

Research New Zealand

Survey of and Qualitative Research with Whānau and Families Who Have Lost a Pēpē/Baby (Technical Report 2)

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Survey of and Qualitative Research with Whānau and Families Who Have Lost a Pēpē/Baby (Technical Report 2)

PREPARED FOR	Te Whatu Ora – Health New Zealand
PREPARED BY	Katrina Magill, Corrine de Bonnaire, Emanuel Kalafatelis, Jane Falloon, Sarah Buchanan (Research New Zealand) and Teresa Taylor (TT Consulting Tāpui)
CONTACT DETAILS	Emanuel Kalafatelis Research New Zealand Phone 04 499 3088 www.researchnz.com
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Definitions

Bereaved woman or person – bereaved woman or person who has lost a pēpē/baby after 20 weeks of pregnancy and up to the 28th day following birth.

Maximum margin of error – is a measure of the accuracy of the data at the 95% confidence level and takes into account the total (or sub-) sample size of the result that is being considered. For example, in the case of the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby that has an achieved sample of n=118, the maximum margin of error is +/-7.9% (at the 95% confidence level).

This means that had we found that 50% of respondents were ‘satisfied’ with their ‘overall experience of care during their pregnancy, labour and birth, postnatal care and the care they and their pēpē/baby (received) in the first few weeks at home’, we could be 95% sure that we would have got the same result had we interviewed every person in the eligible population, give or take 7.9%.

Significant – refers to the fact that the difference between two results is larger than the maximum margin of error. Therefore, this is an **actual or real** difference, rather than one that has occurred because of a sampling anomaly.

Foreword

Te Whatu Ora would like to thank the participants of the the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby who gave their time and generously shared their very personal experiences. Their views, comments and openness are greatly appreciated and will provide valuable insight to help guide future service design and planning.

Executive Summary

IMPORTANT NOTE:

The timeframe of this research is important when considering the results of this survey and qualitative research, given that the antenatal, birth and postnatal care of the mothers and birthing parents who took part falls within the period impacted by the COVID-19 pandemic which had a significant impact on the health sector, as well as New Zealand society in general.

Introduction

This technical report presents the results of the **2022 Survey of Whānau and Families who have Lost a Pēpē/Baby**. The results of **qualitative research** with bereaved women and people, specifically completed to provide insights to inform the National Bereavement Pathway, are also presented.

2022 Survey of Whānau and Families who have Lost a Pēpē/Baby

The 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby was completed between 24 August and 4 October 2022, based on a sample provided by Te Whatu Ora, which represented women and people who had experienced a perinatal death between January 2020 and November 2022.

The results of the survey are based on an achieved sample of n=118 respondents, most of whom had lost their pēpē/baby up to 28 days after birth (39%). The participation rate for the survey is 29%.

The achieved sample has **not** been weighted, mainly because it is reasonably similar to the original sample in terms of how, and when, women and people lost their pēpē/baby (viz. medical termination, pēpē/baby died during pregnancy/labour or the birth, pēpē/baby died within 28 days of the birth).

Survey findings

The key findings of the survey are as follows:

1. **A little over one-half of bereaved respondents (53%, or n=63) were satisfied** with the 'overall standard of care and support they received prior to, during and immediately following the loss of their pēpē/baby'.

Although the results are not directly comparable because of differences in the make-up of the achieved samples, at 74%, satisfaction was higher in 2014.

2. The following could account for the relatively low satisfaction result:

- While two-thirds of all bereaved survey respondents (64%, or n=75) stated they 'received all the care and support they needed at the time' their pēpē/baby died, one-in every-four (27%, or n=32) said they did **not**.
- One-fifth of bereaved survey respondents obtaining scans (20%, or n=11) stated they were '**difficult to obtain**', and over one-quarter (28%, or n=18) stated that they were **not provided with enough information** or explanation about what the test/scan results meant and what options were available to them.
- Similar results were recorded for those obtaining diagnostic tests and/or a post-mortem. One-quarter (26%, or n=31) stated they were **dissatisfied with the information they obtained**.
- Less than one-half of all survey respondents whose pēpē/baby was stillborn as a result of a termination, or whose pēpē/baby was stillborn/died during the pregnancy or labour stated they were 'very satisfied' with the '**amount of privacy they had**' (45% 'very satisfied', or n=53) and one-third said they were 'very satisfied' with '**how well equipped and resourced the hospital seemed to be to provide them with the bereavement care and support they needed**' (32% 'very satisfied', or n=37).
- Some bereaved survey respondents (14%, or n=10) received **no visits or contact** after the death of their pēpē/baby. Almost one-third (30%, or n=20) receiving assessment visits stated **they wanted more visits**. Although most bereaved respondents (89%, or n=41) whose pēpē/baby died up to 28 days after birth reported they had some form of contact subsequent to their pēpē/baby's death, 11% (or n=5) received **no contact**.

3. **Relatively few** bereaved survey respondents received counselling and mental health support:

- While one-half of bereaved survey respondents (57%, or n=67) were offered counselling or mental health support, 46% (n=31) actually received counselling. This represents one-quarter (26%, or n=31) of all survey respondents; meaning that the balance (74%, or n=87) were either **not offered counselling or did not receive it**.
- Three-quarters of respondents who did receive counselling or mental health support (74%, or n=23) found the services 'easy to access' and the same percentage found the timing 'about right' (74%, or n=23). However, some found the timing either '**too soon**' (13%, or n=4) or '**too late**' (6%, or n=2).
- In addition, over one-third (39%, n=12) felt they did **not have enough counselling sessions**.

Qualitative Research with Whānau and Families who have Lost a Pēpē/Baby

The qualitative research included a total of n=18 women and people who had lost their pēpē/baby within the previous 18-months. Research participants took part in small group discussions with other women and people who had lost their pēpē/baby in similar situations (e.g., lost their pēpē/babies during labour). All interviewing was completed between 31 August and 28 September 2022, and was conducted via Teams.

Bereaved women and people were invited to participate in the qualitative research with the assistance of Sands NZ. In addition to the groups of bereaved women and people included in the survey (viz. those who had lost their pēpē/baby after 20 weeks, during labour, within 28 days of birth and whose pregnancies were medically terminated, the qualitative research also included a small group of women and people who had lost their pēpē/babies before 20 weeks.

Qualitative research findings

In many cases corroborating the results of the survey, the key findings of the qualitative research are as follows:

1. **Not all professionals compassionately communicated the news that a pēpē/baby had died** (e.g., one qualitative research participant reported the sonographer walked out of the room in shock, without saying a word, on discovering her pēpē/baby had died).
2. **Good information and advice and being respectful of women's and people's decisions, helped reduce the burden of making decisions about medical terminations.**

In contrast, examples of behaviours that left some women and people feeling unsupported included feeling pressured to terminate their pregnancies; and feeling their decisions to terminate were being questioned.

3. **The experience of miscarrying at home or being sent home to begin an induced labour, was described by some qualitative research participants as “frightening”,** especially for those who were not provided with information to adequately prepare them for the severity of their bleeding and clots.
4. **Qualitative research participants who were cared for by midwives with bereavement training and those who were given rooms where they were unable to see or hear other birthing mothers and people and their pēpē/babies, were more likely to report they were well cared for and supported while in hospital.**

Examples of the supportive behaviours of hospital midwives and/or other hospital staff included: sharing their condolences; regularly checking on women and people to make sure they were OK; helping them with the practical things (e.g., funeral arrangements, paperwork); helping make memories of their deceased pēpē/baby; taking the time to

make sure that women and people who lost their pēpē/babies in labour understood what had happened.

In contrast, the impact of negative hospital experiences added to the distress of some bereaved women and people. For example, seeing and hearing other birthing mothers and people and pēpē/babies; feeling as though they were **being ignored and avoided** after losing their pēpē/babies; **having cultural needs unmet** and disrespected; being sent home to wait for a time that better suited the hospital to birth their deceased pēpē/baby.

5. **Systemic issues and other issues associated with the maternity and perinatal system are having a negative impact on the wellbeing of bereaved women and people, including:**

- **Poor information sharing** (e.g., receiving a welcome pack from the hospital, a call from an anaesthetist in preparation for a Caesarean) left some qualitative research participants feeling unnecessarily distressed.
- The belief by some women and people that there is **a misperception within the maternity and perinatal system that early miscarriages have a relatively minimal and short-term impact on women and people**, leading to those who have early miscarriages being disadvantaged in terms of the quality and extent of the support and care they received.
- **The potential for women and people to slip between the cracks in the system, if they do not have a strong LMC midwifery relationship.** For example, one qualitative research participant felt let down by their midwife (and the other health professionals she had approached for help), when she raised concerns about the wellbeing of her unborn pēpē/baby, who died just days later.
- **Poor access to mental health services during pregnancy.**

6. **The support provided by follow-up visits, counselling and support groups is vitally important for those living with the loss of a pēpē/baby.**

Some bereaved women and people felt well supported in the period immediately following their loss with **follow-up visits and contact** from their LMC and/others (e.g., a hospital social worker, their GP). Others felt “forgotten and alone” because they did not receive any follow-up at home after the loss of their pēpē/baby and that they left the system without any information about where they could get the support they required.

Almost without exception, the bereaved women and people who participated in this research wanted **counselling to help them process their losses**. As such, some were shocked to learn that they were generally not eligible for free, or even subsidised, counselling.

Finding a counsellor was often described as difficult (e.g., long wait times, lack of access to fit-for-purpose subsidised counselling).

Bereaved women and people who found their way to the volunteer support groups for bereaved women and people (e.g., Sands NZ) found the support that they received immeasurably helpful.

7. The bereaved women and people who participated in this research suggested the following improvements to current maternity and perinatal services:

- **Listen to hapū/pregnant women** if they are worried about themselves or their pēpē/baby.
- **Address the shortage** of midwives.
- **Support bereavement education** across the maternity and perinatal workforce.
- Have midwives and other staff with bereavement training **on each shift, in every hospital**.
- **Improve follow-up care** after any perinatal loss.
- Fund and support access to **counselling services** following any perinatal loss.
- **Better information resources** (e.g., information to support women during the miscarriage process; resources to help with grieving; up-to-date information about the volunteer support groups and services).

1.0 Introduction

1.1 Purpose, objectives, and method

The overarching purpose of the 2022 Survey of Whānau and Families Who Have Lost a Pēpē/Baby and the 2022 Survey of Whānau and Families' Experience of the Maternity System was to measure mothers' and birthing parents' perceptions of, and satisfaction with, the maternity/perinatal services they had recently received, and to compare their satisfaction with the results recorded in previous surveys (where possible).

The 2022 Survey of Whānau and Families Who Have Lost a Pēpē/Baby is the third time this survey has been completed. The 2022 Survey of Whānau and Families' Experience of the Maternity System provides the sixth assessment of mothers' and birthing parents' satisfaction with maternity and perinatal services.

In addition to these two surveys providing Te Whatu Ora with an understanding of mothers' and birthing parents' perceptions of and satisfaction with the maternity and perinatal services they have received, the survey results also provide a basis on which to:

- Assess current inequities and barriers to maternity/perinatal care for priority groups. These groups include Māori, Pasifika, young mothers, and birthing parents (defined as 24 years of age and under), and disabled mothers and birthing parents.
- Assess the current framework for primary services.
- Assess the impact of new and ongoing policies.
- Identify women's/people's unmet needs and areas requiring service improvement, particularly with respect to the development of the National Perinatal Bereavement Pathway.
- Inform future planning and service development through the health and disability system.

With respect to the last two objectives outlined above, the 2022 research also included a significant **qualitative** research component as a complimentary study to the surveys.

1.2 Methodological overview

1.2.1 The 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby

This survey was completed between 24 August and 4 October 2022, after ethics approval had been obtained from the Health and Disability Ethics Committee (HDEC), and the survey questionnaire had been extensively redeveloped, cognitively tested, and piloted in 2021.

Bereaved women and people were invited to take part in the survey if they had lost a pepe/baby between 2020 and 2022.

The results of the survey are based on an achieved sample of n=118 respondents, representing an overall participation rate of 29%. Most respondents' pēpē/baby had either died up to 28 days after birth (39%) or during their pregnancy (27%), while 21% of respondents had their pregnancy terminated because of health reasons. Thirteen percent of respondents reported that their pēpē/baby had died during labour.

Although respondents were given the choice of completing the survey online or by telephone, the majority (n=116) opted to complete it online.

Please refer to the appendices for additional methodological information, including a copy of the survey questionnaire.

1.2.2 Qualitative Research with Whānau and Families Who Have Lost a Pēpē/Baby

The qualitative research included a total of n=18 women and people who had lost their pēpē/baby within the previous 18-months.

The primary objective of the qualitative research was to provide an **understanding** of bereaved women's and people's experiences, rather than to quantify these (which was the purpose of the survey). Therefore, while it is possible to identify variations in responses, it is not possible to extrapolate these findings to all bereaved women and people, or to specific groups of bereaved women and people (e.g., those who lost their pēpē/babies during labour).

Research participants took part in small group discussions with other women and people who had lost their pēpē/baby in similar situations (e.g., lost their pēpē/babies during labour). All interviewing was completed between 31 August and 28 September 2022, and was conducted via Teams.

Bereaved women and people were invited to participate in the qualitative research with the assistance of Sands NZ. In addition to the groups of bereaved women and people included in the survey (viz. those who had lost their pēpē/baby after 20 weeks, during labour, within 28 days of birth and whose pregnancies were medically terminated, the qualitative research also included a small group of women and people who had lost their pēpē/babies before 20 weeks.

Please refer to the appendices for additional methodological information, including a copy of the qualitative discussion guide.

1.3 Report notes

Only statistically significant survey results are reported in this report (Section 2) and, because of the relatively small size of the achieved sample of bereaved respondents, no comparisons have been made between respondents on the basis of how and when they lost their pēpē/baby, or their demographic characteristics.

The qualitative research findings are presented in Section 3.

In addition to this technical report (Technical Report 2), additional reports have been prepared as follows:

- A technical report based on the results of a survey of mothers and birthing parents who had given birth between January and November 2021 (Technical Report 1: 2022 Survey of Whānau and Families' Experience of the Maternity System).
- A technical report based on qualitative focus groups with priority audiences that had live births (viz. Māori, Pasifika, young mothers aged under 25 years of age, members of the LGBTQ+ community, and disabled mothers and birthing parents), to provide insights into the experiences of women and people known to be disadvantaged by the maternity and perinatal system. This qualitative research is reported in Technical Report 3: Insights into the Experiences of Mothers and Birthing Parents known to be Poorly Served by the Maternity and Perinatal System.

A summary report has also been prepared based on all three technical reports (New Zealanders' Experiences and Perceptions of the Maternity and Perinatal System 2022. A Summary Report).

2.0 Survey results

This chapter of the report focuses on the findings of the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby. Results are based on the n=118 bereaved survey respondents who had recently experienced a perinatal death.

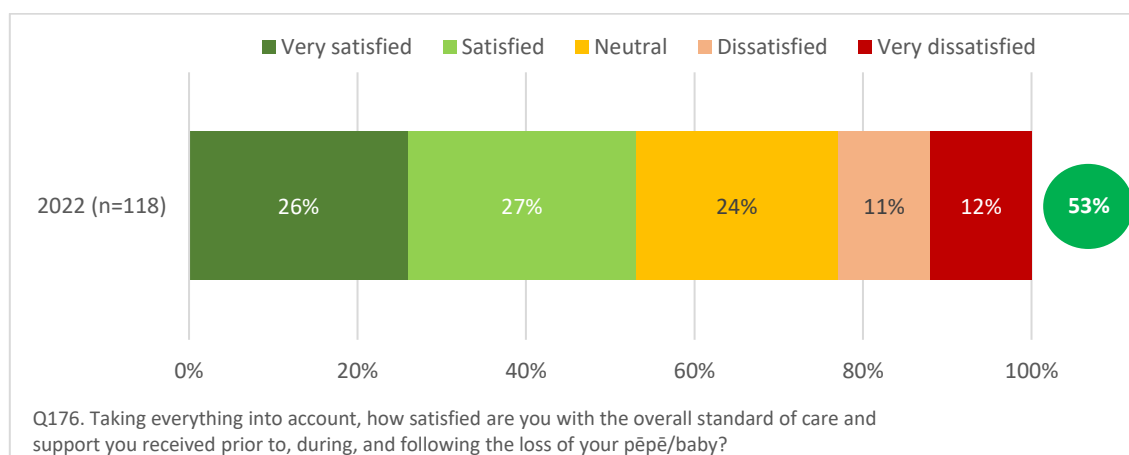
2.1 Satisfaction with the overall experience of care

As illustrated in Figure 1, just over one-half of bereaved respondents interviewed for the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby (53%, or n=63) were 'satisfied' or 'very satisfied' with the 'overall standard of care and support they received prior to, during and immediately following the loss of their pēpē/baby'.

In comparison, approximately one-in-four (23%, or n=27) stated they were 'dissatisfied', and a similar percentage provided a neutral response (24%, or n=28).

Although the results are not directly comparable because of differences in the make-up of the achieved samples, at 74%, satisfaction was higher in 2014.

Figure 1: Overall satisfaction with the care and support received



Below are examples of the feedback received from respondents who were **satisfied** with the care and support they received:

My midwife and all hospital midwives I encountered were sensational human beings, such love and care in their nature. [Pēpē/baby was lost during pregnancy; Very satisfied]

I was fortunate with both of my baby losses [in] that I had a great midwife and obstetrician to provide me and my family with a great amount of care and advice through the most difficult time in our lives. The care I received during both my high-risk pregnancies and the birthing; I cannot fault. [Pregnancy was terminated for health reasons, Satisfied]

In contrast, here is an example of the feedback received from respondents who were **dissatisfied** with the care and support they received:

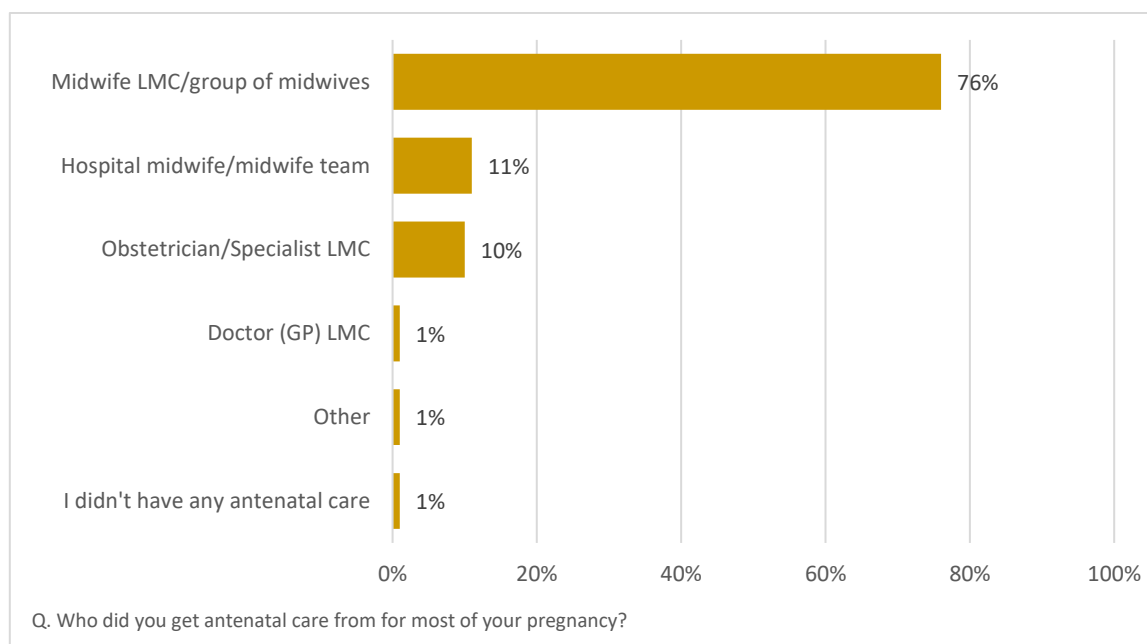
My care was a disaster from start to finish. It left me feeling invisible and like I didn't matter. Having no dedicated midwife meant things were lost and there were so many inaccurate notes. I got mental health support while I was pregnant as I was very anxious and [then] the week after my baby died - they rang me and asked if I was going to kill myself and then [I was] told I would be discharged as this service was only for mums who had babies [who were still alive]. I was not offered any support from a social worker or Māori Health Services. The documentation was wrong, with wrong time of birth and death. I had to get discharge summaries changed several times and they still didn't get it right. It said I had an epidural [but] I didn't. Most of the information was wrong. Other than a Sands [NZ] pack, no real support was given. After I gave birth and when he eventually died the midwife just left and I didn't see anyone until 10pm that night. [Pregnancy was terminated for health reasons; Very dissatisfied]

2.2 Antenatal care

Three quarters of all bereaved survey respondents (76%, or n=90) received antenatal care from a midwife Lead Maternity Carer (LMC) or group of midwives, as did 72% in 2014.

Approximately one-in-ten received antenatal care from a hospital midwife (11%, or n=13) or an obstetrician or specialist LMC (10%, or n=12) (Figure 2).

Figure 2: Antenatal care provider



Unweighted base n=118.

Total may not sum to 100 percent due to rounding.

However, 12% of survey respondents (n=14) reported they did **not** have an LMC. These respondents were asked to report their reasons for this.

Although the sample size is very small, nine of the n=14 respondents said this was because there was shortage of LMC's in their area. This equates to 8% of all bereaved respondents.

