

Maternal, Newborn and Infant Clinical Outcome Review Programme



Saving Lives, Improving Mothers' Care

Core report: lessons learned to inform maternity care
from the UK and Ireland Confidential Enquiries into
Maternal Deaths and Morbidity 2017-19



November 2021

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Full report available at

www.npeu.ox.ac.uk/mbrance-uk/reports

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November 2021

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Foreword

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

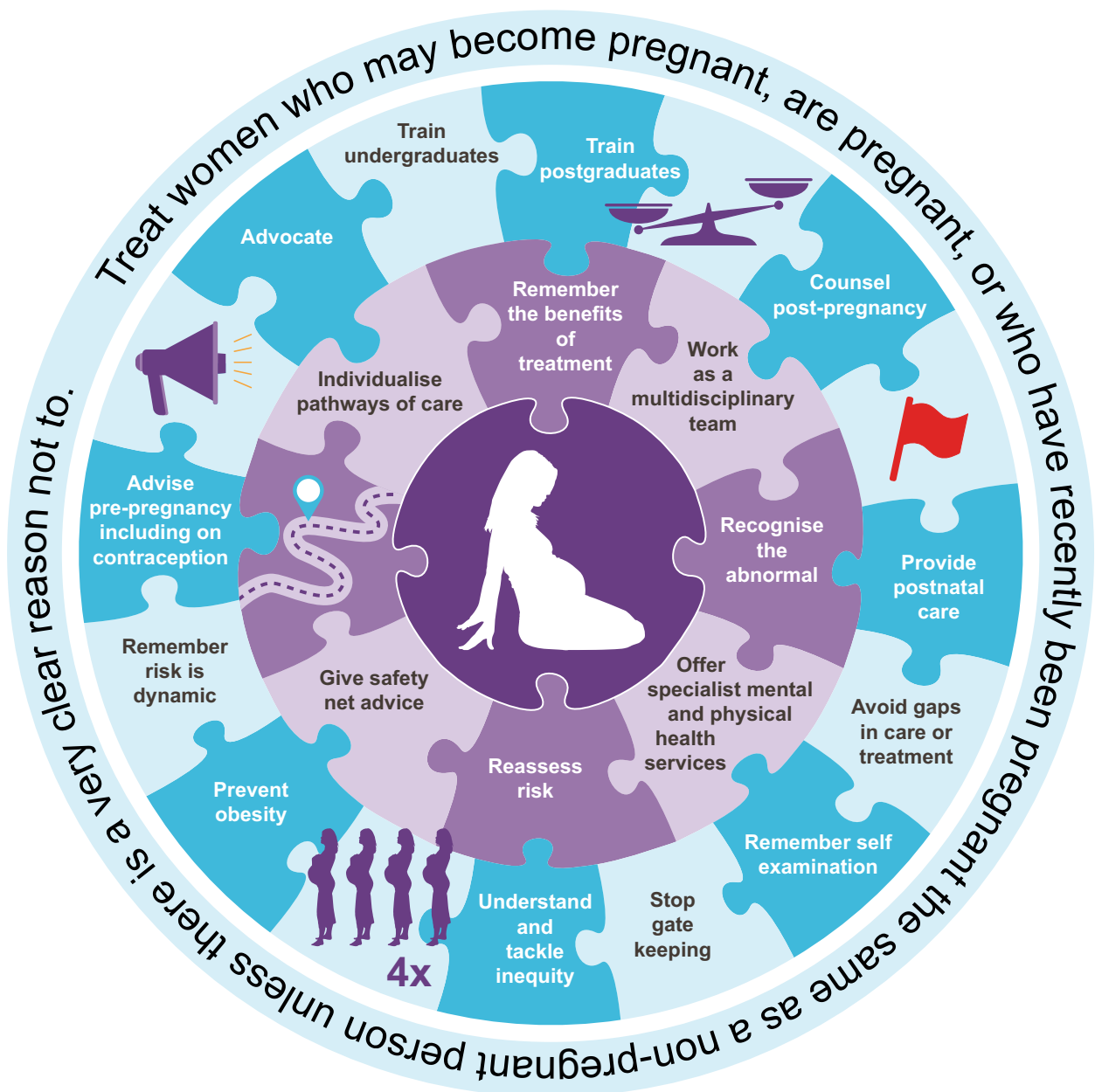


Key messages from the report 2021

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

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**

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

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 here.

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]**.

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

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.

Complete acknowledgments are included in the full report available at www.npeu.ox.ac.uk/mbrrace-uk/reports.

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**

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.

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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.

1.2 Topics covered in MBRRACE-UK maternal reports 2014-20

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: and includes 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.

1.3 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/assets/downloads/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, noting that more than 1500 women aged 45 and over give birth in the UK each year, 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.

Note that this core report presents only the evidence underpinning new recommendations for care. More in depth analysis is available at www.npeu.ox.ac.uk/mbrance-uk/reports.

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

Kathryn Bunch and Marian Knight

Note that more in-depth analysis is available at: www.npeu.ox.ac.uk/mbrance-uk/reports.

All supplementary table references refer to tables in the full report.

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.

