

Developing a method to capture parental experience in a neonatal surgical centre in the context of COVID-19: a qualitative study

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ABSTRACT

Introduction Improved parental experience is related to improved mental and physical health outcomes for the infant. The COVID-19 pandemic abruptly impacted on healthcare delivery and services need information to shape how to manage the disruption and recovery.

Methods Our aim was to develop a systematic process to capture parents' experience of their neonatal surgical healthcare journey during the pandemic. We identified relevant stakeholders and using semistructured interviews, we explored three key themes.

- (1) How to recruit and collect data from representative parents?
- (2) What questions should be asked?
- (3) How to disseminate results for service development?

Results Responses indicated the need to involve 'difficult to access groups' (eg, first language not English, high social deprivation, low health literacy), defined the range of family and patient characteristics variables to be considered for representative responses (eg, antenatal diagnosis, disease complexity, number of siblings, single parent, parental health). The proposed questions were grouped into five main topics: information preadmission; in-patient experience; support during admission; the effect of COVID-19; discharge and posthospital experience. Recommendations for dissemination included local, regional and national fora as well as the need to feedback to participants about the changes made.

Based on the analysis, we developed a semistructured interview which underwent cognitive testing, prepilot and pilot phase testing.

Discussion This protocol is grounded in the views of relevant stakeholders to ensure it captures relevant information in a pragmatic but methodologically sound way. It will next be used to assess parental experience in a large neonatal surgical unit. We hope that the protocol could be adapted and used by other groups.

INTRODUCTION

Patient experience is a key element of healthcare quality, alongside safety and clinical effectiveness. Patients who have a better experience generally have better health outcomes.¹

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Improved parental experience leads to better outcomes for the infant but systematic methods for assessing parental experience are currently lacking, particularly in a neonatal surgical setting.

WHAT THIS STUDY ADDS

⇒ We have created a systematic tool to assess parental experience. This tool can be adapted and used in different settings with the methodology we have shared.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Understanding the perspectives of a considered group of stakeholders improves planning and delivery in a range of situations outside health and is likely to become increasingly important within healthcare. Recognising the needs of less easy to access, but potentially vulnerable, service users is clearly important when trying to improve all outcomes, as well as improving experience. Similarly, the perspectives of staff involved in care (service providers, managers and funders) is likely to be valuable when planning service delivery more broadly.

Within the National Health Service (NHS) information about patient experience is used to identify areas requiring quality improvement and to inform commissioning. The 2010 White Paper, 'Equity and Excellence: Liberating the NHS' had at its core an emphasis on improving patient experience.²

Within the neonatal setting, parental experience is used as a proxy for patient experience.³ It has been widely shown that improved parental experience is significantly related to better outcomes for the infant.⁴⁻⁶ Furthermore, parents who are supported, educated and involved in the care of their baby have better long-term mental health outcomes and



their infant's neurodevelopment outcomes improve.⁷ Understanding the best method of recording patient or parent experience has been studied widely in recent years.⁸ The Picker Institute has designed and validated a questionnaire to assess parental experiences of neonatal care and undertaken data collection on a national scale.³

The experience of parents of surgical neonates is less well understood. For most, a surgical diagnosis brings an additional layer of complexity for an already stressed family and long-term sequelae for the baby and the family may, therefore, follow. The 'Getting It Right First Time' report for paediatric general surgery and urology in England and Wales has recognised that very limited data are collected to inform service transformation and tools in use have poor uptake.⁹ Improving methods to assess the in-hospital experience of children and their families is a key recommendation.⁹ The recent National Institute of Health and Care Excellence guideline 'Babies, children and young people's experience of healthcare' also recognises the central importance of experience in delivery of care and designing of services and the development of a tool to allow measurement of experience is one of only four research recommendations.¹⁰ Recognising there are 'particular groups who may be less likely to be involved in providing feedback on health services', the guideline recommends that the views of these groups should be actively sought.

