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2015 Survey of Bereaved Women

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2015 Survey of Bereaved Women

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Thank you

The Ministry of Health would like to thank all of the women who generously gave their time to participate in the 2015 Bereaved Women Survey. Your views, comments and openness were greatly appreciated and provide valuable insight into the very personal experiences of women in New Zealand who have lost a baby.

Executive Summary

This report presents the results of the 2015 Bereaved Women Survey which was completed between 20 January and 13 April 2015.

The survey results are based on the responses of 114 women whose baby (or babies) passed away between 20 weeks of pregnancy and 28 days following birth. The survey explored women's experiences and satisfaction with the maternity services they received prior to, during and following the loss of their baby.

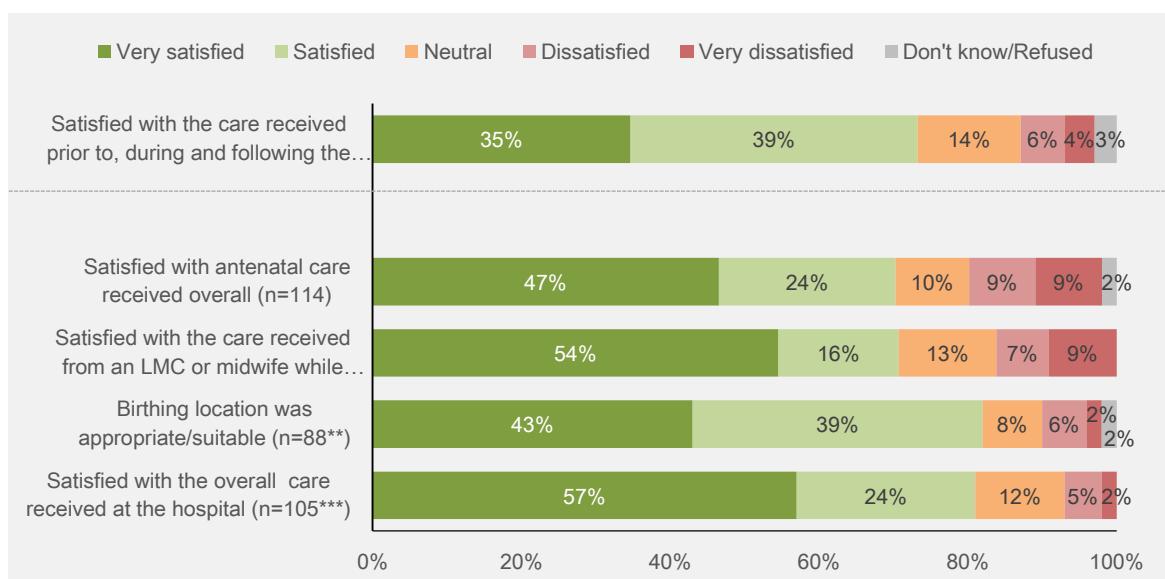
Overview of key results

Of the n=114 women interviewed, three-quarters (74 percent, or n=84) were satisfied or very satisfied with the overall level of maternity care they received (Figure 1). This result is comparable to the first Survey of Bereaved Women in 2011 (67 percent were satisfied or very satisfied in 2011).

Other key results are as follows:

- Prior to the baby's death, 71 percent of all women were satisfied with the antenatal care they had received (n=81).
- Eighty-two percent of women who experienced a still-birth felt that the birthing location or surroundings were suitable or appropriate (n=72).
 - This is significantly higher than the 69 percent recorded in 2011.
- Eighty-one percent of women who gave birth in a hospital were satisfied with the overall level of care they received during their stay (n=85).

Figure 1: Satisfaction with care received prior to, during and following the loss of the baby



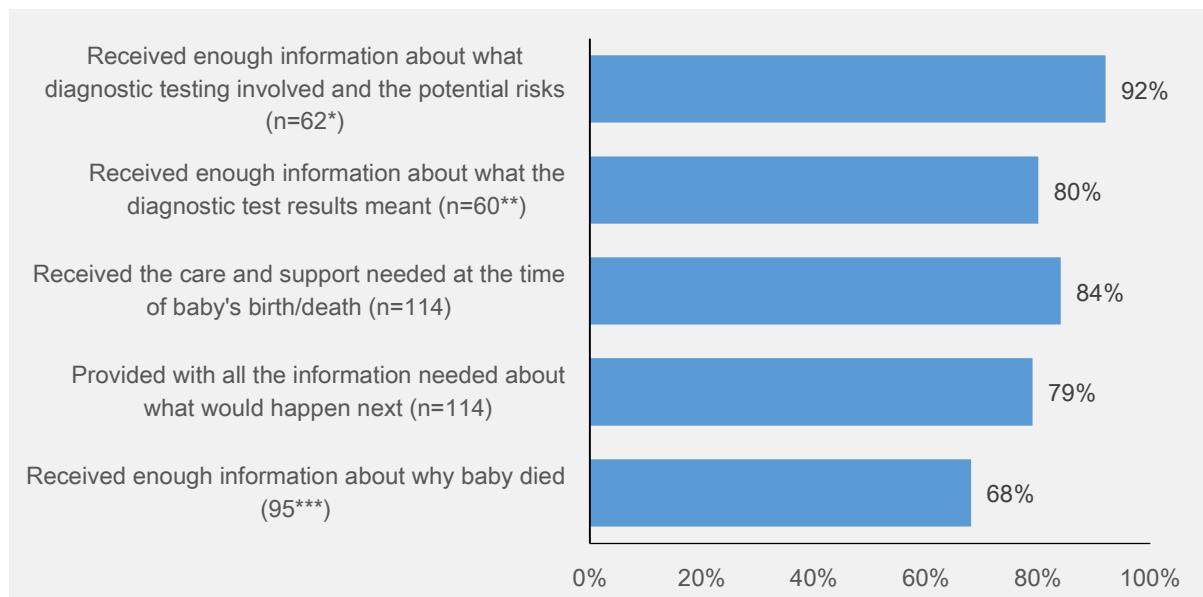
*Sub-sample excludes women who said 'Not applicable'. **Sub-sample excludes those who had a live birth.

***Sub-samples based on women who gave birth in hospital or a birthing unit and excludes those who said 'Not applicable' or did not provide a response to this question.

Most women also felt they had received enough information, care and support (Figure 2):

- ▀ Of those who had diagnostic testing or discussed this option during their pregnancy, 92 percent (n=57) said they received enough information about what diagnostic testing would involve and what the potential risks were.
- ▀ Eighty percent of those who decided to have diagnostic testing felt they received enough information about what the test results meant and what options were available to them (n=48).
- ▀ The majority of women (84 percent or n=96) felt they received all of the care and support that they needed at the time of their baby's birth/death.
- ▀ Seventy-nine percent of women (n=90) reported having received all the information they needed at that point about what would happen next. However, in hindsight almost one-half (45 percent or n=52) said that it would have been useful to have received additional information. For example, about how to make memories with their baby, about funeral preparations and the chance to talk to someone about what they were going through.
- ▀ Of those whose baby died during the pregnancy, during labour or after the birth, 68 percent (n=65) felt they were given enough information or explanation about why their baby had died.
- ▀ Fifty-five percent of women felt that their midwife provided the most helpful information and support at that stage, 33 percent identified their obstetrician as being the most helpful, while 16 percent mentioned their family and friends.

Figure 2: Provision of information, care and support



*Sub-sample based on women who underwent diagnostic testing or had discussed it with a health professional.

**Sub-sample based on women who underwent diagnostic testing.

***Sub-sample excludes those whose pregnancy was terminated due to fetal abnormality.

Conclusion

As mentioned earlier, 74 percent of women were satisfied (or very satisfied) with the overall level of maternity care they received prior to, during and following the loss of their baby.

- This compares well with the results from the 2011 Survey of Bereaved Women (67 percent of whom were satisfied or very satisfied), and to the 2014 Maternity Consumer Survey (77 percent of women who had a live birth were satisfied or very satisfied with the maternity care they had received).

However, 10 percent (or n=11) of the bereaved women interviewed were dissatisfied (or very dissatisfied) with the level of maternity care they received, while 14 percent provided a neutral response and three percent chose not to respond.

Three key areas of improvement identified through this survey were the information and support that is provided to women during and also immediately following their loss, and the appropriateness of the surroundings in which the birth takes place. Each of these are described in more detail below.

- 1. Ensure that the birthing location or surroundings are as suitable/appropriate as possible.**

While some appreciated the fact that there were limited options available at the time, having to see other babies or hear them cry when their own baby had just died, was described as heart-breaking. Although mentioned by fewer respondents than in 2011, this was still raised as an issue by approximately one-in-five women (n=20).

...listening to other women labouring and babies crying is not acceptable to listen to whilst holding your deceased baby in your arms in the same unit.

- 2. Make sure the family is informed not only about what happens to the baby's body, but what their options are (i.e. in terms of funeral arrangements and spending time with the baby).**

Most women who have just lost a baby, have never been in that situation before and did not expect to be that situation now. Clear (and sensitively delivered) information at this point about the process, and the family's options, is invaluable. While most women said they received information about what would happen next with the baby's body, they did not know if they could take the body home or if they could even spend time with the baby before they left the hospital.

In the blur that follows a baby's death, the mother is trying to mentally process what has happened and can very easily miss the only opportunity she (and the rest of the family) may get to see the baby, to touch them, to take their photo or a lock of their hair. They need to be told that these options exist.

For those that lose their babies, I would encourage them to take photos, I didn't think of it at all. A lot of mothers in that situation don't think about it at all and after a few days it's too late.

3. Early involvement of a support person (such as someone from Sands NZ) and access to counselling services is also very important.

On losing a baby, the bereaved parent(s) needs to know that there are other people who understand what they have and are experiencing. Brochures and pamphlets have their place in this regard, but many families are reluctant to make that initial contact themselves and ask for help.

Even if the woman initially rejects the opportunity to talk to someone about her loss when it has just happened, this does not necessarily mean that they would not appreciate the offer a few weeks later, when life has started to return to 'normal'.

I feel there needed to be more support for bereaved parents who are not based in a main centre ... I was coping ok - but felt I needed somewhere/someone to talk to, without feeling like I was burdening my friends and family. I still feel like it'd be great to see someone, but not really sure how to go about this. I fear for the long-term impact of something like this happening to a mum who isn't as strong as me, or who doesn't have the family/friend support.

While no degree of service can alleviate the emotional pain of losing a baby, if each of the key elements described above are delivered, and delivered well (i.e. in a timely and sensitive manner), then it will help to make this maternity experience as positive as it can be.

Background, purpose and approach

The Bereaved Women Survey explores women's views and experiences of the maternity care they received prior to, during and immediately following the loss of their baby. This report presents the results to the second Bereaved Women Survey, which was completed between 20 January and 13 April 2015 with women who lost their baby in 2013.

The Bereaved Women Survey was conducted by Research New Zealand, on behalf of the Ministry of Health, for the first time in 2011. This survey is similar, and thus comparable to the previous 2011 survey.

This survey gives women who have experienced a perinatal death, the opportunity to have their say about their experience of maternity services during their pregnancy, the loss of their baby and in the time following their loss. Specifically, women's experience of maternity services was examined (where appropriate) in relation to:

- Satisfaction with the antenatal care they received prior to their loss.
- Screening and diagnostic testing, and the assistance provided to understand the results of testing and decision options.
- Satisfaction with where the birth took place, and events immediately after the birth¹.
- Satisfaction with the level of support provided after the baby's birth.
- Satisfaction with the overall standard of care that was received.

Women were asked questions relating to the above areas based on the manner in which their pregnancy was terminated or their baby died:

- The pregnancy was terminated for medical or health reason
- Baby died during pregnancy
- Baby died during labour
- Baby died after he or she was born.

¹ For those who experienced a live birth, these questions were asked in relation to the events that occurred immediately after the baby's death.

Approach

The Bereaved Women Survey was completed between 20 January and 13 April 2015 by women who had lost a baby in 2013.

Particular care was taken in creating the survey in 2011 and included extensive pre-testing and piloting. Therefore, only minor changes were made for the current survey, such as the addition of questions which would allow comparisons of the results of this survey with the results of the 2014 Maternity Consumer Survey of women who had live babies.

The following process was followed for the current survey:

1. 421 women were posted an invitation letter (which was co-branded by the Ministry of Health and Sands NZ²) to the address they had provided at the time of their baby's death.

The invitation letter introduced the survey and explained what taking part would involve. This survey was an 'opt-in' survey so if they wanted to participate, the letter asked women to provide their consent for Research New Zealand to contact them by telephone. The letter also gave instructions on how to complete the survey online if they preferred.

2. The online survey was 'open' from the 20th of January 2015 until the 13th of April 2015.
3. Those who had provided their consent (and a preferred contact phone number), were then contacted by one of a very select team of Research New Zealand's interviewers. This small interviewing team was extensively briefed by Sands NZ prior to the telephone interviewing beginning.

At the start of each interview, interviewers asked women to re-confirm their consent to complete the interview. At the end of the interview, women were informed that if they wanted to talk to someone about their loss, they were welcome to contact Sands NZ or if they preferred, Research New Zealand would arrange for a Sands NZ representative to contact them.

Of the 421 women who were invited to take part in the 2015 Bereaved Women Survey, 114 women completed the survey (a participation rate of 27 percent). More than one-half of those who completed the survey did so online (57 percent), while 43 percent completed the survey by telephone.

Of those who took part in the survey, one-in-two lost their baby during pregnancy, while one-in-five lost their baby after he or she was born. A further 17 percent terminated their pregnancy for medical or health reasons and 15 percent lost their baby during labour (Table 1).

² Sands NZ is a voluntary, parent-run, non-profit organisation set up to support parents and families who have experienced the death of a baby at any stage during pregnancy, as a baby or infant.

Table 1: Number of completed surveys by channel and when baby died

	2015 Count	2015 %
Online	65	57
Telephone	49	43
Pregnancy was terminated for medical or health reasons	19	17
Baby died during pregnancy	55	48
Baby died during labour	17	15
Baby died after he or she was born	23	20
Total	114	100

Due to the relatively low sample size, results based on the total sample are subject to a relatively high margin of error of ±9.2 percent, at the 95 percent confidence level. This means that if we found 50 percent of women were satisfied with the maternity care they received, we are 95 percent sure that we would get the same result (plus or minus 9.2 percent) had we interviewed all 421 bereaved women.

A more detailed description of the methodology and participation rates is provided in Appendix C.

Report notes

Results in this report are presented on a total sample basis only. Due to the relatively small sample size (n=114), the results have not been broken down by the four sub-groups of bereaved women based on the manner in which their pregnancy was terminated or their baby died, by age or by ethnicity.

Where possible, results of this survey are compared to the results of the previous survey.

Antenatal care

There is no right or wrong way to access maternity services, and different women can get care from different people at different times. Knowing how women access health services during their pregnancy, and finding out how well those services worked for them, helps the Ministry of Health to make it easier for pregnant women to get the services they need in the future.

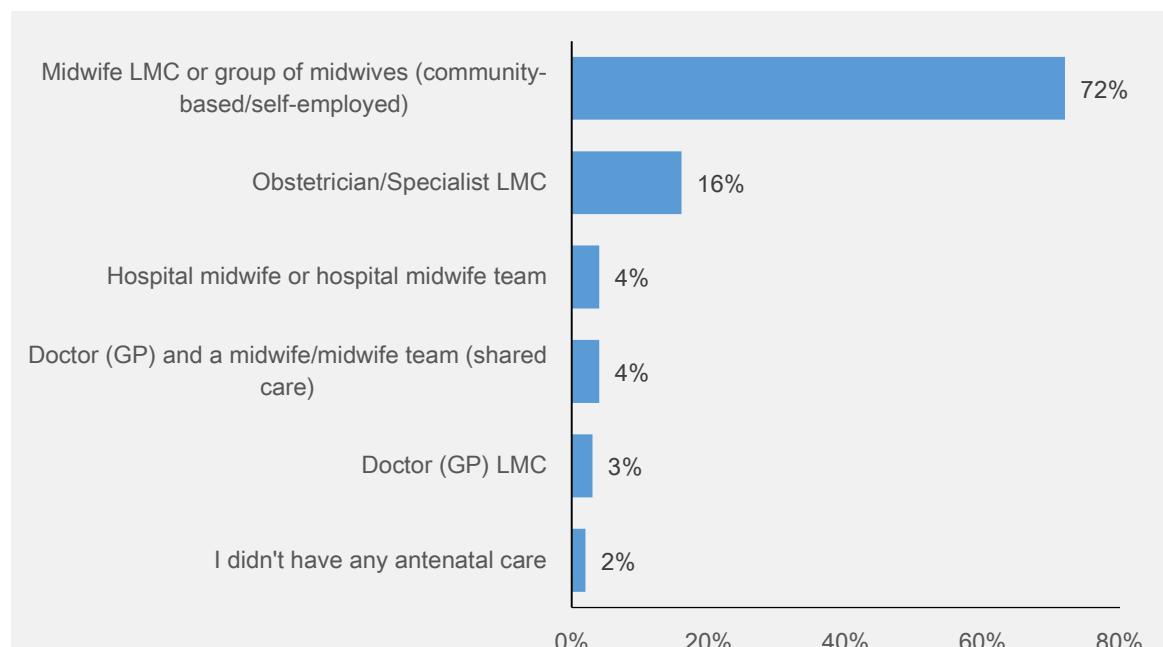
This section looks at the antenatal care received by women during their pregnancy prior to the death of their baby.

Choice of antenatal care provider

All women were asked to identify which health care professional(s) provided most of their antenatal care. Seventy-two percent of respondents (or n=82) reported that they received most of their antenatal care from a midwife LMC or a group of midwives. A further 16 percent (n=18) had an obstetrician or specialist LMC.

Figure 3: Antenatal care provider

Q4. Who did you get antenatal care from for most of your pregnancy?



Base (n=114).

Total may not sum to 100 percent due to rounding.

Reasons for not having an LMC

Women who did not have a LMC (n=11) were asked to describe their reasons for this.

Five of the women interviewed had a hospital midwife or a hospital midwife team as opposed to a LMC. This choice of midwife was made for a variety of reasons:

Ours was recommended through the hospital specialists after we had to stay out of town for the remainder of the pregnancy.