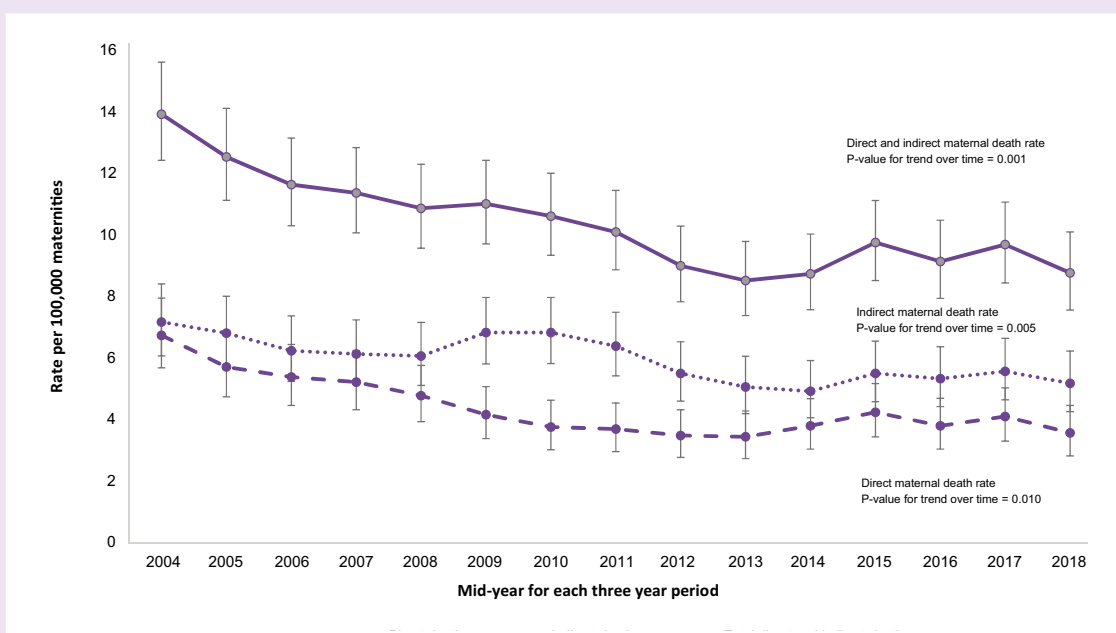
Maternal suicide remains the leading cause of direct deaths occurring within a year after the end of pregnancy.

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, $p=0.314$).

Figure 2.1 (Table S2.1) shows 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, $p=0.009$).

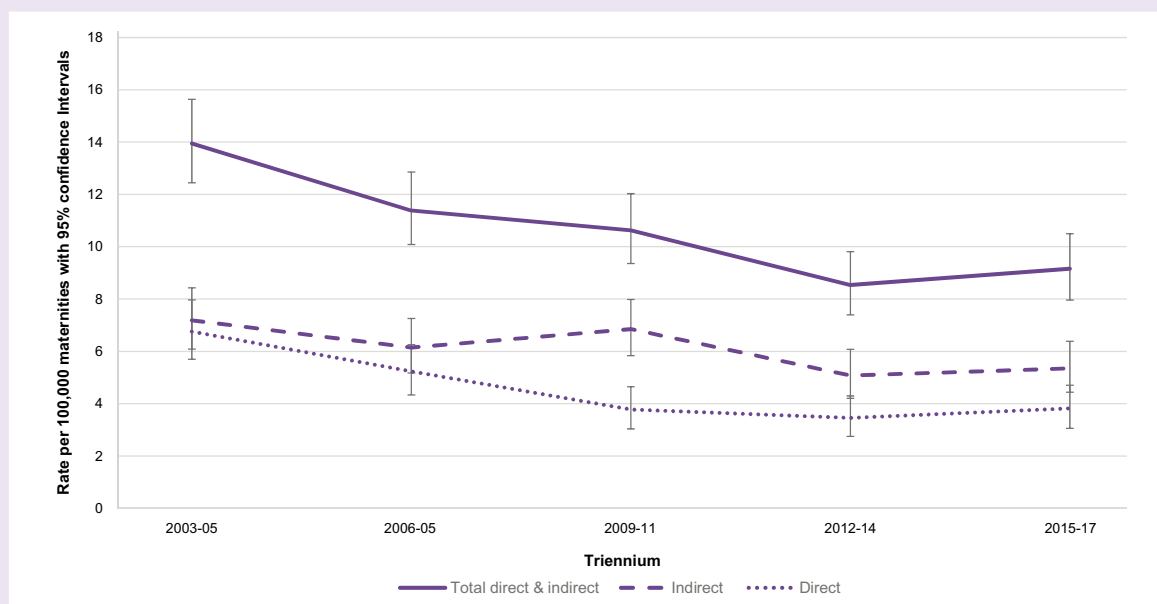
Figure 2.1: Direct and indirect maternal mortality rates per 100,000 maternities using ICD-MM and previous UK classification systems; three-year rolling average rates 2003-2019



Sources: CMACE, MBRRACE-UK

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). Triennial rates are shown in Figure 2.2 (Table S2.2).

