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North West Safe and Sustainable Specialised Health Services for Babies & Children

North West Neonatal Critical Care Review

Report into findings of parent/carer research on the Case for Change and experiences of care

June 2026

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1 INTRODUCTION

Background and context

1.1 Introduction

This report set out the findings of a qualitative engagement exercise to understand the views of parents and carers on the Case for Change for improving neonatal services in the North West. This document was first published in April 2023, and updated in December 2025 by NHS England North West, on behalf of the North West Safe and Sustainable Specialised Health Services for Babies & Children programme team.

The aim of this engagement exercise was to involve parents in the neonatal service transformation process at an early stage, in order to help inform any future options development work. It is therefore only the starting pointing for wider and deeper discussions on the future of North West neonatal critical care.

Some of the patient experience insights gathered will also be used to help inform ongoing neonatal service improvement already work being undertaken by the North West Neonatal Operational Development Network (NWNODN).

1.1.1 Background to the study

The NHS is seeking to improve neonatal services across the North West of England. Currently, some neonatal units do not meet national NHS standards, leading to inconsistent care and outcomes for newborns who are seriously unwell due to factors such as premature birth, low birth weight, or other complications. There are also disparities in the level of specialist care and a mismatch in the number and level of cots to meet demand. Research shows that babies cared for in busy units have much better outcomes than babies cared for in smaller units.

The aim is to enhance the quality, consistency, and sustainability of neonatal care so that all babies and families across the region receive equally high standards of treatment.

As well as the full Case for Change, a shorter summary version has been developed in plain English, which was used to help guide engagement with staff and parents or carers who have experience of these services.

There are four different types of neonatal units provided in the North West, including:

- **Neonatal Intensive Care Units (NICU)**

A NICU unit provides the highest level of care (known as ‘level 3’ care) to the most seriously unwell and/or prematurely born babies, who require ‘intensive care’ and treatment. These units are staffed by a specialist team who are trained with a very high level of expertise in neonatal medicine, and work closely with other specialists, such as fetal medicine and maternity teams. They also provide high dependency and special care for babies.

A NICU provides care for babies who are: born very prematurely or very sick, need prolonged support with breathing (including needing a ventilator), or have complex medical conditions.

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- **Local Neonatal Units (LNU)**

An LNU is a unit that provides 'high dependency' care (known as 'level 2') for babies who need specialist medical support, but do not need to be on an intensive care unit. These units can also provide some very short-term intensive care support, if required, but usually only for up to 48 hours. They also provide special care for babies. However, they cannot support the most seriously unwell babies.

An LNU provides care for babies who are: moderately premature, need support with feeding or temperature, have breathing difficulties requiring short term support, or need treatment such as antibiotics or monitoring.

- **Special Care Units (SCU)**

An SCU is a unit that is only able to provide a more basic level of neonatal care (known as 'level 1') to babies. These units provide support for babies that do not need intensive care or high dependency care but do still require more monitoring and support than is possible on a normal hospital maternity ward. This is known as 'special care'.

A SCU provides care for babies who are: slightly premature, need help with feeding, need monitoring for jaundice or weight gain, or need treatment such as antibiotics or monitoring.

- **Surgical Neonatal Units (SNU)**

In addition to the above neonatal units, the North West also has two surgical neonatal units which provide very specialist surgical support to newborn babies needing operations. One of these units is based at the NICU at St Mary's Hospital in Manchester, and the other is a standalone unit at Alder Hey Children's Hospital in Liverpool.

An SNU provides care for babies who are: born with conditions that need surgery, or need specialist surgical treatment soon after birth

The Case for Change highlights the need for consolidating intensive and high dependency neonatal care in fewer, larger units across the North West. This aims to meet national activity standards, improve outcomes for babies, optimise specialist staff use, and address excess capacity where cot occupancy is low. What this might mean for local hospitals and families is as follows:

For local hospitals:

- Neonatal intensive care may be offered at fewer specialist centres.
- Some Local Neonatal Units could become Special Care Baby Units for babies needing less support.
- Specialist hospitals may increase capacity and staff.
- Maternity and neonatal services will need to coordinate more closely.

For families:

- Babies needing specialist care may need to be treated further from home.
- Babies needing lower levels of care can stay at local facilities.
- More mothers may be transferred to specialist hospitals before birth.
- More babies receiving more consistent, specialised care and better outcomes.

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1.2 Process

Fieldwork took place in March and April and consisted of:

- Three focus groups (one in each ICB area);
- One-to-one interviews (participants selected from across all ICB areas)

Recruitment to these discussions was supported by the NWNODN who provided initial contact information and introduced us as research partners. Due to time pressures, recruitment focused on:

- The Parent Advisory Groups (PAG) in Cheshire and Merseyside, and Lancashire and South Cumbria;
- Spoons, a neonatal charity in Greater Manchester who provide a similar function to the PAGs; and
- The Maternity and Neonatal Voices Partnership (MNVP) in East Lancashire.

This enabled rapid access to parents with recent neonatal experience. From this recruitment, there were a total of forty participants which included:

- Focus groups (29 parents in total):
    - Cheshire and Merseyside Parent Advisory Group (PAG) (n=8);
    - Greater Manchester (Spoons) (n=8); and
    - Lancashire and South Cumbria (n=13).
- One-to-one interviews (with 11 parents in total):
    - Cheshire and Merseyside (n=4);
    - Greater Manchester (n=5)
    - Lancashire and South Cumbria (n=2).

We took a trauma informed approach throughout the process, recognising the sensitive nature of the conversations. A trained member of our team was available to provide one to one support for any participants should they require it during discussions.

1.2.1 Research caveat

Findings are based on a small sample who are already active and informed on neonatal care in the North West and are not intended to be representative of all parents' experiences across the region.

It is also recognised that many of the episodes of care discussed by parents in this report happened a year or more ago, and therefore may not be fully reflective of latest arrangements or ongoing service improvement work that is already underway.

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1.3 Report structure

Following this introduction the remainder of this report is set out as follows.

Section Two: Provides a synthesis of the parent feedback as an emerging discussion of the current neonatal journey from the parent's perspective.

Section Three: Presents the main findings from discussions against the agreed lines of inquiry.

Section Four: Takes a deeper dive into the issues that informed the parent centred neonatal journey.

Section Five: Provides an overview of the findings of the discussions with parents overlaid onto the Case for Change for neonatal critical care in the North West.

Section Six: Sets out the summary, conclusions and outlines recommendations we have drawn from this exercise.

Appendix One: Provides a summary table mapping the main discussion themes from this exercise onto the Case for Change for neonatal critical care in the North West, supported by verbatim evidence from discussions.

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2 THE NEONATAL JOURNEY

A summary of reported experiences from respondents

2.1 Overview

This section provides an overview of parental experiences as a journey from early birth or illness in the context of the safety of the child, rather than a chronological account for an individual infant. This emerging 'composite' neonatal journey can be summarised in the following stages:

- Antenatal/before birth;
- Birth and admission;
- Early neonatal care;
- Stabilisation and ongoing care;
- Transfers, travel, and family logistics;
- Discharge; and
- After discharge.

At each stage of the journey, the core decision was the same:

"…what keeps the baby safest, and can the parent still remain an effective part of care?"

Throughout both group and individual discussions, a consistent theme emerged in which **parents consistently viewed clinical safety and family presence as interconnected rather than separate concerns.**

In discussions parents generally accepted the need for transfer, specialist escalation, and sometimes being farther from home when their child's safety and wellbeing required it. In this context (based on these discussions with a relatively small sample of parents) 'safe care' meant not only the right level of neonatal cot and the right specialist, but also the right explanation, the right handover, and the practical means to stay with baby.

The discussions with parents also suggest that the most frequent issues encountered were process and relational failures rather than formally logged physical harm events, namely:

- Separation from baby after birth, particularly for those people who gave birth, who were very unwell post birth or recovering from caesarean section;
- Separation from siblings while the infant receives neonatal care;
- Fractured and inconsistent communication between teams;
- Inconsistent communication to parents from staff;
- Late or absent interpreter use for those whom English is not their first language;
- Unclear repatriation;
- Variable standards between units;
- Staffing pressure;
- Weak discharge preparation;
- Inadequate accommodation;
- Unclear transfers; and
- Mental-health support that arrived too late or not at all.

