



## South Asian families' experiences of neonatal care

**Bliss**  
for babies born  
premature or sick

# Contents

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<b>Summary of findings</b> .....	<b>3</b>
<b>Introduction</b> .....	<b>4</b>
<b>Methods</b> .....	<b>5</b>
<b>What do we already know?</b> .....	<b>6</b>
<b>Policy context</b> .....	<b>7</b>
<b>Findings</b> .....	<b>8</b>
Care for mothers.....	8
Neonatal care delivery.....	9
Information and support.....	11
Cultural and faith needs.....	12
<b>Conclusion</b> .....	<b>14</b>
<b>Recommendations</b> .....	<b>14</b>
<b>References</b> .....	<b>16</b>

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## About Bliss

Bliss was founded in 1979 by a group of concerned parents who discovered that no hospital had all the equipment or trained staff it needed to safely care for premature and sick babies.

Determined to do something, these volunteers formed a charity to give vulnerable babies the care they deserve. More than 40 years on, Bliss has grown into the UK's leading charity for babies born premature or sick. Bliss champions the right for every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

## Acknowledgements

Primary research for this project was undertaken by Cultural Intelligence Hub, with support from Muslim Mamas, RecommendAsian and MiniAsian who kindly shared adverts for interviews and the survey with their communities.

This report was written by Josie Anderson and designed by Joana Águas.

Each neonatal experience is different, but this report may bring up painful memories if your baby was born needing neonatal care. If you need to talk to someone please reach out to us on [hello@bliss.org.uk](mailto:hello@bliss.org.uk)

# Summary of findings

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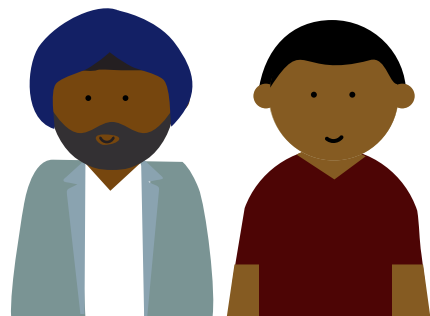
Maternity care was variable with some receiving excellent care which they felt was equitable, while others had a poor experience.



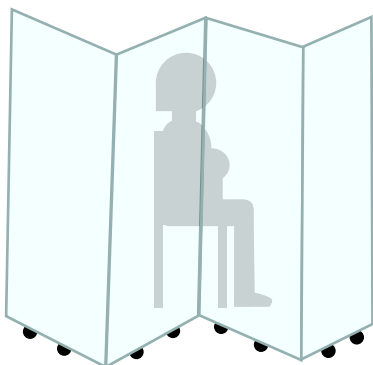
Most participants felt their baby received good care, and they trusted that staff would make the right care decisions.



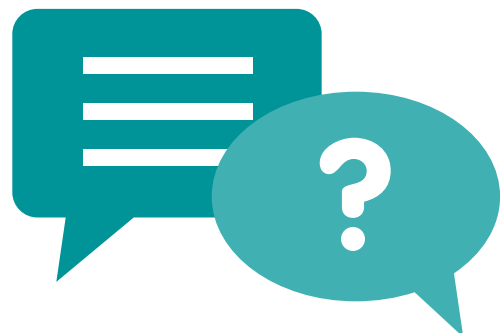
50 per cent of survey respondents had to ask permission for skin-to-skin.



Cultural assumptions may make it harder for fathers to participate in care.



30 per cent of survey respondents felt their needs for privacy and modesty were not understood or respected by staff.



Parents who did not speak English as a first language were more likely to report poor experiences.

# Introduction

Every year, more than 90,000 babies are born needing neonatal care in the UK. This is either because they are born premature (before 37 weeks of pregnancy) or at full term but sick. Research has shown that Asian and Asian British communities have disproportionately poor maternal and neonatal outcomes when compared to White maternal and neonatal outcomes.<sup>1</sup> While there is a growing body of evidence – and active investigation – into how ethnicity and race impact prenatal, antenatal, and maternity care to ensure more women have healthier pregnancies and that more babies are born well, the same attention has not been given to neonatal care.