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

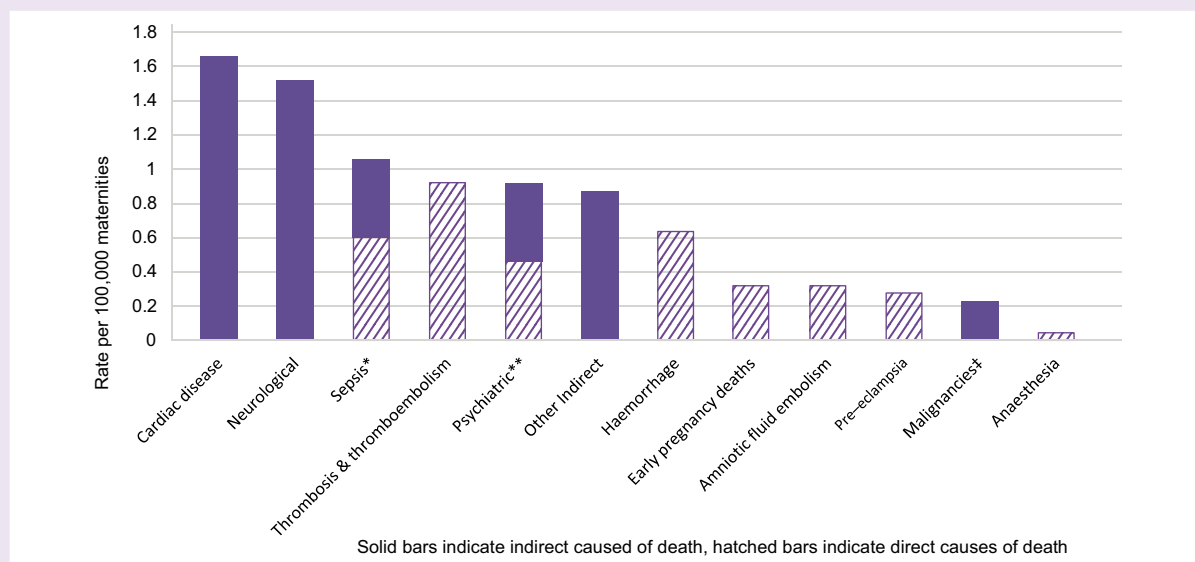


Sources: CMACE, MBRRACE-UK

Deaths due to individual causes

Maternal deaths by cause are shown in Figure 2.3 (Tables S2.3 and S2.4) and according to ICD-MM sub-groups are presented in Figure 2.4 (Table S2.5).

Figure 2.3: Maternal mortality by cause 2017-19



Hatched bars show direct causes of death, solid bars indicate indirect causes of death;

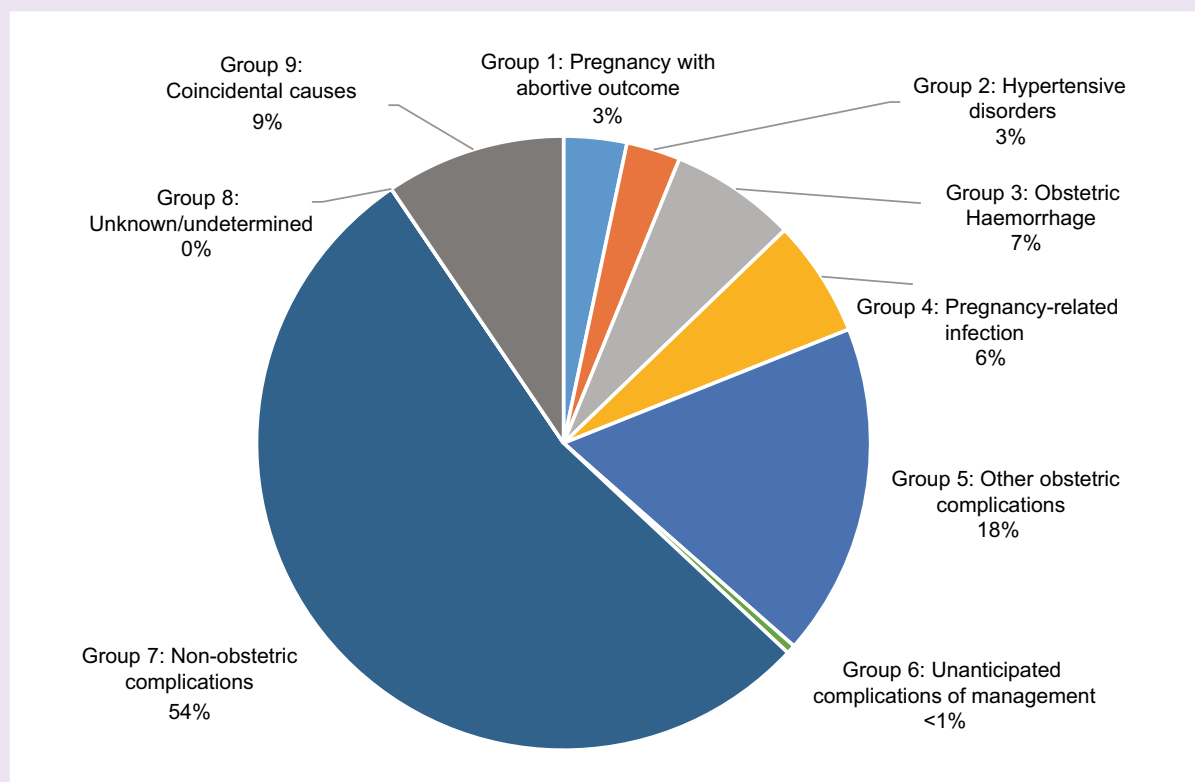
*Rate for direct sepsis (genital tract sepsis and other pregnancy related infections) is shown in hatched and rate for indirect sepsis (influenza, pneumonia, others) in solid bar

**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

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



International comparison

For international comparison, the rate estimate from routine sources of data is much lower (4.10 per 100,000 live-births, 95% CI 3.32-5.01, for 2015-17, Table S2.6) than the actual rates as identified through the UK CEMD, which uses multiple sources of death identification.

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). Rolling rates of late deaths are shown in Figure 2.5 and causes of late death in Figure 2.6.

