Bliss Response: Submission to the National Maternity and Neonatal Investigation Call for Evidence

March 2026

About Bliss

Bliss exists to give every baby born premature or sick in the UK the best chance of survival and quality of life. We champion 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.

Bliss welcomes the opportunity to provide evidence to the National Maternity and Neonatal Investigation.

Summary

- Around 90,000 babies require neonatal care after they are born every year in the UK.
- While safe, effective neonatal care requires close working with maternity services in particular, neonatal services are distinct. They are commissioned completely separately with their own governance and reporting structures, and workforce.
- Most crucially, the neonatal patient population is different. **Babies** are cared for by neonatal services, and a significant shift in thinking is required to ensure that they are considered patients in their own right, who have the capacity to experience both good and bad care which is distinct from the care their mother has received in maternity services; and indeed, distinct from their parents' experience of caring for a baby in neonatal care. We urge the Inquiry, and subsequently the newly-formed Maternity & Neonatal Taskforce, to recognise the need for clear and distinct actions to improve neonatal services, alongside dedicated maternity actions, as well as broader perinatal priorities which may apply across both services
- Neonatal services strive to provide excellent care to babies, and their families, but there is widespread variability in consistency and quality of care provided between different settings – and sometimes even *within* the same hospital.
- To improve neonatal services, action must be taken to:

- Address the **impact of health inequalities,** including through improved collection of babies' own demographic data, development of interpretation and translation services, access independent advocacy and the embedding of Family Integrated Care (FICare) so every parent or carer can participate fully in their baby's care.
- **Stop parents being separated from their babies** including through provision of overnight accommodation, financial support through a national expenses fund and equitable access to and better coordination of maternity and neonatal care.
- **Continue and sustain investment to grow the neonatal workforce** to prevent gains - made during the implementation of the Neonatal Critical Care Review implementation period - being eroded.
- **Commission Transitional Care and Neonatal Outreach services** consistently to ensure babies receive optimal care in locations where they can be kept together with their family, improving care experience and reducing pressure on neonatal units.

Introduction to neonatal care

Around 90,000 babies require neonatal care after they are born, either because they are born prematurely (before 37 weeks of pregnancy) or because they have been born at term, but sick, for example with an infection or genetic condition. Around 1,500 babies will die in the neonatal period every year in England.[1] Many of these deaths will occur in neonatal units.

Neonatal care is a specialised service, and while the care babies receive is often lifesaving, it is also a traumatic start to life. Babies are exposed to stimulation – lights, loud sounds and frequent painful procedures – all of which shape their early development atypically. For their parents, the experience is lifechanging. Rather than taking their baby home shortly after birth, their baby is admitted to hospital – while some parents will know in advance that their baby is likely to need neonatal care after birth, the majority will not. Many will not even know neonatal services exist until the moment they're told their baby needs to be rushed there. How long a baby will stay in neonatal care can vary from days to weeks or months. The timeline is often uncertain, and for very sick babies a neonatal journey is rarely linear, instead being characterised by sudden bursts of progress, and unexpected deterioration.

While neonatal services are inextricably linked to maternity, they are commissioned completely separately with their own governance and reporting structures, an entirely

---

[11] National Child Mortality Database (2025)Child Death Review Data Release: Year Ending 31 March 2025, data table, tab 8 accessed here: https://www.ncmd.info/publications/child-death-review-data-release-2025/

different patient population and workforce – and it is frequently not well understood by decision-makers and policy makers, who often group the two services together. One consequence of this is that babies are rarely understood as a patient group who have the capacity to have good and bad experiences of care.

Further, while parents experience neonatal care as just one point in their journey with their baby, other areas of the system rarely integrate well with neonatal services. This creates disjointed experiences and can compound parental stress, anxiety and trauma. For instance, perinatal mental health services do not fully recognise the increased needs of parents who have been through neonatal care. Similarly, Bliss is aware of women discharging themselves against medical advice because it is easier to be with their baby, travelling in from home, than it is from the postnatal ward a few hundred metres away because maternity and neonatal services are so disjointed.

The response below outlines some of the key challenges neonatal services are experiencing today, and the impact this has on the babies who use the services, and the parents and families who care for them, and also the opportunities to drive forward progress.

Inequitable outcomes

Inequities linked to maternal health outcomes impact the likelihood of a baby requiring neonatal admission, and risk of neonatal mortality. Evidence shows that as much as 72 per cent of neonatal deaths are in babies born before 37 completed weeks of pregnancy[2] and analysis of over 1 million births has suggested that socioeconomic inequalities account for a fifth of preterm births.[3] The statistics about the health inequalities driving England's high rates of preterm birth and neonatal mortality are clear:

- In 2023, neonatal mortality rates remained significantly higher for Black and Asian babies (2.28 per 1,000 births and 2.35 per 1,000 births respectively) compared to white babies (1.50 per 1,000 live births);[4]
- Bangladeshi, Pakistani and Black babies also continue to be disproportionately affected by the higher rates of neonatal mortality associated with socioeconomic deprivation.[5]