This project aimed to gather insight and understanding on:

- Any barriers families from South Asian communities experience when participating in care on the neonatal unit
- Parent perceptions of the care their baby received, and the care and support they received themselves on the neonatal unit
- Information and support needs of families
- Any areas of systemic inequality or inequity experienced by South Asian parents and their babies

The project has also been an opportunity for Bliss to identify how we can be more inclusive in the information and support that we offer, and how we can better advocate for the needs of all babies, and their families.

In this report, we use the term South Asian as an overarching term to refer to people of Indian, Pakistani, Bangladeshi background, and people who identified as having any other South Asian heritage or mixed heritage when participating in the research undertaken by Cultural Intelligence Hub.

We acknowledge the importance of language to the experience of families and to effectively tackling inequalities. Throughout this report, we refer to specific ethnicities or use different descriptors (e.g. Asian or Asian British) to reflect the definitions used in other research. The South Asian community is vast and there are many intersecting identities that can affect people's experience of neonatal care, as well as ethnicity. This can include, but is not limited to, religion or belief, socio-economic status, education, age and literacy. We recognise that our understanding of language is changing over time and we are committed to learning and developing our approach with people from a South Asian heritage to reflect their experiences and perspectives accurately, and ultimately to benefit all babies born premature or sick.

## Methods

Bliss is committed to ensuring every baby has access to consistent high-quality care. This project is one of many to better understand how every baby can receive equitable neonatal care, and also serve as a catalyst for implementing practical national and local changes.

Bliss commissioned Cultural Intelligence Hub, a market research agency which works specifically with South Asian communities, to undertake the qualitative research for this study - this consisted of family interviews and a survey, undertaken between September and November 2021. Participants in the research were largely from the three largest South Asian communities in the UK: Pakistani, Bangladeshi and Indian. All participants in the interviews and survey had had a neonatal experience in the last five years.

Cultural Intelligence Hub conducted nine family interviews with a total of 16 participants, who included mothers, fathers and extended family members:

- Four families were Pakistani, three were Bangladeshi and two were Indian.
- Almost all mothers participating were born in the UK. Other family members, including one of the fathers, did not speak English as a first language and their interview was conducted in their preferred language.
- Just over half of the families had a baby or babies who had been born premature, the remainder were born full term but sick.

There were 48 partial and 30 complete responses to the survey. The small sample size is attributed to potential participants being screened out due to not meeting inclusion criteria (including whether they had experienced neonatal care, and the length of time since their most recent neonatal care experience). A further limitation to the survey was that it was produced in English only.

- Nearly half of participants were Indian
- 90 per cent of respondents were born in the UK
- 90 per cent of respondents had a baby born premature.

## What do we already know?

There is limited information published about ethnicity and neonatal care in the UK, but in 2020, there were 58,446 babies of Bangladeshi, Indian, or Pakistani ethnicity born in England and Wales, of whom 4,391 were pre-term.<sup>ii</sup> In 2017, around 13 per cent of neonatal admissions in England and Wales were of babies born to mothers of South Asian ethnicity, though the data completeness was poor suggesting this may be an under-estimate.<sup>iii</sup>

Mortality rates are significantly higher for Asian and Asian British babies compared to babies of White ethnicity, with stillbirth and neonatal mortality both around 60 per cent higher when compared to White babies.<sup>iv</sup> There is an intersection between ethnicity, age and deprivation. The latest data from MBRRACE-UK finds that neonatal mortality was over three per 1,000 live births for babies with Asian and Asian British ethnicity both to mothers under 25 and over 35, who lived in the most deprived areas.<sup>v</sup> This is in comparison to a UK average neonatal mortality rate of 1.62 deaths per 1,000.<sup>vi</sup> Similarly, the ONS found in 2019, 73 per cent of babies of Asian ethnicity were born to mothers living in the most deprived areas compared to 53 per cent of White babies.<sup>vii</sup>

