Equity for Every Baby: Tackling inequalities in neonatal care linked to ethnicity and socioeconomic deprivation

A state of the nation report: England 2026

Contents

About Bliss

Our vision is that every baby born premature or sick in the UK has the best chance of survival and quality of life. Bliss champions the right of every baby born premature or sick to excellent neonatal care, experience and outcomes. We achieve this by improving care, giving voice to babies, and supporting parents to be partners in care.

Across our 2025-2029 strategy period, we will continue to prioritise equity for all neonatal babies and families:

Equity of care

every baby born premature or sick benefits from Family Integrated Care which builds a culture of partnership between their parents and the neonatal healthcare team

Equity of voice

every baby born premature or sick has their voice and interests represented by Bliss, to influence improvements in all aspects of their care at local, regional and national levels

Equity of support

every baby born premature or sick has well-supported parents who have the information they need, when they need it, to be partners in their baby's care.

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Each experience is different, but this report may bring up painful memories if your baby was born needing neonatal care. It also contains examples of poor care and experiences which you might find upsetting. If you need to talk to someone, please reach out to us on hello@bliss.org.uk.

Executive summary

Every day, over 1,500 babies are born in hospitals in England, with 1 in 7 of them needing specialist neonatal care[1]. These babies do not have an equal chance of survival and long-term health.

This report presents a comprehensive picture, showing the unacceptable and shameful truth that inequities related to socioeconomic disadvantage and minoritised ethnicity are present throughout every step of a baby's journey to, and through, neonatal care.

Our report provides stark insight into how a system under pressure can perpetuate existing health inequalities and lead to poor care and harm for babies and families. Yet this is not inevitable. Change is possible and is being embedded right now on some neonatal units and in initiatives to tackle health inequalities.

Achieving equity for every baby requires bold and decisive action from everyone involved in the commissioning and resourcing, direct delivery, and monitoring of neonatal services, including policymakers, care providers, researchers and healthcare professionals. This project also reaffirms the importance of Bliss continuing to identify how we can be more inclusive and better advocates for the needs of all babies and families.

What we did

We undertook a comprehensive literature review to understand existing evidence on outcomes for babies needing neonatal care who are born into socioeconomically deprived families and minoritised ethnic groups. We wanted to understand:

- how a baby's neonatal care experience and health outcomes are impacted by health inequalities
- what the most significant data and evidence gaps are
- how effective current policy has been at identifying the impact of health inequalities in neonatal settings, and at addressing these.

We worked with two community partner organisations who conducted in-depth one-to-one interviews with nine parents who face challenges relating to socioeconomic deprivation. Additionally, we analysed transcripts from previous Bliss listening events with 11 Black and South Asian parents to identify common themes.

What we found

Unequal risk before and after birth:

- some babies face a **double disadvantage**. They are more likely to need neonatal care and more likely to have poorer outcomes on the neonatal unit
- there is a clear **intersection** between ethnicity and socioeconomic deprivation. Both factors are independent drivers of disparities in care and outcomes, but they also have a combined impact that increases the likelihood of poorer outcomes
- while there is growing evidence of where inequalities exist, and the extent to which they are present, there is **much less evidence on how to address them effectively**
- data gaps are prevalent, and there are **significant issues with data collection**, preventing effective responses to known issues

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[1] NHS England (2025) Maternity and neonatal infrastructure review findings [accessed online:] https://www.england.nhs.uk/long-read/maternity-and-neonatal-infrastructure-review-findings/

- policy intervention has focused on reducing inequity in neonatal outcomes through addressing inequalities during pregnancy and around the time of birth. **There has been limited attention on how inequalities in care delivery within neonatal services may manifest.**

Inequalities in clinical care, and experiences of care:

- evidence shows clear disparities in treatment and care practices, including **lower likelihood of deferred cord clamping and inconsistencies in breastfeeding rates** for minoritised ethnic groups and babies born into deprivation
- Family Integrated Care (FICare) – which enables parents to be partners in delivering their baby's care and decision-making – is proven to improve outcomes for babies but it is experienced inequitably
- **parental presence does not equal participation.** Data shows that parents with minoritised ethnicity and parents experiencing deprivation are less likely to be involved in ward rounds, receive early updates from staff and are not always adequately supported to be involved in their baby's care. We heard that **individualised care** was essential to support increased involvement but was often lacking in practice
- **language and communication issues are a significant barrier to FICare delivery.** Neonatal services frequently lack access to good and reliable systems to support interpretation. We also heard from families that minimal efforts were made to support communication with families who did not speak English
- **when parents are unable to be partners in delivering care, this affects babies' outcomes.** Evidence shows that babies whose parents are more involved in their care have better outcomes. The barriers to parental partnership for parents facing deprivation, and parents from minoritised ethnic groups, have a direct impact on their baby's health and development.

Beyond neonatal care:

- inequalities in parental partnership on the unit mean some parents will be less confident navigating the transition from unit to home. **Some babies go home to conditions which do not facilitate recovery**, and some parents cannot afford to run essential medical equipment
- socioeconomic inequalities impact longer-term developmental outcomes, and there are **ethnic and socioeconomic inequalities in developmental follow-up** rates
- outreach and follow-up services are patchy, resulting in **inequitable access across the country** that increases the risk of poorer health outcomes for these babies as they grow up.

What needs to happen

Making neonatal services more equitable and ensuring every baby has the best chance of survival and quality of life, regardless of their background or circumstances, is the responsibility of everyone working in or around these services: policymakers, care providers, researchers, healthcare professionals and organisations who support babies and families, including Bliss.

Bliss calls for action to ensure:

- equity is embedded in neonatal policy and service design
- financial barriers to parental presence are removed
- communication and interpretation services are high-quality, effective and readily available for every family who needs them
- individualised and culturally responsive care is delivered, supported by staff who are confident and have had the training and support they need to deliver it
- the neonatal workforce has capacity to deliver high-quality, equitable care
- data capture and data quality is improved to support a better understanding of the impact of health inequalities, how they manifest in neonatal care, and how they can be addressed.

Equity for Every Baby

Some babies born premature or sick face a double disadvantage: they are more likely to need neonatal care and more likely to have worse outcomes when on the unit

Financial barriers can limit parental presence and involvement

Inequity related to minoritised ethnicity and socioeconomic deprivation is present throughout every step of a baby's journey to, and through, neonatal care

Interpretation and translation services are poor, impacting FICare delivery

Babies born to families experiencing socioeconomic deprivation are less likely to receive developmental follow up, despite being more likely to have worse developmental outcomes

What needs to change

Embed FICare and ensure equal access to financial support

Improve collection of babies' demographic data

Invest in high-quality translation and interpreting services

Set national targets to reduce inequalities in rates of neonatal mortality, preterm birth and full-term admission

Increase representation in neonatal studies

Note on language

Bliss is committed to inclusivity and to ensuring that every baby and family feel seen, heard and respected. We recognise that language is continually evolving, and we remain responsive to how the individuals, families and communities we work with describe their identities and experiences.

The data available to us often groups together multiple communities, which can obscure diverse experiences, identities and health outcomes. To make sure we accurately convey research findings, it is sometimes necessary to replicate the language of that study. Where possible, we have been specific in our language. No single set of terms will reflect how every individual chooses to self-identify. When referring to Bliss' research participants, we use the language that participants themselves chose when describing their identity.

Where we use the term *parents*, we mean this to be inclusive of all those who have primary caregiving responsibility for babies, including carers and guardians. We recognise that families take many forms, and that not all parents identify as mums or dads.

We use the term 'minoritised ethnic' groups, instead of ethnic minority groups, to recognise that the minoritisation of some ethnic groups is an active process involving power, and does not just relate to the group's size.

When discussing socioeconomic deprivation, we recognise this term can feel stigmatising or reductive. We use it to describe the social and economic conditions that can affect people's health and access to care, such as income, housing, employment and education. We aim to use language that is respectful, accurate and recognises people as individuals, rather than defining them solely by their circumstances.

Introduction

Every day, over 1,500 babies are born in hospitals in England, with 1 in 7 of them needing specialist neonatal care[2].

Every one of these babies admitted to neonatal care will share some common experiences: they will be cared for in a specialised service by highly trained staff; the clinical care they receive will often be lifesaving, but it will also be traumatic – separating them from their parents, exposing them to pain and high levels of stimulation. Their parents or carers will be thrown into a world they're unlikely to have known about before. The most basic expectations they had about life with their newborn – such as feeding and holding their baby – will look very different.

What these babies do not have in common is an equal chance of survival and long-term health. It is an unacceptable and shameful reality that before a baby is even born, their chance of good outcomes is impacted by their ethnicity and their mother's circumstances at the time of their birth.

This report presents a detailed examination of existing literature alongside insights from families whose babies needed neonatal care, specifically families living with the effects of deprivation, and families from minoritised ethnic groups.

It shows that inequity is present through every element of a baby's neonatal experience – increasing their risk of needing neonatal care in the first place, affecting the quality of clinical care and Family Integrated Care (FICare) a baby receives on the unit, and shaping variations in longer-term neurodevelopmental outcomes and follow-up care.

Achieving equity for every baby requires bold and decisive action from everyone involved in the commissioning and resourcing, direct delivery, and monitoring of neonatal services – including policymakers, care providers, researchers and healthcare professionals. At Bliss, this project reaffirms the importance of continuing to identify how we can be more inclusive and better advocates for the needs of all babies and their families.

Neonatal policy context

Neonatal services under the spotlight

Neonatal services have been increasingly under the spotlight over the last decade. This followed the 2016 National Maternity Review, *Better Births*. While primarily a review of maternity services, undertaken in response to the Morecambe Bay Investigation, *Better Births* recognised that maternity and neonatal services are 'inextricably linked' and recommended undertaking a dedicated review of neonatal care[3]. Consequently, the *Neonatal Critical Care Review* made recommendations to address serious service concerns including aligning neonatal cot capacity to meet service demands, addressing significant staffing gaps and enhancing families' experiences[4].

The *Neonatal Critical Care Review* has led to significant and welcome improvements which help create environments that are better able to provide fair and equitable care. The number of neonatal nurses and Allied Health Professionals (AHPs) on units has increased, new roles at Operational Delivery Network (ODN) level have been created and building projects to improve cot capacity have been supported. However, the review did not specifically focus on tackling health inequalities within neonatal services.

Understanding inequalities in neonatal care

In the years since the *Neonatal Critical Care Review*, there have been several high-profile reviews and inquiries focused particularly on improving safety in maternity and neonatal care. This has been accompanied by a growing national awareness of health inequalities and more programmes designed to tackle them.

To date, policies and initiatives have largely focused on addressing health inequalities in maternal outcomes, and addressing disparities in neonatal mortality and morbidity through interventions to improve maternal health during pregnancy and optimise care around the time of birth.

There has been much less attention on how health inequalities affect babies' outcomes and the care they receive *within* neonatal services, and limited targeted action to better understand and address these issues.

While *Better Births* recognised that health inequalities can affect babies' outcomes, its recommendations did not include care in neonatal units. In the raft of reports and reviews which have followed (including the *Long Term Plan (2019), Three Year Plan for Maternity and Neonatal Services (2023)* and *Fit for the Future: 10 Year Health Plan for England* (2025)), the recommendations and policy proposals aimed at tackling health inequalities continually fail to target neonatal units.

For instance, while the 2021 NHS Pledge committed to *'improve equity for mothers and babies from Black, Asian and Mixed ethnic groups and those living in the most deprived areas'*, the Equity and Equality Guidance used by Local Maternity and Neonatal Systems (LMNS) to develop their Equity and Equality Plans (EEPs) contained no specific priority actions related to care for babies within neonatal units. Taking action on maternal mortality, morbidity and experience was a priority, yet there was no equivalent for babies[5] [6].

Most recently, neonatal services have been under the spotlight of the National Maternity and Neonatal Investigation (Amos review). While the Terms of Reference indicated that the Investigation would have a significant focus on health inequalities[7], and the interim report acknowledged that babies who need neonatal care are subject to variable outcomes tied to their ethnicity or the social circumstances they are born into[8], this has disappointingly not translated into the final report, published just days ago (30 June 2026).

It is expected that the newly formed Maternity and Neonatal Taskforce will develop an action plan in 2026 to set out a new path for how neonatal and maternity services should be delivered to ensure optimal outcomes and safe care. In light of the findings from the Review, it is more important than ever to ensure the experiences of babies who are cared for by neonatal services are front and centre, and to make inroads towards addressing the significant disparities in care and outcomes identified in this report.

Recognising strained resources for staff on neonatal units

Throughout this report we focus on babies' and families' experiences of neonatal care. We have found evidence of significant variation in experiences and outcomes, and interactions with staff that lacked compassion and curiosity. In some cases, care was affected by assumptions that were made about families based on their ethnicity or social background, which could have harmful consequences.

We recognise that poor quality care often reflects a system under pressure, and that services may lack the resources needed to provide equitable care to all babies and families. A good example of this is the lack of consistent access to translation and interpreting support.

Our report discusses the significant harm that can arise when these services are lacking, meaning parents are unable to fully participate in their baby's care. At the same time, we found that systemic issues play an important role in challenges relating to interpreting.

Research shows wide variation between services, with isolated initiatives, limited coordination and inconsistent access to high-quality interpretation[9] [10] [11]. Limited funding and high costs can lead to 'healthcare providers focussing on lowering costs at the expense of quality'[12] [13].

Healthcare professionals (HCPs) have reported concerns about the quality and accuracy of available interpreting services, including interpreters misrepresenting or not directly translating what they've said. This can make staff reluctant to use them, choosing instead to communicate directly with parents who have limited English[14] [15].

A lack of clarity about what qualifications interpreters working in neonatal services should have, and what exactly their role is, exacerbates the situation. This is particularly important when a discussion involves phrases which are not directly translatable in all languages.

Problems also arise due to gaps in guidance, training and support, for both interpreters and HCPs who may be caring for families with language needs in the context of highly sensitive, emotionally charged conversations involving complex medical information[16]. In this context, HCPs can find it very challenging to manage language barriers, particularly in urgent situations.

Staff experiences of the neonatal environment

Workforce challenges significantly impact the care practices explored in this report. Neonatal teams cannot deliver safe and equitable care unless their working conditions enable them to do so[17]. Where they are enabled, healthcare professionals describe providing FICare as being "rewarding and providing job satisfaction"[18].

In the UK, current neonatal nurse shortages mean that only 79 per cent of units meet the recommended ratio of nurses-to-patients[19]. Neonatal workforce challenges directly affect the care babies and families receive. High workloads and inadequate staffing levels lead to care being missed, including discharge planning and supporting and teaching parents – which are areas where we have found persistent inequalities and variable practice (see chapters 2 and 3)[20].

Despite the challenging environments and conditions they are working in, neonatal staff do not have enough psychological support, and this can have a huge impact. In a Bliss survey of over 700 neonatal staff members, more than half (52 per cent) reported experiencing anxiety or compassion fatigue, and a quarter reported flashbacks or intrusive thoughts. The most common factors staff highlighted as contributing to poor mental health and wellbeing were understaffing (87 per cent), and unmanageable workloads (68 per cent)[21].

It is also important to consider the increasingly hostile environment some staff are experiencing when working in NHS Hospital services – with instances of racial abuse, verbal and physical attacks on the rise[22]. While we do not know how common these instances are in neonatal care, working in this environment can make people more guarded and make it harder to build trust, affecting both families and staff.

