An evaluation report, a partnership between:

life's little treasures foundation
*Supporting Families of Premature & Sick Babies*

ACU
AUSTRALIAN CATHOLIC UNIVERSITY

# Leaving a little heart

## Evaluating the impact of Life's Little Treasures Foundation's products and services for families of premature and sick babies across Australia

## ACKNOWLEDGEMENT OF COUNTRY

In recognising Aboriginal and Torres Strait Islander people's spiritual and cultural connection to Country, and in continuing ACU'S commitment to Reconciliation, we would like to acknowledge the First Peoples and Traditional Owners and custodians of the Country where ACU campuses and Life's Little Treasures Foundation (LLTF) offices are located.

We respectfully acknowledge our Elders, past and present, and thank them for their guidance as we walk in their footsteps.

## ABBREVIATIONS USED IN THIS REPORT

| | |
|---|---|
| **ACU** | Australian Catholic University |
| **ELBW** | Extremely Low Birth Weight |
| **LBW** | Low birth weight |
| **LLTF** | Life's Little Treasures Foundation |
| **NBW** | Normal birth weight |
| **NICU** | Neonatal Intensive Care Unit |
| **SCN** | Special Care Nursery |
| **PTS** | Post traumatic stress |
| **SCU** | Special Care Unit |
| **VLBW** | Very low birth weight |
| **VPT** | Very preterm |

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## PROJECT ACKNOWLEDGMENTS

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## ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Study procedures conformed to the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2023)*, where they were conducted according to the study protocol approved by the Human Research Ethics Committee, ACU (2024–3596H). Informed written consent was obtained from the participants.

## AUTHOR CONTRIBUTIONS

All authors made a significant contribution to the work reported.

## DISCLOSURE

The authors report no conflicts of interest in this work.

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# 1. Introduction

Life's Little Treasures Foundation (LLTF) is a leading Australian charity committed to supporting families of premature or sick babies. LLTF provides practical resources and emotional support through approximately 150 Neonatal Intensive Care Units (NICUs) and Special Care Units (SCUs) across Australia. These services are available both during hospital stays and after a family's transition home.

Founded by parents with the lived experience of having a premature or critically ill baby, LLTF's programs are uniquely informed by a firsthand understanding of the emotional and practical challenges that families face. A core element of LLTF's approach is fostering connection between families and others who have shared similar experiences.

Extensive research has shown that having a preterm, low-birth-weight (LBW) or unwell baby can significantly impact parental mental health and well-being.(1) The NICU experience is often traumatic, with effects that can persist well beyond the first year of life.(2) Eeles et al. identified key research priorities of NICU parents, including the need for greater focus on child development and parental mental health.(3)

In response, LLTF, in collaboration with Australian Catholic University (ACU), undertook a project to evaluate the impact of four LLTF core services, including:

- **Guidebooks:** for families in NICUs and SCNs
- **NICU Connections:** peer support groups for families during their baby's hospitalisation and post-discharge time
- **Precious Prem Packs:** packages with practical items for parents and babies
- **Little Bag of Calm:** tips, tools and activities to promote parental self-care.

The project explored the experiences of parents who accessed LLTF's services and assessed whether these offerings align with evidence-based factors that support parental well-being. Specifically, the project sought to answer the following questions:

1. What are the common experiences of, and psychological impact on, families of premature or sick babies?
2. What are families' experiences of LLTF products and services?
3. Does being well informed improve the experiences of families in NICUs or SCUs?
4. Do LLTF products and services align with factors that enable positive wellbeing following the birth of a premature or very sick baby?

### METHODOLOGY

A mixed-methods approach was used to gather both quantitative and qualitative data, in which:

- quantitative data were collected via a large-scale survey of parents who have used LLTF products and services
- qualitative insights were gathered through focus groups with a subset of survey participants, offering deeper understanding of their experiences.

The qualitative analysis followed an interpretive framework, aiming to richly describe parents' perceptions of LLTF's support.

### 1. LITERATURE REVIEW

A comprehensive review of existing research addressed the following question:

**What are the common experiences and psychological impacts on families of premature or sick babies?**

This review explored:

- the prevalence of anxiety, depression and other mental health challenges in this population
- key difficulties that parents faced
- the impact of parental mental health on bonding and child development
- factors that support or hinder parental well-being.

### 2. SURVEY

A national survey collected demographic data and explored families' experiences with LLTF products and services. The participants were parents who had received LLTF services within three years of the birth of a premature or sick baby, and the survey was open to one or both parents, aged 18 and older.

### 3. FOCUS GROUPS

Participants were invited to join focus groups to provide more detailed feedback and insights.

# 2. Literature review

The birth of a baby is typically a time of joy and anticipation. However, when a baby is born prematurely or with significant health complications, it can become an intensely stressful and emotional experience for parents. In Australia, approximately 1 in 10 babies (8.3%) are born preterm (defined as before 37 weeks of gestation), and 6.5% were LBW, posing an increased risk of illness and death in infancy.(4)

## WHAT ARE THE COMMON EXPERIENCES OF, AND PSYCHOLOGICAL IMPACTS ON, FAMILIES OF PREMATURE OR SICK BABIES?

In 2022, 9,903 newborns were admitted to one of the 25 tertiary-level NICUs across the country, accounting for 3.3% of the 300,684 live births recorded that year. Of these, 9,661 infants (3.2% of live births) required ventilatory support, highlighting the severity of their medical needs.(5) This unexpected and often traumatic experience can have profound effects on maternal mental health.(6) Research indicates that such stress can impair a mother's ability to cope and care for her infant, potentially leading to adverse outcomes in the child's growth and development.(7, 8)

In Australia, the prevalence of maternal mental health disorders during the perinatal period is estimated to range between 10% and 20%.(9, 10) Alarmingly, a longitudinal study conducted at a major tertiary hospital revealed a significant rise in maternal anxiety and depression between 2013 and 2022. During this period, rates of anxiety increased from 7.4% to 18.4%, depression from 13.6% to 16.3%, and combined anxiety and depression from 16.5% to 22.6%. These figures were even higher among Indigenous mothers and mothers of premature infants, underscoring the need for targeted mental health support in these populations.(11)

### Prevalence of mental health difficulties in parents of premature infants

Psychological distress, including anxiety and depression, is frequently reported in mothers of term-born babies, but rates are significantly higher among parents of preterm babies.(1) Studies show that during the newborn period, 30%–50% of mothers and 30%–60% of fathers of LBW infants experience symptoms of depression.(12) Among parents of preterm infants, depression affects 40% of mothers and 36% of fathers, while anxiety affects 48% of mothers and 47% of fathers. These elevated rates can persist for up to 36 months corrected age.(2, 13, 14)

Even seven years after birth, parents of very preterm (VPT) children report significantly higher levels of anxiety ($p = 0.03$), depression ($p = 0.03$), parenting stress ($p < 0.001$) and poorer family functioning ($p < 0.05$) than parents of term-born children.(15)

Prematurity is not the only factor contributing to parental psychological distress. Mothers of infants with bronchopulmonary dysplasia report higher depression scores and a slower reduction in symptoms over the first three years of life.(14, 16) Parents of two-year-olds with moderate disabilities report greater personal strain and family impact than those whose children have mild or no disabilities.(17) Similarly, parents of 18-month-old children with developmental delays experience more personal distress than parents of developmentally typical infants.(18) Mothers experience post-NICU psychological trauma for months or years after the newborns' NICU stay, and it can have a long-term effect on the functioning of mothers of premature babies.(19)

Despite the well-documented prevalence of mental health challenges in this population, few perinatal or social risk factors have been consistently identified as predictors of long-term anxiety or depression. Research on the role of medical risk factors is mixed: some studies suggest a link between neonatal medical complications and parental anxiety (20), while others find no significant association between medical risk and psychological distress.(21, 22) Regardless, it is evident that preterm birth can have an ongoing negative influence on parent mental health, family functioning (12) and the parent–infant attachment relationship.(23)

### Key difficulties parents face

A systematic review of 49 studies involving 8,447 parents of infants admitted to NICUs identified several risk factors for post-traumatic stress (PTS) and anxiety.(23) These included a prior history of mental health issues, parental perception of greater infant illness severity, shorter gestational age (< 33 weeks) and very low birth weight (VLBW; < 1000g). Additionally, stress related to the NICU environment was significantly associated with both PTS and anxiety. The review also highlighted the high comorbidity of perinatal anxiety, depression and PTS, with the presence of one condition increasing the risk of others.(23)

Emerging evidence also suggests that prenatal mental health, particularly anxiety, has a more pronounced effect on parent–infant interactions than postnatal mental health. For instance, paternal prenatal symptoms have been linked to increased unresponsiveness and infant passivity, while postnatal symptoms are associated with reduced engagement during social exchanges.(24)

In a comprehensive review of parent and family outcomes following preterm birth, several factors were linked to poorer family functioning.(13) It is not

only the characteristics of the preterm infant that are strongly associated with parent and family outcomes, but also parent and social factors. Evidence from studies focusing on preschool years indicates that families of VPT and VLBW children experience greater challenges and overall poorer functioning than families with term-born children.(6, 7, 25, 26)

LBW and prematurity are associated with a wide range of long-term physical and psychological challenges in children, including cognitive and neurological delays, behavioural issues and attention-deficit disorders, many of which persist into adolescence.(25-30) Among VPT and VLBW infants, specific characteristics such as the severity of medical complications, presence of neurodevelopmental disabilities, and lower birth weight have been identified as strong predictors of adverse parental and family outcomes and a heightened negative impact on family well-being.(31-34)

Parental and environmental factors such as lower socioeconomic status, limited parental education, (18, 32, 34-38) reduced marital satisfaction,(39) and inadequate social support (1) have also been identified as important predictors of adverse parent and family outcomes after VPT or VLBW birth. (14) Although extremely low birth rate (ELBW) and VLBW have been associated with increased rates of marital discord and separation during preschool and adolescence, some families report that their child's health challenges have strengthened family bonds.(35, 37) Parents of ELBW and VLBW children are also less likely to have additional children than parents of normal birth weight (NBW) children. (35, 37) Although financial hardship does not appear to differ significantly between families of ELBW and NBW adolescents,(35) ELBW status may impact maternal education attainment, with mothers of ELBW children advancing their education at a slower rate by the time their children reach adolescence.(33) Additionally, parents of ELBW young adults report greater negative impacts on employment than parents of NBW young adults.(31)

The evidence highlights the complex interplay between neonatal factors, such as prematurity, LBW and medical complications, and a range of parental and environmental influences that shape family outcomes. These challenges often extend well beyond the NICU, affecting family functioning, parental well-being and long-term socioeconomic trajectories. Given the strong associations between parental mental health and child developmental outcomes, it is essential to explore how psychological distress following neonatal admission may influence early parent–infant bonding and the child's emotional and cognitive development.

