HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Black maternal health, HC 895

Wednesday 14 May 2025

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Watch the meeting

Members present: Paulette Hamilton (Chair); Ben Coleman; Dr Beccy Cooper; Jen Craft; Josh Fenton-Glynn; Andrew George; Alex McIntyre; Gregory Stafford.

Women and Equalities Committee member also present: Sarah Owen.

Questions 1 - 66

Witnesses

I: Tinuke Awe, Co-founder, Five X More.

II: Shanthi Gunesekera, Co-CEO, Birthrights UK; Professor Marian Knight, Director and Professor of Maternal and Child Population Health, National Perinatal Epidemiology Unit; Sonah Paton, Co-founder and Director, Black Mothers Matter.

Examination of witness

Witness: Tinuke Awe.

Q1 **Chair:** I would like to welcome everyone to the Committee. This is the first evidence session on black maternal health. I am acting Chair today, because Layla Moran is off on maternity leave. She will be off for a few months, so I am standing in. I would like to welcome Sarah Owen, who is a friend of mine. She chairs the Women and Equalities Committee. Welcome, Sarah. We really appreciate you coming today.

I would like the first panel member to introduce herself. There were supposed to be two of you, but unfortunately your co-founder is not very well.

Tinuke Awe: My co-founder, Clo, could not be here today. I am Tinuke Awe. I am a co-founder of an organisation called Five X More, which is dedicated to changing and highlighting black maternal health outcomes in the UK.

Q2 **Ben Coleman:** Tinuke, thanks for coming in. It is really good to see you.

I have watched your TED talk. What you are doing is brilliant. It is just a tragedy that you have to do it. Not everyone may have heard what you had to say in that TED talk. I wonder whether you can tell us a bit about your own experience that led you to co-found Five X More.

Tinuke Awe: Yes, absolutely. On a side note, if you have not watched the TED talk, I implore you to watch that because it is fantastic. I am a little bit biased because obviously I am in it, but we did a TED talk in January, which was absolutely phenomenal. It has been really well received.

I was pregnant in 2017 with my first child. It was a relatively interesting pregnancy, to say the least. I was showing signs of high blood pressure and protein in my urine from about midway through the pregnancy, but it was not picked up until right at the end that I had pre-eclampsia. As you know, pre-eclampsia can be life-threatening for both mum and baby, but that was not picked up until right at the end. I will never forget the look of shock on the midwife's face when she saw me at the last appointment. I looked like I had swallowed a house. I was so big due to all the water retention and the swelling. She told me to go straight to the hospital, where I was told I had pre-eclampsia and would need to be induced.

The process was not entirely explained to me properly. I felt like I was definitely coerced into it. The conversation was, "You cannot leave this hospital without having the baby," as opposed to explaining what the risks of induction are. If I had known what the full risks were, I would have maybe taken a few steps back to weigh up all my options. I was basically told, "Right, you have 24 hours for the hormones to kick in with the induction." A few hours later, I was experiencing quite a lot of pain. Obviously, I now know I was in labour. I asked the midwife to check me over, and nobody checked me. No one believed I was in labour. It was just a series of really unfortunate events.

Q3 **Ben Coleman:** They did not believe you were in labour.

Tinuke Awe: They did not believe I was in labour.

Q4 **Ben Coleman:** You said, "I am in labour." What did they say?

Tinuke Awe: They did not check.

Ben Coleman: They did not check.

Tinuke Awe: They did not check how many centimetres I was dilated. They did not check anything. I remember one of the midwives saying, "You are making this much noise now. What will you do when you are actually in labour?" without realising that I was in labour.

I was left for a few hours. I do not want to be too gory, but we are talking about maternity here. It was a really terrible time. I was on the toilet; I was vomiting. It was awful. When my waters broke, they checked me. They realised that I was almost ready to push. Again, there was another look of shock that I will not forget. That is plastered in my mind. The midwife pressed the emergency button; loads of people started coming in; baby's heart rate was dropping. It was quite a scene.

By this point, I was exhausted. I was so tired. I had passed the threshold for any pain relief. I could not push; I could not push. At this point I was 10 centimetres, and they were urging me to push. I just could not because I was so tired from that experience of, "I told you I was in labour. I am in so much pain." It was just really awful.

I ended up having an assisted delivery. That is not the end of the world, to be honest. So many people have assisted deliveries all the time. It is part and parcel. Nothing comes out of it. I feel like it could have been avoided if someone had just checked me over at the beginning, if they had believed me when I said I was in pain.

Q5 **Ben Coleman:** That is really quite shocking. That is your experience. You have also talked to lots of other black women and black mothers. What are the most common themes that you are hearing? What are the things that you are hearing? Is it about being listened to? Are there other things that come out? What makes you think that this is a particular experience that black women have as opposed to all women?

Tinuke Awe: At the time of founding Five X More, I was running an organisation called Mums and Tea. I was talking to loads of black women at the time about what their experiences were like. It was just really shocking. It was very similar. People were not being listened to. There were emergency situations related to sepsis. Some young moms were told, "You are sweating because you are breastfeeding," and sent home when actually they had retained placenta. There were all these kinds of things where people are not believed when they speak up.

To your point about how we know it is particularly black women, we have done some research. The Black Maternity Experience Report 2022 was the largest report on black women's experiences in the UK to date. We have a survey that is currently closed—we are crunching the numbers at the moment—which will be able to give some new data. I do not have that right now, so I will be giving some quotes from our last report, if that is okay.

In terms of some of the negative experiences that we heard from that, there was some information around attitudes, knowledge and assumptions carried by health professionals when it comes to black women. Some specific quotes are, "I had an episiotomy and the stitches fell out. I am at high risk from infection due to my sickle cell. They kept refusing to have a look. By the time a doctor looked, the stitches had fallen out and was infected. This then triggered a sickle cell crisis."

I have one here about an "African pelvis". "I had to go for a 36-week scan and there were concerns that my daughter was not growing. At the scan the doctor commented that west African women hold babies higher up in their pelvises, so it was just baby's position.

Another one here says, "One midwife, when doing the sweep, said that the reason for dilation taking so long for me was probably due to an African pelvis. Even though I was on pain relief, I was mortified that she believed there was such thing as an African pelvis."

There is another one here about the stereotype of being strong as a black woman and being able to handle pain. One woman was told that she was big and strong, so there was no need to worry. Another woman recounted that she was told, "Women like you should be able to handle the pain."

I particularly wanted to talk on this. I find that bit quite ironic because, if the belief is that black women are stronger and that they can handle the pain, surely if a black woman is telling a health professional that they are in pain, they must be at their absolute limit or threshold, and therefore they should not be dismissed, according to those very standards.

Q6 **Ben Coleman:** That is absolutely right. I remember seeing—I think it was during covid—a "Panorama" programme by David Harewood. It was really shocking. There was a mother in her 40s talking about how her daughter had gone to the doctor and complained of being in pain. She was told that black women could suffer more pain. They told her that a black woman's pelvis was different. They would not listen to her. She died and the baby died. It was the most terrible thing.

To hear you say this, it clearly is a general issue. How do we change the system so that people listen to black women and do not make stupid assumptions that cause damage to people and worse?

Tinuke Awe: You just nailed it. People should stop making stupid assumptions. They are not based on any evidence.

Ben Coleman: I say "stupid assumptions". The phrase I should use is "racist assumptions". How do we get that to change?

Tinuke Awe: We have to start off with a level of compassion. It is that active listening piece. We know that the NHS is really overstretched. We know that working on maternity wards can be absolutely crazy, with the lack of staff and such high workloads. We have a level of empathy for health professionals. When you are really busy, that level of empathy can be lost.

Q7 **Ben Coleman:** Is it about empathy? You will be busy. You will be treating white women, black women from a Caribbean background who have lived here for generations, women who have really recently arrived from, say, Somalia, and people from an Asian background. You will be treating all sorts of people. You will be treating white women as well. You will be rushed.

Tinuke Awe: Yes.

Ben Coleman: That does not mean they say to white women, "You cannot stand as much pain as a black woman," "Your pelvis is a different shape," or whatever. Is there something further back that needs to happen before they get on to a busy ward and are confronted with these situations?

Tinuke Awe: To your point, the state of maternity is bad for everyone, regardless of race. So many white women are having really bad experiences, as well as black women. It is just that the stats tend to be a lot worse for us. We must also bear that in mind.

I feel like there just needs to be a complete overhaul of the system. The way that things are being taught within the medical profession, such as what certain conditions look like on black skin, is a big issue, which so many campaigners are trying to bring to the forefront.

