- **2019 report:** Surveillance data on maternal deaths from 2015-17. Confidential Enquiry reports on deaths from cardiac causes, deaths from pre-eclampsia and eclampsia and related causes, accidental deaths and deaths in early pregnancy, morbidity from newly diagnosed breast cancer and messages for critical care.
- **2020 report:** Surveillance data on maternal deaths from 2016-18. Confidential Enquiry reports on severe morbidity from pulmonary embolism and deaths from epilepsy, stroke, haemorrhage, amniotic fluid embolism (AFE), anaesthesia, respiratory, endocrine and other indirect causes.
- **2021 report (this report):** Surveillance data on maternal deaths from 2017-19. Confidential Enquiry reports on deaths from mental health-related causes, deaths due to thrombosis and thromboembolism, malignancy and homicides, and a morbidity enquiry into the care of women giving birth at age 45 years or older.

Note that maternal deaths associated with SARS-CoV-2 between March 2020 and March 2021 were included in two additional rapid reports (Knight et al. 2020a, Knight et al. 2021). 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 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>).

### Maternal Morbidity

Women are identified for the Confidential Enquiries into Maternal Morbidity in different ways according to the topic. The women giving birth at aged 45 and over were identified from two sources: UK births data from the Office for National Statistics, National Records Scotland or the Northern Ireland Statistics and Research Agency and MBRRACE-UK perinatal mortality surveillance data for January-June 2019. A stratified random sample was drawn from each source as follows:

All births to women aged 45 and over were identified from each source. A stratified random sample of 22 women was drawn from each data source, to include women from each UK nation and each region of England, and to ensure half of the sample were women from white ethnic groups and half from Black, Asian and Mixed ethnic groups to ensure that any messages relating to ethnic inequalities would be identified.

A full set of medical records was requested from each hospital and general practice concerned. The anonymised 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. One woman refused consent, and staff capacity due to the pandemic meant that a second woman was not contacted to seek consent. Imperial College Healthcare NHS Trust refused to supply three sets of records despite extensive correspondence and evidence that MBRRACE-UK holds all appropriate permissions to receive such records. Two further women were subsequently found to be aged under 45 years and were therefore excluded from the enquiry. Thus the care of 37 women is described in Chapter 3.

## 2. Maternal Mortality in the UK 2017-19: Surveillance and Epidemiology

Kathryn Bunch and Marian Knight

### 2.1 Key points

There was a statistically non-significant decrease in the overall maternal death rate in the UK between 2014-16 and 2017-19 which suggests that continued focus on implementation of the recommendations of these reports is needed to achieve a reduction in maternal deaths. **ACTION: Policy makers, service planners/commissioners, service managers, all health professionals**

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

Eight percent of the women who died during or up to a year after pregnancy in the UK in 2017-19 were at severe and multiple disadvantage. The main elements of multiple disadvantage were a mental health diagnosis, substance use and domestic abuse.

Cardiac disease remains the largest single cause of indirect maternal deaths. Neurological causes (epilepsy and stroke) are the second most common cause of maternal death.

There was a statistically non-significant decrease in maternal death rates from direct causes between 2014-16 and 2017-19. Thrombosis and thromboembolism remains the leading cause of direct maternal death during or up to six weeks after the end of pregnancy. Deaths due to obstetric haemorrhage and pregnancy related sepsis occur as frequently as each other and are the next commonest causes of maternal death, followed by suicides.

Maternal suicide remains the leading cause of direct deaths occurring within a year after the end of pregnancy.

### 2.2 Causes and trends

Overall, 211 women died in 2017-19 during or within 42 days of the end of pregnancy in the UK. The deaths of 20 women were classified as coincidental. Thus in this triennium 191 women died from direct and indirect causes, classified using ICD-MM (World Health Organisation 2012), among 2,173,810 maternities, a maternal death rate of 8.79 per 100,000 maternities (95% CI 7.58 – 10.12). This compares to the rate of 9.71 per 100,000 maternities (95% CI 8.46 – 11.09) in 2016-18 (rate ratio (RR) 0.91, 95% CI 0.75-1.10, p=0.314). As in previous MBRRACE-UK maternal reports, information about 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 2017-19 (rate ratio (RR) 0.63, 95% CI 0.52-0.76, p=0.001 for trend in rolling rates over time). The direct maternal death rate has decreased by 47% since 2003-05 with a RR of 0.53 (95% CI 0.40-0.70 p<0.001) and there was a 28% decrease in the rate of indirect maternal deaths (RR 0.72, 95% CI 0.56-0.93, p=0.009).

The progress towards the Government ambition to reduce maternal mortality by 50% between 2010 and 2025 (Department of Health 2017) can be assessed by comparing maternal death rates between the 2010-12 and 2017-19 triennia. Over this time, maternal mortality has decreased by 13%, but this decrease is not statistically significant (RR 0.83, 95% CI 0.72-1.05).

The rates of overall mortality, direct and indirect maternal death in the 2017-19 triennium were once again not significantly different from the rates in 2014-16, the immediately preceding triennium (RR for overall mortality = 0.90, 95% CI 0.74 to 1.09, p=0.279; RR for direct deaths = 0.84, 95% CI 0.62 to 1.15, p=0.260; RR for indirect deaths = 0.94, 95% CI 0.72 to 1.22, p=0.646). It is nevertheless reassuring that the maternal mortality rates, overall, direct and indirect have decreased, albeit not statistically significantly so.

Triennial rates are shown in Table 2.2 and Figure 2.2, and suggest that the rate of decrease in maternal mortality has slowed or is static (Table 2.2 and Figure 2.2 are unchanged from the 2019 and 2020 reports).

**Table 2.1: Three-year rolling average direct and indirect maternal mortality rates per 100,000 maternities, deaths classified using ICD-MM; UK 2003-19 (illustrated in Figure 2.1)**

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
2015-17	2 280 451	87	3.82	3.06 - 4.71	122	5.35	4.44 - 6.39	209	9.16	7.96 - 10.50
2016-18	2 235 159	92	4.12	3.32 - 5.05	125	5.59	4.66 - 6.66	217	9.71	8.46 - 11.09
2017-19	2 173 810	78	3.59	2.84 - 4.48	113	5.20	4.28 - 6.25	191	8.79	7.58 - 10.12

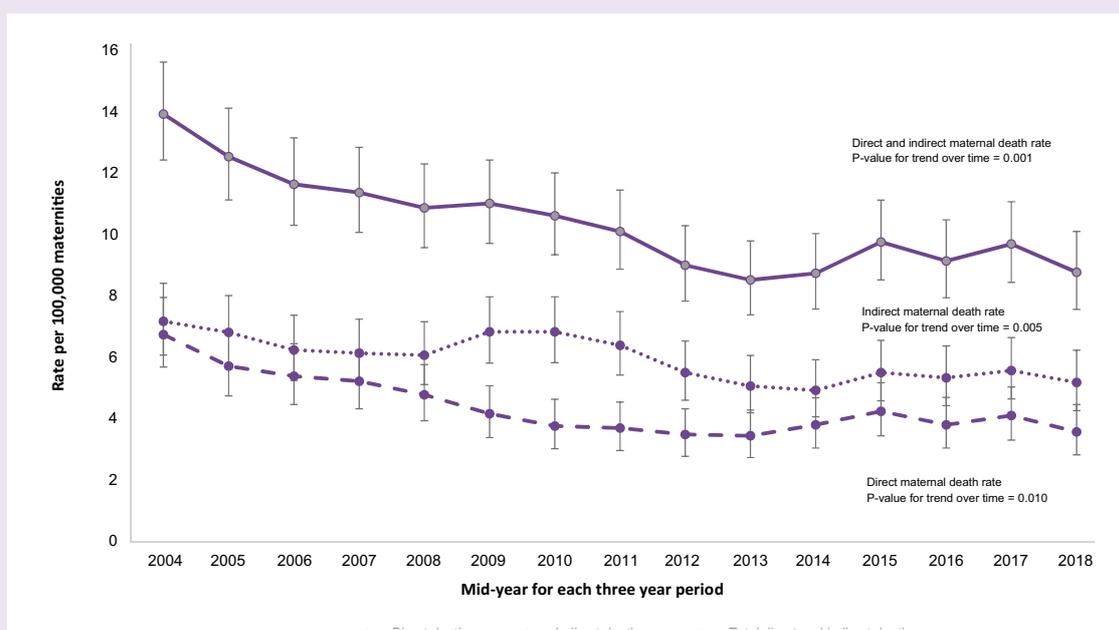
Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

**Table 2.2: Direct and Indirect maternal deaths and mortality rates per 100,000 maternities by discrete triennia, UK using ICD-MM; UK 2003-17 (illustrated in Figure 2.2)**

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
2015-17	87	3.82	3.06 - 4.71	122	5.35	4.44 - 6.39	209	9.16	7.96 - 10.50

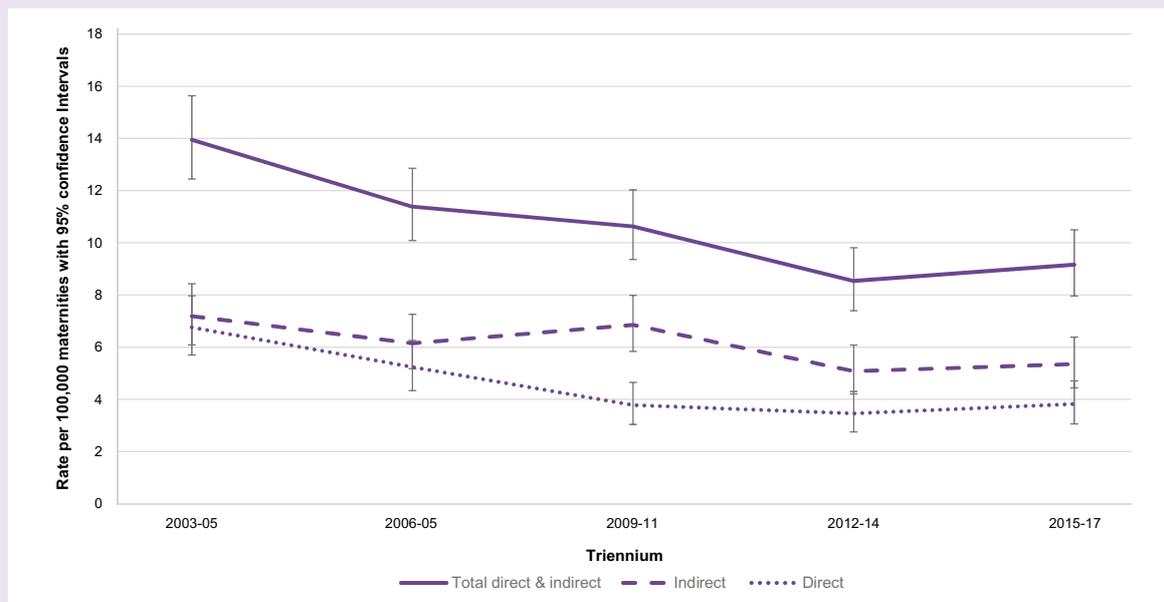
Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

**Figure 2.1: Direct and indirect maternal mortality rates per 100,000 maternities using ICD-MM and previous UK classification systems; three-year rolling average rates 2003-2019**



Sources: CMACE, MBRRACE-UK

**Figure 2.2: Direct and Indirect maternal mortality rates per 100,000 maternities by discrete triennia; UK 2003-2017 (using ICD-MM)**

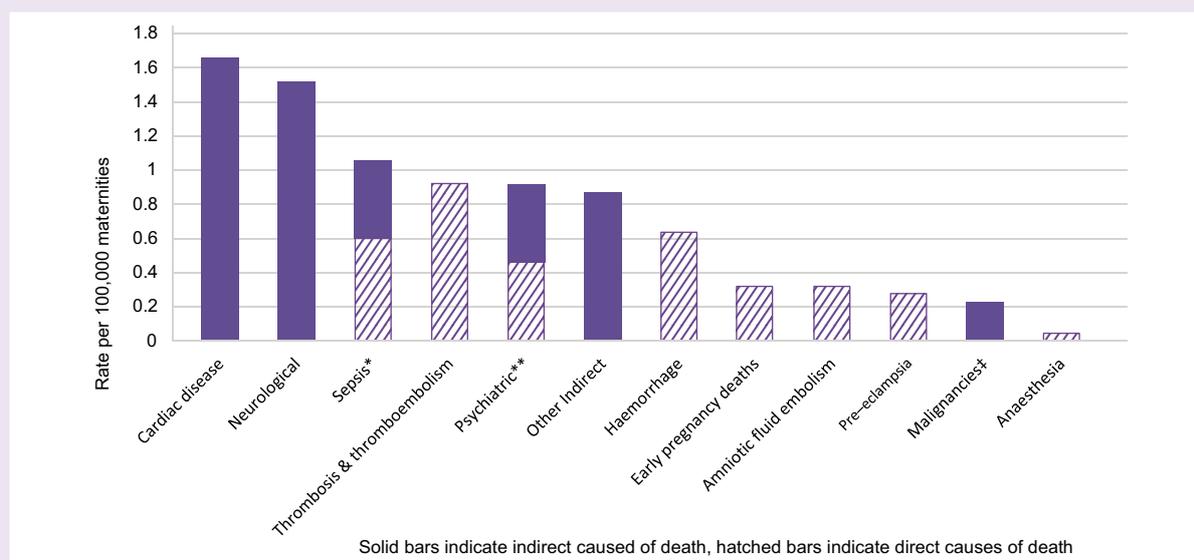


Sources: CMACE, MBRRACE-UK

## 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 (2013-15, 2014-16, 2015-17, 2016-18 and 2017-19) (Table 2.3 and Figure 2.3) and for discrete, non-overlapping triennial periods between 1985-7 and 2015-17 (Table 2.4). The report in 2019 was the final report in a three-year cycle, therefore Table 2.4 was newly updated then with the latest triennial figures and is unchanged for the last two years; 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 and Figure 2.4.

**Figure 2.3: Maternal mortality by cause 2017-19**



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 indirect malignancies (breast/ovary/cervix)

Source: MBRRACE-UK

**Table 2.3: Maternal mortality rates per 100,000 maternities, by cause, by overlapping triennia, 2013 to 2019 2019 (illustrated in figures 2.3 and 2.4)**

	2013-15			2014-16			2015-17			2016-18			2017-19		
	n	Rate	95% CI												
<b>All Direct and Indirect deaths</b>	202	8.76	7.59 – 10.05	225	9.78	8.54 – 11.14	209	9.16	7.96 – 10.50	217	9.71	8.46 – 11.09	191	8.79	7.58 – 10.12
<b>Direct deaths</b>															
Pregnancy related infections - Sepsis*	10	0.43	0.21 – 0.79	11	0.48	0.24 – 0.86	10	0.44	0.21 – 0.81	12	0.54	0.28 – 0.94	13	0.60	0.32 – 1.02
Pre-eclampsia and eclampsia	3	0.13	0.03 – 0.38	6	0.26	0.10 – 0.57	5	0.22	0.07 – 0.51	4	0.18	0.05 – 0.46	6	0.28	0.10 – 0.60
Thrombosis and thromboembolism	26	1.13	0.74 – 1.65	32	1.39	0.95 – 1.96	34	1.49	1.03 – 2.08	33	1.48	1.02 – 2.07	20	0.92	0.56 – 1.42
Amniotic fluid embolism	8	0.35	0.15 – 0.68	9	0.39	0.18 – 0.74	6	0.26	0.10 – 0.57	6	0.27	0.10 – 0.58	7	0.32	0.13 – 0.66
Early pregnancy deaths	4	0.17	0.05 – 0.44	3	0.13	0.03 – 0.38	4	0.18	0.05 – 0.45	7	0.31	0.13 – 0.65	7	0.32	0.13 – 0.66
Haemorrhage	21	0.91	0.56 – 1.39	18	0.78	0.46 – 1.24	11	0.48	0.24 – 0.86	14	0.63	0.34 – 1.05	14	0.64	0.35 – 1.08
Anaesthesia	2	0.09	0.01 – 0.31	1	0.04	0.001 – 0.24	1	0.04	0.001 – 0.24	1	0.05	0.001 – 0.25	1	0.05	0.001 – 0.30
Psychiatric causes - Suicides	12	0.52	0.27 – 0.91	16	0.70	0.40 – 1.13	13	0.57	0.30 – 0.98	14	0.63	0.34 – 1.05	10	0.46	0.22 – 0.85
Malignancy - direct				1	0.04	0.001 – 0.24	1	0.04	0.001 – 0.24	-	-	-	-	-	-
Unascertained - direct	2	0.09	0.01 – 0.31	1	0.04	0.001 – 0.24	2	0.09	0.01 – 0.32	1	0.05	0.001 – 0.25	-	-	-
All Direct	88	3.82	3.06 – 4.70	98	4.26	3.46 – 5.19	87	3.82	3.06 – 4.71	92	4.12	3.32 – 5.05	78	3.59	2.84 – 4.48
<b>Indirect</b>															
Cardiac disease	54	2.34	1.76 – 3.06	55	2.39	1.80 – 3.11	48	2.10	1.55 – 2.79	50	2.24	1.66 – 2.95	36	1.66	1.16 – 2.29
Indirect Sepsis - Influenza	1	0.04	0.001 – 0.24	2	0.09	0.01 – 0.31	1	0.04	0.001 – 0.24	2	0.09	0.01 – 0.32	2	0.09	0.01 – 0.33
Indirect Sepsis – Pneumonia/ others	3	0.13	0.03 – 0.38	6	0.26	0.10 – 0.57	9	0.39	0.18 – 0.75	9	0.40	0.18 – 0.76	8	0.37	0.16 – 0.73
Other Indirect causes	26	1.13	0.74 – 1.65	26	1.13	0.74 – 1.66	23	1.01	0.64 – 1.51	15	0.67	0.38 – 1.11	19	0.87	0.53 – 1.36
Indirect neurological conditions	19	0.82	0.49 – 1.29	24	1.04	0.67 – 1.55	27	1.18	0.78 – 1.72	29	1.30	0.87 – 1.86	33	1.52	1.04 – 2.13
Psychiatric causes – Drugs/alcohol/others	4	0.17	0.05 – 0.44	6	0.26	0.10 – 0.57	7	0.31	0.12 – 0.63	14	0.63	0.34 – 1.05	10	0.46	0.22 – 0.85
Indirect malignancies	7	0.30	0.12 – 0.63	8	0.35	0.15 – 0.69	7	0.31	0.12 – 0.63	6	0.27	0.10 – 0.58	5	0.23	0.07 – 0.54
All Indirect	114	4.94	4.08 – 5.94	127	5.52	4.60 – 6.57	122	5.35	4.44 – 6.39	125	5.59	4.66 – 6.66	113	5.20	4.28 – 6.25
<b>Coincidental</b>															
Homicide	9	0.39	0.18 – 0.74	10	0.43	0.21 – 0.80	7	0.31	0.12 – 0.63	5	0.22	0.07 – 0.52	4	0.18	0.05 – 0.47
Other coincidental	29	1.26	0.84 – 1.81	24	1.04	0.67 – 1.55	20	0.88	0.54 – 1.35	20	0.90	0.55 – 1.38	16	0.74	0.42 – 1.20
All coincidental	38	1.65	1.17 – 2.26	34	1.48	1.02 – 2.06	27	1.18	0.78 – 1.72	25	1.12	0.72 – 1.65	20	0.92	0.56 – 1.42
<b>Late deaths</b>	326	14.14	12.64 – 15.76	286	12.43	11.03 – 13.95	313	13.73	12.25 – 15.33	305	13.65	12.16 – 15.27	284	13.06	11.59 – 14.68

\*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, by discrete triennia, 1985-2017 (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	2015-17	1985-87	1988-90	1991-93	1994-96	1997-99	2000-02	2003-05	2006-08	2009-11	2012-14	2015-17												
All Direct and Indirect deaths	223	238	228	268	242	261	295	261	253	200	209	9.83	10.08	9.85	12.19	11.4	13.07	13.95	11.39	10.63	8.54	9.16												
Direct deaths																																		
Sepsis*	9	17	15	16	18	13	18	26	16	7	10	0.40	0.72	0.65	0.73	0.85	0.65	0.85	1.13	0.63	0.29	0.44												
Pre-eclampsia and eclampsia	27	27	20	20	16	14	18	19	10	2	5	1.19	1.14	0.86	0.91	0.75	0.70	0.85	0.83	0.42	0.08	0.22												
Thrombosis and thromboembolism	32	33	35	48	35	30	41	18	30	20	34	1.41	1.40	1.51	2.18	1.65	1.50	1.94	0.79	1.26	0.85	1.49												
Amniotic fluid embolism	9	11	10	17	8	5	17	13	7	16	6	0.40	0.47	0.43	0.77	0.38	0.25	0.80	0.57	0.29	0.68	0.26												
Early pregnancy deaths	16	24	17	15	17	15	14	11	4	7	4	0.71	1.02	0.73	0.68	0.80	0.75	0.66	0.48	0.17	0.29	0.18												
Haemorrhage	10	22	15	12	7	17	14	9	14	13	11	0.44	0.93	0.65	0.55	0.33	0.85	0.66	0.39	0.59	0.56	0.48												
Anaesthesia	6	4	8	1	3	6	6	7	3	2	1	0.26	0.17	0.35	0.05	0.14	0.30	0.28	0.31	0.12	0.09	0.04												
Other Direct†	27	17	14	7	7	8	4	4	0	0	3	1.19	0.72	0.60	0.32	0.33	0.40	0.19	0.17	-	-	0.13												
All direct	139	145	128	134	106	106	132	107	82	67	74	6.13	6.14	5.53	6.10	4.99	5.31	6.24	4.67	3.49	2.84	3.24												
Indirect deaths																																		
Cardiac disease	23	18	37	39	35	44	48	53	51	51	48	1.01	0.76	1.60	1.77	1.65	2.20	2.27	2.31	2.14	2.18	2.10												
Other Indirect causes	43	45	38	39	41	50	50	49	72	38	33	1.90	1.91	1.64	1.77	1.93	2.50	2.37	2.14	3.03	1.62	1.45												
Indirect neurological conditions	19	30	25	47	34	40	37	36	30	22	27	0.84	1.27	1.08	2.14	1.60	2.00	1.75	1.57	1.26	0.94	1.18												
Psychiatric causes	†	†	†	9	15	16	18	13	13	18	20	†	†	†	0.41	0.71	0.80	0.85	0.57	0.55	0.77	0.88												
Indirect malignancies	†	†	†	†	11	5	10	3	4	4	7	†	†	†	†	0.52	0.25	0.47	0.13	0.17	0.17	0.31												
All Indirect	84	93	100	134	136	155	163	154	170	133	135	3.70	3.94	4.32	6.10	6.40	7.76	7.71	6.59	7.15	5.68	5.92												
Coincidental	26	39	46	36	29	36	55	50	22	41	27	1.15	1.65	1.99	1.64	1.37	1.80	2.60	2.18	0.98	1.75	1.18												

\*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

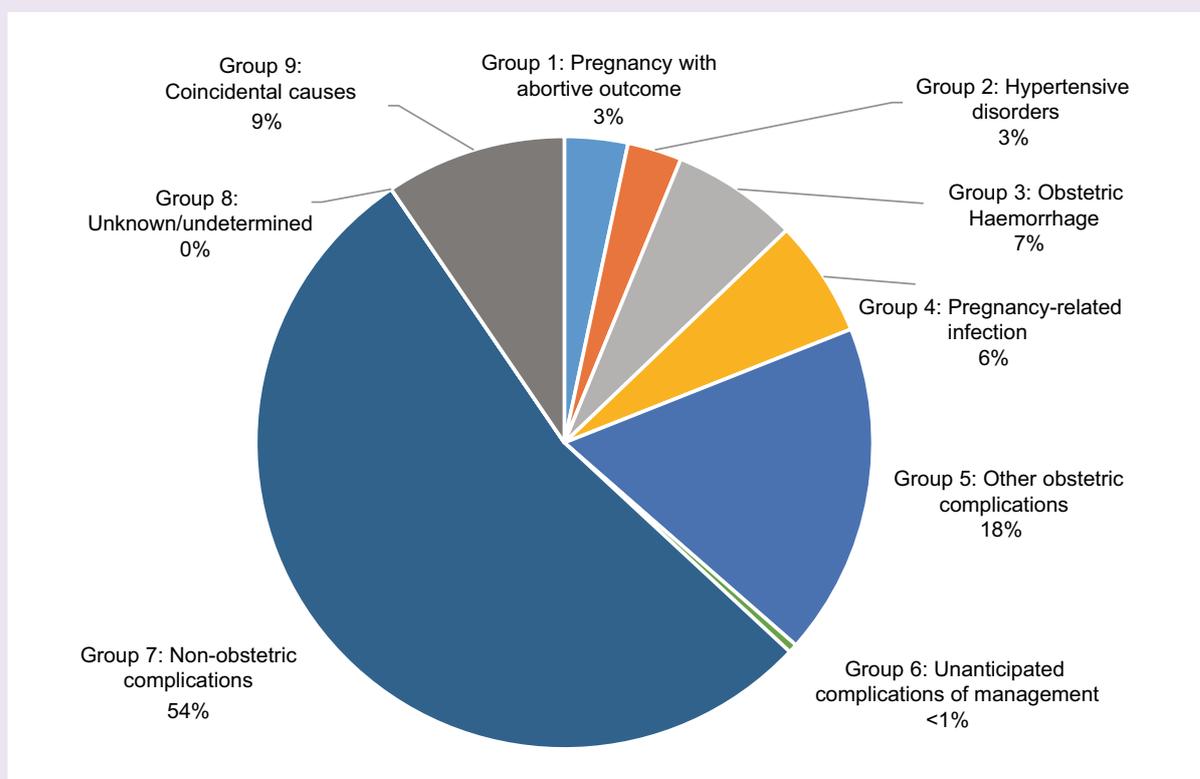
Sources: CMACE, MBRRACE-UK

**Table 2.5: Maternal mortality rates per 100,000 maternities, by cause, by overlapping triennia, using ICD-MM classification, 2013 to 2019 (illustrated in Figure 2.4)**

Cause of death	2013-15			2014-16			2015-17			2016-18			2017-19		
	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	4	0.17	0.05 – 0.44	3	0.13	0.03 – 0.38	4	0.18	0.05 – 4.49	7	0.31	0.13 – 0.65	7	0.32	0.13 – 0.66
Group 2: Hypertensive disorders	3	0.13	0.03 – 0.38	6	0.26	0.10 – 0.57	5	0.22	0.07 – 0.51	4	0.18	0.05 – 0.46	6	0.28	0.10 – 0.60
Group 3: Obstetric Haemorrhage	21	0.91	0.56 – 1.39	18	0.78	0.46 – 1.24	11	0.48	0.24 – 0.86	14	0.63	0.34 – 1.05	14	0.64	0.35 – 1.08
Group 4: Pregnancy-related infection	10	0.43	0.21 – 0.79	11	0.48	0.24 – 0.86	10	0.44	0.21 – 0.81	12	0.54	0.28 – 0.94	13	0.60	0.32 – 1.02
Group 5: Other obstetric complications	48	2.08	1.53 – 2.76	59	2.56	1.95 – 3.31	56	2.46	1.85 – 3.19	54	2.42	1.81 – 3.15	37	1.70	1.20 – 2.35
Group 6: Unanticipated complications of management	2	0.09	0.01 – 0.31	1	0.04	0.001 – 0.24	1	0.04	0.001 – 0.24	1	0.05	0.001 – 0.25	1	0.05	0.001 – 0.30
<b>Indirect causes</b>															
Group 7: Non-obstetric complications	114	4.94	4.08 – 5.94	127	5.52	4.60 – 6.57	122	5.35	4.44 – 6.39	125	5.59	4.66 to 6.66	113	5.20	4.28 – 6.25
Group 8: Unknown/undetermined	0	0	-	0	-	-	0	-	-	0	-	-	0	-	-
<b>Coincidental causes</b>															
Group 9: Coincidental causes	38	1.65	1.17 – 2.26	34	1.48	1.02 – 2.06	27	1.18	0.78 – 1.72	25	1.12	0.72 – 1.65	20	0.92	0.56 – 1.42

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

**Figure 2.4: Maternal mortality proportions by ICD-MM classification 2017-19**



## Direct deaths

Thrombosis and thromboembolism (VTE) continues to be the leading cause of direct deaths occurring within 42 days of the end of pregnancy (Figure 2.3). There has been a welcome decrease in the maternal mortality rate from VTE, which is now at a similar rate to 2012-14 and an encouraging sign of improved detection of risk and better prevention. However, the reviews contained in Chapter 6 suggest that more than two thirds of women's deaths could still be prevented with improvements to care.

