Maternal, Newborn and Infant Clinical Outcome Review Programme

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

Saving Lives, Improving Mothers' Care

Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2020-22

Compiled report including supplementary material

October 2024

HQIP Healthcare Quality Improvement Partnership
University of Leicester
University of Birmingham
The Newcastle upon Tyne Hospitals NHS Foundation Trust
TIMMS
Sands Stillbirth & neonatal death charity
NHS Chelsea and Westminster Hospital NHS Foundation Trust
University of Oxford
Oxford Population Health
NPEU

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Allison Felker, Roshni Patel, Rohit Kotnis,
Sara Kenyon, Marian Knight (Eds.)

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Key messages
from the report 2024

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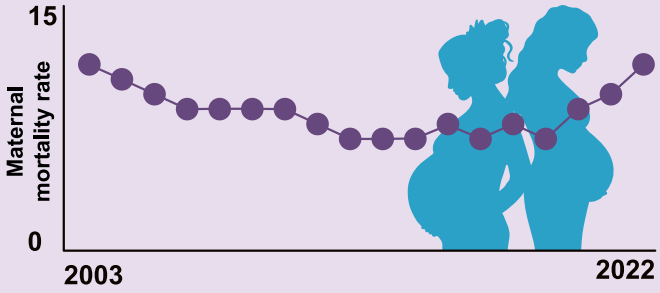
275 women died during pregnancy or up to six weeks after pregnancy in 2020-2022

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



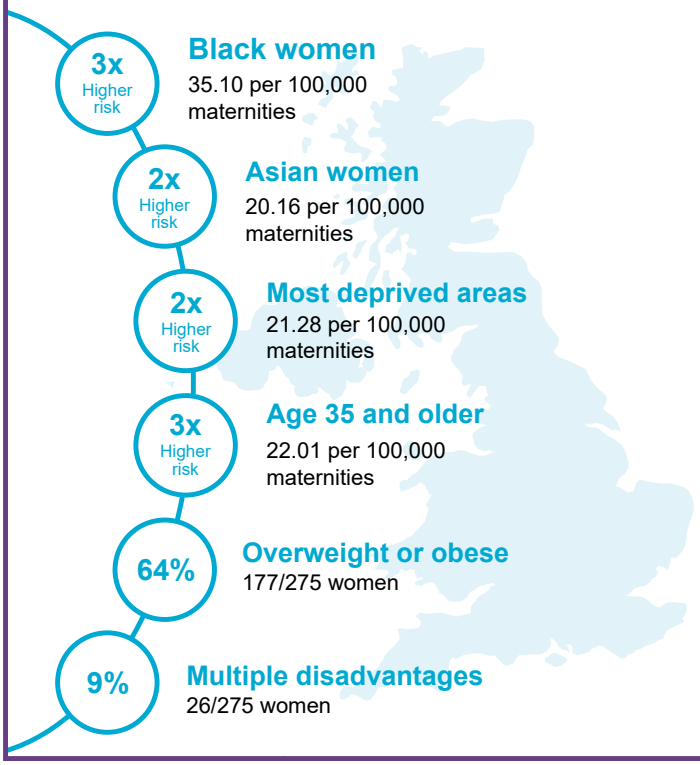
Causes of women's deaths

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

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

Key messages

for the care of women with thrombosis and thromboembolism

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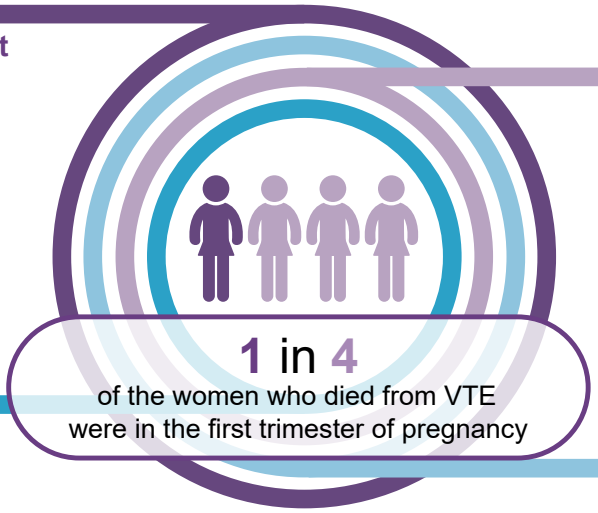
Ensure women at high-risk of venous thromboembolism (VTE) receive pre-pregnancy counselling and are appropriately managed in the first trimester

Early risk assessment
Assess VTE risk at the first opportunity

Pathways for advice
Ensure GPs can obtain timely specialist advice



1 in 4
of the women who died from VTE were in the first trimester of pregnancy

Access to thromboprophylaxis
Clearly define who is responsible for prescribing in early pregnancy

Pathways for referral
Outline how to refer women at high-risk of VTE

Research evidence is needed to restructure the existing national VTE risk assessment tool

The national assessment tool should:

- ☑ Be easy to use, clear and accurate
- ☑ Take into account factors that may arise during pregnancy or in the postnatal period
- ☑ Be based on research evidence

Women should be assessed:

- ☑ At booking or as early in pregnancy as possible
- ☑ After pregnancy, regardless of how the pregnancy ends
- ☑ If they are admitted to the hospital or develop other problems

Evidence-based

Key messages

for the care of women with cancer

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Equity in the treatment of pregnant women with newly diagnosed cancer or a previous cancer diagnosis

21%

of women who died from cancer in 2020-22 entered pregnancy with a history of past or current cancer

Consultant-led, multidisciplinary care should be the standard of care for women with prior cancer diagnoses

Provide pre-pregnancy counselling, including advice on contraception, to women with active or past cancer diagnoses

Investigate any new, persistent or unusual symptoms in pregnant women

Most imaging and treatments for cancer are safe during pregnancy and should not be delayed

Include women in discussions on end-of-life planning and facilitate time spent with their children

Recognise the risk of thrombosis in cancer, undertake risk assessments and provide adequate thromboprophylaxis

27%

of women who died from cancer in 2020-22 experienced a thrombosis or thromboembolism

Key messages

for the care of women with ectopic pregnancies

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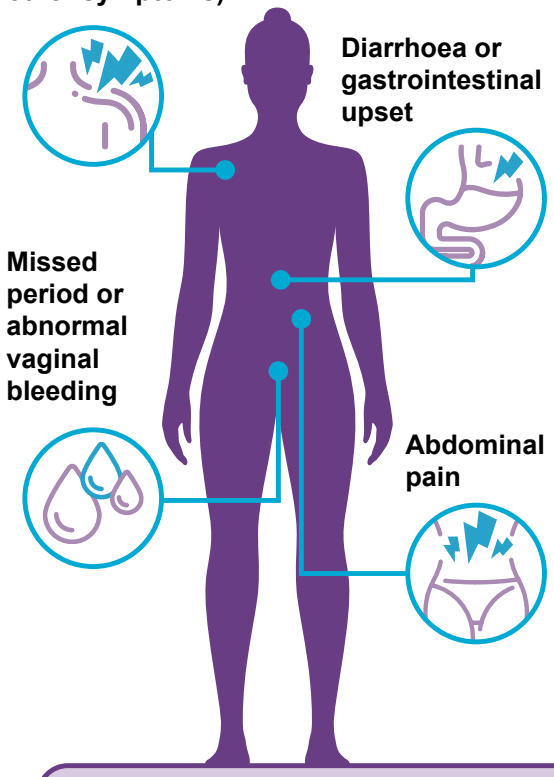
'Think ectopic'

Be aware of the common symptoms of ectopic pregnancy:

Shoulder tip pain (tends to develop with other symptoms)



Diarrhoea or gastrointestinal upset

Missed period or abnormal vaginal bleeding

Abdominal pain

Pre-hospital care

999 calls

Review risk categorisation for women who are pregnant, recently pregnant or who have the potential to be pregnant

Escalate repeat calls or calls made by minors

Ambulance

Urgently transfer reproductive age women in a state of shock or collapse to the emergency department

Resuscitation

Consider pregnancy and the reversible causes of maternal collapse including concealed bleeding

Consider a diagnosis of ectopic pregnancy and do a pregnancy test

Early Pregnancy Assessment Units (EPAUs)

EPAUs should be available 7 days a week

Provide women with an appointment within 24 hours of referral

Key messages

for the care of recent migrant women with language difficulties

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Language needs should be assessed, documented and considered at all stages of maternity care

ASK
Assess women's language needs at booking and every interaction

RECORD
Document women's language needs and interpreter use in the digital maternity record

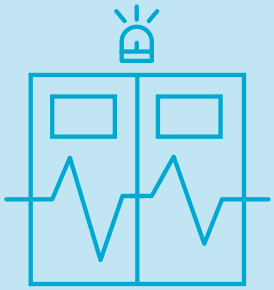
INTERPRET
Use professional interpreter services, at every interaction including emergencies

TRANSLATE
Provide written information in the woman's preferred language

Provide women with information about how to access maternity services in a variety of formats, settings and languages

Registration with GP

Make women aware that they have the right to access primary care, including GPs, without needing to pay or show proof of address



Seeking care in emergency units

When women present to urgent care or the emergency department with an unbooked pregnancy, make a referral to and follow-up with maternity services

Late booking for antenatal care

Consider barriers in access to care, facilitate alternative ways of engagement and be proactive in follow-up when appointments are missed

Executive summary

Introduction

This report, the eleventh 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 2020 and 2022 in the UK. In addition, it also includes Confidential Enquiries into the care of women who died between 2020 and 2022 in the UK and Ireland from thrombosis and thromboembolism and malignancies as well as the care of women who died as a result of ectopic pregnancy between 2021 and 2022.

The report also includes a Morbidity Confidential Enquiry into the care of migrant women who arrived in the UK less than two years prior to giving birth and who had a preferred language other than English. These women were identified from the MBRRACE-UK database of perinatal deaths or through routine national birth records for 2022.

Surveillance information is included for 625 women who died during or up to one year after the end of pregnancy between 2020 and 2022. The care of 38 recent migrant women with language difficulties was reviewed in depth for the Morbidity 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 six different chapters that may be read independently, the topics covered are: 1. Introduction and methodology 2. Maternal mortality surveillance and epidemiology 3. Thrombosis and thromboembolism 4. Malignancy 5. Ectopic pregnancy and 6. Migrant women with language difficulties (morbidity enquiry).

Methods

Maternal deaths are reported to MBRRACE-UK, Northern Ireland Maternal and Child Health (NIMACH) or to Maternal Death Enquiry (MDE) Ireland by the staff caring for the women, 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, National Records of Scotland and Public Health Scotland. For all women who die, MBRRACE-UK requests the full medical records, postmortem reports and, where relevant, copies of any local reviews or investigations including those conducted by the Maternity and Newborn Safety Investigations (MNSI) programme (previously part of the Healthcare Safety Investigation Branch (HSIB)). Full medical records are also requested for the women identified for the Confidential Enquiry into Maternal Morbidity. All documents are fully anonymised prior to undergoing confidential review. Each woman's care is examined by multidisciplinary expert reviewers and assessed against current guidelines and standards (such as that produced by the National Institute for Health and Care Excellence (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. The new national recommendations to improve future care are presented here, alongside a surveillance chapter reporting three years of UK statistical surveillance data.

Causes and trends

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.

Women aged 35 or older had three-fold higher rates of maternal death compared to women aged 20-24. Inequalities in maternal mortality rates remain with a nearly three-fold difference in rates amongst women from Black ethnic backgrounds and an almost two-fold difference amongst women from Asian ethnic backgrounds compared to White women. Nine percent of the women who died during or up to six weeks after pregnancy in the UK in 2020-22 were at severe and multiple disadvantage. The main elements of multiple disadvantage were a mental health diagnosis, substance use and domestic abuse. Women living in the most deprived areas continue to have maternal mortality rates twice that of women living in the least deprived areas, emphasising the need for a continued focus on action to address these disparities.

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

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.

Lessons learned from the confidential enquiries into the care of women who died

This year's confidential enquiries into maternal deaths identified lessons learned from the care of women who died from thrombosis and thromboembolism, malignancies and ectopic pregnancy. Assessors identified many common themes across these topics including the importance of recognising concerning symptoms that indicate underlying conditions. For many women, symptoms such as persistent nausea and vomiting or pain requiring opioids were inappropriately attributed to pregnancy without further investigation of the cause. 'Red flag' symptoms or symptoms requiring repeat presentation are not normal and care should be escalated if women voice concerns. There was evidence of confusion in when and how to use venous thromboembolism (VTE) risk assessment tools and interpret a woman's risk score. Research is needed to restructure the current national assessment tool to make it clearer, more accurate and easier to use. Many women died from VTE in early pregnancy including several at high-risk of VTE, which emphasises the importance of early risk assessment as well as clear pathways for prescribing thromboprophylaxis so women are able to access medication at all stages of care.

Assessors also noted delays in pre-hospital care that may have impacted women's care. This was particularly apparent in the care of women who died from ectopic pregnancy, many of whom faced significant delays in the arrival of ambulance services or in transfer to hospital. In some instances, assessors felt that pregnancy was not considered as part of the differential diagnosis until women arrived in the emergency department and abdominal bleeding was discovered by point-of-care ultrasound. Bleeding from a ruptured ectopic pregnancy requires urgent diagnosis and surgical intervention. It is important to recognise the symptoms and consider the possibility of pregnancy in any woman of reproductive age who collapses.

Many women who died from malignancies, and several who died from VTE, were denied or received inappropriate imaging and treatment because they were pregnant. For many this meant that their symptoms or the extent of their disease was not recognised. Multidisciplinary input and senior review can help facilitate discussions about what imaging modalities and treatments are appropriate for pregnant or recently pregnant women so they can receive the care they need when they need it. This includes discussions around end-of-life planning and palliative care.

Lessons learned from the morbidity confidential enquiry into the care of recent migrant women with language difficulties

It was evident from the care of the women reviewed as part of this year's morbidity enquiry, that many women who had recently arrived in the UK did not understand the NHS or how to access maternity services. Many women booked late in pregnancy and several presented for the first time in pregnancy to the emergency department. Clearer guidance is needed on how to register with a GP who can offer a clear path into maternity services. Most women did not receive adequate support for their language needs throughout their care, as these needs were not regularly documented and professional interpreter services were not available at many interactions including both scheduled visits and in emergency situations. Many women relied on family members or friends to interpret, which is not recommended. In many instances, written information, including consent forms and discharge materials, was also provided in English with no apparent consideration for the woman's level of English or overall literacy. It is important that all information provided verbally or in writing is understood so that women are able to make informed decisions about their health and the health of their babies.

Key messages to improve care

The majority of recommendations that 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. All recommendations based on existing guidance are presented in the relevant chapter of the full, compiled report. Actions needed for which national guidelines are not available are presented below.

New national recommendations to improve care

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]**

Conclusions

This report includes the surveillance information for women who died during and after pregnancy for 2020-22. The maternal mortality rate for this period is significantly higher than that reported that for 2017-19 and this remains significantly higher when deaths due to COVID-19 are excluded. The reasons for this increasing rate are multiple. It was evident from the care of the women reviewed in the confidential enquires that service-related changes necessitated by the COVID-19 pandemic impacted women's care as many faced significant delays when accessing pre-hospital care and others were not provided with specialist supports, such as interpreter services, due to limited availability. However, there were many factors that assessors identified that may be contributing to the increased rate of maternal mortality independent of the COVID-19 pandemic. As discussed in this and previous reports, the current maternity population is becoming more complex. Many of the women who died were older than 35 years of age and the majority were overweight or obese. Many also had multiple morbidities or had multiple adversities including mental health conditions and social complexities. Inequalities also continue persist amongst women from Black and Asian ethnic backgrounds and in women living in the most deprived areas. Addressing these inequalities, complexities and mental health concerns must remain an important focus in order to improve outcomes and prevent maternal deaths.

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Matthew Jolly, National Clinical Director for Maternity Review and Women's Health, NHS England (Past chair)
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Munira Oza, The Ectopic Pregnancy Trust
Nicky Lyon, Campaign for Safer Births
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Royal College of Midwives
Royal College of Paediatrics and Child Health
Royal College of Emergency Medicine
Royal College of Psychiatrists
Faculty of Public Health
Royal Society of Medicine
Royal College of Anaesthetists
Obstetric Anaesthetists' Association
Royal College of General Practitioners
Royal College of Nursing
Royal College of Pathologists
British Association of Perinatal Medicine
British Maternal and Fetal Medicine Society

Glossary of terms

AACE	Association of Ambulance Chief Executives
BMI	Body mass index
CEA	Carcinoembryonic antigen
CI	Confidence interval
CMACE	Centre for Maternal and Child Enquiries
COVID-19	Coronavirus disease 2019
CPR	Cardiopulmonary resuscitation
CT	Computed tomography
CTPA	CT pulmonary angiogram
CVST	Cerebral venous sinus thrombosis
DOAC	Direct oral anti-coagulant
DVT	Deep vein thrombosis
EPAU	Early Pregnancy Assessment Unit
ER	Estrogen receptor
ESMO	European Society for Medical Oncology
FAST Scan	Focused Assessment with Sonography in Trauma Scan
GP	General practitioner
HCG	Human chorionic gonadotropin
HER	Human epidermal growth factor receptor
HQIP	Healthcare Quality Improvement Partnership
HSIB	Healthcare Safety Investigation Branch
ICD-MM	International Classification of Diseases – Maternal Mortality
ICU	Intensive care unit
IMD	Index of Multiple Deprivation
IV	Intravenous
IVF	*In vitro* fertilisation
JRCALC	Joint Royal Colleges Ambulance Liaison Committee
LMWH	Low molecular weight heparin
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MDE Ireland	Maternal Death Enquiry Ireland
MEWS	Maternity Early Warning Score
MMN	Maternal medicine network
MNSI	Maternity and Newborn Safety Investigations
MRI	Magnetic resonance imaging
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NEWS	National Early Warning Score
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIMACH	Northern Ireland Maternal and Child Health
POCUS	Point-of-care ultrasound
PR	Progesterone receptor
PUQE	Pregnancy-Unique Quantification of Emesis
RCOG	Royal College of Obstetricians and Gynaecologists
RH	Resuscitative hysterotomy
RR	Rate ratio (or relative risk)
RRR	Ratio of relative risks
VTE	Venous thromboembolism

Contents

1. Introduction and methods

Allison Felker and Marian Knight

1.1 The 2024 Saving Lives, Improving Mothers' Care report

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 multiple outputs instead of one report as previously produced.

The following outputs have been produced and are available online: ***www.npeu.ox.ac.uk/mbrrace-uk/reports***

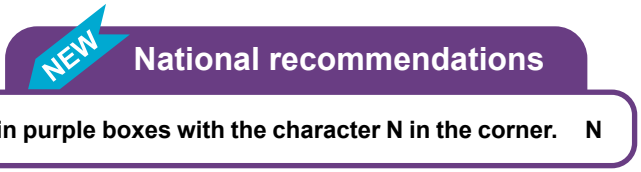
1. A Data Brief with basic statistics concerning maternal mortality published online in advance of the reports. In 2024 this includes information on women who died between 2020 and 2022.
2. A State of the Nation report highlighting the key surveillance findings, new national recommendations and lessons learned from confidential enquiries. In 2020-22 this includes reviews of the care received by women who died from thrombosis and thromboembolism, malignancy or ectopic pregnancy and recent migrant women with language difficulties who experienced morbidity.
3. This compiled report, which includes the full data on maternal mortality rates and the characteristics of the women who died and further lessons and quality improvement messages identified in the mortality and morbidity confidential enquiries. Also included in this compiled report are the background, aims and scope of work, details of methods and author lists.

1.2 Key to colour coding

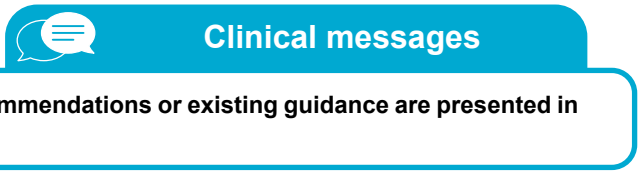
Vignettes concerning the care of women who died are described in blue shaded boxes.

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

Recommendations based on improvements to care identified by MBRRACE-UK reviewers, for which there is no current national guidance and which have not been noted in previous guidance or MBRRACE-UK reports are shown in purple boxes as below:



Clinical messages based on previous recommendations or existing guidance and identiftied by MBRRACE-UK reviewers as needing emphasis are presented in blue boxes.



The majority of recommendations included in the report arise from existing national guidance or previous MBRRACE-UK reports. The source of these recommendations are cited within green boxes as below:

All existing guidance requiring improved implementation is presented in green boxes

NICE 2345

All new recommendations and existing recommendations identified by MBRRACE-UK reviewers as frequently needing improvement are highlighted in the key messages section at the start of each chapter. The professional groups who need to take action are indicated alongside new recommendations.

1.3 Terminology

MBRRACE-UK uses the terms ‘mother and ‘women’ throughout our reports to refer to those who are planning to become pregnant, are pregnant, or who have given birth. We acknowledge that not all people who are pregnant or give birth identify as women or mothers. It is important that evidence-based care for maternity, perinatal and postnatal health is inclusive and personalised to respect people’s gender identities.

2. Maternal mortality in the UK 2020-22: surveillance and epidemiology

Allison Felker and Marian Knight

2.1 Key messages

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.

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.

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.

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.

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 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 that 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). As in previous MBRRACE-UK maternal reports, information about deaths from the Republic of Ireland is not included in this chapter and therefore rates and numbers presented here are comparable with all previous UK reports.

Table 2.1 and Figure 2.1 show rolling three-yearly maternal death rates since 2003 using ICD-MM. The overall decrease in the maternal death rate described in past years' MBRRACE-UK reports does not continue in 2020-22; there is no statistically significant change in the maternal death rate between 2003-05 and 2020-22 (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 deaths including (RR 1.00, 95% CI 0.79-1.26, p=0.142) and excluding (RR 0.74, 95% CI 0.57-0.95, p=0.001) deaths attributable to COVID-19. The direct maternal death rate has continued to rise and is now comparable to rates in 2003-05 (RR 0.94, 95% CI 0.74-1.20, p=0.441).

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).

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).

Discrete triennial rates are shown in Table 2.2 and Figure 2.2. Note that these figures are unchanged from those reported in the 2023 report as there has not been a complete new triennium since.

