Neonatal Services for the Future: A vision for Scotland

Bliss Scotland
for babies born premature or sick

About Bliss Scotland

Our vision is that every baby born premature or sick in Scotland has the best chance of survival and quality of life. Bliss Scotland 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 be prioritising 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.

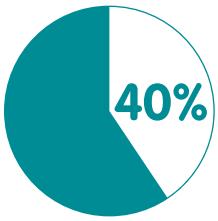
About Neonatal Care

What is neonatal care?

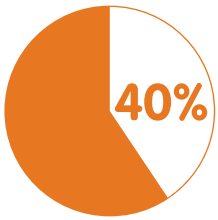
Neonatal care is the type of hospital care that a baby receives if they are born unwell. Babies are admitted to neonatal care shortly after birth, either because they have been born prematurely (before 37 weeks of pregnancy) or at full term but sick. For example, they might have an infection, difficulty breathing or a genetic condition. For parents of these babies, the experience is life changing. Rather than taking their baby or babies home shortly after birth, they are admitted to a specialist hospital unit to receive care which ensures they have the best possible chance of survival and quality of life.

These babies are among the most vulnerable patients cared for by NHS Scotland. They may spend days, weeks, and in some cases months in hospital. According to the most recent available data, in 2024, 108 babies sadly died during the neonatal period (the first 28 days of life) in Scotland[1]. Many of these deaths occurred on the neonatal unit.

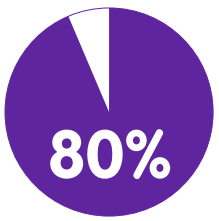
babies born in Scotland is admitted to neonatal care (nearly 5,000 babies per year[2])



of babies admitted are premature, 60% are full term but sick



of babies admitted are twins and multiples



of UK parents say their mental health is affected by a neonatal admission[3]

[1]National Records of Scotland (2025) Vital Events Reference Tables 2024
[2]Public Health Scotland (2025) Births in Scotland
[3]Bliss (2018) Supporting better mental health on the neonatal unit – for parents and staff

How is neonatal care delivered?

Neonatal care is delivered at different levels depending on what type of care a baby needs – intensive care, high dependency care or special care. To read about the different types of care provided in the UK please visit our website.

There are fourteen neonatal units across Scotland, with a fifteenth very small unit that opens periodically. The National Neonatal Network, part of the Scottish Perinatal Network, works to improve care by implementing best practice in neonatal services, and developing national care and service guidelines. Babies are transferred between neonatal units by the Scottish Neonatal Transport Service (ScotSTAR) to make sure babies receive the care they need in the right place, and at the right time.

Families at the centre of care

NHS organisations across the UK strive to deliver neonatal services through a family integrated model of care[4]. The Scottish Perinatal Network has committed to developing a national Neonatal Family Integrated Care (FICare) approach by bringing together professionals and families with lived experience[5]. This model ensures that parents and the wider family are active partners in their baby's care.

Evidence shows that high levels of parental involvement improve short- and long-term outcomes for babies[6], reduce parental stress scores[7] and strengthen bonding[8]. Direct, hands-on care by parents has been linked to increased infant weight gain, improved breastfeeding rates, better infant reflexes at term, and stronger gross motor development by age four to five[9]. When parents can stay on the unit, babies face lower risks of mortality and morbidity and often require fewer days of care[10]. Additionally, enabling parents to take the lead in routine care can ease staffing pressures, allowing clinical teams to focus on more complex tasks. Providing the right infrastructure to support parental presence in neonatal settings is therefore essential.

Enabling neonatal services to deliver FICare is critical, and each of the three priorities set out in this manifesto directly contributes to achieving this aim. We can help reduce inequalities in access and outcomes, ensure parents are supported to remain by their baby's side and highlight the need for adequate staffing by embedding families at the heart of neonatal care – to ensure that babies born premature or sick have the best chance of survival and quality of life.

