



National Maternity Bereavement Experience Survey 2022

Experiences of second trimester
miscarriage

Table of contents

About the National Care Experience Programme	3
About this report.....	3
What were the main findings for those who experienced a second trimester miscarriage?	4
In brief: the National Maternity Bereavement Experience Survey	6
In their own words: Analysis of participants' comments.....	8
Results for each stage of maternity bereavement care	20
Communication and information at the time of diagnosis.....	22
Admission care	24
Labour and birth	26
Care after birth and meeting your baby	29
Postnatal care.....	30
Bereavement care.....	33
Post-mortem examination and investigations	36
Discharge	39
Follow-up care	41
Experiences of partner or support person	44
Overall care experience	47
Conclusion.....	49
Appendix 1 – A technical note on analyses and interpretation	51

About the National Care Experience Programme

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The Programme implements the National Inpatient Experience Survey, the National Maternity Experience Survey, the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey and the National End of Life Survey.

The surveys aim to learn from people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.

A National Care Experience Programme [Survey Hub](#) is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

About this report

Women and their partners who experienced a second trimester miscarriage¹, a stillbirth or the early neonatal death of a baby in one of Ireland's 19 maternity units or hospitals between 1 January 2019 and 31 December 2021 were invited to participate in the National Maternity Bereavement Experience Survey.² This report describes the experiences of participants who experienced a second trimester miscarriage. A national report, and reports on experiences of stillbirth and early neonatal death can be found at yourexperience.ie.

¹ For the purpose of this survey and to ensure accuracy of pregnancy gestation, second trimester miscarriage was classified from 14 weeks of pregnancy.

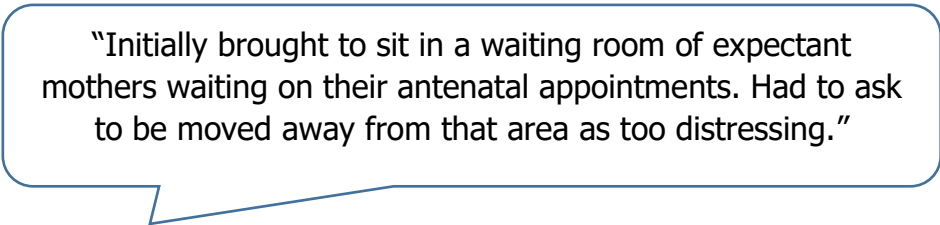
² Earlier losses were not included, as women who experience early pregnancy loss in many cases are cared for in outpatient or general practice (GP) settings, many do not require admission to hospital for care. Some women with first trimester miscarriage do not interact with healthcare services at all. Considering the differences in care settings, contact with healthcare services and treatment options, women's maternity care experiences of early pregnancy loss are different to women who experience 2nd trimester miscarriage and perinatal loss. To understand women and their partners' experiences of care following early pregnancy loss would require a survey questionnaire with questions specific and relevant to their care needs as well as the services provided.

What were the main findings for those who experienced a second trimester miscarriage?

In total, 351 women and 122 partners or support persons³ who experienced a second trimester miscarriage participated in the survey. Participants shared their experiences of the care they received from communication and information at the time of antenatal diagnosis, through to labour and birth, postnatal and bereavement care, investigations, discharge, follow up care and care in the community. Participants who experienced a second trimester loss gave lower ratings of the overall care than participants who experienced other types of loss. In total, 47% rated their care as 'very good', 22% rated it as 'good' and 31% rated it as 'fair to poor'.

Participants identified some positive aspects of their care, both when asked to describe their experience in their own words, and in responses to the other survey questions. When asked what was good about their care, participants highlighted the compassion and sensitivity shown to them by staff, with nurses highlighted in particular. Most participants said that they were given sufficient privacy, and that their cultural, spiritual and religious needs were facilitated and supported.

When asked what could be improved, participants highlighted several areas. Not all participants felt that they were treated with compassion and sensitivity, with comments highlighting issues around sharing areas with parents of healthy babies, as described in the example comment below.



"Initially brought to sit in a waiting room of expectant mothers waiting on their antenatal appointments. Had to ask to be moved away from that area as too distressing."

In addition some participants felt communication and information-sharing could be improved, and they weren't always treated with respect and dignity. A number of issues relating to information at discharge were highlighted, particularly in relation to information and support around mental health, grieving and follow-up care.

The experiences of partners of those who experienced a second trimester miscarriage were also explored. Most partners felt that they were treated with compassion and support, however they highlighted a need for clearer explanations of what was happening, as well as greater supports around grieving and mental health.

³ Partners or support persons will be referred to solely as 'partners' hereafter.

Across the stages of care included in the survey, participants who experienced a second trimester miscarriage gave the lowest rating to the 'Discharge' stage (5.7 out of 10), and the highest to 'Care after the birth and meeting your baby' (7.9 out of 10). In addition, those who experienced a second trimester miscarriage gave significantly below-average ratings for their experiences of 'Labour and birth', 'Postnatal care' and 'Bereavement care'.

The findings of the National Maternity Bereavement Experience Survey show that most parents who experienced a second trimester miscarriage gave positive ratings of the care they received, particularly the respect and sensitivity shown to them by healthcare professionals and other staff. The willingness of participating parents to share their experiences of such a difficult and painful time has also helped identify areas where care can be improved, particularly in relation to information and support relating to grieving, physical recovery, and mental health after leaving hospital.

What happens next?

The HSE and the National Women and Infant Health Programme (NWIHP) will use the survey to inform and underpin NWIHP's work across a range of current and future projects and programmes, including the implementation of the Standards for Bereavement Care following Pregnancy Loss and Perinatal Death. The results will also inform the development of quality improvement plans at national and local levels. These quality improvement plans will describe the steps that the HSE will take to address the issues highlighted by participants in the survey. Quality improvement plans will be available on www.yourexperience.ie in May 2023. The Department of Health will use the information gathered to inform the development of policy in relation to maternity bereavement care. Finally, the findings of the survey will inform HIQA's approach to the monitoring and regulation of maternity care.

In brief: the National Maternity Bereavement Experience Survey

Who was eligible to take part in the survey and how was it conducted?

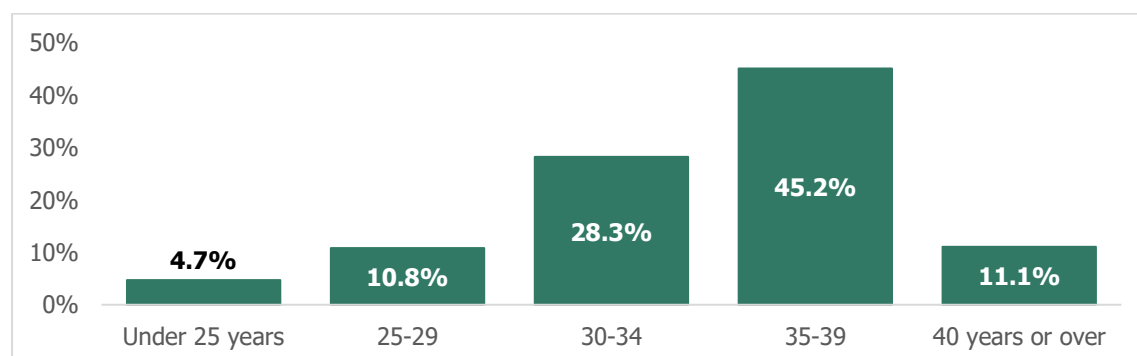
Women aged 16 or over, and their partners, who experienced a second trimester miscarriage (from 14 weeks of pregnancy⁴), a stillborn infant or the early neonatal death of a baby⁵ in one of Ireland's 19 maternity units or hospitals from 1 January 2019 to 31 December 2021⁶ were eligible to participate. This report focuses on the experiences of those who experienced a second trimester miscarriage.

The survey rollout commenced on the 1 September 2022 and remained open for completion for 8 weeks, closing on 31 October 2022. Participation in the survey was voluntary and confidential. Administration and survey fieldwork was carried out by Behaviour & Attitudes on behalf of the partner organisations.

Who participated in the survey?

In total, 351 women and 122 partners who experienced a second trimester miscarriage participated in the survey. A breakdown of participants by age group is provided in Figure 1, with over 70% of participants aged between 30 and 39. Table 1 outlines the year in which participants experienced a bereavement.

Figure 1. Characteristics of participants who experienced a second trimester miscarriage, by age group.



⁴ This criterion was developed with input from clinical experts in the area of miscarriage care, along with parents who experienced miscarriage to help identify a clear, acceptable, sensitive non-medicalised definition for 2nd trimester miscarriage for inclusion in the survey.

⁵ 29 participants experienced an 'other' type of loss, relating to medical terminations or compassionate inductions for fatal foetal abnormalities, unspecified or multiple losses during the survey period.

⁶ This time period was chosen to evaluate current maternity bereavement care experiences of women, following the implementation of the *National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death*.

Table 1. Details on the year bereavement was experienced.

Year bereavement was experienced	No.	%
2019	118	32.7%
2020	122	33.8%
2021	121	33.5%

What questions were asked in the survey?

The survey included 99 questions for the stages of care listed below:

- Communication and information at the time of diagnosis
- Admission care
- Labour and birth
- Care after birth and meeting your baby
- Neonatal care⁷
- Postnatal care
- Bereavement Care
- Post-mortem examination and investigations
- Discharge
- Follow up care
- Overall care
- Partner or support person

90 questions explored the experiences of women who experienced a loss, with an additional nine questions dedicated to the experiences of partners. Five survey questions were in free-text format, asking participants to describe their experiences in their own words.

⁷ Participants who experienced a second trimester miscarriage were not asked to answer the questions on neonatal care, however seven did answer these questions.

In their own words: Analysis of participants' comments

Five free-text questions asked participants to describe their experiences in their own words. These questions are listed below:

- Q75. Is there anything else you would like to tell us about the care you received in hospital from your admission through to your discharge home?
- Q88. Reflecting back on your experience, what was good about your care?
- Q89. Reflecting back on your experience, was there anything that could be improved about your care?
- Q90. Do you have anything else you wish to tell us about your experience of care that is not covered in the survey?
- Q99. Is there anything else that you would like to tell us about your experience?⁸

In total, 965 comments were made by participants who experienced a second trimester miscarriage in response to the free-text questions. The results for each question are presented in the following pages.

A framework approach⁹ was used to analyse the comments received in response to the free-text questions where participants described their experiences. This approach involves multiple analysts reviewing survey comments, identifying a framework of key concepts and themes within the comments, then applying the framework across all survey comments. An analytical framework consisting of 35 themes was developed, with the themes listed in Table 2.

⁸ This question was specific to partners

⁹ Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 2013;13(1):117.

