Understand the reasons for the poorer health outcomes of minority ethnic women during pregnancy

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Executive Summary

South Asian pregnant women are more likely to have poorer maternal and infant outcomes. The focus of this research was to better understand the contributing factors driving this and provide recommendations for improving health outcomes of Minority Ethnic women's during pregnancy and their new-born babies. The findings from this reported highlighted a need for enhance cultural sensitivity and inclusivity of maternal services to improve maternal access and experience. Key recommendations include availability of information in different languages (particularly for women from Afghan Bengali and Napoli backgrounds), access to interpreters, options to access care fort those who are digitally excluded and better understanding of cultural practices to make the women feel more inclusive. Covid pandemic has had a negative financial impact which also needs to be considered when care planning for these ethnic groups.

Introduction

Maternal and infant outcomes remain very poor for many women from BAME groups, particularly among those women who have recently migrated to the UK. Women from South Asian and Black African communities, women living in poverty, and women seeking refuge and asylum are significantly more likely to die in childbirth compared to their White British counterparts. The findings of a recent research indicate that Black and South Asian women living in the most deprived parts of England experience the largest inequalities in pregnancy outcomes – with 17% of births with Fetal growth restriction (FGR) is a condition in which an unborn baby is smaller than expected for the number of weeks of pregnancy (gestational age) , 12% of stillbirths, and 1% of preterm births attributed to ethnic inequality[1]. Currently there is lack of information about these inequalities and which groups are most strongly affected.

Research Proposal

Through our community engagement prior to this research, a number of questions had emerged:

Why women from Asian families don't avail the health services available to them through NHS and its partner's organizations? What are the barriers? What is the situation after Covid? What kind of help and support they are looking for? Is there any genuine need for tailored made culture-sensitive policies?

The aim of this research was, therefore, to collect feedback from women Surrey residents of South Asian backgrounds about their experience during pregnancy and the financial impact of Covid-19. It is hoped that the findings of this report can support maternity care providers to develop culturally appropriate and tailor-made policies to better protect all women and improve the pregnancy outcomes of South Asians and women in Surrey.

Methodology

Qualitative and quantitative methods were used to collect feedback. A questionnaire was co-developed with a group of clinicians, service providers, Public Health and women with lived experiences. Social media platforms and advertisements through various newsletters by SMEF were used to advertise the events. Individual interviews and focus groups were used to collect data. The purpose of the research was clearly explained to the participants. All women consented before taking part and provide photos of their children. Data and