These trends extend beyond the neonatal period with recent findings from the ONS highlighting that babies with Asian ethnicity had the second highest infant mortality rate (death within one year of birth), with an infant mortality rate of 5.5 deaths per 1,000 live births in 2019 compared to an average of 3.7 deaths per 1,000 births across England and Wales.<sup>viii</sup>

There is limited published evidence about the specific perceptions and experiences of neonatal care among families from Bangladeshi, Pakistani or Indian communities. A recent report from the Muslim Women's Network found 44 per cent of mothers were not satisfied with the care provided to their baby or babies during the recovery period after giving birth.<sup>ix</sup> Research from Sands highlighted that for bereaved parents, cultural or community taboo or discouragement around memory-making prevented some South Asian families from undertaking memory-making activities or sharing and discussing these openly with family and friends.<sup>x</sup>

## Policy context

Asian and Asian British women are nearly twice as likely to die during pregnancy or shortly after childbirth.<sup>xi</sup> There is a significant, and welcome, national drive to reduce the disproportionately high maternal mortality rate among Asian and Black women and this accelerated in response to COVID-19. In particular: the government is funding research at the Maternal and Neonatal Health and Care Policy Research Unit (PRU) to investigate the factors associated with the excess risk of maternal death for Black and South Asian women; the Maternity Transformation Programme is implementing a range of targeted strategies to improve maternal and neonatal outcomes, including continuity of carer pathways; and the NHS Equity Strategy for Maternity and Neonatal services is contributing to this change.<sup>xii xiii</sup>

While these interventions aim to improve outcomes before, during and shortly after birth for babies, there are no corresponding strategies or targeted programmes to identify and tackle the impact of health inequality within neonatal units. This is particularly concerning as while there is less evidence relating to neonatal care, the Race Health Observatory found Asian babies were overrepresented in admissions to neonatal units for jaundice<sup>xiv</sup> and the Getting It Right First Time (GIRFT) report highlighted concerns regarding the varied detection rates for cyanosis among certain ethnic groups, including Asian babies.<sup>xv</sup>

The National Ambition in England to reduce the rates of stillbirth, maternal and neonatal death, serious brain injury and preterm birth by 2025, does not include specific targets linked to race or ethnicity.<sup>xvi</sup> This is a significant missed opportunity, especially as the latest evidence shows very high neonatal death rates among babies who are Asian or Asian British. While there has been a decrease in neonatal death rates among babies born after 24 weeks nationally, this is not falling evenly across multiple demographics – suggesting current interventions are not resulting in equitably improving outcomes.

There is an increasing drive towards ensuring neonatal services are providing high-quality family-centred or family-integrated care, which puts parents at the heart of care giving and decision making for their baby. National neonatal transformation programmes in both Scotland and England have identified improving parental involvement as key priorities.<sup>xvii</sup>

This approach is best for babies and best for families. Increased parental involvement in care has been linked with: increased weight gain, improved breastfeeding rates, reduced length of stay, better infant reflexes at term and improved gross motor development in early childhood.<sup>xviii xix xx</sup> This approach also supports bonding and attachment and has been linked with reducing parental anxiety scores, and frequent hands-on care supports parents' perceptions of their role, allowing them to feel like parents – which may be key for their perception of attachment to their baby.<sup>xxi xxii xxiii</sup>

However, achieving these long-term benefits is reliant on parents being able to be present on the neonatal unit. Long uninterrupted periods of time on the unit enable parents to be fully involved in care and decision making, and to engage with parent education to improve confidence, such as sessions on how to bath a baby or how to recognise their baby's cues. There are a multitude of barriers which may prevent parents from being with their baby as much as they need – and want – to be. These may be practical – such as the costs of food and drink, accommodation, travel or childcare for older children – but they can also be cultural. For example, language barriers, inability to access appropriately private areas for feeding, the role of wider family, or inability to undertake religious rites or rituals can make the experience of neonatal care inequitable.

