



National Maternity Bereavement Experience Survey 2022

Experiences of the early neonatal death of a baby

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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 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 the early neonatal death of a baby. A national report, and reports on experiences of second trimester miscarriage and stillbirth 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.

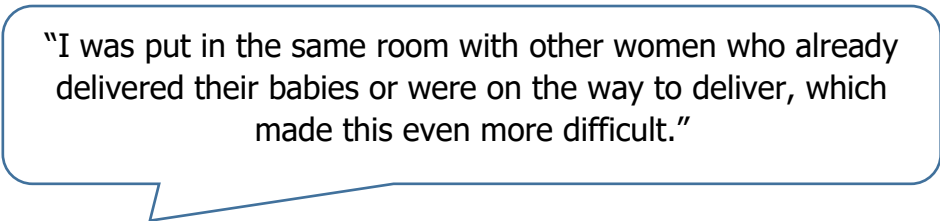
² Earlier losses were not included, as women who experience early pregnancy loss in many cases are cared for in outpatient or general practice (GP) settings, many do not require admission to hospital for care. Some women with first trimester miscarriage do not interact with healthcare services at all. 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 the early neonatal death of a baby?

In total, 98 women and 40 partners or support persons³ who experienced an early neonatal death 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, neonatal care, investigations, discharge home, follow-up care and care in the community. Participants were asked to rate their overall care, with 48% rating their care as 'very good', 26% as 'good', and 26% 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 response to the other survey questions. When asked what was good about their care, participants highlighted the compassion and sensitivity shown to them by staff. Most participants said that staff referred to their baby by name, were aware of their loss, and their cultural, spiritual and religious needs were facilitated and supported.

When asked what could be improved, some participants highlighted that they were not always treated with respect and dignity. In addition, some participants felt communication and information-sharing could be improved, and they weren't always treated with compassion and sensitivity, as described in the comment below.



"I was put in the same room with other women who already delivered their babies or were on the way to deliver, which made this even more difficult."

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 an early neonatal death were also explored. Most partners felt that they were treated with compassion and support, however they highlighted a need for clearer explanations by healthcare professionals, as well as greater supports for grieving and mental health.

Across the stages of care included in the survey, participants who experienced a stillbirth gave the lowest rating to the 'discharge' stage (6.5 out of 10), and the highest to 'bereavement care' (8.5 out of 10). Participants who experienced an early

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

neonatal death gave more positive ratings for the 'bereavement care' than those who had a different type of loss.

The findings of the National Maternity Bereavement Experience Survey show that most parents who experienced an early neonatal death 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 provided at discharge for mental health, grieving, and follow-up care and appointments.

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?

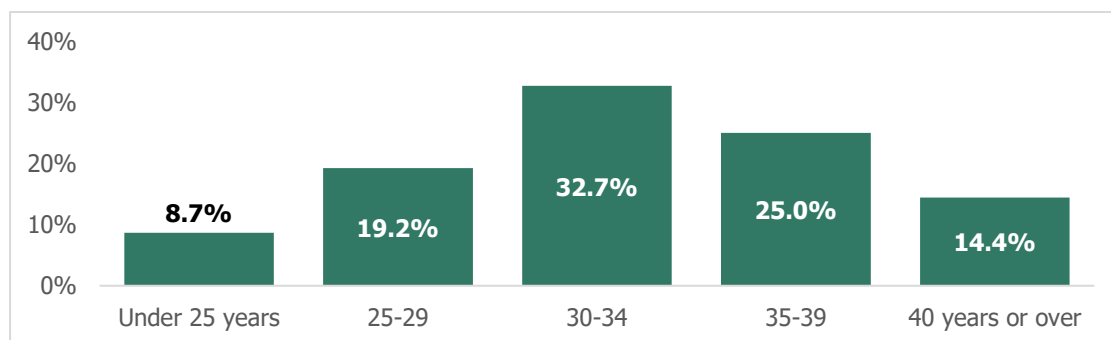
Women aged 16 or over, and their partners, who experienced a second trimester miscarriage (from 14 weeks of pregnancy⁴), a stillborn infant or the early neonatal death of a baby⁵ in one of Ireland's 19 maternity units or hospitals from 1 January 2019 to 31 December 2021⁶ were eligible to participate.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

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, 98 women and 40 partners who experienced the early neonatal death of a baby participated in the survey. A breakdown of participants by age group is provided in Figure 1, with 58% of participants aged between 30 and 39. Table 1 outlines the year in which participants experienced an early neonatal death.

Figure 1. Characteristics of participants who experienced an early neonatal death, 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.⁷

Year bereavement was experienced	No.	%
2019	25	24.0%
2020	36	34.6%
2021	2543	41.3%

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 care⁸
- 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 Figures from the National Perinatal Epidemiology Centre indicate that 118 early neonatal deaths occurred in 2019, and 117 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/NPECPerinatalMortalityinIrelandannualreport2020.pdf>

⁸ 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?⁹

In total, 298 comments were made by participants who experienced an early neonatal death in response to the free-text questions. The results for each question are presented below in the following pages.

A framework approach¹⁰ was used to analyse the comments received in response to the open-ended 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 below.

⁹ This question was specific to partners

¹⁰ 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.

