

Maternity Services Expert Panel – Focus Group with women from East African backgrounds

19 May 2021

Meerat: This is being recorded but if you've got any issues or concerns about that you can contact me - and I'll send my details via Participant A - or you can contact Participant A at any point in the future. If you've got any concerns, we can talk to you about it, or we can remove anything that you've said, it's not a problem. Again, all of it is anonymised as well.

Information is translated by Participant A and B.

Meerat: Because this is for the Houses of Parliament, there are some colleagues from there on the call as well. It's a women's only circle today, but these are some of the colleagues from the Houses of Parliament (*staff turn cameras on*). Again, they're not going to share anything outside of the room, and they're partly here for their own learning to understand how we work with different communities and how we ensure that we hear from these different communities.

Information is translated by Participant A and B.

Meerat: I'm almost coming to the end of my very long string of what I need to say. I will also introduce Rosie, who is from an organisation called National Voices. It's a national partnership of lots of little patient groups and they've kindly offered the Zoom space today, and Rosie's just helping us with the recording. She will make sure that once we've written it all up it gets deleted from everything, and we won't be able to look at this again.

Rosie: And if anyone does have any technical questions or anything at all that I might be able to help with just send me a message in the chat and I'd be very happy to help.

Information is translated by Participant A and B.

Meerat: And just very briefly, I'm sure it won't come up, but the Houses of Parliament staff have a duty in terms of safeguarding, so if anything is raised, they'll have to raise that.

Information is translated by Participant A and B.

Meerat: So, we're here to discuss maternity care and there are specific areas that we want to talk about today. But, firstly, I'd like to ask you to introduce yourselves, and it would be really interesting to hear from you all who you are and any experiences you've had in maternity and having children.

Information is translated by Participant A and B.

Participant C: I have experience with the [hospital name] hospital. I was pregnant and I tried to call to have a midwife, for someone to look after me. Because of the Coronavirus they gave me an appointment in the second month, and in the second month I had my first scan. The lady who did the scan for me said the baby had inflammation around the heart and that after three weeks I need to come back for another appointment. I came back after three weeks and the doctor said to me the baby is fine, he doesn't have any problems, and he's a boy. After that he said to me, "come back after three weeks again". When I came back after three weeks, he said to me, "it's bad news". I said, "what's happening?" and he said your baby has got kidney problems and he can't pass the urine. I said there is no way. I was just asking, seeking, for help from a professional because I believe that I'm in Great Britain, and I think the health is improving so much compared to other countries. He said there is no way to help me with that, he said the baby is going to die, because there is no water around your womb, and all this around your womb is waste from the baby. He told me to come back

after four weeks, and I was confused. How could he say to me your baby is going to die and then give me so long for the third scan? I said, "four weeks?" and he said, "yes". I didn't know what to do and I started to call Participant B and told her I didn't know what to do. I went to the GP and the GP said we can't do anything with it.

In the third week my leg was swollen, and I went to the Emergency Department. They checked me and the doctor gave me another opinion -the third opinion. I felt like it's different opinions from all the doctors which confused me and made me worry more. I said to him "what's happening, is my baby still alive?" He said "yes, your baby is ok, and his heart is beating". I ask him again if my baby is ok, if his health is ok. He said "yes". I told him that in the last scan the doctor had told me that he's got kidney problems and because he's a boy - if it was a girl, it would be different - but because he's a boy he will pass away. And the doctor was laughing, and he said in my experiences it's too early to say that. The baby is too small. I didn't know what to do. After, another doctor came and she was not happy at all. She checked on everything and she took the other doctor with her, and they took approximately 25 minutes to half an hour. She came back by herself, and she said to me, "is your baby IVF?" I said to her, "yes, my baby is IVF", and she said, "do you have another cycle?" And I could see from her body language that she was trying to find out if I can get pregnant again or not. I asked if that was going to help her with something, and she said, "no, but the baby is going to die". I said that recently your colleague said to me that your baby is going to die. I came out, and they said you have to wait until the baby dies. And my leg is swollen but they don't care. I called Participant B and told them what they told me. Because of all the different ideas I have the feeling that my baby is ok, and even until now I feel like my baby was ok. I have this feeling.

At the last scan the doctor said to me "your baby has died in your tummy". I asked how long, and he said one week. I don't know what the side effects are of this, of having the baby inside my body for one week, and I'm afraid that my body is getting poisoned and that the swelling in my leg could be a sign of the problem. He gave me a tablet and he said this tablet will help you to deliver. After one day I came to the hospital to deliver the baby. At 9:30 I delivered the baby, but the placenta didn't come out. They tried and said we can't, we have to transfer you to an anaesthetics room. I went there and the doctor he just tried to practice on me, that's what I feel. He injected me in my back, and I was bleeding, and I said to him stop. I cried and nobody heard. At the same time, he was trying to inject, inject, inject. He wouldn't stop. I felt an electric shock in my right leg. It was too much pain, and I don't want anyone to go through this experience. I said to him "please stop, I'm bleeding" and he told me to wait. They tried to call a specialist for anaesthetics, and they said they would be 5 minutes. They were asking for her, but she was not ready. Why can't the hospital make it so that just in case something happens they have a doctor ready? Not make me wait until the doctor comes, and I'm bleeding all that time. And then when the doctor came, they started clapping. They ignored my feelings. They are glad to do their job and at the same time I felt that they are happy neglecting me because I was losing a lot of blood. I'm dying.

