Health Innovation East Midlands

# Informed choices for ethnically diverse women during pregnancy

Alma Gallagher – Deputy Head of Improvement

Part of the Health Innovation Network

# Purpose

Health Innovation East Midlands
Local change, national impact

The aims of the event are:

1) **Raising awareness** of the broad challenges faced by ethnically diverse women in maternity services
2) **Enable dialogue and collaboration** between frontline clinicians, key decision makers and patient representatives in maternity and neonatal services, building consensus on the problem area and sharing best practice
3) **Showcase JanamApp 2.0** as an innovative digital solution for a specific cohort; women from South Asian backgrounds

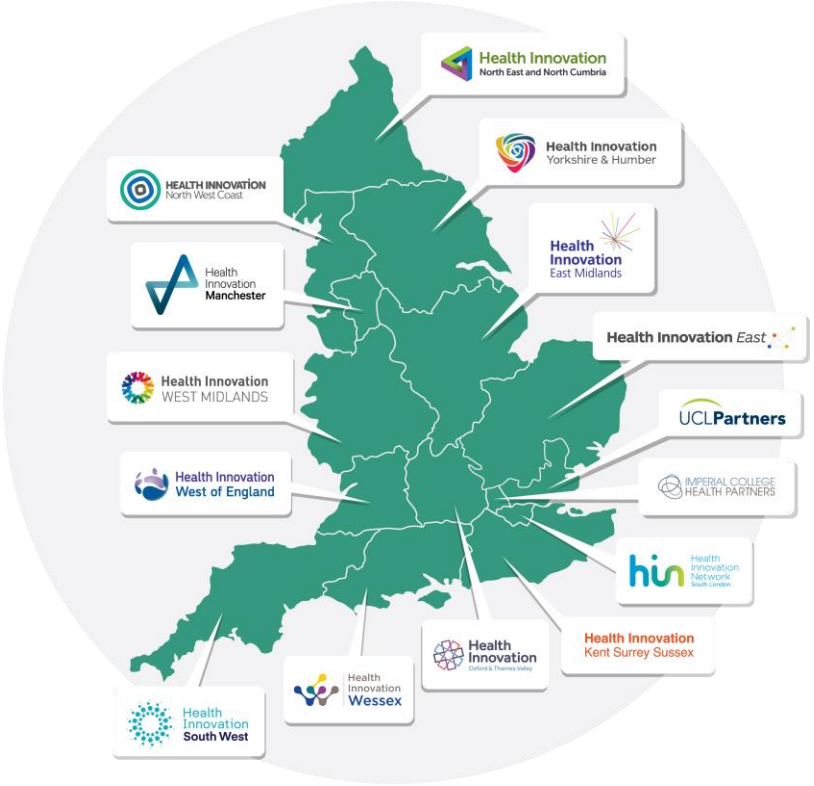
# Agenda

| Time | Item | Lead | Role | Organisation |
|---|---|---|---|---|
| **12:00 – 12:05** | Welcome and introduction | Alma Gallagher (Chair) | Deputy Head of Improvement | Health Innovation East Midlands |
| **12:05 – 12:20** | Keynote address | Wendy Olayiwola | National Maternity Lead for Equality | NHS England |
| **12:20 – 12:25** | Local service perspective from Derby / Burton | Claire Brackenbury | Lead Midwife for Transformation | University Hospitals Derby Burton NHS Foundation Trust |
| **12:25 – 12:30** | 'I don't know' – informed choices video segment | Alma Gallagher (Chair)<br>Angie Doshani | Deputy Head of Improvement<br>Consultant Obstetrician & Gynaecologist & Co-founder | Health Innovation East Midlands<br>University Hospitals Leicester NHS Foundation Trust, JanamApp |
| **12:30 – 12:40** | Audience Q&A | Alma Gallagher (Chair) | Deputy Head of Improvement | Health Innovation East Midlands |
| **12:40 – 12:50** | The journey to JanamApp | Angie Doshani<br><br>Khalood Zaffaron | Consultant Obstetrician & Gynaecologist & Co-founder<br>Patient Representative | University Hospitals Leicester NHS Foundation Trust, JanamApp |
| **12:50 – 12:55** | JanamApp demo | Angie Doshani | Consultant Obstetrician & Gynaecologist & Co-founder | University Hospitals Leicester NHS Foundation Trust, JanamApp |
| **12:55 – 13:00** | Final audience Q&A / summing up | Alma Gallagher (Chair) | Deputy Head of Improvement | Health Innovation East Midlands |

# Health Innovation Networks

Health Innovation East Midlands
Local change, national impact

- One of 15 Health Innovation Networks (HINs) – commissioned by the NHS and UK Office for Life Sciences to operate as the innovation arm of our ICSs and regional partners.
- We tackle national problems, with local understanding…
- And local problems, with national expertise.
- Each health innovation network is fully-embedded in their local health and research ecosystem.
- This drives economic prosperity and growth in all parts of the country and ensures that everyone benefits from innovation.



# National Patient Safety Priorities for Improvement
# Maternity and Neonatal Safety

Health Innovation East Midlands
Local change, national impact

**Aim: To contribute to a reduction in rates of maternal and neonatal death, stillbirths, brain injuries and preterm birth.**

The Network of 15 Patient Safety Collaboratives are commissioned to deliver the following national maternity & neonatal priorities:

1. Optimisation & Stabilisation of the Preterm Infant
2. Deterioration: Implementation of National Early Warning Tools MEWS and NEWTT2
3. Perinatal Culture & Leadership – Ongoing Support

- **Safer Systems of Care**
- **Culture of Safety**
- **Patient & Carer Involvement**
- **Share Improvement Learning**
- **Effective Networks and Collaboration**

**Identify Equity and Reduce Inequalities**

Health Innovation East Midlands

# Keynote

Wendy Olayiwola – National Maternity Lead for Equality, NHS England

# Inequalities Landscape in Maternity in the UK

Wendy Olayiwola. **BEM, FRCM, RM,RN**
National Maternity Lead for Equality
CNO CMiDO BME SAG Midwifery Lead
Professional Midwifery Advocate
Chief Midwifery office NHS England

## Enabling informed choices for ethnically diverse women during pregnancy

28/11/24

# Access, outcomes & experiences of Perinatal Mental Health (PNMH) services among racialised communities & minority ethnic groups

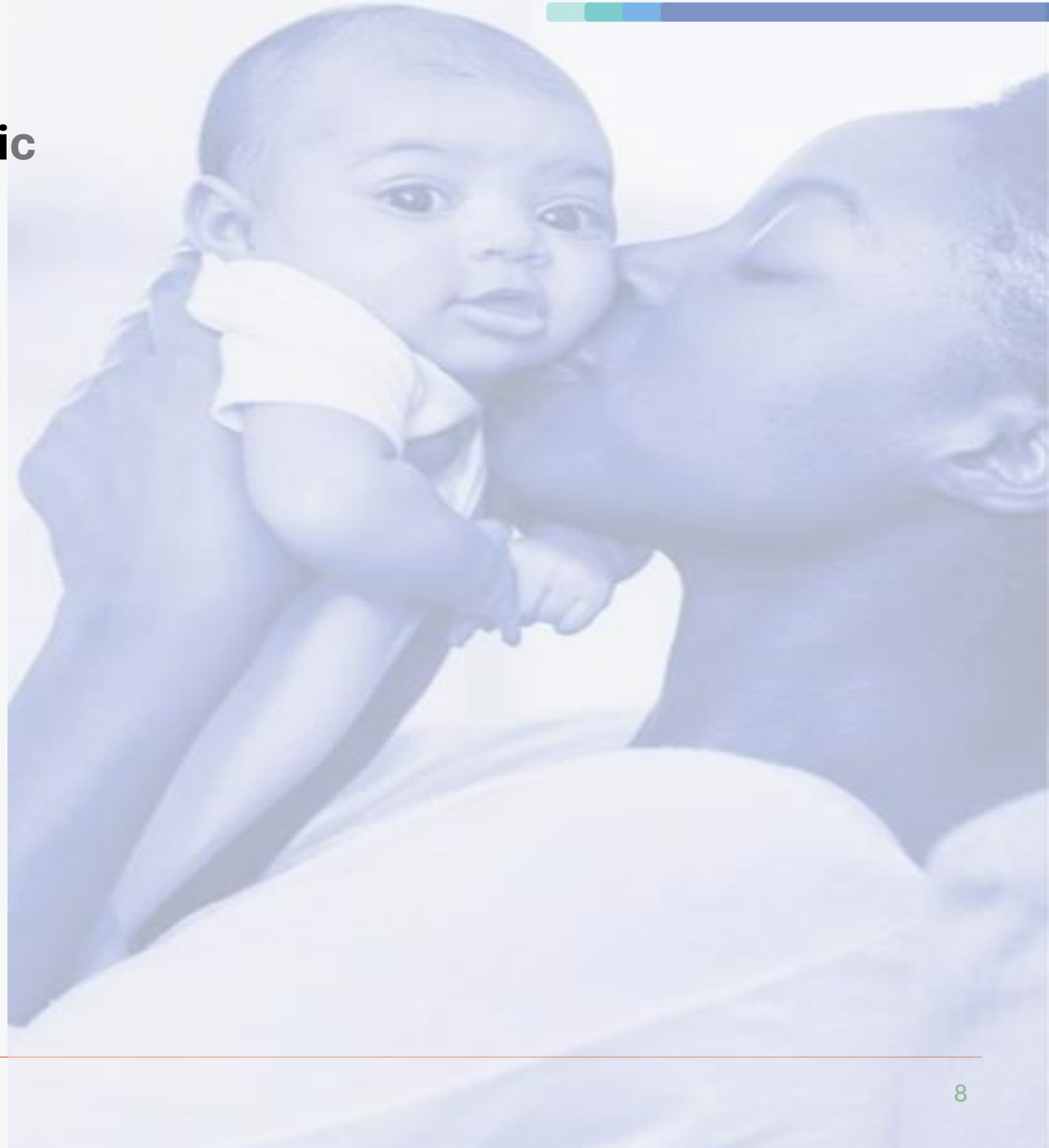
MBRRACE-UK (2023) Death during pregnancy, childbirth and post-partum period

