



The Sands Listening Project

Learning from the experiences of
Black and Asian bereaved parents

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Saving babies' lives.
Supporting bereaved families.



Foreword

December 2023

Sadly, in the UK there are stark and persistent inequalities in rates of baby death among different ethnic groups. The reason for these inequalities is complicated. Ethnicity is never separate from the wider environment in which families live. However, maternity and neonatal services are uniquely placed to have a positive and enduring impact on families' lives. With political ambition and maintained focus through research, policy and practice improvement, more Black and Asian babies' lives can be saved.

The voice of parents whose babies have died is at the heart of this report. Bereaved parents have a unique perspective on their care throughout pregnancy and postnatally. The Sands Listening Project hears specifically from bereaved Black and Asian families, learning about their experiences, good and bad, and their view of what needs to change.

The stories in this report highlight barriers, biases, and poor care, which might be contributing to inequalities in baby deaths in the UK. The report also shines a light on care that works well. There is important learning for those organising, funding and delivering care.

Above all, we would like to thank all the parents who so generously and openly shared their experiences with us. We would also like to thank the many individuals and organisations who supported this work, including Alicia Burnett for helping us to raise awareness, and AMMA Birth Companions and HOPE Bereavement Support CIC for their help in engaging families.

We owe particular thanks to the members of the Project Involvement Group, a collaboration of bereaved parents and specialist Sands bereavement staff from Black and Asian communities, whose insights and honest feedback have helped shape this project at every stage.

Through this project we have made many new connections and strengthened existing ones. These relationships will be invaluable as we continue to work together to ensure inequalities in pregnancy loss and baby death are reduced.

Clea Harmer,
Chief Executive, Sands

Content warning

This report covers areas that can be difficult to read about, including racism, pregnancy loss and the death of babies.

If you need support, the Sands National Helpline provides a safe, confidential place for anyone who has been affected by the death of a baby.

Whether your baby died long ago or recently, we are here for you. The telephone helpline is free to call from landlines and mobiles on **0808 164 3332**. You can also email the team at helpline@sands.org.uk, or use Sands support chat via our website sands.org.uk.

If you feel you need specialist mental health services, please ask your bereavement midwife or your GP for a referral.

If you are worried about your own or your baby's health, then please speak to your health professional.

While information about risk for different groups of people is important to understand the overall picture, it does not tell you everything you need to know about your own or your baby's personal risk. There are many factors that can affect the risk of an individual's baby dying, and those factors can be complex and sometimes include things that people cannot change.

If you are worried about your personal risk, then please speak to your health professional.

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There's just a general lack of understanding still, after the generations and generations of people giving birth, that it doesn't look the same for everybody.

**Mother to a baby who died at 20 weeks
(Mixed white and Black Caribbean)**

Racism is real. And it is something that I definitely have experienced. [...] And I think unless it is challenged and named, and people who are allies also speak to it, then it does filter down to how people treat patients from marginalised communities. Because it's left unchecked. And they carry the same sort of opinions and beliefs and attitudes towards the general public. And that's going to have a massive impact on care and treatment and experiences.

**Participant who experienced a miscarriage
at 16 weeks (Black African)**

Use of language and key terms

Definitions of miscarriage, stillbirth and neonatal death are available on our website.



Bereaved parents and families – these terms are used throughout this report to describe participants, as we know they are acceptable to many of the people we support at Sands. However, we understand that not everyone who experiences pregnancy loss or the death of their baby wishes to be referred to as a parent. Where a preference for alternative language has been shared by a participant it is used when referring to their contributions.



Ethnicity - is a form of collective social identity which encompasses elements of physical features (such as skin colour and hair texture), language, culture, shared history, and common ancestry. It is socially constructed and dynamic; identities and meanings are shaped by ethnic groups' own members and wider society. Data on ethnicity is based on self-declaration by adults and, for children under the age of 12, guidance from the child's parent, guardian or carer. The two-stage approach to categorising ethnic group used in this report is based on that used by the Office for National Statistics. This report refers to ethnicity not race, in line with the language used during data collection and reporting. We do not use collective terms such as Black, Asian and minority ethnic (BAME), which emphasise certain groups and exclude others, while also masking differences between groups. Where it is necessary to refer to broad categories to describe inequalities, we refer to 'minoritised ethnic groups' to recognise that individuals have been minoritised through social processes of power rather than existing in distinct statistical minorities.



Women and birthing people – is used when discussing the whole birthing population, to include individuals who do not identify as women. When discussing our findings, we use gendered language as appropriate to reflect the identity of individual participants.

Project summary

What we already know

In the UK, reports show that rates of pregnancy loss and baby deaths are higher among Black and Asian babies compared with white babies. These differences have been evident for decades, yet there has been little progress in addressing them.

What we wanted to learn and why

We wanted to hear directly from Black and Asian bereaved parents about their experiences of maternity and neonatal care in the UK – what they felt worked well and where care could be improved. With this knowledge we aim to support safer and more positive experiences and, ultimately, save babies' lives.

How we listened to parents

Between March and September 2023, we used interviews and focus groups to learn about the maternity, postnatal and neonatal care experienced by Black and Asian bereaved parents. We heard from 56 parents whose babies died during pregnancy or shortly after the birth since 2016. By focusing on more recent experiences, we aimed to learn about what care is like in the UK today.

What we learnt - key themes and findings

Half of the parents who took part believed that they had received worse care or been treated differently by healthcare staff because of their ethnicity. Parents described a range of safety issues that fell within four key areas of care:

- 1. Being listened to and heard** – Just over half of all parents described healthcare professionals not listening to them or dismissing their concerns, with some linking this to racism or stereotyping. Limited contact with care providers and unclear care pathways made it hard for some parents to know where to go for help when raising concerns.
- 2. Personalised, joined-up care** – Poorly co-ordinated care, involving lots of different healthcare staff, led to delays and errors for some parents. Hostile attitudes and stereotyping from some healthcare staff made it harder for some parents to develop trusting relationships with the many different people involved in their care.
- 3. Communication about safety and risk** – Many parents felt they were not given the information they needed about safety and risk, including about how their ethnicity might affect their pregnancy and the care they were offered. Some parents described feeling anxious when their ethnicity was highlighted as a risk factor but did not lead to enhanced care.
- 4. Safety and learning** – Around a third of parents described a review or investigation having taken place. Just over half of these indicated they had been involved in the process, with most describing negative experiences linked to complex and ineffective review processes, errors and delays, poor communication, and a lack of candour and support.

Next steps

This project helps us understand how systemic issues, along with poor practice and discrimination from some healthcare professionals, may lead to less safe care, with devastating consequences for some Black and Asian families. Concerted effort and targeted action are needed across Government, NHS and other key organisations to make care safer and more equitable in order to save Black and Asian babies' lives.

Background

In 2021

4,870 

babies in the UK were stillborn or died within 28 days of being born.¹

An individual's personal risk of their baby dying can depend on multiple factors, including those related to health and wellbeing, and things that people cannot change, such as their age or where they live.

Data comparing outcomes for different ethnic groups in the UK show that Black and Asian babies are more likely to be stillborn or die in the neonatal period compared with white babies.^{1,2}

This difference is a key factor for decision-makers and care providers to consider when caring for families or planning the provision of services.

Governments across the UK have expressed their commitment to reduce baby deaths. In recent years, previous progress in reducing mortality rates has slowed and even reversed.¹ Rates among babies from minoritised ethnic groups and more deprived backgrounds remain persistently higher and slowest to improve.^{1,2}

Research by Tommy's has shown that Black women in the UK are more likely to experience miscarriage compared with white women.³ However, miscarriages are not systematically counted and reported, which conceals the full picture of pregnancy loss and related inequalities across the UK.⁴

Rates of baby death in different ethnic groups

In 2021 in the UK

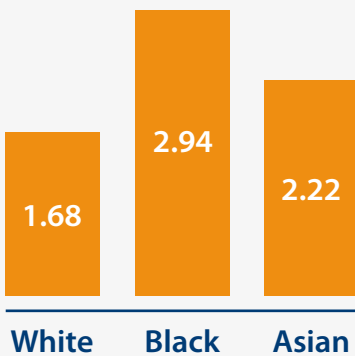


Black and Black British babies were over twice as likely to be stillborn (7.52 per 1,000 total births) compared with white babies (3.30 per 1,000 total births).²



Asian and Asian British babies were over 50% more likely to be stillborn (5.15 per 1,000 total births) compared with white babies.²

Neonatal death rate



The neonatal death rate among babies born at 24 weeks gestation and over was the lowest among white babies (1.68 per 1,000 live births) and highest amongst Black and Black British babies in 2021 (2.94 per 1,000 live births). Neonatal death rates were also significantly higher among Asian and Asian British babies (2.22 per 1,000 live births).²

If, in the period 2017-2021, stillbirth and neonatal death rates for Black and Asian babies had been the same as for white babies,

1,704 babies would have survived.