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[2] NHS England (2025) Maternity and neonatal infrastructure review findings [accessed online:] https://www.england.nhs.uk/long-read/maternity-and-neonatal-infrastructure-review-findings/

[3] National Maternity Review (2016) Better Births: Improving outcomes of maternity services in England – A Five Year Forward View for maternity care

[4] NHS England and NHS Improvement (2019) Implementing the Recommendations of the Neonatal Critical Care Transformation Review

[5] NHS England and NHS Improvement (2021) Equity and equality: Guidance for local maternity systems

[6] NHS England (2021) NHS Pledges to improve equity for mothers and babies and race equality for staff

[7] Department of Health and Social Care (2025) National maternity and neonatal investigation: terms of reference [accessed online:] https://www.gov.uk/government/publications/independent-maternity-and-neonatal-investigation-terms-of-reference/national-maternity-and-neonatal-investigation-terms-of-reference

[8] National Maternity and Neonatal Investigation (2026) Independent Investigation into Maternity and Neonatal Services in England – Interim Report

[9] Sands and Bliss (2018) Audit of Bereavement Care Provision in UK Neonatal Units

[10] Sands and Tommy's Joint Policy Unit (2025) Not Just an Option: Interpreting as an Essential Component of Safe Maternity and Neonatal Care

[11] Sands and Tommy's Joint Policy Unit (2025) Translation and interpreting services in maternity and neonatal care

[12] Sands and Tommy's JPU (2025) Not Just an Option

[13] Clancy M, and Thomas F. (2026) Fostering cultural humility in perinatal palliative care. An interpretative qualitative study from the United Kingdom, *Mortality*, 31(1), 55-75

[14] Sands and Tommy's JPU (2025) Not Just an Option

[15] Sands and Tommy's JPU (2025) Translation and interpreting services

[16] Sands and Tommy's JPU (2025) Not Just an Option

[17] Leake N, et al. (2025) Facilitators and barriers to the practice of neonatal family integrated care from the perspective of healthcare professionals: a systematic review, *Arch Dis Child Fetal Neonatal Ed.*, 110(6):549-555

[18] Leake N, et al (2024) Facilitators and barriers to the practice of neonatal family integrated care, p.F3

[19] Chant K, et al (2026) Job satisfaction, burnout, and intent to stay in neonatal nursing in England and Wales: A cross-sectional survey study, *Intensive and Critical Care Nursing*, Vol 96

[20] Chant K, et al, (2026) Job satisfaction, burnout, and intent to stay in neonatal nursing in England and Wales

[21] Bliss (2021) Bliss research: mental health and well-being of neonatal staff [accessed online:] https://www.bliss.org.uk/bliss-research-mental-health-and-well-being-of-neonatal-staff

[22] BBC News (2026) 'Patients have tried to punch me because of my skin colour' [accessed online:] https://www.bbc.co.uk/news/articles/cly99nzqg6xo

Chapter 1: Increased risk of neonatal admission

Overview

This chapter highlights that babies from certain minoritised ethnic groups, and those born into higher levels of socioeconomic deprivation, face a double disadvantage in relation to neonatal care. They have a disproportionate risk of neonatal admission, and once admitted to a neonatal unit, they are more likely to have worse outcomes – including a higher risk of death while on the neonatal unit, and overall.

Importantly, these inequalities do not operate in isolation: an intersectional lens is needed to understand how ethnicity and socioeconomic status combine to shape experiences and outcomes in neonatal care.

We provide an overview of the existing evidence on socioeconomic and ethnic disparities linked to a neonatal unit admission, focusing on selected key reasons for admission. We prioritised the factors where the UK-based evidence is strongest and where Bliss can make recommendations for improvement.

An awareness and prioritisation of ethnic and socioeconomic inequalities in neonatal care and outcomes must sit at the heart of neonatal and maternity policy and practice. To make sure there is equity in access to services, and care delivery, services must be designed so that they meet the needs of *all* babies.

Premature birth

Premature birth poses serious risks for babies – both for the immediate days and weeks after they are born, and for their long-term health and development. Most neonatal deaths occur in babies born before 37 weeks, and many premature babies will have a lengthy neonatal admission and may have complex health needs which continue post-discharge[23].

Data consistently shows that women from minority ethnic groups and those experiencing high levels of socioeconomic deprivation are at greater risk of having a baby born premature[24] [25] [26] [27] [28].

Impact of deprivation

An analysis of 1.3 million births in England reported premature birth rates of 6.8 per 100 births in the least deprived areas, compared to 8.8 per 100 in the most deprived. This means two extra premature babies for every 100 births in the most deprived areas[29]. Another study estimates that nearly one fifth of premature livebirths between April 2015 and March 2017 would not have occurred if all women had the same risk as the least deprived[30].

Impact of ethnicity

In terms of ethnicity, rates of prematurity ranged from 7.8 per 100 among white women, to 8.6 for Black women[31]. Babies born to Black women have consistently had the highest rates of premature birth since 2007, when data collection began[32].

Differences in premature birth rates between ethnic groups are greatest at earlier gestational ages[33] [34]. The National Maternity and Perinatal Audit (NMPA) reports that babies born to Black and South Asian women had higher rates of premature birth before 32 weeks than babies born to white women. Over an 11-year period, up to 2023, Black women consistently had the highest rates of extremely premature (before 28 weeks of pregnancy) and very premature admissions to neonatal units (between 28 weeks and 32 weeks), with extremely premature admission rates that were nearly two and a half times higher than white women[35 36].

Babies born to Black and Asian mothers, and those from more deprived areas, are more likely to be born premature, and some face a higher risk of being born at very early gestational ages, when health risks are greatest. When babies are from a minoritised ethnic group *and* more deprived areas, the risks are compounded. This highlights the need for ethnic and socioeconomic health inequalities to be central to future neonatal care policy and planning.

Persistent variation

There is evidence to suggest that rates vary significantly at individual provider level. A recent analysis of data showed that within some NHS Trusts, the rates of premature birth amongst Black women and those living in the most deprived areas were nearly three times those for white women and the least deprived[37]. While levels of risk amongst patient populations vary between providers, these figures are nonetheless striking and highlight the work to be done to remedy inequalities in perinatal outcomes[38].

Impact of prematurity

The impact of prematurity has been recognised at the highest levels of policymaking. In 2017, the then-Department of Health set a National Ambition to reduce the rate of premature birth from 8 per cent to 6 per cent by 2025. Despite acknowledging premature birth as a 'major health inequality', due to variations by ethnicity and deprivation, there was no specific mention of health inequalities in the target set by the then-government[A]; and no new or updated targets have yet been set by the current government. The latest figures published by NHS England show there has been no progress towards achieving this ambition – with overall rates of premature birth still around 8 per cent – and that clear disparities persist[39].

The risks linked to premature birth vary depending on how early a baby is born. Babies born before 32 weeks of pregnancy will need highly specialised, and prolonged, care – with the duration of neonatal care increasing with earlier gestational age. These babies are most at risk of neonatal death and serious long-term health problems[40 41]. Risks are greatest for babies born before 28 weeks of pregnancy, and fewer than one in five of these babies leaves hospital without serious complications[42].

To bring down overall rates of premature birth, and ensure equitable outcomes for babies, it is therefore vital to address inequalities in premature birth rates by socioeconomic status and ethnic group.

Full term admission

While much research on health inequalities looks at prematurity, term babies (those born at or over 37 weeks' gestation) make up around 60 per cent of the neonatal unit population[43]. These babies also face disproportionate risks of neonatal unit admissions based on their ethnicity and levels of deprivation.

Analysis of 2012-2022 data from England and Wales[B] reported 'a social gradient in babies admitted to NHS neonatal units'. 15.1 per cent of babies born to mothers living in the most deprived areas were admitted to a neonatal unit, compared to 6.5 per cent from the least deprived areas[44]. This data includes all babies requiring admission (both premature and those born at term).

[A] Department of Health (2017) Safer Maternity Care The National Maternity Safety Strategy – Progress and Next Steps

[B] The vast majority of data used in this analysis was from England, so while there's no separation of the two nations' data, the results will be strongly applicable

The NMPA, which evaluates care processes and outcomes, reports that rates of term admission to a neonatal unit increase with deprivation, and that babies born to South Asian and Black mothers are more likely to be admitted to a neonatal unit at term than those born to white mothers[45]. Reasons for admission also vary by ethnicity. For instance, in England, Asian babies have been found more likely to be admitted to a neonatal unit at term for jaundice[46 47].

Further research indicates that deprivation increases the risk of prolonged neonatal unit admission at term, defined as more than two days of high-dependency or intensive care[48]. A study of babies born after 35 weeks' gestation found that socioeconomic deprivation remained a risk factor for longer Neonatal Intensive Care Unit (NICU) admission even after accounting for other maternal risks, highlighting the central role of structural disadvantage in shaping both admission and length of stay[49].

Low birthweight and fetal growth restriction

Babies from minority ethnic groups and those facing greater socioeconomic deprivation are disproportionately affected by low birth weight (LBW) and Fetal Growth Restriction (FGR). This is important, because both are associated with increased risks of neonatal admission, death, developmental complications and poorer health later in life.

Low Birth Weight (LBW) is defined as weighing less than 2,500 grams when born. While many premature babies are LBW, not all LBW babies are born premature.

Fetal growth restriction (FGR) is when a baby is smaller and lighter than would typically be expected for their gestational age, usually caused by a clinical issue. For some babies, their LBW will have been caused by FGR[50].

Babies from Black, Asian, and 'Mixed and Other' ethnic groups are at greater risk of LBW, and this increased risk remains even after taking socioeconomic deprivation and maternal risk factors into account[51 52]. There is also a strong and well-established association between risk of LBW and markers of socioeconomic deprivation, including lower-level maternal education, occupation and social class[53 54]. Evidence suggests that by the second trimester, the impact of socioeconomic factors on fetal size and growth can already be seen[55].

Studies show the social conditions in which women and birthing people live shapes outcomes for their babies[56 57]. These findings suggest that the stress of racism and poverty have a direct impact on the risk of a baby being born premature or sick.

For instance, one study of nearly 2.3 million births connected a striking rise in rates of premature birth and LBW with the onset of austerity in the UK in the early 2010s, particularly impacting those living in the most deprived areas. While this study focused on babies in Scotland, the lead researcher has explained that, as post-austerity poverty rates are higher in England, we can expect to see similar trends in England[58]. The researchers believe that cuts in social security benefits and services are an important factor in understanding the increased risks for babies. This also aligns with findings from mainland Europe which link austerity with increases in adverse birth outcomes[59].

Similarly, new research has linked the physiological effects of systemic racism and socioeconomic disparities to higher rates of premature birth and FGR in Black women[60].

The risk of babies being born too early and too small is affected by socioeconomic deprivation and by the biological, psychological and material stresses caused by trying to live without enough money and living in social conditions underpinned by structural racism. This highlights how important it is that improving neonatal outcomes and reducing disparities is a responsibility that does not just sit with neonatal, or indeed, maternity services. There is a role for policy which addresses the wider determinants of health to consider neonatal outcomes, particularly those related to LBW and FGR which are so intrinsically linked to prematurity and neonatal admission.

Jaundice

Jaundice is a leading cause of term admissions to neonatal care[61]. Jaundice, if detected early, can be appropriately managed in a transitional care setting, or at home with a neonatal home care team, for most term babies, without any long-lasting harm[62]. However, delays in identifying and treating jaundice can increase the likelihood of a baby requiring admission to a neonatal unit and, in extreme cases, can result in kernicterus, a form of brain damage which causes lifelong disability[63].

While jaundice is very common – affecting 60 per cent of term babies and 80 per cent of premature newborns – there are marked ethnic disparities in assessment and outcomes[64]. For instance, Asian babies have been found more likely to be admitted at term to neonatal care for jaundice. In this study, jaundice was the most common reason for admission from home, suggesting a delay in identification[65].

Limitations in the assessment of jaundice, along with other conditions like cyanosis, in minority ethnic babies have been highlighted by the NHS Race & Health Observatory (RHO), whose work has exposed the racial bias in guidance on assessment as well as in the policies and education for HCPs, which may lead to delays in diagnoses and care for babies with darker skin[66].

Research on kernicterus has found that Black, South Asian, and 'all other' minoritised ethnic groups made up half of all cases in England between 2012 and 2019, although these groups accounted for just a quarter of all babies born during that time[67]. These findings highlight preventable inequalities in neonatal care that contribute to worse outcomes for minority ethnic babies.

Good Practice:
Research is currently being undertaken to reduce health inequalities in jaundice by developing a smartphone app which can detect severe jaundice in all babies, regardless of their skin colour, by taking a photograph of the white part of a baby's eye[68].

Conclusion

The evidence presented in Chapter 1 highlights the double disadvantage faced by babies from minority ethnic groups and those born into greater deprivation. These babies are at disproportionate risk of admission to a neonatal unit.

If we are to improve the lives of every baby, and effectively reduce rates of premature birth, neonatal mortality, and the need for admission to neonatal care, we must consider every aspect of this double disadvantage and pay attention to the wider society and context in which neonatal services exist.

While neonatal care offers an important opportunity to address health inequalities, babies' outcomes are partially shaped before they are born. It is therefore clear that wider prevention strategies, including through strengthened antenatal and maternity pathways, will be needed to effectively address neonatal health inequalities, in addition to changes in the delivery of neonatal care. Ultimately, we will only achieve significant and sustained reductions in rates of admission if we focus on tackling disparities in rates between groups.

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The Government should set clear, national targets to reduce disparities in rates of neonatal mortality, preterm birth, and full-term neonatal admissions between ethnic and socioeconomic groups.

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[23] Gallimore ID, et al, on behalf of the MBRRACE-UK Collaboration (2026) MBRRACE-UK Perinatal Mortality Surveillance, UK Perinatal Deaths of Babies Born in 2024: State of the Nation Report. Leicester: TIMMS, School of Healthcare, University of Leicester.
[24] Office of National Statistics (2023) Birth Characteristics in England and Wales: 2021
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Chapter 2: Care on the neonatal unit

Overview

This chapter explores health inequalities related to care directly on the neonatal unit. It brings together insights from our review of existing evidence and recent qualitative research from Bliss' engagement work where we heard from Black families, South Asian families, and families facing deprivation about their babies' experiences in neonatal care.

We begin by laying out the evidence from national data on ethnic and socioeconomic inequalities in the care that babies receive on the neonatal unit. The chapter then outlines how inequalities inhibit FICare, focusing on barriers to parents being present on the unit, being involved in decision-making, and to communication between parents and staff.

This chapter demonstrates that parental presence alone does not guarantee partnership in delivering a baby's care. Constraints, including practical and financial barriers, prevent some parents from being on the unit as much as they want and need. An individualised approach to care is essential to ensure all babies can benefit equally from FICare.

Our findings show that a range of factors can affect the ability to build equitable partnerships between HCPs and parents in caring for their baby. These include power dynamics between parents and HCPs, language barriers, communication issues and racism.

We also showcase examples of good practice, including respectful, compassionate, culturally responsive care, and we highlight tools to support neonatal teams to deliver individualised care.

Differences in clinical care babies receive on neonatal units

There is much less evidence on inequalities in care and outcomes once a baby has been admitted to a neonatal unit in England, compared to what is known about inequalities during pregnancy and around birth. However, research is emerging which suggests that the care babies receive on the neonatal unit itself can vary according to ethnicity and deprivation, and that these differences may be contributing to long-recognised inequalities in babies' outcomes.

A study of data from more than 700,000 babies admitted to NHS neonatal units in England and Wales found 'stark socioeconomic and ethnic inequalities' in the risk of death before discharge from the neonatal unit in England and Wales[69].

Babies born to Black mothers had the highest risk of death with an 81 per cent higher risk of death on the unit than those born to white mothers. Deprivation also carried significantly increased risks of death. Babies born to mothers in the most deprived areas had a 63 per cent higher risk of dying before discharge from the unit, compared with mothers from the least deprived areas. Socioeconomic and ethnic inequalities independently shape survival in neonatal units. Some of the inequalities identified in this study could be explained by known risk factors, such as gestational age, birthweight and the mother's age. However, not all differences were accounted for, indicating there may be other reasons for such inequalities, such as care practices[70]. Further research is needed to understand what these variations in care may look like.

While more research is needed to identify whether disparities in outcomes occur across different types of clinical care and intervention, there are some insights relating to deferred cord clamping (DCC)[71]. This is a medical intervention that takes place when a baby is born, where the cutting of the umbilical cord is delayed until at least 60 seconds after birth. While it takes place in the delivery suite, it is led by neonatal clinicians ahead of neonatal admission. This is an important clinical intervention, as DCC has been shown to reduce mortality by up to one third in extremely premature babies[72].

A recent study found that babies from Black, Asian, 'Mixed' and 'Other' ethnic groups were less likely than white babies to receive DCC in neonatal units in England, even when level of deprivation was considered[73]. Further interrogation is needed to understand why these clinical disparities exist, what drives them and how to reduce them.

Outside of specific clinical interventions, it is well established that clinical training, guidance and equipment in the UK have historically been designed with lighter skin tones in mind. This can directly impact the care a baby receives. For instance, some staff report finding it harder to cannulate Black, Asian and minority ethnic babies, which may lead to more cannulation attempts, increasing babies' exposure to discomfort and pain, as well as potential delays in care[74] [c].