I came out of the hospital after one day. The next evening, my heart started racing, my heart rate is going up to 114 and I quickly went back to the hospital. They ran to bring the heart machine, but they didn't know what was happening. They took too much blood and I thought that's it. They told me that I'd lost too much blood and that we need to do a blood transfusion, and I was in-between about whether to take it. I wanted to take it because I know it's important, but I didn't want to take it because I don't trust the hospital or the doctors there. Maybe they will transfer me blood with an infection, and I will come out of hospital with another disease. And I told Participant B that I'm not going to take it, but she said please take it. Without her I would be in my grave praying for the people who neglected me that life doesn't treat them the same way they treated me. Because I had

a very high fever, they said that it might be Corona. They took three tests and three times it was negative. They took another blood test. Afterwards they said I had a microbe infection and I said, "where did I get this microbe? And can you write it down for me, because I want to check where I got it from". They told me not to worry, you don't need to go further for it. It's my body, how can they say to me, I don't need to look further? They didn't know how to treat it, they struggled to treat that microbe. Afterwards, I was lying down, and a nurse came in and said, "you've got Corona, quick we're going to take you to the Coronavirus department." I said to her, "if I have Corona I will go, but after three negative tests I want the doctor to explain to me, on paper, why I need to go there. I said bring me this paper and after that I will decide", and she came back and said, "don't worry, the doctor is in a meeting, but he said that you don't need to go there". Because I'm coming from delivery, if I catch Corona I will die. When I stood up for myself, six doctors came, and they checked me, and they gave me two strong antibiotics and in 24 hours I felt better. I still feel now my heart rate is going up, even though they gave me 24 hours monitoring for the heart and they say it is fine. Even now I don't know what was wrong. And the doctor with the injection, I felt like her was trying to study my back. When I stand, I feel the pain, and when I sit for too long, I feel the pain. I feel they wanted me to die. They discharged me and I realised that they wrote down that I had Corona. They said I had Corona, plus the microbe.

Before I went, I asked them what happened to my baby. If there is an illness it will show, and I need to know if there is something genetic that I should know for my next treatment. It will help me to know what happened. They took the sample and one month later they said, "we don't know the problem, but it happens to either every 20 or 20,000 people" - I'm not sure about the figure. I asked why, but they didn't know why. And then when I went to bury my child, I saw too many graves of kids, or unborn babies and babies that died in a short time. Approximately 300 a week because I can see the date when they passed. So, it just made me... did they all pass away the same way as my child or is there something wrong? But I don't know what it is. Also, I don't know where to go to ask, or who to ask. I said this to Participant B, because she arranged everything for me, she helped me a lot, without her I wouldn't know what to do. I told her that I went to the grave, but I saw too many unborn children and babies - they divide them from this side to this side. And it made me scared. When we saw that my husband and I said at the same time "what's happened?" Anyone in my situation would immediately ask the same question. So, my question is what is happening, and why? I feel like we are in Great Britain to get better healthcare, not to be neglected. Sometimes I think it is because of my language? If I was born here, maybe it would be different. Without Participant B I don't know what I would have done. When they transferred the blood if Participant B wasn't there, I would have refused it. It's better to die straight away rather than live with suffering. That's my story. And I need someone who is BAME in the hospital because I don't want anyone to go through what I went through. Please.

Participant A: We hear you.

Meerat. Thank you for sharing. That was really shocking to hear, really horrible to hear, so thank you for sharing. We can only imagine what you were going through, and I don't think any of us think that's acceptable that you went through that.

Participant B: As she said, I worked with Participant C for 24 hours. Telling her that you have to take the blood asking her to let me speak to the consultant. It was 24-hour support.

Participant C: I really, really appreciate it. Whatever the doctor said to me, I didn't trust. I just said, "give me time, I will answer but let me call Participant B and ask her if she thinks it's the right thing

to do. If she said ok, I'll do it". If she said no, believe me I will not do it. Because I trust her. It's about trust. And they say NHS Trust, but they need to change this name. There is no trust.

Participant A: I hope Allah will give you strength to move on and thank you for sharing. We will come back to you because we need to not only share the bad experiences but also talk about what kind of recommendations and solutions that we need to. And you pointed out that you had emotional support, that you had somebody you could call who speaks your language, a community person that is there all the time for you, but at the same time something that we really need to point out that all the bad experiences that people go through are expressed.

Participant C: It's not only me. In the same labour ward, there was a Somalian woman and she lost her child. Her husband was there, and he said to me the child has passed and when I asked him why he said, "I don't know." Nobody explained it. His language is not...it was the same as mine.

Participant A: It's a miscommunication.

Participant C: It would make me feel better if I knew why it had happened to me, if they at least told me.

Participant A: At every stage so you know exactly what is happening.

Participant C: It's hard to feel ignored. If someone would tell me what happened, I would respect that. That's fine. But to be ignored, no.

Meerat: Just to understand, can I ask when this happened? It's just so that I understand, not for anything else.

Participant C: I lost the child, they told me at the appointment, on the [date, July 2020]. And on the [date, July 2020], I went to the hospital because they gave me one day to make the tablets work. This was last year, 2020.

Meerat: Did you go through this alone or was your husband with you?

Participant C: No, my husband was with me. But he didn't know as well, so any questions we asked Participant B.

Meerat: And there was something you said about how you need people in the hospital who look like us, who speak our languages, who come from our cultures. Can you expand on this a bit more? Was there anybody who looked like us in the hospital?

Participant C: In the hospital yes, people are mixed. But inside the maternity ward, no. The nurses are different.

