Bliss – Written evidence (PRT0063)

Summary

1. Almost 58,000 babies are born preterm every year in the UK and 1 in 7 babies receives neonatal care having been born premature or sick. Bliss is the UK charity that champions the right of every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.
2. When a baby is born premature, they spend their first few weeks and months of life in an incubator, usually separated from the comfort of their parents. While the care that they receive is often lifesaving, this is a traumatic start to life.
3. For their parents the experience is life changing. Rather than taking their baby home shortly after birth, their baby is admitted to a specialist hospital unit to receive care that ensures they have the best possible chance of survival and quality of life. How long a baby will stay in neonatal care can vary, from days to weeks or months. Parents will usually have to leave their baby at night repeatedly - night after night - during their stay, as most hospitals are not able to routinely provide parents with a place to be with their baby overnight.
4. Children who have been born preterm are more likely to die in childhood, and are at an increased risk of ongoing health conditions as well as having special educational needs. To reduce these risks, it is essential that existing evidence is put into practice, and that the variation between hospitals that we see at the moment is reduced. This requires:
    - A focus from government on reducing preterm birth rates for every mother and baby;

- Leadership within the health service to implement improvements;
- Funding for fully trained and staffed multidisciplinary teams;
- Increased research spending into best practice as well as how to reduce inequalities in outcomes between groups.

5. Resources must also be provided to develop the neonatal services of the future. Practice in neonatal care has changed. The NHS endeavours to provide Family Integrated Care environments that enable parents to be partners in their baby's care - something that is evidenced to improve care - but the infrastructure and support needed to facilitate this has not kept pace. Parents need:
   - A basic level of accommodation to be with their baby 24/7;
   - Financial support to reduce the economic burden on families;
   - Psychological support.

Neonatal and longer-term care and support

Premature birth: introduction

6. The most serious impact of premature birth is the risk of a baby dying in the first few weeks, months and years of life. In 2021 1,151 babies died in the first 28 days of life, 72 per cent of whom were babies born before 37 completed weeks of pregnancy. Children who have had a neonatal admission make up the majority of deaths under 10 years old[1].
7. Extended perinatal mortality and neonatal mortality have historically reduced over time. Neonatal mortality reduced by 17 per cent between 2013 and 2020[2]. However, that is no longer the case

[1] NCMD (2022), The Contribution of Newborn Health to Child Mortality across England: National Child Mortality Database Programme Thematic Report
[2] Draper ES, et al, on behalf of the MBRRACE-UK Collaboration (2022) MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2020..

- neonatal mortality in England rose from 1.5 per 1,000 live births in 2020 to 1.6 per 1,000 live births in 2021[3].

8. While the vast majority of babies go home from neonatal care, prematurity can have a significant impact on their ongoing health and development into the future, and these risks are higher for children born at the earliest gestations. Preterm birth can impact on long term developmental outcomes, with children born extremely premature:
    - Significantly more likely to have moderate-to-severe overall cognitive and motor disability[4] [5];
    - Significantly more likely to be readmitted to hospital throughout childhood;
    - Significantly more likely to have special educational needs and poorer educational attainment compared to those born at full term[6].

9. Some children (5.7%) who spend time in neonatal care are readmitted to paediatric care, and admission rates are higher in children born at earlier gestations (10% in <24 weekers). Children born at earlier gestations are more likely to have repeated admissions. Around 50% of children cared for in PICU under 2 years old had a neonatal admission[7], meaning reducing premature birth and the ongoing health impacts of this should be a focus of anyone looking to reduce the demand on paediatric services.

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[3] Draper ES, et al on behalf of the MBRRACE-UK Collaboration (2023) MBRRACE-UK Perinatal Mortality Surveillance, UK Perinatal Deaths for Births from January to December 2021: State of the Nation Report..
[4] Moore T, et al (2012) Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies. BMJ. 4;345:e7961..
[5] Coathup V, Boyle E, Carson C, Johnson S, Kurinzcuk J J, Macfarlane A et al. Gestational age and hospital admissions during childhood: population based, record linkage study in England (TIGAR study) BMJ 2020; 371 :m4075
[6] Laing IA, Where should extreme preterm babies be delivered? Crucial data from EPICure Archives of Disease in Childhood - Fetal and Neonatal Edition 2014;99:F177-F178.
[7] Seaton S et al (2024) Characteristics of children requiring admission to neonatal care and paediatric intensive care before the age of 2 years in England and Wales: a data linkage study

Reducing variation in care

10. Optimising care when a mother goes into preterm labour is key to ensuring that as many babies as possible are born alive and with a good chance of survival and quality of life. But there is significant variation across England in how well evidence-based measures are delivered to women in threatened preterm labour.

