



BMJ Open Identifying research priorities in newborn medicine: a Delphi study of parents' views

Abbey L Eeles ,^{1,2,3,4} Alice C Burnett,^{1,2,5,6} Jeanie LY Cheong ,^{1,7,8} Alex Aldis,⁹ Louise Pallot,⁹ Tien Polonidis,⁹ Krista Rust,⁹ Rod W Hunt,^{1,4,5,6} Clare Delany,^{10,11} Alicia J Spittle,^{1,3,8} The Centre of Research Excellence in Newborn Medicine

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For numbered affiliations see end of article.

Correspondence to

Dr Abbey L Eeles;
abbey.eeles@mcri.edu.au

ABSTRACT

Objective Neonatal conditions can have lifelong implications for the health and well-being of children and families. Traditionally, parents and patients have not been included in shaping the agenda for research and yet they are profoundly affected by the neonatal experience and its consequences. This study aimed to identify consensus research priorities among parents/patients of newborn medicine in Australia and New Zealand.

Design Parents/patients with experience of neonatal care in Australia and New Zealand completed an online Delphi study to identify research priorities across four epochs (neonatal admission, early childhood, childhood/adolescence and adulthood). Parents/patients first generated key challenges in each of these epochs. Through inductive thematic analysis, recurring topics were identified and research questions generated. Parents/patients rated these questions in terms of priorities and a list of questions consistently rated as high priority was identified.

Participants 393 individuals participated, 388 parents whose children had received neonatal care and 5 adults who had received neonatal care themselves.

Results Many research questions were identified as high-priority across the lifespan. These included how to best support parental mental health, relationships between parents and neonatal clinical staff (including involvement in care and communication), bonding and the parent-child relationship, improving neonatal medical care and addressing long-term impacts on child health and neurodevelopment.

Conclusions Parents with experience of newborn medicine have strong, clear and recurring research priorities spanning neonatal care practices, psychological and other impacts on families, and impacts on child development. These findings should guide neonatal research efforts. In addition to generating new knowledge, improved translation of existing evidence to parents is also needed.

Preterm birth (<37 weeks' gestation) and serious neonatal conditions, such as major congenital abnormalities, typically require urgent neonatal hospitalisation and critical care, and can have lifelong consequences for the babies and their

Strengths and limitations of this study

- Participants in the study were experts in newborn medicine by virtue of their lived experience (adults whose children received this care or adults who received neonatal intensive or special care).
- The study involved extensive parent/patient engagement from its methodological design to the interpretation and dissemination of the findings.
- A three round electronic Delphi survey was used to identify consensus research priorities among parents/patients of newborn medicine in Australia and New Zealand.
- We took a holistic, lifespan perspective, inviting parents/patients to identify research priorities across different time points, from the neonatal period to adult life.
- Participants were predominantly mothers (university educated) of children born preterm.
- The priorities identified may not reflect the experiences of the wider family unit, including fathers and partners, or the experiences of patients themselves or people with lower socioeconomic status.

families. In Australia, 18% of liveborn babies require care in a neonatal intensive care unit or special care nursery (NICU/SCN).¹ Significant research efforts are directed towards diagnosis of these conditions, improvements to procedural care and clinical outcomes. However, the topics researched are almost exclusively directed by researchers and clinicians, and there is a growing awareness that the views of parents of patients or adults who have experienced time in NICU have not been sufficiently understood or incorporated into research strategy.² Parent/patient involvement can improve the quality and impact of research by using the unique expert knowledge acquired through lived experience, which is unlikely to be represented by other stakeholders.³ Parent/patient involvement also recognises their