Sands-funded research has shown that health inequalities in relation to UK maternity outcomes have been known for over 70 years, yet we still lack effective evidence-based interventions to reduce the disparities.⁵ The deeply concerning conclusions of multiple recent inquiries into maternity safety in England^{6,7,8,9} and Wales¹⁰ clearly demonstrate that much more can and must be done.

Black, Asian and mixed ethnicity women and birthing people have reported systemic issues and discrimination when navigating maternity and neonatal care in the UK.^{11,12,13} Addressing inequalities in care is central to addressing inequalities in outcomes.



Listening to parents

Between March and September 2023, we used interviews and focus groups in a range of formats to learn about the maternity, postnatal and neonatal care experienced by Black and Asian bereaved parents. We wanted to hear from parents whose babies had died at any stage of pregnancy or within 28 days of the birth since 2017. By focusing on more recent experiences, we hoped to learn about what care is like in the UK today.

56 Black or Asian bereaved parents (47 mothers and 9 fathers)

took part in the project by sharing their experiences of pregnancy loss or baby death between 2016 and 2023. One mother attending a focus group had experienced multiple losses, with the most recent falling just outside the project timeframe, in 2016. Her experiences were included in the analysis, providing useful insight into how maternity and neonatal services have changed over time.

34 participants experienced the death of their baby during pregnancy: 16 experienced their loss before 24 weeks (miscarriage) and 18 after 24 weeks (stillbirth).

For 22 participants, their baby died after birth. In all but one case, this was within 28 days of their baby being born (neonatal death). One mother, whose baby died two and a half months after birth, asked nonetheless to share her story, as she believed her maternity and early postnatal care was a significant factor.

28 (50%) were from an Asian or Asian British background.

21 (37.5%) were from a Black or Black British background.

7 (12.5%) had a Mixed Black or Mixed Black British background.

Figure 1 provides more detail about participants' specific ethnic groups.

Figure 1 – Participants by ethnic group

Ethnic category	Number of participants
Asian, Asian British	28
Bangladeshi	3
Indian	15
Pakistani	7
Any other Asian background	3*
Black, Black British	21
Black African	17
Black Caribbean	4
Mixed Black, Mixed Black British	7
Mixed white and Black African	1
Mixed white and Black Caribbean	6
Total	56

* *Chinese, Filipino, British Mauritian*

Anonymised transcripts were generated from voice notes, email exchanges, and interview and focus group recordings. These were then analysed to identify key themes.

While we have not been able to quote every parent in this report, all the accounts we heard influenced the analysis in important ways. Where we have shared the quotes or views of individual participants, we have included information about their relationship to the baby or pregnancy, their experience of loss, and their ethnic group, as self-declared at the time of signing up to the project.

More information about participant characteristics and how we listened to and analysed their experiences can be found under Appendices A and B.

Findings

Introduction to findings

We heard a range of experiences spanning pre-conception, early pregnancy, maternity, postnatal and neonatal care. Parents shared examples of excellent care, and we have included some of these to acknowledge the commitment, sensitivity and skill of many healthcare professionals. Importantly, these positive experiences illustrate what existing good practice looks like. However, the main focus of this report is learning from the stories where parents had concerns about the quality of their care, linked in some cases to their ethnicity or background.





Parents shared different views on whether their ethnicity had been a factor in the care or treatment they received. Of the 48 parents who spoke directly on this topic:

- 6** said they were unsure whether they had been treated differently because of their ethnicity.
- 14** stated explicitly that they did not think their ethnicity had affected their care.
- 28** believed that their ethnicity had affected how they were treated, with some sharing specific examples of racism and bias on the part of healthcare staff.

In addition, some parents who had worked within the NHS provided examples of 'behind the scenes' racist behaviours and language which can affect the care and safety of patients if not addressed.



The key findings are discussed under four themes:

-  1. Being listened to and heard
-  2. Personalised, joined-up care
-  3. Communication about safety and risk
-  4. Safety and learning

Throughout, we draw on parents' accounts to consider how an individual's ethnicity or background might affect how these four key principles of care are applied.



Being listened to and heard

Parents have the highest stake in their baby's care and can contribute crucial information about their own and their baby's health, including signals that something may be wrong. High-profile investigations into failing maternity units have exposed the impact of dismissing parents' concerns.^{7,8} UK maternity policies link listening to women and birthing people and their families to safer and more positive experiences of care.^{14,15,16}

1.1 When this is done well

We heard some extremely positive stories of healthcare professionals who were remembered by parents as having listened to them with empathy and taken their concerns seriously.

Every time I called the maternity ward assessment unit, I was just told, 'If you're concerned, come in.' You know, so I'd been there literally every other day, they'd put us on the monitoring machine, and my daughter's heartbeat was fine. So it was very reassuring. Even when I went there, I'd always say, 'I'm so sorry.' And the staff there were like, 'Please, don't at all say sorry, it's what we're here for.' Very reassuring, comforting, made me feel at ease, like they're there for all the pregnant mothers experiencing any concerns.

Mother to a baby born at 31 weeks who died neonatally (Asian/Indian)

Parents appreciated it when healthcare professionals gave them their time and full attention, making them feel seen and heard. Many described how these kinds of interactions could improve their experience, even when it was not possible to guarantee their baby's wellbeing.

Every single person I had interactions with just made my second pregnancy a lot easier emotionally. Obviously I still had it in the back of my mind that it could happen again. But there was a lot of reassurance about, you know, we can certainly give you extra scans, support. Obviously, not reassurance that we'll give you a healthy baby, but we'll do what we can to make it easier for you.

Mother to a baby who died at 25 weeks (Asian/Bangladeshi)

1.2 When parents' concerns are not listened to

31 

parents who took part in this project described healthcare professionals not listening to them or dismissing their concerns, which they often linked to a lack of empathy.

13 

of these parents indicated that their concerns had not been listened to because of racism or racist stereotyping on the part of healthcare professionals.

This includes participants who had a good knowledge of their health needs and rights, and were able to express themselves clearly. Some 'expert patients' with experience of working within the NHS – including nurses and midwives – described having to fight to be heard and have their concerns taken seriously. They wondered how others without their skills and ability to navigate the healthcare system would manage.

1.2.1 Concerns dismissed as anxiety, excessive worrying or 'paranoia'

Some mothers described how their concerns were dismissed by midwives and doctors and characterised as anxiety or 'paranoia'. This included mothers with a known history of mental health illness or baby loss. Both factors are associated with increased rates of pregnancy loss and baby deaths, and should prompt heightened vigilance and, in some cases, enhanced care.

Case Study 1



This case study describes the experiences of A, a mother of Asian/Pakistani ethnicity. Her symptoms and recurrent fetal movement concerns were dismissed as the effect of anxiety, despite her having previously experienced a stillbirth and small for gestational age baby, because scans and other investigations seemed to show that her baby was developing well.

After repeatedly raising concerns about her baby's movements, A was referred to the 'vulnerable woman's midwife' and actively discouraged from coming into the maternity unit.

[The midwife] told me that I shouldn't be going in with reduced movements. If I was to go in again with reduced movements, [...] they would be thinking about sectioning me, because I kept going in.

A went on to develop pre-eclampsia, and was told by a consultant that her high blood pressure was her own fault.

She said that I am doing that to myself. I am stressing myself out.

After a midwife stepped in and reviewed all of A's results, her baby was born early by emergency caesarean section – alive, but in poor health and with severe growth restriction.

If it wasn't for that midwife who decided to pull everything apart. Every single CTG. Pull out the blood profile. I would have had a dead baby [...] I would have had another stillbirth.

