ANALYSIS OF ENGAGEMENT ON THE NEW MODEL OF NEONATAL CARE

April 2025

CONTENTS

INTRODUCTION

Recommendation 46 of the Best Start states that:
"Excellent communication processes should be developed between neonatal units and with parents to ensure a full understanding of the care pathways for babies. Consistent, standardised information will also be developed to ensure all parents are aware of the options for their baby, in particular for those parents whose babies might have all, or part, of their care out with their local unit."

As part of the next phase of implementing the new model of neonatal care, the Scottish Government engaged with families on implementation of the proposals so that their concerns and priorities are included when the pathways and processes for the new model of care are designed.

A survey was conducted through Citizen Space, the 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 provided by Healthcare Improvement Scotland (HIS) and Bliss the charity for neonatal families.

Where consent to publish was given, all responses have been read and analysed. This report provides an overview of the findings.

Focus Groups

To supplement the survey, the Scottish Government carried out eight online focus groups covering key themes to emerge from the survey, exploring: mental health support, financial support, and communication. The focus groups were held in August 2024, with representation from eleven local authority areas.

Survey respondents who consented to be contacted were invited to take part. (316 respondents).

A summary report can be found at **Annex B**.

The Scottish Government would like to thank everyone who took the time to respond to the new model of neonatal care survey.

WHAT WE ASKED

The survey was launched on Citizen Space on 21 June 2024 and closed on 8 July 2024 and asked a total of 20 questions (7 open and 13 closed).

The survey received 434 responses. Of these, 428 (99%) were from individuals and 6 (1%) from organisations. A breakdown of the number of responses received per health board is presented in **Annex A**.

In responding to the online survey via Citizen Space, participants indicated their agreement to their anonymous responses being shared in our published analysis of responses. The quotes contained within this report are only from responses submitted via Citizen Space where the respondent consented to publication.

It is important to note that the survey was open to all. This self-selection means the views of respondents do not necessarily represent the views of the wider population. However, the views which were received will contribute to future considerations and decisions during the implementation of the new model of neonatal care.

Respondents were invited to answer the following 13 questions -

- Had you had a baby admitted to a neonatal unit?
    - If yes, for the most recent admission, what year was your baby admitted to neonatal care?
    - If yes, for the most recent admission, how long did your baby spend time in the neonatal unit?
    - Was your baby cared for in the neonatal unit within your home health board area?
    - Was there any support that would have been helpful for you during this time that was not available?
- Prior to answering this survey, had you heard of the new model of neonatal care?
    - If you answered yes to Question 6, where did you hear about the new model of neonatal care?
- How do you think information about the new model of neonatal care can be best communicated to members of the public?
- Do you have any questions about how the new model of neonatal care will work in practice?
- What do you think are the most important considerations that need to be taken into account when planning implementation of the new model of neonatal care?
- What support do you think parents will most need if their baby needs to spend time further from home in a neonatal intensive care unit?
- Would you like any further information on any of the following areas of the new model of neonatal care?
- Do you have any other feedback you would like to share with us on the new model of neonatal care?

YOU SAID

All responses were reviewed in full. The responses to the closed questions were analysed by calculating the total counts and percentages for each response option and the range of experiences and opinions raised in responses were noted. For each open text question, these were grouped into similar, common themes.

In reporting on the analysis of open questions, the following descriptors have been used to report on the number of respondents to each question raising a particular issue or theme:

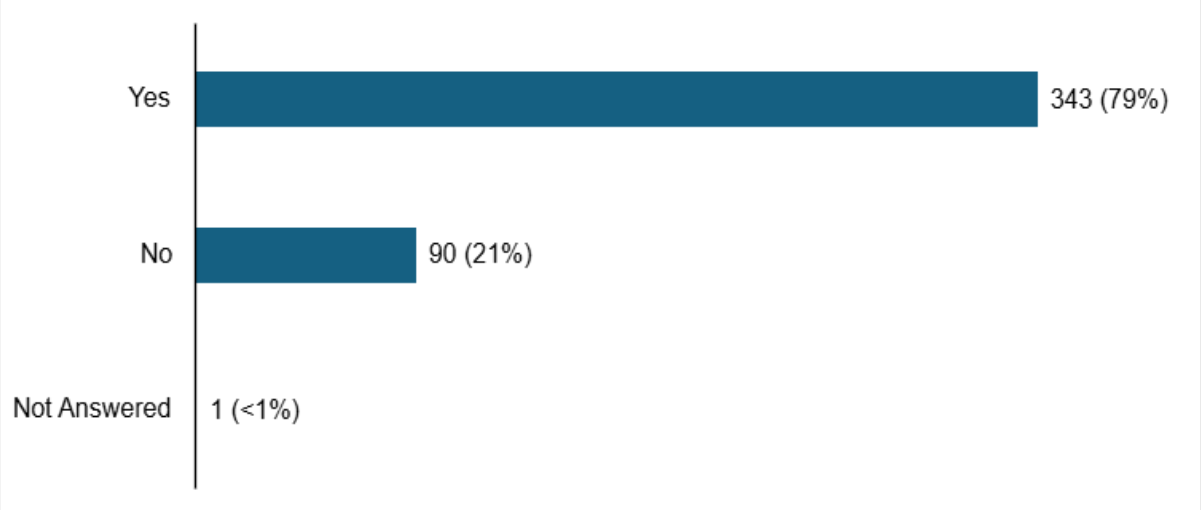
- 'A small number' - up to 5 respondents
- 'A few' - between 6 and 9 respondents
- 'A small minority' - more than 9 respondents but less than 10%
- 'A significant minority' - between approximately 10-24% of respondents
- 'A large minority' - more than a quarter of respondents but less than half
- 'A majority' - more than half

This document reports on responses to each of the questions in turn, in the order in which questions were asked in the survey.

QUESTION 1: HAVE YOU HAD A BABY ADMITTED TO A NEONATAL UNIT? (433 responses)

A total of 433 responses were received to this question. Over three-quarters of respondents (79%) reported that they had a baby admitted to a neonatal unit.

Figure 1: Have you had a baby admitted to a neonatal unit?

