



Whakarongorau  
Aotearoa//  
New Zealand  
Telehealth  
Services//

**Te Whatu Ora**  
Health New Zealand

# Perinatal Bereavement Support Environmental Scan

28 March 2023

**Te mahi tahi puta noa i te pūnaha kia kore rawa ai e mate, e whara ngā māmā me ā rātau pēpi, whānau hoki mai i ngā mate, wharanga rānei ka taea te ārai.**

*Working together across the system towards zero preventable deaths or harm for all women/people and pēpi, families and whānau.*

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## **Executive summary**

### **Purpose of this Report**

Te Whatu Ora commissioned Whakarongorau Aotearoa to work with communities, service providers and whānau experiencing perinatal loss of a pēpi (baby) to understand the current experiences, inconsistencies, and challenges for both parents and support providers. The goal was to identify potential solutions that enable greater reach, better access, and improved outcomes for those experiencing and supporting perinatal loss.

The aim of the environmental scan is to identify what is currently working well, service and support gaps, the inequities that exist and who may be impacted. This will support development of the future bereavement care pathway.

### **Current situation**

Parents of live pēpi are well supported in Aotearoa, both throughout their pregnancies and after their pēpi is born. They have access to their Lead Maternity Carers (LMC) before, during and after the birth, Well Child Tamariki Ora provider (post six weeks), many support groups, and for those that need it, Maternal Mental Health services. Sadly, this level of standardised and structured support is not available to parents who lose their pēpi.

It is estimated that 700-900 kiwi families lose a child every year through stillbirth, foetal abnormality, or Sudden Unexpected Death in Infancy (SUDI), with more than 13,000 additional whānau affected by miscarriage before 20 weeks gestation and approximately 13,000 affected by termination.

A 2019 report released by the Perinatal and Maternal Mortality Review Committee identified that current pathways and services are fragmented, and recommended that Te Whatu Ora (Ministry of Health at the time) "resource, support and facilitate the development of a national perinatal bereavement pathway" for the parents, whānau and support services that care for those who lose pēpi and infants.

### **Environmental scan**

This Report provides a detailed analysis and key themes of current perinatal bereavement support available in Aotearoa, following interviews with 55 people and organisations across the perinatal bereavement ecosystem. It also includes contributions from people working in the sector and the stories of women/people from across the motu who volunteered to participate in one-to-one interviews, sharing their experiences with the healthcare system and the impacts that a child loss has had on the lives of them and their whānau. Their voices illustrate and magnify similar themes identified by those working across the ecosystem.

Additionally, the exploration of international approaches provides insight into the pathways other countries are taking.

### **Key themes identified**

Through the environmental scan and feedback from both health professionals and whānau, there is a very clear sense that perinatal bereavement continues to be fragmented across the motu and across the different professions involved at different

stages of the process. Pathways to support perinatal bereavement (both clinically and personally) are widely different depending on the location and resources available.

A summary of the key themes, along with opportunities to support future enhancements to the pathway, identified through the Report is provided below.

- No two journeys are the same.

*Opportunity to build cultural competency across the sector, that embraces manaaki, will ensure that 'respect, generosity and care' is shown for those parents, whānau and communities' experiencing a perinatal bereavement, and that their individual journey, needs, and experience are taken into consideration.*

- There is a general lack of awareness and understanding of perinatal bereavement in Aotearoa, and most parents are unprepared for this eventuality.

*Opportunity to grow public awareness and resources (including more digital resources) to help people be more informed and connect with communities and support. Increased support and promotion of Non-Governmental Organisations (NGOs) offering perinatal bereavement support and connections would also be beneficial.*

- Cultural competency and awareness is inadequate in most regions, but has a significant impact on a whānau's experience of the bereavement pathway. There is also still significant shame and stigma attached to pēpi loss in Aotearoa. Many women/people blame themselves – what did I do wrong? Health professionals also blame themselves – what did I miss?

*Opportunity to develop an equity-led national framework, with whānau at the core and having a voice in the design.*

- Disparity of experiences exist across the motu, by health professional, location, hospital, and sometimes within the hospital.

*Opportunity to develop a national framework tailored locally, leveraging successes in Counties Manukau and international partners.*

- Often the disparity is due to a limited workforce and those with experience in perinatal bereavement, particularly in smaller or remote regions.

*Opportunity to leverage the national framework to encourage local teams to understand and support the perinatal bereavement pathway, develop more training and resources to support ongoing professional development, and encourage the growth of particularly the Māori and Pacific workforce.*

- The process can feel very clinical, particularly for pēpi under 20 weeks gestation.

*Opportunity to develop perinatal bereavement training for anyone involved in the process – social workers, sonographers, midwives, nurses, and doctors and how they can adapt to the sensitivity of the situation. Create dedicated environments in hospitals / clinics to allow the whānau to process and grieve, and ensure this is separate from the maternity ward.*

- Care often ends at the hospital doors, with limited post-care support provided.

*Opportunity to leverage the national framework to build helpful post-bereavement care information and resources that is provided to every woman/person on what to expect in the coming days / weeks, what support is available, ensure that follow ups are completed, and whānau are connected with social workers / community / NGOs support for a reasonable time following the immediate loss.*

## Summary

The Report includes:

- Insights from the sector
- Voices of whānau with lived experience
- The impact of cultural inequities
- Disparities experienced across Districts
- Models from an international environmental scan
- Enhancing the bereavement pathway
- Future opportunities.

**The insights, voices, experiences, and opportunities highlighted in this Report will be used to inform the design of a national perinatal bereavement support pathway to provide better, more connected, and culturally relevant care for whānau who have experienced the loss of a pēpi.**

## Acknowledgements

*We want to acknowledge all the whānau who have lost pēpi and the health professionals and supporters who have contributed to this environmental scan. The participants in the interviews described in this report*

*have so very generously told us their stories, and provided insight and the human narrative behind this work. It is through their stories and the short lives of their pēpi that we can learn, improve, and grow our support for those who may experience this loss in the future.*

*We thank all those who took part.*

## Insights from the sector

Interviews were completed with 55 people and organisations across the perinatal bereavement ecosystem, identifying high-level insights and themes experienced through current perinatal bereavement support available in Aotearoa.

### Communication & Environment

- The definition of a still-birth in Aotearoa<sup>1</sup> (over 20 weeks gestation, over 400g or born with no signs of life) creates a line in the sand and very different experiences for

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<sup>1</sup> [Information - Terminology used with baby loss in New Zealand \(sands.org.nz\)](https://www.sands.org.nz/information-terminology-used-with-baby-loss-in-new-zealand)

parents. For parents with pēpi over 20 weeks, parental care is usually in the maternity ward, supported by midwives. However, for parents of pēpi under 20 weeks, this includes recognition as a foetus and not a pēpi, no legal registration (Birth and Death Certificates) and hospital care in the gynaecology ward and not the maternity ward, even if they need to birth their pēpi.