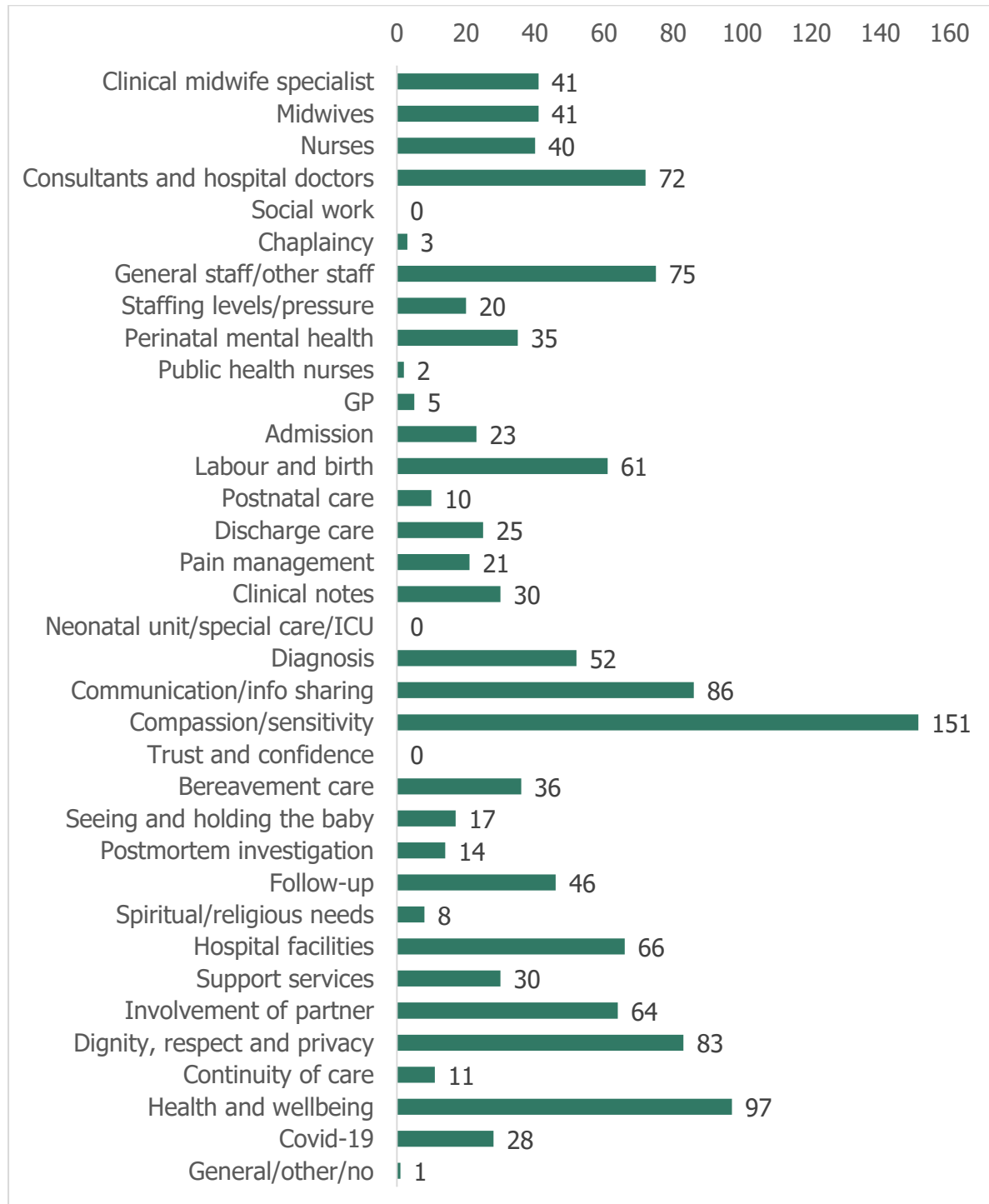
Table 2. List of Comment Themes

Clinical midwife specialist	Diagnosis
Midwives	Communication and information sharing
Nurses	Compassion and sensitivity
Consultants and hospital doctors	Trust and confidence
Social work	Bereavement care
Chaplaincy	Seeing and holding the baby
General staff or other staff comments	Post-mortem investigation
Staffing levels/pressure	Follow-up
Perinatal mental health	Spiritual/religious needs
Public Health Nurses	Hospital facilities
GP	Support services
Admission	Involvement of partner
Labour and birth	Dignity, respect and privacy
Postnatal care	Continuity of care
Discharge care	Health and wellbeing
Pain management	Covid-19
Clinical notes	General/other/no
Neonatal unit/special care/ICU	

Q75. Is there anything else you would like to tell us about the care you received in hospital from your admission through to your discharge home?

This question asked specifically about care received in hospital. In total, participants made 198 comments in response to this question. Figure 2 shows the breakdown of themes covered within these comments.

Figure 2. Responses to Q.75 broken down by theme



The most frequently-occurring theme was 'compassion and sensitivity', which appeared in 151 comments. The next most common themes were 'health and wellbeing' (97 comments) and 'communication and information-sharing' (86 comments). A selection of comments made in response to this question is provided below.

Sample comments

"I was really surprised by the sensitive support and professionals, all the staff I met in the hospital."

"The one thing that that really helped us during this situation was having the bereavement nurse with us during every step after we found out our baby had no heartbeat. From explaining the process, holding my hand and giving our daughter the dignity she deserved. The emotional and practical support saved us."

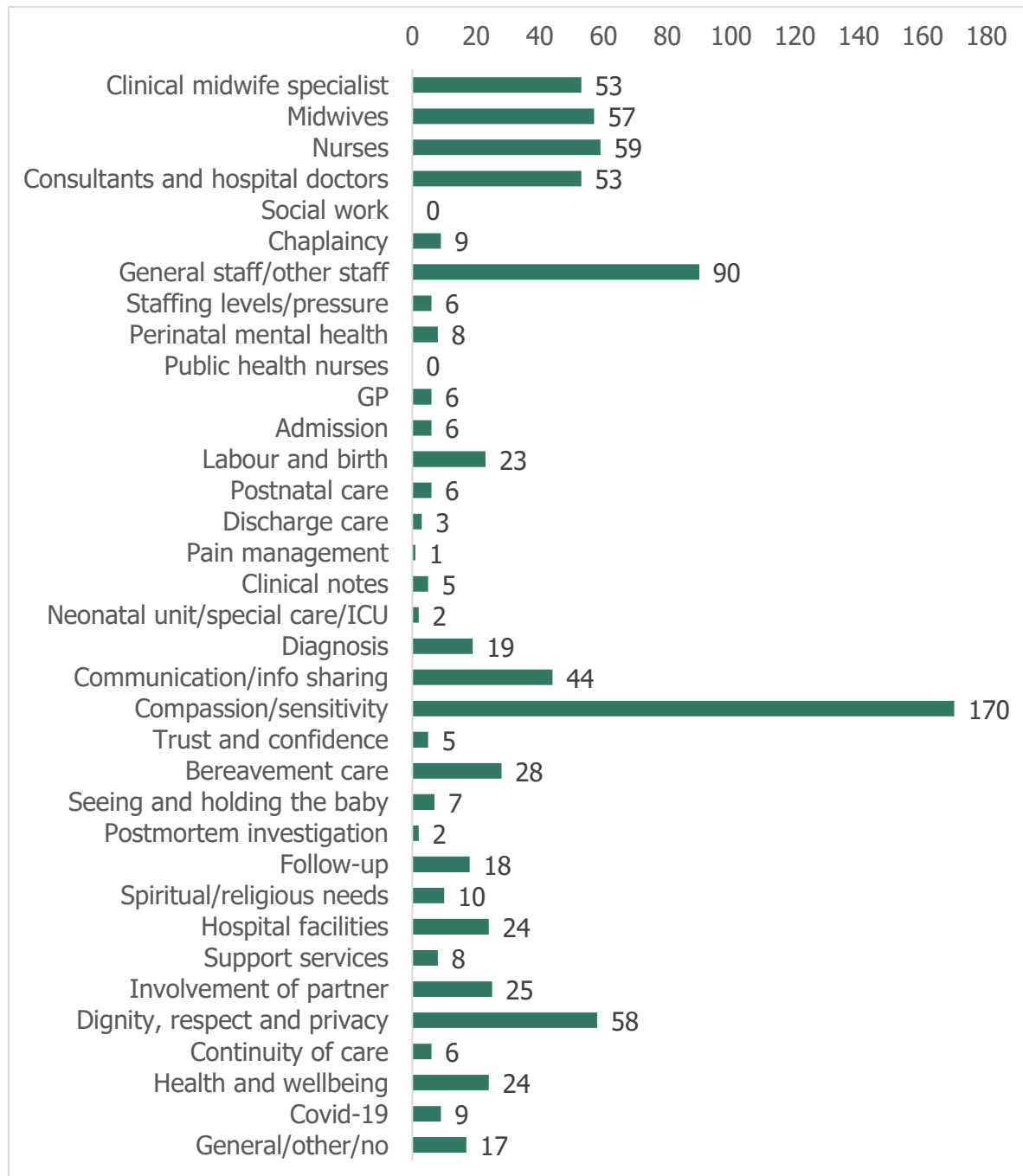
"I had to request to meet with a senior Doctor in order to be able to ask some questions around what had happened. This was not offered. He didn't show much sympathy."

"The main focus was on my physical health I don't remember any mention of my mental health on discharge."

Q88. Reflecting back on your experience, what was good about your care?

In total, participants made 272 comments in response to this question. Figure 3 shows the breakdown of themes covered within these comments.

Figure 3. Responses to Q.88 broken down by theme



The most frequently-occurring theme was 'compassion and sensitivity', which appeared in 170 comments. The next most common themes were 'general staff or

other staff comments' (90 comments) and 'nurses' (59 comments). A selection of comments made in response to this question is provided below.

Sample comments

"All the nurses and doctors were amazing and could not do more for us. They were very accommodating and kind."

"Reception staff and theatre staff were kind and pleasant. Bed was comfortable, nice big bright windows in the room. When nurses were there they were kind and pleasant too."

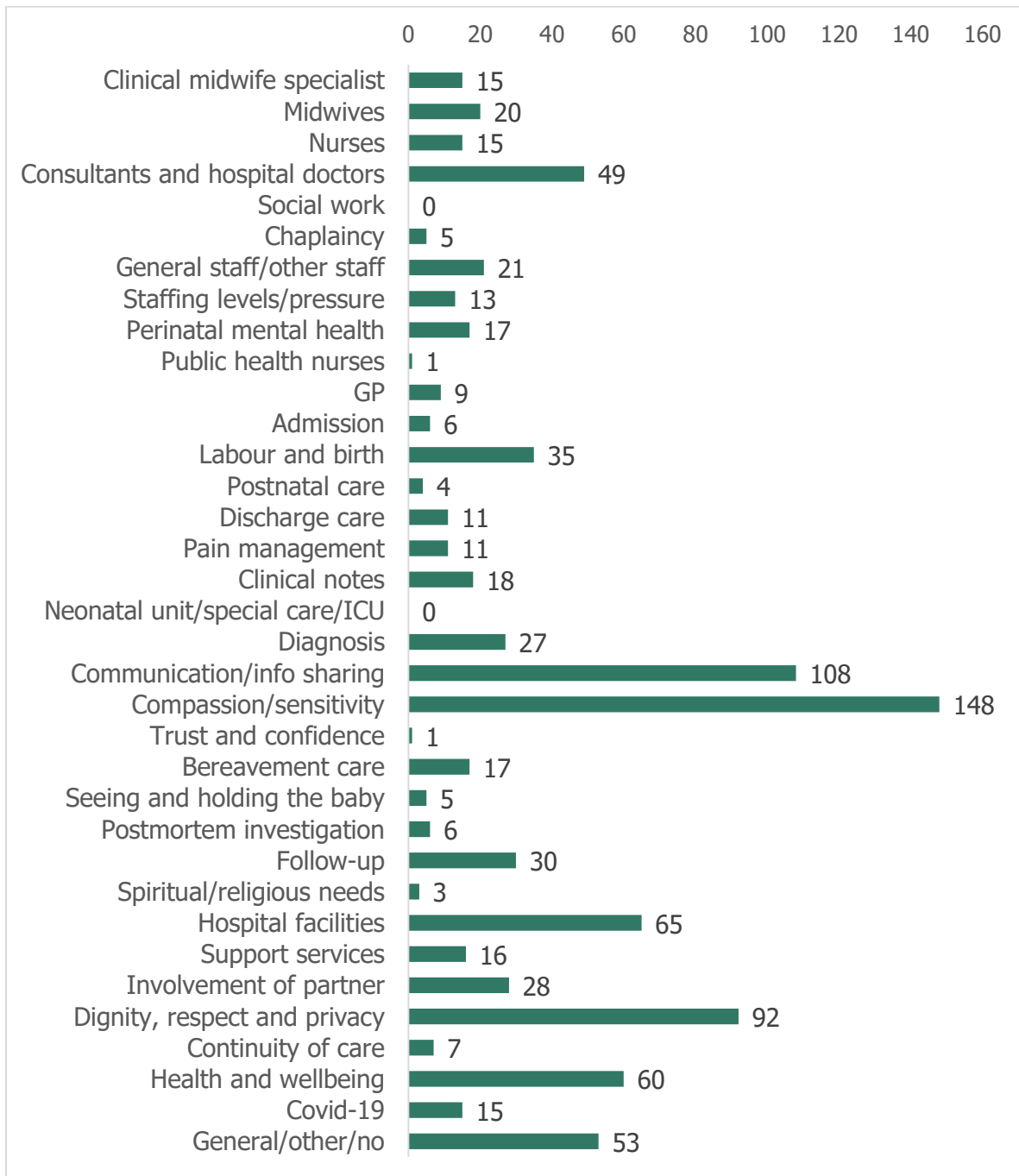
"Nurses were very caring & compassionate. Very respectful of our tiny baby, which really mattered during that time."

"The staff that helped me make memories with my daughter, the chaplain lady that came to baptise her and helped organise the burial."

Q89. Reflecting back on your experience, was there anything that could be improved about your care?

In total, participants made 277 comments in response to this question. Figure 4 shows the breakdown of themes covered within these comments.

Figure 4. Responses to Q.89 broken down by theme



The most frequently-occurring theme was 'compassion and sensitivity', which appeared in 148 comments. The next most common themes were 'communication and information-sharing' (108 comments) and 'dignity, respect and privacy' (92 comments). A selection of comments made in response to this question is provided below.

Sample comments

"When given initial explanation on the miscarriage it was in an area where routine scans were happening and behind a curtain in a very busy area. No privacy, sympathy or empathy shown on this occasion by the junior doctor."