**Black women are 3.8 times more likely to die**

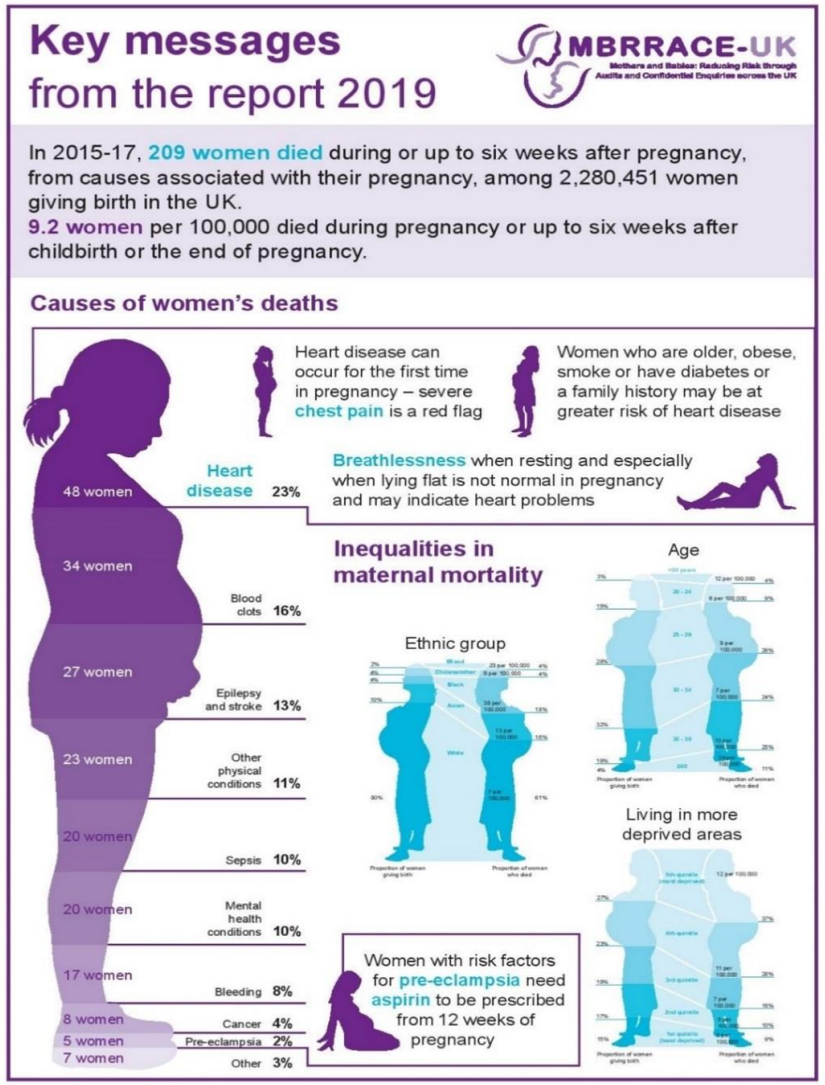
**Asian women are 1.8 times more likely to die.**

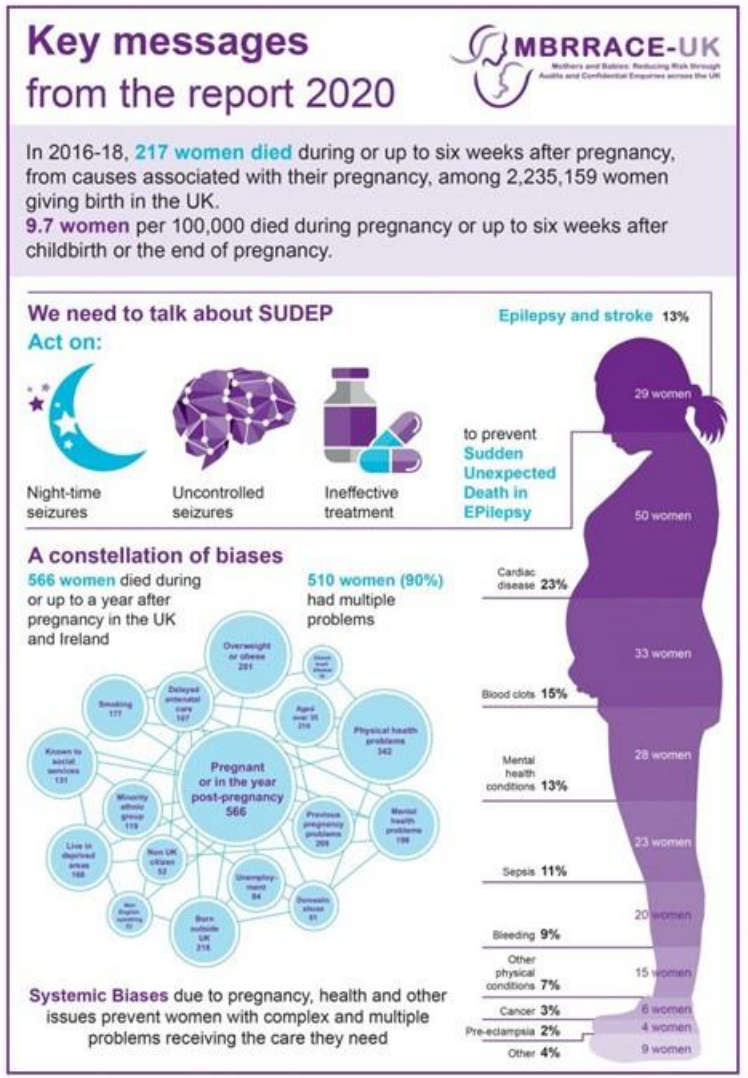
Women from minority ethnic groups have **poorer outcomes and experiences of care**, and face greater barriers **to accessing specialist PMH services.**

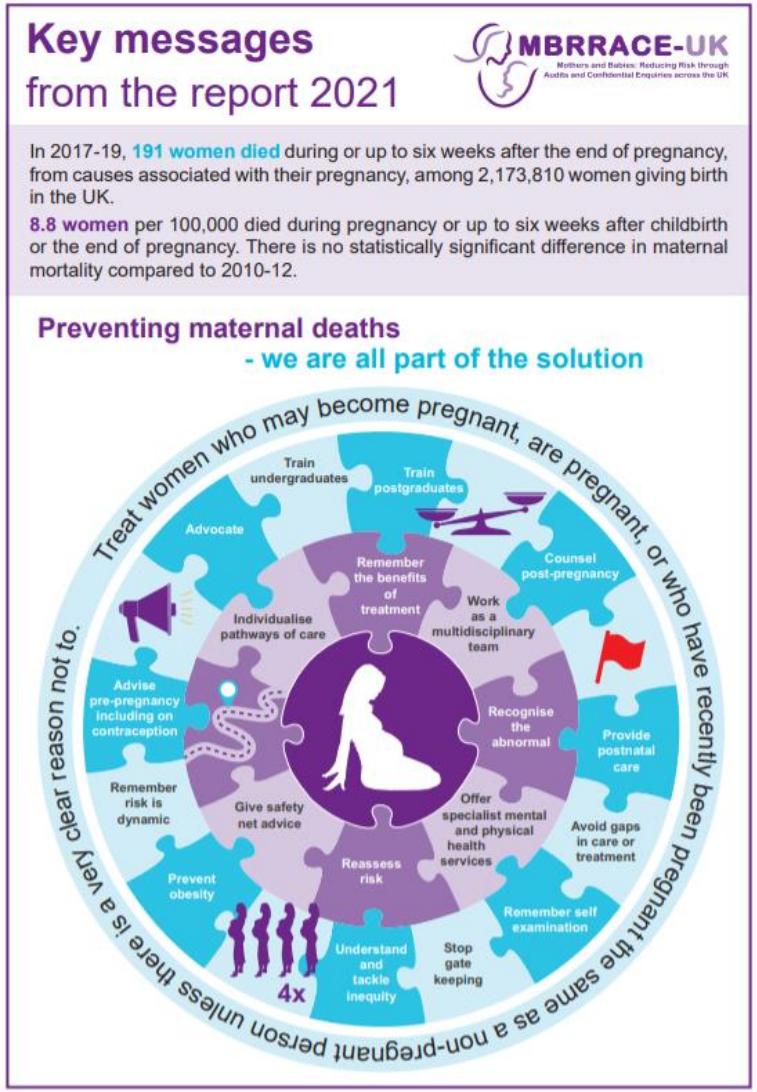
Women from minority ethnic groups experienced **disrupted PMH care during the pandemic**, particularly in relation to digital barriers of accessing remote delivery of care.