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

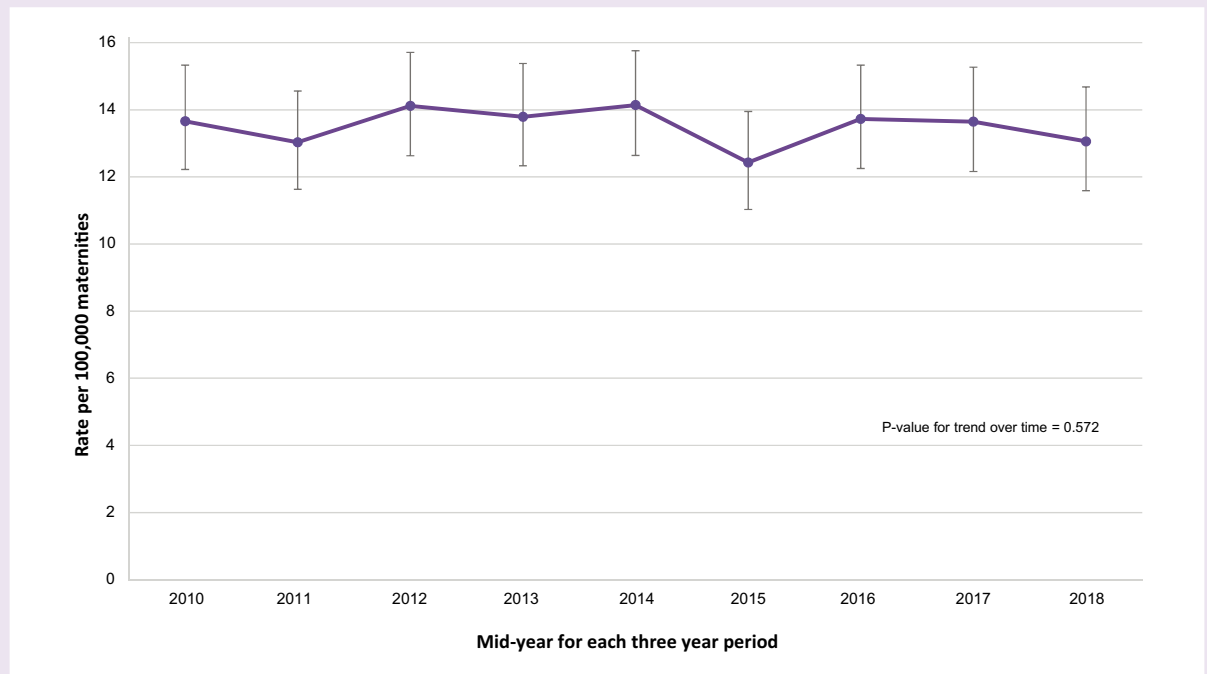
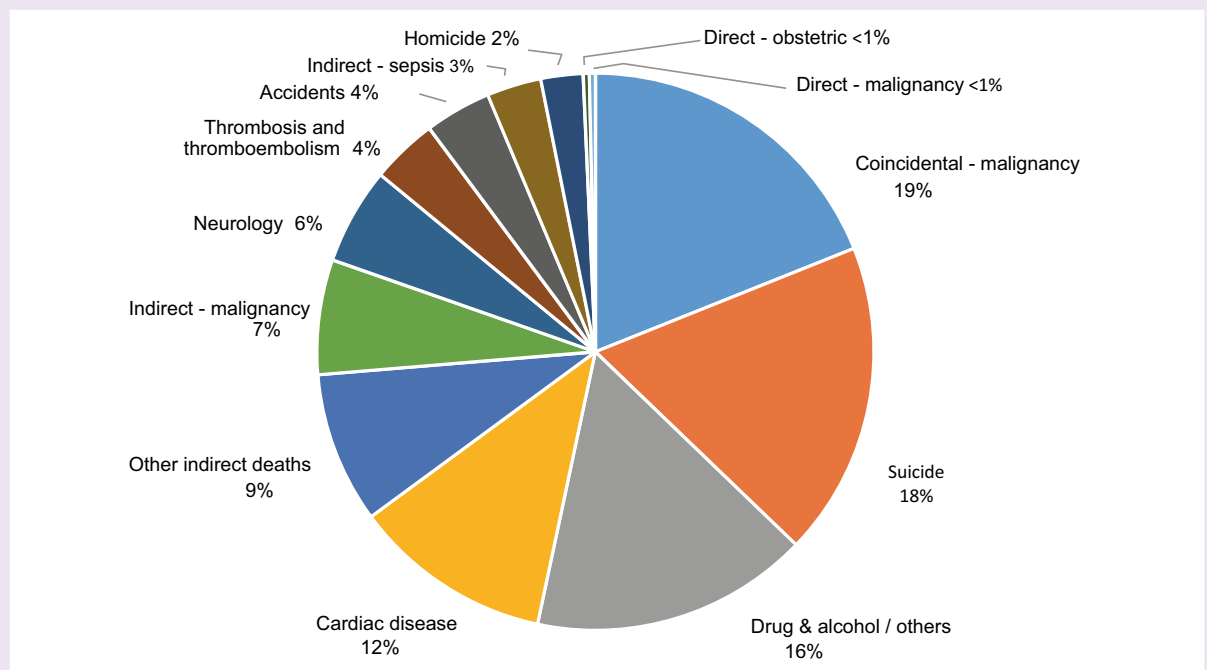


Figure 2.6: Causes of death amongst women who died between six weeks and one year after the end of pregnancy, UK 2017-19