Table 2.1: Three-year rolling average direct and indirect maternal mortality rates per 100,000 maternities, deaths classified using ICD-MM; UK 2003-22

3-year period	Total UK maternities	Direct deaths			Indirect deaths			Total Direct and Indirect deaths		
		n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
2003–05	2 114 004	143	6.76	5.70 – 7.97	152	7.19	6.09 – 8.43	295	13.95	12.45 – 15.64
2004–06	2 165 909	124	5.73	4.76 – 6.83	148	6.83	5.78 – 8.03	272	12.56	11.15 – 14.14
2005–07	2 220 979	120	5.40	4.48 – 6.46	139	6.26	5.26 – 7.39	259	11.66	10.32 – 13.17
2006–08	2 291 493	120	5.24	4.34 – 6.26	141	6.15	5.18 - 7.26	261	11.39	10.09 – 12.86
2007-09	2 331 835	112	4.80	3.95 – 5.78	142	6.09	5.13 – 7.18	254	10.89	9.59 – 12.32
2008-10	2 366 082	99	4.18	3.40 – 5.09	162	6.85	5.83 – 7.99	261	11.03	9.73 – 12.45
2009-11	2 379 014	90	3.78	3.04 – 4.65	163	6.85	5.84 – 7.99	253	10.63	9.36 – 12.03
2010-12	2 401 624	89	3.71	2.98 – 4.56	154	6.41	5.44 – 7.51	243	10.12	8.89 – 11.47
2011-13	2 373 213	83	3.50	2.79 – 4.34	131	5.52	4.62 – 6.55	214	9.02	7.85 – 10.31
2012–14	2 341 745	81	3.46	2.75 – 4.30	119	5.08	4.21 – 6.08	200	8.54	7.40 – 9.81
2013-15	2 305 920	88	3.82	3.06 – 4.70	114	4.94	4.08 – 5.94	202	8.76	7.59 – 10.05
2014-16	2 301 628	98	4.26	3.46 – 5.19	127	5.52	4.60 – 6.57	225	9.78	8.54 – 11.14
2015-17	2 280 451	87	3.82	3.06 – 4.71	122	5.35	4.44 – 6.39	209	9.16	7.96 – 10.50
2016-18	2 235 159	92	4.12	3.32 – 5.05	125	5.59	4.66 – 6.66	217	9.71	8.46 – 11.09
2017-19	2 173 810	78	3.59	2.84 – 4.48	113	5.20	4.28 – 6.25	191	8.79	7.58 – 10.12
2018-20	2,101,829	109	5.19	4.26 – 6.26	120	5.71	4.73 – 6.83	229	10.90	9.53 – 12.40
2019-21	2,066,997	113	5.47	4.51 – 6.57	128	6.19	5.17 – 7.36	241	11.66	10.23 –13.23
2020-22	2,028,543	129	6.36	5.31 – 7.56	146	7.20	6.08 – 8.46	275	13.56	12.00 – 15.26

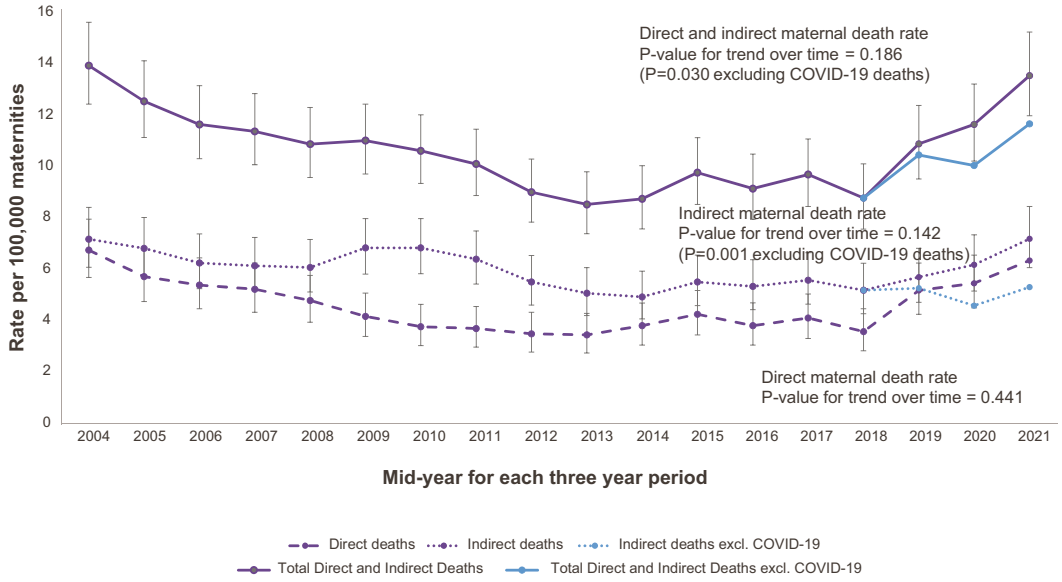
Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Table 2.2: Direct and Indirect maternal deaths and mortality rates per 100,000 maternities by discrete triennia, UK using ICD-MM; UK 2003-20

Triennium	Direct deaths recorded			Indirect deaths recorded			Total Direct and Indirect deaths recorded		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
2003–05	143	6.76	5.70 – 7.97	152	7.19	6.09 – 8.43	295	13.95	12.45 – 15.64
2006–08	120	5.24	4.34 – 6.26	141	6.15	5.18 – 7.26	261	11.39	10.09 – 12.86
2009-11	90	3.78	3.04 – 4.65	163	6.85	5.84 – 7.99	253	10.63	9.36 – 12.03
2012–14	81	3.46	2.75 – 4.30	119	5.08	4.21 – 6.08	200	8.54	7.40 – 9.81
2015-17	87	3.82	3.06 – 4.71	122	5.35	4.44 – 6.39	209	9.16	7.96 – 10.50
2018-20	109	5.19	4.26 – 6.26	120	5.71	4.73 – 6.83	229	10.90	9.53 – 12.40

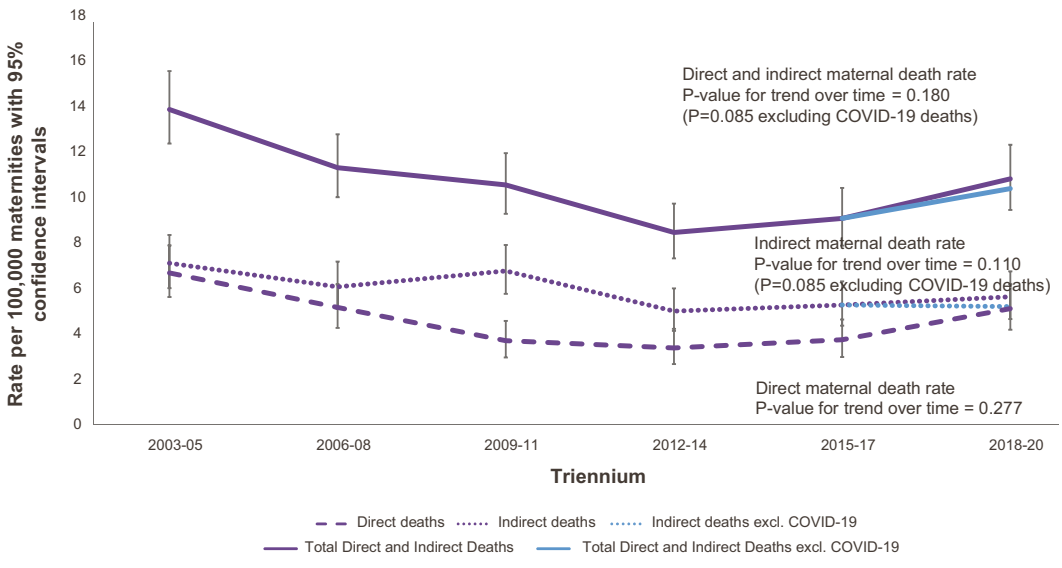
Sources: CMACE, MBRRACE-UK, Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Figure 2.1: Direct and indirect maternal mortality rates per 100,000 maternities using ICD-MM and previous UK classification systems; three-year rolling average rates 2003-2022



Sources: CMACE, MBRRACE-UK

Figure 2.2: Direct and Indirect maternal mortality rates per 100,000 maternities by discrete triennia; UK 2003-2020 (using ICD-MM)

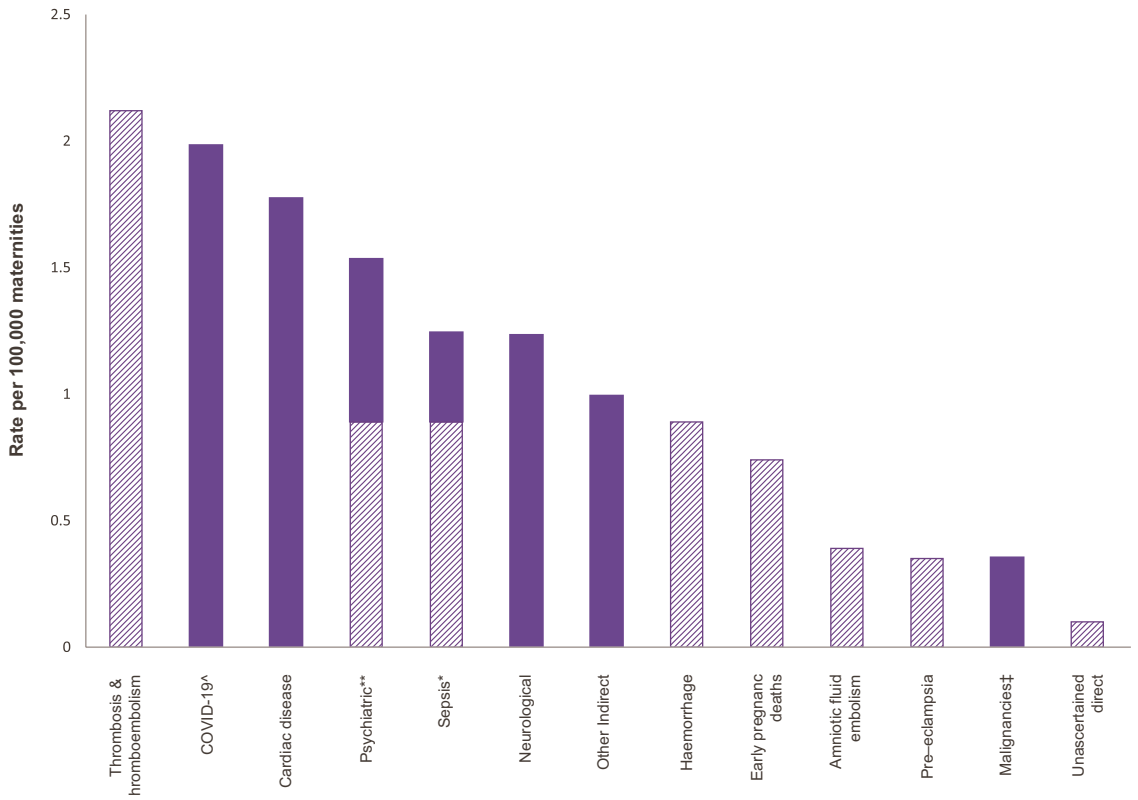


Sources: CMACE, MBRRACE-UK

Deaths due to individual causes

Maternal deaths by cause are shown in Figure 2.3 and Tables 2.3 and 2.4. Rolling three-year rates for individual causes are presented for five overlapping triennial reporting periods (2016-18, 2017-19, 2018-20, 2019-21 and 2020-22) (Table 2.3) and for discrete, non-overlapping triennial periods between 1985-7 and 2018-20 (Table 2.4). This current report is the second report in a three-year cycle, therefore Table 2.4 is unchanged from the 2023 report; deaths by suicide have been included amongst indirect deaths in Table 2.4 to allow for comparability to earlier years. Three-year rolling rates for causes of death classified according to ICD-MM sub-groups are presented in Table 2.5 and Figure 2.4.

Figure 2.3: 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

Table 2.3: Maternal mortality rates per 100,000 maternities, by cause, by overlapping triennia, 2016 to 2022

	2016 - 2018			2017-19			2018-20			2019-21			2020-22		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
All Direct and Indirect deaths	217	9.71	8.46 – 11.09	191	8.79	7.58 – 10.12	229	10.90	9.53 – 12.40	241	11.66	10.23 – 13.23	275	13.56	12.00 – 15.26
Direct deaths															
Pregnancy related infections - Sepsis*	12	0.54	0.28 – 0.94	13	0.60	0.32 -1.02	17	0.81	0.47 – 1.29	15	0.73	0.41 – 1.20	18	0.89	0.53 – 1.40
Pre-eclampsia and eclampsia	4	0.18	0.05 – 0.46	6	0.28	0.10 – 0.60	8	0.38	0.16 – 0.75	9	0.44	0.20 – 0.83	7	0.35	0.14 – 0.71
Thrombosis and thromboembolism	33	1.48	1.02 – 2.07	20	0.92	0.56 – 1.42	29	1.38	0.92 – 1.98	33	1.60	1.10 – 2.24	43	2.12	1.53 – 2.86
Amniotic fluid embolism	6	0.27	0.10 – 0.58	7	0.32	0.13 – 0.66	9	0.43	0.20 – 0.81	8	0.39	0.17 – 0.76	8	0.39	0.17 – 0.78
Early pregnancy deaths	7	0.31	0.13 – 0.65	7	0.32	0.13 – 0.66	9	0.43	0.20 – 0.81	14	0.68	0.37 – 1.14	15	0.74	0.41 – 1.22
Haemorrhage	14	0.63	0.34 – 1.05	14	0.64	0.35 – 1.08	16	0.76	0.44 – 1.24	17	0.82	0.48 – 1.32	18	0.89	0.53 – 1.40
Anaesthesia	1	0.05	0.001 – 0.25	1	0.05	0.001 – 0.26	1	0.05	0.001 – 0.27	1	0.05	0.001 – 0.27	-	-	-
Psychiatric causes - Suicides	14	0.63	0.34 – 1.05	10	0.46	0.22 – 0.85	20	0.95	0.58 – 1.47	16	0.77	0.44 – 1.26	18	0.89	0.53 – 1.40
Malignancy - direct	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Unascertained - direct	1	0.05	0.001 – 0.25	-	-	-	-	-	-	-	-	-	2	0.10	0.01 – 0.34
All Direct	92	4.12	3.32 – 5.05	78	3.59	2.84 – 4.48	109	5.19	4.26 – 6.26	113	5.47	4.51 – 6.57	129	6.36	5.31 – 7.56
Indirect															
Cardiac disease	50	2.24	1.66 – 2.95	36	1.66	1.16 – 2.29	34	1.62	1.12 – 2.26	33	1.60	1.010 – 2.24	36	1.77	1.24 – 2.46
Indirect Sepsis - Influenza	2	0.09	0.01 – 0.32	2	0.09	0.01 – 0.33	2	0.10	0.01 – 0.34	1	0.05	0.001 – 0.27	1	0.05	0.001 – 0.28
Indirect Sepsis – Pneumonia/ others	9	0.40	0.18 – 0.76	8	0.37	0.16 – 0.73	6	0.29	0.11 – 0.62	7	0.34	0.14 – 0.70	6	0.30	0.11 – 0.64
Indirect Sepsis – COVID-19							9	1.60	0.73 – 3.04	33	2.64	1.82 – 3.71	38	1.98	1.40 – 2.72
Other Indirect causes	15	0.67	0.38 – 1.11	19	0.87	0.53 – 1.36	24	1.14	0.73 – 1.70	19	0.92	0.55 – 1.44	20	0.99	0.60 – 1.52
Indirect neurological conditions	29	1.30	0.87 – 1.86	33	1.52	1.04 – 2.13	27	1.28	0.85 – 1.87	22	1.06	0.67 – 1.61	25	1.23	0.80 – 1.82
Psychiatric causes – Drugs/alcohol/others	14	0.63	0.34 – 1.05	10	0.46	0.22 – 0.85	14	0.67	0.36 – 1.12	9	0.44	0.20 – 0.83	13	0.64	0.34 – 1.10
Indirect malignancies	6	0.27	0.10 – 0.58	5	0.23	0.07 – 0.54	4	0.19	0.05 – 0.49	4	0.19	0.05 – 0.50	7	0.35	0.14 – 0.71
All Indirect	125	5.59	4.66 – 6.66	113	5.20	4.28 – 6.25	120	5.71	4.73 – 6.83	128	6.19	5.17 – 7.36	146	7.20	6.08 – 8.46
Coincidental															
Homicide	5	0.22	0.07 – 0.52	4	0.18	0.05 – 0.47	4	0.19	0.05 – 0.49	5	0.24	0.08 – 0.57	6	0.30	0.11 – 0.64
Other coincidental	20	0.90	0.55 – 1.38	16	0.74	0.42 – 1.20	14	0.67	0.36 – 1.12	15	0.73	0.41 – 1.20	15	0.74	0.41 – 1.22
All coincidental	25	1.12	0.72 – 1.65	20	0.92	0.56 – 1.42	18	0.86	0.51 – 1.35	20	0.97	0.559 – 1.49	21	1.04	0.64 – 1.58
Late deaths	305	13.65	12.16 – 15.27	284	13.06	11.59 – 14.68	289	13.75	12.21 – 15.43	311	15.05	13.42 – 16.81	329	16.22	14.51 – 18.07

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

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

Table 2.4: UK Maternal deaths and mortality rates per 100,000 maternities by cause, by discrete triennia, 1985-2020 (Maternal deaths by suicide classified as indirect for comparability)

Cause of death	Numbers												Rates per 100,000 maternities											
	1985-87	1988-90	1991-93	1994-96	1997-99	2000-02	2003-05	2006-08	2009-11	2012-14	2015-17	2018-20	1985-87	1988-90	1991-93	1994-96	1997-99	2000-02	2003-05	2006-08	2009-11	2012-14	2015-17	2018-20
All Direct and Indirect deaths	223	238	228	268	242	261	295	261	253	200	209	229	9.83	10.08	9.85	12.19	11.4	13.07	13.95	11.39	10.63	8.54	9.16	10.90
Direct deaths																								
Sepsis*	9	17	15	16	18	13	18	26	16	7	10	17	0.40	0.72	0.65	0.73	0.85	0.65	0.85	1.13	0.63	0.29	0.44	0.81
Pre-eclampsia and eclampsia	27	27	20	20	16	14	18	19	10	2	5	8	1.19	1.14	0.86	0.91	0.75	0.70	0.85	0.83	0.42	0.08	0.22	0.38
Thrombosis and thromboembolism	32	33	35	48	35	30	41	18	30	20	34	29	1.41	1.40	1.51	2.18	1.65	1.50	1.94	0.79	1.26	0.85	1.49	1.38
Amniotic fluid embolism	9	11	10	17	8	5	17	13	7	16	6	9	0.40	0.47	0.43	0.77	0.38	0.25	0.80	0.57	0.29	0.68	0.26	0.43
Early pregnancy deaths	16	24	17	15	17	15	14	11	4	7	4	9	0.71	1.02	0.73	0.68	0.80	0.75	0.66	0.48	0.17	0.29	0.18	0.43
Haemorrhage	10	22	15	12	7	17	14	9	14	13	11	16	0.44	0.93	0.65	0.55	0.33	0.85	0.66	0.39	0.59	0.56	0.48	0.76
Anaesthesia	6	4	8	1	3	6	6	7	3	2	1	1	0.26	0.17	0.35	0.05	0.14	0.30	0.28	0.31	0.12	0.09	0.04	0.05
Other Direct‡	27	17	14	7	7	8	4	4	0	0	3	0	1.19	0.72	0.60	0.32	0.33	0.40	0.19	0.17	-	-	0.13	-
All direct	139	145	128	134	106	106	132	107	82	67	74	89	6.13	6.14	5.53	6.10	4.99	5.31	6.24	4.67	3.49	2.84	3.24	4.23
Indirect deaths																								
Cardiac disease	23	18	37	39	35	44	48	53	51	51	48	34	1.01	0.76	1.60	1.77	1.65	2.20	2.27	2.31	2.14	2.18	2.10	1.62
Other Indirect causes	43	45	38	39	41	50	50	49	72	38	33	41	1.90	1.91	1.64	1.77	1.93	2.50	2.37	2.14	3.03	1.62	1.45	1.95
Indirect neurological conditions	19	30	25	47	34	40	37	36	30	22	27	27	0.84	1.27	1.08	2.14	1.60	2.00	1.75	1.57	1.26	0.94	1.18	1.28
Psychiatric causes	†	†	†	9	15	16	18	13	13	18	20	34	†	†	†	0.41	0.71	0.80	0.85	0.57	0.55	0.77	0.88	1.62
Indirect malignancies	†	†	†	†	11	5	10	3	4	4	7	4	†	†	†	†	0.52	0.25	0.47	0.13	0.17	0.17	0.31	0.19
All Indirect	84	93	100	134	136	155	163	154	170	133	135	140	3.70	3.94	4.32	6.10	6.40	7.76	7.71	6.59	7.15	5.68	5.92	6.66
Coincidental	26	39	46	36	29	36	55	50	22	41	27	18	1.15	1.65	1.99	1.64	1.37	1.80	2.60	2.18	0.98	1.75	1.18	0.86

*Including early pregnancy deaths as a result of sepsis

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

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

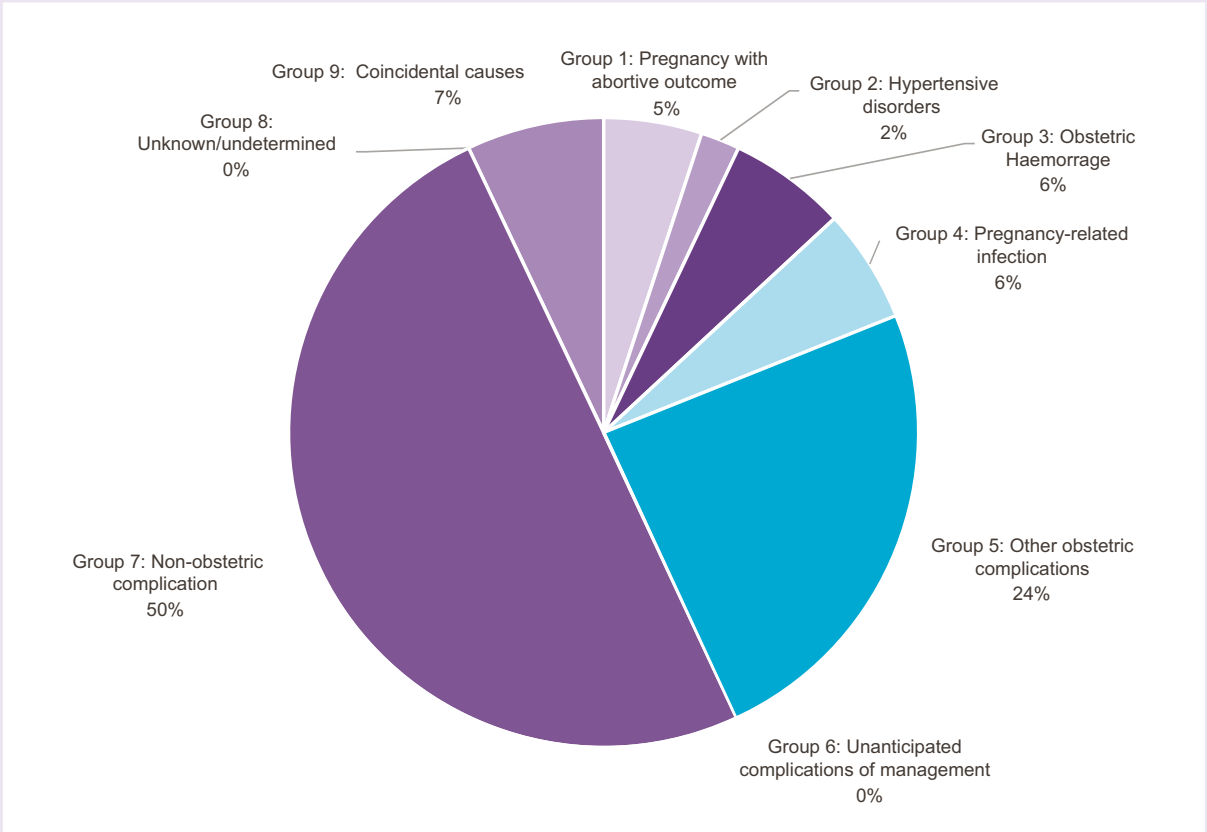
Sources: CMACE, MBRRACE-UK

Table 2.5: Maternal mortality rates per 100,000 maternities, by cause, by overlapping triennia, using ICD-MM classification, 2016-22

Cause of death	2016-18			2017-19			2018-20			2019-21			2020-22		
	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI	n	Rate	95% CI
Direct causes															
Group 1: Pregnancy with abortive outcome	7	0.31	0.13 – 0.65	7	0.32	0.13 – 0.66	9	0.43	0.20 – 0.81	14	0.68	0.37 – 1.14	15	0.74	0.41-1.22
Group 2: Hypertensive disorders	4	0.18	0.05 – 0.46	6	0.28	0.10 – 0.60	8	0.38	0.16 – 0.75	9	0.44	0.20 – 0.83	7	0.35	0.14-0.71
Group 3: Obstetric Haemorrhage	14	0.63	0.34 – 1.05	14	0.64	0.35 – 1.08	16	0.76	0.44 – 1.24	17	0.82	0.48 – 1.32	18	0.89	0.53-1.40
Group 4: Pregnancy-related infection	12	0.54	0.28 – 0.94	13	0.60	0.32 – 1.02	17	0.81	0.47 – 1.29	15	0.73	0.41 – 1.20	18	0.89	0.53-1.40
Group 5: Other obstetric complications	54	2.42	1.81 – 3.15	37	1.70	1.20 – 2.35	58	2.76	2.10 – 3.57	57	2.76	2.09 – 3.57	71	3.50	2.73-4.41
Group 6: Unanticipated complications of management	1	0.05	0.001 – 0.25	1	0.05	0.001 – 0.26	1	0.05	0.001 – 0.27	1	0.05	0.001 – 0.27	-	-	-
Indirect causes															
Group 7: Non-obstetric complications	125	5.59	4.66 to 6.66	113	5.20	4.28 – 6.25	120	5.71	4.73 – 6.83	128	6.19	5.17 – 7.36	146	7.20	6.08-8.46
Group 8: Unknown/ undetermined	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Coincidental causes															
Group 9: Coincidental causes	25	1.12	0.72 – 1.65	20	0.92	0.56 – 1.42	18	0.86	0.51 – 1.35	20	0.97	0.559 – 1.49	21	1.04	0.64-1.58

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

Figure 2.4: Maternal mortality proportions by ICD-MM classification 2020-22



Direct deaths

Thrombosis and thromboembolism (venous thromboembolism (VTE)) continued to be the leading cause of direct deaths occurring during or within 42 days of the end of pregnancy in 2020-22 (Figure 2.3 and Table 2.3). The maternal mortality rate from VTE has increased over previous years' reports and is now more than twice that of any other direct cause. The 2020-22 mortality rate from VTE has significantly increased compared to 2017-19, the last complete triennium (RR 2.30, 95% CI 1.33-4.14, p=0.002), suggesting that improvements to care identified in chapter 3 of this report are necessary to reverse this trend.