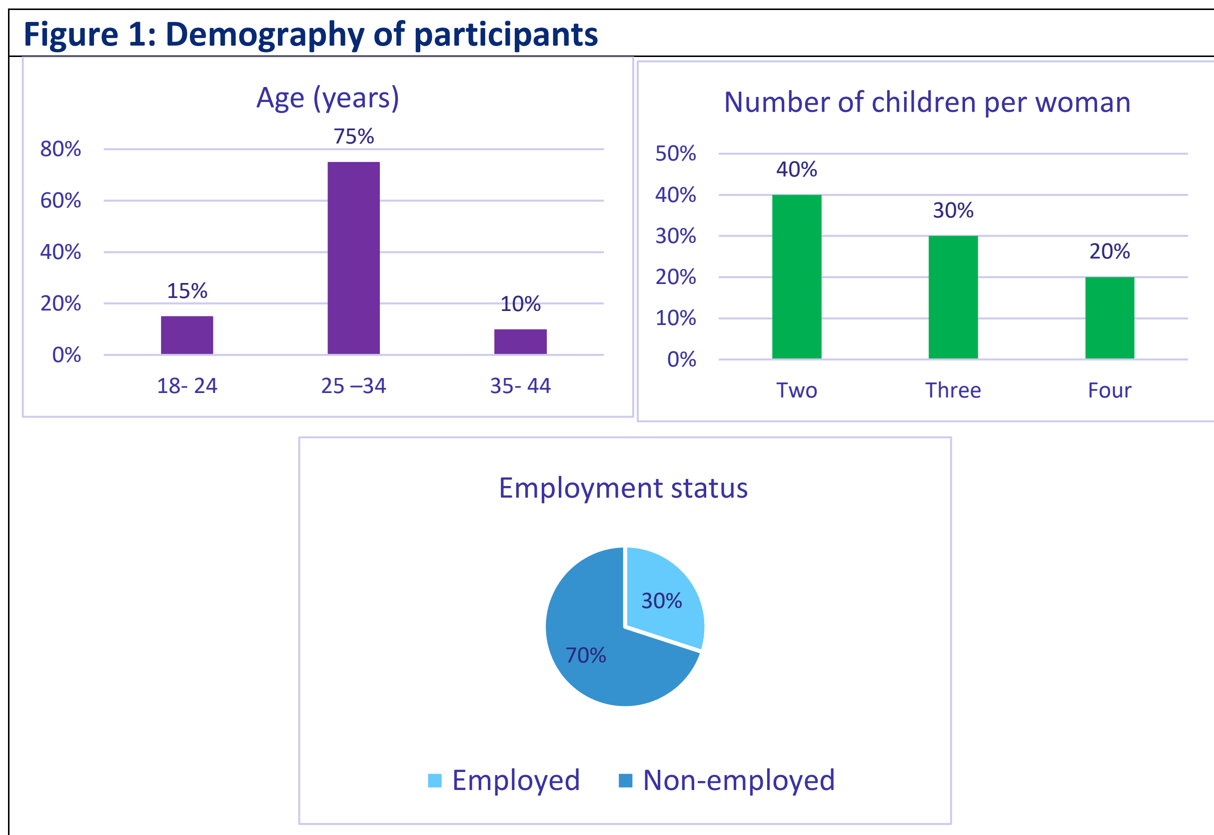
information collected after the interviews and focus groups were kept in a secure location to maintain confidentiality. Data from the questions were analyzed to draw key themes.

Results

Demography of participants

60 Surrey resident women from six different South Asian countries took part in this research. They) from Afghanistan, Bangladesh, India, Pakistan, Nepal, and Sri Lankan ethnic backgrounds (age range 18-44) took part in this research. First language spoken included Urdu, Hindi/Tamil, Bengali, Nepali, Dui, Sinhala and Tamil. All the participants were married and had children under the age of four. Thirty percentage indicated they were doing some part-time work (Figure 1).