Breastmilk feeding support

> *"Mum shared that she did all the cares for the babies, she was able to make her own choices about how they were fed, how often, how much they should take. The nursing staff were around but didn't need to intervene. She felt supported by the hospital and was grateful for their reassurance."*
> *Interview by partner organisation working with parents at risk of, or who have suffered, removal of children from their care*

Due to prematurity or illness, babies who need neonatal care often cannot feed directly from a breast or bottle and need to first be fed in other ways. Mothers are encouraged to express breast milk by hand or pump, and this milk is then given to the baby through a tube or syringe. Mothers are advised to begin expressing breast milk within one or two hours after giving birth, and at least eight times a day to maintain milk supply[75]. For many, this is an unfamiliar and difficult process, compounded by the stress of their baby's neonatal admission, and by often being unwell themselves or exhausted from birth.

National data shows that babies born at less than 34 weeks to Black and Asian women are less likely to receive breastmilk in their first two days of life than babies born to white women[D]. This is despite the fact that evidence shows that white women are less likely to breastfeed overall, and that by 14 days post-birth, Black and Asian babies born premature were more likely to be receiving their mother's own milk. This may indicate that Black and Asian women are not being given the same support as white women to express milk immediately after birth[76]. The same study also found that babies born to parents living in greater deprivation are also less likely to receive early breastmilk[77].

While this data reveals the existence of inequalities, it offers limited insight into the causes. Through work with community partners, Bliss has identified opportunities to better support Black and South Asian parents, as well as those experiencing socioeconomic deprivation, with feeding.

One mum in our engagement work with communities facing deprivation recalled a time she was brought to tears by a nurse after trying to feed her baby:

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[c] We are using broad categorisations here for ethnicity, as these were the designations given in the NHS Race and Health Observatory report.

[D] These were the categories used within the report.

> *"I was breastfeeding, standing up…and then the woman [nurse] came in and she was like, 'oh, I saw you when your friend was here… you were just like swinging your baby around breastfeeding. You can't do that. Like, that's not how to breastfeed.' And I was like. 'Oh', because I thought I was doing well, because he'd latched on for like a good 10 minutes. And obviously I didn't say this to her, I just cried…I was just like, 'oh, sorry'. And then like she left and I cried. I think it's just a lot of pressure, isn't it?" Mum, interviewed by a partner organisation working in communities facing deprivation*

While mums from all ethnic and socioeconomic backgrounds can find it difficult to breastfeed and navigate expressing breast milk, NNAP data suggests the difficulties are compounded by being from a more deprived area or a minoritised ethnic group. Factors identified in the remainder of this chapter offer some insights into further barriers which may be contributing to additional challenges and less support for some families.

Modesty and cultural needs

> *"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." Mum, Bliss South Asian families' experiences of neonatal care report.*

A lack of privacy and modesty on neonatal units can be challenging for women of any ethnicity or faith, yet this may be especially important for women from minoritised ethnic groups.

Previous research by Bliss found that being able to maintain modesty and privacy, including during feeding and skin-to-skin care, was important for all the South Asian women who participated, especially for Muslim women. Yet nearly a third of respondents felt these needs were not understood or respected by staff, and parents reported that the inability to observe modesty needs made breastfeeding and skin-to-skin more challenging[78].

Ultimately, this has an impact on the care a baby receives. As highlighted in the following sections, it is well evidenced that babies have the best outcomes when their parents are fully involved in caregiving. Central to this in neonatal units is comforting touch, skin-to-skin care and breast milk feeding, for mothers who wish to do this. Individualising care, so it is sensitive of, and responsive to, individual parent needs and preferences – including cultural and faith-related – is important for maximising these direct caregiving opportunities.

Inequalities as a barrier to FICare

> *"It's very strange when you're in [neonatal care], it's like a pressure cooker… because you have this expectation, especially when it's your first, that you're gonna go in, have your baby, put them in the car seat, come home." Mum, interviewed by a partner organisation working with communities facing deprivation*

What is FICare?

It is well established that babies have better outcomes when their parents are partners in delivering their care. Neonatal units enable this through embedding Family Integrated Care (FICare) – a model of care which promotes a culture of partnership between parents and HCPs. In England, the *Service Specification for Neonatal Critical Care* states that 'each unit must provide a Family Integrated Care approach', integrating parents and carers into the care team to enable informed decision-making and delivery of developmentally supportive cot-side care[79].

FICare aims to empower parents and carers to feel confident in their role as their baby's primary caregivers during their neonatal stay. Parents are supported by staff to participate in as many aspects of their baby's care as they wish, including hands-on care like feeding, nappy-changing, and comforting their baby during procedures. This model also supports parents to make decisions about their baby's care and advocate for their baby.

To implement FICare equitably, practice must be individualised, reflecting that parent partnership looks different for every family. It takes *time and trust* for parents to feel confident parenting their baby in neonatal care and to develop those strong, trusting relationships with staff which are so important. Indeed, research suggests that when families are invited to share what matters to them, they are more likely to ask for anything which might support them[80].

Good practice:
The Bliss Baby Charter provides units with a clear framework designed to build the foundations of FICare.

Why is FICare important for babies?

Evidence shows that both physical and emotional closeness are essential for developing strong parent–infant bonds. Extended periods of parental presence are associated with increased parental confidence and reduced stress and anxiety[81 82]. Parental involvement is proven to be best for babies' developmental outcomes, with long periods of direct care being linked to weight gain and improved breastfeeding rates. It also yields benefits for the wider neonatal service, including earlier discharge, reduced readmission, and increasing the amount of time staff have for clinical duties[83].

Barriers to parental presence on the unit

At the heart of successful FICare delivery is supporting parents to be present on the neonatal unit. Parental presence is the most fundamental starting point for enabling babies to benefit from partnership in care, creating opportunities for parents to build confidence, provide hands-on care and participate in shared decision-making.

Despite its importance, not all parents are able to be on the unit as much as they would like. There are many reasons for this: several are common across families, such as work commitments or caring responsibilities for other children, while others disproportionately affect some families (such as those experiencing socioeconomic deprivation). These barriers can limit opportunities for parents to participate in their baby's care.

Financial barriers

> *"Previous research from Bliss found families face an average additional cost of £405 per week while a baby is in neonatal care." Bliss, Impact of the Cost of Living Crisis, 2022.*[E]

It should never be the case that a family's financial circumstances prevent them from being with their baby, yet this is a reality for many. Babies whose parents face financial challenges may experience reduced parental presence on the unit and reduced opportunities for hands-on care, limiting their opportunity to benefit fully from FICare.

Previous research by Bliss shows that financial pressures have a significant impact on parental presence on the unit. In a survey of nearly 2000 parents, more than half (52 per cent) said that costs impacted how involved they could be in their baby's care[84] [F].

While age and socioeconomic status should not be conflated, we know there is an over-representation of young parents within more socioeconomically deprived communities, and that these factors compound barriers on the unit[85]. In a survey of young parents specifically, 64 per cent told Bliss their family finances suffered because of their baby's neonatal admission. For young parents, the financial impact of a neonatal stay can also affect the wider family, who may help cover costs[86].

The unexpected additional costs associated with neonatal care are well documented – arising from lack of overnight accommodation near the hospital, daily travel, food and drink costs, childcare and more[87].

Travel and accommodation

Previous Bliss research found that travel is, on average, the biggest cost for parents with a baby on a neonatal unit. Parents who use public transport, who are more likely to be on lower incomes, spend around £18 more a week on travel than those who use their own car. An astonishing 84 per cent of public transport users told Bliss that access to transport prevented them being as involved as they wanted to be in their baby's care. For parents using cars, parking fees can add up to hundreds of pounds during their stay[88].

Many families would prefer to stay directly on the neonatal unit, particularly if they must travel long distances or the daily costs of travelling to the unit are prohibitive. However, Bliss has found that for every ten babies that need to stay overnight in neonatal care, there is only one room available for a parent to stay with them[89].

Accommodation on and near neonatal units is critical by reducing separation of babies and their parents, and can help parents manage costs as onsite accommodation is generally free of charge. Ultimately, when parents cannot travel due to lack of funds, and cannot access accommodation, they simply cannot attend the unit as much as they need or want, meaning that their baby misses out on vital interaction and care which supports their development.

[E] This figure was based on survey responses detailing costs families experienced in the five years up to and including 2022. It is likely unanticipated expenditure, and financial pressure is higher on families now as the cost of living has continued to rise.
[F] Method: self-selecting survey disseminated through Bliss social media and email newsletters, and via partner organisations in February and March 2022. 1928 respondents

The need for more financial support

Neonatal units across England work hard to support parents to be with their baby. However, support is often patchy, means-tested and reliant on unstable charitable or grant funds[90]. For instance, some units can provide meals, but this may be only to breastfeeding mothers, or at some hospitals parents might be able to access emergency bursaries if they meet strict criteria.

Bliss recently worked with a community organisation to hear from parents facing socioeconomic deprivation. Even though all were struggling financially while their baby was in neonatal care, none of the parents we heard from were offered any support that would have alleviated financial stress at this time. This can exacerbate the strain of a neonatal experience and leave parents feeling unsupported.

> *"[We] basically got told, like, 'fend for yourself, it's your baby, your responsibility. We can't do nowt.' So again, another sort of added stress to the already stressful situation." Mum, interviewed by a partner organisation working in communities facing deprivation*

Good practice:
Providing financial support for families is a proven way to increase parent partnership in their baby's care and reduce separation.

Since 2018, families with a baby in neonatal care in Scotland have been able to access funding to cover travel, food and accommodation costs (through the Neonatal Expenses Fund, now the Young Patients Family Fund). An evaluation found that this support reduced financial stress and enabled parents to spend more time with their babies on the neonatal unit[91].

There is growing recognition of the financial pressures families face when a child requires hospital care. In February 2026, the UK Government announced a £10 million support package for families of children with cancer, acknowledging the costs of long hospital stays and travel. Families with babies in neonatal care often face similar challenges, highlighting the need for a consistent and universal approach to financial support.

Involvement in decision-making

> *"She [the mum] felt happy raising concerns or asking questions. Giving an example of raising worries about one of the babies' breathing, she was told she was right to raise this, so she felt taken seriously." Interview by partner organisation working with parents at risk of, or who have suffered, removal of children from their care*

The importance of shared decision-making

The importance of being informed and supported to participate in shared decision-making is reflected in the NHS England *Neonatal Critical Care Service Specification* and NICE guidelines[92][93].

However, analysis of national data shows ethnic and socioeconomic inequalities in two important measures of parental involvement: consultation with a senior member of the healthcare team, and parental involvement in ward rounds. These two elements of care have national guidelines that should be followed when a baby is admitted to a neonatal unit, to enable parental partnership. The National Neonatal Audit Programme (NNAP) uses data on ward round involvement to assess how involved parents are in decision-making.

National data on inequalities in decision-making

NNAP data shows that Asian parents, and parents from more deprived areas, are less likely to be updated by a senior member of the neonatal team within 24 hours of their baby's admission[94][G]. Parents from more deprived areas, and parents from all ethnic groups other than white are also less likely to be included on consultant ward rounds than parents from less deprived areas and parents who are white[95]. These ethnic and socioeconomic inequalities were evident even after accounting for a range of clinical and maternal factors.

This study highlights the cumulative impact of multiple disadvantages, estimating that 48 per cent of white parents from the least deprived groups are likely to be included in ward rounds, compared to 37 per cent in the most deprived. By contrast, 36 per cent of Asian parents from the least deprived groups are likely to be included in ward rounds, while this drops to 27 per cent in the most deprived groups[96].

The inequalities highlighted by this data reveal missed opportunities for minority ethnic parents, and those from more deprived areas, to be informed, involved, and confident in their baby's care, and to develop relationships with clinical members of their baby's care team. This evidence also means missed opportunities for the clinical team to hear insights from these parents, which may lead to delays in diagnoses and care for their babies.

Parent engagement insights on challenges in decision-making

The data above suggests that more needs to be done to remove barriers to parental involvement in ward rounds. Our work with families also highlights additional barriers and enablers to supporting parents to be actively involved in planning and decision-making about their baby's care.

[G] Asian is the categorisation used in the study

Parental presence does not equal involvement

An example from our engagement work with families facing deprivation, carried out in partnership with community organisations, illustrates that parental presence and parental *involvement* are not the same thing.

One mum had two babies who – at separate times – needed long stays in neonatal care. With her first baby, although she was *"there all day, every day"*, she was very uninvolved and unsupported. With her second baby, childcare responsibilities meant she was only able to be at the hospital for four hours a day; however, she was substantially more involved in his care.

> *"[With my daughter] I didn't really touch her, or I didn't change a nappy. I didn't do the feeds with the feeding tube because I was scared. Whereas with [my son] I was very hands on and did it all and felt confident. It was completely different ends of the scale for them both." Mum, interviewed by a partner organisation working in communities facing deprivation*

Enabling parents to be present on the unit is the first essential step towards parental partnership in care, but presence on the unit does not guarantee equity in involvement. Effective communication and relationships with staff are also critical for meaningful parental partnership (see page 28).

Power dynamics and involvement in decision-making

Evidence suggests that even when families feel informed about their baby's care, they can still feel less *involved* in decision-making. This reflects widely observed power dynamics in healthcare, where professionals decide what is to be done, then communicate this to patients. FICare requires a culture-shift away from this approach.

Our engagement work with families facing deprivation showed that top-down approaches to neonatal care continue to exist, with families reporting receiving information about their baby's care, but not being involved in decision-making[97].

> *"It was sort of, you will do this or this will happen. Although you got given the information, you didn't really have a choice because they'd already decided for you." Mum, interviewed by a partner organisation working in communities facing deprivation*

Parents explained that feeling part of discussions about their baby's care would have made them feel more empowered.

> *"They just told me what was happening... I think maybe [if staff had involved me a bit more] I wouldn't have felt so little." Mum, interviewed by a partner organisation working in communities facing deprivation*

The need for individualised care in decision-making

FICare is grounded in an individualised approach to care that responds to each family's wants and needs. While some families tell us they would have liked to be more included in decisions about their baby's care, others say they feel that a division of responsibilities is appropriate. There are also cultural differences in attitudes towards clinical decision-making, and not all parents will feel comfortable inputting into this[98]. What is important is that all parents are given enough information and support to make the decisions they want to make, and that staff adopt a curious stance in understanding the choices parents make.

Decision-making is complex. It is shaped by practical barriers, such as language, as well as less visible factors like power dynamics, psychological and cultural safety, and communication. These all affect how confident and comfortable parents feel in making decisions about their baby's care and asking for support or clarification.

Confidence and power dynamics in practice

Confidence and power dynamics emerged as a theme in the interviews with families in deprived communities. These factors can impact shared decision-making about a baby's care.

Asking more from staff or challenging a medical professional responsible for your baby's care can make parents feel vulnerable. How confident people are in healthcare settings, and in dealing with medical professionals, will be shaped by a range of factors. Research shows that being from a lower socioeconomic background is associated with reduced confidence levels, compared to individuals from higher socioeconomic backgrounds[99] [100]. Neonatal professionals have also reported that some parents 'get more attention and time because of their education levels and their confidence in asking'[101].

In our engagement work with families facing deprivation, half of the parents we heard from said they did not feel comfortable asking questions or raising concerns[102].

Some parents reflected on the impact of being young, first-time mums, and not having the confidence to speak up.

> *"I think, like, I felt like it wasn't my place to sort of ask." Mum, interviewed by a partner organisation working in communities facing deprivation*

Individualised care is critical, as confidence and comfort will be shaped by intersecting factors.

Some parents internalised part of the blame for inequalities in decision-making, noting that their own personalities made it harder to ask questions or raise concerns. Others, however, felt that if staff had a better understanding of their personal circumstances and offered more support, they would have felt more able to be involved in their baby's care.

> *"Interviewer: Did you feel comfortable asking questions or raising concerns?*
>
> *Mum: Yes. With [my son], not so with [my daughter]. I do think a lot of it's down to age and building on the confidence and it being completely new and not knowing. Whereas with [my son] I had a bit more knowledge and a bit more, I feel like I've got the confidence to say, 'oh, is this what's going on?'...*
>
> *[With my daughter, I] definitely felt like there should have been a bit more comfort, a bit more guidance. For them to think, oh, 'she's only young. Maybe she does need a little bit more support.'" Mum, interviewed by a partner organisation working in communities facing deprivation*

Some parents reported feeling as though they were under scrutiny and being judged, making it harder to establish a sense of equal partnership and shared decision-making.

Personal and professional power dynamics on the unit can make speaking up difficult. For instance, one young, first-time mum felt uncomfortable with how some nurses tube-fed her baby. Yet, she didn't feel it was her place to comment as it felt like telling them how to do their job.

