Missing Voices
Saving Lives, Improving Mothers' Care: Lay Summary 2022

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

229 women died during or up to six weeks after the end of pregnancy in 2018-20

10.9 women per 100,000 giving birth
24% higher than 2017-19

27 of their babies died
366 motherless children remain

A further **289 women** died between six weeks and a year after the end of pregnancy in 2018-20

13.8 women per 100,000 giving birth

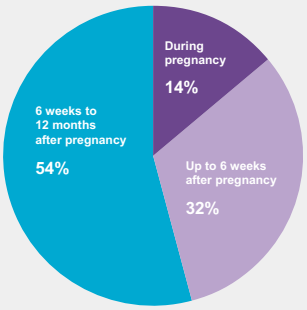
9 women died from covid-19

Excluding their deaths, **10.5 women** died per 100,000 giving birth

19% higher than 2017-19

1 in 9 women who died had severe and multiple disadvantage

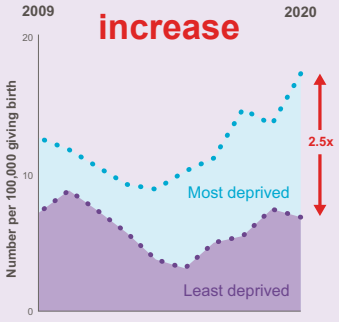
Most women died in the postnatal period **86%**



Black women were **3.7x** more likely to die than white women (**34 women** per 100,000 giving birth)

Asian women were **1.8x** more likely to die than white women (**16 women** per 100,000 giving birth)

More women from **deprived areas** are dying and this continues to **increase**



In 2020, women were **3x** more likely to die by **suicide** during or up to six weeks after the end of pregnancy compared to 2017-19

1.5 women per 100,000 giving birth

Saving Lives, Improving Mothers' Care 2022: Lay Summary

Lisa Hinton on behalf of the MBRRACE-UK lay summary writing group: Clotilde Abe (Fivexmore), Atinuke Awe (Fivexmore), Marcus Green (Action on Pre-Eclampsia), Jennifer Holly (NCT), Sara Kenyon (MBRRACE-UK), Kirsty Kitchen (Birth Companions), Marian Knight (MBRRACE-UK), Jenny Kurinczuk (MBRRACE-UK), Liz Thomas (AvMA), Toni Woodman (Maternal Mental Health Alliance).

The United Kingdom's Confidential Enquiry into Maternal Deaths represents the gold standard around the world for rigorous investigations to drive improvements in maternity care. The Enquiry recognises the importance of learning from every woman's death, during and after pregnancy, not only for staff and health services, but also the family and friends they leave behind.

This is the ninth MBRRACE-UK annual report and details the care of 536 women who died during, or up to one year after, pregnancy between 2018 and 2020. The report includes detailed chapters on mental health and multiple adversity, cardiovascular care, hypertensive disorders, early pregnancy disorders and accidents. The report also includes a specialist enquiry into the care of 61 women with diabetic ketoacidosis in pregnancy.

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

Sounding the alarm on inequalities

This year's report highlights the significant impact on women's health of the increasing inequalities in the United Kingdom, in terms of deprivation and disadvantage. These maternal deaths are the tip of the iceberg, and cannot be dismissed as a minority issue. Although this report is the first to include figures for Covid-19 deaths, these must not obscure the wider trends. This report details increases in the overall maternal death rate in the UK between 2015-17 and 2018-2020, even when the nine deaths from Covid-19 in this period are excluded. The Government's ambition is to reduce maternal mortality in England by 50% between 2010 -2025, yet maternal mortality has increased by 8% since 2010-12. These figures contrast starkly with the perinatal picture, where the number of baby deaths has reduced steadily over a similar period. This report calls urgently for a continued focus on the broader physical and mental health of the mother, and a greater focus on understanding and addressing the social determinants of health.