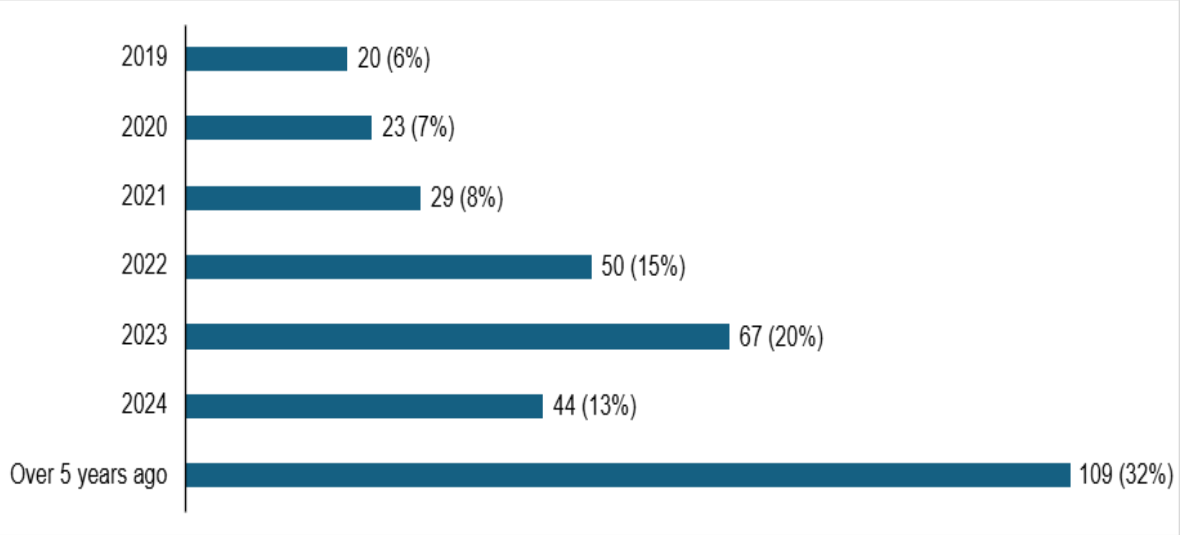


QUESTION 2: IF YES, FOR THE MOST RECENT ADMISSION, WHAT YEAR WAS YOUR BABY ADMITTED TO NEONATAL CARE? (342 responses)

Respondents who had a baby admitted to a neonatal unit were asked what year their baby was admitted. A total of 342 responses were received to this question.

There was a spread of respondents, from those who had very recent experience of neonatal care to those whose baby was admitted more than 5 years ago. A third of respondents (33%) had their baby admitted in the last couple of years, with 20% reporting that their baby was admitted in 2023 and 13% in 2024. Just under a third of respondents (32%) reported that their baby was admitted over 5 years ago.

Figure 2: For the most recent admission, what year was your baby admitted to neonatal care?

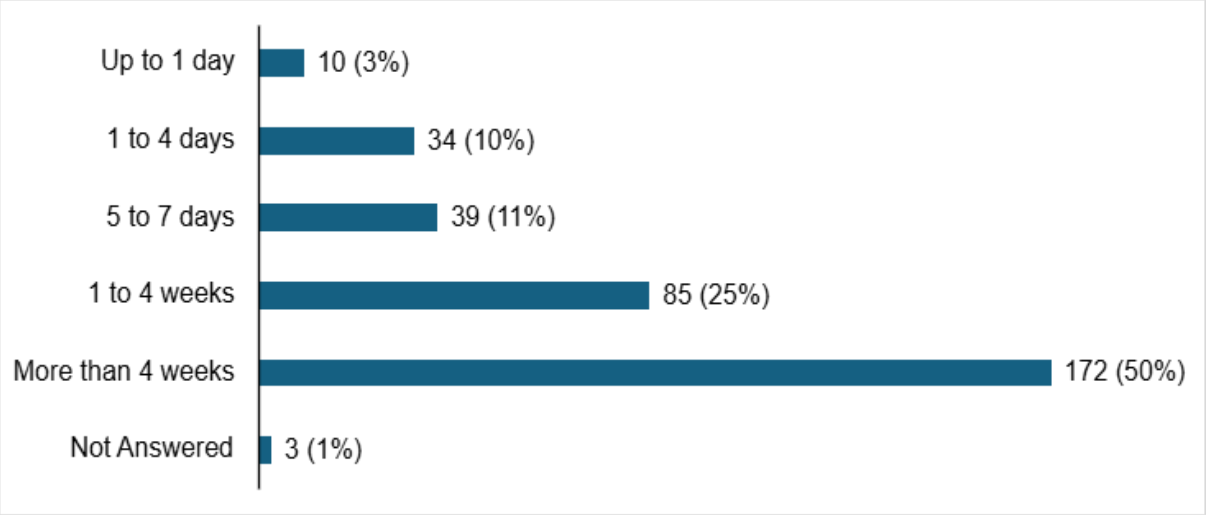


QUESTION 3: IF YES, FOR THE MOST RECENT ADMISSION, HOW LONG DID YOUR BABY SPEND TIME IN THE NEONATAL UNIT? (340 responses)

Respondents who had a baby admitted to a neonatal unit were asked how long their baby spent in the neonatal unit. A total of 340 responses were received, with 3 respondents who had a baby admitted opting not to answer this question.

Half of respondents (50%) reported that their baby spent more than 4 weeks in the neonatal unit, and a quarter (25%) reported that their baby spent 1 to 4 weeks in the neonatal unit. Just under a quarter (24%) reported that their baby spent up to a week in the neonatal unit, with 3% spending up to 1 day, 10% spending 1 to 4 days and 11% spending 5 to 7 days.

Figure 3: For the most recent admission, how long did your baby spend time in the neonatal unit?

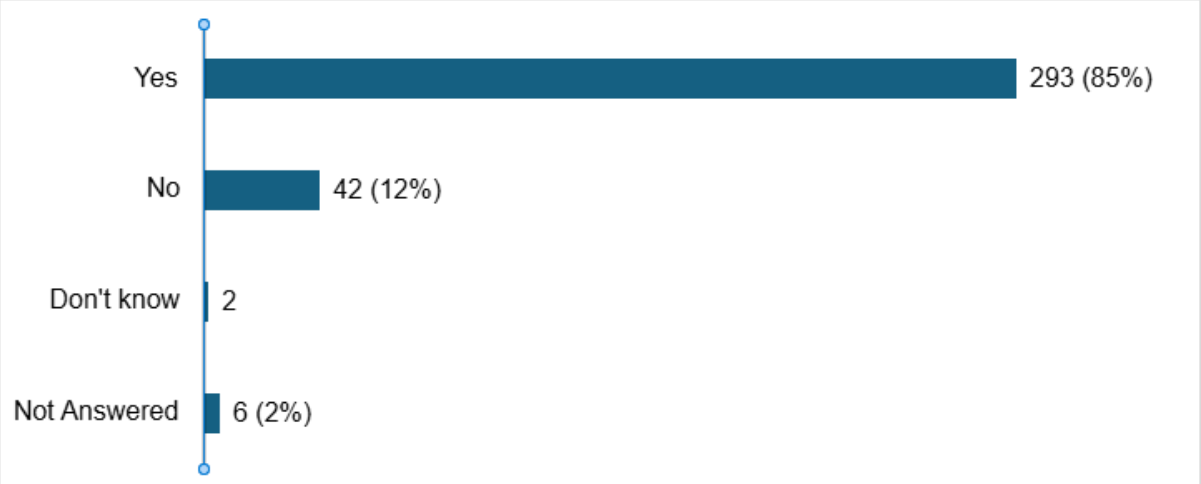


QUESTION 4: WAS YOUR BABY CARED FOR IN THE NEONATAL UNIT WITHIN YOUR HOME HEALTH BOARD AREA? (338 responses)

Respondents who had a baby admitted to a neonatal unit were asked whether their baby was cared for in the neonatal unit in their home health board area. A total of 338 responses were received with 5 respondents who had a baby admitted opting not to answer this question.