Participant A: But not somebody who can understand you, what you're going through, that can relate to you?

Participant C: No.

Participant A: Can I ask- I don't know if this is appropriate- but Participant B works in the FGM (Female Genital Mutilation) clinic, that's where you met her and you've built a relationship with her, but she's not there in the maternity ward. You explained really well what you went through and if Participant B was there would that change anything? If she was there physically and not on the phone?

Participant C: Having someone with you helps you to feel like you have someone behind you. There's someone supporting you. If you've been through a bad time, losing a baby is not easy, it's hard for every woman and I'm not just talking about me - I wouldn't want any women to go through what I went through. It would make a difference having her there. She speaks my language and can explain more to me. When the doctor is translating sometimes, I didn't understand. You have a question in your mind, but you can't explain it in English. If English was my native language I would speak, and I wouldn't need anyone.

Participant A: What about the emotional distress you've been going through? It's not only the language it's the emotion of losing a baby. Does Participant A help you with those emotions as well?

Participant C: She was like a mum to me. I kiss her feet; believe me she was my mum. We moved here away from our families. It's hard when you have family calling you from home and asking how the baby is. I've been waiting for this baby for 9 years.

Participant A: It's very painful.

Participant C: When I call her, even before when the baby was in my stomach before the worst time and I couldn't hear my baby, I would tell her all my worries. She would tell me don't do this, do that. I don't know how to describe, there are no words, to say how thankful I am.

Participant A: I'm so glad that you had that help. That she was able to answer your call at any time and I'm so glad that she was there throughout. We'll let you sit for a while, and we will come back to you when we get to the solutions. Thank you for sharing.

Participant C: I want to go and see the grave for my baby, but what can I say to the baby? I didn't stand up for you. I still feel like there was nothing wrong with the baby. There were lots of different opinions and maybe they didn't know what to do with that.

Participant B: Participant A said that the problem is that she feels like there was no follow up for her baby, and at the same time there was the ignorance at the hospital, bad treatment at the hospital and no support. She questions why she came here to Britain; we have to say it's a good NHS but actually it's not. She's sharing her story because it's nearly one year now and when I speak to her every day she is crying, and she is thinking about her baby but there is no follow up.

Participant A: Do you think some counselling might help, because I know that you're grieving, you lost a baby that you've been waiting for, for 9 years. Did the hospital offer any counselling support?

Participant C: No.

Participant A: Do you think you might need counselling?

Participant C: Yes, because I'm blaming myself a lot.

Participant A: I think we might be able to offer some support and we'll follow up with this case.

Participant C: I think as well if I had changed hospital, it might have been different. That's what I feel. But, when I went there to the grave and saw so many kids in a short period of time so maybe there is something wrong, it's not only one hospital.

Meerat: I know it's easy for us to say, but it isn't your fault. You're not to blame at all. For those of us who have had loss we know how you're feeling, but we don't want you to blame yourself.

Participant B, can I ask with the women that you tend to support and help, is this an unusual situation?

Participant B: Yes, for Participant A it is a different experience. But the women I meet at the FGM (Female Genital Mutilation) clinic sometimes have the same problem in the maternity unit, with the neglect and not knowing how to speak with them, and they ask if we can talk to the consultant and help them through the maternity ward. If they have a scan, they ask me to talk to the consultant on the phone. My hours are until 5, but I ignore my time and help after. So, for Participant C it was 24 hours because she was bleeding overnight, and at 12am or even 3 am I would talk to her and ask her how she was feeling. Sometimes I sleep for 2-3 hours and then wake up for my work as usual. It's not just Participant C, I feel for many women from the FGM clinic I have to follow them right through to the maternity ward. It's not just at the clinic.

Participant A: I have to say we have a contract to deliver and support women at the FGM clinic, it's a specialist clinic where the maternity ward will refer a woman to if they find out she has FGM. But what happens is that often the women want continued care. I think we have 3-4 emergencies where women call to say, "they're taking me in to have the baby, please can you come to me, I've no one beside me" and we've gone to be with them. It can take hours, it could take days, and we'll constantly be there supporting them. But it's out of what we're supposed to be delivering. We're not midwives, we're community workers. But that trust and support that they feel that they get from the FGM clinic they want throughout. And we have a fantastic health advocate who's there and willing to do it. We cannot force her to do it because it is not part of the project, but they do it to help the women and continually help the women. But this is what is needed. If you see the women that work in the FGM clinic they are calm and more relaxed because we are there with them supporting the women, so they feel more comfortable, compared to the maternity ward which is more intense. The women are confused, there is so much miscommunication, the midwives and the doctors might be quite tired and there's no emotional support or advocacy support that can help these particular women. Even as I was having my baby a long time ago, I was literally helping women to have a baby, because the doctors couldn't communicate with her. I had to go there, while I was in labour, to inform the woman what the doctors wanted her to do. So, it's really difficult when you're there and you know that the experience is not easy.

Participant D is translated by Participant A.

Participant D: I had a similar experience to Participant C. Before I had my baby now, I lost three babies. The first one I lost when I was five months pregnant. I used to go to the GP and the doctors regularly and nobody told me the kind of condition that I was going through. I used to go to the hospital for every appointment and nobody advised me. I started bleeding one day, a very painful bleed, and I didn't know I had to call an ambulance, so I took a minicab to the hospital. I told the receptionist that I was going through a painful process, that I'm in pain and I need to see a doctor and lie down, and she told me "people will come to see you, just sit there." I was sitting there for hours going in and out of the toilet, bleeding really heavily, and suddenly the baby just came out and dropped on the floor. That's when they started rushing. It was so much pain and even now I don't go near the hospital because of the treatment that I received that day. When the baby dropped on the floor they rushed, they took me inside and the placenta was not able to come out, I was bleeding very heavily. They started a blood transfusion straight away. They gave two litres of blood because I lost a lot of blood. It took a while to get the placenta out and sort the problem out and I suffered a lot. This was my first baby and my first experience I had in this country.

