

Research New Zealand

New Zealanders' Experiences and Perceptions of the Maternity and Perinatal System 2022 A Summary Report

April 2023



Confidential

New Zealanders' Experiences and Perceptions of the Maternity and Perinatal System
2022 – A Summary Report

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| PREPARED FOR | Te Whatu Ora – Health New Zealand |
| PREPARED BY | Corrine de Bonnaire, Sarah Buchanan, Jane Falloon, Mati Fryer, Emanuel Kalafatelis, Katrina Magill (Research New Zealand) and Teresa Taylor (TT Consulting Tāpui) |
| CONTACT DETAILS | Emanuel Kalafatelis Research New Zealand Phone 04 499 3088 www.researchnz.com |
| PROJECT NUMBER | #5254 |

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Definitions

Māori mothers and birthing parents – self-reported.

Pasifika mothers and birthing parents – self-reported.

Young mothers and birthing parents – aged 24 years or under.

Disabled mothers and birthing parents – self-defined based on their response to the short version of the Washington Group Set of Disability Questions.

Weighting – is the statistical process that is used to correct for any imbalances in an achieved sample, as a result of purposefully over-sampling specific population groups of interest and/or sampling error.

For example, the Survey of Whānau and Families' Experience of the Maternity System over-sampled priority groups, including Māori, Pasifika, and young mothers and birthing parents, so that their results could be examined with confidence. This over-sampling was corrected as a result of the weighting process, resulting in the achieved sample for the survey being representative of the population from which it was selected.

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, results based on the achieved sample for the Survey of Whānau and Families' Experience of the Maternity System of n=4,354 are subject to a maximum margin of error is +/-1.58% (at the 95% confidence level).

Statistically significant result – 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 whānau who participated in the 2022 New Zealanders' Experiences and Perceptions of the Maternity and Perinatal System for their time and generosity. Their views and comments have provided valuable insight into the personal experiences of whānau within the New Zealand maternity system and will support future service planning.

1.0 Executive summary

IMPORTANT NOTE:

The timeframe of this research is important when considering the results of this 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.

This report provides a summary of the key results of a programme of research completed in 2022 to record New Zealanders' experiences of the maternity and perinatal system in Aotearoa New Zealand. This programme of research relates to Te Whatu Ora – Health New Zealand's obligation under the New Zealand Maternity Standards Audit Criterion 15 to carry out a national consumer survey of maternity and perinatal services at least every three years (15.2).

In addition to measuring respondents' **satisfaction** with their experiences of the maternity and perinatal system in Aotearoa New Zealand, the other key objectives of the research programme were to:

1. **Identify the barriers and inequities** of the maternity and perinatal system.
2. **Identify unmet needs** and areas requiring service improvement.

Method

This summary report is based on the results of **three** streams of research:

1. A confidential survey with an achieved sample of n=4,355 mothers and birthing parents who had given birth between January and November 2021.

Approximately N=12,000 were invited to complete this voluntary survey and, therefore, the participation rate for the survey was 36%. Specific priority groups (viz. Māori, Pasifika, and young mothers and birthing parents (defined as 24 years of age and under)) were over-sampled so that their results could be examined with confidence. A fourth priority group, disabled mothers, and birthing parents, was self-defined through the survey.

The detailed results of this survey are reported in Technical Report 1: A Survey of Whānau and Families' Experience of the Maternity System.

2. A confidential survey of n=118 women and people who had lost their pēpē/baby in the two years before the survey (24 August 2022), augmented with in-depth qualitative interviews with n=18 bereaved women and people.

The participation rate for the survey was 29%, based on N=413 receiving an invitation to complete this voluntary survey.

The detailed results of this stream of work are reported in Technical Report 2: A Survey of, and Qualitative Research with, Whānau and Families who have Lost a Pēpē/Baby.

3. Qualitative research with a sample of n=24 mothers and birthing parents, representing mothers and birthing parents from population groups known to be poorly served by the maternity and perinatal system (viz. Māori, Pasifika, LGBTQ+, young, and disabled mothers and birthing parents).

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.

This summary report is mostly written from the perspective of the survey research results. We therefore encourage readers to refer to the technical reports for the in-depth qualitative information that was collected in terms of the priority groups, including LGBTQ+ mothers and birthing parents.

The qualitative research with bereaved women and people also included women and people who lost their pēpē/baby before 20 weeks. The survey research did not include either of these two groups in sufficient numbers for reporting purposes.

Key findings

The infographics (Figure 1 and Figure 2) on the following pages highlight the key results (all quantitative differences noted are statistically significant):

- **79% of mothers and birthing parents with live births were satisfied** with the ‘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’.

While this is similar to the result recorded in 2014, the percentage stating they were ‘very satisfied’ is significantly lower (41% in 2022 compared with 48% in 2014).

- While the survey results for the priority groups of mothers and birthing parents who had a live birth, reflect the results for all mothers and birthing parents (i.e., the total sample), there are some notable exceptions. For example:
 - **Disabled respondents** were significantly **less satisfied** than other groups (and, therefore, in comparison with the total sample of all respondents) with their ‘overall experience of care’, and with **every** specific stage of their maternity and perinatal journey.

- While the infographic shows that **Māori** were as satisfied as other priority groups with their ‘overall experience of care’, the detailed results show them being significantly **less satisfied** with the care and support they received during two specific stages of the maternity and perinatal journey (viz. the care and support they received from their LMC/midwife while hapū/pregnant, and the care and support received from hospital/birthing unit staff during their labour and birth).
- The results of the survey and qualitative research for **mothers and birthing parents who had a live birth** (including their suggestions) suggest the need to focus on or make improvements in the following areas:
 - **Midwives** – to ensure there are sufficient numbers of midwives and/or they are available so that mothers and birthing parents have choices and options.
 - **Antenatal classes, specialists, tests and scans, and WellChild Tamariki Ora and Whānau Āwhina Plunket providers** – to provide access and availability (and reduce costs).
 - **Hospitals** – to improve the hospital experience for the mothers and birthing parents of all priority groups, including in order to meet the cultural needs of Māori mothers and birthing parents, and the identity needs of LGBTQ+ mothers and birthing parents.
 - **Communication and information** – to ensure that communication and information is customised/fit-for-purpose for the diverse range of mothers and birthing parents (i.e., in terms of content; form – e.g., paper vs. digital; channel/platform – e.g., internet, social media, etc.; and ‘look and feel’).
 - **Follow-up care and support** – to ensure that this is at an appropriate level.
- In contrast to the level of satisfaction for mothers and birthing parents who had a live birth, **53% of bereaved mothers and birthing parents were satisfied** with their ‘overall experience of care’.

This is significantly **lower** than that recorded in 2014 (74%).

- Many of the areas of focus noted above also relate to **bereaved women and people** but, in addition, the following areas require focus based on the survey results and qualitative research (and their suggestions):
 - **Testing services (e.g., scans and tests)** – to improve access to these services, by making them more available and reducing costs.
 - **Communication and information** – particularly to help make decisions at critical times and explain outcomes.
 - **Hospitals** – to improve hospital experiences, including the need to provide privacy, and the understanding and sensitivity with which health professionals interact with bereaved women and people, especially when a pēpē/baby has died or it is evident that they are unlikely to survive.
 - **Follow-up and support** – especially by midwives, and improved access to counselling services.

Figure 1: Summary – Mothers and birthing parents with a live pēpē/baby

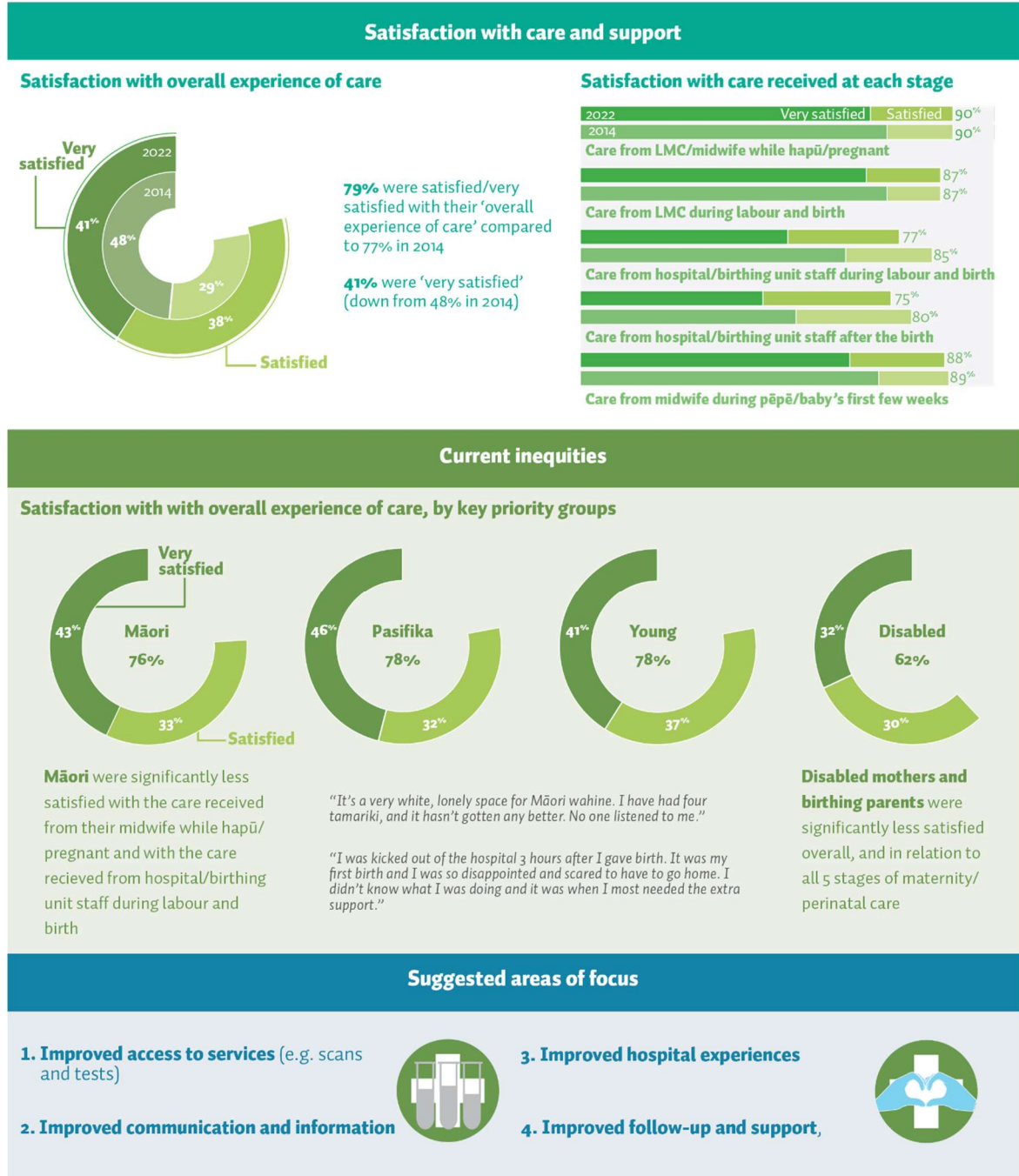
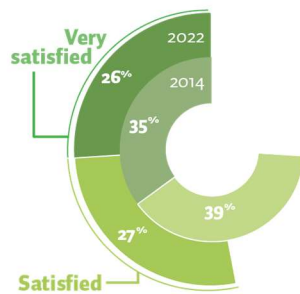
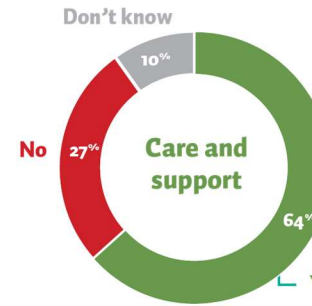


Figure 2: Summary – Mothers and birthing parents who have lost their pēpē/baby

Satisfaction with care and support



53% were satisfied/very satisfied with the 'overall standard of care and support' (down from 74% in 2014)
26% were 'very satisfied' (down from 35% in 2014)



64% felt they received all the care and support they needed at the time of their pēpē/baby's death, while **27%** did not and **10%** were unsure

Midwives play a key role in providing care and support

76% received antenatal care from a midwife LMC or group of midwives.