---

[2] NCMD (2022), The Contribution of Newborn Health to Child Mortality across England: National Child Mortality Database Programme Thematic Report

[3] Jardine J, Walker K, Gurol-Urganci I, et al. Adverse pregnancy outcomes attributable to socioeconomic and ethnic inequalities in England: a national cohort study. Lancet. 2021;398(10314):1905-1912. doi:10.1016/S0140- 6736(21)01595-6

[4] MBRRACE-UK (2025 report on 2023 data)

[5] MBRRACE-UK (2025 report on 2023 data)

- Black women are more than twice as likely to give birth extremely prematurely as White women. [6]
- A cohort study by the National Maternity and Perinatal Audit (NMPA) found that the risk of preterm birth was 4.9% in the least deprived group, compared to 7.2% in the most deprived.[7]
- Recent data looking at National Neonatal Audit Programme (NNAP) measures found some aspects of perinatal optimisation differ according to ethnicity – for instance, Black babies are less likely to receive delayed cord clamping (DCC). DCC is linked to improved outcomes, including lower rates of neonatal mortality.[8]

While there is more limited evidence exploring inequities in neonatal outcomes once babies are admitted to the neonatal unit, this is beginning to emerge. [9] A recent study which analysed data from the National Neonatal Research Database (NNRD) found that babies born to Black mothers are 81% more likely to die in neonatal care, and those whose mothers live in the most deprived areas were found to have a 63% higher chance of dying before discharge. This study found that while these figures dropped significantly when adjusted to account for pre-existing risk factors present at the time of admission to neonatal care, some inequalities remain, suggesting in-unit factors, such as care practices, might contribute to persistent inequalities. [10]

Further, research from the NHS Race & Health Observatory (RHO) showed skin-colour related assessments are inadequate for a culturally diverse society, potentially leading to delays in diagnosis or misdiagnosis of conditions like jaundice in babies with darker skin tones.[11] Delay in diagnosis can be serious, with recent research showing that 50 per cent of all cases of kernicterus – a rare but serious condition arising from untreated jaundice which can cause

---

[6] Kirstin Webster and National Maternity and Perinatal Audit (NMPA) Project Team, Ethnic and Socioeconomic Inequalities in NHS Maternity and Perinatal Care for Women and their Babies: Assessing care using data from births between 1 April 2015 and 31 March 2018 across England, Scotland and Wales (2021 https://maternityaudit.org.uk/FilesUploaded/Ref%20308%20Inequalities%20Sprint%20Audit%20 Report%202021_FINAL.pdf

[7] Jardine J, Walker K, Gurol-Urganci I, et al. Adverse pregnancy outcomes attributable to socioeconomic and ethnic inequalities in England: a national cohort study. Lancet. 2021;398(10314):1905-1912. doi:10.1016/S0140- 6736(21)01595-6

[8] Pettinger K, Pons Perez S, Legge H, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity: a retrospective cohort study. *BMJ Paediatrics Open*

[9] Saberian, Samira et al. (2025) Inequalities in neonatal unit mortality in England and Wales between 2012 and 2022: a retrospective cohort study, The Lancet Child & Adolescent Health, Volume 9, Issue 12, 857 - 867

[10] Saberian, Samira et al. (2025) Inequalities in neonatal unit mortality in England and Wales

[11] NHS Race Health Observatory (2023) Review of neonatal assessment and practice in Black, Asian and minority ethnic newborns Exploring Apgar score, the detection of cyanosis and jaundice.

brain damage – were from Black, South Asian and "all other" ethnic groups, despite representing only 25 per cent of live births.[12]

These wide variations in health outcomes and survival are unacceptable but not well understood. There is considerable research needed to identify and interrogate inequity within and between neonatal units, and there is an urgent need to improve ethnicity data collection.

Often, a mother's own ethnicity is used as a proxy in research as collection of their baby's ethnicity is poor – even though this can be different. Additionally, poor data collection is a barrier to more comprehensive analysis. For instance, outcomes for babies based on ethnicity are reported as broad categories – i.e. "Black", "Asian" "Mixed" and "White". Not only does this risk ethnicity being viewed homogenously, it masks significant variation within these groups.

The latest data from the National Child Mortality Database (NCMD) describes significant variations within broad ethnic groupings for infants (babies who died under 1 years old). For instance, while the infant death rate for White British and Northern Irish is 2.7/1,000, this rises steeply to 4.1/1000 for White Gypsy or Irish Traveller and to 5.2/1,000 for White Irish. This variation is apparent in other groupings too - within Asian/Asian British, Pakistani ethnicity has an infant death rate of 7.2/1,000 but Chinese ethnicity is 2.6/1,000[13]. Robust data is needed so similar interrogation can be undertaken specifically for neonates.

Inequalities are not only apparent in terms of stark differences in mortality and morbidity, but also in patient experiences and access to care. Our submission will highlight the multi-faceted ways in which babies experience inequitable care.