# Analyse the trend in the data....



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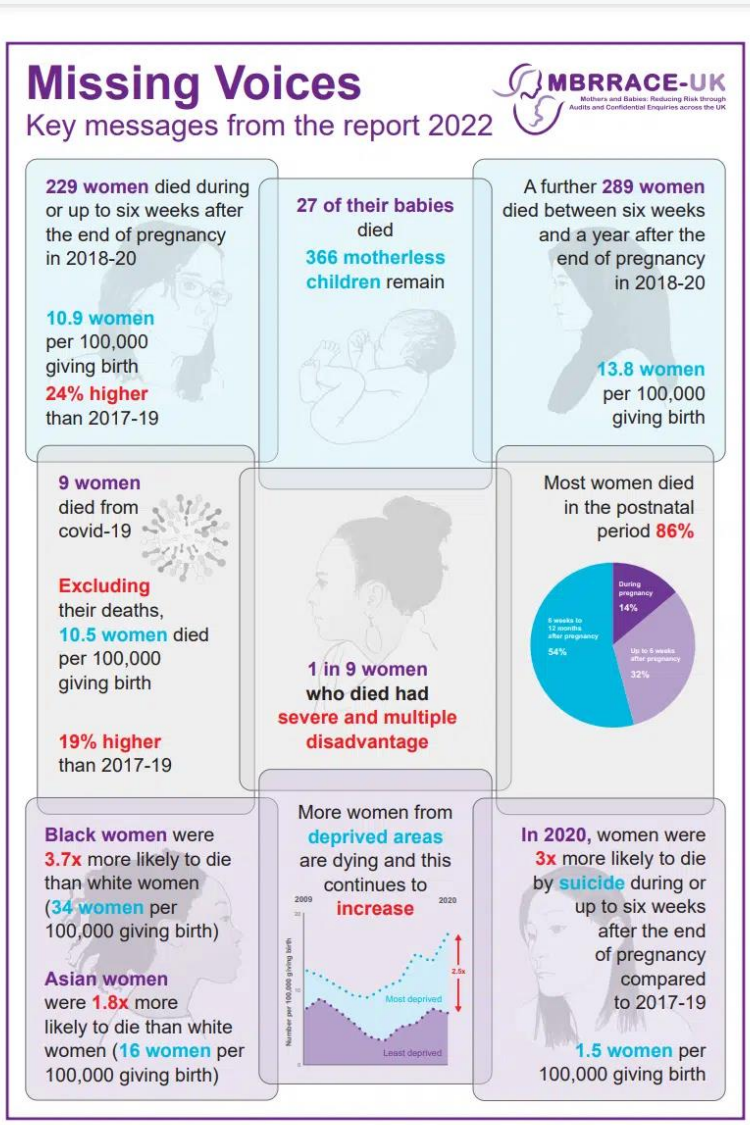
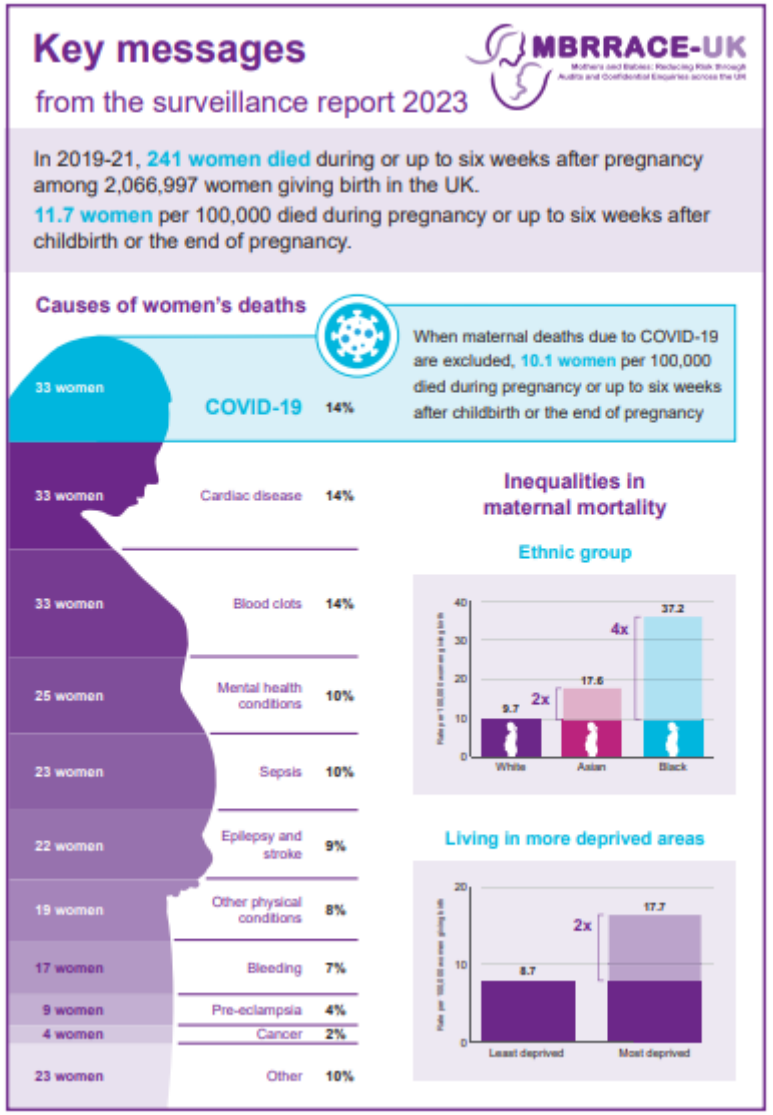
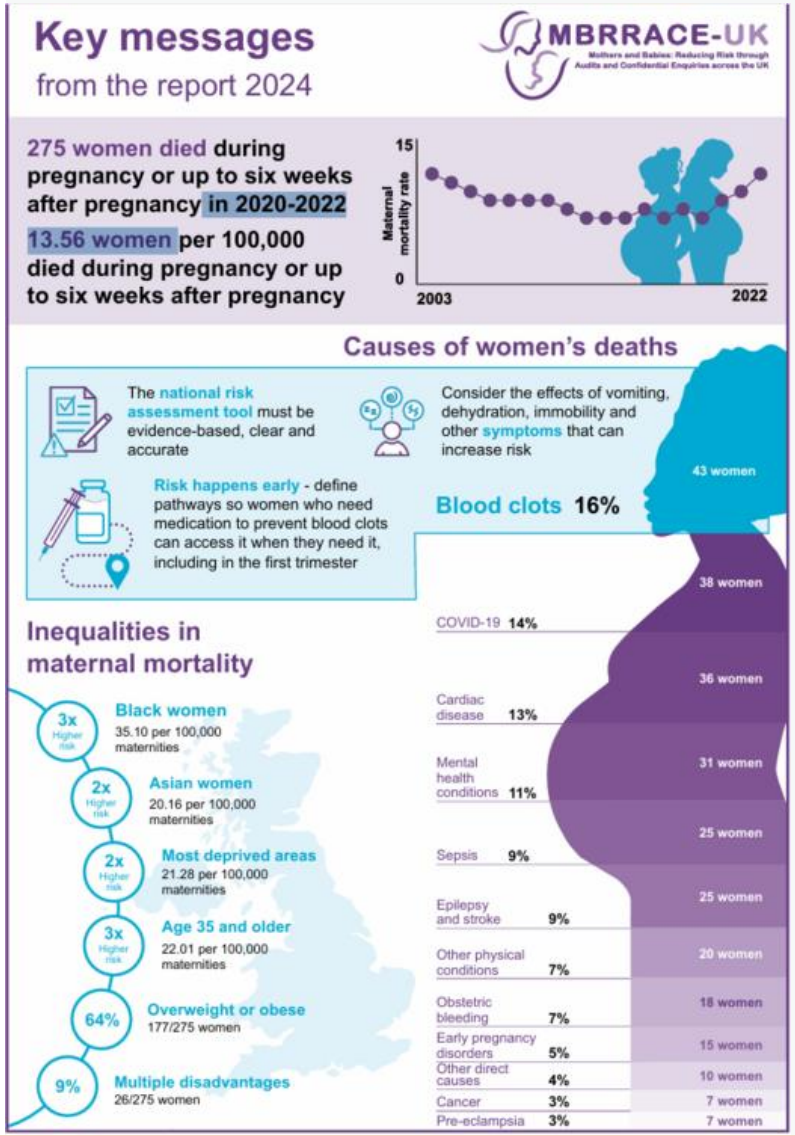
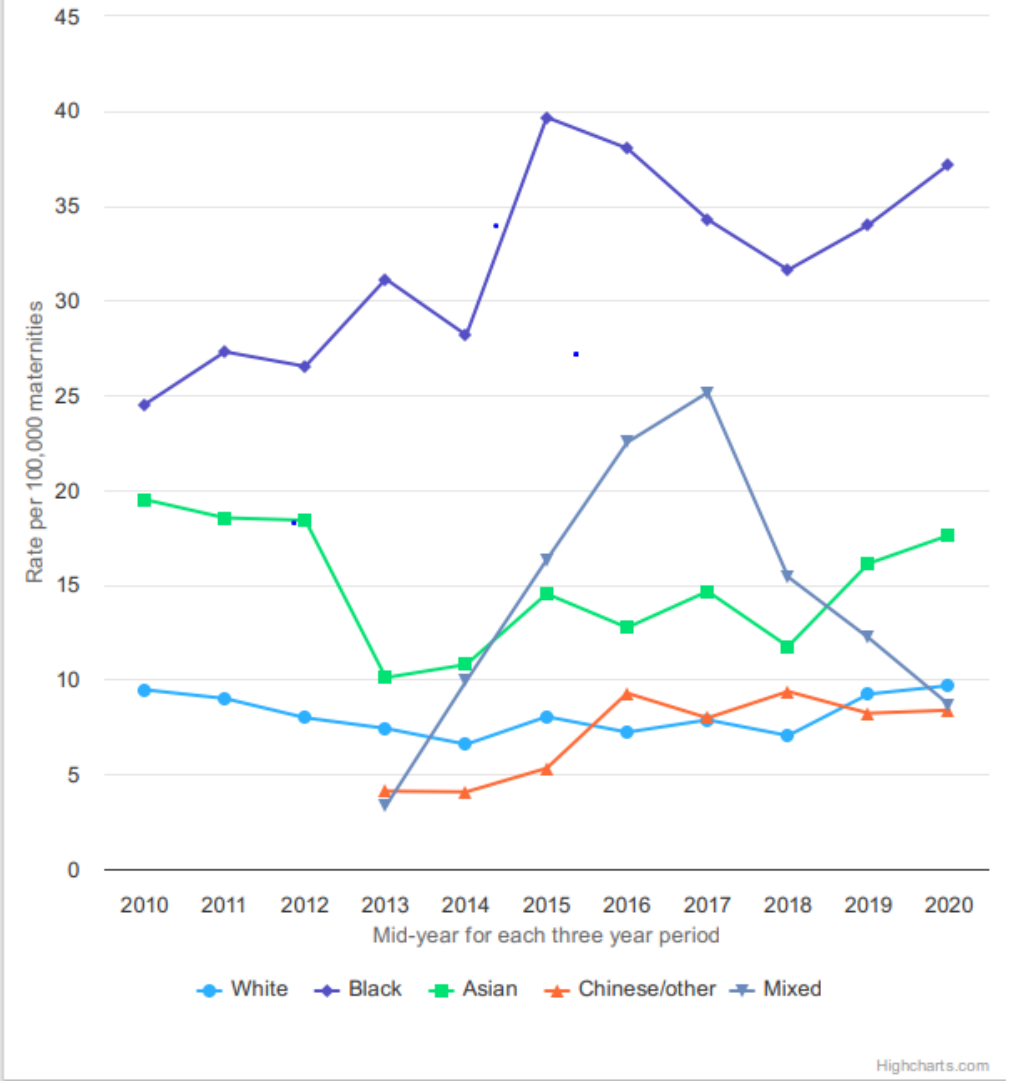


