

**Patient and public involvement in neonatal research –  
experiences and insights from parents and researchers**

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**Title: Patient and public involvement in neonatal research – experiences and insights from parents and researchers**

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## **Abstract**

### **Background**

Involving parents in decisions about the care of their infant is common practice in most neonatal intensive care units. However, involvement is less common in neonatal research and a gap appears to exist in understanding the process of patient and public involvement. The aim of this study was to explore parents and researchers' experiences of patient and public involvement in a neonatal research project.

### **Methods**

A qualitative design was employed, consisting of two focus group interviews, one dyadic interview, and four individual interviews with parents and researchers. The interviews followed a semi-structured guide specific to both parents and researchers. Data were analysed using content analysis as described by Graneheim and Lundman.

### **Results**

A total of nine parents and four researchers participated in the study. Seven themes were consolidated into three core concepts: *Embracing the ethos and pathos of patient and public involvement*, *Finding the path to maximise meaningful involvement*, and *Building expertise in patient and public involvement*. The core concepts highlighted both similarities and differences, as well as challenges and facilitators, of the experiences of the patient and public involvement process.

### **Conclusion**

Patient and public involvement in research was a mutually beneficial process, facilitating learning and reflective opportunities for parents and researchers. However, there were challenges that emphasised the need for rapport building between parents and researchers, valuing everyone's unique perspective and expertise, with clear communication and well-defined roles and goals. These insights offer a contribution for future patient and public involvement in health research.

### **Plain English summary**

It is usual practice to involve parents in decisions about their babies care in neonatal intensive care units, but their involvement in research is less common. Although patient and public involvement in research is increasing, there is a lack of strategies to ensure meaningful involvement.

This qualitative study used interviews, to explore how parents and researchers experienced patient and public involvement in a research project about couplet care in a neonatal intensive care unit.

Nine parents and four researchers participated and the analysis revealed several themes that describes their experiences. These themes were consolidated into three main concepts: 1) Embracing the ethos and pathos of

patient and public involvement, which focuses on the emotional and ethical aspects of involvement, 2) Finding the path to maximize meaningful involvement, which addresses the strategies and methods to ensure effective involvement, and 3) Building expertise in patient and public involvement, which emphasizes the need for developing skills and knowledge for better involvement practices. These core concepts provide a comprehensive understanding of how to enhance involvement, not only in the neonatal setting, but research in general.

### **Keywords**

Patient and public involvement, PPI, family-centered care, neonatal intensive care unit, NICU, qualitative research.

### **Manus**

## Background

Involving parents in decisions about the care of their infant is widely practiced across neonatal intensive care units (NICU) worldwide (1). However, parents' involvement can be hindered by their experiences of giving birth to a sick and/or premature infant, which for many can be stressful and traumatic (2). Family-centered care is one of the central pillars of modern neonatology care, whereby parental involvement is integrated into clinical practice (3). The four principles of family-centered care are 'dignity and respect', 'shared responsibility', 'knowledge sharing', and 'the embracement of a negotiated partnership between healthcare professionals and families' (3-5). Although involvement and establishment of partnerships are central within neonatal care, the principles are not widely adopted within neonatal research (6). However, for research to be relevant to this patient group, researchers need to understand the priorities of the family, especially following the emotionally distressing situation of having a sick and/or preterm infant (6).

The widely held principle of patient and public involvement (PPI) in research is defined as '*...research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*' (7, p. 6). PPI has gained traction in the movement toward involving and establishing partnerships with patients, families, and caregivers in research, not only as research participants but also as active contributors to the what and how research is conducted. The rationale for involvement is based on three key tenets: First, the democratic principle asserting that patients have a right to be involved in research about their health conditions; Second, politically and economically, the accountability and transparency of research are enhanced; and third, the experiential knowledge and lived experiences brought by the involved individual enhances the quality of research and potential impact (8-10). Consequently, PPI in research has rapidly evolved internationally, especially in Europe and North America over the past decade (11, 12). A growing body of evidence is investigating patient engagement and involvement, patient - researcher partnerships, and patients as co-researchers and the perceived benefits of this involvement (13). However, there appears to be a gap in understanding of the process that ensure involvement is meaningful is yet to be elucidated (13-15). The aim of this study was to explore how PPI was embedded into a research project and to explore parents' and researchers' experiences of being involved. This paper refers to 'parents' who were PPI representatives as active study partners.