Family Integrated Care (FICare): experiences of babies and their families

Neonatal services in England strive to deliver Family Integrated Care (FICare), a model of care which promotes a culture of partnership between parents and staff. Parental involvement in care is critical for bonding and forming secure attachments. Providing direct, hands-on care allows parents to *feel* like parents - which may be key for their perceptions of attachment to their baby - and physical and emotional closeness is crucial for forming strong parent-infant

---

[12] Baskaran, Gale and Jawad et al. (2023) Kernicterus in neonates from ethnic minorities in the UK, Archive of Diseases in Childhood. Fetal and Neonatal Edition, 108:432-433

[13] NCMD, (2025) Child Death Review Data Release

bonds.[14] Parents who are supported to be with their baby for prolonged periods report increased parental confidence, and reduced stress and anxiety scores.[15]

Ensuring parents can be partners in their baby's care is proven to be best for babies' developmental outcomes. Evidence has shown that long periods of direct care led to increased weight gain and improved breastfeeding rates, and skin-to-skin care has been linked to better infant reflexes at term and better gross motor development at 4-5 years.[16,17]

Barriers to parental presence and FICare

For babies, and their parents, to fully benefit from a FICare approach, they need time – but parental presence on the neonatal unit is curtailed by many practical and social barriers.

Finances

Practically, the costs associated with having a baby in neonatal care are high and prevent parents from being with their babies. Bliss has conducted research assessing the financial toll that having a baby in neonatal care can have on families. Families in our research spent an additional £405 per week, on average, to cover additional unexpected expenses like food, drink, travel, parking and accommodation.[18] One in four families also reported needing to borrow or increase their debt while their baby was in neonatal care.[19]

Our findings show that neonatal care can push families into financial insecurity – but it is important to recognise that many families will already be at this point before their baby is admitted to the neonatal unit. The additional costs simply cannot be absorbed, and so they cannot be with their baby as frequently as they want to be. Some parents will not be able to be with their baby every day due to these barriers. Not only is this likely to impact parental confidence and mental health – but it will have an impact on their baby's care experience too, contributing to inequities.

Support for families with a baby in neonatal care in England is fractured and patchy. While many hospitals try to provide some support, these often come with stringent and exclusionary criteria (such as meals only being available to breastfeeding mothers). They are

---

[14] Treherne SC et al (2017). Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU. J Obstet Gynecol Neonatal Nurs.

[15] O'Brien K et al (2018) Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health. 2018 Apr;2(4):245-254

[16]Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial (O'Brien et al, 2018)

[17] Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU (Treherne et al, 2017)

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

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

also vulnerable to funding cuts (often funding for this type of support is provided by a charity, or comes from an underspend which might not be there the following year).

Since 2018, families with a baby in neonatal care in Scotland have received support for travel, subsistence and accommodation costs.[20] An evaluation of this scheme found that parents reported that the fund relieved financial anxieties and enabled them to spend more time with their babies on the neonatal unit.[21] Recently, the Government in England announced a £10 million financial support package to help families of children affected by cancer, rightly recognising the considerable toll on family finances if families need to travel daily for prolonged periods of time, often to hospitals very far from home - all of which are parallels to the experience of parents when their baby is in neonatal care.[22]

'Expenses funds' are tried, tested and impactful. Bliss strongly recommends that NMNI considers recommending the development of a Neonatal Expenses Fund for families in England to ensure no baby experiences separation from their parents due to financial constraints.

Accommodation

Parents of babies in neonatal care are not routinely provided with somewhere to stay with their baby overnight. This means that, unlike in other children's health services, parents are usually separated from their baby repeatedly throughout their time in hospital. This is despite evidence which suggests that when parents can stay on the unit with their baby, the risks of mortality and morbidity are reduced and babies are likely to require fewer care days than babies whose parents cannot stay on the neonatal unit.[23]

In a 2022 survey of more than 1,900 parents, Bliss found that 75 per cent did not have access to overnight accommodation when their baby was critically ill and 87 per cent said this stopped them from being involved in their baby's care at least sometimes.[24]

National standards have mandated that parental accommodation should be available for parents of sick babies in neonatal care since 2009[25] and this was reaffirmed most recently in the NHS England Service Specification for Neonatal Critical Care update: "Facilities and

---

[20] The Neonatal Expenses Fund was established in 2018 and was available to all families with a baby in neonatal care in Scotland. This has since been subsumed into the Young Patients Family Fund, whereby parents and siblings of any hospitalised child can claim support with travel, food and accommodation.

[21] Scottish Government (2019) Neonatal expenses fund year one: evaluation

[22] Department Health and Social Care (2026) Government to cover travel costs of children with cancer https://www.gov.uk/government/news/government-to-cover-travel-costs-of-children-with-cancer

[23] Lehtonen (2020) Family Rooms in Neonatal Intensive Care Units and Neonatal Outcomes: An International Survey and Linked Cohort Study

[24] Bliss (2024) Families kept apart: Parent accommodation on the neonatal unit in England.