# Findings

## Care for mothers

A baby's admission to neonatal care is often preceded by a traumatic birth or birth requiring intervention. As such, it is common for mothers to have medical needs of their own and to require inpatient care after their baby is born. Recent Bliss research has identified that there is often a disconnect between maternity and neonatal services which can make it more difficult for mothers to be involved in their baby's care and can leave them no choice but to compromise their own care to be with their baby.<sup>xxiv</sup>

For women participating in this study, experiences of maternity care were variable, with some receiving excellent care which they felt was equitable, while others had a poor experience.

The women who spoke positively about their experiences reflected that they felt staff were attentive to their needs and provided good aftercare. This was particularly important for women who had undergone surgery. Some women were also pleased with how staff pre-empted their needs – for example, providing wheelchairs to help them attend the neonatal unit or providing baby care items and breast pumps.

However, other women reported feeling unsupported physically and emotionally. Some reported receiving poor care and being left in pain. There was a particular theme around lack of feeding support with participants reporting receiving no help to breastfeed and offered no support to ease pain or discomfort.

It was also perceived that women who did not have English as their first language did not receive equitable care, and staff did not always try to understand their needs. Among the women who discussed experiences of poor care, they felt that some of this was discriminatory.

*"I could see the other mothers in the ward who did not speak English. One kept saying she was in pain, but they just ignored her." - Indian mother*

*"I was not confident in the level of care; I had to be assertive and constantly telling the nurses. The communication was very poor; they wouldn't tell me what was happening and I was very anxious. I was kept waiting for hours to know what was happening. It was only after several hours I got to see the baby." - Bangladeshi mother*

Separate information from Bliss research conducted January – March 2022 included a small sample of mothers who identified themselves as Pakistani, Bangladeshi, Indian or Asian British (N=17) who answered questions about their own inpatient care while their baby was in neonatal care.

While numbers are small, two thirds of them said they were never, or only sometimes, kept informed about their baby's condition while in neonatal care (11 out of 17) and more than half were not as involved in their baby's care as they wanted to be (9 out of 17).



## Neonatal care delivery

The area of most importance for families participating in the project was the quality of medical care provided to their baby. As with inpatient post-natal maternity care, experiences were varied though the majority were positive about the care their baby received.

Among the respondents who reflected positively on their baby's neonatal admission, there was a high degree of trust in the medical professionals who were caring for their baby. They were confident that staff were making the right care decisions.

Overall, 88 per cent of survey respondents were satisfied with the quality of care delivered by the health care professionals. More than four in five respondents also felt they were treated with respect and 78 per cent felt they were well supported and listened to.

"I think that we were blessed. The NHS, the neonatal ward, the staff. We put so much trust into them. They take care of everyone. It was a good experience." - **Indian mother**

"I felt my daughter's care was top notch. I felt she was getting good care. The nurses were attentive to the baby and the parents as well. You can't stay with the baby all the time in the hospital, but when you see such level of care you feel reassured that your baby is safe and well looked after."

- **Bangladeshi mother**

For participants who did not have a good experience, they reported care which lacked compassion and abrasive attitudes from staff which made it difficult to engage and to feel well supported. While it was acknowledged that some of this may have been driven by variations in working culture between different hospitals, these experiences were reported more commonly by parents who were less confident in English.