> *"Mum: I'll be honest, like when you watch them doing it, some of the nurses will just come in and do it really fast. And then like he'll throw up all his milk afterwards, whereas that one nurse at the night-time was so slow with it and like took the extra care. Whereas I feel like others were just sort of like, 'oh, well, you know, it's a tube just [expresses quick movement], that's it.' And you're like sat there and you're watching them and you're like, 'no... I don't think that's the right way to do it'.*
>
> *Interviewer: Did you feel you could say anything about that?*
>
> *Mum: No…I think it was because I was young. And because I was a first-time mum and they know their job. They know how they do it and how they want to do it. So you feel like you are not in the right place to tell them to do anything, like how they're doing their job is wrong. And I think as well…I felt like I was under scrutiny rather than them." Mum, interviewed by a partner organisation working in communities facing deprivation*

The sense of being judged and under scrutiny is something we heard from other parents, which both reflects and can exacerbate existing power dynamics on the unit[103].

The idea that there's a set way things are done on the unit meant parents didn't always feel able to ask for things outside the 'official' rules (such as relatives visiting outside set hours). In some cases, when parents *did* ask for things, we heard that staff responded with flexibility and kindness to facilitate their requests. This highlights the importance of early conversations to build relationships and establish trust to facilitate ongoing dialogue about what families need, recognising that things may change during their time on the unit.

For other parents, recognition of constraints staff were under limited their sense of what level of care they felt they could ask for. One mum explained how this resulted in her feeling she had to remain on the unit constantly, taking on more of the direct caregiving role than she felt comfortable with, despite being a maternity in-patient herself and having another child at home.

> *"I think it was sort of selfishly me thinking, 'oh, well you're not doing as much for my baby.' But then when you look around, you see all the other babies. It's like you can't really say naught to 'em. You don't feel like you can.*
>
> *So that's when I sort of took a step back, and I were like 'right, I'll just sort of stay here and do it myself.' You know? Which is sad." Mum, interviewed by a partner organisation working in communities facing deprivation*

Good practice:
Bliss has worked with healthcare professionals and parents, including parents and carers who have experienced health inequality, to develop a toolkit to support units to deliver an equitable model of FICare.

We know that early conversations between parents/carers and healthcare professionals can help to build relationships and foster a culture of partnership based on trust and respect.

The Early Conversations toolkit includes a framework for what to consider before, during and after a conversation, along with conversation prompts.

By helping to identify parental concerns and support needs early on in their neonatal stay and developing a personalised care plan, Early Conversations provides a universal approach to individualised care that enables better outcomes and experiences for all babies and families.

Barriers to communication

Communication and relationships which enable FICare

> *"Communication is key." Mum, interviewed by a partner organisation working in communities facing deprivation*

In our work with families from deprived communities and minoritised ethnic groups we heard that delivering high quality care, in line with a FICare approach, is not just about the immediate provision of medical care to the baby, or about sharing medical information with parents. We heard that compassionate, collaborative, and sensitive communication between families and staff – which is responsive to each family's individual wants and needs – is extremely important.

We found that the quality and style of communication varied between units, and between different staff members on the same unit[104]. For parents, this variation could add an additional layer of stress to an already difficult experience.

Some parents expressed their gratitude for the care their baby received, and acknowledged the pressures that staff are under, but felt they could have been more involved in their baby's care, and had a better overall experience, if communication had been better.

> *"At least she's home. And she was okay, and I'm thankful for 'em, in the sense that they did, you know, give her the medical side of things. I'll always be grateful for that… But as per like the treatments in between and the dealing with family and stuff like that... It could be worked on. 'Cause it's a very sensitive time…*
>
> *I understand they're overworked… [but] you shouldn't treat people like that." Mum, interviewed by a partner organisation working in communities facing deprivation*

When good relationships and communication were not established, parents felt less comfortable generally on the unit.

Some parents shared examples of abrupt, dismissive, and critical communication from HCPs which made them less comfortable asking questions or raising concerns. This ultimately contributed to parents being less informed and less involved in their baby's care.

> *"[Communication was] few and far between. It were sort of [us being] spoken to. And when we did come across and sort of, you know, ask questions…It were quick, short, snappy answers…That made me reluctant to ask any more…you know, like, when you feel like you're pestering?" Mum, interviewed by a partner organisation working in communities facing deprivation*

One mum we heard from had two experiences of neonatal care, with two separate babies in two separate hospitals, and a real contrast in experiences which highlighted how important effective communication and caring relationships can be in supporting FICare delivery.

> *"[With my daughter] there could have been more communication and support. Whereas with [my son] I kind of made friends with some of the nurses… and it were nice to go in and think, oh, 'so and so's got him today' because we kind of built a relationship. Whereas with [my daughter] I never really had that, to be honest. Never really had a close relationship or chats." Mum, interviewed by a partner organisation working in communities facing deprivation*

Language barriers

> *"They'd call her husband and then her husband would tell her [what was happening with their baby], but she doesn't know if this was before things would happen or after." Relative of a mother – listening event with South Asian families*

When language support services are absent or inadequate, this can have a serious, detrimental impact on parental partnership, wellbeing, and on a baby's care. Indeed, there is a growing evidence base which has identified avoidable harm to babies and families linked to language and communication-related inequalities[105].

No parent should be left in the dark about what is happening with their baby in neonatal care. However, our research found that when parents do not speak English or don't have a confident grasp of it, they are less able to be involved in their baby's care and are much less aware of what care their baby needs and is receiving[106].

The importance of professional interpreters and individualised care

Despite the serious consequences of unaddressed language barriers, interpreters are not always used, even when a language need is known. Reasons for this are discussed in greater detail on page 10.

Professional interpreters should be offered and used, and care should be tailored so each family can understand and take part in their baby's care. Staff should not default to 'easier' alternatives – such as relying on family members – or make assumptions about language needs.

This is particularly important in the neonatal context, as parents have shared how hard it can be to take in information and express themselves while their baby is on the unit, even if they speak 'good' English.

Parents in our engagement work with Black and South Asian families had experiences of limited or no attempts being made to use interpretation services, and family members being heavily relied upon to relay information instead. From these conversations it seemed that using relatives as interpreters was routine, rather than a last resort, on some neonatal units. In some cases, the relatives who were relied on for interpreting described 'popping in' to the unit when nearby, underscoring the inconsistency and unreliability of this arrangement[H].

> *"I would end up interpreting for her via the phone. There was a couple of times when that happened." Relative of a mother – listening event with South Asian families.*

> *"They didn't [get a translator]. They waited for me to come in and I think I was just driving by and I thought, oh, we'll just pop in." Relative of a mother - listening event with South Asian families.*

We found that if one of the baby's parents spoke English, they were often used to interpret for the other, even if the English-speaking parent was the mum who was ill or recovering after birth. As one mother explained, her inability to fully absorb the information given to her meant her husband did not receive information about their baby.

[H] While guidance against such practices exists, there is plenty of evidence that people other than professional interpreters are used for interpreting in maternity and neonatal care, including staff, friends, and family members (Sands and Bliss, Audit of Bereavement Care Provision in UK Neonatal Units, 2018; Sands and Tommy's Joint Policy Unit, Not Just an Option: Interpreting as an Essential Component of Safe Maternity and Neonatal Care; Sands and Tommy's Joint Policy Unit briefing paper: Translation and interpreting services in maternity and neonatal care; Clancy and Thomas, 2025; Kenyon SL, Gallimore ID, Evans TC, Page GL, Felker A, Fenton AC (Eds), on behalf of the MBRRACE-UK Collaboration. MBRRACE-UK Perinatal Confidential Enquiry, The care of recent migrant women with language barriers who have experienced a stillbirth or neonatal death: State of the nation report. Leicester: TIMMS, Department of Population Health Sciences, University of Leicester. 2024)

> *"They didn't mention anything about translator…when you're just sort of going like in and out of sleep... it is so difficult to grasp that info...But yeah, he [husband] didn't have the information."*
> *Mother taking part in listening event with South Asian families.*

We also heard that staff assumptions could affect whether interpreting services were offered.

One mother felt her husband was not offered language support related to caring for their baby because of assumptions about how involved South Asian fathers would want to be, meaning interpretation was not considered a priority[107].

Assumptions about English-language skills can mean that interpreting services are not used. This may create difficulties for parents who are tasked with processing and communicating in another language at a stressful and traumatic time.

Informal communication

Effective communication that supports parents to be partners in their baby's care goes beyond simply informing them about medical care in formal settings like ward rounds. When parents cannot make use of informal opportunities to communicate with staff, inequalities deepen.

An experienced neonatal nurse illustrates the inequality produced when:

> *"You're leaving one set of parents sitting in the corner, because they don't speak very good English and once a day you're using Language Line to have a medical conversation with them on the ward round so that they get a once a day update on their baby, but other families can talk to the staff whenever they want to… They could ask anything any time and that's not equal opportunity, is it?"*
> *(Helen, neonatal nurse, quoted in Clancy and Thomas, 2025).*

In our listening events with South Asian families, several participants (including mothers or partners) did not speak English confidently, or at all. The parents who spoke little or no English were less informed about and less involved in their baby's care. They also had fewer chances to talk to staff and fewer check-ins about how they were coping, which made the neonatal unit feel very isolating.

> *"Facilitator: Were you offered emotional support or did you ever ask for any emotional support for your wellbeing?*
>
> *Mother: No.*
>
> *Facilitator: So you never asked and they never approached you?*
>
> *Mother: No.*
>
> *Facilitator: [They never asked] How you were feeling, if you were feeling down or…sleeping? [Or if you] are eating?*
>
> *Mother: They just came and they're doing their duties and they go back again.*
> *Facilitator: …how did you feel?*
> *…*
> *Mother: I feel lonely."*
> *(Mother taking part in a listening event with South Asian families)*

Isolation can make it harder for parents to bond with and care for their baby. When parents are cut off from their usual support and staff cannot help them manage their emotions, they 'can remain in a perpetual state of threat and trauma.'[108] We heard from one mother that when there were staff on the unit who spoke the same language, this made a noticeable difference to how involved and informed she felt.

> *"She said there was a day when there was a nurse on the neonatal unit who spoke her language and she felt more involved and [it] makes a big difference what was occurring... also when there was a doctor who could speak multiple languages and then when he spoke to her, asked her, 'what language do you speak?' He said, 'I can speak those languages, I'll speak to you.' And then he told her and she felt more involved in all that as well. And that makes a big difference. It's only sometimes these things happen, though." Relative translating for a mother taking part in a listening event with South Asian families*

Celebrating good practice

It is important to acknowledge where improvements could be made, but also to celebrate good practice.

In our engagement work with families facing deprivation, we asked parents to reflect on their communication and relationships with staff on the neonatal unit. We heard many examples of excellent compassionate care from neonatal staff, creating a dynamic where parents felt comfortable raising concerns, asking questions, and felt supported to be involved and confident in caring for their baby.

The parents we spoke to highlighted relatively simple things like patience, openness, friendliness, staff offering reassurance and acknowledging parents' feelings, as making a positive difference to their neonatal experience.

> *"The nurses on neonatal [unit] were fabulous... if there were any issues, then, yeah, I could have gone to them… it's just about having that relationship that you can actually speak to people." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"I sat there with her [neonatal nurse] and she was like feeding him the milk and it was just so lovely… as his mum to see someone else being so lovely with your baby." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"[I felt comfortable asking questions or raising concerns] if I needed to then yeah, the staff were really friendly… It was all brilliant. I couldn't fault any of them." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"It's a horrible thing [the neonatal unit] to be in but…communication is key. With having such informative staff and people working together, it just makes the whole experience so much better." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"[The staff] were fantastic. I'd have been lost without them… they'd bring me cups of teas, coffee, and they'd be like, "don't you worry." … We'd been there so long, we all just worked as a team." Mum, interviewed by a partner organisation working in communities facing deprivation*

Case study: Use of Interpreter on Wheels (IoW) devices in the Newborn Intensive Care Unit (NICU) at St Mary's Hospital, Manchester University NHS Foundation Trust (MFT)

Manchester Foundation Trust (MFT) services care for a linguistically diverse population, and interpretation services are needed frequently. Indeed, some 25 per cent of pregnancy booking appointments are conducted in languages other than English.

Beginning as a pilot in acute areas of the Trust, MFT initially ran a three-month trial using 15 "Interpreter on Wheels" (IoW) devices: iPads mounted on mobile stands, pre-loaded with an app that enabled HCPs to connect to interpreters via on-demand video calls. IoW language support was introduced to the NICU in October 2025 with the aim to support FICare delivery. The IoW device would expand the options available to staff, which already included face-to-face and telephone interpreters. The IoW is:

- **Accessible:** 24/7 availability in 500+ languages, including British Sign Language
- **Cost effective:** they only pay for the number of minutes used
- **Environmentally friendly:** eliminates interpreter travel
- **Convenient:** an interpreter can almost always be accessed within minutes.

Roll-out of the IoW

Between October 2025 and April 2026, 103 video calls were successfully made on the NICU and translation in nine different languages has been facilitated, with Arabic and Urdu the most supported.

The standard process around informing families about the IoW includes ensuring parents understand that the service is free to use, and how it supports two-way communication. Parents have some control over who supports their conversations, such as being able to request either a male or female interpreter, and can even request the same interpreter again, providing continuity and developing trust.

Staff can undertake checks prior to the conversation with parents, such as ensuring the interpreter isn't a friend or relative, providing context to the appointment and alerting the interpreter if there is anything additional they need to be aware of, like safeguarding concerns.

The interpreter's role is essential for effective communication, to make the appointment safe and make any consent-taking valid.

Impact

Parents have informally provided positive feedback on the difference IoW devices have made to interactions with staff, particularly regarding the speed and quality of communication.

Significantly, the IoW is being used to enable more informal communication with parents *in between* formal medical updates. Utilising interpreters to support staff to communicate with parents outside of ward rounds is paramount for building trust and equity of care.

Feedback from the Multi-Disciplinary Team has been universally positive, with the IoW drastically improving access to interpretation.

"I used the interpreter on wheels today…Nice to be able to see the interpreter. So quick and easy. Thank you to whomever put the work in to make that available to us." *Consultant neonatologist*

Encouragement

Encouragement from staff was a consistent theme highlighted as a real positive, or something parents wished they'd had more of that would have improved their experience and helped them be more involved in their baby's care.

> *"You'd have your favourite nurses because they're the ones that are nicer to you or tell you you're doing well." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"[I felt reassured when] the nurses would say 'you're doing well' ...or, 'you know what you're doing.'" Mum, interviewed by a partner organisation working in communities facing deprivation*

In line with an individualised approach to care, it was acknowledged that some parents may need more encouragement than others.

> *"[With my first child I could have been given] a little bit more encouragement because I were only 18 when I had [baby], so it were, it was scary and daunting…I could have had more encouragement and support [like] 'come on, it's not as scary as it looks.' And 'I'll help you do this.'" Mum, interviewed by a partner organisation working in communities facing deprivation*

Unhurried care

Parents we heard from valued staff providing unhurried support and taking the time to show them what to do. It is easy to see how this approach can be more difficult in services which are stretched and under-resourced. However, as some families may be less confident in asking for additional time or clarification, an unhurried approach to care may play an important role in addressing health inequalities within FICare.

> *"Showing that it's not that hard [would have helped me be more included in my baby's care] because nurses do it as a job so it looks easy and they're doing it, not fast, but they know what they're doing, whereas if they just slowed it down a little bit and explained it a little bit more, I probably would've felt more comfortable [doing cares for my baby]." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"I'd say [I felt] especially supported with the nappy change…They could've just explained it and left me to it, you know? They have got enough of their own things to be cracking on with. But they didn't. They took their time, and they helped me through it." Mum, interviewed by a partner organisation working in communities facing deprivation*

Institutionalised and interpersonal racism

It is an uncomfortable truth that institutionalised racism can shape patient experiences in healthcare settings and contribute to health inequalities. The neonatal unit does not feel like a safe place for every family. Judgement, hostility, or prejudice from other families can compound this, making the whole unit feel unsafe. Awareness of this fact must inform neonatal care delivery, and actions must be taken to confront racism in both interpersonal and institutionalised forms.

There is evidence that a lack of awareness about personal bias exists amongst some HCPs and that instances of racism and cultural stereotyping occur on neonatal units. For instance, in one study a neonatal nurse relayed being 'in handover and the nurse who was handing over, referred to the baby as "little Mohammed"'. Realising 'that she had literally said it because of the colour of his skin', the nurse said she 'hated myself afterwards because I didn't react to it in the moment'[109].