My midwife was recommended to me by a friend.

I was a high risk pregnancy.

Had a midwife in [Town/City] and then moved to [Town/City] and changed midwife there to a hospital midwife.

I wanted to use the hospital team.

Four of the women interviewed reported having received shared care from their GP and a midwife or midwife team. This decision was most commonly made for medical or health-related reasons or because the pregnancy was considered high risk.

I was referred to [Place] midwives by my GP - in having identical twins I was high risk and ended up with the [Town/City] hospital neonatal team early on anyway.

I had a LMC as well, so it was shared between her and the foetal medicine department during my pregnancy.

I had a community midwife shared care with a specialist as [I] had lost my first baby and had to have a c-section.

When I first met my midwife, she was so concerned because I was a big girl and she said I have to have shared care. Being my first pregnancy, she was so obsessed with my weight that I also got sent to the dietitian. I had my first appointment, then I came back and I had another midwife and then I only saw her a couple of times, and then I had him. She was on holiday, so I had another midwife. It was a mess. You're supposed to make an intimate connection with your first midwife. I just think that it being my first pregnancy, I realise I'm a big girl, but it's not all about that.

Two of the women interviewed reported that they did not have any antenatal care. Both of these women explained that this was because they had not known they were pregnant.

I did not know I was pregnant.

I didn't know I was pregnant until about 6pm on [date].

Satisfaction with antenatal care received

All women were asked to rate how satisfied they were with various aspects of the antenatal care they received. This was measured on a scale of 1 to 5 where 1 = very dissatisfied and 5 = very satisfied.

As shown in Figure 4, satisfaction with the various aspects of the antenatal care received was high. The most positively rated aspect was in relation to appointment times and places being convenient for women (80 percent, or n=89, reported being satisfied or very satisfied with this).

At least one-half of women were also 'very satisfied' with the following aspects of care:

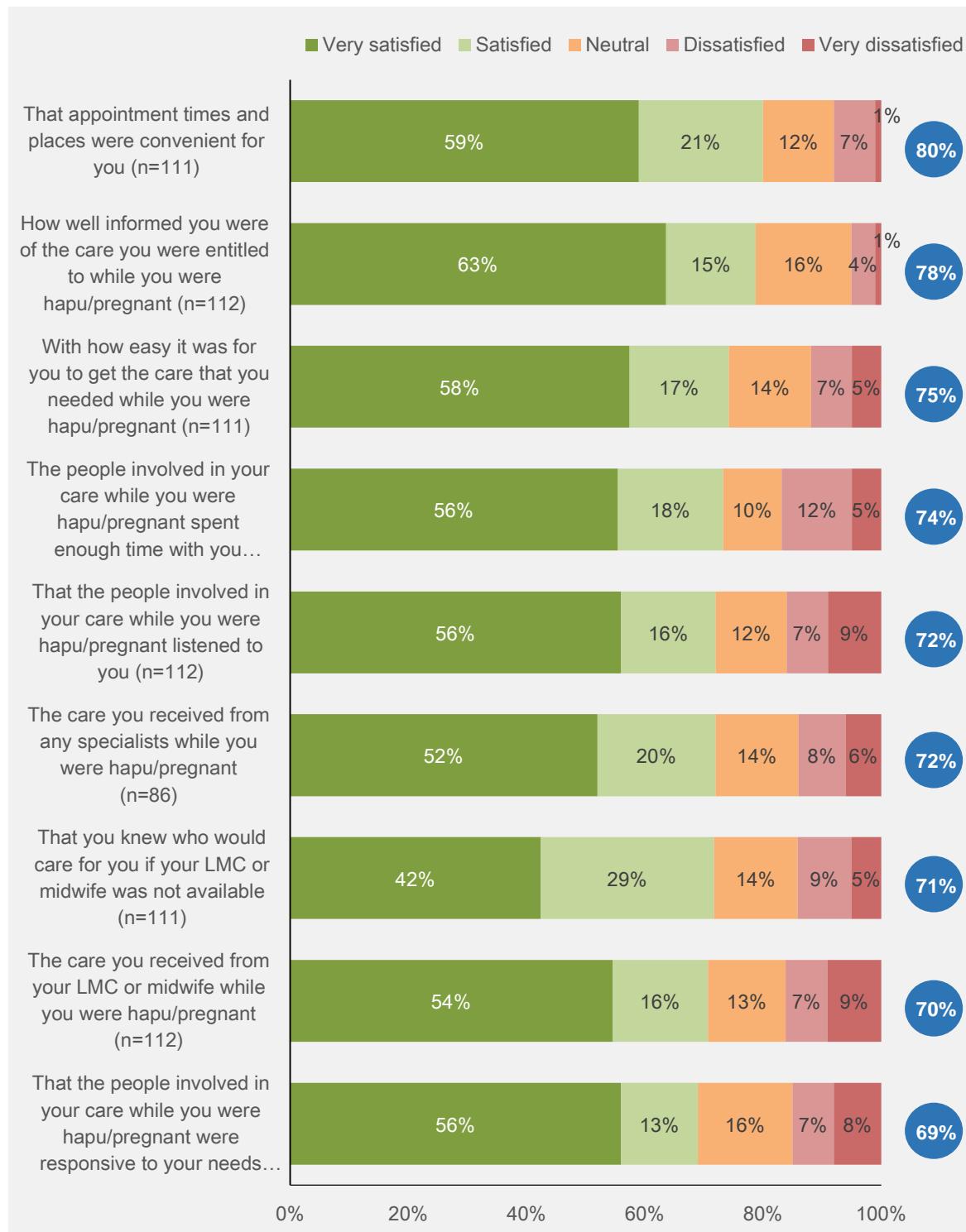
- Being well informed of the care they were entitled to while hapū/pregnant (63 percent, or n=71, were very satisfied)
- How easy it was to get the care that they needed (58 percent, or n=64, were very satisfied).
- The people involved in their care spent enough time with them (56 percent, or n=62).
- The people involved in their care listened to them (56 percent, or n=63).
- The people involved in their care were responsive to their needs (56 percent, or n=62).
- The care they received from their LMC or midwife (54 percent, or n=61).
- The care they received from specialists (52 percent, or n=45).

However, less than half (42 percent, or n=47) were very satisfied with knowing who would care for them if their LMC or midwife was not available.

The backup midwife would be a good start, meeting her beforehand would be good. I had to meet mine when I gave birth and wasn't happy with her attitude towards my sister during labour. My son was born still and them having a go at each other in the same room didn't help me at all!

Figure 4: Satisfaction with the antenatal care received

Q6. Thinking about the antenatal care that you received while you were pregnant/hapū, so before the birth, how satisfied were you with the following?



Please note: Sub-samples are based on women who provided a response for each statement – excludes those who answered 'not applicable'.

Totals may not sum to 100 percent due to rounding.

%

Percent of women who were satisfied + very satisfied.

Women were also asked to rate their satisfaction with the overall standard of maternity care they received while they were hapu/pregnant. Reflecting the high satisfaction with specific aspects of antenatal care, 71 percent of all respondents (n=81) were satisfied or very satisfied with the overall standard of maternity care they received during their pregnancy.

This result is in line with the result reported in the 2011 survey where 70 percent were satisfied or very satisfied with the overall standard of maternity care they received during their pregnancy.

Figure 5: Overall satisfaction with the maternity care received during the pregnancy

Q7. How satisfied were you with the overall standard of maternity care that you received during your pregnancy?



Early detection of potential problems or difficulties

During pregnancy women should be advised of screening tests that are available for a number of conditions that may affect their baby. Depending on the screening results, some women are offered diagnostic tests to confirm if their baby has a condition. Choosing whether to undergo screening is an important decision. Women should be provided with enough information and support so that they can make a decision that is right for them and their whānau/family.

This section explores the extent to which women who experienced a perinatal death had any early indications or prior warning that there was something wrong with the pregnancy, and the information and support they received during this time.

All women were asked if there was any indication that there was a problem with their pregnancy, and if so, when they found out (Figure 6).

Two-thirds of women (65 percent or n=74) reported having some indication, before the birth, that there might be a problem.

- Forty-two percent (n=48) said it was suspected that there might be a problem during their second trimester of pregnancy. Seven percent (n=8) reported indications of a problem in their first trimester, whilst 16 percent (n=18) did not know there was an issue until they reached their third trimester.

One-third (32 percent, or n=37) of all women said that there were no indications at all during their pregnancy that anything was wrong.

These results are not significantly different from those recorded in 2011.

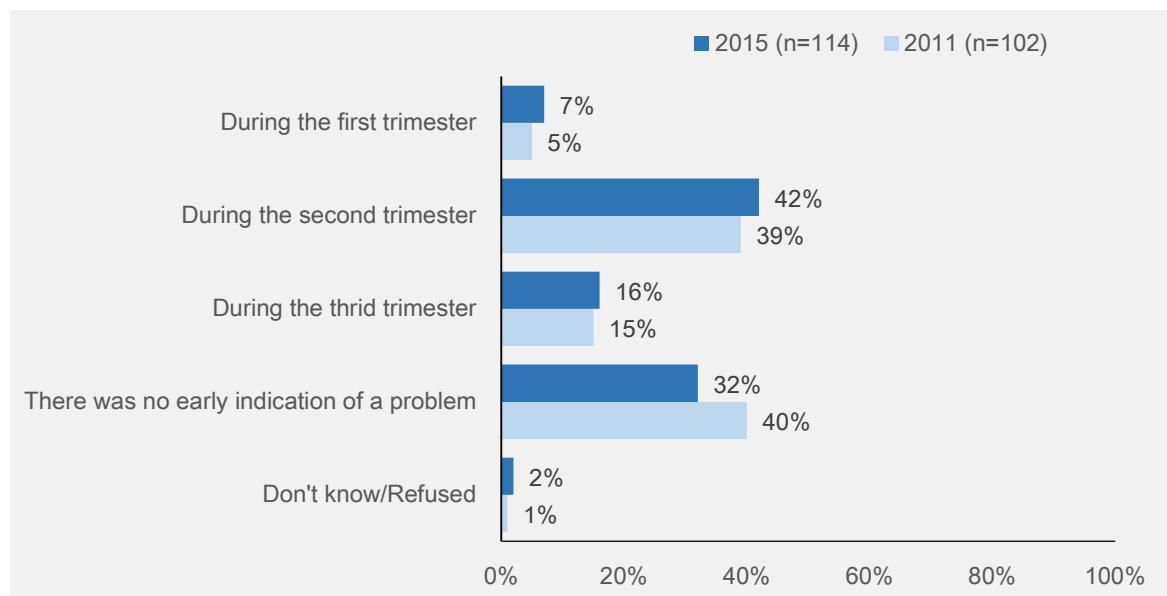
Figure 6: Early indications of problems or difficulties

Q8. About how many weeks into your pregnancy was it first suspected that there was a problem? [Baby terminated due to fetal abnormality]

Q45. Prior to your baby's death, was there any indication that there may have been a problem? If yes: At what point was this? [Baby died during pregnancy]

Q82. Before you went into labour, was there any indication that there may have been a problem, or that there may be difficulties with the birth? If yes: At what point was this? [Baby died during labour]

Q117. Prior to your baby's birth, was there any indication that there might be a problem? If yes: At what point was this? [Baby died after he/she was born]



Totals for each year may not sum to 100 percent due to rounding.

Screening

All women were asked whether they had undergone a screening test and if they had had an anatomy scan during their pregnancy.

The majority of women (85 percent or n=97) reported having an anatomy scan 18-20 weeks into their pregnancy. Seventy-nine percent (n=90) recalled having screening tests for Down Syndrome and other conditions or birth defects.

- These results are similar to those reported in the 2011 survey (91 percent had an anatomy scan and 72 percent underwent screening tests in 2011).

Women who reported having screening tests or scans were then asked if there were any indications at that point that there was a problem with their pregnancy (Figure 7). Again, the results are comparable to those recorded in 2011.

Thirty-nine percent of all women (n=44) reported that one (or both) of the tests or scans had identified a problem with the pregnancy or baby's development.

Only the anatomy scan because they were trying to see if he was breach - and that was when we discovered there were other abnormalities.

Our problem, twin to twin transfer syndrome, was diagnosed after we were sent to a specialist, who did ultrasounds to confirm it.

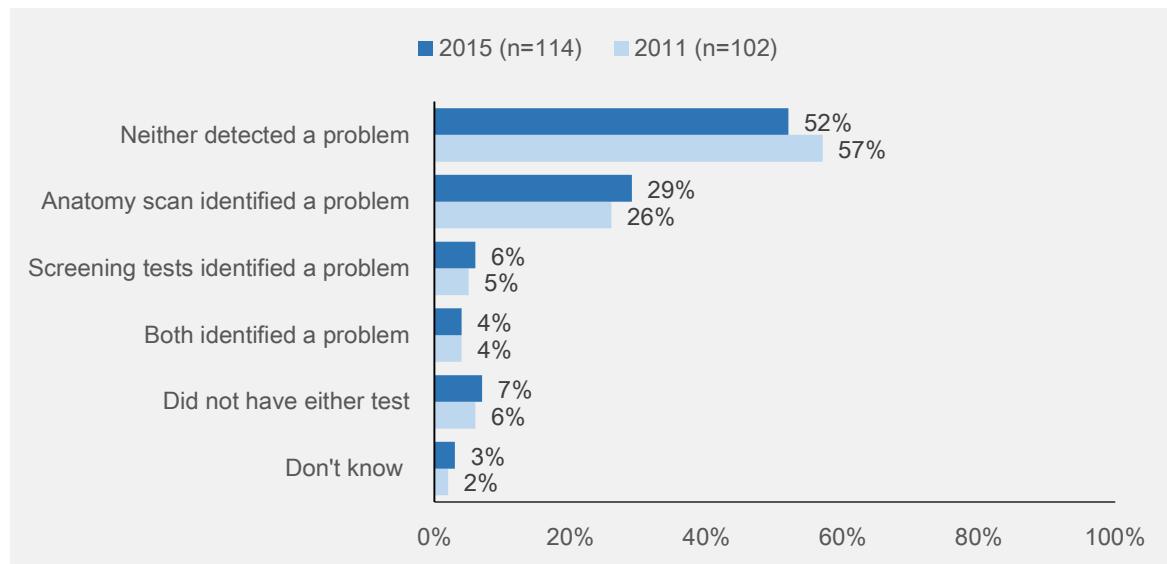
- One-half (52 percent, or n=59) of all women reported that no potential issues or problems had been raised with them as a result of the anatomy scan or screening tests.

I definitely think that, obviously, I am not a doctor but I do believe - the obstetrician said that if he had seen the late scan it would have raised alarm bells but it did not do this for the radiologist at the time. That was really the crucial point. We were told that apart from the growth, [Name] was healthy. The post-mortem could not test the metabolic system, we were told he was not strong enough to go through labour. At our following pregnancy we were told that anything like that is easy to intervene with. If somebody had done something he would be here now.

My first 10-22 weeks I spent with my family in [Country]. All the diagnostic tests and screenings (Down syndrome, anatomy scan, etc.) were done there. They all showed normal range. When I came back to New Zealand I asked my midwife to repeat my 20 weeks scan in New Zealand because I didn't fully trust the care in [Country]. But my midwife refused, saying that screening is the same everywhere. I didn't insist then, but now I can't stop thinking what if it could make a difference. What if sonographers have better skills, what if machines are better in New Zealand? What if they could notice any problem? I understand that they might not do. But the idea that it could make a difference doesn't leave me alone.

Figure 7: Screening test(s) which identified a problem with the pregnancy

Q12, Q48, Q85, Q120. Did either of these screening tests identify that there was a possible problem?



Diagnostic testing

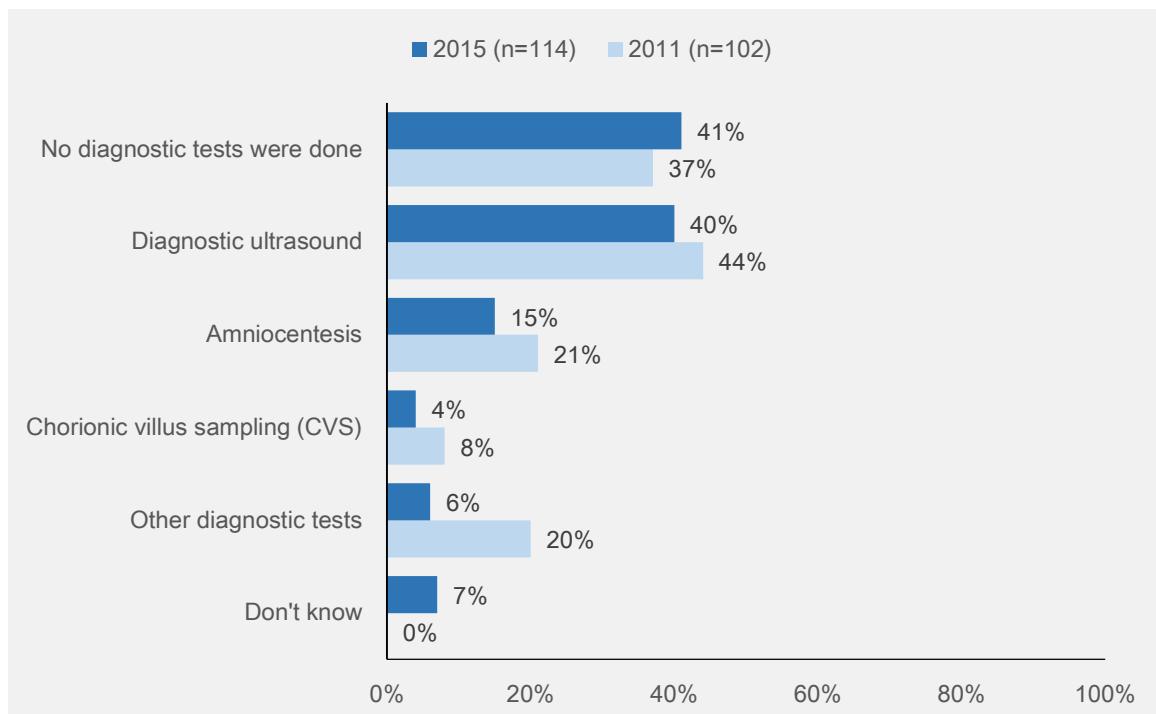
Fifty-two percent of all women (n=60) reported having undergone some type of diagnostic testing during their pregnancy.

