

Maternity Experiences of Muslim Women from Racialised Minority Communities

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(The Baroness Gohir of Hall Green)

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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.

TRIGGER WARNING

This report contains distressing accounts related to experiences of pregnancy, labour and post-labour; including discrimination and baby loss.

Acknowledgements

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- The RCOG Race Equality Taskforce which acted as a catalyst for the research to be conducted.
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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, which 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

1.1 Purpose of the Inquiry

1.1.1 Aim

The aim of this inquiry is to illuminate the maternity experiences of Muslim women in the UK, particularly of those from Black, Asian and other minority ethnic backgrounds and to better understand the factors influencing the standard of maternity care they receive, which in turn could be contributing to the inequality in outcomes for them and their babies. Given that the diverse ethnic backgrounds of Muslim women, White Muslim women were also included in the research to explore if their experiences differed from non-White Muslim women. The research also aims to reduce inequalities by recommending improvements to the safety and quality of maternity care given to women from racialised minority communities.

1.1.2 Objectives

To achieve the aims of the inquiry, the research sought to collect the views of Muslim women about their antenatal, intrapartum (during labour, birth and the time immediately after birth) and postnatal care. It focuses particularly on their experiences over the five years preceding the fieldwork undertake, to explore:

- When women perceived they had received sub-standard care and how they
 experienced this, paying particular attention to any poor outcomes or near misses
 (i.e. events where the mother or the baby could have died).
- When women perceived they had been treated in a discriminatory way and how they experienced this including whether it was associated with their intersecting identities (i.e. due to a combination of ethnicity, religion and social class).
- When women perceived they had been treated in a discriminatory manner at an individual level and how they experienced this i.e. through differential actions / treatment because of stereotypes and assumptions (unconscious bias) or through negative physical, verbal or other subtle behaviours (conscious bias).
- How discrimination at a structural / institutional level was expressed through
 policies and practices resulting in differential access to services e.g. not sufficiently
 addressing faith or cultural needs or risk factors e.g. underlying health conditions and
 comorbidities (simultaneous presence of two or more diseases or medical conditions).
- When women perceived they had positive experiences and what factors contributed to this.

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.

1.2 Maternity Care and Safety

According to the Office for National Statistics more than 600,000 babies are born in England and Wales every year and approximately a quarter of the women giving birth are from minority ethnic groups. In 2020 for example, there were 613,936 live births in England and wales.¹ All women, regardless of their background, should have positive maternity experiences and outcomes because they deserve personalised care i.e. the right care, at the right time according to their needs.² A national survey by the Care Quality Commission (the regulator of all health and social care services in England) indicates that many women (over 80%) do have a positive experience of maternity services, but that the standard of care does fall short for some women.³ The consequence of poor outcomes, even for a minority of women, can be life changing which is why maternity incidents remain the single highest cost of claims against the NHS in England. Obstetrics claims remain the largest proportion, at 59% of the total estimated value of claims (£4.2 billion), and represented 11% of the number of the total number of 10,816 new claims reported in 2020/21.⁴

Shortages of midwives and obstetricians will no doubt also have an impact on the quality of care and any government must ensure that maternity services are well resourced. However, investigation of maternity services in recent years have highlighted other safety concerns. For example, serious failings at the Furness General Hospital, managed by Morecambe Bay NHS Trust, included concerns about clinical competence, a culture of midwives promoting normal childbirth 'at any cost,' failure to escalate concerns and failure to investigate adverse incidents and learn lessons.⁵

Donna Ockenden found similar trends when she led the inquiry into maternity services at Shrewsbury and Telford NHS Hospitals Trust including the review commissioned by the Secretary of State for Health.^{6a} She discovered that women were not being listened to, that their concerns were being dismissed, and that they were not given sufficient information about risks. High risk pregnancies were also left under midwifery care or inappropriately managed by obstetricians in training and there were failures to recognise deterioration in a mother and escalate concerns. Other safety concerns included inappropriate use of oxytocin (which is used to make contractions stronger) and there was a desire to keep caesarean sections low leading to traumatic births.^{6b} It appears that Nottingham University Hospitals NHS Trust may be the next to be investigated following safety concerns raised by families.⁷ It is important to note that the Care Quality Commission has rated 38% of maternity services as requiring improvement in safety, which is very concerning.⁸

Against this backdrop in the variation in standard of care in different parts of the UK, how are Black, Asian and minority ethnic women affected? A review to assess the progress made in maternity services since the publication of Better Births in 2016 and the 2015 Report of the Morecambe Bay Investigation, states that further action is still required, emphasising the need to tackle inequalities in outcomes for women and babies particularly from the most vulnerable groups such as Black, Asian and minority ethnic and those from the most deprived areas. The report also states that despite progress being made over the last decade in reducing perinatal and maternal mortality, (according to indicators which are used to measure the success of the maternity care being delivered), the rates of maternal deaths, stillbirths and neonatal deaths for Black and Asian groups remain high. This appears to suggest that the risk of failure for Black, Asian and minority ethnic women could be exacerbated because of their race, ethnicity and socio-economic background.

1.3 Intersecting Faith with Other Inequalities

and Maternal Outcomes

Although faith is not used when reporting maternity indicators, religious identity (including how it intersects with the other identities) also has the potential to impact on the quality of health care and health outcomes because of perceived negative stereotypes. For example, particularly over the last 20 years, negative stereotypes about Muslims have been propagated across the Media, in Politics and society. As healthcare professionals do not live in a vacuum they will be exposed to these messages. As a result, this could explain why one study found that Muslim women engaging in maternity services lacked the confidence to discuss concerns or ask questions related to religious values (such as wanting to see a female doctor) because of their anticipation of healthcare professionals not having a positive opinion of them being Muslim.¹⁰

Another qualitative investigation of English-speaking, first-time pregnant Muslim women found that while religion is a comfort and resource for them, it can also be a source of contention and anxiety in a maternity setting, especially when they feel misunderstood and stigmatised for their beliefs. The study suggested that a lack of awareness amongst healthcare professionals around religious values and how Muslim women may feel when expressing their needs could inhibit them getting optimal care that acknowledges their needs.¹¹

Earlier research conducted by The Maternity Alliance in 2003 found that the poor care of some Muslim women was linked to healthcare information not being accessible to those for whom English was not their first language. It also discovered a lack of understanding by healthcare professionals of how cultural and religious beliefs could affect maternity experiences (e.g. being able to maintain modest dress such as the hijab, prefering to be seen by women doctors, being able to pray and have dietary requirements met). Muslim women research participants also revealed insensitive care which appeared to result from the professional holding stereotypical and racist views. 12 A more recent review conducted in 2020 similarly found that Muslim women who experienced insensitive care, linked it to discrimination.¹³ Discriminatory stereotypes can result in pain and symptoms not being taken seriously and being dismissed, which in turn can lead to poor outcomes. One example of such a stereotype, although associated with race but also affecting Muslim women, is a long standing one known as "bibi-itis" or "Mrs Bibi or Begum syndrome" (derived from Begum and Bibi being common surnames of Pakistani and Bangladeshi women) where South Asian women (particularly those who cannot speak English) are assumed to be exaggerating their health concerns.¹⁴ These assumptions are not just held by White doctors - some doctors from racialised minority communities also continue to propagate these racist and sexist narratives. 15

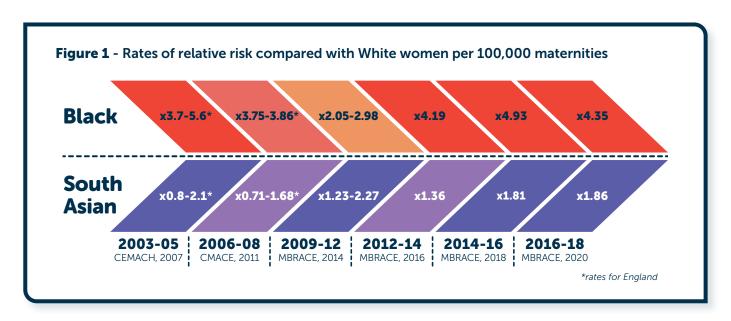
There are over 3 million Muslims (4.8% of the population) making them the second largest religious group in the UK, who are culturally, ethnically and linguistically very diverse (Census, 2011). Given the number of Muslim women using maternity services, it is important to understand how their religious identity may be impacting on the way they experience maternity care, especially if they are to be provided with individualised care (i.e. the right care at the right time according to their needs as mentioned earlier). For example, a woman's Islamic faith may: influence her birth plan (which may include rituals and customs); result in her limiting male presence during maternity care; lead to her wanting modest covering / dress while on the maternity ward; influence the value she places on breast feeding (i.e. regarding it as highly important) or the value on foetal screening to check for genetic or chromosomal conditions (she may be reluctant due to beliefs on abortion); or she may prefer spiritual/ faith based counselling to help with perinatal or postnatal depression. As highlighted already, Muslims are diverse, and their religious practice is equally diverse. Cultural beliefs and practices vary country to country too, and sometimes within countries.

Like in all communities there are also misconceptions held that need challenge and education; such as the belief that colostrum (first form of breast milk) is unclean, and therefore is not given to newborns thus depriving them of nutrition. Acknowledging the aforementioned intersecting identities is vital to improving the understanding of maternity service users and the care they receive.

1.4 Racial Disparities in Maternal Health Outcomes

1.4.1 Higher risk of death

Although there has been an overall decrease in maternal death rates between 2003-05 and 2016-18, the maternal mortality rates for minority ethnic women continue to remain higher when compared to White women. 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, emphasising the need for a continued focus on action to address these disparities. Another group that requires attention is women from mixed ethnic groups who have a two-fold difference in mortality rates according to the seventh MBRRACE report published in 2020.¹6 When the rates are examined from previous 'Confidential Enquiries into Maternal Deaths in the United Kingdom,' it appears there has been a widening of the disparity between BAME minority ethnic (particularly Black women) and White women as demonstrated in **Figure 1** below. Although the mortality rates seemed to decrease between 2003-05 and 2009-2012, they have increased from 2009-12 to 2016-18, particularly for Black women.



The babies of Black and South Asian women are also at a greater risk of dying. According to the sixth annual MBRRACE-UK report, compared to babies of White ethnicity, babies of Black or Black British ethnicity remain at over twice the risk of stillbirth at 117% and 45% increased risk of neonatal mortality, while babies of Asian or Asian British ethnicity are at 57% increased risk of stillbirth and at 59% increased risk of neonatal mortality.¹⁷

1.4.2 Women Born Outside the UK

The mortality rates for ethnic minorities can be partially explained by the fact that some of these women may be new migrant women who may experience difficulties such as accessing antenatal care and communication barriers. When characteristics of women who died between 2009–12 were analysed in the MBRRACE report published in 2014, over a third (34%) were born outside the UK. These women had been in the UK for a median of 4 years (range 1 month to 21 years) before they died. More than 70% of them were from South Asia (mainly India, Pakistan, Bangladesh and Sri Lanka) and Africa (mainly Nigeria, Somalia and Ghana). Also, 13% of the women born abroad were from Eastern Europe (primarily from Poland) and the remainder were from other parts of Europe and North America. Similar trends have been observed in the aforementioned 2020 MBRRACE report for the period 2016-18, which highlighted the deaths of women from China and Romania.

1.4.3 Higher rate emergency caesareans, postpartum haemorrhage and birth without intervention

In addition to these alarming statistics, there are other deep differences in health outcomes for BAME women and their babies. The National Maternity and Perinatal Audit (NMPA), led by the Royal College of Obstetricians and Gynaecologists in partnership with other bodies, analysed three year (2015-2018) maternal and perinatal data, which showed that Black women had a higher rate of experiencing a birth without intervention (without epidural/spinal/general anaesthesia or episiotomy) than White women. Although this may appear to be a positive outcome, the question arises whether some of these women required an intervention but did not receive it. For example, were they denied pain relief despite requesting it or was it too late for pain relief because of delays in admitting them to hospital even though they were in 'active' labour? This will be explored in the research. The rates of emergency caesarean birth were also highest for women from Black ethnic groups followed by South Asian women when compared to those for White women. Black women also had higher rates of major postpartum haemorrhage (>1500 ml of blood loss)¹⁹

1.4.4 Higher rates of pre-term births, stillbirths and neo-natal admissions

The same National Maternity and Perinatal Audit also revealed that socioeconomic and ethnic inequalities were responsible for a substantial proportion of stillbirths, preterm births, and births with FGR (foetal growth restriction) in England. The largest inequalities were seen in Black and South Asian women in the most socioeconomically deprived quintile. Babies born to women from South Asian and Black ethnic groups had higher rates of preterm birth before 32 weeks of gestation than babies born to White women.

The Apgar score is a quick test performed on a newborn baby to check how well the baby is doing outside the mother's womb by examining the baby's breathing effort, heart rate, muscle tone, reflexes and skin colour with a score of 7 and above indicating the baby is in good health. The audit showed that Apgar score rates of less than 7 (at 5 minutes) are higher for babies born to Black women and lower for babies born to women from South Asian and Other ethnic groups when compared to babies born to White women. Interestingly, despite the lowest rates of having an Apgar score of less than 7, neonatal admission (at term) is higher for babies born to those from South Asian as well as for Black ethnic groups when compared to babies born to White mothers.

1.4.5 Higher rates of obstetric anal sphincter injury

There also appears to be ethnic differences in the rates of obstetric anal sphincter injury (OASI), which is a third or fourth degree tear (in the perineum that extends into the anus)²⁰ - more common with a first vaginal birth. One study, which analysed births over a five-year period indicated that African-Caribbean women are at an increased risk of OASI,²¹ a condition that can be a contributory factor to longer-term anal incontinence and faecal urgency. Another investigation which looked at births over a seven year period found the risk of severe tearing at second birth was higher in Asian women.²²

1.5 Explanations for Racial Disparities

1.5.1 Disaggregating Ethnic Groups

When discussing poor outcomes of minority ethnic women, the data is often analysed for broad ethnic groups such as Black women or South Asian women while other minority women are grouped together as 'other.' However, these women do not make up homogenous groups and it is essential to breakdown the data further to assess how the poor outcomes vary between the minority ethnic groups to better understand the contributing factors and to be able to develop informed effective strategies and interventions to improve their maternity care. It is noted that the MBRRACE reports from 2016 onwards do not show the mortality rates for the specific ethnic groups and instead aggregate the rates to cover larger ethnicity groupings i.e. Black, Asian etc, which masks the disparity in mortality rates between these groups. For example, confidential enquiry data from 2009-2012 showed that the mortality rate for Black African women was higher (2.98) when compared with Black Caribbean women (2.05). The rates between ethnic groups in the aggregate South Asian groupings also differed during the same period i.e. Indian women (2.3), Bangladeshi women (1.23) and Pakistani women (1.5).²³

When data is disaggregated for severe morbidity conditions, the rates differ significantly across the ethnic groups. For example, a national study by Nair et al., (2014) using data from the United Kingdom Obstetric Surveillance System (UKOSS) from February 2005-January 2013, found that while severe sepsis was most common among the Black Caribbean and Indian women, peripartum hysterectomy, placenta accreta and uterine rupture, grouped as haemorrhagic disorders were most common among the Bangladeshi, Pakistani and Black African groups. This above-mentioned study which included 1,753 women with severe maternal morbidity, also demonstrated a significantly higher risk of severe morbidity between 43% and 83% among women belonging to the Pakistani, Bangladeshi, Black Caribbean, Black African and other non-White (non-Asian) minority ethnic groups compared with White European women. The investigation also reported that after accounting for possible confounders and other factors, socio-demographic and clinical factors had little effects on the data²⁴ These ethnic disparities are also supported by an earlier UKOSS study in which Knight et al., (2009) demonstrated that the unadjusted relative risk of having a 'near-miss' condition to be more than two times higher in Black Caribbean and African women and about 49% higher among Pakistani women.²⁵

1.5.2 Contributing Factors

Finding an explanation for the inequality in health outcomes is complex because it involves an interplay of the following factors:

Physiological

such as age, obesity (BMI>30), smaller body frame or medical co-morbidities, which may be pre-existing or occur during pregnancy (e.g. cardio-vascular disease, hypertension, diabetes, asthma, anaemia, thyroid disorders, low vitamin D, urinary tract infections, obesity, previous pregnancy problems and mental health conditions).

Cultural and other behaviours

such as smoking, alcohol intake and drug use, level of utilisation of antenatal care services, spacing between pregnancies, female genital mutilation and consanguineous marriages that can lead to congenital anomalies.

Social and Economic Disadvantage

such as wealth, income, occupation, property ownership, education level, immigration status and English language proficiency.

The above factors could explain some of the differences in maternal and baby outcomes that have been observed. For example, prevalence of diabetes is higher among South Asian and Black groups than in the White population and obesity prevalence is higher in Black adults. ²⁶ Deprivation levels are higher among minority ethnic groups and they are over-represented in deprived communities - for example, people from BAME groups make up 15% of the total population, but account for 22% of the population in the most deprived areas.²⁷ The Better Births report noted that a higher number of stillbirths occurred in those areas with more deprived populations²⁸ which is supported by ONS data - in 2020, babies with a parent from higher managerial, administrative and professional backgrounds had a rate of 2.6 deaths per 1,000 live births while babies with a parent from routine and manual backgrounds had a rate of 4.8 deaths per 1,000 live births.²⁹ Nair et al's., (2014) research (mentioned earlier) found that the difference in maternal outcomes observed cannot all be explained by sociodemographic and clinical factors. Although socio-economic disadvantage (caused by cumulative systemic / structural discrimination) is the main factor driving ethnic health inequalities, the role of interpersonal discrimination and discriminatory policies and practices within maternity services must be considered in how they contribute to the adverse mother and baby outcomes including any variations in treatment within minority ethnic communities which could result in a hierarchy of bias.

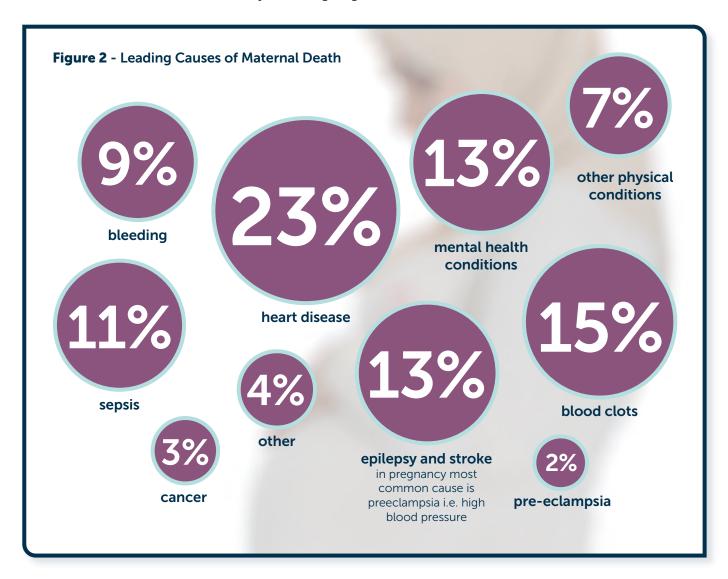
1.5.3 Covid-19 Risks for Minority ethnic Pregnant Women

Unfortunately, the Covid-19 pandemic has exacerbated poor maternity outcomes for Black, Asian and minority ethnic women including higher mortality rates. A UK Obstetric Surveillance System (UKOSS) study on the risk factors and outcomes among pregnant women with SARS-CoV-2 infection conducted in 2020 found that 55% of the pregnant women admitted to hospital with COVID-19 were from minority ethnic backgrounds, even though they only make up a quarter of the births in England and Wales and BAME people make up about 14% of the population. The analysis also showed that when these women reached their third trimester, Asian women were four times more likely than White women to be admitted to hospital with COVID-19 during pregnancy, while Black women were eight times more likely. Pregnant women who were over the age of 35 and who had a BMI of 25 or more, and those who had

pre-existing medical problems (such as high blood pressure and diabetes) were also at higher risk of developing severe illness and requiring admission to hospital.³⁰ Living in areas or households of increased socioeconomic deprivation is also known to increase risk of developing severe illness, highlighting the structural inequalities that are contributing to women's poor health outcomes.³¹

1.6 Leading Causes of Maternal Deaths

It is important to understand the leading causes of maternal death in the general population to explore how attitudes, stereotypes and institutional racism could affect decisions and actions. An analysis by the seventh MBRRACE-UK report of the 2.2 million pregnancies in the three-year period 2016-2018, shows that 217 women died during or up to six weeks after their pregnancies from pregnancy-related causes. A breakdown of statistics indicates that the leading cause of the maternal deaths was cardiovascular heart disease (including heart attacks, heart failure and heart rhythm problems) (**Figure 2**). Mental health conditions remain the leading cause of pregnancy-associated deaths between six weeks and a year after giving birth.³²



1.7 Legal Duty to Eliminate Discrimination

Under the Equality Act 2010 health and social care providers have a legal duty to reduce inequalities between patients in terms of access to health services and the outcomes achieved. There are nine protected characteristics under the Equality Act 2010, which are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief and sex. Health providers clearly need to do so much more to eliminate the disparities in health outcomes for Black, Asian and minority ethnic women and their babies. They need to focus on the mechanisms through which inequalities originate (i.e. policies and practices through which indirect discrimination occurs) so they are better able to serve the needs of their diverse populations. More effective practices need to also include monitoring through robust data collection that allows for rapid identification of gaps and for learning to take place. As highlighted in the findings of this report, more detailed and more timely data on ethnicity and religion would enable patterns to be spotted and so that appropriate interventions can be designed.



2 Methodoloy

2.1 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.

2.2 Research Team

Logistical support was provided by Muslim Women's Network UK administration staff. Key members of the research team comprised of:

Shaista Gohir OBE (Co-Supervisor, Researcher and Author)

Shaista Gohir OBE has a wealth of experience in the BAME civil society and has worked in complex environments at a very senior level with expertise in governance and scrutiny. She leads Muslim Women's Network UK. Her work in the health sector includes being a Non-Executive Director of the University Hospitals of North Midlands NHS Trust and the Women's Voices Lead to Royal College of Obstetricians and Gynaecologists.

Faeeza Vaid MBE (Co-Supervisor and Researcher)

With an academic background in Law and Religious Studies, and extensive understanding of the lived experiences of Muslim women in the UK, Faeeza was the Executive Director of the Muslim Women's Network UK (MWNUK) between September 2011- December 2021. Her area of expertise is on issues of inclusion, diversity, equality and justice for minority groups. She is also Trustee of The Smallwood Trust and joined the MWNUK Board in January 2022.

Dr. Suriyah Bi (Researcher)

Dr Suriyah Bi is a researcher, lecturer, and academic activist. She is passionate about creating a fairer and more equal society for all and in 2018 founded the Equality Act Review. She takes a particular interest in researching British Muslim experiences, and using anthropological methodology, is keen to re-centre marginal experiences at the centre of policymaking.

2.3 Research Question Development

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. Feedback resulted in adjustments being made and the final draft consisted of 55 questions, which included demographic and contact information questions. The questions were divided into the distinct themes to make it easier to track experiences through the maternity journey. Responses to these questions were then sought online via Survey Monkey software. When women were selected for in depth conversations about their experiences, the interviews were conducted in a semi-structured manner and guided by these questions. All women interviewed received a £30 gift voucher.

The research questions were divided into the following themes:

About the Pregnancy and Birth

In this section, background information was asked about the pregnancy such as how long ago the pregnancy experience occurred or whether there was a current pregnancy as well as other information such as underlying health conditions or other factors (including telephone / virtual consultations, mental health or domestic abuse), that could have had an impact on the pregnancy experience as well as outcomes for mother and baby.

Antenatal Care During Pregnancy

In this section, questions were asked to determine the experiences and levels of satisfaction of the healthcare received during the pregnancy which included antenatal appointment attendance (including barriers to attendance), healthcare professional understanding of cultural /religious backgrounds and about the identification and management of complications and risk factors (including mental health and domestic abuse).

Labour, Childbirth and Post-birth Care

In this section, questions were asked to determine the experiences and levels of satisfaction of the healthcare received during labour, birth and the recovery phase. This included healthcare professional understanding of cultural /religious backgrounds and safety concerns as well as identification and management of risk.

Post Natal Care

In this section, questions were asked to determine the experiences and levels of satisfaction of the healthcare received up to 6 weeks after giving birth, which included healthcare professional understanding of cultural / religious backgrounds and the identification of emotional wellbeing and mental health needs.

Attitudes During Maternity Care

In this section, questions were asked to determine the women's perception of attitudes towards them by healthcare professionals during their pregnancy, birth and postnatal period such as whether they experienced micro-aggressions (including what these looked like) and if they felt they were treated in a prejudicial way or unequal manner, on what grounds and by whom.

Additional Information

This section focussed on finding out women's sources of information, awareness of their rights in maternity care, knowledge about the complaints service and if they used it and for which part of their maternity care.

2.4 Data Collection

Survey Dissemination

The online survey was promoted through the stakeholder networks of the APPG on Muslim Women and its Secretariat, the Muslim Women's Network UK. This included through its national membership, women's rights activists, women's groups and politicians. The survey was also promoted through social media, Bounty (the pregnancy, birth and baby app), which also has a significant number of minority ethnic Muslim members. As the survey was long with a total of 55 questions (including demographic information) and likely to take on average over 15-30 minutes to complete, an incentive of being entered into a prize draw to win one of three £100 vouchers was offered. Women were instructed to fill in separate surveys if they wanted to share information on more than one pregnancy.

Target Audience

As Muslim women are from a range of ethnic backgrounds, it was important to ensure that this diversity was reflected in the respondents and mirrored the census data as much as possible. When gaps emerged, action was taken to increase outreach to women from particular ethnicities. As the research was primarily focussed on finding out about more recent pregnancy and childbirth experiences (within the previous 5 years), this was emphasised in the survey information. However, women were told that if their experiences were more than five years old and they really wanted to share their perspectives, they could still participate, as this could allow a comparison of older and newer experiences.

Sampling Period

The online survey was conducted between February to June 2021, with the vast majority of responses received within the first two months of launch (97%). The survey was kept open for an additional three months to allow targeted promotion of the online survey to address demographic gaps such as the lower level of Black women responding to the survey. Black Muslim women make up approximately 10% of the Muslim population in Britain.³³ However, analysis of data after two months showed that only 4% of participants identified as Black African /Caribbean /Other. Targeted awareness of the survey increased the proportion of Black women responding to 5%. To mitigate some of this gap, a focus group was held with ten Somali women for an in-depth discussion about their experiences with an interpreter for those women who were not proficient in English.

Semi-structured Interviews

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. After conducting in depth conversations with 37 women, further women were not contacted for interviews as the feedback received appeared to have reached 'saturation' as no new themes were being observed. The women were chosen to reflect the diversity of Muslim women in terms of education levels, profession, ethnicity, ages and location, place of birth (e.g. born in the UK or had migrated), and dress (e.g. women who wore the headscarf and those who did not).

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Most women shared experiences of pregnancies that occurred up to five years ago. However, some spoke about pregnancies that occurred up to ten years ago. All of the women had single term pregnancies except one who also had a twin pregnancy. The experiences were also wide ranging which included first time motherhood, miscarriage, ectopic pregnancy, stillbirth, neonatal loss, near misses where women or their babies were a risk of serious harm, having had female genital mutilation and maternity during the Covid pandemic. All women were proficient in English including those born outside of the UK therefore an interpreter was not required. The women were interviewed mostly via Zoom and some via telephone and the interviews recorded. A £30 voucher was given as a thank you for taking part in the study.

Focus Group

One focus group was held with 10 Somali women in Birmingham. This was not in the initial plans but added to the research due to the lower survey response rates from Black Muslim women. This was arranged through a community activist who also acted as an interpreter for those women who were not proficient in English. The women were also provided with information about ethics and data protection. The women were given £30 vouchers as a thank you for participating in the focus group.

2.5 Ethics and Data Protection

The following ethical issues were considered during the study, which the interviewees were informed about prior to the interview, in writing and verbally:

Informed Consent

Information was provided on who was doing the research, reasons for it, the funder and how the research would be used. A consent form was also provided to obtain permission to use the material.

Interviewee Wellbeing

Reassurance was provided that the interviewed could be stopped at any point during the interview. Information about the support that was available (such as counselling and other services) was also provided.

Confidentiality

Any information that would make the interviewees identifiable would be removed such as their names and those of their babies.

Data Protection / Storage

Reassurance was provided that any information that would make the interviewees identifiable would be removed such as names and that any recordings would be stored safely (according to MWNUK data protection policies), restricting access to the team working on the project and deleting recordings upon completion of the project.

2.6 Data Analysis

Before the survey data could be interpreted, it was 'cleaned' to eliminate responses that were considered as inauthentic or unwanted outliers. For example, participants who may have only filled in the survey to be eligible to be entered into the prize draw. Using analytical tools these were easily identifiable such as by examining response times, not entering demographic information and skipping numerous questions. Of the 1940 responses received, 1022 were completed and met the criteria for a high-quality data set, which was then analysed. The draft report was sent to the MWNUK board and to external peers to review and provide feedback prior to its publication.

2.7 Limitation of the Study

A. Selection, recall, observation and confirmation bias

The investigation was limited in scope in terms of the types of Muslim women reached (selection bias). As the research sought the views of Muslim women through online surveys, which also mostly provided the source of interviewees for in depth discussions, this meant that some women were excluded from the study. For example, women who lacked proficiency in the English language, women who did not have access to the internet or those who do not have the full access to maternity care services due to their immigration status such as asylum seekers and refugees, were unlikely to be aware of the research. However, if this research shows that Muslim women, who have no communication needs, are educated and able to advocate for themselves, still have poor experiences and outcomes, then it can be argued that those who face further barriers are even more likely to have negative experiences. There was also an under-representation of Black Muslim women in the survey responses. With targeted promotion, their proportion was increased from 4% to 5%, which fell short of the 10% target (their proportion according to 2011 Census data). However, this was mitigated by holding a focus group with 10 Somali women.

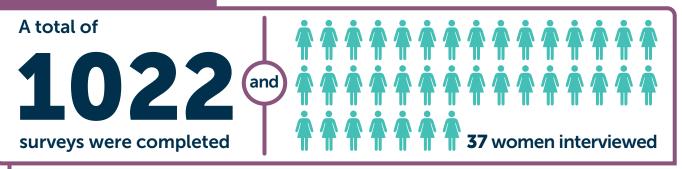
There was also concern that women who were frustrated with their experiences may have been more motivated to respond to the online survey or those who only recalled the negative experiences or remembered them worse than they actually were (recall bias). As the women were aware they were being studied, they may have consciously or unconsciously altered the memories they shared (observation bias). Bias could have also occurred during the interpretation of the study data i.e. unconsciously looking for information that confirmed opinions already held (confirmation bias). This of course means that the research responses cannot be directly generalised to the Muslim female population in the UK. However, as discussed later in the report, the majority of Muslim women (over 70%), were either satisfied or very satisfied with their maternity care. As for the significant minority who were not, the research provides a good sense of what is contributing to poorer outcomes. Such women were therefore deliberately chosen to be interviewed.

B. Effects of Covid pandemic on maternity services

Some of the survey respondents and interviewees had pregnancy and birth experiences during the Covid pandemic, which means that there is a risk that some of the data may be skewed. The Covid pandemic presented many challenges to maternity services such as minimising risks to mother, baby and staff as well as having to cope with staff shortages caused by illness and having to isolate. These pressures resulted in maternity services having to be adapted and modified, which could have impacted on the standard of care provided. Although the full effect on maternity outcomes is not fully understood yet, some women may not have been satisfied with their care because of the changes that were implemented.

Characteristics of Respondents

3.1 Overview



A total of 1022 surveys were completed and 37 women interviewed. Most women (98%) who responded to the online survey had singleton pregnancies. Only 2.5% indicated they had a disability with most indicating some learning needs. 94% of the women gave birth in the same locality in which they received antenatal care. The 6% who did not, either moved to a different region, came to live in the UK or moved between trusts or hospitals within same locality. An overview of the study participants is provided in **Tables 1-6** (demographics) and **Figures 3-9** (pregnancy characteristics and labour and birth outcomes).

3.2 Demographics of Research Participants

The ethnic make-up of the online respondents was fairly representative of the Muslim population in the UK, except for the Black African / Caribbean / Other (includes Black British) group, which was 5.5% and therefore half of what was anticipated. Therefore, to support this dataset a focus group was held with Somali women in Birmingham.

The majority of the participants (two thirds) gave birth between the ages of 26 and 35. Most of the women were highly educated having completed education to A level and above. In fact, two thirds were educated to graduate and post graduate level. Given their education level, it was not surprising to find that half of the women were in either lower or higher managerial or professional roles. One fifth were homemakers or carers.

The locations of the respondents reflected the geographical distribution of the Muslim population in Britain. According to the Census (2011), 76% of the Muslim population live in four regions: London, West Midlands, the North West and Yorkshire and The Humber and 67% of the online survey respondents came from those regions. Also, most of the women were born in the UK and 15% had been living in the UK for more than 10 years. Only a very small number of women were therefore new migrant women i.e. approximately 10% had only been in the UK for five years or less. As highlighted in the introduction chapter, new migrant women make up a significant number of maternal deaths in the UK (i.e. 34% of maternal deaths). The experiences of this cohort of study participants and migrant women interviewed can therefore provide valuable insights into what factors are contributing to their poorer outcomes.

Tab	le 1 -	Fthr	nicity
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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.

Table 2 - Geographical Distribution

Location	Census Data for Muslims % (2011)	Online Survey Respondents % (1022)	Semi-Structured Interviews % (37)	
East of England	5.5%	3.5%	2.7(1)%	
East Midlands	5.2%	6.3%	0%	
London	37.4%	27.9%	35.1% (13)	
North East	1.7%	2.8%	0%	
Northern Ireland	0.1%	0.8%	0%	
North West	13.2%	13.8%	16.2% (6)	
Scotland	2.8%	2.4%	0%	
South East	7.5%	11.1%	10.8% (4)	
South West	1.9%	3.4%	5.4% (2)	
Yorkshire & Humber	12.0%	9.5%	5.4% (2)	
Wales	1.7%	2.5%	0%	
West Midlands	13.9%	16.0%	24.3% (9)	

^{*}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

Table 3 - Age (during the pregnancy)		
Age	Online Survey Respondents % (1022)	Semi-Structured Interviews % (37)
16-17	0.1%	0
18-20	1.5%	0
21-25	14.1%	13.5% (5)
26-30	35.5%	37.8% (14)
31-35	30%	18.9% (7)
36-40	14.8%	13.5% (5)
41-45	3.5%	16.2% (6)
45+	0.5%	0

Table 4- Country of Birth		
Time period living in the UK	Online Survey Respondents % (1022)	Semi-Structured Interviews % (37)
All my life	70%	70.3% (26)
Less than 3 years	4.2%	0
3-5 years	6.2%	2.7% (1)
6-10 years	4.5%	5.4% (2)
More than 10 years	15.2%	21.6% (8)

Table 5 - Education Level		
Education Level	Online Survey Respondents % (1022)	Semi-Structured Interviews % (37)
No Qualifications	1.1%	0
GCSE	6.9%	10.8% (4)
A levels	11.2%	0
Post 16 certificate	7.5%	8.1% (3)
BA / BSc	45.8%	35.1% (13)
MA / MSc	20.9%	35.1% (13)
PhD	1.9%	5.4% (2)
Prefer not to say	4.9%	5.4% (2)



Table 6 - Od	ccupation
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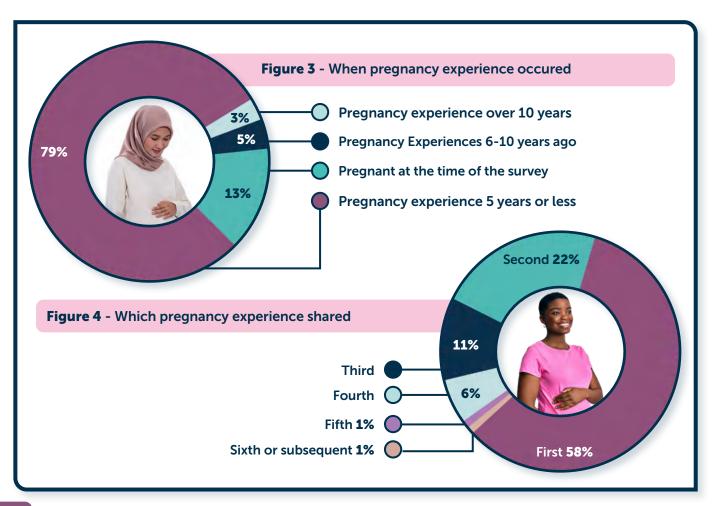
Occupation	Online Survey Respondents % (1022)	Semi-Structured Interviews % (37)	
Higher managerial, administrative and professional occupations	24.2%	24.3% (9)	
Lower managerial, administrative and professional occupations	20.1%	35.1% (13)	
Intermediate occupations	5.0%	10.8% (4)	
Small employers and own account workers	0.6%	0	
Lower supervisory and technical occupations	1.4%	8.1% (3)	
Semi-routine (sales, service, technical, operative, agricultural, clerical, child care) occupations	4.3%	0	
Routine occupations (sales, service, production, technical, operative, agricultural)	3.7%	0	
Student	1.6%	0	
Self employed	4.6%	0	
Never worked / long term unemployed	1.2%	0	
Home-maker, parent carer	22%	18.9% (7)	
Other	4.1%	0	
Prefer not to say	7.3%	2.7% (1)	

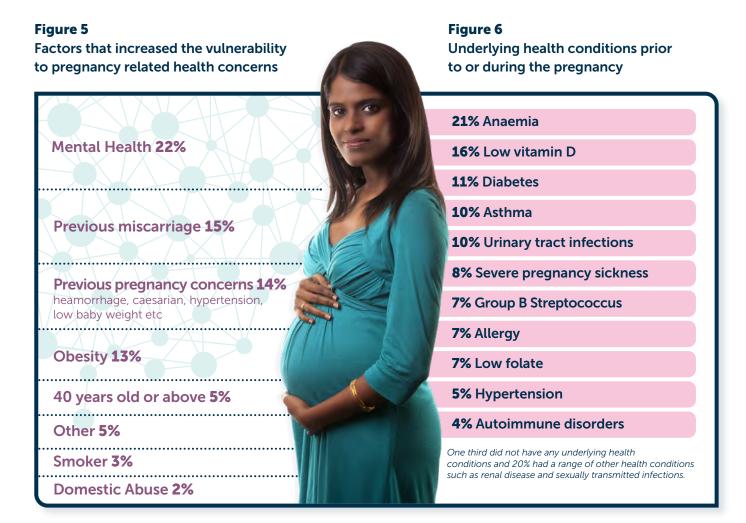
Note: Occupations of women ranged from doctors, pharmacists, teachers, solicitors, academics, social workers through to those working in the charity sector and supervisory roles to homemakers.

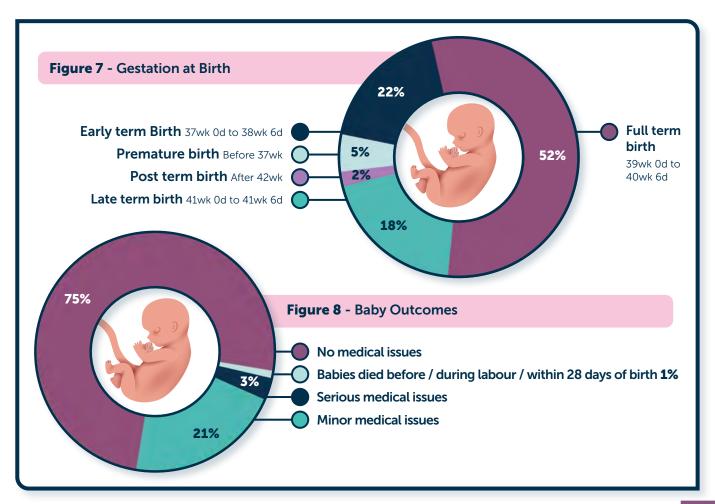
3.3 Pregnancy Characteristics

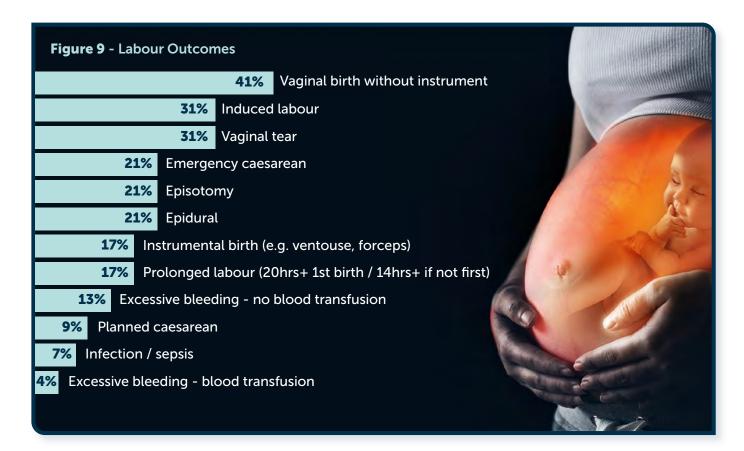
The vast majority, 941 (92%) had their pregnancy experiences up to five years ago (see Figure 1) and more than half of the women shared experiences about their first pregnancy (see Figure 2). A significant number, 130 (13%) were pregnant at the time of conducting the survey, while others had given birth during the pandemic (just over one third). Another 40% had their pregnancy experiences within the last five years prior to the pandemic. As most of the maternity experiences examined in this inquiry are recent, they will contribute to the better understanding of the current quality of maternity care provided to Muslim women particularly from minority ethnic backgrounds. However, as a significant cohort had their pregnancies during the Covid pandemic (approximately 50%), some of the findings may not be representative of the standard maternity care usually provided because services had to be modified, which may have resulted in both improved care in some aspects and poorer care in others. This will be discussed further in chapter 13.

Muslim women were presented with a range of vulnerability factors that could increase risk of pregnancy related health concerns and were asked to select as many of them that applied. About half of the women said they had no vulnerability factors while 20% indicated mental health, 15% previous miscarriage, 14% had and other previous pregnancy concerns such as haemorrhaging, hypertension and caesarean (see Figure 3). Women were also asked to select as many underlying health conditions that applied to them prior to or during the pregnancy. Two thirds indicated a range of conditions and the top health issues included anaemia, diabetes, low vitamin D, asthma and urinary tract infections (see Figure 4). A more in-depth analysis according to ethnic group is conducted in chapter 7. Of the 892 women who had given birth and their birth outcomes are shown in **Figures 3-9**. The rates of emergency caesarean birth (21%) induced labour (31%) and vaginal tears (31%) appeared high and will be analysed further in chapter 8.









4 Perceptions of Maternity Care

4.1 Overview

The women were asked to rate their standard of maternity care to find out their perceptions about the care received and so that the different aspects (i.e. antenatal, intrapartum and postpartum care) could be compared. The women who were pregnant at the time of the survey (13%) were excluded for this analysis. Although most women were satisfied with their maternity care, the level of satisfaction declined as the women progressed through their maternity journey. 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%). Although some rated their care as average, the differences became starker when examining the 'poor' or 'very poor' ratings. 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' (see **Table 7** for the breakdown).