Family Integrated Care (FiCare) was referred to by several parents in discussions as a model that would address these issues, and we have referenced this in the summary journey. FiCare is a neonatal care model that partners parents with healthcare

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professionals, transforming parents into primary caregivers rather than just visitors. This approach reduces parental stress, fosters close parent-infant interaction and shared decision-making.

2.2 Summary journey

The stages in the neonatal journey as described in our discussions with parents are summarised in the table below.

Journey stage	What parents describe	Safety concern (parent lens)	Enabling conditions (FiCare aligned)
Antenatal/before birth	Often unprepared; neonatal admission experienced as sudden and disorientating.	Parents cannot absorb or act on information; reduced ability to participate in care decisions.	Early education/awareness; staged information in plain language; early signposting to support.
Birth and admission	Crisis entry; potential separation; urgent decisions and rapid clinical action.	Separation and unclear rationale undermine trust and increase distress at critical moments.	Clear transfer/admission briefings; proximity planning; early opportunities for contact.
Early neonatal care	Information overload; jargon; uneven understanding within families; reliance on self-interpretation.	Misunderstanding care plan and terminology; barriers to informed participation and consent.	Plain-English communication standard; interpreter pathways; repeat explanations and comprehension checks.
Stabilisation and ongoing care	Parents want to be treated as parents, not visitors; involvement improves confidence.	Exclusion leads to helplessness and reduced preparedness; inconsistency across shifts/units increases anxiety.	Embed FiCare as standard; consistent involvement expectations; staff support and facilities that enable presence.
Transfers, travel, and family logistics	Travel, parking, accommodation, childcare and work pressures shape ability to stay involved.	Reduced presence undermines FiCare and bonding; inequity where resources/transport are limited.	Guaranteed accommodation; travel/parking support; sibling-sensitive spaces; clear repatriation rules.

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Journey stage	What parents describe	Safety concern (parent lens)	Enabling conditions (FiCare aligned)
Discharge	Relief mixed with fear as monitoring stops and responsibility shifts to parents.	Under-preparation increases anxiety and risk of crisis/over-reliance on emergency services.	Early discharge planning; hands-on training; rooming-in/step-down; emotional readiness addressed.
After discharge	Delayed processing of trauma; variable follow-up; ongoing anxiety about deterioration.	Loss of support and unclear pathways; mental health needs emerge after formal care ends.	Joined-up community follow-up; staged mental health support; clear escalation guidance and contacts.

The individual stages are discussed in more detail below.

2.3 Antenatal/before birth: entering the pathway without preparation

Parents frequently describe neonatal admission as a sudden, traumatic, and disorientating event, with limited prior knowledge of neonatal care and terminology.

Several respondents describe families as moving almost immediately into "*survival mode,"* a state in which they could not easily process technical language or think ahead to transfer, discharge, or life at home. That matters for parents because the earliest hours are exactly when crucial decisions and explanations occur.

The need for early education and awareness is presented as protective, where parents have more preparation, they report reduced anxiety and greater confidence engaging with care. Many parents highlighted that antenatal classes in which such matters are discussed are often scheduled after the majority of early births.

Implications:

- Embed early awareness and staged information delivery into maternity pathways (not as an optional add-on).
- Standardise plain-language explanations of common interventions, the unit environment and likely decisions.

NICE (National Institute for Health and Care Excellence) postnatal guidance requires clear language, tailored timing, appropriate interpreters, and explicit checks that parents understand the information they have been given.

2.4 Birth and admission: crisis, separation and immediate safety Decisions

At admission, parents focus on survival. They often accept transfers or specialist pathways when they believe it clearly improves outcomes for the baby. They also describe separation and uncertainty as deeply distressing and destabilising especially after emergency caesarean birth or when the baby was moved away before the mother could physically follow. The evidence suggests acceptability improves when

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the rationale for decisions is explained clearly and when systems protect parent/baby proximity. Parents repeatedly described physical closeness as vital.

Implications:

- Treat admission/transfer communication as a safety-critical step (standard scripts, named contacts, repeat explanations).
- Plan for proximity (parent accommodation/access) as part of the clinical pathway, not as after the fact mitigation.

2.5 Early neonatal care: communication, comprehension and informed participation

A dominant theme is of parents struggling with *"doctor speak*," acronyms and fragmented communication between teams. The communication environment in this early stage is repeatedly described as fragile, with parents reporting:

- Clinician jargon,
- Acronyms,
- Poor coordination between postnatal and neonatal teams, and
- Opaque or inconsistently used interpretation pathways.

This was amplified for families with limited or no English, with reports that some parents did not know interpreters were available or that interpreters were informally reserved for only the most critical moments. This had the effect of parents in these circumstances unsure of the reasons for their baby's neonatal care and the wider implications.

"Imagine what that's like if you've got a language barrier… and you have no idea."

This was reported as not just a patient experience issue: it directly affects understanding of diagnosis, feeding, transfer, consent, discharge, and the parent's ability to act as a safe carer. The effect is reduced confidence to ask questions, reliance on external sources, and perceived risk in decision-making.

Implications:

- Implement a region wide communication standard (plain English, repetition, comprehension checks).
- Make interpreter access visible, routine, and prompt; provide translated written/digital materials at admission, transfer, and discharge.

2.6 Stabilisation and ongoing care: FiCare model

Discussions with some parents highlighted the importance of the Family Integrated Care (FiCare) model. Using this model and from the discussion with parents appears to show:

- When parents are actively involved (feeding, routine care, shared decision-making), confidence increases, bonding strengthens and discharge feels more manageable.

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- Conversely, when involvement is inconsistent or dependent on local culture/staffing, parents report feelings of exclusion, helplessness, and reduced readiness for home care.

Implications:

- Ensure FiCare is fully and consistently rolled out across all units, supported by the NWNODN with workforce time, training and enabling facilities.
- Define consistent expectations for parental involvement so experience does not vary by site or shift.
- FiCare has been embedded across North West Neonatal Units over the last few years.

2.7 Transfers, travel, and inequity: practical barriers

Discussions around inequity and issues such as sibling separation, show that travel distance, parking costs, lack of accommodation, childcare responsibilities, and inability to drive are decisive determinants of whether parents can be present. Parents describe accommodation close to the unit as transformative. Practical burdens are repeatedly framed as part of safety because they govern presence, involvement, and continuity.

In terms of practical inequity, the strongest examples from our discussions concern the following issues:

- Parking;
- Fuel;
- Hotels;
- Public transport;
- Work absence;
- Lack of childcare; and
- The impossibility of safely commuting long distances soon after surgery.

Sibling separation was described as a repeated harm, not a side issue.

"I felt like I just abandoned him."

Families without cars, spare income, or strong informal support networks were particularly exposed.

Implications:

- Set guaranteed accommodation and travel/parking support standards for any higher-level unit or pathway involving travel.
- Build sibling-sensitive policies (family spaces, visiting flexibility were clinically safe, childcare signposting) into pathway standards.
- Ensure Equality and Health Inequalities Impact Assessment is scenario based (e.g., non-drivers, parents post-caesarean, families with multiple children).

2.7.1 Transfers and cot-side life

As an extension of the above discussion, the parent's perspective is that the first major decision point is often whether to transfer to a more specialist centre. From the discussions parents were usually willing to accept greater distance when the safety rationale was visible, such as:

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- better expertise;
- clearer planning;
- surgical capability; or
- a more appropriate level of intensive care.

That acceptance was, however, consistently conditional. It depended on the local team:

- Recognising and explaining why transfer was necessary;
- Preserving maternal and family access as far as possible; and
- Ensuring later repatriation closer to home when the baby was stable.

Once the baby is in ongoing specialist care, the journey becomes less about a single dramatic event and more about cot-side life:

- Learning routines;
- Managing alarms and uncertainty;
- Staying near the baby; and
- Trying to remain a parent rather than a visitor.

