Bliss Scotland briefing:

The Best Start Programme new model of neonatal care

January 2024

About Bliss Scotland

Bliss Scotland is the leading Scottish 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.

Summary

- There are currently 14 neonatal units in Scotland, eight of which are Neonatal Intensive Care Units (NICUs).
- In 2017, the *Best Start: A Five Year Forward Plan for Maternity and Neonatal Services in Scotland* included the recommendation to reduce the number of NICUs in Scotland to three, based on evidence that the smallest and sickest babies have the best chance of survival and quality of life when they are born and cared for in higher volume neonatal intensive care units.
- In July 2023 the Scottish Government formally confirmed that the number of neonatal intensive care units in Scotland would be reduced from eight to three, and announced that the location of the three NICUs would be Queen Elizabeth University Hospital in Glasgow, Edinburgh Royal Infirmary, and Aberdeen Maternity Hospital.
- Under this new model **no neonatal units will close**, with the remaining NICUs redesignated as Local Neonatal Units (LNUs). However, a small number of babies will receive intensive care further from home under this model, before being transferred back to a neonatal unit closer to home as their condition improves and they get closer to discharge.
- The intention with the new model of care is that mothers in suspected extreme pre-term labour will be transferred before they give birth to maternity units in the hospitals with NICUs. It is recognised that it will not always be possible to transfer mothers before they give birth, and in those cases the specialist neonatal transfer service, ScotSTAR, will transfer babies after they have been born and stabilised, in specialist ambulances equipped to care for neonates.
- The next stage of the process to implement this new neonatal model of care over the coming years is to model the required capacity at the three remaining NICUs and to plan care pathways, co-location of services, and to engage families in how the model will be implemented.
- Bliss Scotland supports the reconfiguration of neonatal services in Scotland. The 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.
- However, these changes will have a significant impact on families if their baby needs to receive some of their care at a unit further away, and this distance risks reducing opportunities for parents to be partners in their baby's care.
- Babies do best when their parents are also able to be at their cotside and playing a hands-on role in their care. We therefore recommend that the implementation phase fully considers how the Scottish Government and Health Boards can provide the support parents need to address the barriers to being with their baby as much as possible. These include provision of financial support for travel, and provision of parent accommodation and facilities at each of the NICUs.

Background

Around 5,200 babies a year are admitted to neonatal care in Scotland. In 2017, a review of neonatal and maternity services, the *Best Start: A Five Year Forward Plan for Maternity and Neonatal Services in Scotland*, was published. This set out 76 recommendations aimed at improving the quality of care and outcomes for mothers and babies across these services. The Scottish Government accepted all the recommendations made in the report, and they are now in the process of being implemented. Bliss Scotland was fully involved in the review that led to the development of the Best Start Plan, supported the final report and its recommendations, and has continued to be involved in the implementation of the plan over recent years.

One of the main recommendations for neonatal services was to make sure that they were set up in a way which will provide the safest, high-quality care for babies now and into the future. The 2017 review found that Scotland had too many Neonatal Intensive Care Units (NICUs) for the number of babies who are born every year who need long term intensive care or very specialist treatment. It recommended that some of these NICUs become Local Neonatal Units (LNUs) instead, with the care for the sickest babies concentrated in three NICUs. In July 2023 the location of the three NICUs was announced, and planning is now under way for implementation of this new neonatal model of care over the coming years.

What is the new model of neonatal care in Scotland?

Neonatal services in Scotland will be changing over the coming years to make them safer, more effective and to make sure babies born premature or sick have the very best chance of survival and quality of life.

The number of NICUs will reduce from eight to three, with the remaining units becoming 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 starts in January 2024, with expected roll out from 2025.
- **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.

Frequently Asked Questions

When will changes be implemented?

Work will get underway to develop detailed planning and modelling to support successful implementation of the new model of care in January 2024, and it is expected to be fully operational by 2025. Planning for implementation will include:

- Developing pathways so that pregnant women and babies are transferred to the neonatal unit that can provide the appropriate care they need, as close to home as possible.
- Prioritising an approach which facilitates the transfer of pregnant women before they give birth; and the transfer of babies back to their local unit – called "repatriation" – as soon as they are well enough.
- Modelling work to inform the expansion of capacity as required at the three designated NICUs.

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. 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 includes updated data which added to the evidence already taken into account for the original *Best Start* report.

What was Bliss Scotland's involvement in the Best Start Review?

As the leading neonatal charity in Scotland, Bliss Scotland was invited to join the Review Group which developed the Best Start Five-Year Plan. Following the Review's publication, Bliss Scotland was also asked to join the Best Start Programme Implementation Board – which was tasked with overseeing the implementation of all 76 recommendations – and subsequently also joined the Perinatal Sub-Group, which has been providing more in-depth input to the implementation of the recommendations relating to neonatal care.