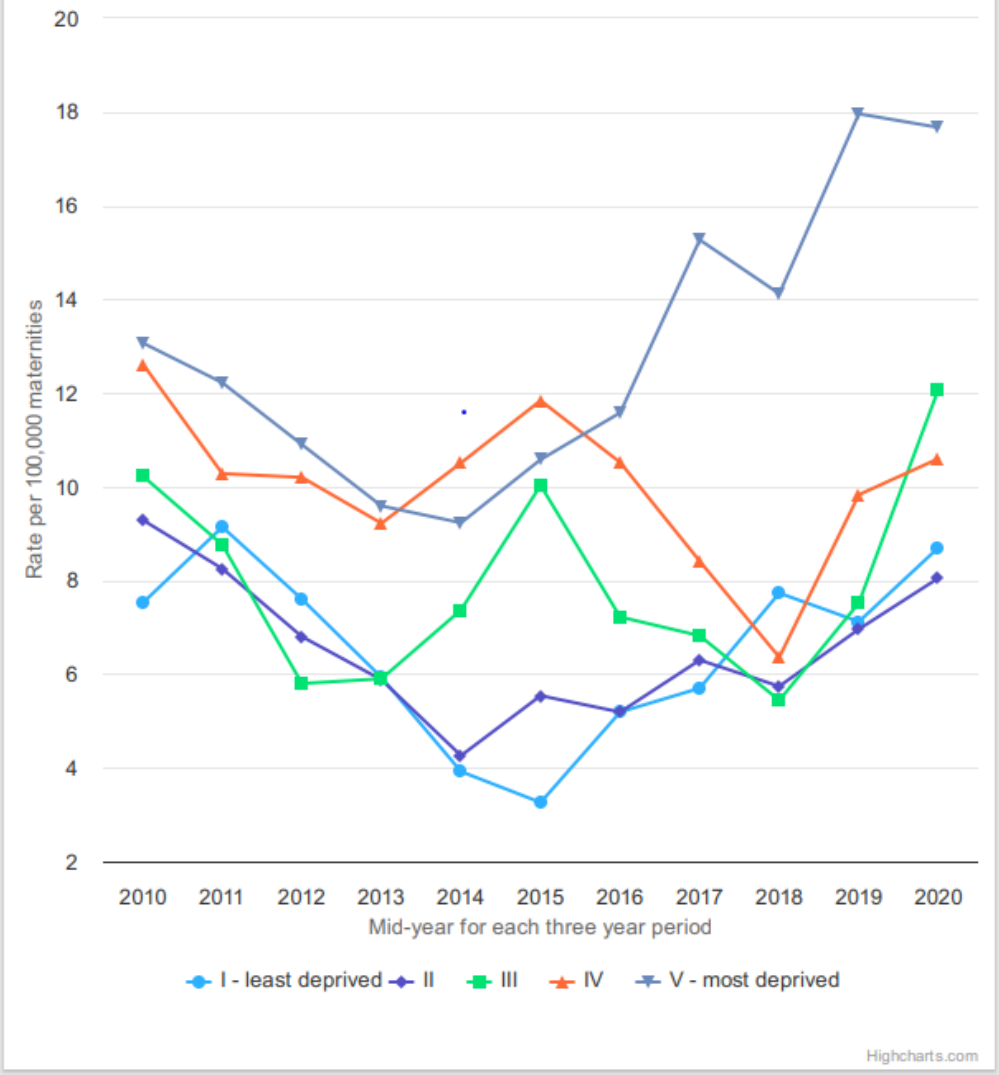



## Figure 3. Maternal mortality rates 2009-21 among women from different ethnic groups in England*




## Figure 4 Maternal mortality rates 2009-21 among women from different levels of socio-economic deprivation in England*



# Inequalities in Perinatal Mortality - MBRRACE-UK 2023

Figure 5: Stillbirth and neonatal mortality rates by babies' ethnicity: United Kingdom and Crown Dependencies, for births in 2016 to 2021

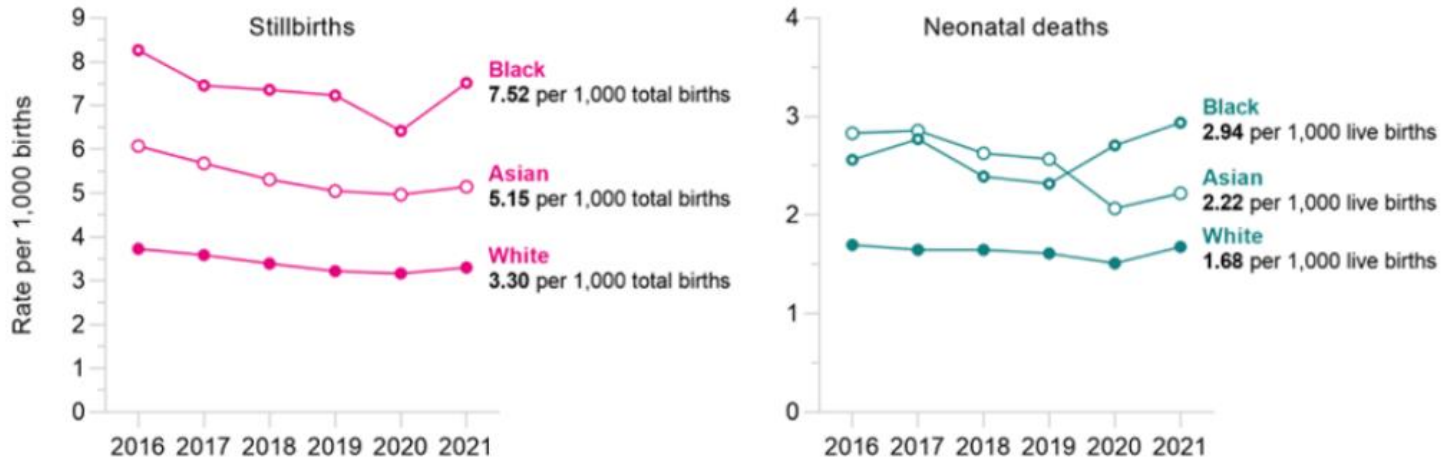
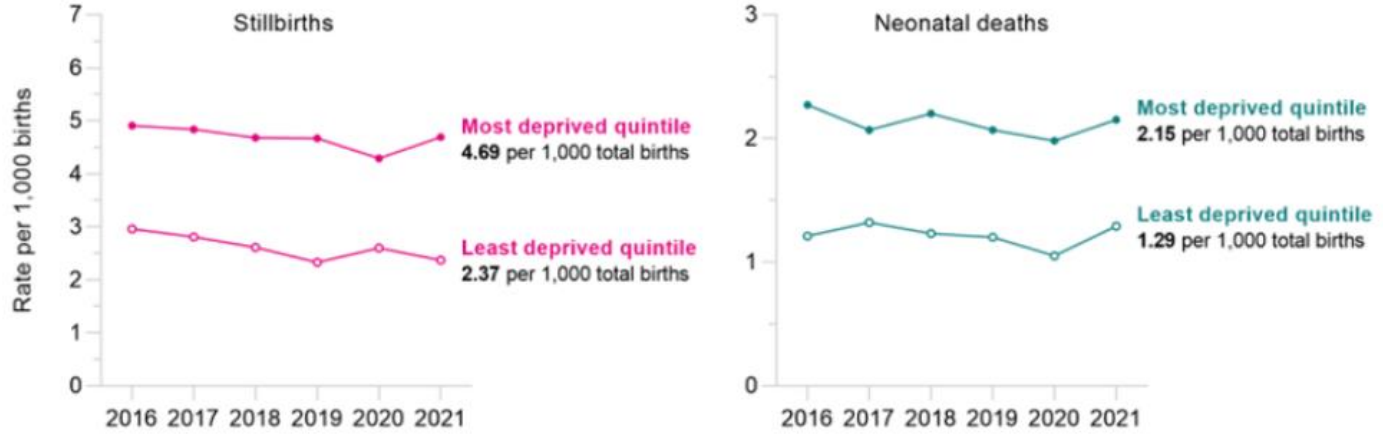


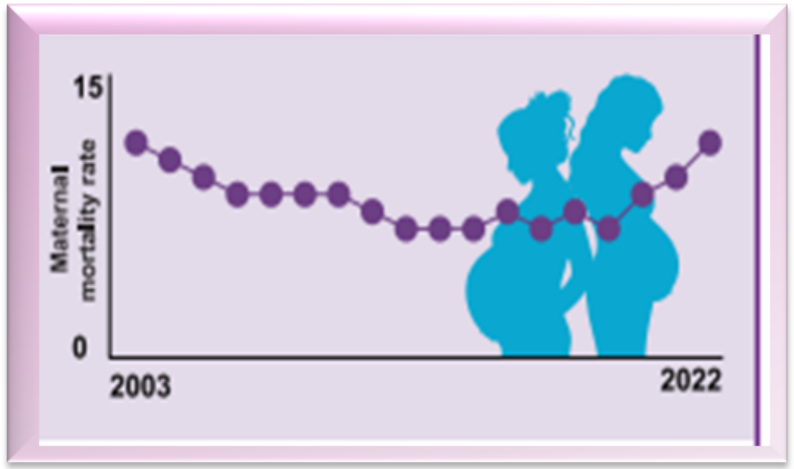

Figure 4: Stillbirth and neonatal mortality rates by mothers' socio-economic deprivation quintile of residence: United Kingdom, for births in 2016 to 2021



