



National Maternity Bereavement  
Experience Survey 2022

Experiences of stillbirth

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## 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 miscarriage<sup>1</sup>, 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.<sup>2</sup> This report described the experiences of participants who experienced a stillbirth. A national report, and reports on experiences of second trimester miscarriage and early neonatal death can be found at [yourexperience.ie](http://yourexperience.ie).

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

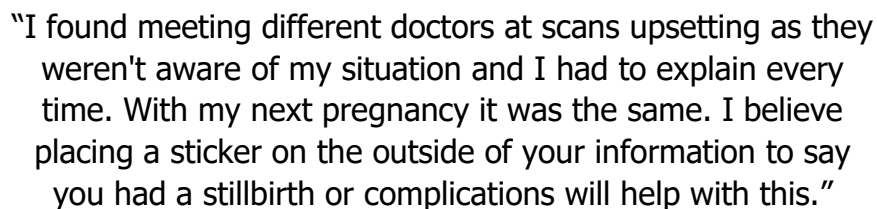
<sup>2</sup> Earlier losses were not included, as women who experience early pregnancy loss in many cases are cared for in outpatient or general practice (GP) settings, many do not require admission to hospital for care. Some women with first trimester miscarriage do not interact with healthcare services 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 stillbirth?

In total, 178 women and 65 partners or support persons<sup>3</sup> who experienced a stillbirth 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 home, follow up care and care in the community. Participants were asked to rate their overall care, with 62% rating their care as 'very good', 23% as 'good', and 14% as 'fair to poor'.

Participants identified some positive aspects of their care, both when asked to describe their experiences 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 midwives highlighted in particular. Most participants said that they were treated with respect and dignity, and 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 respect and dignity. In addition, some participants said that communication and information-sharing could be improved, and they were not always treated with compassion and sensitivity, as described in the comment below.



"I found meeting different doctors at scans upsetting as they weren't aware of my situation and I had to explain every time. With my next pregnancy it was the same. I believe placing a sticker on the outside of your information to say you had a stillbirth or complications will help with this."

A number of issues relating to information at discharge were highlighted, particularly in relation to information and support around mental health, and follow-up care. In addition, participants who experienced a stillbirth were not always given sufficient support for breast care and lactation.

The experiences of partners of those who experienced a stillbirth were also explored. Most partners felt that they were treated with compassion and support, however they highlighted a need for their specific needs to be acknowledged, as well as greater supports for grieving and mental health.

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<sup>3</sup> 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 stillbirth gave the lowest rating to the 'discharge' stage (6.8 out of 10), and the highest to 'care after the birth and meeting your baby' (9 out of 10). Participants who experienced a stillbirth gave more positive ratings of their care than those who had a different type of loss, across seven stages of care. Above-average ratings were given for the 'admission', 'labour and birth', 'care after the birth and meeting your baby', 'postnatal care', 'bereavement care', 'discharge', and 'partner's experience' stages of care.

The findings of the National Maternity Bereavement Experience Survey show that most parents who experienced a stillbirth 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 support for breast care and lactation, follow-up appointments, 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](http://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?

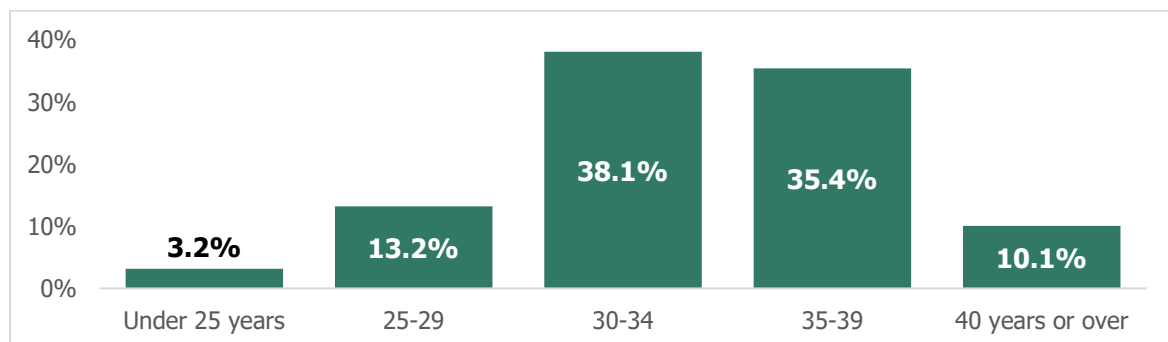
Women aged 16 or over, and their partners, who experienced a second trimester miscarriage (from 14 weeks of pregnancy<sup>4</sup>), a stillborn infant or the early neonatal death of a baby<sup>5</sup> in one of Ireland's 19 maternity units or hospitals from 1 January 2019 to 31 December 2021<sup>6</sup> were eligible to participate. This report focuses on the experiences of those who experienced a stillbirth.

The survey rollout commenced on 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, 178 women and 65 partners who experienced a stillbirth 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 stillbirth.

**Figure 1. Characteristics of participants who experienced a stillbirth, by age group.**



<sup>4</sup> 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.

<sup>5</sup> 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.

<sup>6</sup> 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.<sup>7</sup>**

<b>Year bereavement was experienced</b>	<b>No.</b>	<b>%</b>
2021	37.6%	71
2020	31.2%	59
2019	31.2%	59

### **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 care<sup>8</sup>
- 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.

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<sup>7</sup> Figures from the National Perinatal Epidemiology Centre indicate that 242 stillbirths occurred in 2019, and 240 in 2020. Figures for 2021 have not yet been published.  
[https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/annualreports/NPECPerinatalMortalityinIrelandannualreport2018\\_2019contentinteractive.pdf](https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/annualreports/NPECPerinatalMortalityinIrelandannualreport2018_2019contentinteractive.pdf)  
<https://www.ucc.ie/en/media/research/nationalperinatalepidemiologycentre/NPECPerinatalMortalityinIrelandannualreport2020.pdf>

<sup>8</sup> Questions on neonatal care were only asked to those parents who experience the early neonatal death of a child.

## 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?<sup>9</sup>

In total, 470 comments were made by participants who experienced a stillbirth in response to the free-text questions. The results for each question are presented in the following pages.

A framework approach<sup>10</sup> was used to analyse the comments received in response to the free-text questions where participants described their experience. 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.

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<sup>9</sup> This question was specific to partners

<sup>10</sup> 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.



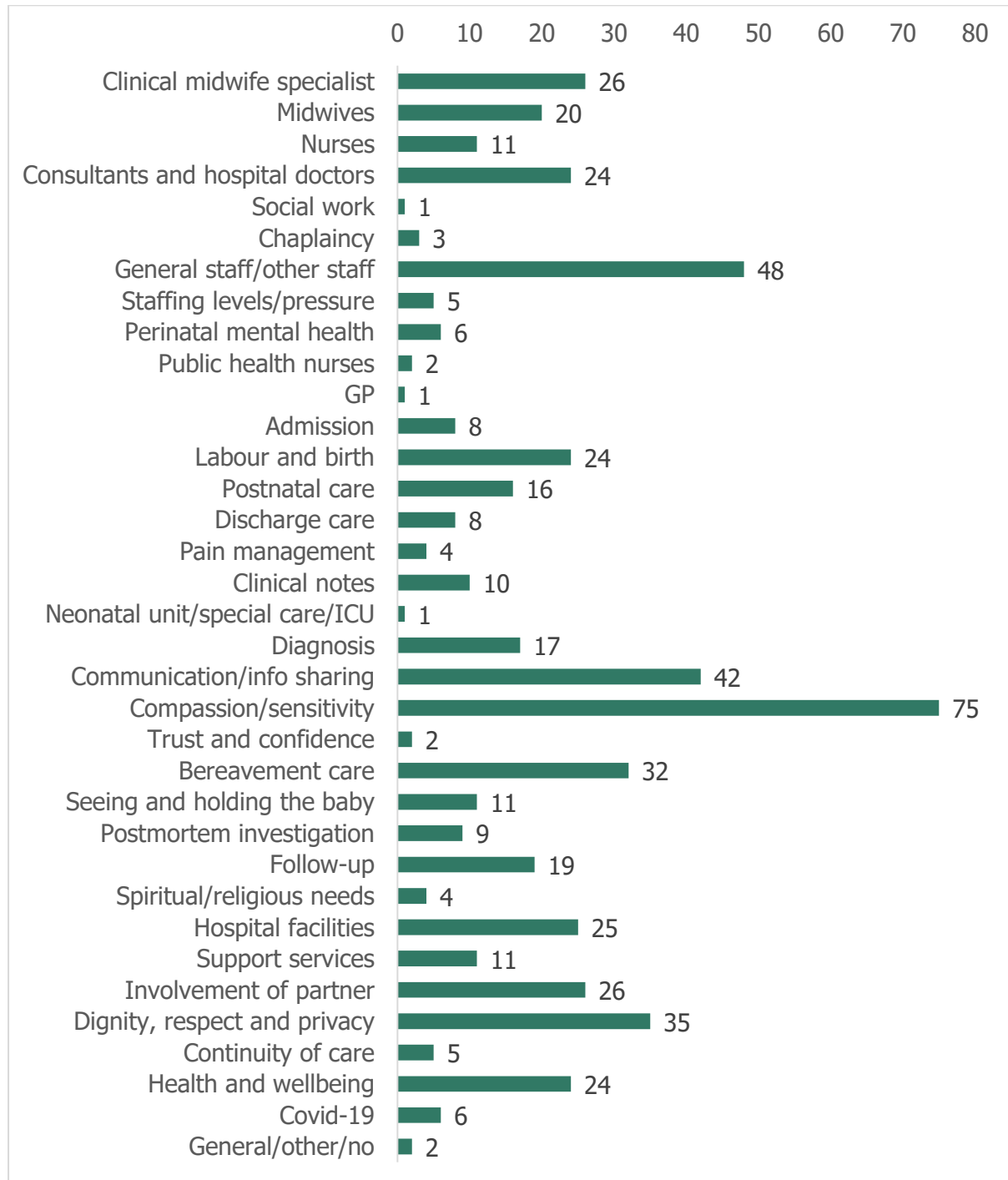
**Table 2. List of Comment Themes**

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 103 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 75 comments. The next most common themes were 'general staff or other staff comments' (48 comments) and 'communication and information-sharing' (42 comments). A selection of comments made in response to this question is provided below.

### Sample comments

"I am completely happy with the care I received. The doctors and nurses were kind, caring, full of respect and sympathy for my husband and our little angel. Although it was an incredibly painful time in our lives, our experience in the hospital from when we got our awful news to when we left with our angel was a very positive one. We are full of gratitude for the care we received while we were there."

"Care received in hospital was outstanding, the people who work in this area are amazing."

