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Learning from parental experience in a neonatal surgical unit: a qualitative service evaluation

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ABSTRACT

Objectives Patient experience is directly related to health outcomes, and parental experience can be used as a proxy for this in neonatal care. This project was designed to assess parental experience of neonatal surgical care to inform future service developments and improve the care we provide.

Methods This was a qualitative study using rapid qualitative analysis. The study was carried out in a large neonatal surgical intensive care unit in the UK. Parents of infants treated by the neonatal surgical team between March 2020 and February 2021, during the COVID-19 pandemic were included. Purposive sampling was used to ensure that a representative range of parents were interviewed. A semistructured interview was created and tested in a previous phase of work. This questionnaire was used to ask parents open questions about different aspects of their infants' healthcare journey from the antenatal phase through to discharge from the neonatal unit (NUU).

Results Rapid qualitative analysis was employed, and parental experiences were grouped into five main categories: before admission to the NNU, initial admission to NNU, information and support, COVID-19 and discharge. Within these five groups, we highlighted positive experiences to be fed back to the healthcare teams to reinforce good practice, areas that warranted improvement and suggestions for service development.

Conclusions The wealth of data generated from the interviews has been summarized and shared with healthcare teams who are putting the service improvement suggestions into practice. The tool is available for services that wish to measure parental experience.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Parental experience is hugely important in the neonatal surgical setting, particularly in the context of family integrated care. However, formal assessment of this is lacking.

WHAT THIS STUDY ADDS

⇒ This is the first use of our recently-developed interview tool to gain an in-depth understanding of parental experience on the neonatal unit from admission to discharge.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Using the observations of a representative range of families, key areas of good practice and areas for improvement have been identified, leading to actionable suggestions for service improvements. Workstreams have been created to implement these improvements. Since these improvements were based partly on the perspective of 'difficult to access' groups, they may be more likely to successfully improve parental experience for the whole cohort of families we look after. In turn this is likely to reduce health inequality, be more effective and reduce wasted effort. While our findings can be adapted to assess and improve neonatal surgical care in other centers, the tool may be applied to other settings to define and address the needs of patients, service providers and other key stakeholders.

INTRODUCTION

Positive patient experience is associated with improved health outcomes[1] as well as being intrinsic to the delivery of humane care. Within the neonatal setting, parental experience can be used as a proxy for patient experience.[2] The Neonatal Critical Care Review emphasizes the need for enhancing the family experience.[3] Nevertheless, the 'Getting It Right First Time' (GIRFT) report for pediatric general surgery and urology in England and Wales acknowledges that 'the method of collecting patient experience data is lacking for pediatric surgery',[4] and the National Institute of Health and Care Excellence (NICE) guideline 'Babies children and young people's experience of healthcare' notes that since particular groups may be less likely to provide feedback, their views should be actively sought.[5]

Family integrated care (FICare) is an important component of modern neonatal practice. It establishes parents as partners in care by providing education and psychosocial support to enable them to gain confidence and become their infant's main caregiver. FICare improves health outcomes, including parental experience,[6 7] and our unit introduced a model of FICare in 2017.

In March 2020, the SARS-CoV-2 (COVID-19) pandemic abruptly changed the delivery of healthcare. A large-scale review demonstrated that the restrictions significantly negatively affected the care provided for neonates and led to a poor experience for parents, the wider family and healthcare professionals.[8] The authors highlight how bonding and developmental care practices suffered and articulate the unique characteristics of high-quality neonatal care and the extreme vulnerability of many neonatal patients.[9] A key message was that an in-depth understanding of the unintended consequences that COVID-19 has had in a neonatal setting was needed. There was also a need to create tools and guidelines to be able to adapt to any ongoing or future changes.[8]

Our project was designed in the early stages of the pandemic to capture how parental experience of neonatal surgical care had been affected and to inform future service developments.

METHODOLOGY

Participants

Participants in the study include parents of infants treated by the neonatal surgical team during the COVID-19 pandemic, between March 2020 and February 2021 were reruited in this study.

Design

A semistructured interview was developed and tested (online supplemental table 1). Key characteristics of patients and families had been defined previously to guide purposive sampling.[10] Information about the project was advertised using posters, social media and through the neonatal unit (NNU) staff. Families interested in participating were provided with written and verbal information available in a range of languages. Each interview was conducted by two members of the project team. Audio recordings were taken to enable accurate transcription. One interviewer transcribed the interviews verbatim. The interview team comprised 10 members and included nurses, a nurse manager, a trainee advanced clinical practitioner, and trainee and consultant surgeons and neonatologists. All were trained and coached in interview techniques and qualitative analysis by a clinical psychologist.

The project was delivered without funding except for translation services, supported by our pediatric surgery department.

Patient and public involvement

Parents are used as proxies for the patients in the neonatal setting. Parents have been integral to this work from design to completion. Parents were key stakeholders involved in the initial design, creation and cognitive testing of the interview tool. A different group of parents were the participants who were interviewed to generate our results and they have given suggestions for service improvements going forwards.

Analysis

Qualitative analysis is typically complex, time-consuming and arguably unsuitable in situations where information is sought quickly, such as during a health crisis. Thus, the project was informed by the 'rapid assessment process'[11] and particularly 'rapid qualitative analysis', which was adapted for this study.[12 13] Traditional qualitative methods involve detailed and time-consuming analysis of transcriptions which the researcher reads and re-reads repeatedly while they identify emergent themes and their relationship to each other, attempting to capture the experiences of participants. In contrast, rapid qualitative analysis is a form of 'top-down' analysis where many of the parameters are defined from the start, it is designed to answer specific questions about the service rather than produce a theoretically driven account of patient experience.

The interview questions provided the framework for the analysis. Each question was summarized using a neutral domain name, for example, 'preparation for leaving the unit'. A summary template was written listing all questions and domains, with columns for participant responses and quotations. An example of a summary template used in the analysis (online supplemental table 2). Any responses that did not fit existing domains were added to a new category. The summary template was piloted by the six members of the analysis team on one interview to test suitability. Minor changes were made to domains and an extra column detailing possible service implications was added. When consistency was established, transcripts were divided between the team for analysis, with each analyzed independently by two team members who agreed on a final summary for each participant. All summaries were combined to produce an initial matrix for all participants. The matrix was then divided between five members of the team who produced summary matrices for five aspects of the patient journey: before admission to the NNU, initial admission to the NNU, information and support, COVID-19 and discharge. A final summary of parental themes and service implications was created.