This is the area that has the closest connection with FiCare. Parents valued being taught to feed, comfort, change, and observe their baby, and they repeatedly described accommodation near the unit as transformative because it allowed rapid attendance during deterioration, greater participation in care, and less exhausting shuttling between hospital and home.

2.8 Discharge: The abrupt shift from monitored care to parent-led care

The final major transition is repatriation, discharge, and home. Parents describe discharge as a point of high anxiety: relief is mixed with fear of losing professional monitoring of baby's condition and managing complex needs alone.

Preparation for this transition is often described as late and inconsistent. Parents value early introduction of discharge planning, 'hands on' learning, and emotional reassurance. However, in our discussion sessions parents described it as a sudden shift from continuous monitoring to personal responsibility, often with late conversations about discharge, variable training, and little space to process what the admission had done to them psychologically.

Implications:

- Standardise discharge preparation across units and embed it throughout admission (not just at the end).
- Support "rooming in" or step-down approaches to build confidence before discharge.
- Treat emotional readiness as part of discharge readiness alongside clinical criteria.

2.9 After discharge: delayed trauma and the need for continuity

Parents describe long lasting impacts, with many saying that psychological impact often emerges later, after the crisis has passed and leaving the unit. Follow-up is often

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perceived as inconsistent or superficial, reinforcing the need for staged, trauma informed support across the whole pathway and beyond discharge.

Implications:

- Provide consistent follow-up support and clear pathways between neonatal units and community services.
- Offer staged mental health support that recognises delayed impact and integrate peer support as a core component.

2.10 Crosscutting issues

The following issues are consistently mentioned across all stages of the journey to a greater or lesser degree:

- Parent/baby proximity is repeatedly described as foundational to both perceived and practical safety.
- Communication quality (plain language, consistency, interpreter access, joined-up teams) directly affects parents' ability to engage safely.
- FiCare is not 'nice to have': it operationalises safe care by building competence, confidence, and continuity.
- Practical supports (accommodation, travel, parking, food/rest space, Wi-Fi) are enablers of presence and therefore safety.
- Psychological support must be universal and staged across admission, discharge, and post-discharge.

2.11 Outline ideal journey

The summary feedback from parents suggests that the optimal neonatal pathway is determined by factors beyond mere proximity or centralisation of units.

Parents in this sample infer the view that the ideal pathway combines:

- Timely specialist escalation with protected parent/baby proximity;
- High quality interpretation and plain language communication;
- Clear repatriation rules;
- Early discharge teaching; and
- Sustained psychological/community follow-up.

The diagram on the following page summarises this 'ideal' neo-natal journey.

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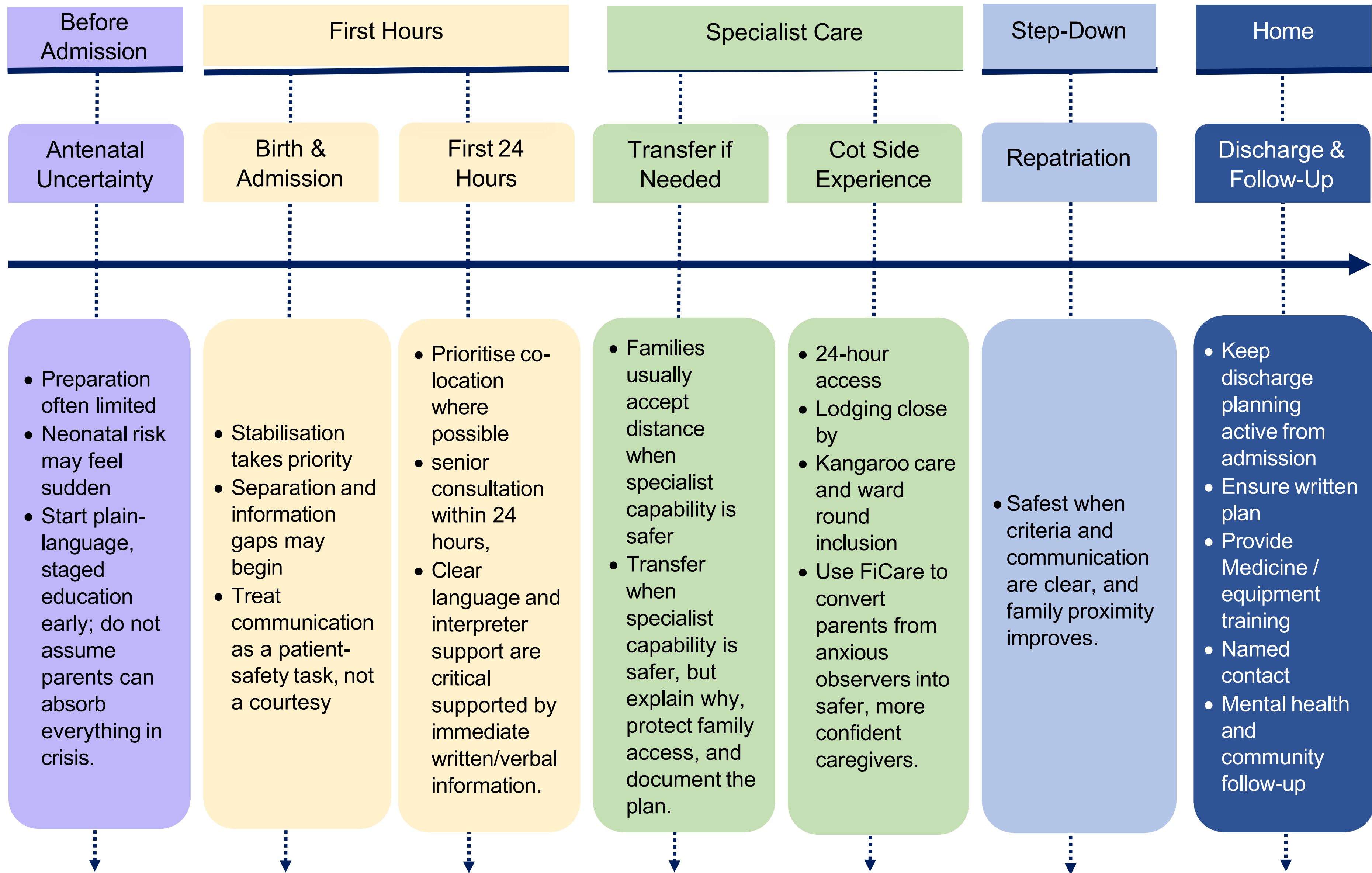

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3 MAIN THEMES AND FINDING FROM DISCUSSIONS

The outcomes of group and one-to-one discussions

3.1 Introduction

This section summarises the main findings by topic, using the discussion guide applied in all parent conversations. The guide framed the research around five core inquiry areas:

- What matters most;
- Right care in the right place;
- Travel and transfers;
- Inequalities and access; and
- Future priorities.

Although discussions did not always follow this structure, the transcripts of one-to-one and group conversations strongly reflect it: parents often returned to these topics with little prompting, suggesting the guide aligns well with lived experience.

3.2 What matters most?

The clearest answer to the opening question is that what matters most is not a single thing. Families described a cluster of needs that had to be met together:

- staying physically close to the baby,
- trusting the professionals,
- being included in care, and
- understanding what was happening.

Of those, **proximity** was especially powerful. One parent, in the Cheshire and Merseyside focus group, said that being able to be next to their daughter *"all the time"* was the critical factor. This was contrasted with another parent's experience of being discharged after an emergency caesarean section and separated from the baby, which they described as being *"absolutely devastated"* about. Another parent made a similar point, saying that being able to stay at Ronald McDonald House at Arrowe Park Hospital meant they could reach their daughter within minutes when alarms or emergency calls happened at night.