Throughout both the Best Start Review and its implementation to date, Bliss Scotland's role has been to advocate for what is in the best interests of babies born premature or sick, in line with our charitable mission. A significant focus for us throughout has therefore been 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. As part of this work, we are proud of having worked closely with the Scottish Government on the development of the Neonatal Expenses Fund – now the Young Patients Family Fund – which has provided significant support to families to overcome the financial barriers that many of them face to being with their baby in neonatal care.

We have also undertaken ongoing policy work on neonatal nurse, medical and allied health professional (AHP) staffing, and have worked directly to support all neonatal units in Scotland with implementing a number of recommendations around improving 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.

What is Bliss Scotland's position on these changes?

Bliss Scotland supports the reconfiguration of neonatal services in Scotland. The 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.

Practical support for families with a baby in neonatal care

Financial pressures and the lack of accommodation for parents provided within neonatal services can be a considerable worry for parents when their baby is in neonatal care and can act as a barrier that means parents are not able to spend as much time with their baby as they would like.

Bliss' research across the UK shows that more than half of parents say that their finances have an impact on their ability to be by their baby's side in hospital, with around one in five saying that finances impacted their ability to be involved in their care "significantly". Travel is the biggest cost for most families, but when a family has an older child at home, the additional cost of childcare is their largest cost and can be prohibitive to being at the hospital.

Accommodation on or near the neonatal unit is not routinely provided on units, and while some families have access to this type of support, the majority of parents return home at night, leaving their newborn baby in hospital without a parent. This clearly impacts on parents' vital role as partners in their baby's care, with 87% of parents who responded to a UK-wide survey who didn't have access to overnight accommodation saying that this stopped them from being involved in their baby's care at least sometimes.

Under the new model of care**, 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.

The Young Patients Family Fund, and the availability and quality of family facilities on neonatal units, is of increasing importance as Scotland moves to a more centralised model of neonatal care. The planned reconfiguration of neonatal services in Scotland is in line with best practice in terms of clinical care for babies, both across the rest of the UK and internationally, but we know that babies do best when their parents are also able to be at their cotside and playing a hands-on role in their care.

Bliss Scotland therefore believes that much more can and should be done to make this model of care work better for families, to improve the provision of Family Integrated Care and ensure that every baby born premature or sick in Scotland has the best chance of survival and quality of life.

Bliss Scotland recommendations to improve practical support for families

Changes to the Young Patients Family Fund

The Neonatal Expenses Fund – now the Young Patients Family Fund (YPFF) – was first introduced in 2018 as part of the *Best Start* programme and has since undergone evaluation by the Scottish Government. The Scottish Government evaluation showed that the scheme relieved financial anxieties during a very stressful period, and helped parents spend more time with their babies in the neonatal unit as a result of being able to claim.

Through the current scheme parents can claim *some* expenses for subsistence and travel and may be able to claim back the cost of accommodation. However, the scheme does not cover all expenses, the process for claiming is cumbersome and usually requires upfront payment, and parents do not always know about the scheme until it is too late.

Bliss Scotland recommends that the following improvements be made to the YPFF scheme:

- Uprate the amounts that can be claimed in line with inflation
- Expand the scheme to include other expenses that are a barrier to parents being with their baby on the neonatal unit, such as childcare costs
- Ensure clear communication with families about what they can claim, including how larger costs such as accommodation and higher cost travel expenses can be paid for upfront by Health Boards directly; as well as clarity and consistency of approach on claiming for taxis
- Digitise the scheme to make it easier to claim.

Accommodation and facilities

The reconfiguration of services in Scotland does mean that a small number of babies will be cared for further from home than previously. Travelling a long distance to be with a baby in hospital can take a big toll on families. To ensure that an additional burden is not placed on these parents, we are calling on the Scottish Government to ensure that the necessary investment is available to provide appropriate accommodation for parents at each of the three Scottish NICUs. NICUs should be able to provide:

- Accommodation for both parents on-site or close to the unit
- Kitchen facilities so that families can make meals and hot drinks
- Areas on the unit where parents can relax and take time away, without leaving the hospital
- Facilities for older siblings to be present on the unit
- Shower and toilet facilities

Conclusion

The new model of neonatal care in Scotland will bring services in line with best practice, including UK-wide clinical standards, that will improve the number of babies who survive and have a good outcome having been born prematurely or very sick. Bliss Scotland supports these proposals, but continues to push for further parent involvement in the process going forward.

As detailed planning starts to get under way to support implementation of the next phase of the Best Start programme for neonatal care, including the transition to the new neonatal model of care with three NICUs, there is an important opportunity for the Scottish Government to learn from and build on the success of the NEF, and subsequently the YPFF, in its first 5 years in operation.

As detailed above, the existing YPFF scheme is an excellent basis for supporting parents in Scotland when they have a baby born premature or sick. Going forward the scheme must now be updated and improved to offer the best support possible for parents with a baby admitted to neonatal care in Scotland in the future. It is also essential that Scottish Government can provide the investment necessary to deliver accommodation for parents when their baby is in neonatal care.