## WHAT ARE THE IMPACTS OF PARENT MENTAL HEALTH DIFFICULTIES ON MOTHER–BABY BONDING AND CHILD DEVELOPMENT?

This early postnatal period is a critical window for establishing secure parent–infant attachment. However, psychological distress in parents following a NICU or SCN admission can significantly disrupt this bonding process, particularly as these infants already face significantly increased developmental challenges.

Parental mental illness is a well-established risk factor for impaired parent–infant relationships. (40) Maternal depression during the postnatal period has been shown to adversely affect the quality of mother–infant interactions, with long-term implications for children's attachment security, social development, behaviour, and cognitive and intellectual functioning,(41-43) while anxiety has also been shown to negatively affect both the parent–infant relationship and child developmental outcomes.(44, 45)

Furthermore, early self-regulation difficulties in infancy, such as persistent sleep or feeding problems, have been linked to delays in motor, language and cognitive development, as well as to ongoing relational difficulties between parent and child.(46) The quality of the parent–infant relationship during the first years of life plays a pivotal role in shaping the infant's developing brain and attachment system. (47)

Understanding and addressing the impact of neonatal admission on parental mental health is crucial, as compromised caregiver well-being is linked to poorer child developmental outcomes, which highlights the need for targeted interventions that support both parent and child.

## WHAT POSITIVELY SUPPORTS WELL-BEING OUTCOMES FOR THIS POPULATION?

Parents of NICU babies have outlined their research priorities in a paper by Eeles.(3) These include:

1. supporting parent mental health
2. establishing and strengthening partnerships between parents and staff (actively including parents in their babies' care)
3. supporting and nurturing the early parent–infant attachment relationship
4. improving neonatal medical care.

Beyond the neonatal period, child development and parent/family mental health and well-being became more of a focus.

Although evidence is limited, early engagement in infant care, effective parent–staff communication, strong social support and the use of positive coping strategies have been suggested as protective factors against PTS and anxiety in parents.(23)

Several global initiatives—such as the Baby-Friendly Hospital Initiative,(48) the Humane Neonatal Care Initiative,(49) Family Integrated Care (50, 51) and the Creating Opportunities for Parent Empowerment program (52)—have been implemented to reduce mother–infant separation, enhance infant well-being and strengthen maternal coping capacities. These interventions not only alleviate maternal anxiety, but they have also been associated with improved maternal–infant bonding and reduced levels of chronic maternal stress. These programs are all based on Evidence-based interventions that support parent–infant bonding in the NICU and focus on enhancing emotional connection, promoting parental involvement and reducing stress in a highly medicalised environment.

Key components include the following:

1. **Kangaroo mother care:** This is one of the most well-supported interventions, involving skin-to-skin contact by placing the infant directly on their parent's chest. This practice promotes warmth, bonding and physiological stability. Studies have shown that kangaroo mother care improves maternal attachment, reduces parental stress, enhances breastfeeding success and supports infant

development.(21) Additional benefits include improved thermal regulation, increased maternal milk supply, better infant growth and enhanced mother–infant bonding.

2 **Family-centred developmental care:** This approach emphasises individualised care plans that actively involve parents as partners in decision-making and caregiving. It often includes environmental modifications, such as reducing noise and light, and structured support for parent–infant interaction.(53, 54)

Evidence from two systematic reviews indicates that early intervention programs after preterm birth that include parental psychosocial support (and often developmental support for the infant) are associated with fewer symptoms of maternal depression and anxiety.(55, 56)

3 **Parental involvement in infant care:** Encouraging parents to participate in routine care activities, such as feeding, diaper changes and bathing, helps foster a sense of competence and emotional connection. This involvement has been linked to improved bonding and reduced parental anxiety.(57) Facilitating parent presence at the bedside and integrating the parents into care routines not only alleviates immediate stress, but it also contributes to better neurodevelopment outcomes for preterm infants. Moreover, frequent visitation is associated with a lower risk of postpartum depression and a stronger maternal–infant bond.(58)

Parents are central stakeholders in shaping the neurodevelopmental trajectory of their preterm infants. Through sensory interactions, including smell, taste, touch, sound and visual engagement, parents can directly influence their infant's long-term outcomes. Actively incorporating parents into neonatal care and minimising barriers to their presence in the NICU are thus critical for optimising developmental outcomes.

However, consistent parental presence in the NICU can be challenging. Financial and logistical burdens, such as transportation costs, have been identified as significant barriers, with nearly half of mothers in one study citing transportation as a limiting factor for daily visitation.(59) Additionally, factors such as having other children at home and living far from the hospital are consistently associated with reduced visitation frequency, often compounding the difficulty of sustained parental involvement and hence reducing the parents' opportunity to bond with their baby and develop a strong connection.(60, 61)

Supporting the well-being of parents with infants in the NICU is a priority requiring a multifaceted, evidence-based approach that prioritises emotional, psychological and developmental needs. Key protective factors include early and active parental involvement in infant care, strong communication and partnerships with healthcare staff, and access to psychosocial support. Empowering parents as integral partners in neonatal care not only enhances their well-being, but it also plays a critical role in shaping their child's developmental trajectory.

LLTF is a national charity committed to supporting the mental health and emotional well-being of families with sick or premature babies. Established by parents with lived experience, LLTF delivers evidence-informed resources and services designed to reduce psychological distress, foster resilience and promote connection during the neonatal journey.

LLTF's core services include the following:

1 **Guidebooks:** expertly developed guides offering practical advice, emotional support strategies and key information to help parents navigate the complexities of neonatal care. These resources aim to reduce anxiety and empower families with knowledge during a highly stressful period.

2 **NICU Connections:** LLTF's signature peer support program offering both online and in-person support for families. It includes a professionally moderated online peer support program that is available during a baby's hospitalisation and post-discharge. Delivered via private Facebook groups, this initiative provides a psychologically safe space for parents to share experiences, access emotional support and build a community with others facing similar challenges. Alongside the online groups, NICU Connection Morning Tea events are held in hospitals, giving families the opportunity to connect face to face in a warm and supportive environment while taking a much-needed break during their hospital journey.

3 **Precious Prem Packs*:** carefully curated care packages containing essential items and supportive materials to assist families during their baby's hospital stay. These packs are designed to offer comfort, reduce stress and provide practical guidance tailored to the neonatal experience. (**Since this project began, the* Precious Prem Pack *has been renamed the* Little Treasures Welcome Pack.)

4 **Little Bag of Calm*:** a mental health–focused self-care toolkit featuring mindfulness activities, milestone cards and therapeutic resources. This initiative encourages parents to engage in restorative practices that support emotional regulation and psychological well-being during their time in the neonatal unit. (**Since this project began, the* Little Bag of Calm *has been renamed the* Parent Support Pack).

Although these services are widely valued by families, their impact on parental mental health and overall well-being has not yet been formally evaluated. LLTF is thus undertaking a comprehensive assessment to gauge the effectiveness of these four core services, with the goal of enhancing support outcomes and informing future service delivery.

# 3. Survey

A national survey collected demographic data and explored the experiences of families who had accessed LLTF products and services. Consumer 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.(62, 63) The participants were parents who had received LLTF products and services within three years of the birth of a premature or sick baby, and the survey was open to one or both parents, aged 18 and older.

Information obtained from the literature review was used to inform the survey, which aimed to answer research questions two, three and four:

2 What are families' experiences of LLTF products and services?

3 Does being well informed improve the experiences of families in the NICU or SCU?

4 Do LLTF products and services align with what supports facilitators of positive well-being following the birth of a premature or very sick baby?

Developed from existing tools, a large online and anonymous national survey run through Qualtrics collected demographic and quantitative data about the parents and children/babies who use LLTF products and services, as well as asked specific questions (using Likert-scale-type responses) about each product or service and the broad experiences that these families faced. Qualitative data were collected via free responses to questions in the survey, which asked participants to describe their experiences in their own words. Participants followed a web link to the survey from the advertisement or participant information letter, and they completed an online consent form before answering a series of questions. Data from the surveys were managed within the Qualtrics platform, which is securely housed on the ACU system. No data were retained if participants decided to leave the survey before submitting it. Data were cleaned by checking for missing values, duplicates and formatting errors.

## METHODOLOGY

Quantitative data were analysed using Microsoft Excel (version 2506). The quantitative analysis undertaken included descriptive statistics, such as the mean (for numeric answers) and mode (for fixed-choice questions). Frequencies and percentages were calculated using Excel's COUNTIF and pivot table functions to summarise categorical variables (e.g., gender, education level).

