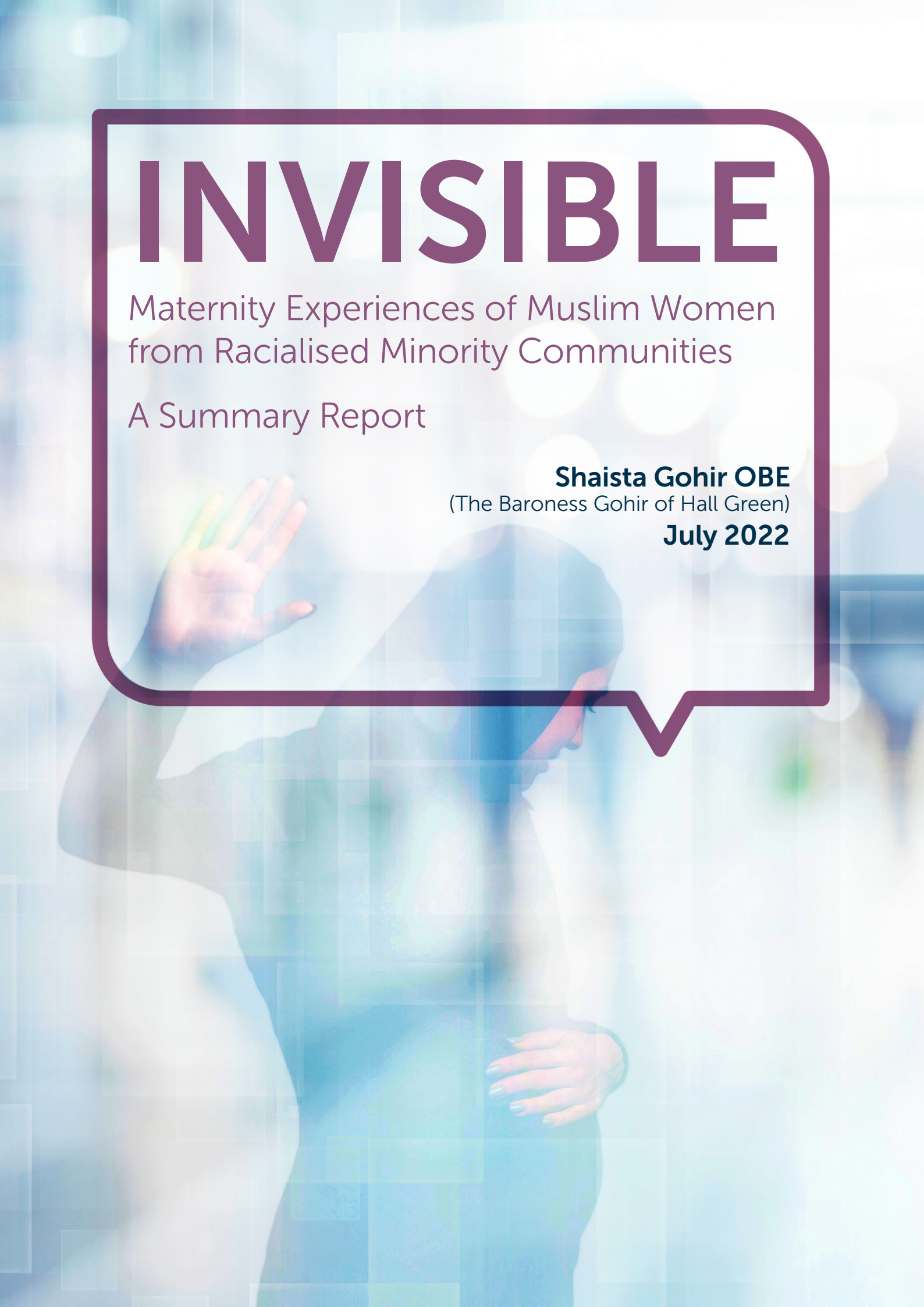

INVISIBLE

Maternity Experiences of Muslim Women from Racialised Minority Communities

A Summary Report

Shaista Gohir OBE
(The Baroness Gohir of Hall Green)

July 2022

The full (220 page) report contains detailed analysis and can be downloaded from the Muslim Women's Network UK website:

www.mwnuk.co.uk/reports.php

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Foreword

Caroline Nokes MP

Co-chair of APPG on Muslim Women

The statistics on maternal, neonatal and stillbirths already tell us that racial inequality exists in maternity care provision. The accounts provided by Muslim women showed what that inequality in treatment looked like from their perspective during pregnancy, labour, birth, and postnatal period. Some of the accounts were shocking and show that sometimes less favourable treatment was also related to a woman's faith and other intersecting identities. Women were let down by some individual healthcare professionals and also systems that did not meet their needs. Although this research focused on Muslim women who are from diverse ethnicities, the findings will benefit all women.

Naz Shah MP

Co-chair of APPG on Muslim Women

Every woman has the right to feel safe when accessing maternity services, to be treated with respect and dignity, to enjoy her pregnancy and have a positive birth experience. Significant progress in reducing adverse outcomes and reducing maternal mortality rates will only happen if all stakeholders involved in shaping and delivering maternity care listen to and learn from minority ethnic women in a meaningful way. Although work is already underway to improve the quality of maternity care, the findings of this report can also help to shape maternity services so they can better meet the needs of women who have intersecting identities. We are therefore grateful to all of the women who participated in the research to help make the maternity experiences of Muslim women more visible.

Acknowledgements

The APPG on Muslim Women and Muslim Women's Network UK would like to thank the following individuals and organisations who provided valuable input, advice and support that contributed to making this report possible

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- **The research participants** who gave their time to fill in a lengthy survey and for sharing their experiences through in-depth interviews, even though it meant having to sometimes recall very traumatic events.
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This maternity research has been conducted by Muslim Women's Network UK on behalf of and in partnership with the APPG on Muslim Women.

APPG on Muslim Women

Launched
October 2020

Purpose
To support social justice and equality for Muslim women and transform their lives by debating, scrutinising, investigating and raising awareness of issues affecting them to influence practice, policy, legislation and attitudes.

Secretariat
Muslim Women's Network UK is a national award-winning charity that works to improve social justice and equality for Muslim women and girls through research, advocacy, campaigning and through the operation of its national Muslim Women's Network Helpline and Counselling Service (www.mwnuk.co.uk).

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1 Introduction

Purpose of the research

The aim of this inquiry was to investigate the maternity experiences of Muslim women in the UK, particularly from Black, Asian and other minority ethnic backgrounds, to better understand what factors were influencing the standard of maternity care they received and which may be contributing to poorer outcomes for them and their babies. Given the diverse ethnic backgrounds of Muslim women, White Muslim women were also included in the research to explore if their experiences differed from those of non-White Muslim women.

The study focussed on the care given throughout the pregnancy - the antenatal, intrapartum and postnatal period. Experiences of sub-standard care were analysed to find out whether they were associated with the women's intersecting identities (e.g. ethnicity, religion, class), whether attitudes were due to unconscious bias (e.g. negative stereotypes / assumptions) or conscious action (e.g. microaggressions) and what role (if any) organisational policies and practices played. Particular attention was paid to how near misses occurred as this information could help to save lives of mothers and babies. To show what good practice looks like, positive experiences were also highlighted.

Reasons for conducting the research

Although the Ockenden inquiry[1,2] had already uncovered safety concerns such as women not being listened to, high risk pregnancies being inappropriately managed and failures in recognising deterioration in a mother and not escalating concerns, it did not examine how the standard of care varied between different groups of women and how it could be contributing to the poorer maternity outcomes for women and their babies from racialised minority communities.

There is a more than four-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.[3] They also have a higher proportion of stillbirths, preterm births, and births with growth restriction, higher rates of emergency caesarean birth, higher rates of major postpartum haemorrhage and higher rates of experiencing a birth without intervention.[4] Other adverse outcomes include, higher rates of obstetric and sphincter injury.[5]

Terminology

The term 'racialised minority (communities)' has been used because unlike 'BAME,' it does not privilege or erase any particular social group according to real or imagined physical characteristics such as skin colour, within a system where 'whiteness' is considered the norm. Conversely, it does acknowledge that all groups are subjected to processes of racialisation, that they are not part of a single minority but may be located at the intersection of several different minoritised groups. However, the term 'BAME' (Black, Asian and Minority Ethnic) or 'minority ethnic groups' has also been used in the report because its use is more widespread in the UK.

2 Methodology

Overview

A mixed methods approach was taken to conduct this research which included drawing from a combination of:

- Literature review including statistics on disparities in maternity outcomes;
- Online survey to gather views from a large number of Muslim women **(survey completed by 1022 participants);**
- Semi-structured interviews to gain deeper insights into personal experiences **(37 interviews conducted**);
- Focus group to hear from Somali women as they were underrepresented in the survey responses **(10 women participated**);
- Other maternity care stakeholders who provide additional support to pregnant women such as doulas, interpreters, were interviewed **(3 interviews conducted**); and
- Muslim Women's Network UK's organisational knowledge about the issue.

Survey development, data collection and analysis

The inquiry took place in 2021. The online survey was promoted through the stakeholder networks of the APPG on Muslim Women and its Secretariat, the Muslim Women's Network UK (MWNUK). Just over two thirds of the women selected for the in-depth semi-structured interviews were identified from the survey respondents. The other women who were interviewed were found through MWNUK's existing networks. Ethical considerations during the study, (which interviewees were informed of prior to the interview) included informed consent, interviewee wellbeing, confidentiality and data protection and storage.

Before conducting the research, women with previous maternity experiences were consulted when developing the survey questions. To test the robustness of the survey, other women who had not been involved in the design were then asked to test the questions and the responses to ensure that they were understood as intended and that bias had been avoided. The final draft consisted of 55 questions, which included demographic and contact information questions. The research questions were divided into the following themes: about the pregnancy and birth, antenatal care during pregnancy, labour, childbirth and post-birth care, postnatal care, attitudes during maternity care and additional information (which focussed on how maternity knowledge was accessed, awareness of maternity rights and about the complaints service).

Limitations

The investigation was limited in scope, in terms of the types of Muslim women reached (selection bias). For example, women who lacked proficiency in the English language and women who did not have access to the internet were unlikely to be aware of the research. Other types of bias that may have affected the research included women who were most frustrated with their experiences being motivated to participate and unconscious bias occurring during the interpretation of the study data. Another limitation was that some of the survey respondents and interviewees had pregnancy and birth experiences during the Covid pandemic, which presented many challenges to maternity services such as staff shortages.

3 Characteristics of Research Participants

A total of **1022** surveys were completed and **37** women interviewed

Demographic information

Age: The majority of the participants (two thirds) gave birth between the ages of 26 and 35.

Country of Birth: Most women were born in the UK (70%).

Location: Most of the women were from the London, North West, South East, West Midlands and Yorkshire and Humber.

Education: Most of the women were educated to A level and above (80%), with most being educated to graduate and post-graduate level.

Occupation: Half of the women were in either lower or higher managerial or professional roles. About one fifth were homemakers or carers.

Ethnicity: The ethnic make-up of the online respondents was broadly representative of the Muslim population in the UK, except for the Black African / Caribbean / Black British / Other group, which was 5.5% and therefore half of what was anticipated (**Table 1**).

Table 1 - Ethnicity

Ethnicity	Census Data for Muslims % (2011)	Online Survey Respondents % (1022)	Semi-Structured Interviews % (37)
Arab	6.6%	4.8%	8.1% (3)
Asian Other	7.2%	4.6%	5.4% (2)*
Bangladeshi	14.9%	14.9%	21.6% (8)
Black African / Caribbean / Other (includes Black British)	10.1%	5.5%	13.5% (5)**
Indian	7.3%	12.0%	10.8% (4)
Mixed Ethnic (Asian, Black and Other)	3.8%	5.0%	10.8% (4)***
Pakistani	38%	40.8%	27.0% (10)
White	7.8%	9.0%	2.7% (1)
Other	4.1%	2.2%	0
Prefer not to say	n/a	1.3%	0

Note: *Does not add up to 100% due to rounding and in the semi structured interviews where possible a greater focus was placed on interviewing certain groups of women as online survey data showed they had poorer experiences e.g. Arab, Bangladeshi and Black women.*

*Asian Other - 1 Afghan and 1 Indonesian woman interviewed **Black African (3), Black Caribbean (1), Black Other (1)
*** Mixed Ethnic – 1 South Asian mixed, 1 Arab / White, 1 Black Caribbean / White interviewed and 1 Pakistani / East African

Pregnancy characteristics of survey participants

When pregnancy occurred: The vast majority, 941 (92%) had their pregnancy experiences up to five years ago (**Figure 1**).

