Celebrating Milestones

Design to Empower & Reduce Uncertainty for Families on their

Neonatal Journey

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgments), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

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Glossary

The term ‘parent’ is used in this research project to loosely define the mother, father or caregivers of a neonate, biological or not.

The term whānau or family is used in this research project to refer to the neonate’s parents and their wider support system.

Medical Terminology & Abbreviations

neonate	infant, newborn baby.
gestational age	the length of time from conception to birth, generally measured in weeks. Full term is 38-42 weeks.
preterm or premature infant	infants who are born less than 37 weeks of gestational age.
SCBU	Special Care Baby Unit (Level 2)
NICU	Neonatal Intensive Care Unit (most critical infants)
NNU	Neonatal Unit
DHB	District Health Board
FIC	Family-Integrated Care
paediatrician	doctors who specialise in treating babies and children.
Neonatal Nurse	care for up to 4 babies at a time.

CPAP	Continuous Positive Airway Pressure, helps baby breathe.
Phototherapy	a treatment for jaundice (baby is exposed to blue fluorescent lights).
Kangaroo care	when parent holds infant skin-to-skin, improves outcomes and facilitates bonding.

Māori Words

Māori	indigenous person of Aotearoa/New Zealand.
pēpi	baby.
whānau	family group.
Te Whare Tiaki Pepi	The Special Care Baby Unit
harakeke	New Zealand flax, plant.
rito	the heart of the harakeke plant, a new shoot.
awhi rito	leaves that embrace the centre shoot of the harakeke.
whakawhanaungatanga	process of establishing relationships.
mātauranga māori	knowledge, traditions, values, philosophies derived from Māori culture.

In the effort to use inclusive language, this research acknowledges that most birthing parents are women, but not all. This work is approached with a feminist lens and does not overlook the social, political, and cultural expectations placed on mothers. Inclusive language does not mean drawing away from the sacredness of the womb, womanhood, and motherhood but rather a celebration of parenthood and acknowledges the wide range of users that navigate neonatal healthcare. The terms 'parent', 'partner' or 'support person' are used frequently throughout this exegesis. 'whānau' (the Māori word for family) is also used to describe the wider support system of a family unit, which may include friends and close relatives of a baby. This inclusive language recognises that:

- *Not everyone capable of being pregnant and giving birth identifies as a woman. For example, people who identify as non-binary or transgender people are capable of birthing.*
- *Not all mothers are the birthing parents and not all partners are fathers — for example, same-sex female couples or adoptive parents.*
- *Not all mothers or birthing parents are in a relationship or have a relationship with the child's other biological parent — for example, a single mother.*

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Abstract

This project explores how educational resources for parents navigating neonatal care in New Zealand could be better designed using a human-centred design approach. In New Zealand, there has been considerable work done in neonatal care across various hospitals and former District Health Boards (DHBs) to provide education and support to parents. However, this information is scattered in different mediums—digital media, apps, websites, books, paper copies, booklets, brochures or is being passed on verbally. Moreover, resources largely differ in content and volume from one hospital to another. Historically, we went from having limited information on infant-care, to an overwhelming amount with conflicting messages. The findings of this research point to there being a need for a family-integrated resource for whānau of neonates staying in Special Care Baby Units (SCBUs) that celebrate milestones and facilitate effective communication between all those involved in the care team. A key insight from this research was the need to reimagine how we deliver vital information about the neonate's treatment and care to whānau in a way that is empowering and trauma sensitive, as they prepare to transition from hospital to home. This research was conducted using a human-centered design approach to identify the unmet needs of parents of premature babies navigating neonatal care, define areas for potential improvement, and explore how design can contribute to address these.

Positioning the Researcher

Figure 1. *K. Newman (2022), Small Steps, A Mental Health Toolkit for New Mum's*

I am passionate about all things related to women's health and products that make the world a better place. In my undergraduate studies, I designed a perinatal mental health toolkit for new mothers. It received a Social Innovation award from AUT and was a finalist for the Best Award. I've begun working as a Design and Marketing Assistant and 3D Scanning Consultant for MyReflection—they custom-craft breast prostheses for people who have had a mastectomy because of breast cancer. I enjoy collaborative, purpose-driven projects focusing on women's health or social innovation. I was awarded a summer studentship with AUT's Good Health Design—the project included an analysis of and proposal for Waitemata DHBs telehealth webpage. I have completed a 'Design for Health and Wellbeing' and 'Ethics in Research' papers in the first semester of my postgraduate studies. I am interested in better understanding New Zealand's healthcare system, how people navigate it and what touch-points could be improved through clever design.

Introduction

Neonatal care is a sensitive, emotionally charged space in hospitals where sick and premature babies are looked after. Neonatal care is for babies who have had a difficult start to life and need extra support to be healthy and strong before they can be sent home with their families. Complications around birth make those first days, weeks, or even months look different from what a parent may have envisioned (Spence et al., 2023). Seeing a newborn with tubes and equipment surrounding their little, fragile bodies can be difficult to process as a parent (Fernández Medina et al., 2018). While a baby is getting better and growing bigger in the hospital, parents also get delivered a lot of information to absorb and process. It can be quite overwhelming to keep track of a child's day-to-day and week-to-week progress, and it involves a steep learning curve. It consists of learning about their child's condition and the treatments they are receiving, as well as education around infant developmental care—for example, learning how to give nutrition to an infant that is too small to be breastfed. Or, learning how to engage safely with 'kangaroo care' and its benefits, otherwise known as 'skin-to-skin'. Parents' experiences can be further hindered by barriers like medical jargon, lack of accessibility, and inconsistent information. This is information parents of healthy babies don't necessarily have to worry about. For parents of premature or unwell babies, this is in addition to already being distressed about their child's survival.

In this design research, I will unpack and analyse the resource whānau are given to help them navigate neonatal care and identify areas for improvement considering the values of human-centred design. I have also carried out semi-structured online interviews and site visits to a New Zealand hospital to engage with experts in this field, such as nurses, paediatricians, and a birth trauma specialist. Additionally, I have conducted a contextual review to deepen my understanding of parent experiences in

neonatal units beyond my personal relationships, as well as understand the historical context of child-rearing in New Zealand. This helped me familiarise myself with the latest methods and approaches to parent education in neonatal units and further understand the complexities and barriers in healthcare. The research methods employed in this study align with the methodical design-thinking approach known as the 'Double-Diamond (DD) Framework' (UK Design Council, 2015). The DD framework is known for problem-solving and innovation in complex systems (Norman, 2013), such as healthcare. The findings from these research methods allowed me to draw evidence-based insights. These insights were used to inform a design brief and a set of recommendations for designers and clinicians who are interested in creating educational resources for future families in New Zealand entering neonatal care. By implementing these recommendations, I have developed a proposed solution to address the challenges faced by users in neonatal care units. This research project not only addresses the identified problems but also represents culminating this research as a tangible and innovative design outcome. It is not intended to be the sole solution to problems faced by parents and clinicians in neonatal care, but rather a response to the major themes identified through this design research.

Contextual Review

Neonatal Care and the Trauma of Premature Birth

Empowerment through Information

The Plunket Society

Cultural Lense

Family Intergrated Care (F.I.C)

Current Resources

DESIGN belongs in Healthcare

Neonatal Care and the Trauma of Premature Birth

If becoming a parent wasn't already one of the most significant transitions a person goes through in their lifetime, having an infant born prematurely or born with special healthcare needs requiring hospitalisation only brings additional pressures (Roque et al., 2017).

Over 5000 babies are born prematurely in New Zealand each year, some as early as 23 weeks (Brooker, 2023; Gregory, 2022).

Figure 2. The Neonatal Trust (2020) What to expect when it wasn't what you expected, page. 7

Figure 3. *Photograph of critical cot space from site visit at Waitakere Hospital*

A baby born at 37 weeks gestation—3 weeks earlier than usual— or earlier, is considered preterm. The earlier a baby is born, the lower the birth weight and the higher the risk of health complications (Al-Wassia & Saber, 2017). Neonatal care is the umbrella term for various levels of infant care, specifically in hospitals. A baby born early, with a low birth weight, or unwell at birth may be admitted to a Special Care Baby Unit (SCBU), while a baby born alive at less than 28 weeks gestation is considered being extremely preterm; such babies, as well as those who need intensive care, are more likely to be hospitalised at a Neonatal Intensive Care Unit (NICU) at birth. SCBU babies are nicknamed 'feeders and growers' and are at a lower risk of health complications compared to NICU babies.

Neonatal units are complex clinical environments impacted by various social, cultural and economic factors affecting families and staff (Coughlin, 2021). Every family's neonatal

journey is unique. One consistent factor is the emotional burden placed on families, which undoubtedly impacts every aspect of their lives. Research suggests that stress around the time of pregnancy, birth and newborn days can become generational perinatal distress, especially when care isn't accessible or culturally appropriate (Coughlin, 2021; H. Walker, 2022). The extent of care required by a newborn is not the only element that contributes to parental distress during their baby's hospitalisation; unforeseen circumstances surrounding the birth itself, such as premature labour or emergency C-sections, frequently lead to considerable distress, as parents try to come to terms with their new, as opposed to expected, reality (Lasiuk et al., 2013; Spence et al., 2023).

"Several parents discussed their imagined experience of delivering a medically stable, term newborn, or described a point when they went from hoping to continue on with their pregnancy to gaining knowledge and realizing all of the potential challenges with delivering a preterm infant"

Spence et al. / Parent Experiences in the NICU and Transition to Home (2023) p. 6

The emotional impact of having a hospitalised infant is often accompanied by feelings of dread, anxiety, and a sense of emptiness within the sterile clinical environment (Fernández Medina et al., 2018; Coughlin, 2021). In a typical neonatal unit, a baby will be surrounded by various monitors, tubes, and wires, which can feel uneasy to witness, and the physical separation can be traumatic (Soni & Tscherning, 2021) (see figure 3). This might not be what parents imagine for their baby's first weeks of life. It's common for parents to feel a sense of grief and like they have missed out on the joyous entrance into parenthood they had envisioned - In that sense, both parents can experience this as birth trauma ("My Birth Story" (2018); PADA.)

Birth trauma isn't limited to having a physically painful birth experience. Baby's poor health, the length of their hospitalisation, prolonged uncertainty, a sense of helplessness, significant disruptions in life and changes in their expectations of what it means to be a parent in a NICU/SCBU environment are contributing factors (Barthel et al., 2020; Lasiuk et al., 2013). Things such as skin-to-skin contact are important for infant-mother bonding and barriers such as transportation cause significant disruption for those

families who don't live near hospitals where neonatal care is available (Gianni et al., 2018; Gómez-Cantarino et al., 2020; Soni & Tscherning, 2021). Occasionally, the birthing person will be ready to be discharged from hospital before their baby, and depending on the hospital and capacity, parent(s) will have to travel daily from hospital to home to see and care for their baby (NICU | Te Whatu Ora, n.d.). The consequences of birth trauma resulting from a sick or preterm newborn have far-reaching effects on parent. Relationships, mental state, and financial well-being decline as they devote substantial time and effort to caring for their child in the hospital (Coughlin, 2021; Lasiuk et al., 2013; Soni & Tscherning, 2021).

Trauma can affect all aspects of our well-being, also affecting one's capacity to take on and interpret new information (Birth Trauma Insights | My Birth Story New Zealand, n.d.; Coughlin, 2021). This is especially apparent during emergency births and in the midst of a clinical neonatal environment, where families are already overwhelmed and overloaded with changing information (Coughlin, 2021).

Figure 4. *Brooker & Little Miracles Trust (2024). Violet – 27 Weeks Gestation*

Whānau at the Centre

"Parents are not visitors. Parents are parents—their child's first and most important caregiver"

Bracht et al. / Advances in Neonatal Care Vol 23/2 (2023) p. 105.

There are many approaches to ensuring whānau are prepared and well supported on their neonatal journey, such as providing education resources to parents (Mazur et al., 2021). Different hospitals utilize various models to guide their care teams in providing quality care for babies and their families, to ensure the well-being of the baby and their family, as well as to prepare them for discharge.

Family-Centred Care (FCC) model is highly valued among care providers and is internationally recognised (Ansari et al., 2023; Bracht et al., 2013; Gómez-Cantarino et al., 2020; Soni & Tscherning, 2021). In the context of Aotearoa NZ, Mātauranga Māori has also been proposed as a culturally appropriate and holistic approach in the context of neonatal care.

Figure 5. Te Ahukaramū Charles Royal (2007). 'Te Waonui a Tāne – forest mythology - Symbolism of trees and plants'

Māori (indigenous peoples of New Zealand) are known to be disproportionately represented with poorer health outcomes, and this is consistent with higher rate of premature birth and perinatal distress (Adcock et al., 2021; H. Walker, 2022). In the context of Aotearoa (New Zealand), which is a bicultural society, "Mātauranga Māori" can be understood as the collective knowledge and cultural perspectives of the indigenous people, which is commonly translated as Māori knowledge. Walker's (2022) report Āhurutia Te Rito: It takes a village, aims to unpack parental mental health concerns through a feminist and Māori cultural lens that is appropriate to women and family health in Aotearoa NZ. This report advocates for a family-centric, holistic, and culturally sensitive approaches in order to tackle perinatal distress. It also emphasises the importance of strengthening whānau units and communities in Aotearoa New Zealand – a concept often symbolized by the Harakeke (flax) in Te ao Māori (Figure 5 & 6). The heart of the plant represents the child, while the surrounding leaves symbolize the wider family and ancestors who provide protection.

A way to strengthen whānau relationships is through a Māori concept called whakawhanauatanga, which loosely translates to establishing relationships, and is very applicable surrounding birthing practices and post-natal care (Adcock et al., 2021; Bishop, 1995). If the care team is well connected, a family's relationships with neonatal staff can improve neonatal outcomes and allow parents to feel supported and a part of the care team (Adcock et al., 2021; H. Walker, 2022). This approach embodies the holistic perspective of Mātauranga Māori and shares common aspects and objectives with FCC models.

Figure 6. *Photograph of the base of the Harakeke (flax) in Titirangi*

Family Integrated Care (FIC)

Family-centred approaches have demonstrated effectiveness in giving parents confidence and offering continuous support throughout their journey from pregnancy to parenthood. Overall, FCC refers to the care team supporting the whānau – a more inclusive version of FCC – FIC goes a step further by actively including the whānau as an integral part of the care team (Ansari et al., 2023; Bracht et al., 2013). When referring to the care team, it encompasses everyone involved in ensuring the health and well-being of the neonate or whose role is to support the whānau throughout their neonatal journey. Thus, the care team typically includes the parents or support people, bedside nurses, a family liaison nurse, and doctors. The team may also extend to include wider whānau, physiotherapists, lactation consultants, social workers, radiographers or pharmacists, depending on what the whānau needs.

When children are sick in hospital, parents are present

around the clock to comfort them and be involved in their care and the health decisions made. However, when it comes to neonatal intensive care, this parenting dynamic seems to change with the complexity of care and limited visitation resulting in parent-infant separation (Gómez-Cantarino et al., 2020). FCC approaches strive to bridge this separation and include parents in the decision-making process and empower them as the main caregivers, a role that often gets overlooked when nurses and doctors are primarily responsible for caring for the infant (Bracht et al., 2013; Gómez-Cantarino et al., 2020). To ensure this happens nurses then move between being caregivers and educators to support parents to assume the position of primary caregivers (Coughlin, 2021; Gómez-Cantarino et al., 2020).

Consistent with the FCC approach, the SCBU staff must ensure they are not only providing care to infant, but that they help the family reach important developmental milestones before discharging them and ensuring a safe transition home. Every neonatal journey is unique and the milestones to reach discharge may vary depending on each infant's needs. This is all a part of the 'parent curriculum' – which can be overwhelming. Each milestone comes with a lot of new skills, on top of adjusting to life as a parent of a newborn. Some common goals include the skin-to-skin, baby being able to breathe without help, reaching a healthy weight, parents gaining knowledge about their baby's unique requirements, and feeling capable of caring for their child at home (Mazur et al., 2021).

Healthcare Messages, Parent Education, and the Plunket Society

Figure 7. Auckland Libraries Heritage Collections Footprints 02469, Alton (1947). A Plunket nurse gives a talk promoting 'natural feeding' (breastfeeding) to a group of young women, Auckland

The way our society approaches parenting and infant care has changed significantly in the last 100 years (Stevens et al., 2009). Community knowledge has been the backbone of New Zealand culture and child-rearing. Women's organisations - such as the Plunket Society established by Dr Frederic Truby King in 1907 - facilitate this sharing of knowledge (Clendon, 2009; Cox, 2018; Else, 1993). It takes a village to raise a child, and Plunket has been around for generations in New Zealand.

"By 1993 the society had touched the lives of at least three generations of women and their families"

- Cox, E. / NZ History Online, Royal New Zealand Plunket Society, para. 1 (2018)

In the 40s, infant mortality was at an all-time high; Truby King decided to do something about it and founded the Plunket Society, which distributed resources for mothers (Cox, 2018; Sullivan, 2007). According to King himself, few mothers breast-fed as it was seen as unfashionable and 'lower-class' did not believe fresh cold air was dangerous (King, 1913). Babies were often fed by a wet nurse if the family could afford one, or a mix of buttermilk, barley, bread, and water – cow's milk was not pasteurised and tested for contamination like we have nowadays. It seems unfathomable today that any good parent would feed a newborn anything other than breastmilk, however it was common practice at the time. To educate families and distribute healthcare messages, Dr. King wrote several books for mothers and expectant mothers such as 'Modern Mothercraft' and 'Feeding and Care of Baby' (figure 8). Caregivers have traditionally been known to be mothers or young women in the family unit, which is apparent in the language of King's handbooks and direction towards the maternal caregiver. In modern day, caregivers of our children cover a wider demographic, which includes fathers and non-biological parental roles.

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Figure 8. T. F. King (1913). Feeding and Care of Baby [cover] issued by the Royal New Zealand Society for the Health of Women & Children.

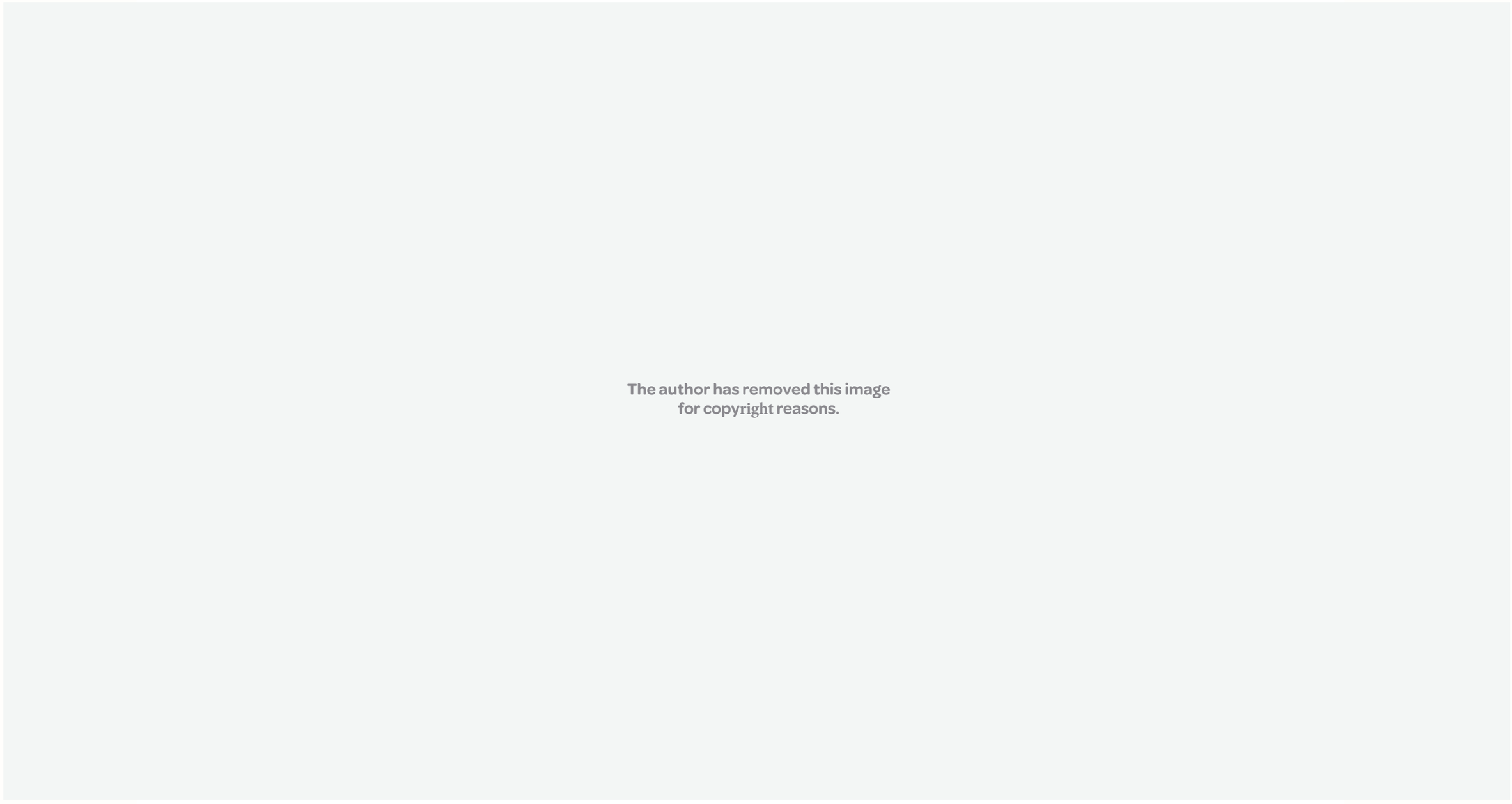


Figure 9. *Collection of Plunket Resources distributed from 1903, mixed media collage*

The methods in Feeding and Care of Baby (King, 1913), encouraged natural breastfeeding, cleanliness, and fresh air to keep babies healthy and prevent disease. In a time where medical care and information were limited, Dr King's book was a groundbreaking and valuable resource for mothers in New Zealand (Sullivan, 2007).

King's teachings, although argued to be controversial (Writes, 2019), gained the trust of mothers in New Zealand and the Plunket books became a reliable resource for child-rearing. King's legacy and The Plunket Society was a fundamental change in how parents in New Zealand accessed information about infant care and contributed notably to how society now views infant nutrition (Cox, 2018).

Plunket gradually evolved into a highly structured and community-led nursing initiative, wherein dedicated Plunket nurses would diligently visit mothers and their children either in the comfort of their homes or at designated clinics. This remarkable commitment to enhancing community health was further bolstered by various fundraising activities and active participation from up and down the country, united in their mission to support mothers and safeguard the well-being of children.

The pioneers of the Plunket Society changed the game to infant nutrition. 'Feeding and Care of Baby' developed various versions over the years into the widely known 'Plunket book'. In recent generations, Plunket book' - officially titled the 'Well Child/Tamariki Ora Health Book' – had become an iconic and trusted source and keepsake for New Zealand mothers (Clendon, 2009) *see page 101*. The Plunket book itself is just a small representation of what the Plunket 'movement' really means to New Zealanders. Plunket's evolvement in New Zealand is a brilliant example of community-driven change, and the power of women supporting women.

(next page) *Figure 10.* *Mixed Media collage - Plunket Society from 1903, Large version*

Catching back up to the 2020s: nowadays, we have technology, medical advancements, baby products, the development of breast milk alternatives, and a plethora of information at our fingertips, giving parents more options for caring for their infant, whether that be a more holistic or clinical approach. This, however, doesn't necessarily make knowing what to do as a parent, easier. Not all information is useful, helpful, or accurate. In New Zealand, there has been a lot of work done in neonatal care across our hospitals and former District Health Boards (DHBs) to provide education and support to parents that is trustworthy. However, this information is scattered in different mediums — digital media, apps, websites, books, paper copies, booklets, brochures, or is being passed on verbally. Society went from having local and limited information on infant-care to being bombarded with an overwhelming amount of conflicting messages. Navigating healthcare resources is like trying to soak up knowledge from a storm of information and advice, like a ship caught in a torrential downpour of guidance from various directions.

Current Resources in Zealand

In a typical neonatal care setting in New Zealand, nursing teams deliver developmental care education and, to include family, use a variety of resources in a variety of mediums – paper-based, digital or demonstrated and shared verbally. Upon arrival and throughout their hospital stay, families navigating neonatal care may receive a range of tools and information (both paper-based and online) to learn about developmental care and settle into the unit. Below are some examples of the resources currently used around New Zealand:

a) A Welcome Letter from the Unit

b) 'Parent and Nursing Responsibilities in NICU' print out.

c) 'Baby Steps to Discharge' table print out.

d) Flight Care Plan to Home

e) Print outs on specific conditions or treatments a baby is experiencing

f) The Little Miracles Trust Handbook or printed resources

g) IFDC App: Integrated Family Delivered Neonatal Care

h) Pepi Care App

i) Plunket Book

j) Brochures for charities and support available such as Bellyful, Little Miracles Trust, The Neonatal Trust, the Well Foundation, community groups.

The use of these resources varies among neonatal units in New Zealand and differs from one hospital to another. Not all hospitals utilize them consistently. Additionally, the number of resources given to parents also differs between hospitals. In some cases, parents are provided with a stack of resources that are often wordy and overwhelming as their distribution coincides with a stressful time in their baby's care. More importantly, they are often written and/or put together by the staff on a neonatal unit who lack design skills to produce a quality user-friendly and appealing resources. A participatory design approach would ensure stakeholder and user feedback is included in the process (see page 120)

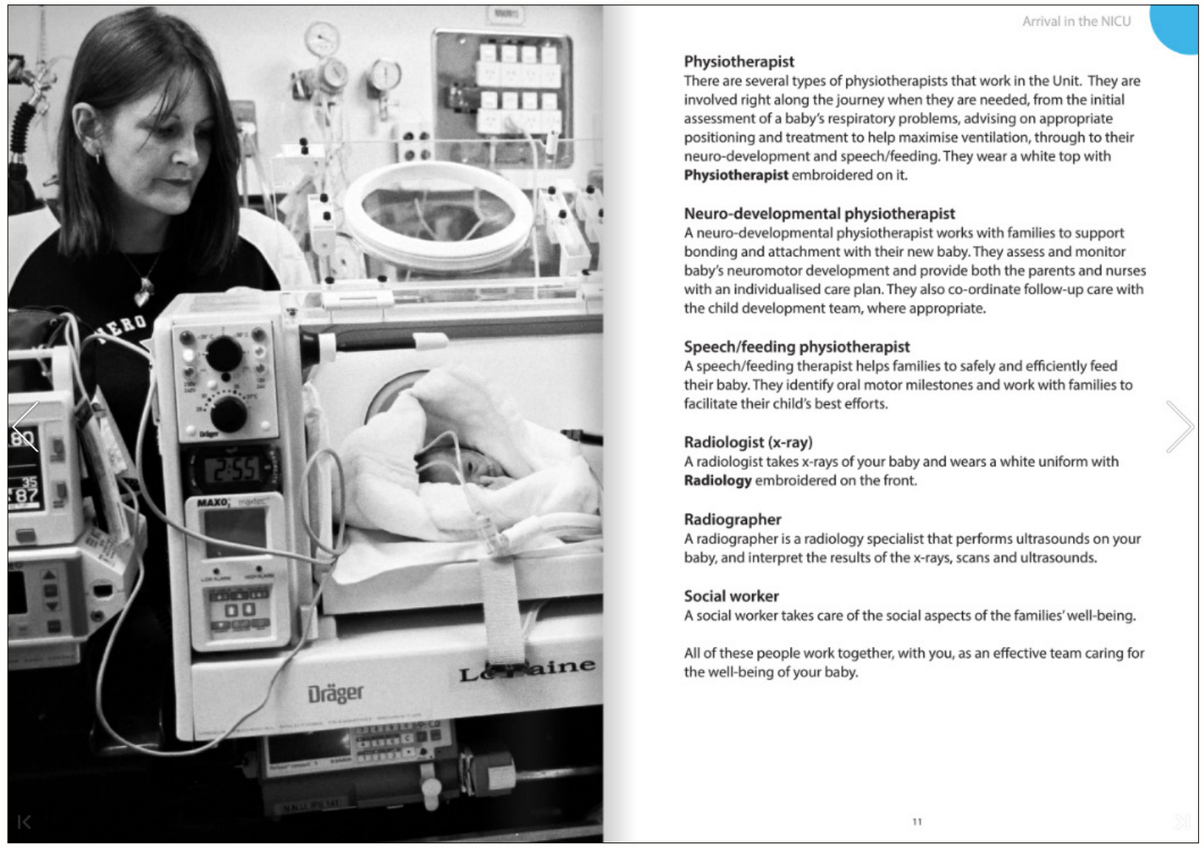


Figure 11. The Little Miracles Trust (2020) What to expect when it wasn't what you expected

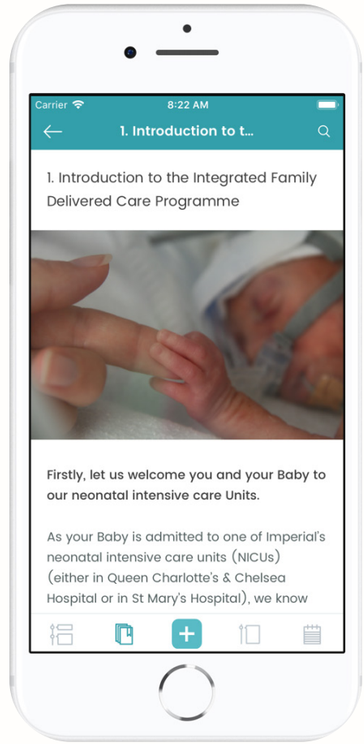


Figure 12. IFDC (n.d) App, Introduction Page

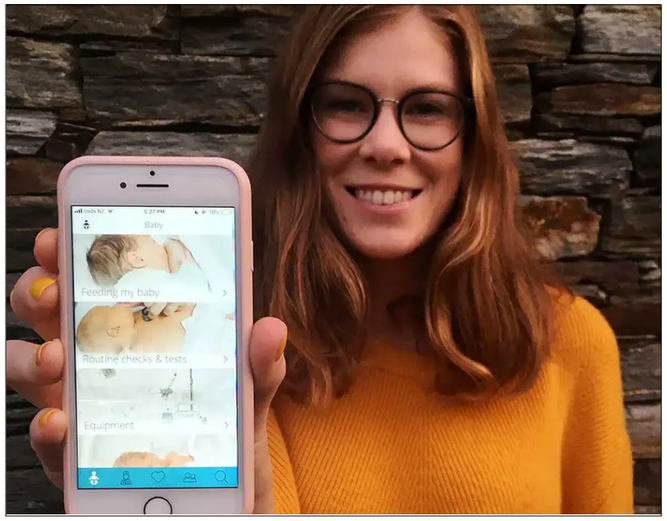


Figure 13. Gibson (2023) Doctoral Researcher Charlotte Gibson with the Babble app, which was launched in 2016

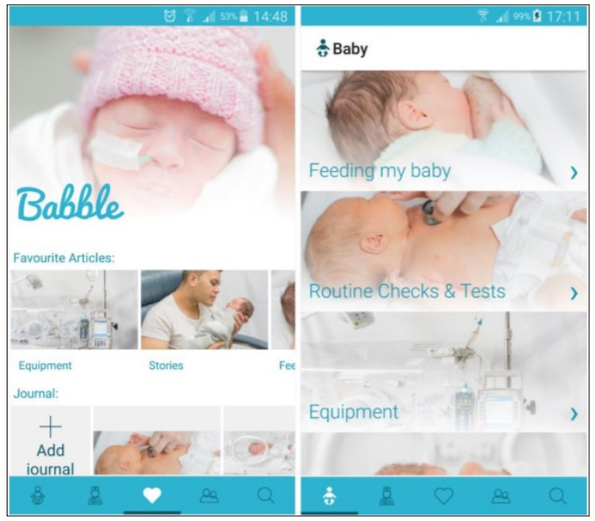


Figure 14. Babble NZ (n.d) Neonatal Family App Overview

Figure 15. Waitemata District Health Board (n.d) Welcome to SCBU Brochure,

Table of contents

- Welcome 1
- New to the NICU 2
  - Orientation checklist
  - Important information
  - Case management
  - Monitors and alarms
  - Weight chart
  - Who's who in the NICU
- Pumping and breastfeeding 14
  - Lactation FAQs
  - Importance of breastmilk
  - Breastfeeding basics
  - Breast pump kit care
- NICU social work 19
  - Common parent reactions
  - Social security and low birth weight program
- Developmental care 25
  - Parenting a premature baby
  - Just Roo It!
  - Quiet hour
  - NICU therapy services, OT, ST PT and child life
- Parent to parent 35
  - NICU University
  - Postpartum support
  - NICU journey bead program
  - NICU family advisory council
- Planning for discharge 42
  - Checklist to go home
  - Choosing baby's pediatrician
  - Selecting a daycare
  - Before going home
  - Discharge for babies receiving SSI
- Caring for baby at home 50
  - Important information for discharge
  - Respiratory syncytial virus (RSV)
  - Important phone numbers
- Glossary 55

My NICU orientation checklist

Please be sure to check off the following items as you complete them. ✓

- ☐ I have learned about hand washing and how to prevent the spread of infection.
- ☐ I have learned about the NICU's visitation guidelines.
- ☐ I have filled out my visitor/parent contact card.
- ☐ I have learned about the best times to call the NICU for updates on my baby.
- ☐ I understand the NICU's cell phone guidelines.
- ☐ I have received education on the medical equipment being used to help my baby get better.
- ☐ I have been to the admitting office to confirm insurance and receive my parking card and KD Café discount card.
- ☐ I have met with my social worker.
- ☐ I have signed my NICU partnership agreement.
- ☐ I have met with a lactation consultant.
- ☐ I have met with a parent support coordinator.
- ☐ I have participated in NICU classes and activities.
- ☐ I have started my journey beads.

Figure 16. NICU 101 The essential guide for CHKD NICU parents, Contents page & My NICU Orientation Checklist

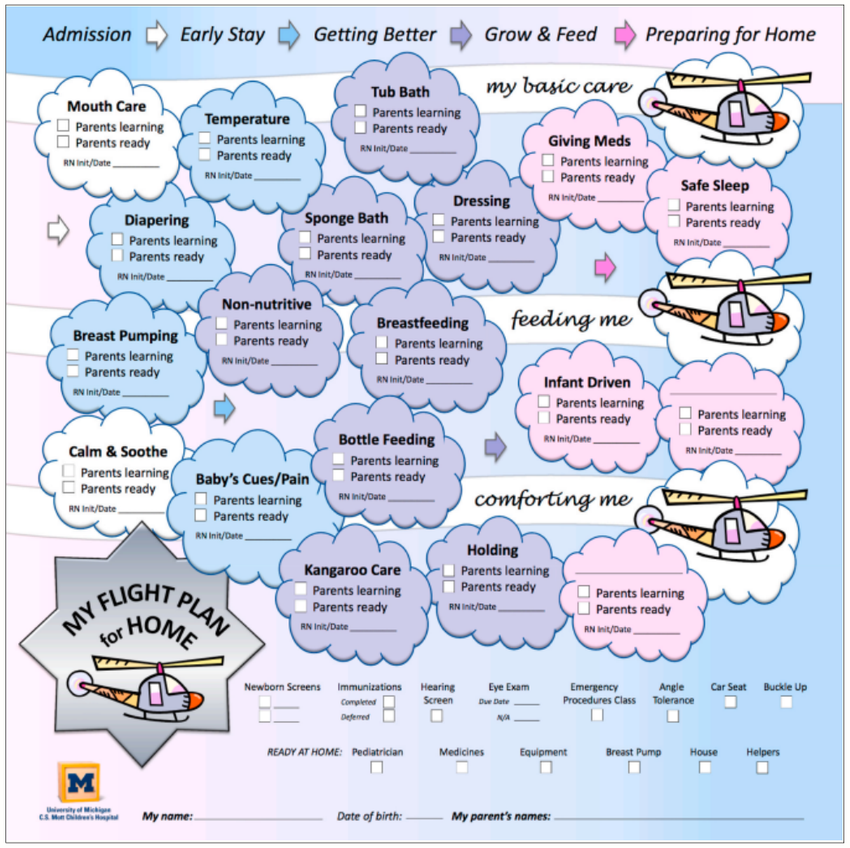


Figure 17. Miller & Nemshak (2013). My Flight Plan for Home parent discharge preparedness tool

Figure 18. Well Child Tamariki Ora (2024). My Health Book

A number of current resources for parents navigating neonatal care are in the form of mobile apps. However, although comprehensive in some cases, either hospital specific and licensed (e.g., Auckland's Middlemore Hospital's Babble app), hospital specific and intended for a specific purpose (e.g., Pepi Care App designed and trialled at Auckland's Waitakere Hospital SCBU that primarily allows clinicians to remotely monitor the infant's progress via a tablet-style device and scales given to parents for a quicker discharge), or promoted but not available for download from the link provided on the Hospital's website at the time of this research (e.g., Auckland's Starship Children's hospital's Starship NICU Journal app).

The lack of digital resources tailored to the Aotearoa New Zealand neonatal care context is even more prominent in provincial hospitals. During this research, multiple neonatal staff referred to and recommended an international digital resource by the Imperial College of London, known as the IFDC app (Integrated Family Delivered Care). Apps intended for parents in the neonatal context often don't have the most user-friendly interfaces. Some are praised by the staff for improving accessibility, aiding nursing workload and improving parent education in the neonatal spaces. However, there could be improvements to all of them, and majorly that is to do with how they are designed, and the fact that they are often not designed by human-centred designers knowledgeable in usability and aesthetics. The IFDC app seems to be a much more user-friendly version of any local resource we have for New Zealand families currently navigating neonatal care.

Figure 19. Logos of Pepi Care App, Integrated Family Delivered Care App, Babble App and Starship NICU Journal App

A detailed analysis of the resources based on the review of literature and criteria identified through the subsequent expert interviews is provided in the Assessment of Resources section in the Documentation of Research chapter.

Design Belongs in Healthcare

When I talk about 'design' in healthcare, I don't mean littering hospital waiting rooms with pretty posters or bombarding patient with pamphlets and worksheets. I mean design research. Design for people. Design thinking. Collaboration. Creativity. Empathy. Thinking outside of the box to solve big, systemic problems in our world (Kelley & Kelley, 2023; Matthews et al., 2023). One of those big, systemic problems being healthcare. Healthcare is complex, hierarchical, overworked, and under-resourced, in every capacity (Nakarada-Kordic et al., 2021).