In March 2020, the COVID-19 pandemic significantly impacted on healthcare delivery across the NHS. Severe restrictions were enforced, leading to reduced visiting and parental access to neonatal units. All non-essential patient/parent contacts, including parent education and support stopped/ceased, and parents and babies were often separated for prolonged periods.¹¹ Staff have highlighted the vulnerability of parents of infants in the neonatal intensive care unit (NICU) and the potential exacerbation caused by pandemic restrictions, calling for a focus on family well-being.¹² Thus far, however, the impact remains unknown for surgical newborns.¹³ It is not yet clear how restrictions might be adapted to minimise impact on families, and what the long-term implications for services and service users may be. Services need information to plan for recovery and to be able to assess and respond in a timely fashion for any reintroduction of restrictions in the future. Information gained during the pandemic may also offer insight into delivery of care in a non-pandemic setting.

OBJECTIVE

To develop a systematic process to capture parental experience of their neonatal surgical healthcare journey during the pandemic, using questions prioritised by a range of stakeholders; to evaluate how to disseminate any actional messages and for the project to be feasible and information governance compliant in the NHS setting.

This project was the first part of a two-phase piece of work. The second phase of the project was to use the tool

we developed to assess parental experience. This will be reported separately.

METHODS

The project was conducted in a large UK NICU caring for neonatal surgical and medical patients, with an established focus on family integrated care, and staffed by neonatal and paediatric surgical services. Data collection was between July 2020 and January 2021. The project was delivered by a multiprofessional group with a range of relevant expertise (see [table 1](#)) at pace, and unfunded, in the setting of the pandemic. The intention was for the work to be both 'good enough' and potentially reproducible in other clinical contexts or healthcare settings.

An initial scoping review was undertaken of published tools that measure parental experience in paediatric surgical patients. Given the novel context of the research, a decision was made to use qualitative methods, which allow a broader range of participant responses. Training was provided to the project team on qualitative interviewing and thematic analysis of qualitative data. We identified key stakeholders from the following groups: service users, service providers, service managers and service commissioners and funders. A broad range of stakeholders were approached to take part. Twenty-six of 35 identified stakeholders contributed ([table 2](#)).

A semistructured interview (SSI) was developed by the team, using open questions and relevant to the specific stakeholder. The purpose of the stakeholder interviews was to determine:

1. How to recruit representative parents and collect data
2. What questions should be asked
3. How to disseminate results for service development

Following consent, two members of the team performed the interviews. These were conducted following contemporaneous government guidance and COVID-19 etiquette, either remotely using Microsoft Teams or face-to-face. One member of the team interviewed the participant and the other recorded the meeting, to enable accurate transcription.

The SSI was piloted in two stages (pilot and pilot). Cognitive testing of the questions themselves was completed to confirm that respondents' understanding of the questions was as intended; for example, commonly used neonatal terminology such as 'TOF' may be interpreted both as tracheo-oesophageal fistula and Tetralogy of Fallot.

The transcripts were assessed using thematic analysis by a three-person team. Key themes and subthemes were identified within the three areas of specific interest and used to inform the development of a protocol (preparation for/delivery of interview) for use with parents in a second phase of this project. A registry of challenges and unexpected barriers was maintained in case of use when delivering other similar projects.

Table 1 Team members and expertise involved in project

Number	Initials	Team members	Expertise
1.	HC	Paediatric surgery trainee	Interview Preparation of manuscript
2.	EC	Paediatric surgery trainee	Interview Transcription Preparation of manuscript
3.	BL	Paediatric surgery consultant	Project lead Communication Managing deadlines Implementation and closedown Preparation of manuscript
4.	GL	Clinical psychology consultant	Project lead Qualitative analysis expert and project advisor Pilot and cognitive testing lead Training for qualitative interviews Preparation of manuscript
5.	EL	Medical student	Literature review Preparation of manuscript
6.	AL	Foundation trainee	Interview Transcription Organisation Preparation of manuscript
7.	DM	Medical student	Literature review Preparation of manuscript
8.	JM	Caldicott guardian	Information governance Preparation of manuscript
9.	LM	Neonatal consultant	Project lead Family integrated care lead Phase 1 analysis Interview Transcription Preparation of manuscript
10.	RM	Paediatric surgery trainee advanced clinical practitioner	Interview Transcription Organisation Preparation of manuscript
11.	FM	Neonatal surgery lead nurse	Interview Transcription Organisation Preparation of manuscript
12.	WM-N	Paediatric surgery trainee	Interview Transcription Preparation of manuscript
13.	GS	Health economist	Project overview Preparation of manuscript
14.	JS	Paediatric surgery consultant	Project lead Project steer Phase 1 analysis Interview Preparation of manuscript

RESULTS

How to recruit, collect and record data from representative parents?