Trust in staff was the second major component. Even where families described frightening or chaotic journeys, they often distinguished between the stress of the system and the care shown by individual nurses and clinicians. One parent said it was the clinical and Ronald McDonald staff who *"carried"* them through ten weeks away from home. One parent described a rotation of nurses as *"incredible."* One interviewee emphasised how the calm, caring response of staff helped their partner manage the double trauma of fearing for both them and their baby. These accounts suggest that confidence in staff did not come only from technical skill; it came from staff stepping *"beyond nursing,"* remaining calm, and providing relational as well as clinical support.

The third element was **communication**. One parent told us that clinicians explained their son's heart and other complications in terms they *"would not have a clue"* about and that they had to go home and Google acronyms to make sense of them. Another

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parent described the postnatal and neonatal teams as not really talking to each other, leaving them to bridge the gap between the ward and the unit. What parents wanted was not simply more information, but usable, timely, emotionally aware information delivered in plain language and joined up across teams.

A final core theme under "what matters most" was **emotional acknowledgement**. Several parents described the need for someone to ask not only how the baby was, but how they were. One contrasted the clinical attention on their son with the absence of anyone asking if they "…*were alright*." Another highlighted the value of being connected with a parent-led charity (Spoons) and being reassured by nurses that they were doing their best.

The discussions show that feeling supported meant being treated as a person living through crisis, not only as the parent of a neonatal patient.

3.3 Right care in the right place

The discussion guide's central policy question is whether the "right care" may sometimes mean care that is further away but more specialist. Parents on the whole provided a nuanced answer. There is significant acceptance of the principle, one parent stated very plainly that if more distant care meant *"you're safe, and more importantly, your baby's safe*," then parents would accept it. Another, whose daughter moved across multiple hospitals for specialist surgical care, said they would rather have *"…stayed where proper specialist capability existed than move somewhere closer but less safe."* In the Lancashire and South Cumbria group, one parent described how seeing different levels of neonatal and paediatric intensive care made clear the importance of the right level of care being available when needed.

However, this support is consistently conditional, not absolute. Parents did not say *"specialist is always better"* in a simple way. Instead, they described situations in which specialist centres felt safer because there was a clearer plan, more experienced staff, and faster intervention. One parent contrasted long periods of uncertainty at a local unit with the point at which transfer to Liverpool and open-heart surgery planning finally introduced clarity and progress. Another parent and their partner described the importance of rapid, decisive action when both baby and mother were at risk. This indicates that what families are really endorsing is not centralisation per se, but visible capability and decisive care.

At the same time, parent raised a clear warning about any perceived degradation of local capability. In the Cheshire and Merseyside focus group, one parent asked, *"…are we de-skilling the workforce?"* That concern is important because it reframes the debate. Families were not only thinking about where the best intensive care should sit; they were also thinking about what happens when a baby is born suddenly or deteriorates before transfer.

Participants wanted confidence that local hospitals would still recognise emergencies, stabilise babies, and coordinate effectively with specialist centres. The evidence from discussions therefore supports specialist concentration only if it is paired with a convincing account of how local response capacity will be protected.

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There is also a strong communication dimension here. Parents want to understand **why** decisions are being made. There is an implication from the discussions that acceptability improves when families can see the rationale for transfer or specialist escalation and worsens when change feels driven by abstract system logic rather than by the baby's actual needs. This would appear to make transparency a central part of the "right care" question.

3.4 Travel, transfers and inequalities

The strongest findings in the discussions, perhaps, sit at the point where the discussion topics "travel and transfers" and "inequalities and access" sections meet.

Families repeatedly described transfer, distance, and accommodation as among the hardest parts of neonatal care. Separation from the baby during or after birth carries particular weight:

"There shouldn't be a separation at any point."

One parent, recounting another mother's experience of being discharged after a caesarean birth without staying with her baby, showed how quickly separation can become a family-wide crisis.

Accommodation changes everything in these accounts. One parent described the Arrowe Park Ronald McDonald set-up as transformative because it meant they were *"upstairs"* and effectively immediately available if their daughter deteriorated. Other parents described the value of having a facility that allowed them to stay close. One parent maintained that concentrating care only works if parents can also be accommodated there, whether through Ronald McDonald, parent rooms, or other practical arrangements. These testimonies show that accommodation is not a peripheral comfort issue; it is a direct enabler of parental presence, bonding, breastfeeding, and emotional survival.

The discussions also revealed persistent problems in transfer and repatriation processes, with observations that it is not always clear when or whether a baby will be transferred back to the local unit. One parent gave an anecdotal account of families brought from the Isle of Man to Bolton describing repatriation planning as traumatic and logistically fraught. Several parents describe movement between multiple hospitals, often at moments of deterioration, creating a constant sense of instability. The issue is not only the transfer itself; it is the lack of clarity, predictability, and emotional preparation around it.

Considering "inequalities and access" in this context, participants highlighted practical access burdens. One parent identified how difficult longer journeys would be for parents with siblings at home, parents recovering from caesarean sections, and families without someone to drive them. Another described the guilt of feeling they had *"abandoned"* their older child during long neonatal stays. The Spoons group raised concerns about support being limited only to households on means-tested benefits. The net effect is that distance is never just geography. It amplifies unpaid care burdens, loss of income, transport dependence, and physical recovery after birth.

Health literacy is another important access issue. One participant explicitly said that they and their partner are *"…fortunate because we both work in the NHS and knew*

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what questions to ask, and recognise the jargon...," therefore they found the pathway *"clear"* and *"structured*." The counterpoint to this was provided by participants who spoke of instances where families do not understand the terminology or the intensive care environment and therefore found that the experience can be alienating and frightening. This is an inequality of confidence and comprehension as much as of money or geography.

3.5 Future priorities for service design

When participants looked forward, discussions offered, in summary, five main priorities:

1. The first priority is family accommodation and basic practical support. Parents did not describe this as a vague aspiration. They described real need, which included:

    - Somewhere to sleep;
    - A chair fit to sit in;
    - Access to food;
    - Kitchens;
    - Privacy;
    - A quiet room;
    - Parking that does not become financially punishing; and
    - Accommodation close enough that a 'crash' call does not become a race against distance.

    One parent was explicit in stating that accommodation is the complementary *"flip side"* of concentrated care.

2. The second priority is better communication and preparation. One parent was particularly clear in their articulation of this issue:

    - They described being offered a NICU tour that never happened; and
    - Being told about a quiet room for cuddles when the end of the baby's life was approaching long before it happened and then discovering that the reality did not match what they had imagined.

    Their account shows that families need preparation not only for intensive care pathways but also for bereavement pathways, including what the environment looks like, what equipment may still be attached, and what to expect physically and emotionally.

    A recurring additional issue in this context is the need for plain English explanations from the beginning.

3. The third priority is psychological support that works in real life, not only in theory. Several parents described being in *"survival mode."*

    - One participant reported being unable to engage with the psychotherapist on the unit at the time, even though their partner found it helpful.
    - Another stated the view that feedback and reflection should happen later because parents are too overwhelmed during admission and close to discharge to say what really mattered.

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- Yet another spoke about trauma and PTSD continuing well after discharge, including the after-effects that emerge later in children and parents.

The implication is that services need both immediate and delayed support offers, with follow-up after families have had time to process events.

4. A fourth priority is joined-up care and consistent standards across teams.

- One parent provides a description of *"…postnatal and neonatal teams not speaking to each other…"* as a clear example of process failure that increases distress.
- Another provided an account of feeling their baby was *"forgotten"* because his name was not on the board in the unit, and therefore he did not receive the same small markers of inclusion as other babies. This example shows how inconsistent practice can become emotionally significant, even over comparatively shorter stays.

The overall sentiment is that parents want reliable systems, not reliance on them as individuals or families to spot and compensate for gaps.

3.6 Overall conclusions

Across all discussions (focus groups and one-to-one interviews), parents describe neonatal care as a profoundly disruptive and often traumatic experience, but not one defined only by clinical treatment.

The evidence from discussions shows that what mattered most was being close to the baby, trusting staff expertise, understanding what was happening, and being supported practically and emotionally to stay involved. Participants were often highly positive about individual nurses, units, and life-saving care, but they were equally clear that good clinical care on its own was not enough if families were separated, left confused, or expected to absorb the logistical and emotional burden alone.