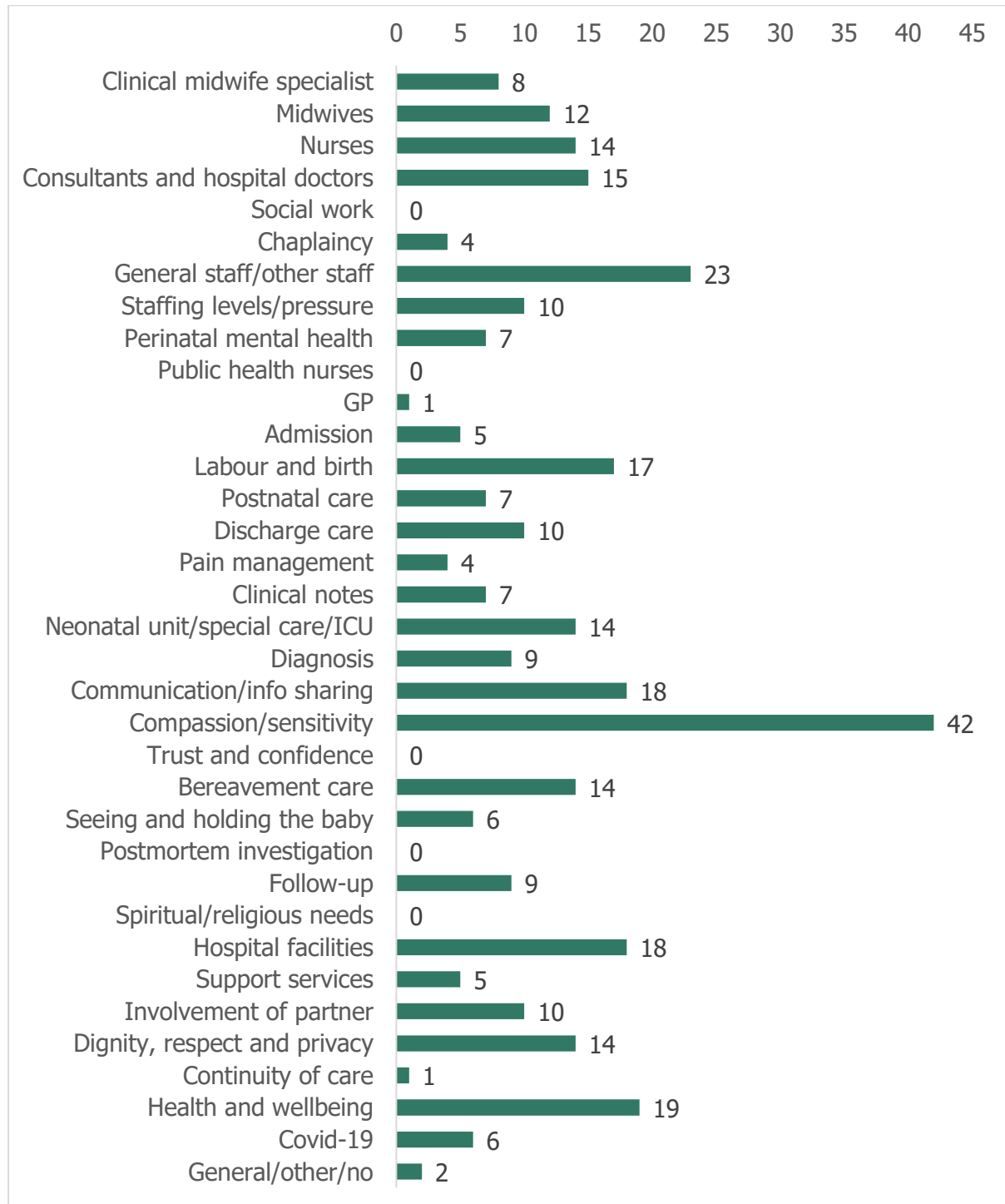
Table 2. List of Comment Themes

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 60 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 42 comments. The next most common themes were 'general staff or other staff comments' (23 comments) and 'health and wellbeing' (19 comments). A selection of comments made in response to this question is provided below.

Sample comments

"We were treated very well by all the hospital staff. They gave us plenty of time and didn't rush us. They were kind and supportive as we were very shocked at the time that our child had died."

"I got really good care in hospital and the staff were very sensitive to our situation. Even though there were COVID restrictions my husband was allowed to stay with me all the time."

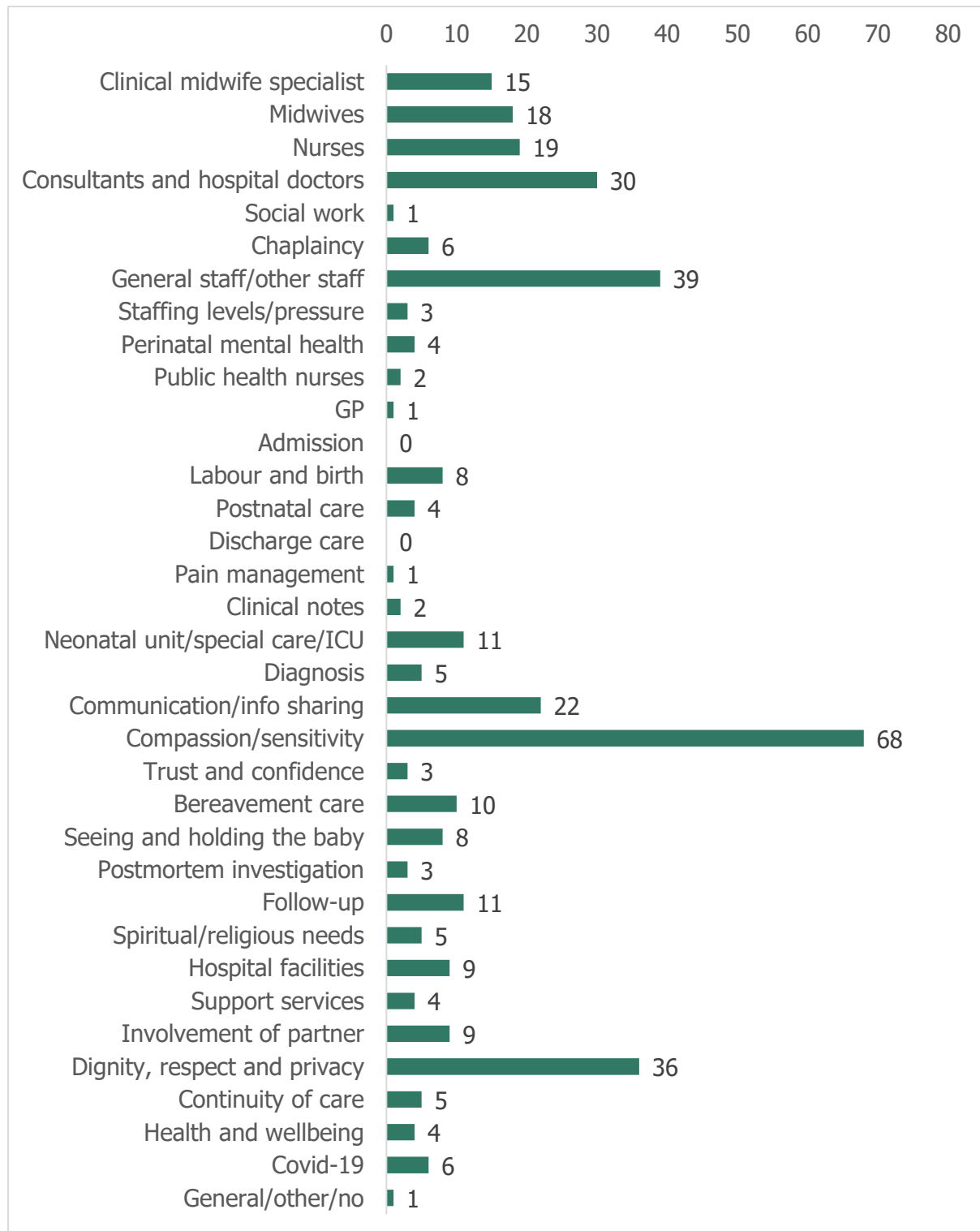
"On one occasion a gynae registrar came to examine me to see if I could have more pain relief and she didn't empathise with me, engage with me, and was so rough in her examination that I felt like an animal and this really hasn't left me."