Deaths due to suicide, sepsis and obstetric haemorrhage were the next most frequent direct causes of maternal death in 2020-22, occurring at equal rates. Note that, as described in previous reports, the majority of maternal suicide deaths occur between six weeks and a year after pregnancy. The rates of maternal mortality from suicide, sepsis and haemorrhage continue to marginally increase. Though these increases are not statistically significant, they are consistent and represent a troubling trend of increasing maternal deaths due to direct causes. Similarly, deaths in early pregnancy while not significantly increased from previous years, occurred at rates more than twice that of the last complete triennium 2017-2019 (RR 2.30 95% CI 0.88-6.66, p=0.066). Relevant lessons for the care of women who died in early pregnancy from ectopic pregnancy are discussed in chapter 5 of this report. The maternal death rate from pre-eclampsia and eclampsia was non-significantly lower than in 2019-21 but remained four times higher than the lowest observed rate in 2012-14. Mortality rates from amniotic fluid embolism remain essentially unchanged and no deaths due to anaesthetic causes were identified in 2020-22.

Indirect deaths

Deaths due to indirect causes comprise just over half (53%) of direct and indirect maternal deaths in the UK. COVID-19 remained 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, as in previous reports, cardiac disease remains the largest single cause of indirect maternal deaths (1.77 per 100,000 maternities (95% CI 1.24-2.46)) (Figure 2.3 and Table 2.3). There has been a decrease in the maternal mortality rate from cardiac disease since enhanced case ascertainment was introduced (2003-05) but this is not statistically significant (RR 0.78, 95% CI 0.49-1.23) and maternal death rates due to cardiac disease increased in 2020-22 after steady decreases in the three preceding, overlapping triennia. In the 2020-22 triennium, neurological causes were the third most common indirect cause of maternal death, with a statistically non-significant decrease in mortality compared to 2017-19. Mortality rates from other indirect causes have increased, although non-significantly, since 2017-19 and are comparable to rates in 2019-21.

International comparison

For international comparison, data are presented in Table 2.6 to highlight the maternal mortality ratios estimated for the UK using routinely reported data. The rate estimate from routine sources of data is much lower (just over half) than the actual rates as identified through MBRRACE-UK, which uses multiple sources of death identification. This emphasises the importance of the additional case identification and checking undertaken by the MBRRACE-UK team to give an accurate maternal mortality estimate.

Table 2.6: Maternal mortality ratios* per 100,000 live births calculated based on deaths identified from routine sources of data, UK: 1985-2020

Triennium	No. of deaths identified through death certificates	Maternal mortality ratio	95% CI	Denominator number of live births
1985-87	174	7.67	6.61-8.90	2,268,766
1988-90	171	7.24	6.24-8.42	2,360,309
1991-93	150	6.48	5.52-7.60	2,315,204
1994-96	158	7.19	6.15-8.40	2,197,640
1997-99	128	6.03	5.70-7.17	2,123,614
2000-02	136	6.81	5.76-8.05	1,997,472
2003-05	149	7.05	6.00-8.27	2,114,004
2006-08	155	6.76	5.78-7.92	2,291,493
2009-11	134	5.57	4.67-6.60	2,405,251
2012-14	110	4.65	3.82-5.60	2,368,125
2015-17	95	4.10	3.32-5.01	2,317,363
2018-20	129	6.04	5.04-7.18	2,136,242

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

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

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

In the triennium 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). This compares to a late pregnancy-related mortality rate of 13.66 per 100,000 maternities in 2009-11, the first MBRRACE-UK confidential enquiry report (RR 1.19, 95% CI 1.02-1.39, p=0.219 for trend in rolling rates over time). The rate of late deaths has been consistently rising across the previous overlapping triennia, and is now significantly increased from 2017-19 (RR 1.24 95% CI 1.06-1.46, p=0.008). Rolling rates of late deaths are shown in Figure 2.5 and causes of late death in Figure 2.6. In 2020-22, maternal suicides continued 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 accounted for 34% of maternal deaths during this period.

Figure 2.5: Pregnancy-associated maternal mortality rates six weeks to one year after the end of pregnancy, UK, 2009-2022

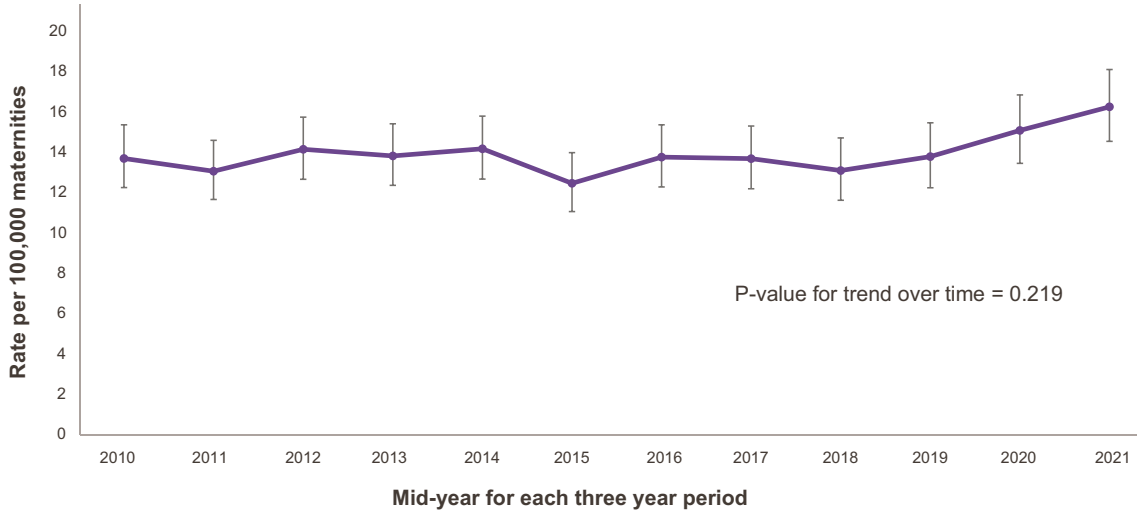
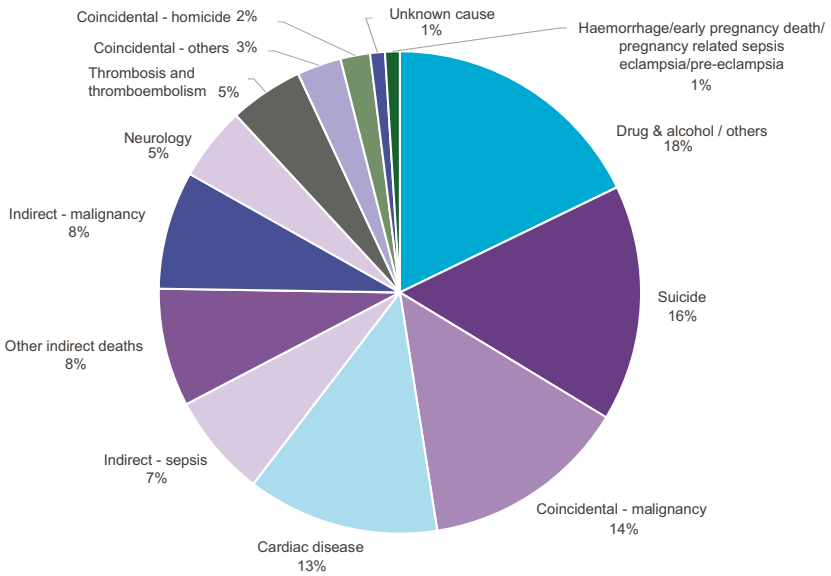


Figure 2.6: Causes of death amongst women who died between six weeks and one year after the end of pregnancy, UK 2020-22



2.3 The characteristics of women who died 2020-22

The women and babies

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 (Table 2.7). Thirty-three (12%) women had a pregnancy loss at ≤20 weeks' gestation. The remaining 163 women gave birth to a total of 166 infants, 116 (70%) survived and 50 died (34 babies were stillborn and 16 died in the neonatal period). The 275 women who died left behind a further 385 children; thus, a total of 501 motherless children remain. The majority of the 163 women who gave birth did so in hospital (83%). A further 9% of women gave birth in an emergency department or an ambulance and 8% at home (Table 2.8). In this triennium 121 (74%) of the women who gave birth at ≥20 weeks' gestation had a caesarean birth; 33% of these were a resuscitative hysterotomy as part of attempted resuscitation of the woman. A total of 43 babies were born following resuscitative hysterotomy of which 18 (42%) were born after 32 weeks' gestation. Seven out of the 18 babies born after 32 weeks' gestation survived, six were stillborn and five died in the neonatal period. Of the 25 babies delivered at 32 weeks or less, six survived, 14 were stillborn and five died in the neonatal period. Thus, 13 (30%) of the total of 43 babies born following resuscitative hysterotomy survived, 20 (47%) were stillborn and 10 (23%) died in the neonatal period.

Table 2.7: Timing of maternal deaths in relation to pregnancy 2020-22

Time period of deaths in the pregnancy care pathway	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Total (n=275) Frequency (%)
Antenatal period			
≤20 weeks	34 (26)	156 (11)	50 (18)
>20 weeks	7 (5)	22 (15)	29 (11)
Postnatal on day of delivery	32 (25)	23 (16)	55 (20)
Postnatal 1-41 days after delivery	56 (43)	85 (58)	141 (51)

Table 2.8: Place of childbirth amongst women >20 weeks' gestation who died after giving birth 2020-22

	Direct (n=71) Frequency (%)	Indirect (n=92) Frequency (%)	Total (n=163) Frequency (%)
Home	6 (8)	7 (8)	13 (8)
Hospital (except emergency department)	61 (86)	74 (80)	135 (83)
Emergency department or ambulance	4 (6)	11 (12)	15 (9)

Socio-demographic characteristics

The socio-demographic characteristics of women who died in 2020-22 are shown in Table 2.9.

The rates of maternal mortality varied by age, socio-economic status and ethnic background of the women, factors that are known to be independently associated with an increased risk of maternal death in the UK (Nair, Kurinczuk et al. 2015, Nair, Knight et al. 2016). Maternal mortality rates were highest amongst women aged 35 and older, those living in the most deprived areas and amongst women from particular ethnic minority groups (Table 2.10).

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.

While women living in the most deprived areas continued to have the highest maternal mortality rates there has been an increase in recent years in maternal mortality in women living in all areas, including the least deprived areas. In 2020-22, the mortality rate for women living in the least deprived areas was higher than that of women living in the second Index of Multiple Deprivation (IMD) quintile (Table 2.10 and Figure 2.7). This increase in the mortality rate of the group used as the baseline needs to be borne in mind when interpreting the relative risks and ratio of relative risks (Tables 2.10 and 2.11).

As noted in the 2016 report, we are no longer able to obtain denominator figures for specific ethnic groups, instead aggregate rates using larger ethnicity groupings are presented in Tables 2.10 and 2.11 and Figure 2.8. 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 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).

Table 2.9: The socio-demographic characteristics of women who died 2020-22

Characteristics	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Total (n=275) Frequency (%)
Age			
<20	3 (2)	2 (1)	5 (2)
20 – 24	11 (9)	7 (5)	18 (7)
25 – 29	30 (23)	33 (23)	63 (23)
30 – 34	39 (30)	40 (27)	79 (29)
35 – 39	29 (22)	47 (32)	76 (28)
≥ 40	17 (13)	17 (12)	34 (12)
Parity			
0	42 (33)	42 (29)	84 (31)
1 to 2	62 (48)	71 (49)	133 (48)
≥3	22 (17)	32 (22)	54 (20)
Missing	3 (2)	1 (1)	4 (1)
UK citizen			
Yes	107 (83)	125 (86)	232 (84)
No	9 (7)	12 (8)	21 (8)
Missing	13 (10)	9 (6)	22 (8)
Ethnicity			
White European	91 (71)	92 (63)	183 (67)
Indian	6 (5)	8 (6)	14 (5)
Pakistani	2 (2)	17 (12)	19 (7)
Bangladeshi	2 (2)	2 (1)	4 (1)
Other Asian	4 (3)	3 (2)	7 (3)
Black Caribbean	3 (2)	5 (3)	8 (3)
Black African	4 (3)	13 (9)	17 (6)
Others/ Mixed	13 (10)	5 (3)	18 (7)
Missing	4 (3)	1 (1)	5 (2)
Woman's region of birth			
United Kingdom	90 (70)	100 (68)	190 (69)
Eastern Europe	5 (4)	5 (3)	10 (4)
Western Europe	0 (0)	2 (1)	2 (1)
Asia	9 (7)	20 (14)	29 (11)
Africa	6 (5)	9 (6)	15 (5)
Australia and North America	1 (1)	0 (0)	1 (<1)
Central & South America & Caribbean	1 (1)	0 (0)	1 (<1)
Missing	17 (13)	10 (7)	27 (10)
Socio-economic status (Index of Multiple Deprivation (IMD) of postcode of residence)			
First quintile (Least deprived)	16 (12)	11 (8)	27 (10)
Second quintile	13 (10)	15 (10)	28 (10)
Third quintile	31 (24)	22 (15)	53 (19)
Fourth quintile	23 (18)	32 (22)	55 (20)
Fifth quintile (Most deprived)	39 (30)	56 (38)	95 (35)
Missing	7 (5)	10 (7)	17 (6)
Socio-economic status (Occupational classification)			
Employed (Either woman or partner)	83 (64)	108 (74)	191 (69)
Unemployed (Both)	14 (11)	23 (16)	37 (13)
Missing	32 (25)	15 (10)	47 (17)
Able to speak/understand English			
Yes	120 (93)	140 (96)	260 (95)
No	4 (3)	6 (4)	10 (4)
Missing	5 (4)	0 (0)	5 (2)
Living arrangements			
With partner	94 (73)	109 (75)	203 (74)
Living alone	9 (7)	9 (6)	18 (7)
With parents/extended family	10 (8)	8 (5)	18 (7)
Others	5 (4)	11 (8)	16 (6)
Missing	11 (9)	9 (6)	20 (7)
Domestic abuse (prior to pregnancy/ during pregnancy)			
Yes	22 (17)	21 (14)	43 (16)
No	56 (43)	91 (62)	147 (53)
Missing	51 (40)	34 (23)	85 (31)
History of abuse as a child			
Yes	12 (9)	3 (2)	15 (5)
No	53 (41)	78 (53)	131 (48)
Missing	64 (50)	65 (45)	129 (47)
Known to social services			
Yes	32 (25)	29 (20)	61 (22)
No	72 (56)	102 (70)	174 (63)
Missing	25 (19)	15 (10)	39 (15)

As highlighted in the 2023 report, disparities in mortality rates between ethnic groups are partly driven by a disproportionate number of maternal deaths from COVID-19 amongst women from ethnic minority groups. Of the 38 women who died from COVID-19 in 2020-22, 16 were Asian (12 of Pakistani origin) and six were Black. Compared to 2019-21, there was a statistically significant increase in the mortality rate for White women in 2020-22 (RR 1.26, 95% CI 1.00-1.60, p=0.048). As with the IMD quintiles, this increase in the mortality rate of the group used as the baseline must be borne in mind when interpreting the relative risks and ratio of relative risk for different ethnic groups (Table 2.10 and 2.11).

A comparison of relative risks between 2017-19 and 2020-22 and estimated ratios of relative risk of maternal death for different age groups, IMD quintiles and ethnic groups are shown in Table 2.11. There were no statistically significant differences in the relative risks for any age or ethnic group between 2017-19 and 2020-22. While not statistically significantly different, the relative risk for women living in IMD III in 2020-22 is more than two times higher than in 2017-2019 (RRR 2.33, 95% CI 0.96-5.45, p=0.056).

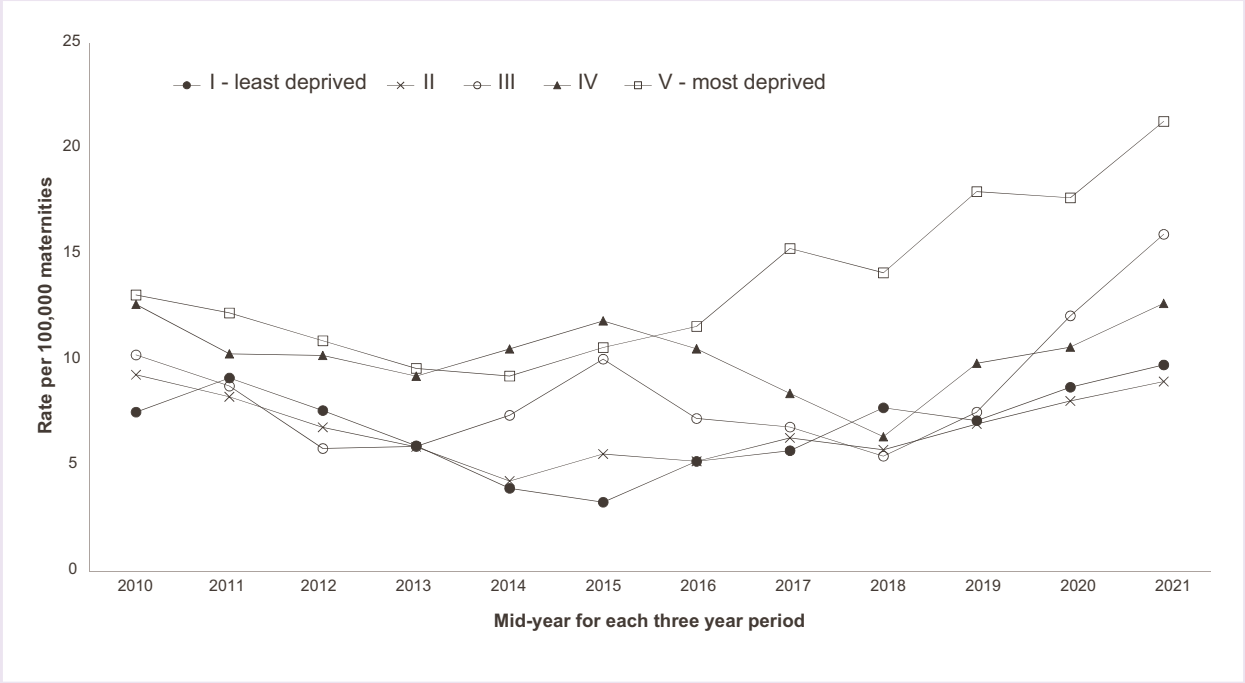
Table 2.10: Maternal mortality rates amongst different population groups 2020-22 (illustrated in Figures 2.7 and 2.8)

	Total maternities 2020-22	Total deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
Age (years)						
<20	49,130	5	10.18	3.30 to 23.75	1.42	0.41 to 3.97
20–24	251,497	18	7.16	4.24 to 11.31	1 (Ref)	-
25–29	534,336	63	11.79	9.06 to 15.08	1.65	0.96 to 2.96
30–34	693,638	79	11.39	9.02 to 14.19	1.59	0.94 to 2.82
35–39	401,169	76	18.94	14.93 to 23.71	2.65	1.57 to 4.70
≥ 40	98,601	34	33.48	23.88 to 48.18	4.82	2.65 to 9.06
IMD Quintiles (England only)						
I (Least deprived/ highest 20%)	245,864	24	9.76	6.25 to 14.52	1 (Ref)	-
II	278,737	25	8.97	5.80 to 13.24	0.92	0.50 to 1.68
III	307,350	49	15.94	11.79 to 21.08	1.63	0.98 to 2.78
IV	355,050	45	12.67	9.24 to 16.96	1.30	0.77 to 2.23
V (Most deprived/ lowest 20%)	413,519	88	21.28	17.07 to 26.22	2.18	1.38 to 3.58
Ethnic group (England only)						
White (inc. not known)	1,291,758	158	12.23	10.40 to 14.29	1 (Ref)	-
Asian	203,369	41	20.16	14.47 to 27.35	1.65	1.14 to 2.34
Black	82,621	29	35.10	23.51 to 50.41	2.87	1.86 to 4.28
Chinese/ others	71,074	6	8.44	3.10 to 18.37	0.69	0.25 to 1.54
Mixed	36,712	6	16.34	6.00 to 35.57	1.34	0.48 to 2.97

Table 2.11: Comparison of the relative risk of maternal death among different population groups between 2017-19 and 2020-22 (illustrated in Figures 2.7 and 2.8)

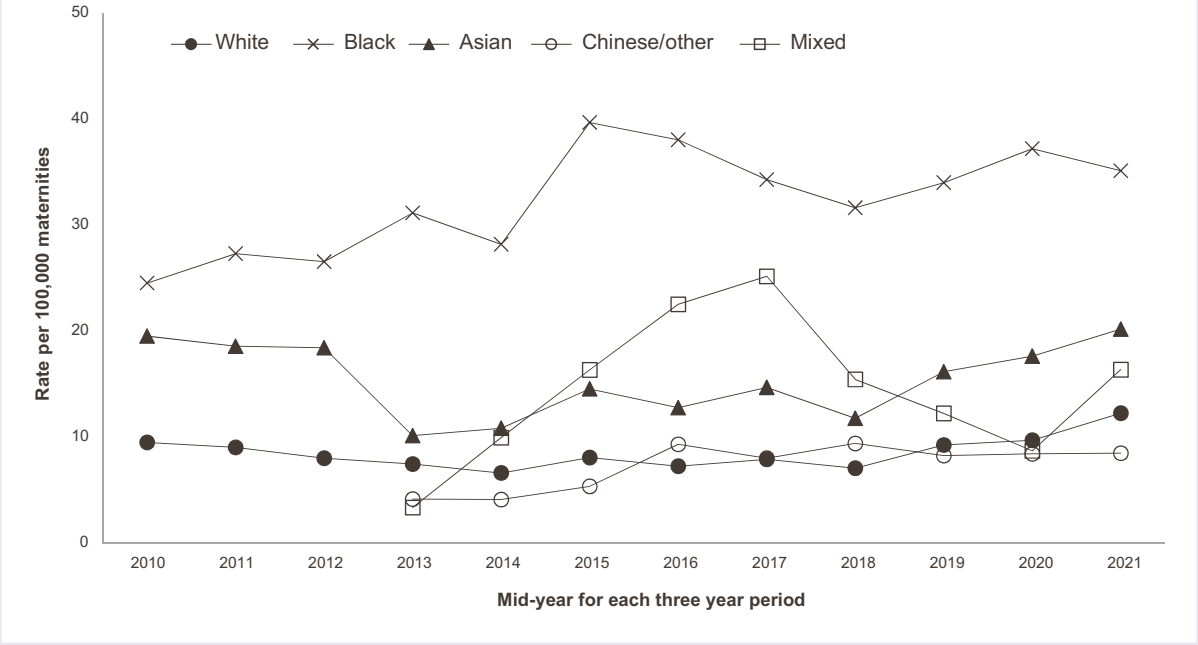
	2017-19		2020-22		Ratio of the relative risks (RRR) (comparing 2020-22 with 2017-19)	95% CI	P-value
	Relative risk (RR)	95% CI	Relative risk (RR)	95% C			
Age (years)							
<20	2.25	0.90 to 5.23	1.42	0.41 to 3.97	0.63	0.15 to 2.65	0.530
20–24	1 (Ref)	-	1 (Ref)	-	-	-	-
25–29	1.36	0.79 to 2.44	1.65	0.96 to 2.96	1.21	0.55 to 2.69	0.635
30–34	1.04	0.60 to 1.89	1.59	0.94 to 2.82	1.53	0.68 to 3.34	0.295
35–39	1.73	0.99 to 3.13	2.65	1.57 to 4.70	1.53	0.69 to 3.39	0.293
≥ 40	3.72	1.92 to 7.27	4.82	2.65 to 9.06	1.30	0.51 to 3.12	0.575
IMD Quintiles (England only)							
I (Least deprived/ highest 20%)	1 (Ref)	-	1 (Ref)	-	-	-	-
II	0.74	0.37 to 1.49	0.92	0.50 to 1.68	1.24	0.50 to 3.12	0.643
III	0.70	0.35 to 1.40	1.63	0.98 to 2.78	2.33	0.96 to 5.45	0.056
IV	0.82	0.44 to 1.56	1.30	0.77 to 2.23	1.59	0.69 to 3.62	0.275
V (Most deprived/ lowest 20%)	1.83	1.09 to 3.18	2.18	1.38 to 3.58	1.19	0.58 to 2.44	0.632
Ethnic group (England only)							
White (inc. not known)	1 (Ref)	-	1 (Ref)	-	-	-	-
Asian	1.67	1.00 to 2.66	1.65	1.14 to 2.34	0.99	0.54 to 1.82	0.970
Black	4.49	2.77 to 7.00	2.87	1.86 to 4.28	0.64	0.34 to 1.20	0.159
Chinese/ others	1.33	0.52 to 2.84	0.69	0.25 to 1.54	0.52	0.15 to 1.80	0.301
Mixed	2.19	0.70 to 5.28	1.34	0.48 to 2.97	0.61	0.16 to 2.37	0.480

Figure 2.7: Maternal mortality rates 2009-22 among women from different levels of socio-economic deprivation in England*



*Data for England only due to availability of denominator data

Figure 2.8: Maternal mortality rates 2009-22 among women from different ethnic groups in England*



*Data for England only due to availability of denominator data

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 and citizenship was not recorded for a further 17%. Overall 8% of the women who died were not UK citizens although this may be an underestimate since citizenship was not recorded for 8% (Table 2.9). Women who died, who were born abroad and who were not UK citizens had arrived in the UK a median of 3 years before they died (range 3 months to 19 years). Women who died and who were born abroad were from Asia (50%, mainly Pakistan, India, and Bangladesh), Africa (26%, in particular South Africa, Ghana and Somalia) and Eastern Europe (17%, predominantly Poland, Romania and Slovakia) with the remainder (7%) from other parts of Europe, the Americas, Australasia and the Caribbean. Note that almost all of the deaths of women who were born in Pakistan were due to COVID-19. Table 2.12 shows the rates of death amongst women born in selected countries with the highest number of deaths. Similar to the previous triennium, there was no statistically significant difference in 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 rates compared to women born in the UK (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 chapter 6 of this report. Of the 21 women who died who were born outside the UK, and who were known not to be UK citizens, none were refugee/asylum seekers, six were European Union citizens (29%) and 15 (71%) had another or unknown status.