The most commonly reported diagnostic test was a diagnostic ultrasound (40 percent, or n=46), followed by amniocentesis (15 percent, or n=17). Four percent (n=4) reported having chorionic villus sampling, and six percent (n=7) said that they underwent some 'other' diagnostic test (Figure 8).

When compared to 2011, the only statistically significant difference in this regard was the extent to which women reported having 'other' diagnostic tests (which decreased from 20 percent in 2011 to six percent in 2015).

Figure 8: Diagnostic testing

Q13, Q49, Q86, Q121. What diagnostic testing was done to help confirm that there was a problem?



Totals for each year may not sum to 100% due to multiple responses.

Women who did not have diagnostic testing during their pregnancy were asked if anyone had discussed testing with them. While 19 percent reported that this had been discussed (n=10), 69 percent (n=37) said that no-one had discussed diagnostic testing with them or suggested they undergo tests.

Of those who had diagnostic testing or discussed this option (n=62), 92 percent (n=57) felt that they were given enough information about what the tests involved and what the potential risks were. This is comparable to the 83 percent of women in the 2011 survey who felt they were given enough information.

Information and support received when the problem has been confirmed

Of the women who underwent diagnostic testing, 80 percent (n=48) believed that they were given enough information about what the test results meant, and what options were available to them.

- ▀ Following the discovery of a foetal abnormality, n=19 women made the decision to terminate their pregnancy.
- ▀ Sixteen of those whose pregnancy was terminated felt that they were given all the information they needed to make an informed decision (84 percent).
- ▀ Most (84 percent, or n=16) also felt that they were given enough time to make their decision.
- ▀ Those whose pregnancy was terminated, were asked if there was any additional information or support they would have liked at the time. While 42 percent (n=8) said that they did not need any additional information or support at the time, 53 percent (or n=10) did provide suggestions in this regard. A selection of those comments are provided below:

What the timeframe for the termination process would be.

The problem was with the midwife, as she didn't know anything about Thalassemia and didn't trust me that I needed a test to confirm the risk for the baby. Another issue for me was that there was a long period of time from the decision I made to the procedure. Since I made the decision to end the pregnancy (which was the recommended option), there was a week to wait for it to happen and in such a condition, for me, it was a century. It wasn't easy carrying a baby that you are going to kill, just the thought [of it] is unbearable.

Probably speaking to somebody who has had a child who was in the same situation.

I would have liked to actually meet with someone who had been through a TFMR or had training in this particular type of grief. We did meet with the social worker, but that was not helpful.

I guess I would have liked to, after the major conversation with the paediatrician and obstetrician, have a follow up phone call or follow up email as a kind of courtesy. I felt like I was left alone with this decision and I had to approach them for any information.

Being given access to a counsellor whilst making a decision, as well as being offered one afterwards.

I think time would be one factor and maybe just more details, and maybe for me it was more like I lived in a cloud of hope that things are going to be alright, and it got shattered within pretty much two days, so I think for me it would've been helpful if the first hospital just would have been very black and white about things and not cloud me in a sense that it would all work out; that was my biggest problem. They kind of, every obstetrician from the first hospital gave me different answers and outcomes, so they were all not agreeing on one thing, so every day I heard something different because every day I saw someone different, so they gave me hope that everything is going to be alright and then I got transferred and all these hopes pretty much got shattered in two days, because someone for the first time in 24 weeks talked black and white to me about how things were going to be. I thought being more black and white probably would have prepared me more about the decision I would have made. And learning about SANDS earlier.

- Fifty-five women reported that their baby died during pregnancy.
 - While one-third (33 percent or n=18) of these women lost their baby in their second trimester, the rest were in their third trimester. Twenty-nine percent (or n=16) lost their baby at 35 weeks or more.

Those whose baby died during pregnancy or whose pregnancy was terminated, were asked who they received information, support and advice from when making their decisions about what would happen next (i.e. whether or not to continue with the pregnancy, or for those whose baby had already passed, what to do in regards to the birth of the baby).

- Women were most likely to have received information, support and advice from a midwife (59 percent, or n=44), or an obstetrician (46 percent, or n=34). Some women also reported receiving information, support and advice from other hospital staff (15 percent, or n=11), a specialist (12 percent, or n=9), and a support worker/counsellor (12 percent, or n=9).
- When asked who provided the most helpful information, support or advice, 39 percent (n=29) identified their midwife, and 36 percent (n=27) said an obstetrician was the most helpful.

Table 2: People who provided information and support when the problem was confirmed

Q16. Who was involved or provided information, support or advice to help you make your decision after you got your diagnostic results? [Baby terminated due to fetal abnormality]

Q54. Who was involved or provided information, support or advice to help you understand what had happened and what decisions needed to be made with regard to the delivery of your baby? [Baby died during pregnancy]

Q17. Which one of them provided you with the most helpful information, support or advice when you were making your decision? [Baby terminated due to fetal abnormality]

Q55. Who provided you with the most helpful information, support or advice? [Baby died during pregnancy]

	Base =	All helpful people	Most helpful person
		74*	74*
Midwife		59	39
Obstetrician		46	36
Other hospital staff		15	8
Family/friends		15	8
Specialist		12	9
Support worker/Counsellor		12	1
GP		7	4
Nurse		5	1
Sands NZ		3	1
Registrar		0	1
Other		4	3
Don't know/No response		4	4

Total may exceed 100 percent because of multiple response or rounding.

*Sub-sample based on women whose baby was terminated due to fetal abnormality or who died during the pregnancy.

The results do not differ significantly between 2011 and 2015 in regards to the information and support received when the problem was confirmed during pregnancy.

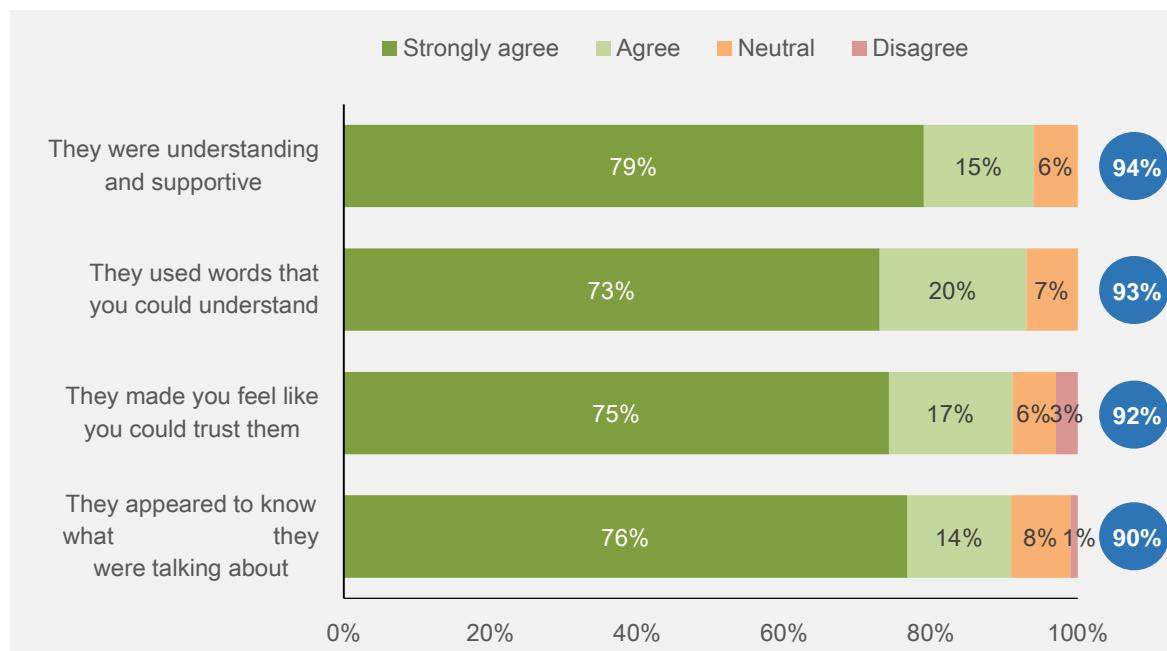
Women whose pregnancy was terminated or whose baby died during pregnancy, were asked to rate the ‘most helpful’ person against a list of four key attributes on a scale of 1 to 5 where 1 = strongly disagree and 5 = strongly agree (Figure 9).

At least 90 percent of women (n=64) agreed or strongly agreed that each of the four attributes applied to their ‘most helpful’ person.

These results are not significantly different to those of the 2011 findings.

Figure 9: Attributes of the person who provided the most helpful information, support and advice when making decision about the pregnancy/birth

Q18, Q56. Thinking specifically about [the most helpful person], on a scale of 1 to 5, where 1=strongly disagree and 5=strongly agree, how much do you agree or disagree that this person ... ?



Base (n=71).

Sub-sample based on women whose pregnancy was terminated due to fetal abnormality, or whose baby died during pregnancy and who provided a response to this question.

Totals may not sum to 100 percent due to rounding.

%

Percent of women who agreed + strongly agreed.

The birth

The care women receive during the birth should help them feel reassured and safe. Women have the right to be listened to, to be told what's happening to them and their p  pi/baby, and to make their own decisions. Care providers should talk with women about their needs and respect their wishes.

The results in this section focus on the birth, including women's views on the birthing location and the information and support that was provided at the time.

Appropriateness of the birthing location

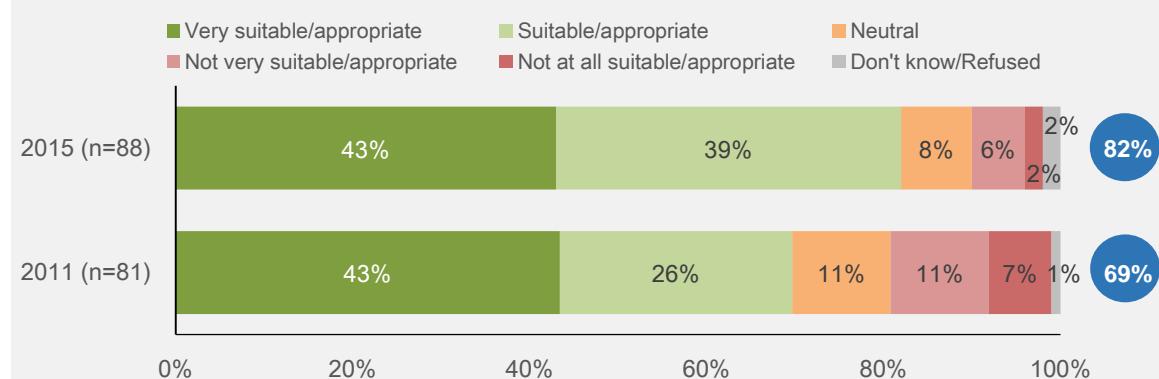
Women whose baby died during the pregnancy, during labour, or after their baby was born were asked to identify where the birth had taken place.³

- The majority (96 percent or n=91) said they gave birth in a hospital. One percent gave birth at a birthing unit (n=1) and three percent (n=3) gave birth somewhere else.
- Two-thirds of women whose baby died during labour or after they were born (65 percent, or n=26) confirmed that they had given birth in the location in which they had originally intended to give birth.

Eighty-two percent of women (n=72) who had a stillbirth (as a result of a termination, or whose baby was stillborn during the pregnancy or labour) felt the birthing location was suitable or appropriate.⁴ This result has significantly increased from the 69 percent of women who felt their birthing location was suitable or appropriate in 2011 (Figure 10).

Figure 10: Perceived suitability or appropriateness of the (still) birth location

Q22, Q58, Q93. Thinking about where the birth took place, how suitable or appropriate do you feel the surroundings were?



Please note: Sub-samples exclude those who had a live birth.
Totals for each year may not sum to 100 percent due to rounding.

% Percent of women who agreed + strongly agreed.

³ Those whose pregnancy was terminated were not asked to identify where the termination took place.

⁴ Those who experienced a live birth were not asked about the appropriateness of the birthing location.

Women who experienced a stillbirth were asked if there was anything they would have changed about the location or surroundings where they gave birth that would make it easier or more appropriate for women in the same situation.

While 45 percent of women (n=41) who had a stillbirth said that they would not change anything, the remainder (55 percent or n=50) offered suggestions in regards to changes they felt could be made to the location or surroundings to make it easier or more appropriate for women in the same situation.

- The most common suggestion was in relation to their proximity to other mothers and newborn babies (this was mentioned by 22 percent, or n=20 of those who experienced a stillbirth):

I found it really hard going back through the maternity ward to the room that I was in. Obviously a way of avoiding that, or being in a slightly separate area would have been better.

Would not put them on a ward where other babies were being born and were alive.

To not be near the maternity ward. It was made even more heart breaking when in bed at night listening to babies crying knowing that you will never hear your own baby cry.

Before I gave birth I was put in a maternity ward with children who were alive; it was really difficult to deal with. I don't know where else they would put me though. I was told I could not go into the wards because they could not look after me there. It was hard to be in a ward with babies who had survived and were living, it was heart-breaking. But I doubt they can have a ward for women with stillborn babies, [although] that would be ideal.

Knowing that my baby would be stillborn it was difficult being in the standard birthing unit with new babies. Hearing new babies and excited families/visitors was difficult under the circumstances. The nursing staff were very apologetic but explained there was no other birthing suites available for people in our situation.

Not having to walk past other women giving birth to live babies - my room was at the end of the hall.

It was not easy to hear the cries of other newborns.

Ideally if delivering a baby that has died or will die, it would be better to not hear all of the other women in labour throughout the ordeal.

I often avoided walking around the ward, like suggested by the midwives that looked after me in the hospital, as I didn't really want to see the other women, knowing that their babies were most likely fine and healthy. Or to hear the sound of another baby's heartbeat, knowing my child had none.

Be in a room that is away from other babies (alive). It upset me to have to hear women getting monitored and crying babies.

- Five percent felt the surroundings or décor could be more welcoming or appropriate (n=5).

To make it more homely for the mum, I don't know. It was such an urgent [thing]. I don't think a normal mum would have had their baby where I had mine. In the normal circumstances, just [make it] more homely for the mum.

Make the rooms not so gloomy when you know you are going to lose babies.

I felt like I was... it was kind of you had to take these drugs and wait for a long time. It was kind of in a sterile hospital delivery space, I could hear other people around me - I had my own space, of course, my own room. But it was an emotional thing to give birth to your child who you knew wasn't going to make it, and it felt sterile, it would have been nice, [to have] I don't know, something more calming instead of sterile.

- Five percent felt that more/better facilities could have been provided (not only for themselves, but also for their partners) (n=5):

Just the bereavement room that they have, they almost need to make it a bit bigger and a bit more cheerful. It's a little bit away from the birthing unit, like it's down the corridor and in the side, but it's really tiny and really bland. It's just a double bed, a couple of chairs, a shower and toilet, so there's not a lot of room and it's a bit cramped.

Be in a room that has a bathroom; being so emotionally upset I did not like having to go into the hallway and see other women.

[Have a] spare sofa bed or something else [so] that the family member could accompany me during [the] night.

I think that once you find out this information, they need to have an area to take the family. Like an area where the family is told that their loved one has not survived the situation, an area where you actually get to sit down with information all around you.

- Four percent said they felt there should not have been baby pictures and other decorations on the walls (n=4).

Being in a room with breastfeeding and photos of babies and things are not great.

Remove [the] poster at the end of the bed showing [a] newborn baby – [it was] upsetting to look at, labouring with a dead baby.

I guess there was a lot of baby things and posters on the walls for pregnancy. There was just a lot of visual cues to having a baby that was going to be alive, so that was quite hard.

- Three percent would have liked better communication/understanding from hospital staff (n=3).

Also the support staff (cleaners, people delivering food, etc.) seemed to be unaware of our situation and were constantly intruding into the room.

Some were incredibly amazing, but on the other hand, there were some who were not good at all. I did not get the care I felt I needed. My blood pressure was really important, to do with the sickness that I had, and there were times when we were told that my blood pressure had been taken at a specific time, but it wasn't getting done regularly, and it was written on my notes that it had been taken, but it hadn't been taken. There was something taken out [incorrectly] and there was blood on the floor ... I think the other thing was I had a doctor come in that was very particular, because my case was very rare, she wanted my placenta and my blood for research. She woke me up, literally in the middle of the night, to sign for that. It was very inappropriate. I think staff need to be really conscious of timing ... I think generally, the manner of people, there were a couple of people when we got our first scan and it was really uncomfortable for the things she said were just really blunt, the delivery of what she was saying was so important. The delivery of what they're saying to you, to anyone who is losing a child, is really important. A little empathy and the manner of what they say to you, for me, makes such a big difference. The doctors and staff who were that way, made such a big difference [compared] to the ones who weren't that way.

One of the paediatric nurses made a stupid joke (about the boys needing to be Samoan because of their size) which was really inappropriate [given] the circumstances and Dr [Name] had to reassure me that the boys who had been delivered and were being taken to NICU were ok but just needed a bit of help with breathing. She also then asked about their names and when my husband said "[name of child]" she said "Not another [name of child]". This paediatric nurse needs some training on how to speak to people in a sensitive fashion or, better still, not speak at all if she cannot show any empathy for someone else's predicament.

Information and support received during and immediately following the birth

Eighty-four percent of women (n=96) felt that they received all of the care and support they needed at the time of their baby's birth⁵ while 14 percent did not (n=16).

The Sands group was really helpful with their room and packages I received. I loved the packages, they were full of information and had a Certificate of Life for my girl which I thought was amazing and it is currently on her memorial wall. The care I received was more than enough, I appreciate everyone who helped me.

The specialist team at [City] Hospital were all phenomenal and extremely compassionate for which we are eternally grateful.

My support and care that I received during our time in hospital was outstanding. The medical staff were simply amazing.

Women were also asked if they felt they were provided with all the information they needed about what would happen next, following their baby's birth/death. At the time, the majority of women (79 percent or n=90) believed they received all the information they needed. However, in hindsight almost one-half (45 percent or n=52) said that it would have been useful to have received additional information.

- ▼ Nine percent would have liked to have been better prepared for how they might interact with their baby and make memories (n=10).