Methods of recruitment recommended by the stakeholders were use of posters within the hospital, advertising on the unit's closed parent Facebook group (if allowed) and word of mouth. Interpreters would be available for both translations of conversations and for written

Table 2 Role of each stakeholder

Number	Stakeholder	Role
1.	Service users	Mother and father baby 1 Father of baby 2 Mother and father baby 3
2.	Service providers	Neonatal surgical sister x 2 Neonatal HCA x 1 Neonatal nurse x 1 Surgical outreach nurse x 1 Surgical consultant x 1 Neonatal consultant x 2 Paediatric surgical trainee x 2
3.	Service managers	Paediatric consultant & infectious diseases lead Children's service general manager Neonatal lead nurse Neonatal surgical lead nurse Paediatric surgery lead clinician Family integrated care nurse Caldicott guardian Lead nurse
4.	Service commissioners	Local clinical commissioning group Health informatics Women's health NHS improvement

NHS, National Health Service.

documents. It was noted that financial support for this would be necessary (the hospital management team, who had been formally involved from the beginning of the project, agreed to make this available).

Stakeholders recognised that a broad range of parents and patients would be needed to ensure that the unit's general parent population was reflected and to make implementation more likely to address the needs of those in greatest need of support. Characteristics thought by stakeholders to be important when recruiting were included in the data collection form (table 3).

It was recommended to consult COVID-19 experts on how guidance changed over time to allow data to be viewed in context. Stakeholders recommended that parents should be offered feedback from the completed study.

The recommended recruitment process started with advertising with posters in four languages in different sites on the neonatal unit and around the hospital and on Facebook. Initial contact was to be supported where needed by ward staff and permission for the project team to contact families recorded. This was a key step from the perspective of the Caldicott Guardian (and Trust lead for Information Governance) who reviewed the process. Reassurance was to be given to families that any data would be stored anonymously, in a way that was consistent with data protection rules, that participation (or non-participation) would not affect their care and that withdrawal from the study at any time was acceptable. Necessary demographic and clinical information about families willing to participate was to be obtained and

**Table 3** Screening template used to record patient and family characteristics and permission to view clinical records

Baby details		
Admission type	Acute/elective	
Antenatal diagnosis	Yes/no	
Has the baby been cared for within other areas of the neonatal unit or other wards in Leeds?	Yes/no	
Has baby been cared for in other neonatal unit?	Yes/no	
What was the highest level of care?	Ward area on surgical neonatal unit/High Dependency Unit/NICU	
Which surgical speciality?	Upper GI/lower GI/thoracic/general/urology	
Gestational age at birth	24–28/29–32 / 33–37/ >38	
Gestational age at surgical presentation		
Additional co-morbidities		
Length of hospital stay in days		
Parents/family details		
	Mother	Father/partner
Permission to review baby's medical records?	Yes/no	Yes/no
Has your baby been cared for at any other neonatal unit?	Yes/no	Yes/no
Have any previous children had care at this or another neonatal unit?	Yes/no	Yes/no
Would you consider yourself a single parent?	Yes/no	Yes/no
What is your postcode? How long did it take you to travel to hospital to see your baby? (in minutes)	Minutes	Minutes
In total how many siblings does your baby have?		
How many of these siblings live permanently at your home?		
Mothers age in years (please circle)	<20/21–25/26–30/31–40/40+ Prefer not to say	<20/21–25/26–30/31–40/40+ Prefer not to say
Marital status	Single Married Cohabiting Separated Divorced Prefer not to say	Single Married Cohabiting Separated Divorced Prefer not to say
Ethnicity		
First language (please specify)		
Will you require an interpreter?	Yes/no	Yes/no
Do you have access to WiFi at home?	Yes/no/yes but limited	Yes/no/yes but limited
Highest level of education	None Some high school High school College Batchelors degree Masters degree PhD or Higher Prefer not to say	None Some high school High school College Batchelors degree Masters degree PhD or Higher Prefer not to say
Do you have a disability?	Yes/no/prefer not to say	Yes/no/prefer not to say
Was this a multiple pregnancy (ie, twins triplets)?	Yes/no/prefer not to say If yes please specify	1.
Was this pregnancy assisted (ie, In Vitro Fertilisation)	Yes/no/prefer not to say	
On completion of this project would you like to receive feedback of our findings?	Yes/no Email	Yes/no Email
NICU, neonatal intensive care unit.		