Muslim women's ratings of postnatal care and intrapartum care not being as positive as antenatal care is in line with a national NHS survey of the general maternal population conducted in England.³⁴ However, the factors contributing to Muslim women's poorer experiences may not necessarily be the same as for the general maternal population. These may also vary within sub ethnic groups, which will be explored in this research.

Table 7 - Satisfaction Rating of Maternity Care							
How would you rate your care?	High standard of care	Good standard of care	Average standard of care	Poor standard of care	Very poor standard of care	Don't know / Can't remember	
Antenatal care	34%	36%	19%	6%	4%	0%	
Labour, birth and immediate post birth care	28%	32%	21%	9%	9%	34%	
Postnatal care	21%	33%	26%	10%	8%	2%	

Maternity care satisfaction levels were also compared for UK born women and migrant women, (who made up one third of the respondents). Although similar patterns emerged of lower satisfaction levels for intrapartum and postnatal care, there was a difference in views about antenatal care. A greater percentage of migrant women rated their care as 'poor' or 'very poor' compared with UK born women, which may suggest different level of care and / or barriers related to maternity information provision.

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The findings did also reveal some positive news - that maternity experiences have improved in the last five years compared with the previous 10-15 years, which may indicate some improvement in maternity services. For example, when examining responses of the cohort of 81 women who had their maternity experiences over five years ago, the percentage rating their antenatal, intrapartum and postnatal care as 'poor' and 'very poor' was double compared to those giving similar ratings in the last five years.

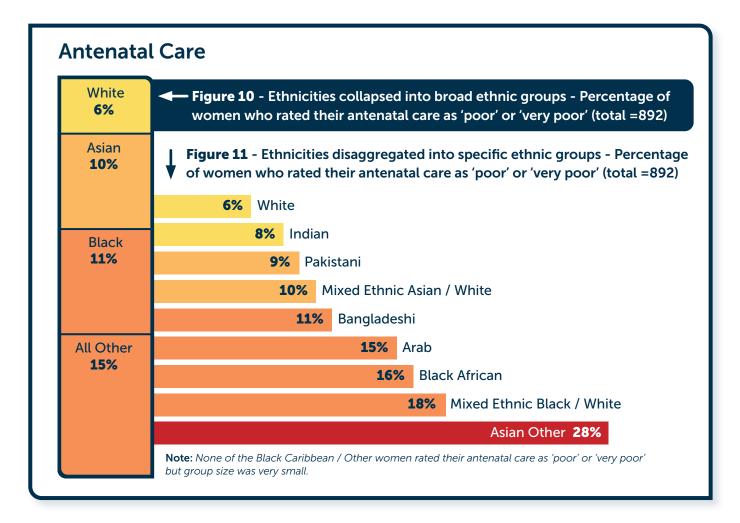
4.2 Perceptions of Maternity Care Between

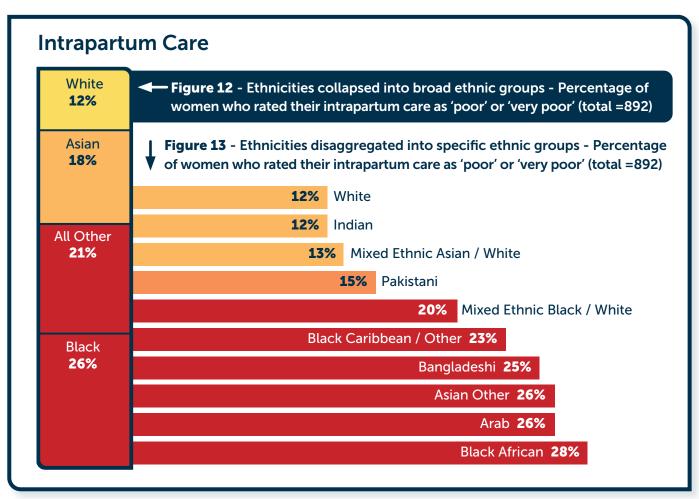
Sub-ethnic Groups

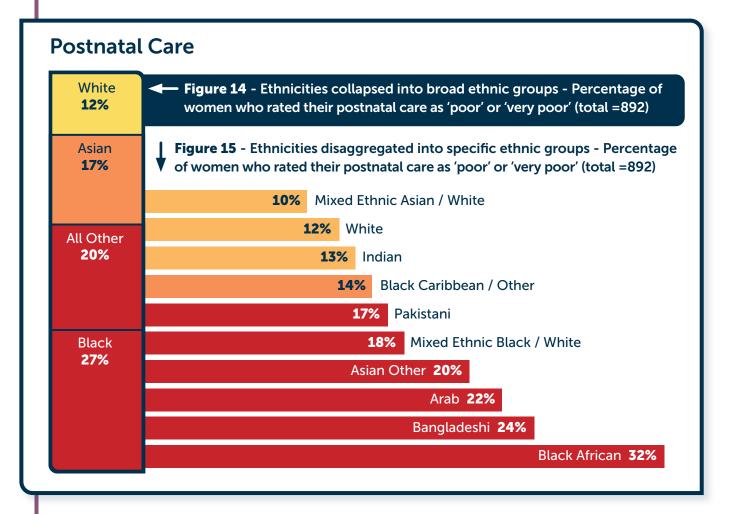
When the ratings were broken down by broad ethnic groups such as White, Asian and Black and then sub divided further, there were notable differences in perceptions of maternity care between the different ethnic groups (see **Figures 10-15**). A striking and concerning pattern emerged suggesting a potential hierarchy in ethnic bias in maternity care provision. Black women were most likely to receive poorer standards of care followed by South Asian women. However, Bangladeshi women were an outlier in the South Asian group as the standards of care they received was similar to that of Black women. White Muslim women were the most likely to be satisfied with their maternity care perhaps suggesting their White advantage contributed to better quality of care. The findings are perhaps not surprising as various maternity indicators highlighted in the introduction, such as mortality rates and other health outcomes are worst for Black women followed by South Asian women.

However, the data for Black and South Asian women are only part of the story due to the distinct variation in experiences within these broad ethnic groups. Other ethnic groups must also not be overlooked. A deep dive into the data also revealed that Arab and Asian Other women also stated 'poor' and 'very poor' satisfaction levels similar to those of Black women. These were: Arab women – antenatal (15%), intrapartum (26%) and postnatal (22%) and Asian Other women – antenatal (28%), intrapartum (26%) and postnatal (20%). Of the Black group, Black African women indicated poorer satisfaction levels compared to Black Caribbean women.

Within the South Asian ethnic group, Bangladeshi and Asian Other women were more likely to have poorer experiences compared with Pakistani and Indian women. However, the experiences of the Indian ethnic group were similar to those of the White cohort of women, which correlates to findings reported in another study which examined service use and perceptions of care in minority ethnic women from different groups compared to White women. The Indian ethnic group in the UK tends to be of a higher socioeconomic position relative to other South Asian groups such as Pakistanis and Bangladeshis, which could provide an explanation for the similarities between Indian and White women. However, the Bangladeshi and Pakistani women who participated in the survey only lagged slightly behind in their socioeconomic position compared to the Indian women - 70% of Indian and Pakistani women were educated to degree, masters or Phd level while 65% of Bangladeshi women had the same education levels. About half of the Indian women were in lower or higher managerial or professional occupations with just under half of Pakistani and Bangladeshi in the same positions.







4.3 Ethnicity Data and Inequality

When discussing the poor maternity outcomes of minority ethnic women, data is usually grouped into broad categories of 'Asian' and 'Black' women, an approach that misses the fact that the experiences and outcomes vary between the different sub-ethnic groups. 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. The data in this research demonstrates the importance of disaggregating maternity data to better understand the perceptions, experiences and outcomes for women during their pregnancies so that the quality of their maternity care can be improved. However, for this to happen accurate recording and reporting of ethnicity groups is required. It is essential that women self-identify their ethnicity and staff do not classify the ethnicity by appearance or according to their own interpretation. For example, one woman who had stated she was East African but of Indian origin discovered during one of her antenatal appointments that her ethnicity had been interpreted and recorded as Black African instead of Indian. Where small numbers of minority ethnic groups precludes analysis, efforts should still be made to scrutinise the data – not using the data at all may contribute to maternity harms.

Poorer healthcare experiences can be associated be with lower social economic status and deprivation. The responses were therefore examined for the 70% of the women who were educated to BSc / BA level and above and then those who were in lower / higher managerial or professional jobs. Their standard of care ratings was the same as those with a lower socioeconomic position, which implies other factors contributing to their poorer care.

Poor healthcare experiences could also be associated with whether women are born in the UK or are migrant women. Overall, around 30% of the survey and interviewees were born outside of the UK. When this data was broken down further, the following differences were noted: Arab, Asian Other and Black women had higher rates of being born outside of the UK, which were 55%, 51% and 73%. For Arab and Black women, half had lived in the UK for less than 10 years and for Asian Other women this figure was one third. For the other groups, women born outside the UK were as follows: Bangladeshi (12.5%), Indian (23%) and Pakistani (22.5%). It is interesting to note that of all the minority ethnic groups, Indian women had the highest satisfaction levels, yet they had similar percentage of women born outside the UK to Pakistani women and higher than for Bangladeshi women, who were one of the groups with lowest satisfaction levels. This indicates that women being born outside of the UK can only partly explain the differences in maternity experiences.

Other factors contributing to Muslim minority ethnic women's poorer experiences will therefore be examined in the subsequent chapters and will include: staff attitudes and whether they were treated with kindness and compassion; dignity and respect during care; were sufficiently informed and involved in decision making; provided with information; recognition and responses to change in condition and symptoms and action; women being believed etc.

4.4 Learning

Although most (70%) minority ethnic Muslim women receive high or good standard of antenatal care, the ratings of postnatal care and intrapartum care are not as positive. This potentially indicates a decline in attention to maternal health needs during these periods of care, which may be a result of not fully understanding risks associated with different ethnic groups. Some minority ethnic women, who are having the poorest experiences (such as Arab, Asian Other, Bangladeshi, Mixed Ethnic Black / White and Black African women), are even more invisible because ethnic groups are not disaggregated during data analysis, which means policies and practices that can improve their outcomes are not being identified.



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.



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.

Descriptions of Antenatal Care

5.1 Overview

Antenatal care is essential in protecting the unborn baby's health as well as the mother's physical and psychological health and includes monitoring, screening, diagnosing and preventing complications as well as providing support, information and health advice to the women. Although most women (70%) rated their antenatal care as 'high' or of 'good standard' and regarded it more positive than their intrapartum and postnatal care, this chapter explores more detailed perceptions of antenatal care to find out why 1 in 5 women found their care 'average' and 1 in 10 considered it 'poor' or 'very poor' (as already highlighted in chapter 4).

These experiences could explain why minority ethnic women have poorer maternity outcomes. However, as the antenatal period encompasses many issues, some of these have been pulled out and addressed in separate chapters such as early pregnancy loss, underlying maternal health conditions, domestic abuse, mental health, Covid pandemic adapted care, attitudes of healthcare professionals (including microaggressions) and making complaints about poor healthcare.

5.2 Access to Antenatal Care

5.2.1 Choosing services

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. Although hospital data is available such as rates for stillbirths, labour inductions, 3rd / 4th degree tears, emergency caesareans, haemorrhage etc., it is clear such information was not being accessed by women from racialised minority communities. These women need to be enabled to make informed decisions, which can only happen if there is greater awareness of the existence of this information, including how the adverse outcome rates vary with ethnicity. 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 likely contribute to poorer outcomes.

"There is a difference in medical care across boroughs, and we were not given the choice to select hospitals. I had no freedom to decide which hospital but I educated myself and knew I could choose, so I put my foot down."



MW12 - Arab Pregnancy experience in 2011, aged 27 "After conducting online research and becoming more aware of potential poor quality of care and treatment by reading abysmal reviews of one particular hospital, I decided to choose an alternative hospital."



MW34 - Bangladeshi Pregnancy experience in 2019, aged 40

"I felt bullied, belittled and patronised."

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:

"I was stopped from accessing the different options available for labour and birth. They said to me you need to know what you're doing. She spoke to me in a condescending way like I was stupid for wanting a water birth. Then she said you can only use water birth if you're not high risk. She made me feel like I'm high risk."



In another example, one interviewee said she wanted an elective caesarean birth to avoid third degree tears but felt it was a battle to get it. She said she even felt bullied in the process:

"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."



These experiences suggest some health care providers may be deliberately limiting where and how minority ethnic women give birth.

5.2.2 Antenatal Appointment Attendance

An overwhelming majority attended all of their antenatal appointments (94%), with 3% attending most of them, 1% attending few of them and 1% not attending any. However, these results need to be treated with caution and will not be applicable to all Muslim women because the majority who participated in the survey were of a higher socioeconomic status (see chapter 3). The reasons provided for late booking of antenatal appointments and missed appointments are listed in Box 1 and women of lower socioeconomic status are probably more likely to be affected by many of these factors.

Box 1 - Reasons provided for late booking of antenatal appointments

Poor health

This included both poor physical and mental health (e.g. severe pregnancy sickness, depression etc.,) which in some cases was so debilitating that women became bed bound.

Caring responsibilities

This was especially problematic for women with increased appointments for pregnancies that were considered higher risk.

- Previous negative healthcare experiences
 This included poor attitudes of staff and
 low standard of care.
- Travel

This included locations not being accessible or not having sufficient funds, especially when there were additional appointments (due to increased risks).

Unaware of pregnancy

Due to irregular menstrual cycles such as with women who have polycystic ovarian syndrome (PCOS).

Taking time off work

Some women found it hard to take time off work because of their employers.

Newly arrived in the UK

Having moved to the UK during the pregnancy from another country.

Changing GPs or hospitals

Due to unsatisfactory care or because of moving home, which was sometimes necessary to due to domestic abuse or because family support was needed.

Cancellation of appointments

By the midwife or doctors during the Covid pandemic, which included scans.

Self-isolation

Because a family member had tested positive for Covid or were shielding.

Being forgotten

Even though women had contacted their GP or hospital they seemed to get lost in the system and not contacted.

Delayed access to antenatal care ("late booking") is linked to increased mortality and morbidity for mother and baby. To reduce such adverse outcomes the factors contributing to 'late booking' and 'missed appointments' must be addressed. For example, some women explained that they had no local family support and partners found it difficult to take time off work to care for children especially for high-risk pregnancies where there were more appointments. Under current laws, a pregnant woman's partner has the right to unpaid time off work to only go to two antenatal appointments. Even though women have a legal right to take paid time off work for antenatal appointments, a few of the women said their employers made it difficult and were not understanding when they had increased appointments. Challenging employers led to further negative discriminatory treatment, which caused further mental distress.

Muslim women are already marginalised in the workplace, experiencing differential treatment because of their ethnicity and their faith. It is not unreasonable to suggest that they are more likely to also experience discrimination when they are pregnant even though pregnancy is also a protected characteristic. While discrimination in the workplace is not within the scope of this research project, the fact that employer policies and procedures can contribute to the poor health of the women and their babies is relevant. Women may not even be aware of their rights as pregnant employees and about obligations of employers to conduct health and safety risk assessments and allow paid time off to receive antenatal care. This information should therefore be provided in antenatal information packs at booking.

Although telemedicine has been common practice during the Covid pandemic, it was not preferred by pregnant women (as addressed in chapter 13). To avoid gaps in monitoring their pregnancies, women who are likely to miss some of their appointments because of poor health, should be identified in the system and offered phone appointments. Also, when women need to change GPs or hospitals during their pregnancies, healthcare systems should be designed to prevent women from being overlooked, as in this example, as it puts them at risk:

"I moved my surgery from one city to another after the 20th week but I was not referred to a hospital up till my 37th week. They'd come up with lame excuses. An email or letter referral can go through a technical fault once, twice, thrice... but more than that just seemed unreal."

(Online survey)

Some women are getting lost in the system even when they haven't changed healthcare service providers:

"I did not see my midwife for the first visit until after my 20-week scan. I complained 3 times about this as I was a first-time mum and this neglect of care was increasingly frustrating."

(Online survey)

5.2.3 Midwife Access

When women were 'booked in' some were unable to get hold of their midwives. Although staff shortages and sickness will have contributed to this, midwives not being accessible cannot be solely blamed on the Covid pandemic as this was also an issue for women prior to the pandemic:

"It was a nightmare chasing up the GP and midwifery team. Midwives didn't turn up. Waited two hours. I conducted a lot of research myself."



MW9 - Pakistani Pregnancy experience 2019, aged 29

Another woman also made a similar comment:

"Getting info from Google is much easier than calling around and trying to get hold of midwives"



MW5 - Pakistani Pregnancy experience in 2019, aged 21

One first time mother suffered from depression and sickness. When she experienced severe headaches, she became more worried but was unable to get through to her midwife despite numerous calls. Instead she was be passed around from one midwife to another. This neglect led to her changing hospitals where her care was much better even though it was during the Covid pandemic, which she described as follows:

"I was seeing my midwives in person, it was a different feeling. It's more inviting and less hostile. The midwives are friendlier and take more time with you, and they check-in with you."



MW3 - Asian Other Pregnancy experience in 2021, aged 30

5.3 Antenatal Information Provision

5.3.1 Written Information

Women should be fully informed during their pregnancies. Not having information can prevent women from enjoying their pregnancies and increase their risk of poor outcomes. Not being aware of what good care should look like will mean they will not be able to assert their rights or navigate the maternity system. Also, not being aware that they may be at a higher risk of certain health conditions (as discussed in chapter 7) and not recognising symptoms will mean they will not raise concerns. However, a consistent theme amongst survey respondents and the women interviewed was that they were not being provided with such information. In fact, there was a huge information gap and most women said they had to search various websites and download mobile applications. Every pregnant woman should have equal access to information but this was certainly not the case. Only a few women interviewed said they were given information packs. Some women said they were given a few leaflets but had to find the rest of the information they needed online.

Some of the interviewees said that information provision had been better in previous pregnancies and now it was just expected that women would just find it themselves because of the internet. Even the knowledge between the women who had found information online really varied with only a couple of women being highly informed about their choices, care pathways, informed decision making / consent and their human rights. Not surprisingly, first time mums were the most anxious when they did not receive adequate information. However, it is important to note that most of these women were from a higher socio-economic group. Those with limited skills in the English language or in literacy are highly unlikely to have access to such information thus exacerbating maternity inequalities further. Making all relevant pregnancy information available according to the specific needs of women and in different formats and languages will play an important role in reducing adverse outcomes for mother and baby. The main information sources used by the women (who responded to the survey) to meet their needs are listed in **Table 8**.

"First time, I was given lots of information booklets. I also got vitamins and iron. But the second time I got no hand outs and no tablets. The previous information was helpful as it made me feel less anxious."



MW25 - Pakistani Pregnancy experience in 2011, aged 25 and in 2016, aged 30 "I was given a few leaflets but not provided with information about monitoring foetal movements, nutrition or ICP. I spoke to friends and went online to find out. Mostly googled and used Bounty app."



MW36 - Bangladeshi Pregnancy experience in 2018, aged 23



Table 8 - Main sources of Maternit	y Information
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Table	8 - Main sources of Maternity Information								
Most p	opular sources								
64%	Bounty website								
64%	Emma's Diary								
63%	NHS website								
59%	Apps (Peanut, Mush, Phillips Pregnancy+, Bounty)								
56%	Friends and family								
Second	d 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.

5.3.2 Midwife Responses

Women said that they could not fulfil their information needs via their antenatal appointments either. Midwives were not providing explanations even when they were being asked questions. When midwives provided differing advice to the same question, it left women feeling confused and more anxious. South Asian women who are at a higher risk of gestational diabetes and thus pregnancy complications, were not being provided with the consistent and appropriate advice thus putting them at risk.

"I did not like was being told only to go to hospital when your waters break. If I had listened to that advice then I would have lost my baby. The midwives didn't properly explain when to go in."



MW35 – Pakistani Pregnancy experience in 2016, aged 25

"I was not asked how I feel or if I have any anxieties. It was my first baby and I was worried and had a lot of questions which every time I asked were not answered properly. I left my appointments feeling frustrated many times."

"Felt my queries were not dealt with properly. My blood pressure would be high and then given medication to lower then as soon as lowered I was allowed to go home without being informed reasons and the effects."

(Online survey)

(Online survey)

"There was no midwife assigned to me, it was just me, google and my friends and family. In the third trimester they also told me had diabetes. And had to do regular finger prick tests. Midwives don't know how to deal with diabetes. I found a Facebook group I joined which helped me control my diabetes." When she was informed that she had a Low PAPP-A, she was not provided any further information about its implications leaving her anxious and worried: "I had to research this myself, it meant that the baby may be small, and I may have a placenta issue. (When I discovered this), I started panicking at work, because they did not explain this to me."



MW18 – Pakistani Pregnancy experience in 2020, aged 30

"Felt like another pregnant women, a tick list presented. Questions raised but most of them did not have answers or were kept very brief or in some cases directed elsewhere." "When I needed answers regarding diet for gestational diabetes towards my due date, it was unclear. Information was contradictory between midwives and dietitian"

(Online survey)

(Online survey)

"I was seen by different midwives and eventually the midwife that took over had little to no experience or interest in her job. When my partner or I asked questions, she failed to give answers. I dreaded my appointments with her as she just didn't provide the care or reassurance that I needed. As I was near the end of my pregnancy, I was seen by another midwife who was so helpful, reassuring, gave useful advice and I also found out that the previous midwife had left her job. Her disinterest was very apparent and it was a relief to know that she was no longer serving any other pregnant women."

(Online survey)

"Never had consistent answers as I had different midwives every time."

(Online survey)

"My midwife kept changing and the ones I got did not provide me any good advice or reassurance I just kept being told to go online."

"I was told about my placenta being low lying and I need repeat scans but what risks involved was never explained I had to do my own research to understand what it all meant for me and my baby."

(Online survey)

(Online survey)

"I was not given nutrition advice or about symptoms to be aware of. This made me anxious as it was my first baby and had to find that information online. I used to read a lot on google and asked friends and family. When I had questions, I was not satisfied with the answers, there was no detail. I was just told 'don't worry everything is under control.' I did not feel informed. I was not told about monitoring baby movements by the midwives"



MW35 – Pakistani Pregnancy experience in 2016, aged 25

"I left my appointments feeling frustrated many times."

"The midwives were not very forthcoming when it came to listening to concerns. One midwife told me the foods I eat do not have an impact on my body. I found this very hard to believe especially as I was told I had gestational diabetes and was told I had to follow a strict diet to control my blood sugars."

(Online survey)

5.3.3 Antenatal Classes

Antenatal classes are also a good source of information to help prepare for labour and birth as well as how to look after and feed the baby. They can therefore be a vital source of reassurance, especially for first time parents. The courses can provide a better understanding of what will happen and the choices that will be available to make informed decisions about types of births, pain relief, complications and care pathways. Having this knowledge can therefore help women and their birthing partners to make informed decisions which can help to reduce poor outcomes.

However, the research revealed that this type of advice and support is not readily available and appears to be on the decline leaving women to resort to paying for courses themselves. For example, several women interviewed said there were no local classes and they had to resort to paying for the courses themselves. The women said they were aware of their privilege of having the education and the finances to be able to find alternative private services, which would not be accessible to other women. There were examples of women not even being made aware about the existence of antenatal classes

INVISIBLE

This means that while White and minority ethnic middle class women will be able to continue accessing the advice despite cuts in services those living in the most deprived areas will miss out. Minority ethnic groups will therefore be most impacted by the cuts in free NHS classes as they are over-represented in deprived communities and will be in most in need of the information. This provides an example of maternity policies and processes (i.e. cuts in services) that are exacerbating maternal inequalities because minority ethnic women are being denied information that would improve their pregnancy outcomes.

Even the antenatal classes that had moved online because of the Covid pandemic were not accessible to the women as they were not well advertised. Although online classes will not be accessible to all women (if they continue after the pandemic) because they may not be familiar with online tools, they can provide an opportunity to reach women who would not be able to attend physical classes. For example, some women felt unable to attend classes due to male presence, distance, caring responsibilities or poor physical / mental health. Both physical and online classes should also be adapted so they are more inclusive to meet the needs of women such as by being culturally sensitive and by providing them in different languages. For example, one White female Muslim convert who wears the face veil signed up for a virtual class but chose to keep her camera off, which was not acceptable to the host of the session. She was made to feel very uncomfortable in front of the other participants. She also commented that the classes were not diverse and the attendees were middle class White couples.

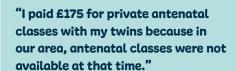
"My pregnancy was in 2018 and I found a lot of classes were cancelled."

(Online survey)

"I did not have any antenatal classes due to Covid, there were some online but they were very hard to find. There were also videos of antenatal classes that were put on the hospital website, which were helpful."



MW14 - Mixed Ethnicity (Other) Pregnancy experience in 2020, aged 30





MW1 - Indian Pregnancy experience in 2012, aged 28

"The antenatal classes were at the end of the second trimester and I privately paid for them (£65) - once a week for six weeks, because it was female only and private. Oid not go to NHS ones due to being mixed."



MW13 - Black Caribbean Pregnancy experience in 2019, aged 25

"I'm doing my own research, signing up to classes but there are no antenatal classes. I don't have access to any online, the information is not there."



MW3 - Asian Other Pregnancy experience in 2021, aged 30

"I attended private antenatal classes. I don't remember being offered any by my midwife via NHS."

(Online survey)

"Antenatal classes information was in the book – had signed up to them but unable to go as was too poorly during pregnancy."



MW36 – Bangladeshi Pregnancy experience in 2018, aged 23 "There were no antenatal classes locally, I was expecting to go to classes."



MW9 - Pakistani Pregnancy experience in 2019, aged 29 "I did yoga every week, which I privately paid for because there were no antenatal classes in my area."



MW1 - Indian Pregnancy experience in 2018, aged 34

"Registered for antenatal classes but nothing available in my area so went online and found online course on hyno-birthing and paid for that."



MW31 – Pakistani Pregnancy experience in 2021, aged 30

5.4 Quality of Routine Antenatal Care

To see how well the women thought they were supported by midwives and other health professionals during their pregnancy, their perceptions of antenatal care were explored. Notable themes emerged such as not feeling informed, not having continuity of care, not being listened to, concerns being ignored, having rushed appointments, care not being respectful and being pressured into decisions. Of 1022 respondents, 15% said they were 'somewhat dissatisfied' or 'very dissatisfied' that their risk factors (e.g. any existing health conditions or those developed during pregnancy) were identified, understood and dealt with appropriately. Also, 14% said they were 'somewhat dissatisfied' or 'very dissatisfied' that their complications during their pregnancy were identified and dealt with quickly and they were referred to appropriate care pathways. While these numbers may appear small, they amount to significant numbers of women.

Those who had their pregnancies during the Covid pandemic, were not keen on virtual appointments:

"I did not like telephone appointments as you cannot be open and honest. Seeing me in person they would be able to better see how I am and ask more questions and be able to physically examine me if required – which provides more assurance."



MW31 – Pakistani, Pregnancy experience in 2021, aged 30

Concerns about antenatal care during the pandemic, which included lack of access to midwives is covered more in depth in chapter 13. The lack of information provision during routine appointments has also been covered in previous sections.

When women were asked how easy they found it to ask questions and raise concerns to get more information during their antenatal appointments, 55% said it was very easy, 27% said it was somewhat easy. However, 1 in 10 women said it was 'somewhat' or 'very hard.' Main reasons cited for not being heard included:

- Rushed appointments and not having the same midwife;
- Not being listened to and concerns being dismissed (unless they were assertive); and
- Not being treated in a respectful or dignified manner.

5.4.1 Rushed appointments and no continuity of care

Seeing different midwives at the routine appointments left women feeling anxious and also confused because they would give differing advice as discussed earlier in this chapter. As discussed in other chapters, women find it difficult to disclose any mental health issues and domestic abuse they may be experiencing. If there was continuity of care women would have more confidence to put their trust in the midwife to make such disclosures. Whether the midwife was the same or a different one, women also said they were not provided with the opportunity to ask questions or raise concerns because the appointments were usually rushed. Not giving women sufficient time, especially those who may not be proficient in English and first-time mothers, may be contributing to not detecting early signs of potential pregnancy complications.

"I had support from the diabetes team but the actual baby doctor was always different and not all was nice or talk to you."

(Online survey)

"I felt sometimes the midwives did not fully understand my questions or concerns, and in their rush, not really answer me or put me at ease where I had concerns." "I was seen 4/5 different midwives rather than seeing 1/2 midwives. Some were more than happy to ask questions while others were quick to get you out the door."

(Online survey)

(Online survey)

"Everything is very separated, so you will have bloods at a different place, your scan at a different place, your midwife sees you in a different place. there is no continuity, everything is broken up, and the system makes you feel broken."



MW3 – Asian Other Pregnancy experience in 2021, aged 30

"Felt very rushed because it's my second pregnancy not as concerned whereas I'm having more issues and pains in this pregnancy than my first."

(Online survey)

"Staff always in rush to get you out of there as quickly as possible. Some questions and concerns of mine were left unanswered."

(Online survey)

"I felt my questions may be silly to ask but also with some appointments I felt rushed. The midwife had other appointments after me so I felt at times my appointments were rushed so I felt like I couldn't ask."

(Online survey)

"I was rushed out of my appointments and didn't get to ask my questions."

"I felt rushed at appointments. Midwife was never the same person."

(Online survey)

(Online survey)

"I felt like midwives didn't have time to answer my questions so I could ask only the most important one or two. And If I mentioned any bothering/continues pain the answer was always 'use paracetamol' even without asking further details or any other symptoms."

(Online survey)

5.4.2 Not listening and dismissing concerns

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 the antenatal care both by the survey respondents and the women who were interviewed. Healthcare professionals were described as rude, blunt, patronising, abrupt, dismissive, having negative body language, lacking experience and even as 'gaslighting.' Some of the experiences described amounted to women having treatment for which they had not given informed consent. These points should be carefully considered by the Royal Colleges and hospital trusts when planning training and they should examine whether there is a culture of such attitudes amongst some of their professionals. The care varied within the same setting and depended on which midwife or doctor the woman was lucky or unlucky enough to get.

"Some midwives made it hard for you to say no injections etc."

"I feel they don't want to listen to what I have to say."

(Online survey)

(Online survey)

"I felt I was not given the opportunity to ask questions. Hurried along and when concerns were raised around giving birth was told this was a conversation for another time - by then it had been too late." "The nurses, midwives and obstetricians who were quite dull/blunt were probably unbothered because the clinics were so busy, but the doctors who listened to me were from foreign countries, black, and Muslims."

(Online survey)

(Online survey)

"Some drs/midwives are rude and will laugh at some of the questions. They may have been midwives for a long time but we were first time parents."

(Online survey)

"I wasn't listened to and I was almost forced to have treatments I didn't want. I underwent procedures that were unnecessary because they used scare tactics." "Up until I met my actual midwife, at 28 weeks, I felt like I was just a box to be ticked for phone call appointments. Maternity helpline was always the answer."

(Online survey)

(Online survey)

"I had a particularly unprofessional and unhelpful midwife. In the last month of my last trimester, I had to go to the hospital several times and mentioned this and they changed me to a different midwife and from thereon in I had excellent service."

"My concerns seemed to be dismissed as my midwife was also pregnant and due before me so she seemed to have already 'clocked out', I then had temp midwives who covered until the new midwife started and she seemed very inexperienced."

(Online survey)

(Online survey)

"My midwife was unfriendly, and was not open to questions. She would cut me off at times and try to shut me down whenever I asked questions. She did not ask any questions about my mental health, despite my history of postnatal depression."

(Online survey)

"When I raised concerns, I felt as if they were dismissed and not taken further."

"Consultant did not listen and / or brushed it off, gaslighting all the way."

(Online survey)

(Online survey)

Interestingly, women said that they were only heard when they started to become assertive and vocal because they had learned from previous experiences:

"I sometimes felt rushed and sometimes felt that the midwives were not looking at my personal journey but lumping me with other pregnant women with gestational diabetes. They were at times unsympathetic to our experiences of an isolated pregnancy and it is only when I spoke up for myself they changed their tune."

(Online survey)

When women made midwives aware that they were informed and knowledgeable the standard of care improved:

"I expressed that I was medically underweight and concerned for my baby, but she laughed at me. When she knew that I had knowledge, she did things properly then onwards. They assume you don't know anything so they take advantage of you and do what they want however they want."



MW13 - Black Caribbean Pregnancy experience 2019, aged 25

5.4.3 Dignified and Respectful Care

During health conversations women encountered tones and phrases that have made them feel uncared for, disrespected, dismissed, not believed, judged and unwelcome. In addition to examples provided in this chapter, these are also covered in other chapters, particularly in chapter 14. Language matters and it is crucial that language and tone are inclusive and respectful. In addition, phrases that imply bias or that are stigmatising should be avoided, otherwise those already marginalised in the healthcare system are at risk of being excluded further as demonstrated by the experiences shared by the women throughout this report.

Some of the care provided to the women also lacked dignity and respect such as carrying out examinations without informing women about what was about to happen to them leaving them traumatised. Also, minimal consideration was given that examinations would cause women pain. Although pain and discomfort cannot always be avoided, women felt that healthcare professionals were unnecessarily rough in the way they handled them and felt they amounted to microaggressions, which are discussed further in chapters 8 and 14. However, these experiences also suggest healthcare professionals have become desensitised to women's pain and the needs of women and they are a recipient of care rather than a partner in the care that is given.

She was given a cervical exam by White female doctor — "I was given no warning. It was rough, very traumatic. There was no communication about what was about to happen. I flinched as I had sexual abuse in the past. I said I need a moment. She responded if you want to find out this is the only way. She carried on for another 10-15 mins but it felt like forever."



MW33 – Indian Pregnancy experience in 2020, aged 29 "In the third trimester I developed perineum pain in the groin and became bed bound. When I went to the hospital to get it checked out, a White doctor was incredibly rude and gave me an unnecessary rectal exam. I was crying and she said, 'why are you crying' in an aggressive way, rolling her eyes. I had my leggings around my knees and I was severely exposed and facing the wall. It was dehumanising and humiliating exam, she used a gel and she didn't offer any tissue, no privacy to put clothes back on. She made me feel like I was a nuisance, she then went off for 20-30 minutes."



MW7 – Arab Pregnancy experience in 2020, aged 25

Other examples of care not being dignified included being neglected during hospital admissions in the antenatal period:

"I had a horrible experience at the hospital and struggled to talk about it as I was left in vomit and diarrhea for a couple of hours."

(Online survey)

Examinations should be carried out in a sensitive manner. Antenatal appointments ought to be a safe space where women feel able to mention issues they would want considered during any examinations such as historic sexual abuse / violence. Women are unlikely to mention such issues if the healthcare professionals do not have compassionate attitudes:

"I am a victim of sexual assault (but not domestic abuse) and had to explain that up front, to ensure that I was handled sensitively."

(Online survey)

For example, other negative attitudes where the care was not respectful involved women feeling ridiculed or patronised. These behaviours suggest that professional development is required to challenge such attitudes and improve service user engagement and communication skills.

"I remember his attitude - I remember being spoken to like I was stupid, and this was a Muslim Asian male doctor."



MW1 - Indian

Pregnancy experience in 2012, aged 28

She told midwife early on when history was taken about the sexual abuse including anxiety about cervical exams, but felt it was disregarded: "The appointment was very short (less than 5 minutes). As had I anxiety, I had lots of questions but was unable to ask them. She was very abrupt on the phone. When I said I had questions, she said haven't you read the pack in a very patronising way. I was asked token questions such as 'is everything ok.' There was no space to ask questions. She was so dismissive and patronising that I ripped up my questions and I didn't want to ask them"



MW33 – Indian

Pregnancy experience in 2020, aged 29

"When I rang the midwife and said I'm in pain, she laughed at me and said 'you're having a baby of course you're going to be in pain.' I tried to complain, but never heard back."



MW9 – Pakistani

5.5 Ultrasound Scan Experiences



Ultrasound screening is part of routine antenatal care for pregnant women. However, a number of women complained about the attitudes of the sonographers. They were perceived as uncaring, which had a negative emotional impact on the women. From the examples provided below, further training is required. Some of the women who needed additional reassurances because of their experiences or because of the pregnancy information gap (discussed in the previous section), paid for additional private scans – an option that would not be affordable to all women. Some hospital trusts were charging mothers a small fee for the scan image of their baby, such as £5-6. While such a fee may appear small, this would disproportionally impact on women on low incomes who may be financially struggling, who would be prevented from having a memento of an important occasion.

"When I went in for my 12 week they were just really cold and dismissive."



MW23 – Asian Other Pregnancy experience in 2021, aged 30

"I didn't like the way the scans were carried out, she wouldn't even look at us (me and my husband, who had a beard). She was looking at the screen and said 'I need to concentrate' and held her finger up, when we asked a question. I did go for a private scan pre-birth and paid £95 for a scan."



MW9 - Pakistani Pregnancy experience in 2019, aged 29 "When I went for my 12-week scan,
I found the sonographer blunt, rude
and miserable. She made us feel
uncomfortable given it was meant to be
a happy moment for us. When I thanked
her she did not even respond. The only
nice thing she did do was give us a free
image of the baby as usually you are
supposed to buy a token for I think £5."



MW36 - Bangladeshi Pregnancy experience in 2018, aged 23

"I don't have that level of trust. That become more apparent with every interaction that I had at the radiography department; I just lost a lot of trust in it all which is a shame to say."



MW30 – White Pregnancy experience in 2021, aged 27

"She made us feel uncomfortable given it was meant to be a happy moment for us."

5.6 Antenatal Risk Assessment

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 some 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. The accounts provide evidence of near misses and stillbirths as a result of substandard antenatal care, from which lessons need to be learned to improve safety.

"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)

"I had to chase up including consultant appointments in order to get a plan but still had it after I experienced bleeding at 32 weeks. I felt lost in the system with almost no explanation."

(Online survey)

Pre-eclampsia is a condition that causes high blood pressure during pregnancy and after labour. It can be dangerous and even fatal if not treated. However, even when women presented with 'red flag signs' for pre-eclampsia were ignored, putting the lives of mother and baby at risk. One woman **(MW37)** interviewed was repeatedly dismissed by different midwives, which indicates a systemic failure rather than a problem with a particular midwife. If she had not become assertive then she and her baby could have died.

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."

There were numerous other examples of signs of pre-eclampsia being missed or ignored:

"I developed very swollen legs and feet as well as slight swelling in my hands but this was all dismissed as 'normal' even though I was unable to wear shoes and keeping my feet elevated did not help to subside this symptom. I was never checked for pre-eclampsia."

(Online survey)

In other examples, ignoring and not investigating 'red flag' symptoms resulted in stillbirths. In one harrowing case **(MW16)**, an investigation found that the failures comprised of staff errors as well as organisational procedures. The NICE guideline for safe midwifery staffing³⁶ defines a delay of 30 minutes or more between presentation and triage as a 'red flag event'. However, the mother was made to wait for three hours. Also, non-clinical staff who did not have the training to handle enquiries from pregnant women were handling calls on the triage service, thus contributing to the delay in care. Hospital trusts should not wait until such incidents occur or have 'near misses' before reviewing how its triage services are staffed. All hospital trusts should review their maternity triage systems and ensure they are staffed by a senior midwife and can be accessed 24 hours a day, seven days a week.

MW16 - Indian. Pregnancy experience in 2019, aged 35 (STILLBIRTH)



She was 10 days over her due date and over 41 weeks pregnant. At the antenatal appointment, the midwife measured her blood pressure as high. Despite signs of pre-eclampsia, she was sent home. She then called the triage service and spoke to someone (non-medical staff) in the morning who advised her to get some rest and call back later as it was early contractions. After she had rested she called back as she didn't feel the baby move. She then spoke to medical staff (midwife) who advised her to come in. There was a delay as her notes were mislaid and she had to wait in triage for 3 hours. By the time she was seen her baby had died. It took her three days to deliver her baby. When she asked the midwife for an epidural she was told she didn't need one. She said: "I felt unheard, and unseen."

MW11 -Bangladeshi. Pregnancy experience in 2006, aged 24 (STILLBIRTH)



"They didn't take note of when I was telling them there was green discharge (meconium).

They said it was normal and they sent me home. The baby had swallowed meconium and been poisoned, but they didn't listen to me when I told them about the discharge. After the baby died, the notes where she had written about the green discharge had mysteriously disappeared."

"I felt unheard and unseen."

Focus Group FG2 -Somali. Pregnancy experiences in 2012 & 2018 (PRETERM BIRTH & STILLBIRTH)

One woman had a preterm birth at 28 weeks and a previous stillbirth over 9 years ago because obvious unusual signs were not actioned or escalated: "I went to the hospital because I had tummy pains, the baby was not moving growth had halted but the doctors did not pick this up. At a hospital appointment they recorded protein in her urine, high Blood Pressure and a urine infection, but I was told to go back home and to call her midwife. Within a few days I started bleeding clots and ambulance had to be called. I delivered my baby but she was dead. Because of the huge amount of blood loss, I had to have a blood transfusion. When I went on the Friday my daughter had a chance, rather than dying in my belly."

There were also situations described which amounted to potential 'near misses.' Women with pregnancy complications were left chasing midwives and doctors to receive the care and medical treatment they needed to reduce the risk of harm: "

"The midwife didn't take it seriously when I had ketone present in my urine. Oismissed it as minor but the following week I was admitted to hospital with severe abdominal pains and dehydration with high ketone levels."

(Online survey)

In another example a woman felt her condition was downplayed:

"Blood test showed that I had low Papp-A, but I was not prescribed aspirin and was told that it is common for women to get low Papp-A and not to worry."

(Online survey)

There were also examples of treatment offered that could have been life threatening indicating sub-standard clinical knowledge. Fatal consequences were only avoided because women persisted and / or challenged healthcare professionals:

"The dosage of insulin they gave me was too high as I kept feeling very unwell and faint. Sometimes I could not function or even open my eyes, but every time I raised concerns, they kept blaming me. I think they made mistakes but kept blaming me, implying I was the one doing something wrong,"



MW21 – Pakistani Pregnancy experience in 2020, aged 31.

Even though South Asian women are more likely to have gestational diabetes compared to women from other ethnicities, numerous women gave examples of why they thought it was mismanaged:

"I was diabetic, which I found out in the 37th week after I finally got my referral to the hospital. The midwives at the hospital were shocked that the community midwives (who were from another hospital) referred me so late and did not bother to take my blood sugar tests themselves"

(Online survey)

Diabetes is also discussed in chapter 7 on maternal health conditions.

Women with previous negative pregnancy related outcomes were surprised that their maternity history was not considered in subsequent pregnancies. It led to them not receiving additional care and monitoring, thus putting them and their babies at increased risk. Where there were medical explanations for why something did or did not happen, the statements made by the women show that communication of such decision making was lacking leaving women confused, mistreated and uncared for.

MW15 - Bangladeshi. Pregnancy experience in 2021, aged 35



At 20 weeks she was told that she had a low-lying placenta and told there would be a follow up, but this did not happen. She was not provided with any explanations about what that was or its implications and had to find out through online searches. She then constantly chased up but to be told someone would call her back but again was ignored. When she started bleeding at 32 weeks she went to the hospital to be told that her placenta may be coming away. When she had to return to hospital at 34 weeks, a junior doctor advised her to take codeine: "The doctor told me to take codeine but didn't look at my notes that I was asthmatic. I looked again on google and the medicine leaflet in the box, and it said if asthmatic do not take codeine. He also told me that codeine doesn't go through placenta, but he was wrong, it does go through the placenta to the baby. He gave the wrong advice. I was so angry."