## Study context

The current study describes the reflections of the PPI experience within a research project about couplet care in a NICU in the Capital Region of Denmark. Couplet care is defined as "*the provision of care for a sick and preterm infant in close proximity to and coupled with the care for the mother from the birth of the infant*" (16, P. 18). The research project consist of three studies, with the overall aim of assessing current knowledge and practice before implementation of couplet care. PPI was embedded in the research

project to enhance and improve the quality of the research, address gaps in practice from parents' perspectives, and support the design, methods, and interpretation of the project results. Eight families were recruited post NICU admission by one of the authors (EC) in 2022. During the families admission period EC worked as a physician in the NICU. Along with a nurse, she identified potential families and informed them about the project via phone. If the parents expressed interest, the first author (MB) contacted them and invited them to an initial meeting. The parents were recruited based on the following criterias: 1) Admission route in the NICU, 2) Ability to reflect on their personal experience and apply it on behalf of other families, 3) Knowledge of the NICU environment and care practices and 4) Experience of separation from their infant after childbirth. Parents had experience of the NICU between 2019 and 2021 and were perceived to possess relevant experiential knowledge. Seven families (n = 13 parents) consented to participate. However, one family moved to a different location during the study and were unable to attend meetings after the third session, and therefore did not participate in the research presented in this article. The sessions were facilitated by a team of four researchers, consisting of a PhD student and her supervisory team. The first session, the initial meeting, was held in January 2022 as an information sharing session. Parents participated actively in all sessions (outlined in Table 1), which aimed for a high level of collaboration and partnership.

**Table 1. Overview of PPI sessions**

<b>Session no. and date of sessions</b>	<b>Purpose</b>	<b>Activity</b>	<b>Objective of session</b>
No. 1 26-01-2022	Start-up session	<u>Plenum discussion:</u> <i>“If you could mention one thing you would have changed during the admission, what would that be?”</i>	<ul style="list-style-type: none"> <li>• Creating a safe and secure space and relationship in the group</li> <li>• Establishing a common foundation for collaboration and partnership</li> <li>• Introduction to the project and the role of being a family ambassador.</li> </ul>
No. 2 29-03-2022	Follow up from the first session and start-up session	<u>Two activities:</u> 1. Fathers group – how has it been to become a father 2. Input to questionnaires  <u>Home assignment:</u> Pilot-test of the questionnaires to be used in a quasi-experimental study	<ul style="list-style-type: none"> <li>• To come up with input and qualify questionnaires</li> <li>• To tell about their experiences of being admitted</li> <li>• Approval of terms of reference</li> </ul>
No. 3 08-05-2022	The parents were involved in the process of participant information and developing new name for the department	<u>Two activities:</u> 1. Finding a new name to the department – brainstorming session 2. Input and design of participant information to a quasi-experimental study	<ul style="list-style-type: none"> <li>• To bring ideas and input, design and qualify participant information</li> <li>• Identify a new name for the department</li> </ul>
No. 4 13-09-2022	The parents were involved in the process of qualifying and providing input to an observation guide	<u>Pre-activity:</u> 1. Reading extracts from the medical journal  <u>Two activities:</u> 1. Write down what you saw, hear, thought, did, and how it made you feel based on the parts from the medical journal 2. Write down advice to nurses and parents on post-it	<ul style="list-style-type: none"> <li>• To produce a first draft of an observation guide based on families’ experiences</li> </ul>
No. 5 27-02-2023	The parents were involved in the final qualification of the observation guide	<u>Pre-activity:</u> 1. Visit in the neonatal intensive care unit.  <u>Activity:</u> 1. Identify themes based on the notes to the medical records in session four	<ul style="list-style-type: none"> <li>• To identify with topics for an observation guide</li> </ul>

## Methods

The aim of the research presented in this article was to explore the experiences of PPI from both parents' and researchers' perspectives. A qualitative interview-based approach was carried out to answer the following broad research questions:

1. *What are the experiences and perceptions of both parents and researchers involved in the PPI activities?*
2. *What are the facilitators and challenges to participation in PPI activities?*

The methods and results are reported in this paper following the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist (17) (See additional file 1).

## Participants

All 13 parents and the four researchers from the couplet care research project were informed and asked to participate in the study; Nine parents agreed to participate, while two fathers declined for unknown reasons. The parents consisted of six mothers and three fathers, representing six families who were involved in the PPI sessions. The parents were all in their thirties, and their educational level ranged from having completed a school education to higher education. Four parent-couples were parents for the first time, with different birthing experiences. The gestational age of the parents' infants ranged from being born extremely premature in week 24 to full term in week 41+5, with an admission ranging from one week to approximately two months. The interviewed parents had attended at least two PPI sessions and had no prior experience engaging in PPI activities. The group of researchers consisted of one PhD student who facilitated the PPI sessions and three experienced clinical researchers (two professors and one associate professor) who co-facilitated the sessions, supported the PhD student, or acted as observers depending on the activities undertaken.