There are many reasons designers should be involved in helping develop services and resources for healthcare. Patient or person-centred care models share key principles with human-centred design approaches, both of which focus on improving experiences for people. Design researchers use evidence-based, design thinking methods such as collaboration and user-testing, to explore systems broadly and examine underlying issues that affect people and identify key focus areas (Nakarada-Kordic et al., 2021; Norman, 2013).

Human-centred design promotes problem solving by

fostering creativity to consider alternative 'out the box' thinking (Norman, 2013). Creative and empathic research methods applied in healthcare allow designers to gain a deeper understanding of patients and their families beyond their illnesses, as well as understanding the staff perspectives.

By adopting a design approach that prioritizes patient experiences, we can identify opportunities to improve these experiences and create often simple design solutions that may contribute to improved quality of care, despite healthcare being stretched thin. This approach encourages healthcare professionals to think differently, imagine new possibilities, and view the healthcare system holistically (Nakarada-Kordic et al., 2021).

Many studies show the value design and creative methods can bring to healthcare, especially in the context of designing resources using different mediums intended to benefit a variety of people affected by health conditions – for example, co-designing resources for ADHD with children (Powell et al., 2021), engaging young people with lived experience of psychosis in co-design of an educational

Figure 20. Walker et al. (2020) Response to user feedback about the amount of text used on the Beat Bad Bugs characters which aims to explain drug-resistance infections in community pharmacies.

online resource (Nakarada-Kordic et al., 2017), co-designing an app for rehabilitation from brain injuries (Babbage et al., 2022;), and designing tailor-made resources for carers of people with dementia (Black et al., 2019), to name a few (see figures 23, 21 & 22). Design can also be effective in collaborating with communities to communicate key public healthcare messages (e.g., Stones et al., 2022; S. Walker et al., 2020) – see figure 20.

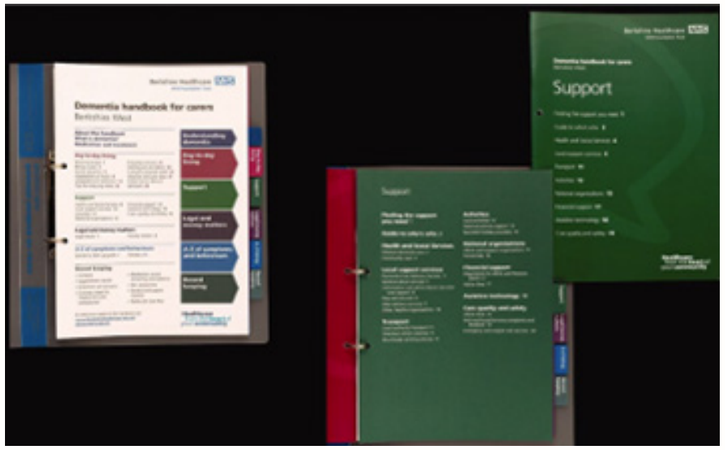


Figure 22. Black et al. (2019) Designing information for families caring for people with dementia

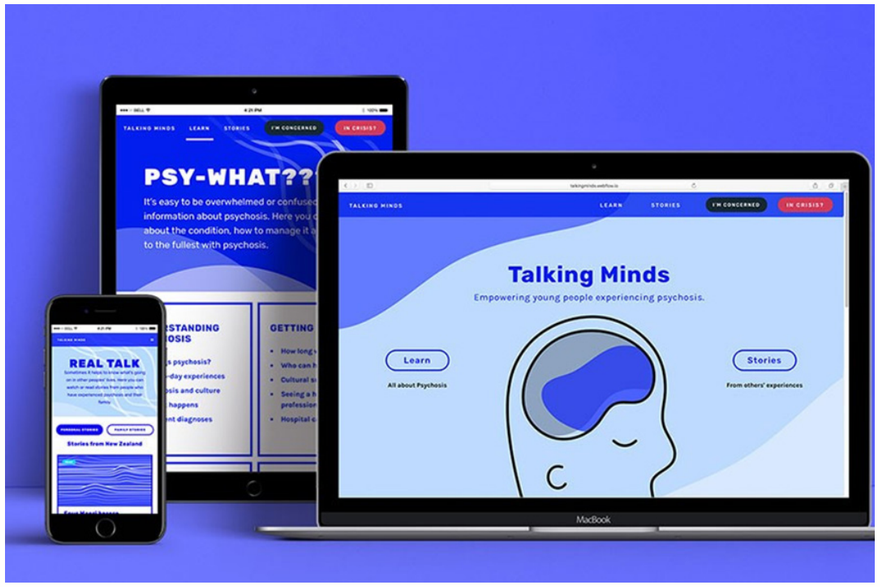


Figure 21. Nakarada-Kordic et al., (2017) New Resource for Youth with Psychosis - AUT News

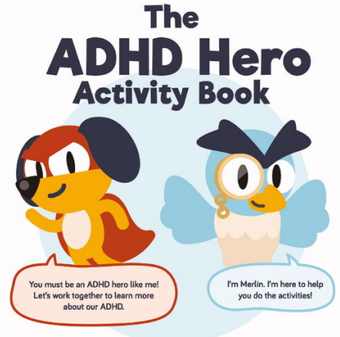


Figure 23. Powell et al. (2021) A co-designed prototype psychoeducational activity book for seven- to eleven-year-olds with ADHD

Despite the demand for, and demonstrated value of having good quality user-centred and often co-designed resources in a variety of healthcare contexts, there seems to be a lack of peer-reviewed accounts of similar design research and solutions developed in the context of neonatal healthcare, let alone those using a participatory approach. In the context of New Zealand specifically, there is little evidence to date of effective implementation of design, and even less so with involvement from design researchers in neonatal units. This points to opening up the possibilities of what a 'resource' might look like in a neonatal space – does it have to be paper-based, a website or an app? Or can we use HCD to creatively deliver information in an engaging way? An out-of-the-box solution, informed by users' needs is needed to educate and empower parents, instil confidence, and track neonatal milestones to reduce uncertainty as they make the transition from the hospital to their homes.

The Knowledge Gap

The evidence of literature and my analysis of existing and historic educational resources for parents highlights the need for human-centred designed, trauma-informed and family-integrated resources to support whānau navigating neonatal care in New Zealand hospitals. Developing resources with this mindset would help parents feel supported and empowered to assume the role of their baby's primary caregiver while in the hospital. This could in turn contribute to a regained sense of control, reduced mental health risks, improved infant closeness, improved developmental outcomes, and better preparation for discharge (Ansari et al., 2023).

Research Question

How might applying a human-centred design approach to healthcare resources empower and reduce uncertainty for families navigating neonatal care?

This research aimed to

- understand the informational needs of parents navigating neonatal healthcare spaces
- understand the current landscape of educational tools and resources available to parents while their premature baby is hospitalised
- identify criteria that may remove barriers for families to accessing and interpreting relevant information about their baby's condition, when they need it
- generate novel, stakeholder-informed human-centred design solutions to improve the whānau experience in a neonatal unit from birth to discharge, ultimately giving parents' confidence to assume the primary caregiver position early on in their neonatal journey.

Methodology Chapter

This chapter outlines the methodologies and methods employed in this project as part of the design research process. The two main methodologies underpinning this research are Human-Centred Design and the Participatory Design approaches. The research process followed the Double Diamond Framework (UK Design Council, 2015). Therefore, the methods are classified according to the two main phases of research: Discovery methods and Development methods. Ethical considerations relevant to this research are also outlined, as well as the methods of data analysis.

Methodologies

This research project is primarily supported by the Human-Centered Design (HCD) approach, which is a problem-solving approach that focuses on understanding human needs and perspectives to enhance the user experience (Melles et al., 2021; Norman, 2013). The key benefits of HCD revolve around its commitment to comprehending user needs and understanding their broader contexts at the individual, whanau, community, and societal levels. Understanding the structural aspects of the health system and its impact on care quality was a crucial aspect of this study.

To further enhance the user-centric principles of HCD, I have also incorporated the participatory design approach into my process (Sanders & Stappers, 2007, 2014). Participatory design emphasizes collaboration and involves the participation of various individuals, including users, participants, and stakeholders, in the design process. This approach ensures that the design is influenced by the perspectives and insights of those it is being designed for, and build's trust by those who will receive it (Holter, 2022). In this study, non-designers such as clinicians and community stakeholders were actively involved in decision making

through expert interviews and consultation.

The skills and thinking required for design are not only beneficial for designers but also essential for creating good, meaningful design (Verganti, 2017). Values such as critical analysis, collaboration, empathy, self-awareness, creative thinking, and effective communication are all important factors in the design process and ensure user's needs are taken into account.

In this research project, the participants were individuals within the neonatal community, including neonatal nurses, lactation consultants, paediatricians, and family support workers. These individuals have firsthand experience in neonatal care or occupations that involve supporting those going through their neonatal journey. To ensure that the needs of families navigating neonatal care were considered, the intention was to involve the whānau with experiences of SCBU (see the Ethical Considerations section below, and the Documentation of Research for details). I engaged with literature (see contextual review, page 6) and consulted with experts who work closely with these families. Additionally, one of the participants had personal firsthand experience as a parent of an infant hospitalised in neonatal care, in addition to their professional knowledge in neonatal care. (see interview findings page, 64).

Ethical Considerations

When conducting research as a designer in a complex clinical environment such as SCBU or NICU without clinical training or direct lived experience of this context, it was crucial to consider potential risks and take appropriate precautions.

I perceived there to be minimal risk in engaging experts in neonatal care in my research due to the considerations we put in place and the details submitted for university ethical approval. Anonymising the data in the outputs of the research ensures protections of participants from any identifiable information that may relate to their specific place of work.

Regarding whānau with lived experience of in-patient neonatal care, I had to understand that revisiting memories around the birth of one's baby and the time in hospital may be triggering or emotional. Therefore, I planned the data collection methods to be as non-intrusive as possible. Research methods were carefully designed to benefit all participants, with a strong emphasis on reducing harm, and being considerate of parent's time. To be most productive and sensitive with participants' time, I consulted with clinicians prior to conducting more in-depth interviews to learn as much as I can about the context. This allowed me time to discover the knowledge gap between clinicians and families and identify any tensions or pain points that could become design opportunities.

Data collection involving whānau with lived experience of neonatal care ultimately proved to be a challenge. Originally, a co-design workshop with whānau was planned, with much thought given to the logistics of the venue and activities to make it convenient and engaging for the participants to be able to express themselves safely and comfortably without evoking potential traumatic memories. Ethical approval was granted for this workshop by the University's Ethics Committee. However, during the recruitment phase, there was interest from parents outside of Auckland to participate and the scheduled date being a problem for Auckland Whānau (possibly as the timeline for the workshop coincided with end of the year holidays). This pushed out deadlines and resulted in a change of method to interviews,

with an online option to open up the research to whānau around New Zealand. Although the whānau interviews ultimately did not take place (again, potentially due the long summer holiday season in NZ), the planning process served as a valuable learning experience in terms of contemplating potential interactions with the participants, considering the sensitivity of the topic. The planning of the interview questions was a primary factor to be considered. Rather than asking participants to share a difficult experience, the questions were formulated to highlight the positive aspects of their experience. For example: "What is a favourite memory you have of your child? Who was your biggest supporter through your neonatal journey? Tell me about Graduation Day (last day of SCBU)". (see interview questions in appendix A). For all interviews that were conducted, I reminded participants they could end the session at any time, ask to have their data removed, or decline to answer questions, without judgement.

In the planning of the data collection with parents (whānau interviews), the invitations were also extended to a participant's partner or support person, who could take part themselves or just be there to listen and support. This recognises that it takes a village to raise a child and values the family unit, whatever that might look like for someone (H. Walker, 2022). These considerations were all outlined in the participant information sheets and consent forms (please see appendix B).

PFWWarticipants in attendance would be required to read a Participant Information Sheets and sign a consent form prior to attending the interview. Part of the consent process plan also included giving participants a considerate amount of time to decide if they wanted to take part and had opportunities to ask questions. I would remind the interviewees of their anonymity, and I verbally confirm their understanding of the signed consent form before beginning any audio recordings. All these considerations would ensure informed consent and limit any feelings of coercion or conflicts of interest.

I applied for ethics approval from Auckland University of Technology Ethics Committee AUTEC -for this project. The research plan included a detailed outline of the methods I intended to use, which required collaboration with others. The formal ethical approval for this study was granted

Human-Centred Design (HCD) and The Double Diamond Framework

The HCD approach in this study was enacted through the Double Diamond (DD) framework, which is a 4 step design process model (UK Design Council, 2015) that helps designers understand complex problems, such as research in healthcare. The DD framework visualises a methodical approach whilst not restricting creativity, involving an iterative process of 'diverging' and 'converging' of ideas (see figure 24). This ensures the designers understand problems in depth, develop their ideas, test them and communicate their solutions in a systematic way.

The first phase of the DD framework, Discovery, aims to minimise assumptions through discovery and in-depth understanding of wants, behaviours, motivations, emotions, and true needs of the users in the area being investigated.

Taking a broad approach in the early stages of the design process – as represented by the diverging triangular shape of the diagram (see figures 24 & 25) – ensures that the design researcher is being open minded and commits to understanding as much as possible about the users and their context to gain insight and therefore define the problem and/or need from the users' perspective. Similarly, Norman (2013) argues that good design aims to meet the needs of its users, through observation and study of the user with a focus on discoverability and usability – which are the pillars of HCD.

In order to fully comprehend and empathize with the experiences of individuals navigating neonatal care units in New Zealand, in this research I utilised various data collection methods and design-led methods. The discovery phase was implemented in this research through a contextual review, observations at site visits, discussions with key stakeholders, peer critique (hikoi & korero), and interviews with healthcare professionals and parents with experiences of in hospital neonatal care. The details of

these are described in the ‘Discovery Methods’ section of this chapter (figure 25). The discovery methods focus on empathy and understanding of the problem, which converges to ‘defining’ via a design brief. In this research, mind mapping was used as part of the define phase to narrow down the focus of the research.

The methods used in the development and deliver phases of the DD framework are referred to below as ‘Development Methods’ (see figure 26). This was an iterative design process informed by the findings from the interviews, analysis of resources, literature and site visits of the case study hospital, Waitakere Special Care Baby Unit (SCBU).

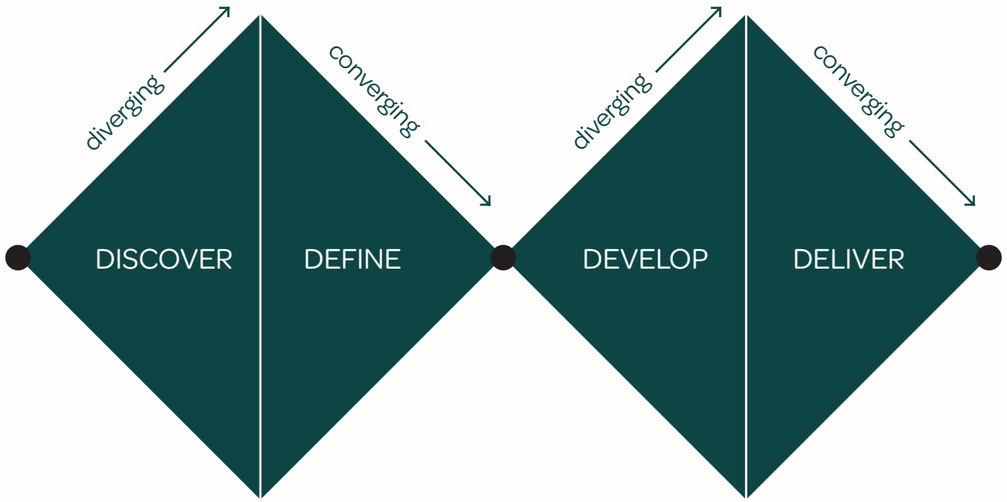


Figure 24. *Double Diamond Framework, British Design Council (2015)*

Discovery Methods

Figure 25. The first diamond: Discovery Phase

Site Visits

To understand the neonatal space, I needed to be amongst it. Part of understanding the context is putting yourself in somebody else's shoes. I had to imagine what it would be like to be a caregiver with an infant in the hospital. How would I get to the hospital? Where would I park? Are the signs to get to the correct unit easy to follow? Will someone give me directions of where to go? What is the neonatal unit like? Is it scary and overwhelming? Would it be scary to see a baby hooked up to wires and machines? Would the furnishings seem cold and sterile? Or would warm and welcoming nurses greet me? What information and resources would someone give me to help?

As someone with no prior knowledge of neonatal care, except for the experiences of my family members who have been through it, I was curious with questions. I had the privilege of meeting with clinicians at the hospital, which allowed me to gain valuable insights into the dynamics and functioning of the neonatal unit. The Special Care Baby unit at Waitakere hospital, which was a part of the Waitematā District Health Board (DHB) in New Zealand (now Te Whatu Ora/Health New Zealand Waitematā), graciously gave me several tours of their facility and took the time to answer my curious questions. The observations and findings from these site visits are presented in the Documentation of Research Chapter (see page 52). I was able to engage in discussions with clinicians regarding the unit's areas for improvement and we also simulated the unit's operations through role play. I was given the paperwork and resources that are usually given to families under their care. Furthermore, they took me on a tour of the unit, highlighting the main areas such as the family lounge, nursing station, storeroom, emergency station, individual infant rooms, mother's lounge, and feeding station.

Contextual Review

A contextual review outlines the scope of the research by analysing literature related to the context. This method was pivotal to confirm what was already known about parental education about newborns, particularly in the neonatal space. Despite substantial work being done in terms of resources for parents, it was necessary to identify the gaps in knowledge and justify using a design-led approach within the healthcare context. Another reason conducting a contextual review was integral was to better understand the experiences of parents who go through a neonatal journey. Unpacking the work done at Mount Sinai Hospital in Canada was particularly insightful (Bracht et al., 2013, 2023).

I also investigated the effects of the Plunket Society in New Zealand at a local level, examining its impact on our perceptions of community health, as well as our approach to raising children and the education about important milestones along the way. Moreover, some of the contextual review took place during the development stage of the research as I explored the role of nostalgic design in influencing these attitudes through the iterations of the generationally popular Plunket books and other education resources that were distributed around the time of the society's founding.

Mind Mapping

Mind mapping is a divergent, ideation tool that is frequently used amongst designers (Jones & Morrison, 2021; Kelley & Kelley, 2023). I use mind mapping as part of most of my creative processes to make sense of what I know, and what I need to know, particularly if the context is complex and unfamiliar. It involves a large piece of paper and markers to map out keywords and phrases to do with the topic, and I link together correlations with arrows. Mind maps help me to articulate my curiosity in a tangible and visual form. I usually use mind mapping technique at the beginning of projects, and jot down everything I know about the topic on a large piece of paper, which sits on a wall in my workspace for majority of the project. In this research, I also utilised this method during pivotal parts of the project such as, where brainstorming was needed to feed into the ideation phase and planning the data collection methods from participants.

Expert Interviews

I conducted three semi-structured online interviews with participants whose professions understand the complex nature of neonatal care. This method was one of the most important part of this research project because it confirmed some of my hunches and findings from the contextual review, site visit observations and analysis of resources. These interviews were particularly important as I was unable to conduct research with parents directly, and so staff who work in neonatal spaces are the second best to gain insight into the needs of families and the operations of a neonatal unit.

I had a list of questions to guide the conversation (see Appendix F). However, participants were given the opportunity to share their thoughts freely on where they thought neonatal care could be improved regarding information resources and family-centred care practices. Before the interview, I emphasised to the participants that the interview would be semi-structured and casual in nature and that I was there to listen and learn from them. I audio-recorded the interviews and transcribed them. The

participant's identifiable information, such as their names and which hospitals they have worked, are removed to protect their privacy. One was a birth trauma specialist, a nurse and a family support worker, all familiar with and supporting families on their neonatal journeys as part of their professions. The findings from the expert interviews were analysed thematically using a design thinking approach. The themes disseminated directly informed the criteria used to analyse current resources and the design brief.

Data Analysis

Empathy Mapping

Empathy mapping serves as a design thinking tool that facilitates the exploration of users' needs and desires (Foglieni et al., 2018; Kelley & Kelley, 2023.) The goal is to cultivate empathy among designers and stakeholders, encouraging them to empathize with the users they are designing for. It is a data analysis tool that can be used when observing users and/or their environment, but also to summarise user data from different data collection sources. Empathy maps categorise and visualise what a user might be seeing, hearing, thinking, feeling and doing. Understanding users beyond their illnesses is essential to design empathically and create better outcomes (Cleveland Clinic, 2013). This tool helped me develop a connection to users navigating neonatal care, allowing me to empathise with challenges that come with having a hospitalized infant. Visual mapping methods outlines the observations from site visits and literature (page 60).

Thematic Analysis

I used thematic analysis to analyse the data derived from audio transcripts of expert interviews. Thematic analysis is a flexible yet methodical, analytical process to analyse qualitative data that is applicable in many methodological frameworks (Clarke & Braun, 2013; Tuckett, 2005). I found this method to be a highly practical and productive way to identify themes from the audio transcripts such as user pain points and similarities of clinical recommendations. To employ this approach, I extracted insights by following a design research guide used at IDEO – a world leading design and innovation company – which involves taking good notes, and 'downloading' key ideas on post it notes (Cooper-Wright, 2015). The post-it notes were used to represent the key ideas discussed during the interviews. These notes were then organized into themes, and the insights derived from them informed the criteria for both the subsequent analysis of resources and the design brief. The findings from the interviews can be found in the documentation of research page 64.

Assessment of Resources

I spent many months collecting and researching resources that are available to families in New Zealand experiencing neonatal care. I found these resources from my visits to Hospitals in Auckland, recommendations by participants and prospective participants, neonatal charities and Google searches. Resources varied in volume and quality and came in a multitude of mediums, both printed and digitized versions. The usability of the resources I gathered was evaluated through a scoring system that took into consideration the themes and insights directly influenced by the findings of expert interviews and the parental needs identified in literature. The findings from this analysis are reported in the Documentation of Research chapter (see 86).

Development Methods

Figure 26. The second diamond: Development Phase

Peer Critique

The participatory design framework establishes that for the best outcomes, designers cannot work in isolation, but should engage in seeking regular and constructive criticism from other designers and stakeholders. Throughout this research, this was sought through Peer Critique and Stakeholder Feedback.

In our design cohort, we had two types of meetings: 'Crit Sessions' and 'Hikoi & Kōrero' (walk and talk). During 'Crit Sessions', we presented our findings and prototypes to the group and engaged in discussion and feedback. These meetings have been really enlightening for me, as they have provided me with new perspectives and insights. In 'Hikoi & Kōrero', we had uninterrupted conversations about our projects with a partner, allowing us to verbalize aspects that we may not have considered before. Afterwards, the cohort presented what they have learned about each other's projects, creating a sense of community and fostering a broader understanding of design research of healthcare topics. It assisted me in recognizing instances in which my concepts were flawed or had not been clearly conveyed.

Stakeholder Feedback

I reached out to key stakeholders that are familiar with the operations of neonatal care for consultation and feedback. During the development stage of my research, I went back to those I'd initially consulted with earlier on in the project for site visits and recruitment to obtain feedback on the design direction. These were staff that work in the neonatal units (NICU nurses, family liaison nurses, paediatricians) or were community stakeholders such as The Little Miracles Trust, The Neonatal Trust and Birth Trauma Aotearoa. I hope to present the findings of this design research to these communities following the submission of this exegesis.

Mood Boarding

Mood boarding is a creative method used by artists and designers to visualize and communicate ideas. Typically, a mixed media approach is used, incorporating photography, mark-making, textures, colours, found objects, or the work of other artists. It brings together visual elements based on the designer's intended mood, emphasizing certain textures, forms, or associations. As part of this design research, I developed mood boards to showcase the shared design elements between historical resources and artwork that evoke a sense of nostalgia for New Zealand families, particularly regarding the Plunket society. Mood boards were also useful during the ideation phase to visually communicate my ideas.

Ideation

Ideation is an integral part of any design process, where the designer must come up with lots of ideas. This is a divergent thinking process, where quantity is more important than quality. Designers often use sketching or rapid-fire prototyping to come up with as many ideas as possible regarding the aims (Foglieni et al., 2018; Kelley & Kelley, 2023). Designers are encouraged to 'go crazy' with as many broad ideas as possible during the ideation phase, without too much thought about feasibility. This fosters creativity and consideration of new ideas. My ideation is documented through mind-mapping, sketching, mood boards, concept matrix and rapid-fire prototyping in the Documentation of Research chapter (page 92).

Concept Matrix

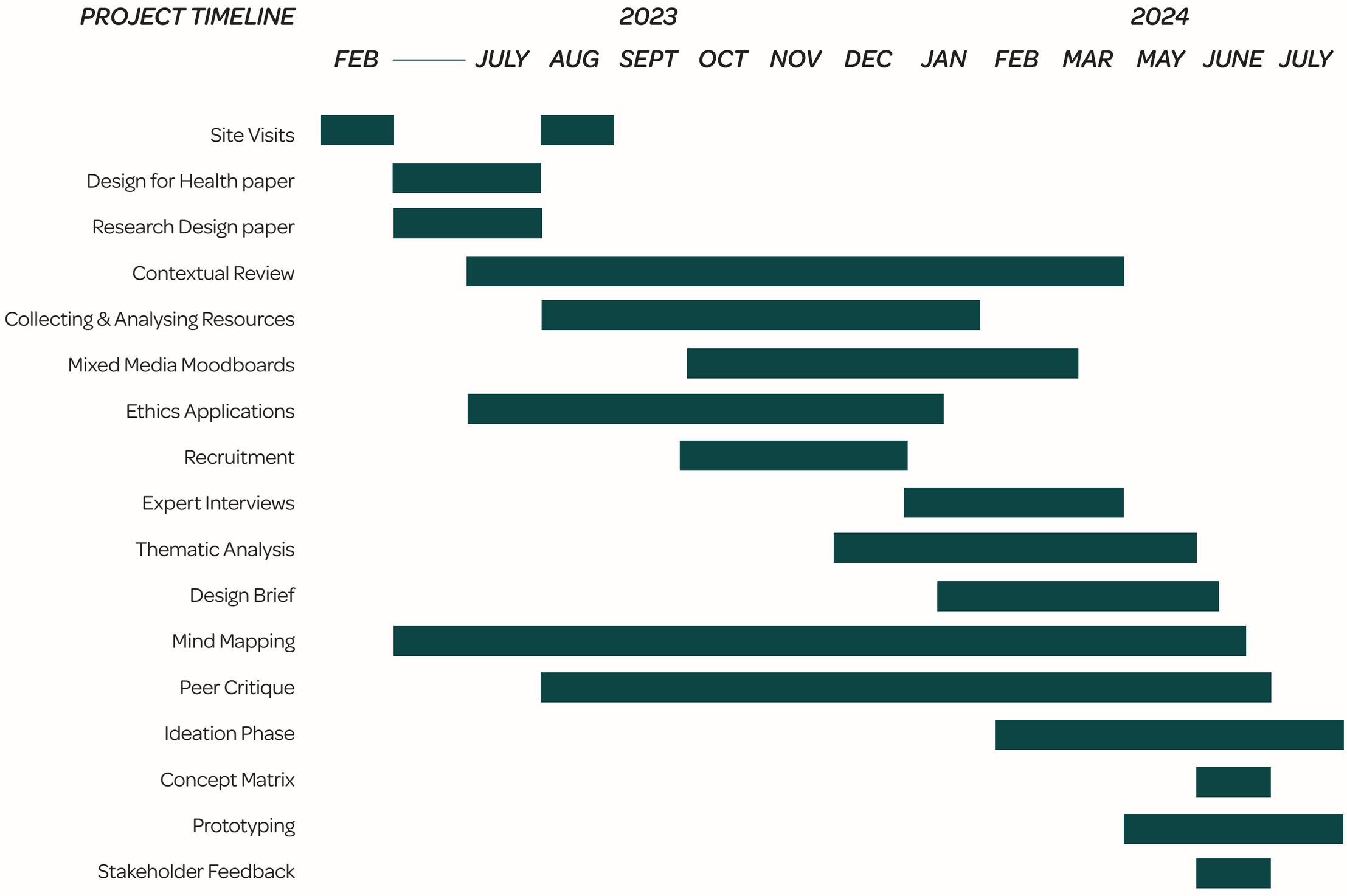
A concept matrix is a convergent method to help researchers narrow down their ideas through a scoring system to see which concepts feasibly meet the set criteria. It is used in literature-reviews but can also be utilised in the design process. In the context of a design thinking process, I picked my top concepts from the ideation phase and scored them based on how they met the needs of the users, the details of which are outlined in the design brief. This method was repeated after consultation with stakeholders to refine my prototypes. The concept matrices and findings are documented on page 105.

Prototyping

Prototyping is an experimental, creative and iterative process. It is a way to make visual and tangible ideas in a non-committal manner. Quality of prototypes can vary depending on their purpose. (please see documentation of this iterative process from page 112). Constructing quick low fidelity mockups was useful for me to communicate and test ideas with my peers and stakeholders (see page 120). Prototypes usually undergo multiple iterations and become increasingly refined based on the insights and discoveries from each iteration. These changes may involve considerations of functionality, feasibility, materials, or aesthetics.

The outcome of this design research will be communicated through a high-fidelity prototype in preparation for examination.

PROJECT TIMELINE



Documentation of Research

This chapter presents an overview of the documentation and findings obtained from each method employed in this research. This chapter is split into two phases: 'Discovery Research' and 'Development Research,' separated by the 'Design Brief', demonstrating how I utilised the double diamond framework - the diverging and converging of ideas, as outlined in the Methodology Chapter. The methods are documented, and then findings and commentary are summarised. The 'discovery research' findings shaped the design brief, which then influenced how I approached the 'development research'. Designers and researchers can find recommendations in this chapter for assessing the usability and appropriateness of neonatal resources. The design brief is open and recognises that there are numerous creative avenues that can be explored in response.

The healthcare professionals' input at different stages of the research was instrumental to this process. While I researched relevant literature on neonatal care and used existing resources to identify important milestones, it was the input from neonatal experts, particularly the feedback received towards the end of the project, that helped improve the design.

During the 'development phase' of this chapter, I illustrate how my design choices are influenced by literature, observations, and expert interviews, by following the criteria outlined in the brief. My creative process is often communicated visually through mind maps, sketches, and collages. Captions explain my thought process and decision making.

DISCOVERY RESEARCH

Site Visits

Waitakere Hospital SCBU served as a case study in this research. It is unlikely to be representative of the practices of all neonatal units in New Zealand, but it provided me with a good understanding of the atmosphere, mood, and processes of a typical neonatal unit. Interacting with clinicians proved to be incredibly valuable in gaining insights, and together we identified many opportunities for design to improve their processes while I was there. I was advised I could take photos of the unit, as long as any identifiable feature of families and babies were avoided.

Figure 27. *SCBU Staff showing us the operations and layout of a typical cot space .*

Figure 28. *Wayfinding signage at Waitakere Hospital*

Observation 1:

Parents are given a lot of information in paper form.

Some of the crucial resources intended for whānau were more often than not created by the staff themselves. The Flight Care Plan to Home (as discussed in the contextual review), was also mentioned to be a paper-based tool that this unit used.

Figure 29. Brochures and other paper-based resources available in the Family Room of the Waitakere Special Care Baby Unit

Observation 2:

Three parent rooms are available for families to stay at the hospital with their baby semi-independently a few nights before discharge to help them transition from hospital to home.

The intention behind the parent rooms is to help build the parents' confidence to assume the role of the primary caregiver over their child, with a member of clinical staff just a call button away if help is needed. The parent rooms are inside SCBU but are the furthest rooms away from the nurses' station and are separated from the more critical babies' cot spaces by a long corridor During my visit, there was some discussion with staff regarding the location of the parent rooms in the unit, mainly that, symbolically, they should be positioned closest to the exit rather than the furthest. The staff said they have had positive feedback from whānau about the parent rooms and were grateful for this being a care option in their unit – it was spoken of as 'a luxury' for neonatal units.

Figure 30. Parent rooms at the Waitakere Special Care Baby unit designed for overnight stay before transitioning to home care. [1]

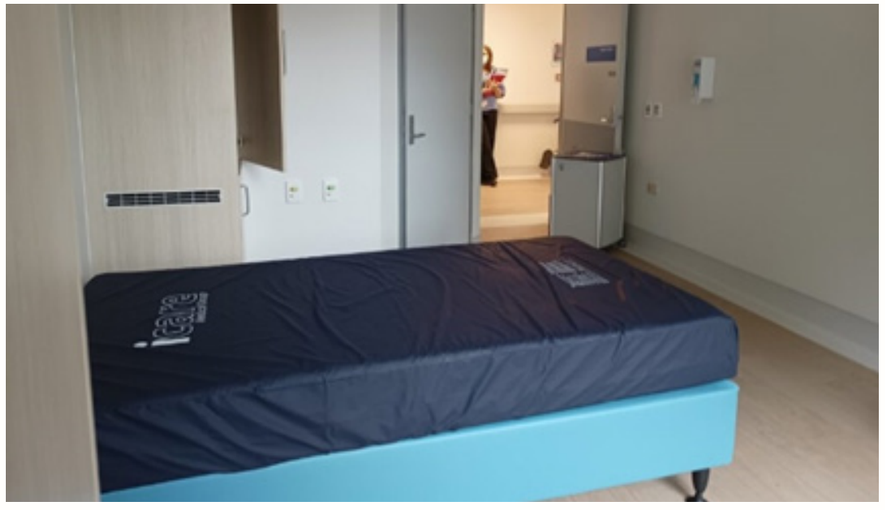


Figure 31. Parent rooms at the Waitakere Special Care Baby unit designed for overnight stay before transitioning to home care. [2]

Observation 3:

The Mother's Lounge available in the unit adjacent to the parent rooms furthest away from cot spaces is a space designated for breast-pumping or engaging with other mothers in a quieter environment. However, I was informed by the staff that parents tend to not use this area and would rather stay with their baby in their cot space.

The Mother's Lounge being far from the unit creates physical distance and reduces bonding time, which is already hindered by incubators and clinical equipment surrounding the cot, and the time away from the hospital and the baby. This room is occasionally re-purposed for workshops and private discussions, such as CPR training and palliative care advice. At the time of my visit, it seemed to be used as overflow storage for equipment such as cots. The furnishing's however, did seem more homely than the rest of the unit. Note the bulky dividers and furniture which makes the space feel crowded.

Figure 32. Mother's Lounge at the Special Care Baby Unit

Figure 33. Tea and Coffee Station in the Mother's Lounge at the Special Care Baby Unit

Observation 4:

Most SCBU cot spaces have a wall mounted whiteboard to convey key information regarding the patient.

Typically, these whiteboards had the name/s of baby, their birthday, and who their parents were written by a staff member in whiteboard marker (Figure 34; was not able to photograph a whiteboard in use due to privacy) - for example (not real patient and parents' names): "Baby Emily-Rose; 32 weeks; Mum: Rachel; Dad: Peter"; or: "It's Timothy's 100-day birthday!". Often the whiteboards were decorated with drawings. I found these personalised whiteboards to be very heart-warming and to me highlighted the dedication and care that the nurses not only provide to their patients, but to their families, too. It was discussed that there was potential to use magnets or similar to utilise the wall space to make the environment more welcoming and personalised for families.

Figure 34. Typical set up of chairs, trolley and whiteboard in the cot spaces, some whiteboards are larger.

Observation 5:

The cot spaces feel sterile and intimidating.

There is little natural light in this part of the unit, and everything appears to be on wheels to quickly be maneuvered in an emergency. Although fascinating to see the technology that supports the smallest and most critical of babies in hospital, it was easy to imagine how the machines, tubes and screens surrounding the baby would be difficult and even traumatic to witness for the parents. Some of the cot spaces in the unit have a fold out bed where one parent can sleep. Each cot space had at least one recliner chair for parents' comfort.

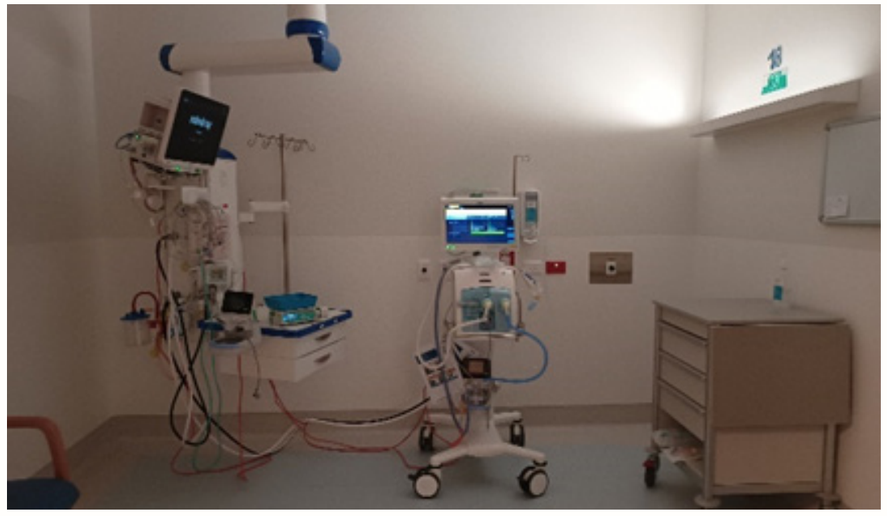


Figure 35. Rooms in Waitakere Special Care Baby Unit designed for infants that need the most intensive care and emergency intervention [1]

Figure 36. Rooms in Waitakere Special Care Baby Unit designed for infants that need the most intensive care and emergency intervention [2]

Observation 6:

Neonatal care feels like a community.

It was quickly obvious that Bellyfull and Little Miracles Trust – two major neonatal charities in NZ - are strongly committed to the well-being of parents in this unit. At the time of my visit, there was a freezer in the family room that was fully stocked with frozen meals donated by a charity to support the parents that have likely spent countless hours, days, and sometimes nights in the unit, despite the unit not being designed for parents to stay in the hospital for the full duration of their babies' hospitalisation. Parents home-life and routines have likely been turned upside and down and support from these charities in the form of resources, care packages and home-cooked meals make that stressful start to parenthood just a little bit easier.