Figure 1: Demography of participants

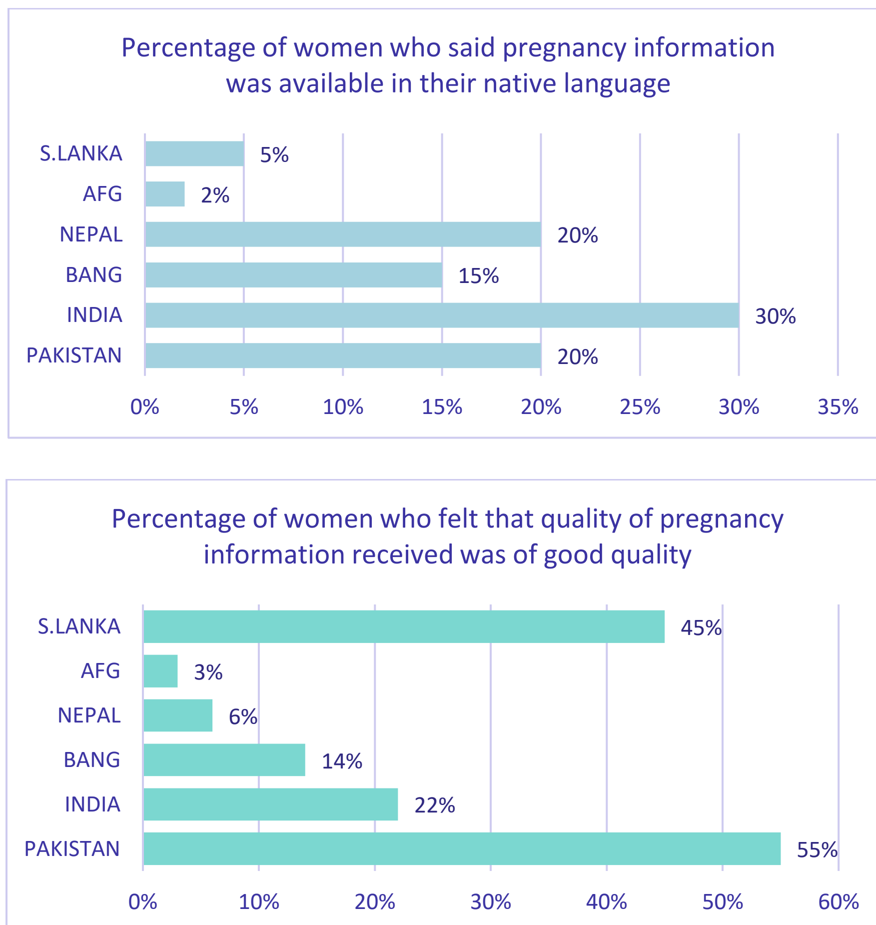


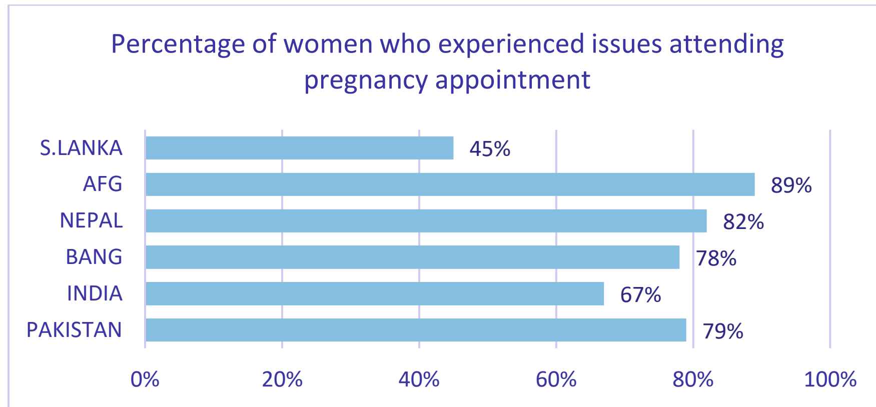
[1] Adverse pregnancy outcomes attributable to socioeconomic and ethnic inequalities in England: a national cohort study - The Lancet

Experience of women about information and attending outpatient appointment during pregnancy

Figure 2 shows the variation in feedback received about the availability of information in different languages and quality of information provided during pregnancy. Only 2% of women from Afghan background said that information was available in their native language and only 5% felt that the quality of information shared with them was of good quality. This observation was also noted in Napoli and Bengali women. A higher proportion of women from Afghan, Napoli and Bengali backgrounds also said they had experienced issues attending outpatient appointments (Figure 2).

Figure 2 Experience of women about information and attending appointment during pregnancy