## Data collection

Parents interviews were conducted in November and December 2023, approximately two years after the first PPI session. These included two focus group interviews (FGI): One held online (n = 4) and one in-person (n = 3), as well as dyadic interviews (n = 2). The interview methodology, selected as the preferred method of collecting data as a means of exploring experiences, was chosen based on parents' preferences. Authors AB and IP who are experienced researchers conducted the interviews. Interviews used two semi-structured interview guides (See additional files 3 and 4), tailored separately for parents and researchers. In addition to the interview guide, posters featuring highlights from five sessions served as a recall supplementary guide during the interviews (See additional file 2). Individual online interviews with the four researchers were undertaken in December 2023 by author JS, who was the independent study adviser. The decision to use the external advisor was an attempt to ensure an open discussion and minimise bias if the



researchers interviewed each other. The interviews ranged from 32 minutes to 1 hour and 25 minutes (Mean 55 minutes). All interviews were voice recorded and transcribed using a web-based programme ‘Good Tape’, and then thoroughly read by the first author, to check for accuracy (MB).

### Data analysis

Data were analysed using Graneheim and Lundman’s (18) inductive content analysis. The analysis included seven steps: 1) Transcripts were read several times by MB to obtain an overall impression and familiarity with the data; 2) Meaning units of relevance were identified and subtracted; 3) Meaning units were condensed, keeping the description close to the text; 4) Each condensed meaning unit was labelled with a code; 5) Codes were linked into descriptive categories; 6) Categories were linked to developing themes, which explain and gives answers to the research questions. Tables 2 and 3 illustrate the process of moving from meaning units and codes derived from data to categories and themes. As an additional step, 7) Core concepts combining the parents’ and researchers’ interview themes were developed. Stages 2 -7 were an iterative process, where MB, AB, and IP debated and discussed the codes and categories until a final agreement was reached. JS reviewed the data in themes 6 and 7 as an additional quality measure.

**Table 2. The process from meaning units to codes (Step 2-4): Interviews with researchers and parents**

Research questions	Meaning units	Condensed meaning unit	Code
What are the experiences and perceptions of both parents and researchers involved in the PPI activities?	<i>“I didn't, at the beginning... I did not really know how this could happen, you know, how we would manage this one, but I think it was a good idea” (R2)</i>	At the beginning I didn’t think PPI design was appropriate. I didn’t not how we could manage in practice	Being sceptical
What are the facilitators and challenges to participation in PPI activities?	<i>“The main purpose was to kind of be sure that we read the needs of the families correctly. To kind of validate our thoughts about would this be good for you as well?” (R3)</i>	Families were involved to validate researchers’ thoughts if it would be a good idea for the families as well	Validating researchers’ thoughts
	<i>“But I think it was like a feeling that we could contribute in all sorts of ways, but we had no idea what I was, like what the framework was, and that made it difficult” (M6)</i>	Unaware of what the framework was, which made it difficult to contribute with what one could offer	Lack of framework
	<i>“It was different when we could actually meet the others at the hospital... It was different at the second meeting because we could be there in person, so it makes a big difference” (F1)</i>	It makes a difference to have a physical attendance than meeting online	Physical attendance

R = Researcher, M = Mother, F = Father

**Table 3: The process from codes and categories to a theme (Step 5 and 6): Interviews with researchers**

Theme	Embracing PPI philosophy			
Category	Shifting attitudes – from scepticism to importance	Towards mutual aspiration	Moral responsibility - mutual respect and engagement	Inclusivity
Codes	<ul style="list-style-type: none"> <li>• Being sceptical</li> <li>• Importance of PPI</li> <li>• Embracing PPI principles</li> <li>• Valuing possibilities of involvement</li> <li>• Overwhelmed</li> <li>• Qualification of study</li> <li>• Unsure of level of involvement</li> <li>• Uncertainty about utilization</li> <li>• Moral obligation to involve</li> <li>• Importance of engagement</li> <li>• Central in research</li> <li>• Improved research process and materials</li> </ul>	<ul style="list-style-type: none"> <li>• Meaningful engagement</li> <li>• Meet parents needs</li> <li>• Validating researchers’ thoughts</li> <li>• Valuing family perspective</li> <li>• Creating equality</li> <li>• Mutual understanding of perspectives</li> <li>• Shared values</li> <li>• Sense of achievement</li> <li>• Clear expectations</li> </ul>	<ul style="list-style-type: none"> <li>• Doing the right things</li> <li>• Having empathy</li> <li>• Engagement must be valuable</li> <li>• Creating safe spaces</li> <li>• Partnership</li> </ul>	<ul style="list-style-type: none"> <li>• Valuing time</li> <li>• Balancing all contributions</li> <li>• Ensuring inclusivity</li> <li>• Inclusion of parents’ voices</li> <li>• Actively listening</li> <li>• Bringing forth participant experiences</li> </ul>