inherent right to contribute to research directions and methods.⁴

Existing studies involving parent/patient research in newborn medicine have restricted their scope to specific time periods, such as pregnancy and the neonatal period⁵⁻⁷ or childhood,⁸ and/or to specific questions, such as interventions and treatments⁶ or defining a core outcome set for neonatal research studies.⁹ While parent/patient priorities have been reported separately from those of other stakeholders in these studies, sampling only parents/patients is likely to have the least risk of authority bias on the opinions expressed. In studies focusing on the antenatal and neonatal periods, families have highlighted prevention and prediction of preterm birth, care of mothers, psychosocial support for families during and after hospital admission, treatments for newborn medical complications, infant feeding and the presence of health inequities as high priorities.⁵⁻⁷ Parents/patients also highlight the following outcome measures as their priorities for any research study: rates of survival, major medical complications or conditions, healthcare-related adverse events, pain and suffering, as well as impacts on the parent–infant relationship.⁹ When parents/patients were asked to consider the childhood period, education, social-emotional outcomes and parental well-being emerged as high priorities.⁸ These studies represent important early advances in understanding what research domains are important to parents/patients in newborn medicine. However, these parent/patient views were collected together with clinician/researcher views, which may have introduced authority bias. There remains a need to listen to the independent perspective of parents and patients in generating and prioritising areas of research and to take a holistic, lifespan perspective that acknowledges the potential for priorities to evolve across time. Therefore, this study aimed to identify consensus research priorities for newborn medicine among parents/patients, with an explicit focus on independent parent/patient-generated priorities from the neonatal period to adult life.

METHODS

Design and participants

This study used an electronic Delphi survey, a well-established method for enabling a group of experts to address a complex problem and reach consensus.¹⁰ The Delphi method involves asking experts recurring questions through a series of surveys. Experts receive feedback of group responses and can then modify their response while maintaining anonymity, which is intended to eliminate potential sources of conflict and bias around expressing divergent opinions.^{11 12} A three-round survey was used in this study as this is the minimum number recommended to generate consensus¹³ and additional rounds produce minimal change in group consensus.¹⁰ To avoid bias in the consensus-building process, the round 3 survey was only sent to participants who responded in round 2.

In this study, participants were considered to be experts in newborn medicine by virtue of their lived experience as parents whose children received neonatal care or adults who as babies, received this care themselves in Australia or New Zealand. Based on the American Academy of Pediatrics levels of neonatal care,¹⁴ a NICU in Australia or New Zealand is the equivalent of a level III or IV, whereas a SCN would be defined as a level I or II. Eligibility criteria included survey respondents being 18 years of age or older, reading and writing in English, either independently or with the assistance of a family member, friend or colleague, and identifying as a parent of someone who was admitted to a NICU or SCN or identifying as a person who was admitted to a NICU or SCN as a baby. Participants were recruited on the basis of having some experience of NICU or SCN. This sampling approach was deliberately broad to capture people motivated to discuss their experience whether recent or in the past. This sampling technique aimed to enhance the likelihood that participants would be willing to engage with the Delphi process rather than aim for generalisable data or results based on a particular type of participant sample. Participants were recruited over 2 weeks from September 2019 using social media pages and websites of the Centre for Research Excellence (CRE) in Newborn Medicine, Murdoch Children's Research Institute and parent support groups for preterm and sick newborns in Australia and New Zealand. 'Snowballing' recruitment was also used, whereby participants and members of the CRE in Newborn Medicine Consumer Advisory Group (CAG) were encouraged to share the study with their networks. Members of the CAG who were involved in data analysis, outlined below, were excluded from participation.

Patient and public involvement

During the CRE in Newborn Medicine's quarterly CAG meeting, members, all of whom are past patients of neonatal care, either as a parent of a baby who required neonatal care or as an adult who received neonatal care themselves, brainstormed and revised the research question and initial Delphi survey design. Further patient involvement occurred by way of the CRE CAG members refining the participant information statement and improving the appropriateness and wording of other research documents (ie, the online invitation to participate and social media copy), assisting with recruitment to the study by sharing the participation link with their networks, assisting with the analysis of qualitative data and preparing and revising the study manuscript. Results of the current study will be shared with participants through email and will include a link to the published article, a plain language summary and a short video abstract from the research team providing a summary of the results.

Delphi survey process

Survey data were collected and managed using secure Research Electronic Data Capture (REDCap) tools^{15 16} hosted at the Murdoch Children's Research Institute. Data