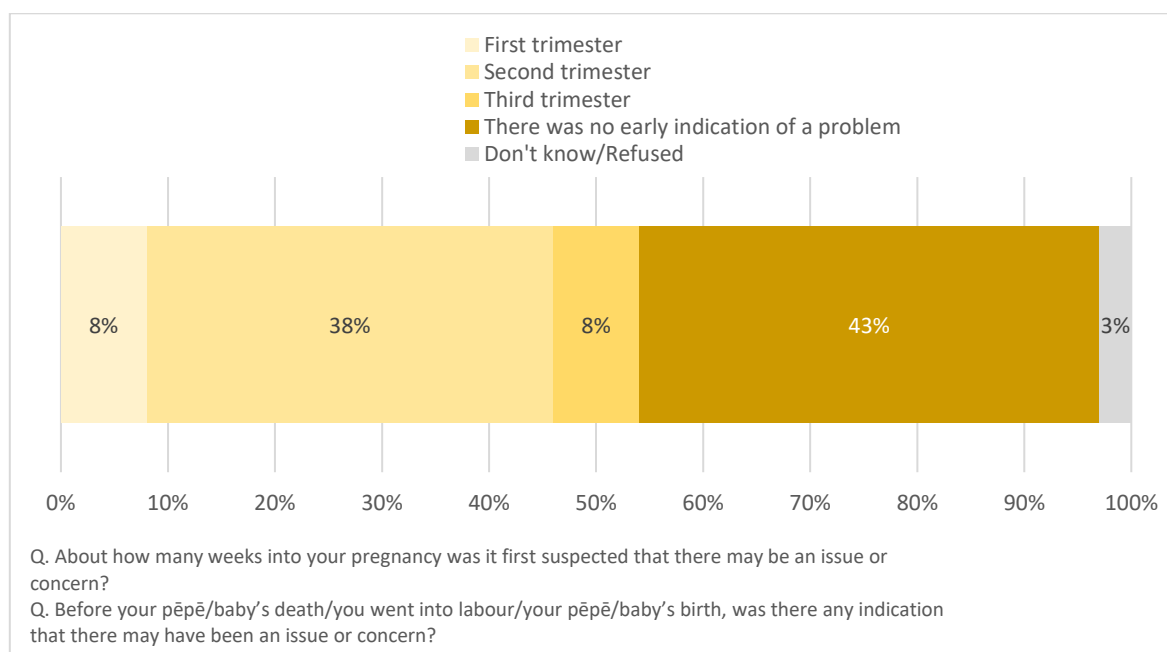
Another n=2 respondents wanted or needed to use the hospital team of midwives.

2.3 Early detection of potential issues or concerns with the pregnancy

All bereaved survey respondents were asked if there were any early indications, or if it was suspected that there might be an issue or concern with their pregnancy. A little over one-half (54%, or n=64) stated there were **some early warning signs**.

Most of these arose during the second trimester (38%, or n=45), although 8% (n=10) said they were in their first trimester when it was first suspected that there may be an issue or concern. Another 8% (n=9) reported indications of concerns in their third trimester (Figure 3).

Figure 3: Early indication of issues or concerns



Unweighted base n=118.

Totals may not sum to 100 percent due to rounding.

The n=95 respondents whose pregnancy was terminated, whose pēpē/baby died during labour or the birth, or whose pēpē/baby died within 28 days of the birth (and for whom there were early indications or concerns), were asked if anyone had suggested they have tests or scans to see if there might be a problem.

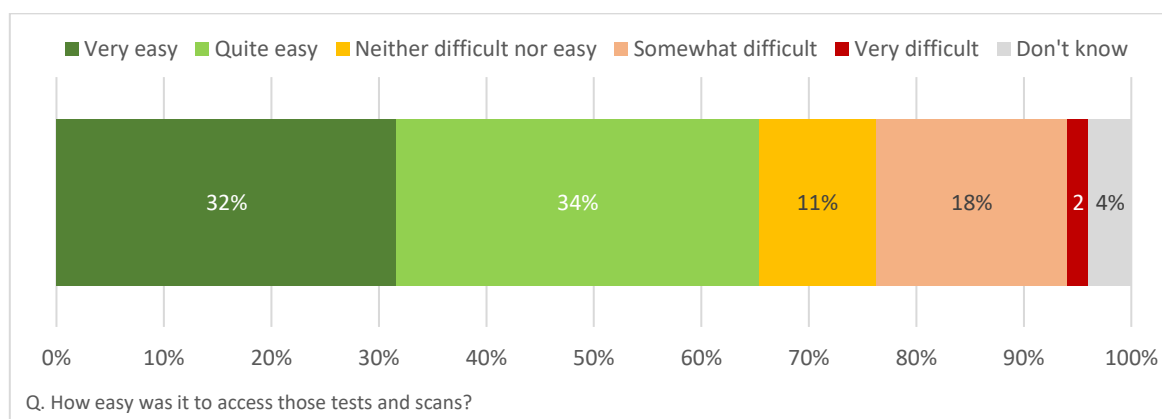
Sixty percent (n=57) of these respondents stated that someone had suggested they have tests or scans.

Almost all (98%, or n=56) of those for whom tests, or scans were suggested, subsequently had a test or scan. This equates to 47% of all bereaved respondents.

2.4 Accessing services

As illustrated in Figure 4, one-third of bereaved survey respondents (32%, or n=22) who had tests or scans to detect any possible issues or concerns, found that accessing those services was **'very easy'**. Another 34% (n=19) found it **'quite easy'**. However, the remaining third provided a neutral response (11%, or n=6) or said that accessing tests and scans was difficult (20%, or n=11).

Figure 4: Accessibility of tests and/or scans



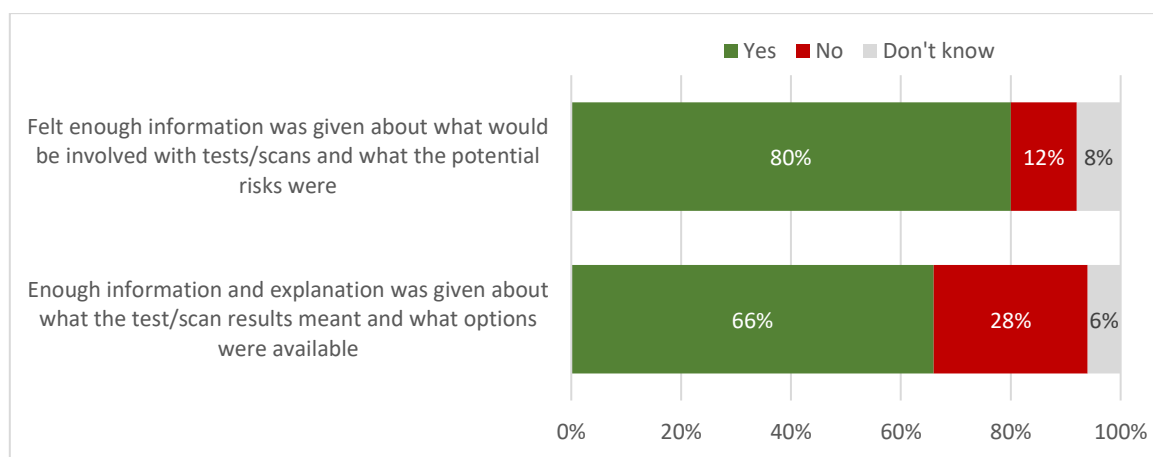
Unweighted base n=56.

Sub-sample based on respondents who had tests/scans to identify if there was a problem. Total may not sum to 100 percent due to rounding.

Most of bereaved respondents (80%, or n=51) who had tests or scans, felt that they were provided with enough information **beforehand** about what would be involved and what the potential risks were (Figure 5 overleaf).

However, **fewer** (66%, or n=42) felt that they were provided with enough information or explanation about **what the test/scan results meant and what options were available to them**. Just over one-quarter (28%, or n=18) believed they were **not** provided with enough information or explanation.

Figure 5: Whether respondents were given enough information about tests/scans



Unweighted base n=64.

Sub-samples are based on respondents who had tests/scans to identify if there was a problem.

Total may not sum to 100 percent due to rounding.

2.5 Information and support provided to those **terminating** their pregnancy

Following the discovery of a foetal abnormality, 21% (n=25) of bereaved survey respondents made the decision to **terminate their pregnancy**:

- Most (72%, or n=18) of those whose pregnancy was terminated felt that they were given **enough time** to make their decision.
- Seventy-two percent (n=18) felt they were given **all the support they needed** to decide how to proceed.
- Most also felt that they were given **all the information they needed** to make an informed decision about ending the pregnancy (72%, or n=18).

The five respondents who felt that they didn't have all the information they needed to make that decision were asked what additional information or support they needed at the time. Examples of their replies are as follows:

They gave me all the worst-case scenarios and scared me so much I felt I had no other choice. They had a preference on what should be done but told me it was my choice.

[I] just felt rushed and had questions but [it] was hard to get answers that I could understand, [instead of] medical terminology.

I would have liked to have a better understanding of the potential quality of life my son [would have had], had he survived to term based on his diagnosis. Also, a better understanding of who else we could have consulted for a second opinion or understanding.

Once they had made their decision, 80% of those who decided to end their pregnancy (n=20) felt they were given enough information about **what to expect** in terms of the termination procedure, labour, and birth.

2.6 Information and support provided to those whose pēpē/baby died during pregnancy

Twenty-seven percent of bereaved survey respondents (n=32) reported that their pēpē/baby died **during pregnancy**.

- While most (62%, or n=20) of these respondents lost their pēpē/baby in their third trimester, 31% (n=10) experienced their loss in their second trimester and 6% in the first trimester (n=2). Thirty eight percent (n=12) lost their pēpē/baby at 35 weeks or more.
- Most were told by their GP that their pēpē/baby had died (53%, or n=17), or by a midwife (hospital-based – 22%, or n=7 or LMC – 6%, or n=2). A further 16% (n=5) were told by a sonographer or radiographer.

Just under one-half of respondents (47%, or n=15) were 'very satisfied' or 'quite satisfied' with how caring and supportive these health professionals were when they were told their pēpē/baby had died. However, 28% (n=9) reported being 'neither satisfied nor dissatisfied' while 25% (or n=8) were 'very' or 'somewhat dissatisfied'.

Although 59% (n=19) of those whose pēpē/baby died during the pregnancy felt they were given all the information they needed about what would happen during labour and the birth of their pēpē/baby, in hindsight, 66% (or n=21) said that additional information would have been helpful.

Most of the comments about additional information that would have been helpful, were about being prepared for **pēpē/baby's appearance** after birth:

To be made aware of how my baby may look, because it's a terrifying time and I was terrified to see my baby. I wasn't aware how he could look or how his skin could be, the amount of meconium covering him or the fact his head would move around and his nose would bleed. It was traumatic to have to figure it all out alone.

To be explained the process of having a stillbirth, that I could bathe, hold, dress my baby without harming her. Explained why stillbirth babies have blood red lips, that blood leaks from their nose and mouth.

I wish I'd had some warning about how her skin might be damaged and deteriorated. I wasn't expecting that, and it really haunted me.

Hospital tried to call the photographer once I gave birth but couldn't get hold of anyone, would have liked this set up earlier. Wasn't aware his skull would sink in. We were in shock but would have liked to have done hand and feet moulds at the time.

Other information that women and birthing parents would have liked included information about what would happen during and after, including pain relief and side effects of medication and how to care for pēpē/baby post-birth):

That I would be given no pain relief during labour as it was risky. No one told me this.

Side effects of the medication used to induce labour, that I would likely stay overnight, what to bring with me.

Probably just what the process would be after having our baby. We knew we had to birth her, but didn't know anything about what you do, how long you stay, what support is available, about burying or cremating your child etc.

Pamphlets would have been great, then you can re-read and comprehend. We received very little information and when we did it was verbal and directed at only one person (the mother).

If and how I could see my baby and spend time with them. Ways to remember and celebrate them.

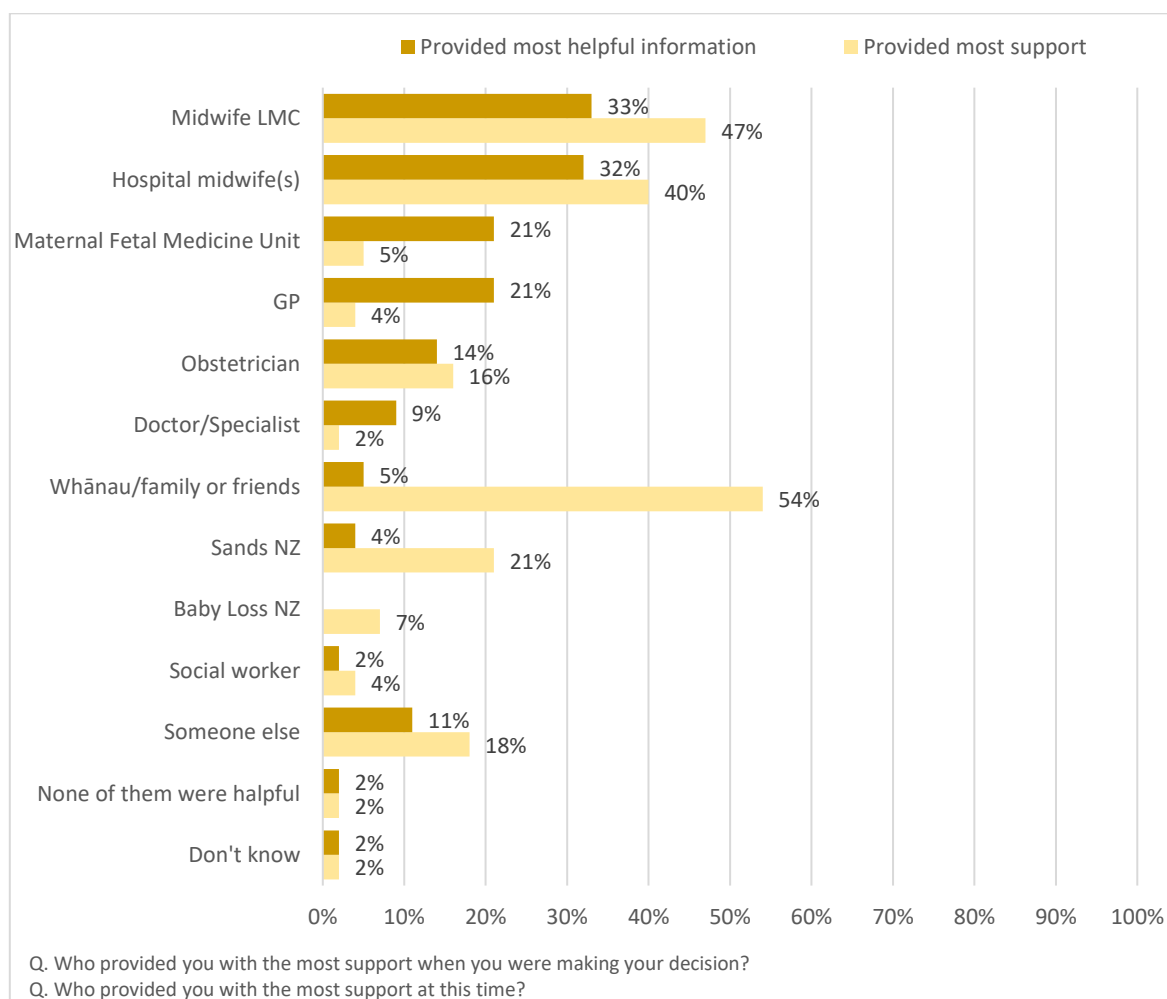
2.7 Most helpful information and support when making decisions

Bereaved survey respondents whose pēpē/baby died during pregnancy or whose pregnancy was terminated (n=57), were asked who provided them with the most helpful information and support when **making their decisions** about what would happen next (i.e. whether or not to continue with the pregnancy, or for those whose pēpē/baby had already died, what to do in regard to the birth of the pēpē/baby).

The most **helpful information** from a health professional/support group came from either their midwife Lead Maternity Carer (33%, or n=19) or a hospital midwife (32%, or n=18), followed by health professionals from the Maternal Foetal Medicine Unit (21%, or n=12) or their GP (21%, or n=12) (Figure 6).

In terms of support, 54% (n=31) said their whānau/family or friends were the most **supportive** when making their decision, followed by their midwife (LMC – 47% or n=27, hospital – 40% or n=23).

Figure 6: Who provided the most helpful information and support about making decisions



Unweighted base n=57.

Sub-sample is based on respondents who terminated their pregnancy due to health reasons or pēpē/baby died during pregnancy.

Total may not sum to 100 percent due to multiple response.

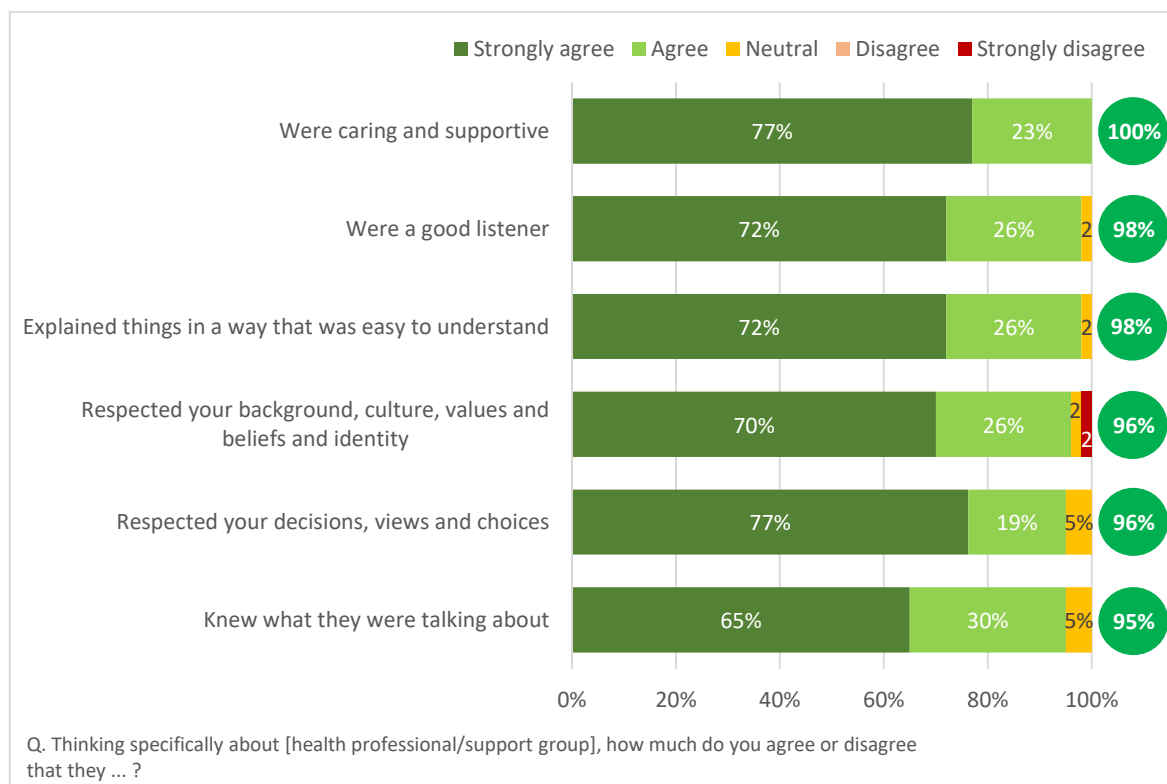
Respondents whose pregnancy was terminated or whose pēpē/baby died during pregnancy, and who identified a health professional or support group as ‘most supportive’, were asked to rate them against a list of six key attributes.

As illustrated in Figure 7, these supportive health professionals/support groups were rated very highly in terms of all the attributes, with at least 70% (n=30 out of n=43) ‘strongly agreeing’ that five of the six applied:

- They respected their ‘background, culture, values and beliefs and identity’ (70% ‘strongly agreed’).
- They were a ‘good listener’ and ‘explained things in a way that was easy to understand’ (72% ‘strongly agreed’ with both of these attributes).
- They were ‘caring and supportive’, and ‘respected their decisions, views and choices’ (77% ‘strongly agreed’ with both of these attributes).

Slightly fewer respondents ‘strongly agreed’ that their ‘most supportive’ health professional/support group ‘knew what they were talking about’ (65% ‘strongly agreed’ with this).

Figure 7: Attribution ratings for most supportive health professional/support group



Unweighted base n=43.

Sub-sample is based on respondents who terminated their pregnancy due to health reasons or pēpē/baby died during pregnancy.

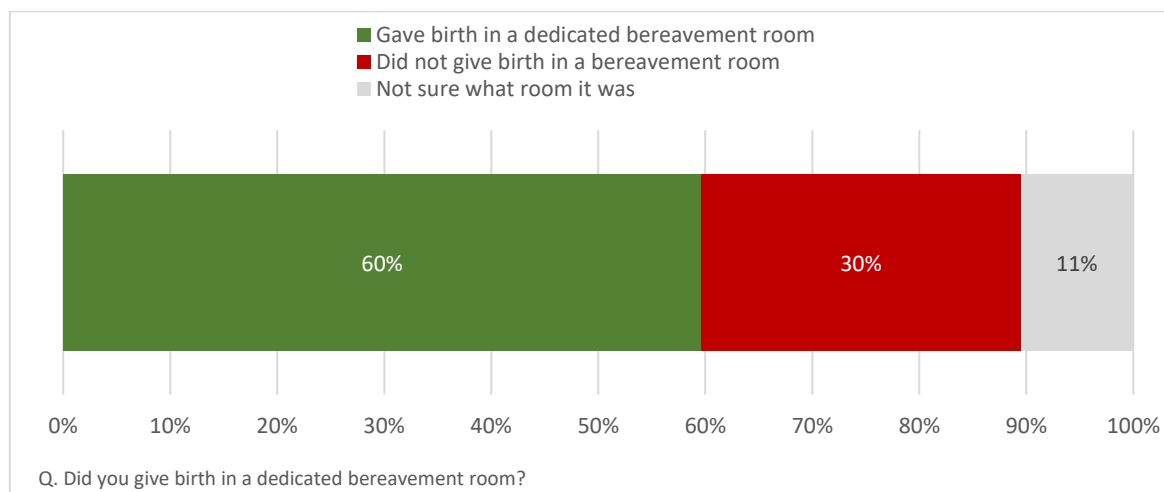
Totals may not sum to 100 percent due to rounding.