"They had not checked notes to see I had sickle cell, luckily my mum came in with me and told them."

(Online survey)

"I developed gestational diabetes quite late in my pregnancy (it was discovered at 32 weeks), by which point my baby had grown quite big. I felt that I should have been monitored more closely especially since I was at high risk of contracting GD because of other factors (ethnicity, BMI, family history). I was made to feel that it was my fault that my baby had grown so big, but in reality, the condition was diagnosed too late."

(Online survey)

It took her losing two babies in the second trimester for her to be given a higher level of consultant led care. "To prevent premature birth I was given steroids, pessaries and aspirin as well a stitch to close the cervix during the third pregnancy. I was also monitored more intensely. This level of care should have also been provided during my previous pregnancy and the outcome could have been different. Ouring my last pregnancy, my care changed again and was not provided with the same level of monitoring and had to ask for additional care."



MW2 – Pakistani Pregnancy experience in 2015, aged 37

"The consultants at my appointment were good, however they did not consider that my previous 2 pregnancies were also premature births due to early contractions. I had 2 previous emergency c sections. They did not plan that I was most likely to have this baby early too."

(Online survey)

Another recurring theme was the issue of the foetal growth. Sometimes, women were told their babies were either too big or too small:

"I find out when I got induced baby was measuring small and should have been offered extra growth scans."

(Online survey)

In another example one woman said:

"I wasn't made aware that my baby was big and only found out during labour,"

(Online survey)

Several women interviewed mentioned that they had raised concerns that their baby may not be growing, but they were dismissed. Although some women gave up and put their trust in healthcare professionals, others persisted in getting their worries taken seriously. Women felt that there was an inconsistency in the way foetal growth was being measured, including their natural biological body size and that of their spouses not being considered.

"When my baby was born she was 5 pounds, which is a low birth weight, the hospital midwives found it very strange that the antenatal midwife did not pick this up. But I was constantly dismissed at my appointments. I generally didn't feel much movement or kicks, but whenever I would ask about it the midwife would just say 'yeh yeh that's fine.' It wouldn't get explored. This was pretty much at every appointment and nothing ever was done."

"Another issue was when I used to go to community midwife, she would do fundal height with her hand, every midwife does it differently, and then she would say I'm off the charts and send me for a scan. That unnecessarily worried me, they would say the baby is too big it could be diabetes, they could really get rid of fundal height checks and just do scans. Every midwife does it differently and it's not accurate at all."



MW28 - Mixed Ethnic Black Pregnancy experience in 2019, aged 19



MW5 - Pakistani Pregnancy experience in 2019, aged 21

When she became worried about her baby's growth, she contacted the midwife. However, she was not taken seriously: "It was my first baby, they thought I was overthinking, and they brushed my concerns off." When she eventually persuaded the midwife to measure the baby, she told her 'the baby was fine.' When the midwife changed, she was told that although her baby was not growing (after being measured again) that her 'baby was fine.' As her concerns were not being listened, she logged her concerns on an app she was using in front of the midwife. When she got home she received a call for an appointment for a scan. The scan confirmed the baby was not growing and she may need an induction. She remained worried and the following week she contacted triage again to raise concerns of reduced foetal movements at which point she was induced. She believes that had she not persisted, decisions could have put her baby at risk: "I had to fight them to get advice, support, and the medical thing I needed at that time."



MW29 - Black African Pregnancy experience in 2021, aged 25 "It was shocking because all through my pregnancy I was concerned about baby's weight and they told me it was normal. I felt due to us being South East Asian/Chinese the fact that they kept saying my baby was going to be small. Then right at the end they said baby was not growing normal and I needed to have the baby right away. I asked why I needed to give birth right now and they said because they didn't want the placenta to stop working. They booked me in for a induction the following week and I was able to complete my shopping and also have my mum with me."



Another recurring theme (and also mentioned in other chapters) was the level of pain experienced by women not being taken seriously or believed resulting in them not being offered treatment to relieve symptoms. There seemed to be little (if any) understanding of how the discomfort and pain was impacting on the women's quality of life and mental health.

"I had issues with my hip and back but was always told it was just pregnancy. When it came to last trimester I could barely walk they finally discovered I had pregnancy girdle pain but it got to point they wanted to induce me at 40weeks. I then told them this pain was what I had during every pregnancy in last trimester I was told someone should have picked it up. I received no physio for it or pain relief until last two weeks of pregnancy and still suffer with the pain."

(Online survey)

"I should feel respected and safe. I suffered from pelvic dysfunction during the pregnancy which made everyday tasks extremely difficult. I was not referred to a physiotherapist who made to feel like I was exaggerating my discomfort even though no one checked me."

(Online survey)

"It was my first baby, they thought I was overthinking, and they brushed my concerns off."

5.7 Positive Antenatal Experiences

When women have good antenatal 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 already highlighted in chapter 4, 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. As the comments by both survey respondents and interviewees indicate, common good practice, not surprisingly, was related to attitudes and communication skills such as listening, being friendly and approachable, responding to questions and showing compassion.

"The midwives were really good at answering my question."

(Online survey)

"Healthcare professionals were easy to talk to and willing to listen"

(Online survey)

"The doctor who I saw was a specialist and she answered all my questions with concern. She was Asian and so I think spoke to me as a professional should, without stereotyping."

(Online survey)

"Body language (doctors) didn't seem opened so it's quite hard to make conversation (excludes my midwife, she's always been amazing and I refer to her for everything instead)."

(Online survey)

"I was under the care of the homebirth midwives who were based in the community centre in my area. I saw the same 2 midwives throughout my pregnancy and was able to build a good relationship with them. I asked questions and they sometimes referred me to others for further info."

(Online survey)

"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

"When I went in for reduced foetal movements I was constantly reassured by the onduty midwives — no matter what it is come in you would rather be sure, 'we would rather you come in and it be nothing, this is what we are here for it is our job and don't think about burdening us.' I found that an empowering and positive thing. They said listen to your body and your baby — you know your body best."



MW34 – Bangladeshi Pregnancy experience in 2019, aged 40 "The midwife was very nice, friendly and approachable."

"Midwife was very informative,"

(Online survey)

(Online survey)

She had experienced bleeding. Prior to her scan, the nurse was very attentive and listened to her acknowledging that she was anxious because of her history of miscarriages



MW17 – Bangladeshi Pregnancy experience in 2019, aged 39

"All my care was before Covid and I had excellent face to face contact with my midwife."

(Online survey)

She described her midwife (who was Black), as 'brilliant' and that she managed to balance between being professional and personable: "She managed to be really caring yet straight down the line." However, when her midwife was not available, she found the other appointments quite 'mechanical,



MW34 – Bangladeshi Pregnancy experience in 2019, aged 40

"I was with the home birth team. All appointments were at my home. The whole team were very approachable and passionate about providing the best quality care and advice."

(Online survey)

"It was difficult to get answers from my midwife and so I decided to change midwives. My 2nd midwife was lovely and it was easier to ask for information."

(Online survey)



5.8 Learning

High quality antenatal care is an integral part of improving pregnancy outcomes, but too many women from racialised minority communities are being failed during the antenatal period. Not being provided advice and personalised care according to the specific health needs of minority ethnic women is covered separately in chapter 7, 'Maternal Health Conditions.' When they receive poor care, it not only prevents them from enjoying their pregnancies but also increases their risk of having pregnancy complications and less favourable outcomes. While substandard care by health professionals (such as dismissing concerns and vital signs being missed) was contributing to poor health outcomes, many of the problems were due to systemic issues. For example, women being denied choice in where and how to give birth, there being huge gaps in information provision and cuts in services such as antenatal classes. These examples, plus healthcare staff not being accessible and appointments being rushed seem to indicate that maternity services are not being sufficiently resourced according to the needs of local populations. The inadequate resourcing may also be contributing to negative staff attitudes if staff numbers are not sufficient. Although factors contributing to staff shortages (such as working conditions, salary etc.,) must therefore be urgently addressed by the government, improvements in antenatal competencies (such as knowledge and communication skills) of the midwifery and obstetric workforce is also needed.



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



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.



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 minority ethnic women.



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.

Early Pregnancy Loss

6.1 Overview



Early pregnancy losses are those that end in the first trimester such as due to miscarriage or an ectopic pregnancy. A pregnancy loss at any stage of the pregnancy can be devasting for women, their partners and other family members. The emotional grief can be overwhelming particularly for women who have experienced previous pregnancy losses. Online survey responses and interviews showed that the care received by some of the women was not sensitive, compassionate and not in compliance of NICE guidelines. Some women had to wait because they could not access Early Pregnancy Units as they were not open in the evenings and weekends.

6.2 Ectopic Pregnancy Experiences

A few survey participants mentioned having ectopic pregnancies including one of the women interviewed who lost her fallopian tube because doctors failed to recognise she had an ectopic pregnancy despite presenting a number of times with severe pain. Her concerns and pain were dismissed leaving her at risk as rupture of her fallopian tube could have caused internal bleeding which could have led to severe harm or death.

MW33 - Indian. Pregnancy experience in 2019, aged 28



"I felt something was not right and had a lot of pain after discovering I was pregnant but it was a battle to get a scan as I had 'anxiety' written on my notes, so they kept saying wait. When I eventually went into the non-emergency walk in, I was told by a male Muslim doctor 'inshallah' (God willing) you will be fine. Although the words were comforting, I wanted to be taken seriously. I was sent home and returned two days later with continued sharp pains but this time told they did not have the equipment to do a scan and sent home again and advised to take a paracetamol. I was given an appointment for the Early Pregnancy Unit and this time given an internal scan / examination but told it's too early to tell if there is a pregnancy. My sharp pains continued to be ignored. They suggested "it's just ligament pain, it's is your muscle stretching getting ready for pregnancy." It was only when I returned for the fourth time, I was checked and told the fallopian tube had ruptured."

6.3 Miscarriage Experiences

Miscarriage is defined as the spontaneous loss of pregnancy before the foetus reaches viability. The term therefore includes all pregnancy losses from the time of conception until 24 weeks of gestation³⁷ and an ectopic pregnancy is one that grows outside the uterus (womb) and cannot survive, which also poses a serious risk to the woman.³⁸ Fifteen percent of the survey respondents mentioned having a miscarriage, which is lower than expected as 1 in 5 or 20% of pregnancies in the UK end in miscarriage (according to the Tommy's website). However, this figure is unlikely to accurately represent the proportion of women who had experienced a miscarriage or ectopic pregnancies as they may have chosen to focus on their other pregnancies in their responses. About 25% of the women who participated in in-depth interviews had had miscarriages, with many experiencing more than one.

Lack of compassion and insensitive care was a recurrent finding as highlighted by some survey comments.

"No one in the NHS cared about my previous miscarriage. I'm still waiting for someone to apologise for how I was treated when we discovered my missed miscarriage when I had my scan at 13 weeks, my baby had died at 9 weeks. I went in and she said are you excited to see your baby and within minutes it was the 'product of conception,' is 'dead' and it was never a baby. I was made to wait in the room adjourning the scan room and had to listen to 3 other couples have their happy scans. I was treated poorly when I explained that due to forceps in my 1st labour my vagina hurts in sex and so it would hurt when they put the tablets in my vagina to make my baby leave my body and was told to 'get over it,' it doesn't hurt really. I never got a picture of my baby. My options for losing my baby were go home and go through a pain like labour or stay in the hospital next to newborn babies. I was promised by my doctors I would get extra and earlier scans in my next pregnancy it never happened they didn't care."

(Online survey)

Such attitudes are unlikely to be isolated incidents; several of the women interviewed also provided similar examples of insensitive care. Other themes included women not always being provided with options of medical treatment to empty the uterus completely and being expected to expel the pregnancy alone at home, not being provided with information on what to expect nor guidance on how to dispose of the foetal tissue. This caused emotional distress and anxiety and also led to women feeling unprepared and unable to dispose of their foetus in a dignified manner. Some of these experiences have been highlighted in the case studies, which includes being made to wait hours to be told again that a miscarriage had occurred with no additional information provided.

MW4 - Bangladeshi. Pregnancy experience in 2015, aged 37



She was given a scan after reporting bleeding but told to go home afterwards and not offered a 'dilation and curettage' procedure. Although she was checked weekly, the foetus did not expel until three weeks later, which she felt had put her at risk of infection: "There were contractions and one big push, the sack came out, it was horrific. It was on my mum's bathroom floor. I flushed it down the toilet. The pain was horrific. They gave me a scan after to check it all had come out but I had to miscarry alone and that was devastating."

MW4 - Bangladeshi. Pregnancy experience in 2020, aged 42



When she had bleeding, her GP referred her to the EPU, which told her she could not come in because of Covid and to miscarry at home adding 'you've done this before you can do it again.' This judgement was made without confirming she was miscarrying. She was only invited to come in after she paid for a private scan and an obstetrician consultant friend phoned them on her behalf. However, despite the healthcare staff not being sure whether there was still a pregnancy, they insisted on giving her methotrexate. According to NICE guideline on Miscarriage and Ectopic pregnancy, Methotrexate should only be offered when there is a definitive diagnosis of an ectopic pregnancy, and a viable intrauterine pregnancy has been excluded. "They were really pushy with the methotrexate. They didn't know if it was ectopic or not but yet still they opted for methotrexate. It was not explained to me. If it was a viable pregnancy, they would have killed the baby. I went home and had another expulsion few weeks later and had a scan afterwards."

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.

MW25 - Pakistani. Pregnancy experience in 2011, aged 25



When she suspected having a miscarriage and phoned in for advice, she was met with a hostile attitude: "I started contracting at home and bleeding and was scared. Blood clots were coming out. When I called the miscarriage unit, the nurse said: 'Do you want me to take you in so I can change your bloody sheets and I am not going to change your bloody sheets. You stay home. You will be fine with it."

A family member was so angry about the tone and language used that he went to the unit to complain. However, the line manager defended the nurse. An apology was only issued when the matter was escalated to senior management and the family mentioned considering legal action. As only a verbal apology was issued, it was unclear whether any genuine attempts were made to learn from the incident and prevent future incidents. The woman felt the tone and language used was because of her accent - she had newly migrated to the UK but was highly educated to degree level and fluent in English.

MW32 - Black African. Pregnancy experience more than 10 years ago, aged 20s



She was told her bleeding was due to an ectopic pregnancy and that she needed to undergo surgery otherwise her life was at risk. However, after waking up from the anaesthetic she was told that the pregnancy was fine and it was not ectopic. She returned home but started experiencing really bad period pains. Although she contacted the hospital several times within two weeks, she was not invited to come in and instead advised to take a paracetamol. Two weeks later she miscarried and blames the unnecessary surgery. "I started bleeding very heavily; there was a pool of blood on the floor. I got an urge to push. I sat on the toilet (not knowing what to do) and the baby just dropped in the toilet (it was around 15 weeks). I could not catch my baby. I could see everything. I could see its human features. I tried to put my hands in the toilet collect it but kept slipping out of my hands." When reporting what happened to the hospital she said they called her in to check all foetal tissue had been expelled. However, she said she refused to go in and preferred to risk having an infection because she no longer trusted healthcare professionals and continued to mistrust them in her subsequent pregnancies which included another miscarriage: "I was worried they would take out my womb and then say it's a mistake." She found her experience deeply traumatic and was visibly upset when recalling it.

MW36 - Bangladeshi. Pregnancy experience in 2018, aged 23



When she went to the Early Pregnancy Unit at 12 weeks with heavy bleeding she waited for one hour before being given a scan. After being informed about the miscarriage, she was made to wait a further 2.5 hours to be told the same thing by a doctor in a conversation lasting only a few minutes. She was not given options such as 'dilation and curettage.' As she was not aware this procedure existed she could not ask for it: "I went home and let it happen naturally. After 3-4 days, I had contractions and it came away and then another few days later I had another large clot come out. I called the EPU but they said you will be ok and did not offer to check me or provide advice about symptoms to be concerned about. I felt forgotten. It was very hard as I had not family support (as they lived in other cities)."

"If it was a viable pregnancy, they would have killed the baby."

6.4 Standards of Care

According to the NICE guidelines for managing miscarriage and ectopic pregnancy,³⁹ all women who are given care for early pregnancy complications should be:

- treated with dignity and respect;
- provided with oral and written information;
- be supported in a sensitive manner;
- informed about what to expect during the course of their care and recovery period; and
- provided a choice in how they want to manage the miscarriage:
 - expectant management (waiting for the miscarriage to happen where tissue passed out naturally)'
 - medical (medication is taken to pass out the tissue); or
 - surgical (surgery is used to remove remaining pregnancy tissue).

So why are some women not provided with options for treatment and expected to and even encouraged to go home and expel the foetal tissue at home? Questions arise whether such actions are related to saving costs and bed spaces and, whether such policies disproportionately impact on the care of certain minority ethnic groups because they are less likely to complain. If this is the case, it could amount to systemic sexism and /or racism. While this question cannot be conclusively answered here, it should be considered when reviewing maternity care. Providing a simple leaflet with advice on how to collect and dispose of the foetus would go a long way towards minimising the trauma for women. Even simple advice, such as placing a bowl in the toilet to collect the foetus so it can be disposed of in a more dignified manner, such as burying it in the garden, would be helpful for those who wish to do this. An example of good practice found online included an information leaflet by the Liverpool Women's Foundation Trust, 'Disposal of pregnancy remains following miscarriage at home'.⁴⁰

Pregnancy losses are traumatic events, whether it is their first experience or they had a previous experience, and affect women differently. Pregnancy loss can lead to grief, anxiety and / or depression which can impact the woman's work life and her ability to fulfil her caring responsibilities. If women are truly at the centre of care, pregnancy loss would not be minimised or dismissed and women would be screened for mental health problems. Additionally, if needed, women should be provided with psychological support and information for early pregnancy loss bereavement care (which should include culturally / faith sensitive options). However, the women interviewed were shown little or no empathy and none were asked about their mental health or provided with any information on bereavement services:

"I was given no space to grieve. I was given the news and then sent back to the waiting room to cry in front of everyone."

(Online survey)

6.5 Learning

Some women were not listened to resulting in misdiagnosis, causing unnecessary avoidable pain and suffering as well putting lives at risk, for example, signs of an ectopic pregnancy being missed. Other themes noted in early pregnancy loss care included microaggressions, lack of compassion, stereotyping (including those with poor mental health labelled as overreacting), lack of dignity and respect and care pathway options for managing miscarriage being denied. These factors prevented women from making informed decisions and contributed to increased distress and trauma as well as amounting to discrimination at both an individual and systemic level.



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.



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.

Maternal Health Conditions

7.1 Overview

Pregnant women with health conditions have increased risk of pregnancy complications and may require additional support and closer monitoring. As already highlighted in chapter 3, the survey respondents indicated they had the following health conditions: anaemia (21%), low vitamin D (16%), diabetes (11%), asthma (10%), urinary tract infections (10%), Group B Streptococcus (7%), severe pregnancy sickness (8%), low folate (7%), and hypertension (5%). A breakdown by ethnic group is presented in **Table 9** and key trends noted from the survey data are discussed in the following sections. Some of these and other health conditions are discussed in depth in the following sections. Women also had other comorbidities - 13% indicated obesity (body mass index of over 30) and 5% said they were 40 years and above during the pregnancy.

For some of the health issues, there was an ethnic variation in prevalence, with White Muslim women being least likely to have the health conditions listed in the survey. 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. Another consequence of poor physical health during and after pregnancy can be poor mental health.

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%

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

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

7.2 Anaemia

One fifth of the 1022 survey respondents said they were anaemic. Several of the women interviewed mentioned they had iron deficiency anaemia when they became pregnant. Anaemia therefore appears to be quite common in minority ethnic women. This finding is supported by a study in Newcastle Upon Tyne (although it is two decades old) which reported that anaemia was common among women of South Asian and Chinese ethnic origin and suggested the prevalence in Black Caribbean, Indian, Pakistani and Bangladeshi women was about three times higher than the general population.⁴¹

There is an association between maternal anaemia and poor maternal and perinatal outcomes including increased risks of low birthweight, preterm birth, perinatal mortality, neonatal mortality, increased risk of haemorrhage, and decreased ability to tolerate blood loss, leading to circulatory shock and death. 42,43,44 Anaemia also increases susceptibility to infection. As the prevalence of all of these complications is higher amongst Black, South Asian and other minority ethnic women, anaemia may partly provide an explanation for these. For example, four (of the 37) women interviewed, mentioned severe blood loss. Of the 1022 survey respondents, 13% said they experienced excessive blood loss and 4% said they had severe blood loss and needed a transfusion.

It is vital that anaemia is identified and treated during early pregnancy. However, during interviews, women said that although they were advised to take supplements, only some of them were given these free of charge; others were advised to purchase them. Although women seemed to be aware of the importance of taking supplements, they appeared unaware of the risks of anaemia or the dangers associated with deficiencies of vitamins, minerals and nutrients (such as vitamin D, folic acid etc). Better educational information about these could therefore potentially contribute to improved outcomes so women take greater care in maintaining their nutrition throughout the pregnancy.

7.3 Low Vitamin D

There was a large variation in vitamin D deficiency amongst the different groups of women surveyed. Arab women were most likely to have low vitamin D (almost 1 in 3), followed by Pakistani and Bangladeshi women (almost 1 in 5). Vitamin D deficiency increases the risk of pre-eclampsia, gestational diabetes, preterm birth, and low birth weight - complications which are already associated with women from racialised minority communities. To prevent health risks to the mother and her baby, women from racialised minority ethnic communities at higher risk of vitamin D deficiency should be routinely screened during early pregnancy and given nutrition advice and prenatal vitamins. If the same general advice and treatment is being provided to all minority ethnic women (because they are all deemed as higher risk groups), without any testing, then those women who are extremely deficient in vitamin D will not be receiving high enough doses as the dose of vitamin D in over the counter supplements is not high enough to treat vitamin D deficiency.

7.4 Low Folate

The survey responses indicated that Pakistani and Arab women were slightly more likely to be low in folate compared with women from other racialised minority communities, which may be linked to lack of awareness of the importance of taking folic acid when planning a pregnancy. Risks associated with folate deficiency include placental abruption (where placenta separates from the wall of the uterus before birth) and neural tube defects in the baby (birth defects of the brain, spine, or spinal cord). Despite the high educational levels of the women interviewed many did not mention taking supplements prior to their pregnancies. Pre-conception advice campaigns on the importance of folic acid and other vitamins, minerals and nutrients should target Black, Asian and other minority ethnic women particularly those with lower educational levels.

7.5 Group B Strep

Group B Streptococcus (also known as GBS or group B Strep) a normal bacterium which is carried by 20-40% of UK adults, most commonly in the gut and in women in the vagina. Being a carrier is usually without symptoms or side-effects. Although most pregnant women will not be affected by it, there is a small risk that a woman carrying GBS during pregnancy can cause miscarriage, premature labour or stillbirth, outcomes which are already associated with women from racialised minority communities. GBS can pass to the baby around childbirth and can cause serious life-threatening illness in the baby, including sepsis, pneumonia and meningitis, and even death. Most newborn babies can be protected by giving intravenous antibiotics in labour to women who are carrying GBS.

The RCOG Guidelines states that although GBS carriage rate varies among racial groups, the highest rates are seen in people of Black African ancestry and the lowest in people of South Asian ancestry.^{45a} However, the survey responses showed that Indian women followed by Bangladeshi women were most likely to be carrying GBS. The lower survey response rate from Black women probably explains why GBS was not markedly high in this group. The slightly elevated rates amongst Indian and Bangladeshi women compared to the average response rate cannot be overlooked. Could the RCOG guidance be resulting in GBS being missed in South Asian women because they are considered unlikely to have it?

Data from Public Health England found the highest rates of group B Strep infection in babies aged 0-90 days in black (1.10/1000), Asian (0.94) and Chinese/other (0.92) infants. The rates were lower in White (0.81) and mixed race babies (0.60). However, these groups mask significant variance – within the Asian group, the rates in Bangladeshi and Pakistani babies were highest, and lowest in Indian babies.^{45b}

GBS can cause other infections including infections in the urinary tract. Symptoms of other infections should therefore not be ignored as they can be an indicator of GBS. One Black first-time mother reported having symptoms of a urinary tract infection but was repeatedly dismissed every time she raised concerns even though she belonged to a racial group considered most likely to have GBS. Dismissive attitudes by the midwife potentially put the baby's life at risk.

MW29 - Black African. Pregnancy experience in 2021, aged 25



She started to have severe itching a couple of months before she was due to give birth. However, when she told the midwife, she was told it was 'nothing' and it was 'normal' and did not arrange for any tests to be done. This left her very worried so she started looking up information online and contacted the midwife again with her symptoms. She was dismissed again and told to 'stay off the Internet' and 'not to believe everything' she was reading. Eventually with persistence her urine was tested. She was tested positive for GBS and informed she would need to take antibiotics before she gives birth.

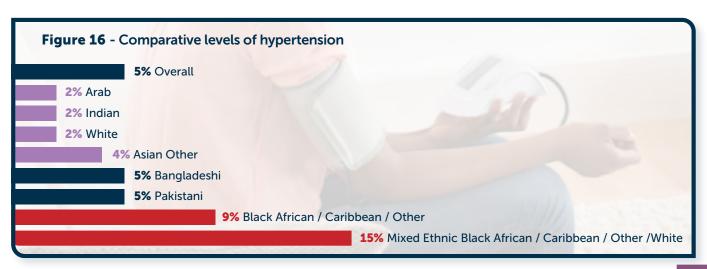
Currently testing for GBS is not routinely offered to all pregnant women. However, infections and consequent poor outcomes could be prevented if women who are most likely to be carriers (such as those identified in this research) are identified and provided with information about risks and options for treatment so they can make an informed decision. Currently these women are unlikely to be aware about their increased risk. Further research should be conducted to confirm if women in minority ethnic groups in the UK are more likely to carry GBS and whether their babies are at higher risk of developing GBS infection. Interestingly, a study led by the London School of Hygiene & Tropical Medicine in the UK has found that India has the highest number of pregnant women worldwide who carry Group B Streptococcus, which causes nearly 150,000 stillbirths and infant deaths globally every year.⁴⁶

7.6 Urinary Tract Infections

The survey showed that Bangladeshi women were most likely to have urinary tract infections (17%) followed by Black African / Caribbean / Other women (11%). Pregnancy causes many changes in the woman's body that increase the likelihood of urinary tract infections. As these infections may lead to preterm labour and low birth weight (complications already associated with these groups of women), additional screening should be considered for these women accompanied by more targeted awareness raising so they do not ignore symptoms.

7.7 Hypertension

The survey responses showed that White, Indian and Arab women were least likely to have hypertension (Figure 16). Compared to these groups of women, Bangladeshi and Pakistani women were two times more likely to have hypertension, Black (African/Caribbean/ other) women were 4.5 times more likely but mixed-race Black (African, Caribbean, other/ White) women were 7.5 times more like to have the condition. The high rates of hypertension, particularly in Black and Black / White mixed-race women may explain their higher mortality rates because high blood pressure can cause pregnancy complications such as pre-eclampsia, eclampsia, stroke, the need for induction (giving medicine to start labour), and placental abruption; all of which can put the mother's and baby's life in danger. Interestingly, the differing hypertension rates between the groups of women corresponds quite closely to the maternal mortality – South Asian women are two times more likely to die and Black women 4-5 times more likely to die during pregnancy or the post-partum period. Early detection of high blood pressure is vital in improving management and outcomes for these women. These 'high risk' women should therefore have heightened antenatal surveillance and enhanced pregnancy management. More regular monitoring and providing equipment to self-monitor could help achieve this.



7.8 Diabetes

The survey results found that Bangladeshi women and Asian Other women were most likely to have diabetes followed by Pakistani women compared to other groups of women. According to the data, these women were around two times more likely to have diabetes compared to Indian, Black and White women. The findings were broadly in line with research which already suggests that diabetes is more common in the South Asian population in the UK. Women from the Asian Other ethnic group being as likely to have diabetes as some of the South Asian women was an interesting finding. This perhaps confirms findings of a study that analysed routinely collected data from 2004 to 2012 from a maternity unit in London, which suggested that East Asian women appeared to face a similarly high risk of diabetes to South Asian women.⁴⁷

Gestational diabetes occurs when hyperglycaemia (high blood glucose levels) occurs during pregnancy. It is common condition but varies with ethnicity - 15% of women with a South Asian heritage may develop this complication whilst White women may only be affected in 3% of cases. In most cases it can be managed through diet and exercise with only small numbers requiring insulin. Gestational diabetes raises the risk of high blood pressure, preeclampsia, large-for-gestational-age newborns, caesarean births, preterm birth and stillbirth. Also, women with gestational diabetes are also more likely to develop type 2 diabetes after giving birth.

The risk of adverse outcomes can be reduced if the condition is detected early and managed well. However, early detection will only be successful if appropriate thresholds (according to a woman's ethnicity) are used for assessment. For example, analysis of antenatal data (2007-11) from Bradford Royal Infirmary suggested lower thresholds were required so that greater numbers of South Asian women could be diagnosed.⁵⁰ This does not appear to be taking place and as the interviews with women revealed, the standard of their care varies and is not personalised according to their risks.

MW22 - Bangladeshi. Pregnancy experience in 2020, aged 42



Towards end of her pregnancy, the woman was told by midwife that her sugar level was very high. However, when she asked how high, the midwife did not know and responded by saying she would get back to her but failed to so do. Not knowing left the woman anxious and worried, especially as she had gestational diabetes and caesarean births in her previous pregnancies. During her previous pregnancies she had appointments with an obstetrician. Any appointments given were cancelled and she was always chasing to be seen. The first time she saw a doctor was on the day of her caesarean birth. Although this pregnancy was during the Covid pandemic and maternity services were modified, she was a high-risk case. Given her previous history and other risk factors such as age, she should have been better managed. The standard of care put the mother and baby at risk of adverse outcomes.

MW21 - Pakistani. Pregnancy experience in 2020, aged 31



She had her pregnancy during the Covid pandemic, during which she developed gestational diabetes. She had to self-monitor her blood sugar levels four times a day. She found this difficult because she was a single parent with young children including one who had special learning needs. She also felt that the dosage of insulin give was too high as she kept feeling very unwell, weak and faint. However, during her antenatal appointments she said she would be told off rather than be listened to about her concerns about her health: "Sometimes I could not function or even open my eyes, but every time I raised concerns, they kept blaming me. I think they made mistakes but kept blaming me, implying I was the one doing something wrong." Dismissing her concerns put the mother and her baby at risk of adverse outcomes.

7.9 Asthma

Arab women, Asian Other women and mixed-race Black / White women were most likely to have asthma according to the survey. Poorly controlled asthma can increase the risk of high blood pressure and therefore preterm birth. Other complications can include having babies of low birth weight and restricted growth. Women should be supported to create an asthma management plan that should include avoiding triggers and medication. As mixed-race Black / White women are already at higher risk of hypertension, this should also be considered in any care plans.

7.10 Hyperthyroidism

When enquiring about existing physical health issues, some of the women surveyed revealed they had an under active thyroid (hypothyroidism). Although a specific question was not asked about this health condition, several women chose to mention this in the comments box. Inadequately treated hypothyroidism has been associated with negative pregnancy outcomes such as high blood pressure, anaemia, increased risk of miscarriage, premature birth (before 37 weeks of pregnancy), or even stillbirth. According to the British Thyroid Foundation, women with hypothyroidism are likely to need higher doses of their medication to reduce the risk of pregnancy complications. ⁵¹ Given the negative experiences of minority ethnic women already discussed and the way that their concerns may be being dismissed, there is a worry whether something like this would be recognised given that it is not a common condition.

7.11 Severe Pregnancy Sickness



Although nausea and vomiting in pregnancy (NVP) is a very common symptom that affects 50-90% of pregnant women, between 0.3% and 3% of pregnant women experience excessive nausea and vomiting.⁵² Survey data showed higher than the average prevalence rates - 80 women (8% of the respondents) reporting they had hyperemesis gravidarum (HG). The data confirms findings of a study which found that Black, Asian, and minority ethnic women are disproportionately affected by HG. The research showed that these groups of women are not only more likely to be affected and but also have more severe symptoms and that young age, socioeconomic deprivation, nulliparity (woman who has not given birth to a child), a female foetus, multiple pregnancy, history of HG in a previous pregnancy, thyroid or parathyroid dysfunction, hypercholesterolemia (high cholesterol) and Type 1 diabetes are all risk factors for HG.⁵³ Of the 37 women interviewed, seven (19%) said they had HG and that the experiences were often traumatic, sometimes requiring hospital admission. Some of the said they even contemplating suicide or ending the pregnancy because of the extent of their suffering.

MW4 - Bangladeshi. Pregnancy experience in 2019, aged 32



Despite telling her GP, she was not informed that medication could be prescribed. As she thought there was no help available and she had to just endure the severe sickness as she had during a previous pregnancy. She started to see specs of blood in her vomit and her mental health deteriorated. She said she was only helped when she became suicidal and offered options for treatment by the doctor, which helped but was upset she was allowed to suffer needlessly:

"(This time) the HG (hyperemesis gravidarum) started earlier, I was living in the bathroom and making unattractive noises 100x a day, I was retching but nothing was coming out. Everything smelt, from shower gel to perfume it would send me into a vicious cycle of vomiting and nausea. The sickness just took over. My mental health was very low. I told my husband to get a knife and stab me to stop the pain. He had to the call the ambulance. I was taken to the Early Pregnancy Unit and put on a drip and given hydration treatment. However, The matron thought I was overreacting, her tone of voice was sarcastic. It upset me that why did I go to such extreme health experiences to get basic treatment. Why did the GP/Midwife not mention it?"

MW36 - Bangladeshi. Pregnancy experience in 2018, aged 23



"I had very bad sickness. Anything I was drinking and eating I was vomiting out. I was in and out of hospital every other week. I was prescribed different medications and they were not helping. I ended up getting very dehydrated and being put on an IV drip. On one occasion I was so sick that I tore my oesophagus and stomach lining as I was vomiting blood. I called the paramedic who took me to hospital."

MW12 - Arab. Pregnancy experience in 2011, aged 27



"I had severe HG during pregnancy, I was sick 24 hours of the day. I was depressed, and took time off work. At 5 months pregnant, I was reading about pregnancy termination that's how bad my sickness was. I did not enjoy my pregnancy. I would have panic attacks. I had to sort myself out and think of coping strategies."

If minority ethnic women are more at risk of severe HG, it means that their symptoms are not being recognised or managed early enough causing women to suffer unnecessarily. In nearly all of the cases, the pregnancy sickness was ignored by GPs and midwives and there was hardly recognition of the impact upon their quality of life and mental health. Women were also not informed that treatment was available until they became dehydrated or became mentally very unwell. Such hospital admissions cause an additional burden on the health service and are preventable. When women are offered treatment, they should be provided with information about the benefits, risks and alternatives options so they can make informed decisions. For example, updated guidance by the Medicines and Healthcare products Regulatory Agency in 2020, states that ondansetron, if taken during the first trimester of pregnancy, is associated with a small increased risk of the baby having a cleft lip and/or cleft palate.⁵⁴ It is essential that important information such as this is provided in a way that is fully understood by all women equally. When providing such information consideration should be given to learning needs, poor mental health or language needs (e.g. when English is not the first language).

7.12 Intrahepatic cholestasis of pregnancy (ICP)

Intrahepatic Cholestasis of Pregnancy (ICP) is a liver disorder which occurs during pregnancy and is associated with preterm labour, foetal distress and, in the worst cases, stillbirth. The condition usually starts from 28 weeks onward in pregnancy and the first sign is usually itching.⁵⁵ It affects around 5,500 women each year in the UK but most prevalent in South Asian and Latin American women.⁵⁶

As ICP can be a serious condition, pregnant women need to recognise the signs. To be able to do that, they need to be made aware of the condition by healthcare professionals and provided with information. However, this study revealed that women are not being provided with details. Although a question about ICP was not asked in the online survey, several women volunteered that they had itching symptoms and were diagnosed with ICP. The vast majority of the women (just over 80%) who were interviewed were not given any information ICP. Some women said they only knew about it and what symptoms to look out for because they found out about it when conducting internet pregnancy research or through the websites or apps they were using. However, several women did not even know what it was.

It could be that midwives are not providing information about ICP and are dismissing symptoms because they consider the condition 'rare' using White women as their reference point. According to the ICP Support charity, it is the most common pregnancy-specific liver disease there is.⁵⁷ Overlooking the fact that it is more common in South Asian women not only amounts to not providing personalised care but such failure to provide information to women who are at higher risk of developing the condition, amounts to systemic discrimination. Not providing much need health information could be linked to health staff being concerned about receiving too many enquiries from concerned pregnant women about itching symptoms because all itching may not be because of ICP. This could be compounded by the 'Bibi' syndrome mentioned in introduction of the stereotype of South Asian women exaggerating symptoms. However, denying their right to information is putting women at risk. If anything, it could be argued that they more likely to put up with discomfort and pain before complaining as they are culturally used to being told to suffer in silence. Urgent action is therefore needed to address this gap.

One of the women interviewed had signs of possible ICP although it was not diagnosed because it was not investigated and she was unaware about the condition so didn't connect all of her symptoms or mention them:

"I had severe itching under my bump at around 7 months and was so bad it started to bleed. I did not report concerns as I did not know. However, I experienced severe back pain and vomiting which I did report and had to call the ambulance more than once."



She explained that she kept getting sent back home and eventually went into preterm labour at almost 35 weeks. She mentioned that her severe vomiting and back pain continued after giving birth and she was eventually diagnosed with gallstones, after she kept going back. Her concerns were continuously dismissed. Although she was not given any explanation for the pre-term birth or the gallstones nor tested for ICP, her symptoms and outcomes may have been linked to it.

INVISIBLE

Another interviewee said she had itching and when she reported it to the midwife. It was dismissed as eczema and was not checked out despite her ethnicity placing her in a higher risk group of having ICP:

"I did start itching during the pregnancy and they said that it sounded like pregnancy eczema. They said if it continued and if the itching was mainly my palms and bottom of feet then to contact them. The itching was so intense I would make myself bleed. Ouring all of my pregnancies I can't recall being told about it, but I was aware of it as my first cousin suffered from it and her baby had to be delivered early. So, I sort of knew what to look out for."



MW22 – Bangladeshi, pregnancy experience in 2020, aged 42.

7.13 Polycystic Ovary Syndrome

Polycystic ovary syndrome (PCOS) is a common condition affecting 1 in 10 women in the UK. Women diagnosed with PCOS, may find it more difficult to become pregnant and are at higher risk of diabetes. If they become pregnant, they are also at risk of complications during pregnancy, labour, and birth. Some women may not even be aware they have PCOS because their symptoms may have not been fully investigated by GPs. There are also racial differences, with South Asian women having a higher rate of PCOS than White women.⁵⁸ Considering the potentially higher risk for these women, they should receive additional care and monitoring. Three of the women interviewed had the condition, all of whom were South Asian. However, the risks associated with a PCOS pregnancy did not appear to have been explained to them. One woman mentioned not even being listened to when she raised concerns:

"I called the doctor (GP) about the pain and the pregnancy, but he didn't do anything," and later the growth of her baby had not been picked up: "The baby was not growing. It was not picked up at the scan."



MW19 – Bangladeshi, pregnancy experience in 2020, aged 28

7.14 Learning

Often when discussing risks of pregnancy complications and adverse outcomes for women from racialised minority communities, their ethnicities tend to be collapsed into broad groups such as Black, Asian and Other. Although the data in this study confirms what is already known, that these women do carry a higher risk because of their co-morbidities, it also demonstrates that these risks can vary considerably across the different ethnic sub-groups. To provide equal maternity care, healthcare providers must better understand the medical needs of all women according to their specific ethnicities. This will only happen if data collection and analysis is fully inclusive. For this to successful, ethnic groups must be accurately recorded in the first place and as specifically as possible and the sub-ethnic groups determined by the women themselves. For example, one interviewee said that she had to correct her ethnicity on patient records. Her ethnicity was not interpreted correctly when she said she was East African / Indian:

During one antenatal appointment when the midwife was assessing the growth of her baby, she noticed that she was described as Black African in the patient records. She had to point out that although she her parents were from East Africa, her ethnicity was Indian and told them that 'her body frame / size was that of an Indian.



When analysing maternity data to improve understanding and needs of women to inform healthcare, researchers should also avoid collapsing data into broad ethnic groups. For example, the data here and in other chapters show that Arab women are currently being overlooked. They have poor experiences and have underlying health conditions that also increase their pregnancy risks, but are rarely mentioned in discourse on poor maternity outcomes.

Despite being at increased risk of pregnancy complications, minority ethnic women can still have healthy pregnancies with positive outcomes. If these women are at heightened risk, then maternity policies and procedures should be shaped to be able respond to their needs such as through relevant information provision and early detection and management of their health conditions. Yet, as demonstrated by the case studies here and in other chapters women are not always provided with important information about risks that may be more relevant to them (such as ICP) and therefore are unaware of symptoms to flag up. In fact, some medical professionals are not even bothering to take a woman's medical history:

"I was also never asked about symptoms, family history of any illnesses, and in my family, we have diabetes."



Risks are therefore being missed or when diagnosis is made, they are not followed up or are managed poorly (such as in the cases of gestational diabetes).

Further examples, with fatal consequences are detailed in chapter 8 on the perceptions of intrapartum care. The quality and variation of information provided during antenatal appointments was also a concern and discussed in chapters 5 and 12 on the perceptions of antenatal care and maternal mental health.

INVISIBLE

It was noted from interviews that despite the deficiency in certain vitamins, minerals and nutrients, not all women were provided with free supplements. Some of the women interviewed said they had been provided them in previous pregnancies but in more recent pregnancies had not and were only given basic information verbally. If the reasons for changes in the practice of giving out written information and providing free vitamins etc., is due to less resources being available, then funding decisions leading to this are likely to disproportionately impact on minority ethnic women and those from poorer socioeconomic backgrounds.



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.

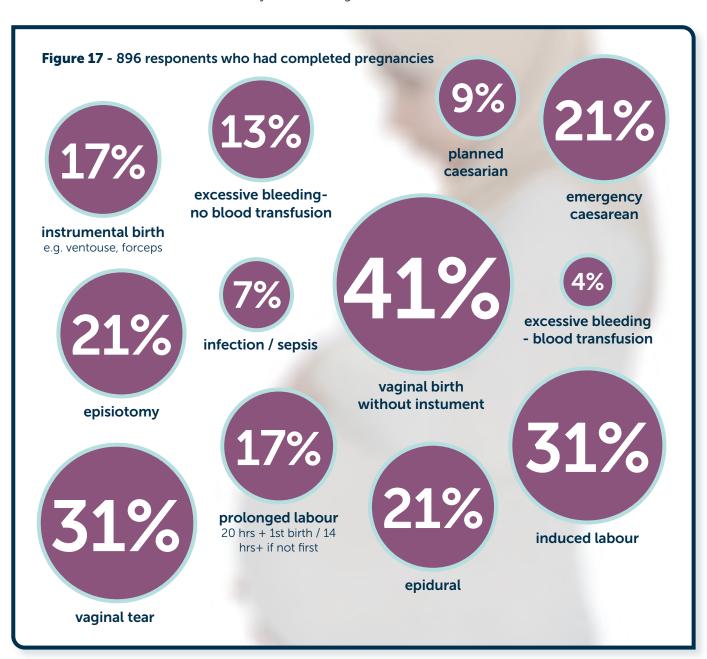


Improve measures to increase the accuracy in recording a pregnant woman's sub-ethnic group.