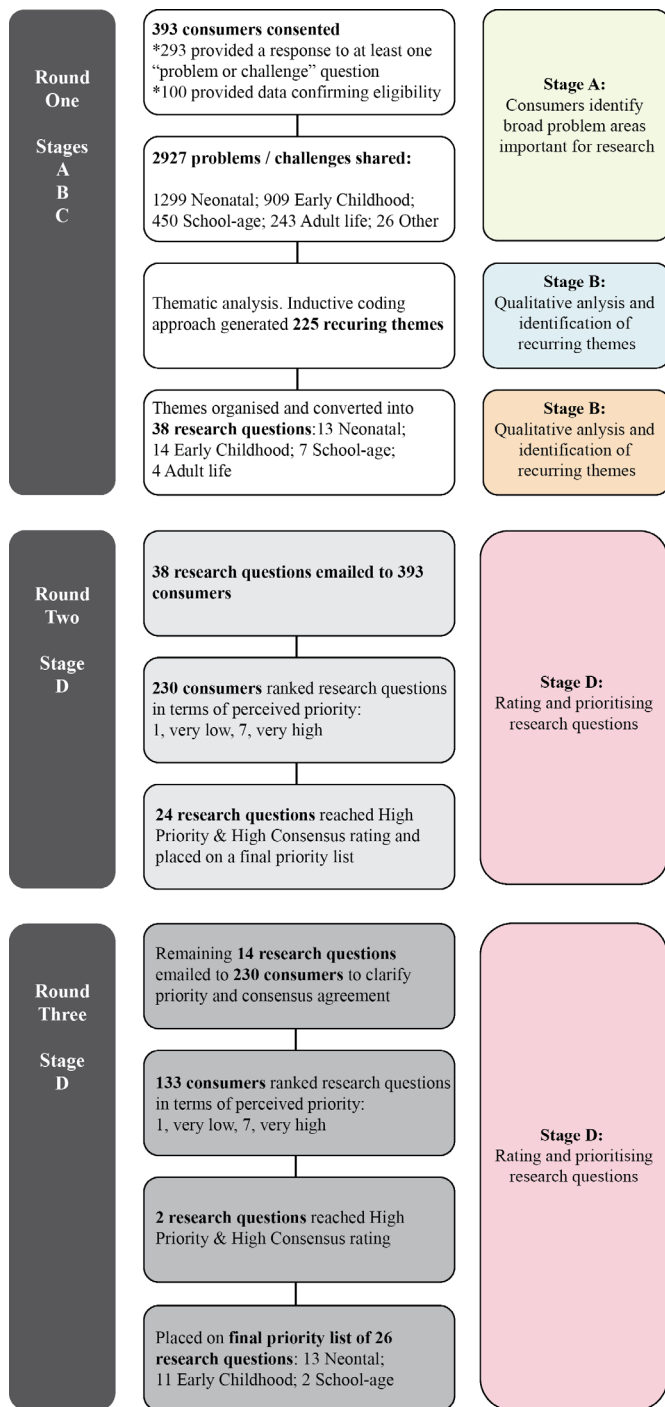


Figure 1 Delphi survey process

collection and analysis and the development of the Delphi survey encompassed the following stages: (A) identifying broad problem areas that parents/patients considered were important areas for future research; (B) qualitatively analysing problem areas and identifying recurring themes; (C) organising and converting recurring themes into research questions and (D) rating and prioritising research questions. **Figure 1** details the process followed. The three-round Delphi survey and its corresponding stages are described below.

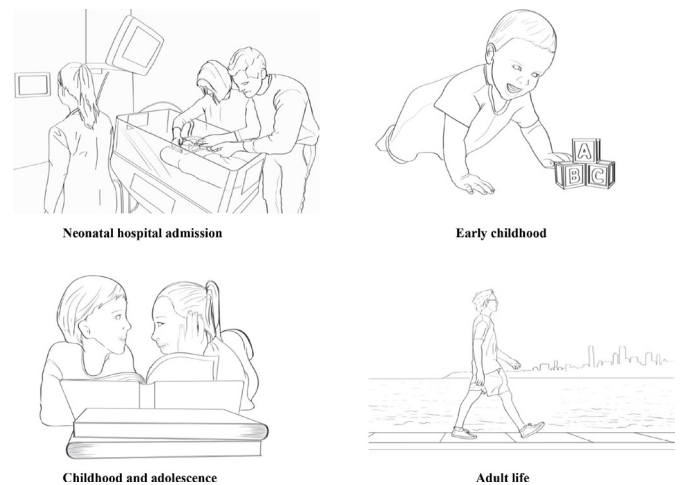


Figure 2 Black and white line drawings accompanying the different epochs

Round 1 (stages A–C). The purpose of round 1 was to collect basic demographic data and gather the expertise of parents/patients through identifying areas they consider important for research. In the absence of a clear literature base to develop the survey and to capture a pure representation of parent/patient priorities, we asked open-ended questions,¹⁷ rather than providing participants with a list of researcher-generated research topics. Participants were asked to ‘Please briefly describe up to six problems or challenges associated with premature birth or other newborn conditions in this period’ for each of four epochs (the neonatal hospital admission; early childhood; childhood and adolescence; and adult life). Each epoch was accompanied by a black and white line drawing (**figure 2**) to assist participants’ recall and conceptualisation of their concerns.¹⁸ Black and white line drawings were used as opposed to photographs or colour drawings to assist participants to visualise and recall a specific epoch but without eliciting an emotional reaction induced by real people and children.¹⁹ Participants were invited to respond to all epochs if they wished, regardless of their current experience.