stored in a secure manner accessible only to members of the study team; the wish of families to be contacted with feedback and preferred contact details were to be

recorded. Parents' choice of methods by which to conduct the interview (face-to-face, remote by videoconference using information governance safe programmes (MS

Teams or Skype) or by telephone was to be recorded). The need to ensure social distancing/PPE rules was recognised for face-to-face interviews.

All interviews were to be conducted by two members of the project team; one to ask questions and one to ensure that conversations were recorded, and then transcribed. This mechanism was deemed necessary to allow accurate recording and analysis of the discussion. A reliance on note taking during the interview, especially if done by the person involved in the discussion, was seen likely to lead to hidden bias and interrupt the flow of the conversation.

A room on the neonatal unit but away from the clinical area was deemed ideal but identifying space that was sufficiently private and not in use for clinical discussion with families or staff breaks (during the pandemic) was an important consideration. Written questionnaires were considered, but the project team decided that open discussion would yield richer data. Parents should be able to identify the best time for the interview to be conducted; given this was an unfunded project and that interviewers usually had clinical commitments, it was recognised that this may produce challenges and compromise may sometimes be needed. Parents should be given the questions before the interview to allow them time for consideration.

Data were to be recorded on a shared folder within MS Teams accessible only to team members. This included all transcripts and a spreadsheet setting out patient and family characteristics deemed important by stakeholders. The spreadsheet was to be updated as families were recruited.

Specific input from the Caldicott Guardian was obtained both during the stakeholder analysis stage and when finalising the protocol. This ensured that for this hospital and likely others working under the same rules, the project's information governance was not only appropriate but was also being implemented in the spirit intended. An unintended positive consequence was improved collaboration with the information governance team.

What questions should be asked?

Stakeholder suggestions grouped into five main topics: information before admission; in-patient experience; information and support during admission; the effect of COVID-19 on experience and discharge and posthospital experience. Subthemes were identified for each, and these informed the development of open-ended questions that would populate the parent interview. Stakeholders indicated that information about the whole healthcare journey should be captured if mentioned in interviews. This meant that factors affecting parental experience outside the unit's specific purview would be recorded and commissioners (and others) would have the opportunity to act. A prepilot stage, a pilot stage and then cognitive testing were completed. Results of this demonstrated that minimal refinements of the original

questions were required, and this was accordingly carried out. Questions used are listed in [box 1](#).

Dissemination of results for service development

The methods of dissemination recommended were verbal and written. Verbal presentations to local (eg, lead nurses and consultants, unit business meetings, governance meetings and hospital 'Schwarz rounds'), regional (eg, neonatal networks) and national bodies (eg, British Association of Paediatric Surgeons) were recommended. Written dissemination as a publication was suggested. Stakeholders recommended the use of quotes from people and then a series of recommendations.

Stakeholders advocated collaboration with management colleagues to ensure that suggestions were implemented. If the project identified 'quick fixes', then hospital operational meetings were recommended. If more challenging themes were identified, it was recognised that change may take a long time and be more difficult. Linking in with other relevant services, such as perinatal mental health services and a programme supporting people without access to digital technology at home, was suggested.

It was recommended that feedback be provided to participants about the changes made 3–6 months following the end of data collection. It was suggested that we provide a way for families to stay involved in supporting change in the long term. Reaudit or resurvey following intervention was suggested and a recommendation was made to obtain data to evaluate the link between the parent feedback and subsequent changes to parent experience and other aspects of care.

Interviews took up to 1 hour with commensurate amounts of time spent transcribing the discussion.

Unexpected issues encountered that may be applicable to other teams were noted (see online supplemental box 1).