2.8 Place of birth

Bereaved survey respondents whose pēpē/baby died during labour or up to 28 days after being born (n=61), were asked to identify where the birth of their pēpē/baby had taken place. The majority (90% or n=55) reported having given birth in a hospital, while 7% (n=4) gave birth at home and 3% (n=2) at a birthing unit.

Respondents whose pēpē/baby was stillborn (during the pregnancy or as a result of a termination), were asked if they gave birth in one of the hospital's dedicated bereavement rooms. As shown in Figure 8, 60% (n=34) reported that they had given birth in a dedicated bereavement room. Another 30% (n=17) said they did not, and 11% (n=6) were unsure.

Figure 8: Whether respondents gave birth in a dedicated bereavement room or not



Unweighted base n=57.

Sub-sample based on respondents who gave birth at a hospital. Respondents whose pēpē/baby died up to 28 days after birth were not asked this question.

Total may not sum to 100 percent due to rounding.

Respondents whose pēpē/baby died during labour were asked if they had access to a dedicated bereavement room **after** the birth. Of the n=15 respondents, n=11 reported having access to a dedicated bereavement room.

2.9 Improving the place of birth

Bereaved survey respondents whose pregnancy was terminated, or whose pēpē/baby died during the pregnancy or in the 28 days after birth (n=103), were asked if there was anything they would **change** about the location or surroundings of where they gave birth.

While 41% (n=42) said they would **not** change anything, 44% of respondents (n=45) did provide some suggestions, the most common of which (suggested by 24%, or n=25 respondents) was to have been in a **private room** away from the maternity ward (and therefore away from hapū/pregnant mothers and live babies).

The following are comments about the difficulties associated with a lack of privacy and especially the distress associated with being able to see and hear babies and their parents and whānau.

The room was awful, no privacy. All my whānau were coming to see my son and I couldn't leave the room because I didn't want to see babies and pregnant mothers, so I had to go bathroom in the same room as my baby and my whānau. There was not even a door of the bathroom just a curtain. I could hear babies crying all night. I would wake up and think my son might be alive and I was crazy, but I wasn't.

[Pēpē/baby was terminated]

Be further away from other birthing rooms. Could hear lots of the other babies and I did not want to leave the room, despite the long labour, as I didn't want to go through the maternity ward, etc. [Pēpē/baby was terminated]

Not to be put in a room at the end of the maternity suite, to be allocated a room away from happy parents, pregnant mothers and crying babies. To have a specialised team of nurses caring for you. To be made to feel important, not an inconvenience that you are birthing a dead baby. [Pēpē/baby died during pregnancy]

2.10 Care and support following birth/pēpē/baby's death

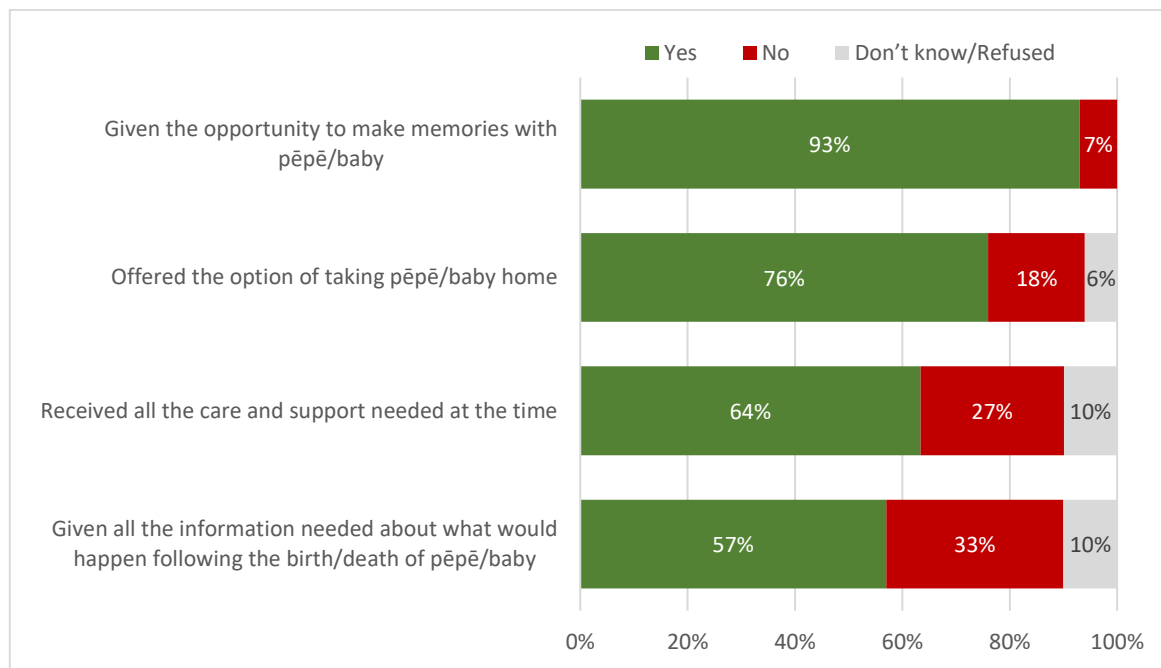
All bereaved survey respondents were asked a series of questions about the care, support and options provided to them **following the birth/death** of their pēpē/baby.

As illustrated in Figure 9, two-thirds (64%, or n=76) felt they received all the care and support they needed at the time, while 37% did **not** (or were unsure) (n=44).

Most (93%, or n=110) reported that they were given the opportunity to make memories with their pēpē/baby and three-quarters (76%, or n=90) were offered the option of taking their pēpē/baby home.

In comparison, a little over one-half 57% (n=67) stated that they were given all the information they needed about what would happen following the birth/death of their pēpē/baby while one-third (33%, or n=39) said they did **not** receive all the information they needed at that point and another 10% were unsure (n=12).

Figure 9: Care and support received after the birth



Unweighted base n=118.

Totals may not sum to 100 percent due to rounding.

2.11 Immediate information needs following pēpē/baby's birth/death

The n=103 bereaved survey respondents whose pregnancy was terminated, or whose pēpē/baby died during pregnancy or up to 28 days after the birth, were asked if they felt they were provided with all the information they needed about what would happen next, following their pēpē/baby's birth/death. At the time, 56% (n=58) believed they received all the information they needed.

In hindsight, one-half (48%, or n=49) said it **would** have been useful to have received additional information at that time, particularly with regard to the appearance of their pēpē/baby and what support services would be available to them (Figure 10 overleaf). Comments in this regard were as follows:

- The **appearance of their pēpē/baby** (n=15):

What to expect them to look like at that gestation. [Pēpē/baby was terminated]

How baby would look and why after being born days after passing away, how to keep them cool at home, what they would look like after a post-mortem.

[Pēpē/baby was terminated]

The condition of my baby's skin and what would happen to it. I was given no information about how to care for his skin or look after him except perhaps by my midwife but now it is a blur because I didn't know he was going to come out like that, I didn't know it would get harder to clean him. [Pēpē/baby died during pregnancy]

How to hold baby, what they would look like, what post-mortem deterioration would look like. [Pēpē/baby died during pregnancy]

- Information about the **support services available** (e.g., counselling, social workers, dealing with the funeral) (n=14):

Maybe someone to talk to who specialises in baby loss. Not just a paper brochure from Sands [NZ] given to us. [Pēpē/baby was terminated]

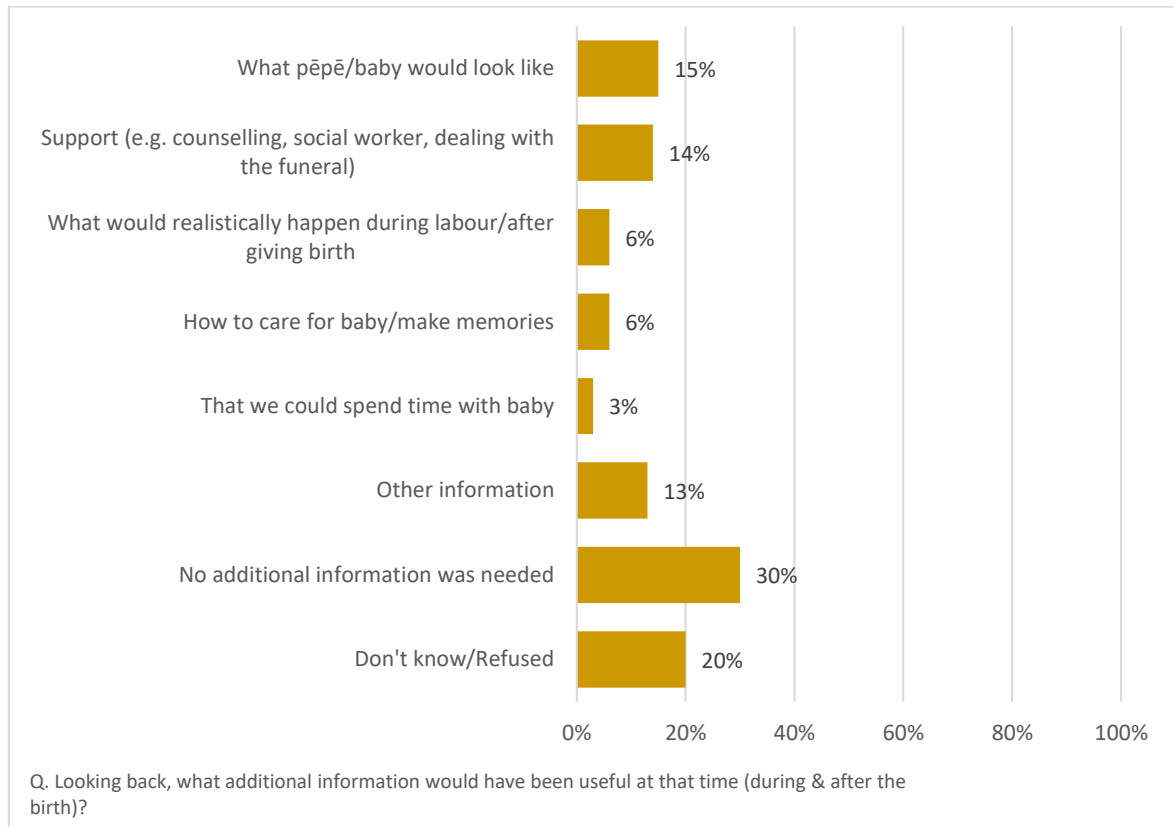
Mental Health support - I was told the public system was too full to see me. I paid a private psychologist; this was unacceptable in this circumstance. Someone to ring and make arrangements with the funeral director - I was given a list, but had to ring them and work with them myself with no support from the hospital.

[Pēpē/baby died up to 28 days after birth]

Connection with the funeral director/services, outside of the logistics of them picking up our baby - they know a lot about grief and this process, and that support happened after we had the courage to contact them to arrange things; but it meant that first hurdle of contacting them was so hard - it felt so final and so big to do and so separate to everything happening in the hospital, but it didn't need to be like that and they were great. Some of the things we could do with baby weren't always clear to us in the fog of grief - we had a lot of support to 'make memories' and do a few bits of pieces, but this was also our first baby and we didn't always know how to do some of them so we just didn't because we didn't know how - not because we didn't want to. For new parents, don't forget there is a natural intimidation or desire to do things right even if our baby has passed away.

[Pēpē/baby died up to 28 days after birth]

Figure 10: Additional information respondents wanted after their pēpē/baby's birth/death



Unweighted base n=103.

Respondents whose pēpē/baby died during labour were not asked this question.

Total will not sum to 100 percent due to multiple response.

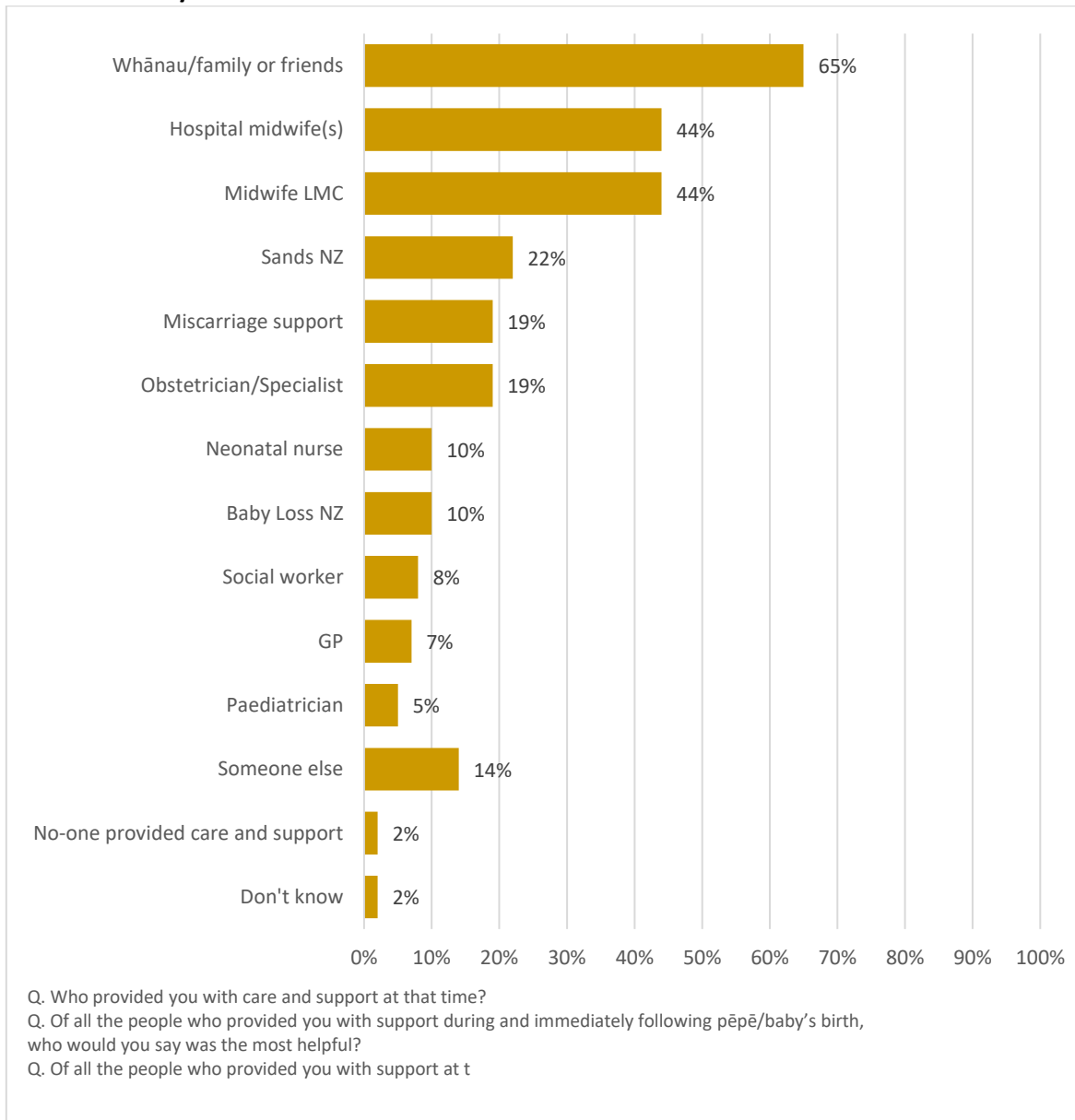
2.12 Care and support immediately following pēpē/baby's birth/death

As illustrated in Figure 11 overleaf, bereaved survey respondents' whānau/family or friends were identified as the most helpful, caring, or supportive people **during and immediately after the birth/death** of their pēpē/baby (65%, or n=77).

In addition, about one-half said that both the hospital midwife or their LMC midwife was the 'most helpful' (both 44%, n=52), while 19% (n=22) identified their obstetrician/specialist as 'most helpful'.

A similar percentage identified Sands NZ as 'most helpful' (22%, or n=26) and 19% (n=22) Miscarriage Support.

Figure 11: Most helpful, caring, or supportive person/support group during labour and after the birth/death



Unweighted base n=118.

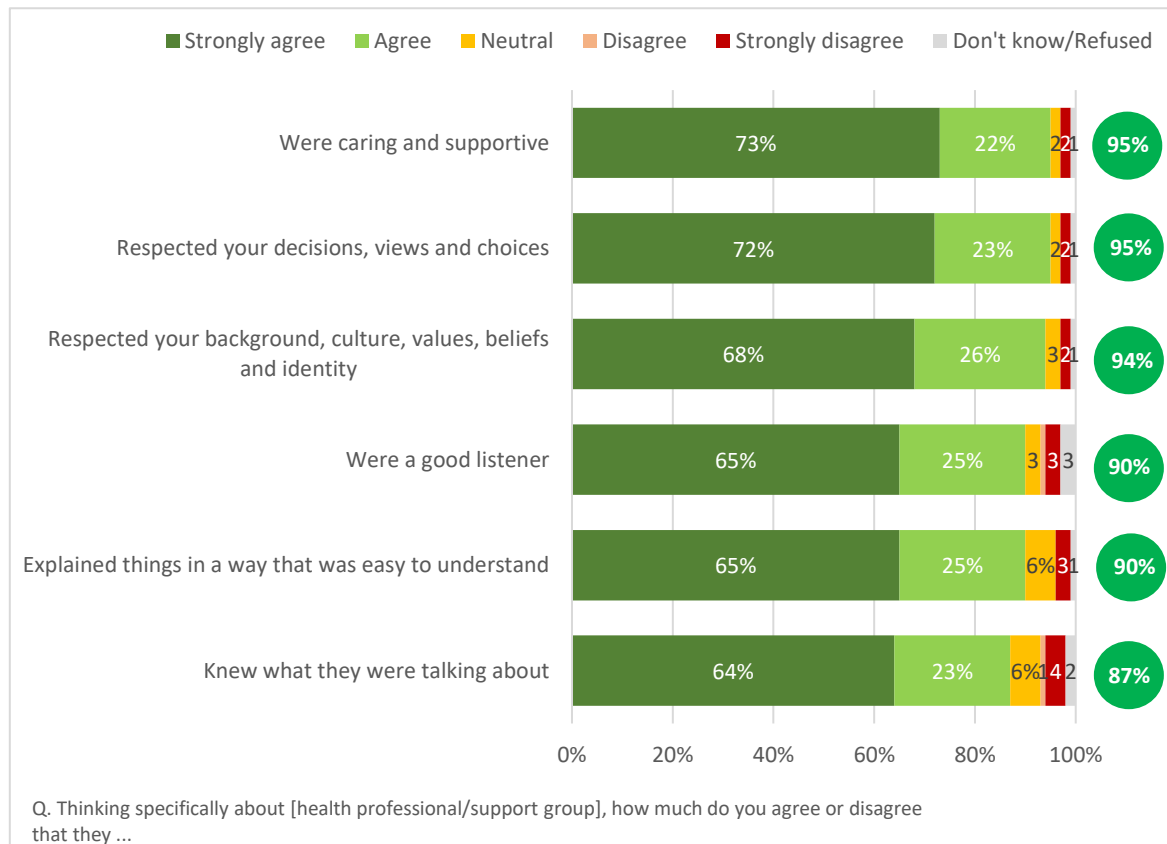
Total will not sum to 100 percent due to multiple response.

Where respondents identified a health professional/support group as ‘most helpful’, they were asked to rate them against a list of six key attributes. As illustrated in Figure 12, these health professional/support groups were rated very highly in terms of all the attributes, with at least two-thirds strongly agreeing that each applied:

- They respected their ‘background, culture, values and beliefs and identity’ (68% ‘strongly agreed’, or n=67).
- They respected their ‘decisions, views, and choices’ (72% ‘strongly agreed’, or n=71).
- They were ‘caring and supportive’ (73% ‘strongly agreed’, or n=72).

Slightly fewer respondents strongly agreed that they ‘were a good listener’ (65% ‘strongly agreed’, or n=64), ‘explained things in a way that was easy to understand’ (65% ‘strongly agreed’, or n=64) and ‘knew what they were talking about’ (64% ‘strongly agreed’, or n=63).

Figure 12: Attribute ratings for health professionals/support groups who were most supportive during and immediately following the birth/death



Unweighted base n=99

Totals may not sum to 100 percent due to rounding.