"I was parked by a hospital door as instructed by staff so I could get my baby out of the hospital in a coffin without anyone seeing, and was given a parking ticket and rushed out like it was a big dirty secret."

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

In total, participants made 86 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 68 comments. The next most common themes were 'general staff or other staff comments' (39 comments) and 'dignity, respect and privacy' (36 comments). A selection of comments made in response to this question is provided below.

Sample comments

"I felt that the staff really cared that my child had died and wanted to do their best for me. They gave me time and they treated my baby with such dignity and kindness. I felt safe when I was in the hospital even though nobody could tell me why my child had been fine up until the last push - and then died. I felt the staff did all they could for me."

"The bereavement counsellor was excellent, she really supported me and I felt listened to when needed. Also the 3 midwives that were there with us throughout our stay in the hospital."

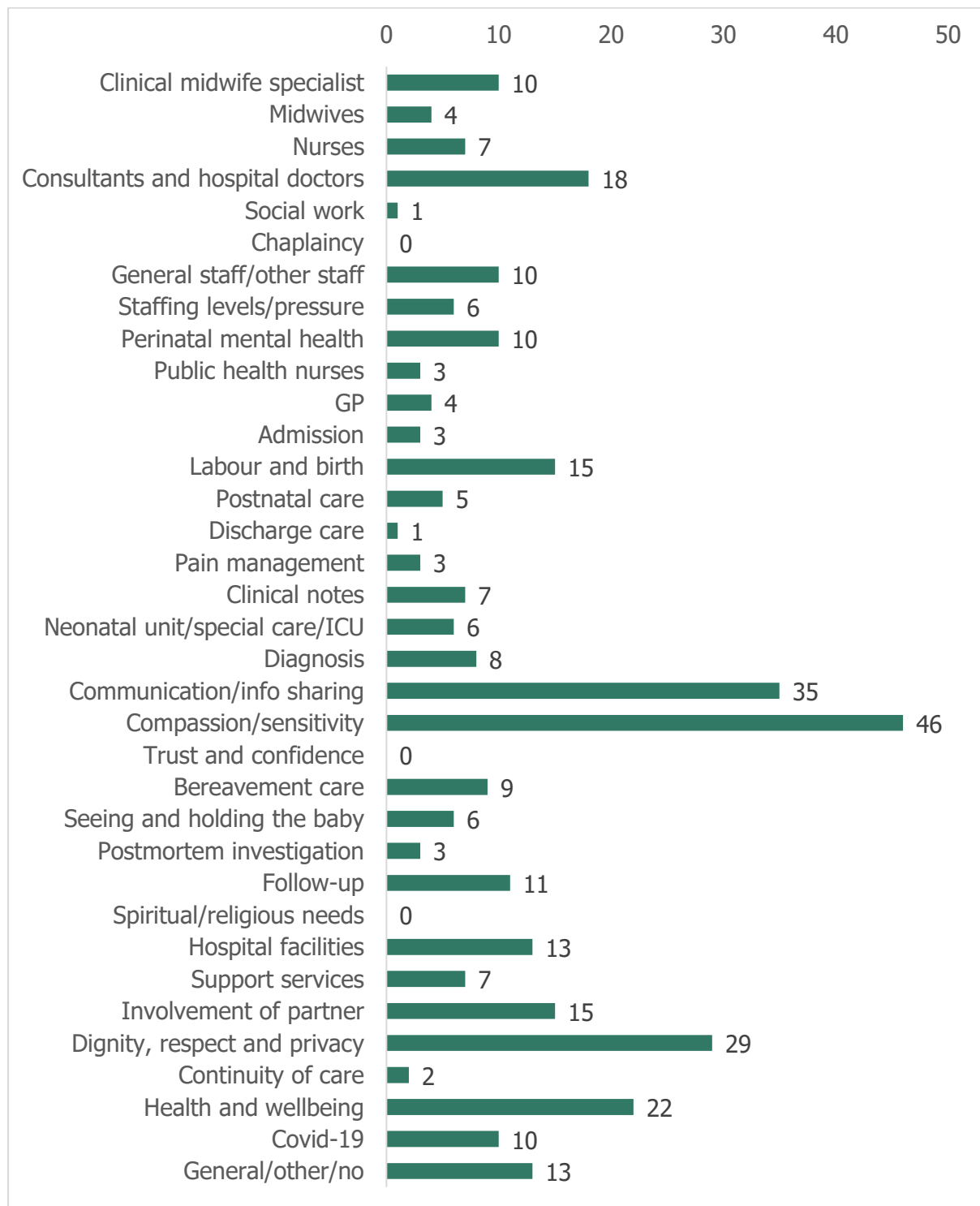
"All staff from porters to doctors to nurses were fantastic. They treated me with respect and compassion"

"The fetal medicine unit were amazing. Our situation was so, so difficult in that our daughter had a multiple fetal anomalies but her condition was not deemed fatal enough to interrupt the pregnancy. So I carried her knowing she would die. We were treated with such compassion and kindness by the fetal medicine team and my consultant who went above and beyond for us. She contacted multiple specialists to try and get a consensus in order to provide the care she thought we needed. Everyone we encountered was very sensitive to our situation. The nurses who looked after my daughter were also very kind and we were confident she was well looked after in her short life."

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

In total, participants made 82 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

"One thing that could be improved, I understand there are waiting times however when a mother knows her baby will not survive, waiting with other mothers is incredibly difficult. We should always be looked after first."

"The admission and care during labour should have been much better. No woman no matter what the circumstances should be going through labour in a public waiting area and worry if she would be seen in time to give birth in a respectful and dignified way."