- Compassionate communication on delivering bad news is variable. Healthcare team members sometimes lack accurate and current information about the loss. Often it is a sonographer delivering the news, many of whom have not received any training on how to do this and / or in a culturally sensitive way, and guidelines available are out of date.
- There appears to be a breakdown in communication between community LMCs and some hospitals - where LMC community midwives believe they are not welcome in the hospital, or are made to feel at fault over patient care.
- There is significant duplication across regions as teams have created the best system they can to support whānau. Within many hospitals, there is a level of confidence that staff could support bereaved whānau well, but the structure of the organisation puts up too many barriers for them to provide it.
- Specialised bereavement rooms (away from the birthing area) are important to bereaved parents and their whānau, making them feel acknowledged and respected as parents. However, whānau access to these rooms depends on which facility they are in regionally and the stage of loss (ED, Maternity, NICU, gynaecology).
- Some hospitals try to make moving through the hospital as gentle as possible. Counties Manukau provides parents with a pink slip so other hospital staff are aware of the situation and can apply the appropriate processes and sensitivities.
- GP post-loss support depends on whether they are informed, how proactive the GP clinic is to enable them to support the woman/person and whānau, and the wider support available. New initiatives are being rolled out to support better community care. Te Tumu Waiora<sup>2</sup> initiative (a new model of primary mental health and addictions care and support) is trying to close the gap between primary and secondary care, and it is a big step in the right direction of providing better community care. However, this is not in all GP clinics.
- Another positive initiative is a new Sudden Unexpected Death in Infancy (SUDI) bereavement pathway<sup>3</sup> - based on a duty of care to mitigate eventual harm ensuring wrap around care for whānau who lose their babies. This is setting the bar for community care.

## Education

- Formal education does not prepare anyone for this environment. Most health professionals develop a special set of skills on the job, and it gets easier as they gain more experience. Nurses, social workers, sonographers, radiologists, and junior doctors have all asked for in-house training, they know what they shouldn't say but not what

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<sup>2</sup> [Te Tumu Waiora](#)

<sup>3</sup> [SUDI Prevention | SUDI Prevention Coordination Service \(sudinationalcoordination.co.nz\)](#)

they can say. Some can attend free elective in-house workshops by passionate midwives and sector advocates - if it is on offer in their region and if it doesn't clash with their schedule. Unfortunately, staff turnover makes it hard to always have staff trained in perinatal loss. Health professionals with English as a second language can find it especially hard providing bereavement support.

- Midwifery training seems to focus on live births. Perinatal bereavement is barely mentioned. Neonatal Intensive Care Unit (NICU) nurses are leaders in this area. They have quite intentional training and palliative care is part of it. They have created a palliative care pathway used across the motu. Most consultants have often also completed palliative care support training, although how they utilise the skills learned varies.
- Cultural competence is becoming a core component of many professional healthcare education curriculums. Although this is excellent and may help influence and evoke change as they move through the health system, graduates are often unprepared for how Euro-centric systems are when they enter hospitals.
- All staff and supporters interacting with bereaved parents (health professionals or not) need specialist perinatal bereavement support training, so they feel confident and prepared to speak with parents and so parents are supported appropriately at all touchpoints.

### **In-hospital support**

- The level of ongoing care community midwife LMCs provide to women/people varies and is very dependent on if/when the woman/person registers for care, the region they are in, the stage of loss and the health professional's interpretation of the Primary Maternity Services Notice 2021. In some instances, the LMCs do not feel welcome in the hospital and then the woman/person loses the connection with someone they have built up trust with.
- There are 4-5 perinatal loss hospital midwife specialists across Aotearoa - mainly in the main centres, other regions don't have access to this resource. There is no standardised job description for this role with some very hands on with whānau and others in the background handling administration. Lack of resource has also resulted in a small number of core midwives looking after a whole ward of women/people, resulting in limited continuity of care and some women/people feeling abandoned with the (perceived) focus being those women/people who have living pēpi.
- Counties Manukau has an onsite specialist Bereavement Care team and facility, providing non-clinical bereavement support to parents and whānau - the only hospital in Australasia to offer this. The level of empathy and care provided to bereaved whānau via this unique support system is excellent.
- Māori and Pacific liaison teams in the hospital (if available) can provide specific cultural support to both staff and whānau. However, this is often based on a check of the wards or National Health Index (NHI) number, meaning many will fall through the gaps. Whānau being welcome, present, and involved is an important part of the grieving

experience, staff must determine who the whānau spokesperson is and never assume they know who to talk to.

- Faith based support is also very important to some parents and many call on hospital chaplains for support.
- All parents should be offered the option to speak with a social worker. Some can provide short term intervention grief counselling on the ward – often the only counselling the woman/person will receive. However, there appears to be variance in the grief counselling capability of social workers across the regions.
- Although in some regions partners are included in the care provided (treated as a unit), in others support is heavily focussed on the woman/person. Some partners (including surrogacy, LGBTQI+ or Whāngai) can feel like part of support team for the woman/person, but they are also bereaved and need support.
- Knowing the sex of the pēpi is important to allow the whānau to name the pēpi and get the right name and gender on the Birth and Death Certificates. However, where the gestation is under 20 weeks, some doctors say that the sex is undeterminable and that while genetic testing can be done, this takes two weeks, meaning the whānau can't name the pēpi in this time. Baby Loss NZ (charity) promotes a way to quickly identify gender in this age bracket, but this is not commonly known.

### **Understanding post-mortems**

- Parents are not always given the information and support they need (at the right time) to make informed decisions about their own care and the care of their pēpi, or to feel prepared for the journey ahead. One of the hardest decisions parents must make is regarding post-mortem – the results of which can help whānau in subsequent pregnancies and alleviate blame, but can be extremely difficult and sometimes costly.
- Whānau are more likely to make better, informed decisions about post-mortem when talking about it with someone they trust, which can be difficult with high staff turnover and rushed workplaces focussed on live pēpi. Cultural beliefs, time away from pēpi, costs and transportation were identified as the main barriers to agreeing to a post-mortem.
- With only four regions across the motu having a perinatal pathologist, the location of these resources has a big impact on whether or not whānau choose to consent to post-mortems and is therefore an inequity to those in regions with no in-house pathologist. It is important that whānau understand and are given the option of all the testing alternatives available.
- The coronial process for unexpected/unexplained deaths and SUDI deaths adds more trauma and complexity to the journey of bereaved parents (police, interviews, re-enactments), although the Ministry of Justice is currently reviewing this process and trying to reduce the number of cases needing referrals.
- Coroners' results can arrive in the post up to three years after the death of their pēpi, although this is being reviewed. This is in medical language that parents need to look up on Google and can be very triggering for parents. The results are important for both



parents and caregivers often to allay any fear or blame that they had 'done something wrong'.

### **Pastoral Care**

- Every person involved in providing support to bereaved parents has different individual needs and for those who have never encountered death before, the loss of a pēpi can be particularly impactful.
- Psychologists and social workers need to be supervised as part of their role, however this may not include dedicated, safe pastoral support.
- Some midwives are provided supervision, but not many. Most pastoral support is from colleagues, friends and whānau, some use EAP but they are not often skilled in perinatal loss counselling. Some pay for their own support to ensure they have a good 'fit' with the counsellor.
- Nurses are similar and tend to find what works for them in pastoral care. Usually this involves talking to other nurses, talking to whānau, and getting some time out. Volunteers also rely on colleagues, whānau and friends to debrief to and chat.
- Healthcare professional group debriefs after a pēpi dies can be valuable to the healthcare professionals who supported the whānau to ensure no one blames themselves.

### **Voices of whānau with lived experience**

In addition to the 55 interviews completed with health professionals and organisations, a further sixteen volunteers from across the motu participated in one-on-one interviews to share their experience with the healthcare system and the impacts that child loss has had on their lives and the lives of their whānau.

Their voices, highlighting their losses and their experiences, as well as their observations about perinatal bereavement support in Aotearoa, echo many of the themes identified in by health professionals and organisations working across the ecosystem.

Key themes and experiences shared by those who have lived through a perinatal loss are summarised below.

#### **Personal and professional support**

Experiencing a miscarriage felt very clinical for many participants. They described a sense of disconnect between themselves and the health professionals as if no one was phased by what was happening to them.