When that happened, they started monitoring me, they made lots of appointments, I regularly went to the doctor, but they never told me what killed the first baby and I felt like it had been neglected so much. Whilst this was happening, I got pregnant with the second baby, and I started to panic

because of what happened to the first baby- and I didn't know what killed the baby- might come back again and they never told me. So, I regularly went to the appointment and when I was three months pregnant, I lost the baby again. I changed the first hospital to the [hospital name] Hospital to get a different experience. I thought the doctors and midwives might be more caring and they might find out what killed my first baby, they might protect my second baby, but I experienced the same experience and had no support. I felt neglected and nobody was telling me what killed the baby, and nobody did a proper investigation of where the cause is coming from. I was not able to understand what was happening. When the bleeding started for my second baby, I went to the hospital and they said, "oh you lost the baby." They said, "go back home, the bleeding will stop, and you lost the baby." That was their answer and that distresses me.

I got pregnant for the third time and lost the baby and then I thought that's it, if I keep losing the baby there must be something and nobody is telling me anything. So, I saved money and went to a private doctor, who comes from Germany and sometimes has a clinic in the UK. So, I registered myself and went to the private doctor and he saw me and said, "tell me what has been investigated and what did they tell you?" and I said they didn't tell me anything. The private doctor did a lot of investigations internally, took different bloods, and then he said the only thing I think you might be suffering from is a blood clot and usually when blood clots happen women lose a baby. But he said if I do a blood clot test it will cost a lot of money and I know you are struggling, so I advise you to go back to your GP and request a blood test. You've lost three babies now and you have to do a blood clot test. I went to the GP and said this is what is happening, and I want to do a blood clot test. The test came back, and I said can I have a printout of my results. They said that it's negative, that I don't need to have a printout of the test, as it is negative. I went to a lot of trouble to get that result. Finally, she managed to get the result paper. I went back to the private doctor from Germany, and I showed him the blood test result and he said that this cannot be correct. He said if you're willing to pay, I'm happy to take the blood clot test and I said I'm willing to pay because I don't want to lose the baby. It came back positive, and he said that usually a blood clot can kill a baby until it's five months' time, that's the risky time, so if you're planning to get pregnant, I will have to follow up. I used to save money to see him every 3 weeks. I used to pay him £85 just to see him, and my treatment was to give me aspirin until my pregnancy becomes five months. I decided not to see the GP, I decided not to trust the hospital, now that I know what the problem is, and the private doctor was helping me. He said that there are two types of blood clots that women suffer from; one is where you need a tablet until your pregnancy becomes 5 months, the other is when you need injections all through your period. He said I'm going to treat you until you're five months and then see how it goes. So, I had the treatment for five months, seeing him every 3 weeks and now I have a baby daughter. And from there I just decided that the hospital or GP is not something that would necessarily treat me or save me.

Now I have my first baby, a health young girl, and now I'm pregnant. As soon as I became pregnant, I contacted the doctor, but because of Coronavirus he's staying in Germany. Luckily, I have his email, so I'm communicating with him through email. He told me straight away to take aspirin, because your condition means that you have to take aspirin until you are five months. I followed his instructions, and he regularly sends me vitamins that I have to take in addition. I'm doing ok. Even though I'm registered with the normal maternity ward, I also follow and pay the doctor and we have meetings every 3 weeks on the phone. I trust him more.

Everybody told me that if you have that experience you have to see a solicitor, seek legal support because this is not something that should happen. It's neglect. I didn't go to a solicitor, I didn't complain but what I believe personally is that out of neglect, out of ignorance, out of not treating

the condition that I lost three babies. No one cares, that's what I believe. But now I have a healthy baby girl, I have one that is coming soon, and I don't trust this health service. So, I follow the German doctor at the moment that helps to keep my pregnancy. I told the hospital that I have a blood clot condition that kills my baby, and now they know they asked me start taking aspirin. I stated that I already had because I'm dealing with a private doctor. They're giving me the same instructions the doctor is giving me, but now I don't listen to them. I just listen and follow that doctor. And this is the kind of health service that we're dealing with. It's a health service that doesn't really care about what women are going through, it doesn't investigate properly, and this is the problem that we're having.

Meerat: Thank you for sharing. Can I ask a couple of questions? When did you lose your first baby and when was your child born? Just so I understand when this happened, especially in relation to Corona as well, because I realise your treatment was changed in Corona.

Participant D: The experience I've been through is worse than Corona. I lost the first baby in January 2018. I lost the second baby in February 2019 and the third baby in July 2019. And on the [date] August 2019, I got pregnant with the fourth baby and had a normal pregnancy with treatment. When I lost the third baby, I went private straightaway, and then he did some tests, and when I found out I was pregnant with my fourth baby and then got treatment straight away.

Meerat: Can I ask which hospital? You said you went to [hospital name] for your second baby, and where did you go for your first baby?