Which pregnancy: More than half (58%) of the women shared experiences about their first pregnancy (**Figure 2**). Of the 1022 survey participants, 892 had given birth and and 130 were pregnant at the time of the survey.

Vulnerability factors: Some women stated they had vulnerability factors that could increase risk of pregnancy related health concerns - 20% indicated mental health problems, 15% previous miscarriage and 14% had other previous pregnancy concerns such as haemorrhaging, hypertension and caesarean (**Figure 3**).

Underlying health conditions: Two thirds indicated a range of conditions and the top health issues included anaemia, diabetes, low vitamin D, asthma and urinary tract infections (**Figure 4**).

Birth outcomes of survey participants

Gestation at birth: Although half had a full term birth, 22% had an early term birth while 18% had a late term birth (**Figure 5**)

Baby outcomes: Although 75% had no medical issues 3% had serious medical issues. Shockingly 1% said Babies died before / during labour / within 28 days of birth (**Figure 6**). In a sample size of 1000, this equates to 10 women but figures of no more than 3-4[6] should have been expected.

Figure 1 - When pregnancy experience occured

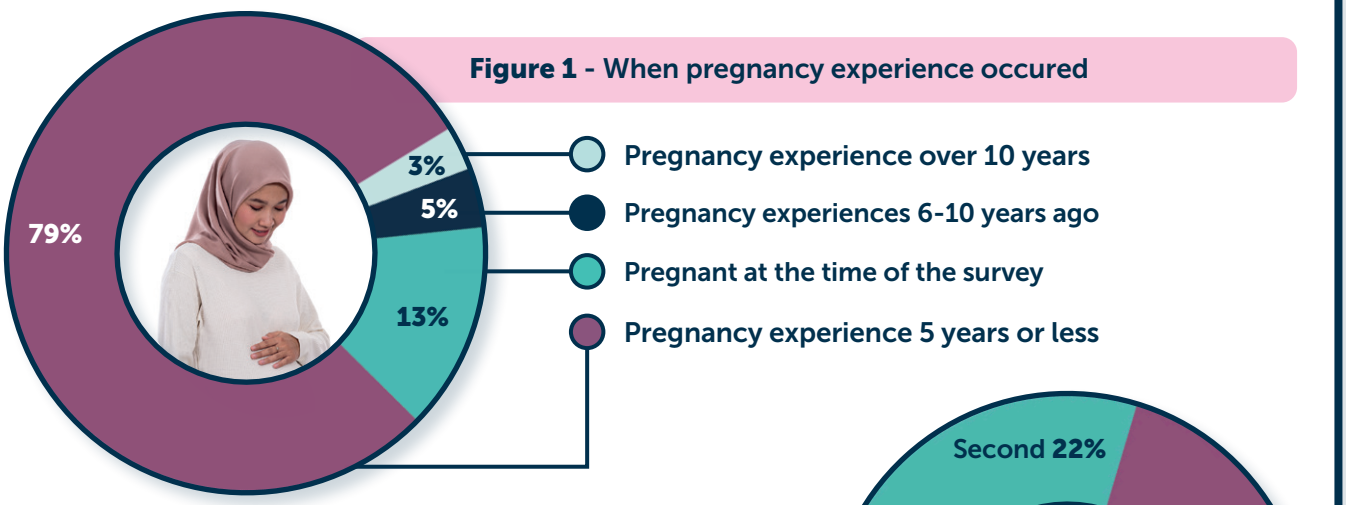


Figure 2 - Which pregnancy experience shared

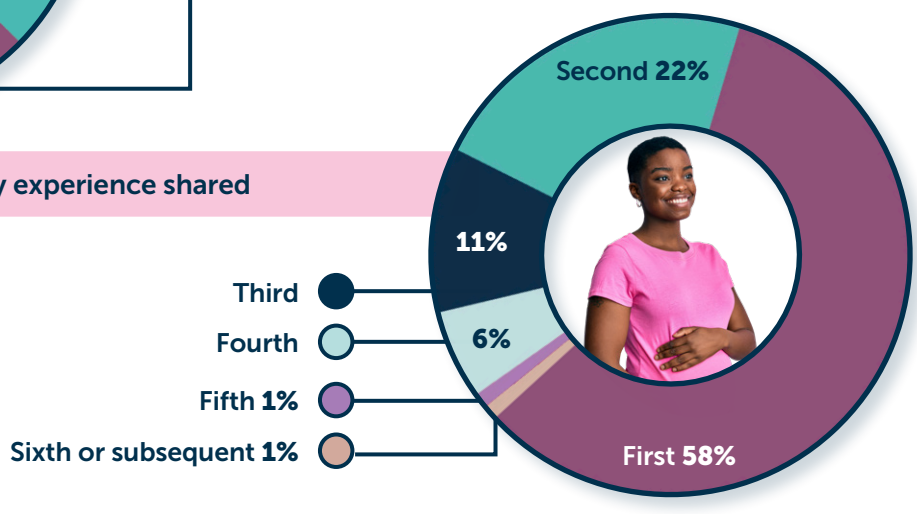


Figure 3
Factors that increased the vulnerability of pregnancy related health concerns

- Mental health problems **22%**
- Previous miscarriage **15%**
- Previous pregnancy concerns **14%**
  heamorrhage, caesarian, hypertension, low baby weight etc
- Obesity **13%**
- 40 years old or above **5%**
- Other **5%**
- Smoker **3%**
- Domestic Abuse **2%**

Figure 4
Underlying health conditions prior to or during the pregnancy

- **21%** Anaemia
- **16%** Low vitamin D
- **11%** Diabetes
- **10%** Asthma
- **10%** Urinary tract infections
- **8%** Severe pregnancy sickness
- **7%** Group B Streptococcus
- **7%** Allergy
- **7%** Low folate
- **5%** Hypertension
- **4%** Autoimmune disorders

One third did not have any underlying health conditions and 20% had a range of other health conditions such as renal disease and sexually transmitted infections.

Figure 5 - Gestation at Birth

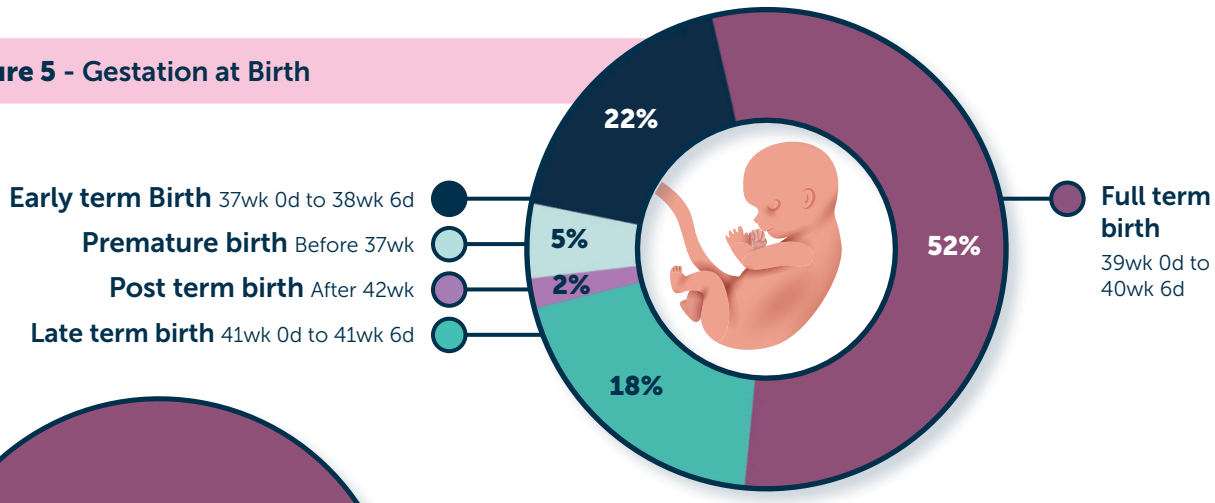
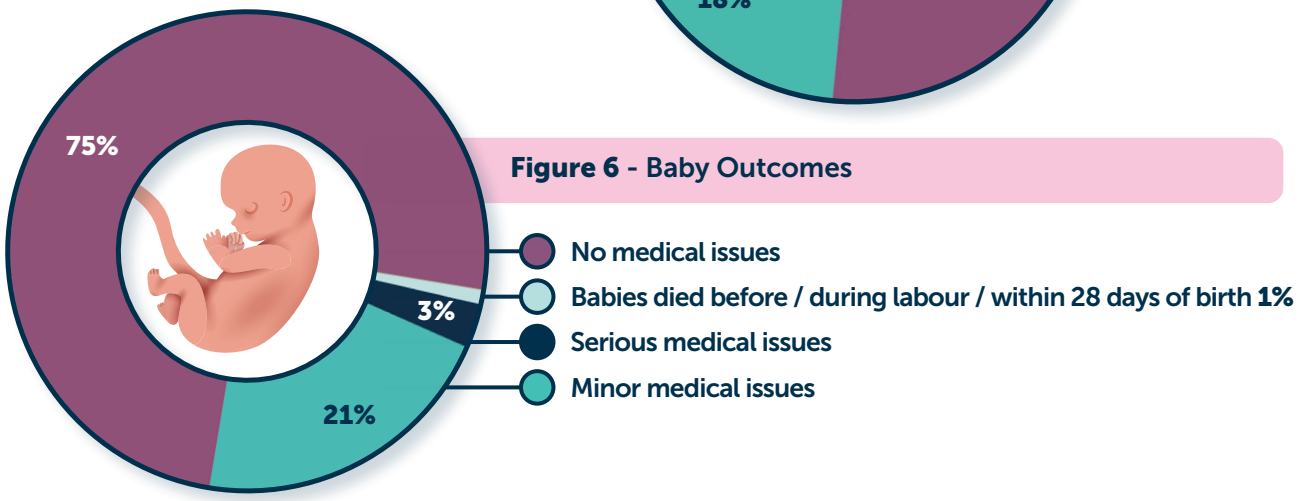


Figure 6 - Baby Outcomes

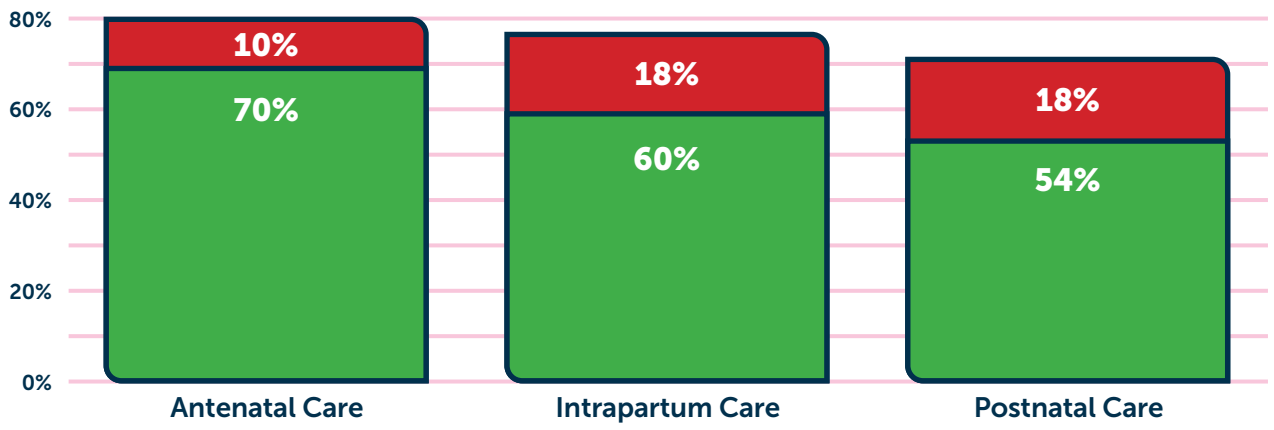


4 Key Findings

1. Poorer experiences during the intrapartum and postnatal periods

The ratings of intrapartum and postnatal care were not as positive as antenatal care - potentially indicating a decline in attention to maternal health needs during these periods of care. Women rated their care as 'high' or 'of 'good standard' as follows: antenatal (70%), intrapartum i.e. during labour, birth and the immediate post birth period (60%) and postnatal (54%). The differences became starker when examining the 'poor' or 'very poor' ratings **(Figure 7**). For example, 10% of women said their antenatal care was 'poor' or 'very poor' but almost double (18%) said their intrapartum and postnatal care was 'poor' or 'very poor.'