Deaths due to obstetric haemorrhage, sepsis and suicide are the next most frequent direct causes of direct death. The rate of maternal mortality from haemorrhage remains unchanged from last year. The mortality rate for pregnancy related sepsis has continued to increase steadily, although not statistically significantly, since its nadir in 2012-14, emphasising the messages from the 2021 rapid report which highlighted the importance of 'thinking sepsis, and not just COVID-19'. There has been a non-statistically significant decrease in maternal deaths by suicide during pregnancy or up to six weeks after pregnancy when comparing 2017-19 with 2014-16 (0.46/100,000 versus 0.70/100,000 in 2014-16; RR 0.66, 95% CI 0.27-1.55, p=0.312), but note, as described in Chapter 4, that the majority of maternal suicide deaths occur between six weeks and a year after pregnancy. The maternal death rate from pre-eclampsia and eclampsia continues to be low but remains non-significantly higher than the lowest observed rate, in 2012-14. Mortality rates from amniotic fluid embolism and anaesthesia remain essentially unchanged with continuing extremely low rates due to anaesthetic causes.

## Indirect deaths

Deaths due to indirect causes still remain the major proportion (59%) of direct and indirect 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 a decrease in the maternal mortality rate from cardiac disease since enhanced case ascertainment was introduced, but this is not statistically significant (RR 0.73, 95% CI 0.46-1.15 when comparing 2017-19 with 2003-05). Neurological causes are the second most common indirect cause of maternal death, with a further statistically non-significant increase in mortality rate with the rate for 2017-19 close to that in 2006-08. 18 women died from SUDEP during or up to a year after the end of pregnancy in 2017-19, a rate of 0.83 per 100,000, 95% CI 0.49-1.31 which remains a concern, as highlighted in the 2020 report (Knight et al. 2020b). Mortality rates from other indirect causes have declined slightly although non significantly since 2014-16 (RR 0.79, 95% CI 0.41-1.48).

## International comparison

For international comparison, data from the 2019 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. This emphasises the importance of the additional case identification and checking undertaken by the MBRRACE-UK team to give an accurate maternal mortality estimate. New figures are not presented in this report, as there has not been a complete triennium since these ratios were calculated.

**Table 2.6: Maternal mortality ratios\* per 100,000 live births calculated based on deaths identified from routine sources of data, UK: 1985-2017**

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
2015-17	95	4.10	3.32-5.01	2,317,363

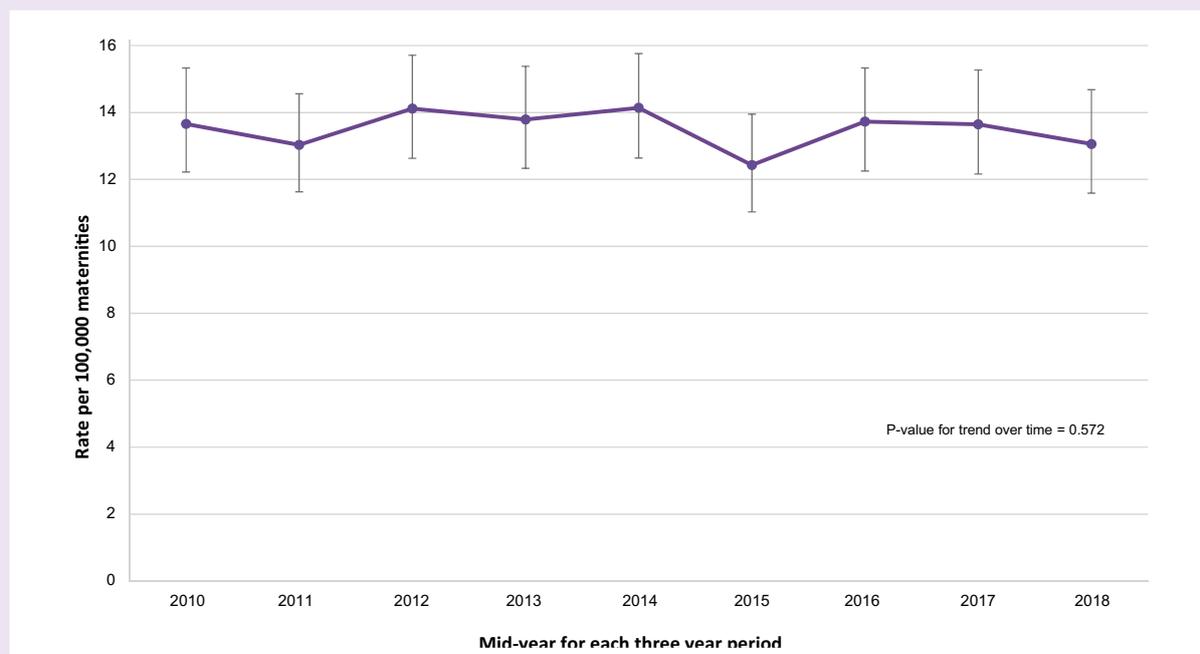
Source: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

\*Note that, for the purposes of international comparison, this table reports the Maternal Mortality Ratio and not the rate as elsewhere in the report.

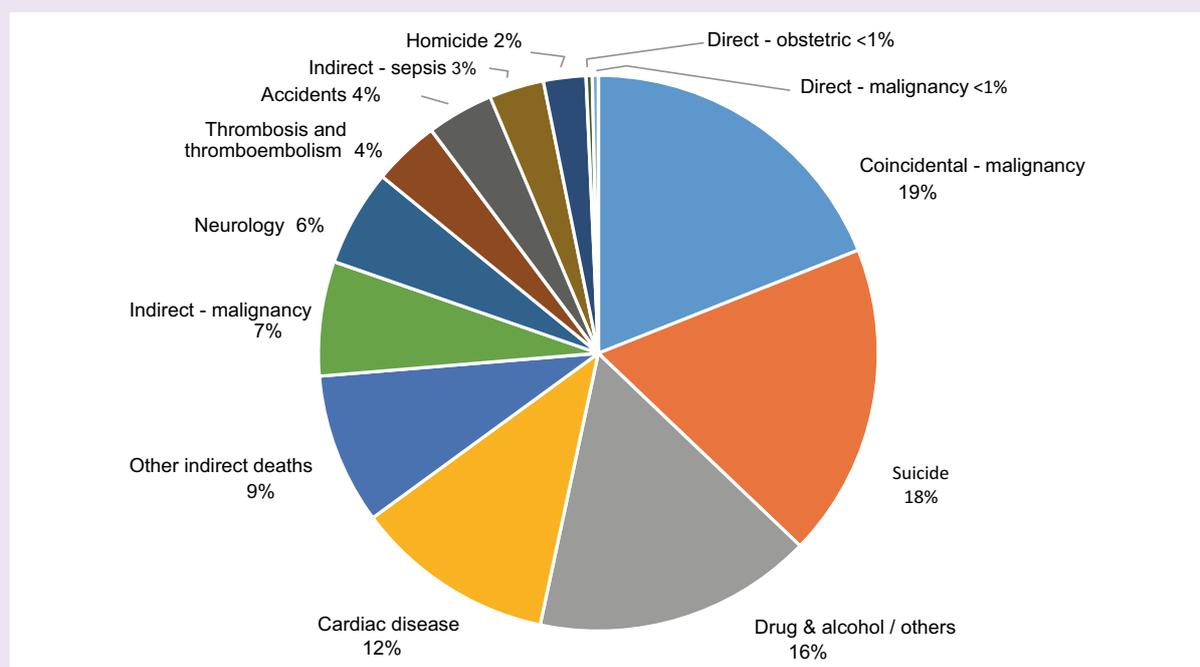
## Women who died between six weeks and one year after the end of pregnancy

In the triennium 2017-19, 284 women died between six weeks and one year after the end of pregnancy, representing a mortality rate of 13.1 per 100,000 maternities (95% CI 11.6 – 14.7). There has been no change in the rate of late pregnancy-related deaths since the first MBRRACE-UK confidential enquiry report. Rolling rates of late deaths are shown in Figure 2.5 and causes of late death in Figure 2.6. Maternal suicides continue to be the leading cause of direct deaths occurring between six weeks and one year after the end of pregnancy.

**Figure 2.5: Pregnancy-associated maternal mortality rates six weeks to one year after the end of pregnancy, UK, 2009-2019**



**Figure 2.6: Causes of death amongst women who died between six weeks and one year after the end of pregnancy, UK 2017-19**



## 2.3 The characteristics of women who died 2017-19

### The women and babies

Of the 191 women who died from direct and indirect causes during or up to 42 days after the end of their pregnancy in 2017-19, 32% (61 women) were still pregnant at the time of their death and of these women 57% were  $\leq 20$  weeks' gestation (Table 2.7). Fourteen (7%) women had a pregnancy loss at  $\leq 20$  weeks' gestation. The remaining 116 women gave birth to a total of 122 infants, 90 (74%) survived, 32 died (28 babies were stillborn and 4 died in the neonatal period). The 191 women who died left behind a further 193 children, thus a total of 283 motherless children remain. The majority of the 116 women who gave birth did so in hospital (82%); 15% of women gave birth in an emergency department or an ambulance, and 3% at home (Table 2.8). In this triennium 70 (60%) of the women who died had a caesarean birth, 20% of these were perimortem as part of attempted resuscitation of the woman. A total of 20 babies were born by perimortem caesarean section of which 8 (40%) were born after 32 weeks of gestation. Three out of the 8 babies born after 32 weeks' gestation survived (4 were stillborn and 1 died in the neonatal period) as did one out of the remaining 12 born at 32 weeks or less (10 were stillborn and 1 died in the neonatal period). Thus 4 (20%) of the total of 20 babies born by perimortem caesarean section survived, 14 (70%) were stillborn and 2 (10%) died in the neonatal period.

**Table 2.7: Timing of maternal deaths in relation to pregnancy 2017-19**

Time period of deaths in the pregnancy care pathway	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Total (n=191) Frequency (%)
Antenatal period			
$\leq 20$ weeks	13 (17)	22 (19)	35 (18)
$> 20$ weeks	4 (5)	22 (19)	26 (14)
Postnatal on day of delivery	20 (26)	17 (15)	37 (19)
Postnatal 1-41 days after delivery	41 (53)	52 (46)	93 (49)

**Table 2.8: Place of childbirth amongst women  $> 20$  weeks' gestation who died after giving birth 2017-19**

	Direct (n=52) Frequency (%)	Indirect (n=64) Frequency (%)	Total (n=116) Frequency (%)
Home	0 (0)	4 (6)	4 (3)
Hospital (except A&E)	45 (87)	50 (78)	95 (82)
Emergency Department or ambulance	7 (13)	10 (16)	17 (15)

### Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2017-19 are shown in Table 2.9. Around a third of the women's records (30%) did not have information on whether they were subject to domestic abuse before or during pregnancy, this is the same as noted in last year's report but an improvement on the 53% reported in 2019. Nevertheless this remains a substantial proportion of women who were not asked about domestic abuse despite guidance that it is important to enquire about this at booking and throughout pregnancy. This is highlighted further in Chapter 4. The rates of maternal mortality varied by age, socioeconomic status and ethnic background of the women, factors which are known to be independently associated with an increased risk of maternal death in the UK (Nair et al. 2015, Nair et al. 2016). Maternal mortality rates are higher amongst older women and those under 20, those living in the most deprived areas and amongst women from particular ethnic minority groups (Table 2.10). While women living in the most deprived areas continue to have the highest maternal mortality rates, there has been a significant increase in recent years in maternal mortality in women living in the least deprived areas (RR 2.37, 95% CI 1.03-5.92,  $P=0.028$ ) when comparing 2017-19 with 2014-16 (Figure 2.8). This increase in mortality rate of the group used as the baseline needs to be borne in mind when interpreting the relative risks and ratio of relative risks tables (2.10 and 2.11). The increase in the mortality rate amongst women living in the least deprived quintile of areas was predominantly due to deaths from cardiovascular disease (8 women, 40% of deaths).

As noted in the 2016 report, we are no longer able to obtain denominator figures for 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 2017-19 was statistically significantly over four-fold higher among women from Black ethnic minority backgrounds compared with white women (RR 4.49; 95% CI 2.77 to 7.00); this is very similar to the figure reported in the 2020 report but represents a non-significant reduction from the five-fold difference reported for 2014-16. Women from Asian backgrounds also continued to be at higher risk than white women (RR 1.67, 95% CI 1.00 to 2.66), as were women from mixed ethnic backgrounds (RR 2.19, 95% CI 0.70-5.28) although, because of the smaller numbers of women involved, this increased risk was not statistically significant. In the comparison of relative risks between 2014-16 and 2017-19 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 except for the ratios of relative risks for the IMD quintiles III and IV (Table 2.11).

It is important to note (Figure 2.7) that the absolute maternal mortality rate amongst women from Black ethnic backgrounds has not increased; although there has not been a statistically significant decrease and the disparity remains wide.

**Table 2.9: The socio-demographic characteristics of women who died 2017-19**

Characteristics	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Total (n=191) Frequency (%)
<b>Socio-demographic</b>			
<b>Age (years)</b>			
<20	6 (8)	3 (3)	9 (5)
20 – 24	7 (9)	12 (11)	19 (10)
25 – 29	19 (24)	32 (28)	51 (27)
30 – 34	17 (22)	29 (26)	46 (24)
35 – 39	19 (24)	25 (22)	44 (23)
≥ 40	10 (13)	12 (11)	22 (12)
<b>Parity</b>			
0	37 (47)	46 (41)	83 (43)
1 to 2	30 (38)	46 (41)	76 (40)
≥3	9 (12)	19 (17)	28 (15)
Missing	2 (3)	2 (2)	4 (2)
<b>UK citizen</b>			
Yes	66 (85)	101 (89)	167 (87)
No	6 (8)	5 (4)	11 (6)
Missing	6 (8)	7 (6)	13 (7)
<b>Ethnicity</b>			
White European	49 (63)	78 (69)	127 (66)
Indian	7 (9)	2 (2)	9 (5)
Pakistani	1 (1)	2 (2)	3 (2)
Bangladeshi	1 (1)	4 (4)	5 (3)
Other Asian	4 (5)	5 (4)	9 (5)
Black Caribbean	2 (3)	7 (6)	9 (5)
Black African	6 (8)	8 (7)	14 (7)
Others/ Mixed	5 (6)	7 (6)	12 (6)
Missing	3 (4)	0 (0)	3 (2)
<b>Woman's region of birth</b>			
United Kingdom	51 (65)	86 (76)	137 (72)
Eastern Europe	2 (3)	3 (3)	5 (3)
Western Europe	3 (4)	0 (0)	3 (2)
Asia	9 (12)	7 (6)	16 (8)
Africa	3 (4)	10 (9)	13 (7)
Australia and North America	1 (1)	0 (0)	1 (1)
Central & South America & Caribbean	2 (3)	1 (1)	3 (2)
Missing	7 (9)	6 (5)	13 (7)
<b>Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)</b>			
First quintile (Least deprived)	7 (9)	13 (12)	20 (10)
Second quintile	11 (14)	9 (8)	20 (10)
Third quintile	9 (12)	12 (11)	21 (11)
Fourth quintile	10 (13)	19 (17)	29 (15)
Fifth quintile (Most deprived)	30 (38)	47 (42)	77 (40)
Missing	11 (14)	13 (12)	24 (13)
<b>Socioeconomic status (Occupational classification)</b>			
Employed (Either woman or partner)	53 (68)	71 (63)	124 (65)
Unemployed (Both)	15 (19)	21 (19)	36 (19)
Missing	10 (13)	21 (19)	31 (16)
<b>Able to speak/understand English</b>			
Yes	72 (92)	108 (96)	180 (94)
No	4 (5)	5 (4)	9 (5)
Missing	2 (3)	0 (0)	2 (1)
<b>Living arrangements</b>			
With partner	54 (69)	77 (68)	131 (69)
Living alone	9 (12)	17 (15)	26 (14)
With parents/extended family	10 (13)	11 (10)	21 (11)
Others	2 (3)	4 (4)	6 (3)
Missing	3 (4)	4 (4)	7 (4)
<b>Domestic abuse (prior to pregnancy/ during pregnancy)</b>			
Yes	6 (8)	9 (8)	15 (8)
No	54 (69)	64 (57)	118 (62)
Missing	18 (23)	40 (35)	58 (30)
<b>History of abuse as a child</b>			
Yes	4 (5)	2 (2)	6 (3)
No	43 (55)	58 (51)	101 (53)
Missing	31 (40)	53 (47)	84 (44)
<b>Known to social services</b>			
Yes	12 (15)	21 (19)	33 (17)
No	58 (74)	76 (67)	134 (70)
Missing	8 (10)	16 (14)	24 (13)

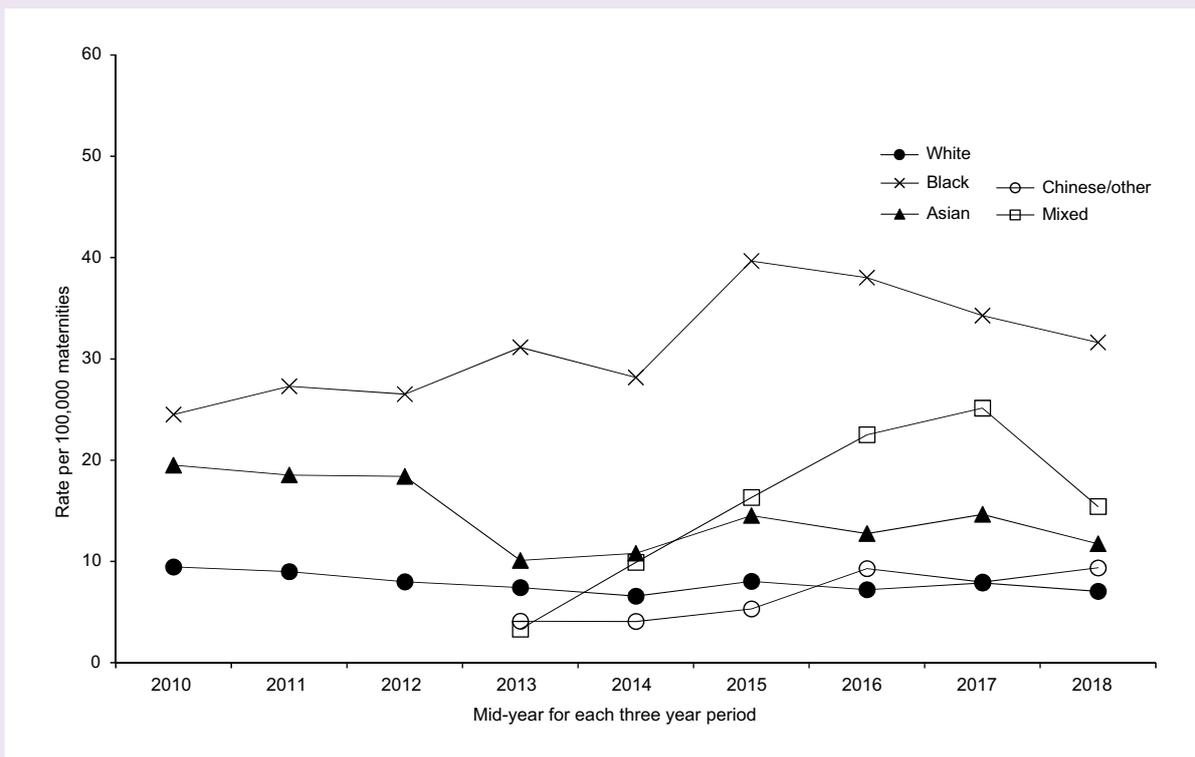
**Table 2.10: Maternal mortality rates amongst different population groups 2017-19 (illustrated in figures 2.7 and 2.8)**

	Total maternities 2017-19	Total deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
<b>Age (years)</b>						
<20	63,825	9	14.10	6.45 to 26.77	2.25	0.90 to 5.23
20-24	303,800	19	6.25	3.77 to 9.77	1 (Ref)	-
25-29	599,593	51	8.51	6.33 to 11.18	1.36	0.79 to 2.44
30-34	704,410	46	6.53	4.78 to 8.71	1.04	0.60 to 1.89
35-39	407,554	44	10.80	7.84 to 14.49	1.73	0.99 to 3.13
≥ 40	94,567	22	23.26	14.58 to 35.22	3.72	1.92 to 7.27
<b>IMD Quintiles (England only)</b>						
I (Least deprived/ highest 20%)	258,598	20	7.73	4.72 to 11.94	1 (Ref)	-
II	295,973	17	5.74	3.35 to 9.20	0.74	0.37 to 1.49
III	331,151	18	5.44	3.22 to 8.59	0.70	0.35 to 1.40
IV	393,371	25	6.36	4.11 to 9.38	0.82	0.44 to 1.56
V (Most deprived/ lowest 20%)	467,457	66	14.12	10.92 to 17.96	1.83	1.09 to 3.18
<b>Ethnic group (England only)</b>						
White (inc. not known)	1,448,043	102	7.04	5.74 to 8.55	1 (Ref)	-
Asian	187,408	22	11.74	7.36 to 17.77	1.67	1.00 to 2.66
Black	79,098	25	31.61	20.45 to 46.65	4.49	2.77 to 7.00
Chinese/ others	74,743	7	9.37	3.77 to 19.30	1.33	0.52 to 2.84
Mixed	32,436	5	15.41	5.01 to 35.97	2.19	0.70 to 5.28

**Table 2.11: Comparison of the relative risk of maternal death among different population groups between 2014-16 and 2017-19 (illustrated in figures 2.7 and 2.8)**

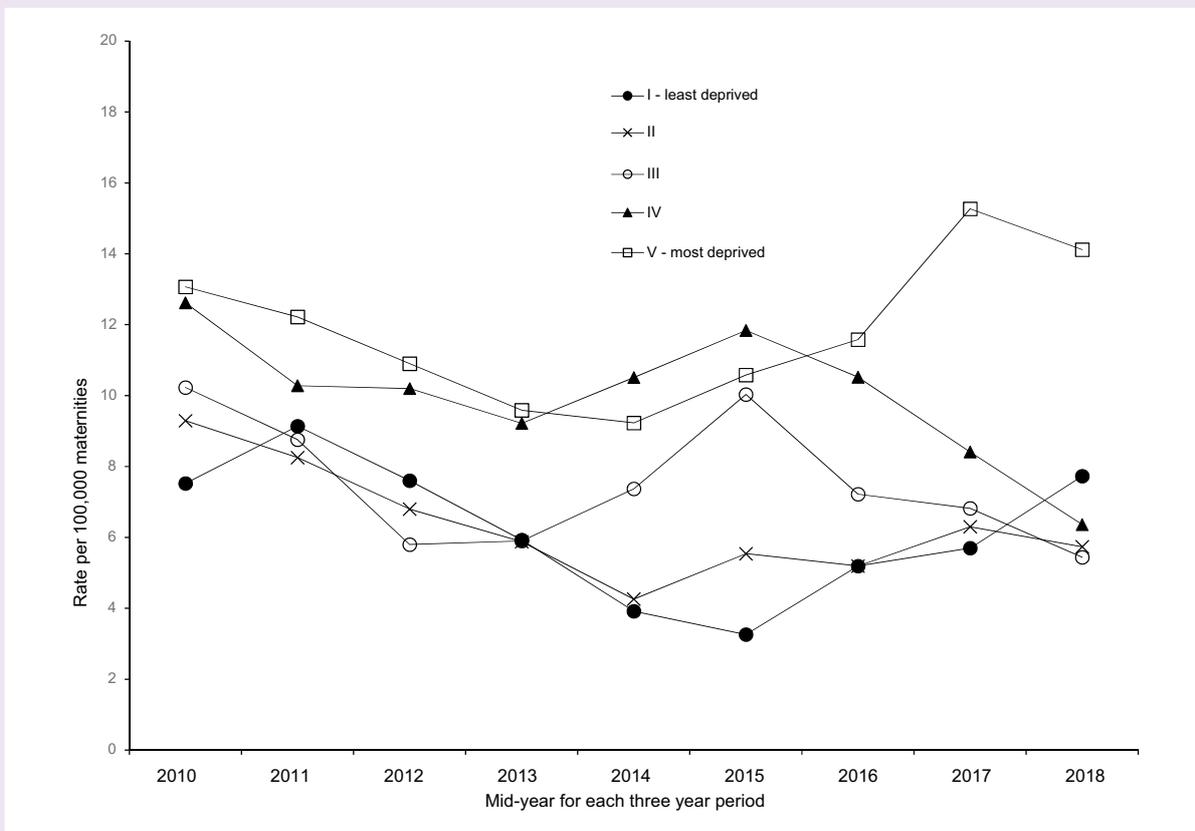
	2014-16		2017-19		Ratio of the relative risks (RRR) (comparing 2017-19 with 2014-16)	95% CI	P-value
	Relative risk (RR)	95% CI	Relative risk (RR)	95% C			
<b>Age (years)</b>							
<20	1.53	0.63 to 3.36	2.25	0.90 to 5.23	1.47	0.44 to 4.95	0.534
20-24	1 (Ref)	-	1 (Ref)	-	-	-	-
25-29	1.12	0.69 to 1.87	1.36	0.79 to 2.44	1.21	0.57 to 2.58	0.613
30-34	1.15	0.71 to 1.89	1.04	0.60 to 1.89	0.90	0.43 to 1.92	0.794
35-39	1.95	1.20 to 3.24	1.73	0.99 to 3.13	0.89	0.41 to 1.90	0.758
≥ 40	3.05	1.63 to 5.64	3.72	1.92 to 7.27	1.22	0.49 to 3.03	0.669
<b>IMD Quintiles (England only)</b>							
I (Least deprived/ highest 20%)	1 (Ref)	-	1 (Ref)	-	-	-	-
II	1.70	0.72 to 4.33	0.74	0.37 to 1.49	0.44	0.14 to 1.36	0.151
III	3.08	1.45 to 7.28	0.70	0.35 to 1.40	0.23	0.08 to 0.66	0.006
IV	3.63	1.77 to 8.40	0.82	0.44 to 1.56	0.23	0.08 to 0.62	0.004
V (Most deprived/ lowest 20%)	3.25	1.59 to 7.48	1.83	1.09 to 3.18	0.56	0.22 to 1.44	0.232
<b>Ethnic group (England only)</b>							
White (inc. not known)	1 (Ref)	-	1 (Ref)	-	-	-	-
Asian	1.81	1.16 to 2.73	1.67	1.00 to 2.66	0.92	0.48 to 1.77	0.809
Black	4.93	3.27 to 7.26	4.49	2.77 to 7.00	0.91	0.49 to 1.68	0.765
Chinese/ others	0.66	0.18 to 1.74	1.33	0.52 to 2.84	2.02	0.49 to 8.31	0.332
Mixed	2.03	0.65 to 4.87	2.19	0.70 to 5.28	1.08	0.26 to 4.49	0.917

**Figure 2.7: Maternal mortality rates 2009-19 among women from different ethnic groups in England\***



\*Data for England only due to availability of denominator data

**Figure 2.8: Maternal mortality rates 2009-19 among women from different levels of socio economic deprivation in England\***



\*Data for England only due to availability of denominator data

Just under a quarter of women who died in 2017-19 (23%) whose place of birth was known were born outside the UK; 22% of these women were known not to be UK citizens and citizenship was not recorded for a further 20%. Overall 6% of the women who died were not UK citizens although this may be an underestimate since citizenship was not recorded for 7%. Women who died who were born abroad and who were not UK citizens had arrived in the UK a median of 4 years before they died (range 0 to 15 years). Women who died who were born abroad were from Asia (39%, mainly India, China and Bangladesh) and Africa (32%, mainly Nigeria), Eastern Europe (12%) with the remainder (17%) from other parts of Europe, the Americas, Australasia 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, overall there was no statistically significant difference in maternal death rate between women born in the UK and those born outside the UK in 2017-19. However, women born in certain specific countries had a higher risk of death, statistically significantly higher in the case of women born in Nigeria, compared to women born in the UK (Table 2.12). Of the 9 women who died who were not UK citizens and were born outside the UK, two were refugees/asylum seekers (22%), one was a European Union citizen (11%) and six (67%) had another or unknown status.