It is outside maternity, but I have a relevant example from my own experience. I remember my son had hand, foot and mouth. There was an outbreak in his nursery. They sent us a bunch of leaflets from the NHS and said, "Go on the NHS website so you can check what that looks like." There were no images of black children. There was no evidence of what hand, foot and mouth looked like on black skin. What exactly health professionals are learning, whether they are black or white, is a very important issue.

So is data collection. I am a nerd.

Chair: We are going to leave it at data collection because there are other people coming in.

Q8 **Sarah Owen:** Thank you to everybody on the Health and Social Care Select Committee for allowing me to guest today. I am the Chair of the Women and Equalities Select Committee, which is a cross-cutting Committee. I am really grateful for these opportunities to guest.

Hello again, Tinuke. This does feel like full circle. I first met Tinuke when I was on the Health and Social Care Select Committee, discussing some of the issues that we are still facing today. One of the policy approaches that we talked about five years ago was continuity of care and how important that was to prevent some of the situations that Ben talked about and you expressed. Has that got any better? Is that still the biggest policy approach that you would want to see? Is it more about the training side of things in maternity services?

Tinuke Awe: It is a mixture of both. Again, we know the NHS is overstretched and midwives are leaving in droves. As it stands, the model of continuity of care is not entirely possible. In my experience, it would have been great for picking up the early signs of pre-eclampsia that I was showing midway through my pregnancy. If I had had the same midwife the whole time, it would have been very different. I definitely agree with that. I was seeing someone different every time. Maybe they are not looking at the notes. Maybe they are not checking. Well, no, not maybe; they did not. They did not pick it up. In that respect, continuity of care would have been absolutely incredible. Having said that, would we be here today if I did not have that experience? I do not know. That is a separate issue.

I would definitely say that continuity of care could play a huge part, as well as training. Something needs to be done about the training.

Q9 **Sarah Owen:** What about the diversity of the workforce? We did also talk about that and how white midwifery tends to be, particularly at a management level. We are not seeing that diversity within NHS structures, and this is causing a particular problem within maternity. From your work with Five X More, have you seen an improvement in that? Have things taken a step back as midwives are leaving?

Tinuke Awe: I am not sure I am able to entirely give a judgment on the workforce aspect. One of the things that we always say in Five X More is that sometimes getting care from a black midwife or a white midwife will not make a difference. You can get a great experience from a white midwife and maybe not such a great experience from a black midwife. It is not a race thing as such. It is not that all white midwives are racist and all black midwives are angels. People have had different experiences with midwives from different races. It is a little bit dangerous to say, “This is happening because white midwives are racist.”

Again, it comes down to the system and the training. They are all learning from the same medical curriculum. If a white health professional does not know what things look like on black skin, maybe a black professional would not either because they have not physically been taught it.

Q10 **Sarah Owen:** The equipment that the NHS uses does not always work with black skin, such as pulsometers. They work well on white skin, but not so well on black skin.

Tinuke Awe: Yes.

Q11 **Sarah Owen:** Thank you for that. When it comes to training, which you talked about, awareness and systemic changes, that relies very much on the trusts themselves. In particular, I know Five X More has worked with some midwives and done some training, but that is very much up to the agency of the people who are doing it. The best ones will continue to access that training and the worst ones will probably continue to deny that they have a problem. Is there something that Ministers could do to improve the situation for the trusts that are less willing to learn?

Tinuke Awe: It would be to make some of this training mandatory. It should be mandatory. It has to be continued professional development, so that people know what they are coming up against and what they can do in their own practice to change it. It is not a one-time thing. It is not a one-and-done situation. This is not just about maternity; we have to consider all areas of health. There are inequalities when it comes to black people and people in ethnic minorities. I definitely feel like that could play a part.

Q12 **Sarah Owen:** There is diversity within diversity. I have an example from Luton that which is very similar to what you had experienced all those years ago. It was less than a year ago. This is a black hijabi woman who is a victim of FGM. She gave birth in the corridor because she was not believed when she said she was in labour, even though she had told the midwives time and time again, "I am in labour." This was her third baby. She knew what she was doing. She knew her body. She gave birth in the corridor. That was less than a year ago. They should have known from her notes that there were complications or potential complications because she was a victim of female genital mutilation.

Among the women you work with, are there also different barriers for women who have experienced FGM, who wear a hijab or who are non-English speaking? I want to delve into the diversity within the diversity here and some of the increasing barriers for different black women as well.

Tinuke Awe: Yes, definitely. Like you said, there are intersections when it comes to black women. We do not all think the same. We do not all look the same. We have different backgrounds. We might be black African or black Caribbean; religion could also play a part, as can whether we are first gen or second gen. We are not a monolith. You cannot treat all black women the same way.

I can talk a little bit about pre-existing conditions, maybe FGM, as you mentioned, and that kind of thing. We do not delve specifically into that realm, but I have some bits on pre-existing conditions that might be helpful.

In our current survey, the one that is going to come out in the next couple of months, we have taken a deeper look into pre-existing conditions and the care plan, or lack of care, that women have been offered. This is something that we will be highlighting in the report when it comes out. In our last report, we collected data to see whether people had pre-existing conditions and found that one-third of women reported not having any prior health conditions; 63% of women had a common health condition; 31% of women stated that they had a medically serious or life-threatening condition; and 31% of women had two or more conditions prior to pregnancy.

There definitely needs to be more done on pre-existing conditions. I would like to read some quotes, if that is okay, to highlight some of these numbers that we are seeing and humanise those. "During my second trimester, I had two episodes of pain caused by fibroid degeneration. It was raised with my GP and the maternity unit. On the second occasion, I was asked to go to the assessment centre, where I thought they would check the baby and release me with pain relief. I was admitted and spent weeks having follow-up scans until I eventually saw a consultant.”

Another one here says, “I had an emergency C-section. I lost 3.3 litres of blood due to fibroids. The team had given me numerous blood transfusions and placed IV lines all over my body.” There is another one here that is more around sickle cell. “I was fobbed off by the phlebotomist, who refused to take my ethnicity form, which my midwife had given me, as she said they did not need it. As such, I was noted as white and my sickle cell test was not done.” This was from a black woman. This example shows how a failure to follow protocol, such as recording ethnicity, can impact one’s care.

Another woman said, “I was informed that I was a beta-thalassemia carrier after opting to be tested for sickle cell anaemia because of my ethnic origin. The main focus was on making sure that my baby was not at risk; therefore my husband was checked. I had to push for further information about where this result came from and what impact it had on my baby. The midwife did not explain this to me. The care was satisfactory. However, they failed to give me a genetic counsellor for my sickle cell trait.”

It is not all bad, though. I do want to point this out. There are a few instances where conditions were managed properly and correctly from the outset. For example, one woman said, “I had high blood pressure from the beginning of my pregnancy. I was monitored regularly. Towards my third trimester, I was monitored weekly.” Another woman said, “I had diabetes in my first pregnancy and tested early on for this. I was also given extra scans as my pregnancy progressed.”

We do not want to scare women when we talk about black women’s experiences. Although we know the majority of women could probably relate to having a terrible experience, it is not all bad. I have had two experiences now. One of them was not great, and one of them was really good. We know that good does exist and we want to highlight more of the good. What can we learn from that? How can we push for more of those things to happen?

Q13 **Sarah Owen:** Where are the good examples happening? We need to see where the good examples are. Then we can push and say, “Why is this not being shared as best practice? This is the standard that others should reach.”

Tinuke Awe: Yes, absolutely. As a practical example, a few weeks ago it was Black Maternal Health Week, which Five X More runs. We try to highlight the intersections of different conditions and different things that can happen as black women. Again, so as not to make it a really negative week where we talk about negative stories, we highlighted 10 positive experiences on our website and Instagram pages, which people can and do learn from. We had a reach of literally hundreds of thousands of people that week, which is really amazing. Loads of health professionals follow us. They can see that black women are having great experiences and what that looks like.

There definitely needs to be more done on what good practice is and how we can take that further. Like I said, it is not all bad. The focus on the good also needs to be there.

Q14 **Josh Fenton-Glynn:** Thank you so much for sharing and bringing your expertise. I am sorry that you have been in the position where you had to build up that expertise. You were talking a bit about what good looks like. Ben spoke briefly about whether it is a training problem. Do you have a sense of the extent to which different ethnic groups are covered in training? Is that specifically looked at in midwifery training or not? If it is, to what extent is it covered? Is it a module on one Tuesday morning or is it a proper part of the midwifery course? Do you know?

Tinuke Awe: That is not something that I can entirely answer. From speaking to student midwives, sometimes they tell us it might be a one-off class or seminar. It is not necessarily embedded within the system. It seems to be a throwaway, if they do get anything to do with differences in ethnicities, what to look out for and that kind of thing.