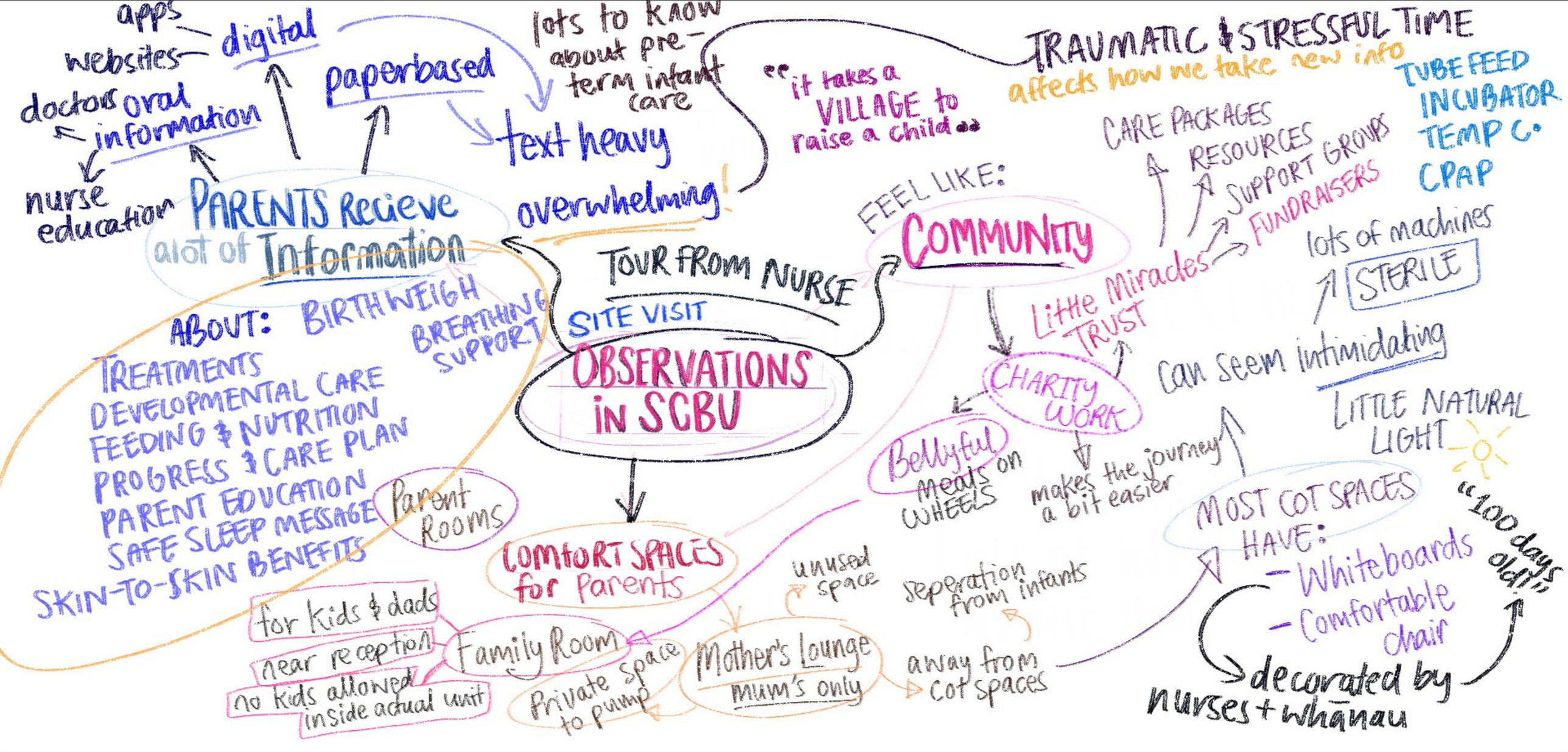
Figure 37. Freezer with homemade meals for parents to enjoy while staying in the unit provided by Bellyful and Little Miracles Charities.

Figure 38. Graduation Day photo prop provided by the Little Miracles Trust.

Graduation refers to an infant being discharged from care to go home. It is a significant and celebrated milestone by the staff and community.

Summary of findings from observations

My observations at Waitakere Hospital SCBU focused on the atmosphere and processes of a neonatal unit to consider the needs of the users in this space. The walkthrough with the staff helped me identify potential opportunities for design improvements. I found that parents were given a lot of information on paper, and some resources were created by the staff. The hospital provides three parent rooms positioned away from the nurses' station and gives families an opportunity to spend a night or two alone with their baby in preparation for discharge. However, to leave the unit, a family would have to walk down a long corridor past the critical care cot spaces to reach the exit - the layout of the unit doesn't seem to symbolise a family 'transitioning' out of the unit to home. The staff mentioned families expressed their appreciation for the parent rooms. However, the Mother's Lounge, intended for breast-pumping and socialising, did not receive frequent usage. My hunch is that parents would prefer to spend quality time near their baby whilst they are in the unit. The unit isn't designed for parents to stay for the entire duration of their baby's admission. I observed the SCBU cot spaces to be sterile and intimidating, with limited natural light. Some rooms had more natural light than others. However, the dim lighting and quiet atmosphere could be to accommodate the sensitivities of the babies. I conversed with the staff about the opportunities to utilise the whiteboards in each cot space with magnets or other means to make the environment more welcoming and personalised for families. This is a simple yet potentially impactful design intervention to help keep parents in the 'care loop'. What stood out the most was the unit's sense of community, where families, staff, and charities are all in the same space to give their babies the best start in life, despite medical challenges.



I used mind maps to unpacks my observations of SCBU and the project as a whole. In this map I am noting each key observation from the site visit and showing the links between keywords and ideas. This process serves the dual purpose of visual communication and organising my thoughts to draw insights on where the design opportunities may lie.

Figure 39. *Empathy Map, external and internal stressors of the perinatal period*

Empathy mapping is a method of visually communicating a user's needs, thoughts, and feelings. In this case, I illustrated my interpretation of what the 'mind of a mother' might appear as. The keywords and phrases surrounding her show the distress a mother with a newborn might be experiencing, which doesn't even begin to represent the added trauma of premature birth.

Figure 40. Empathy map 'Mind of Mother'

Expert Interviews

Experts in this study were considered to be people from the professional neonatal community - ideally those who work or have worked in a SCBU in Auckland, New Zealand in the past. Experts also included occupations that support families navigating neonatal care, not necessarily a healthcare worker (for example, family support worker or staff from a neonatal charity). These experts were recruited via advertisement fliers distributed through neonatal charity organisation, Little Miracles Trust and emailing and NNU contacts publicly available from Neonatal Nurses College Aotearoa (See Appendix D for the advertisement).

Three experts consented to take part in the study (see Appendix E for the PIS and consent form) – two were neonatal nurses, one of which had family liaison expertise. Another was a birth trauma specialist. One of the participants also has lived experience as a mother whose newborn was hospitalised. Each expert took part in a semi-structured, online interview. The interview questions were informed by the contextual review and consultation with clinicians during site visits (see Appendix A for the interview questions). The interviews were approximately 45 minutes long. The interviews were recorded with participants' permission and subsequently transcribed, and data was analysed thematically.

Thematic Analysis

The analysis of the interview data started with the process of listening to the audio recording of each interview and reading and re reading of the corresponding transcript. This was followed by the process of 'downloading' of key points or ideas in the form of 'key notes', as described in the methodology chapter (Figure 41).

I categorised the interview notes into themes outlined below and used them to construct insights to inform the subsequent design brief. The insights and corresponding quotes are shown in Table X.

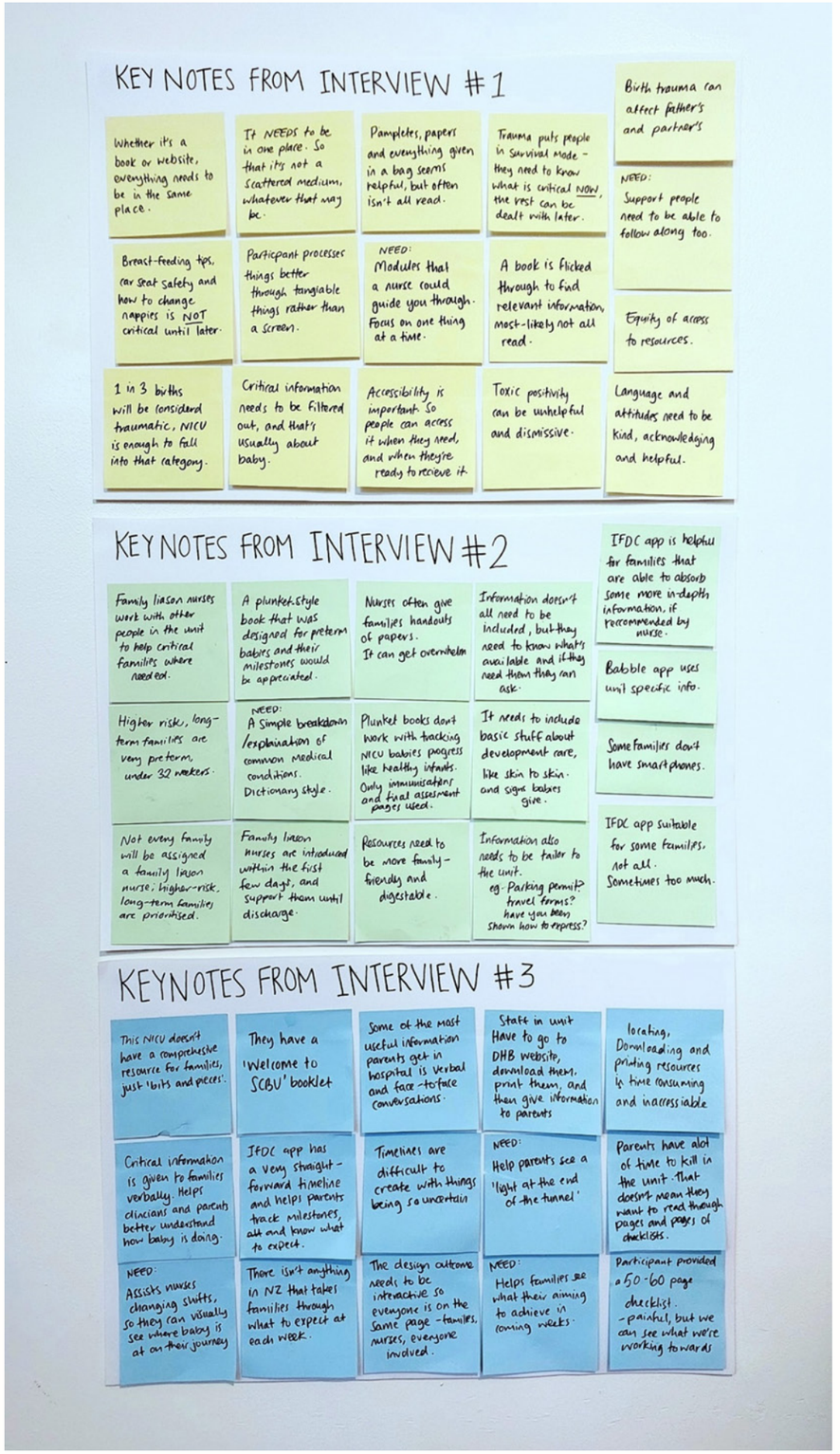


Figure 41. Post-it notes of key points derived from expert interviews, organised by colour to represent each participant

(Next page) Figure 42. Using miro to organise keynotes from expert interviews into themes

what information they need, when they need it.

information, and isn't entirely read.

family that isn't traumatised needs to be able to follow along too.

Toxic positivity can be unhelpful and seem dismissive.

Language and attitudes need to be kind, acknowledging and helpful.

Trauma puts people in survival mode and affects how they process information.

family liason nurse.

of papers, which can get overwhelming.

but families need to know what's available so that if they need them, they can ask.

more family friendly and digestable

example of a unit specific resource.

NEED: A simple explanation of some common medical conditions. Dictionary style.

The IFDC is suitable for some families but not all

information needs to be tailor to a unit, e.g. parking, forms, how/where to express, and what support is available

Resources need to include the basic stuff, as well some more depth information about developmental care.

Some families don't have smart phones.

IFDC app has more in-depth developmental care information, but can be overwhelming for some.

them and then give them to parents.

and inaccessible.

face-to-face.

Timelines are difficult to create with things being so uncertain.

NEED: Help parents see the light at the end of the tunnel.

NEED: Helps families see what their aiming to acheive in coming weeks.

NEED: Assists nurses changing shifts, so they can visually see where baby is at on their journey.

aumatic and stressful time for parents, which on new information.

Critical information needs to be filters out, and that's usually about baby

Language and attitudes need to be kind, acknowledging and helpful.

Trauma puts people in survival mode and affects how they process information.

Critical information is given to families in face-to-face.

Timelines are difficult to create with things being so uncertain.

Toxic positivity can be unhelpful and seem dismissive.

All the information doesn't need to be included in a resource, but families need to know what's available so that if they need them, they can ask.

NEED: Help parents see the light at the end of the tunnel.

IFDC app has more in-depth developmental care information, but can be overwhelming for some.

Theme: Neonatal resource should be tangiable and facilate conversations amoungst the care team

Some families don't have smart phones.

Locating, downloading and printing resources is time-consuming and inaccessible.

NEED: Assists nurses changing shifts, so they can visually see where baby is at on their journey.

Participant processes things better tangiable tools over a digital tools

Parents need to know what is critical NOW, and the rest can be dealt with later.

Family liason nurses work with other people in the unit and connect them with the right care providers.

Books are flicked through to find relevant information, and isn't entirely read.

Resources need to be more family friendly and digestable

Not every family will be assigned a family liason nurse.

The design outcome needs to be interactive so the care team is on the same page - families, nurses, everyone involved.

This hospital doesn't have a comprehensive, unit-specific resources for families, just "bits and pieces".

Some of the most useful information parents get in the hospital is verbal and face-to-face conversations

Conversations help clinicans educate parents, and help parents explain where they feel their baby is at.

Critical information is given to families in face-to-face.

Pampletes, papers and everything in one bag is helpful to keep everything together, but it often isn't all read.

NEED: Support people, or another person close to the family that isn't traumatised needs to be able to follow along too.

Nurses often give families handouts of papers, which can get overwhelming.

Theme: Neonatal resources should be ada

The babble app is an example of a unit specific resource.

information needs to be tailor to a unit, e.g. parking, forms, how/where to express, and what support is available

This hospital doesn't have a comprehensive, unit-specific resources for families, just "bits and pieces".

NEED: modules that a nurse could guide parents through. Focusing on one thing at a time.

Information needs to be consistent and in the same place - regardless of the medium.

are available, but they aren't always engaged

pletes, papers everything in ag is helpful to p everything her, but it often n't all read.

Resources need to be more family friendly and digestable

The IFDC is suitable for some families but not all

Participant provided a 50-60 page checklist style resource - painful but we can see what we are working towards.

Theme: Accessibility and reducing barriers must be considered when designing neonatal resoures.

Some families don't have smart phones.

All the information doesn't need to be included in a resource, but families need to know what's available so that if they need them, they can ask.

People need to be able to access what information they need, when they need it.

This hospital doesn't have a comprehensive, unit-specific resources for families, just "bits and pieces".

Information needs to be consistent and in the same place - regardless of the medium.

Theme: Breaking down the information into m benefit parents, and others involved in baby's

Participant provided a 50-60 page checklist style resource - painful but we can see what we are working towards.

NEED: Support people, or another person close to the family that isn't traumatised needs to be able to follow along too.

NEED: Helps families see what their aiming to acheive in coming weeks.

Resources need to include the basic stuff, as well some more depth information about developmental care

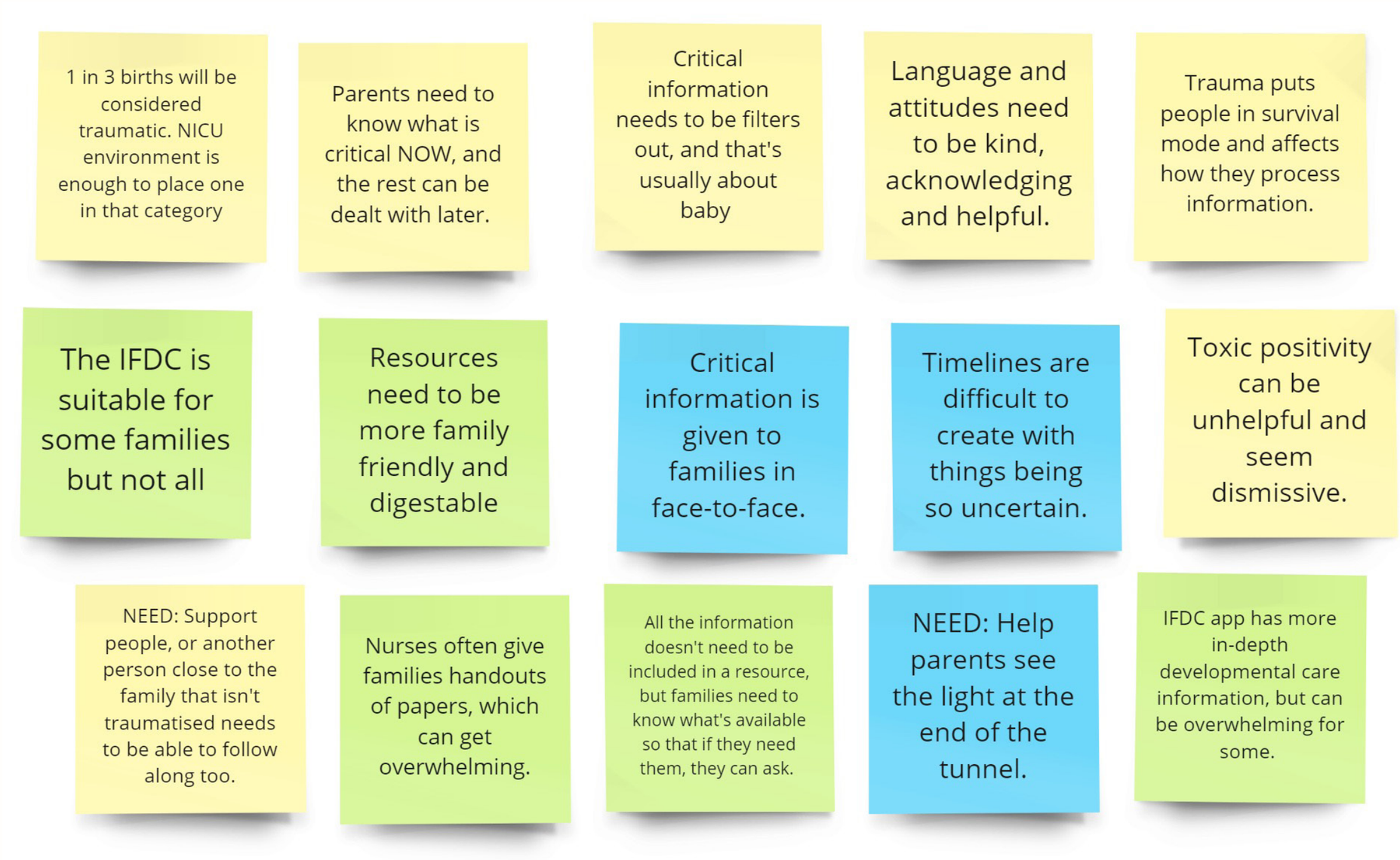


Figure 43. Theme 1: Birth/ NICU Trauma and Interpreting Information

Insight 1: **Neonatal care is a traumatic and stressful time for parents, which affects their ability to take on new information.**

Supporting key quotes from participants

"if someone has experienced a traumatic birth then they are really unlikely to be able to process information. Like you really have to kind of filter out what's critical information, and that's usually about baby. Right, like okay, your baby's getting this treatment because of that, like that is the kind of information to hone in on and focus on"

"If we look at what trauma is in our brain and our body, then that mum or that whānau—because birth trauma can affect fathers and partners and so on—then you just don't have the mental capacity at that point to take information and process information. You are in a state of survival and fight or flight."

"I'm not sure if you know, but research suggests that one in three births will be considered traumatic. I'm not sure how that relates to NICU experiences, but as I said, NICU is enough to make you that one in three. That research considers births that are traumatic for any reason. But if you've got a baby in NICU you're much more likely to fall in that category. I think we don't need any research to tell us and prove that."

"If we consider families that have experienced a traumatic birth in NICU stays. An unwell baby is enough to propel you into that group."

Figure 44. *Theme 2: Effectiveness and Engagement of Current Resources*

Insight 2: **Neonatal resources do exist and are available, but families do not always engage with them.**

Supporting key quotes from participants

"50 or 60 page checklist that I was like, this is painful, but also, for parents to be able to have a copy of this too, and see what we're working towards. Not that because like you say they're kind of in a traumatic situation, they probably wouldn't actually even read through it. I mean they do have a lot of time sitting there, but yeah."

"So, yeah, a bit of a bit of an mixed uptake, I think the bandwidth doesn't need to be really looked at. Not something that I think is necessarily a great resource, but it's got a bits and pieces on there."

"All those forms and pamphlets and whatever that they give to you, the fact that it's in a bag, one little bag, is really valuable, because it's essentially a book. It's all in there. But, again, I don't think I ever read the stuff that was in the bag because if you've got a sick baby your focus is solely on them."

"There's other stuff that you might be given or whatever – my personal experience certainly was that all just fell away. Like I remember getting this ginormous bag of pamphlets and leaflets and books. I couldn't tell you what was in them."

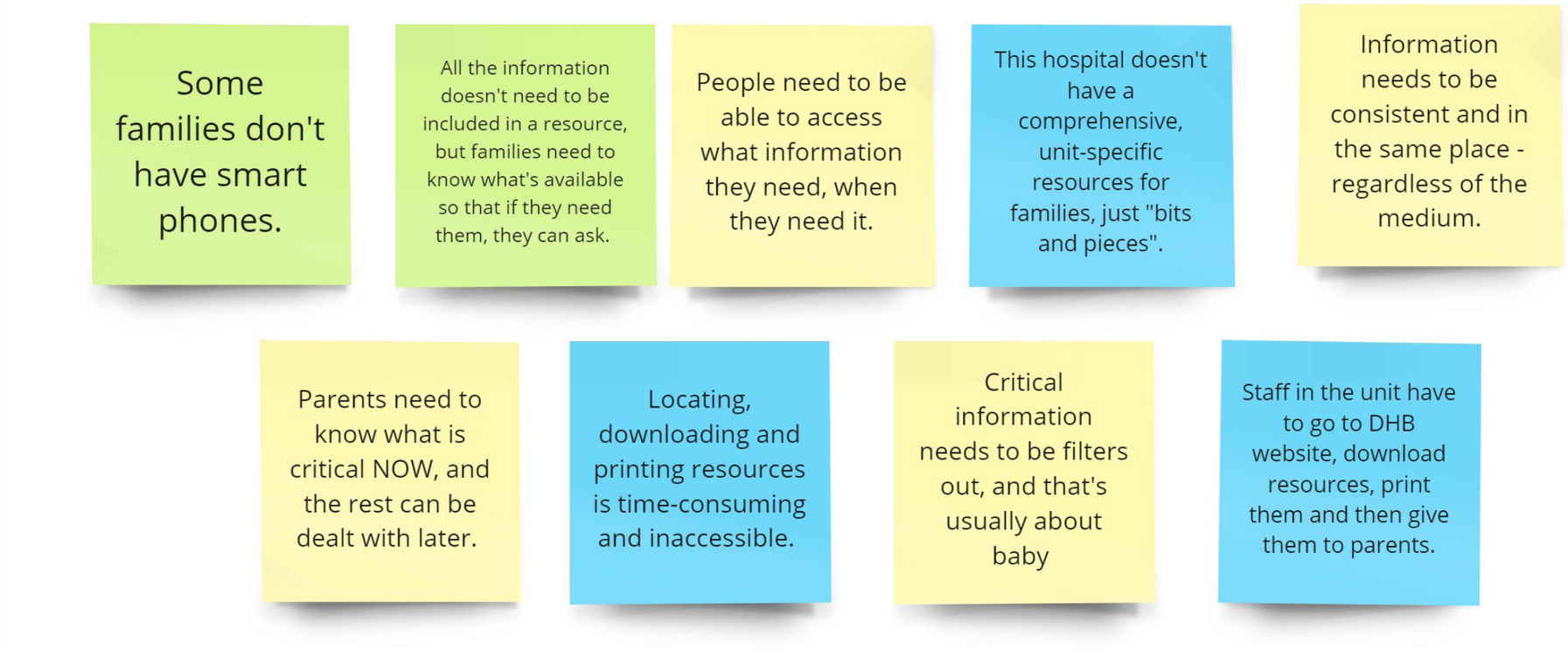


Figure 45. Theme 3: Accessibility

Insight 3: **Accessibility and reducing barriers must be considered when designing neonatal resources.**

Supporting key quotes from participants

"Yeah, so we don't actually really have anything. We use the [redacted for privacy] NICU, parent information brochures, but they're not easily accessible. Like, if you want to grab one, you'd probably have to like go on to the [redacted for privacy] website and download them, and then print them and give them to the parents. Like there's nothing that's really like, easily accessible to just for the parents to be like, 'Oh, that's what they've said might be happening' or 'ah, this is what my baby might have, and so I can have a real little read of that'. Like, it's not actually that easily accessible in our unit."

"Some of our families don't actually have smartphones so it's not for everyone."

"So that one (IFDC app) is really good. But I just wasn't sure if I could direct parents to that. Because it's a UK baseline that is like it's free, I think as well, where they pulled it outside for a while. And I wasn't able to look at it anymore. But then it must have become like available again."

Figure 46. *Theme 4: Facilitating Conversations amongst the Care Team*

Insight 4: **Neonatal resources should be interactive and facilitate conversations amongst the care team.**

Supporting key quotes from participants

"I just do alot of chatting to parents. About where they feel like their baby is at. And what they think they can expect before they go home. Yeah, it's definitely a lot more chatting."

"for support people to to be able to a resource that they could essentially walk the person through. So like, for example, a mother of a mother of a mother, so the grandmother, you know, or the best friend or the partner, so that another person who's close to the whānau, who's not been traumatized, could pick it up and say, Hey, this resource is suggesting that you XYZ"

"Could bring the whole supportive unit that anybody could use it, not just the parents."

"Because one thing I do find a lot of the time is you come back (to work) after a few days, and you're just meeting a family, you don't know them, and they don't know you. You don't know where the babies at. And you're sort of asking questions–but if you could say that visually? So the parents know what they're actually aiming to get to kind of achieve in the next coming weeks."

"Interactive, yeah, that's it. Yeah. And just so that everyone sort of on the same page."

"Sometimes they're fine and it's just a Hi, and bye, you know. Maybe it's great. Sometimes it's a longer conversation about what they might need."

"I'll be like 'so where are we at', and they're sort of like, 'oh I don't really know', so that would be useful".

Insight 5: **A resource doesn't have to be digital; it could be (and probably should be) tangible, too.**

Supporting key quotes from participants

"I'm quite old-school so ya know. I'm not of the TikTok generation ... my opinion is a bit more paper base. I appreciate having a book or something."

"Some of our families don't actually have smartphones so it's not for everyone."

"You know, it doesn't have to be a book, as I say, like, I'm quite, I like to hold things in my hand. And I process stuff better than, like, on a screen or, but there's so many different ways that information can be presented"

The babble app is an example of a unit specific resource.

information needs to be tailor to a unit, e.g. parking, forms, how/where to express, and what support is available

This hospital doesn't have a comprehensive, unit-specific resources for families, just "bits and pieces".

Staff in the unit have to go to DHB website, download resources, print them and then give them to parents.

Locating, downloading and printing resources is time-consuming and inaccessible.

NEED: modules that a nurse could guide parents through. Focusing on one thing at a time.

Information needs to be consistent and in the same place - regardless of the medium.

NEED: Assists nurses changing shifts, so they can visually see where baby is at on their journey.

Figure 47. Theme 6: Unit Specific Resources

Insight 6: **Neonatal Resources should be adaptable for any unit or hospital.**

& plunket books are not designed for pre-term babies.

Supporting key quotes from participants

"For this unit. It would be individualized to this unit so that parents when they first open it they get that real basic information. Like, have you got a parking permit? Have you received travel forms? Have you been shown how to express? Like a real simple checklist"

"I'm kind of imagining a Plunket style book that was designed for a family that had a preterm baby. And you could check off all the milestones and all the things that need to be done that aren't just immunizations. That would be cool. I'd love something like that here."

"We don't use it [plunket record book]. It sits there and we fill in the immunizations and I think like the final assessment before baby goes home, but we don't really use them in the neonatal units."

Figure 48. Theme 7: Breaking Down the Information

Insight 7: **Breaking down the information into modules or milestones may benefit parents & other involved in baby's care.**

Supporting key quotes from participants

"I think from the get go, just that kind of really basic stuff. And then it slips through to the developmental care is really important."

"I know from some feedback from parents from ifdc app, they really liked the developmental milestone thing. So at 24 weeks you can expect this and at 25 weeks you can expect this. It can be quite nice for parents to have a little look through and understand a little bit more about what the baby's doing at each age and what to expect."

"I do think here for some of our young families, videos are quite good. Small, digestible videos."

"And so often we get them blocks of paper, you know, here's this, here's this, here's this and then they just have so much paper, it just gets overwhelming."

Summary of Interview Findings

Neonatal care is a traumatic and stressful time for parents, affecting their ability to take on new information. While many neonatal resources exist, they are not always effectively implemented or used by families. It is important to minimise barriers when designing resources, such as considering equity of access for whānau and ease of implementation for neonatal staff. Simplifying the information into manageable topics, drawing from the principles of developmental care theory, would be extremely beneficial in assisting parents with the overwhelming task of understanding the critical and non-critical information related to their sick baby. Many methods can communicate information, whether it's through digital means, printed materials, visual aids, or verbal interactions. The critical information needs to be filtered out first, and then the non-critical information delivered throughout the hospital stay. Alternatively, that specific information regarding a query or treatment plan can be located and interpreted efficiently and kindly, considering the sensitive nature of the environment. This includes communication between parents, nurses, doctors, and other support people, so that focus can solely be on the baby. Users, but also neonatal experts, often appreciate a tangible aspect of these resources, rather than them being solely digital. An interactive element that encourages conversations among the care team would make an innovative neonatal resource as families value the verbal, face-to-face interactions that help address their concerns. Bedside nursing plays a vital role in this process, complemented by material and digital resources to support their role as caregivers and educators. It is important to avoid simply providing isolated pamphlets, books, or websites without the human support, as this leaves families unsure of where to begin or even causes them to overlook these resources entirely. These interview findings suggest that incorporating interactive elements into a neonatal resource would be beneficial. This would help everyone involved in the care team understand the baby's progress, the next steps, and celebrate the milestones achieved.

Analysis of Neonatal Resources recommended in expert interviews

Whilst I came across countless informational resources for parents navigating a neonatal journey, I felt it most efficient to document my thoughts on the locally used and recommended resources. This section notes the positives and drawbacks of each resource. Besides the Flight Care Plan to Home, the rest of these resources are digital. Poorly designed digital resources can cause accessibility issues and contribute to digital inequity. The most successful resource in terms of content, user-friendliness and categorisation is the IFDC app, which is also not intended for New Zealand neonatal units.

My Flight Plan to Home

My Flight Plan for Home. An evidence-informed discharge preparedness tool used to identify learning needs of parents of NICU infants and document when learning is achieved. NICU indicates neonatal intensive care unit.

Figure 49. *My Flight Plan to Home*

My Flight Plan to home is an evidence-based discharge preparedness tool designed for families in NICU (Mazur et al., 2021). Through consultation I discovered this resource was being utilised at Waitakere SCBU by the nurses printing it on A4 paper.

Positives

The colours of the clouds show progression of the neonatal journey from white, blue, purple to pink.

I like that there is an option to show parents are learning and have been introduced to the topic before signing off that they are fully confident. This could allow parents to communicate areas they may be struggling with.

Great to keep a 'checklist' in a creative way. This allows for every family's journey to be different, yet ticks all the boxes that are needed, with spare clouds to add topics specific to the family's needs.

Drawbacks

Text is small and could be hard to read

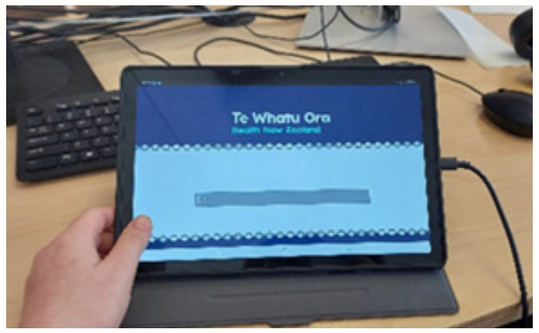
It's unclear which task or milestone comes next. Although I like that the layout is flexible to each family's journey, it could flow a bit more organically.

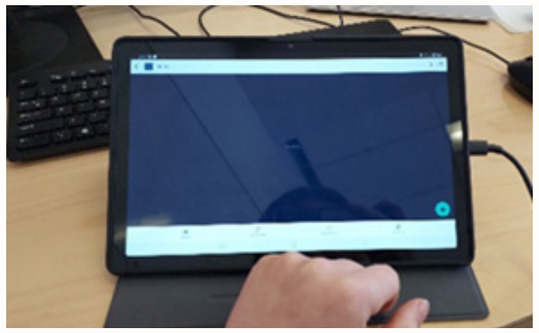
The 'parents learning' and 'parents ready' is repetitive.

Visually clashes and may be hard to follow. Additionally, the colours are low contrast which decreases readability

Visually Crowded

Pepi Care App





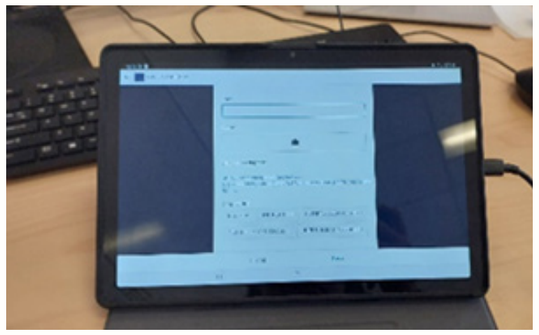


Figure 50. Photograph of Pepi Care app on the tablet lended to me by Waitakere SCBU

Pepi Care is a pilot telehealth programme being trialled at Waitakere SCBU, which supports low-risk infants, or 'feeders and growers', to be discharged earlier than usual. A family could be discharged from hospital and sent home with a set of baby scales and via a tablet and instruction cards which is packaged up in the blue backpack (pictured above). This allows doctors to monitor baby's progress remotely as parents weigh their babies and log it on the app. The app also has a lot of information for parents to read and watch, as well as message or video call clinicians. Waitakere SCBU was kind enough to lend me the Pepi Care Tablet as a role play scenario and assess what types of resources they supply their families.

Positives

Families are able to be discharged sooner than usual. Makes room for other patients, and parents are safely able to bring their baby home quicker.

Clinicians are able to monitor babies remotely.

Parents are viewed as the most important part of the care team.

The added support improves family's confidence for discharge.

Tablet and data included considers accessibility as not all families may have access to a device or Internet.

Great that the entire system comes with the backpack so the parents can

Figure 51. Photograph of Pepi Care bag, scales and instruction mini flipbook that goes with the tablet.

Breastfeeding	37
Tube feeding & Weaning	4
Tongue-tie	3
Medication	4
Parenting & well being	4
Safety & Emergency	4
Hygiene & Infection	3

Figure 52. Table showing the categories of information on the Pepi Care app and the number of resources assigned to each categories.

carry baby, the scales and tablet wherever they need to go. The scales could be redesigned to be more compact.

Drawbacks

The system isn't user friendly if it needs instructions to navigate. Human-centred design factors such as affordances and discoverability should be considered for ease of use.

The logo looks unfinished and low contrast.

The app on the tablet is difficult to navigate. A lot of the pages are blank, and it's not clear where to find to enter the baby's weight or send a clinician and message quickly.

The educative side of the app, while important to have, is overwhelming to navigate. Most of the resources aren't integrated into the app but rely on external resources such as links to websites or YouTube videos which can be changed. The information is extremely text heavy and repetitive, which may overwhelm a new parent.

I created an audit analysing all the pages of resources that were on the Pepi app. I categorised them into themes to test for any repetition. There is repetitive information about infant nutrition, which most comes from external resources that are available by googling the topic.

Babble App

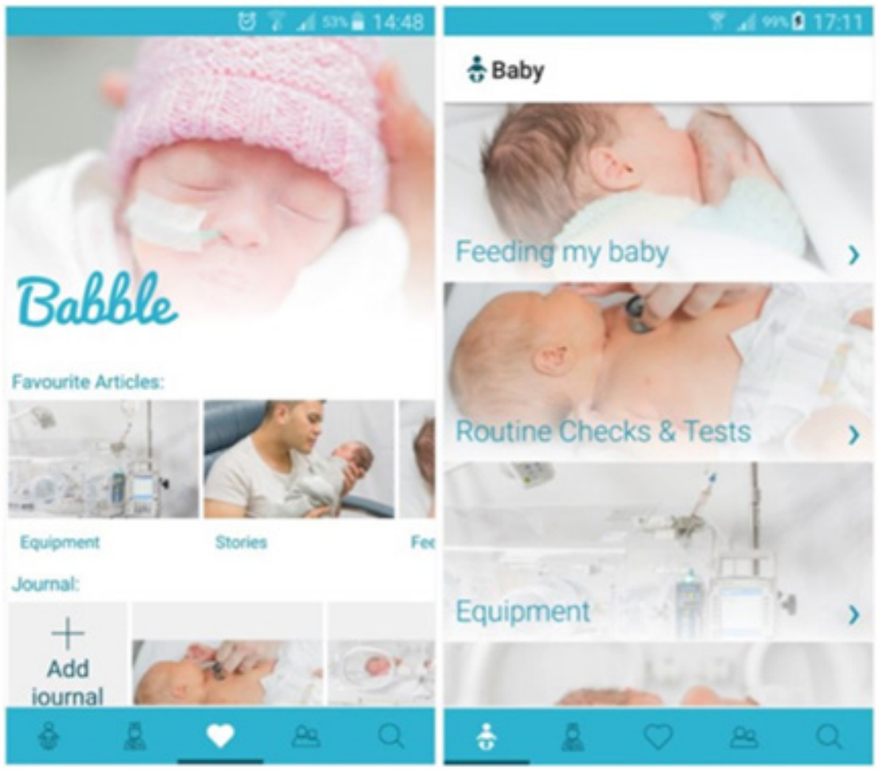


Figure 53. Screenshots of the homepage of Babble App

This app is most useful for parents or expecting mothers and fathers. It offers access to a wide range of useful and relevant information regarding the care of a newborn baby, information about the Central DHB's neonatal unit and other interesting features such as learning about others stories." - Alice Ao, student nurse, University of Auckland, Healthify 2016

"Currently there is unit-specific information about the neonatal units in Palmerston North, Middlemore Hospital and Counties Manukau, but much of the information provided about these units would also be relevant elsewhere." - Dr Alice Miller, FRNZCGP, Locum GP, Wellington Region, Healthify 2021

Positives

Allows users to create personalized profiles and access saved articles and journal entries. It has real-life pictures of infants at different stages of developmental care . It provides clear and useful information on various topics related to baby care, making it a great resource for families. Users can also connect with others through community features and stay updated with Babble news. The content is written by medical staff from neonatal units in New Zealand (Health Navigator Charitable Trust, 2024).