Round 1 data were qualitatively analysed using thematic analysis, in order to identify and report patterns (or themes) within the data. All initial data analysis was conducted by authors ALE and ACB using an inductive approach, and independent coding in the form of a code-defining approach was applied to a subset of data to check the quality of the analysis.²⁰ Analysis of round 1 data was conducted manually using the steps outlined by Braun and Clarke²¹ and data were managed using QSR International’s NVivo V.12 software.²² Authors RWH and KR (a senior neonatologist and a member of the CAG, respectively) assisted in reviewing the coding structure to ensure congruence and identify any missing elements. The final identification, naming and definition of themes, based on the initial structured coding, was then organised and converted into a list of research questions and was completed collaboratively by ALE, ACB, AJS, CD, KR and

RWH. This step involved these authors meeting regularly to review the codes and associated data and to identify research-based questions that accurately captured and could address these concerns.

Round 2 (stage D). The purpose of round 2 was to prioritise the research questions generated from the parent/patient-reported experiences in round 1. Participants were asked to rate the importance of each research question using a seven-point Likert scale (1, very low priority; 7, very high priority). Median ratings and inter-quartile ranges were calculated. Questions with a median score of 6 or 7 and an IQR of 1 or less were considered to be 'high priority' and 'high consensus' (ie, 75% or more of the sample agreeing the priority level is a 'fairly high' or higher priority) and were included in the priority list.

Round 3 (stage D). The purpose of round 3 was to prioritise research questions that did not reach the high priority-high consensus threshold in round 2. The same seven-point Likert scale was used and participants received feedback about ratings from the wider sample. All questions that reached high-priority consensus were added to the final research priority list, and those that did not were excluded. Illustrative quotations were selected from one of the recurring themes within each priority area.²³

Participants' consent was implied by completing online registration to the round 1 survey, which is standard procedure.

RESULTS

Sample characteristics

The overall sample included 393 participants. Participants were predominantly parents whose babies had been admitted to NICU or SCN (n=388, 99%). Five participants were adults who required a neonatal unit admission at birth. Due to the sample being predominantly parents and for the sake of brevity, hereinafter, we will use the term parents when referring to the participants in our study and describing the results, which is inclusive of the small number (n=5) of people who identified as adults who had experienced neonatal care at birth. Sample characteristics are reported in table 1. The most frequent reason for NICU/SCN admission was preterm birth and the mean gestational age of those infants was 30.3 weeks (SD 3.6). Participants were predominantly from Australia, female and university educated. Three-quarters of participants identified the neonatal or early childhood periods as closest to their current experience.

Round 1

In round 1, 293 of 393 (75%) participants gave 2927 responses regarding problems and challenges, from which 225 recurring themes were coded (figure 1). Key concerns raised in the neonatal period were; parents' mental health and factors such as separation from their child, a lack of involvement in their child's care and ensuring systems of care explicitly included practical

Table 1 Sample characteristics

		Total n (%)
Location of hospitalisation	Australia	262 (67)
	New Zealand	131 (33)
Level of care first admitted to	NICU	296/388 (76)
	SCN	90 (23)
	Not sure	2 (1)
Main reason for admission	Preterm birth	306/388 (79)
	Surgery for congenital abnormality	12 (3)
	Full-term but infection/sick	49 (13)
	Another reason	21 (5)
Sex	Female	313/388 (81)
	Male	74 (19)
	Other/prefer not to say	1 (0.3)
Education	Left school <16 years of age	9/375 (2)
	Finished year 11 (second last year of high school)	11 (3)
	High school certificate	51 (14)
	University degree	241 (64)
	TAFE/trade qualification	64 (17)
Closest epoch to current experience	Neonatal	39/238 (16)
	Early childhood	137/238 (58)
	Childhood and adolescence	51/238 (21)
	Adult	11/238 (5)

Denominators vary due to missing data.