54% of those whose pēpē/baby died during pregnancy or was terminated identified midwives as 'the most helpful' in aiding decision-making.

69% identified their midwife as 'the most helpful' during and immediately after the birth/death of their pēpē/baby.

67% of those whose pēpē/baby died up to 28 days after birth identified midwives as the person they had contact with after the death.

"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."

"The bereavement midwives 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."

Suggested areas of focus

1 Improved communications, understanding and sensitivity:



25% of those whose pēpē passed during pregnancy were 'dissatisfied' with how caring and supportive their health professionals were when they were told their pēpē/baby had passed.

27% of those whose pregnancy was terminated, or whose pēpē/baby passed during pregnancy or labour disagreed that they 'received all the care and support they needed at the time'.

(More) information about the appearance of their pēpē/baby and information about the availability of support services would have been helpful at the time.

"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."

2 Improved access and explanations of scans/tests:



59% had scans or tests during their pregnancy

25% were not provided with enough information about what the scan/test results meant and what options were available to them.

57% had further diagnostic tests conducted following the pēpē's death

37% had a post-mortem conducted after pēpē's death

Less than one-half were satisfied with the information received from the tests or post-mortem.

44%

3 Improved hospital experiences:



Less than one-half were **very satisfied** with the amount of **privacy** they had in hospital

45% very satisfied

26% satisfied

"My shattering news was dropped on me like a bomb with no care or compassion, "There's no heartbeat, your baby's dead", in a room with 7 staff present for no good reason all staring at me while my world shattered. It felt like a show and I was the frontline act. It's private and absolutely should be treated as so."

One-third (32%) were very satisfied with how **well resourced the hospital was** to provide them with the bereavement care and support they needed.

32% very satisfied

32% satisfied

4 Improved follow-up and access to support services:



86% of those whose pregnancy was terminated, or their pēpē/baby passed during pregnancy or labour, received contact from a health professional subsequent to their pēpē passing.

14% received no contact.

89% of respondents whose pēpē died up to 28 days after also received some form of contact.

11% received no contact.

30% of those who received post-contact would have preferred more visits.

26% received counselling following the death of their pēpē

31% were offered counselling but didn't take it up

36% were not offered counselling

2.0 Research objectives, Expert Advisory Group, ethics approval and method

2.1 Research objectives

The main objectives of this research programme were to provide Te Whatu Ora with a basis on which to:

- Assess current levels of **satisfaction** with mothers and birthing parents using the maternity and perinatal system in Aotearoa New Zealand.
- Assess current **inequities and barriers** for priority groups and those known to be poorly served by the maternity and perinatal system. These groups include Māori, Pasifika, LGBTQ+ mothers and birthing parents, young mothers, and birthing parents (defined as 24 years of age and under), disabled mothers and birthing parents, and bereaved mothers and birthing parents.
- Assess the current **framework** for primary services.
- Assess the **impact** of new and ongoing policies.
- Identify women's and people's **unmet needs and areas requiring service improvement**, particularly with respect to the development of the National Perinatal Bereavement Pathway for bereaved mothers and birthing parents.
- Inform **future planning**, for future service development through the health and disability system changes.

2.2 Expert Advisory Group

To provide guidance and advice, an Expert Advisory Group (EAG) was established, comprising members representative of many of the 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.
- Dr George Parker, representing the LGBTQ+ community.
- Tish Taihia, Clinical Midwife Manager Ngā Hau Mangere Birthing Centre, representing the Pasifika community.
- Melanie Tarrant and Pania Mitchell from Sands NZ.

2.3 Ethics approval

Ethics approval was obtained from the Health and Disability Ethics Committee (HDEC) in 2021.

2.4 Method

2.4.1 The Survey of Whānau and Families' Experience of the Maternity System

This confidential survey was completed between 10 August and 4 October 2022.

The results of the survey are based on an achieved sample of n=4,355 mothers and birthing parents, recruited from a sample (approx. n=12,000) randomly selected from all mothers and birthing parents who had given birth between January and December 2021 (N=48,662).

Te Whatu Ora identified several priority groups and, as such, Māori, Pasifika and young mothers and birthing parents were over-sampled so that their results could be examined with confidence. A fourth priority group, disabled mothers and birthing parents, was self-defined through the survey.

Potential respondents were given the option of completing this voluntary survey on paper, online or by telephone. The participation rate for the survey was 36%.

The results of the survey have been weighted to correct for over-sampling of the priority groups. Results based on an achieved weighted sample of n=4,355 mothers and birthing parents are subject to a maximum margin of error of +/- 1.58% (at the 95% confidence level).

This means that had we found 50% of respondents were satisfied with the maternity and perinatal services they received, we could be 95% sure of getting the same result had we interviewed everyone in the eligible population. Larger margins of error apply for the sub-samples of respondents representing the priority groups.

The team that was responsible for this survey included Emanuel Kalafatelis (Managing Partner, Research New Zealand), Katrina Magill (Quantitative Research Director, Research New Zealand) and Sarah Buchanan (Senior Research Manager, Research New Zealand). All three were also responsible for the 2014 survey work.

Please refer to the technical report on the Survey of Whānau and Families' Experience of the Maternity System for a copy of the survey questionnaire. A copy of the survey invitation letter and the Participant Information Sheet may also be found in this report, as well as more detailed methodological information.

2.4.2 Qualitative study with priority groups known to be poorly served by the maternity/perinatal system

This qualitative research included a total of n=24 mothers and birthing parents from population groups known to be poorly served by the maternity and perinatal system (viz. Māori, Pasifika, LGBTQ+, young, and disabled mothers and birthing parents), who participated in mainly small online group discussions, between 31 August and 28 September 2022.

Decisions about whom to include in the sample and the recruitment criteria were made in consultation with Te Whatu Ora.

Research participants were either recruited through a networking approach or had identified that they would like to participate in further research, after participating in the cognitive testing for the 2022 Survey of Whānau and Families' Experience of the Maternity System, or the survey itself. Participants were all fully informed about the research and had consented to take part prior to being interviewed.

The team responsible for the research 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.

Please refer to the technical report on the Insights into the Experiences of Mothers and Birthing Parents known to be Poorly Served by the Maternity and Perinatal System for a copy of the Discussion Guide, Information Sheet and Consent form, as well as more detailed methodological information.

2.4.3 The Survey of and Qualitative Research with Whānau and Families who have Lost a Pēpē/Baby

The survey

This confidential survey was completed between 24 August and 4 October 2022.

The target population for this survey was bereaved women and people whose pēpē/baby had died in the two years prior to the date of the survey (N=413). All of these bereaved women and people were invited to complete this voluntary survey by way of a posted letter and given the option of doing so either online or by telephone. The survey was endorsed by Sands NZ.

By the final close-off date, n=118 had responded, mostly online. Most of these respondents participated (n=88) via the survey invitation, although some (n=24) also participated as a result of a generic link placed on the websites of Te Whatu Ora, Research New Zealand and Sands NZ. Another n=6 responses were included from the cognitive testing. Based on the number responding to the survey invitation, the participation rate for the survey is 21%.

The results of the survey have **not** been weighted, mainly because the achieved sample was reasonably comparable to the original sample. Most respondents' pēpē/baby had died up to 28 days after birth (39%), which is very close to the 42% in the original sample.

The team responsible for this survey was the same team as that responsible for the Survey of Whānau and Families' Experience of the Maternity System.

Please refer to the technical report on the Survey of and Qualitative Research with Whānau and Families who have Lost a Pēpē/Baby for a copy of the survey questionnaire. A copy of the survey invitation letter and the Participant Information Sheet may also be found in this report, as well as more detailed methodological information.

Qualitative research

A total of n=18 women and people who had lost their pēpē/baby within the previous 18-months took part in small online group discussions with other women and people who had lost their pēpē/baby in similar situations (e.g., lost their pēpē/baby during labour). All interviewing was completed between 31 August and 28 September 2022.

Decisions about whom to include in the sample and the recruitment criteria were made in consultation with Te Whatu Ora.

Bereaved women and people were invited to participate in the qualitative research with the assistance of Sands NZ. This included placing invitations to participate in the research on Sand NZ's Facebook pages. 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 bereaved women and people who had lost their pēpē/baby before 20 weeks.

The team responsible for the research was the same team as that responsible for the qualitative research with mothers and birthing parents from priority groups known to be poorly served by the maternity and perinatal system.

Please refer to the technical report on the Survey of and Qualitative Research with Whānau and Families who have Lost a Pēpē/Baby for a copy of the Discussion Guide, Information Sheet, and Consent form, as well as more detailed methodological information.

2.5 Report notes

This summary report is structured around Te Whatu Ora's objectives for the research programme and comprises **three** sections:

1. **Satisfaction** with maternity and perinatal services.
2. **Barriers and inequities** of the maternity and perinatal system for **priority groups**, and their unmet needs.
3. **Barriers and inequities** of the maternity and perinatal system for **bereaved women and people**, and their unmet needs.

The report is mostly written from the perspective of the survey research results, with the qualitative research used to provide greater insight, particularly with respect to understanding barriers, inequities, and unmet needs.

Survey results relating to the Survey of Whānau and Families' Experience of the Maternity System highlight statistically significant differences between the priority groups and comparisons are made with the 2014 results, where possible.

Results relating to the Survey of Whānau and Families who have Lost a Pēpē/Baby are reported as they apply to the following groups of bereaved women and people and, where possible, for the total sample:

- Bereaved women and people whose pregnancy was medically terminated.
- Those whose pēpē/baby died after 20 weeks.
- Those whose pēpē/baby died during labour.
- Those whose pēpē/baby died up to 28 days after birth.

Comparisons with the equivalent survey in 2014 are limited because of the small sample sizes and the fact that, overall, different numbers of each of the above groups of bereaved women and people completed that survey.

In all cases, statistically significant survey results are shown as **red** (for a result significantly **lower** than the result for the total sample) or **green** (for a result significantly **higher** than the result for the total sample) in the tabulations.

Given that this report is mostly written from the perspective of the survey research results, readers are encouraged to refer to the qualitative research in Technical Reports 2 and 3 for a more in-depth understanding of the experiences of priority groups and bereaved women and people. The qualitative research also discusses the experiences of LGBTQ+ mothers and birthing parents and bereaved women and people who lost their pēpē/baby before 20 weeks.

The survey results do not include reporting in relation to either of these two groups because insufficient numbers of LGBTQ+ mothers and birthing parents participated in The Survey of Whānau and Families' Experience of the Maternity System, and because women and people who lost their pēpē/baby before 20 weeks were not specifically included in The Survey with Whānau and Families' who have Lost a Pēpē/Baby.

3.0 Satisfaction with the maternity and perinatal system

3.1 The satisfaction of mothers and birthing parents who had a live birth with their 'overall experience of care'

Summary

- **79% of mothers and birthing parents who had a live birth were satisfied** with the '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'.

While this is similar to the result recorded in 2014 (77%), significantly **fewer** mothers and birthing parents in 2022 rated their satisfaction with the best possible answer (i.e., 'very satisfied'); 41% in 2022, down from 48% in 2014.

- The overall satisfaction results for Māori (76%), Pasifika (78%) and young mothers and birthing parents (78%) reflect the results for the total sample in general.

However, **disabled respondents** were significantly **less likely** to be satisfied (62%) and this is reflected in the percentage providing a 'very satisfied' answer (32%, compared with 41% of all respondents).

- In general, respondents expressed a relatively high level of satisfaction with **every** stage of the care they received during their maternity and perinatal journey.

However, as with their overall experience of care, the percentage giving the best possible answer of 'very satisfied' at each stage of their journey was significantly **lower** than in 2014. This was particularly the case for the following **three** stages:

- The care received in the **hospital/birthing unit during labour and birth** (50% reported being 'very satisfied' in 2022, compared with 64% in 2014).
- The care received in the **hospital/birthing unit after the birth** (44% reported being 'very satisfied' in 2022, compared with 52% in 2014).
- The care received from their **midwife during pēpē/baby's first few weeks** (65% reported being 'very satisfied' in 2022, compared with 72% in 2014).