## RESULTS FROM THE SURVEY ANALYSIS

There were 226 returned questionnaires. Not all questions were mandatory, so there were a varying number of responses to each question.

## DEMOGRAPHICS

The majority of respondents (93%) were female (210/226), in which 51% were between the ages of 31 and 40 (115/226) and 61% had a minimum of a university-level education (142/226). Of the respondents, 74% were born in Australia (168/226), 17% were born in a non–English speaking country (40/226), 4% in New Zealand (9/226), 4% in the United Kingdom (9/226), and less than 1% in the United States of America and Canada (2/226).

See Graphs 1 and 2 on page 16 for further information.

## EXPERIENCE OF DELIVERY AND HOSPITAL STAY

Most babies were born between 28 and 36 weeks. The gestational ages of babies at birth are detailed below:

- 23–24 weeks: 8 babies (4.2%)
- 25–27 weeks: 27 babies (14.3%)
- 28–30 weeks: 46 babies (24.3%)
- 31–33 weeks: 50 babies (26.5%)
- 34–36 weeks: 50 babies (26.5%)
- 37–38 weeks: 8 babies (4.2%).

Following birth, 65% of babies spent time in both the neonatal intensive care unit (NICU) and the special care nursery (SCN):

- both the NICU and SCN: 147 (65%)
- the SCN only: 45 (19.9%)
- the NICU only: 34 (15%).

The overall average length of stay in the hospital was 55 days, with the shortest stay being 7 days and the longest 6 months. Although some babies went home quickly, most stayed for 1–3 months. Overall, 85% of the babies required respiratory support following birth (161/190). The conditions diagnosed after birth included:

- Bronchopulmonary Dysplasia (BPD)/chronic lung disease: 16 (40%)
- retinopathy of prematurity: 10 (25%)
- intraventricular haemorrhage: 9 (22.5%)
- necrotising enterocolitis: 5 (12.5%).

See Graph 3 on page 17 for further information.

At the time the survey was completed, 14 children had been diagnosed with a developmental delay, 7 with a hearing impairment, 6 with Cerebral Palsy, 3 with a cognitive impairment and 2 with a visual impairment. Other noted conditions included Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), low muscle tone, nystagmus, feeding issues, microcephaly and other rare syndromes, such as Kabuki Syndrome, Schwann Diamond Syndrome, Trisomy 21, pulmonary stenosis and critical portal vein stenosis.

## DIAGNOSIS

Most babies (99%) were either 'premature' or 'premature and very sick'. Only 3 babies were classified as 'very sick'. Further, 70% were singleton pregnancies and 30% were multiple. Overall, 130 (58%) mothers were admitted to hospital before their babies were born, 102 (45%) had emergency c-section and 161 (71%) required respiratory support after birth. The most common reason for the baby being born early was that waters broke early (32%).

## WHAT TYPE OF INFORMATION WAS RECEIVED IN HOSPITAL AND HOW HELPFUL WAS THE INFORMATION?

- Early parent support: average response for helpfulness was 7/10.
- Information about the baby's medical condition: average response for helpfulness was 8/10.
- NICU/SCN information: average response for helpfulness was 8/10.
- Financial information: average response for helpfulness was 2/10 (this was the category participants found the least helpful).
- Mental health information: average response for helpfulness was 5/10.
- Community and government support services: average response for helpfulness was 4/10.
- Not-for-profit organisations (i.e., LLTF): average response for helpfulness was 8/10.

In summary, medical, NICU/SCN and not-for-profit support information were rated as the most helpful, while financial and community or government service information were rated the least helpful.

## EXPERIENCES OF LLTF PRODUCTS AND SERVICES

The LLTF services received and accessed included:

- Brekkie Bar: 72 (30.5%)
- Little Readers Read-A-Thon: 61 (25.8%)
- NICU Connections Morning Tea (face to face, hospital): 48 (20.3%)
- Help via support line (1300 MY PREMMIE): 40 (16.9%)
- NICU Connections in Hospital live chat (Facebook): 34 (14.4%)
- NICU Connections at Home live chat (Facebook): 31 (13.1%)
- Financial assistance: 15 (6.4%)
- NICU Connections for Dads live chat (Facebook); 5 (2.1%).

See Graph 4 on page 18 for further information.

In summary, approximately 1 in 3 families used Brekkie Bar and 1 in 4 joined the Little Readers Read-A-Thon held in hospitals, while the dad-focused Facebook group was the least accessed.

The parents who attended the NICU Connections Morning Teas or NICU Connections online Facebook groups found them:

- very helpful: 23 (42.6%)
- helpful: 18 (33.3%)
- somewhat helpful: 9 (16.7%)
- not helpful: 4 (7.4%).

The LLTF resources and products received included the following:

- Precious Prem Pack: 215 (91.1%)
- A Guiding Hand for Families in Special Care Nurseries: 44 (19%)
- A Guiding Hand for Families in NICU and Special Care Nurseries: 83 (36%)
- Little Bag of Calm (self-care pack): 78 (33.1%)
- My Colourful Journey (sibling colouring book): 22 (9.3%)
- My Brave Journey (bereavement sibling colouring book): 1 (0%).

See Graph 5 on page 19 for further information.

Almost all families received a Precious Prem Pack, over half received Guiding Hand booklets, and approximately one-third received the self-care Little Bag of Calm. Fewer families received sibling resources.

**Precious Prem Pack:** Overall, 215 respondents received a Precious Prem Pack (91.1%). Of those who received the Precious Prem Pack, 53% found this product 'very helpful', 23.7% found them 'helpful' and 9% found them 'somewhat helpful', as shown below:

- Very helpful: 144 (53%).
- Helpful: 51 (23.7%).
- Somewhat helpful: 20 (9%).

See Graph 6 on page 19 for further information.

Responses to experiences with this product are summarised below:

- It gave me practical items to help with the newborn stage: 161 (74.8%).
- It helped me celebrate the birth of my baby: 130 (60.4%).
- It helped me have a better understanding of the supports available: 120 (55.8%).
- It provided me with helpful information to navigate my situation: 114 (53%).
- It helped me feel more prepared for the arrival of my baby: 61 (28.4%).
- It helped me feel more confident as a parent: 54 (25.1%).
- It helped me bond with my baby: 38 (17.6%).
- It helped me access items I couldn't afford: 36 (16.7%).

In summary, the most valued aspects of the Precious Prem Pack were the practical items and the sense of celebration of the baby's birth, followed by support information and guidance.

**A Guiding Hand for Families in NICU and Special Care:** Overall, 132 parents received this product (55.9%). Of these respondents, 65.2% found it 'very helpful', 20% found it 'helpful' and 4.5% found it 'somewhat helpful', as shown below:

- Very helpful: 72 (65.2%).
- Helpful: 26 (20%).
- Somewhat helpful: 6 (4.5%).

### The most reported impacts included the following:

- Educated me on what to expect in the NICU or SCN: 86 (65.2%).
- Helped me understand the supports available: 69 (52.3%).
- Made me feel less alone: 63 (47.7%).
- Gave coping strategy ideas: 54 (40.9%).
- Empowered me to ask more questions about my baby: 52 (39.4%).
- Encouraged me to participate more in my baby's care: 52 (39.4%).
- Helped me cope better in hospital or at home: 51 (38.6%).
- Reading stories from other parents gave me hope: 50 (37.9%).
- Helped me process emotions: 40 (30.3%).
- Helped with transition to home: 38 (28.8%).
- Helped with transition from NICU to SCN: 31 (23.5%).
- Helped me bond with my baby: 27 (20.5%).

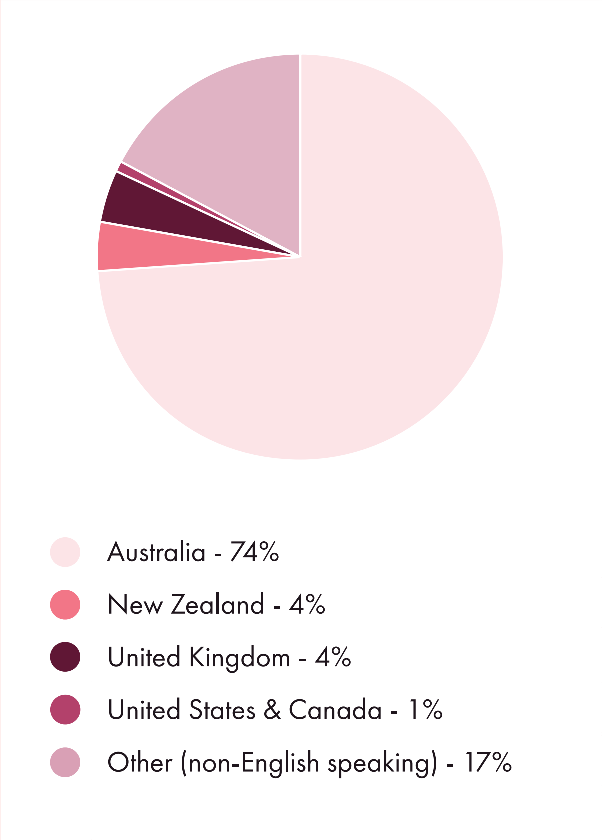
The majority valued the guidebooks for education, supporting awareness, reducing isolation, and coping strategies, with over 65% citing education about the NICU and SCN being the main benefit.

Specific responses from parents included the following:

- It helped me better manage visits and questions from family and friends.
- It gave helpful ways for family so they could help and communicate the way we needed at the time.