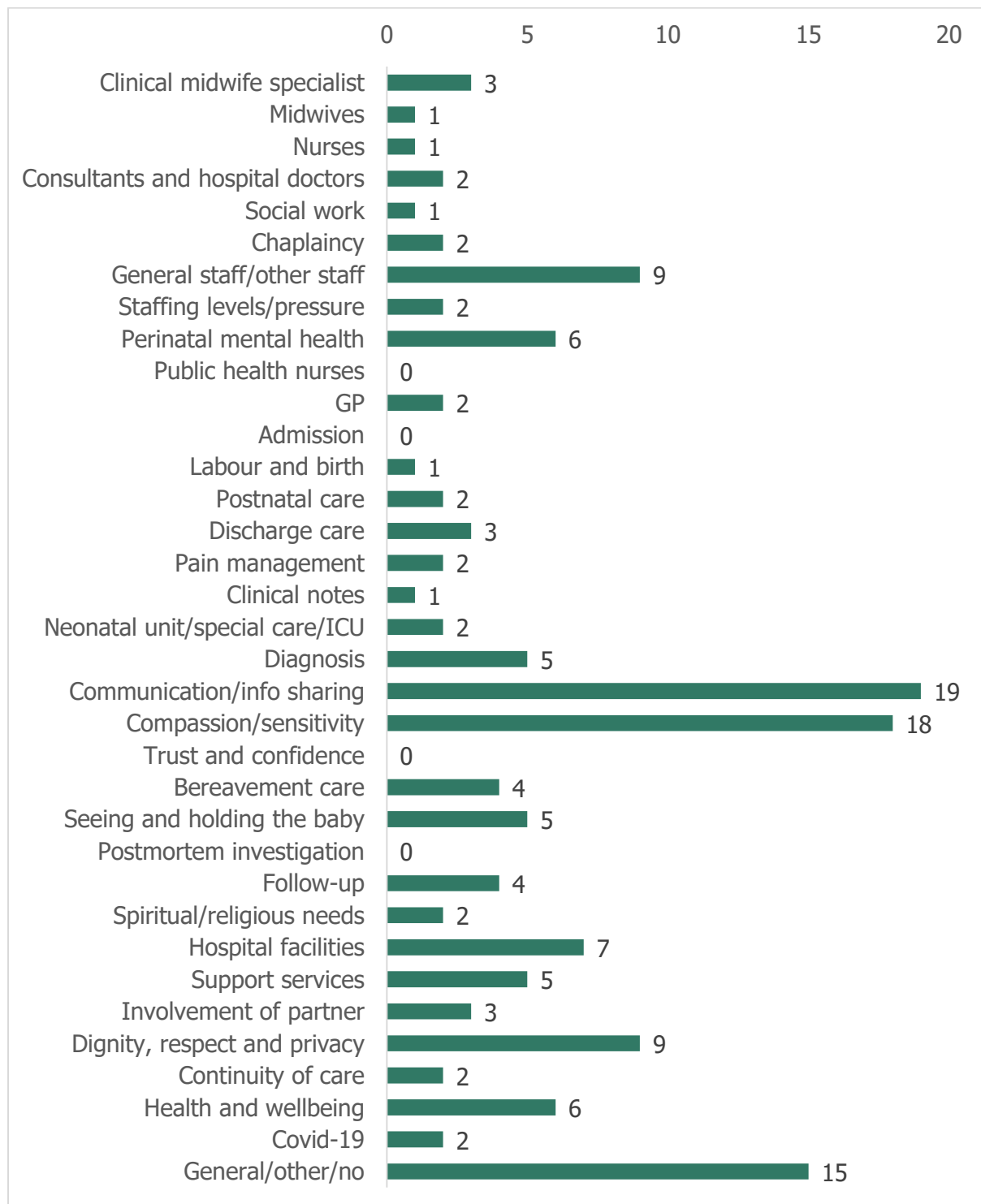
"My little one was a twin. And she used to have a purple butterfly on her incubator to let all members of staff she was a surviving twin, this was to save myself or my husband being asked where was twin 2. But I was asked numerous times where was twin 2 and I don't feel enough staff knew about this initiative."

"I think there should have been some sort of flagging system so anybody dealing with me knew about my baby's diagnosis. Having to explain that often was very upsetting, staff being unaware of the situation inadvertently asked insensitive questions."

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 50 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

"I think we were very fortunate to have the care we did and I hope such a high standard of compassion and skillful care is offered to all bereaved parents. The care we received helped us hugely in those dark days. Thank you."

"The nurses and doctors as well as all the other staff, cleaners, cooks, waiting staff.. they do fabulous work and sometimes don't get the recognition they deserve."

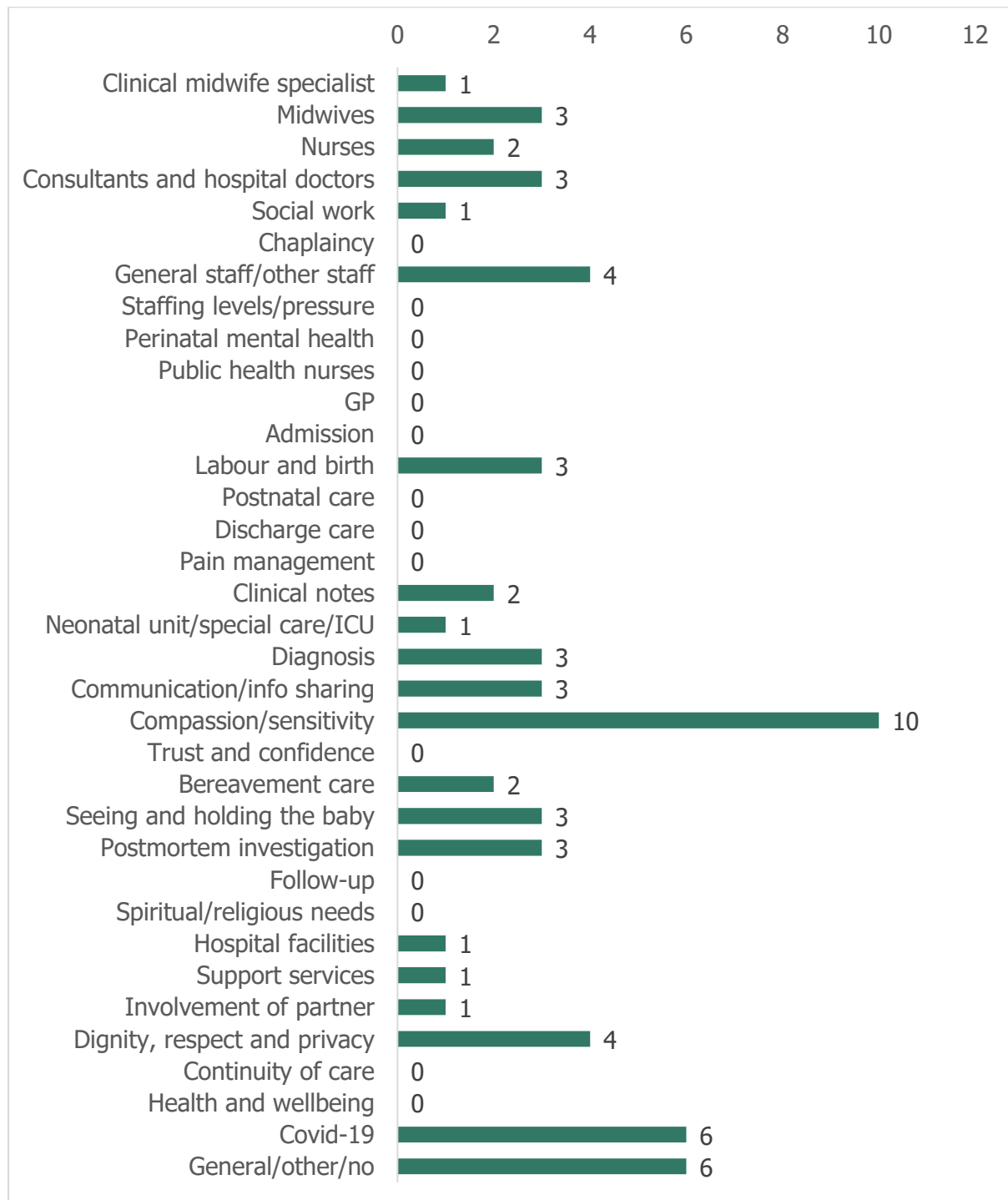
"I feel staff should call a rep or volunteer from Feileacain (or a little lifetime foundation) or encourage the parent to call Feileacain to get advise on what might be nice to do before you say goodbye to your baby. I wish we could have been advised to get certain photos and 3D hand casts of our babies. These are simple things to do but in a time of trauma and heartbreak it is difficult to think of these things. Other bereaved parents or charity volunteers are happy to assist and advice."