[4]British Association of Perinatal Medicine (2021) Family Integrated Care: A BAPM Framework for Practice
[5]NHS Scotland (2025) Racialised Health Inequalities Action Plan and interpretation toolkit
[6]Waddington et al (2021) Family integrated care: Supporting parents as primary caregivers in the neonatal unit
[7]Bergman (2019) Birth practices: Maternal-neonatal separation as a source of toxic stress
[8]Kutahyalioglu (2022) Effects of family-centered care on bonding: A systematic review
[9]Franck et al (2022) Neonatal outcomes from a quasi-experimental clinical trial of Family Integrated Care versus Family-Centered Care for preterm infants in the US NICUs
[10]Lehtonen (2020) Family Rooms in NICUs and Neonatal Outcomes: An International Survey and Linked Cohort Study

1. Address inequalities to give every baby the best chance in life

Due to serious inequalities, many babies – including babies from minority ethnic communities and babies born into socio-economically deprived areas – experience disadvantage at birth and are more likely to have poor short- and long-term outcomes.

Bliss Scotland recommendations to give every baby born premature or sick equitable care:

- Develop proactive programmes to reduce inequalities in neonatal care, experience and outcomes
- Prioritise the routine, standardised collection of newborn ethnicity and social deprivation data across all Health Boards
- Invest in research to identify and interrogate inequity between babies from different demographic backgrounds.

Background

Currently, inequalities exist in the care, experience and outcomes of babies born premature or sick in Scotland, and much more needs to be done to reduce unwarranted variation in outcomes. Many of the ways that these inequalities manifest within neonatal care are clearly identifiable – for example, babies from certain ethnic or socio-economic backgrounds have a significantly higher risk of preterm birth[11], and of neonatal mortality[12]; and parents from lower socio-economic backgrounds are likely to face financial barriers which prevent them from being partners in their baby's care[13]. However, there are also still many unknowns. While it is not well understood how the outcomes of a neonatal stay may vary for babies from different backgrounds, there is emerging evidence that suggests care practices on the neonatal unit could contribute to persistent inequalities in survival[14]. Similarly, the extent to which differential experiences of neonatal care may affect some parents' ability to be involved in their babies' care is also not well understood.

In Scotland, 13 per cent of births in 2023/24 were to women from ethnic minority backgrounds (based on maternities with known ethnicity[15])[16]. While this represents a relatively small proportion of total births, it is vital that the experiences and outcomes of these families are not overlooked. The neonatal mortality rate in Scotland in 2023 was 1.61 per 1,000 live births[17]. However, there are significant disparities in neonatal mortality rates by socio-economic deprivation and by ethnicity. This data is not disaggregated by nation, however across the UK, neonatal mortality rates are highest for Asian babies (2.35 per 1,000 live births), then Black babies (2.28 per 1,000 live births) and lastly White babies (1.50 per 1,000 live births)[18]. Overall, neonatal mortality

[11]House of Lords Preterm Birth Committee (2024) Preterm birth: reducing risks and improving lives
[12]MBRRACE-UK (2025) Perinatal mortality surveillance
[13]Bliss (2022) Impact of cost-of-living crisis in neonatal care
[14]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
[15]It is important to note that a baby's ethnicity may not always match that of their mother
[16]Public Health Scotland (2024) Births in Scotland
[17]MBRRACE-UK (2025) Perinatal mortality surveillance
[18]MBRRACE-UK (2025) Perinatal mortality surveillance

decreased in 2023 from 2022 for babies of all ethnicities, but deprivation disparities are widening. For the second year in a row, neonatal mortality rates increased amongst mothers from the most deprived areas (from 2.38 per 1,000 live births in 2022 to 2.50 in 2023)[19]. This highlights the significant and systemic health inequalities facing specific groups in the population, and accurate data is essential to be able to start addressing them.

It is well documented that babies are more likely to die shortly after birth if they are born to mothers already facing inequality or disadvantage. In 2023/24, nearly a quarter of all maternities in Scotland were to women living in the most deprived areas, who face significantly higher risks of premature birth[20] which increases the risk of neonatal mortality[21]. This data paints a stark picture of the deep links between socio-economic status and early health outcomes, underscoring the need for targeted investment in neonatal services in areas of high deprivation.

