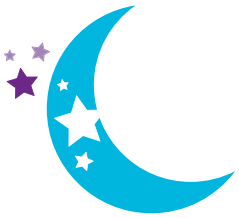
Saving Lives, Improving Mothers' Care 2020: Lay Summary

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

In 2016-18, **217 women died** during or up to six weeks after pregnancy, from causes associated with their pregnancy, among 2,235,159 women giving birth in the UK.
9.7 women per 100,000 died during pregnancy or up to six weeks after childbirth or the end of pregnancy.

We need to talk about SUDEP

Act on:



Night-time seizures

Uncontrolled seizures

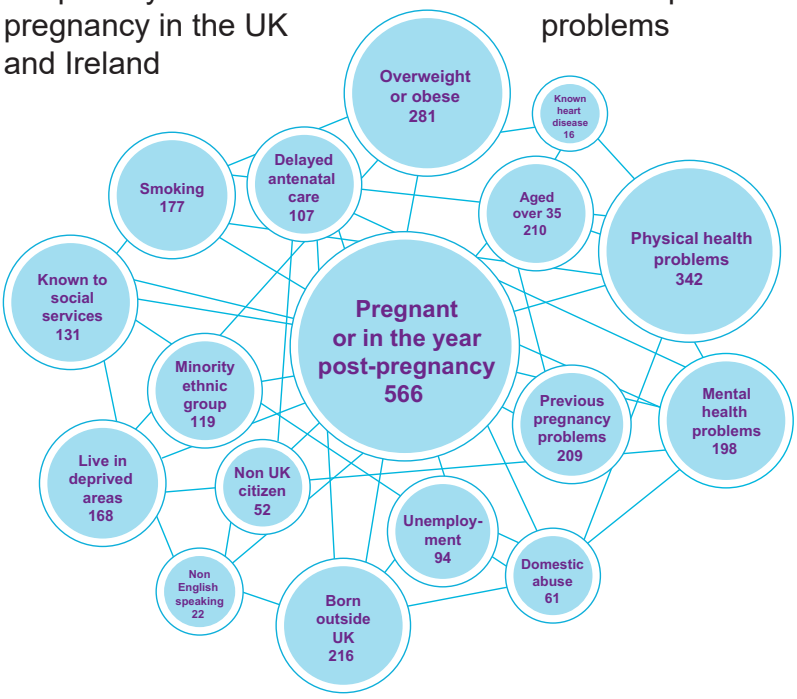
Ineffective treatment

to prevent **Sudden Unexpected Death in EPilepsy**

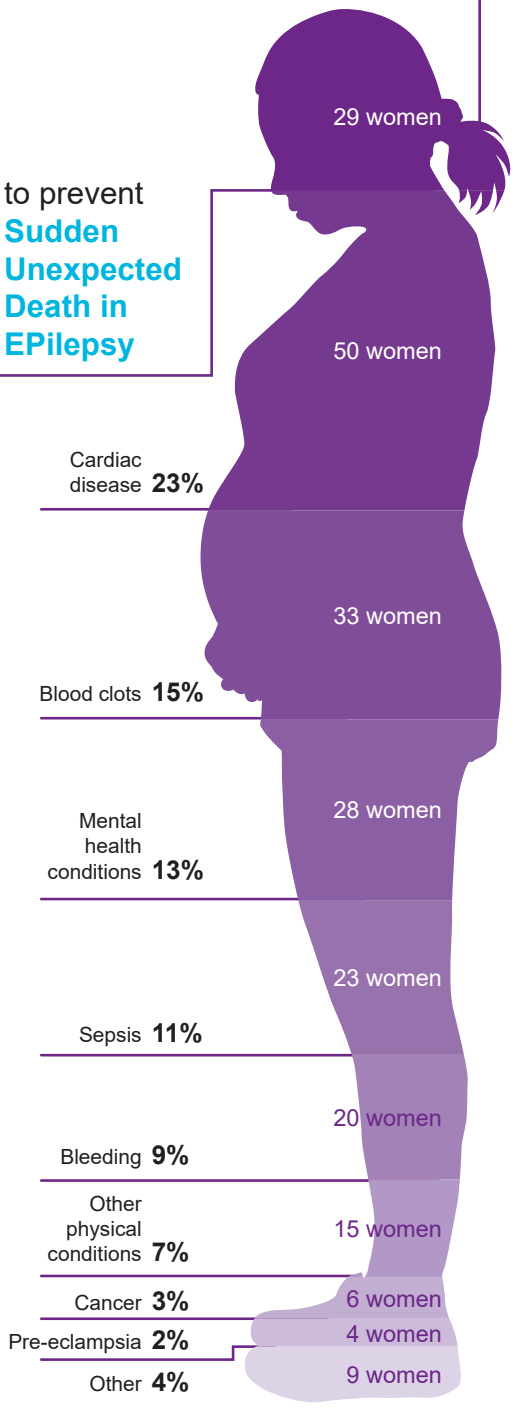
A constellation of biases

566 women died during or up to a year after pregnancy in the UK and Ireland

510 women (90%) had multiple problems



Systemic Biases due to pregnancy, health and other issues prevent women with complex and multiple problems receiving the care they need



Saving Lives, Improving Mothers' Care 2020: Lay Summary

Lisa Hinton on behalf of the MBRRACE-UK lay summary writing group

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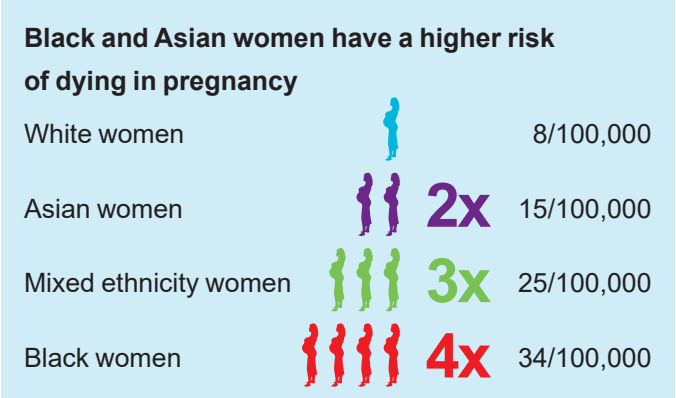
The United Kingdom's Confidential Enquiry into Maternal Deaths represents a gold standard around the world for investigations and improvements in maternity care. Through its rigorous reviews, the Enquiry recognises the importance of learning from every woman's death, during and after pregnancy, not only for staff and health services, but also the family and friends she leaves behind. This year the report examines in detail the care of 547 women who died during, or up to one year after, pregnancy between 2016 and 2018 in the UK and Ireland from epilepsy and stroke, general medical and surgical disorders, anaesthetic causes, haemorrhage, amniotic fluid embolism and sepsis. The report also includes a Morbidity Confidential Enquiry into the care of 34 women with pulmonary embolism.