Seven Asian mothers described how Asian women were often assumed by healthcare professionals to 'exaggerate' their health concerns.

When I'd go in for a check, you just feel like they're treating you as if, like the stereotype of, 'Oh, it's an Asian woman. They're always worrying', you know, 'They're always exaggerating things'. And even if that is a stereotype, even if you do think that, you should still take it seriously, no matter what. Because [...] this a child's life.

Mother to a baby born at 37 weeks who died neonatally (Asian/Pakistani)

One mother of Asian/Bangladeshi ethnicity whose baby died at 20 weeks shared the view that Asian women were sometimes 'raised not to be confrontational'. For her, this meant it could be harder for them to voice their concerns, meaning healthcare professionals really needed to listen to what Asian women were saying and take their concerns seriously.

The account of one mother of Asian/Pakistani ethnicity who had worked within the NHS confirmed that some maternity professionals will openly express harmful stereotypes about Asian mothers. For example, she had heard Asian mothers repeatedly referred to as 'princesses' to imply that they were high maintenance or entitled, which may lead to their views being discredited and not listened to.



1.2.2 Accessing care

A number of parents described how the attitudes and language they encountered when initially sharing their concerns over the phone discouraged them from attending their maternity unit for further tests and checks.

*Language has just been so important. Especially [...] at triage, when I was calling, and I was having these Braxton Hicks, and I was getting told, 'Well if you feel you need to come in.' [...] Which questioned a lot for me, in terms of, 'Actually, do I need to go in?' Because the professional's actually saying, you know, I've kind of told you what you need to know. [...] It should have been, 'We have got a long wait, but we **advise**'. And I think that's very important as well.*

Mother to a baby who died at 28 weeks (Asian/Indian)

So in regards to the first pregnancy, when it was quite late, and I went to [the Early Pregnancy Unit]. The nurse that we actually seen that took my blood pressure was the nurse that I spoke to on the phone a few hours prior to turning up. And she was quite rude on the phone to me to begin with. You know, 'There's nothing serious, bleeding's quite normal', like, 'Come tomorrow'.

Mother to babies who died at 9 and 8 weeks (Asian/Indian)

A number of parents described particular challenges raising concerns and accessing the appropriate care in early pregnancy, when it was not always clear who was responsible for their care and whom they should speak to if worried about their own or their baby's health.

The first 12 weeks I bled constantly. And trying to get help or get someone to take me seriously during that time was really, really difficult. [...] I felt like I was just constantly brushed off. Nobody was interested in why I was bleeding or what was going on. It almost felt like they assumed I'd just had a miscarriage and I would get on with it. I remember being sat in A&E and crying my eyes out. [...] They couldn't scan me in the A&E, the [Early Pregnancy Unit] just weren't interested in seeing me. [...] It's a very scary thing when you start bleeding and you're pregnant, especially if you've had a loss previously. [...] It was a really awful experience.

Mother to a baby who died at 12 weeks (Asian/Indian)

1.2.3 Investigating altered fetal movements

Several parents described how they had come into the hospital after feeling their baby's movements had slowed or changed, sometimes attending repeatedly, but that this was not investigated thoroughly.

From about 25 weeks [I was] quite concerned. You know, my baby [...] wasn't moving as much as I feel like she should have been. So I was in hospital on a few occasions. And I kind of got reassured constantly. And then I think it was about the 32 week mark at the antenatal appointment. And I was saying, you know, she feels very small, she looks small, everyone who looks at me says she looks very small. Again, was told, 'Everything's fine.' [...] And then again two weeks later at the 34-week appointment, I was again sharing concerns, 'She's small. She's not moving enough.' [...] And then it was at 37 weeks that I lost [her].

Mother to a baby who died at 37 weeks (Mixed white and Black Caribbean)

Some parents wondered why they were being told to report altered fetal movements if more was not going to be done to confirm their baby was well. Others described how having their concerns dismissed made them feel like a 'burden', and less likely to report changes in their baby's movements in the future.

They'd make me feel a bit uncomfortable with that, 'Oh, you're fine. You know you only came in that week, and the heartbeat's fine, everything's fine'. And then I just felt like a burden. To be honest. They just made me feel so uncomfortable. As if, 'Oh, she's here again'. But then why say to them, why say to the patients that, you know, 'Come in whenever you're a bit concerned'?

Mother to a baby who died at 39 weeks (Asian/Pakistani)

1.2.4 Experiences of pain

Some parents felt that stereotyping among healthcare professionals contributed to them not being listened to when they were afraid or in pain. A number of mothers described how the stereotyping of Black or mixed white and Black women as 'strong', 'feisty' or 'dramatic' had prevented midwives and doctors from recognising when they were at their most vulnerable.

I think they just could not recognise in me actual fear. They just saw this [...] feisty, strong, brown woman. [...] And actually I was so scared I couldn't speak. I was just like blank. And they kept saying stuff like, 'You're so brave. You're doing so well, you're so brave'. And I just thought, you haven't even asked me if I'm OK. Because if you had asked me, you would know that I am not OK. And that this is not bravery, this is fear.

Mother to a baby born at 26 weeks who died neonatally (Mixed white and Black Caribbean)

If you're consistently having to having to fight to have your pain seen and heard, [...] the edge is gonna tip. You know, you're going to then quite often become angry. Or if it's not angry, you know. Because, culturally, people can express things differently. And some people will minimise their own pain. And they're not getting the adequate relief that they need.

Participant who experienced a miscarriage at 16 weeks (Black African)

Several parents shared how a failure to respond to their reports of contractions and pain had led to them labouring and giving birth on their own, in the wrong place, or without the right care:

My contractions worsened and I told the midwife to get a doctor to check me because I believed I was in labour. The doctor took 3 hours to come and I was told that I wasn't in labour. At around 9:30pm the contractions worsened again and I was still on the antenatal ward. I was given gas and air for my pain and left alone. It was after visiting hours so my partner had already gone home. I stood up off my bed and my waters broke and I had pushed my first twin out. It took me about 5 seconds to realise what had happened and I screamed for help. I was immediately taken to the labour ward and suddenly everyone was taking me seriously. I felt so let down because I knew I was in labour but I was told that I was being dramatic.

Mother to twins born at 26 weeks who died neonatally (Black Caribbean)

1.2.5 Concerns about a baby's wellbeing

One mother described her struggle to have her baby's feeding difficulties taken seriously, despite repeatedly asking for help:

I had to go to the hospital, the nurse suggested that maybe my mode of feeding wasn't efficient for her to be refusing, said I should try using baby feeder or ensure she's well latched and you know all of that, but she wasn't diagnosed of any sickness whatsoever. I returned back home, tried the methods I was told to, but it still remained the same. At this point, my baby started to look so malnourished and every time I took her to the hospital to complain, they took it with levity and this got to me a lot because I just wanted her to eat and be okay. [...] The situation continued on for about a whole week. [...] I woke up to a baby that had stopped breathing one night. And when this happened, I felt like the worst had happened.

Mother to a baby born at 35 weeks who died neonatally (Black African)

This mother never discovered the cause of her baby's death, but felt that her baby was neglected, because the professionals she sought help from 'all thought it wasn't so much of a problem'.

1.2.6 Signs and symptoms of ill health in mothers

Several parents described how signs and symptoms of diabetes, high blood pressure and pre-eclampsia, and other less common medical problems had been missed, despite them repeatedly reporting their concerns and worsening health.

One mother, who experienced symptoms linked to her baby's medical condition, believed there was a delay in healthcare professionals identifying the true cause of her symptoms because they could not see past her ethnicity and diabetes as an associated risk factor:

There was clear indicators of the rash and the excess fluid. But it was all down to, well this person's Asian, they've got diabetes, it's that. When clearly it was more than that. So yeah, just raising awareness. Don't judge a book by its cover in a similar scenario.

Mother to a baby born at 29 weeks who died neonatally (British Mauritian)

Case Study 2



This case study describes the experience of B, a mother of Asian/Bangladeshi ethnicity, who developed severe pre-eclampsia and HELLP syndrome (a rare and serious pregnancy complication that affects the blood and liver).

B was pregnant during the Covid-19 pandemic. From 22 weeks, she repeatedly told midwives that she was worried about her rapid weight gain and severe swelling.