On the central question of whether the 'right care' may sometimes be further from home, there was a conditional acceptance of more specialist, more concentrated care. Families were willing to travel further if that clearly meant safer care, stronger specialist capability, or better outcomes. That acceptance was, however, heavily qualified, dependent on transfer pathways working well, local teams remaining capable of handling emergencies, parents being able to stay near the baby, and communication being clear and empathetic. In effect, participants did not separate clinical quality from family experience: they treated them as part of the same safety question.

The strongest cross-cutting finding is that families experienced practical and emotional infrastructure as core service issues, not secondary comforts. Accommodation, parking, kitchens, Wi-Fi, rest space, sibling arrangements, breastfeeding support, peer support, and follow-up psychological care were repeatedly described as decisive to whether care felt survivable. The discussions also showed inequalities are discussed less in abstract demographic terms and more through concrete burdens: not driving, recovering from a caesarean, having other children at home, lacking money for repeated travel, or being treated out of area.

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Taken together, the discussions point to a consistent design principle for any future service model:

- Families can accept change when they can see the clinical logic; but
- Only if the model is built around parent-baby proximity, communication, accommodation, transfer clarity, local emergency capability, and trauma-informed support.

Overall, the discussions tell a coherent story:

- Families want neonatal services designed around clinical safety, but also around family presence, emotional containment, and practical reality.
- They do not reject change in principle.
- In many cases they explicitly accept that very sick or very premature babies may need care in fewer, more specialist centres.
- They reject any framing of change that treats travel, separation, accommodation, communication, or trauma as secondary issues.

The discussions show that these are not secondary issues to families, they are central parts of whether care is experienced as safe, humane, and workable.

The most important finding for future engagement is therefore that:

- Parents are more likely to support service redesign when the conversation starts not with bed numbers or unit categories, but with what families need in order to survive neonatal care without avoidable separation, confusion, isolation, and financial strain.

3.6.1 Summary by area of inquiry

Main area of inquiry	Main themes
What matters most	• Proximity to the baby; • Trust in staff; • Clear information; • Emotional reassurance; • Being treated as a parent, not an observer.
Right care in the right place	• Conditional support for specialist concentration; • Willingness to travel if safety improves; • Concern about local capability and de-skilling.
Travel and transfers	• Separation is deeply distressing; • Accommodation is critical; • Transfer and repatriation processes are often unclear; • Distance multiplies family strain.
Inequalities and access	• Practical inequalities dominate: transport, cost, childcare, recovery after birth, confidence navigating services, health literacy

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Main area of inquiry	Main themes
Future priorities	• Family accommodation; • Plain-English communication; • Better preparation; • Local emergency capacity; • Psychological follow-up; • Later feedback

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4 DEEP DIVE INTO THE ISSUES

A closer look at key issues

4.1 Introduction

Having considered first the neonatal journey as described by parents and then looked at the reported issues by line of inquiry this section provides a detailed look at the key specific issues that inform the journey.

4.2 Importance of early antenatal education in neonatal care

The discussions highlighted the importance of early antenatal education in improving parental preparedness for neonatal care. Many parents described entering neonatal services unexpectedly, with little knowledge of neonatal environments, procedures, or support services, which increased fear, anxiety, and emotional distress.

4.2.1 Key issues identified

- **Lack of preparedness for neonatal admission:** Parents often experienced premature birth or neonatal admission suddenly, before receiving adequate antenatal education or birth preparation.
- **Limited understanding of neonatal environments:** Many families felt unprepared for the appearance, sounds and intensity of neonatal units, including medical equipment and clinical procedures.
- **Emotional shock and anxiety:** The absence of prior education increased fear, panic, and feelings of loss of control during neonatal admissions.
- **Difficulty understanding medical information:** Parents found clinical language and fast-moving conversations overwhelming, particularly during crisis situations.
- **Lack of awareness of support services:** Families often only discovered accommodation, peer support, charities, and psychological support after admission or by chance.
- **Poor understanding of neonatal pathways and transfers:** Parents reported confusion and anxiety about transfers between hospitals and different levels of neonatal care.
- **Need for practical preparation:** Families wanted more information about travel, accommodation, childcare, financial pressures, and the realities of long hospital stays.
- **Importance of accessible and repeated education:** Parents highlighted the need for early, staged and jargon free education using plain English, visual aids, and realistic explanations.
- **Need for tailored support for higher risk families:** Parents felt families at increased risk of premature birth should receive enhanced preparation and earlier engagement with neonatal teams.

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4.2.2 Conclusion

The findings show that early antenatal education can significantly improve parental confidence, understanding and emotional preparedness for neonatal care. Parents consistently emphasised that better preparation would reduce fear and uncertainty, improve communication and support families throughout the neonatal journey.

4.3 Variability in standards of neonatal care (the importance of consistency)

The conversations revealed a consistent and significant theme: variation in standards of care between neonatal units. While many parents describe examples of excellent clinical care, these experiences are often contrasted with inconsistencies across hospitals, wards and even shifts within the same unit. This variability has a profound impact on parental confidence, emotional wellbeing, and overall experience of care.

This section explores how inconsistent standards are experienced, the impact on families, and why greater consistency is viewed as essential in future service design.

4.3.1 Key issues identified

- **Variation between hospitals and units:** Parents experienced different standards of communication, support and clinical care when transferred between units. Some units were described as organised and supportive, while others felt disjointed or neglectful.
- **Inconsistency within the same unit:** Care quality often depended on staffing levels, staff experience, and shift patterns. Parents reported inconsistent communication, involvement in care and response times.
- **Poor communication and coordination:** Families described inconsistent use of plain language, conflicting information from different teams and gaps in communication between maternity and neonatal services.
- **Unequal access to support services:** Access to psychological support, accommodation and peer support varied widely between units, leading to unequal experiences for families.
- **Emotional and practical impact on families:** Inconsistency increased anxiety, confusion, and emotional distress. Parents often felt responsible for navigating systems and filling communication gaps themselves.
- **Inequity across the system:** Experiences differed depending on location, timing, and resources available, creating what parents described as a postcode lottery in standards of care.
- **Challenges during transfers:** Transfers between units were identified as particularly stressful due to differing systems, expectations, and practices.

4.3.2 Conclusion

Parents consistently identified consistency as essential to safe, compassionate, and effective neonatal care. The findings highlight the need for standardised

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communication, coordinated care processes, equal access to support services and reliable care experiences across all neonatal units.

4.4 Communication and translation issues in neonatal care

The review identified significant communication challenges, with particular concerns relating to interpreter access, language barriers, and the use of complex clinical terminology. Although explicit references to non-English-speaking families were limited to a small number of discussions, broader communication problems were common throughout the discussions.

4.4.1 Key issues identified

- **Interpreter access and visibility:** Participants described interpreter services as unclear, inconsistently used, and sometimes only available during critical situations. Families were often unaware that interpreters could be requested.
- **Reliance on informal translation:** Staff occasionally relied on bilingual colleagues instead of structured interpreting services, raising concerns about consistency, confidentiality, and informed decision-making.
- **Use of medical jargon:** Parents frequently reported difficulty understanding clinical language, acronyms, and technical explanations. Many felt overwhelmed and had to search online afterwards for clarification.
- **Impact on informed decision-making:** Poor communication reduced parents' understanding of their baby's condition, treatment, and care options, which may have affected confidence and participation in decisions.
- **Emotional and psychological impact:** Families described feelings of confusion, anxiety, and isolation when information was not explained clearly or in an accessible way.
- **Examples of effective communication:** Positive experiences were linked to staff who explained information clearly, avoided jargon, and adapted conversations to the family's level of understanding.

4.4.2 Conclusion

The findings suggest that communication difficulties are a widespread issue within neonatal care settings. For families facing language barriers, these challenges are likely to be significantly greater. The evidence highlights the need for clearer interpreter pathways, accessible information, consistent plain English communication, and improved support for families throughout neonatal care.