The vast majority of respondents (85%) reported that their baby was cared for within their home health board area. Just over a tenth (12%) reported that their baby was not cared for within their home health board area.

Figure 4: Was your baby cared for in the neonatal unit within your home health board area?

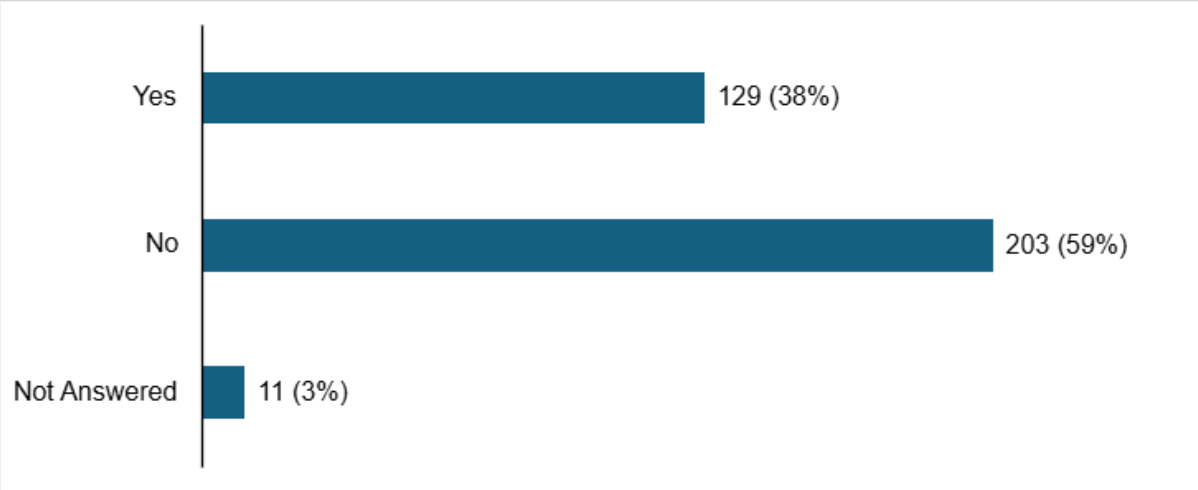


QUESTION 5: WAS THERE ANY SUPPORT THAT WOULD HAVE BEEN HELPFUL FOR YOU DURING THIS TIME THAT WAS NOT AVAILABLE? (332 responses)

Respondents who had a baby admitted to a neonatal unit were asked whether there was any support that would have been helpful during that time that was not available. A total of 332 responses were received with 11 respondents who had a baby admitted opting not to answer this question.

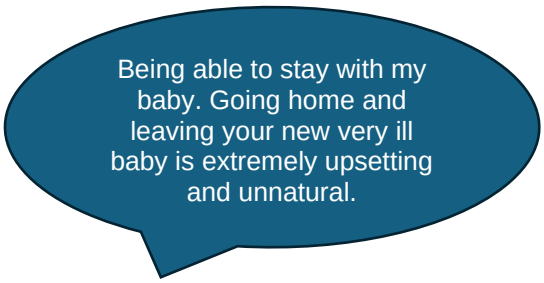
Over a third of respondents (38%) reported that there was support that would have been helpful that was not available, while almost two-thirds (59%) reported that there was not.

Figure 5: Was there any support that would have been helpful for you during this time that was not available?



Respondents who answered “No” to Question 5 were then asked to specify what support would have been helpful. A total of 148 responses were received.

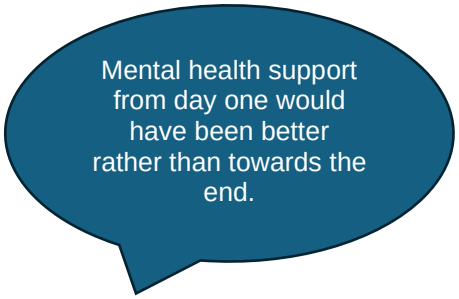
Respondents suggested a range of support that would have been helpful that was not available to them.

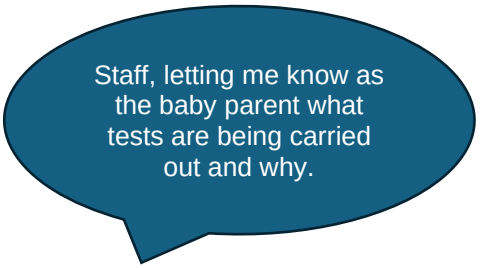


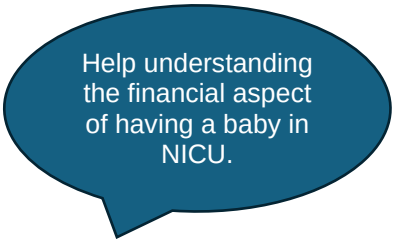
Nine overarching themes were identified through open text responses to this question, which have been ordered from most to least frequently mentioned. They were -

- **accommodation for parents and families at the neonatal unit** for the duration of their stay, suggested by a large minority of respondents.

- **better communication from healthcare staff** in the neonatal unit - including in relation to feeding, medical treatment and outcomes, and transfer. This was suggested by a significant minority of respondents.
- **feeding support** - including more support with establishing feeding, greater breastfeeding expertise among staff in the neonatal unit and ensuring mothers are close to the baby to enable breastfeeding. This was suggested by a significant minority of respondents.
- **financial support for parents** - including for travel, food and parking costs. This was suggested by a significant minority of respondents.
- **mental health support for parents** – including emotional and mental health support while their baby is in the neonatal unit and after they return home. This was suggested by a significant minority of respondents.
- **support for parental involvement in their baby's care** to support bonding. This was suggested by a few respondents.
- the need for **extended maternity and/or paternity leave** for parents of a baby in the neonatal unit. This was suggested by a few respondents.
- **greater capacity and/or beds in hospitals close to the parents' home.** This was suggested by a small number of respondents.
- **community services and sources of support**. This was suggested by a small number of respondents.