Perceptions of Intrapartum Care

8.1 Overview

Women were less satisfied with their care during the intrapartum period (labour, birth and the period immediately after birth while in the care of the maternity unit) compared with their antenatal care. Of the survey respondents, 60% rated their care as 'high' or 'of good standard' compared with 70% for antenatal care. However, 18% (almost 1 in 5 women) actually said their standard of care was either 'poor' or 'very poor'. To find out what may be contributing to this poor care, this chapter analyses experiences during labour and birth. **Figure 17**, summarises medical interventions and some of the outcomes of the 892 women surveyed who had given birth.



Most of these interventions and outcomes will be covered in this chapter, except sepsis, which will be discussed in chapter 9 on 'Perceptions of Postnatal Care.' Intrapartum experiences in the study showed found 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.

Pain management

Women's complaints of pain not heard and pain relief denied

Examinations and interventions

Women not given the agency to make informed decisions and instead being pressured to agree without being able to give informed consent

Managing and monitoring labour

Mother and baby not being monitored resulting in adverse outcomes e.g. tears, blood loss, emergency caesareans, traumatic births and baby loss

These three factors are explored in depth in the following sections and can provide learning for why maternal and perinatal outcomes are worse for Black, Asian, Arab and other minority ethnic women. The majority of women (78%) were also unhappy with the non-clinical aspects of their care. More than half of them (57%) expressed concerns related to the attitudes of midwives and doctors (explored further in chapter 14). There were some positive experiences of compassionate care, examples of which have been provided towards the end of this chapter. The quality of the maternity facilities was also criticised as highlighted in the following comments.

"I felt like I had a 17th century type of birth - the room was dark, there was one lamp to see. I could not believe that literally next door was a world leading hospital where all the technology was but not in the area, I was in."



MW23 - Mixed Ethnic Other Pregnancy experience in 2019, aged 33 "The midwife was very unsupportive she shoved me in a room, sitting in a wheelchair holding my baby it was like a cupboard room. This was 40 minutes after birth because they said they did not have any beds. I sat there until they came and got me. It was bizarre."



MW4 - Bangladeshi Pregnancy experience in 2009, aged 31

"I was wheeled into a large room where the heating had broken and I was shivering while giving birth,"



MW14 – Mixed Ethnic Other Pregnancy experience in 2020, aged 30 Several women mentioned that they had put a lot of thought into their birth plans but they were completely ignored:

"I had a care plan, but this was not followed. We had discussed everything pre-labour but they did not refer to it during the labour."



MW10 - Indian

Pregnancy experience in 2009, aged 28.

The women said they found such attitudes disrespectful as it was a very important occasion for them. The negative experiences of intrapartum care caused long term emotional trauma leaving women with symptoms of Post Traumatic Stress Disorder (PTSD) and anxiety:

"It is still in my mind the thought of 'what if I listened to them' about not coming in to hospital until my waters broken and also not just accepting being left in the room without being examined when I went into labour. I could have lost him (the baby). I am still shaken by it."



MW35 - Pakistani

Pregnancy experience in 2016, aged 25

Some women said they were put off having another baby or vowed never to attend the same hospital again. They also no longer trusted medical professionals:

"They did not listen to me. Now I don't believe what doctors say."

(Online survey)

Maternal mental health experiences are discussed in chapter 12.

8.2 Pain Management

The issue of pain was probably the most spoken about topics during the research. Of the women surveyed, only two thirds were 'very or somewhat satisfied' with being provided with pain relief of their choice. About 1 in 5 women were either 'somewhat or very dissatisfied'. Many of the survey participants and the women interviewed spoke of there being a disconnect between midwives / doctors and the pain vocalised and experienced by the pregnant women. This was not just about being denied pain relief during labour, but also during examinations or when performing procedures. The following themes emerged:

8.2.1 Theme One: Painful procedures conducted with no regard to women's pain

Examples were provided of doctors putting their hands inside the woman to turn the baby within the womb. Sometimes this was done without warning and consent was not obtained. Women described it as an extremely excruciating experience, which they were not pre-warned about. They said that, even if the pain was unavoidable, if they had been alerted to the procedure being painful and kept informed that the procedure may be needed, they could have psychologically braced themselves to expect the pain. If women are kept engaged during such painful procedures, their pain levels could also help as a guide for procedures to be done more safely.

"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 "The (Chinese female) doctor tried to move the baby. She put both hands inside me and turned the baby. She was horrible. She put her hands inside me three times — it hurt like hell! But, the midwife was lovely and put a spatula inside and handled me gently."



MW32 - Black African Pregnancy experiences over 10 years ago, aged 20s

The membrane sweep was another procedure mentioned where there was no communication and where women were not informed about the discomfort they would endure:

"No one talks about how invasive painful a vagina sweep can be – someone sticking their hand up your vagina and feeling inside you."



MW34 - Bangladeshi Pregnancy experience in 2019, aged 40

Even though individual's pain thresholds will differ, dignified and respectful care should involve giving women some idea about the level of pain that is likely to be expected prior to the commencement of any procedure. If women are mentally prepared for some pain, it is likely to be less shocking.

Another example of pain level being dismissed was during an epidural injection. The pain should have indicated problems with the way it was being administered rather than deeming the woman as difficult:

"When she (White female doctor) was putting it in my back I was screaming in pain. When I was telling her (about the pain), she was not listening and instead acted annoyed. She was sighing and huffing and puffing and commenting, I am doing it as well as I can.'
When another (White male) anaesthetist tried, he did it first attempt and I barely felt it."



MW3 – Asian Other Pregnancy experience in 2021, aged 30

8.2.2 Theme Two Women expected to not vocalise their pain

Sometimes women were expected to endure their pain silently. They were made to feel uncomfortable for vocalising their pain. Not making noise was associated with being strong and being noisy with being weak and not coping. Women spoke about the extent of their pain being diminished and not taken seriously. These attitudes may be related to stereotypes of ethnic women exaggerating their pain. It is disrespectful to women to expect them to suffer in silence.

"I was sitting on a bed and having contractions and the readings not being able to be taken properly, I was told 'don't move, there's no need to scream, there's no need to overreact, all women have contractions, just deal with it.' There was an issue with the readings because the monitor wasn't working properly, not because of my belly shape as I was told."



MW1 – Indian Pregnancy experience in 2018, aged 34 "I was told 'calm down and be quiet.' I was made to feel like I can't make a single sound. I kept asking for pain relief for 4 hours and was ignored. I wanted an epidural. One doctor did then say, you can make noise if it helps."



8.2.3 Theme three Women's pain not listened to and pain relief denied

The survey results indicate that women from racialised minority communities are less likely to receive pain relief. According to the survey results, 21% of the women had an epidural, which is lower than a national survey of women's experiences of maternity care in which 31% of women said they received an epidural in 2019.⁵⁹ The latest National Maternity and Perinatal Audit of Ethnic and Socio-economic Inequalities in NHS Maternity and Perinatal Care also shows that when comparing women from all other ethnic groups, those from Black ethnic groups had higher occurence of experiencing a birth without any intervention at all.⁶⁰ However, these results should not be interpreted to mean that minority ethnic women are opting not have pain relief. For example, women's accounts showed that pain relief was denied even though they requested it. A delay in care due to pain being dismissed resulted in women being rushed in which meant it was too late for them to have an epidural.

Sometimes pain relief can be delayed when an anaesthetist is not available immediately. However, the majority of the cases involved women's wishes being ignored and instead being pushed towards having a 'natural birth,' a concern already highlighted by the Ockenden review. Another concerning finding was that the degree of women's pain not being believed. Pain levels provide an indicator of intensity of contractions and therefore how close women are to giving birth. Not listening to women resulted in the progression of labour not being estimated correctly and therefore not being managed appropriately e.g. providing monitoring:

"They delayed admitting me because they did not believe me when I told them my water broke plus my baby ate his poo."

(Online survey)

Women were not being believed until there were signs of foetal distress or the baby's head was crowning, leaving birthing partners to call for help, sometimes resulting in emergency situations. One former doula who volunteered to support vulnerable women such as domestic abuse victims and refugees, said that the labour of all ten women she helped had one common theme - their pain was not believed and they were being told they were not ready to come to the hospital even though they were in established labour. The delay meant that by the time they were allowed in to the hospital, they were ready to give birth and therefore missed out on the opportunity to have pain relief:

"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

"When my labour was induced, I asked for gas and air. The midwife kept saying 'but you're so strong, you don't need gas and air'. I then asked for an epidural, again told, 'you're so strong, you don't need an epidural.' I felt like I was going to die! Without telling me, they increased the dosage in the IV that's why my contractions were so strong. They didn't give me an epidural, they just didn't respond to my continuous requests for pain relief. I felt betrayed. I was left at 6am and nobody came to see me till 10am. I kept telling them baby is here and they were not listening, they said you can't go from 5cm to pushing, the head was there and I was tearing. My husband alerted them that the baby was coming. I would not have had a second-degree tear if they had looked at me, assessed me, examined me."



MW6 – Black Other Pregnancy experience in 2020, aged 31

"I made it very clear that I wanted an epidural but they didn't like giving it. She thought my pain was exaggerated. One midwife started dancing with me she said, 'the spirit of women is to give birth, we were made to give birth, you can do it, it's a natural process.' Ouring labour I was panicking and pressed the red button, and I was told the doctors were going to come. The baby's head was crowning and heart rate was dropping. The baby didn't cry he was just blue and had low blood sugar levels. We were in hospital for three days after that."



MW12 – Arab Pregnancy experience in 2014, aged 30

"I was not given epidural despite asking for it during the 15-hour labour. There seems to be a push towards 'natural' births. It's like having a natural birth is a badge of honour. This has been translated to medical profession and birthing norms."



MW23 - Mixed Ethnic Other Pregnancy experience in 2019, aged 33 "When I was induced the midwife told me 'why do you have to spoil your childbirth by taking pain relief?' The midwife I had was a Black Caribbean midwife. She didn't think birth was a big deal and compared to women in Africa who just get on with it."



MW10 - Indian Pregnancy experience in 2009, aged 28

"I kept asking for pain relief for 4 hours and was ignored. I wanted an epidural. Occtors come across as arrogant. I know they have lots of knowledge but they also need to listen patients who know their body."



MW21 – Pakistani Pregnancy experience in 2020, aged 31

"The pain was so severe and I asked for the epidural several times and was told, 'you can't have it because you haven't booked it — you need to have pre-booked it. So many people want it and there are only 1-2 specialists and not everyone can have it, they are too busy.' Instead I was given an alternative eventually several hours later, an injection in my thigh."



MW25 – Pakistani Pregnancy experience in 2016, aged 30 In one extremely sad case **(MW16)**, the baby died prior to birth due to a catalogue of errors. Even though the staff knew she would have a stillbirth, the mother was shown no compassion and not provided with any analgesia despite asking for it:

"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

Underestimating the stages of labour, lack of monitoring and then having to deal with a rushed birth will undoubtedly increase the risk of haemorrhage, vaginal and/or cervical tearing or laceration and emergency caesareans. Women also said that pushing without pain relief left them exhausted, too tired to push and the baby becoming distressed:

"I was actively pushing with zero pain relief but was too tired during the later hours and the baby was becoming very stressed. The child was stuck."



MW10 – Indian Pregnancy experience in 2009, aged 28

Attitudes towards pain relief will vary and women should not have to feel lucky enough to be on a shift where they will be heard:

"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

"There seems to be a push towards 'natural' births. It's like having a natural birth is a badge of honour."

8.3 Examinations and Interventions

8.3.1 Theme one: Pelvic Examinations and Procedures

If women are to be at the centre of their care, permission must be sought from them for healthcare professionals to conduct examinations and procedures. For women to make an informed decision and give consent, they must be provided with sufficient information that should include medical justifications, any alternative options that are available, and the risks and benefits of each. However, there was plenty of evidence that women were not even asked for their consent prior to examinations and procedures and were pressured to accept interventions to accelerate birth even without clear medical need. These issues are addressed in the following sections. Interactions were described as disrespectful, being treated like children and patronising. The case studies below indicate that medical practice has not made sufficient progress since the landmark 2015 Montgomery ruling which lays out the correct standards of care, dialogue and discussion to ensure informed consent.⁶²

'I went in as I was in labour to check my dilation. The Midwife was very blunt and told my partner to stand right between my legs even though I wanted him near my head for support. When she went to check she saw that I had lots of discharge and made a very disgusted face and threw me some tissue and told me to clean myself up. I was in extreme pain and just did as told. She then entered me without warning and handled me very roughly. I wanted to cry."

(Online survey)

Not obtaining consent and allowing trainees to observe and conduct examinations or procedures was raised several times during interviews:

"I was examined by trainees and was not given a choice. I knew they were trainees from their name badges. I had two young trainee midwives and one sticks her fingers into me and said you're only 3cm. I then told them I don't want any trainees to examine me, I knew that was my right."



In another example, trainees were taught suturing after a vaginal tear:

"A midwife stitched me up and all the while she was showing the junior ones how to stitch, but she didn't ask me whether it was ok for the trainees/junior midwives to watch. I felt like an experiment,"



Although not all women will object to trainees, they have a right to refuse and assumptions should not be made. Women found it disrespectful not being asked for their permission.

Interventions during labour (such as membrane sweeps, inductions, caesareans, use of forceps and ventouse, and episiotomies) should only be done if there is a need for them such as reducing mother and foetal distress and improve outcomes. However, time and time again interventions that appeared unnecessary were recommended or even undertaken (often without consent):

"The midwife said 'let me give you a sweep and stretch, which is a medical procedure but she didn't ask for my consent, the consent was out of the window. This made me feel like women's bodies are not their own, there's a lack of consent and lots of pressure."



MW6 – Black Other Pregnancy experience in 2020, aged 31

As evidenced in the case studies, little effort if any was made to have respectful conversations with the women. In non-emergency situations space was not allowed for the mother to weigh up the possible benefits of an intervention offered against any potential detrimental effects. The testimonies show women were not being listened to, care was presented to them in a way that suggested no alternatives, they were pressured to agree to procedures and their decisions rushed so that healthcare professionals obtained the result they wanted:

"I refused the induced labour but was pressured into having a sweep as a compromise."

(Online survey)

These practices suggest midwives and doctors want to overly control the birth process. Inductions of labour was perhaps the clearest example of this, which is discussed in the next section.

MW34 - Bangladeshi. Pregnancy experience in 2019, aged 40



"No one said in the antenatal appointment you can refuse a membrane sweep that you can say, I do not consent to a membrane sweep. I learnt all of this in my hypno-birthing class that at every stage when an intervention is offered you as the birthing person have the right to say not yet, not now and say 'explain to me why you think this is necessary.' You have a right at every stage what is being done to you and why. I don't think this is explained clearly enough. It's your body and it's your right to say why are you doing this to me."

8.3.2 Theme two: Labour Inductions

Of the 892 survey respondents, almost one third (31%) had an induced labour. For a more accurate analysis, results were compared to pre-pandemic rates of 20% of women being induced in the UK,^{63a} rather than the latest figures showing rates rising to as much as 40%.^{63b} It means that Muslim women are 55% more likely to have an induced labour. Hospital data from 2011-12 and 2018-19 shows that medical intrapartum interventions such as inductions and both emergency and elective caesareans have been increasing.⁶⁴ A deeper analysis of figures should be conducted to see if there is any correlation with ethnicity.

If the mother or baby's health is at risk, the birth may need to be accelerated by arranging a caesarean birth or by inducing labour, which involves starting uterine contraction artificially. Reasons for having labour induction could include uterine infection, high blood pressure, signs of placental separation from the uterus, excessive foetal growth due to gestational diabetes, restricted foetal growth, too little amniotic fluid around the baby etc. As Black, Asian and other minority ethnic women have a heightened risk of pregnancy complications, this may partially explain the higher induction rates of the women surveyed. However, survey comments and the interviews uncovered that a major factor contributing to the higher induction rates is the pressure being exerted by doctors to have an induction without strong or sometimes any medical justifications.

Several women interviewed spoke of being pressured 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:'

"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)

This tactic of emotionally blackmailing women by accusing them of putting their baby at risk was also repeated by other women. In the case of **MW21**, she was also threatened with Social Services. The women who were knowledgeable about their rights, such as when an induction would become necessary, did stand up to the midwives and obstetricians and challenge what they were being told. These women managed to avoid being induced and had positive birth outcomes after having a spontaneous labour or were able to negotiate a compromise:

"I refused the induced labour but was pressured into having a sweep as a compromise."

(Online survey)

MW21 - Pakistani. Pregnancy experience in 2020, aged 31



Due to her gestational diabetes she said she was being pressured to give birth at 37 weeks and not managed according to her personal risk. She was told her baby would be large despite all monitoring indicating she and her baby were fine. However, she refused and agreed to be regularly monitored instead. This had happened before: "I was pressured and bullied and was even shouted at - she (obstetrician) had said: 'Because you are refusing medical care, you are risking the baby's life and we will call the social services'." However, this time she said she did not to let them accuse her of 'refusing care' or let them use that as a threat to coerce her to change her mind: "I know my body and didn't want to deliver the baby if my body was not ready and the baby was not ready."

She challenged the doctors and told them that she was not putting her 'baby in danger' and willing to change course if the baby became distressed. She ended up giving birth at around 40 weeks. Her baby was born average size and not really big as suggested.

The issue of accurate estimation of baby size was brought up in the chapter 5 (Perceptions of Antenatal Care). It was highlighted again by women who were advised to have an induction because of concerns about their babies being considered smaller or larger than expected. They felt that baby size estimations were not accurate yet were influencing decisions on birth options offered to the women. Where the calculations were correct, decisions made were not always in the best interest of mother and baby. For example, when there were concerns that the baby was going to be large, women were not being offered a caesarean - as in case MW2, who even with an episiotomy, ended up with tears.

In cases where babies were small, the mothers were potentially being put through an induction process that could be traumatic for them as highlighted by case **MW34**. Due to concerns about the growth of her baby, a decision was taken at 36-weeks for an induction. However, she was not satisfied in the way it was presented as it did not involve informed consent initially:

"The language of 'we are going to induce you' did not sit well with me. You are going to offer me an induction and you are going to tell me what an induction involves (in details) and then we are going to agree to an induction. I found that language really paternalistic of 'we know what the right things is and we are going to do it'."



MW34 - Bangladeshi Pregnancy experience in 2019, aged 40.

However, this was followed by a very positive experience, where a different opinion was offered. The consultant informed the mother that labour would be exhausting and painful for her and the baby as it could potentially last for 2-3 days after which she could end up with an emergency caesarean. She provided detailed reasons why a planned caesarean would be the best outcome for her and her child:

"My single best experience of my whole pregnancy was with a White female consultant, who was very clear in her explanation. It was one of the most respectful conversation I had during my whole pregnancy. She explained that my baby had a better chance of thriving outside where it could be better monitored and that given the small size, the baby was not ready for labour."



MW34 - Bangladeshi Pregnancy experience in 2019, aged 40.

However, the woman also revealed that during the appointment her (White) husband had accompanied her and thinks this may have contributed to her positive experience.

MW18 - Pakistani. Pregnancy experience in 2020, aged 30



There was pressure for her to have an induction because her baby was considered small. However, she felt that her ethnicity and build had not been considered: **"For an Asian woman who is not very tall, the baby was a good size. I managed to convince them I don't want to have the baby earlier and managed to delay it until around 40 weeks."** However, her request for a caesarean was denied and she eventually ended up having an emergency caesarean.

MW3 - Asian Other. Pregnancy experience in 2021, aged 30



When her waters broke she was told to return after 24 hours. Upon returning she was told she would need to have an induction (without being provided a reason): "I did not understand from my research why I couldn't wait to see if went into labour naturally. Although waters had now broken just over 24 hours earlier, online information said it can be up to 72 hours before an induction was necessary. She (midwife) was off with me because I did not want induction."

MW19 - Bangladeshi. Pregnancy experience in 2020, aged 28



When her waters broke two weeks before the due date, she went into hospital. She was told by doctors they wanted to induce her. She questioned the justification for the decision as it was not discussed with her. Hours later she naturally went into labour, which reinforced her decision not to just accept what is being told: "I did not want an induction. I wanted my body to tell me when it was ready to deliver."

MW33 - Indian. Pregnancy experience in 2020, aged 29



She was told that she would be induced early because her baby was going to be big. However, she challenged the decision and told doctors she wanted to get to 40 weeks before it was considered as she had read the NICE guidelines. She also questioned why they thought the baby would be large when she did not have gestational diabetes. She could not understand why her build was not considered i.e. that she was short and had a small frame so the baby may seem bigger: "My waters were broken and I was given a drip to speed up the delivery. The baby reacted to drip and heart rate fluctuated. I eventually had to have a caesarean."

MW2 - Pakistani. Pregnancy experience in 2015, aged 37



She was told she would be having an induction at 38 weeks as they were predicting her baby would be 10lb. However, she wondered why she was not offered a caesarean given the size of the baby. In hospital she thought she was being examined but was being induced instead. During her labour, forceps were used and despite being given an episiotomy, she still had perineal tears:

"I felt like I was a recipient of care rather than a partner in my care. Decisions were made for me."

The numerous similar experiences suggest that there may be a culture amongst some doctors to unnecessarily steer minority ethnic women towards inductions. When there is an increased risk of pregnancy complications, minority ethnic women appear to be lumped together regardless of their individualised risk. For example, women with well-controlled blood glucose being treated the same as women with a poorly controlled diabetic pregnancy, thus pushing them needlessly towards early labour inductions. Even women without risks were being persuaded to have an early induction of labour. Such attitudes may have influenced the draft guidance published by NICE in 2021 that recommended inducing labour at 39 weeks for women from minority ethnic backgrounds even if they had uncomplicated pregnancies just because they carry a higher risk of pregnancy complications.⁶⁵ These recommendations were rightly criticised particularly by women's rights and maternity campaigners. They were even branded as racist and discriminatory because they implied that because of their ethnicity these women should be given inductions even if there were no medical reasons to do so. Thankfully, the recommendation has been withdrawn after concerns were raised. However, the approach taken requires attention because it may shed light on what may be taking place in hospitals as confirmed by women's experiences in this research. This comment by an online survey participant provides an example of an induction being recommended that was unlikely to be related to risk, otherwise she would have been followed up:

"I was told that due to my age, I'd be induced at 37 weeks and then I was ignored in my last trimester, after contacting the obstetrician multiple times for an update,"

(Online survey)

If she indeed needed a caesarean for medical reasons then her case is even more concerning as she was then overlooked.

The blanket recommendation from NICE would have meant minority ethnic women with healthy pregnancies being denied the right to make an informed decision and not having the opportunity to have a spontaneous labour, the benefits of which could outweigh a labour induction for them. Case MW33 provides a good example of this, where the baby's heart rate fluctuated resulting in a caesarean. So, why is it considered acceptable to put the bodies of women from racialised minority communities through an unnecessary process without robust evidence or medical justification? Additionally, women are also not being informed of the toll that inductions could have on their bodies:

"They don't explain (induction) is making your body do something it is not ready to do.

There can be a variation in how much it progresses levels of pain – how different women respond to induction is not explained,"



For example, in the previous section on pain management, case **MW6** highlights the severity of pain caused by artificially starting and then accelerating contractions, yet no pain relief was provided.

How decisions are made and how care is given by obstetricians and midwives to Black, Asian and minority ethnic women is clearly contributing to their unfavourable outcomes and should be a greater area of focus if a step change in reducing the inequalities in maternity outcomes is to be achieved. For example, are stereotypes and attitudes towards them influencing decisions and care provided to them. Even when women have pregnancy complications, their risks can be reduced if they are: listened to; symptoms are spotted and escalated; treatment is provided at the right time; and they are provided with the right information at all stages of their pregnancy so they can make informed decisions. However, time and time again the accounts by women showed that the standard of care was falling short of what should have been provided.

INVISIBLE

Some women also said they suspected that their labour was rushed (via inductions) because the hospital wanted to free up beds more quickly. For example, in case **MW6**, the timing of her induction seemed to be driven by what was convenient for the hospital and not what was best for her. Other women had similar experiences particularly during the pandemic, unexpectedly being told during a hospital appointment that an induction needed to be started immediately even though there was no imminent risk to the baby or mother. This left women no time to call their partners in or return home briefly to collect personal items to help them feel more prepared. As partner were not allowed because of Covid, women were left to make decisions alone.

MW6 - Black Other. Pregnancy experience in 2020, aged 31



"There was also pressure to make decision and I never really trusted professionals due to my previous experiences. The doctors say we know best, they asked me if they could induce me, but said that they were busy tomorrow, but we could do it all now, and I just wasn't prepared. There was a lot of pressure to make rapid choices. My husband was not allowed into the appointments, and scans. It was difficult to be at all alone and it was made more difficult due to Covid. I felt like I was the only parent, whereas at home it's joint parenting. I do remember them continuing to say 'we know best', which made me feel like a child."

Although inducing women to suit staffing levels in maternity units would of course be unethical and such claims cannot be proven, it should be considered for further research with. the rates of inductions for different hospitals compared with data disaggregated by ethnic groups. Other poor outcomes that could be linked to inductions should also be investigated by ethnic group such as impacted foetal head, where a baby's head can be lodged firmly in the mother's pelvis following strong uterine contractions. For example, The Early Notification Scheme progress report shows that impacted foetal head is an emerging problem in the UK, affecting a staggering 9% of cases reported to them. ⁶⁶ Although research is required to understand the cause of impacted foetal head, some theories in circulation include increasing rates of induced labour, how the labour is managed and caesareans being performed at a late stage of labour. ⁶⁷

8.3.3 Theme three: Caesarean births

Planned Caesarean Births

Of the Muslim women surveyed, 9% said they had a planned caesarean birth. This is slightly lower than the national average in England of 11.5%.⁶⁸ This could be a positive sign. However, the findings could also indicate that they are being denied the choice of having a planned caesarean birth as a few of the women mentioned wanting one but then being dissuaded from it. In one case (already mentioned in chapter 5) the woman felt bullied:

"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.

In other situations the mother's history would suggest that a caesarean birth was needed but was not always considered. For example, **MW22**, had to have a caesarean after being in labour for two days during which time her baby had swallowed meconium. In her next pregnancy she was going to be put through another labour but insisted on having a caesarean because of her previous difficult labour. She was seemingly proved right because obstetricians found that it was hard to get her baby out and they would have become stuck during labour:

"If they had not listened (and made to go through labour first), then the baby would have been in trouble,"



MW22 - Bangladeshi Pregnancy experience in 2009, aged 30

This example illustrates why a planned caesarean can be necessary, especially for a high-risk pregnancy. It may be recommend for a number of reasons such as low-lying placenta, labour not progressing, bleeding or pre-eclampsia. It may also be advised for women in prolonged labour before the situation becomes critical. However, some of the women interviewed said they were advised to have a caesarean without strong medical reasons and felt pressured to agree. They said that they were not given sufficient time to see if labour progressed and similarly to labour inductions the underlying reasons may have been linked to non-medical reasons e.g. wanting to move women along to free the space for the next woman in labour. The findings could also suggest a risk averse culture in some hospitals where caesareans are favoured amongst doctors. As women have mentioned feeling 'bullied,' it could suggest some women are pressured more than others although motivations were not clear.

MW1 - Indian. Pregnancy experience in 2012, aged 28



"I felt 'pressured' and 'bullied' to have a caesarean immediately without being provided options. It was an older Indian woman consultant. She said 'I have had a look at scans and twin 2 has not grown for two weeks and if you don't have a caesarean today you will basically be killing your baby.' I just burst out crying, like how could you say that? I was made to feel pushed, like I didn't have a choice (to have the caesarean on the day). However, I insisted on having options explained whether having a natural birth was possible and whether the caesarean could wait until the following morning, which I found out it could. I did feel at that moment that I was just a 'stupid Asian woman.' The doctor was Asian so the stereotypes also come from within the community."

MW25 - Pakistani. Pregnancy experience in 2016, aged 30



"After being in labour during the night, my waters broke at 6am but by 8am medical staff told me you have been here for too long and we need to get the baby out. They wanted to give me a c-section. I could not understand why they wanted to do this because they had not been monitoring the baby's heart so they had no evidence the baby was in distress. When my sister challenged the decision and asked if we could continue with the labour, this was accepted by the medical team without fuss. I felt that this reaction indicated that there was no medical reason for offering a caesarean but that they probably wanted the bed. The midwife was on my side and said: 'you can push and have a normal delivery and the baby will be safe.' 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."

MW31 - Pakistani. Pregnancy experience in 2021, aged 30



"By the evening labour had progressed and I had been pushing for 4 hours. However, the obstetrician came and decided to do a c-section. I said I don't want it, I have worked this hard. I felt deflated. No one asked me what I wanted. The baby was fine and not distressed. They just wanted to move my labour on and no explanation was given to as to why it was necessary. However, the midwife (who was White) advocated for me. She was brilliant, she said (to the obstetrician), the baby's head is just there, and urged the doctor to try forceps. She was very positive and also kept me going more than my husband did. And during the forceps, she was right next to me reassuring me. The doctor agreed to have a go with forceps, which worked. However, they cut me (episiotomy) and did not tell me."

Emergency Caesarean Births

As already mentioned in the introduction, the recent maternal and perinatal audit found that the rates of emergency caesarean birth were higher for Black and South Asian women when compared to those for White women.⁶⁹ The survey results also confirmed these findings - of the 892 women who had given birth, 21% had an emergency caesarean, which was higher than the national average in 2020 of 16% (according to the maternity service monthly statistics published on NHS Digital).⁷⁰ Because of the sudden and unexpected nature of emergency caesareans, they are associated with poorer maternal and perinatal outcomes and will therefore likely be contributing to the higher minority ethnic maternal and perinatal mortality and morbidity rates.

An examination of what the care and decision making looked like prior to the life-threatening situations can provide learning to improve safety of maternity services. As already mentioned, women were delayed from coming into hospital because their pain was not believed. This sometimes contributed to emergency caesareans still births and neo-natal death as in case **FG1**.

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.

Women not being check upon for long periods was one contributing factor such as in one example from the focus group:

When she was over 40 weeks she was induced. She was in labour all night and most of the days but not checked very often. However, eventually when she was checked up on, she was rushed for an emergency caesarean.

FG5 - Somali woman (Focus Group) Pregnancy experience in 2014

Another factor linking the few emergency caesarean cases analysed from interviewees was electronic foetal monitoring - babies were either not monitored at all, monitors were switched off, accurate readings were not taken, readings were not being interpreted properly or unusual readings were not escalated for action. Some case studies are provided in section 8.4.

8.3.4 Theme four: Assisted (Instumental) Birth

According to the NHS website 1 in 8 (12.5%) births involve an assisted birth, (also known as an instrumental birth) which is when forceps or a ventouse suction cup are used.⁷¹ However, of the 892 survey participants who had given birth 1 in 6 (17%) said they had an instrumental birth. There are increased risks of adverse outcomes associated with these procedures such as brain damage / facial injuries of the baby and the mother experiencing more severe pain, perineal tears, postpartum haemorrhaging and obstetric trauma. The higher rates of instrumental births is also therefore likely to contributing to poor health outcomes of minority ethnic mothers and their babies.

8.4 Managing and Monitoring Labour

The intrapartum stories of Muslim women showed that substandard management of their labour was contributing poorer outcomes for them and their babies. Practices were in fact putting their safety at risk resulting in 'near misses' and in some cases led to fatalities. Even when women raised concerns they were not always listened to.

Of the 839 survey participants who answered questions about their labour:

24%

said that they were
'somewhat dissatisfied' or
'very dissatisfied' with the
maternity care given after
raising concerns during
labour and birth

40%

said that they felt that their safety was put at risk by healthcare providers during labour, birth and the recovery periods with 13% saying they were 'very concerned' about safety.

33%

said that they were
'concerned' about the
safety of their baby /
babies and that they were
put at risk by healthcare
professionals while 12%
actually said they were
'very concerned.'

Two main factors contributed to the dissatisfaction and concerns: the delays in admitting women in established labour or those who had high risk pregnancies and women not being checked for up to 6-9 hours during their labour. These factors also had an impact on perineal tears, episiotomies and postpartum haemorrhage, all of which will be discussed in the following sections.

8.4.1 Theme one: Delays in Admitting Women to the Birth Setting

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. Not believing the severity of women's pain contributed to these midwifery decisions and have already been discussed in previous sections. Such delays put the mother and baby at risk. For example:

"I was having contractions but still kept being sent home as I wasn't dilated to 4cm. By the time my waters broke, there was meconium in the waters. My daughter and me ended up staying in hospital after for one week due to her infection. This could have been avoided had I been admitted into hospital earlier."

(Online survey)

Other similar examples are highlighted in the previous section on 'pain management,' and show that women know their bodies best and midwives should be more flexible in their approach and not assume all women will have textbook pregnancies e.g. the level of pain and the dilation of the cervix may not match. As cases **MW28** and **MW5** show that despite being less than 4cm upon examination, their contractions were regular and strong.

MW28 - Mixed Ethnic Black. Pregnancy experience in 2019, aged 19



When she called the midwife to say she was in in pain and in labour, she was told that she would be like this for the next 3 or 4 days. When she called again the next day she was dismissed again and told, 'If you were in labour you wouldn't be able to walk or talk love.' However, she trusted her own instincts and went to the hospital anyway. Although examined was sent home and told again you will be like this for a week or so. The early hour of the morning her waters broke and she spotted blood and returned to the hospital: "When I got there it was the same midwife and she was just rolling her eyes and went to get the paperwork. It was just me and my husband in the room and I basically just started giving birth there and then. The midwife rushed back in and within 20 minutes my daughter was out." When I thought about it later on, I just felt that if they had just listened to me earlier on and admitted me they may have realised about the 'poo' (meconium)."

MW5 - Pakistani. Pregnancy experience in 2019, aged 21



When she went into hospital with labour pains, the midwife checked her but told her to go back home even though she was 3cm dilated. The midwife did not believe her about the severity of pain: "I told her my pain is 1 minute apart and that we had an app for measuring the contractions. She thought I was pretending and she didn't take me seriously. I kept telling her my baby is coming." Instead she chose to stay in the waiting room and called the midwife again and requested that she check how dilated she was, but she refused stating she would need to wait four hours due to the risk of infection: "We didn't go home, but went to a friend's house where I said to my husband I need a really bad 'poo.' I had told him when I was doing research that if I ever say that to you, take me to the hospital. Thank God he remembered. We knew that the baby was coming, the head was there. We rushed to the hospital and my husband drove dangerously cutting red lights, when we got there I could not even walk in, and when I got there somehow my husband helped me I fell to the floor and the porters took me to the room. The midwife came and I was already pushing without pain relief. Within 10 minutes of arriving at the hospital the baby was born. I had the baby in a waiting room it was not a birthing suite. We did complain, they told us we had a spontaneous birth, I told them it was not a spontaneous birth, we had come before 2 hours ago."

The delays highlighted were also linked to the 'phone' and 'in person' triage systems, which failed to recognise women with high risk pregnancies. One case (MW16), who was ten days overdue, had pre-eclampsia and reported reduced foetal movements, experienced a delay in care because non-clinical staff did not have the training to triage her initial phone call appropriately. Furthermore, even when she presented herself at triage she was made to wait for three hours before being seen. Devastatingly, by that time her baby had died. Prior to her triage experience, the pre-eclampsia had not been escalated during her previous antenatal appointment even though she had gone past her due date. To add to her trauma, she was shown no compassion during labour; she not given any pain relief despite requests. She was not checked and left to go through labour and when a doctor finally came to see her, brought four students in without asking for her permission. The lack of respect and dignity in this situation was appalling.

MW16 - Indian. Pregnancy experience in 2019, aged 35 (STILLBIRTH)



She was 10 days over her due date and over 41 weeks pregnant. At the antenatal appointment, the midwife measured her blood pressure as high. Despite signs of pre-eclampsia, she was sent home. She then called the triage service and spoke to someone (non-medical staff) in the morning who advised her to get some rest and call back later as it was early contractions. After she had rested she called back as she didn't feel the baby move. She then spoke to medical staff (midwife) who advised her to come in. There was a delay as her notes were mislaid and she had to wait in triage for 3 hours. By the time she was seen her baby had died. It took her three days to deliver her baby. When she asked the midwife for an epidural she was told she didn't need one. She said: "I felt unheard, and unseen."

In another case, MW25 also had to wait a long time in the triage waiting area and was only given a bed when her husband escalated concerns and reminded staff that she was at a higher risk of complications. In this example, (which was pre-pandemic women) were expected to wait alone while in labour adding to their negative experience of maternity services. In this scenario, the two women (including the case study) pushed back about not having birthing partners with them. However, it must have been distressing for the third woman to be unaccompanied. Some women may not have the confidence to advocate for themselves and challenge unreasonable requests, particularly if they are less proficient in English.

MW25 - Pakistani. Pregnancy experience in 2016, aged 30



She went to the hospitals when her contractions were 4 minutes apart. She was told to wait on a chair in a waiting room, where two other women were also waiting one black (Somali) and one South Asian. They were also in pain having contractions. She was told her birthing partner (sister) could not wait with her. Her sister refused to leave (because one of the other women had someone with her). So eventually they agreed to let her sister stay with her. She had to wait in that chair a further 2 hours having contractions which seemed to be getting closer together and without pain relief. She was not given a bed until her husband mentioned that the previous birth was by a caesarean and that she should be monitored more closely, it was only then they put her in a room.

8.4.2 Theme two: Absense of Maternal and Foetal Monitoring During Labour

Not monitoring women during labour was a common occurrence. Women felt abandoned and neglected during labour. Their accounts revealed significant periods of time elapsing between assessments. Some women were not checked for up to 6-9 hours leaving women worried and without pain relief. Medical attention was not given until birthing partners called for help because they saw the baby's head crowning:

"I had to push and fight to be heard the whole time."

(Online survey)

There were examples where the lack of maternal and electronic foetal monitoring compromised the safety of mother and baby. Some of the cases of neglect involved near misses, (including emergency caesareans) and stillbirths. Women being neglected for long periods also increased the likelihood of severe perineal tears because there was no time for interventions such as controlled cuts (episiotomies).

Focus Group FG3 -Somali. Pregnancy experience in 2021

At 39 weeks she went to the hospital because the baby was not moving. After being examined she was told she would need to be induced. She said they gave her a 'pill' and sent her back home and returned the following day. The next day back at the hospital she was having contractions but the baby's heart was not monitored until much later in labour: "Nurses should go back to school and be trained... and take seriously what the patients are saying. They are understaffed and I know this makes a difference. But I felt as if something is wrong with me when my requests weren't being heard. You're vulnerable and you doubt yourself."

Such was the level of negligence at times that even mothers who were considered high risk, were not monitored during labour. For example, one woman interviewed (MW37) who at 36 weeks had pre-eclampsia and was told that she and her baby could die unless the baby was delivered, was not monitored during her labour. Mothers with pre-eclampsia progress rapidly through labour (compared with those who do not have the condition) but she was told she was 'lying' when she said she was ready to push within 1.5 hours of her waters being broken.

MW37 - Pakistani. Pregnancy experience in 2017, aged 30



"I had pre-eclampsia but I was left to labour with no check-ups. My waters were broken at 2cm (dilation) and after that I was not checked and the baby's heart not monitored. I was in so much pain but refused pain relief and was told by the midwife (who was Black), 'you are just in labour' implying it was not that bad. She also told me I was too loud and to be quiet and that I was waking up other women. Within less than 1.5 hours of the waters being broken, I felt ready to push. My mother kept asking the midwife to check me who kept refusing saying that I could not be ready to push and basically saying I was lying. My mother begged her to check. The midwife then did so very reluctantly. She was so angry when she was checking and kept and tutting. However, her attitude changed when she saw the baby's head and started shouting at my mother to press the emergency button."

Case Study - Online Survey (STILLBIRTH)

One woman (Indian ethnicity, degree educated and born outside the UK) who responded to the survey said she lost her baby during labour. She was in her 20s, had no health conditions or concerns, it was her first pregnancy and it was a late term birth. She said she had a prolonged labour and felt that healthcare staff were negligent in the care they provided because she was 'just left in labour and her baby's heart rate not monitored.' She eventually had to have a caesarean. She also said that the midwife was rude to her, which included negative tone of voice and believed her treatment was linked to her race and faith, being a Muslim. Despite the negative outcome and poor experience, she was not given any information on making a complaint. However, she said that she did make a complaint, but only informally.

MW3 - Asian Other. Pregnancy experience in 2021, aged 30



She started feeling pain and kept saying to nurse about it who did not believe her level of pain and did not check her and said she did not want to introduce an infection. She urged her to check: "I am telling you, she is here, I am wanting to push. When she called obstetrician, I was 10cm and ready to push."

MW13 - Black Caribbean. Pregnancy experience in 2019, aged 25



"When I was in labour in the same room as another woman separated by a flimsy curtain. There was no pain relief during labour. Only after a long time the midwife finally checked me and found the baby was there crowning. They tried to measure the baby's heart rate, then dragged me into another room to give birth. It was so rushed after seeing the head, it was unnecessary they could have avoided all that had they just checked me and seen how I was progressing. But no one took notice. They did not spend time observing me. The assumption was that the first baby takes time, Everyone I saw was White. Ouring labour, I was wearing the headscarf but during birth I took off. My mum was always wearing it though. After giving birth I spoke to other (White) women who had also given birth at the same hospital and realised I had a very different experience."

MW14 - Mixed Ethnic Other. Pregnancy experience in 2020, aged 30 (NEAR MISS)



When she asked to be examined the midwife responded by saying she does not need to be checked for another 6 hours. She also requested an epidural but no one returned to check on her for several hours. As this was during the night, her partner was told to go home. She was alone all night crying in pain with no pain relief and unchecked. When her husband came in the morning he found her vomiting. Although the midwife came she still did not examine her. When the shift had changed she was examined and found to be fully dilated. She had been left alone in labour all night during which time the baby's heart rate was not monitored. When she made a complaint, the hospital admitted making 23 errors, which included 9 hours without a check and not being given antibiotics during labour as swabs showed an infection. The trauma has also affected her mental health and she believed her poor treatment was linked to her race and faith because she was visibly Muslim (wore hijab) and her husband had a beard.

MW21 - Pakistani. Pregnancy experience in 2012, aged 22 (NEAR MISS)



"I was left on my own with my husband and the midwife would come by every 1-2 hours to check on me. I did not give birth until 5 hours later. I was in so much pain but not offered or made aware of pain relief available. Eventually I was told it was too late for pain relief and given co-co-codamal, which made no difference. I was in so much pain, I thought I was going to pass out so my husband checked and could see the baby's head so he called the midwife. When she came she pressed the red button and suddenly I had a whole team around me. It appeared that the baby was at risk because it was stuck and had been in that position for a while. They had to pull him out. I thought he had passed away when he came out, he looked like purple jelly, his head was flat shaped because he had been stuck in one position for too long. I did not feel safe and they put my baby in danger. Had my husband not checked and seen the baby's head, he would have died. It was a traumatic birth and still feel traumatised by the experience."

