Maternal, Newborn and Infant Clinical Outcome Review Programme

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

Saving Lives, Improving Mothers' Care

State of the Nation Report

Surveillance findings and lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths from thrombosis and thromboembolism, malignancy and ectopic pregnancy 2020-2022, and morbidity findings for recent migrants with language difficulties.

October 2024

HQIP Healthcare Quality Improvement Partnership
University of Leicester
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www.npeu.ox.ac.uk/mbrrace-uk/reports/maternal-reports/maternal-report-2020-2022

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Contents

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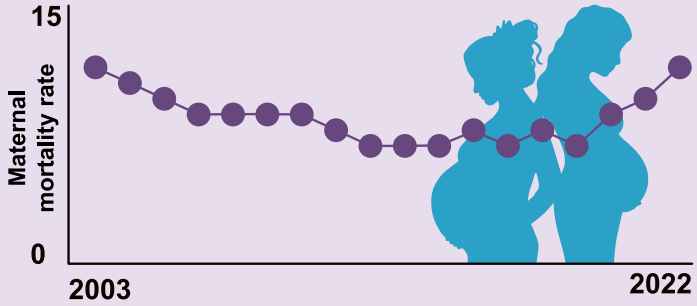
Key messages
from the report 2024

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

275 women died during pregnancy or up to six weeks after pregnancy in 2020-2022

13.56 women per 100,000 died during pregnancy or up to six weeks after pregnancy



Causes of women's deaths

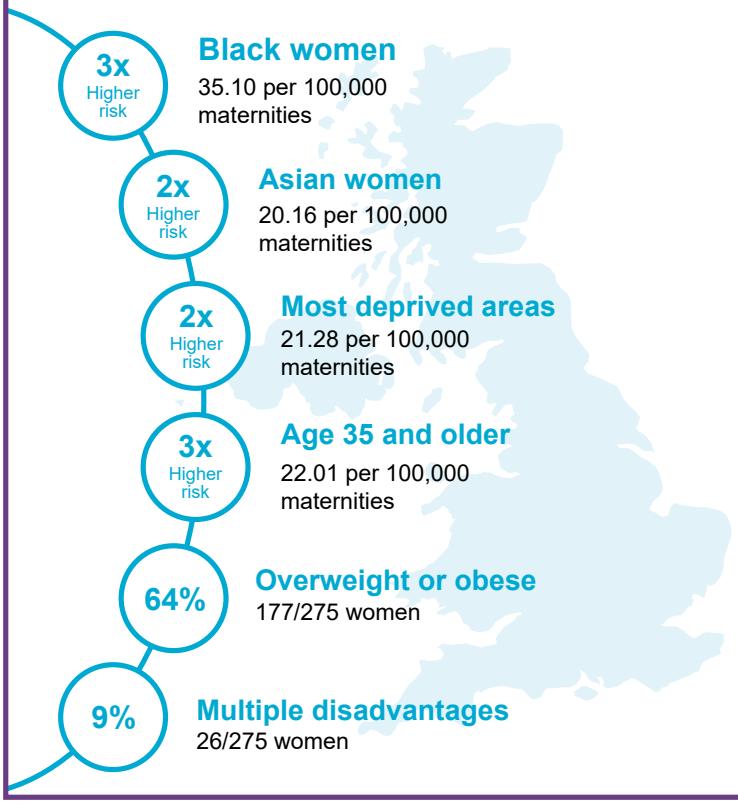
The **national risk assessment tool** must be evidence-based, clear and accurate

Consider the effects of vomiting, dehydration, immobility and other **symptoms** that can increase risk

Risk happens early - define pathways so women who need medication to prevent blood clots can access it when they need it, including in the first trimester

Blood clots	16%
COVID-19	14%
Cardiac disease	13%
Mental health conditions	11%
Sepsis	9%
Epilepsy and stroke	9%
Other physical conditions	7%
Obstetric bleeding	7%
Early pregnancy disorders	5%
Other direct causes	4%
Cancer	3%
Pre-eclampsia	3%

Inequalities in maternal mortality



3x Higher risk — **Black women**
35.10 per 100,000 maternities

2x Higher risk — **Asian women**
20.16 per 100,000 maternities

2x Higher risk — **Most deprived areas**
21.28 per 100,000 maternities

3x Higher risk — **Age 35 and older**
22.01 per 100,000 maternities

64% — **Overweight or obese**
177/275 women

9% — **Multiple disadvantages**
26/275 women

1. Introduction and methods

In accordance with funder requirements, the findings of the Maternal, Newborn and Infant Clinical Outcome Review Programme, including the MBRRACE-UK Confidential Enquiry into Maternal Deaths and Morbidity are now released as a condensed State of the Nation report highlighting the key surveillance findings, national recommendations and new lessons learned from the review of the care received by women who died from specific causes or experienced morbidity and were recent migrants with language difficulties.

Supplemental material including the full data on maternal mortality rates and the characteristics of the women who died, quality improvement messages concerning the women who died from specific causes and those included in the morbidity enquiry into migrant women, and the background, details of methods and chapter authors for different topics is available online at:

www.npeu.ox.ac.uk/mbrrace-uk/reports/maternal-reports/maternal-report-2020-2022

Key to colour coding

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

Vignettes concerning the care of women who had severe morbidity but survived are described in purple shaded boxes with the character M in the corner. ***M***

Key surveillance findings

Key surveillance findings are presented in purple boxes.

National recommendations

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

Clinical messages

Clinical messages to emphasise previous recommendations or existing guidance are presented in blue boxes.

All existing guidance requiring improved implementation is presented in green boxes

NICE 2345

2. Summary messages

2.1 Key surveillance findings

Key surveillance findings

1. There was a statistically significant increase in the overall maternal death rate in the UK between 2017-19 and 2020-22. This increase remained statistically significant when deaths due to COVID-19 were excluded, which suggests a concerning trend independent of COVID-19 specific deaths.

2. Thrombosis and thromboembolism is now the leading cause of maternal death followed by COVID-19 and cardiac disease; together, these three causes represent 43% of maternal deaths during or up to six weeks after pregnancy.

3. Deaths from mental health-related causes continue to account for a large proportion (34%) of deaths occurring between six weeks and a year after the end of pregnancy with deaths due to substance misuse and other psychiatric causes the leading cause of deaths in this period.

4. Women living in the most deprived areas had a maternal mortality rate twice that of women living in the least deprived areas, emphasising the need for a continued focus on action to address these disparities.

5. There was a nearly three-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.

2.2 National recommendations

NEW **National recommendations**

1. Clearly define the rapid access pathways for prescribing thromboprophylaxis to ensure that women known to be at risk are able to access thromboprophylaxis when they need it, particularly in the first trimester **[ACTION: Integrated Care Boards and Health Boards]**

2. Restructure the existing national VTE risk assessment tool based on research evidence to produce an assessment that is easy to use, clear and accurate and that includes factors that may arise in the postnatal period **[ACTION: National Institute for Health and Care Research in consultation with the Royal College of Obstetricians and Gynaecologists]**

3. Revise and implement guidance for cancer diagnosis and management in pregnant women to include clear recommendations on the use and safety of diagnostic imaging modalities in pregnant women with a history of or with newly diagnosed cancer **[ACTION: Royal College of Obstetricians and Gynaecologists in partnership with other royal colleges and professional societies]**

4. Update end-of-life care guidance to include recommendations for the appropriate service delivery to pregnant or recently pregnant women including the need to recognise decline, facilitate time spent with their baby and hold conversations around provision of consent for advanced resuscitation **[ACTION: National Institute for Health and Care Excellence]**

5. Review ambulance service algorithms for risk categorisation to ensure that 999 calls regarding women who are pregnant, recently pregnant or have the potential to be pregnant are appropriately managed, which may include early navigation and assessment. Ensure that repeated calls and calls made by minors are escalated to enable a rapid response by appropriately trained paramedics **[ACTION: NHS England and ambulance service commissioners in the devolved nations]**

6. Ensure the digital maternity record includes details of language needs including the use of formal interpreter services, to ensure that these are taken into consideration at all interactions, including in emergency situations **[ACTION: Professional Record Standards Body and equivalents in the devolved nations]**

2.3 Clinical messages

Clinical messages

1. When pregnant women present to the emergency department with nausea and vomiting they should be assessed using a validated index such as the Pregnancy Unique Quantification of Emesis (PUQE) score to accurately determine the severity of their symptoms.

2. Imaging and interventions, including chemotherapy, mammography and mastectomy should be used in pregnancy unless there is a clear contraindication. Consulting with the maternity medical team on what imaging is appropriate may help ensure that pregnant women are not wrongly denied treatment.

3. 'The 5 H's and 4 T's': When a woman of reproductive age has a sudden cardiac arrest, pregnancy (HCG) should be considered as a 5th cause of collapse alongside the 4 H's and 4 T's

4. 'Think ectopic': Ensure that women and clinicians are aware of the typical symptoms of ectopic pregnancy, which include:
   - Pain in the lower abdomen
   - A missed period or vaginal bleeding different from a normal period
   - Shoulder tip pain (tends to develop with other symptoms)
   - Diarrhoea or gastrointestinal upset

5. Closed-loop communication should be used to ensure information is understood. When giving verbal information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly.

6. Be proactive in follow-up when appointments are missed and facilitate alternative ways of engagement where possible.

7. Maternity care should aim to produce equity in outcome rather than equality in care. Different women have different needs that should be taken into account when providing individualised care. Considerations such as aligning appointments to reduce time away from work can help improve experiences and outcomes.

3. Surveillance and epidemiology

Note that more in-depth analysis is available at:
www.npeu.ox.ac.uk/mbrrace-uk/reports/maternal-reports/maternal-report-2020-2022

3.1 Causes and trends

Overall, 296 women died in 2020-22 during pregnancy or within 42 days of the end of pregnancy in the UK. The deaths of 21 women were classified as coincidental. Thus, in this triennium 275 women died from direct and indirect causes, classified using ICD-MM (World Health Organisation 2012), among 2,028,543 maternities, a UK maternal death rate of 13.56 per 100,000 maternities (95% CI 12.00-15.26). This compares to the rate of 11.66 per 100,000 maternities (95% CI 10.23-13.23) in 2019-21 (rate ratio (RR) 1.16, 95% CI 0.97-1.39, p=0.088). Maternal mortality rates for each of the four UK nations are not significantly different from the overall UK rate, noting that these comparisons have very limited statistical power.

Nine of the deaths which occurred between March and December 2020, 24 of those during 2021 and five of those during 2022 were directly attributable to COVID-19 infection. If the 38 deaths directly caused by COVID-19 are excluded, the maternal mortality rate for 2020-22 would be 11.68 per 100,000 (95% CI 10.24-13.27), higher than the corresponding rate for 2019-21 (10.06 (95% CI 8.74-11.53)) but not significantly so (RR 1.16 (95%CI 0.96-1.41), p=0.116).