*"We felt like we were going through an invisible experience."*

*"While the nursing staff that supported them were lovely, there was a sense of disconnect between us and the health professional. It was like no one was phased by what was happening to us, it was a 'normal' thing to the clinical staff, but it was not normal for us or our whānau."*

*“Everything started to feel too clinical when they started the miscarriage process - we felt there needed to be a different level of care, more bereavement awareness and support.”*

A number of parents were interviewed who had more than one perinatal bereavement. They commented that it felt as if their previous history of loss did not follow them into their next pregnancy. For one whānau, even though they instinctively knew that they needed more specialised help, the medical profession had not *“connected the dots.”*

*“Where my depression comes from is could they have done something, could I have done something. I get they said that there is nothing that could have been done but still in my mind I went to see them weeks before and I feel like I could have done something earlier.”*

*“It took us losing four babies for someone to care, before any intervention was offered to us, and it shouldn’t be like that. We shouldn’t have to go through all that before someone refers us to a specialist. We asked with our twins, and it felt like it fell on deaf ears.”*

Underpinning many of the stories the participants shared was a feeling of lack of respect for their opinions, the questions they had, the insight they had gained from their experience/s, and for their respective cultures.

*“When the medical staff finally understood my condition and listened to me, I was able to get the support and the help that I needed to carry my two girls to full term.”*

*“Our whānau parked outside in the carpark in a show of support (during COVID).”*

Those whānau who had experienced their first loss spoke about their trauma at not knowing and understanding what to do – do they pray, do they hold the pēpi, do they dress the child? Looking back, they describe it as the most traumatising night of their lives, because they did not know what to do.

*“If there was more support or care for me, then I think that I would have been able to have my pēpi with me. I didn’t know what to ask or do.”*

*“I felt like there was not enough information provided about pregnancy and the potential for pregnancy loss. If we had known more about how common miscarriage was, what signs to watch for and what to do / expect if something is wrong, it may have made them both more aware of what we need to consider.”*

## **Post-birth care**

As is evidenced in some of the international models, post-birth care is often in written pamphlet form handed over to parents when they leave care, particularly for those who have lost a child at early gestation.

Where this information was offered to any of the interview participants, they highlighted how inappropriate and culturally unsafe this was.

*“It felt like - oh, your baby died, here you go, here is some information for you. But I just lost my baby, I’m not going to read that. At the time that everything is happening it all becomes a blur, no one is in their right state of mind. Whilst*

*bereavement care was great, it needs to be a follow up team to offer care when maybe the parents have settled, funeral arrangements complete and there is more capacity to listen.”*

Many parents also spoke about the need for post-birth as well as post-support follow-up when things have “settled”.

*“To have somebody follow up with me a few weeks after would have really helped me in my healing journey.”*

*“There needs to be a team of people who follow up with the mums, providing post bereavement support. At the time that everything is happening, it all becomes a blur, no one is in their right state of mind. Whilst bereavement care was great, there needs to be a follow up to this care, when maybe the parents have settled, funeral arrangements complete and there is more capacity to listen.”*

*“Education is the most important thing that needs to be addressed, second, is people and connecting with them. There is nowhere for people to check in and follow up and in the end, people just give up. We need a service where people check in on you, to help you deal with the aftermath of pēpi loss, to be frank, that is ultimately what hardened my heart’.”*

Many of the participants also didn’t know about some of the Non-Governmental Organisations (NGO) services available.

### **Mental Health support**

As has been widely reported through other recent research<sup>45</sup>, the need for mental health support through any bereavement process was a very common theme identified by many whānau. Overall, there was a strong indication of mental health issues, shared by whānau who experienced pēpi loss.

Some of the mental health issues experienced by some whānau created a breakdown in the marriages or partnerships and many described turning to addictions, including alcohol, drugs, food, and sex. The myriad of emotions and trauma that parents experienced and recounted revealed the complexity of their trauma.

*“I know it probably will sound weird to hear this, but honestly I felt like I needed to take all the blame for this entire issue, instead of harming myself, being addicted to drugs or alcohol, I was addicted to the blame.”*

*“There was a lot of blame placed on me for losing baby, blamed by my whānau that my lifestyle caused the stillbirth – if I didn’t drink while pregnant, maybe my son would have been able to survive to full term. I shouldered a lot of the blame, and this drove me to become addicted to alcohol and drugs. Life back then was crazy, my life no longer had purpose.”*

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<sup>4</sup> Ministry of Health, [Maternal Mental Health Service Provision in New Zealand: Stocktake of district health board services](#)

<sup>5</sup> [Fifteenth Annual Report of the Perinatal and Maternal Mortality Review Committee: Reporting Mortality and Morbidity 2020 | Health Quality & Safety Commission \(hqsc.govt.nz\)](#)

For some of the whānau, they shared that these addictions were to fill a void, and in some cases, they identified that this was the only time they felt happy, any other time they felt a deep depression. They described that their mental health and addictions also greatly impacted their wider whānau, with some unable to provide the best life for the (living) children because of the loss of the pēpi.

*“Many days, post baby loss, I would sit still and not move, sit, and do nothing or just lie in bed and only get up to go to the bathroom. I fell into a deep depression and felt miserable because a piece of me was missing. I barely did the basics, and when my partner would come home from work, he would take me out somewhere for a ride or to eat. Food became our escape, our happy place.*

*To the point that we became so addicted to the distraction that food provided, that we became addicted to eating.”*

Some whānau spoke of a general lack of support provided at the time of loss, while for others offered support, this was often in the form of brochures and pamphlets that were handed to them after losing their pēpi.

Many interviewees identified that there is a need for more wrap-around and after-loss services, after allowing the families time to grieve before they are able to receive and actually take on the help that is offered to them. Connecting in with the families after a few weeks to check in and make sure that they are okay is what is needed to ensure that the people get the help that they need

Parents also spoke about finding their own mental health support, with social media a source where they could find the individuals and the groups who would understand their trauma.

*“From a mental health perspective, in this current age with social media, it is a lot easier for me to join mothers’ groups, and pages where people have the same or similar condition as me and it meant I was able to hear other people’s stories and I was finally able to resonate with them. All this I had to find on my own and it was not something that was offered to me by healthcare professionals.”*

Peer support was also identified as important for parents and whānau, enabling them to talk to people who have been through a similar experience, especially in the early stages – they can provide a spark of hope that things might be ok in the future.

*“Even though counselling and peer support is available. When you encounter other women (who have experienced what you have), you feel so much better.”*

Several interviewees referred to their experience with Sands NZ. Sands NZ is the largest and most well-known not for profit organisation supporting bereaved parents in some regions across the motu via peer support groups, kanohi ki te kanohi (face-to-face) groups, closed online groups and by freephone. They offer non- judgemental peer support only - they are not a counselling service. There is significant reliance across the motu on Sands, which places a lot of pressure on them.

## **Lack of education**

Many whānau commented on the lack of education, or the lack of information available, particularly for first pregnancies, in regard to both general antenatal education as a prevention for loss, as well as education when a loss happens.

This lack of information not only made it harder to have a positive experience, but also meant parents were left unsure of how to support themselves to carry a healthy pēpi to full term.

*“As first-time parents, we felt like there was not enough information provided about pregnancy and the potential for pregnancy loss. If we had known more about how common miscarriage was and what to expect, it may have made us both more aware of what we needed to consider and look out for.”*

Some women/people shared that the lack of knowledge came from not understanding what they should expect when they become pregnant, and it was felt that there is an assumption that women/people know what to do and where to go to seek this information on their own. For young first-time mums, those aged between 17 and 20 years old, they shared they had no idea what to expect with pregnancy. They didn't know if they needed to check if they were bleeding, didn't know what to do when their waters broke, and really did not understand the pregnancy journey at all.