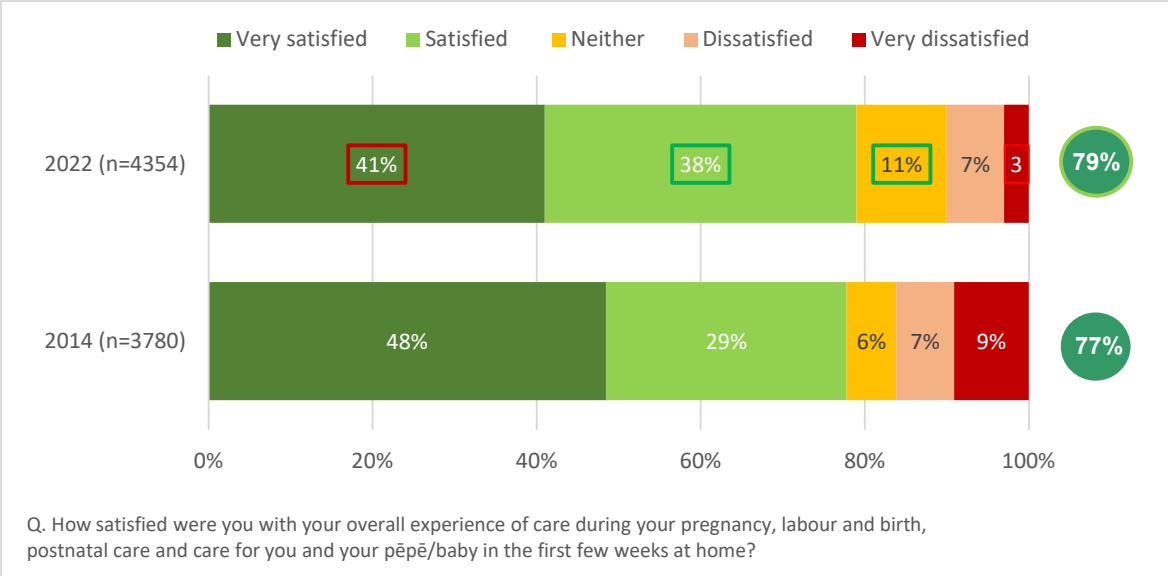
- Analysis has revealed that, the care received in the hospital/birthing unit **after** the birth, and the care received from their midwife during pēpe/baby's **first few weeks**, have the greatest impact on women's and people's satisfaction with their overall experience of the maternity and perinatal system.
- Women's and people's satisfaction with specific aspects of the care and support they received are discussed in Section 4.

3.1.1 Overall satisfaction

Eight-out-of-ten mothers and birthing parents (79%) who had a live birth stated they were **satisfied** with the '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'.

While this is a similar result to that recorded in 2014 (77%), significantly **fewer** respondents in 2022 rated their satisfaction with the best possible answer (i.e., 'very satisfied'); 41% in 2022, down from 48% in 2014 (77%) (Figure 3).

Figure 3: Overall satisfaction with maternity and perinatal care



The 2022 sub-sample excludes one respondent who said, 'Don't know'. Results outlined in red denote a significantly lower result compared to 2014, while results outlined in green denote a significantly higher result.

3.1.2 Satisfaction with the stages of the maternity and perinatal journey

In general, respondents expressed a relatively **high** level of satisfaction with **every** stage of their maternity and perinatal journey (Figure 4 overleaf).

However, as for their overall satisfaction, the percentage giving the best possible answer of 'very satisfied' at each stage was significantly **lower** than in 2014:

- Their satisfaction with their **LMC while they were hapū/pregnant** (70% reported being 'very satisfied' in 2022, compared with 74% in 2014; a relative difference of 5%).
- Their satisfaction with their **LMC during labour and birth** (69% reported being 'very satisfied' in 2022 compared with 74% in 2014; a relative difference of 7%).
- Their satisfaction with the **hospital/birthing unit during labour and birth** (50% reported being 'very satisfied' in 2022, compared with 64% in 2014; a relative difference of 22%).
- Their satisfaction with the **hospital/birthing unit after the birth** (44% reported being 'very satisfied' in 2022, compared with 52% in 2014; a relative difference of 15%).
- Their satisfaction with their **midwife during pēpē/baby's first few weeks** (65% reported being 'very satisfied' in 2022, compared with 72% in 2014; a relative difference of 10%).

Figure 4: Satisfaction with care received at each stage of the maternity and perinatal journey



Sub-samples are based on respondents who provided a response for this question and excludes respondents who said, 'Not applicable'.

Totals may not sum to 100 percent due to rounding.

Results outlined in red denote a significantly lower result compared to 2014, while results outlined in green denote a significantly higher result.

3.2 Bereaved women's and people's satisfaction with their 'overall experience of care'

Summary

- **53% of bereaved women and people were satisfied** with the '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'.

This is a significantly **lower** level of satisfaction than in 2014, when it was 74%.

- Bereaved survey respondents' satisfaction with specific aspects of the care and support they received are discussed in Section 5.

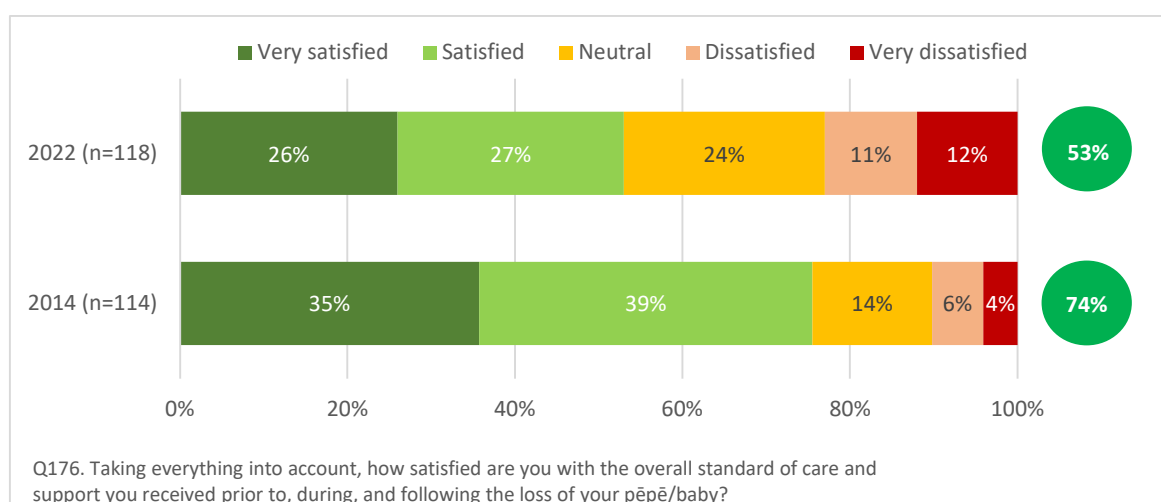
3.2.1 Overall satisfaction

Just over one-half of bereaved respondents interviewed for the Survey of Whānau and Families who have Lost a Pēpē/Baby (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' (Figure 5).

Satisfaction was higher in 2014 (74%).

In comparison, approximately one-in-four (23%, or n=27) in 2022 stated they were dissatisfied, and a similar percentage provided a neutral response (24%, or n=28).

Figure 5: Overall satisfaction with the care and support received



3.2.2 Satisfaction with care and support received during and after the birth

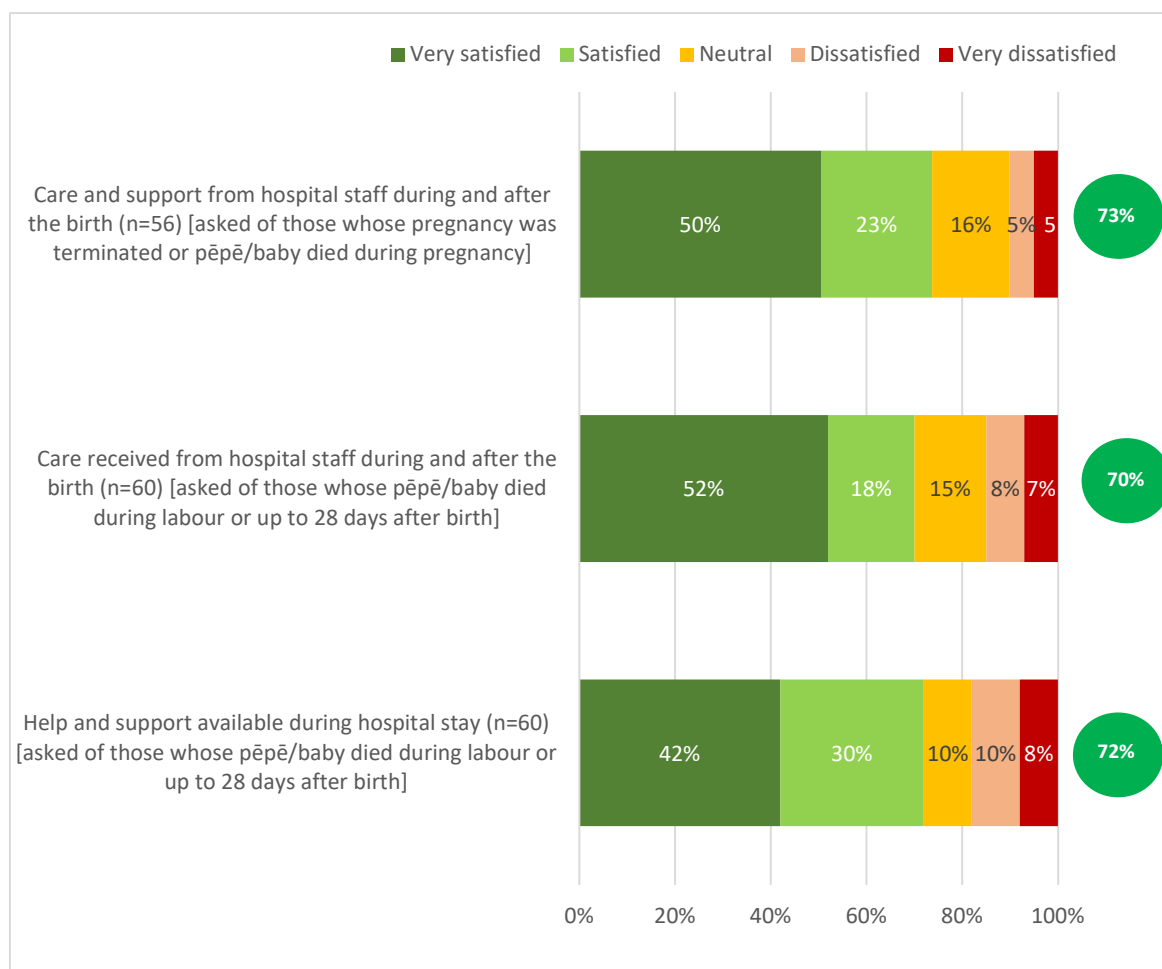
With this in mind, we can see that whilst one-half of those respondents (52%, or n=31) were ‘very satisfied’ with the care received during their hospital stay, fewer (42%, or n= 25) were ‘very satisfied’ with the help and support that was available to them at the time.

Figure 6 shows the extent to which bereaved respondents felt satisfied with the care and support they received from hospital staff during and after the birth.

As this question was asked slightly differently depending on the situation, the sub-sample numbers differ. For example, bereaved respondents whose pēpē/baby died during labour, or up to 28 days after the birth were asked about the care, and the help and support they received, separately.

With this in mind, we can see that whilst one-half of those respondents (52%, or n=31) were ‘very satisfied’ with the care received during their hospital stay, fewer (42%, or n= 25) were ‘very satisfied’ with the help and support that was available to them at the time.

Figure 6: Bereaved women’s and people’s satisfaction with care received at during and after the birth



4.0 Barriers and inequities of the maternity and perinatal system for priority groups, and their unmet needs

This section focuses on identifying the barriers and inequities of the maternity and perinatal system for **priority groups** (viz. Māori, Pasifika, young (defined as 24 years of age and under) and disabled mothers and birthing parents), as well as their unmet needs.¹

The results are based on a combination of the survey results for the Survey of Whānau and Families' Experience of the Maternity System, as well as the results of the qualitative research.