DISCUSSION

As this project evolved, we realised that the pragmatic approach we had adopted has parallels to that of a 'rapid research' model. While our project is a service evaluation as opposed to research, the approach is similar. Rapid research is essential when a timely, 'good enough' understanding is required of a novel situation such as during the COVID-19 pandemic.¹⁴ The definition of 'rapid' can vary significantly and this phase of our investigation into parental experience falls well within that remit. One challenge for undertaking this study in a timely manner is the choice of a qualitative, interview-based methodology, often associated with a lengthy analysis stage. We, therefore, adapted the rapid qualitative methods for our purpose and setting.¹⁵

Service improvement/development and parent experience projects often take place without full inclusion of the perspectives of 'hard to reach' groups: ethnic minorities, non-English speakers and socially deprived groups. It

**Box 1** Template for the questions used

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 (eg, 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 two 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 (eg, 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 was not in the information given to you?
7. Do you think the pandemic affected the communication you received?
8. Were the NICU COVID-19 rules 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 were not 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 rules influence how you and anyone else important for your baby (eg, 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 the Emergency Department, seeing your General Practitioner, 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.

is imperative that all these groups are included to reduce health inequity, recognised to be a particular issue during the pandemic.¹⁶ The perspectives of a range of healthcare professionals and managerial colleagues add to this cognitive diversity, allowing more complete identification of real-world challenges and solutions. Ensuring that all stakeholder groups were involved has, therefore, allowed varied perspectives to influence the protocol for a definitive phase.

We recognised that completing the study would be challenging, as there was no funding available to support it. We acknowledge that the process would have been more efficient and completed in a more satisfactory time frame if we had dedicated time allocated to this project, as opposed to undertaking it alongside clinical commitments and the added pressures of the pandemic. Nevertheless, the project team was brought together by a common interest in improving outcomes through improving parental experience. The neonatal unit already had an ethos of collecting and using parental experience to develop the service as part of its family-integrated model of care. Within a limited period and with limited resources, we have demonstrated that it is possible to develop a systematic method to assess parental experience. We believe that the resultant protocol will be fit-for-purpose, data secure and allow equity.

There was a relatively low number of service users involved in this phase, both for the questionnaire and the pilot and cognitive testing. This was mainly because of time and the progression of the pandemic. Challenges encountered are set out in online supplemental box 1. We anticipate that some of these might be encountered were similar projects to be delivered elsewhere at a later date. We hope that by recording them, these challenges may be predicted and circumvented by other teams carrying out similar work. One other issue to be considered when eliciting parent perspectives on the impact of pandemic restrictions is that they may have no other experience with which to compare, and in hindsight we might have sought the views of parents who did have this experience.

The next phase of the project is to use the protocol we have developed to assess parental experience in a large neonatal surgical unit. It is also hoped that this may be adapted and used by other groups to measure parental experience in their units. Engaged and involved healthcare professionals and parents will help to develop more effective and family-centred neonatal services which is essential in ensuring optimal long-term outcomes for our patients and their families.

It has been argued that ‘while medicines are carefully tested with laboratory research and clinical trials before they can be licensed and prescribed for patients, health policies affect whole populations and have the potential for great benefit or harm, but they are often designed and implemented without transparent and balanced use of evidence or thorough evaluation of their impact’.¹⁷ Both on a local or on a larger scale, we recognise the potential to use stakeholder analysis methodology to influence policy for other aspects of our service, including clinical, academic, educational and

managerial issues. From early in our project, collaboration with a union representative and management colleague was undertaken with this in mind and as a way of improving collaboration to improve staff satisfaction and stability, therefore improving patient outcomes.

We describe a mechanism to rapidly obtain the perspective of a full range of stakeholders to determine a study protocol. As well as being applicable to carer experience on a surgical newborn unit during the pandemic, the methodology may be used in other settings, potentially with minimal resource and in the context of a pandemic.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants but the project was reviewed by the Trust R&I Research Governance Lead who confirmed that this did not require Health Research Authority or NHS Research Ethics Committee approval as this was service development. Approval for this project was also gained from the Trust Caldicott Guardian exempted this study. Participants gave informed consent to participate in the study before taking part.

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