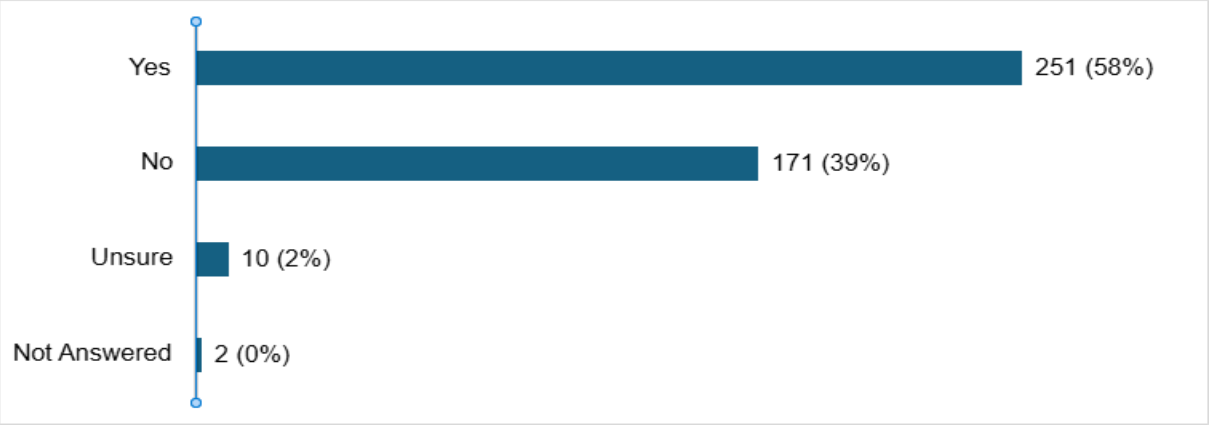
A significant minority used their response to this question to raise an objection to the new model. Concerns that were raised include:

- the potential for parents to be long distances from their baby under the new model of neonatal care.
- the perceived closure or reduction in service at specific neonatal units, including at University Hospital Wishaw.

QUESTION 6: PRIOR TO ANSWERING THIS SURVEY, HAD YOU HEARD OF THE NEW MODEL OF NEONATAL CARE? (432 responses)

All respondents were asked whether, prior to answering the survey, they had heard of the new model of neonatal care. A total of 432 responses were received to this question. Of these, almost three-fifths (58%) had heard of the new model of neonatal care, and two-fifths had not (39%).

Figure 6: Prior to answering this survey, had you heard of the new model of neonatal care?

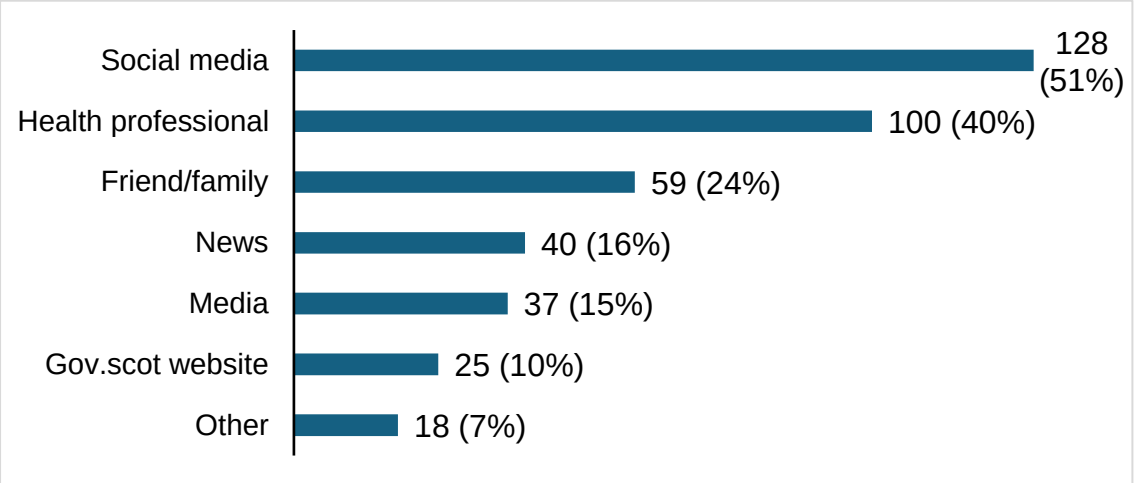


QUESTION 7: IF YOU ANSWERED YES TO QUESTION 6, WHERE DID YOU HEAR ABOUT THE NEW MODEL OF NEONATAL CARE? (281 responses)

Respondents who reported that they had heard of the new model of neonatal care prior to answering the survey were asked where they had heard about it. Respondents were asked to select all that applied from a series of 7 response options. There was a total of 281 responses to this question, of which 251 answered "Yes" to Question 6. Only responses from those who selected "Yes" to Question 6 are presented, although the overall pattern is the same when all 281 responses are included.

The most commonly reported ways in which respondents had heard about the new model of neonatal care were via social media (51%) and via a health professional (40%). Just over a quarter selected friends / family (24%), Smaller proportions selected news (16%), media (15%) and the Gov.scot website (10%).

Figure 7: Where did you hear about the new model of neonatal care?



Respondents who selected 'Other' were asked to specify where they had heard of the new model of neonatal care.

A total of 34 responses were received, indicating that respondents in addition to those who selected 'Other' responded to this question.

The most common way that respondents heard about the new model of neonatal care was through a third sector organisation, noted by a few respondents, and through health professionals or while in hospital, noted by a small number of respondents. A small number of respondents reported other online sources, and a small number noted that they had been made aware through campaign groups.

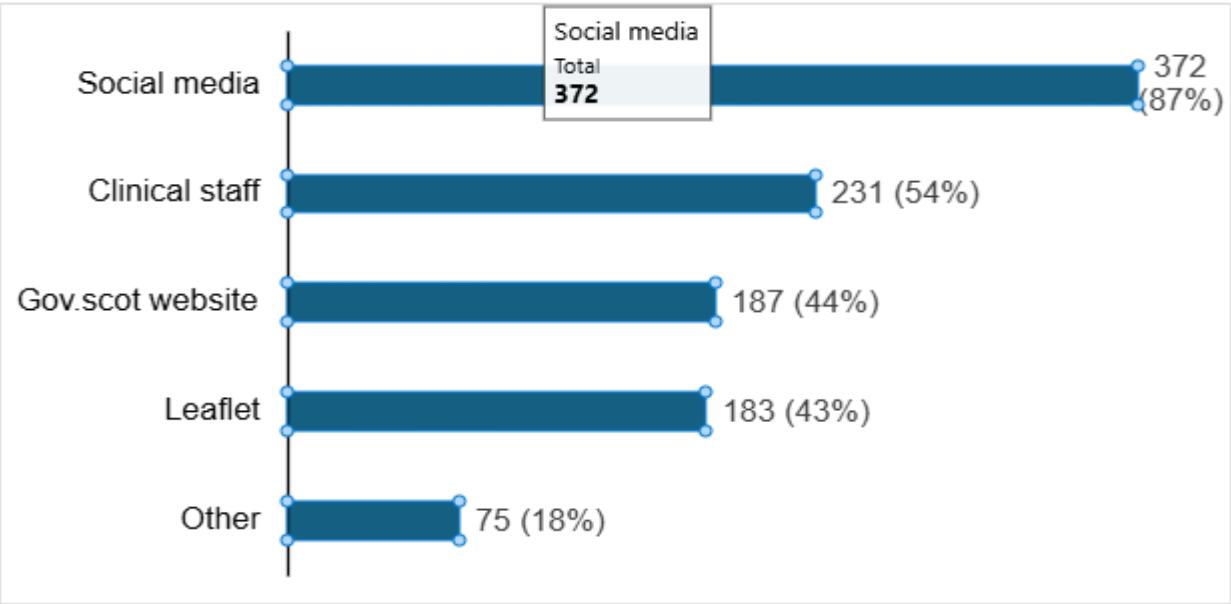
A small number of respondents used this question to raise an objection to the new model, echoing the themes raised in response to Question 5.