I had concerns. I went to triage, and each time I went, I was dismissed. They told me that I was young, it was my first baby, I'm fine.

Despite a family history of severe pre-eclampsia, maternity professionals sometimes linked B's frequent high blood pressure readings to anxiety.

When B attended the hospital for a scan at 28 weeks, her husband advocated for her over the phone, urging the obstetrician to examine B's legs where there was severe oedema.

I think he thought that I couldn't advocate for myself. [...] I kept saying, 'Look, they're not listening to me. They're not listening.'

At this point, the severity of B's symptoms was recognised. The scan revealed her baby was very small, and there was reduced blood flow to the placenta.

And they said, 'Oh you didn't tell us you were concerned.' And I thought, I've been in every other week. And disregarded.

A test for pre-eclampsia was finally done. B was now experiencing headaches, visual disturbance and 'every symptom going'. Nonetheless, the doctor's diagnosis of multiple organ failure and the need for immediate delivery came as a shock.

B's baby was born at 28 weeks via caesarean section. Despite initial positive signs, his condition deteriorated rapidly after he developed necrotizing enterocolitis, a severe gastrointestinal infection that mostly affects premature babies. B and her husband made the difficult decision not to resuscitate their baby to avoid causing him more harm.



Personalised, joined-up care

Personalised and well-coordinated care is an important factor in safe and positive maternity and neonatal experiences.^{14,15,16,17} When this is achieved, care plans incorporate what is important to families, as well as taking into account individual risk factors that may change over time. Maternity policy from across the UK links continuity of carer, where one lead professional or a small group of known midwives or doctors provide care throughout the whole maternity experience, with personalised care and improved outcomes.^{14,15,16,17} Women and birthing people from minoritised ethnic groups have been identified as a priority when rolling out midwifery continuity of carer in England, to promote safer and more equitable care.¹⁴

2.1 When this is done well

A number of parents described in very positive terms healthcare professionals who had made time to connect with them and provide personalised care that accommodated their individual needs and preferences. Some could identify individuals who had advocated for them and provided a consistent point of contact throughout their experiences of care.

I'd met [my consultant] at 16 or 17 weeks [...]. From that point on, she was my advocate. She had met with me as many times as I needed to [...] And because of the pains that I was still experiencing at 16-17 weeks, she'd really helped push for as many scans as needed. She had booked me in for an appointment to see her just so she could listen to the heartbeat herself. It wasn't until about 22 weeks when I had said that, you know, I'm feeling less movements. [...] And she'd seen me straight away. She was brilliant. [...] And she just carried on, making sure that I was being seen to as and when I needed. And that had really helped me.

Mother to a baby who died at 25 weeks (Asian/Bangladeshi)

While it was clear that continuity of carer could support positive, joined-up care, we also heard about healthcare professionals who had provided personalised care over the course of just one encounter, through simple gestures and a warm and empathic approach.

I can't remember her name. But she was a lovely midwife. Very warm. You could see in her face that she had empathy. She was really, really nice. I felt really comfortable with her. If I was crying, she'd give me a hug. [...] She explained everything. She said I didn't have to rush to make decisions. She was [...] a really nice midwife.

Mother to a baby who died at 20 weeks (Black Caribbean)

2.2 Fragmented care with limited continuity of carer

Many parents' accounts included examples of fragmented and sometimes impersonal care from a stretched workforce. These issues were heightened when care was split across different NHS Trusts or teams, with some parents explaining how poor referral or communication systems within and across teams had led to unsafe care. Over a third of parents highlighted early pregnancy as a time when they had particularly wanted more consistent contact with maternity professionals, with some struggling to access the care they needed.

Very few parents felt they had had any meaningful continuity of care from midwives or obstetricians. As a result, most parents found themselves having to repeat information and re-establish relationships at each care encounter. For some families, this meant that important signs and symptoms were missed.

There's always been a different person, there's never been the same person. Even when you're meant to be consultant-led. You never see your consultant. So every single time it's always someone different.

Mother to a baby born at 29 weeks who died neonatally (British Mauritian)

You're seen by so many different doctors and junior doctors, and so on. And it was changing all the time, and having to repeat myself over and over again. And, you know, repeat why I need to have this medication and not that one, and so on.

Participant who experienced a miscarriage at 16 weeks (Black African)

When I went for my check up with my midwife, I said, 'What kind of movement am I looking out for? It's not regular, it's not constant'. [...] At this point, I do need to mention that [...] I wasn't seeing the same midwife designated in my care plan. Not having that continuity and rapport with the same midwife definitely was an aspect too where things [weren't] being picked up quicker.

Mother to a baby who died at 39 weeks (Asian/Pakistani)

Some parents described receiving greater continuity of carer after an experience of loss. However, others with a history of loss were not able to access specialist support in the early stages of pregnancy, contributing to increased anxiety and, in some cases, delays or omissions in care.



Case Study 3



This case study shows how a series of errors from early pregnancy contributed to the death of twins born to C, a mother of mixed white and Black Caribbean ethnicity, despite her working hard to access the care she knew she needed.

In 2022, after two miscarriages, C discovered she was eight weeks pregnant with twins. At her first midwife appointment, she explained that she had previously had surgery on her cervix and would need a scan to check its length. Between 10 and 17 weeks, C repeatedly called her community midwives asking when this scan would take place. Each time, she was told she had been referred.

At 17 weeks, C contacted the scan department herself and an emergency scan was arranged for two days later. It showed that her cervix was short for a twin pregnancy, and an appointment was made for her to see a consultant obstetrician the next week. However, on the day of this appointment, it was cancelled and rescheduled for a month later.

At 22 weeks, the day before she was due to meet the consultant, C went into premature labour. The next day, her son and daughter were born.

But there was nothing they could do. They were too small. And we wasn't in a hospital that could support them.

A review found that there were nine errors of neglect in C's care:

And that's the hardest point. [...] the reality of it is, I can't blame one person. It's the system that let me down.

C has since learnt that early errors in documentation led to her pregnancy being mis-categorised as 'low risk', meaning that she did not receive the appropriate care. Poor communication between departments and confusion about who was responsible for her care contributed to a series of cancellations and delays.

If the NHS just listened to me. And just put my appointment through when I was constantly asking. [Crying, finding it hard to speak] If they had the notes there properly. I wouldn't have been treated that way. They neglected me. And all I get from it is, 'I'm sorry'.

Several parents explained that it could be more challenging to establish personal relationships with healthcare professionals as someone from a minoritised ethnic group. Some linked this to mistrust on their own part – the result of poor experiences as well as historic abuses and injustices within healthcare. Other parents described how stereotyping or racist views could be a barrier to healthcare professionals seeing them as an individual.

Every time I've had a new midwife through my pregnancies [...] the initial kind of meeting always feels a bit weird. Because of being an ethnic minority, and also Muslim and the way I dress. But then once that initial ice is broken, and people understand like, no, I can, you know, communicate. I can, like, pass my message across. [...] Once that initial kind of thing is over then it's OK.

Mother to a baby who died at 31 weeks (Asian/Pakistani)

Fears that new healthcare staff could hold harmful stereotypes or racist views may add another layer of complexity and anxiety to Black and Asian parents' interactions with maternity and neonatal professionals.

3



Communication about safety and risk

Good communication is central to effective maternity and neonatal care. Maternity policy across the UK emphasises the importance of providing women and birthing people with unbiased, evidence-based information in appropriate languages and formats, and creating opportunities for discussion, so that they can identify potential problems and make informed choices about their care.^{14,15,16,17}

3.1 When this is done well

Around a third of parents described having experienced, at some stage in their care, a detailed and personalised discussion about their safety or risk factors, with some healthcare professionals taking a 'whole person' approach.

I've got polycystic ovaries, which makes you higher risk of having gestational diabetes as well as my ethnicity. And I had fairly positive conversations with my midwives about things like that. [...] They kind of explained it, but they didn't necessarily highlight it [was] because of my race. They just said, 'You as an individual are at higher risk.' I think that's the thing that sometimes people forget. Yes, I am Indian, but I'm also a human being, and I'm female, and I'm a person. And [...] whilst it makes up who I am, it doesn't define me to the point of, I can be stuck in a homogeneous group with everybody else who fits that category.