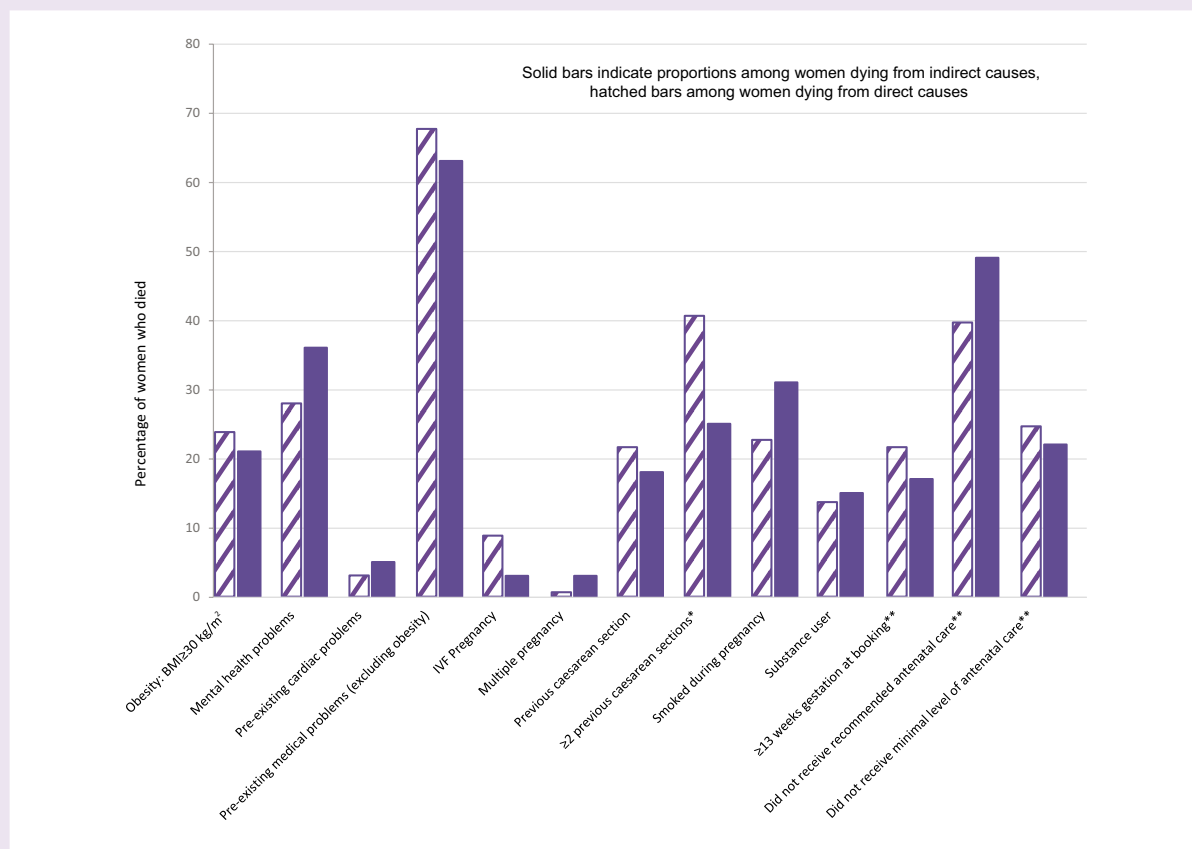
2.3 The characteristics of women who died 2017-19

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 ≤ 20 weeks' gestation (Table S2.7). 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 S2.8).

Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2017-19 are shown in Figure 2.7 (Tables S2.9-S2.16).

Figure 2.7: Selected characteristics of women who died from direct or indirect causes 2017-19



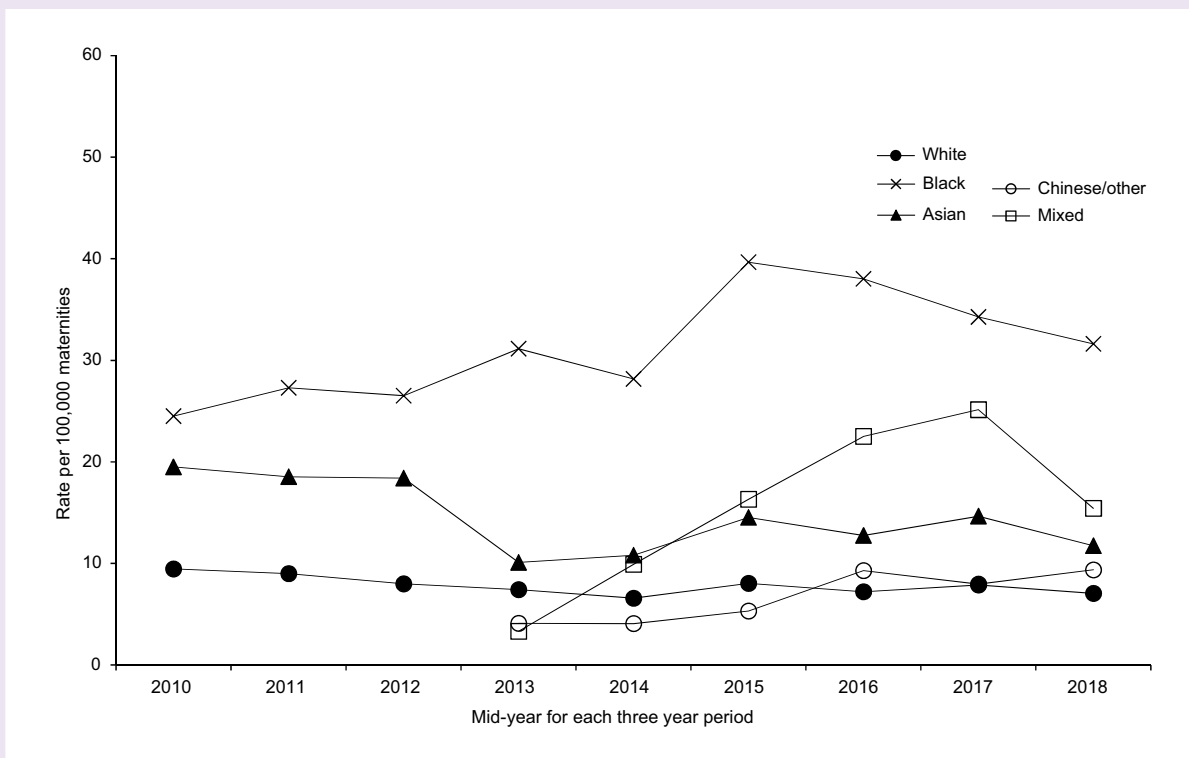
*Amongst women who had a previous caesarean birth

**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.

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 2.9). 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) (Figure 2.8). 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.