2.13 The hospital experience during and following pēpē/baby's birth/death

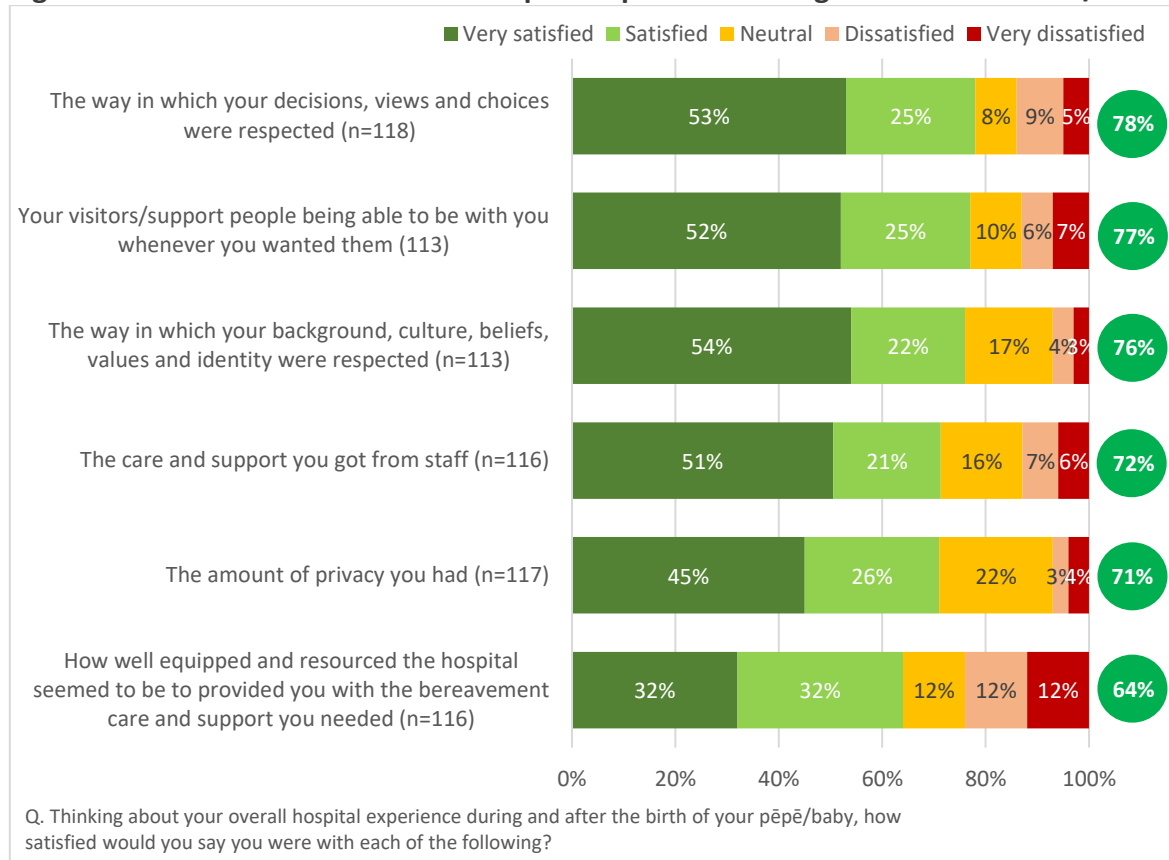
All bereaved survey respondents were asked to rate specific aspects of their hospital experience during and after the birth/death of their pēpē/baby.

As illustrated in Figure 13, respondents were generally satisfied with most aspects of their hospital experience, with approximately three-quarters reporting they were 'satisfied' or 'very satisfied' with:

- The way their decisions, views and choices were respected (78%, or n=92)
- Their visitors and support people were able to be with [them] when they wanted (77%, or n=87)
- The way in which [their] background, culture, belief, values, and identity were respected (76%, or n=86)
- The care and support they received from staff (72% or n=84)
- The amount of privacy they had (71%, or n=59)

The aspect of their hospital experience that bereaved respondents were **least satisfied** with was, 'how well equipped and resourced the hospital seemed to be to provide [bereaved women and people] with the bereavement care and support [they] needed' (64%, or n=74). This is due to the fact that significantly fewer respondents reported being 'very satisfied' (32%, or n=37) with this aspect of their care.

Figure 13: Satisfaction with overall hospital experience during and after the birth/death



Sub-samples exclude those who said, 'Not applicable'.

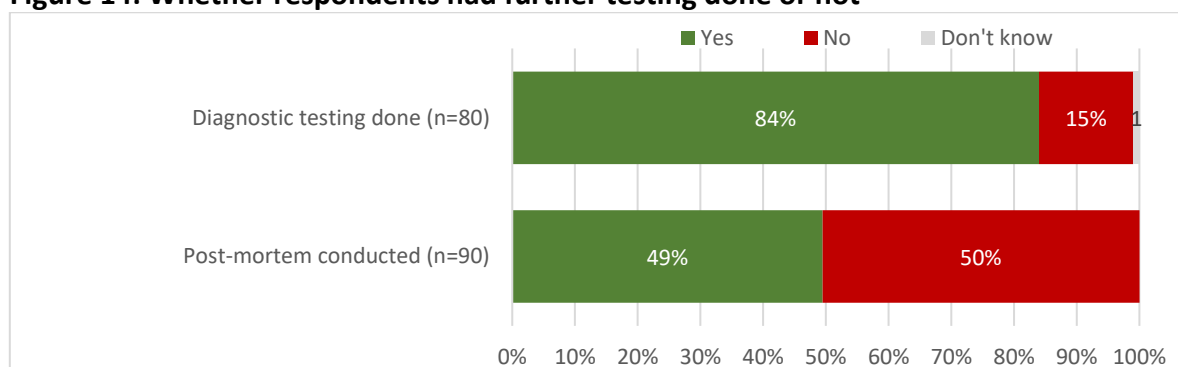
Totals may not sum to 100 percent due to rounding.

2.14 Diagnostic testing following pēpē/baby's birth/death

Almost all bereaved survey respondents (98%) recalled being asked if they wanted further testing or a post-mortem carried out following the birth/death of their pēpē/baby, although not all chose to go ahead with it (Figure 14).

- Two-thirds (68%, or n=80) were asked if they wanted diagnostic testing carried out; 84% (n=67) of whom decided to have this testing conducted.
- Three-quarters (75%, or n=90) were asked if they wanted a post-mortem for their pēpē/baby; 49% (n=44) of whom decided to do so.

Figure 14: Whether respondents had further testing done or not



Totals may not sum to 100 percent due to rounding.

Respondents who had further diagnostic testing done were asked their reasons for doing so. The main reason they decided to go ahead with the testing was to find out **what happened/why their pēpē/baby died** (59%, or n=47).

We were hoping to get a reason for our baby passing, we were looking for answers.
[Pēpē/baby died during pregnancy]

To see what had happened as there were no clear indications of what caused it and hoping to get some answers, so I didn't continue to blame myself.
[Pēpē/baby died during pregnancy]

Another 11% (n=9) wanted to find out if it could **happen again** in the future.

I wanted to know if it was my fault or if my body did something wrong. Our NIPT tests were fine, so I was desperate to have a reason. Also for (hopefully) a future pregnancy, I hoped it would be useful if there was more information.
[Pēpē/baby died during labour or birth]

Ten percent (n=8) wanted diagnostic testing done to **check for genetic abnormalities**.

We wanted to make sure it was only structural defect and [there wasn't] any genetic component. [Pēpē/baby was terminated]

Respondents who were asked if they wanted **diagnostic testing** but decided **not** to go ahead with it (15%, or n=12), were asked their reasons for this. Reasons for not going ahead with further diagnostic testing included already having enough information about why their pēpē/baby died, cultural reasons, and not being able to see any benefits.

We had so much testing in the 6 weeks since we found out about our son's major heart issue, we knew exactly what was wrong with him, we just wanted him to be left alone then. [Pēpē/baby was terminated]

Against tikanga. [Pēpē/baby died during pregnancy]

We knew why we went into preterm labour. Cervical insufficiency. [Pēpē/baby died during labour or birth]

Respondents who had a **post-mortem** carried out were also asked their reasons for doing so. Again, the main reason for deciding to have a post-mortem was to help them to fully understand **what happened to their pēpē/baby** (78%, or n=35).

There was no obvious cause to why he died, so we wanted to try and find anything that could have been a possible reason. [Pēpē/baby died during pregnancy]

Another 16% (n=7) wanted to know **how to prevent what happened** happening in the future.

I needed answers to find out what happened. If it was something preventable, or something that is genetic, then I would know I wouldn't want to try again. Or knowing it is preventable and there is something we can do to help next time. [Pēpē/baby died during labour or birth]

Respondents gave varied reasons for **not** having a post-mortem carried out. Thirty-six percent (n=16) wanted their pēpē/baby's body **respected**:

Beyond the non-invasive testing, I wanted to respect my baby from being cut open and tested further. [Pēpē/baby died during pregnancy]

Because I wanted to keep my baby with me and didn't want strangers touching her or her body being cut open. [Pēpē/baby died during pregnancy]

Another 33% (n=15) said they didn't want a post-mortem carried out because they **knew what went wrong**:

We didn't choose a post-mortem, as we were pretty sure we knew why she had died and also, we felt like we needed her close and not handled further. [Pēpē/baby died during pregnancy]

Twenty-nine percent of respondents (n=13) **didn't want their pēpē/baby taken or sent away from them**.

I was not comfortable with my baby being sent and having this process. [Pēpē/baby was terminated]

Having to take him out of district away from his whānau! And, also, being traumatised from the nurse telling me they cut his head and chest open. [Pēpē/baby died during pregnancy]

I didn't want to wait for my baby's body to come back. The estimated wait time was too long. [Pēpē/baby died up to 28 days after birth]

One fifth of respondents did not think a post-mortem would give them any more information (n=9).

Of the n=46 respondents whose pēpē/baby died up to 28 days after birth, 28% (or n=13) reported that their pēpē/baby's death was referred to a coroner. Due to the low base number, no further analysis of this sub-group of women and birthing parents is presented.

2.15 Satisfaction with the information about why pēpē/baby had died

Survey respondents whose pregnancy was terminated or whose pēpē/baby died during the pregnancy (n=57) were asked how **helpful** the information was that they received about why their pēpē/baby had died.

- Opinions were divided in this regard. While 40% (n=23) felt the information was 'quite/very helpful', 33% (n=19) rated it as being 'very/somewhat unhelpful'.

Respondents whose pēpē/baby died during labour or up to 28 days after the birth (n=61) were asked how **satisfied** they were with the information received about why their pēpē/baby died.

- Almost one-half (48%, or n=29) were 'very/somewhat satisfied' with the information they received in this regard, while 20% (n=12) were 'very/somewhat dissatisfied'.

When asked what else they would have liked to have known, 35% of all bereaved survey respondents (n=41) said they didn't want any additional information and 23% (n=27) were unsure.

Twenty-four percent (24% or n=28) said they wanted to know why it happened because their results had been **inconclusive**.

I would've liked to know the reason he died but they weren't able to find one.

[Pēpē/baby died during labour or birth]

I wish I knew why she came so early but tests are inconclusive.

[Pēpē/baby died up to 28 days after birth]

Three percent (n=4) wanted to know if anything could have been done to prevent what happened or could be done in the future.

More details around what I can do differently to prevent this in future.

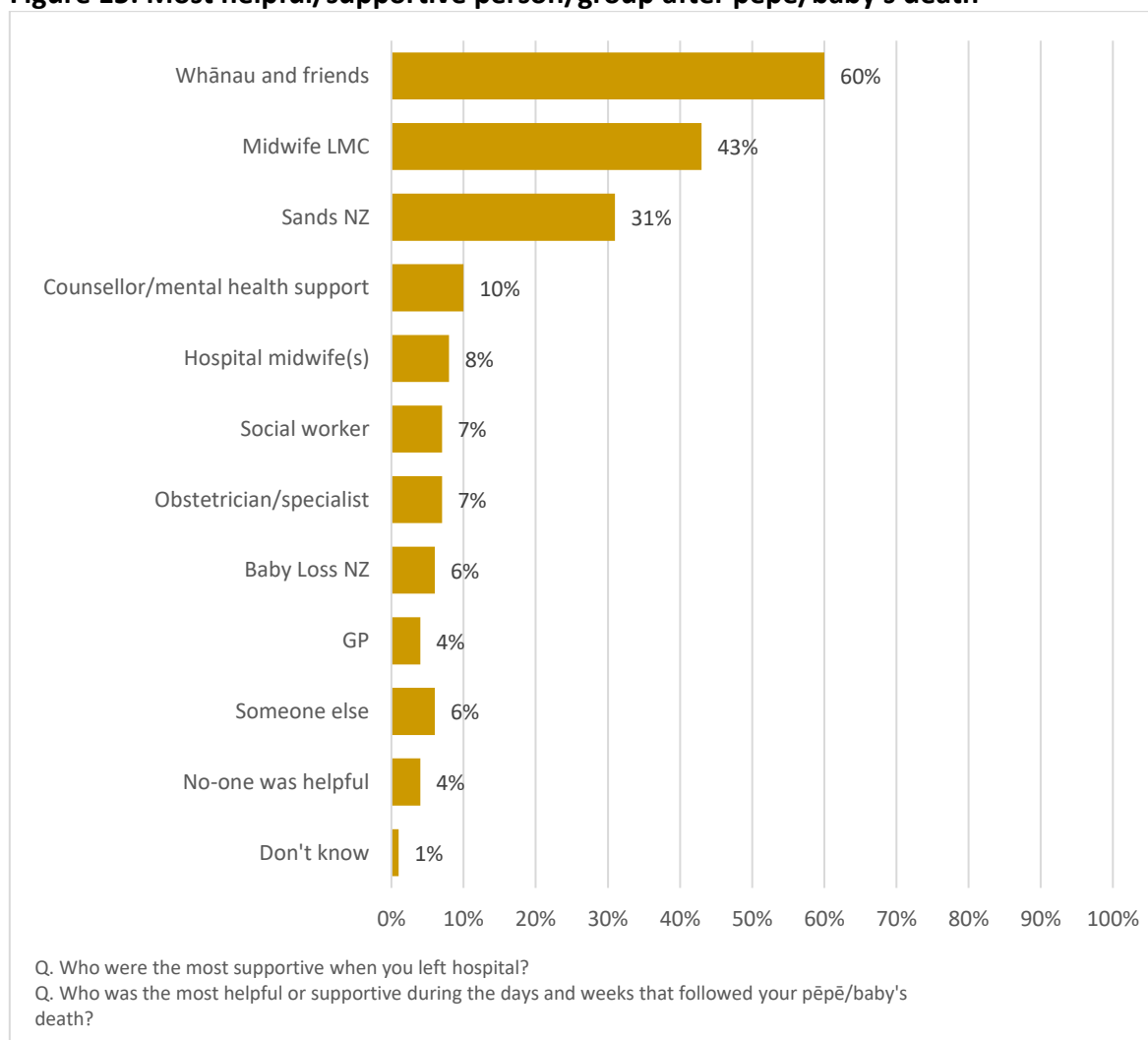
[Pēpē/baby was terminated]

2.16 Care and support during the days and weeks following pēpē/baby's death

Bereaved survey respondents whose pregnancy was terminated or whose pēpē/baby died during the pregnancy or labour (n=72) were asked to identify who was 'most helpful or supportive' **in the days and weeks that followed**.

As illustrated in Figure 15, respondents most frequently identified their whānau and friends as being the most supportive (60%, or n=43), followed by their midwife LMC (43%, or n=31) and Sands NZ (31%, or n=22).

Figure 15: Most helpful/supportive person/group after pēpē/baby's death



Unweighted base n=72.

Respondents whose pēpē/baby died up to 28 days after they were born were not asked this question.

Total will not sum to 100 percent due to multiple response.

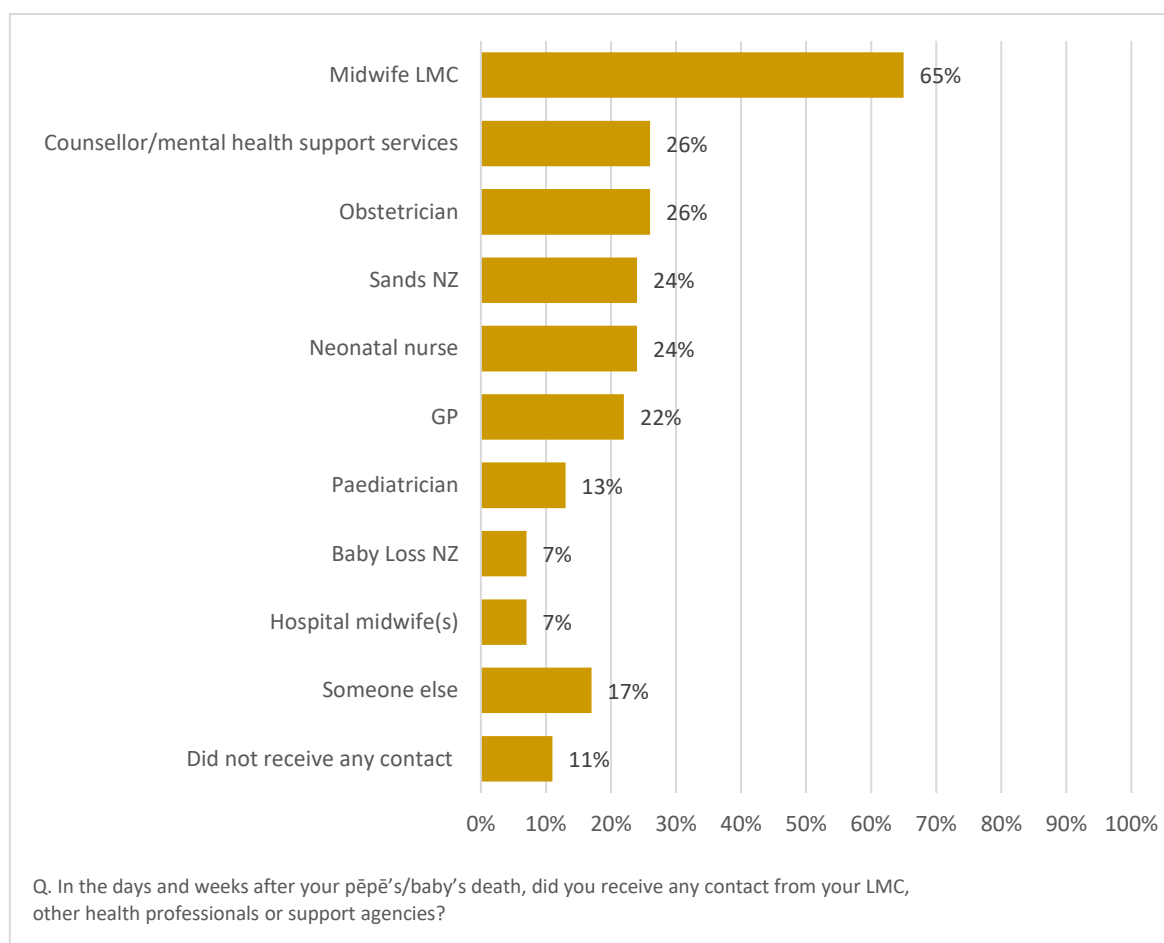
2.17 Contact from LMC, other health professionals and support agencies following pēpē/baby's death

Bereaved survey respondents whose pēpē/baby died up to 28 days after birth (n=46) were asked if they had received any **contact** from their LMC, other health professionals or support agencies after their pēpē/baby had died.

Most received some form of contact (89%, or n=41). As illustrated in Figure 16, two-thirds of respondents were contacted by their midwife LMC after the loss of their pēpē/baby (65%, or n=30). Approximately one-quarter also received contact from a counsellor or mental health support services (26%, or n=12), an obstetrician (26%, or n=12), Sands NZ (24%, or n=11), a neonatal nurse (24%, or n=11) or their GP (22%, or n=10).

Eleven percent (n=5) received **no** contact.

Figure 16: Who respondents whose pēpē/baby died up to 28 days after birth received contact from after pēpē/baby's death



Unweighted base n=46.

Only respondents whose baby died up to 28 days after they were born were asked this question.

Total will not sum to 100 percent due to multiple response.

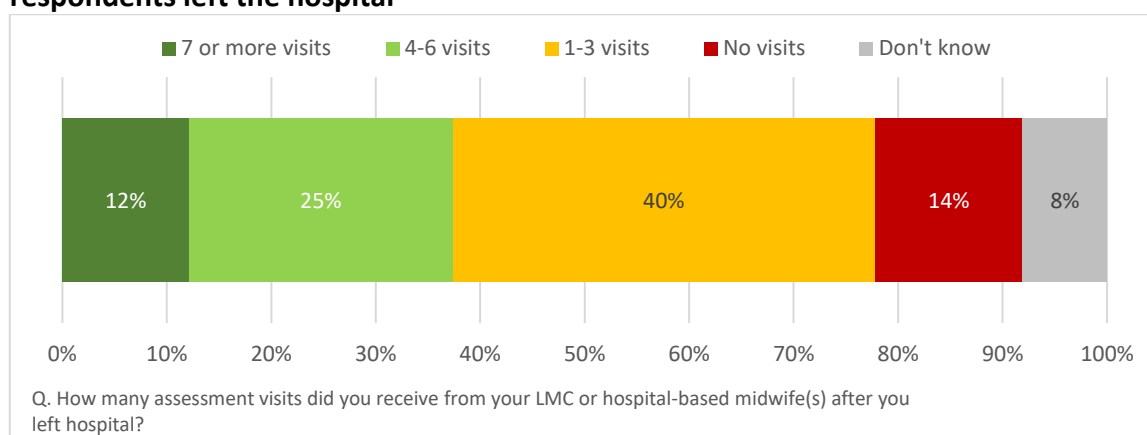
2.18 Midwife assessment visits after leaving hospital

Bereaved survey respondents whose pregnancy was terminated, or whose pēpē/baby died during the pregnancy or labour (n=72), were asked how many **assessment visits** they received from their LMC or hospital-based midwife after they left hospital.

As illustrated in Figure 17, 40% (n=29) received 1-3 visits, 25% (n=18) received 4-6 visits and 12% (n=9) received 7 or more assessment visits from their midwife after leaving the hospital. Another 8% (n=6) could not remember how many visits they received and 14% (n=10) reported having received **no** assessment visits from their midwife after leaving the hospital at all.