The 2024 Neonatal Mortality Review Report in Scotland found there was almost twice the number of deaths for multiple births than expected[22], underscoring that disparities in mortality and neonatal admission rates are not restricted to inequalities between ethnic groups and income; rates of neonatal death and admission to a neonatal unit are also higher in babies born as part of a twin or multiple pregnancy.

Understanding disparities and how to reduce them

The disparities in neonatal outcomes between ethnic groups and the poorer outcomes faced by those in areas of higher deprivation are shocking. Some of these differences are evidently related to the care received antenatally in maternity services, and wider socio-economic issues faced by their family. As part of work to tackle this, the Short Life working group on racialised inequalities produced an action plan in 2025 with fourteen short, medium and long-term recommendations to support Health Boards in anti-racism planning to improve outcomes and experiences for women and families[23].

There is a lack of data about the ways that inequalities drive differences in neonatal outcomes and, crucially, how the inequalities that exist in society play out on the neonatal unit. Some work to fill this evidence gap has already begun, for example, research shows that the widespread use of diagnostic tools which rely on changes in skin colour to identify serious illness in newborns put Black, Asian and minority ethnic babies at risk[24,25]. Recommendation five of NHS Scotland's Racialised Health Inequalities action plan states that "NHS Boards and the Scottish Perinatal Network [should] explore the current availability and the use of bilirubinometers to detect newborn jaundice in darker skin toned neonates and babies, in response to reports of poor visual detection of jaundice in babies with darker skin, by March 2027"[26].

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[19]MBRRACE-UK (2025) Perinatal mortality surveillance
[20]Public Health Scotland (2024) Births in Scotland
[21]Thomson et al (2021) Socioeconomic inequalities and adverse pregnancy outcomes in the UK and Republic of Ireland: a systematic review and meta-analysis
[22]Health Improvement Scotland (2024) Neonatal Mortality Review Report
[23]Scottish Government (2025) Racialised Health Inequalities Action Plan and interpretation toolkit
[24]KWISA (2024) Nothing About Us Without Us: Women of African and Caribbean Heritage Community Voices Report
[25]NHS Race Health Observatory (2023) Review of neonatal assessment and practice in Black, Asian, and minority ethnic newborns
[26]NHS Scotland (2025) Racialised Health Inequalities Action Plan and interpretation toolkit

Research by Bliss found that families on lower income typically have lower levels of parental involvement[27]. We have also highlighted inequalities in the way families from South Asian backgrounds[28] and young parents[29] access and experience neonatal care. Therefore, investment must be made in research to identify and interrogate inequity between babies from different demographic backgrounds to drive evidence-informed improvements.

The importance of improving data collection

Public Health Scotland has worked with NHS Boards to make improvements in the completeness and accuracy of maternal ethnicity data recording and reporting. However, there needs to be a drive to accurately record babies' ethnicities, as mothers and babies do not always share the same ethnicity. This is essential for exploring disparities in outcomes for babies needing neonatal care.

Recommendation thirteen of NHS Scotland's Racialised Health Inequalities Action Plan states that the Scottish Government should work with national partners and Health Boards to "Identify appropriate mechanisms to monitor progress in addressing inequalities in experiences and outcomes in perinatal care…"[30]. To deliver on this recommendation, neonatal services must be equipped with robust and inclusive data systems that reflect the diversity of the populations they serve. Without accurate ethnicity data for babies, efforts to monitor and address inequalities in neonatal outcomes will remain incomplete.

[26]Bliss (2022) Impact of cost-of-living crisis in neonatal care
[27]Bliss (2022) South Asian Families' Experiences Report
[28]Bliss (2021) Neonatal care through a young parent lens
[29]NHS Scotland (2025) Racialised Health Inequalities Action Plan and interpretation toolkit

2. Support parents to be at their baby's cot side and involved in care

Neonatal services are configured to ensure babies have the best possible chance of survival and quality of life. Babies need to receive the right level of care, at the right time, for this to be possible. While services always aim to support babies as close to home as possible, the specialised nature of neonatal care means that sometimes care must be provided unavoidably far from home.

