Bliss Scotland briefing: Best Start New Model of Neonatal Care



Members' Business Motion (S6M-17186)
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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.

Summary

- The Best Start review set out a new model of neonatal care, including a vision for the
 organisation of neonatal services to align with evidence for providing the highest quality care
 to the sickest babies
- Eight years on, the new model is still not fully implemented, and the resources needed to do this safely while providing support to families have not been delivered in full
- Despite progress since 2017 in delivering many of the Best Start's recommendations across maternity and neonatal services, there remains uncertainty over when or how full implementation of the new neonatal model of care – confirmed by the Minister in July 2023 – will take place
- Bliss Scotland has found that for every ten babies that need to stay overnight, there is only
 one room available for a parent to stay with them
- The Young Patients Family Fund is an excellent resource. The implementation of the new
 model offers a valuable opportunity to ensure that every parent can access the fund and be
 as involved in their baby's care as possible

About neonatal care

1 in 7 babies born in the UK require some level of neonatal care after birth, and the care they receive is vital to their long-term health. **Around 5,200 babies a year are admitted to neonatal units in Scotland.** Babies may be admitted shortly after birth because they have been born prematurely (before 37 weeks of pregnancy), or because they are born at full term but with a condition that requires hospital care (such as an infection). These babies often need intensive medical support in an incubator or cot during the first days, weeks, or even months of life. Sadly, some babies die before they are discharged.

This care is often lifesaving – but it can also be deeply traumatic for babies and their families. Babies are exposed to pain, stress, and environments they are not ready for. Many are routinely separated

from their families for extended periods, as most hospitals do not provide sufficient facilities for parents to stay overnight.

The Best Start New Model of Neonatal Care

Background

In 2017, The <u>Best Start plan</u> recommended reducing the number of Neonatal Intensive Care Units (NICUs) in Scotland to three, **based on evidence that very small and sick babies have better outcomes when cared for in higher volume centres. No neonatal units will close.**

Under the New Model of Care, the <u>Scottish Government estimates</u> that between 50 and 60 babies will be affected by the change in model of care every year, meaning they would receive their intensive care further from home. Once their care needs have reduced, these babies will be transferred to hospitals closer to their home for the continuation of their care.

Embedding this evidence-based reconfiguration model, which aims to improve outcomes for the sickest babies, would bring neonatal services in Scotland in line with best practice and align with the models in place throughout the rest of the UK and other high-income countries. Indeed, the new model of care has been tested since 2019, with early implementer sites at Victoria Hospital, Fife and Crosshouse, Kilmarnock.

Following a pause to the whole Best Start programme during Covid, additional up-to-date data were fed into the 2023 Options Appraisal Report, which confirmed the proposed new model of care was still necessary. Up-to-date data was also used for the 2024 final modelling report on demand and capacity modelling.

However, **the impact on families must not be overlooked**. Receiving care further from home can reduce parents' ability to be partners in their baby's care – something proven to benefit outcomes. Improving access to overnight accommodation and ensuring the Young Patient Family Fund is fit for purpose is crucial for successful implementation of the New Model of Care.

Stalling progress

Despite the importance of fully implementing the new model of care, there have been limited updates since the <u>Scottish Government's July 2023 statement</u>, either for families who may be affected in future or, critically, for the staff working in neonatal services across Scotland. Those working to improve the lives of babies born premature or sick need an **update on progress** towards implementation of the new model of neonatal care, a **clear timescale** for when the new model will be fully operational, and a commitment that **resources will be made available to implement the new model of care safely.**

In late December 2024, the Minister responded to a <u>question in Parliament</u> with "the expectation that a phased transition to the new model will begin in the new year", however there has been no update since on the timeline or progress towards implementation.

Additionally, it is important for the Scottish Government to set out how it will ensure that what it sees as **essential criteria**, including adequate staffing and provision of overnight accommodation, are met in line with its planned timescale. This should include an update on how ongoing delays to the opening of the new Baird Family Hospital in Aberdeen may affect the provision of facilities and accommodation for families with babies cared for in the Aberdeen neonatal intensive care unit.

Ensuring the Best Start new model of neonatal care delivers the highest standards of care for the most vulnerable babies

Prioritising safety

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 a hospital which provides a high volume of neonatal intensive care to these 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 must continue to be in place, as these ensure 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. In all of these cases, the small number of babies who needed to be transferred after birth were stabilised at their birth unit and transferred by the specialist neonatal transport service as soon as they were stable enough to be moved.