Like Sarah mentioned, we have training that we give to health professionals in hospitals, but they have to self-identify. They have to write in and say, "We would love to take this training." It is not mandatory at all; it is just something that we offer. For the people attending, it is not mandatory for them to attend either. Again, it will be the people who are interested, who want to learn and who want to do better who will probably be attending that. It is certainly not for everyone.

Q15 **Josh Fenton-Glynn:** It is not an expected part of continuing professional development or anything like that?

Tinuke Awe: Not that I know of, no.

Q16 **Alex McIntyre:** Thank you ever so much for your answers so far. I just wanted to come back to something that you said in your initial remarks about feeling like you were almost held captive in the hospital until you had an intervention. You were not able to leave and you felt pressured into making a decision.

I have an 18-month-old and we went through it fairly recently. One of the things that we learned when we were doing all our research before was that you have that agency. Lots of women do not realise that when they are going into it, because it is such a scary moment. You have so many things going through your mind and so many things happening in your body at the same time. Trying to advocate for yourself can be really difficult in medical scenarios where you have professionals around you. It is so important for women to advocate for themselves and it is important to empower them to do so.

I wanted to find out from you what the Government could be doing to empower women to advocate better for themselves in those scenarios. We have talked a lot about how the profession needs to listen more, but how can we improve that advocacy to make sure we are getting the right outcomes?

Tinuke Awe: You can work with us. On a serious note, though, we have our five recommended steps, which was our first-ever resource. Anyone can use those. We are in the remit of working with black women. Essentially, these are a few steps for self-advocacy. I wish I had had those the first time round, because I did not. Just for context, when we launched Five X More officially, I was pregnant with my second child. I was like, "I absolutely do not want this to happen to me again. What can we do?", hence that was our first resource.

We definitely need to do more to give women agency to speak up for themselves. I wish this was happening in a few months' time because we would be able to give you some data from our new report. From looking at some of the early stuff, I know that self-advocacy piece is starting to come through.

Again, it is about giving women that sense of agency to know what their rights are, that they can seek a second opinion and all of that. National campaigns might be something worth looking at. We need to get the balance right. We know what the stats are. We do not want to continue talking about the stats. You have to move forward into positive action. Maybe instead of saying, "Black women are likely to die," we should be saying, "Here is what you can do to stay safe during pregnancy." The messaging also needs to be really right if you are going to go down that route.

Q17 **Alex McIntyre:** I was completely ignorant about this two years ago, if I am perfectly honest. One of the things that I learned is that you can do nothing. When people are offering you an intervention, you assume that you have to take whatever is being offered, but the option is available to say, "What happens if we do nothing right now? Is this something that can wait for two hours or does it have to happen in the next 30 minutes?"

In the studies that you have done so far, is there a disproportionate impact on black women in terms of having that agency to be able to advocate for themselves? If so, is there something particularly targeted that the Government need to do to improve that?

Tinuke Awe: Things such as white coat syndrome are very real. So many people are taught, "Doctor knows best." The doctor is the one who has been through the training, so pretty much anything they say is a given.

It is about giving women the power back. You know your body better than anyone. If you feel like this particular health professional is not listening to you, you can ask for a second opinion. You can escalate this or you can ask more questions. Ultimately, we want more women to feel like they have all the information they can to make informed decisions. Unfortunately, we are not seeing that at the moment.

Q18 **Chair:** There is just one question from me, Tinuke, even though I am chairing this meeting, because this is too close to home, for many reasons that I will not say now.

Many women, black and white but particularly black for the purposes of this meeting, live with things such as fibroids, sickle cell trait, high blood pressure or diabetes, which they will talk more about in the other panel. The problem is that many of these diagnoses are not even looked at when you are pregnant. It seems to be that the conditions you are living with are ignored when you are pregnant. Did you find that to be the case from the women you talked to when you were doing your piece of research, and from your experience when you were going through this?

Tinuke Awe: Yes, absolutely. We can talk about pre-conception as well. I have some data here from Public Health England. In 2018, it found that 45% of pregnancies and one-third of births in England are unplanned, meaning that people are going into pregnancy without knowing a lot about their family history and that kind of thing.

We were part of the former Government’s Maternity Disparities Taskforce. We are developing a pre-pregnancy guidance plan that aims to enable women from ethnic minority communities to make informed decisions about their health and well-being prior to pregnancy. That is really important. Some of these issues can become exacerbated or be ignored while you are pregnant.

I would like to highlight the case of D’lissa Parkes as an example. This might have been what you were talking about, Ben, from that TV show. D’lissa Parkes suffered from constipation from an early age. Essentially, her medical notes were not linked with her maternity notes. Her antenatal scans showed a displaced uterus, but it was not acted upon. At 38 weeks, they had made a decision to turn her baby manually while she was pregnant because the baby was breech. She experienced a lot of pain after this and went to the hospital in the early stages of labour. She complained of being constipated, but she was sent home with suppositories. Again, they were not looking at the actual issue that she was having.

Unfortunately, D’lissa ended up having an emergency C-section, but there was a faecal mass in her colon, which basically forced her womb out of shape. She suffered multiple heart attacks that day, and unfortunately she died that night. Her daughter sustained a brain injury leaving her blind, deaf and unable to walk.

I feel like it is important for health professionals and the Government, who are making some of these decisions, to let women know the importance of talking to their family about their family and health history. There needs to be an emphasis on talking about pre-existing conditions and current conditions, no matter how small or unrelated they think they are. Those issues can indeed become exacerbated when you are pregnant. More definitely needs to be done in terms of women taking ownership of their health beforehand and health professionals realising what is going on.

Chair: Tinuke, thank you for coming today. We are going to change panels, but thank you so much for your input this morning. It has been really informative.

Tinuke Awe: Thank you so much.

Examination of witnesses

Witnesses: Shanthi Gunesekera, Professor Marian Knight and Sonah Paton.

Q19 **Chair:** Thank you for coming this morning. Starting with Sonah, can you introduce yourselves to the Committee, please?

Sonah Paton: My name is Sonah Paton, I am a mother of three. I have had three quite different maternal experiences. My first child was born quite small and quite poorly after I went into spontaneous labour at 28 weeks. My second pregnancy was pretty clinically unremarkable, but it was full of times when I was very aware of my blackness. For my third baby, I found myself leaning out of statutory services. He was born at home, and it was lovely.

My varying experiences inspired me to train as a doula and set up an organisation called Black Mothers Matter, which exists to support and celebrate black pregnancies.

Professor Knight: My name is Marian Knight. I am professor of maternal and child population health at the University of Oxford. I lead the MBRRACE-UK confidential inquiries into maternal deaths and morbidity. I am responsible, sadly, for the statistics that have brought us here.

Shanthi Gunesekera: I am Shanthi Gunesekera. I am the co-CEO of the charity Birthrights, alongside Janaki Mahadevan. Birthrights is the UK charity protecting and championing human rights through pregnancy and childbirth. We do that by providing rights-based and unbiased information for women and birthing people. We provide training to healthcare professionals and civil society organisations. We act as a critical friend; we challenge trusts. We are prepared to use the law strategically to create change. We undertake research, policy influencing and campaigns.

You may be aware of our 2022 report into systemic racism. This year we have also published a report looking at the state of home birth services in the UK and the disproportionate impact that that is having on marginalised communities.

Q20 **Andrew George:** My first question is on the stats, so it is probably to you, Marian, if that is okay. We have looked at the stats. We have heard that the statistics indicate that black women are five times more likely to suffer maternal death than other groups. As a brief opening remark in less than a minute, what are the highlights? What does the data tell us about the differences?

Professor Knight: I always want to start these things by reminding anybody listening, particularly black women, that maternal death is rare.

Andrew George: Yes, exactly.

Professor Knight: It is really important that women are not going into pregnancy terrified, which is where the work of Sonah and her colleagues is crucial. The death rate for black women is now about two and a half times higher than it is for white women. The black maternal death rate is about 28 per 100,000. For white women, it is around 12 per 100,000.

I do see some green shoots. You have heard from Tinuke. When she and Clo set up their fantastic advocacy organisation, it was a fivefold difference, so the difference has decreased. The black maternal death rate has continued to come down very slightly. The difference is partly because there has been an increase in the maternal death rate among white women, so do not over-interpret the statistics. There is still a long way to go.

Q21 **Andrew George:** To take a heartless devil's advocate position—do not misinterpret what I am asking—to what extent is that statistic explained by other factors? Ethnic group A might happen to be more deprived and have different health comorbidities, et cetera, compared to ethnic group B. If you go across the whole population and you put people into different groups, not everyone is going to have the same outcome, although one can understand about averages. To what extent can it be explained only by ethnicity? To what extent can it be explained by other factors?