Participant D: [Hospital name] is the first one. The second one is [hospital name]. If they send me to [first hospital name] I don't go there. For the third one I was registered with [hospital name]. I lost the third one, but the good thing about [third hospital name] is that at least they cared when I was bleeding. They said do you want us to clean you? Would you like to stay here? They gave those options, to either go back or stay because I was losing blood. I decided to go back home. I had my fourth child in [third hospital name] and I'm 8 months now and I'm registered to have my fifth child in [third hospital name]. I find [third hospital name] more helpful than others.

Meerat: Thank you. Can I just ask, this is a broader question, why do you feel these experiences are happening? What is it about the healthcare service that means it's....you've said that they haven't listened or that they don't understand, but I'm just trying to ask what you think it the reason why this still happened in the UK health service?

Participant D: It's communication. When people see that you cannot communicate properly, they do not care about the way that they treat you. I feel if you cannot communicate the way you want it and you cannot express the way you want things to be done, nobody is there to help you.

Participant C: I agree with her. That's what we've been through. Even when you talk to them, you're not sure whether to say what you want. That's what I feel. It makes me feel that I have two options; I have to speak native English or have enough money to pay for private. I'm saving to have another baby and I work 50 hours, because I want to save money. We are in Great Britain, why do we have to kill ourselves to get treatment?

Participant D: As soon as you walk into the maternity ward you hardly see a doctor or consultant, but you do see the unwelcoming faces of the midwives. As soon as you walk in you feel you are in a battle stage environment, like you have to fight for everything. You feel like the environment is not welcoming. The care you get is not the proper care that you're not supposed to get. They call it maternity service, but it's really hard to walk into that environment. Sometimes I bring someone

with me to help me say something and to help me with the language. They can speak for me. But because of Corona you're not allowed to have someone come in and speak on your behalf. It's a difficult place to be. It's very uncomfortable. I have a friend who moved from Holland, and she saw this experience and she told me that she has never seen this kind of maternity care. Because in Holland the care you get is different. And in Holland you get continued care so that when you have the baby there is ongoing care that comes to your house. They teach you how to do things because you are a new mother. She said she was shocked to see this kind of care and that the maternity care is not fit for use. My friend said she will now have her baby in Holland, she cannot have any more babies here. It's really painful to be part of that maternity service. That experience is worse than corona. With Corona, there is a reason behind it because it is a virus that infects everyone, but the experience that we've been through was the worst experience that I've been through.

Participant A: Thank you for sharing.

Participant E: I recently had a baby in October 2020. This is my first child. I understand that I had it during Coronavirus, I understand what was happening and the guidelines we needed to follow, I'm an NHS worker- a [specialist role]- so I was aware of the regulations because we have the same regulations in our own hospital. In my case, I felt that I was constantly targeted because I am Somali. They were making little comments like, "how many children does your mum have?" and I'd respond two and they would say, "that's unusual, Somali women usually have 10 children". I'd never experienced that, so I didn't know how to react. Is it normal for you guys to say this? Because I'm a health worker and we don't attack people in terms of their culture. Not everyone is the same. They would also make comments like...I had little bands on my stomach, and there were two midwives in the room, and they were acting as if I didn't understand English - and I do understand English - and she would say, "you know that's a witchcraft thing, why do you have it on your stomach?" And I said that it's not that and she completely dismissed my feelings.

I was late in labour, so I was 42 weeks, and they said they were going to induce me, and I said that's fine, just get the baby out of me in the safest way possible. During my induction I was hospitalised on Sunday, and I understand that on Sunday people are busy and there's not a lot of staff, so I was understanding. My husband was there, and they kept making comments like "are you in an arranged marriage" or "were you forced to marry each other?" And I would say, "no", that we were together since high school. They said that that was unusual, as this is what Somali people do. I was just like; do you know every Somali person?

They gave me a room around 11 o'clock and nobody visited me until 8 at night. No one even offered me a cup of water. My husband had to go downstairs to get me water. You can understand that I was being induced so I was in pain and nobody came into the room, nobody said anything to me. The doctor came in and said that it looks like I was going to have to go down the surgery route, and I said how can that be possible as I only came in at 11 this morning. I asked her to at least give my body the chance to go through the labour naturally. She said, "no, we're going to have to do this quickly, I think you should have the surgery". She would have her colleagues coming in my room every hour and tell my husband, "She's in pain, I don't think she's coping, can you please sign this form for surgery?". And I would say, "I'm conscious, I can give my own consent, why do you have to ask my husband? I understand what you're saying, can I make my own decisions in terms of what I can do for me and my baby? Of course you can intervene if I am in danger, if my baby is in danger, please do whatever you need to do if my baby's heart level drops but whilst the heart rate is fine please let me try and have this baby naturally." And they said that they don't think I can do that, and they will give me five hours and see how that goes.

Four hours later she came back and said that she was going to check how dilated I was, and without my consent she broke my water. Now I understand that once your water is broken you have 24 hours to get the baby out. I told her that she didn't have consent to break my water and she said, "I'm sorry, it happens, I'm a doctor so I have to go with my instincts." I told the midwife and she said what's that about. I told her that I now have 24 hours to have this baby and if not, I'm going to have to get a C-Section and I really did not want to go through with a C-Section. The midwife said that they're just doctors, that we're the midwives and we know better than them and that they shouldn't have done that, but what can you do. I feel like they were infighting between them, and if the doctors and midwives understood each other, instead of digging their own graves, it would make a little bit more sense to me personally. In the end it turned out I had to have the C-Section. I would say that the doctor was good doing the surgery and I will give him praise for that. I didn't get any support at the end after coming home. Obviously, being a first-time mum, I felt I had to do everything. I'm used to being a very active person so as soon as I was discharged, I was standing up already trying to figure it out. If the midwife had said to me that once you had given birth you should relax and let the wound heal it would have been useful, but I wasn't given that sort of advice.