Summary

- Compared with other priority groups, **disabled respondents** were the most likely to report experiencing issues with the care and support they received, including accessing services.
- Based on the barriers and challenges that the priority groups face (Midwives – to ensure there are sufficient numbers of midwives and/or they are available so that mothers and birthing parents have choices and options).
 - **Antenatal classes, specialists, tests and scans, and Well Child Tamariki Ora and Whānau Āwhina Plunket providers** – to provide access and availability (and reduce costs).
 - **Hospitals** – to improve the hospital experience for the mothers and birthing parents of all priority groups, including in order to meet the cultural needs of Māori mothers and birthing parents, and the identity needs of LGBTQ+ mothers and birthing parents.
 - **Communication and information** – to ensure communication and information is customised/fit-for-purpose for the diverse range of mothers and birthing parents (i.e., in terms of content; form – e.g., paper vs. digital; channel/platform – e.g., internet, social media, etc.; and 'look and feel').
 - **Follow-up care and support** – to ensure that this is at an appropriate level.

¹ Insufficient numbers of LGBTQ+ mothers and birthing parents were interviewed in the survey. However, they were interviewed in depth for the qualitative research and, therefore, we recommend referring to Technical Report 3 for insights relating to this group.

- Figure 7), the results of the survey and qualitative research (including their suggestions) suggest the need to focus on or make improvements in the following areas:
 - **Midwives** – to ensure there are sufficient numbers of midwives and/or they are available so that mothers and birthing parents have choices and options.
 - **Antenatal classes, specialists, tests and scans, and Well Child Tamariki Ora and Whānau Āwhina Plunket providers** – to provide access and availability (and reduce costs).
 - **Hospitals** – to improve the hospital experience for the mothers and birthing parents of all priority groups, including in order to meet the cultural needs of Māori mothers and birthing parents, and the identity needs of LGBTQ+ mothers and birthing parents.
 - **Communication and information** – to ensure communication and information is customised/fit-for-purpose for the diverse range of mothers and birthing parents (i.e., in terms of content; form – e.g., paper vs. digital; channel/platform – e.g., internet, social media, etc.; and ‘look and feel’).
 - **Follow-up care and support** – to ensure that this is at an appropriate level.

Figure 7: Barriers and inequities of the maternity and perinatal system for priority groups, and their unmet needs

| Service | Priority groups affected |
|---|---|
| Most mothers and birthing parents had an LMC ; 5% did not . | One-half of those without a LMC stated this was because of a shortage in their area; a reason given by all priority groups. |
| 17% had issues accessing ultrasounds . | Disabled respondents and Pasifika were more likely to state they had issues accessing ultrasounds (57% because of service availability; 31% because of cost). |
| 37% went to Hapū wānanga/Pregnancy and Parenting Education/Antenatal classes . | Fewer percentages of all of the priority groups went to these classes (between 20-29%). Disabled respondents who attended were less likely to be satisfied. Pasifika, young respondents, and disabled respondents who did not attend, typically said this was because: they were not aware of them; did not know enough about them; could not afford to go; or had other commitments. |
| 56% were satisfied with the accessibility of Well Child Tamariki Ora or Whānau Āwhina Plunket providers ; 65% were satisfied with the accessibility of specialists . | Disabled respondents were significantly less likely to be satisfied. |
| LMCs and other healthcare providers (79%) and friends and whānau/family (73%) were the main sources of information about how to care for newborns. Many also searched for information on the Internet (59%); 40% used specific websites or apps; 35% received information through social media. | |
| Most were satisfied with the quality of information received about various topics relating to pregnancy, birth and caring for newborns. | Māori reported lower levels of satisfaction with information about antenatal classes and giving birth (as did young respondents); Pasifika about antenatal screening and immunisation/vaccination; and disabled respondents on all information topics. |
| 86% reported having paid for at least one pregnancy-related service . | Māori and Pasifika were less likely to have paid for services; disabled respondents were more likely to have paid for visits to their doctor about their pregnancy (for reasons other than a pregnancy test). |

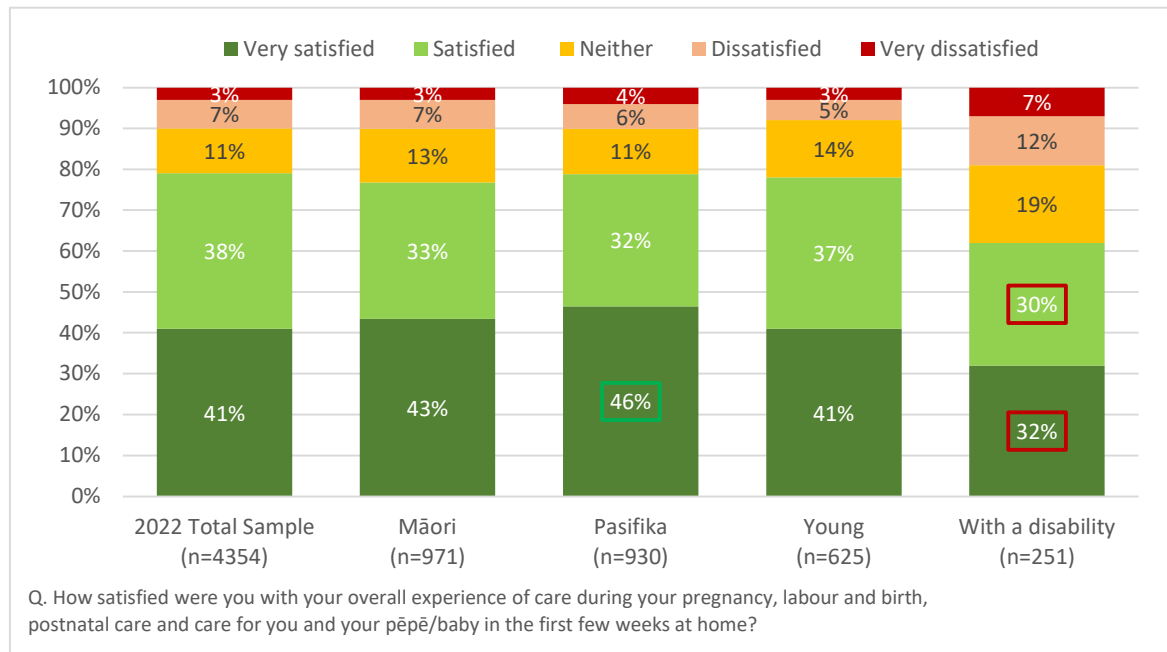
4.1 Satisfaction with their overall experience of care

Figure 8 shows the priority groups’ satisfaction with the ‘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’.

While the overall satisfaction results for Māori (76%), Pasifika (78%), and young mothers and birthing parents (78%) reflect the results for all respondents (79%), **disabled respondents** were significantly **less likely** to be satisfied with the care they had received (62%).

This is reflected in the percentage of disabled respondents providing a ‘very satisfied’ answer (32% compared with 41% of all respondents).

Figure 8: Overall satisfaction with maternity/perinatal care, by priority groups



Sub-samples are based on respondents who provided a response for this question and excludes those who said, ‘Not applicable’.

Results outlined in red denote a significantly lower result compared to 2014, while results outlined in green denote a significantly higher result.

Totals may not sum to 100 percent due to rounding.

4.2 Satisfaction with the care and support received from the hospital/birthing unit after birth

An analytical procedure called regression analysis was completed to identify the specific stages of the maternity and perinatal journey which account for most of respondents' satisfaction with their overall experience. Two specific stages were identified as most influential:

1. The care respondents **received at the hospital/birthing unit after the birth** of their pēpē/baby.
2. The care respondents **received from their midwife during pēpē/baby's first few weeks**.

4.2.1 The care priority groups received at the hospital/birthing unit after the birth of their pēpē/baby

As noted in Section 3.1.2 and compared with all other stages of the maternity and perinatal journey, the percentage of all respondents stating they were 'very satisfied' was the **lowest** for the care they **received in the hospital/birthing unit after the birth** of their pēpē/baby (44% in 2022, compared with 52% in 2014; a relative difference of 15%).

Table 1 overleaf examines satisfaction with this stage by the priority groups and shows some significant differences. Whereas Māori (47%) and young mothers and birthing parents (48%) were 'very satisfied' to the same extent as all respondents (i.e., the total sample), Pasifika mothers and birthing parents (50%) were significantly **more likely** to state they were 'very satisfied'.

In comparison, **disabled respondents** were significantly **less likely** to state they were 'very satisfied' (38%). That is, they were the **least** satisfied with the care they received in the hospital/birthing unit after the birth. In particular, they were the **least** satisfied with the following aspects of the care they received during this stage:

- The extent to which **visitors or support people** were able to be with them whenever they wanted them (30% stated they were 'very satisfied', compared with 42% of all respondents).
- The amount of **privacy** they had (41% and 49%, respectively).

Perhaps also reflecting their lower satisfaction with the care and support they received at the hospital/birthing unit after the birth of their pēpē/baby, **disabled respondents** were significantly **less likely** to have felt ready to leave the hospital or birthing unit when they did (68%, compared with 78% of all respondents). In fact, they were significantly **more likely** to report that they had left the hospital or birthing unit before they felt ready because they didn't like it there (15%, compared with 9% of all respondents).

Table 1: Satisfaction with postnatal care received at the hospital/birthing unit after birth, by priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|--|------------------------------|------------|---------------|------------|---------------|
| The overall care received at the hospital/birthing unit after the birth | | | | | |
| Unweighted base = | 4175 | 922 | 901 | 598 | 245 |
| <i>Satisfied/Very satisfied</i> | 75 | 73 | 75 | 74 | 60 |
| Very satisfied | 44 | 47 | 50 | 48 | 38 |
| The amount of privacy you had | | | | | |
| Unweighted base = | 4164 | 923 | 897 | 599 | 244 |
| <i>Satisfied/Very satisfied</i> | 78 | 76 | 74 | 76 | 63 |
| Very satisfied | 49 | 52 | 50 | 50 | 41 |
| Readiness to leave hospital/birthing unit | | | | | |
| Unweighted base = | 4211 | 929 | 912 | 604 | 246 |
| Felt ready to leave the hospital/birthing unit | 78 | 77 | 81 | 80 | 68 |
| I didn't like it there, so I left before I felt ready | 9 | 8 | 7 | 9 | 15 |
| The care and attention you got from staff | | | | | |
| Unweighted base = | 4156 | 922 | 895 | 597 | 243 |
| <i>Satisfied/Very satisfied</i> | 71 | 71 | 74 | 70 | 59 |
| Very satisfied | 42 | 46 | 49 | 47 | 34 |
| The help and support that was available to you during your stay | | | | | |
| Unweighted base = | 4114 | 909 | 885 | 592 | 239 |
| <i>Satisfied/Very satisfied</i> | 70 | 70 | 73 | 70 | 56 |
| Very satisfied | 42 | 45 | 48 | 48 | 35 |
| Your visitors/support people being able to be with you whenever you wanted them | | | | | |
| Unweighted base = | 3997 | 883 | 876 | 590 | 233 |
| <i>Satisfied/Very satisfied</i> | 67 | 65 | 66 | 61 | 48 |
| Very satisfied | 42 | 45 | 44 | 42 | 30 |

Sub-samples are based on respondents who provided a response for this question and excludes those who said, 'Not applicable'.

Figures in red are significantly lower when compared to the total sample, figures in green are significantly higher when compared to the total sample.

Totals may not sum to 100 percent due to rounding.

4.2.2 The care priority groups received from their midwife during pēpē/baby’s first few weeks

As noted in the previous section, the care that respondents received from their midwife during their pēpē/baby’s first few weeks was identified as one of the two most influential stages of their maternity and perinatal journey.

Focusing on this stage, most respondents (63%) stated they received 1-6 home visits from their midwife in the first few weeks following the birth and 29% received 7-12 visits. However, in 2014, a significantly higher percentage reported receiving 7-12 visits (34%).