Professor Knight: That is a very valid question. It is difficult to answer for maternal mortality because the numbers are relatively small. Doing that adjustment is difficult with maternal mortality.

Q22 **Andrew George:** I do not mean only maternal mortality, but, for want of a better expression, unsatisfactory outcomes from the birth process.

Professor Knight: You anticipated the next bit of my sentence. We can look at maternal morbidity and severe complications in pregnancy. When we look at that, differences in deprivation explain only a small part of the difference between black women and white women. Complications and comorbidities—you heard quite a lot about that from Tinuke—explain some of the difference. We have to think very carefully about pre-pregnancy care and how we can help with that.

Q23 **Andrew George:** From your experience of talking to the profession, to what extent is it a factor of benign ignorance or malignant discrimination?

Professor Knight: I am a researcher and I have not had those conversations. In our confidential inquiry, we have full copies of the medical records of the women who die. There is a big difference between what is documented in a record and what may be exchanged verbally. However, we see evidence of women's ethnic background being differentially referred to throughout. Again, Tinuke gave you an example of a woman not even being believed about her own ethnic background. We see that in the documented records.

We do not see evidence of malignant racism, but I would not expect that to be documented.

Andrew George: No.

Professor Knight: We do see examples of some of the misbeliefs that we heard from Tinuke.

Q24 **Andrew George:** To what extent can you pan this across to other health conditions? In other words, do you see the same disaggregation and difference in terms of both outcome and treatment in other health conditions? I am sorry; being pregnant is not a health condition. I do not want to get myself in hot water. Do you know what I mean? In other words, is this similarly a factor in other specialties?

Professor Knight: I research entirely in the area of pregnancy and early childhood, so I can really only talk with any expertise around pregnancy and infant health. We know there are inequalities in outcomes between different ethnic groups in other health conditions, but I cannot compare.

Q25 **Andrew George:** No, that is fine. I have two other quick questions. The first is about your communications with health professionals, the Royal College of Midwives, NICE and others. This information has been presented to them. What reaction do you get from them? They must be alarmed to think this is going on.

Professor Knight: The Royal College of Obstetricians and Gynaecologists, together with the Royal College of Midwives, has a specific group focusing on the health of black women and women from other ethnic minority backgrounds. That has now been disbanded, although they clearly still recognise it as an important problem. I do not know about current activities ongoing in the royal colleges. My interactions are more with NHS England and colleagues at that level.

Q26 **Andrew George:** This may be an evaluation that is beyond your analysis of statistics, but, if white women were experiencing these outcomes as opposed to black women, do you think there would be a different sense of urgency and action taken within the system to address the issue?

Professor Knight: I am pausing to answer that question because it depends on which white women. We clearly see a big disparity between white women who live in deprived areas and white women who live in affluent areas. Do we have action to address that? I am not sure we do.

Andrew George: Thank you very much. That is very helpful.

Q27 **Dr Cooper:** I have a supplementary question, Marian, around the trend in your data. You have talked about the fact that the numbers are coming down, which is great, and the relative difference. Unfortunately, maternal mortality for white women is going up. Have you modelled the trend of where you see the numbers going? In other words, have you done any analysis that says, "In five or 10 years' time, we expect it to have decreased by X%"? In that modelling, have you worked various scenarios as to what might bring that trend down further?

Professor Knight: The simple answer is no. I do not want to make excuses, but it is very difficult to do nuanced modelling with maternal mortality figures. One of the things that you might let me say later is that we really need nuanced data on maternal morbidity. We do not have it.

Q28 **Dr Cooper:** If it is okay, Chair, I will also ask about nuanced modelling data. Marian, please talk about that. It would be good to hear about the research that needs to be done still. That would be really helpful.

Professor Knight: As MBRRACE, we have a responsibility for monitoring baby deaths as well as maternal deaths. Baby deaths, sadly, are more common, but that means we have been able to develop what we would describe as a real-time data monitoring tool. Every hospital has a live data viewer in which they can see every death occurring in their hospital. They can see trends; they can look at different groups, so they have a way of immediately responding to changes in patterns. They also have an immediate way to see the impact of any interventions or changes they make, such as the training we talked about.

We do not have anything like that for maternal morbidity. That is what I would love to do because it would give us a way of evaluating our actions. The question earlier was, "What does good look like?" We do not know because we often do not evaluate what we do. We have no way of doing that easily and quickly. If we had a data system—data gives us so many opportunities—we would be able to evaluate what we do and spread the good across the country.

Q29 **Dr Cooper:** I will move on in a second, but why has this data on maternal morbidity and mortality not been collected already?

Professor Knight: Understandably, do we want our staff to be spending time collecting data when they could be caring for patients? We are now at a time of opportunity. Our electronic systems are so advanced that we can do it without the additional staff burden. We have a window of opportunity to do it now.

Q30 **Dr Cooper:** That is really helpful. Thank you. Sonah and Shanthi, I would like to move on to talk about an issue that Tinuke raised in the first panel around the health of black women entering pregnancy compared to other ethnic groups. I am thinking about pre-existing conditions and how the health of black women compares to other ethnic groups in the population.

Once black women are pregnant with these pre-existing conditions, how well are their health needs met? Shanthi, I will start with you.

Shanthi Gunesekera: I completely agree that we need to have greater awareness of how different conditions manifest in different bodies. That is a really clear finding from the 2022 Birthrights report. You do not receive training on how to recognise sepsis or jaundice in different bodies. However, I really want to emphasise that there is nothing wrong with our bodies as black and brown women or birthing people that could explain away the disparities that we are seeing in maternal outcomes and experiences.

There is a very concerning metanarrative going on around pregnancies and bodies being increasingly clinically complex. There has been evidence provided by Soo Downe and others to show that the increasing rates of interventions are not matched by the risk profile changing at the same rate. One has to be really cautious around this angle of bodies and lifestyles being the problem. You will have seen, from various sources of evidence, that this is about racism in all its forms.

We also need to contextualise this. The maternity system is broken for everyone. You have seen so many reports into the state of maternity care in different hospitals and trusts. Women, whatever their background, are having a horrendous time for the most part. What we can see at the heart of all of these inquiries and reports is that women are not being listened to. Their voices are not being listened to. The decisions that they are making about their bodies and care are not being respected.

Fundamentally, we have a right to decide what happens to our bodies and our care. We have the right to be given unbiased information to be able to make that decision. We have the right for that information to be accessible and not to be coerced into certain practices. When that system is bad for everyone, we see that it is disproportionately bad for black, brown and other marginalised communities.

The fundamental problem is about a misunderstanding of rights. There is no understanding of rights, from the frontline to the regulatory services. The fact that we have these rights is just not understood, so the system is being designed without our rights in mind. It is not enabling person-centred care. It is not enabling us to make informed decisions about our bodies and our care.

When you have this metanarrative of clinical complexity and increasing risk, the response is through that lens. We are seeing stricter guidelines and pathways as to what needs to happen for different communities or demographic groups, which instantly locks out whole communities from being able to make informed decisions about their care. If you come from this community, you are suddenly on this pathway.

For example, in our recent home birth report, we see that black women are being denied access to home birth services because of their ethnicity or demographic group. In these circumstances, people are preferring to opt for unassisted birth, where there is no medical care or intervention. That is not out of an empowered decision to free birth but because they feel like there is no other option, because the service is not listening to their voices or providing them with a safe space where they are getting personalised discussions about the risks they are facing.

Within that context, while this is about racism at a relational level—there are huge issues with healthcare professionals around microaggressions and racist stereotyping, as Tinuke described—we need to understand that healthcare professionals are operating within a system where they are not enabled, empowered or supported to give person-centred care.

The problems are institutional, systemic and structural. Therefore, the solutions need to be at all those levels. From looking at the responses of different NHS trusts and the NHS as a whole—I am on the NHS's equity and equality steering group and stakeholder council—it almost feels easier for the NHS, in the face of these huge problems, to reach for cultural interventions, such as anti-racism training for staff and leadership, and clinical interventions and pathways. If we really want to effect meaningful change for black and brown women and other marginalised communities, we need to look at this at a structural level.

At Birthrights, we are calling for new legislation. We think there should be a new safe maternity care Act that makes clear how human rights and other law applies to maternity care to make sure everyone, from the frontline to the managers, commissioners and regulators, understands and ensures that safety, accountability, freedom of choice and equity are at the heart of everything to do with maternity care.

We need to end NHS charging, which is limiting access for women and birthing people, whether they face charging or not, particularly marginalised vulnerable women and birthing people. We need to prevent the dismantling of core maternity services. The Government are talking about more NHS community-based care, and yet we are seeing the rolling back and prevention of home birth and community-based services.