**Results**

Four themes from parents and three themes from researchers’ accounts emerged from the data analysis. The final stage of the analysis involved merging these themes into three core concepts, giving insight into both parents’ and researchers’ experience of the PPI process. The three core concepts and the associated themes that emerged from the analysis are presented in Table 4. Parents extracts are labeled ‘M’ or ‘F’ for mother and father, respectively, and researcher extracts are labeled ‘R’, to maintain anonymity when presenting the data.

**Table 4: Core concepts and associated themes**

<b>Core concepts</b>	<b>Parents – themes</b>	<b>Researchers – themes</b>
<b>Embracing the ethos and pathos of patient and public involvement</b>	<ul style="list-style-type: none"> <li>• Altruistic motivation and family values</li> </ul>	<ul style="list-style-type: none"> <li>• Embracing PPI philosophy</li> </ul>
<b>Finding the path to maximize meaningful involvement</b>	<ul style="list-style-type: none"> <li>• Bringing the puzzle all together</li> <li>• The golden moment to participate</li> <li>• The continuum of involvement</li> </ul>	<ul style="list-style-type: none"> <li>• Meaningful engagement: Barriers and facilitators</li> </ul>
<b>Building expertise in patient and public involvement</b>		<ul style="list-style-type: none"> <li>• PPI skills development</li> </ul>

Table 5 presents a summary of the challenges and facilitators of PPI from both parents' and researchers' perspectives. The first author (MB) extracted these challenges and facilitators from the codes as the themes were being developed, to serve as key considerations to support future researchers in implementing PPI in research projects. The challenges and facilitators presented in Table 5 are a list, and not linked or paired statements.

**Table 5: Challenges and facilitators to patient and public involvement**

<b>Challenges</b>	<b>Facilitators</b>
Time-management of sessions	Creating a safe physical and mental space
Role-distribution of researchers	Diverse group of PPI representatives
Ensuring clarity of purpose and objectives	Consistency of researchers present in all sessions
Hybrid and online sessions	In person sessions and online sessions
Time span between sessions	Explicit and visual feedback
Knowing and drawing on PPI members competencies	Working in smaller groups rather than plenum discussions
Diverse group of PPI representatives	Debriefing
Pitching the activity at the right level	Role clarification
Timely interruption of discussions	Support within the research group
Balance between structure and flexibility	Having an expert facilitator as a part of the research group
Appropriateness of the activities	Time frame during sessions
Expectation alignment	Timing of sessions
Limited PPI experience	Deadlines
Adapting to new roles	Voluntary participation
	Thorough preparation and systematic planning

## **CORE CONCEPT 1: Embracing the ethos and pathos of patient and public involvement**

Both parents and researchers endorsed the principles and values associated with PPI in research, embracing both ethos and pathos. The concept included the themes of *altruistic motivation and family values* and *embracing PPI philosophy*. Parents' participation in the research process was motivated by a desire to amplify their voices for the benefit of future admitted families, a goal that was also shared by the researchers when considering PPI in research:

*"We wanted to be sure that we were doing things right and to hear their story, and to make the research more practical relevant, because we as researchers always think we know what's best for the patient, but is it really the best?" (R3).*

Listening to parents' stories and experiences was a motivating factor for using PPI in research, as it helped to qualify the couplet care study and meet the needs of those directly affected by the outcomes of the research. Three parents were motivated by their academic background and a personal interest in research. Although all parents participated altruistically, most of them found contributing resulted in a 'therapeutic space' as described by one mother:

*"There was also somehow some therapeutic aspect of being guided through some of these themes... so there was also some reassurance for me, that there was still some connection to the process we had been through. So, I also got something out of it myself" (M3)*

Most of the activities served as a therapeutic space where parents could re-enter their experiences. However, the act of revisiting the past to refresh their memories also brought forth negative emotions for some, such as feelings of claustrophobia when returning to the NICU. While the researchers perceived it was important to bring forth parent's experiences by bringing them back to their admission period, the parents felt that the activity did not fully serve its intended purpose. Their memories of the NICU admission were so deeply ingrained that they would not forget them, thereby making the activity unnecessary.

All four researchers described the importance of PPI and its centrality to health research. However, two of the researchers came to the study from an underpinning scepticism, feeling overwhelmed, and uncertainty about the level of involvement of families across the couplet care study, could be achieved.