RESULTS

Twenty-four participants were recruited.Each of the characteristics deemed important by the stakeholder analysis in the phase I work were represented by at least one of the families recruited (table 1).[10] A total of 18 interviews were carried out, 6 interviews with parents together and 12 interviews with parents separately. A mixture of virtual and face-to-face interviews were undertaken as determined by participant preference. Interviews were typically between 30 min and 90 min. Descriptive results are presented further. The summary results tables (online supplemental tables 3–7).

Table 1 Participant characteristics

Participant characteristics: infant			Participant characteristics: parent		
Presentation (%)	Acute	96	Depravation index (1–10) (%)	1–5	54
				>5	42
	Elective	4		Unknown	4
Number of siblings (%)	0	38	Mother's age (years) (%)	<20	8
	1	33		20–25	8
	2	4		26–30	21
	3+	21		31–40	33
	Unknown	4		40+	17
Multiple morbidity (%)	Yes	71	Single parent (%)	Yes	13
				No	83
	No	29		Unknown	4
Antenatal diagnosis (%)	Yes	25	Marital status (%)	Single	21
				Cohabiting	38
				Married	33
				Separated/ divorced	0
	No	75		Unknown	8
Length of stay (days) (%)	1–14	8	Ethnicity (%)	White British	67
	15–31	42		Other European	17
				African	4
				Asian	4
	>31	50		Unknown	8
Care at another hospital (%)	Yes	79	First language (%)	English	76
				Other European	17
	No	21		Other	8
Care in another department within trust (%)	Yes	25	Highest education level (%)	None	4%
				Some high school	13
				High school	17
				College	17
				Bachelor's degree	13
				Master's degree	8
	No	75		Unknown	29
Highest level of care (%)	Ward	13	Internet at home (%)	Yes	58
	HDU	8		No	13
	NICU/PICU	79		Unknown	29
Specialty (%)	Upper GI/thoracic	12.5	Disability (%)	Yes	0
				No	67
	Lower GI	87.5		Unknown	33
Gestation at birth (weeks) (%)	24–27	33	Travel time to hospital (min) (%)	<20	21
	28–31	4		20–39	4
	32–35	21		40–59	38
				60+	8
	36+	42		Unknown	33

Continued

Table 1 Continued

Participant characteristics: infant			Participant characteristics: parent		
Gestation at presentation (weeks) (%)	24–27	4	IVF (%)	Yes	21
	28–31	21		No	60
	32–35	21		Unknown	29
	36+	54			
Current gestation (weeks) (%)	24–27	0	Multiple pregnancy (%)	Yes	8
	28–31	4		No	88
	32–35	4			
	36+	83			
	Unknown	8		Unknown	4

GI, gastrointestinal; HDU, high-dependency unit; IVF, In vitro fertilization; NICU, neonatal intensive care unit; PICU, paediatric intensive care unit.

Before admission to NNU

There was sometimes confusion among the parents who received a diagnosis postnatally as to why the diagnosis had been made antenatally, even for conditions not typically identified antenatally. A sense that a diagnosis may have been missed lowered confidence in the clinical team:

> *'We thought if anything would have been wrong, it would have shown on the amniocentesis.'*

The lack of diagnosis led to an inability to prepare for admission:

> *'[It was] overwhelming at first…felt hysterical at first but calmed down.'*

When a diagnosis had been identified antenatally, both partners being able to access counseling and appointments together was important:

> *'It is really upsetting to talk about it to be honest. I don't think I have processed it myself yet.'*
> *'I had to do all the scans on my own which I found really upsetting.'*

During admission to NNU

The initial transfer to the NNU was identified as a particularly stressful event:

> *'The transfer from one unit to another unit was the worst part of it all. It took a long time for the transfer to happen.'*
> *'I think a midwife should have taken me to neonatal, that would have been very helpful; they could have then said 'this is [baby]'s mum, could someone please show her around.'*

A recurrent theme was the importance of personalizing care:

> *'Young mums need a bit more support and a bit more explanation.'*
> *'I had had a C-section on a different ward and were unable to go anywhere, while [baby] was going to theatre, I could not come to [baby].'*

Staff kindness was easily recognizable, and the importance of the broader team on health outcomes was emphasized:

> *'To say it was a really rubbish situation it was really lovely, they were all great, understanding.'*

Comments on accommodation and non-clinical areas provided actionable information for service planning for established and potential new build:

> *'It's not a hotel but everything is perfect still.'*
> *'Got permit for free parking but there was still not always a parking space. Drove around a lot.'*

Comments on the clinical areas highlighted the need for increased privacy and natural light:

> *'…was ridiculous to deprive the babies of this much light.'*

The financial burden was acknowledged:

> *'It is extremely expensive to have a baby admitted to [hospital] due to the costs around it.'*

The availability of a kitchen to help decrease costs for families, lockable cupboards, free coffee and tea, reliable free Wi-Fi and a video link to access the ward when needed were all regularly raised and described as 'a lifesaver'. These interventions are relatively inexpensive ways to improve experience.

Information and support

Communication was a key theme, and overall, information was felt to be clearly presented and regularly updated:

> *'The amount of information about the baby was enormous; thanks to the quality of the team, I understand everything.'*

Diagrams were felt to be particularly useful, for example, to help visualize aspects of anatomy. Some families felt that staff were not always available, for example, at weekends. Understanding how to access the team was not always clear, especially early in the stay: what to do if the ward round did not enter their cubicle, for example.