The report includes details of 229 women who died in pregnancy or up to 6 weeks after the end of their pregnancy. Excluding the women who died from Covid-19 this represents an increase of 19% compared to 2017-19. The report also details the deaths of 289 women who died up to 12 months after this post-partum period. There were increases in maternal death rates from direct causes such as suicide, pre-eclampsia and haemorrhage.

Significantly, mental ill-health and heart disease are now on an equal footing as the cause of maternal deaths in the UK. Added together they represent 30% of maternal deaths during or up to six weeks after pregnancy. Mental ill-health in pregnancy and beyond is an increasing cause of maternal death; 40% of deaths within the year after pregnancy were from mental health causes, with maternal suicide remaining the leading cause of direct deaths in this period.

Covid-19

This report includes information on nine women who were pregnant or within six weeks of the end of their pregnancy who died from Covid-19 between March and December 2020. This was the period before any treatments or vaccinations were available. Future reports will focus on the longer-term impact of Covid-19 on both direct and indirect deaths, but in the ten months of the pandemic covered in this report there is little doubt that the disruptions as a result of the pandemic also contributed to some other maternal deaths.

Inequalities

Ethnic inequality endures; there remains a more than three-fold difference in maternal mortality rates among women from Black ethnic backgrounds, and an almost two-fold difference amongst women from Asian ethnic backgrounds, compared to White women. These disparities have reduced from previous reports, but warrant a continuing focus. However, this report also highlights the *increasing* impact of deprivation and severe and multiple disadvantage on maternal outcomes. Women living in the most deprived areas are more than twice as likely to die as women living in the wealthiest areas. 11% of the women who died in the UK in 2018-20 were at severe and multiple disadvantage, the main elements being a mental health diagnosis, substance use and domestic abuse. This is known to be an underestimate, however, due to poor data collection on these and other factors.

In interpreting this report, it is important not to conflate ethnicity with deprivation. While the sustained effort on ethnicity-associated inequalities must not waver, now is the time to engage with other inequalities as well. We need to look beyond maternity services in addressing these issues, and build in greater consideration of the social determinants of health. Actions need to be focused on postnatal care and holistic support in the first year after birth, as well as during pregnancy.

Women's voices are missing

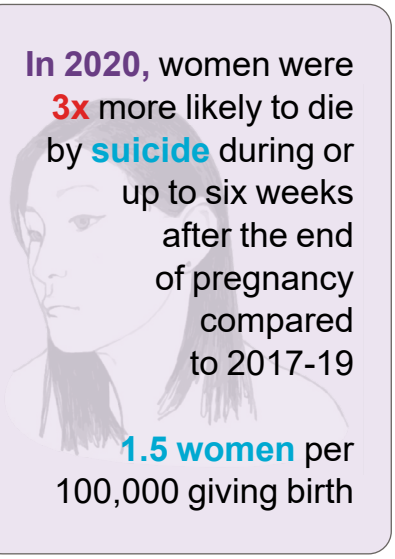
Many of the women who died, particularly those with mental ill-health or facing multiple adversity, struggled to engage with health and social services. This report recognises women need individualised services to meet their needs. Lack of engagement may be a reflection that their needs are not being met. Actions are required to understand and work with these women. The lack of data on women's social circumstances and the best way to care for women who require complex intersecting services needs to be addressed urgently. The advocates and support charities who work with women at high risk have a critical role to play; it is these organisations that can help make sure these women's voices are heard, and their needs recognised and responded to.

Mental health and multiple adversity

Patterns of multiple adversity remain extremely common in women who die by suicide, substance misuse, homicide or accidental death. Suicide deaths occurred both antenatally and postnatally, but mostly after the end of pregnancy. Very few women who died by suicide in 2020 had formal mental health diagnoses, but significant numbers had a history of trauma. Services need to commit to trauma-informed care, and recognise the importance of trauma history and professional sensitive enquiry about underlying factors. Involvement of specialist perinatal mental health teams, particularly in the care of women with a significant history or involvement with mental health services, is paramount.

