Bliss Scotland briefing:

Bliss' role in the Best Start Programme new model of neonatal care

December 2025

About Bliss Scotland

Bliss Scotland is the leading Scottish charity that 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.

Context

In recent weeks and months, there has been significant coverage of plans to reconfigure neonatal units in Scotland, following recommendations made in the *Best Start – Five Year Plan for Maternity and Neonatal Care* report in 2017 and subsequently accepted in full by the Scottish Government. During some of this coverage **there has been significant misinformation about, and misrepresentation of, Bliss Scotland's role in the Best Start implementation process, which is important to correct.** This has included criticism of Bliss Scotland for not engaging with families as part of the decision-making process through the Best Start Programme.

What was the original proposal to introduce a new model of neonatal care in Scotland?

In 2015, the Scottish Government announced it would undertake a review of maternity and neonatal services in Scotland. This review took 18 months, and incorporated a wide programme of engagement with service users, led by Health Information Scotland on behalf of the Scottish Government. Bliss was represented by our then Policy & Campaign Manager on the main review group (as one of 24 group members), and on the neonatal models of care sub-group (as one of 22 sub-group members). Both the main review group and the sub-group also included representation from Health Boards including NHS Lanarkshire, NHS Tayside and NHS Grampian.

The outcome of this maternity and neonatal review was the publication, in January 2017, of the *Best Start – Five Year Plan for Maternity and Neonatal Care*. Based on detailed review of the latest evidence and clinical best practice, this included the recommendation: *"it is proposed that three to five neonatal intensive care units should be the immediate model for Scotland,* ***progressing to three units within five years****."* The Scottish Government subsequently accepted the Best Start recommendations in full, and set up an Implementation Programme tasked with delivering these recommendations.

How was Bliss Scotland involved in the Best Start Implementation Programme?

Following the publication of the *Best Start,* Bliss Scotland – represented by its Chief Executive – was asked to join the Best Start Programme Implementation Board (as one of 24 members), which was tasked with overseeing the implementation of all 76 Best Start recommendations. Bliss Scotland's Chief Executive subsequently also joined the Perinatal Sub-Group (as one of 21 members), which was tasked with providing more in-depth input to the implementation of the recommendations relating to neonatal care. Bliss Scotland was represented on both groups until the formal closure of the Best Start Programme in December 2024.

Did Bliss Scotland seek to engage with families as part of their input to the Programme Board or Perinatal Sub-Group?

Bliss Scotland's role as part of Best Start Programme implementation was not to engage directly with families; indeed, the terms of reference for both the Implementation Board and the Perinatal Sub-Group prevented us from doing so, with specific requirements:

- *"to preserve the confidentiality of papers and discussions"*
- That members *"will not discuss or disclose any programme related management information without prior agreement from the Chair"*

In the discussions across both groups, **Bliss Scotland consistently put forward the importance of regular and ongoing communication with both families and neonatal health professionals**, and encouraged the Best Start Programme Team to develop a communications plan through which to do so; however Bliss Scotland was not in a position to initiate this communication directly.

Once the decision had been announced about the locations of the three neonatal intensive care units, in July 2023, Bliss Scotland continued to advocate very strongly across both groups for clear and regular communications with families about the plans, and for the Scottish Government to undertake rapid and direct engagement with families to shape implementation detail – **however Bliss Scotland was never tasked with undertaking this engagement directly**. When Scottish Government engagement did finally take place in June/July 2024, Bliss supported this through providing input on the questions asked through the Citizen Space open consultation and subsequent focus groups.

What did Bliss Scotland contribute through their input to the Programme Board and Perinatal Sub-Group?

Bliss Scotland's role on both groups was to advocate for what is in the best interests of babies born premature or sick, in line with our charitable mission, and in the context of the implementation of the agreed Best Start recommendations.