Drawbacks

Have to have a phone to take advantage of this resource.

The app seems to only be licensed currently to Counties DHB and unable to be used elsewhere. However, anyone can download the app and select an area that is licensed to make the app work and access the same information.

The layout is somewhat easy to navigate, but visually cluttered.

IFDC (Intergrated Family Delivered Neonatal Care) App

Figure 54. Screenshot of the Developmental Timeline pop-up on the IFDC App

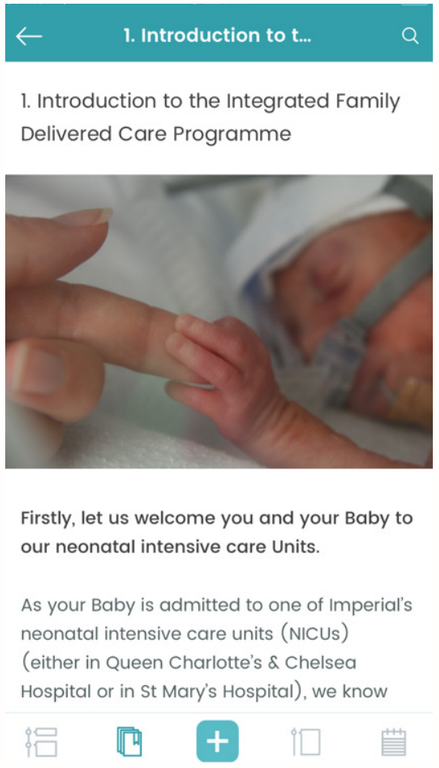


Figure 55. Screenshot of the IFDC App Introduction page

Positives

Indepth overviews of developmental care and what to expect and different gestational ages.

It overcomes medical jargon but provided a glossary and overall avoid medical jargon.

The app is visually appealing and easy to navigate. The menu button situated in the bottom middle of the screen allows for easy navigate and tracking of milestones, both big and small.

This resource was highly praised in the expert interviews.

Drawbacks

Again, such as the Babble app, the user must have access to a personal smart phone device to be able to take advantage of this resource.

Is designed overseas (Bracht et al., 2013) and not intended to be used in New Zealand Neonatal units.

No unit specific information for the processes and practices of New Zealand Hospitals

Assessment of Neonatal Resources used in New Zealand

I assessed nine recommended resources according to eleven criteria derived from the themes extracted from expert interviews and relevant literature in the contextual review (Table 1). Each resource was evaluated against each key criterion to determine if it met the criteria, with possible outcomes being 'Yes', 'No', 'Somewhat', or 'Unsure'. An 'Unsure' result indicates that I was unable to determine whether or not a specific resource met the criteria as part of this research project.

The resources assessed range from the welcome letter parents receive upon admission to the parent education handbooks and apps available to support parents on their journeys.

Yes, meets the criteria

Somewhat meets the criteria

No, does not meet the criteria

Unable to determine

Table 1. Assessment of Resources according to eleven criteria

Criteria	Flight Care Plan to Home	Pepi Care App	Parent / Nurses Responsibilities Checklist	Welcome to SCBU letters	NICU 101 Handbook	Little Miracles Trust Online Handbook	Babble App	IFDC App	Whānau Awhina Plunket Book
Is it considerate of the reader's capacity to take on new information?	●	■	▲	●	■	▲	▲	●	■
Is the language / content appropriate to the sensitive nature of NICU/ SCBU?	●	▲	●	●	●	●	●	●	■
Do families tend to engage with this resource in the way it was intended to be used?	▲	▲	▲	●	▲	▬	●	●	■
Is this resource easily accessible to neonatal families?	▲	■	●	●	■	▲	▲	▲	■
Does it help families overcome barriers to accessing information?	■	■	▲	▲	■	▲	●	●	■
Is it interactive?	●	▲	▲	■	■	▲	▲	●	■
Is it tangible? (not just text-based, or digital)	■	▲	■	■	■	■	■	■	■
Does it facilitate conversations amongst the care team?	●	●	▲	▲	■	■	▲	▬	▲
Is this adaptable to any neonatal unit or hospital?	●	▲	●	●	●	●	▲	▲	■
Can multiple people on the care team utilize this resource?	●	●	●	■	■	■	▲	■	▲
Is the information broken down into digestible modules or milestones?	●	■	▲	■	■	■	▲	●	▲

CONVERGING

THE DESIGN BRIEF

The Design Brief

A design brief based on the discovery research described above was formulated to inform the requirements of the design outcome to be explored as part of the development phase of this research.

These were as follows:

- Design an interactive resource for whānau in neonatal units to celebrate the milestones of their premature infant, as they achieve the necessary targets and treatments in order to be discharged home. The outcome should also assist nursing staff to deliver quality care and trauma-informed parental education.
- The outcome must help parents understand what steps are needed to be discharged from hospital to reduce uncertainty about what that might look like for them. Every neonatal journey varies from family to family; however, certain milestones must be achieved by all before the whānau can be sent home from hospital.
- The milestones should include categories from the Infant Developmental Care modules, as well as celebrate other ‘firsts’ that a mother or parents might experience in the unit. The outcome should help parents celebrate these milestones, no matter how big or small they might feel and allow everyone on the care team to see where baby is at on their individual journey. This empowers parents to feel prepared to be involved in their caretaker role and reduce uncertainty in what can be a stressful time for families.
- The outcome should have a positive, validating, uplifting or light-hearted tone. This is often an tiresome and upsetting time for whānau, and most would consider themselves to have had a traumatic birth experience. Trauma affects the way we are able to digest information. Thus, the outcome should mostly rely on imagery and visual communication as opposed to text. Text may be used, but it shouldn’t be the main or only form of conveying vital information.
- The outcome must be in a creative forum, and preferably tangible as opposed to digital mediums such as a website

or app. If the outcome is a digital medium, it needs to be compatible with a physical resource, and accessible to its users.

- Be mindful if the outcome lives in the hospital space, in the neonatal units. There are often sterile spaces, so the outcome may need to be able to be cleaned to hospital standard. Unless it is intended as single-use per family, where the family will take the resource home at discharge. Be mindful there is often limited space in the neonatal units as is—larger objects may not be feasible unless justified.
- To ensure accessibility across hospital and neonatal spaces in New Zealand, the outcome needs to be feasibly mass-produced. Cost to manufacture practicality and accessibility should be considered.

The Users: For a family-integrated approach to care, the outcome should suit the needs of all those on the care team in the neonatal unit, including:

- Birthing parent – e.g. mum
- Primary support person – e.g. partner of mum or father
- Neonatal Nurses – these staff work on shifts and may not always be the same person.
- Paediatricians
- Other support people a family might require – e.g. lactation consultants, family liaison nurses, etc.

DEVELOPMENT RESEARCH

Development Research

This section documents the second phase of the research, otherwise known as the second diamond. It is a response to the design brief that shows the creative exploration and consideration of design choices and shows an example of how one may aim to respond to the design brief - it is not the only way. I begin by unpacking the design brief in the mind map to generate ideas, followed by lots of thumbnail sketches on Post-it notes, mood boards and more mind maps. This section also includes a concept matrix, an exercise to help me narrow my ideas into a concept that has developed and will continue to evolve in the weeks leading up to the examination. This section also covers the key takeaways from consulting with stakeholders, which was a beneficial part of the process. The second diamond of the documentation research chapter shows an iterative design process using mixed media - digital and tangible elements.

Figure 56. Mind mapping to unpack the design brief

Mood Boarding
for inspiration

Figure 57. Te Papa History Collection (2012) Toy 'Buzzy Bee' from 1943

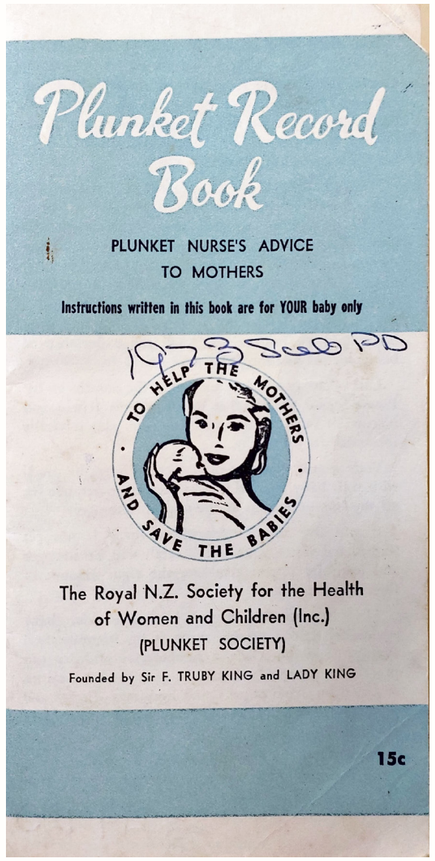


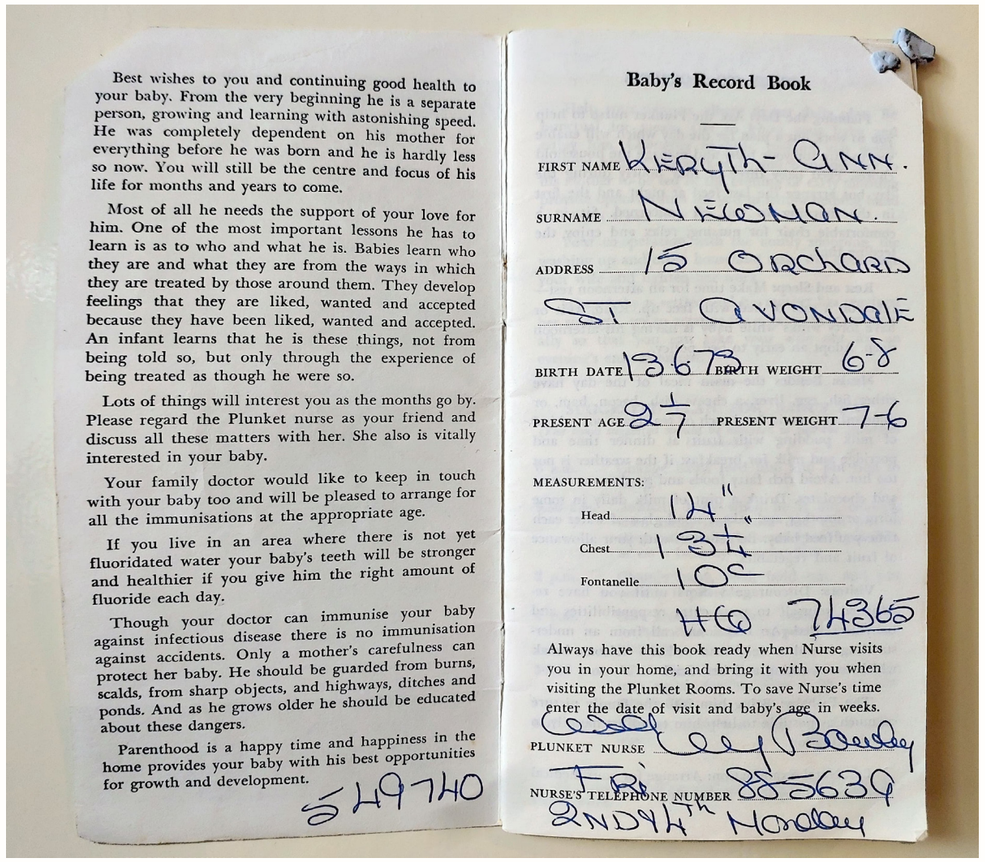
Figure 58. Aunty Keryth-Ann's Plunket Book from 1978 - 1979 (front cover)

Figure 59. Edmonds (1908 - 2016) Cookery Books History

Figure 60. Goodnight Kiwi Memoribillia (1976-94, 2007-)

Creating Nostalgia

Nostalgia is comforting, the best of a better time. Playful, thoughtful design is often used to tap into the memories and feelings of a pastime through objects. Nostalgia makes me think of objects and icons that transport us to a different time, specifically growing up in New Zealand: Buzzy Bee (figure 57); L&P bottles; Tip Top dairies; Plunket books (see pages 94-100); DVDs and video stores; Mickey Mouse; School bus concession cards; Knucklebones; Edmonds cookbook (Figure 59). Each generation has distinctly designed objects that invoke memories. But how can we design nostalgic and iconic objects for the next generation? I think it has something to do with designing things to last a lifetime. They must be useful, enjoyable, and human enough that we use these objects time and time again. They must also have a bold design that is easily recognisable. The examples of the Edmonds Cookbook and Truby's original Baby Care Books stand out to me due to their distinctive quality as a curated collection of guidance and information. Both embody a sense of a treasured compendium of advice and knowledge from those who came before.



Best wishes to you and continuing good health to your baby. From the very beginning he is a separate person, growing and learning with astonishing speed. He was completely dependent on his mother for everything before he was born and he is hardly less so now. You will still be the centre and focus of his life for months and years to come.

Most of all he needs the support of your love for him. One of the most important lessons he has to learn is as to who and what he is. Babies learn who they are and what they are from the ways in which they are treated by those around them. They develop feelings that they are liked, wanted and accepted because they have been liked, wanted and accepted. An infant learns that he is these things, not from being told so, but only through the experience of being treated as though he were so.

Lots of things will interest you as the months go by. Please regard the Plunket nurse as your friend and discuss all these matters with her. She also is vitally interested in your baby.

Your family doctor would like to keep in touch with your baby too and will be pleased to arrange for all the immunisations at the appropriate age.

If you live in an area where there is not yet fluoridated water your baby's teeth will be stronger and healthier if you give him the right amount of fluoride each day.

Though your doctor can immunise your baby against infectious disease there is no immunisation against accidents. Only a mother's carefulness can protect her baby. He should be guarded from burns, scalds, from sharp objects, and highways, ditches and ponds. And as he grows older he should be educated about these dangers.

Parenthood is a happy time and happiness in the home provides your baby with his best opportunities for growth and development.

549740

Baby's Record Book

FIRST NAME KERYTH-ANN.

SURNAME NEWMAN.

ADDRESS 15 ORCHARD ST AVONDALE

BIRTH DATE 1978 BIRTH WEIGHT 6-8

PRESENT AGE 2½ PRESENT WEIGHT 7-6

MEASUREMENTS:

Head 12"

Chest 13½"

Fontanelle 10c

HQ 74365

Always have this book ready when Nurse visits you in your home, and bring it with you when visiting the Plunket Rooms. To save Nurse's time enter the date of visit and baby's age in weeks.

PLUNKET NURSE [illegible]

NURSE'S TELEPHONE NUMBER 885639

FRI 2ND 4TH Monday

Figure 61. Aunty Keryth-Ann's Plunket Book from 1978 - 1979 (inside cover)

Similarly to Edmonds Cookbook, Plunket Books has developed its visual identity over the years (see figure 59), but the communities have always been familiar with Plunket and its services. Plunket books are cherished by mothers and families in New Zealand, preserving precious memories of a baby's first moments; most Kiwi kids have one.

"It's a treasure we get to keep forever about you. Your Plunket nurse's handwriting about all of our firsts, your weight overtime. It's something special" - Debbie Newman, my mother.

In discussions with my own whānau about our precious Plunket books, I was able to track down my late Aunty's Plunket book, who died as an infant in 1979. This old booklet is a time capsule, from the handwriting, the old-fashioned language used, the notes and advice from the nurse, and the tracking of the milestones. Every baby should be able to have a record kept like this, despite prematurity or health complications, to bring comfort to parents. Like the Edmond's Cookbook example, the Truby's Baby Care books have developed over time into our treasured Plunket Books. This informs the collage-style mood boards I created to set the tone for my creative process (see pages 97-100).

The author has removed this image for copyright reasons.

Figure 62. *Plunket History Collage - Karitane Nurses*

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Figure 63. *Plunket History Collage - I became a Plunket Nurse*

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Figure 64. *Plunket History Collage - "community-driven"*

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Figure 65. *Plunket History Collage -Save the Plunket Service*

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Figure 66. *Plunket History Collage - Our Babies*

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Figure 67. *Plunket History Collage - Socrates*

Figure 68. *Logo clippings from the New Zealand Royal Plunket Society resources, 1910-1980s*

I noticed a pattern while researching Plunket's historical resources. The circular emblem is recurring. Many depict a maternal figure, such as a mother, nurse, or Princess Diana (Sullivan, 2007). Although the gender roles may seem outdated, I think there are design elements I can draw from here to replicate this iconic imagery from New Zealand history with a more modern tone and language in the context of special infant care.

Figure 69. Napier Plunket Community Hub Plunket.org.nz, (2024)

Figure 70. 1990s - 2020 Plunket logo, rebranded to lighten up the image and be more recognisable in the community (Sullivan, 2007)

Figure 71. Wellington mum shows her child their plunket book, Blenchyden (2011)

There was a major shift in the way Plunket presented itself as a brand in the 2000s in an effort to modernise parenting practices and move away from the controversial eugenic beliefs held by Truby King (Writes, 2019). While a positive shift, I think there is some of the nostalgia and tangibility lost in Whānau Āwhina Plunket's 2020s rebrand. There are design elements from all versions of Plunket that I would like to consider in the look and feel of my neonatal resource, to pay homage to the rich history of child-rearing organisations in New Zealand.

Figure 72. 2020 rebrand to Whānau Āwhina Plunket, Plunket.org.nz, (2024)

Ideation Sketches

This section marks the start of the ‘ideation’ phase, where ideas to respond to the design brief are generated, culled, or refined through sketching, mind maps, mood boards, peer and stakeholder critique, and prototyping.

STORYBOOK TO TAKE HOME TO OTHER SIBLINGS

online modules, OPEN accessible website. SAME PLACE!

visible journey. whiteboard.

sign in stand

STAMPS

in Plunket book like passport

EXPLAINS JOURNEY

ACTIVITY BOOK

CELEBRATING TIME OF JOURNEY

KORU FERN BUSH

1 WEEK 1 MONTH 100 DAYS

PLANTS

ANIMALS

1sts

other animals? kangaroo care.

DOLPHIN BATH?

100 DAYS

BADGES AWARDS

KANGAROO AWARD

BREAKING IT DOWN

1 2 3

Orientation
. staying
. going home

COLOURING? LOTS OF TIME

FIRST BATH

in unit computer

EDUCATION STATION

wheels mobile

special edition plunketbook

MY HEALTH JOURNEY

whānau awhina

NO DATES!

for preemies

BUILD YOUR OWN FLIGHT PLAN.

MY JOURNEY

1KG

1 WEEK

SKIN TO SKIN

TUBEFED

"OUR BABIES" unit celebration board

baby goals

parent goals

Figure 73. Rough Ideation Sketches on post-it notes

INITIAL IDEAS

HOW CAN WE TRACK + CELBRATE MILESTONES???

LIKE CANCER-FREE RING A BELL TO GRADUATE SCBU

Too LOUD for babies

REDUCE SOUND USE TOUCH?

IMPRESSIONS OF STONES

EACH FORM REPRESENTS EACH ACHIEVEMENT

USE THE WALL SPACE TO VISUALISE JOURNEY

GOALS

ACHIEVEMENTS

dad

Dr.

Nurse

Mama

THE CARE TEAM

MY NEONATAL JOURNEY BOOK

LIKE A JOURNAL OR PASSPORT COLLECTING STAMPS/ MILESTONES

stickers/ stamps collected in plunket book or Specific SCBU "passport" for neonatal babies.

150 DAYS

SAFE SLEEP TRAINED

SKIN-TO-SKIN

MOVE TO COT

BRAVERY

1 WEEK OLD

1500 g

FIRST BATH

100 DAYS

OFF CPAP

SKIN-TO-SKIN

DEVELOP EMBLEMS FOR EACH MILESTONE.

COLOURS

LOGOS

PLANTS

BADGES

SHAPES

ANIMALS

TYPOGRAPHY

MAGNETS

TOKENS

STAMPS

WAITAKERE SCBU AWARDS

actual mile'stones' whānau could collect in a box

↳ too big?

↳ too heavy?

TANGIBLE!

WELCOME TO SCBU

INCUBATOR

COT

DISCHARGE

TOO TEXT HEAVY!

MY NEONATAL JOURNEY

BABY:

PARENTS:

tabs to navigate each phase of the journey. Easy to find information looking for. Too Big? All-in-one place.

personalisation

↳ feels special for each family

Figure 74. Initial ideation, sketch brainstorm

Concept Matrix

I utilised a concept matrix to aid my design decisions and narrow down concept development. This tool evaluates each concept based on the design brief criteria. I assigned scores ranging from 1 to 5 to evaluate how well each concept met the criterion. The concepts that receive the highest scores suggest which ones are most likely to be workable.

Table 2. Concept Matrix to determine which concept is most feasible to develop

	PLUNKET STYLE BOOK TAILORED FOR PREEMIES	PARENT ACTIVITY & COLOURING BOOK	NATIONAL HEALTH NZ WEBSITE FOR NEONATAL INFO	MILESTONES REPRESENTED BY ANIMALS AKA KANGAROO CARE	
Is it considerate of the reader's capacity to take on new information?	3	4	3	5	
Is the language / content appropriate to the sensitive nature of NICU/SCBU	4	4	4	4	
Are families likely to engage with this resource?	3	3	3	5	
Could this help families overcome barriers to accessing information about their baby's care & condition?	3	3	4	3	
Could this concept be feasibly adaptable to any neonatal unit or hospital in NZ?	4	5	4	5	
Is it tangible & interactive? (not just text-based, or digital)	2	4	1	5	
Considering manufacturing, could this be made accessible to neonatal families?	3	5	2	5	
Could be used in a hospital setting?	3	3	2	4	
Does this concept aim to facilitate conversations amongst the care team?	2	2	1	5	
Is the information broken down into digestible modules or milestones?	2	4	3	5	
Total scores	29	37	27	46	

Brainstorming & Mood Boarding

to communicate an idea

During a peer critical session I brainstormed a list of key milestones, as well as some potential animals that they could be associated with. The following pages present mood boards to depict how I envision each animal representing a milestone.

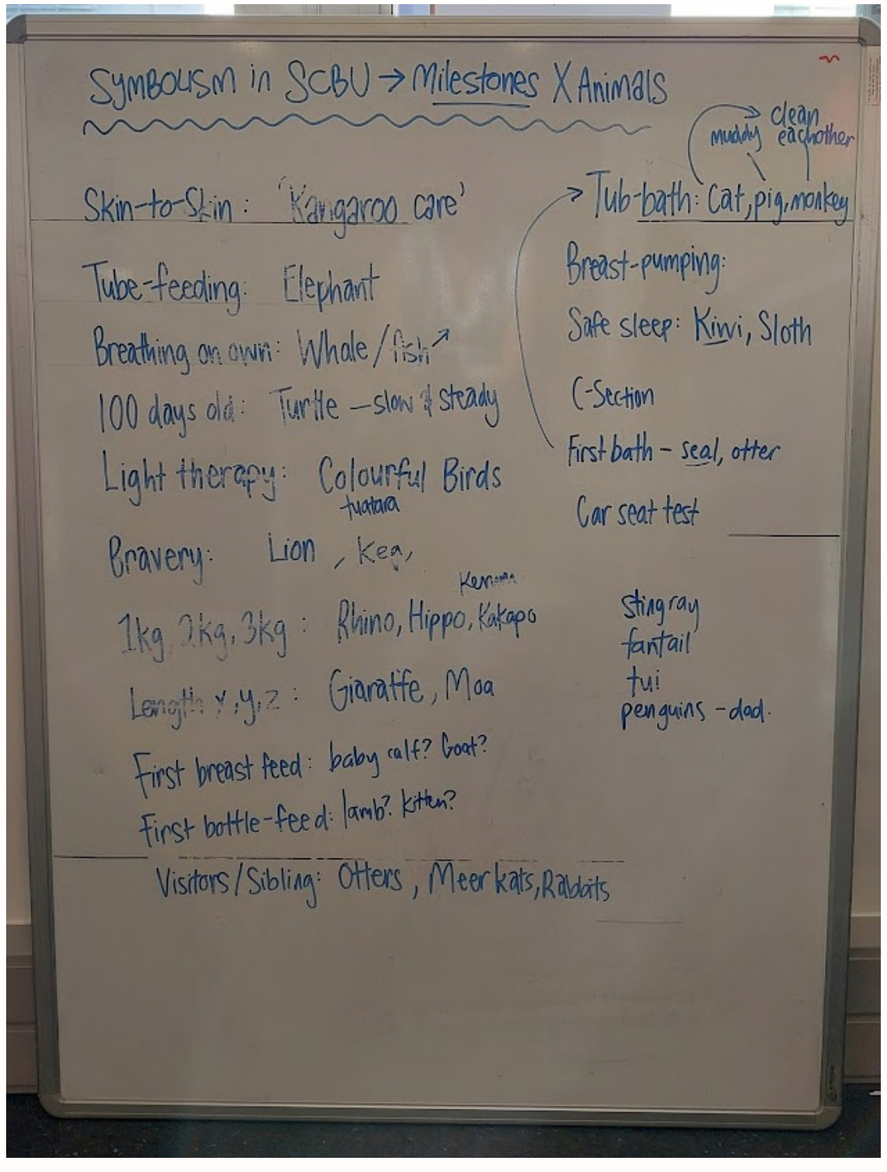


Figure 75. Brainstorm on whiteboard exploring the symbolism of animals and which animals could be associated with neonate's & their famiy's milestones

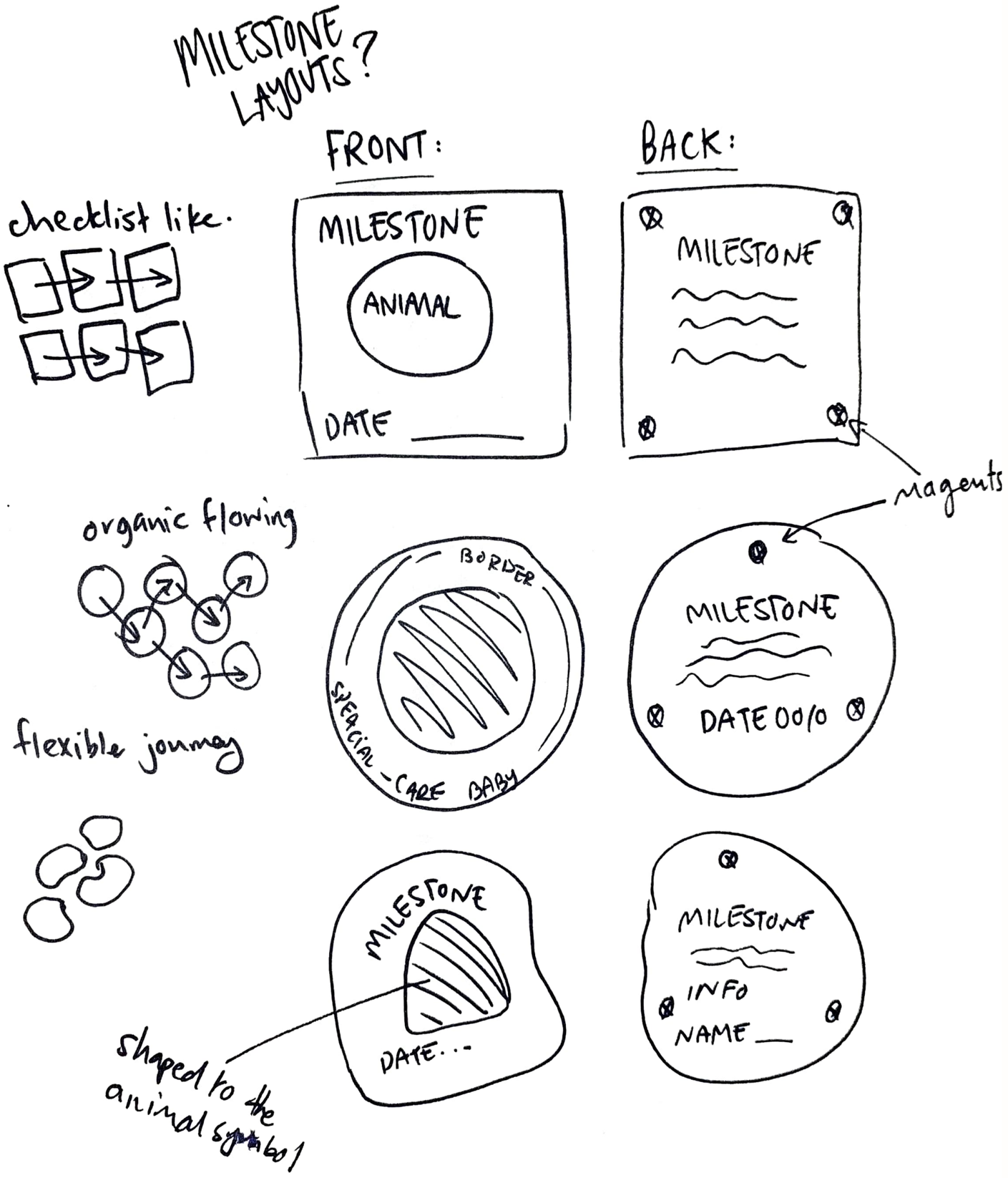
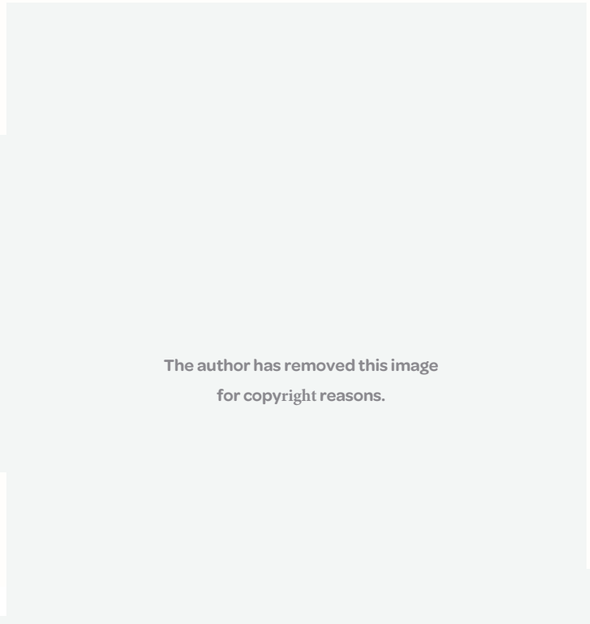


Figure 76. Ideation Sketches exploring the possibilities of physical milestones to record and celebrate different types of neonatal journeys.

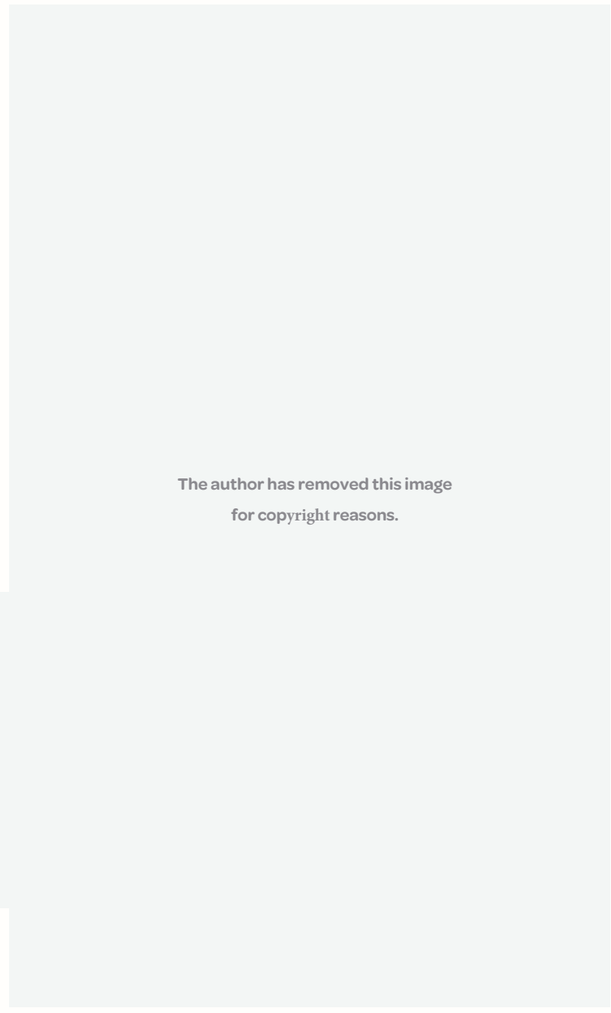
Bright-light therapy

Tuatara also needs exposure to light to be healthy and strong.

kidshealth.org.nz/phototherapy-treatment-jaundice



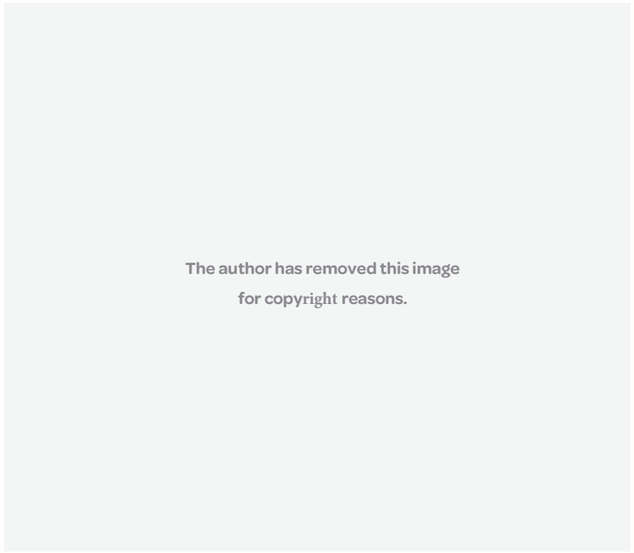
Tuatara Magnet
Designed and Sold by mailboxdisco



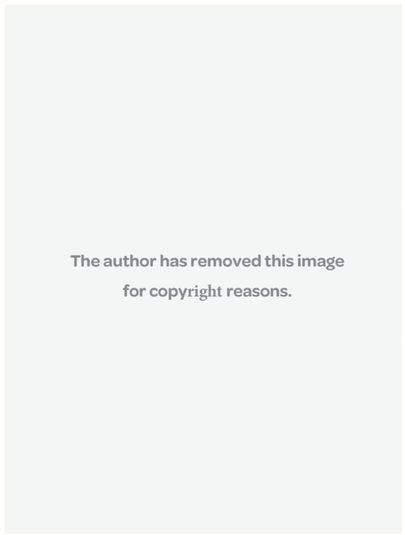
Without full-spectrum lighting, tuatara can suffer nutritional secondary hyperparathyroidism.

https://www.stuff.co.nz/environment/3313967/Lack-of-UV-light-harming-tuatara

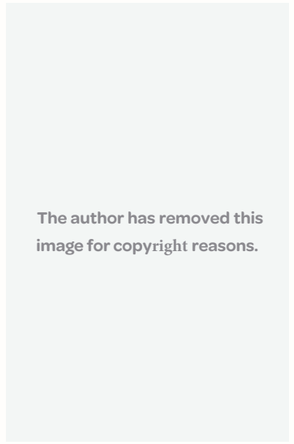
Figure 77. Animal mood board: Tuatara/Blue-light therapy



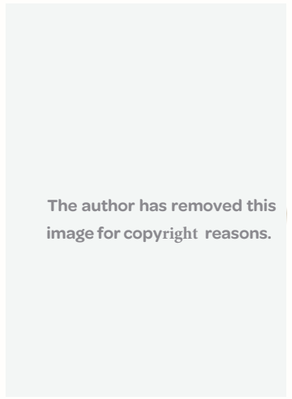
AWelshLad / *Getty Images*



Michelle Martin, 2019
No, My Children's Feeding Tubes Aren't Convenient



Kate Good,
Onegreenplanet.org



George Bokhua
skl.sh/georgeb2

tigatelu / *Freepik.com*

Tube-feeding

Elephants uses its trunk to eat and drink, just like a tube!

Source Unknown

Figure 78. Animal mood board: Elephant/Baby being tube-fed

Safe Sleep

Kiwis are nocturnal and sleep during the day.

The author has removed this image for copyright reasons.

The Little Kiwi Collection by
Bob Darroch

The author has removed this image for copyright reasons.

Olivia Bezett,
Doodlewear.co.nz

Department of Conversation,
New Zealand, Rowi Kiwi

kidshealth.org.n

z

Goodnight Kiwi, 1976-94, 2007-

Goodnight Kiwi memorabilia

The author has removed this image for copyright reasons.

plunket.org.nz

Figure 79. Animal mood board: Kiwi/Safe Sleep message

Figure 80. Mood board: Exploring colour pallete and emblem of the tuatara representing a neonate completing a neonate undergoing blue-light / phototherapy treatment.

How could users intergrate these animals into the day to day care routine? Perhaps, each animal could be placed on their cotspace white board, or stuck inside their Plunket Book or similar neonatal journal. Some parents love to hold onto items that hold significant memories such as hospital wristbands , photos, letters, locks of hair.