Table 2.12: Maternal mortality rates according to mother's country of birth (selected countries) 2020-22

Woman's country of birth	Maternities 2020-22	Total Deaths	Rate per 100,000 maternities	95% CI	Relative risk (RR)	95% CI
UK	1,456,937*	190	13.04	11.25 to 15.03	1 (Ref)	-
Outside UK	571,606*	58	10.15	7.71 to 13.12	0.78	0.57 to 1.05
Specific countries						
Bangladesh	20,714‡	3	14.48	2.99 to 42.32	1.11	0.23 to 3.30
India	48,974‡	8	16.34	7.05 to 32.18	1.25	0.53 to 2.52
Pakistan	50,666‡	10	19.74	9.47 to 36.29	1.51	0.71 to 2.84
Poland	43,502‡	3	6.90	14.20 to 20.15	0.53	0.11 to 1.57
South Africa	8,854‡	3	33.88	6.99 to 98.99	2.60	0.53 to 7.71

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

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

**Country of birth not recorded for 27 women who died

It is also of note that around a third of the women's records (31%) did not have information on whether they were subject to domestic abuse before or during pregnancy and almost half of the women's records (47%) were missing documentation regarding whether women had a history of abuse as a child. These proportions are similar to those noted in the last three years' reports, but nevertheless represent a substantial proportion of women who were not asked about domestic and/or childhood abuse. This is despite guidance that it is important to enquire about domestic abuse at booking and throughout pregnancy. Moreover, 22% of women who died were known to social services. This proportion is similar to that reported in 2019-21 (21%) but well above the 17% reported in 2017-19, further highlighting the vulnerability of many women who died.

It has been increasingly noted in these enquiries that women at severe disadvantage appear to be over-represented amongst the women who die. Of the 625 women who died in the UK in 2020-22 during or up to one year after pregnancy, 78 (12%) were considered to have multiple disadvantage on the basis of the data available (Table 2.13). This is a similar proportion to that reported for 2019-21 (12%) but a significant increase from the proportions reported for earlier triennia. Note, however, that this change may be a reflection of increasing disadvantage, better recording of data or a combination of both. As in past years, the main elements of multiple disadvantage were a mental health diagnosis (either current or in the past) (78/78 women with multiple disadvantage), domestic abuse (72/78 women) with multiple disadvantage) and substance use (66/78 women with multiple disadvantage). This must continue to be regarded as a minimum estimate, since these three factors remain amongst the most poorly recorded in women's medical records. For all the women who died during pregnancy or within 42 days of the end of pregnancy, information was missing from 10% for mental health diagnoses, 12% for substance use and 31% for domestic abuse.

Table 2.13: Multiple disadvantage among women who died 2020-22

	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Coincidental (n=21) Frequency (%)	Late Deaths (n=329) Frequency (%)	Total (n=625) Frequency (%)
Score* of <3	113 (88)	136 (93)	19 (90)	279 (85)	547 (88)
Score* of 3 or more	16 (12)	10 (7)	2 (10)	50 (15)	78 (12)

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

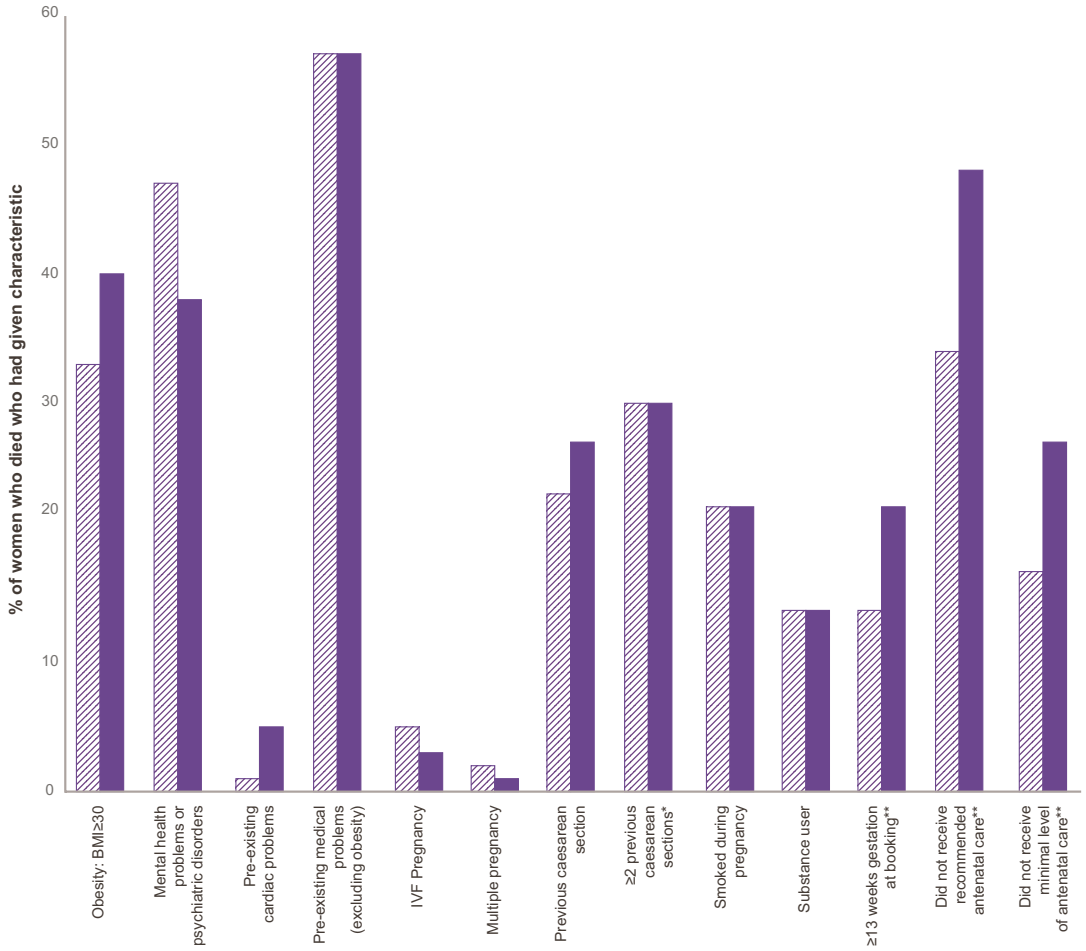
Medical and pregnancy-related characteristics

Studies have shown that 66% of the increased risk of maternal death in the UK can be attributed to medical comorbidities (Nair, Knight et al. 2016). The medical and pregnancy-related characteristics of the women who died in 2020-22 are shown in Figure 2.9 and Tables 2.14-2.16. Over half (57%) of the women who died in 2020-22 were known to have pre-existing medical problems and 42% were known to have pre-existing mental health problems (Figure 2.9 and Table 2.14). The proportion of women with known pre-existing mental health problems has steadily increased over the previous triennia and is now almost double the proportion reported in the 2018 MBRRACE-UK report (24%). Over a third (37%) of the women who died in this triennium were obese (BMI ≥ 30kg/m^2) and a further 27% were overweight (BMI 25-29kg/m^2) (Figure 2.9 and Table 2.14). The proportion of obese women has been gradually increasing and is now significantly higher than the proportion reported in 2017-19 (23%); the proportion of overweight women was similar to 2017-19 (29%). Comparable to previous years' reports, in the 2020-22 triennium, 11 women (4%) who died during or up to six weeks after pregnancy in the UK had a pregnancy as a result of an assisted conception procedure and 70 women (25%) had at least one previous caesarean section (Figure 2.9 and Table 2.15).

Other characteristics of women who died

Inadequate utilisation of antenatal care services and substance misuse have been shown to be associated with increased risk of maternal death in the UK (Nair, Kurinczuk et al. 2015, Nair, Knight et al. 2016). The prevalence of substance misuse among women who died in 2020-22 did not differ from that noted in the previous reports (Table 2.16) and the proportion who received recommended levels of antenatal care remained low. Just over half (51%) of women who received antenatal care, received the recommended level of care according to National Institute for Health and Care Excellence (NICE) antenatal care guidelines (booking at 10 weeks or less and no routine antenatal visits missed) (National Institute for Health and Care Excellence 2019a) (Figure 2.9 and Table 2.16).

Figure 2.9: 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.

Table 2.14: Selected medical conditions and characteristics identified amongst women who died 2020-22 (illustrated in Figure 2.9)

Medical condition/characteristic	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Total (n=275) Frequency (%)
Body mass index (BMI)			
<18	2 (2)	2 (1)	4 (1)
18 – 24	40 (31)	40 (27)	80 (29)
25 – 29	35 (27)	40 (27)	75 (27)
≥ 30	43 (33)	59 (40)	102 (37)
Missing	9 (7)	4 (3)	14 (5)
Mental health problems or psychiatric disorders			
Yes	61 (47)	55 (38)	116 (42)
No	50 (39)	81 (55)	131 (48)
Missing	18 (14)	10 (7)	28 (10)
Pre-existing cardiac problems			
Yes	1 (1)	7 (5)	8 (3)
No	116 (90)	134 (92)	250 (91)
Missing	12 (9)	5 (3)	17 (6)
Any pre-existing medical problem (excluding obesity)			
Yes	73 (57)	83 (57)	156 (57)
No	44 (34)	58 (40)	102 (37)
Missing	12 (9)	5 (3)	17 (6)

Table 2.15: Pregnancy-related characteristics of the women who died 2020-22 (illustrated in Figure 2.9)

Medical condition/characteristic	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Total (n=275) Frequency (%)
Pregnancy known to be as a result of assisted reproductive techniques			
Yes	6 (5)	5 (3)	11 (4)
No	123 (95)	141 (97)	264 (96)
Multiple pregnancy			
Yes	2 (2)	1 (1)	3 (1)
No	127 (98)	145 (99)	272 (99)
Previous caesarean section			
Yes	30 (23)	40 (27)	70 (25)
No	89 (69)	96 (66)	185 (67)
Missing	10 (8)	10 (7)	20 (7)
Previous caesarean numbers (among women who had a previous caesarean section)			
1	21 (70)	28 (70)	49 (70)
≥2	9 (30)	12 (30)	21 (30)

Table 2.16: Other characteristics of women who died in 2020-22 (illustrated in Figure 2.9)

Characteristics	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Total (n=275) Frequency (%)
Smoking			
Smoker	29 (22)	32 (22)	61 (22)
Non-smoker	83 (64)	99 (68)	182 (66)
Missing	17 (13)	15 (10)	32 (12)
Substance user			
Yes	18 (14)	21 (14)	39 (14)
No	87 (67)	116 (79)	203 (74)
Missing	24 (19)	9 (6)	33 (12)
Received any antenatal care*			
Yes	90 (70)	122 (84)	212 (77)
No	39 (30)	24 (16)	63 (23)
Gestational age at booking (among women who received any antenatal care) (weeks)			
≤10	69 (77)	78 (64)	147 (69)
11 – 12	7 (8)	15 (12)	22 (10)
>13	13 (14)	27 (22)	40 (19)
Missing	1 (1)	2 (2)	3 (1)
Received *recommended* antenatal care† (among women who received any antenatal care)			
Yes	54 (60)	55 (45)	109 (51)
No	31 (34)	59 (48)	90 (42)
Missing	5 (6)	8 (7)	13 (6)
Received a minimum level of antenatal care† (among women who received any antenatal care)			
Yes	70 (78)	79 (65)	149 (70)
No	15 (17)	33 (27)	48 (23)
Missing	5 (6)	10 (8)	15 (7)

*Includes 6 women who died in early pregnancy (≤10 weeks' gestational age).

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

Classification of quality of care

This section includes information on 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). Table 2.17 and Figure 2.10 show the classification of care as agreed by the assessors for the 166 women who died. Only the women whose case notes were available with sufficient information for an in-depth review are included. Among the women who died, 17% were assessed to have received good care. For another 45%, assessors felt that improvements in care may have made a difference to their outcome.

Opportunities to improve care were also identified for the majority of recent migrant women with language difficulties whose care was reviewed for the morbidity confidential enquiry in chapter 6 of this report (Table 2.17 and Figure 2.11). Of the 38 women included in the morbidity confidential enquiry whose care was reviewed, it was thought that improvements to care may have made a difference to the outcome or experience for 66%. Improvements in care that would not have changed their outcome or experience were also identified in 18% of the women.

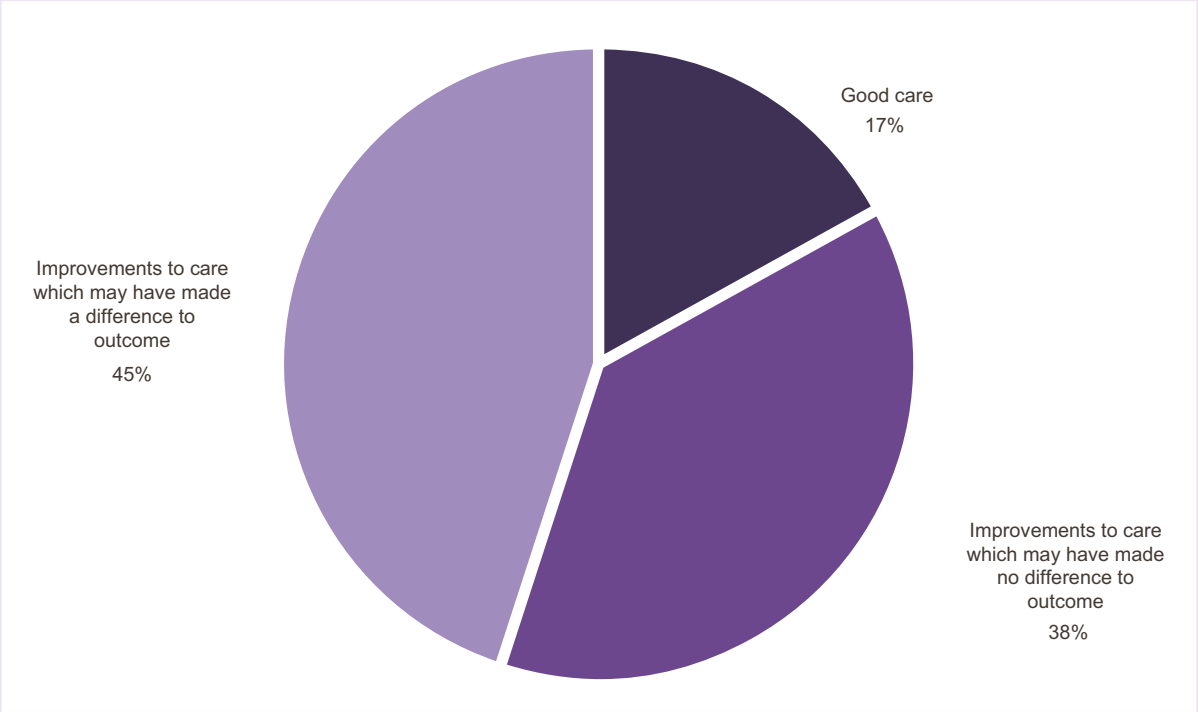
Table 2.17: Classification of care received by women who are included in the confidential enquiry chapters, UK and Ireland (2020-22*) (illustrated in Figures 2.11 and 2.12)

Classification of care received	Women who died (n=166)** Number (%)	Migrant women with language needs (n=38) Number (%)
Good care	29 (17)	6 (16)
Improvements to care which would have made no difference to outcome	63 (38)	7 (18)
Improvements to care which may have made a difference to outcome	74 (45)	25 (66)

*the confidential enquiry into deaths due to ectopic pregnancy includes only the women who died in 2021 and 2022

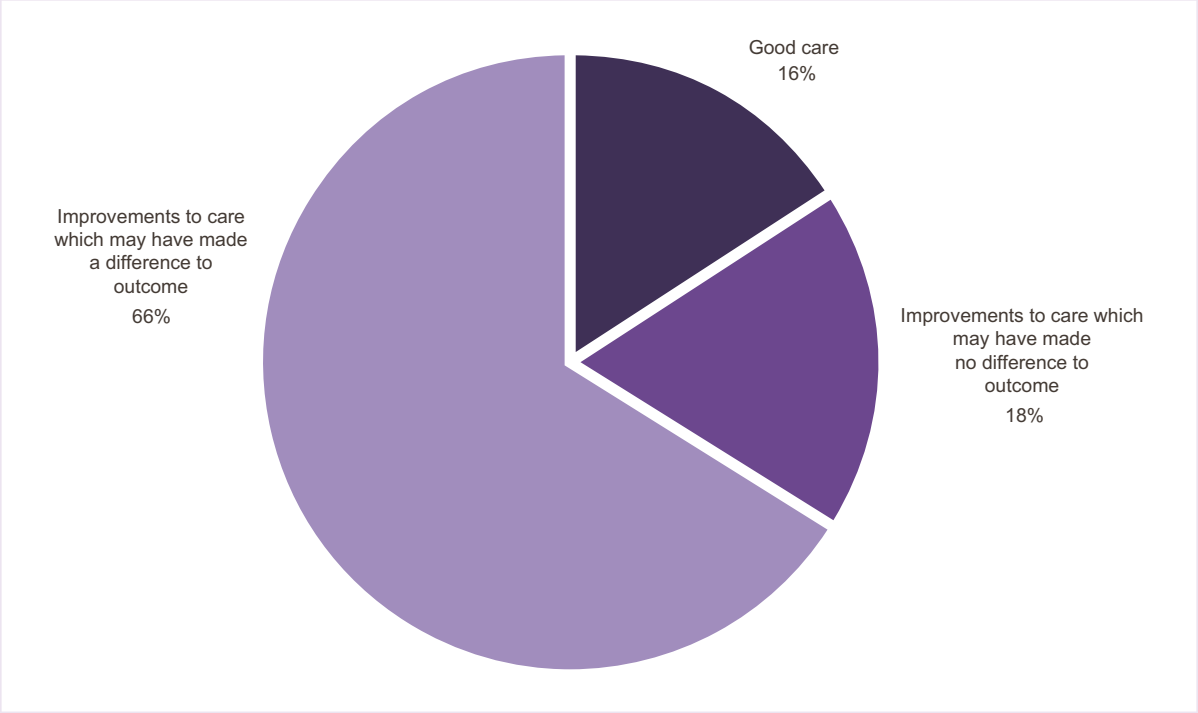
**includes only women whose case notes were available with sufficient information for an in-depth review

Figure 2.10: Classification of care received by women who died and are included in the confidential enquiry chapters, UK and Ireland (2020-22)*



*the confidential enquiry into deaths due to ectopic pregnancy includes only the women who died in 2021 and 2022

Figure 2.11: 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



Local clinicians' reports

The proportion of reports received from local clinicians of those requested for the confidential enquiry has been steadily increasing in past reports and is now close to 90% (Table 2.18). Local clinicians' reports are absolutely essential to allow MBRRACE-UK assessors to fully take account of any local system factors impacting on care, and we are particularly grateful at the effort and commitment to the enquiry this represents. We urge clinicians to continue to return their reports in a timely manner and provide their personal reflections and lessons learned from women's care.

Table 2.18: Percentages of local clinicians' reports received for women whose care was examined for the confidential enquiry chapters in this report

Specialty group	Percentage of reports requested that were received
Obstetricians	87
Anaesthetists	91
Midwives	91
Critical Care Clinicians	85
Emergency Medicine Specialists	81
GPs	93
Physicians	80
Total	88

Postmortem examination

There was substantial variation in the proportion of women who had a postmortem examination, according to the cause of death. For women with records available, a postmortem examination was carried out for almost two thirds (65%) (Table 2.19). The figure was 77% for women who died from direct causes, 62% amongst women who died from indirect causes, 57% amongst women who died from coincidental causes and 61% amongst women who died between six weeks and one year after the end of pregnancy. As noted in previous reports, establishing the cause of women's death with a high quality autopsy is essential not only to improve future care, but to ensure any family counselling or testing is conducted where appropriate.

Table 2.19: Postmortem information for maternal deaths in the UK 2020-22

Postmortem type	Direct (n=129) Frequency (%)	Indirect (n=146) Frequency (%)	Coincidental (n=21) Frequency (%)	Late Deaths (n=329) Frequency (%)	Total (n=625) Frequency (%)
No Postmortem	30 (23)	55 (38)	9 (43)	120 (37)	214 (34)
Postmortem completed	99 (77)	91 (62)	12 (57)	202 (61)	404 (65)
Records not available	0 (0)	0 (0)	0 (0)	7 (2)	7 (1)

3. Messages for the prevention and treatment of thrombosis and thromboembolism

Allison Felker, Chandrima Biswas, Anita Banerjee, Mandish Dhanjal, Lynne Campbell, Steve Cantellow, Samantha Holden, Rachel Rees, Felicity Coad, Teresa Kelly and Marian Knight on behalf of the MBRRACE-UK deaths due to thrombosis and thromboembolism chapter writing group.

Chapter writing group members: Anita Banerjee, Margarita Bariou, Lisa Barker, Chandrima Biswas, Lynne Campbell, Steve Cantellow, Matthew Cauldwell, Bernard Clarke, Felicity Coad, Katie Cranfield, Mandish Dhanjal, Hilde Engjom, Allison Felker, Nicky Gammie, Fiona Hanrahan, Samantha Holden, Teresa Kelly, Sara Kenyon, Marian Knight, Rohit Kotnis, Lucy MacKillop, Bhaskar Narayan, Roshni Patel, Rachel Rees, Robin Russell, Sarah Vause, Nicky Vousden

3.1 Key messages

New 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 **[ACTION: Integrated Care Boards and Health Boards]**

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]**

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]**

Existing guidance and recommendations requiring improved implementation

Develop a mechanism to ensure that all VTE risk assessment tools used for pregnant and postpartum women are consistent with national guidelines (Knight, Bunch et al. 2021a)

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 (Royal College of Obstetricians and Gynaecologists 2015a)

Antenatal thromboprophylaxis for those with previous VTE should begin as early in pregnancy as practical (Royal College of Obstetricians and Gynaecologists 2015a)

If women need thromboprophylaxis as soon as they become pregnant there should be clear pathways for them to access prescriptions and support to ensure compliance (Knight, Bunch et al. 2018)

Risk assessment should be repeated again intrapartum or immediately postpartum (Royal College of Obstetricians and Gynaecologists 2015a)

There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply in practice. There is an urgent need for development of a tool to make the current risk assessment system simpler and more reproducible (Knight, Bunch et al. 2018)

Risk assessment should be repeated if the woman is admitted to hospital for any reason or develops other intercurrent problems (Royal College of Obstetricians and Gynaecologists 2015a)

Women at high-risk of haemorrhage with risk factors including major antepartum haemorrhage, coagulopathy, progressive wound haematoma, suspected intra-abdominal bleeding and postpartum haemorrhage may be managed with anti-embolism stockings (AES), foot impulse devices or intermittent pneumatic compression devices. Unfractionated heparin (UFH) may also be considered (Royal College of Obstetricians and Gynaecologists 2015a)

Thromboprophylaxis should be started or reinstituted as soon as the immediate risk of haemorrhage is reduced (Royal College of Obstetricians and Gynaecologists 2015a)

Risk assessment should be performed in each woman at least once following delivery and before discharge and arrangements made for low molecular weight heparin (LMWH) prescription and administration (usually by the woman herself) in the community where necessary (Royal College of Obstetricians and Gynaecologists 2015a)

Ensure that guidance on care for pregnant women with complex social factors is updated to include a role for networked maternal medical care and postnatal follow-up to ensure that it is tailored to women's individual needs and that resources in particular target vulnerable women with medical and mental health comorbidities and social complexity (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. 2021a)

[During maternal resuscitation] if there is no response to CPR after five minutes, undertake a TIME-CRITICAL transfer to the nearest emergency department, ideally with an obstetric unit attached (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022)

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

Consider CPR for 60-90 minutes after administration of thrombolytic drugs (Resuscitation Council UK 2021)

In addition to the general arrest team, there should also be a senior midwife, an obstetrician and an obstetric anaesthetist included in the team in cases of maternal collapse (Chu, Johnston et al. 2020)

Individual hospitals should have an agreed protocol for the objective diagnosis of suspected VTE during pregnancy. This may recommend the involvement of obstetricians, radiologists, physicians and haematologists (Royal College of Obstetricians and Gynaecologists 2015b)

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 (PE) should have an electrocardiogram (ECG) and a chest X-ray (CXR) performed (Royal College of Obstetricians and Gynaecologists 2015b)

Women of reproductive age presenting to the Emergency Department collapsed, in whom a pulmonary embolism is part of the differential diagnosis, 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)

3.2 Background

Women are at a significantly higher risk of VTE during pregnancy and postpartum and it remains a major cause of maternal mortality and morbidity (Knight 2008, Royal College of Obstetricians and Gynaecologists 2015a). In 2020-22, thrombosis and thromboembolism surpassed cardiac disease to become the leading cause of maternal death in the UK. This is likely due, at least in part, to a higher prevalence of risk factors in the current maternity population. Past MBRRACE-UK reports have noted that a high proportion of women who die are overweight or obese. This is an important risk factor for VTE as are advanced maternal age and interventions such as caesarean section. Thus, it is likely that VTE-related deaths will continue to rise as the current maternity population becomes increasingly complex. Improved awareness of women's complex risk factors and careful consideration for the detection and prevention of VTE is required to prevent this trend.