The suggestions of what we could do to create memories of our baby - photos and who might be able to take them, castings of hands/feet, being encouraged to spend as much time as possible with your child etc. I now regret not having any photos to look at of our baby.

They could provide you with some information. Sands told us different techniques with handling the baby, so how the baby's skin is very sensitive. I think that the hospital could explain it a little bit more.

It would have been helpful to have been given information about making memories with my baby.

More support of sentimental information, i.e. take lots of photos.

Probably some advice to get photos of baby's hands and feet. I never got to see his hands and feet and I wished that I had.

⁵ For those who experienced a live birth, this refers to the point at which their baby died.

I would like to have known that I could have my baby with me anytime. I just had to ask for her, I didn't realise this until the last day when I was discharged. Also, however silly it may seem professionally, skin to skin contact is important for the mother, even if baby has already passed.

Potentially more information given to me in person regarding keepsakes, it's a Sands thing. They have a Sands box that has all the information, but if staff could encourage more keepsakes, as some are time-oriented, [and] sometimes it's easier to get them earlier on.

Just to sit and understand what could be done before you buried your baby or sitting with an experienced bereaved mother to know there are opportunities to have feet cast, or photos taken. Once your baby is cremated/buried it's too late and those memories can't be bought back. It is so important. Giving someone pamphlets at a time like this which is the last thing they want to read is a waste of time for the things which need to be done immediately.

[I was] told of what would happen for medical purposes but not really advised of what we could do if we wanted to for bonding purposes. [We had] some things done but maybe a better checklist should be in place - things I know were offered to other mums but not me.

- Eight percent of respondents (n=9), said it would have been good to have known about Sands NZ earlier, or to at least have a counsellor or support person available to them – someone who understood what they were going through.

The post care, I think, Sands were amazing, their care box, and reading materials were amazing. I think at that time of grief, you are vulnerable, you can't go to ask anyone. I think I would have appreciated if someone had rung me, to see if we want to go for a coffee, have a chat, because you just don't have the strength to make that first point of contact, instead it would be good for someone to contact you first.

I think for me funeral options, like for example I didn't know there was a place where you can take your baby yourself for cremation; I got a list of like funeral homes and stuff but just a bit more information with what options you can have. I think Sands would be another good source for it because they know so much, so just really talking to a Sands lady, that someone visits you straight after and maybe instead of the social worker to give you a bit more options.

Basically having Sands there, they didn't tell me that they had existed, a lady told me, who also lost a baby, about Sands. So I recommend that they should have Sands at all hospitals.

I think sometimes you need, not necessarily like a social worker, but a mother who's been through it to come see you. I had a friend who had lost a baby around the same time, and she was very helpful, and you can't always talk to your parents about it. Even if they did lose a grandchild it's a different kind of hurt.

As I was leaving hospital on a Sunday there is no social worker available. I think there should be one available 24/7 at the ward! As I left [I was] very emotional and not knowing if there was any services to talk about things e.g. counsellors.

Better explanation of what the after care should be. How many visits, when, who from. Better counselling services, to be offered by the health service.

- Eight percent would have liked more information about the funeral preparations (i.e. where to go, who to contact, what happens with the body etc.) (n=9).

Information about what would happen to my baby in the next few days prior to cremation - what to organise e.g. funeral director, birth/death certificates.

How to contact the undertaker, where baby could be buried. I found this out by reading through a pamphlet but it would have been helpful if the nurses could've told me.

Some better descriptions of funeral and cremation options.

Transportation of her body – [Name] died in [Town/City] and we were from [Town/City]. The only option we were given (perhaps due to time constraints?) was to transport her body in a cardboard box - this felt a little 'clinical'. When we arrived at the cargo counter at Air NZ, they didn't know how to deal with the situation - and they were very unprepared, which meant they were very insensitive.

We were not aware that we could take baby home. In our emotional state we did not ask nor check on this and assumed from our chosen option he had to stay at the hospital and go into the morgue, then crematorium. We realised later that we could have brought him home and chosen what to do from there.

There was some basic info but little things that would have helped would have been knowing the cost of cremation etc. as we were on one wage as this was our second child so wasn't sure if we had the money (expecting it to be hundreds) only to finally find out it was only around \$30.00.

- ⦿ Five percent said there was a need for clear, consistent, step-by-step information about what would happen next and what they had to do (n=6).

I don't think they explained [things] around the autopsy, and what that would mean, or what would actually be done, and how fast they had to do it. They didn't explain enough about what we were entitled to, to pay for funeral costs or anything either.

I come from a medical background. I had a lot of questions about what was happening and nothing was answered, it wasn't fully looked in to. Staff did not know how to deal with us before and after.

The process of investigation etc. written down and given to me along with contact details for those I could follow up with (email would have been especially helpful as talking on the phone was difficult).

- ⦿ Three percent (n=3) mentioned that the length of time it takes to receive autopsy results is very long. Understanding why their baby died is very important and so the wait was very difficult.

Baby had to be sent away for an autopsy, bloods and that. Not much you could change, but if they can shorten the time [between] when baby passed away and telling you why baby died that would be good; it's just that if they can be shortened it helps the grieving. I waited for like three and half months before I heard about anything that happened and that's a long time to wait.

One of the frustrating things that we found was that we consented to a post mortem, and then we were told it could be several months until we got the results. So that was difficult. When I was trying to get the results and they said they hadn't arrived, and then all of a sudden they were sent within half a day to the specialist. Initially they were up to ten to twelve weeks to get the results, and of course [baby] died on the [date], and New Year's is a long time to wait. All we wanted to know was what had happened.

Maybe to keep in contact, it might be nice to have some information. We get didn't get the autopsy results until 13 months later, it took a very long time, they said it was due to a paperwork problem.

- ⦿ Three percent would have liked practical information about the birth and after-effects (i.e. some were unprepared for the physical pain involved with the birth, the milk flow, etc.) (n=3).

To do with baby, everything was taken care of. To do with me, my milk came in [and] I couldn't do anything. They did offer me pamphlets to take. My midwife said that she was there to help me, but she wasn't. Maybe if they gave me something to read, how to help myself was all I wanted to know. [There was] nothing for me to read, it was around Christmas time and I would have had to pay for after hours. They did give me medication and things like that but when you're in mourning, your world is

upside down and you don't care. Something to read, following discharge [would have been good as I] didn't know half the stuff, it was just blur, blur, blur.

How hard it was to push out a baby that wasn't moving on its own. The cord being short at 21 weeks, the pain. I was never given pain relief and I was left to pretty much labour on my own considering I have tachycardia.

I found it difficult to get information about how to dry up my milk supply as hospital midwives would not come to see me. Our baby was in PICU in [Hospital] and the nurses there were extremely helpful. It wasn't in their area of expertise but they did manage to find me a hand expresser to take home to help me dry up which was extremely helpful. It felt to me that as soon as the hospital midwives heard I wanted to stop my milk supply they weren't interested in helping me - never mind that the request came from PICU and obviously something traumatic was taking place. This was very distressing and made what was happening so much more difficult.

- Two percent said they would have liked clear, unbiased advice on the positives and negatives of having a post-mortem or autopsy (n=2).

I was told by several nurses/midwives that the autopsy wasn't necessary, as in most cases they find no cause of death. I feel that this advice is not appropriate, women should not be convinced either way.

It would have been good to know what kind of time restrictions there were, for example, is it better to do a post mortem as soon as possible, or does it not matter if it is a bit delayed, and how rapidly the body would deteriorate.

- Two percent were satisfied with the information they received, but felt it would have been much more useful if they had received it earlier (n=2).

I think the only thing I would say was that after it all happened, they said did you want your husband to stay the night and because it was overwhelming and things, if we had known beforehand, that my husband could stay, we would have made arrangements to come with a birth bag, but they didn't say it till after the birth of the baby. It was too far to go back home to pack a bag, and my husband didn't want to go shopping for new clothes. Just advance notice on hubby being able to stay at the hospital would be good.

Most helpful or supportive person

Women whose pregnancy was terminated due to fetal abnormality (n=19) were asked who provided them with the most helpful information or support following the termination.

Most felt that their midwife was the most helpful or supportive person during this time (n=12 or 63 percent). Others found that family and friends (n=6 or 32 percent), Sands (n=6 or 32 percent) or an obstetrician (n=5 or 26 percent) helped them through this time.

One hundred percent of women whose pregnancy was terminated said that the 'most helpful' person was understanding and supportive (n=19). Women also said that this person appeared to know what they were talking about (95 percent or n=18), used words that they could understand (95 percent or n=18) and made women feel like they could trust them (94 percent or n=18).

Memory making

Almost all women (98 percent, or n=112) were given the opportunity to take something as a memory of their baby (i.e. hand and footprints, photographs, a lock of hair). This is similar to the 97 percent of women who were given the same opportunity in 2011.

- Ninety-two percent of women (n=105) said that they did take some form of memento or keepsake of their baby.
- Six percent chose not to take anything as a keepsake (n=7), whilst the remaining two percent were not provided with the opportunity to do so (n=2).

The hospital or birthing unit stay

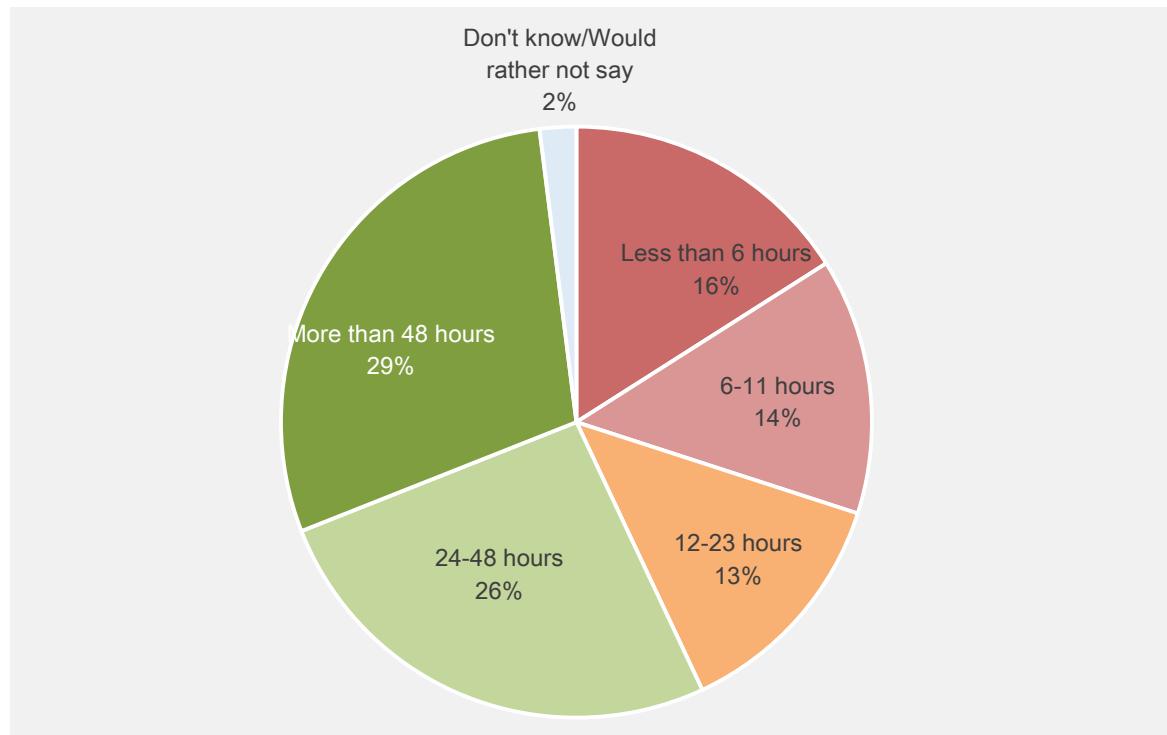
The results presented in this section will help the Ministry of Health to improve the way in which bereaved mothers are cared for in hospital or at a birthing unit immediately after birth.

Length of stay

Women who gave birth in a birthing unit or at a hospital were asked how long they stayed after they gave birth (Figure 11).

Fifty-five percent of women stayed in a hospital or birthing unit for at least 24 hours after they gave birth (n=47), with 29 percent remaining for more than 48 hours (n=30). However, 30 percent left the hospital or birthing unit within 12 hours of giving birth.

Figure 11: Length of stay in hospital or a birthing unit after giving birth



Base (n=105).

Please note: Women who did not give the response options 'At a birthing unit' or 'At a hospital' in response to the question "Where did you give birth?" were not asked about their length of stay in a hospital or birthing unit.

When they left the hospital or birthing unit, most women (79 percent, or n=83) felt they were ready to do so.

Of the fifteen women who felt they had left before they were ready, four said they had left because they were discharged (e.g. the hospital was too full) and three left because they did not like the hospital environment. Another four women said they did not feel ready to leave because they were struggling emotionally to deal with the fact that they would be leaving hospital without their baby, while others left because they had other responsibilities (n=2).

I felt that we were in a bereavement room - the staff were nice but we felt that we were supposed to leave by that time. Our children were being looked after by friends and we had to get back to them but I felt I would have liked another day - given all the questions and everything - dealing with the death that was still ongoing. To have a whole day and not have those questions would have been good - I had also had surgery and had not eaten so physically it would have been a good idea. It was quite tiring.

I would've liked it to have been longer, because then we would've just had longer with him before we had to come home, because we weren't taking him home with us. I suppose we just wanted it set out as an option for us to stay another night.

They made me leave.

I felt obligated and expected to leave.

I felt out of place in the maternity ward having a still birth.

It was more being not emotionally ready to leave our little girl behind. It didn't feel right leaving her.

No, I don't think you ever can. [You] don't want to leave your baby behind.

Medically I was ready to go home, I had other responsibilities at home, but my baby was in NICU so that was pulling me also.

Satisfaction with care received at a hospital or birthing unit

Women who gave birth in a hospital or birthing unit were asked to rate their satisfaction with the overall level of care they received, as well as different aspects of care they received while they were there. This was based on a 5 point scale where 1 = very dissatisfied and 5 = very satisfied.

Eighty-one percent of women (n=85) were satisfied or very satisfied with the overall care they received at the hospital or birthing unit, with more than one-half saying that they were very satisfied (57 percent or n=60).⁶

The staff at the hospital were amazing. [They were] very caring and supportive of whatever we wanted to do. We could hold our baby and have him in the room for as long as we wanted and when he wasn't in the room, they assured us he was taken very good care of. They didn't rush us to make any decisions and gave us all the information we needed and answered all our questions. With me, it wasn't a case of there being anything wrong with our baby, it was a problem in the pregnancy so the obstetrician was great at explaining how it all happened and making it easier to come to terms with.

At least one-half of women were very satisfied with the following aspects of care they received while in the hospital:

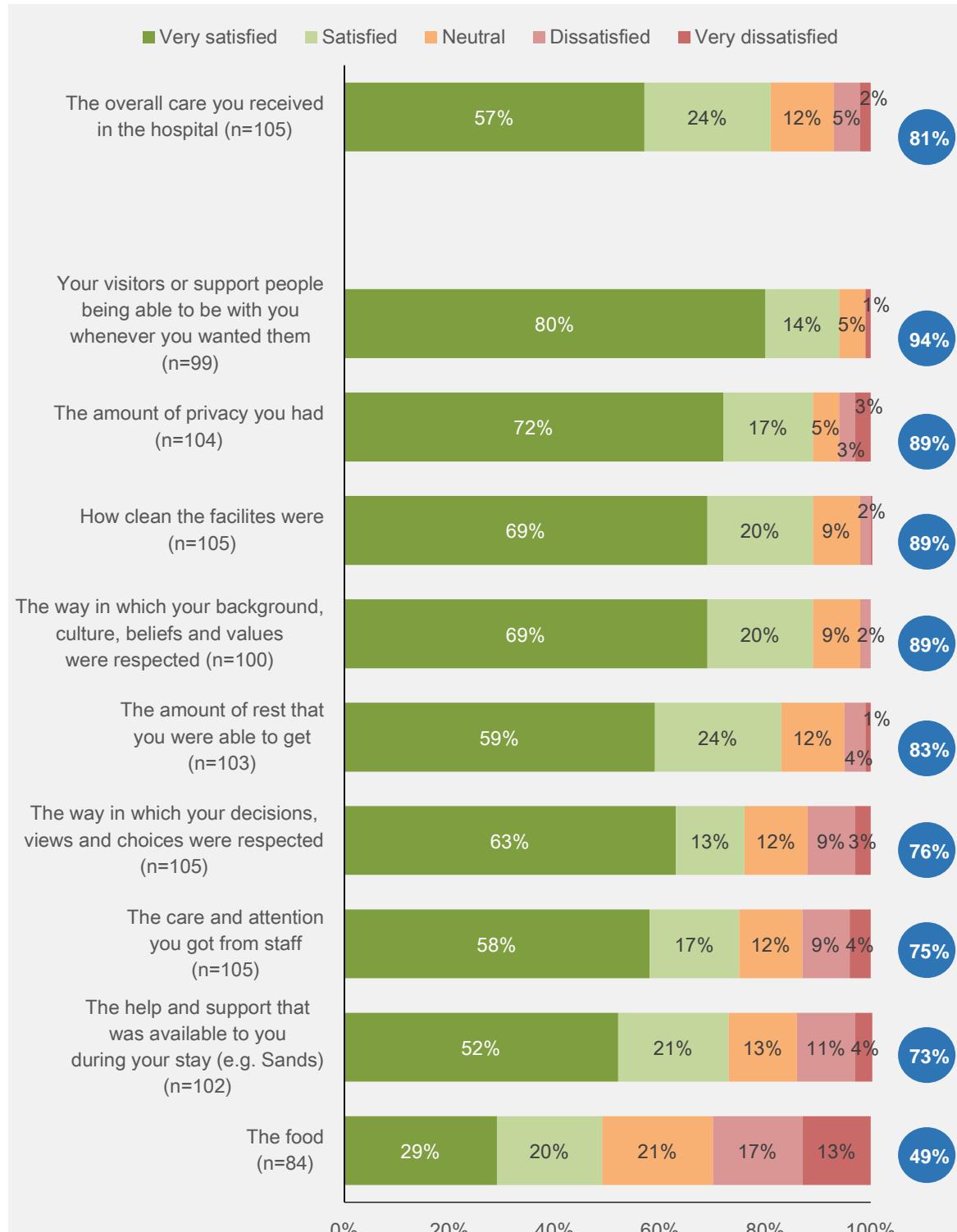
- Visitors or support people being around whenever women wanted them to be (80 percent or n=79).
- The amount of privacy they had (72 percent or n=75).
- The cleanliness of the hospital (69 percent or n=72).
- The way in which their background, culture, beliefs and values were respected (69 percent or n=69).
- The way in which their decisions, views and choices were respected (63 percent or n=66).
- The amount of rest they were able to get (59 percent, or n=61).
- The care and attention received from staff (58 percent, or n=61).
- The help and support that was available to them during their stay (52 percent, or n=53).