Mother to a baby who died at 12 weeks (Asian/Indian)

Several parents described how important it was that healthcare professionals offered something positive when sharing bad news and supporting them to make difficult decisions:

[The Consultant] would sometimes come up to the ward when I went into the side room, and she would sit with me for like 40 minutes, just asking me what I wanted to do. And even when I said to her, you know, 'I just want to go home' or 'I don't want to be here, and I just wanna go home to my kids. I just want this to be over with.' [...] She'd give me the realness of the situation, but she wasn't pushy. She would sit there, let me say what I wanted to say, and she would say, 'Yes, OK, you can, by all means, if you want to carry on, we'll support you. But you know, I have to tell you that there is another side to it.' But it's the way she said it.

Mother to a baby who died at 20 weeks (Black Caribbean)

3.2 Parents need more information and time to ask questions

Many parents found that they had limited opportunities to ask questions or have detailed conversations with midwives and obstetricians. This left them feeling poorly informed about their own or their baby's health, and what was happening in their care.



The nurses seemed so uncaring of all the times I went for checkups, (except for very few) it was like they weren't expecting you to ask questions, you should already know all about the pregnancy so even trying to relate with them about how I felt was like a big deal.

Mother to a baby born at 35 weeks who died neonatally (Black African)

What needs to be improved would be answering questions, because it was my first and I definitely had a whole lot of questions that needed answers, but only few did I get answers too. I had to do the answering myself by looking up the web or asking friends and family about their experiences.

Mother to a baby born at 36 weeks who died neonatally (Black African)

Several first-time parents described seeking out information themselves, with some expressing frustration and disappointment with the limited contact they had with midwives and doctors in early pregnancy.

It felt very much like [...] but I don't know anything about having a baby. What am I supposed to do for these first few weeks? And so you're just sort of frantically Googling. And that's oftentimes not the greatest thing to do. It's just like a world of anxiety. But it does feel like there is a portion of time where you just sort of get missed and forgotten about. When actually you just need someone to be there and say, 'I know that this is new to you. How can I help?'

**Mother to a baby born at 26 weeks who died neonatally
(Mixed white and Black Caribbean)**

3.3 Communication and language

All parents but one chose to be interviewed in English for this project, even when this was not their first language. In one focus group, there was discussion among participants about their relative advantage as confident English speakers when navigating complicated systems and information.

I absolutely feel sorry for women who are [...] an ethnic minority if English is not their first language. [...] Look at what we've got. We've got well-spoken women here who are born and brought up in the UK. We can talk about our experience, but I do feel sorry for the girls, for the ladies who have nothing.

Mother to a baby who died at 39 weeks (Asian/Pakistani)

One mother, who was seeking asylum at the time of her loss, reflected on how important it was that she could understand English when receiving complex information about one of her twins' health conditions.

What helped was also the fact that I could understand, I can speak English. I can read and write English. [...] But sometimes, I just imagine if I could not speak English or if I could not read. Or if my understanding of English was not so good. It would have been a bit difficult for me to understand the situation at that point in time.

**Mother to twins born at 37 weeks, one of whom died neonatally
(Black African)**

One mother of Asian/Pakistani ethnicity who chose to be interviewed in Urdu described how she was seen at three different hospitals when trying to access a scan following bleeding at 12 weeks. At no point was she offered a professional interpreter, with healthcare staff relying on her husband to explain to her what was happening. She later requested to see her notes and was upset to see that the written record did not agree with what she had understood to be happening at the time. This discrepancy further undermined her trust in those involved in her care.

3.4 Inaccurate or insufficient safety information

A small number of parents gave examples of misleading or inaccurate information they had received from midwives and doctors, which meant that they did not know when to seek help. One mother described how she had delayed seeking help for reduced fetal movement because she was told by a midwife that the reduced activity was normal because her baby had 'no space to move' so late in pregnancy.

I did repeat this to the bereavement officer, and they said, 'That should not have ever been said to you.' Purely because that gave me the false [reassurance] [...] That was just stuck in my head for those last couple of days. I could have had an earlier intervention.

Mother to a baby who died at 39 weeks (Asian/Pakistani)

Another mother described how stereotyping on the part of her midwife meant that she did not receive detailed and accurate information about healthy diet and risks.

Going back to my community midwife. You know how they're supposed to be first port of call and everything like that. And she told me that I was overweight and things. One of the things she said to me was that I need to stop eating oily food. I need to 'stop eating oily curries.' Those were her exact words. My partner was there with me, and I was kind of at a loss for words at that point. And my partner [...] said to her, 'Well, why are you making the assumption she's eating foods like that?'

Mother to a baby who died at 25 weeks (Asian/Bangladeshi)

Experiences like these may undermine parents' trust in the information provided by healthcare professionals, making them less likely to seek their advice in the future.

3.5 Differences in information

One bereaved mother of mixed white and Black Caribbean ethnicity described how, in a review of her care, it was highlighted that the information she had received in the form of an antenatal wallet was different from that given to white families in her area, although this was not judged to be a factor in her own loss. The mother explained that the written content shared with Black and Asian parents had a stronger emphasis on how families can advocate for themselves, with less detailed information about signs, symptoms and risks. It is important that Black and Asian families know how to raise concerns and are supported to challenge unsafe practice. However, this mother felt that such advice should be given in addition to the key safety information that should be provided to all families by the NHS. Maternity services have a clear responsibility to ensure that all appropriate safety information is communicated to all families and that additional information or advice is always shared alongside up-to-date safety information.



3.6 Discussing ethnicity and risk

3.6.1 Conversations were limited and not personalised

Many of the parents who took part in this project were aware of the association between ethnicity, certain pregnancy complications, and higher rates of baby deaths. However, very few recalled discussing ethnicity and risk in any detail with the professionals involved in their care.

I don't think ethnicity was ever even mentioned. It was never considered a factor in my care, I don't think. I think it should have been. [...] It never actually came up in any kind of conversation with anyone. Other than, is there a history of [...] sickle cell. [...] That was the only question I think I ever got asked, that was it.

Mother to a baby who died at 37 weeks (Mixed white and Black Caribbean)

When healthcare professionals had discussed ethnicity and risk with parents, the conversations were mostly described as lacking detail. The significance of ethnicity was sometimes implied rather than stated, and the information provided did not take account of parents' individual circumstances, characteristics, and wider clinical picture.

I'm mixed race inheritance. And [the midwife] was like saying to me, 'Oh, where you from?' [...] 'Are you African, are you Caribbean? Just tick one of them.' [...] I said, 'I'm not African.' She goes, 'Oh well, are you Caribbean?' She goes, 'Oh, a lot of Caribbeans, Africans get a lot of blood pressure problems, diabetes.'

Mother to a baby who died at 24 weeks (Mixed white and Black Caribbean)

3.6.2 A known risk factor, but no enhanced care

Some parents knew or were told that their ethnicity was considered a 'risk factor' in pregnancy but were not offered any enhanced care related to it. This could lead to confusion or doubt about whether they were receiving the right level of support.

For me, it was more to do with my ethnicity should have [...] given me a bit more of a bigger, better care plan.[...] My ethnicity should have helped, prevented what was going on. [...] I'm not a medical professional and I myself could see, I already fitted in the criteria of being at higher risk towards the end of my pregnancy.

Mother to a baby who died at 39 weeks (Asian/Pakistani)

There was some evidence that an awareness among healthcare professionals of the higher rates of miscarriage and stillbirth in some ethnic groups led to dismissive, even fatalistic, attitudes, which carried through to their conversations with parents.

Quite negative [care] from the GP in terms of [my second loss] being brushed off as just one of those things, because women from an Asian background tend to go through more miscarriages and that that was pretty much it. It was just, you know, 'Women of your ethnicity are sort of prone to going through loss'. And it almost felt to me as, 'Expect it! You know, it was brushed off as it's bad luck or one of those things, or just keep trying.

Mother to babies who died at 2 and 7 weeks (Asian/Indian)

And I've been told like, when I had the stillbirth, 'Oh, it's common in Black people, stillborns.'

Mother to a baby who died at 24 weeks (Mixed white and Black Caribbean)

The conversation referred to in this last quote took place on the postnatal ward, shortly after the mother's loss.