[25] Department of Health and NHS (2009) Toolkit for High-quality Neonatal Services

resources must be available....this includes sufficient accommodation...for all families to support a family integrated care approach."[26]

Despite this recognition, there have been repeated missed opportunities to make progress. The NHS Long Term Plan committed to "invest in improved parental accommodation"[27] - a commitment later renewed in the Three-Year Delivery Plan for Maternity and Neonatal Services.[28] Across this time span, the delivery of the Neonatal Critical Care Review (NCCR) was underway and, once again, while the level of parent accommodation was identified as a key action to make progress against[29], no capital investment was ever made forthcoming specifically to address this. The delivery phase of the NCCR is now over, and no new investment in the programme is expected. There has been limited meaningful progress towards achieving the original aims of the programme in relation to improving parental accommodation.

While there is some positive work underway through the New Hospitals Programme to ensure hospitals of the future provide a gold-standard of accommodation for parents of babies in neonatal care, this is not a comprehensive solution. There must be focus on improving access to accommodation and sleeping spaces in the short-to-medium term or the benefits of FICare will never be fully realised for most babies and families. Bliss recommends:

- A capital investment scheme to enable Trusts to apply for capital funding to renovate existing spaces or construct additional space to be used as overnight accommodation rooms and/or facilities such as kitchens
- A long-term capital investment strategy to enable Trusts that require larger sums of money to construct or completely renovate part of a building
- The development of a small grants programme so Trusts can apply for funding immediately to buy new furniture or equipment to improve the neonatal environment and provide parents with the facilities to support them being partners in their baby's care.

Inequity in parental and family experiences

In addition to practical barriers, there is a growing body of evidence demonstrating that parents have variable experiences of partnership in care depending on their personal characteristics.

---

[26] NHS England (2024) Neonatal Critical Care Service Specification
[27] NHS England (2019) The NHS Long Term Plan
[28] NHS England (2023) Three-Year Delivery Plan for Maternity and Neonatal Services
[29] NHS England (2019) Implementing the Recommendations of the Neonatal Critical Care Transformation Review

Experiences of fathers

For many fathers, the transition into neonatal care happens abruptly and can feel overwhelming and emotionally demanding. They often report feeling overlooked and uncertain of what to do, expected to support their partner, stay composed, and cope with their own worries.[30]

Our research with fathers of babies born premature or sick found that more than half of fathers said they could not be at the hospital while their baby received neonatal care, and 30 per cent said they could not get to the unit every day.[31] Fathers want to be there, but they are often the ones keeping everything together outside the unit. For example, looking after the mum, caring for other children, working and maintaining the household.

"I was having to juggle looking after another child and do the nursery drop-offs and all of that while carrying on as normal, splitting my time on the unit when I could and then running to where my wife was [on the maternity ward] then with my laptop and my work phone trying to organise work. I felt if I'm totally honest with you guys I felt totally out of my depth." (Fathers focus group participant)

With the introduction of statutory neonatal leave and pay, more fathers should now be able to spend time with their baby on the unit. However, even when fathers can be with their baby, there is much more to be done to help them be involved in care. Fathers told Bliss they do not receive the same level of training and information as mothers. The lack of tailored communication can be disempowering, and sometimes even the basics like a chair for them to sit on cot-side is missing.[32]

"I'd spent two hours a day sat with him but not really encouraged to interact. The medical team made me feel very much like I was a spare part". (Fathers focus group participant)

Timely and tailored support for fathers can be transformative in giving them confidence to be partners in their baby's care – staff on neonatal units need to proactively identify and implement practical ways to do this.

"[The nurse] ended up being a really big advocate for us of going to the unit and saying unless there's a medical reason or the staff is too busy…you are allowed to touch your children, you are allowed to hold your children, you are the father, you can see their notes." (Fathers focus group participant)

---

[30] Bliss (2026) Dads project survey and focus group, *Unpublished internal data*

[31] Bliss (2024) Barriers to involvement in care; Fathers' experiences

[32] Bliss (2024) Barriers to involvement in care; Father's experiences

"They floated the idea to me to change her nappy and get involved. I was shocked, I was like no way I can do that with all these wires, it was almost like defusing a bomb or something, but the fact that they were encouraging me to do it so early and she was so critical and they made time to train me and my wife separately, it became the one thing I looked forward to doing." (Fathers focus group participant)

Impact of health inequalities

An analysis of NNAP measures has shown that parents from minoritised ethnic groups were less likely to receive an update on their baby's condition from a senior clinician within 24 hours of their baby being admitted, and were also less likely to be involved in ward rounds.[33] The same was true for the most deprived families, when compared to the least deprived.[34] Both interaction points are key for ensuring parents are informed, able to be involved in decision making, and share their own thoughts and concerns about their baby's care and behaviour.

Other research exploring experiences of palliative and end-of-life care show that issues are often exacerbated for "culturally diverse" families due to communication difficulties and divergent beliefs between[35]). One study found that staff could become frustrated and hostile towards parents, due to not understanding their cultural values.[36]

Bliss' own research working with families from various backgrounds and communities aligns with this emerging research. We have found:

- More than a fifth of younger parents did not feel well supported on neonatal units, with some experiencing age-related discrimination

"I think sometimes people look down their noses at you without realising they are doing it. There was quite an obvious difference in how I was spoken to compared to how the other parents were spoken to" (Mum, 24 who had her first neonatal experience at 15)

- Half of the parents who took part in our survey of South Asian parents had to ask permission for skin-to-skin and nearly a third felt their needs for privacy and modesty were not understood or respected by staff.