11. There are multiple guidelines and quality improvement programmes[8], [9] aiming to improve this. However, a key issue for UK maternity and neonatal services is that best practice is not being implemented to the same extent at every hospital and for every baby.

12. MBRRACE-UK consistently reports high variance in neonatal mortality rates that are not explained hospital population. More than 60 per cent of Trust and Health Boards' mortality rates fall more than 5 per cent outside of the norm for their type of unit[10].

13. NNAP[11] data also consistently shows high levels of variation in the administration of antenatal steroids, deferred cord clamping, antenatal magnesium sulphate and many other evidence-based measures that give babies born early the best chance of survival and positive outcomes. For example, it is well evidenced that babies born at less than 27 weeks' gestation should be born at a hospital with a Neonatal Intensive Care Unit (NICU). While in some Trusts 92 per cent of babies born under 27 weeks are born at a hospital with a NICU, in other areas this rate is just 68 per cent.

14. Bliss believes that, to some extent, we already have many of the tools needed to considerably reduce the impact of preterm births, but we need to see a tight focus from government on reducing preterm birth rates consistently for every mother and baby, and

[8] NHS England (2023) Saving babies' lives version 3: a care bundle for reducing perinatal mortality
[9] BAPM, Perinatal Optimisation Pathway
[10] Draper ES, er al, on behalf of the MBRRACE-UK Collaboration (2023) MBRRACE-UK Perinatal Mortality Surveillance, UK Perinatal Deaths for Births from January to December 2021: State of the Nation Report.
[11] National Neonatal Audit Programme (NNAP) Summary report on 2022 data

leadership within the health service to implement improvements systematically.

15. Beyond the effective implementation of existing evidence-based best practice, there is much about maternity and neonatal care which is under researched, and there remain many unanswered questions about how to reduce neonatal mortality and morbidity. It is therefore also essential that the Government commits further investment into research in this area - currently the national spend on research funding into baby deaths lags far behind that in other areas of healthcare[12].

Health inequalities

16. There are concerning differences in preterm birth and neonatal mortality rates between ethnic groups and socio-economic groups. While there is some evidence about the factors in maternity services that lead to worse outcomes for mothers and babies from Black and Asian backgrounds and those from lower socio-economic groups, the same evidence base does not currently exist about the neonatal care that babies receive.

17. While we know that babies from Black and Asian backgrounds and those from lower socio-economic groups are more likely to receive neonatal care, there is not currently data readily available about the difference in morbidity or overall neonatal experience or outcomes between groups of babies. Collection of babies' ethnicity data through NNAP has very high rates of missing data, and the limited ethnicity reporting available therefore currently uses a proxy of maternal ethnicity – which in itself still has around 20% missing data – which does not adequately reflect the population.

[12] Sands & Tommys Joint Policy Unit (2023), Preventing pregnancy loss and baby deaths: Improving the research environment

18. To ensure that every baby born preterm benefits from the best chance of survival and quality of life Bliss believes that:
    - There is considerable research needed to identify and interrogate inequity within and between neonatal units and to improve ethnicity data collection;
    - The Government should commit to clear targets to reduce inequalities in the rates of neonatal death, brain injury and pre-term birth across socio-economic and ethnic groups and between neonatal units;
    - The Government should ensure there is clinical leadership in this area by appointing a National Neonatal Safety Champion.

Neonatal staffing

19. To improve long-term outcomes of children who were born premature it is essential that neonatal units are able to 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[13] sets out clearly the optimal staffing required to provide care, but we know from national audits[14] [15] that these standards are far from being met. For example, the latest NNAP data shows that around 30 per cent of shifts did not have the required number of nurses (an increase on the previous year) and that this was much higher in intensive care where the very sickest babies are cared for.
20. Provision of Allied Health Professionals (including physiotherapists, occupational therapists, speech and language therapists and dieticians), as well as psychological professionals and pharmacists, is essential to ensuring that babies have the best outcomes. But the

[13] NHS England (2024), Neonatal Critical Care Service Specification
[14] National Neonatal Audit Programme (NNAP) Summary report on 2022 data
[15] Neonatal GIRFT (2020) A snapshot of neonatal services and workforce in the UK

availability of these services is patchy at best, with the neonatal GIRFT programme reporting that less than half of neonatal services had regular dietetics, physiotherapy, speech and language therapy and occupational therapy services, and 63 per cent of units having no psychology services.

21. 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 the standards set out in national guidance. The Government must ensure the safety and quality of neonatal services by investing in increasing numbers of nursing and medical staff; Allied Health Professional numbers; and psychological professionals, pharmacists, and the neonatal community outreach workforce.