QUESTION 8: HOW DO YOU THINK INFORMATION ABOUT THE NEW MODEL OF NEONATAL CARE CAN BE BEST COMMUNICATED TO MEMBERS OF THE PUBLIC? (426 responses)

All respondents were asked how they think information about the new model of neonatal care can be best communicated to members of the public. Respondents were asked to select all that applied from a series of 5 response options. There were 426 responses to this question.

The most commonly selected option was social media selected by 87% of respondents. Just over a half (54%) selected clinical staff. Just over two-fifths selected Gov.scot website (44%) and leaflet (43%).

Figure 9: How do you think information about the new model of neonatal care can be best communicated to members of the public?



Respondents who selected 'Other' were asked to specify how they think information about the new model of neonatal care could be best communicated to members of the public. A total of 111 responses were received, indicating that respondents in addition to those who selected 'Other' responded to this open question.

A number of ways that the new model of neonatal care could be communicated to members of the public were suggested.

In addition, a small minority of respondents highlighted that neonatal care is not discussed during pregnancy, with some respondents commenting that they would like to have been told what neonatal care is and possible situations that could lead to the baby having to be sent there to be explained at midwife appointments.

The most common suggestion was communication through healthcare staff, including midwives and health visitors, which was suggested by a large minority of respondents.

A small minority of respondents suggested:

- news outlets
- GPs and health centres

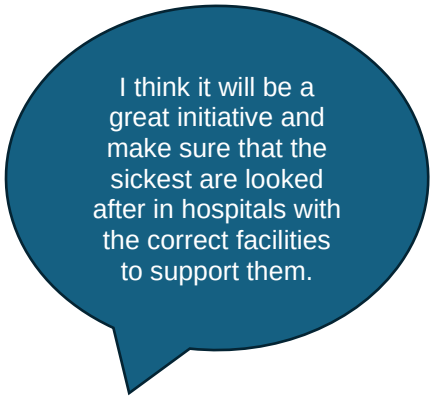
A few respondents suggested third sector organisations.

A small number of respondents suggested:

- social media
- leaflets
- politicians
- e-mail communication
- childcare/educational settings

> All parents should be made aware of what neonatal care is during pregnancy, so it's less of a scary unknown when it happens to you.

QUESTION 9: DO YOU HAVE ANY QUESTIONS ABOUT HOW THE NEW MODEL OF NEONATAL CARE WILL WORK IN PRACTICE? (237 Responses)



A significant minority of respondents raised questions and comments on the following topics:

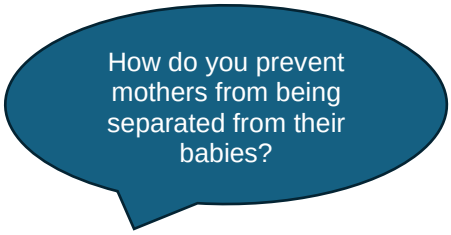
- the impact of separating mother and baby, for example disrupting the breastfeeding journey
- the logistics of transferring babies to a neonatal unit following birth, including perinatal deaths due to transfer; and transfer time being affected if there was a road traffic incident.
- the importance of access to a support network for parents of babies receiving neonatal care, including support from other family members

A small minority raised questions and comments on:

- the lack of available support and childcare for siblings at home while parents are within the neonatal unit.
- the importance of facilities and accommodation for parents and families in or close to the neonatal unit
- what the existing evidence base is for the new model of neonatal, whether evidence has been taken into account and/or the importance of engaging with parents and clinicians to build the evidence base
- the potential for negative clinical outcomes for babies receiving care under the new model of neonatal care.
- the potential for negative impacts for neonatal staff working under the new model of neonatal care and the potential for negative impacts on workforce recruitment and retention.
- the need for mental health support for parents and families

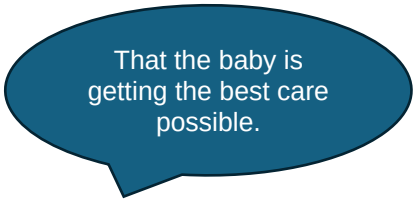
A significant minority used their response to this question to raise an objection to the new model. Specific concerns that were raised include:

- Risks around the transfer of mothers and babies
- Lack of neonatal care provision in certain geographic areas, including concerns regarding the neonatal unit at Wishaw
- The need for mother and baby to stay together in the same hospital, and for the baby's other parent and wider family to visit
- The potential for staff de-skilling in the local neonatal units



QUESTION 10: WHAT DO YOU THINK ARE THE MOST IMPORTANT CONSIDERATIONS THAT NEED TO BE TAKEN INTO ACCOUNT WHEN PLANNING IMPLEMENTATION OF THE NEW MODEL OF NEONATAL CARE? (394 responses)

Keeping families together and not separating mother and baby was most commonly raised as the most important consideration that needs to be taken into account when planning the implementation of the new model of neonatal care. This was raised by a large minority of respondents.



This was followed by:

- **the need to minimise the distance that parents and/or families need to travel** from home to the neonatal unit, raised by a large minority of respondents.
- **the provision of mental health/psychological support** to parents, raised by a significant minority of respondents.
- **ensuring that parents have close geographical proximity to their support network** including family and friends, raised by a significant minority of respondents.
- **minimising clinical risks to baby**, raised by a significant minority of respondents.
- **hospital / unit capacity**, including ensuring sufficient cot availability, raised by a significant minority of respondents.
- **financial impacts for parents and families**, raised by a significant minority of respondents.
- **childcare for siblings**, raised by a small minority of respondents.
- **parental leave from work**, raised by a small minority of respondents.

QUESTION 11: WHAT SUPPORT DO YOU THINK PARENTS WILL MOST NEED IF THEIR BABY NEEDS TO SPEND TIME FURTHER FROM HOME IN A NEONATAL INTENSIVE CARE UNIT? (411 responses)

The majority of respondents to this question suggested accommodation for parents and families as the support they will need most if their baby needs to spend time further from home in a neonatal care unit.