Honesty was highly valued, including for bad news:

> *'I didn't feel that they were keeping any secrets. That's sometimes what you worry about, is there something they are not telling me.'*

However, when there had been a loss of trust, this had important consequences:

> *'There was an incident when [baby] got an abscess from a cannula that was inserted. We did not know how honest they were about this. … but it felt like they were trying to shove it under the carpet in fear of us complaining.'*

Continuity of care across staff groups appeared important:

> *'It is almost like you have the same nurse for the whole time really that you are in hospital because they all know what is going on and it is great.'*

Most knew and appreciated the offer of talking to a counsellor, but the team, particularly the nurses, were also an important source of support. Information about the experience of bereavement was striking; small things mattered and had a lasting impact:

> *'The stuff they did before [X] died and afterwards, it was never too much. Like we left some of his clothes here and they posted them out to us… I don't think I could have been as strong as I was if they weren't as strong as they were as well.'*

Participants with limited English appreciated the efforts to find interpreters but expressed a preference for quicker solutions:

> *'I would be happy with Google translate sometimes.'*

COVID-19 impact

Parents generally felt they and their baby were safe although desperate to get them home to their 'little bubble'. They worried they were potentially vulnerable:

> *'COVID was always at the back of the mind.'*

Strict implementation of infection prevention guidance was seen as reassuring. There was frustration over discrepancy between testing for visitors and staff:

> *'[We] Don't really believe in COVID but accept restrictions.'*
> *'It was just strange that the medical staff were not being swabbed.'*

Parents were able to clearly articulate the impact of restrictions:

> *'It must be horrible for babies to just feel rubber and plastic all the time.'*
>
> *'The only people who were touching her were medical staff. For 5 weeks we did not hold our baby, which made the bond we initially had disappeared. The only people touching her were medical staff for interventions.'*

Discharge

Parents generally felt well prepared for discharge; they noted help with paperwork and good follow-up from the surgeon and the team. Support from clinical nurse specialists, the community team and outreach nurses was important. This included emotional support, noted particularly by one parent who sadly lost their baby:

> *'There is nothing I can imagine that could have helped us more.'*

The distress generated when discharge was delayed was striking. Provision of 'goal-based' criteria for discharge might allow less focus on a specific time:

> *'It is a strange feeling to have your baby at home after long invasive support, which is why still having access in the community is essential.'*

With the benefit of hindsight, parents often acknowledged that they were not as well prepared psychologically as they thought, and they have become hypervigilant:

> *'A bit of a shock to the system, but nothing more could've been done.'*
> *'I just have to be more careful and really watch my baby for any signs.'*

Service improvements

The insights into parental experience have led to local service improvements and influenced projects already underway. Various workstreams were created to formulate meaningful responses to the parents' concerns, thereby developing our service and improving the care we provide. A summary of the resultant improvements is shown in table 2. A comprehensive list of the improvements made and further improvements planned can be found in online supplemental tables 3–7.

DISCUSSION

The value of measuring parental experience in the neonatal setting is well recognized. Despite this, NICE and GIRFT have highlighted the lack of mechanism for collecting these data and make a clear recommendation that this should be addressed.[4 5]

The impact of COVID-19 on neonatal care is emerging in the literature. Given the importance of FICare, it is understandable how visiting restrictions have been particularly detrimental in this setting. Work from across the globe has demonstrated how restrictions have negatively impacted parental well-being, increased parental concerns about bonding and childhood development, and reduced parental confidence in caring for their infant.[9 14–16] Our study adds support to these findings and

Table 2 Examples of service improvements

Aspect of patient journey	Examples of service improvements informed or instigated
Before admission to NNU	► Monthly fetal medicine multidisciplinary team meetings and 6 monthly reviews of fetal medicine clinic. ► Video tour of NNU now available prior to admission. ► Midwives now bring mothers to the NNU on their first visit, and the family care team provides orientation to the unit.
During admission to NNU	► Psychology service now in place. ► Parents are actively encouraged to attended ward round. Their attendance is recorded and audited across the service. ► Badgernet video diaries used frequently to connect families with their baby when not on the unit. ► New screens purchased to help provide more privacy. ► Parking permits available for families, some designated parking spaces protected for neonatal family use.
Information and support	► Joint neonatal and surgical ward rounds from Monday to Friday and weekly multiprofessional team meetings to have holistic oversight of progress and ongoing care planning. ► Every patient has a named neonatologist and named surgeon, with this displayed by the bedside. ► Poster with details and picture of staff uniforms and job roles to help families understand different staff roles. ► Hospital chaplaincy team starting to facilitate weekly coffee morning for families. ► Our new NNU podcast ‘Unexpected Beginnings: The Neonatal Unit’. This is hosted by veteran neonatal parents and runs through key aspects of being a parent on the NNU to provide support for other parents.
COVID-19 impact	► Regular communication and letters given to all parents in relation to any infection prevention control issues. ► Parental feedback on COVID-19 concerns disseminated to all teams involved in neonatal care.
Discharge	► Implementation of criteria-led discharge to help manage parental expectations and reduce delays on day of discharge. ► Multidisciplinary discharge meetings arranged for more complex infants, district general hospital teams invited virtually if there is a surgical neonate returned to local center. ► Weekly ‘discharge huddle’ to discuss patient flow, outstanding tasks and any family needs. ► Extra basic life support training sessions for staff so more staff is able to support parental training and reduce delays on discharge.

NNU, neonatal unit.

offers further insight from groups that are representative of the range of families we look after, including families traditionally seen as ‘difficult to access’. We have interviewed parents with a range of characteristics (eg, deprivation index, health literacy, first language, single-parent and two-parent families, ages, and distance travelled) whose infants themselves had a range of characteristics (eg, gestational age, disease complexity, and length of stay). We believe that this has made the information obtained more likely to reflect real-world experience and make the attempt to improve service delivery more likely to be effective.

It is valuable to have the perspective of families who have observed the service closely for many hours. Many of the issues raised have simple solutions, and we are collaborating with healthcare teams to develop and implement change. A number of the areas for improvement can be addressed by building on the ‘culture and values’ already in place. Other recommendations, such as the importance of kitchens, can be used to inform the plans for our new children’s hospital, currently under development. The insights into the direct and indirect impact of COVID-19 will inform preparation for potential future challenges. However, despite the context of the pandemic, most of the themes were not related exclusively to COVID-19. Therefore, we believe our results can give insight more broadly into the general experience of parents on the surgical NNU.

The amount of information obtained was extensive. This is hard to present academically and challenging to manage clinically. The main value of this project is taking these results forward so they can lead to service development. Several workstreams have been created, for example, the antenatal workstream, with input from relevant healthcare groups to prioritize the themes and actionable improvements.

