PE2099/B: Stop the proposed centralisation of specialist neonatal units in NHS Scotland

Minister for Public Health and Women's Health written submission, 11 October 2024

Thank you for the opportunity to respond to the petition noted above.

In addition to my letter to the committee dated 11 June 2024 I would like to respond to the points raised within your letter of 25 September 2024.

The Best Start: A five Year Forward Plan for Maternity and Neonatal Care was published in 2017. It sets out a future vision for maternity and neonatal care which focuses on putting women, babies and families at the centre of maternity and neonatal care to ensure they receive the highest quality of care according to their needs.

The Best Start report was the result of a Strategic Review of Maternity and Neonatal Services in Scotland. The Review was chaired by an NHS Chief Executive and conducted by clinical experts, NHS service leads, academics and service user representatives. It examined choice, quality and safety of maternity and neonatal services in consultation with service users, the workforce and NHS Boards, and supported by analysis of current evidence.

Within the published report The Best Start recommended that Scotland should move from the current model of eight Neonatal Intensive Care Units (NICU) to a model of three units supported by the continuation of current NICUs redesignated as Local Neonatal Units (LNU's).

I think it is important to reiterate the reason why the Best Start expert report recommended this change, and therefore why we are moving forward with it.

The recommendation was based on evidence that outcomes, including survival, for the very smallest and sickest babies are best when they are cared for in units with high volume throughput (defined as care for more than 100 very low birthweight babies a year) and where there are collocated specialist services (such as neonatal surgery). This evidence is widely supported, and now forms the basis of professional guidance published by the British Association for Perinatal Medicine (the professional body for neonatology and a specialist society of the Royal College of Paediatrics and Child Health), and the majority of existing service models in other parts of the UK are aligned to this.

Based on the number of very low birthweight babies that are born in Scotland the Best Start Programme Board determined that three units would be a sustainable model for Scotland. I think all parents across Scotland would expect us to act in the interests of the best evidence and deliver services that improve the chances for the very smallest and very sickest babies.

You asked how clinicians and staff at neonatal intensive care units were consulted before the decision to centralise services was taken. The recommendation to move to three Neonatal Intensive Care units was made in the Best Start report published in 2017. The recommendations of that report were accepted by Ministers when it was published, and this was communicated to the Scottish Parliament at that time.

The Best Start report was the culmination of the work of the Review of Maternity and Neonatal Services. The 24 members of the Review Group included representative clinicians

who were drawn from 9 NHS territorial Boards, including each of the 7 Boards that host Neonatal Intensive Care Units (NHS Ayrshire and Arran, NHS Fife, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Lanarkshire, NHS Lothian and NHS Tayside). The Review Group recommendations were informed by the work of the Sub Groups, including the Neonatal Models of Care Sub Group. The 22 members of the Neonatal Sub Group also included representatives of each of the Boards that host Neonatal Intensive Care Units (highlighted above). The full membership of both of these groups can be found in Appendix E and Appendix F of The Best Start report.

As part of the review, the Review team visited all 14 Boards across Scotland and met with teams from maternity and neonatal services. In addition, the Scottish Health Council led a programme of service user engagement across all NHS Territorial Boards, which were supplemented with bespoke service user events. Over 600 staff and 500 service users contributed to the review process. The detail of this engagement is set out in Chapter 4 of The Best Start report. The recommendations in The Best Start were a triangulation of the evidence (also detailed in Chapter 4 and Appendix G), plus the views of staff and service users, brought together by the Review Group.

Following the publication of the Best Start report, the Best Start Implementation Programme Board was established. The Programme Board agreed to establish the Perinatal Sub Group with the responsibility to take forward the recommendations on Neonatal Intensive Care. The members of the Perinatal Sub Group were appointed based on the organisations they represented, not the Boards they were from (for example Chair of the Scottish Neonatal Consultants Forum, Chair of the Scottish Neonatal Nurses Forum, representative from Heads of Midwifery, Scottish Ambulance Service and ScotSTAR and Bliss, a leading charity representing neonatal families).

The petition that you have received has a particular focus on the neonatal unit in Wishaw. It may be helpful to note that Lynne Clyde, Head of Midwifery at NHS Lanarkshire, was a member of the Perinatal Sub Group representing Heads of Midwifery and involved throughout the options appraisal process. In addition, Heather Knox, at that time Chief Operating Officer for NHS Lanarkshire initially chaired the Perinatal Sub Group and sat on the Best Start Programme Board however, stood down from chairing the Perinatal Sub Group before it actually undertook the options appraisal as she perceived a conflict of interest with her Lanarkshire role.

So in summary, a range of neonatal and maternity clinical voices were represented both in the development of The Best Start report that made the recommendations to move to three neonatal intensive care units, and in the development and undertaking of the Options Appraisal process that determined where those units would be located.

You asked about the impact of the distance between home and hospital on the wider family, particularly other children, and what steps are being taken to mitigate any impact. We continue to prioritise parents as key partners in caring for their baby and have facilities on neonatal units so that parents and siblings can be with their baby as much as possible. This is in line with the Best Start ethos of keeping mothers and babies, and families together as much as possible with services designed around them.