What I feel we're missing, especially at [hospital name], is the communication, or lack of communication to the mothers from the midwives, the lack of understanding of people's cultures and respecting people's cultures. I think that's a very important point, that you shouldn't judge people on where they come from. If you go to [hospital name] the majority of people that are sitting in the waiting room are all foreigners, let's not lie to each other, yet our healthcare professionals have no idea what to say. It's either lack of knowledge or they're just plain rude. I don't know what they discuss in meetings, because if I made comments like that in my Trust, I would surely lose my job. Why do you care about how many children my mother had? My mum has two children, is that unusual? I had my first child at 27, it's unusual for some people but for me it's fine.

Participant A: It feels like there's one rule for you as a healthcare professional and one rule for others. And it depends on where you work and where you are at.

Participant E: I think we need, especially at [hospital name], somebody that represents us and that understands us. Either you train people to understand or have people there that understand and respect. You should understand and respect people regardless of their gender, their race, their religion. You should respect them regardless of what they are, but I feel that we are not getting the same respect. As soon as I say I'm a [specialist role], they sort of step back and act a certain way. It's all a bit complicated. I'm not planning on having my next baby any time soon, but I hope I don't experience what I experienced previously.

Participant A: The sad thing is that you are an English speaker, you speak fluent English, and you were experiencing that, and we were hearing from Participant C and D about communication being a barrier. Hearing from you that even as an English speaker you still experienced stereotyping and targeting and commenting on who you are. It's really sad.

Participant E: It's almost like my feelings don't exist, like no one cares about me.

Meerat: Thank you that was really interesting to hear and frustrating at the same time. One of the commitments that has been made in maternity is about having the same carers all the way through, and in your view what do you think about having that kind of commitment? So having the same person all the way through to help you.

Participant E: So, I think that would be a great idea, because I felt like every time, I had to face a new person and I felt a bit scared, because I wondered, what are they going to say now or what are they

going to do to me now? It's almost embarrassing because to me I didn't grow up in Somalia, I grew up in this country, so imagine what it would feel like for someone who didn't speak English, who didn't know what to do or what to say. How would it impact them in this sort of situation? So, in my view having one midwife might be helpful and also having somebody that can understand us and our culture's views. Just someone who understands what human rights is.

Participant A: I have to say, I had that one-person experience. I think it was piloted many years ago, where you can choose one midwife who takes you from the start all the way till you have your baby, and if you go to the hospital that midwife will have to come and help you to deliver. I was so lucky choosing a Somali speaking midwife, because there have been some friends that I know who haven't had a choice or were not able to speak their language or that they can relate to. Even though I didn't need interpretation, I just felt like I wanted somebody from my culture, and I had the best experience. But what they have told me is that even though they selected one midwife, the experience that they came across was not the same as my one. They really struggled. For some of them language was a struggle. They didn't know what the midwife was doing, the midwife was angry with them when they call her in the middle of the night, they just turned up at the hospital because they are in pain and then they had to call the midwife to come in because her patient came so it was a really horrible experience that they had. So, when doing that, I think you have to be mindful of how that will be dealt with, because if people are already going through distress and stereotyping and language and communication problems it has to be something that is thought about.

Meerat: Thank you, that's really helpful to hear actually. Participant E just before we move on, can I ask did you have a personalised care plan?

Participant E: No. Because of Coronavirus I only had three appointments with the midwives, actually four, and two scans. So altogether maybe six appointments.

Meerat: OK great. Because one of the other things that they're proposing, or they think that they'll propose, is having a personalised care and support plan but from my own experience of pregnancy I'm not always sure it's clear that we have things like that, so I just wanted to hear. I realise we've got about 10 minutes left so does anyone else want to share anything.

Participant B translates for Participant F

Participant F: My experience starts in 1993 and the birth took place in the 36th week because I was bleeding, and I went to [hospital name] Hospital. When I went there, they took me straight away to the operation room, they told me that as I have bleeding, they have to do a C-Section. And then my child stayed in an incubator for one month. The second pregnancy in 1996, at 34 weeks the same thing happened, my blood pressure rose, so I went to the GP, and he told me that your blood pressure is very high, and you need to go straight to the hospital. I stayed in the hospital for three days, my blood pressure was very high, and then they asked me to do a caesarean operation again, at 34 weeks. The baby came and then they put my daughter in an incubator. I asked the doctor why it has happened like that for me at 34 and 36 weeks, I need to know, and he didn't give me any reason. I told him that I can follow, but he still didn't give me any reason. Two years later, I had my third pregnancy, and at 32 weeks the same thing happened, my blood pressure was very high, and I went to [hospital name] hospital, and they told me they need to take the baby out by C-Section. Straightaway they told me that the baby is not going to live because no nutrition has reached the baby. Still, I need to know why it happens for me. Why does my blood pressure get high, what is the cause of this? They gave me a liquid injection on that day and then the baby came and unfortunately died after one day.

I became pregnant again with my fourth baby and the same thing happened. My blood pressure rose, and the baby died. I lost two babies. And I've asked the doctor so many times, why it happened, "give me the reason as I need to follow up what happened to me," especially after 34 and 36 weeks. He didn't me any reason, he just ignored me and told me that the answer was that the food doesn't reach the child at that time. I was so upset, and I feel that they neglected me. I had a lack of treatment and no follow up at all. At the same time, I feel like they don't understand me. Even at the time I told the doctor, I didn't want any more babies. He said this is what I want you to do. He didn't even recommend for me to have treatment, he just told me yes stop. That made me so upset about that. I need to know why my baby died and why my pressure rose.