Figure 1 (***Supplemental Table 2.1***) shows rolling three-yearly maternal death rates since 2003 using ICD-MM. The overall decrease in maternal death rate described in past years' MBRRACE-UK reports does not continue in 2020-22; there is no statistically significant change in maternal death rate between 2003-05 and 2020-22 (risk ratio (RR) 0.97, 95% CI 0.82-1.15, p=0.186 for trend in rolling rates over time). If the 38 deaths directly due to COVID-19 are excluded, there would be a significant decrease in overall maternal death rates between 2003-05 and 2020-22 as in past years (RR 0.84 95% CI 0.70-1.00, p=0.030). Similar trends were observed for the rates of indirect and direct maternal deaths.

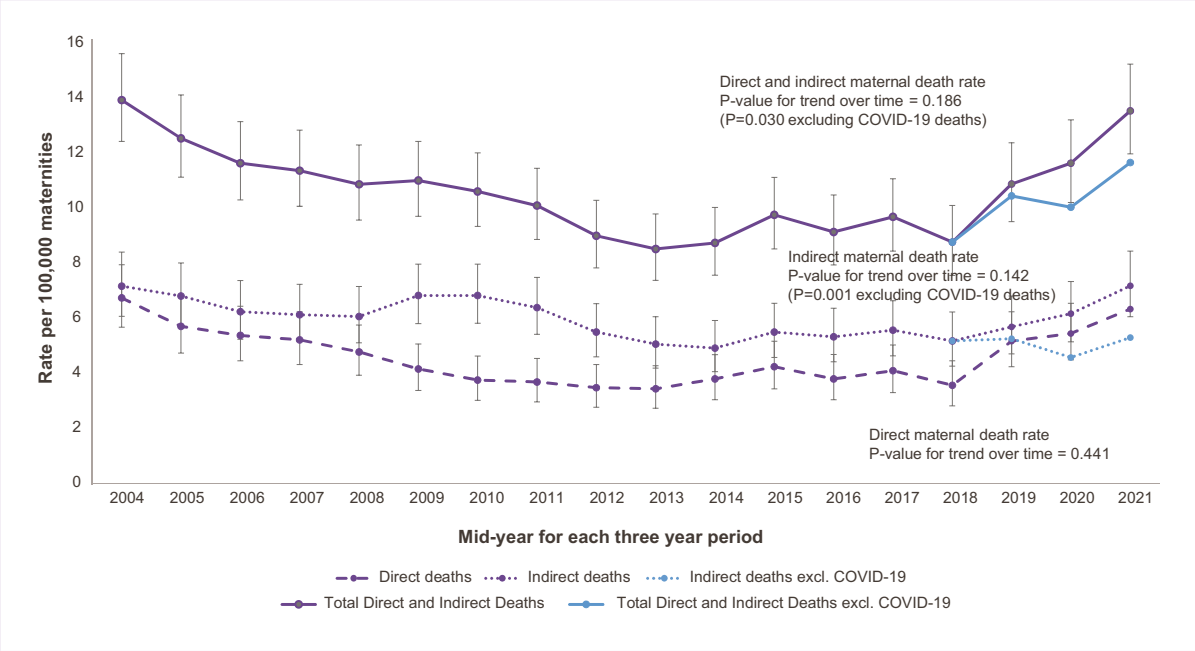
The rate of overall maternal mortality in the 2020-22 triennium was statistically significantly increased from that in 2017-19, the immediately preceding triennium (RR 1.54, 95% CI 1.28-1.87, p<0.001). This increase was also observed for direct maternal deaths (RR 1.77, 95% CI 1.33-2.38, p<0.001) and indirect maternal deaths (RR 1.38, 95% CI 1.08-1.79, p=0.009). If deaths due to COVID-19 are excluded, the rate for overall maternal mortality remains statistically significantly higher than in 2017-19 (RR 1.33 95% CI 1.09-1.62, p=0.003) and the rate for indirect maternal deaths is similar to 2017-19 (RR 1.02 95% CI 0.78-1.35, p=0.859).

Key surveillance findings

There was a statistically significant increase in the overall maternal death rate in the UK between 2017-19 and 2020-22. This increase remained statistically significant when deaths due to COVID-19 were excluded, which suggests a concerning trend independent of COVID-19 specific deaths.

The progress towards the ambition to reduce maternal mortality by 50% between 2010 and 2025 in England (Department of Health 2017) can be assessed by comparing maternal death rates between the 2009-11 and 2020-22 triennia. Over this time, maternal mortality has increased by 27%, (RR 1.27 95% CI 1.07-1.52). Even when maternal deaths directly due to COVID-19 are excluded, maternal mortality over this period has increased by 10% (RR 1.10, 95% CI 0.92-1.32).

Figure 1: Direct and indirect maternal mortality rates per 100,000 maternities using ICD-MM and previous UK classification systems; three-year rolling average rates 2003-2022



Sources: CMACE, MBRRACE-UK

3.1.1 Deaths due to individual causes during pregnancy or up to six weeks after the end of pregnancy

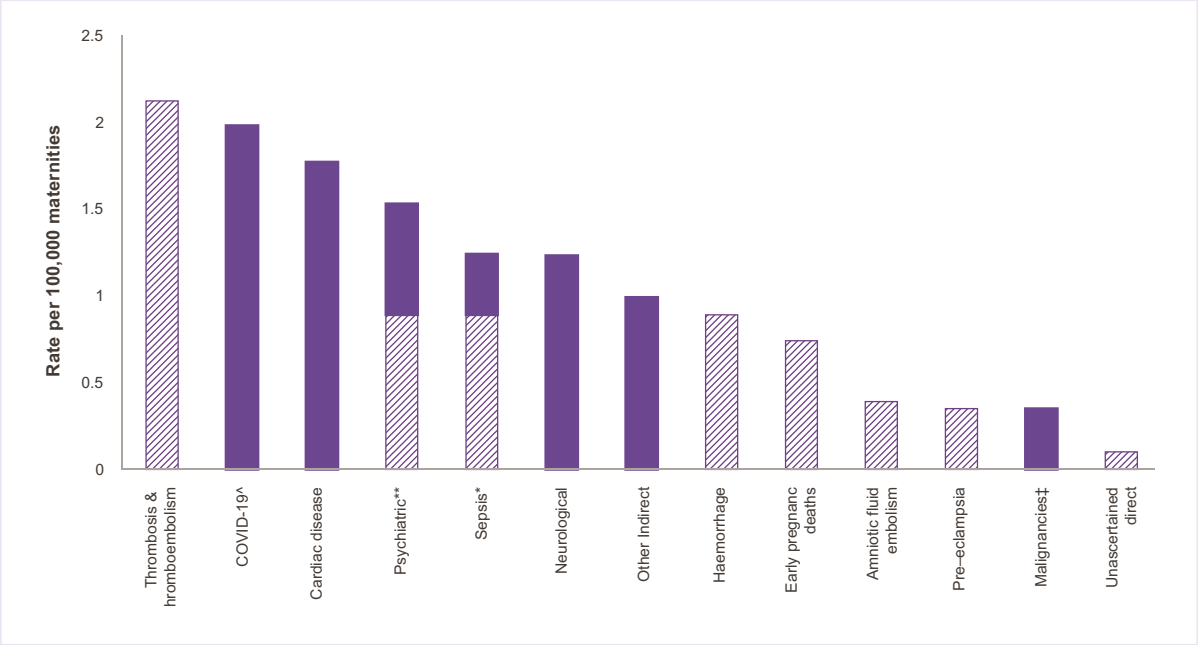
Maternal deaths by cause are shown in Figure 2 (***Supplemental Table 2.3***) and deaths classified according to ICD-MM subgroups are presented in Figure 3 (***Supplemental Table 2.5***). Thrombosis and thromboembolism (venous thromboembolism (VTE)) continues to be the leading cause of direct deaths occurring during or within 42 days of the end of pregnancy. The maternal mortality rate from VTE is more than twice that of any other direct cause and has increased significantly since 2017-2019, the last complete triennium (RR 2.30 95% CI 1.33-4.14, p=0.002). This suggests that improvements to care identified in section 4.1 of this report are necessary to reverse this trend.

Deaths due to indirect causes comprise just over half (53%) of direct and indirect maternal deaths in the UK. COVID-19 remains the leading cause of indirect maternal death in 2020-22 with a maternal mortality rate of 1.98 per 100,000 maternities (95% CI 1.40-2.72) based on the number of maternities between March 2020 and December 2022, the period of the pandemic. If deaths directly attributable to COVID-19 are not considered, cardiac disease remains the largest single cause of indirect maternal deaths, as in previous reports.

Key surveillance findings

Thrombosis and thromboembolism is now the leading cause of maternal death followed by COVID-19 and cardiac disease; together, these three causes represent 43% of maternal deaths during or up to six weeks after pregnancy.

Figure 2: Maternal mortality by cause 2020-22



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

^Rate for COVID-19 deaths calculated using maternities March 2020 to December 2022 as denominator

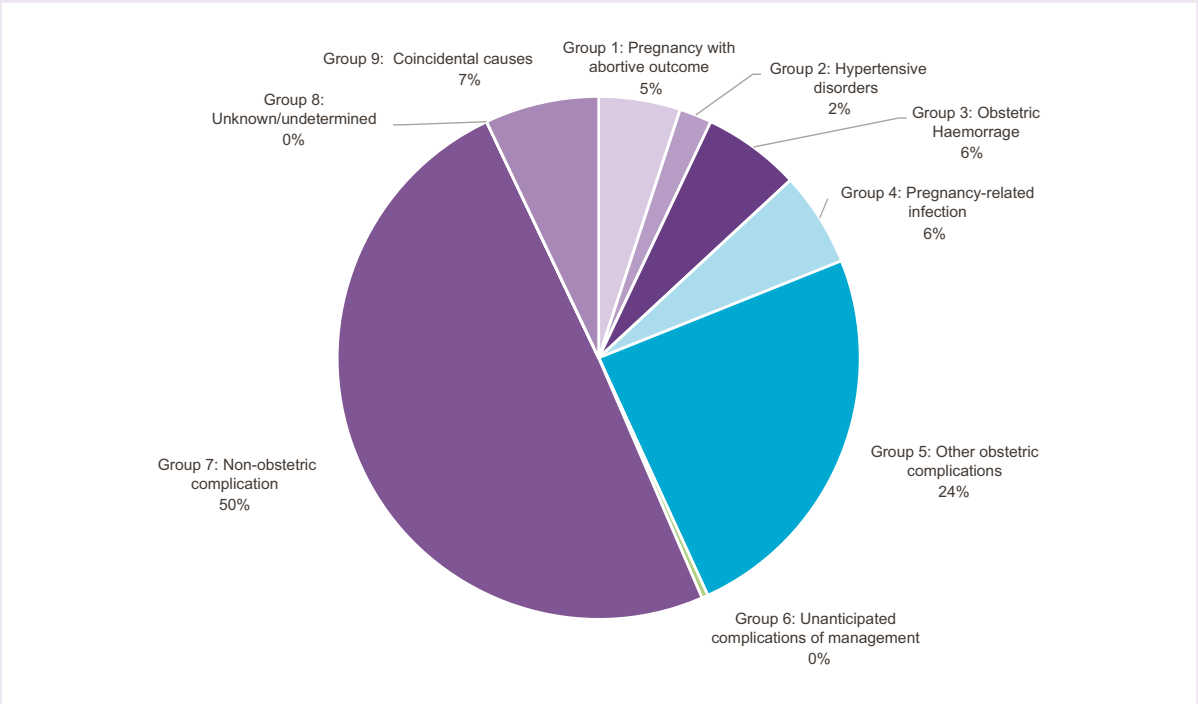
**Rate for suicides (direct) is shown in hatched and rate for indirect psychiatric causes (drugs/alcohol) in solid bar