To this point about good practice that was talked about earlier, there are teams within the NHS or individuals who are really trying to provide person-centred care, but the institution is preventing that. Sorry, I know I am talking a lot.

Q31 **Dr Cooper:** No, what you are saying is really valuable. I am going to bring in Sonah. What you are saying is really interesting. Regardless of what you look like and where you are from, person-centred care is absolutely the gold standard. You were talking about other marginalised communities. Do you want to talk about socioeconomic disadvantage and where people are starting from in terms of their ability to access good nutrition and good health services? We know that disproportionately more people from minority ethnic communities are socioeconomically disadvantaged. Sonah, I do not know whether you wanted to talk about that at all.

Sonah Paton: From our work and experiences, there is quite a lot of anecdotal evidence that tells me that often the response from healthcare professionals to some of those existing conditions looks really different for black women compared to others. For example, if a black woman is starting her pregnancy journey and is diabetic or has a high BMI, her midwife is much less likely to offer interventions around movement or good nutrition and much more likely to rush to medication or more clinical intervention.

Q32 **Dr Cooper:** Why is that, Sonah?

Sonah Paton: You would have to ask midwives. I have my suspicions, but that is probably a question for healthcare professionals. We see it in pre-eclampsia and measuring blood pressure. Going to an NHS maternity environment is often quite a stressful time for a black woman. If her blood pressure is reading consistently higher when she is at appointments, being able to look at that situation a bit more critically and maybe take that woman's blood pressure in a home environment or a community where she feels a bit more at ease can make a massive difference to how pre-eclampsia is recognised and managed throughout her pregnancy journey.

For my white friends and neighbours, that softer, first-step clinical care is offered much more frequently and encouragingly than it is to people within black communities.

Q33 **Dr Cooper:** That is really interesting. Shanthi has mentioned person-centred care. Do you have any thoughts about how we can bridge that inequity with different styles of approach based on skin colour? Do you have any thoughts about how that might be improved or addressed?

Sonah Paton: Having confident, honest and thoughtful conversations about the ways that race and racism show up in all their different dimensions across maternity care is probably the first step.

From my own experience, my first connection with maternity was my booking appointment, which is typical, where your weight and height are recorded, and your BMI is worked out. BMI is flawed. I was told at the start of each of my pregnancies that I was overweight. As a black woman, I feel quite confident that I am not overweight. I also know that, if I am being told I am underweight, and BMI is the marker for that, there is probably a whole heap of black women who are underweight for a black woman and are not being flagged, and going through pregnancy underweight is very dangerous.

Being able to think critically about all of these touchpoints that happen and that disproportionately negatively affect black women is one of the first things that need to happen.

Dr Cooper: That is so helpful, Sonah. BMI is an interesting discussion, and it comes up with the national child measurement programme as well. It is a really interesting discussion in terms of different body sizes, so thank you for bringing that up.

Q34 **Gregory Stafford:** I want to focus on antenatal care. All the written evidence that we have been provided suggests that black women are less likely to have adequate access to antenatal care. Why do you think that is and what steps should providers of antenatal care take to change this?

Sonah Paton: Again anecdotally, there were a lot of times in my antenatal care where I was not represented or the information I was given was not particularly relevant, and I could find more relevant or accurate information about me and my pregnancy outside of NHS provision. By my third pregnancy, that is exactly what I did.

We often talk about black women who are perhaps disengaged or not engaging with antenatal services. There are a lot of women who have followed that path and, either consciously or unconsciously, if the antenatal provision is not relevant or does not feel safe, will not engage with it. Something as small as being able to see a black baby in utero is a real novel thing. We use it as standard in all of our provision because we are catering for black mothers, but, if you are a midwife and you are trying to engage someone in talking about their pregnancy, and all the literature and information you have is of white bodies and white babies, it is just quite hard. It does not feel relevant and there is other information elsewhere. That is part of it.

Going back to all those softer or subtle moments when people are made very aware of their blackness, like I just described in that booking appointment, these add up or tot up as you go along your maternity journey. As you come to the end of it and your exposure to your midwife and care team becomes more frequent, and those moments become more frequent, it can feel a lot safer to disengage and protect yourself.

Q35 **Gregory Stafford:** That is helpful. Thank you. It was very powerful to hear about the problems once someone has accessed antenatal care. I suppose what I am trying to focus in on is why, according to the evidence that we have received, black women are less likely to have adequate access at the start and, therefore, access antenatal care later.

Shanthi Gunesekera: The question is why people are not wanting to engage with it. We understand the provision of maternity care not just from our own personal experiences but from our communities and from the news. There is a real issue of trust around safety and being listened to.

Where people do not attend antenatal services, we have seen hospital policies requiring referral to social care or the police, despite it being within your rights to not access antenatal care or to decline medical intervention. Equally, when people do access antenatal care and make informed decisions about their bodies and their care, perfectly lawful decisions, we again see a consistent number of people approaching us being referred to social services or the police for those decisions. That is a small example of showing how the system is not demonstrating it as a place of safety and trust for communities to access, alongside, as I mentioned, NHS charging and anxieties around that, and a misunderstanding around gatekeeping or fear of costs.

Q36 **Chair:** I do not want to butt in, but I need to ask you a question. If people are not engaging and social services are called, is that all communities or just the black and Asian community?

Shanthi Gunesekera: I do not have data. The policy is there for anyone not accessing antenatal care. We are working with a trust at the moment on its policy. I suspect you would see that policy being enacted more for particular communities but that is conjecture on my part.

Q37 **Gregory Stafford:** We, as a Committee, want to make some recommendations to improve, in the case of the questions I am asking, access to antenatal care and make sure that, again according to the evidence, black women come up to at least the average of access. What I am trying to get to is what steps we should be recommending to providers and, indeed, the NHS as a whole, as well as social services. What should we be recommending to improve this?

Professor Knight: We need to think about a lifelong approach. What we have heard very clearly from everybody is how your experiences before you get pregnant influence your access to pregnancy care. We have to recognise where trust is lost and where trust already exists. We also have to recognise that the system as it is designed at the moment—and this is my interpretation of later booking—is not working in a personalised way for all women.

Why are we not thinking more about community models of antenatal care where women, particularly black women, can access the care they need in the community with people they trust and a continuity model of a trusted person? It may or may not be the midwife. It may be a doula. It may be another trained professional from their community. We need to think more inventively about our models to make them work for the groups of women they are clearly not working for at the moment, and we need to evaluate what we do, so that we know what is working and we can spread it.

Sonah Paton: I was going to build on that. I feel like we have a great example of best practice in Bristol. At Black Mothers Matter, we have a pregnancy group and we received funding for a one-year pilot from our local NHS trust. That was open to anyone at any stage of gestation up until the time they gave birth. Engagement was really high. People engaged with us from as soon as they got a positive pregnancy test. They are able to connect in with us on a regular basis. All the sessions have a NHS midwife present; they do not lead the group but they are available.

We can provide continuity of care. We can talk about a range of topics that impact pregnancy, so that could be housing, relationships, nutrition or exercise, and facilitate people in engaging in NHS antenatal care but via the community, because we have that trust and understanding, and we can talk about the specifics of navigating the system as a black person, or potential responses when the obstetrician inevitably says, "I think you should be induced."

Conversations like this that cannot happen in classic midwife appointments or antenatal provision can happen really well and richly in the community with support from statutory services. That is a model that works really well and, just from the pilot in Bristol, has been lifesaving.

Q38 **Gregory Stafford:** That is really interesting. With your permission, Chair, we would like to see any evidence you have on that. We are looking for examples of best practice, so that is really helpful.

Shanthi Gunesekera: There are so many examples of community-led support, which is really important, but it cannot detract from the dismantling of NHS community provision. We are seeing community-based, midwife-led maternity units being withdrawn or dismantled. The two need to go hand in hand.

Q39 **Alex McIntyre:** To follow up on that before I go to the questions I am meant to be asking, we heard last week in a separate evidence session about family hubs and the importance of having more of the antenatal checks in those family hubs. That pilot in Bristol sounds really interesting. Do you think that model could work in a family hub, in terms of taking that pilot out to the network of family hubs so that they are out in every community?

Sonah Paton: In theory, yes. Building on what Shanthi said, there needs to be proper investment. Like I said, we were funded for a one-year pilot, but within our Black Mothers Matter team we have ex-midwives, we have people who are really skilled in navigating NHS systems and we have the support of our local trust, which is actually the support of two individuals who are really committed to improving black maternal health in the south-west. Those are some really key factors in making that successful. Like Shanthi said, when we look at community-based solutions, there is an assumption that those are cheaper or not of the same quality as statutory services. As long as that approach is not taken and this is invested in properly, it is a fantastic potential model that could have really big influence.