Adequate and sustained staffing

Adequate and sustained funding is crucial to delivering the new model of neonatal care safely and effectively. It is needed to **ensure there are enough trained staff in each unit**, especially as intensive care is concentrated in fewer locations. Bliss' latest research on Allied Health Professional, Psychologist and Pharmacist (AHPPP) provision found that there is an **88 per cent shortall** in Scotland between the recommended AHPPP staffing levels for units and the staffing levels currently being achieved. This is significantly higher than the UK average of 67 per cent.

Funding is also essential for increasing cot capacity and the nursing and medical staffing required to go with it, in particular at the largest of the three designated Neonatal Intensive Care Units for Scotland, the Royal Hospital for Children in Glasgow.

Overnight accommodation for parents

Travelling long distances to be with a baby in hospital can take a big toll on families. <u>Bliss' Families</u> <u>Kept Apart in Scotland campaign</u> found that **for every 10 babies that need to stay overnight on the unit, there is only one room for a parent to stay with them.** This means that parents are likely to be routinely separated overnight from their newborn during their time in neonatal care.

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 in all neonatal units. This is essential for the successful implementation of the new model of care, as overnight accommodation is vital for enabling parents to be partners in their baby's care.

Young Patients Family Fund

Bliss' <u>research across the UK</u> 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".

Under the new model of care, the Young Patients Family Fund (YPFF) 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. However, our Families Kept Apart in Scotland report found that the YPFF, while an excellent support to many families, is utilised inconsistently across units when it comes to accessing accommodation and staff lack confidence in helping parents to access this support.

Barriers to access include that there's no online portal or easy way to submit claims. Efforts should be made to streamline the system for making claims and this work should involve parents with recent experience of neonatal care. It is also important that *all* staff involved in claims understand how to apply to the Fund. Supporting parents to access the YPFF, including for accommodation expenses, is of increasing importance as Scotland moves to a more centralised model of neonatal care.

Bliss Scotland

Bliss Scotland, the leading neonatal charity in Scotland, has been involved in the Best Start Five Year Plan since its development. After the Best Start's publication, Bliss Scotland was invited to join the Best Start Programme Implementation Board and the Perinatal Sub-Group; both of which have now been closed. Across the programme, Bliss Scotland's role has been to advocate for the best interests of babies born premature or sick, with a strong focus on supporting parents to be partners in their babies' care.

Bliss Scotland worked closely with the Scottish Government to develop the Neonatal Expenses Fund, now called the <u>Young Patients Family Fund</u>, and continues to carry out policy work on neonatal nurse, medical and allied health professional staffing. All neonatal units in Scotland are also working to improve parental involvement in care through the Bliss Baby Charter.

Recommendations

- The Scottish Government must urgently update on the planned timetable for implementation
 of the new model of neonatal care, and commit to providing the full resourcing necessary to
 ensure this happens in a safe and measured way
- The Scottish Government must work with regions and health boards to deliver the required investment to ensure neonatal units have adequate nurse, medical, Allied Health Professional, Psychologist and Pharmacist staffing for their new numbers of cots, in line with national standards for numbers and skillset
- As part of the implementation process for the new model of neonatal care, the Scottish
 Government must identify capital investment required to bring all parent accommodation up to
 a minimum standard on neonatal units
- The Scottish Government should develop a small grants programme so that units can apply for funding immediately to buy new furniture or equipment to improve the neonatal environment and provide parents with the facilities to support them being partners in their baby's care
- All staff involved in administering the Young Patients Family Fund, from unit staff to cash office and finance teams, must understand the remit of the fund and apply it consistently. Additionally,

the current claims process may be a barrier to access, and work should be undertaken, in partnership with families whose babies have received neonatal care since it's been in place, to streamline it and make improvements.

Conclusion

The new model of neonatal care in Scotland will bring services in line with best practice, including UK-wide clinical standards, to improve the number of babies who survive and have good health outcomes 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.

This debate is a chance to stand up for the needs of the most vulnerable babies and the families who care for them. MSPs are encouraged to support the motion and ask the Scottish Government for the clarity, commitment and investment needed to ensure the Best Start model is delivered in full and as it was intended, and works in practice - not just on paper.