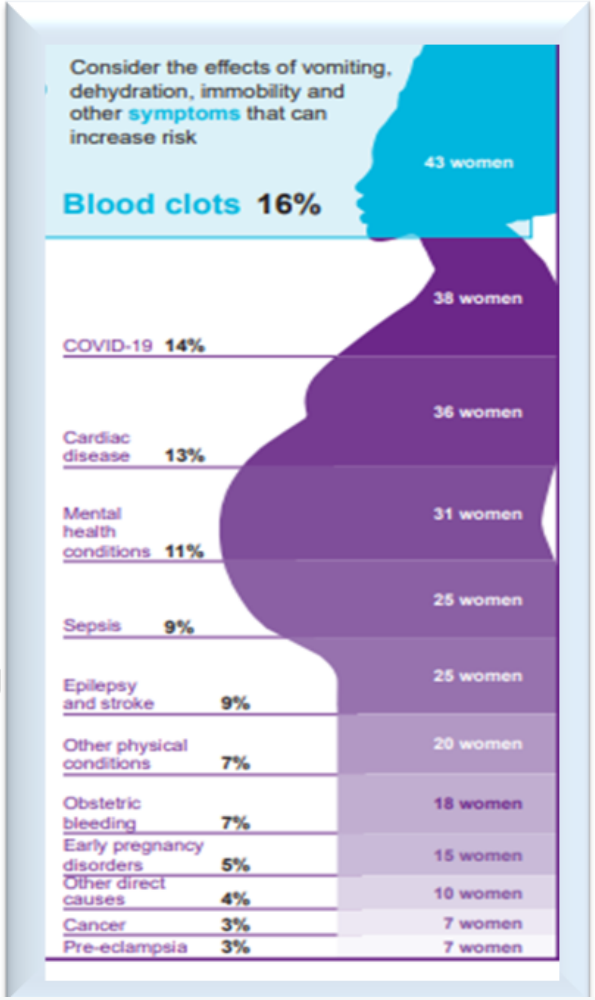
# MBRRACE (Maternal Mortality ) Report (summary)

MBRRACE-UK_Maternal_FULL_Compiled_Report_2024_V1.1.pdf (ox.ac.uk)

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




- Compared to 2019- 21, there was an increase in the overall mortality rate for White women in 2020-22
- 22% known to social care
- 18% Lived alone
- 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.




| Mortality | 2018 – 2020 % (n) | 2019 – 2021 % (n) | 2020 – 2022 % (n) |
|---|---|---|---|
| All deaths in pregnancy to 42 days PN | 10.9 (261) | 11.66 (293) | 13.56 (296) |
| Co-incidental | 20 | 21 | 21 |
| Direct/Indirect | 241 | 293 | 275 |
| Covid 19 | 24 | 38 | 38 |
| Direct | 5.19 (113) | 5.47 (128) | 6.36 (129) |
| Indirect | 5.71 (138) | 6.19 (144) | 7.20 (146) |

# Migrant women and Language needs (n38)

**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.**

**Finding**

Almost 1:3 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).

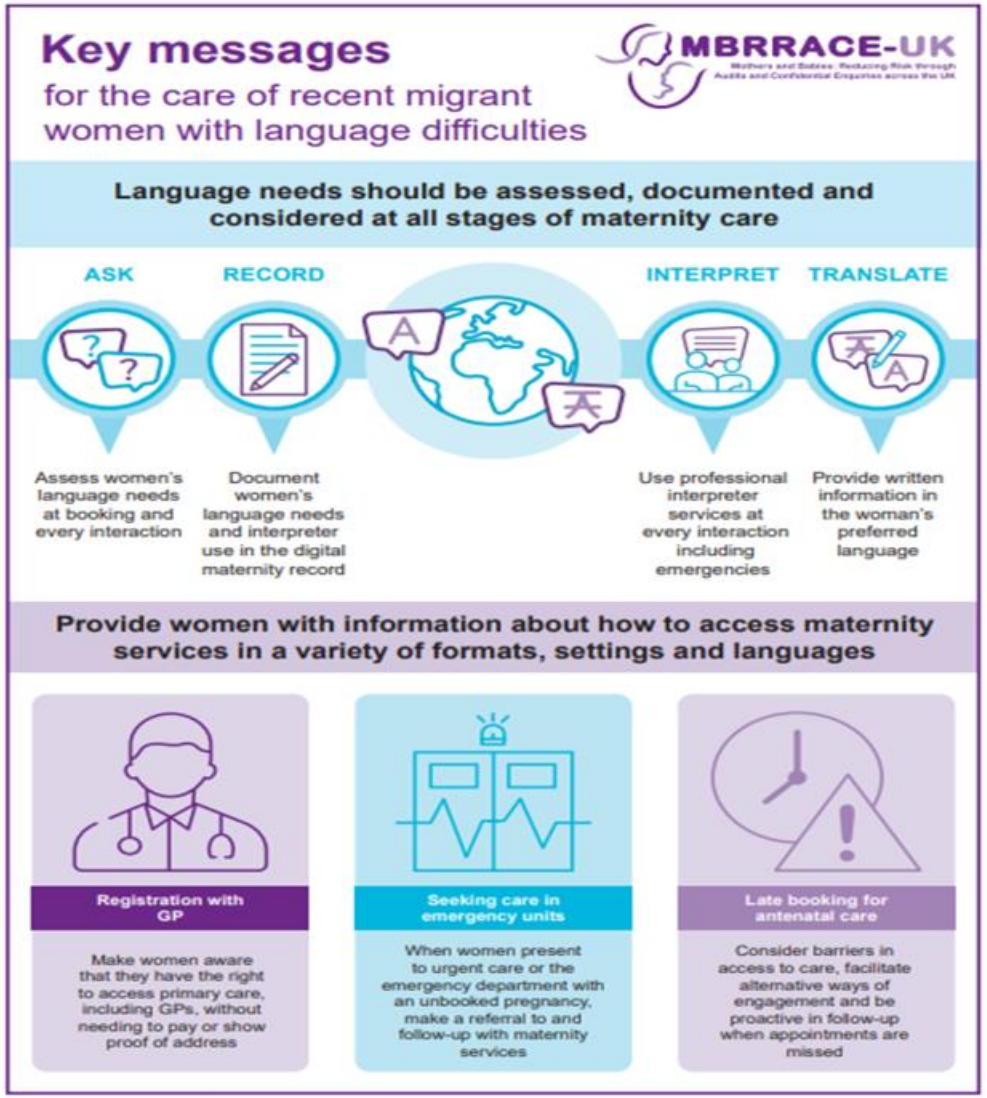
Certain countries were overrepresented amongst the women who died. This includes both Pakistan and India

61% of the women it was documented that a family member had interpreted on at least one occasion

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

Evidence of micro-aggressions 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.

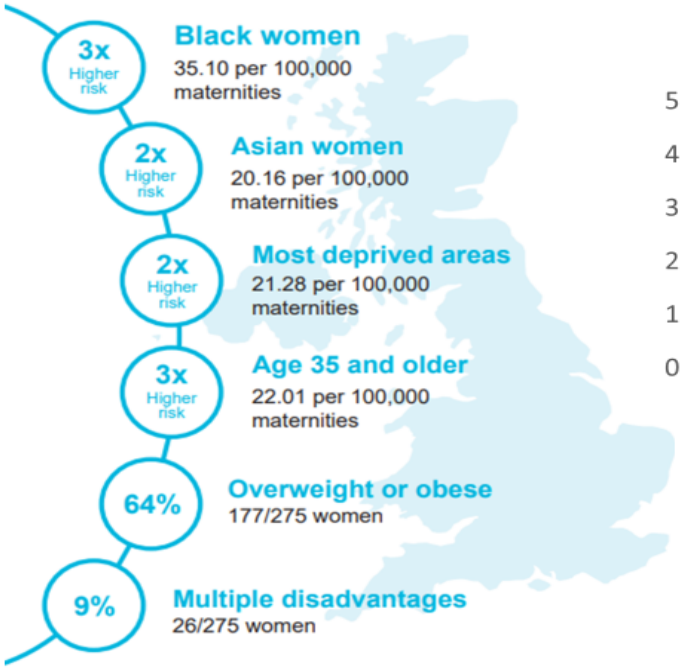
Assessors also noted that some women's background may have affected their quality of care, such as cultural or religious beliefs not being considered in bereavement support following a perinatal loss.