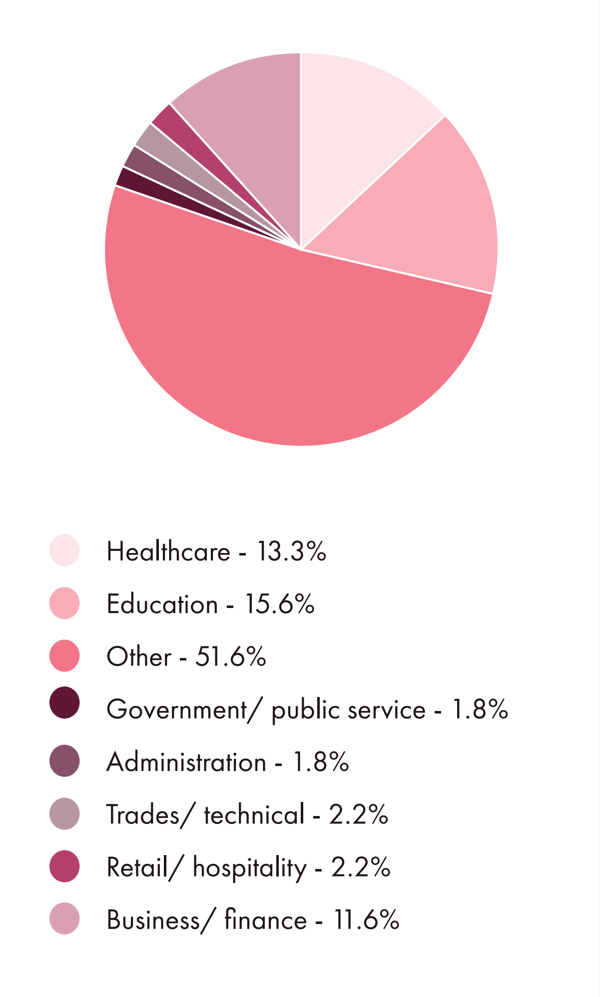
**GRAPH 1.**

**Country of birth**



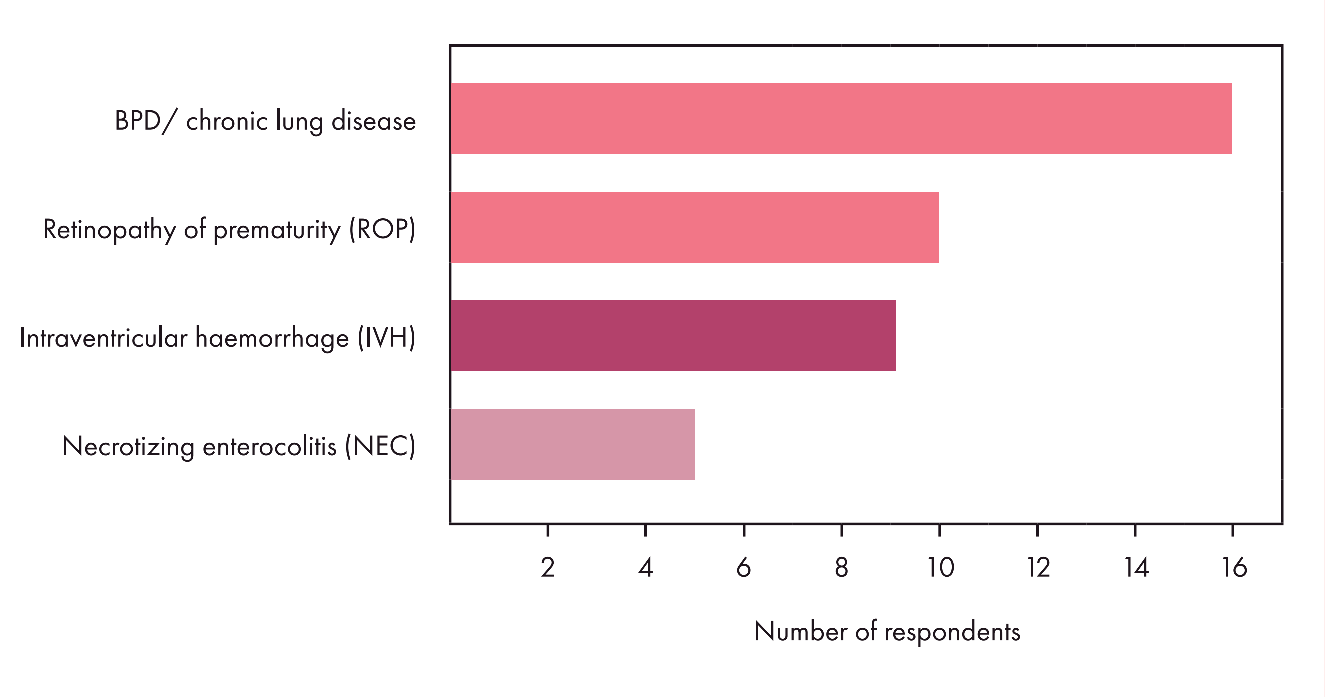
**GRAPH 2.**

**Occupation categories of survey respondents (Q5)**



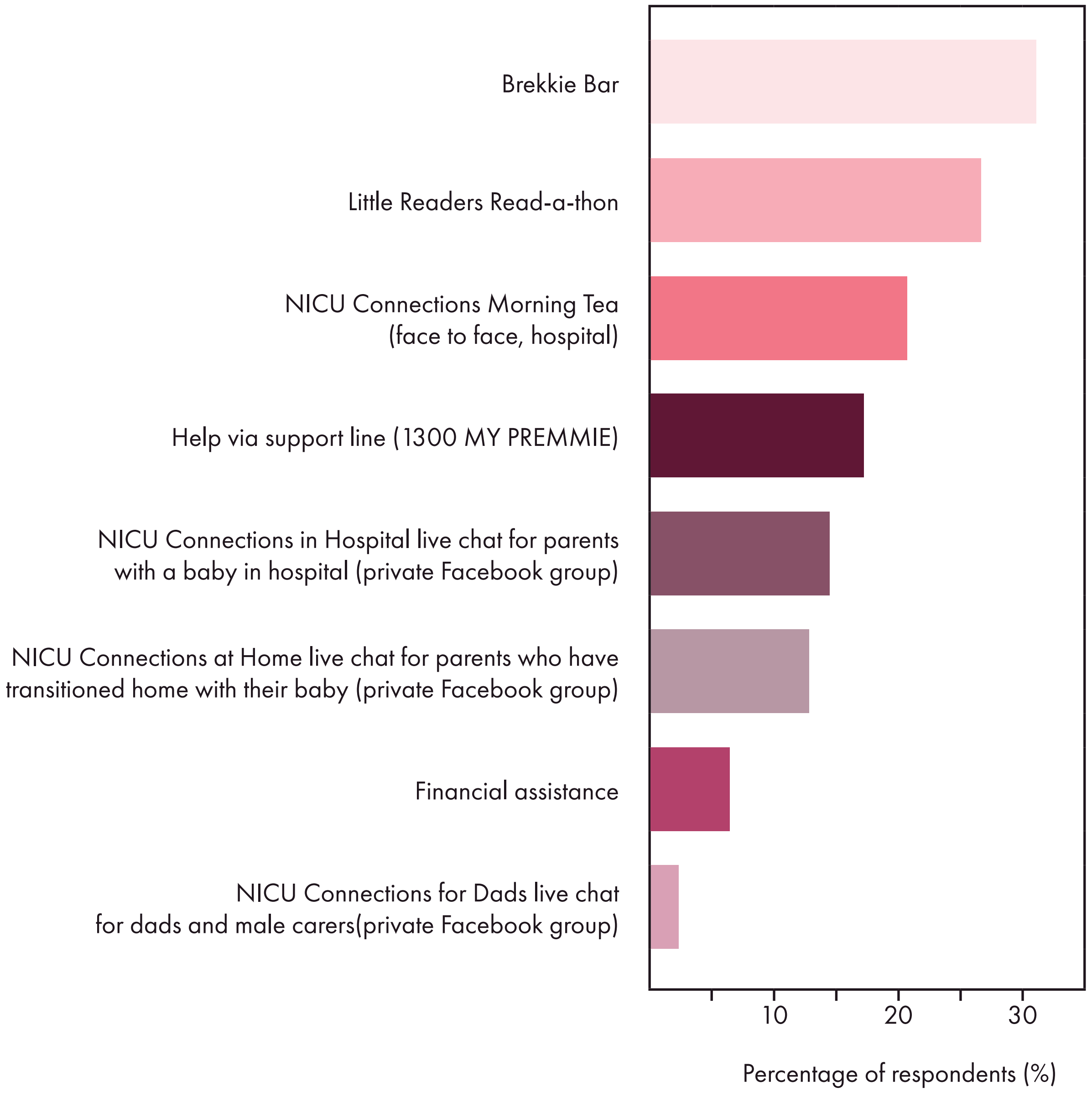
**GRAPH 3.**

**Conditions developed by babies (Q54)**



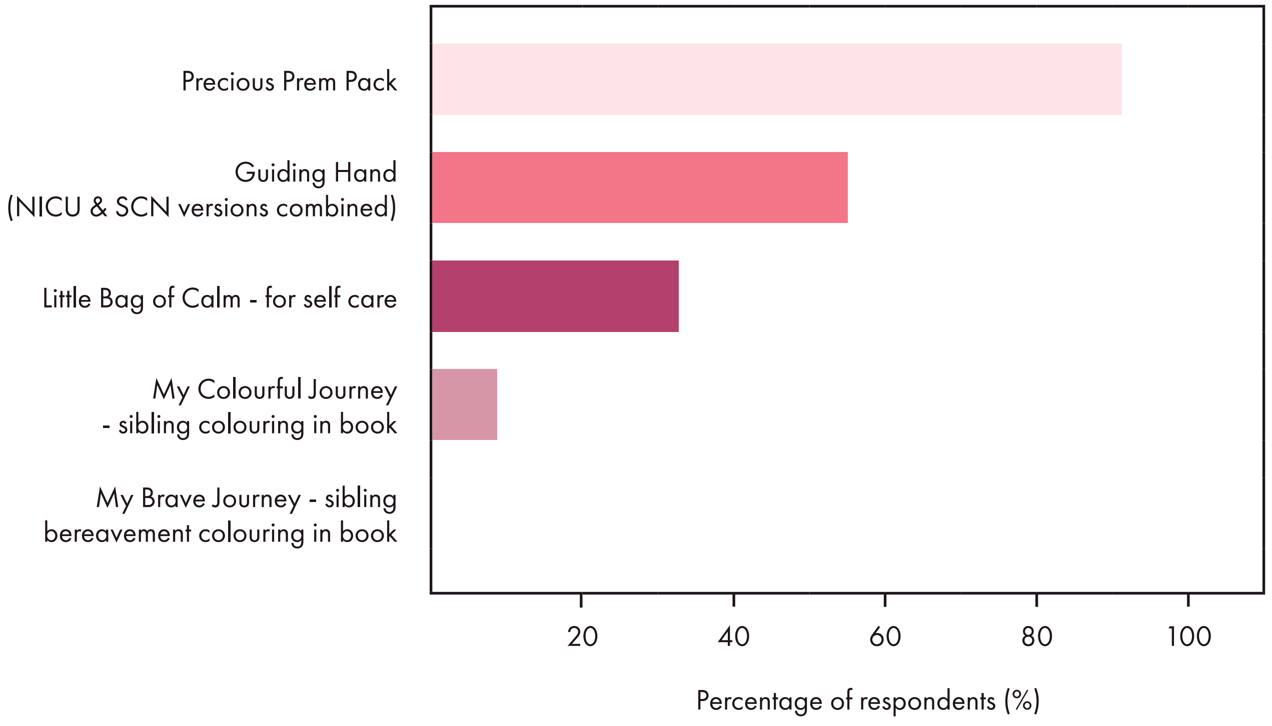
**GRAPH 4.**

**LLTF services accessed by respondents (Q67; N= 236)**



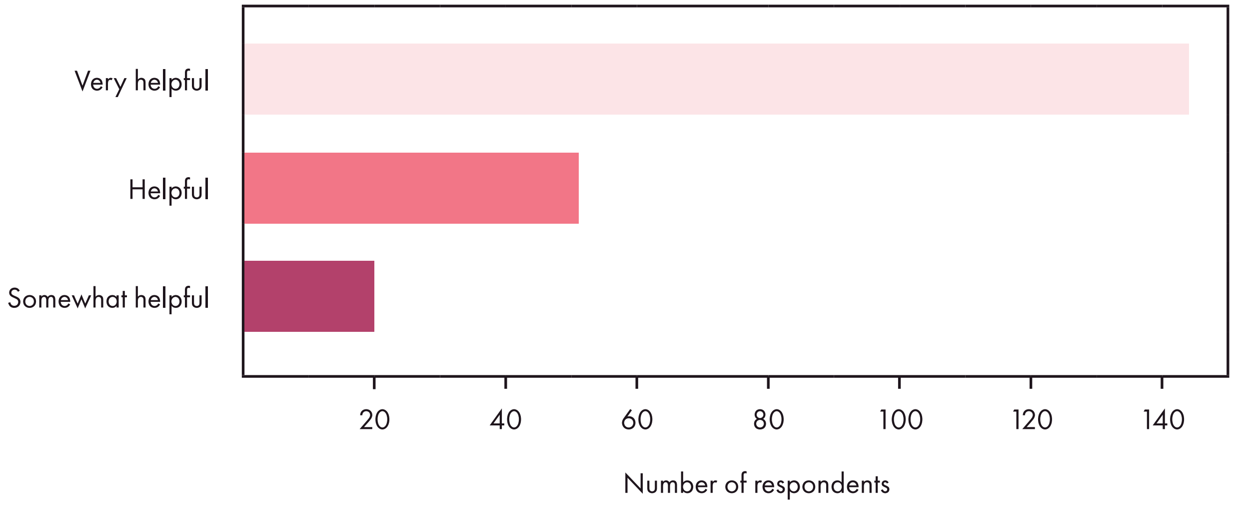
**GRAPH 5.**

**LLTF products received by respondents (Q68; N= 236)**



**GRAPH 6.**

**Helpfulness rating distribution (Q71)**



# 4. Focus groups

To gain deeper insight into parental experiences with LLTF products and services, a series of focus groups were conducted. These sessions aimed to explore the perceived impact of LLTF's offerings on parental mental health and well-being, particularly during and following NICU or SCN admissions.

The focus groups were designed to address the following research questions:

1. What are families' experiences of LLTF products and services?
2. Does being well-informed improve the experiences of families in the NICU or SCN?
3. Do LLTF products and services align with what supports facilitators of positive well-being following the birth of a premature or very sick baby?

## METHODOLOGY

Participants were recruited from a subset of survey respondents who voluntarily expressed interest in further involvement. To ensure inclusivity and accessibility, focus groups were offered both in-person and online, enabling participation from families across all Australian states and territories, including those in regional and remote areas.

To maintain anonymity and confidentiality, interested participants were directed to a separate registration form following the survey. Ethical approval was gained from the institutional ethics committee. Informed consent was obtained prior to participation, with all responses being de-identified for analysis.

Each session was co-facilitated by the study's chief investigators and recorded via Microsoft Teams. Participants responded to a series of semi-structured questions designed to elicit detailed feedback on their experiences with LLTF products and services. Example questions included the following:

- In what ways, if any, did LLTF products influence your experience of having a preterm or sick baby?
- What aspects of support most positively affected your mental health and overall well-being?
- What additional support or resources would have been beneficial during this time?
- How did you perceive the value of engaging with individuals who have lived experience?

All focus group recordings were transcribed and uploaded into QSR NVivo (version 15) for qualitative analysis. An inductive thematic approach was used, allowing themes to emerge directly from participant responses. Coding and analysis were conducted by the principal investigator (JH), with themes being refined to reflect key areas, including product use, parental mental health, emotional support, and service impact.

To minimise potential bias in the focus group process, several strategies were employed: interviewers were independent of LLTF, a consistent semi-structured interview format was used across all groups, and data collection continued until thematic saturation was reached (i.e., no new relevant information was emerging).

Audio data were transcribed verbatim using Microsoft Teams software, and transcripts were imported into NVivo for analysis. Each transcript was read multiple times to sensitise the researcher to the meanings that participants ascribed to their experiences. The analysis followed Braun and Clarke's six-phase framework: familiarisation, coding, theme development, review, definition and naming.(64)