It is also of note that 17% of women who died were known to social services. This proportion is lower than in the 2020 report (20%) but still well above the 12% reported in 2012-2014, highlighting further the vulnerability of many women who died.

**Table 2.12: Maternal mortality rates according to mother's country of birth (selected countries) 2017-19**

Woman's country of birth	Maternities 2017-19	Total Deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
UK	1,582,356*	137	8.66	7.27 to 10.24	1 (Ref)	-
Outside UK	591,454*	41	6.93	4.97 to 9.40	0.80	0.55 to 1.14
Specific countries						
<i>Bangladesh</i>	21,349‡	4	18.74	5.11 to 47.97	2.16	0.58 to 5.67
<i>China</i>	9,488‡	3	31.62	6.52 to 92.38	3.65	0.74 to 10.90
<i>India</i>	40,430‡	3	7.42	1.53 to 21.68	0.86	0.17 to 2.56
<i>Nigeria</i>	18,263‡	7	38.33	15.41 to 78.96	4.43	1.75 to 9.37

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

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

\*\*Country of birth not recorded for 13 women who died

It has been increasingly noted in these enquiries that women at severe disadvantage appear to be over-represented amongst the women who die. Severe and multiple disadvantage amongst pregnant women has been defined in other work (Birthrights and Birth Companions 2019). Not all elements of this definition were available in MBRRACE data, but of the 495 women who died in the UK in 2017-19 during or up to one year after pregnancy, 40 (8%) were of women considered to be at severe and multiple disadvantage on the basis of the data available (Table 2.13). This is the same proportion as reported for 2016-18. The main elements of multiple disadvantage were a mental health diagnosis (either current or in the past) (all women with multiple disadvantage), substance use (35/40 women with multiple disadvantage) and domestic abuse (37/40 women with multiple disadvantage). This must continue to be regarded as a minimum estimate, since these three factors are amongst the most poorly recorded, with, for women who died in pregnancy or within 42 days of delivery, information missing about mental health diagnoses for 9%, on substance use for 8% and on domestic abuse for 30%. Such information is even more likely to be missing for women dying between six weeks and one year after delivery.

**Table 2.13: Severe and multiple disadvantage among women who died 2017-19**

	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Coincidental (n=20) Frequency (%)	Late Deaths (n=284) Frequency (%)	Total (n=495) Frequency (%)
Score* of <3	72 (92)	107 (95)	18 (90)	258 (91)	455 (92)
Score* of 3 or more	6 (8)	6 (5)	2 (10)	26 (9)	40 (8)

\*Three or more of: substance abuse, domestic abuse, abuse in childhood, arrival in UK within last 5 years, refugee or asylum seeker, mental health diagnosis, female genital mutilation, and known learning difficulties

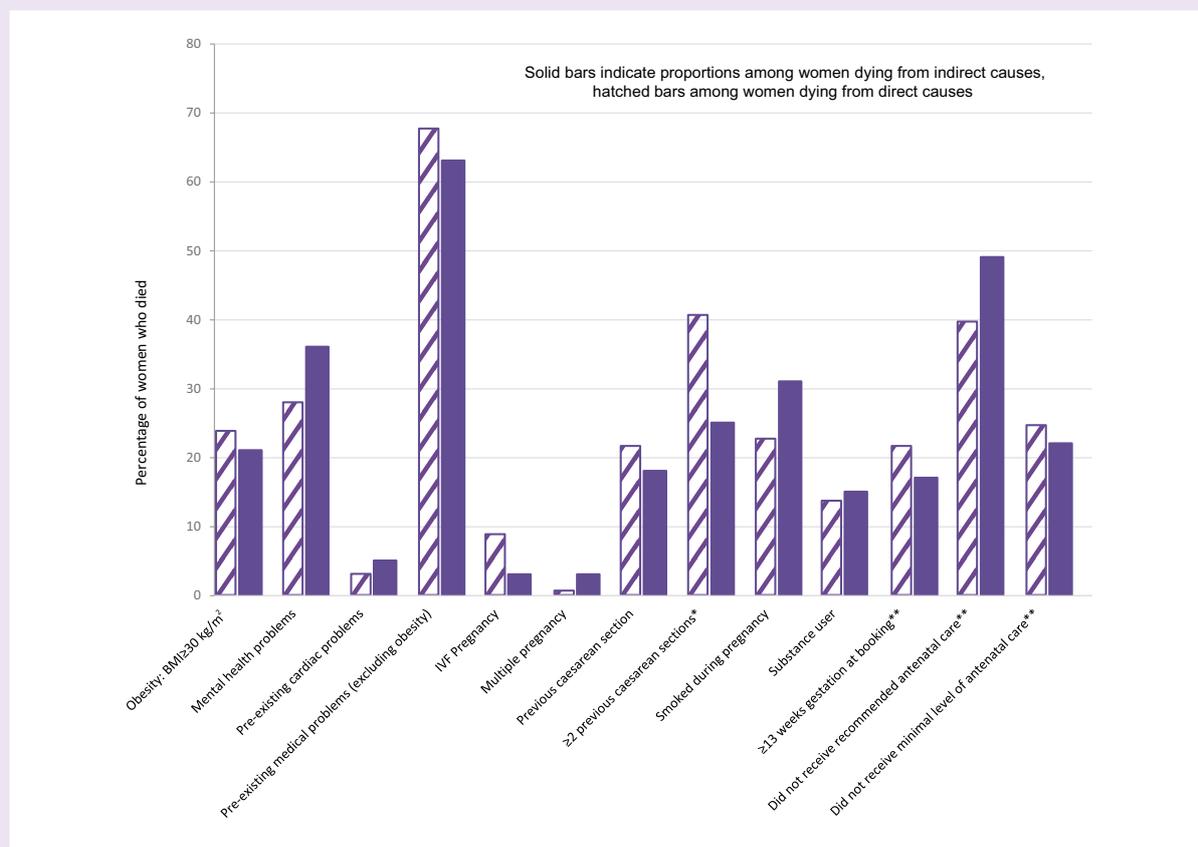
## Medical and pregnancy-related characteristics

Studies have shown that 66% of the increased risk of maternal death in the UK could be attributed to medical comorbidities (Nair et al. 2016). Two-thirds (65%) of the women who died in 2017-19 were known to have pre-existing medical problems (Table 2.14) and 33% were known to have pre-existing mental health problems. Of note for 9% of women who died in 2017-19 it was reported to be unknown whether they had previous or pre-existing mental health problems, this proportion is similar to the previous triennium. Nearly a quarter (23%) of the women who died in this triennium were obese (BMI  $\geq$  30kg/m<sup>2</sup>) and a further 29% were overweight (Table 2.14). In this triennium, 10 women (5%) who died during or up to six weeks after pregnancy in the UK in 2017-19 had a pregnancy as a result of an

assisted conception procedure (Table 2.15), this compares to 8 women (4%) in 2014-16. Several of the chapters in this report emphasise the need for guidance on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of co-morbidities such as cardiac disease and cancer.

The pregnancy-related characteristics of the women who died in 2017-18 are shown in Figure 2.9 and Table 2.15.

**Figure 2.9: Selected characteristics of women who died from direct or indirect causes 2017-19**



\*Amongst women who had a previous caesarean birth

\*\*Among women who received any antenatal care. 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.

**Table 2.14: Selected medical conditions and characteristics identified amongst women who died 2017-19 (illustrated in Figure 2.9)**

Medical condition/characteristic	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Total (n=191) Frequency (%)
<b>Body mass index (BMI) (kg/m<sup>2</sup>)</b>			
<18	1 (1)	0 (0)	1 (1)
18 – 24	32 (41)	44 (39)	76 (40)
25 – 29	20 (26)	35 (31)	55 (29)
≥ 30	19 (24)	24 (21)	43 (23)
Missing	6 (8)	10 (9)	16 (8)
<b>Mental health problems or psychiatric disorders</b>			
Yes	22 (28)	41 (36)	63 (33)
No	48 (62)	62 (55)	110 (58)
Missing	8 (10)	10 (9)	18 (9)
<b>Pre-existing cardiac problems</b>			
Yes	2 (3)	6 (5)	8 (4)
No	75 (96)	103 (91)	178 (93)
Missing	1 (1)	4 (4)	5 (3)
<b>Any pre-existing medical problem (excluding obesity)</b>			
Yes	53 (68)	71 (63)	124 (65)
No	24 (31)	38 (34)	62 (32)
Missing	1 (1)	4 (4)	5 (3)

**Table 2.15: Pregnancy-related characteristics of the women who died 2017-19 (illustrated in Figure 2.9)**

Medical condition/characteristic	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Total (n=191) Frequency (%)
Pregnancy known to be as a result of assisted reproductive techniques			
Yes	7 (9)	3 (3)	10 (5)
No	71 (91)	110 (97)	181 (95)
Multiple pregnancy			
Yes	1 (1)	3 (3)	4 (2)
No	77 (99)	110 (97)	187 (98)
Previous caesarean section			
Yes	17 (22)	20 (18)	37 (19)
No	60 (77)	91 (81)	151 (79)
Missing	1 (1)	2 (2)	3 (2)
Previous caesarean numbers (among women who had a previous caesarean section)			
1	10 (59)	15 (75)	25 (68)
≥2	7 (41)	5 (25)	12 (32)

## 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 et al. 2015, Nair et al. 2016). The prevalence of substance misuse among women who died in 2017-19 did not differ from that noted in the previous reports (Table 2.16) and the proportion who received recommended levels of antenatal care still remains low. Fewer than half (42%) 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 2.16: Other characteristics of women who died in 2017-19 (illustrated in Figure 2.9)**

Characteristics	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Total (n=191) Frequency (%)
Smoking			
Smoker	18 (23)	35 (31)	53 (28)
Non-smoker	50 (64)	61 (54)	111 (58)
Missing	10 (13)	17 (15)	27 (14)
Substance user			
Yes	11 (14)	17 (15)	28 (15)
No	62 (79)	86 (76)	148 (77)
Missing	5 (6)	10 (9)	15 (8)
Received any antenatal care*			
Yes	65 (83)	94 (83)	159 (83)
No	13 (17)	18 (16)	31 (16)
Not known	0 (0)	1 (1)	1 (1)
Gestational age at booking (among women who received any antenatal care)			
≤10	34 (52)	56 (60)	90 (57)
11 – 12	9 (14)	19 (20)	28 (18)
>13	14 (22)	16 (17)	30 (19)
Missing	8 (12)	3 (3)	11 (7)
Received recommended antenatal care <sup>†</sup> (among women who received any antenatal care)			
Yes	29 (45)	38 (40)	67 (42)
No	26 (40)	46 (49)	72 (45)
Missing	10 (15)	10 (11)	20 (13)
Received a minimum level of antenatal care <sup>†</sup> (among women who received any antenatal care)			
Yes	38 (58)	61 (65)	99 (62)
No	16 (25)	21 (22)	37 (23)
Missing	11 (17)	12 (13)	23 (14)

\*Includes 7 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

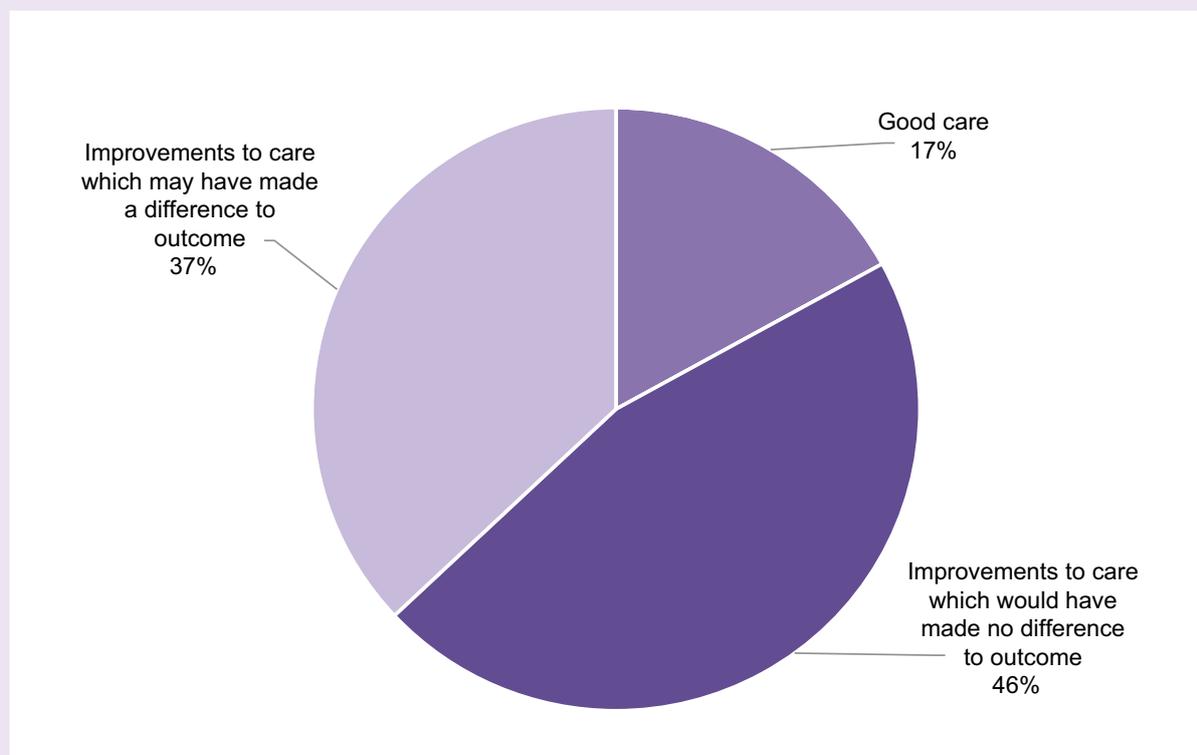
This section includes information on women who died between 2017 and 2019 and are included in the confidential enquiry chapters of this report (including women who died between six weeks and a year after the end of pregnancy and women from the Republic of Ireland), along with the 37 women who gave birth at 45 years of age or older and are included in the morbidity enquiry. Table 2.17 and Figure 2.10 shows the classification of care as agreed by the assessors for the 231 women who died and whose case notes were available with sufficient information for an in-depth review. Among the women who died, 17% were assessed to have received good care, but detailed assessment showed that for another 37% improvements in care may have made a difference to their outcome. Opportunities to improve care were identified amongst two thirds (70%) of women who gave birth at 45 years of age or older; in 29% was it thought that improvements may have made a difference to outcome, but of note, improvements to care which would have made no difference to outcome were identified in 40% (Table 2.17, Figure 2.11).

**Table 2.17: Classification of care received by women who died and are included in the confidential enquiry chapters and for whom case notes were available for an in-depth review or women aged 45 years of age or older included in the morbidity enquiry, UK and Ireland (2017-19) (illustrated in Figures 2.10 and 2.11)**

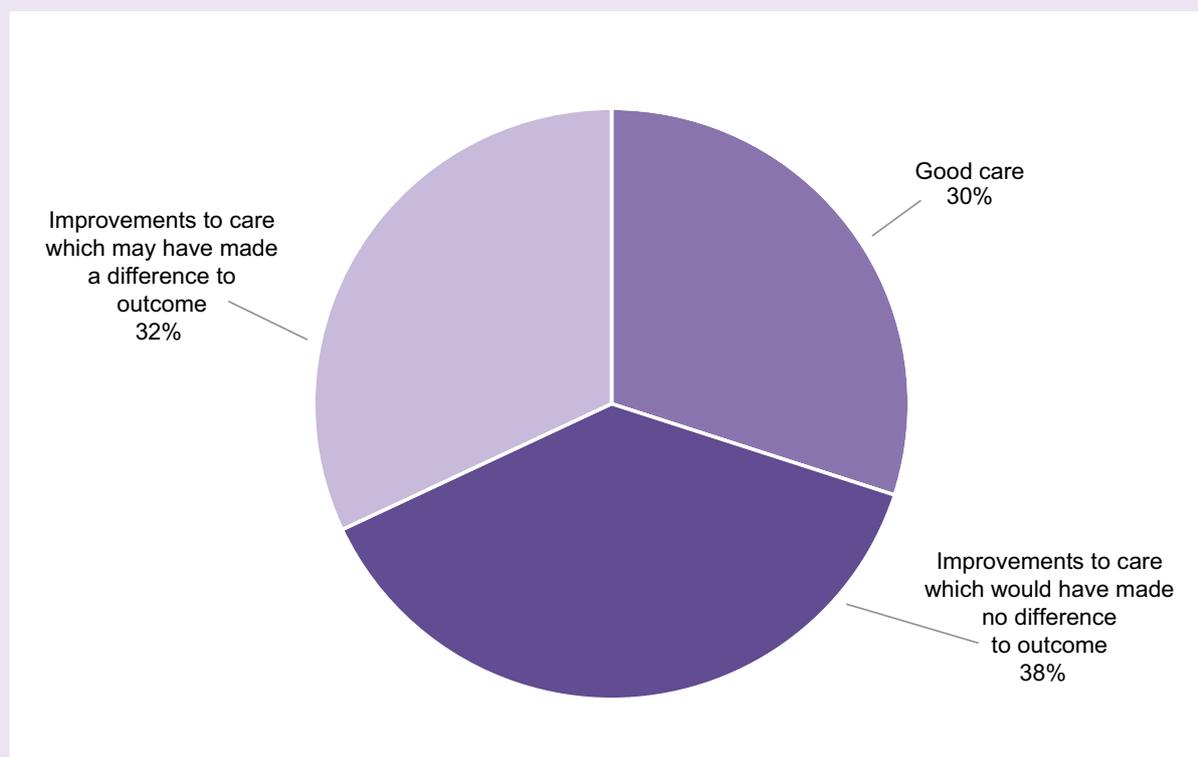
Classification of care received	Women who died (n=231)* Number (%)	Women who survived after giving birth at ≥45 years of age (n=37) Number (%)
Good care	39 (17)	11 (30)
Improvements to care which would have made no difference to outcome	106 (46)	14 (38)
Improvements to care which may have made a difference to outcome	86 (37)	12 (32)

\*includes only women whose case notes were available with sufficient information for an in-depth review considered in chapters 4-6

**Figure 2.10: Classification of care received by women who died and are included in the confidential enquiry chapters and for whom case notes were available for an in-depth review, UK and Ireland (2017-19)**



**Figure 2.11: Classification of care received by women aged 45 years of age or older included in the morbidity enquiry, UK and Ireland (2017-19)**



## Local clinicians' reports

The proportion of reports received from local clinicians of those requested for the confidential enquiry remains static at around 80% (Table 2.18). 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 2.18: Percentages of local clinicians' reports received for women whose care was examined for the confidential enquiry chapters in this report**

Specialty group	Percentage of reports requested that were received
Obstetricians	85
Anaesthetists	79
Midwives	78
Critical Care Clinicians	62
Emergency Medicine Specialists	84
GPs	88
Physicians	77
Psychiatrists	72
<i>Total</i>	82

## Postmortem examination

There was substantial variation in the proportion of women who had a post-mortem examination, according to the cause of death. For women with records available, overall a post-mortem examination was carried out in less than three quarters (68%) (Table 2.19). However, the figure was 91% for women who died from direct causes, 80% amongst women who died from indirect causes, 65% amongst women who died from coincidental causes and only 58% amongst women who died between six weeks and one year after the end of pregnancy. As noted in previous reports, establishing the cause of women’s death with a high quality autopsy is essential not only to improve future care, but to ensure any family counselling or testing is appropriate.

**Table 2.19: Post-mortem information for maternal deaths in the UK 2017-19**

Specialty group	Direct (n=78) Frequency (%)	Indirect (n=113) Frequency (%)	Coincidental (n=20) Frequency (%)	Late Deaths (n=284) Frequency (%)	Total (n=495) Frequency (%)
No	7 (9)	23 (20)	6 (30)	100 (35)	136 (27)
Post	71 (91)	90 (80)	13 (65)	165 (58)	339 (68)
<i>Hospital</i>	7 (10)	12 (13)	0 (0)	19 (12)	38 (11)
<i>Coroner</i>	64 (90)	78 (87)	13 (100)	146 (88)	301 (89)
Not	0 (0)	0 (0)	1 (5)	19 (7)	20 (4)

## 2.4 Morbidity Enquiry - women giving birth at 45 years of age or older

A stratified random sample of women giving birth at aged 45 and over was identified from two sources: UK births data and MBRRACE-UK perinatal mortality surveillance data for January-June 2019. As described in section 1.4, 37 of these women who survived were included in the morbidity Confidential Enquiry.

The characteristics of the women who gave birth at 45 years of age or older and were selected for inclusion in the Confidential Enquiry into Maternal Morbidity are shown in Table 2.20. It is worth noting that, in contrast to the women who died overall, besides being much older, they were also more likely to be having their second or subsequent pregnancy, to be overweight or obese, to have undergone fertility treatment and to be having a multiple pregnancy. Only a small proportion (5%) of these older women smoked. Over half (59%) had a pre-existing medical or mental health problem compared with 74% (141/191) of women who died.

**Table 2.20: Characteristics of the women who gave birth at 45 years of age or older**

Characteristics	Total (n=37) Frequency (%)
Age at delivery 45 or over	37 (100)
Parity	
0	13 (35)
1-4	21 (57)
≥5	3 (8)
Conception	
Spontaneous	19 (51)
IVF	18 (49)
Multiple Pregnancy	
Yes	7 (19)
No	30 (81)
Ethnicity	
White European	18 (49)
Asian	9 (24)
Black	9 (24)
Mixed	1 (3)
Socioeconomic status (Occupational classification)	
Employed (Either woman or partner)	25 (68)
Missing	12 (32)
Body mass index (BMI) kg/m <sup>2</sup>	
18-24	8 (22)
25-29	8 (22)
≥30	20 (54)
Missing	1 (3)
Smoking status	
Yes	2 (5)
No	34 (92)
Missing	1 (3)
Any pre-existing medical or mental health problem (excluding obesity)	
Yes	22 (59)
No	15 (41)

# 3. 2021 Maternal morbidity enquiry: messages for the care of older mothers

Sarah Vause, Dawn Kernaghan, Cathy Nelson-Piercy and Marian Knight on behalf of the MBRRACE-UK care of older mothers chapter-writing group

Chapter writing group members: Kathryn Bunch, Paula Chattington, Bernard Clarke, Philippa Cox, Rachael James, Sara Kenyon, Dawn Kernaghan, Marian Knight, Jenny Kurinczuk, Catherine Nelson-Piercy, Robin Russell, Sophie Russell, Judy Shakespeare, Derek Tuffnell, Sarah Vause

## 3.1 Key messages

### New recommendations

Collate recommendations from relevant guidelines into a single definitive source of guidance on the care for older women in pregnancy, including both women planning assisted reproduction and those who conceive spontaneously **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians]**.

Develop guidance on single embryo transfer for older women undergoing in vitro fertilisation, particularly in the context of medical co-morbidities **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians, British Fertility Society]**.

Do not delay consultant appointments and evidence-based effective preventive interventions such as aspirin pending the results of investigations such as prenatal diagnosis **[ACTION: All Health Professionals]**.

Recognise that 'post-pregnancy' counselling is as important as pre-pregnancy counselling for future pregnancies and for joining up obstetric and medical care to optimise a woman's long-term health **[ACTION: All Health Professionals]**.

### Existing recommendations requiring improved implementation

Guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of co-morbidities such as cardiac disease and cancer [Saving Lives, Improving Mothers' Care 2019] **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians, British Fertility Society]**.

Women with a BMI 30 kg/m<sup>2</sup> or greater wishing to become pregnant should be advised to take 5 mg folic acid supplementation daily, starting at least 1 month before conception and continuing during the first trimester of pregnancy [RCOG Green-top guideline 72] **[ACTION: All Health Professionals]**.

Women who have a major risk factor [including age>40] should be referred for serial ultrasound measurement of fetal size and assessment of wellbeing with umbilical artery Doppler from 26–28 weeks of pregnancy [RCOG Green-top guideline 31] **[ACTION: All Health Professionals]**.

Advise pregnant women at high risk of pre-eclampsia, or with more than one moderate risk factor for pre-eclampsia to take 75–150 mg of aspirin daily from 12 weeks until the birth of the baby [NICE NG 133 Hypertension in pregnancy] **[ACTION: All Health Professionals]**.

Assess the risk of gestational diabetes using risk factors in a healthy population. At the booking appointment, check for the following risk factors: BMI above 30 kg/m<sup>2</sup>, previous macrosomic baby weighing 4.5 kg or more, previous gestational diabetes, family history of diabetes (first-degree relative with diabetes), an ethnicity with a high prevalence of diabetes. Offer women with any of these risk factors testing for gestational diabetes [NICE Guideline NG3 Diabetes in pregnancy] **[ACTION: All Health Professionals]**.

All women should undergo a documented assessment of risk factors for VTE 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 [RCOG Green-top guideline 37a] **[ACTION: All Health Professionals]**.

When giving women (and their partners) information about antenatal care, use clear language, and tailor the timing, content and delivery of information to the needs and preferences of the woman and her stage of pregnancy. Information should support shared decision making between the woman and her healthcare team, and be: offered on a one-to-one or couple basis, supplemented by group discussions (women only or women and partners), supplemented by written information in a suitable format, for example, digital, printed, braille or Easy Read, offered throughout the woman's care, individualised and sensitive, supportive and respectful, evidence-based and consistent, translated into other languages if needed. [NICE Guideline NG201 Antenatal care] **[ACTION: All Health Professionals]**.

[In the event of preterm birth before 27 weeks of gestation] management of labour, birth and the immediate neonatal period should reflect the wishes and values of the mother and her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals. Decisions and management should be regularly reviewed before and after birth in conjunction with the parents; plans may be reconsidered if the risk for the fetus/baby changes, or if parental wishes change [Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation. A BAPM Framework for Practice] **[ACTION: All Health Professionals]**.

Write a care plan for women with pre-eclampsia who have given birth and are being transferred to community care that includes all of the following: who will provide follow-up care, including medical review if needed, frequency of blood pressure monitoring, thresholds for reducing or stopping treatment, indications for referral to primary care for blood pressure review, self-monitoring for symptoms [NICE Guideline NG133 Hypertension in pregnancy] **[ACTION: All Health Professionals]**.