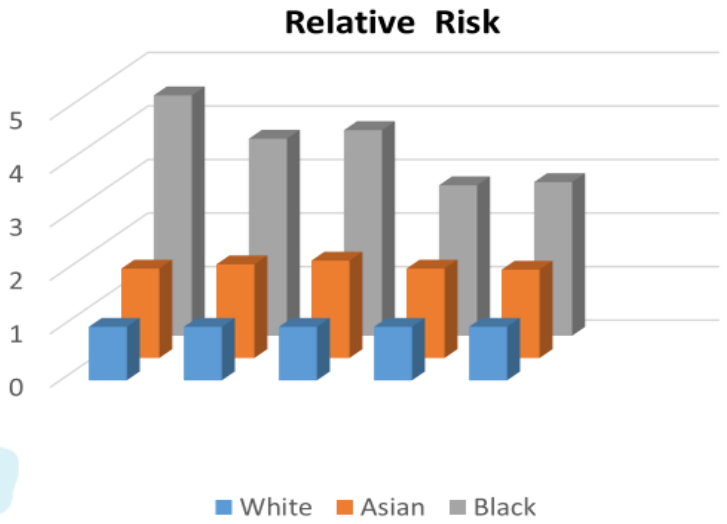


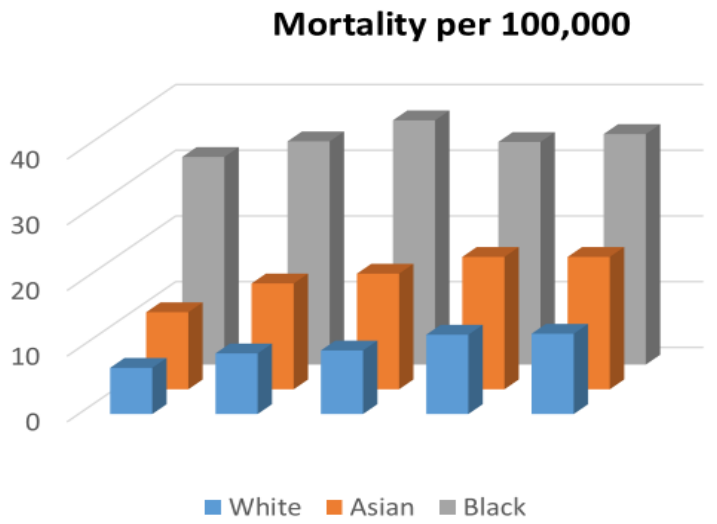
# Inequalities

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

## Inequalities in maternal mortality

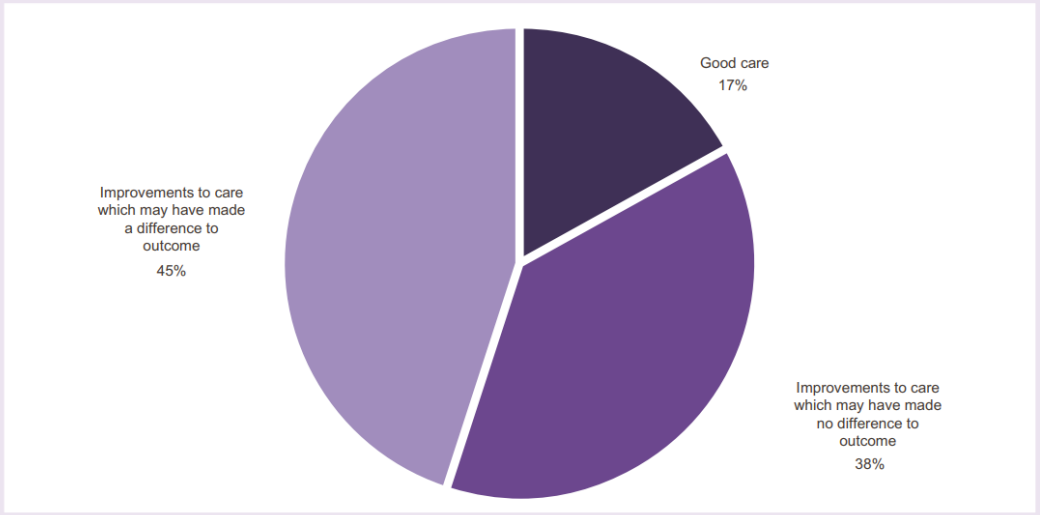


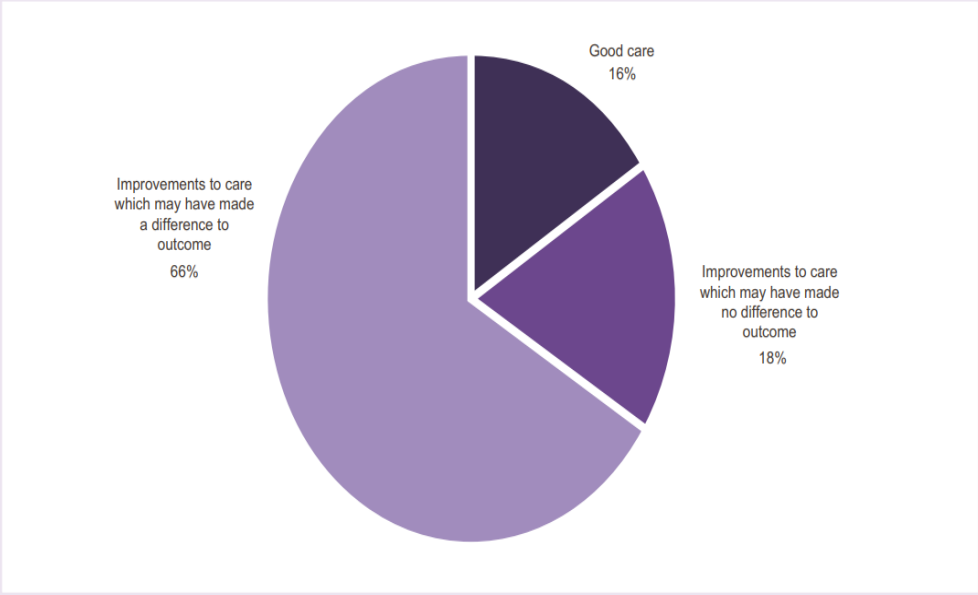
# Classification of quality of care for women who are included in the confidential enquiries

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




MBRRACE-UK - Maternal State of the Nation Report 2024 10

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



# We know enough to ACT

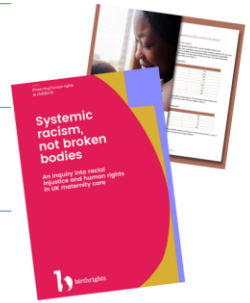
## Summary…

Both reports state that not all Black Asian Minority Ethnic women have negative experiences with maternity services

Women had positive experiences when they received personalised care, informed consent, good communication in which procedures and medical advice were adequately explained, and cared by a racial diverse multidisciplinary team

The impact of racism and misconception on quality of care was frequently addressed. Microaggression, stereotyping, and assumptions made by healthcare professionals providing maternity care had a negative impact on experiences and care

Both reports made sound recommendations to improve the outcomes and experiences of Black Asian and Minority Ethnic women in maternity care, which can help shape future policies and guidelines



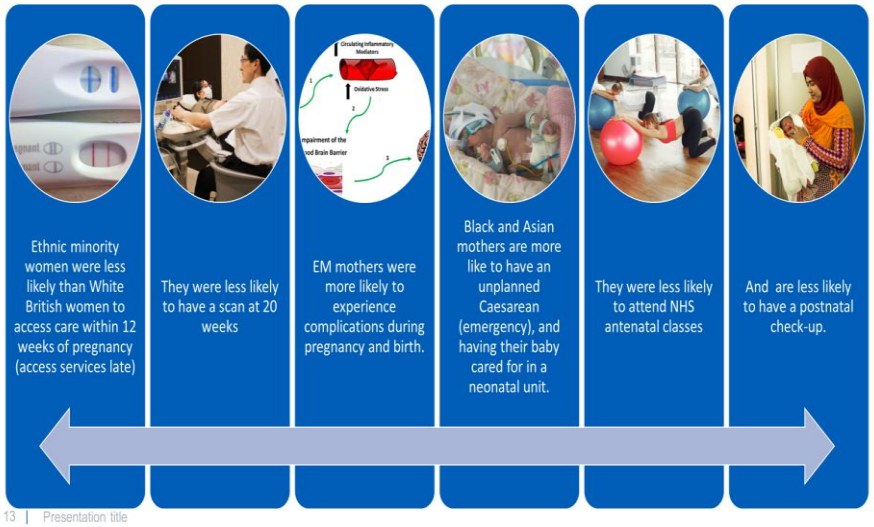

## What women want

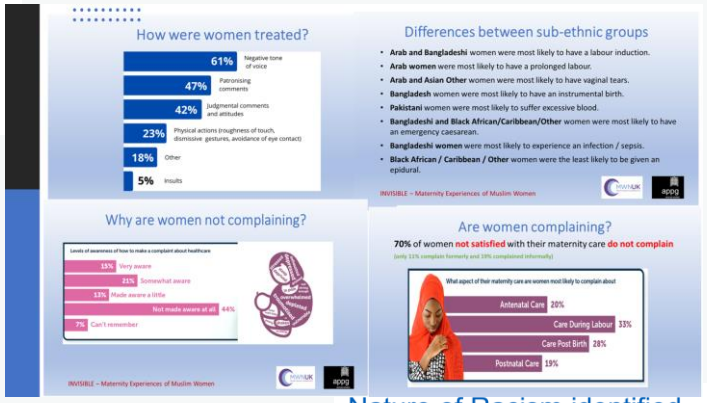
- Women want health professions to stop making assumptions about their Ethnicity
- Women want to be listened and to be heard
- Women want more antenatal appointments
- Women want more information about their birthing options
- Processes like induction should be explained properly

## INVISIBLE: SIX KEY THEMES EMERGED

- DATA GAP
- MATERNITY INFORMATION GAP
- NOT LISTENED TO
- NEGLECTED
- CARE LACKED DIGNITY AND RESPECT
- FEEDBACK NOT CAPTURED

## What do we know :




## Identified Issues for different Ethnic Groups

### Black women:

- implicit and explicit bias impacting the care
- women not being listened to despite repeat presentations
- Black British women said to have a "low pain threshold". Examples included women receiving inadequate pain relief for sickle cell crises
- lack of awareness or understanding of the importance of women's backgrounds. For example, one woman was described variously as Caribbean, from Sierra Leone and from Jamaica.

### Asian women

- Downgrading or dismissal of symptoms
- Microaggressions: these occurred in all ethnic groups but were most common in women of Asian ethnicity.
- Agitation in women who did not speak English was attributed to mental health problems when women were severely physically unwell.