*“There was a lack of information for first time mums and what to expect when you are pregnant. There needs to be more information and people to help you understand and explain what needs to be done, what to do if something is wrong and if there are any issues that you experience any particular pain what the pain should feel like there needs to be more information around when you contact a midwife when you go straight to the hospital and when you can go directly to your doctor.”*

There is also an assumption that pregnancy information provided to women/people will be read and absorbed. However, some shared that they found the information overwhelming, and others spoke about a lack of time and opportunity, given many had other children and commitments. Many whānau preferred kanohi ki te kanohi in order to understand certain situations they might experience during their pregnancy.

## **Dedicated bereavement facilities**

Several women/people shared some of the traumatising experiences they had when they lost their child and were moved into a maternity ward - in some cases, sharing a room with a woman/person who had just given birth to a healthy child. Lack of awareness on the part of others and being asked how their pēpi was, making it really difficult for them to share that their pēpi had not survived the birth.

*“As a family, we would have preferred to be moved to a whānau room rather than being placed in the maternity ward. We had our baby who was stillborn, and we were in a space where mothers had children, we heard babies crying and it made it really difficult for us.”*

Participants felt that there was no mana in the way they were treated. They felt strongly that they needed a safe space, and that these should be available in every hospital where pregnant women/people are treated.

*“There needs to be a space for mothers who have lost their child to go, this space would be a safe space for all mothers. Surely there is enough people who have lost their baby that warrants having this space for us. A place that does not have babies crying, bereavement team and people to support as well as an understanding that there are other mothers there who have experienced the same loss.”*

They suggested that it would be very beneficial if there was a dedicated space for women/people who experience any perinatal loss, at any gestation. This space could provide opportunities for women/people to come in and share with other women/people that are in the ward, share with people who have counselling training that can support them and their entire whānau in their grief.

*“We were moved into an area for parents who have lost their children, and it was great to have the opportunity for our entire family to come through and be with us during this time. I was able to hold my girl, and be with her. We had the whānau room for 3 days which really helped with the healing process.”*

The setup of the bereavement rooms is key to honouring tikanga and other cultural rituals for many families:

- opening windows allowing the spirit of the pēpi to leave the room
- providing a bowl of water outside the room so anyone who goes in when pēpi is in there can cleanse themselves before and after entering the room
- blessing the room or bedspace after the pēpi passes
- a discrete sign on the door to acknowledge that a bereaved whānau occupy the room.

*“Me and my husband are pākehā, but we chose to practise the Māori culture, the Te Ao Māori approach helped us to honour our daughter in life and in death and I would not have it any other way.”*

### **Dignity and recognition for pēpi**

In most situations, the remains of the pēpi are treated with dignity and respect. Unfortunately, there are some examples where this didn't / wasn't able to happen due to resources.

*“We went home to arrange the funeral, and came back with the casket supported by our whānau. There was no safe space for us to go to with the casket. We went to the main reception holding the casket and the process was not nice, there was no mana in their experience. We waited at the reception for a long time, there was no record of <our pēpi>, and no one was able to tell me where she was.”*

Other examples shared (by both health professionals and some whānau) included:

- taking the pēpi to post-mortem in a kidney tray or wrapped in a dirty surgical cloth

- taking the pēpi home in an envelope box, another in a wax placenta box
- pēpi having black ink on hands / feet
- coroner's agent taking pēpi in a bag.

### **Practical support**

Support with administration can make a big difference to whānau as it can be overwhelming.

*“The papers that I had received was placed together with my discharge papers, it was when I reached home and looked at my discharge papers then I found them in there. It was at that point that I broke down. It would have been great for somebody who was able to sit down with me take me through the brochures that I have received and advise me on what was available, when I am ready, I have the brochures that I can refer to and I can utilise.”*

Social workers, bereavement teams and midwives often help coordinate cremation/burial, help with transport (e.g., to a mosque to be blessed). This support is especially useful when English is not the parents' first language (pamphlets and other support materials should be available in all languages). Support for whānau could be as simple as setting up a zoom meeting for parents to connect with other whānau overseas. It is important to ask what parents need.

Many whānau comment that, on discharge, it is important to ask who will help you when you get home? (in front of others). For some women/people and whānau, there can be a lot of shame and stigma, so parents are less likely to ask for help.

There is also concern (raised by both interviewed health professionals and whānau) that parents are not often prepared for their journey ahead, including transitioning post-discharge as well as getting back into routines – bereavement cards and flowers, what to do with the nursery and baby things, going back to work, trying again, and the next pregnancy following perinatal loss.

*“Upon return to work after a week of losing baby- everyone would ask and make comments like “how's the baby” “its ok, you can have another one”. The process of going back to work and having to deal with people and their insensitive comments pushed us a few steps back as a couple.”*

### **Positive experiences**

Parents also spoke about the positive aspects of their experiences and many of these stories revolved around the services offered by NGOs such as Baby Loss NZ, Sands, and Little Miracles Trust.

It is not surprising that these charities are so passionately driven by people who have, more often than not, themselves had an experience of perinatal bereavement. It is their compassion and their knowing, and their respect that strengthens the connections they have with the whānau they support.

*“Baby Loss NZ 100% was the best support. Being able to capture the memories especially in a time where I would never think to organise or have something like that done, once I picked up my items, it really helped with the healing process.”*

*“I absolutely loved Baby Loss, this is the group that really supported me, and they made sure that I was able to capture my son’s memories. This is the level of care that I appreciated the most. They really lifted a massive burden from me.”*

There were also those parents who spoke kindly of medical staff in some hospitals.

*“Medical staff at XX hospital were great, even though they didn’t know what to do or how to handle this situation, they did the best that they could.”*

*“The support that we received post birth from the Bereavement Team was amazing, I could definitely not fault them in anything that they did because it was supportive, they provided all the information to my mum and sister, they captured memories through Baby Loss so that we can continue to remember him and how much he saved us as a family, the bereavement team were amazing.”*

## **The impact of cultural inequities**

The environmental scan identified multiple themes and continuing challenges around cultural competency and the current gaps in supporting different cultural needs and wants, particularly relating to disparities in the perinatal experience and cultural understanding of Māori, Pacific, and Indian communities.

The top reoccurring themes are that cultural competency is as important as clinical competency and that no two journeys are the same. Every situation is unique, so that individualised care is necessary to meet bereaved parents’ personal, cultural, and religious needs.

Some whānau feel their situation or culture is not understood or appreciated both before and after a perinatal bereavement, which made them feel judged or isolated when they did need support. For example, whānau with close connections to their marae and iwi can often feel better supported and connected than whānau living in the cities. However, transfers to hospital means moving away from whānau and manaaki, which can leave them feeling alienated and isolated. Hospital care is often viewed as a last resort, with a general preference for home birth, followed by low level primary care units.

For many of the bereaved parents, the lack of cultural support and awareness further added to the trauma of their experience. Some of our interviewees commented:

*“To feel culturally safe, it’s multifaceted. Culturally when we do celebrate life, we have a healthy way of doing it. I was not offered the support I needed, this is a fundamental element of who we are. I can’t say now, if it would have made a difference at the time, but I feel like it would have made it safe for me to express myself.”*

*“As a Māori, I feel it is really important to have a wraparound service, not only to have medical professionals support but support for whānau as well. Workshops with our whānau, having this kind of service in our spaces would be great.”*



*“I cannot stress enough how important it is to have a wraparound service for all of our people when they experience this bereavement, regardless of what background, regardless of what religion, we need a wraparound service. It is important for our families and our first-time mums and our dads that there is a follow up supporting our families who experience this.”*

*“Looking at MoH changing to Te Whatu Ora, it needs to be more than kupu, more than words. We need to engrain it into our conscious practice.”*

### **Te Ao Māori approach**

Two Pākehā women shared with us that a Te Ao Māori approach had been beneficial for them and their whānau to go through as a healing process, and that it was through this approach they were each able to find healing. Amongst the activities that they participated in were Mirimiri, Matariki, Planting of a tree, and Māori Tangi practices.