Figure 7 - Standards of care ratings



2. Hierarchy in bias and invisibility of certain ethnic groups

When the maternity care ratings were broken down by broad ethnic groups such as White, Asian and Black and then sub divided further, there were notable differences in perceptions of maternity care between the different groups. Black women were most likely to receive poorer standards of care followed by South Asian women. Of the Black group, Black African women indicated poorer satisfaction levels compared to Black Caribbean women. Bangladeshi women formed an outlier in the South Asian group as the standards of care they received were similar to that of Black women. Arab and Asian Other women also had satisfaction levels similar to those of Black women. The data is summarised in **Figures 8-13**.

Some minority ethnic women, who are having the poorest experiences (such as Arab, Asian Other, Bangladeshi, and Black African women) are invisible because ethnic groups are not disaggregated during data analysis, which means policies and practices that can improve their outcomes are not being identified. Using broad categories in analysis and thus making broad assumptions about a group is a form of unconscious racial bias and an example of systemic discrimination.

Antenatal Care

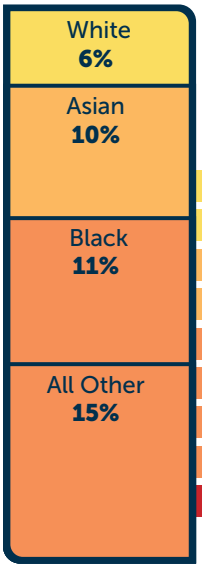
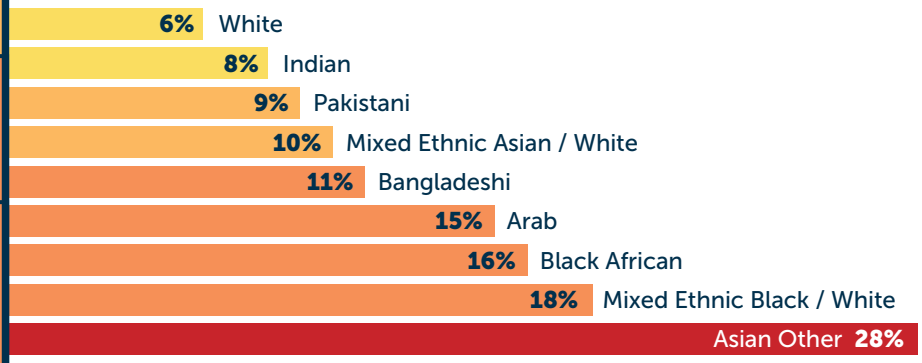


Figure 8 - Ethnicities collapsed into broad ethnic groups - Percentage of women who rated their antenatal care as 'poor' or 'very poor' (total =892)

Figure 9 - Ethnicities disaggregated into specific ethnic groups - Percentage of women who rated their antenatal care as 'poor' or 'very poor' (total =892)



Note: *None of the Black Caribbean / Other women rated their antenatal care as 'poor' or 'very poor' but group size was very small.*

Intrapartum Care

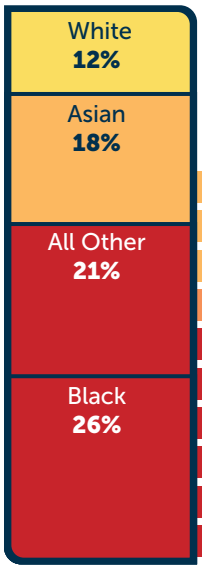
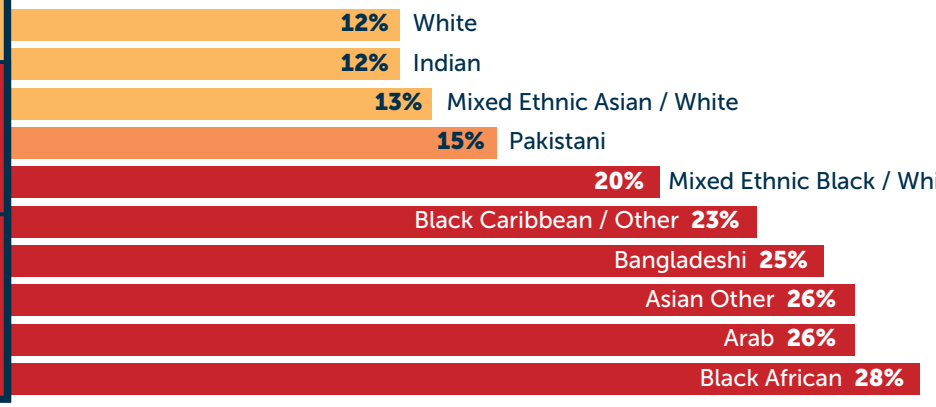


Figure 10 - Ethnicities collapsed into broad ethnic groups - Percentage of women who rated their intrapartum care as 'poor' or 'very poor' (total =892)

Figure 11 - Ethnicities disaggregated into specific ethnic groups - Percentage of women who rated their intrapartum care as 'poor' or 'very poor' (total =892)



Postnatal Care

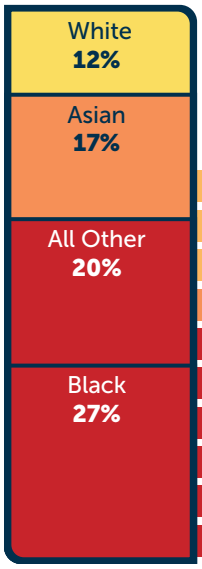
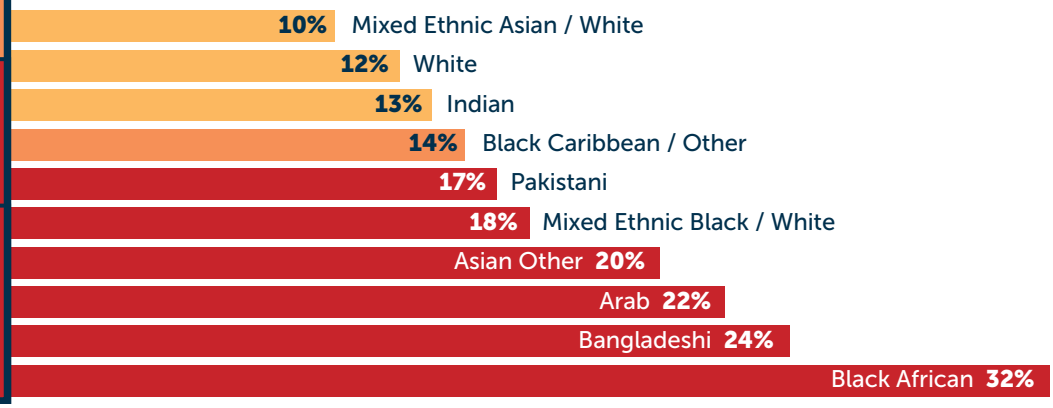


Figure 12 - Ethnicities collapsed into broad ethnic groups - Percentage of women who rated their postnatal care as 'poor' or 'very poor' (total =892)

Figure 13 - Ethnicities disaggregated into specific ethnic groups - Percentage of women who rated their postnatal care as 'poor' or 'very poor' (total =892)



3. Women denied choice

Maternity services were not equally accessible to all women. They were denied choice when accessing services, procedures and interventions. Most women did not seem to have knowledge of how to check the standard of maternity care being provided by hospitals which is important information that could help with decision making. The few women who were informed said it influenced which hospitals they definitely wanted to avoid, but sometimes their choices were denied. Forcing women to have care where they feel they will be at greater risk will contribute to poorer outcomes.

Women were also prevented from choosing how they wanted the birth to happen such as having an elective caesarean, water birth or home birth. Women felt they were discouraged from pursuing these options without good reason. When women had a miscarriage, they were not offered medical treatment to empty the uterus completely and were instead expected to expel the pregnancy at home, which is not in compliance of NICE guidelines on miscarriage care. There were also numerous examples of women being denied the opportunity to have a natural birth because they were pressured, coerced and even bullied into having a labour induction (discussed later) even when it was not medically justified. Women had to unnecessarily suffer because they were denied pain relief despite repeated requests.

> **"The consultant was White female doctor. The way she spoke to me was nothing less than bullying, she was very condescending, belittling, and she said 'I see five of you lot per day.' She tried to say we don't have slots to book you in, saying they were busy and booked up. I came out wanting to cry. I felt bullied, belittled and patronised. She even said 'it's not your choice whether you get a c-section.' However, when I saw a female doctor of Pakistani origin she told me that I did have a choice."**

MW7 - Arab
Pregnancy experience in 2020, aged 25

4. Substandard miscarriage care

Fifteen percent of survey participants indicated they had experienced a miscarriage. This may have been lower than the national average of 20% of pregnancies in the UK ending in miscarriage[7] because women may have chosen to focus on their other pregnancies in their survey responses. The women who were interviewed had higher rates of miscarriage of 25%. Many of them had experienced more than one. Miscarriage care provided was not in compliance of NICE guidelines (as mentioned previously). Care was insensitive and lacked compassion and women were denied treatment options. Pregnancy loss was also minimised with little empathy shown and the women were not provided with psychological support and information for early pregnancy loss bereavement care, which when provided should also include culturally / faith sensitive options. Women were also not provided with information on what to expect nor guidance on how to dispose of the foetal tissue in a dignified manner.

MW22 - Bangladeshi. Pregnancy experience in 2017, aged 39

She had miscarriages before each of her four full-term pregnancies. She also said she received 'very bad' aftercare each time including being made to wait one week for a scan. Although she did have the 'dilation and curettage' procedure to remove tissue from her uterus when she miscarried at 12 weeks, she was not given information about what to expect afterwards causing her a lot of emotional distress and anxiety: **"I don't know if it was done properly and wasn't if the bleeding at home was the baby or the placenta. I was very upset at home and crying quite hard. Then something fell out (in my underwear). It looked like a baby."** She indicated it was as big as her fist and said she did contact the hospital but wasn't called back in.

5. Antenatal information not accessible

Women were not provided with sufficient antenatal education, which is essential for a safe pregnancy. They were therefore not adequately aware of symptoms they needed to report. A consistent theme was not being provided with printed information. Women were also not given information specific to the needs of minority ethnic women such as their increased risk of certain pregnancy complications. Women reported the quality of information declined with each pregnancy. They were not able to fulfil the information gap via antenatal appointments either as midwives were not always accessible. When they were available other barriers emerged: negative attitudes (such as being dismissed and not listened to), not provided with enough time to ask questions or discuss concerns, signposted elsewhere because midwives lacked the knowledge. Antenatal classes which are a vital source of information, were not always available locally. Women reported relying on finding information themselves online via websites and mobile phone applications. A few women resorted to paying for antenatal classes. Such alternative options would not be accessible to all women depending on socio-economic backgrounds. The lack of antenatal information made first time mothers the most anxious. If this gap in antenatal education is not addressed, it will put mothers and babies at risk of harm. The main information sources used by the women (who responded to the survey) to meet their needs are listed in **Table 2**.

Table 2 - Main sources of Maternity Information

Most popular sources	
64%	Bounty website
64%	Emma's Diary
63%	NHS website
59%	Apps (Peanut, Mush, Phillips Pregnancy+, Bounty)
56%	Friends and family
Second most popular sources	
38%	Mumsnet
36%	Baby Centre
26%	Netmums
18%	Pampers
15%	What to expect
13%	Social media groups
12%	NCT
11%	Local parent support groups / children's centres / Sure Start etc.
11%	Tommy Centre
11%	Made for mums
Less popular sources	
8%	Social media influencers
7%	Whatsapp groups
5%	Muslim Mamas
5%	Other*
3%	RCOG Patients leaflets
2%	Birthrights
2%	Podcast
1%	BBC Tiny Happy People

Note: *Examples provided by women in the other category included doulas, antenatal classes, breast feeding network, apps such as Baby Buddy and Best beginnings, Flo app, One born every minute (TV Show), books, private midwife for antenatal education, maternity collective, You Tube, hypno-birthing, Ovia, midwife blogs, NICE guidelines, magazines, leaflets in the antenatal packs.*

6. Gaps in the quality of antenatal care

Although women were more satisfied with their antenatal care compared with intrapartum and postnatal care, there were many examples of substandard care by health professionals such as dismissing concerns (including pain), not offering treatment to relieve symptoms, inconsistency in the way foetal growth was being measured, sub-standard clinical knowledge and vital signs being missed, which contributed to poor health outcomes. Some of the issues appeared systemic such as maternity services not being appropriately resourced according to the needs of local populations. Healthcare staff were not always accessible and appointments rushed. Decisions were not communicated leaving women feeling confused, mistreated and uncared for. Women who required additional care and monitoring were not provided with it, thus putting them and their babies at increased risk. For example, even though pre-eclampsia can be life threatening, it was not always recognised or concerns were not escalated.