## Nature of Racism identified…

| Nature of racism | Examples | Calls to action |
|---|---|---|
| Individual interactions | Being ignored and disbelieved<br>Racist stereotypes and microaggressions<br>Dehumanisation<br>Denial of pain relief | Commit to be an anti-racist organisation<br><br>Make Black and Brown women and birthing people decision-makers in their care and in the wider maternity system |
| Education and training | White bodies as the 'norm' or default<br>Failure to recognise conditions e.g. jaundice, sepsis<br>Lack of cultural understanding | Commit to be an anti-racist organisation<br><br>Decolonise maternity curriculums and guidance |
| Policies and frameworks | Ethnicity as grounds for induction within policies<br>'High risk' pathways based on ethnicity alone<br>Lack of representation in clinical evidence and committees<br>NHS charging regime and failure to provide interpreting services | Decolonise maternity curriculums and guidance<br><br>Make Black and Brown women and birthing people decision-makers in their care and in the wider maternity system<br><br>Dismantle structural barriers to racial equity through national policy change |
| Workforce | Lack of senior representation<br>Higher rates of disciplinary action<br>Bullying and toxic culture | Commit to be an anti-racist organisation<br><br>Create safe, inclusive workforce cultures |

# Why Equity and Equality?

## Equity is a clinical quality aim, a legal duty and a government commitment

- Equity is a matter of justice
- It is an aim of good quality clinical care (Institute of Medicine 2001)
- Legal duties
    - NHS Constitution: principle 1 – social duty to promote equality and reduce health inequalities; principle 3 – treat patients and staff with respect, dignity, compassion and care
    - Health & Social Care Act 2012: duty to reduce inequalities
    - Equalities Act 2010: NHS should have 'due regard' to exercise functions to reduce inequalities

- Social determinants of health account for between **30-55%** of health outcomes (WHO 2023)

- 'Persisting inequalities…indicate that we must think beyond maternity care to address the underlying structures that impact health before, during and after pregnancy…' Dr Nicola Vousden (MBRRACE-UK 2024)

# Aims and values

Equity means that all mothers and babies will achieve health outcomes that are as good as the groups with the best health outcomes

## Twin aims

- Improve **equity for mums and babies** from Black, Asian and Mixed ethnic groups and for those living in the most deprived areas
- Improve **race equality for staff** working in maternity and neonatal services

## Values

- **Proportionate universalism:** action is universal but with a scale and intensity proportionate to the level of disadvantage (Marmot 2020)
- **Coproduction:** parents and NHS staff work in partnership to improve care
- **Collaboration:** system working to address the social determinants of health

## Objective 1: Care that is personalised

Personalised care gives people choice and control over how their care is planned and delivered. It is based on evidence, what matters to them, and their individual risk factors and needs. This information can be included in each personalised care and support plan to help ensure **that service users do not have to repeat their story.**

# What is Personalised Care?

- **Personalised care gives people choice and control over how their care is planned and delivered.**
- **It is based on evidence, what matters to them and their individual needs and circumstances.**


Better Births identified that:

*"Women wanted to be listened to about what they want for themselves and their baby, and to be taken seriously when they raised concerns."*

# Personalised Care means that…

**Maternity and neonatal professionals:**

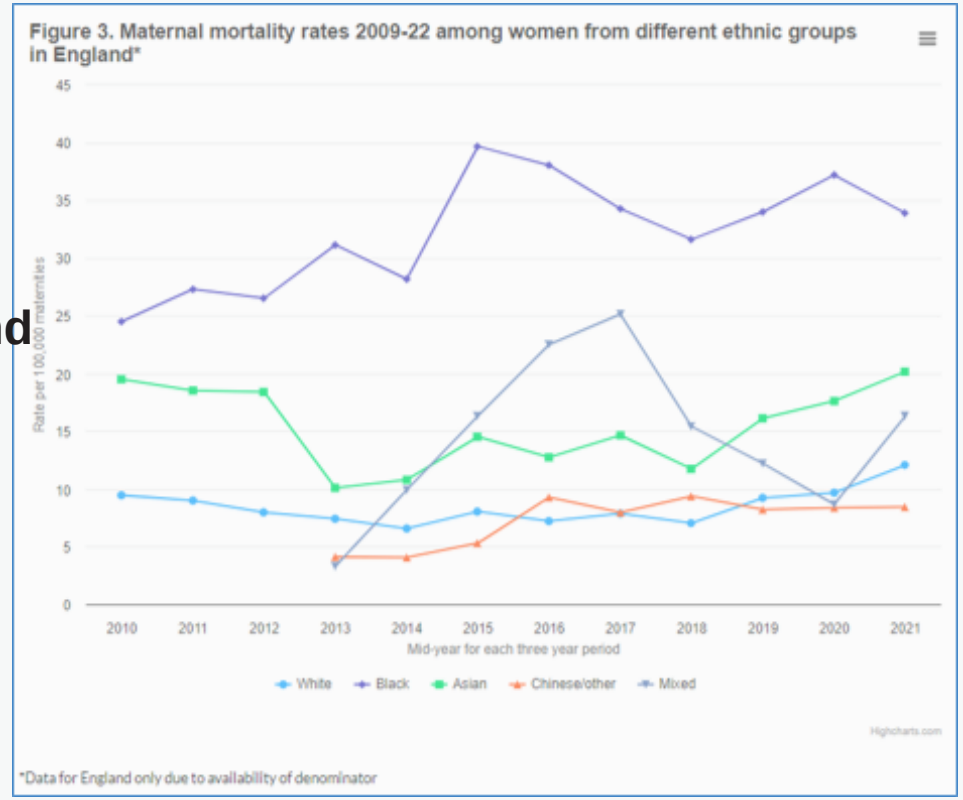
- Support service users/parents/ birthing people to understand the choices available
- Share unbiased, evidence-based information in a language and format service users/parents understand
- Encourage service users/parents to share what matters to them
- Support service users in **making informed decisions** about their care/involve parents in decisions about their baby's/babies' care
- Understand and **respond to the needs** and preferences detailed in each service users' Personalised Care and Support Plan (PCSP)
- Regularly review and update the PCSP with each service user in line with the current situation

# Personalised Care means that…

# Personalised Care is Safer, more Equitable Care

- It takes into consideration the individual needs and preferences of each service user.
- Evidence shows that personalised care enables better outcomes and experiences, as well as **reduced health inequalities**
- Personalised care also has a **positive impact on health inequalities, taking account of different backgrounds and preferences, with people from lower socioeconomic groups** able to benefit the most from personalised care.
- Informed decision making helps to enable:
    - More realistic expectations
    - A better match between individuals' values and treatment choices
    - Fewer unnecessary interventions.

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



# Impact of current work

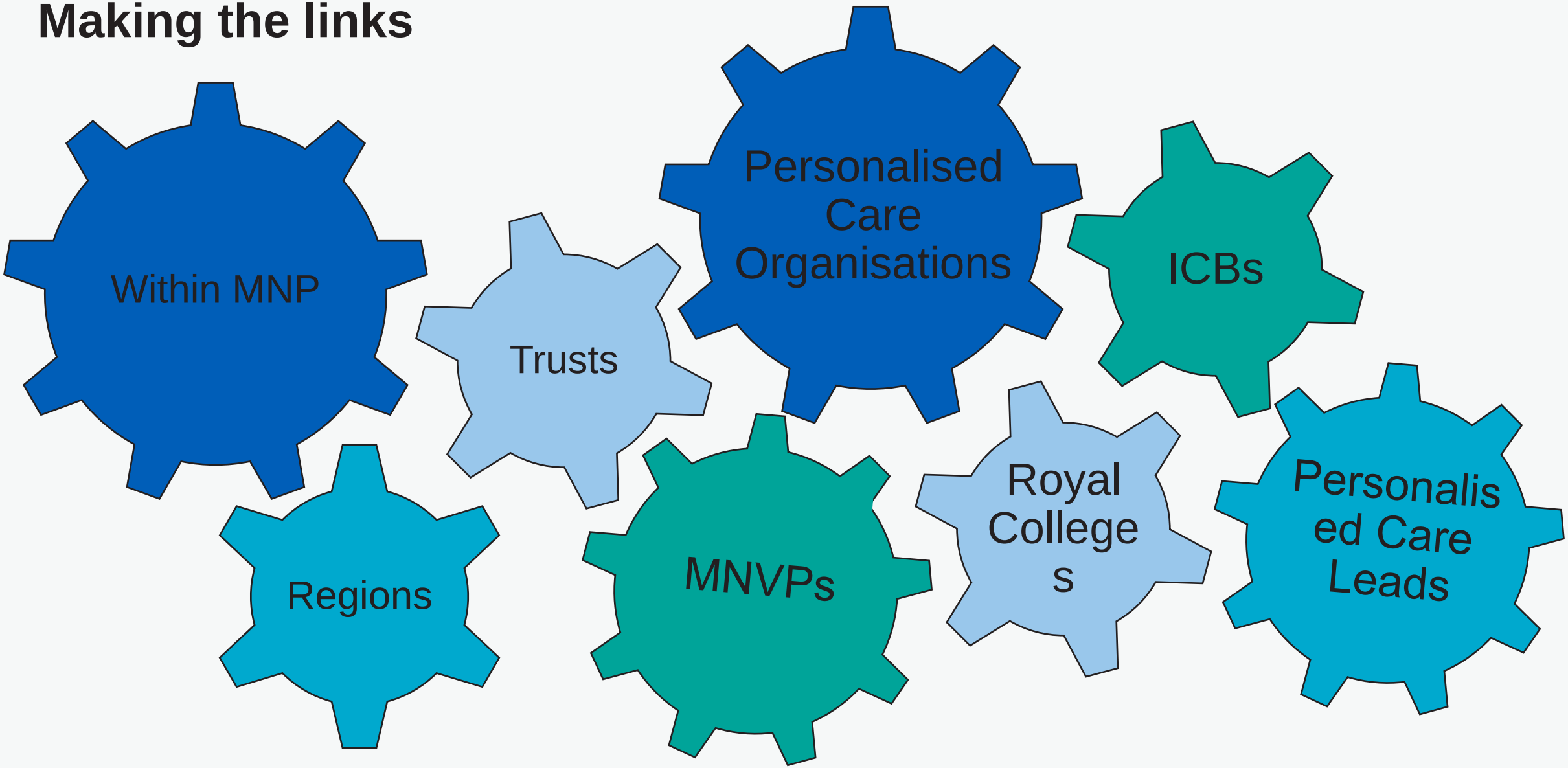
## There is evidence of impact in several areas; especially for enhanced midwifery continuity of carer and data quality