From the beginning of this project, we understood the potential for scalability to other clinical pathways. Other aspects of care (clinical outcomes, process, and resource use) might usefully be considered by assessing cognitive diversity, and the methodology used here may be applicable. A recent study into crisis leadership in the health service in Slovakia during the pandemic found that having a detailed understanding of the perspective of representative stakeholders allowed cognitive diversity and was a source of trust, satisfaction, and engagement in medical teams and helped inform rapid decision making.[17] As in many fora outside medicine, it seems likely that capturing a variety of perspectives, and understanding the different needs and thought processes of a curated range of people will usefully add rigour to how services are designed.

We hope our interview tool and findings can be of use in other settings. While some observations may be specific to our center, others may be directly applicable elsewhere. The interview tool, however, is something that can be used widely.

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Contributors All authors (AL, EC, RM, FM, WM-N, HC, BJ, DM, EL, VT, JGM, GSS, LM, GL, JS) were involved in the conceptualisation of the work. GL, LM and JS led on study design. EC, HC, BJ, AL, GL, FM, LM, RM, WM-N and JS contributed to the data collection. EC, AL, FM, LM and JS contributed to data analysis, led by GL. AL, GL, LM and JS led on the written manuscript, with contributions from all authors (EC, RM, FM, WM-N, HC, BJ, DM, EL, VT, JGM, GSS) and all authors have approved the final version of the submission. JS acts as guarantor and takes full responsibility for the work.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants, but upon review by the Trust Research and Innovation Research Governance Lead, this project was confirmed as a service development project and thus did not require Health Research Authority or NHS Research Ethics Committee approval. Approval for this project was also obtained from the Trust Caldicott Guardian. All participants gave informed consent to participate in the study before taking part.

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Date and Time of Interview

Consent recorded? Y/N

Purpose of the interview and what we want them to do

Set out the main areas there will be questions so each get enough focus (e.g, before admission and early on, then during the stay, then communication, COVID-19, and thoughts around leaving the unit)

Thinking about when you were pregnant and when your baby was first born

1- What were your main worries about the thought of coming into hospital?
    a. Were you worried about the pandemic, or did the pandemic have any other affect?
2- Did you know what to expect for you and your baby's care once your baby was born?
    a. Did you think that the pandemic might have an effect?
3- Did you know who the team looking after your baby were?
    a. Did you know which consultant neonatologist and which consultant surgeon was in charge of your baby's care, and how the 2 link?
4- Were you made to feel welcomed by the team looking after your baby?
    a. Did you feel that they were approachable?

Thinking about the neonatal unit

1. What are your thoughts on the room(s) where your baby was?
2. What do you think about your privacy while on the ward?
    a. Do you think the pandemic affected your privacy?
3. Do you have any other comments regarding practical things that made a difference to you? For example, the parents' accommodation, refreshment areas, anything to do with your ability to travel to and from the hospital to visit or parking?
    a. Did you notice any effects on these that might have been caused by the pandemic?
4. Is there anything else about practicalities of being on a neonatal unit we should have asked you?

Considering the information and support you received

1. For your personal circumstance did you need additional help (for example an interpreter) and was this provided for you?
2. Did you understand your baby's diagnosis and treatment as much as you would have liked?
    a. Were you able to talk to nursing staff and the doctors as much as you wanted?
3. How do you feel about the amount of information you were given?
    a. Too much? Too little?
4. Were you ever given conflicting information?
5. Were you aware of how to access emotional and practical support for you before, during or after your baby's admission? Was there anyone who was a 'constant' person all the way through?

6. Is there anything you would have liked to have known that wasn't in the information given to you?
7. Do you think the pandemic affected the communication you received?
8. Were the rules about COVID-19 easy to understand?
    a. Were the rules always followed the same way by different staff members or families? Did you notice differences between rooms? What happened when rules weren't followed?
9. Do you recall the rules changing?
    a. If so, how soon did you get to know?
10. Did you feel confident that information about your baby's care was shared well between the members of the team, including nurses, doctors and everyone else in the team?

Thinking about COVID-19

1. Did the pandemic change how safe you felt for you and your baby?
2. Do you think that the pandemic and its regulations influence how you and anyone else important for your baby (for example your partner) were able to bond with your baby?
3. Do you have other children? Has having your baby in hospital affected them?
    a. Do you think that the pandemic affected this?
4. Are there ways in which you think the pandemic might have affected the way that staff cared for your baby?
5. Are there any other sources of stress that we have not asked about?

Leaving the unit

1. When you leave the neonatal unit, do you know if it will be to another ward, or to go home? How prepared do you/did you feel for discharge from the neonatal unit?
2. Did someone make you aware of the support that is available to you for when you do get home, for example, coming to A&E, seeing your GP, support from family?
3. Do you have any particular concerns for your baby once they are at home, having had surgery?
4. Are there any additional concerns or practical problems caused by the pandemic?

Time Interview Finished

Supplementary Table 1. Interview Questions

Question	**Domain**
Thinking about when you were pregnant and when your baby was first born	
What were your main worries about the thought of coming into hospital?	General anticipatory worries (including effect of COVID-19)
Were you worried about the pandemic, or did the pandemic have any other affect?	
Did you know what to expect for you and your baby's care once your baby was born?	Expectations of newborn care (including effect of COVID-19)
Did you think that the pandemic might have an effect?	
Did you know who the team looking after your baby were?	Knowledge of team
Did you know which consultant neonatologist and which consultant surgeon was in charge of your baby's care, and how the 2 link?	
Were you made to feel welcomed by the team looking after your baby?	Feeling welcomed
Did you feel that they were approachable?	
Thinking about the neonatal unit	
What are your thoughts on the room(s) where your baby was?	Parental view: room
What do you think about your privacy while on the ward?	Parental view: privacy (including effect of COVID-19)
Do you think the pandemic affected your privacy?	
Do you have any other comments regarding practical things that made a difference to you? For example, the parents' accommodation, refreshment areas,	Parental view: practicalities (including effect of COVID-19)