Similarly, a parent in this study reported feeling that a white nurse was neglecting a Black baby and delivering inequitable care based on skin colour[110]. Highlighting 'a lack of self-awareness', the article concludes 'that personal bias, individual limitations and family perceptions were not always considered within interactions' between parents and staff[111]. The RHO has also identified lack of cultural understanding and culturally tailored care as a problem in maternity and neonatal care[112].

Racism, both in systems and in everyday interactions, is not talked about enough within the specific context of neonatal care. Even though it is critical, it is often missing from national discussions, research, and policy. There is strong evidence of racism in maternity care, but much less exploration of racism in neonatal care[113 114].

Assumptions based on race and ethnicity

Successful FICare depends on staff having the awareness and time to adopt an open stance so that they can understand what individual families need and tailor their care accordingly.

Our research found that within neonatal care, assumptions are made about families which may not reflect their actual experiences, needs, or wishes. Evidence shows that assumptions can impact parents' psychological safety, lead to misunderstandings, damage relationships between staff and parents, and create missed opportunities for involving families as partners in their baby's care[115 116].

Bliss has conducted three listening events with neonatal parents from minority ethnic communities in different parts of the country. In all three, assumptions based on race and ethnicity emerged as a prominent theme, which manifested in several distinct ways.

Two of the listening events were conducted with South Asian families, and in both, families reported that assumptions were made that they or their relatives did not speak English, based primarily on their appearance – affecting how they were communicated with, and the level of information provided to them. In one instance a Pakistani grandmother, who was heavily involved in her grandchild's care, found that staff did not speak to or share information with her, despite her English fluency and her daughter's requests that she be kept informed. This grandmother wore a headscarf and the family felt that assumptions were made about her English proficiency.

> *"My mum was really heavily involved...but I just felt like there'd be times where the nurses...they didn't really acknowledge my mum. Even though my mum was born in Pakistan, she came to the UK when she was seven. She speaks better English than I do... So I used to say to them, you know, if I'm going to toilet, "speak to my mum, and if I'm not here, to speak to my mum. Let her know what's going on." And, and they wouldn't, they didn't do that'. Mum, taking part in a South Asian families listening event*

Some parents also reported receiving different care and treatment to other families on the unit or experiencing staff making assumptions about their feelings and behaviours based on their ethnicity or race.

In one instance, a Black mother reflected that staff openly commented that her behaviour (smiling often, though her baby was incredibly poorly) was unusual, but they lacked the curiosity to ask questions, leaving her with no support.

Previous experiences of discrimination and prejudice

When people have directly experienced discrimination and prejudice or know that their family or community has faced it, particularly in healthcare settings, we cannot expect those experiences to be left at the door. It will be on parents' minds, and the threat of further discrimination, or of being treated differently, can be enough to make parents from marginalised groups feel less safe and comfortable on the unit. This will inevitably shape how parents interact with HCPs and how they expect to be treated[117].

We heard this in our engagement work with South Asian families:

> *"My family's all turned up with balloons and everything [to the postnatal ward before baby was taken to a neonatal unit]. And I thought, being Asian, we are gonna get told off because there was 10 of us in the room. So we were more worried about that. [facilitator: You were expecting that?] Yeah, we were expecting to be told off." Mum, taking part in a listening event with South Asian families).*

HCPs can improve communication by recognising how parents' past experiences of discrimination and prejudice may shape their expectations and reactions, and by communicating in ways that show their values and priorities are going to be understood and respected[118].

Mistrust and fear amongst Black parents

In our engagement work with Black parents, mistrust and fear of reprisals were common themes. Parents expressed concern about social services involvement and concern that they and their behaviour were being scrutinised[i].

Organisations like Black Mothers Matter have highlighted the societal and cultural expectation to be strong, which weighs particularly heavily on Black women[119].

The Black parents we heard from placed great importance on being strong, or presenting as strong even if they were struggling, and this was intertwined with feelings of fear and mistrust.

Knowing people whose children had been removed by social services or hearing about cases of what seemed like unwarranted child removal created a deep-seated fear for some parents. This can lead Black parents to hide their feelings of overwhelm and anxiety. Staff may interpret this as parents coping well, meaning opportunities to offer support and build trust are missed.

> *"We have a history where social services come in, ask questions later, and act first, and they take away our children. So this is what we know that happens within our communities. So obviously, if you've had your baby, you don't want the baby to be taken away. So through fear, I think my standard response will be, "I'm fine." Even through my pregnancy, even if I was crying through my pregnancy and feeling not so great, the midwife calls me, "I'm fine." Mum, speaking in Bliss' In Conversation With....podcast*

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[i] To note, this section covers themes that emerged from our listening event with Black parents, but consent was not sought to publish direct quotations. Where these themes align with experiences explored in other research, or in Bliss' podcast *In conversation with…* we have drawn on quotes from these sources.

The fear that if Black parents made their struggles known, this might be used against them, was also raised as a barrier to seeking support for mental health, highlighting racial disparities in access to support.

> *'When they come around and they ask me for what type of support I'll be needing, and I say, "What have you got to offer?" Because, you know, I was scared. I didn't know what sort of support they're going to offer me. And then with the experience of the way they're asking regarding safeguarding, so I was careful and... I don't want anything to affect my child. Like, you know, I don't want anyone to take my baby away... So anything, if they're asking me for support, I'll be sceptical. You know, I wanna know what is on offer. I wanna know where this is leading to." Dad, speaking in Bliss' In Conversation With...podcast*

In our listening event with Black families, the sense of mistrust seemed to be exacerbated by the fact that these parents were in a predominantly white area, with parents reflecting on their different treatment in terms of their stark minority status.

Isolation from parent camaraderie on the unit

On the unit, families can form relationships with one another which can be a source of support during a neonatal stay.

However, some parents participating in our engagement work felt they were treated differently because they or their family dynamic looked different from others on the unit. Some parents described how other parents interacted "cautiously" with them, were not as welcoming, and did not chat to them in the same way they did with other parents, reflecting that this was because they wore hijab and were Black.

Threat

In our engagement with Black parents, we heard that difficult interactions with other parents contributed to the neonatal unit feeling inherently unsafe. When shared family spaces did not feel comfortable, this – combined with the fear and mistrust explored earlier – meant Black parents had no spaces where they could just *be*.

> *"You know...I can't say that I felt 100% safe, but I just had to trust and go with the process...But yes, you know, I'm not blaming them for the fact that – Yeah ... I felt like a foreigner... But I am blaming this country, for the fact that we continuously feel like foreigners." Mum, speaking in Bliss' In Conversation With....podcast*

Mistrust, scrutiny and judgement in our work with families facing deprivation

In our engagement work with families facing deprivation, the feeling of being tested and scrutinised was raised. Although this was not directly tied to fear of social services in the same way as in the Black parents' group, the feeling of being closely watched could still harm parents' mental health. It also appeared to make it harder to build a true partnership in care and may have reinforced existing power imbalances on the unit.

> *"I felt people looking as if to say she's young, she doesn't really know what she's doing." Mum, interviewed by a partner organisation working in communities facing deprivation*

> *"Because everything was so regimented and like I had to write down every time he weed, every time he pooed, every time I'd fed him, like when I'd pumped, how much I pumped, I felt like I was under scrutiny… I think that's the main reason why I cried so much…you felt like you were on a test. It was a test. You had to do well and your baby had to do well to be able to go home. And that's how it felt for me. Rather than, 'oh, they're helping look after us'. It was more like, we need to pass the test or they won't let us out…in my mind I felt like I was being watched… judged."* *Mum, interviewed by a partner organisation working in communities facing deprivation*

Linking this feeling to the fact she was a young, first-time mother, the reflection above also mirrors findings from Bliss' research with young parents. Bliss found that the fear of being watched and judged by neonatal staff acted as a barrier to being involved in their baby's care[120].

> *"I felt like everyone was watching me and judging me as a parent. I was a first-time mum and wasn't sure how to change a nappy, let alone on 3lb twins in incubators covered in wires and tubes."* *Mum, taken from Bliss (2021) Neonatal care through a young parent lens.*

We also heard how dismissive communication could lead to parents feeling less safe on the unit and less able to seek support.

One mum told us that the only staff member she felt able to turn to, and trust with her baby, was the receptionist, who treated her with compassion and offered reassurance. She suggested that the receptionist felt more relatable to her, which seemed to foster a sense of shared understanding and trust. In contrast, she did not experience this connection in her interactions with healthcare professionals on the unit.

> *"There was this lady in [the hospital] and she was the receptionist. She was an Asian lady. She's quite common, sort of thing. She won't mind me saying that, 'cause she's said it herself... She was just [absolutely] me rock in there. Every time I would cry and she was like, 'Come on, let's go have a cup of tea. You're all right. Come on, calm down. You just sit there'. Or 'You go do this.' Unfortunately, that's the only person that I can say I felt really sort of, you know, close with…*
>
> *In a ward full of midwives, doctors, everything like that, why is the receptionist the one person that the patient can talk to and feels like, you know, they can have that common...She's the only one that I'd sort of leave [my baby] with her. You know, I didn't feel like I trusted anyone else.*
>
> *I was very dead set on, like, don't do any observations if I'm not present. Like, don't, basically, don't touch her. And that were because of how scared it got me the whole process. I just felt that... If they're [the healthcare professionals] that disregarding of me and my feelings, then they're gonna be the same with my daughter."* *Mum, interviewed by a partner organisation working in communities facing deprivation*

It feels incredibly vulnerable to leave your poorly baby in the care of another person. How staff communicate with parents has an immense impact not only on their experience of neonatal care, but also on how safe they feel their baby is on the unit[J].

For this mum, the fact that she felt neither comfortable nor psychologically safe on the unit, combined with a lack of support and clear communication to help her be involved in her daughter's care, meant she was not as involved as she would have liked. Her baby was receiving phototherapy for jaundice, and while staff told her that she could take her daughter out of the incubator, it seems that a lack of support to give hands-on care to her baby in a way that was not going to delay her discharge meant she did not feel able to do this.

[J] Howes, Budd, and Norton (2026) find the same thing in their research on lesbian and queer+ parents' experiences of neonatal units (Howes, A., Budd, B., & Norton, E. (2026). "Oh, who's the mum?": a thematic analysis of neonatal experiences of lesbian and queer+ parents, *Journal of Reproductive and Infant Psychology*, 44(4), 973–987).

> *"When she was in the neonatal, she was in the incubator. And they basically said, like, 'You can get her out and you can hold her, but obviously it's best if... she stays in there.' So when it came to feeding and stuff like that, I was sort of reluctant to get her out because I wanted her out of that as soon as possible." Mum, interviewed by a partner organisation working in communities facing deprivation*

The sense of being scrutinised and tested is a barrier to the open dialogue which underpins FICare.

This might be exacerbated for parents based on intersectional factors, including being from more deprived areas. One mum interviewed by our community partner explained that although she didn't know how much staff knew about her circumstances, she wondered if the family would have been treated differently if they'd been 'posher'.

> *"Because it was just me and my husband and we were young and like we didn't really have that much money and like we lived in like a council [house]- I dunno if they knew any of this stuff though, that's the thing. But you always feel like a little bit, maybe if we were more like posher people and had like our parents around, we might have been treated a bit differently maybe, but…it's just with certain people, isn't it?" Mum, interviewed by a partner organisation working in communities facing deprivation*

The psychological impact of a neonatal stay

Having a baby on a neonatal unit can have a serious psychological impact on parents.

In a survey of neonatal parents by Bliss, 96 per cent of respondents reported that their mental health suffered as a result of their baby's neonatal stay, and some parents reported suicidal thoughts and feelings. Despite these statistics, only 40 per cent of parents remembered being offered support for their mental health on the neonatal unit, and just over half of these went on to access support. 27 per cent of respondents told Bliss they didn't receive any support at all, including from friends and family[121].

There are well-established inequalities linked to ethnicity and deprivation in the prevalence of mental health problems and in access to, and experiences of, services[122] [123]. This may make it more likely for some parents to experience mental health challenges during a neonatal stay, but less likely to receive appropriate support.

Financial barriers can exacerbate parents' distress, isolation, and limit the effectiveness of support. More than three quarters of parents surveyed by Bliss said that the costs associated with going to the hospital to see their baby had a negative impact on their mental health[124]. For parents who are already struggling financially before their baby is admitted to neonatal care, the psychological impact of financial instability may be particularly severe.

Good practice
We know that some neonatal services loan mobile phones to families during their admission. As units move away from paper resources, this helps ensure that families can access information and support even if they do not own a smartphone.

Examples of compassionate care

In our work with families facing deprivation, parents shared examples of compassionate care that positively impacted their psychological wellbeing on the neonatal unit.

Parents said they valued and would have liked more staff interactions that recognised how difficult the experience was, and that offered reassurance and compassionate care, tailored to their individual needs.

> *"I felt like such an inconvenience, crying my eyes out, and she's [neonatal staff] like, 'It's fine. Don't you worry'…They were fantastic. I'd have been lost without them." Mum, interviewed by a partner organisation working in communities facing deprivation*
>
> *"There was a counsellor on the ward… when I really wasn't okay, I spoke to her …she did well with making me feel better." Mum, interviewed by a partner organisation working in communities facing deprivation*
>
> *"I'd say [I] definitely felt supported when [my son was] going through the harder days when he was stopping breathing completely... I felt a bit silly crying at times and they were like 'it's completely normal'...I didn't feel silly for being upset and stuff and feeling like you have to be strong." Mum, interviewed by a partner organisation working in communities facing deprivation*

While these examples highlight the compassionate care delivered on neonatal units and its impact, they stand in stark contrast to what we heard in our engagement with Black parents. In particular, the sense of not having to be strong was notably absent, highlighting differences in how comfortable families may feel showing vulnerability on the unit.

Identifying who needs support

In determining who needs psychological support, neonatal teams may rely on assumptions or gut instincts, which can introduce unconscious bias in whether parents are offered psychological support, and what kind of support they receive. As a result, families may be treated differently, and this can reinforce existing health inequalities[125].

As previously mentioned, Black parents can face heightened expectations to be strong, and this was a significant theme in our engagement work with families. While we heard that there could be a positive side to this, helping parents 'get through' the neonatal experience, it could also involve suppressing pain and make it harder to access support.

"Affinity bias"[K] can also affect how parents' feelings and behaviours are interpreted. This happens when we see someone as similar to ourselves and feel more understanding towards them. As a result, some parents' behaviour may be judged more critically than others if it is out of the frame of reference that is familiar to that health professional[126].

This difference in empathy is likely to affect how support needs are recognised and responded to, including whether families are offered appropriate psychological support.

[K] Affinity bias is the unconscious tendency to favour, view positively, or connect with people who have a similar background, set of interests or demographics as you. This can lead to unfairness.