*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 indirect malignancies (breast/ovary/cervix)

Source: MBRRACE-UK

Figure 3: Maternal mortality proportions by ICD-MM classification 2020-22



3.1.2 The women who died between six weeks and one year after the end of pregnancy

In the triennium 2020-22, 329 women died between six weeks and one year after the end of pregnancy, representing a mortality rate of 16.22 per 100,000 maternities (95% CI 14.51-18.07). The rate of late deaths has been consistently rising across the previous overlapping triennia, and is statistically significantly increased from 2017-2019 (RR 1.24 95% CI 1.06-1.46, p=0.008). Rolling triennial rates of late deaths are shown in Figure 4 and causes of late death in Figure 5. Maternal suicides continue to be the leading cause of direct deaths occurring between six weeks and one year after the end of pregnancy and deaths from psychiatric causes as a whole account for 34% of maternal deaths during this period.

Key surveillance findings

Deaths from mental health-related causes continue to account for a large proportion (34%) of deaths occurring between six weeks and a year after the end of pregnancy with deaths due to substance misuse and other psychiatric causes the leading cause of deaths in this period.

3.2 The characteristics of the women who died 2020-22

Of the 275 women who died from direct and indirect causes during or up to 42 days after the end of their pregnancy in 2020-22, 29% (79 women) were still pregnant at the time of their death and of these women, 50 (63%) were ≤20 weeks' gestation (***Supplemental Table 2.7***). The majority of the 163 women who gave birth did so in hospital (83% excluding the emergency department); 9% of women gave birth in an emergency department or an ambulance, and 8% at home (***Supplemental Table 2.8***)

Figure 4: Pregnancy-associated mortality rates six weeks to one year after the end of pregnancy, UK, 2009-2022

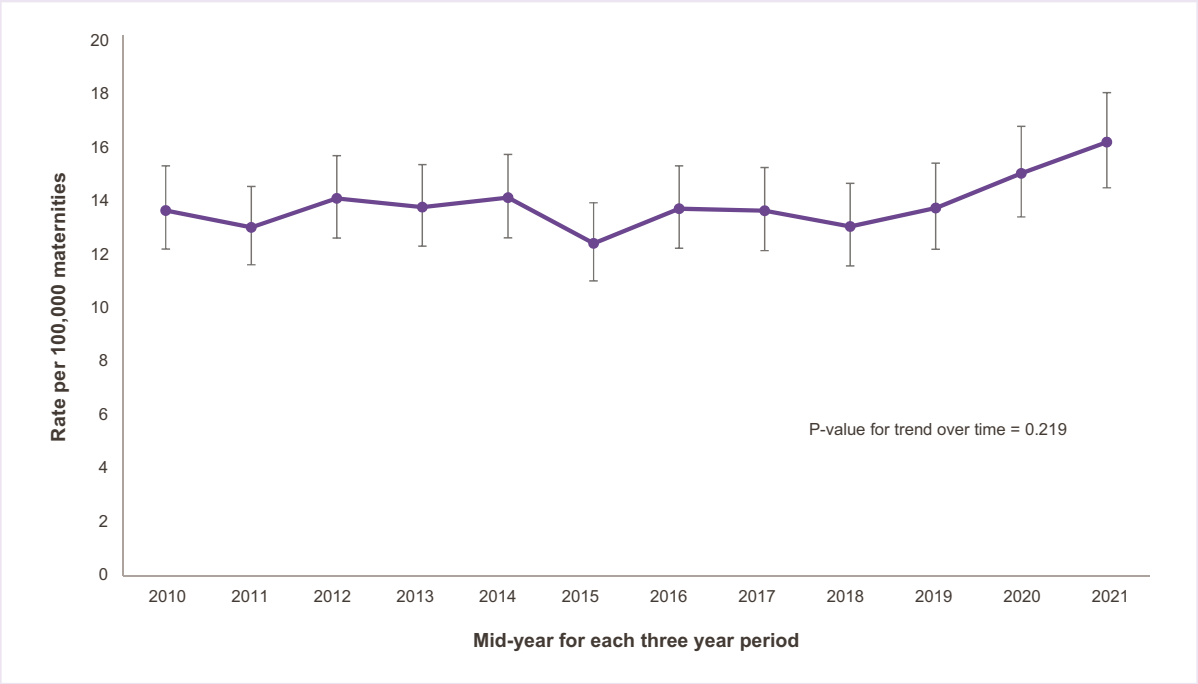
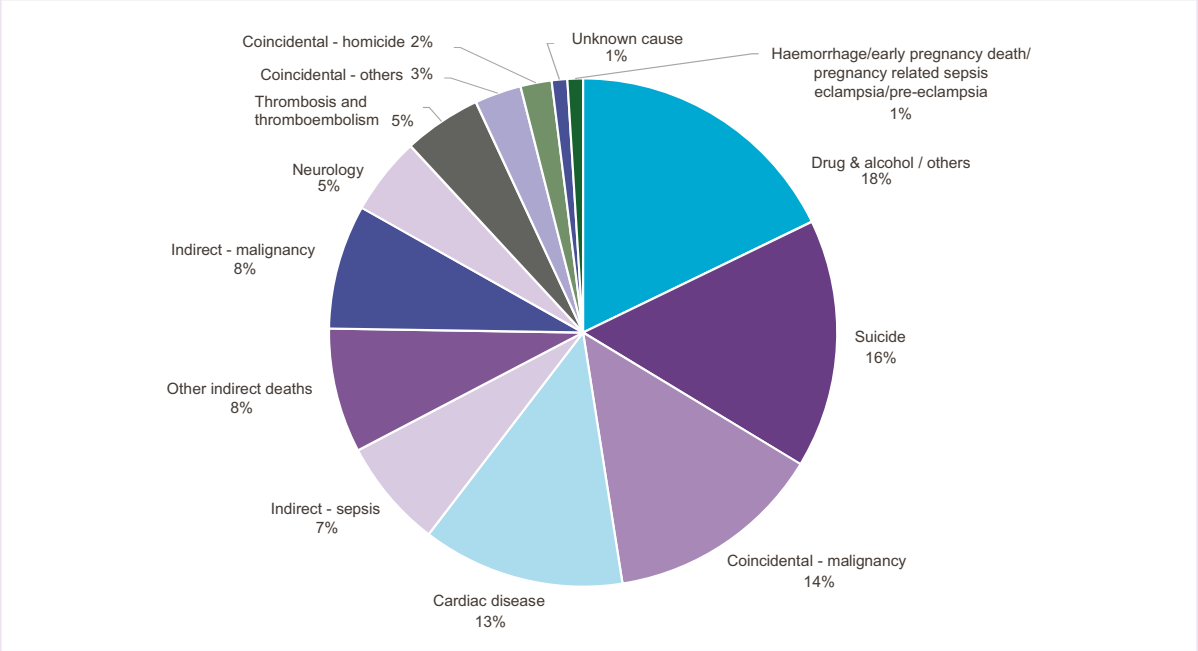


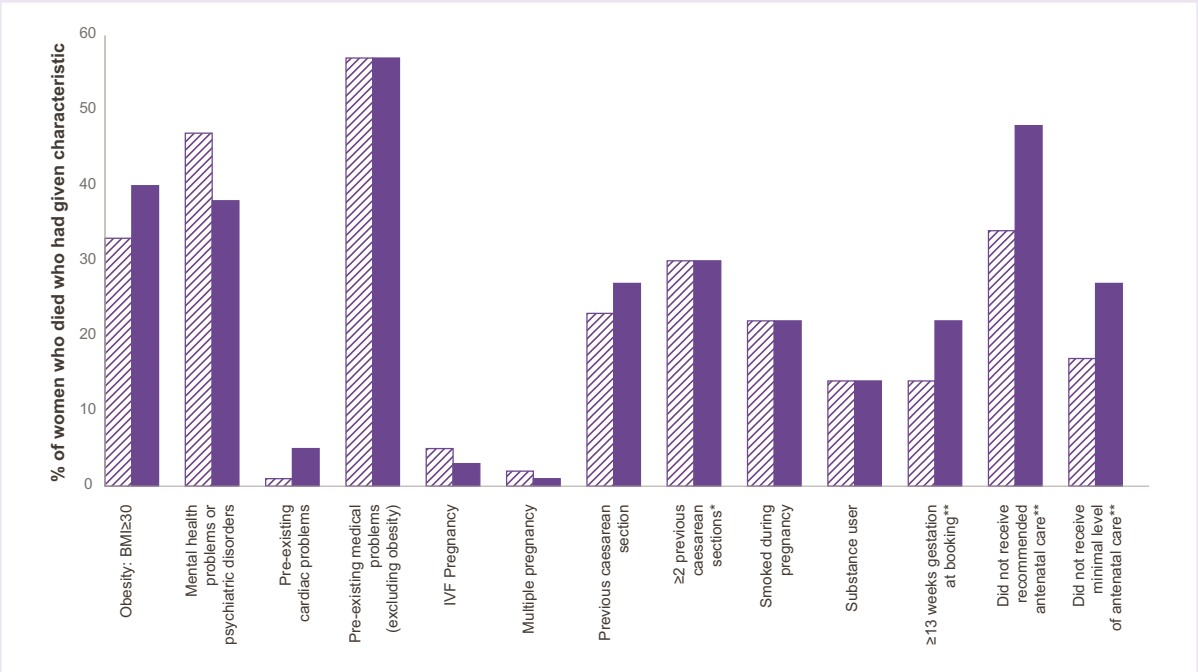
Figure 5: Causes of death amongst women who died between six weeks and one year after the end of pregnancy, UK 2020-22



3.2.1 Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2020-22 are shown in Figure 6 (***Supplemental Tables 2.9-2.16***).