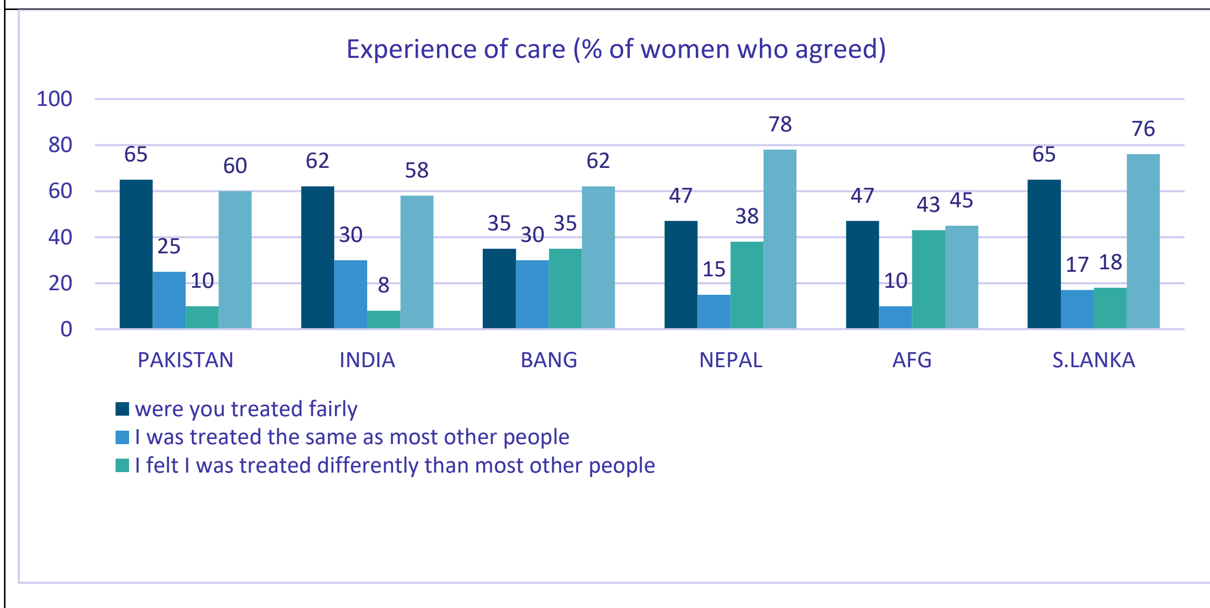




Experience of care and support received during pregnancy

We also asked women about the overall experience of care and their treatment by the health and care providers. Overall, the majority of women reported a positive experience of care received during pregnancy. However, they felt that they were treated differently and not always the same as most other people (Figure 3). Only 35% of women from Bengali and 47% of women from Afghan, Nepali backgrounds reported they felt they were treated fairly. Only a small proportion of women from these ethnic backgrounds reported they felt they were treated the same as most other people (Figure 3).

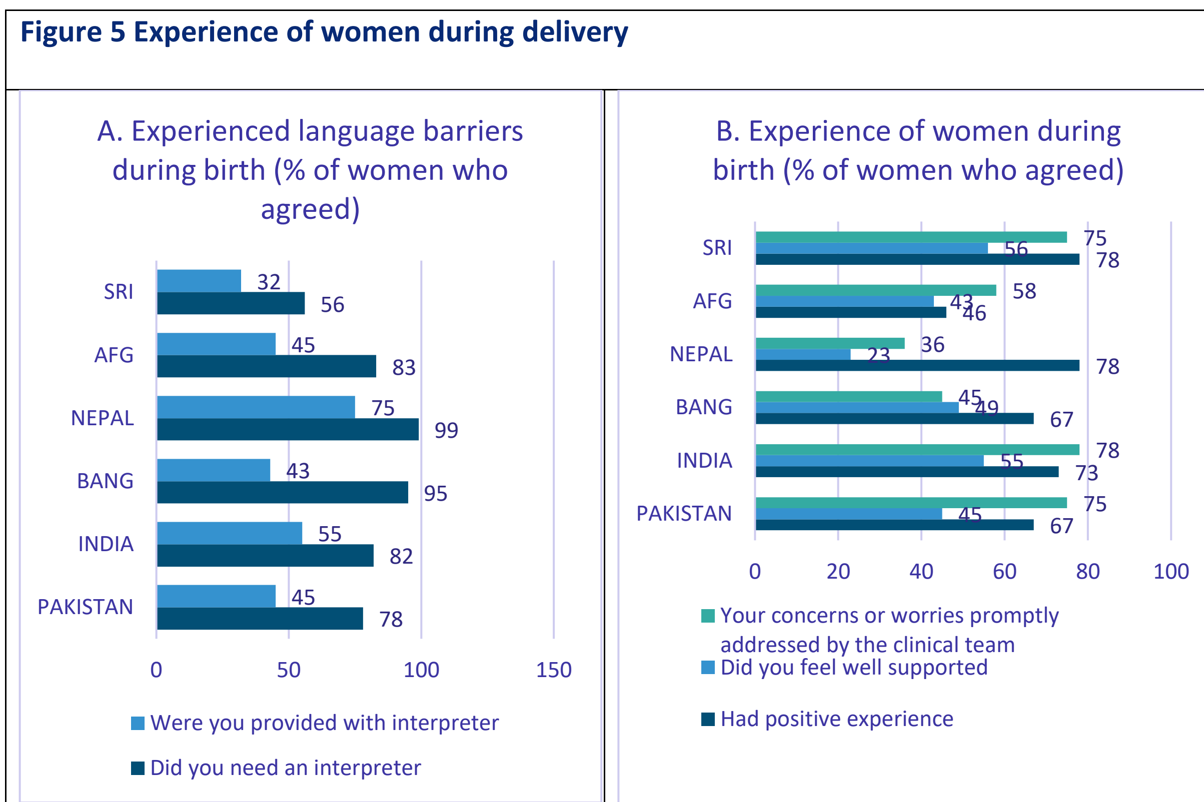
Figure 3 Experience of care and support received during pregnancy