---

[33] Pettinger K, Pons Perez S, Legge H, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity: a retrospective cohort study. *BMJ Paediatrics Open*

[34] Pettinger K, Pons Perez S, Legge H, et al. (2025) Does neonatal care delivery in England and Wales vary by deprivation and ethnicity: a retrospective cohort study. *BMJ Paediatrics Open*

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

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

"[There was] no consideration when doing skin to skin as there was no privacy from males and I cannot expose myself in front of men" (Mum of a premature baby)

- Our work with families from South Asian and Black communities also had a recurrent theme of assumptions being made about families because of their race and ethnicity, and experiences of racism.

"People that I spoke to...definitely had a prejudice. They weren't brave enough to express it directly to me...They must have forgot my colour, seriously some of their language was really not PC." (Black mother, participating in a Bliss listening event)

- Families from Black communities have expressed a very real fear of social services involvement and other reprisals if they were to be construed as not coping, and that they were treated differently by both staff and other parents on the neonatal unit, meaning they had no safe space.

"I don't have the trust to tell them I'm not ok. Because I don't want them to take my baby. I know it's not like this...they're not actually taking my baby. But I couldn't stop myself from thinking this way. I couldn't trust them." (Black mother, participating in a Bliss listening event)

A full repository of our publicly available work exploring how neonatal care is experienced by different communities is included in the Appendix.

A significant theme which has emerged in Bliss' own work, as well as being well documented in research literature, is the significant impact on care quality and experience when parents require translation or interpretation services. These services are critical to the safe running of maternity and neonatal units and yet are woefully inadequate – both in terms of their availability, and quality.[37] Families who have engaged with Bliss' projects who required this support frequently describe it as not being available, or even offered, with staff relying heavily on - and even just defaulting to - family members to translate. These parents are more likely to report poor care, and to have fewer opportunities to care for their baby directly and be involved in decision-making about their care.

"They didn't mention anything about translator...a lot of the information was given to me as opposed to my husband [who did not speak English]. And when you just sort of going like in and out sleep, it is so difficult to grasp that info and because I didn't know much myself - it was my first pregnancy- ... I think when you don't [know] what to expect, you don't really know what questions to ask at the time either. It was sort of, 'this is what's going to happen [then] this is what's going to happen'. But yeah, [my husband] didn't have the information. He

---

[37] Sands & Tommy's Policy Unit and VCSE health well being alliance (2025), Not Just an Option: Interpreting as an Essential Component of Safe Maternity and Neonatal Care

had the reassurance, but not the information." (South Asian mother, participating in a Bliss listening event, describing how information was given to her and her husband, when her and her baby became very unwell during labour).

"[I speak English as a second language and] I couldn't do that effort. I was emotionally too stressed to make that effort. Speak another language and express myself in the way that I want to because the language doesn't help to be honest and there's an extra pressure that I should be kind of meeting their expectations in some way. I can't do it." (Black mother, participating in a Bliss listening event)

These unacceptable variances in parental partnership in care have a direct impact on the baby's own experience. If parents are unable to communicate their needs or understand how they can be involved or feel unable to attend the unit frequently due to poor relationships with staff, their baby receives less hands-on care from their parents.

Maternity and Neonatal Independent Senior Advocates (MNISA)

While many different solutions are required to ensure babies and their families have equitable care, one may be the role of advocacy in ensuring families voices are heard, listened to and acted upon.

A pilot of the MNISA role has been evaluated, showing overwhelmingly positive experiences for the families who were supported by the role, all of whom had experienced adverse outcomes. Families reported that the independence of this role from the hospital was key, the role helped to ensure accountability was upheld, families could navigate the system and enabled family concerns to be acted upon.[38] The pilot also showed that the case load had been of a less-deprived cohort than expected, and that mothers with white ethnicity were overrepresented - and identified a range of recommendations to broaden access.[39]

Despite limitations to its reach during the pilot phase, it did prove that there is a need for independent advocacy support, and that when it is available it is effective and impactful. This makes it even more disappointing that the opportunity to build and refine this important service is likely to be lost, due to the programme's funding reportedly being pulled.[40]

Workforce

---

[38] Rapid Service Evaluation Team (2025), Mixed-methods evaluation of the Maternity and Neonatal Independent Senior Advocate (MNISA) Pilot in England: Final report

[39] Rapid Service Evaluation Team (2025), Mixed-methods evaluation of the MNISA

[40] Health Service Journal (2025) National scheme to support families after baby deaths faces axe https://www.hsj.co.uk/quality-and-performance/national-scheme-to-support-families-after-baby-deaths-faces-axe/7040159.article

To improve long-term outcomes of children who are born needing neonatal care, it is essential that neonatal units can provide the best care for babies. At the most basic level this means ensuring that units are staffed appropriately. The Service Specification for Neonatal Critical Care[41] sets out clearly the optimal staffing required to provide care, but we know from national audit[42,43] that these standards are far from being met.

