Citizen Participation and Public Petitions Committee Wednesday 11 September 2024 13th Meeting, 2024 (Session 6)

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

Introduction

Petitioner Lynne McRitchie

Petition summary Calling on the Scottish Parliament to urge the Scottish

Government to stop the planned downgrading of established and high-performing specialist neonatal intensive care services across NHS Scotland from a level three to a level two and to commission an independent review of this decision in light of contradictory expert opinions on centralising services.

Webpage https://petitions.parliament.scot/petitions/PE2099

1. This is a new petition that was lodged on 14 May 2024.

- 2. A full summary of this petition and its aims can be found at **Annexe A**.
- 3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.
- 4. Every petition collects signatures while it remains under consideration. At the time of writing, 1,612 signatures have been received on this petition.
- 5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered.
- 6. The Committee has received a new submission from the Minister for Public Health and Women's Health, which is set out in **Annexe C** of this paper.

Action

7. The Committee is invited to consider what action it wishes to take.

Clerks to the Committee September 2024

Annexe A: Summary of petition

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

Petitioner

Lynne McRitchie

Date Lodged

14 May 2024

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to stop the planned downgrading of established and high-performing specialist neonatal intensive care services across NHS Scotland from a level three to a level two and to commission an independent review of this decision in light of contradictory expert opinions on centralising services.

Previous action

A petition against the proposal has over 20,000 signatures.

Numerous communications to MSPs from concerned parties.

Jackie Bailie MSP brought forward a motion to debate this issue in the chamber on 20th September 2023.

Meghan Gallagher MSP also extended this debate to support the petition to stop downgrading of specialist neonatal services in NHS Lanarkshire during Member's Business on 20th September 2023 in Scottish Parliament.

Background information

These plans would affect services across Scotland, including specialist neonatal units in University Hospital Wishaw which is award winning, Ninewells in Dundee and Victoria Hospital in Kirkcaldy.

The centralisation of neonatal services to three units in Glasgow, Edinburgh and Aberdeen could place additional stress on expectant parents and premature babies. Clinical whistleblowers have said that the decision to downgrade these facilities could endanger the lives of vulnerable babies and place remarkable strain on families.

There is a particular focus on retaining services at University Hospital Wishaw (Neonatal unit of the year 2023). Downgrading this unit would mean that NHS Lanarkshire, Scotland's third largest health board, that serves a population of 655,000 people, may lose a high-functioning service for babies/families which would have a potentially disastrous knock on effect on services in NHS Greater Glasgow and Clyde, NHS Lothian and NHS Grampian.

Annexe B: SPICe briefing on PE2099



Background

Neonatal units operate at 3 different levels. These are described by the <u>Scottish</u> <u>Perinatal Network</u> as follows:

Level 1 – Special care baby units (SCBU) - provide special care (e.g. tube feeding and/or intravenous antibiotic therapy for babies who are born no more than eight weeks preterm). They may also, by agreement between Boards, provide some high dependency services (e.g. some forms of breathing support).

Level 2 – Local neonatal units - provide specialised and high dependency care, including assisted ventilation and short-term neonatal intensive care.

Level 3 – Neonatal Intensive Care Units (NICU) - provide the full range of medical neonatal care, including for babies and their families referred from other units for specialised care (e.g. surgical and/or cardiac services). Neonatal intensive care is needed for approximately one in 50 babies born in Scotland. Pregnant women at high risk of delivering before 27 completed weeks' gestation (before 28 weeks' for twins) and / or a baby expected to weigh less than 800g are, if possible, transferred before delivery to a maternity facility co-located with a NICU.

The Scottish Government published <u>The Best Start: A five-year forward plan for Maternity and Neonatal Care in Scotland</u> in 2017. The was the report of a review which was tasked with improving maternity and neonatal services in Scotland.

One of its key recommendations was to centralise specialist services by reducing the number of neonatal intensive care units (NICUs) from eight to three.

"The Best Start Recommendation 45 - Neonatal intensive care: The new model of neonatal services should be redesigned to accommodate the current levels of demand, with a smaller number of intensive care neonatal units, supported by local neonatal and special care units. Formal pathways should be developed between these units to ensure that clear agreements are in place to treat the highest risk preterm babies and the sickest term babies in need of complex care in fewer centres, while returning babies to their local area as soon as clinically appropriate. Three to five neonatal intensive care units should be developed, supported by 10 to 12 local neonatal and special care units."

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This recommendation was subjected to an options appraisal by a perinatal subgroup which explained in <u>its final report</u>:

"The recommendations for the new neonatal model of care are underpinned by strong evidence that population outcomes for the most premature and sickest babies are improved by delivery and care in units looking after a "critical mass" of these babies."

The evidence referred to was a review which was published as part of the Best Start report (see Appendix H).

This was later supported by an update to the Framework for Practice from the British Association of Perinatal Medicine (BAPM) which looked at 'Optimal arrangements for Neonatal Intensive Care Units in the UK including guidance on their Medical Staffing'.

The BAPM framework recommends that NICUs should admit at least 100 very low birth weight babies a year and undertake at least 2,000 intensive care days per year.