When treating women with antihypertensive medication during the postnatal period, use medicines that are taken once daily when possible [NICE Guideline NG133 Hypertension in pregnancy] **[ACTION: All Health Professionals]**.

After childbirth, effective contraception should be discussed and offered prior to discharge from maternity services. If women cannot be provided with their preferred method of contraception prior to discharge from maternity services, they should be offered effective bridging contraception and information about accessing local contraceptive services [Guidance on the provision of contraception by maternity services after childbirth during the COVID-19 pandemic] **[ACTION: All Health Professionals]**.

## 3.2 Background

All previous reports have shown the increased rate of maternal mortality in older mothers, and the same is true for this triennium with an almost fourfold higher maternal mortality rate amongst women aged 40 or over, compared to women aged 20-24 years. The proportion of women giving birth at older ages continues to increase (Office for National Statistics 2020), and women are entering pregnancy with more pre-existing physical and mental health co-morbidities and multi-morbidity (Whitty et al. 2020). However, the chapters in the reports are divided by cause of death and each chapter contains small numbers of older women. By examining the care of older mothers as a specific group across all specialties this morbidity study sought to provide generic messages about how to improve their care, together with specific messages concerning the care of women with pre-existing and multiple morbidities. As noted in Chapter 1, for the purposes of this enquiry the older mothers considered were women giving birth at age 45 or over.

## 3.3 The women whose care was reviewed

The 37 women whose care was examined for the purposes of this chapter were a stratified random sample of women giving birth at age 45 or older identified from national data. As described in chapter 2, the sample was stratified to ensure inclusion of women from all four UK nations, all regions of England, and to include women who had live born and stillborn babies as well as women whose babies died in the neonatal period. All women were alive at the time of their inclusion and did not die in the year following the end of pregnancy. Due to the way in which women were selected for inclusion, this sample includes a high number of women whose babies died, and it must be noted that these figures cannot be generalised to indicate rates of stillbirth or baby death in this age group. Stillbirth and neonatal death rates according to maternal age are included in the MBRRACE perinatal mortality surveillance reports and are 1.5-2 fold higher amongst women aged 40 and over compared to women aged 30-34 (Draper ES et al. 2020).

The older women whose care was examined fell broadly into two groups. Some were women who had several previous children, their pregnancy was often unplanned, many were late to engage with maternity services and often they chose to make decisions against the advice of those caring for them. Half were women who had conceived through assisted reproduction techniques, frequently with donated embryos and often had multiple pregnancies (7/18, 39%) (Table 3.1). Only one woman had clearly undergone IVF in the UK. Many of these women had not undergone a pre-pregnancy assessment and embarked on pregnancy with pre-existing medical conditions such as hypertension and other cardiac risk factors.

**Table 3.1: Characteristics of the women who gave birth at 45 years of age or older and whose care was examined for the purposes of this chapter (n=37)**

Characteristics	Total (n=37) Frequency (%)
<b>Age at delivery (years)</b>	
45	8 (22)
46	13 (35)
47	6 (16)
48	3 (8)
49	1 (3)
≥50	6 (16)
<b>Parity</b>	
0	13 (35)
1-4	21 (57)
≥5	3 (8)
<b>Conception</b>	
<i>Spontaneous</i>	19 (51)
<i>Assisted reproduction</i>	18 (49)
<b>Multiple Pregnancy</b>	
<i>Yes (all following assisted reproduction)</i>	7 (19)
<i>No</i>	30 (81)
<b>Ethnicity</b>	
<i>White European</i>	18 (49)
<i>Asian</i>	9 (24)
<i>Black</i>	9 (24)
<i>Mixed</i>	1 (3)
<b>Socioeconomic status (Occupational classification)</b>	
<i>Employed (Either woman or partner)</i>	25 (68)
<i>Missing</i>	12 (32)
<b>Body mass index (BMI) (kg/m<sup>2</sup>)</b>	
18-24	8 (22)
25-29	8 (22)
30-34	14 (38)
35-39	3 (8)
≥40	3 (8)
<i>Missing</i>	1 (3)
<b>Smoking status</b>	
<i>Yes</i>	2 (5)
<i>No</i>	34 (92)
<i>Missing</i>	1 (3)
<b>Any pre-existing medical or mental health problem (excluding obesity)</b>	
<i>Yes</i>	22 (59)
<i>No</i>	15 (41)

## 3.4 Overview of care and lessons to be learned

### Key guidance about care particularly relevant to the care of older women

A non-English-speaking obese woman in her early 50s with essential hypertension, hyperlipidaemia, a previous history of gestational diabetes and a strong family history of cardiac disease underwent in vitro fertilisation with two embryos replaced resulting in a dichorionic diamniotic twin pregnancy. She was initially incorrectly assessed as low risk for venous thromboembolism, but this was corrected, and low molecular weight heparin was commenced at 28 weeks. She was commenced on aspirin, but nevertheless developed pre-eclampsia, gestational diabetes and intrauterine growth restriction. Her blood pressure was difficult to control with signs of fetal compromise. She underwent an emergency caesarean birth at 33 weeks followed by a major postpartum haemorrhage. Both babies were admitted to the neonatal intensive care unit. The woman was discharged home after five days with prescriptions for low molecular weight heparin for six weeks and anti-hypertensives. She was advised to have her blood pressure checked by the GP the following week. M

This woman illustrates many of the themes concerning the care of older women identified, including assisted reproduction in a woman with multiple co-morbidities with no evidence of pre-IVF counselling, two embryo replacement resulting in an even higher risk pregnancy, multiple pregnancy complications with management made more challenging due to translation difficulties, an emergency preterm birth without any prior anaesthetic assessment and limited plans for post-pregnancy care.

Guidance relevant to the care of older pregnant women, due to their multiple risks, is contained within multiple guidelines, and fewer than a third of women received care in line with every relevant guideline. In view of the increasing numbers of women giving birth at older ages, assessors felt that it would be helpful to have a single collated source of recommendations for the care specifically of older women.

**Collate recommendations from relevant guidelines into a single definitive source of guidance on the care for older women in pregnancy, including both women planning assisted reproduction and those who conceive spontaneously.** N

### Counselling prior to assisted reproduction

For women who choose to embark on assisted reproduction treatment, there is always an opportunity for pre-pregnancy assessment and optimisation of a woman's health. This may include weight reduction, smoking cessation, and changes to medication. The risks of pregnancy should be clearly described including the chance of needing iatrogenic preterm delivery with its associated neonatal complications. For women with serious co-morbidities the welfare of existing children and those from the index pregnancy must be considered. An older mother, with a shortened life expectancy due to her medical condition, may not be able to support her children as they grow. A child with neurological disability consequent to preterm delivery, may require lifelong support (El-Toukhy et al. 2018).

Risks of multiple pregnancy compound the co-morbidities encountered in older mothers. Single embryo transfer reduces the chance of multiple pregnancy, the greatest avoidable risk of IVF. The Human Embryology and Fertilisation Authority now set limits for multiple pregnancies for IVF units. Although the pregnancy rate is lower in older mothers, single embryo transfer is medically appropriate for any woman with significant co-morbidity. Furthermore, many of those having IVF at older ages use eggs donated from much younger women, resulting in higher quality embryos and an increased risk of multiple pregnancy with multiple embryo transfer.

**Guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of co-morbidities such as cardiac disease and cancer.**

**Saving Lives, Improving Mothers' Care 2019 (Knight et al. 2019)**

A 55 year old woman became pregnant with twins following in vitro fertilisation. She had a previous caesarean birth with massive obstetric haemorrhage. It is unclear whether she had received any pre-pregnancy counselling. She had appropriate consultant antenatal care, with serial growth scans, although there is no evidence of her being offered low molecular weight heparin thromboprophylaxis, which should have been prescribed from 28 weeks. She went into preterm labour at 32 weeks and underwent a caesarean birth following steroids and magnesium sulphate. Immediately after the birth of the twins she had significant blood loss associated with atony. It took three hours to control her bleeding. The whole procedure was managed under spinal anaesthesia with no evidence of an arterial line, oxygen or use of active warming devices. Her final measured blood loss was over seven litres with six units of blood and clotting factors given and seven litres of crystalloid. Her postnatal recovery was uncomplicated and she was appropriately managed with low molecular weight heparin until six weeks postpartum. No local review of her care was undertaken, the reason given was that her care had been managed well. M

This woman's multiple pregnancy increased her risk of postpartum haemorrhage, with older women being less able to compensate for such physiological stress. Despite obvious gaps in the way in which this significant haemorrhage was managed, no learning occurred as her care was not critically reviewed. There are no specific requirements mandated for investigating maternal morbidity incidents, other than a requirement to participate in MBRRACE-UK maternal morbidity enquiries such as this one. The NHS England/Improvement Patient Safety Incident Response Framework 2020 (NHS England and NHS Improvement 2020) suggests that "maternity-related incidents identified as a 'current local priority for patient safety incident investigation' or an 'emergent risk for which the potential for new learning is so great that it warrants a full investigation' should be investigated". It is important to ensure such priorities are established.

**Develop guidance on single embryo transfer for older women undergoing in vitro fertilisation, particularly in the context of medical co-morbidities.**

**Include specific maternal morbidities within individual hospital priorities for incident investigation.** N

## Aspirin and folic acid

An obese 48 year old woman with multiple medical co-morbidities conceived spontaneously and booked early for antenatal care with her midwife. She was started on high dose folic acid. Screening tests revealed a high risk of trisomy 21. The consultant appointment was delayed while the woman and her partner were considering her options, resulting in a delay to prescription of aspirin. The baby was noted to be small for gestational age at the 20-week anomaly scan. Two weeks later an intrauterine death was diagnosed. She was advised to discuss postnatal contraception with her GP. M

Some aspects of this woman's care were good; she was correctly offered 5 mg folic acid and serial growth scans in view of her age and BMI. However, she was not offered low dose aspirin for pre-eclampsia prophylaxis possibly because those counselling her about the high risk Down's screening assumed she may opt for a termination or because it was assumed this would take place at the (subsequently delayed) consultant appointment. Older women, particularly those who conceive spontaneously (rather than with donor eggs), are more likely to have a fetus with Trisomy 21 or other chromosomal abnormality. It is important that other aspects of their care are not delayed, whilst investigations are performed.

**Women with a BMI 30 kg/m<sup>2</sup> or greater wishing to become pregnant should be advised to take 5 mg folic acid supplementation daily, starting at least 1 month before conception and continuing during the first trimester of pregnancy.**

**RCOG GTG 72 Care of Women with Obesity in Pregnancy (Royal College of Obstetricians and Gynaecologists 2018)**

**Women who have a major risk factor [including age>40] should be referred for serial ultrasound measurement of fetal size and assessment of wellbeing with umbilical artery Doppler from 26–28 weeks of pregnancy**

**Women in whom measurement of symphysis fundal height is inaccurate (for example: BMI > 35, large fibroids, hydramnios) should be referred for serial assessment of fetal size using ultrasound**

**RCOG GTG 31 The Investigation and Management of the Small-for-Gestational-Age Fetus (Royal College of Obstetricians and Gynaecologists 2013)**

Advise pregnant women at high risk of pre-eclampsia to take 75–150 mg of aspirin daily from 12 weeks until the birth of the baby. Women at high risk are those with any of the following:

- hypertensive disease during a previous pregnancy
- chronic kidney disease
- autoimmune disease such as systemic lupus erythematosus or antiphospholipid syndrome
- type 1 or type 2 diabetes
- chronic hypertension.

Advise pregnant women with more than 1 moderate risk factor for pre-eclampsia to take 75–150 mg of aspirin daily from 12 weeks until the birth of the baby. Factors indicating moderate risk are:

- first pregnancy
- age 40 years or older
- pregnancy interval of more than 10 years
- body mass index (BMI) of 35 kg/m<sup>2</sup> or more at first visit
- family history of pre-eclampsia
- multi-fetal pregnancy.

NICE NG 133 Hypertension in pregnancy (National Institute for Health and Care Excellence 2019)

Do not delay consultant appointments and evidence-based effective preventive interventions such as aspirin pending the results of investigations such as prenatal diagnosis. **N**

### Uteroplacental insufficiency – Aspirin, serial growth scans and management of reduced fetal movements

It is well established that older women have an increased risk of uteroplacental insufficiency resulting in small for gestational age fetuses and an increased risk of stillbirth (Dhanjal and Kenyon 2013).

An obese grand-multiparous woman of African origin in her late 40s was booked for midwife-led care. Aspirin was not prescribed and she did not meet local criteria for serial growth scans. At 38 weeks symphysis fundal height measurements showed a trajectory crossing decreasing centiles but she was not referred for further assessment of growth. Induction was booked for 41 weeks gestation. She presented in spontaneous labour at 40 weeks gestation when an intrauterine death was diagnosed. Her stillborn baby was noted to be growth restricted. **M**

Having a stillborn baby is a catastrophic event for all parents. Although there would undoubtedly have been emotional consequences, this woman did not suffer physical morbidity. However, any pregnancy in an older woman carries an increased risk and therefore it is important that appropriate care is provided to optimise the outcome. In this woman's case, serial growth scans could have detected a small for gestational age fetus and enabled early induction. For all older women aspirin should be advised, serial growth scans undertaken and advice given in relation to monitoring of fetal movements (<https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-your-babys-movements-in-pregnancy.pdf>). Clinicians should have a low threshold for investigating and intervening.

**Accepting the proviso that all management decisions should be agreed with the mother in the cases of fetuses <3rd centile and with no other concerning features, initiation of labour and/or delivery should occur at 37<sup>+0</sup> weeks and no later than 37<sup>+6</sup> weeks gestation. Delivery <37<sup>+0</sup> weeks can be considered if there are additional concerning features, but these risks must be balanced against the increased risks to the infant of delivery at earlier gestations.**

**Fetuses between 3rd – 10th centile will often be constitutionally small and therefore not at increased risk of stillbirth. Care of such fetuses should be individualised and the risk assessment should include Doppler investigations, the presence of any other high risk features for example, recurrent reduced fetal movements, and the mother's wishes. In the absence of any high risk features, delivery or the initiation of induction of labour should be offered at 39<sup>+0</sup> weeks.**

Saving Babies Lives version two (NHS England 2019a)

## Gestational diabetes screening

An obese 50 year old woman conceived twins following in vitro fertilisation. She had a history of previous gestational diabetes, previous caesarean births and was being treated for a mental health problem. At booking she was taking estradiol, prednisolone and enoxaparin as 'add-on' treatments to her IVF. She was diagnosed with gestational diabetes at 15 weeks when her prednisolone was stopped. She was advised to take aspirin and serial growth scans were arranged. She had a planned caesarean birth at 37 weeks. She was discharged with six weeks of low molecular weight heparin and ongoing mental health support and had an uncomplicated postnatal course. M

It is not uncommon for IVF units to prescribe additional non-evidence-based 'add-on' therapies despite the lack of efficacy data for improved implantation and this sometimes includes steroid therapy. This woman was obese and therefore at risk of gestational and type 2 diabetes and also had a mental health problem and was therefore susceptible to the psychiatric side effects of steroid therapy. The assessors could not find evidence that the woman had been counselled about these potential side effects or that any steps had been taken to test her for pre-existing diabetes or institute blood glucose monitoring.

**Assess the risk of gestational diabetes using risk factors in a healthy population. At the booking appointment, check for the following risk factors:**

- **BMI above 30 kg/m<sup>2</sup>**
- **previous macrosomic baby weighing 4.5 kg or more**
- **previous gestational diabetes**
- **family history of diabetes (first-degree relative with diabetes)**
- **an ethnicity with a high prevalence of diabetes.**

**Offer women with any of these risk factors testing for gestational diabetes.**

**NICE Guideline NG3 Diabetes in pregnancy (National Institute for Health and Care Excellence 2020b)**

## Venous thromboembolism risk assessment

Many of the women whose care was assessed, including the woman described in the previous section, were at increased risk from venous thromboembolism (VTE) in pregnancy because of their age, obesity and IVF. On the basis of these factors alone, many had a VTE risk score of three which should have prompted use of prophylactic low molecular weight heparin from 28 weeks.

**All women should undergo a documented assessment of risk factors for VTE 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.**

**Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015b)**

## Communication

An obese grand-multiparous woman in her 40s had an unplanned pregnancy and booked late for antenatal care. She had a complex previous obstetric history. She declined aspirin although it was advised. She had serial growth scans and repeated admissions for small antepartum haemorrhages. She was admitted with suspected pre-term labour but declined steroids. She established in labour and gave birth at 35 weeks. She was prescribed low molecular weight heparin but was unable to administer it herself. It was administered at home by her community midwives. A postnatal follow up appointment was arranged with her obstetrician but the woman did not attend. M

This woman received good care with regard to ensuring she received appropriate thromboprophylaxis. However she declined aspirin, maybe because she considered it unnecessary. Several other women remained reluctant to follow medical advice. Many of these women declined preventive treatments such as low dose aspirin and low molecular weight heparin but they also declined interventions including induction of labour and caesarean section. Language barriers, compounded by time critical situations, added a further layer of complexity to the discussions with some of these women, although assessors noted the difficulty of assessing the nuance of the discussions on the basis of electronic records.

Such discussions are often lengthy, challenging and frustrating however even if a woman chooses not to follow medical advice there needs to be provision for ongoing management. Every effort should be made to engage women in decisions regarding their care, if necessary by framing such discussions around the benefit of such interventions for her baby.

**When giving women (and their partners) information about antenatal care, use clear language, and tailor the timing, content and delivery of information to the needs and preferences of the woman and her stage of pregnancy. Information should support shared decision making between the woman and her healthcare team, and be: offered on a one-to-one or couple basis, supplemented by group discussions (women only or women and partners), supplemented by written information in a suitable format, for example, digital, printed, braille or Easy Read, offered throughout the woman's care, individualised and sensitive, supportive and respectful, evidence-based and consistent, translated into other languages if needed.**

**NICE Guideline NG201 Antenatal care (National Institute for Health and Care Excellence 2019)**

## Neonatologist input

An obese 45 year old woman with chronic hypertension and multiple fibroids conceived twins following in vitro fertilisation. There was no evidence of documented pre-pregnancy counselling. Her blood pressure was poorly controlled from early pregnancy and she had evidence of impaired renal function. There were concerns over fetal growth. Membranes around the first twin ruptured in the second trimester and the twin was noted to have died. A discussion with a neonatologist was documented, but it is unclear whether the British Association of Perinatal Medicine (BAPM) framework was followed. She had an emergency classical caesarean section under general anaesthesia followed by a major postpartum haemorrhage and a prolonged complicated post-operative course. The outcome for her extremely preterm second twin is not known. M

The British Association of Perinatal Medicine (BAPM) published 'Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation. A Framework for Practice' in October 2019. Some women gave birth before the BAPM Framework was published but nonetheless, there was little evidence in several women that detailed informed discussions had taken place between obstetric and neonatal professionals and parents when extreme preterm birth was anticipated.

**Management of labour, birth and the immediate neonatal period should reflect the wishes and values of the mother and her partner, informed and supported by consultation and in partnership with obstetric and neonatal professionals.**

**Decisions and management should be regularly reviewed before and after birth in conjunction with the parents; plans may be reconsidered if the risk for the fetus/baby changes, or if parental wishes change.**

**Perinatal Management of Extreme Preterm Birth before 27 weeks of gestation. A BAPM Framework for Practice (British Association of Perinatal Medicine 2019)**

## Postnatal care

A 45 year-old non-English speaking woman with a singleton pregnancy presented for antenatal care in the first trimester. A booking appointment was delayed by six weeks due to the need for an interpreter. She was offered but declined aspirin. She developed severe pre-eclampsia in the early third trimester and had an urgent caesarean birth after receiving steroids for fetal lung maturation. Postoperatively she was hypertensive, leading to nifedipine being added to her oral labetalol. She was discharged without a clear postpartum plan. Around four weeks later, she was readmitted with uncontrolled hypertension and converted to amlodipine and enalapril. M

This woman also declined aspirin and again this may relate to the particular discussion that took place. The NICE guideline for management of hypertension in pregnancy stresses the importance of a clear postnatal antihypertensive plan transmitted to primary care. Labetalol requires three times a day dosing and is not ideal for postpartum use when enalapril (once a day) may be used. Women with pre-eclampsia are at increased risk of subsequent hypertension, cardiovascular and cerebrovascular disease. Therefore targeted postnatal care when issues regarding long term health and lifestyle can be discussed is appropriate. Although older women becoming pregnant spontaneously may be less likely to receive pre-pregnancy counselling, the opportunity to provide 'post-pregnancy' counselling is equally important for future pregnancies and for joining up obstetric and medical care to optimise a woman's long-term health.

**Write a care plan for women with pre-eclampsia who have given birth and are being transferred to community care that includes all of the following:**

- **who will provide follow-up care, including medical review if needed**
- **frequency of blood pressure monitoring**
- **thresholds for reducing or stopping treatment**
- **indications for referral to primary care for blood pressure review**
- **self-monitoring for symptoms.**

**When treating women with antihypertensive medication during the postnatal period, use medicines that are taken once daily when possible.**

**Offer enalapril to treat hypertension in women during the postnatal period, with appropriate monitoring of maternal renal function and maternal serum potassium.**

**For women of black African or Caribbean family origin with hypertension during the postnatal period, consider antihypertensive treatment with: nifedipine or amlodipine if the woman has previously used this to successfully control her blood pressure.**

**NICE Guideline NG133 Hypertension in pregnancy (National Institute for Health and Care Excellence 2019)**

**Recognise that 'post-pregnancy' counselling is as important as pre-pregnancy counselling for future pregnancies and for joining up obstetric and medical care to optimise a woman's long-term health.** N

## Postnatal contraception

A multiparous woman in her late 40s had an unplanned pregnancy more than ten years after her previous birth. She had shared care but was not prescribed aspirin until her first consultant visit at 21 weeks. She had serial growth scans and a vaginal birth after induction at 39 weeks. The plan for postnatal contraception was that an implant would be inserted at her GP six-week check, but this was not undertaken due to the coronavirus pandemic. M

The risks associated with advanced maternal age were not initially recognised in this woman, and aspirin was only commenced in the mid trimester when its benefit would have been minimal. As she had conceived spontaneously, there was the need for effective contraception. Although this need was recognised it was not provided. Whilst the woman may have wanted to use an implant in the longer term, she could have been provided with another appropriate form of contraception prior to leaving hospital, for example a depot injection or a supply of the progesterone only pill. During the coronavirus pandemic the difficulty of women accessing contraception was recognised and guidance produced to support provision of contraception prior to discharge from hospital. In addition, some progesterone-only

oral contraceptives are now available over the counter to improve access. Guidance on upper age cut-offs for when contraception is needed are available from the Faculty of Sexual and Reproductive Healthcare (Faculty of Sexual and Reproductive Healthcare 2017).

**After childbirth, effective contraception should be discussed and offered prior to discharge from maternity services.**

**Maternity services with staff trained in postpartum insertion of intrauterine contraception and an etonogestrel implant should offer insertion of a long-acting reversible contraception (LARC) device to all medically eligible women prior to discharge from maternity services.**

**Women for whom LARC is unavailable, unacceptable or unsuitable should be offered a supply (at least 6 months) of the desogestrel progestogen-only pill (POP) prior to discharge (so long as they are medically eligible).**

**If women cannot be provided with their preferred method of contraception prior to discharge from maternity services, they should be offered effective bridging contraception and information about accessing local contraceptive services.**

**Guidance on the provision of contraception by maternity services after childbirth during the COVID-19 pandemic FSRH RCM RCOG Feb 2021 (Hardman et al. 2021)**

### 3.5 Conclusions

The majority of older pregnant women whose care was reviewed for the purposes of this chapter had pre-existing co-morbidities, assisted reproduction, obesity, or all three. Several had pregnancies additionally complicated by multiple pregnancy. On the basis of this multitude of risk factors in addition to older maternal age, the majority should be offered aspirin to prevent pre-eclampsia, screening for gestational diabetes, serial growth scans and thromboprophylaxis antenatally and/or postnatally. Fewer than a third of women received all relevant preventive interventions and investigations, and for a third of women different care may have made a difference to their outcome (Table 3.2). For most women there was the opportunity for ‘post-pregnancy’ care and counselling to optimise long-term health and this rarely took place. The immediate post-pregnancy period is a window of opportunity to initiate interventions to improve future health and for older women who may have already established co-morbidities this is an opportunity that must be taken.

**Table 3.2: Classification of care received by older women whose care was reviewed for the purposes of this chapter, UK, 2019**

Classification of care received	Women whose care was reviewed Number (%) N=37
Good care	11 (30)
Improvements to care which would have made no difference to outcome	14 (38)
Improvements to care which may have made a difference to outcome	12 (32)

# 4. Improving mental health care and care for women with multiple adversity

Roch Cantwell, Andrew Cairns, Kathryn Bunch and Marian Knight on behalf of the MBRRACE-UK mental health chapter-writing group

Chapter writing group members: Julie Anderson, Philip Banfield, Kathryn Bunch, Andrew Cairns, Roch Cantwell, Louise Clarke, Sarah Cohen, Bill Fawcett, Samantha Holden, Sara Kenyon, Alison Kirkpatrick, Marian Knight, Jenny Kurinczuk, Kim Morley, Judy Shakespeare, Derek Tuffnell.

## 4.1 Key messages

### New recommendations

Consider previous history, pattern of symptom development and ongoing stressors when assessing immediate risk and management of women with mental health symptoms. Plans should address immediate, short-term and long-term risk **[ACTION: All Health Professionals]**.

Ensure there are clear and explicit pathways into specialist perinatal mental health care, which take into account all other aspects of perinatal mental health provision, including specialist roles within midwifery and obstetric services, in order to avoid any confusion over roles and responsibilities **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.

Ensure perinatal mental health services do not exclude patients on the basis of diagnosis, where they would ordinarily be seen by general adult mental health teams **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.

Ensure specialist services have the capacity to assess and manage all women who require secondary care mental health services, and be able to adjust for the altered (generally lowered) thresholds for assessment in the perinatal period. This should not prevent shared management of women already engaged with another service, where that is in their best clinical interests **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.

If psychotropic medication has been discontinued in advance of, or during, pregnancy, ensure women have an early postnatal review to determine whether they should recommence medication, carried out either by the GP or mental health service depending on the level of pre-existing mental health care **[ACTION: All Health Professionals]**.

Where a woman with severe postnatal illness has previously responded well to treatment then there should be an expectation of a good recovery from subsequent postpartum episodes. Ensure that it is recognised that discharge from inpatient care before recovery is achieved is likely to be associated with continued risk **[ACTION: All Health Professionals]**.

While relatives provide invaluable support to the woman, complementing the care provided by universal and specialist services, they should not be given responsibilities beyond their capabilities or be expected to act as a substitute for an effective mental health response **[ACTION: All Health Professionals]**.

Women with substance misuse are often more vulnerable and at greater risk of relapse in the postnatal period, even if they have shown improvement in pregnancy. Ensure they are reviewed for re-engagement in the early postpartum period where they have been involved with addictions services in the immediate preconception period or during pregnancy **[ACTION: All Health Professionals]**.

Ensure local incident review teams are multidisciplinary in composition and that investigations are carried out across organisational structures where indicated **[ACTION: Hospitals/Trusts/Health Boards]**.

## Existing recommendations requiring improved implementation

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 [Saving Lives, Improving Mothers' Care 2015] **[ACTION: All Health Professionals]**.

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 [Saving Lives, Improving Mothers' Care 2018] **[ACTION: Hospitals/Trusts/Health Boards, All Health Professionals]**.

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 [Saving Lives, Improving Mothers' Care 2015] **[ACTION: All Health Professionals]**.

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 [Saving Lives, Improving Mothers' Care 2017] **[ACTION: All Health Professionals]**.