MW27 - Black African. Pregnancy experience in 2013, aged 32 (NEAR MISS)



"When I was in labour, I was advised to walk to quicken things but said I couldn't because I was in so much pain. They just thought I was lazy and my pain wasn't real. I eventually did try follow the advice and collapsed. Then suddenly it was 'code red'- everything happened so fast and I taken into theatre as they said the baby needs to be taken out. First, they tried forceps and then Ventouse. I knew something was wrong - she wasn't breathing. She was immediately taken to the side and everyone rushed to save the baby." She later found out that her daughter was back to back on her spine, hence the incredible pain: "Had they checked me earlier, they would've realised her position. They just thought I was lazy and my pain wasn't real. I wasn't given an explanation. I don't want to have another baby because of the pregnancy and because of the trauma of the delivery.... I can't trust anyone."

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."

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%⁷² indicating that they are twice more likely to have a prolonged labour. If labours are taking an unusually long time, the mother and baby should be closely monitored because of the increased risks of uterine infection, low levels of oxygen for the baby causing brain damage, stillbirth, postpartum haemorrhaging, obstetric trauma and psychological trauma. However, it is clear from the experiences described this is not always taking place thus contributing to the adverse outcomes.

Case Study - Online Survey (STILL BIRTH)

One woman (of Bangladeshi ethnicity, degree educated and UK born) who responded to the survey said she lost her baby during labour. She was in her 20s, it was her third pregnancy and it was a late term birth. She had low vitamin D, anaemia, a thyroid condition and was a smoker. She was also at increased risk due to her previous pregnancy health concerns and outcomes. She was induced and left in prolonged labour. During her labour she said she experienced microaggressions by the midwives and the obstetricians, which included patronising comments, negative tone of voice, judgemental comments / attitudes and physical actions such as the way she was treated. She believed her treatment was linked to her race and faith. Although not informed by hospital staff about making a complaint, she had been provided with information during her routine antenatal appointments and did make a formal compliant in writing.

INVISIBLE

Cardiotocography (CTG) is a well-established method to check foetal wellbeing and screen for foetal hypoxia. However, some Muslim women also flagged their babies heart rate was not checked via the electronic foetal monitor. Others raised concerns about the lack of confidence in the staff taking readings i.e. whether they were being interpreted correctly, being taken seriously or unusual reading escalated appropriately. In the case of **MW1** the monitor kept moving because of its design but she was being blamed. Despite the heartbeat being irregular, action was not taken until the heart rate dropped and it became an emergency situation, which could possibly have been avoided.

The NHS introduced the Saving Babies Lives Care Bundle in 2016⁷³ leading to NHS trusts introducing interventions and processes that would reduce the risk of stillbirth, which included foetal monitoring by trained and qualified staff. Guidance states that all staff who care for women in labour are required to undertake an annual training and competency assessment on cardiotocograph (CTG) interpretation and use of auscultation. Even more recent labour experiences show that despite this guidance, foetal monitoring is not being conducted even in high risk cases and readings are not always being interpreted correctly thus putting babies at risk. As CTG interpretation is a high-level skill and is susceptible to variation in judgment (even over time), more work is clearly needed to ensure all training is reviewed and refreshed annually. Given staff absence and sickness particularly during Covid, any gaps in training are likely to have worsened. Hospital boards and particularly the Board Maternity Lead should therefore seek assurance that any gaps are being addressed by senior management.

MW1 - Indian. Pregnancy experience in 2018, aged 34



"I remember being told that my tummy is not the right shape and we can't get the readings that we need. I was made to feel like it was my fault, but the equipment was not suitable for someone who was not massive and the nodules kept moving making it difficult to get a heart reading. After several hours a senior consultant (White Eastern European) came and said the baby's heartbeat keeps skipping every three minutes, and after my next surgery I will come to see you. However, then the baby was in distress. I needed to be taken for a caesarean immediately as the baby's heartbeat had dropped. I then had an emergency caesarean and they found that the cord was around the baby's neck. This could have been picked up earlier but they made me feel like it was my fault that the readings weren't right (because the monitor had kept moving)."

MW9 - Pakistani. Pregnancy experience in 2019, aged 29



"They never said or spotted any warning signs during the labour, they were monitoring the heart rate but despite this were unable to tell that he had a chord around his neck. I had a back-back birth when the baby's back was against my back and that's what probably caused the tear, but no one mentioned this or the cord."

MW11 - Bangladeshii. Pregnancy experience in 2013, aged 31



As her waters had broken and labour had not progressed, she was induced. However, they switched the monitor off and stopped monitoring her baby. Eventually when the monitor was turned back on, the baby's heart rate had dropped and baby had become distressed resulting in an emergency situation where she was rushed for an emergency c-section.

MW24 - Pakistani. Pregnancy experience in 2019, aged 28



"I was contracting every 10 minutes and vomiting a lot, but they told me to go home and come back when I was having contractions every 3 minutes. I thought I should be in the hospital. I went back in during the evening shift. When I would ring the bell that's when the midwife would arrive otherwise she would not, as the unit was short staffed. I was pushing for 12 hours, the baby's heart rate was decelerating, I picked this up when they were muttering to one another. They wanted to wait till the shift hand over before moving me. I did not understand why I had to wait until hand over for this, which took 30-40 minutes to complete after which, I saw a doctor for the first time while being there and in labour. They told me they will use forceps. This failed and they rushed me to theatre as the baby's heart rate dropped and so did my blood pressure. I felt really unwell. I had an emergency c-section. The baby had forceps marks and bruising on his face. He also had a squidgy head due to the pushing. The midwife and doctor came to see me regarding the forceps mark on baby's face and apologised. They said it was not intentional. They also sent an independent photographer who photographed birth injuries."

8.4.3 Theme three: Perineal Tears and Episiotomies

Women being neglected for long periods also increases the likelihood of severe tears because there is less time for interventions such as controlled cuts (episiotomies). This corresponds with the survey findings which show that women are more likely to have a tear than an episiotomy - one third (31%) of the 892 survey respondents who gave birth said they had a vaginal tear. However, the survey question had not asked the women to differentiate between a minor tear or a deeper third- or fourth-degree perineal tears, which extend into the muscle that controls the anus (anal sphincter). The average rate of third or fourth-degree perineal tears is about 3-4% and slightly higher for first time mothers at around 6%.⁷⁴ The 31% is likely to include a significant number having these deeper tears given the accounts uncovered by this research and the fact that it is already known that African-Caribbean women and Asian women are more likely to have an obstetric anal sphincter injury (as already discussed in the introduction chapter). When asked about episiotomy 21% said they had the procedure, which is higher than the national average of 14%.⁷⁵ The tears had a really negative impact emotionally and physically.

Inappropriate episiotomies of women with FGM was also noted by the interpreter interviewed who had supported many Somali women during their maternity care:

"When women compared their labour experiences to what they had in other European countries, UK medical professionals were making far more cuts than were needed. They were horrible and nasty and gave lots of cuts." (Interpreter)

She also observed that even though the chances of Somali women developing an infection because of the extra stitches (because of the numerous cuts), they were often not provided with advice on how to care for the stitches to aid healing nor informed of symptoms of infection to be aware of so medical help could be sought earlier.

"Due to negligence they damaged my vagina 15.02.2020 I'm still waiting to be fixed. They had to quickly cut me open as they gave me diamorphine 20 mins before they realised I was fully dilated and according to the NHS website they shouldn't have done it, it affected my baby's breathing and made me sick I couldn't hold my baby for 4 hours."

(Online survey)

"The whole situation with my tear did affect me a lot. I did not receive much empathy at the time if I'm honest."

(Online survey)

"They talked about a controlled episiotomy so I would not tear. They said they would do it but then did not. Then I tore second degree."



MW23 - Mixed Ethnicity Other, Pregnancy experience in 2019, aged 33

"Had 3rd degree tear for first birth, and second degree tears for pregnancy no2 and 3."

(Online survey)

"I developed a fistula because of the 4th degree tear which they didn't notice and it led me to have a colostomy. I'm waiting to have an operation on my perineum before they do a bag reversal."

(Online survey)

"I did have a 3rd degree tear which required me to have a procedure, it needed more than just stitches. I thought it was normal, but only recently I found out that it was not normal because my baby was small I should never have had the tear."



MW9 – Asian Other Pregnancy experience in 2019, aged27

At 35 week + 5 days I went into hospital (after waters broke). The day-time staff were amazing, but once it hit 6pm and they swapped shift, the nurse wouldn't even believe I was in labour. She said I could be this way for weeks. She was a young White midwife - She gave me only 1 dose of antibiotics when I was supposed to have 3 and so after birth, I got streptococcus. I faced 17.5 hours of labour mostly alone, the midwives were not supportive. When they came in occasionally they did not examine me nor check progress or baby movement. When they eventually examined me after shouting at me, I had dilated 9cm. I tore and lost so much blood."



MW20 – BMixed Etnic (Asian) Pregnancy experience in 2020, aged 32

8.4.4 Theme four: Postpartum Haemorrhage

Of the 892 survey participants, 17% indicated having postpartum haemorrhage (PPH). This is very high when compared with the average national figure of 7% for England⁷⁶ 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.⁷⁷

The National Maternity and Perinatal Audit looking at differences in maternity outcomes for women and their babies from different ethnic groups and those who live in deprived areas in Great Britain, also shows that Black women have higher rates of major postpartum haemorrhage (1500ml or more) followed by women categorised as 'Other.' 78 The 'Other' category, which is not broken down further highlights the importance of breaking down data down to sub-ethnic groups so some communities do not get ignored or overlooked. The same study showed that South Asian women were no more likely to experience blood loss compared to White women. This does not correlate with the findings of this research as the largest cohort of the survey responses were from South Asian women. Furthermore, 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, it is important to note this cohort was much smaller is size. These results therefore show how current mainstream research obscures poorer outcomes of some minority ethnic women, which means when planning interventions to address inequalities, they continue to be overlooked. One group that particularly tends to have very negative experiences throughout their maternity care was Somali women. This was highlighted by the other stakeholders spoken to as a part of the research such as dhoulas / interpreters, which led to a focus group being set up. One woman in the group (FG2) recounted how she lost so much blood after a stillbirth that she needed a blood transfusion. Another woman in the same focus group (FG6) said she also had to have a blood transfusion but was given the wrong blood type which made her very unwell. Another recurring feature of this case was symptoms being ignored; better care may have resulted in a different outcome. This case has already been mentioned in chapter 5 on Perceptions of Antenatal Care.

The reasons for the excessive blood loss were not clear from the survey results. As the rates of other interventions such as instrumental birth, perineal tears, episiotomy and emergency caesareans were higher, they are most likely to be the cause. Instrumental births no doubt carry a higher risk of causing excessive blood loss due to the nature of procedure, which means that cases should be escalated in a timely manner and performed by an experienced doctor. However, this does not always happen as demonstrated by case **MW26**. Interestingly, in this scenario the woman also sensed team dynamics were at play and wondered whether the more junior Asian doctor was deliberately not being supervised by the more senior White doctor. This is important to highlight given the higher rates of Black, Asian and minority ethnic NHS staff being victims of bullying, harassment or abuse from colleagues. This will be discussed again later in chapter 14.

MW26 - Arab. Pregnancy experience in 2013, aged 30 (NEAR MISS)



When doctors became concerned about her and her baby's wellbeing she was taken to theatre and the ventouse was tried. However, the birth of her baby was undertaken by a junior (Asian) doctor who she felt was inexperienced. Her mother requested the more senior doctor (who was White) to remain and supervise, but was dismissive. Consequently, she ended up losing a lot of blood and had to have a blood transfusion: "A more senior doctor should have been done it. It was clear that there was team dynamics between them which was projected on to my body and this is something that should not have happened. At various points my mum (who is a doctor) got to look but the midwife told her to sit back down."

Not monitoring the labour adequately and poor post-birth care also contributing to excessive blood loss. In case FG4 the midwife did not believe the woman when she said she was ready to push and left the room which meant there was no medical staff present when the situation escalated. Although she did receive help, a lot of blood was lost. In another case (MW28), the new mother was put into a life-threatening situation where she lost a lot of blood because her uterus had not contracted, but was not listened to by the nursing staff when she reported feeling very unwell and in pain. Both women were fortunate not to have lost their lives.

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.

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."

8.5 Positive Experiences of Intrapartum Care

As women are more likely to offer information about adverse events, they were also asked about positive aspects of their care during labour and birth during the research interviews. The examples below provide useful learning about what compassionate care looks like and how it improves the labour and birth experience and include: listening to women, speaking to them in a friendly tone, kept informed, small acts of kindness, considering the birth plan, and showing empathy. They felt heard and seen:

"A senior midwife responded to my concerns over the care during delivery, and took the time to discuss it with me, which helped a lot."

(Online survey)

MW36 - Bangladeshi. Pregnancy experience in 2018, aged 23



Followed by weeks of itching she went into preterm labour at 35 weeks. She was given pethidine and gas and air. However, she was not checked throughout the night and her baby was not monitored. However, she noticed her care change when the shift changed and another midwife and a student came on. Permission was asked if student midwife could be present to which she agreed: "The were (both White) and were amazing. They made me feel comfortable and also advised my husband how to be helpful e.g. cold towel on my head. They also gave me cup of water with a straw. They monitored the baby and really looked after me. They were really encouraging with their words — not harsh or strict. Even said to my husband if he wanted to feel the head when it was visible. They were reading my book and knew what I wanted. I was not cut but had to have internal stitches. Even said if you need me to stop to let me know I can give you more numbing. Also asked how I was feeling throughout. They were so caring they even brought me toast and tea and the student midwife got a bath ready for me. They had to put baby in a warm cot. He had jaundice as well. I went back to give them cards and chocolates."

MW36 - Bangladeshi. Pregnancy experience in 2021, aged 30



"Everyone (in the theatre) was nice introduced themselves and explained what they were going to do. It made me feel relaxed because I knew what was happening. They tried ventouse then forceps which worked and gave me episiotomy and asked for permission. However, I lost a lot of blood 1.5 litres."

MW34 - Bangladeshi. Pregnancy experience in 2019, aged 40



She found that the surgeon's and anaesthetist's words uplifting even though they were brief interactions: "My surgeon was amazing. She was a Russian woman who filled me with so much confidence. 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. He looked over the curtain and said she is nearly out. Oon't worry. When they brought her out they held her up and she said take a photo. My surgery was really positive."

MW32 - Black African. Pregnancy experiences more than 10 years ago, aged 20s



"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."



8.6 Learning

This study shows that one in five Muslim women receive 'poor' or 'very poor' care because, they 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 (**Figure 18**). Access to care options and rates of adverse outcomes can be used as a measure of the quality of maternity care that women receive. It is clear from the findings that the quality of care provided to a significant minority of Muslim women (whether they are Black, South Asian, Arab or of any other minority background), is of poor quality and unacceptable.



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)

After eliminating ethnic groups where sample sizes were really small, an analysis of the data by sub-ethnic groups revealed further inequalities as follows:

- Arab and Bangladeshi women were most likely to have a labour induction.
- Arab women were most likely to have a prolonged labour.
- Arab and Asian Other women were most likely to have vaginal tears.
- Bangladesh women were most likely to have an instrumental birth.
- Pakistani women were most likely to suffer excessive blood loss.
- Bangladeshi and Black African / Caribbean / Other women were most likely to have an emergency caesarean.
- Bangladeshi women were most likely to experience an infection / sepsis.
- Black African / Caribbean / Other women were the least likely to be given an epidural.

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This may explain the particularly poorer satisfaction rates amongst these groups of women as shown in chapter 4. A blanket approach cannot therefore be taken when trying to reduce poorer outcomes and reduce maternal mortality rates as the contributing factors will vary. For example, South Asian women are often all lumped together but as the data in this research demonstrates, Bangladeshi women and Pakistani women will in some instances have poor experiences for different reasons.

Women were not believed or listened to particularly about their pain which included red flag symptoms being missed. Midwives and doctors appeared desensitised to women's pain, which was sometimes reflected in their negative attitudes which included admonishing women. Women were expected to suffer in silence. They were not treated with dignity and respect and the care lacked compassion, which included pressuring them into decisions they did not want (particularly having an induced labour), neglecting them for long periods when they were in labour (of up to several hours) during which time they were not examined, not monitored and foetal monitoring not conducted. Not managing labour appropriately also contributed to traumatic labour and birth experiences and emergency situations because warning signs were not detected early enough. The attitudes, practices and systems made the maternity care so unsafe that it sometimes resulted in still births, neonatal deaths and near misses which could have resulted in harm or even death. Experiences left women with post-traumatic stress and no longer trusting healthcare professionals. The survey data supports these findings because it showed a disproportionate number of women experiencing stillbirths and neonatal deaths - 1% from over 1022 responses, which equates to 10 women, but figures of no more than 3-4 should have been expected.

It is important to note that most of the women surveyed and interviewed were from a higher socio-economic background, who were perhaps more aware of their rights. If this is the level of healthcare service they are receiving, then women from poorer and more deprived backgrounds or new migrant women who may not be proficient in English are even more likely to receive poor and unsafe maternity care when they go into labour.

A cross cutting theme in the accounts provided by women was the attitudes of midwives and obstetricians such as not listening, not taking symptoms seriously, recommending medically unnecessary interventions, pressuring women into decisions, making decisions for them, not providing choice of options, lacking compassion during interactions and feeling they have a right to speak / engage with negative language / tone etc. These attitudes could be based on stereotypes and beliefs held about minority ethnic women, which may vary with sub-ethnic group. In some cases, minority ethnic women may even be considered more challenging to manage because of more risk factors associated with them and underlying fears of making errors could be contributing to sometimes over medicalising birth.

Also, health professionals may be adapting their approach depending on who they are dealing with e.g. less attention given to groups who are perceived as submissive or less knowledgeable about their rights and therefore considered more likely to accept lower standard of care and less likely to complain. Less attention may also be given to groups perceived as over emotional as they may be considered to be exaggerating symptoms. As attitudes are thought to be a significant contributor to the inequalities that exist in maternity services, most recommendations made are therefore related to addressing cultural and behavioural shifts, which need to also happen at NHS Trust Non-Executive Director (NED) board level.



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.



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.



Data on postpartum haemorrhage should be disaggregated down to the level of 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.



RCOG and RCM should jointly address the bias regarding 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.



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.



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.



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

Perceptions of Postnatal Care

9.1 Overview

The area of maternity care in which Muslim women expressed the lowest confidence was postnatal care, which is similar to the findings of CQC Maternity Surveys. Only 54% of the survey respondents rated their care as of 'high' or 'of good standard' compared with 60% who gave this rating to their intrapartum care and 70% who gave this rating to their antenatal care. It was concerning to find that almost 1 in 5 (18%) of women found their postnatal care 'poor' or 'very poor.' To find out what may be contributing to this poor care, this chapter analyses experiences during the first few months after giving birth.

9.2 Post Birth Care in Hospital



The care given to women and their babies immediately after they have given birth is critical for their bonding as well safety and emotional wellbeing. After an exhausting and sometimes traumatic period, too often women were left to fend for themselves and felt neglected. Of the 839 women who provided responses about their postnatal care, more than half (55%) said that they were concerned about their healthcare during the recovery period - with almost 1 in 5 (18%) stating they were 'very concerned.' Those who had a caesarean said that despite it being a major surgery, which made them less mobile and in pain, they were not given any respite and expected to 'get on' with doing things for themselves. They felt this would not happen with other major surgeries. First-time mothers especially found this period in hospital extremely difficult.

"They were very busy and no compassion shown - only time a nurse comes to you is on the drugs round. They didn't help with bathing the baby, or even lifting him out of the cot. Was in extreme pain due to tear and stitches, they wouldn't even bring a food trolley, expected women to walk and get collect food, it was horrific experience. All 3 times I discharged myself as I couldn't cope and needed support with lifting the baby in and out of cot, due to the soreness of my stitches."

(Online survey)

Negative experiences included:

- Not providing opportunities for immediate skin to skin contact with the baby;
- Delays in suturing of tears or episiotomies;
- Long delays before women were cleaned and washed;
- Not providing pain relief despite repeated requests;
- Given incorrect dosage of medication;
- Not recognising symptoms of infection;
- Not recognising excessive blood loss (also covered in the chapter 8);
- Not catheterising women who had an epidural risking bladder damage;
- Not doing the required health checks on the new-borns;
- Not listening to concerns about the new-born's health;
- Not helping to care for the babies such as help with feeding (breast feeding is addressed in chapter 10), changing them or simply picking them up and handing them to their mothers (a problem that was worse during Covid as partners and family were not allowed in);
- Not aiding mothers to see their babies who were in the neonatal unit, (which was sometimes on a different floor making it even harder for women who'd had caesareans);
- Not offering any food and water leaving women to go hungry and dehydrated after a tiring labour;
- Not giving assistance to go to the bathroom; and
- Engaging with women in an aggressive attitude (addressed in chapter 14).

While these examples of poor afterbirth care will not be limited to minority ethnic women, they may experience poorer care due to bias or communication barriers, the consequences of which could be fatal. Even basic needs, like providing food and water, were not being met and when they were eventually given food, no consideration was given to their dietary requirements e.g. vegetarian or 'halal' food. After long labours women were exhausted and hungry. Those who had excessive blood loss were even more fatigued but were expected to get up and walk around and be able to pick up their babies despite the potential risk of dropping them. Some women said that they were only taken care of when they collapsed or when the shift changed. Another issue brought up by around 14% of the women interviewed was not having the opportunity to have skin-to-skin contact and having to ask for it even though this is important to do immediately after birth because of its benefits to both mother and baby as it helps with bonding and milk production.

"On the first night I had own room and midwife and the care was better with more expertise - she was more compassionate and understanding but the calibre of staff was different on the postnatal ward. My experience was awful. It was horrific. It was traumatising. The baby was crying and on me constantly wanting to feed. I had a lack of sleep. I had not had a break, not eaten and not had a drink. The midwife could see I was struggling but when I asked for help she raised her voice and had a go at me. It was only when I asked for someone else she change tone / lowered voice. I said if you are not going to help, me can I have someone else."



MW3 – Asian Other Pregnancy experience in 2021, aged 30 "With my third c-section, I was in pain and could not move but still had to get out of the bed and get the food myself. It was only when I fainted that the nurses started to taking (care) of me. The birth pains were so agonising but I was only given pain killers after repeated requests."



MW22 - Bangladeshi Pregnancy experience in 2017, aged 39 "When I asked for help to go to the bathroom she said 'I've got 20 other women just like you I will come to you when I can.' At that point I had also not been with my baby for 18 hours (as she was in the neonatal unit) and not getting help (wheelchair) to go and see her."



MW1 - Indian Pregnancy experience in 2012, aged 28

"I also had a second-degree tear and they stitched me up. Five hours later I went into recovery, no shower, no feeding baby, who had pooed in the towel and there were no clothes on him. I was still in the same gown and underpants I gave birth in."



MW19 - Bangladeshi Pregnancy experience in 2020, aged 28

"The baby had jaundice so I stayed for three days and kept under a sunbed, he was constantly being sick. I kept saying something is not right but no one was listening."



MW9 - Pakistani Pregnancy experience in 2019, aged 29 "I was unable to get up due to the c-section. Nights were tough, I would press the buzzer but they midwives / nurses would never come. In the mornings the midwives were not pleasant."



MW24 - Pakistani Pregnancy experience in 2019, aged 28

"Other women spoke about their babies being on a different floor when being placed in ICU care and mothers not being assisted and supported in seeing their babies even though they were struggling with their own health. Also, no information was provided about the health of the baby."



MW15 - Bangladeshi Pregnancy experience in 2021, aged 33

"The midwife who was going to administer the vaccination, picked up my daughter and said she is quite yellow and asked if anyone had checked her for jaundice to which I said no. When she checked they discovered the levels were quite high and rising."



MW28 - Mixed Ethnic Black Pregnancy experience in 2019, aged 19 "I am vegetarian or eat halal food only / don't eat pork. There were no food options for me. I got given I bread slice with the thinnest slice of tomato after being there for 15 hours and in labour that was what I was given to eat."



MW23 - Mixed Ethnicity Other Pregnancy experience in 2019, aged 33 A surprising finding was a few examples of midwives allegedly making false entries on patient records such as stating they had made checks or asked questions about mental health and domestic abuse, which had not been done. In once example (MW29), the interviewee said that even though no-one had checked her stitches (for a second-degree tear), the midwife had recorded she had checked her stitches. The woman complained to a manager about this and received a verbal apology. These are serious allegations and hospital trusts should consider how they can be assured that such incidents can be identified through standard processes and staff held accountable.

If standards of post-birth care in maternity units are declining generally or are associated with particular staff or shifts, then hospital trusts should have mechanisms in place to identify this. An obvious method will be collecting feedback from mothers and / or their families through surveys. Response rates are likely to be low because completing surveys will not be a priority for tired mothers, they may lack trust because of their negative experiences or feel they won't be taken seriously. This is discussed further in the chapter 15 on 'Complaining About Maternity Care.' Mechanisms should therefore be introduced to address this gap and capture feedback from the majority of maternity service users across all of the diverse groups of women served. A recommendation on capturing feedback has already been made in the chapter 8 on 'Perceptions of Intrapartum Care.' Prior to discharge, women could be asked to complete an online response via an iPad / tablet PC. To ensure confidentiality, the results should not be immediately accessible by the midwifery staff on shift. Where surveys are not filled in, a link to a survey should be sent to the mother's mobile phone and further reminders sent. Consideration will of course need to be given to those who would find it difficult to access and respond to surveys through these methods and alternative channels provided.

"The midwife could see I was struggling but when I asked for help she raised her voice and had a go at me."

9.3 Maternal Near Misses

Sometimes sub-standard care led to a deterioration of physical health and 'near miss' situations, which could have been fatal to the mother. For example, a woman in the focus group **(FG1)** said she was given the incorrect dosage of a drug after her caesarean, which caused her to be admitted to intensive care.

Focus Group FG1 -Somali. Pregnancy experience over 10 years ago (NEAR MISS)

One woman ended up in intensive care after her caesarean and blamed clinical incompetence:

"I believe I was given an incorrect dosage or medication (through the drip) which saw me end up in intensive care while they gave me an antidote. I don't think they knew what they were doing. I was in intensive care, and my husband was with the baby. He couldn't bring the baby to me. I feel like the bond between me and my baby was broken as I could not breastfeed my child."

In another example, **(MW25)** was only catheterised after a long delay by which time her bladder had been damaged. She was only given the catheter after repeated requests and being more assertive. Delayed recognition of and action on abnormal vital signs such as urine output is a midwifery red flag event that was missed.

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



"After giving birth 10.30am, I was not urinating and my bladder did not seem to be working so at 2pm I alerted nurses and also asked for a catheter. I kept asking for it all afternoon and was not given one until 8pm and that was only because I became more vocal and went to the desk and demanded to be seen. I said, 'listen, call the doctor now! I need to speak to someone urgently.' I was told no one was available but once I became more vocal and sterner in my requests (rather than asking politely), a doctor came to see me quickly. However, by then my bladder had been damaged as it had been over stretched. I then had to wear a urine collection bag for the next four weeks to rest my bladder."

Other women interviewed provided examples of how other abnormal vital signs were also missed because they were not listened to about feeling very unwell, which caused delays their care. Missed or delayed care (e.g. delay of 60 minutes or more in washing and suturing) or delayed recognition or action on abnormal vital signs are likely to be red flag warnings of midwifery staffing shortage or competency.⁸⁰ However, these could also signal an issue with staff attitudes. For example, **MW28** lost a lot of blood (which could have been fatal) because she was made to wait more than two hours before being sutured. This case had already been detailed in chapter 8 on the 'Perceptions of Intrapartum Care'. Similar stories were also found in the survey comments:

"I had to be cut twice and lost a lot of blood. I wasn't given a blood transfusion for days. It's only when I felt like I was going to drop my daughter a few times they realised I need the transfusion."

(Online survey)

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. However, given the accounts provided through the interviews, these are likely to include severe cases of sepsis. For example, one interviewee said that during her one week stay in hospital she found the staff very supportive, who she said were from diverse ethnicities. However, she witnessed another woman on the ward, who could not speak English, crying and groaning in pain, but was dismissed. When the interviewee tried to help by interpreting for the woman in distress, the midwife told her this was not allowed. The new mum was ignored until she collapsed. However, by that time her condition had deteriorated so much that she had to be placed in the intensive care unit.

MW25 presented as being very unwell twice with abnormal signs, each time indicating likely sepsis. The first time was before being discharged from hospital, but she was still told to go home. However, her husband brought her back into hospital because her condition deteriorated. It is astonishing that further investigations were not considered given how she was presenting i.e. not able to walk or talk. She felt at the time her treatment was connected to her ethnicity and the fact she was from Pakistan and spoke with an accent. She said that the midwife and doctor were both White and the junior doctor just parroted what the midwife said. **MW3** also returned to the hospital after giving birth because she was feeling unwell. She too was sent back home, and was only taken seriously and sepsis identified when she went back to the hospital and her husband asked for their concerns to be escalated.

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.

MW3 - Asian Other. Pregnancy experience in 2021, aged 30 (NEAR MISS)



"After a couple of days, I started feeling unwell. At first, I thought I was having postpartum sweats. I had high blood pressure and was shivery and went back to the hospital. The midwife (who was Black) was dismissive. She showed attitude and annoyance by dragging her feet when she walked. She kept poking until she found my vein to take blood and blood went everywhere and I had to ask for plaster. She sent me back home. However, I felt worse and had temperature. I was shivering so bad that I thought I was dying so I went to Accident and Emergency. They did bloods and transferred me back on to postnatal ward. I was told I had sepsis and they looked concerned. I was given antibiotics and kept in for one week. I was also low on iron and they considered giving me a transfusion. If I was listened to when I first went in and not dismissed, I would not have gotten so bad. I had to take blood thinners and also could not feel my left side properly for a while."

In the cases mentioned, the conditions of the new mums had to become extreme and almost fatal before being taken seriously. These scenarios provide examples of maternal near misses i.e. surviving a life-threatening condition related to pregnancy or childbirth. It is important to learn from these 'near misses' as the care provided preceding these events will have common aspects to care that has led to maternal deaths particularly involving haemorrhage and sepsis. As already highlighted in the 'Introduction' chapter both of these are amongst the leading cause of maternal mortality – sepsis (11%) and blood loss (9%). The accounts demonstrate how poor postnatal care is contributing to poor outcomes of minority ethnic women including their deaths.

It is alarming that women were being dismissed when the risk factors for maternal sepsis in pregnancy includes being 'of black or other minority ethnic group origin,' as well diabetes, anaemia and history of pelvic infection.^{81a} The health conditions mentioned are all risks associated with minority ethnic women, trends that have also been highlighted in the survey results and discussed in the chapter 7 on 'Maternal Health Conditions.'

Rapid diagnosis is critical in preventing severe sepsis, septic shock and multiple organ failure, but it is clear that some maternal healthcare providers are failing to recognise signs and symptoms and even when they are uncertain, are not escalating concerns. The cases suggest poor risk assessment including insufficient recognition of risks associated with minority ethnic women, which is probably contributing to the increased maternal mortality rates of Black and Asian women. Given the attitudes of some medical professionals described throughout the report, it is also not unreasonable to suggest that bias and stereotypes may also have played a role in underdiagnosing sepsis. Further research is clearly needed to find out whether there are racial disparities in the diagnosis of sepsis and the reasons for hospital re-admissions for new minority ethnic mothers.

Meanwhile, training on early detection of sepsis should be reviewed and strengthened to ensure medical professionals better understand the increased risks for Black, Asian and other minority ethnic women and that not all signs and symptoms are always present. As sepsis is a leading cause of maternal death, a sensible approach would be to assume sepsis and then try and rule it out.

9.4 Neonatal Care

It was not just mothers who received sub-standard care, Muslim women 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.' The issue of tongue tie was brought up a number of times:

"It took 3 weeks for the first appointment. the procedure wasn't done correctly the first time, and we continued with problems until they repeated it after another 3 weeks. Those first 6 weeks could have been so different for me emotionally if they just had the tongue tie done straight away (in the first place) before I was discharged from hospital."

(Online survey)

In chapter 10 on 'Breastfeeding Experiences,' further examples of not spotting babies having tongue tie have been provided. Other examples included not identifying jaundice. In another example, a baby was returned to the wrong place:

"My baby after birth was returned back to the wrong bed where no1 was there, left alone crying."

(Online survey)

In one case, the wrong baby was given phototherapy. **MW24** (Pakistani, pregnancy experience in 2019, aged 28) said her baby was given phototherapy, but after a few days she was told that her baby did not need it as the bloods tests had gotten mixed up with another baby's results. Not only did this mother miss important time with her new baby but another baby had delayed treatment for jaundice, the consequences of which could have been serious such as brain damage. One of the Somali women in the focus group recalled the medical staff wanting to switch off the incubator:

"On day 11 the machines were switched off the incubator as baby was not making any progress, but the baby lived for another 7 days. I had to travel back and forth on the bus even though I had a caesarean birth. Even after the last time, they promised to look after me - and they didn't."

FG1 - Somali woman (Focus Group). Pregnancy experience 2018.

9.5 Postnatal Care at Home

Once women returned home they felt abandoned and neglected. They said that midwives failed to prepare them (during the antenatal care) for this part of the maternity period. A common complaint was not being provided with information about symptoms and complications to be concerned about and flag up following birth and how these could impact on the quality of their lives. The top issue was poor mental health, which is covered in a separate chapter. Another key concern was not being aware of signs of infection / sepsis and of the best ways to take care of stitches following a perineal tear, episiotomy or caesarean:

"I suffered from a horrible c section infection. I don't know how I managed to look after a newborn during that time."

(Online survey)

In another example, one Black African woman said that following a difficult birth involving forceps and then ventouse, she was not told until much later (when she had problems) that she had been 'cut inside and outside' and that it would take time to heal. Another Black woman explained that even though she had been 'cut to her back passage,' she was not provided with additional information and not made aware of aftercare and symptoms of infection and consequences of it. She said she ended up seeking advice from family members. Even though the cuts were severe, they were normalised to the women i.e. told this was a 'normal' part of giving birth.

When women did ask for help, for example from the GP, they felt not heard and dismissed. They felt that that no-one cared about their pain and suffering:

"They didn't care I had been damaged in labour."

(Online survey)

Another woman said:

"The only thing the doctor was concerned about was trying to convince me to get the coil contraceptive and spent the whole appointment trying to convince me and book me in and dismissed everything else"

(Online survey)

Prolapse care was another issue raised:

"Did not provide support for my prolapse or provide knowledge or information on how to prevent it from getting worse... which eventually happened."

(Online survey)

MW3 also had a similar experience.

MW3 - Asian Other. Pregnancy experience in 2021, aged 30



"After a few weeks felt a bulge and had it checked — needed to sort pelvic floor.

Was only grade 1-2 and was put on waiting list which is 10 months and by that time will get worse grade 3-4 so have gone private and having women's health physio — pessary, rehab and pelvic floor. If it runs in the family e.g. mum and sister have pelvic floor dysfunction — we should get support during and after pregnancy."

The postnatal period is a time where women may be feeling overwhelmed with a new baby and not paying attention to themselves, even when 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. However, 22% of women were 'somewhat dissatisfied' or 'very dissatisfied' with their 6-8 week postnatal check-up (which is usually done by GPs). About 15% also indicated being dissatisfied with the postnatal health check-up for them and their baby/babies that usually takes place within the first 10 days following the birth (usually carried out by midwives).

First time mothers and women who were living far away from families especially those who had migrated to the UK, found this period particularly difficult and needed additional support, advice and information. Women described this period as 'being left to fend for yourself.' Some went further to say that the postnatal period was one of the 'worst experiences in their life.' They also said that the focus of the home visits by health professionals tended to be mostly on the baby and felt they had to pretend to be okay in front of them:

"All focus is on baby and not on woman about how she is feeling. There is a pressure to perform for the health visitor (doesn't want to feel like a failure) e.g. tidy, make up etc."



There was also dissatisfaction with health visitor and midwife home visits in terms of access and attitudes; these are also mentioned in the chapters on breastfeeding, maternal mental health, and impact of the Covid-19 pandemic on maternity care. Health visitors appeared to be particularly criticised:

"Health visitor was not reachable on many occasions and did not ring me back on despite messages left with staff."

(Online survey)

Women complained that their health visitors were difficult to contact and when they were available were not helpful, lacked knowledge or rushed and did not listen:

"I felt rushed and that they just wanted to get to tick the boxes for all they had to do."

(Online survey)

Women's experiences confirm that public health cuts have left health visitor service unable to offer the minimum level of support in some areas.^{81b}

MW31 described the postnatal period as "the worst period of her maternity care and that no one prepares women for it." Her case also highlights the need for strengthening triaging processes at hospital Accident and Emergency Departments (A&E) so new mothers are triaged and dealt with quickly. Postpartum visits to the A&E Department should be analysed and broken down by ethnicity (including sub-ethnic groups) to find out reasons why women present themselves to the hospital via this route to better identify and address the gaps in postnatal care. Others also spoke about attending A&E departments:

"I spoke to my health visitor ONCE throughout my postnatal period. was shocked. tried to contact her about a rash my baby had and ended up having to go A&E because she was so useless."

(Online survey)

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 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."

"I don't see the point of my health visitor at all. I think health visitor. My baby developed allergies from the foods I was consuming. Although the doctor was supportive and understanding she said it was foremilk and completely denied that allergens/allergies could pass through breast milk. I had to gauge the situation with my own intuition and eliminate things from my diet in order to help my baby grow, because my baby had begun losing weight rapidly and was not holding in any milk at all. My baby also suffered from laryngomalacia which I was informed about by the GP at a walk-in centre. I had to take my baby there one Sunday after nonstop inconsolable crying, constant dirty nappies and sudden body rashes. The body rashes were completely ignored and I was told it was eczema and the crying colic, which wasn't the case because there had never been a colic issue before or later especially after eliminating certain foods from my diet. My baby dropped from the 91st centile to a horrifying figure."

(Online survey)

Women were angry about being misdiagnosed when they presented with postpartum health concerns. One woman **(MW31)** said she had to diagnose faecal impaction herself because the GP failed to do so. She was surprised that despite postpartum constipation being quite common and 'excruciatingly painful,' it was not spoken about much and felt that most women would be unaware of even though bowel obstruction can be life threatening.

MW31 - Pakistani. Pregnancy experience in 2021, aged 30



"I suffered from faecal impaction (e.g. badly constipated and was in so much pain that it was too painful to pass wind). When I asked my GP or mentioned it to other healthcare professionals (midwife / health-visitor) no one gave me any advice or told me what it could be. My pain was ignored. It was so painful, I could not pass wind. I eventually went online and found information on 'Netmums' and the 'Peanut app,' which pointed towards me having an anal fissure. Armed with that information, I asked the nurse at the GP's surgery to examine me, who then confirmed it was the case."

9.6 Positive Experiences of Postnatal Care

As women are more likely to offer information about adverse events, they were also asked about positive aspects of their postnatal care during the research interviews. The examples given provide useful learning to improve care and included: support with emotional wellbeing, giving sufficient time to listen, small kindnesses to make the hospital stay more comfortable and helping with the newborn:

"The nurse was nice and took my baby and told me to rest as I was exhausted,"



MW35 - Pakistani,

Pregnancy experience in 2016, aged 25.

Some of the good practice came from the trainees and auxiliary nurses, who perhaps need to be better utilised on maternity wards.

"The midwife who discharged me was absolutely amazing but the health visitor was a different case."

"Very good follow up care. Even helped me with my baby nappy change at a time as I was very weak."

(Online survey)

(Online survey)

"My health visitor was amazing. I was going through some bullying and emotional abuse at that time. She would advise me."

(Online survey)

MW33 - Indian. Pregnancy experience in 2020, aged 29



"The midwife really advocated for me — her support was unbelievable. She continued to help me up to 6 weeks into postnatal period. She visited me every 2-3 days for 6 weeks until my baby hit birth weight."

MW34 - Bangladeshi. Pregnancy experience in 2019, aged 40



"They (the assistants and trainees) come in to do blood pressure and temperature checks — they were kind. They were diverse Pakistani, Bangladeshi, White and were all lovely. They had the mental space to ask what does this patient need and what can I do to make your life easier. For example, one of them came and held my baby for an hour. The old Jamaican dinner lady who was also lovely. It was their small kindnesses that made a difference (e.g. got her a proper large towel for her body rather than a small one). But the senior doctors and midwives were alienating in their conversations — not really connecting on a human level."

9.7 Learning

Women are not being prepared for the postnatal period by not being provided with information about what to expect, including conditions that could develop and warning signs and symptoms to be aware of. They are being neglected and abandoned with little or no support and left to suffer mentally and physically. When medical help is sought, women are not believed and too easily dismissed and red flag signs are missed. Delayed care during this period of maternity care not only causes unnecessary suffering, but is also compromising the safety of mothers and newborns. Substandard postpartum care is therefore likely to also be contributing to the higher stillbirth, neonatal and maternal mortality rates amongst Black, Asian and other minority ethnic women. To prevent further unnecessary deaths, a reform is needed of postnatal care which includes system changes as well as a cultural shift in attitudes.



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 minority ethnic mothers. If this data is not readily available, then hospital trusts should record this data in a way that is easily accessible.



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.



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.



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.



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.

10 Breastfeeding Experiences

10.1 Overview



As breastfeeding has health benefits for both mother and baby, the World Health Organization recommends that exclusively breastfeeding for 6 months (without water or other fluids) is the optimal means of feeding infants. In the Maternal and Child Nutrition guideline, the National Institute for Health and Clinical Excellence recommends increasing breastfeeding rates by education and information provision on its benefits, and overcoming barriers followed by proactive support during the postnatal period that encourages breastfeeding.⁸²

Breastfeeding is regarded as highly important in the Islamic faith and is mentioned in the Quran (2:233). Although the Quran recommends breastfeeding a baby for up to two year of age, it is not mandatory and most Muslim women are likely to breastfeed for a shorter period than that. However, given the benefits of breastfeeding combined with their faith perspective, Muslim women are likely to want to try and breastfeed if they are able to.

It was not possible to determine how satisfied women were with their breastfeeding support as this question was not asked in the online survey. However, breastfeeding experiences did feature in the comments sections and were mostly negative. During the interviews, this theme was therefore explored further and the responses were mixed. When describing their negative experiences, most women said they were cared for by White midwives with a few saying they had Black midwives. The most positive experience involved support from a male mid-wife:

- "I was not asked if it was ok to have a male midwife. I was taken aback by the male midwife
- but he was very good. He was chatty and so lovely and supported me a lot with breast feeding. I didn't wear my hijab I didn't care I didn't mind."



MW33 – Indian, pregnancy experience in 2020, aged 29

INVISIBLE

This was in complete contrast to one woman who said after dealing with different midwives, her most negative experience was at the hands of one who had a similar background to her, which was South Asian.

"The worst experience I had was from a South Asian midwife who was a breastfeeding specialist who came in and said 'my approach is tough love, I tell my mums you need to just get on with it (breastfeeding). It's not always easy and is painful but you need to just get on with it.' I sat there holding back tears already feeling like I had failed. I was already coping with bodily trauma (coping with major mental and physical trauma of major surgery)."