"More training for staff, more compassion from staff. And mothers and fathers should NOT be left in areas where babies are being discharged from hospital"

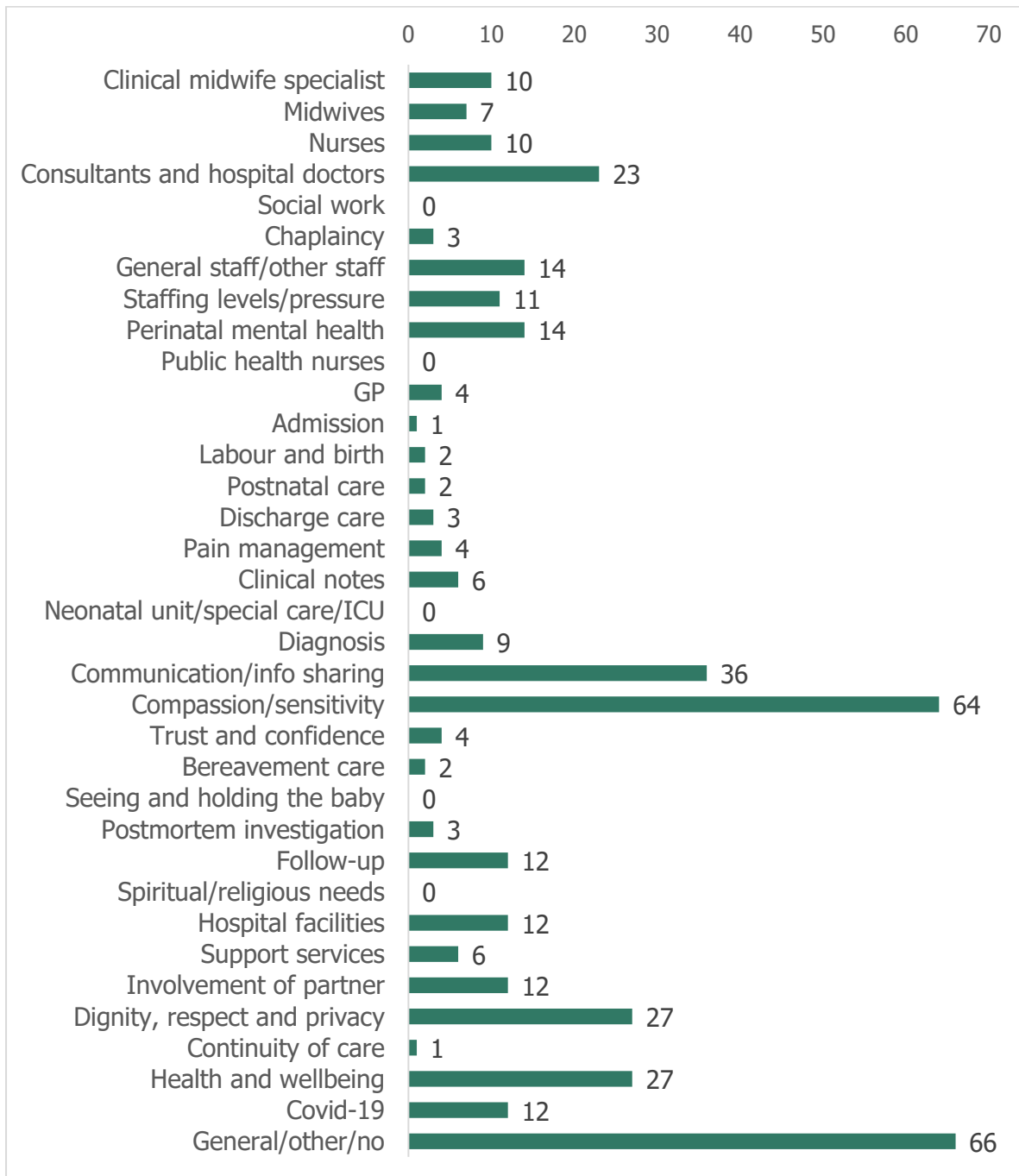
"Talking through what to expect after getting diagnosis of a fatal foetal abnormality, preparing the parents for after the delivery and expected funeral arrangements."

"I tried to access supportive care from the hospital and my calls were never returned, they were extremely hard calls to make."

Q90. Do you have anything else you wish to tell us about your experience of care that is not covered in the survey?

In total, participants made 167 comments in response to this question. Figure 5 shows the breakdown of themes covered within these comments.

Figure 5. Responses to Q.90 broken down by theme



The most frequently-occurring theme was 'general or other comment', which appeared in 66 comments. The next most common themes were 'compassion and sensitivity' (64 comments) and 'communication and information-sharing' (36 comments). A selection of comments made in response to this question is provided below.

Sample comments

"Féileacáin are an amazing support and help make memories with your baby. They made the loss very dignified and you felt seen and they made the experience very special with the care and consideration they give to a tiny little baby placed in a beautiful knitted crib. I think they are an essential part of the care provided."

"I'm glad you're doing this survey I hope positive changes happen to help other women in the future. Particularly women who lose babies in 2nd trimester"

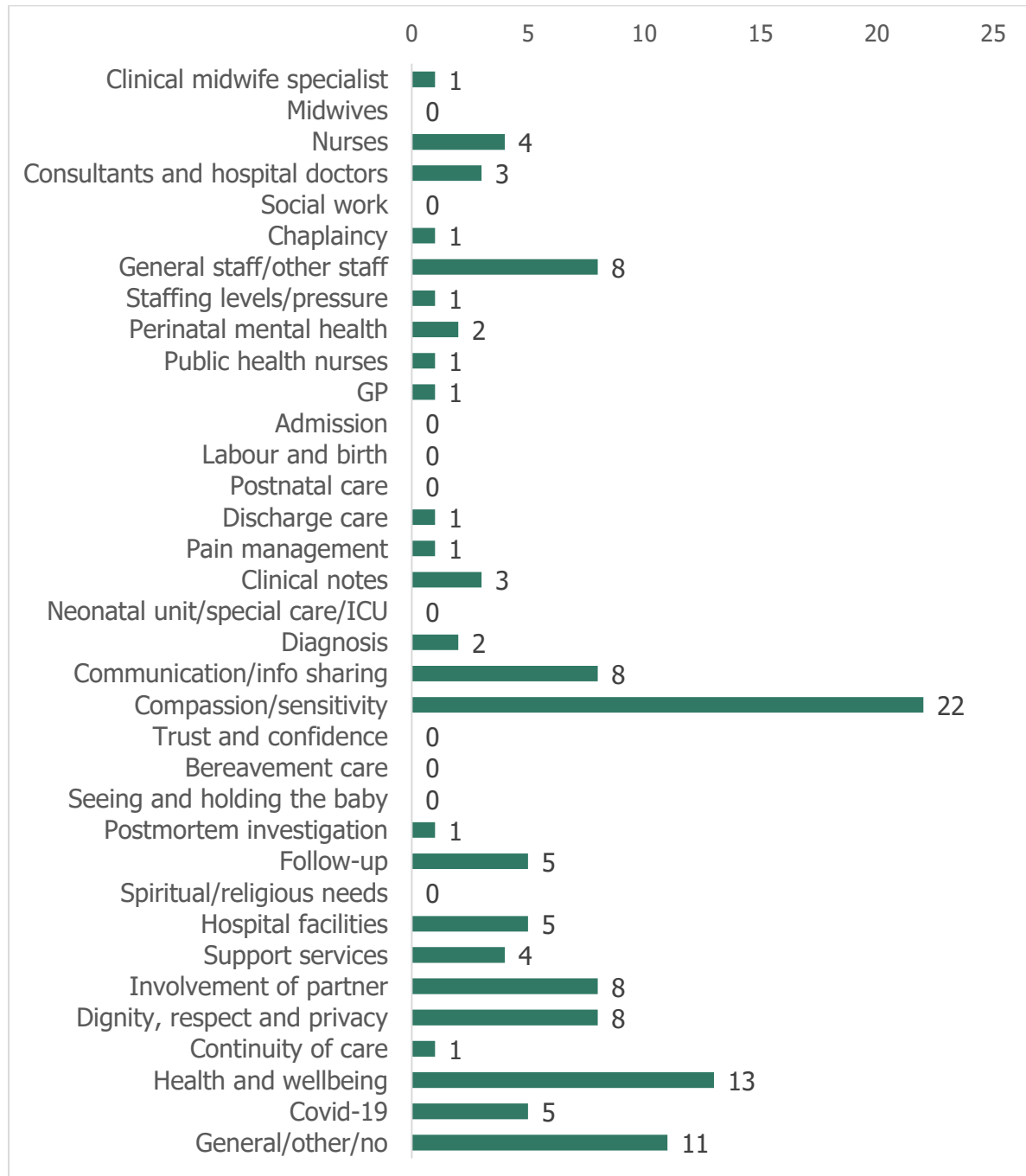
"The actual medical part was top quality, all of my bad memories are due to the experience surrounding it. Surely some compassion and consideration can be afforded on these worst days."

"I think a letter should be sent to your GP and they should be obliged to make a phone call or set up an appointment with you afterwards to check in etc. I fell pregnant 6 weeks after my loss and my doctor was not aware of my loss (and if she was she didn't mention it) which is very cold. It wasn't until 6 months after that birth I had the courage to see help from the doctor."

Q99. (Partner) Is there anything else that you would like to tell us about your experience?

This question was included in the dedicated section for partners and support persons. In total, participants made 52 comments in response to this question. Figure 6 shows the breakdown of themes covered within these comments.

Figure 6. Responses to Q.99 broken down by theme



The most frequently-occurring theme was 'compassion and sensitivity', which appeared in 22 comments. The next most common themes were 'health and wellbeing' (13 comments) and 'general or other comments' (11 comments). A selection of comments made in response to this question is provided below.

Sample comments

"It was a very harrowing time for my wife and I, losing our little girl and giving birth to her healthy twin brother. Thankfully he is a well happy child. The care and attention we got from the health care professionals was excellent and we are forever grateful for that!"

"A difficult time was made easy by the excellent staff who understood what our needs would be and supported as best they could."

"The after support for the mother was poor to none. Post-natal depression was an issue for my partner."

"I was never advised of any support organisations, or how this experience could affect me, apart from my partner & family members checking in, I was never spoken to or giving advice from any health care professionals."

Results for each stage of maternity bereavement care

The stages of maternity bereavement care

The National Maternity Bereavement Experience Survey follows the maternity bereavement care journey and captures the pathway of maternity bereavement care from communication and information at the time of antenatal diagnosis¹⁰, through to labour and birth, postnatal and bereavement care, neonatal care, investigations, discharge home, follow up care and care in the community. The survey questions are grouped into 12 stages. A short description of these stages is provided below. The number of questions related to each stage is also shown.

1. Communication and information at the time of diagnosis
 - a) 10 questions. Experiences of care, support, interactions and provision of information at the time of baby's diagnosis.
2. Admission care
 - a) 3 questions. Experiences of care when admitted for induction of labour or delivery, focusing on admission planning and the hospital environment.
3. Labour and birth
 - a) 10 questions. Experiences of interactions with healthcare professionals, pain management and involvement in decisions while in labour and giving birth.
4. Care after birth and meeting the baby
 - a) 4 questions. Experiences of meeting the baby, and the support and privacy provided.
5. Neonatal care¹¹
 - a) 6 questions. Experiences of care in the neonatal unit, including visiting, involvement in decisions and communication.
6. Postnatal care
 - a) 11 questions. Experiences of hospital care after the birth, including physical and emotional support.
7. Bereavement care
 - a) 7 questions. Experiences of support with practical and emotional aspects of dealing with the bereavement.
8. Post-mortem examinations and investigations
 - a) 6 questions. Experiences of the post-mortem examination process, including timeframes and communication.
9. Discharge care
 - a) 5 questions. Experiences of preparation for leaving the hospital and provision of information and support for returning home.

¹⁰ Diagnosis includes a medical condition, which meant that a baby or babies could die before or after they were born or that a baby had no heartbeat.

¹¹ Participants who experienced a second trimester miscarriage were not asked these questions

10. Follow-up care

- a) 7 questions. Experiences of care at home after discharge, including care from a GP or Public Health Nurse.

11. Overall care

- a) Overall experiences of care including feeling respected and being provided with sufficient support.

12. Partner or support person

- a) 9 questions. Experiences of a partner or support person, including involvement in decisions and provision of support.

Interpreting the results of the stages of care

Scores out of 10 are given for relevant questions belonging to a stage of care or to a stage as a whole. A score of 0 indicates a very negative experience and a score of 10 indicates a very positive experience. Some questions simply provide descriptive information and these questions are not given a score out of 10.