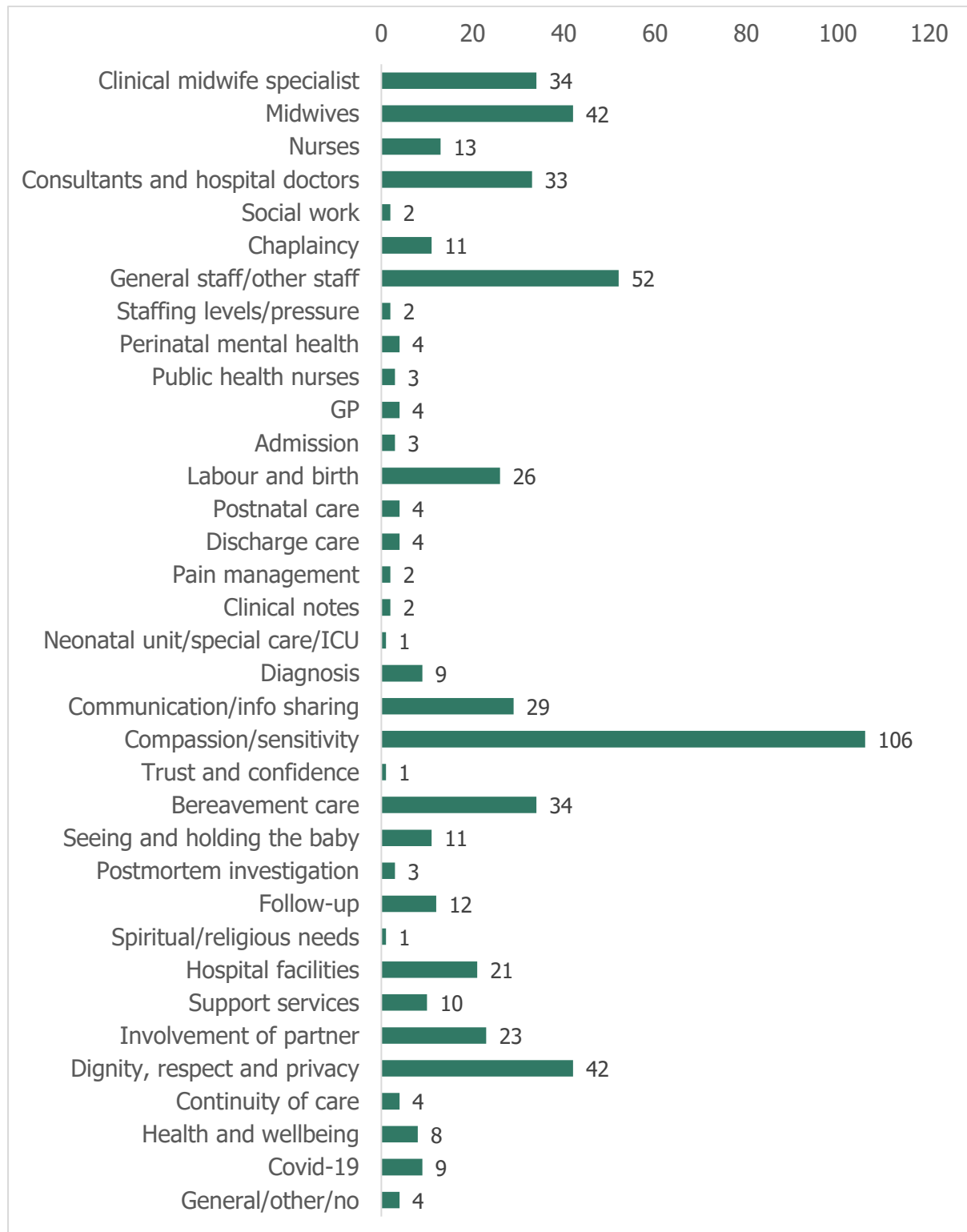
"I know it's not always possible but I think there just be a different section of the hospital for women to give birth in these situations as I was giving birth to our girl who I knew had passed, it was in a labour ward where other women giving birth to healthy babies which isn't nice to hear when you are trying to give birth and grieve for your baby who has passed."

"I was never explained the process of milk donation which is something I would have done."

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

In total, participants made 146 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 106 comments. The next most common themes were 'general staff or other staff comments' (52 comments), 'midwives' (42 comments) and 'dignity, respect and privacy' (42 comments). A selection of comments made in response to this question is provided below.

### Sample comments

"The staff looked after me really well and helped myself and my husband through a very difficult time. Of special mention is the fact that they asked during admission if we had a name picked for our little boy and every single member of staff called him by his name from that second on. It made him so real even before he was born, which was especially important as we knew we were going to lose him."

"Bereavement midwife was very helpful and understanding."

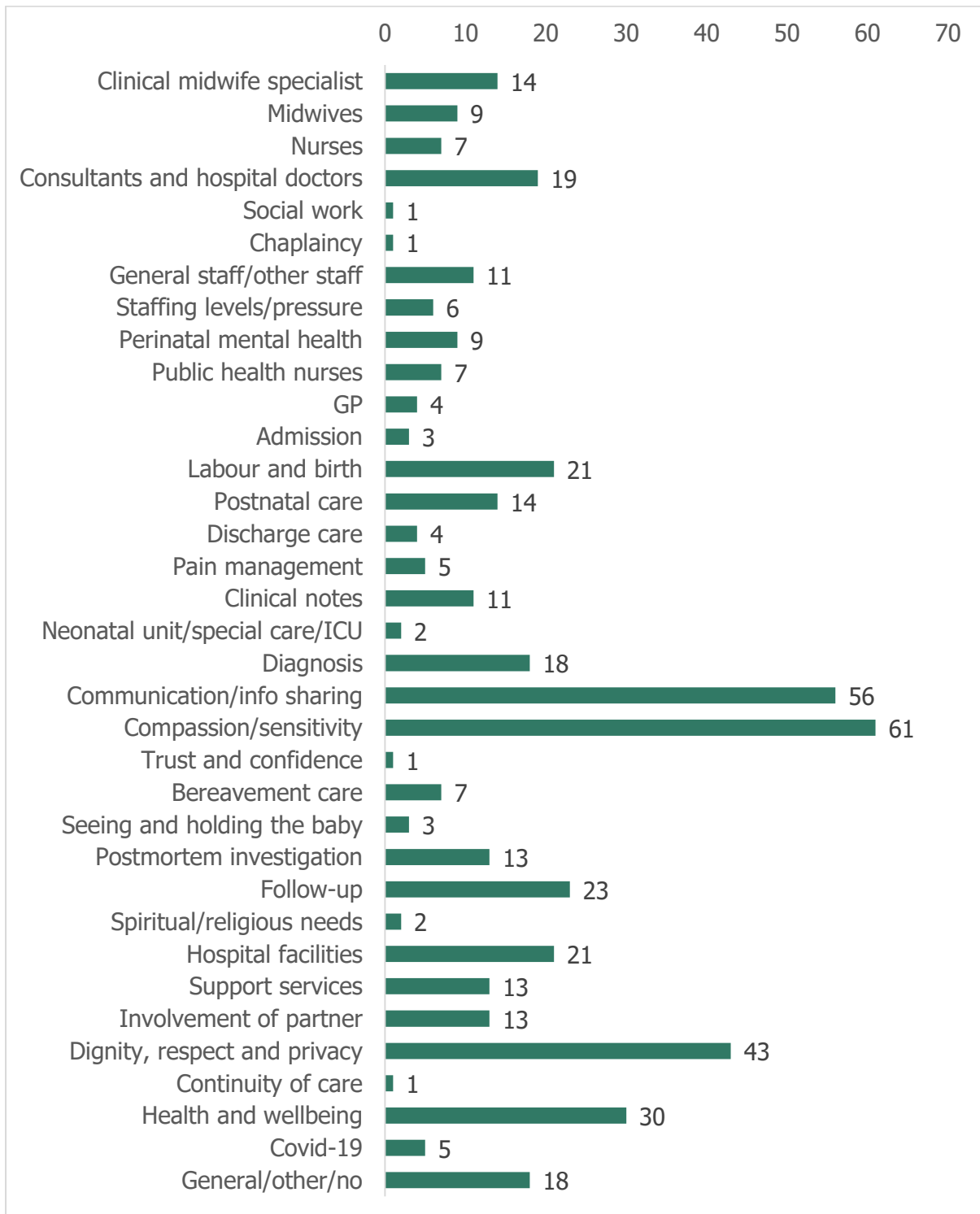
"I was very lucky to be under a great obstetrician who took care of me very well. The Feileacain memory box we received and the clothes from the chaplain were absolutely amazing as we had nothing for our son that would fit him"

"The midwives and nurses just understanding the pain and grief you are going through. They nearly feel the pain for you. Supporting us 100% and doing the best they could to help with the pain of birth"

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

In total, participants made 125 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 61 comments. The next most common themes were 'communication and information-sharing' (56 comments) and 'dignity, respect and privacy' (43 comments). A selection of comments made in response to this question is provided below.

### Sample comments

"Improved information and communication on birth would have been helpful when in the hospital. The time frame of post mortem - were initially advised half day and then took over day and half and was very stressful waiting for our baby to return and arrived half an hour before a religious service was planned. Our baby was due to arrive much earlier. A one day post mortem would have been much less upsetting, the overnight stay was difficult."

"To ensure that all staff looking after you are briefed on your situation in order to avoid having to explain over and over as this can be exhausting. It would definitely help to be put in contact with a trained counsellor and a list of helpful therapies."

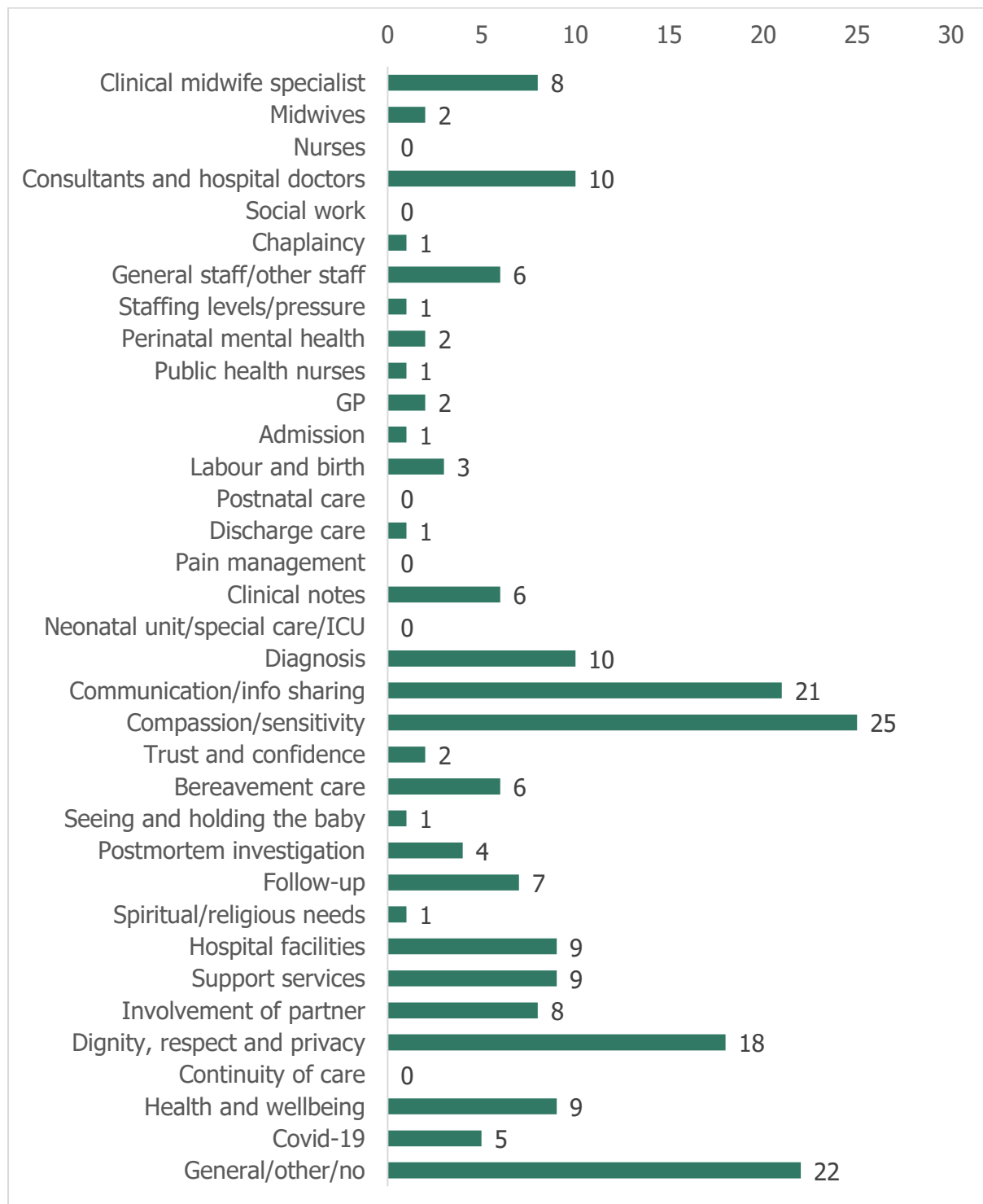
"Some health care professionals could do with learning to show a bit of compassion and actually listen to what people who don't speak medical jargon are trying to say."