This was followed by general financial support and mental health support, which was raised by a large minority of respondents.

A significant minority of respondents made suggestions under the following themes:

- travel expenses
- support from family and friends
  childcare for siblings
  a neonatal unit close to home and their support network
- meals for parents while at the neonatal unit
- keeping mother and baby together

A small minority of respondents suggested:

- parental leave from employment
- reimbursement for loss of earnings
- better communication from healthcare professionals at the neonatal unit and access to technology that would enable virtual contact with their baby.

A small number of respondents suggested reimbursement for household expenses.

A significant minority used their response to this question to raise their concerns, including: -

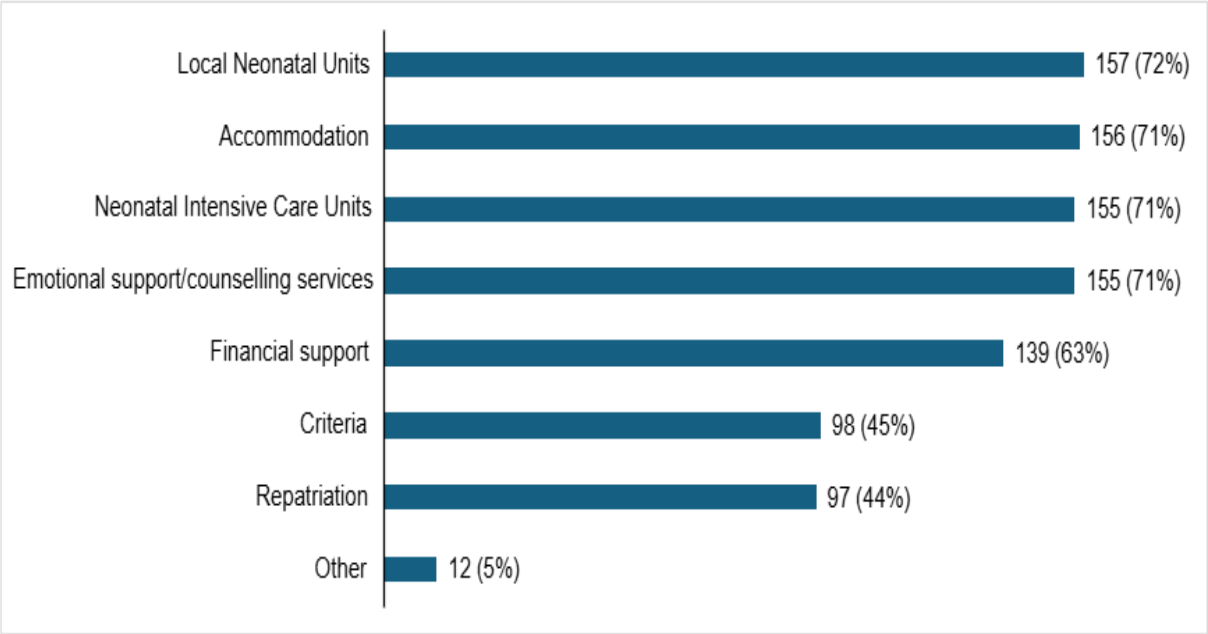
- feeling that there is not any support that is appropriate and that splitting a family up at this time is both cruel and unnecessary.
- families should be close by and able to return to their own home at night whilst knowing that they were only a short journey away if there was a deterioration.

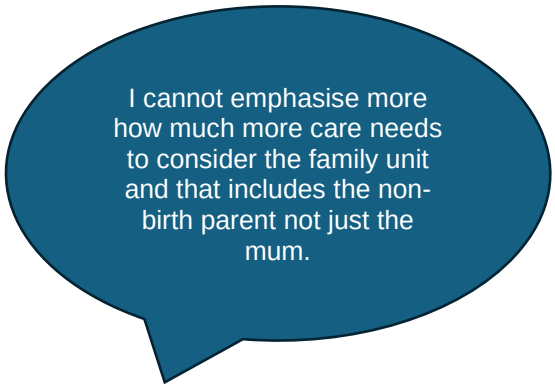
QUESTION 12: WOULD YOU LIKE ANY FURTHER INFORMATION ON ANY OF THE FOLLOWING AREAS OF THE NEW MODEL OF NEONATAL CARE? PLEASE SELECT ALL THAT APPLY (219 responses)

All respondents were asked to select the areas where they like more information about the new model of neonatal care. Respondents selected all that applied out of 8 response options. A total of 219 responses were received to this question.

Just under three-quarters of respondents selected Local Neonatal Units (72%), accommodation (71%), Neonatal Intensive Care Units (71%), and emotional support/counselling services (71%). Just over two-thirds selected financial support (63%) and just under half selected criteria (45%) and repatriation (44%).

Figure 10: Would you like any further information on any of the following areas of the new model of neonatal care?





Respondents who selected 'Other' were asked to specify what additional information they would like. A total of 15 respondents answered this question, indicating that respondents in addition to those who selected 'Other' responded to this open question.

A small number of respondents said:

- more information about all options listed e.g. childcare for older siblings, figure regarding predicted impact on maternity and ambulance services
- availability of Allied Health Professional (AHP) services
- help or healthy meals and snacks.

QUESTION 13: DO YOU HAVE ANY OTHER FEEDBACK YOU WOULD LIKE TO SHARE WITH US ON THE NEW MODEL OF NEONATAL CARE? (195 responses)

Almost all respondents to this question raised an objection or concern with the new model of neonatal care. The majority of respondents raised a general objection that did not focus on any specific concern. Where specific concerns were raised, these focused on the following perceptions:

- **negative impacts on families** e.g. parents being separated from older children whilst their baby is in the neonatal unit, raised by a significant minority of respondents.
- **clinical concerns for babies and clinical risks around the transfer of babies** to the neonatal unit after birth, e.g. not sufficient time for transfer between units, raised by a small minority of respondents.
- **negative impacts on staff**, e.g. how staff will remain skilled when their skills are not being used, raised by a small minority of respondents.

A small number of respondents mentioned support for the new model of neonatal care or expressed a need to promote understanding of what the model will involve.

YOU SAID, WE DID

The information collated has now been provided to the three Regional Chief Executives, the Regional Planners, the Young Patient Family Fund Leads and the neonatal community, all of whom will work together to ensure implementation of the new model of neonatal care

As part of developing the outcomes (the improvements we want to see) and the actions (how we will get there), we will take account of the key feedback themes outlined in this report.

In addition, we would like to update on some of the progress made to date.

Evidence

You said

- why are you changing the way neonatal care is provided in Scotland?