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 [Saving Lives, Improving Mothers' Care 2015] **[ACTION: All 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 [Saving Lives, Improving Mothers' Care 2018] **[ACTION: 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. 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 [Saving Lives, Improving Mothers' Care 2018] **[ACTION: NHSE/I and equivalents in the devolved nations and Ireland]**.

Healthcare professionals working in universal services and those caring for women in mental health services should monitor regularly for symptoms throughout pregnancy and the postnatal period, particularly in the first few weeks after childbirth [NICE guideline CG192 Antenatal and Postnatal Mental Health] **[ACTION: All Health Professionals]**.

Ask the woman about domestic abuse in a kind, sensitive manner at the first antenatal (booking) appointment, or at the earliest opportunity when she is alone. Ensure that there is an opportunity to have a private, one-to-one discussion. [NICE Antenatal care guideline NG201] **[ACTION: All Health Professionals]**.

## 4.2 Background

Mental ill health remains one of the leading causes of maternal death in pregnancy and the first postnatal year. This report is the third to review the care of all women who died by suicide in pregnancy and up to the end of the first postnatal year, providing a continuous period of 11 years of comprehensive review. The chapter also reviews the deaths of women with substance misuse, some of whom may have died by non-intentional overdose, and the women who were victims of homicide. A strong theme remains that many of these women had multiple adversity.

Specialist perinatal mental health services have developed significantly since the last mental health themed report, with recommendations for expanded provision in all four UK nations and in Ireland (Health Service Executive 2017, National Assembly for Wales 2017, The Regulation and Quality Improvement Authority 2017, NHS England 2019b, Perinatal Mental Health Network Scotland 2019). While there are still areas with little or no provision, and no time frame, for example, for provision of Mother and Baby Units in some UK nations, there is clear governmental commitment to address this in the coming few years. In keeping with this, there are new lessons to be learned about specialist team functioning in this report. Where specialist teams were involved, due to the methodology of the enquiry, we are not able to distinguish whether these were new or more established services.

### 4.3 The women who died

This report includes 62 women who died by suicide between 2017 and 2019 in the UK and Ireland during pregnancy or up to one year after the end of pregnancy, a rate of 2.64/100,000 maternities (95% CI 2.02-3.38). Four of these women had a primary diagnosis of substance misuse and, in addition, a further 58 women died in relation to substance misuse during pregnancy or up to one year after the end of pregnancy (2.47 per 100,000 maternities, 95% CI 1.87-3.19). Overall, including both women who died by suicide and related to drug and alcohol misuse, 5.11 women per 100,000 maternities died during pregnancy or up to one year after the end of pregnancy from a mental health-related cause. This represents almost a quarter of all deaths of women during pregnancy or up to a year after the end of pregnancy.

Eleven women were murdered during pregnancy or up to one year after the end of pregnancy (0.47 per 100,000 maternities, 95% CI 0.23-0.84).

The women who died by suicide had a median age of 31.5 (IQR 26-36), the majority (92%) were from white ethnic groups and were UK citizens (87%). Of concern was the high proportion (7/62, 11%) of women who died by suicide who were teenagers (11 per 100,000 teenagers giving birth). This compares to only 2/71 (3%) in the 2014-16 triennium (2.5 per 100,000 teenagers giving birth, RR 4.45, 95% CI 0.92-21.4, Fisher's exact  $p=0.049$ ). Almost half of women who died by suicide (46%) were from the two most deprived quintiles of areas of residence, 18% were known to be subject to domestic violence and 37% were known to social services. The majority (87%) received some antenatal care, but this was the NICE recommended level of care for fewer than half (48%) (Table 4.1).

The majority of women who died from substance misuse were multiparous (78%) and from White ethnic groups (98%). More than half (57%) were known to live in the two most deprived quintiles of area of residence, around one third (31%) were known to be subject to domestic violence and two thirds (66%) were known to social services. The majority (86%) received some antenatal care, but this was the NICE recommended level of care for only a quarter (26%) (Table 4.1).

Of the 11 women who were murdered, only 4 (36%) were known to be victims of domestic abuse. Note, however, that information on domestic abuse was missing for around a third of women from all three groups.

**Table 4.1: Socio-demographic characteristics of women who died by suicide, from substance misuse or by homicide, UK and Ireland 2017-2019**

Characteristics	Suicide (n=62) Frequency (%)	Substance misuse (n=58) Frequency (%)	Homicide (n=11) Frequency (%)
<b>Socio-demographic</b>			
<b>Age</b>			
<20	7 (11)	1 (2)	0 (0)
20 – 24	5 (8)	7 (12)	1 (9)
25 – 29	13 (21)	13 (22)	6 (55)
30 – 34	16 (26)	12 (21)	3 (27)
35 – 39	19 (31)	18 (31)	1 (9)
≥ 40	2 (3)	7 (12)	0 (0)
<b>Parity</b>			
0	13 (21)	5 (9)	1 (9)
1 to 2	26 (42)	23 (40)	2 (18)
≥3	9 (15)	22 (38)	4 (36)
Missing	14 (23)	8 (14)	4 (36)
<b>UK or Rol citizen</b>			
Yes	54 (87)	52 (90)	9 (82)
No	3 (5)	2 (4)	0 (0)
Missing	5 (8)	4 (7)	2 (18)
<b>Ethnicity</b>			
White incl. missing	57 (92)	57 (98)	7 (64)
Other ethnicity	5 (8)	1 (2)	4 (36)
<b>Socioeconomic status (Index of Multiple Deprivation (IMD) of postcode of residence)</b>			
First quintile (Least deprived)	6 (10)	1 (2)	0 (0)
Second quintile	6 (10)	1 (2)	0 (0)
Third quintile	10 (16)	6 (10)	1 (9)
Fourth quintile	14 (23)	10 (17)	4 (36)
Fifth quintile (Most deprived)	14 (23)	23 (40)	3 (27)
Missing	12 (19)	17 (29)	3 (27)
<b>Domestic abuse (prior to pregnancy/ during pregnancy)</b>			
Yes	11 (18)	18 (31)	4 (36)
No	29 (47)	23 (40)	3 (27)
Missing	22 (35)	17 (29)	4 (36)
<b>History of abuse as a child</b>			
Yes	6 (10)	2 (3)	1 (9)
No	25 (40)	22 (38)	5 (45)
Missing	31 (50)	34 (59)	5 (45)
<b>Known to social services</b>			
Yes	23 (37)	38 (66)	3 (27)
No	32 (52)	16 (28)	7 (64)
Missing	7 (11)	4 (7)	1 (9)
<b>Received any antenatal care</b>			
Yes	54 (87)	50 (86)	9 (82)
No	8 (13)	7 (12)	2 (18)
Not known	0 (0)	1 (2)	0 (0)
<b>Gestational age at booking (among women who received any antenatal care)</b>			
≤10	34 (63)	21 (42)	8 (89)
11 – 12	12 (22)	4 (8)	0 (0)
≥13	7 (13)	20 (40)	1 (11)
Missing	1 (2)	5 (10)	0 (0)
<b>Received recommended antenatal care<sup>†</sup> (among women who received any antenatal care)</b>			
Yes	26 (48)	13 (26)	7 (78)
No	23 (43)	30 (60)	1 (11)
Missing	5 (9)	7 (14)	1 (11)
<b>Received a minimum level of antenatal care<sup>†</sup> (among women who received any antenatal care)</b>			
Yes	36 (67)	20 (40)	7 (78)
No	11 (20)	23 (46)	1 (11)
Missing	7 (13)	7 (14)	1 (11)

<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.

## Pregnancy or postnatal loss

Twenty-three women who died by suicide (37%) had experienced loss of some kind related to the pregnancy or infant (Table 4.2). Ten had loss in pregnancy (3 miscarried; 9 had a pregnancy termination) and one had a neonatal death. Ten women had ongoing social services proceedings related to the care of their children or their infant had been removed into care.

Losses were more evident among women who died from substance misuse; overall 33 women (57%) experienced a loss of some kind (Table 4.2). The majority (n=25, 43%) were related to ongoing social services proceedings related to the care of their children or their infant had been removed into care.

Pregnancy losses were infrequent amongst women who died by homicide.

**Table 4.2: Pregnancy or postnatal loss or threatened loss amongst women who died by suicide or substance misuse, UK and Ireland 2017-19**

Type of loss	Suicide Number of women (%) N=62	Substance misuse Number of women (%) N=58
Pregnancy loss	3 (5)	3 (5)
Neonatal death	1 (2)	0 (0)
Post-termination of pregnancy	9 (15)	5 (9)
Infant removed into care or care of relatives and/or ongoing social services proceedings	10 (16)	25 (43)
No known loss events	39 (63)	25 (43)

## Mode of suicide

As in previous reports, the majority of women who died by suicide, died violently (Table 4.3). This was true across all time periods. The commonest mode of suicide, for those with information on mode of death (58/62) was by hanging (n=36, 62%). Eleven women died of intentional overdose. Three women included codeine in the overdose and two overdosed on insulin. Other substances used included cyclizine, metformin, paracetamol, propranolol, pentobarbitol, quetiapine and tramadol. A number of women took multiple substances and alcohol was a factor for some women.

There was one instance of infanticide amongst the women who died by suicide.

**Table 4.3: Mode of death by suicide, UK and Ireland 2017-19**

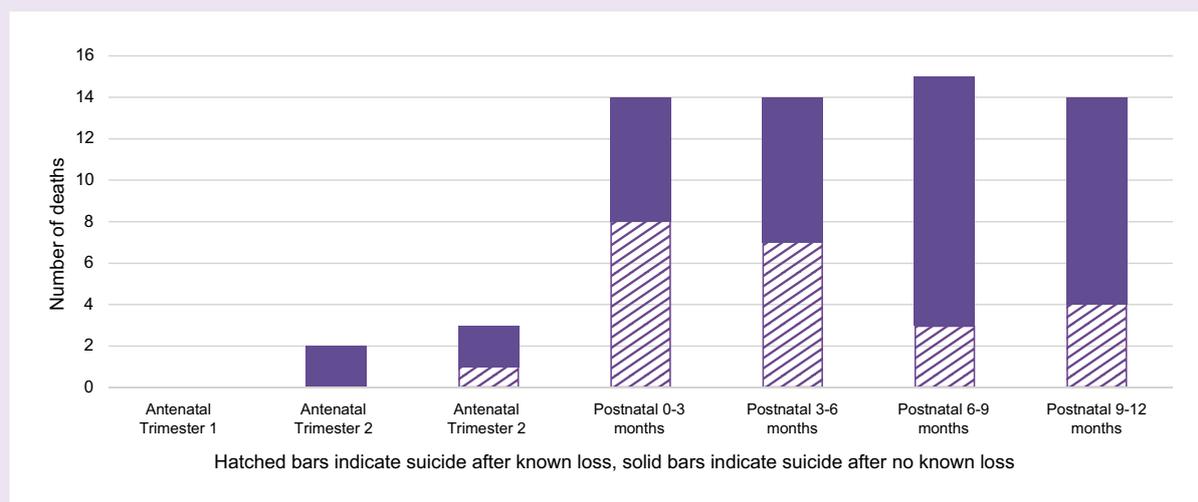
Mode of death	Number of women (%) N=58
Hanging	36 (62)
Overdose	11 (19)
Traffic/train	5 (9)
Fall from height	3 (5)
Carbon monoxide poisoning	1 (2)
Drowning	1 (2)
Suffocation	1 (2)

\*For 4 women the mode of suicide could not be ascertained

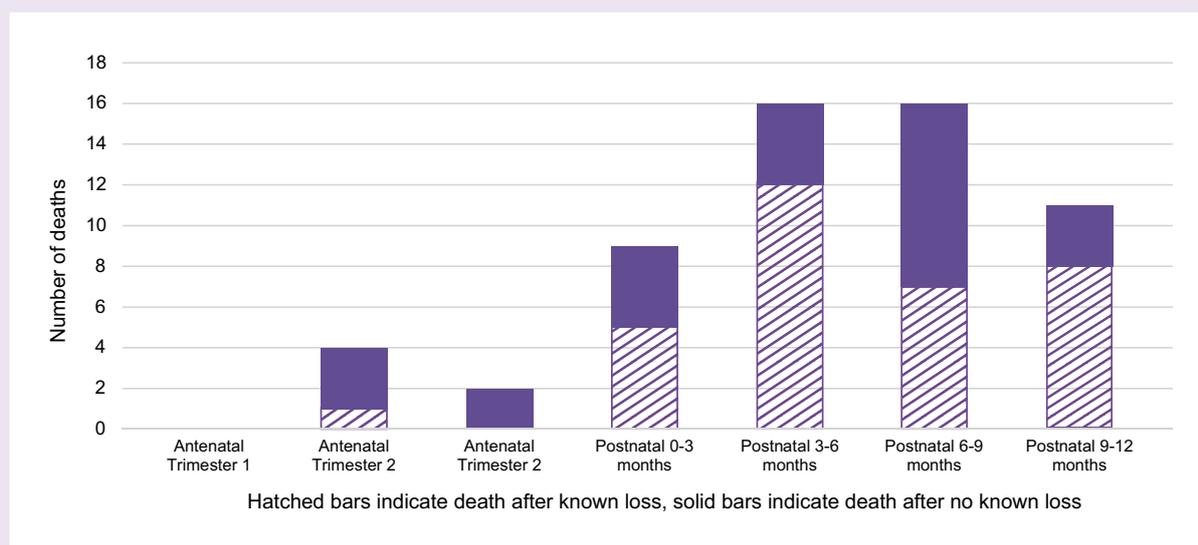
## Timing of death

As has been noted previously in these reports, the majority of women who died by suicide died in the postnatal period, and their deaths occurred evenly across all four quarters of the postnatal year (Figure 4.1). However, women who had experienced a pregnancy loss event (including removal of infant into care or ongoing social services proceedings) made up a greater proportion of those who died by suicide in the first six months post-pregnancy (Figure 4.1), suggesting additional vulnerability as highlighted in previous reports. More deaths in relation to substance misuse occurred in the middle six months of the postnatal year with most deaths in women with pregnancy or postpartum loss events occurring in months 3-6 (Figure 4.2). Nine of the 11 homicide deaths occurred in the postnatal period, with seven of these occurring within six months of the woman giving birth.

**Figure 4.1: Timing of death by suicide in pregnancy and the post-pregnancy period, UK and Ireland 2017-19**



**Figure 4.2: Timing of deaths from substance misuse in pregnancy and the post-pregnancy period, UK and Ireland 2017-19**



## Mental health diagnoses

Attribution of a diagnosis remains challenging, given the continued very low return of mental health records to the Enquiry. In the main, diagnoses are made by assessors indirectly, using information in maternity or primary care records.

There was sufficient information to establish a diagnosis for 47 of the 62 women who died by suicide. Of these, 40 (85%) had a past history of treatment for mental health problems in primary or secondary care. Depressive disorder was the most frequent diagnosis (n=26; 55%) in the episode which led to their death. Of these women, three had clear psychotic symptoms and a further three had probable psychosis. An additional seven women had a psychotic diagnosis (postpartum psychosis, n=3; bipolar affective disorder, n=2; schizophrenia, n=1; schizoaffective disorder, n=1), giving a total of 13 women (28%) who had probable or definite psychosis.

Four women who died by suicide had a primary diagnosis of substance misuse. Other diagnoses included mixed anxiety and depression, emotional instability, autistic spectrum disorder, bereavement reaction, and chronic pain.

Three quarters of women (44/58) who died from substance misuse had a mental health diagnosis; three of the 11 women who were murdered had a mental health diagnosis (27%).

## Involvement with services

The highest level of care was ascertained in 53 of the 62 women who died by suicide (Table 4.4). Five women had received Mother and Baby Unit (MBU) care and a further four were admitted to a general adult mental health ward. Only three women were engaged with community perinatal mental health teams (in addition to those who also had inpatient care). However, a number of women had been referred but not seen. This is discussed below. In all, eight women (15%) had specialist contact (community and/or MBU).

**Table 4.4: Highest level of care for women who died by suicide, UK and Ireland, 2017-19**

Level of care received	Number of women (%) N=62
Mother and Baby Unit	5 (8)
Adult inpatient	4 (6)
Community perinatal mental health team / perinatal mental health day service	3 (5)
Adult community mental health team	3 (5)
Crisis / home treatment / liaison team	10 (16)
Other psychiatry	2 (3)
Addictions	3 (5)
Specialist mental health midwife / obstetrician	2 (3)
GP / maternity professional / health visitor	21 (34)
Unascertained	9 (15)

The primary contact for ten women (16%) was with home treatment or unscheduled care services. Four out of every 10 women had contact solely with universal services.

Two of the three women with a primary addiction diagnosis were seen by specialist addictions services.

## 4.4 Overview of care and lessons to be learned

### Communication

As in all previous enquiries, there are further examples in this report where communication in the initial information provided to maternity services did not include relevant mental health history.

A woman with a past history of bipolar affective disorder and postpartum psychosis requiring Mother and Baby Unit admission after a previous birth died violently by suicide in late pregnancy. While maternity services were aware of her bipolar diagnosis at booking, the details of her past psychiatric history and specific perinatal risk were not communicated and she did not receive specialist mental health care.

Communication of loss or traumatic events, where risk may be increased, is particularly important. For one woman with complex adversity, her GP was not made aware of her children's removal into care which occurred several weeks before her death. For a second woman, who died violently while experiencing a psychotic depressive disorder, the treating mental health team were not informed of her recent termination of pregnancy.

**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**

**Saving Lives, Improving Mothers' Care 2015 (Knight 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.**

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

## Red flags

The 2015 report highlighted red flags which may indicate suicide risk, and which should prompt urgent senior psychiatric assessment. They include (i) recent significant change in mental state or 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. In addition, the 2018 report added the requirement to have specialist assessment for any women who self-harmed (whether violently or not) in pregnancy or the early postpartum period.

A woman in her 30s died violently within two months of the birth of her first baby. She had no previous psychiatric history but developed what appeared to be rapid onset anxiety and depressive symptoms three weeks after giving birth. She became more depressed with preoccupation about her baby's health and her belief that she was inadequate as a mother. She self-harmed by lacerating her arm and was described as guarded in most assessments. The offer of admission to a Mother and Baby Unit was declined and she was managed by the home treatment team.

This woman demonstrated all three red flag features. Although many aspects of her care were well-managed, her risk was underestimated and there was a delay in assessment after concerns were first raised about her deteriorating mental state. An initial presentation with anxiety which is new and uncharacteristic should prompt early review and exploration for emerging symptoms of more significant mental disorder. The rapidity and depth of deterioration in relation to pregnancy is sometimes alarming and can proceed at a pace that traditional risk assessment scores will under-predict. The limitations of such risk predictors in pregnancy must be borne in mind as over-reliance on risk assessment scores led to several instances where signs were ignored and the opportunity for intervention missed.

Another woman also demonstrated change in mental state, rapid deterioration and estrangement from her infant, but her fluctuating symptoms gave false reassurance, and she was discharged from mental health care sooner than was indicated by the severity of her symptoms.

A woman in her 30s, with a history of anxiety symptoms, once again developed anxiety in pregnancy, which then settled. She developed anxiety and disturbed sleep in the early postpartum period and described an episode which may have been psychotic or dissociative in nature. She was referred to the local perinatal mental health service but declined earlier review. When assessed she was noted to be significantly depressed with profound beliefs that her baby did not like her. She was commenced on antidepressants but presented to the Emergency Department within a few days where her symptoms of restlessness and agitation were ascribed to the antidepressant. She reported feeling better shortly afterwards and again declined an early specialist review. When she was seen a few days later she was reported as having lost motivation and being anxious. Three days later her GP noted no mental health concerns. She changed antidepressant and reported some improvement. She was discharged at that point by the perinatal mental health team but died by hanging two weeks later.

A further woman with no past psychiatric history described thoughts of ending her life by hanging, drowning or shooting herself within a fortnight of giving birth. She was reviewed by her GP and other professionals, but no-one seemed to recognise how out of character this was for her. She died violently three months after delivery.

**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.**

**Saving Lives, Improving Mothers' Care 2015 (Knight et al. 2015)**

There was a concern for one woman that the professional assessing her informed her of her 'red flag' risks, suggesting she monitor herself for these, rather than acting to address the risk itself. Red flag presentations should be a prompt to initiate appropriate risk management and should not be used as a checklist without an accompanying plan for intervention.

## Amber flags

Amber flags indicate risk for recurrence of major perinatal mental illness, particularly in the early postpartum. They include (i) any previous history of psychosis, (ii) women with a family history of bipolar disorder or postpartum psychosis who themselves have mood disorder or change in mental state, and (iii) using personal and family patterns of occurrence and re-occurrence to inform risk management strategies.

There were six women reported to the Enquiry who had a prior diagnosis of psychotic disorder – two with bipolar affective disorder (one of whom had a previous postpartum admission), two with previous postpartum psychosis, and one each with schizophrenia and schizoaffective disorder. Four had their risk appropriately recognised, three of whom were referred to the specialist perinatal mental health service. The fourth woman declined referral but had appropriate preventative care in pregnancy. The remaining two women (one with bipolar affective disorder, one with previous psychotic depression) did not receive preconception advice or have appropriate preventative management in pregnancy. One was discharged by her mental health team during pregnancy as she was well, with advice to get in touch with services if she had problems.

A woman in her late 30s died violently in the third trimester. She had a prior Mother and Baby Unit admission after her first child was born and had a diagnosis of bipolar affective disorder. She also required inpatient care after the birth of her second child. She was discharged from mental health care two months before her last pregnancy. The discharge letter made no mention of risk in future perinatal periods and though her diagnosis of bipolar disorder was identified at booking, the plan put in place was that she could see her GP at her own request if her mood deteriorated.

This woman's need for specialist assessment and preventative intervention was not recognised. All women who have experienced major perinatal mental illness should be provided with information on (i) future risk, (ii) the availability of risk management strategies, and (iii) the need for re-referral during subsequent pregnancies to consider safety plans and active discussion about how and when to seek help, either because the woman recognises she is in difficulty or when others around her do.

**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.**

**Saving Lives, Improving Mothers' Care 2017 (Knight et al. 2017)**

## Risk assessment and management

A woman in her 20s died violently a few weeks after a termination of pregnancy. She had a prior history of self-injury, though this was not known at booking. Within two weeks of the termination she presented to her GP with low mood and suicidal thoughts. Over a two-month period, beginning with thoughts of not wanting to be alive, she moved on to specific ideas of suicide, followed by actual self-injury, attempted drowning, overdose and attempted hanging. On the last three occasions that she was seen (primary care psychological therapies service, GP and mental health liaison) she described recent significant self-harm and, on two occasions, the inability to keep herself safe. None of these encounters resulted in any plan for her immediate safety. In her last presentation she described recent onset of psychotic symptoms and thoughts of violent suicide. She said that she could not keep herself safe. Despite this being documented by the assessor, the assessment describes her as having no 'actual plans or intent' and that there was no evidence of mental health crisis warranting hospital admission. She was discharged from the Emergency Department and died on the following day.

Despite this woman's acute presentation and documented risks, there was no active planning to ensure her immediate safety. Her symptoms were downplayed.

There is a clear duty on assessing services to risk manage in the immediate, short and long-term. It is also important to keep in mind that risk is dynamic and may change, even over short periods of time.

**Consider previous history, pattern of symptom development and ongoing stressors when assessing immediate risk and management of women with mental health symptoms. Plans should address immediate, short-term and long-term risk.** **N**

Previous reports have commented on assessments of risk which state that the woman's child is a protective factor. There were a number of instances of this again being reported, despite there often being clear evidence that this was not the case.

A woman died violently in early pregnancy. She had experienced complex adversity and had a history of self-harm, sometimes with significant suicidal intent. At the time of discovering her pregnancy she had recently taken an overdose and was describing ongoing suicidal thoughts, but the liaison psychiatry assessment documents her family as being 'strongly protective'. Shortly before her death, and despite two recent overdoses, thoughts of violent self-harm and increased alcohol intake, an urgently requested mental health assessment cites her children as protective factors. She died four weeks later.

For this woman, her mental distress overwhelmed any stated protective effect that thoughts of her children may have had. It is vital that assessors integrate such statements into an evaluation of risk that takes into account other significant vulnerabilities, including in this instance acts of self-harm already made despite describing her children as protective. It is also important to recognise that risk is not static and a woman who firmly believes she would not act to end her life because of her children may think differently when she is more isolated or experiencing acute stress.

## **Crisis, liaison and home treatment teams**

Previous reports have recommended that non-specialist teams who may be involved with women during the perinatal period, often at times of crisis or worsening mental state, should have additional training in understanding the distinctive features and risks associated with perinatal mental illness. A number of examples reported to this Enquiry also demonstrated a lack of awareness of perinatal patterns of symptom development and a tendency to downplay significant changes in mental state.

A woman in her late 30s died violently seven months after the birth of her third child. She had a previous history of severe postpartum mental illness requiring psychiatric admission and had made significant, violent attempts to end her life at that time. She was not referred to specialist services in pregnancy and developed worsening depressed mood after childbirth. She was referred to a crisis service three days before her death who noted her worsening mood but did not recognise her particular risk. They suggested she access psychological self-help.

A woman with a history of lowered mood in a previous postnatal period and ongoing anxiety symptoms, developed a sudden deterioration in mental state in the immediate postpartum. There was evidence that she had psychotic symptoms and she disclosed that she had recently attempted to end her life by violent means. She was reviewed by the liaison psychiatry service who judged her self-harm act to have been 'impulsive'. They planned to review her again on the following day. There was a lack of recognition of her recently altered mental state and the distinctive risks she faced. She died violently before her review the following day.

**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.**

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

## Specialist perinatal mental health services

There were many examples reported to the Enquiry where women should have been referred to specialist services and were not. Indeed, it was striking how few women were engaged with specialist community services.

A woman died violently while an inpatient on a general psychiatry ward, toward the end of the first postnatal year. Despite a history of hospital admission for depression with suicidal ideation after the birth of her first child, she was not referred to perinatal mental health services but was seen by a specialist midwife and her pre-existing community mental health team. She experienced worsening mood associated with significant risk and was admitted under the Mental Health Act, but to a general psychiatry ward rather than to a Mother and Baby Unit. She repeatedly asked to be discharged and was sent home within a matter of a few days. No care co-ordination took place with relevant agencies such as health visiting and there did not appear to be any evaluation of risk in relation to her children. She died within days of discharge.

An approach which included perinatal mental health services, both for community and inpatient care, is likely to have resulted in decisions on risk and management which took into account the specific perinatal context. She may also have been more willing to receive inpatient care if accompanied by her baby.

However, there was also a concerning number of instances of specialist services having restrictive referral criteria or refusing to assess the woman based on diagnosis.

One woman was not seen by her local service as 'the perinatal mental health service was not commissioned to see personality disorders'. Another two woman with a similar diagnosis were not seen by the specialist service despite both having had inpatient care in the perinatal period. Another service restricted referrals to 'antenatal women at high risk'. In some cases, referrers had to go through a CMHT and could not access the specialist team directly. A further woman had her referral moved from the perinatal to the home treatment team and back again, being refused assessment on the first occasion because she was deemed unsuitable 'due to her violent suicidal intentions'.

A lack of a timely response was also a feature for a number of women.

A woman who died violently in pregnancy was seen by her specialist midwife and described pervasive depressive symptoms, persistent thoughts of suicide, multiple social stressors and excessive alcohol use. The midwife could not refer urgently to the perinatal mental health service and referred instead to an unscheduled care team who, after assessing her the following day, made a referral on. She was contacted by the perinatal mental health team two weeks later and an initial appointment made for four weeks after that. She died the week before her appointment. [XV624]

**Ensure specialist services have the capacity to assess and manage all women who require secondary care mental health services, and be able to adjust for the altered (generally lowered) thresholds for assessment in the perinatal period. This should not prevent shared management of women already engaged with another service, where that is in their best clinical interests.** N

**Ensure perinatal mental health services do not exclude patients on the basis of diagnosis, where they would ordinarily be seen by general adult mental health teams.** N

Where pathways into care were not clear, there was, at times, confusion over which service had been engaged and delays in referral to the specialist mental health team. As services expand further, including the development of maternity psychological therapies teams, it will be important to ensure new services are fully embedded within clear care pathways.