*“During a Matariki event at their local marae, each person was asked to stand and share the name of someone who had passed away that year. We shared our pēpi’s name with the community. This was the first time we no longer felt alone. From there, the entire community wrapped their arms around us and supported us through our journey.”*

*“I was referred to a Mirimiri service with the local marae and this helped release the tension through my body that I’d felt during her miscarriage. The support from the community meant we had a memorial ceremony and planted a tree in honour of our pēpi. Through our Māori culture and practices, this was the first time we were made to feel the pregnancy was more than ‘non-viable’ baby - it was our child.”*

Some women/people had had experiences at multiple hospitals across the motu and noted a clear distinction with cultural safety being present in one hospital but not in the others. It was generally felt that there needs to be a lot more focus placed on cultural safety across Aotearoa.

Whānau shared that it is extremely important for health care professionals to understand their people, to want to understand their people, to take time and effort to understanding the needs of their people, so that they can offer the best level of appropriate support at the right time.

Whānau can usually spend up to five days with their pēpi and they should be offered the option to take their pēpi home. Māori and Pacific parents generally prefer to take their pēpi home. Unfortunately, parents are not always offered this option and parents don’t think to ask. Keeping the pēpi cool can be difficult due to equipment breaking down or not available due to lack of resourcing. It is important to consider cultural appropriateness in refrigeration and reusing cooling mats. Whānau need to be given the options and asked what they want.

To ensure equity and inclusion, interviewees stated there is a need for health care professionals to approach each situation and each whānau with respect, providing care for bereaved parents that acknowledges and supports their personal, cultural, and religious needs. In particular, anyone working with bereaved whānau should understand the

concept of mātauranga and Māori health models. It is also important to acknowledge that variation exists within Tikanga, and presumptions and generalisations cannot be made regarding different cultures or cultural practices.

**There was consensus across the interviewees that improving cultural competency for health care professionals across Aotearoa is likely to be most important and impactful area of focus that could make the most difference to the perinatal bereavement experience.**

### **Cultural stigma**

There is also stigma around the loss of a pēpi across some ethnic groups in Aotearoa.

Within the Pacific community, there is still very much a sense that it is hard to share that parents have lost their pēpi, and identified feeling shame and sometimes a sense of sin. Parents tend to suffer on their own, trying to hide their hurt and tragedy, which can end up affecting them mentally and impacting relationships with whānau and their communities.

Indian whānau identified that there is a general lack of cultural understanding and traditions, and some interviewees identified that there is often limited whānau or community support available, which contributes to the risk of physical and cultural isolation. International research<sup>6</sup> also identified that terminations and perinatal loss are also more commonly accepted within this community, so they grieve differently, don't blame anyone, don't call the pēpi by name, move on. Male partners can also be forthright in the care of their partners and decline support on their behalf, often to prevent them feeling more pain.

### **Disparity experienced across Districts**

It is a challenge to separate and comment on different regions of Aotearoa in terms of perinatal bereavement support. The environmental scan identified broad disparities amongst districts, with varying resources, available support, training, expertise, and protocols.

To provide an understanding of the variance in services and resources, insights of three different Districts have been highlighted, based on the environmental scan and interviewees feedback - Counties Manukau, Hauora a Toi / Bay of Plenty, and one of the smaller rural areas, Te Tai Tokerau / Northland.

**Counties Manukau** is the busiest District in NZ and appears to have the most comprehensive bereavement support in the country, particularly for early loss and stillbirths.

This may be attributed to dedicated bereavement facilities and the presence of two perinatal loss midwife specialists, a specialist Perinatal Loss Bereavement Team that supports all women/people who have a pregnancy loss at any point of gestation, social workers trained in grief counselling and the involvement of charities such as Baby Loss NZ. The District also has nurses, doctors, a chaplain, and Māori/Pacific Liaison teams.

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<sup>6</sup> [Social and Cultural Factors associated with perinatal grief in Chhattisgarh, India](#); National Library of Medicine; [Social and Cultural Factors Associated with Perinatal Grief in Chhattisgarh, India - PMC \(nih.gov\)](#)

Parents bereaved by both early loss and stillborn births are offered three counselling sessions (and the potential for six) post discharge.

LMC expertise and level of support is not consistent across the District.

Women/people admitted for terminations do not receive the same level of clinical care as others experiencing a perinatal bereavement.

**Hauora a Toi / Bay of Plenty** is reportedly under-resourced with a lack of workforce in this speciality and few health care professionals wanting to work in the perinatal bereavement space, perhaps due to the unavailability of training.

Facilities and services were described by interviewees as not catering to the needs of whānau. Whānau are not consistently receiving or seeking prenatal support and therefore, may not understand what they need to be aware of and how to monitor their pregnancy, which may add to the challenges in receiving the appropriate care. Some LMC's are part of the birth process, some refer care to the hospital. Depending on a parent's requests, LMC's follow up post-natally.

There appears to be a lack of free counselling available post discharge, and the means-tested service that is available is inundated with requests, while assistance offered by social workers is generally not utilised. This is not to say that the teams are not working to develop new pathways, particularly for bereavements under 20 weeks gestation, but the lack of resources and protocols appears to be challenging.

**Te Tai Tokerau / Northland** was described by the interviewees as '*seriously understaffed*' with health care professionals generally having limited perinatal bereavement experience.

In 2016, a new bereavement room (the 'Butterfly Room') and pathways for whānau were designed with Sands and has been well received, but inadequate resources have resulted in struggling to source baskets, memory boxes and other resources for grieving whānau.

Limited resourcing and experience in perinatal bereavement in the area results in reduced access to these services. There are no social workers trained in counselling within the maternity unit. However, some General Practitioners (GPs) are able to connect families to these professionals. It was also noted that while parents are offered three free counselling sessions, only an estimated 20% take up this service as many prefer to seek support from their whānau and iwi instead.

LMC coverage on discharge is described as 'very good' with 100% of whānau receiving a visit, whether from their own LMC or one from the hospital, as well as a follow up meeting with a clinical consultant at six weeks. Sands are highly regarded, although inadequate resourcing has led to fundraising and the provision of resources locally, such as gowns being organised by local iwi.

## **International models**

An international scan of key perinatal bereavement models has been completed, with many countries in a similar position to Aotearoa – still working towards a consistent approach to improve the experience for both the parents and professionals supporting those parents.

The three stand out models were in Ireland, England / Scotland, and Canada. Currently, Ireland appears to be the most advanced and effective framework across the globe, while the Canadian model has a strong focus on cultural competency and consideration, and the England / Scotland model has seen great success in creating a collaborative, national framework that can be locally delivered.

All three frameworks provide insightful approaches and resources that Aotearoa could take learnings from and repurpose.

## Ireland

Following consultation, Ireland developed and launched The National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death<sup>7</sup> in 2016.