"I wish I had had more support to donate my breastmilk instead of being encouraged to suppress it against my wishes."

**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 71 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 'compassion and sensitivity', which appeared in 25 comments. The next most common themes were 'general or other comments' (22 comments) and 'communication and information-sharing' (21 comments). A selection of comments made in response to this question is provided below.

### **Sample comments**

"I had excellent follow up care on my subsequent pregnancy from my consultant and bereavement midwives through the high-risk clinic, with my son's memory and presence very much remembered by my care givers."

"It was a devastating position to be in, but every single staff member I dealt with were absolute angels and they couldn't do enough for me or my partner"

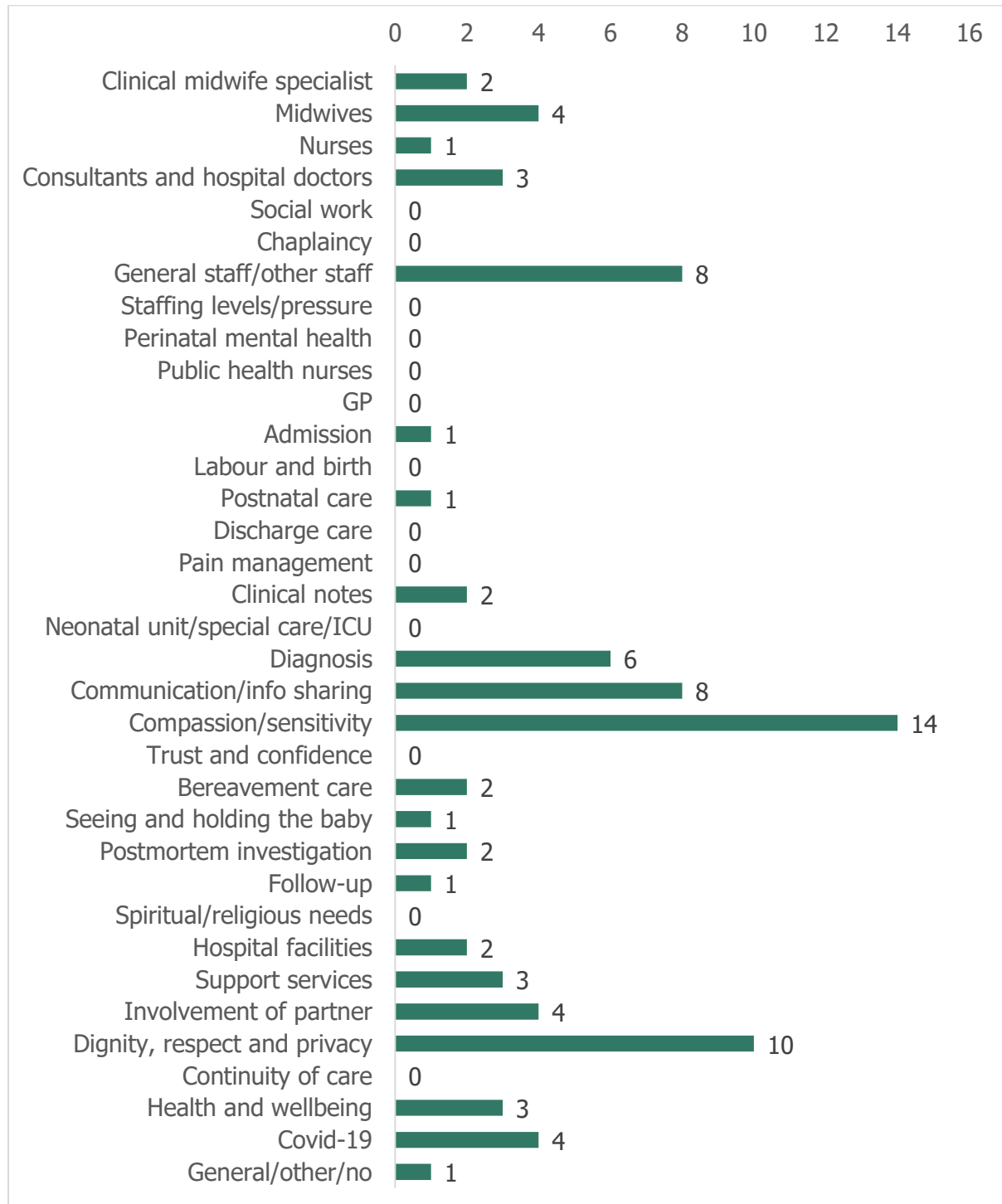
"Leaving the hospital was hard, we went out back door into building site passed a line of pregnant ladies."

"Every situation is different but it would help for the mother not to have to visit the same rooms/area that they were in when they were told that their baby had died as this is a real trigger and can easily bring on a panic attack."

**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 25 comments in response to this question. Figure 7 shows the breakdown of themes covered within these comments.

**Figure 7. Responses to Q.99 broken down by theme**



The most frequently-occurring theme was 'compassion and sensitivity', which appeared in 14 comments. The next most common themes were 'dignity, respect and privacy' (10 comments), 'general staff or other staff comments' (8 comments), and 'communication and information-sharing'. A selection of comments made in response to this question is provided below.

### **Sample comments**

"The midwives and bereavement midwife and all the staff at [hospital] went above and beyond for us at the worst moment of our lives they couldn't have done anymore. I just want to thank them for everything they did."
--

"A little lifetime were an invaluable support"
--

"When we first came to talk about our baby being unwell we were told to take a seat in the public area while they found out where we were going to, and we were so upset so I think for anyone going through this there should be a private waiting area going in a door that public don't use."
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"I wasn't allowed to be with my wife when she was told our baby had died, she was told this heartbreaking information alone due to covid 19 restrictions. I was brought in shortly afterwards."
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## 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 diagnosis<sup>11</sup>, 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 care<sup>12</sup>
  - 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.

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<sup>11</sup> 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.

<sup>12</sup> Participants who experienced a stillbirth 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.

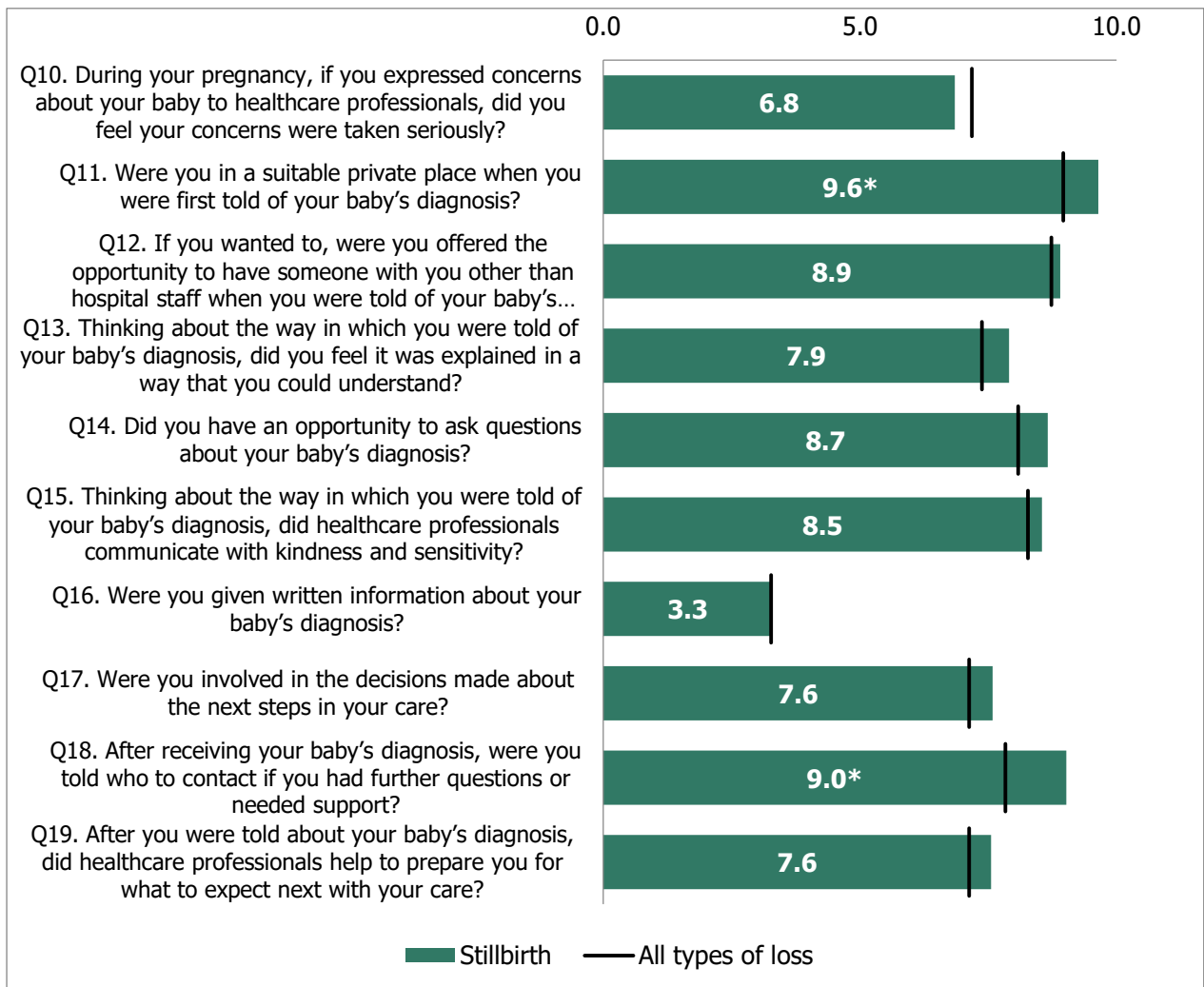
## Communication and information at the time of diagnosis

The questions for this stage of care asked about experiences relating to receiving a diagnosis that their baby or babies could die before or after they were born or that their baby had no heartbeat. In total, 92 (52%) of participants who experienced a stillbirth 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 8. The highest-scoring question for this stage of care related to privacy, with 82 participants (97%) 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 51 participants (61%) saying they did not receive such information.