Enabling parent partnership in care

Family Integrated Care

22. While there is much work to be done to reduce the mortality and morbidity experienced in babies born preterm, there is a long way to go, and it is unlikely that premature birth will ever reduce to zero. In light of this, it is extremely important that governments and NHS bodies ensure that neonatal units are fit for purpose.

23. Neonatal services in the UK strive to deliver Family Integrated Care, a model of care which promotes a culture of partnership between parents and staff. Further, 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 bonds[16]. Parents who are supported to be with their baby for

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

prolonged periods report increased parental confidence, and reduced stress and anxiety scores[17].

24. 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[16,15]. Evidence also suggests that when parents can stay on the unit with their baby:
    - The risks of mortality and morbidity are reduced;
    - Babies are likely to require fewer care days than babies whose parents cannot stay on the neonatal unit[15].
25. However, achieving high levels of parental involvement in their babies' care is a challenge for numerous reasons, including the lack of overnight accommodation on the neonatal unit and the additional financial pressure of having a premature baby in neonatal care. Parents' ability to be involved in their baby's care is affected by many factors, and different groups face specific challenges[18,19].
26. No barrier should be placed between a parent and their sick baby, and the Government must provide the resources necessary for NHS England, Neonatal Operational Delivery Networks (ODNs) and individual services to support all parents to be involved in their baby's care - regardless of background or circumstance.

Keeping families together overnight

27. Parents of babies in neonatal care are not routinely provided with somewhere to stay with their baby overnight. This means that,

[17] 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..
[18] Bliss (2022) South Asian families' experiences of neonatal care
[19] Bliss (2021) Neonatal care through a young parent lens

unlike in other children's health services, parents are usually separated from their baby repeatedly throughout their time in hospital.

28. 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[20]. It is clear that neonatal services are struggling to provide the basic facilities that parents need to be partners in their babies' care.

29. While it has been a requirement for many years that neonatal services provide adequate overnight accommodation for services, provision is still poor. As far back as 2009, the Department of Health Toolkit for High-Quality Neonatal Services recommended that overnight accommodation should be provided for families whose baby was receiving intensive care, with one parent room per intensive care cot located within 10-15 minutes' walking distance of the unit. Most recently, the updated NHS England Service Specification for Neonatal Critical Care, published in March 2024, requires that "Facilities and resources must be available to enable parents/carers to be resident with their baby for as long as they want and are able to be. This includes sufficient accommodation on or close to the neonatal unit for all families" (pg. 15) to support a family integrated care approach[21].

30. However, this level of facilities is simply not being met - the Getting It Right First Time (GIRFT) National Speciality report into Neonatology found that only 30% of Neonatal Intensive Care Units (NICUs) meet the standard for provision of overnight parental accommodation[22].

[20] Method: self-selecting survey disseminated through Bliss social media and email newsletters, and via partner organisations in February and March 2022. 1928 respondents. Two focus groups conducted in March 2022 with a) dads (n=9) and b) parents who were on a low income/struggled significantly with finances during their baby's neonatal stay (n=5)
[21] NHS England (2024) Neonatal Critical Care Service Specification
[22] Neonatal GIRFT (2020) A snapshot of neonatal services and workforce in the UK

31. Acknowledging the need to develop family facilities on neonatal units, the NHS Long Term Plan committed to "invest in improved parental accommodation"[23] (pg.49). This commitment has been renewed in the Three-Year Delivery Plan for Maternity and Neonatal services to ensure that "parents are partners in their baby's care in the neonatal unit through individualised care plans utilising a family integrated care approach, together with appropriate parental accommodation"[24] (pg. 10). However, investment in these facilities has not been forthcoming.

32. Bliss believes that investment is urgently needed to ensure that hospital estates do not hold neonatal services back from delivering a family integrated approach to care. We recommend that:

    - The Government provides a facilities grant scheme so that Trusts can apply for funding to buy new furniture or equipment to improve the neonatal environment;
    - Long term capital investment is identified by the Treasury to develop the estates that services need for all parents to stay overnight with their babies;
    - Estates guidance/building notes are updated to reflect current practice around parental partnership in care, so that these facilities are seen as essential rather than 'nice-to-have'.

Co-ordination of maternity and neonatal care

33. A lack of co-ordination of care between the postnatal ward and neonatal unit can be a barrier to in-patient mothers seeing their baby, even when they are well enough, and this can result in some mothers compromising their own care to be with their baby.

[23] NHS England (2019) The NHS Long Term Plan
[24] NHS England (2023) Three-year delivery plan for maternity and neonatal services B

34. While still an inpatient, mothers and birthing parents can face the choice of compromising their own care or not seeing their baby. Once discharged they may struggle to get to/from the hospital, particularly after a caesarean section.