One-half (53%, or n=35) of respondents who received an assessment visit) from their midwife were satisfied with the number of visits they received; 30% (n=22) wanted 'more visits' and 3% (n=2) would have preferred 'less visits'. The other 20% (n=9) were unsure.

Figure 17: Number of LMC/hospital-based midwife(s) assessment visits received after respondents left the hospital



Unweighted base n=72.

Respondents whose pēpē/baby died up to 28 days after they were born were not asked this question.

Total may not sum to 100 percent due to rounding.

Two-thirds of bereaved respondents whose pregnancy was terminated, or whose pēpē/baby died during the pregnancy or labour (62%, or n=45) felt that their LMC/hospital midwife was able to provide the care and information they needed following their bereavement. One-third (32%, or n=23) did not feel their midwife was able to provide them with what they needed at the time, while another 6% (n=4) were unsure.

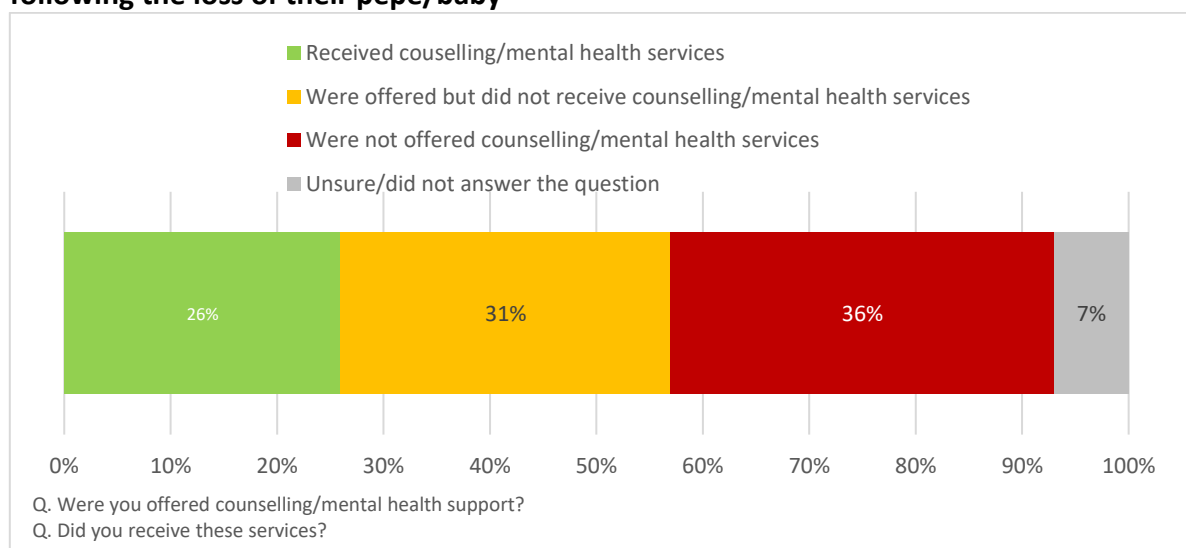
Two thirds of respondents whose pregnancy was terminated or whose pēpē/baby died during pregnancy or labour (68% or n=49) attended a follow-up appointment 6-12 weeks after their pēpē/baby's death. Most of those who did attend a follow-up appointment were given advice about future pregnancies (90% or n=44).

2.19 Receiving counselling or mental health support

One-half of bereaved respondents (57%, or n=67) were offered counselling or mental health support and 46% (n=31) of these respondents actually received counselling. This represents 26% of all bereaved respondents (Figure 21):

- 74% (n=23) of the respondents who received counselling found the services ‘**easy to access**’.
- 74% (n=23) found the **timing** ‘about right’, while 13% (n=4) felt it was too soon and 7% (n=2) thought it was too late.
- 48% (n=15) thought the **number of sessions** they had was ‘about right’, while 39% (n=12) felt they ‘did not have enough’.

Figure 18: Whether or not respondents received counselling/mental health support following the loss of their pēpē/baby



Unweighted base n=118.

Total may not sum to 100 percent due to rounding.

2.20 Additional contact, information, and support following pēpē/baby's death

All bereaved survey respondents were asked if there was any additional contact, information or support they would have liked to have received after the death of their pēpē/baby.

Overall, 43% (n=51) of respondents reported that they would have liked to have received additional contact, information or support following their loss. In particular, 28% (n=33) would have liked to have received **loss/grief counselling**:

I would have liked a referral to a grief counsellor, but did see a social worker once for a talk. I felt it was OK, but a grief counsellor would have been more appropriate and been able to provide a better level of care and help that I needed.

[Pēpē/baby was terminated]

A counsellor for me or my children especially, but even something for my husband. We weren't given anything and although we would have support from family if needed, contacting counsellors and the cost is not accessible for so many people.

[Pēpē/baby died during pregnancy]

There was no professional help offered to me. I've always had my family, but they were also grieving and dealing with feelings of going through a new process/emotions that sometimes it was hard to reach out to them and I did not and do not know where to reach out for that support. [Pēpē/baby died during labour or birth]

Mental health support, without having to pay for it privately in a vulnerable time.

[Pēpē/baby died up to 28 days after birth]

3.0 Qualitative research results

This section of the report focuses on the findings of the results of the qualitative research that was completed with bereaved women and people. Results are based on the n=18 women and people who had lost their pēpē/baby within the previous 18-months.

The findings of the qualitative research supplement the findings of the survey research, by providing a deeper **understanding** of bereaved women's and people's experiences of the maternity and perinatal system.

3.1 Learning something was wrong, or pēpē/baby had died

Some qualitative research participants first learned that there was something wrong or that their pēpē/baby had died while having an ultrasound scan.

Two women found out that their pēpē/babies had died during routine scans. Both were unprepared for the news and were shocked. In one of these examples, the sonographer dealt with the situation, by saying, "Sorry", and walking out of the room. In the other example, the woman, who was unable to have her husband with her because of COVID-19 restrictions, was ushered out of the private radiology service where she had had her scan, because she was crying uncontrollably.

I found out at a scan. My 12-week scan got pushed out because everything came back fine on the NIPT test, so I was told. The sonographer was saying, "You must be so excited!". And when she did the scan there was no heartbeat. My baby had passed away. She took the wand off me and passed me a paper towel said, "I'm so sorry", and walked out of the room. I had no idea what to do. I was horrific... I have had bad experiences with sonographers, and I think it's actually a big problem. Like, my midwife told me not to go to certain companies. [Bereaved under 20 weeks]

We had a scheduled scan, but the previous day I had not felt much movement. I called my midwife who said, "That's fine". When we went for the scan the next morning, it was the first day of the second lock-down last year, so my partner was not allowed to go in. The lady who did the scan said there was no heartbeat, and I can't remember what happened after. I think I was in shock. I have promised I will never step foot in that place again. They pushed us out the door because I was making too much noise wailing. They didn't even give me a few minutes to process it. They just said go. They got my partner, and they pushed us out. They called the midwife, and the midwife called us and told us to go home. [Bereaved over 20 weeks]

In the third example, a woman found herself in the situation of having to console the student sonographer, when her scan confirmed that her pēpē/baby was not going to survive.

When they wanted to check the waters, they sent me down to scanning and they didn't bother to ring up the ultrasound people and say, "Hey, this lady may be told at this ultrasound that her baby is going to turn out to be crap". I got a poor student that started crying. So, I'm trying to console her. You don't need that. Just another example of the basic stuff the hospital has got wrong. [Bereaved – medical termination]

3.2 Making decisions about medical termination

Some qualitative research participants' pregnancies were defined as high-risk, because they or their pēpē/baby had a problem and were cared for by Maternal Foetal Medicine (MFM). During the time they were under the care of MFM, these women were all required to decide whether to terminate or continue with their pregnancies.

The focus of the discussion in this section of the report is on the support women and people in this situation receive to help them make these decisions.

Positive experiences

Bereaved women and people who were satisfied with the support they received felt that they were provided with the information and advice they needed to make their decisions, and that their decisions were respected.

Those who were under the care of MFM for longer periods of time valued the opportunity to seek information and advice from a variety of sources, including getting a second opinion. They also valued the support they received from their MFM midwife, who was their main point of contact.

I just want to say that, under the care of Maternal Foetal Medicine, we received good medical advice and had access to anyone... My midwife from there, who was my contact person, got information that I needed from whoever we wanted to speak to – a palliative care nurse, and the cardiac surgeons. [Bereaved – medical termination]

Information-wise, we received all the information that we could have received, and we asked for a second opinion, as well, and then had another scan and a separate cardiologist saw us and explained it really well, with the diagrams of what is wrong with the baby's heart and what surgeries they're going to do, if we decide to go ahead, and what were the success rates of the surgery. I think that we were given all the information that helped us make a tough decision. [Bereaved – medical termination]

My Maternal Medicine Midwife was my go-to person, basically. If I had questions, that is who I went to ... I also liked speaking to the specialists. [Bereaved – medical termination]

Some bereaved women and people were also fortunate enough to have support from their community midwife during this difficult period.

She supported me in a way that I needed at the time. I didn't realise 'till after just how much she was supporting me. She let me guide myself. She wasn't putting any expectations or pushing me in either direction. She was just there for me. [Bereaved within 28 days after birth]

Negative experiences

Qualitative research participants who were dissatisfied with the support that they received to help them make their decisions felt that their decisions were not respected. This included feeling pressured to terminate, when that was not what they wanted, or before they were ready; or feeling distressed about their decision to terminate being questioned.

When I first had my initial consult with the DHB, it was very clinical and 'you should do this'. When me and my partner opted against termination, which was one of their suggestions, I found it very inappropriate, because of the way it was offered... I can't remember the exact wording, but I felt very cornered and so did my husband, who is very strong and sure of his own thoughts... I feel as though, if there was another lady who wasn't as headstrong as what me and my partner are, then that woman could potentially be pushed to do something she really doesn't want to do. [Bereaved within 28 days after birth]

So, I went for a scan the next morning and there were no waters at all. My stomach had gone down. But the baby was happy and healthy and kicking and doing wonderful. So, it was really hard to understand why I had to terminate. They wanted me to take the pills straightaway. There was quite a lot of pressure to take the pills. "Take the pills". I said, "No...". [Bereaved – medical termination]

The first night at the [name of clinic], the gentleman doctor who did the first part of the [termination] process with me, was very blunt and didn't show compassion or care. I felt like he was questioning my decision... Just going, "Are you sure?". When you're there to get it done, that is unhelpful. Of course, I was not bloody sure. So, he put me in tears afterwards. [Bereaved – medical termination]

3.3 Miscarrying at home

Two of the qualitative research participants who lost their pēpē/babies at under 20 weeks (one of whom miscarried at home and the other of who was sent home to begin their labour), found the experience of being unsupported at home frightening.

Calling her midwife when she started bleeding, a woman who spontaneously miscarried at home, described feeling completely unprepared for the severity of the bleeding and clots.

I didn't really know what to expect and probably should have gone to the hospital, retrospectively, but, at the time, I didn't want to bother anyone. It was a Saturday night, and it was a different midwife to what I usually have, and my toddler was asleep... I had to go straight to the toilet because there was so much blood and clots, but I never managed to get the foetus... There was a point when I looked down and thought I saw a foetus and kind of pulled it out. That was a horrible experience for me; not knowing if this is the foetus or another clot. [Bereaved under 20 weeks]

Another woman who learned she had lost her pēpē/baby during a scan, was administered misoprostol and sent home to begin her labour. While reassured to some degree by the information she had been provided, including numbers to call if she was worried, as the bleeding got heavier, she got increasingly frightened. For this woman, one of the most distressing aspects of this experience was ringing the emergency number she had been given several times and being repeatedly told to stay at home.

So, when we found out our baby had died during a scan, we went to [name of hospital], where I was administered misoprostol and told to go home and come back in a couple of days. I was told that there may be some sort of bleeding, but to manage it. For me, it was really important to have the bit of paper that told me what to expect, because the bleeding can be quite triggering and terrifying. It also had phone numbers of who to call if I was worried. It was a direct line into the gynie clinic. That was really important to me... I started bleeding really heavily at home, to the point where I felt quite unsafe... My bleeding got very heavy to the point that I was afraid, and I called the number. They just kept telling me to stay at home. I wasn't in a good place, because I was bleeding really heavily and then I started to see clots the size of grapefruits. My husband took me, and I ended up delivering 20 minutes after getting there... Being told to stay home, when I needed to go to the hospital was really challenging for me. I am still feeling the effects of that; of not trusting. [Bereaved under 20 weeks]

3.4 Hospital experiences - during and following birth and medical termination

Qualitative research participants' experiences of the hospital, during and following the birth of their pēpē/baby or a medical termination, is discussed here in terms of their positive and negative experiences of the hospital environment, hospital midwives and other staff.

The hospital environment

The hospital environment either helped or detracted from bereaved women's and people's hospital experiences.

Qualitative research participants who had given birth in larger hospitals, where it was possible to effectively separate bereaved parents, so they did not see or hear other birthing mothers/people and their pēpē/babies, reported having better experiences.

[Location] hospital has a separate ward for grieving parents. We stayed with [name of baby] for two days and didn't hear a single baby or any sort of labour event or anything like that. We were completely secluded and safe. [Bereaved during labour]

Where I was in [name of hospital], it was a birthing suite, but different from where babies who are going to live are. So, I did not have that problem. [Bereaved – medical termination]

In comparison, those who saw and heard other birthing mothers/people and pēpē/babies found the experience distressing; so much so that some chose to discharge themselves early.

Because I had a Caesar, I stayed in hospital. They cleared a double room at the end of the corridor for us. They made up a bed for my husband and we had [name of baby] with us in an ice bed. The only thing was, it was in the maternity ward, so you could hear all the other babies being born and crying. [Bereaved within 28 days after birth]

Going into the maternity assessment unit in the [name] hospital was probably the most traumatic experience of all because you are going into a place where all the pregnant people are, and it's got posters everywhere about your happy healthy baby. I found that really triggering having to sit there waiting for my appointment. So, maybe if there was a separate area or less intense posters on the wall or something like that, would have made it more sensitive. [Bereaved under 20 weeks]

We left the hospital quickly after the Caesarean because it was not a very nice environment to be in... I could just hear babies crying and I could hear a doppler in the next room... So, we could hear his heartbeat... I had a full day of labour, a Caesarean under general anaesthetic and, when I woke up, my husband had to tell me my baby had died. [Bereaved during labour]

Hospital midwives and other staff

The main factor determining qualitative research participants' satisfaction with their hospital experiences was the quality of the care and support provided by hospital midwives and other staff.

Positive examples of the hospital staff and their actions that left women and people feeling cared for and supported included:

- Being under the care of a specialist bereavement midwife.

My experience with the bereavement midwives was that they were amazing... They were so kind. They really took things slow and gave us a lot of options. Like, if we wanted to stay overnight, where did we want baby to be... taking us through things like the post-mortem procedures and how we wanted that to unfold... They wrote everything down... I can't fault them. They obviously had really specific training and they had a lot of experience, which is what I needed. [Bereaved under 20 weeks]

I had a midwife who only worked with bereaved parents. I was so grateful to have her because she was really nice, and I knew she was just there for me, and other women like me. [Bereaved – medical termination]

- Acknowledging their dead pēpē/baby and sharing their condolences.

The cleaner came in but, before she started cleaning, she came over and she put her hand on the baby and said, "Hello", and kind of talked to her a little bit. I really hold on to that. It was lovely of her to come and acknowledge the baby... It was just little things like that, that individual people did, that made it lovely. [Bereaved within 28 days after birth]

The hospital surgical team I encountered were fantastic. They were the most phenomenal people I have met in my life... The entire team came up and said, "I'm sorry". They made me feel safe. [Bereaved under 20 weeks]

- Not leaving bereaved parents alone – checking on them to make sure they were OK.

And then, when I was brought in for aftercare, the nurses there stayed with me and texted my husband that I was out. They kept me overnight because I have a [name] disorder they wanted to monitor. My husband got to stay with me, and they were in and out checking that I was OK. [Bereaved under 20 weeks]

- Going “the extra mile” to meet their needs and make them comfortable.

I had a good experience with the nurses or the midwives in the delivery suite at [name] hospital. They said to me, because it is 20 weeks to the day, you will need to have your baby buried or cremated by law, and we will need a birth certificate. I said that I really want to bring this baby home, bury him and plant a tree. I said on some of the paperwork, I’m 20 weeks and on some, I’m 19 weeks and six days. The midwife said, “Wait here”. She came back after 20 minutes and she went, “I have done the paperwork. If it is important for you to bring your baby home, I can go with that one...”. That was really empowering care. I just felt really grateful to her for listening to us and going away and doing that. So, there were a couple of experiences that stood out, where people just went the extra mile. [Bereaved under 20 weeks]

They brought a little candle in for me. It was great. [Bereaved under 20 weeks]

- Helping with “the practical stuff” (e.g., funeral arrangements and paperwork).

I really valued the practical stuff. They gave me a list of all these different funeral places and the midwife had asterisked her favourites. She had marked up the one that does free cremation, and they will give you a little urn and you can keep your daughter with you for as long as you need to... That made it easier to pick, out of a huge list of choices... There was actually a brochure about where the family could get support... Information about how the post-mortem would work, and whether or not we wanted to get one. [Bereaved – during labour]

I was very lucky that there was a particular hospital midwife, who went through the autopsy forms and the funeral forms with me. She walked me through them, and she wrote the answers for me. [Bereaved during labour]

- Doctors taking the time to talk to research participants who had lost their pēpē/babies during labour about what happened, when they were able to take in what they had to say (i.e., after the event and again later).

I think something really good that my doctor did, that I hope would be something that lots of doctors do, was, when I came out of surgery she was there, and she said that she would like to tell me what happened. I said “Yes”, and she said, “You’re not going to remember it”, and she came back the next morning to tell me again. And then she saw me before I left, as well. So, that really meant a lot. I think all the doctors and anaesthetists came to visit me and talked me through what had happened, to the best of their knowledge. I think, for me, that was something very important and it would be beneficial for lots of people. Afterwards, I was in so much shock, I wasn’t able to process anything. I think the communication is probably more important the following day. [Bereaved during labour]

We had a really good experience, too. The consultant who delivered [name] came to see us at 7am the next morning and then she came to our home in about 10 days and sat with us for the afternoon and went through everything. [Bereaved during labour]

- Encouraging women and people to make memories of their pēpē/baby or taking the initiative on their behalf, because they know how grateful they will be to have a few mementos in the future.

The midwives in the delivery suite said, “I can try and get a footprint from your baby”, and me in that state went, “Oh, don’t worry about it, it’s OK”. I was still in shock and was trying to be a good patient and not make a fuss... She came back half an hour later and said, “I managed to get a wee footprint, even though he is quite small”. And I treasure it so much. I think that was a very beautiful thing that she did... A very kind thing that stood out... She had that knowledge to know that, maybe I wasn’t in the best spot to really think about what I wanted... There was also a basket in the room that they said, “Take whatever you want” ...fabric to wrap him in and teddies. So, that was really lovely, as well. [Bereaved under 20 weeks]

One of the staff on the ward contacted Heartfelt and was kind of quite pushy with it, but I am glad she was... It felt a bit weird at the beginning, but they said, “It’s better to have them and, if you don’t want them, you don’t have to look at them...”. We had hands and footprints, and they gave us a certificate of life form... All the nurses from NICU who looked after [name] came in and gave us hugs, and they did little name cards for them [twins], with little mermaids on them and filled out a Plunket book for them with all their details. It was really lovely. [Bereaved within 28 days after birth]

I got some beautiful photos of my two oldest girls together and she got to meet her little sister. I will always be grateful for that. I don't know if other hospitals do it... We actually got presented with a pair of twin bears. One stayed with [name] and the other came home with us. We got the lock of hair. We got the hand and feet impressions. [Bereaved during labour]

- Making sure that they know they have the option to take their pēpē/baby home and, for those who do not want to, helping them say their goodbyes.

The midwife had given us choices about how we were to leave our baby and go home. She said it was going to be hard for you to leave [name] alone in this room. So, she said, "Would you feel better if you said your goodbyes and I wheeled her away, so you aren't the ones leaving". [Bereaved during labour]

On the other hand, qualitative research participants who described their experience as "substandard care", believed that this **was** because their pēpē/baby had died or was going to die.

I was put at the end of the maternity ward, so I saw happy mums with new-born babies. I felt like, because my baby wasn't living, we weren't worth getting the care that others got. [Bereaved over 20 weeks]

I was put in the maternity unit with all the birthing mothers and, because I was having a baby who was not going to survive, I wasn't really a priority for them, and I was literally just left... My 18-year-old daughter had to go out and say, "Hey, my mum's diabetic, you guys haven't been in to do a blood pressure or a temperature, when you were telling her two days ago that she was going to die if she had her baby, and now you don't care". Once I had him, they were all gone. The midwife left. They just left straightway and then never saw anyone again until 11pm. I had him at 10am. [Bereavement – medical termination]

Being ignored and avoided

At the heart of these perceptions are research participants' experiences of not being listened to; staff behaving insensitively; and being "ignored" and "avoided" for hours on end, without even the offer of food or water. These experiences left women and people feeling "ostracised" and "invisible".