While 84% of respondents who received visits said the number was ‘about right’, 15% stated that the number was ‘not enough’, and this was particularly the case amongst **disabled respondents** (26%) (Table 2).

Table 2: Right amount of home visits received, by priority groups

| Unweighted base = | 2022 Total sample 4351 % | Māori 969 % | Pasifika 929 % | Young 623 % | Disabled 250 % |
|------------------------|--------------------------------------|-------------------|----------------------|-------------------|----------------------|
| Right number of visits | 84 | 83 | 83 | 84 | 73 |
| Not enough visits | 15 | 16 | 15 | 15 | 26 |
| Too many visits | 1 | 1 | 2 | 1 | 1 |

Sub-samples are based on respondents who provided a response for this question and excludes those who said, ‘Not applicable’.

Figures in red are significantly lower when compared to the total sample, figures in green are significantly higher when compared to the total sample.

Totals may not sum to 100 percent due to rounding.

While most respondents were satisfied with the overall care they received from their midwife during these home visits, **disabled respondents** were **less likely** to be satisfied (Table 3).

Table 3: Satisfaction with overall care received from midwife at home, by priority groups

| Unweighted base = | 2022 Total sample 4308 % | Māori 955 % | Pasifika 922 % | Young 623 % | Disabled 244 % |
|---------------------------------|--------------------------------------|-------------------|----------------------|-------------------|----------------------|
| <i>Satisfied/Very satisfied</i> | 88 | 87 | 89 | 88 | 82 |
| Very satisfied | 65 | 67 | 68 | 68 | 62 |
| Satisfied | 23 | 20 | 21 | 20 | 20 |
| Neutral | 7 | 8 | 6 | 8 | 9 |
| Dissatisfied | 3 | 2 | 2 | 1 | 5 |
| Very dissatisfied | 2 | 2 | 3 | 3 | 4 |

Sub-samples are based on respondents who provided a response for this question and excludes those who said, 'Not applicable'.

Figures in red are significantly lower when compared to the total sample, figures in green are significantly higher when compared to the total sample.

Totals may not sum to 100 percent due to rounding.

To an extent, this might account for the **lower** percentage of **disabled respondents** expressing satisfaction with nearly every aspect of the care they received at this stage, and especially the significantly lower percentage stating they were 'very satisfied' with way '(their) midwife **listened** to (them)' (58%, compared with 66% of all respondents) (Table 4).

Table 4: Satisfaction with postnatal care received at home, by priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|--|------------------------------|------------|---------------|------------|---------------|
| The information you received about what care your pēpē/baby was entitled to | | | | | |
| Unweighted base = | 4312 | 960 | 923 | 619 | 248 |
| <i>Satisfied/Very satisfied</i> | 83 | 81 | 81 | 81 | 68 |
| Very satisfied | 49 | 53 | 50 | 52 | 43 |
| Satisfied | 34 | 28 | 31 | 29 | 25 |
| Neutral | 12 | 11 | 12 | 12 | 20 |
| Dissatisfied | 4 | 5 | 3 | 3 | 8 |
| Very dissatisfied | 2 | 2 | 4 | 3 | 4 |
| That your midwife listened to you | | | | | |
| Unweighted base = | 4334 | 965 | 925 | 623 | 250 |
| <i>Satisfied/Very satisfied</i> | 90 | 88 | 88 | 88 | 81 |
| Very satisfied | 66 | 67 | 66 | 69 | 58 |
| Satisfied | 24 | 21 | 22 | 19 | 23 |
| Neutral | 6 | 7 | 8 | 7 | 10 |
| Dissatisfied | 3 | 3 | 2 | 3 | 4 |
| Very dissatisfied | 2 | 2 | 3 | 3 | 4 |
| That your midwife was responsive to all of your needs | | | | | |
| Unweighted base = | 4327 | 965 | 919 | 622 | 250 |
| <i>Satisfied/Very satisfied</i> | 87 | 85 | 86 | 86 | 75 |
| Very satisfied | 64 | 65 | 64 | 68 | 58 |
| Satisfied | 23 | 20 | 22 | 18 | 17 |
| Neutral | 7 | 9 | 9 | 8 | 13 |
| Dissatisfied | 4 | 4 | 2 | 3 | 5 |
| Very dissatisfied | 2 | 2 | 4 | 3 | 6 |

Continued.

Table 4 (Continued): Satisfaction with postnatal care received at home, by priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|--|------------------------------|------------|---------------|------------|---------------|
| The way in which your background, culture, beliefs, values, and identity were respected | | | | | |
| Unweighted base = | 4098 | 930 | 891 | 590 | 236 |
| <i>Satisfied/Very satisfied</i> | 91 | 87 | 89 | 89 | 84 |
| Very satisfied | 66 | 67 | 64 | 68 | 63 |
| Satisfied | 25 | 20 | 25 | 21 | 21 |
| Neutral | 7 | 9 | 8 | 8 | 11 |
| Dissatisfied | 1 | 2 | 1 | 1 | 3 |
| Very dissatisfied | 1 | 1 | 3 | 2 | 2 |
| The way in which your decisions, views and choices were respected | | | | | |
| Unweighted base = | 4319 | 961 | 917 | 619 | 247 |
| <i>Satisfied/Very satisfied</i> | 91 | 88 | 87 | 88 | 81 |
| Very satisfied | 65 | 67 | 63 | 66 | 61 |
| Satisfied | 26 | 21 | 24 | 22 | 20 |
| Neutral | 6 | 8 | 8 | 7 | 12 |
| Dissatisfied | 2 | 3 | 2 | 2 | 4 |
| Very dissatisfied | 2 | 2 | 3 | 3 | 3 |
| The advice from your midwife on caring for your pēpē/baby | | | | | |
| Unweighted base = | 4300 | 952 | 922 | 620 | 245 |
| <i>Satisfied/Very satisfied</i> | 91 | 90 | 91 | 90 | 84 |
| Very satisfied | 65 | 68 | 66 | 70 | 61 |
| Satisfied | 26 | 22 | 25 | 20 | 23 |
| Neutral | 6 | 6 | 5 | 7 | 8 |
| Dissatisfied | 2 | 2 | 1 | 2 | 5 |
| Very dissatisfied | 2 | 2 | 3 | 2 | 3 |
| The advice from your midwife on caring for yourself | | | | | |
| Unweighted base = | 4317 | 956 | 922 | 624 | 246 |
| <i>Satisfied/Very satisfied</i> | 87 | 87 | 87 | 85 | 81 |
| Very satisfied | 61 | 64 | 64 | 66 | 55 |
| Satisfied | 26 | 23 | 23 | 19 | 26 |
| Neutral | 8 | 8 | 7 | 8 | 9 |
| Dissatisfied | 3 | 3 | 1 | 2 | 7 |
| Very dissatisfied | 2 | 3 | 4 | 4 | 9 |

Continued.

Table 4 (Continued): Satisfaction with postnatal care received at home, by key priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|---|--|--------------------|-----------------------|--------------------|-----------------------|
| Mental health checks from your midwife | | | | | |
| Unweighted base = | 4297 | 951 | 917 | 618 | 246 |
| <i>Satisfied/Very satisfied</i> | 83 | 81 | 82 | 82 | 75 |
| Very satisfied | 58 | 60 | 59 | 60 | 54 |
| Satisfied | 25 | 21 | 23 | 22 | 21 |
| Neutral | 10 | 10 | 11 | 10 | 9 |
| Dissatisfied | 4 | 5 | 3 | 4 | 7 |
| Very dissatisfied | 3 | 4 | 4 | 5 | 9 |

Sub-samples are based on respondents who provided a response for this question and excludes those who said, 'Not applicable'.

Figures in red are significantly lower when compared to the total sample, figures in green are significantly higher when compared to the total sample.

Totals may not sum to 100 percent due to rounding.

4.3 Satisfaction with other stages and aspects of their maternity and perinatal journey

4.3.1 Lead maternity carer

Nearly all respondents received antenatal care, most receiving it from a Lead Maternity Carer (LMC) (95%). In most cases, the LMC was a midwife LMC or group of (community based or self-employed) midwives (88%). Over one-third of respondents (36%) selected their LMC from the New Zealand College of Midwives 'Find Your Midwife' website.

There are no statistically significant differences by the priority groups with regard to their LMC, with the exception that **Māori** were significantly **more likely** to state their choice of LMC was influenced by the extent to which their LMC 'respected their background, culture, beliefs, values and identity' (27%, compared with 22% of all respondents).

Most respondents (72%) first saw their LMC within 7-12 weeks of their pregnancy, although 14% said this occurred very early on in their pregnancy (at six weeks or less). This means that 86% of respondents first saw their LMC during their first trimester. However, Māori, Pasifika and young respondents were all significantly more likely to have waited until after their first trimester before seeing an LMC (16%, 23% and 17% respectively, compared with 12% of the total sample).

Respondents expressed high levels of satisfaction with their LMC during various stages of their maternity and perinatal journey; 90% stated they were satisfied with the care and support they received from their LMC while they were hapū/pregnant; during their labour and birth (87%) and in terms of their postnatal care (88%).

Reflecting this, the qualitative research with priority groups revealed that positive midwife relationships helped mothers and birthing parents to feel safe and empowered throughout their maternity and perinatal journeys. Positive midwife relationships were defined in terms of having a 'good connection', and a high level of trust.

Midwives were valued for their roles as educators, translators, guides, advocates, and a life buoy, as well as for being accessible and affirming.

Continuity of care from a midwife appears to improve satisfaction. When care was received from a team of midwives, mothers and birthing parents more often reported communication issues and found it difficult to develop a 'good connection'.

Other sources of dissatisfaction included midwives not being available, not fulfilling their role as educator, and not being respectful.

4.4.2 Accessing additional antenatal services

Although most respondents (81%) reported having **no** issues with respect to accessing additional antenatal services (e.g., ultrasound scans, specialists, and Telehealth), one-in-five did (19%), and this was mostly in relation to accessing ultrasounds.

Overall, **disabled respondents** (28%) were the **most likely** to report having experienced access issues in general, although this was the case for **Pasifika** respondents as well, in terms of accessing ultrasounds (21%). The main reasons for these accessibility issues related to **service availability, cost, and travel**.

The qualitative research with priority groups revealed that the most significant barrier to having ultrasound scans was **cost**. Other barriers included confusion about which providers were subsidised; limited appointment options; booking process variations between providers; having to go to scans alone because of COVID-19 related restrictions; and dealing with sonographers who were perceived as uncaring and insensitive.

4.4.3 Attending antenatal classes

Thirty-seven percent of all respondents reported attending antenatal classes. However, **Māori** (31%), **Pasifika** (20%), **young** (32%) and **disabled respondents** (29%) were significantly **less likely** to have attended.

Most respondents who did not attend antenatal classes said this was because it was not their first pēpē/baby (66%). Other reasons included, having **other commitments, not knowing enough about them** and **cost**. These reasons were more likely to be given by **Pasifika, young respondents, and disabled respondents**.

The qualitative research revealed that Wānanga and antenatal classes which were well run and targeted at specific community groups (e.g., young Pasifika mothers and birthing parents) were much more likely to be enjoyed and valued by the mothers and birthing parents who attended them.

The qualitative research confirmed and provided greater insight in terms of the barriers to starting and continuing antenatal classes and Hapū Wānanga. These included not being provided at times that were convenient (especially, in terms of fitting around work); long travel times; not being well advertised; mothers and birthing parents not thinking they were eligible to attend; a poor fit with classmates; and the course not being well run.

When respondents were asked to rate their satisfaction with specific aspects of their antenatal care, **disabled respondents** were significantly **less likely** than other priority groups to be satisfied with the following (Table 5 overleaf):

- They **knew who would care for them** if their LMC or midwife was not available (38%, compared with 48% of all respondents).
- The people involved in their care spent **enough time** with them (40%, compared with 54%).
- The people involved in their care were **responsive** to all of their needs (41%, compared with 56%).
- How **easy** it was to get the services that they needed while they were hapū/pregnant (41%, compared with 50%).
- The care received from **specialists** (44% and 53%, respectively).
- That the people involved in their care while they were hapū/pregnant **listened** to them (44%, compared with 60%).