Q40 **Alex McIntyre:** Shanthi, we talked briefly about the report, I am sure lots of your answers already have drawn from that 2022 report. In a minute—I know this is really difficult to do—could you summarise the key findings of that report?

Shanthi Gunesekera: It was about the nature of racism, including individual interactions, so being ignored and disbelieved, racist stereotypes, microaggressions, dehumanisation, denial of pain relief, which you heard about from Tinuke, education and training, so white bodies as the norm or default, failure to recognise conditions such as jaundice and sepsis, lack of cultural understanding, policies and frameworks, ethnicity as a grounds for induction within policies, high-risk pathways biased on ethnicity alone, lack of representation in clinical evidence and committees, the NHS charging regime, failure to provide interpreting services, workforce lack of senior representation, higher rates of disciplinary action, bullying and toxic culture.

Q41 **Alex McIntyre:** Is that all under the banner of systemic racism?

Shanthi Gunesekera: Yes. That covers relational, systemic and institutional.

Q42 **Alex McIntyre:** That report was in 2022. Has there been any progress in addressing those issues since that report?

Shanthi Gunesekera: From the report we have just done into the state of home birth services in the UK and the impact that is having on marginalised communities, I do not feel positive about progress. Women and birthing people from marginalised communities still feel like their voices are not heard and their decisions are not respected.

Q43 **Alex McIntyre:** Sonah, I want to come back to something you said. You do not have to answer this question if you do not feel comfortable, but you said you have your suspicions about why things have not happened. Does that align with what Shanthi just said? Do you think that might be part of the issue?

Sonah Paton: I cannot remember what I had my suspicions over. I am a suspicious person.

Q44 **Alex McIntyre:** It was about the differences in how people had been treated and you had your suspicions, and you referred it back to medical professionals as to why they might deal with certain groups differently. It was Beccy’s question about pre-existing conditions, and diabetes was the example you gave. You do not have to answer this question, but I would be very keen to hear what your suspicions are, because you have done a lot of work in this space.

Sonah Paton: I get lots of signals that black and brown female bodies continue to be undervalued or of less value to lots of people who have power and the ability to make change and decisions. That is a suspicion I have and the current state is a bit of a reflection of that.

Shanthi Gunesekera: If you look at, for example, clinical negligence claims within the NHS, 40% of those are accounted for by maternity care. The cost to the NHS of the systemic failure in maternity care is huge, and it is sort of leading to a defensive risk avoidance approach by hospitals and trusts. In many cases, the legal teams are almost setting the clinical policies about who can access what. You have that risk-averse, defensive position without an understanding that the best way to safe care is through women and birthing people having a voice in decisions about their bodies and their care, and that is going to be safest for both the person giving birth and the healthcare professional providing that support.

At the moment, that is not understood and so you are seeing a risk-based approach where you have blanket policies in place. That contributes to why some healthcare professionals may respond with the most extreme response in certain scenarios.

Q45 **Alex McIntyre:** We have also talked about the pilot you have run in Bristol. Are you aware of any other policy initiatives or programmes that are out there that enable communities to provide culturally competent care?

Sonah Paton: I am biased because I founded Black Mothers Matter, but I do think we have built a fantastic model of care in Bristol and the south-west. It is not just a community model of care, but is supported by the local authority and NHS. Building a much more connected picture of maternity where everyone is included and considered makes a massive difference in outcomes and experiences for those most at risk.

Q46 **Alex McIntyre:** Opening up that question to the rest of the panel, is anyone else aware of particular areas?

Professor Knight: There are definitely other models. The Lambeth Early Action Partnership is an example that has recently evaluated improvements in child development, maternal mental health and, in fact, parental mental health, so paternal mental health as well. There are definitely models. The challenge often is that you have one year of funding, but how can you evaluate the impact in one year? It is really difficult.

Alex McIntyre: It is hard to deliver systemic change.

Sonah Paton: Funding joy and creativity in black maternity is really important and I know is so impactful in improving experiences and outcomes for black women, but finding a funder to commit to that is a real challenge.

Q47 **Ben Coleman:** I used to be on the integrated care board for north-west London and I spent a long time trying to get it to recognise structural racism as an issue. It did, and it has instituted a programme. I do not know how much difference it has made, but this partly came out of covid, when lots of black people did not want to be vaccinated because they did not trust the NHS, crudely. If you have had worse treatment, worse access and worse outcomes, it is understandable.

It was a real issue in getting people in the NHS anywhere, particularly white people, to talk about structural racism because they think you are accusing them of racism. You are not. The system, however, can be biased against you, which it is, and there are huge issues. How much do you think the NHS as a whole recognises structural racism as an issue that needs to be addressed?

Shanthi Gunesekera: There is recognition of the need to address racism. I do not know whether there is understanding of what that means. That is at an NHS level. Our experience echoes yours when we are delivering training. There is a recognition that racism might exist, but not here.

Sonah Paton: From my experience, people often feel so wildly uncomfortable even saying "black woman", "race" or "racism", which is a signal that they are not comfortable to have those conversations. I again have seen great work and change in Bristol. There is a programme called Black Maternity Matters, which is a long and deep anti-racist programme that supports healthcare professionals and senior leaders to develop those competencies and confidences in talking about race and addressing systemic issues.

I truly believe, if we can get that programme to enough people and work out what the tipping point is, there will be a culture shift. That will be really impactful in the way NHS organisations in Bristol and in the south-west are able to talk about race and tackle issues of racism.

Professor Knight: In the NHS and in the structure we have, we do not think about it in that way. If it is a system that does not provide care for particular groups of women in the way they need it, we do not think about it as structural racism.

Q48 **Ben Coleman:** We do not really think about it. There is no ethnic proper ethnicity measurement for operations that people go into. We are not just talking about maternal health. When Penny Dash came to see us, she talked very encouragingly about improving data in the NHS. Through data, ethnicity data, and talking to people and listening to these things, should we say there is a great opportunity to improve that?

Professor Knight: While we are on data, we need to have women's experiences as part of the data, because that is how we will then clearly show that what we are providing is not what women need.

Q49 **Alex McIntyre:** My next question is on continuity of care. We touched upon it in the first session. From my own experience of it, we were really lucky. Our community midwife was the same throughout and she ended up being on call on the day of delivery, so she was actually delivering midwife. Having spoken to a lot of people and parents since, that experience is incredibly rare. This is quite a wide-ranging question, but what can be done to improve the continuity of care that women and particularly black women receive throughout their pregnancy?

Shanthi Gunesekera: I agree that there is lots of evidence that shows the impact continuity of care can have, particularly for black and brown women and birthing people, but our 2022 report also showed that there are limitations on that within the existing system. While racism is so prevalent and there is so little support for person-centred care, you could end up having continuity with someone who is not the right person for you. While you have the right to ask for a change of carer, I know from my own experience that that will feel really awkward, even if you do not have to provide a reason. It is a really important ambition, but we need to recognise that it is not the solution on its own. It needs to sit alongside a wider set of issues.

I just want to make a small point related to what Ben was saying around data. When looking at ethnicity data, trusts have autonomy under the patient safety incident response framework to decide which patient safety incidents to investigate, and may not investigate ones based on ethnicity. We may get a skewing of the data there.

To Marian's point, it is really important that we are not just looking at clinical outcomes. What could be clinically good could still be a really horrendous experience for someone and have long-term psychological impact as well.

Q50 **Alex McIntyre:** On that data point, in 2022 NHS England took out the target date for that continuity of care piece because of the staffing levels and the ability within the system to actually provide it. Is that impacting our ability to understand the impact that is having and the data we are able to collect around continuity of care?

Professor Knight: I do not have an answer to that. I do not know that we have good staffing data on continuity of carer. The point I wanted to make is that the evidence is that there are lots of different models of continuity of carer. It does not have to be a midwife. Some of what Black Mothers Matter provides is effectively providing that continuity of carer.

We could be thinking about different models of that single trusted relationship to help navigate and advocate. Again, maybe we need to be thinking more broadly than continuity of midwife care. As you quite clearly point out, it can work—you had a fantastic example—but sometimes it does not.

I just wanted to make sure that we are handing over. There is often a huge gulf postnatally. We do not have health visitors in the way we used to. Even when we have continuity for some part of the maternity pathway, it might then disappear. We have to make sure that that care is being handed over.

Q51 **Alex McIntyre:** Picking up on the point that Marian made, do you think there is perhaps not enough focus on the role that doulas and others can play in providing continuity of care?