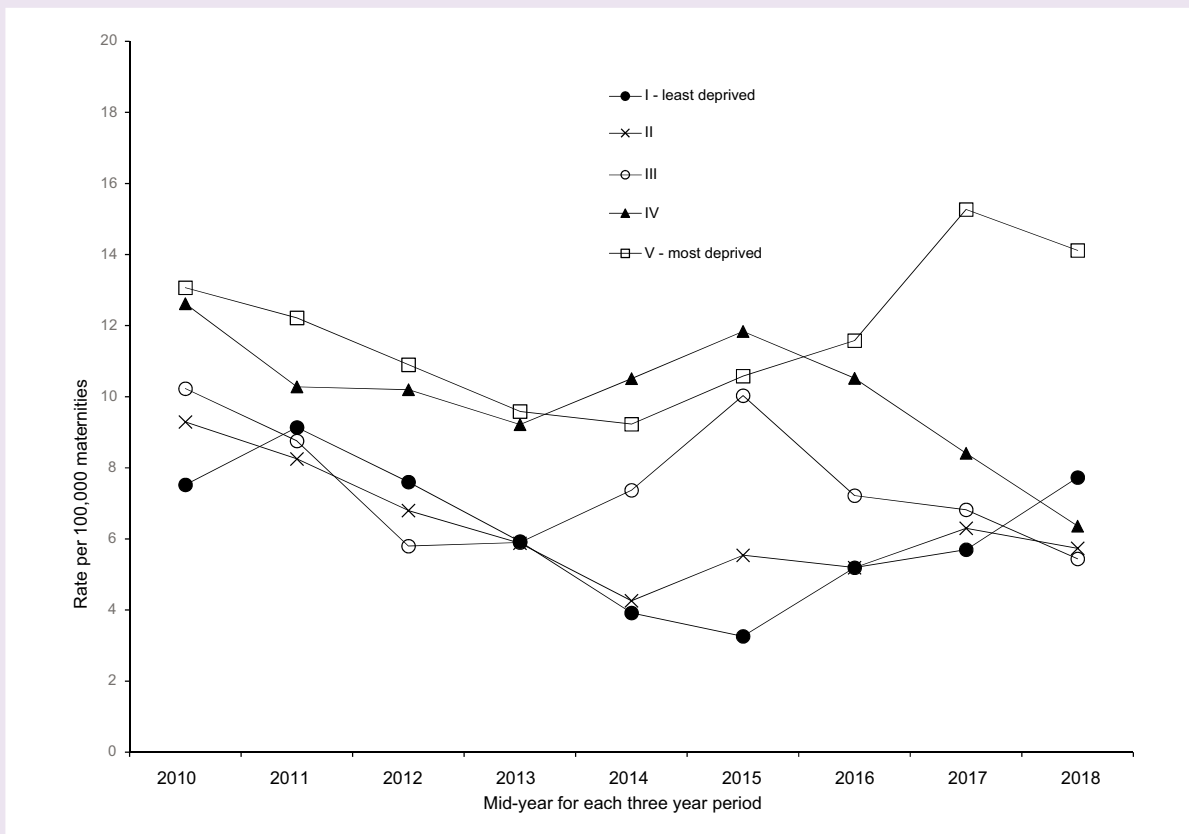
It is important to note (Figure 2.8) that the absolute maternal mortality rate amongst women from Black ethnic backgrounds has not increased; although there has not been a statistically significant decrease and the disparity remains wide.

Figure 2.8: Maternal mortality rates 2009-19 among women from different ethnic groups in England*



*Data for England only due to availability of denominator data

Figure 2.9: 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

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 (Table S2.17) 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. 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% (Figure 2.11, Table S2.17).

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)