Experience of women during delivery

Majority of women indicated that they needed access to an interpreter. This was highest amongst women from Napoli (99%), Bengali (95%) and Afghan (83%) backgrounds. Although the interpreters were provided, this varied across different ethnic backgrounds. For example, roughly half of women from Bengali and Afghan backgrounds were provided with an interpreter (Figure 5A). We also asked women about their overall experience and level of care and support received during delivery. Most reported a positive experience. However, there were variations in women's feeling of being supported and their concerns addressed promptly. For examples 75% of Indian, Pakistani and Sir Lankan women felt that their concerns were addressed promptly. This compared with 36% of women from Nepali, 45% in Bengali and 56% in Afghan ethnic backgrounds. Approximately 50% of women felt they were well supported (Figure 5B).

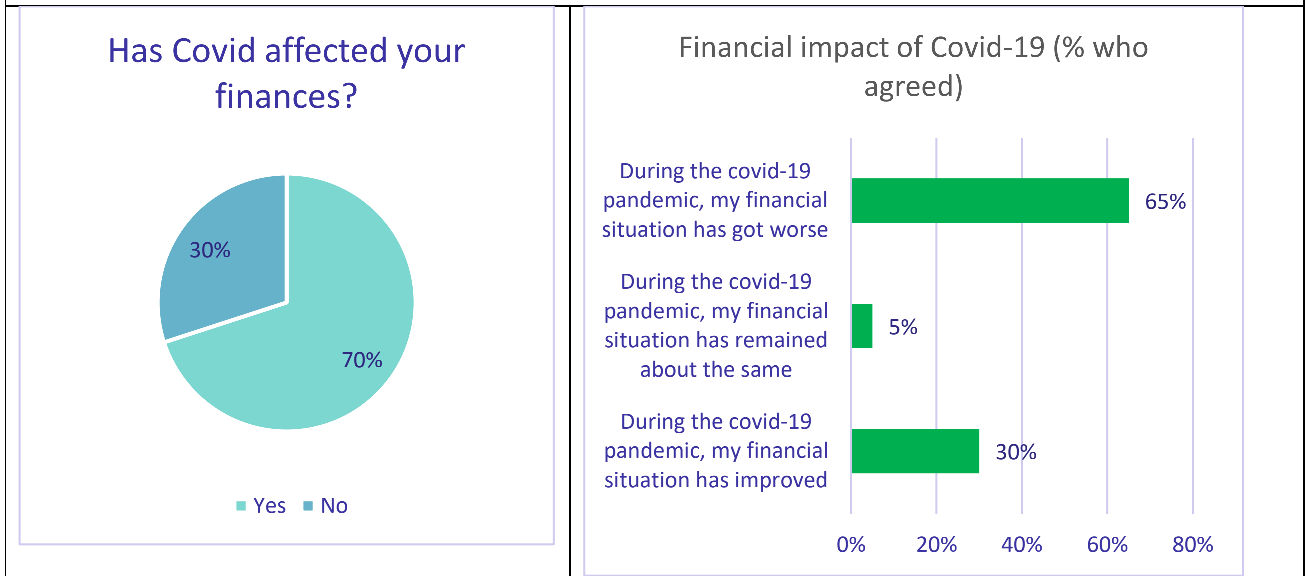
Figure 5 Experience of women during delivery



The financial impact of covid-19

Covid-19's financial impact on families was felt across the different ethnicities; 75% reported that the pandemic had impacted them financially. The majority (65%) reported that Covid-19 has worsened their financial situation (Figure 6).