Participants who experienced a stillbirth were more likely than average to say they were in a suitable private place when they received their baby's diagnosis, and were more likely to say they were told who to contact if they had further questions or needed support.

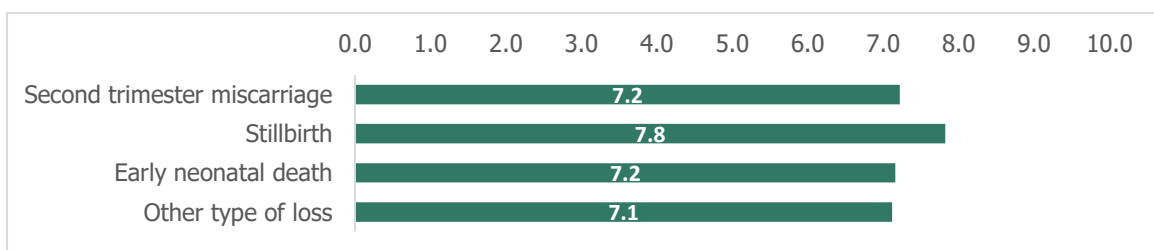
**Figure 8. Individual questions for 'Communication and information at the time of diagnosis'.**



\* indicates a significant difference from the national average

Comparisons of ratings for this stage by the type of loss participants experienced are shown in Figure 9. No statistically significant differences from the national average were identified for this stage of care.

**Figure 9. 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 stillbirth (78, 91%) said they were admitted to single room.

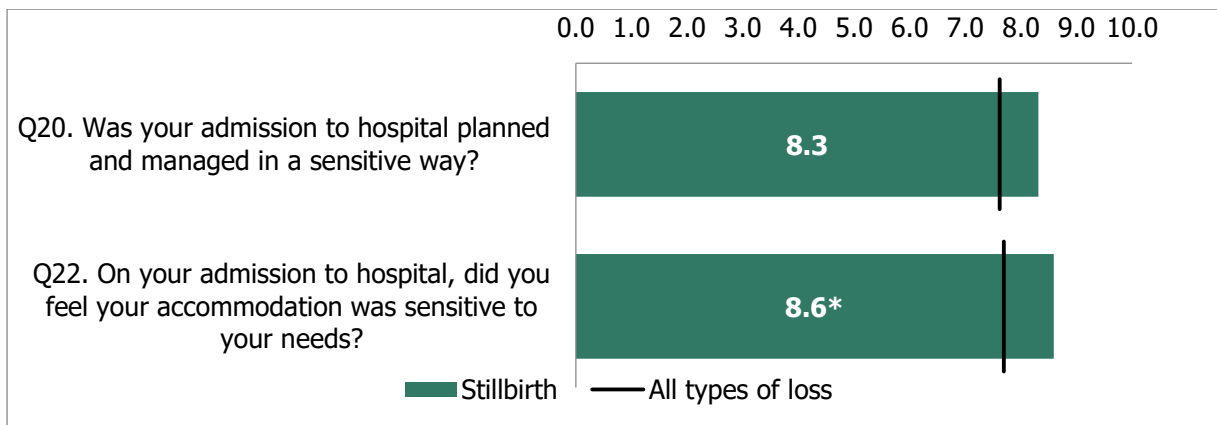
The two other questions for this stage were scored out of 10 and the results are presented in Figure 10. These questions asked participants if their admission was managed sensitively, and whether their hospital accommodation was sensitive to their needs. In response to Question 20, 53 participants (72%) said that their admission was 'definitely' planned and managed in a sensitive way. In total, 66 (78%) said that their accommodation was 'definitely' sensitive to their needs. Participants who experienced a stillbirth gave above-average ratings for this question.

**Table 3. Results for question on hospital accommodation at admission**

<b>Q21. On your admission to hospital, which of the following best describes your accommodation where you spent most of your time?</b>		
	No.	%
Single room (not shared)	78	90.7%
Shared room	3	3.5%
Labour ward	7	8.1%
Antenatal ward	1	1.2%
Postnatal ward	0	0.0%
General ward	1	1.2%
Emergency ward	0	0.0%
I wasn't admitted overnight	0	0.0%
Other	2	4.5%



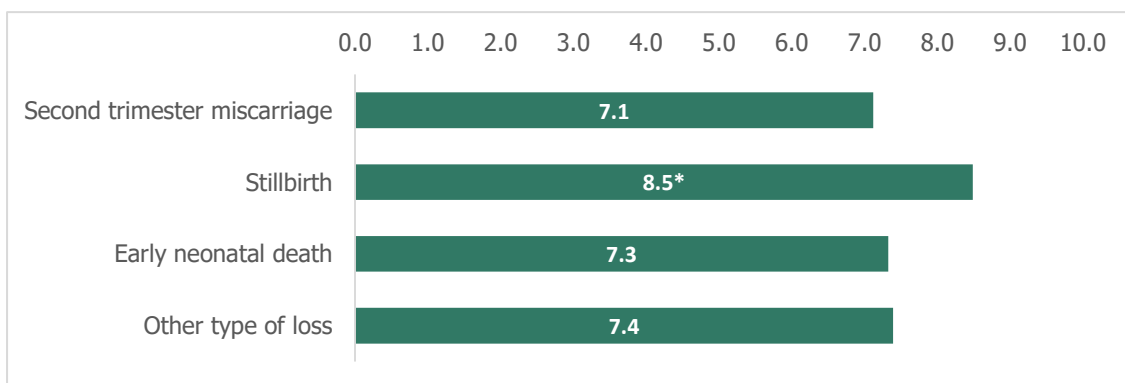
**Figure 10. Individual questions for 'Admission care'.**



\* 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 11. Participants who experienced a stillbirth rated this stage of care more positively than the national average.

**Figure 11. 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 stillbirth (165, 93%) 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 12.

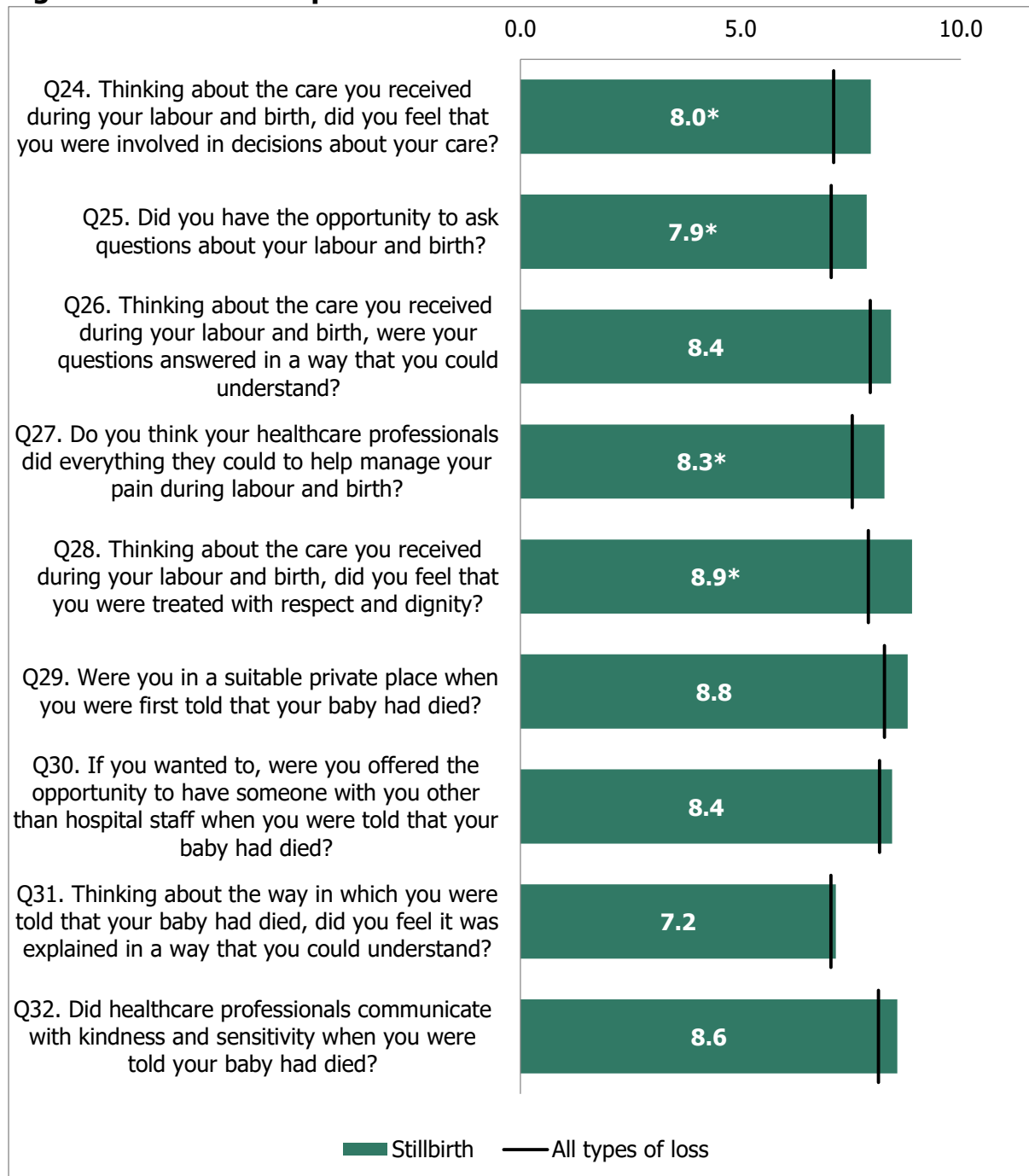
**Table 4. Results for question on whether participant was accompanied during the labour and birth**

<b>Q23. Were you accompanied by anyone other than healthcare professionals during the labour and birth of your baby?</b>		
	No.	%
Yes, by my partner	165	92.7%
Yes, by a support person (such as a family member, friend or doula)	14	7.9%
No, I was alone	3	1.7%
I did not want to have someone with me	0	0.0%
I was not able to have someone with me due to COVID-19 restrictions	2	1.1%
I was not able to have someone with me for other reasons	0	0.0%

The highest-scoring question for this stage related to respect and dignity, with 145 participants (82%) saying they were always treated with respect and dignity during their labour and birth. The lowest-scoring question for this stage related to clear explanations, with 16 participants (14%) saying that their baby's death was not explained to them in a way that they could understand.

Participants who experienced a stillbirth gave above-average ratings for four questions on this stage of care, relating to involvement in decisions, opportunities to ask questions, pain management, and respect and dignity.