"I feel at times some staff/departments used Covid as an excuse for substandard care. However, when common sense, proper precautions and compassion was used, the care I received was excellent."

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 20 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

"The nurses were very kind, but we got an awful shock when our baby was taken away so quickly after birth. All was going grand until the last minute and then we don't know what happened. The post mortem or the inquest gave no answers. Everyone in the hospital was so kind to my partner and myself and looked after our little baby very well. They also welcomed our family in to meet our child."

"The care and support given by the staff was very much appreciated at the time could not have done more or been more supportive and helpful"

"It was very hard not being able to attend all appointments due to COVID. Even once our baby was diagnosed with a fatal foetal anomaly and I was given permission to attend appointments we still had to repeatedly explain why I was allowed in to the hospital. This was very upsetting for both my wife and I."

"I also believe facilities should be provided for at least 1 parent to stay beside the baby for longer periods of time and that when it was clear that the baby wasn't going to make it and life support withdrawn that a more private and peaceful room should be provided as it wasn't for us, and the noise and commotion in the NICU room didn't give us the last peaceful and private time with our baby as they passed away."

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 diagnosis¹¹, 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
 - 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. Follow-up care

¹¹ 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.

- 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.

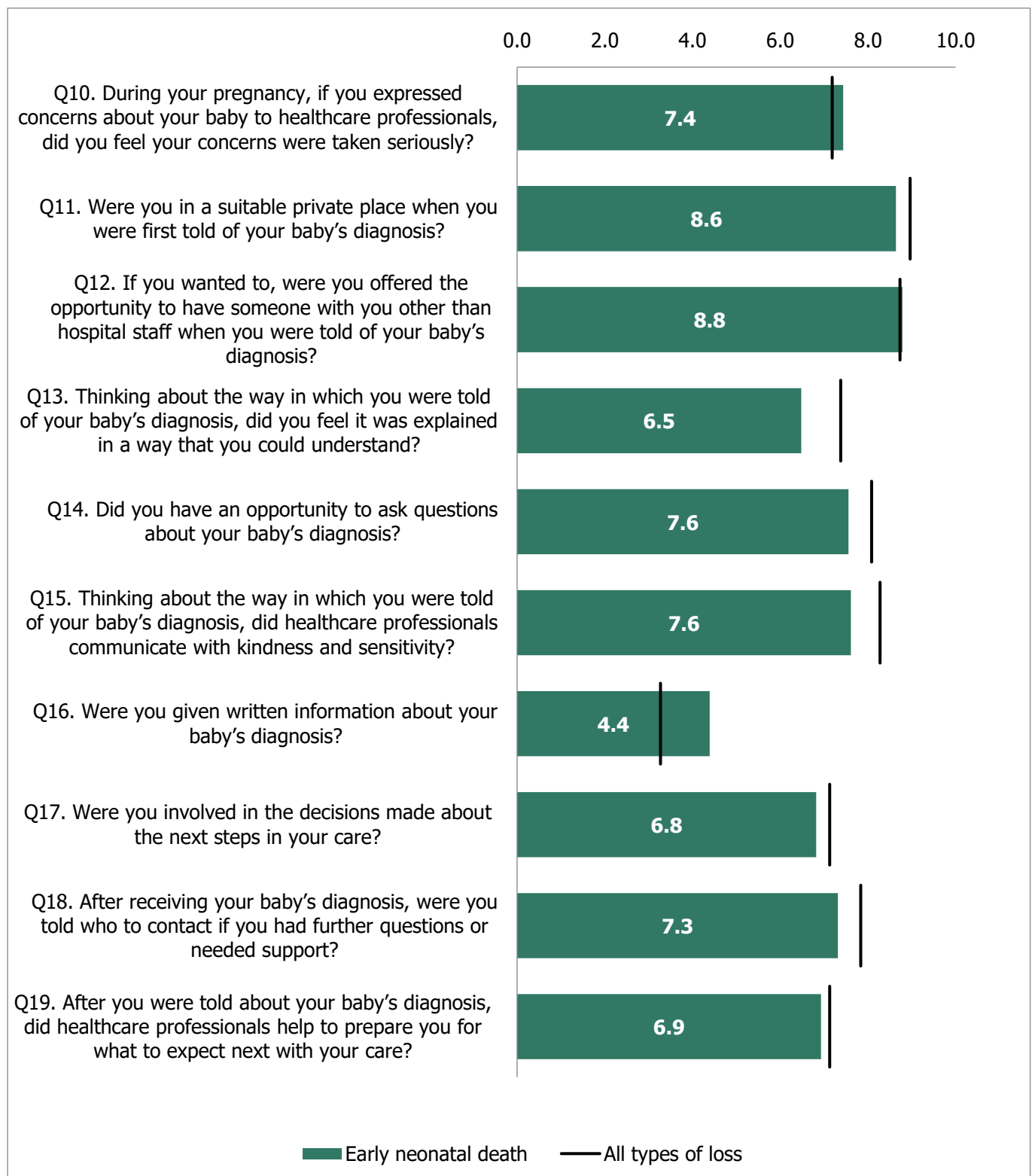
Statistical tests were carried out to examine if there were significant differences between the national average and scores for individual questions and stages of care. For further information on the analyses please see Appendix 1.

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, 54 participants (55%) who experienced the early neonatal death of a baby 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 being accompanied, with 29 participants (88%) saying that they were offered the opportunity to have someone with them when they were told about their baby's diagnosis. The lowest-scoring question related to receiving written or printed information about the diagnosis, with 23 participants (56%) saying they did not receive such information. For these questions, there were no significant differences from the average for all types of loss.