anything to do with your ability to travel to and from the hospital to visit or parking?	
Did you notice any effects on these that might have been caused by the pandemic?	
Is there anything else about practicalities of being on a neonatal unit we should have asked you?	
Considering the information and support you received	
For your personal circumstance did you need additional help (for example an interpreter) and was this provided for you?	Presence of additional help (if needed)
Did you understand your baby's diagnosis and treatment as much as you would have liked?	Understanding /ability to talk to team
Were you able to talk to nursing staff and the doctors as much as you wanted?	
How do you feel about the amount of information you were given?	Information amount
Too much? Too little?	
Were you ever given conflicting information?	Presence of conflicting information
Were you aware of how to access emotional and practical support for you before, during or after your baby's admission? Was there anyone who was a 'constant' person all the way through?	Access to emotional/practical support: Before – During – After; consistency
Is there anything you would have liked to have known that wasn't in the information given to you?	Unmet information needs
Do you think the pandemic affected the communication you received?	Information about COVID-19
Were the rules about COVID-19 easy to understand?	Understanding of COVID-19 rules (differences/changes/consistency?)
Were the rules always followed the same way by different staff members or families? Did you notice differences between rooms?	

What happened when rules weren't followed?	
Do you recall the rules changing?	
If so, how soon did you get to know?	
Did you feel confident that information about your baby's care was shared well between the members of the team, including nurses, doctors and everyone else in the team?	Parental view: information was shared between team
Thinking about COVID-19	
Did the pandemic changed how safe you felt for you and your baby?	Feeling safe
Do you think that the pandemic and its regulations influence how you and anyone else important for your baby (for example your partner) were able to bond with your baby?	Impact on bonding with baby
Do you think that the pandemic affected this?	
Do you have other children? Has having your baby in hospital affected them?	Impact on siblings
Do you think that the pandemic affected this?	
Are there ways in which you think the pandemic might have affected the way that staff cared for your baby?	Parental view: impact on staff
Are there any other sources of stress that we have not asked about?	Other sources of stress
Leaving the unit	
When you leave the neonatal unit, do you know if it will be to another ward, or to go home? How prepared do you/did you feel for discharge from the neonatal unit?	Preparation for leaving unit

Did someone make you aware of the support that is available to you for when you do get home, for example, coming to A&E, seeing your GP, support from family?	Awareness of support available
Do you have any particular concerns for your baby once they are at home, having had surgery?	Concerns at home
Are there any additional concerns or practical problems caused by the pandemic?	Other concerns

Supplementary Table 2. An example of a summary template from our analysis

Before Admission

Knowledge of the baby's condition

Themes	**Quotes**	**Actions**	**Service improvements**
Difficulty processing antenatal diagnosis The need for clear information in this period Potential for unintended consequences of knowing there may be an abnormality Importance of balanced antenatal discussion to managing expectations	*"Was told but didn't want to believe it"* *"Conflicting information carried on throughout the whole antenatal period... If you are already anxious, nervous and have no idea what is going to happen, it is frustrating."* *"It is really upsetting to talk about it to be honest. I don't think I have processed it myself yet."*	Feedback to staff on real world positive and negative effect of antenatal counselling Need updated parent information leaflets	Monthly fetal medicine MDT clinic- includes neonatologist, obstetrician, surgical nurse, midwife and paediatric surgeon Fetal medicine clinic reviewed 6 monthly Antenatal counselling- includes support information- paediatric immediate life support, practical advice Close links with family care team on NNU- meet parents, orientate to the ward, answer practical questions Video tour of NNU now available
The value of trust in staff by parents who need confidence in professionals	*"Felt safe already, staff brilliant"* *"I know someone from my hospital that was transferred here with their heart the wrong way round; so I know it is a good hospital"*	Feedback to staff and the potential to roll out feedback network-wide	Family care team Poster about good communication tips for staff- considering parent feedback
Confusion when some congenital abnormalities were not detected on antenatal scans	*"We thought if anything would have been wrong, it would have shown on the amniocentesis"* *"overwhelming at first…'felt hysterical at first but calmed down"*	Need to conduct work to determine what this group of families need to know in the immediate, short term and long-term Consider postnatal meeting between foetal medicine and families if further explanation needed. This could include review of antenatal scans and review of performance to serve as audit	Neonatology team can link to obstetric team to meet parents for de-brief if required

Parents' general worries

Themes	Quotes	Actions	Service improvements
Parents frightened about first going onto the unit Parents worried about the wellbeing of their other children	*"petrified"* *"didn't know what was going to happen"*	Video tour to show the rooms and incubator 'Supersibs' and sibling support packs potentially useful	Video tour of unit now done and being updated. This is shared antenatally Neonatal operational delivery network (ODN) work stream to include videos for other units Our neonatal unit podcast "Unexpected Beginnings- The Neonatal Unit". Hosted by veteran neonatal parents going through key aspects of being a parent on the neonatal unit to provide support for other parents, including an episode on 'Juggling Siblings'

COVID-19 specific issues

Themes	Quotes	Actions	Service improvements
Difficulty of antenatal care with COVID-19 restrictions. It was difficult for the mother to attend scans and clinics alone, and difficult for the father to be excluded	*"I had to do all the scans on my own which I found really upsetting"* *"It's like being separate families as being split up so often!"* *"It was too much information to take in on your own"* *"Husband felt left out and couldn't do anything"*	Consider video consultations as a standard offer when a parent is unable to attend because of COVID Consider partner in terms of ongoing bonding and long- term well-being of the child as well as parents	Regular communication and letters given to all parents in relation to any IPC issues Families kept updated
Parental uncertainty about risks of COVID-19 for baby Conflicting information about COVID-19 protocols	*"scared that [baby] would get COVID-19 and she is obviously very vulnerable"* *"The rules kept on changing all the time. You would ask someone questions about our appointments regarding COVID-19 regulations, and nobody really knew the answer"*	Collaborate with local, regional and national teams Regional Q&A or FAQ as an efficient mechanism of information dissemination	Parental feedback on COVID-19 concerns and communication disseminated to all teams involved in neonatal care Presented regionally and nationally also

Preparation for Transfer			
Themes	**Quotes**	**Actions**	**Service improvements**
Parents found transfer very stressful and found it hard not to be allowed to travel with baby	*"The transfer from one unit to another unit was the worst part of it all. It took a long time for the transfer to happen, but the people were lovely"*	Feedback to local transport network and involve them	Members of research team are actively involved in Neonatal Operational Delivery Network (ODN) co-production work streams to include project outcomes in all work eg -transfer of surgical neonate information resources about all neonatal units in the region -align practiced regionally to reduce the variability of care across the regional NNU Working with the neonatal ODN and local neonatal transport service to help families access information and resources about transfer and the different type on neonatal units Our regional neonatal transport team routinely collect feedback on care and transport experience with a quick response (QR) code on the incubators/beds. As a transfer involves care in multiple centres this inherently collects feedback on the differences between centres. Our unit is looking into using bedside QR codes as a tool to collect timely feedback.