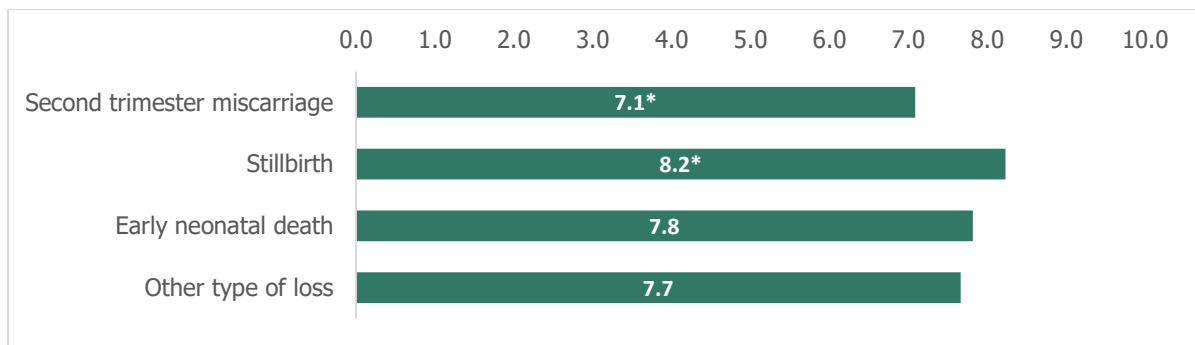
**Figure 12. Individual questions for 'Labour and birth'.**



\* indicates a significant difference from the national average

Comparisons of ratings for this stage of care by type of loss participants experienced are provided in Figure 13. Participants who experienced a second trimester miscarriage gave significantly below-average ratings for this stage, while those who experienced a stillbirth gave above-average ratings.

**Figure 13. Comparison of 'Labour and birth' by type of loss experienced.**



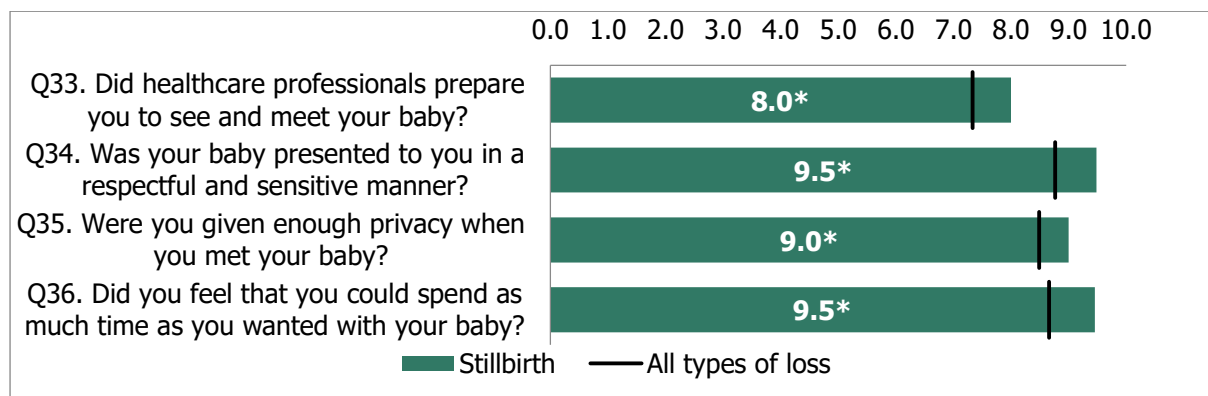
\* indicates a significant difference from the national average

## 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 14.

The joint-highest scoring questions for this stage related to whether a participant’s baby was presented to them in a respectful and sensitive manner, and whether they could spend as much time as they wanted with their baby. 159 participants (91%) said that their baby was ‘definitely’ presented to them in a respectful and sensitive manner, while 156 (89%) said ‘yes, completely’ when asked if they could spend as much time as they wanted with their baby. The lowest-scoring question for this stage related to how healthcare professionals prepared participants to see and meet their baby. 13 participants (7%) said that healthcare professionals did not prepare them for this. Participants who experienced a stillbirth rated all questions for this stage above the average for all types of loss.

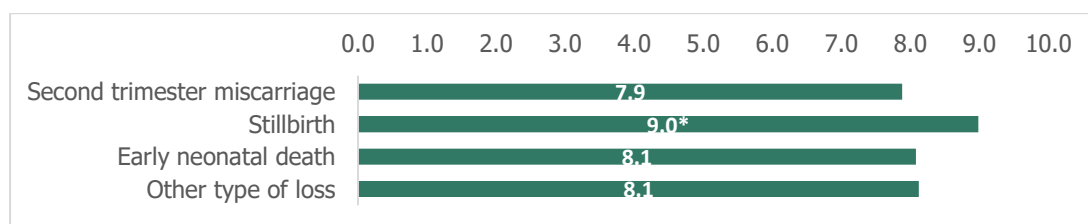
**Figure 14. Individual questions for ‘Care after birth’.**



\* 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 15. Participants who experienced a stillbirth rated this stage of care more positively than the national average.

**Figure 15. 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 stillbirth about their experiences in the maternity hospital or unit following the birth.

The first question in this section asked participants who had experienced a stillbirth about their hospital accommodation after their baby was born, and the results are shown in Table 5. In total, 106 participants (60%) said that they were accommodated in a single room, with 88 (49%) accommodated in a bereavement room.<sup>13</sup>

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**

<b>Q43. After your baby was born, which of the following best describes your accommodation?</b>		
	No.	%
Single room (not shared)	106	59.6%
Bereavement room (a specific family room designed to facilitate bereaved families)	88	49.4%
Shared room	2	1.1%
Labour ward	5	2.8%
Antenatal ward	1	0.6%
Postnatal ward	0	0.0%
General ward	1	0.6%
Emergency ward	0	0.0%
I wasn't admitted overnight	1	0.6%
Other	3	1.7%

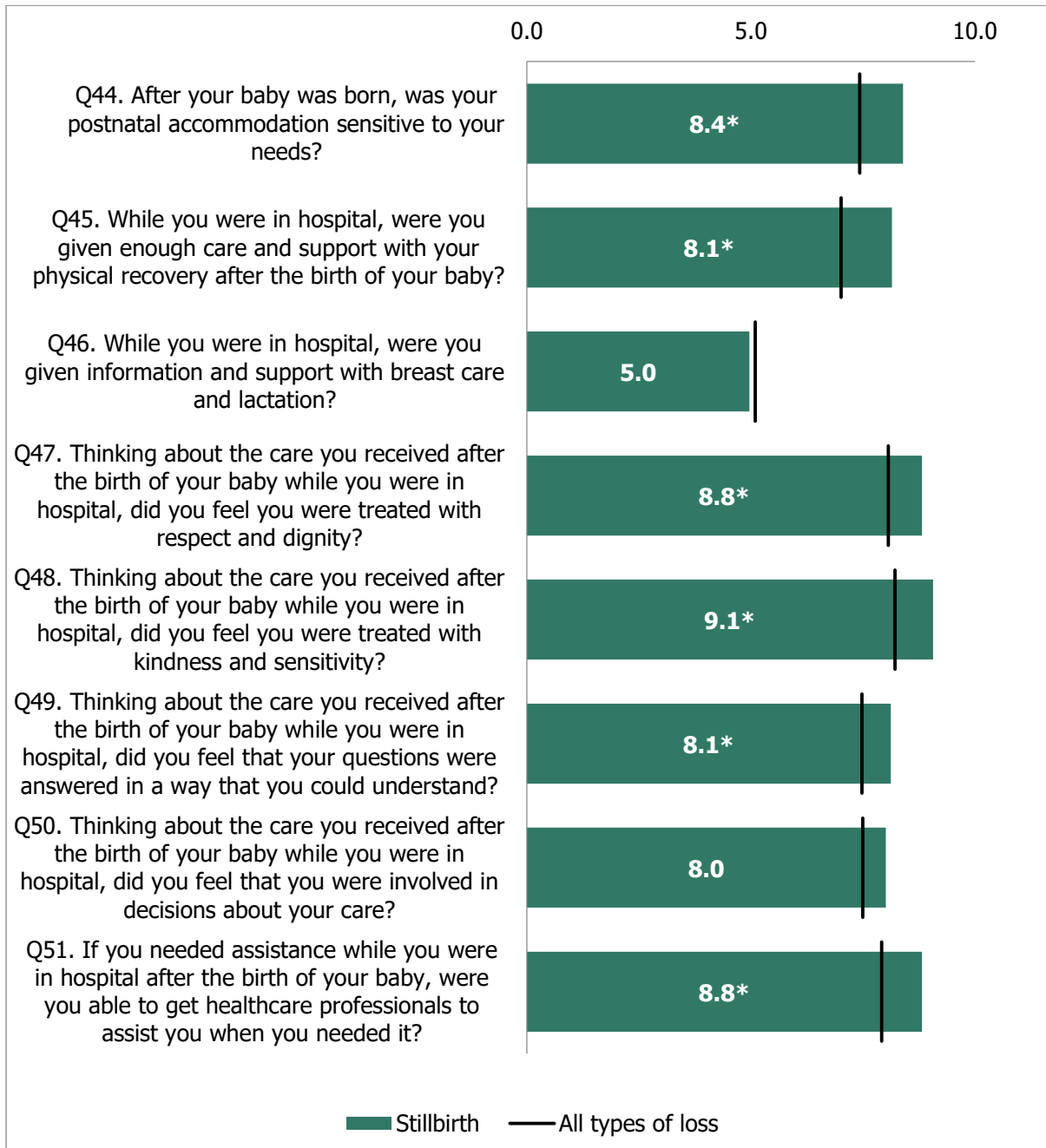
The highest-scoring question for this stage related to kindness and sensitivity, with 146 participants (83%) saying that they were 'always' treated with kindness and

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<sup>13</sup> The question allowed multiple answers as participants may have been accommodated in a number of different rooms.

sensitivity. The lowest-scoring question for this stage asked about breast care and lactation, with 47 participants (32%) saying that they were not given information and support relating to breast care and lactation. Participants gave above-average ratings for six questions relating to this stage of care.

**Figure 15. Individual questions for 'Postnatal care'.**



\* indicates a significant difference from the national average

Comparisons of ratings for this stage 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 stillbirth 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. No participants 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. 114 participants (64%) said that their family or friends were offered the opportunity to meet their baby, while 48 (27%) 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**

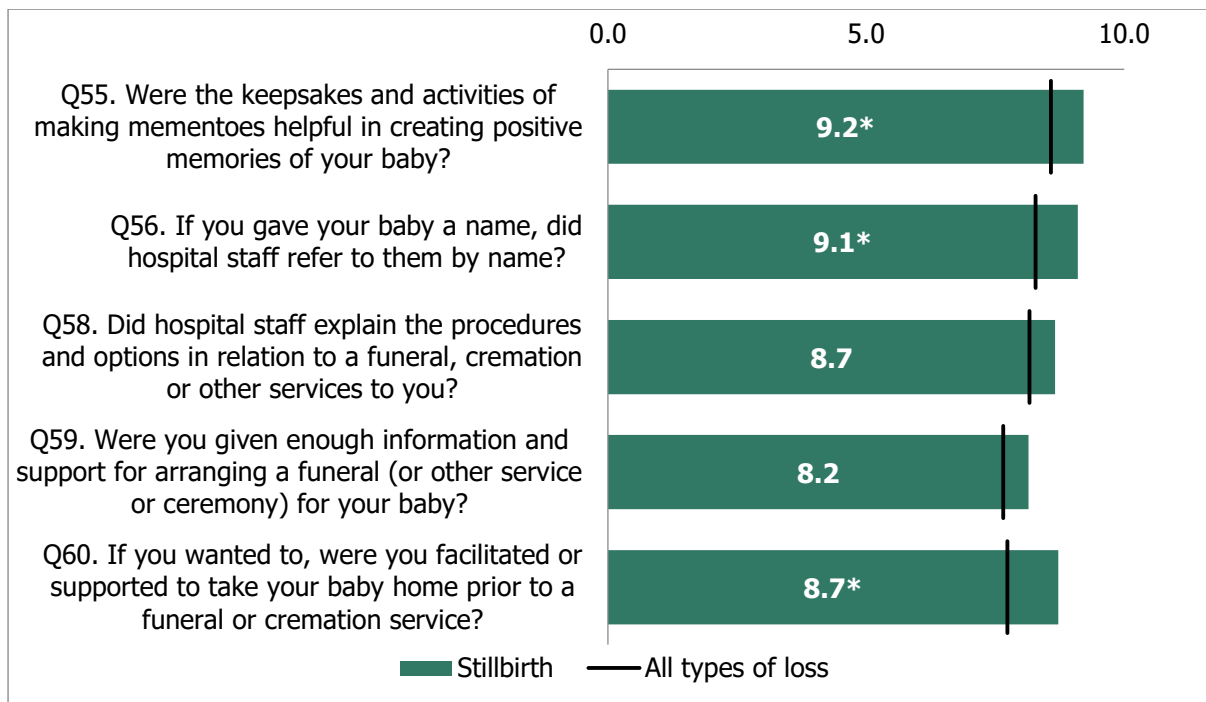
<b>Q54. Were you offered the opportunity to...</b>		
	No.	%
Name your baby	176	98.9%
Spend time with your baby	178	100.0%
Hold your baby	176	98.9%
Dress your baby	127	71.3%
Bath your baby	39	21.9%
Take a lock of your baby's hair	113	63.5%
Have photos with your baby	167	93.8%
Have a copy of your baby's hand print or foot print	173	97.2%
Have a naming or blessing ritual or ceremony	131	73.6%
Create a memory box	162	91.0%
Use a Bereavement alert symbol	110	61.8%
I was not offered any of these	0	0.0%
I did not want any of these	0	0.0%