3.3 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 represents an overall mortality rate of 2.87 per 100,000 maternities (95% CI 2.20-3.67).

Selected characteristics of the women who died from thrombosis and thromboembolism are shown in Table 3.1. 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 (24%) continued to smoke. Thirteen of the 63 women who died (21%) had a history of VTE. Twenty-two women (35%) 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.

Table 3.1: The socio-demographic characteristics of women who died from thrombosis and thromboembolism, UK and Ireland 2020-22

Characteristics	Number of women (%) N=63
Age	
<25	9 (14)
25-34	33 (52)
≥35	21 (33)
Parity	
0	19 (30)
≥1	42 (67)
Missing	2 (3)
Body mass index (BMI)	
18-24	11 (17)
25-30	25 (40)
≥30	24 (38)
Missing	3 (5)
Ethnicity	
White European	56 (89)
Black	4 (6)
Other minority ethnic group	3 (5)
Smoking	
Smoker	12 (19)
Non-smoker	42 (67)
Missing	9 (14)

3.4 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 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. 2021a) and continue to persist. Assessors noted several areas that seemed to consistently generate ambiguity or confusion when implementing the RCOG guidance.

Develop a mechanism to ensure that all VTE risk assessment tools used for pregnant and postpartum women are consistent with national guidelines (Knight, Bunch et al. 2021a)

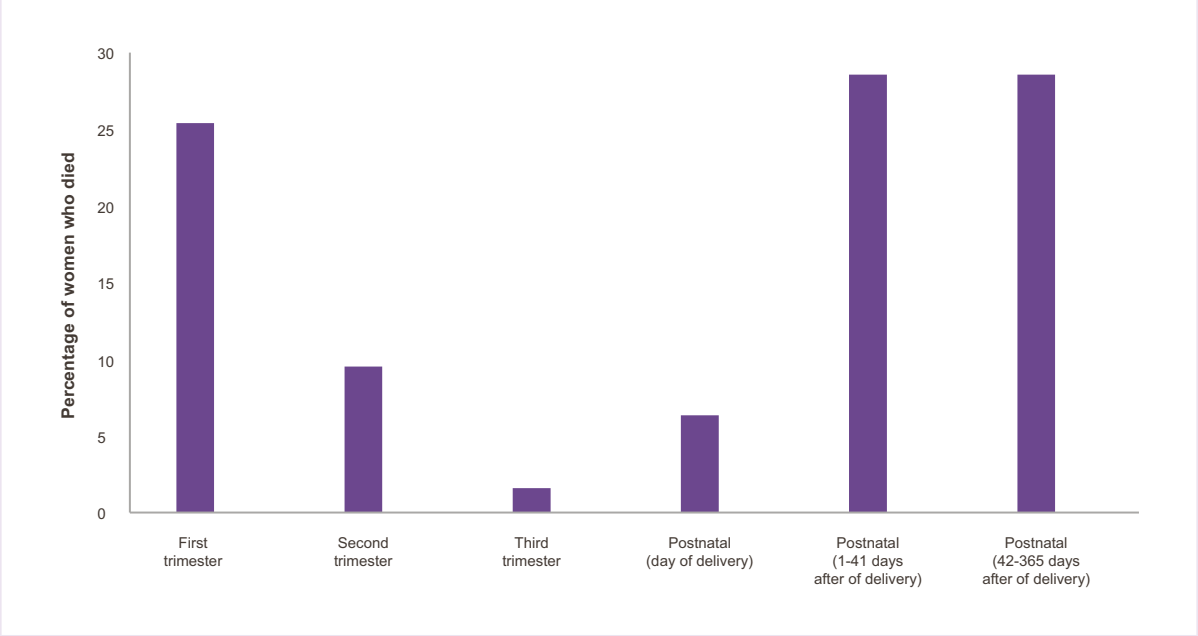
For instance, severe hyperemesis can lead to dehydration and immobility, which further increases the risk of VTE. Hyperemesis and dehydration is currently given a score of one in the RCOG's VTE risk assessment tool (Royal College of Obstetricians and Gynaecologists 2015a), but whether this is weighted 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 (Figure 3.1); 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.

Figure 3.1: Timing of VTE in women who died from thrombosis and thromboembolism, UK and Ireland, 2020-22



Extended evidence underpinning the new national messages

Pre-pregnancy counselling and early management in women with known risk factors for VTE

A woman in her 40s died from a bilateral pulmonary embolism in the first trimester of pregnancy. She had a complex obstetric history including a previous pregnancy complicated by pre-eclampsia and a DVT following a termination of pregnancy several years prior. She also had a miscarriage in the year preceding her current pregnancy. Prior to her miscarriage her VTE risk in that pregnancy was scored at five with a plan to offer LMWH from 28 weeks' gestation. After medical management of the miscarriage, she was not re-assessed for VTE risk or provided with thromboprophylaxis. She also had no counselling regarding future pregnancies. When she became pregnant again, she requested a booking appointment that was scheduled for a month later. The day prior to her appointment she collapsed and was unable to be resuscitated.

This woman had a history of deep vein thrombosis (DVT) and was considered high-risk for VTE. At the booking appointment for her previous pregnancy, she had a VTE risk assessment score of five and should have been offered low molecular weight heparin (LMWH) from the first trimester as well as after her miscarriage (Royal College of Obstetricians and Gynaecologists 2015a). When she became pregnant after her miscarriage, it is unclear if she knew about the importance of thromboprophylaxis. Women at high-risk for VTE, especially those with a history of VTE, should receive pre-pregnancy counselling to ensure they are aware of the risks of VTE and need for thromboprophylaxis as soon as they recognise they are pregnant. This must also be communicated to GPs alongside clear guidance on prescribing and referral pathways.

Assessors identified that several women with critical risk factors, such as a history of VTE or thrombophilia, faced difficulty obtaining a prescription for thromboprophylaxis early in pregnancy. Often it was unclear who was responsible for the prescribing and what the referral pathway was for access or advice. In some instances, GPs struggled to obtain advice from secondary care leading to delays in treatment. A shared decision-making plan with clear sign posting and documentation detailing how to access thromboprophylaxis at all stages of pregnancy and in all settings is required.

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.

Antenatal thromboprophylaxis for those with previous VTE should begin as early in pregnancy as practical.

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

If women need thromboprophylaxis as soon as they become pregnant there should be clear pathways for them to access prescriptions and support to ensure compliance (Knight, Bunch et al. 2018)

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 (CVST), 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 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.

Risk assessment should be repeated again intrapartum or immediately postpartum.

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

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. 2021a). 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.

There is clear evidence that doctors and midwives find existing risk scoring systems difficult to apply in practice. There is an urgent need for development of a tool to make the current risk assessment system simpler and more reproducible (Knight, Bunch et al. 2018)

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**

Risk is dynamic

A woman in her mid-20s had three admissions for hyperemesis within two weeks of each other early in the first trimester. On each occasion she was given IV fluids and discharged after her nausea and vomiting improved. A VTE risk assessment was undertaken at booking when she was designated as low-risk. There was no re-assessment of her risk during any admission. She collapsed at home where she had CPR for over an hour before transfer to the emergency department. She was thrombolysed but resuscitation was unsuccessful. Postmortem showed bilateral pulmonary emboli.

Although this woman's VTE risk was assessed at booking, this was not re-assessed during any of her hospital admissions. Guidance from the RCOG states that VTE risk assessment should be repeated at all hospital admissions or if a woman develops other problems in the antenatal period (Royal College of Obstetricians and Gynaecologists 2015a). Risk is not static; there may be periods of increased risk that develop throughout pregnancy and postnatally that make it essential to re-assess VTE risk at every opportunity.

Risk assessment should be repeated if the woman is admitted to hospital for any reason or develops other intercurrent problems.

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

3.5 Recurring lessons to be learned

Considerations for thromboprophylaxis

Subtherapeutic doses of LMWH

A young morbidly obese woman repeatedly presented with headaches in the first trimester that required admission to the emergency department on three occasions. She was diagnosed with a cerebral venous sinus thrombosis, started on LMWH and discharged. She was not weighed in the emergency department and her initial treatment was suboptimal for her weight. The dose was amended in the second trimester at which time a management plan was made that included anti-Xa testing. Anti-Xa testing was not available locally and results were not always reviewed leading to further subtherapeutic LMWH doses. Early in the third trimester she reported shortness of breath and chest pain before collapsing. A bedside echocardiogram showed no signs of pulmonary embolism and she was not given thrombolysis. Postmortem showed a massive acute pulmonary embolism.

This woman received subtherapeutic doses of LMWH after a CVST was discovered. Several other women with suspected or confirmed VTE also received subtherapeutic doses of LMWH and many developed thromboses while on LMWH or soon after cessation. Management plans for thromboprophylaxis use during pregnancy and postnatally should be agreed upon by a multidisciplinary team, including obstetric haematologists if needed, and consistently monitored. It is essential that appropriate adjustments are made to dosing. This may involve reweighing women to help guide the weight appropriate prophylactic LMWH dose (Knight, Bunch et al. 2021a).

Gaps in intrapartum and postpartum thromboprophylaxis

A woman in her 30s with a complex medical history had an emergency caesarean section at term. She had a postpartum haemorrhage of 1000mL and complications of the neuraxial block meant she was immobile for an extended period after surgery. LMWH was withheld while awaiting blood test results with the first dose given 12 hours after caesarean section. She had a postnatal VTE risk assessment score of two and was discharged with LMWH for 10 days administered by a community midwife. Approximately two weeks after birth she called 999 with abdominal and chest pain and nausea. She arrested multiple times and thrombolysis was given for her pulmonary embolism. She was admitted to critical care but died a few days later.

As in past MBRRACE-UK reports (Knight, Bunch et al. 2020, Knight, Bunch et al. 2021a), assessors noted that there were gaps in the provision of thromboprophylaxis around labour and immediately after birth. Most women will be able to start LMWH soon after giving birth, often four hours after a spinal block or removal of an epidural catheter and after discussion with an anaesthetist (Royal College of Obstetricians and Gynaecologists 2015a). Assessors noted that the decision to delay LMWH for this woman was made by a multidisciplinary team after taking her postpartum haemorrhage into consideration. LMWH is safe to give when a woman's platelets are 50 x 109/L or more. Those with low platelets or at high-risk of bleeding post-surgery should be offered interim alternatives including anti-embolism stockings and early mobilisation, where possible.

Women at high-risk of haemorrhage with risk factors including major antepartum haemorrhage, coagulopathy, progressive wound haematoma, suspected intra-abdominal bleeding and postpartum haemorrhage may be managed with anti-embolism stockings (AES), foot impulse devices or intermittent pneumatic compression devices. Unfractionated heparin (UFH) may also be considered.

Thromboprophylaxis should be started or reinstituted as soon as the immediate risk of haemorrhage is reduced.

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

Postnatal medication

It is not clear why this woman had her postnatal LMWH administered by a community midwife, but this practice ensured that she received her thromboprophylaxis. Studies show that women's adherence to LMWH decreases postnatally (Patel, Auyeung et al. 2012, Rottenstreich, Karlin et al. 2020) and there was evidence of this in several women who died who were prescribed LMWH in the postnatal period. There were a few instances when women were prescribed LMWH in hospital but did not pick up their prescriptions at discharge and were not followed up. This should be flagged by the hospital discharge team and GP to ensure that medication is provided. Often, as was observed in early pregnancy (section 3.4), assessors noted that there was confusion around pathways for prescribing thromboprophylaxis after pregnancy. For postpartum women requiring LMWH prophylaxis, there should be clear local guidelines identifying who is responsible for prescribing and this should be clearly communicated between primary and secondary care. For women with ongoing anti-coagulation needs there must also be clear information provided to women and their GP regarding pathways for follow-up and re-assessment after the initial 10 day or six week prescription.

Risk assessment should be performed in each woman at least once following delivery and before discharge and arrangements made for LMWH prescription and administration (usually by the woman herself) in the community where necessary.

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

Novel oral anti-coagulants

The use of direct oral anti-coagulants (DOACs) after routine elective surgery (such as orthopaedic surgery) is commonplace and may represent an opportunity to provide more accessible VTE prophylaxis postpartum. The use of DOACs in breastfeeding women is often limited due to concerns over passage into breast milk. Preliminary evidence suggests that dabigatran etexilate and rivaroxaban are present in very low amounts in breast milk, so the risk of infant exposure to clinically significant amounts is low (Muysson, Marshall et al. 2019, Saito, Kaneko et al. 2019, Ayuk, Kampouraki et al. 2020). However, as is the case for most research involving pregnant and breastfeeding women, more conclusive studies are needed.

Thromboprophylaxis prescribing and monitoring for vulnerable women

A woman with significant mental health problems booked early and was assessed as a high-risk for VTE. LMWH was not prescribed. She was referred for smoking cessation and perinatal mental health services but did not attend either appointment. She was reviewed at 28 weeks' gestation and prescribed LMWH but did not collect it from the pharmacy. There was little documented discussion about the importance of, or adherence to, thromboprophylaxis. She gave birth and left hospital the same day. LMWH was dispensed after her discharge and not picked up. She was reviewed in the community and assessed for her mental health but there were no enquires about thromboprophylaxis. Three weeks after giving birth, she collapsed at home and died from a pulmonary embolism.

Many women who died from VTE were vulnerable; almost half had some element of disadvantage (n=31, 49%). Past MBRRACE-UK reports have called for guidance to ensure that pregnant and recently pregnant women with complex social factors or medical and mental health comorbidities receive personalised care that is tailored to their individual needs (Knight, Bunch et al. 2023). This woman was referred to multiple specialist services during pregnancy but there was no follow-up when she did not attend. As emphasised above, there was also no follow-up when she did not pick up her LMWH prescription from the pharmacy. As there was little documented discussion regarding

the importance of LMWH in her notes it is unclear if she fully appreciated her risk of VTE or the need for medication. When prescribing medication, it is important to ensure that the woman is fully aware of why it is being prescribed and the risks associated with not taking it. Guidelines exist that can help foster discussions about medication adherence (National Institute for Health and Care Excellence 2009), which should take place at each interaction. However, updates to existing clinical guidance and additional educational tools for clinicians are necessary for better consideration of individual vulnerabilities in decision-making.

Ensure that guidance on care for pregnant women with complex social factors is updated to include a role for networked maternal medical care and postnatal follow-up to ensure that it is tailored to women's individual needs and that resources in particular target vulnerable women with medical and mental health comorbidities and social complexity (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. 2021a)

Clinical messages

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

Diagnosis and management of suspected VTE

Pre-hospital care

As described in chapter 5 of this report concerning the care of women who died from ectopic pregnancy, significant delays were observed in ambulance response times and transfer to hospital when women collapsed in the community. There was also variability in the resources deployed, which raises further questions about how pregnant women are identified and triaged when they contact 999. Assessors identified that pre-hospital teams with varying clinical capabilities were sent to manage women who had collapsed in pregnancy. In some instances, the deployment of insufficiently trained or equipped teams prolonged the time that women were treated at the site of collapse without definitive intervention, such as thrombolysis, being offered.

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

[During maternal resuscitation] if there is no response to CPR after five minutes, undertake a TIME-CRITICAL transfer to the nearest emergency department, ideally with an obstetric unit attached.

JRCALC Clinical Practice Supplementary Guidelines 2022 (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022)

The use of thrombolysis was inconsistent amongst the women who collapsed outside of hospital due to availability and concerns about bleeding risks. The risks of thrombolysis should be weighed against the most reasonable diagnosis and considered when pulmonary embolism is the likely cause of collapse. Shared decision-making and support from a multidisciplinary team are vital in these instances. If thrombolysis is not an option for pre-hospital teams, the woman should be urgently transferred to hospital for treatment. For several women, assessors felt that resuscitation attempts were not undertaken correctly or were performed for too short a duration following thrombolysis. The Resuscitation Council UK recommends that cardiopulmonary resuscitation should be considered for 60-90 minutes after the administration of thrombolytic drugs (Resuscitation Council UK 2021).

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

Consider CPR for 60-90 minutes after administration of thrombolytic drugs (Resuscitation Council UK 2021)

There were no instances of pre-hospital resuscitative hysterotomy (RH) amongst the women who died from VTE and it was unclear if any of the pre-hospital teams had the capability to perform this procedure. Although there is limited evidence concerning the success of RH when performed out of hospital, this intervention can facilitate the return of spontaneous circulation in the mother and should be performed, when possible, in women over 20 weeks' gestation (or when the uterus is palpable above the umbilicus) if there is no response to CPR after four minutes (Chu, Johnston et al. 2020, Resuscitation Council UK 2021). It is essential to ensure that pre-hospital teams attending maternal cardiac arrests are appropriately trained in all aspects of maternal resuscitation so that they are able to provide appropriate life-saving interventions. For many of the women who were brought to hospital following a collapse, multidisciplinary teams were assembled in advance of their arrival as is recommended (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022) but the composition of these teams was variable. A standardised approach, similar to the process for trauma patients, can help ensure that appropriate and senior staff are involved in all instances of maternal collapse.

In addition to the general arrest team, there should also be a senior midwife, an obstetrician and an obstetric anaesthetist included in the team in cases of maternal collapse.

RCOG Green-top Guideline 56 (Chu, Johnston et al. 2020)

Senior review and multidisciplinary care

A woman in her late 20s in the first trimester of pregnancy, and with no significant past medical history, presented to the emergency department early in the COVID-19 pandemic. She had palpitations, shortness of breath, chest pains and tachycardia. She did not have a chest x-ray or any other imaging because she was pregnant, and a Wells' score was used to assess her risk of VTE. She was not seen by an obstetrician or senior staff and was discharged with a diagnosis of possible upper respiratory viral infection. Pulmonary embolism was not considered. A few days later she was brought to the emergency department by ambulance and had a cardiac arrest on arrival. She was thrombolysed and a CTPA showed bilateral pulmonary emboli. She was admitted to the ICU but died shortly afterwards.

This woman presented to the emergency department early in the COVID-19 pandemic and assessors felt there was evidence of confirmation bias as her symptoms were wrongly attributed to a respiratory infection. Staff shortages also meant that she was not seen by an obstetrician or senior staff. Past MBRRACE-UK reports have emphasised the importance of obstetric consultation and senior review when pregnant or recently pregnant women are treated in the emergency department (Knight, Bunch et al. 2018, Knight, Bunch et al. 2019).

This woman was inappropriately assessed using Wells' criteria, which are not validated in pregnancy (Simcox, Ormesher et al. 2015, Goodacre, Horspool et al. 2019) and she was not provided with appropriate imaging. An obstetric consultation might have prompted a more accurate VTE risk assessment and a chest x-ray, possibly leading to earlier consideration of pulmonary embolism. Several other women who presented to the emergency department had inaccurate assessments of their condition due to use of the National Early Warning Score (NEWS) instead of the Modified Early Warning Score (MEWS) that is recommended for pregnant women (Knight, Bunch et al. 2022b).

Individual hospitals should have an agreed protocol for the objective diagnosis of suspected VTE during pregnancy. This may recommend the involvement of obstetricians, radiologists, physicians and haematologists.

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

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)

Imaging

As occurred for this woman as well as many others described in this chapter and elsewhere in this report, assessors noted that imaging was inappropriately denied to them because they were pregnant. There were also many examples where point-of-care ultrasound (POCUS) was used inconsistently in the emergency department. The use of POCUS, such as a Focused Assessment with Sonography in Trauma (FAST) scan to differentiate between possible VTE and ectopic pregnancy should be standard when women collapse in early pregnancy (Knight, Nair et al. 2016).

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

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

Women of reproductive age presenting to the Emergency Department collapsed, in whom a pulmonary embolism is part of the differential diagnosis, 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)

Service interruptions due to COVID-19

The impact of the COVID-19 on service delivery was observed in many of the women who died and whose care was reviewed in this chapter and others. Diagnostic efforts were often overshadowed by COVID-19 leading to confirmation bias when women displayed respiratory symptoms. Many women also had remote consultations due to COVID-19 that meant that their symptoms or condition were not fully appreciated. Pulmonary embolism is associated with non-specific symptoms and cannot be diagnosed or excluded over the telephone. It is imperative that women with suspicious symptoms are seen in person for a full assessment (Knight, Tuffnell et al. 2015). In addition to impacting diagnoses, COVID-19 also created hesitation in hospital attendance and impacted woman's experiences and management upon admission.

3.6 Additional messages identified from HSIB/MNSI reviews

As in previous reports, the MBRRACE-UK and Maternity and Newborn Safety Investigations (MNSI) (previously the Healthcare Safety Investigation Branch (HSIB)) teams worked together to identify additional messages from the local investigations conducted by MNSI.

Thirty-one women of the 38 who died from VTE in pregnancy or up to six weeks postpartum in England during the 2020-22 period had an HSIB/MNSI investigation (82%). Across these investigations, MNSI/HSIB made 50 safety recommendations to maternity and non-maternity services within secondary care, pre-hospital and primary care services and commissioners.

These safety recommendations echo the themes detailed from MBRRACE-UK reviews described earlier in this chapter. This section emphasises messages learned from discussions with families and staff.

Senior review and multidisciplinary care

An older woman with a history of VTE attended a consultation with her GP in very early pregnancy requesting thromboprophylaxis. The GP made repeated unsuccessful attempts to access an urgent obstetric review for the woman so that she could commence thromboprophylaxis, before ultimately referring her to the community midwife. She was unable to initiate thromboprophylaxis before she collapsed and died at home in the first trimester from a pulmonary embolus.

What MNSI/HSIB learned from talking to staff

Primary care staff noted that there are many systemic hurdles that GPs face including online guidance, electronic referral systems for maternity services and telephone or email access to direct obstetric advice. Many obstetric clinicians believe that thromboprophylaxis should only be given following the confirmation of a viable intrauterine pregnancy via ultrasound scan. The GP caring for this woman was unaware of the process for arranging such a scan.

The best pathway for seeking routine obstetric advice is not via the on-call obstetrician due to the nature of that role's inherent workload pressures. Instead, hospitals should collaborate with their regional healthcare systems to ensure that robust, easily accessible advice and referral pathways are in place for accessing urgent obstetric care.

Prescribing of thromboprophylaxis

> An older woman had four risk factors for VTE (age, parity, smoking and raised BMI). She was prescribed LMWH in the antenatal period and for six weeks postnatally. Three weeks after giving birth, the woman collapsed and had a cardiac arrest at home. The postmortem examination identified the cause of death as pulmonary embolism and deep vein thrombosis.

What MNSI/HSIB learned from talking to the family

Staff believed that because this woman had been prescribed thromboprophylaxis in previous pregnancies, she understood its importance and how to self-administer it. However, MNSI/HSIB learned from the family that the woman did not take the prescribed thromboprophylaxis in either her current or her previous pregnancy. They also learned that she did not like the idea of injecting the medication into her abdomen whilst pregnant; she was not aware that she could use other sites, such as the leg, for the injections. This knowledge may have supported her to self-administer the LMWH.

Whenever thromboprophylaxis is prescribed, women should be advised on the reasons why the medication is being recommended and the importance of adherence. In addition, a discussion is required to ensure that women can self-inject confidently and so they are given an opportunity to voice their concerns. This helps ensure that support is given to overcome anxieties around taking and administering thromboprophylaxis injections.

Communication between healthcare providers

> A young woman with learning difficulties and mental health problems booked early in her second pregnancy. She attended the emergency department in her second trimester with chest pain and abnormal breathing and was prescribed a treatment dose of LMWH. An outpatient diagnostic appointment was scheduled but she did not attend. The woman gave birth by planned caesarean section at term and was prescribed a 10 day course of postpartum thromboprophylaxis. Three weeks after giving birth she collapsed and had a cardiac arrest. Pulmonary embolism was identified at postmortem.

What MNSI/HSIB learned from talking to family and staff

In this hospital's pathway of care, pregnant women less than 28 weeks' gestation who were diagnosed and treated for a pulmonary embolism were required to inform maternity staff of their pulmonary embolism themselves rather than the hospital notifying the obstetric team directly. MNSI/HSIB learned that this woman did not share any information about her diagnosis and treatment for a pulmonary embolism with maternity staff throughout her pregnancy.