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

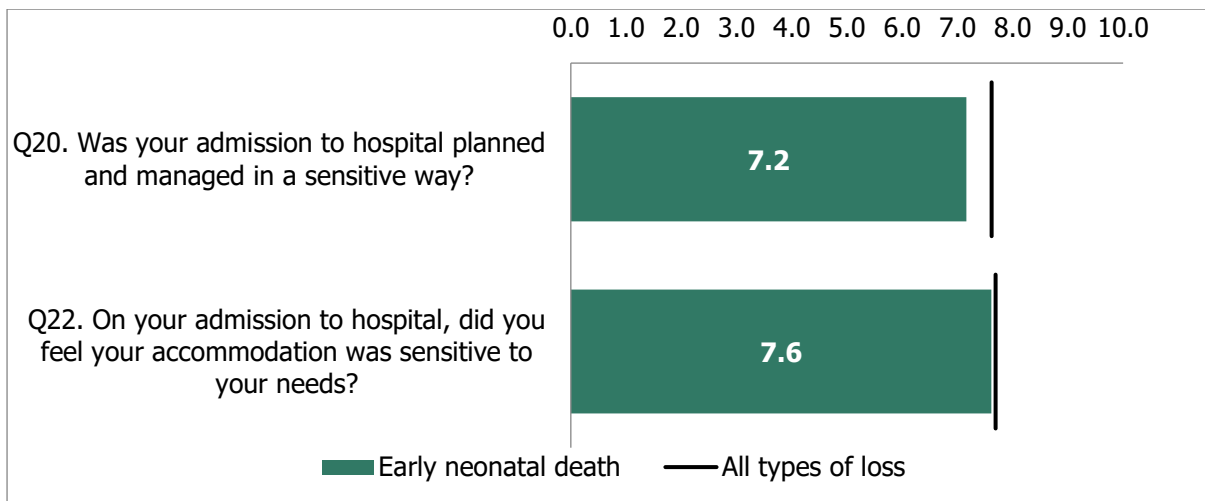
This stage included three questions on experiences of being admitted to hospital. One question asked participants to describe the type of room or ward they were admitted to. The results for this question are presented in Table 3. Most participants who experienced an early neonatal death (31, 71%) said 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, 21 participants (57%) said that their admission was 'definitely' planned and managed in a sensitive way, while 29 (66%) 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)	31	70.5%
Shared room	3	6.8%
Labour ward	3	6.8%
Antenatal ward	1	2.3%
Postnatal ward	0	0.0%
General ward	5	11.4%
Emergency ward	1	2.3%
I wasn't admitted overnight	0	0.0%
Other	2	4.5%

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 the early neonatal death of a baby gave similar ratings to 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 an early neonatal death (86, 88%) 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.

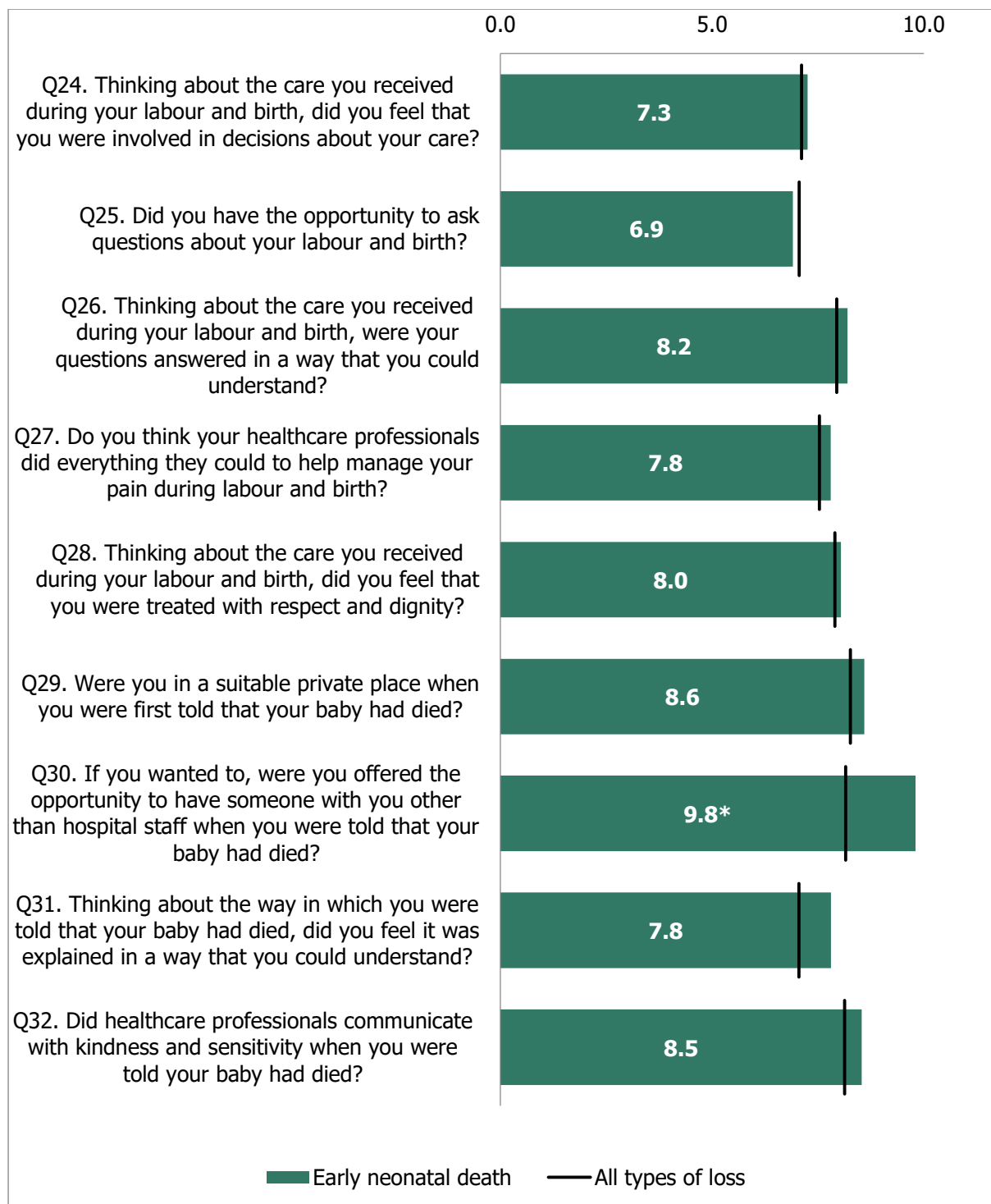
Table 4. Results for question on whether participant was accompanied during the labour and birth

Q23. Were you accompanied by anyone other than healthcare professionals during the labour and birth of your baby?		
	No.	%
Yes, by my partner	86	87.8%
Yes, by a support person (such as a family member, friend or doula)	0	0.0%
No, I was alone	5	5.1%
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	3	3.1%
I was not able to have someone with me for other reasons	4	4.1%

The highest-scoring question for this stage related to being accompanied, with 50 participants (98%) saying they were offered the opportunity to have someone with them when they were told that their baby had died. This question also scored significantly above the average for all types of loss.