The same thing happened for my oldest daughter who was born in 1993. She gave birth last year. She went through the same experience; she had a rise in blood pressure. They took her to the [hospital name] Hospital, and they told her that you have to go home. You have to come back when the contractions are every three minutes, not ten minutes, and she said when she went home, she was crying and was saying that it was very painful. She told them she had to come to the hospital, and they told her no. Because she lived in [area], [hospital name] is far for them, so how can she wait for three minutes between the contractions? I called my cousin who is a gynaecologist in [country] and said my daughter is in lots of pain, is vomiting, and they told her to not come to the hospital until there are three minutes between contractions. And my cousin told me, "you have to go to the hospital right now otherwise your daughter is going to die, and so is the baby". She called them and said that the contractions are three minutes now and I've got to come. When I got to the hospital with my daughter, straightaway they took her to the operation. My daughter is unconscious, and her baby's heartbeat has become low. In less than half an hour they took her to the operation. My other daughter decided not to have a baby here in this country and will go somewhere else to have it.

Before I thought it might be the communication because we are a different culture, and we have a language barrier, but my daughter is born here and the language is very good, the communication is very good. I think it's the stereotype because they told her you have to go to your house and wait there. In that time, she's in pain and telling them that she needs the baby to come out. How can they tell her to go home? I don't think it's about the communication, I think it's only about the stereotype. I don't think they understand that we are human. They look at us as different and not as a human being. We look forward to having people from our community in the hospital, especially in the maternity ward, to help us, to support us, to understand us, to talk to the doctor. We need them to be with us there.

Meerat: Thank you for sharing that.

Participant A translates for participant G

Participant G: Usually I don't have a lot of problems at the hospital when I'm having a baby - I have other children - but I don't know if it is do with Coronavirus, and I had a baby during Corona time, but this time I had a bad experience. I was told that I would be induced, so even though I usually don't have a normal labour and they induce me, but this time I was induced in a difficult way. So, this time my water was broken, and when my water was broken, they found that the baby was not facing the right direction and was facing another angle, and I experienced a lot of pain.

I've been through a lot because of Corona, because before it wasn't like that. I feel I have been through a bad experience where I have been induced, I went through pain, they started to give me an epidural to calm the pain down. I reacted to the epidural, and I felt itchiness and I wasn't able to

feel my legs and I think it was reacting to my body as I had never had one before. I had to fight with the midwives and the doctors to remove this epidural, because it's not working for me and I'm going through even more pain than I was going through before. After lots of challenge, they removed the epidural but then that induced medication was on, and it was painful. But what worried me was every time they would come in and say you might have to think about a caesarean, that we don't think you'll give birth normally. They would say that the baby might be at risk, but at the same time they would say to wait. I said if my baby is at risk, I just want to go through with a caesarean as I don't want to lose the baby, but they said we can't go through we have to wait, and we have to see. And then I developed an infection, I went through more pain, and they had to treat the infection. At the end I was able to deliver the baby normally, but after a long painful process. There was no understanding, I feel like there was no care there, and during the long labour they would come and say we need to do a Corona test, and I would say it was done just a minute ago and they would say we need to do it again. So, they kept coming back with Corona tests. They said I can wear a mask while I am in labour. I said, "how am I going to wear a mask? I'm in pain". There was no care, no support, and no understanding. I had to stay in the hospital because the baby had eaten its poo and it was a distressing time for the baby, it was a distressing time for me, and they had to keep us for one week to treat me and the baby. It was a really bad experience, and not one that I had before, and it happened because of Coronavirus.

Meerat: Thank you for sharing. Is there anything that you would like to add Participant A?

Participant A: I think there were a lot of experiences that were shared, but I think now we need to know the best things to do, what you would like to see. You have mentioned a bit about we want people who speak our language, we want people that can understand us, we want a health team to be trained, but what else do you think we might need. We don't work in the hospital, but what we experience in the FGM clinic that we support the midwives, is that women are really engaged, women want to come, they feel comfortable and some of them even say please can you continue our care and go to our maternity. What do you think? Because the care that you get at the FGM clinic do you think that would be better if you get it at the maternity services. Is there something that maternity services can offer you, that they offer at the FGM clinic?

Meerat: I think what I will do is summarise what we've said today and see if we can figure out some key recommendations from what you've all said, and then share them with you to see if those are what you think are important. Because what I'm hearing Participant A is exactly that, the government have this commitment to personalised care, but what I'm unsure about is whether they're thinking of how community organisations can support that personalised care. All this extra support that you've highlighted, that sounds like it's incredibly important. Can we highlight that, and can we say that the government need to expand their thinking beyond midwives and doctors? How can we continue to support and engage community organisations like yours?

Participant A: But this is not the first time we're hearing all this distress and people's experiences. We heard them many years ago when we were involved in the BME health forum consultation. How many times do the government want to hear from people who are not heard and people who are struggling? At the same time, on this commitment when will this be actioned? We do get all these consultations, and people want to hear from those in the community, but we don't see that in action. We might see policies and things being written but the change is not there. And it's really clear that it is something that has been happening for many years. It has not just started.