Figure 6 Financial impact of covid-19



Experience of first-time mums and those who were not born in the UK

The findings from 60 Southern Asian mothers also showed variation in experience of first-time mums and those who not born in the UK. First time mothers experienced more challenges compared to those who have already had children. Women who had children before the pandemic felt the experience was different post-covid. For example, during Covid-19, maternal individuals expressed their depression as they were alone in their labour phase, going to the scans and when their baby was birthed. After a C- section for example, new mothers needed some help, however their partners were not allowed in the hospital and staff were not able to help partly due to language barriers.

Mums who were born and bred in UK also had a different experience than those who immigrated and consequently had a language barrier and no awareness about NHS healthcare system. Most of them appreciated the NHS services and found it very helpful.

Case Studies

Aisha's experience of NHS maternity services during Covid-19

By Attia Aslam

Aisha is 24 and came from Pakistan as a new spouse last year during a pandemic. She was 6 months pregnant with her first child, so registered with the GP as a priority. She also signed up to English language and computer classes straight away but could not continue these after having her baby.

Despite being impressed by the education system, NHS and other services provided in the UK, Aisha says she did not have a good experience when having her baby. In particular, she found her midwife's behavior terrifying. While reviewing Aisha's maternity file from Pakistan, the midwife threw the file on the table and said the notes did not meet UK standards.

Due to language barriers, Aisha found it difficult to understand what she was being told, to answer questions and to ask for the support she needed. This issue was exacerbated due to Covid-19 restrictions, which meant that her husband was not allowed to be present at appointments and during labor.

This was Aisha's first child, and her lack of experience meant she would have benefited from support from family or partners, as well as interpreters. However, no-one was allowed to accompany her. She also described how no physical or moral support was available because of staff shortage in labor ward. After a long labor, Aisha had to go through a C- section. Despite being in recovery from her operation, she had to look after the baby herself. No support was offered regarding feeding her baby or changing nappies in the first few hours after delivery.

Muslim custom requires that a baby should be washed before his first feed, that a family member gives a prayer in the presence of the baby, and that the first thing baby should taste is honey. However, none of these requirements could be carried out.
Although she was very satisfied with many aspects of the services and care provided by very well-trained staff, Aisha suggests that NHS staff should be trained to give extra time and support to first time mums, a little more help with feeding the baby and in cultural awareness more generally. She found online midwife appointments unhelpful and believes she would have benefitted from more face-to-face support from GPs, midwives, and other support.
During pregnancy Aisha was offered a Covid vaccine, but no one was able to reassure her that this was good for the baby.
Although she is fully aware that Covid-19 is a factor underlying some of her negative experiences, her first pregnancy and labor has left her with some very upsetting memories of what should be a happy time to be celebrated.

Case Studies by Ambreen Muzaffar

Case Study I

One of the women's pregnancies and giving birth was like a nightmare. Her first child suffered from hypoxia; a condition of oxygen deprivation around the time of birth, which

resulted in serious brain damage and cerebral palsy. She had no complications during pregnancy with this child. But unfortunately, that child died in a care home when she was 4.5 years old. She strongly believes that her child was treated differently after birth, and she was not provided with the due and right amount of support. During that time, they were also struggling to renew their visa here in the UK and her husband was working long shifts to meet both ends. The woman was not able to understand the medical terminologies and was not provided with an interpreter.

Her second child is normal and almost three years old now but her third child suffers from down syndrome. The mum confirmed that she came to know quite late about her third child's condition, almost when she was six months pregnant, it was quite late for her to abort the child and she preferred to give birth to avoid further health complications. She had requested an advance blood test to check about conceiving and chances of miscarriage, but never got this opportunity.

Covid played a much worse role with her husband's job loss and on top of it, her all-pregnancy appointments were quite far in either London or in Royal Surrey Hospital. There was no female staff to check and communicate with her. She has been through physical, emotional, and financial difficulties. Her first child was admitted to the hospital for one month and instead of hospital transport, she used a taxi to commute.

Case Study II

Another women's water breaks fifteen days before her due date and her nearby hospital where she was about to give birth refused to take her and she had to use a taxi to end up in Winchester hospital where she delivered the child on arrival. Her husband, an IT consultant was undergoing Chemo and staying with their two boys (5 and 3 years). She stated this delivery experience was quite intense and stressful with a last-minute change of hospital and different staff. The experience to travel alone in a taxi while having delivery pains was the worst experience she encounters.