We did/We are doing

- due to pioneering advances in medical care, babies born at the extremes of prematurity today stand a much better chance of healthy survival
- the 'Best Start' considered evidence which showed improved outcomes for the very smallest and sickest babies when they are cared for in units with higher volume throughput. These are babies who are born at less than 27 weeks' gestation, weigh less than 800 grams, or who need multiple complex intensive care interventions or surgery
- this recommendation is aimed at the most premature and sickest of babies and is based on a review of evidence, (carried out by Dr Anna Gavine, Dr Steve MacGillivray and Prof Mary Renfrew of the University of Dundee and published alongside the 'Best Start')
- the evidence showed that outcomes for very low birth weight babies (VLBW) are better when they are delivered and treated in NICUs with full support services, experienced staff and a critical mass of activity and supported by the publication of the BAPM Service Quality Standards (British Association for Perinatal Medicine))
- In 2019, NHS England also published implementing the Recommendations of the Neonatal Critical Care Transformation Review

Communication

You Said

- Scottish Government and NHS Boards need to consider how appropriate information on neonatal care could be shared with all pregnant women, especially those with a higher risk of a premature birth or complications

- different levels of detail should be provided at different times – a need to be respectful of the headspace the parents are in at a time of great stress and anxiety

- consider how Badger, vCreate and similar apps can be used to share clinical information between different health boards, be adapted to send prompts to parents and share information with the wider family

- communication, both from hospital staff and access to IT communication (e.g. video link to their baby)

- where appropriate and with parents' consent, share supporting information with wider family so tasks can be delegated, or there can be a second pair of ears

We did/we are doing

- Ready Steady Baby! is your guide to pregnancy, labour and birth and early parenthood up to 8 weeks. Information on neonatal care can be found at Babies who need extra care | Ready Steady Baby! (nhsinform.scot)

- We have updated Parent Club website Premature babies | Parent Club to provide additional information to parents who may require information on neonatal care in Scotland.

- the Neonatal Care: Information Leaflet for women in Scotland provides information for families on the new model of care, different levels of care and where care is provided, and what to expect in the event of the need to transfer mother and/or baby and has been added to BadgerNet Maternity App.

- in January 2024, the Scottish Perinatal Network Family Integrated Care (FICare) group hosted a FICare Day at the V&A museum in Dundee with the aim of developing a national strategy for standardising family integrated care in Scotland. The event brought together a variety of multidisciplinary healthcare professionals as well as by a number of families (including some NICU graduates themselves!) and third-sector groups. Five key focus areas were identified: unit access, unit orientation, unit transition and discharge, psychological support and allied health professionals. Within the Scottish Perinatal Network FICare group, dedicated short life working groups have been formed to address each area

- ahead of the event, more than sixty families with neonatal care experience completed a questionnaire exploring their experiences. Key themes in the

responses were lack of preparation for a move between units, the physical transfer of their baby with the neonatal transport team and the challenges of transition to a new neonatal unit.

- These themes aligned with those in the Scottish Government neonatal care qualitative research debrief which also highlighted the need for practical parent information, reassurance on how babies will be moved and concerns about accommodation and sibling care. These insights have shaped the focus of new resources

- The Scottish Perinatal Network has launched a new, easily accessible resource developed for neonatal unit parents in Scotland. The resource has been designed collaboratively by parents and healthcare staff from across Scotland, in response to parental feedback. It brings together essential practical information to support parents during their time in the neonatal unit. We know navigating a neonatal unit stay and moves between neonatal units can be challenging and we hope this helps to make the journey a little bit easier. Information is available for all Neonatal Units and Paediatric Intensive Care Units (PICUs) in Scotland and is accessible on the Scottish Perinatal Network webpage. Neonatal Units - Scottish Perinatal Network

- The Scottish Government has funded the use of vCreate a secure video messaging service – in neonatal units. VCreate continues to play a vital role in keeping families connected to their baby, especially when they are unable to be physically present. Video and photo updates offer reassurance, help reduce anxiety for families who may feel distanced and can support breast milk expression. Updates not only provide a sense of connection but also act as 'diary' documenting key milestones and moments during the baby's time in the unit. Families can choose to share these updates with relatives and friends ensuring that no one misses out on these significant moments

- this system has led to the introduction of many new features including vCreate's multi-language tool, enabling the auto-translation of messages and forms into 12 different languages to better support patients and families whose first language is not English

- information technology systems spanning the whole care spectrum are viewed as essential by staff to deliver streamlined care with the new proposed model. Most NHS Boards have an electronic maternity system in place or are in the process of procuring or installing a system. In neonatal care, almost every unit is Scotland is operating on the BadgerNet system. BadgerNet records data about the baby and the care received

Financial Assistance/Accommodation

You said

- There is a need for accommodation onsite or close to the Neonatal Unit
- Parents require financial support to cover costs incurred while their baby is in the neonatal unit, including for accommodation, travel, food, and to compensate for loss of earnings
- provide information/advice on accommodation, transportation, and sibling childcare as soon as parents know they are travelling to neonatal intensive care
- Parents would like assistance in caring for siblings, including the provision of childcare or whole family accommodation
- Parents would like to be in close geographical proximity to family and friends
- Can Scottish Government extend maternity and paternity leave

We did/we are doing

- the Young Patients Family Fund provides reimbursement of travel, food and accommodation costs for parents with babies in neonatal care to ensure those parents can be with their babies. In addition, NHS Board accommodation is available to parents/carers, and this should be accessed in the first instance. NHS Boards can organise accommodation for you and your family
- Health Boards will endeavour to include the fundamental principles of keeping mother and baby together, positioning parents as partners in decision-making around the baby's care, parents providing as much care as possible for their own babies and having regular communication between partners and clinical staff
- the key features of the family-centred model are:
    - the further development of a model of neonatal care across Scotland that keeps mothers and babies together in a postnatal ward when the baby has modest additional care needs and minimises the need for admission to a neonatal unit
    - the provision of care for all babies as near to home as possible, while recognising that a small number of the most vulnerable preterm babies and the sickest term babies in need of complex care will receive some of their neonatal care in one of a smaller number of neonatal intensive care units. When this happens parents will be supported to be with their babies
    - the development of clear, agreed pathways for babies to be returned to their local or special care neonatal unit (or, if possible, home), following treatment in a neonatal intensive care unit or local neonatal unit

- parents must be involved in decision-making throughout and particularly in the practical aspects of care as much as possible. This includes encouraging kangaroo skin-to-skin care and early support for breastfeeding
- the provision of support and facilities to allow parents to spend as much time with their babies as possible while they are in neonatal care, including the provision of overnight accommodation
- the development of a model of early discharge for babies who have additional care needs who can be safely managed in the community

- employment law, including the provision of neonatal leave and pay is a matter reserved to the UK Government and as such the Scottish Government does not have the power to implement changes to provision for Scotland.