## RESULTS

A total of 20 parents participated in one of six 60-minute focus groups—in which one was conducted face to face and five were held online.

The researchers found areas of significant similarities as well as some variation in patient experience. To illustrate the findings, quotations have been selected to give examples of key themes. Five overarching themes emerged following data analysis: 1) products received or experienced, 2) product impact, 3) lived experience, 4) accessibility and 5) suggestions.

### LLTF PRODUCTS AND SERVICES THAT PARTICIPANTS RECEIVED OR REMEMBERED EXPERIENCING

The focus groups were conducted to assess the impact of four core services provided by LLTF, including:

1. **Guidebooks for Families:** information resources for families in the NICU or SCN
2. **NICU Connections:** peer support groups available during hospitalisation and post-discharge
3. **Precious Prem Packs:** information and practical items provided to support parents and babies
4. **Little Bag of Calm:** a collection of tools and activities designed to promote parental self-care.

#### Key findings

1. The Guidebooks for Families, referred to by participants as the 'information book', was mentioned 21 times, indicating moderate engagement and perceived value.
2. NICU Connections was rarely mentioned during the focus groups, suggesting limited awareness or engagement among participants.
3. The Precious Prem Packs received the most attention from participants, with over 100 mentions across its various inclusions. Specific items highlighted include:
   - the knitted blanket—16 mentions
   - clothing items—12 mentions
   - the storybook—7 mentions
   - the Britax car seat insert—8 mentions
   - the Medela breast pump and Baby Bunting vouchers—2 mentions.
4. Little Bag of Calm, commonly referred to as the 'parent support pack', received fewer mentions overall, but the components that stood out included the:
   - milestone cards—10 mentions
   - colouring book—4 mentions
   - positive affirmation messages—5 mentions
   - journal—8 mentions.

#### Additional insights

Although not part of the formal evaluation, the Breakfast Bar was frequently mentioned (21 times), indicating its popularity and potential value to families.

The focus groups revealed varied levels of engagement with LLTF products and services, with the Precious Prem Pack standing out as the most widely remembered and appreciated offering. Participants highlighted specific items, such as the knitted blanket, clothing, storybook and Britax car seat insert, as particularly useful or meaningful. Although the Guidebooks for Families were moderately referenced, NICU Connections saw minimal engagement, suggesting limited awareness.

The Little Bag of Calm, though less frequently mentioned, had components such as milestone cards and affirmation messages that resonated with some parents. Notably, the Breakfast Bar—though not part of the formal evaluation—was frequently cited as a valuable and comforting service, underscoring the importance of accessible, tangible support during a highly stressful time.

### PRODUCT IMPACT

To try and delineate which LLTF products and services align with facilitators of positive well-being following the birth of a premature or very sick baby, the participants were asked about the products that they mentioned were the most impactful.