There are a number of barriers to parents' ability to be by their baby's cot side and involved in care. These include a lack of overnight accommodation for parents on the unit, and the financial burden associated with a neonatal admission. Most parents must leave their baby's side in hospital overnight, because somewhere to sleep on a neonatal unit is not routinely provided. Parents need practical and financial support to enable them to be with their baby as much as possible.

Bliss Scotland recommendations to support parents to be at their baby's cot side and involved in care:

- Identify capital investment required to bring all parent accommodation up to a minimum standard on neonatal units. This is also essential for ensuring service redesign (see page 10) happens in a safe and measured way
- Uprate the Young Patients Family Fund in line with inflation, and improve the Fund's reach and effectiveness by working in partnership with families and the staff who administer it.

Accommodation

Providing parents with somewhere to stay – whether that be in on-site private rooms, in family accommodation near the hospital, or on pull out beds at the cot-side – is key to enabling and delivering the benefits of FICare. However, inadequate provision of accommodation across Scotland is resulting in parents being unable to be partners in their baby's care on a regular and consistent basis. For some parents, this lack of infrastructure means they are unable to be with their baby every day.

Our research found that:

- Nearly nine in ten babies in Scotland cannot have their parents stay in a room overnight on the unit[31]
- 87 per cent of UK parents without access to overnight accommodation say that this stopped them being involved in their baby's care[32]
- Parents describe leaving their baby at night to return home as one of the hardest parts of having a baby in neonatal care
- To many parents, meaningful involvement in their baby's care often means doing night-time feeds and being with their baby during the night – just as they would expect to do at home or on a paediatric unit[33].

[31]Bliss (2024) Families Kept Apart in Scotland
[32]Bliss survey results from a sample of more than 1900 parents
[33]Bliss survey results from a sample of more than 1900 parents

Young Patients Family Fund

The Young Patients Family Fund (YPFF), launched in 2021 and built on the Neonatal Expenses Fund (NEF), which was introduced in 2018 and represented a significant step forward in increasing equity for families with children in hospital. By covering costs related to travel, food, and accommodation, the YPFF helps reduce financial stress during what is an incredibly difficult time. The 2019 evaluation of the NEF showed that financial support enabled parents to spend more time with their babies in neonatal care[34], easing anxieties and strengthening parent-infant bonds.

Now embedded as a core part of support for families, the YPFF has laid a strong foundation for ensuring parents and carers are not excluded from care due to cost and sets a standard for financial support across the UK. However, anecdotal feedback from both families and healthcare professionals suggests that awareness and accessibility could be improved even further to ensure more families benefit[35].

Importantly, while the YPFF does offer support for accommodation costs, there remains a gap between this and the ideal – having accommodation available on or near the unit itself. Continued investment in parent accommodation on neonatal units over the medium to long term is vital to ensure proximity, comfort and continuity of care, especially for those facing long stays or those whose homes are further away.

[34]Scottish Government (2019) Neonatal Expenses Fund year one: evaluation
[35]Bliss (2023) Bliss Scotland position statement: Improvements to the Young Patients Family Fund

3. Create a neonatal workforce for the future

Babies need to be cared for by a fully staffed, multidisciplinary team of healthcare professionals to have the best outcomes. However, workforce levels on neonatal units do not currently meet safe staffing standards set out by national bodies.

Bliss Scotland recommendations to ensure the safety and quality of neonatal services:

- Invest to ensure neonatal units have adequate nurse and medical staffing for their numbers of cots, in line with national standards for numbers and skillset
- Include neonatal Allied Health Professional, Psychology and Pharmacy staffing in local and regional workforce plans.