Supplementary Table 3. Before admission

Admission to Hospital

Initial phase of care

Themes	**Quotes**	**Actions**	**Service Improvements**
Appreciation for welcoming team	*"to say it was a really rubbish situation it was really lovely, they were all great, understanding"* *'felt like a family'*	Feedback to all staff, especially nursery nurses, the very positive comments	Fetal medicine MDT workstream commenced to support service improvements- 6 monthly review meetings Veteran parent volunteers back to support families Metric to ensure parents spoken to in first 24 hours Psychology service now in place We need to reintroduce 'super sibs'- volunteer service supporting siblings on the neonatal unit
The need more support around transitions and initial admission	*"I started crying at the cot of a baby that was not mine, because I thought that was [baby]. That is how little information I had upon admission"* *"I think a midwife should have taken me to neonatal, that would have been very helpful; they could have then said 'this is [baby]'s mum, could someone please show her around"*	Consider an 'Induction' for new families as we do for staff. Perhaps this could be a role of the surgical liaison neonatologist Consider video tours of the unit that are updated with any ward change with in future waves of the pandemic	Welcome posters on NNU- practical information Family care team involvement- orientation to unit etc Named neonatologists/Surgeons Two neonatal consultants are now assigned as designated links to the surgical team Communicated to midwife team to bring mother on 1st visit Plan to develop photo books of the unit/equipment etc

			“Unexpected Beginnings- The Neonatal Unit” podcast episodes on ‘what is a neonatal unit?’ and ‘meeting your baby for the first time’
During Admission			
Themes	**Quotes**	**Actions**	**Service improvements**
Parents valued individualised care Physical and emotional challenges will exist for all new mothers following the birth; some will be particularly vulnerable Language barriers were addressed well. Interpreters ere offered and available but they were not always very effective. Some families preferred faster, easier and less official means	*“The beads, Vcreate etc., white board were all very helpful. It was nice we could decorate the cot, it was all personal”* *“young mums need a bit more support and a bit more explanation”* *“I had had a C-section on a different ward and unable to go anywhere, while [baby] was going to theatre, I could not come to [baby], nobody was able to come and get me”* *“Language barriers are professionally dealt with”* *“Some interpreters difficult to understand”* *“ I would be happy with google translate sometimes”*	Tailor information and advice to the specific family. We need to be aware of specific groups and characteristics that may need tailored care. These could include; ‘young’ mums, family that conceived through IVF, those with language barriers, families with other health needs Feedback on interpreting services and their use. Think how best to use interpreting services; Offer translation in different ways (person/app/google) for day to day work. Need to consider information governance risks phone applications	Simple measures were very appreciated and helpful Badgernet videos regularly utilised Events to promote with staff on special occasions eg Mother’s Day, Fathers Day, Easter, birthdays etc Staff utilising virtual interpreting services more often in addition to face-to-face: telephone, video, google translate

Operational issues

Themes	**Quotes**	**Actions**	**Service improvements**
Importance of clear introductions and clear channels of communication	*“important to have one person you can talk to, one person you are happy with, you could go to talk to and trust”* *‘big unit, moved rooms a lot so didn’t get to know many nurses well; Was told who surgeon was but did not meet until after surgery’*	Named nurses and named consultants needed (medical and surgical) and ensure the link between the neonatal and surgical teams is clear Reminder to staff importance of introducing themselves and their role	Parents actively encouraged to attended ward round. Their attendance is recorded and audited across the service Named consultants Name boards at bed space for families to see Joint neonatal and surgical ward rounds daily Discussion with expert transport teams to develop feedback mechanisms so families can feedback on whole of healthcare journey

Building, environment, and practical issues

Themes	***Quotes***	***Actions***	***Service improvements***
Appreciation of accommodation with the clean, spacious, private rooms nearby. This eased financial worries Appreciation for WIFI Travelling and parking a common source of stress as well as the indirect expense of the admission	*“a life-saver”* *“it’s not a hotel but everything is perfect still”* *“It is extremely expensive to have a baby admitted to LGI due to the costs around it”* *“Got permit for free parking but there was still not always a parking space. Drove around a lot”*	Acknowledge the financial strain associated for these families Inform planners of new building that the kitchen is very important, and parents need their own space within this. And note the importance of wifi to the Digital Leeds project mentioned by commissioners No easy parking solution. Perhaps promote public transport and be clear with parents what the parking situation is like, so they know what to expect	Family care team and lead oversee all aspects of parental care & support Family integrated care well established on NNU Financial support from hospital charity for families Some meal and refreshment provision. Ability to order parent food out of hours for families transferred in Families have access to hospital parent accommodation/ facilities-free of charge. Designated parent facilities-kitchen, sitting/dining room

			Free parking permits available for families. Some designated parking spaces protected for neonatal family use
Issues with building structure and lack of privacy	*“all parents could hear about our child and we knew about theirs”* *“There was no natural light. I could not believe the room would be designed like this, and this was ridiculous to deprive the babies of this much light.”* *“The rooms are so loud, what with the building being this old, which is bad for the babies I believe.”*	With the planned new build, we need a mix of single rooms and open bays, private space for families and more reclining chairs Ensure appropriate access to screens/rooms/secure environment for expressing	New screens purchased to help provide more privacy in surgical newborns area. Screens have an ‘under the sea’ theme to match the room décor. The screens are wall mounted between each bed space There is a designated breastfeeding room and parent consultation room already in place for additional privacy