In line with previous MBRRACE-UK recommendations, all pregnant women presenting to the emergency department with medical problems, including VTE, should be referred and discussed with the obstetric team (Knight, Tuffnell et al. 2015). This woman's care required careful multidisciplinary planning and management and direct referral was needed to support a coordinated approach.

3.7 Messages for pathology

The majority of the women who died from VTE had a postmortem examination (n=50, 79%). The standard of the postmortem examinations was generally acceptable, although key information such as height and weight were absent in some reports.

Of the five women who died from CVST, three (60%) had a postmortem examination. Pathology assessors agreed with the cause of death in all five women but felt that obesity and recent pregnancy should have been included within the cause of death for two women.

Of the 56 women who, after review, were considered to have died from pulmonary thromboembolism, nine (16%) did not have a postmortem examination. For two of the women who did not have a postmortem examination, the clinical diagnosis of pulmonary thromboembolism was not clear and assessors felt that a postmortem examination

should have been undertaken to confirm the cause of death. For almost all of the women who had a postmortem examination, the diagnosis of pulmonary thromboembolism was considered to be appropriate by pathology assessors; there was only one woman where this cause of death was not clear.

There were two women who had a different cause of death given by the pathologist undertaking the postmortem, but, on review, the findings were considered to be consistent with pulmonary thromboembolism. As such they are included in this chapter.

> A woman had a witnessed collapse early in the second trimester. Prior to her collapse she had shortness of breath and a tight chest. CPR was performed, with brief return of spontaneous circulation. A scan in hospital showed free fluid in the abdomen and a working diagnosis of ectopic pregnancy was made. At laparotomy no source of bleeding, including ectopic, was identified and further resuscitation was unsuccessful. At postmortem, a thrombus was present in the pulmonary artery. The leg veins were not investigated. Hepatic and splenic lacerations were also identified but dismissed as the source of intra-abdominal haemorrhage as there were no rib fractures related to resuscitation.

This woman was one of several where the originating site for thromboembolus was not sought. Pathology assessors emphasised the need to investigate leg veins especially if DVT is included in the cause of death. The pathologist conducting this woman's examination did not appear to consider the link between CPR attempts, liver injury and haemoperitoneum and dismissed the liver and splenic lacerations as the source of bleeding. Assessors highlighted that young people often have compliant ribs and will not often have fractures after CPR.

Messages for pathologists

- Assessment of the originating site of pulmonary thromboembolism and adherence of thromboembolism can be very helpful in providing information about the timeline of events
- Risk factors for thrombus formation, such as pregnancy (including hyperemesis gravidarum) and obesity, should be reflected in the cause of death – pregnancy at any stage can increase the risk of VTE
- Include basic data such as weight and height in all postmortem reports
- Liver injuries do occur as a result of CPR; in younger individuals this may not be accompanied by rib fractures

3.8 Conclusions

There was sufficient information to assess the care of 62 of women who died from thrombosis and thromboembolism in 2020-22 (Table 3.2). Opportunities to improve care were identified for the majority of women reviewed (n=56, 91%) and assessors felt that different care may have made a difference to the outcome for 40 women (65%). Thrombosis and thromboembolism is now the leading cause of maternal death during pregnancy and up to six weeks after the end of pregnancy and mortality rates due to VTE have more than doubled since the last confidential enquiry into thrombosis and thromboembolism deaths in 2021. Assessors emphasised the need for better research evidence in order to restructure the existing VTE risk assessment tool and make it clearer, more accurate and easier to use. Risk assessment should begin early in pregnancy and there should be clear pathways for prescribing thromboprophylaxis so that women at known risk of VTE are able to access it at all stages of care, including the first trimester and after pregnancy. Clinicians must better recognise the symptoms of VTE and appreciate that risk factors are dynamic and require re-assessment throughout pregnancy and in the postnatal period. Communication with women regarding the risk of VTE and importance of thromboprophylaxis may help improve adherence to LMWH and prevent future deaths.

Table 3.2: Classification of care received by women who died from thrombosis and thromboembolism, UK and Ireland, 2020-22

Classification of care received	Women who died (n=62) Number (%)
Good care	6 (10)
Improvements to care which would have made no difference to outcome	16 (26)
Improvements to care which may have made a difference to outcome	40 (65)

4. Improving diagnosis and care of women with cancer

Hilde Engjom, Allison Felker, Cathy Nelson-Piercy, Vinnie Sodhi, Joanna Girling, Esther Youd, Roshni Patel, Angela Hancock, Arlene Wise and Marian Knight on behalf of the MBRRACE-UK deaths due to malignancies chapter writing group

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4.1 Key messages

New 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 **[ACTION: Royal College of Obstetricians and Gynaecologists in partnership with other royal colleges and professional societies]**

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]**

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]**

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]**

Existing guidance and recommendations requiring improved implementation

Guidance is needed for breast oncologists to ensure timely staging investigations are conducted in women with breast cancer in pregnancy to guide appropriate future care (Knight, Bunch et al. 2019)

Advice on appropriate contraception and postponement of pregnancy should be given to women under investigation for suspected breast cancer (Knight, Bunch et al. 2019)

It is important that individuals who have or have had breast cancer receive accurate, consistent information about contraception and support to achieve appropriate, effective contraception that is acceptable to them (The Faculty of Sexual and Reproductive Healthcare 2023)

For women with cancer, advice on postponement of pregnancy should be individualised and based on treatment needs and prognosis over time. Most women should wait at least 2 years after treatment, which is when the risk of cancer recurrence is highest (Royal College of Obstetricians and Gynaecologists 2011)

Women planning a pregnancy after treatment for breast cancer should consult their clinical oncologist, breast surgeon and obstetrician (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. 2021b)

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. 2021b)

Nausea and vomiting of pregnancy (NVP) is diagnosed when onset is prior to 16 weeks of gestation and other causes of nausea and vomiting have been excluded (Nelson-Piercy, Dean et al. 2024)

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for breast cancer if they are aged 30 and over and have an unexplained breast lump with or without pain (National Institute for Health and Care Excellence 2023)

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for breast cancer in people with skin changes that suggest breast cancer or aged 30 and over with an unexplained lump in the axilla (National Institute for Health and Care Excellence 2023)

Develop clear guidance on imaging in pregnancy, including for both diagnosis and staging (Knight, Bunch et al. 2021b)

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. 2021b)

Ensure early senior involvement of the maternal medical team for any pregnant or postpartum woman admitted with [concerning symptoms of medical illness in pregnancy], whatever her gestation and wherever in the hospital she receives care (Knight, Bunch et al. 2021a, Knight, Bunch et al. 2021b)

The decision to continue the pregnancy should be based on careful discussion of the [breast] cancer prognosis, treatment and future fertility with the woman and her partner and multidisciplinary team (Royal College of Obstetricians and Gynaecologists 2011)

If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant women (Knight, Tuffnell et al. 2015)

If the ultrasound suggests ovarian cancer, refer the woman for further investigation using a suspected cancer pathway referral (for an appointment within 2 weeks) (National Institute for Health and Care Excellence 2023)

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 (National Institute for Health and Care Excellence 2023)

If the woman presents with a clinically suspicious cervix she should be referred for colposcopic evaluation in line with guidelines from the British Society for Colposcopy and Cervical Pathology (Royal College of Obstetricians and Gynaecologists 2011)

Cancer is a recognised risk factor for thromboembolic disease and women should be prescribed thromboprophylaxis in accordance with RCOG guidelines (Royal College of Obstetricians and Gynaecologists 2015a)

The postnatal care plan for women with complex and multiple problems should include the timing of follow-up appointments, which should be arranged with the appropriate services before the woman is discharged and not left to the general practitioner to arrange (Knight, Bunch et al. 2018)

The multidisciplinary team review outcome should be forwarded to the obstetric team and the family doctor (Royal College of Obstetricians and Gynaecologists 2011a)

Support and enable adults approaching the end of their life to actively participate in decision-making (National Institute for Health and Care Excellence 2019c)

4.2 Background

The deaths of women from cancer are often thought to be coincidental to pregnancy. Many countries do not include these in their review of maternal deaths due to the belief that the death would have occurred irrespective of the woman's pregnancy. A recent systematic review estimated that 1 in 1000 women giving birth experience a cancer diagnosis during or up to one year after pregnancy with approximately 25% of these diagnoses occurring during pregnancy (Dalmartello, Negri et al. 2020). The global incidence of female cancers (breast, cervical, uterine and ovarian cancers) is increasing amongst women of childbearing age (Sun, Yu et al. 2024) and rates of cancer in pregnant women should be expected to increase with the rising age of the maternity population.

As previous MBRRACE-UK reports have highlighted, being pregnant or recently pregnant can greatly impact the quality of care received by women with all medical conditions, including cancer. The ongoing exclusion of pregnant and breastfeeding women from research, including new treatment trials, also means that there is limited evidence to guide the management of cancer during pregnancy. Where guidance is available, it is typically sparse and sometimes contradictory. As such, MBRRACE-UK continues to review the care of all women who died from cancer during preg-

nancy or up to a year postnatal regardless of the type of cancer and whether it might be classified as 'coincidental'. The lessons learned from these confidential enquiries are invaluable for improving the diagnosis and management of malignancy associated with pregnancy.

4.3 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). The nature of the malignancies are shown in Table 4.1.

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.

Table 4.1: Nature of the malignancies in the woman who died, UK and Ireland, 2020-22

Characteristics	All deaths during pregnancy or up to one year after pregnancy N=94	Death in pregnancy or up to six weeks after the end of pregnancy N=19	Death between six weeks and one year after the end of pregnancy N=75
Breast and gynaecological malignancies	**34**	**7**	**27**
Breast	25	6	19
Ovary	6	1	5
Cervix	3	--	3
Other malignancies	**60**	**12**	**48**
Gastrointestinal	27	6	21
Haematological	8	2	6
Brain	7	2	5
Bone/soft tissue	3	1	2
Lung	3	-	3
Skin	3	-	3
Urinary tract	2	-	2
Other	6	-	6
Unknown primary	1	1	--

4.4 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. 2021a). 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.

Guidance is needed for breast oncologists to ensure timely staging investigations are conducted in women with breast cancer in pregnancy to guide appropriate future care (Knight, Bunch et al. 2019)

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 (chapter 6). 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

4.5 Recurring lessons to be learned

Good care

An older woman was diagnosed with grade 2 HER2+ breast cancer early in her third pregnancy. She had local surgery and was booked for consultant-led obstetric care with multidisciplinary input including an obstetrician, midwife, oncologist, endocrinologist and mental health practitioners. She was started on thromboprophylaxis early and received chemotherapy throughout pregnancy. She had a vaginal birth at term and was discharged to the care of a community midwife and health visitor. She had a subsequent mastectomy but died 10 months later after palliative care.

This woman received exemplary care. She had coordinated, multidisciplinary care throughout her pregnancy and had consistent follow-up after birth provided by both a community midwife and health visitor. Chemotherapy was appropriately initiated and continued throughout her pregnancy as is recommended (Loibl, Azim et al. 2023). She also was appropriately assessed for VTE risk and started on thromboprophylaxis at her initial booking appointment. She had a vaginal birth at term in line with current guidance, which states that the mode or timing of birth should not be affected by breast cancer provided chemotherapy is stopped 2-3 weeks prior to allow for the mother's bone marrow recovery and minimise problems with neutropenia. Vaginal birth allows for more rapid recovery and earlier recommencement of chemotherapy and should be aimed for (Royal College of Obstetricians and Gynaecologists 2011a, Loibl, Azim et al. 2023).

Contraception and pre-conception counselling

Contraception

A woman in her 20s was diagnosed with triple negative breast cancer and treated with surgery, chemotherapy and radiotherapy. Less than one year after being diagnosed, shortly after her treatment ended, she became pregnant. Prior to her diagnosis she had been taking oral contraceptives. After treatment she briefly resumed menstruation but there was no indication that conversations around contraception, fertility or pregnancy occurred. She decided to continue the pregnancy following discussion with her oncologist. From mid-pregnancy she reported scar and shoulder pain and metastases were discovered shortly after she gave birth. She died from metastatic disease one month later.

Several women who became pregnant during or shortly after completing treatment for cancer did not seem to be aware that they could get pregnant naturally. Very few were counselled regarding their fertility or contraception options and almost all the pregnancies in women with previous cancer diagnoses were unplanned. Women, and those caring for them, should be aware that they can become pregnant while undergoing treatment and therefore need contraceptive advice.

Assessors noted that even in instances where contraception counselling occurred, there were limited contraception options for those with a history of breast cancer. The Faculty of Sexual Health and Reproductive Medicine advises against the use of hormonal contraception, including combined hormonal contraceptives and progestogen-only contraceptives, after any breast cancer (regardless of hormone receptor status) due to their potential effect on the risk of recurrence or the occurrence of another breast cancer. Instead they recommend the use of non-hormonal contraceptives including barrier methods and the copper intrauterine device. They note, however, that there are no robust data regarding the effect of contraceptive hormones on the risk of recurrence/occurrence (The Faculty of Sexual and Reproductive Healthcare 2023).

Advice on appropriate contraception and postponement of pregnancy should be given to women under investigation for suspected breast cancer (Knight, Bunch et al. 2019)

It is important that individuals who have or have had breast cancer receive accurate, consistent information about contraception and support to achieve appropriate, effective contraception that is acceptable to them (The Faculty of Sexual and Reproductive Healthcare 2023)

Pre-conception counselling

A woman in her 30s underwent surgery, chemotherapy and radiotherapy for triple negative breast cancer. Three months after completing treatment she became pregnant for the first time. The pregnancy was wanted but unplanned. In the third trimester she developed breathlessness, chest wall pain and some breast changes. Recurrence of her breast cancer was suspected and she had a caesarean birth at term. A postpartum CT scan showed liver and bone metastases. She received palliative chemotherapy but died a few months later from metastatic breast cancer.

Amongst the six women who were diagnosed with triple negative cancer prior to pregnancy, five had become pregnant less than two years after their primary diagnosis and start of treatment; three, including the women above, were pregnant within the first year. The sixth woman was diagnosed more than two years prior but had a recurrence in the year preceding her pregnancy. It is generally recommended that women with cancer avoid pregnancy during treatment and some time after due to the use of teratogenic agents (The Faculty of Sexual and Reproductive Healthcare 2023). For women with breast cancer, the current RCOG guidance recommends waiting at least two years after treatment before becoming pregnant as this is when the risk of recurrence is highest (Royal College of Obstetricians and Gynaecologists 2011a). In the event of a recurrence, this period of time also allows for the optimisation of diagnosis and successive treatment. Both of the women discussed here had high-risk breast cancers and should have received adequate pre-conception counselling to provide them with information on reliable, acceptable contraception and advice on delaying pregnancy. It is important to consider a woman's individual prognostic factors when offering advice on the postponement of pregnancy.

For women with cancer, advice on postponement of pregnancy should be individualised and based on treatment needs and prognosis over time. Most women should wait at least 2 years after treatment, which is when the risk of cancer recurrence is highest.

Women planning a pregnancy after treatment for breast cancer should consult their clinical oncologist, breast surgeon and obstetrician.

RCOG Green-top Guideline 12 (Royal College of Obstetricians and Gynaecologists 2011a)

One woman with ovarian cancer was diagnosed less than one year before becoming pregnant. Assessors felt that she received good pre-conception counselling. Assessors did not identify any evidence of pre-conception counselling or contraceptive advice amongst the women who died from other, non-breast or gynaecological malignancies and who had been diagnosed prior to pregnancy.

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. 2021a)

Recognition of symptoms

Symptoms of primary malignancies or of recurrence/metastases in women with known cancer can be subtle or obscured by pregnancy. These symptoms include nausea and vomiting, anaemia that does not resolve with iron supplementation, headaches, pain not responding to analgesia and rectal bleeding or changes in bowel movements. Any new, persistent or unusual symptoms should be properly investigated as incorrect attribution to pregnancy or another cause can result in delayed diagnosis and treatment for women with cancer.

'Red flags'

An older woman presented with severe headache, facial neuralgia and blurred vision in the third trimester. Her symptoms were initially attributed to a migraine and sinusitis. Over the next three weeks she complained of worsening symptoms and was advised to take codeine to manage the pain. Pre-eclampsia was considered and ruled out. At 38 weeks' gestation she attended maternity triage for the second time with a severe headache. Her distress was attributed to a mental health issue and she had a psychiatric assessment while awaiting an MRI. The MRI showed a brain mass and she was subsequently diagnosed with a brain tumour. She had an emergency caesarean birth and died a month later.

This woman's symptoms were wrongly attributed to pregnancy or unrelated conditions despite concerning 'red flags' (Royal College of Physicians 2019). She repeatedly presented with severe headaches and associated symptoms requiring opioids but there appeared to be little diagnostic curiosity regarding her symptoms. Instead, those caring for her attributed them to migraines, pre-eclampsia or a mental health condition.

Recurrent symptoms that necessitate re-presentation and increasing pain management have been themes in previous reports. Repeated presentation with the same symptom is itself a 'red flag' and requires investigation and multidisciplinary input. All professionals working in maternity services or caring for pregnant or postpartum women should be aware of 'red flag' symptoms and escalate concerns in a timely manner for further investigation.

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. 2021a)

Vomiting and weight loss

A woman had repeated presentations for nausea and vomiting early in her second pregnancy that required hospital admission in the second trimester. She did not experience these symptoms in her first pregnancy. Her symptoms, including associated abdominal pain and weight loss, were attributed to pregnancy-related hyperemesis gravidarum. Her symptoms persisted postpartum with upper abdominal pain. Three months after birth she was diagnosed with metastatic colon cancer and died shortly after.

Hyperemesis gravidarum is a diagnosis of exclusion; it should only be considered when other causes of nausea and vomiting during pregnancy have been excluded. Any ongoing or persistent symptoms need to be investigated further with a proper history, examination and tests (Nelson-Piercy, Dean et al. 2024). It is not common for women to experience nausea and vomiting in subsequent pregnancies if they did not previously. Marked weight loss and abdominal pain are not common features of hyperemesis and should raise concerns.

Nausea and vomiting of pregnancy (NVP) is diagnosed when onset is prior to 16 weeks of gestation and other causes of nausea and vomiting have been excluded.

RCOG Green-top Guideline 69 (Nelson-Piercy, Dean et al. 2024)

This woman was one of many who had repeat presentations for nausea and vomiting throughout their pregnancy. As discussed in chapter 3 of this report concerning women who died from thrombosis and thromboembolism, women with nausea and vomiting in pregnancy should be assessed using a validated index such as the Pregnancy Unique Quantification of Emesis (PUQE) or Hyperemesis Level Prediction (HELP) tool so that the severity of their condition is recognised (Nelson-Piercy, Dean et al. 2024). This includes any associated weight loss such as this woman experienced. Guidance from the RCOG suggests that women with significant weight loss (greater than 5% of their body weight) be considered for inpatient admission (Nelson-Piercy, Dean et al. 2024). It is not clear how much weight this woman lost throughout her pregnancy as only her booking weight was recorded in her maternity notes, but her oncology notes suggest that she weighed less at delivery than at booking. It is important to consider regularly weighing women experiencing ongoing nausea and vomiting in pregnancy, regardless of the underlying cause. Weight loss in pregnancy is always a concerning symptom.

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.

Anaemia

> A woman was anaemic throughout her fourth pregnancy. She was commenced on oral iron supplementation and her anaemia was not investigated further. She presented on a few occasions with abdominal pain during her pregnancy. Five weeks postnatally she presented again with abdominal pain and vomiting. This persisted and she also reported weight loss and neck swelling. After investigations she was diagnosed with a high-grade B-cell lymphoma and died within a few weeks.

> An older primiparous woman had anaemia from early pregnancy that did not respond to oral iron supplementation. She contacted maternity triage with abdominal pain and constipation and a month later, in the late second trimester, she presented with extreme tiredness and had abnormal liver function tests. An ultrasound and MRI showed multiple metastatic lesions. A liver biopsy confirmed gastrointestinal adenocarcinoma. She had an extremely preterm caesarean birth due to maternal compromise and died four weeks later.

These women were two of seven who were noted to have anaemia that did not respond to iron supplementation during their pregnancy. A fall in haemoglobin is common in pregnancy but should be investigated if it does not respond to treatment or occurs in conjunction with other symptoms. Assessors noted that often there was no further investigation into ongoing anaemia and no consideration of associated causes that could be contributing. The British Society for Haematology recommends a repeat full blood count and haemoglobin testing for pregnant women 2-3 weeks after the initiation of oral iron replacement to assess their response to treatment (Pavord, Daru et al. 2020). Assessors felt that appropriate follow-up and investigation for both these women may have led to an earlier diagnosis.

'Remember the essentials'

> A woman had repeatedly reported constipation and rectal bleeding in her second and third trimester. This was attributed to haemorrhoids by the midwifery team. In the second trimester she attended maternity triage with ongoing bleeding and was examined by a junior doctor who reported normal findings consistent with haemorrhoids. Due to persistent rectal bleeding she was examined by a surgeon two months later. A palpable rectal tumor was found and diagnosis of rectal cancer confirmed. She had a preterm caesarean birth followed by palliative chemotherapy and radiation but died six months later.

This woman, along with several others, had repeated presentations with rectal bleeding that was attributed to haemorrhoids without adequate clinical examination, senior review and specialist referral. Assessors felt that inadequate investigation of symptoms was a common occurrence amongst the women who died, regardless of the nature of their symptoms and stressed the value of 'remembering the essentials'. This includes obtaining a full detailed medical history, including family history and genetic testing for identified familial cancers where appropriate. It is also important to conduct appropriate clinical examinations and listen carefully to women's concerns.

Breast self-examination

> An older woman informed her midwife about an engorged left breast in her third trimester of pregnancy. She was advised to see her GP if she had concerns. Less than two weeks later she presented to maternity triage with other symptoms including changes in bowel movements and weight loss. Upon examination a registrar noted that her left breast was tender and swollen and her nipple was indrawn. A breast surgeon suspected inflammatory breast cancer that was confirmed by biopsy. She had a preterm caesarean birth and died a month later.

Fifteen (60%) of the women who died from breast cancer were diagnosed during pregnancy. Pregnancy-associated breast cancer is rare, but the incidence appears to be increasing in part due to an older and more obese maternity population. Pregnancy itself does not appear to affect the prognosis for women with breast cancer compared to non-pregnant women of similar age and stage, provided that it is appropriately managed (Royal College of Obstetricians and Gynaecologists 2011a, Amant, Von Minckwitz et al. 2013, Puchar, Despierres et al. 2022, Loibl, Azim et al. 2023).

All women, whether pregnant or not, are advised to be 'breast aware' and perform regular breast self-examinations as this may allow for earlier detection. Information on breast self-examination is available at ***www.nhs.uk/common-health-questions/lifestyle/how-should-i-check-my-breasts/***. If there are any symptoms of breast pain, lumps in the breast or abnormal nipple appearance or discharge, women are encouraged to report these to their GP who should conduct an appropriate examination and make a referral to a breast specialist team. Pregnant and breastfeeding women should be offered the same examination and staging as for non-pregnant women including ultrasound and mammography (Royal College of Obstetricians and Gynaecologists 2011a, Loibl, Azim et al. 2023).

Refer people using a suspected cancer pathway referral (for an appointment within 2 weeks) for breast cancer if they are aged 30 and over and have an unexplained breast lump with or without pain.

Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for breast cancer in people with skin changes that suggest breast cancer or aged 30 and over with an unexplained lump in the axilla.

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

Assessors noted that several of the women who died from breast cancer in 2020-22 had cosmetic breast implants. Women with cosmetic breast implants still have breast tissue and can develop breast cancer. Women and those caring for them should be aware that implants may make it more difficult to perform self-examinations and mammography may be less effective at detecting breast cancer in women with implants (NHS England 2022).

The care of pregnant women with prior cancer diagnosis

A vulnerable young woman with a history of colon cancer had been treated with surgery and chemotherapy. She was scheduled for two year follow-up surveillance by abdominal CT but this was deferred as she was found to be pregnant. She was booked for consultant-led care with a plan for regular carcinoembryonic antigen (CEA) monitoring. During pregnancy she self-referred on three occasions with abdominal pain that was attributed to pregnancy. No imaging was undertaken and she was not seen by a colorectal specialist. She was induced and had a preterm vaginal birth due to fetal growth restriction. She presented three weeks after birth with shortness of breath and chest pain. A chest x-ray showed lung inflammation that was attributed to a chest infection. A CT scan two months postpartum showed recurrent local disease and metastases in the spine and lungs. She died four months later.

This woman's care illustrates several of the themes discussed in this chapter. She did not appear to receive any pre-conception counselling, she repeatedly presented with symptoms that were attributed to pregnancy rather than recurrent cancer and she was inappropriately denied imaging because she was pregnant.

Twenty women entered pregnancy with a known history of past or current cancer. Women with a history of malignancy require a high index of clinical suspicion and recurrence should always be included in the differential diagnoses when there are unexplained symptoms. 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.