What this year's report shows

Pregnancy remains very safe in the UK. In 2016-18 242 women, of the 2,235,159 giving birth, died during or up to six weeks after pregnancy, 547 during or up to one year after their pregnancy. Heart disease remains the leading cause of death, followed by thrombosis and thromboembolism (blood clots). Maternal suicide is the fifth most common cause of women's deaths during pregnancy and its immediate aftermath, and is the leading cause of death over the first year after pregnancy.

A key focus in this year's report is the concerning doubling in the number of women who are dying from Sudden Unexpected Death in Epilepsy (SUDEP). In many instances these deaths are linked to inadequate medications management for these women either before or during their pregnancy. More women now die from epilepsy during or after their pregnancy than those who die as a result of pregnancy hypertensive disorders. It remains important nevertheless to always check for pre-eclampsia which may complicate pregnancies of women with other underlying health conditions.



Outcomes for women are not equal. There remain gaps in mortality rates between women from different areas, women of different ages and women from different ethnic groups. This year's report shows a continued gap between the mortality rates for women from Black, Asian, mixed and white ethnic groups. What is encouraging is that individuals, groups, third sector organisations, research units and professional societies, the NHS and government bodies have responded positively to these unequal outcomes with multiple actions ranging from the first national Five x More Black Women's Maternal Health Awareness Week to a new Race Equality Taskforce.