Supplementary Table 4. Admission to hospital

Information and Support on the NNU

General

Themes	Quotes	Actions	Service Improvements
Information was clearly, presented, diagrams were useful Parents distressed when they searched online to find information	*"The amount of information about the baby was enormous; Thanks to the quality of the team, I understand everything"* *"It is difficult to understand; diagrams have solved all this; It is not the difficulty of the information that was upsetting, but the content and how rushed everything inevitably was"* *"a bad move because you only ever remember the bad stuff from those websites"*	Encourage use of diagrams, have some standard diagrams of normal anatomy and some showing abnormalities we encounter what we can then draw on Ensure good written and web resources for parents provided or signposted	Neonatal project work stream set up to help review and implement service improvements Photo books planned to be developed- linking in with ODN co-production work streams Surgical outreach signpost parents to resources/websites/charities All parent information leaflets reviewed for quality of information and will be available shortly for families and staff
Parents felt the team were always honest, even if giving bad news	*"as much as I didn't want to hear it, looking back I think well, I needed to hear it. As much as it's a job for them, they're doing the best possible thing which is being honest."* *"I didn't feel that they were keeping any secrets. That's sometimes what you worry about, is there something they are not telling me."*	Feedback to staff their candour is noticed and appreciated	Continue this care
Care felt personal	*"is almost like you have the same nurse for the whole time really that you are in hospital because they all know what is going on and it is great"* *"to have a bit of a giggle amid all the seriousness felt very human"* *"The family care team was absolutely amazing. Always present, every single day. 'Do you need this', 'do you need that'. It was brilliant"*	Aim for consistency in staff over different shifts	Positive feedback to staff given to share feedback from families and to encourage continues good practice for supporting families We need to review process for continuity of care from nursing team
Feeling of being overwhelmed by having an unwell baby	*"I basically said goodbye to him before surgery thinking the worst. I completely understand that they would paint the worst picture"*	Prepare parents as best as possible with explanations, photos and videos	Development of psychosocial MDT underway - links with unit safeguarding nurses

	“I never knew anything about neonatal medicine, so it was completely new”		
Some poor communication	*“We never got the amount of information about the stoma we wanted …Nobody came to sit down with us about that procedure before it happened”’* *“Communication could have been better and promises should be kept: Excluded from room during precious visiting time because of procedures with other babies; procedures delayed and parents not updated as promised”* *“Would like to have spoken to surgeons more, the surgeon actually doing operation we only caught by chance and we had about 30 seconds to speak to them”*	We need to work on improving communication. Specific areas highlighted that we need to be aware of include: - Anomaly screen is particularly stressful – i.e., looking for other abnormalities when one has been found - Less information is available at weekends - Parents sometimes too tired to take things in – need things repeating - Hard to hear staff when wearing a mask	Better joined up MDT working to help with communication, decision making and consistent care planning including: - Joint neonatal and surgical ward rounds Mon-Friday - Weekly multi-professional team meeting to have holistic oversight of progress ongoing care planning Named consultants for each surgical neonate- neonatal and surgical - to lead with care, communication and decision making. Named consultants meets with family for updates Name boards at cot-side so families know who named consultants are Parents encouraged to attend ward rounds Audit on parent presence on ward rounds Nursing staff advocate for families and request meeting with surgeon/neonatologist if family request Poster with details and picture of staff uniforms and job roles to help families understand different staff roles Poster shared with staff with helpful ‘top tips for good communication’. This was shared in Neonews (our weekly neonatal newsletter)

Conflicting information presents a large problem	*"I saw 4 consultants on different days, and everybody wanted to do something"* *"If you change the plan every single day, how will you know if it was working or not?* *"The teams did not really communicate well. They would tell us one thing and then 5 hours later they told us they were not going to do it anymore"* *"It was a bit cross-wired, because someone had said he had had a good night, but then it turned out he had not had a good night and was sick a lot"*	Need to improve internal communication for consistency If there are different opinions or the plan needs to change then we need to explain why	As previous
Specific			
Parents were aware of the counsellor but low uptake of service	"..might have been easier if it was in person. Talked to the staff instead" *"the nurses' job is even harder now, where you have to be additional emotional support because the parents don't have it from anywhere else"*	Needs to be more visible and accessible Nurses seen to be very supportive, but particularly important for families when isolated from other support	Psychology service now embedded on NNU Hospital Chaplaincy team starting to facilitate weekly coffee morning to support families Lots of resource posters with QR codes to help signpost families to support Hospital charity funds available to apply for families needing financial support
Bereavement care	*"The stuff they did before X died and afterwards, it were never too much. Like we left some of his clothes here and they posted them out to us... I don't think I could have been as strong as I was if they weren't as strong as they were as well"*	Feedback to staff Encourage ongoing training with butterfly trust	Funding for a bereavement nurse- not in post yet Close links established with regional hospices Bereavement clinical room available
Video links are helpful in reducing anxiety	*"a God-send and helped us through… For any parent, mum or dad, it is the best thing"*	Extend the utilisation of virtual platforms to support families	Bagdernet video diaries used frequently to connect families with their baby when not on the unit

Supplementary Table 5. Information and support on the neonatal unit

Impact of COVID

COVID-19 information

Themes	Quotes	Actions	Service Improvements
Parents generally felt well informed and accepted the rues Frustration about rule changes	*"there were signs everywhere. I was told in advance when I had to get my covid test, when dad was supposed [to get his]"* *"Don't really believe in Covid but accept restrictions"* *"The rules kept on changing all the time… You would ask someone questions about our appointments regarding COVID-19 regulations, and nobody really knew the answer"*	Be transparent regarding uncertainty or when things have changed	Regular communication and letters given to all parents in relation to any infection prevention and control (IPC) issues

COVID-19 worries

Themes	Quotes	Actions	Service Improvements
The potential risk to the baby was a constant additional worry	*"Covid always at the back of the mind"*	Be mindful of the impact of covid and how worrying it is	The COVID-19 team at Leeds Children's Hospital provided written information More psychological support available