.NICU, neonatal intensive care unit; SCN, special care nursery; TAFE, technical and further education.;

strategies to assist parents to bond with their child. In the early childhood epoch, participating parents highlighted concerns about the type of knowledge they needed to feel confident about supporting their children's health and development and how they can access appropriate healthcare, support services and early interventions. Their own mental health and coping strategies remained a concern. Questions about how their child might be affected developmentally and what resources are required to support recurred in the adolescent and young adult epochs. These themes were organised and converted into 38 research questions. See online supplemental table 1 for the recurring themes identified in each overarching research question.

Rounds 2 and 3

A total of 230 individuals participated in round 2. Of the 38 research questions, 14 did not reach the high-priority high-consensus threshold and were re-presented in round 3. No questions were rated as a low priority with

consensus. Of the participants in round 2, 133 (58%) completed round 3.

Consensus priorities

Participants consistently rated 26 research questions as high priority (table 2). No research questions from the adult period reached the high-priority, high-consensus threshold, though all had median rankings of 5 ('fairly high priority') and IQRs of 4–6 (see online supplemental table 2).

DISCUSSION

Parents of children requiring neonatal care in Australia and New Zealand identified multiple high-priority areas of research in the neonatal, early childhood and childhood/adolescence periods. Top priority areas were mainly in the neonatal epoch and included research into supporting parent mental health, establishing and strengthening partnerships between parents and staff (how parents could be actively included in their babies' care), supporting and nurturing the early parent–infant attachment relationship, and improvements in neonatal medical care. Longer-term priority areas focused on the impacts of neonatal conditions on children's health and development, parent and family well-being, and family resources, as well as the delivery of health and developmental services and information.

The stress and psychological impact of having an infant admitted to a neonatal unit was a recurring and strongly expressed theme in round 1, consistent with empirical data. Anxiety and depression more frequently affect parents of preterm infants compared with parents of healthy term born infants²⁴ and symptoms of psychological distress have been shown to persist up to 2 years postbirth.²⁵ Furthermore, post-traumatic stress disorder has been reported in up to 41% of mothers who have had an infant in a NICU, occurring as long as 14 months after their infant's birth.²⁶ In the current study, a lack of effective psychological supports available to not only mothers, but fathers and partners, was consistently reported. Understanding and addressing the impact of a neonatal admission on parent mental health is vital as parent mental health problems are associated with poorer child development outcomes.²⁷

A key overriding message was the need for clinical staff to engage collaboratively with families in caring for their babies and for hospital systems and procedures to be oriented towards support for families, including minimising separations between parents and infants and managing financial burdens. Parents described that their relationships with clinical staff in the neonatal period encompassed multiple challenges. They reported a lack of inclusion by staff in caring for their babies and a desire to partner with care teams in decision making. Frequently, parents referred to a lack of confidence in caring for their baby, which was interpreted as being exacerbated by the actions of clinical staff. Parents wanted clinical staff to

share information about their baby's care and medical status in individualised ways.

These concerns align with the goals and ideals of both family-centred care and family integrated care (FiCare), models of care now supported by many neonatal units around the world. However, implementation and sustainment of evidence-based models of care within the dynamic nature of a healthcare system is challenging and the results of this research highlight that the goals of family-centred care are not yet being achieved in practice, and there remains a need to continue to strive for research agendas and clinical practice which focuses on strategies to improve family centred care in Australian and New Zealand neonatal units. Family-centred care is 'an approach to healthcare that is respectful of and responsive to individual families' needs and values'.²⁸ Evidence suggests that programmes that actively integrate parents into the care of their infant and support the parent–infant attachment relationship are associated with improvements in parent well-being and child development outcomes.²⁹ Such programmes foster equal partnerships between staff and parents in the neonatal unit^{30–32} and our findings suggest families would be highly supportive of further intervention studies in this area.

A recurring theme in the current study was how physical separation of parents from their babies affected the bonding experience and the parent–infant attachment relationship. Whether through the lack of facilities for parents to stay with their babies, maternal healthcare needs, or the hospital's distance from home and other children, the significant stress associated with this separation warrants attention. Working within units' physical constraints, much can be done to create opportunities for closeness between parents and babies, which supports the development of the parent–infant attachment relationship. These include the consistent and prolonged practice of skin-to-skin kangaroo care, engaging and partnering with parents in everyday care giving, and demonstrating developmentally supportive touch and other sensory experiences such as the use of parental voice.