We were basically left in that room, until I went into active labour the following day. So, 8pm Friday night we went in, and I went into active labour at about midday the next day. I was in hospital for 18 hours and got offered no food. Basically, I was ignored. I got moved to the birthing suite to birth my baby. After I gave birth to her, they told us that we could go back to that room, and I said to them, "You haven't offered me any food or looked after me and I want to go home". So, we took our baby home. It was like they were going to catch something off us. That's how we were treated. We were basically forgotten and left. Like, "Just put that lady down there because she has got a dead baby, instead of a living one...". The experience that I had at my local hospital has been the worst, and I hate it. Every single midwife and nurse on the ward, including my own, let me down. [Bereaved over 20 weeks]

This was my most horrific experience... By the time I got to hospital, my contractions were strong. I got there, and the hospital midwife put me in a room, and said, "I'll be back in a bit". She didn't come back for two hours. When she came back, I said, "I need some pain relief", and she sort of brushed it off, going, "No, no. Your labour has just started...". Twenty minutes later, I got my sister to get the midwife and she managed to get her to give me some gas. For the next two hours, I was breathing through my contractions with gas. It got to the point when I felt my son descend and it was like, "Holy crap, he's coming". My sister pushed the emergency button and all the midwives started coming and it was frantic and I'm, like, "My baby is coming". The same midwife goes to me, "No he's not". She lifts up my gown and he is almost crowning. They started pushing me down the corridor and, in the process, they swapped gas bottles. The next gas bottle I got wasn't working... I was in excruciating pain. When I told her it wasn't working, she said, "No, no. Keep breathing". I gave it to my sister, and I was like, "Can you puff on this and tell me if its working?". It wasn't working. So, again, I wasn't listened to. My son was born a minute later. And, once he was born, everyone left and, about midnight, I was moved to a room where they put bereaved parents... I didn't see anyone until the next morning. I got not food, nothing to drink... [That experience made me feel] very isolated. Everyone ran away and I don't know whether it was because they know they made all these mistakes and they just wanted to escape that, or they don't give a shit... That experience made me feel not listened to; not valued; not heard, and, given my situation, it was very weird. I felt shoved to the side and not cared about. [Bereaved within 28 days after birth]

I didn't leave with a lot of faith in the hospital system. There were two nice midwives, but with some of them, you felt like you were just there. They would be laughing outside of your room, and it was like, "Go away! Don't laugh there".

[Bereaved over 20 weeks]

Not having cultural needs met

Not having their cultural needs met while in hospital was a source of dissatisfaction for some whānau Māori research participants. Examples of the ways in which they felt that their cultural needs were not met included:

- Cultural needs being assumed based on their physical appearance.

I would have liked to have been asked my ethnicity, and for them not to have made assumptions on the basis of what I look like. [Bereaved – medical termination]

- No help to meet cultural needs outside of complying with wishes.

They were happy to comply with cultural needs, in terms of when all my whānau came to visit. They put water at the door and all that kind of jazz. But there was no facilitation or help for the hospital service [for anything else]. I had to reach out to the Māori Health Unit myself, because they had me recorded as Pākehā, to find a kaumatua for the service in the hospital chapel.

[Bereaved – medical termination]

- The perception that there was a general lack of awareness amongst hospital staff about what was culturally appropriate and respectful.

I'm NZ Māori, myself. I had my ethnicity down there and I just feel like, when it comes to cultural practices, people need to be more aware of what is appropriate; what is respectful; what is traditional; and the alternative services that could be offered to those that are of Māori culture. [Bereaved – medical termination]

My partner is Māori. So, of course, taking the placenta home and taking my son home as he is, that's the culturally appropriate thing to do. But, when I said, "No" [to an autopsy and the placenta being tested], their reply was along the lines of, "Oh, are you sure" ... I felt there was a bit of pressure to do what they were asking for scientific purposes, when they knew I wanted to take everything home for my partner and his family. It felt very disrespectful.

[Bereaved within 28 days after birth]

Even simple things like, when I took bubba out, he was in a harakeke basket, all the people just kept on working. My whole whānau is following me with this baby and they didn't stop to look up; stand up. Nothing. They didn't even open the window when bubba was born. [Bereaved – medical termination]

Being sent home to wait to birth their dead pēpē/baby

Being sent home to wait to birth their dead pēpē/baby, because it was the weekend or because of staff shortages, was described by some research participants as leaving them feeling “traumatised” and “neglected”.

Because it was Saturday, they said they had no staff. They wanted me to wait until Monday. I wasn't happy with that. I told them I wanted my son out now. I want to hold him. I just thought, when they found no heartbeat, they would rush to do something to save him, but they were just sorry. I just felt neglected. [Bereaved over 20 weeks]

[Name's] movements decreased on Thursday. That night, we went to the hospital and were told there was no heartbeat. I wanted to birth her that night. The hospital told me there weren't enough staff on, so they sent me home with a Sands pamphlet and a script for sleeping pills and told me to wait for 24 hours... I was traumatised that I had to have my dead baby inside me and wait to have her. [Bereaved over 20 weeks]

Not bringing pēpē/baby home

Not being asked if they want to or deciding not to bring pēpē/baby home in the blur of their grief, was a decision that was later regretted by some research participants.

You are just in the blur of everything happening. Not sleeping and recovering. So, you expect everyone else to do the thinking for you... I would have wanted to bring them home. We didn't get to bring them home as babies. We brought them home in boxes. So, none of my family got to meet them and hold them, before we cremated them... We weren't given the option of bringing them home. That was never discussed with us. [Bereaved within 28 days after birth]

3.5 Systemic and other issues

Qualitative research participants identified several issues that have the potential to negatively impact on the welfare of bereaved women and people, which are either systemic in nature or associated with other parts of the maternity and perinatal system.

These include poor information sharing between different parts of the maternity and perinatal system; the belief amongst some bereaved women and people that there is a misperception within the maternity and perinatal system that early miscarriages have a minimal and short-term impact on women and people; the potential for women and people to slip between the cracks in the system if they do not have a strong LMC relationship to advocate for them; and poor access to mental health services during pregnancy.

3.6 Poor information sharing

Some research participants became distressed when they were contacted by people from different parts of the system who were unaware of their pēpē/baby's death (e.g., a welcome pack to the hospital, a call from an anaesthetist in preparation for a Caesarean).

Before discovering that there was something wrong with this pregnancy, I opted for a C-Section and, while I was going through the [termination] process, I got a call to see a specialist doctor, who administers anaesthesia. So, it was a shock to me that the systems are not integrated. They didn't know that I am having a medical termination. And, on top of that, I had my termination in July, and Friday last week [October], I got an email that I am booked in for a C-Section. So, that's one area where I would definitely like to see improvement... I got a similar thing. It was only about a week afterwards that I got my welcome pack to [hospital name] maternity services, you will be birthing here. [Bereaved – medical termination]

It would have been nice if they had informed the pharmacy [that my baby had died]. I was on insulin when I was pregnant, so, when I went in after I had baby to get some medication, they said, "Oh, have you had your baby? Where's the baby? We want to see the baby". I had to explain in the middle of the pharmacy, because I live in a small community where everybody knows everybody, that the baby died. He went as white as a ghost, and I was distraught and ran out. Simple things like that are retraumatising. You shouldn't have to go through that and explain. There should have been some discharge summary that, with your permission, goes to the pharmacy to say, 'This has happened. They're not going to require their insulin anymore'. [Bereaved – medical termination]

3.7 Beliefs about early miscarriages

Qualitative research participants, who experienced miscarriages, expressed concern about what they believe is a common misperception within the maternity and perinatal system; that is, that early miscarriages have a relatively minimal and short-term impact on the women and people who experience them. The following illustrate the effect this has had on some bereaved women and people in this situation.

It is a really huge thing to go through in a really short amount of time, especially in the acute phase... And I just think it goes against what we think we know about miscarriage. There are all these narratives like, 'Oh, it's just a heavy period' or 'It's not a shock when it happens'. When it happens, it is huge, because it is a really scary physical experience. There is a lot of grief, and it can be identity changing. It is just so much bigger than you'd ever imagine. [Bereaved under 20 weeks]

I have had five miscarriages and I lost my son [name] in April this year, and it has had a huge impact on my life. [Bereaved under 20 weeks]

Seeing miscarriage for the prolonged process it can be and that it carries into a subsequent pregnancy. There can be a huge amount of anxiety there, and I don't think that is acknowledged or talked about. Pregnancy after miscarriage can be agony every day for as long as that pregnancy goes on for is a really tough thing to go through, and I think it's something else women need support with. [Bereaved under 20 weeks]

The following illustrate how this misperception resulted in them feeling disadvantaged in terms of the quality and extent of the support and level of care they received.

It was eleven days later that I actually saw someone in person. At that point, they realised, "Oh, you should have had an Anti-D injection in the first 72 hours", because I am Rhesus negative. So, they were like, "Oh, that's fine, we will give it give it to you now..." But all the research I have read since says that it should have happened in the first few days. So, that made me quite angry, knowing that could affect future pregnancies. Having all that information at the start would have been useful. [Bereaved under 20 weeks]

In comparison [with losing a baby at under 20 weeks], when we lost our 20-day [old] daughter this year, we were offered so many things in terms of memory making and support and resources and piles of paperwork in terms of places to go for different things. Whereas, a miscarriage, they almost treated it like, 'Oh well that's so common'. So, they don't really treat it as [involving] grief, and I just think it would have been important to have had the support at the time. [Bereaved under 20 weeks]

3.8 Not having a strong LMC advocate

Two women described experiences where they did not receive the care and support they needed. While it is difficult to pinpoint why this occurred, it was evident that one had a poor relationship with her midwife and felt unheard by her and everyone else she turned to for help, given her concerns about the welfare of her pēpē/baby. The other had **no one** person within the service whom she could contact when she needed help.

Unfortunately, I wasn't with a community midwife service [as there was no midwife available]. I was with the midwife service through the hospital, so I saw a different midwife every single time I went to the clinic. I also had diabetes, so I was being managed by the specialists, which, again, I saw a different registrar every single time. I never saw the same person. When my waters suddenly broke at 20 weeks, I didn't know who to call, and when I did, they were on the phone. I had a pamphlet that said to ring the maternity ward. I was on the phone waiting for an hour until someone answered the phone... I didn't hear from anyone because I had no consistent midwifery care. I had no one consistent to talk to... I would have thought that they would have had a specialist midwife who just dealt with bereaved people who were going to have babies that were going to die. [Bereaved – medical termination]

I contacted Healthline. That was the first thing that I did. I called them at 2am because I was struggling to breathe, and I was coughing constantly. I had a fever and the chills. Everything was not right. He was 37 weeks at the time... She just said take a rest, paracetamol and fluids and all those things. I asked if I should go to ED and she said, "Definitely not...". I messaged my midwife at 6am that same morning. She replied exactly the same. I waited until 8am, when our local clinic was open. I wanted to see someone. I got there and saw the nurse. She asked a couple of questions. I was hoping she would get the doppler to just listen to the heartbeat. This was two days before he passed away... because of my symptoms, she told me to go back home or wait in the car, I was like, "OK, you are the third person to say just relax, it's nothing serious. I'll go home". So, I went home, Thursday, Friday, Saturday, nothing was getting better... On Saturday morning, I woke up and there was blood on my bed. I called the midwife, and she asked me to go to hospital to delivery, and that's where they found no heartbeat... I felt I wasn't listened to. Because I knew there was something wrong. They could at least examine the baby. They know I am OK because they can see, but they can't see what's going on inside and I feel like my biggest guilt and regret now is not pushing them to listen, to just examine me... After my baby died, my midwife was crying because she said she didn't understand me. [Bereaved over 20 weeks]

3.9 Poor access to mental health services during pregnancy

Some bereaved women and people reported being unable to access the mental health services they needed during their pregnancies.

I had depression from the start of pregnancy, and I was under [the care of the] crisis team at the time. Then I was transferred to Maternal Mental Health, but that was when my pregnancy was continuing. When this happened [medical termination], I immediately needed a different kind of mental health support, but the Foetal Medicine Clinic said you need to speak to Maternal Mental Health to get to speak to someone and it's going to take a long time. This didn't make sense to me. They are dealing with bereaved parents, especially in the first few weeks, when you are overwhelmed with your hormones, what has happened and grief, and we have to be on a waiting line? I kept on following-up with the key worker at Maternal Mental Health and four weeks after the termination, I finally got an appointment to see a psychologist. [Bereaved – medical termination]

During my pregnancy I had been so anxious because I felt like something wasn't quite right, even though the scans said he was perfect. It was because of this bleeding. I had never had bleeding before. They referred me to the Maternal Mental Health Service, but I didn't get any support from them during this time... Two weeks after I had baby, I hadn't heard from the lady, and then she rings and says, "Looks like your baby has died, so you are no longer eligible for our service, so we are going to discharge you. Are you going to kill yourself, or are you thinking or killing anyone else?" And, I just said, "Not today", and hung up. So, I went back to my GP, who referred me to Community Mental Health. They said, "No, you are not in the worst 3%, which is what they only see...". [Bereaved – medical termination]

3.10 Living with loss

The lived experiences shared by the bereaved women and people who participated in this research clearly communicate that the impact of the loss on themselves and the effect of the loss felt across their whānau and families cannot be measured by the length of their pēpē/baby's gestation, or how or why the pēpē/baby died.

All the bereaved women and people who participated in this research experienced a significant loss, for which they needed ongoing support.

I think there should be a pathway [for access to counselling services] through the DHB that is funded for 6-months, and you have unlimited [access] to somebody. I think that person should be a psychologist. I think that those structured sessions are really good. It is not just helping you process grief; it is helping you process trauma. It's been massive for me going into another birth and understanding that this will be different and why. [Bereaved during labour]

While for some, the need for support was immediate, for others, this was delayed until it was triggered by an event, such as their pēpē/baby's due date, another pregnancy, or the death of another child – an event which may have been weeks or even months after their loss.

It wasn't until weeks later that we thought, actually, this is a major thing, and we need to deal with it... The hospital briefly said, "Do you want any sort of formal counselling or formal support?". We were in such shock; we didn't think we needed it. We just wanted to get out of there... Once we left there, we thought, oh we have been discharged now, that's that, we can't get support. [Bereaved under 20 weeks]

I wasn't until my daughter died 20 days post birth this year that we realised we never processed our grief of the last year. [Bereaved under 20 weeks]

3.11 Follow-up by the LMC and hospital

Some qualitative research participants reported feeling as though they were well supported, both throughout and immediately following their losses, by either their LMC, the hospital and/or their GP.

My midwife was fantastic. She was absolutely brilliant, right from the beginning to the end. I could not fault her... Even after her contract finished, she offered to pop in and see me for a coffee, or she would just give me a call to check in and tell me I can reach out to her whenever I like. I did appreciate that. [Bereaved – medical termination]

I wasn't allowed to leave the hospital without having booked an appointment with a social worker for the week after. So, I essentially had a compulsory meeting with the social worker in a week's time after [name] was born, which was really, really, awesome. I was also given a book about grief and how to handle it... with beautiful images and poetry in it and information about funerals. I felt inundated with information. I still have them to this day. [Bereaved during labour]

I think I got lucky. I had a brilliant midwife. She was my midwife for both of my losses. She is very experienced and really kind. She took care of that emotional need I had when I had my first miscarriage. I was on the phone to her that night discussing options of how to proceed, and she said, "Light a candle for your baby tonight and try and get a good night's sleep". Things like that really stood out. [Bereaved under 20 weeks]

Others felt that they did not get as much support from their midwives as they would have liked after the loss of their pēpē/baby, assuming this was either because they were overworked and/or because their priorities were elsewhere (i.e., on delivering and caring for other pēpē/babies).

Your midwife can play a big part in your grieving process. I feel like mine didn't. I think she was only there 2-3 weeks after; it wasn't up to the 6-weeks, and she didn't warn me that this was the last time she would be seeing me... The only time she came over to my house was because I asked for the report of the placenta. She just dropped it off in the mailbox and left. [Bereaved over 20 weeks]

I had a fairly good experience with my midwife, but I must admit that, in hindsight, they're so overworked and that's a huge problem across-the-board. But, at the time when you are into your grief, she was busy going off delivering other babies and I was just feeling quite ignored because my baby had died... All of that felt really hard. [Bereaved – medical termination]

On the other hand, some women and people said that they did not receive any follow-up at home after the loss of their pēpē/baby and that they left the system without any information about where they could get the support they required. This left them feeling forgotten and alone.

In a nutshell, I just feel like I was forgotten and pretty much as soon as I left the hospital that day, I had to go and navigate everything myself. [Bereaved – medical termination]

While I was in the system, I had doctors and I had midwives. There were people checking on me. You've got stuff happening all the time. And then you go home and have the funeral, and then it's just quiet and you don't know what to do. [Bereaved during labour]

With my [four] early losses, all except for one, I have had to have medical interventions to end them. We were never told about Sands [NZ], or anything. We were just in hospital and then sent home. So, we didn't get any information on where to get support or anything like that. [Bereaved within 28 days after birth]

As well as its toll on the birthing parent, one qualitative research participant expressed their concern about the ripple effect of this lack of support on their whānau/family, and perhaps even intergenerationally.

You are going to have so much intergenerational trauma from this, because it affects you in so many ways; it affects your kids and it's going to affect their kids. Things could be done so much better, if they had the basis of some love, respect and kindness and treating people like they're humans who have just lost children. [Bereaved – medical termination]

3.12 Counselling services

Almost without exception, the bereaved women and people who participated in this qualitative research would have liked counselling to help them process their losses.

I was in quite a bad place... It puts quite a lot of pressure on, just even within my own relationship with my partner and my relationship with my children. [Bereaved within 28 days after birth]

As such, it came as a shock to learn that that they were generally not eligible for free, or even subsidised, counselling. So, if they wanted it, they would have to both source it and fund it themselves.

I asked the hospital midwife about grief counselling. She was very apologetic and said, "It's not a free service and it's very expensive". I was a bit shocked, thinking, how am I supposed to do this? There is a lot put on women to go and find the care themselves and to access counselling and pay for it themselves. Those things are huge hurdles. It's not easy and it's not accessible for everybody. [Bereaved during labour]

For someone who never wanted mental health services in the past, I was under the impression from the news that there was all this funding for mental health... And the one time I really needed it, it was like you're entitled to nothing... You are basically offered nothing, and you have to fight for things. Maybe counselling is not for everyone and that's absolutely fine, but you should be offered it, at the very least. [Bereaved – medical termination]

For those who persisted in looking for counselling services, finding a counsellor was described as “a struggle”, and often involved waiting for a month or more.

It took four or five months to get any counselling in place, and it was a real battle. [Bereaved within 28 days after birth]

Those who were fortunate enough to find funded counselling services, generally did so through the support of their GP, or through their employers or a family member's EAP.

I struggled to get counselling... So, for perinatal services to say they can't see us because we don't have living children, that's just another kick to the guts of not being acknowledged as parents... We ended up getting counselling through my mother-in-law, who works for the hospital. She put it through her EAP and then the EAP counsellor kept extending it. [Bereaved within 28 days after birth]

Unfortunately, the counselling, when received, often did not meet their needs because there were not enough sessions and/or because they were unable to establish a rapport with the counsellor.

I went through three EAP sessions through work, but it's not enough. Even the three sessions you get referred to through your GP is not enough. Six sessions are not enough to dig deep. [Bereaved – medical termination]

I got to see a grief intervention counsellor that my GP referred me to. She didn't read my notes before I walked in. I never saw her again and I have seen no one since because I can't afford \$150. [Bereaved – medical termination]

So, I tried some free sessions through work. Unfortunately, I got someone who, when I said 23-weeks' gestation, she said, "Is that small? I don't know much about babies". She was quite airy-fairy and into strange techniques that just did nothing for me at all. [Bereaved during labour]

As such, those who could afford it, ended up paying for counselling themselves.

I think it is hard to find someone you gel with. For the first consult, she didn't know why I was there. I got four free sessions and then I ended up pursuing a psychologist who I had seen once before. I have probably done 10 sessions and only three of those were funded. I haven't seen her much recently, but I will probably need to go back after the birth of our next baby, as I think that will be a new grief wave. [Bereaved during labour]

3.13 The role of volunteer support services

While generally not seen as a substitute for counselling, research participants who found their way to the volunteer support groups for bereaved women and people, such as Sands NZ and Baby Loss NZ, found the support that they received as being immeasurably helpful.

It is not good enough that you should have to rely on volunteers from Sands [NZ] or a Facebook group to get mental health support. That should never be a thing... We should be able to get professional help and quickly. [Bereaved – medical termination]

I found a lot of my support through Sands [NZ] and then I also found their Facebook group – ending a wanted pregnancy, which you have actually got to apply for. I can't remember how I found that, but it's where I got most of my support after the fact. [Bereaved – medical termination]

Depending on who they were, women and people benefited from the catharsis of being able to talk about their loss, knowing that they would be listened to compassionately, especially when whānau/family and friends had grown tired of listening, and/or just being able to listen to, and/or read about the experience of others who had similar experiences.

I joined Sands' [NZ's] Bereaved whānau page. I read other people's stories... I just needed other people's stories to feel a connection with people, and none of my friends or family members had been through it. So, there was a real fracture there. [Bereaved under 20 weeks]

I have been to the Sands [NZ] meetings, and it's quite good. So, it's like common ground for everybody to talk... I feel I can just open-up about my baby. Whereas other people [in my life] just shy away, and tell me, "Come on, you need to move on". [Bereaved over 20 weeks]

As well as well as helping to deal with their losses, these groups are also valued for the support they provide through subsequent pregnancies and children.

Pregnancy after loss is hard. Parenting after loss is hard. So, it has been good that they [Sands NZ] have been the ones following us through and giving us support. Not just through the loss of our girls, but also through the birth of our boy, and everything that comes along with that. Sands [NZ] are amazing. [Bereaved within 28 days after birth]

Women and people who discovered that there were no support groups for bereaved parents in the towns or cities where they lived were understandably disappointed.