Women were less satisfied with the food they received during their time in hospital (49 percent were satisfied or very satisfied with the food they received, 30 percent were dissatisfied or very dissatisfied and 21 percent gave a neutral rating).

⁶ These questions were changed between the 2011 and 2015 surveys therefore no comparisons are made between these results and the results from the 2011 survey for this question.

Figure 12: Satisfaction with care received at the hospital or birthing unit

Q37, Q74, Q109, Q128. Thinking about your overall hospital experience, how satisfied were you with each of the following?



Totals may not sum to 100% due to rounding.

Please note: sub-samples are based on women who gave birth in hospital or a birthing unit and excludes those who said 'Not applicable' or did not provide a response to this question.

%

Percent of women who were satisfied + very satisfied.

Understanding why the baby died

It can be important for parents to find out more information regarding their baby's death. Further diagnostic testing or a post-mortem examination may help to determine why the baby died. Knowing more about baby's death may help with the grieving process. Women should be provided with enough information and support so that they can make decisions that are right for them and their whānau/family.

This section looks at the information provided to women and their decisions about further testing to help them understand why their baby had died.

Provision of information as to why the baby died

Women whose baby died during the pregnancy, labour or after the birth were asked if they felt that they were given enough information or explanation about why their baby had died. While 68 percent felt that they received enough information (n=65), one-in-four (27 percent or n=26) did not.

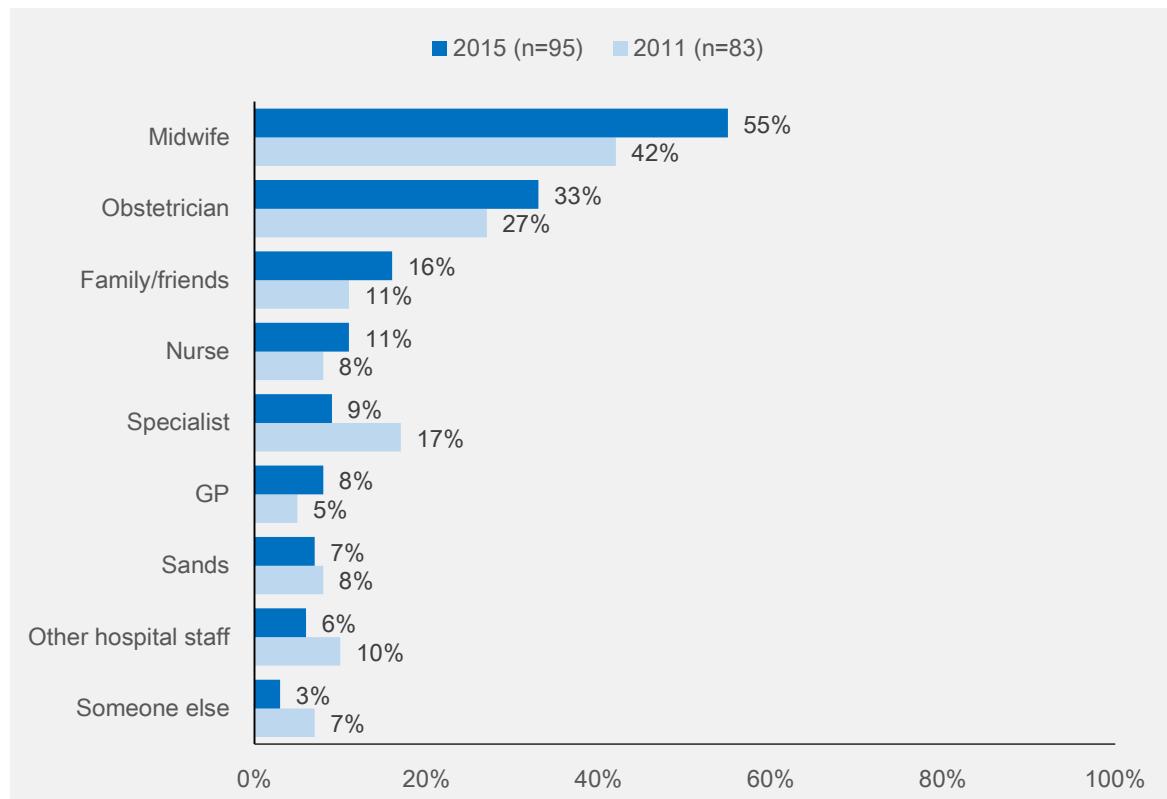
- ▼ These results are similar to the 2011 findings where 65 percent of women felt they received enough information or explanation as to why their baby died.

Of all the people who provided support and information at that stage, more than one-half of women identified their midwife as being the most helpful (55 percent or n=52). Thirty-three percent identified their obstetrician (n=31), 16 percent their family and/or friends (n=15) and 11 percent a nurse at the hospital (n=10).

- ▼ Although the 2015 results may seem different to those of 2011, the differences are not statistically significant.

Figure 13: The person considered to have been the most helpful in providing information and support following baby's death

Q72, Q107, Q147. Of all the people who provided you with support and information at that stage, who would you say was the most helpful?



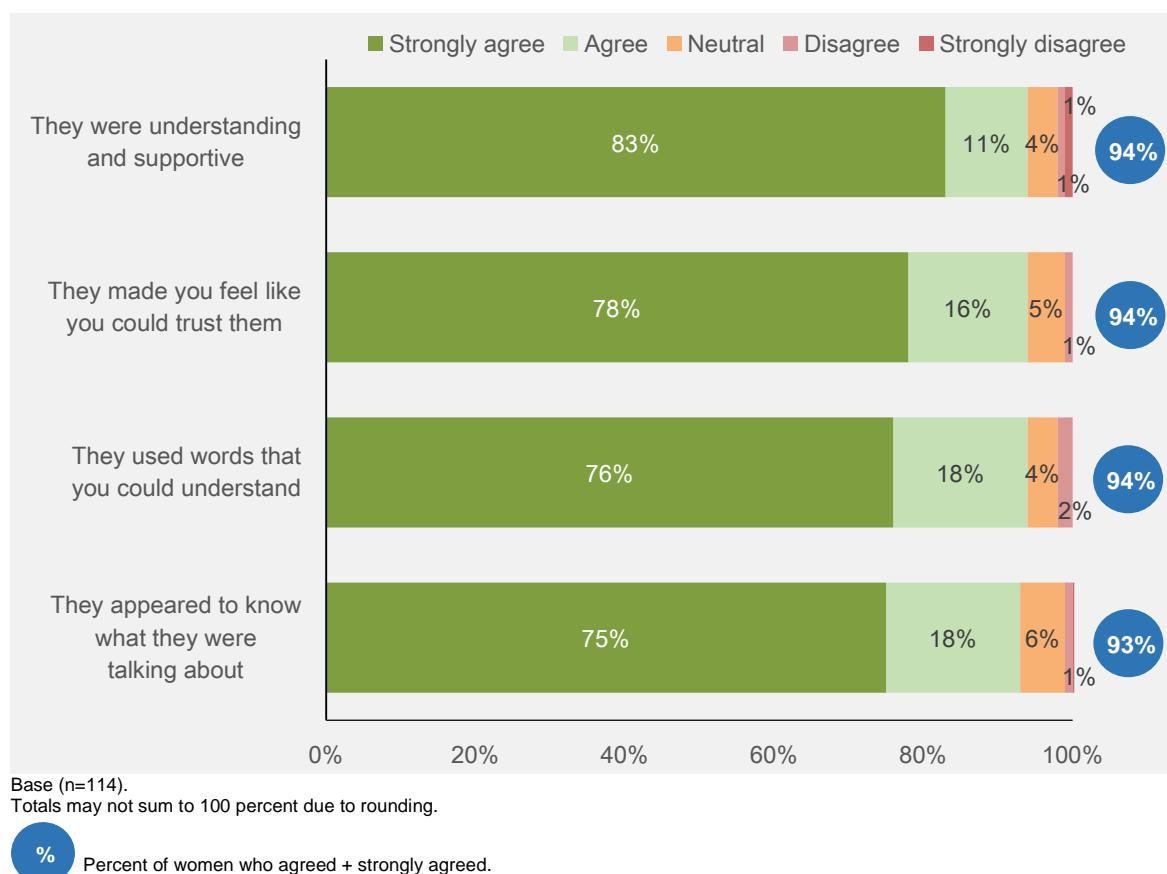
The totals for each year will not sum to 100 percent because women could provide multiple responses to this question.

Women were also asked to rate the ‘most helpful’ person in relation to four key attributes, on a scale of 1 to 5, where 1 = strongly disagree and 5 = strongly agree (Figure 14).

The ‘most helpful’ person was rated highly in relation to all of the key attributes measured, with women being most likely to strongly agree that this person was understanding and supportive (83 percent).

These results are also similar to those recorded in 2011 as the majority of women agreed with each of the statements regarding their most supportive person (in 2011 between 86 percent and 90 percent agreed or strongly agreed that the ‘most helpful’ had the four key attributes measured).

Figure 14: Key attributes of the person considered to be the ‘most helpful’



Further diagnostic testing

Following the baby's death, one-half (51 percent or n=58) of women were asked if they wanted further diagnostic testing to be carried out.

- ⦿ Of the 58 women who were asked if they wanted further diagnostic testing, 78 percent decided to have further tests done (n=45).
- ⦿ Of the 56 women who were not asked about further diagnostic testing, 12 percent said that they would have liked more testing to be done (n=7), while 77 percent did not want further tests to be done (n=43).

These results are not significantly different from the 2011 results.

Post-mortem examinations

Following their baby's death, the majority of women (82 percent or n=94) were asked if they wanted a post-mortem to be carried out to determine the cause of death.

- ⦿ Of the 94 women who were asked if they wanted a post-mortem to be conducted, 67 percent decided to go ahead with it (n=63).
- ⦿ Of the 20 women who were not asked about a post-mortem being carried out, only 10 percent (n=2) said they would have liked a post-mortem to have been done. Eighty percent said they had been asked, they would have declined (n=16).

The n=31 women who decided they did not want a post-mortem conducted were asked to identify their reasons for this.

- ⦿ Twenty of the women who did not want a post-mortem, felt that it was not necessary as they already had all of the information they needed regarding the cause of death:

There was no point since the genetic test was clear. Even if there was a mistake, I wouldn't want to know post factum.

It wasn't necessary because we already knew she had Triploidy Syndrome.

We already knew why he died, he got an infection and we just left it up to them.

Because we already knew that she died from complications.

I knew there wasn't anything medically wrong with her. She was perfect, no abnormalities run in our family, other children [were] healthy. It was labour, not health, that was the cause of death.

Because it was obvious why he was going to die. We already knew if he survived the birth, the doctor said that he would only survive a matter of minutes or an hour. So we already knew why.

Because we understood why he died, we knew he had the information. The doctors explained to us, from that initial diagnosis, what his chances of surviving were, even if it looked like he seemed to be doing well, he was getting worse. It was his heart, because there was a hole in his heart he couldn't cope, so it all made sense to me. The morning they called us about 4-5am, it was clear to us that he wasn't coping. My husband is a doctor and basically said that this was it, so I accepted it.

The baby was healthy, it was the placenta and [blood] vessels which ruptured and depleted our baby of blood.

We understood the life-threatening condition that our daughter had before she was born.

We knew already from the specialist why she had passed.

We accepted that it was his umbilical cord which took his life as when he was born it was wrapped around his neck three times and the midwife had to use her little finger to rip it off.

We knew what was wrong and could clearly see when she was born.

- ⦿ Eight women said they chose not to have a post-mortem conducted because they were uncomfortable with the procedure:

We considered [that] nothing was to be gained by having our baby undergo a post-mortem, and did not want him to be 'cut-up'. I understand that the post-mortem would have been done with the greatest of care and respect but I did not want it for our child.

Because I knew what had happened and I didn't want my baby to be cut and poked anymore. I just wanted him peaceful and with me.

I didn't want my child to be cut up. I already knew [what] he had died of. He'd already suffered, so I didn't want him to suffer more.

I didn't get a post-mortem done, it was external not surgical. I did not want to cut up my baby. Just took swabs and tests on the outside but nothing done on the inside.

Personally, we didn't like the idea of our precious wee man being touched - we did let the placenta get examined and felt content with any knowledge this could bring.

My son passed away and there's nothing we could do to bring him back! We didn't want anyone touching his body and wanted to bury him the way he came into this world.

- Two of the women explained that a post-mortem was against their religious or cultural beliefs:

This could be a cultural belief; my babies were born as a whole, they were complete, and I didn't see the need to dissect them or remove anything from them. I wanted to keep them intact and bury them intact. I was informed before on what the condition was, we didn't really need anything else to know what had happened.

Because it's my belief and I'm against it, and I don't want my baby to be cut up.

- Two women chose not to have a post-mortem as they felt the results may not have been conclusive:

Was told it probably wouldn't provide any further information. Placentas were sent off for testing.

We were told that generally in most cases with stillborns you can see if the baby's not well or if there's something wrong with it. Because he looked perfectly healthy we weren't worried, but the placenta didn't look right and we later found that a part had gone grey and had started to die, had collapsed in its own weight.

- One woman, and her husband, did not want to be parted from their babies, they wanted to spend time with them:

My husband did not want our babies taken away.

Support received following the loss

This section looks at the support women and their families received in the days and weeks that followed the loss of their baby.

Contact and support received

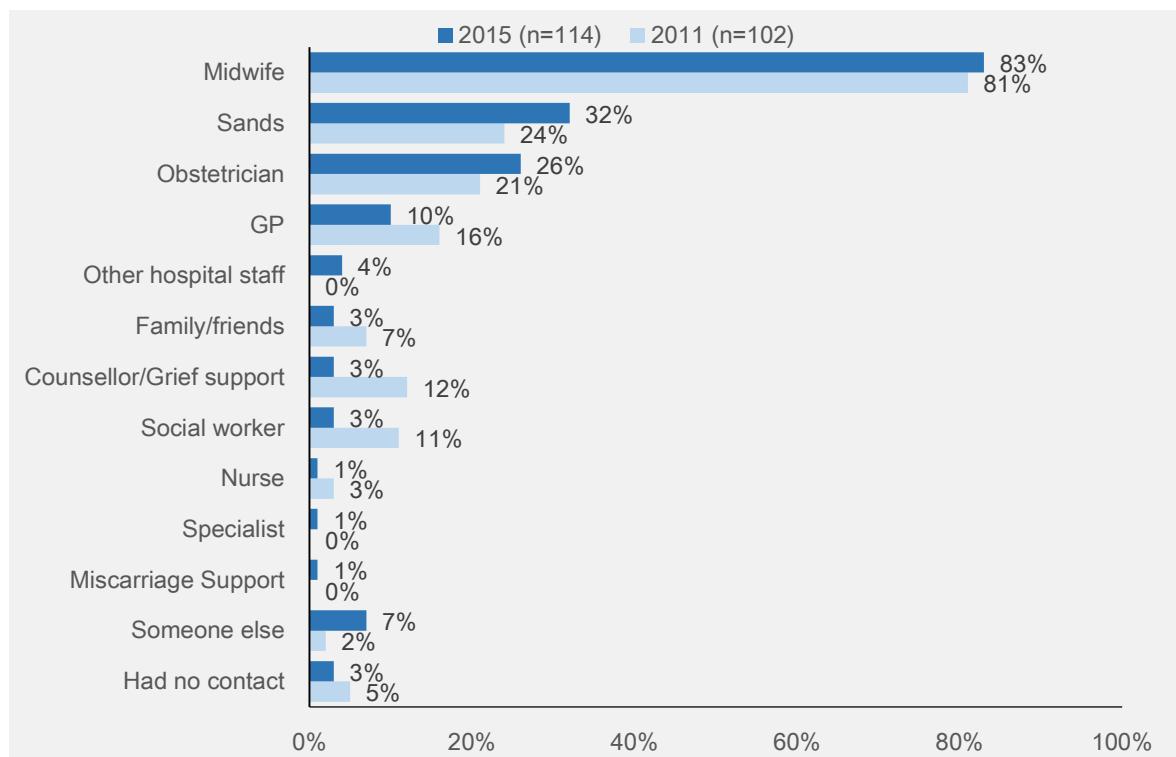
Ninety-seven percent of women (n=111) received some form of follow up contact after their baby's birth/death.

As illustrated below, in the days or weeks that followed the loss of their baby, most women were contacted by their midwife (83 percent or n=95), Sands (32 percent or n=37), an obstetrician (26 percent or n=30), and/or their family doctor/GP (10 percent or n=11).

The current results show that only three percent of women reported being contacted by a counsellor/grief support person or a social worker following the loss of their baby. This is significantly lower than in 2011 (in 2011, 12 percent reported being contacted by a counsellor/grief support person and 11 percent reported being contacted by a social worker).

Figure 15: Contact received in the days and weeks following the loss

Q41, Q78, Q113, Q149. After you left the hospital [In the days and weeks that followed], did you receive any contact from your LMC, other health professionals or support agencies?



The totals for each year will not sum to 100 percent because women could provide multiple responses to this question.

When asked to identify which of these people was the most helpful or supportive during that time, 71 percent mentioned their midwife (n=81), 17 percent said Sands (n=19) and 11 percent identified their obstetrician as the most helpful (n=13).

They were also asked if there was any additional contact, information or support that they would have liked to receive at the time.

Although one-half (54 percent, or n=62) of all women said they did not need any additional information or support, one-in-three (34 percent) would have liked more.