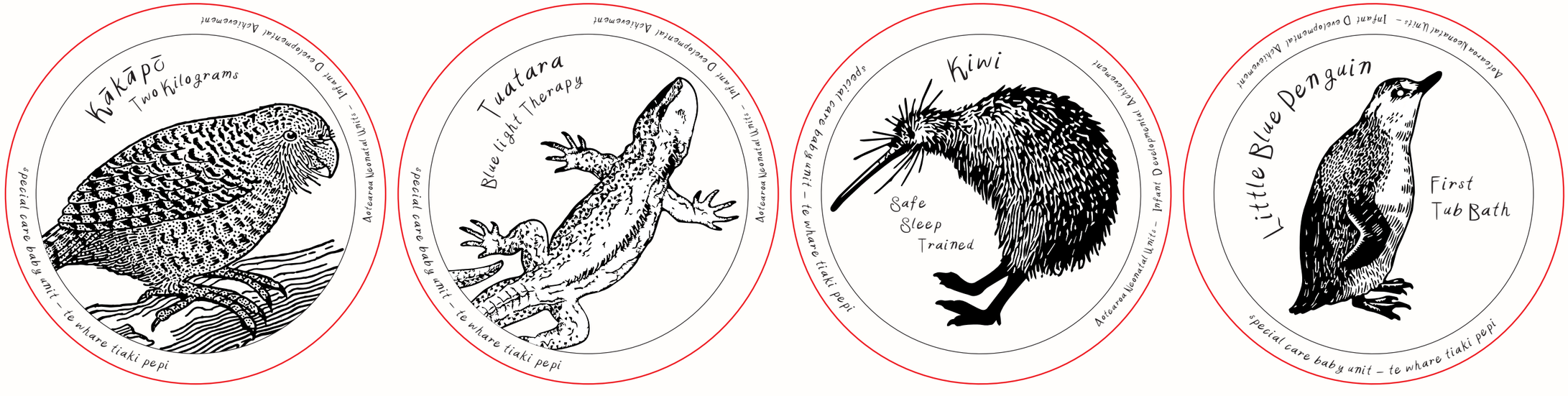
stylised, cute look intended to be friendly and child friendly.

It would add a nostalgic aspect if families could take a small piece of the design home. Maybe, in the form of a sticker or stamp rather than having single use tool for each family that comes into the unit. However, that could work it the material is suitable.

Figure 81. Moodboard: Exploring an emblem of the Elephant representing a neonate being tube-fed

The iterations that follow are influenced by drawings from the Auckland Museum Handbook: Native Animals of New Zealand by A.W.B Powell (1975 edition), which I stumbled upon at a second-hand store while looking for old plunket resources. I looked for vintage New Zealand heritage resources to incorporate into the design for added richness and nostalgia.

Fronts:



Backs:

Figure 82. Adobe Illustrator file prepared to prototype what milestone tokens might look using digital fabrication - the Kākāpō, the Tuatara, the Kiwi, the Little Blue Penguin.

Figure 83. The Kākāpō token being lasercut on MDF (front)

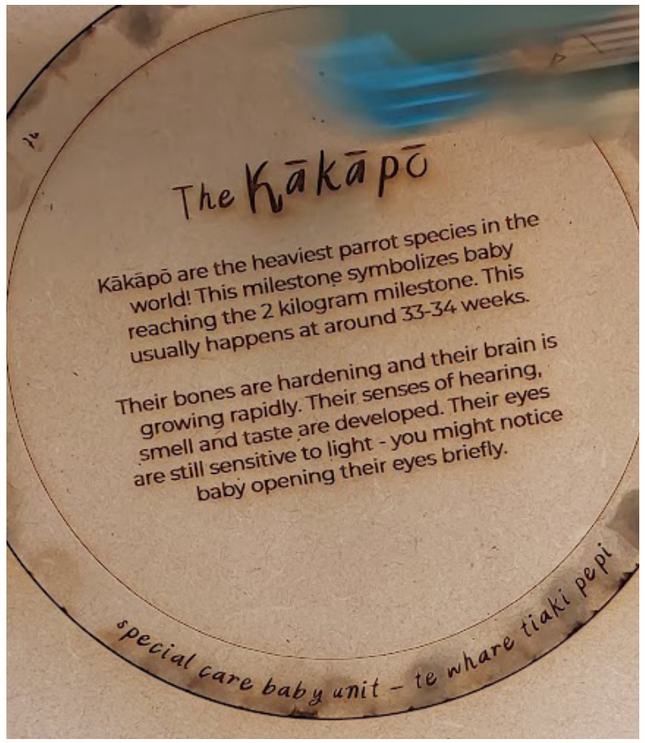


Figure 84. The Kākāpō token being lasercut on MDF (back, showing description of weight milestone)

Figure 85. The Little Blue Penguin token being lasercut on 2mm plywood (front)

Laser engraving was a great option for rapid-fire prototyping due to the fairly quick turnaround and inexpensive materials.

The MDF produced the best outcome for readable text, and the macrocarpa was the best to capture the depth ad detail of the animals with minimal burns smudging into the design.

Figure 86. The Little Blue Penguin & Kākāpō tokens lasercut on macrocarpa

Figure 87. Upclose of the The Kākāpō token lasercut on macrocarpa (front) showing the depth of the engraving

Figure 88. Upclose of the The Kākāpō token lasercut on plywood (front) showing the depth & detail of the engraving

Although I don't intend on the final outcome being made with MDF or low-quality plywood, it serves its purpose to test and explore ideas.

A high quality timber could be a lovely option for a final product – which would have to be sealed to meet the hospital standards of cleanliness (wood is porous and would be hard to clean).

The headings came out well in my custom font engraved into the plywood, if the text was big enough. Small text seemed to burn too much making it hard to read. The textures gave it a completely different look and feel than the digital mock up could ever communicate.

Figure 89. Up close of the The Kākāpō token lasercut on mdf (front) and the relief the engraving leaves on putty

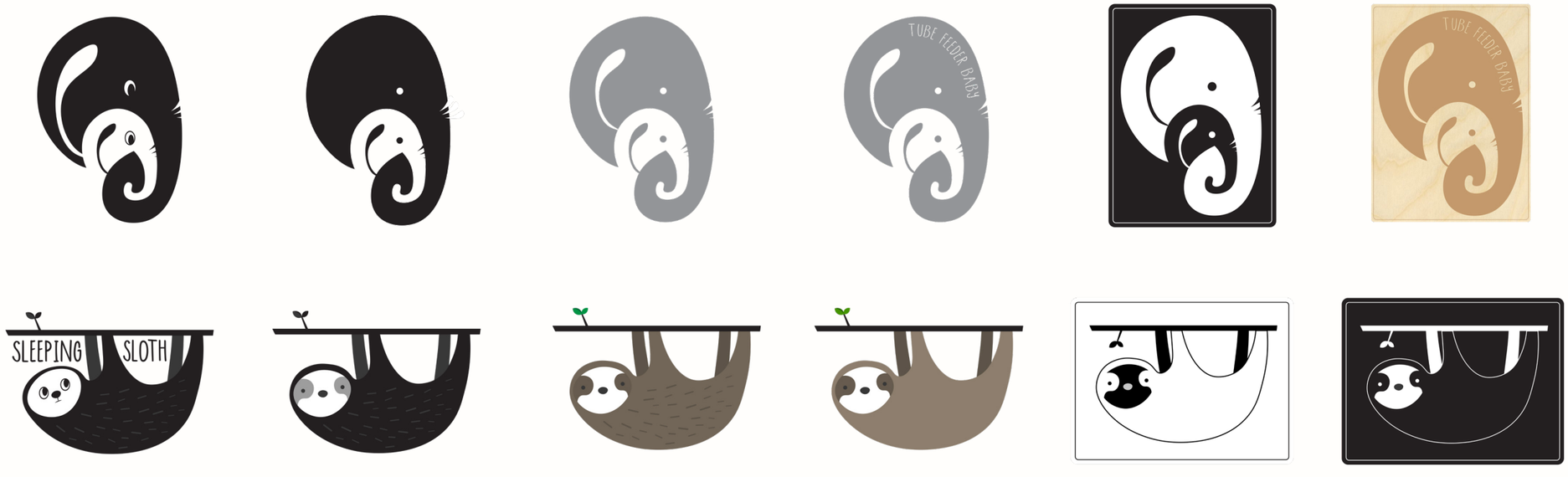
The depth and texture of the burn marks made me wonder of the possibilities of using digital fabrication techniques to easily mass-produce relief stamps that could replicate the image over and over again, removing the need for every family to take a physical token home with them.

Figure 90. Experimentation of MDF tokens being used as stamps to transfer the image onto paper

Figure 91. Photograph of workspace, with important milestones on post-it notes, ideation sketches and prototypes

The next steps were to refine a cohesive illustration style and refine which milestones would be most important to communicate.

I developed more ideas for animals to be associated with key milestones and experimented with hand-drawn and vector-drawn iterations.



Iterations of three potential milestones to be associated with the Elephant, Sloth and Turtle. They represent a baby being tube-fed, safe sleep training and the 100 day milestone.

Figure 92. Vector mock ups displaying a stylised iterations of animals representing SCBU milestones

Figure 93. Vector mock ups displaying refined stylised animals representing SCBU milestones as stamps

Exploration of what the Milestones could look like as 'stamps' to collect inside a baby's Plunket book or Journal. Office ink stamps often have a limited colour palette of black, blue and red. In this iteration, I have tried a very stylised, simplified approach to explore the limitations of what stamping might look like.

Stakeholder Feedback

During the ideation and prototyping stages, I sought input from key stakeholders with whom I had built relationships over the course of this research project. This included the members of staff met on the Waitakere SCBU site visits, people from various organizations whom I consulted with during the recruitment phase, such as Little Miracles Trust, as well as the experts I interviewed. I emailed stakeholders updates and proposals for concepts, seeking feedback on the design and content. Their expertise and professional insights were invaluable, ensuring the clinical accuracy of the concept and offering suggestions for improvement.

Key Takeaways from Stakeholder feedback, regarding associating SCBU milestones with Animals (see appendix G for the items feedback was sought on).

<table>
<tr><td colspan="2">Finding 1: The ‘SCBU Animals’ concept was well received by stakeholders.</td></tr>
<tr><td>The stakeholders had a positive response about the concept of Animals being associated with milestones, particularly the idea of them being in the form of something tangible such as tokens. They felt that it aligned well with their existing processes and believed it would work effectively. There was, however, feedback on which milestones should be included and the language used to communicate each milestone. This feedback is unpacked in the findings below. All respondents were particularly helpful in referring credible resources to pull accurate medical information for parents from sources such as the Babble app, IFDC app and Flight care plan to home.</td><td>“I really like the ideas of the tokens. I think it is a great idea”

“[it] fits in with the journey I have created using a Kiwi in a forest ... so I think it would work really really well. Well done!”</td></tr>
</table>

Finding 2: **Remove wording that refers to babies meeting certain milestones at the 'normal' time. For example, "this normally happens at the 33-34week mark"**

In regard to the 'Kakapo milestone' representing a neonate reaching the 2-kilogram weight goal, a neonatal nurse I consulted with pointed out that premature babies in their unit often don't meet the 2kg mark until they are much older. For example, two babies currently in her care are 40 weeks and 37+3 weeks who are not yet 2kg.

The suggestion to remove mention of standard infant development timelines was a reminder that the neonatal community knows very well that every family's journey with neonatal care looks different. The aim of the milestones is to celebrate their progress, not compare their progress.

Finding 3: **Consider how parents might interact with or keep the milestone 'tokens'.**

Although there was a positive response to the concepts presented to stakeholders, a common query was the medium the milestones would be created in as this wasn't clear in the early prototypes I shared with them. It was proposed that the 'milestone tokens' could be something parents could hold onto as a keepsake. A scrapbook and magnets were suggested. This progression and consideration of materials is shown in the mock up iterations (see page 127 onwards)

"What will parents do with all the tokens?"

"Will the milestone cards be like little tiles for the parents to keep?"

"Some sort of scrap book is a good idea so that they can tick off, or fill in the milestones with their tokens, depending on how big they are"

Finding 4: **A key milestone is baby being removed from respiratory supports.**	
One of the key themes that emerged from the stakeholder consultation was the need to celebrate the milestone of an infant being able to breathe on their own. This milestone is significant as it indicates the baby's progress towards good health and well-being.	"Their baby needs to be comfortably breathing on their own, off respiratory support before going home" "Off CPAP... babies will go onto High Flow and then possibly low flow as additional steps before being off oxygen"

Finding 5: **A key milestone is baby moving from incubator to a cot**	
Another key theme identified from the stakeholder consultation was the need to celebrate the milestone of an infant being moved from an incubator to a cot. This milestone is highly significant as it means parents can finally care for their baby in a bassinet, which may seem like a more typical post-natal experience opposed to the physical barrier of an incubator. It also indicates that a family is nearing the tail-end of their hospital stay, allowing them to start receiving discharge education and the hand-over of care. This education includes important topics such as safe sleep practices, preventing shaken baby syndrome, CPR training, and learning essential skills like feeding, dressing, and bathing their baby.	"We also mark the movement from an incubator into a cot/ bassinet as another marker of progress and it is often at this point that we teach safe sleep message." "Their baby needs to be maintaining their temperature in a cot before going home This could be a card for moving out of an incubator into a cot."

Notes from a brainstorm after a peer critical session. I was exploring which animals should be associated with which milestones after receiving stakeholder feedback on which were most important. To refine the concept, I considered catergorising weight goals together and the age celebrations together under the same animal. This simplifies the concept and shows the infants progression, rather than having an animal for each that doesn't have a strong symbolic connection to the achievement.

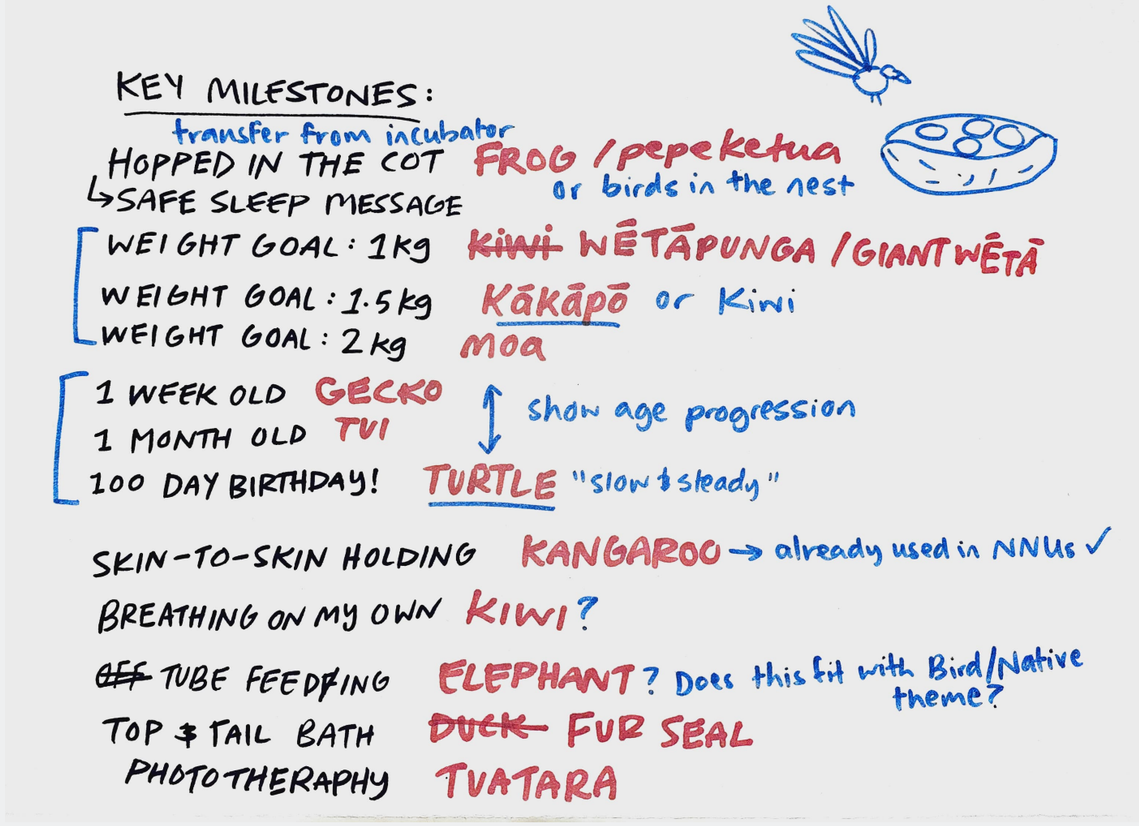


Figure 94. Brainstorm notes (refined milestones in black, animals in red, peer critique in blue)

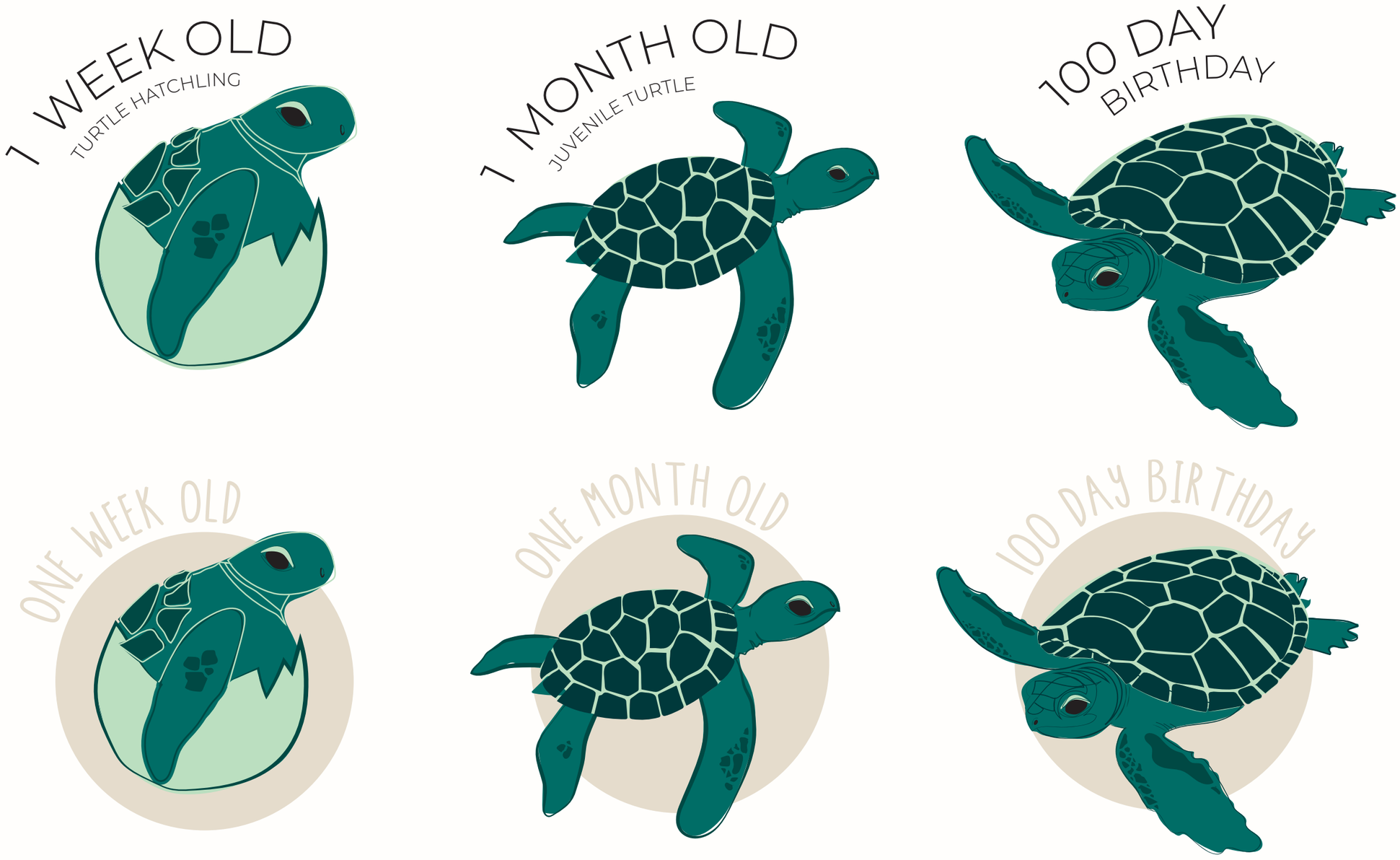


Figure 95. Vector mock-ups: iterations of a Turtle representing age milestones or time spent in unit

Figure 96. Vector mock-ups: iterations of a Kererū representing weight goals, specifically the 1 kilogram mark

Figure 97. Vector mock-ups: iterations of a Kangaroo, which commonly is associated with skin-to-skin practices

Milestone 4: Transfer from incubator to cot / Fantail nest

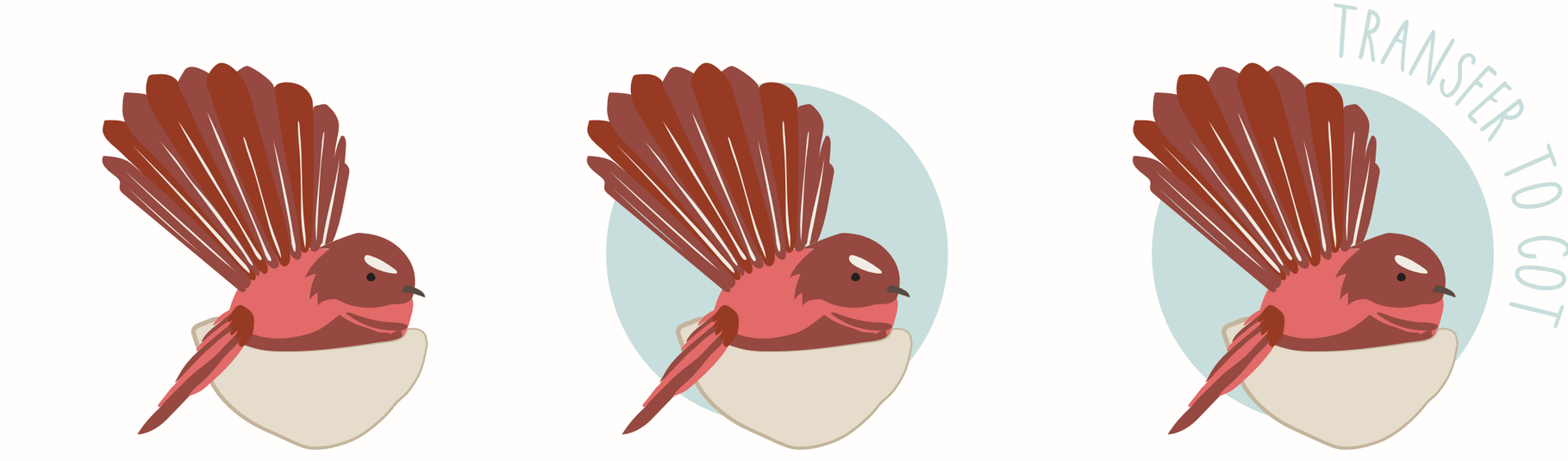


Figure 98. Vector mock-ups: iterations of a Fantail in a nest, representing a neonate being transferred from an incubator to a cot

Milestone Group 5: Off respiratory support / Tūī

Figure 99. Vector mock-ups: iterations of a Tūī, representing a neonate breathing independently without the support of a CPAP machine

Figure 100. Vector mock-ups: iterations of an Otter, representing parents giving their baby their first tub bath, also nicknamed 'top & tail' in the unit

Figure 101. Vector mock-ups: iterations of a Tuatara, representing a neonate undergoing blue-light or phototherapy which is a treatment for jaundice

Figure 102. Mock-up of what the Animal milestones concept could look like as stickers

Figure 103. Mock-up of what the Animal milestones concept could look like displayed on a board for each neonate to collect

Figure 104. A mock-up of Animal milestones as magnets on a whiteboard in a cot space, visible to the entire care team, to track a baby's progress

Figure 105. The final concept: Tangible milestones to be used and displayed in the cot space and celebrate each family's unique journey

Discussion Chapter

Celebrating Milestones along the Neonatal Journey - the final design outcome

This project aimed to explore how applying a human-centred design approach might empower and reduce uncertainty for families navigating neonatal care. I was interested in a participatory approach and utilising input from experts to inform an evidence-based design concept that helps families along their neonatal journey.

The final design outcome is a tangible object intended to be used 'in SCBU' to communicate the key things parents needed to know about their baby's progress as they prepared for discharge.

This toolkit is designed per the principles of family integrated care, which aim to be trauma-sensitive and encourage parent education - which promotes discharge readiness, as discussed in the contextual review chapter. Because of the dynamic nature of neonatal units, where numerous clinicians and care providers are involved, this tool is meant for the entire care team. Its goal is to make sure everyone is informed and on the same page about the baby's progress and the learning gaps of the parents. By celebrating milestones as they come, parents are empowered to take on the role of the primary carer and have confidence for discharge and transitioning home.

The value of visual and tangible user-centred design solutions

The time a family spends in neonatal units, from birth to transitioning home, is often referred to as a 'journey'. Standardised discharge preparedness tools designed for NICU, such as 'My Flight Plan for Home', have used the analogy of 'travel' to depict the neonatal journey (Mazur et al., 2021). Analogies, such as objects, structure, food, and nature, are often used in healthcare to help patients better understand medical issues and terminology (Hildenbrand, 2021). Similarly, inspired by 'kangaroo care' - the nickname for skin-to-skin holding in neonatal units (Suitor, 2023) - my proposed design concept aims to celebrate the critical growth and health improvements or milestones of the infant, where a 'milestone' is designed to be associated with an animal that represents it.

Existing research shows that visual communication effectively conveys complex health information to patients (Houts et al., 2006; Osborne, 2006; S. Walker et al., 2020). To depict the milestones through my design output, I aimed to use animals native to New Zealand and/or those with a significant connotation associated with the achievement. For example, the turtle represents the baby being 100 days old, like the tortoise and the hare parable to stay slow and steady, or the Kākāpō (world's heaviest parrot), which symbolises 1500g weight goal. The intention behind accentuating the visual aspect was to provide a more inviting and intuitive presentation compared to typical health information design that can feel impersonal and text-heavy.

Those involved in the study indicated that the resource was a good fit for neonatal care processes and terminology, and they could envision integrating it into their practice. Clinician participants were particularly appreciative of the structured milestones that made parent education and infant progress goals more manageable. Additionally, they valued how the outcome could be used as a tangible representation of a family's accomplishments during their time in the unit. Overall, this suggests the potential for simple visuals to play an important role in the communication of health information in ways that are more engaging. In doing so, information could be broken down and easier to process, which ultimately leads to better understanding, acceptance and discharge preparedness, as is also shown by previous research (Davidson et al., 2020; Mazur et al., 2021)

Thinking differently and working together to meet users' needs

At the start of my design research journey, I thought this project would be an opportunity to redesign and merge the overwhelming amount of current neonatal resources.

I dedicated a lot of time to coming up with ideas for a neonatal booklet. I imagined it would be a Bible-like resource in one convenient place, containing all the information a parent needed to know. No more papers and pamphlets to carry around. However, as I delved deeper into the context, I realised I needed to pivot and completely change my approach. What would be the benefit of trying to do the same thing other organisations have tried to do but none of them were 100% perfect and included everything? Why would I redesign an informational booklet when there are already lots of textual resources out there?

I realised I needed to do something different. I wanted to demonstrate the potential of applying a human-centred design research process in a complex healthcare setting. I aimed to challenge conventional thinking and explore alternative ways to communicate critical information while meeting user needs effectively.

Human-centred design approaches and patient-centred care share similar values, and their application with a participatory approach can enhance the patient experience and improve outcomes (Melles et al., 2021). Design thinking

can apply to almost any problem (Norman, 2013). However, designers rarely have extensive knowledge in complex contexts, such as healthcare, so the participatory approach has been crucial for this research project. Without the joint expertise of both design-thinking and clinical input in this design research project, the outcome would likely be less user-centred. In addition, this research demonstrates the importance of ongoing collaboration and subject-matter expert input throughout the design process to increase the likelihood of the design solution meeting the real needs in the given healthcare context.

Limitations and Recommendations for Future Research

Involvement of end-users with lived experience

When conducting research in healthcare settings, identifying the frequency and impact of challenges that end-users face over time can help gain a deeper understanding of their needs (Groeneveld et al., 2018). Research suggests that including end-users as equal partners enhances insights and ensures that new healthcare innovations are influenced by lived experiences, which enhances patient outcomes (Bird et al., 2021; Haste et al., 2023). However, there are often barriers to involving end-users in health research due to medical ethical considerations that prevent researchers

from fully engaging with end-users (Groeneveld et al., 2018). Some of these types of barriers were experienced during this research project, and as a result, there were changes to data collection methods to mitigate them.

I had initially planned a co-design workshop with NICU whānau in conjunction with another student design researcher investigating a different aspect of neonatal care. However, there were unforeseen logistical barriers that ended up making the co-design workshop no longer viable. For ethical reasons, I was not allowed to recruit parents currently in a neonatal unit, or through healthcare providers directly. Despite the effort being made to schedule the workshop outside school drop off/pick up times, the vast geographical spread of Auckland meant I had to choose a venue for the co-design workshop that may have not suited already busy parents not residing around or having easy access to the location. There was also an interest among families from outside the Auckland region to participate in this study, which was outside of my initial scope of research. While consulting on the recruitment for the co-design workshop, I was made aware that Auckland is known among the NICU/SCBU/NNU community to have some of the best facilities and care available in New Zealand. Guided by this feedback and following the initial slow uptake in recruitment, the invitation was eventually extended to parents outside of the Auckland region to best meet the aims of this research. Finally, to make the research more accessible to a broader range of prospective participants, the method of engagement was changed from a co-design workshop to online interviews, with the same aims and guidelines as the planned workshop, now adapted for an individual setting.

Unfortunately, in the end, I could not recruit whānau to participate in the interview process. The second attempt at recruitment coincided with the long summer holiday in New Zealand, and, ultimately, the effort to keep recruiting had to be abandoned in order to meet the research timelines.

Since research shows that family integrated in the care team is beneficial for neonatal outcomes, it only makes sense that their input is considered in the design of resources they can benefit from (Ansari et al., 2023; Bracht et al., 2013; Craig, 2017). Ensuring that the input and needs of parents and caregivers with neonates in hospitals is integrated into any resource, system or product design, a participatory design

approach is integral to a suitable design outcome.

Clearly, the biggest limitation of this research is the lack of direct input from whānau with lived-experience of neonatal care. Although I did not conduct any whānau interviews, it is worth noting that a participant from the expert interviews had personal lived experience as a NICU mother. This participant also had professional expertise in neonatal care. However, it is important to recognise that this is just one parent's perspective, which may have been influenced by their professional knowledge of the system and its processes. Therefore, it is possible that some key issues and parents' needs may have been missed by relying largely on an expert perspective.

In cases where direct patient access is not available, experts can be regarded as the next best alternative. In the context of neonatal care, experts (particularly nurses) work closely with the parents, witness their day-to-day experiences in the unit, and monitor the baby's progress. Their insights are valuable in understanding the overall dynamics and challenges faced by parents in neonatal care. It is also important to emphasise the importance of FIC and how all stakeholders, including experts, should collaborate to address the needs of parents, as confirmed by participants in the expert interviews.

It is important for design researchers to be flexible and adaptable in their engagement methods to accommodate participants' needs throughout the research process (Nakarada-Kordic, 2017) In the future, design researchers should make an effort to carefully plan recruitment and data collection to allow enough time and flexibility for parents to participate in the process. Co-design is the ultimate enactment of the participatory approach – designing with, rather than for end users– where the end user is an equal partner participating in all the stages of the design process (Matthews et al., 2023; Sanders & Stappers, 2014). Therefore, future research in this context should employ an inclusive co-design process – that is equally accessible to both healthcare professionals and whānau and ensures their voices are equally valued – to ensure the needs of all users are met.

Working as a designer in healthcare

Although experiencing healthcare from the perspective of a designer researcher was frustrating at times, I found the personable connections I made with industry experts enlightening and encouraging. This included hospital site visits, expert interviews, and stakeholder feedback gathering. I found that all clinicians I spoke with were very receptive and open to design opportunities, especially during the SCBU tour. During the site visits, the staff pointed out areas of need and provided valuable insights on how the space and objects in the unit could be improved. This initial consultation proved extremely valuable during the project's discovery phase. Additionally, the feedback gained towards the end of the project was instrumental in refining the design. Overall, my experience mirrors previous findings that involving healthcare providers in the design process is crucial for the design of health projects to be successful (Nakarada-Kordic et al., 2017).

Based on my experience, I would highly recommend that future design researchers working in the neonatal space involve clinical experts more frequently throughout the design process. This would allow for a more in-depth and comprehensive exploration of design iterations. In retrospect, involving stakeholders earlier and more often in the design and development phase would have provided more time for extensive design iterations. This could have been achieved by hosting stakeholder discussions to develop the concept on a regular basis. As I continue to refine the design outcome, I intend to develop and consult with stakeholders further. This will ensure that the design considers the needs of the end-users as well as the logistics and feasibility of implementing such a tool in neonatal units.

Most of my consultations with stakeholders have been conducted individually via Zoom or email. I would recommend conducting a co-design workshop or a similar collaborative research method to enhance the collaborative aspect of the design research. This approach would allow for a more productive use of time and quicker implementation of feedback and prototyping iterations. Participants in the workshop could also be invited to engage in a rapid-fire prototyping activity, further enhancing the collaborative nature of the process.

Pilot implementations and user testing

The design criteria outlined in this research can be used by clinicians or designers wanting to innovate information resources and systems for parents navigating neonatal care, to increase the likelihood of the designed outcome being usable, ensure that the families being involved as an equal partners of the care team, and so that they may feel more prepared for discharge from hospital.

In order to ensure that the design outcome of this research is optimally developed before considering national implementation, I propose conducting pilot implementations and user testing. This would involve trialling the design as a pilot product in selected SCBUs, allowing for user testing to evaluate the effectiveness of tangible milestones tools in improving discharge preparedness. This assessment can determine if the tool has improved families' experience, empowered them, and prepared them for discharge while collecting feedback on its practical application. To further develop the design, gathering feedback through a co-design workshop would be effective, allowing for input from a range of perspectives.

The Final Prototype

An Intuitive Tool for Families & The Neonatal Care Team

Figure 106. Final Product - Hero Shot 1

My solution is a set of magnets that are designed to sit in the space and be used as a communication tool amongst the care team, each magnet representing a goal or milestone a family achieves. It helps the care team visually see the baby journey of growing, healing and preparing for discharge.

Design choices including the material, format, and placement, are intentional and purposeful. They are focused on evidence for this research project, with a focus on being human-centred and symbolising the complex, unique journeys that each family experiences in the neonatal process.

Figure 107. Final Product - Hero Shot 2

The kangaroo! The animal that inspired it all. The kangaroo is already internationally recognised to symbolise skin-to-skin.

Figure 108. *Final Product - Hero Shot 3*

Figure 109. Final Product - Hero Shot 4

I was interested in playing with the element of nostalgia. My approach was to simplify the illustrations, stripping them back to their most timeless and essential forms. I challenged myself artistically to show a sense of uniqueness in each piece, whilst ensuring they remained cohesive as a whole set.

Neonatal units also often tend to be cluttered spaces, so it was important that the design outcome could sit off of tables and countertops. I also received feedback through the interview phase that any resources that had to be ‘opened’ (such as a book or website) were less likely to be accessed. Having the accomplishments and key goals displayed on the wall allows for it to be visible to parents and everyone else on the care team. Anyone that walks into the cot space can see at a glance where the baby is at – this was an important criterion to consider family-integrated care through discussions with nurses in the interviews.

Figure 110. *Final Product - Context Image*

Figure 111. Final Product - Hero Shot 1

Figure 112. Final Product - Hero Shot 5

Figure 113. Final Product - Hero Shot 6

It was important to me that this could be a timeless and sweet design icon that could last and would be remembered for generations, like a lot of the graphic design I explored in historical documents from the Plunket Society.

The circular, symmetrical, medallion-style layout is heavily inspired by the old NZ Plunket logos. I wanted to include this subtle design element to pay homage to women's and children's health organisations that are historical New Zealand. You can see the resemblance on page 100 of the exegesis. This is my modern take on those emblem style designs

The tokens are made from reclaimed timber I salvaged from a job site, which would have otherwise been discarded. I love the idea of repurposing something that would typically be thrown away, especially for something meaningful. The wood is intended to be kept as a lasting keepsake, giving it a second life. Bringing a warm, earthy material into the sterile hospital environment was a deliberate choice. Hospitals are often cold and clinical, designed to keep people alert, but the contrast of textured wood aims to create a more inviting, healing atmosphere—something particularly important in neonatal units where families spend long hours.

I also wanted to challenge the prevalence of single-use materials in healthcare spaces. The timber represents durability and longevity, standing in contrast to the temporary, wasteful materials commonly used in hospitals. Each piece of wood is unique, with its own grain, colour, and imperfections, celebrating the individuality of every milestone. This personalisation contrasts with mass-produced, uniform materials.

I was mindful of infection control and cleanliness, so the timber is coated with a protective resin, and the engraved areas are sealed and filled to ensure they're easy to wipe clean.

Figure 115. *Final Product - Hero Shot 8*

I chose to use the Māori name for the SCBU on the bottom border of each one - The Māori language was a dying language is having a revitalisation which is very exciting, so I felt it important to use the Māori translation. However, the Māori version isn't exactly the direct wording of Special Care Baby Unit.

te whare refers to the house or residence

tiaki means to guard, protect over, to look after, nurse, and care for.

And *pepi* means the baby

So the name Te Whare Tiaki Pepi directly translates to: *The place where babies are nursed, cared for and protected.*

A beautiful and fitting name to represent SCBU and belongs in the design.

The flexibility of the magnets allows both families and clinicians to personalise the information and represent each baby's unique journey. I intentionally avoided rigid, one-size-fits-all charts or grids, ensuring the design felt organic and adaptable to each family's needs. The round shape of the magnets reflects this organic, less structured approach, moving away from the typical grid-like checklists often found in neonatal resources.

Figure 116. *Final Product - Hero Shot 9*

Figure 117. Final Product - Hero Shot 10

I acknowledge that the milestones I've identified here are not the only significant achievements an infant and their whānau may accomplish during their time in the hospital. I would like to implement a pilot program to test how parents feel about using these magnets in their cot spaces and whether they do facilitate conversation and make them feel empowered as their baby's primary caregivers.