There is no Sands [NZ] support groups in [place name]. There is not a single baby loss or bereavement group in [place name]. We got told when we left the hospital, it was one thing I asked is there support in the community for us and they said,

“Yes, there’s lots”, and I found out that there is none. So, that was extremely disheartening. [Bereaved over 20 weeks]

The hospital gave us the Sands [NZ] pamphlet, but there is no Sands [NZ] group in Dunedin. Way later, I found out there was a baby bereavement group in Dunedin, but I never got the pamphlet. [Bereaved over 20 weeks]

3.14 Suggested improvements

Reflecting their desire to improve the care and support they experienced so that others will have better experiences, the bereaved women and people who participated in this research suggested the following improvements to current services:

- **Listen to hapū/pregnant women and people if they are worried about themselves or their pēpē/baby**

If a hapū/pregnant woman or person says they are worried about their own or pēpē/baby's wellbeing, it is important to hear what they are saying and respond appropriately.

I think, if you feel something is wrong, you should be listened to. [Bereaved over 20 weeks]

Understand that we know our bodies and we know our babies and if we say there is something wrong, we need to be listened to, and at least have it investigated. Not just being brushed off because they are the professional and they know better. [Bereaved within 28 days after birth]

- **Address midwife shortages**

Bereaved women and people were particularly keen to see the shortage of community midwives and hospital midwives addressed.

Pay our midwives enough, so our hospitals have staff in them. Our hospitals are so poorly staffed, and no one is doing their job, because they're so stretched. [Bereaved over 20 weeks]

Having a key midwife that follows you through the journey is really important. That is so important for the future of midwifery that you don't get a different person every time, and they don't have that rapport with you. So, what I would love to see, in an ideal world, is that you have that continuity of care and that you have that rapport with your person. Because when you are giving birth, having that familiar environment and that familiar person wherever possible makes a huge difference to the birth, as well. [Bereaved over 20 weeks]

- **Support bereavement education across the maternity and perinatal workforce**
Better training across the maternity and perinatal services workforce, in terms of caring for and supporting women and people with high-risk pregnancies and those who have lost their pēpē/babies.

I really believe that there needs to be training in the hospitals and all maternity sectors. Like a crash course on how to deal with bereaved parents and how to walk them through their experience. [Bereaved over 20 weeks]

I think, the first thing is having staff that are properly trained to deal with situations like us [i.e., high risk pregnancies where the baby has a problem and the subsequent death of the baby], because if you have got that, then you have a basis to build a healthy relationship between the midwife the mother and the family. That is, essentially a positivity within such a negative journey that is about to start. [Bereaved within 28 days after birth]

I think women need comfort and compassion. I think those soft skills are really important for health professionals. [Bereaved under 20 weeks]

- **Have midwives and other staff with bereavement knowledge on each shift in all hospitals**

Having bereavement midwives and/or other specially trained staff in every hospital to support women and people, from the time they learn that their pēpē/baby had or might die, to the time they go home.

I would like to see a team of midwives and nurses in every maternity sector in the hospitals nationwide. Not every midwife or nurse wants to be trained in it. Then pick staff who are interested... and have them trained in walking through with the parents from the moment the baby's heart stops. That there is a team of 2-3 people that will hold your hand and walk you through what is going to happen and will be there with you every step of the way if you want it... I was close to dying when I gave birth to my baby, and they didn't care for me at all through that process. So, I just think there need to be people that give a shit and listen to mothers through the whole thing. At the end of the day, we know what's best. We just need guidance. We need to be listened to and we need to be told what to expect with your baby who has died and what is going to happen. [Bereaved over 20 weeks]

Midwives that deal specifically with parents who have been given bad news that they could or are going to lose their child... If you are an expectant parent knowing you're going to potentially lose your child and you know you have the opportunity of having a midwife who can support you through this. [Bereaved within 28 days after birth]

One of my biggest bits of feedback with the hospital has been about whether there should have been a grief specialist they could call on to help us make decisions, because we had to. I had never planned a funeral in my life and then you are holding your baby. We had a capsule in the car and the baby bag. It was awful. My husband had to go home and take the capsule out before he drove me home, so that I wouldn't lose my mind. Someone to help him with that. There must be someone in the hospital setting that they can call that just helps you navigate huge decisions in a trauma period... Having someone to say to us, "Hey, look, I know this is a busy time. It's crazy, but do you want access to a chaplain, cultural support, and a social worker?", because we didn't get one of those either. [Bereaved during labour]

- **Improve follow-up care following any perinatal loss**

All bereaved women or people need to be followed-up with when they return home after their loss, including sporadic follow-up after six weeks, as required.

A go-to [support] person who continues for a period of time afterwards. Because, for a lot of people, there are other tough times that come up, your due date, etc. [Bereaved – medical termination]

If they have an LMC they have been working with, giving the LMC the scope to be able to continue working with that person beyond the scope now because, to be honest, it was my midwife who probably save me. But the relationship with the DHB nearly killed me. [Bereaved within 28 days after birth]

A follow-up and it wouldn't have had to be that much, a text message, a phone call to say, "How are you going? Hey, all these things that we offered you when you were in shock and grief are still available to you. Let me know if you want me to help you access them". [Bereaved under 20 weeks]

- **Fund and support access to counselling services for any perinatal loss**

The provision of counselling services that can be accessed quickly and easily and is fully funded is clearly necessary. Some research participants also thought such services should be extended to include partners and children. These services should also be on offer to access later, for those who initially decline the option but find themselves/others struggling down-the-track.

I think there should be some sort of mental health support immediately after the [termination] process... If you're struggling with the grief of losing a baby and you have no mental [health] support, it becomes very hard because, from what I felt after the termination, you lose a sense of who you are and it's very difficult to make good sense of your life when you lose a baby unexpectedly in those circumstances. [Bereaved – medical termination]

Can I just say, the biggest thing, which I can't believe, is that there is no counselling funded. That when you leave the hospital you are just [hung] out to dry... Any counselling provided should be couples counselling. It shouldn't be hard to find counselling or work out if your insurance will pay for it. The option should just be there. It should be an open invitation. They should check up on you after three months and say, "How are doing? Do you still want this?". [Bereaved over 20 weeks]

- **Better information resources**

Making sure that women and people are provided with, or know where to access the following information content:

- A resource where you can see a pēpē/baby at different stages of gestation, to help parents decide if they want to see their pēpē/baby and, if they do, to prepare them for this.

What I would love to see happen is a resource, where you can view baby at different gestational stages beforehand. It was important for me to know what my baby was going to look like. That was an important part of me making the decision, do I want to see them or not once they had been born? I think it is an important thing to do for your grief, and you only have one opportunity. For both of my miscarriages, I was on Google search looking for 12 week and 19-week Foetuses. I needed to see it, but it is horrific Googling that on your own at home. How about a resource that your midwife could share with you or someone at the hospital? Like, a beautiful I coffee table book and its photos taken in a beautiful way that you could have a look at beforehand. That, I think, would be a real help... Or, if there is a link to a resource somewhere online where they could send you a PDF, so you didn't have to Google it. [Bereaved under 20 weeks]

- Information about grief for parents, and the rest of the whānau/family.

What does grief look like? Is it the fact that I'm not sleeping? What are some ways that I can live well with this grief? And how can I find people that understand, because I don't have support from my usual support network; a lot of them don't understand. I felt really alone, so, I naturally sought out people who had been through the same thing. I wanted to hear stories and understand that my experiences were normal. And, I guess, because it goes on for so long. We think of miscarriage as this event that happened and it's done and people just go, "Oops, oh well, time to move on", but it's with you forever. I think, when I had a miscarriage, I didn't understand that. I just felt like, why am I not over this? [Bereaved under 20 weeks]

I'm actually going to speak on behalf of my husband. A lot of the information that was targeted for miscarriage and everything else was targeted at women, and rightfully so, it's traumatic thing to go through. But there was nothing for him to be able to take and read himself or any support. They are just as much a part of it... And for children too... Something for them to read about grief. They experience it too. They feel it. My two-year-old still thinks there is a baby in my tummy. How do we explain it? [Bereaved under 20 weeks]

- Information about making memories of their pēpē/babies. For example, an information sheet listing the local service providers and their contact details.

One thing that still frustrates me is that we never got proper photos done and things like that. I thought that I had said yes to this, but with everything going on, the information just got lost. The one thing I really wanted was for the local hospital to have an information sheet, that had Heartfelt's contact and if you want plaster casts of feet and hands, contact is this. [Bereaved – medical termination]

- Up to date information about the volunteer support groups and services that are available for bereaved women and people, their whānau and families in their local area.

Having [information about] the organisations and support groups out there actually given to you. So that you can contact them if you want, not just stumble across them. [Bereaved within 28 days after birth]

So much of what is available to us [bereaved whānau] is just done by amazing charities, that often you learn of in hindsight, because you show an interest in this area... You just learn about all these amazing people out there that are doing volunteer things, and yet, at the time you are not in the headspace to be dealing with that. Just to have something written down for this local authority. This is what you can get, here is the number, that would have been so helpful. [Bereaved – medical termination]

I didn't realise I was a support kind of person, until I was pressured into it. But through that, I have met some really amazing people and some really supportive people. So, I think, having that option there and given to you is really important. [Bereaved within 28 days after birth]

- Information about the miscarriage process, including what to expect, how to save the foetus, and in what circumstances to go to hospital.

I think, if there was a way I could have been told, if this happens, this is the way that you can manage it without losing the foetus, that would have been beneficial... I think, having that knowledge beforehand that this is something that is probably going to happen. This is how you can do it if you are bleeding that much... Having written information telling you when to go to the hospital would have been quite useful. [Bereaved under 20 weeks]

- Information about the hospital complaints system.

I laid a complaint and I had to jump through five different hoops to do that. There needs to be a clear pathway for women to give feedback. [Bereaved under 20 weeks]

Mindful of the difficulties they had processing information when they were in shock and overwhelmed with grief, bereaved women and people wanted important information in a printed form, so that they had a reference of what they needed to know.

Appendix A: Survey methodology

The 2022 Survey of Whānau/Families who have Lost a Pēpē/Baby was completed in **five** stages as follows:

1. **Stage 1: Research development.**

This stage commenced with the formation of an Expert Advisory Group (EAG) and obtaining ethics approval from the Health and Disability Ethics Committee (HDEC) in 2021. The EAG members represented the diverse perspective of stakeholders within the maternity sector:

- Dr Lesley Dixon of the New Zealand College of Midwives.
- Jade Chase, Chief Advisor Pae Ora - Māori Health, Ministry of Health.
- Tish Taihia, Clinical Midwife Manager Ngā Hau Mangere Birthing Centre, representing the Pasfika community.
- Melanie Tarrant and Pania Mitchell from Sands NZ.
- Dr George Parker, representing the rainbow community.

As part of this stage, we reviewed and redesigned the 2014 survey questionnaires (and recruitment letters and other communication materials) to ensure they were fit-for-purpose, before cognitive testing them.

The cognitive testing of the questionnaire for the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby was completed using Belson's double-back method. Fourteen respondents participated in this testing, which was completed between 21 March and 1 April 2022. These respondents had lost one or more pēpē/babies and included those who had most recently lost their pēpē/baby by termination; stillborn during pregnancy; stillborn during labour; or within 28 days of birth. Two respondents identified as Māori and all others as European/Pākehā.

On average, respondents took 15-20 minutes to complete the survey questionnaire, with most commenting that the questioning was clear, and they could easily move through the logically ordered sections, which reflected their maternity journey.

Respondents were pleased to have had the opportunity to have their voices heard and to know that what they have shared would help improve the bereavement 'pathway' for bereaved women and people who lose pēpē/babies moving forward. Importantly, many said that the tone of the survey was empathetic and that they found it cathartic having the opportunity to tell their story.

A copy of the final survey questionnaire, the Participant Information Sheet and survey invitation letter/reminder may be found in Appendix B.

2. Stage 2: Pilot.

Before fully launching the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby, a pilot was conducted, between 13 June and 11 July 2022, as follows:

- The pilot simulated the survey process and involved a random sample of 100 bereaved women and people. These potential respondents were selected from a contact database provided by Te Whatu Ora and sent a survey pack containing a pre-notification letter, inviting them to take part in the survey, and an information sheet.

As the survey contains four different ‘pathways’ depending on when bereaved women and people lost their pēpē/baby, it was not practical to send out a paper questionnaire. Therefore, respondents were given the option of completing the survey either online or by telephone.

- However, subsequent to the packs being received by these respondents, it was discovered that the delivery date field in the contact database was not necessarily related to the date of a pēpē/baby that was lost – it was the date of the most recent birth. Although all of the cases selected for the sample had lost a pēpē/baby, some of them had since had a live birth and in these instances, the letter had incorrectly quoted that delivery date as being the date that they had lost their child. This issue potentially impacted n=50 of the 100 potential respondents; n=5 of whom contacted either Research New Zealand or Sands NZ directly with a query.

This matter was corrected by Te Whatu Ora and letters of apology were sent to these respondents, advising them that all records had been double-checked and were now correct. Due to the sensitive nature of this survey, no reminder notifications were sent to encourage survey participation.

- By the time the pilot was closed on 11 July 2022, six respondents had completed the survey online (and none had chosen to do the survey by telephone). That is, a response rate of 6%. Two of these respondents each had their pregnancy terminated for health reasons, had lost their pēpē/baby during pregnancy, or had lost their pēpē/baby up to 28 days after birth. All were aged over 25 years of age; one each identified as Māori and Pasifika, and four of other ethnicities.

We surmised that this lower-than-expected response rate was due to a combination of the contact database issues mentioned above, the opt-in nature of the survey and the fact that potential respondents had only been contactable based on their address at the time of the loss of their pēpē/baby (i.e., their contact details could be out-of-date).

Based on the results of the pilot, the major recommendations made and accepted by Te Whatu Ora, affecting the methodology for the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby were as follows:

- Use alternative contact information available via Te Whatu Ora; specifically email addresses and telephone contact numbers.
- Promote the survey on the social media platforms used by Te Whatu Ora and its consumer groups and include a link to the survey on Research New Zealand's website (only eligible for bereaved women or people, given a survey access code is required to start the survey).
- Remove any reference to a loss date in communications sent to potential respondents.
- Send a 'gentle' email reminder to bereaved women/people, encouraging late-responders to complete the survey.

3. Stage 3: Full launch.

The 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby was launched on 24 August 2022, with a survey invitation sent to the target population of bereaved women/people who had lost a pēpē/baby in the two years prior to this date.

By the close-off date of 4 October 2022, responses had been received from n=118 respondents. This was after one gentle email reminder had been sent and generic links had been placed on our website, as well as Sands NZ's and Te Whatu Ora's websites.

A response was received from a total of n=118 bereaved women and people, as follows:

- n=25 pregnancy was terminated for health reasons.
- n=32 pēpē/baby died during pregnancy.
- n=15 pēpē/baby died during labour.
- n=46 pēpē/baby died up to 28 days after birth.

Almost all of the surveys were completed online (n=116), with only n=2 being completed by telephone. The overall participation rate for the survey is 29%.

Most of the response to the survey was from those respondents who received a specific invitation letter (n=88). Another n=24 also completed the survey after clicking on one of the generic survey links.

Table 1: Overall survey response

	2022
Invited to complete the survey by letter	413
Completed the survey via the generic link	24
Participated in cognitively testing the survey	6
Survey completed:	
Online	116
By telephone	2
Total completed	118
Participation rate*	29%

4. Stage 4: Processing.

As an interim step before the analysis of the results to the survey, the survey data was processed as follows:

- A 'master' dataset was created combining the online response with the interviews completed by telephone.
- Where possible, 'other specify' answers to questions were then coded using the existing code frame to these questions, or new codes were added.
- All verbatim comments were depersonalised of names, places or situation which might directly or indirectly identify a respondent.

The data for the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby was **not** weighted and, therefore, when considering the results it is important to remember the structure of the achieved sample (refer above – Stage 3).

5. Stage 5: Analysis and reporting.

The results of the 2022 Survey of Whānau and Families who have Lost a Pēpē/Baby have been analysed and reported by the total achieved sample only. The sample size does not support analysing and reporting the results by the bereavement 'pathways' or by any demographic variable.

Results based on the total achieved sample of n=118 are subject to a maximum margin of error of plus or minus 7.9% (at the 95% confidence level).

Appendix B: Survey Questionnaire, Survey invitation letter and Participant Information Sheet

[Survey invitation letter]

Dear/Tēnā koe [Name]

Survey for Families/Whānau who have lost a Pēpē/Baby

What does taking part involve?

To ensure your wellbeing we encourage you to have a support person at your side while you complete the survey. You can do the survey, in about 15 minutes:

By telephone

If you would like to do the survey over the phone, please call Research New Zealand on 0800 273 732.

Online

Step 1: Go to www.researchnz.com

Step 2: Click on **Current Surveys**

Step 3: Choose **Survey for Whānau/Families who have lost a Pēpē/Baby**

Step 4: Enter your **Survey Access Code:** <<Pin>>

It is FREE to complete the survey online – your data use charges are covered by Health New Zealand's Sponsored Data Initiative.

OR scan the **QR code** to go straight to the start of the survey and enter your **Survey Access Code:** <<Pin>>

We are aware that you recently experienced the loss of your pēpē/baby – please accept our sincere sympathies. We are writing to invite you to take part in a national survey about your maternity (perinatal) care during your pregnancy and the support, care, and information you received during and after your loss.

This survey is to help us find out how to best support whānau/families who experience this heart-breaking loss. Your insight and feedback will help us to make improvements to the care provided to other women/people who lose their pēpē/baby.

Taking part in the survey is completely voluntary and confidential. If you choose to take part, you will not be personally identified in any way when the results are reported.

Please read the participant information sheet for more information about the survey and how the results will be used.

Your wellbeing is important to us. We understand that answering the survey questions and recalling your experiences at the time when you lost your pēpē/baby may raise uncomfortable emotions. Please contact Sands NZ if you would like to talk to someone to help you through any distress carrying out the survey has caused. Sands NZ are a voluntary organisation who support parents and whānau/families who have experienced the death of a pēpē/baby. Information and regional contact details, including phone numbers, are available on their website - www.sands.org.nz.

We have asked an independent company, Research New Zealand, to conduct this survey on our behalf. So if you have any questions about the survey, either before or after completing it, please contact Sarah Buchanan, Senior Researcher, at Sarah.M.Buchanan@researchnz.com.

Yours sincerely/Nāku noa, nā

Mark Powell

Acting Group Manager

Community Health System Improvement and Innovation

Reference Number: <<IDNO>>

Participant Information Sheet

2022 Survey for Whānau/Families who have Lost a Pēpē/Baby

You are invited to take part in the **2022 Survey of Whānau/Families who have Lost a Pēpē/Baby**.

Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason. If you do want to take part now, but change your mind at any point, that's okay, you can pull out of the survey at any time.

The following information is here to help you decide if you'd like to take part.

What is the purpose of the survey?

This survey is being funded by Health New Zealand (the Ministry of Health).

The results of this survey will be used by Health New Zealand (the Ministry of Health) to make sure the maternity care services provided to women/people in Aotearoa New Zealand are of the highest possible standard, including those that have lost a pēpē/baby. The results will help to inform the National Bereavement Pathway by identifying any areas that need to be improved, to better support whānau/families in the future.

The survey updates similar surveys completed in previous years and therefore will help evaluate whether recent changes to care services have had the desired impact or whether further changes need to be made.

The completion of the survey is endorsed by the New Zealand College of Midwives and Sands NZ (www.sands.org.nz) and is also supported by various consumer organisations, including those specifically providing services to Māori and Pasifika peoples.

Why and how have you been selected?

Your name and contact details were randomly selected from your hospital and/or Lead Maternity Carer records held by Health New Zealand (the Ministry of Health). These records show that you lost a pēpē/baby in the last two years.

What types of questions will you be asked?

The survey will include questions in the following areas:

- The level of care you expected to receive and whether your needs were met to your satisfaction.
- What was good and what could have been better.
- Whether or not you received the information you wanted and had all your questions answered to your satisfaction.
- Whether you had any problems getting the services you needed, including the cost of these services.

What's involved in completing the survey?

First and most important of all, completing the survey is **completely voluntary, anonymous, and confidential**.

However, if you choose to complete the survey:

- **No preparation** will be required.
- It will only take about **15 minutes to complete**.
- You will have the **choice** of completing it online or via a scheduled telephone appointment with an interviewer.
- You are welcome to have a **support person** with you while you complete the survey.
- You **will not have to answer** any questions if you don't want to.
- You will be able to **stop at any time**, restart or decide **not to continue**.
- At **no** stage will you be asked to provide any personal information.

To emphasise, the information you provide will remain **confidential** and you will **not** be identified – either directly or indirectly – in any reporting. Your answers will be combined with the answers provided by other people who complete the survey, in the form of summary statistics and anonymous comments.

What will happen to the information you provide?

A very small team of researchers at Research New Zealand are the only people who will be able to see your individual survey responses. Any information relating to you personally (e.g., your name) will be removed from the survey data and deleted from their records

when the survey period ends. This means the final dataset that contains everyone's survey answers will be completely anonymous.

This final dataset containing everyone's survey answers will be analysed by the researchers based on broad groups of people defined, for example, by their age or ethnicity. As mentioned above, you will **not** be identified – either directly or indirectly – in any analysis and reporting.

This final (anonymous) survey dataset will be stored securely by the researchers, indefinitely, in a secure government approved local cloud-based storage system, and access to this will be strictly controlled in accordance with their Code of Practice.

Who are the researchers?

Research New Zealand (www.researchnz.com) has been employed by Health New Zealand (the Ministry of Health) to manage this survey on its behalf. Research New Zealand managed the previous surveys.