Figure 6: Selected characteristics of women who died from direct or indirect causes 2020-22



Hatched bars indicate direct causes of death, solid bars indicate indirect cause of death

*Amongst women who had a previous caesarean birth

**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.

Women aged 35 or older had significantly increased rates of maternal death compared to women aged 20-24 (the reference group) (RR 3.08, 95% CI 1.86-5.38, p<0.001). Women aged 35-39 were almost three times more likely to die (RR 2.65, 95% CI 1.57-4.70, p=0.001) and women over 40 years of age were almost five times more likely to die (RR 4.82, 95% CI 2.65-9.06, p<0.001)) compared to women aged 20-24 (***Supplemental Table 2.10***). Women living in the most deprived areas continue to have the highest maternal mortality rates but there has been an increase in recent years in maternal mortality in women living in all areas, including the least deprived areas (Figure 7 and ***Supplemental Table 2.10***). The mortality rates among women from different ethnic groups are shown in Figure 8 (***Supplemental Table 2.10***). The risk of maternal death in 2020-22 was statistically nearly three times higher among women from Black ethnic minority backgrounds compared with White women (RR 2.87; 95% CI 1.86-4.28); this mortality rate is lower than the figure in the 2023 report, but not statistically significantly so. Women from Asian backgrounds also continued to be at higher risk than White women (RR 1.65, 95% CI 1.14-2.34).

Key surveillance findings

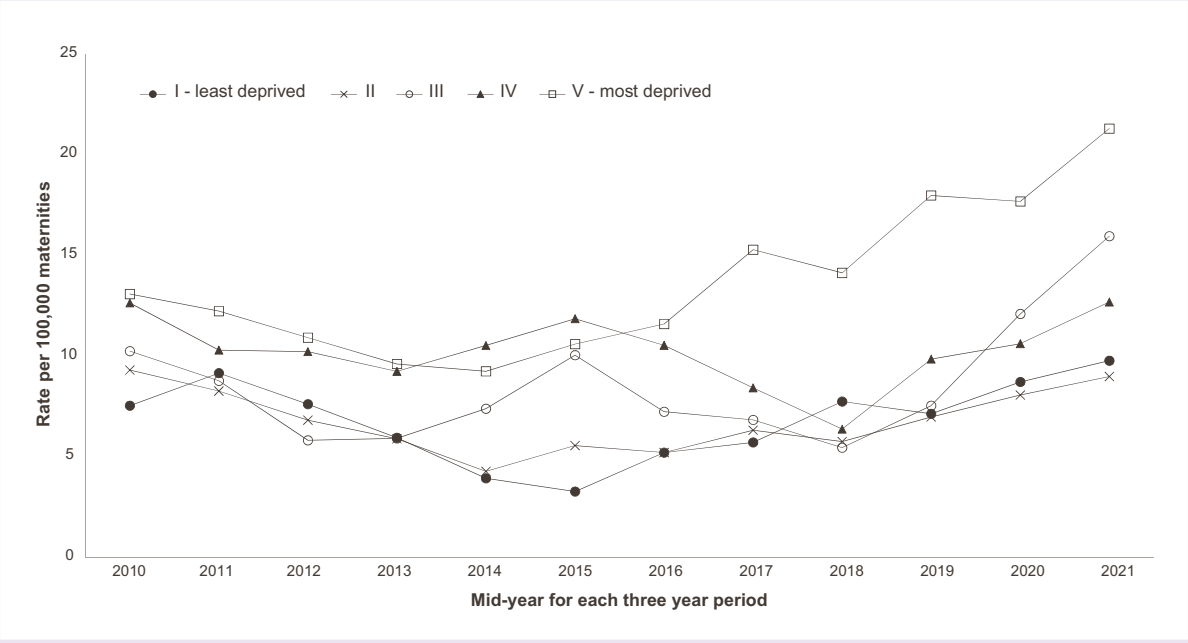
Women living in the most deprived areas had a maternal mortality rate twice that of women living in the least deprived areas, emphasising the need for a continued focus on action to address these disparities.

Key surveillance findings

There was a nearly three-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.

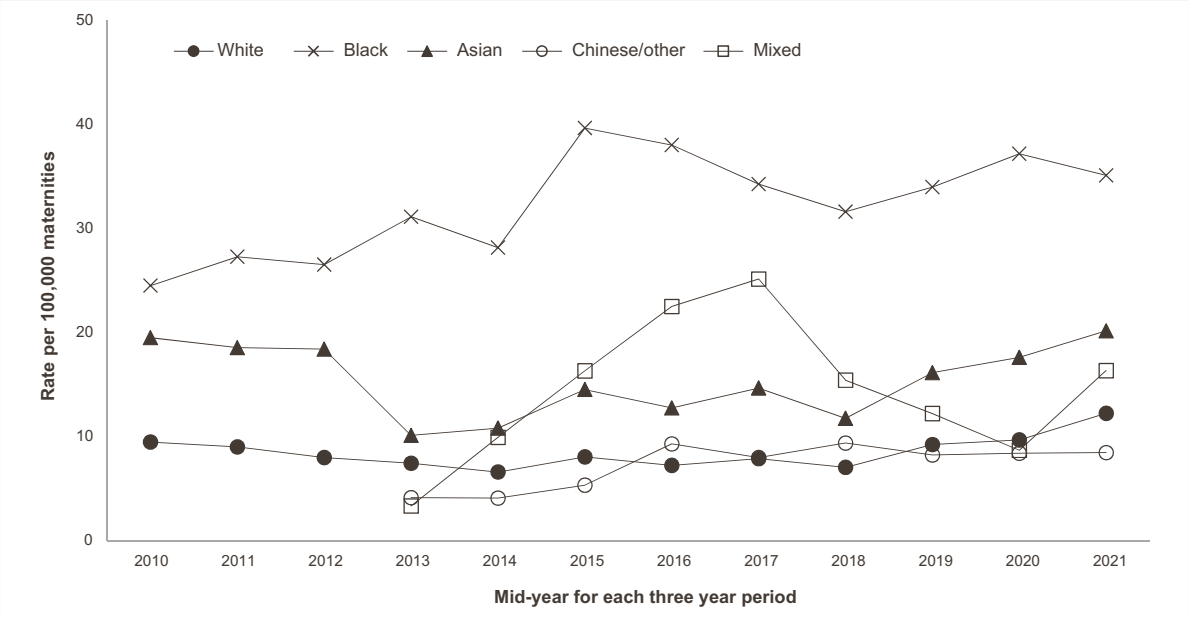
Almost a quarter of women who died in 2020-22 (23%), and whose place of birth was known, were born outside the UK; 36% of these women were known not to be UK citizens. Women who died, who were born abroad and who were not UK citizens had arrived in the UK a median of three years before they died (range three months to 19 years). There was no statistically significant difference in the maternal death rate between women born in the UK and those born outside the UK in 2020-22; however, women born in certain countries did have a non-significantly higher mortality rate compared to women born in the UK (***Supplemental Table 2.12***). This finding highlights the importance of this year's morbidity confidential enquiry into the care of recent migrants who have language difficulties. Lessons learned for the care of these women are included in section 5 of this report.

Figure 7: Maternal mortality rates 2009-22 among women according to deprivation of their area of residence in England*



*Data for England only due to availability of denominator data

Figure 8: Maternal mortality rates 2009-22 among women from different ethnic groups in England*



*Data for England only due to availability of denominator data

3.2.2 Classification of quality of care for women who are included in the confidential enquiries

This section includes information on the women who died in 2020-22 and who are included in this year's confidential enquiry reports (including women who died between six weeks and a year after the end of pregnancy and women from the Republic of Ireland). Figure 9 (***Supplemental Table 2.17***) shows the classification of care as agreed by the assessors for the 166 women who died and Figure 10 (***Supplemental Table 2.17***) shows the classification of care for the 38 women who were included in the morbidity confidential enquiry. Only the women whose case notes were available with sufficient information for an in-depth review are included.

Figure 9: Classification of care received by the women who died and are included in the confidential enquiries, UK and Ireland 2020-22*