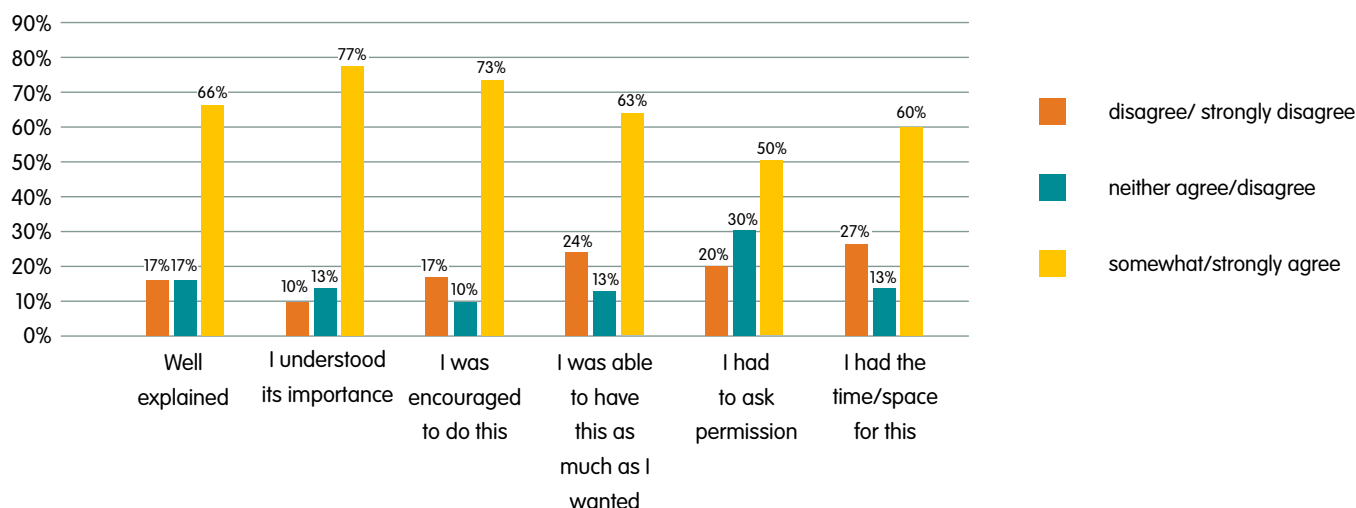
"I saw that they were handling my son really roughly but they didn't explain why that was, so I was really upset. I didn't know what was happening." - **Bangladeshi father**

## Skin-to-skin

Skin-to-skin or Kangaroo Care is when a baby is placed against the parent's chest. This type of care has a multitude of benefits, including: improved lactation and successful establishment of breastfeeding, and increased weight gain for the baby. Supporting parents to engage in this care, as well as other types of comforting touch which can help soothe and settle their baby – and may be effective for managing pain – is important for babies and their families.

The importance of skin-to-skin care was well understood, and participants wanted to do this as much as possible. However, it is concerning that half of the participants said they had to ask permission to do skin-to-skin and two-fifths felt they did not have sufficient time and space to undertake this as they wanted to.

### Being able to have skin-to-skin contact



Given the importance of skin-to-skin as an intervention which supports improved outcomes for babies and supports bonding, opportunities for this contact should be maximised. It is concerning that so many parents who took part in this study experienced barriers to holding their baby as much as they wanted to.

“Yes. I was (skin to skin explained). I was thank God, it was done after 10 days. Because she very, you know, fragile, she had many tubes in her head. So, I held after ten days, one nurse made it happen. She said, I don't care how this is going to happen. I'm going to make Yeah. And oh my god, it was the best gift.” - **Indian mother**

Participants whose babies had been born during the COVID-19 pandemic experienced their opportunities for involvement in skin-to-skin and caregiving being limited by access restrictions. This is in line with Bliss' 2021 report *Locked out: the impact of COVID-19 on neonatal care* which found the impact of such restrictions resulted in 41 per cent of parents surveyed saying that bonding had been affected at some point during their journey, and 69 per cent feeling that their mental health had got worse as a result of their experience.<sup>xxv</sup>

## Fathers' involvement in care

Some fathers and partners who were interviewed felt excluded from the care of their baby, particularly if they were not born in the UK and/or did not speak English as a first language. It was felt staff assumed that culturally they would not want to be involved, and so this was less supported. While this chimes with other research which suggest perceptions of the paternal role can lead to fathers and partners being less encouraged to be involved in care delivery – and supported to fulfil this role – insights from this work suggest that this may be compounded if staff are racially or culturally stereotyping.