*"I was sceptical of how we could actually involve people in the project, how it could be done in practice... are we just involving to involve, does it makes sense in this particular project" (R1)*

The researchers initial scepticism and uncertainty were primarily due to lack of experience, while they found the value and approach of PPI to be important. Their concerns centered around the practicalities of involvement and whether it could genuinely benefit the couplet care research project. Despite their initial scepticism, they experienced a shift in attitude, recognizing the importance of engagement and the moral

obligation to involve parents, which the other researchers shared. This shift highlights the evolving understanding and appreciation of PPI's value in research. Parents and researchers reflected on the ethical principles and emotional engagement, a dual embrace that underscores a commitment to PPI and the importance of integrating it into research.

## **CORE CONCEPT 2: Finding the path to maximise meaningful involvement.**

Finding the path to meaningful involvement was shaped by experiences and perspectives on how to maximise involvement through clear expectations and the structure of the activities. Parents and researchers emphasised the importance of a structured approach while enabling open discussion, addressing practicalities, and finding ways to enhance involvement. The core concept was formed of three themes from the parents' perspective: *'Bringing the puzzle all together'*, *'The golden moment to participate'*, and *'The continuum of involvement'* and one theme from the researchers' perspective: *'Meaningful engagement; barriers and facilitators'*.

Parents and researchers expressed a need for a clear purpose and defined expectations of each activity, which was a challenge during the sessions. Researchers highlighted that, at times, the purpose of some activities was implied, hindering the facilitation of the activities, which they attributed to a lack of planning and preparation. The researchers found it challenging to find a balance between a structured and flexible approach, as they wanted to embark on the research journey collaboratively with parents. Conversely, parents wanted the opportunity to work more freely with tasks:

*"I remember this particular activity very well, and I think it might be the freer and more flexible framework that allows for contribution in the way one wants or with whatever comes to mind"* (M3)

Parents highlighted flexibility in engagement, voluntary participation and the practical activities as essential and facilitating. Deadlines helped parents prioritise the activities while managing a family with small children, which was also a consideration when they agreed to participate. The sessions were planned on weekdays from 5 to 7 pm, as chosen by the parents, as researchers were mindful of finding the right time, format, and space for the activities, which were all perceived as facilitating for enabling parents involvement. There was disagreement among parents about the setting for the activities: some preferred the flexibility of online sessions, while others found it difficult to interact online. Researchers also noted this, acknowledging the benefits of online participation, but highlighted that the sessions should be either online or in-person, as hybrid sessions hindered inclusivity and overall involvement.

The balance between a more structured and flexible approach was a factor in time management during and between sessions. Parents perceived that the time between sessions was too long, and in hindsight, it might have been better to have more frequent sessions. Time management during the sessions was challenging, emphasised by both parents and researchers, as most sessions often ran over time. From the researcher's

perspective, this was due to lack of systematic planning and thorough preparation. While having a time frame, at the first session, the facilitator found it difficult to keep to time, not wanting to close discussions and requiring input from an experienced facilitator. Parents requested for sessions to keep to time, such as timely interruption of free discussion and more focus on the actual activity during the session to enhance involvement.

*“Maybe it goes back to the framing and structure, but to say ‘you can contribute with the free talk, but we have some things we need to get done’, something along those lines will probably be okay to say or ‘now you can talk freely, but afterwards we need to focus’ (M1)*

Parents found the scope of their involvement too broad and needed clear guidance, especially at the start of the project, where they struggled to understand the overall purpose of PPI and link to the couplet care project. Parents revealed that explicit feedback and a visualisation of their contribution would have been helpful and reassuring, and for some, the lack of feedback led to doubting the value of their contributions and a leaning towards not contributing. The researchers were aware of the need to acknowledge parents’ contribution but had not appreciated the level of feedback that would have been useful to parents. However, most parents perceived that they contributed significantly and were valued as an important part of the research process. Parents experienced varying depth of involvement throughout the activities, ranging from informing to empowerment. However, parents found the overall level of involvement to be appropriate:

*“I don’t feel like we’re not being listened to, at the level it is right now, but I agree that it has mainly been in providing input, and I think it has been very good... we hope and trust that you will take it forward to a level where decisions can be made and actions can be taken” (M4).*

Researchers reported that they initially aimed for a higher level of involvement, such as collaboration and partnerships, from the inception of the project. Most researchers emphasized that if they used PPI again, they would begin earlier in the research design process. None of the parents initially expected to be involved in a partnership with the researchers about the project; however, some ultimately experienced the relationship as such. The relationship between parents and researchers developed over time, facilitated by having the same individuals facilitate the sessions, which helped build rapport and foster successful work and collaboration. As one parent noted:

*“It gave a comfort, making it a safe space, that you were all [researchers] there” (M1)*

From the first session, researchers prioritized creating a physical and emotional safe space by providing food, a pleasant setting, and a spacious room, emphasizing a friendly and comfortable environment. This approach aimed at building rapport, thereby enhancing involvement and collaboration. Parents highlighted that dividing them into smaller groups with different tasks encouraged collaboration and discussion. This was effective across groups for example consisting only of mothers or fathers, mixed groups, or as couples.