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

<b>Q57. Were your family or friends offered the opportunity to meet your baby?</b>		
	No.	%
Yes	114	64.0%
No, but I would have liked them to	5	2.8%
No, I did not want them to	7	3.9%
Family and friends were not able to visit due to COVID-19 restrictions	48	27.0%
Family and friends were not able to visit for other reasons	4	2.2%

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 152 participants (85%) 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 the baby home prior to the funeral, with 14 participants (10%) saying that they were not facilitated or supported to take their baby home prior to the funeral or cremation service. Participants who experienced a stillbirth gave above-average ratings on questions relating to mementoes creating positive memories, staff referring to their baby by name, and being facilitated to take their baby home.

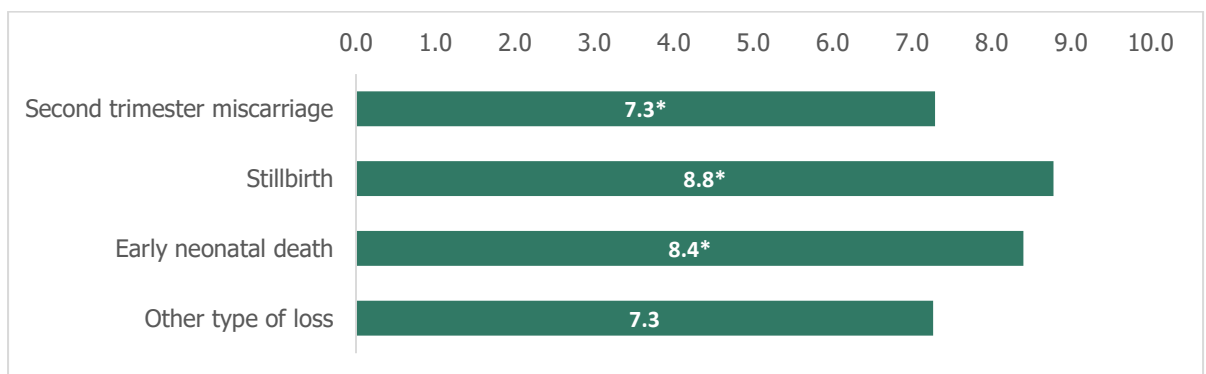
**Figure 17. Individual questions for 'Bereavement care'.**



\* 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. 63 participants (35%) said that their baby had a consented post-mortem, while 40 participants (23%) said their baby had a coroner's post-mortem.<sup>14</sup>

**Table 8. Results for question on post-mortem examination**

<b>Q61. Did your baby have a post-mortem examination?</b>		
	No.	%
Yes, a consented post-mortem	63	35.4%
Yes, a coroner's post-mortem	40	22.5%
No, I declined a post-mortem examination	51	28.7%
No, I was not offered a post-mortem examination	24	13.5%

Participants were asked when they had received a follow-up appointment to receive the results of the tests and investigations. Findings for this question are shown in Table 9. 42 participants (41%) said that they received the results within one to three months. Six participants (6%) said they had waited for longer than 18 months.

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<sup>14</sup> 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.

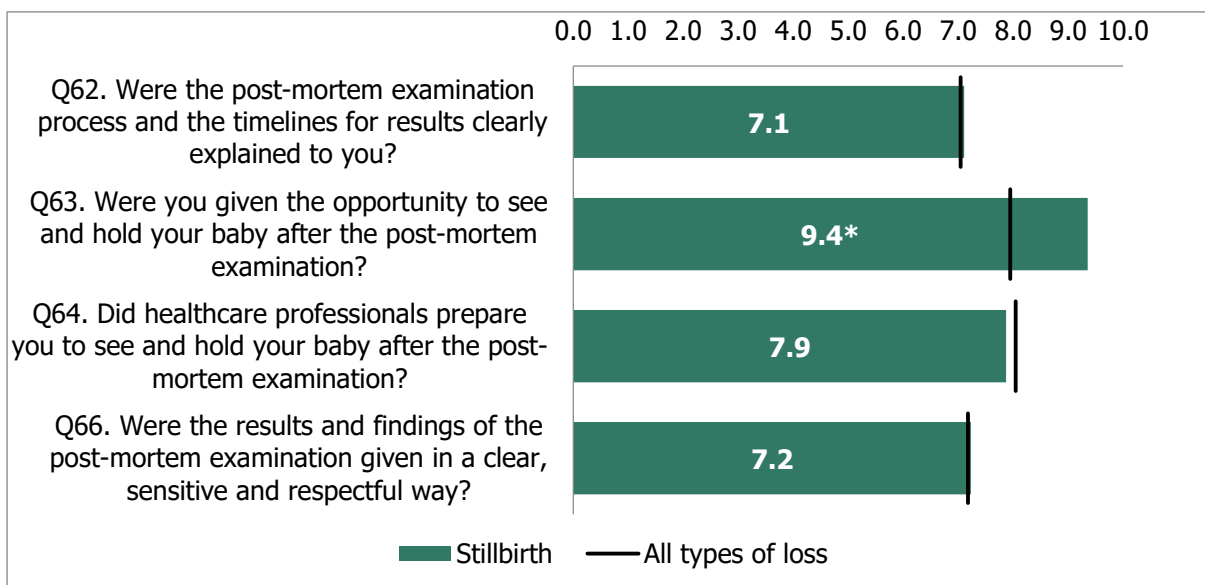
In the case of a coroner's post-mortem examination, parents are informed of the reason for this requirement and the process is explained to the parents along with written information. Parent's consent is not required for a post-mortem examination instigated by a Coroner.

**Table 9. Results for question on follow-up appointment**

<b>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?</b>		
	No.	%
I haven't received the results	11	10.7%
1 to 3 months	42	40.8%
4 to 6 months	26	25.2%
7 to 11 months	13	12.6%
12 to 18 months	5	4.9%
Longer than 18 months	6	5.8%

The results for the four other questions in this section are shown in Figure 19. The highest-scoring question for this stage related to having the opportunity to see and hold their baby after the post-mortem examination. 87 participants (94%) said that they were given this opportunity. This question scored above the average for all types of loss. The lowest-scoring question related to explanations, with 14 participants (14%) saying that the post-mortem examination process and timelines were not clearly explained to them.

**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

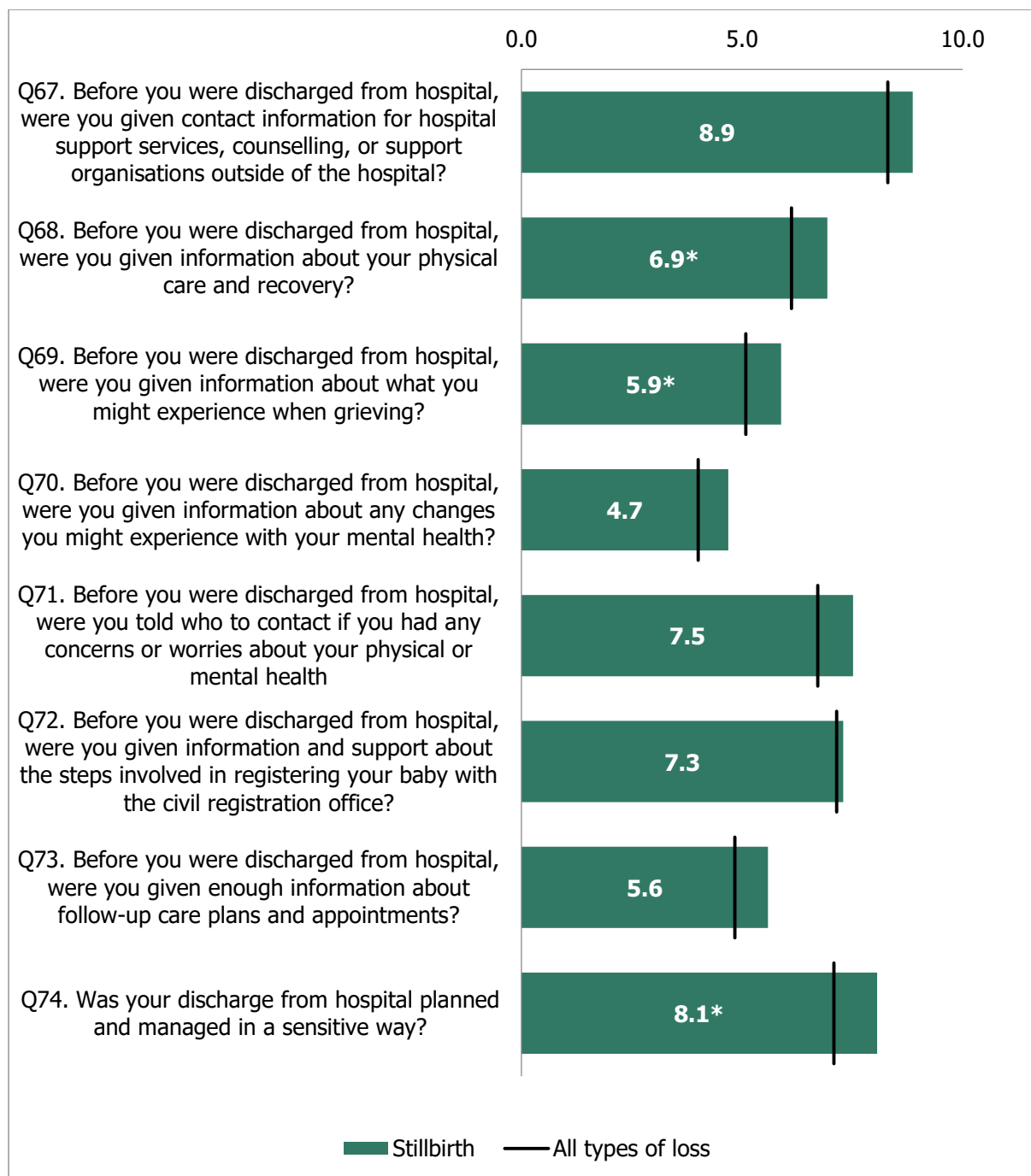
This section included eight questions that asked participants who experienced a stillbirth about the information and support provided to them prior to being discharged from hospital.