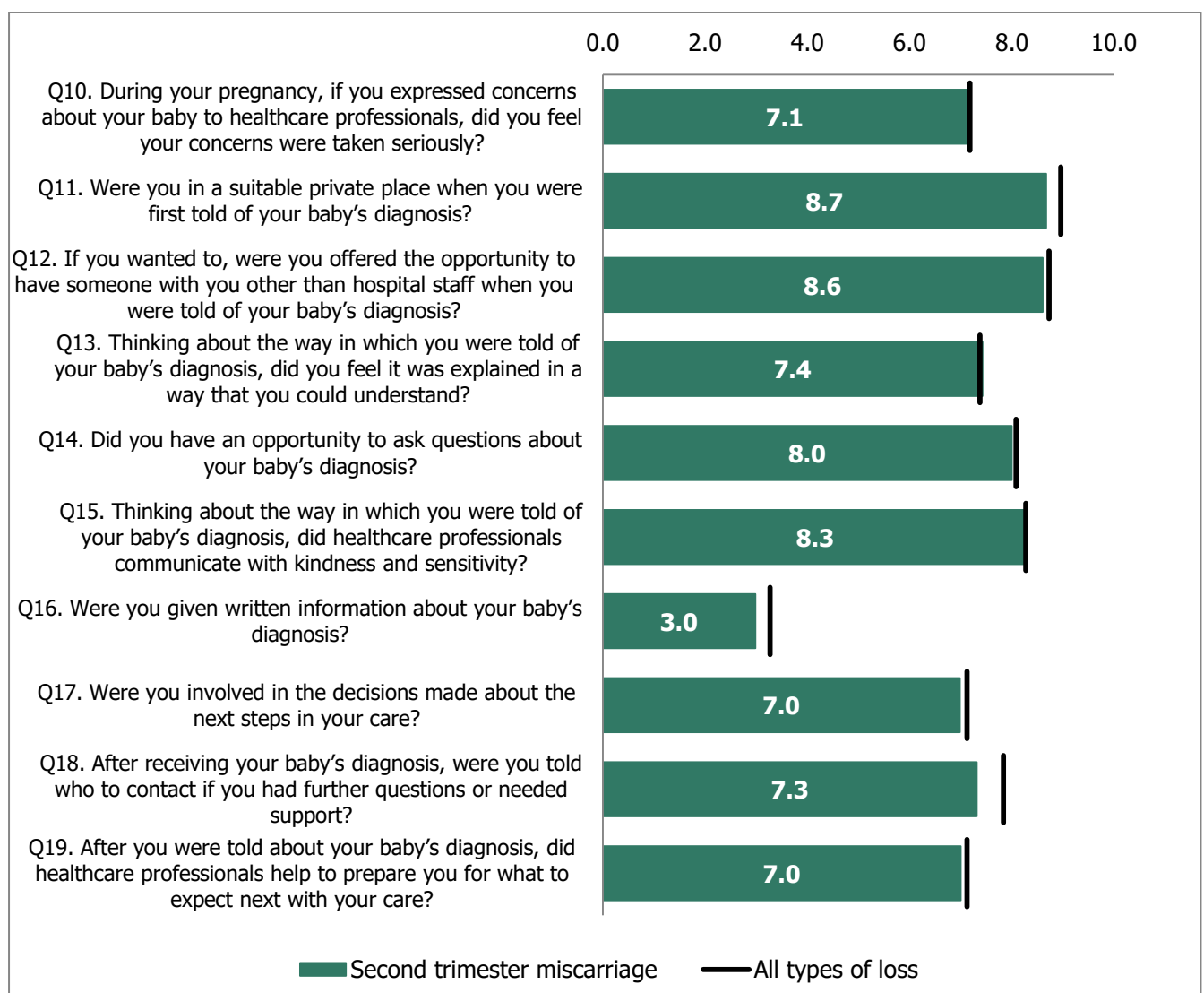
Statistical tests were carried out to examine if there were significant differences between the national average and scores for individual questions and stages of care. For further information on the analyses please see Appendix 1.

Communication and information at the time of diagnosis

The questions for this stage of care asked about experiences relating to receiving a diagnosis that the baby or babies could die before or after they were born or that the baby had no heartbeat. In total, 135 (62%) of participants who experienced a second trimester miscarriage said that they had not received such a diagnosis. Those who had not received a diagnosis did not answer these questions.

Ten questions for this stage of care were given a score out of 10, and the results are presented in Figure 7. The highest-scoring question for this stage of care related to privacy, with 118 participants (87%) saying that they were in a suitable private place when first told about their baby’s diagnosis. The lowest-scoring question related to receiving written or printed information about the diagnosis, with 87 participants (70%) saying they did not receive such information.

Figure 7. Individual questions for ‘Communication and information at the time of diagnosis’.



Comparisons of ratings for this stage by the type of loss participants experienced are shown in Figure 8. No statistically significant differences from the national average were identified by type of loss for this stage of care.

Figure 8. Comparison of 'Communication and information at the time of diagnosis' by type of loss experienced.



Admission care

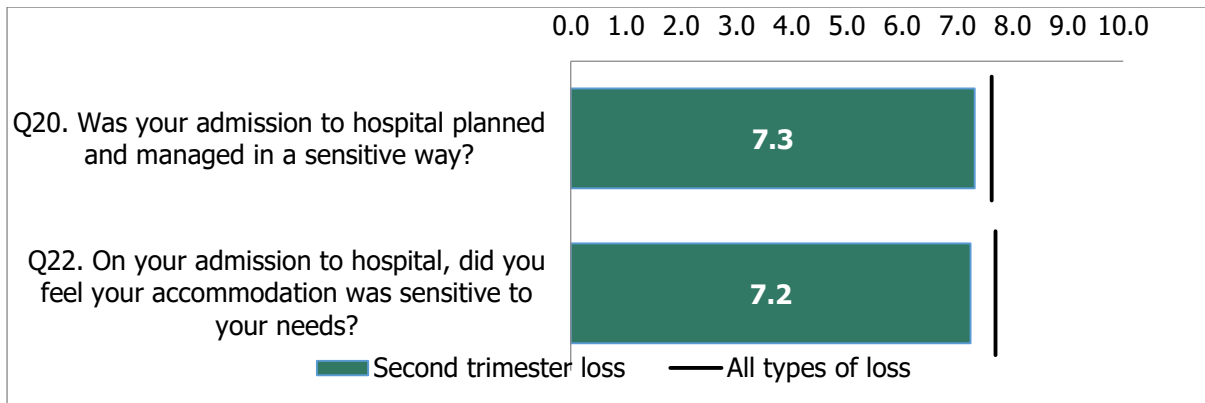
This stage included three questions on experiences of being admitted to hospital. One question asked people to describe the type of room or ward they were admitted to. The results for this question are presented in Table 3. Most participants who experienced a second trimester miscarriage (113, 84%) said they were admitted to a single room.

The two other questions for this stage were scored out of 10 and the results are presented in Figure 9. These questions asked participants if their admission was managed sensitively, and whether their hospital accommodation was sensitive to their needs. For these questions, 67 participants (56%) said that their admission was 'definitely' planned and managed in a sensitive way, while 73 (58%) said that their accommodation was 'definitely' sensitive to their needs.

Table 3. Results for question on hospital accommodation at admission

Q21. On your admission to hospital, which of the following best describes your accommodation where you spent most of your time?		
	No.	%
Single room (not shared)	113	84.3%
Shared room	7	5.2%
Labour ward	5	3.7%
Antenatal ward	12	9.0%
Postnatal ward	3	2.2%
General ward	0	0.0%
Emergency ward	4	3.0%
I wasn't admitted overnight	9	6.7%
Other	5	3.7%

Figure 9. Individual questions for 'Admission care'.



Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 10. Participants who experienced a second trimester miscarriage gave ratings that were not significantly different from the national average, while participants who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 10. Comparison of 'Admission care' by type of loss experienced



* indicates a significant difference from the national average

Labour and birth

There were ten questions in this section, including a question asking participants if they were accompanied during their labour and birth. The results for this question are shown in Table 4. Most women who experienced a second trimester miscarriage (260, 75%) said that their partner accompanied them during labour and birth.

The other nine questions in this section explored involvement in decisions, pain management and communication during labour and birth. The results for these questions are shown in Figure 11.

Table 4. Results for question on whether participant was accompanied during the labour and birth

Q23. Were you accompanied by anyone other than healthcare professionals during the labour and birth of your baby?		
	No.	%
Yes, by my partner	260	74.5%
Yes, by a support person (such as a family member, friend or doula)	13	3.7%
No, I was alone	38	10.9%
I did not want to have someone with me	4	1.1%
I was not able to have someone with me due to COVID-19 restrictions	24	6.9%
I was not able to have someone with me for other reasons	11	3.2%

The highest-scoring question for this stage related to privacy, with 177 participants (79%) saying they were in a suitable private place when they were first told that their baby had died.

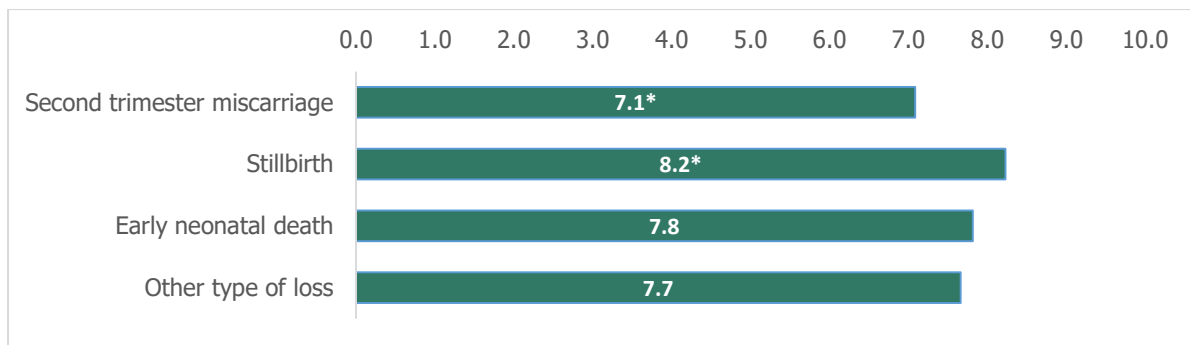
The joint-lowest scoring questions for this stage related to involvement in decisions, opportunities to ask questions, and clear explanations. 58 participants (18%) felt that they weren't involved in decisions about their care during labour and birth, while 44 (14%) said that they did not have the opportunity to ask questions. In addition, 35 participants (15%) felt that their baby's death was not explained to them in a way that they could understand.

Figure 11. Individual questions for 'Labour and birth'.



Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 12. Participants who experienced a second trimester miscarriage gave significantly below-average ratings for this stage of care.

Figure 12. Comparison of 'Labour and birth' by type of loss experienced.



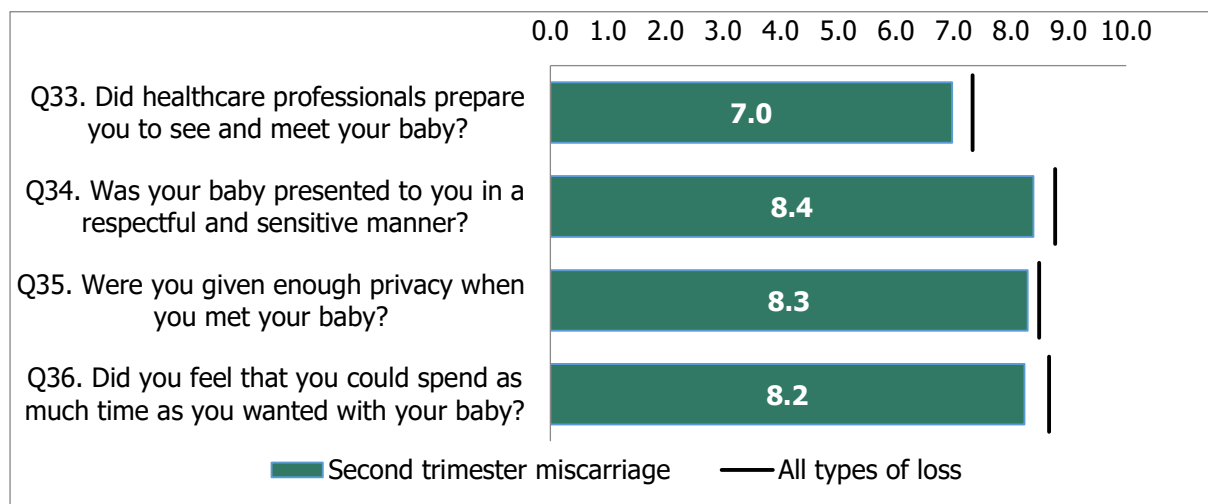
* indicates a significant difference from the national average

Care after birth and meeting your baby

Each of the four questions for this stage of care were given a score out of 10 and the results are shown in Figure 13.