Meerat: I agree, and for those of us that have heard these stories over tens of years that frustration is still there. So, I definitely hear that, and I think what I'll try and get is some kind of understanding

of the timelines. The timelines are in place, and I'll share these with you, and whether you think this will happen. I'm as sceptical as you Participant A, but there's that frustration. All of the experiences that we have heard here today are really traumatic and shouldn't happen. We should be learning from them, and I don't feel that we are. It is a case of connecting where we are and what will happen next. There are timelines in place but what I think could be interesting as well is how community organisations can check and say this isn't happening and how can we direct that information and feed that back- and that is a bit that I'm really unsure about as well.

Participant A: I've been to maternity boards, many different maternity boards, and they're not in contact with this kind of community. They're not interested to hear other voices, it's just the voices that represent the majority. But there are a lot of people who are really struggling and who need that proper support, which they have a right to get, and they never receive it.

Meerat: So, this isn't the end of the conversation, for me and the people involved. I think this is important for too many of us to have this conversation and walk away. But I don't know what the next stage is. I think it's perhaps a case of we feed this back to the government like we need to, but also, we continue the conversation, and there might be other people who can help us to take this forward. We've heard these stories and it makes me angry that we're still hearing them and I'm wondering how we can connect with other organisations to help drive things forward. Because also, we're getting tired as well. We're getting tired of hearing these stories. And Participant B you shouldn't have to work the hours you work because the support should be there. So, it's looking at how we can connect with other organisations who can help and take some pressure off. And you'll still have to have those relationships because that's what they won't be able to do but could they do something else or help in some way. I don't know yet. I hope we can continue conversations.

Participant A: Yes, hopefully something can be done, after what we've been through.

Participant H: I'm one of the healthcare advocates and I just want to add on. As Participant A said earlier, these women have just shared their experiences of how they have been treated in the hospitals and I think this is not the first time that we are conducting interviews and hearing their views. I'm not sure if I'm right, but I think there is a lack of accountability, because if the hospitals and the members of staff are continuing to treat ladies in this way and they're not questioning them and there is no accountability, how are they going to change them. And not doing that means that it will encourage women not to share their stories because they will wonder what's the point, no one is doing anything about it. I was participating in another research group on COVID-19 and when I asked them what do you think? We should do differently, and they were almost saying, what will the government do about it and I'm not saying anything because no one is doing anything about it. So, I think if we don't take actions to challenge the hospitals and the medical staff then I think everything will be the same thing. The community will suffer as it is suffering right now. The thing that we need to focus on right now is to challenge the hospitals and ask for ways to stop the mistreatment that they are doing. For example, the question where most of the community members felt offended is around how many children you have. It's the same question I was hearing people complaining about in 2013, and it's quite unfortunate that it is still happening, they are still continuing and still getting away with it.

Meerat: We hear you. We are frustrated. I think the challenge is how do we stop being frustrated and shift that onto people with the resources and the power to do things, who should be doing things. And that's not saying that we'll step away from what we're doing and step away from talking to our communities and people, but I feel like we need to push responsibility onto other people as well.

Participant J: I understand that you're looking for solutions, are the staff members that work at the maternity wards retrained or could they have a reminder where they go back and get retrained? Because sometimes you lose that compassion and empathy for people after working for many years or losing lives. Because day in and day out you are going in and you are exhausted yourself. And we are thankful for the job that they do, but maybe having training sessions or having a talk where they can get the staff to think logically and to... sometimes I think they see minorities as animals to be honest with you and not as human beings. Because the words that come out of their mouth as they're leaving is see you next year. They don't know if they're going to see you next year. Or thinking that after you've had the first child you know it all, that pregnancy no matter what struggles you're having that that pregnancy is an easy pregnancy and they just leave you to it. There is no compassion for someone who have already had a child, or two or more, they are left alone and not taken care of. I understand that first time mums have their own struggles, but I think there should be the same care given regardless of whether you've had two to three children or if it's your first baby.

Meerat: Thank you. I hear that and I definitely echo that. While I don't know the details of how much training people have in hospitals, and I assume that varies, there is something about perhaps us as people who use the service knowing that and having more access to that information. You shouldn't have to ask me; we should all be able to find out that information.

Participant A: I just wanted to say that the FGM clinic team, the midwives and the healthcare advocates do deliver regular training for midwives in the maternity department just to tell them how to treat women who have experienced FGM. But maybe there is more training that needs to be done.

Meerat: It does sound like the FGM clinic is a very good model. I want to thank you all for being here today. Before we go can I just check in with everyone. We've covered really traumatic stuff, and things that we would hope that no one would ever experience in their lives, so before we go, I just want to check in with everyone that everyone is feeling ok and if there is any support they need afterwards they know who to contact.

Participant A: I just want to inform you that we do have a counselling service, in Somali and Arabic, so if there is any follow up support that you need, we are happy to offer counselling and we can also reach out to our partners to support you.

Meerat: Participant C, I can see your face on the screen so how are you feeling?

Participant C: Now I feel better because I can use my voice. Because it's not just my story, I have a friend and they told her she has to get rid of the child because it is not well. And she cried and said no, and she said I feel my baby is ok. But now she has a baby, a very nice girl. So why did they ask her? I don't want anyone else to go through this and I want my voice to be heard.

Meerat: Thank you all for sharing. It's been a sad but informative session and I will continue to get in touch with you all about this session and I'm keen that we really push this forward and that Participant A and I aren't here in another 10 years hearing the same stories. So that's a personal commitment. So, let's keep on connecting to figure out how can we tackle these issues and improve care for our daughters.