| Intervention | Impact |
|---|---|
| **Enhanced midwifery continuity of carer:** more holistic support for women in the 10% most deprived areas; a Core20PLUS5 area of focus | • 37 teams established at Q4 23/24; increased funding for 24/25 to launch up to 210 teams<br>• Groups with the poorest outcomes are more likely to receive this model of care<br>• A new NHSE analysis of outcomes using MSDS records suggests MCoC is associated with, in 4/5 statistical models used, significant decreases in:<br>  • pre-term birth for women living in the most deprived areas<br>  • stillbirths for black women |
| **Culturally Competent Genetics Services:** 10 pilot sites in areas of high need | • Aims to improve access to genetics services for underserved groups<br>• There is anecdotal evidence of improved access to care to allow informed reproductive decision-making; an evaluation is underway to better understand impact |
| **Ethnic coding data quality** is a Maternity Incentive Scheme ask | • Ethnic coding data completeness in MSDS has improved year-on-year<br>• From 85% in 2019 to 95% in 2023<br>• This helps us better understand health outcomes |
| **Support for the workforce** to address racism and discrimination experienced by women and staff | • Four nationally-run programmes develop midwifery staff (from bands 6+) from ethnic minority groups and develop allies from White ethnic groups<br>• Seasonal nuggets webinar and an equality strategy to support the workforce<br>• Cultural competence and cultural safety e-learning training refreshed in December 2023<br>• Clinical training aids worth >£2,500 received by 140 sites with maternity and neonatal services in May 2024 to support care for women and babies with Black or dark skin |

# What more can NHS England do to address these inequalities?

| Challenges | Steps taken to address this | What more can we do to address these challenges? |
|---|---|---|
| Inequalities of access and outcomes | • Enhanced Continuity of Care<br>• Equity and Equality Guidance for Local Maternity and Neonatal Systems | |
| Addressing the quality of personalised care planning | • Multidisciplinary Training<br>• Virtual Patient Scenarios (antenatal, intrapartum and postnatal) | |
| Ensure MNVPs are representative of the communities they serve | • MNVP Guidance sets out that '*Effective MNVPs will reflect the ethnic diversity of the local population and reach out to seldom heard groups, including those most at risk of experiencing health inequalities, parents with experience of neonatal care, and bereaved families.'* | |
| Getting timely feedback from women and families | • CQC Survey<br>• MNVPs<br>• Patient reported experience measure (PREM) which provides real time data | |

# Making the links



# What good looks like for Service Users

**Timeliness: Access to Care**

**Experience: Respectful Treatment**

**Safe: Culturally Competent Care**

**Equity: Equitable Health Outcomes**

**Efficiency /Effective: Informed Decision-Making**

(IOM 2001)

# Strategies to Address Maternity Care Disparities

01

**Addressing Implicit Bias and Racism in maternity care**

02

**Improving Access to High-Quality Maternity Care**

03

**Culturally Competent Care Models**

04

**Policy and Systemic Change**

05

**Building Trust and Community Engagement**

• .

# Whose Responsibility, is it?

## Shared Responsibility!

- Frontline staff (Doctors, Midwives, Nurses)
- Healthcare Institutions (Hospitals, Clinics, Maternity Units)
- Government and Policy Makers
- Professional Bodies and Medical Associations
- Public Health Organisations
- Service Providers
- Community Organisations and Advocacy Groups
- Women and Families

# Thank you

Health Innovation East Midlands

# Local service perspective from Derby / Burton

Claire Brackenbury - Lead Midwife for Transformation,
University Hospitals Derby Burton NHS Foundation Trust

University Hospitals of Derby and Burton NHS Foundation Trust

# Informed Choices for Diverse Women During Pregnancy

## Local Service Perspective

Claire Brackenbury

Lead Midwife for Transformation

# National Context and Local Focus

- Next step to understand the local position
- Equity in Maternity Services
  - To achieve personalised care, women need to receive information in a way which they understand and is relevant, alongside being involved in their care and having meaningful conversations with practitioners.
  - Do all women have this? Without equity in information and discussion, there will not be the same opportunities for women to be involved in their care and seek advice when needed during their pregnancy.
- Local Challenges at UHDB:
  - Focused on addressing poor outcomes for those most at risk.
  - Initial priorities: Access into services, Communication, and Engagement.

# Access into Services

University Hospitals of Derby and Burton NHS Foundation Trust

- Building links with local community leaders has helped to inform how to support improvements
- They raised there was a lack of awareness about maternity services, therefore this is an area to focus which should in turn improve:
  - Earlier booking gestation
  - Encourage seeking support if there are concerns
  - Empower women to raise concerns about their care if they have not received the care they should have

# Effective Communication

- Information should be:
  - Delivered in a language and format women understand.
  - Personalised so women see its relevance to them.
- Bridging this gap ensures women understand how to navigate pregnancy and access care.

# Engagement with communities

- For maternity services to improve outcomes and experience they need to understand what local communities need from the service. For this to occur we need to listen so services are developed together.
  - Establish relationships with community leaders.
  - These relationships need to be sustained with regular feedback so they can see visible action.
  - This will build trust by demonstrating commitment and accountability. Changes to services will only be effective if there is trust, this will support improved outcomes and long-term engagement

# Action so far

University Hospitals of Derby and Burton NHS Foundation Trust

- Virtual translator devices, means quick access to interpreters is available 24/7
- Planning for a coproduced video to outline what maternity services offer and how to access them.
- Attending triage without the need to call first for those who do not have English as a first language.
- Implementation of the Janam app underway, provide information that is culturally and linguistically appropriate.
- Cultural competency training for all staff and further in-depth training for reception and support staff
- Resource packs developed so staff can access the tools to support those who do not have English as their first language
- Workshops to support meaningful conversations to enhance personalisation of care
- Review of outcomes by ethnicity, deprivation and language spoken
- Recruitment to cultural safety midwife

Only beginning of the journey; whole MDT need to understand their role to play in improving outcomes and reflect on their own unconscious bias.

# Thank You

Health Innovation East Midlands

# The journey to JanamApp

Angie Doshani - Consultant Obstetrician & Gynaecologist, University Hospitals Leicester & Co-founder, JanamApp

Khalood Zaffaron - Patient Representative

# The Journey to the JanamApp

Mrs Khalood Zaffaron & Prof Angie Doshani

# How did it all start?

# OUR KEY TEAM MEMBERS

JANAM APP

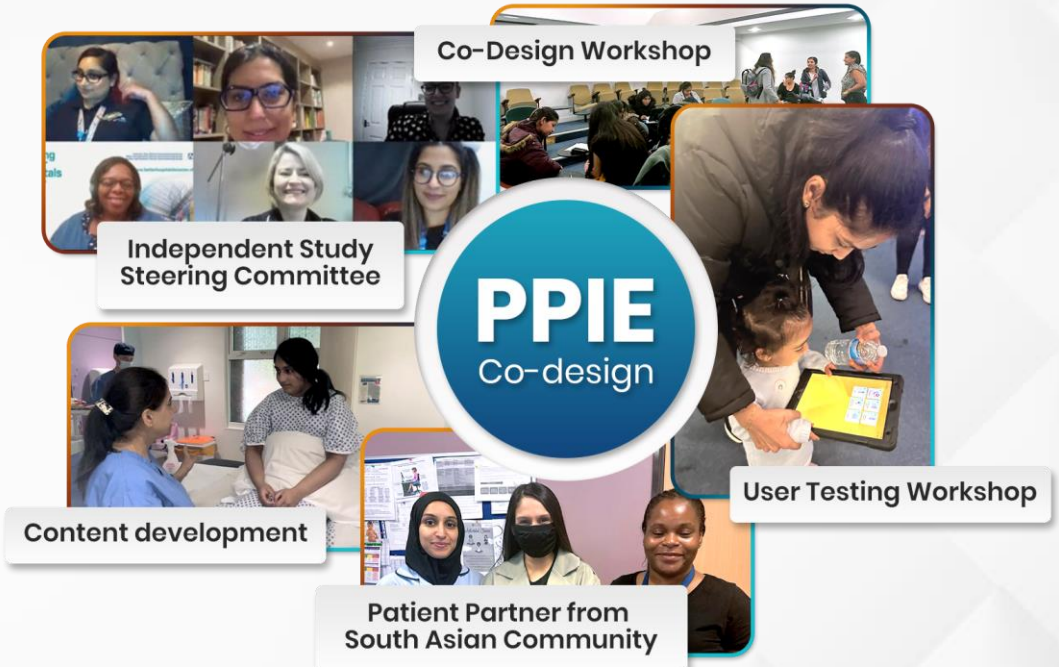
**PROF ANGIE DOSHANI**
Founder and Project Lead

**DR CERI JONES**
Head of Clinical Evaluation

**MRS JETHI KARAVADRA**
Lead Midwife & MDT Liaison

**FLORETTA COX**
Consultant Midwife

**DR SAMEER NAKEDAR**
Digital Technology Lead

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JANAM APP

# One stop pregnancy information guide for South Asian mums

Prof Angie Doshani

info@janamapp.co.uk
www.janamapp.co.uk

Health Innovation East Midlands

# Q&A / Closing Remarks

Alma Gallagher – Deputy Head of Improvement

# Get in touch

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# Further information

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