- Ten percent said that they would have liked some form of counselling to help them with their grief (n=11).

More counselling at the time from hospital. I needed more. Work were very supportive - both my partner and I had counselling through the week of dealing with our loss but we were never offered [it] from the health service.

It would have been good for someone to come and see us about the grief counselling. I ended up waiting three months to get some help there. Even just a routine medical check-up would have been good, with all your bloods to make sure you're recovering properly. The Ministry [of Health need] to consider when you go through a loss like that, it's quite normal that you have a long period when you feel quite down. Although grief counselling can help that process it would be good to have a process to help you get back to life again, to help you back to how life is again. Maybe back to fitness or back to life. The grief counselling only really helps you to have someone to talk to, and having someone to talk to doesn't really get you out of the gloom. All of your friends and networks carry on, they've got kids and life to work with, and they aren't always there for you. I am not good at asking for that sort of support, so it would have been nice to have more of that, more of a hands-on help.

Free counselling would have helped.

I think that potentially some kind of counselling. My GP ended up organising counselling for me and my husband, but only because she found the initiative to. I think it could be organised by the hospital. I think after any loss of a child, if that could be provided, that could be really beneficial.

Some counselling would have been good. I am not quite sure what else is available.

Mental health/specific grief counselling - this is severely lacking. I suffered from severe depression afterwards, [and I] lost my job as well. There was absolutely no medical support from PHO or otherwise. I saw my GP who sent requests to PHO for counselling, but I had to end up paying for private counselling as they took so long to contact me.

I feel there needed to be more support for bereaved parents who are not based in a main centre ... I was coping ok - but felt I needed somewhere/someone to talk to,

without feeling like I was burdening my friends and family. I attended one session with the counsellor - I didn't connect with her. I knew another private practice counsellor who I would have loved to see (who had worked with the [Town/City] Community Mental Health team prior), however I wasn't able to transfer my funding to her. This meant that I didn't continue seeing anyone and I still feel like it'd be great to see someone, but not really sure how to go about this. I am an educated, strong and self-aware person - I know how to access the support I need (generally!). I fear for the long-term impact of something like this happening to a mum who isn't as strong as me, or who doesn't have the family/friend support.

- Eight percent would have liked to have received follow up contact from the hospital (n=9).

Information from the hospital about the ongoing investigation as I felt I left the hospital and was forgotten about. I had no idea what was going on and neither did my husband or family.

Probably just a follow-up from the hospital, and then obviously an explanation from the scan people.

I had to ring MFM in [Town/City] to get post-mortem results and to make a follow up appointment. The doctor who was looking after us had left and I think our file was forgotten.

Further contact from the DHB. I was advised at a follow up consultation (six months after my daughter was born) that we had been forgotten and had slipped through the cracks. Contact was only made by the hospital team after I tried to obtain the files for a private consultation. The hospital need to keep better contact with the parents so they are aware of what's happening with the results of their child's case and when they might expect to have their questions answered. Also, [it is] not clear who at the hospital the parents should direct any query to if they are waiting.

I was given a call by the hospital at about six weeks afterwards. It would have been good to receive this call slightly earlier (e.g. around two weeks) as that is when life is starting to go back to 'normal' (i.e. return to work etc.) and six weeks kind of seemed like you had been forgotten about. We also met with the specialist and midwife at the Maternal Fetal Medicine Unit at about six weeks, which was great - a chance to have any final questions asked and put to rest.

- Seven percent would have liked to have had contact from Sands NZ (n=8), particularly in the early days following their loss.

A call from someone who has been there and gets it, just to know you are not alone. Sands is such a big organisation it's daunting to make that first call.

Maybe from Sands; some further information at that stage. Basically from what I can remember they show up, they give you a basket with everything you need to bury your baby and then you don't see them again.

It's hard to say, you need time to process what has happened and family was great but it could have been good to have someone like Sands call and just have a chat. I know I could have called them but I didn't, but had they called me, I probably would have talked to them about it.

I kind of wonder, Sands the stillbirth association. I opted not to be involved with them because I go to church and they were very supportive of me. I just wonder if they had contacted me, like reaching out. I felt like I was on my own for a while. I thought of contacting them but I got busy. Just think that it would be nice if Sands contact people during this time.

The SANDS info pack would have been great earlier. It would have been good to have been put in touch with other couples who had experienced similar.

- Four percent would have liked to have received contact from their LMC (n=5).

I would have liked my midwife to be a part of my [recovery].

Not really but would appreciated if my initial midwife, if she [had] called or at least texted me.

I only had two visits from the midwife. I told her I was ok, but I wasn't really. It was my fault that I didn't get more help at that time because I didn't ask for it. I knew I could have rung the social worker at the hospital for more help and support but I didn't because I thought I was ok, but I wasn't really. Maybe if she had rung me, maybe I would have opened up to her. I always felt like my midwife was in a rush when she came to visit me so I didn't confide in her as I didn't want to trouble her, she seemed so busy.

Overall satisfaction with the care received

This section summarises women's overall satisfaction with the overall level of care they received prior to, during and following the loss of their baby.

Women were asked to rate the overall care they received, taking into account their experience prior to, during and following the loss of their baby. This was measured on a scale of 1 to 5 where 1 = very dissatisfied and 5 = very satisfied.

Three quarters of women (74 percent, or n=84) were satisfied or very satisfied with the overall standard of care they received.

We received such excellent care. The nurses at the hospital were kind and caring. We felt very looked after in every aspect.

The care that I got was really quite outstanding.

Overall, I was satisfied and felt very supported. It's hard to answer the questions with 'very satisfied' considering the circumstances as it was a devastating experience.

These results are not significantly different from the 2011 survey where 67 percent of women reporting being satisfied or very satisfied with the overall care they received.

Figure 16: Satisfaction with the overall standard of care received prior to, during, and following the loss of the baby

Q152. Taking everything into account, how satisfied are you with the overall standard of care that you received prior to, during and following the loss of your baby?



Appendix A: Pre-notification letter



Sands
25 years of being there

Dear

Re: Maternity Services Feedback Survey – Survey of Bereaved Mothers

We are aware that in 2013 you experienced the loss of your baby – please accept our sincere sympathies. We are writing to invite you to take part in a national survey about your maternity care during your pregnancy and the support, care and information you received during and after your loss.

As you may be aware, your child's passing was reviewed in great detail at the time by the team involved, by their peers within a couple of weeks of the event at the DHB level, and finally by the Perinatal and Maternal Mortality Review Committee (PMMRC). This survey is not to determine what happened to your baby specifically, but more how the process was for you and your family. We want to know how to support families through this ordeal, and your insight and feedback is very important.

If you feel straightaway that this is not a project you would like to be involved in or if it is not the right time for you to talk about your experiences, simply ignore this letter.

The Ministry of Health is working alongside Sands New Zealand to make changes and improve services if necessary. Sands is an organisation that provides support to parents and families who have experienced the death of a baby.

Research New Zealand, an independent research company, has been contracted by the Ministry of Health to conduct this very important piece of work.

Taking part in the survey is voluntary and involves a 15-30 minute telephone interview that will include questions about maternity care during pregnancy and the care, support and information received during and following the death of your baby. Your responses are confidential. You will not be identified in any way.

If you would like to talk with someone about the project before deciding to take part, we are happy to answer your questions. Please ring Linda Penlington at Sands on (04) 379 9073 or 021 297 4801, or Laura Ross at the Ministry of Health on (04) 816 2162. If you would like to speak to someone at Research New Zealand, please call 0800 500 168 and ask for Katrina Magill.

If you are willing to take part in this research, please complete and return the consent form below to Research New Zealand and one of their interviewers will contact you to arrange a convenient time to complete the survey by telephone. The form can be posted using the enclosed reply paid envelope or you can email your consent to katrina.magill@researchnz.com

Or, if you prefer, you can complete the survey online, by going to www.researchnz.com and selecting 'The Bereavement Survey' under 'Current Online Surveys' (or scan the QR code below using your Smartphone or tablet) and entering this ID number: **BER2455** and password: **DGWNJUS**.

The online survey will be open until the 7th of April 2015. Please take this opportunity to have your say.

Yours sincerely



Chai Chuah

Acting Deputy Director-General
Ministry of Health

Linda Penlington

Sands New Zealand

CONSENT FORM:

(Please the box below if you are willing to take part in this survey)

Yes, I would like to take part in the Survey of Bereaved Mothers.

The best number to contact me on is: ()

Office use only:

Appendix B: Questionnaire

Appendix C: Methodology

This section provides a detailed description of the development and implementation of the 2015 Bereaved Women Survey.

Survey design

The Survey of Bereaved Women was first carried out in 2011 and, at the time, was the first survey of its type to have been undertaken in New Zealand.

Particular care was taken in the development of the original questionnaire in 2011 and as such, minimal changes were made for the 2015 survey. The changes that were made, were done so to allow comparisons with the results of the 2014 Maternity Consumer Survey (this is a national survey of women who had live babies).

A copy of the final survey questionnaire is included in this report as Appendix B.

Recruitment and methodology

This survey received ethics approval from the Southern Health and Disability Ethics Committee (reference: 14/CEN/160).

Following ethics approval, the 2015 survey proceeded as follows:

1. The Ministry of Health provided Research New Zealand with an electronic file containing the names and addresses of 421 women who had experienced a perinatal death⁷ two years prior (in 2013), from the National Mortality database.
2. An invitation letter was posted to all women to the address they had provided at the time of their baby's death.

The invitation letter introduced the survey and explained what taking part would involve. A consent form was also attached to the letter. Those who wished to complete the survey by telephone were asked to sign and return the consent form and to provide the telephone number (either a mobile or landline number) on which they wished to be contacted.

The letter also provided instructions on how to access the survey online, if they preferred to complete it electronically.

Although no reminder calls or reminder letters were sent, a second letter was posted shortly after the initial invitation letter when it was discovered that reply paid envelopes had not been included in the initial mailing.

⁷ Perinatal deaths are those which occur between 20 weeks of pregnancy and up to 28 days after birth.

3. The survey was 'open' online from the 20th of January 2015 until the 13th of April 2015.
4. For those who wanted to complete the survey over the telephone, a minimum of five attempts were made to contact each bereaved mother once they had provided their consent. These attempts were made on different days and at different times.

The interviewing team was extensively briefed by Sands NZ prior to the telephone interviewing.

At the start of each interview, interviewers asked respondents to re-confirm their consent to complete the interview. At the end of the interview, respondents were informed that if they wanted to talk to someone about their loss, they were welcome to contact Sands NZ or if they preferred, Research New Zealand would arrange for a Sands NZ representative to contact them.

Participation rates

Of the 421 women who were invited to take part in the 2015 Bereaved Women Survey, 114 women completed the survey. More than one-half completed the survey online (57 percent), while 43 percent completed the survey by telephone.

One-in-two women lost their baby during pregnancy, while one-in-five lost their baby after he or she was born. A further 17 percent terminated their pregnancy for medical or health reasons and 15 percent lost their baby during labour.

Table 3: Number of completed surveys by channel and when baby died

	2011 Count	2011 %	2015 Count	2015 %
Online	-	-	65	57
Telephone	102	100	49	43
Pregnancy was terminated for medical or health reasons	19	19	19	17
Baby died during pregnancy	53	52	55	48
Baby died during labour	9	9	17	15
Baby died after he or she was born	21	21	23	20
Total	102	100	114	100

The overall participation rate⁸ for the 2015 surveys was 27 percent (Table 4). This is an improvement on the participation rate of 18 percent in 2011.

⁸ As this was an 'opt-in' survey, only a participation rate can be calculated.

Table 4: Overall participation rates by year

	Number of completed surveys	Participation rate
	Count	%
2011	102	18
2015	114	27

Participation rates by ethnicity, age and DHB region are shown in Table 5.

Table 5: Response rates by time of death, ethnicity, age and DHB region

	Number of completed surveys	Participation rates for 2015
	Count	%
Age		
24 years and under	11	10
25 and over	103	34
Ethnicity		
European	89	43
Mäori	12	13
Pacific	4	8
Asian	7	11
Middle Eastern/Latin American/African	1	11
Other (Residual categories)	1	100
DHB		
Northland	4	21
Waitemata	15	31
Auckland	16	31
Counties Manukau	14	19
Waikato	8	22
Lakes	1	7
Bay of Plenty	4	29
Tairawhiti	1	33
Hawke's Bay	5	23
Taranaki	4	33
Midcentral	5	31
Whanganui	0	0
Capital and Coast	3	19
Hutt	5	45
Wairarapa	3	50
Nelson Marlborough	7	54
West Coast	0	0
Canterbury	11	28
South Canterbury	1	13
Southern	7	54
Overall	114	27

Sample characteristics

The two figures below, and the table on the following page, compare the demographic characteristics of the 114 women who completed the survey (respondents) against the characteristics of the target population (all women who experienced a perinatal death in 2013).

Figure 17: Age

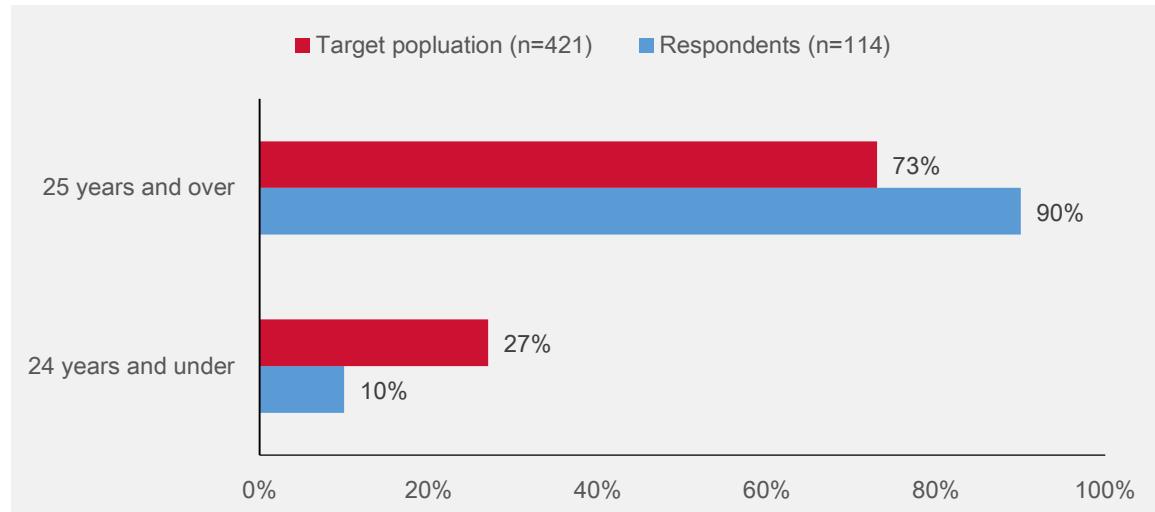
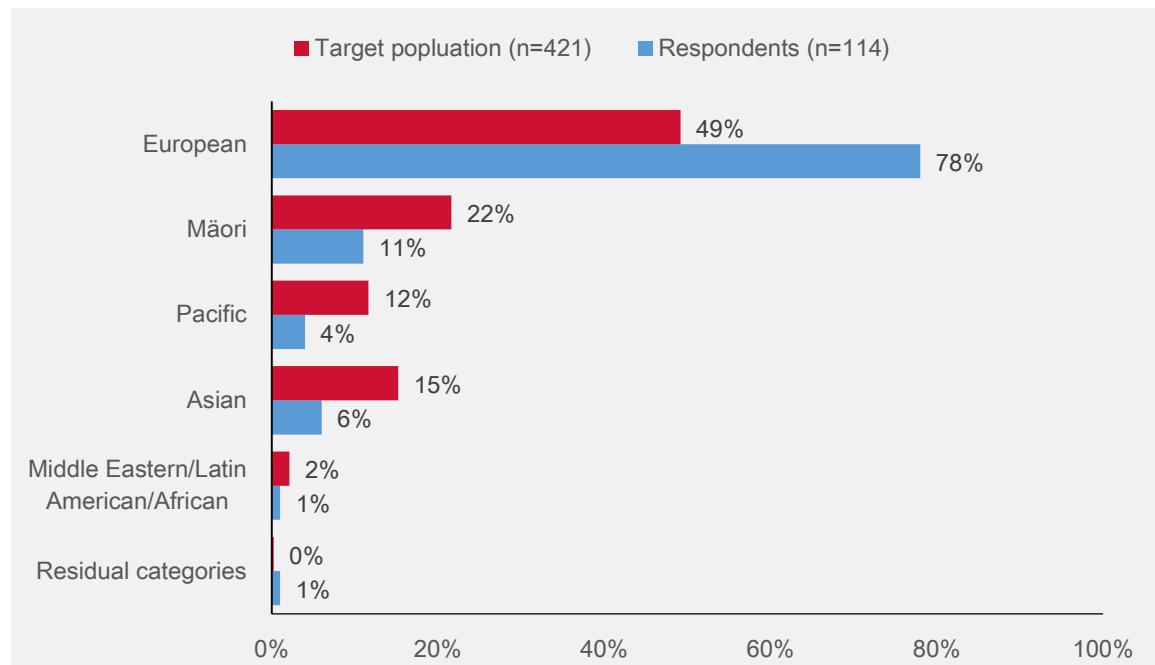


Figure 18: Ethnicity



In order to make a comparison between the target population and the sample ethnicity results, ethnicity is based on the data held by the Ministry of Health.

Table 6: DHB where birth occurred

	Base=	Total sample 114 %
DHB area		
Auckland	14	
Waitemata	13	
Counties Manukau	12	
Canterbury	10	
Waikato	7	
Nelson Marlborough	6	
Southern	6	
MidCentral	4	
Hawkes Bay	4	
Hutt Valley	4	
Taranaki	4	
Bay of Plenty	4	
Northland	4	
Wairarapa	3	
Capital & Coast	3	
Lakes	1	
South Canterbury	1	
Tairawhiti	1	
West Coast	0	
Whanganui	0	

Total may not sum to 100 due to rounding.

Accuracy

Given the size of the total achieved sample, results based on the total sample are subject to a relatively high margin of error of plus or minus 9.2 percent (at the 95 percent confidence level).

Note also that the survey data has not been weighted as this procedure is not recommended on a sample of this size.