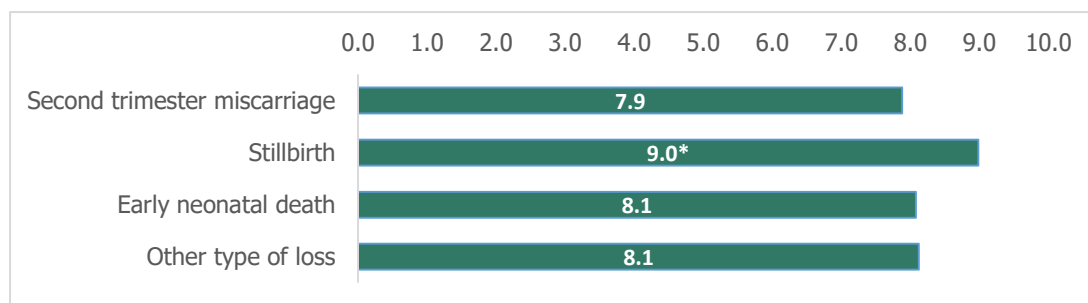
The highest-scoring question for this stage asked participants if their baby was presented to them in a respectful and sensitive manner, with 226 participants (78%) answering 'yes, definitely'. The lowest-scoring question for this stage related to how healthcare professionals prepared participants to see and meet their baby. 50 participants (17%) said that healthcare professionals did not prepare them for this.

Figure 13. Individual questions for 'Care after birth'.



Comparisons of ratings for this stage of care the type of loss participants experienced are provided in Figure 14. Those who experienced a second trimester miscarriage gave a similar rating to the national average, while participants who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 14. Comparison of 'Care after birth' by type of loss experienced.



* indicates a significant difference from the national average

Postnatal care

This section included 10 questions that asked participants who experienced a second trimester miscarriage about their experiences in the maternity hospital or unit following the birth.

The first question in this section asked participants who had experienced a second trimester miscarriage about their hospital accommodation after their baby was born, and the results are shown in Table 5. In total, 217 participants (62%) said that they were accommodated in a single room, with a further 84 (24%) accommodated in a designated bereavement room. The other questions for this section were scored out of 10 and the results are shown in Figure 15.

Table 5. Results for question on hospital accommodation in the postnatal period

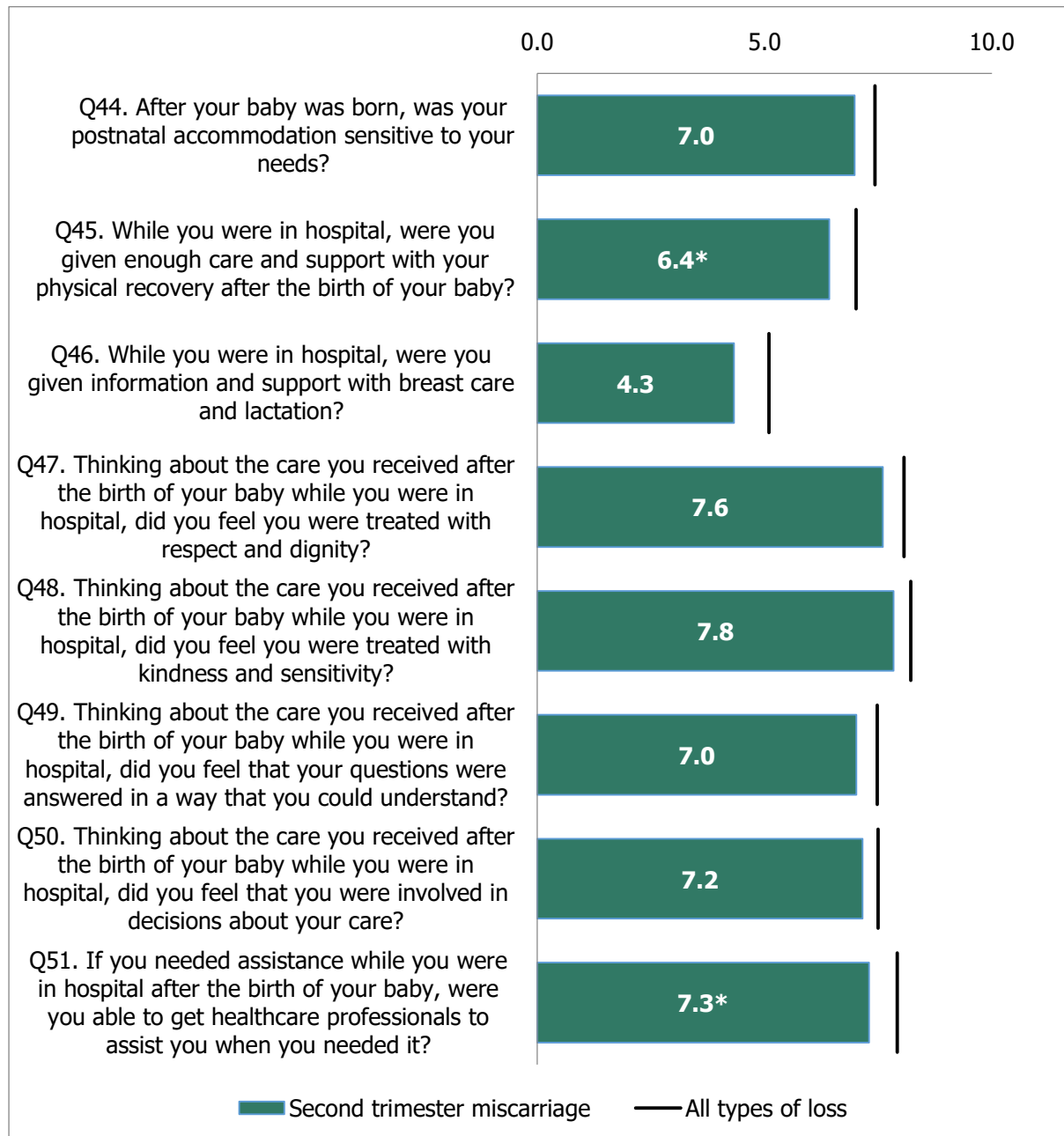
Q43. After your baby was born, which of the following best describes your accommodation?		
	No.	%
Single room (not shared)	217	62.2%
Bereavement room (designated facility for bereaved families)	84	24.1%
Shared room	12	3.4%
Labour ward	8	2.3%
Antenatal ward	6	1.7%
Postnatal ward	5	1.4%
General ward	11	3.2%
Emergency ward	8	2.3%
I wasn't admitted overnight	35	10.0%
Other	10	2.9%

The highest-scoring question for this stage related to kindness and sensitivity, with 226 participants (66%) saying that they were 'always' treated with kindness and sensitivity. The lowest-scoring question for this stage asked about breast care and lactation, with 58 participants (43%) saying that they were not given information and support relating to breast care and lactation.

Two questions scored significantly below the national average. Participants who experienced a second trimester loss were less likely than average to say they were

given enough support with their physical recovery after the birth, and were also less likely than average to say they were able to get assistance from healthcare staff when they needed it.

Figure 15. Individual questions for 'Postnatal care'.



* indicates a significant difference from the national average

Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 16. Participants who experienced a second trimester miscarriage gave significantly below-average ratings, while those who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 16. Comparison of 'Postnatal care' by type of loss experienced



* indicates a significant difference from the national average

Bereavement care

This section asked seven questions about bereavement care and supports provided to parents. The first question asked whether parents who experienced a second trimester miscarriage were offered the opportunity to interact and make memories with their baby in a number of ways. The results for this question are shown in Table 6. Most participants said they were offered multiple ways of interacting with and making memories with their baby, including naming them, taking photographs, creating a memory box, and other activities. 46 participants (13%) said that they were not offered any of these options.

Question 57 asked if family or friends were offered the opportunity to meet the baby, and the results for this question are shown in Table 7. 78 participants (22%) said that their family or friends were offered the opportunity to meet their baby, while 127 (36%) said that this was not possible due to COVID-19 restrictions.

Table 6. Results for question on opportunities to interact and make memories with the baby

Q54. Were you offered the opportunity to...		
	No.	%
Name your baby	258	74.1%
Spend time with your baby	258	74.1%
Hold your baby	230	66.1%
Dress your baby	57	16.4%
Bath your baby	5	1.4%
Take a lock of your baby's hair	20	5.7%
Have photos with your baby	169	48.6%
Have a copy of your baby's hand print or foot print	165	47.4%
Have a naming or blessing ritual or ceremony	154	44.3%
Create a memory box	215	61.8%
Use a Bereavement alert symbol	114	32.8%
I was not offered any of these	46	13.2%
I did not want any of these	18	5.2%

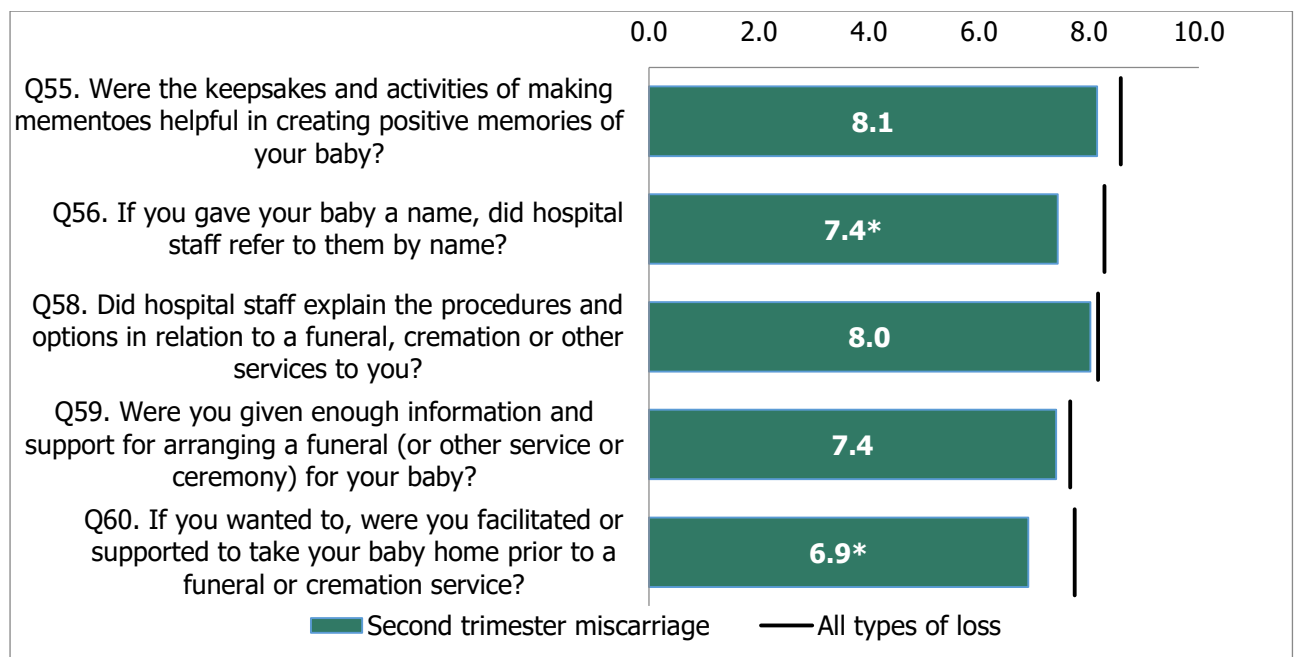
Table 7. Results for question on family or friends having an opportunity to meet the baby

Q57. Were your family or friends offered the opportunity to meet your baby?		
	No.	%
Yes	78	22.3%
No, but I would have liked them to	27	7.7%
No, I did not want them to	88	25.2%
Family and friends were not able to visit due to COVID-19 restrictions	127	36.4%
Family and friends were not able to visit for other reasons	29	8.3%

The five other questions in this section asked about emotional and practical support, and the results are shown in Figure 17. The highest-scoring question for this stage related to memory-making, with 198 participants (71%) saying that the activities of making mementoes were 'definitely' helpful in creating positive memories of their baby. The lowest-scoring question related to being supported to take their baby home prior to the funeral, with 59 participants (24%) saying that they were not facilitated or supported to take their baby home prior to the funeral or cremation.

Two questions scored below the national average. Participants who experienced a second trimester miscarriage were less likely than average to say that hospital staff referred to their baby by name. These participants were also less likely to feel supported to take their baby home.

Figure 17. Individual questions for 'Bereavement care'.