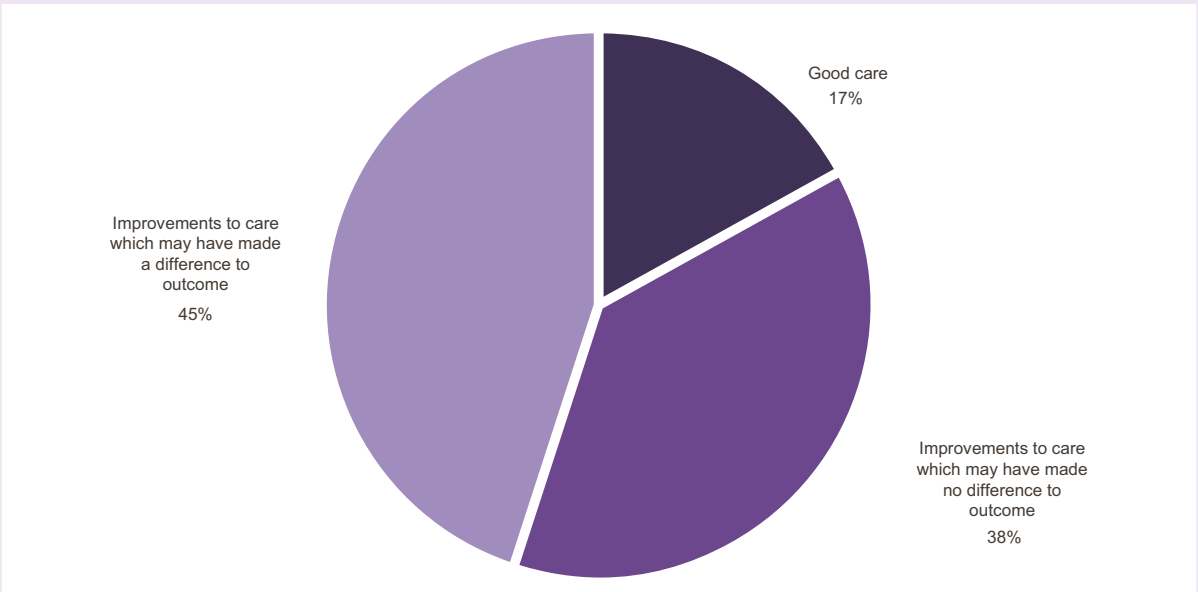
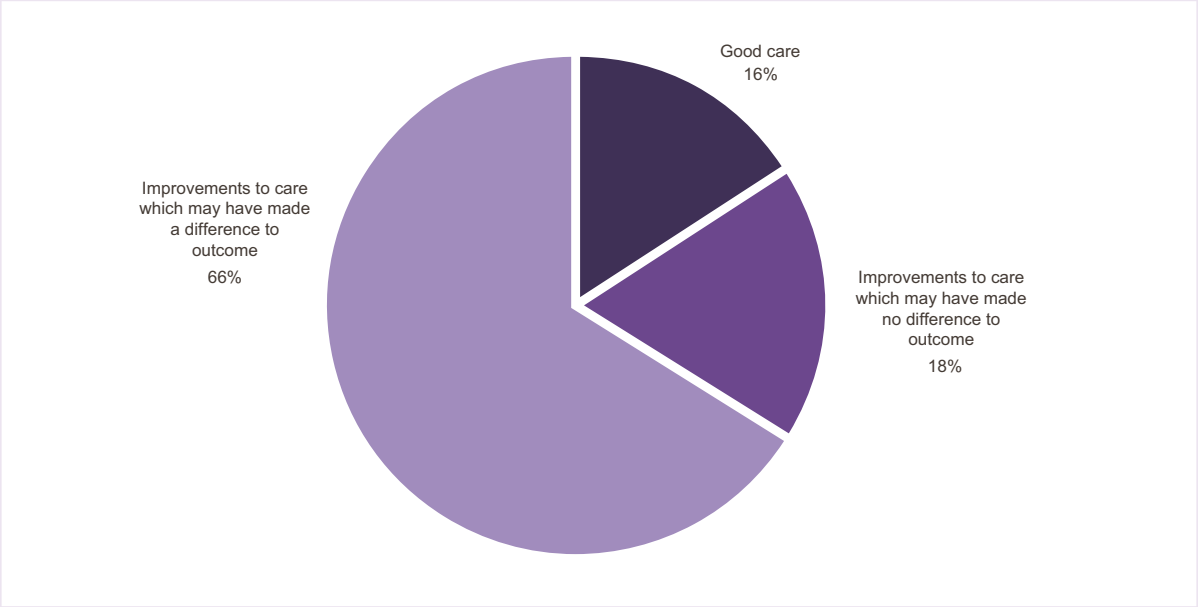


Figure 10: Classification of care received by the women who are included in the morbidity confidential enquiry into the care of migrant women with language needs, 2022



4. Confidential enquiries into maternal deaths

4.1 Thrombosis and thromboembolism

4.1.1 The women who died

In the UK and Ireland 45 women died from thrombosis and thromboembolism during or up to six weeks after pregnancy in 2020-22. There were a further 18 women who died between six weeks and one year after pregnancy. Together this represented an overall mortality rate of 2.87 per 100,000 maternities (95% CI 2.20-3.67).

Twenty-four (40%) of the women, whose BMI was known, were obese (BMI ≥30 kg/m^2) and a further 42% were overweight (BMI ≥25 to <30 kg/m^2). Seventeen women (27%) were between the ages of 35 and 39 and another four (6%) were over the age of 40. Of the 54 women whose smoking status was known, 12 (22%) continued to smoke. Thirteen of the 63 women who died (21%) had a history of VTE. Twenty-two women (35%) were were still pregnant at the time of their death and, of the 36 women who gave birth, 16 (44%) had a caesarean birth.

COVID-19 vaccination was not the cause of thrombosis or thromboembolism in any of the women who died. One woman who died had a positive test for COVID-19 at the time of her death but this was not thought to have contributed to her fatal pulmonary embolism.

For the 62 women whose care was reviewed, opportunities to improve care were identified for the majority of women (n=56, 91%). Assessors felt that different care may have made a difference to the outcome for 40 women (65%).

4.1.2 Overview of care and new lessons to be learned

Appreciation and assessment of symptoms

An older multiparous Black woman presented with vomiting late in the first trimester. She had a history of hyperemesis in a prior pregnancy. Her GP prescribed an antiemetic without further assessment. Two weeks later, at her booking appointment, she was noted to still be vomiting and her midwife referred her to the emergency department. A VTE assessment was carried out using the hospital's local assessment tool and she was deemed low-risk. She was discharged and advised to continue taking cyclizine. Four days later her nausea and vomiting seemed to be improving but she complained of pain in her upper leg which persisted for two days. She collapsed and died at home before a scheduled GP appointment. Bilateral pulmonary emboli and a deep vein thrombosis (DVT) were found at postmortem.

This woman had a history of hyperemesis and vomiting in her current pregnancy that was disabling enough to prompt a referral to the emergency department. In the emergency department a VTE risk assessment was performed using the hospital's own risk assessment tool, but the woman was incorrectly categorised as low-risk as the calculation did not take her hyperemesis into account. For several of the women who died from thrombosis and thromboembolism, local scoring systems were used to calculate VTE risk instead of the standardised, national VTE risk assessment guidance produced by the Royal College of Obstetricians and Gynaecologists (RCOG). This woman should have been offered thromboprophylaxis according to her assessed risk using the RCOG guidance (Royal College of Obstetricians and Gynaecologists 2015a). Assessors noted that many women did not have correctly calculated VTE assessment and risk categorisation even when the RCOG guidance was used. Scoring inaccuracies in VTE risk assessment have been demonstrated repeatedly in past reports (Knight, Bunch et al. 2020, Knight, Bunch et al. 2021) and continue to persist. Assessors noted several areas that seemed to consistently generate ambiguity or confusion when implementing the RCOG guidance.

For instance, severe hyperemesis can lead to dehydration and immobility, which further increases the risk of VTE. Hyperemesis and dehydration is currently given a score of one in the RCOG's VTE risk assessment tool (Royal College of Obstetricians and Gynaecologists 2015a), but whether this is weighted appropriately is not clear given the potential risk of associated mobility impairments in women with hyperemesis. Assessors noted that 14 women (22%) whose care was reviewed had potential mobility impairments, due to either hyperemesis or injury, which may have contributed to their subsequent thromboses. The woman above was unable to undertake normal activities due to her symptoms, but it is not known if the staff treating her fully recognised the severity of her condition as no IV fluids were administered and there were no changes to her antiemetic medication.

Clinical messages

When pregnant women present to the emergency department with nausea and vomiting they should be assessed using a validated index such as the *Pregnancy Unique Quantification of Emesis (PUQE) score* to accurately determine the severity of their symptoms.

This woman's care also highlights a common theme identified in the review of women who died from thrombosis and thromboembolism relating to the risk of VTE in early pregnancy. Sixteen (25%) of the women who died were in their first trimester of pregnancy; 15 were still pregnant at the time of their death and one died shortly after a first trimester pregnancy loss. Assessors noted that there appeared to be a perception amongst clinicians that early pregnancy is safe and late pregnancy is the period of risk with regards to VTE. This notion should be challenged, especially in women at high risk of VTE. Amongst the women who died in the first trimester, five had a history of VTE, six had severe hyperemesis, a third were obese and a third were aged 35 or older.

NEW **National recommendations**

Clearly define the rapid access pathways for prescribing thromboprophylaxis to ensure that women known to be at risk are able to access thromboprophylaxis when they need it, particularly in the first trimester. N

Accurately assessing the risk of thrombosis after pregnancy

A morbidly obese woman died from cerebral venous thrombosis two weeks after giving birth. At booking she was described as low risk for VTE. She had a vaginal birth at term with elevated blood pressure that subsequently settled. She was discharged with low molecular weight heparin prescribed for 10 days. Her VTE risk score was not re-assessed prior to discharge. Two weeks after giving birth she became confused and a CT scan showed extensive bilateral venous sinus thrombosis. She died four days later.

This woman's care was appropriate throughout most of her pregnancy and after she gave birth. Assessors also felt she received good care upon her arrival in the emergency department with a prompt working diagnosis of cerebral venous sinus thrombosis, confirmation with head CT and appropriate subsequent management. However, as with the woman described earlier, assessors noted confusion regarding interpretation of the current RCOG thromboprophylaxis guidance pertinent to her care (Knight, Bunch et al. 2018).

At the time of discharge, this woman would have been considered to have a parity of three. It is also likely that her weight gain in pregnancy would have raised her BMI over 40 kg/m^2. Had her risk been re-assessed postnatally as is recommended by the RCOG (Royal College of Obstetricians and Gynaecologists 2015a), she may have been placed in a higher risk category, which would have recommended low molecular weight heparin (LMWH) for six weeks. However, assessors reviewing this woman's care were unsure how to consider her most recent pregnancy in the parity calculation. As such, the postnatal risk scores calculated by the assessors were also inconsistent.

There was also confusion amongst assessors as to which weight should be used when calculating the VTE risk score and if women should be reweighed after giving birth. The difficulty in accounting for weight changes during pregnancy has been highlighted in past reports, which recommended that women be reweighed at 28 weeks' gestation and postpartum (Knight, Tuffnell et al. 2015, Knight, Bunch et al. 2021). This is especially important to consider when women's booking BMI is on the

borderline between categories as this woman's was. It has been suggested that BMI may be too broadly classified with risk scores stratified into two groups, one for women with a BMI ≥30 kg/m^2 and a second higher risk category for women with a BMI ≥40 kg/m^2 (Royal College of Obstetricians and Gynaecologists 2015a). These wide categories mean that some women who would benefit from thromboprophylaxis may be missed with the current scoring system (Simpson, Lawrenson et al. 2001, Jacobsen, Skjeldestad et al. 2008) .

It is clear from the care of these two women and others reviewed for this and past confidential enquiries, that the current RCOG VTE risk assessment guidance is not being used or interpreted correctly. While it is apparent that the guidance would benefit from revision to make it clearer and less complicated to use, any restructure must be evidence-based. This will require appropriate research to accurately assess the outcomes associated with different risk factors.

NEW **National recommendations**

Restructure the existing national VTE risk assessment tool based on research evidence to produce an assessment that is easy to use, clear and accurate and that includes factors that may arise in the postnatal period. **N**

4.1.3 Recurring lessons to be learned

Assessors identified that several women with a known history of VTE faced difficulty obtaining a prescription for thromboprophylaxis early in pregnancy as it was unclear who was responsible for the prescribing and what the referral pathway for access or advice was. This also occurred after pregnancy when women were transferred back to primary care. These findings re-emphasise the need for clear and effective pathways for prescriptions and rapid provision of LMWH both in early pregnancy and after delivery (Royal College of Obstetricians and Gynaecologists 2015a, Knight, Bunch et al. 2018, National Institute for Health and Care Excellence 2018, Knight, Bunch et al. 2020, Knight, Bunch et al. 2021).