Table 5: Satisfaction with antenatal care received, by priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|--|------------------------------|------------|---------------|------------|---------------|
| The care you received from your LMC or midwife while you were hapū/pregnant | | | | | |
| Unweighted base = | 4282 | 954 | 912 | 617 | 246 |
| <i>Satisfied/Very satisfied</i> | 90 | 87 | 89 | 88 | 84 |
| Very satisfied | 70 | 71 | 69 | 72 | 62 |
| That the people involved in your care while you were hapū/pregnant listened to you | | | | | |
| Unweighted base = | 4317 | 957 | 912 | 615 | 248 |
| <i>Satisfied/Very satisfied</i> | 89 | 86 | 88 | 85 | 76 |
| Very satisfied | 60 | 59 | 58 | 55 | 46 |
| How well informed you were of the care you were entitled to while you were hapū/pregnant | | | | | |
| Unweighted base = | 4192 | 937 | 890 | 604 | 242 |
| <i>Satisfied/Very satisfied</i> | 88 | 85 | 83 | 84 | 76 |
| Very satisfied | 63 | 65 | 60 | 62 | 50 |
| The care you received from any specialists while you were hapū/pregnant | | | | | |
| Unweighted base = | 3614 | 836 | 824 | 540 | 233 |
| <i>Satisfied/Very satisfied</i> | 85 | 79 | 83 | 79 | 73 |
| Very satisfied | 53 | 48 | 53 | 49 | 44 |
| That the people involved in your care while you were hapū/pregnant were responsive to all of your needs | | | | | |
| Unweighted base = | 4237 | 948 | 900 | 608 | 245 |
| <i>Satisfied/Very satisfied</i> | 85 | 82 | 83 | 82 | 71 |
| Very satisfied | 56 | 55 | 55 | 56 | 41 |
| The people involved in your care while you were hapū/pregnant spent enough time with you | | | | | |
| Unweighted base = | 4316 | 959 | 913 | 614 | 249 |
| <i>Satisfied/Very satisfied</i> | 85 | 81 | 82 | 80 | 72 |
| Very satisfied | 54 | 53 | 52 | 51 | 40 |
| How easy it was for you to get the services that you needed while you were hapū/pregnant | | | | | |
| Unweighted base = | 4317 | 959 | 916 | 618 | 246 |
| <i>Satisfied/Very satisfied</i> | 82 | 79 | 81 | 77 | 67 |
| Very satisfied | 50 | 51 | 50 | 50 | 41 |
| That you knew who would care for you if your LMC or midwife was not available | | | | | |
| Unweighted base = | 4256 | 946 | 905 | 611 | 241 |
| <i>Satisfied/Very satisfied</i> | 77 | 73 | 79 | 71 | 64 |
| Very satisfied | 48 | 49 | 50 | 46 | 38 |

Sub-samples are based on respondents who provided a response for this question and excludes those who said, 'Not applicable'.

Figures in red are significantly lower when compared to the total sample, figures in green are significantly higher when compared to the total sample.

Totals may not sum to 100 percent due to rounding.

4.4.4 Satisfaction with place of birth and care received during labour and birth

Most respondents (87%) reported giving birth at a hospital and 9% in a birthing unit. Two-thirds (69%) of hospital births were planned, but 18% were not. Unplanned hospital births were significantly more likely to be the case for **Māori** (24%), **young** (26%) and **disabled respondents** (26%). One-half of respondents (51%) who gave birth in a hospital stated this was their preference, while 36% said it was because of its location relative to where they lived.

As noted in Section 3.1.2, most respondents (87%) were satisfied with the overall level of care they received from their LMC during their labour and birth. However, at 77%, satisfaction with the overall care received from **hospital/birthing unit staff during labour and birth** was significantly **lower**.

The qualitative research concurred with the finding that most survey respondents reported positive or very positive experiences in relation to their midwife's involvement in the births of their pēpē/babies. The qualitative research also found that some mothers and birthing parents who had extended hospital stays (e.g., because of pregnancy complications or because their pēpē/baby needed extra care), also reported very positive experiences.

Mothers and birthing parents who reported less than satisfactory hospital experiences, said these resulted in them:

- **Feeling frightened and vulnerable** (e.g., because: they didn't trust the system; they experienced the hospital environment as non-inclusive; they were left alone for a long period of time; they did not feel properly prepared for birth).
- **Feeling unwelcome** (e.g., because: they did not fit-in; staff were perceived as insensitive and unhelpful; they felt pressured to leave the hospital before they were ready).
- **Feeling pressured**. Some young mothers and birthing parents reported feeling pressured in their decision making (e.g., to have a COVID shot, to breastfeed, to start birth control).

Māori, Pasifika, and young respondents were all satisfied to more or less the same extent with the care they received **from their LMC** during their labour and birth. In comparison, **disabled respondents** were significantly **less likely** to state they were 'very satisfied' (63%, compared with 69% of all respondents).

Similarly, **disabled respondents** were significantly **less likely** to state they were 'very satisfied' with the overall care **from hospital/birthing unit staff** during their labour and birth (41%, compared with 50% of all respondents).

Reflecting this, **less** than one-half of **disabled respondents** stated they were ‘very satisfied’ with nearly **every** aspect of the care and support they received throughout their labour and birth (

Table 6 overleaf):

- The **support** available to them immediately following birth (39%, compared with 49% of all respondents).
- The **location and surroundings** where they gave birth (37%, compared with 46% of all respondents).
- The way in which their decisions, views and choices were **respected** (40%, compared with 54% of all respondents).
- The **pain relief** they received (41%, compared with 52% of all respondents).
- The way in which the people involved in their labour and birth, **communicated** with them (42%, compared with 54% of all respondents).
- The **information** received about what was happening throughout their labour and birth (43%, compared with 51% of all respondents).
- The way in which their background, culture, beliefs, values and identity were **respected** (48%, compared with 58% of all respondents).

Māori, Pasifika and young mothers and birthing parents also recorded **lower** levels of satisfaction with several aspects of the care they received during their labour. For example, 82% of Māori were satisfied with the way in which their 'background, culture, beliefs, values and identity were respected', compared with 86% of all respondents).

The unmet cultural needs of Māori mothers and birthing parents and the unmet identity needs of LGBTQ+ mothers and birthing parents were identified in the qualitative research as a source of dissatisfaction with hospital experiences.

Examples of the cultural needs of Māori mothers and birthing parents which were unmet in the hospital environment included needs being assumed, requests to meet needs not being followed, and demonstrations of a lack of cultural respect.

Examples of the identity needs of LGBTQ+ mothers and birthing parents which were unmet included being constantly misgendered, having to justify actions outside of the hospital norm, being exposed to non-inclusive heteronormative and cisnormative language, and non-inclusive physical spaces.

Table 6: Satisfaction with particular aspects during labour and birth, by priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|--|------------------------------|------------|---------------|------------|---------------|
| How confident you were in the skills of the people caring for you | | | | | |
| Unweighted base = | 4332 | 969 | 925 | 620 | 250 |
| <i>Satisfied/Very satisfied</i> | 87 | 84 | 84 | 83 | 78 |
| Very satisfied | 64 | 62 | 60 | 61 | 54 |
| The way in which your background, culture, beliefs, values, and identity were respected | | | | | |
| Unweighted base = | 4092 | 932 | 900 | 596 | 234 |
| <i>Satisfied/Very satisfied</i> | 86 | 82 | 83 | 83 | 74 |
| Very satisfied | 58 | 58 | 56 | 56 | 48 |
| The way in which your decisions, views and choices were respected | | | | | |
| Unweighted base = | 4305 | 959 | 920 | 618 | 248 |
| <i>Satisfied/Very satisfied</i> | 82 | 78 | 79 | 78 | 67 |
| Very satisfied | 54 | 53 | 54 | 49 | 40 |
| The available choices as to where you were able to give birth | | | | | |
| Unweighted base = | 4199 | 934 | 914 | 608 | 244 |
| <i>Satisfied/Very satisfied</i> | 81 | 74 | 79 | 76 | 64 |
| Very satisfied | 50 | 48 | 51 | 49 | 42 |
| Any pain relief you received | | | | | |
| Unweighted base = | 3608 | 781 | 783 | 516 | 214 |
| <i>Satisfied/Very satisfied</i> | 80 | 80 | 82 | 77 | 68 |
| Very satisfied | 52 | 54 | 52 | 49 | 41 |
| The way in which the people involved in your labour and birth communicated with you | | | | | |
| Unweighted base = | 4321 | 962 | 923 | 622 | 249 |
| <i>Satisfied/Very satisfied</i> | 80 | 75 | 79 | 72 | 66 |
| Very satisfied | 54 | 52 | 54 | 49 | 42 |
| The location and surroundings where you gave birth | | | | | |
| Unweighted base = | 4307 | 960 | 920 | 613 | 249 |
| <i>Satisfied/Very satisfied</i> | 79 | 74 | 79 | 74 | 59 |
| Very satisfied | 46 | 47 | 52 | 47 | 37 |

Continued.

Table 6 (Continued): Satisfaction with particular aspects during labour and birth, by priority groups

| | 2022 Total sample % | Māori % | Pasifika % | Young % | Disabled % |
|---|------------------------------|------------|---------------|------------|---------------|
| The information you received about what was happening throughout your labour and birth | | | | | |
| Unweighted base = | 4301 | 955 | 921 | 617 | 246 |
| <i>Satisfied/Very satisfied</i> | 79 | 74 | 78 | 73 | 66 |
| Very satisfied | 51 | 50 | 51 | 49 | 43 |
| The support available to you immediately following birth | | | | | |
| Unweighted base = | 4308 | 956 | 920 | 619 | 245 |
| <i>Satisfied/Very satisfied</i> | 75 | 75 | 77 | 74 | 58 |
| Very satisfied | 49 | 51 | 53 | 52 | 39 |

Sub-samples are based on respondents who provided a response for this question and excludes those who said, 'Not applicable'.

Figures in red are significantly lower when compared to the total sample, figures in green are significantly higher when compared to the total sample.

Totals may not sum to 100 percent due to rounding.

4.4.5 Satisfaction with access to providers for postnatal care

In addition to any postnatal care provided by midwives, respondents were also asked about the accessibility of other providers, namely Well Child Tamariki Ora or Whānau Āwhina Plunket, and any specialists. In general, respondents were significantly **less** satisfied with the accessibility of both types of providers than they were in 2014 (e.g., 29% were 'very satisfied' with their access to Well Child Tamariki Ora or Whānau Āwhina Plunket, compared with 55% in 2014).

Disabled respondents were significantly **less likely** to be 'very satisfied' with the accessibility of the specialists that they or their pēpē needed to see (25%, compared with 33% of all respondents).

Mothers and birthing parents from priority groups who participated in the qualitative research reported that signing up to Whānau Āwhina and Well Child Tamariki Ora was easy, but some were disappointed with the frequency and number of home visits they received.