MW34 - Bangladeshi Pregnancy experience in 2019, aged 40

She said it was condescending hearing those words when she was at her most vulnerable and trying her best. She added that she did not want her judgement but her support which she could have provided by giving reassurance and reasons for why her baby may not be latching. The experience was so upsetting for her that she did not want to see that midwife again. Some women did express concerns receiving care from a healthcare professional of the same ethnic background as it did not always result in better care and this is explored in chapter 14.

Even if many Muslim women are having positive experiences of establishing breastfeeding, it is important to find out why a significant number are not as highlighted by their comments in the online survey and interviews.

The five main themes that emerged were:

- lack of information provision
- lack of breastfeeding support
- no night time breastfeeding support
- lack of bottle-feeding support and shame associated with bottle-feeding
- and no breast pump feeding support

These themes are discussed more in depth in this chapter. A recurring complaint across the themes was the lack of support in the method chosen by the mothers, which had a hugely negative impact on their emotional wellbeing, especially if they had also had a traumatic birth experience. At times assumptions were being made about women that they should be able to breastfeed because they were not first-time mothers or because of their ethnicity. The pressures of breastfeeding, lack of support, the tiredness associated with it and, feeling overwhelmed impacted women's mental health and should therefore be considered during any breastfeeding postnatal care.

10.2 Lack of Breastfeeding Information

Women were not being provided with helpful information during the antenatal period which could improve breastfeeding management. For example, many of the women interviewed were unaware that they could start expressing and collecting colostrum during their pregnancy and freezing it for use after birth. Such information would also need to include myth busting information because cultural beliefs of some minority ethnic communities may be contributing to women regarding colostrum as unclean.

"I was not told about colostrum harvesting. If I was told I could have done that, I could have taken it to the hospital and used that to feed baby (via my partner) and could have had a rest."



MW3 - Asian Other Pregnancy experience in 2020, aged 30

"I never got told about antenatal classes till far too long and late into pregnancy, I struggled with breastfeeding, I was not getting any breastmilk because I didn't know I had express before birth so that you could give my baby milk. I was really anxious, the formula was the first proper feed. He's used to formula now so I barely breastfeed."



MW7 - Arab Pregnancy experience in 2020, aged 25

10.3 Lack of Breastfeeding Support

From the women's accounts it was clear that when they had difficulties breastfeeding and asked for help they felt dismissed, not supported and left to struggle on their own, which caused emotional distress to the mother. Women were not being provided with timely advice, support or equipment such as nipple shields, breast pumps or access to experts. The lack of support was resulting in women giving up on breastfeeding with some speculating the lack of support being linked to a bottle-feeding culture amongst some midwives. Also, women raised concerns that the staff on the wards did not have sufficient knowledge about health conditions that would prevent feeding, thus putting babies at risk of harm. A few women resorted to paying for support and advice, which they were able to do because of the advantage of their higher socioeconomic status, further highlighting the social class health equality gap.

"As a first-time mother I struggled with breastfeeding support especially as my baby wasn't gaining the weight she needed to. I was pressured to mix feed as she had tongue tie. I was never offered support on how to breastfeed and reached out to a lactation consultant, who I had to pay for."

(Online survey)

"One person came to ask about my care and I told her that I felt the midwives were being very dismissive and that no one had helped me breastfeed even though I wanted to and she listened but did nothing."

(Online survey)

"Even though I wanted to breastfeed, the midwives kept encouraging me to formula feed. They would make comments such as 'oh are you still breastfeeding him, why don't you do combined feeding?' or You are always feeding him, putting him down. I believe there is probably a culture of formula feeding amongst midwives hence why they don't give support to breastfeed."



MW21 - Pakistani Pregnancy experience in 2020, aged 31

"The birth was two years ago. I really struggled with breastfeeding after postpartum, lactation consultant was twiddling her thumbs, there was an old video playing in a VCR from the 1980s at one of my GP appointments and that was literally all I saw about breastfeeding. No one sits and tells you about breastfeeding or the reality of having a baby."

feed her. I felt helpless and I asked the midwife for help. All I was told was 'just keep trying' and eventually I felt like a failure and just gave her bottle milk. I could feel my breasts getting hard, I asked the nurse how to make my milk come out. She told me to just try. I was trying,"

"She wouldn't latch on when I tried to



MW8 - Pakistani Pregnancy experience in 2019, aged 29



MW27 - Black African Pregnancy experience in 2013, aged 32

"People came to help latch her they were not trained to tell if she was feeding properly - they were not trained. None of the nurses/midwives knew she had a tongue tie, they said my nipple bleeding and bruising was normal. One morning a specialist breastfeeding consultant came in, and she put her finger in baby's mouth and she said she has a tongue tie. I would have given up breastfeeding if I had gone home without seeing a breastfeeding specialist. I should have seen the specialist earlier. I then had to wait three weeks to get the tongue tie corrected, it's a procedure that takes 5 seconds to fix but it took that long. Ouring the first procedure they didn't do it properly, so I had to go back three weeks later to have the procedure again. So, in 6 weeks I was pumping and feeding her from bottles."



MW23 - Mixed Other Pregnancy experience in 2019, aged 33

"When my daughter was struggling with breastfeeding, I asked a midwife for help as I was exhausted, she dismissed me and said it's your baby you can feed her how you wish!" "I was told I was fibbing when I said breastfeeding hurt and was in tears. She disregarded my feelings and what I saidI was finding difficult. I didn't get help."

(Online survey)

(Online survey)

"My health visitor gave me incorrect information about breastfeeding. She knew I wanted to exclusively breastfeed, and knew it was going well but she was trying to push formula on me."



MW30 - White Pregnancy experience in 2021, aged 27 "As a first-time mother I wasn't sure about breastfeeding. I felt like I didn't grasp the concept but the midwife wasn't interested. Signed my baby off. He lost 12.8% body weight and I was back in hospital 3 days after discharge,"

(Online survey)

One woman who had twins was not provided any additional support to facilitate breastfeeding even though she had had a caesarean birth and with one of her babies on another floor in the neonatal unit. She felt health staff may have been deliberately obstructive so they could 'formula feed' her baby. She said the health staff would not bring the baby to her even though she struggled to walk to the neonatal unit. She asked for a wheelchair and was not given one and told none were available. She was very upset to find out that rooms were available near the neo-natal unit but she was not offered one. Even though she had informed the midwives that she wanted to breastfeed, she was told the baby had already been given 'formula.' She started to express her breast milk and stored it in the fridge, but this then disappeared, which she found devastating:

"I have to say for a moment breastfeeding missing milk is like the worst thing that can happen, because the amount of energy it takes to express like you're a milking cow. I was under pressure to ensure I had enough breastmilk so they wouldn't formula feed her. I do feel they deliberately threw the milk away so they could formula feed her."



MW1 - Indian Pregnancy experience in 2012 aged 28

During her second pregnancy she again had negative experiences at the same hospital and felt bullied during a vulnerable time. When she found it hard to breastfeed her newborn and raised it with the nurse she was told:

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



MW1 - Indian Pregnancy experience in 2018, aged 34

Assumptions are therefore being made about women because they have had a child/children or if they are from particular communities. However, the same woman felt her treatment may have also been linked to her faith because she took off her headscarf in the hope that the attitudes towards her would change:

"One of the nurses basically started to speak to me like I was stupid. She said, 'lots of 'you' give your babies formula so then so what's your problem.' So, by day three, I took my headscarf off and I made sure that I was more vocal - it was a very conscious shift."



MW1 - Indian Pregnancy experience in 2012 aged 28

Differential treatment being linked to a woman's background was also highlighted by other women. For example, one woman said that she may have been provided with an excellent service because of her English language skills and noted that those on the same ward who could not speak English were treated differently

There were four other women on the ward who could not speak English properly. They invited me for breastfeeding sessions, even though this was my third child, but the other women on the ward who could not speak English properly were not invited."



10.4 No Night-time Breasfeeding Support

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.

"At 2am I pressed the button, the midwife came and presented herself in a way like I had disturbed her vibe, I said I'm struggling to get baby to latch. She said 'you should know how to breastfeed, you've done it before.' She was so awful and rude. For all I know was my baby could be tongue tied, which is a serious health condition from which the baby could die."

"I was unable to get up due to the c-section. Nights were tough, I would press the buzzer but they midwives / nurses would never come. My mum did come to help and she would give formula as a top-up to the breast, but the midwives at night would not support me. In the mornings the midwives were not pleasant, and were dismissive of breastfeeding."



MW4 - Bangladeshi Pregnancy experience in 2009, aged 32



MW24 - Pakistani Pregnancy experience in 2019, aged 28

"After the husband left, during the night shift around 10/11pm, there was no breastfeeding support from the midwives, the baby was distressed and wanted a feed. Ouring the day time my husband expressed concerns, but they never took any notice. I wanted someone to sit with me and help me breastfeed but that did not happen with the latching on. Nobody took us seriously to check in, my husband had to google search. Once I was home, community midwives came to see me, and I went to the lactation cafes and they gave me nipple shields due to the size of the baby's mouth. She could feed better with them."



MW13 - Black Caribbean Pregnancy experience in 2019, aged 25



10.5 Lack of Pump Breasfeeding Support



A few women mentioned that all advice seems to be geared towards regular breastfeeding including when accessing popular websites. One woman said she managed to pump breast milk for nine months and said this was only possible because she found lots of helpful information scattered amongst blog posts, on forums and Facebook groups such as 'Exclusively Pumping Mums UK.' She managed to find details on types of breast pumps such as medical grade pumps being regarded as the best, techniques and, optimum times to pump. She said this information was not easy to find and took a lot of time and effort. However, such information should be easily accessible to all women and be provided during the antenatal period.

The women interviewed who had difficulties breastfeeding also said that they did not receive support to express milk and found it hard to access high quality equipment on the wards, which was even more problematic if they had to be readmitted to hospital due to complications related to the pregnancy.

"I found the pressure to breastfeed overwhelming. Given that my baby was in hospital for so long, she didn't latch well and the attempts to breastfeed her while also pumping and topping up with formula was a lot. The health visitors and breastfeeding support team kept telling me to persist or to switch to formula. I chose to exclusively pump and was heavily discouraged by the health visitors. They did not provide me with support or help and told me that my milk supply would dry up anyway. At an already traumatic state, they did not help. I didn't feel like I could share my mental health concerns with them, as they added to the anxiety I felt. They did sign post services though."

(Online survey)

"I Found conversations around breastfeeding very difficult and unsupportive. Entire conversation is focussed on breastfeeding via the breast. Need to recognise that breastfeeding is incredibly difficult for some women. I breast fed via breast pump for 9 months. I had no support in that journey. I was laughed at by the midwife and health visitor said let's see how long that lasts. You will move on to formula. All helps, tips and support was found online on Facebook and blog post,"



MW34 - Bangladeshi, Pregnancy experience in 2019, aged 40

"I also did not know how to breastfeed. When I asked the midwife, she gave me cutting eyes and said you just put your breast in the baby's mouth. I also asked for a breast pump, but the midwife did not respond for 6 hours. I eventually found one myself and began using it. Two Asian ladies visited me from the breastfeeding team and helped me breastfeed,"



MW19 - Bangladeshi, Pregnancy experience in 2020, aged 28 "I needed some there with me physically tell me and show me what to do rather than telling me on the phone. It was one telephone call then I was left to it. There is nothing or very little out there if you use a pump which is what I had to resort to as baby did not latch back on."



MW31 – Pakistani, Pregnancy experience in 2021, aged 30

"I was admitted to hospital. I asked for a breast pump so I could continue breastfeeding my baby but was told they didn't have one. It could not be taken out of the maternity ward."



MW36 – Bangladeshi, pregnancy experience in 2018, aged 23

10.6 Shame Associated with Bottle feeding

Not all women are able to exclusively breastfeed for a variety of reasons, which may include just not have the energy to sustain it. However, they can be made to feel guilty about their choice to bottle feed or doing mixed feeding. This was causing women mental distress because they were in some cases already feeling guilty:

"There is so much shame around stopping breast feeding and feeling like you are failing,"

(Online survey)

Another woman said:

"Didn't feel comfortable explaining I found breastfeeding difficult even though it was second child I would have liked someone to say it's ok to bottle feed. Having another child and trying to keep up with breastfeeding was very difficult."

(Online survey)



10.7 Learning

Mothers are being failed, especially during the night when breastfeeding support appears to be non-existent. When babies have feeding difficulties, concerns are dismissed and insufficient help provided, including the failure to diagnose tongue tie leading to delays in treatment. Women's choices are not always supported and sometimes even obstructed. The lack of compassion, pressure and judgemental attitudes is causing women anxiety and adding to their mental distress at their most vulnerable time. The information provided is limited and often does not included tips that would benefit women and their babies such as collecting and storing colostrum during pregnancy, expressing milk for breastfeeding or other tips such as using nipple shields.

Some women are resorting to seeking information themselves online and paying for breastfeeding advice privately. However, not all women have the means to rely on such options. Insufficient infant feeding support is therefore disadvantaging women from poorer socio-economic backgrounds the most. Failing to provide mothers with support tailored to their needs will no doubt be contributing to them giving up on breastfeeding within the first six months, which is considered the optimum time for the best health benefits for mother and baby.



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.



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



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

11 Domestic Abuse

11.1 Overview



Domestic abuse may begin before or during pregnancy and may get worse during pregnancy or soon after giving birth. According to Safe Lives, around 30% of domestic abuse begins during pregnancy, while 40–60% of women experiencing domestic abuse are abused during pregnancy.⁸³ This risk of harm to pregnant women and their unborn babies increased during the Covid pandemic. In the first lockdown, calls to the National Domestic Abuse helpline rose by 25%.⁸⁴ During 2020, calls about domestic abuse also increased by 16% on the Muslim Women's Network Helpline.⁸⁵ The worsening of domestic abuse has also been confirmed by the rise in number of domestic abuse offences recorded by police in England and Wales during the pandemic.⁸⁶

Domestic abuse during pregnancy already increases the risk of miscarriage, foetal injury, infection and premature birth. It can also cause mental distress to the woman and put her life in danger. Although women of any social class, age or ethnic background can be a victim of domestic abuse, women from racialised minority communities may be more vulnerable if they have language barriers or insecure immigration status, as this may prevent them from disclosing any abuse. It is therefore crucial that healthcare professionals use antenatal appointments as an opportunity to enquire about domestic abuse. Despite the NICE guidelines recommending that enquiries are made about domestic abuse during pregnancy,⁸⁷ not all women are being asked about it.

11.2 Domestic Abuse Screening

Two thirds of the women who responded to the survey were 'satisfied' or 'very satisfied' about being asked about domestic abuse. However, 14% were 'neither satisfied nor dissatisfied' and 9% were either 'dissatisfied' or 'very dissatisfied' while 9% could not remember. These responses indicate that about 1 in 4 women are not being sufficiently screened for domestic abuse. The dissatisfaction rates (i.e. 'dissatisfied' or 'very dissatisfied') were compared for women according to their ethnicity to investigate whether there were differences in perceptions of domestic abuse screening. There were striking differences – the dissatisfaction rates were the highest for Arab (14%), Asian Other (14%), Pakistani (13%) and Black African / Caribbean / Other women (14%), followed by Bangladeshi women (10%) Indian (5%) and White women (5%).

Of the 37 women interviewed some had not been asked at all, others only during the first antenatal appointment. Some said domestic abuse was not raised until the postnatal period. Examples of comments in **Figure 19** highlight this variation in practice.

Figure 19

Domestic abuse screening during pregnancy - variation in practice shown by survey comments

"This was always asked with all my appointments."

"They didn't ask me. I only saw the leaflet in the toilets."

"Was only asked this question after I delivered my baby. I should have been asked at the outset." "The midwife took me aside (away from my husband) and asked about DV. It filled me with confidence."

"They asked the questions like they're scanning supermarket checkout items without having any feeling."

"Not that I was at risk but I was never asked, maybe as my husband did always attend my appointments."

"It was complicated to raise issues of domestic violence when my partner was present."

"Oon't think it was explored beyond my first appointment where it was asked." "was always asked privately and by various people in the antenatal team." "I was asked twice. I'm happy they are asking, but it needs to be more often."

"I wasn't asked this question other than by the health visitor."

"I was asked about potential OV in a discreet manner."

"I was asked if there's domestic abuse on the telephone. There was no abuse but if there was I would not feel comfortable."

- good practice
- average practice
- poor practice

"Not that I was at risk but I was never asked, maybe as my husband did always attend my appointments."

The inconsistent approach means that some women are not provided with the opportunity to makes disclosures that could potentially save their lives and the lives of their babies:

"I was never asked about domestic violence by a midwife when pregnant, midwives didn't ask me if I did, I would have said yes, but no one ever asked me."



MW11 - Bangladeshi

Pregnancy experience more than 10 years ago, aged 23

(she lost her baby towards the end of her pregnancy)

Another similar experience included:

"I was not asked about it – not suffering it (at the time) but had in my previous marriage when I was 21 years old."



MW33 - Indian,

Pregnancy experience in 2020, aged 29

Although there was no indication that the poor practice in these cases (or from the online comments) was linked to discrimination, rushed appointments and dismissive attitudes (which sometimes were perceived as discriminatory) are discussed in other chapters. Negative attitudes also resulted in women not having enough confidence in healthcare professionals to raise safety concerns as illustrated by the following comments:

"I was not suffering the abuse so it did not affect me, but I didn't feel anyone cared so even if I did have concerns I wouldn't ask them for support."

understanding."

"You don't feel 100% secure in telling

situation because of fear of them not

them everything about your home

(Online survey)

(Online survey)

Some of the online survey participants and the interviewees said they assumed that the reason for midwives not enquiring about domestic abuse may have been because they were accompanied by their partners Although, midwives may be trained to employ tactics to speak to women alone (as highlighted by this interviewee), they not have time or cannot be bothered to follow good practice:

"They asked my husband to leave and asked me a domestic violence question."



MW12 - Arak

Pregnancy experience 2011, aged 27

Other women also provided positive examples of domestic abuse screening and follow up care, demonstrating the impact of good practice as highlighted by the case study below.

MW27 - Black African. Pregnancy experience in 2013, aged 32



During one of her antenatal appointments the midwife asked her how things were at home and mentioned domestic abuse. The woman disclosed that her husband had repeatedly pushed her out of the marital home and in the process bruising her arms each time. She explained how she would sit in the park and eventually return home. The midwife referred the woman to a local organisation and she was provided support through a domestic abuse support worker. The support worker contacted her every week and gave her information on how to apply for alternative housing which she did.

It is important to note that when healthcare professionals make referrals to domestic abuse support services, where possible, specialist support services are identified that can support women according to her needs e.g. those that are able to adapt to cultural, faith or language needs. When screening for domestic abuse, it is important to enquire about all forms of abuse not just physical abuse. For example, during her postnatal period, one of the interviewees explained how financial and emotional abuse by her husband contributed to her postnatal depression, which was not picked up by the health visitor until she became suicidal.



11.3 Learning

Healthcare professionals such as midwives and health visitors who are in regular contact with women during and after their pregnancy are ideally positioned to enquire about and identify domestic abuse, make referrals to specialist services and if necessary, involve social services. Given the inconsistent approach taken as highlighted by this research, healthcare providers should review why all of their staff do not have a consistent approach to domestic abuse screening within their services. All women should have an equal opportunity to disclose abuse and also have trust and confidence in the healthcare staff to be able to do so.



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.



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

12 Maternal Mental Health

12.1 Overview



Perinatal mental health problems are those which occur during pregnancy or in the first year following the birth of a baby and as many as 1 in 5 pregnant / new mothers are experiencing them during this time.⁸⁸ A slightly higher statistic was reflected in the survey results - 22% of Muslim women said their mental health was affected during maternity, potentially indicating greater emotional wellbeing needs.

Mental health may deteriorate for a number of reasons as highlighted by the online comments and interviews such as:

- Physical health problems or pregnancy complications (e.g. high blood pressure, severe pregnancy sickness or health conditions that develop after birth)
- Having a traumatic birth
- Worrying about the baby's health
- Infant feeding difficulties
- Baby loss
- Managing employment
- Managing caring responsibilities or other personal commitments
- Not having support
- Being isolated
- Having previous adverse pregnancy outcomes
- Exhaustion
- Domestic abuse
- Experiencing discriminatory treatment by healthcare professionals.

The perinatal period is clearly a time of significant risk to women's mental health and the Covid pandemic is likely to have made this even more challenging as psychological services have been even more difficult to access. The proportion of Muslim women saying they were very satisfied with the mental health support they received was higher during the antenatal period than for the postnatal period. Conversely, the proportion saying they were very dissatisfied was higher for postnatal period than the antenatal period as shown in **Table 10**.

Table 10 - Satisfaction levels of mental health support for women who gave birth within the previous 5 years (n=811)

Satisfaction levels of Care (whether asked / appropriate support provided)	Antenatal Period	Postnatal Period
Very satisfied	44%	36%
Somewhat satisfied	23%	26%
Neither satisfied or dissatisfied	12%	12%
Somewhat dissatisfied	12%	8%
Very dissatisfied	8%	12%
Don't know / can't remember	1%	6%

After eliminating data for those women who had a neutral opinion (i.e. who were 'neither satisfied nor dissatisfied'), there was a notable difference when the data was broken down by ethnicity. All ethnic groups were less satisfied with their postnatal mental health care except for Arab women who more dissatisfied during the antenatal period. White and Indian Muslim women were the most satisfied with mental health care during (over 70%) and after pregnancy (just under 70%). The next group was Pakistani women who had satisfaction rates of just over 60% for both the antenatal and postnatal period. Although Black women had similar rates to Pakistani women during their antenatal period, their satisfaction rates dropped during the postnatal period to just under 50%, which meant that of all groups they were the least satisfied with their postnatal mental healthcare. Just over 50% of Bangladeshi women were satisfied with their antenatal and postnatal mental healthcare.

When focussing on the dissatisfaction rates, Arab women had the highest dissatisfaction rates followed by women from the Asian Other group (**Figure 20**). These trends also broadly reflect the overall satisfaction rates of maternity care amongst the sub-ethnic groups as already discussed in chapter 4. The differences that keep emerging between the different groups of women need to be examined to find explanations. As already discussed in chapter 4, all differences cannot be explained by socioeconomic status or because women are born outside the UK. In the following sections, women's accounts of their experiences will help to at least identify the gaps in care that are contributing to their poor mental health care.



12.2 Antenatal Mental Healthcare

When focussing on the dissatisfaction rates for mental healthcare and support during the antenatal period, the number of women that being 'dissatisfied' or 'very dissatisfied' were as follows:

- 2 in 5 for Arab women
- 1 in 3 for Asian Other women;
- 1 in 5 for Bangladeshi, Pakistani and Black women; and
- 1 in 10 for White and Indian women.

These differences highlight the importance of disaggregating data and how broad categories mask inequalities. The reasons for these differences in experiences need to be explored further. As the vast majority of the women who took part in this research were of a higher socio-economic status, their inequality cannot be linked to their class. That a greater proportion Arab (55%), Asian Other (51%) and Black (73%) women were born outside of the UK so this could be a contributory factor. For example, they are more likely to be isolated with less family and social networks and their needs may be missed by healthcare professionals, which did surface during the research:

"Having no immediate family here in the UK, my concerns were not taken into consideration much."

(Online survey)

An analysis of the survey comments, some of which are highlighted in **Figure 21**, revealed the following main themes.



Women were not being asked about their mental health and when they requested help, their concerns were dismissed

When women were asked and mental health needs identified, their needs were not met sufficiently.

Figure 21 - Antenatal Period - Survey comments about mental healthcare

Positive experiences

"I got asked but not every time – staff were lovely."

My anxiety after miscarriage was dealt with amazingly."

"Face to face home appointments were brilliant."

"My midwife referred me to a social worker and perinatal mental health team."

"I was definitely asked about my mental health at appointments."

Inadequate support

"They asked me and referred me, but the referral was not accepted."

that queried this after a traumatic birth."

"It was only one GP

"I was referred to the mental health team but after 6 weeks was left to it."

"They asked because it's a risk factor in my notes. I don't think they would have asked otherwise."

"I was asked by there was no regard for this during second half of my pregnancy."

"I did express about my mental health which they did take on board but the help came very late."

"Staff often asked how I was but never delved further."

"They did ask about my mental health during appointments but I felt rushed."

"It felt like a tick box question."

Not asked or dismissed

"Mental health was not assessed or spoken about."

"Was told it was normal to feel low."

"I was refused counselling because I was not suicidal."

"No mention or questions of mental health asked or even discussed throughout pregnancy or after birth."

"I don't recall them ever asking despite the fact that I had been on anti-depressants for a few years before the pregnancy."

"No one asked about my mood even though this was my 3rd time having hyperemesis."

"They said they would put me on the radar, but no follow up or call to see how I was doing." "Midwife did not probe about my mental health but ticked she had asked in my records"

"Midwife didn't seem interested in exploring my emotional state."

Similar concerns were raised by the women interviewed who also said that they were not provided with information about symptoms and how to seek help. Women are therefore missing out on the benefits of early detection and education on the issue, which could help with greater awareness of postnatal depression after giving birth. There were several examples of women who were interviewed sharing accounts of feeling so unwell from pregnancy sickness that it made them feel like terminating the pregnancy and even becoming suicidal (also see chapter 7 on maternal health conditions). These women were not offered any psychological support despite their very obvious distress when they were seen by health professionals.

MW3 - Asian Other. Pregnancy experience in 2021, aged 30



"I experienced perinatal depression. I wasn't formally diagnosed but I knew I had it. I was always crying, the pregnancy made me feel really down and depressed. I was getting really negative and dark thoughts. I wasn't enjoying my pregnancy because I was so severely sick during the first trimester it was not ending. I was constantly breaking down to my partner, I was an emotional wreck."

MW4 - Bangladeshi. Pregnancy experience in 2009, aged 32



"My mental health was very low. I told my husband to get a knife and stab me to stop the pain. I thought no one could help me. It upset me that why did I go to such extreme health experiences to get basic treatment. I was also never told about mental health support, or offered anything, or even asked at any of my appointments during antenatal or postnatal."

MW18 - Pakistani. Pregnancy experience in 2020, aged 30



"The letter said I was not eligible for counselling due to low risk level but because I had CBT before, I thought I would have been high priority. They asked me questions such as where does the husband work, I said he was a banker, they realised we were not poor, there was no OV, that's what determined low risk. I would now like some perinatal mental health counselling but again, this is not available to me."

MW36 - Bangladeshi. Pregnancy experience in 2018, aged 23



"I felt depressed at around 5-6 months of pregnancy. I was not asked and ended up seeking help myself because I felt really low and felt suicidal. I contacted my GP and was referred, but it was a kind of talking therapy rather than counselling as when I called it was a different person."

INVISIBLE

If UK born women are being dismissed in this manner when they ask for help while also displaying 'red flag' signs, then migrant women are even less likely to be heard. It is clear from these accounts that NICE guidelines on Antenatal and Postnatal Health (CG192)⁸⁹ are not being followed. These recommend that not only should healthcare professionals be enquiring about a woman's mental health but also have an awareness of barriers they may have. Arab, Asian and Black women are from cultures where mental ill health carries a much greater stigma making it very difficult to disclose any problems with their mental health. This may be further exacerbated by worrying about being perceived as a bad mother, also linked to cultural attitudes within their communities and family. If these women are already facing many barriers that make it difficult to talk about their mental health, this is then being made worse by healthcare professionals who are dismissing their concerns or not providing support according to their needs.

Positive experiences by some of the women are included in Figure 2 to show the unequal care received by women. One woman said she only received any help, (having been denied care despite requests for help), once she complained:

"I was given specialist care after my complaint to PALS"

(Online survey)

Other women said that after initially being ignored when they requested for help, they stopped asking even though their mental health deteriorated:

"This just felt like a tick box question with no follow up. I don't bother mentioning my wellbeing anymore."

(Online survey)

It was also concerning to find that women were being denied support because their mental health was not considered poor enough (i.e. they were not suicidal based on assessments by non-clinical staff) or because they had already come into the pregnancy with a history of poor mental health and had accessed treatment previously:

"I was referred to the Mental Health Midwife. However, I was told because I'd already had some therapy for my PTSD and that my mental health was connected to the situation I was in then there wasn't really any point in seeking further treatment."

(Online survey)

These comments indicate how overstretched NHS mental services are contributing to inadequate care.

12.3 Postnatal Mental Healthcare

When focussing on the dissatisfaction rates for mental healthcare and support during the postnatal period, the number of women that were 'dissatisfied' or 'very dissatisfied' were as follows:

- 1 in 3 Arab and Asian Other women;
- 1 in 4 Bangladeshi and Black women;
- 1 in 5 for Pakistani and Indian women; and
- 1 in 10 for White women.

Even Indian women who had similar dissatisfaction rates to White women during the antenatal period were as dissatisfied with their postnatal mental health care as Pakistani women. Women's reasons for not being content with their mental healthcare during the postpartum period were similar to those during pregnancy: of not being asked, having concerns dismissed or receiving little or late support. During the postnatal period (as discussed in the chapter 9), women felt more overwhelmed, abandoned, ignored and forgotten during a time when they were the most exhausted because they were sleep deprived, managing a new baby (especially first-time mums), breastfeeding, and juggling other caring responsibilities - all of which provides a good understanding of why women often have poorer mental health during the postnatal period. Situations were even more difficult for those with physical health problems caused by traumatic births or when babies were unwell.

As already highlighted in the introduction chapter, mental health conditions remain one of the leading causes of pregnancy-associated deaths between six weeks and a year postnatally. Against this backdrop and given women's poor physical health during the postpartum period, it is surprising that greater effort is not being made to screen and follow up on mental health and emotional wellbeing. This suggests that this is not an area of maternal health considered a priority by the government or healthcare providers and hence it is not properly resourced.

When women's accounts were examined, the following six main themes emerged, which are discussed further.

- 1. Women not disclosing despite being asked;
- 2. Women not being provided with information;
- 3. Women not being asked or their concerns being dismissed;
- 4. Women's mental health not considered poor enough to be given support;
- 5. Previous history of poor mental health ignored; and
- 6. Women asked but insufficient support or follow up.

The few examples of positive experience that were provided by women were due to the attitudes of individual healthcare professionals. Having consistent high quality care throughout the maternity period seemed rare but an example was found:

"I was asked about mental and emotional wellbeing both by my doctor at my six-week check as well as nurses and health visitors that conducted their visits. I feel everyone did their part to ask and check,"

(Online survey)

Screening was sometimes conducted through a detailed questionnaire and interventions also included speaking to partners and family members and suggesting how they could better provide support:

"She asked if I needed help and I broke down. She supported me in explaining to the family if they recognised my feelings and to consider allowing me to visit my mother and stay there for a few nights. This was extremely helpful."

12.3.1 Theme one: Women not disclosing despite being asked

Some women said they were asked about their emotional wellbeing but lacked the confidence to say anything:

"I didn't feel able to bring this up so they didn't know."

(Online survey)

For this reason, some preferred having questionnaires, although this method would not be appropriate for everyone:

"I prefer someone giving me a questionnaire to write it down."

(Online survey)

Other barriers to talking about mental health included being asked in the presence of other people such as family members or students or trainees:

"There were students in the room and I didn't feel comfortable to talk about my feelings so openly in front of them."

(Online survey)

One of the women interviewed also raised this as a concern. Greater stigma and shame being associated with mental health within some cultures was also a barrier, meaning that women continue suffering in silence.

"Health visitors were excellent, but when asking about my mental health, it was only as a tick box exercise. I went to see the GP and she had a trainee doctor in the room, so I did not feel comfortable saying anything, as I did not feel it was a safe environment."

MW19 - Bangladeshi
Pregnancy experience in 2020, aged 28

"Asian women don't talk about mental health and are expected to get on with it. There is a stigma attached. If you say you are suffering then, it is considered bad – that you are not doing a good enough job with your child so you pretend you are ok."



MW31 - Pakistani Pregnancy experience in 2021, aged 30

12.3.2 Theme two: Women not being provided with information

Not being provided with information was mentioned repeatedly. This resulted in delays in seeking help as symptoms were not recognised. This was then made worse when they were being told by friends, family and sometimes even health professionals that it was 'normal to feel low.' Information would not only help in the recognition of symptoms but also help women better understand the emotional changes they were experiencing. Women had to rely on finding their own information online:

"I've also been using online resources such as mind website for PTSD and anxiety,"



MW14 - Mixed Ethnicity (Other) Pregnancy experience in 2020, aged 30 "The health visitor asked if I was feeling 'down.' I stated I was not but as at the time as it was a very overwhelming experience - I couldn't differentiate between feeling down and with feeling overwhelmed. I later realised I was suffering postnatal depression."

"I was experiencing separation anxiety from my newborn, but didn't realise this was a thing until much later. I assumed it was just a new mum feeling. These were not mentioned or pick up on. It was a broad depression anxiety (on questionnaire), I answered no. The box was ticked and we moved on."

(Online survey)

(Online survey)

MW35 - Pakistani. Pregnancy experience in 2016, aged 25



"Information would have helped me better understand what was happening to me emotionally. In some ways felt abandoned. I felt overwhelmed. I felt down and used to cry a lot but would not tell my family. I was feeling like I was not a good mother because I cannot breastfeed and I am not looking after him (baby) properly. I was also knackered for the first few weeks and not feeling like myself and just wanted to sleep all the time. Talking to a therapist would have helped to spill the beans about how I was feeling. I could not tell my family as they would not understand (and be dismissive)." She felt in her culture you are expected to get on with it especially by the elders.

12.3.3 Theme three: Women not asked or concerns dismissed

Not being asked about emotional wellbeing was also repeatedly mentioned with many women stated that the checks during the postpartum period (first six weeks following birth) by the community midwife, health visitor and the GP were focussed on the baby and the mother's physical health but not her mental health despite recommendations in the NICE guidelines. There were also a few examples of women who had lost their babies before or during labour who were not provided with any bereavement care. A few women mentioned feeling so desperate that they ended up paying for therapy, again highlighting how women from higher socio-economic backgrounds being able access healthcare privately when NHS services didn't meet their needs. Women from poorer backgrounds would not be able to access such facilities.

In the most serious cases women contemplated suicide. One interviewee (MW36) gave a detailed account about how she was going to take her own life. Women are only becoming visible to healthcare professionals when their mental health has deteriorated severely, yet early detection could prevent women getting into a crisis situation.

MW36 - Bangladeshi. Pregnancy experience in 2018, aged 23



"When my baby was 5 weeks old, I gave the baby to my mum and left the house. Before leaving I told my mum, I can't do this anymore. I was so overwhelmed. I then switched off my phone and walked to a bridge that is over a motorway. I was going to jump off it. However, I decided to switch my phone back on to look at my son's photos for the last time and sat down in a park by the bridge and I cried and cried. Then a policeman arrived and found me because my mum had contacted the police. My health visitor was informed who then involved social services. Finally, I felt listened to and received the necessary support."

"I constantly told my health visitor
I was not feeling well. My EPOS
(Edinburgh Postnatal Depression
Scale) also scored high. She did
nothing about it, just said she would
check up on me but never did. I spoke
to my GP about it, they did nothing.
I sought private therapy."

"I went to the doctors for my 6 week check-up. All they did was ask me if I'm feeling okay. No in depth conversation about my mental health which I did need help with. Luckily, I have a very supportive family who have helped me however it's not like this for all people."

(Online survey)

(Online survey)

"Nobody asked me about my moods. I had lost my confidence and felt traumatised with the emergency c-section and painful recovery. None of this was addressed.

Just the physical checks of the wound healing."

(Online survey)

"Emotional and mental well-being were not touched upon! Coupled with the pandemic, it was very tough going through the postnatal blues."

"They didn't ask me about it nor offered any support. I had postnatal depression and this was not identified until month later."

(Online survey)

(Online survey)

"Most questions were related to physical health, postnatal exercises, breastfeeding and the baby's health as far as I can remember, not emotional health."

(Online survey)

"I was very low and no one asked."

(Online survey)

"I felt that any concerns were downplayed."

(Online survey)

"I had a particularly tough time postpartum. I still to this day have had no help from medical professionals."

My first pregnancy and birth (now 8.5 years ago) was horrendous. No mental health care or emotional support was provided."

(Online survey)

(Online survey)

"I also paid privately for about 10-12 sessions at £50 an hour."



MW11 -Bangladeshi

Pregnancy experience more than 10 years ago, aged in her 20s

"My anxiety got so bad I couldn't eat, sleep and cry all day. I couldn't focus on my work. My midwife did not ask me about my mental health even though it was in my notes and that I need extra support."

"I was not offered any mental health care, I was just given a leaflet, but no one reached out. I dejected mentally; I couldn't lose another baby. There was no support."



12.3.4 Theme four: Women asked but insufficient support or follow up

When enquiries were made about mental health, these were not always in-depth conversations and often women felt it was a tick box exercise. Also, when women revealed they were struggling with their mental health and how it was affecting them, it was not followed up appropriately and they felt forgotten. Waiting too long for help during such a vulnerable time in a woman's life can have fatal consequences given the suicide rates amongst this group of women. Also, services were not always accessible and only a small number of sessions are provided. There appears to be lack of recognition that the complex mental health needs of the women, including severe trauma and bereavement means that women may need long term support.

MW16 - Indian. Pregnancy experience in 2019, aged 35



"I did not have the support I needed after birth. The bereavement midwife came once to introduce herself. I was contacted a few weeks after, but that was not really helpful. They gave me a leaflet and a memory box. I didn't hear from the hospital. There was particularly no support for mental health. I asked my GP to organise counselling, but it was very short due to funding issues. I then had some through a voluntary trust from a bereaved parent's charity."

"Asked about it, limited conversation."

(Online survey)

"After birth I've been on the postnatal therapy waiting list for 4 months."

(Online survey)

"I never got asked about my emotional and mental health wellbeing until my 6 week check up on the phone when I did the questionnaire about it. Initially on the phone or any check-ups for my baby no one really asked."

"I was only ever asked about my mental health and well-being by the healthcare worker who visited the house, but never by my midwife. She was sympathetic but could not offer any kind of support. I had postnatal depression."

(Online survey)

(Online survey)

"They would ask about my mood but no follow up. Wasn't happy with the questionnaire and set answers setting."

(Online survey)

MW20 - Mixed Ethnic (Asian). Pregnancy experience in 2020, aged 32



"A lovely midwife I met signposted me to a service, but I could not attend as it was outside the residential boundary. I think I need long-term therapy based on the birth trauma."

12.3.5 Theme five: Previous history of poor mental health ignored

Prior to their pregnancies, some women had pre-existing mental health conditions such as anxiety, depression and post-traumatic stress disorder. Even when this was flagged up, it was sometimes ignored, which could be putting women at risk of self-harm. Women with a history of mental health illness should be routinely offered support as they are even more likely to suffer from anxiety and depression during the maternity period.

"Previous pregnancy resulted in postnatal depression and it wasn't thoroughly checked and I was anxious the second time Around but there wasn't much support."

(Online survey)

"On the whole care was focused on my physical wellbeing and that of my child. I have a longstanding history of anxiety and depression. Although I self-referred to get CBT therapy during my pregnancy to pre-emptively combat any postnatal depression, I didn't feel there was much emphasis on this post giving birth and if I had not referred myself I would not have been encouraged to talk about any issues I may face or were facing emotional or mentally. The only time was during a postnatal check up where I filled out a form documenting my emotional well-being. Often appointments were brief and a quick question of are you feeling ok? Seem to be the only vague nudge to speak about mental health."



12.3.6 Theme six: Women not taken seriously or assessed as depressed enough

One of the most worrying findings was women's mental health not being considered poor enough to receive interventions. For example, if they were not feeling suicidal, they would not be given any help. Assumptions were made that women were coping with motherhood, their mental health was fine. Mental health should not have to deteriorate considerably before women are given any support as this is putting them at risk of serious harm as demonstrated by the survey comments and interviews. The findings indicate that women had to meet very high thresholds to be considered unwell enough to be offered therapeutic treatment. Despite women being in crisis and displaying 'red flag' symptoms, worryingly they were still being missed and considered as not meeting thresholds. There was evidence that initial mental health assessments were being made by non-clinical staff, which in part contributed to women's needs being missed. There were examples of women not being given any help until they reached crisis point (also mentioned earlier) including attempting to take their own life.

MW7 - Arab. Pregnancy experience in 2020, aged 25



"If they saw that you were giving enough care to the baby and on the outside were together, they would tick you off the list and move on to their next person. I did ask to be referred to the for MH counselling sessions, more often they're looking or someone obviously depressed and down. At an 8-week check-up they did ask about MH and they filled out a form. But I'm experiencing it more now four months after birth than I felt it the first six weeks. They need to offer something for MH for pregnant women for the first 6 months after birth."

"Professional acknowledged my changes however did not provide advice or support, generalised my feeling saying it happens and is natural."

(Online survey)

"I suffered severe depression. I asked for support but was just told it's normal to feel like that but what I needed was someone external to speak to."

(Online survey)

"I was asked and I responded as honestly as I could. I was very young, just turned 20 with my first child and didn't know whether what I was feeling was normal, but I wasn't deemed quite depressed enough!"

(Online survey)

"I was diagnosed with PTSD and PNO. Nobody did a check up on me after the hospital and refused to give me appointments for counselling (when requested)."

(Online survey)

"Not satisfied because they didn't listen to my concerns on postnatal depression and did a chart test and told me it wasn't severe and no extra support given."

MW25 - Pakistani. Pregnancy experience in 2016, aged 30



She felt overwhelmed and depressed and was struggling. Even though the midwife referred her, the person who assessed her at the hospital (who was not a counsellor) told her (after asking her questions) she could not have counselling because her score did not reach the threshold: 'You are not feeling suicidal, you cannot have counselling, we will wait until you give birth.' This really upset her.

"I was asked and they gave me a follow up appointment all over the phone, I was referred again but was told again I wasn't suicidal so they didn't accept it. At times I did become suicidal especially after the email I was sent by them as I had lost hope and felt like no one cared. Eventually I told health visitor it was manageable now but I know how bad it was a few weeks back also the questionnaire only focuses on the last week. The health visitor said she will contact them again and ask them to reconsider. However, after that phone appointment I have not had any sort of contact with anyone from the health visitor team or about the counselling,"

(Online survey)

MW14 - Mixed Ethnicity (Other). Pregnancy experience in 2020, aged 30



"If they saw that you were giving enough care to the baby and on the outside were together, they would tick you off the list and move on to their next person. I did ask to be referred to the for MH counselling sessions, but they were looking or someone obviously depressed and down."

MW8- Pakistani. Pregnancy experience in 2019, aged 29



"I felt invisible. When the health visitor asked me about my mental health after my son was born, she was looking more around my living room which was really nicely done up, so she thought I had it all together."

12.4 Learning

Women are being denied timely psychological support during and after their pregnancies even when they have a history mental illness. Women are reaching crisis point and feeling suicidal before their need for support is recognised by healthcare professionals. Women do not always feel able to trust frontline professionals enough to disclose their anxieties because of their dismissive approach, use of insensitive language and microaggressions. Even when they disclose their concerns, they are dismissed or not followed up. When women do not meet the thresholds for referrals to the 'Specialist Perinatal Mental Health Service,' they can be and should be helped by alternative methods.