Sonah Paton: Yes, there are definitely ways that we can think creatively about filling those gaps and providing continuity of care, in that a solid, fantastic relationship can come from a whole load of different people. Quite often, the women we speak to do not distinguish between the different types of healthcare professionals who are involved in their maternity journey. They could not tell you the difference between a midwife, an obstetrician and a health visitor. They are just part of that team. Consistency, postnatally as well, like Marian said, could have great impact.

Q52 **Chair:** You have all talked about continuity of care and everything in my head keeps saying "individualised care". What I do not hear is that the person is treated as an individual. When did we lose that in the maternity system?

Professor Knight: I am not sure I have an answer to that. The model as it is designed at the moment is about the staff wanting to deliver it, rather than with the woman at the centre. That is why having women's voices embedded in any service design change has to be essential.

We have gone post-pregnancy. I just want to come back to pre-pregnancy. That is where we really need to start the individualised care, because we could help women so much before pregnancy to prepare for pregnancy, to get the medications right—you were talking about diabetes at the beginning. That would enable women to be empowered from before pregnancy, from school, to know what they need as an individual. Having to advocate for individualised care is not an ideal place to be, but as a minimum that at least then helps women know what they should be being provided with.

Shanthi Gunesekera: Just to make a quick addition, we need to recognise the foundations of the NHS. I am not sure whether, "When did we lose individualised care?" is the right question, because so much of it is founded on a kind of colonialist, racist, patriarchal approach. That is the history of maternity care. We need to recognise that, but I would probably say that covid exacerbated the sense that the NHS can implement blanket policies and get away with it.

Q53 **Jen Craft:** I am quite interested, following along a lot of the discussions, that one of the key issues that black women face is this sense of almost a reluctance to access NHS services, because you feel it is not a safe place to be and it is not the place where you will get the treatment that you need. I wonder whether, in the field of mental health support, particularly postnatal mental health support, that is particularly acute, given the almost double hurdle. If you are having a mental health crisis or experiencing poor mental health, those feelings might be exacerbated. Sonah, you might like to talk to that.

Sonah Paton: Where we see huge and, often, like I said, life-saving impact is postnatally creating places and spaces where black women can talk more freely about mental health and struggles. Also, it is normalised. We talk a lot about physical recovery from pregnancy or from giving birth, but the mental recovery, and having regular places, spaces and times where that is planned in and a scheduled part of your recovery, is really important for black women for lots of reasons.

Black women do not present with mental health issues in the same way that white women might, for lots of reasons. They will present later to healthcare professionals when things are much more extreme or severe, or require much heavier clinical interventions. I am not sure if these are the right words, but lots of the softer and lighter interventions offered by the NHS, such as talking therapies or vitamins, do not really feel fit for purpose for anyone who is not white and middle class. For that reason, having places and spaces where black women can focus on mental health is critical.

Q54 **Jen Craft:** That is really interesting. I noticed that black women are much more likely to be admitted to inpatient treatment for postnatal maternal care, but also much less likely to access and receive initial mental health treatment. Do you think there is a systematic thing happening where black women are unable to receive the right treatment at the right time when it comes to postnatal mental health care?

Sonah Paton: Yes, and there is a real risk for black women being honest and vulnerable with their mental health that is different to white women. We have talked about the social services and police being involved, especially postnatally, or after just having a baby. Again, I do not have data, but anecdotally that feels like it comes a lot quicker and a lot heavier for people in our community who express mental health concerns than it does for other women.

Say you had a neighbour, a friend or a cousin who was in mental health distress and called someone for help, when their midwife had said, "Call for help," and ended up with their kids being removed or placed somewhere else temporarily, or ended up being restrained. The collective knowledge on mental health support among the black community is that it is not safe, and to stay away and to find other ways to deal with that.

Q55 **Jen Craft:** Is there a training issue with NHS clinical staff when it comes to mental health support, or is there more of a solution in finding those community-based interventions, because that trust is so far removed that trying to just train people to recognise differently presenting mental health conditions or late-presenting mental health conditions is not sufficient?

Sonah Paton: It has to be both. There is not one solution that will fix it. It has be both and invested in from both sides.

Q56 **Jen Craft:** Shanthi, you might be able to speak to this a bit. What kind of incentives could be built into the system to encourage both clinical staff and maybe community-based approaches to recognise the unique challenges that black women face with their postnatal mental health?

Shanthi Gunesekera: I do not know whether I can answer that. This is part of the general decolonising of the training curriculum and not seeing white bodies or white as normative. There is loads of really, really good community-led support out there and it is just thinking through how to support those community-led structures that are in place as well.

Q57 **Jen Craft:** Marian, looking at the data, are there any gaps in understanding the drivers for black maternal mental health either being picked up too late or not being treated appropriately? Are there any gaps in the data as to how that drives postnatal mortality?

Professor Knight: In terms of postnatal mortality, we have clear data on that, but again, because the numbers are small, I cannot show a statistical difference between black women and white women. We have to recognise, when we are talking about perinatal mental health services, that we still have a long way to go before we have enough perinatal mental health services.

Often, women have to access community mental health teams who do not have perinatal expertise and will not recognise how quickly women's mental health can deteriorate in the perinatal period. They definitely will not recognise different patterns of distress, for example. We have to recognise that there is a long way to go in terms of getting to a stage of ideal postnatal mental health care, and this is for black women or white women.

I would be interested in Sonah's perspectives, but in some communities there is a huge amount of stigma around mental health conditions already, and it is even greater. When you are also fearful of social services involvement, having the enabling women and—it speaks back to the trusted relationships—somebody with whom you can express the distress you are feeling in a way that is understood, listened to and acted on, is what you really need. I do not know whether you have anything in terms of thinking about stigma.

Sonah Paton: No, just that it exists, not for all black communities, but it does exist and there is definitely a generational pressure or difference in understanding of mental health. That can be quite hard to navigate depending on if you are first or second generation in this country. From having conversations, quite often black women do not have the family support to talk about mental health because it is understood so differently between generations if there has been quite recent migration.

All these things build a slightly different picture of perinatal mental health for black women that is not often picked up or considered by mainstream services.

Q58 **Jen Craft:** It is a case of having something that is more bespoke, recognising that, in black women's experience postnatally, especially in the field of mental health, there are a number of different things interplaying.

Would you say something along those lines around people having that awareness and acknowledgement that there will be a whole set of different reasons, whether cultural stigma, the experience people have had to date with maternal services in general, or awareness of past bad treatment and seeing a neighbour, a friend or a cousin having an awful experience? Is it enough for people to start to acknowledge that or does something bespoke as to how that is handled going forward need to be developed?

Sonah Paton: I would say again a mix of both. There is not one approach that will work for all but a mixed approach is really important. Recently, everyone has become really trauma-informed. Trauma-informed practice seems to go into everything we do and the way we consider lots of our healthcare and social care. I would like to see the same for race-informed or racially informed. It is not necessarily a specific service or offering. It is the way that business is done. It is the way that services are provided. In the same way that they are moving to be more trauma-informed, they should also be racially informed.

Jen Craft: Thank you so much. I could talk about this all day, but I am going to hand back to the Chair.

Chair: Thanks, Jen. We are going to move swiftly on.

Q59 **Josh Fenton-Glynn:** In 2022, we had the Maternity Disparities Task Force. By the looks of things, there has not been much movement. What do you think the main blockages to movements in that are?

Shanthi Gunesekera: What do I think? The issue is really big and, like I said, it is on multiple levels in terms of structural, systemic, institutional and relational, and therefore, if you are trying to tackle it through only one of those lenses, you are never going to solve the whole problem.

Alongside that, I am not sure I fully understand, and you probably understand much better than I do, but the level of teeth that national bodies have with local trusts is also a factor. What is expected from local trusts and the autonomy that they are given can mean that this idea of, "Yeah, racism exists, but not here," is going to be embedded everywhere. Sorry, that was quite a short answer compared to my previous answers.

Q60 **Josh Fenton-Glynn:** My instinct is almost to look at the other shifts that are going on in the NHS. What could we do to tie them in with the work that clearly needs to be done in this area? The final example we were given by the last speaker was one of those where the notes were not integrated, and there were racial elements, but there is also just basic incompetence. That is why we have this idea of a digital shift.

The two care-related shifts are hospital to community and sickness to prevention. Sickness is not quite relevant with maternity services because it is not being sick; it is a medical event, but things are going wrong.

I wonder whether there is an opportunity here to be grasped. If we are saying we need to move from hospital to community, and the more medicalised births seem to be informed by more trauma, from what Sonah was saying, and we are also looking at prevention, I feel like there is an opportunity there. Sonah, could you talk a bit about that? What can we do to work more towards prevention? How can we use, perhaps, some of the skills that you have developed in Bristol and some of the examples there?