Analysis

Because of the sample size, the results to this survey have been analysed and presented on a total sample basis only. Although some questions in the survey were only asked of a sub-group of respondents, any results based on a sub-sample size of fewer than n=30 respondents must be treated as indicative only.

Constraints and limitations

When considering the results of the 2015 Bereaved Women Survey, the following constraints and limitations apply:

1. Survey design –the survey questionnaire consisted of mostly questions of a ‘closed’ nature, with the focus placed on aspects of the maternity services provided which were of interest to the Ministry of Health. While every attempt was made to be inclusive of the entire birthing and termination process, including events pre- and post-birth, it is possible that the interview did not include some aspects considered important by bereaved women. To an extent, the opportunity to provide comment via the open-ended question at the end of the interview, gave respondents the opportunity to elaborate on any particular aspect of their experience, if they chose to do so.
2. Interviewing methodology – for the 2015 survey, both telephone and online interviewing were included in the methodology. However, these methods may have constrained the ability to conduct interviewing on an unstructured basis and explore bereaved women’s experiences in-depth, and placed some more practical limitations on the amount of information that could be collected.

In our opinion, while a face-to-face interviewing approach may have produced more in-depth information, such an approach would have been much more costly.

3. Participation – although the participation rate to the 2015 survey was higher than the rate achieved for the 2011 survey, it was still below the average for surveys we conduct. However, is likely to do with the sensitive nature of the subject topic of the survey and the opt-in method of recruitment. Every practical step was taken to optimise the response to the survey, including the mailing of pre-survey notification letters.

An alternative methodology (e.g. a paper-based, self-completion approach or a face-to-face approach) would not necessarily have yielded a better participation rate.

As the response rate for Maori and Pacific women who had lost a baby was low, we recommend additional activity be undertaken in future to investigated and increase the participation rates among these groups.

4. Analysis – the relatively small achieved sample of 114 respondents means that the results are not able to be analysed and compared against by the four sub-groups of bereaved women based on the manner in which their pregnancy was terminated or their baby died, by age or by ethnicity. The analysis and reporting of the survey results has only been possible on the basis of the total achieved sample.
5. Accuracy – the relatively small achieved sample of 114 respondents also means that the survey results are subject to a relatively high margin of error of plus or minus 9.2 percent (at the 95 percent confidence level). This means that had we found 50 percent of the bereaved women who were interviewed were satisfied with the overall standard of care they had

received, we could be 95 percent sure that between 40.8 percent and 59.2 percent of the whole population were satisfied .

Appendix D: Verbatim comments

At the end of the survey, women were asked if they would like to make any final comments about the care they had received. A large variety of comments were given about specific aspects of the care they received, while other comments provided more general feedback about their experience.

Positive comments:

I have to say it was for the worst day of my life, but I felt very protected and safe. They took such care of us, and made sure, like it was the little things that made it bearable. It was the little details I felt was excellent.

We were looked after really well, but it helped that one of the twins survived and we were in NICU for so long. So many people (Australia and New Zealand) gave us so much support. Once the twins arrived, although it was a trying time, we were in the rollercoaster ride of NICU, so we may have had visits from Sands but we were so overwhelmed with our premmie that I couldn't honestly say.

To be put in such a horrific situation and have to deal with it and absorb everything is not easy. I felt the nurses/people that came and went were really sensitive to the situation and wonderful - one in particular seemed quite young but she was incredibly professional and did her job well. Perhaps just letting the lady who came to take bloods from me know that there was a little baby that had passed in the room may have been a good idea as her reaction could've been more subtle. We did feel a bit of pressure from the obstetrician to have the post-mortem on baby but I have had her in subsequent care, and pregnancy, and found her wonderful. Perhaps her scientific mind really wanted to check baby out and find out what happened but for us it wasn't going to change anything finding out what happened, he was already gone.

The staff at [Town/City] hospital were fantastic. They keep it to minimum on their staff, like one per shift. I think they have set it up really well, they were amazing. The staff that helped do the delivery, they all are really lovely.

The specialist team at [Town/City] Hospital were all phenomenal and extremely compassionate for which we are eternally grateful.

Thank you to everyone who helped make the experience just a bit easier e.g. Sands; [Town/City] Hospital; even the ladies that knit the tiny clothes you can use. It helped to know that people care.

Thank you for allowing my husband to stay with me over night at the hospital.

Just that talking to Sands helped a lot and my midwife and the nurse supported me. I've tried to carry on, it was really hard, but I'm really grateful for all these people.

It was good. I am very much satisfied with everything.

If it gets to a point where the Ministry are considering some changes it would be great for the women to get together and go through those options, like a working group of some kind.

I remember saying to people at the time how impressed I was with how every decision through every point in time, from the moment when we knew what had happened, the decision was up to me and I was given all the information. I thought that was great, because I felt like I wasn't made to do anything. The obstetrician was great, offered statistics, and said things like "Women who do this in x y and z are more likely to do better in a longer term", which I found incredibly helpful. I honestly thought that the obstetrician was just incredible. For that one [Q52] the reason why I put that as three, rather than a four or a five, was it was about the one thing in my pregnancy I didn't do any research on, because of my age, I got quite a shock when I saw the results because the statistics, which if I'd stopped and thought about it, the statistics get worse from age 35 onwards. I was shocked and surprised when I got those results back.

I'm happy for someone from a DHB or the Ministry of Health to contact me if they require my further assistance to help the future bereaved mothers' better during bereavement.

I don't think anything could have been improved, everyone was really supportive. Perhaps a special room for mothers who are giving birth, so that there's not as much stuff to remind you. My husband and I both really appreciate the help and support.

A lot of peoples' experiences are so different. We were pretty lucky, I guess, with the care we received and the circumstances, like having no one else in the ward. I think it would have been really different if there had been other women birthing at the same time.

Comments that are both positive and negative:

It was just with the midwife, the lack of support that was probably the only thing. For me, like I said, if my personality type was quite weak, I wouldn't have coped as well if I didn't have family support and my husband as well. I went through counselling, that was good. But that wasn't through the public system, it was through private. [Town/City] hospital was amazing. It was a horrible situation, but it was a beautiful experience.

When I was having my 19-20 week scan, I found I had lost one of my babies. I think the sonographer, they need some form of empathy or training for scanning so if it does happen there is some procedure you take; some people go into shock and then the mother will go into shock. I would like to mention a few names if that's ok, with the people that helped me. [Name] the Secondary Care Midwife and the Specialist [Name] they were both good and the lady that delivered my babies, don't know where she is now, I think she has gone back to [Country].

The specialists (both at the Foetal Medicine Clinic and [Town/City] Hospital) and the [Town/City] Hospital midwives were excellent. The handling of breaking the immediate news of my baby's condition was done with great sensitivity by the radiologist. However, both my partner and I were extremely disappointed by the behaviour of my midwife. It felt like that once the condition was found that she tried to have as little to do with us as possible. I had a single, brief, phone call from her after our baby was born in which she seemed to be calling because she was required to and not from any real interest in my care. She had also behaved this way during an early miscarriage I had had in a previous pregnancy. It may have been a common scenario for her in her job but she made us feel like we were wasting her time by not having a "live" baby to deal with. I have since had another baby with a different midwife who was wonderfully supportive and now realise that her behaviour was unprofessional and I would not recommend her services to any of my friends or family.

The only negative, in really the whole experience, apart from it being a pretty awful experience to go through, was a sonographer from [Town/City] hospital, so we had our 20 week scan in the community and it was raised there was clearly a problem and so we had to go to [Town/City] hospital just to get it confirmed and there was a junior sonographer there; perhaps she wasn't aware of the gravity of the situation but she was very overly excited and you know pointing out that here's the baby's heart and you know here's the baby's, I mean if the baby was fine that would be really an appropriate way to behave but because we were going in, you know, understanding that this was a sad situation, it wasn't appropriate. So that would be really our only negative with the whole experience, perhaps people working in a tertiary hospital in that area might just need to think about how they act around those people coming in, you know, they may have done their own research and may know what's on the cards so perhaps maybe be a bit more neutral with their behaviour or excitement levels. I'm not sure if that makes sense, but if it was a completely normal pregnancy that would be really lovely but when you're actually going in something not feeling particularly great it made it worse really. That would be my only comment and I did write it on the feedback form to the hospital because everything else

was wonderful but it was just that, just to be aware perhaps that you need to tread quite carefully in those early days.

Since becoming a member of the baby-loss community, I have learnt that there are such things as cuddle cots which allow families to spend more time with their baby with dignity. I truly believe that these should be available to as many newly bereaved families as possible. Time is all we have with these babies and as much as possible is best. Part of the reason we didn't spend as long with our baby was so that he could have a post mortem ASAP. But to have longer with him would have been amazing.

Probably more investigation into the bleeding that I was experiencing, I didn't feel it was thoroughly checked out. Obstetrician told me afterwards that she thought I would lose them but the severity hadn't been communicated to me and I was in the process of being transitioned back to the hospital midwife. Hospital care on the night of the miscarriage was great.

My worst experience was at A+E. My waters broke at 20 weeks, so I called my midwife who told me to go directly to A+E and she would send them a fax to explain my case. When I arrived at A+E my baby was still alive, I could feel her kicking, but the water was still seeping out and I was really worried. I just felt I wanted to lie down in the hope of stopping the water seeping out. The staff at the reception desk ignored me for 20 minutes, and then when I finally did get to speak to them and they were totally clueless as they hadn't read the fax that had come through from my LMC. I spent the entire day in the medical admissions unit and was kept nil by mouth, but I was still pregnant and I didn't know what was happening. No professionals came to see me except [for the] nurses doing my observations for the whole day (8 am - 4 pm). I didn't complain or make a fuss, I know hospitals are very busy places, but I was really scared. Then my LMC came in to see me and was furious. She went off and soon afterwards the obstetrician came to see me and told me that because all the water had been lost there was no hope of the baby surviving. This was the first time I realised I was going to lose my baby. I was allowed to go home soon afterwards to wait for the natural progression of labour but I had been nil by mouth all day, I was in shock and I fainted six times between the medical admissions unit and the carpark. I felt dreadful. My baby was still alive, I could feel her kicking Tuesday morning (when the waters broke) until Thursday evening. My contractions started on the Friday morning and I went to the birthing suit at [Town/City] Hospital where I had a much better experience. The staff had been pre-warned about me coming in, and they were very kind and sensitive to my needs. However, the staff at the birthing suite did not contact my LMC to tell her I was in labour, and I didn't even think to, it was all too traumatic. Therefore, my baby was delivered by the staff on shift that day. They were very good and I had no problems with their care, but it might have been nice for my LMC to be there as I knew her. She didn't come and see me that day at all, and I was in hospital in the delivery suite [from] 5 am until 4 pm.

Most of the staff at [Town/City] hospital were helpful and thoughtful during our initial stay and then again after the birth. It was just unfortunate that the midwife that was on when we actually went into labour and gave birth wasn't very supportive or thoughtful and made

it a very upsetting time for us, especially when our baby was left at the end of the bed alive when we assumed he wasn't.

My support and care that I received during our time in hospital was outstanding. The medical staff were simply amazing. My concern sits with the follow-up care for a grieving mum who doesn't live in a main centre.

My only challenging point was the care from the specialist who, because my baby was not going to live long, I think her life was not given enough importance. For example, I was strongly discouraged to have a c-section, but it may have meant she would have been born alive and I could have held her alive, and I don't think the specialist had empathy towards how important that is for a parent. I understand they have to be pragmatic and have to think of my health, when my baby is not going to thrive, but that's a little bit difficult to cope with. I also think that having some kind of Sands room or something may be beneficial at [Town/City]. I was lucky they could isolate me but some other mothers might not be so lucky. The staff did everything they could to make sure I was not exposed to other mothers, so they did really well in that respect. I was fortunate because I had time to prepare, I knew from 20 weeks that she was not going to live long. The social worker was really helpful at [Town/City], she had a lot of information and was really helpful so she should be recognized. Just recently, the thing about having time, my baby was up and down from the morgue and I had the midwife who was looking after me, they were quite happy to go and get her for me. Only one time did I feel she was a bit sick of bringing my baby back to me from the morgue. But if I hadn't have had to put her in the morgue, that she could have actually stayed with me, that would have been better. If that was possible to do in my room or something, like when babies have an incubator, if there was a way of keeping her cool so that she could stay with me, because we had such limited time. That would have been an improvement. [Town/City] were fantastic and I got a lot of help and support and I can't really fault anything.

Just the pain relief thing, for them to check, in any circumstances it should be checked, so it doesn't happen again. But everything else was perfect, especially the Sands group. I spoke with one lady and she was amazing.

It was just the little things that could have helped, things like fresh linen daily and having the cups cleaned and changed in my room rather than me having to do it. I sent a letter to [Hospital] afterwards advising of the issues and things that would be best for other families in this situation, I got a reply saying they were implementing most of them so that was good.

I think that my midwife was very busy and didn't give me much attention. I felt like [I was] in a factory where I am just the next on the lend [sic]. When I explained to her at our first meeting the risk that I am carrying she even didn't check it up and for weeks she was saying that all other tests are good and there's no need to worry. But I felt that there was a problem and had to push her hard at least to find out that we have to contact the genetic service department, from where I got professional and prompt service and kind support. I just think that midwives need to have regular training and since the population in [Town/City] is growing and it is very international, they need to know about disorders

that are typical for some parts of the world. And also, if they don't have the capacity to look properly after many pregnancies, to be careful what they choose. We are talking about the most magical thing - creating a new life, it's not about money, and the best gift they can give is the gift of attention. There are very passionate midwives there that are great. I had the opportunity to meet one of them in the hospital and I was grateful for having her for support.

I think it would be nice if a Sands representative made contact a few days following a loss (at the permission of the mother) just to reach out and see if there was anything they could do or let the mother know they were there. And I'd like to say that the memory boxes provided were really sweet. I had no idea this service was around until my loss. The staff and midwives at [Hospital] in [Town/City] were fantastic. Thank you!

When they have to make a decision, any degree of waiting or any degree of normal administration hiccups can seem like a mammoth thing to me. So as much as possible, if that can be streamlined, and information be tight, more so than in any normal case would be good. I have to say the care I received, particularly on the day and care after taking my daughter's body away, was pretty amazing. The midwives were pretty amazing.

I cannot speak more highly of Dr [Name] and his team at [Town/City] Hospital. I am pregnant again, and I have chosen to be under complete hospital care. I would not entertain the idea of a community midwife again. This is my fourth baby. With this pregnancy, I was organised special CVS testing in [Town/City] straight away, because of my past history. Professional grief counselling for families is practically non-existent. We were lucky [that] we had a strong family unit. I can see why many families breakdown during these sad times. There is no professional support for the mum/dad and siblings.

I would have been grateful for some reference to the fact I lost twins, not just one baby in the letter I was sent regarding this survey. I would love to help other mothers who went through this type of loss but I'm not sure how. I felt the team at [Town/City] Woman's Ward were so kind in treating my husband and I as parents despite our loss. This was extremely important to us. They also allowed us to stay together in hospital by providing us a double hospital bed. I don't know how I would have coped without being able to have him there every minute. The only improvement I feel would have been at the early stages of my pregnancy, when realising I had identical twins I feel I should have had a little more priority at [Town/City] Hospital to see the more senior Obstetricians, I understand it's a training hospital however, in my case I needed experienced and reassuring care.

Negative comments:

I would like to make note of what happened, it would be appreciated that it be put on my file, whether my pregnancy was my first child, or anything of my nature, because I have another child that is here. I would expect the hospital to have that information. I would like to make note that after a month after my son passed away, I was asked to send confirmation about my LMC, I think in future that it should be requested. I know that my situation may be different to other people.

I basically fell through the crack about a lot of things. Why the specialists didn't do tests of what was going on, why the nurses didn't really do things, I could go on forever. I felt the staff were really lacking, not in professional wise but like in the wards. Pain killers were not working and the staff treated you funny after that. The specialist I was under was arrogant, the information that he didn't know was like he didn't want to know it. Staffing issues, was like a lot of the time it took a long time for someone to get to you, like there is not enough staff on that shift. There was another thing, we just home after and we got posted out a questionnaire about how we felt, but when [we] looked at the questions properly, they were all really closed questions, it wasn't anything like what we went through or how we felt but it more like a hospitality questionnaire on how the staff were. [It] felt like a slap in the face. I thought the reason of the questionnaire was about our loss. When we decided to try for another baby, we had no support at all. Just our midwife that helped us. I pushed to go through the hospital, our doctors were being useless.

There was so much in our circumstance that could have been improved on, from the moment we found out to the months afterwards, of things that went wrong. I think the main things that hospitals could get right is the terminology they use, that's a huge thing. These babies are people's lives and dreams, they're not terminations and fatal demises and products of conceptions. Even, for example, the question that you asked in the beginning "did you chose to have the baby terminated or the pregnancy terminated?" well you didn't choose to have an abortion. I can see people getting upset at the question. That question in itself could be seen as very offensive. When I was 34 weeks pregnant and sitting there and I had a midwife say to me "what we do now to carry on with the termination", it's certainly not a termination and I am sure as a woman you can understand that. I guess one other thing, is that when surveys like this are done they need to understand that it's really important to the family's involved the information you guys are gathering. A process like this is where the person's job is to be quite clinical and get the answers over the phone is probably not the way to get the information they need. Everyone has a story and having someone on the phone asking yes and no questions and they can't actually discuss it with you, it must be hard for you and hard for us as well. To you it may be just a miscarriage but to me my life shattered that day, you know, it just depends on your perspective.

The main concern was Dr [Name]. Within the complicated pregnancy and that [Name] would not prepare to fly with me down to [Town/City], he just needed to sign it off. We have other children, [and it was] very stressful traveling to [Town/City] and back home - a five hour journey. Not drinking enough fluid, and with that pressure on my bladder with the fluid that I was drinking, I felt so sick. All the [Town/City] people at the hospital were

disgusted with him. That's why I have gathered all this information and organized this meeting, I was just disgusted with him. I do have those notes still, if you need it or anyone else.

The lady that took my baby girls footprints was not gentle enough with her and didn't care how she was handling her. I was very upset about that.