4.5 Service improvements suggested by the priority groups

Reflecting a desire to improve their own and others' experiences of maternity and perinatal services in the future, mothers and birthing parents who participated in the qualitative study suggested the following improvements to current services:

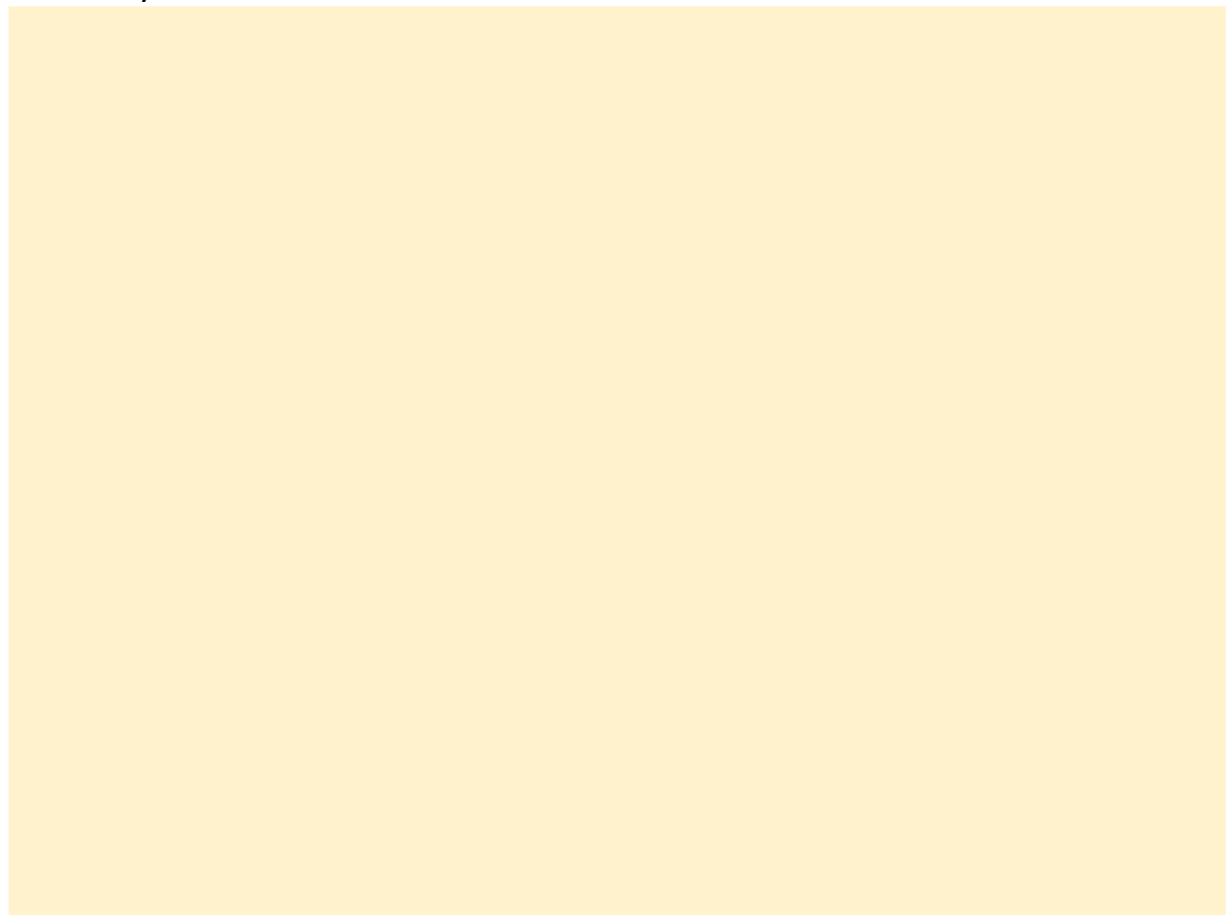
- **Make more community LMC and hospital midwives available and accessible** (including Māori, Pasifika, and LGBTQ+) and better staffed hospitals.
- **Identify and remove the barriers to accessing services.** For example, cost and access to scans, and access, availability, and advertising of antenatal classes and Hapū Wānanga.
- **Make services more inclusive.** For example, by treating everyone with compassion and respect; always asking about cultural, spiritual and identity needs; by providing cultural training; and by using inclusive language.
- **Customise information content and channels to improve communication.** For example, by developing more information on the platforms that appeal to younger mothers and birthing parents (e.g., YouTube, Apps); ensuring printed information is up to date; that the language; and that the look and feel of information is inclusive.
- **Address the power imbalance.** For example, by making sure that mothers and birthing parents are fully informed before making decisions; that they understand that they have choices; and that they understand that their choices should be exercised without feeling pressured.
- **Support more birthing options** within hospitals, for those who want but can't have home births. For example, a 'safe' hospital-based home birth option and a hospital-based Māori cultural birthing option.

5.0 Barriers and inequities of the maternity and perinatal system for bereaved women and people, and their unmet needs

In this section, the focus is placed on identifying the barriers and inequities of the maternity and perinatal system for **bereaved women and people**, as well as their unmet needs.

The results are based on a combination of the survey results for the Survey of Whānau and Families who have Lost a Pēpē/Baby and the qualitative study with these women and people.

Summary



- Figure 9 overleaf summarises the barriers and unmet needs for bereaved women and people.
- Based on the barriers and challenges that bereaved women and people face, the results of the survey and qualitative research (as well as their suggestions) suggest the need to focus on or make improvements in the **same** areas as those for mothers and birthing parents who had a live birth (refer to Section 4), **as well as** in the following areas:
 - **Testing services (e.g., scans and tests)** – to improve access to these services, by making them more available and reducing costs.
 - **Communication and information** – particularly to help make decisions at critical times and explain outcomes.
 - **Hospitals** – to improve hospital experiences, including the need to provide privacy, and the understanding and sensitivity with which health professionals interact with bereaved women and people, especially when a pēpē/baby has died or it is evident that they are unlikely to survive.
 - **Follow-up and support** – especially by midwives, and improved access to counselling services.

Figure 9: Barriers and inequities of the maternity and perinatal system for bereaved women and people, and their unmet needs

| Aspect of care and support | Issue |
|---|---|
| <p>47% of bereaved survey respondents said that issues with their pregnancy were detected/confirmed early on through tests or scans.</p> | <p>20% who had tests or scans had difficulties accessing those services.</p> <p>28% were not provided with enough information about what the test/scan results meant and what options were available to them.</p> |
| <p>While 64% felt they received all the care and support they needed at the time of their pēpē/baby's death, 37% did not.</p> | <p>Most (93%) were given the opportunity to make memories with pēpē/baby; 76% the option of taking their pēpē/baby home.</p> <p>One-in-three did not receive all the information they needed about what would happen following their pēpē/baby's birth/death.</p> |
| <p>57% had further diagnostic testing conducted following their pēpē/baby's death; 37% had a post-mortem.</p> | <p>One-quarter were dissatisfied with the information from diagnostic testing and/or the post-mortem as to why their pēpē/baby had died.</p> |
| <p>86% whose pregnancy was terminated, or whose pēpē/baby died during the pregnancy or labour, received an assessment visit from their midwife after they left the hospital.</p> | <p>14% received no visits or contact following the death of their pēpē/baby; almost one third (30%) of those who did receive a visit would have preferred to have received more visits.</p> |
| <p>One quarter (26%) received counselling or mental health support following their pēpē/baby's death.</p> | <p>57% were offered counselling or mental health support following their pēpē/baby's death; almost one-half were not offered this support.</p> <p>43% would have liked to have received additional contact, information or support following their loss; 28% specifically mentioned that they would have liked to have received loss/grief counselling.</p> |

5.1 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. However, 12% of survey respondents (n=14) reported they did **not** have an LMC, most frequently because of a **shortage** in their area.

5.2 Early detection of potential issues or concerns with the pregnancy

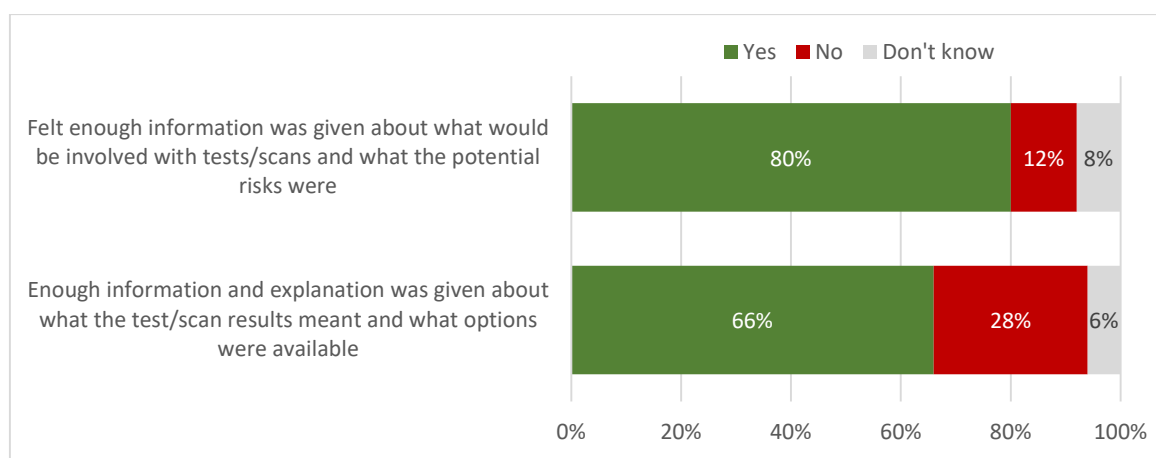
The n=95 bereaved survey respondents whose pregnancy was terminated for medical reasons, whose pēpē/baby died during labour or the birth, or whose pēpē/baby died within 28 days of the birth (and for whom there were early indications or concerns), were asked if it was suggested they have tests or scans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

Sixty percent (n=57) of these respondents stated that tests or scans were suggested and almost all (98%, or n=56) subsequently had a test or scan.

One-third of respondents (32%, or n=22) who had tests or scans, found that accessing these 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).

Most of the bereaved survey 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 10). 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 in this regard.

Figure 10: Whether bereaved mothers and birthing parents 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.

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

One-fifth of bereaved survey respondents made the decision to terminate their pregnancy for medical reasons (21%, or n=25).

Almost three-quarters of these respondents (72%, or n=18) felt that they were given **enough time** and were given **all the information they needed** to make an informed decision about ending the pregnancy (72%, or n=18). However, the remainder felt they were **not** given enough time (28%, or n=7) or all the information they needed (28%, or n=7).

At the time, 62% (n=16) felt they were given **all the support they needed** to decide how to proceed.

Once they had made their decision, 80% (n=20) felt they were given enough information about **what to expect** in terms of the termination procedure, labour, and birth. The remainder felt they were **not** given enough information about what to expect (20%, or n=5).

The qualitative research sheds further light on the experiences of mothers and birthing parents faced with having to decide whether to terminate their pregnancy. The findings were as follows:

- Mothers and birthing parents who were satisfied with the support they received when faced with making this decision, felt that they were provided with the information and advice they needed, and that their decisions were respected.
- Those who were under the care of Maternal Foetal Medicine (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.
- Some bereaved mothers and birthing parents had support from their community midwife during this difficult period.
- Those 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 that their decision to terminate was being questioned.
- The qualitative research also found that, in addition to the accessibility of information and the importance of who provided it, the form in which it was provided was also important. For example, some bereaved women and people

commented on the importance of having the information in writing, as this was both more permanent and immediately accessible.

5.4 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. Most were told by their GP or doctor 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 these respondents (47%, or n=15) were 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 dissatisfied.

The distress caused by health professionals who did not have the necessary skills and sensitivity to communicate that their pēpē/baby had died, was clearly demonstrated in the personal descriptions of the experiences of several women in the qualitative research.

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, 66% (or n=21) said, in hindsight, 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.

Relatedly, some qualitative research respondents, who chose to see their deceased pēpē/baby, were unprepared for what their pēpē/baby would like, how delicate their skin was, and how their appearance might change over time. This lack of preparedness added to the distress of some mothers and birthing parents.

Several mothers and birthing parents who lost their pēpē/baby at home or who had been sent home to begin their labour (including two who had lost their pēpē/baby at under 20 weeks) described the experience as “*frightening*”. They commented that being adequately prepared beforehand with accurate information about what to expect and who to contact in an emergency (provided both in writing and verbally) would have helped.

5.5 Most helpful support and information 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 support and information 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 following the birth of the pēpē/baby).

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

These supportive health professionals/support groups were rated very highly in terms of a number of attributes, including that they were ‘caring and supportive’, and ‘respected their decisions, views and choices’ (77% ‘strongly agreed’ that both of these attributes applied); they were a ‘good listener’ and ‘explained things in a way that was easy to understand’ (72% ‘strongly agreed’ that both of these attributes applied); and that they respected their ‘background, culture, values, beliefs and identity’ (70% ‘strongly agreed’ that this applied).

The most **helpful information** from a health professional/support group also 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).

5.6 Access to a dedicated bereavement room

Respondents whose pēpē/baby died during pregnancy or who had a medical termination, were asked if they gave birth in one of the hospital’s dedicated bereavement rooms. Sixty percent (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.