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

RCOG Green-top Guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

As illustrated above and in previous reports, assessors noted that clinicians often did not appreciate that a woman's risk of VTE is dynamic. Risk factors such as BMI, smoking status and immobility can change and new risk factors such as infection can arise during or after pregnancy. All women should be properly (re)assessed for VTE risk during pregnancy and in the intrapartum or immediate postpartum period (Knight, Tuffnell et al. 2015, Royal College of Obstetricians and Gynaecologists 2015a, Knight, Bunch et al. 2021).

Risk assessment should be repeated again intrapartum or immediately postpartum.

RCOG Green-top Guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

In several instances, assessors noted that it was unclear whether women were adhering to their thromboprophylaxis regimen. Some women did not pick up their prescriptions from the pharmacy and there was no follow-up as was recommended in past reports (Knight, Tuffnell et al. 2015, Knight, Bunch et al. 2021). There was also limited evidence of discussions with women about the importance of medication adherence, the safety of medication during pregnancy and breastfeeding and the risks of VTE. Medication adherence is a common theme in these reports as many women are concerned about the risk of taking medications when pregnant or breastfeeding (Knight, Bunch et al. 2023).

Ensure that assessment of adherence to administration forms part of the antenatal or postnatal assessment of women prescribed low molecular weight heparin (Knight, Bunch et al. 2021)

As was also observed amongst women who died from ruptured ectopic pregnancies discussed in section 4.3 of this report, assessors noted many instances of pre-hospital delays and and inappropriate prioritisation or management of acute thrombotic events in the community. Upon arrival on the scene, there were also inconsistencies in the availability and appropriate use of thrombolysis (Royal College of Obstetricians and Gynaecologists 2015b) and evidence of inappropriate resuscitation attempts (Resucitation Council UK 2021), including not recognising the importance of resuscitative hysterotomy to assist in some instances of maternal resuscitation.

Consider thrombolytic drug therapy when pulmonary embolus is suspected or confirmed as the cause of cardiac arrest (Resucitation Council UK 2021)

Assessors noted that there was little appreciation of the symptoms of thrombosis in many women who died from thrombosis and thromboembolism. This included headaches and photophobia and leg pain. In several instances, clinicians examining the women demonstrated confirmation bias that lead them to wrongly attribute symptoms of thrombosis to pregnancy or other complications such as COVID-19. When a woman presents with new, persistent or unusual symptoms in pregnancy they should be properly investigated (Knight, Tuffnell et al. 2015, Knight, Bunch et al. 2018, Royal College of Physicians 2019, Knight, Bunch et al. 2023). This should include proper imaging, such as point-of-care ultrasound, senior overview and obstetric consultation when pregnant or recently pregnant women report to the emergency department (Knight, Tuffnell et al. 2015). This was not the case for several women whose care was reviewed.

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

Women presenting with symptoms and signs of an acute pulmonary embolism should have an electrocardiogram (ECG) and a chest X-ray (CXR) performed.

RCOG Green-top Guideline 37b (Royal College of Obstetricians and Gynaecologists 2015b)

4.2 Malignancy

4.2.1 The women who died

Overall, 94 women died from malignancy during pregnancy or in the year after the end of pregnancy in 2020-22 in the UK and Ireland (4.28 per 100,000 maternities, 95% CI 3.46-5.24). Nineteen women died during or up to six weeks after the end of pregnancy, a mortality rate of 0.87 per 100,000 maternities (95% CI 0.52-1.35). Seventy-five women died from cancer between six weeks and one year after the end of pregnancy (3.42 per 100,000 maternities, 95% CI 2.69-4.28).

No women died from direct malignancies (choriocarcinoma) in 2020-22.

Breast and gynaecological malignancies

Thirty-four women died from indirect malignancies including breast and gynaecological cancers in the UK and Ireland during or up to one year after pregnancy in 2020-22, a mortality rate of 1.55 per 100,000 maternities (95% CI 1.07-2.16). Of these women, seven died during pregnancy or up to six weeks after the end of pregnancy, six from breast cancer and one from ovarian cancer. Twenty-seven women died from six weeks to one year after pregnancy, 19 from breast cancer, five from ovarian cancer and three from cervical cancer.

Nine women who died from breast and gynaecological malignancies had been diagnosed with cancer prior to pregnancy, 15 were diagnosed during pregnancy, two were diagnosed at the time of birth and eight were diagnosed after pregnancy. Only two (22%) of the women who were diagnosed with cancer prior to becoming pregnant had evidence of pre-pregnancy counselling.

Other malignancies

Sixty women died from other malignancies in the UK and Ireland during or up to one year after pregnancy in 2020-22, a mortality rate of 2.73 per 100,000 maternities (95% CI 2.08-3.52). Twelve women died during pregnancy or up to six weeks after pregnancy, six from gastrointestinal tumours, two from haematological malignancies, two from brain tumours, one from a bone/soft tissue tumour and one from cancer of unknown primary origin. Forty-eight women died between six weeks

and one year after pregnancy, 21 died from gastrointestinal tumours, six from haematological malignancies, five from brain tumours, three from lung cancer, three from skin cancer, two from bone/soft tissue tumours, two from cancers of the urinary tract and six from tumours in other sites.

The care of 92 women who died from malignancies in 2020-22 was reviewed; notes were not available for two women from the Republic of Ireland and thus their care could not be reviewed. Amongst all women who died from malignancies, assessors felt that 23 women (25%) received good care. For the majority of women who died (n=44, 48%), assessors identified improvements in care that would not have made a difference to the outcome. Improvements to care that may have made a difference were identified for 25 women (27%).

4.2.2 Overview of care and new lessons to be learned

Delays in treatment and investigations due to pregnancy

A woman of mixed ethnic background presented in primary care with a breast lump when she was in the first trimester of pregnancy. She was referred for further examination at a breast clinic on the 'two week' waiting list but was not seen until six weeks after her initial presentation. Clinical examination indicated breast cancer with axillary lymph node spread and biopsy confirmed a high grade triple negative breast cancer. A mammogram was not undertaken due to pregnancy and staging included abdominal ultrasound and chest and spine x-rays. There was limited multidisciplinary team discussion and care was divided across hospitals. She was recommended to start chemotherapy during pregnancy and received five cycles. She had a vaginal birth at term following induction of labour and surgical treatment with mastectomy and axillary gland removal was performed two weeks later. A CT scan at six weeks postpartum revealed extensive disease, including liver and lung metastases. Palliative chemotherapy and radiation was planned, but she had rapid disease progression and died from her breast cancer a few weeks later.

This woman experienced several delays prior to getting a cancer diagnosis and imaging before she started chemotherapy was limited as there were concerns about its use in pregnancy. Previous reports have noted the need for guideline development for imaging and staging of cancers during pregnancy (Knight, Bunch et al. 2021). New guidelines from the European Society for Medical Oncology (ESMO) have recently been issued in relation to the management of breast cancer during pregnancy (Loibl, Azim et al. 2023) but there is a need to update and implement similar guidelines in the UK. The ESMO guidelines recommend breast ultrasound and mammography for the primary diagnosis of breast cancer during pregnancy (Loibl, Azim et al. 2023). For this woman, a mammogram was not undertaken due to her pregnancy, but she did receive abdominal ultrasound and chest and spinal x-rays, which are recommended for staging. These guidelines also emphasise the benefit of chest CT or diffusion weighted MRI if there are factors indicating high-risk of metastatic disease such as a large primary tumour, enlarged axillary nodes, triple negative or HER+ biomarkers, or high mitotic activity with Ki67 (Loibl, Azim et al. 2023).

A lack of appropriate imaging was also a common theme for women with other cancers, both in women with recurrent disease and with newly diagnosed cancer during pregnancy. Assessors emphasised that most imaging modalities and treatments are safe during pregnancy and women should not be inappropriately denied them simply because they are pregnant. Assessors felt that better multidisciplinary discussion and collaboration between oncology and the maternity medical team was needed to improve imaging in pregnant women. This woman's oncology, surgical and maternity care were spread across different clinics and hospitals and there was little evidence of communication between the different teams caring for her. Assessors felt that this may have impacted the care she received.

Clinical messages

Imaging and interventions, including chemotherapy, mammography and mastectomy should be used in pregnancy unless there is a clear contraindication.

Consulting with the maternity medical team on what imaging is appropriate may help ensure that pregnant women are not wrongly denied treatment.

Once this woman was diagnosed, she received five cycles of neoadjuvant chemotherapy. However, incomplete staging investigations meant that the extent of her disease was not recognised, and this may not have been the appropriate management. She was induced at 37 weeks due to intrauterine growth restriction, but her birth plan lacked information about her cancer and mastectomy was delayed until after birth.

NEW **National recommendations**

Revise and implement guidance for cancer diagnosis and management in pregnant women to include clear recommendations on the use and safety of diagnostic imaging modalities in pregnant women with a history of or with newly diagnosed cancer. **N**

Triple negative breast cancer in women of reproductive age

Information about tumour biomarkers was available for all of the 25 women who died from breast cancer. Eighteen (72%) had a triple negative tumour, one of whom was the woman described above, five women had ER/PR+ biomarkers and two had HER+ biomarkers. Of the women with triple negative breast cancer, six were diagnosed prior to pregnancy, nine were diagnosed during pregnancy and three were diagnosed after pregnancy.

The majority of women (23/25, 92%) who died from breast cancer were younger than 40 including 94% of the women with triple negative tumour biology. In England, 10% of newly diagnosed breast cancers occur in women under the age of 47. Among women aged 30-46 at the time of breast cancer diagnosis, approximately 50% have a high grade tumour, 18-26% have stage 3 disease and 23-30% have a tumour that is ER negative (Gathani, Reeves et al. 2021). These statistics highlight the aggressiveness of breast cancer in women of reproductive age, particularly for women of Black ethnic origin who have the highest risk of breast cancer with more severe characteristics (Gathani, Reeves et al. 2021).

It is important to keep in mind that women who have breast cancer in pregnancy have similar prognoses to young non-pregnant women with the same stage and disease subtype, provided their cancer is adequately managed (Loibl, Azim et al. 2023)

Recognition of deterioration and compassionate end-of-life care.

A recently arrived refugee woman presented to her GP with haemorrhoids and constipation in the early first trimester but did not wish to be examined. She was referred for booking and was appropriately documented as needing an interpreter, which was provided for the majority of antenatal visits. On several occasions she complained of painful haemorrhoids and increased bowel movements with blood in the stool. She allowed a doctor to examine her on one occasion and internal and external haemorrhoids were noted. At her 20 week anomaly scan masses were observed in her pelvis. She was found to have aggressive, metastatic colorectal cancer. After her diagnosis, multidisciplinary discussions were held regarding her treatment and outcome. The woman and her husband chose to end the pregnancy to commence palliative radiotherapy and chemotherapy. She was referred for palliative care and died a few months later.