What families thought went well

Themes	Quotes	Actions	Service Improvements
Feeling safe that the staff followed rules and visitors were not allowed	*"tested regularly - what more could they do - Really good, doing everything"* *"I did not feel unsafe at any time. I have seen the staff cleaning their hands, changing their aprons, gloves etc"* *"I think the pandemic made it kind of safer"*	If any further waves we should be reassured our measures made parents feel safe Acknowledge previously unrecognised positive impact of the infection control rules eg some parents enjoy stricter visiting policies	More information about testing
Frustration that there were sometimes double standards – social distancing for parents	*"told off for not social distancing but then the staff were all round the work station – looks like work most of the time but not always! Didn't like that"*	Staff must follow rules	Written information was created which acknowledged that rules may change over the course of the pandemic. This recognised the

but staff congregate around station Discrepancies between hospitals	*"It was just strange that the medical staff were not being swabbed"* *"There did seem to be a little discrepancy regarding family visits"* *"We were so happy that the rules in Leeds were more lenient towards that"*	Be open to people pointing out discrepancy and be able to explain or correct Need consistency of rules between different wards and units or explanation for differences Comparison with other centres needs feedback to network real time to identify useful differences	variability between centres and over time. Written information also explained that beyond COVID-19 there are differences between hospitals, and it is not possible and not always appropriate for centres to be the same Paediatric Grand Rounds provided a time to highlight any concerns
The restrictions caused stress. Parents worried about their other children not bonding with the baby and worried about the development of the baby who is only interacting with people hidden behind personal protective equipment	*"Sibling only sees on facetime/photo. Doesn't talk about baby"* *"siblings didn't see twin before he died"* *"these are Newborns the first few weeks of their lives are critical for bonding"* *"they learn a lot from facial expressions"* *"the only people who were touching her were medical staff. For 5 weeks we did not hold our baby, which made the bond we initially had disappear only people touching her were medical staff for interventions"* *"It must be horrible for babies to just feel rubber and plastic all the time"* *"the nurses got [sibling] a Build-a-Bear, a storybook, which was brilliant, and helped us massively. [Sibling] is 5 years old. He realises he has a brother, and is able to give him little presents, and keeps being interested in all the updates, but has never managed to see him in real life"*	Nurses very engaged in helping siblings bond – positive feedback for build a bear Acknowledge impact on siblings and offer advice In end-of-life cases we should reconsider sibling visiting. The siblings weren't able to visit a dying sibling, they had to wait until he had already died and was in a hospice. This seems very difficult and needs addressing	'Sibling packs' created to ensure siblings that were unable to visit had activities to involve them in care Understanding of the importance of relatives visiting for end-of-life care led to more visiting being allowed in end-of-life care as the pandemic progressed

Supplementary Table 6. Impact of COVID-19

Discharge

Preparedness for leaving the unit

Theme	**Quotes**	**Action**	**Service Improvements**
Parents generally felt well supported in preparation for discharge Can be stressful if discharge delayed Importance of support from clinical nurse specialists, community team, and outreach nurses Some realised with hindsight that they were not as well prepared psychologically as they thought	*"The LGI gave us all the information we needed"* *"The outreach nurses have been amazing"* *"Bit of a shock to the system….but nothing more could've been done - getting psyched up"* *"I don't think I was prepared in a way. I think I thought I was."* *"We were desperate to leave hospital"*	Ensure family utilise Family Integrated Care documentation re discharge planning Consider wider family in discharge planning- utilise virtual forums for training/information Need clear discharge criteria and communicate this to family. If discharge is 'goal based' then families will be perhaps less focussed on an agreed time that may then change Reality of discharge different than expected – we need to work on this transition and managing expectations	Multi-disciplinary discharge meetings arranged for more complex infants Family integrated care imbedded in the ethos of care delivery. Discharge planning document utilised Weekly 'discharge hudddle' to discuss patient flow and what needs to be completed and any family needs, teaching, information etc plus weekly MDT ward round to highlight discharge needs. Feedback to the neonatal surgical outreach team the positive feedback on their involvement Extra BLS training sessions for staff so more staff able to support parental training and reduce delays on discharge Implementation of criteria led discharge- helps manage parental expectations and reduce delays on day of discharge
Managing bereavement of a newborn	*"There is nothing I can imagine that could have helped us more than was already done for us after the baby's passing"*	Continuity of care important for end-of-life care	

Adjusting to life at home

Theme	Quotes	Action	Service improvements
Good follow up support provided Re-admittance can be unexpected and difficult - some happy if needed to come back in, some not as prepared as they thought Many parents had built up a high level of trust in the hospital team, and sometimes worried about a perceived lack of expertise in their local hospital/ health visitor when home	*“in safe hands”* *“We felt prepared to go home. We just had not anticipated that he would have to be readmitted to hospital. I do not think anyone could have known”* *“Even now that we have been discharged, we are always assured to have contact with the ward in case something goes wrong or for more questions”*	Continue to signpost clear communication channels for families at home Acknowledge that readmissions emotionally difficult - need preparation Professional conversations with family needed to reduce lack of trust in other organisations	Current service review of Neonatal surgical outreach provision and what service needs are Aim to improve parent contacts and availability for specialist discharge planning and education Outreach nurses go to district general hospitals (DGHs) to facilitate earlier repatriation and joined up care with DGH and tertiary centre. DGH team invited to MDT virtually if there is a surgical neonate returned to local centre
The difficulty of adjusting to life at home Feeling isolated at home on discharge Appreciation for community teams	*“We had to get used to life out of hospital. All the alarms, beeping and those noises”* *“It is a strange feeling to have your baby at home after long invasive support, which is why still having access in the community is essential”* *“I just have to be more careful and really watch my baby for any signs”* *“quiet but struggling”* *“There’s always those things in the back of your mind and you don’t want to sound an idiot to the doctors asking what if, what if, what if?”* *“We haven’t really seen anyone since we came home. … It has just been us in our own little bubble. It is difficult some days”*	Feedback to community teams Make time to answer all questions prior to discharge Need to signpost sources of support for parents including outreach, GP, health visitors, mental health support	Feedback to community team “Unexpected Beginnings- The Neonatal Unit” podcast episode ‘Going home’ explores issues around getting reading to go home, adapting to life away from the neonatal unit, managing the associated anxiety and the role of the transitional unit in the process Good coordination of discharge and communication facilitates. Needs some review and improvement

Supplementary Table 7. Discharge from hospital