High quality antenatal care is crucial for detecting maternal health problems in early pregnancy so that they can be managed so mothers are supported to have safe births. However, accounts of the women interviewed revealed that sometimes the care was so poor that it put mothers and their babies at risk of serious harm and death. There were instances of near misses and stillbirths as a result of substandard antenatal care.

"My maternity care at (one hospital) I was poorly managed, despite having a bleed early in my pregnancy. It was difficult for me to get a clear plan and to schedule in for my elective c-section. As this was left so late I ended up having a placenta abruption and required an emergency c-section at another hospital where the staff were fantastic."

(Online survey)

7. Women not listened to

Healthcare professionals listening to women is an essential part of delivering safe care. Women not being listened to and their concerns being dismissed by midwives and doctors was the biggest criticism of maternity care. They were described as rude, blunt, patronising, abrupt, dismissive, having negative body language, lacking experience and even as 'gaslighting.' These attitudes led to women not having the confidence to disclose concerns (including about their mental welling and domestic abuse), which would contribute to early signs of potential pregnancy complications being missed. Women were not always provided with the opportunity to give informed consent to procedures and interventions. They were also not believed about the severity of pain they were experiencing, especially during labour, when it should indicate progression of labour. Midwives did not believe women were in established labour and wanted to 'push.' They were only believed when their health deteriorated, their baby became distressed or they were about to give birth, which resulted in emergency situations. These attitudes towards how quickly labour should be progressing may suggest the White female body is being used as the standard reference point. Obstetricians and midwives also seemed desensitised to women's pain.

"Midwives could not read the women's pain and therefore usually underestimated the stage of labour. This appeared to be due to stereotypes of BAME women of perhaps exaggerating pain. Yet it was the opposite and in fact the women introverted the pain. Women would usually be then rushed in." Former Doula

8. Lack of compassion, respect and dignity

During their maternity interactions, more than half of the women (57%) felt they were not treated with respect and dignity in the way they were spoken to or through other acts of care giving. Not being listened to (already discussed) was also regarded as disrespectful. Attitudes were insensitive and lacked compassion and empathy. During health conversations women encountered phrases that made them feel uncared for, disrespected, dismissed, not believed, judged and unwelcome. Examinations and procedures were conducted without informing women what was about to happen to them leaving them traumatised. Although pain and discomfort cannot always be avoided, women felt that healthcare professionals were unnecessarily rough. In one extremely sad case (**MW16**), the baby died prior to birth due to a catalogue of errors. Even though staff knew she was delivering a stillborn baby, she was shown no compassion and not provided with any analgesia despite asking for it. Furthermore, four students were also brought into the room without asking for her consent, which was insensitive and inappropriate during such a traumatic time.

> **"It was a terrible day the day she was born. I asked for an epidural and the midwife said I didn't need one. Then I asked 7 hours later, the midwife did not listen and the consultant came in and she was not soft at all (both were White). I wasn't a priority. I needed to go to the theatre at the end of labour, baby needed forceps, no epidural was given as there were other emergencies."**

MW16 – Indian
Pregnancy experience in 2019, aged 35

9. Cultural competence gap

There is a clear cultural competence gap across maternity services. However, the gap is slightly higher amongst staff giving intrapartum care. Health professionals having a 'very good' or 'good' knowledge and understanding of the culture of the women they served was reported as follows:

Antenatal Care	Intrapartum care	Postnatal Care
37%	**32%**	**36%**

Closing the cultural competence gap could help to improve the attitudes of healthcare staff towards minority ethnic women and contribute to more positive experiences for the women. This could involve developing specific toolkits or e-learning packages on faith and cultural practices during Muslim women's pregnancy and birth.

10. Antenatal care not personalised according to risk

A breakdown by ethnic group is presented in **Table 3** of the health conditions of the survey respondents which increased their risk of pregnancy complications. Despite the likelihood of certain minority ethnic groups having particular health issues, additional screening is not being offered and their care not always managed according to their risk. About 1 in 4 women were also not sufficiently screened for domestic abuse. If minority ethnic women are not being provided advice and care according to their specific health needs (because they are being missed or not given sufficient attention), then this is likely to contribute to poorer pregnancy outcomes such as emergency caesareans, preterm birth, need for induced labour, haemorrhaging, sepsis, lower birth weight and other physical conditions which in turn may be leading to their and their babies' higher mortality rates. Sometimes the care was so poor that it put mothers and their babies at risk of serious harm and death. Risks were missed even when women reported symptoms or concerns they were not escalated or managed poorly.

Table 3 - Underlying Health Conditions (survey responses)

Ethnic Group (numbers)	Anaemia	Low Vitamin D	Low Folate	Group B Strep	Diabetes	Urinary Tract Infections	Hyper tension	Asthma
Overall	21%	16%	7%	7%	11%	10%	5%	10%
Bangladeshi (152)	15%	18%	7%	8%	15%	17%	5%	9%
Pakistani (417)	24%	18%	9%	6%	12%	10%	5%	8%
Indian (123)	20%	14%	3%	10%	8%	7%	2%	9%
Asian Other (47)	21%	9%	4%	4%	15%	6%	4%	15%
Arab (49)	25%	30%	8%	4%	10%	8%	2%	12%
Black African / Caribbean / Other (56)	18%	14%	5%	7%	7%	11%	9%	7%
Mixed Ethnic Black African / Caribbean / Other/ White (13)	15%	15%	0%	0%	0%	0%	15%	15%
White (92)	14%	10%	7%	4%	8%	8%	2%	11%

Note: *Total survey responses 1022 - Mixed Asian / White / mixed other were not included as sample sizes really small*

above overall survey response / same as overall survey response / below overall survey response

MW37 - Pakistani. Pregnancy in 2017, aged 30 (NEAR MISS)

"From 30 weeks I started to feel unwell. My body started to swell. My husband would take me in couple of times a week. Each time I was told to go back home. The midwives I saw were both Black and White. They would measure my blood pressure which would be very high but I would be told that it was normal for pregnancy. The midwives would say the doctors are too busy to see you. They would also take blood and urine samples but when I would return there was no results as they would lose the samples. However, with each week I felt worse. I started to get headaches, blurry vision, even a loss of consciousness and would feel really hot sweaty, clammy and felt like my head was about to explode. But I was told the same thing that it was normal to feel like this because it was summer and to cool myself down with fans. By the time I reached 36 weeks I felt so unwell that I knew something was not right. I had also searched online about my symptoms. You know your own body and I was told to ignore myself. This time when I was told to go back home I became more vocal and said that I would not leave until I was seen by a doctor. She begrudgingly called one. When the doctor checked my blood pressure, he was so concerned that he ordered an emergency scan and when it was escalated to the consultant was told 'your condition is so serious that you could die and your baby could die and we need to get your baby out as soon as possible.'"

11. Poor management of labour and birth

One in four women (24%), said they were 'somewhat dissatisfied' or 'very dissatisfied' with the initial response received when they first contacted the maternity unit about being in active labour. Even when women said they were in established (active) labour, they were told not to come in to the labour ward / maternity unit or sent home if they presented at triage. Even though women know their bodies best, midwives were inflexible in their approach and assumed women have textbook pregnancies e.g. not understanding that the level of pain and the dilation of the cervix may not always match. It was also noted that 'phone' and 'in person' triage systems also failed to recognise women presenting with high risk. Around 17% of women surveyed said they had prolonged labour which is 20 hours or more for a first birth or 14 hours or more if it is not the first birth. This appears to be very high when compared with figures for England of around 8%.[8] When labours were taking an unusually long time, the mother and baby were not always closely monitored despite increased risks of uterine infection, low levels of oxygen for the baby (which could cause brain damage), stillbirth, postpartum haemorrhaging, obstetric trauma and psychological trauma.

MW35 - Pakistani. Pregnancy experience in 2016, aged 25 (NEAR MISS)

"My blood pressure and heart rate were checked but I was not even examined to see how much I was dilated and left in a room with my husband. I was not even offered any pain relief. I was told to press the button when I started getting the urge to push. I asked the midwife to examine me because I knew something was not right but was ignored. I was not even checked to see how much I had dilated. After only 5 minutes I pressed the button and pleaded again to be checked at which point I was. However, then suddenly attitudes and reactions changed and became urgent and was told that the baby's heart rate had dropped and needed to be delivered immediately. I was given and episiotomy and the baby delivered via ventouse."

12. Poor intrapartum outcomes

Almost 1 in 5 women (18%) said their standard of care was either ''poor or 'very poor.' To help understand the reasons for their poor experiences, **Figure 14** summarises medical interventions and some of the outcomes of the 892 women who had given birth. Intrapartum experiences in the study found that the following factors were contributing to adverse outcomes which included 'near misses' that put the life of mothers and babies at risk and also resulted in stillbirths: pain management, examinations /interventions, and managing and monitoring labour.

The rates of outcomes of the survey participants were also compared to national annual rates and are shown in **Figure 15**. The results were striking – Muslim women are less likely to receive pain relief, more likely to have their labour induced, less likely to be able to choose to have an elective caesarean, more likely to undergo an emergency caesarean, more likely to have an instrumental birth, more likely to have a prolonged labour, more likely to have an episiotomy and more likely to have excessive blood loss. These provide a measure of the quality of maternity care that women receive. Two contributory factors were: the delays in admitting women in established labour or those who had high risk pregnancies and also women not being checked for up to several hours during their labour. Some women stated not being checked for up to 6-9 hours. It was also noted from the survey data that Arab women were most likely to have a prolonged labour.

Figure 14 - Labour Outcomes

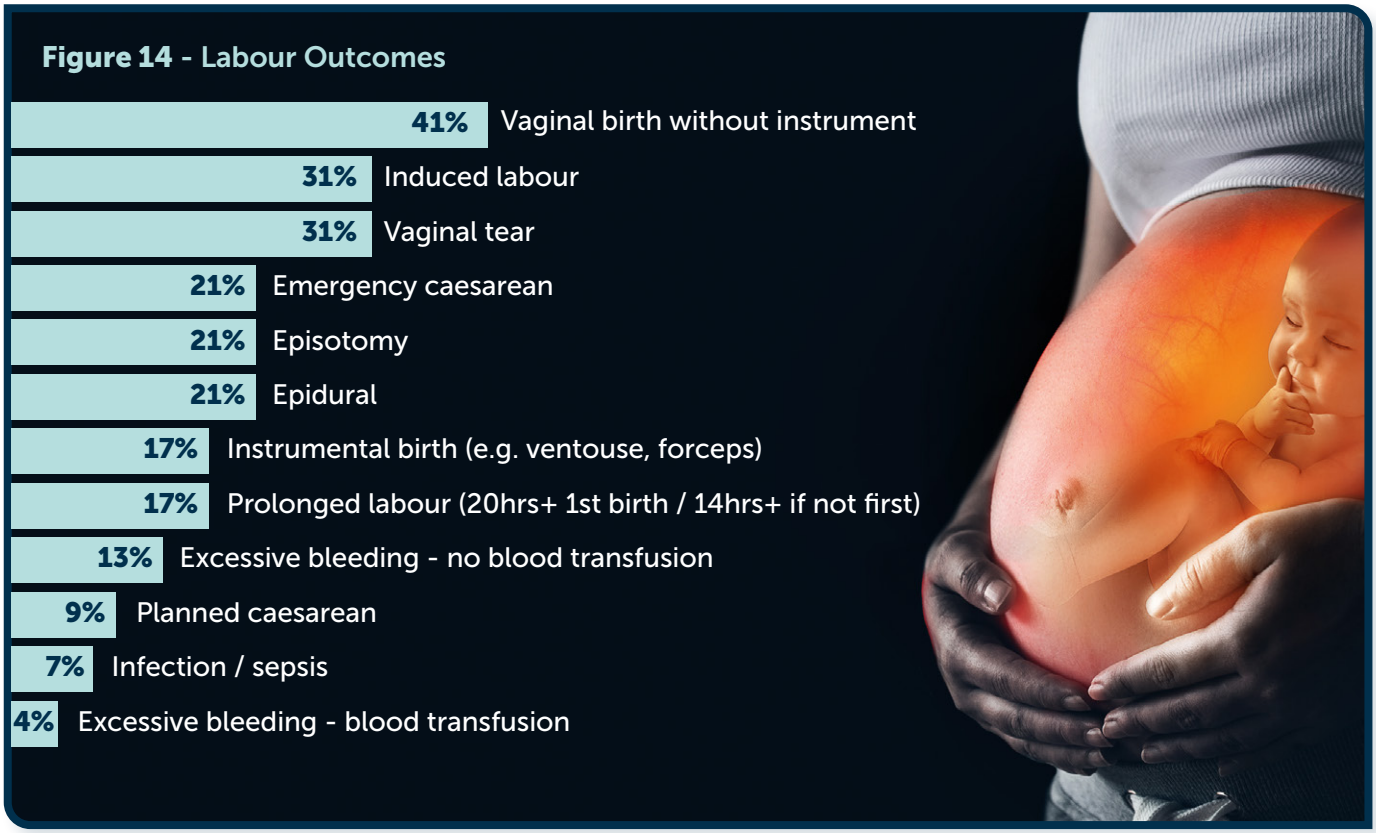


Figure 15
Summary of Inequalities experienced by Black, Asian and Minority Ethnic Muslim women