Assessors noted that this woman's cancer was very aggressive. Prior to her 20 week scan she had persistent symptoms that were not fully investigated. Once the cancer diagnosis was made, assessors felt that she received good multidisciplinary care. Her need for an interpreter was documented and one was provided for all interactions as recommended (National Institute for Health and Care Excellence 2010) and emphasised in this year's morbidity enquiry (section 5). Assessors specifically highlighted that many of the individuals caring for this woman showed extreme empathy. They made significant efforts to ensure her end-of-life care was compassionate including making multiple referrals to social services, agencies and community groups to help the family.

However, for several other women, assessors felt that their deterioration due to disease progression was recognised late, as the focus was on the ongoing pregnancy. There was also evidence of little or no planning for emergencies. This resulted in cardiac arrest responses with prolonged CPR or unnecessary hospital admissions, which reduced opportunities for the woman to spend time with her baby. Collaboration across specialists with the woman's needs at the centre and one person coordinating her care are needed for optimal end-of-life planning.

NEW **National recommendations**

Update end-of-life care guidance to include recommendations for the appropriate service delivery to pregnant or recently pregnant women including the need to recognise decline, facilitate time spent with their baby and hold conversations around provision of consent for advanced resuscitation. **N**

4.2.3 Recurring lessons to be learned

Twenty women entered pregnancy with a known history of past or current cancer. It is important to ensure that this history is known by every person caring for the woman and that her care is multidisciplinary and consultant-led. As has been repeatedly emphasised in past reports, women with a known history of cancer should receive pre-pregnancy counselling including advice on contraception, postponement of pregnancy and the risks of recurrence. The RCOG recommends that women with a history of breast cancer wait at least two years after treatment to become pregnant (Royal College of Obstetricians and Gynaecologists 2011).

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 (Knight, Bunch et al. 2021)

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 (Knight, Bunch et al. 2021)

As in previous reports, assessors noted that many of the women's symptoms, including new onset nausea and vomiting, anaemia that did not resolve with iron supplementation and rectal bleeding were wrongly attributed to pregnancy conditions despite concerning 'red flags'. Symptoms of cancer or of metastasis in women with known cancer can be subtle or concealed by pregnancy. New, persistent or unusual symptoms should be investigated properly, especially when they necessitate repeat presentation.

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 (Knight, Bunch et al. 2021)

Assessors noted that many abnormal symptoms or signs of cancer were not followed up appropriately. This was particularly apparent in the care of women with cervical and ovarian cancer. In several instances, a family history of cancer was not asked about or not considered when women presented with unusual symptoms. There were also a few examples of care where ovarian cysts or abnormal cervical appearances were noted during routine scans and examinations but not investigated further. These are missed opportunities for earlier diagnosis and should be escalated.

If the ultrasound suggests ovarian cancer, refer the woman for further investigation using a suspected cancer pathway referral (for an appointment within 2 weeks).

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

NICE NG12 Suspected cancer: recognition and referral (National Institute for Health and Care Excellence 2023)

In total, 25 women with malignancy also experienced a thrombosis or thromboembolism. As for women who died from thrombosis and thromboembolism (section 4.1), assessors noted that several women who died from cancer were not provided with appropriate prophylaxis during pregnancy or postpartum. For women with medical comorbidities including cancer, antenatal prophylaxis should be considered beginning at 28 weeks' gestation and extend for at least 10 days' after birth, even if the woman has no other risk factors (Royal College of Obstetricians and Gynaecologists 2015a). Assessors felt that consideration should be given to extending the provision of thromboprophylaxis after pregnancy for women with cancer, since many of the women who had thromboses died more than six weeks after pregnancy.

Cancer is a recognised risk factor for thromboembolic disease and women should be prescribed thromboprophylaxis in accordance with RCOG guidelines.

RCOG Green-top Guideline 37a (Royal College of Obstetricians and Gynaecologists 2015a)

4.3 Deaths due to ectopic pregnancy

4.3.1 The women who died

The 2022 report included a chapter on lessons learned from deaths due to early pregnancy disorders and included women who died from 2018-20. A review of deaths due to early pregnancy causes occurring in 2021-22 was expedited due to concerns over the number of deaths due to ectopic pregnancy. During this two-year period in the UK and Ireland, 12 women died from an early pregnancy-related cause, all due to ectopic pregnancy. Thus, in 2021-22 the rate of deaths in early pregnancy is 0.82 per 100,000 maternities (95% CI 0.42-1.43). Although not statistically significantly different, this is almost twice the rate in 2018-20 (RR 1.91, 95% CI 0.74-5.14, p=0.147).

For the 12 women whose care was reviewed, assessors identified improvements to care for all the women, and felt that improvements to care may have made a difference to the outcome for nine women (75%).

4.3.2 Overview of care and new lessons to be learned

Urgent response and resuscitation of women with sudden collapse

A woman died from a ruptured ectopic pregnancy following a cardiac arrest at home. She was actively trying to conceive but was unaware she was pregnant after experiencing some light bleeding 10 days before. Immediately prior to her collapse she experienced abdominal pain, diarrhoea, vomiting and nausea. Her husband commenced CPR until ambulance crews arrived 20 minutes later and continued resuscitation attempts. The woman was not moved for more than one hour and was not given any fluids as part of resuscitation attempts. En route to hospital the ambulance was delayed due to equipment failures and the woman did not arrive until 2.5 hours after the initial 999 call. A pregnancy test revealed elevated HCG and a FAST scan showed fluid in the abdomen. A ruptured ectopic pregnancy was diagnosed and the woman underwent an emergency laparotomy two hours after her arrival in hospital; five hours after her initial collapse.

Potential pregnancy did not seem to be considered until this woman reached hospital. There was a delay in the arrival of ambulance crews with the first arriving more than 20 minutes after the 999 call. This woman's condition was classified as a Category 1 call that, according to NHS England's Ambulance Response Programme (***www.england.nhs.uk/urgent-emergency-care/improving-ambulance-services/arp/***), should lead to an average response time of seven minutes. Assessors felt that the rural location of this woman's collapse may have contributed to this initial delay, but also noted that there were significant delays in transferring the woman to the hospital where she could have had the cause of her collapse properly investigated and treated. Previous reports have recommended that women of reproductive age who collapse with no obvious cause should be transferred urgently to the emergency department (Knight, Nair et al. 2016). The Joint Royal Colleges Ambulance Liaison Committee (JRCALC) guidelines also recommend a time critical transfer to the emergency department or early pregnancy unit if a woman collapses in early pregnancy (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022).

Ten (83%) of the women reviewed contacted emergency services and nine of these women (90%) faced significant delays in the arrival of ambulance services and/or in transfer to hospital. For a few women, ambulances did not arrive until hours later. While pandemic-era service demands may have contributed to these delays, it was not the sole reason. It was unclear from the reviews how women were triaged when they called 999 as assessors felt that several were wrongly categorised as low priority (Category 3 or 4). Additionally, there seemed to be no escalation in their categorisation when repeat 999 calls were made or when calls were made by minors. Women's calls were also not prioritised when they reported that they were pregnant or had a history of ectopic pregnancy.

NEW **National recommendations**

Review ambulance service algorithms for risk categorisation to ensure that 999 calls regarding women who are pregnant, recently pregnant or have the potential to be pregnant are appropriately managed, which may include early navigation and assessment. Ensure that repeated calls and calls made by minors are escalated to enable a rapid response by appropriately trained paramedics. N

Assessors observed that this woman, and others, did not receive adequate fluid replacement during resuscitation. In several instances it seemed that hypovolaemia due to intra-abdominal bleeding was not considered as a cause of collapse despite evidence of a distended abdomen. When a woman is bleeding from an ectopic pregnancy, extended resuscitation increases the risk of cardiac arrest and death. For resuscitation to be successful in these women, the bleeding must be stopped by surgical intervention. This requires urgent transfer to hospital without delay (Knight, Nair et al. 2016). It is crucial to keep in mind the reversible causes of maternal collapse (4 H's and 4 T's) when attending to a pregnant woman in a state of collapse. In women who are not known to be pregnant it is also vital to consider the possibility of pregnancy as an underlying cause of the collapse.

Clinical messages

'The 5 H's and 4 T's'

When a woman of reproductive age has a sudden cardiac arrest, pregnancy (HCG) should be considered as a 5th cause of collapse alongside the 4 H's and 4 T's.

4.3.3 Recurring lessons to be learned

Many of the women whose care was reviewed had typical symptoms of ectopic pregnancy but the diagnosis was not considered until they were in extremis. NICE guidance recommends that pregnancy tests are offered during clinical assessment of women of reproductive age even if symptoms are non-specific (National Institute for Health and Care Excellence 2019).

During clinical assessment of women of reproductive age, be aware that they may be pregnant, and think about offering a pregnancy test even when symptoms are non-specific.

NICE NG126 Ectopic pregnancy and miscarriage: diagnosis and initial management (National Institute for Health and Care Excellence 2019)

Clinical messages

'Think ectopic'

Ensure that women and clinicians are aware of the typical symptoms of ectopic pregnancy, which include:

- **Pain in the lower abdomen**
- **A missed period or vaginal bleeding different from a normal period**
- **Shoulder tip pain (tends to develop with other symptoms)**
- **Diarrhoea or gastrointestinal upset**

Assessors noted that in general there was good care in the emergency department after women arrived in a state of collapse. Of the seven women with ectopic pregnancies who presented to the emergency department, all underwent imaging, the majority by a Focused Assessment with Sonography in Trauma (FAST) scan that identified free fluid in the abdomen. Assessors also noted that several emergency departments were pre-alerted to the arrival of the women and senior multidisciplinary staff were involved in their care, including gynaecology consultants.

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

It was evident that women are still facing challenges accessing services in Early Pregnancy Assessment Units (EPAUs). Women were referred for appointments more than 24 hours after initial presentation due to a lack of availability and weekend closures, calls were not returned as some units did not have call logs and there was no follow-up for women who did not attend appointments. As has been previously highlighted, there is an ongoing need to ensure that EPAUs are available seven days a week and provide a full range of services including ultrasound and assessment of HCG levels (Knight, Nair et al. 2016, Royal College of Obstetricians and Gynaecologists 2016, National Institute for Health and Care Excellence 2019).

Regional services should be organised so that an early pregnancy assessment service is available 7 days a week for women with early pregnancy complications, where scanning can be carried out and decisions about management made.