Additionally, the diversity of parents in terms of education and experiences was also seen as a positive aspect of the collaboration and involvement. This perspective was shared by the researchers, who were conscious of recruiting PPI representatives with a range of backgrounds and experience. However, the diversity among parents also created challenges in delivering the sessions and activities, as experienced by one of the researchers:

*“I do believe that there were some who didn’t think they participated or did enough. For some, it was good to have the space to talk about their experience, but for others it was not enough. And in that sense, it was a diverse group of people.... I remember thinking that it was clear that the parents were very different, and all participated in a different way” (R3).*

It was challenging for the researchers to pitch the activities at the right level, balancing between easily achievable activities and those that required greater depth of thinking or were more emotive to ensure that everyone was involved meaningfully, and gaining information that could shape the couple care study. The researchers perceived it was important to invite parents to be involved in academic endeavours such as co-authorship of articles, however this wasn’t perceived as important for the parents. Some parents felt their professional competencies could have been used more, while others felt their involvement met their expectations:

*“I certainly think I have been used to the extent that I have been available, if one can say like this” (M2) “I feel the same way, but I also think that I actually could have been used more, since I work with exactly this in another format (M6).*

Parents emphasized that researchers need to provide guidance and examples on where and how parents’ competencies could be utilized. In some sessions with more complex activities, researchers found themselves having unrealistic expectations of the parents’ competencies, highlighting the importance of having in depth knowledge of the parents as PPI representatives, both in terms of their personal involvement by sharing their stories and their educational background.

### **CORE CONCEPT 3: Building expertise in patient and public involvement**

**The concept** ‘....’ included the researchers’ theme, ‘*PPI skills development*’, which was shaped by knowledge and skills development, role clarification, and reflexivity as researchers. The core concept was developed solely from the researchers’ perspective, as their experiences about facilitation, novice roles and knowledge of PPI were evident, while such experiences were not prominent in the parents’ experiences. The researchers followed a ‘learning by doing’ approach and despite their limited experience, they all developed their understanding of the theory and process of PPI before the first session through reviewing the literature, international guidance, and discussing with other researchers to maximise parents’ involvement in the sessions. Yet, the prospect was, for some, overwhelming, described as:

*“None of us had experience from PPI before... In the beginning, it was just learning by doing ...I got a little bit overwhelmed about it how much time you need to spend, also to plan the sessions, and I don't think that we have given it the time it needed” (R1)*

The researchers also drew on their experiences in similar situations, such as undertaking and facilitating focus group interviews, while acknowledging was different to facilitating PPI sessions. It was deemed essential for all the researchers to have an expert facilitator, at least as a part of the project group, with key skills to ensure that everyone feels heard:

*“I think you need some knowledge and experience in facilitating groups. And you need to be so confident in that role, that you can see, listen, and observe each individual family ambassador, but also the dynamic, what is going on in the group” (R4)*

The facilitator role was described as a role that needs developing and one that you become confident with over time. The role of the facilitating PPI within researcher was filled with uncertainty due to the adaption to a new role and the need for support. All the researchers highlighted that supporting each other was a facilitating aspect of the project and helped develop confidence with their own role during the PPI sessions. However, it was also perceived as difficult for the researchers to support each other in a meaningful way while being in a new role and situation oneself. Adapting to new roles was perceived as challenging and required ongoing self-reflection and openness to change. Role clarification was of concern for all the researchers in varying degrees and ways, along with the distribution of roles between them. At the beginning of the PPI process, the roles of the researchers were unclear, as described by the facilitating researcher:

*“It was difficult for me to know my role, and the others' role, and be comfortable with it, also because I am an introverted person, making it difficult to facilitate, and for instance, in one of the sessions the families were addressing R4 because she was the one taking charge in session one” (R1).*

The researchers continuously reflected on their roles, skills, and experiences of PPI both during and after the sessions. Debriefing was highlighted as essential after the sessions to discuss challenges, successes, and areas for improvement. However, the debriefing sessions were not always timely due to lack of planning.