The lowest-scoring question for this stage related to opportunities to ask questions, with 12 participants (14%) saying that they did not have the opportunity to ask questions.

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

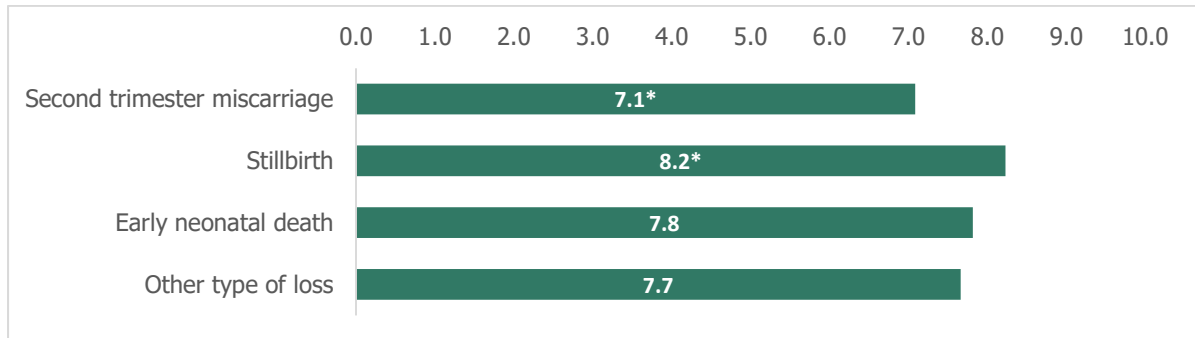


* indicates a significant difference from the national average

Comparisons of ratings for this stage of care by type of loss participants experienced are provided in Figure 12. Participants who experienced an early neonatal death gave ratings similar to the average. Those who experienced a second trimester

miscarriage gave significantly below-average ratings, while those who experienced a stillbirth gave above-average ratings.

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



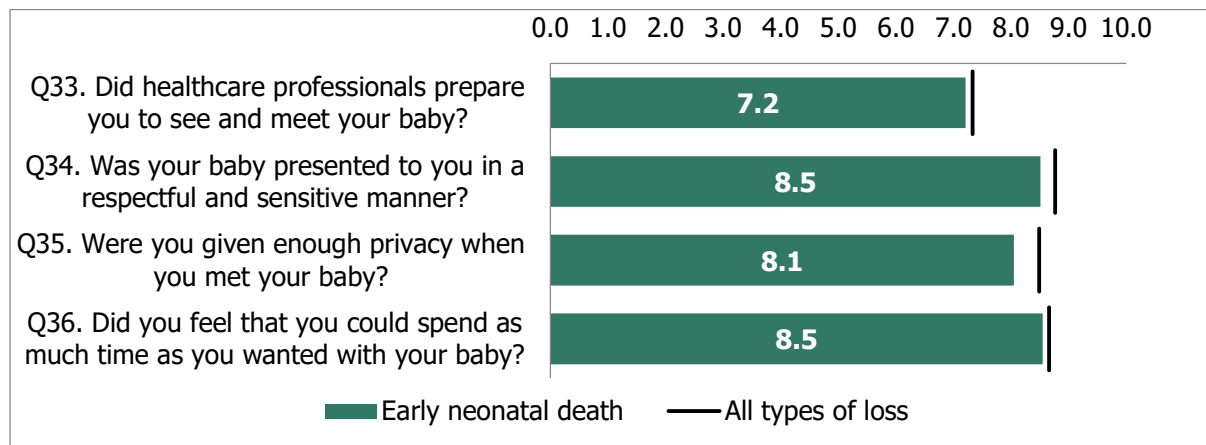
* indicates a significant difference from the national average

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.

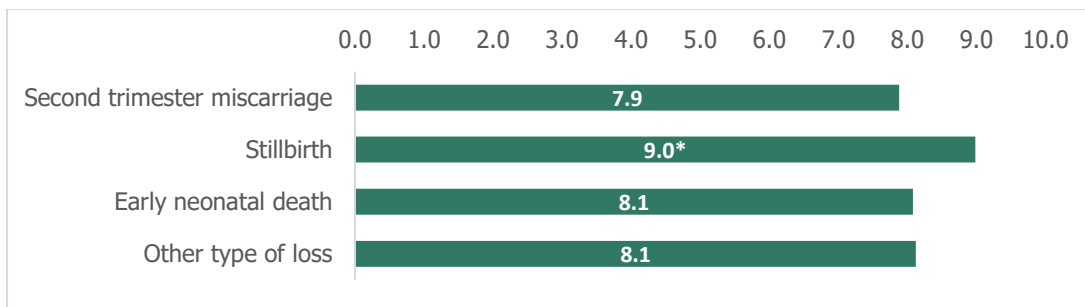
The joint-highest scoring questions for this stage asked participants if their baby was presented to them in a respectful and sensitive manner, and if they could spend as much time as they wanted with their baby. In total, 72 participants (77%) said that their baby was 'definitely' presented to them in a respectful and sensitive manner, while 75 participants (81%) answered 'yes, completely' when asked if they could spend as long 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. 14 participants (15%) 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 by the type of loss participants experienced are provided in Figure 14. Those who experienced an early neonatal death 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

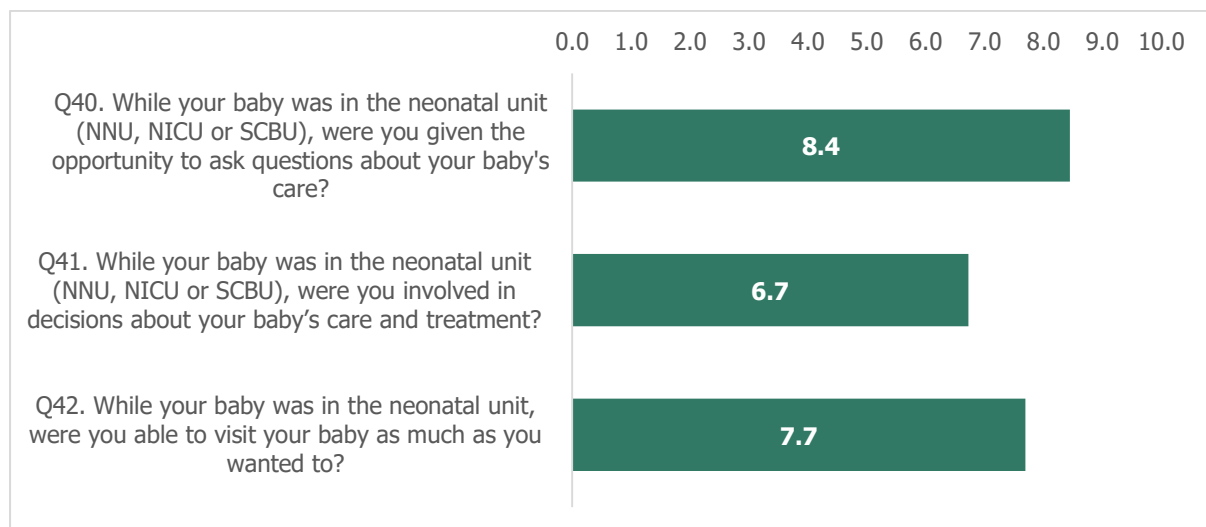
Neonatal care

Six questions explored experiences of care in a neonatal unit.¹² Participants who experienced a second trimester loss or stillbirth were not asked these questions.