35. Bliss' research[25] found that:

    - 50 per cent of inpatient mothers said they weren't as involved in their baby's care as they wanted to be while they were in postnatal care;
    - 20 per cent said they couldn't see their baby whenever they wanted, even once they were well enough;
    - 16 per cent of inpatient mothers told us they were "never" kept informed about their baby's condition.

36. The most frequent barriers to physically being able to be on the neonatal unit with their baby are around a lack of physical assistance getting to the neonatal unit and the need to be physically on the postnatal ward for meals and medication. Mothers generally rely on their partners or other friends / family members to take them to the neonatal unit, usually in a wheelchair – however this is not a sustainable solution when partners/support people cannot be at the hospital all the time.

Family finances

37. Another barrier to family integrated care is that the cost associated with having a baby in neonatal care is high, preventing parents from being with their babies. Bliss found that the average additional cost of having a baby in neonatal care was £405 per week, and one in four families had to borrow money or increase their debt during this time.[7]

The Young Patients Family Fund: Learning from Scotland

The Scottish Government provides families with financial support if they have a child in hospital called the Young Patients Family Fund. Parents can claim back the cost of travel, subsistence, and accommodation. An evaluation of the scheme's predecessor (the Neonatal Expenses Fund, first introduced in 2018) found that parents reported that the fund relieved financial anxieties during a very stressful period and helped them spend more time with their babies in the neonatal unit as a result of being able to claim.

[25] Bliss (2024) Bliss Baby Report 2024: Focus on maternity and neonatal care

38. The costs of travel and subsistence for families of babies born premature or sick are high, and can be prohibitive to some families being involved in their baby's care. Families, particularly those on low incomes, face an unfathomable choice between being fully involved in their baby's care and getting into debt.

39. Bliss recommends the introduction of a Neonatal Expenses Fund in England, to give every baby born sick or premature equitable access to family integrated care.

Taking time away from work

40. Parents find the lack of additional maternity and paternity leave during a neonatal admission very challenging, as it stops one parent from being with their baby in neonatal care. Practically, this means that many fathers return to work while their baby is still critically ill in hospital. The need for parents of babies to have additional paid leave while their baby is in hospital has been well established in Parliament. The Neonatal Care (Leave and Pay) Act will introduce this right for qualifying parents from April 2025.

41. However, self-employed parents, agency workers and other groups will not benefit from this new legislation, so we would like to see the Government review support for those parents. Dads and non-birthing parents in particular report feeling pulled in many directions: supporting the birthing parent in postnatal care; being there for their baby; returning to work; and looking after other children.

42. Psychological support

43. Having a premature baby can have serious psychological consequences for parents[26]. Research has shown that up to 50 per cent of parents whose babies received neonatal care experience Post Traumatic Stress Disorder as well as higher rates of anxiety and depression[27]. Parents are not always able to access the support they need on the unit, and access to community perinatal mental health services is challenging while their baby is in the hospital. For example, mental health specialist psychological support is only available in one in five NICUs and one in ten LNUs/SCUs during the week, and is completely absent at weekends[28].

44. Access to psychological support for parents who have had a baby born preterm can improve outcomes through means such as: providing an opportunity for birthing and non-birthing parents to talk about their birth experience; supporting parental bonding; and aiding adjustment to bad news[24,29].

45. Bliss recommends that the Government invests appropriately in the workforce to deliver psychological support for every family with a baby in neonatal care who needs it, ensuring equitable access to their services at unit level in line with standards.

Conclusion: Bliss' priority areas for action:

46. Preterm birth has a significant impact on babies and their families and this effect can be life-long. There are clear areas for improvement to reduce mortality and morbidity rates for these babies. Bliss recommends that:

    - Action is taken to **implement existing best practice** and guidance, and targets are set to reduce mortality and

[26] ODN Psychology Leads (2022) Psychology Staffing on the Neonatal Unit
[27] NHS England (2021) Supporting mental healthcare in a maternity and neonatal setting: Good practice guide and case studies
[28] Neonatal GIRFT & RCPCH (2020) A snapshot of neonatal services and workforce in the UK
[29] The British Psychological Society (2016), Perinatal Service Provision: The role of Perinatal Clinical Psychology

morbidity rates specifically in groups that are affected by **health inequalities;**

- **Investment in research** to explore the best ways to prevent or reduce premature birth, neonatal mortality and ongoing issues relating to prematurity for every baby, regardless of background;
- The **multidisciplinary teams** required to deliver neonatal care are invested in so that every baby and their family can benefit from the best care;
- Measures are taken to **stop parents being separated from their babies** including through provision of overnight accommodation, financial support, time off from work and better coordination of maternity and neonatal care.

27 March 2024