At Bliss Scotland we recognise the significant concern from families that the proposals will result in a small number of the smallest and sickest babies having to travel further for their care, and the impact this will have on those families having to travel far from home and away from their support networks. Indeed, this is already the situation facing families in other parts of Scotland without a NICU. **A significant focus for us throughout the Best Start was therefore on identifying how parents can best be supported to play a hands-on role in their babies' neonatal care, which we know is vitally important to babies and their families.**

Bliss Scotland worked closely with the Scottish Government to develop the Neonatal Expenses Fund, now called the Young Patients Family Fund, which provides financial support for travel, food and accommodation costs for all neonatal parents. We have also advocated through the Best Start programme and wider campaigning for more dedicated parent accommodation on or near neonatal units so that families have somewhere to stay close by to their baby. In recent years we have also successfully campaigned for legislation which introduced a statutory entitlement to neonatal leave and pay for all employed parents through the Neonatal Care (Leave and Pay) Act, which came into effect in April 2025, enabling both parents to be at their baby's cotside throughout their neonatal stay.

What has happened since the Best Start Programme formally closed at the end of 2024?

Since the formal closure of the Best Start Programme at the end of 2024, Bliss Scotland has continued to push for progress with the implementation of the new neonatal model of care through a variety of means, including briefing parliamentarians for debates in the Scottish Parliament and through letters and meetings with officials and Ministers. We understand that a Task & Finish Group has been established with representation from the three NHS Scotland regions to finalise and take forward detailed implementation plans for neonatal reconfiguration.

At this point, we recognise that neonatal services in Scotland are not currently in a fit state for the final stage of reconfiguration to go ahead, with more progress needed at the designated three NICUs – in Edinburgh, Aberdeen and at the RHC in Glasgow – including investment in additional staffing and cots to be able to accommodate the additional capacity required. Bliss Scotland is disappointed at the lack of progress with implementation plans through 2025, and with the lack of transparency from the Task & Finish Group in how plans are progressing; including a lack of any timeline and milestones towards implementation.

Bliss Scotland continues to support the principles of centralisation of neonatal intensive care services in Scotland in line with the Best Start recommendations and with evidence and clinical best practice, but the right resources need to be in place to enable this to happen, including further workforce planning and capacity building. We are concerned that progress continues to stall in ensuring services are prepared to transition to the new model safely, and we continue to press the Scottish Government to invest the required resources to ensure this can happen in the coming months.

As referenced in our first submission to the Citizen Participation and Public Petitions Committee ahead of their meeting on the 8 October, we are also concerned about the significant levels of misinformation circulating regarding the plans. This misinformation has been heightened in recent months and we are increasingly alarmed and frustrated to hear repeated references – both in the media and directly from MSPs – to services closing down, the process and safety of transfers and drawing on family experiences which, given the gestations and clinical status of their babies, would not be affected by the planned changes.

These proposals are difficult, the concern around them understandable, and debate about how to implement them safely is vitally needed. **But that debate needs to be undertaken in a measured way and grounded in the facts**, rather than perpetuating misinformation in the way that we have seen in recent months, which only serves to generate fear and concern amongst the public.

What other work does Bliss Scotland deliver?

Bliss Scotland has worked directly over many years to support all neonatal units in Scotland to improve parental involvement in care through our quality improvement programme the Bliss Baby Charter. All neonatal units in Scotland are working to improve their care through the Bliss Baby Charter, with the intention that all units reach gold accreditation standard over time.

Bliss Scotland also provides support directly to families whose babies are cared for in neonatal units across Scotland, through the provision of comprehensive information on our website, access to direct support through our email helpline, direct messaging on social channels, and access to one-to-one emotional support with trained volunteers in virtual sessions. In addition, some units in Scotland have access to trained Bliss Champion volunteers, who attend those units regularly to provide face-to-face emotional support to families with babies on those units.

Appendix: Frequently Asked Questions

What are the changes taking place, and why?

The core recommendation in the new neonatal model of care is to reduce the number of neonatal intensive care units (NICUs) from eight to three, with the remaining units becoming Local Neonatal Units (LNUs). The three NICUs will be:

- Queen Elizabeth University Hospital in Glasgow
- Simpson's Centre for Reproductive Health, Edinburgh Royal Infirmary
- Aberdeen Maternity Unit.