Research shows that the safety of neonatal services relies on units meeting nationally mandated minimum staffing numbers. Where there are not enough nurses, doctors, and Allied Health Professionals, Psychologists and Pharmacists (AHPPPs), babies are likely to have worse outcomes[36] – including higher mortality rates – than those who are treated in neonatal units that meet both the required staffing numbers and skills mix[37]. Additionally, having a fully functioning workforce is key to a more centralised service (see page 10) working well.

Investment into quality and training roles is also important for retention of staff on neonatal units, which is a major problem due to the pressures of the job coupled with the issues that come with an understaffed service[38].

Evidence shows that there are under-staffing challenges visible across nursing and – most acutely – in AHPPP provision in Scotland:

- The average rate of compliance to neonatal nurse staffing standards is 80 per cent[39]. Scotland sits just below this average at 77 per cent[40]
- In Special Care Units, 25 per cent of nursing shifts were below rostered numbers[41]
- Bliss research found that Scotland is quite a significant outlier when it comes to AHPPP provision compared to the rest of the UK. Scotland has the largest overall shortfall of AHPPP staffing – sitting at 88 per cent – between recommended staffing levels and the level of staffing currently being provided[42,43]. For example, it has a 94 per cent shortfall in occupational therapy compared to 56 to 76 per cent in other nations, and 79 per cent shortfall in dietetics compared to 40 to 60 per cent in other nations[44].

[36]Scottish Government (2017) The Best Start Model of Neonatal Care
[37]Watson et al (2016) The effects of a one-to-one nurse-to-patient ratio on the mortality rate in neonatal intensive care: a retrospective, longitudinal, population-based study
[38]Bliss (2018) Mental health and wellbeing of neonatal staff
[39]National Neonatal Audit Programme (2023)
[40]National Neonatal Audit Programme (2023)
[41]Royal College of Paediatrics and Child Health (2020) A snapshot of neonatal services and workforce in the UK
[42]Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy Roles in Neonatal Care
[43]Perinatal Network Scotland (2024) Neonatal Allied Health Professionals in Scotland: Building the future workforce
[44]Bliss (2025) Filling the gaps: A spotlight on Allied Health Professional, Psychological and Pharmacy Roles in Neonatal Care

Service redesign to give the best care to the smallest and sickest babies

On average, nearly 5,000 babies are born needing neonatal care in Scotland every year, and around 1,000 of these will need neonatal intensive care.[45] This volume is far too low to sustain more than three NICUs in Scotland and extensive work has established that this volume requires three NICUs, in line with clinical best practice and professional guidelines. Bliss Scotland fully supports the centralisation of neonatal services in Scotland. This is critical to improving the care babies receive, meaning that more extremely premature and extremely sick babies will survive and survive well.

This service design is in line with UK-wide clinical guidelines set out by the British Association of Perinatal Medicine (BAPM)[46], which detail the activity levels required to sustain a NICU service, as well as best practice globally.

To be successfully implemented, the centralisation of neonatal services must have funding to develop on-unit accommodation for parents in each of the three NICUs and ensure facilities on neonatal units meet the needs of the families using them. Moreover, service redesign needs to ensure there are enough trained staff in each unit, especially as intensive care is concentrated in fewer locations. Therefore, adequate and sustained funding is crucial to delivering service redesign safely and effectively.

Bliss Scotland has received funding from the Scottish Government to support the implementation of the Bliss Baby Charter across neonatal units in Scotland. This funding enables the delivery of our work directly to all 14 neonatal units to improve FICare and ensure parents are active partners in their baby's care. The funding also supports Bliss' wider work to provide information and emotional support to families with babies in neonatal care.

Bliss Scotland has also been involved as a stakeholder in the Best Start Programme which set out a future vision of maternity and neonatal services across Scotland, including service redesign.

[45]Public Health Scotland (2025) Births in Scotland
[46]BAPM (2021) Optimal Arrangements for Neonatal Intensive Care Units in the UK including guidance on their Medical Staffing

Join the family

If your baby is on a neonatal unit because they were born premature or sick, you're not alone. Find practical information, emotional support and a community of families with a neonatal experience at **bliss.org.uk**

Join the family, search Blisscharity on

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