Delivering support

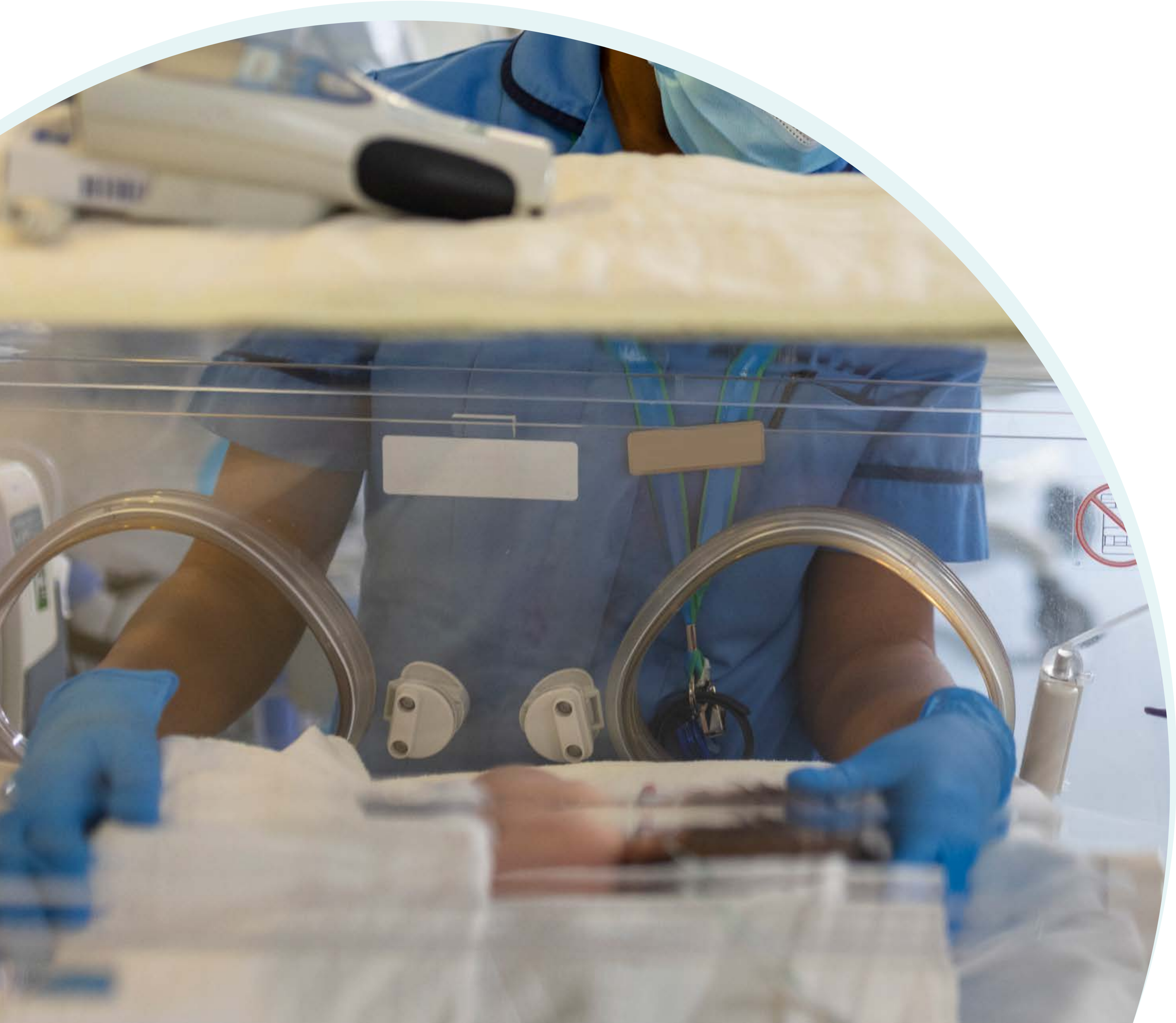
Individualised care is crucial for understanding and responding to parents' psychological support needs.

Research shows that parents want psychological support that reflects their individual values, traditions, personal circumstances and communities[127] [128]. However, evidence suggests that support is not always tailored to meet the needs of diverse families. For example, support groups are often led and attended mainly by white families, which can feel less safe or accessible for parents of minoritised ethnicity[129].

To ensure the support offered feels fitting and appropriate for a family, their culture and values need to be considered. However, a review of psychological support in neonatal care found that many approaches are based on Western cultural values, which may not work equally well for all families[130].

It also found that interventions tend to focus on parents at the cot-side, with less attention given to the baby's cultural background or to connecting families with their wider support networks, such as extended family. This matters because wider social support often has a substantial impact on parents' wellbeing[131].

When services do not take account of parents' circumstances and contexts, opportunities are missed to provide support that feels relevant and meaningful. If care works better for some families than others, this can lead to unequal outcomes, with some babies benefiting more from their parents' confidence and ability to take part in their care.



Faith and spirituality

For some parents, faith and spirituality play an important role, helping them feel supported and guided during their neonatal care experience[132].

Parents draw on practices such as religious songs and prayer to support themselves and their babies whilst on the unit.

In our work with Black and South Asian families, families frequently spoke of the solace, strength and support their faith provided them. For some parents, faith was their only source of support, showing the importance of facilitating faith practices, as well as highlighting gaps in other forms of psychological support.

> *"[I'm] obviously [a] great believer in faith...I believe me doing the Dua[L] and stuff is gonna help me... So that's what I did morning, noon, and night...Because that's what got me through it. [There was no support] Nothing. Mum, taking part in a listening event for South Asian families*

> *"When I went to visit [my child] as well and I just like got my phone out and I just sat on the chair. I just prayed, prayed." Mum, taking part in a listening event for South Asian families*

This makes culturally responsive care an essential part of delivering FICare in neonatal services (as discussed later in this chapter), by ensuring that parents are supported in ways that meet their needs.

Good practice:
Bliss has worked with the Relational Practice, Black Mothers Matter, and parents who have experienced neonatal care to create a series of videos for neonatal healthcare professionals.

The videos explore the psychological impact of a neonatal stay and the challenges faced by staff and parents, particularly by those who already experience health inequalities.

By sharing insights, practical tips, and examples of good practice, these resources are designed to support units to deliver FICare, address health inequalities, and help to improve the psychological experience of a neonatal stay for all families, particularly those from marginalised groups.

These videos are available, and free to all, on the NHS Learning Hub.

[L] In Islam, 'Dua' translates to prayer. It is a profound act of worship where a Muslim person directly calls upon or communicates with Allah to ask for help, seek forgiveness, express gratitude or share personal hopes and fears.

Culturally responsive care

A neonatal admission can negatively affect parents' sense of identity and contribute to feelings of isolation[133]. Celebrating babies' and parents' identities and facilitating families' connections to their cultural identity and wider support networks can help counteract this[134]. This may be particularly important for parents who have experienced oppression and discrimination, as these parents report feeling unsafe to express their identity which, in turn, limits opportunities to connect their baby with their cultural identity[135].

There are many elements to culturally responsive care. For example, in many cultures, extended family are extremely important and may play a critical role at the time of birth, in times of crisis, and decision-making[136].

For some families, culture and faith are central to their experience of neonatal care. This may be particularly true for parents from minoritised ethnic groups[137].

There is clear evidence that culturally responsive care is important to families[138]. In our projects with Black and South Asian families, Bliss has consistently heard that being able to honour cultural and religious practices carries huge significance for families[139].

When their values and beliefs are acknowledged and actively supported, parents report feeling more respected, comfortable, and having improved experiences on the neonatal unit. It is therefore hugely important that parents feel comfortable honouring the practices that are important to them.

However, not all families feel able to express their cultural or religious identity openly on the unit. Some parents described modifying their behaviour or encouraging family members to be discreet, due to discomfort, lack of privacy, or concern about how they would be perceived:

> *Facilitator: "You said you didn't feel very comfortable, kind of saying the prayers and doing some those things...what would have made you feel more comfortable?"*
>
> *Mum: "I guess, I think talking to somebody [explaining that this is something people have to do, that] it's compulsory, basically. And mine's a bit more privacy as well. Maybe less awkward…[you worry] the other parents, they're thinking, 'what's going on here?' It's not a bad thing, but just a bit of privacy as well. Maybe had the curtain go around, the curtain couldn't go round either…"*
>
> *Mum: "[My husband] did have prayer times but I used to say, oh, just do it in the chair… I never wanted to make it [a big thing], you know what I mean?"*
>
> *Facilitator: "Do you feel that he was secretive then doing that?"*
>
> *Mum: "Yeah."*
> *Excerpt from a listening event with South Asian families*

There is also evidence of gaps in cultural awareness among staff and inconsistent delivery of culturally responsive care. Previous research by Bliss found a third of South Asian women felt that healthcare professionals did not fully understand the importance of cultural or faith-related needs, such as modesty[140].

At the same time, in our review of the literature and our engagement work with Black and South Asian families, we heard many examples of culturally responsive care delivered well. This included staff facilitating faith practices, supporting cultural rituals, creating spaces to respect modesty needs, and showing curiosity and respect for families' beliefs. Parents were also encouraged to decorate their baby's cot or contribute to their 'about me' posters[141] [142]. Our research suggests that units in culturally diverse areas, or those with a diverse staff, may be better at delivering culturally responsive care[143].

In some cases, support from other parents also helped families feel more comfortable expressing their faith.

> *"[We] regularly played the Quran for him… some of the nurses were Muslim as well, so yeah, it felt really sort of relaxed… I tried to play it as quietly as we could, but other parents would come up to us and say it 'puts our children right to sleep'… it felt really, really comfortable." Mum, taking part in a listening event with South Asian families*

When care is not culturally responsive, the core principles of FICare cannot be fully realised. Conversely, when staff show curiosity, respect, and openness to families' values and beliefs, this can strengthen relationships, support psychological safety, and enable meaningful parental involvement in care.

> *"[The nurse] was really interested and when Adhan was being read[M], she gave us a piece of paper, so she was aware….obviously it depended which nurse she got, but some were aware of it…There was the respect there. And then when… I said, "oh, the mosque priest is coming". And she said, 'oh, do you mean the Imam?" Mum, taking part in a listening event with South Asian families*

To ensure consistency and avoid placing additional strain on staff, culturally responsive care should be embedded as a core priority within neonatal services.

Good practice:
Bliss has co-designed information resources with parents for parents – to help let neonatal staff know about the cultural and religious practices that are important to them, and to inform parents about the services that are available to them to support their faith and spiritual needs[144].

Palliative and bereavement care

When a baby dies in neonatal care, their parents' experiences on the unit can shape their memories and have a profound and lasting impact on their mental health and wellbeing.

Poor service infrastructure can inhibit good end-of-life and bereavement care. Language barriers and lack of interpreting services can impact informed consent, culturally responsive end-of-life care, and prevent families from being involved in discussions about memory-making when their baby dies on a neonatal unit[145]. Research by Bliss and Sands has also found that just 12.3 per cent of interpreters received 'specific training on issues surrounding baby loss'[146].

Without a clear understanding of a family's needs, values and expectations, even well-intentioned actions by healthcare professionals can marginalise parents, undermine trust, and compound trauma at a time of profound vulnerability. Effective communication between staff and parents is therefore one of the most important facilitators of culturally responsive palliative and bereavement care in neonatal settings[147].

When expectations around ethics, authority and faith are not understood, bereavement care can become conflictual and damaging[148].

[M] This is the practice of reciting the Adhan - the Islamic call to prayer - usually into the baby's right ear shortly after birth, ensuring the child's first heard words are a declaration of faith.

Families may start from faith-based principles rather than what healthcare professionals may consider to be clinically pragmatic. An example from an article in *Mortality* details the experience of a Muslim family whose baby was approaching end of life. The family had initially expressed a wish for their baby to be cared for at home, and arrangements were underway to support this. When the family later appeared to change their plans, staff became frustrated. It was only after consulting the Muslim chaplain that staff understood the family's concerns related to their preference for an early burial, which could be difficult to arrange over a weekend[149]. The impact of such misunderstandings on parents may be feeling judged, dismissed or stigmatised while navigating the most difficult moments of their life.

Good practice:
The neonatal unit at Birmingham Women's and Children's NHS Foundation Trust has access to a bespoke bereavement suite that was co-designed with families, and in conversation with Muslim chaplains, to create a space, and services, that meets the needs of all families. The Woodlands House bereavement suite encapsulates the ethos of culturally competent and individualised care, the space has no visible markers of any faith, but it is fully equipped to meet the practical needs of Muslim families (of multiple ethnicities).

Staff make no assumptions about what Muslim families may want and need. However, early burial may be important for Muslim families, and the bespoke space means that bereaved mothers – who are often in-patients when their baby dies – can now be involved in Ghusl (ritual washing) and Kafan (shrouding) ceremonies if they wish. There is also enough space for extended family members. Families, and especially mums, have been very grateful that they can now be involved in these rituals.

Further practical guidance to support diverse families is available in the National Bereavement Care Pathway[150].

Fathers

For babies in neonatal care, the role of fathers is just as important as that of mothers, and dads should also be empowered to be a partner in delivering their baby's care. However, dads report receiving less information, support, training and encouragement than mothers[151].

While there is limited research generally on fathers' experiences in neonatal care in England, and more so for fathers from minoritised ethnic groups and more deprived areas, research indicates that the barriers faced by all fathers may be exacerbated for these groups[152 153].

Bliss' own research supports this, finding that fathers on lower incomes may face severe financial pressures that limit their time on the unit, including needing to return to work[154]. Similarly, for fathers from minoritised ethnic groups, language barriers, cultural norms, and staff assumptions can intersect with gendered barriers to further restrict their ability to be partners in care delivery.

Our engagement work suggests South Asian fathers who are not UK-born or who do not speak English as a first language are sometimes assumed to be less interested in being involved in their baby's care. We heard from families that these assumptions can affect whether interpreting services are prioritised, and how much support is given to support involvement in caregiving[155].

> *"I think it's like language barrier things for him as well. They should have someone there [to] translate… I'm not sure they asked him to be involved in their [baby's] care." Mum, taking part in a listening event with South Asian families*

Research with fathers of minoritised ethnicity describes how they may face expectations – both internal and external – to be strong and to prioritise supporting their partner, which can limit help-seeking for their own mental health[156] [157].

> *"It was a little bit difficult at the beginning. It was difficult with mental health. It was terrible, it was difficult, it was hurting. Lot of trauma, lot of, you know, crying at the beginning. But then you need to be there for the baby. You need to reset yourself, refocus." Dad, speaking in Bliss' In Conversation With...podcast*

In some cases, this expectation is reinforced by services, contributing to isolation and unmet support needs[158].

These overlapping factors highlight the specific support needs of fathers and reinforce the importance of individualised care.

Conclusion

Parental presence is necessary for FICare, but it does not guarantee participation. Effective FICare depends on understanding and responding to individual families, rather than making assumptions based on ethnicity, socioeconomic status, or background.

Our engagement work with families shows that communication and compassionate, individualised care are critical in enabling parental involvement. Where staff lack curiosity or fail to recognise families' needs, opportunities to support participation are missed. Ultimately, this directly affects the care a baby may receive from their parents.

Power dynamics and psychological safety play a key role in shaping equitable care. Experiences of discrimination, mistrust, and structural inequalities undermine parental partnership which negatively impacts babies. There remains work to be done to ensure that all families, particularly those from minoritised ethnic backgrounds or facing socioeconomic deprivation, feel consistently safe, respected, and able to be open and vulnerable on the unit.

We must ensure every baby can benefit from individualised, Family Integrated Care (FICare) by identifying and addressing the financial, practical and communication barriers that disproportionately affect some families:

2 The Government should establish a financial support package for families to support with a range of unanticipated costs which occur when a baby is admitted to neonatal care, modelled on the support provided through the travel fund for families of children and young people who have cancer.

3 The Government should set out a plan for long-term investment in overnight accommodation for parents with a baby in neonatal care, supported by short-term actions such as updating the guidance in the Neonatal Health Building Note and developing a small grants programme for NHS Trusts to improve their existing facilities.

4. Integrated Care Boards and NHS Trusts should ensure adequate funding, provision and oversight of high-quality interpreting and translation services.

5. Neonatal units should ensure all staff are trained and supported to deliver culturally responsive care, utilising tools such as the Bliss Baby Charter and Bliss' Early Conversations Toolkit to improve practice.

6. Neonatal units should proactively review their existing financial and practical support, like meal provision, and Neonatal Operational Delivery Network should ensure equity across the region.

7. Neonatal units should ensure all families are informed as early as possible about the support available to them and are reminded of this throughout admission, utilising tools such as the Bliss Baby Charter to audit and improve practice. Neonatal units should ensure that dedicated staff hold these responsibilities and that mechanisms are in place to ensure all families are receiving this information.

Continued and sustained investment is needed to grow the neonatal workforce, ensuring that every baby has equitable access to the full suite of multi-disciplinary care and services, and that staff can work in a safe, supportive environment, where they feel confident to provide the highest standard of compassionate care:

8. The Government must invest to ensure evidence-based staffing standards can be met across medical, nursing, Allied Health Professionals, Psychologists and Pharmacists.

9. NHS Trusts should ensure all neonatal staff receive training and ongoing support in culturally responsive care, equipping them to identify and respond to inequalities, understand families' diverse circumstances, and tailor care to individual needs in day-to-day practice.

10. NHS Trusts should make training in culturally responsive palliative and bereavement care mandatory for all neonatal staff, ensuring they can provide compassionate, individualised support that reflects the cultural, faith and practical needs of each family at end of life.

11. NHS Trusts should ensure that psychologists working on neonatal units have adequate time and resources to ensure their remit includes providing support to the neonatal staffing team, as well as families.