▼ 1.5x less likely	to be given an epidural for pain relief (21% in survey compared with 31% in UK)
▲ 1.6x more likely	to have their labour induced (31% in survey compared with 20% in UK)
▼ 1.3x less likely	to be able to access a planned caesarean (9% in survey compared with 11.5% in England)
▲ 1.3x more likely	to have an emergency caesarean (21% in survey compared with 16% in UK)
▲ 1.4x more likely	to have an instrumental birth (17% in survey compared with 12.5% in UK)
▲ 2.1x more likely	to have a prolonged labour (17% in survey compared with 8% in England)
▲ 1.5x more likely	to have an episiotomy (21% in survey compared to 14% in England)
▲ 2.4x more likely	to have a postpartum haemorrhage (17% in survey compared with 7% in England)

13. Women denied pain relief

The issue of pain was the most spoken about topic (along with not being listened to). Women said they were also expected to endure their pain silently and made to feel uncomfortable for vocalising their pain. Of the women surveyed, 1 in 5 women were either 'somewhat or very dissatisfied' with being provided with pain relief of their choice and 21% said they had an epidural which is lower than the national average of 31%.[9] Black African / Caribbean / Other as well as Mixed Ethnic Black / White women were the least likely to be given an epidural (note – the size of the latter group was small in the survey responses). These findings should not be interpreted to mean that women were opting not have pain relief. Their accounts showed that pain relief was refused even though it was requested. Another contributory factor was delays in care due to pain being dismissed - women would then be rushed in which meant it was too late for them to have an epidural. Being made to push without pain relief left women exhausted, too tired to push and the baby becoming distressed.

> **"One midwife was Bangladeshi, same ethnicity as me, and she told me 'I'll be honest with you, they won't give you anything until the shift change and new nurses arrive."**

MW19 - Bangladeshi
Pregnancy experience in 2020, aged 28

14. Women pressured to accept interventions without consent

Women were not always asked for their consent prior to examinations and procedures. They were pressured to accept interventions (such as membrane sweeps, inductions, caesareans, use of forceps and ventouse, and episiotomies) to accelerate birth even without clear medical need. Women were not alerted to procedures being painful so they could brace themselves, instead they would be shocked by the pain which was traumatising. Not obtaining consent when allowing trainees to observe and conduct examinations or procedures was also raised several times during interviews - one woman said ***'I felt like an experiment.'***

> **"The baby was not coming out and the head not in right place and not engaged. I was told I needed assistance. He (the doctor) put his hand inside without warning or permission. It was the most painful experience I had."**

MW3 - Asian Other
Pregnancy experience in 2021, aged 30

15. Women pressured to have labour Inductions

Of the 892 survey respondents, almost one third (31%) had an induced labour. This figure is much higher than the national annual average of 20% being induced in the UK.[10] *(Note: For a more accurate analysis, results were compared to pre-pandemic rates rather than the higher induction rates during the pandemic)*. It meant Muslim women were 1.6 times more likely to have an induction. The survey results showed that Arab and Bangladeshi women were most likely to have a labour induction. During the interviews this was the most talked about intervention. There appears to be a culture amongst some doctors to unnecessarily steer ethnic minority women towards inductions without medical justifications for their decisions. Women were not informed of the toll that inductions could have on their bodies and their babies. There were many examples of women being pressured and emotionally blackmailed into having an induction without being provided strong reasons. They were not given the opportunity to try and naturally go into labour or given time to see if the labour progressed. Some women described it as trying to **'rush'** labour, being ***'bullied'*** into a decision and being treated ***'like a child.'*** One woman was threatened with being reported to Social Services.

> **"The midwives and doctors at the hospital who saw me tried to push me into accepting birth interventions and tried to repeatedly scare me by saying my baby would be stillborn before I had even been diagnosed with anything. They tried to make me accept a pre-term induction without any justification."**
>
> **(Online survey)**

16. Women more likely to have emergency caesareans and instrumental births

Of the 892 women who had given birth, 21% had an emergency caesarean, which was higher than the national average 16% in 2020.[11] Also, 1 in 6 (17%) said they had an instrumental birth (use of forceps or a ventouse suction cup) compared to the national average of 1 in 8 (12.5%) assisted births[12] This means that they were at increased risk of adverse outcomes associated with these procedures such as brain damage / facial injuries to the baby and the mother experiencing more severe pain, perineal tears, postpartum haemorrhaging and obstetric trauma. It was noted that Bangladeshi women were most likely to have an instrumental birth and Bangladeshi and Black African / Caribbean / Other women were most likely to have an emergency caesarean. What care and decision making looked like prior to these situations was investigated. Contributory factors included delays in allowing women to attend hospital because their pain was not believed and women not being checked upon for long periods during labour - in some case up to 6-9 hours. Inadequate electronic foetal monitoring was another factor - babies were either not monitored at all, monitors were switched off, accurate readings were not taken, readings were not being interpreted properly or unusual

Focus Group FG1 -Somali. Pregnancy experience in 2018 (NEO-NATAL DEATH)

At 38 weeks when her waters broke she called in (maternity ward) and was told to wait for ten hours before attending hospital. When she eventually went in, she was examined and told she needed an emergency caesarean. Her baby was cared for in the neo-natal unit but did not survive.

17. Women more likely to experience postpartum haemorrhage

Of the 892 survey participants, 18% indicated having postpartum haemorrhage (PPH). This is very high when compared with the average national figure of 7% for England[13] indicating that they are 2.4 times more likely to experience excessive blood loss. Of the women who had PPH, 1 in 4 needed a blood transfusion. This is a concerning finding because PPH is one of the leading causes of maternal death in the UK - 9% of maternal deaths are attributed to this.[14] When breaking the data down by sub-ethnic group, the results showed that Pakistani women are slightly overrepresented with 20% saying they had PPH compared to the survey average of 18%. The group with the highest rates was the Mixed ethnic Black / White women, which was 27% - however the number of respondents in this group was very small. As the rates of other interventions such as instrumental birth, perineal tears, episiotomy and emergency caesareans were higher for these women, they are most likely to be the cause. It was noted from the survey results that Arab and Asian Other women were most likely to have vaginal tears.

Focus Group FG4 -Somali. Pregnancy experience in 2016 (NEAR MISS)

As she was overdue, her labour was induced and they also broke her waters to speed up the labour. Soon after her waters were broken she told the midwife she was ready to push. However, she was not believed as the midwife said it was not possible for her to be ready to push so soon and left her to labour with her husband. When she started pushing, the baby was half out and her husband ran out to call for help. Her baby came out still enveloped in the placenta. Several doctors came and she was taken to theatre as it became an emergency situation. it was touch and go but she survived. Due to heavy blood loss she was in a coma for three days. Her baby had to be given intensive care. When they both started recovering, they were put on a shared ward and not put in a private room despite the trauma experienced.

18. Maternal sepsis missed

Some of the women interviewed provided examples of how their abnormal vital signs were missed because they were not listened to about feeling very unwell which caused delays in their care. A worrying trend noted in the survey results was that 7% said they were diagnosed with an infection or sepsis within the first few days or weeks of giving birth. It was not clear from the data how many had sepsis. A deeper analysis of the data showed that Bangladeshi women were most likely to experience an infection / sepsis. Women recounted not being believed by midwives and sent home and then having to return to the hospital including to the Emergency Department and being diagnosed with sepsis. Missing signs of sepsis is concerning given that it is amongst one of the leading causes of maternal mortality.[15]

MW25 - Pakistani. Pregnancy experience in 2016, aged 30 (NEAR MISS)

When they tried to discharge her, she said she felt extremely unwell but they did not listen to her concerns or give her additional checks to investigate: **"I wasn't feeling well and felt lethargic. I couldn't even walk, but they still discharged me. The nurse told me 'your blood pressure is low because you have just given birth. Go home and eat, you will be fine?' I felt so unwell that I waited another 2 hours after being discharged on the same bed. I had no energy to even walk."**

When she went home her condition worsened. Even though she had not eaten she was vomiting dozens of times and becoming dehydrated: **"I had a severe body ache. It was extreme like I had run 1000 miles. I couldn't stand or walk unaided or bathe. I couldn't take care of my baby. I collapsed. I couldn't even wake my husband who was there in front of me until he woke up. I asked him to call the ambulance. You know when something is wrong with your body and it is not normal, you just know."** When her husband took her into the hospital, she couldn't even stand up so he had to use a wheel chair to go in: **"I couldn't talk either, I could barely say two words together and was breathless."**

The midwife and junior doctor, who were both White checked her temperature, blood pressure and did urine test and then told her that because she didn't have a urinary tract infection or temperature that she should go back home and return if it she gets worse, gets a temperature or vomits again. However, her husband was not convinced and demanded to speak to a more senior doctor. A senior Asian female doctor came who asked a lot more questions and then checked her stitches and noted that one was missing and that she had not been stitched properly and there was pus and she had an infection. Blood and other tests showed she had sepsis. Despite key warning signs for sepsis she was going to be sent home, which is likely to have been fatal – given how her condition had worsened rapidly. She was then admitted to hospital.

19. Gaps in the quality of post birth and longer term postnatal care

More than half (55%) of the women surveyed said that they were concerned about their healthcare during the recovery period. They were also not satisfied with the care provided to their babies - 44% said they were concerned about the quality of care provided to their baby / babies during the recovery period after giving birth, with 13% saying they were 'very concerned.' After an exhausting and sometimes traumatic period, too often women were left to fend for themselves. They felt neglected, abandoned, not listened to and with little or no support and left to suffer mentally and physically. First-time mothers especially found this period in hospital extremely difficult. While these examples of poor afterbirth care will not be limited to women from racialised minority communities, they may experience poorer care due to bias or communication barriers, the consequences of which could be fatal. For example, when medical help was sought, women were not believed, too easily dismissed and red flag signs missed, such as signs of maternal sepsis, urine output and excessive blood loss. Sometimes sub-standard care led to a deterioration of physical health and 'near miss' situations that compromised the safety of mothers and their newborns. A reform of post birth care is clearly needed. Examples of negative post birth hospital experiences included: delays in suturing of tears or episiotomies; not recognising symptoms of infection; not recognising excessive blood loss; not catheterising women who had an epidural risking bladder damage; and not listening to concerns about the new-born's health

MW28 - Mixed Ethnic Black. Pregnancy experience in 2019, aged 19 (NEAR MISS)

"I was having severe pain in my stomach but I was told 'that's just your uterus contracting'. I kept saying it's getting really bad, and was told again and again that the changeover staff would come and speak to me.... but they didn't. I was bleeding quite a lot and I was in a lot of pain. I raised it about 5-6 times, but was just left there. I waited 2.5 hours for someone to come and take me to get stitches. As I was helped into the wheelchair I blacked out and lost consciousness. I was later told I had lost too much blood... I can't remember... 3-5 times more than normal. I was told my uterus had stopped contracting so the doctors were having to try and contract it manually. The doctors were rushing in, it was an emergency."