Sonah Paton: It is about starting investment and maintaining interest in the topic. It feels like, as someone in a grassroots movement, the topic can be picked up and something is going to happen, and then something else comes in and distracts it, whereas the reality for me and my community is that this is what we are really living. For us, lots of our organisation’s successful impacts have been made possible by key individuals in places of power who have really maintained an interest in this topic and are determined to keep changing.

I do not think there is any quick solution that will solve it all. Continuous trying and investment in development will make a difference. I think some more joined-up working between community organisations, people in the community, NHS organisations and the local authority will be really helpful as well.

Q61 **Josh Fenton-Glynn:** Maybe that is something that we need to look at in our recommendations in terms of making sure that we are doing that with the shift.

Professor Knight: We can capture exactly what we need in those three shifts. In terms of the sickness to prevention, if we have good pre-pregnancy care for women who have pre-existing conditions, we can work with those women to optimise their health during pregnancy, which will prevent pregnancy complications.

In terms of the analogue to digital, there is so much more we could do to help with personalised care, but also we are doing some research around using data for an early warning system, so again helping to hear women’s voices and prevent complications, of which infection is one of the leading ones.

In terms of hospital to community, we could do so much more with community continuity of carer-type models.

Shanthi Gunesekera: I was going to add that they are really great ambitions, but it is just so divorced from the reality of what is already happening that, at the point that the plans come in place to implement those ambitions, things will have gone so far back that it is almost impossible.

You have this idea of hospital to community, and yet within the last three months, midwife-led units or whole maternity units have been closing in localities, because they have deemed that the local demographic is too high risk for needing these services, or that there is not enough take-up, but that is based on these really blanket policies that are in place where certain people are not offered options, so they are already taken down the high-risk pathway without individualised care. It is so short-sighted.

You are starting from a point where you are not going to be able to get to that place unless you halt and reverse that dismantling now. In terms of prevention, I just would iterate and reiterate the importance of understanding rights-based care and of respecting our right to make decisions about our bodies and our care. If that is understood, it could unlock a lot of other issues within the services.

Q62 **Josh Fenton-Glynn:** It is so key in maternity care as well, because it is one of those areas where people are most vulnerable and being empowered gives a real opportunity.

I am just going to move on, very quickly, Professor Knight. How well do you think that the Government are evaluating the impact of what they have done so far and how can they do it a bit better?

Professor Knight: I started with this point. We need to evaluate what we do, because we need to capture the good and scale it up. There is a real limit to what we can do by solely monitoring maternal mortality. We have to monitor maternal morbidity and the severe complications, and women's experience. Only then will we have the data about what works. We will know it much more quickly as well, because there are many more women who have complications. Every woman has an experience, and that will allow us to move much more quickly.

Q63 **Sarah Owen:** I have some quick supplementary questions, so I am going to ask individuals to answer them. Sonah, on the agency that black women have around what type of birth they want, we have heard a lot about how women are trying to advocate for less medicalised births, but it is really important that there will be some women who choose, like me, to have a C-section. I was afforded all the privileges of being able to speak the language, being able to advocate for myself, but I still had to fight for that. How are you ensuring that black women and other marginalised minorities are actually being heard when they say, "I want more medical intervention and I want to have a different kind of birth"?

Sonah Paton: That responsibility lies with the workforce. As organisations, through the work Clo and Tinuke do, and the work Birthrights does, we can give black women all the tools to advocate for themselves, and give them all the knowledge, but ultimately, when they show up at a hospital, it is up to that healthcare professional, who plays such a big part in that experience. For me, as a black woman, if I speak up or speak loudly, that is very often misconstrued as me being aggressive.

There was a case of a lady in Liverpool, and she unfortunately died. Her medical notes were shared and you could see where she was clearly trying to advocate for herself. I knew that from reading her medical notes as a black woman. She was described as aggressive or a bit difficult, and things like that. I guess that burden of allowing black women to advocate for themselves lies within the NHS and those systems and structures.

Q64 **Sarah Owen:** Marian, we have heard from Shanthi and Sonah about how we need to have a much more joined-up between the community, health visitors and maternity services as a whole. With the three-year delivery plan for maternity and neonatal services, and all the government initiatives, how big an impact is the workforce? We know that, from the Royal College of Midwives, midwives are doing 100,000 hours a week of overtime unpaid. This is leaving the idea of training, let alone person-centred care, as a complete unicorn for many midwives and maternity services that really want to be able to do it. How important is it that we get that part of the workforce right?

With health visitors, there is a huge disparity between England, Wales and Scotland. Continuity of care for health visitors in England is just 45%; in Wales it is 85% and in Scotland it is 90%. How are we going to see standardisations along there, Marian?

Professor Knight: I am not sure I am the right person to talk about workforce. When we look at the care of the women who died, we see clear evidence of workforce pressures. For example, there have been simultaneous emergencies and they have not been able to undergo a caesarean section at the timing they need. That evidence is clear.

We could think more creatively about some task shifting. There are lots of tasks that we do not necessarily need our midwives or doctors to be doing, and we should think about what other parts of the workforce could do that, to help free up some of that time for midwives to have these trusted relationships that women clearly need. I am not saying that we do not need more midwives. We clearly do need more midwives, and that evidence is very strong.

Q65 **Sarah Owen:** Shanthi, this last one is for you. You have answered questions from Ben, Andrew and Alex about the reluctance to accept that there is racism within an NHS trust. They might accept that it is happening outside, that there is racism and that there is systemic racism, but they do not really fully understand it or see it in themselves. I am going to give you a really clear example. My hospital in Luton, Luton and Dunstable hospital, had a CQC inspection last year. That report came back with racism for staff and for patients, clearly racism, and that is really strongly put in that CQC report within maternity services.

What onus is there on that NHS trust to do better or to actually reach out to people such as Sonah, Tinuke and Five X More? What can trusts that are clearly being evaluated as underperforming and, in this case, as racist do to do better and improve? Is there a standard way forward, or does there need to be a standardisation in how to progress out of that poor level of service?

Shanthi Gunesekera: That is a huge question. There is a responsibility on the trust to change in terms of providing services to the communities it serves, but also a legal obligation in terms of direct and indirect discrimination. We know that there are lots of healthcare professionals who want to provide person-centred care and provide rights-based care, but they are not operating within a workforce culture that enables that.

It is often a toxic, bullying culture, so there is a real issue around leadership in some of these trusts and bringing a rights-based lens to it. The training we provide to healthcare professionals is always delivered by someone with a legal background, often a practising lawyer, and someone with a healthcare background, often a practising midwife. What they really emphasise through the training is that providing rights-based care does not take any more time, but it is just about the culture that sits around that.

There is an onus to look, throughout all of a trust's approach, at how it provides care, what its policies are, how it supports out-of-guidelines care to enable person-centred care, and how it supports staff to provide individualised care. Within that sits ensuring that the staff and the trust as a whole are providing culturally competent care and understand how racism is showing up in their trust. We also cannot continue to push the onus always on the healthcare professionals or, indeed, the trusts when there are these wider systemic and structural issues that are influencing that as well

Q66 **Chair:** The last question is from me. I just want you to give two quick things. This Committee needs to deliver recommendations and we want to present things to Government to help push this agenda forward. Think about what two things each of you would like to see us put in our report to help us make those recommendations to Government.

I am going to start with you, Shanthi, because you finished the last point. We want quick fire. What two things would you like to see after the discussions today?

Shanthi Gunesekera: You could have a million specific, individual, tangible things, but the one thing I would say is that you need new legislation to make clear how human rights law and other law applies to maternity care and make sure that everyone, across frontline healthcare professionals, managers, commissioners and regulators, understands that safety, accountability, freedom of choice and equity need to be at the heart of how the NHS delivers maternity care.

Professor Knight: I have already said my two. My first would be funded pre-pregnancy care. We know that 90% of women can benefit from pre-pregnancy care and advice. My second would be real-time data monitoring for maternal morbidity to allow us to respond when things are going the wrong way, but also recognise when we put in interventions that are effective so that we can scale them up and spread.

Sonah Paton: I would say support for our workforce to develop their anti-racist skills, competencies and confidence so they are better able to support black birthers, and ensuring that community is involved in the design and delivery of services and that is met with sufficient long-term investment.

Chair: Thank you so much. It has been absolutely incredible having you here today and thank you for really holding this Committee’s attention. Thank you, thank you, thank you. I would like to say a special thank you to Sarah, who also has made a fantastic guest appearance on our Committee.