#### Guidebooks for Families

Responses to the Guidebooks for Families were mixed, with most people appreciating the information it provided. Some of the responses are highlighted below:

*I read it very slowly... my brain couldn't absorb much information at a time, but I did. I thought it was valuable.*

> *"Those materials are really helpful in giving hope and understanding and talking through the issue... the plain language was really helpful, I think, not just for us, but also for family."*

*It created a connection between us too, and, and also, I think the book really helped me and my partner.*

*But the book, I think, was the most important thing to me... it was like a handbook guideline on how to go through the journey. I remember taking photos of pages from the book and sending them to family.*

> *"It provided me with a lot of information, and it just made me more focused... and provided me with some strategies to move forward. Because I kind of felt helpless and I kind of felt like I wasn't providing for my daughter and I was bit of a failure of a mum."*

*Absolutely one of the best things I could have got because I read the booklet which I think is like [a] couple 100 pages long or something. I read the whole thing before he even arrived. It just prepared me.*

*The most impactful were the things that I was given straight away, which was the booklet and the book for my son.*

*It would be great to have some pictures of, you know, some fragile bubs who have survived with so many complexities.*

> *"But when we see such success stories with facts and, you know, the time that they have spent in the hospital for so long and, you know, [they're] still able to come with flying colours and stuff, that was really, really helpful."*

However, some did not even receive the book at all, while others found reading to be too overwhelming and made the following comments:

> *"I definitely wasn't in a frame of mind to be reading a thick book."*

*I didn't actually read it.*

*I wasn't mentally ready to sit and read. I did listen to, like, audiobooks and podcasts and things like that, but I didn't read anything at all.*

*I actually didn't get this book.*

Further comments were also made about the appropriateness of the book for their situation; for example, some received a preterm book while their baby was not preterm, so it was not relevant to them, while others received the book while they were inpatients awaiting the arrival of their baby, so they had a lot of time to read:

> *"I had so, so much time sitting in the hospital."*

*My recollection of the book is that it was very focused on premature babies.*

Many found the Guidebook for Families to be an invaluable source of information and emotional support, as well as a tool for connection—both with their partners and extended family. It helped some parents feel more prepared and empowered during a time of uncertainty. However, others found the guidebook overwhelming or inaccessible due to their mental state, while a few did not receive it at all. There were also comments about the relevance of the content, with some noting that the focus on prematurity did not align with their specific circumstances. These varied responses highlight the importance of tailoring resources to individual needs and ensuring timely, appropriate delivery to maximise their impact.

### Precious Prem Pack (Little Treasures Welcome Pack)

Regarding the items included in the Precious Prem Pack, participants expressed a range of opinions regarding which products were most useful versus those that had the greatest emotional impact.

The Britax car insert was noted to be very practical:

*The Britax insert would definitely be the most useful. Especially between having an early baby and then we only had a normal car seat, not a capsule.*

*The car insert was the most practical—[we] couldn't actually get the insert for our car seat in the shops.*

> *"There was an insert for the car seat that kind of supported her head, and that's something we used for the longest time. I think until she was nearly six months old. Every time we used that, we were kind of reminded of the kindness that we received at the hospital from the organisation."*

The sibling colouring book and journal were also found to be helpful by those who received them, although not all participants had access to these items:

*I think the book that you gave my son, my oldest, the oldest sibling, to introduce him to the concepts and the images that he would see in the NICU was really very helpful.*

*I did get a really beautiful, like, children's book… which was really special. So that was really, yeah, that was really valued.*

> *"Getting the journal was huge. [It] made a huge impact because I was a little bit, I guess, of a robot and [I] became factual and just, like, tried to become very logical and more of a problem solver."*

*The journal I found very helpful, and I did [it] almost every day, especially [for] the first, I would say, 4 weeks.*

*I actually didn't have a journal in my Precious Prem Pack.*

The knitted blanket and clothing were deeply appreciated by many participants. Although some noted a positive impact on their mental health, for most, these items were seen as thoughtful gestures rather than emotionally transformative. Participants also raised concerns about the appropriateness of certain clothing items, particularly regarding sizing, compatibility with medical equipment, and suitability for different climates; for example, needs in Melbourne or Canberra differ significantly from those in Townsville:

> *"The small clothing and the hats were probably not mentally helpful, but they were physically helpful."*

*The first time being dressed and it was a really special occasion, and it was in the Precious Prem Life's Little Treasures' outfits that were handmade. So, that's a special memory for me.*

*The little blanket that was in there was a really pretty blanket that was, like, the perfect size for a premmie baby.*

*It's nice to, you know, there is something there that it's, like, a little gift, like with the blanket. There was a little note in there that, you know, it's just kind of a heartfelt message. At that time, it was really tough and it's a bit of a whirlwind, and there's pain from the caesarean and my partner had to go back to work, so anything that's just kind of a support from the community is really lovely.*

*The knitted products and the little onesies, that that was a game changer. I was very overwhelmed. Bonding with my baby, the tiny clothes were really nice.*

*"I think the pack was helpful for my mental health because it provided things that I didn't even think that we needed because it was so unexpected. So, that sort of took that pressure off."*

*By the time that I got the pack and we left the hospital... they were a little bit too small for my baby.*

*"He didn't get to wear any of the clothing that was made because they didn't put any clothing on him until he was about 35 weeks. But he wore all of the beanies, and there was, like, blankets and stuff in there that he definitely used all of those things."*

*Being mindful, but you've obviously got cords and stuff coming out. So, if there's zippers, either the double zipper or the press studs. So, you can have the leads and stuff come out from, like, the foot monitor.*

*Bonding with my baby, the tiny clothes were really nice.*

One item that deeply resonated with many participants was the fabric hearts, which they could leave with their baby when they had to be apart:

*The little hearts and stuff you get, I used those every day.*

*Fabric hearts that [you] would put inside your bra and then every time you went in, you would swap the one that was in the incubator with the one that was in your bra so that your scent went to the baby and you felt like the baby was closer to [you].*

*[I was] very touched by it, that once again people are handmaking these things that help you bond with your baby when you don't know what you're doing.*

*The hearts... that was massive for me to develop a connection with my babies, because I basically went into shock after they were born and [I] couldn't comprehend that they were here on the outside world because I'd spent so much time preparing.*

*"Walking away from the hospital and leaving a little heart that you had tucked in your bra all day was just like leaving a little piece of myself there with them."*

*I think leaving the hospital without them was harder than the actual birth.*

The few participants who received the 20% discount voucher for a Medela breast pump expressed deep appreciation, especially given their strong focus on feeding and nurturing their baby. For many, breastfeeding was seen as one of the few tangible ways they could support their newborn. In contrast, the $10 Baby Bunting voucher was generally viewed as less useful—some found it had expired, while others reported that it was not accepted at their local store:

*To be able to order that breast pump with the 20% off voucher. I think that breastfeeding was so important to me.*

*[The] 20% off medulla [Medela] products voucher—most useful.*

*"[The] 20% voucher, because breastfeeding [is] central to bonding."*

*An important thing.*

*I think it was, like, $600 for price, yeah. Not everyone can afford it.*

*And [it] is so connected with how you're coping mentally.*

*We got a $10 [Baby Bunting] voucher. But you know, it was not really helpful, to be honest from my perspective.*

*We're very lucky to have lots of family and friends who were able to support us, and we got lots of hand-me-downs and stuff. But obviously there's people who are in a tougher financial position than I am. And obviously, you know, I took it to Baby Bunting to use, and then I saw that it expired, and I was like, damn it... obviously that would be a very big difference to somebody who, you know, might have needed that extra box [of] nappies. Maybe something to do with nappies? Because, I mean, nappies are super expensive. They only come in packs of 30 and they're, like, $17 a pack and, you know, that might last you three days [or] so. It's quite a big expense when you bring home such a little bub.*

Participants identified a range of LLTF products in the Precious Prem Pack that had a meaningful impact on their well-being following the birth of a premature or very sick baby. Among the most practical items was the Britax car seat insert, which was praised for its usefulness and long-term value. The knitted blanket and clothing were viewed as thoughtful and comforting, with some noting their role in bonding and emotional support, and others raising concerns about sizing and suitability across different climates and medical contexts. The fabric hearts emerged as one of the most emotionally resonant items, helping parents maintain a sense of closeness with their baby during separation. The 20% Medela breast pump voucher was highly valued by those who received it, reinforcing the importance of breastfeeding as a means of connection and care. In contrast, the $10 Baby Bunting voucher was generally seen as less helpful due to expiration issues and limited usability. The sibling colouring book and journal were also appreciated, particularly for supporting sibling understanding and parental emotional processing, though not all participants received them. Overall, the feedback highlights the importance of both practical support and emotionally meaningful gestures that are tailored to the diverse needs and circumstances of families navigating neonatal care.

### Little Bag of Calm (Parent Support Pack)

The Little Bag of Calm was warmly received by recipients, who noted that the affirmation cards had a positive impact on their mental health:

*You know, I thought I was doing what I could, you know. I was working. I was seeing a psychologist. I thought I was doing what I could, but then, just like I said, the simple affirmations that I would ordinarily just find trite or cliched actually really resonated with me at that time.*

*Positive affirmation messages—but at this time, when I'm feeling so vulnerable and depleted and emotional and everything like that, they really actually had a big impact on me, and they really helped.*

*Keep calm. I think there was, like, a pack of cards, not gaming, but you opened up the cards and it's just told you something [that] was inspirational that helped me.*

*My mental health started to suffer really bad. So, I was grateful that I could do something like some drawing in there to sort of keep your mind off things. And also, I actually still keep this on the shelf because it's pretty important to me now. It's called a little box of calm.*

The Little Bag of Calm was a well-received component of LLTF's offerings, with several participants highlighting its positive impact on their mental health during a highly vulnerable time. Affirmation cards, in particular, were noted for their unexpected emotional resonance, and for offering comfort and encouragement when it was most needed. Other elements, such as colouring-in and creative activities, provided a welcome distraction and a sense of calm amid the stress of neonatal care. For some, the pack became a lasting symbol of support, with items still kept as meaningful reminders of that period. These responses underscore the value of simple, emotionally supportive tools in promoting parental well-being.