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[70] Saberian et al (2025) Inequalities in neonatal unit mortality in England and Wales between 2012 and 2022

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[74] NHS Race and Health Observatory (2023) Review of neonatal assessment and practice in Black, Asian and minority ethnic newborns

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[76] Pettinger K, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity

[77] Pettinger K, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity

[78] Bliss (2022) South Asian families' experiences of neonatal care

[79] NHS England Specialised Commissioning (2024) Neonatal Critical Care Service Specification

[80] Jane K, et al. (2025) Being a parent in neonatal care environments: A survey of the acceptability of sound and song for parents with seriously unwell infants on UK neonatal units, *Journal of Neonatal Nursing*, Volume 31, Issue 3

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[85] Bliss (2021) Neonatal care through a young parent lens

[86] Bliss (2021) Neonatal care through a young parent lens

[87] Bliss (2022) Bliss briefing: Impact of cost-of-living crisis in neonatal care

[88] Bliss (2022) Bliss briefing: Impact of cost-of-living crisis in neonatal care

[89] Bliss (2024) Families Kept Apart in England: Overnight accommodation for parents

[90] Bliss (2016) Families Kept Apart: barriers to parents' involvement in their baby's hospital care

[91] Scottish Government (2019) Neonatal Expenses Fund year one: evaluation

[92] NHS England Specialised Commissioning (2024) Neonatal Critical Care Service Specification

[93] National Institute for Health and Care Excellence (2019) Specialist neonatal respiratory care for babies born preterm, Recommendation 1.6.5

[94] Pettinger K, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity

[95] Pettinger K, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity

[96] Pettinger K, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity

[97] This is evident in multiple reports including: Bliss (2021) Neonatal care through a young parent lens, Bliss (2022) South Asian families' experiences of neonatal care and the engagement work undertaken by Flourishing Families in 2026 for this report.

[98] Clancy and Thomas (2025). Fostering cultural humility in perinatal palliative care.

[99] Social Mobility Commission (2024) Childhood Origins of Social Mobility revised and updated

[100] British Psychological Society (2022) How social class is reflected in our Psychology [accessed online:] https://www.bps.org.uk/psychologist/how-social-class-reflected-our-psychology

[101] NHS Race and Health Observatory (2023) Review of neonatal assessment and practice in Black, Asian and minority ethnic newborns. P.130

[102] This includes one mum who had two babies who both needed neonatal care. During her first experience she did not feel comfortable asking questions or raising concerns, but she did during the second.

[103] See also: Bliss (2021) Neonatal care through a young parent lens

[104] See similar findings in Bliss (2021) Neonatal care through a young parent lens

[105] See, for example, Kenyon et al. (2024) Sands and Tommy's Joint Policy Unit (2025) and Pettinger et al. (2025)

[106] This includes Bliss (2022) South Asian families' experiences of neonatal care; and our recent listening events

[107] This experience was relayed by a mother participating in a Bliss listening event for South Asian families, and similar experiences can be found in Bliss (2022) South Asian families' experiences of neonatal care

[108] Jane, K., et al (2025). Supporting continuing bonds for parents with infants with uncertain futures on neonatal units in the United Kingdom: co-designing a culturally sensitive music therapy intervention. *Frontiers in Psychiatry*, 16, Article 1633878 p.8

[109] Clancy and Thomas (2025). Fostering cultural humility in perinatal palliative care p.64

[110] Clancy and Thomas (2025). Fostering cultural humility in perinatal palliative care.

[111] Clancy and Thomas (2025). Fostering cultural humility in perinatal palliative care p.64

[112] NHS Race and Health Observatory (2023) Review of neonatal assessment and practice in Black, Asian and minority ethnic newborns.

[113] Peter M, Wheeler R, Abe C, Awe A., Five x More. (2025) The Five x More Black Maternity Experiences Survey: Continuing the Conversation on Black Maternal Care in the UK

[114] Birthrights (2022) Systemic racism, not broken bodies An inquiry into racial injustice and human rights in UK maternity care

[115] Clancy and Thomas (2025). Fostering cultural humility in perinatal palliative care.

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[121] Bliss (2022) What parents told us through our mental health survey [accessed online:] https://www.bliss.org.uk/parents/support/impact-mental-health-premature-sick-baby/is-it-common-for-parents-to-struggle-with-mental-health

[122] Kings College London (2022) People from ethnic minority backgrounds experience persisting inequality in their treatment for common mental health problems in England [accessed online:] https://www.kcl.ac.uk/news/people-from-ethnic-minority-backgrounds-experience-persisting-inequality-in-their-treatment-for-common-mental-health-problems-in-england

[123] The King's Fund (2024) Mental health 360: inequalities [accessed online]: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/mental-health-360-inequalities

[124] Bliss (2022) Bliss briefing: Impact of cost-of-living crisis in neonatal care

[125] Bliss and The Relational Practice (2025) How culture can be developed to support parents with the psychological impact of a neonatal stay [accessed online:] https://www.bliss.org.uk/health-professionals/supporting-health-professionals/video-resources

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[127] Jane K, et al. (2025). Supporting continuing bonds for parents with infants with uncertain futures on neonatal units in the United Kingdom

[128] Sands (2021) Sands Surveys of Parents and Families from Black and South Asian Communities: Full Report

[129] Sands (2021) Sands Surveys of Parents and Families from Black and South Asian Communities

[130] Jane K, et al. (2025) Parents' experiences of psychotherapeutic support on the neonatal unit: A mixed methods systematic review to inform intervention development for a multicultural population, *Nurs Crit Care*, 30(3)

[131] Jane K et al (2024) Parents' experiences of psychotherapeutic support on the neonatal unit

[132] This emerged as a theme within Bliss run listening events, and further evidence can be found in Jane K, et al. (2025) Being a parent in neonatal care environments; and Hassan H, et al. (2025) Ethnic minority fathers' experiences of the Neonatal Care Unit: barriers to accessing psychological support, *J Reprod Infant Psychol*, 43(4):1011-1023

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[136] Redman H, Clancy M, Thomas F. (2024) Culturally sensitive neonatal palliative care: a critical review, *Palliat Care Soc Pract*, 18

[137] Jane K, et al. (2025) Being a parent in neonatal care environments

[138] This emerged as a strong theme in Bliss listening events, and has been evidenced in the wider literature. Please see: Clancy and Thomas (2025), Jane et al. Being a Parent (2025) and Bliss (2022) South Asian families' experiences of neonatal care

[139] This was evident in our listening events and in Bliss (2022) South Asian families' experiences of neonatal care

[140] Bliss (2022) South Asian families' experiences of neonatal care

[141] Jane et al. (2025) Being a parent in neonatal care environments

[142] Bliss (2022) South Asian families' experiences of neonatal care

[143] This emerged as a theme in Bliss' listening events, and in Bliss (2022) South Asian families' experiences of neonatal care

[144] Please see: https://www.bliss.org.uk/parents/in-hospital/being-a-parent-on-the-neonatal-unit/family-integrated-care

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[149] Clancy and Thomas (2025). Fostering cultural humility in perinatal palliative care.

[150] National Bereavement Care Pathway (2024) Supporting diverse families

[151] Bliss (2024) Bliss briefing: Father's experiences of neonatal care

[152] Jane et al. (2024) Parents' experiences of psychotherapeutic support on the neonatal unit

[153] Hassan H, et al. (2025) Ethnic minority fathers' experiences of the Neonatal Care Unit

[154] Bliss (2024) Bliss briefing: Father's experiences of neonatal care

[155] This emerged as a theme in Bliss' listening events, and in Bliss (2022) South Asian families' experiences of neonatal care

[156] Sands (2021) Sands Surveys of Parents and Families from Black and South Asian Communities

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Chapter 3: Discharge, follow-up and longer-term development after leaving the neonatal unit

Overview

This chapter shows that existing inequalities can affect how confident families feel navigating the transition from unit to home, and whether their homes are suitable for the baby's recovery.

It highlights socioeconomic inequalities in developmental outcomes, and ethnic and socioeconomic inequalities in developmental follow-up. Patchy service provision, coupled with the additional challenges some families face in accessing developmental follow-up, increases the risk of poorer health outcomes for these babies as they grow up[O].

Discharge

Discharge from the neonatal unit represents a significant transition for babies and families, marking the shift from hospital-based clinical care to care largely delivered at home and within the community. For many families, this transition can be a time of joy as well as anxiety, marking a point of heightened vulnerability[159]. Babies may require complex care at home, ongoing medical appointments and even re-admission to hospital.

The impact of inequalities in parent partnership on the transition home

In line with the *Neonatal Critical Care Service Specification*, discharge planning should begin from the point of admission, with parents supported to be involved in their baby's care throughout their stay on the unit[160]. This ongoing involvement helps build parents' confidence and skills well before they go home. Early and regular conversations about both the baby's care and the family's wider needs are essential, particularly for parents who may not have been able to spend as much time on the unit.

If parents are not well supported to be primary carers for their baby on the unit, and do not feel informed or able to ask questions, they are more likely to struggle when they go home. An example from our engagement work with families facing socioeconomic deprivation demonstrates this.

One mum with two distinct neonatal experiences reflected on the impact of her experience and confidence on the transition home. Her confidence and comfort levels were not dependent on the medical severity of her baby's condition, but on the knowledge and experience gained in caring for her baby*:*

> *Mum: "[second baby] came home with extra things than what [his sister] came home with."*
> *Interviewer: "How was that? Trying to juggle feeding tubes and oxygen?"*
> *Mum: "If it was [my daughter] I would've been worried and scared. [With my daughter] I didn't really touch her, I didn't change a nappy. I didn't do the feeds with the feeding tube because I was scared. Whereas with [my son] I was very hands on and did it all and felt confident." Mum, interviewed by a partner organisation working in communities facing deprivation*

[O] We acknowledge that for some babies, their whole life is lived on the neonatal unit, and that they very sadly die without going home. For a range of reasons, other babies will not be able to go home with their birth parents. Working from the evidence base we have, this chapter focuses on babies who are discharged home with their parents.

Given the evidence of ethnic and socioeconomic inequalities in parental involvement in their baby's care on the unit – explored in Chapter 2 – there may be inequalities in how supported parents feel taking their baby home, making the transition from unit to home more difficult.

Neonatal outreach and community support after discharge

Strengthening neonatal outreach services, and ensuring they are suitable for all families, may help to address some of these barriers. Outreach services provide care for babies at home from specialist nurses and Allied Health Professionals, Pharmacists and Psychologists (AHPPPs), with support from the hospital team. They can help babies go home sooner, reduce time apart from parents, and sometimes prevent the need for admission to neonatal care altogether[161].

Currently, there is significant variation in the availability of dedicated Neonatal Community Outreach Teams (NCOTs) across England, and in some Operational Delivery Networks (ODNs), only around 20 per cent of neonatal units have access to a dedicated outreach team[162].

The neonatal workforce is currently commissioned only for cotside nurses. Funding outreach services would ensure more babies receive care in the right place, at the right time, and, if delivered effectively, may help to address some of the gaps experienced by families who had fewer chances to build confidence in caring for their baby on the unit[163]. This aligns with the focus, in the NHS 10-Year Plan, on shifting care from hospitals into the community.

Good practice:

Since the introduction of neonatal Allied Health Professional (AHP) services at New Cross Hospital, Wolverhampton, more babies are being discharged home on short-term tube feeding. Many do not meet the criteria for community Speech and Language Therapy or Dietetic services, despite having ongoing feeding and growth needs.

To address this gap, the in-patient AHP team introduced weekly multidisciplinary surveillance meetings with the Neonatal Community Outreach Team. These meetings support the development of individualised, collaborative management plans. This approach enables earlier identification of challenges, particularly for families experiencing socioeconomic deprivation and from ethnically diverse backgrounds, helping to tailor support and reduce inequalities in feeding outcomes and early growth.

Living conditions and support after discharge

Babies leaving neonatal care, especially those born premature or with ongoing medical needs, are more vulnerable than other babies. Many will need continued care after they go home. They are also at higher risk of respiratory illness and infection, which makes warm, safe and suitable homes critical for their healthy recovery and development.

Poor housing conditions, such as cold or damp homes, are linked to higher rates of respiratory illness in young children[164]. A lack of space for medical equipment, or overcrowded living conditions, can also make it harder to safely care for these babies.

Yet many babies leave neonatal care for home environments that do not facilitate the best chances of recovery. In a Bliss survey about the impact of the 2022 cost-of-living crisis, 74 per cent of parents responding said rising energy costs made it likely they would not be able to keep their home warm over winter[165]. Nearly half of families responding who relied on electrically powered medical equipment for their baby were worried about whether they could afford to keep it running. Some families said they had already had to stop using essential equipment because of the cost[166].

These findings highlight potentially unsafe conditions for babies and a deeply distressing situation for parents. No parents should have to choose between keeping their baby safe and meeting basic needs such as food and heating for themselves and their families.

Neurodevelopmental outcomes

Advances in obstetric and neonatal care mean that more premature babies are surviving than ever before, particularly those born very or extremely early. However, improvements in survival have not been matched by the same level of progress in long-term developmental outcomes[167].

Premature birth is associated with differences in how a baby's brain develops. Babies born early are more likely to experience a range of developmental and neurodevelopmental conditions, including cerebral palsy, motor coordination difficulties, ADHD and autism. At a population level, they are also more likely to experience differences in learning and educational outcomes, and may face additional barriers later in life, including in employment and independent living[168]. These outcomes vary widely between individuals and are strongly shaped by access to timely support and wider societal factors[169].

A baby's developmental outcomes are strongly shaped by socioeconomic challenges, meaning that risks are higher for babies born into families experiencing deprivation[170] [171]. It is especially important to consider these risks for babies born prematurely, as they are more sensitive to the effects of socioeconomic deprivation than babies born at term[172] [173] [174]. This increased sensitivity continues into childhood[175].

Being from *less* deprived circumstances can act as a 'neuroprotector', meaning that higher socioeconomic status actually protects premature babies from some of the developmental risks associated with being born early[176].

There is strong evidence that socioeconomic factors can have an impact on long-term development that is similar to severe neonatal complications[177] [178]. As this shows, improving developmental outcomes for premature babies requires attention to social factors, like socioeconomic deprivation, as well as medical factors[179] [180] [181] [182].

It is critical that neonatal services identify and respond to social risk factors both during babies' time on the neonatal unit and after discharge. This represents a key intervention point and a clear opportunity to reduce the higher risks faced by babies from deprived backgrounds and support better outcomes for these babies.

Providing support that breaks down barriers and enables families to participate fully in FICare, offering high-quality outreach services, and strengthening developmental follow-up can all help to reduce the negative impact on a baby's quality of life and promote healthier development[183].

There is very little evidence on the role of social factors, including deprivation, in outcomes for babies with hypoxic-ischaemic encephalopathy (HIE), intrauterine growth restriction, perinatal stroke or congenital heart disease. More research needs to be done to understand the role of social risk factors including deprivation on outcomes for these babies[184].

Inequalities in two-year follow-up

It is important that every baby can access high-quality developmental follow-up, so that any needs they have are identified and supported early on. However, evidence shows that there are ethnic and socioeconomic inequalities in two-year follow-up rates, meaning that not all babies are accessing this support.

Enhanced developmental support and surveillance up to two years (corrected) should be provided to all children who were born before 30 weeks' gestation, and to babies born before 37 weeks' gestation who have additional risk factors (e.g. having had neonatal bacterial meningitis). Additionally, all children who were born before 28 weeks' gestation should receive enhanced developmental follow-up when they are four years old (uncorrected)[185]. This programme monitors a child's development and will give parents advice based on their needs and is usually based at the hospital where the baby was discharged from[186].

Follow-up is critical, as it allows for early identification and support if a child has developmental delays. This is particularly important in the context of socioeconomic deprivation, which is known to increase the risk of poorer long-term developmental outcomes[187].

Recent data indicates that, after accounting for other factors, babies born to parents from more deprived areas were 21 per cent less likely to have a two-year follow-up than babies in the least deprived groups. After accounting for other factors, Black babies had 34 percent lower odds of receiving two-year follow-up than white babies. For babies of 'Other' ethnicity, the odds were 46 per cent lower than white babies[188]. This may result in delayed assessments and missed opportunities for early intervention, impacting the long-term development and quality of life for these babies.

These inequalities sit within wider gaps in developmental follow-up. Not all neonatal units have dedicated local follow-up services, and recent research found gaps in 2-year neurodevelopmental follow-up[189].