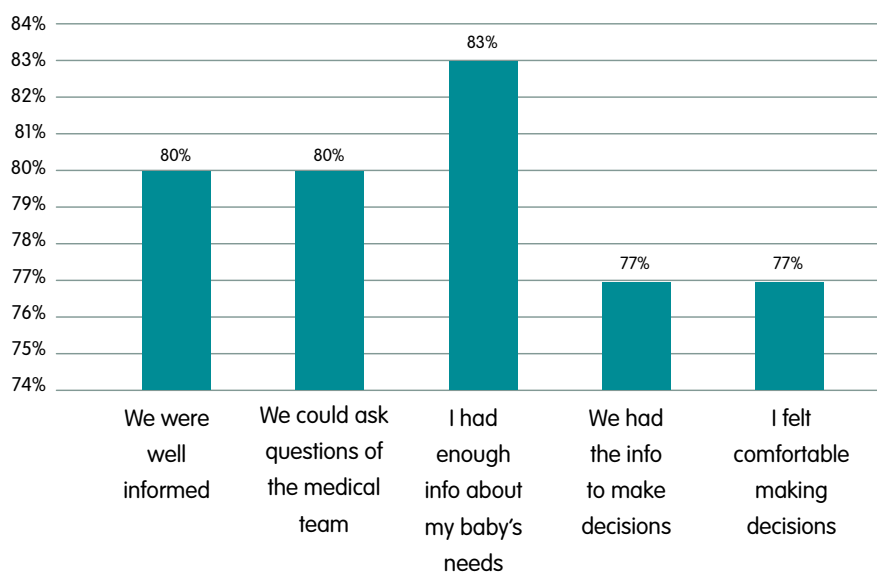
Further exploration would be needed to confirm this and undertaking specific work with fathers should be a priority for future investigation and research.<sup>xxvi xxvii xxviii</sup>

## Information and support

Information and support are key to ensuring parents can care for their babies. It is important that all members of the neonatal team – including nurses, doctors and allied health professionals – can communicate and support parents effectively. Giving them the information and advice they need can empower families to be actively involved in decision-making about their baby's care, and true partners in care delivery.

### Information

Generally, parents felt well-informed about their baby's care but less involved in decision-making. 83 per cent felt they had enough information about their baby's health needs, but a slightly lower percentage – 77 per cent – felt they had enough information to make informed decisions about care, and the same proportion reported feeling comfortable with making decisions. This disconnect between feeling involved in caregiving and being involved in decision-making has been identified in other Bliss research.<sup>xxxix</sup>



Some participants also felt they did not receive the information they needed when they needed it, resulting in having to chase and ask multiple times, particularly with regards to information around the time of birth or when their baby's care was considered less serious.

Participants who were less confident in speaking English were more likely to report not being as informed as they needed to be. While our study did not explore the availability and quality of translation services, other studies have shown repeatedly that provision can be patchy and inappropriate.<sup>xxxix</sup>

**“They did explain everything to me. Although at first, I was left outside and had to keep asking for information.” - Indian father**

Research from Bliss and Sands found that when providing bereavement care, more than a fifth of neonatal units could not always use face-to-face interpreters when required. Many units also make use of family members to perform this function, with more than 90 per cent asking fathers or partners to do this at least sometimes, and 89 per cent saying they would routinely ask other children of the mother to translate where necessary.<sup>xxxii</sup>

Recent findings from the Birthrights inquiry into racial injustice and human rights in maternity care identified lack of appropriate interpretation and translation services as a systemic issue which prevents women from making informed choices about their or their baby's care.<sup>xxxiii</sup>

## Support

A neonatal admission can turn a family's world upside down. They are frequently unexpected and often follow a traumatic or difficult birth. Many families describe existing on 'auto-pilot' while on the neonatal unit, only realising the significant toll the experience has had on their mental health and wellbeing post-discharge.