Women expressed the lowest confidence in postnatal care with only 54% rating their care as of 'high' or 'of good standard' and almost one in five women (18%) found their postnatal care 'poor' or 'very poor.' Once women returned home they felt abandoned and neglected. Maternity care providers did not prepare women for the postnatal period – women were not provided with information about what to expect, including conditions that could develop and warning signs and symptoms to be aware of. The postnatal period is a time where women may be feeling overwhelmed with a new baby and not paying attention to themselves, even if their health deteriorates during this time. Information provision about symptoms to look out for, advice on how to take care of physical and emotional wellbeing and where to seek further help should therefore be an essential part of postnatal care.

MW31 - Pakistani. Pregnancy experience in 2021, aged 30

"It was the worst ever and has put me off having another child. My labour experience was more positive. I had prepared myself for the labour experience (what to expect) but no one prepared me for how exhausting and draining it would be. They didn't tell me about aftercare for the episiotomy and any other physical symptoms to be aware of and about mental health. When I told my midwife about pain, she only glanced down there and said 'It is fine, you are supposed to feel uncomfortable at this point as the stitches are dissolving.' When the pain got worse and I developed a temperature, I saw my GP who gave me antibiotics. However, the symptoms persisted and I ended up going to A&E but had to wait 11 hours to be seen despite being a new mum."

20. Substandard breastfeeding support

A recurring theme in the interviews was the lack of support in the method of feeding chosen by the mothers, whether it was breastfeeding, bottle feeding or breast pump feeding. Despite the fact that babies can be born at any time, lack of breastfeeding advice and support during the night was repeatedly highlighted, especially by those who had long difficult and traumatic births or who had caesareans. When mothers asked for help they felt dismissed, not supported and left to struggle on their own, which caused emotional distress. They were not being provided with timely advice, support or equipment such as nipple shields, breast pumps or access to experts. There were failures to diagnose tongue tie leading to delays in treatment. The lack of support resulted in some women give up on breastfeeding while others resorted to paying for support because of the advantage of their higher socioeconomic status, further highlighting the social class health equality gap. Assumptions were sometimes made about women being able to breastfeed because they were not first-time mothers or because of their ethnic background. There were examples of women made to feel guilty about their choice to bottle feed or do mixed feeding.

> **"Women from your communities should know how to (breast feed)."**

MW1 - Indian
Pregnancy experience in 2018, aged 34

21. Substandard perinatal mental health support

Just over one in five women (22%) said their mental health was affected during maternity. When satisfaction rates were broken down by ethnicity, there was a variation between different groups (**Table 4**). Arab and Asian Other women had the highest dissatisfaction rate. Women were reaching crisis point and feeling suicidal before their need for support was recognised by healthcare professionals. Women did not always feel able to trust health professionals enough to disclose their anxieties because of their dismissive approach, use of insensitive language and microaggressions. Even when they disclosed their concerns, they were dismissed or not followed up. Women who did not meet the thresholds for referrals to the 'Specialist Perinatal Mental Health Service,' were not signposted to alternative support.

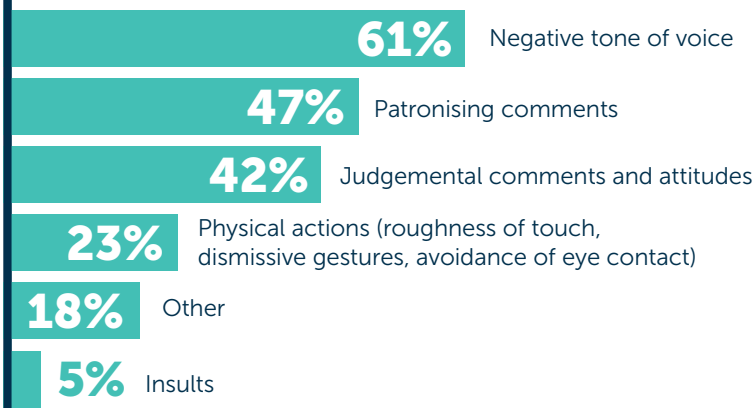
Table 4

ANTENATAL PERIOD 'dissatisfied' or 'very dissatisfied'	POSTNATAL PERIOD 'dissatisfied' or 'very dissatisfied'
2 in 5 for Arab women	1 in 3 Arab and Asian Other women
1 in 3 for Asian Other women	1 in 4 Bangladeshi and Black women
1 in 5 for Bangladeshi, Pakistani and Black women	1 in 5 for Pakistani and Indian women
1 in 10 for White and Indian women	1 in 10 for White women

22. Negative attitudes of healthcare staff

There was evidence of discrimination which involved women being blamed, humiliated and insulted as well as being coerced and bullied into decisions. Women felt particularly bullied during intrapartum care. Negative attitudes were particularly noted when pressuring women to have labour inductions (already discussed). Tactics used to coerce women included blaming them and accusing them of putting their babies at risk. Women described being treated as children. The interactions often left them traumatised during such a vulnerable time. Sometimes attitudes and actions also left mothers fearing for their wellbeing and the safety of their baby. Some behaviours described by the women amounted to 'maternity abuse' (as such behaviour in any other setting such as at home or at work would be described as abuse or bullying). When women or their birth partners became assertive because of the sub-standard care being provided, they were viewed as unreasonable, demanding and angry. Black women who participated in interviews also felt they were perceived as trouble-makers. One third of the women surveyed (31%,) said they experienced microaggressions (i.e. indirect, subtle or unintentionally negative verbal / non-verbal interactions) during their maternity care. About 11% were unsure what they had experienced were microaggressions because of their subtle nature. A breakdown of the nature of the microaggressions and examples are provided in **Figure 16** and **Table 5**.

Figure 16 - Microaggressions experienced



"At the hospital I had a scan the lady was pushing so hard on my tummy I had pain for about a week or two."

(Online survey)

While it is difficult to ascertain how much of the differential treatment is because of direct racism or xenophobia, the likelihood is that these would have played a part in at least some cases. Healthcare professionals do not live in a vacuum and will be exposed to the current climate of negative stereotypes of Muslims and migrants that are constantly reinforced by the media and politicians. These narratives will undoubtedly contribute to unconscious bias, assumptions and prejudices. Some women explained that certain hospitals were known for the way they treated ethnic minority women and avoided being booked into them. On receiving differential treatment, many women said they felt it was down to them being a woman of colour. Sometimes this prejudice was quite overt.

"The midwife called my name and said very loudly 'hope this one can speak English'."

"Women from 'your communities', should know how to breastfeed."

"All you people do is make babies."

"I see five of you lot per day."

Interview comments

"The spouses of other women who were White, were in attendance, but mine was not allowed. They became aggressive and told me my husband needs to leave. The White women/couples were not told. The only one other Asian woman with a loose headscarf was also told that her husband had to leave."

MW19 – Bangladeshi
Pregnancy experience in 2020, aged 28

Some of the women put unfriendly and hostile encounters down to their 'Muslim appearance' (such as wearing the headscarf or spouses having a beard). This included encounters with sonographers and reception staff. Some women resorted to removing their headscarf because of their treatment. The Somali women in the focus group provided the most unfavourable assessments of healthcare professionals. They felt certain about being subjected to racist attitudes, even describing their maternity experiences as 'horror stories.' Prior to giving birth in the UK, most had given birth previously in other European countries including Norway and Holland. They all agreed that in these countries, healthcare professionals treated them with more kindness, consideration and compassion. In contrast they summed up their UK experiences as 'dangerous' where they were left fearing for their lives and those of their babies. The treatment was also described as dehumanising because of the physical force sometimes used on them. The lack of compassion shown at times was shocking.

"During the delivery, the baby was pulled so hard the woman I was supporting said she felt like her whole womb had been pulled out. Later she was complaining for months about severe pain, which was dismissed until I then went with her to the doctor and insisted she was checked and she had prolapse. In another example, they damaged the womb of another woman and had to take it out and they didn't even bother telling - she found out months later."

Interpreter

While most of the negative experiences uncovered in the research involved White healthcare staff, a level of intracultural bias was also noted. Sometimes there was dissatisfaction was with minority ethnic healthcare professionals including those who shared the same racial or ethnic background as the women. Examples were provided of negative treatment by Black midwives, South Asian male obstetricians and occasionally South Asian midwives. Negative attitudes and behaviours of White healthcare professionals towards minority ethnic staff was also highlighted as a concern, which can also contribute to unsafe healthcare. If maternal, foetal and neonatal health is to be improved significantly, there needs to be a significant shift in attitudes towards people from Black, South Asian, other minority ethnic communities

Table 5 - Comments from interviews

"I felt my labour was deliberately speeded up at every step (breaking my waters, giving me an episiotomy) rather than letting it take its natural course."	"The way she spoke to me was nothing less than bullying, she was very condescending, belittling, and she said 'I see five of you lot per day."	"Maternity nurse did not help me to put my legs on the bed I was very sore. She left me with my underwear down and blood covered sanitary towel."
"We felt invisible."	"She was so awful and rude."	"I felt unheard, and unseen."
"I asked to stop the examination because of pain and was ignored and told to 'man up'."	"I remember making 'dua' (prayers) and saying to my husband, they are going to kill me."	"A humiliating experience - standards have dropped so low they do not care for the mum."
"I took my headscarf off and I made sure that I was more vocal - it was a very conscious shift."	"I do remember them continuing to say 'we know best', which made me feel like a child."	" I do feel they deliberately threw the milk away so they could formula feed."
"They made mistakes but kept blaming me, implying I was the one doing something wrong."	"Consultant did not listen and / or brushed it off, gaslighting all the way."	"Women from 'your communities' should know how to (breast feed)."
"I was also in a lot of pain, they were always late with painkillers."	"I was shell shocked, discharged myself from hospital after 24hours."	"I was in excruciating pain yet a nurse berated me for asking for help."
"I was crying and begging for a long time."	"I was treated like a nuisance and had to beg for help."	"I was getting scoffed at mocked and ignored."
"I was ignored and shouted at by the staff."	"The midwife kept shouting at me whilst I was in active labour."	"I remember being spoken to like I was stupid."
"I found the sonographer blunt, rude and miserable."	"I sat there holding back tears already feeling like I had failed."	"I was told I was fibbing when I said breastfeeding hurt."
"The midwife kept rolling her eyes."	"I felt 'pressured' and 'bullied' to have a caesarean."	"Friends kept telling me 'they'll mash you up'."
"Shouting and blaming for not pushing baby out instead of being encouraging and motivating."	"I had a door shut on my face and spoken to in a harsh tone – was apologised to eventually."	"I was made to feel like I was being demanding and unreasonable. I remember feeling like they resented me even being there."

23. Suffering in silence – women not complaining

The majority of women (70%) who are not satisfied with their maternity care do not complain. A key reason for not complaining is not being informed of the complaints process (**Figure 17**). Other factors include poor physical and mental health, not having the time or energy due to looking after a newborn and having other caring responsibilities, not having confidence in the complaints process and worrying how it may negatively impact future care. When women do complain, it is most likely to be about care during labour followed by the postnatal period (**Figure 18**).