This is happening because evidence shows that the smallest and sickest babies – in particular those born below 27 weeks' gestation or weighing less than 800g – have a better chance of surviving if they are born in units which see lots of babies like them, rather than units which only care for small numbers of extremely sick babies each year. This is in line with UK-wide clinical guidelines set by the British Association for Perinatal Medicine (BAPM), as well as best practice globally. It is intended that this change will improve the care babies receive, and that more extremely premature and extremely sick babies will survive and survive well.

Key points about this change:

- **No units will close.** The units which will no longer be a NICU will become Local Neonatal Units. LNUs will still provide neonatal care for the majority of their local population, including a level of neonatal intensive care.
- **For most babies who need neonatal care, this change should not affect which hospital they receive care in.** Only a very small number of the smallest and sickest babies needing specialist care will be cared for in a different hospital under these changes.
- **If a newborn baby in any hospital suddenly becomes seriously ill there are always trained staff available to give them the immediate treatment they need. All services are equipped to provide this care safely.** If needed, they can be transferred to a NICU or the most appropriate unit once they have been stabilised, using specialist neonatal transport.
- **The changes will be phased – babies on the unit now will not have their care changed.** Planning for implementation of these changes has started, with further detail to come on the exact timeframe for the changes to be made.
- **The Young Patients Family Fund will continue to provide financial support to enable parents to be with their babies.** Through this fund, parents can receive financial support to help with the cost of travel, food, and accommodation.

Which babies will be affected?

Only a very small number of the smallest and sickest babies needing long-term intensive care will be transferred to a different hospital for some of their care – the Scottish Government has estimated that this will affect around 50 babies per year. This will particularly affect babies born at less than 27 weeks' gestation, babies weighing less than 800 grams, or babies who need complex life support. However, for most babies needing neonatal care, this change should not affect the hospital they receive care in.

What is the evidence for this model of care?

There are multiple studies that indicate that this model of care provides the smallest and sickest babies with the best chance of survival and quality of life. Data collected from the EPICure 2 study in 2006 was used to understand the designation of unit and size compared to neonatal outcomes for babies born before 27 weeks' gestation. It confirmed that NICUs with higher levels of activity had significantly better outcomes than smaller ones. Another large UK study from the Neonatal Data Analysis Unit published in 2014 showed that infants admitted to a high-volume neonatal unit at the hospital of birth were at reduced risk of neonatal mortality.

Data in the UK is further supported by international evidence. Findings from the French Epipage-2 cohort study in 2011 revealed that the survival at discharge of babies born between 24 and 30 completed weeks of gestation was lower in hospitals with lower volumes of neonatal activity. Survival without neuromotor and sensory disabilities at 2 years increased with hospital volume, from 75% to 80.7% in the highest volume units. Evidence from the US, Australia and other parts of Europe also supports this approach.

Does this mean babies will have to travel hundreds of miles for specialist care?

Babies will typically be cared for at their nearest NICU, which for the majority of babies will mean being transferred to Glasgow or Edinburgh, with those who live in the north of Scotland being cared for in Aberdeen. For example, women at risk of extreme pre-term birth in Lanarkshire will normally be taken to Glasgow for their baby to be born. Work is ongoing to ensure that each NICU has the appropriate capacity to implement these changes.

Will babies be cared for far from home for all of their neonatal admission?

While the babies affected by these changes will receive some of their care further from home, they will not need to receive all of their care in a NICU. Babies will be repatriated to their local neonatal unit as soon as it is safe to do so.

Will moving more babies compromise their safety?

Evidence from across the UK, and internationally, shows that the smallest and sickest babies have the best chance of survival and quality of life if they are cared for in a NICU with high levels of activity. It is on this basis that the decision has been made to reduce the number of NICUs in Scotland, to improve the outcomes and mortality rates of babies.

This new model of care will lead to safer care for babies but does mean that a small number of babies will be cared for further from home. To successfully implement this, it is essential that women who show signs of preterm labour are identified promptly, and that clear pathways are put in place

so that they can be transferred to their nearest hospital with a NICU before giving birth. There is already guidance in place about in-utero transfers to support this across Scotland.