Ensure that a system is in place to enable women referred to their local early pregnancy assessment service to attend within 24 hours if the clinical situation warrants this.

NICE NG126 Ectopic pregnancy and miscarriage: diagnosis and initial management (National Institute for Health and Care Excellence 2019)

As in previous reports, vulnerable women remain disproportionately represented amongst the women who died from ectopic pregnancy (Knight, Bunch et al. 2022). Five of the women who died from ectopic pregnancy had elements of disadvantage including a mental health diagnosis, substance use, domestic abuse or language difficulties. Assessors felt that some of these vulnerabilities, particularly known mental health problems, may have prevented women's concerns being heard or acted upon. Assessors also felt that language difficulties impacted the care received by women due to miscommunication between women and staff in the absence of interpreter services.

Vulnerable and young women remain disproportionately represented amongst those who have died from ectopic pregnancy. Ensure care is personalised to provide appropriate additional safety measures (Knight, Nair et al. 2016)

5. Confidential morbidity enquiry into the care of recent migrants with language difficulties

5.1 The women whose care was reviewed

A stratified random sample of women who were born abroad, had arrived in the UK less than two years prior to giving birth and who were identified as having a preferred language other than English were drawn from the MBRRACE-UK database of perinatal deaths or through routine national birth records for 2022. Of the 39 women identified from the two databases, records were received for 38 women. Due to the nature of the sampling strategy, many of the women (n=24, 63%) experienced a perinatal death from 24 weeks' gestation; a further two women experienced a pregnancy loss at ≤20 weeks' gestation.

The largest numbers of these women were from Pakistan (n=10, 26%) and Romania (n=7, 18%). Thirteen women were known to be pregnant when they arrived in the UK. For most of the women who did not arrive in the UK pregnant it was unclear how long they had been in the country prior to becoming pregnant. For the women where this was known, the median time in the UK before becoming pregnant was five months.

For the 38 whose care was reviewed, assessors felt that improvements in care may have made a difference to the outcome or the woman's experience for 25 women (66%). Six women (16%) were assessed to have received good care and for seven (18%), improvements in care were identified that would have made no difference to their outcome or experience.

5.2 Overview of care and new lessons to be learned

Assessment, documentation and support of language needs

> ***A nulliparous Hindi-speaking woman attended her first booking appointment at 16 weeks' gestation. At this appointment, her language needs were not assessed or documented but Google translate was used. It is unclear whether questions about her mental health needs were asked or understood. She was identified as low-risk, had a normal anomaly scan and her next antenatal appointment was scheduled for 28 weeks' gestation, several weeks later than recommended. At the 28 week appointment a family member acted as interpreter and she reported a two week history of reduced fetal movements. No fetal heartbeat was detected and intrauterine death was confirmed by ultrasound. Another doctor acted as an interpreter to deliver this news to the woman and her partner. Post-mortem examination confirmed a 22 week sized fetus with no abnormalities. M***

Inconsistent or missing assessment and documentation of language needs was a common theme in women's care. This woman's midwife appeared to have concerns regarding the woman's comprehension of English as Google translate was used at the booking appointment, but there was no formal assessment recorded regarding the need for an interpreter. It is essential to assess women's language interpretation and translation needs at booking and properly document these needs to plan for subsequent care. Language barriers do not resolve themselves and should be considered and re-assessed at every interaction during and after pregnancy.

National guidance states that services such as Google translate should not be used in healthcare settings as they are not quality assured. Rather, professional interpreter services, either remote or in person, should be used for every interaction (Office for Health Improvement and Disparities 2021). This was not the case for this woman and the majority of women whose care was reviewed. Assessors noted that formal interpreter services were rarely used either in person or via telephone. When appropriate interpreter services were used, they were not provided consistently at every encounter.

Assessors noted that the absence of formal interpreter services was of particular concern when discussions were about critical or sensitive information, including surgical consent, ultrasound results and discharge from hospital with the baby. For this woman, there was no interpreter present during a discussion about the importance of being aware of fetal movements including how and when to escalate concerns. If proper interpretation had been provided, assessors felt it may have resulted in an earlier diagnosis of intrauterine death. Assessors also emphasised that any critical or sensitive discussions such as these, should include closed-loop communication to ensure that the correct information is heard and understood by the woman.

Clinical messages

Closed-loop communication should be used to ensure information is understood. When giving verbal information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly.

NEW National recommendations

Ensure the digital maternity record includes details of language needs including the use of formal interpreter services, to ensure that these are taken into consideration at all interactions, including in emergency situations. N

Provide maternity staff with guidance and training to ensure accurate identification and recording of language needs in order to support personalised care. This should include guidance about when it is appropriate to use healthcare professionals as interpreters (Draper, Gallimore et al. 2023b, Draper, Gallimore et al. 2023a)

At this woman's 28 week appointment a family member acted as the interpreter. This was a common occurrence amongst the women whose care was reviewed. For most (61%) of the women it was documented that a family member had interpreted on at least one occasion; six women were never or rarely seen without a family member interpreting, including during sensitive conversations. NICE guidance states that every woman should have a one-to-one consultation, without her partner, a family member or a legal guardian present, on at least one occasion to facilitate discussions of sensitive issues (National Institute for Health and Care Excellence 2010). Assessors felt that the use of family members as interpreters may have led to potential safeguarding or sensitive issues not being explored for many women.

Understanding and navigating maternity pathways

A vulnerable, young woman from Romania was living in temporary accommodation with her partner and two children. They had registered with social services but did not have a GP. The woman reported her pregnancy at 26 weeks' gestation when she attended the emergency department for an unrelated minor health problem. A booking appointment was made that included transport and interpreting services, but the woman did not attend. A safeguarding midwife visited in person and informed her of her next appointment using an interpreting service. Booking and ultrasound were completed at 28 weeks' gestation using a telephone interpreter. Three weeks later the woman gave birth in the community, two days before her next planned visit. Resuscitation attempts were made, but postmortem confirmed the baby had died a week before birth. A telephone interpreter was used to explain the events and to request consent for postmortem. The woman did not attend hospital for postnatal follow-up. M

This woman booked her pregnancy late and assessors felt that this may be because she was not registered with a GP. It is unclear why she was not registered since she and her family had access to social care, homelessness support and a health visitor. Her initial visit to the emergency department, and community birth, suggests that she did not understand, or was not able to access, maternity care pathways. Challenges with accessing care were noted for many women. NICE guidance suggests that the provision of information regarding how to find and use antenatal services should be available in a variety of formats, settings and languages. Healthcare providers can also help support the uptake of antenatal care by undertaking training about the specific social, religious and psychological needs of women (National Institute for Health and Care Excellence 2010).

Assessors observed several barriers that could have contributed to the late booking and missed antenatal appointments that were frequently observed amongst the women whose care was reviewed. These barriers included digital exclusion when reminders and appointment changes were sent by text message in English, a lack of understanding of how to access appropriate care pathways demonstrated by delayed presentation, and insufficient financial resources to attend appointments, particularly among women living in temporary accommodation with no recourse to public funds. This woman did not attend a number of appointments despite the provision of transport services, but it is unclear if she was asked about the reason for

these missed appointments. Previous MBRRACE-UK reports have emphasised the importance of follow-up when women do not attend scheduled appointments. In this instance, the woman was appropriately safeguarded and a midwife followed up in person after the first missed booking appointment.

Clinical messages

Be proactive in follow-up when appointments are missed and facilitate alternative ways of engagement where possible.

This woman's care demonstrates several aspects of good care, including appropriate safeguarding and the consistent use of interpreters. It appears that her individual circumstances, including homelessness, were recognised and attempts were made to facilitate access to care. Many women had other elements of good care including hospital and community support to advocate on their behalf and help them navigate maternity care pathways. The assessors highlighted that that these examples reflect the greater level of care required for some women to experience a positive pregnancy experience and outcome.

Clinical messages

Maternity care should aim to produce equity in outcome rather than equality in care. Different women have different needs that should be taken into account when providing individualised care. Considerations such as aligning appointments to reduce time away from work can help improve experiences and outcomes.

5.2.1 Recurring lessons to be learned

Almost all women whose care was reviewed received written information in English, regardless of whether they had the language competency or literacy necessary to read and understand health-related written information. Most often this occurred when written consent was obtained for procedures and at discharge from hospital, when large amounts of written information was provided.

Health related written documents (for example health information leaflets) in English which are usually made freely available to patients should be translated where needed into other languages at no cost to the patient… Check whether a person can read health related information in their preferred language before offering translated written materials (Office for Health Improvement and Disparities 2021)

For several women assessors identified that considerable time and resource was required, or used, to provide comprehensive care using interpreter services. Assessors emphasised the need to allow for additional time and other resources when caring for women with language barriers. This was also true for postnatal visits with community midwives where considerable support and information may be required.

To allow sufficient time for interpretation, commissioners and those responsible for the organisation of local antenatal services should offer flexibility in the number and length of antenatal appointments when interpreting services are used, over and above the appointments outlined in national guidance.

NICE CG110 Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (National Institute for Health and Care Excellence 2010)

As noted above, many women were not registered with a GP and did not appear to be aware of their ability to register without proof of address. Women should be made aware that consultations and treatment at GPs and other primary care services are free to all individuals living in the UK (Office for Health Improvement and Disparities 2023). GP practices in England, Wales and Scotland are also not required to ask for proof of identity, address or immigration status from patients (NHS England 2023, NHS Inform 2023, Office for Health Improvement and Disparities 2023, NHS Wales 2024). Women should also be made aware that maternity care and treatment related to gender-based violence (including female genital mutilation) are free at the point of access (Office for Health Improvement and Disparities 2023).

Offer the woman information on access and entitlement to healthcare.

NICE CG110 Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (National Institute for Health and Care Excellence 2010)

For many women, there was evidence of microaggressions or biases in care relating to their ethnicity, language or migrant status. For example, language, ethnicity, citizenship and nationality were recorded with varied accuracy, suggesting greater cultural competency is required amongst clinicians. There were also challenges with communication that resulted in altered quality of care and impacted women's autonomy in decision-making.

Develop national guidance and training for all health professionals to ensure accurate recording of women's and their partner's self-reported ethnicity, nationality and citizenship status, to support personalised care (Draper, Gallimore et al. 2023b, Draper, Gallimore et al. 2023a)

Develop training and resources for all maternity and neonatal staff, so they can provide culturally and religiously sensitive care for all mothers and babies (Draper, Gallimore et al. 2023a, Draper, Gallimore et al. 2023b)

6. References

Available as supplementary material at: ***www.npeu.ox.ac.uk/mbrrace-uk/reports/maternal-reports/maternal-report-2020-2022***

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