In addition to the psychological impacts for families, parents also recognised that advances in medical care to prevent and treat neonatal conditions and complications should be a high priority. Parents wanted research into improving management and long-term health outcomes related to specific organ systems such as respiratory and cardiac health, congenital and chromosomal conditions, treatment side effects, infection and other complications. In addition to improvements in neonatal medical care, addressing the feeding information and support needs of families, improving antenatal and postnatal care for mothers, including the consistency and continuity of care, and improving preparation for discharge by giving information and anticipatory guidance about their children's future health and development were high priorities for parents. These findings aligned with previous studies, which have highlighted prevention and prediction of preterm birth, survival, major medical complications or

**Table 2** Consensus research priorities in order of mean ratings within epochs, with illustrative quotations from one of the recurring themes within the overarching research question

Research questions	Illustrative quotations	Median (IQR)	M (SD)	Overall rank
Neonatal Period				
How can the neonatal experience affect parents' mental health and how can this be improved?	<i>Counselling and support should be offered straight away. Parents are traumatised and very few nurses can actually deal with them. I have had a baby in NICU twice. I had PTSD from the first but was offered zero support before, during or after. Counselling should be part of the process.</i>	7 (6–7)	6.36 (0.84)	1
How can hospital systems and procedures support families in the neonatal period?	<i>I think we will look back on this time and consider it grotesque that we would ask mums to leave babies behind and drive home each night going against the power of parental love.</i>	7 (6–7)	6.32 (0.93)	2
How can families and health professionals work together when babies are in hospital?	<i>The people in SCN are very caring, but you are made to feel as if you're not needed. You need to assert yourself to look after your own baby.</i>	7 (6–7)	6.31 (0.97)	3
How can parents be best supported to bond with their babies?	<i>Feeling like my baby wasn't my baby and having to ask permission to touch my baby.</i>	7 (6–7)	6.24 (0.97)	4
What is important about staff-parent relationships and interactions during the neonatal period?	<i>Complacency of staff who work in NICU / that is their norm. They work there every day so it's normal for them - it's not normal for a new mum in a NICU so having compassion from staff no matter how Groundhog Day it is, is really important</i>	6 (6–7)	6.22 (1.01)	5
How can medical care for babies be improved?	<i>My daughter had CHD as well as being prem. This was very hard to deal with, and a challenge for what needed to be prioritised first.</i>	6 (6–7)	6.17 (1.07)	6
How can families be supported in practical ways during the neonatal period?	<i>The juggle of my toddler & unborn child whilst admitted pre birth and again post birth when the baby was in NICU was challenging. My toddler could only come for limited periods to visit & every time he had to go home whilst I was admitted, we both cried. During an already stressful time, this stress on all of us was really hard.</i>	6 (5–7)	5.88 (1.08)	10
What information and support do parents need about feeding?	<i>The premature feeding process and needs are different to that of a full term baby initially and there is little knowledge of this, for example, lack of sucking reflex and its consequence on milk or bottle feeding</i>	6 (5–7)	5.87 (1.10)	11
How can feelings of isolation and separation be understood and improved for all members of the family?	<i>My husband wasn't able to stay at the hospital with me and our baby. We were airlifted to a city away from home to have our daughter due to a full NICU in our home city. We were both traumatised and needed each other and being apart was hard</i>	6 (5–7)	5.86 (1.06)	12
How and where should mothers receive postnatal care?	<i>Little help from staff during postnatal stay. As my baby was in NICU I was very much left to myself since I was 'well'</i>	6 (5–7)	5.77 (1.14)	14
How can healthcare during pregnancy be improved?	<i>Even though I had a high risk pregnancy there really was no education given on what the risks or likelihood my babies would have to spend time in the NICU/SCN and what to expect. It was overwhelming and traumatic.</i>	6 (5–7)	5.72 (1.15)	17