Of the n=15 respondents whose pēpē/baby died during labour, 73% (n=11) reported having access to a dedicated bereavement room after the 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 qualitative research suggested that those 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.

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.

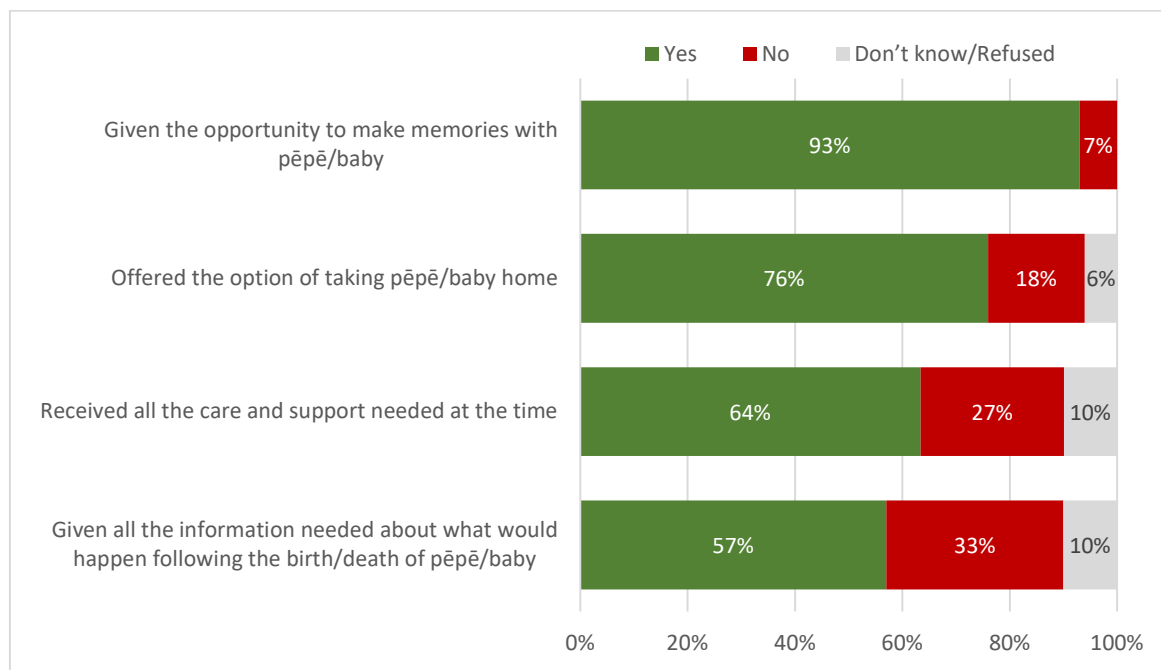
5.7 Care and support, and information received following pēpē/baby’s death

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 11, 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 11: Care and support received after the birth/death



With the benefit of 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.

5.8 Most helpful care and support immediately following pēpē/baby's birth/death

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 the hospital midwife or their LMC midwife was the 'most helpful' (both 44%, n=52), while 19% (n=22) identified their obstetrician/specialist as the 'most helpful'. A similar percentage identified Sands NZ as the 'most helpful' (22%, or n=26) and 19% (n=22), Miscarriage Support.

Where respondents identified a health professional/support group as the 'most helpful', they were asked to rate them in terms of a number of key attributes. In general, they were rated highly. For example, 73% (n=72) strongly agreed that they were 'caring and supportive'; 72% (n=71) strongly agreed that they respected their 'decisions, views and choices'; and 68% (n=67) strongly agreed that they respected their 'background, culture, values and beliefs and identity'.

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

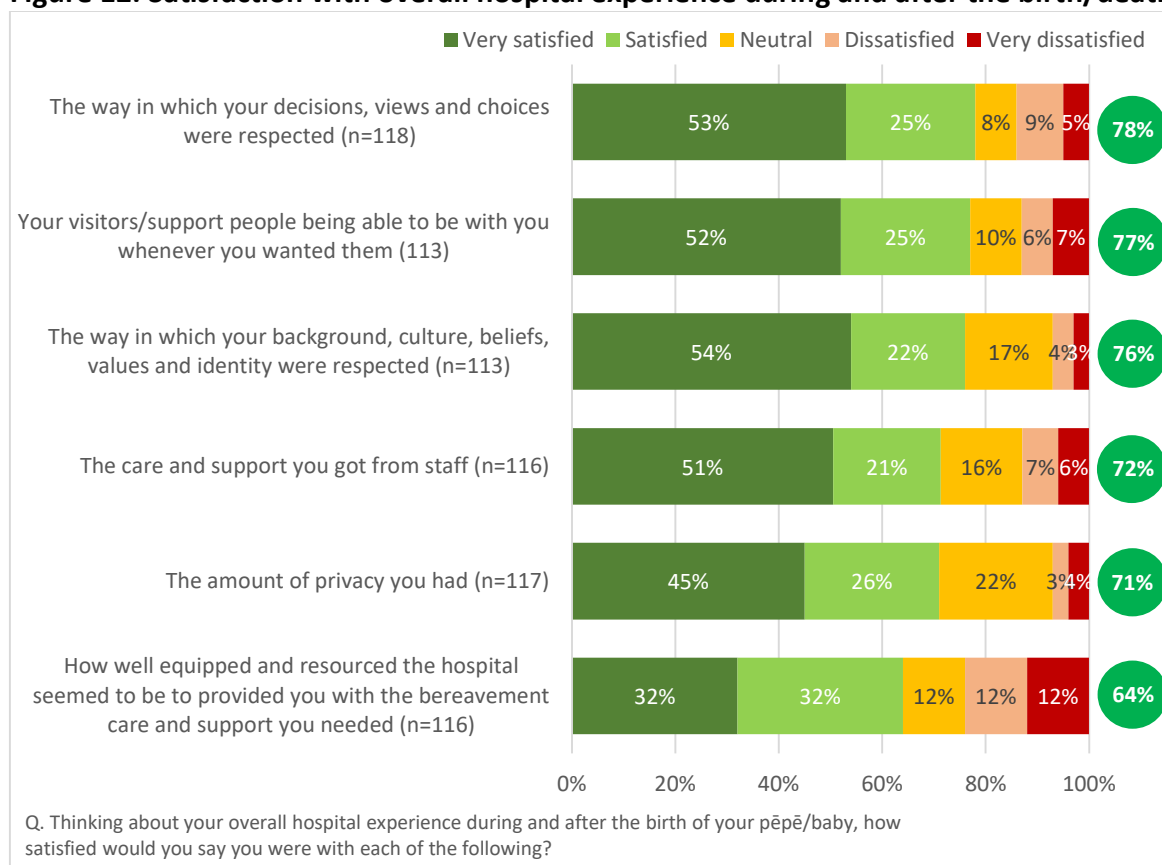
5.9 The hospital experience during and following pēpē/baby's birth/death

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 12 overleaf, respondents were generally satisfied with most aspects of their hospital experience, with approximately three-quarters reporting that they were 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); and the 'care and support [they] received from staff' (72%, or n=84).

In comparison, the aspects of their hospital experience that bereaved respondents were **least satisfied** with were, the 'amount of privacy they had' (71%, or n=59) and 'how well equipped and resourced the hospital seemed to be to provide [them] with the bereavement care and support [they] needed' (64%, or n=74).

Figure 12: 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.

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 hospital staff.

Examples of the actions of hospital midwives and other staff that left mothers and birthing parents feeling cared for and supported, included:

- Being under the care of a specialist bereavement midwife.
- Acknowledging their deceased pēpē/baby and sharing their condolences.
- Not leaving bereaved parents alone – checking on them to make sure they were OK.
- Going “*the extra mile*” to meet their needs and make them comfortable.
- Helping with “*the practical stuff*” (e.g., funeral arrangements and paperwork).
- 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).

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

On the other hand, negative hospital experiences included the following, which left bereaved women and people describing themselves as feeling “ostracised”, “invisible”, “traumatised” and “neglected”:

- Not being listened to; staff behaving insensitively; and being “ignored” and “avoided” (reportedly, sometimes for hours on end).
- Not having their cultural needs met was a source of dissatisfaction for some whānau Māori research participants. For example:
 - Cultural needs being assumed, based on their physical appearance.
 - No help to meet cultural needs outside of complying with wishes.
 - The perception that there was a general lack of awareness amongst hospital staff about what was culturally appropriate and respectful.
- Being sent home to wait to birth their dead pēpē/baby (e.g., because it was the weekend or because of staff shortages).
- Not being asked if they wanted to, or deciding not to bring pēpē/baby home, was later regretted by some research participants.

5.10 Diagnostic testing following pēpē/baby's death

Almost all bereaved survey respondents (98%) recalled being asked if they wanted further testing or a post-mortem carried out following the death of their pēpē/baby.

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.

When 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, opinion was divided. While 40% (n=23) felt the information was helpful, 33% (n=19) rated it as being unhelpful.

Respondents whose pēpē/baby died during labour or up to 28 days after the birth (n=61) were also asked how **satisfied** they were with the information received about why their pēpē/baby died. Almost one-half (48%, or n=29) stated they were satisfied, while 20% (n=12) were dissatisfied. Respondents who were dissatisfied were mostly dissatisfied because the information was inconclusive.

5.11 Care and support received from midwife and support groups after returning home

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.

Nine-of-every-ten respondents received some form of contact (89%, or n=41); two-thirds of respondents were contacted by their midwife LMC (65%, or n=30), while approximately one-quarter by 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).

However, one-of-every-ten received **no contact** (11%, or n=5) from their LMC, other health professionals or support agencies after their pēpē/baby had died.

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.

Forty percent (n=29) stated they received 1-3 visits, 25% (n=18) received 4-6 visits, and 12% (n=9) received seven 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 at all after leaving the hospital.

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. However, 30% (n=22) wanted 'more visits' and 3% (n=2) would have preferred 'less visits'. The other 20% (n=9) were unsure.

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. However, 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.

Reflecting this, 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.

Others did not get as much support from their midwives as they would have liked, or they left the system without follow-up or any information about where they could get the support they required. This left them feeling forgotten and alone.

Qualitative research participants who found their way to the volunteer support groups for bereaved mothers and birthing parents, such as Sands NZ and Baby Loss NZ, found the support that they received as being immeasurably helpful.

Bereaved 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 talk and be listened to, and/or read about the experience of others who had similar experiences.

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

Bereaved 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.

5.13 Receiving counselling or mental health support

One-half of bereaved survey 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.

Three-quarters (74%, or 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.

One-half (48%, or n=15) thought the **number of sessions** they had was 'about right', while 39% (n=12) felt they 'did not have enough'.

All 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**.

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

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.

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

For those who decided to access counselling services, finding a counsellor was described as "*a struggle*", and was reported to often involve waiting for a month, or more.

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. However, funded counselling 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.

5.14 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 included:

- **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 bereaved 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 bereaved women and people. This, in turn, results in those who have early miscarriages being disadvantaged in terms of the quality and extent of the support and care they received.
- The potential for bereaved 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.

5.15 Service improvements suggested by bereaved women and people

Reflecting a desire to improve their own and others' experiences of maternity and perinatal services in the future, bereaved women and people who participated in the qualitative study suggested the following improvements to current services:

- **Listen and act** if hapū/pregnant mothers and birthing parents are worried about themselves or their pēpē/baby.
- Address community and hospital **midwife shortages**.
- **Support bereavement education** across the maternity and perinatal workforce.
- **Have midwives and other staff with bereavement knowledge on each shift in all hospitals**, to support bereaved women and people, from the time they learn that their pēpē/baby had or might die, to the time they go home.
- **Improve follow-up care** following any perinatal loss, so that all bereaved women and people are followed-up when they return home after their loss, including sporadic follow-up after six weeks, as required.
- **Fully fund and support access to counselling services** for any perinatal loss, so that services can be accessed quickly and easily and can be accessed later, for those who initially decline the option, but later find themselves or their whānau/family struggling.
- **Better information resources**. For example, information to support women during the miscarriage process; resources to help prepare whānau/families for seeing and caring for their deceased pēpē/baby; resources to help with grieving; up-to-date information about volunteer support groups and services).