Seven 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 women 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 149 participants (89%) 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 62 participants (39%) saying that they were not given information about changes they might experience with their mental health.

Participants who experienced a stillbirth gave higher than average ratings on three questions for this stage, relating to provision of information about physical care, grieving, and their discharge being planned and managed in a sensitive way.

**Figure 21. Individual questions for 'Discharge'.**



\* 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 22. Participants 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 stillbirth seven questions about their experiences of care at home after their discharge from hospital, and their follow-up care.

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. 103 participants (58%) said that they saw a GP, while significant numbers also saw a bereavement midwife or obstetrician. On the other hand, 10 participants (6%) 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. Four participants (2%) had not accessed any supports.

The remaining five questions for this section were scored out of 10 and the results are shown in Figure 23.

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

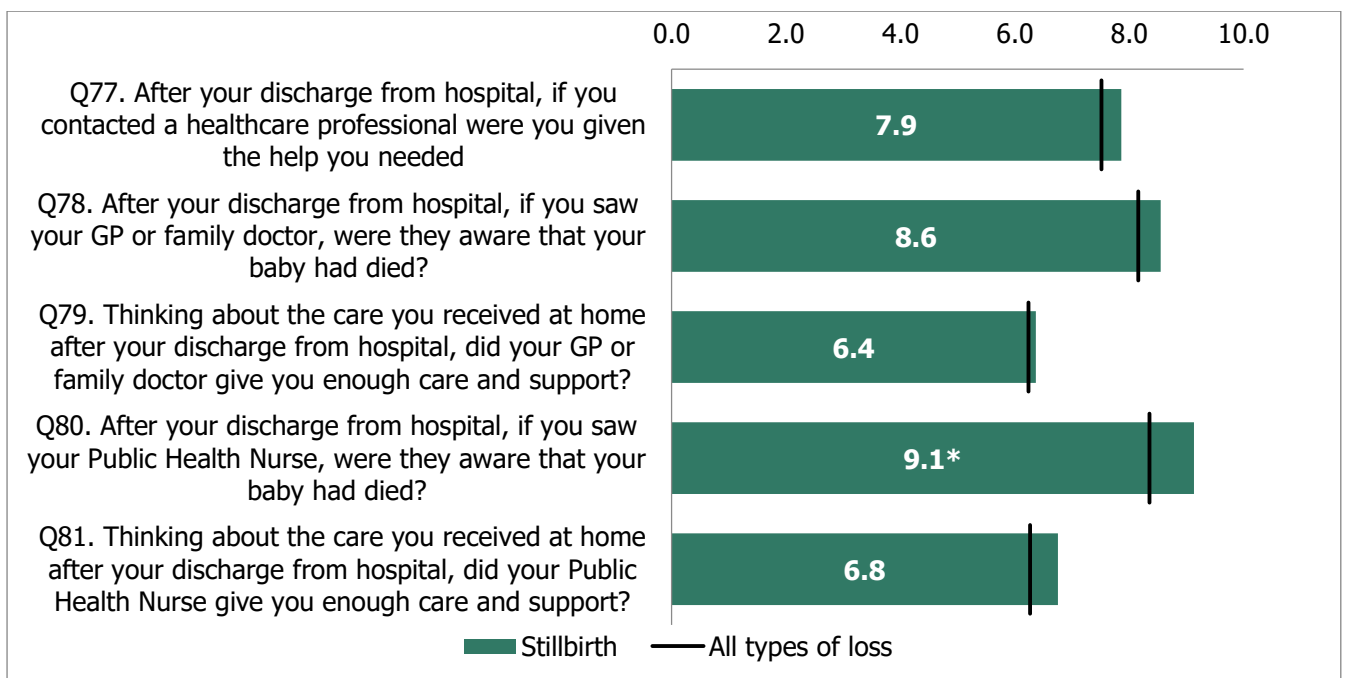
<b>Q76. After your discharge from hospital, who did you see as part of your follow-up care?</b>		
	No.	%
Family doctor (GP)	103	57.9%
Public Health Nurse (PHN)	73	41.0%
Bereavement midwife or nurse specialist in the hospital	102	57.3%
Mental health services	19	10.7%
Obstetrician or gynaecologist after discharge	54	30.3%
Consultant paediatrician or neonatologist	9	5.1%
Other	6	3.4%
I had to attend the hospital emergency department because of complications	12	6.7%
I had a follow-up appointment at the hospital but I declined to attend	2	1.1%
I haven't had any follow-up care since my discharge from hospital	10	5.6%

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

<b>Q82. After your discharge from hospital, what supports did you access?</b>		
	No.	%
Partner	143	85.1%
Family	134	79.8%
Friends	113	67.3%
Bereavement support organisations/advocacy groups	88	52.4%
Hospital support services	30	17.9%
Professional counselling	65	38.7%
Other	9	5.4%
I did not access any supports	4	2.4%

The highest-scoring question related to Public Health Nurses, with 95 participants (91%) saying that their Public Health Nurse was aware that their baby had died. This questions scored above the average for all types of loss. Question 79 was the lowest-scoring question for this stage, with 34 participants (23%) saying that their GP or family doctor did not give them enough care and support.

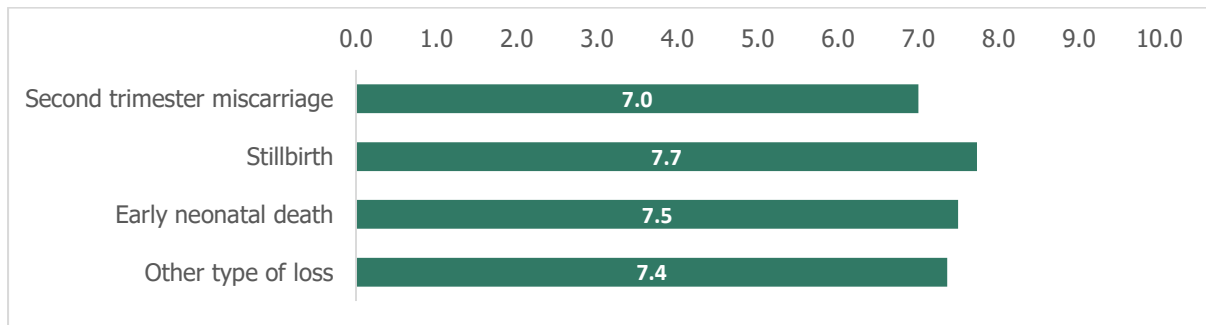
**Figure 23. Individual questions for 'Follow-up care'.**



\* 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 a stillbirth. 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.

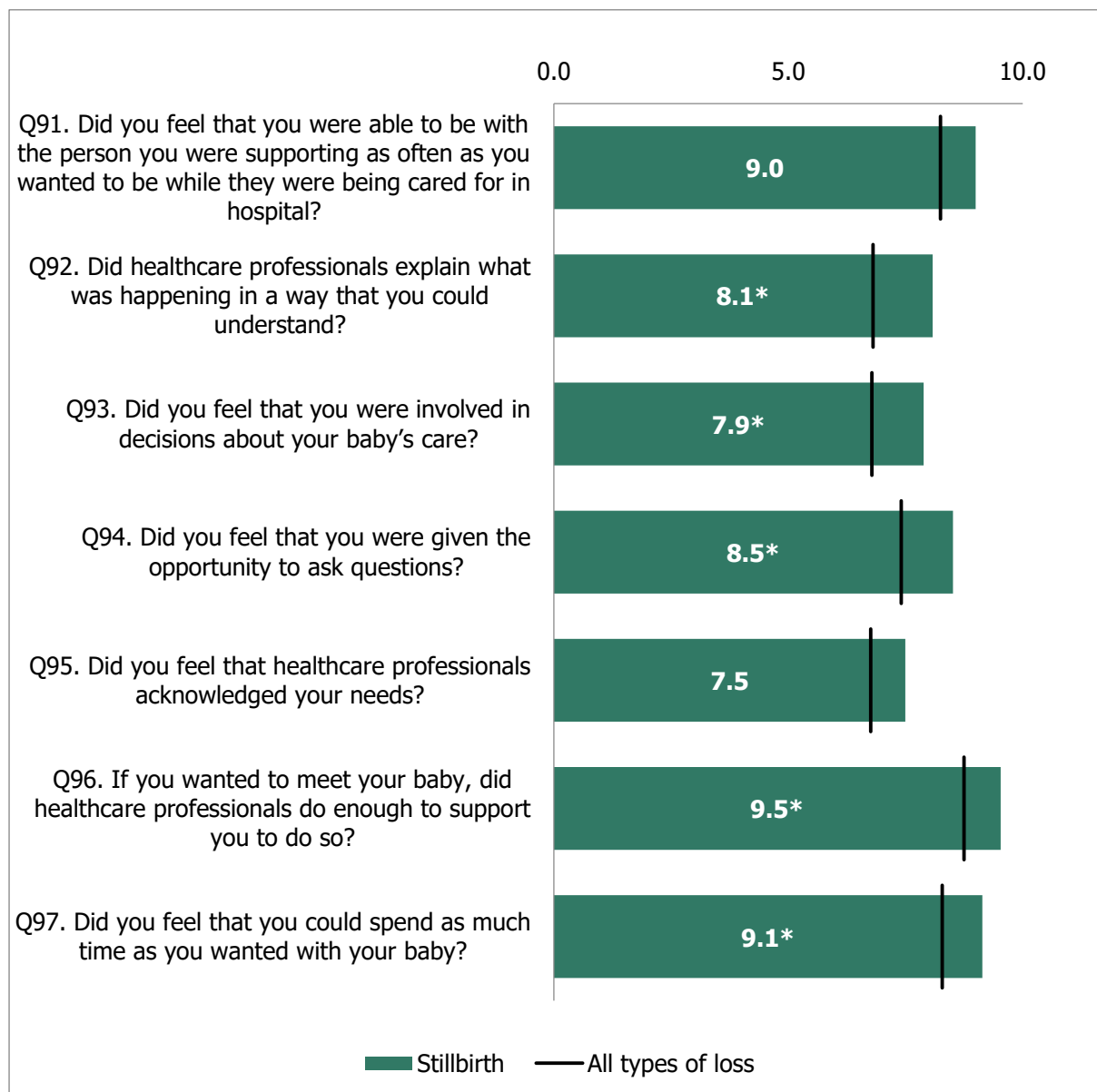
Participants were also asked about the supports they accessed and the results for this question are shown in Table 12. The most common sources of support were partners, family and friends. Nine participants (14%) said that they did not access any supports.

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

<b>Q98. If you sought support after the loss of your baby, what supports did you access?</b>		
	No.	%
Partner	52	81.3%
Family	41	64.1%
Friends	33	51.6%
Family doctor or GP	10	15.6%
Bereavement support organisations/advocacy groups	21	32.8%
Hospital support services	9	14.1%
Professional counselling	10	15.6%
Other	0	0.0%
I did not access any supports	9	14.1%

The highest-scoring question for this stage related to feeling supported to meet the baby, with 56 participants (88%) saying that healthcare staff 'definitely' did enough to support them if they wanted to meet their baby. The lowest scoring question related to acknowledgement, with six participants (9%) feeling that healthcare professionals did not acknowledge their needs. Participants who experienced a stillbirth rated five questions for this stage above the average for all types of loss.