As a key part of the next phase, Scottish Government has consulted with families on implementation of the proposals, so that we can take account of their concerns when the pathways and processes for the new model of care are designed, and it is important that we hear the voices of those families to input into design of service delivery.

A survey was conducted through Citizen Space, Scottish Government's online consultation hub, to gather and consider the views of interested stakeholders on the new model of

neonatal care and what matters to them. This process has been supported and input sought by HIS and Bliss the charity for neonatal families.

The survey was launched on Citizen Space on 21 June 2024 and asked 20 questions (7 open and 13 closed).

The survey received 434 responses. Of these, 428 were from individuals and 6 from organisations.

To supplement the survey, the Scottish Government conducted focus groups to interrogating key themes to emerge from the quantitative research study. The focus groups explored three themes: mental health support, financial support, and communication.

The results of the survey and focus groups are now being shared to support implementation.

Analysis of the responses will take place to determine an action plan to target areas of public concern and how these can be mitigated.

We have a number of measures already in place to support families who have babies in neonatal care including:

- Providing accommodation for parents to stay on or near neonatal units;
- Roll out of the Young Patients Family Fund (formerly the Neonatal Expenses Fund) to support families with the costs of travel, accommodation and food whilst their baby is in neonatal care;
- Provision of accommodation for parents/carers on or near the neonatal unit.

and

- Repatriating babies to their local neonatal units as soon as clinically possible.

You asked about ScotSTAR resources to respond to all transport requests following the introduction of the new care model. The Scottish Government commissioned detailed modelling work from RSM UK Consulting LLP to inform planning for transition to the new model of care. Their work involved engagement with both operational and strategic stakeholders, including ScotSTAR to validate data, generate and test planning assumptions and their report was published on 29 May 2024 and can be accessed at New Model of Neonatal Care – RSM UK Consulting - Report

Following the modelling work that RSM UK undertook we asked the Regional Chief Executives to develop implementation plans to deliver the new model of care, and as part of this to engage with the Scottish Ambulance Service and ScotSTAR on capacity. I am aware that the regional planning teams have met with ScotSTAR as part of their planning process, and capacity is an ongoing part of discussions moving forward with implementation.

Finally, you asked how the new model will affect care for high-risk babies not born at a hospital with a neonatal intensive care unit between birth and transfer to such a unit.

If it is identified during the pregnancy that there is a high risk of the baby (or babies, in multiple pregnancies) needing specialist intensive care after birth – for example for an identified heart or surgical problem – then all antenatal care will be planned with the input of a specialist maternity team, and with an expectation that the woman will be transferred to a maternity unit in a hospital with a NICU on site when it is time to give birth. This is the model that is in operation now across Scotland, for example in relation to neonatal surgery, which is

only available in three units in Scotland, and pathways and protocols are in place to transfer mothers before they give birth.

If a pregnant woman goes into extreme pre-term labour, or looks like she is going to, depending on the timing of this, she will be transferred by ambulance to a maternity unit in a hospital with a NICU on site, if it is safe to do so, to give birth to the baby there. In the case of an unexpectedly unwell baby or, if there is no time to transfer the woman before a preterm birth, the baby will be born in the nearest hospital and given immediate short-term intensive care on site to stabilise the baby, before being transferred to a NICU by the specialist neonatal transport service ScotSTAR when it is safe to do so.

Experience of operating this model of care in Ayrshire and Fife has shown that this works well, with the vast majority of mothers in suspected pre-term labour being transferred prior to birth. The Scottish Perinatal Network has a programme of work underway to support all Boards in Scotland to strengthen processes and pathways to ensure extremely pre-term babies are born in units with an alongside Neonatal Intensive Care Unit.

Babies receiving care in one of the three intensive care units will be transferred back to their local neonatal unit for ongoing care as soon as possible.

I would like to also provide clarification to the committee regarding a point that was raised on 11 September 2024.

Since my appointment and the announcement of the location of the 3 specialist intensive care neonatal units for highest risk babies in Aberdeen Maternity Unit, Edinburgh Royal Infirmary and Queen Elizabeth University Hospital in July 2023, I have met with families and clinicians from across Scotland, including in the University Wishaw Hospital.

On the 9 Nov 2023 I attended a meeting at the Scottish Parliament with Wishaw neonatal campaigners and elected representatives. On the 26 Feb 2024, I visited Wishaw General neonatal unit and met with staff to discuss the new model of care. On the 21 May 2024, I met Fulton McGregor, Wishaw Campaigners and former Wishaw Clinicians.

In addition, on 7 February 2024, I visited Ninewells neonatal unit in Dundee to award them with the Bliss Baby Charter gold award. In order, to gain additional clinical insight into the new model of neonatal care, on 22 August 2024 I visited NHS Greater Glasgow and Clyde Neonatal unit within Queen Elizabeth University Hospital and on 1 October 2024, I visited the New Royal Infirmary neonatal unit to see the work of the clinical teams and discuss the new model of neonatal care.

I am aware the prior to the announcement of the three units, my predecessor Maree Todd also had the opportunity to attend the neonatal units to meet with staff and families.

I hope this information has provided additional reassurance to the committee that we are looking all areas highlight as part of the implementation process so we can provide the best care in Scotland for our neonatal babies.

Yours sincerely,

Jenni Minto MSP