Appendices

Appendix A

Whānau Interviews: Guideline and Indicative Questions

Interview guideline & indicative questions

reimagining neonatal care through whānau interviews

The interview will be semi-structured and casual in nature. The researcher will have the following agenda as a guide to the conversation. The participant will have the opportunity to freely share their opinion about any aspect regarding the research project and neonatal care. The participant is to be treated as the expert here – they have lived experience; The researcher aims will approach the conversation with empathy and learn from the participant(s).

Interview Itinerary: 45 minutes approximately

1. Meet in-person or set up video call.
2. Thank interviewee for their time and introduce yourself.
3. Verbally go over consent form and confirm audio recording is okay.
4. Introduction to the researcher and their area of research.
5. Use following activities to guide the conversation:

A) Optional Icebreaker - **Shared Values Activity** (displayed on cards)

Lay the cards out on the table. Ask participants to organise the cards based on what is most important to them when accessing healthcare for their family.

Each participant can pick their top 3 values cards. For example: 'safety', 'community', 'informed' might be the top values. This activity may be used as an icebreaker, used at the end to conclude discussion, or repeated at the end of the discussion. The overall idea is that these values cards be used as talking points. For Zoom/online calls, this activity may be skipped if deemed unnecessary, or words shown on screen.

B) **Read the follow scenario:**

'A mama pregnant with her first child. Her and her partner are excited for their baby boy's arrival. Mama unexpectedly goes into pre-term labour at 30 weeks. Her baby is born generally healthy, however with a low birth weight which is to be expected at 10 weeks early.

The whānau is admitted to the Special Care Baby Unit for monitoring while baby grows to a normal full-term weight. Mama is having trouble breastfeeding. A lactation consultant tells mama to "just keep trying, it will take some getting used to for your first-time breastfeeding".

Discuss this scenario.

What are your thoughts on this scenario?
Does this sound familiar?
What might this mama be feeling?
What advice would you give this mama?
What might they need? Emotionally or practically?
What information / education / resources implemented might help future families who have hospitalized infants?

What piece of advice would you give someone who has just been admitted to neonatal care and is overwhelmed with it all?

6. Thank the interviewee again for their time and end meeting.

Appendix B.1
Whānau Interviews: Consent Form

consent form

AUT UNIVERSITY
NEW ZEALAND

reimagining neonatal care through whānau interviews

Project Supervisor: Ivana Nakarada-Kordic,
Researcher: Kayla Newman

☐ I have read and understood the information provided about this research project in the Information Sheet dated 09/01/2024.

☐ I have had an opportunity to ask questions and to have them answered.

☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the
study at any time without being disadvantaged in any way.

☐ I understand that I will remain anonymous, meaning any identifiable information about me, including
from the audio-transcription, will be removed from the data.

☐ I understand that if I withdraw from the study then, I will be offered the choice between having any
Data identifiable as belonging to me removed or let it continue to be used. However, once the findings have been produced, removal of my data may not be possible.

☐ I agree to take part in this research.

I consent to the interview being audio recorded. I understand I may verbally withdraw consent at any
time. I understand that the audio-recording will be transcribed (please tick one):
Yes ☐ No ☐

If yes to the next questions, please provide your best contact detail(s) below.

I wish to receive a summary of the research findings (please tick one):
Yes ☐ No ☐

I would like to be contacted for potential follow-up research after this workshop (please tick one):
Yes ☐ No ☐

Participant's full name _____

Participant's signature

_____

Date

__ / __ / ____

Approved by Auckland University of Technology Ethics Committee, 23/299

Appendix B.2

Whānau Interviews: Participant Information Sheet

AUT UNIVERSITY
NEW ZEALAND

participant information sheet

reimagining neonatal care through whānau interviews

Date Information Sheet Produced 09/01/2024

Project Title
Collaborative design for parents navigating neonatal care and transitioning from hospital to home.

About the Researcher

Kia ora, my name is Kayla Newman.
I am passionate about all things related to women's health and products that make the world a better place. I have a background in Industrial design, and I'm currently studying for a Master of Design at Auckland University of Technology. Throughout my research, I aim to use a collaborative design approach to create a resource for families in neonatal care, as they transition from hospital to home.

Purpose of the Research

I understand that having a baby born prematurely or with special healthcare needs can be a challenging time for families. Our aim is to collaborate with families and professionals in the neonatal community. Through interviews, we hope to unpack how we might better support families when it comes to educational resources and tools.

Taking care of a baby with special needs can feel overwhelming. Your input is crucial in helping us rethink how we support parents in SCBU through personal, well-designed educational solutions for a more family-centred approach to care. This research is all about understanding what parents go through when their newborns spend time in the Special Care Baby Unit (SCBU).

You will have the opportunity to freely share their opinion about any aspect regarding the research project and neonatal care. As a participant, you will be treated as the expert here, as you have lived experience. As a researcher, I aim to approach the conversation with empathy and learn from you. This will aid me in my design process to redesign and consolidate a relevant and informative resource for future families starting a neonatal journey.

How do I agree to participate in this research?

You can agree to participate in this research by contacting the researcher, Kayla Newman (dsh9292@autuni.ac.nz) to set up an interview date and time. You can choose between an in person or an online interview (via Zoom). You will also need to sign a consent form before the interview commences. You may email me the signed consent form prior to the interview or sign a physical copy on the day.

Note: video-call interviewers must sign a digital copy of the consent form. Please also feel free to ask us any questions you may have regarding the study.

Your participation in this research is voluntary (it is your choice), and whether you choose to participate will not benefit or disadvantage you. You can withdraw from the study at any time. Suppose you choose to withdraw from the study. In that case, you will be offered the choice between having any data identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

Each interview will be a semi-structured discussion on what you believe someone navigating neonatal care for the first time might need to know or hear.

The interview will be casual in nature and will take approximately 45 minutes of your time. The researcher will have a list of questions to guide the conversation, and you will have an opportunity to freely share your opinion about any aspect regarding the research project and neonatal care. You are the expert here; I am here to listen and learn from you.

We will work together to imagine what a good experience at SCBU In terms of information and education provided should look like for families. We hope to use some of the findings and learnings from these interviews to help design solutions for resources or tools that will benefit future families who go through a neonatal care journey.

The questions will be generalised and not specific to your neonatal journey. An example scenario will also be provided to help with our discussion. Some examples of questions that may be asked:
What support did you have and what did you wish you had?
What are your thoughts on (persona scenario)?
What might this mama be feeling?
What advice would you give this mama?
What might they need? Emotionally or practically?

You are welcome to share as much or as little detail as you would like about your experiences. You may also choose to decline to comment on any questions. This will be a safe and non-judgmental space to share your opinions about neonatal care.

What are the benefits?

There is no direct benefit to you. Your contribution to this research project may help create better educational resources and experiences for future parents with babies at SCBU.
The researcher is an AUT student and is not employed by any healthcare organisation. There is no monetary gain for researchers. The benefit for the researcher is obtaining a master's qualification through successfully completing the project.

What are the discomforts and risks and how will these discomforts and risks be alleviated?

Although I perceive there to be minimal risk, I understand that you may be worried about the privacy of yourself, your child and your family. Your data will remain confidential, meaning we will remove all identifiable data, including your name, occupation, gender, and workplace from any outputs of this research. You will still be known to the researcher interviewing you. You can also opt out of the interview being audio-recorded (outlined in the consent form). Audio recordings will not be shared with anyone and will be transcribed. Any identifiable information will be removed.

We also understand that revisiting memories surrounding the birth of your baby may be triggering and emotional. You may end the interview anytime or choose not to respond to specific questions. You are welcome to bring your partner or another support person. We encourage all parents, caregivers and whānau, not just the birthing person, to have their say - we know it takes a village to raise a child. All attendees will need to read this Participant Information Sheet and sign a separate consent form to agree to be part of this research.

What opportunity do I have to consider this invitation?

You have up to two weeks to consider and accept the invitation to participate in an interview. Please contact us if you have any questions before signing the consent form. We want you to be able to make an informed decision about whether this interview is right is right for you.

The research (Kayla Newman) will get in touch to schedule an interview. You may reschedule or cancel at any time with no disadvantage to you.

Will I receive feedback on the results of this research?

If you would like to receive information about the results of this research, you can let us know, and we will send the research summary to you once the study is completed.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to
the Project Supervisor Ivana Nakarada-Kordic, ivana.nakarada-kordic@aut.ac.nz
Approved by Auckland University of Technology Ethics Committee on 14th November 2023, 23/299, 23/300. Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC: Liz Binns, ethics@aut.ac.nz, 921 9999 ext 6038.

Helpline Services

Walsh Trust
www.walsh.org.nz
(0800) 192574
Provides free community-based mental health support and residential service.

The Grief Centre
www.griefcentre.org.nz
(09) 418 1457
Provides counselling, bereavement phone support, professional training and community and group support sessions to ensure people are well-supported through their grief and loss journey.

Approved by Auckland University of Technology Ethics Committee, 23/299

Appendix C
AUTEC Approval

Auckland University of Technology Ethics Committee (AUTEC)

22 November 2023

Ivana Nakarada-Kordic
Faculty of Design and Creative Technologies

Dear Ivana

Re Ethics Application: **23/299 Collaborative design for parents navigating neonatal and transitioning from hospital to home.**

Thank you for your responses to AUTEC's conditions.

Your ethics application has been approved for three years until 14 November 2026.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC.
2. All public facing documents must have the AUTEC approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTEC, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTEC grants ethical approval only. You are responsible for obtaining management permission for access from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online http://www.aut.ac.nz/research/researchethics

For any enquiries, please contact ethics@aut.ac.nz
(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: dsh9292@autuni.ac.nz

AUTEC Approval (amended data collection method)

Auckland University of Technology Ethics Committee (AUTEC)

30 January 2024

Ivana Nakarada-Kordic
Faculty of Design and Creative Technologies

Dear Ivana

Ethics Application: **23/299 Collaborative design for parents navigating neonatal and transitioning from hospital to home.**

Thank you for submitting your application for an amendment to your ethics application.

The amendment to the data collection protocol is approved, subject to:

1. Clarification if interviews are replacing the workshop as a method of data collection; or is the opportunity to take part in an online interview an additional method of data collection;
2. Clarification of who the participants are in the interview i.e.. Will it be one parent or both parents;
3. Clarification whether any prototype educational resources that have been developed will be discussed;
4. Amendment of the Participant Information Sheet as follows:
    a. Inclusion of all the subheadings from the AUTEC exemplar i.e. cost, privacy and who to contact for further information;
    b. Revision of "how we support" to "how parents are supported", as the researcher is not a DHB employee;
5. Amendment of the Consents Form as follows:
    a. Revision of the data being "anonymous" to "deidentified" as interviews are not an anonymous method of data collection;
    b. Revision of the bullet point that refers to "after this workshop" as the participants are not taking part in a workshop
6. Provision of an updated advertisement that reflects the activities that the participant is being asked to take part in.

Please provide a response to the conditions in a memo and attach any altered documents, such as the Information Sheet, Consent Forms, Survey.

Please reference the application number and study title in all correspondence.

The Committee is always willing to discuss with applicants the points that have been made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood.

When the conditions have been met, you will be notified of the full approval of your ethics application. Full approval is not effective until all the conditions have been met. Data collection may not commence until full approval has been confirmed. If these conditions are not met within six months, your application may be closed, and a new application will be required if you wish to continue with this research.

If you have any enquiries about this application, please contact us at ethics@aut.ac.nz.

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: dsh9292@autuni.ac.nz

AUTEC Approval (amended data collection method)

Auckland University of Technology Ethics Committee
(AUTEC)

30 January 2024

Ivana Nakarada-Kordic
Faculty of Design and Creative Technologies

Dear Ivana

Ethics Application: **23/299 Collaborative design for parents navigating neonatal and transitioning from hospital to home.**

Thank you for submitting your application for an amendment to your ethics application.

The amendment to the data collection protocol is approved, subject to:

1. Clarification if interviews are replacing the workshop as a method of data collection; or is the opportunity to take part in an online interview an additional method of data collection;
2. Clarification of who the participants are in the interview i.e.. Will it be one parent or both parents;
3. Clarification whether any prototype educational resources that have been developed will be discussed;
4. Amendment of the Participant Information Sheet as follows:
    a. Inclusion of all the subheadings from the AUTEC exemplar i.e. cost, privacy and who to contact for further information;
    b. Revision of "how we support" to "how parents are supported", as the researcher is not a DHB employee;
5. Amendment of the Consents Form as follows:
    a. Revision of the data being "anonymous" to "deidentified" as interviews are not an anonymous method of data collection;
    b. Revision of the bullet point that refers to "after this workshop" as the participants are not taking part in a workshop
6. Provision of an updated advertisement that reflects the activities that the participant is being asked to take part in.

Please provide a response to the conditions in a memo and attach any altered documents, such as the Information Sheet, Consent Forms, Survey.

Please reference the application number and study title in all correspondence.

The Committee is always willing to discuss with applicants the points that have been made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood.

When the conditions have been met, you will be notified of the full approval of your ethics application. Full approval is not effective until all the conditions have been met. Data collection may not commence until full approval has been confirmed. If these conditions are not met within six months, your application may be closed, and a new application will be required if you wish to continue with this research.

If you have any enquiries about this application, please contact us at ethics@aut.ac.nz.

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: dsh9292@autuni.ac.nz

Auckland University of Technology, Private Bag 92006, Auckland 1142, New Zealand.
T: +64 9 921 9999 ext. 8316: E: ethics@aut.ac.nz: www.aut.ac.nz/researchethics

Appendix D

Expert Interviews: Advertisement and Recruitment Script

Kia ora koutou,

We are reaching out to inform you about a study, "Collaborative design for parents navigating neonatal care and transitioning from hospital to home".

I will be interviewing people involved in neonatal care, specifically SCBU. These could be nurses, midwives, doctors, family support workers, consultants or anyone whose role is to support families somewhere along their neonatal journey.

Please pass this on to your network or anyone you think might be interested in participating (poster attached).

Title: Collaborating with neonatal experts to reimagine how we might better support parents on their journey.

Who: Neonatal workers

When: The interview can be scheduled any time between December and February.

Where: Auckland region or via Zoom.

Contact: Kayla Newman

dsh9292@autuni.ac.nz

Our primary focus is to propose a design for a new resource for families navigating an often-unexpected neonatal journey. Suggestions of what to include and feedback on this design will be needed later. You can find out more here.

Please do not hesitate to reach out if you have any questions.

Kind regards,

Kayla Newman

Appendix E.1
Expert Interviews: Participant Information Sheet

Reimagining Neonatal Care through semi-structured expert interviews.

Collaborating with neonatal experts to reimagine how we might better support parents on their journey.
Date Information Sheet Produced **7/11/2023**

Project Title

Reimagining Neonatal care

About the Researchers

Kia ora, my name is Kayla Newman.

I am passionate about all things related to womens' health and products that make the world a better place. I have a background in Industrial design, and I'm currently studying for a Master of Design at Auckland University of Technology. Throughout my research, I aim to use a collaborative design approach to create a resource for families in neonatal care, as they transition
from hospital to home.

Purpose of the Research

The aim of this research is to work with professionals and communities to better understand the experience of parents whose newborn has spent extended periods in the hospital, specifically SCBU (Special Care Baby Unit) and how they can be best supported on their journey from hospital to home. I understand that having a baby with special healthcare needs is a challenging time for families. This can be overwhelming for some parents to navigate. With your input, I would like to reimagine how we support parents navigating SCBU and design educational solutions for a more family-centered approach to care.

How do I agree to participate in this research?

You can agree to participate in this research by contacting the researcher, Kayla Newman (dsh9292@autuni.ac.nz) to set up an interview date and time. You can choose between an in person or an online interview (via Zoom). You will also need to sign a consent form before the interview commences. You may email me the signed consent form prior to the interview or sign a physical copy on the day.

Note: video-call interviewers must sign a digital copy of the consent form. Please also feel free to ask us any questions you may have regarding the study.

Approved by Auckland University of Technology Ethics Committee on 14th November 2023 , 23/299

Your participation in this research is voluntary (it is your choice), and whether or not you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time. Suppose you choose to withdraw from the study. In that case, you will be offered the choice between having any data identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

The interview will be semi-structured and casual in nature. The researcher will have a list of questions to guide the conversation, and you will have an opportunity to freely share your opinion about any aspect regarding the research project and neonatal care. You are the expert here; I am here to listen and learn from you.

What are the discomforts and risks and how will these discomforts and risks be alleviated?

Although I perceive there to be minimal risk, we understand that you may be worried about your relationship with your employer or workplace. Your data will remain anonymous, meaning we will remove all identifiable data, including your name, occupation, gender, and workplace. You will still be known to the researcher interviewing you. You also have the option to opt out of the interview being audio-recorded (outlined in the consent form). Audio recordings will not be shared with anyone and will be transcribed. Any identifiable information will be removed.

What are the benefits?

There is no direct benefit to you. Your contribution to this research project may help create better educational resources and experiences for future parents with babies at SCBU and may ultimately help professionals working in this space be better equipped to provide educational support.

Researchers are AUT students and are not employed by any healthcare organisation. There is no monetary gain for researchers. The benefit for researchers is obtaining a Master's qualification in successfully completing the project.

How will my privacy be protected?

You will not be anonymous to the researchers.

At no point will you be asked to disclose your specific place of work, only your role in the context of neonatal care. In the likely circumstances where your place of work may be mentioned during the interview or recruitment, this information will be de-identified from the data.

Only the researchers will have access to your identifiable information. Participants will remain anonymous in all the outputs of this research, and any identifiable data (such as your name) will be kept confidential. Everything the researcher collects will be kept for at least six years and then destroyed.

Approved by Auckland University of Technology Ethics Committee on 14th November 2023 , 23/299

What are the costs of participating in this research?

There is no monetary cost to participating in this workshop, other than your time. We anticipate the interview will be approximately 45 minutes long to allow time for in-depth discussion. However, this can be scheduled to accommodate for the time you have available if you wish.

What opportunity do I have to consider this invitation?

You have up to two weeks to consider and accept the invitation to participate in this research.

Will I receive feedback on the results of this research?

If you would like to receive a summary of this research once the study is completed or attend a student exhibition to celebrate the completion of this project, you can indicate so on the consent form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor Ivana Nakarada-Kordic, ivana.nakarada-kordic@aut.ac.nz
Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC: Liz Binns, ethics@aut.ac.nz, 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher:

Kayla Newman, dsh9292@autuni.ac.nz

Project Supervisor

Ivana Nakarada-Kordic, ivana.nakarada-kordic@aut.ac.nz

Approved by Auckland University of Technology Ethics Committee on 14th November 2023 , 23/299

Appendix E.2
Expert Interviews: Consent Form

AUT UNIVERSITY
NEW ZEALAND

Consent form

Project Title: Reimagining Neonatal Care through semi structured expert interviews.
Project Supervisor: Ivana Nakarada-Kordic
Researcher: Kayla Newman

☐ I have read and understood the information provided about this research project in the Information Sheet dated 06/11/2023.

☐ I have had an opportunity to ask questions and to have them answered.

☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

☐ I understand that I will remain anonymous, meaning any identifiable information about me, including from the audio-transcription, will be removed from the data.

☐ I understand that if I withdraw from the study then, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

☐ I agree to take part in this research.

I consent to the interview being audio recorded. I understand I may verbally withdraw consent at any time. I understand that the audio-recording will be transcribed (please tick one):
Yes ☐ No ☐

I wish to receive a summary of the research findings (please tick one):
Yes ☐ No ☐

I would like to be contacted for potential follow-up research after this workshop (please tick one):
Yes ☐ No ☐ If yes, please provide your best contact detail(s) below:

Participant Name _____

Participant Signature

_____

Date signed / /

Approved by Auckland University of Technology Ethics Committee on 14th November 2023 , 23/299

Appendix F

Expert Interviews: Indicative Questions

Expert Interview Agenda

Overview: Anticipated Interviewees are experts in the neonatal care community, such as nurses, pediatricians, midwives, lactation consultants, family support workers etc. Interviewees may be employed by Te Whatu Ora or be a part of a third-party organisation or charity. Neonatal nurses specifically will be integral to the success of the expert interview process as they are directly involved in infant care and educating parents.

1. Meet in-person or set up video call.
2. Thank interviewee for their time and introduce yourself.
3. Verbally go over consent form and confirm audio recording is okay.
4. Introduction to the researcher(s) and the area of research.
5. Use following questions to guide the conversation:

Interview Itinerary: 45 minutes approximately

a. What is your role in a neonatal unit, specifically regarding parent education and preparing families to transition home?

b. What aspect of care could parents be more involved in? Based on your experience, what hinders them from being involved in this care?

c. Are there any design elements, products, or resources you find helpful in your day-to-day work?

d. When are the parents most present in the unit?

e. Do mothers and families socialise with each other in the unit? Or do they tend to stay in their rooms?

f. What piece of advice would you give someone who has just been admitted to neonatal care and is overwhelmed with it all?

6. Ask follow-up questions allow interviewee time to speak about their area of work and ask further questions about the area of research.
7. Thank the interviewee again for their time and end meeting.

Appendix G

Stakeholder Feedback Script

Subject: Feedback on a design

Hi _____

I have a follow-up question for you. I remember when you showed me the flight care plan resource in SCBU. I've done more research on it, and I was wondering if you could give me your take. I want to use my milestone concept to help with discharge preparedness, just like the flight plan aims to do.

My Flight Plan for Home. An evidence-informed discharge preparedness tool used to identify learning needs of parents of NICU infants and document when learning is achieved. NICU indicates neonatal intensive care unit.

My question is, which clouds/milestones on the 'flight care plan to home' do you consider the most crucial? Or are they all equally important for parents to know before discharge?

Any thoughts ideas appreciated. Thanks

Cheers,

Kayla

Subject: Feedback on a design

Kia ora _____,

I hope you're well! It's been a while since I've been in touch. I'm the design research student from AUT Good Health Design. I abandoned some of the interviews I had been in touch with you about due to all the red tape. But alas, I got a few interviews done from those involved in SCBU/NICU from other cities, which was super helpful!

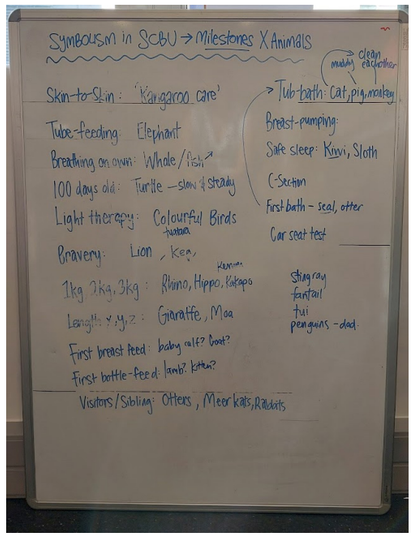
Since then, I've been working on a concept for a neonatal resource for parents that I'd like to run by you and get your thoughts on...

The project is titled Celebrating Milestones: Design to Empower & Reduce Uncertainty for Families on their Neonatal Journey

I'm designing a resource aimed to celebrate those special milestones a family goes through in neonatal care, in an educative way. First cuddle, first breastfeed, breathing without oxygen, weight goals, 100-day birthday etc.. It also aims to help parents learn about their baby's condition, treatments and care plan in a tangible, pleasant, light-hearted way.

The concept is inspired by the metaphor of the 'kangaroo', which is the animal associated with skin-to-skin - as I'm sure you're familiar with! So, I've tried to think of different animals that could represent other milestones and turn them in tokens/badges that parents could collect upon their families achieving it.

Here are some of the associations I've brainstormed up so far:



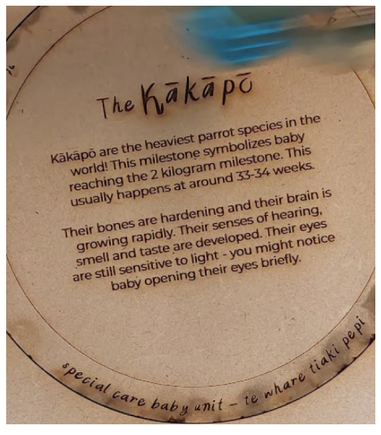
My question to you is... Do you have any other ideas for significant milestones that should be incorporated into this design? Do these associations I have so far make sense? Or am I missing the mark, and are they offensive? I'm totally open to criticism! To get a sense of how I envision these 'SCBU animal' milestones being implemented, I've mocked up a few.

Front:

Back:

Mock up version:

Example of information printed on the back of each milestone, talking about the milestone/treatment, and how it relates to the animal:



Obviously, this is all the development stages! Anything can be changed and added at this point. So I'd really appreciate any feedback or criticisms you have, given your expertise in SCBU. Feel free to forward this to others who might have thoughts on this concept, too.

Kind regards,

Kayla Newman

Appendix H.1
EA1 Ethics Application

Please do not staple your application

AUT
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

Auckland University of Technology Ethics Committee (AUTEC)

For AUTEC Secretariat Use only

_____/_____

EA1

Application for Ethics Approval by AUTEC

Please print this application single sided in greyscale and do not staple. Once this application has been completed and signed, please read the notes at the end of the form for information about submission of the application for review.

Notes about Completion

- Ethics review is a community review of the ethical aspects of a research proposal. Responses should use clear everyday language with appropriate definitions being provided should the use of technical or academic jargon be necessary.
- The AUTEC Secretariat and your AUTEC Faculty Representative are able to provide you with assistance and guidance with the completion of this application which may help expedite the granting of ethics approval.
- The information in this application needs to be clearly stated and to contain sufficient details to enable AUTEC to make an informed decision about the ethical quality of the research. Responses that do not provide sufficient information may delay approval because further information will be sought. Overly long responses may also delay approval when unnecessary information hinders clarity.
- AUTEC reserves the right not to consider applications that are incomplete or inadequate. Please do not alter the formatting or numbering of the form in any way or remove any of the help text.
- Comprehensive information about ethics approval and what may be required is available online at http://aut.ac.nz/researchethics
- The information provided in this application will be used for the purposes of granting ethics approval. It may also be provided to the Graduate Research School, the Research and Innovation Office, or the University's insurers for purposes relating to AUT's interests.
- The Form is focussed around AUTEC's ethical principles, which are in accordance with the *Guidelines for the approval of ethics committees* in New Zealand.

To respond to a question, please place your cursor in the space following the question and its notes and begin typing.

A. *Project Information*

A.1. What is the title of the research?

If you will be using a different title in documents to that being used as your working title, please provide both, clearly indicating which title will be used for what purpose.

Collaborative design for parents navigating neonatal and transitioning from hospital to home.

A.2. Is this application for research that is being undertaken in stages? ☐ Yes ☒ No

If the answer is 'Yes' please answer A.2.1 and the following sections, otherwise please answer A.3 and continue from there.

A.2.1. Does this application cover all the stages of the research? ☒ Yes ☐ No

If the answer is 'No' please provide details here of which stages are being covered by this application, otherwise please answer A.3 and continue from there.

A.3. Who is the applicant?

When the research is part of the requirements for a qualification at AUT, then the applicant is always the primary supervisor. Otherwise, the applicant is the researcher primarily responsible for the research, to whom all enquiries and correspondence relating to this application will be addressed.

Dr Ivana Nakarada-Kordic

A.4. Further information about the applicant.

A.4.1. In which faculty, directorate, or research centre is the applicant located?

Good Health Design, Art and Design, Design and Creative Technologies

A.4.2. What are the applicant's qualifications?

PhD, MSc, BSc

A.4.3. What is the applicant's email address?

An email address at which the applicant can be contacted is essential.

ivana.nakarada-kordic@aut.ac.nz

A.4.4. At which telephone numbers can the applicant be contacted during the day?

021 104 7180

A.5. Research Instruments

A.5.1. Which of the following does the research use:

☐ *a written or electronic questionnaire or survey* ☐ *focus groups* ☒ *interviews*
☐ *observation* ☐ *participant observation* ☐ *ethnography* ☐ *photographs*
☐ *videos* ☐ *other visual recordings* ☒ *a creative, artistic, or design process*
☐ *performance tests*
☒ *some other research instrument (please specify)*

Co-design workshop

Please attach to this application form all the relevant research protocols. These may include: Indicative questions (for interviews or focus groups); a copy of the finalised questionnaire or survey in the format that it will be presented to participants (for a written or electronic questionnaire or survey); a protocol indicating how the data will be recorded (e.g. audiotape, videotape, note-taking) for focus groups or interviews (Note: when focus groups are being recorded, you will need to make sure there is provision for explicit consent on the Consent Form and attach to this Application Form examples of indicative questions or the full focus group schedule. Please note that there are specific confidentiality issues associated with focus groups that need to be addressed); a copy of the observation protocol that will be used (for observations); full information about the use of visual recordings of any sort, including appropriate protocols and consent processes; protocols for any creative, artistic, or design process; a copy of the protocols for the instruments and the instruments that will be used to record results if you will use some other research instrument.

A.5.2. Who will be transcribing or recording the data?

If someone other than the applicant or primary researcher will be transcribing the interview or focus group records or taking the notes, you will need to provide a confidentiality agreement with this Application Form.

The Primary Researcher, Kayla Newman and Research Partner, Sherin Shaji (MDes student).

A.6. Please provide a brief plain English summary of the research (300 words maximum).

Please provide a simple response to each of these three questions: What are you trying to find out? Who are you wanting to involve? and What would you like them to do for you?

Neonatal care is the umbrella term for various levels of infant care, specifically in hospitals. There are levels of intensity to care an infant may require, meaning a family may be admitted to a neonatal intensive care unit (NICU) or a Special Care Baby Unit (SCBU), or both. Not all hospitals in New Zealand have both, meaning a family may need to transfer between hospitals to access the necessary care for their child.

A neonate (meaning infant) may require being in hospital for a range of reasons. SCBU babies are commonly low risk patients but have a low birth weight (LWB). The earlier a baby is born, the lower the birth weight and increases the risk of health complications. Having an infant premature or with special healthcare needs can be a stressful and unexpected entrance into parenthood (Fernández Medina et al., 2018, Lasiuk et al., 2013). Special Care Baby Units (SCBU) provide educational resources to support parents transitioning from hospital to home; however, these resources are often scattered across various mediums, making it overwhelming to navigate.

This research aims to use a collaborative design approach to improve the experience of parents/caregivers in neonatal care transitioning from hospital to home through the design of a comprehensive, user-friendly educational resource that will empower them to be an equal partner in the care of their newborn.

The research will involve conducting interviews with experts in neonatal care (e.g., nurses, lactation specialists, paediatricians, etc.) and facilitating a co-design workshop with parents/caregivers of babies who were hospitalised at birth to understand the experiences and educational needs of parents/caregivers around the care of a premature baby and generate ideas for how to design educational resources to better support these needs.

It is anticipated that the outcome of this research will be a prototype of an educational resource or product for parents navigating SCBU for the first time – a reimagined approach to neonatal post-discharge support.

A.7. Additional Research Information

A.7.1. Is this research an intervention study? ☐ Yes ☒ No

An Intervention Study is defined in NEAC's National Ethical Standards for Health and Disability Research and Quality Improvement. as "A study in which an investigator controls and studies an intervention(s) provided to participants for the purpose of adding to knowledge of the health effects of that intervention(s). The term 'intervention study' is often used interchangeably with 'experimental study'. Many intervention studies are clinical trials." (p.247)

A.7.2. Is this Health and Disability Research? ☒ Yes ☐ No

Broadly speaking, health and disability research should:
- *aim to answer a question or solve a problem and therefore generate new knowledge to prevent, identify and treat illness and disease*
- *have the ultimate purpose of maintaining and improving people's health – in the sense of a state of physical, mental and spiritual wellbeing, rather than simply the absence of disease or infirmity*
- *support disabled people to be included, participate more, exercise choice and control, and be more independent*
- *address health and disability disparities*
- *contribute to whānau ora.*

This description is necessarily broad; we acknowledge that people's health is influenced by a much wider range of social factors than their health care. (NEAC's National Ethical Standards for Health and Disability Research and Quality Improvement, p.28)

A.7.3. Does this research involve people in their capacity as consumers of health or disability support services, or in their capacity as relatives or caregivers of consumers of health or disability support services, or as volunteers in clinical trials (including, for the avoidance of doubt, bioequivalence and bioavailability studies)? ☒ Yes ☐ No

B. *The Ethical Principle of Research Adequacy*

AUTEC recognises that different research paradigms may inform the conception and design of projects. It adopts the following minimal criteria of adequacy: the project must have clear research goals; its design must make it possible to meet those goals; and the project should not be trivial but should potentially contribute to the advancement of knowledge to an extent that warrants any cost or risk to participants.

B.1. Is the applicant the person doing most of the research (the primary researcher)? ☐ Yes ☒ No

If the answer is 'No' please answer B.1.1 and the following sections, otherwise please answer B.2 and continue from there.

B.1.1. What is the name of the primary researcher if it is someone other than the applicant?

Kayla Newman

B.1.2. What are the primary researcher's completed qualifications?

Bachelor of Design, Industrial

B.1.3. What is the primary researcher's email address?

An email address at which the primary researcher can be contacted is essential.

dsh9292@autuni.ac.nz

B.1.4. At which telephone numbers can the primary researcher be contacted during the day?

B.2. Is the primary researcher

☐ *an AUT staff member* ☒ *an AUT student*

If the primary researcher is an AUT staff member, please answer B.2.1 and the following sections, otherwise please answer B.3 and continue from there.

B.2.1. In which faculty, directorate, or research centre is the primary researcher employed?

If the response to this section is the same as that already given to section A.4.1 above, please skip this section and go to section B.2.2.

B.2.2. In which school or department is the primary researcher employed?

B.3. When the primary researcher is a student:

B.3.1. What is their Student ID Number?

19077157

B.3.2. In which faculty are they enrolled?

Faculty of Design and Creative Technologies

B.3.3. In which school, department, or Research Centre are they enrolled?

School of Art and Design

B.4. What is the primary researcher's experience or expertise in this area of research?

Where the primary researcher is a student at AUT, please identify the applicant's experience or expertise in this area of research as well.

The primary researcher, Kayla Newman has a bachelor's degree in industrial design. In her undergraduate studies she designed a perinatal mental health toolkit for new mothers which received a Social Innovation award and is a nominated Best Award finalist. She was awarded a summer studentship with AUT's Good Health Design – the project consisted of an analysis of and proposal for Waitemata DHBs telehealth webpage. She has completed a 'Design for Health and Wellbeing' and 'Ethics in Research' papers in her first semester of postgraduate studies.

The applicant, Ivana Nakarada-Kordic has a background in human factors, health psychology, and applying design and qualitative methodologies in the context of health and wellbeing. She has worked in partnership with Auckland and Waitematā DHBs on research projects to improve experiences and outcomes of in-hospital and community health services for patients, families, and staff. She has taught Ethics in Research, Design for Health and Wellbeing, Design for Social Impact, Research Methods, and Contextual Review postgraduate papers in the School of Art and Design.

B.5. Who is in charge of data collection?

Expert Interviews: Kayla Newman

Co-design workshop: The primary research Kayla Newman and research partner, Sherin Shaji

B.6. Who will interact with the participants?

Expert Interviews: Kayla Newman

Co-design workshop: The primary research Kayla Newman and research partner, Sherin Shaji

B.7. Is this research being undertaken as part of a qualification? ☒ Yes ☐ No

If the answer is 'Yes' please answer B.7.1 and the following sections, otherwise please answer B.8 and continue from there.

B.7.1. What is the name of the qualification?

Master of Design

B.7.2. In which institution will the qualification be undertaken?

Auckland University of Technology (AUT)

B.8. Details of Other Researchers or Investigators

B.8.1. Will any other people be involved as researchers, co- investigators, or supervisors? ☒ Yes ☐ No

If the answer is 'Yes' please answer B.8.1.1 and the following sections, otherwise please answer B.8.2 and continue from there.

B.8.1.1 What are the names of any other people involved as researchers, investigators, or supervisors?

Sherin Shaji

B.8.1.2 Where do they work?

-

B.8.1.3 What will their roles be in the research?

Sherin Shaji – Co-design workshop facilitator

B.8.1.4 What are their completed qualifications?

Sherin Shaji – Bachelor in Spatial Design

B.8.2. Will any research organisation or other organisation be involved in the research? ☒ Yes ☐ No

If the answer is 'Yes' please answer B.8.2.1 and the following sections, otherwise please answer B.9 and continue from there.

B.8.2.1 What are the names of the organisations?

The Little Miracles Trust, Bellyful NZ

B.8.2.2 Where are they located?

The Little Miracles Trust – Ward 92 NICU, Level 9 I, Auckland City Hospital, Park Road, Grafton, Auckland

Bellyful NZ – multiple branches across New Zealand

B.8.2.3 What will their roles be in the research?

These organisations will distribute advertising about the study through their newsletters or noticeboards to invite potentially eligible participants to be interviewed (experts) or participate in a co-design workshop (parents/caregivers).

B.9. Why are you doing this research and what is its aim and background?

Please provide the key outcomes or research questions and an academic rationale with sufficient information, including relevant references, to place the project in perspective and to allow the project's significance to be assessed.

Neonatal care is the umbrella term for various levels of infant care, specifically in hospitals. There are levels of intensity to care an infant may require, meaning a family may be admitted to a neonatal intensive care unit (NICU) or a Special Care Baby Unit (SCBU), or both. Not all hospitals in New Zealand have both, meaning a family may need to transfer between hospitals to access the necessary care for their child.

A neonate (meaning infant) may require being in hospital for a range of reasons. SCBU babies are commonly low risk patients but have a low birth weight (LWB). The earlier a baby is born, the lower the birth weight and increases the risk of health complications.

Becoming a parent is already one of the most significant transitions a person goes through – and having a premature infant or infant with special healthcare needs requiring hospitalisation brings added emotional, physical, and financial pressures. The emotional impact of having a hospitalised infant is often accompanied by feelings of dread, anxiety, and a sense of emptiness within the sterile clinical environment (Fernández Medina et al., 2018). Perinatal distress is already a growing concern in New Zealand. Walker's 2022 report in collaboration with the Tindall foundation, suggests that generational and societal factors cause perinatal distress for parents in New Zealand, and proposes a more family centric, holistic, and culturally sensitive approach to care (Walker, 2022).

In order to create something beneficial for parents who have infants with special healthcare needs, we need to understand what work has already been done. Recognition is deserved to acknowledge and honour the pioneers of women's health and birth care, in New Zealand history, as they are the foundation of this project.