Midwives, doctors and health visitors appear to be desensitised to the mental health needs of Black, Asian, Arab and other minority ethnic women. While poor care may be related partly to inadequate training, the negative attitudes of healthcare professionals are a barrier, which includes stereotypes such as assuming women have sufficient support from extended family and networks. Some of the failures are due poor systems such as non-clinical staff making mental health assessments and insufficient resources. Commissioners must improve funding for maternal mental health services, including within the charity sector, so that services can be provided in the community. This should also include culturally appropriate perinatal mental health services that meet the needs of minority ethnic women.



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.



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.



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.



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



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 minority ethnic 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.

13 Impact of Covid-19 Pandemic on Maternity Care

13.1 Overview

During the Covid pandemic, maternity services in the UK had to be adapted and modified to minimise the spread of Covid-19 and to safeguard women, their babies and families and also healthcare staff. This resulted in a reduction in face to face appointments during antenatal care and introducing remote consultation methods such as telephone and video calls. Of the 1022 online survey respondents, 507 (50%) were either pregnant or had their pregnancy in the previous 12 months i.e. during the pandemic, and particularly during the lockdown periods. We therefore explored how Covid-adapted maternity services affected the pregnant Muslim women, a significant minority of whom already have poor experiences.

13.2 Antenatal Care Experiences During the

Covid-19 Pandemic

Women who had their pregnancies during the Covid-19 pandemic did acknowledge that they understood the need for remote appointments, but most indicated they preferred face to face appointments. Remote maternity consultations left women anxious and worried, particularly those who were first time mothers and / or those who had been experiencing poor mental health. Even women who were not victims of domestic abuse raised concerns on the lack of privacy to talk about such issues should the need arise. Women also said that often they were asked closed questions and not provided the space to expand on their feelings anyway.

While a few women did share positive experiences, most raised the following key problem areas (as demonstrated by the comments):

- 1. Midwives not being available
- 2. No continuity of care
- 3. First time mothers not feeling supported
- 4. Not feeling informed
- 5. Feeling neglected and not important
- 6. Health being put at risk
- 7. Lack of privacy
- 8. Technology barriers

13.2.1 Theme one: Midwives not being available

The midwives either missed virtual appointments or did not answer calls or return messages left on the number they had provided to be contacted with any concerns. A few women even described their antenatal care during the pandemic as 'non-existent.' Women were left chasing midwives.

"Called many times couldn't reach them."

"My antenatal support was non-existent."

(Online survey)

(Online survey)

"I was given telephone appointments that were missed by the midwife on two separate occasions. I was still working at the time and would need to be excused for the appointments but no one would call."

(Online survey)

"I did feel able to discuss my concerns freely with my midwife. She was unreachable on several occasions."

(Online survey)

"I had to ring a number of times to see if I had any appointments due as no-one had initiated any."

(Online survey)

Some Positive Experiences

"My experience was 'wonderful. I felt the NHS were taking full precautions for themselves but also for me during my antenatal checks."

(Online survey)

"Telephone video calls were carried out due to the pandemic, although not ideal they were better than nothing."

(Online survey)

"Helpful - followed up with a text for my clinic appointment."

(Online survey)

"My questions were answered on the phone but I wanted the midwife to check on the baby."

(Online survey)

"They were very prompt with their phone calls and took time to answer questions."

13.2.2 Theme two: No continuity of care

Women said they had different midwives which sometimes resulted in different opinions being provided which caused confusion.

"I did not talk to my assigned midwife but spoke to a student midwife working with her." "Ouring Covid had to attend multiple health care centres seen by a different midwives throughout."

(Online survey)

(Online survey)

"Made complaint to PALS and was given face to face appointments with a new midwife after having consultations over the phone, always a different person and lots of different opinions."

(Online survey)

13.2.3 Theme three: First time mothers not feeling supported

Women who were experiencing their first pregnancy were particularly anxious as they did not know what to expect and felt worried they were not having physical check-ups.

"I would have liked more face to face appointments as this was my first pregnancy and I had lots of questions which I feel went unanswered. I mainly relied on the internet for information." "Being pregnant for the first time it would be nice to be able to see the midwives face to face as over the phone wasn't suitable."

(Online survey)

(Online survey)

"This was my first pregnancy. I didn't feel like I knew what I was doing and didn't have anyone in my family to ask. I needed reassurance and needed to ask many questions but felt like I didn't get the opportunity to do so as I didn't have many face-to-face appointments."

13.2.4 Theme four: Not feeling informed

Women did not feel informed because they were not always provided sufficient space to ask questions. They also felt that the maternity information that was provided remotely was inadequate and they were left to find it themselves through the internet or family and friends.

"Very little contact/information given in early pregnancy when I had little knowledge of pregnancy conditions myself." "Very short appointments and didn't feel personal. Felt like I was being told info from a book."

(Online survey)

(Online survey)

"It's me that is doing all the chasing up for my appointments whether it's scan or check-ups. I know what/when my appointments should be because friends/family have told me the normal procedures that should happen. There's a lack of communication for pregnant patients. I've been getting my information off the NHS website and Google in regards to the Corona virus and what I should be doing. Last week I had a dating scan (which I had to chase up personally for my appointment) in the hospital and it was the first time I seen a midwife during my pregnancy."

(Online survey)

Research published in 2020 (in the first few months of the pandemic) showed there was a higher risk of being infected and being admitted to hospital for women of Black, Asian or other minority ethnic backgrounds. ⁹¹ A few of the women interviewed had given birth after the publication of the report i.e. at the end of 2020 or during the first half of 2021. However, none of the women had been informed that they were at increased risk, which would have enabled them to take extra precautions. One of the women had Covid in February 2021. Not providing such information to a group considered vulnerable is a form of systemic discrimination.

Experience during Covid - email sent to MWNUK during the research

"It's me that is doing all the chasing up for my appointments whether it's scan or check-ups. I know what/when my appointments should be because friends/family have told me the normal procedures that should happen. There's a lack of communication for pregnant patients. I've been getting my information off the NHS website and Google in regards to the Corona virus and what I should be doing. Last week I had a dating scan (which I had to chase up personally for my appointment) in the hospital and it was the first time I seen a midwife during my pregnancy. My experience at the hospital was very different to what I expected. Everything was very fast and rushed and it felt 'military'. The main focus for the employees was to get me in and out as soon as possible."

13.2.5 Theme five: Feeling neglected and not important

Women felt 'not cared for' because appointments would be rushed and did not feel personal. Some commented that it felt like a 'tick box exercise.' This prevented women from raising concerns they had and some said that when they did these were more easily dismissed because it was not a face to face meeting.

"It was short and brief. Felt pushy and "Felt very formal like I was checked off on a tick chart. It was all rushed." not informative." (Online survey) (Online survey) "I felt as though it was just a box ticking exercise and wasn't able to discuss any concerns as I would have been able to do if it had been in person." (Online survey) "Very brief calls, not much discussed, "Helpful but not as personal due to felt dismissed." covid19." (Online survey) (Online survey) "I had one phone call appointment but it was poor. It was rushed and I forgot many things I wanted to ask and I was not asked anything other than 'how are you'. " (Online survey) "Wished the midwives would have taken more time with the call instead of rushing through the questions." (Online survey)

13.2.6 Theme six: Health being put at risk

Women said that if they were having face to face appointments, they were not having the routine physical checks and their babies were not being monitored. They worried that risks were being missed. There were examples of women who were not seen by any healthcare professionals until they were considerably advanced in their pregnancies.

"Not given the same level of care as a face to face appointment."

(Online survey)

(Online survey)

"At 36 weeks appointment via phone calls were pointless as foetal / other it was so difficult to get a hold of a midwife to talk about concerns."

(Online survey)

(Online survey)

"I was told I needed a phone consultation when in fact I needed to go in and that made things difficult."

(Online survey)

"Only had face to face appointments for thyroid follow ups that could have been given over the phone, and to take blood tests & blood glucose test. Currently 28 weeks and just had my 1st midwife appointment face to face to see how my pregnancy is going. BMI over 35, and not been booked scans that should have been done after 2nd scan. Not been booked face to face appointments prior to this, despite services going back to normal. Was previously refused glucose test, despite meeting the criteria to be offered one. Very unhappy so far until todays 1st face to face appointment."

(Online survey)

13.2.7 Theme seven: Lack of privacy

Another limitation of virtual consultations that was mentioned by some women was the lack of privacy at home which made it difficult to disclose any sensitive information such as domestic abuse.

"You can't explain on the day how your feeling, you might be busy with something and forget because you are on a call and not in the 'right environment' to speak what's really on your mind."

(Online survey)

"It's easy to hide how you are feeling over the phone, appointments face to face makes it easier to tell someone how you feel because it's actually feels like your talking to a person and not a phone."

(Online survey)

13.2.8 Theme eight: Technology barriers

Women were left to find information themselves. Although the women who participated in this research had the ability to do that there will be many other women who would not be able to access the information online putting them at a disadvantage as having access to the right information improves maternity outcomes. Use of technology also presented problems such as unclear telephone lines or not being able to access online platforms because of incompatibility issues. Survey comments included:

"My phone wasn't up to date enough to use the platform the NHS provided but luckily my midwives have an iPhone like I do and could use FaceTime."

(Online survey)

"The line was poor. We were both having to guess what the other said."

13.3 Postnatal Care Experiences During the

Covid-19 Pandemic

The survey comments and the interviewees strongly suggested that the postnatal experiences were far worse than the antenatal experiences during the Covid pandemic. As already highlighted in chapter 9, even prior to the pandemic, postnatal care was considered poorer than antenatal care. Not having fact to face contact after giving birth made women feel abandoned and lonely, especially first-time mothers or those who had a traumatic or caesarean birth. To be seen physically was considered highly important so women and their babies could be examined and supported according to their personal needs. Women felt neglected because they were unable to contact anyone on the contact numbers given. They had to insist on being seen by a healthcare professional or health visitor as demonstrated by comments from women via the online survey.

"It is never the same as seeing someone in person. Especially postnatally when you need that support if it's your first child."

"Required breastfeeding support. Only so much that can be done via zoom. In person support would be more efficient. No support given."

(Online survey)

(Online survey)

"I was misinformed about a 6-week check-up for my baby. I was told due to Covid baby will not undergo 6-week check-up yet and I would have to wait to hear from them. This information came from the health visitor. At 6 months I was invited by the GP surgery to have my daughters '6-week check-up.' The doctor said I should have contacted to make an appointment. I did not do this because I was told due to Covid I couldn't. I mean a 6-week check-up was done at 6 months!"

(Online survey)

"The first telephone I had with the health visitor was fine but even though that she had given me her number, I could never contact her after that first time. There were times that I really needed help but no one was there to answer which is really sad."

"I understand that the home visits were not able to take place due to Covid and lock down rules, but I only had been contacted by my health visitor once. I thought I would have been contacted a couple more times possibly."

(Online survey)

(Online survey)

"I had only 2 phone calls from a midwife and health visitor. I had to ask for them to come in and visit."

(Online survey)

"After the birth I felt abandoned - no effective support given by midwives after traumatic birth."

"The actual single phone review was not particularly detailed nor very informative."

(Online survey)

"I had one physical visit from health visitor and one telephone video appointment even though I was released from hospital within 24 hours of having a c section."

(Online survey)

"Postnatal checks were disgusting. No one checked me. I had to ask to be checked and by then, it was too late - 3 weeks post baby I had an infection and a fused labia. Was then meant to have a physical check to arrange surgery but they cancelled it the day before and gave me a phone appointment, which was pointless. How can they physically examine my vagina internally via a phone consultation? Then I had to keep ringing just to get another phone consultation and was told I would have healed naturally and I could have sex. The doctor should not be allowed to tell people they have healed without an examination. I had to keep ringing to eventually get a physical examination to be told I need major surgery. I can't have sex, my relationship is suffering and I can't have my smear test so my health is now at risk."

13.4 Learning



During the pandemic, women did not feel informed because they could not access the midwife or health visitor. They found the phone appointments limiting as there was no privacy to have discussions about sensitive topics or ask questions. They also did not feel reassured or safe because they were not provided with sufficient information and unable to have the routine physical antenatal checks. Although the unavailability of healthcare staff would have been linked to staff shortages due to sickness and redeployment of staff during the pandemic, the standard of antenatal care prior to the pandemic was already problematic (as discussed in Chapter 5).

The women who participated in this research were mostly educated to at least degree level and employed in professional roles, which gave them the confidence and means to chase healthcare professionals with phone calls, insist on face to face meetings, find information online or even pay for support privately. As these women were having difficulties in being heard and accessing maternity care, then women from socially disadvantaged backgrounds would have had even less control over their maternity care.

It is clear that telemedicine should not become the norm and fully replace face to face appointments. Although it has advantages (it is greener, reduces need to take time off work, saves parking fee and reduces risk of Covid exposure), it is clear from the responses that women prefer the reassurance of in person appointments. This was, especially the case for first-time mothers, those with mental health needs, those with risk factors and those who have had previous traumatic births. Also signs of domestic abuse and mental health difficulties, would be difficult to detect remotely. If healthcare providers are likely to pursue a hybrid model of maternity care which incorporates virtual consultations, then it needs to work for both patients and the NHS. For example, during the study some women mentioned they missed antenatal appointments because they were unwell due to severe pregnancy sickness. In such situations a virtual appointment would be better than non-attendance. Telehealth could also be used to monitor remotely.



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.



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

Perceptions of Attitudes and Behaviours of Maternity Healthcare Providers

14.1 Overview

Throughout the report the accounts provided by Muslim women about their maternity experiences have included examples of negative attitudes and behaviours by healthcare staff. Some of these are explored further in this chapter so they can be analysed collectively. There was evidence of discrimination which involved women being blamed, humiliated and insulted as well as being coerced and bullied into decisions (particularly in respect of labour inductions that women did not want or were not medically needed). Certain attitudes and actions also left some women fearing for their wellbeing and the safety of their baby. If women were subjected to similar behaviours in their personal lives it would be described as abuse. If these behaviours happened in a workplace setting, it would amount to harassment. When such behaviours occur in the course of receiving maternity care, perhaps should be described as 'maternity abuse.' Using the right language to describe women's experiences, even if it is uncomfortable to do so, may result in more healthcare staff being held to account and altering the culture that exists amongst some staff. Women described being treated differently because of their race, ethnicity, Muslim faith, age. Many were aware that their intersecting identities triggered different treatment.

"I'm not sure whether my experience was because I am Black and Muslim and also a young mum. All I know is that I am those things and I had a terrible experience."



The care this woman received, which put her and her baby's life at risk, are discussed in Chapter 8. This included not being believed she was in labour and then not being stitched and left to bleed,

"I felt because of my age I was dismissed. My hijab was on during the appointments and conversations, with different doctors it was age, with some it was because I was Muslim, but there was a pronounced feeling of being dismissed because I was a nuisance, you have a bit of pain, handle it. I was definitely feeling othered like I didn't belong.



MW7 - Arab Pregnancy experience in 2020, aged 25

How minority ethnic women feel and their perceptions may provide a good measure of the quality of care they receive. Their accounts cannot therefore be ignored when considering the factors contributing to their unequal health outcomes. 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. As already mentioned in the 'Introduction,' 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. The following sections examine the attitudes of healthcare providers and perceptions of the maternity service users in more depth to find out how microaggression, bullying and stereotypes are manifested. It is important to acknowledge that women also recounted positive interactions with healthcare staff, examples of which have been provided in previous chapters of this report. It is also vital that learning from these experiences provides ideas about what good practice can look like.

14.2 Cultural Competence

Survey participants were asked how well they thought their culture was understood by the healthcare professionals with whom they interacted during their appointments. The responses which are summarised in **Table 11** show 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

37% 32% 36%

Postnatal Care

Culturally appropriate care during this time would contribute to more positive experiences:

"They seem very unaware of other cultures and religions, hence do not provide an equal service for all."

(Online survey)

However, there was particular praise for the home-birth midwives:

"Home birth team very well informed able to understand different religions and cultures."

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	Antenatal	Intrapartum	Postnatal
Very good knowledge and understanding	15%	14%	14%
Good knowledge and understanding	22%	18%	22%
Some knowledge and understanding	24%	27%	24%
Very little knowledge and understanding	16%	17%	14%
No knowledge and understanding	6%	10%	8%
Not sure / Can't remember	17%	14%	18%

14.3 Microagressions

Of the 1022 survey participants, almost one third of women (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. When these women (n=451) were asked for more details, they cited negative tone of voice as the most common experience (61%) followed by patronising comments (47%), judgmental comments and attitudes (42%), physical actions such as roughness of touch, dismissive gestures and avoidance of eye contact (23%) and insults (5%) - see **Figure 22** and **Table 12**.



The 18% who experienced other forms of microaggressions, described these as:

- Being ignored and neglected e.g. not being monitored and not given medication when compared with other women;
- Not being treated with respect and dignity such as left in blood-soaked bedding or allowing males to be present despite instructions for them not to be present;
- Pressured to be discharged despite feeling unwell;
- Pressured to walk despite being in extreme pain;
- Pressured, emotionally blackmailed and even bullied into being induced;
- Deliberately not being provided pain relief when stitched for perineal tears despite requests and being vocal about the pain felt; and
- Deliberately speeding up labour.

MW3 - Asian Other. Pregnancy experience in 2021, aged 30



"The midwife had to go for break and had a different one — my legs were in stirrups and I had a cramp in my leg and told as was in pain and she was nasty and responded: 'What do you want me to do about it?' Her tone — was rude. When the other midwife returned she was lovely and massaged my leg."

MW18 - Pakistani. Pregnancy experience in 2020, aged 30



"After an emergency caesarean. The consultant was cold, he did not look at us. When the baby was delivered, I asked if he was ok but they did not answer me."

MW34 - Bangladeshi. Pregnancy experience in 2019, aged 40



"That was one of the worst examinations I have had in my life. I could tell the doctor was annoyed to have to see me because she was at the end of her shift and about to go home. She said I am going to press on your scar to see if it hurts and jabbed it so hard...I nearly leapt off the bed it was so painful. The midwife was next to me holding my hand and told the doctor, 'doctor please' (implying to be more gentle). That midwife was amazing. She said darling I am so sorry it's so painful and stroked my hair." She explained that had she been warned by the doctor that the examination was going to hurt she would have mental prepared for the pain.

MW29 - Black African. Pregnancy experience in 2021, aged 25



She recalled being treated 'differently while she was on the ward. She described being ignored during the medication round: "When this midwife got to my side of the ward, she pretended someone had called her and she didn't come to me. She would do the same thing the next day, whenever she was on shift. It was only until there was another midwife on shift who gave me the medication I needed to help me open my bowels."

When she called for help using the emergency button she was ignored, but when she complained to the midwife about being ignored she was told that, 'we want our staff to encourage new mums to do well when they get home.' When she questioned her about what constituted an emergency (and how they would know), the midwife looked at her computer screen and left. She also felt her baby was treated differently such as formula milk being spilt on him soaking him and when other mums were asked about their babies, but she was not.

Table 12 - 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."		

14.4 Bullying, Blaming and Coercion

A strong theme that emerged especially in Chapter 8 on the perceptions of intrapartum care was women feeling pressured and coerced into agreeing to interventions, particularly inductions when these were not medically necessary. The cases in Chapter 8 suggest that labour and birth are becoming over medicalised for minority ethnic women:

"I felt pressurised by the professionals to make decisions."

(Online survey)

Although the Ockenden Report highlighted that women were not always given interventions because some midwives favoured 'natural' birth, it is important that care does not now become over medicalised. There may be a tendency or culture of advising on inductions for example because of the higher risk of complications associated with minority ethnic women. However, blanket approaches such as this can amount to systemic racism because assumptions are being made which will not apply to all women and it denies them personalised care. It is surprising that despite the Montgomery Ruling women are not provided the opportunity to give informed consent. Some medical professionals may consider minority ethnic women easier to pressure into agreeing with their decisions. Such attitudes are not only an abuse of power but may be permitting cultures of coercion to flourish in hospitals.

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 women traumatised during such a vulnerable time. The blame culture seemed quite common, including in cases of FGM:

"The doctor had told me you failed to deliver normally because you had FGM, and you have to have c-section."



MW32 – Black African Pregnancy experiences more than 10 years ago, aged 20s

When labour does not progress, words should not imply women have failed and more sensitive language should be chosen.

Birthing partners were also not treated with respect and dignity. There were also examples of birthing partners who were from ethnic minorities backgrounds not being allowed to stay while others (who were White) were allowed to remain:

"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

There were also plenty of examples of women feeling bullied during their antenatal and postnatal care (as has already been highlighted in previous chapters). Breast feeding experiences were particularly negative as evidenced in Chapter 10: "

"When I mentioned breastfeeding concerns and I was bluntly told by the midwife I 'didn't try hard enough'."

MW21 - Pakistani. Pregnancy experience in 2020, aged 31

During Covid she had diabetes and needed to monitor blood sugar levels 4 times a day. She was not always doing them all because she is a single mum with 4 children, of which one is an autistic child. She felt this was not taken into consideration when the midwife was berating her.

"The midwife was always telling me off and being harsh. During one antenatal appointment, she was angry with me for not filling it in and she said 'it's your fault, you don't care about your baby.' — she banged the book shut, then gave me the silent treatment and then walked out of the room and slammed the door shut. Another midwife came in and said, 'don't mind her she is having a bad day'."

MW2 - Pakistani. Pregnancy experience in 2017, aged 39

During (one antenatal appointment) a European Spanish nurse shouted at her as if she was 'dumb' for not correctly recording her sugar levels. On another occasion, she was 'told off' for not having collected a sufficient urine sample. However, she wanted to know how heavily pregnant women are supposed to do that and why a pan was not provided to make it easier.

MW19 - Bangladeshi. Pregnancy experience in 2020 (during Covid), aged 28

During the night when she was in active labour her husband should have been allowed but was not permitted to join her. She was not given an epidural despite asking for it. One midwife of the same ethnicity told her 'I'll be honest with you, they won't give you anything until the shift change and new nurses arrive.' When the shift changed she again asked for epidural. When her husband was eventually allowed in at 9am and questioned why an epidural had not been given, the midwife started shouting at him saying, 'don't tell me how to do my job.'

14.5 Language, Dignity and Respect

During their maternity interactions, more than half of the women (57%) felt they were not treated with respect and dignity. Sometimes this was due to the tone in which women were spoken to (including sarcasm) or not being listened to (a theme throughout the report). They felt they were not shown dignity and respect in the language used when they were spoken to or in the acts of care giving.

Although such attitudes will not be limited to minority ethnic women, in the case of the latter, these will be further influenced by biases and prejudices linked to race, ethnicity, faith and / or migration status. As the following examples and those elsewhere in this report demonstrate, the interpersonal skills of maternity healthcare professionals need to be improved. Training should include raising awareness of the impact of attitudes and language used on the women.

"When I went in over my due date, I had to go in every second day and at 41 weeks, the midwife said 'you wouldn't want a dead baby', and the couple nearby gasped."



MW9 - Black Other Pregnancy experience in 2020, aged 31

"Patronising NHS staff, treated me like I was a nuisance (during antenatal care), did not respect my wishes and not a caring kind nature to the NHS staff at all."

(Online survey)

"When they were stitching me up they asked my husband 'if he worked.' Their choice of words was poor, they indicated they didn't think he was working but on benefits."



MW6 - Black Other Pregnancy experience in 2020, aged 31

"I had patronising comments from a midwife during labour. I told her the gas and air was making me feel sick and she told me it was all in my mind!!! I then vomited in front of her."

(Online survey)

"Anytime I asked a question I was treated in a disrespectful way. The first question I asked at one of my first appointments was when I needed to fill in my birth plan and the response from the White British midwife was 'I'm not going to be giving birth for you'. She completely ignored and twisted my question. Anytime I asked questions I wasn't given clear answers and was spoken down to."

(Online survey)

"The first sweep was a traumatic experience, the midwife was huffing and puffing about NHS resources, complained about the room, she did my sweep and when she was done I asked if she had finished and she looked at me saying 'what you want more'!"

(Online survey)

"Some of the community midwives coming out to my house during the first lockdown were absolutely awful. I couldn't understand how women like these were in their profession no compassion whatsoever very rude and abrupt."

Another aspect of dignity and respect was when women wanted privacy linked to their cultural and religious beliefs. This should be something routinely considered for all women. A recurring theme was not wanting any male presence unless it was absolutely necessary. While women understood such requests could not always be accommodated, they provided examples of when requests could have been met but were not. For example, for pre-planned appointments during antenatal care, women could be added to the schedules of female doctors and midwives. One woman commented on a trans woman being present when she was receiving care:

"They had a transitioning man to female come in and out without knocking or letting his presence be known."

(Online survey)

Cis-women's rights are currently much-debated and will also need to be addressed in the healthcare sector, especially in relation to faith groups.

"I was not given a private area for breastfeeding and was expected to breastfeed in front of men in a waiting area." "I asked for no men during my labour regardless. However, when I was in surgery getting stitches, I had men at the back of the room."

(Online survey)

(Online survey)

"As a hijabi woman I expected some type of privacy or at least some respect by asking if male figures could come but none of this was done." "They understood I wanted a female only environment and were respectful but I would have wanted more understanding and support for my religious beliefs."

(Online survey)

(Online survey)

"I don't think they're very familiar with Muslims as I live in an area where there are not that many Muslims. They didn't respect my request for only female medical professionals to see me during labour."

(Online survey)

"Time of birth I asked for all female staff, as I was admitted and was in labour at 35 weeks, and there wasn't all female staff, male staff had to attend as it was a twin pregnancy." "When I had my baby they were encouraging me to breast feed and a male nurse was present I didn't feel very comfortable about this and had to ask him to leave."

(Online survey)

(Online survey)

"They didn't understand when I asked for females only in appointments to take bloods and things like that,"

(Online survey)

"I preferred the curtain round the door area and female staff, all were obliging once I expressed my preference."

"I asked for a man not to be present during my caesarean due to my religious beliefs, which was not fulfilled."

(Online survey)

"Even when I explained they were not respectful and during my labour one midwife tried to bring a male doctor in when there was no need to and I said I didn't want him in and she told me "it's not the end of the world" in response to me asking for him not come in. Also, my birth plan has written in many places about modesty and not wanting a male staff unless life or death, this was not respected. Even after birth the blue curtain around my bed was left wide open despite me asking many times to close it and not keep coming in when I was trying to breast feed and there were males around. I even cried a couple of times about this and just wanted to go home despite being weak because the lack of respect for my modesty and privacy was so violated."

(Online survey)

14.6 Race, Ethnicity and Culture

- Stereotypes and Assumptions

14.6.1 English Proficiency

There were clear examples of midwives and doctors making assumptions about the English proficiency of maternity service users, based on race and / or appearance (e.g. dress). The interactions left women less willing to ask for help:

"I was scared to ask questions because just before I was asked to go in to my appointment, the midwife called my name and said very loudly 'I hope this one can speak English.' Although I am a Doctor myself, I was upset and couldn't ask anything."

(Online survey)

Other women also recalled similar experiences:

"We have a dress style and a skin colour, different languages, and that comes with a set of assumptions nurses and doctors make. They didn't think I spoke English,"



MW11 - Bangladeshi pregnancy experience in 2016, aged 34

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

14.6.2 Clothing, Names and Accents

One interviewee who had four children said she noted the difference in her care between when she wore the jilbab (long Islamic dress) compared with when she wore more Western clothes such as jeans. Another interviewee (MW22) mentioned how she felt attitudes varied with the clothing she wore. She shared that although she wore the hijab, she had not experienced negative attitudes, but felt it was linked to her western clothes i.e. she wore jeans and dresses, and was articulate and had an English accent. However, while on the hospital ward, she witnessed other South Asian women being treated negatively, which she felt was connected to their accents (as well as English language proficiency):

"They were quite snappy with the other Asian women when they asked for help and would take ages to respond."



MW22 - Bangladeshi Pregnancy experience in 2020, aged 42

Where telephone appointments were concerned, bias was linked to having a 'foreign sounding' name or an accent:

"But they were dismissive of me and undermining me just from reading my name and based on telephone consultation, without even meeting me first."

(Online survey)

One woman, who at the time of her pregnancy had newly migrated to the UK, was convinced the nurse's response to being contacted as part of the miscarriage unit was because she spoke with an accent. She was told:

"Oo you want me to take you in so I can change your bloody sheets and I am not going to change your bloody sheets. You stay home. You will be fine with it."



MW 25 - Pakistani Pregnancy experience in 2011, aged 25

Women described being viewed as 'stupid' because they were Asian:

"They treated me like a stupid Asian woman who did not know anything,"



MW24 - Pakistani Pregnancy experience in 2019, aged 28

"I am not going to change your bloody sheets."

14.6.3 Race and Ethnicity

Some women explained that certain hospitals were known for the way they treated minority ethnic women and avoided being booked into them. One interviewee (MW3) said that she did not choose a particular nearby hospital as her friends had warned her about the poor care received by minority ethnic women. On receiving differential treatment, many women said it was down to them being a woman of colour:

"My hijab makes no difference, my friends don't wear hijab and have had the same experience. They see the colour of your skin."



MW32 - Black African

Pregnancy experiences more than 10 years ago, aged 20s.

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

Sometimes the prejudice was quite overt. One woman (**MW1**) had negative experiences again during her second pregnancy at the same hospital and felt bullied when she struggled with breast feeding. She was told: 'Women from 'your communities' should know how to breast feed,'. Assumptions not only resulted in ignorant comments and delayed care but also meant that important information was not provided thus further contributing to unequal care. Another woman was made to feel very uncomfortable when she was told during labour:

"The baby's head is here so start pushing. You have done this to yourself. You made your bed you lie in it. All you people do is make babies."



MW32 - Black African

Pregnancy experiences more than 10 years ago, aged 20s.

"All you people do is make babies"

While women acknowledged that staff shortages may have contributed to their negative experiences, they were clear about feeling invisible and not being listened to because of their race. Black women tended to be very critical about their treatment often reflective of how poor their experiences were:

"The cold shoulder, you can sense it, they don't want you. They belittle you with the comments. It can be the way they pull the chair. Tone of voice, talking slowly."



MW32 - Black African

Pregnancy experiences more than 10 years ago, aged 20s.

"The cold shoulder, you can sense it, they don't want you. They belittle you with the comments."

They also questioned whether staff had been trained to care for women in all of their diversities:

"Nurses should go back to school and be trained... and take seriously what the patients are saying. They are understaffed and I know this makes a difference. But I felt as if something is wrong with me when my requests weren't being heard. You're vulnerable and you doubt yourself."

FG3 - Somali woman (Focus Group) Pregnancy experience in 2021.

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. **FG7**, suffered severe blood loss and 'felt lucky to be alive.' She strongly felt her poor treatment was linked to discriminatory attitudes:

"we are seen as others."

This point was confirmed by the woman who acted as an interpreter voluntarily for the Somali women in her community. She said that over the last 20 years she had witnessed too many women being treated in a hostile way because of the colour of their skin, race, faith and clothing:

"When you're Black you don't matter. To top it off you're Muslim, you don't matter."

She said that the treatment Somali women received was dehumanising because of the physical force sometimes used on them:

"Ouring 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."

The women in the focus group said that, although they felt racism levels were generally higher in the other European countries, doctors and nurses were able to prevent any biases impacting on their professional role:

"The experience was fantastic. In Norway they took care of me very well. They were more nice and more kind and did their job well. Even if they held racist views, they were professional and didn't let that impact how they treated you. In the UK I was always made to feel different."

A repeated criticism by all of the women in the focus group was not being listened to unless they became assertive, which was then viewed as being hostile:

"They were not listening or hearing me. The problem is that they don't believe us.... Unless we kick up a fuss. But then it's a problem because we are seen as angry."

Other Black women who participated in interviews also felt they were perceived as trouble-makers, which impacted on the quality of their care:

"I was told 'your people need Vitamin O.' The other nurses and doctors did not intervene. I did challenge to ask what was meant by this comment, but I think they added to my notes that I was a 'troublemaker,' which affected attitudes towards me afterwards. There's lots of stereotypes about black women. It didn't matter what I did or said they had preconceived ideas about me as a black woman."



MW6 – Black Other pregnancy experience in 2014, aged 23.

A number of interviewees said that when they or their birth partners became assertive, it was not received well and they were viewed as unreasonable and demanding:

"He (my husband) is half African and half Arab. He is visibly ethnic. They thought he was being aggressive... even though he is not an aggressive person at all. He just wanted them to be efficient (when he urged doctors to do something because she was being ignored even though she was bleeding and losing lots of blood)."



MW28 – Mixed Ethnic Black Pregnancy experience in 2019, aged 19.

As the rates of stillbirths, neonatal mortality and maternal mortality are higher in the UK than some of the other high-income European countries ^{92a, 92b} insights from Somali women who have also given birth in other European countries should be studied further. Their stories could help to identify why some women have unequal outcomes. It is essential that engagement is increased, particularly with Black women who have more recently migrated to the UK; their voices are often overlooked because Black women are often grouped homogeneously which leads to maternity care staff missing differences between their experiences and those of UK-born Black women.

INVISIBLE

There was also a lack of understanding about the diversity of Muslim women and that they can belong to many different races or ethnicities. Prior assumptions were often made about ethnic groups and names associated with them. Women were made to feel quite uncomfortable which was made worse when the interactions were in public. Inaccurately recording ethnic group has already been mentioned when discussing antenatal care in the report.

"I happen to be a Black Spanish Muslim but I was asked three times by the same person what box was to tick for 'ethnic background' to verify whether I was actually Spanish."

(Online survey)

"As a White British Muslim, I found myself being stereotyped by staff. On a number of occasions, they assumed that because I had an Asian origin name that I had actually been checked in under someone else's name. Also, Once, I was the only Muslim in a waiting room and they shouted an Asian origin name and because nobody responded the staff assumed it was me and walked closer to me and kept calling and shouting the name at me as if I was that person and didn't understand. I had to tell them it wasn't my name for them to stop."

(Online survey)

"It was interesting in the sense that my partner is of mixed heritage and when I specified this his White English heritage was ignored. So rather than stating he was mixed Asian (White English and Iranian) he was purposefully put down as Iranian. This happened in previous pregnancies also (in my first pregnancy despite me filling in forms my son was noted as being Bangladeshi when none of us are of Bangladeshi heritage). When my husband went for genetic testing because his heritage was not noted down fully the nurses had to phone him when he came home to ask exactly when his heritage was as it was necessary to know for the test. It would helpful for professionals to understand heritage needs to be noted accurately and just because I look like a brown Muslim woman it doesn't mean my husband is and he can be of a different ethnicity."

(Online survey)

"Every time I walk in, they don't see me, they see a set of assumptions, I don't feel seen." There was also a gap in knowledge about female genital mutilation (FGM) in terms of which communities may be FGM practicing and even how FGM varies. This resulted in women assumed to have had FGM just because of their race and the fact they had migrated to the UK. Some women were not being believed when they said they had not had FGM and were not from communities that practiced it:

"FGM in south east Asia is not at all the same as in other parts of the world very frustrating."

(Online survey)

Although questions about FGM need to be asked as a part of maternity care, they need to be handled sensitively women should not be made to feel like they are being interrogated. One Black woman said that because she wore the jilbab and the niqab (face veil), the midwives assumed she was Somali and asked if she had been 'circumcised.' When she told them she was not Somali, they kept asking her about where she was from including about her parents and did not appear satisfied with her answers. She said she found it frustrating that professionals are not all trained to use the right language to find out about a person's race and ethnicity:

"The language needs to be better. The way I looked, the first worry, every time I walk in, they don't see me, they see a set of assumptions, I don't feel seen. I don't confront them about my feelings because I'm worried I won't be cared for. I try my best not to take it personally but rather an opportunity to educate them. Some of the things the professionals say would really crush people."



MW6 - Black Other,

Pregnancy experience in 2014 and 2016, aged 23 and 26.

Another area where stereotypes left women feeling uncomfortable was diet. Some healthcare staff assumed women from particular communities all had the same diet and did not bother to ask them.

"The gestational diabetes midwife made a lot of assumptions about our diets during an introductory session and would assume that Asians ate rice and curry every day and black people ate plantains etc every day. My family does not eat a lot of rice and curry."

(Online survey)

"I do feel like stereotypical remarks were made about diet which didn't apply to me but staff thought it did because I was Asian. For example, cooking heavy meals with oil and salt."

14.7 Faith in Maternity Care

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. As already mentioned when some women were not listened to, they became more assertive although they were then viewed as demanding and angry. Some women resorted to removing their headscarf after repeatedly being dismissed and because of comments made about them:

"I took my headscarf off and I made sure that I was more vocal - it was a very conscious shift."



MW1 - Indian

Pregnancy experience in 2012, aged 28 (twins).

In her next pregnancy she made sure she was more aware of her rights:

"When the (White male) consultant came to see me he said, 'Calm down honey, all women have babies,' I thought to myself I'm not going to be bullied again. I wasn't wearing a headscarf, I know now not to wear one in a hospital."



MW1 - Indian

Pregnancy experience in 2018, aged 34

Women should not be made to feel they will be treated differently because of the covering on their head, particularly when modesty is an essential part of faith for some Muslim women.

Although wanting privacy and respecting modesty has already been mentioned more generally, it was also a key issue linked to faith. Women felt that sometimes male doctors were deliberately called to tend to them because they had asked for female doctors. The validity of these claims could not be verified and it may be that only male doctors may have been on duty. If such allegations have merit, they would constitute a form of microaggression:

"I asked for female members of staff but a male doctor was called to break my waters."

(Online survey)

Trying to maintain modesty as much as possible and minimising male presence was also mentioned in their birth plans by some women, which tended to be ignored. Midwives often lacked understanding of the importance of these requests:

"My wants as a Muslim woman in regards to modesty etc. was not respected and the staff seemed to struggle to understand my wishes around modesty,"

(Online survey)

Another survey response included this comment:

"I had a male nurse even though I asked for female. He said no one else available. My friend came in straight after me and she had female. Clearly there was someone available."

(Online survey)

When requests cannot be met, this should be explained to women with the reasons so they do not feel they are being completely ignored. This would help settle anxieties.

MW30 - White. Pregnancy experience in 2021, aged 27



"Before my hospital appointment I called the department to request a female staff member and that was confirmed as okay over the phone. However, when I spoke to the receptionist and asked for a female, I was told I couldn't have a female as they didn't have any female sonographers in on that day. I explained I was more than happy to wait for a female but the receptionist was very abrupt and rude, and I felt like I was an inconvenience to her. When I told her I'd previously spoken to PALS about this... as soon as I mentioned PALS, she changed her attitude and was like, 'fine, you just have to wait'..."

MW26 - Arab. Pregnancy experience in 2014, aged 30



"Both my mum and I are hijab wearing Muslim women. The midwife became visibly very uncomfortable with our faith when we began talking about dignity and modesty, she just disengaged. She had negative body language. Her body language was cold when we discussed covering up during labour. Her response to our request for female only carers included a cold stare and lack of acknowledgment. She didn't say we will do what we can, she was instead explaining things slowly and loudly, she was of White/English background. Her manner changed when I mentioned both mum and I were doctors, she started to treat us with respect. However, I terminated my booking (at that maternity service)."

MW30 - White. Pregnancy experience in 2021, aged 27



"I took part in an antenatal class over Zoom. I was singled out because I didn't want to put my camera on because there were men on the call as well. I explained to the host privately on chat that for religious reasons, I do not feel comfortable, and I was told, 'you need to turn your camera on, or I'll have to remove you from the call'. It was really upsetting, and my husband said to leave the call if they were treating me like that. I'm quite thick skinned and I wanted to stay on and wanted to gain access to the information — but it was an upsetting experience. I reported my experience to PALS and they have asked me to speak in front of their board in a few months' time to relay my experience to them."

MW14 - Mixed Ethnic Other. Pregnancy experience in 2020, aged 30



This interviewee decided she would never go to the same hospital again. She believed that her poor treatment and the attitude of the particular midwife in charge of her care was linked to both her race and also faith because she was visibly Muslim - her husband had a beard and she wore the hijab. 'they would not have left me to labour on my own and make 23 errors in the process had I not been brown and visibly Muslim.' MW14 was a doctor and she was treated in this way.

MW30 - White. Pregnancy experience in 2021, aged 27



"While waiting I found that if she was dealing with a woman who was White or not of any obvious religious background, she was fine. But there was a Malaysian woman who she was very rude to and it really just upset me, seeing that she was treating people like that. She wore a jilbab and niqab. 'In a city that's so diverse, I expect quite a few women would request that service [female sonographers]. And even if you're not religious, you might have been sexually assaulted or you might have another reason why you don't want to see a man and to be spoken that way by a receptionist, it's just not on really."

Birth plans are likely to contain information about faith and culturally based rituals that the women want to undertake. Having the space and understanding to be able to include these would provide reassurance. For example, as soon as the baby is born Muslims will whisper the 'azaan' (call to prayer) in the baby's ear:

"There were many things I didn't get to do because of the way labour happened and the way I struggled, I was so out of energy and things like the 'azaan,' the dates for the baby I missed out on. A bit of my life has been taken away from me,"



One woman **(MW29)** felt that the midwife was making jokes about her reciting prayers. In her case the midwife was White Eastern European. There were other examples of negative attitudes expressed by midwives from similar backgrounds. Given the increasing levels of recruitment of midwives and nurses from abroad, including from European countries where more negative views are held about ethnic minorities,⁹³ additional training should be provided to ensure there is an awareness of the communities being served and of the UK's equality legislation.

"I was high on gas, and I was praying, saying 'La Ilaha Illallah,' I kept on saying that during the whole delivery process. The (Indian) doctor who induced me said to the midwife (who was White Eastern European), 'oh she's already praying', the midwife said, 'you're not in labour and you're already crying' but I wasn't crying. The doctor then told her, 'No I think she is praying'."



MW29 - Black African Pregnancy experience in 2021, aged 25

"When the doctors see you with hijab they demean you. They keep repeating themselves and say 'do you understand what I mean.' They didn't respect my view. My opinion did not matter. They were not hearing me. They refused to consider my history and my notes"

(Online survey)

"I also found that the staff were not letting me know if a male doctor was coming to see me, I needed the time to cover but never had this."



MW6 - Black Other Pregnancy experience in 2020, aged 31 There was a lack of awareness that, because of religious beliefs, some women may not want medication that contains animal products (e.g. vegans) and for Muslims particularly pork derived products are not permitted. Although what is acceptable or not may vary from one Muslim to another, it is important to have awareness of their beliefs so the women are giving truly informed consent to the medication administered and alternatives can be offered where possible. Sometimes Islamic bodies publish advice on permissibility of such products if they are lifesaving. Being able to direct women to such information can be helpful.

"I knew that heparin contains porcine so I said I didn't want it, doctors should be more aware and accepting of this and know of alternatives. Fortunately, I had done my research and advised them of the alternative medication to order."

(Online survey)

Examples such as this would be important to include in any cultural competency training. Another area of concern was dietary needs, which should be an obvious part of intrapartum care but these were not very well understood:

"I was only offered a 'halal meal' after I asked the question. Some staff didn't even know what 'halal' was or that it was an option."

(Online survey)

There was a common perception that there was no interest amongst some healthcare staff to understand different needs:

"I wasn't asked on cultural or religious needs. It seems it's a tick box process and not much info is asked."

(Online survey)

"I asked to reschedule an appointment with the midwife as I couldn't attend it due to observing Ashara (religious sermon in Muslim culture). Was asked by the midwife, 'why is your religion stopping you for looking after your baby?' I found it rude and disrespectful as she made an assumption without knowing any background knowledge or history. I just wanted a appointment later on in the afternoon on the same day, instead received disapproving looks as though it was a big ask."