3.7 Information to support decisions

Several parents described how a lack of rationale and 'top-down' approach, where maternity and neonatal professionals simply told them what they should do, made it hard for them to trust the information they received when making decisions about their care.



I hear it all the time, 'Ethnicity, you got to have tests cause of your ethnicity'. [...] it's like, oh Black people, Asian people, mixed race people, whatever the case is, we're the ones have all these problems. And the white race, it's like they never get the problems. And if it does, it's like once in a while.

Mother to a baby who died at 24 weeks (Mixed white and Black Caribbean)

Case Study 4



This case study describes the experience of D, a father of Black Caribbean ethnicity whose first baby was stillborn at 41 weeks. D's story highlights the importance of maternity and neonatal professionals providing a clear and personalised rationale when supporting Black and Asian parents to make decisions about their care.

In their second pregnancy, following the stillbirth of their son, D and his partner received enhanced care from a team specialising in pregnancy after loss. In a review of what had happened in their first pregnancy, D's partner learnt that she had developed gestational diabetes, which was undiagnosed at the time, and therefore untreated.

D explained that his partner had declined diabetes screening in her first pregnancy due to a lack of knowledge and explanation. This was in the context of the Covid-19 pandemic and widespread misinformation about ethnicity and health risks.

Because we heard, especially within the Black community [...] you don't go through that [screening], because they'll just say that generally [to all Black mothers].

Reflecting on their experience, D explained why it is so important that healthcare professionals provide a rationale when making recommendations to parents from minoritised ethnic groups, particularly when ethnicity is being discussed as a risk factor.

It's like more explanation or rationale has to go in. Because, you know, a lot of people, given things that have happened in the past, aren't just gonna make the decision, 'Oh, thanks for telling me, let's do it.'

The couple had had a far more positive experience of care in their second pregnancy, with opportunity for detailed, respectful conversations with professionals.

In this pregnancy, the gestational diabetes was picked up even before my partner had it. But the rationale, even though there was fear and a lot of resistance from us, you know, we also understood it. Because it was explained to us. [...] So I just feel that discourse can be there, and it does really make such a difference to actually be informed. Because it empowers us as parents, you know, to really make the best decisions for baby.



Safety and learning

When a baby dies, reviews and investigations are an important opportunity to provide answers for parents about what happened, learn where care could have been improved, and identify actions to increase safety. The information that families provide is vital to piecing together a full picture of what happened.

Some UK maternity policies recognise that working with parents in reviews and investigations is a key part of safety work, and that NHS Trusts should respond effectively with empathy and candour to families who raise concerns about their care.^{14,15} The National Perinatal Mortality Review tool¹⁸ has been introduced in NHS maternity and neonatal units to support standardised perinatal mortality reviews, with embedded opportunities for parent contributions. However, in a 2023 Sands survey exploring the experiences of bereaved parents in the UK, 45% of all parents said that they were not aware of a review taking place, and 22% of parents bereaved in the last three years did not know a review was happening.¹⁹

Of the parents who took part in the Listening Project, 20 described some kind of a review having taken place, with 11 indicating that they had been involved in the process to some degree, or at least had the findings fed back to them. The experiences shared show how the issues faced by some Black and Asian parents throughout their care can carry through to processes of review and investigation, in particular, not being listened to, poor communication, and a lack of trust.

4.1 When this is done well

Two mothers shared positive experiences relating to the review process. One described how a proactive approach to seeking feedback, quick response to her concerns, and good communication, represented a 'glimmer' of positivity following her stillbirth.

After I'd had my stillbirth, the bereavement midwife had given me a survey questionnaire [...] where I was able to put down any concerns or complaints that I did have. And that was looked into quite quickly, I want to say within four to six weeks. And obviously I'd mentioned my community midwife and how she'd stereotyped, how I was thrown back and forth and things like that. And [...] I was spoken to about it very quickly and something was done about it. So it's just a little positive.

Mother to a baby who died at 25 weeks (Asian/Bangladeshi)

Another mother explained how an individual midwife with a commitment to safety and candour helped make sure a review into her care was done well and centred on her needs and priorities.

I made a complaint with PALS. but the lady dealing with the investigation, she said to PALS, 'Put yours on hold, because by the time I've done my report, it's just gonna answer all the things that you're going to go and do anyway'. And [...] although it's an internal investigation, she's really focusing on making sure that there's an outcome for me in this situation. Because I still want to have more children. But I want to feel safe enough to.

**Mother to twins born at 22 weeks who died neonatally
(Mixed white and Black Caribbean)**

4.2 Not being involved in reviews or investigations

Many parents said they were not involved in review and investigation processes, although the underlying reasons for this were varied. Some parents were unsure whether there had been a review of their care. Others said they did not want to engage with a system that had failed them and take part in a review that they perceived would have little benefit for them and their family.

There wasn't any review to start with because they weren't of great help when she needed it most so why try to look into the care received after she's gone.

Mother to a baby born at 35 weeks who died neonatally (Black African)

A number of parents, who were unhappy with their care or the outcome of a review, described not having the energy or time to initiate a complaints process that was likely to be traumatising and involve a 'fight' to be heard.

Where is my proof? What am I going to say? How do I raise it? And again, it's about bringing up something that. [Crying] I've had a horrible life-changing experience, quite traumatic. But then. It's like fighting, isn't it? It's like fighting. It's like fighting for something that no-one's gonna believe.

Mother to a baby who died at 30 weeks (Asian/Pakistani)

Others chose not to complain about their care, as they did not want to attribute blame, or harm an already struggling healthcare service.

The doctor and nurses did what they could, and I actually take the blame for her death even though it's hard living with it.

Mother to a baby born at 33 weeks who died neonatally (Black African)

I remember saying [to my husband], 'Shall I complain? Because it just makes no sense that this had happened. [...] And he said, 'You're gonna complain, and you're gonna affect a system that's already failing. And already crumbling. So why are you gonna cause them more harm?'

Mother to a baby born at 28 weeks who died neonatally (Asian/Bangladeshi)

For these parents, review and complaint processes seemed to be associated primarily with identifying who was responsible for a baby's death. This might reflect a lack of detailed information from maternity and neonatal professionals about the broader aims of improving safety and the quality of care and finding answers for parents.

4.3 Negative experiences of reviews or investigations

Seven parents described negative experiences linked to complex and ineffective review processes, errors and delays, and a lack of candour and support. For some of these parents, such experiences reduced their trust in the review processes and findings, and made them feel that understanding what had happened to their baby was not a priority for the hospital staff involved.

I kept trying to be part of the conversation. But it was almost like [the doctor] closed me out. [...] We tried to get some of our questions asked. Because we thought we were going to have that space. And I think they probably answered about two of them. [...] And those questions were never really answered. We just had to try and answer them ourselves, you know, in different ways.

Father to a baby who died at 41 weeks (Black Caribbean)

One mother was contacted by a hospital representative two and a half years after her baby died to let her know they were going to review the care given.

And I was shocked because it's been two years. How are you even gonna remember? It's too late. But she said, 'Oh, because of COVID, and it's just been a backlog. Usually we're meant to do it within three to six months.' And I was just shocked that [...] finally they're having a meeting. With all the doctors, consultants, cardiologists, you know, whoever is involved. Now they're sitting down and discussing what happened. But that should have happened straight away when it was fresh. I just felt like we were kind of pushed to a side, forgotten.

Mother to a baby born at 37 weeks who died neonatally (Asian/Pakistani)

Following her miscarriage at ten weeks, one mother of Asian/Indian ethnicity had wanted her baby to be sent for cytology. She was given several different reasons for why this could not be done before eventually discovering an error had been made and covered up by the doctor involved. Several other parents described errors in care (for example, the loss of a placenta or incorrect paperwork) that had prevented them getting answers about why their baby died. A number of parents described feeling disappointed or let down by the outcome of review processes and a lack of candour and accountability on the part of hospital staff.



Case Study 5



This case study shares the story of E, a mother of mixed white and Black Caribbean ethnicity, whose baby died after being born at 26 weeks. It shows how parents who wish to challenge review findings and get answers about their baby's care may need considerable time, energy and resources.

E felt her waters break when she was 26 weeks pregnant and gave birth to her daughter via emergency caesarean the next day. Her baby died five days later, after having haemorrhages in her brain and lung.