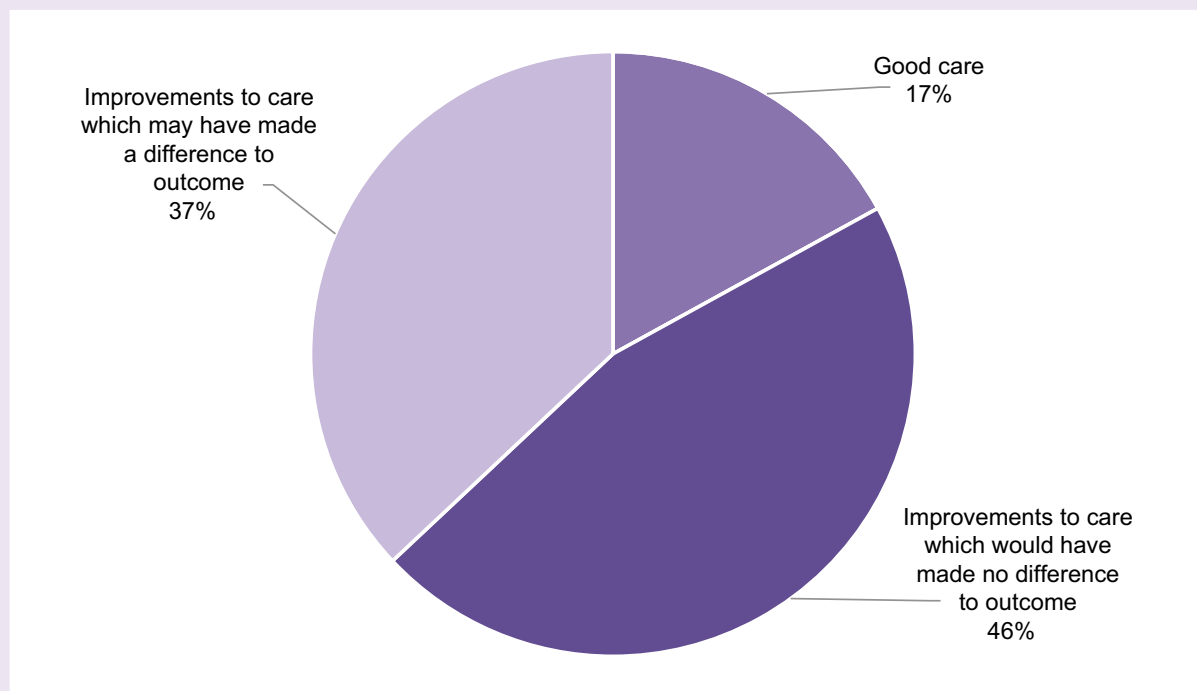
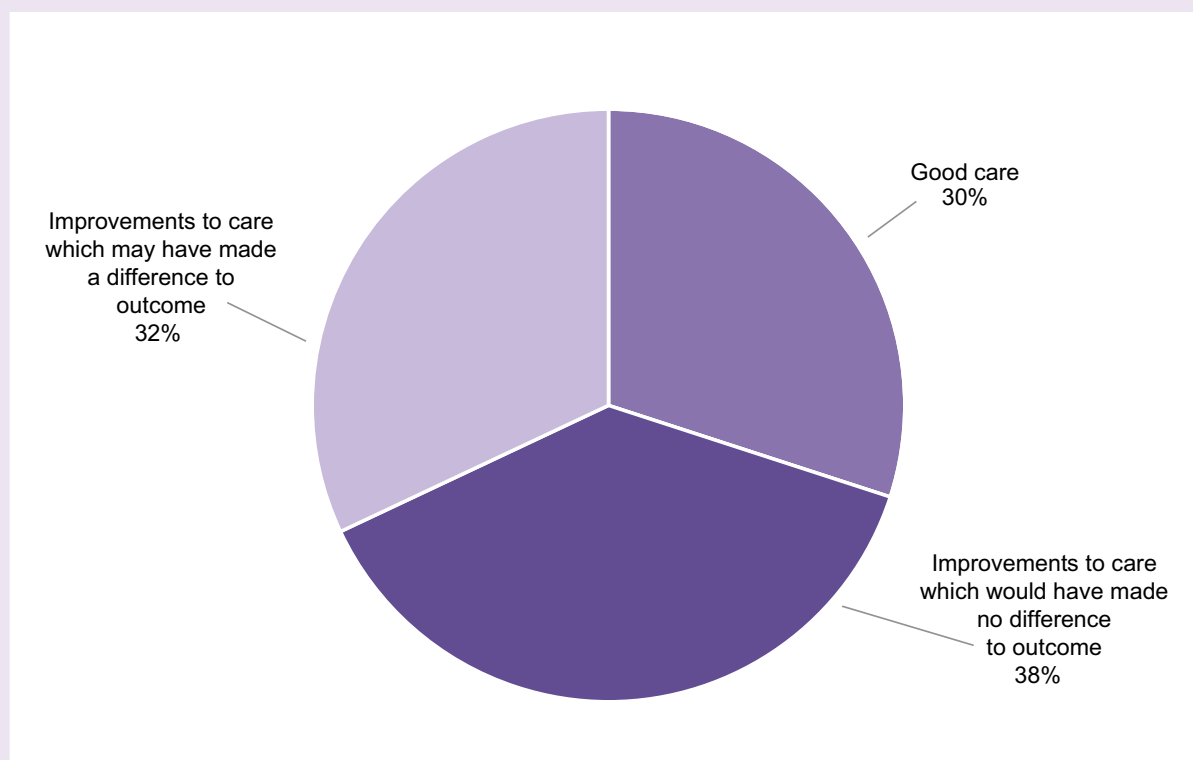


Figure 2.11: Classification of care received by women aged 45 years of age or older included in the morbidity enquiry, UK and Ireland (2017-19)



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 1.3, 37 of these women who survived were included in the morbidity Confidential Enquiry.

3. 2021 Maternal morbidity enquiry: core 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

Note that more in-depth analysis is available at: www.npeu.ox.ac.uk/mbrrace-uk/reports.

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]**.

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.

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 birth data. 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. 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%). 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.

3.4 Overview of care and new 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.

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. 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.

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

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. 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.

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

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 32% of women (12/37) 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.

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.

Note that more in-depth analysis is available at: www.npeu.ox.ac.uk/mbrrace-uk/reports.

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]**.

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. 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).

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).

Pregnancy or postnatal loss

Twenty-three women who died by suicide (37%) had experienced loss of some kind related to the pregnancy or infant. 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.

As in previous reports, the majority of women who died by suicide, died violently. 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, pentobarbital, quetiapine and tramadol. A number of women took multiple substances and alcohol was a factor for some women.