Access to support on the unit – either through an onsite counsellor or psychologist, and even just through day-to-day support from clinical staff or peer-support – can make a significant difference to the confidence of parents to be involved in caregiving and can reduce feelings of isolation. Despite this, only around half of participants reported having access to the emotional support they needed.

Research from Sands also suggests that emotional support needs for families who are Black or Asian are not fulfilled following bereavement. Their insights suggest that where support exists, it may not always be suitable. For example, peer-support groups which are facilitated, and attended, by predominately White people can feel unsafe or unrelatable.<sup>xxxiv</sup>

## Cultural and faith needs

The neonatal environment needs to be a space where families feel welcome, respected and safe in order for all families to have an equitable experience of family-centred or family-integrated care. These approaches empower parents to be partners in care delivery and decision making for their baby or babies.

While participants felt that understanding of cultural and faith needs was variable, parents living in areas with large South Asian populations generally felt their needs were well met, suggesting health services serving areas with larger South Asian communities have a better understanding of culturally appropriate care.

Some participants however also expressed that not all services and staff understood the importance of extended family and their role at the time of birth. This was challenging for parents who had their baby during the COVID-19 pandemic and were subject to unit-based restrictions to parent access and wider family or friends visiting.

## Rites and rituals

For many participants, being able to honour their cultural and faith rites which were meaningful to them was of huge significance. This was most pertinent in the immediate hours and days following birth, and for those families whose baby died.

Some participants in our study experienced excellent care. For example, one mother reflected how staff proactively facilitated the presence of a Hindu priest to perform end-of-life prayers for her baby, without the family having to request this. Another family were asked questions by their baby's care team about upcoming festivities which were important to them, so they could have a greater understanding.

*"They understood our needs to say prayers for baby. Would ask questions about festivities coming up so they could have more knowledge." - Indian mother*

*"When I wanted to do skin-to-skin, they ensured the curtains covered us properly as they knew how important modesty was for me (I wear the Islamic attire), they always asked before they could enter. I was also able to pray in the prayer room and also recite Quran to my child without being disturbed." - Pakistani mother*

However, other participants described being unable to fulfil the rites and rituals that were meaningful for them, suggesting that the importance of these practices were not fully understood on the unit:

“As Muslims we must allow baby to hear adhan once they are born. We were not able to perform adhan in baby’s ear until 11th day.” - **Bangladeshi mother**

Separate research undertaken by Bliss, which has explored more generally the barriers to participating in neonatal care and was conducted between January and March 2022, found 64 per cent (9 out of 17) of survey respondents identifying as having South Asian ethnicity felt their cultural and/or faith needs were either not well-understood or only sometimes understood.

“I was told to give my baby a name already as they didn’t want to refer to him in their meetings as boy. He was 4 days old... We name our babies on the 7th day in our religion. His dad...had not yet met him. I wasn’t going to name him without his dad seeing him first or agreeing it.” - **Mother of a baby born premature, who contributed to Bliss’ Barriers research project**

### **Modesty and privacy**

For all women participating in our research, being able to maintain modesty and privacy, particularly during feeding, was important – and this was particularly so for Muslim women. Where services were unable to provide adequate private space or failed to acknowledge the significance of modesty and privacy, this could cause undue stress.

While more than 80 per cent of women felt they could adhere to their cultural or faith needs for modesty, nearly a third (30 per cent) felt that healthcare professionals did not fully understand why this was important to them. This suggests there may be a cultural awareness gap.

Some participants did not feel the need for modesty and privacy was understood. This made breastfeeding more difficult and stressful, with 17 per cent of survey participants either disagreeing or responding neutrally to the question regarding whether they could take care of their baby in private and in ways that were comfortable to them and allowed them to adhere to cultural or faith needs for modesty.

The reasons for this were often multi-faceted, with some participants reflecting services lacked the practical resources to provide the privacy they needed – such as a lack of screens or private areas. In other cases, women felt uncomfortable because male doctors would walk into spaces which were intended to be private without notice, or because the male partners of other women on the unit were also present.