### Breakfast Bar

Although not part of the original scope of our study, the 'brekkie bar' was regarded as a valuable service by families. However, its availability was inconsistent across hospitals, and it was not regularly stocked:

*I was getting up [at] around 6:00 in the morning to try and get into the hospital before the doctors came and over at 8, and often [while] skipping breakfast, and just with all of the added costs of parking and buying food while I was out. When I was going up every day, it was nice to just have a little snack available in the kitchen area.*

*Be great 'cause, like, we're hungry all the time.*

*There was a breakfast corner where they had, like, brekky bars and juices and things like that. I think that was something that was really helpful for us, especially because we were just travelling all the time from home to the hospital, like 3–4 times a day. I think that was something that really helped, kind of, my partner and I to bond to talk about our experience, [and] to just, kind of, take a bit of rest and have some food.*

*And, like, I know for my husband and I, like, that practical support was so helpful.*

*And it was also a place to connect with other parents who also had children in the NICU or the special care.*

*Snack box [was] empty by lunchtime most days.*

*Signs [were] up about breakfast supplies, but there was never anything there.*

*"The breakfast and the dinners would have been great, but that wasn't offered at our hospital that we were at."*

*But also, I think, like, the sense of community, like, other people who have gone through this just because I didn't know anybody that had gone through it personally. So, I had no friends to talk to about it, who'd been through it.*

Although not originally included in the scope of the study, the Breakfast Bar emerged as a highly valued service among participants. It provided practical support during a time when many parents were juggling early hospital visits, emotional stress and financial strain. The availability of snacks and drinks offered not only physical nourishment but also moments of respite and connection—with partners and other NICU parents. However, its impact was limited by inconsistent availability across hospitals and frequent issues with restocking. Participants emphasised the importance of such simple, tangible support in fostering a sense of care and community during a challenging period.

Apart from NICU Connections, all products were considered valuable by participants, although participants differed in their views regarding which items were most practical versus those that offered emotional support. The diversity of responses highlights the importance of tailoring support to individual needs and circumstances, particularly across different hospital settings and geographical locations. Additionally, participants shared feedback on the accessibility of LLTF products and services, offering several suggestions for service improvement.

### LIVED EXPERIENCE

Founded by parents with firsthand experience of having a premature or critically ill baby, LLTF products and services were developed by individuals who deeply understand the emotional and practical challenges that families in neonatal care face. Research shows that resources created by those with lived experience tend to be more relevant, foster greater trust and lead to improved outcomes.(63) With this in mind, participants were asked whether they were aware that LLTF products and services were designed by parents who had been through similar experiences—and whether that knowledge influenced their perception of the support provided:

*Not for me personally.*

*That would, like, interest me more, even more so in the products. I think knowing that they're from someone, yeah, with a lived experience.*

*"A lot of people who work for Life's Little Treasures have premmie babies. When I've got questions, because most of them have got older children than me, I actually can feel comfortable asking them, you know, what their experience was."*

*I don't think it made a difference because the information just kind of seemed like general information anyway.*

*Yeah, I did find that helpful, and it's, like, it was always helpful reading people's narratives.*

*The selection of things and especially the communications, like the written communications and services, were all very care focused, so I felt like it was very easy. I trusted everything.*

*"I think it's just nice to know that people have walked this path before. And having them, you know, I was kind of aware that all the volunteers had had some kind of experience in this space. And it's, I think you can see that in what they pick and what they choose for you."*

*I really appreciated that. It was put together by people who knew exactly what you needed, and not too much stuff.*

*Clearly, it was evident that there was a lot of thought that went into it, and it was, again, I keep saying it*

*was quite touching, but there was a personal aspect to it. I felt they have walked a similar walk.*

Participants expressed a range of views regarding the significance of LLTF's lived experience foundation. For many, knowing that the products and services were designed by parents who had navigated similar neonatal journeys added a layer of trust, relevance and emotional connection. They appreciated the thoughtful selection of items and the care evident in the communications, which felt personal and empathetic. Some found comfort in being supported by people who had 'walked the same path', and they valued the opportunity to ask questions and share experiences with LLTF staff and volunteers. However, a few participants noted that this aspect did not influence their perception, either because they were unaware of it or they felt that the materials were general in nature. Overall, the lived experience element was a meaningful contributor to the sense of support and authenticity for many families.

## ACCESSIBILITY TO LLTF PRODUCTS AND SERVICES

As focus group discussions progressed, it became clear that accessing LLTF products and services was often challenging. Many participants only discovered the resources by chance, indicating a lack of consistent visibility. Moreover, since all focus group participants had already accessed the services, it is likely that many others within the participating hospitals were unaware of their existence altogether:

*I only just received the pack because of a poster that was displayed in the SCN to say that if you, if you'd like to have a pack, you know, to email them.*

*One hospital did not have much information, and in the other hospital within Melbourne premises, they had LLTF booklets and stuff.*

> *"I remember one night sitting having dinner in that little kitchenette area and kind of looking at the pamphlet for little treasures, being like, 'Oh, that'll be really nice for all of those families in there.' Then, kind of a bit of a moment where it's like, 'Oh, we're that family.'"*

I did see some advertisements about morning tea or parents' group, but the information wasn't clear. Like, the location or the time was unclear. So, under normal circumstances, I would probably look up, maybe call them to find the information, but at that time, I just didn't have the mental capacity to do that.

*We only found out because we happened to arrive during a morning tea. I don't remember any posters being up or handouts.*

> *"They had some flyers at the reception there about their Precious Prem Pack, [a] poster on the wall."*

*I think there was just one other parent that I saw [who] had the same pack as me. I think the others would have definitely loved the pack as well, but I don't think they have the information.*

*I talked to other premmie mums, and they didn't even know that you could order a Precious Prem Pack, and some of them went off and did it.*

> *"[I] saw flyers around the hospital for Life's Little Treasures in the parents' room at a time. So, it's not really anyone to tell you about stuff. But we saw, you know, things like bath wash and baby shampoo laid out with the breakfast packs as well. And then that got me looking into things, and we ordered a premmie pack online."*

*There was no information given from hospital or, like, no-one else.*

*I do recall that there wasn't much communication, hardly any about it.*

*After I receive my pack, I told other parents in special care that there was a little flyer up on the counter and to go and grab it and get themselves a pack of little goodies... no-one else was telling us about it.*

*I only just received the pack because of a poster that was displayed in the SCN to say that if you, if you'd like to have a pack, you know, to email them.*

*I think there needs to be greater awareness... because it is an incredible offering or support.*

*It [play groups] was advertised on a hospital page. But when I called the contact, they had no idea what I was talking about. So, it was just a lot of searching for things myself.*

> *"It's a wonderful thing that's able to be provided, and you know, any kind of little ray of hope in that, you know, turmoil in your life is wonderful. And it's lovely to have the support of the community."*

Throughout the focus group discussions, it became evident that awareness and accessibility of LLTF products and services were inconsistent and often reliant on chance encounters. Many participants only discovered the offerings through incidental means—such as spotting a flyer, attending a morning tea or hearing from another parent—rather than through structured communication. This lack of visibility meant that numerous families may have missed out on valuable support simply because they were unaware of its availability. Participants expressed a strong desire for clearer, more proactive communication and promotion of these services, which emphasises that even small gestures of support can make a significant difference during such a challenging time.

## SUGGESTIONS

Given that the primary aim of this study was to evaluate the impact of LLTF products and services, participants were invited to share their suggestions for how the service could be improved:

*Somebody on call from Life's Little Treasures to be able to talk to when you're struggling.*

*"To... have some resources for mums on the impact it can have on mental health, and even some statistics perhaps to validate, like, you know, if they are struggling."*

*If you have, like, an online chat service, like, that was made from AI. And you could just sit there, talk about how you feel. I think it does feel like you're talking to a real person. So, obviously you can't hire people all the time to have, like, therapy care or someone to chat to who knows what you're going through. I would have preferred to be anonymous speaking with someone. But if I was sitting on the computer, relaxing, watching YouTube and just chatting with, like, a robot or something, I think I could do that. I think that would help me because I didn't have to see this person and have to hear this person, but I'm still getting validation back.*

*"Having, like, a buddy system, like someone [or] a volunteer, [who] you can just chat to about your specific, you know, what's happening at the time would be helpful. 'Cause, obviously they had been through it or, you know, they're close to someone who's been through it before."*

*But those few weeks that I was on bed rest in the hospital. I think it would have been really helpful to have that material.*

*"I probably think [it] might be really cool if they end up developing something for mothers who are already in the hospital waiting or on bed rest like I was. It would be awesome just to generate, you know, women who are in Victoria that are in this situation, either in the hospital or at home, and [who] can talk each day while they're on bed rest and, you know, say 'life sucks today.' You could get a grant for that, to develop something for that— 100% you can get a grant for that because it'd be, yeah, and you, it could be, that could be an app."*

*"I would potentially be happy to volunteer and run activities here for, like, [to] run a mother's group for people that might have prem babies that would like to speak with other people."*

*Social support with other people who wanted that same thing.*

*I would have really, really liked to go to a parent support group.*

*Staying in touch with the organisation.*

*"I feel like they should develop a mums group. I would have really benefited to have a mums group that was for premature babies."*

*Some more things also, you know, aimed to support families of sick children. The service they provide, I think, is giving parents hope in a time where things feel at times incredibly hopeless and completely overwhelming. And I just feel, yeah, I do feel there's a bit of room for giving that hope to parents and families of sick babies, as well as the parents of the premmie babies.*