The way our society approaches parenting, and infant care has changed significantly in the last 100 years (Stevens et al., 2009). Caregivers have traditionally known to be mothers or young women in the family unit. In modern day, we acknowledge that caregivers of our children cover a wider demographic including fathers and non-biological parental roles. Historically, resources for child-rearing were specifically tailored towards the maternal caregiver – the first informative book called 'Feeding and Care of Baby', was written by Dr F.T King in 1913 and released by the Royal New Zealand Society for the Health of Women & Children, more

commonly known as the Plunket Society (RNZPS) (King, 1913). In a time where medical care and information was limited, King's book was a groundbreaking and valuable resource for mothers in New Zealand. King's legacy and The Plunket Society was a game-changer for how parents in New Zealand accessed information about infant care and made a notable contribution to how society now views infant nutrition (Cox, 2018). In recent generations, the widely known 'the Plunket book' - officially titled the 'Well Child/Tamariki Ora Health Book' – had become an iconic and trusted source and keepsake for New Zealand mothers (Clendon, 2009).

Nowadays, we have technology, medical advancements, baby products, the development of breast milk alternatives, and plethora of information at our fingertips, giving parents more options when it comes to caring for their infant, whether that be a more holistic or clinical approach. In NZ there has been a lot of work done in neonatal care across different hospitals and former District Health Boards (DHBs) to provide education and support to parents. However, this information is scattered in different mediums — digital media, apps, websites, books, paper copies, booklets, brochures, or is being passed on verbally. We went from having limited information on infant-care, to an overwhelming amount with conflicting messages, particularly around breast-feeding.

Using design thinking, methods, and outputs in the context of healthcare has the potential to help people navigate the healthcare systems more easily and to enhance their experiences in this context (Chamberlain & Craig, 2017). Designers can engage with communities to gain insights into their specific needs and experiences, enabling the development of more tailored and effective interventions through what we call, co-design – short for collaborative design.

Co-design frameworks being used in healthcare serve as evidence that a collaborative design approach could be successfully applied in neonatal care context. For example, collaborating with people living with dementia (Rodgers, 2017), working with communities to improve care for children with chronic health conditions (Bird et al., 2021) and reimagining remote collaboration during the COVID-19 pandemic (van Beusekom & Amann, 2021). Co-design involves engaging end users of products/ services/ systems/ environments in all the phases of the design process – from gaining insight into their lived experience and identifying the needs and wants of those affected, to prototyping solutions that meet those needs together.

While our healthcare system may not intentionally fail to meet the needs of users by not always involving users in the development of solutions, there are examples of service design that have potential and could be developed further with end-user input (Shaw et al., 2018).

The main objectives of this research are:

- analyse the current resources available/provided to parents with newborn infants in neonatal care and assess their usability and effectiveness.
- investigate the needs of parents navigating neonatal healthcare, to improve the experience from admission to SCBU, to transition to home.
- design easy to use and empowering solutions that educate and build parents' confidence to take over care of their infant post-discharge.

1. Semi-structured expert interviews
Interviews with experts in neonatal care, such as nurses, are most appropriate as they have first-hand experience in the structure of SCBU and have developed relations with families at all stages of their neonatal journey (Coughlin, 2021). Lactation consultants, family support workers and contributors to neonatal charity may also provide valuable insights to this research.

2. Co-design workshops with SCBU graduate families. The workshop will include a series of creative activities designed to help participants voice their opinions regarding neonatal care in a non-intrusive away and provide ideas for design solutions that would meet the education and information needs of families in this context.

'Graduate' or 'veteran' parents with previous experience in the SCBU could offer valuable perspectives (Macdonell et al., 2013) on practical approaches and potential improvements by engaging in co-design activities. A generative co-design process, based on evidence, that is suitable for healthcare (Bird et al., 2021, O'Callaghan et al., 2019) – this approach is essential to uncover the true needs of people navigating neonatal care, so that the proposed solution can accommodate these needs in the most appropriate way.

B.10. What are the potential benefits of this research to the participants, the researcher, and the wider community?

There are a range of potential foreseen benefits of carrying out this research for all involved including the researcher(s), participants, and the wider neonatal community. There is no direct monetary benefit for anyone involved.

The primary researcher (Kayla Newman) will benefit from the experience of conducting design-led research in the health and wellbeing context, gaining a qualification, and a proposed design outcome. The researcher may also gain fulfilment by contributing to the neonatal community. The role of the primary researcher as a designer is to understand, refine and consolidate all the resources within neonatal healthcare to create beneficial innovations that are user-friendly for families and clinicians.

The co-design workshop may allow a safe space for SCBU 'graduate' families to feel listened to and heard about their opinions on how post-natal life can be improved.

The design outcome has the potential to assists nurses and neonatal staff with their workload to provide quality care when educating parents. Experts in neonatal care will have an opportunity to share their professional opinions and insights on neonatal care, what worked and did not work in the past in terms of parent education. Their contributions to this research may inform a meaningful outcome that may be proposed to be used in their practice in the future. Overall, healthcare workers and community workers in neonatal care share a common goal of improving care for families – this research allows them a safe space to contribute to potential solutions.

Expert interviews will also benefit the trajectory of this research because the learnings from the interviews will determine how next stage of the research (co-design workshop) will run – a contribution to knowledge and awareness of neonatal care and thus benefiting the wider neonatal community and families affected.

B.11. What are the theoretical frameworks or methodological approaches being used?

This research is underpinned by the Human-centered design (HCD) approach. HCD is a problem-solving design approach that considers a human's needs and perspectives to improve the user experience (Melles et al., 2021).

A framework adapted from the UK Design Council Double Diamond Framework guides the researcher through stages of the research process; discover, reframe, generate, develop, and deliver. Similar frameworks have been developed for other co-design projects (Bird et al., 2021). (Please see Appendix 1: Methodological Frameworks)

A family-integrative and interdisciplinary approach is applicable and essential in this space for transformative change. The researcher will engage with experts working in the neonatal context and parents with lived experience of in-hospital neonatal care. A participatory co-design approach will be used in this research to gain insights into specific needs and experiences, enabling the development of more tailored and effective design interventions.

Engaging with stakeholders through collaborative methods such as interviewing and co-design workshops will ensure I discover the true needs within the context of neonatal care as opposed to designing solutions for this context biased off my own assumptions. This will be an iterative design process informed by the findings from the interviews and the co-design workshop.

B.12. How will data be gathered and processed?

Please provide your data collection protocols, describing step by step how you will be interacting with participants when collecting data.

Expert interviews:

Participants will be experts in the neonatal context that are knowledgeable about the process from prenatal, birth, admission to SCBU, discharge and post-discharge care (e.g., discharge co-ordinators, paediatricians, neonatal nurses, midwives, lactation consultants, family support workers, etc.).
Participants will have the option to be interviewed in person or online (via Zoom). The interview will be audio recorded with the participant's consent. Data from individual interviews will be synthesised and themes constructed using thematic analysis (Haste et al., 2023).

The expert interviews will be conducted in an informal, semi-structured manner at mutually agreed location and time.

(Please see Appendix 11: Interview protocol)

Co-design workshop:

The researcher will distribute advertisement flyers to independent charity organisations, The Little Miracles Trust, and Bellyful NZ, with participants already involved in their own volition. The distributed advertisement flyers would contain the researcher's emails, which the participants would use to express

their interest. The researchers will email the potential participants an invitation to the workshop with the PIS and a consent form. The participants will be allotted at least two weeks to deliberate.
The information in the participant information sheet and consent form will be reiterated verbally at the start of the co-design workshop, and participants will have the opportunity to ask for clarifications prior to signing the consent form. Participants will be reminded that they can decide to what degree they wish to contribute to the workshop and withdraw entirely from the co-design workshop at any point, should they wish. They will sign a consent form before the start of the workshop, formally giving their consent to participate.

The study's eligible participants will consist of parents with a child who was admitted to SCBU and must be at least one year old and was discharged in 2022 or earlier. These parents should have been in a New Zealand SCBU (Special Care Baby Unit) within the period ranging from 2012 to 2022. The parents must be 18+ and live in the Auckland region. Participants must be confident in reading and speaking English.

The primary researcher will co-facilitate the workshop with the researcher partner (Sherin Shaji) – applying for ethics approval separately). The workshop aims to meet with parents who have had a newborn hospitalised at an SBCU to discuss their retrospective insights on their experience and needs around neonatal care education and information through creative methods.
Each researcher will facilitate a section of the workshop, and together, as a group, we will discuss our interpreted findings and wrap up with an afternoon tea. The comprehensive workshop is scheduled to last approximately 3 hours.

Part A: of the workshop will focus on the neonatal physical environment and how improving it could enhance the parents' experience, from being in the family room to going home. Run by Sherin Shaji – please see separate EA1

Part B: of the workshop will consist of a discussing what educational tools participants had to support them during their neonatal journey both in hospital and post-discharge. We will also what values are important to participants when accessing healthcare of their family through a card sorting game (Please see Appendix 7: Shared Values Activity Cards). Run by the primary researcher, Kayla Newman

(Please see Appendix 6: Co-design workshop plan)

B.13. How will the data be analysed?

Please provide the statistical (for quantitative research) or methodological (for qualitative or other research) justification for analysing the data in this way.

Co-design workshop:

The workshop facilitators (Kayla Newman and Sherin Shaji) will transcribe and anonymise any notes from the workshop and take photos of any outputs created. Towards the end of the workshop, the researchers will summarise key insights collectively with participants. Formulating and discussing these insights together will ensure we have correctly interpreted the messages and themes the participants have communicated with us. This collaborative process will ensure our findings are accurate, so that meaningful design outputs can be generated.

The thematic analysis will enable the researcher to construct themes related to parents' retrospective insights and opinions on neonatal care. Any outputs that are identifiable to the participants will be anonymised and digitised. Data will be synthesised, and themes constructed using thematic analysis (Haste et al., 2023). This analysis will help the primary researcher identify a design opportunity. Thematic analysis will aid in categorising themes related to critical parent education that can celebrate and support parents on this challenging journey.

Interviews:

The primary researcher (Kayla Newman) will write up a summary for each interview/participant. This summary will include insights, patterns, notes of discussion points, key quotes etc. Data from individual interviews will be synthesised and themes constructed using thematic analysis (Haste et al., 2023). These themes will be then used as key areas to consider and incorporate in the design of a comprehensive educational resource.

The aim of this research is to discover what is most important to parents (end-users) and experts in neonatal care, making thematic analysis an appropriate strategy for analysing qualitative data from expert interviews and the co-design workshop. The structure of the thematic analysis will be based on Clarke and Braun's (2013) 6-step process:

Step 1: Familiarise the data.

1.1 Transcribe the data from interviews into a word document.

1.2 First pass reading: for understanding and accuracy.

1.3 Second pass reading: write memos and note insights. Keep these notes separate from the data.

Step 2: Generate initial codes, open coding approach.

2.1 assign a code to each line or statement the participant says.

Step 3: Combining codes into themes.

3.1 Sort through codes to categorise them. (For example, breastfeeding, tube feeding)

3.2 Provide rationale to identify the codes.

Step 4: Sort the categories into themes and review.

Step 5: Define and name the themes – reflect if these themes answer my research question. This will determine the significance of the data in relation to the context of the research.

Step 6: Write up a report for each participant/method and include this in discussion of findings chapter.

B.14. Has any peer review taken place? ☒ Yes ☐ No

If your answer is 'Yes', please specify and provide evidence e.g. a letter of confirmation.

☐ *AUT Competitive Grant* ☐ *External Competitive Research Grant*
☒ *PGR1* ☐ *PGR2* ☐ *PGR9* ☐ *Independent Peer Review**

Optional exemplars for evidencing peer review are available from the Ministry of Health (HDEC) website (http://ethics.health.govt.nz/) or from the Forms section of the Research Ethics website (http://aut.ac.nz/researchethics)

C. *General Project Details*

C.1. Likely Research Output

C.1.1. What are the likely outputs of this research?

☒ *a thesis* ☐ *a dissertation* ☐ *a research paper* ☒ *a journal article*
☐ *a book* ☐ *conference paper* ☐ *a documentary* ☒ *an exhibition*
☐ *a film* ☐ *some other artwork* ☒ *other academic publications or presentations*
☒ *Some other output, please specify*

A prototype of a product, service or artwork that serves as an educational resource to support parents navigating neonatal care.

C.2. Research Location and Duration

C.2.1. In which countries and cities/localities will the data collection occur?

Auckland, New Zealand

C.2.1.1 Exactly where will any face to face data collection occur?

If face to face data collection will occur in participants' homes or similarly private spaces, then a Researcher Safety Protocol needs to be provided with this application.

Expert interviews will be conducted in a mutually agreed location. This may be online if preferred by the interviewee (via Zoom).

The exact location of the **co-design workshop** has not yet been booked. We will seek a venue that is not connected to any healthcare spaces or the university. We will book a community centre in the Auckland area, for example, Nurturing Families charity community hall in Henderson Valley.

C.2.2. In which countries and cities/localities will the data analysis occur?

Auckland, New Zealand

C.2.3. When is the data collection scheduled to commence?

Expert interviews: Tuesday 24th October to Friday 24th November (5 weeks, approximately average 1 interview per week)

Co-design workshop: November 2023

C.3. Research Participants

C.3.1. Who are the participants?

Parents/caregivers with infants who graduated from a New Zealand SCBU (Special Care Baby Unit) within the period ranging from 2012 to 2022 and turning at least one this year would be invited as participants. The parent should be 18+ years old and confident in speaking English.

Expert Interviews: Participants will include experts in the neonatal community, such as neonatal nurses, lactation consultants, paediatricians, family support workers and midwives.

C.3.2. How many participants are being recruited for this research?

If you are unsure, please provide an indicative range.

Co-design workshop: 4-10 participants – this number will allow for the participants to comfortably exchange their experiences of the physical space in a relatively small group. Participants will be organised into smaller break-out groups to discuss various topics before presenting to the larger group, thus fostering a relaxed environment for communication.

Expert Interviews: 3-5 participants from different neonatal occupations.

C.3.3. What criteria will be used to choose who to invite as participants?

Co-design workshop participant criteria:

Parents with infants who graduated from a New Zealand SCBU (Special Care Baby Unit) within the period ranging from 2012 to 2022 and turning at least one this year would be invited as participants. The parent should be 18+ years old and confident in speaking English.
With this invitation, the researcher subtly expressed a deliberate intention to include the baby turning at least one this year. The researcher is looking for participants who have infants who received care in a neonatal healthcare unit and who would have had some time post-discharge to have gained some experience looking after a small child, but also without having experienced the unfortunate circumstance of infant mortality.

Expert interviews participant criteria:

Experts in professional neonatal community, ideally who work or have worked in a SCBU in Auckland, New Zealand. Experts also include occupations that support families navigating neonatal care, not necessarily a healthcare worker. Confident speaking English.

C.3.3.1 How will you select participants from those recruited if more people than you need for the study agree to participate?

Expert Interviews: Prioritise invitations to have a range of **interviewees** from each category:

- Neonatal Nurses specialising in SCBU.
- Family Liaison Nurse
- Discharge facilitator
- Nursing Educators
- Lactation Consultants/ Nurse Specialist – Lactation
- Family support workers
- Participants who currently work at a SCBU in Auckland.

Co-design workshop:
Participants will be selected on a 'first come, first serve' basis if they meet our inclusion criteria (see section C.3.3). Participants will express their interest by contacting us via the researcher's email addresses as displayed on the advertisement flyer and PIS. The first three eligible participants that contact us will be invited to the workshop, to a maximum of ten.

C.3.4. Will any people be excluded from participating in the study?

☒ Yes ☐ No

Exclusion criteria apply only to potential participants who meet the inclusion criteria. An exclusion criterion is any characteristic that ought to disqualify any potential participant from recruitment into the study. Consider exclusion criteria when there are heightened risks due to power differences in the relationship, recent injury, or other characteristics that might place potential participants at unreasonable risk of harms.

If the answer to this question is 'Yes' please answer C.3.4.1 and the following sections, otherwise please answer C.3.5 and continue from there.

C.3.4.1 What criteria will be used to exclude people from the study?

Any participants who struggle to comprehend or express themselves in English. This is stated in the PIS.

For the co-design workshop, any participants whose infants have not been discharged from a New Zealand SCBU between 2012 and 2022 and/or whose infant is not at least one year old. This is stated in the PIS.

C.3.4.2 Why is this exclusion necessary for this study?

Confidence in English speaking and comprehension is essential so participants can fully participate in the interview or workshop and for the researcher to collect data accurately. Participants with experiences before 2012 might have difficulties recollecting their encounters in neonatal care. The health system is also different today than it was ten years ago. Recruiting participants with experiences after 2022 would potentially be intrusive, given the immediacy of their experiences and having to look after a young infant. To protect the emotional well-being of participants, the researcher subtly expressed a deliberate intention to include the baby turning at least one this year. The researcher is looking for participants who have infants who received care in a neonatal healthcare unit and who would have had some time post-discharge to have gained some experience looking after a small child without having experienced the unfortunate circumstance of infant mortality.

C.3.5. Recruitment of participants.

Please describe in detail the recruitment processes that will be used. If you will be recruiting by advertisement or email, please attach a copy to this Application Form

C.3.5.1 How will the initial contact with potential participants occur?

The researcher will distribute advertisement flyers to independent charity organisations, The Little Miracles Trust and Bellyful NZ, with participants already involved in their own volition. The charity organisations would place the advertisement flyers in newsletters or notice boards.

- The Little Miracles Trust newsletter and public areas/notice boards?
- Bellyful newsletter and social media platforms
- Contacts publicly available on nzno.org.nz (Neonatal Nurses College)
https://www.nzno.org.nz/groups/colleges_sections/colleges/neonatal_nurses_college/national_nicu_scbu_units

C.3.5.2 How will the contact details of potential participants be collected and by whom?

The distributed advertisement flyers would contain the researcher's emails, which the participants would use to express their interest.

Only the primary researcher and researcher partner (Sherin Shaji) will have access to these details and correspondence regarding those interested in co-design workshop.

C.3.5.3 How will potential participants be invited to participate?

The distributed advertisement flyers would contain the researcher's emails, which the participants would use to express their interest. The researchers will email the potential participants an invitation to the workshop with the PIS and a consent form. The participants will be allotted at least two weeks to consider the invitation and RSVP.

C.3.5.4 How much time will potential participants have to consider the invitation?

Potential participants will be given at least two weeks to decide whether to accept or decline the invitation.

C.3.5.5 How will potential participants respond to the invitation?

The researcher's email will be on the recruitment advertisement and participant information sheet. Participants will contact the researcher to respond to the invitation by email.

Should any inquiries arise, they are provided with an email address for contact.

C.3.5.6 How will potential participants give consent?

Co-design workshop:

Each participant of the co-design workshop will need to be provided with the PIS and a consent form with the invitation. Researchers will go over the participant information sheet and consent form verbally at the start of the workshop. The participants will have the opportunity to seek clarification. Participants will be reminded that they can decide to what degree they wish to contribute to the workshop and withdraw entirely from the co-design workshop at any point, should they wish. They will sign a consent form before the start of the workshop, formally giving their consent to participate.

Expert interviews:

The participant will be emailed a PIS and consent form prior to scheduling an interview time. The participant will need to sign a hard copy if in-person or a digital copy if over Zoom before the interview can commence. The researcher will verbally go over consent form before recording begins.

C.3.5.7 How and when will the inclusion criteria and exclusion criteria given in sections C.3.2 and C.3.3 be applied?

Individuals who do not meet the inclusion criteria of the co-design workshop will not be invited to participate in the study. This will be clearly stated in the PIS and reiterated in an email to those who express interest.

C.3.5.8 Will there be any follow up invitations for potential participants?

Potential participants will be given up to two weeks before receiving a follow-up email. After this, there will be no further contact if they do not respond.

D. *Partnership, Participation and Protection*

D.1. How does the design and practice of this research implement the principle of Partnership in the interaction between the researcher and other participants?

How are the researcher and the participants working together? How will your research design and practice encourage a mutual respect and benefit and participant autonomy and ownership? How will you ensure that participants and researchers will act honourably and with good faith towards each other? Are the outcomes designed to benefit the participants and/or their social or cultural group? How will the information and knowledge provided by the participants be acknowledged?

Participation in the research entails voluntary engagement in all data collect methods. Throughout this research project, importance will be placed on mutual respect and safeguarding participant autonomy. The information outlined in the participant information sheet will clearly outline that all individuals involved in the research will have the autonomy to withdraw at any point without any repercussions from the researcher. Potential participants will always have access to the primary researcher via email, allowing them to seek clarifications, address inquiries, and obtain information about the project.

All participants' opinions, ideas, and perspectives will be regarded as equal, irrespective of their professional, social, or cultural backgrounds. Each participant's input will be respected and valued as an expert reflection of their unique experiences. The primary researcher will communicate this principle to all participants in the consent form and verbally emphasise the significance attributed to their opinions, ideas, and views at the beginning of the co-design workshop and all interviews.

The outcomes of the co-design workshop involvement may not benefit the participants directly, although being able to share experiences of the same setting under similar circumstances may provide comfort and a sense of belonging to some participants in the workshop, as may working together to reimagine neonatal support.

The primary researcher will acknowledge the data provided by the participants in the research findings, especially within the thesis acknowledgement section. Measures will be taken to ensure the utmost confidentiality of the information, thereby safeguarding the participants' identities.

D.2. How does the design and practice of this research implement the principle of Participation in the interaction between the researcher and other participants?

What is the actual role of participants in your research project? Will participants be asked to inform or influence the nature of the research, its aims, or its methodology? Will participants be involved in conducting the research or is their principal involvement one of sharing information or data? Do participants have a formal role as stakeholders e.g. as the funders and/or beneficiaries of the research? What role will participants have in the research outputs (e.g. will they be asked to approve transcripts or drafts)?

The role of participants in the expert interviews is to share their opinions and insights on neonatal care and discuss areas where they believe parents could be supported better, specifically when looking at the educational resources and information available to parents navigating neonatal care.

Participants in the co-design workshop will collaborate closely with the primary researcher, predominantly engaging in open discussions about their experiences, narratives, ideas, and reflections on the neonatal healthcare environment through immersive activities. Importantly, there will be no involvement beyond the workshop session, and no external commitments will be demanded from the participants.

They may benefit by feeling that their thoughts and views are valued in the development of outcomes that may affect them. They will also contribute to generating and approving the summary of key insights from the workshop at the end of the workshop session. The outcomes of the research are intended to benefit participants by allowing them to contribute their views and ideas to the design of interventions intended to improve the experiences of future parents navigating neonatal care. Participation may also allow parents to feel a sense of belonging to a wider community of whānau who have gone through similar experiences with their newborn and may feel like their views are validated and understood within this community.

D.3. How does the design and practice of this research implement the principle of Protection in the interaction between the researcher and other participants?

How are the researcher and the participants protecting each other? How will you actively protect participants from deceit, harm and coercion through the design and practice of your research? How will the privacy of participants and researchers be protected? How will any power imbalances inherent in the relationships between the participants and researchers be managed? How will any cultural or other diversity be respected?

Distribute advertisement flyers to independent charity organisations, The Little Miracles Trust, and Bellyful NZ, with participants already involved in their own volition.
The participants will be given enough time to consider their participation (2 weeks).
The distributed advertisement flyers would contain the researchers' emails, which the participants would use to express their interest. Those participants who contact the primary researcher will be emailed an invitation to the workshop with the PIS and a consent form.
Researchers will go over the PIS verbally at the start of the workshop, and participants will have the opportunity to seek clarification. Participants will be reminded that they can decide to what degree they wish to contribute to the workshop and withdraw entirely from the co-design workshop at any point, should they wish. They will sign a consent form before the start of the workshop, formally giving their consent to participate.

All participants' opinions will be equally valued regardless of their academic, social, or cultural backgrounds. The information gathered from participants will solely be accessible to the primary researcher, research partner, and supervisor and will be kept confidential. Any presentation of data utilised as research outputs will be anonymised. Participants will be reminded that the information discussed during the workshop should not be shared outside this setting.

The icebreaker activity in the co-design workshop will remind participants of this, where they will discuss at their shared values as a group **(see Appendix 6 for the workshop plan and Appendix 7 for a photo of the Shared Values cards).**

The information gathered from participants will be accessible only to the primary researcher, research partner, and supervisors and will be kept confidential and safely stored (see section H9-11 for data storage). Any presentation of data utilised as research outputs will be anonymised._

To respect participants' autonomy and time, I will reassure them that they may take a break, leave the interview/co-design workshop, or withdraw from the study at any time without judgement or consequence. I will allow participants to ask questions before the session begins and at any point during the research session. To maintain integrity and transparency throughout the research, I will share my interpretations with participants to ensure I understand their responses accurately towards the end of the interview/co-design workshop. This will allow participants to add or remove details and provide the most precise and unbiased results.

To protect the privacy of participants, all identifiable information, such as names and workplaces will be removed from the subsequent reports.

The eligibility/ exclusion criteria to participate in this study is also intended to protect the emotional well-being of participants. Likewise, the co-design workshop is structured with focus on needs and experiences related specifically to educational support through neonatal care so as not to evoke any unpleasant memories or trauma associated with having a premature baby.

E. *Social and Cultural Sensitivity (including the obligations of the Treaty of Waitangi)*

E.1. What familiarity does the researcher have with the social and cultural context of the participants?

The primary researcher has completed three papers as part of her postgraduate study: Contextual Review (ARDN808), Ethics in Research (ARDN801), and Design for Health and Wellbeing (DESN806). Through engaging with these papers, the researcher learned about the significance of social and cultural contexts in healthcare design and research. Throughout the research, the primary researcher will be

aware of the challenges that participants may encounter while participating, particularly regarding their social and cultural backgrounds.

Although this research is not explicitly intended to benefit Māori specifically, there is an acknowledgement of the proportionately lower health outcomes of Māori and Pasifika people in New Zealand. The design and findings of this project must consider the inequities in our health system. Topics we anticipate being discussed in the expert interviews will be the accessibility, usability and readability of neonatal care and resources. This intention is reflected in the question prompts (please see Appendix 11: Interview protocol & Questions). We also want to identify any potential barriers to accessing care and information for a patient, in which ethnicity may play a part but is not assumed.

Some Māori tikanga and values the researcher would like to engrain in this research project:

REO: use of basic te reo Māori (Māori language) kupu(words) in korero(conversation) and potential outcomes. To challenge myself, connect deeper with whānau Māori participants, and support New Zealand's bilingual direction. An extension of this knowledge will be learning terminology around Birth Tikanga.

KOHA: In Māori culture if it is common to bring Koha of kai/food, money or gifts when visiting whānau or friends. To show gratitude and respect for participants' time and contribution to research, the researcher will give an informal Koha after the interview – a $20 petrol voucher, thank you card and refreshments for during the workshop and a morning/afternoon tea afterwards.

WHAKAWHANAUTANGA: is a means to establish good relations and strengthen communities. (Bishop, 1995). We will engrain the concept into the research by facilitating a safe and welcoming environment — a casual, semi-structured discussion style. The interview, if in person may be over coffee, in which the researcher will pay for. Participants will be invited to the final Master of Design student exhibition at the end of the year to celebrate a community's collaborative contribution to the work.

E.2. What consultation has occurred?

Research procedures should be appropriate to the participants. Researchers have a responsibility to inform themselves of, and take the steps necessary to respect the values, practices, and beliefs of the cultures and social groups of all participants. This usually requires consultation or discussion with appropriate people or groups to ensure that the language and research approaches being used are relevant and effective. Consultation should begin as early as possible when designing the project and should continue throughout its duration.

All researchers are encouraged to make themselves familiar with Te Ara Tika: Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members which is able to be accessed through the Research Ethics website. Researchers may also find Te Kaahui Maangai a directory of Iwi and Maaori organisations to be helpful. This may be accessed via the Te Puni Kookiri website (http://www.tkm.govt.nz/). As well as these documents, the Health Research Council has published Pacific Health Research Guidelines, and Guidelines on research involving children. (see http://www.hrc.govt.nz). There are also guidelines by various organisations about researching with other populations that researchers will find helpful.

- Three site visits to Waitakere SCBU. Tours given by Dr Maneesh Deva (Neonatal paediatrician) and Lauriane McMurdo (Discharge coordinator at Waitakere Hospital)
- Analysis of Pepi care app (a SCBU early discharge resource) provided by Maneesh Deva.
- Email correspondence with The Little Miracles Trust and Bellyful charity organisations.

E.2.1. With whom has the consultation occurred?

Please provide written evidence that the consultation has occurred.

Please see appendix 1: Evidence of consultation

Maneesh Deva
Clinical Lead Innovation i3, Honorary Lecturer UoA, General Paediatrician WDHB, Intern Supervisor MCNZ
maneesh.deva@waitematadhb.govt.nz

Jacqui Standford
Communications Advisor at Bellyful NZ
jacqui.stanford@bellyful.org.nz

Jadey Drury
Service Deliver Manager, The Little Miracles Trust
jadey@lmt.org.nz

Rachel Friend
CEO of The Little Miracles Trust
jadey@lmt.org.nz

Lauriane McMurdo

Waitakere SCBU
Lauriane.McMurdo@waitematadhb.govt.nz

Michelle Goldfinch
Fundraising Executive at Well Foundation
michelle@wellfoundation.org.nz

Tina Saltmarsh
Charge Nurse Manager NSH SCBU
Tina.Saltmarsh@waitematadhb.govt.nz

Stephen Reay
Director of Good Health Design
stephen.reay@aut.ac.nz

E.2.2. How has this consultation affected the design and practice of this research?

The consultation provided the primary researcher with significant insights into the operational mechanisms of the Special Care Baby Unit (SCBU) at Waitakere Hospital. The on-site visit to the Waitakere Hospital SCBU (Special Care Baby Unit) familiarised the researcher with the facility's physical layout and structure. During the visit, two staff members offered their experiences and perspectives on family-integrated care and the need for research in on the parent experience. Maneesh and Laurianne also shared potential design opportunities they had identified, such as the Pepi care app and refining educational resources for parents in the unit to be easier to understand.

Rachel Friend, The Little Miracles Trust's CEO, has expressed a strong interest on behalf of their organisation to contribute to the research efforts and extend any assistance around supporting recruitment.

Jacqui Stanford, the Communications Advisor of Bellyful NZ, expressed pleasure in sharing the promotional materials on their official social media page and newsletters.

Michelle Goldfinch has given us recommendations to recruit neonatal experts through NZNO and has put us in contact with Charge Nurse Tina Saltmarsh.

Please see appendix 1: Evidence of consultation

E.3. Does this research target Māori participants? ☐ Yes ☒ No

All researchers are encouraged to make themselves familiar with Te Ara Tika: Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members

If your answer is 'No', please go to section E.4 and continue from there. If you answered 'Yes', please answer the next question.

E.3.1. Which iwi or hapu are involved?

E.4. Does this research target participants of particular cultures or social groups? ☐ Yes ☒ No

AUTEC defines the phrase 'specific cultures or social groups' broadly. In section 2.5 of Applying for Ethics Approval: Guidelines and Procedures it uses the examples of Chinese mothers and paraplegics. This is to identify their distinctiveness, the first as a cultural group, the second as a social group. Other examples of cultural groups may be Korean students, Samoan husbands, Cook Islanders etc., while other examples of social groups may be nurse aides, accountants, rugby players, rough sleepers (homeless people who sleep in public places) etc. Please refer to Section 2.5 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures (accessible in the Ethics Knowledge Base online via http://www.aut.ac.nz/about/ethics) and to the relevant Frequently Asked Questions section in the Ethics Knowledge Base.

If your answer is 'No', please go to section E.5 and continue from there. If you answered 'Yes', please answer the next question.

E.4.1. Which cultures or social groups are involved?

E.5. Does this research focus on an area of research that involves Treaty obligations? ☒ Yes ☐ No

All researchers are encouraged to make themselves familiar with Te Ara Tika: Guidelines for Maori Research Ethics: A framework for researchers and ethics committee members.

If your answer is 'No', please go to section E.6 and continue from there. If you answered 'Yes', please answer the next question.

E.5.1. Which treaty obligations are involved?

Although this research is not explicitly intended to benefit Māori specifically, there is an acknowledgement of the proportionately lower health outcomes of Māori and Pasifika people in New Zealand. The design and findings of this project must consider the inequities in our health system. Topics we anticipate being discussed in the expert interviews will be the accessibility, usability and readability of neonatal care and resources. We also want to identify any potential barriers to accessing care and information for a patient, in which ethnicity may play a part but is not assumed.

E.6. Will the findings of this study be of particular interest to specific cultures or social groups? ☐ Yes ☒ No

If the answer is 'Yes' please answer E.6.1 and the following sections, otherwise please answer F.1 and continue from there.

E.6.1. To which iwi, hapū, culture or social groups will the findings be of interest?

E.6.2. How will the findings be made available to these groups?

F. *Respect for the Vulnerability of Some Participants*

"Vulnerable persons are those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests. Individuals whose willingness to volunteer in a research study may be unduly influenced by the expectation, whether justified or not, of benefits associated with participation, or of a retaliatory response from senior members of a hierarchy in case of refusal to participate may also be considered vulnerable." (Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants, World Health Organisation).

F.1. Will your research involve any of the following groups of participants? ☐ Yes ☒ No

If your research involves any of these groups of participants, please clearly indicate which ones and then answer F.2 and the following section, otherwise please answer G.1 and continue from there.

☐ people unable to give informed consent? ☐ your (or your supervisor's) own students?
☐ preschool children? ☐ children aged between five and sixteen years?
☐ legal minors aged between sixteen and twenty years?
☐ People lacking the mental capacity for consent?
☐ people in a dependent situation (e.g. people with a disability, or residents of a hospital, nursing home or prison or patients highly dependent on medical care)?
☐ people who are vulnerable for some other reason (e.g. the elderly, persons who have suffered abuse, persons who are not competent in English, new immigrants)? – please specify

F.2. How is respect for the vulnerability of these participants reflected in the design and practice of your research?

F.3. What consultation has occurred to ensure that this will be effective?

Please provide evidence of the consultation that has occurred.

G. *Informed and Voluntary Consent*

G.1. How will information about the project be given to potential participants?

A copy of all information that will be given to prospective participants is to be attached to this Application Form. If written information is to be provided to participants, you are advised to use the Information Sheet exemplar. The language in which the information is provided is to be appropriate to the potential participants and translations need to be provided when necessary.

The researcher will distribute advertisement flyers to independent charity organisations, The Little Miracles Trust, and Bellyful NZ, with participants already involved in their own volition. The distributed advertisement flyers would contain the researcher's emails, which the participants would use to express their interest, and a QR code to PIS. The researchers will email the potential participants an invitation to the workshop with the PIS and a consent form. The participants will be allotted at least two weeks to consider participating.

PIS will be sent to participants for both interviews and co-design workshop. PIS may be re-sent to participants via email upon request. All correspondence between participants and researchers will be via email (AUT student account).

The information in the participant information sheet and consent form will be reiterated verbally at the start of the co-design workshop/interviews, and participants will have the opportunity to ask for clarifications before signing the consent form. Participants will be reminded that they can decide to what degree they wish to contribute to the workshop and withdraw entirely from the co-design workshop or interview at any point, should they wish. They will sign a consent form before commencing, formally giving their consent to participate.

G.2. How will the consent of participants be obtained and evidenced?

AUTEC requires consent to be obtained and usually evidenced in writing. A copy of the Consent Form which will be used is to be attached to this application. If this will not be the case, please provide a justification for the alternative approach and details of the alternative consent process. Please note that consent must be obtained from any participant aged 16 years or older. Participants under 16 years of age are unable to give consent, which needs to be given by their parent or legal guardian. AUTEC requires that participants under the age of 16 assent to their participation. When the nature of the research requires it, AUTEC may also require that consent be sought from parents or legal guardians for participants aged between 16 and twenty years. For further information please refer to AUTEC's Applying for Ethics Approval: Guidelines and Procedures.

Participants will be emailed the participant information sheet and the consent form when they contact the researcher to express their interest in the research.

For the co-design workshop, at the start of the workshop, the researcher will go over the participant information sheet verbally, and participants will have the opportunity to ask questions. They will then be provided with a physical copy of the consent form to sign.

Please see appendix 5: Consent form for co-design workshop participants and appendix 4: PIS for co-design workshop

For the in-person interviews, participants will sign a consent form before the interview starts. For the online (Zoom interviews), a digital copy may be signed and sent to the researcher. The researcher will verbally go over the consent for and the participants will have the opportunity to ask questions. The researcher will verbally confirm consent for audio recording for commencing – given they have ticked 'Yes" to audio recording on the consent form. The participant will be reminded that they may withdraw consent to audio recording at any time and ask for the recording to be paused or stopped at any time.

Please see appendix 10: Consent form for interview participants, appendix 11: Interview protocol and, appendix 9: PIS for expert interviews

G.3. Will any of the participants have difficulty giving informed consent on their own behalf? ☐ Yes ☒ No

Please consider physical condition, cognitive status, age, language, legal status, or other barriers.

If the answer is 'Yes' please answer G.3.1 and the following sections, otherwise please answer G.4 and continue from there.

G.3.1. If participants are not competent to give fully informed consent, who will consent on their behalf?

Researchers are advised that the circumstances in which consent is legally able to be given by a person on behalf of another are very constrained. Generally speaking, only parents or legal guardians may give consent on behalf of a legal minor and only a person with an enduring power of attorney may give consent on behalf of an adult who lacks capacity.

G.3.2. How will these participants be asked to provide assent to participation?

Whenever consent by another person is possible and legally acceptable, it is still necessary to take the wishes of the participant into account, taking into consideration any limitations they may have in understanding or communicating them.

G.4. Is there a need for translation or interpreting? ☐ Yes ☒ No

If your answer is 'Yes', please provide copies of any translations with this application and any Confidentiality Agreement required for translators or interpreters.

H. *Respect for Rights of Privacy and Confidentiality*

H.1. How will the researchers respect the privacy and confidentiality of participants?

Please note that anonymity and confidentiality are different. For AUTEC's purposes, 'Anonymity' means that the researcher is unable to identify who the participant is in any given case. If the participants will be anonymous, please state how, otherwise, if the researcher will know who the participants are, please describe how the participants' privacy issues and the confidentiality of their information will be managed.