E experienced poor quality and insensitive care throughout. As a qualified nurse, she was shocked at the lack of empathy she encountered. After reviewing the medical notes, E and her husband became concerned about the care their daughter had received and poor staffing levels in the unit.

The neonatal nurses and midwives had documented, 'Waiting for the doctor, baby looks like this' [...] They were spotting that something wasn't right, but they just couldn't do anything because they were waiting for medical staff.

E and her husband made a complaint to the hospital. During the review that followed, they were frustrated by a lack of candour and empathy from hospital staff, and the contradictory information they received.

They've spent so long just trying to hide things [...] and defend themselves, that they've forgot that actually, you know, that we're people who have been affected by the loss of a child.

Unable to trust the review's findings, the couple have now requested that it be redone by a different hospital. Taking their complaint this far has required time and resources, and a high level of understanding on their part.

My husband [...] he did a lot of research. [...] And then we actually privately paid for somebody to look at my daughter's X-rays and scans to get an independent picture on what was going on there. And we have health insurance, which also includes solicitor cover. [...] I think we contacted as many sort of independent people as we could, to figure out the best way to go forward.

Two years after their daughter's death, they are still fighting for answers.

One mother described making a complaint in the antenatal period following her community midwife's dismissive and insensitive attitude, stereotyping, and failure to provide information about her baby. She later discovered that the complaint had not been documented in full or formally logged. Frustrated by the lack of accountability and failure to listen, the mother raised a formal complaint through PALS to run alongside the hospital's own review.

Because I thought to myself, what's the point having a review done when it's not gonna be accurate, and it's gonna be recorded, and parents are not listened to. So how are you gonna make changes?

Mother to a baby who died at 24 weeks (Mixed white and Black Caribbean)

Several parents described there being a lack of support or advocacy throughout the review process, making it hard for them to participate fully and understand the content of the review.

Because you're sat amongst professionals who are giving you all this information. And it's about processing that information and having someone to support you in that. Because I don't know if their practice was right or not because I'm not a medical professional. I just had to take on what they were saying and believe that it wouldn't happen again.

Mother to a baby who died at 26 weeks (Asian/Indian)

4.4 More than a 'learning curve'

Many parents recognised that review processes could be an important part of learning and safety. However, several expressed that 'learning' from their baby's death was not enough, and that they wanted hospitals to take greater accountability, apologise for any errors, and make it clear what changes had been made.

One mother's baby died after healthcare professionals missed signs of gestational diabetes and failed to act on abnormal test results, despite her being known to be at higher risk of diabetes. She was told that 'no-one was to blame' and offered no explanation for these failings beyond 'a lack of communication'.

In the report it just states that it's something for learning [...] But for me and my husband that's not really something that needs to be a learning curve. Because it may, I'm not sure, but it may have saved my daughter. [...] So for us, that's not a learning curve, that is something that needs to be addressed.

Mother to a baby who died at 28 weeks (Asian/Indian)



Language that implies a baby's death is an opportunity for learning may be extremely distressing to bereaved parents. One mother described how upsetting it was when a doctor repeatedly attempted to examine her baby while she was still in the bereavement suite, holding her son in her arms.

[The doctor] kept on saying, like, 'We need to learn from this. We need to learn from this.' And in my mind, I was just thinking, this is my son. You don't need to learn from him right now, you just need to leave us alone. Because I didn't have my son so that someone could learn from him.

**Mother to a baby born at 29 weeks who died neonatally
(British Mauritian)**

Poor experiences of care, discriminatory attitudes, and historic failings may make it hard for Black and Asian parents to trust healthcare professionals. Where parents already have concerns about whether their baby received safe care, they may struggle to trust hospital staff to provide accurate information as part of the review process, and to believe in assurances of future improvements.



Conclusion

In hearing directly from Black and Asian bereaved parents, this Listening Project brings new understanding to how maternity and neonatal care can be improved. We acknowledge there are some gaps in the experiences included here, particularly from families in the devolved nations, and from those who face English language barriers. Nonetheless, the stories we have shared are important examples of how systemic issues, along with certain practices and behaviours on the part of individual professionals, have led to less safe maternity and neonatal care for some Black and Asian families.



What needs to change



It is vital that healthcare staff listen to Black and Asian parents and take their concerns seriously – both ‘in the moment’, when parents are worried about their own or their baby’s health, and later, when they raise concerns about the quality and safety of their care.



Care should be structured in a way that supports good communication between staff and families. This makes it possible for Black and Asian parents to develop positive, trusting relationships with the people looking after them. At every stage of pregnancy, it should be clear to parents whom they should speak to when they need help, and where they can access the care and information they need.



Healthcare professionals must be able to have personalised, detailed conversations with Black and Asian parents about possible risks that might affect them or their baby. Conversations must be sensitive and tailored to the individual needs of each family, which in some cases will require the use of professional interpreting services. Where ethnicity is associated with an increased chance of certain complications or medical problems, parents need to know they will get the care required to keep them and their baby as safe as possible.



When a baby dies, Black and Asian parents should get the information and support they need to take part in reviews and investigations if this is something they want to do. Complaints systems should be accessible, simple and fair, so that parents can formally share their concerns and feel confident that action will be taken.

Sands is committed to supporting these changes by sharing what we have learnt from this project through our research, education, policy and campaigning work. We will continue to put parents’ voices at the heart of our work, with a particular focus on groups that are more likely to be affected by pregnancy loss and the death of their baby, but whose stories are often not included in research.

The Government has a duty to address the wider social determinants of health. Actions focused on improving maternity and neonatal services will make care safer for Black and Asian families. In addition, these areas of care have a role to play in the wider drive for health and social equity across ethnic groups.



Governments must:

1. Set out long-term, funded plans aimed at eliminating inequalities in pregnancy loss and baby deaths.
2. Ensure that maternity services have the staff capacity, skills and resources required to assess and care for women and birthing people effectively, so that the risk factors affecting each individual are recognised and their impact reduced.
3. Initiate and fund a research programme to inform the development of effective interventions to address health inequalities and save babies' lives.
4. Take steps to ensure that all maternity safety improvement schemes include a focus on tackling inequalities, with action, progress and impact monitored.



Professional bodies and regulators must:

1. Provide clear, co-produced guidance for healthcare professionals on how maternity and neonatal care needs to consider ethnicity when undertaking ongoing risk-assessment and developing personalised care plans.



The NHS must:

1. Provide all women and birthing people with agreed minimum core safety messages, in a format that is accessible for them.
2. Provide maternity and neonatal professionals with the ongoing training and information they need to have unbiased, personalised discussions about the significance of ethnicity for an individual's maternity and neonatal safety.
3. Ensure that any review, investigation or complaints process includes meaningful consideration of the impact of ethnicity on the care received, examining the potential role of racism or discrimination.



Closing words

At the heart of this report are the babies who have died. For each person who told us their story, the loss of their child or early end of their pregnancy has caused immense pain. They have shared their experiences, not only to help us understand what kind of care is needed after loss, but also to inform work to save babies' lives. This report shows that the voices of some Black and Asian parents still go unheard. Their perspectives are critical opportunities to learn about how maternity and neonatal care can be made safer and more equitable at every stage.

We leave the closing words to three parents whose experiences helped shape this report. In sharing their reasons for taking part, they remind us of the importance of taking this work forward: to raise awareness, improve experiences, and save babies' lives.



I guess everyone can be the cause. I guess if we don't speak out about what we are facing, people won't actually know what's wrong.

Father to a baby born at 32 weeks who died neonatally (Black African)

I'm hoping obviously this will all feed into something a bit bigger. Hopefully people will pay attention to that and then, in the future, other people will have [...] better experiences.

Mother to a baby who died at 12 weeks (Asian/Indian)

I'm looking for answers, but at the same time looking for support, and to help others not fall in this category that I'm in at the moment. [...] Let's hope that we can take something forward with this.

Mother to a baby who died at 39 weeks (Asian/Pakistani)

Appendix A

Supplementary information about participant characteristics

Experiences of loss

Figures 2 to 4 provide more information about participants' experiences of loss. Several participants had experienced more than one loss between 2016 and 2023. The information shared here relates to their most recent experience of loss at the time of signing up to the project.