Neonatal Nursing

Neonatal nurses provide most of the direct care to babies who require it in neonatal units. There is clear evidence that nurse-to-baby ratios adopted within national standards should be regarded as minimum levels.[44,45] Nurse staffing levels directly correlate with mortality rates, with settings with higher nurse-to-baby ratios having an improved adjusted risk for survival, and services which have more Qualified in Specialty (QIS) nurses[46], have a reduced risk of mortality.[47]

The NCCR Implementation programme resulted in significant levels of investment into growing the neonatal nursing workforce in recent years. The funding through this programme also enabled investment into roles aimed at improving workforce education and retention at Operational Delivery Network (ODN) level.

However, most of the newly recruited workforce were non-QIS trained. Ensuring a focus on nurse education and career progression is essential for maintaining and retaining a highly-skilled neonatal nursing workforce. Currently, there are significant barriers to achieving QIS:

- Significant variation in content of QIS courses, leading to varying skill levels across the country and duplication of effort (e.g. staff needed to be 'retrained' if they move to a new setting)
- Challenges with securing funding and time to undertake training
- Undertaking QIS results in increased levels of expertise and greater responsibility within the neonatal unit. However – unlike with other specialties, such as midwifery –

---

[41] NHS England (2024), Neonatal Critical Care Service Specification

[42] National Neonatal Audit Programme (NNAP) Summary report on 2024 data

[43] Neonatal GIRFT (2020) A snapshot of neonatal services and workforce in the UK

[44] Milligan, D W, Carruthers, P, Mackley, B Ward Platt, M P, Collingwood, Y Wooler, L, Gibbons, J, Draper, E, Manktelow, B N (2008) 'Nursing workload in UK Tertiary Neonatal Units', Archives of Disease in Childhood, 93(12), pp.1059-1064

[45] Pillay, T, Nightingale, P, Owen S, Kirby D, Spencer, S A (2011) 'Neonatal Nursing Efficacy: practical standards of nursing care provision in a newborn network', Archives of Disease in Childhood, 96(Suppl 1), A36

[46] Watson, S I, Arulampalam, W, Petrou, S, Marlow, N, Morgan, A S, Draper, E S, Modi, N on behalf of the Neonatal Data Analysis Unit (NDAU) and the Neonatal Economic, Staffing and Clinical Outcomes Project (NESCOP) Group (2016) ' The effects of a one-toone nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study', Archives in Disease and Childhood – Fetal and Neonatal Edition, 101(3), F195-200

[47] Hamilton, K E, Redshaw, M E,Tarnow-Mordi, W (2007), 'Nurse staffing in relation to risk-adjusted mortality in neonatal care', Archives of Diseases in Childhood – Fetal and Neonatal Edition, 92(2), F99-F103

there is no automatic progress to Band 6 once the qualification has been gained, following a period of consolidation. [48]

Neonatal medical staffing

Neonatal units need to have right number and mix of medical staff to manage babies' care safely and effectively. It is very important that the guidelines on the minimum number of medical staffing are met. There are fewer medical staff than nurses working on neonatal units, so even one or two gaps on a medical rote can have a big impact on babies' care and how well the unit operates.

There is significant variation in compliance with medical standards at all levels of neonatal unit has been highlight in the Getting It Right First Time neonatal medical workforce report.[49] Bliss fully supports the evidence and recommendations submitted to the NMNI regarding medical staffing, including that there must be analysis of the reasons driving gaps being undertaken and a specific medical workforce plan for neonatal services to be developed.[50]

Allied Health Professionals, Psychological and Pharmacy professionals (AHPPPs)

Neonatal AHPPPs are core to the multidisciplinary teams (MDT) that babies born premature or sick need in order to have the best chance of survival and quality of life. Where units are staffed across these professional groups, these team members add up to more than the sum of their parts, providing support to the whole MDT. They play a vital role in improving short-and-long term outcomes for babies and contributing to the safer provision of care. For instance:

- Early intervention from a **physiotherapist** can support early diagnosis of motor problems, help to prevent ongoing complications, promote better motor and cognitive outcomes, and mitigate longer-term care costs.[51]
- Improving the nutritional care of babies can reduce their risk of developing co-morbidities of prematurity such as necrotising enterocolitis (NEC), retinopathy of prematurity (ROP) and bronchopulmonary dysplasia (BPD). **Dietetic**-led protocols can

---

[48] Neonatal Nurses Association (2024), House of Lords Preterm Birth Committee – written submission from the Neonatal Nurses Association

[49] Getting It Right First Time (2022) Neonatology – Workforce GIRFT Programme National Specialty Report.