- however, the Neonatal Care (Leave and Pay) Act 2023 received Royal Assent on 24 May 2023 and came into force on 6 April 2025. It is available to employees from their first day in a new job for leave and after 26 weeks service for pay. It applies to parents of babies who are admitted into hospital up to the age of 28 days, and who have a continuous stay in hospital of 7 full days or more. It provides parents with a right to 12 weeks' leave and pay when their baby requires neonatal care in addition to existing parental leave entitlements.

- the Scottish Government strongly believes that everyone should have access to reasonable support from employers when they become parents and support a gender-balanced use of employee benefit and family-related leave. This can help prevent parents from feeling forced to go back to work before either they or their baby is ready and additionally ease the financial burden.

- we will continue to work with the UK Government and to look for ways to ensure that pregnant women and new parents are not disadvantaged at work.

Mental Health Support

You said

- Parents require emotional and mental health support while their baby is in the neonatal unit and when they return home

- prioritise mental health/emotional support communications, and particularly those that help parents recognise their needs

- offer mental health and emotional support to parents who have experienced trauma in neonatal intensive care and are pregnant again

We did/we are doing

- you can find out which services are available in your Health Board (pages 12 – 34). Health Boards strive to continuously update and improve these services - Perinatal and infant mental health services: update - gov.scot

- recommendation 37 of the A The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland request that all NHS Boards should review their current access to perinatal mental health services to ensure early and equitable access is available to high quality services, with clear referral pathways. NHS Boards should ensure adequate provision of staff training to allow staff to deliver services to the appropriate level. Primary midwives, in partnership with primary care colleagues, should play a proactive and systematic role in the identification and management of perinatal mental health care

- recommendation 38 asked that the Scottish Government should ensure that Perinatal Mental Health is a key focus in the Mental Health Strategy: 2017-2027 , and that appropriate connections are made with the new models of care described here in that strategy. Page 24 refers

- recommendation 30 - Each unit must identify a lead obstetrician who has, or who will develop, appropriate expertise in fetal medicine. There must be good ongoing communication with, and information for, parents as well as robust referral pathways in each NHS Board to ensure strong links between local and regional/ national centres

We thank everyone who took part in the survey.

ANNEX A - WHICH NHS BOARD YOU LIVE IN?

Option	Total	Percent
NHS Ayrshire & Arran	8	2%
NHS Borders	3	1%
NHS Dumfries & Galloway	4	1%
NHS Fife	26	6%
NHS Forth Valley	10	2%
NHS Grampian	46	11%
NHS Greater Glasgow and Clyde	35	8%
NHS Highland	8	1%
NHS Lanarkshire	179	41%
NHS Lothian	23	5%
NHS Orkney	1	<1%
NHS Shetland	3	1%
NHS Tayside	83	19%
NHS Western Isles	0	0 %
I do not live in Scotland	0	0%
Do not wish to provide	4	1%
Not Answered	1	<1%
Total	**433**	**100%**

ANNEX B - QUALITATIVE RESEARCH SUMMARY - FOCUS GROUPS

Background and method

Eight online focus groups were held in August 2024, with representation from eleven local authority areas. Participants included those with lived experience of neonatal care in Scotland as well as relevant charities and representatives from the healthcare sector (nurses and psychologists from neonatal wards). Those with lived experience had previously completed a quantitative survey exploring their experiences of neonatal care and had agreed to be recontacted for further research. A majority of this sample were females with a minority of male partners represented.

The qualitative research explored three topic areas in relation to lived experience of Neonatal Care in Scotland - Financial Support, Mental Health and Communication Needs. The research was carried out by the Strategy and Insight Team within Scottish Government Communications. Insight from this research informed implementation plans for the roll-out of the new model of neonatal care across Scotland.

General views of neonatal care

Expert, compassionate care from hospital staff was consistently mentioned – a majority thought that staff went 'over and above' for them at every opportunity. They felt looked after.

Many attendees were worried about neonatal units being downgraded (reducing the range of facilities currently available). There was concern that downgraded units could put increased strain on neonatal care, with worry that parents needing the highest level of care could be neglected. Transport was another key theme, particularly in the context of the stress and anxiety of transferring their baby to a new hospital.

Financial Support – Young Patients Family Fund (YPFF)

Most of the sample were aware of the fund and among those who had made a claim, many were positive about it. There was a feeling that it contributed to reducing financial related stress. Take-up was encouraged by staff in the neonatal ward.

While there was a desire to be made aware of the fund as soon as possible (but with minimal information), day 4 - 6 of being in the unit was felt to be the optimum time to digest fund information, after any initial shock had subsided. The biggest barrier to claiming is perceived stigma and the feeling that others need the financial support more than they do.

The attendees noted the importance of continually reminding parents about the fund throughout their time in the neonatal ward (as many didn't understand how long they could be in for), communicating that you don't have to claim right at the end – you can claim partway through (to help with cashflow) and highlighting that the fund covers themselves, partner and any other children they may have.

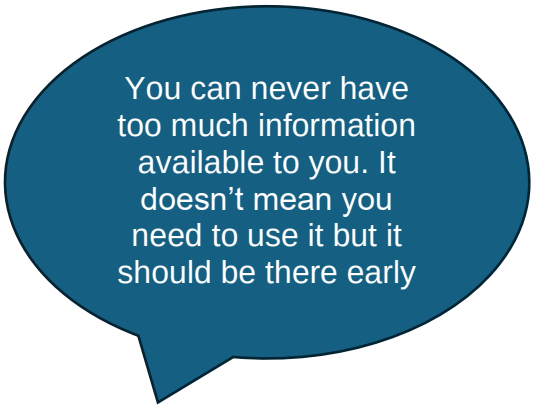
Mental health and emotional support

Most of the sample had received mental health support and accessed this through ward psychologists. There was effusive praise of this, in particular: visibility of psychologists, being able to access support after discharge, continuity of care, both parents being included, response times, availability of appointments, wider clinical team awareness and wider support from all staff.

All agreed that mental health and emotional support is 'vital' for parents in neonatal care. Attendees felt that this support should be prioritised above other support services and offered immediately after admission.

Communications needs

Attendees noted the need for parental information about the hospitals where their baby would be receiving neonatal intensive care such as the transfer process, facilities (including sustenance, accommodation and sibling care) and the team, and information about expectations of the parents including expressing milk and cleaning the pump.



Recommendations to come from the research in relation to communications generally, include the following:

- personalising information as much as possible.
- communicating through neonatal ward posters (which was felt to be highly effective).
- considering the use of different levels of detail in communications, to cater for different appetites for and ability to consume information at different times.
- communicating information on accommodation, transportation and sibling childcare.
- prioritising mental health/emotional support communications overall.
- highlighting mental health and emotional support to parents who have experienced trauma in neonatal intensive care and are pregnant again.