The information about pain relief for my dead baby's induced delivery was really inadequate and not appropriately tailored to the circumstance. The midwife told me I could have pethidine or [an] epidural, that's it. I didn't want either as I wanted to be as 'present' as possible for my dead baby's delivery, knowing it was my only time with him. I didn't want to be drowsy, numb or nauseous. I'd had a labour without analgesia for my first healthy baby and knew what to expect, and because this baby was small then it would be quick and intense, but I was frightened that the pain at the end would feel more unbearable because I knew my baby was dead and I wanted to talk to about other analgesia options in case I freaked out towards the end. I was frightened too that I would bleed a lot and be in danger. I wanted to speak to the anaesthetist about other options e.g. PCA, but my midwife seemed angry and offended about this. Then the anaesthetist was busy, but I was told he initially refused to come. Then when he came it was too late, and he was very rude when he appeared. Unfortunately this was while I was on the toilet and in the final stages of labour. I'll never forget his exact words to me in labour which were "I can't help you". He didn't introduce himself, I didn't know who he was and couldn't see his name badge. I later found out he was the specialist but he was so rude and seemed to be out of his depth. I initially thought he must have been a junior trainee. His interpersonal skills were pretty lacking. If he had just been human and caring and offered a reassurance to help then it would have decreased my suffering in that moment so much. Instead I felt abandoned and frightened, and even angry at how unprofessional he was. In the end he did stay and did help me, and I am grateful for that. Also apparently he did try to come to talk to me after delivery, but I was in the shower so I missed him. It all seemed like an unnecessarily stressful misunderstanding. I think the anaesthetic department should produce a simple page of information with options for women in my situation before they labour with their dead babies so they can make an informed choice.

The fathers seem to get forgotten about when a baby is lost, I understand that the mother needs to be taken care of but the father has lost a child too and they are grieving not only for the loss of a child but how helpless they are when it comes to helping their partner. Questionnaires and support should be given to the partners, just the same.

The DHB/hospital need to be more forthcoming with information around the investigation. It is ok if it is going to take time but someone needs to touch base with families from time to time to let them know what's going on. I did not hear from the hospital until August after [Name] died in April and then the next delay was until the following May which was well over a year after the death. I have just this past January heard from them again. The gaps between communications are too long and unacceptable. I don't need them to speed up an important investigation but I need to hear from them on a more regular basis.

TMFR is a complex grief and it would have been beneficial to have received counselling from someone familiar with the emotions and feelings this brings. I am not one to ask for help so stoically I did it myself, but honestly, it would have been better if I had automatically been enrolled with a psychologist or someone who would have helped me work through the journey. Also, it would have been of huge benefit to actually talk to someone who has been through a TMFR in real life. I found companionship in forums that are based in the USA specifically for TMFR, and they have been beyond helpful, and I have made lifetime friends through it, but actually talking to someone face to face who understands would have been very helpful. My next point, when offered the choice to CTT or TMFR, I had to look online for resources and support. I eventually found a community, but it would have been helpful to have been pointed in the direction of available resources when I needed them most. The Baby Center USA forums for loss and grieving have very active communities for all sorts of these situations, there are forums for people who CTT and others for TMFR, and for pretty much every diagnosis you can imagine. It would have been useful to have been given a list of these forums, or at least encouraged to go there and have a read. The TMFR one, in particular, would have been extremely helpful to have had access to after I had made the decision but before the TX, as it contains lots of personal stories, suggestions, regrets, and most importantly support from others who are going through the exact same thing at the exact same time. Sands may be helpful for some, but honestly it was weird for me to go to a Sands meeting and hear people talking about having an abortion (not for medical reasons) when I had just made the most devastating decision of my life to say goodbye to my daughter. This is why I say TMFR needs some different care/support. Sorry for the ramble, but I hope it helps improve the service for other women who are yet to walk this path.

Sands operating in the [Region] needs to be seriously looked at. Maybe I should have contacted them earlier and got more advice? About a week after the funeral I reached out to them and received a phone call back a couple of days later. The counsellor sounded like she was emptying her dishwasher as she was talking to me, I was absolutely distraught and felt that she wasn't giving me the time of day. After the call she asked me if I wanted her to call me back, which I said yes to. We made a time and date for the phone call, then she never rang me back at that time or on that date. It was like four days later. So when she finally did ring back, I told her to forget about it. I found my own grief counsellor which I paid privately to go to. I also found the funeral director to be more helpful than Sands. Don't offer a support service that can't be maintained to an acceptable standard.

My partner who was more conscious of what was happening around us may have had a different experience. He thinks that I was neglected after the delivery when I was bleeding heavily, as there was a shift change at the hospital. However, eventually my midwife managed to get the attention of the hospital staff and I was rushed off for a D&C which I think was critical as I lost three litres of blood and had a transfusion. If I had been left much longer it may have been dangerous. The midwife spent a lot of time trying to get staff attention and they didn't come. However I was barely conscious at this time so don't really remember it, my partner says that it was very stressful. He was worried about losing me as well as the baby and he couldn't get attention from the staff, but eventually they came.

One of the doctors in the newborn unit was not at all empathetic. He talked in medical jargon and was not at all understanding of emotional wellbeing. Everyone else was wonderful, although one of the receptionists made me feel guilty for needing a place to stay in [Place]. There is nowhere in the newborn unit to cry, everyone stares at you and there are too many relatives running up and down the corridor, no privacy, they should have a quiet area like a chapel.

One of my concerns about the pregnancy is the 12 week scan. I had a lot of problems with that scan, I had to have it twice. [There were] delays in processing [and] when it was finally back it was incorrect. It did not show what was wrong. I had a real problem with the way they presented the results i.e. stats 1/100,000 chance of having the "trisomy 18" you would think there was virtually no chance. At 20 weeks [it was a different story] they first gave a false representation of the facts.

On presentation to the hospital at 18 weeks, [I was] assessed by a very junior house surgeon, carried out a PV exam in non-sterile manner. This should not have happened as I had ruptured membranes and she could have introduced bacteria. [She] didn't appear to know what she was doing. [I was in a] fairly vulnerable state to be 'practised on'. The midwife's advice re: bleeding was "some people bleed for their whole pregnancy" - when perhaps it's best to advise that it's not normal to bleed during pregnancy - especially with twins. I feel I could have received better advice during this time i.e., don't return to work until the bleeding has stopped.

Not to be surrounded by babies.

More support when the baby died rather than "these things happen". More encouragement to spend time with my baby/bathe her etc. Encouragement to get an autopsy done, rather than told that we don't often get answers. Truth about the state of the baby. When we saw our baby she was very undernourished with bones protruding, however we were told everything looks normal. I researched on my own and found out her birth weight was very low (due to growth restriction). When I raised questions, I was met with "these things happen and we don't know why". Why are we not involved in the perinatal mortality review? There were problems with my care (midwife not responding to reports of decreased movements) that are not evident in clinical notes. No counselling services available - I asked and was directed to Sands support group which I wasn't too comfortable with. Recommendations for grief counselling would be good, such as the grief centre.

Midwife could keep a closer eye on the mother.

Maybe the communication between hospitals, because one hospital had my maiden name and one had my married name, so when I was transferred they didn't know who I was.

Losing a baby is still very much a taboo topic. No one wants to admit that something so horrific can happen. Employers need to be better equipped to embrace these mothers

returning to work. It is very difficult and can add further mental stress and grief. My employer was appalling.

Listen to the mum and make sure that knowing the situation she is in, make sure that there is information, making sure they got something to refer to, like for help, and that kind of stuff.

Just the midwife part of it could be improved. I think they just have too many forms to fill out and boxes to tick that they don't get to listen to each one separately. I think because there are so many forms they are too busy.

Just some of the things that I said, like more funded on the bereavement side of things, like casting of feet and hand of baby, inkless bracelet on baby and more time in the hospital before you go home. You don't have to make a decision really quickly and don't have to rush an autopsy getting done. Like just to know that you have more time.

It would be nice if there was some sort group of women in [Town/City] where I live, of those who have lost babies. Maybe, I think I know of one of something that happens every year. They have a celebration of prematorion. Maybe have women ring up and ask if they want to have a chat and coffee. I feel that because I have been [through] something, like I would share and help other women; that would be the only thing.

It was the error of difficulty of getting conflicting advice from the healthline and the GP. I don't know what the end answer was. Don't know how you would sum it up. Conflict with medical advice, different advice, regarding chicken pox, phoned healthline.

If a mother receives a general anaesthetic she should have a written account of what happened to her and her baby in those hours following recovery. It's a big gap that I just don't understand what was happening.

I'm talking about [Name] hospital in [Town/City]. Maybe if they change their care and listen to their patients it might help, and their attitudes don't work. The majority of them, they look down on their patients. They need to learn to respect people.

I would really like to say, [about] the process the hospital had around the community midwife, they make it too hard for women who have just had a baby, especially a c-section. And it means that these people keep making these mistakes, because women are unable to complain that there's something wrong. The process is way too long. There needs to be something changed around how the women make complaints to the hospital. There needs to be a survey about women having a baby after an infant loss, because it's as traumatic as having lost the baby. It allows you to normalise the birth and know if you are satisfied, and confront the issue of your loss, and understand if you were satisfied with what happened when the baby died. The only other thing is the Sands group, I don't think it works for me as a woman. I am the kind of person who needed someone to call me a few days later to see how I was. I would find it very hard to ring someone and ask for help.

I would just like to say that doctors should make sure there is enough staff on hand. Don't get a hapū mum in to the hospital after travelling from [Town/City] to [Town/City] and tell the hapū mum that a nurse will be in soon to take some blood then, when the nurse comes in tells the hapū mum "sorry we are understaffed, you can either stay the night or we will call you to come back tomorrow". That is so not nice. And also, when asked if photos or part of the placenta can be taken and the hapū mum says "no!", that should be the end of it, no need for the nurse to ask again and again and get the same answer.

I went to my doctor the weeks before I gave birth and I went with swollen feet and severe hypertension. This did not prompt the doctor to do any further testing which would have picked up on my pregnancy.

I was under a cardiologist and midwife and obstetrician and not one of them talked to each other. At 18 weeks I was on beta blockers and at one point my iron was low, next to none, and I was never told till I was 14 weeks. I was also on beta blockers and around 15 weeks my meds got changed without the obstetricians consent, or so he told me, and 6 weeks later my baby passed at 21 weeks. But the post-mortem also showed that she stopped growing at the same time. I was never given any scans in between my meds changing to check for foetal growth. I was high risk but I was never treated as one.

I think, in general, I support improved education for independent midwives across the board. I think the GP should be more responsible for making more decisions. In regards to obstetrics, they should be required to take pregnancy into consideration while considering diagnostics. I don't feel that GPs should be separated from midwives for pregnant women. I don't think they should be separated from pregnancies.

I think the only thing is the group Sands, I wish they got more involved afterwards. I would have liked more support from them afterwards. Like from people with similar experiences.

I think that it would be helpful for all staff to be aware of the precise background to a delivery so that all care is taken to not make a stressful situation even more stressful by having to deal with comments/"jokes"/observations that are not needed nor sought. We had one staff member (health care assistant) come bowling in before her holiday looking for the triplets, the comments from the paediatric nurse on delivery and an anaesthetist turning up to check on my pain relief when we were trying to spend some private time with [Name]. I also had difficulties in going to see my other two sons in NICU because no one told me how I could go about seeing them. One of the NICU paediatricians, instead of respecting that I needed to spend some time with my dead son, seemed to be reprimanding me for not making my way to NICU when she should have started by asking me if anyone had talked to me about how I went about seeing my two sons who were in NICU. In fact I had to wait for a long time for a wheelchair to be fetched (when it would have been more efficient to send my husband out looking for one) to get from ward 96 to NICU given my C-section earlier that morning. I felt that, at times, my needs were not met because I was not given an opportunity to voice how I was feeling.

I think my only comments would be the initial care, when I said that I couldn't feel my baby move. I think looking back, I was trying to be strong and not be paranoid, I look

younger than what I am. But looking back I would have liked my midwife to say that we would look into it more. I think if we had reacted then, who knows. And also the aftercare with the doctor, when they tell you what their findings are, their experiences could have been a little bit nicer.

I think just, the midwife needs to take a bigger role; I don't know if her mind is hopeless, she just wasn't good. We felt really left in the cold, no real guidance from the start when we learnt that our baby was sick. It all worked out in the end when we got the help, but it was all custard in the beginning, when she could have done more.

I think it would be a big improvement if woman in the woman's unit were given proper meals and not just sandwiches. I was there two days and that's all we were given. Luckily, I had family coming and going! But not every woman is in the same case. Take into mind, most of these woman are either having miscarriages or still births for which a sandwich isn't, in my opinion, efficient. I also think midwives should have to review their procedures every time a stillborn happens in their care. The most horrifying thing for me was receiving three phone calls from a lady from Auckland University wanting to do a surgery on me literally for days after losing my daughter. I found it very rude and intruding! There should be a letter written to you, not a personal phone call on your cell phone.

I think doctors could make it easier for midwives to have communication with you while you are in hospital as my midwife was blocked from having contact with me. The doctors should have had more communication with me as a patient as well as my husband. Overall, the midwives at [Hospital] (well the one called [Name]) scared the hell out of my husband and myself and has made it difficult for myself to return to [Hospital].

I just think it is really important to focus on the value of life - every life is meaningful - I think wherever it is possible, focusing on saving the life of the baby or doing everything possible for that to happen should really be at the back of the minds of those involved in the lives of mothers and babies and that is not what is happening for us in [Town/City].

I just think [being] given the opportunity to have a second opinion in the hospital would [help] and, I feel strongly about it. I feel that you are vulnerable, not clear minded. You don't really have a voice of your own, so you have someone to second guess. I think in the hospital I feel a lot depends on the doctor you get on the day, and how things turned out, part of me feels like we got the wrong doctor on the wrong day.

I just hope the next girl, women or lady that is in my position, that if they want to stay in hospital to get monitored in regards to the baby getting well, the hospital should respect that and not send them home without diagnosing the problem.

I just feel that the specialists in the gynaecology in [Town/City], that do the pregnancy stuff, I feel they should listen to the patients more and respect our wishes. Because I wanted stitches and they didn't want to listen so baby was born and then he died.

I have written through this survey regarding the timeline within a month of our son being born. The other thing which was hard was the time it took to wait for the result of the post-mortem, it took 4 months. We were told leaving the hospital that it would be 2-3months. I had to keep calling the hospital to get an appointment which was disappointing. I can say, it has been 2 years and 2 months since our first son, [name] came into the world. We have since given birth to another son, [Name], in August 2014. We had wonderful help through the maternal high risk clinic at [Hospital], we couldn't fault the care through the pregnancy, birth and after care. It was the complete opposite to the care we received from our midwife with [name]. If we were not offered care through the high risk with our second pregnancy we would have paid for private care. We would have not had care with a LMC midwife.

I feel as though a number of gynaecologists and obstetricians at [Town/City] hospital did not give me adequate care. ... At 18 weeks, my obstetrician should have ensured a cervical measurement via a trans-vaginal ultra-sound, due to a miscommunication this did not happen. When I did present with symptoms of premature labour ... my husband and I decided to go to hospital. At [Town/City] emergency department the Gynaecologist did not order a transvaginal ultrasound they did an external examination of the cervix. ... Finally at 23 weeks after the second trip to the emergency room I got the transvaginal ultrasound which showed a severe funnelling of the cervix. I got an emergency cerclage placed and I was in hospital for a night. On my third trip into the emergency department when I was in real labour at 24 weeks the receptionist called up to maternity ward to see if I could go straight to the ward. In front of me she was told by the charge nurse in the department that I was not allowed there but had to be assessed in the emergency ward. ... Dr [Name] from [Town/City] DHB is the shining star of this story, as soon as she engaged with me, she gave me respect, hope and confidence in her ability within her profession to do the very best for me and my family including my unborn child. This women gave me the chance to meet my son and have him in my life for a short but precious time. My husband and I will be eternally grateful for the opportunity to meet our son alive. ... Once my son was born I cannot speak highly enough of the rest of my care. Right from the duty midwives at [Town/City] DHB that held my hand during birth through to Dr [Name] who fought to get our guy a space at NICU through to the highly skilled team of specialists that cared for him at NICU during his 7 days on this earth. I think there are many ways to improve treatment of high risk pregnancies at [Town/City] DHB.

I do think that the hospitals and midwives and staff could warn mothers about placental eruptions because I didn't know it could happen.

I am pretty sure, being a big girl, I am not the only one that is aware that you can get gestational diabetes early. We are looking after our own health. Being my first pregnancy, it shouldn't have been the main concern that I am big. Sure I had bleeding from seven weeks, they just fobbed me off saying that I was having a miscarriage. There should have been more investigations about why that bleeding was happening. If they gave me those scans, and it's not coming from him, well obviously you should work out where it's coming from. I understand that [provider] is like seven midwives, but you shouldn't keep swapping them from one to another. That was the most frustrating part. I think I am owed an apology, I honestly do. That was my first pregnancy, you know. I had no clue what was

going on. I think it could have been prevented. His post-mortem came back and there was nothing wrong with him except that he had [anaemia], which was caused by the bleeding, which caused the infection.

Huge let down was my midwife, [she] was not listening to me when I said that there was something wrong. I can understand my midwife saying that, it's quite normal. I'm pregnant again, but because my daughter that I lost was small, she died in me and when I gave birth four days later, my daughter was already deteriorating. The midwife should listen to the mum more, because I knew and that was the biggest let down, my midwife didn't listen to my concerns, and not having Sands there.

Everything, to be honest about things, not know you in the sense of security, when the facts are showing something different. If it's clear that the pregnancy is not going to work, maybe get some from Sands to take to you through it so you know what's available to you, so you can make use of it. So when it happens, you're not in the state to make quick decisions. Talking to someone from Sands because it's someone who has been there before, and just knowing the person, so you can build the relationship with someone who has been there before. The thing [that] would help is just knowing them.

Easier access for a Sands liaison to [get to the] hospital. Education and information for midwives (both core and community midwives), social workers, medical staff on resources available to women and families. Better access/funding to counselling services for mother, partners and siblings. A more appropriate area than a birthing unit for birth. Please note, listening to other women labouring and babies crying is not acceptable to listen to whilst holding your deceased baby in your arms in the same unit! Thank you for the opportunity to take part in this survey, it is appreciated.