* indicates a significant difference from the national average

Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 18. Participants who experienced a second-trimester loss rated this stage significantly lower than the national average, while those who experienced a stillbirth or early neonatal death gave more positive ratings.

Figure 18. Comparison of 'Bereavement care' by type of loss experienced.



* indicates a significant difference from the national average

Post-mortem examination and investigations

The six questions in this section asked parents about their experiences of post-mortem examinations and the communications around them. 123 people (35%) said that their baby had a consented post-mortem, while five people (1.4%) said their baby had a coroner's post-mortem.¹²

Table 8. Results for question on post-mortem examination

Q61. Did your baby have a post-mortem examination?		
	No.	%
Yes, a consented post-mortem	123	35.0%
Yes, a coroner's post-mortem	5	1.4%
No, I declined a post-mortem examination	91	25.9%
No, I was not offered a post-mortem examination	132	37.6%

Participants were asked when they had received a follow-up appointment to hear the results of the tests and investigations. Findings for this question are shown in Table 9. Most participants (65%) said that they received the results within one to three months. No participants said they had waited for longer than 18 months.

¹² A consented post-mortem examination takes place with the written consent of the parents following discussion with a senior obstetrician or neonatologist and the provision of written information on the process.

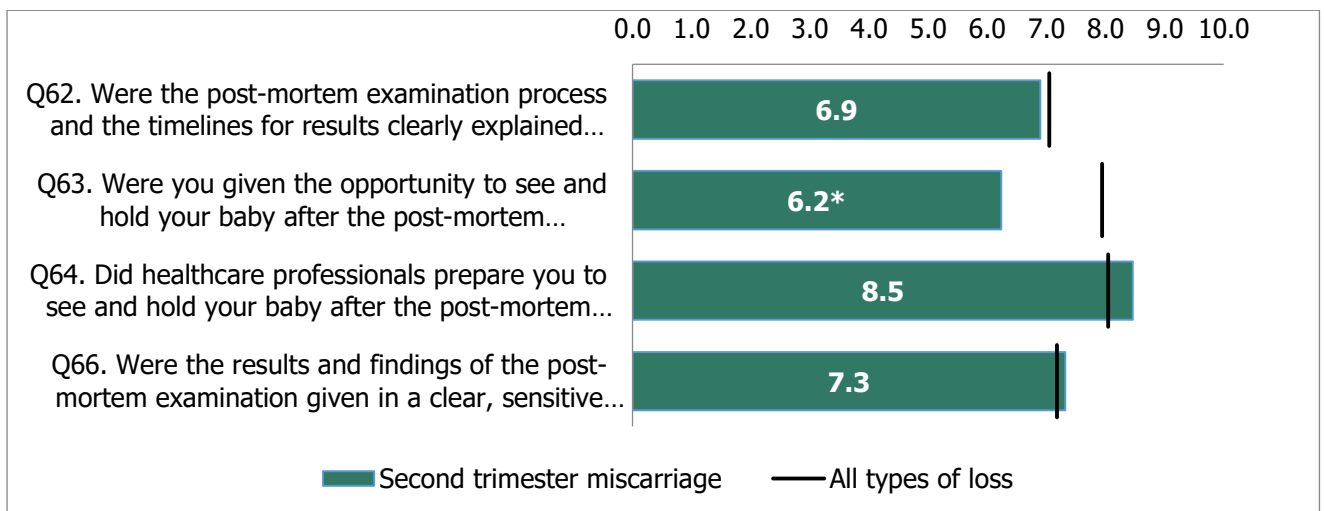
In the case of a coroner's post-mortem examination, parents are informed of the reason for this requirement and the process is explained to the parents along with written information. Parent's consent is not required for a post-mortem examination instigated by a Coroner.

Table 9. Results for question on follow-up appointment

Q65. How soon after the post-mortem examination did you have a follow-up appointment with a consultant or team in the hospital to receive the results and findings?		
	No.	%
I haven't received the results	5	3.9%
1 to 3 months	83	64.8%
4 to 6 months	31	24.2%
7 to 11 months	8	6.3%
12 to 18 months	1	0.8%
Longer than 18 months	0	0.0%

The results for the four other questions in this section are shown in Figure 19. The lowest-scoring question related to being given the opportunity to see and hold their baby after the post-mortem examination, with 32 participants (38%) saying they were not given this opportunity. The highest-scoring question for this stage related to being prepared to see and hold the baby after the post-mortem examination. 37 participants (71%) said that they were 'definitely' prepared to see and hold their baby after the post-mortem examination. Participants who experienced a second trimester miscarriage were less likely than average to say they were given the opportunity to see and hold their baby after the post-mortem examination.

Figure 19. Individual questions for 'Post-mortem examination and investigations'.



* indicates a significant difference from the national average

Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 20. There were no significant differences from the national average by type of loss.

Figure 20. Comparison of 'Post-mortem examination and investigations' by type of loss experienced.



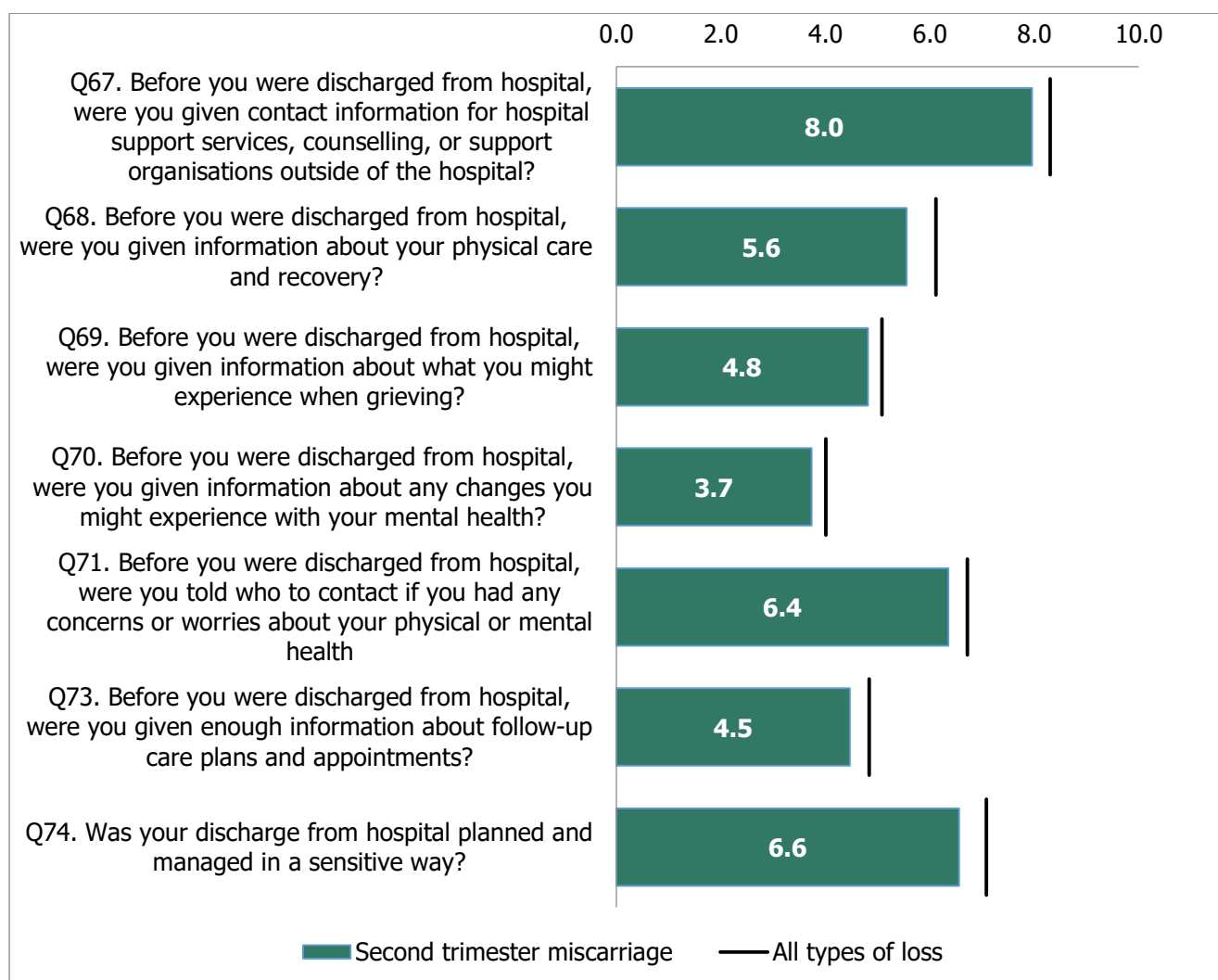
Discharge

This section included seven questions that asked participants who experienced a second trimester miscarriage about the information and support provided to them prior to being discharged from hospital.

Six questions for this section were scored out of 10 and the results are shown in Figure 21. The final question in this section was a free-text question asking participants if they had any additional comments about their experiences in hospital from admission through to discharge.

The highest-scoring question for this stage related to provision of information for support services, with 265 participants (80%) saying that they were given contact information for hospital support services, counselling or support organisations outside of the hospital. The lowest-scoring question related to information about mental health, with 167 participants (52%) saying that they were not given information about changes they might experience with their mental health.

Figure 21. Individual questions for 'Discharge'.



Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 22. Participants who experienced a second trimester miscarriage gave similar ratings to the national average, while those who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 22. Comparison of 'Discharge' by type of loss experienced



* indicates a significant difference from the national average

Follow-up care

This section asked participants who experienced a second trimester miscarriage seven questions about their experiences of care at home after their discharge from hospital, and the follow-up care provided by the hospital.

The first question for this stage asked participants who they saw as part of their follow-up care, and the results are shown in Table 10. 153 participants (44%) said that they saw a GP, while significant numbers also saw a bereavement midwife (37%) or an obstetrician (34%). On the other hand, 71 participants (20%) said that they had not had any follow-up care since leaving hospital.

The final question in this section asked about the supports that participants accessed after they were discharged from hospital, and the results are shown in Table 11. The most common source of support accessed by participants were partners, family and friends. 11 participants (4%) had not accessed any supports.

Table 10. Results for question on follow-up care providers.

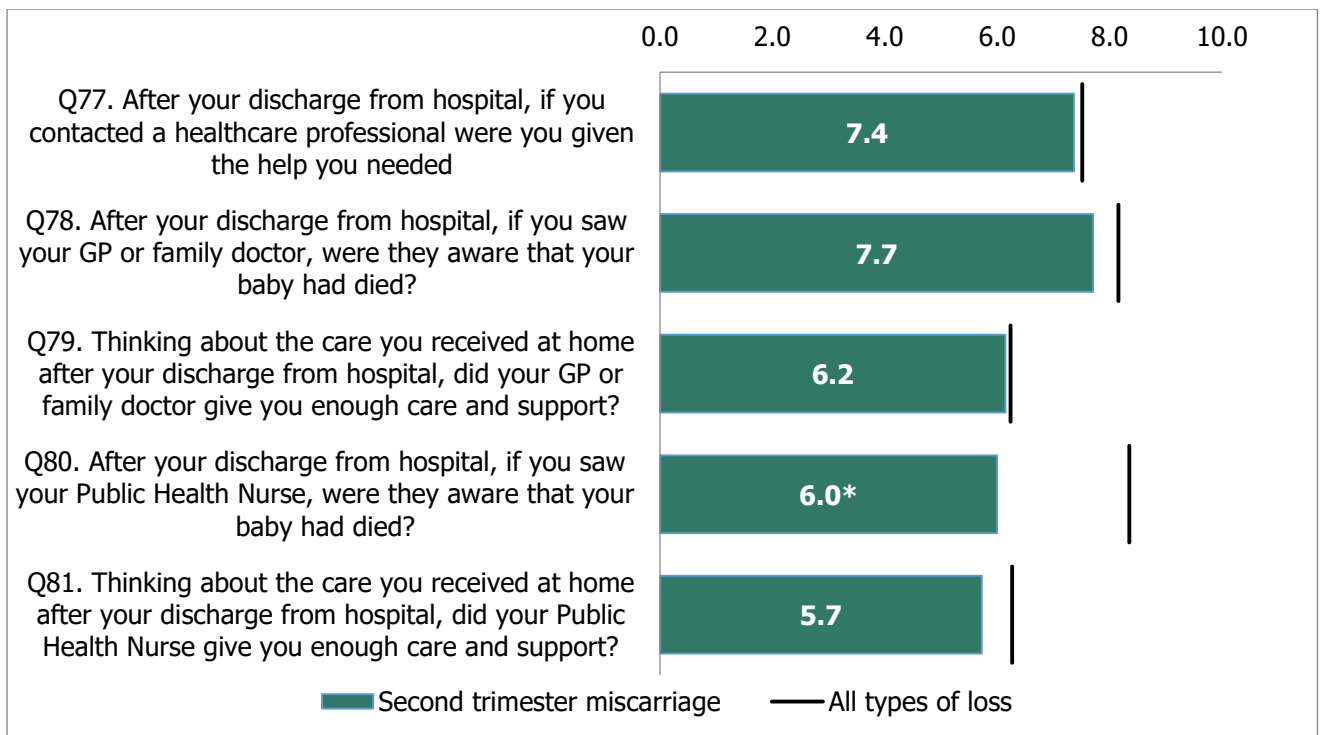
Q76. After your discharge from hospital, who did you see as part of your follow-up care?		
	No.	%
Family doctor (GP)	153	43.6%
Public Health Nurse (PHN)	28	8.0%
Bereavement midwife or nurse specialist in the hospital	131	37.3%
Mental health services	26	7.4%
Obstetrician or gynaecologist after discharge	119	33.9%
Consultant paediatrician or neonatologist	9	2.6%
Other	26	7.4%
I had to attend the hospital emergency department because of complications	28	8.0%
I had a follow-up appointment at the hospital but I declined to attend	3	0.9%
I haven't had any follow-up care since my discharge from hospital	71	20.2%

Table 11. Results for question on supports accessed after discharge.