4.5 Parental separation and wider family impacts

The discussions with participants in group and one-to-one conversations highlighted the significant emotional, practical, and financial impact that neonatal care has on parents, siblings, and wider family life. Families described being forced to balance time between hospital care and responsibilities at home, often while coping with trauma, physical recovery, and limited support.

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4.5.1 Key issues identified

- **Separation from siblings:** Parents described feelings of guilt and distress caused by prolonged separation from children at home. Many felt torn between caring for their baby in hospital and supporting their other children.
- **Childcare and routine disruption:** Neonatal admissions disrupted nursery, school, and family routines. Families often struggled to manage childcare, especially when travelling long distances or where one parent still needed to work.
- **Impact on maternal wellbeing:** Mothers reported emotional overload while recovering from birth or surgery, travelling to neonatal units and managing responsibilities for the wider family.
- **Transport and accommodation difficulties:** Travel challenges and lack of nearby accommodation increased separation and stress for families. Parents highlighted the importance of accommodation close to neonatal units.
- **Financial and work-related strain:** Families experienced financial pressure from travel, accommodation, and childcare costs, alongside work disruptions and reduced flexibility.
- **Limited support networks:** Some parents lacked family or community support, making it more difficult to balance neonatal care with other family responsibilities.
- **Positive impact of family centred support:** Access to accommodation, family rooms and flexible visiting arrangements helped reduce stress and allowed families to stay connected.

4.5.2 Conclusion

The findings demonstrate that separation from siblings and disruption to family life are major harms experienced during neonatal care. Families consistently identified the need for better accommodation, practical support, flexible visiting arrangements and recognition of sibling and wider family impacts within service planning.

4.6 Practical inequity in neonatal care

Parents identify significant practical inequalities affecting families during neonatal care. The strongest themes relate to transport difficulties, accommodation shortages, financial pressures, family responsibilities, and unequal access to support. These challenges directly affected families' ability to remain involved in their baby's care.

4.6.1 Key issues identified

- **Transport and travel difficulties:** Families described major challenges with long distance travel, limited public transport, fuel costs, parking charges and reliance on taxis or multiple buses.
- **Accommodation shortages:** Lack of nearby accommodation increased separation between parents and babies. Families valued accommodation close to neonatal units, but access was inconsistent.

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- **Financial strain:** Parents experienced financial pressure from travel, accommodation, parking, food, and loss of income, particularly where support was limited to means tested benefits.
- **Impact on working families:** Working parents on statutory pay reported significant hardship, often feeling excluded from financial support schemes.
- **Sibling care and family disruption:** Families struggled to balance neonatal care with childcare responsibilities, work commitments and maintaining routines for siblings.
- **Limited support networks:** Parents without family or community support experienced greater practical and emotional burden during neonatal admissions.
- **Language and health literacy barriers:** Some families struggled to understand medical information or access interpreter support, increasing inequality for those already facing practical challenges.
- **Importance of family centred support:** Positive experiences were linked to free parking, accessible accommodation, family rooms, and practical support that reduced stress and separation.

4.6.2 Conclusion

The findings show that practical inequalities significantly shape family experiences during neonatal care. Transport, accommodation, financial support and family centred services should be treated as essential elements of neonatal care pathways to ensure equitable access and reduce stress for families.

4.7 Preparing parents for neonatal discharge

Parental discussions highlighted significant concerns about how parents are prepared for neonatal discharge. While clinical care during admission was often strong, many parents felt insufficiently prepared for the emotional, practical, and medical responsibilities of caring for their baby at home.

4.7.1 Key issues identified

- **Discharge as a source of anxiety:** Parents described discharge as stressful due to the sudden transition from constant clinical support to caring for their baby independently.
- **Limited early discharge planning:** Many families reported that discharge discussions happened too late in the care journey, leaving them unprepared for what to expect at home.
- **Inconsistent information and support:** The quality of discharge preparation varied between units and staff, leading to unequal levels of understanding and confidence.
- **Insufficient practical preparation:** Parents wanted more opportunities to practise caring for their baby, including feeding, managing equipment, and recognising signs of deterioration.

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- **Emotional readiness often overlooked:** Discharge preparation focused mainly on clinical readiness, while parental anxiety, emotional recovery and confidence were not consistently addressed.
- **Poor continuity between services:** Weak communication between hospital and community services left some parents feeling unsupported and responsible for navigating follow up care themselves.
- **Need for clear and accessible communication:** Parents valued plain language, repeated explanations, written guidance, and practical demonstrations to support understanding.
- **Variation across neonatal units:** Discharge planning processes differed widely depending on local practices, staffing and individual clinicians rather than a standardised approach.

4.7.2 Conclusion

The findings show that discharge preparation is a critical but inconsistently delivered part of neonatal care. Parents need earlier, clearer, and more practical support that addresses both clinical and emotional readiness. Standardised discharge education and stronger links with community services are essential to improve confidence and support safer transitions home.

4.8 The need for consistent mental health support in neonatal care

The discussions with parents highlighted the significant emotional and psychological impact of neonatal care on parents and families. While some units provide strong mental health and peer support, experiences across the region are highly inconsistent, leading to unequal levels of emotional care and support.

4.8.1 Key issues identified

- **Emotional trauma during neonatal care:** Parents described neonatal care as overwhelming, traumatic, and emotionally exhausting, with many feeling they were in survival mode throughout admission.
- **Lack of routine emotional support:** Some parents reported that no one checked on their emotional wellbeing or recognised signs of distress during their neonatal experience.
- **Inconsistent access to psychological services:** Availability of psychologists, psychotherapists and emotional support varied significantly between units and locations.
- **Importance of peer support:** Peer support was identified as one of the most valuable forms of emotional support, helping parents feel understood and less isolated.
- **Limited support after discharge:** Many parents only processed their trauma after leaving hospital but follow up mental health support was often limited or viewed as superficial.

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- **Poor signposting and awareness:** Even where support services existed, parents were not always informed about them early enough or in a consistent way.
- **Fragmented support across services:** Mental health support was often poorly connected between maternity services, neonatal units, and community care, creating gaps in continuity.
- **Reliance on charities and informal networks:** Parents frequently depended on charities, peer groups, and personal support networks because formal mental health support was inconsistent.
- **Long term impact on families:** Unresolved trauma and anxiety affected parental confidence, bonding, attachment, and wider family wellbeing long after discharge.

4.8.2 Conclusion

The findings show that mental health support is an essential part of neonatal care but is currently delivered inconsistently across the region. Parents highlighted the need for universal, trauma informed and long-term emotional support that is integrated throughout the neonatal pathway and available equally to all families.

4.9 Summary and recommendations

Three themes recur across the discussions:

1. Inconsistency is itself a source of harm: families cannot predict what support, explanation or practical help will be available;
2. Practical support is inseparable from care quality: Travel, accommodation, parking, childcare and access to understandable information all affect whether parents can remain involved; and
3. Transitions are weak points: admission, transfer, and discharge repeatedly expose gaps in communication, continuity, and emotional support.

The central conclusion is that neonatal care is not experienced only as a clinical pathway; it is also an information, support, and access pathway. The feedback from parents does not suggest a lack of commitment from staff. Instead, it shows that good care is too dependent on local practice, staffing, and chance. The most important improvement would be to design family support into the pathway from the start, with clear standards that apply across admission, transfer, inpatient care, and discharge. A more consistent family centred model could be likely to reduce anxiety, strengthen parental confidence, and improve equity.

Based on the views of this small, and initial, sample of parental opinion some emerging practical recommendations could include:

- Establish a standard early antenatal information offer for families at risk of neonatal admission, including practical guidance on the neonatal environment, support services, and likely care pathways.

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- Adopt a common communication standard across units, including plain English, repeated explanations, clear interpreter pathways, and routine checking of understanding.
- Treat transport, accommodation, parking, and sibling support as core parts of care planning so that parental presence is not determined by family income or location.
- Start discharge planning early and use a structured approach that includes hands-on practise, written guidance, and clear handover to community services.
- Provide universal trauma-informed emotional support across the pathway, with routine check-ins, reliable signposting, and access to peer support during admission and after discharge.