*"But I think it'll be amazing to have the sick baby, kind of, voice a bit stronger in there too, yeah. I do think it would be really impactful and very validating for a lot of parents of sick babies to have a sick baby pack."*

*More inclusions for the sick babies as well, and not just premmie babies. But just, you know, perhaps maybe a bit more balance in that space, even if you get that informative stuff and then maybe some distraction stuff, which is colouring in books.*

*Adding things like frozen meals for the freezers in the NICU, like dinners. Again, that would have been incredible for us, and we were incredibly blessed that our friends and family gave us enormous amounts of frozen meals, which we literally just kept in the freezer at the NICU.*

*Maybe some muffins, meals to heat up.*

*Photo journal booklet... you could put photos of your child's journey, like their first bath. And it was really aimed at, obviously, you know, kids that are in the NICU. And that was really beautiful. There was a set of milestone cards. But if there was a booklet as well where you could put photos when they reached each milestone, because you take a photo of your baby with the milestone card. You know, my baby came off CPAP [continuous positive airway pressure] today, or whatever.*

*"It'd be awesome if there was, like, an app that, you know, you could log something that, you know, you may have forgotten, and you don't have your journal on you. Like, that would be super helpful."*

*Include the three-month milestone, six-month milestone, one-year milestone.*

*Maybe a sustainable, like, drink bottle would be good to add to the pack, just 'cause I remember not drinking enough water to be able to breastfeed all the time.*

*Breastfeeding or pumping would be great information.*

*Milk expressing. Like, I think that's one of the hardest parts of having a NICU baby, like, I found. Maybe there could have been a bit more information about that, because you end up basically just expressing all the time.*

*"Not everyone can breastfeed, so information like that would be helpful. Because I ended up feeling like a failure quite a bit because I couldn't feed my own child, so."*

*Have kind of, like a, like a dad's book or second partner, non-birthing partner, book to kind of offer them as well, and be like, this is also important for you.*

*I don't know whether it would be something that could be teed up with the Ronald McDonald House [to let parents know about LLTF]. That they kind of preach it a little bit more, or from the staff at the hospital themselves.*

Participants offered a wide range of thoughtful suggestions to enhance LLTF services, reflecting both practical needs and emotional support preferences. Key themes included expanding mental health resources—such as access to peer support, anonymous chat options, and materials addressing the psychological impact of neonatal care.

Many advocated for more inclusive support for families of critically ill (not just premature) babies, including tailored packs and communication. Suggestions also emphasised the value of community-building through parent groups, buddy systems and volunteer-led activities. Practical ideas such as frozen meals, sustainable drink bottles and enhanced breastfeeding support were also proposed. Additionally, participants recommended developing digital tools, such as apps for journaling and milestone tracking, and improving outreach through hospital partnerships and clearer communication. These insights highlight opportunities for LLTF to broaden its reach, deepen its impact and continue evolving in response to the diverse needs of families.

# 5. Discussion

This discussion examines how LLTF products and services may influence parental mental health and well-being following the admission of a baby to a neonatal unit. Through focus group sessions, participants shared personal reflections on their interactions with LLTF's offerings, providing insight into whether these resources contributed to a more positive experience during a highly stressful time. Central to this exploration was the question of whether LLTF's support aligns with known facilitators of psychological resilience and well-being in the context of premature or critical neonatal care.

Previous research by Eeles et al.(3) has highlighted key priorities for parents of NICU-admitted babies, which include supporting parental mental health; fostering collaborative partnerships between parents and healthcare staff through active involvement in care; supporting and nurturing early parent–infant attachment; and enhancing the quality of neonatal medical care. These priorities align closely with evidence-based interventions designed to strengthen parent–infant bonding within the NICU.(48-52) Such programs aim to reduce stress, promote emotional connection and encourage parental engagement in a highly medicalised environment.

Core components of these interventions include kangaroo care, family-centred developmental care, and active parent participation in infant care.

How LLTF products and services align with these priorities is detailed below.

### 1 LLTF products and services support parental mental health.

- LLTF strongly aligns with support for parent mental health.
- Participants emphasised the importance of emotional support through affirmation cards, journaling, creative activities and access to peer or anonymous support.
- Suggestions for mental health resources, validation through statistics, and AI-based chat services directly support this principle.
- The Little Bag of Calm and emotional resonance of items such as fabric hearts show that LLTF's current offerings are already contributing meaningfully in this area.

Opportunities for enhancement include:

- expanding mental health resources to include tailored materials for different stages (e.g., antenatal bed rest, post-discharge)
- considering the integration of mental health referral pathways.

### 2 LLTF products and services foster collaborative partnerships between parents and healthcare staff.

- There is a moderate alignment of LLTF with fostering collaborative relationships.
- Although not a dominant theme in participant feedback, some suggestions touched on the value of feeling understood and supported by staff and volunteers with lived experience.
- The desire for clearer communication and consistent promotion of LLTF services suggests a need for stronger collaboration between LLTF and hospital staff.

Opportunities for enhancement include:

- training hospital staff or even Ronald McDonald House to actively introduce LLTF resources and encourage parent involvement
- developing joint initiatives with hospitals to embed LLTF offerings into routine care pathways.

### 3 LLTF products and services support and nurture early parent–infant attachment.

- There is a strong alignment between LLTF and nurturing the early parent–infant attachment.
- Items such as fabric hearts, milestone cards and photo journals were deeply valued for fostering connection during separation.
- Breastfeeding support and practical items such as clothing and blankets were seen as tools for bonding and caregiving.

Opportunities for enhancement include:

- expanding kangaroo care–related resources and education
- including more tools that facilitate touch, smell and presence (e.g., wearable items, scent cloths).

### 4 LLTF products and services enhance the quality of neonatal medical care.

- There is an indirect alignment between LLTF and enhancing neonatal medical care.
- Although LLTF does not directly provide medical care, its products and services support families navigating the medical environment.
- Suggestions for better breastfeeding support, equipment-compatible clothing, and practical items such as car seat inserts show a desire for products that complement medical care.

Opportunities for enhancement include:

- collaborating with clinical teams to ensure that LLTF products align with medical protocols (e.g., clothing design for leads and monitors)
- considering co-developing educational materials with clinicians on developmental care and kangaroo care.

Special focus: Kangaroo care, family-centred developmental care, and parent involvement

- There is an emerging alignment between LLTF and family-centred care.
- Although not explicitly mentioned by participants, the emotional and bonding tools provided by LLTF (fabric hearts, milestone cards, journals) support the principles of family-centred developmental care.
- Suggestions for more inclusive and personalised support indicate a readiness for deeper engagement in care.

Opportunities for enhancement include:

- introducing resources that educate and encourage kangaroo care
- developing materials that empower parents to participate actively in their baby's care, even in high-acuity settings.

# 6. Conclusion

In conclusion, this study affirms the positive impact of LLTF products on the mental health of parents with preterm and sick babies, which highlights their role in fostering early parent–infant attachment. To extend this benefit to a broader population, increasing awareness and improving accessibility to these resources is essential. In doing so, LLTF could significantly enhance support for more families navigating the challenges of neonatal care.

### STRENGTH OF THE STUDY

This study has provided a comprehensive review of many of the LLTF products and services, and of the impact they have on parents who have had a premature or sick baby in a neonatal unit.

### LIMITATION OF THE STUDY

Despite all efforts to reduce the effect of researcher opinion, as with all qualitative research, there is inherent researcher bias. Even though data were collected until saturation, their interpretation is not entirely free of the researchers' opinion.

# 7. Recommendations

Drawing on participant feedback and identified areas for improvement, we have distilled six key themes to guide the enhancement of LLTF's products and services.

### 1 Increase awareness and accessibility

- Ensure consistent and proactive promotion of LLTF services across all participating hospitals.
- Use multiple channels (e.g., posters, flyers, digital screens, staff referrals) to inform families about available resources.
- Train hospital staff to routinely mention LLTF services during patient interactions.
- Consider a welcome pack or orientation session for new NICU and SCU families that includes LLTF information.

### 2 Tailor resources to individual needs

- Ensure the relevance of the Guidebook for Families for both preterm and non-preterm (i.e., critically ill) families.
- Offer alternative formats such as audio versions or condensed guides for parents who may struggle with reading due to stress or time constraints.
- Tailor pack and resources for diverse family structures and including dedicated material for non-birthing partners.
- Consider climate and equipment compatibility when selecting clothing items for the Precious Prem Pack.

### 3 Enhance emotional support offerings

- Continue and expand the inclusion of items such as fabric hearts and affirmation cards, which were deeply meaningful to many parents.
- Access to on-call support or anonymous chat services through online platforms.
- Provide optional journaling tools and creative activities to support mental health and reflection.
- Exploring ways to personalise emotional support items based on family preferences or needs.

### 4 Improve practical support

- Ensure that the Britax car seat insert remains a standard inclusion due to its high level of utility.
- Review the value and usability of vouchers, ensuring that they are current, widely accepted and of meaningful financial assistance.
- Consider expanding practical items to include more feeding-related support, given the emotional significance of breastfeeding.
- Provision of hydrations tools such as reusable drink bottles.

### 5 Standardise and expand the Breakfast Bar

- Make the Breakfast Bar a formal part of LLTF offerings across all hospitals.
- Ensure regular restocking and clear signage to improve reliability and visibility.
- Use the space to foster community and peer connection among NICU and SCU families.

### 6 Enhance Community Connection

- Buddy systems and peer support groups.
- Volunteer-led activities and parent groups.
- Opportunities for shared experiences and emotional bonding.

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