Recent research highlights the rapid increase in infant removal. Professionals in maternity services and beyond must be alert to the impact of stigma and fear of child removal, as this may influence women's willingness to disclose symptoms of mental illness, thoughts of self-harm or substance misuse. Perinatal mental health services don't continue to work with women if a baby is removed so the continuity of appropriate mental health support for these women should be a priority. 20% of women who died during or up to six weeks after pregnancy were known to social services and this proportion is increasing, emphasising again the need to ensure coordinated care across complex and intersecting services.

Two thirds of women who died by suicide used violent methods, and the increased rate of teenage suicide remains a significant concern.



In 2020, women were **3x** more likely to die by **suicide** during or up to six weeks after the end of pregnancy compared to 2017-19

1.5 women per 100,000 giving birth

Key messages for health professionals

- New expressions or acts of violent self-harm are ‘red flag’ symptoms. Take them seriously.
- Be aware of sleep disturbance and stigma.
- Recognise the complexity and multiple challenges facing each woman you care for, including any history of trauma.
- Pre-birth and post-birth care is vital.
- Don’t allow women to fall through the gaps.
- Be the person to hear and act.

8 women
died from pre-eclampsia

0.4 women
per 100,000 giving birth

4x higher than the lowest ever rate in 2012-14

Pre-eclampsia

There will continue to be a significant number of women affected by pre-eclampsia and other hypertensive disorders for the foreseeable future. We cannot afford to become complacent about their care.

- Ensure the Patient Group Direction allowing the prescription of aspirin for pregnant women at risk of pre-eclampsia by midwives and pharmacists is comprehensively implemented.
- Ensure that women’s electronic records can be easily accessed and shared when they receive care in different settings.

Heart disease

Women continue to enter pregnancy with a greater range and number of risk factors for heart disease. Recognising heart disease when it occurs for the first time in pregnancy, or immediately after pregnancy, is therefore vital. Considering heart disease as part of the differential diagnosis for women presenting with pain, wheeze and breathlessness remain vital actions. Pre-pregnancy, be aware and address risk factors.

- Wheeze can be due to pulmonary oedema. Consider wheeze that does not respond to standard asthma management as a ‘red flag’.
- Raised respiratory rate and/or heart rate, chest pain and breathlessness are important signs and symptoms of heart disease.
- Be aware of the common risk factors for heart disease and venous thromboembolism, and ensure women are made aware of the red flag symptoms.

Risk factors for heart disease

- Older age
- Smoking
- Obesity
- Diabetes
- Hypertension/pregnancy hypertensive disorders
- Family history of premature coronary disease
- Hypercholesterolaemia

Advocacy and peer support

Advocacy and peer support groups are a critical part of the maternity landscape with a role to play in providing information, advice and empowering people to seek help. They can also help in the design or development of services for those women that services find it hard to engage with.

- The UK has many high quality voluntary sector and patient advocacy groups, where appropriate liaise with and signpost to them and their resources.
- These groups should be involved, along with the communities they support, in the evaluation and future development of maternity services.

Key messages for women, partners and families

- Pregnancy can affect your health in the nine months you are pregnant, and beyond.
- Think about your health before and after, as well as during your pregnancy.
- If you have a pre-existing health condition, try to get specialist advice before you get pregnant. Don't stop existing medication without expert advice.
- Stay connected with your usual care teams, and keep your GP and midwife informed.

Ectopic pregnancy

- Ectopic pregnancy is rare, but be aware of signs and symptoms. These include a missed period or signs of pregnancy, tummy pain down one side, shoulder tip pain, discomfort when going to the toilet, vaginal bleeding or brown watery discharge.

Mental health

- Mental health is special in pregnancy, the mind can change as well as the body. These are signs to be aware of, in yourself, a loved one or friend.

Red flags to look out for, and seek advice from your midwife, GP or mental health team:

- Do you have new feelings or thoughts that you have never had before, which make you disturbed or anxious?
- Are you experiencing thoughts of suicide or harming yourself in violent ways?
- Are you having severe struggles to sleep?
- Are you feeling incompetent, as though you can't cope, or estranged from your baby? Are these feelings persistent?
- Do you feel you are getting worse?