The Four Standards, which are described as the pillars of bereavement care following pregnancy loss and perinatal death, are:

- **Bereavement Care** - central to the mission of the hospital and offered in accordance with the religious, secular, ethnic, social, and cultural values of the parents who have experienced a pregnancy loss or perinatal death.
- **The Hospital** - ensuring systems are in place so that bereavement care and end-of-life care for babies is central to the mission of the hospital and is organised around the needs of babies and their families.
- **The Baby and family** - each baby/family receives high quality palliative and end-of-life care that is appropriate to their needs and to the wishes of their parents.
- **The Staff** - all hospital staff have access to education and training opportunities in the delivery of compassionate bereavement and end-of-life care in accordance with their roles and responsibilities.

A National Implementation Group (NIG) carried out the work, which identified forty overarching recommendations, developed into six work streams:

1. Quality and Service Improvement
2. Policies and Procedures
3. Information Technology
4. Referrals and Integration
5. Perinatal Palliative
6. Education, Training, and Staff Support.

In acknowledging that the execution of healthcare standards is often unsuccessful, a report on the implementation of the National Standards for Bereavement Care following pregnancy loss and perinatal death across all 19 maternity units in Ireland was released in July 2021<sup>8</sup>. The report “*acknowledged the work and commitment in each Maternity Unit to*

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<sup>7</sup> [National Standards for Bereavement Care - HSE.ie](#)

<sup>8</sup> [HSE National Standards for Bereavement Care](#)

*implement or begin the implementation of infrastructural recruitment and practice recommendations.”*

The Irish model provides an excellent framework for hospital support, including implementation, structures, and audits.

However, it is very resource intensive, which could make replicating it prohibitive for smaller countries, like Aotearoa. In addition, there is little post-discharge support, no social support for terminations, and there appears to be a lack of understanding around cultural support – so there is still work to be done.

### **England and Scotland**

In 2017, England and Scotland launched the National Bereavement Care Pathway (NBCP)<sup>9</sup>, which seeks to increase the quality of, and reduce the inequity in, the bereavement care provided by healthcare professionals after the loss of a baby or pregnancy at any gestation.

The NBCP acknowledged five pregnancy and baby loss pathways:

- Miscarriage (including molar and ectopic pregnancy)
- Termination of Pregnancy for Foetal Anomaly (TOPFA)
- Stillbirth
- Neonatal Death
- Sudden Unexpected Death of an Infant up to 12 months.

Guidance materials for the five loss pathways have been regularly updated after input from parents and professionals. There are also eLearning programmes available for professionals to complete training on caring for those bereaved by the loss of a pēpi<sup>10</sup>.

The pathway is based on a set of nine bereavement care standards:

1. A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
2. Bereavement care training is offered to staff who come into contact with bereaved parents, and staff are supported to access this training.
3. All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
4. There is a bereavement lead in every healthcare setting where a pregnancy or pēpi loss may occur.
5. Bereavement rooms are available and accessible in all hospitals.
6. The preferences of all bereaved families are sought, and all bereaved parents are offered informed choices about decisions relating to their care and the care of their babies.

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<sup>9</sup> [National Bereavement Care Pathway Scotland - Launch - Scottish Cot Death Trust](#)

<sup>10</sup> [National Bereavement Care Pathway - elearning for healthcare \(e-lfh.org.uk\)](#)

7. All bereaved parents are offered opportunities to make memories.
8. A system is in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement to enable continuity of care.
9. Healthcare staff are provided with, and can access support and resources to deliver high quality bereavement care.

One of the key findings of the final evaluation report in 2019<sup>11</sup> suggests that across the pilot sites, the NBCP ‘supported effective coordination and collaboration at a national level, enabling the project to succeed at a local level’.

As of 1 January 2023, 108 NHS England Trusts (84%) had committed to adopting the nine NBCP standards, while 21 (16%) were yet to do so.

## Canada

In Canada, supporting families through loss and grief is an integral part of Family-Centred Maternity and Newborn Care. Perinatal loss includes infertility during the preconception period, foetal death during pregnancy (miscarriage, ectopic pregnancy, induced abortion, and stillbirth) and infant death in the first year of life (neonatal or post-neonatal death).

There is recognition that the perinatal period is a sensitive time for all women/people, and acknowledgement in their guide, *‘Honouring Indigenous women’s and families’ pregnancy journeys’*<sup>12</sup>, that it is “*particularly challenging for Indigenous People for whom discrimination, racism, dehumanising interactions, and a loss of autonomy in the healthcare system are everyday experiences.*”

Canadians have identified the ‘Four R’s of cross-cultural dialogue Framework’ as the basis of the change that needs to be undertaken in practice at both an individual and organisational level, in “*collaboration with Indigenous Peoples, recognising and respecting their cultural needs, preferences and priorities.*”

- Respecting Indigenous Peoples for who they are.
- Providing Indigenous Peoples with information that is relevant to and respectful of their worldviews.
- Encouraging reciprocity in healthcare relationships.
- Enabling Indigenous Peoples to exercise responsibility and agency over their health.

Adopting this framework into the clinical environment, and informed by lived experience of Indigenous People, the Canadians have further developed six key principles to guide healthcare providers so that they provide ‘culturally safe, humble, and trauma-informed perinatal care to Indigenous women.’

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<sup>11</sup> [Evaluation of the National Bereavement Care Pathway \(NBCP\): Final report \(Wave two\) | Sands - Saving babies' lives. Supporting bereaved families.](#)

<sup>12</sup> [Honouring Indigenous Women’s and Families’ Pregnancy Journeys: A Practice Resource to Support Improved Perinatal Care Created by Aunties, Mothers, Grandmothers, Sisters, and Daughters | I-Portal: Indigenous Studies Portal \(usask.ca\)](#)

- Cultural Safety and Cultural Humility - ensuring that patients are receptive to care because they feel supported and safe and that healthcare providers, recognising the limits of their understanding, seek guidance from their patients.
- Self-Determination - explaining options so patients can make informed decisions about their treatment and care.
- Trust Through Relationship - fostering a connection with patients built on trust.
- Respect - demonstrating an understanding of, and respect for, traditional practices and knowledge.
- Anti-Indigenous Racism - building awareness of overt and covert racism and developing policies and procedures to deal with racist incidents.
- Strength and Resilience-Based Practice - promoting positive outcomes by focusing on a patient.

### **Learning from others**

Overall, Aotearoa can learn from international models that are already operative. This includes strategies such as:

- Developing collaborative pathways with communities for cultural understanding.
- Ensuring there are clear guidelines and available resources that are regularly updated for professionals.
- Designing centrally but implementing and embedding processes locally.
- Creating detailed checklists to develop patient-led pathways and systems.

However, it is also clear that there is no perfect model or one-size-fits all approach.

Some models are resource intensive, some models are just guidelines with checklists rather than integrated pathways, many regions still struggle to effectively address cultural understanding and competency, some areas do not address less-common stages or reasons for loss, especially termination and unexpected death, and some models still only offer information for parents in pamphlet form.

### **Enhancing the bereavement pathway**

Based on the environmental scan completed, there are additional and specific findings in relation to the loss type / category that could help inform future perinatal pathway development.

These have been broken into the different gestational periods:

#### **Early loss: 12 weeks to under 20 weeks gestation**

The journey for this group of bereaved families, even if the woman/person needs to birth the pēpi, appears to be very different to those with babies over 20 weeks gestation and the delivery of services seems to be varied in terms of support, and handled differently in each region and hospital, and even departments within hospitals.

For example, at Waikato Hospital, care of miscarriages has moved from a semi-acute service to a non-acute service with a delay in women/people being seen moved from 24-48 hours to five days. Other national examples cited include families who have suffered a miscarriage not being admitted past ED and “*leaving the ED with their pēpi in a box and nothing else*”.

In one region, nurses themselves are buying boxes to ensure that whānau can take their pēpi home.