A woman who died violently in early pregnancy was seen by liaison services following an overdose. They believed she had already been referred to the perinatal mental health team, whereas in fact she had been referred to a specialist midwife.

A woman with bipolar affective disorder, including previous postpartum relapse, whose diagnosis was recognised at booking, was then referred on to a specialist midwife and obstetrician, but not to a perinatal mental health service. No plan was put in place for mental health management. She died violently in late pregnancy.

**Ensure there are clear and explicit pathways into specialist perinatal mental health care, which take into account all other aspects of perinatal mental health provision, including specialist roles within midwifery and obstetric services, in order to avoid any confusion over roles and responsibilities.** N

## Care of women experiencing pregnancy or postnatal loss

As noted above (Table 4.3), 37% of women who died by suicide had experienced a pregnancy or postnatal loss event and 57% of women who died from substance misuse had a similar loss event. Women are even more at risk after a perinatal loss event and good communication and care coordination are therefore essential.

A teenage woman died violently six weeks after termination of pregnancy. She had a history of emotional instability, and it is commented that the termination would have less impact mentally than continuing with the pregnancy. She had a first degree relative with bipolar affective disorder and she herself became acutely unwell, requiring psychiatric admission shortly before her death. The mental health team was not made aware of her recent termination.

While this woman had developed a severe mental disorder, its characteristic features of rapid deterioration accompanied by significant risk may have been better appreciated if understood in the perinatal context.

A woman died violently the day after she was informed by social services of an impending court date for removal of her infant into care. She had a long history of emotional instability and impulsivity and had previously harmed herself with significant suicidal intent. She also had a strong family history of suicide. She was engaged with adult mental health services. The child-care social worker and community psychiatric nurse had an informal discussion about her mental state in the context of possible child protection proceedings, but her significant vulnerability does not appear to have been communicated. Mental health services were not aware that she had been informed of the likely imminent removal of her infant and, though they visited within a short period of time of the woman's meeting with her social worker, she had already died.

For this very vulnerable woman with complex adversity, it would have been important to ensure good co-ordination of care so that she could receive maximum support and assessment of risk in the context of receiving distressing information.

**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.**

**Saving Lives, Improving Mothers' Care 2015 (Knight et al. 2015)**

## Engagement with relatives

In previous reports there have been concerns that relatives were not listened to or did not have sufficient understanding of risks associated with perinatal mental illness. These issues again appear in this report.

A woman died of an overdose several months after termination of pregnancy. She had developed a range of physical health concerns and received repeated investigations, but the possibility of a mental health cause does not appear to have been considered. Her family became increasingly concerned for her mental state and contacted her GP repeatedly describing a range of depressive symptoms and social withdrawal consequent on her physical health worries, which prevented her from going out. She had indicated to the GP that she did not want information about her health disclosed to her family and, for that reason, the GP would not see her relatives. Accounts were given to the practice of her engaging in self-harm and the family attempted to communicate their fear that she might end her life. They had contacted a mental health professional who also alerted the GP to their concerns, but she died on the same day.

In this case, relatives' escalating concerns were not listened to. There appears to have been a fundamental misunderstanding of the obligation for confidentiality which, while it may prevent disclosure of information about the patient, does not stop professionals listening to relatives and receiving information, particularly where there are concerns for safety. For this woman, her reluctance to see her GP may also have been driven by disturbed mental state and so information from other sources would have been particularly important in deciding whether a more assertive plan to assess her was required.

The relatives of another woman who had a range of 'red flag' symptoms declined the offer of MBU admission. Had they been given information on the specific risks she faced, they may have been able to make a more informed decision.

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

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

For another woman, it is clear that relatives were given responsibility beyond their capacity or expertise, when asked to monitor significant suicidal ideation and a rapidly deteriorating mental state. They were in no position to safeguard her adequately, which required professional intervention in a safe environment.

**While relatives provide invaluable support to the woman, complementing the care provided by universal and specialist services, they should not be given responsibilities beyond their capabilities or be expected to act as a substitute for an effective mental health response.** N

## Prescribing issues and lack of active management

There were a number of examples of failure to prescribe or deprescribing because the woman was pregnant. In other instances, there was a lack of active management.

A woman died by overdose of medication for a physical health problem in the aftermath of a neonatal death. Her endocrinologist had advised her to reduce her antidepressant in pregnancy though there is no evidence of consultation with her GP or a mental health professional.

A woman with a previous history of suicidal thoughts in the context of anxiety and low mood, died violently during her third trimester. She was treated with low dose antidepressant but was advised to stop by her GP on discovering the pregnancy. She presented repeatedly with worsening anxiety, sleep disturbance and low mood. Many alternatives to antidepressant medication were proposed but she was repeatedly told that medication could not be prescribed. She was given conflicting advice on the safety of promethazine in pregnancy and no single professional took overall responsibility for issues around prescribing in pregnancy.

Another woman was advised to stop her antidepressant by a liaison mental health professional after discovering her pregnancy. Overall, there was a concerning failure to consult with the primary prescriber or others with expertise on prescribing in pregnancy, when giving advice to women on taking medication in pregnancy. These decisions usually require careful weighing up of advantages and disadvantages, with women being supported to make their own or shared choice based on the best available evidence.

There were also examples of failure to treat based on misunderstanding of other risks. One woman was advised not to take her antidepressant because of risk of exacerbation of epilepsy, despite a recommendation of medication by a neuropsychiatrist. Another woman who had a deteriorating bipolar depression requested the addition of an antidepressant to her mood stabilising regime. This was declined based on the risk of triggering a manic episode, but no other medication management plan was put in place. She died a few days later.

**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.**

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

There is a new lesson on prescribing derived from a number of instances reported to this Enquiry. These were women who were on prescribed medication on discovering the pregnancy and who made the decision to discontinue. For several, there was no re-evaluation in the postnatal period, when they were more likely to be vulnerable to relapse, or whether they would benefit from recommencing medication, either prophylactically or to manage emergent symptoms.

A woman who died violently four months after delivery had been treated with antidepressants in primary care, for anxiety and panic. She made the decision to stop medication herself on discovering the pregnancy. She remained well throughout pregnancy. There was no discussion of medication intentions after delivery, and she had no additional input from her GP after her six-week check.

**If psychotropic medication has been discontinued in advance of, or during, pregnancy, ensure women have an early postnatal review to determine whether they should recommence medication, carried out either by the GP or mental health service depending on the level of pre-existing mental health care. N**

On occasion, women with severe postnatal relapse were not adequately treated and continued to display symptoms. This included some women who were admitted to MBU care and had historically responded well to treatment yet were discharged despite continuing to display symptoms.

**Where a woman with severe postnatal illness has previously responded well to treatment then there should be an expectation of a good recovery from subsequent postpartum episodes. Ensure that it is recognised that discharge from inpatient care before recovery is achieved is likely to be associated with continued risk. N**

## Complex adversity

Similar themes have emerged in this Enquiry to those reported previously, with regard to increasing numbers of women presenting with complex psychosocial adversity, often in the context of prior and ongoing trauma. These women may be particularly vulnerable and are over-represented among those who lose custody of their children and those with primary or comorbid substance misuse. They may engage less well with maternity and mental health care. Many of these women are given diagnoses of emotional instability or personality disorder. There is evidence that, having attracted such a diagnosis, there was reluctance to re-evaluate it even in the light of significant new symptoms emerging. Emotional instability, or a diagnosis of personality disorder, increases the risk of comorbid mental illness rather than diminishing it. The establishment of therapeutic relationships is key and professionals need to understand the woman's story rather than simply the headline issues of mental disorder, substance misuse and domestic abuse. There needs to be effective inter-agency communication, including between routine meetings.

A woman in her mid 20s died several months postpartum of an overdose. She had a history of mental health difficulties including anxiety and low mood, self-harm, and alcohol and drug misuse, probably including prescribed opioids. She was in an abusive relationship and her lifestyle was chaotic. She was also being investigated for headaches and seizures. An older child had been removed into kinship care and there were ongoing child protection proceedings in this pregnancy, resulting in her baby being removed into foster care shortly after birth. In the months after delivery, she became homeless. Although she was involved with a number of agencies, including perinatal mental health, addictions and crisis services, social services and neurology, the focus for all agencies seems to have been symptomatic management and while different services communicated with each other, there was limited true inter-disciplinary working or an attempt to understand the reasons behind her difficulties. Assessments were superficial in nature – on one occasion the crisis team’s assessment tool recorded ‘no risk identified’ despite very recent overdose.

## Substance misuse

In addition to the women who died through suicide, 58 women died in relation to substance misuse. Nearly half of these women (27/58) showed evidence on post-mortem of polysubstance misuse. The effects of acute or chronic cocaine use were the next commonest drug-related finding at death, followed by opiates alone, the chronic effects of alcohol abuse, and amphetamines. In polysubstance misuse, combinations of opiates and benzodiazepines were common, and several were also taking pregabalin/gabapentin prescribed (typically for chronic pain) or illicitly. Prescribers were not always aware of the misuse potential of these drugs. In one case a GP continued prescribing opiates and pregabalin despite recording concern about dependence and escalating doses, but with no referral on to a relevant service. A small number of deaths involved propranolol (propranolol overdoses having also been a feature of previous reports) and gases (butane/propranolol).

Public Health England data showed that approximately 1% of women were known to use drugs during pregnancy (Public Health England 2019). Similar data has been published for Scotland relating to 2014/15 (Scobie and Woodman 2016) and this found that 50% of those that used drugs were using opiates. Accepting that not all women currently using drugs will be recorded and some will abstain in pregnancy and then recommence postpartum, these 58 women suggest a death rate in the order of 0.5% (50 per 10,000) of women who use drugs in pregnancy.

In the main these women had complex problems with a history of multiple adversity such as childhood abuse, adult abuse, social services involvement and child removal. There was often a pattern of increased substance misuse and disengagement after children were removed. As in previous reports there were instances of poor information sharing between professionals.

A number of women had a known prior history of substance misuse but denied current use during pregnancy. In several cases there was evidence to the contrary but further questions were not asked. In other instances, appearance was taken as reassurance of abstinence: “the patient’s demeanour gave me no reason to doubt”. It was not unusual for maternity records to make no further comment about substance use after booking. Several women died from the chronic effects of substance misuse including liver failure, pancreatitis and myocarditis. A number had had recent overdoses of illicit drugs either shortly before pregnancy or during pregnancy.

The importance of continuity of care was not always recognised either during the episode of care or in the subsequent local incident review. Several of the pregnancies had been unplanned and some women chose to have a termination. They would have benefitted from contraceptive advice. However, many of the deaths were very late in the first postpartum year/year after pregnancy loss (by whichever means).

A small number of women were hostile and at times aggressive which led to an understandable caution around engagement, particularly in home visiting. In some instances, professionals worked hard to try and manage these challenges.

A white British woman who was employed and living with her partner gave birth to her third child by caesarean section under general anaesthetic. She had a past history of depression. She had stopped her antidepressant two weeks before booking but reported feeling well (Whooley negative) and declined onward referral to mental health services (at booking and again mid-pregnancy). She reported a history of cannabis use more than two years previously. She had no previous social services involvement. She was discharged home the day after delivery and, at this time, was stated to be not using illicit drugs. She died six months postpartum of cocaine toxicity.

In a number of instances women continued to use illicit substances but did not engage with services. It is important the professionals remain inquisitive and do not rely on previous denials of ongoing substance misuse.

A woman in her 30s died by violent suicide seven months after delivery. She had a significant history of alcohol dependence including Wernicke's encephalopathy and delirium tremens. There was also a history of recurrent overdose. Shortly before discovering the pregnancy, she was engaged with addictions services and had commenced acamprosate. However, she defaulted from follow-up. She was reassessed by addictions services in mid-pregnancy who noted that she had been abstinent for most of the pregnancy though they also noted a number of depressive symptoms. She was discharged back to her GP when she did not attend an arranged follow-up appointment. After giving birth she developed worsening depressive symptoms, later complicated by a return to alcohol misuse.

Some women were engaged with specialist addiction services during pregnancy but disengaged or were discharged, having had evidence of an improvement in substance use problems. However, as with women with other mental illness, they may be more vulnerable in the postpartum period, particularly where there are child protection proceedings. It would be helpful for these women to be reassessed in the early postpartum to consider re-engagement with services addressing their substance use, if this has not already been put in place as part of the postnatal mental health plan.

**Women with substance misuse are often more vulnerable and at greater risk of relapse in the postnatal period, even if they have shown improvement in pregnancy. Ensure they are reviewed for re-engagement in the early postpartum period where they have been involved with addictions services in the immediate preconception period or during pregnancy.** N

## Local incident reviews

In a number of instances local reviews of care were either not carried out or failed to integrate the different services involved in the woman's journey of care. Several would have benefitted from the involvement of specialists in perinatal psychiatry. As an example, one woman who died by overdose had complex mental and physical health problems. She was referred to psychiatry but not seen. The incident review team were of a single discipline and did not involve mental health despite its obvious relevance. Involvement of all pertinent members of the wider multidisciplinary team is needed to ensure that all relevant lessons are learned to improve future care.

**Ensure local incident review teams are multidisciplinary in composition and that investigations are carried out across organisational structures where indicated.** N

## Record keeping and mental health record returns

**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.**

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

The last mental health themed Enquiry strongly recommended a pathway to ensure that mental health records were released to MBRRACE-UK. An additional challenge more evident in this Enquiry was the increasing prevalence of electronic mental health records. There is a tendency for these to be more proforma-based and reviewers noted a reduction in the detail of narrative accounts of mental state and risk assessments. It is important for clinicians to be able to document and reflect their thinking in what are often very complex and nuanced assessments. Furthermore, non-mental health professionals such as midwives and obstetricians frequently made no comment as to mental state even in patients where there was a known risk of relapse. This is not consistent with NICE Antenatal and Postnatal Mental Health guidance.

**Healthcare professionals working in universal services and those caring for women in mental health services should monitor regularly for symptoms throughout pregnancy and the postnatal period, particularly in the first few weeks after childbirth.**

**NICE guideline CG192 Antenatal and Postnatal Mental Health (National Institute for Health and Care Excellence 2014)**

## Domestic violence and abuse

No routine enquiry was made about domestic violence throughout a woman's pregnancy. Her partner was present at all visits. She had a normal birth and was discharged home. There is no documentation about whether routine enquiry about domestic abuse was made at postnatal visits. She was murdered by her partner a few weeks later when it became apparent that the woman had a long history of domestic violence.

An Eastern European woman attended the emergency department in late pregnancy with abdominal pain. She was not booked for antenatal care. No enquiry was made about domestic abuse although a safeguarding referral for the child was made. She was murdered by her partner a few days later.

An asylum seeker disclosed prior domestic abuse at booking, but denied any current episodes and therefore no further action was taken. She was murdered by her partner a few months later.

Overall, for all the women whose care was reviewed for the purposes of this chapter, a quarter (n=33) were known to be victims of domestic abuse, although it remains of concern that for 43 women (33%) this information was missing. As for the women described above, identification of domestic abuse, appropriate safeguarding referral for both the woman and her child, as well as continued awareness of the possibility of ongoing abuse all remain important. Eight of the women are known to have been murdered by a partner or former partner; all perpetrators were known to their victim. It is of note that multiple adversity was a major theme amongst the women who were murdered, with mental health problems, substance abuse, migrant or asylum seeker status, non-English speaking all evident, which may have made disclosing abuse even more difficult. These women emphasise in particular the need for complex and nuanced care first highlighted in the 2020 report.

**Ask the woman about domestic abuse in a kind, sensitive manner at the first antenatal (booking) appointment, or at the earliest opportunity when she is alone. Ensure that there is an opportunity to have a private, one-to-one discussion.**

**NICE Antenatal care guideline NG201 (National Institute for Health and Care Excellence 2019)**

## 4.5 Conclusions

This report emphasises once again the importance of immediate risk management and the need for awareness amongst crisis, liaison and home treatment teams of the concerning signs of perinatal mental illness and the rapid deterioration which can occur, particularly postnatally. Early postnatal reviews are therefore needed not just for women at high risk of early postpartum mental illness but also those who have discontinued medication in pregnancy, or who have stopped engagement with addictions services. Gatekeeping was highlighted as a concern in the 2020 rapid report (Knight et al. 2020a); the reviews in this report have identified concerning barriers to referral or assessment put in place by specialist perinatal mental health teams. Clarity is needed over how new roles or services, such as specialist midwives, obstetricians or psychological therapies services, fit into pathways into care, avoiding any confusion over referral routes.

Whilst it is unclear whether the significant increase in teenage maternal deaths by suicide reflects the known increasing prevalence of child and adolescent mental health problems, it emphasises that these messages are equally applicable across pregnant women of all ages, and especially those who have had a pregnancy loss event. Multiple adversity features highly for many of the women whose care was reviewed for the purposes of this chapter; care for these women has to be a major improvement focus. Assessors felt that improvements in care might have made a difference to outcome for 67% of women who died by suicide, 29% of women who died from substance misuse and 18% who died by homicide (Table 4.5).

**Table 4.5: Classification of care received by women who died by suicide, from substance misuse or by homicide for whom there was sufficient information to assess their care, UK and Ireland 2017-2019**

Classification of care received	Women who died by suicide Number (%) N=61*	Women who died from substance misuse Number (%) N=48*	Women who died by homicide Number (%) N=11
Good care	2 (3)	10 (21)	3 (27)
Improvements to care which would have made no difference to outcome	18 (30)	24 (50)	6 (55)
Improvements to care which may have made a difference to outcome	41 (67)	14 (29)	2(18)

\*Insufficient information to classify care for one woman who died by suicide and ten who died from substance misuse.

# 5. Improving diagnosis and treatment of cancer

Joanna Girling, Janet Brennand, Anita Banerjee, Arlene Wise, Kathryn Bunch and Marian Knight on behalf of the MBRRACE-UK malignancy chapter-writing group

Chapter writing group members: Anita Banerjee, Janet Brennand, Kathryn Bunch, Becky Ferneyhough, Charlotte Frise, Joanna Girling, Malcolm Griffiths, Kate Harding, Sara Kenyon, Marian Knight, Jenny Kurinczuk, Sebastian Lucas, Seema Quasim, Judy Shakespeare, Derek Tuffnell, Arlene Wise, Esther Youd.

## 5.1 Key messages

### New recommendations

Ensure that postgraduate medical and surgical curricula include training in the need for contraceptive advice to women of reproductive age and how to ensure that it is provided **[ACTION: Academy of Medical Royal Colleges]**.

Ensure that postgraduate medical and surgical curricula include training in the need for pre-pregnancy planning to women of reproductive age with medical problems such as cancer **[ACTION: Academy of Medical Royal Colleges]**.

Ensure that women with active or very recent cancer treatment are seen by an obstetric consultant in the first trimester to allow discussion of individual risks and choices **[ACTION: Service Planners/Commissioners, Hospitals/Trusts/Health Boards]**.

Ensure that all clinical staff caring for pregnant or postpartum women, whatever the location of care, are aware of the concerning 'red flag' symptoms described in the RCP Acute care toolkit 15: Managing acute medical problems in pregnancy **[ACTION: Hospitals/Trusts/Health Boards]**.

Develop clear guidance on imaging in pregnancy, including for both diagnosis and staging **[ACTION: Royal Colleges of Radiologists, Obstetricians and Gynaecologists, Physicians]**.

Ensure symptoms of possible cancer are followed up postnatally. If they do not resolve, they are unlikely to be due to pregnancy **[ACTION: All Health Professionals]**.

### Existing recommendations requiring improved implementation

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. Non-hormonal methods of contraception are recommended for women wishing to avoid pregnancy after treatment of breast cancer [RCOG Green-top guideline 12] **[ACTION: All Health Professionals]**.

Women with a significant risk of recurrence (localised disease of  $\geq 1$  mm thickness) who wish to become pregnant after surgery for stage I or II melanoma should be advised to delay pregnancy for two years postsurgery, as the likelihood of recurrence is highest during this period. Pregnant women who present with growing or changing pigmented lesions should be treated as non-pregnant women [SIGN Guideline 146] **[ACTION: All Health Professionals]**.

Guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of co-morbidities such as cardiac disease and cancer [Saving Lives, Improving Mothers' Care 2019] **[ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians, British Fertility Society]**.

Ensure early senior involvement of the maternal medicine team for any pregnant or postpartum woman admitted with [concerning symptoms of medical illness in pregnancy], whatever her gestation and wherever in the hospital she receives care [MBRRACE-UK Rapid report 2021] **[ACTION: All Health Professionals]**.

Care should be taken of pressure points in the obstetric population as well as other populations [Saving Lives, Improving Mothers' Care 2018] **[ACTION: All Health Professionals]**.

Investigate and treat pregnant and postpartum women the same as non-pregnant women unless there is a clear reason not to [Multiple MBRRACE-UK Reports] **[ACTION: All Health Professionals]**.

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 [RCOG green-top guideline 63] **[ACTION: All Health Professionals]**.

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for women if, on examination, the appearance of their cervix is consistent with cervical cancer [NICE NG12] **[ACTION: All Health Professionals]**.

Face to face treatment may be preferable when: the patient has complex clinical needs, you need to examine the patient, it's hard to ensure, by remote means, that patients have all the information they want and need about treatment options [GMC guidance on remote consultations] **[ACTION: All Health Professionals]**.

In general, for women with breast cancer, early delivery to avoid delays in chemotherapy should not be recommended. For women diagnosed with breast cancer in the third trimester, the risk-benefit is likely to favour both mother and baby if a woman can receive at least two cycles of chemotherapy prior to a term (39-40 week) birth [Saving Lives, Improving Mothers' Care 2019] **[ACTION: All Health Professionals]**.

The birth of the baby should be timed after discussion with the woman and the multidisciplinary team. Most women can go to full term of pregnancy and have a normal or induced delivery [RCOG Green-top guideline 12] **[ACTION: All Health Professionals]**.

## 5.2 Background

Deaths of women from cancer during or after pregnancy are typically classified as 'coincidental' and therefore neither counted nor investigated as part of reviews of maternal deaths in many countries. These MBRRACE-UK reports have contended before that there are many examples where women's care is compromised simply because they are pregnant or postpartum, and this is a clear argument for including the deaths of women with cancer in comprehensive reviews of the care of women who die during or after pregnancy. This report is no different and this chapter contains reviews of the care of all women who died from cancer during pregnancy or up to a year postnatal, irrespective of the type of cancer and whether the woman's death might be epidemiologically classified as 'coincidental' to pregnancy. The most recently published UK data shows that pregnant women have a 48% higher age-standardised incidence rate of cancer in comparison to non-pregnant women of reproductive age (National Cancer Registration and Analysis Service 2018). A possible explanation for this observation is related to more frequent examination and therefore an increased chance of detection, however, the frequently reported lack of recognition of concerning symptoms in pregnancy argues that this may not be the case. As emphasised in Chapter 3, the age at which women enter pregnancy is increasing, thus cancer, with its age-association, is likely to be seen more frequently among pregnant or postpartum women in the future. Learning lessons to improve diagnosis and management of malignancy in association with pregnancy will therefore become even more important.

## 5.3 The women who died

Eighty-nine women died during or up to one year after pregnancy from malignant disease during 2017-19 in the UK and Ireland. Fourteen women died during or up to six weeks after the end of pregnancy, a mortality rate of 0.60 per 100,000 maternities (95% CI 0.33-1.00). Of these 14 women, 5 died from breast cancer, 3 from brain or CNS tumours, 3 from gastrointestinal tumours, 1 from a haematological tumour and 1 from a lung cancer (Table 5.1). One woman died with an unidentified primary tumour. Only five of these 14 women (36%) had an autopsy, 3 of which were coronial or fiscal and the other 2 hospital-initiated.

Seventy-five women died from cancer between six weeks and one year after the end of pregnancy. Of these 75 women, 18 died from gastrointestinal tumours, 15 from breast cancer, 7 from brain or CNS tumours, 7 from lung cancer, 6 from skin cancer, 6 from haematological tumours, 4 from soft tissue tumours, 3 from cancer of the cervix, 2 from ovarian cancer and 1 from choriocarcinoma. Four women died from tumours in other sites and 2 women died with an unidentified primary. Detailed records were available for review for 66 of these women, thus in total the care of 80 women was reviewed.

**Table 5.1: Nature of the malignancies in the women who died, UK and Ireland 2017-19**

Nature of malignancy	Deaths in pregnancy or within 6 weeks of delivery Number of women N=14	Deaths between 6 weeks and 1 year after delivery Number of women N=75
Choriocarcinoma		1
Breast	5	15
Cervix		3
Ovarian		2
Bone		1
Brain/CNS	3	7
Gastrointestinal	3	18
Haematological	1	6
Lung	1	7
Skin		6
Soft tissue		4
Other		3
Unknown primary	1	2

## 5.4 Overview of care and lessons to be learned

### Contraception and pre-pregnancy counselling

#### Contraception

A woman became pregnant during treatment for a malignant melanoma. She had received no contraceptive advice. She chose to continue the pregnancy, but this limited her treatment options, including her eligibility to participate in clinical trials of treatment. The usual staging investigations were not undertaken. She died from metastatic disease a few weeks after giving birth.

Several women became pregnant during or shortly after completing cancer treatment and no-one had discussed contraception. All medical staff, of whatever specialty, should be aware that women of reproductive age may become pregnant during treatment for mental and physical health conditions and therefore need contraceptive advice. All staff should be able to provide that advice.

**Ensure that postgraduate medical and surgical curricula include training in the need for contraceptive advice to women of reproductive age and how to ensure that it is provided. N**

A woman with triple negative breast cancer underwent a wide local excision and axillary clearance followed by chemotherapy with an anthracycline and radiotherapy. She was seen by the fertility team to discuss options around fertility preservation prior to treatment. No contraceptive advice was given and at the end of treatment she discovered she was pregnant. She booked in the first trimester but was not seen by a consultant until six weeks later. Venous thromboembolism risk was assessed as intermediate and thromboprophylaxis was not indicated at that stage. In the second trimester of pregnancy she reported a two-week history of breathlessness. Pulmonary embolism was suspected, but a VQ scan was subsequently cancelled by a junior doctor after further evaluation of her symptoms. Two weeks later she re-presented with back pain and worsening breathlessness when lying flat and pulmonary embolism and metastatic cancer were diagnosed. Concerns over her condition led to an extremely preterm caesarean birth a month later. No consideration appears to have been given to chemotherapy during pregnancy. She died six months postnatally.

Although this woman received advice on fertility preservation, she was not advised about contraception. Additionally, once pregnant she did not receive counselling from someone with appropriate expertise until relatively late in the second trimester, when she first attended a consultant antenatal clinic.

Two women had long-acting reversible contraception removed on advice prior to cancer chemotherapy but it was not replaced with alternative contraception (such as a copper intrauterine device).

A woman underwent wide local excision and further axillary clearance following a diagnosis of breast cancer. Her oncologist instructed that her hormonal intrauterine system should be removed prior to chemotherapy but did not provide advice concerning alternative contraception. A different member of the oncology team advised her to discuss contraception with her GP. She continued with chemoradiotherapy until the following year and shortly afterwards she presented with an unplanned pregnancy. Her oncologist advised that it would be safe to proceed with the pregnancy. She booked for consultant care. She smoked but was assessed as having no risk factors for thromboembolism. There was no recognition of the potential link between her radiotherapy and cardiomyopathy and/ or restrictive lung disease, or the chemotherapy link with cardiomyopathy. A plan was made for routine care with no follow up. She had an uncomplicated birth at term, but presented with metastatic disease shortly afterwards. She received palliative care at home before her death a few weeks later.