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5 THE CASE FOR CHANGE

Synthesis of Findings Against the Case for Change

5.1 Introduction

Discussions with parents asked directly about what mattered most, the balance between specialist expertise and distance, travel and transfer experiences, access barriers, and future design priorities. Across all discussions, those prompts yielded a highly consistent family centred picture: proximity, trust, communication, coordination, and the ability to stay involved mattered as much as, and often more visibly than, abstract organisational design. Participants did not reject specialist concentration in principle; instead, they repeatedly insisted that the family consequences of concentration are part of the same safety problem, not a separate one.

5.2 Participant views compared with the Case for Change

The Case for Change document makes a strong clinical argument:

- Many North West units do not meet the revised activity standards;
- Outcomes improve where the right levels of specialist activity and skill are sustained;
- Workforce, transport, estate, and geography all matter; and
- Previous insight already pointed to travel, parking, accommodation, kitchens, and Wi-Fi as parent concerns.

Overall, the discussions with parents confirmed much of that logic:

- Several participants describing feeling safer once they reached a unit or team that was obviously more specialist, more decisive, or more coherent in its planning.
- Participants explicitly accepted travel if it meant safer care:
- One participant contrasted an extended period of “waiting around” before transfer with the clearer, more specialist planning she encountered after transfer;
- In the Lancashire and South Cumbria group participants spoke of their reassurance when babies reached the right care or when expert transport teams arrived.

At the same time, the feedback from parents does not support centralisation as a standalone answer. Participants consistently described safety as something produced by a chain of factors: competent local recognition and stabilisation, timely expert transfer, clear communication, reliable repatriation arrangements, and parent presence. More than one participant raised the same strategic concern from different angles:

> *“If very experienced staff are drawn away from local units, the system may improve safety in specialist centres while reducing safety for unexpected emergencies before transfer.”*

That challenge is especially important because the Case for Change document itself acknowledges maternity, transport, and patient flow interdependencies; parent’s responses show exactly how those interdependencies are experienced on the ground.

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The Case for Change document's "Existing Patient Insight" section says that parents and carers valued services but had concerns about travel, parental accommodation, car parking, kitchens, and stable Wi-Fi. The discussions in this exercise strongly validate that statement and add much richer detail, namely:

- Ronald McDonald accommodation was repeatedly described as transformative where it existed, but several accounts also showed inconsistent access, late signposting, outdated facilities, or lack of guaranteed space.
- Parking was described not as a minor comfort issue but as a cumulative financial and practical pressure.
- Families spoke about sofas in reception, the need for a dark room to cry or rest in, the impossibility of maintaining routines for siblings, and the strain of long journeys when one parent still had to work.

In other words, discussions in this exercise do not merely agree with the Case for Change's parent insight summary; they show that these practical supports are among the most decisive levers of real-world acceptability.

On inequalities, the fit is only partial. The Case for Change document gives substantial attention to deprivation, ethnicity, smoking, diabetes, teenage pregnancy, and wider population need. The discussions with parents, by contrast, focused far less on demographic categories and far more on practical inequality:

- Whether parents could drive;
- Whether they had informal childcare;
- Whether they had income flexibility;
- Whether public transport was viable;
- Whether they were recovering from surgery;
- Whether they lived out of area; and
- Whether they had a support network.

The responses from this sample of opinion does not undermine the Case for Change equity argument, rather it sharpens it. For future actions, the equalities and health impact assessments should not be limited to demographic risk alone; they should test concrete family scenarios, because those are the forms of inequity that dominated lived accounts.

Additionally, it should be recognised that the sample is not representative of the entire population of parents in the North West of England. The discussions tended to disproportionately include professionals, which leads to the added observation that recruitment to ensure voice from equalities and socioeconomically deprived groups will need active consideration in the next stages of sampling opinion.

Finally, the weakest area of coverage, viewed from the parent lens, in the Case for Change is the psychological dimension. The overall approach to this insight exercise was trauma informed safeguards and where appropriate considered bereavement pathways; however the Case for Change narrative itself gives less weight to these issues than parent discussions do.

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Parents described:

- Prolonged trauma;
- Survival mode;
- Follow-up needs that emerge later;
- Support pathways that varied sharply depending on where care occurred and whether families were in or out of area: and
- Participants provided accounts of (i) the importance of a quiet room and final cuddles during bereavement; (ii) being unable to use support while still in survival mode; (iii) insufficient out-of-region perinatal mental health services.

All of these point to the same conclusion: psychological support is not supplementary; it is part of safe neonatal pathway design.

5.3 Implications

The programme's current direction is best understood not as a yes/no question about centralisation, but as a design challenge with clear conditions for legitimacy. Discussions with parents in this exercise show that families can accept concentration of specialist care when the clinical case is visible and trustworthy, but they are far less likely to accept it if the burden of making it workable is left to parents. The recommended approach is therefore to make family-facing requirements explicit in the redesigning of services in the same way that activity standards and workforce requirements are made explicit.

The main implications are:

1. The next engagement or options development stage should publish a clear, parent readable explanation of why change is being considered, what evidence supports it, and how each option would affect emergency births, transfers, accommodation, travel, and local unit capability. Participants repeatedly signalled concern that the programme could be interpreted as cost cutting unless the clinical logic is made visible and specific.
2. The programme should define a minimum family support standard before any options are appraised. This should cover accommodation, parking, travel reimbursement, kitchens, Wi-Fi, private family space, sleeping/rest arrangements, and flexibility for sibling/family involvement. In all the discussions, these were some of the most concrete, repeatedly mentioned conditions for making more distant care bearable.
3. Any future model should protect local neonatal stabilisation and trust. The evidence from the discussions suggests that families distinguish between planned specialist pathways and unforeseen emergencies. Solutions will need to show how local maternity-linked services will keep enough expertise, staffing confidence, and escalation support so centralisation does not create avoidable risk before transfer.
4. Any future model of care should explicitly incorporate later reflection. Several participants described leaving hospital in survival mode and only realising later what had or had not worked. A single feedback point close to discharge will miss important evidence.

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6 SUMMARY AND CONCLUSIONS

What parents told us and what this means for future service design

6.1 Summary

The discussions with parents across the North West have been fascinating, and humbling in equal parts. We are extremely grateful to the forty participants who took part in this engagement exercise for speaking so openly and honestly about the trauma they experienced during their neonatal journey, including those who faced bereavement.

Against that context, this review provides a qualitative account of parental experience to inform proposed redesign of neonatal critical care services in the North West of England. The underlying Case for Change is that some units do not meet national standards, specialist capacity is uneven, and there is a policy direction towards concentrating intensive and high dependency care in fewer, larger centres.

The evidence base in this report is qualitative and intentionally exploratory: fieldwork comprised three focus groups and eleven one-to-one interviews, involving forty parents in total. We would also like to explicitly draw attention to the fact that the sample is small, engaged and not statistically representative of all families in the North West.

Parents do not treat clinical safety and family experience as separate issues. They largely accept transfer or more distant specialist care when the safety case is visible and convincing, but that support is conditional. It depends on rapid local recognition and stabilisation, clear explanations, safe transfer, predictable repatriation, and practical arrangements that allow parents to remain close enough to stay involved in care.

The most consistent weaknesses described are not episodes of overt clinical harm, but process and relational failures, namely:

- Fragmented communication;
- Inconsistent standards between units and shifts;
- Weak interpreter access;
- Abrupt separation from baby and siblings, and
- Avoidable burdens linked to travel, parking, accommodation, and childcare.

The importance of Family Integrated Care (FiCare), plain-English communication, and protected parent/baby proximity as operational requirements for safe and humane care are consistent needs rather than optional enhancements.

The wider significance of the findings is that any future service model is likely to be judged not only on activity thresholds, workforce sustainability, or estate efficiency, but on whether it:

- Reduces avoidable separation;
- Improves continuity; and
- Mitigates the practical and psychological burden placed on families.

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Discharge preparation, post-discharge follow-up and mental health support emerge as particularly important weaknesses, suggesting that pathway redesign should extend beyond the neonatal cot to the full family journey before, during and after admission.