*“We need to debrief. In the beginning, I was thinking and I had planned that we should debrief after each session. That was not happening. I think that was a big mistake. It was not happening due to several reasons” (R4).*

Continuous reflexivity and structured debriefing sessions were perceived as facilitating for the improvement of the sessions, though it was not given the time it needed. As the process continued, the roles between researchers became clearer, and the researchers developed skills and gradually turned their initial lack of experience into confidence when undertaking PPI activities. This growing confidence also extended between



the researchers themselves. Researchers, initially inexperienced in PPI, which led to a 'learning by doing' approach, ultimately grew confidence, fostering mutual trust and enhancing the PPI process.

## **Discussion**

The results of this study provides insight into parents and researchers experiences of PPI and potential challenges and facilitators to involvement in a research project. The results revealed that integration of PPI is a mutually beneficial process where both parents and researchers benefitted from the collaboration. The diverse group of parents and researchers brought varied experiences, highlighting the nuanced approach needed to maximize meaningful involvement. Key aspects of this included developing rapport, role and contribution clarity, practical organisation of sessions, clear communication and feedback, and balancing structure and flexibility of activities. These key aspects align with the results of other researchers who have examined the experiences of PPI process in depth (19-21).

Embracing both the ethos and pathos recognized the fundamental values of PPI while acknowledging the emotional aspect of engaging patients and the public in healthcare research. Researchers reflected on being aware of the tokenistic aspect of PPI, and the uncertainty of ensuring meaningful the involvement at the start of the study. This scepticism, often linked to researchers' inexperience with PPI, reflects broader criticisms that PPI can sometimes be reduced to a 'box-ticking' exercise (22). Such concerns emphasize the importance of providing clear guidance on the purpose of PPI, along with appropriate education and support, which was also evident in the results presented. When these elements are in place, PPI has the potential to move beyond mere tokenism and become a truly impactful part of the research process (23). The researchers in this study overwhelming wanted the parents to be involved meaningfully, and it was 'worth doing' in the current context of developing a new neonatal service. In recent years, there has been a focus on establishing the evidence base for PPI, with some studies and systematic reviews examining the impact of PPI (24, 25). However, it is argued that impact might be more usefully conceived as a form of experiential knowledge and might not enhance our understanding of when, why, and how involvement makes a difference (26).

Finding the path to maximise meaningful involvement, described in the second core concept, included the experiences of the PPI process being iterative, where researchers and parents continuously learned and adapted approaches. In line with this, the results highlighted the importance of thorough preparation for parents and researchers. Tasks should be identified based on the PPI representatives' and researchers' knowledge and skills, which was experienced as a challenge from both parents and researchers perspectives. Some of the parents found that their competences were not fully utilised and researchers thought parents would want to engage in academic activities for example through co-authorship, but this in general did not seem important for the parents. However, in contrast co-authorship has been identified as important part of PPI, with guidance available on how to best achieve these (27). Further, the diversity of the PPI

representatives, particularly in terms of their educational background and admission course, which the parents noted as a strength, made it challenging to balance the sessions. A diverse PPI group has been described in studies as important for PPI representatives and essential for reducing potential health inequality (19, 28). Training and preparation has in research been identified as essential to improve the perceived challenges of time and ethical issues in PPI (20). A possible way to balance and pitch activities at the appropriate level is through the training of PPI representatives, which has also been recommended in the literature, particularly in research methods (19). Training in research methods and PPI could enhance understanding of roles and expectations within the PPI process.

Our results emphasized the importance of identifying precise tasks, aims, roles, and expectations at every stage and for all involved. Previous studies have highlighted that misunderstandings can arise when there is a mismatch between the expectations of PPI representatives and researchers (19, 29). The misunderstanding could potentially explain some of the feelings of non-contribution and doubts about their involvement experienced by the parents in this study. Other studies have reported feelings of frustration, self-doubt, and the ‘real’ impact of their involvement in projects from the perspectives of PPI representatives (19, 30). In this study, the parents emphasized that more explicit feedback, both written and oral, could have alleviated some of these persistent feelings of non-contribution. Overall, the involved parents felt they contributed to the research process, ranging from being informants to empowerment, suggesting that involvement can take many forms and at various levels. This suggests that striving for a full partnership is not necessary for the involvement to be valuable for PPI representatives. Involvement can occur at different stages and in various forms, depending on the specific project, for example ranging from informing to engaging in partnership (31). Furthermore, PPI representatives role can change within the study, and it is important to be prepared for and attentive to this, to promote clarity and openness throughout the process (32).