Continued

Table 2 Continued

Research questions	Illustrative quotations	Median (IQR)	M (SD)	Overall rank
How can families be best prepared for taking their babies home from the neonatal unit?	<i>Transitioning home was very, very stressful. Which is probably the opposite of what people would think it should be. Seeing your baby go through so much, and also knowing how quickly things can go terribly wrong can make going home a terrifying prospect.</i>	6 (5–6)	5.63 (1.07)	19
How can mothers' physical recovery after birth be improved?	<i>Rehabilitation post c-section was non-existent due to the stress, worry & prioritization of our baby in the NICU. I am still suffering terribly with chronic lower back problems due to poor functioning core, from doing nothing except sit in hospital chairs or the car for 2 months+post c-section.</i>	6 (5–6)	5.52 (1.23)	24
Early Childhood Period				
How can neonatal conditions affect the development of children's skills and abilities and how can this be improved?	<i>Despite regular follow up, it was hard to know if we should expect any learning difficulties etc as she progressed through to starting kindergarten.</i>	6 (6–7)	6.15 (0.96)	7
How can parents have good mental health and emotional wellbeing?	<i>... the pain, distrust and trauma from your baby being extremely unwell never really leaves you, and it definitely impacts how you parent</i>	6 (5–7)	6.00 (0.97)	8*
How can neonatal conditions affect young children's health and medical outcomes, and how can this be improved?	<i>Immune problems, more prone to becoming ill and when they do become ill it seems to hit them a bit harder.</i>	6 (5–7)	6.00 (1.00)	8*
How can neonatal conditions affect feeding for young children, and how can this be improved?	<i>Issues associated with weight gain/feeding/diet. My son came home with a NGT. We established breastfeeding but because of his RDS he struggles to gain weight and feed well because he was always so tired.</i>	6 (5–7)	5.76 (1.10)	15
What knowledge do community health professionals need to support families with young children?	<i>Lack of knowledge in Child Health Nurses with premature babies, they cause unnecessary anxiety with their comparison to full term babies or their misunderstanding of what is expected of a premature baby post discharge.</i>	6 (5–6)	5.66 (1.10)	18
What financial impacts do families experience?	<i>Financial impact of not being able to go back to work with day care not being a sustainable option for our baby's health due to her weaker immune system.</i>	6 (5–7)	5.58 (1.28)	20
What knowledge do parents need to feel confident about supporting their children's health and development?	<i>Lack of information on what to expect long term in the preschool years. Felt that there was focus on leaving NICU and nothing after this. I feel unsure about when to expect my daughter to meet her milestones, start solid food etc</i>	6 (5–6)	5.55 (1.06)	21
How can healthcare, support services, and early intervention be improved for young children?	<i>Lack of appointments or availability with specialists or allied health services for example, OT, speech etc in regional areas.</i>	6 (5–6)	5.54 (1.10)	22
How can young children's health needs impact on parents' feelings of isolation and access to support?	<i>Isolation is hard with any baby but with a prem sick baby it is harder as you have to move away from family & support for treatment.</i>	6 (5–6)	5.53 (1.07)	23

Continued



Table 2 Continued

Research questions	Illustrative quotations	Median (IQR)	M (SD)	Overall rank
What is the impact on family relationships and how can this be improved?	<i>My husband and I both suffered significant trauma over what happened to our son and on top of the pressures of having a new baby being hard enough, the added complications of our unique experience caused our marriage to suffer.</i>	6 (5–6)	5.51 (1.09)	25
How can families and health professionals work as equal partners in caring for young children?	<i>When your baby continues to have feeding issues after leaving hospital and you can't access help you need as GP, physio, community health nurse, OT just tell you to discuss it with the paediatrician [and] once you get an appointment, a parent's concerns are dismissed.</i>	6 (5–6)	5.43 (1.03)	26
<i>Childhood and Adolescent Period</i>				
How can neonatal conditions affect the development of school-aged children's skills and abilities and how can this be improved?	<i>I didn't know the issues from birth were going to lead to delayed development, which was only picked up late just before school.</i>	6 (5–7)	5.85 (1.06)	13
What are the long-term health and medical impacts on the child and how can these be improved?	<i>Health issues arising as a result of being preterm that were not originally evident.</i>	6 (5–7)	5.76 (1.08)	16

*Equal ranking

conditions, medical treatments and adverse events, pain and suffering, feeding, the impacts on the parent-infant relationship, and support for families after discharge from hospital as research priorities.^{5 6 9}