Imaging during pregnancy

As discussed in section 4.4, this woman and several others were inappropriately denied imaging and investigation because they were pregnant. This woman's routine surveillance CT was postponed until two months postpartum at which time she had advanced metastatic disease. An alternate plan was made for carcinoembryonic antigen (CEA) testing during pregnancy, but assessors found no evidence in the woman's notes that this took place. There was also no evidence of a discussion around a change of imaging modality such as MRI. Consistent, coordinated surveillance throughout pregnancy is essential in women with a history of past or current malignancy. Discussions around surveillance and imaging should be multidisciplinary. Most imaging modalities are safe during pregnancy and obstetric input can help guide what is and is not appropriate for pregnant women with cancer.

Develop clear guidance on imaging in pregnancy, including for both diagnosis and staging (Knight, Bunch et al. 2021a)

Multidisciplinary expertise and senior review

This woman was appropriately referred for consultant-led care as should be the standard of care for all women with active or past malignancy. According to local guidance and thresholds, some women with active or recent malignancy may be referred to specialist centres, either Maternal Medicine Networks (MMN)(England) or centres with maternal medicine expertise (Wales/Scotland/NI). Once referred, the women can then be risk stratified based on their individual condition to avoid overwhelming the systems.

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. 2021a)

Ensure early senior involvement of the maternal medical team for any pregnant or postpartum woman admitted with [concerning symptoms of medical illness in pregnancy], whatever her gestation and wherever in the hospital she receives care (Knight, Bunch et al. 2021b, Knight, Bunch et al. 2021a)

There were several women who had discussions with their oncologists concerning termination of pregnancy when they became pregnant during or soon after completing cancer treatment. Assessors felt that conversations such as these should be multidisciplinary with obstetric input so that women are provided with all the relevant information to make a decision and receive appropriate care. Multidisciplinary input also ensures that there are individuals with the appropriate skills and expertise available in order to avoid delays when women do request a termination of pregnancy.

The decision to continue the pregnancy should be based on careful discussion of the [breast] cancer prognosis, treatment and future fertility with the woman and her partner and multidisciplinary team.

RCOG Green-top Guideline 12 (Royal College of Obstetricians and Gynaecologists 2011a)

Appropriate follow-up for abnormal findings

A woman had an ovarian mass noted at her 12 week fetal scan. Her midwife advised her to speak to her GP if she had any concerns. She was not referred for further examination. Two months later she was admitted to general surgery with abdominal pain and vomiting. A large mass was palpable and visible on ultrasound. She was referred to the gynaecology oncology multidisciplinary team and had an MRI and surgical treatment with salpingo-oophoerectomy at 22 weeks' gestation. Pathology confirmed an ovarian carcinoma. Chemotherapy during pregnancy was discussed but she chose to delay treatment until after her baby was born. She had an elective caesarean section at term. An open omental biopsy at caesarean and postoperative chest CT confirmed metastatic disease. She died a few months postpartum.

When an ovarian mass is seen during a routine antenatal scan, it should be examined and reported according to the standard protocols: an urgent referral should be made to a consultant obstetrician for assessment and development of a plan for ongoing care including testing for tumour markers, follow-up imaging and further specialist referral. This woman's cancer was aggressive and if her care had been escalated for senior review after her 12 week scan it may have led to earlier diagnosis and surgical management. Assessors noted that once her cancer was diagnosed, it was not staged appropriately, as was the case for many other women who died. Investigation and management should be escalated according to criteria used for non-pregnant women and this should not be delayed because of the pregnancy.

If a cancer diagnosis is suspected, investigations should proceed in the same manner and on the same timescale as for a non-pregnant women (Knight, Tuffnell et al. 2015)

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

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

A grand multiparous woman with social and mental health complexities had never had a cervical smear. This was not recognised in her previous pregnancies. She had multiple unplanned visits with vaginal bleeding. At various admissions she had repeated speculum examinations performed by junior doctors who reported normal findings. She was not referred for senior review until the late third trimester when a trainee noted a suspicious appearance of her cervix. The consultant was unable to visualise the cervix but palpated a large mass and suspected cancer. A category 3 caesarean section and cervical biopsy were performed. Biopsy and postnatal staging confirmed metastatic cervical cancer. She received palliative treatment and died four months postpartum.

This woman had never had a cervical smear but this was seemingly not followed-up; cervical smears were not undertaken during or between her previous pregnancies. In her current pregnancy there was a recommendation for a postnatal smear but opportunistic screening was not considered during the pregnancy before she presented with abnormal symptoms and findings.

When women experience vaginal bleeding in pregnancy, a cause coincidental to the pregnancy should be considered. The cervix should be visualised and a digital examination performed unless there is an obstetric contraindication. This woman had several attendances for vaginal bleeding with speculum examinations performed by junior doctors, but her care was not escalated for senior review until her final presentation. Each occurrence of vaginal bleeding requires assessment by a senior obstetrician or gynaecologist and colposcopy should be considered if there is no obstetric cause or the appearance of the cervix is suspicious. This referral should occur within two weeks (National Institute for Health and Care Excellence 2023).

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)

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

RCOG Green-top Guideline 63 (Royal College of Obstetricians and Gynaecologists 2011b)

VTE risk assessment

Twenty-five women with malignancies also experienced a thrombosis or thromboembolism. The odds of a VTE in pregnant women with an active malignancy are almost seven-times greater than those in a pregnant women without malignancy (Folkins, Miller et al. 2024). As noted in the care of women who died from thrombosis and thromboembolism (chapter 3), assessors felt that several women who died from cancer did not have accurate VTE risk assessments and were not provided with appropriate prophylaxis during pregnancy or postpartum. For women with medical comorbidities including cancer, the RCOG recommends considering antenatal prophylaxis beginning at 28 weeks' gestation and extending for at least 10 days after birth, even if the women has no other risk factors (Royal College of Obstetricians and Gynaecologists 2015a). Considering the significantly greater odds of VTE in women with malignancies, assessors felt that consideration should be given to extending the provision of thromboprophylaxis throughout pregnancy and for a longer period after pregnancy for all women with cancer.

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)

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**

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

Communication

A few women chose to access private care due to delays in NHS referrals. Assessors noted that there was little interface between these two systems as clinical information or results were often not shared. Similar communication errors were noted between primary and secondary care as there appeared to be little information conveyed to GPs about ongoing cancer care plans when women were discharged from maternity services. As has repeatedly been demonstrated in past reports, there were also concerns expressed about emergency medical records and linkages between different centres or hospitals. It is essential that all information about a woman's medical condition and pregnancy are recorded and widely accessible to all staff caring for her.

The postnatal care plan for women with complex and multiple problems should include the timing of follow-up appointments, which should be arranged with the appropriate services before the woman is discharged and not left to the general practitioner to arrange (Knight, Bunch et al. 2018)

The multidisciplinary team review outcome should be forwarded to the obstetric team and the family doctor.

RCOG Green-top Guideline 12 (Royal College of Obstetricians and Gynaecologists 2011a)

Autonomy in decision-making for end-of-life care

As discussed in section 4.4, there was evidence of significant challenges in balancing medical, palliative care with considerate, compassionate end-of-life care for pregnant or recently pregnant women with cancer. For many women there was little evidence that psychological support was considered or provided and some women struggled to discuss the terminal nature of their disease and end-of-life care. This included provision of consent for do not resuscitate orders, which was sometimes provided by the family without the woman's knowledge and often not discussed as part of a supported conversation with the woman, her family and a multidisciplinary team. It was also unclear from the care of several women whether considerations were made towards limiting interventions in order to facilitate more time spent with their children.

Support and enable adults approaching the end of their life to actively participate in decision-making.

NICE NG142 End of life care for adults: service delivery (National Institute for Health and Care Excellence 2019c)

It was also occasionally noted that women were advised not to breastfeed when they were taking opioids for pain relief. While breastfeeding during chemotherapy is not advised (Royal College of Obstetricians and Gynaecologists 2011a) there is increasing evidence to suggest that the use of prescribed opioids is safe during breastfeeding (Zipursky, Gomes et al. 2023). Women taking opioids for chronic pain should be supported to breastfeed (Turner, Allen et al. 2023) provided they are not taking the chemotherapy drugs trastuzumab or tamoxifen (Royal College of Obstetricians and Gynaecologists 2011a). It is essential that women are allowed to exercise control and autonomy over the end of their lives. Pregnant and recently pregnant women should have the same quality of care as any non-pregnant person and should be properly informed and involved in all decisions relating to their care.

Self-reflection

At chapter writing, assessors noted that several local clinicians' reports were completed with very little or no self-reflection on what could be learned from the woman's death. The purpose of the MBRRACE-UK confidential enquiries is to learn lessons from the care of women who died so that similar events can be avoided in the future. It is essential that this opportunity for learning is appreciated by all involved in these enquiries.

4.6 Messages for pathology

Placental histology

A woman was diagnosed with grade 3 triple negative breast cancer less than one year before becoming pregnant. Prior to pregnancy she was treated with surgery, chemotherapy and radiation. During her third trimester she was diagnosed with metastatic carcinoma in her liver. She had a preterm caesarean birth and palliative chemotherapy postpartum until her death four months later. Placenta histology showed micrometastases in the intervillous space.

This woman had metastatic infiltration on the maternal side of the placenta. Maternal tumours rarely involve the placenta and even more rarely cross the placenta to affect the baby. As such, routine placental histology is not indicated where the pregnancy has a normal outcome. However, a clinician may discuss a request for placental examination in a mother with cancer with the local pathologist (Evans, Goodings et al. 2022).

Writing a death certificate

The majority of the women who died from malignancies in 2020-22 did not have a postmortem examination (n=79, 84%). This is not usually necessary when someone has died after having cancer, but in this review period there were several examples of poorly constructed causes of death on death certificates that may have benefited from a more thorough pathological review. For instance, for some women the cause of death did not mention the primary site of origin for metastatic cancers. In other women the cause of death omitted the word 'tumour' or 'cancer' (e.g. metastatic small cell neuroendocrine). Terminology was also duplicated in some causes of death and indistinct or incorrect in others.

Points to remember

- Death certificates provide vital information for population statistics on causes of death. The certificate should be as complete and accurate as possible
- The primary site of the tumour should be stated if it is known. If it is not known it is acceptable to say 'of likely xxx origin'
- The tumour type (so far as it is known) should be stated – the terminology in the histopathology report can be helpful to use if applicable
- Qualitative terms like 'advanced' or 'widespread' when describing metastatic cancer do not provide valuable information and should be avoided

4.7 Conclusions

The care of 92 women who died from malignancies in 2020-22 was reviewed (Table 4.2). 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 44 women who died (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%). Assessors noted that there were often delays in making a cancer diagnosis or identifying recurrence because women's symptoms were wrongly attributed to pregnancy and not appropriately investigated. Any new, persistent or unusual symptoms that arise in pregnancy require follow-up, especially when women have repeated presentations for the same symptoms. The use of imaging modalities to investigate, diagnose and stage malignancies was often not appropriate and many women were denied imaging because they were pregnant. For many, this meant that the extent of their disease was not recognised. Similar themes were observed with delays in treatment, including chemotherapy. For women who had a known cancer diagnosis prior to pregnancy, there was limited evidence of pre-conception counselling including discussions around the need for contraception, which resulted in unplanned pregnancies. In these instances it is important to make a plan for management with multidisciplinary input as early as possible in pregnancy so that women can receive the investigation and treatment they need. This multidisciplinary care should continue during end-of-life planning and palliative care where women's needs and desires must be considered in all conversations.

Table 4.2: Classification of care received by the woman who died from malignancies, UK and Ireland, 2020-22

Classification of care received	All women who died from malignancies n=92	Women who died from breast and gynaecological malignancies (n=34) Number (%)	Women who died from other malignancies (n=58) Number (%)
Good care	23 (25)	9 (26)	14 (24)
Improvements to care which would have made no difference to outcome	44 (48)	9 (26)	35 (60)
Improvements to care which may have made a difference to outcome	25 (27)	16 (47)	9 (16)

5. Lessons for the care of women with ectopic pregnancies

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5.1 Key messages

New 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 **[ACTION: NHS England and ambulance service commissioners in the devolved nations]**

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]**

Existing guidance and recommendations requiring improved implementation

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

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

Maternal collapse can result from a number of causes. A systematic approach should be taken to identify the cause (Chu, Johnston et al. 2020)

Haemorrhage [in early pregnancy] may occur mainly (or completely) within the abdomen…with little or no external loss but pain and signs of hypovolaemic shock (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022)

Any woman of childbearing age may be pregnant and, unless there is a history of hysterectomy there must be a high index of suspicion that any abdominal pain or vaginal bleeding may be pregnancy related (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022)

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

Be aware that atypical presentation for ectopic pregnancy is common (National Institute for Health and Care Excellence 2019b)

Be aware that ectopic pregnancy can present with a variety of symptoms. Even if a symptom is less common, it may still be significant. Common symptoms of ectopic pregnancy include abdominal or pelvic pain, amenorrhoea or missed period and vaginal bleeding with or without clots. Other reported symptoms include breast tenderness, gastrointestinal symptoms, dizziness, fainting or syncope, shoulder tip pain, urinary symptoms, passage of tissue and rectal pressure or pain on defecation (National Institute for Health and Care Excellence 2019b)

A woman with a suspected ectopic pregnancy and deteriorating symptoms should be urgently seen by a senior gynaecologist (Knight, Nair et al. 2016)

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 (National Institute for Health and Care Excellence 2019b)

Women of reproductive age presenting to the Emergency Department collapse, 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)

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 (National Institute for Health and Care Excellence 2019b)

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 (National Institute for Health and Care Excellence 2019b)

[In cases of maternal collapse] there should be an aggressive approach to volume replacement, although caution should be exercised in the context of pre-eclampsia or eclampsia. (Chu, Johnston et al. 2020)

Transfer should be supervised by an adequately skilled team with appropriate equipment (Chu, Johnston et al. 2020)

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)

5.2 Background

In the UK, the incidence of ectopic pregnancy, defined as any pregnancy implanted outside of the uterus, is approximately 11 per 1,000 pregnancies. This amounts to around 12,000 ectopic pregnancies each year. Risk factors for ectopic pregnancy include a previous ectopic pregnancy, tubal damage, smoking, older maternal age, infertility and fertility treatment including *in vitro* fertilisation (IVF). However, about a third of women who have an ectopic pregnancy will have no discernible risk factors (Royal College of Obstetricians and Gynaecologists 2016, National Institute for Health and Care Excellence 2019b). Coupled with the variable risk factors, many of the signs and symptoms of ectopic pregnancy are atypical and resemble other common conditions. Recognising the possibility of ectopic pregnancy in women of reproductive age remains imperative to allow for prompt intervention and prevent complications including tubal rupture and death from hypovolaemic shock.

5.3 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).

The characteristics of the 12 women who died as a direct result of ectopic pregnancy, and whose care was reviewed in this confidential enquiry, are shown in Table 5.1. A third of the women were aged 35 or older at the time of their deaths and the majority (67%) were nulliparous. Half of the women who died were White and half were from ethnic minority groups, primarily of Asian background. For the six women whose smoking status was known, two were smokers. None of the pregnancies were a result of assisted reproductive technologies.

Table 5.1: The socio-demographic characteristics of women who died following ectopic pregnancy, UK and Ireland, 2021-22

Characteristics	Total (N=12) Frequency (%)
Age (years)	
<35	8 (67)
≥35	4 (33)
Parity	
Nulliparous	8 (67)
Multiparous	2 (17)
Missing	2 (17)
UK/Irish Citizen	
Yes	6 (50)
No	2 (17)
Missing	4 (33)

Characteristics	Total (N=12) Frequency (%)
Ethnicity	
White European	6 (50)
Asian	3 (25)
Black or other minority ethnic group	3 (25)
Woman's region of birth	
UK/Ireland	5 (42)
Outside UK/Ireland	3 (25)
Missing	4 (33)
Smoking	
Smoker	2 (17)
Non-smoker	4 (33)
Missing	6 (50)

5.4 Overview of care and new lessons to be learned

Urgent response and adequate 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).

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

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

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

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.

Maternal collapse can result from a number of causes. A systematic approach should be taken to identify the cause.

RCOG Green-top Guideline 56 (Chu, Johnston et al. 2020)

Haemorrhage [in early pregnancy] may occur mainly (or completely) within the abdomen…with little or no external loss but pain and signs of hypovolaemic shock.

Any woman of childbearing age may be pregnant and, unless there is a history of hysterectomy there must be a high index of suspicion that any abdominal pain or vaginal bleeding may be pregnancy related.

JRCALC Clinical Practice Supplementary Guidelines 2022 (Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and Association of Ambulance Chief Executives (AACE) 2022)

5.5 Recurring lessons to be learned

Consider a diagnosis of ectopic pregnancy

In approximately 7% of women, an ectopic pregnancy may be asymptomatic (National Institute for Health and Care Excellence 2019b). In many other women, symptoms may be atypical, subtle or resemble other common conditions. A significant number of women will also not be aware that they are pregnant. It is important, as with all diagnoses, to avoid confirmation bias. Until pregnancy can be excluded, ectopic pregnancy should be considered in the differential diagnosis for women of reproductive age with atypical symptoms.

Recognition of symptoms

A woman booked for maternity care at eight weeks' gestation. This booking was done over the telephone due to COVID-19 restrictions. At booking she reported that her previous menstrual period was lighter than usual. A week after booking at a face-to-face appointment with her midwife she felt light headed after blood tests. Later that afternoon her husband called the GP to report that the woman had fainted a few times that day. The GP attributed her dizziness and fainting to the blood test and not eating enough. She was not seen in person. That evening she again complained of feeling faint before she collapsed at home and could not be resuscitated. A ruptured ectopic pregnancy was identified at postmortem.

Assessors felt that the possibility of ectopic pregnancy should have been considered earlier in this woman's care. When she booked, a detailed history was taken during which she reported a lighter than normal period, a possible symptom of ectopic pregnancy. It is essential that clinicians take a full, detailed history for women at booking or when they present with atypical symptoms. This history should include the date of their last menstrual period and any changes in bleeding different from their normal period. In most cases, symptoms of ectopic pregnancy occur 6-8 weeks after the last menstrual period.

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

For this woman, her only other symptom aside from a lighter period was repeated syncope. It is unlikely that having bloods taken earlier in the day would cause persistent dizziness several hours later. Repeated fainting events within a day are not normal and should have prompted further investigation including face-to-face evaluation. A physical evaluation may have led to a consideration of ectopic pregnancy. For 40% of adults, taking a full history and conducting a thorough examination will identify the cause for syncope (Reed and Gray 2006). It is likely that the COVID-19 pandemic contributed to this woman's care as there appeared some reluctance to recommend a face-to-face evaluation.

Simulated case scenarios can be used to raise awareness of atypical symptoms caused by an ectopic pregnancy. It is important that all staff caring for women of reproductive age with atypical symptoms, regardless of a known pregnancy, consider and exclude an ectopic pregnancy. Dismissing symptoms or attributing them to another cause can narrow the differential diagnosis and put women at risk of ruptured ectopic pregnancy.

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**

Be aware that atypical presentation for ectopic pregnancy is common.

Be aware that ectopic pregnancy can present with a variety of symptoms. Even if a symptom is less common, it may still be significant. Common symptoms of ectopic pregnancy include abdominal or pelvic pain, amenorrhoea or missed period and vaginal bleeding with or without clots. Other reported symptoms include breast tenderness, gastrointestinal symptoms, dizziness, fainting or syncope, shoulder tip pain, urinary symptoms, passage of tissue and rectal pressure or pain on defecation.

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

Good care

A woman had severe abdominal pain, shortness of breath and shoulder pain when she was known to be in the early weeks of pregnancy. She was brought to the emergency department by ambulance and collapsed on arrival. She was attended to by senior staff and resuscitated. An ultrasound showed blood in the abdominal cavity and she was transferred to theatre. At laparotomy she was found to have a ruptured ectopic pregnancy but she deteriorated and died five days later.

A woman presented to the emergency department in early pregnancy feeling faint with diarrhoea. She was reviewed by a multidisciplinary team including obstetrics and gynaecology. A cardiac arrest and major haemorrhage call were put out and she and was transferred to theatre an hour after her arrival. She died shortly after surgery.

Both of these women demonstrated many typical symptoms of ectopic pregnancy including abdominal pain, shoulder tip pain and gastrointestinal upset. The assessors felt that the care these women received in hospital was of a high-standard and was appropriately multidisciplinary and consultant-led. Bleeding from an ectopic pregnancy can be sudden and catastrophic and abnormal symptoms, especially in the presence of a positive pregnancy test, require urgent assessment, senior review and multidisciplinary involvement (Knight, Nair et al. 2016, Knight, Bunch et al. 2019).

A woman with a suspected ectopic pregnancy and deteriorating symptoms should be urgently seen by a senior gynaecologist (Knight, Nair et al. 2016)

Pregnancy testing and ultrasound scanning

A woman of reproductive age called 111 complaining of abdominal pain, nausea and diarrhoea. Following a subsequent call to her GP she was seen by a nurse the next day who suggested her symptoms were due to viral gastroenteritis. She was prescribed an antiemetic and antispasmodic. The pain intensified the following day and the woman's partner called emergency services again. The woman reported feelings of confusion and drowsiness and was advised to self-refer to the emergency department. Upon arrival in the emergency department the woman had a cardiac arrest and collapsed. A pregnancy test was positive and a FAST scan detected intra-abdominal haemorrhage. She underwent a laparotomy for a ruptured ectopic pregnancy but died four days later.

As with the women previously described, this woman showed typical symptoms of ectopic pregnancy but, unlike some of the other women, she was not aware she was pregnant. A pregnancy test was not offered until she collapsed in the emergency department and a diagnosis of ectopic pregnancy was not considered until she was in extremis. Guidance from NICE 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 2019b). It was unclear whether a history was taken to rule out the possibility of pregnancy during her multiple contacts with healthcare providers prior to her arrival in the emergency department. If pregnancy had been considered earlier it may have prompted a different diagnosis and allowed for earlier intervention.

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 2019b)

Assessors felt that the care this woman received once she arrived in the emergency department was good. She had a POCUS upon arrival that revealed intra-abdominal bleeding, a working diagnosis of ruptured ectopic pregnancy was made and pregnancy was confirmed with an HCG test. This is in line with guidance and recommendations from past reports (Knight, Nair et al. 2016, National Institute for Health and Care Excellence 2019b). Assessors noted that in general there was good care in the emergency department after women arrived in a state of collapse. Of the eight women with ectopic pregnancies who presented to the emergency department, most underwent imaging with a

FAST scan that identified free fluid in the abdomen. However, there were a few instances where junior doctors were advised to refer women to early pregnancy units rather than order pregnancy tests or perform ultrasound scans in the emergency department. On other occasions, serum HCG tests or transvaginal ultrasound were not available when needed. As a minimum, when any woman of reproductive age presents with vague or atypical symptoms and there is diagnostic uncertainty, an accurate menstrual history should be taken and a pregnancy test should be standard care before pregnancy can be excluded from the differential diagnosis (Knight, Nair et al. 2016).

Women of reproductive age presenting to the Emergency Department collapse, 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)

Access to Early Pregnancy Assessment Units (EPAUs)

A woman with limited English called the early pregnancy assessment unit after experiencing bleeding following a positive pregnancy test. She left a voicemail requesting a scan but the message was not clear and staff were unable to contact her. A few weeks later she developed severe abdominal pain and contacted ambulance services. Communication difficulties were evident on the call. A relative made two further 999 calls but arrival of the ambulance was delayed. She was quickly transferred to hospital with a pre-alert to emergency staff but arrested before arrival and could not be resuscitated.

It was evident that women are still facing challenges accessing services in Early Pregnancy Assessment Units (EPAUs). This woman's call was not returned by staff at the EPAU as language difficulties meant that her message and contact information were not understood. She also faced communication difficulties when she rang 999 a few weeks later, which led to further delays in her transfer to hospital and subsequent diagnosis and treatment of her ectopic pregnancy. The problems faced by women with language difficulties in accessing care are addressed more in chapter 6 of this report. If this EPAU unit had a call log or access to interpretation services this may have facilitated follow-up with this woman.

Often referrals for appointments at EPAUs were made more than 24 hours after initial presentation due to a lack of availability and weekend closures. 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 2019b). In situations where services are not available seven days a week and women cannot be seen within 24 hours, women should be referred to other facilities that offer specialist assessment and ultrasound, including the emergency department (National Institute for Health and Care Excellence 2019b).

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 2019b)

Appropriate resuscitation response in women with concealed bleeding

A woman with no significant past medical history complained of shortness of breath before collapsing at home. CPR was initiated by her husband and continued when ambulance services arrived 10 minutes later. No fluids were given until almost an hour after arrest when the air ambulance team arrived. Her abdomen was noted to be distended but hypovolaemia was never considered. Resuscitation attempts stopped 1.5 hours after the woman collapsed. The woman had received <500mL fluid in total. Postmortem examination revealed a 2000mL intra-abdominal haemorrhage secondary to ruptured ectopic pregnancy.