Q82. After your discharge from hospital, what supports did you access?		
	No.	%
Partner	246	87.9%
Family	200	71.4%
Friends	172	61.4%
Bereavement support organisations/advocacy groups	96	34.3%
Hospital support services	66	23.6%
Professional counselling	75	26.8%
Other	10	3.6%
I did not access any supports	11	3.9%

The remaining five questions in this section were scored out of 10 and the results are shown in Figure 23. The highest-scoring question related to GP care, with 185 participants (77%) saying that their GP or family doctor was aware that their baby had died. Question 81 was the lowest-scoring question for this stage, with 19 participants (35%) saying that the public health nurse did not give them enough care and support. Participants who experienced a second trimester miscarriage were significantly less likely than average to say that their Public Health Nurse was aware their baby had died.

Figure 23. Individual questions for 'Follow-up care'.



* indicates a significant difference from the national average

Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 24. There were no significant differences from the national average by type of loss.

Figure 24. Comparison of 'Follow-up care' by type of loss experienced.



Experiences of partner or support person

This section of the survey focused on the experiences of the partner or support person who was present with the mother during her experience of second trimester miscarriage. There were nine questions in this section, including one free-text question.

The first eight questions in this section were scored out of 10 and the results are shown in Figure 25. These questions asked participants about their experiences of communication and involvement.

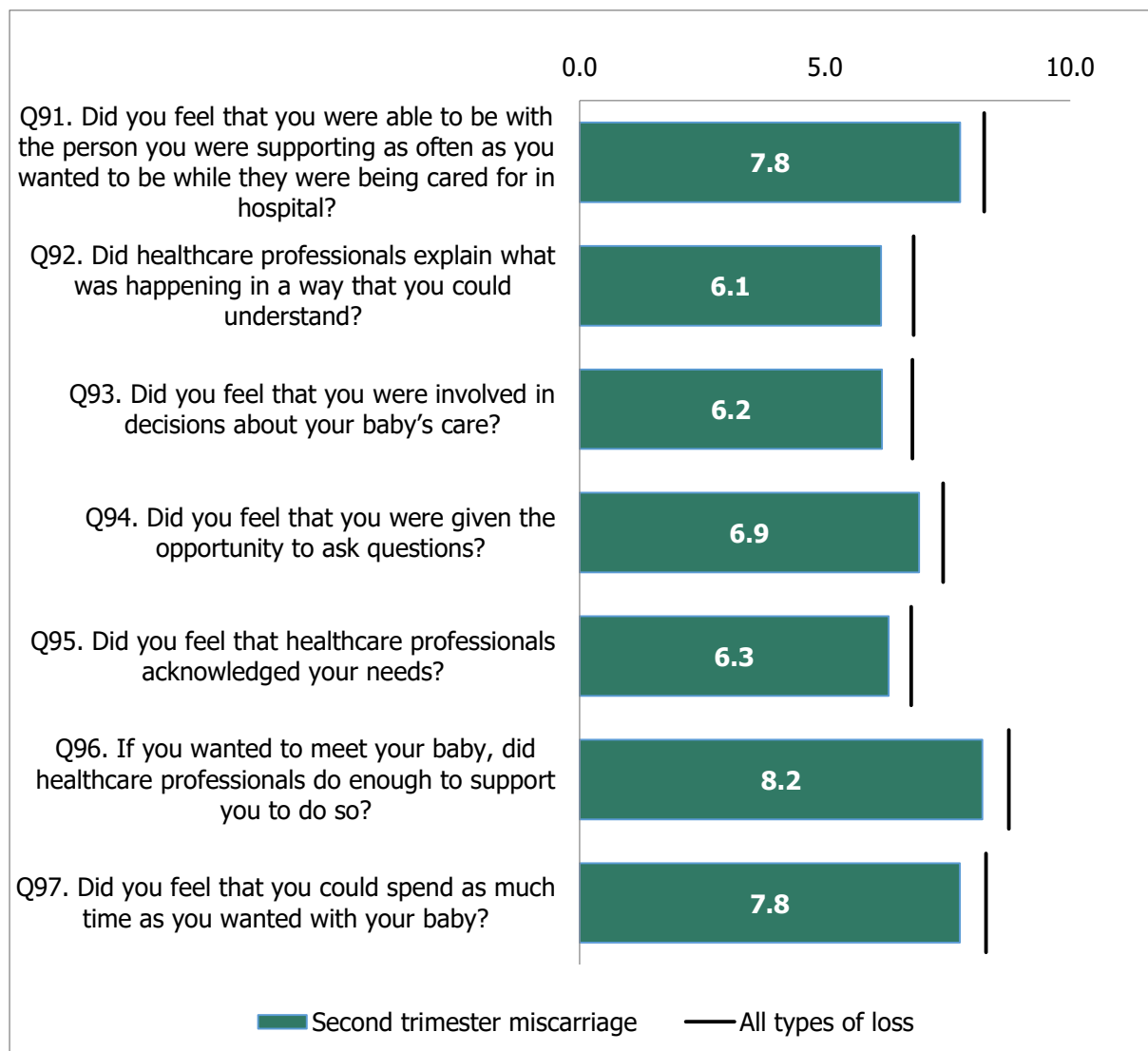
Participants were also asked about the supports they accessed and the results for this question are shown in Table 12. The most common sources of support were partners, family and friends. 34 participants (28%) said that they did not access any supports.

Table 12. Results for question on supports accessed by partner or support person

Q98. If you sought support after the loss of your baby, what supports did you access?		
	No.	%
Partner	75	62.0%
Family	52	43.0%
Friends	42	34.7%
Family doctor or GP	7	5.8%
Bereavement support organisations/advocacy groups	15	12.4%
Hospital support services	7	5.8%
Professional counselling	8	6.6%
Other	2	1.7%
I did not access any supports	34	28.1%

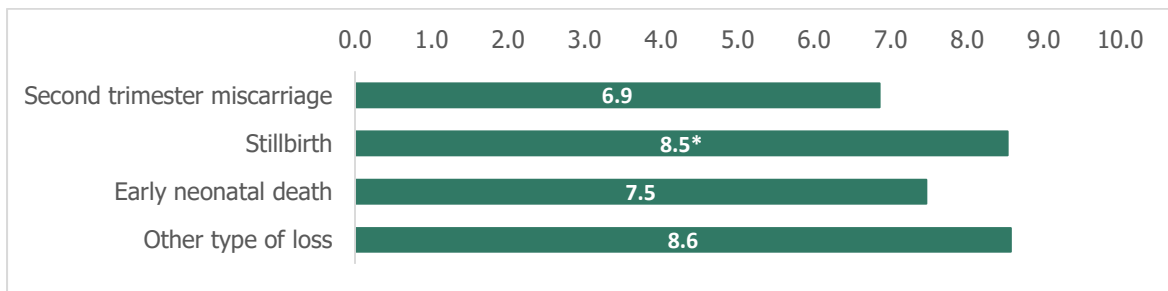
The highest-scoring question for this stage related to feeling supported to meet the baby, with 80 participants (73%) saying that healthcare staff 'definitely' did enough to support them if they wanted to meet their baby. The lowest-scoring question related to clear explanations, with 26 participants (22%) saying that healthcare professionals did not explain what was happening in a way they could understand.

Figure 25. Individual questions for 'Experiences of partner or support person'.



Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 26. Participants who experienced a second trimester miscarriage gave ratings that were not significantly different from the national average to the national average, while those who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 26. Comparison of 'Experiences of partner or support person' by type of loss experienced



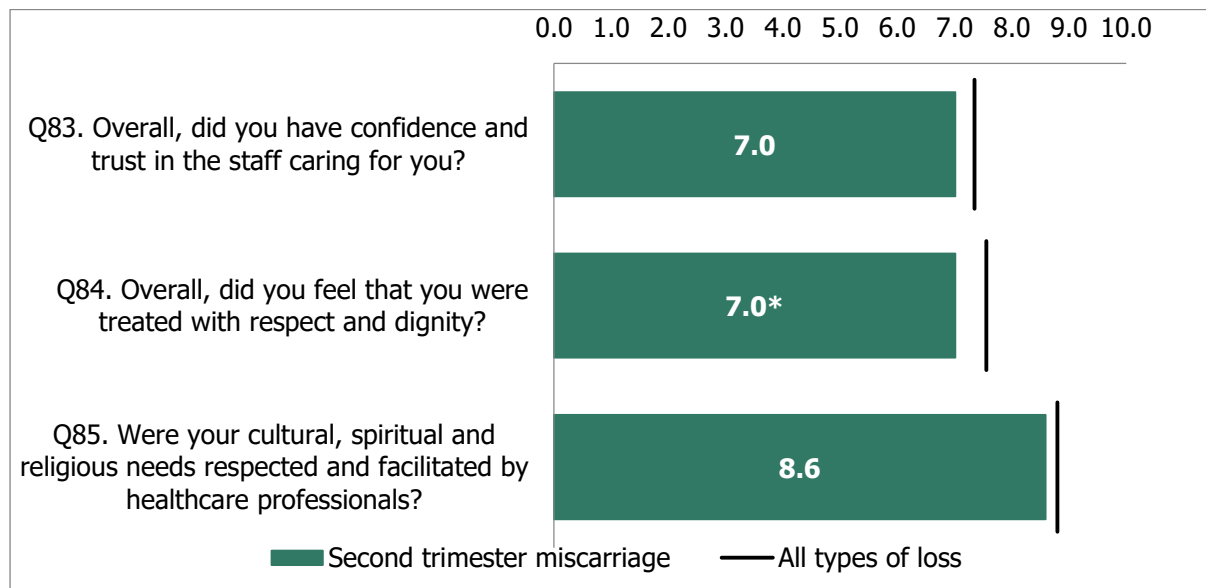
* indicates a significant difference from the national average

Overall care experience

What were the overall care experiences of participants?

Five questions were included in this section. The first three questions were scored out of 10 and the results are shown in Figure 27. The highest-scoring of these questions related to respect for cultural needs, with 177 participants (78%) saying that healthcare professionals 'definitely' respected and facilitated their cultural, spiritual and religious needs. The joint-lowest scoring questions related to confidence and trust, and respect and dignity. In total, 54 participants (15%) said that they did not have confidence and trust in the staff that treated them. 57 participants (16%) said that they were not treated with respect and dignity. Participants who experienced a second trimester miscarriage were significantly less likely than average to say they were treated with respect and dignity.

Figure 27. Individual questions for 'Overall experience'.



* indicates a significant difference from the national average

Participants were also asked about the support services they were offered while they were in hospital, with the results shown in Table 13. The most commonly offered support was a bereavement midwife or nurse specialist, with 260 participants (75%) saying they were offered this service. 49 participants (14%) said that they weren't offered any hospital support services, with four (1%) saying that no hospital support services were available.