For the purposes of carrying out the current survey, they are an 'agent' of Health New Zealand (the Ministry of Health), and under the New Zealand Privacy Act 2020, have been given the information they need to contact you. When the survey is finished (see above), they will delete this information from their computer system, as is required by their Code of Practice.

Has this research received ethics approval?

Yes, the New Zealand Health & Disability Ethics Committee (www.ethics.health.govt.nz) has provided ethics approval for the surveys.

What are your rights?

You have the right to ask for a copy of the information that you have provided in completing the survey.

You also have the right to ask that any information you disagree with to be corrected, and you have the right to ask that all of your survey responses be deleted if that is what you want to happen.

Can you find out about the results of the survey?

Yes, Health New Zealand (the Ministry of Health) will publish the report on its website, and Research New Zealand will email a summary of the results to anyone who requests this.

Do you have any other questions or concerns?

If you have any other questions or concerns, please contact **Sarah Buchanan**, Senior Researcher Director, Research New Zealand (Sarah.M.Buchanan@researchnz.com) or

0800 273 372. If Sarah cannot answer your query, she will forward your questions to the appropriate contact at Health New Zealand (the Ministry of Health) or Sands NZ.

You can find a regionally based Sands NZ volunteer to talk to at www.sands.co.nz, including their phone contact details.

If you would like to talk to someone who isn't directly involved in the survey, you can contact an independent health and disability advocate:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz>

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this survey (Ref number: 2021 EXP 11335) on:

Phone: 0800 ETHIC

Email: hdecs@health.govt.nz

Appendix C: Qualitative Research methodology

The qualitative Research with Whānau/Families Who Have Lost Pēpē/Babies was completed as follows.

Sample characteristics

A total of n=18 women and birthing parents who had lost a pēpē/baby in the last 18 months contributed to the study. As shown in Table 1, this included bereaved mothers and people whose pēpē/babies had died before 20 weeks, after 20 weeks, during labour, within 28 days of birth, and those who had medical terminations.

Table 1: Sample summary

	2022
Bereaved before 20 weeks	4
Bereaved - medical termination	4
Bereaved after 20 weeks	4
Bereaved during labour	4
Bereaved within 28 days of birth	2
Total	18

Recruitment criteria and approach

Decisions about whom to include in the sample and the recruitment criteria were made in consultation with Te Whatu Ora. It is of note that a small sample of women and people who had lost their pēpē/baby before 20 weeks was specifically included in the qualitative research, as they were not able to be included in the survey.

The recruitment criteria for the groups with bereaved mothers and people were primarily based on when and how pēpē/baby had died. Namely, if pregnancies were medically terminated; if pēpē/baby had died before 20 weeks; after 20 weeks; during labour; or before 28 days after birth.

While no attempt was made to control for any other criteria, observation suggests that the final sample was reasonably diverse in terms of their social economic realities and where in Aotearoa/New Zealand research participants lived (including from the north and south islands and from large and small urban and rural communities). It is noted that the sample included those who had lost one pēpē/baby and those who had lost multiple pēpē/babies. It also included some women and people whose losses were very recent.

The recruitment of bereaved mothers and people was largely made possible through the generous assistance of Melanie Tarrant (the EAG member for Sands NZ). Her assistance in this regard included placing invitations to participate in the research in Sands NZ's Facebook pages, where bereaved women and people were invited to opt into the research by emailing Research New Zealand. The recruitment process for those who opted into the research was conducted by Research New Zealand by email. Once establishing which of the groups potential participants met the criteria for, they were sent an information sheet about the research (including FAQs), and a consent form (see Appendix D), of which they were asked to read, sign and return, which each did, before attending an interview. All interviews were also confirmed by email.

The final sample for the qualitative research included some bereaved women and people who had also participated in the cognitive testing of the Survey of Whānau Who Have Lost a Pēpē/Baby or the survey itself.

The Research Team

The team responsible for the qualitative research with bereaved women and people was led by Corrine de Bonnaire, (Partner, Qualitative Research, Research New Zealand), working in close collaboration with the Research New Zealand's Kaupapa Māori research partner, Teresa Taylor (TT Consulting Tāpui). Teresa (Ngāti Tūkorehe, Ngāti Raukawa, Ngāti Kahungunu, Ngāti Kuia, NZ Pākehā) was fully involved in all stages of the research process and was responsible for ensuring that cultural issues were considered and accurately interpreted in the interviews conducted with whānau Māori.

Other members of the research team included Jane Falloon (Qualitative Research Director, Research New Zealand) who assisted with the interviewing and Mati Fryer (Research New Zealand). Mati (Te Ātiawa, Ngāti Raukawa, Cook Island Māori) was responsible for recruitment.

Ethics Approval

Ethics approval was obtained from the Health and Disability Ethics Committee (HDEC) for the surveys, but they advised that this was not necessary for the qualitative study on the basis that it was regarded as a minimal-risk observational study (Standard Operating Procedures for Health and Disability Ethics Committees Version 3.0, clause 28, page 12).

Nevertheless, the study was undertaken in a way that met established ethical standards as set out in the National Ethical Standards for Health and Disability Research and Quality Improvement (2019).

Interviewing

All interviewing for the qualitative research was completed between 31 August and 28 September 2022. While the intention was to conduct five small discussion groups with bereaved women and people (each with four participants who had lost their pēpē/babies in similar circumstances), because of recruitment difficulties and last-minute participant cancellations, the bereaved women, and people whose pēpē/babies had died before 28 days were interviewed as a dyad.

All interviewing was completed online as Teams meetings. The decision to conduct the groups online, as opposed to face-to-face, was primarily because of the COVID-19 situation. The online forum also had the benefits of being convenient for participants (especially those with pēpē/babies) and providing a degree of anonymity/privacy (enhanced further for those who chose to leave their cameras off).

All discussions with bereaved women and people, were facilitated by the primary researcher.

Each of the group discussions and the dyad were also attended by another member of the research team, whose role it was to take notes and support the facilitator.

Group discussions and interviews were each 60 minutes in duration. At the beginning of each interview, respondents were asked: to confirm that they understood that their participation was on a voluntary, confidential, and on a fully informed basis; and for permission to audio-record and transcribe these for analysis purposes.

Discussion guides were used as an 'aide memoir', to ensure information requirements were consistently explored. The discussion guide, information sheets (FAQs) and the Consent form (see Appendix D) were all developed in consultation with Te Whatu Ora and in consultation with Melanie Tarrant of the EAG.

All research participants were provided a koha as thanks for their participation in the research.

Analysis and reporting

Analysis commenced during the fieldwork phase of the research and was conducted on an iterative basis. At the completion of the fieldwork stage, transcripts were read multiple times and, through a process of coding, themes relevant within and across groups were identified.

The report was written by the primary researcher in consultation with the Kaupapa Māori researcher. The close involvement of the Kaupapa Māori researcher ensured that issues of cultural significance for Māori were considered and accurately interpreted.

Limitations of this research

It is important to note that the findings of this research with bereaved women and people are based on a small number of research participants (n=18) selected using a non-random sampling method.

Finally, as a qualitative research study, the objective was to provide an understanding of the findings, rather than to quantify these. Therefore, while it is possible to identify variations in responses, it is not possible to extrapolate these findings in quantitative terms (e.g., prevalence) to all bereaved women and people, or to specific groups (e.g., those whose pregnancies were medically terminated). As such, the results must be regarded as indicative only when considering populations of interest.

Researcher insights

Bereaved women and people were motivated to participate in this qualitative research as they hoped that their input would lead to service improvements that would make a difference.

It is of note that many of those who participated in this research commented that they found their experience positive, some even sending thank you notes. While tears were shed in most of the groups, the bereaved women and people found having the opportunity to share their experiences in a safe environment cathartic. The women and birthing parents in all groups were generous in their emotional support of one another.

Appendix D: Qualitative research - Sample Discussion Guide, Information Sheet, and Consent form

Discussion Guide

Qualitative Research Stage – Terminations

Maternity Services Research (#5254)

Research purpose and objectives

The overriding purpose of this qualitative research stage is to provide a rich understanding of women's/people's experiences of maternity services. This, along with the results of the survey research, will help inform improvements to maternity services and childbirth education classes, and the development of the National Perinatal Bereavement Pathway.

The specific objectives of the qualitative research are to provide a greater understanding of:

- ❖ *What maternity services look like when they are working well and not working well, including when people's cultural, identity and other needs are met and not met.*
- ❖ *The barriers and enablers to accessing maternity services.*
- ❖ *How women/people would like to see maternity services improved in the future.*

Introductions (10 min)

Objectives: To ensure group participants are fully informed and consent to participation.

"Nau mai, haere mai, welcome to our focus group. Introduce self and Jane and then explain will start with a karakia, housekeeping stuff, any questions and then your introduction before we get into our discussion.

Kia hoki ngā whakaaro ki a rātou kua whetūrangiatia, okioki atu koutou, moe mai rā. Tātou ngā waihotanga o rātou mā, ngā mihi nui.

May we remember those who have passed away and wish them well on their journey. For those of us here today, greetings to you all.

Reiterate the purpose of the research:

- ❖ Te Whatu Ora asked independent researchers, Research New Zealand, and TT Consulting Tāpui Limited to undertake this research to provide insights into how maternity services are being experienced by different groups in the community (e.g., Māori, Pasifika, gender diverse people, those with long term disabilities).
- ❖ Discussions will cover what worked well and didn't work well; how well needs (including cultural and identity needs) are being met and not met; any barriers experienced to accessing services; and the improvements they would like to see.

Explain how the results of the research will be used:

- ❖ The findings, along with the results of a survey that is running alongside the hui/focus groups, will be pulled together in a report for Te Whatu Ora. The findings will help inform improvements to maternity services and will contribute to the development of the National Perinatal Bereavement Pathway. The development of a national bereavement care pathway will ensure that a consistent standard of care is offered to all bereaved parents/whānau experiencing pregnancy and infant loss in Aotearoa.

The voluntary and confidential nature of participation:

- ❖ Te Whatu Ora are not told who attends the hui/focus groups and reporting will not identify individuals. Responses will be grouped together and reported on a thematic basis and quotes, if used, will remove any identifiable information.
- ❖ Confirm participants don't need to answer questions if they don't want to, and that they may withdraw from the research at any time.

How the hui/group will be run and other housekeeping matters:

- ❖ Confirm the length of the hui/focus group - up to 90 minutes.
- ❖ Encourage participants to be honest and frank about their experiences.
- ❖ Reassure participants that this is not a test (i.e., there are no right or wrong answers).
- ❖ Emphasise the importance of being always respectful of each other, including if they have differences of opinion (e.g., listening, not having side conversations, agreeing to disagree if there are differences of opinion).
- ❖ Explain that the hui/focus group will be audio recorded and that this will be transcribed to assist with the analysis of the findings. The audio recording, transcript any other information about group participants will remain the property of Research NZ and will be destroyed at the completion of the research.

Confirm that participants consent to having the discussion/kōrero recorded for analysis purposes.

Discuss any questions/concerns about participation.

Invite participants to introduce selves - tell us their name, where they are from and a little about their baby that brings them here today.

Group Discussion

Explain to group participants that the discussion will be broken into two parts, each of about 35-40 min. The first part will focus on the **information and advice** they received and how this could have been improved. The second part will focus on the **care and support** they received and what would have better met their needs. As well as sharing their own experiences with the group they will be asked to complete an individual exercise (hence requiring the pen and paper).

Information and advice (35 min)

Objective: To understand how well the information and advice you received from your LMC and other health professionals after you learned you were going to lose your baby met your needs; and how this could be improved.

What makes information and advice valuable: (3 min)

To make sure that we get the most from our discussion, we are just going to take a couple of minutes to talk about the various factors that determine whether we notice and value information and/or advice. I'll start the ball rolling. For example, how relevant we believe the information or advice is to us personally and whether we respect who it has come from/who's telling us.... What else determines whether we notice and value information (e.g., preferences for form (e.g., written, verbal, visual) or channels, comprehension, amount of detail)?

Group discussion – Examples of when information and advice needs are met and not met (e.g., information not received or that could have been better quality): (25 min)

*For this part of the discussion, think back to the **information and advice** that you needed at the different stages of your loss. **What information/advice did you need/want [work through the points in time below]. How did this compare with what you got?***

- ❖ When you discovered something was wrong and were making the decision to end their pregnancy.

- ❖ In preparation for, and during the termination procedure, labour, and birth.
- ❖ During your time in hospital after pēpē/baby was born.
- ❖ In the days and weeks after pēpē/baby died.

If not already covered, *what would you have liked to have known about [discuss each of the information areas below]. What information/advise did you receive, how well did this meet you're your needs?*

- ❖ Making memories with their pēpē/baby.
- ❖ The decisions that needed to be made in the period shortly after pēpē/baby died (e.g., how to care for baby, taking baby home, funeral arrangements).
- ❖ Why pēpē/baby died.
- ❖ Further diagnostic testing (e.g., of the placenta) or pēpē/baby having a post-mortem.

Group discussion – Better information and advice: (5 min)

- ❖ Thinking about the information and advice you received, what would you change so that it better met your, and your whānau/family's needs.

Care and support (35 min)

*Objective: To understand how well the **care and support** provided by your LMC, other health professionals and support organisations (e.g., Sands NZ) met your needs; and how this could be improved.*

Rating scales: (5 min)

*Before we discuss things as a group, we'd like you each to independently rate the **care and support** you received from **your LMC and other health professionals**. To start off can you please write 1 a – d down the left hand of your paper. On a scale of 1-7, where 1= very poor and 7 = excellent, please rate the care and support that you received [work through the list below]:*

1(a). When you discovered something was wrong and were making the decision to end their pregnancy.

1(b). In preparation for, and during the termination procedure, labour, and birth.

1(c). During your time in hospital after pēpē/baby was born.

1(d). In the days and weeks after pēpē/baby died. (Ask participants to consider any care and support they received from support organisations (e.g., Sands NZ), as well as the care and support they received from their LMC and any other health professionals, when answering this.

*Can you now write 2 a, b, c...e down the left-hand side of your paper. Still thinking about the **care and support** that you received from your LMC and other health professionals, and using the same scale, but this time where 1 = didn't meet any of my needs and 7 = met all my needs extremely well, we are going to rate how well each of your following needs were met and respected:*

2(a) physical needs

2(b) emotional needs

2(c) cultural needs

2(d) spiritual needs

2(e) identity needs.

Group discussion - Examples of when care and support needs are met and not met: (25 min)

*Some of you were very satisfied with the care and support that you received at different times, while others of you were dissatisfied. **Working through each stage, as below, ask those with high ratings** to share examples of what your LMC and other health professionals did that made you rate the care and support you received [insert stage] so highly. **Still focusing on the same stage, ask those with low ratings** to share what happened that made you rate the care and support you received [insert stage] low:*

- ❖ When you discovered something was wrong and were making the decision to end your pregnancy.
- ❖ In preparation for, and during the termination procedure, labour, and the birth.
- ❖ During your time in hospital after pēpē/baby was born.
- ❖ In the days and weeks after pēpē/baby died.

If not already covered, briefly discuss - *how well do you believe....?:*

- ❖ your LMC and the other health professionals were trained/equipped to support bereaved whānau/parents.
 -
- ❖ your decisions and views were listened to.
 -
- ❖ the care and support you received helped in the grieving process.

Group discussion – Better meeting support and care needs: (5 min)

- ❖ *Thinking about the care and support you received at the different times discussed previously, what changes would need to be made to ensure that this better met your, and your whanau/family's needs.*
- ❖ *Which of these changes that would make the most difference.*

Hui/focus group conclusion (5 min)

Ask group participants for final comments.

Thank participants, followed by Karakia.

Kia tau to rangimārie irunga i a tatou katoa.

Kia mataara, kia manawanui, kia mākohā.

May peace and calm be bestowed upon us all.

Be aware, be steadfast, be kind and compassionate.

Information Sheet for Focus group participants

Te Whatu Ora | Health New Zealand - Maternity Services Research 2022

Thank you for indicating that you may be interested in participating in a maternity services' focus group.

This sheet aims to give you some background information to help you decide if you'd like to participate, or not. In making your decision, you may like to discuss the research with others. Also, we will be happy to answer any questions you may have about the research and your involvement (see the contact details at the end of the sheet).

Whether or not you decide to take part is your choice.

Why are you being invited to take part?

You have been nominated to take part in a small focus group (of four participants) with others, who like you have lost a pēpē/baby in the last 2 years. Depending on the focus group you will have been nominated to participate in, you will have other things in common with the other group participants (e.g., how you lost your baby).

What is the purpose of the research?

What you and other focus group participants have to say about your experiences of the service you received from you Lead Maternity Carer (LMC) and other health professionals will help to improve maternity services in the future and help inform the Perinatal National Bereavement Pathway. The development of a national bereavement care pathway will ensure that a consistent standard of care is offered to all bereaved parents/whānau experiencing pregnancy and infant loss in Aotearoa.

Who's funding and carrying out the research?

The focus groups are part of a larger programme of maternity services research (including survey research) being funded by Te Whatu Ora | Health New Zealand. This research is supported by the New Zealand College of Midwives and various consumer organisations, including those providing services to Māori and Pasifika peoples and organisations supporting women/people who have lost their babies (e.g., Sands NZ).

Te Whatu Ora have commissioned Research New Zealand (www.researchnz.com) and their Māori research partner TT Consulting Tāpui Limited to carry out the research on their behalf. Researchers from these organisations will be responsible for facilitating the focus groups, analysing, and reporting the findings

What's involved in participating in the hui/focus group?

Participation is **voluntary, anonymous, and confidential**.

If you choose to participate:

- **No preparation** is required.
- You don't have to share any information you don't want to, and you can withdraw from the research at any time.
- It will take **90 minutes of your time**.
- **Areas for discussion** will include:
 - Whether the care and support and the information and advice you received from your LMC (e.g., midwife) and other health professionals met all your needs, including your cultural and identity needs.
 - whether your LMC and other health professionals were trained/equipped to support bereaved whānau/parents.
 - Whether your decisions and views were listened to and that the care and support that you received helped you grieving process.
 - Your ideas about how the care and support and the information and advice you and your whānau/family received could be improved.
- **You will be provided with a koha** of \$70 as thanks.

What will happen to the information you provide?

With your consent, an audio recording, written transcript, and notes will be made for the focus group you attend. This information will be collected for all the hui/focus groups being conducted and will provide the dataset for analysis and reporting. This information, along with any personal held about you (e.g., your name and contact details) will be stored securely by Research New Zealand and TT Consulting Tāpui Limited for the duration of the research and will only be accessed by the researchers responsible for the Hui/focus groups and the transcriber.

The results of this research will be published, but any verbatim (quotes) used in the report, will be anonymised, so that no one will be able to identify you.

At the completion of the research, the audio recordings, notes, and the personal details of participants (e.g., name, contact details) will be destroyed and the transcripts made from

the audio-recordings will be anonymised. The anonymised transcripts will be stored indefinitely by Research New Zealand, in a secure government approved local cloud-based storage system. Access to this will be monitored and restricted.

Will this research meet accepted ethical standards?

The researchers abide by the ethical and professional conduct standards outlined by the ICC/ESOMAR International Code on Market, Opinion and Social Research and Data Analytics.

While this qualitative stage (i.e., the hui/focus groups) was deemed to be out of scope for Health and Disability Ethics Committee (HDEC) review and, as such, did not require HDEC approval, it will be conducted in such a manner that meets the established ethical standards set out in the [National Ethical Standards for Health and Disability Research and Quality Improvement | National Ethics Advisory Committee](#)

Where can you find out about the results of the focus groups?

At the completion of the research, Te Whatu Ora will publish a report of the findings on its website. Research New Zealand will email you a summary of the findings if you request this.

Who should you contact if you have any other questions or concerns?

If you would like to opt in or out of this research, or if you have any other questions or concerns you would like to discuss, please contact **Mati Fryer**, Research New Zealand (mati.fryer@researchnz.com) or 021 268 0504.

Mati is also able to refer you to the appropriate member of Research New Zealand or Te Whatu Ora to answer your query.

If you would like to talk to someone who isn't directly involved in research, you can contact an independent health and disability advocate:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz>

If you would like to talk to someone about your loss, please contact Sands NZ. They are a voluntary organisation who support parents and whānau/families who have experienced the death of a pēpē/baby. Information and regional contact details, including phone numbers are available on their website - www.Sands.org.nz



Research Participation Consent Form

Maternity Services Research 2022 – Qualitative Research stage

PLEASE RETURN YOUR COMPLETED CONSENT FORM IN ADVANCE OF YOUR HUI/FOCUS GROUP TO mati.fryer@researchnz.com

I understand the following:

- This research is being conducted by Research New Zealand limited and TT Consulting Tāpui Limited, on behalf of Te Whatu Ora | Health New Zealand.
- My involvement in this research is completely voluntary, which means I don't have to participate in any discussions or activities in the hui/focus group that I do not want to and that I can withdraw from the research at any time, without explanation.
- My participation in this research will remain confidential to Research New Zealand limited and TT Consulting Tāpui Limited. This means that Te Whatu Ora will not know that I have taken part in the research, I will not be personally identified in any reporting and, at the completion of the research, any information that might identify me will be destroyed or anonymised.

I agree to the researchers from Research New Zealand limited and TT Consulting Tāpui Limited taking notes and audio-recording the hui/focus group I participate in. The notes, audio-recording, and a written transcript of the audio-recording, will be used for the sole purpose of helping the researchers analyse and report on the findings of the research.

Name:

Date:

If you would like to receive a summary of the report once it is written up, please provide your email address below.

Email: _____

If you are happy for your koha to be paid directly into your bank account, please provide your bank account details below. If you would prefer an alternative, please let us know.

Bank account details: _____