Figure 17 - What aspect of their maternity care are women most likely to complain about

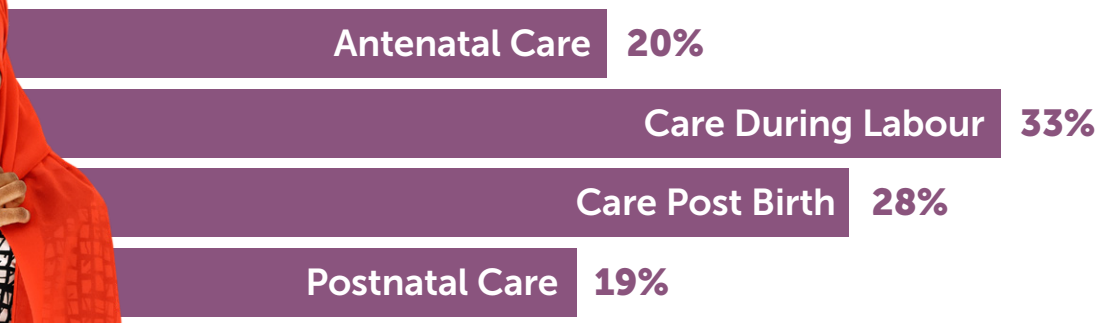
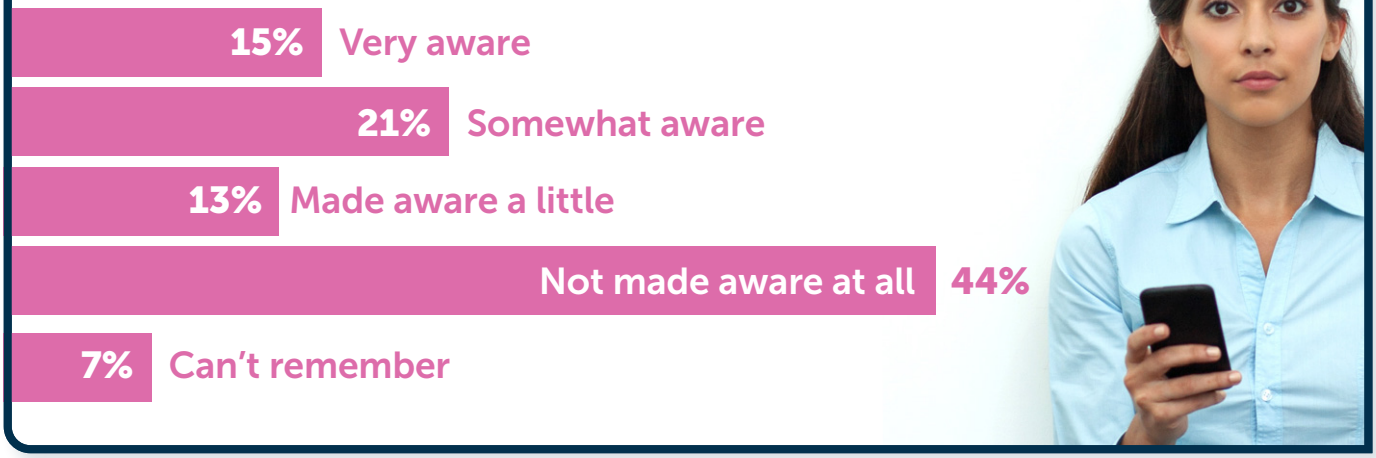


Figure 18 - Levels of awareness of how to make a complaint about healthcare



Astonishingly NHS Resolution, the body that deals with claims of compensation on behalf of NHS England and works to resolve concerns and share learning and improvement, do not collect data on ethnicity (which was confirmed by a Freedom of Information request). It is clear that healthcare service providers are not being held to account and are missing the opportunity to learn from groups of women who tend to have the poorest experiences and outcomes. Not learning means the same mistakes continue to be made.

> **"In terms of ethnicity breakdown, this information is not held as it is not recorded in our claims management system."** NHS Resolution (FOI response)

5 Positive Experiences

As women are more likely to offer information about adverse events, they were also asked about positive aspects of their maternity care. When women have good experiences, the positive impact on their emotional wellbeing can be long lasting. Such experiences also increase trust and confidence in healthcare staff, enabling patients/women to raise any concerns earlier so that any complications can be identified more quickly thus reducing risks. As 70% of Muslim women rated their care as 'high' or 'of good standard,' it is therefore important to recognise what this good practice looks like so it can be replicated. It involved listening to women, giving them sufficient time, speaking to them in a friendly tone, keeping them informed (and involved in decisions), considering their birth plans, considering their faith and cultural needs, supporting their wellbeing, showing empathy, showing small acts of kindness (such as making the hospital stay more comfortable) and helping with newborns. These aspects of care made women feel respected, heard and seen.

"The first midwife I had was brilliant and was really lovely (she was White). With second pregnancy I found out at 9 weeks. She was smiley and friendly. She asked how I was feeling. She acknowledged my miscarriage and was empathetic and asked if I wanted to talk about it. She explained what she was going to do and what would happen in follow up appointments. She also advised that if I felt that anything did not feel right to please call. I felt reassured, which was important because I was feeling so nervous."

MW36 – Bangladeshi
Pregnancy experience in 2018, aged 23

"Diane (midwife) who was White was lovely. She said you should listen to your body and you will know if something is not right. I was then examined and the cord was wrapped around neck. The doctor said you are in danger your baby is in danger we need to take you to theatre. The doctors just wanted to take me to theatre for a c-section. But the midwife who was senior wanted to at least try and to move baby to move cord from baby's neck."

MW36 – Bangladeshi
Pregnancy experience in 2018, aged 23

"My surgeon was amazing. She started by introducing herself with a big smile and started with we are going to get this baby out as quickly as possible and as safely as possible. She came in and said it's a good day, we are gonna have a good surgery. You are going to be amazing and so strong and just those words were so uplifting. When she came in, she spoke to me directly – made me feel capable and able. I was incredibly vulnerable and anxious. It was just what I needed to hear. "

"My anaesthetist was also lovely and he talked to me the whole time. He took my mind off. He also explained what was happening. He said you won't feel pain but you will feel a lot of movement and a lot of pressure. That was incredibly reassuring because I knew what to expect. He updated me through the entire procedure."

MW36 – Bangladeshi
Pregnancy experience in 2018, aged 23

During this pregnancy they thought the child was at risk of being born with Patau or Edward's syndrome. Consultant and midwife/healthcare staff were brilliant. They had adequate knowledge on the Islamic perspective of aborting a foetus and whether this would be acceptable depending on the outcome of test results and length of pregnancy. I had further questions around the topic and at my next visit the consultant had looked into the matter further. "

(Online survey)

6 Conclusion

Key themes

The provision of maternity services was variable and inequitable. The following **six themes** emerged as contributory factors to poor maternal outcomes of Muslim women from racialised minority communities:

DATA GAP

The needs, experiences and outcomes of minority ethnic women were **invisible** because of gaps in accurately collecting ethnicity data and it not sufficiently being disaggregated further into sub-groups during analysis and publication, thus masking certain ethnic groups most affected by poor maternity care.

MATERNITY INFORMATION GAP

Women felt **invisible** when their antenatal and postnatal information needs were not being met, which included not being made aware of information specific to their needs as minority ethnic women (such as their increased risk of certain pregnancy conditions and complications so they could recognise symptoms).

NOT LISTENED TO

Women felt **invisible** when they were not listened to and dismissed when they raised concerns (e.g. red flag symptoms such as sepsis, hypertension, urine output and excessive blood loss); denied choice in services, procedures and interventions (such as selecting hospitals, having elective caesareans or having pain relief); and when they were not given the opportunity to provide informed consent (such as being pressured to have labour inductions against their wishes).

NEGLECTED

Women felt **invisible** when they were neglected and abandoned during maternity care provision. They were not offered treatment to relieve symptoms during the antenatal period and were left for long periods and not monitored during the labour and the post birth period thus putting them and their babies at risk of harm. When life threatening symptoms were diagnosed, they were not always appropriately escalated. There was very little if any new-born feeding and mental wellbeing support in the postnatal period during a very vulnerable time when women were exhausted.

CARE LACKED DIGNITY AND RESPECT

Women felt **invisible** when their maternity care lacked dignity and respect because examinations and procedures were carried out without their informed consent. They also encountered verbal and non-verbal microaggressions which included tones and phrases from healthcare staff that made them feel bullied, coerced, humiliated, insulted, uncared for, disrespected, dismissed, not believed, judged, unwelcome and not listened to - some behaviours could even be described as maternity abuse.

FEEDBACK NOT CAPTURED

Women were **invisible** because when they had negative experiences healthcare practitioners and maternity service providers did not get to know about them because they did not use the complaints service due to not being made aware of it or not having the confidence in it. Opportunities to learn from them and improve care were therefore being missed.

Discussion

Inequalities were persistent throughout maternity care – antenatal, intrapartum and postnatal. 'Near misses' were also observed where the mother and / or baby could have lost their life. Cases were also uncovered where failures in care had more serious consequences such as stillbirths and neonatal deaths as well as mothers becoming very unwell with sepsis, extreme blood loss or pre-eclampsia. The testimonies were shocking and poor care was associated with delays in obstetric care because women were not listened to or neglected. While pregnancy and birth cannot be risk free, it was clear from the numerous and powerful accounts, that the harms and risks the mothers and babies were exposed to, were avoidable. The findings have been very similar to those in the Ockenden inquiry.[16] Although pressure on women to have natural births was observed, so too was a culture of over medicalising birth without reasonable medical cause by some healthcare professionals.

As the vast majority of the women who took part in the research were of a higher socio-economic status, the key drivers to substandard maternity care were structural / institutional failures (policies and practices within the maternity care settings resulting in differential access to maternity services) and individual-level treatment (negative attitudes towards women by midwives and obstetricians). Both factors were often inter-related and resulted in indirect and direct discrimination, which were associated with women's intersecting identities.

The poor maternity outcomes for Black and South Asian women have been known for twenty years or so but there has not been a step change in reducing maternal mortality rates because health practitioners and NHS service providers have been focussing on the wrong root causes. Women appear to have been exclusively held responsible for poor outcomes because of their higher risk of pregnancy complications due to their individual characteristics or behaviours e.g. having chronic health conditions, a higher BMI, social disadvantage etc. However, minority ethnic women from across the socioeconomic spectrum (including those who have no underlying health concerns) had negative experiences. Focusing on mothers has avoided the uncomfortable truth that health care service delivery systems, and the people who work in them are contributing to poor maternal outcomes.

With current challenges facing the NHS, it is now easy to shift the blame on to workforce shortages. Although workface shortages will no doubt contribute to poor healthcare staff attitudes and poor maternity care, the findings provide clear evidence that a culture exists amongst some midwives and obstetricians of being desensitised to women's pain and of negative attitudes towards women from racialised minority communities. There were plenty of examples of women being subjected to microaggressions and being bullied, especially to have labour inductions. While it was not always due to discrimination, it was clear that some maternity staff do treat women less favourably because of their race, ethnicity, faith, clothing and accent. For example, sexist and racist stereotypes that assume South Asian women are exaggerating their health concerns (also known as Mrs Bibi or Begum syndrome) contributed to women not being listened to.

However, the current discourse on discrimination in maternity care tends to only focus on race. Religious discrimination is often overlooked even though a sizeable number of minority ethnic women will be Muslim. Some Muslim women felt they (and sometimes their partners) were treated less favourably and made to feel uncomfortable because of their Islamic faith. Muslim women should not have to resort to removing their headscarf or having to dress in Western clothes to be seen and heard and to be treated respectfully. To tackle the inequalities in maternity care, a better understanding is needed in how multiple forms of discrimination are associated with poor maternity outcomes.

In fact, there was a clear evidence of a hierarchy in ethnic bias in maternity care provision. When the ratings of the standard of maternity care provided were broken down by broad ethnic groups such as White, Asian and Black and then sub divided further, there were notable differences in perceptions of maternity care with Black African, Bangladeshi, Arab, Asian Other women and mixed Ethnic Black / White being the most dissatisfied with their care which is likely to reflect the quality of maternity care they received.

Calls to action

To address the key findings, there are **four calls to action**.

1 Better Data Collection

Equality data can provide powerful tools against discrimination as it can be used to hold individuals and organisations to account. Where small numbers of minority ethnic groups preclude analysis, efforts should still be made to scrutinise the data – not using the data at all may contribute to maternity harms.

2 Addressing NHS Process and Workforce Gaps

To ensure the best quality and safe maternity care is being provided, effective scrutiny will be needed at NHS Trust board level, especially by maternity safety champions. They should be provided training to better understand the inequities and inequalities that exist in maternal health. Improvements such as having safe midwifery staffing levels during all shifts and ensuring maternity and mental health requests are triaged by appropriately qualified practitioners will make maternity services safer for all women. However, maternity services also need to be adapted and tailored to meet the needs of ethnically diverse local populations so that these populations too can be provided with personalised maternity care.

Maternal outcomes can also be improved if breastfeeding and mental wellbeing support services are better resourced and culturally appropriate. When women are not satisfied with their maternity care they should be better supported to make a complaint and trust and confidence in the process needs to improved. Negative attitudes towards co-workers from racialised minority communities can also have an impact on the quality of maternity care provided to women. Such workplace cultures should not be allowed to flourish.

3 Improving Clinical, Interpersonal and Cultural Staff Competence

Resolving inconsistencies in care will have to involve a cultural shift in attitudes towards Black, Asian and minority ethnic women, speaking up, learning and transparency. These conversations should start at midwifery and medical schools. To shift attitudes, strong messaging and guidelines will be required on what constitutes acceptable / unacceptable behaviour. An essential component of this will have to be listening properly (not just notionally, but hearing them to be understood), understanding women's pain better and providing training to be able to overcome any biases and stereotypes that may be held about different groups of women. It will also be important to understand that when assessing ethnic minority women (such as monitoring progression of labour), that the White female body should not be used as the standard reference point. Women know their body the best and that includes minority ethnic women.