There are also concerning gaps in four-year developmental follow-up for all babies. Currently, only 6.8 per cent of eligible children receive follow-up[190]. Children entitled to this follow up are among the most vulnerable to developmental delay. New guidance from the British Association for Neonatal Neurodevelopmental Follow-Up (BANNFU) says it should be offered to children who were born before 28 weeks' gestation, and other children at high-risk, including those with HIE and those living with the challenges caused by deprivation (BANNFU, Developmental follow-up, surveillance and support at the age of four years for more information, 2026). Sadly, there is no funding, commissioning or accountability for follow up services at four years, so local initiatives and resources are heavily relied on[191].

Conclusion

Discharge from neonatal care is a pivotal moment that can deepen existing inequalities. Some babies return to home environments that do not support their recovery and development and are less likely to receive follow-up care, allowing pre-existing and in-hospital inequalities to persist and deepen. As seen in Chapter 2, these challenges are closely linked to families' experiences on the unit. When parents lack confidence, the transition home can be more frightening.

Babies born prematurely from more socioeconomically deprived backgrounds and some minoritised ethnic groups are less likely to receive timely follow-up and early support, despite being more affected by the long-term impacts of social disadvantage. Addressing this requires engaging all parents in discharge planning, ensuring consistent access to community outreach and developmental follow-up, and tackling wider socioeconomic and structural inequalities.

Neonatal community outreach and developmental follow-up can play an important role in reducing these inequalities, but access to services is currently inconsistent. Expanding coverage and ensuring all families can benefit from this support, aligned with the NHS 10 Year Plan's focus on reducing health inequalities and shifting care into the community, will be essential to giving every baby the best possible start in life.

Addressing the combined impact of ethnicity, deprivation and the wider social context into which babies are discharged is critical, not only for safe transitions home, but for improving long-term health and developmental outcomes for the most vulnerable babies and their families.

12

Local authorities and other relevant bodies should work with neonatal services to ensure that no baby's discharge from neonatal care is delayed due to unsafe or unsuitable home conditions, including lack of reliable energy supply or adequate housing.

13

The Government should ensure neonatal community outreach services are commissioned consistently to ensure more babies receive care at home, reducing separation, improving care experience and reducing pressure on acute hospital services. This should include ensuring Allied Health Professional, Pharmacy and Psychology input can continue to be facilitated at home. Priority for service development should be in areas with higher levels of deprivation and poorer access to follow-up support.

14

Neonatal units should comply with the Neonatal Critical Care Service Specification for discharge planning, ensuring that planning starts at admission for all babies and that unit staff are able to identify any support that families may need to care for their baby at home.

15

Neonatal units should share best practice to improve rates of 2-year follow-up, with a specific focus on improving access and attendance among babies from more deprived backgrounds and minority ethnic groups.

16 The National Neonatal Audit Programme should include measures to monitor uptake of 4-year follow-up, and compliance against best practice guidance.

17 The Government should ensure that the forthcoming Single Patient Record can support greater uptake of eligible children receiving 4-year follow-up, by ensuring there are systems in place to proactively identify eligible children within community health care (e.g. GP services) and reach those at higher risk of being lost to follow-up.

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Chapter 4: Evidence gaps

While *Equity for Every Baby* has drawn on a wealth of evidence from a range of reports, reviews and papers, there are significant evidence and data gaps which limit our ability to assess fully the impact of ethnic and socioeconomic inequality within the context of neonatal services. The impact of this is stark, and means we do not fully understand *how* babies' care and outcomes may vary depending on their personal characteristics. Where there is insight, we do not fully know *why* variation exists or *what* interventions will be effective.

Consequently, the effectiveness of policies aimed at reducing health inequalities is likely to be limited by ongoing inconsistencies in data collection, definitions and gaps.

Data gaps

Current literature lacks sufficient evidence focused specifically on the care experiences of babies themselves, including how these experiences may vary and the implications for both short- and long-term outcomes. While this report has examined the ways in which parental engagement in FICare can be constrained by a range of factors, the corresponding impact on babies remains less clearly understood.

Although there is strong evidence that enabling FICare practices leads to improved outcomes for both babies and their parents, there is limited insight into how variability in lived experiences, even within the same neonatal unit, influences these outcomes. It remains unclear at what point reduced opportunities for hands-on parental care begin to contribute to suboptimal developmental or clinical outcomes for babies.

Ethnicity

While data collection is improving over time, gaps in ethnicity data remain evident in many studies. Sometimes data can be missing entirely, or mother's ethnicity is used as a proxy when the baby's is not recorded, even though these can be different. This can impair the accuracy of conclusions and affect the efficacy of any interventions put into practice. For instance, the latest NNAP data reported that 11.4 per cent of babies born in 2024 and admitted to a neonatal unit had missing ethnicity data[192].

Fuelled in part by poor data collection, the inability to disaggregate ethnicity beyond broad groups (for example, 'white' or 'Black') presents several issues. First, this risks presenting ethnic groups as homogenous and fails to account for the rich cultural, social and religious nuances that define ethnicity. It significantly limits our ability to consider intersectionality as part of analysis and a 'lack of precision' can mean that needs are going unmet[193] [194] [195].

Second, broad categorisation can mask important variation in outcomes[196] [197]. For instance, the National Child Mortality Database can disaggregate infant deaths (deaths under 1 year) in detail. It shows that babies with white British ethnicity had a death rate of 2.7 per 1,000, rising to 4.1 per 1,000 for babies with white Gypsy or Irish Traveller ethnicity and 5.2 per 1,000 for those with White Irish ethnicity. Similar variations were seen in other groupings – with Pakistani babies having a mortality rate of 7.4 per 1,000 compared to Chinese babies having a mortality rate of 2.6 per 1,000 – yet both fall within the broad descriptor of 'Asian/Asian British[198].'

Socioeconomic deprivation

As with ethnicity, there are challenges with data collection and classification when trying to understand the impact of socioeconomic deprivation on neonatal experiences and outcomes. Studies do not collect information about socioeconomic deprivation in a standardised way, limiting the ability to compare and synthesise data. There are also practical challenges – collecting this data is not easy to do accurately. Many studies use broad measures like the index of Multiple Deprivation, which provides a level of deprivation quintile score based on postcode. While this provides an indicator, it is very broad and can mask huge variation. Many people will live in areas considered 'deprived' who are not faced with the challenges caused by deprivation themselves, and vice versa.

Additionally, in one review of 70 studies, only 15 measured or reported maternal education status[199]. This data gap undoubtedly limits our understanding of how to improve outcomes for babies. Although it is well established that family and social factors play a significant role in shaping developmental outcomes, it is a 'very poor state of affairs' that most studies, as this review showed, did not attempt to measure these influences [200].

Intersectionality

As the previous chapters have demonstrated, the exact causes of neonatal ethnic and socioeconomic inequalities are not well understood, likely reflecting a complex interplay of factors. We know there is intersectionality between ethnicity and deprivation which increases the risks faced by certain babies. It is well-known, for instance, that a much larger proportion of babies from Asian Bangladeshi, Asian Pakistani, and Black ethnic groups[P] are born to mothers living in the most deprived areas[201]. Some research suggests that socioeconomic disadvantage explains between a quarter and a third of the differences in birth outcomes between ethnic groups[202].

However, despite contributing substantially to inequalities between ethnic groups, deprivation does not explain them, and more research is needed to understand the reasons behind ethnic inequalities[203 204 205 206].

Role of policymakers and researchers

Policymakers and researchers have a crucial role to play in better addressing these data and evidence gaps, and they should consider whether *the way they currently work* might be unintentionally reinforcing existing inequalities.

It has been noted that there has been a tendency, across multiple disciplines, for researchers to consider ethnically diverse communities as "hard to reach". This puts the blame onto participants for being under-represented, rather than acknowledging issues within the design and approach of the research itself[207].

Bliss' work to tackle health inequalities shows that communities are not "hard to reach". Meaningful engagement instead requires time to build trust, understand lived experiences and work closely with communities. However, researchers and policymakers are often constrained by timelines and budgets, making it difficult to take this approach and encouraging reliance on established methods. This can reinforce existing inequalities.

Commissioning bodies and research funders therefore have a key role to play in improving the quality and effectiveness of research into neonatal inequalities.

[P] MBRRACE-UK reports as 'Black ethnic groups' because of small numbers included in the data.

18 NHS Trusts should work with their Neonatal ODN to improve the rate of collection, accuracy and reporting of babies' demographic data, including ethnicity, and standardise the recording of deprivation, ensuring this information is used both to strengthen research and analysis and for units to identify and respond to families' needs from the earliest stage.

19 Neonatal research, including clinical trials, should be designed, funded and conducted to ensure meaningful inclusion of babies and parents of minoritised ethnicities and those experiencing socioeconomic deprivation; including proactive approaches to patient and public involvement (PPI) to ensure these parents are adequately represented in PPI activities.

Bliss will continue to champion equity in our policy and influencing work, including routinely monitoring the impact we have for babies facing socioeconomic deprivation and from minoritised ethnic groups.

Bliss will continue to review its information, support services and parent engagement approaches to ensure they are culturally responsive and shaped by families facing inequalities, including through targeted outreach and partnerships with community organisations.

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Conclusion

Equity is not a reality for every baby born premature or sick in England. The picture is clear: a baby's start in life is profoundly shaped by their ethnicity and socioeconomic status.

Some babies face greater risks from the outset. Those born into deprivation or from certain ethnic backgrounds are more likely to arrive too early, too small, or unwell. This increases their likelihood of neonatal admission, where their experience of care can vary significantly.

Our findings have shown that when parents are not well-supported, lack trust and confidence, feel unsafe or are not supported to communicate effectively, their baby receives less hands-on care. Improving equity in FICare provision is multi-faceted – it requires both Government-led initiatives to remove the financial and practical barriers to enable families to be present on the unit, and localised change to ensure that parental presence can transform into partnership in caregiving.

Improving outcomes requires policymakers to look beyond hospital walls and address the wider social determinants of health, and access to care, that shape babies' outcomes before and after they leave the unit. We need better data to understand and respond to neonatal health inequalities and better ways of identifying and removing barriers to FICare on the unit.

It is not inevitable that some babies will have a worse start in life, or that they may not get to live at all, simply because of their ethnicity, or the socioeconomic circumstances they are born into.

The Government, NHS Trusts and Integrated Care Boards, national organisations and researchers, and all those inside and outside the neonatal unit, have a responsibility to act on the evidence and listen to what parents consistently tell us. Every baby born premature or sick in the UK deserves an equal chance of survival and to have the best quality of life.

Methodology

This report focuses on the impact of socioeconomic deprivation and ethnicity and the care experiences and outcomes for babies who are born needing neonatal care.

We recognise that there are many other factors which may contribute to inequitable experiences and outcomes in neonatal care. Because there is a more limited evidence base on how these inequalities contribute to different outcomes for babies, and because these factors require their own dedicated investigation and focus, we do not address them in this report. We urge researchers and research funders to prioritise health inequalities in all their forms. Neonatal services and teams should consider the barriers that may affect babies and their families. They should make clear, focused efforts to address these barriers. This will help ensure that all babies have the best possible start in life.

In this report, we used a mix of existing evidence and new insights from parents to build a clear picture of the issues.

We undertook a detailed literature review to understand what is already known and where there are gaps. We searched PubMed using key search terms related to ethnic and socioeconomic inequalities, including articles published 2015-present, with data relevant to England. Full texts were assessed and reviewed.

We worked with two partner organisations that support families facing challenges relating to socioeconomic deprivation. Together, they carried out nine one-to-one interviews with parents. One organisation runs a programme to support women and men who are at risk of, or who have suffered the removal of one or more children from their care. The other supports families dealing with the challenges caused by deprivation.

We also analysed transcripts from previous Bliss listening events with Black and South Asian parents. This helped us identify common themes in parents' experiences and perspectives. To note, in our listening event with Black families, consent was not sought to publish direct quotations. Where these themes align with experiences explored in other research, or in Bliss' podcast '*In conversation with…*' we have drawn on quotes from these sources to contextualise the themes.

We brought together findings from all these sources and analysed them to identify key themes and patterns across the evidence.

Why did we consider socioeconomic deprivation and ethnicity together?

We recognise that while individuals within broader groups have distinct experiences, there are also shared challenges. Highlighting these common barriers is an effective way to inform service and policy changes that benefit all families. For this reason, we chose not to discuss ethnic and socioeconomic inequalities separately in this report.

At the heart of our approach is the belief that every baby and their parents should be safe, comfortable, and supported on the unit. Successful FICare therefore needs to be tailored to each family's individual needs.

We also recognise that approaches such as providing staff with training on specific cultures or religions can sometimes lead to assumptions. Instead, we emphasise the importance of engaging each family with openness and curiosity, asking what matters to them and what support they need to be partners in their baby's care.

Throughout the report, we have made a conscious effort to highlight differences in experiences where they exist, so that groups are not treated as homogeneous. In some sections, one group may receive more attention than others, reflecting the strength and availability of the evidence.

Glossary

Cultural responsiveness: We recognise that related terms such as cultural competence and cultural humility are used in policy and healthcare settings. We use cultural responsivity to emphasise an ongoing, active commitment to listening, learning and adapting practice in response to the needs and experiences of babies and families.

Deferred Cord Clamping: A practice where the umbilical cord is not cut straight after birth, but after at least 60 seconds. This can improve outcomes, especially for premature babies.

Equity and Equality Plans: Plans developed by Local Maternity and Neonatal Systems (LMNS) to set out how progress would be made against key priority areas for equity and equality across the LMNS region.

Family Integrated Care: A model of neonatal care which promotes a culture of partnership between families and staff. This enables parents to become confident, knowledgeable and independent primary caregivers.

Full term: Babies born from 37 weeks of pregnancy.

Health Inequalities: Unfair and avoidable differences in health across the population and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care that is available to them.

Institutionalised racism (in healthcare settings): When healthcare systems or policies unfairly disadvantage people from certain groups, leading to worse access, treatment, or outcomes.

Intersectionality: The way that different parts of an individual's identity such as ethnicity, gender, social class overlap to compound discrimination and disadvantage.

Local Neonatal Unit: Sometimes referred to as a Level 2 Unit, this is for babies who need a higher level of medical care and for babies born after 27 weeks' gestation who weigh over 1000 grams. These units may also provide short-term intensive care.

Neonatal care: Specialist care for babies who are born premature, unwell, or who need extra support after birth.

Neonatal Intensive Care Unit: Sometimes referred to as a Level 3 Unit, this is for babies needing the highest level of medical care, or for babies who do not fit the criteria for local or special care units. Babies admitted here are usually born before 27 weeks' gestation and/or are very sick.

Morbidity: The presence or level (rate) of ill health in a population.

Neonatal mortality rate: The number of deaths of babies within the first 28 days of life per 1,000 live births in a given time period.

Psychological safety: The feeling of being safe, respected, and able to ask questions or raise concerns without fear.

Premature: Babies born before 37 weeks of pregnancy.

Socioeconomic deprivation: When people have fewer resources and opportunities, often linked to income, education, housing, and employment. This can affect health and access to care.

Special Care Baby Unit/Special Care Unit: Sometimes referred to as a Level 1 Unit, they are for babies who do not need intensive or a high level of medical care, and are for babies born after 32 weeks' gestation.

Structural racism: Ways in which systems, policies, and institutions create and maintain unequal outcomes for people from different ethnic backgrounds.

Transitional Care: Is provided to babies who need some additional support – either straight after birth or ahead of being discharged from the neonatal unit – but do not need the level of specialist care provided on neonatal units. In this model, mothers are also in-patient and are cared for with their baby, avoiding separation. Transitional Care is a model of care, and so may be provided in a range of settings – including a dedicated Transitional Care area, the postnatal ward or as part of the neonatal unit.

Wider determinants of health: The social, economic, and environmental factors that influence health, such as housing, income, education, and access to services.

Abbreviations

AHPPP	Allied Health Professional, Psychologist and Pharmacist
BAPM	British Association of Perinatal Medicine
DCC	Deferred Cord Clamping
EEPs	Equity and Equality Plans
FICare	Family Integrated Care
FGR	Fetal Growth Restriction
HCP	Healthcare Professionals
LBW	Low Birth Weight
LMNS	Local Maternity and Neonatal System
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries
NICU	Neonatal Intensive Care Unit
NMPA	National Maternity and Perinatal Audit
NNAP	National Neonatal Audit Programme
ODN	Operational Delivery Network
RHO	NHS Race and Health Observatory

Campaign with us

Campaigning is a great way to make a difference to babies born premature or sick and their families. Sign up to our campaign network at
bliss.org.uk

Join the family, search Blisscharity on

Registered charity no. 1002973 Scottish registered charity SC040878