“It wasn’t always easy as we couldn’t get a private space. Very limited, no adequate chairs available to carry out breastfeeding.” - **Bangladeshi mother**

“I was on a ward and trying to breastfeed. There was no privacy and there were men on the ward visiting their wives. It was a little uncomfortable.” - **Pakistani mother**

“Also no consideration when doing skin to skin as there was no privacy from males and I cannot expose myself in front of men. In my culture and religion it is encouraged to visit if someone is sick in hospital. I had to turn people away.” - **Mother of a baby born premature, who contributed to Bliss’ Barriers research project.**

## Conclusion

This study provides valuable insight into how South Asian communities in the UK experience neonatal care. The families involved largely had positive experiences, trusted the medical team and wanted to be guided on how best to be involved in their baby's care.

However, it also reveals instances of poor care, particularly for women after birth, and instances where care was not culturally appropriate. A lack of understanding of specific cultural and faith practices – such as requirements around modesty or awareness of specific rituals around birth and death – can impact family wellbeing and their overall experience of neonatal care.

It is also important to recognise that while this research provides useful insights into how neonatal care is experienced by families from South Asian communities, the sample size across both the interviews and survey was small, and most participants spoke English as their first language. There was a perception among participants that families who did not speak English received poorer care, which chimes with existing research. It is imperative that further research is undertaken to explore this within the context of neonatal care to ensure care is provided equitably to all families.

## Recommendations

### 1. Bliss

This project has been an opportunity to understand how Bliss can better meet the needs of families from South Asian communities. Over the course of our strategy period 2022-25, we will:

- Review the feedback we give to units through the Baby Charter to improve experiences, such as requiring detailed information about access to translated materials or interpretation services, and access to private spaces and privacy screens which are readily available and meet the needs of the families using them.
- Ensure our work is representative and culturally appropriate by involving families from South Asian communities in the development and evaluation of our information, support services and policy work.
- Ensure major projects are developed with reference to the conclusions of this report, such as our project to develop Family Integrated Care accreditation standards.
- Commit to improving the accessibility of our parent-facing support and information, especially focussing on caring for seriously ill babies, touch and skin-to-skin care, and volunteer and digital support.
- Work towards maximising the accessibility of our information and support for all families including; aiming to have information available in the most commonly spoken languages in the UK; and recruiting Bliss champion volunteers whose experience and background is diverse and representative of the communities their hospital serves.
- Facilitate the sharing of best practice in cultural awareness and practical solutions to inclusivity through Bliss organised healthcare professional training and influencing.
- Seek to partner with organisations who represent South Asian families, to hold listening and learning events, to develop and deliver services.

## 2. Neonatal service providers

The findings of this study highlight opportunities for health services to facilitate improved support for families from South Asian communities. We recommend that health services should:

- Ensure families from these communities are consulted when producing or updating national, regional or Trust specific guidance to ensure it is inclusive of their needs.
- Ensure maternity and neonatal healthcare professionals attend cultural competency or cultural awareness training.
- Review the availability of translated or other accessible materials and interpreter services and identify how these could be improved to better meet the needs of the local population for the service.
- Ensure all parents are encouraged to participate in skin-to-skin, as well as other cares, and empower families to engage in this proactively. Tools such as the Bliss Baby Charter can be used for individual neonatal units to audit how well units are performing.
- For individual neonatal unit: assess the adequacy of private space (including availability of private screens) and improve availability where required.
- For Neonatal networks, maternity networks and local maternity systems (where applicable): identify how best to ensure continuation of care for inpatient mothers with babies in neonatal care. Consideration should be given to training, and to the development of policies and procedures for care for this specific cohort of women.
- For national NHS Services and Governments: ensure all parents have access to psychological support in line with national standards.

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"I think that we were blessed. The NHS, the neonatal ward, the staff. We put so much trust into them. They take care of everyone. It was a good experience."  
**- Indian mother**

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