6.2 Conclusions

From the discussions with this small sample of parents it is possible to draw the following conclusions:

A. Specialist concentration appears acceptable to parents only where the clinical rationale is explicit and the family consequences are actively mitigated.
- **Evidence type:** qualitative focus groups and interviews; synthesis against the Case for Change.
- **Assumption:** claimed outcome gains from centralisation still require primary quantitative validation through activity, transport, and outcomes data.

B. Parent-baby proximity should be treated as a core safety enabler, not a comfort issue, because parents repeatedly link presence to trust, participation, bonding, and readiness for discharge.
- **Evidence type:** journey mapping, cross-cutting themes, verbatim accounts.
- **Assumption:** operational impact on breastfeeding, readmissions and patient experience should be confirmed through routine data.

C. Communication failures materially weaken informed participation and confidence, particularly where jargon, poor cross-team coordination or late interpreter use are present.
- **Evidence type:** recurring parent-reported communication examples across multiple sections.
- **Assumption:** the prevalence of these failures across all units is unknown and needs audit evidence.

D. Variability between units, and sometimes within units, creates a perceived ‘postcode lottery’ in standards of care, support, and discharge preparation.
- **Evidence type:** comparative parent narratives and the deep-dive section on consistency.
- **Assumption:** standardisation costs and feasibility need provider-level operational assessment.

E. Practical inequality is one of the strongest themes in the report; distance becomes most harmful where it combines with poverty, lack of transport, postnatal recovery, work pressures, or childcare responsibilities.
- **Evidence type:** parent narratives on parking, fuel, hotels, public transport, sibling separation, and income strain.
- **Assumption:** full equality implications require broader sampling and a scenario-based equality impact assessment.

F. Discharge and post-discharge support are insufficiently standardised, leaving parents anxious at the point when monitoring falls away and responsibility increases.
- **Evidence type:** discharge and follow-up sections; parent accounts of abrupt transition.

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- **Assumption:** links between discharge variation and downstream urgent care use require primary local data

G. Psychological and peer support should be considered integral to pathway design because trauma often emerges after the acute phase and current provision is uneven.

- **Evidence type:** deep-dive findings on mental health and follow-up; repeated references to "survival mode."
- **Assumption:** demand, uptake and staffing models need further analysis before scaling.

6.3 Recommendations

This leads us to make the following outline recommendations for consideration by the programme team:

- Publish a parent-facing service model and minimum pathway standard. This should explain the clinical Case for Change, what will remain local, when transfer is required, and what families can expect at each stage.
- Adopt a mandatory family support standard for all pathways involving higher-level neonatal care. At minimum this should cover accommodation, parking, travel reimbursement, rest space, Wi-Fi, food access, and sibling-sensitive arrangements.
- Protect local stabilisation capability and clarify transfer and repatriation rules. Centralisation should proceed only with explicit assurance on emergency recognition, neonatal transport escalation, maternal transfer and return closer to home when clinically appropriate.
- Standardise communication, interpreter access, and Family Integrated Care practice across the region. Introduce plain-English communication standards, comprehension checks, visible interpreter pathways, and consistent expectations for parental involvement in care and ward rounds.
- Implement a standard discharge and community handover pathway. Discharge preparation should begin early, include hands-on training and rooming-in where feasible, and end with a clear written plan, named contact and joined-up community follow-up.
- Commission a staged mental health and peer-support offer extending beyond discharge. Support should be trauma-informed, universal in offer, and timed both during admission and after families have had space to process events.

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6.4 Alignment of conclusions and recommendations

The table below maps the main conclusions to the priority actions that most directly address them.

Conclusions	Linked recommendations
Conditional support for specialist concentration; importance of local capability	Publish a parent-facing service model; protect local stabilisation, transfer, and repatriation
Parent-baby proximity and practical inequality as safety issues	Set a minimum family support standard covering accommodation, travel, parking, and sibling support
Communication, interpreter access, and inconsistent standards	Standardise communication, interpreter practice, and FiCare expectations
Weak discharge, follow-up, and mental health support	Introduce a standard discharge pathway and staged psychological and peer-support offer

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APPENDIX ONE: MAPPING THE CASE FOR CHANGE TO PARENTAL RESPONSES

The table below maps the main discussion themes and verbatim evidence from discussions against the Case for Change:

Discussion guide theme	What emerged from discussions	Illustrative quote	Alignment with the Case for Change
What matters most	Physical closeness to the baby was treated as foundational, not optional.	*"…being able to be next to her all the time"*	Qualifies the Case for Change: any redesign must prevent avoidable separation.
What matters most	Parents framed "excellent care" as proximity plus trust in teams.	*"…trust and confidence in the teams"*	Supports the quality/workforce rationale but expands it into a relational duty.
Right care in the right place	Some participants explicitly accepted longer travel when safety gains were clear.	*"If it means you're safe, and more importantly, your baby's safe"*	Supports, but only conditionally.
Right care in the right place	Specialist centres felt safer when they had a clearer plan and better explanations.	*"…it's a specialised hospital … the team was a lot, lot different"*	Supports the specialist expertise argument.
Right care in the right place	Families were willing to stay away from home if the unit could safely manage deterioration.	*"…we would rather have stayed"*	Supports capability over convenience for the sickest babies.
Travel and transfers	Parents saw separation during transfer as deeply harmful.	*"There shouldn't be a separation at any point."*	Challenges any option that increases separation risk.
Travel and transfers	Accommodation that kept parents physically close altered the experience of safety.	*"…being upstairs, you were there within minutes"*	Qualifies the Case for Change: accommodation is part of safe design.
Travel and transfers	Transfer pathways were not always clear enough, especially around repatriation.	*"…it's not always clear that you'll be transferred back to your local unit"*	Challenges current pathway clarity.

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Discussion guide theme	What emerged from discussions	Illustrative quote	Alignment with the Case for Change
Communication and compassionate care	Parents struggled with technical language during crisis.	*"I would not have a clue … what they were trying to say to me"*	Challenges current communication standards.
Communication and compassionate care	Cross-team coordination between postnatal and neonatal care was described as weak.	*"…the two teams don't really talk to each other"*	Challenges current operational integration.
Communication and compassionate care	Good transfer communication created a markedly different experience.	*"I was told every single step"*	Supports a stronger communication standard as a mitigation.
Inequalities and access	The discussions stressed fuel, parking, hotels, public transport, and childcare more than abstract inequality language.	*"…the cost of parking, the cost of the fuel now"*	Supports the equity rationale, but points to practical access barriers as the most visible form.
Family impact and practical support	Accommodation close to the unit was repeatedly valued.	*"…having that facility to be close to him … was so important"*	Strongly supports the Case for Change document's existing patient-insight points on accommodation.
Family impact and practical support	Other children were a major source of guilt and constraint.	*"I felt like I just abandoned him"*	Qualifies centralisation: sibling impact must be planned for.
Workforce and coordination	Parents sometimes felt they were compensating for staffing pressure.	*"I almost picked up the slack sometimes of the unit being understaffed"*	Supports the workforce-pressure claim in the Case for Change.
Workforce and coordination	Small markers of process failure affected trust and belonging.	*"I felt that we were forgotten"*	Challenges consistency and parent experience in current services.

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Discussion guide theme	What emerged from discussions	Illustrative quote	Alignment with the Case for Change
Workforce and coordination	Participants worried that centralisation could weaken local emergency capability.	*"Are we de-skilling the workforce?"*	Challenges any solution that concentrates expertise without protecting local teams.
Psychological support and follow-up	Many accounts described prolonged trauma.	*"…absolutely catastrophic for people's mental health"*	Exposes a gap: this needs more explicit weight in option design.
Psychological support and follow-up	Parents often could not reflect properly while still in the pathway.	*"…you're in that survival mode"*	Supports later follow-up and later-stage feedback collection.
Psychological support and follow-up	Bereavement-related preparation and expectations were sometimes poorly handled.	*"…the quiet room for cuddles until* (he) *passed"*	Exposes a gap around bereavement pathway design.

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Thank You

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