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



\* 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 26. Participants 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**



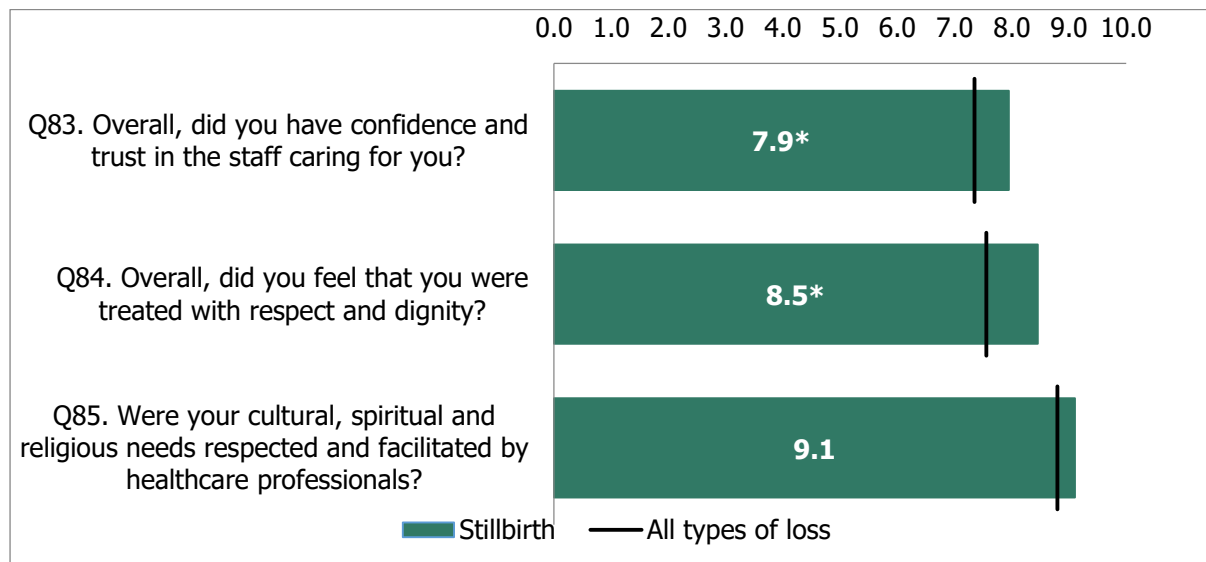
\* indicates a significant difference from the national average

## 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 114 participants (85%) saying that healthcare professionals 'definitely' respected and facilitated their cultural, spiritual and religious needs. The lowest-scoring question related to confidence and trust, with 10 participants (6%) saying that they did not have confidence and trust in the staff that treated them. However, participants who had a stillbirth rated this question above the average for all types of loss. In response to the other question in this section, 127 participants (71%) said that they were always treated with respect and dignity. This question also scored above the average for all types of loss.

**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 154 participants (88%) saying they were offered this service. Four participants (2%) said that they weren't offered any hospital support services, with two (1%) saying that no hospital support services were available.



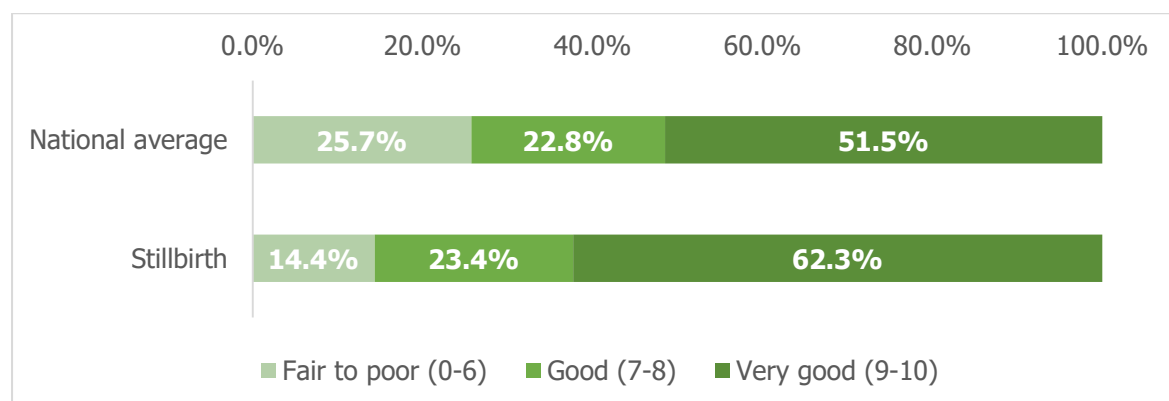
**Table 13. Results for question on hospital supports offered to participant**

<b>Q86. Were you offered any of the following hospital support services?</b>		
	No.	%
Chaplaincy or pastoral care	121	69.1%
Social Work	33	18.9%
Bereavement midwife or nurse specialist	154	88.0%
Perinatal (pregnancy-related) Mental health service	23	13.1%
Perinatal (pregnancy-related) Palliative Care team	4	2.3%
Paediatrician/Neonatologist	9	5.1%
Other	3	1.7%
I wasn't offered any hospital support services	4	2.3%
No hospital support services were available	2	1.1%
Don't know or can't remember	4	2.3%

**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, 104 participants (62%) rated their care as 'very good', 39 (23%) as 'good' and 24 rated it as 'fair to poor' (14%).

**Figure 28. Overall ratings of care**



## Conclusion

### **Experiences of maternity bereavement care for a stillbirth between 2019 and 2021**

In total, 178 women and 65 partners or support persons generously shared their experiences of stillbirth through the National Maternity Bereavement Experience Survey. Participants described all aspects of their experiences of maternity bereavement care.

While 86% 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, and follow-up care and appointments. In addition, participants who experienced a stillbirth were not always given sufficient support for breast care and lactation.

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 midwives in particular. In addition, participants said that most staff treated them with respect and dignity. In addition, staff members respected their cultural and religious needs.

The experiences of partners of those who experienced a stillbirth were also explored. Most partners felt that they were treated with compassion and support, however they highlighted a need for greater acknowledgement of their specific needs, 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. Participants who experienced a stillbirth gave more positive ratings of their care than those who had a different type of loss, across seven stages of care. Above-average ratings were given for the 'admission', 'labour and birth', 'care after birth the birth and meeting your baby', 'postnatal care', 'bereavement care', 'discharge', and 'partner's experience' stages of care.

In conclusion, the findings of the National Maternity Bereavement Experience Survey show that most parents who experienced a stillbirth 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 mental health, follow up appointments, and breast and lactation care.

### **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](http://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.<sup>15</sup>

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?

- o Yes, always (10)
- o Yes, sometimes (5)
- o No (0)
- o 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 responded to this question (30/5=6). Thus, the average score for Question 56 is 6 out of 10.

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<sup>15</sup> Care Quality Commission. NHS Patient Survey Programme: Survey Scoring Method 2015.

**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.

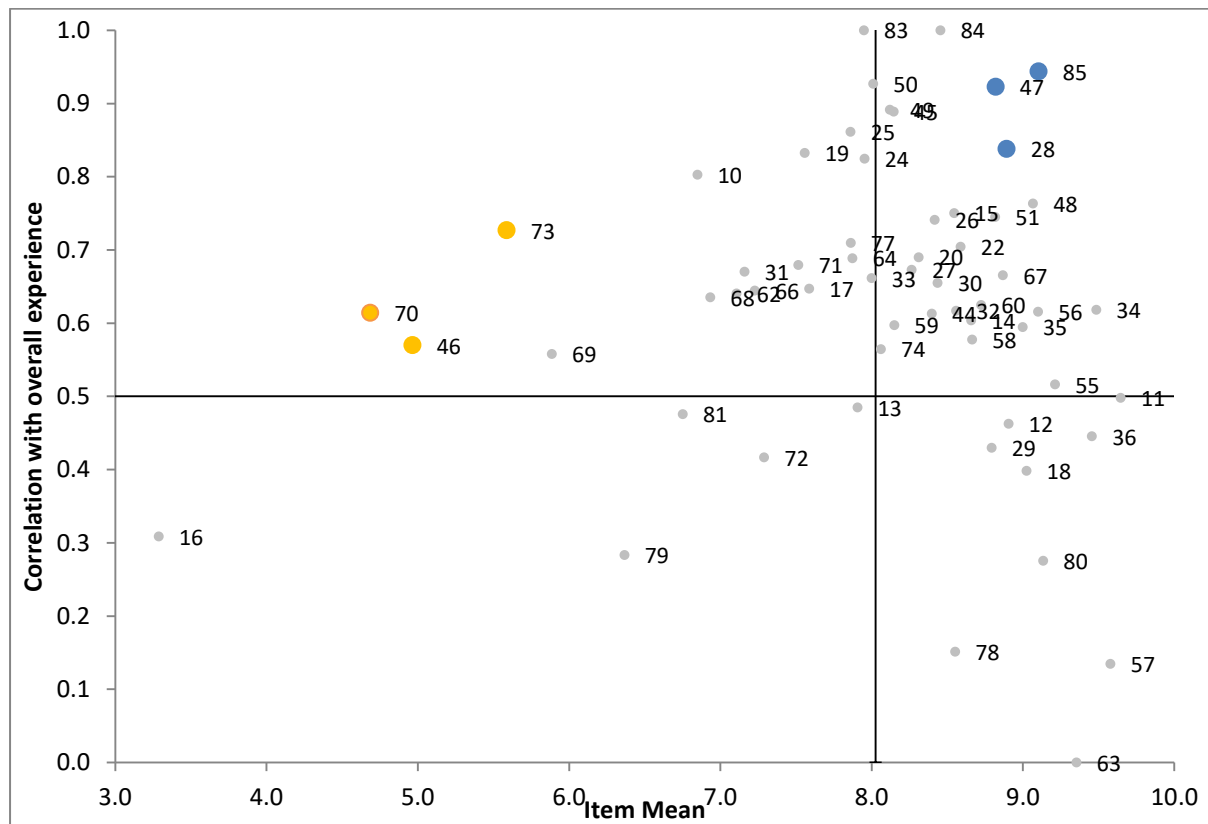
Results on questions comparing two groups of residents (e.g., those who share a bedroom and those who do not) were compared using a ‘t-test’ at the 99% confidence level. A t-test is a statistical test used to compare the average scores of two groups. A statistically significant difference means it is 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 12 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. Q28. Thinking about the care you received during your labour and birth, did you feel that you were treated with respect and dignity?
  - a. 145 participants (82.4%) said that they were always treated with respect and dignity during their labour and birth.
  
2. Q47. Thinking about the care you received after the birth of your baby while you were in hospital, did you feel you were treated with respect and dignity?
  - a. 141 participants (79.2%) said that they were always treated with respect and dignity after the birth of 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. Q46. While you were in hospital, were you given information and support with breast care and lactation?
  - a. 47 participants (32.4%) said that they were not given information and support with breast care and lactation.
2. Q70. Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?
  - a. 62 participants (39%) said that they were not given enough information about changes they might experience to their mental health 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. 47 participants (27.6%) 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  
Maternity  
Bereavement  
Experience  
Survey