The options appraisal group scored each of the existing NICUs in accordance with short listed criteria, definitions, weightings and site information. The existing units were scored as follows:

- 1. Queen Elizabeth University Hospital, Glasgow (99)
- 2. Edinburgh Royal Infirmary (93)
- 3. Aberdeen Maternity Hospital (82)
- 4. Ninewells, Dundee (53)
- 5. Princess Royal Maternity, Glasgow (34)
- 6. Wishaw General (30)
- 7. Victoria Hospital, Kirkcaldy (24)
- 8. Crosshouse Hospital, Kilmarnock (18)

This resulted in the subgroup recommending the retention of NICUs in Glasgow, Edinburgh and Aberdeen, and for the remaining units to be downgraded to level 2 neonatal units.

Scottish Government action

The Scottish Government accepted the recommendations of the Best Start report and work is underway to implement the new model of care.

As part of this, the Scottish Government contracted RSM UK Consulting LLP to undertake detailed modelling and capacity planning work, to inform local implementation plans.

The report was published on 29 May 2024: New Model of Neonatal Care – RSM UK Consulting - Report.

Scottish Parliament Action

The <u>removal of specialist neonatal services in Lanarkshire was debated</u> in the Scottish Parliament on 20 September 2023.

Kathleen Robson Senior Researcher (Health and Social Care) SPICe Research 11 June 2024

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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Annexe C: Written submission

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

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The <u>Best Start: A five Year Forward Plan for Maternity and Neonatal Care</u> 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).

The recommendations for the new neonatal model of care was underpinned by strong evidence that population outcomes for the most premature and sickest babies are improved by delivery and care in units looking after a critical mass of these babies, with experienced staff, and with full support services. These services include access to on-site paediatric, surgical, laboratory and radiology services, which are beneficial for the most preterm babies.

The smallest and sickest babies are defined as those born at less than 27 weeks gestation, that weigh less than 800 grams, or who need multiple complex intensive care interventions or surgery. The model of neonatal intensive care described in Best Start aligns with guidance from the British Association of Perinatal Medicine (the professional body for Neonatal medicine) on <u>'Optimal Arrangements for Neonatal Intensive Care Units in the UK'</u> published in 2021, and with existing service models across the UK.

The Best Start Programme Board initiated an options appraisal process to identify where the three neonatal intensive care units would be located, and the Perinatal Sub Group of the Best Start was established to take this forward. The process of determining which units should be providing Neonatal Intensive Care was undertaken by an expert group, including clinical leads and service user representatives, and their recommendations, published within the Options appraisal report, that Queen Elizabeth University Hospital, Edinburgh Royal Infirmary and

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Aberdeen Maternity Unit should be designated as the three Neonatal Intensive Care Units for Scotland.

Wishaw General will have a Local Neonatal Unit (LNU) under the new model. As an LNU the unit will continue to provide a level of intensive care and will be able to care for singleton births over 27 weeks gestation, but the most preterm and sickest babies will receive specialist complex care in one of the three NICUs, returning to their LNU as soon as clinically appropriate.

The Framework for Practice 'Criteria to Define Levels of Neonatal Care including Repatriation within NHS Scotland', published on the same day as the announcement, describes the new model of care.

In advance of these changes, the model was tested in two early implementer areas, involving four units. The testing phase of the new model, including transfer pathways and repatriation is operating well, with only a very small number of out of pathway transfers. Learning from the testing continues to inform change as we move forward with full implementation of the model across Scotland. The findings and key learning points are contained within the options appraisal report.

The intention with the new model of care is that mothers in suspected extreme preterm labour are transferred before they give birth (*in-utero*) to maternity units in the hospitals that have neonatal intensive care units. Those maternity units will have expanded capacity to receive those women. 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 those babies in specialist ambulances equipped to care for neonates. This has been established practice for many years in Scotland.

Babies requiring specialist NICU care in one of the three centres will return to a local neonatal unit closer to home as soon as they are well enough to move and step down the care they need.

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. In addition, Scottish Government has 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, to validate data, generate and test planning assumptions and their report was published on the 29 May 2024 and can be accessed at New Model of Neonatal Care — RSM UK Consulting - Report

The new model of neonatal care is supported by a range of stakeholders and clinicians, including Bliss the leading charity for babies born premature or sick, who recognise that this new model of care is based on strong evidence and will improve

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the safety of services for the smallest and sickest babies. Bliss also represent parents voices on the Best Start Programme Board and the Perinatal Sub Group.

We continue to safeguard parents as key partners in caring for their baby. The Best Start aims to keep mothers and babies, and families together as much as possible with services designed around them therefore, we are providing them with the opportunity to feed into the development stages of implementation. As a key part of the next phase, Scottish Government will be consulting 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.

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;

and

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

The Young Patient Family Fund (formerly the Neonatal Expenses Fund) provides vital financial support covering the costs of travel, food and accommodation to allow families to be with their babies in neonatal care. In addition, NHS Boards have accommodation available to parents/carers on or near the neonatal unit.

This decision has been made on the basis of evidence and expert advice, and this change is being made to improve outcomes for these very smallest and sickest babies.

Yours sincerely,

Jenni Minto MSP