### **Termination – general, and due to anomalies**

Although the law regarding termination of pregnancy changed in 2020, a national pathway of care for women/people and whānau, as well as for staff within the hospital system, has not been given the focus it needs.

The added complexity of termination due to anomalies is additionally challenging.

Attention also needs to be focused on the professional development, supervision and overall mental and emotional wellbeing of staff who work with women/people and whānau in these challenging cases.

### **Stillbirth - over 20 weeks gestation**

Although there is significant variation across the motu, whānau of stillbirth pēpi seem to receive the highest level of care compared to loss at other stages of gestation.

However, due to staff shortages, there is a strain on the overall system, impacting on all levels of care. Additionally, a lack of dedicated, private space for women/people to deliver away from other maternity events, is potentially problematic and additionally traumatising.

### **Neonatal loss – birth up to 28 days**

There is variance between the NICU across the motu. Feedback from one region felt well supported and blessed with a Māori Health team who work with the whānau, staff and chaplain ensuring that the unique needs of each whānau, as far as possible, can be met. However, in other regions, NICU are less controlled and supported environments, care is more variable and can change according to who is on duty, and if other medical and nursing teams beyond the NICU are involved.

A positive development is the NICU Palliative Care Pathway developed by NZ Nurses which is used across the motu. Embedding this pathway well across the motu, along with improved cultural competency, would be a positive focus.

### **Infant Loss: 29 days – 1 year**

One of the challenges of a long stay in NICU is that women/people can lose contact with the LMC, and they can find themselves with no support when they return home. While midwives say they are not funded to follow up after six weeks, some do.

The gap in bereavement support for whānau whose pēpi passes away after 28 days is that they do not meet the criteria for referral to counselling services and many NICU are not in a position to provide, refer or signpost parents to any other support.



## **Perinatal palliative care**

When faced with the palliative care of their pēpi, a clear process setting out timelines, available support services, referral opportunities, counselling, etc., will make it easier for them to manoeuvre through the incredible challenges they will face.

Some communities offer palliative care in the community so that pēpi can die at home.

## **Perinatal Hospice (continuing a pregnancy knowing pēpi will die)**

A perinatal palliative care approach may be appropriate for parents who continue their pregnancy after antenatal diagnosis of fatal foetal anomalies / life-limiting conditions as well as for those who opt for termination of pregnancy.

## **Multiples**

There are few insights or research available for perinatal bereavement involving twins, triplets, or more, whether that be a loss of all pēpi, or one of the pēpi while others survive.

One of our interviewees lost one of her triplets, with two pēpi surviving. She then had to carry all three pēpi through to term, knowing that one was already lost. Once giving birth, the focus of the clinical team was on the surviving pēpi while the woman/person needed to simultaneously grieve one child while starting to take care of the two surviving children.

While this experience is not common, it requires more focus, understanding and support to understand the unique complexities of losing one or more pēpi.

## **Upskilling health professionals**

Formal education, training, and cultural competency - all staff and supporters interacting with bereaved parents (including nurses, social workers, sonographers, radiologists, and junior doctors) need specialist perinatal bereavement support training, so they feel confident and prepared to speak with parents, what they should and shouldn't say, in a culturally appropriate way so that parents are supported appropriately at all touchpoints.

## **Improving processes**

Coroners' cases (generally includes any unexpected, unexplained loss) – concerns from interviewees included the manner processes are handled, particularly interactions with the police who act as the coroner's agents in the community, the length of time coroner's reports take to be completed, information sharing and communication to LMCs and GPs, and official language used in reports. There are, however, some promising signs of change with clinical advisors being recruited to work with the coronial services to, for example, make decisions as to whether a report is needed.

Loss due to accidental death, medical mismanagement, and negligence further complicates the grief that whānau experience and may compromise cultural responsiveness. Support can be provided through the advocacy service within the Health and Disability Commission (HDC), however, there is no clear, simple pathway for parents to explore why their pēpi died and the process that needs to be followed in these situations.

At a time when whānau are grieving, challenges such as needing confirmation from the coroner that the death was accidental, getting a medical certificate, filling in ACC forms

that may or may not be accepted, a lack of counselling or referrals for whānau members all serve to make the situation even more complex than it already is.

## Future opportunities

There are many opportunities identified through this Report to improve the perinatal bereavement pathway, and connect the ecosystem to ensure that women/people and whānau are informed, safe, respected, and supported throughout this harrowing experience.

### 1. Develop a perinatal loss national framework

Good perinatal bereavement care should not be a lottery based on where you live and who you interact with on the day you reach out for support.

Learning from our international counterparts, **development of a national framework that is developed centrally but tailored locally, which sets out the principles and standards of care, is needed to develop consistency and equity across the motu.** A more consistent approach to providing support is important both for whānau and for those providing the care.

While the environmental scan identified conflicting ideas from across the sector on whether the development of national framework will be effective, international models have shown that a national approach tailored to local needs has delivered the greatest success. Community healthcare needs to come from communities, they know what needs to be done and how it can happen, so collaborating and co-designing *with* the sector throughout the process is likely to help achieve the best success in Aotearoa.

To ensure that all those working in, or impacted by, perinatal bereavement in Aotearoa have their voices included, **any new development should be jointly and collaboratively created by health professionals, bereaved parents and their whānau, supporters, experts, and researchers in this field.**

### 2. Put whānau at the core

**Listening to and understanding whānau with lived experiences** has the strongest potential to bring about positive changes in the health system.

**Showing manaaki** will ensure that 'respect, generosity and care' is shown for the people who use services, their whānau and communities' and that their knowledge and experience is taken into consideration.

**Cultural education and awareness of what this looks like as part of the perinatal bereavement pathway is key** to supporting this, while providing greater opportunities for whānau to share their stories in environments (and channels) that they are comfortable and allows them to build whakawhanaungatanga will assist with the grieving process.

### 3. Develop equity pathways

**Grow and sustain the Māori workforce and resources that enable easy access to local and cultural support**, i.e., Kaumatua and Kuia (from local hapū / iwi).

Building pathways of community matching, for example, a Tongan social worker supporting Tongan women/people, can help create equitable pathways for pregnant women/people. This includes ensuring workforces reflect the communities they serve, and others working in those communities are upskilled to ensure they have the skills and understanding to work with whānau from diverse ethnic and cultural backgrounds.

#### 4. Centralise systems and resources

**Empower champions (or teams of 2) in every hospital** contributing to the development of the pathways, connecting across the ecosystem, and leading out the implementation of pathways in their district, subject to resources of individual hospitals and local communities.

**Implement an integrated software system** to ensure no care falls through the gaps or is held by one midwife.

**Dedicated perinatal care rooms in all hospitals and facilitation of all births in maternity care**, even if under 20 weeks.

**Centralise resources** to ensure a base level of equipment is available to all districts (e.g., manaaki mats or cuddle cot), including supplies for memory making, such as clothing, vessels etc., would ensure equitable access across the motu. This will remove a significant barrier for many regions. One option is to fund a charity like Baby Loss NZ to make this service available nationwide.

#### 5. Implement more training and online resources

There is a strong need for **more perinatal bereavement training, resources, and ongoing professional development to be available**, accessible, and relevant for all clinicians, from midwives and doctors, and sonographers to social workers.

Mandatory modules on perinatal bereavement should be included in the curriculum for all midwifery / nursing training, and clinical supervision must be proactively available for professionals, particularly those supporting whānau with perinatal bereavement, thereby contributing to the wellbeing of the workforce.