Information shared and the identity of participants will remain confidential in the research. While the participant will not be anonymous to the researcher, research partner or supervisors, the researcher can provide confidentiality by ensuring that any public information is de-identified.

Participants will be informed that they can withdraw from the research at any time. If they choose to withdraw from the research, they can choose to have their data removed and destroyed. However, once the research has been published, there is no guarantee that the data can be removed.

It is inevitable for the researcher to know who the participants are. The researcher will keep participants' information confidential and will ensure they cannot be identified through any of the data and reported outcomes. Should a participant choose to disclose any personal information that may compromise their confidentiality in anything they create in the co-design workshop, the researcher will omit these during analysis and any outcomes produced.

H.2. Will any participants be identifiable in the research outputs or findings? ☐ Yes ☒ No

If your answer is "Yes", please answer H.2.1, otherwise please answer H.3

H.2.1. What level of confidentiality is able to be offered to participants and how will this be managed?

If the research involves small or distinctive groups of participants or procedures such as interviews conducted at the worksite, or focus groups with peers, researchers should identify the level of participant confidentiality that can be offered in the Information Sheet. If participants or groups will be identified, please state why this is appropriate, how this will happen, and how the participants will give consent.

H.3. What information on the participants will be obtained from third parties?

This includes use of third parties, such as employers or professional organisations, in recruitment.

No information about participants is gathered from third parties that is not already publicly available.

H.4. How will potential participants' contact details be obtained for the purposes of recruitment?

Contact details of participants will be obtained when the participant contacts the researcher to participate in the research. The researchers will email the potential participants an invitation to the workshop with the PIS and a consent form. The participants will be allotted up to least two weeks to decide on whether they wish to participate.

H.5. What identifiable information on the participants will be given to third parties?

Identifiable information about participants will not be given to third parties.

H.6. Who will have access to the data during the data collection and analysis stages?

Expert Interviews data: The applicant and the primary researcher.

Co-design workshop data: The primary researcher, research partner (Sherin Shaji) and supervisors.

H.7. Who will have access to the data after the findings have been produced?

Expert Interviews data: The applicant and the primary researcher.

Co-design workshop data: The primary researcher, research partner (Sherin Shaji) and supervisors.

H.8. Are there any plans for the future use of the data beyond those already described? ☐ Yes ☒ No

The applicant's attention is drawn to the requirements of the Privacy Act 1993 (see Appendix I of AUTEC's Applying for Ethics Approval: Guidelines and Procedures). Information may only be used for the purpose for which it was collected so if there are plans for the future use of the data, then this needs to be explained in the Information Sheets for participants. If you have answered 'Yes' to this question, please answer section H.8.1.1 and continue from there. If you answered 'No' to this question, please go to section H.9 and proceed from there.

H.8.1.1 If data will be stored in a database, who will have access to that information, how will it be used, for what will it be used, and how have participants consented to this?

H.8.1.2 Will any contact details be stored for future use and if so, who will have access to them, how will they be used, for what will they be used, and how have participants consented to this?

H.9. Where will the data be stored once the analysis is complete?

Please provide the exact storage location. AUTEC normally requires that the data be stored securely on AUT premises in a location separate from the consent forms. Electronic data should be downloaded to an external storage device (e.g. an external hard drive, a memory stick etc.) and securely stored. If you are proposing an alternative arrangement, please explain why.

Data will be stored separate from consent forms in a lockable cabinet in the Good Health Design (the applicant's) office at the AUT City Campus. Digital data will be stored on an external hard drive in a lockable cabinet in the Good Health Design office.

H.9.1. For how long will the data be stored after completion of analysis?

AUTEC normally requires that the data be stored securely for a minimum of six years, or ten years for health data. If you are proposing an alternative arrangement, please explain why.

Digital data will be stored on an external hard drive for six years.

H.9.2. How will the data be destroyed?

If the data will not be destroyed, please explain why, identify how it will be safely maintained, and provide appropriate informed consent protocols.

Digitally stored data will be permanently deleted, and any physical data will be shredded and disposed of.

H.10. Who will have access to the Consent Forms?

Expert interviews consent forms: The applicant and the primary researcher.
Co-design workshop consent forms: The applicant, the primary researcher and researcher partner.

H.11. Where will the completed Consent Forms be stored?

Please provide the exact storage location. AUTEC normally requires that the Consent Forms be stored securely on AUT premises in a location separate from the data. If you are proposing an alternative arrangement, please explain why.

The completed consent forms will be stored in a lockable cabinet in the Good Health Design office at the AUT City Campus, in a separate cabinet from the data.

H.11.1. For how long will the completed Consent Forms be stored?

AUTEC normally requires that the Consent Forms be stored securely for a minimum of six years, or ten years in the case of research involving health data. If you are proposing an alternative arrangement, please explain why.

The consent forms will be stored for a minimum of six years.

H.11.2. How will the Consent Forms be destroyed?

If the Consent Forms will not be destroyed, please explain why.

Digitally stored data will be permanently deleted, and any physical data will be shredded and disposed of.

H.12. Does your research involve the collection of personally identifiable and sensitive data? ☐ Yes ☒ No

Sensitive data can be used to identify an individual, object or location and has a risk of discrimination, harm or unwanted attention. Sensitive data potentially poses a substantial threat to those who are or who have been involved in it, especially if it is shared inappropriately, or if it falls into the wrong hands. If you have answered 'Yes' please identify what data is being collected and how it is sensitive and provide a Data Safety Management Protocol (see the Forms section of the Research Ethics website for a guide to drafting one). If the answer is 'No', please answer H.13 and continue from there.

H.13. Does your project involve the use of previously collected information or biological samples for which there was no explicit consent for this research? ☐ Yes ☒ No

If the answer is 'Yes' please answer H.13.1 and the following sections, otherwise please answer H.14 and continue from there.

H.13.1. What previously collected data will be involved?

H.13.2. Who collected the data originally?

H.13.2.1 Why was the information originally collected?

H.13.2.2 For what purposes was consent originally given when the information was collected?

H.13.3. How will the data be accessed?

H.14. Does your research involve the collection of information about organisational practices? ☐ Yes ☒ No

AUTEC applies a broad definition to the term 'organisations'. It could include for example, businesses, hospitals or clinics, schools, or sports clubs and teams if the answer is 'Yes' please answer H.14.1, otherwise please answer I.1 and continue from there.

H.14.1. How will the authorisation to access the organisation or its staff for research purposes be obtained?

H.14.2. Could disclosure of this information potentially disadvantage the organisation or the participants? ☐ Yes ☒ No

If your answer is 'Yes", please answer H.14.2.1, otherwise please answer H.14.3

H.14.2.1 How will the risks associated with potential disadvantages be managed?

H.14.3. Will the participants or anyone else in the organisation be identified in this information? ☐ Yes ☒ No

If your answer is "Yes", please answer H.14.3.1, otherwise please answer I.1 and continue from there.

H.14.3.1 How will the potential risks involved be managed?

If the research involves procedures such as interviews conducted at the worksite, or focus groups with peers, researchers should identify the level of participant confidentiality that can be offered in the Information Sheet.

I. *Minimisation of risk*

I.1. Risks to Participants

Please consider the possibility of moral, physical, psychological or emotional risks to participants, including issues of confidentiality and privacy, from the perspective of the participants, and not only from the perspective of someone familiar with the subject matter and research practices involved. Please clearly state what is likely to be an issue, how probable it is, and how this will be minimised or mitigated (e.g. participants do not need to answer a question that they find embarrassing, or they may terminate an interview, or there may be a qualified counsellor present in the interview, or the findings will be reported in a way that ensures that participants cannot be individually identified, etc.) Possible risks and their mitigation should be fully described in the Information Sheets for participants.

I.1.1. How much time will participants be required to give to the project?

Interviews will be scheduled for approximately 30-45 minutes. Time may vary due to the informal, semi-structured nature of the interviews. Interviewees will not be obligated to stay for the duration of the session (consideration of the high-demand schedules of healthcare workers).

The co-design workshop is scheduled to last for an approximate duration of 3 hours. Participants/families will be welcomed to mix and mingle post-workshop.

I.1.2. What level of discomfort or embarrassment may participants be likely to experience?

Expert Interviews:

Although we foresee there to be minimal risk, we will remind participants that they may excuse themselves at any time or choose not to respond to some or any questions. We will not ask questions about specific details of past patients that the interviewee has cared for.

Co-design workshop:

Although we foresee there to be minimal risk, we will remind participants that they may excuse themselves at any time or choose not to respond to some or any questions.

We understand that revisiting memories around the birth of one's baby and time in hospital may be triggering or emotional. Therefore, the workshop will include a series of creative activities designed to help participants voice their opinions around resources for neonatal care in a non-intrusive way. This allows parents to share their opinion about neonatal care scenarios in general, without having to disclose the details of their personal story. We will also extend invitations to the co-design workshop to partners or a support person if the participant wishes to bring someone along, who will participate and be there to listen and support – this approach recognises that it takes a village to raise a child and values the family unit. This will minimise any emotional discomfort. All in attendance will be required to read PIS and sign a consent form to be in attendance.

I.1.3. In what ways might participants be at risk in this research?

We foresee there to be minimal risk to a neonatal expert participating in an interview. Anonymising the data in the outputs of the research will protect the participant from any identifiable information that may relate to their specific workplace.

The co-design workshop will be facilitated in a welcoming, casual, and friendly manner. Parents will have been informed via the PIS that they may bring small children with them to the session if they like, as well as a support person. The support person will have to sign a consent form also.

I.1.4. In what ways are the participants likely to experience risk or discomfort as a result of cultural, employment, financial or similar pressures?

I.1.5. Will your project involve processes that are potentially disadvantageous to a person or group, such as the collection of information, images etc. which may expose that person/group to discrimination, criticism, or loss of privacy? ☐ Yes ☒ No

If your answer is 'Yes', please detail how these risks will be managed and how participants will be informed about them.

I.1.6. Will your research involve collection of information about illegal behaviour(s) which could place the participants at current or future risk of criminal or civil liability or be damaging to their financial standing, employability, professional or personal relationships? ☐ Yes ☒ No

If your answer is 'Yes', please detail how these risks will be managed and how participants will be informed about them.

I.1.7. If the participants are likely to experience any significant discomfort, embarrassment, incapacity, or psychological disturbance, please state what consideration you have given to the provision of counselling or post-interview support, at no cost to the participants, should it be required.

Adult research participants in Auckland are able to utilise counselling support from the AUT Counselling Team, otherwise you may have to consider local providers for participants who are located notionwide, or in some particular geographical area or who are children. You may discuss the potential for participant psychological impact or harm with the Head of AUT Counselling, if you require. Please check the relevant Frequently Asked Question on the research ethics website as well and ensure the appropriate wording in included in the Information Sheet when counselling opportunities need to be offered.

I.1.8. Will any use of human remains, tissue or body fluids which does not require submission to a Health and Disability Ethics Committee occur in the research? ☐ Yes ☒ No

e.g. finger pricks, urine samples, etc. (please refer to section 13 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures). If your answer is yes, please provide full details of all arrangements, including details of agreements for treatment, how participants will be able to request return of their samples in accordance with right 7 (9) of the Code of Health and Disability Services Consumers' Rights, etc.

I.1.9. Will this research involve potentially hazardous substances? ☐ Yes ☒ No

e.g. radioactive material, biological substances (please refer to section 15 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures and the Hazardous Substances and New Organisms Act 1996).

If the answer is 'Yes', please provide full details, including hazardous substance management plan.

I.2. Risks to Researchers

If this project will involve interviewing participants in private dwellings, undertaking research in unfamiliar cultural contexts either in New Zealand or overseas, doing research in a place to which a travel warning applies, or going into similarly vulnerable situations, then a Researcher Safety protocol should be designed and appended to this application. This should identify simple and effective processes for keeping someone informed of the researcher's whereabouts and provide for appropriate levels of assistance. A guide to drafting one is provided in the forms section of the Research Ethics website.

I.2.1. Are the researchers likely to be at risk? ☐ Yes ☒ No

If the answer is 'Yes' please answer I.2.1.1 and then continue, otherwise please answer I.3 and continue from there.

I.2.1.1 In what ways might the researchers be at risk and how will this be managed?

I.3. Risks to AUT

I.3.1. Is AUT or its reputation likely to be at risk because of this research? ☐ Yes ☒ No

If the answer is 'Yes' please answer I.3.1.1 and then continue, otherwise please answer I.3.2 and continue from there.

I.3.1.1 In what ways might AUT be at risk in this research?

Please identify how and detail the processes that will be put in place to minimise any harm.

I.3.2. Are AUT staff and/or students likely to encounter physical hazards during this project? ☐ Yes ☒ No

If yes, please provide a hazard management protocol identifying how harm from these hazards will be eliminated or minimised.

J. *Truthfulness and limitation of deception*

J.1. How will feedback on or a summary of the research findings be disseminated to participants (individuals or groups)?

It is normally courteous to provide participants with a one or two page summary of the findings of the research. Please ensure that this information is included in the Information Sheet.

The participants will have an option to state in the consent form whether they wish for a summary of the research findings to be emailed to them to an email address of their choice.

J.2. Does your research include any deception of the participants, such as non-disclosure of aims or use of control groups, concealment, or covert observations? ☐ Yes ☒ No

Deception of participants in research may involve deception, concealment or covert observation. Deception of participants conflicts with the principle of informed consent, but in some areas of research it may sometimes be justified to withhold information about the purposes and procedures of the research. Researchers must make clear the precise nature and extent of any deception and why it is thought necessary. Emphasis on the need for consent does not mean that covert research can never be approved. Any departure from the standard of properly informed consent must be acceptable when measured against possible benefit to the participants and the importance of the knowledge to be gained as a result of the project or teaching session. This must be addressed in all applications. Please refer to Section 2.4 of AUTEC's Applying for Ethics Approval: Guidelines and Procedures when considering this question.

If the answer is 'Yes' please answer J.2.1 and the following sections, otherwise please answer J.3 and continue from there.

J.2.1. Is deception involved?

J.2.2. Why is this deception necessary?

J.2.3. How will disclosure and informed consent be managed?

J.3. Will this research involve use of a control group? ☐ Yes ☒ No

If the answer is 'Yes' please answer J.3.1 and the following sections, otherwise please answer K.1 and continue from there.

J.3.1. How will the Control Group be managed?

J.3.2. What percentage of participants will be involved in the control group?

J.3.3. What information about the use of a control group will be given to the participants and when?

K. *Avoidance of Conflict of Interest*

Researchers have a responsibility to ensure that any conflict between their responsibilities as a researcher and other duties or responsibilities they have towards participants or others is adequately managed. For example, academic staff members who propose to involve their students as participants in research need to ensure that no conflict arises between their roles as teacher and researcher, particularly in view of the dependent relationship between student and teacher, and of the need to preserve integrity in assessment processes. Likewise researchers have a responsibility to ensure that any conflict of interest between participants is adequately managed for example, managers participating in the same research as their staff.

K.1. What conflicts of interest are likely to arise as a consequence of the researchers' professional, social, financial, or cultural relationships?

No conflicts of interest exist or are anticipated in the future.

K.2. What possibly coercive influences or power imbalances are there in the professional, social, financial, or cultural relationships between the researchers and the participants or between participants (e.g. dependent relationships such as teacher/student; parent/child; employer/employee; pastor/congregation etc.)?

There are no known power imbalances between the researchers and any potential participants. Experts and SCBU graduate parent participants will not cross paths in any research events. For example, there will be no doctors or neonatal experts present at the co-design workshop with parents of SCBU children.

Interviewees will be interviewed individually and outside of their work hours.

Nonetheless, the researcher is committed to minimising this imbalance by fostering a collaborative co-design environment where all participants are valued equally as experts in their own experience contributing to design solutions that will benefit future whānau undergoing neonatal care.

K.3. How will these conflicts of interest, coercive influences or power imbalances be managed through the research's design and practice and how will any adverse effects that may arise from them be mitigated?

Interviewees (neonatal care experts) will be interviewed individually and outside of their work hours. Data collection involving parent participants will be conducted separate to the data collection involving experts.

The researcher will reduce potential power imbalances by using simple terminology when explaining activities during the co-design workshop. The researcher will refrain from using specialised design terminology, especially when non-designers need to clarify or readily understand activities. It will be reiterated that participants' contribution is invaluable as end-users of healthcare spaces with unique experiences and circumstances.
The researcher's role in the co-design workshop is that of a facilitator rather than an interviewer, guiding participants through open discussions, supported by a range of simple hands-on activities.

K.4. Does your project involve payments or other financial inducements (including koha, reasonable contribution towards travel expenses or time, or entry into a modest prize draw) to participants? ☒ Yes ☐ No

If the answer is 'Yes' please answer K.4.1 and the following sections, otherwise please answer K.5 and continue from there.

K.4.1. What form will the payment, inducement, or koha take?

Koha encompasses the provision of refreshments during the co-design workshop, alongside expressing gratitude through a gift voucher to cover the cost of transport to/from the workshop.

K.4.2. Of what value will any payment, gift or koha be?

The participants will be thanked for their participation by providing a $20 gift voucher to cover transport costs.

K.4.3. Will potential participants be informed about any payment, gift or koha as part of the recruitment process, and if so, why and how?

Participants will be informed via the PIS that a light refreshments will be provided as part of the co-design workshop. They will be presented a gift voucher at the end of the workshop as a token of appreciation for their participation and to offset travel costs.

K.5. Have any applications for financial support for this project been (or will be) made to a source external to AUT? ☐ Yes ☒ No

If the answer is 'Yes' please answer K.5.1 and the following sections, otherwise please answer K.6 and continue from there.

K.5.1. What financial support for this project is being provided (or will be provided) by a source external to AUT?

K.5.2. Who is the external funder?

K.5.3. What is the amount of financial support involved?

K.5.4. How is/are the funder/s involved in the design and management of the research?

K.6. Have any applications been (or will be) submitted to an AUT Faculty Research Grants Committee or other AUT funding entity? ☒ Yes ☐ No

If the answer is 'Yes' please answer K.6.1 and the following sections, otherwise please answer K.7 and continue from there.

K.6.1. What financial support for this project is being provided (or will be provided) by an AUT Faculty Research Grants Committee or other AUT funding entity?

Master's Research Material Grant

K.6.2. What is the amount of financial support involved?

$500

K.6.3. How is/are the funder/s involved in the design and management of the research?

Breakdown of costs was provided.

K.7. Is funding already available, or is it awaiting decision?

Research will be self-funded, with support from Material research grant (available).

K.8. Do the applicant or the researchers, investigators or research organisations mentioned in Part B of this application have any financial interests in the outcome of this project? ☐ Yes ☒ No

If the response is 'Yes', please provide full details about the financial interests and how any conflicts of interest are being managed, otherwise, please respond to section K.9 and continue from there.

K.9. Are the participants expected to pay in any way for any services associated with this research? ☐ Yes ☒ No

If the response is 'Yes', please provide full details about the charges and describe how any benefits will balance the burdens involved as well as how any conflicts of interest are being managed. Otherwise please respond to section L.1 and continue from there.

L. *Respect for Property*

Researchers must ensure that processes do not violate or infringe legal or culturally determined property rights. These may include factors such as land and goods, works of art and craft, spiritual treasures and information.

L.1. Will this research impact upon property owned by someone other than the researcher? ☐ Yes ☒ No

If the answer is 'Yes' please answer L.1.1 and the following sections, otherwise please answer L.2 and continue from there.

L.1.1. How will this be managed?

L.2. How do contexts to which copyright or Intellectual Property apply (e.g. research instruments, social media, virtual worlds etc.) affect this research and how will this be managed?

Particular attention should be paid to the legal and ethical dimensions of intellectual property. Care must be taken to acknowledge and reference the ideas of all contributors and others and to obtain any necessary permissions to use the intellectual property of others. Teachers and researchers are referred to AUT's Intellectual Property Policy for further guidance.

The researcher will own any intellectual property generated through the research following the Intellectual Property (IP) policy of the Auckland University of Technology (AUT).

M. *References*

Please include any references relating to your responses in this application in the standard format used in your discipline.

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Appendix H.2

Amendment to Ethics Application for online interviews

Please do not staple your report

AUT
TE WĀNANGA ARONUI O TĀMAKI MAKAU RAU

AUCKLAND UNIVERSITY OF TECHNOLOGY ETHICS COMMITTEE (AUTEC)

For AUTEC Secretariat Use only

EA2

RESEARCH PROGRESS REPORT OR APPLICATION FOR AMENDMENT

NOTES ABOUT COMPLETION

- The AUTEC Secretariat and your AUTEC Faculty Representative are able to provide you with assistance and guidance with the completion of this report or application.
- The information provided in this Report will be used for the purposes of granting ethics approval. It may also be provided to the Graduate Research School, the Research and Innovation Office, or the University's insurers for purposes relating to AUT's interests.
- Please ensure that you are using the current version of this form before submitting your form.
- Please ensure that all questions on the form have been answered and that none have been deleted.
- Please deliver or post to the AUTEC Secretariat, room WU406, fourth floor, WU Building, City Campus or email to ethics@aut.ac.nz. The internal mail code is D-88. The courier address is 46 Wakefield Street, Auckland 1010.

To respond to a question, please place your cursor in the space following the question and its notes and begin typing.

A. *Project Information*

A.1. AUTEC Application Number and Project Title

23/299 Collaborative design for parents navigating neonatal care and transitioning from hospital to home

A.1.1. Current Expiry date

14 November 2026

A.2. Are you making an annual progress report? ☐ Yes ☒ No

If you have responded 'Yes" to this question, please complete part B of this form

A.3. Are you making an application for amendments? ☒ Yes ☐ No

If you have responded 'Yes" to this question, please complete part C of this form

A.4. Has the title altered since ethics approval was given? ☐ Yes ☒ No

If the answer is 'Yes', please answer the following question, otherwise please answer section A.5 and continue from there.

A.4.1.1 What is the proposed new title for the research?

A.5. Who is the applicant?

Dr Ivana Nakarada-Kordic

A.5.1. Has the applicant altered since ethics approval was given? ☐ Yes ☒ No

If the answer is 'Yes', please answer the following, otherwise please go to Part B and continue from there..

A.5.2. Who is the new applicant?

When the research is part of the requirements for a qualification at AUT, then the applicant is always the primary supervisor. Otherwise, the applicant is the researcher primarily responsible for the research, to whom all enquiries and correspondence relating to this application will be addressed.

A.5.2.1 In which faculty, directorate, or research centre is the applicant located?

A.5.2.2 What are the applicant's qualifications?

A.5.2.3 What is the applicant's email address?

An email address at which the applicant can be contacted is essential.

A.5.2.4 At which telephone numbers can the applicant be contacted during the day?

C.2. What amendments to the data collection protocols are needed?

Change from a co-design workshop to interviews to collect data from whānau who have experienced neonatal care due to infant prematurity or other special healthcare needs. We believe this method is more appropriate for our participants, given feedback from the community. (Please see the correspondence attached).

- There has been an interest in families from outside the Auckland region to participate in this study.
- This consultation has proven valuable, and it is important to me to consult with a range of families to inform my design process.
- We have been made aware that Auckland is known among the NICU/SCBU/NNU community to have some of the best facilities and care available.
- The primary researcher believes there will be valuable knowledge from expanding the target group from Auckland region to nationwide, to best meet the aims of this research.
- There were unforeseen barriers to families being able to attend the co-design workshop on the proposed date and location. This was shown in slow uptake in recruitment, and feedback from the community. We believe the flexibility of individual interviews will remove these barriers.
- Provides a remote option, such as a Zoom call or telephone. We currently have 3 participants who expressed interest in a remote option.
- The interview will still be conducted with the same aims and guidelines from Part B of the co-design workshop, facilitated by Kayla Newman. However, it will be adapted to suit the style of a semi-structured interview rather than a group setting. Please see tentative questions/ interview guide attached.

The updated participant-facing documentation has been attached – Consent form and participant information sheet.

C.3. What amendments to the research aims are needed?

The aims of the interviews will remain the same as Part B (Kayla Newman's part) of the co-design workshop

C.4. What amendments to the research methodology are needed?

Amendment required to replace a method of data collection, from a co-design workshop to semi-structured interviews. A collaborative, family-centred approach will still be taken.

C.5. What changes are there to the proposed research outputs?

No amendments to the research outputs.

C.6. What other amendments to the research are required?

No other amendments at this stage.

E. Checklist

Please ensure all applicable sections of this form have been completed and all appropriate documentation is attached as an incomplete form will not be considered by AUTEC.

Have you discussed this form with your AUTEC Faculty Representative, or a member of the AUTEC Secretariat? ☒ Yes ☐ No

Is this form related to another ethics application? If yes, please provide the application number of the other application. ☒ Yes ☐ No

23/300 - A Threshold Journey: Neonatal Parents' Transition from the Special Care Baby Unit to Home

Are you seeking ethics approval from another ethics committee for this research? If yes, please identify the other committee. ☐ Yes ☒ No

Section A	***Project information provided***	☒
Section B	***Progress Report information provided***	☐
Section C	***Amendment details provided***	☒
Section D	***References provided***	☐
Section E	***Checklist completed***	☐
Section F.1 and 2	***Applicant and student declarations signed and dated***	☒
Section F.3	***Authorising signature provided***	☐

Spelling and Grammar Check (please note that a high standard of spelling and grammar is required in documents that are issued with AUTEC approval)

Attached Documents (where applicable)

Participant Information Sheet(s)	☒
Consent Form(s)	☒
Questionnaire(s)	☐
Indicative Questions for Interviews or Focus Groups	☒
Observation Protocols	☐
Recording Protocols for Tests	☐
Advertisement(s)	☐
Researcher Safety Protocol	☐
Hazardous Substance Management Plan	☐
Any Confidentiality Agreement(s)	☐
Any translations that are needed	☐
Other Documentation	☒

F. *Declarations*

F.1. Declaration by Applicant

- ***The information in this report or application is complete and accurate to the best of my knowledge and belief. I take full responsibility for it.***
- ***In conducting this study, I agree to abide by all applicable laws and regulations, and established ethical standards contained in AUTEC's Applying for Ethics Approval: Guidelines and Procedures and internationally recognised codes of ethics.***
- ***I will continue to comply with AUTEC's Applying for Ethics Approval: Guidelines and Procedures, including its requirements for the submission of annual progress reports, amendments to the research protocols before they are used, and completion reports.***
- ***I understand that brief details of this report may be made publicly available and may also be provided to the Graduate Research School, the Research and Innovation Office, or the University's insurers for purposes relating to AUT's interests.***

Signature ***22/01/2024*** ***Date***

F.2. Declaration by Student Researcher

- ***The information in this report or application is complete and accurate to the best of my knowledge and belief.***
- ***In conducting this study, I agree to abide by all applicable laws and regulations, and established ethical standards contained in AUTEC's Applying for Ethics Approval: Guidelines and Procedures and internationally recognised codes of ethics.***
- ***I will continue to comply with AUTEC's Applying for Ethics Approval: Guidelines and Procedures, including its requirements for the submission of annual progress reports, amendments to the research protocols before they are used, and completion reports.***
- ***I understand that brief details of this report may be made publicly available and may also be provided to the Graduate Research School, the Research and Innovation Office, or the University's insurers for purposes relating to AUT's interests.***

Signature ***08/12/2023*** ***Date***

F.3. Authorisation by Head of Faculty/School/Programme/Centre

- ***The information in this report or application is complete and accurate to the best of my knowledge and belief.***
- ***In authorising the continuation of this study, I declare that the applicant is adequately qualified to undertake or supervise this research and that to the best of my knowledge and belief adequate resources are available for this research and all appropriate local research governance issues have been addressed.***
- ***I understand that brief details of this report may be made publicly available and may also be provided to the Graduate Research School, the Research and Innovation Office, or the University's insurers for purposes relating to AUT's interests.***

Signature ***25/01/2024*** ***Date***

Community feedback - Consultation with prospective participants.

[redacted]
To: Kayla Newman Fri 24/11/2023 11:48 AM

Hi Kayla,

Thanks for responding. I guess the idea of being bombarded with information at the start of the journey sounds so foreign as well – definitely more like being left in the dark without a baby, elsewhere!

Yes, I'd be interested in a remote option.

Thanks,
[redacted]

[redacted]
To: Kayla Newman Thu 23/11/2023 1:50 PM

Hi, I saw your ad on Birth Trauma Aotearoa and they suggested I email you my feedback.

I've had two neonatal babies in two different units (SCBU and NICU), in two different DHBs. This is normally something I'd be willing to participate in but the requirement to be face to face in Auckland is a huge barrier for people, and BTA suggested I email you my feedback that you're going to get a hugely biased point of view by effectively narrowing it down to people in or near Auckland. The Auckland units are known within the NICU community to be the best in the country, what you get in Auckland is so, so much nicer and more comprehensive than what you get out here in SCBUs in more rural parts of the country, or when you're shipped away to NICU that's not your local.

Hope it goes well but please consider in the future expanding it to the rest of the country,

Cheers
[redacted]

[redacted]
To: Kayla Newman Fri 1/12/2023 7:47 PM

Kia ora Kayla,

Thanks for getting in touch and, yes, getting into the Christmas spirit! I'm not sure I'm quite ready yet, though!

I'm sorry you're finding challenges with recruiting participants for the study but a good idea to hold off for a bit, until you can find the right number of whānau - you may find a renewed interest after the silly season is done.

I'd be happy to interview with you and share what I know - at this stage I imagine it will have to be next year, I'm afraid, as my days are pretty full as we gallop towards Christmas.

Let me know when you're thinking and we can set up a zoom.

Have a great end of year,
Kate

[redacted]
To: Kayla Newman Fri 1/12/2023 5:11 PM
💗 1

Hi Kayla,

Oh that's a shame, but I understand. Yes I'm happy with a remote option via Zoom or something.

Cheers,
[redacted]

indentifiable information from community feedback as evidence in the amendment has been removed to protect privacy.

Appendix H.3

Response to conditions of AUTEC approval (online interviews)

21 February 2023

Ethics Application: 23/299 Collaborative design for parents navigating neonatal care and transitioning from hospital to home.

Thank you for your response regarding application for an amendment to our ethics application on 30 January 2024.

Here are responses to your following points and conditions raised.

AUTEC comments	Applicant Response
1. Revision of Information Sheet from "how we support" to "how parents are supported", as the researcher is not a DHB employee;	This revision was already made. Please see highlights in the information Sheet below.
2. Revision of the Consent Form to include a field for contact details to be provide should the participant like to be contacted for follow-up research;	Please see updated Consent form below
3. Revision of the advertisement to include "research".	"This research aims" added, Please see updated advertisement below.

Attached:

Participant information Sheet
Consent Form
Recruitment Advertisement

AUT UNIVERSITY
NEW ZEALAND

participant information sheet

reimagining neonatal care through whānau interviews

Date Information Sheet Produced 09/01/2024
Project Title
Collaborative design for parents navigating neonatal care and transitioning from hospital to home.

About the Researcher

Kia ora, my name is Kayla Newman.
I am passionate about all things related to women's health and products that make the world a better place. I have a background in Industrial design, and I'm currently studying for a Master of Design at Auckland University of Technology. Throughout my research, I aim to use a collaborative design approach to create a resource for families in neonatal care, as they transition from hospital to home.

Purpose of the Research

I understand that having a baby born prematurely or with special healthcare needs can be a challenging time for families. Our aim is to collaborate with families and professionals in the neonatal community. Through interviews, we hope to unpack how we might better support families when it comes to educational resources and tools.

Taking care of a baby with special needs can feel overwhelming. Your input is crucial in helping us rethink how parents are supported in the Special Care Baby Unit (SCBU) through personal, well-designed educational solutions for a more family-centred approach to care. This research is all about understanding what parents go through when their newborns spend time in SCBU.

You will have the opportunity to freely share their opinion about any aspect regarding the research project and neonatal care. As a participant, you will be treated as the expert here, as you have lived experience. As a researcher, I aim to approach the conversation with empathy and learn from you. This will aid me in my design process to redesign and consolidate a relevant and informative resource for future families starting a neonatal journey.

How was I identified and why am I being invited to participate in this research?

You have been invited to participate as you have expressed interest in being interviewed and sharing your thoughts given your experience in neonatal care. For this research, we are looking for parents, caregivers, and whānau whose babies were discharged from a New Zealand SCBU (Special Care Baby Unit) within the period ranging from 2012 to 2022. To be eligible to participate, your child who was admitted to SCBU must be at least one year old. You must be 18+, confident in reading and speaking English and live in the Auckland region.

How do I agree to participate in this research?

You can agree to participate in this research by contacting the researcher, Kayla Newman (dsh9292@autuni.ac.nz) to set up an interview date and time. You can choose between an in person or an online interview (via Zoom). You will also need to sign a consent form before the interview commences. You may email me the signed consent form prior to the interview or sign a physical copy on the day. Note: video-call interviewers must sign a digital copy of the consent form. Please also feel free to ask us any questions you may have regarding the study.

Your participation in this research is voluntary (it is your choice), and whether you choose to participate will not benefit or disadvantage you. You can withdraw from the study at any time. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

Each interview will be a semi-structured discussion on what you believe someone navigating neonatal care for the first time might need to know or hear. The interview will be casual in nature and will take approximately 45 minutes of your time. The researcher will have a list of questions to guide the conversation, and you will have an opportunity to freely share your opinion about any aspect regarding the research project and neonatal care. You are the expert here; I am here to listen and learn from you.

We will work together to imagine what a good experience at SCBU In terms of information and education provided should look like for families. We hope to use some of the findings and learnings from these interviews to help design solutions for resources or tools that will benefit future families who go through a neonatal care journey.

The questions will be generalised and not specific to your neonatal journey. An example scenario will also be provided to help with our discussion. Some examples of questions that may be asked:

What support did you have and what did you wish you had?
What are your thoughts on (persona scenario)?
What might this mama be feeling?
What advice would you give this mama?
What might they need? Emotionally or practically?

You are welcome to share as much or as little detail as you would like about your experiences. You may also choose to decline to comment on any questions. This will be a safe and non-judgmental space to share your opinions about neonatal care.

What are the benefits?

There is no direct benefit to you. Your contribution to this research project may help create better educational resources and experiences for future parents with babies at SCBU. The researcher is an AUT student and is not employed by any healthcare organisation. There is no monetary gain for researchers. The benefit for the researcher is obtaining a master's qualification through successfully completing the project.

What are the discomforts and risks and how will these discomforts and risks be alleviated?

We understand that revisiting memories surrounding the birth of your baby may be triggering and emotional. You may end the interview anytime or choose not to respond to specific questions. You are welcome to bring your partner or another support person. We encourage all parents, caregivers and whānau, not just the birthing person, to have their say - we know it takes a village to raise a child. All attendees will need to read this Participant Information Sheet and sign a separate consent form to agree to be part of this research.

Please do not hesitate to contact the researcher with any questions or concerns.

How will my privacy be protected?

Although I perceive there to be minimal risk, I understand that you may be worried about the privacy of yourself, your child and your family. Your data will be deidentified, meaning we will remove all data that may identify you, including your name, occupation, gender, and workplace, from any outputs of this research. You will still be known to the researcher interviewing you. You can also opt out of the interview being audio-recorded (outlined in the consent form). Recordings will not be shared with anyone and will be transcribed. Any identifiable information will be removed.

What is the cost of participating in this research?

There is no monetary cost of participating in this research. The interview will take approximately 45 minutes of your time.

What opportunity do I have to consider this invitation?

You have up to two weeks to consider and accept the invitation to participate in an interview. Please contact us if you have any questions before signing the consent form. We want you to be able to make an informed decision about whether this interview is right is right for you. The researcher (Kayla Newman) will get in touch to schedule an interview. You may reschedule or cancel at any time with no disadvantage to you.

Will I receive feedback on the results of this research?

If you want information about the results of this research, you can tell us, and we will send the research summary once the study is completed. Please advise me on the consent form.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor Ivana Nakarada-Kordic, ivana.nakarada-kordic@aut.ac.nz

Approved by Auckland University of Technology Ethics Committee on 14th November 2023, 23/299, 23/300. Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC: Liz Binns, ethics@aut.ac.nz, 921 9999 ext 6038.

Researcher Contact Details

Kayla Newman
dsh9292@autuni.ac.nz

Helpline Services

Walsh Trust
www.walsh.org.nz (0800) 192574
Provides free community-based mental health support and residential service.

The Grief Centre
www.griefcentre.org.nz (09) 418 1457
Provides counselling, bereavement phone support, professional training and community and group support sessions to ensure people are well-supported through their grief and loss journey.

Approved by Auckland University of Technology Ethics Committee, 23/29

AUT UNIVERSITY NEW ZEALAND

consent form

reimagining neonatal care through whānau interviews

Project Supervisor: Ivana Nakarada-Kordic,
Researcher: Kayla Newman

☐ I have read and understood the information provided about this research project in the Information Sheet dated 09/01/2024.

☐ I have had an opportunity to ask questions and to have them answered.

☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

☐ I understand that my privacy will be protected, and my data will be deidentified, meaning any identifiable information about me, including my name will be removed from the data, including any audio-transcriptions. I understand I will still be known to the researcher.

☐ I understand that if I withdraw from the study then, I will be offered the choice between having any data removed or let it continue to be used. However, once the findings have been produced, removal of my data may not be possible.

☐ I agree to take part in this research.

I consent to the interview being audio recorded. I understand I may verbally withdraw consent at any time. I understand that the audio-recording will be transcribed (please tick one):
Yes ☐ No ☐

If yes to the next questions, please provide your best contact detail(s) below.

I wish to receive a summary of the research findings (please tick one):
Yes ☐ No ☐

I would like to be contacted for potential follow-up research after this interview (please tick one):
Yes ☐ No ☐

Participant's full name _____

Participant's signature

_____

Date ___ / ___ / ____

Contact email _____

Approved by Auckland University of Technology Ethics Committee, 23/299

REIMAGINING NEONATAL CARE

through whānau interviews

I am looking for:
Parents and caregivers of graduate Special Care Baby Unit babies to be interviewed (online available)

FIND OUT MORE

HTTPS://SHORTURL.AT/ANQX9

We understand that having a baby with special healthcare needs is a challenging time for families. This research aims to reimagine resources provided in neonatal care that support parents on their journey from hospital to home.

Please email:
Kayla Newman dsh9292@autuni.ac.nz

Approved by Auckland University of Technology Ethics Committee on 14th November 2023 , 23/299, 23/300

AUT UNIVERSITY

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