Case studies III

Some women were told to stay home due to covid, despite they were having a lack of baby movements in the last trimester.

Those mums who delivered children pre and post covid have very different experiences. Those mums who have older children and delivered after a gap of more than 5 to 7 years were not started same being considered as they know everything. They said, every child and pregnancy is different and they don't remember everything by heart. It should be mandatory to treat everyone with the same care, with or without previous childbirth experience.

Suggestions for improving maternal services

When we asked women if they had any suggestions for improvement, 47% said cultural sensitivity, 37% said tailored to existing health- status and 16% said no improvements requited. Some of the suggested area for improvement are listed below:

1. Access to information and materials in different languages (targeted for women from **Afghan, Bagnoli and Napoli** backgrounds) and access to interpreters during outpatient appointments and delivery.

2. More **female staff** necessary in the labour room as some mums feel uncomfortable with male doctors, nurses or interpreters.

3. Most people are **digitally excluded**, hence finding it hard to go online appointments; online midwife appointments are not deemed as useful.

4. More **interpreters needed** for those who do not have English as their first Language.

5. More **understanding of cultural diversity** is needed. Midwives should be familiar to different cultures and customs. They should understand and be supportive with other countries medical reports as every country has different within their healthcare. Some female parents said that it would be great if our **traditions and cultures were understood** better and advised accordingly with adequate information and support. They explained that it felt awkward during a midwife visit if she does not understand how we are bringing up our child, for example, sleeping or the weaning process. In terms of religion, some prefer to wash their baby before their first feed or a practice regarding honey tasting. There was also an occurrence where a baby's first prayer was not permitted, as no one was allowed to come into the hospital during the Covid- 19 outbreak.

6. More **help and support should be initiated regarding feeding a baby for first**- time mums who struggle after a C-section.

7. More information also needed on the effects of the **Covid vaccine** and on clinical trials.

8. Some families **suffered financially** during the event of Covid-19; **baby vouchers** could be helpful.

9. **Limited access to GPs during pregnancy**. Some women said that if they had an issues their GPs would normally refer them back to visit the midwifes which happens once after six weeks or more. If a referral is made in between visits to the midwife, the healthcare advisor would call back. However, some women said that if that call was missed, their referral would automatically get closed. Some women also said that routine appointments are only available with a minimum of two to three weeks waiting time and admin staff are not always very friendly. This can put some women off to make contact and get help if they experience any issues.

10. Many women were worried about their families due to lockdown restrictions and potential mental health risks attached. More support would be beneficial for the **mental health of parents and children.**

11. Women who were financially stressed may have been taking care of younger children already and keeping them entertained was not easy during the lockdown.

Conclusion

Covid is an eye opener to emphasize on the importance of tailor made and culture sensitive maternity care for south Asian women specifically focusing on first 1000 days of the newborn. But on other hand, NHS and UK maternal care is among the best in world. NHS is like a spinal cord and survival is not possible without it**.**

Recommendation

- To raise awareness about health information and services available to the expectant and newborn mums (ensure they are culturally sensitive): availability of information in different languages, access to female healthcare professionals, access/how to access interpreters.
- To remove barriers so women from ethnic minority backgrounds can enjoy and feel socially included by increasing cultural awareness amongst health and care providers
- To consider the socioeconomic status of families in relation to available health care services/ care planning.
- Improve access to face-to-face appointments to reduce the impact of digital exclusion
- To help improve their wellbeing and cognitive skills.
- To help improve maternity health literacy

Thank you, NHS, by Ambreen Muzaffar

When I was low you uplifted me.
When I was slow, you supported me.
When I was blue and about to collapse, you were like some oxygen.
When I was not able to understand, you assured me comfort.
You cleaned my dirty sheets and bleeding pads.
You helped me to understand system with pride and dignity.
You aided me when I was at the lowest of energy and with no hope.
You offered me round the clock maternal support
You gave me the first warm feeling after giving birth in form of a cup of tea with sandwich.
There was no fear to make payments for treatments.
NHS, you're like an angel in disguise
Thank you, all the cleaners, Midwives, Nursers, GP, Doctors and Specialists. Thank you, NHS

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NHS

NHS England and NHS Improvement