[50] BAPM (2026) Evidence submission for Amos Review March 2026

[51] South West Neonatal Network. Evidence repository to support the development of Allied Health Professions and Clinical Psychology services in Neonatal Units within the South West.

also reduce the impact of nutrition-related complications such as vitamin deficiencies and metabolic bone disease.[52,53,54,55]

- **Neonatal pharmacy** roles directly on the neonatal unit are one of the most consistently identified strategies to reduce medication errors – which are common in neonatal settings – with some studies showing that up to 80% of errors could have been prevented through pharmacist monitoring.[56,57] Drug errors carry significant risks of severe morbidity and death, and there have been recent high-profile cases demonstrating this.[58] Bliss fully supports all recommendations made by the Neonatology Specialist Interest Group of the Neonatal & Paediatric Pharmacy Group (NPPG) to the NMNI, including that national workforce commissioning strategies mandate compliance with NPPG staffing standards, both at unit and network level.[59]

Recent Bliss research found that on average there was a 60% shortfall between recommended AHPPP staffing levels for units and the staffing levels currently being achieved – with variation between individual roles.[60] This pattern is also seen at ODN level, with a 60% shortfall between staff in post compared to staffing standards.[61]

While these figures show a concerning disparity, context is important. This is a *significant* improvement since the Getting It Right First Time (GIRFT) Audit in 2019, and this improvement has been driven by funding through both the NCCR and Ockenden funding (which was released in 2021). This led to substantial growth in both in-unit and ODN level roles which have had a considerable impact.

---

[52] British Dietetic Association (2022). Dietitian Staffing on Neonatal Units.

[53] Smith M, Mustapha M, The evolving role of dietitians in neonatal units and beyond, Paediatrics and Child Health, https://doi.org/10.1016/j.paed.2024.02.002

[54] Mustapha M et al., Nutrition of preterm and term infants in the neonatal unit, Paediatrics and Child Health, https://doi.org/10.1016/j.paed.2024.10.002

[55] Mustapha M, Blair H, Leake N, Johnson V, van den Akker CHP, Embleton ND. The evolution of nutritional care in preterm infants with a focus on the extreme preterm infant. J Hum Nutr Diet. 2024;1–12. https://doi.org/10.1111/jhn.13353

[56] Manias E, Kinney S, Cranswick N, Williams A. Interventions to reduce medication errors in pediatric intensive care. *Ann Pharmacother*. 2014;48(10):1313–1321.

[57] Fortescue EB, Kaushal R, Landrigan CP, et al. Prioritizing strategies for preventing medication errors and adverse drug events in pediatric inpatients. *Pediatrics*. 2003;111(4 Pt 1):722–729.

[58] BBC (2024) Babies died after hospital neglect - inquest jury https://www.bbc.co.uk/news/articles/cg64rg016e3o

[59] NPPG (2026) Response from the Neonatology Specialist Interest Group of the Neonatal and Paediatric Pharmacy group (NPPG)

[60] Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy Roles in Neonatal Care

[61] Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy Roles in Neonatal Care

There is no new funding attached to the NCCR expected to enter the system, and the Ockenden funding has lost its ringfencing.

There is a real risk that these important gains will slowly be eroded, and Bliss has already heard anecdotally of network-level pharmacy role contracts not being renewed into the next financial year. Due to the low compliance with staffing standards, babies already face inequitable access to these services; it is a postcode lottery. These inequities are set to deepen if the continued resourcing and permanent, recurrent funding needed to grow and develop the services is not injected into the system.

Interaction with other services

Neonatal care does not just take place within a neonatal unit:

- Various models of **Transitional Care (TC)** exist, designed to care for babies with low additional care needs alongside their mother, with care often delivered by both maternity and neonatal staff.[62] This model avoids separation of mother and baby, reduces unnecessary interventions and – in services where it is highly developed – can almost replace Special Care.
- **Neonatal Outreach** provides ongoing care to babies at home via specialist nurses and AHPs, with oversight from the discharging hospital's clinical team. While service provision is currently extremely varied, the first framework for practice from the British Association of Perinatal Medicine (BAPM) was published in 2025[63]. Neonatal Outreach can help babies home sooner – even those receiving more complex care (like needing oxygen or tube feeds) – reduce parental separation and even prevent the need for admission to neonatal care entirely (e.g. a small number of services can provide blue-light therapy for jaundice in a home setting, or can support babies to receive antibiotics at home[64]).

The potential of providing neonatal care through these two services which exist outside of a physical neonatal unit are enormous – particularly for baby and family bonding and relationships, as both enable families to be kept together when they otherwise might be separated.