The Faculty of Sexual and Reproductive Health (FSRH) UK Medical Eligibility Criteria for Contraceptive Use (UK MEC) provides clear guidance on contraception suitable for use in women during and after cancer treatment (<https://www.fsrh.org/ukmec/>).

**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 2015a).**

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

## Pre-pregnancy counselling

Several women died from metastatic melanoma diagnosed during pregnancy. Most of the women who died had a relatively short gap between completion of their cancer treatment and their pregnancy. When the pregnancy was planned, it was unclear whether women had received any pre-pregnancy advice. Women should receive specialist advice regarding the gap after treatment before becoming pregnant – a space of two years is recommended for most cancers where guidance exists. It is important to recognise that the gap is not because pregnancy is thought to impact on the course of the disease but because recurrence risks are greatest in the two years after initial diagnosis and pregnancy may impact on the treatment options the women can receive.

**Women with a significant risk of recurrence (localised disease of  $\geq 1$  mm thickness) who wish to become pregnant after surgery for stage I or II melanoma should be advised to delay pregnancy for two years post-surgery, as the likelihood of recurrence is highest during this period.**

**Pregnant women who present with growing or changing pigmented lesions should be treated as non-pregnant women.**

**SIGN Guideline 146 Cutaneous melanoma (Scottish Intercollegiate Guidelines Network 2017)**

**Ensure that postgraduate medical and surgical curricula include training in the need for pre-pregnancy planning to women of reproductive age with medical problems such as cancer. N**

Two women with a cancer diagnosis who conceived by IVF overseas, died following their pregnancies. It is unclear what counselling they received. As noted in Chapter 3, nuanced individual counselling is particularly important for older women undergoing assisted reproduction, as they are more likely to have co-morbidities including cancer. The needs of the child must be considered in such discussions.

**Guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of co-morbidities such as cardiac disease and cancer.**

**Saving Lives, Improving Mothers' Care 2019 (Knight et al. 2019)**

## **During pregnancy – women with a prior diagnosis**

### **Early consultant review**

Guidance is needed on how quickly women should be seen in an obstetric consultant clinic after pregnancy is diagnosed following a previous cancer diagnosis. Several women were not seen until mid-late second trimester by which time discussions about continuing the pregnancy could not be undertaken.

A woman conceived six months after completing mastectomy, radiotherapy and chemotherapy for breast cancer. She did not see a consultant until the second trimester. She developed new nausea and vomiting from 20 weeks of pregnancy, initially attributed to hyperemesis gravidarum. She developed a headache and a CT brain scan was normal. Soon after she developed cranial nerve palsies and had a neurology review. MRI without contrast was normal, but lumbar puncture showed raised opening pressure and malignant cells. She received sensitive and carefully planned palliative care and multidisciplinary planning but deteriorated rapidly and died shortly after an extremely preterm birth.

All women of childbearing age with a cancer diagnosis must have the opportunity to discuss pregnancy planning and contraception so that they make informed decisions. Usually it is preferable to delay pregnancy until the period with greatest likelihood of recurrence, generally 2 years, has passed, and women should be actively offered and supported to access reliable contraception during that time. Women who conceive unexpectedly should be seen by oncology and maternity services in the first trimester so that a full discussion about the individual risks and the options potentially including termination of pregnancy can be undertaken.

**Ensure that women with active or very recent cancer treatment are seen by an obstetric consultant in the first trimester to allow discussion of individual risks and choices.** **N**

The charity Mummy's Star (<https://www.mummysstar.org/>) provides additional advice and support for women with a cancer diagnosis in pregnancy.

## **During and after pregnancy – making a diagnosis**

### **Maternal medicine expertise**

Several women became unwell in the first trimester of pregnancy, and were cared for in acute medical or ambulatory care units. There was confusion over who to call for advice, and as a result women's cancer diagnoses were missed and therapy delayed. This included some particularly chemosensitive cancers where earlier diagnosis may have made a difference to the outcome. The 2021 rapid report on COVID-related maternal deaths emphasised the role of the maternal medicine team – this applies equally to women with other medical conditions in early pregnancy.

**Ensure early senior involvement of the maternal medicine team for any pregnant or postpartum woman admitted with [concerning symptoms of medical illness in pregnancy], whatever her gestation and wherever in the hospital she receives care.**

**Saving Lives Improving Mothers' Care Rapid report 2021 (Knight et al. 2021)**

The purpose of networked maternal medicine services, in development in many areas of the British Isles, includes ensuring that every woman with pre-existing medical problems has timely access to a specialist in the preconception period, during and after pregnancy, and there is similar access for women with de-novo medical conditions that arise during pregnancy including a new diagnosis of cancer (NHS England 2019b, Mackillop 2021). The maternal medicine centres (MMC) are intended to be the hub of the networks and enable access to an appropriately skilled multidisciplinary team, with an obstetrician with subspecialty training in maternal medicine and an obstetric physician with appropriate training and a specialist midwife, to work alongside obstetric anaesthetists and with input from other relevant medical specialties. The local clinical leadership within each network will enable equitable disease identification, escalation and delivery of care across the region. This will support the development of seamless pathways

and training across the local networks and beyond. Education and the bridging of primary and secondary care in all areas of maternal medicine is key to the success of the networks. At the time of writing (June 2021) these structures are still in their infancy; accelerating implementation will be essential to decrease maternal mortality rates.

## Symptoms

### Red flags

A woman had recurrent headaches throughout her pregnancy with episodes of blurred vision and a fall. She had an uneventful birth but developed a headache associated with vomiting and raised blood pressure postnatally. She was treated for pre-eclampsia and discharged. She was readmitted a week later with a persistent severe headache, raised blood pressure and further episodes of blurred vision. She continued to be treated for pre-eclampsia for a further few days even though she developed vomiting. Concerns over a possible venous sinus thrombosis led to a CT scan, on which her cerebral tumour was diagnosed. She died a few months later.

Throughout pregnancy and postpartum, this woman's symptoms were attributed to pregnancy conditions despite concerning 'red flags' (Box 3.1). Symptoms of cancer may be subtle and certain signs and symptoms may overlap and be masked by physiological changes during pregnancy. Recurrent symptoms necessitating re-presentation and increasing analgesia from simple analgesia to opioids have been recurrent themes in previous reports. 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.

#### **Box 3.1: Red flags in the history and examination of a pregnant patient presenting with headaches:**

- Sudden-onset headache / thunderclap or worst headache ever
- Headache that takes longer than usual to resolve or persists for more than 48 hours
- Has associated symptoms – fever, seizures, focal neurology, photophobia, diplopia
- Excessive use of opioids

**RCP Acute care toolkit 15** Managing acute medical problems in pregnancy (Royal College of Physicians 2019)

The RCP 'Acute care toolkit 15: Managing acute medical problems in pregnancy' highlights a range of red flags in pregnancy, including concerning chest pain, back pain and breathlessness as well as headaches, and emphasises that early involvement of experienced decision makers should take place if red flags are present. All clinicians caring for pregnant and postpartum women, whatever the location of care, should be aware of this guidance.

**Ensure that all clinical staff caring for pregnant or postpartum women, whatever the location of care, are aware of the concerning 'red flag' symptoms described in the RCP Acute care toolkit 15: Managing acute medical problems in pregnancy.** **N**

### 'Be breast aware'

The symptoms of pregnant women should be treated with the same seriousness as those of a non-pregnant individual. A positive diagnosis should always be sought, rather than just excluding what is considered to be the most likely diagnosis.

A young multiparous woman was seen on several occasions early in the third trimester by her GP, antenatal clinic staff and in the emergency department with non-specific symptoms including chest pain not resolving with opioids, dizziness and shortness of breath. She was either not examined or the examination was performed through clothing, and the large cancer filling her breast with nipple retraction and axillary lymphadenopathy was not detected. She had been aware of the lump and nipple change for several weeks but had not volunteered the information presumably because she had not been asked directly; the tumour was inoperable. Her condition deteriorated quickly and she died shortly after an emergency preterm birth.

All women are advised to be 'breast aware' and report to their GP if they notice any changes. This breast self-awareness is equally important during pregnancy, and women should be advised of this. Information for women is available at <https://www.nhs.uk/common-health-questions/womens-health/how-should-i-check-my-breasts/>.

Maternity staff should be aware of non-specific presentations of breast cancer, and should ask women with chest symptoms if they have noticed any breast or nipple changes. Women with persistent complaints of chest pain that does not have a clear cause, especially when strong analgesia is required, should have a face-to-face assessment including history and physical examination (if any suspicion of cancer symptoms.)

## Recurrent presentation

A woman complained on multiple occasions of diarrhoea, vomiting, abdominal and chest pain from the middle of her pregnancy and in the postnatal period for which no clear cause was found. Her symptoms were assumed by her carers and herself to be due to pregnancy or a benign process such as irritable bowel syndrome. She collapsed a few weeks after giving birth and was found to have extensive lymphadenopathy. She died from complications of disseminated malignancy of uncertain origin a few weeks later.

A positive diagnosis should be sought for women with persistent or recurrent symptoms, and they should not automatically be attributed to pregnancy. Postnatal follow up should be considered as a safety mechanism. Pregnant women with persistent symptoms should be advised and empowered to seek further care if they do not settle after they have given birth.

## Vomiting and weight loss

A woman had multiple hospital admissions for vomiting, abdominal pain and weight loss (reaching 20% of her booking weight) in the first and second trimester. A longer admission in the third trimester led to the diagnosis of inoperable pancreatic cancer and early caesarean birth was recommended. She died in hospital a few weeks after birth following excellent multi-professional support by the palliative care team including planning for care of the children after her death and end of life care.

Hyperemesis gravidarum is a diagnosis of exclusion; on-going and persistent symptoms especially marked weight loss should not be attributed to it, and should be investigated further. Pain is not a common feature of hyperemesis and should also raise concerns. As has been repeatedly noted by these enquiries, premature birth imposes risks to the baby and limitations on the mother and family's opportunities to spend time together, and should not be planned unless there are clear benefits.

## Normalising symptoms

A woman had abdominal pain on several occasions in the second trimester before investigations for presumed pyelonephritis revealed ascites and subsequently a diagnosis of inoperable colorectal adenocarcinoma was made. She had an operation to relieve bowel obstruction, and subsequently developed pressure sores and bilateral pulmonary emboli. She had three cycles of chemotherapy during the pregnancy before an early caesarean birth due to fetal concerns. She continued chemotherapy but died a few months after giving birth.

It is common for women and maternity staff to normalise new symptoms during pregnancy. It is important only to do this once a structured approach has ruled out other causes.

As this woman illustrates, women with cancer are particularly vulnerable to other morbidities. Pregnant women with active cancer are at risk of thromboembolism, especially following surgical procedures, and should be considered for antenatal thromboprophylaxis. As highlighted in the 2018 report, lengthy surgical procedures also place women at risk of pressure sores. Maternity staff may be less familiar with preventing, detecting and managing pressure sores. Maternity units should ensure awareness of strategies to promote and assess tissue viability, especially when involved in the care of sick women.

**Care should be taken of pressure points in the obstetric population as well as other populations.**

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

### Overlap with symptoms of pre-existing disease

A woman who had Crohn's disease which was in remission and did not require treatment had a vaginal birth. A month after giving birth she developed abdominal pain and underwent hemicolectomy and end ileostomy formation for multiple bowel perforations. A poorly differentiated neuroendocrine carcinoma was diagnosed, and rapid peritoneal spread occurred in the following weeks. She died in a hospice six months after giving birth.

It is unclear whether this woman had early symptoms which were attributed to her Crohn's disease, but it can be particularly difficult in these circumstances to differentiate cancer symptoms. For women with pre-existing medical disorders, the antenatal period can be an opportunity to ensure that management is optimised, to rectify if they are not receiving appropriate care for their medical condition as well as providing holistic maternity care. There are national guidelines recommending best care for pregnant women with inflammatory bowel disease and each maternity unit should consider how best to apply these locally and within their regional Maternal Medicine Network (Selinger et al. 2021).

This may include plans for colonoscopic surveillance for cancer, since inflammatory bowel disease is a known risk factor (Lamb et al. 2019).

A multiparous woman with known latent TB developed severe back pain in the second trimester, and a CT scan showed spinal lesions. Spinal TB was felt to be the likely diagnosis, so TB treatment was started. There was discussion about performing a biopsy but following multi-professional discussion, fetal concerns about contrast media, radiation exposure and need for a general anaesthetic led to the decision to defer diagnosis until after birth. She developed such increasing intensity of pain that she had a preterm caesarean birth. A week after giving birth a guided spinal biopsy revealed metastatic adenocarcinoma likely of gastrointestinal origin. She had palliative radiotherapy but deteriorated rapidly and died a few weeks later. Post-mortem revealed extensive metastatic pancreatic cancer.

This woman should have been investigated and a tissue diagnosis made during pregnancy. Inappropriate assumptions should not have been made. It is important to ensure that pregnant women receive at least the same quality of care as those who are not pregnant.

**Care should be taken of pressure points in the obstetric population as well as other populations.**

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

### Vaginal bleeding

Three women died from cervical cancer. Two women had recurrent vaginal bleeding during pregnancy. A third woman had no bleeding during pregnancy, but had abnormal cervical findings on digital examination following admission for induction of labour. Speculum examination was performed as part of the assessment in all women.

A woman was reviewed in the mid second trimester with recurrent vaginal bleeding. Her last cervical smear was 7-8 years previously. Her cervix appeared normal on speculum examination. She was referred for colposcopy, and biopsy diagnosed cervical cancer. Following multi-disciplinary team discussion the management plan was for combined caesarean section and radical hysterectomy at 28 weeks gestation. The caesarean section was performed under spinal anaesthetic with the hysterectomy under planned general anaesthesia. She commenced chemotherapy two weeks after giving. After 4 cycles of chemotherapy it was evident she had disease spread and she died a few months postpartum.

This woman had a speculum examination and although the cervix looked normal other features in her history prompted referral for colposcopy which was achieved in an appropriate time frame. Unfortunately, a rare type of cervical cancer, with a poor prognosis, was diagnosed. There was MDT discussion regarding management. There was thoughtful anaesthetic planning which enabled the woman to be awake for the birth of her baby.

The other woman who presented with recurrent vaginal bleeding also had an incomplete cervical smear history. She had repeated speculum examinations which described her cervix as being either normal, or having an ectropion. It was only on digital examination, during admission for induction of labour, that a firm cervical mass was identified.

The third woman, where again digital examination raised the initial suspicion of a cervical lesion, was referred for colposcopy after she had given birth. It was intended that she should be reviewed 2-3 weeks' postpartum. However, the examination did not take place until three months postpartum, by which time she had advanced disease. Pregnant and postpartum women should be managed according to the standard two-week pathway for a suspected cancer diagnosis; if necessary, this must be ensured by direct telephone contact with the colposcopy department.

**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.**

**Green-top guideline 63: Antepartum haemorrhage (Royal College of Obstetricians and Gynaecologists 2011)**

**Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for women if, on examination, the appearance of their cervix is consistent with cervical cancer.**

**NICE NG12 Suspected cancer – recognition and referral (National Institute for Health and Care Excellence 2015)**

## Point of care tests

A postnatal woman attended the emergency department after feeling unwell for ten days, with abdominal pain, vomiting and diarrhoea. She was noted to be jaundiced with hepatomegaly and ascites. She reported consulting her GP about a breast lump two months previously which was felt to be benign. After admission she collapsed, and a blood gas was taken which showed a metabolic acidosis. The initial focus was on the response to this; the haemoglobin of 38 g/L, also recorded on the blood gas analysis was not initially recognised. Her intra-abdominal bleed was diagnosed subsequently but she died shortly afterwards from her metastatic breast cancer.

There were a few examples, such as this, where abnormal values on point of care testing were not picked up, or results not fully explained. Assessors felt this indicated a need for these results to be presented with normal ranges and for training on full interpretation. The 2020 report highlighted a need for guidance and training on the use of point of care coagulation tests; the reviews conducted for this report suggest that the need for training on use and interpretation of point of care tests is perhaps wider. Guidance on point of care testing from the Welsh Government (Welsh Scientific Advisory Committee 2017) notes that the major risks of point of care testing are 'poor operator competence, lack of supervision, governance, failure to implement quality assurance processes, inappropriate testing by inexperienced personnel, lack of understanding on the limitations of use and uncertainty on how to act on the results. Adequate checks and balances must therefore be in place to prevent medical errors and reduce risks.'

**Produce guidance on which bedside tests should be used for assessment of coagulation, training and interpretation**

**Saving Lives, Improving Mothers' Care 2020 (Knight et al. 2020b)**

**Only Staff that have been adequately trained should carry out [point of care testing] procedures. Competency must be assessed and training and competency records maintained.**

**Welsh Scientific Advisory Committee, Policy on the Management of Point of Care Testing (POCT). What, When and How? (Welsh Scientific Advisory Committee 2017)**

## Imaging during pregnancy

There were several examples where imaging was not done, both for diagnosis and staging.

A woman in her first pregnancy initially presented to her local emergency department with a history of cough, chest pain, haemoptysis and headache in the first trimester. She had a history of mental health problems. A chest x-ray at the time showed an 'unusual' shadow. Although a CT was suggested in case of a 'non-benign' cause, the department refused to perform one due to early pregnancy. A multidisciplinary team decided she should be treated for a lower respiratory tract infection and discharged. She re-presented on four occasions with persistent symptoms. She also started to vomit with worsening headache. Several weeks after her initial presentation she had a CT scan and biopsy that confirmed lung cancer with brain metastases. She was started on palliative treatment and was seen regularly by the maternity team. She died a few weeks later.

The reluctance to use appropriate imaging led to a delay making the diagnosis by several weeks and resulted in the woman presenting on multiple occasions with worsening symptoms, some of which, such as vomiting and fatigue, were attributed to pregnancy. Her worsening headache was attributed to migraine. Although she had just been told she had a terminal illness and was unlikely to survive until fetal viability, her uncertainty about which treatment option to take was attributed to her mental health condition and she was assessed for capacity by three different psychiatrists. Once she had returned from receiving palliative radiotherapy at another hospital palliative care was involved. Follow-up by obstetrics was frequent and regular.

**Develop clear guidance on imaging in pregnancy, including for both diagnosis and staging.**

**N**

## Language and virtual consultation

An older woman had an episode of facial drooping, loss of speech and difficulty breathing intermittently over two days in the early third trimester. Her husband phoned a community midwife on call helpline and was advised that she should attend labour ward. She did not do so. There was no record of that conversation in her antenatal notes as several different forms of documentation were used at the hospital concerned. She attended for planned caesarean birth at term. Her husband described that for two weeks she had forgetfulness, headache, vomiting and tiredness. During the caesarean, she was unable to understand English; staff attributed this to nerves and spoke with her in her native language. The day after birth the woman expressed concerns that she could not speak or write some words in either English or her first language; staff thought she was confused. A psychiatric assessment occurred the next day, a psychiatric cause was excluded, and the following day an intracranial tumour was identified on MRI. Dexamethasone was commenced and neurosurgery planned, but she collapsed and died from an intracranial haemorrhage before surgery could take place.

The 2021 rapid report highlighted instances where virtual consultation in the context of language difficulties led to a lack of understanding on both sides. Difficulties due to language were evident at several points in this woman's care and the nuance that may be lost when discussing symptoms in a second language must not be forgotten. The difference between reporting someone as "drowsy" versus "unrousable" is significant yet requires substantial language skill. In this instance it is unclear to what extent the severity of this woman's symptoms in the third trimester were miscommunicated, nor to what extent the need for follow-up was understood.

**Face to face treatment may be preferable when:**

- **The patient has complex clinical needs**
- **You need to examine the patient**
- **It's hard to ensure, by remote means, that patients have all the information they want and need about treatment options.**

**GMC guidance on remote consultations (General Medical Council 2021)**

## Continuity of carer

Continuity of carer is important to allow identification of changes in women's wellbeing, use of language and physical appearance. During the antenatal period, nine different staff reviewed this woman. In the postnatal period before her collapse 41 staff were involved in her care, a lead consultant was not identified and there was no sense of responsibility, which made it hard for the family to know who to talk with.

## Mental health mislabelling

Changes in a woman's behaviour or loss of a second language can be signs of intracranial pathology and should not be ignored. If psychiatric concerns are raised, organic causes should be addressed in conjunction with psychiatric review, rather than after.

## Effective medical records

There should be an effective way to ensure that all communications between the woman and healthcare professionals during her pregnancy are recorded and readily accessible to women and staff. This woman's concerning symptoms reported via the maternity triage system were not available in her antenatal notes, and her lack of attendance was not therefore followed-up. If a variety of IT systems are used in the hospital, effective easy to use links must be developed between them. When women do not attend for expected visits, these must be followed up.

## Timing of birth

A non-English-speaking multiparous woman had an unplanned pregnancy one year after mastectomy and breast reconstruction for a high-grade breast cancer; she declined chemotherapy. Due to the risk of her contraceptive implant increasing breast cancer recurrence it was removed, she declined alternative contraceptive options. In mid-pregnancy she had local recurrence and started chemotherapy. Birth was planned for 34 weeks' gestation, following which she underwent mastectomy, radiotherapy and further chemotherapy. She died a few months after birth from her metastatic disease.

As noted above, reliable and acceptable contraception must be made available to women having treatment for breast cancer, it is the responsibility of all health care providers involved in their care to ensure that this happens, and clear pathways should be arranged locally. When women have English as a second language, there must be opportunities to discuss management in their first language, to ensure there is complete understanding. This should be with a professional translator unless a member of the team is fluent in that language.

As these reports have previously emphasised, timing of birth should be considered by a multidisciplinary team, as often it is in the woman and the baby's best interests to continue until term or close by. Regions should develop local pathways to ensure that professionals with obstetric and obstetric medicine expertise are present within every multidisciplinary team for pregnant women with cancer.

**In general, for women with breast cancer, early delivery to avoid delays in chemotherapy should not be recommended. For women diagnosed with breast cancer in the third trimester, the risk-benefit is likely to favour both mother and baby if a woman can receive at least two cycles of chemotherapy prior to a term (39-40 week) birth.**

**Saving Lives, Improving Mothers' Care 2019 (Knight et al. 2019)**

**The birth of the baby should be timed after discussion with the woman and the multidisciplinary team. Most women can go to full term of pregnancy and have a normal or induced delivery.**

**GTG 12 Pregnancy and breast cancer (Royal College of Obstetricians and Gynaecologists 2015a)**

## Postnatal follow-up

A woman complained of backache in the early third trimester, but this was not investigated. She also had abnormal liver function tests for which a cause was not attributed and postnatal follow up was not arranged. Six months postpartum she presented to the emergency department with vomiting and backache. Hepatomegaly was detected and imaging arranged. Metastatic adenocarcinoma of the lung with spine and liver metastases was diagnosed and she died shortly afterwards.

When abnormal blood results occur in pregnancy it is essential that after birth there is a reliable process to ensure that either they have resolved or that on-going investigations are performed. Postnatal follow-up of this woman's pain and/or her abnormal blood results might have allowed for earlier diagnosis and treatment of her cancer.

**Ensure symptoms of possible cancer are followed up postnatally. If they do not resolve, they are unlikely to be due to pregnancy.** N

## 5.5 Conclusions

While improvements in care which may have made a difference to outcome were only identified for 8 women (10%) with cancer, improvements in care were identified for three quarters of women overall (Table 5.2). The most frequent theme identified concerned making a diagnosis; in particular, recognising worrying symptoms and avoiding normalisation bias. Follow-up, notably postnatally, to ascertain whether symptoms resolve, is an important safety net and could help ensure earlier diagnosis and treatment. For women known to have cancer, the strongest theme was a need for early planning – ensuring appropriate contraceptive advice prior to treatment, and enabling a consultant obstetric or obstetric medicine appointment in early pregnancy to plan management. Involvement of the wider multi-disciplinary maternal medical team, including in early pregnancy, will help ensure that women with cancer get the investigation and treatment they need.

These women all died prior to the SARS-CoV-2 pandemic, and yet language and virtual consultation, a pertinent theme in the context of the pandemic, was identified as an area where care could be improved. Given the likelihood of delayed presentation, delayed diagnosis and delayed treatment as a consequence of the pandemic, these messages for the care of women with cancer before, during and after pregnancy are especially important.

**Table 5.2: Classification of care received by women who died from cancer and for whom case notes were available for an in-depth review, UK and Ireland, 2017-19**

Classification of care received	Women who died from cancer Number (%) N=80*
Good care	21 (26)
Improvements to care which would have made no difference to outcome	51 (64)
Improvements to care which may have made a difference to outcome	8 (10)

\*Insufficient information to assess care for 9 women who died between 6 weeks and a year after the end of pregnancy

# 6. Messages for the prevention and treatment of thromboembolism

Marian Knight, Amanda Bellis, Arlene Wise, Sebastian Lucas and Catherine Nelson-Piercy on behalf of the MBRRACE-UK thromboembolism chapter-writing group

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## 6.1 Key messages

### New recommendations

Develop a mechanism to ensure all VTE risk assessment tools used for pregnant and postpartum women are consistent with national guidance **[ACTION: NHSE/I and equivalents in the devolved nations and Ireland]**.

Develop guidance on reweighing women at 28 weeks and postpartum to more accurately determine their VTE risk score and the appropriate prophylactic dose of LMWH if it is felt that weight gain in pregnancy may have led to either an increase in their VTE risk score or a change in the weight appropriate prophylactic LMWH dose **[ACTION: Professional Organisations]**.

Ensure that assessment of adherence to administration forms part of the antenatal or postnatal assessment of women prescribed low molecular weight heparin **[ACTION: All Health Professionals]**.

### Existing recommendations requiring improved implementation

Original source in brackets

Women with previous VTE should be offered pre-pregnancy counselling and a prospective management plan for thromboprophylaxis in pregnancy made. Those who become pregnant before receiving such counselling should be referred at the earliest opportunity in pregnancy to a clinician with expertise in thrombosis in pregnancy [Green-top guideline 37a] **[ACTION: All Health Professionals]**.

Consider all long-distance (more than four hours) travel (not exclusively by air) to be a risk factor for venous thromboembolism in pregnancy [Green-top guideline 37a] **[ACTION: All Health Professionals]**.

There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply consistently in practice. There is a need for development of a tool to make the current risk assessment system simpler and more reproducible [Saving Lives, Improving Mothers' Care 2018] **[ACTION: NHSE/I and equivalents in the devolved nations and Ireland]**.

Ensure that women on prophylactic and treatment dose anticoagulation have a structured management plan to guide practitioners during the antenatal, intrapartum and post-natal period [Saving Lives, Improving Mothers' Care 2020] **[ACTION: Hospitals/Trusts/Health Boards]**.

Ensure that a consultant reviews and prioritises women prescribed prophylactic and treatment dose anticoagulation waiting for induction of labour in order to reduce the time women are not receiving low molecular weight heparin [Saving Lives, Improving Mothers' Care 2020] **[ACTION: Hospitals/Trusts/Health Boards]**.

It is recommended that anticoagulation with unfractionated heparin, including a weight-adjusted bolus injection, be initiated without delay in patients with high-risk pulmonary embolism. Systemic thrombolytic therapy is recommended for high-risk pulmonary embolism [2019 ESC Guidelines for the diagnosis and management of acute pulmonary embolism] **[ACTION: All Health Professionals]**.

