

Lived experience testimonies

We heard two accounts of pregnancy and birth from lived experience witnesses. We are extremely grateful to both witnesses for sharing their stories with us.

One story we heard was that of a Black mother whose partner died not long after she gave birth. She told us of how she received no specialised support relating to her bereavement and struggled with her mental health as a new mother as a result. When she sought help from her doctor, she was turned away and repeatedly passed between services, with no one willing to take responsibility for her care. This woman felt like she was allowed to 'slip through the cracks' and did not receive appropriate care as a result. We also heard how she did not receive care appropriate to her HIV diagnosis, especially in the context of pregnancy. This compounded the difficulties she faced during her maternity care. She called for greater services available to those with HIV during pregnancy and an improvement in signposting to bereavement services.

We also heard from another Black mother who was not given appropriate mental health care during and after pregnancy. This mother had made professionals aware of her diagnosis of anxiety and depression. She sought help from her GP, who said they were unable to help with antidepressants as a result of her pregnancy. She was also told she couldn't be helped by them to access talking therapy, as she received this privately. This mother described feeling completely let down by the maternity care system. She was not signposted to appropriate services, and felt that she had been 'abandoned' to deal with her mental health issues, without any support.

This mother also told us how she was mixed up with another mother and asked to take her baby for a measurements appointment, an error that illustrates both poor administration and a lack of personalised care.

Group Support and Peer Advocacy

All witnesses, both lived experience and professional, told us that there is a strong need for group setting support, especially for Black mothers.

- It was highlighted that these are not readily accessible within the NHS because services are so overstretched.
- Participants told us the NHS is not necessarily good at signposting women towards the voluntary organisations which provide these services. Lived experience witnesses strongly highlighted that this would have been immensely helpful if it had been offered to them. They note that they were 'not heard' or 'listened to' when they most needed support and this had a profoundly negative impact on their pregnancy and birthing experience as a whole.

- We heard from the group that more support should be offered to mothers in a group setting. This would be especially appropriate for Black mothers. However, this is not available in overstretched services.
- There should be peer support available at every step of the pregnancy and birthing process to help ensure that Black women are able to advocate for themselves.

Data, Training, and Workforce Gaps

- We heard how ethnicity data is not being accurately collected. As a result, those services which wish to make improvements to Black maternal health are unable to do so with a clear vision of where improvements would be most effective.
- We heard from senior stakeholders from the NHS Race and Health Observatory. They told us of the value of engaging with service users and supporting discussion with them to better understand their experiences and how these can be improved. We also heard about the value of race and ethnicity data to carrying out their work. We heard that there needs to be greater accountability for instance of harm to patients and a recognition that harm perpetuated by racism is a safety issue for patients.
- We collectively heard that cultural competency training needs to be mandated and improved. Our lived experience witnesses suggested that poorer outcomes for Black mothers is specifically perpetuated by bias directed towards them. Participants believed that training would help to reduce this bias, by teaching healthcare providers how to deliver culturally appropriate care. We also heard that training should be classroom based, by specially trained facilitators.
- Participants told us that a lack of funding is preventing good training.
- We heard that continuity of care, particularly in maternity services for Black women, was failing. Black mothers are not receiving continuity of care and this prevents them from feeling safe and well cared for during pregnancy. Where continuity of care is lacking, mothers feel that they cannot ask meaningful questions about their care. This is impacting outcomes.
- Participants also highlighted that lack of interpretation services also contributes to poor care. Where a language barrier is present, it reduces women's opportunity to advocate for themselves.

Dynamics Between Black Women and Black Midwives

- We also heard that Black midwives may become ‘too familiar’ with Black women who are giving birth. We heard that this may be because they’re less fearful of complaints from Black mothers. We were told that this might perpetuate poor care for Black mothers and should be actively tackled. Black midwives may be more likely to perpetuate the trope of ‘strong Black woman’, which can be harmful to Black women during birth.
- Participants told us how it can be the case that Black midwives can perpetuate racist assumptions towards Black mothers, whether of the same or differing cultures and ethnicities, as much as practitioners of other races. Black women may struggle to speak out against Black midwives as they do not want to perpetuate difficulties for members of their own ethnicity, who they suspect are already mistreated in the workplace.

Whistleblowing, Complaints, and Workplace Culture

- Participants told us that complaints made against healthcare staff are often not sufficiently investigated or acted upon. Participants told us that more should be done to ensure that healthcare services investigate complaints and hold people accountable. They said there should be a greater encouragement amongst staff to whistleblow where poor care was seen being delivered by colleagues.
- They also noted that no midwife, of any ethnicity, will be able to deliver compassionate maternity care if they are unhappy in the workplace. This, they said, is common due to maternity services being overstretched and staff being overworked.
- There was also a suggestion that tackling racism against healthcare staff from minority ethnic backgrounds needs to be prioritised and quashed, as this perpetuates poor care for minority ethnic patients.

Funding, Innovation and Role of the Third Sector

- Across the group, there were multiple and repeated calls for increased funding to tackle issues in Black maternity care.
- Some participants told us that greater flexibility around budgeting and spending should be permitted to Trusts. There were suggestions that this would allow better ‘creativity’ and the ability to more readily meet the needs of the local population through innovative solutions. Others raised serious concerns about the loss of ringfenced funding for maternity services. Participants recommended that this be reinstated.

- There was suggestion that the third sector could be called upon to improve NHS services. Participants noted the good work being done by the third sector and suggested that the NHS could draw on their expertise, if proper funding was provided to foster collaboration. It was suggested this might be a good idea as third sector organisations tend to have closer links with those with lived experience. There was a suggestion that this could be integrated as part of the three big shifts in the 10-year health plan.
- Good practice should be more readily shared amongst services and learning should be transferred to improve services nationally. Participants suggested that this was not readily happening at current.