In contrast to previous studies, our study took a lifespan perspective of neonatal conditions, asking parents to consider several epochs. Parents consistently identified child development and parent/family mental health and well-being as priority areas beyond the neonatal period. This is not surprising given that neonatal conditions can have lifelong implications for development. Preterm birth is the most well researched of these neonatal conditions, particularly with respect to longer-term developmental consequences, and was the most frequent condition in our sample. Preterm birth increases the chance of impairments in neurosensory, physical, social-emotional and academic functioning,^{33–35} and around one in two infants born extremely preterm will experience a developmental impairment of varying severity in early childhood.³⁶ In addition, preterm birth can have an ongoing negative influence on parent mental health, family functioning²⁵ and the parent–infant attachment relationship.³⁷ Parents also identified education needs regarding understanding how neonatal conditions can affect development, both for themselves and for community health professionals. In a recent study, which included a relatively small group of parents and patients, education, social-emotional outcomes and parental well-being were high priority areas of research beyond the neonatal period.⁸

Our participants likewise identified knowledge gaps for education providers as a research area, however, this did not reach the high priority-high consensus threshold. This may reflect the fact that our sample predominantly comprised parents whose children were younger than school age.

Previous studies identifying research priorities in neonatal care have generally included a mix of researchers, clinicians and parent participants. These studies have often included research topics drawn from the literature, inherently generated by researchers and clinicians, which introduces an element of bias to parent priorities. Unlike previous studies, our study has adopted the approach of focusing solely on the lifespan research priorities of parents of neonatal care in a large sample size. Our strong inclusion of parents throughout the entire study, from identifying their problems and challenges to rating the research questions that are of greatest importance to them, is a considerable strength of the study.

We acknowledge some limitations of this study and important avenues for future research. There was attrition across the three rounds. However, we retained a large sample in the context of the existing parent/patient literature.^{6 8 9} The sample predominantly comprised parents of children born preterm, so we could not examine whether priorities differed between parents and patients (those who had been critically ill as newborns themselves, or between various neonatal conditions). Furthermore, participants were predominantly mothers and a high

proportion were university educated (64%). The priorities identified may therefore not reflect the experiences of the wider family unit, including fathers and partners, or the experiences of parents with lower socioeconomic status. Although all research questions had a median rating of 'fairly high priority' or greater, priority ratings gradually decreased across the epochs and no research questions from the adult period reached the high-priority, high-consensus threshold. Only 1% of participants were adults who required a neonatal unit admission at birth and three-quarters were parents of infants or young children. Therefore, the lived experience of challenges in adulthood was less represented, which may have contributed to items in this epoch receiving lower ratings. This finding may also reflect a desire for preventative interventions early in life to reduce the frequency and severity of later difficulties. To minimise participant burden, we collected basic demographic data but did not capture ethnicity data. People from a minority or migrant background are likely to experience distinct challenges in engaging with the healthcare system.⁷ Future research is also needed to understand the needs of these and other potentially vulnerable groups of parents and patients.

CONCLUSION

The public health implications of critical illness in the newborn period are substantial and long-lasting. The identification of a parent-led research agenda provides direction to researchers and clinicians in addressing problems that can translate to more relevant, positive impacts for families who have experienced neonatal care. To maximise these impacts, novel and translational research is needed across development, with a particular focus on parental mental health, collaborative neonatal care, child development and family well-being.

Author affiliations

¹Clinical Sciences Theme, Murdoch Childrens Research Institute, Parkville, Victoria, Australia

²Newborn Research, The Royal Women's Hospital, Parkville, Victoria, Australia

³Department of Physiotherapy, University of Melbourne, Parkville, Victoria, Australia

⁴Department of Paediatrics, Monash University, Clayton, Victoria, Australia

⁵Department of Neonatal Medicine, The Royal Children's Hospital, Parkville, Victoria, Australia

⁶Department of Paediatrics, University of Melbourne, Parkville, Victoria, Australia

⁷Neonatal Services, Royal Women's Hospital, Parkville, Victoria, Australia

⁸Obstetrics and Gynaecology, University of Melbourne, Parkville, Victoria, Australia

⁹Consumer Advisory Group, Murdoch Childrens Research Institute Centre of Research Excellence in Newborn Medicine, Parkville, Victoria, Australia

¹⁰Children's Bioethics Centre, The Royal Children's Hospital Melbourne, Parkville, Victoria, Australia

¹¹Department of Medical Education, University of Melbourne, Parkville, Victoria, Australia

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ORCID iDs

Abbey L Eeles <http://orcid.org/0000-0002-2420-8776>

Jeanie LY Cheong <http://orcid.org/0000-0001-5901-0455>

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