As mentioned in chapter 3 and section 5.4, and as demonstrated by the care of this woman, there was evidence of significant variation in the management of women who collapsed out of hospital. This included a range of resources deployed to the scene and ambulance or pre-hospital teams with different training and capabilities responding to similar calls. While many women who experience ruptured ectopic pregnancies will not be aware that they are pregnant, there was evidence from both the confidential enquiries into the care of women who died in early pregnancy and from those who died later in pregnancy from thrombosis and thromboembolism (chapter 3) that the management of maternal cardiac arrest in the community needs improvement. Advanced life support training from Resuscitation Council UK covers maternal cardiac arrest separately in their 'Special circumstances Guidelines' (Resuscitation Council UK 2021). Simulation training and the integration of pregnancy-related considerations into the mainstream cardiac arrest algorithm may help to improve confidence and preparedness of teams involved in maternal resuscitation attempts.

For this woman, fluids were not provided as part of her resuscitation attempts until arrival of the air ambulance an hour after collapse. The underlying cause of her collapse, including the reversible causes of cardiac arrest (4H's and 4T's) did not seem to be considered and she did not receive adequate volume resuscitation. Crystalloids are universally available and blood products may sometimes be carried by pre-hospital teams. If blood products or other interventions are not available or if there is no response to CPR, it is essential to undertake a time critical transfer to the hospital for multidisciplinary assessment and intervention.

[In cases of maternal collapse] there should be an aggressive approach to volume replacement, although caution should be exercised in the context of pre-eclampsia or eclampsia.

Transfer should be supervised by an adequately skilled team with appropriate equipment.

RCOG Green-top Guideline 56 (Chu, Johnston et al. 2020)

Women's concerns

As in previous reports, vulnerable women remain disproportionately represented amongst the women who died from ectopic pregnancy (Knight, Bunch et al. 2022b). Five of the women who died from ectopic pregnancy had disadvantages including a mental health diagnosis, substance use, or domestic abuse. Another two women had language difficulties that may have impacted the care they received due to miscommunication between women and staff in the absence of interpreter services. The importance of access to interpreting services is discussed more in chapter 6. Assessors felt that some of the vulnerabilities experienced by these women, particularly mental health problems, may have prevented their concerns being heard or acted upon.

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)

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**

In a survey conducted by The Department of Health and Social Care in England as part of the Women's Health Strategy development, 84% of women reported instances where they had not been listened to by healthcare professionals (Department of Health and Social Care 2022). Similar evidence suggests that women's complaints of abdominal pain are more likely to be dismissed by healthcare professionals than men's (Windrim, McGuire et al. 2024). Of the women who sought medical attention for their ectopic pregnancy prior to their death, 80% were falsely reassured or had their concerns dismissed by healthcare professionals. More detailed studies into the potential impact of unconscious bias on the quality of healthcare provided to women, especially vulnerable women, is required to ascertain how to better configure services and train healthcare professionals.

5.6 Conclusions

There was sufficient information to assess the care for the 12 women who died from ectopic pregnancy in 2021 and 2022. 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%) (Table 5.2). While the number of women included in this confidential enquiry is small, bleeding and collapse due to the rupture of an ectopic pregnancy can be rapid and catastrophic. Such events require urgent diagnosis, transfer to hospital and surgical intervention to stop the bleeding and save lives. Improved awareness of the symptoms of ectopic pregnancy by both women and clinicians can help identify ectopic pregnancies before collapse and improved access to EPAUs can help with earlier identification and intervention.

Table 5.2: Classification of care received by women who died from ectopic pregnancy, UK and Ireland, 2021-22

Classification of care received	Women who died (n=12) Number (%)
Good care	0 (0)
Improvements to care which would have made no difference to outcome	3 (25)
Improvements to care which may have made a difference to outcome	9 (75)

6. Lessons on morbidity in recent migrant women with language difficulties

Nicky Vousden, Allison Felker, Stephanie Heys, Kailash Bhatia, Anita Banerjee, Upma Misra, Sara Kenyon, Felicity Plaat, Linda Dubeil, Sophie Russell, Sarah Vause, Roshni Patel, Seema Quasim and Marian Knight on behalf of the MBRRACE-UK morbidity chapter writing group

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6.1 Key messages

New 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 **[ACTION: Professional Record Standards Body and equivalents in the devolved nations]**

Existing guidance and recommendations requiring improved implementation

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)

It is important to record in the patient's health record and other associated patient administrative systems the patient's preferred spoken language (including dialect), the patient's preferred written language (including their level of literacy or health literacy in their preferred language) and whether the patient requires an interpreter. Include this information when referring patients to other healthcare professionals (Office for Health Improvement and Disparities 2021b)

Ensure that reliable interpreting services are available when needed (National Institute for Health and Care Excellence 2021)

In order to facilitate discussion of sensitive issues, provide each woman with a one-to-one consultation, without her partner, a family member or legal guardian present, on at least one occasion (National Institute for Health and Care Excellence 2010)

Healthcare professionals should help support women's uptake of antenatal care services by using a variety of means to communicate with women, telling women about antenatal care services and how to use them and undertaking training in the specific needs of women [who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English] (National Institute for Health and Care Excellence 2010)

If a woman books late in pregnancy, ask about the reasons for the late booking because it may reveal social, psychological or medical issues that need to be addressed (National Institute for Health and Care Excellence 2021)

Patients need relevant information to be shared in a way they can understand and retain, so they can use it to make a decision. To help patients understand and retain relevant information you should use an interpreter or translation service if they have difficulty understanding spoken English (General Medical Council 2020)

When giving spoken information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly (National Institute for Health and Care Excellence 2010)

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 2021b)

Not everyone can read or write in their preferred language or have the level of literacy required to understand health related written information. Check this before offering translated written materials. Visual content like images and diagrams may be more helpful when a person has low health literacy (Office for Health Improvement and Disparities 2021b)

Cultural, spiritual and religious considerations are important when requesting language interpreters. In some situations, patients may wish to have an interpreter of the same religion, cultural background and sex. In other situations, patients may wish to request an interpreter that is not from their community (Office for Health Improvement and Disparities 2021b)

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 (National Institute for Health and Care Excellence 2010)

For women who do not have a booking appointment at the first contact with any healthcare professional discuss the need for antenatal care and offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy (National Institute for Health and Care Excellence 2010)

Healthcare professionals should reflect on how they provide services to patients holding diverse cultural, spiritual and religious beliefs (Office for Health Improvement and Disparities 2021b)

Offer the woman information on access and entitlement to healthcare (National Institute for Health and Care Excellence 2010)

Healthcare professionals should ensure they have accurate information about a woman's current address and contact details during her pregnancy by working with local agencies that provide housing and other services for recent migrants, asylum seekers and refugees, such as asylum centres (National Institute for Health and Care Excellence 2010)

Develop a UK-wide specification for identifying and recording the number and nature of social risk factors, updated throughout the perinatal care pathway, in order to offer appropriate enhanced support and referral (Draper, Gallimore et al. 2023a, Draper, Gallimore et al. 2023b)

Ensure that guidance on care for pregnant women with complex social factors is updated to include a role for networked maternal medical care and postnatal follow-up to ensure that it is tailored to women's individual needs and that resources in particular target vulnerable women with medical and mental health comorbidities and social complexity (Knight, Bunch et al. 2023)

Healthcare professionals should be given training on the specific social, religious and psychological needs of women who are recent migrants, asylum seekers or refugees (National Institute for Health and Care Excellence 2010)

Ensure maternity services deliver personalised care, which should include identifying and addressing the barriers to accessing specific aspects of care for each individual (Draper, Gallimore et al. 2023a, Draper, Gallimore et al. 2023b)

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. 2023a, Draper, Gallimore et al. 2023b)

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)

6.2 Background

Similar to other high-income countries, the proportion of people migrating to the UK has been steadily increasing over recent years. In 2022, 14% of the UK's total population was born outside the UK; 4% of which were asylum seekers or refugees (Sumption, Walsh et al. 2024, Walsh and Jorgensen 2024). This is reflected in the current maternity population. In 2022, almost 1 in 3 live births in England and Wales were to women born outside of the UK, the highest proportion observed since reporting began (Office for National Statistics 2023).

Results from MBRRACE-UK indicate that maternal mortality is disproportionately higher for some women born outside the UK. Figures in this year's report (chapter 2) show that approximately 30% of the women who died in 2020-22 were born outside of the UK and women from certain countries were overrepresented amongst the women who died. This includes both Pakistan and India, which are the two most common countries of birth for mothers born

outside the UK (Office for National Statistics 2023). Studies have shown that migrant women, particularly asylum seekers or refugees, interact with and experience maternity services differently to women born in the UK. Many migrant women book later in pregnancy due to unfamiliarity with UK antenatal services and challenges with access, and can experience additional barriers if they have limited English language proficiency (Higginbottom, Evans et al. 2019, McKnight, Goodwin et al. 2019). Amongst the women who died in 2020-22 during pregnancy or shortly after pregnancy, 4% were not able to speak and/or understand English. This rate is likely to be higher in the general maternity population, as studies suggest that 17% of all people who had been in the UK for less than two years, cannot speak English well or at all (Fernández-Reino and Brindle 2024).

As the rate of immigration continues to rise, maternity services in the UK will need to adapt to support the unique needs of migrant women, particular those who face additional obstacles in access due to language difficulties. This morbidity enquiry aims to identify lessons learned from the care of such women, to improve their outcomes and experiences of care.

6.3 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.

Some of the socio-demographic characteristics of the women are shown in Table 6.1. The majority of women were from Asia, primarily Pakistan (n=10, 26%) and there was also a large number of women from Romania (n=7, 18%). Most women were not in their first pregnancy (55% multiparous) and 13 women (34%) were known to be pregnant when they arrived in the UK. For most of the women who were not pregnant on arrival in the UK, 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. Six women (16%) were known refugees or asylum seekers, but citizenship status was not known or not documented for half of the women whose care was reviewed.

Table 6.1: The socio-demographic characteristics of recently arrived migrant women with language difficulties, 2022

Characteristics	Number of women (%) N=38
Age (in years)	
≤24	9 (24)
25-34	23 (61)
≥35	6 (16)
Parity	
Nulliparous	15 (39)
Multiparous	21 (55)
Missing	2 (5)
Woman's region of birth	
Africa	3 (8)
Asia	25 (66)
Eastern Europe	10 (26)
Ethnicity	
White European	10 (26)
Asian	25 (66)
Black	3 (8)
Citizenship status	
EU Citizen	5 (13)
Refugee/asylum seeker	6 (16)
Other	8 (21)
Not documented or not known	20 (50)
Arrived in the UK pregnant	
Yes	13 (34)
No	21 (55)
Unknown	4 (11)

6.4 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. Postmortem 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 2021b). 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).

It is important to record in the patient's health record and other associated patient administrative systems the patient's preferred spoken language (including dialect), the patient's preferred written language (including their level of literacy or health literacy in their preferred language) and whether the patient requires an interpreter. Include this information when referring patients to other healthcare professionals (Office for Health Improvement and Disparities 2021b)

Ensure that reliable interpreting services are available when needed.

NICE NG201 Antenatal care (National Institute for Health and Care Excellence 2021)

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.

In order to facilitate discussion of sensitive issues, provide each woman with a one-to-one consultation, without her partner, a family member or legal guardian present, on at least one occasion.

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)

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.

Healthcare professionals should help support women's uptake of antenatal care services by using a variety of means to communicate with women, telling women about antenatal care services and how to use them and undertaking training in the specific needs of women [who are recent migrants, asylum seekers or refugees, or who have difficulty reading or speaking English].

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)

If a woman books late in pregnancy, ask about the reasons for the late booking because it may reveal social, psychological or medical issues that need to be addressed.

NICE NG201 Antenatal care (National Institute for Health and Care Excellence 2021)

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.

Good care

A multiparous woman arrived in the UK as a refugee from Ukraine late in her second trimester. She was living with a host family and booked for antenatal care within two weeks of arrival. An interpreter was used during her face-to-face booking appointment and in all subsequent hospital midwife and consultant appointments and ultrasound scans. She was appropriately referred for consultant-led care and social support. She had an induction for post-maturity, which was explained by an interpreter and LanguageLine was used at the start of labour. She had an uncomplicated labour and gave birth to a live baby. Postnatally the community midwife used Google translate and she had additional visits for support. M

This woman's care illustrates the positive experience that many migrants have when they interact with the NHS and UK healthcare providers (Higginbottom, Evans et al. 2019). She was booked for antenatal care shortly after arrival in the presence of a face-to-face interpreter. She also appeared to have face-to-face or telephone interpreter services for all subsequent antenatal appointments and scans. In the intrapartum period she also had appropriate interpreter support during sensitive and important discussions including induction of labour, analgesia and delivery options. While Google translate was used postnatally, which is not recommended, she did receive additional community support visits. This example illustrates the benefit of advocacy and supports, such as host families, for helping women navigate the healthcare system and ensuring that they receive equitable care. Exploring methods to establish connections between maternity care and community groups or voluntary organisations who provide support to migrant women may improve women's experiences of healthcare.

6.5 Recurring lessons to be learned

Considerations for interpretation and translation services

Interpreter use in emergency situations and discussions of consent

> A low-risk woman was in her second pregnancy having had a previous caesarean birth. She booked early and was noted to require an interpreter. Interpreters were not present for most of her ultrasounds and antenatal appointments. At her 30 week appointment she agreed to a vaginal birth after caesarean section with an interpreter present. At 38 weeks' gestation she expressed concerns over the size of her baby and requested a caesarean birth that was declined. This request was repeated a week later but was declined again as there was no availability on elective caesarean lists. No interpreter was present for either request. The woman went into spontaneous labour and a decision was made for a category 2 caesarean birth due to obstructed labour. No interpreter use was documented during her intrapartum care, including consent for epidural or caesarean section. There was also no indication that the information provided to her at discharge from hospital was in a language she could understand. M

As illustrated in section 6.4 of this report, women's language needs must be accurately assessed and documented at all stages of care. The offer, availability and use of professional services, including face-to-face and telephone interpreters, must also be recorded in all instances (Office for Health Improvement and Disparities 2021b). This woman's language needs were documented at booking, but she was rarely seen with an interpreter present. Importantly, she did not seem to have access to interpreter services during key discussions including when she requested a caesarean birth and when she later provided consent for an emergency caesarean birth. Assessors noted that provision of interpreter services was less frequent during unplanned emergencies compared to scheduled appointments. While this is not unexpected due to resource capacities, particularly for face-to-face interpreters, service providers must recognise that emergencies can arise during the intrapartum period and have contingency plans in place such as the use of telephone interpreters. It is essential that interpreters are present for discussions of consent so that women fully understand what is being asked and make informed decisions about their care.

Patients need relevant information to be shared in a way they can understand and retain, so they can use it to make a decision. To help patients understand and retain relevant information you should use an interpreter or translation service if they have difficulty understanding spoken English (General Medical Council 2020)

When giving spoken information, ask the woman about her understanding of what she has been told to ensure she has understood it correctly.

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)

Translation of written materials

As for the woman above, 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 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. For several women, assessors felt that their inability to understand written materials may have affected their decision-making and outcomes. Translation of standardised consent forms and patient information can help provide relevant information to non-English speaking women and the development and availability of visual resources can help improve comprehension for women with limited literacy.

The RCOG has launched a translation pilot project to make patient information more widely accessible (***www.rcog.org.uk/for-the-public/translated-patient-information***). There are also several other professional organisations and charities that offer trusted, quality assured pregnancy and birth information in many different languages (***www.tommys.org/pregnancy-information***, ***www.labourpains.org/translated-information/overview***). Signposting to existing resources and continuing the development of translation programmes can help improve women's experiences of care.

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 2021b)

Not everyone can read or write in their preferred language or have the level of literacy required to understand health related written information. Check this before offering translated written materials. Visual content like images and diagrams may be more helpful when a person has low health literacy (Office for Health Improvement and Disparities 2021b)

Women's choice of interpreter

Assessors noted that in several instances women declined professional interpretation services when they were offered. More research is needed to fully explore the barriers and facilitators to the use of interpreter services for diverse groups, but it is important to recognise that women from different cultural, ethnic and religious backgrounds may have concerns around privacy or may not feel comfortable discussing their health with a stranger, a community member or a man (Office for Health Improvement and Disparities 2021a). Indeed, some women declined clinical examinations because only male clinicians were available. When providing interpretation support, it is important to consider women's preferences, including the use of female interpreters, if available. Requesting the same interpreter for subsequent visits can also help build trust in order to facilitate sensitive conversations such as those related to mental health or trauma (Office for Health Improvement and Disparities 2021b, Office for Health Improvement and Disparities 2021c).

Cultural, spiritual and religious considerations are important when requesting language interpreters. In some situations, patients may wish to have an interpreter of the same religion, cultural background and sex. In other situations, patients may wish to request an interpreter that is not from their community (Office for Health Improvement and Disparities 2021a)

Some women also expressed hesitancy to speak to interpreters or clinicians without their partner or a family member present. Other women requested the use of a friend or family member for interpretation. While this introduces safeguarding risks as described in section 6.4, it is important to respect women's choices while also emphasising the importance of professional interpreting. Where women request the use of a friend or family member to interpret, the decision should be communicated by the woman herself in her preferred language without the presence of their family member or carer to ensure that the choice is her own (Office for Health Improvement and Disparities 2021b).

Time required for interpretation

For several women, assessors identified that considerable time and resources were required to provide comprehensive care using interpreter services. Assessors emphasised the need to allow for additional appointment time 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. National guidance suggests planning for the interpreted session to take around double the length of time as a session without an interpreter (Office for Health Improvement and Disparities 2021b). This re-emphasises the need to properly document language needs so that service providers can account for this when scheduling consultations.

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)

Support for recent arrivals accessing the NHS

Use of urgent and emergency services

> A young Bangladeshi woman arrived in the UK early in her second trimester of pregnancy. She had not registered with a GP and had no antenatal care in the UK. She presented to the emergency department at 22 weeks' gestation with abdominal pain and bleeding. She was cared for by a Hindi-speaking doctor who took her medical history. It was discovered that she had had a previous failed medical termination of pregnancy in Bangladesh and a suspected rupture of membranes two weeks prior to presentation. She had a spontaneous vaginal birth of a live baby who died shortly after. The woman was discharged after birth with bereavement support using an online interpreting service and considerations for safeguarding. M

As described in section 6.4, it was apparent that many women did not fully understand how to access the appropriate services within the NHS. As with the woman described here, more than a third of the women seeking care did so via urgent and emergency units rather than established maternity pathways. Many women were not known to be pregnant before they presented to the emergency department. It was evident from the care of these women that they had not been provided with the necessary information about the purpose of, and how to access, antenatal services as recommended by NICE (National Institute for Health and Care Excellence 2010). While most women had onward referrals and follow-up with maternity services after presenting to the emergency department pregnant, assessors also identified several missed opportunities for entry into maternity services and safeguarding of vulnerable women.

For women who do not have a booking appointment at the first contact with any healthcare professional discuss the need for antenatal care and offer the woman a booking appointment in the first trimester, ideally before 10 weeks if she wishes to continue the pregnancy.

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)

Similarly, there was evidence of difficulties accessing ambulance services in the care of several women and their babies. Some women did not appear to know about 999 or how to access ambulance services as they arrived in the emergency department via other methods, including taking the bus with very sick children.

Abortion services

The woman above had a failed termination of pregnancy prior to her arrival in the UK but did not appear to access abortion services once in the country. It is not clear if this was because she was unaware of her ongoing, unwanted pregnancy or if she did not know how to access such services. Some migrant women may also have religious and cultural sensitivities towards discussions of reproductive health, including abortion (Office for Health Improvement and Disparities 2021c). Many migrant women also face additional barriers such as social isolation and lack of support that can impact their willingness or ability to access such services (McKnight, Goodwin et al. 2019). These should be considered when counselling women about termination of pregnancy.

Healthcare professionals should reflect on how they provide services to patients holding diverse cultural, spiritual and religious beliefs (Office for Health Improvement and Disparities 2021a)

GP services and the right to access care

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) and people should not be refused services on these grounds. Women should also be made aware that maternity care,

family planning services (including contraceptive services but not termination of pregnancy or infertility treatment) 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)

Respectful care for migrant women

Appreciation of vulnerabilities

Many of the women whose care was reviewed were vulnerable. Some vulnerabilities were related to women's immigration status, as was the case for the six women who were refugees or asylum seekers. Many women also experienced vulnerabilities relating to social support, financial situations and insecure housing. Almost a quarter of women whose care was reviewed were known to be living in poor conditions or temporary accommodation such as hotels. There is a protected period from 34 weeks' gestation until six weeks after birth, when women on asylum support should not be moved (Refugee Council 2021). This ensures that there is continuity of care with maternity care providers, mental health support and social services and continued proximity to any social/family support in the area. However, this may prolong stays in unsuitable accommodation, and assessors noted that several women were moved frequently outside of this protected period, which may have impacted continuity of care and led to missed appointments.

Healthcare professionals should ensure they have accurate information about a woman's current address and contact details during her pregnancy by working with local agencies that provide housing and other services for recent migrants, asylum seekers and refugees, such as asylum centres.

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)

Women who have recently arrived in the UK, particularly as refugees or asylum seekers, often have a limited social network, with minimal family support (McKnight, Goodwin et al. 2019). This social isolation can compound physical and mental health conditions and create additional difficulties when accessing care, such as limited support to look after older children. As has been stated in past MBRRACE-UK reports (Knight, Bunch et al. 2023), women with complexities and vulnerabilities should receive individualised care. In order to do so, social risk factors must be asked about, considered and recorded. When women do not attend appointments, the reasons must be explored and the language around engagement and 'compliance' reframed so that the blame is not placed on women. Rather, medical professionals need to be sensitive to the challenges vulnerable women face, and explore alternatives to help women access maternity care.

Develop a UK-wide specification for identifying and recording the number and nature of social risk factors, updated throughout the perinatal care pathway, in order to offer appropriate enhanced support and referral (Draper, Gallimore et al. 2023b, Draper, Gallimore et al. 2023a)

Ensure that guidance on care for pregnant women with complex social factors is updated to include a role for networked maternal medical care and postnatal follow-up to ensure that it is tailored to women's individual needs and that resources in particular target vulnerable women with medical and mental health comorbidities and social complexity (Knight, Bunch et al. 2023)

Healthcare professionals should be given training on the specific social, religious and psychological needs of women who are recent migrants, asylum seekers or refugees.

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)

Several women had evidence of considerable financial need that affected how they engaged with maternity care. Appointment reminders sent over text and digital maternity notes requiring internet access can create a digital divide for those without access to a smartphone or computer. Some women had to take multiple modes of public transport to attend appointments and some were unable to take time off work. Migrant women are also more likely to be considered high-risk, which results in an increased number of antenatal appointments and exacerbates the issue.

Healthcare professionals should be cognisant of the impact that these financial difficulties may have on care. Aligning appointments can help reduce the number of trips required and discussing the timing of appointments with women and their partners can mitigate the need to take time off work. Offering appointments at the woman's residence can also facilitate access to care as can providing women with a specific contact number for use, especially in an emergency.

Ensure maternity services deliver personalised care, which should include identifying and addressing the barriers to accessing specific aspects of care for each individual (Draper, Gallimore et al. 2023b, Draper, Gallimore et al. 2023a)

Microaggressions and discrimination

As has been detailed in past MBRRACE-UK confidential enquiries (Draper, Gallimore et al. 2023b, Draper, Gallimore et al. 2023a), and other studies into the care of women from minority ethnic backgrounds (Knight, Bunch et al. 2022a, Vousden, Bunch et al. 2024), there was evidence of microaggressions or biases in care for many of the women relating to their ethnicity, language or migrant status. For example, there were several instances of language, ethnicity, citizenship and nationality not being recorded or recorded with varied accuracy in women's notes. Assessors also noted that some women's background may have affected their quality of care, such as cultural or religious beliefs not being considered in bereavement support following a perinatal loss. There were also examples where challenges with communication impacted women's autonomy in decision-making. These examples all suggest that a greater cultural competency is required amongst clinicians.

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. 2023b, Draper, Gallimore et al. 2023a).

6.6 Conclusions

There was sufficient information to assess the care for all 38 women included in the confidential enquiry. Assessors felt that improvements in care may have made a difference to the outcome or 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 (Table 6.2). To improve equitable access and outcomes for migrant women, interventions must be co-developed to improve their understanding of the NHS and how to access maternity services. This may take the form of connections with community supports, or clearer guidance on how to register with a GP where more information can be provided. Once women are booked for maternity services, care must be individualised and culturally-sensitive. Efforts must be made at every interaction to assess and document language needs and provide professional interpretation or translation support to ensure that information is understood and that women are able to make informed decisions about their health and the health of their babies.

Table 6.2: Classification of care received by recent migrant women with language difficulties, 2022

Classification of care received	Women whose care was reviewed (n=38) Number (%)
Good care	6 (16)
Improvements to care which would have made no difference to outcome	7 (18)
Improvements to care which may have made a difference to outcome	25 (66)

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