High blood pressure or pre-eclampsia during or after your pregnancy

- You may need to take aspirin if you are at risk of pre-eclampsia. Ask your midwife, GP or pharmacist.
- You should expect to have your blood pressure and urine tested at every antenatal visit. Make sure this is happening. If it is not, ask why not.

Factors which put you at moderate risk of pre-eclampsia:

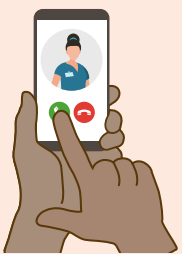
- First pregnancy
- Age 40 years or older
- Multiple pregnancy
- Pregnancy interval of more than 10 years
- Body Mass Index (BMI) of 35 or more
- Family history of pre-eclampsia

Heart disease

- Heart disease can occur for the first time in pregnancy.
- It is important to let someone know if you have a family history of heart disease or sudden death.

Red flags to look out for, and seek advice:

- you have severe chest pain spreading to your jaw, arm or back
- your heart is persistently racing
- you are severely breathless when resting, especially if it happens when you lie flat
- you experience fainting *while* exercising



Pregnant? Caring for Pregnant Women?

FIVEXMORE

Use these 6 Steps (https://www.fivexmore.com/6steps)

FOR HEALTH PROFESSIONALS	FOR WOMEN, THEIR FRIENDS AND FAMILIES
1 LISTEN	**SPEAK UP**
Be a champion – challenge, inspire change, value each and every woman in your care. We all experience our emotions differently. Listen to *what* is being said as opposed to *how* it is being said. Recognise when a woman is at risk.	If you feel that something isn't right, don't stay silent. Make sure you speak to a health care professional. It's really important to share the whole picture of yourself and the multiple challenges that you face in your health and social situation.
2 BE OR FIND AN ADVOCATE	**FIND AN ADVOCATE**
'Mind the gap'. Advocates can help navigate across the health and social care sectors	Find an advocate, a family member or friend, who can speak on your behalf.
3 KNOW WHEN TO SEEK A SECOND OPINION	**SEEK A SECOND OPINION**
Be confident to challenge incorrect practice when you see it. Know when you have reached the limit of your expertise, and who to contact.	You are allowed to ask for a second opinion if you feel you need to.
4 MAKE A DIAGNOSIS	**TRUST YOUR GUT FEELING**
Challenge your assumptions – don't assume symptoms are due to pregnancy. Make a diagnosis rather than simply excluding a diagnosis.	Speak up. Nobody knows your body better than you. If you think that something is not right, don't dismiss it, trust your instincts.
5 BE WOMAN-CENTRED	**DO YOUR RESEARCH**
Research and offer models of care most appropriate for each women taking into account their preferences and values. Find out what resources exist to support accurate communication of risk, shared decision-making and tailored risk management.	Do your research on pregnancy and labour, via trusted sources like NHS.uk, nice.org.uk, patient.info and the specialist organisations listed below. Or ask someone to help you find out more.
6 DOCUMENT AND COMMUNICATE	**DOCUMENT EVERYTHING**
Ensure maternity care is properly recorded and include all conversations, including those about reducing risk. Make sure that women, their friends and families and everyone involved in her care has the information they need to provide her with seamless timely care.	Make sure that any treatment or medication that you are given is written down in your maternity notes by your doctor or midwife. The information from all conversations you have should also be in your notes, including any about reducing your risks. Keep your own notes for your own personal records, so you can cross reference.

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

avma action against medical accidents

ACTION ON PRE-ECLAMPSIA PROMOTING SAFER PREGNANCY

OXFORD POPULATION HEALTH UNIVERSITY OF OXFORD NPEU

FIVEXMORE

nct 1ST 1,000 DAYS NEW PARENT SUPPORT

MATERNAL MENTAL HEALTH ALLIANCE Awareness Education Action

birth companions