However, while there are frameworks which establish how these services *should* operate, in reality there is no consistency across the country – and where there is no consistency, there is no equity. A baby cared for in a service which can support oxygen therapy at home will be

---

[62] BAPM (2017) Neonatal Transitional Care A Framework for Practice

[63] BAPM (2025) Neonatal Outreach Service A BAPM Framework for Practice

[64] https://arc-swp.nihr.ac.uk/research/projects/neonatal-oral-antibiotics-at-home-noah/

discharged much quicker than a baby in services where it is not, but access to this service is a postcode lottery

A clear barrier to developing both these services and improving consistency lies in commissioning. Currently, the neonatal workforce is commissioned for 'cot side' nurses only. Bliss supports the Neonatal Nurses Association's (NNA) call for TC and Neonatal Outreach services to be commissioned, to enable the improved flow of babies through the system. This would ensure more babies receive care in the right place, at the right time – even if that place is not in a neonatal unit.[65]

Postnatal and in-patient care for mothers

One of the most challenging times for families often arises when the mother is still receiving in-patient care while her baby receives neonatal care. Maternity and neonatal services – while often very close in terms of physical proximity – often operate in complete silos. Bliss' research exploring the coordination of these services found:[66]

- Half of in-patient mothers said they weren't as involved in their baby's care as they wanted to be while they were in postnatal care
- A fifth said they couldn't see their baby whenever they wanted – even once they were well enough.

"Couldn't see him for nearly 24 hours as husband needed to leave overnight and there was no porter available to take me there in a wheelchair."

- Mothers compromised their own care and often experienced a lack of assistance to help them move between wards, often relying on their friends and family.

"I neglected my own health and pushed myself too hard as I had to get up and walk to the NICU myself due to short staffing. Being in the NICU all the time also meant that I kept missing all my meds and meals."

- 16% of mothers told us they were never kept informed about their baby's condition and there was no protocol on the postnatal or neonatal wards for relaying information between NICU and the postnatal ward.

"When they took my baby from the delivery room I had no idea of his health, where he was gone or when I would see him next. Eventually, I could go to see him but was required to be back at certain times for check-ups/monitoring. No updates on my baby were available to me when I was on the postnatal ward."

---

[65] NNA (2024) House of Lords Preterm Birth Committee – written submission for the Neonatal Nurses Association

[66] Bliss (2023) Coordination of maternity and neonatal care: barriers to involvement of care

Improving the coordination between these services would have a significant positive impact on babies and their mothers. Bliss is aware of pockets of good practice – for example, a unit where a member of maternity staff can come to the neonatal unit to provide medication to mums who are in-patient, and services where meals can be delivered directly to the neonatal unit. But this is not widespread or consistent.

Conclusion

Neonatal services provide life-saving care to some of the NHS' most vulnerable patients every day. As our response has set out, it is a service which is marked by variation and inconsistency. Dedicated staff strive to provide the best care they can for the babies on their units, but that care might not be optimal for reasons beyond their control - crumbling estates, lack of resources to fully-fund AHPPP services, limited interpretation or translation available – the list could go on.

We urge the Inquiry, and subsequently the newly-formed Maternity & Neonatal Taskforce, to recognise the need for clear and distinct actions to improve neonatal services, alongside dedicated maternity actions, as well as broader perinatal priorities which may apply across both services.

Ultimately, it is individual babies who are paying the price. Around 90,000 babies need neonatal care every year, and yet the quality and consistency of that care can differ widely – between hospitals and even *within* a single hospital. Bliss recommends that:

- Action is taken to address the **impact of health inequalities**. This must centre the impact of health inequalities on babies' own outcomes and experiences of neonatal care. There must be commitments to:
    - Improve collection of babies' own demographic **data,** particularly ethnicity, to enable accurate research and analysis.
    - Development of **interpretation and translation services**, to improve quality and availability, to improve safety of care delivery and ensure all parents are informed and can be partners in care and decision-making for their baby.
    - Fund and develop **independent advocacy** services to ensure more families are feel listened to, heard and have their concerns acted upon.
    - **Embed FICare** so every parent or carer can participate fully in their baby's care.
- Measures are taken to **stop parents being separated from their babies** including through provision of overnight accommodation, financial support through a national expenses fund to ensure consistent provision and equitable access and better coordination of maternity and neonatal care.

- **Continued and sustained investment is made to grow the neonatal workforce** so evidence-based staffing standards can be met, consistently. Without this, gains made during the implementation of the NCCR in terms of nurse staffing and AHPPP development both on-unit and at ODN level are at risk of erosion.
- **Transitional Care and Neonatal Outreach services are commissioned** consistently to ensure babies receive optimal care in locations where they can be kept together with their family, improving care experience and reducing pressure on neonatal units.

Appendix: Bliss evidence bank

- Neonatal care through a young parents lens
- South Asian families' experience of neonatal care
- Bliss briefing: Impact of the cost-of-living crisis on neonatal care
- Bliss briefing: coordination of maternity and neonatal care: barriers to involvement in care
- Bliss briefing: father's experiences of neonatal care
- Bliss in conversation with....episode talking to two Black parents about their experiences of neonatal care
- Zarina shares her neonatal experiences
- Yasmeen shares her neonatal experiences
- Sobia shares her neonatal experiences
- Muriam shares her neonatal experiences
- Bliss and Black Mothers Matter – Supporting Black families for equitable outcomes on the neonatal unit
- Bliss and Black Mothers Matter - Practical tips and reflections for supporting Black families through an antiracist lens
- Inequity in neonatal care webinar
- Locked-out: the impact of COVID-19 on neonatal care