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

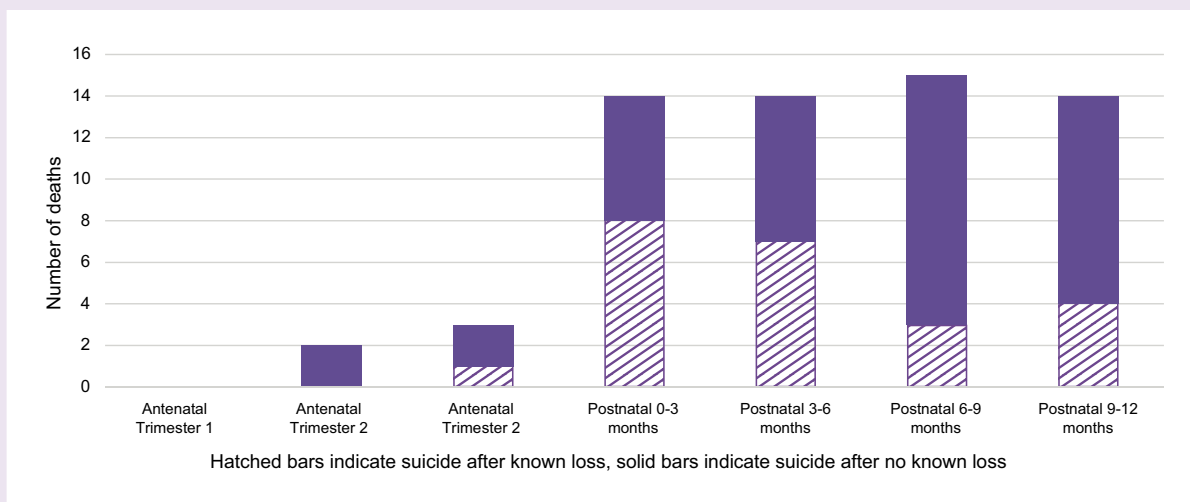
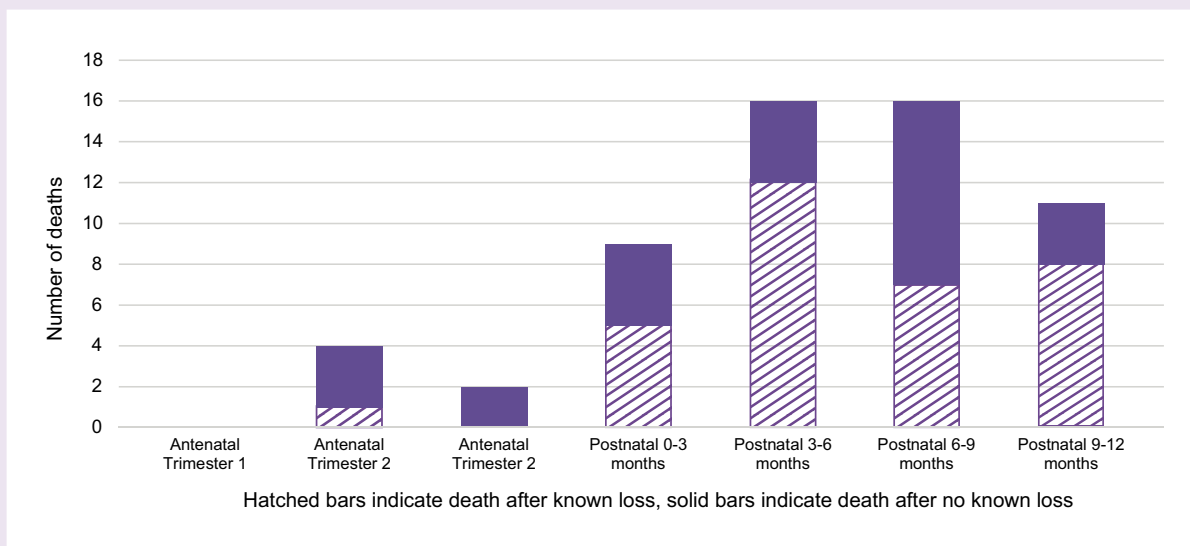


Figure 4.2: Timing of deaths from substance misuse in pregnancy and the post-pregnancy period, UK and Ireland 2017-19



Mental health diagnoses

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.

4.4 Overview of care and new lessons to be learned

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

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 could not access the specialist team directly.

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

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. For some women, it was 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 women 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 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

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. 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.

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

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. 2020); 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 (41/61 with sufficient information to classify care), 29% of women who died from substance misuse (14/48 with sufficient information to classify care) and 18% who died by homicide (2/11).

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.

Note that more in-depth analysis is available at: www.npeu.ox.ac.uk/mbrrace-uk/reports.

5.1 New recommendations for care

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**].

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 epidemiological 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. One woman died with an unidentified primary tumour.

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.

5.4 Overview of care and new 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

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.

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

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

Red flags symptoms

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'. 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. 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

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

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 out of 80 women (10%) with cancer, improvements in care were identified for three quarters of women overall (59/80). 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 multidisciplinary 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.

6. Messages for the prevention and treatment of thromboembolism

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Note that more in-depth analysis is available at: www.npeu.ox.ac.uk/mbrrace-uk/reports.

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]**.

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/m² or greater is associated with at least a four-fold increase in odds of venous thromboembolism, and a BMI of 25-29kg/m² 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).

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/m² 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/m² or greater, 15 (47%) had a BMI of 35kg/m² or greater, 12 (38%) had a BMI of 40kg/m² or greater and 5 (16%) had a BMI of 45kg/m² or greater.

6.4 Overview of care and lessons to be learned

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).

Develop a mechanism to ensure all VTE risk assessment tools used for pregnant and postpartum women are consistent with national guidance N

Crossing boundaries

A young woman had a booking BMI of 45kg/m² 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.

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.

Ensure that assessment of adherence to administration forms part of the antenatal or postnatal assessment of women prescribed low molecular weight heparin. N

6.5 Conclusions

Improvements in care which may have made a difference in outcome were identified for nearly two thirds of women who died from venous thromboembolism (21/31). 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).

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8. Glossary of terms

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

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