#### 6. Increase awareness / communications of perinatal bereavement

Perinatal bereavement is a silent epidemic across Aotearoa and globally. **Awareness needs to be increased in the community to minimise cultural stigma and shame**, to normalise conversations about miscarriage, stillbirth and pēpi loss, and to raise awareness of how impactful perinatal bereavement can be on whānau wellbeing.

At the most basic level, **women/people and whānau need reliable, accurate information given in a sensitive and supportive manner**. They need to be able to feel heard and express their feelings and experiences in a safe environment.

Opportunities include:

- An enhanced website of information, resources, and videos where they can seek trusted information and support in the bereavement pathway, for the parents as well as whānau and friends.

- Utilise social and digital media to build awareness and inform people where they can connect with community and support groups.
- All communications and digital content should be culturally relevant and multi-lingual.

## 7. Increase promotion and funding for websites and NGOs

The Whetūrangitia website<sup>13</sup> is very helpful and was developed for whānau and friends of bereaved parents, but the website needs to boost its awareness, which is currently in planning.

Another positive initiative is a new SUDI Bereavement Pathway<sup>14</sup> - based on a duty of care to mitigate eventual harm ensuring wrap around care for whānau who lose their babies. This is setting the bar for community care.

There are also multiple NGOs across Aotearoa, for example, SANDS, Baby Loss NZ, and Little Miracles Trust, that work tirelessly to provide services for parents and whānau, particularly post discharge after a perinatal bereavement.

There is an opportunity for government to consider **promoting and funding these organisations** so that they can continue the essential work they are doing to fill the gaps left by a lack of statutory services, instead of having to expend energy on fundraising.

## 8. Offer counselling and mental health support for parents

While this part of the pathway is being captured under separate pieces of work<sup>15,16</sup>, it seems important to highlight that the need for **ongoing counselling and mental health support** for parents and whānau was raised by most interviewees.

# APPENDIX

## 1. One-on-one whānau interviews

16 interviews were conducted with whānau who have experienced a perinatal bereavement.

A key element in selecting these participants was to ensure there was demographic spread (by District, Age, Ethnicity, Experiences) to provide a broad view of the bereavement pathway experience.

### District

- 1 based in Whangarei
- 8 based in Auckland
- 1 based in Waikato
- 4 based in Bay of Plenty

<sup>13</sup> [Information for bereaved family and whānau experiencing the death of a baby or child | Whetūrangitia \(services.govt.nz\)](https://services.govt.nz)

<sup>14</sup> [SUDI Prevention | SUDI Prevention Coordination Service \(sudinationalcoordination.co.nz\)](https://sudinationalcoordination.co.nz)

<sup>15</sup> Perinatal and Maternal Mortality Review Committee - [Fifteenth Annual Report of the Perinatal and Maternal Mortality Review Committee: Reporting Mortality and Morbidity 2020 | Health Quality & Safety Commission \(hqsc.govt.nz\)](https://www.hqsc.govt.nz)

<sup>16</sup> Te Hiringa Hauora First 1,000 Days - [First 1,000 Days | Te Hiringa Hauora/Health Promotion Agency \(hpa.org.nz\)](https://www.hpa.org.nz)

- 2 based in Mid Central
- 1 based in Wellington
- 1 based in Christchurch

## Age

This is the recorded age at time of interview, with perinatal loss occurring between the ages of 19 and 42 years.

- 5 aged 20-29 years
- 4 aged 30-39 years
- 7 aged 40-49 years
- 2 aged 50+ years

## Ethnicity

- 4 identified as European
- 6 identified as Māori
- 6 identified as Pacific

## 2. Engagement with the perinatal bereavement ecosystem

Interviews have been conducted with the following ecosystem providers:

### Te Whatu Ora Districts

- Te Tai Tokerau / Northland ○ Clinical Midwife Manager and PMMRC Local Coordinator ○ Maternity Quality and Safety Leader ○ Māori Health Advisor
- Counties Manukau ○ Perinatal Loss Midwife Specialist and PMMRC Local Coordinator ○ Family Liaison Nurse NICU ○ Social Workers under 20 weeks ○ Social Worker over 20 weeks ○ Treasured Babies team NICU ○ Kaitipu Ora
- Te Toka Tumai / Auckland ○ Perinatal Loss Midwife Specialist and PMMRC Local Coordinator ○ Perinatal Pathologist ○ Perinatal Pathologist ○ National Perinatal Pathology Co-ordinator ○ Women's Health Social Worker
- Waitematā ○ Perinatal Loss Midwife Specialist and PMMRC Local Coordinator
- Waikato
  - Midwife and PMMRC Local Coordinator and losses over 16 weeks
- Hauora a Toi / Bay of Plenty ○ Midwife and PMMRC Local Coordinator
- Lakes ○ Midwife and PMMRC Local Coordinator ○ Obstetrician
- Taranaki ○ Midwife and PMMRC Local Coordinator
- Whanganui ○ Midwife and PMMRC Local Coordinator
- Te Pae Hauora o Ruahine o Tararua / Mid-Central ○ Midwife and PMMRC Local Coordinator
- Capital, Coast & Hutt Valley ○ PMMRC Local Coordinator ○ Senior NICU Nurse
- Canterbury ○ Midwife and PMMRC Local Coordinator
- Southern ○ Midwife and PMMRC Local Coordinator

- Neonatologist and a lecturer at the University of Otago

### **Other health providers**

- GP, Otara Family Health Clinic
- HIP, Otara Family Health Clinic (Te Tumu Waiora)
- Radiologist
- Nga Kete Matauranga Pounamu Charitable Trust, Invercargill
- Whānau ora
- Community Midwives (x2)

### **Supporters**

- Chairperson, Sands NZ
- Minister, Henderson Presbyterian
- Huggable Hearts
- General Manager, Baby Loss NZ • Little Miracles Trust

### **Grief Counselling**

- The Grief Centre
- PADA - Perinatal Anxiety and Depression Aotearoa
- Consultant Clinical Psychologist, Maternal Mental Health, Northland
- 1737
- Women's Refuge
- Mother's Helpers

### **Death Services**

- Funeral Director, Ann's Funeral Home, Wiri
- Communio/Bereavement Care Coordinator, Counties Manukau

### **Tertiary and other educational bodies**

- Sands NZ
- Baby Loss New Zealand
- Vicki Culling Associates
- Te Tatau o te Whare Kahu/ Midwifery Council of New Zealand
- Lecturer at AUT Midwifery school
- RANZCOG (RANZCOG - Royal Australian and New Zealand College of Obstetricians and Gynaecologists)
- Radiologist
- Kaiāwhina - Toitū te Waiora

### **Researchers**

- Hākui
- Research New Zealand
- Midwife Researcher/Stillbirth CRE/PSANZ

### **Government Departments**

- Department of Internal Affairs, Whetūrangitia website
- Ministry of Business, Innovation & Employment
- Ministry of Justice, Coronial Services
- MoH Children Director of Child and Youth Health re Coronial Services
- ACC

- Health Quality and Safety Commission, PMMRC
- Health Quality & Safety Commission.

### **3. Stages / Reasons of loss**

The following stages / reasons of loss have been captured as part of this environmental scan:

- Fertility
- Very early loss – Under 12 weeks gestation
- Early loss – 12 weeks to under 20 weeks gestation
- Termination - general
- Termination - due to anomalies
- Termination - due to social determinants, under 20 weeks
- Termination - due to social determinants, over 20 weeks
- Stillbirth - over 20 weeks gestation
- Loss due to medical negligence
- Loss due to accidental death
- Unexpected/unexplained loss • Neonatal loss – birth up to 28 days
- Perinatal palliative care.

### **Researchers and Authors**

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