Figure 2 - Year of loss

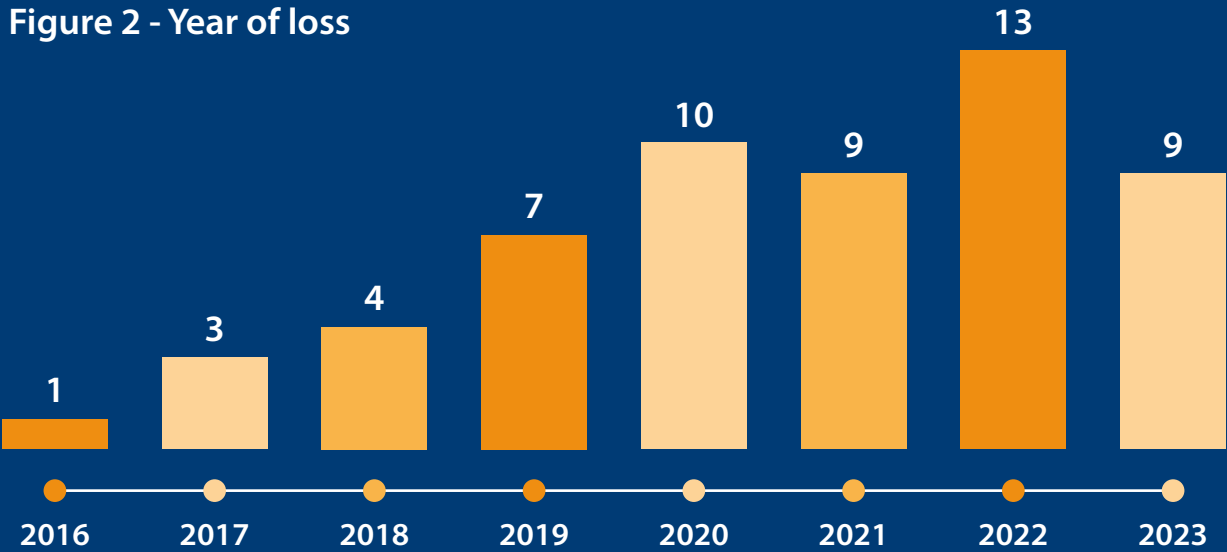
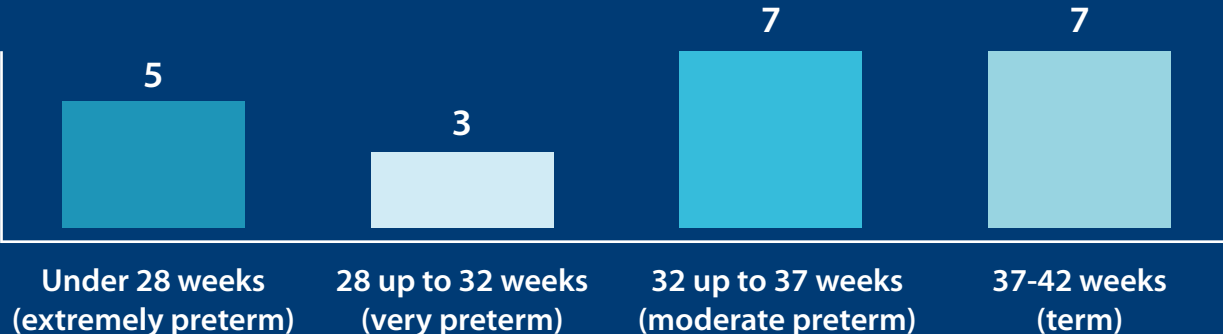


Figure 3 - Type of Loss



Figure 4 - Gestation at birth where there was a neonatal death



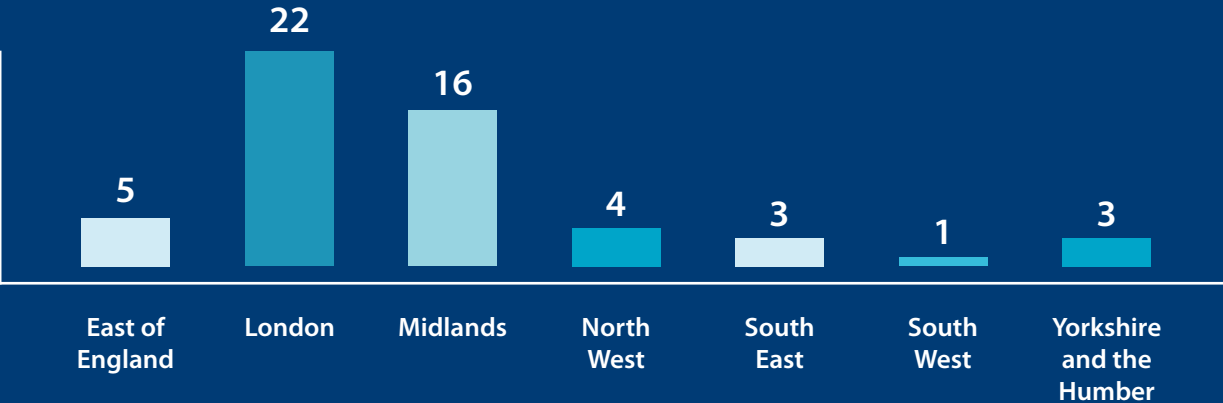
Geographic information

Figures 5 and 6 provide information about where participants were living and, if in England, the specific region in which they received their care when their baby or babies died.

Figure 5 - Participants' country of residence at the time of their loss



Figure 6 - English regions where participants received care



Appendix B

Supplementary information about how we listened to and analysed participant experiences

Interviews and focus groups

Our aim was to make this project as accessible as possible. When deciding what methods to use, we were guided by the participants themselves. Initially, we ran focus groups and individual interviews via Zoom. As the project progressed, we learnt that some participants preferred to share their stories in emails or using WhatsApp voice notes, sometimes over the course of several days. Interpreter services were available to all participants if needed. One mother requested to do her interview in a three-way WhatsApp call with an Urdu-speaking translator.

By working flexibly and accommodating individual preferences where possible, we were able to hear a greater range of experiences and perspectives. Figure 7 provides more detail about the different formats used when listening to participants' stories.

Figure 7 - Formats for interviews and focus groups

Format	Number held	Number of people who took part
Interview (Online)	18	19*
Interview (Phone call)	1	1
Interview (WhatsApp voice notes)	3	3
Interview (Email)	10	10
Focus group (Online)	4	20
Focus group (In person)	1	3
Total	37	56

**One interview was with a couple*

Processing participants' accounts

Auto-transcription software was used to turn audio-recordings from Zoom interviews and focus groups into transcripts. The content of WhatsApp exchanges was turned from voice notes into text with the help of voice-recognition software. All transcripts were hand-checked and edited by a member of the Sands Saving Babies' Lives team to make sure the final transcripts agreed with what participants had said. When processing the content of email interviews, written responses were transferred verbatim from email exchanges to create a new transcript. Details that could be used to identify the participants, their families, or the people and services involved in their care were removed at the time of transcription or transfer.

Analysing participants' stories

Members of the Sands Saving Babies' Lives team led the analysis, in dialogue with members of the Project Involvement Group. The anonymised transcripts were read line-by-line and phrase-by-phrase. Analytic codes and categories were constructed and refined to identify important themes that linked closely to parents' accounts. NVivo software was used to help manage the data and analytic processes, with codes and categories refined over time into a coding framework. For this initial report, we have focused on codes and categories with clear relevance to the overarching themes of safety and the significance of ethnicity in care experiences. We look forward to sharing more of what we have learnt in future publications and outputs.

Sharing participants' words

To ensure quotes represent participants' original words, meaning and tone, we have avoided editing their content as much as possible. For the sake of concision, repeated words and phrases were generally removed along with frequent expressions of hesitation and thought (e.g. 'um', 'er', 'like'). Occasionally, we added words or short phrases to make the meaning clear – these insertions are indicated through the use of square brackets. If the inclusion of information about participant characteristics or circumstances would have risked a breach of confidentiality, it has been removed from quotes. Beyond this, their content is unchanged. Our aim was for those reading this report to hear the words of participants much as we did, with their unique character and style of speech.

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