## 6.2 Background

These reports have noted before the high proportion of women who die during or after pregnancy who are overweight or obese. Overweight or obesity is an important risk factor for venous thromboembolism, with studies suggesting that a BMI of 30kg/m<sup>2</sup> or greater is associated with at least a four-fold increase in odds of venous thromboembolism, and a BMI of 25-29kg/m<sup>2</sup> with around a 1.5-2 fold increase. The National Maternity and Perinatal Audit (NMPA) report noted that in 2016/17 for the first time, more than half (50.4%) of women with a recorded BMI at booking were overweight or obese, up from 47.3% in 2015/16 (NMPA Project Team 2019). Although there are no more recent NMPA data, it is to be anticipated that this trend has continued, thus emphasising the importance of the messages in this chapter for prevention of morbidity and mortality in our current maternity population.

## 6.3 The women who died

Thirty-two women died in the UK and Ireland from venous thromboembolism during or up to a year after the end of pregnancy, 31 of whom died from pulmonary embolism (PE) and one from a cerebral venous sinus thrombosis. Twenty-one women died during or up to six weeks after the end of pregnancy, among an estimated 2,352,291 women giving birth, a maternal mortality rate of 0.89 per 100,000 maternities in the UK and Ireland (95% CI 0.55-1.36 per 100,000 maternities). The decrease in the UK mortality rate compared to the 2014-16 triennium is not statistically significant (0.92 deaths per 100,000 maternities compared to 1.39 per 100,000, RR 0.66, 95% CI 0.38-1.15, p=0.14) (Chapter 2).

Seven women were undelivered at the time of their death, three of whom were in the first trimester and four in the second.

Of particular note among the women who died from venous thromboembolism was the relatively high proportion of young, obese women. Eight of the women who died (25%) were aged under 25 years, and five of these women (63%) had a BMI of 40kg/m<sup>2</sup> or greater. This emphasises the ongoing importance of early public health efforts to prevent overweight and obesity.

Overall, 23 of the women who died (72%) were overweight or obese on the basis of their first recorded weight in pregnancy, 19 (59%) had a BMI of 30kg/m<sup>2</sup> or greater, 15 (47%) had a BMI of 35kg/m<sup>2</sup> or greater, 12 (38%) had a BMI of 40kg/m<sup>2</sup> or greater and 5 (16%) had a BMI of 45kg/m<sup>2</sup> or greater.

## 6.4 Overview of care and lessons to be learned

### Pre-pregnancy counselling

A woman in her first pregnancy with a history of a previous unprovoked DVT was seen by her GP in the first trimester with a threatened miscarriage. She reported that she was short of breath on exertion. She had a tachycardia, though a PE was not considered likely by the GP. She was subsequently referred to the early pregnancy unit where she was seen twice. She additionally attended the emergency department. Three weeks after her last visit she collapsed at home and despite thrombolysis she died from her massive pulmonary embolism.

In spite of this woman's history of DVT, thromboprophylaxis was not considered by her GP, early pregnancy unit or emergency department staff. Low molecular weight heparin would have been indicated from early pregnancy. It is possible that her shortness of breath and tachycardia when she was first seen were due to a PE. Although the GP considered this diagnosis no further assessment was made. There is no evidence that the woman had any awareness that she should receive thromboprophylaxis in pregnancy, nor that pre-pregnancy counselling was offered. Implications for future pregnancy should always be considered for young women being treated for any medical condition and they should be advised pre-emptively and appropriately. It is important to note that if women become pregnant before receiving such advice they should be offered thromboprophylaxis as soon as practicable from the time of identification of the risk – including early in the first trimester if guidance indicates.

**Women with previous VTE should be offered pre-pregnancy counselling and a prospective management plan for thromboprophylaxis in pregnancy made. Those who become pregnant before receiving such counselling should be referred at the earliest opportunity in pregnancy to a clinician with expertise in thrombosis in pregnancy.**

**Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015b)**

## Risk is dynamic

### Reassessment of risk

As has been noted in the mental health chapter, women's risks, before, during and after pregnancy, are not static. Periods of increased risk of VTE occur during and after pregnancy, which underpins recommendations to reassess VTE risk at every opportunity. Several women had episodes, such as hospital admission, concurrent gastrointestinal infections when they became dehydrated, or periods of immobility, when their risk of VTE was raised. This risk was either not recognised, because reassessment was not carried out, or not acted on.

An older woman with extreme obesity and a history of mental health problems was admitted for inpatient mental health care in mid-pregnancy. No VTE assessment was performed. She gave birth at term and was prescribed thromboprophylaxis for seven days. She had several admissions for mental health care postnatally but did not receive any further thromboprophylaxis. She collapsed and died from a pulmonary embolism while an inpatient in a mental health unit.

Assessment of VTE risk is equally important when pregnant and postpartum women are admitted to mental health settings. At the time of her admission for mental health concerns antenatally, this woman should have received thromboprophylaxis, which should have continued for the remainder of her pregnancy. Similarly, because the risk of VTE is even higher postnatally reassessment of risk, particularly when women are (re)admitted, whether for physical or mental health concerns, is imperative. Assessment of VTE risk is an expected standard for any hospital admission, being captured as part of a care quality assessment, and therefore mechanisms to ensure this assessment is undertaken are required to be robust. This applies to all healthcare settings in secondary care (maternity, surgical, medical) and mental health hospitals.

**All women should undergo a documented assessment of risk factors for VTE 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.**

**Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015b)**

### Long-haul travel

Two women died from pulmonary embolism after lengthy car journeys to continental Europe. The significance of these journeys was not recognised when these women presented with breathlessness; in one woman this may have been due to inadequate interpretation services. It is important to remember that risk increases with long periods of immobility due to long-distance car travel as well as air travel.

**Consider all long-distance (more than four hours) travel (not exclusively by air) to be a risk factor for venous thromboembolism in pregnancy**

**Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015b)**

### Variation in electronic systems of risk scoring

Assessors observed wide variation in the tools used to document VTE risk, some of which did not reflect national guidance and therefore risk was assessed incorrectly. A recommendation made previously in these reports was the need for a tool to make risk scoring consistent. This review again emphasises that not only is a tool required, but that there is a need to ensure the tool is consistent across all systems and routes of use (paper or electronic).

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

**Saving Lives, Improving Mothers' Care 2018 (Knight et al. 2018)**

## Crossing boundaries

A young woman had a booking BMI of 45kg/m<sup>2</sup> and a booking weight of 125kg. In the late second trimester she complained of chest pain. She underwent a CTPA and a pulmonary embolism was excluded. She was given the correct dose of LMWH until PE was excluded. A few weeks later she presented with a second episode of chest pain and a heart rate of 130 bpm. A PE was excluded on the basis of a normal echocardiogram and the fact a venous thromboembolism was excluded weeks earlier. She had a third presentation of chest pain during the antenatal period. She gave birth at term and was discharged on LMWH, dose calculated on the basis of her booking weight. She collapsed and died from a pulmonary embolism a week later after a two day history of chest pain and breathlessness.

**Doses of LMWH are based on weight. For thromboprophylaxis the booking or most recent weight can be used to guide dosing**

**Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015b)**

**Box 6.1: Suggested thromboprophylactic and treatment doses for antenatal and postnatal LMWH (Adapted (Royal College of Obstetricians and Gynaecologists 2015b, National Institute for Health and Care Excellence 2020a))**

	Enoxaparin	Dalteparin	Tinzaparin
Standard prophylactic dose			
<i>Weight &lt; 50 kg</i>	20 mg daily	2500 units daily	3500 units daily
<i>Weight 50–90 kg</i>	40 mg daily	5000 units daily	4500 units daily
<i>Weight 91–130 kg</i>	60 mg daily*	7500 units daily	7000 units daily*
<i>Weight 131–170 kg</i>	80 mg daily*	10 000 units daily	9000 units daily*
<i>Weight &gt; 170 kg</i>	0.6 mg/kg/day*	75 u/kg/day	75 u/kg/day*
High prophylactic dose			
<i>Weight 50–90 kg</i>	40 mg 12 hourly	5000 units 12 hourly	4500 units 12 hourly
Treatment dose			
<i>Calculated by weight</i>	1 mg/kg/day in 2 divided doses	200 u/kg/day in 2 divided doses	175 u/kg once daily
*may be given in 2 divided doses			

There is no evidence to guide dosing of LMWH in obese pregnant and postpartum women, but suggested doses are given in RCOG guidelines (Royal College of Obstetricians and Gynaecologists 2015b) (Box 6.1). However, when women's weights are close to thresholds at booking, reweighing may be appropriate if it is likely, as in this woman, that weight gain would have led to a change in dosage regimen. In this instance, a 6kg weight gain would have led to a different prophylactic dose. Since RCOG guidelines recommend prophylaxis from the first trimester, at 28 weeks or postpartum, dependent on risk factors, assessment of weight at these timepoints for women who are close to thresholds will help ensure correct doses are prescribed.

**Develop guidance on reweighing women at 28 weeks and postpartum to more accurately determine their VTE risk score and the appropriate prophylactic dose of LMWH if it is felt that weight gain in pregnancy may have led to either an increase in their VTE risk score or a change in the weight appropriate prophylactic LMWH dose (Box 6.1)** N

It was additionally unclear whether this woman administered LMWH after her discharge from hospital. Assessors noted that several women were likely to have been omitting their LMWH partially or completely, and it is important that women's adherence with administration is taken into account in any assessment.

## Gaps in thromboprophylaxis around labour and birth

A woman with learning difficulties and known risk factors for thromboembolism received appropriate antenatal thromboprophylaxis. She was admitted for induction of labour and her thromboprophylaxis was omitted. Induction was delayed and she eventually had a caesarean birth. Although she received postnatal thromboprophylaxis in a timely manner this was 60 hours after her previous dose. She was well supported by community teams to administer LMWH postnatally but collapsed and died of a pulmonary embolism two weeks after discharge. Post-mortem examination revealed a large pelvic vein thrombosis which histology suggested had probably originated around the time she gave birth.

Assessors felt that this woman had been well supported both antenatally and postnatally to receive thromboprophylaxis, though the time between admission and giving birth without receiving her thromboprophylaxis may well have been significant and could have been avoided with better communication. Similar gaps in thromboprophylaxis around the time of labour and birth were noted in the 2020 pulmonary embolism morbidity enquiry (Knight et al. 2020a). The importance of close liaison with obstetric anaesthesia and consultant obstetric review to minimise the time without LMWH while awaiting and undergoing induction of labour need continued emphasis. In women at high risk of VTE LMWH should not be withheld until labour is established, and discussion regarding the necessary 12 hour window prior to regional analgesia should be individualised. Consultant prioritisation of women awaiting labour induction must include consideration of the length of time women have been without thromboprophylaxis. It is also important to note that LMWH can be promptly and appropriately restarted after birth. Most women will be able to start low molecular weight heparin soon after delivery (4 hours after a spinal block or removal of an epidural catheter, after discussion with the anaesthetist).

**Ensure that women on prophylactic and treatment dose anticoagulation have a structured management plan to guide practitioners during the antenatal, intrapartum and post-natal period.**

**Ensure that a consultant reviews and prioritises women prescribed prophylactic and treatment dose anticoagulation waiting for induction of labour in order to reduce the time women are not receiving low molecular weight heparin.**

**Saving Lives, Improving Mother's Care 2020 (Knight et al. 2020a)**

## Thrombophilias and additional risk

A woman with known antithrombin III deficiency was closely managed with therapeutic level anticoagulation during pregnancy. She was admitted for an elective caesarean birth at term, which was delayed. She had no fluid for almost 24 hours and no low molecular weight heparin for 48 hours peri section. She was discharged with two weeks of prophylactic dose low molecular weight heparin with a plan for her to return to hospital to collect a further two weeks' supply, and to continue for six weeks postnatally. She complained of breathlessness going upstairs and pain in her leg for a few days before she collapsed with a cardiac arrest from which she could not be resuscitated. Her postmortem examination indicated that the DVT underlying her pulmonary embolism dated from around the time she had given birth.

This woman was a very high risk for VTE and this was closely managed antenatally but she received less support postnatally. As with the previous woman's death, gaps in anticoagulation around the time of birth were an issue (she had no LMWH for 48 hours at her time of greatest risk), additionally, in this instance, compounded by confusion over the postnatal LMWH dose, and the requirement for her to return to the hospital to collect additional supplies. It is unclear whether she did receive additional supplies. She could have been managed with anti-thrombin III concentrate around the time of caesarean section to reduce her risk.

It is also possible that due to the woman's age, social circumstances and a new baby, her adherence with injections diminished to a point that she was no longer protected. She had been warned about red flag symptoms but did not appear to seek help when these apparently did happen. The local investigation of this woman's death noted

the difficulties in ensuring injectable medicine is given appropriately in the community and raised the question of whether a community based service for this and/or more and closer postpartum management of high risk women would be valuable.

**Women with previous VTE associated with antithrombin deficiency (who will often be on long-term oral anticoagulation) should be offered thromboprophylaxis with higher dose LMWH (either 50%, 75% or full treatment dose) (see Appendix IV) antenatally and for 6 weeks postpartum or until returned to oral anticoagulant therapy after delivery.**

**Management should be undertaken in collaboration with a haematologist with expertise in thrombosis in pregnancy and consideration given to antenatal anti-Xa monitoring and the potential for antithrombin replacement at initiation of labour or prior to caesarean section.**

**Green-top guideline 37a (Royal College of Obstetricians and Gynaecologists 2015b)**

For women in whom the treatment burden of LMWH injections is great the option of warfarin postpartum should be considered, and in those who have decided not to breastfeed, direct oral anticoagulants (DOACs) which have the added advantage of not requiring blood test monitoring, could be offered as an alternative to injections.

## Postnatal thromboprophylaxis supply

A woman known to be at high risk of venous thromboembolism booked late but was nevertheless seen in a joint obstetric/haematology clinic and prescribed appropriate thromboprophylaxis. She was given an immediate supply. However, the clinic letter asking the GP to prescribe further doses was not sent electronically until nearly two months later, after the woman had given birth. She was prescribed postnatal thromboprophylaxis for six weeks, but it was not available to her at the time of discharge and she did not return to collect it. She did request low molecular weight heparin from her GP but that was also not collected. She died three weeks later from a pulmonary embolism.

There were communication issues throughout this woman's care which added to her risk. There were delays in communication between secondary and primary care, but also between the hospital and community midwifery staff. Her social circumstances would have made it very difficult to return to hospital to collect her prescription, but it is not clear her midwife was aware LMWH had been prescribed and therefore to check whether it had been administered. These enquiries have emphasised before the importance of women receiving a full postnatal course of LMWH on discharge from hospital (Knight et al. 2015), and it was reassuring that this did occur in many instances, however, it is insufficient to ensure that LMWH is prescribed; it must also be dispensed and handed to the woman at the time of discharge. Furthermore, once dispensed, it is good practice for community midwives to check that the woman is actually administering the injections, understands the indication and is reminded of the red flags for VTE.

**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.**

**Saving Lives, Improving Mothers' Care 2015 (Knight et al. 2015)**

## Diagnosis

### Groin pain

A woman presented to her GP with groin pain in the second trimester of pregnancy, which was assumed to be musculoskeletal in origin. Two weeks later she collapsed and died from her PE despite thrombolysis and a timely perimortem caesarean section.

Although this woman was not noted to have any risk factors for VTE, it is important to recognise that groin pain may be a symptom of pelvic vein DVT. In cases such as this where iliac / pelvic vein thrombosis is a differential diagnosis, an ultrasound assessment may not suffice to make the diagnosis; magnetic resonance venography of the pelvic vessels is more sensitive in the diagnosis of clots above the inguinal ligament.

## Headache

A woman presented in the third trimester with symptoms and signs of pre-eclampsia including several days of headache and blurred vision. She was appropriately prescribed antenatal thromboprophylaxis. She had a caesarean birth due to worsening blood pressure. Thromboprophylaxis was withheld postnatally due to a platelet count of  $80 \times 10^{12}/L$ . Postnatally her primary complaint remained unrelenting headache with episodes of blurred vision. She collapsed and died from a cerebral venous thrombosis a few days later.

The co-existence of pre-eclampsia made diagnosis of an alternative pathology much more difficult in this woman, and cerebral venous sinus thrombosis is a rare condition with no obvious risk factors in this woman apart from her pregnancy. There were, however, as identified in the local hospital review, indications that pre-eclampsia was not the sole explanation for her headache. Headache was from the outset, the predominant symptom for this woman. It was worse than she had experienced before, relentless and unresponsive to interventions. She had symptoms of raised intracranial pressure, including a high BP, though the focus before her caesarean was on her pre-eclampsia. After giving birth the significance of her headache was not recognised in time for treatment that could have altered the course of her illness. Pre-eclampsia can be associated with intracerebral haemorrhage and even if cerebral venous sinus thrombosis was not in the differential diagnosis urgent brain imaging was indicated. Red flag headache symptoms are emphasised in the RCP Acute care Toolkit, and the importance of neurological examination in such instances must be re-emphasised.

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

**Saving Lives, Improving Mothers' Care 2015 (Knight et al. 2015)**

### **Box 6.1: Red flags in the history and examination of a pregnant patient presenting with headaches:**

- Sudden-onset headache / thunderclap or worst headache ever
- Headache that takes longer than usual to resolve or persists for more than 48 hours
- Has associated symptoms – fever, seizures, focal neurology, photophobia, diplopia
- Excessive use of opioids

**RCP Acute care toolkit 15** Managing acute medical problems in pregnancy (Royal College of Physicians 2019)

## Treatment

A young woman with a BMI of over  $50\text{kg}/\text{m}^2$  but no other known risk factors for VTE had a spontaneous labour and birth and was discharged with 10 days of thromboprophylaxis. Four weeks later she collapsed and was short of breath. She was not seen by a consultant in the emergency department for more than three hours. A CTPA within the next hour confirmed the presence of a saddle embolism, with bilateral pulmonary emboli and right heart strain. She received her first dose of LMWH two hours later but subsequently collapsed. Thrombolysis was then given but she did not survive.

This woman was clearly at high risk and haemodynamically unstable. Triage indicated she should have been reviewed within an hour, but review did not take place until three hours after admission. She had a saddle embolus which is life threatening. In pregnant women with acute PE at high or intermediate high risk of mortality (defined as haemodynamic instability, right ventricular dysfunction on CTPA or echocardiogram and / or raised biomarkers such as troponin or NT-proBNP) management should be with intravenous unfractionated heparin and consideration given to systemic or catheter directed thrombolysis.

Such decisions are difficult and mandate urgent discussion between the emergency department, haematology, cardiology, obstetrics, obstetric anaesthetics, interventional radiology and the obstetric medicine team.

**It is recommended that anticoagulation with unfractionated heparin, including a weight-adjusted bolus injection, be initiated without delay in patients with high-risk pulmonary embolism.**

**Systemic thrombolytic therapy is recommended for high-risk pulmonary embolism.**

**2019 ESC Guidelines for the diagnosis and management of acute pulmonary embolism developed in collaboration with the European Respiratory Society (ERS) (Konstantinides and Meyer 2019)**

**Collapsed, shocked women who are pregnant or in the puerperium should be assessed by a team of experienced clinicians including the on-call consultant obstetrician.**

**Women should be managed on an individual basis regarding: intravenous unfractionated heparin, thrombolytic therapy or thoracotomy and surgical embolectomy.**

**Management should involve a multidisciplinary team including senior physicians, obstetricians and radiologists.**

**Green-top guideline 37b (Royal College of Obstetricians and Gynaecologists 2015c)**

## 6.5 Pathology

In the majority of the 32 maternal deaths from thromboembolism, the autopsy made a diagnosis which was not known before. In the four cases where no autopsy was performed, all had positive diagnostic computed tomography pulmonary angiogram (CTPA) scans after a collapse, which raises the question of what the autopsy can contribute beyond identifying clots in the pulmonary arteries, and whether thrombo-histology is important.

A woman collapsed at home in the first trimester. She had a normal BMI but a past history of DVT. Peri-mortem computed tomography pulmonary angiogram showed a large pulmonary embolism, and there was no autopsy. Three weeks earlier she had complained of shortness of breath on exertion, but no actions were taken. An autopsy, with description and histology of the clots in her lung and, if present, in calf and more proximal veins, could have provided a chronology of the venous thromboembolism, and thus indicated whether the fatal thromboembolic process might have been preventable through earlier anticoagulation.

### Chronology of venous thromboembolism

In acute VTE, i.e. occurring in the minutes or hours before cardiovascular collapse, the thrombi are non-adherent to the intima of source veins and pulmonary arteries. Histologically they have a fresh appearance and there is no organisation at the intima-thrombus interfaces. Histology is also useful in confirming the presence of true antemortem thrombi versus post-mortem artefactual clot in the uncommon instances where there is doubt macroscopically.

If the VTE process is chronic, developing over days to weeks, there is organisation visible at the intima interface in the source veins. In the pulmonary arteries, if the thrombi are adherent, with histological organisation, it means that the thromboembolus arrived well before the final collapse. These issues inform on the pathogenesis of VTE and on possible opportunities for its prevention. Gross thrombus adherence information and histopathology can identify its chronology and thus when opportunities for mitigation and prevention could have occurred.

It follows that the pathologist has to decide how much information to provide in a VTE autopsy report. In the 25 available VTE autopsy reports to review, a wide range of approaches is evident. At one extreme, 'coiled thrombi' (which indicates embolism from distal veins rather than thrombus formation in situ) in a pulmonary artery was the only evidence provided. In contrast, another report noted the presence or absence of thrombi, with gross and (selected) histological description, along the whole pathogenetic venous chain: calf vein, femoral vein, pelvic and uterine vein, inferior vena cava, right atrium, right ventricle, main pulmonary artery, left/right pulmonary artery, the five lobar pulmonary arteries, and the distal lung arteries.

Whilst nearly all reports documented the location in the pulmonary arterial tree of the emboli, only one included the thrombus diameter (which indicates its anatomical venous origin) and only three noted whether or not the thrombus was adherent to the arterial intima. Surprisingly, 10/25 autopsies did not examine the calf veins (where most thrombogenesis is thought to start). Fifteen autopsies had some histology of the VTE, but only eight stated whether or not there was organisation of the thrombus. Thus in only a minority of VTE deaths was there any firm documentation that the thromboembolic process was acute or chronic.

## The pathological cause of death

As noted earlier in this chapter, obesity is emphasised as a major risk factor for VTE. It was not evident that this was widely recognised amongst pathologists. Of the 16 women whose BMI was 30kg/m<sup>2</sup> or more, obese by definition, 'obesity' featured in only 5 (31%) of documented cause of death sequences. However, pregnancy per se as a risk factor for VTE is better recognised, being mentioned in two thirds of those women who died within 50 days of delivery (in the later deaths, the thrombophilic effect of pregnancy has declined, and in many instances the pathologist would not necessarily have been informed that the woman had been pregnant).

## Recommendations for pathologists

**As best practice, in autopsies with pulmonary thromboembolism, pathologists should:**

1. **State whether the emboli are grossly adherent in the pulmonary arteries and note their diameter.**
2. **Examine the whole venous tree from calf veins to right ventricle for the presence or absence of thrombi, and document the findings (note: examining the femoral veins in the thigh is a mutilating procedure and, reasonably, is usually omitted).**
3. **Examine adherent thrombi histologically to provide a definitive chronology of the VTE process.**
4. **Take greater care in constructing the cause of death, to ensure that 'obesity' and 'pregnancy' are listed appropriately.**

## 6.6 Conclusions

Improvements in care which may have made a difference in outcome were identified for nearly three fifths of women who died from venous thromboembolism (Table 6.1). The concerning findings of this chapter, particularly regarding the deaths of young, extremely obese women with venous thromboembolism must prompt its use as part of counselling and discussion both before and during pregnancy. Whilst it is important not to stigmatise women who are overweight or obese, it is equally important to recognise the risk of fatal VTE that women with a raised BMI face. As this chapter has identified, even weight gains of a few kilogrammes in pregnancy may move women across dosing thresholds placing them at increased risk. Overweight and obese women with low weight gain are at lower risk of pregnancy complications than similar weight women with medium and high weight gain (Santos et al. 2019), although their risks still remain higher than women with a BMI in the normal range. We must ensure that we discuss restricting weight gain in pregnancy with women who are overweight and obese not only to reduce their very real risk of fatal venous thromboembolism but to ensure a reduction in a range of other pregnancy complications (Santos et al. 2019).

**Table 6.1: Classification of care received by women who died from venous thromboembolism and for whom case notes were available for an in-depth review, UK and Ireland, 2017-19**

Classification of care received	Women who died from VTE Number (%) N=31*
Good care	3 (10)
Improvements to care which would have made no difference to outcome	8 (26)
Improvements to care which may have made a difference to outcome	21 (58)

\*Insufficient records to assess for one woman

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## 8. Appendix

Responses provided by NHS England on actions taken as a result of recommendations made in the 2020 Saving Lives, Improving Mothers' Care report (received 17th July 2021)

Recommendation	Action taken (on behalf of Executive Quality Group Clinical Audit Sub-group)
<p>1. Develop guidance to ensure SUDEP awareness, risk assessment and risk minimisation is standard care for women with epilepsy before, during and after pregnancy and ensure this is embedded in pathways of care. [ACTION: Royal Colleges of Obstetricians and Gynaecologists, Physicians].</p>	<p>Held a round table meeting with relevant stakeholders (including Royal College of Obstetricians and Gynaecologists (RCOG)) to discuss the findings of this report and other national audits looking at epilepsy. This meeting generated a number of actions, including RCOG incorporating these findings into 'Epilepsy in Pregnancy' guideline.</p>
<p>2. Develop guidance to indicate the need for definitive radiological diagnosis in women who have an inconclusive VQ scan [ACTION: Royal Colleges of Physicians, Radiologists, Obstetricians and Gynaecologists].</p>	<p>Discussed internally in NHS England and NHS Improvement, and externally with Royal College of Physicians.</p> <p>Developing additional guidance in this area is not currently felt to be a priority area given:</p> <ul style="list-style-type: none"> <li>a) Relatively small numbers of cases this affects</li> <li>b) Clear NICE guidance on diagnosis and treatment of PE and RCOG Green Top guidance also in place</li> <li>c) Complexity of scanning this group and high number of clinical variables</li> <li>d) Finite resource for making guidance which is currently being prioritised elsewhere</li> </ul>
<p>3. Produce guidance on which bedside tests should be used for assessment of coagulation and the required training to perform and interpret those tests [ACTION: Royal Colleges of Anaesthetists, Obstetricians and Gynaecologists, Physicians].</p>	<p>Intercollegiate committee on haematology (RCP and RCPATH) are actively taking this forward, working with Royal College Of Anaesthetists and RCOG.</p>
<p>4. Establish a mechanism to disseminate the learning from this report, not only to maternity staff, but more widely to GPs, emergency department practitioners, physicians and surgeons [ACTION: Academy of Medical Royal Colleges].</p>	<p>Wrote to the Academy of Medical Royal Colleges. Summary report disseminated to members with an ask for Royal Colleges to summarise their learning from the report.</p>
<p>5. Develop clear standards of care for joint maternity and neurology services, which allow for: early referral in pregnancy, particularly if pregnancy is unplanned, to optimise anti-epileptic drug regimens; rapid referral for neurology review if women have worsening epilepsy symptoms; pathways for immediate advice for junior staff out of hours; postnatal review to ensure anti-epileptic drug doses are appropriately adjusted [ACTION: NHSE/I and equivalents in the devolved nations and Ireland]</p>	<p>Discussed at recent epilepsy round table meeting - Development of maternal medicine networks is hoped to address many of these issues relating to maternity services. These networks will be contiguous with integrated care systems and aim to co-ordinate the care of pregnant women across the system rather than individual trusts.</p>



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ISBN: 978-1-8383678-9-3