Where babies do need to be transferred to a NICU after birth, specialist neonatal transport services are in place, and are already a routine – and vital – part of ensuring babies are cared for at the best hospital to meet their needs. When the new model of care was tested (in 2019/20) only a very small number of babies were moved after birth; and in all cases the small number of babies who need to be transferred after birth will be stabilised at their birth unit and transferred by the specialist neonatal transport service as soon as they are stable enough to be moved.

The Best Start review was published in 2017, is this evidence out of date?

Since the *Best Start: A Five Year Forward Plan for Maternity and Neonatal Services in Scotland* was published in 2017, work has been under way to implement the 76 recommendations aimed at improving the quality of care across maternity and neonatal services.

In order to ensure successful implementation of the proposed new neonatal model of care:

- The new model of care was tested at two sites in Scotland, starting in 2019, and data and insight from this early implementation pilot has informed the development of the final proposal.
- The Perinatal Sub-Group reviewed the current data about the profile of babies in neonatal care, post-Covid, to ensure this had not changed significantly during the pandemic.
- The Options Appraisal Report published in 2023 included updated data which added to the evidence already taken into account for the original *Best Start* report.

What is Bliss Scotland's position on these changes?

Bliss Scotland supports the reconfiguration of neonatal services in Scotland. The Best Start recommendation to reduce the number of NICUs aligned with the findings of Bliss Scotland's own Baby Report, published in 2017, which concluded: *"Scotland has a large number of neonatal intensive care units in relation to its total number of units, with nearly half being designated at Level three… Clinical best practice stipulates that the very smallest and sickest babies have improved mortality and morbidity outcomes if they are cared for within a smaller number of highly specialist hubs… These findings indicate that the Scottish Government should take stock of the current service design and assess it to see whether it is currently set up to provide optimal care to the very smallest and sickest babies which are cared for by the service."*

The Best Start new model of neonatal care is based on evidence that shows reducing the number of intensive care units from eight to three will improve outcomes for very sick and small babies, including survival rates and long-term neurodevelopment. This is because staff are more easily able to improve and maintain their skills and meet standards of clinical best practice if they are treating a higher number of the smallest and sickest patients; and also because evidence shows that the smallest and sickest babies do best when their neonatal care is located in a hospital which also has a range of other specialist services on-site, such as neonatal surgery. Ultimately, this means babies will receive safer care and will have better outcomes.

This change will also bring neonatal services in Scotland in line with the British Association of Perinatal Medicine (BAPM) standards on how to organise services safely and effectively. This will bring Scotland in line with best clinical practice, and in line with how other neonatal services are organised in the UK and similar countries globally.

In future, the vast majority of babies will still be cared for in their nearest neonatal unit, and the Scottish Government estimates that between 50 and 60 babies will be affected by the change in model of care every year, meaning that in future they will receive their intensive care further from home.

Will this change put babies at greater risk due being transferred further from home?

We have heard repeated concerns from the Petitions Committee, MSPs and parents that reconfiguring services will put babies at risk, due to the need for transfer. However, it is the *current* configuration of services which is more likely to be posing a risk.

The new model of neonatal care aims to ensure that mothers are transferred to a centre with a neonatal intensive care unit before they are born – **meaning their baby is born with the right specialist services on-site, including access to paediatric surgery and specialist services such as cardiac and renal** – with no need to transfer until they are well enough to move to a neonatal unit closer to home. This is optimal for this group of extremely fragile babies who weigh under 800g or who are born before 27 week's gestation.

Recent evidence from the Optiprem study – based on more than 18,000 babies born in England between 27 and 32 weeks – showed that babies born at 27 weeks gestation are at an increased risk of serious brain injury if they needed to be transferred within the first 72 hours of birth. This correlates with findings of other research which has found babies born before 27 weeks are more likely to experience serious brain injury, if transferred after birth.

With a high proportion of neonatal intensive care services operating with no or limited access to co-located specialities and low-throughput of the sickest babies, this is what is happening in Scotland, currently.