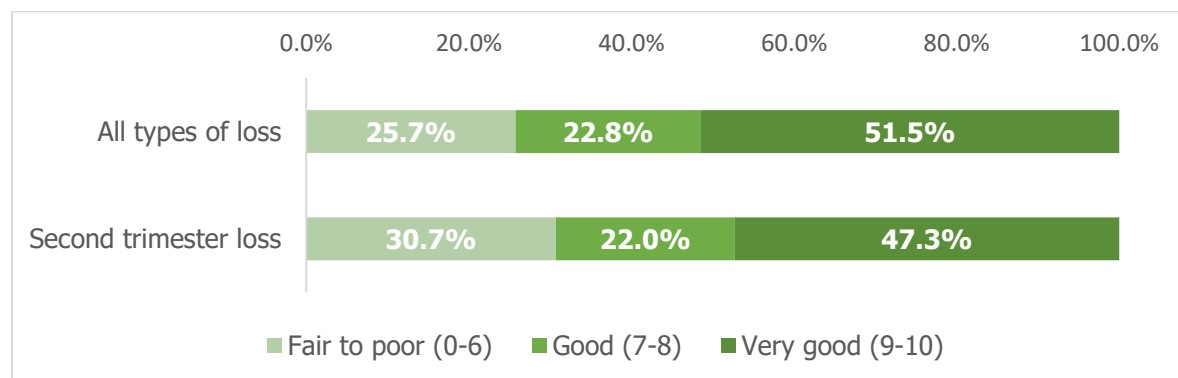
Table 13. Results for question on hospital supports offered to participant

Q86. Were you offered any of the following hospital support services?		
	No.	%
Chaplaincy or pastoral care	167	48.3%
Social Work	19	5.5%
Bereavement midwife or nurse specialist	260	75.1%
Perinatal (pregnancy-related) Mental health service	29	8.4%
Perinatal (pregnancy-related) Palliative Care team	2	0.6%
Paediatrician/Neonatologist	4	1.2%
Other	6	1.7%
I wasn't offered any hospital support services	49	14.2%
No hospital support services were available	4	1.2%
Don't know or can't remember	14	4.0%

How did participants rate their overall care?

Question 87 asked participants to rate their overall care from 0 to 10, with 0 indicating that they received very poor care and 10 indicating that they received excellent care. In total, 157 participants who experienced a second trimester miscarriage (47%) rated their care as 'very good', 73 (22%) as 'good' and 102 rated it as 'fair to poor' (31%). Thus, those who experienced second trimester miscarriages gave poorer overall ratings of the care they received than those who experience different types of loss. A comparison is shown in Figure 28.

Figure 28. Overall ratings of care



Conclusion

Experiences of maternity bereavement care for second trimester miscarriage between 2019 and 2021

In total, 351 women and 122 partners or support persons generously shared their experiences of second trimester miscarriage through the National Maternity Bereavement Experience Survey. Participants described all aspects of their experiences of maternity bereavement care.

While 69% of participants rated the overall care they received as 'good or very good' and highlighted positive aspects of the care they received, a number of areas for improvement were also identified. When asked to describe in their own words how care could be improved, participants expressed a desire for more consistent communication across services involved in their care, and to be consistently treated with respect, dignity and compassion. Participants also identified a need for greater information-provision at discharge, particularly in relation to mental health, grieving, and follow-up care and appointments.

Participants also highlighted multiple areas where they had positive care experiences. In their responses to the free-text survey questions, participants praised staff for their caring and sensitive attitudes, with numerous comments mentioning nursing staff in particular. In addition, participants said that staff presented their baby to them in a respectful and sensitive way, and that they were given sufficient privacy when meeting their baby. In addition, staff members assisted participants when they needed it, and respected their cultural and religious needs.

The experiences of partners of those who experienced a second trimester miscarriage were also explored. Most partners felt that they were treated with compassion and support, however they highlighted a need for clearer explanations of what was happening, as well as greater supports for grieving and mental health.

The survey questionnaire was divided into stages of care, with multiple questions for each stage. The highest-scoring stage of care was 'care after birth and meeting the baby', with 'discharge' the lowest-scoring stage. In addition, those who experienced a second trimester miscarriage gave significantly below-average ratings for their experiences of 'Labour and birth', 'Postnatal care' and 'Bereavement care'.

In conclusion, the findings of the National Maternity Bereavement Experience Survey show that most parents who experienced a second trimester miscarriage were positive about the care they received, though a significant number were not. The willingness of participating parents to share their experiences of such a difficult and painful time has also helped identify areas where care can be improved, particularly in relation to supports for grieving and mental health after leaving hospital.

What happens next?

The HSE and the National Women and Infant Health Programme (NWIHP) will use the survey to inform and underpin NWIHP's work across a range of current and future projects and programmes, including the implementation of the Standards for Bereavement Care following Pregnancy Loss and Perinatal Death. The results will also inform the development of quality improvement plans at national and local levels. These quality improvement plans will describe the steps that the HSE will take to address the issues highlighted by participants in the survey. Quality improvement plans will be available on www.yourexperience.ie in May 2023. The Department of Health will use the findings to help inform the development of policy in relation to maternity bereavement care as appropriate.

Finally, the findings of the survey will inform HIQA's approach to the monitoring and regulation of maternity care.

Appendix 1 – A technical note on analyses and interpretation

Preliminary note

Please note that values in figures do not always add up to 100% exactly. This is due to rounding.

Scoring methodology

The scores for the survey were calculated by grouping survey questions into stages of care. Scores are presented for individual questions making up a stage of care. The responses to all questions in each stage of care were also summarised to form overall scores ranging from 0-10. The National Maternity Bereavement Experience Survey scoring methodology is based on the methodology adopted by the Care Quality Commission on behalf of the National Health Service (NHS) in England, subsequently used in the National Inpatient Experience Survey and National Maternity Experience Survey.¹³

Below is an example of how response options were converted into scores. It should be noted that only evaluative questions could be scored, that is questions that assessed an actual experience of care. Routing or demographic questions were not scored. More 'positive' answers were assigned higher scores than more 'negative' ones. In the example, 'No' was given a score of 0, 'Yes, sometimes' was given a score of 5 and 'Yes, always' was given a score of 10. The last response option, 'Don't know' was categorised as 'missing'. It was not scored as it cannot be evaluated in terms of best practice.

Example of a scored question

Q56. If you gave your baby a name, did hospital staff refer to them by name?

- Yes, always (10)
- Yes, sometimes (5)
- No (0)
- I did not give my baby a name (M)

The following table below shows how scores were calculated for a specific question. In this example, the scores of five respondents are presented. The score for Question 56 of the survey is calculated by adding the scores in the right hand column (10+10+5+0+5), before dividing them by the number of people who

¹³ Care Quality Commission. NHS Patient Survey Programme: Survey Scoring Method 2015.

responded to this question (30/5=6). Thus, the average score for Question 56 is 6 out of 10.

Q56. If you gave your baby a name, did hospital staff refer to them by name?

Respondent	Score
1	10
2	10
3	5
4	0
5	5
Sum of scores	30

Scores for the stage of care (scales) were constructed by calculating the average scores for all questions belonging to that stage.

Comparing groups – When is a difference a ‘real’ difference?

Statistical tests were carried out to examine if there were significant differences in reported experience across different groups (that is by age group or type of loss experienced).

A ‘z-test’ was used to compare experience data at the 99% confidence level. A z-test is a statistical test used to examine whether two population mean scores are different when the variances are known and the sample size is large. A statistically significant difference means it is very unlikely that results were obtained by chance alone if there was no real difference. Therefore, when a score is ‘higher than’ or ‘lower than’ the national average, this is highly unlikely to have occurred by chance.

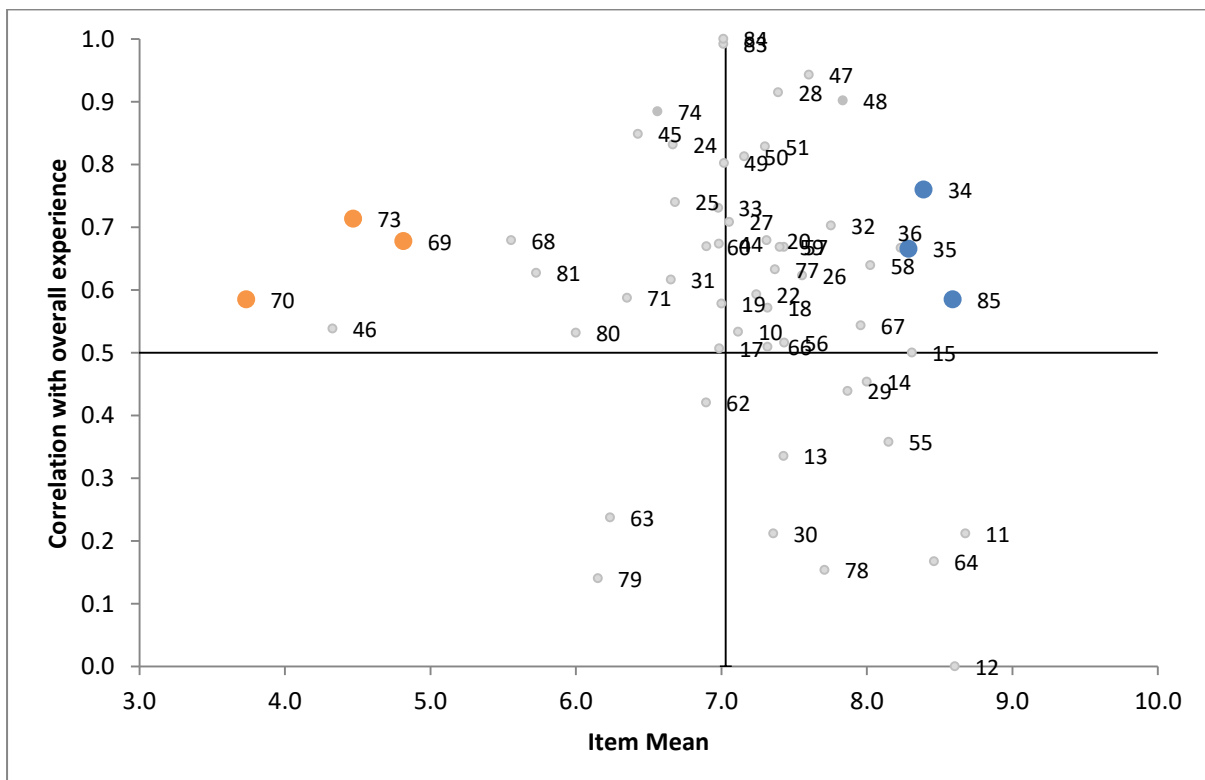
Results on questions comparing two groups of residents (e.g., those who share a bedroom and those who do not) were compared using a ‘t-test’ at the 99% confidence level. A t-test is a statistical test used to compare the average scores of two groups. A statistically significant difference means it is very unlikely that results were obtained by chance alone if there was no real difference. Therefore, when a score is ‘higher than’ or ‘lower than’ a comparison group, this is highly unlikely to have occurred by chance.

The National Maternity Bereavement Experience Survey technical report, will be available at <http://www.yourexperience.ie/>, and will provide details on all aspects of the analyses, including response rates, mapping of questions to stages of care, computation of scores, and statistical comparisons.

Identifying higher and lower-scoring questions

Figure 29 shows the average score out of 10 for each question on the survey for residents, and how strong a relationship it has with their overall experience. The vertical axis shows the correlation of each question with overall experience, the horizontal axis shows each question’s score out of 10. Questions with high average scores out of 10 and a strong relationship with overall experience are highlighted in blue. Questions with lower scores out of 10 and strong relationships with overall experience are highlighted in orange.

Figure 29. Overall participant experience map



Areas of good care experience

1. Q34. Was your baby presented to you in a respectful and sensitive manner?
 - a. 226 participants (78.2%) said that their baby was 'definitely' presented to them in a respectful and sensitive manner.
2. Q35. Were you given enough privacy when you met your baby?
 - a. 225 participants (77.9%) answered 'yes, completely' when asked if they were given enough privacy when they met their baby.
3. Q85. Were your cultural, spiritual and religious needs respected and facilitated by healthcare professionals?
 - a. 177 participants (78%) said that their cultural, spiritual and religious needs were 'definitely' respected and facilitated by healthcare professionals.

Areas needing improvement

1. Q70. Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?
 - a. 167 participants (51.5%) said that they were not given enough information about changes they might experience to their mental health before they were discharged from hospital.
2. Q69. Before you were discharged from hospital, were you given information about what you might experience when grieving?
 - a. 118 participants (36.3%) said that they were not given information about what they might experience when grieving, before they were discharged from hospital.
3. Q73. Before you were discharged from hospital, were you given enough information about follow-up care plans and appointments?
 - a. 144 participants (43.6%) said that they were not given enough information about their follow-up care plans and appointments before they were discharged from hospital.

Survey analysis and reporting

The survey data was analysed by the National Maternity Bereavement Experience Survey team based in the Health Information and Quality Authority (HIQA).

Quantitative survey data was analysed using the statistical package SPSS (Version 25).

The responses to the open-ended questions were transcribed and anonymised. All references to names, nationalities, and other identifying information were removed from comments.



National
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Bereavement
Experience
Survey