Other inequalities are growing. Women living in the most deprived areas are almost three times more likely to die than those who live in the most affluent areas. The number of women who are known to be experiencing multiple disadvantages when they die has increased by a third since the last report, from 6% to 8%. Women in these situations will often face mental ill-health, domestic abuse and/or misuse substances. However these and other issues are poorly recorded, so these figures should be treated as a minimum estimate and warrant urgent further enquiry. The data highlight a need for greater focus on systemic issues and public health to reduce inequalities and improve safety.

It is also significant that social services were involved in the lives of 20% of the women who died, an increase from 12% in 2012-14. Involvement with social services is an indicator of the otherwise largely invisible levels of need and adversity experienced by many of the women who die. This suggests far greater coordination between social services and maternity care is needed in order to understand and respond to women's circumstances. Our health and social care system does not work well for women with multiple and complex problems. This report draws attention to the constellation of biases that contributed to women's deaths.

It is important to recognise that this report describes messages from the care of women who died before the COVID-19 pandemic. But our early data from 2020 shows that issues highlighted in this report, in particular around the impacts of social and ethnic inequalities, multiple disadvantage and epilepsy, are likely to have been amplified during 2020.

Key messages

Epilepsy and pregnancy: we need to talk about SUDEP and epilepsy risk

Epilepsy is a key focus of this year's report. Although Sudden Unexpected Death in Epilepsy (SUDEP – when someone with epilepsy dies suddenly and no other cause of death can be found) is uncommon, it occurred almost twice as often among women who were pregnant or in the year after pregnancy in 2016-18 compared to the previous three years. Most women who died had clear risk factors for SUDEP but had not had risk or prevention measures discussed with them.

Key messages for health and care professionals

- Women with epilepsy are really at risk, so make sure you support them as well as you can, and as early as you can.
- Check that there has been a positive conversation about minimising SUDEP and other risks alongside the Pregnancy Prevention Programme.
- Use standardised safety tools to check discussion of medication changes are informed and balanced, for example the SUDEP and Seizure Safety Checklist *https://sudep.org/checklist*.
- Shared care across maternity and epilepsy services is important. If social services are involved this joined up working is all the more important. Work together for women with more complex needs. Please don't give up on them. You can make a difference.

Key messages for women and their families

Whether you live with epilepsy, or know someone who does, find out what you need to know to help balance risk and live well with epilepsy *(http://sudep.org)*.

- Well before you think about pregnancy, have a pre-pregnancy discussion with your epilepsy team and agree a plan.
- Don't stop taking your medications when you get pregnant, but do discuss them with your maternity or epilepsy teams to make sure they are right for you and for pregnancy.
- Be aware of what makes your SUDEP and epilepsy risk higher and how you can reduce it – the free EpSMon app can help you with this *(www.sudep.org/epsmon)*.

Mind the gap

This year a key message again is "mind the gap". It is clear from the report that our health and social care systems are not well organised to provide joined-up care for women with multiple health, social and other issues. With permission, we have adapted the Five x More steps to help prevent women from falling through the gaps within and between systems. More detailed and specific actions to help improve health and care systems for women with multiple disadvantage are set out in the 'Holding it all together' report from Birth Companions and Birthrights *(https://www.birthcompanions.org.uk/resources/92-holding-it-all-together)*

Pregnant? Caring for Pregnant Women?

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.

Where to find help and trusted information

NHS Website *https://www.nhs.uk*

NHS Direct Wales *https://www.nhsdirect.wales.nhs.uk*

Ready Steady Baby *http://www.readysteadybaby.org.uk*

Action on Pre-eclampsia *https://action-on-pre-eclampsia.org.uk*

Birth Companions is a leading voice on the needs of women facing multiple disadvantage during pregnancy and early motherhood *https://www.birthcompanions.org.uk*

SUDEP Action *https://sudep.org/*