The understanding of what comprises compassionate and personalised care may vary amongst healthcare staff. Ongoing professional development should therefore ensure healthcare staff have good interpersonal skills, are able to establish trust, are able to show empathy, are able to display conduct that is respectful and dignified, are able to show emotional support, can provide informational support, and can understand maternal needs and be able to prioritise maternal choice. A culture will need to be created where colleagues who are providing unacceptable levels of care or whose attitudes and behaviours contribute to poor experiences and outcomes for women, can be challenged without victimisation. Improving transparency will help support a learning culture when care does not go as well as expected.

4 Maternal Empowerment

Increasing accountability will help to improve the quality of care provided because practitioners, professional bodies and NHS healthcare providers will have to justify their practices. One important step to increase accountability is through maternal empowerment - women must have the agency to be informed and involved in decisions about their maternity care. If women, their birthing partners and their families are equipped with the right information they will have the confidence to spot signs and symptoms to be aware of, recognise when they do not receive optimal care and challenge maternal mistreatment. Such information should include: the level of care to expect; their human rights in pregnancy and birth; information about obstetric procedures; hospital annual rates of obstetric procedures and outcomes; complaints procedures; the need to be particularly aware of signs and symptoms of pregnancy complications; and health conditions associated with different ethnic groups. Maternal empowerment can also be improved through Local Maternity Voices Partnerships (LMVPs), which should involve women that reflect their local populations down to level of sub-ethnic group e.g. Bangladeshi, Somali, Arab etc., and not rely on broad ethnic group data (i.e. Black and Asian), to check for inclusivity.

The Royal College of Obstetricians and Gynaecologists, the Royal College of Midwives, other professional bodies and the NHS bodies and healthcare provider organisations are urged to clearly show how they will support the recommendations in the research by the APPG on Muslim Women, the Ockenden Review as well as other recent reports by Five X More[17] and Birthrights.[18] The trust of women in maternity services needs to be reset with detailed action plans being developed and shared publicly , which should clearly detail lines of accountability, timelines and how progress will be monitored. Bespoke training for maternity staff should contain the many stories and examples included in this and other recent maternity reports.

Concluding remarks

An independent Maternity Commissioner who is from outside the NHS, should be appointed with sufficient powers to provide scrutiny and hold to account all agencies (including the government) that are responsible for delivering safe maternity care for all women. Although the Maternity Transformation Programme was set up 2016 and is responsible for driving forward improvements to maternity services, its board members are in senior positions in the NHS. If the voices of women, about their maternity experiences, continue to be ignored it will be insulting to the women who give evidence to various inquiries including this research and to those families who have lost mothers and babies.

There is a need for change - all those involved in delivering maternity care must not just say they are listening but show they are listening.

7 Recommendations

A total of **45 recommendations** have been made. These have been categorised according to the main **four calls to action** that were identified in the conclusion. Many of the recommendations should already be taking place at hospital trusts. However, the findings suggest that there are significant gaps in practices and in the accountability mechanisms that should be monitoring the effectiveness of processes. Increasing accountability will help to improve of the quality of care provided because practitioners, professional bodies and NHS healthcare providers will have to justify their practices.

Better Data Collection

R1 Ethnicity must be accurately recorded in maternity records down to specific sub-ethnic group, which women themselves should identify to prevent misclassification. All healthcare providers therefore should address ethnicity data gaps and take action to improve quality of data capture.

R2 Healthcare providers must disaggregate data by sub-ethnic groups when planning healthcare so no women are left behind in the maternity care they receive and make the data readily available and accessible for analysis so inequalities can be more easily identified.

R10 Improve measures to increase the accuracy in recording a pregnant woman's sub-ethnic group.

R12 Data on intrapartum interventions such as labour inductions, use of instruments (forceps / ventouse) and caesareans should be disaggregated by both broad and sub-ethnic groups and hospital trusts should be compared to identify whether there is a culture of over medicalising births generally and / or for particular ethnic groups.

R13 Data on postpartum haemorrhage should be disaggregated down to sub-ethnic groups and hospital trusts compared to identify where systems, processes and attitudes need to be addressed to reduce the rates of postpartum haemorrhage.

R15 NHS trusts that provide maternity services should implement effective processes and systems that will capture the views and experiences of the vast majority of its maternity service users, broken down by ethnicity, and report the findings to its Board of Non-Executive Directors annually and findings actioned. A range of channels should be used including display of QR codes, follow up links via mobile texts and options to complete via an ipad / tablet PC before discharge.

R18 Further research should be conducted to find out whether there are racial disparities in sepsis diagnosis including rates of maternal sepsis and comparisons also made between hospital trusts. It should also include reasons for hospital re-admissions of new ethnic minority mothers. If this data is not readily available, then hospital trusts should record this data in a way that is easily accessible.

R22 Postpartum visits to hospital Accident and Emergency (A&E) Departments should be analysed and broken down by ethnicity (including sub-ethnic groups) to find out the reasons for re-admissions to the hospital to better identify and address the gaps in postnatal care.

R27 Rates of domestic abuse screening, disclosure rates and actions taken should be electronically monitored to improve accountability.

R39 NHS Resolution should start recording the ethnicity of the compensation claimants in its claims management system and publish this data in its annual reports, which should include ethnicity profiles for the different clinical areas.

Addressing NHS Process and Workforce Gaps

R3 All hospital trusts should review their maternity triage systems and ensure the triage team should include a senior midwife at all times.

R4 Address the gaps in the midwifery workforce in terms of numbers, diversity and competency in knowledge, communication skills and sensitive personalised care according to the needs different ethnic groups.

R7 Have mechanisms that ensure women are provided with options for managing their miscarriage and that they are the ones who take the decisions on how to manage their miscarriage.

R16 NHS Trust board NED maternity safety champions should be required to undergo an induction programme to better understand the inequities and inequalities in maternal health so they can be effective at providing scrutiny and seeking assurance that their trust is providing the best quality and safe maternity care.

R17 Hospital trusts (supported by sufficient funds from government) must ensure there are safe midwifery staffing levels on maternity units during all shifts.

R23 Improve the quality of infant feeding advice and support in a range of formats which encompass a range of infant feeding practices so mothers are able to make informed choices.

R24 Hospital Trusts must take steps to increase and improve breastfeeding support offered on maternity wards at all times, including during night shifts.

R28 To improve accountability, evidence of asking questions about mental health during the antenatal and postpartum period and the information given should be logged in maternity records. This data should be reviewed, aggregated and reported to decision makers.

R31 Triaging of mental health requests should only be done by clinically trained staff.

R32 Thresholds for referral to 'Specialist Perinatal Mental Health Services' should be reviewed and lowered. These services should be expanded and resourced to accept more women and / or alternative expert services provided for women which can be accessed quickly. The services need to be equipped to meet the faith and cultural needs of ethnic minority women, including counselling in different languages. Expertise should also encompass knowledge and understanding of emotional changes associated with motherhood, birth trauma (and associated health problems), new motherhood, coping with caring for a new baby, exhaustion and cultural pressures on new mums about breastfeeding and extended family dynamics.

R33 Implement policies and procedures to ensure remote consultations do not become routine practice, do not exacerbate inequalities and are only used when suitable after the Covid pandemic such as offering it to those who would not be able to attend because of poor health.

R36 When monitoring and improving patient safety, NHS trusts should consider if staff culture and attitude towards co-workers and the women using maternity services is also a contributory factor to poor maternal care and outcomes.

R37 Addressing explicit and implicit bias based on negative assumptions and stereotypes of women because of their race, faith and culture must be tackled as a priority. Systems must be implemented to track progress ensuring medical staff recruited from outside of the UK also understand the communities they service and the UK's equality legislation.

R40 The time limit within which complaints about maternity incidents can be made should be extended or more clarity and awareness provided to women on circumstances that would allow submissions beyond the current 12-month limit.

R45 An independent Maternity Commissioner, who is from outside the NHS, should be appointed to act as a critical friend and hold to account all agencies (including the government) that are responsible for delivering safe maternity care for all women.

Improving Clinical, Interpersonal and Cultural Staff Competence

R11 RCOG and RCM should jointly address the gender and ethnic pain gap in a meaningful way by developing and delivering unconscious bias training which should be a part of mandatory training for all healthcare professionals and be a part of undergraduate educational curriculums.

R14 RCOG and RCM should jointly tackle bias in assessing personalised risk, providing personalised care and obtaining informed consent across all ethnic groups and social classes in a meaningful way by developing and delivering training to its members and include it in undergraduate educational curriculums.

R19 Hospital trusts and professional medical bodies (RCOG and RCM) should review and strengthen training for early detection of maternal sepsis which includes a thorough understanding of risk factors for particular groups of women as not all signs and symptoms are always present.

R21 Strengthen guidelines and training for healthcare professionals involved in postnatal care in the community such as midwives, health visitors, GPs and nurses so they are better able to identify new-born and postpartum symptoms and complications, which should include perinatal and postnatal depression.

R25 Improve healthcare professional knowledge of tongue tie through training to reduce delays in diagnosis.

R26 Staff competencies should be improved to enquire about domestic abuse, tactics of enquiring in a safe space and knowing how to respond to and handle disclosures.

R30 Improve training of healthcare professionals on how to speak about mental health and ask questions sensitively, including in a culturally appropriate manner, and acquiring knowledge of barriers related to faith and culture.

R34 Provide training to healthcare professionals on how to conduct remote consultations in a way that is sensitive and inclusive.

R35 NHS hospital trusts, and professional bodies including the RCOG, RCM, RCGP, RCPCH and IHV and other bodies representing healthcare professionals who interact with women during their maternity care, should review and improve current cultural competence training on a regular basis. All healthcare staff should be provided training to improve their cultural awareness of the different communities they serve, particularly closing the gap for staff involved in intrapartum care. Specific toolkits or e-learning packages should be developed on faith and cultural practices during Muslim pregnancy and birth.

R38 To accelerate a change in attitudes and behaviours of midwives and doctors towards the women in their care, strengthening interpersonal skills combined with reflective practice should be an essential part of their professional development. This should include examples of how their actions and attitudes impact on the care and outcomes of ethnic minority women and how it can make them feel.

R43 Patient Advice and Liaison Service (PALS) should be provided with training and understanding of inequalities including why certain groups are less likely to complain.

Maternal Empowerment

R5 Address the antenatal information gap by ensuring written information (including employment rights during pregnancy) on antenatal classes and hospital annual rates of obstetric procedures and outcomes are accessible and which should cover material specific to the health risks for ethnic minority women.

R6 Harness digital technologies to provide information and healthcare in a way that increases inclusion and does not exacerbate inequalities by:

a. Improving access to maternity healthcare staff by allowing the option of booking appointments directly through an online booking system.
b. Making information more accessible in a culturally sensitive manner according to communication needs of women e.g. additional online antenatal classes including in different languages.

R8 Ensure options are provided to women including signposting them to relevant information on how to dispose of pregnancy tissue if miscarrying at home, which is inclusive and culturally and faith sensitive.

R9 Provide women with written information (including in different languages) about pregnancy related health conditions that pose a higher risk to them because of their racial group.

R20 All women should be provided with a postnatal care information booklet during the antenatal period so that they are aware of potential complications that could occur immediately after birth and also within the first weeks and months. This booklet should also cover caring for their emotional wellbeing, physical health, baby care and wellbeing and include clear referral pathways.

R29 Improve mental health literacy of pregnant women by providing them with written information (including in different languages and formats) about mental health symptoms and NHS and third sector support services, including faith and cultural specialist counselling services. Providing verbal information alone is insufficient as women have to absorb a lot of information during antenatal appointments, all of which will be difficult to retain.

R41 Women should be made aware of complaints procedures routinely with details about what to expect from the process. For example, this information could be included in the handheld antenatal patient notes or form part of the first antenatal appointment. This would help highlight the importance of good quality maternity care to both women and healthcare staff.

R42 Women should be offered support during the complaints process, preferably by an independent advocate e.g. maternity care patient support groups and charities.

R44 Local Maternity Voices Partnerships should improve engagement with ethnic minority women and ensure voices of local populations are represented according to sub-ethnic groups e.g. Bangladeshi, Somali, Arab, Pakistani etc., and not just rely on broad ethnic group data (i.e. Black, Asian etc), to check whether they have been inclusive.

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