Building expertise in patient and public involvement refers to a process which lies beyond simply enhancing the ability to involve parents in the research process. It emphasises key components considered essential for meaningful involvement. The hands-on experience was mentioned as invaluable, underscoring the differences between theoretical understanding and practical application. The need for earlier training on PPI and ongoing support for all members - particularly researchers and study staff – has been identified as an area for improvement in PPI (33). In our study, participating in the PPI process provided novel experiences for researchers and emphasized that facilitating and managing PPI sessions is rewarding but challenging. Previous research has found that role clarification and the setting of expectations are fundamental to successful PPI in health research (34). These findings, along with ours, suggest that greater role clarity, clear guidance and the presence of an expert facilitator can help alleviate some of the

challenges that may arise when managing PPI sessions, without having any particular expertise. Nonetheless, a review points to the growing recognition of the importance and value of PPI in health research (35).

## **Limitations**

This study provides insight into the experiences of PPI in a research project within a group of parents to sick and preterm newborns, that does not appear to have been previously described in publications. Due to the nature of the study, there are some limitations. First, the study explored experiences of PPI from the perspectives of parents and researchers involved within one single study and context, potentially limiting the transferability of the results to other research areas. Second, given the research group's involvement and the interviewers' role within the research project and the PPI sessions, it is possible that parents were more inclined to express positive attitudes and opinions than they would have done with an independent interviewer. Nonetheless, any potential bias is likely minimal, as the data includes positive and negative experiences, which were sought by ensuring confidentiality and an openly formulated interview guide. Furthermore, all researchers were highly experienced in conducting interviews. Third, the interview order may have influenced the researchers' interview, for example reading and analyzing parent data could have led to potential bias or alignment of researchers' own accounts. Researchers' perspectives could have been indirectly informed by the parents' experience, potentially impacting objectivity. Fourth, the study used different interview methods, which means that data are treated differently from the outset. The decision to use different interview formats was intentional, as we wanted to give the parents the autonomy to choose the interview that suited them best, while the four solo interviews were conducted based on the specific roles and expertise of the researchers. Each interview method has its own strengths and limitations, which should be considered. Compared to individual interviews, FGI and dyadic interviews may not explore individual perspectives but a collective response, and there is a potential that participants might conform to what others are sharing. However, the participants chose the type of interview they preferred, and did share positive and negative experience from the workshops and process.

## **Conclusion**

This paper outlines an example of a PPI process within neonatal research from the perspectives of parents and researchers involved. In conclusion, PPI was beneficial, offering learning and reflective opportunities for both PPI representatives and researchers. However, some challenges arose. Researchers' experiences were marked by initial scepticism, a lack of expertise, and difficulties in involving the PPI representatives effectively and meaningfully. Parents experienced mixed feelings of contribution and non-contribution, and they struggled to understand their roles and what researchers expected from them during the PPI process. The results underscore the importance of building rapport and ensuring diversity in the group of PPI representatives and academics despite this being a challenge. Furthermore, facilitating clear, open communication with well-defined expectations, roles, purpose, and goals on both an individual

and project basis is essential to the success of PPI. The experiences of PPI gained from this study provide points to pay attention to, when establishing new PPI groups and the involvement of PPI in research, both within neonatal care and research in general.

### **List of abbreviations**

Neonatal intensive care unit = NICU

Patient and public involvement = PPI

Focus group interview = FGI

### **Declarations**

#### **Ethical approval and consent to participate.**

The study was conducted in line with the Declaration of Helsinki. All participants received oral and written information about the study and provided written consent to participate. Data were handled confidentially and stored on a hospital-secured drive according to the Danish Data Protection Authority (Number: P-2021-872). According to The Danish Research Ethics Committee qualitative studies, including interview studies, are not reportable and therefore no ethical approval has been sought (Reference number: F-21056981).

#### **Consent for publication**

All participants have consented to the pseudonymised publication of the interview data.

#### **Availability of data and materials**

The datasets supporting the conclusions of this article are included within the article and its additional files or are available from the corresponding author at reasonable request.

#### **Competing interest**

None.

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#### **Authors' contribution**

MB: Methodology, Data analysis, Writing, Reviewing and Editing. IP: Data collection, Methodology, Data analysis, Reviewing, and Editing. EC: Reviewing and Editing. AE: Reviewing and Editing JS: Data collection, Methodology, Data analysis, Reviewing and Editing. AB: Data collection, Methodology, Data analysis, Reviewing, and Editing. All author(s) read and approved the final manuscript.

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### **Additional files**

Additional file 1: GRIPP2 long form checklist.

Additional file 2: Posters used during the interviews.

Additional file 3: Interview guide researchers.

Additional file 4: Interview guide parents.