(Online survey)

"You're not in labour and you're already crying?"

Some Positive Experiences

Positive examples of empathetic and compassionate care where women were listened to and their needs considered have been provided in some of the previous chapters. Such care should not depend on luck as highlighted by this comment:

"I know my experience could have been different if I had a different nurse"

(Online survey)

A few good practice cases related to being faith and culturally sensitive; for example on issues such as on abortion, extended family dynamics and pressures, the important role of Islamic rituals and dietary requirements.

"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)

"She even offered me halal food. She asked if I was Muslim and said I will get you halal food."



MW32 - Black African, Pregnancy experiences more than 10 years ago, aged 20s

"My health visitor was also south Asian. She understood how my postnatal depression stemmed from living with my in laws as she had been in a similar situation and so I could relate to her on an emotional level."

(Online survey)

MW22 - Bangladeshi. Pregnancy experience in 2020, aged 42



Positive experience with a Pakistani doctor as she felt they had a shared background (Muslim faith) and that therefore the doctor was more culturally sensitive: "I was wearing my hijab and he helped me and tried to cover my hair for me. He didn't make me feel odd (for wanting it on). I got my husband to play Surah Bakarah on his phone and he helped to put the phone next to my ear." It was clear that this positive gesture meant a lot to this interviewee.

14.8 Intracultural Prejudice

During interviews when women spoke of negative experiences, they were asked about the ethnicity of the midwives and doctors. While most of the negative experiences uncovered in this 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. Some of the interviewees wondered whether their negative behaviour was a result of their own mistreatment in the healthcare system:

"They were extremely low on compassion, perhaps they themselves were not treated with compassion by the organisation [NHS],"



MW26 - Arab pregnancy experience in 2013, aged 30

Examples were provided of negative treatment by Black midwives and occasionally South Asian midwives:

"The majority of my antenatal team were Black women, they are also part of the system. The most patronised I felt was by Black midwives."



MW34 - Bangladeshi Pregnancy experience in 2019, aged 40

Midwives and nurses from Eastern Europe were also criticised:

"I had a White Eastern European midwife, she was a stern woman. My midwife really was not nice. She wasn't very encouraging, not sweet, her tone was harsh, she was just doing the basics of her job with a bad attitude."



MW18 - Pakistani Pregnancy experience in 2020, aged 30

In other examples, White European midwives favoured natural births:

"Some assume you don't know anything, they take the initiative to decide for you. They encourage natural births, but they shouldn't do that because women are different and want different types of births. Why do they get to make decisions for something so personal? They divert you away from the services?"



MW12 - Arab

Pregnancy experience in 2011, aged 27 & 2014, aged 30

INVISIBLE

There was also some criticism of South Asian obstetricians. For example, some South Asian women found Asian male doctors particularly sexist and patronising and felt this was influenced by their view of women from within their own cultures:

"When I went into hospital to monitor the baby's heartbeat I was judged for having multiple babies. The (Asian) Or implied that I was trying for a male baby. When that was not true for myself. I am aware there is a stigma that all Asians want boys."

(Online survey)

In another example, the negative attitudes experienced prompted the woman to train as a midwife:

"I am really put off having another child. Over two years later I don't feel fully recovered. If I did, I would choose a different hospital." I feel Asian women get fobbed off because they are Asian. The Asian, Pakistani, Indian, Bangladeshi doctors also think you are exaggerating and fob you off. I am now studying to become a midwife so I can give the right treatment and care to someone else."



Women felt these doctors would go on deliberate power trips thinking they could get away with it because they were doing it to women of similar backgrounds. One woman had a caesarean planned at 36 weeks and 3 days because of her low-lying placenta and bleeding. During the appointment, she told the doctor she could not carry the baby any more due to the level of discomfort she was experiencing on top of struggling to look after her four children. However, the doctor (who was an Asian male), said he would need to refer her to safeguarding and then walked off:

"The way he talked to me made me look and feel incompetent as a mother, I would never want to put my baby into trouble. I needed help, I didn't need to be referred to safeguarding. He said the way you want your baby out I am concerned about the baby's welfare, which was very wrong, I was explaining why I needed the baby to be born as I was struggling mentally and had other kids to look after and the SPO had deteriorated and I was not being supported with it. Asian professionals make you feel really small, their attitude and behaviour changes, 'I'm a doctor, I'm Asian,' they have a big head. There's power dynamics because they see someone from their community who they can exert power over."



Another woman went to the hospital for a health check-up when she was pregnant with her second child and took her two-year old along with her. She was seen by an Indian (Hindu) male doctor who she felt deliberately tried to scare and bully her: "

He said, 'will you be beating this child too when it is born like you did with your first one?' He then said my son's clothes should be taken off so he can check for bruises. I started crying and afterwards told the midwife and said that I wanted to complain and needed to know his name. But she took me into a room and said 'you are just feeling emotional because you are pregnant.' She gave me some tissues and left the room and did not give me his name."



She wished she had pursued the matter but did not have the emotional strength at the time.

14.9 Staff Attitudes Towards Co-workers

Negative attitudes and behaviours of healthcare professionals towards one another were also mentioned. These insights were voluntarily provided even though this was not specifically asked about in interviews or the online survey. They spoke about witnessing minority ethnic health professionals being treated in a disrespectful manner by White staff and it was not even disguised in front of them, which they found surprising. In one example, the midwife was negative towards the woman and her colleague:

"I was induced but I didn't want to be induced, the labour was long. They then induced me and popped my waters, she made it clear she didn't want me. She was huffing and puffing saying "are you ready yet?" She was a middle-aged White midwife, who was very nasty and rude. The Asian midwife said that there was a room free, but the White midwife said no because I wasn't ready, she started arguing with the Asian midwife which was really unprofessional,"



MW9 - Pakistani pregnancy experience 2019, aged 29

In another example, a junior White female staff member behaved in a negative manner towards the Asian midwife who she was supposed to be assisting:

"The midwife looking after me was a Muslim Asian woman with a hijab on. The midwife has asked a White healthcare assistant to get a ball so I could do some exercise which would help me, she replied there is none without checking. My midwife then went and got me one herself. When it was time to do my observations, the Asian midwife has asked the same healthcare assistant to help with observations but she refused. She had a bad attitude, she started arguing with the midwife whilst I was having labour pains."

(Online survey)

More worrying is that staff behavior with one another can also increase the risk of harm to patients as in the next example, which has already been mentioned in a previous chapter. The woman (herself a medical professional) was shocked that the senior doctor chose not to perform the instrumental delivery or even supervise the less experienced Asian doctor, which resulted in her losing so much blood that she needed a transfusion. Her mother had even asked the senior obstetrician to remain and supervise but was dismissed. She felt it was a deliberate decision because of the tensions she witnessed between the doctors:

"A more senior doctor should have been done it. It was clear that there was team dynamics between them which was projected on to my body and this is something that should not have happened."



MW26 - Arab Pregnancy experience in 2013, aged 30

INVISIBLE

It is clear from the few examples provided that, when minority ethnic staff are treated negatively, it results in poorer maternity experiences. However, women will also be harmed when negative behaviours involve deliberately setting up colleagues to fail. These examples are not surprising because, according to the latest data in the NHS Workforce Race Equality Standard (WRES) report, approximately one third of Black, Asian and minority ethnic NHS staff have been the victim of bullying, harassment or abuse from colleagues. ⁹⁴ They were also more likely to face disciplinary proceedings than their White colleagues.

Discrimination does not just involve bullying but also impacts career progression as highlighted in the next example. One woman involved in providing a 'doula service' who worked closely with midwives, noted that the expertise of minority ethnic midwives was not effectively utilised, and roles better to suited to them were given to White midwives instead:

"When midwives are sent out into the community they are given titles such as 'BAME Specialist Midwives.' However, such labels tend to be only used for White midwives. When BAME midwives are given the same role and who have community knowledge and have the additional languages, no such titles are not used for them — they tend to be kept in hospitals." (Doula Service Manager).

The latter provides an example of how minority ethnic midwifery staff are denied opportunities that can aid their career progression in contrast to how some White staff are enabled with their careers. Another concern not being sufficiently addressed is the significant under representation at of Black, Asian ethnic minorities at senior levels within the NHS. If NHS colleagues are treated in a prejudicial way, then what confidence can women have as service users that they are being treated equally and equitably?

14.10 Class, Age and First-time Mothers

Even women who had the confidence to question the standard of care being provided (because they had prepared themselves by researching information or because of previous maternity service experiences), were not always listened to. The interviews showed that educated middle class, UK born women from professional backgrounds were also subjected to discriminatory attitudes. New migrant women, for whom English is a second language are even more likely to experience negative attitudes, demonstrated through many testimonies. Also, younger and /or first-time mothers in particular seemed to find their experiences quite traumatic. As they were less aware about what to expect, they found it harder to advocate for themselves and harder to be heard:

"No one checked me/examined me or my baby. If I needed a midwife no one came to me, I didn't know where to go either. I got fed up and went to the midwives/doctor's station and said 'will anyone check me? One Somali woman could not speak English and she was treated poorly with the midwives being very rude to her. I kept thinking how can I speak for her, how can I help her? they were very impatient with her and mean. I realised that if you are pushy and aggressive you get support, but not everyone has that personality,"



Another woman acknowledged that her class and education had aided her in overcoming barriers she would have otherwise faced as a South Asian:

"My class allowed me to overcome the barriers that my brownness might present. My class privilege and my education privilege allowed me to negate the barriers of ethnicity. I was also very aware of my privilege. I was a gobby educated brown woman married to a White man. I knew the questions to ask I did a lot of reading. The more you know the better prepared you are. In every appointment I was the one pushing and asking questions."



She also sensed that the presence of her husband (who was White), at some of her appointments, contributed to more positive attitudes. Similarly, one White Muslim woman interviewed also was certain that her privilege also helped her better navigate maternity services:

"If people saw me as just a White woman, who wasn't covered, I'd have no issues whatsoever. If I didn't open my mouth and speak, I'd be walked all over. It's not until people hear my voice and realise that actually this is an educated woman, that I'm taken seriously and that really angers me. I'm quite fortunate that I'm the sort of person that likes to do research and knows my rights and I'm quite vocal about that. I know that there are many women who come across a lot of issues. It frustrates me and upsets me a lot because it shouldn't matter what you wear or what your religion is or how you look, you should all get the same treatment'... 'I can't deny the White privilege I have and after reverting [to Islam] you are put into a minority group, and you have to adapt to what some women had to deal with all their lives."



14.11 Learning

Although prejudice will not be the sole cause of the racial disparities in maternal outcomes, it is highly likely to play a significant role in every aspect of maternity care, given the substantial evidence (in the form of numerous testimonies) provided throughout this report. Negative and uncaring conduct experienced by the Muslim women was corroborated by many others who shared similar accounts. Women were subjected to multiple, intersecting forms of discrimination because of their race, ethnicity, religion, class and gender when they accessed maternity services, which compromised their care. The lack of compassion and culturally insensitive healthcare left women with no confidence in maternity services, which resulted in changing hospitals (if they were able to) or delaying seeking help. While it is impossible to ascertain the proportion of healthcare staff that hold negative views about Muslim and minority ethnic women, this report suggests that it cannot be put down to only small pockets of bad behaviour or 'hot spots.' Given over one thousand responses to the from a range of demographics, the problem is clearly broader than that and may include non-clinical staff such as receptionists.

If maternal, foetal and neonatal health is to be improved significantly, there needs to be a significant shift in attitudes towards Black, South Asian, Arab and other minority ethnic women. This is not just be about being kind and respectful during delivery of care. Healthcare professionals must not use the bodies of White women as the reference point against which assessments are made when considering signs and symptoms. Additionally, minority ethnic women should also not be treated as one homogenous group when determining risk. In previous chapters it was evident from maternity experience this approach was not being taken which led to delay in care and put women and their babies at risk.



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.



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.



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.



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 minority ethnic women and how it can make them feel.

15 Complaining about Maternity Care

15.1 Overview

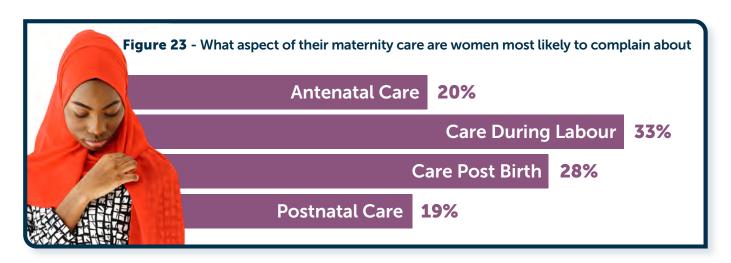


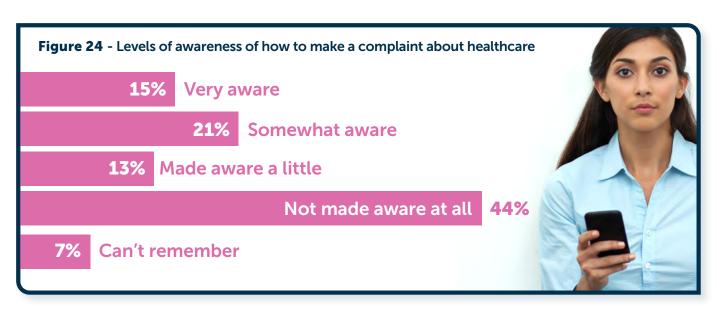
As CQC (Care Quality Commission) inspections have found, the quality of maternity care varies across different hospitals, birthing units and care in the community such as midwives and GPs. If women feel they have received a poor standard of healthcare during and after their pregnancy, they should raise their concerns including making formal complaints. However, women are not complaining. Just under half of the women who indicated that they were not satisfied with their care, but:

- 70% did not complain
- 19% said they complained but only informally
- 11% said they complained formally in writing

The data was explored to find out what women were most likely to complain about when they do. As already discussed in Chapter 4, most women were satisfied with their maternity care, but a significant minority of women rated their maternity care as 'poor' or 'very poor' as follows: antenatal (10%), intrapartum (18%) and postnatal (18%). This shows that women were equally as dissatisfied with their intrapartum care as they were with the postnatal care. However, the responses showed that they were more likely to complain about their care during the intrapartum period, especially about their care during labour (**Figure 23**). This may mean – and the experiences shared by the women interviewed and from the online survey would suggest that it is during this period women and their babies are being most harmed or being put at the greatest risk.

Many women (who should be complaining) were not doing so, even when they describe their care as negligent, because most women are not well informed about the complaints process (**Figure 24**). The data revealed that almost half (44%) of the respondents were not provided any information about how to make a complaint. Only 15% were very aware, with 34% having some / little awareness. Of those who had some / little awareness, 10% said they only found out because they requested the information.





15.2 Reasons for Not Complaining



The reasons for not making a complaint (whether formally or informally) were examined from the survey comments and explored during the interviews. In addition to not being aware of the complaints process, several other explanations emerged, which are discussed further:

- 1. Poor health (of mother and / or baby)
- 2. Trauma (including poor mental health)
- 3. Not having the time or energy
- 4. Concern about negative impact on future care
- 5. Lack of confidence in the complaints process
- 6. Blaming the healthcare system not the staff
- 7. Not being aware of the complaints process
- 8. Influenced by culture and faith
- 9. Not being supported to complain

15.2.1 Reason one: Poor health

Women who were poorly or whose babies were unwell only wanted to focus on themselves, their newborns and family. Some were in too much pain to think about anything else. Women did not prioritise complaining and by the time they had the headspace to consider it, they felt it was too late. According to NHS rules complaints need to made within 12 months from the time of the treatment being complained about.

"After I had my baby I felt too overwhelmed to even think about making a formal complaint. I did intend to several times but never got around to it. Especially as I was poorly for so long, it just seemed too much to even think about. After 7 months when I got better, I felt there was no point as it had been a long time."

(Online survey)

"Because my baby was ill at 4 days old and hospitalised at 10 days old. And she spent her first year of life in and out of hospitals (hospitalised up to 6 times). And so, I had other priorities." "My baby was in neonatal care. Felt had no time to think about complaining as wanted to spend as much time with my baby. She was my main focus."

(Online survey)

(Online survey)

"I was so poorly that I just wanted to deal with other things."

(Online survey)

"When you're in so much pain, it's hard to follow up and/or process it in real time. It's not until you've reflected on those moments that you realise. Especially when you compare it to friends and family who have had similar experiences but different treatments."

15.2.2 Reason two: Trauma and poor mental health

Of all the reasons provided for not complaining, being too traumatised to put in a complaint was the most frequent reason given in the comments box in the online survey. Women were so shaken they just wanted to put the experience behind them and not have to recall it. Women were using similar language to describe their experiences, as 'traumatic' and stating they continued to suffer long after giving birth and resulting in poor mental health. It is clear from the survey comments below that, due to the trauma suffered and the poor ill health, women did not have the capacity to complain.

"I didn't know who to contact. I was extremely traumatised and tried to be strong for my baby."

"I was already stressed out and depressed I didn't want to make myself worse."

(Online survey)

(Online survey)

"I was completely traumatised by my post birth experience, I still have nightmares about it to this day and almost feel like I have developed post-traumatic stress disorder because of it. I can't and couldn't bring myself around to complaining as just thinking about it upsets me so much. I was so close to dying because of their negligence and it was an inhumane way to be treated."

(Online survey)

"I was still pretty shaken by the whole experience and going through things personally, had postnatal depression and generally really low - I didn't complain."

"I was so desperate to be able to come back home and the trauma of the service by all the staffs were so bad that I decided to complain once I feel much better."

(Online survey)

(Online survey)

"I was very traumatised following the whole process, I was drained and unable to carry out a complaint, a year on it still makes me feel deeply upset of how I was treated and if I was not checked at the time I was I could've lost my baby."

(Online survey)

"After having a traumatic 9 months, a 30-hour labour, I was glad to see the back of it all. And didn't complain. I wish I had."

"I was suffering from postnatal depression after leaving the hospital nearly a week later and did not want to think or talk about the experience."

(Online survey)

(Online survey)

"I was traumatised by my first night in hospital after giving birth. I self-discharged the next day and just wanted to forget the awful hospital midwives so I didn't complain."

"My emotional state was so bad after hearing devastating news."

(Online survey)

"I didn't want anything to do with the midwifes and left it. Wish I had done."

"Decided not to complain as I found the whole process very traumatic."

(Online survey)

"I just wanted to finish it not stress myself anymore."

(Online survey)

"I wanted to forget the traumatic experience."

(Online survey)

"To be honest emotions were running high and I was not thinking straight and I just wanted to go home and get some rest."

"I just wanted to forget about it because I already have so much going on but 17 months on and it still haunts me."

(Online survey)

(Online survey)

(Online survey)

15.2.3 Reason three: Not having the time or energy

Not having the energy or time to put in a complaint was the second most mentioned reason in the survey comments box, which is also linked to poor health of the women and their babies. They women said that they were too exhausted due to being sleep deprived, having to look after a newborn and having other caring responsibilities. Women said that they did not feel mentally and physically strong enough to go through a process that was likely to be lengthy.

"Because I was exhausted and sleep deprived. It would have taken too much energy and thankfully we all survived without significant physical harm."

"I couldn't be bothered I needed to look after my baby, elderly parent and other children. So, didn't want to take up anything to mentally drain me more."

(Online survey)

(Online survey)

"Following my placenta rupture I was exhausted and out of it. Some senior doctors came in and asked if I wanted complain but I said no as I wanted left alone and rest. I didn't realise until I went home what had happened."

(Online survey)

"Even though I was very upset about how I was treated after giving birth - I didn't have the time or energy to spend on complaining even though I should have."

wait after the induction, but once my baby is in my hands, safe and happy, I was too busy to think about anything else."

"I wanted to complain about the risky

(Online survey)

"I was feeling vulnerable at that time and did not feel strong enough to make complaint although I wish I had." "I also feel I did not have the energy to do so as I wanted to focus on recovery and my baby and family."

(Online survey)

(Online survey)

"I was depleted physically and mentally and therefore didn't make any complaints."

(Online survey)

"I didn't have the energy to complain! Was too busy trying to be a new mum again!"

"I was too exhausted and had my hands full with a new baby that wouldn't feed."

(Online survey)

(Online survey)

"The period shortly after having your baby is so hectic (leaving hospital, getting to know your baby, breastfeeding) that complaining becomes secondary and seemed trivial at the time."

(Online survey)

It would have taken too much energy and thankfully we all survived without significant physical harm."

15.2.4 Reason four: Negative impact on future care

Women were worried that the quality of their maternity care would be negatively impacted if they raised concerns about individual healthcare professionals, especially if they continued to be treated by them. They were also concerned that complaining could lead to negative attitudes towards them from other colleagues of the healthcare professionals involved thus further affecting their care.

"I felt I couldn't complain without the name of the midwife who was supposed to deliver my baby. And felt like nothing would be done as I saw the midwives protect one another."

(Online survey)

"I did not wish to make a formal complaint in the event this obstetrician ended up as my surgeon."

"I just felt I didn't want to rub anyone the wrong way as I depended on them fully to get the care I needed."

(Online survey)

15.2.5 Reason five: Lack of confidence in the complaints procedure

Some women did not complain because they did not have any confidence in the complaints process. There were examples of women who took initial steps such as drafting letters and emails but then did not pursue the complaint. They believed their complaint would make no difference because they would be ignored, not taken seriously and their experiences would be dismissed and minimised. They felt if service providers did not care when they needed to feel safe, why would they be bothered afterwards.

"I am contemplating writing up a complaint but I feel that I will be pointless. I don't want to waste my time and I don't want to have to think/ talk about the birth to be dismissed or to have my experience minimised."

"I have a complaint letter ready to submit but haven't yet as I'm thinking what's the point as the NHS don't care and anytime I complained to them they ignored me and tried to move on swiftly without actually addressing my complaint."

(Online survey)

(Online survey)

"Can't be bothered as it would be ignored."

(Online survey)

"I did not complain as working in the NHS myself I have an idea of how these complaints don't get taken very seriously so it would've been nothing but a waste of my time." "I was going to do it, but I felt it would not make any difference, so I didn't, nobody cared when I had bleeding and pain at the beginning of my pregnancy (even though I had 4 Miscarriages)."

(Online survey)

(Online survey)

"I did not complain because it was the 1st lockdown and I knew I would be ignored. When I read my discharge notes it was horrible the comment written on it accusing me of not responding (basically saying I was depressed) I was in a lot of pain which they did not help with or understand."

15.2.6 Reason six: Blaming the healthcare system not the staff

Not all women who had grievances blamed the midwives or doctors and some felt it was unfair to criticise them. They thought the low quality of care was related to the NHS system e.g. staff shortages, work pressures and inadequate processes that were in place. They recognised that there were additional pressures on staff due to the Covid pandemic.

"The reasons I was not satisfied are due to inadequate staffing on the postnatal wards. Complaining about this opens staff up to criticism that they don't deserve as they are doing their best in the circumstances."

(Online survey)

"The rest of my care was great. It was just the one incident, I don't blame it on racism but more on the fact there is too much pressure on the staff."

"There is no point - I believe the NHS system leads to these issues and it's not the fault of the individuals per say."

(Online survey)

(Online survey)

"I changed hospitals due to the treatment received."

(Online survey)

15.2.7 Reason seven: Not being aware to the compaints process

As already stated earlier, a large number of women were not made aware of the complaints process, which is further supported by the comments below. All women should be given an equal opportunity to complain and, if they are not, then healthcare service providers are not being held to account. It also means having 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 and other women and their babies have poor yet avoidable experiences. One woman said she felt happy that she and her baby were alive at the end of her experience. Women should not feel lucky to make it through their pregnancy and birth, without losing their lives or theirs or their babies' lives. What must these women be going through to make them feel this way? Furthermore, hospitals should be learning from women's experiences even when they do not submit formal complaints.

Sometimes when women did find out how to complain or had the time, energy and were well enough mentally and physically to pursue the issues, they felt it was too late. For example, according to NHS guidelines, complaints should be submitted within 12 months of the experiences. However, if there are good and justifiable reasons, complaints can be submitted after 12 months, but it is unlikely women will be aware of this or what circumstances would be perceived as justifiable reasons.

"Once I knew you could complain on the website it said I'd left it too late as had to be within 12 months."

"As it was lockdown and didn't have much chance to complain as thought maybe everyone under pressure plus didn't know where to complain."

(Online survey)

"I didn't know how to. I read somewhere you can complain up to certain amount of months. My mental state was not good in that time and I believe I missed the time frame."

(Online survey)

"Was not given any info on how to complain or who to complain to."

"I didn't know where to start and felt the damage was already done."

(Online survey)

(Online survey)

"I never made a complain during any of my pregnancies even though I had terrible experience because I was happy to be alive and my baby to be alive and being able to take them home. Second pregnancy I never knew I can make a complain and there is places to complain and third one I felt what is the point? Does anyone listen? Does anyone care?"

(Online survey)

"I didn't know where to start and felt the damage was already done."

15.2.8 Reason eight: Influenced by culture and faith

Complaint behaviour may be influenced by culture and faith. Muslim women may be less likely to complain. For example, adverse outcomes may be viewed as predestined:

"Because of my religion, I have faith and see it as a test so I didn't complain, I think me and other women need to separate the two, we can't accept bad treatment because we think of it as a test from Allah (God). I kept feeling angry, upset, guilty thinking what could I have done better to receive better treatment and care from them."



MW6 - Black Other Pregnancy experience in 2020, aged 31

15.2.9 Reason nine: Not being supported to compain

Women who did make attempts to raise concerns verbally (face to face or on the phone) did so by raising issues with the ward, midwife, GP, health visitor or the Patient Advice and Liaison Service (PALS) felt unsupported. Some women found PALS unhelpful and were advised by them to contact wards directly to complain, which women felt uncomfortable doing:

"Complaining about racism to a White nurse, another White nurse takes a look at it and assesses it, who is going to understand it?"



MW6 - Black Other Pregnancy experience in 2020, aged 31

Additionally, many of the women felt that the issues were not properly recorded anywhere or they were followed up. Occasionally verbal apologies were offered, but they felt these were to prevent them from escalating matters and to deter them from complaining further:

"They tried to say that everything was fine baby is fine, you don't need to complain."



MW5 - Pakistani Pregnancy experience in 2019, aged 21.

Another interviewee was also put off from complaining:

"I started crying and afterwards told the midwife and said that I wanted to complain and needed to know his (doctor's) name. But she took me into a room and said 'you are just feeling emotional because you are pregnant.' She gave me some tissues and left the room and did not give me his name. When she returned she said, you can go home now."



MW21 - Pakistani Pregnancy experience in 2013, aged 24

There was no confidence that action was or would be taken to change processes, procedures or staff attitudes. Other mechanisms used for feedback were via questionnaires offered on the wards, through surveys received on text after being discharged and by writing negative reviews on Google.

"It was too exhausting for me to tell too many people about my experience initially so I just told the midwife who visited at home the first time and she said she would feed it back. I'm not sure if any action has been taken. I don't have any confirmation that my complaints have been dealt with."

(Online survey)

"We complained to the hospital staff, but because we had been through so much, we focussed on our baby and that baby was safe. A staff member had reassured us that the worst is over and that we are safe and nothing bad had happened to us, therefore we didn't take things forward at the time."

"I planned to do a written formal complaint and started compiling a letter but had a serious cancer diagnosis in the family which took priority and I had no support to take the complaint forward. I felt low and had no energy to see it through."

(Online survey)

"I complained to a manager within the maternity services but I do not feel that she did anything to change practices."

"I did mention what was happening to other healthcare professionals but nothing happened."

(Online survey)

(Online survey)

"I complained informally to the GP regarding the issue."

(Online survey)

"I told my concerns to the health visitor. She said to me to put a complaint in. However, would have been better if she investigated further."

(Online survey)

"I left a comment to the maternity ward before leaving with baby."

"I told my midwife of my experience when she came to my house."

(Online survey)

(Online survey)

"Emailed PALS but they replied telling me to contact the ward manager which I did. And she only offered an apology. I wasn't satisfied so I contacted PALS again via email but never got a reply."

(Online survey)

Of the 37 women interviewed, about one third complained either in writing or verbally. Many did not hear back and did not chase up. The few women who received a response had sent a detailed analysis of events and pursued the matter:

"After receiving poor antenatal care and not being listened to when she raised concerns, she submitted a 5000-word written complaint letter. She was immediately contacted by the head midwife, after which the standard of her care improved greatly and she had a very positive experience for the rest of her pregnancy."



MW33 – Indian

Pregnancy experience in 2020, aged 29

The research even prompted a few women to request their maternity records with a view to potentially making a complaint. It was clear that those who had the confidence to strongly advocate for themselves, and those that persisted and were able to navigate the process, were being responded to quickly. Health service providers were keen to de-escalate situations with these women, perhaps in some instances to avoid litigation.

However, women who are less vocal and raise concerns informally because they have less capacity (due to poor health, exhaustion, trauma etc.,) should not be ignored. These women make up the majority of complainants, which means that if they are ignored, important learning is being missed that could make maternity services safer, respectful and more compassionate. Every hospital should have a mechanism in place to capture learning from these women. The data should be broken down by ethnicity and presented at board level annually to demonstrate that hospital trusts are taking proactive steps to close the maternal mortality ethnicity gap and ensure all women receive a high standard of maternity care.

MW25 - Pakistani



Pregnancy experience in 2011, aged 25

This case has already been highlighted in the 'Early Pregnancy Loss' chapter where the woman who was a new migrant felt the language and tone used towards her was a due to her ethnicity / accent. The hospital only responded to complaints after another family member personally went to the hospital and threatened legal action. It was unclear whether the hospital made any genuine attempts to learn from the incident and prevents its occurrence.

Pregnancy experience in 2016, aged 30

After giving birth to her second child, she was unwell and returned to the hospital with signs of sepsis and was dismissed and sent home to return again to be told to go home again. She was only seen and diagnosed with sepsis because her and husband refused to leave. This case has already been discussed in chapter 9. However, despite her near-death experience, she did not complain and said: "At no stage was I made aware how to complain and was unaware of the process and did not have the energy to find out and pursue it. I was feeling so low and half dead. I was thankful to be alive, so I didn't have the energy to complain."

15.3 Maternity Litigation

As already highlighted in the introduction chapter, maternity incidents remain the single highest cost of claims against the NHS in England. Obstetrics claims remain the largest proportion, at 59% of the total estimated value (which amounts to £4.2 billion), and represents 11% of the number of 10,816 new claims received in 2020/21.95 Given the poor experiences of minority ethnic women, as highlighted throughout this report, they should be expected to be overrepresented in the maternity complaints and litigation data, compromising more than 14% of complaints and claims (as minority ethnic communities make up 14% of the UK population). Instead, it is more likely that these women are underrepresented, since the findings suggest, many of these women are unaware of complaints procedures. Those who are informed, may be reluctant to raise concerns because of the lack of confidence in the complaints process. Research findings by the NHS Ombudsman also confirm that Muslim women are less likely to voice grievances.96

During the research it was not possible to verify the proportion of maternity complaints and litigation claims made by Black, Asian and minority ethnic women. A ten-year study of maternity claims contained detailed information about the claims including breakdown by age groups but analysis by ethnic group was absent. This is surprising given that Black and Asian women having poorer maternity outcomes has been well known for a very long time. The most frequent categories of claims reported in the 10-year analysis are listed in **Table 13** and are the same issues highlighted by both the online survey respondents, women interviewed and the focus group. The three most frequent reasons for maternity claims are related to: management of labour (14.05%), caesarean birth (13.24%) and cerebral palsy (10.65%). Two of these categories, namely cerebral palsy and management of labour, along with Cardiotocography (CTG) interpretation (monitoring the baby's heart rate), tend to be the most expensive claims and together accounted for 70% of the total value of all the maternity claims.⁹⁷

A 'Freedom of Information' request was sent to 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. Data on the ethnic profile of the maternity claimants was requested. The following response was received:

"In terms of ethnicity breakdown, this information is not held as it is not recorded in our claims management system."

This is astonishing. If ethnicity data is not being captured, then it will mask the fact that a higher proportion of minority ethnic women are receiving a poor standard of care with poorer outcomes. It may also potentially mean they are not compensated. This perhaps is one of the clearest examples of systemic discrimination - the NHS is simply not being held accountable and is failing minority ethnic women. NHS Resolution should take immediate action to address this issue and ensure future reports must contain ethnicity data. When voices go unheard, lessons cannot be learned. The NHS is failing these women and women of the future. Mistakes will be repeated again and again, and Black, Asian and minority ethnic women and their babies will continue to suffer avoidable harm and even death as a result.

Table 13 - Total number and value of claims by category between 1st April 2000 and 31st March 2010 (NHS Litigation Authority, 2012)

Category	Number of Claims	% of claims	Value of Claims £	% of total Value
Accident	58	1.14	£728,796	0.02%
Anaesthetic	172	3.38	£19,249,853	0.61
Antenatal care	391	7.68	£144,811,665	4.64
Antenatal investigations	230	4.52	£149,986,770	4.81
Bladder	72	1.41	£8,824,269	0.28
Caesarean section	674	13.24	£216,167,223	6.93
Cerebral palsy	542	10.65	£1,263,581,324	40.52
CTG interpretation	300	5.89	£466,393,771	14.95
Drug error	83	1.63	£8,759,430	0.28
Management labour	715	14.05	£424,039,651	13.60
Maternal death	38	0.74	£20,253,906	0.64
Nursing care	35	0.68	£511,700	0.01
Operative vaginal delivery	160	3.14	£93,659,223	3.00
Other	265	5.20	£40,252,783	1.29
Perineal trauma	441	8.66	£31,202,836	1.00
Postpartum haemorrhage	111	2.18	£3,024,833	0.10
Psychological	28	0.55	£681,791	0.02
Retained swabs	186	3.65	£3,021,910	0.1
Shoulder dystocia	250	4.91	£103,520,832	3.32
Stillbirth	251	4.93	£15,712,695	0.50
Uterine rupture	85	1.67	£103,264,627	3.31
TOTAL	5087		£3,117,649,888	

15.4 Learning

To ensure the voices of these women are heard, attention must be paid to the rate of complaints from Black, Asian and minority ethnic groups. If complaints about maternity care are not being broken down by ethnicity, the aggregated data will mask the fact that poor experiences are higher in certain minority ethnic groups than others. If health service providers are serious about addressing health inequalities, they will identify gaps in the use of their complaints service and then take practical steps to ensure under-represented groups are made aware of complaints procedures, and work to remove the barriers that prevent women from using them. The Equality Act requires healthcare providers to be proactive in eliminating inequalities between different ethnic groups and taking such an approach can contribute towards this.

Maternity litigation claims are very high and NHS Resolution is trying to reduce these. More Black, Asian and other minority ethnic women putting in compensation claims may not be in the interest of the NHS. This may explain in part the lack of effort being made to track the ethnicity of claimants since this would draw attention to the potential inequalities. NHS Resolution and every hospital trust must come up with a clear action plan to address the complaints gap. If they believe there is no complaints gap, they must demonstrate this by being transparent and publishing data according to ethnicity.

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.



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.

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.



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

16 Conclusion

16.1 Key Themes

The provision of maternity services was variable and inequitable. The following main **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.

16.2 Discussion

The aim of this inquiry was to illuminate the maternity experiences of Muslim women, from Black, Asian and minority ethnic backgrounds. The high survey response rate (with over 1000 responses completed) and the representativeness (i.e. broadly reflecting the diversity of the Muslim female population in Britain) combined with a focus group and the 37 in depth interviews with women, provided a high-quality data set. Meaningful patterns and conclusions can therefore be drawn about maternity care that is being provided to Muslim women and also more generally to Black, Asian and minority ethnic women of other and no faith because differential treatment (when it occurred) was not solely connected to a woman's religious background.

Although a minority of women perceived their maternity to be 'poor' or 'very poor,' it is still a significant size, making it too large a group to ignore given that the consequences of sub-standard care can be harmful outcomes as evidenced throughout the report. Women's perceptions of maternity services provide an important indicator of the quality and effectiveness of care provision. Of the approximate 600,000 annual births, 25% (i.e. 150,000) are by minority ethnic women. If the 'poor' or 'very poor' ratings for antenatal care (10%), intrapartum care (18%) and postnatal care (18%) are therefore applied to this minority ethnic population of women who give birth, it could mean that every year around 15,000, 27,000 and 27,000 are likely to be receiving poor / very poor care during the antenatal, intrapartum and postnatal period respectively. The actual numbers of women affected are probably even higher than these estimates because women with lower educational attainment and those with language needs were missing from this research because the women who took part in this study were proficient in English, most of whom were educated to A level and above and many were in professional occupations. Although experiences of migrant women born outside of the UK were captured, the majority were born in the UK.

The findings of this inquiry have been very similar to those in the Ockenden inquiry⁹⁸ such as: lack of professional concern and compassion expressed by staff; infrequent monitoring during labour of women; lack of heart rate monitoring of their babies; women not being listened to and their concerns ignored; delays in escalation of care; significant staffing and training gaps in the midwifery and medical workforce; and lack of transparency with parents when there were adverse outcomes. However, the research also flagged up many other additional issues during minority ethnic women's maternity care provision that compromised the safety of both mother and baby, particularly the bullying of women into having labour inductions. Although Ockenden Inquiry highlighted the pressure on women to have natural births, (which was also a feature in this research), a tendency by some healthcare professionals to over medicalise birth without reasonable medical justifications, was also noted.

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.

This research also found a hierarchy in bias with women from particular sub-ethnic groups, such as Black African, Bangladeshi, Arab, Asian Other women and mixed Ethnic Black / White women experiencing the poorest care. Perceptions of the poor treatment was also backed up by statistical evidence. When the responses from over 892 women who had given birth were compared to national average statistics for birth outcomes, Muslim BAME women were: less likely to have pain relief during labour, more likely to have a labour induction, more likely to have an emergency caesarean, more likely to have an instrumental birth, more likely to have a prolonged labour and more likely to have excessive blood loss. A disproportionate number of women experienced stillbirths and neonatal deaths. A shocking 1% (i.e. 10 women) had these experiences but figures of no more than 3-4 should have been expected.

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 lives. Unfortunately, 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 poor outcomes observed cannot be explained by physiological factors because not all women had medical co-morbidities. Even when they did, they should still be able to have a safe pregnancy and birth if high quality maternity care is provided with additional support and monitoring. Social and economic disadvantage had to also be discounted as a contributory factor to poor outcomes because the vast majority of the women who took part in the research were of a higher socio-economic status. 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), were the key drivers of poor maternity care. Both factors were often inter-related and resulted in indirect and direct discrimination, which were associated with women's intersecting identities (combination of ethnicity, religion and social class).

Uncovering these maternity failures can help to explain why more Black and South Asian women and their babies have higher mortality rates. Lessons must be learned from the poor practices that lead to such adverse outcomes so that other women can be prevented from going through these ordeals. During the research any positive practices that emerged were also reported so that these could provide examples of good practice that can be shared when training staff to better understand the characteristics of compassionate care. In one extremely sad case the baby died prior to birth due to a catalogue of errors. Even though the staff knew she was delivering a stillborn, the woman was shown no compassion and not provided with any pain relief despite asking for it. She was also not checked upon for long periods and when she eventually was four students were bought in without her permission. The lack of respect and dignity in this situation was appalling and should never have happened.

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 their 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, negative experiences and adverse outcomes affect minority ethnic women from across the socioeconomic spectrum including those who have no underlying health concerns that would put them at increased risk. 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.

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During the current challenges facing the NHS it is now easy to shift the blame on to workforce shortages instead. Even though 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 midwives and obstetricians of being desensitised to women's pain and negative attitudes towards women from racialised minority communities. Such attitudes may only exist amongst a minority of staff, but the group is significantly large enough a group to affect the quality of maternity care provision and compromise the safety of mothers and babies. There were plenty of examples of women being subjected to microaggressions and being bullied. While it was not always due to racism, it was clear that some maternity staff do treat women less favourably because of their race, ethnicity, faith, clothing, accent and English proficiency. 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.

16.3 Calls to Action

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

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.

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. Some 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.

Breastfeeding and mental wellbeing support services need to be better resourced, however, the support also needs to be culturally appropriate to improve maternal outcomes. 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 be improved. Negative attitudes towards ethnic co-workers can also have an impact on the quality of maternity care provided to women and such workforce cultures should not be allowed to flourish.

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 minority ethnic women (such as monitoring progression of labour), that the White female body should not be used as the standard reference point. Women know their bodies 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, can understand maternal needs and be able to prioritise maternal choice. A culture will also 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 fear of victimisation. Improving transparency will help support a learning a culture when care does not go as well as expected. Relationships between the different disciplines involved in maternity care will also need to be strengthened.

Maternal Empowerment

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. 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; about obstetric procedures; hospital annual rates of obstetric procedures and outcomes; complaints procedures; and 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 involve women in the development of safer local maternity services. LMVPs should ensure they hear from women that reflect their local populations down to sub-ethnic group e.g. Bangladeshi, Somali, Arab etc., and not rely on broad ethnic group data (i.e. Black, Asian etc), to check whether they have been inclusive.

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 state 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 More¹² and Birthrights,¹³ all of which have similar findings.

16.4 Concluding Remarks

The aim of this inquiry was to illuminate the maternity experiences of Muslim women, from Black, Asian and minoritThe trust of women in maternity services needs to be reset with detailed action and training plans being developed and shared publicly, which clearly detail lines of accountability, timelines and how progress will be monitored. Bespoke and readily accessible training for maternity staff should contain the many stories ϑ examples included in this and other recent maternity reports.

The lay women's voice needs to be strengthened in shaping maternity services. A Maternity Commissioner who is independent, who has gravitas and 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 that have given evidence to the various inquiries including this research and to those women and their 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.



Local Maternity Voices Partnerships should improve engagement with minority ethnic 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.



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.

18 Recommendations

Recommendations have been provided at the end of each chapter. 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



Chapter 4

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.



Chapter 4

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.



Chapter 7

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



Chapter 8

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.



Chapter 8

Data on postpartum haemorrhage should be disaggregated down to the level of 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.



Chapter 8

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.

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Chapter 9

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 minority ethnic mothers. If this data is not readily available, then hospital trusts should record this data in a way that is easily accessible.



Chapter 9

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.



Chapter 11

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



Chapter 15

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



Chapter 5

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



Chapter 5

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.



Chapter 6

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.



Chapter 8

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.



Chapter 8

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



Chapter 10

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.



Chapter 10

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



Chapter 12

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.



Chapter 12

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



Chapter 12

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 minority ethnic 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.



Chapter 13

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.



Chapter 14

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.



Chapter 14

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.

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Chapter 15

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.



Chapter 16

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



Chapter 8

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.



Chapter 8

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.



Chapter 9

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.



Chapter 9

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.



Chapter 10

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



Chapter 11

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.



Chapter 12

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.



Chapter 13

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



Chapter 14

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.



Chapter 14

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 minority ethnic women and how it can make them feel.



Chapter 15

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



Chapter 5

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 minority ethnic women.



Chapter 5

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.



Chapter 6

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.



Chapter 7

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.



Chapter 9

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.



Chapter 12

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.



Chapter 15

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.



Chapter 15

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



Chapter 16

Local Maternity Voices Partnerships should improve engagement with minority ethnic 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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