76 participants (12%) said that their baby was admitted to a neonatal unit. Of these, 13 said that their baby was transferred to another hospital for specialist neonatal care, while five participants said that they were admitted to the same hospital as their baby.

Three questions in the section explored experiences of communication, decision-making and visiting the neonatal unit. The results for these questions are shown in Figure 15. The highest-scoring question for this stage related to opportunities to ask questions, with 54 participants (71%) saying that they were 'definitely' given the opportunity to ask questions about their baby's care. The lowest-scoring question related to involvement in decisions, with 12 participants (16%) saying that they were not involved in decisions about their baby's care and treatment while they were in the neonatal unit.

Figure 15. Individual questions for 'Neonatal care'.



¹² When referring to neonatal care, the terms neonatal intensive care unit (NICU), or special care baby unit (SCBU) may also be used.

Postnatal care

This section included 10 questions that asked participants who experienced an early neonatal death about their experiences in the maternity hospital or unit following the birth.

The first question in this section asked participants about their hospital accommodation after their baby was born, and the results are shown in Table 5. In total, 52 participants (53%) said that they were accommodated in a single room, with a further 39 (40%) accommodated in a designated bereavement room.¹³

The other questions for this section were scored out of 10 and the results are shown in Figure 16.

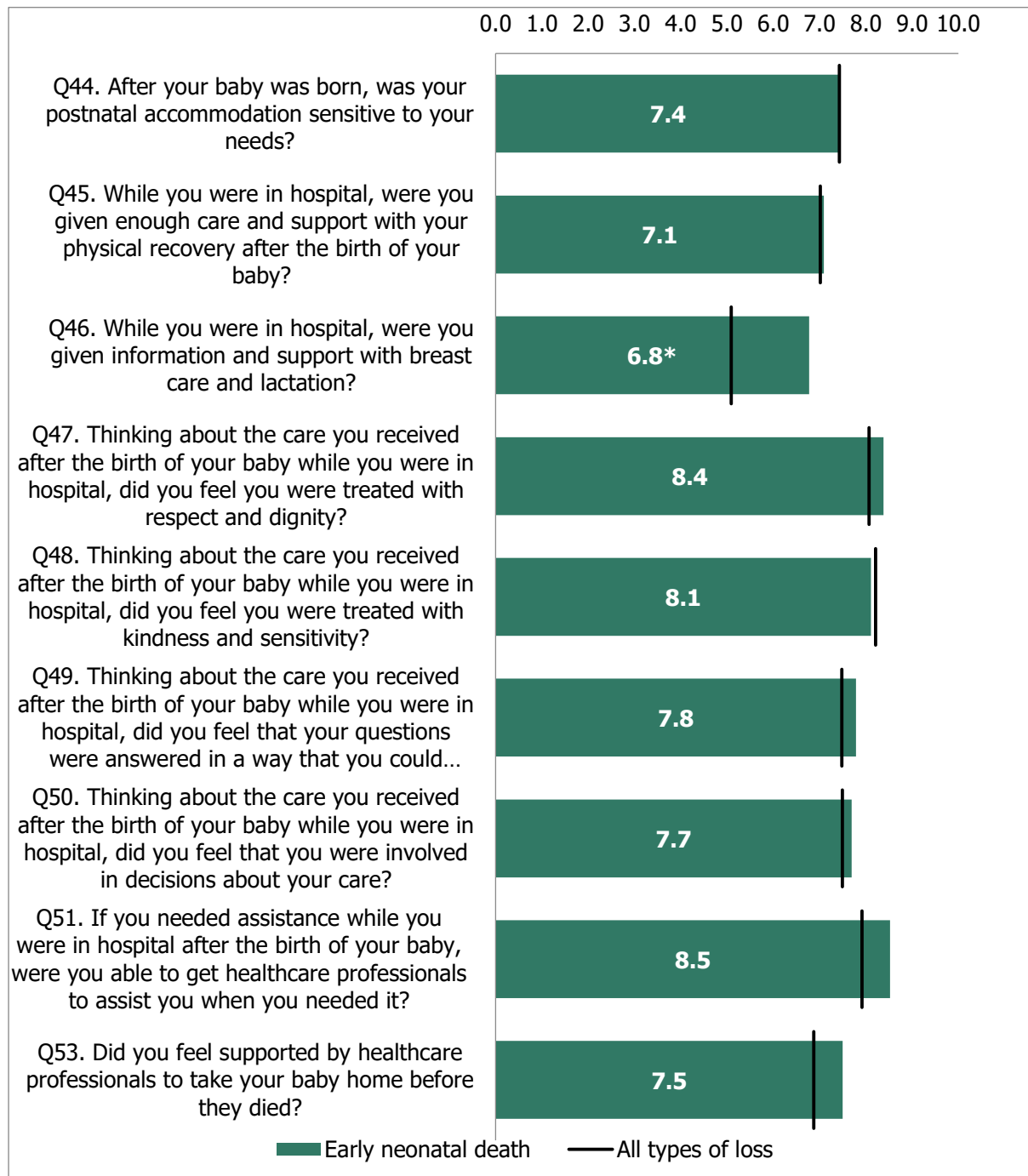
Table 5. Results for question on hospital accommodation in the postnatal period

Q43. After your baby was born, which of the following best describes your accommodation?		
	No.	%
Single room (not shared)	52	53.1%
Bereavement room (designated facility for bereaved families)	39	39.8%
Shared room	4	4.1%
Labour ward	4	4.1%
Antenatal ward	3	3.1%
Postnatal ward	7	7.1%
General ward	9	9.2%
Emergency ward	0	0.0%
I wasn't admitted overnight	0	0.0%
Other	3	3.1%

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

The highest-scoring question for this stage related to assistance from healthcare professionals, with 56 participants (72%) saying that they were 'always' able to get assistance when they needed it. The lowest-scoring question for this stage asked about breast care and lactation, with 13 participants (17%) saying that they were not given information and support relating to breast care and lactation. Nevertheless, this question scored above the average for all types of loss.

Figure 16. 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 17. 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 17. 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 an early neonatal death 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.

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. 60 participants (61%) said that their family or friends were offered the opportunity to meet their baby, while 27 (28%) 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

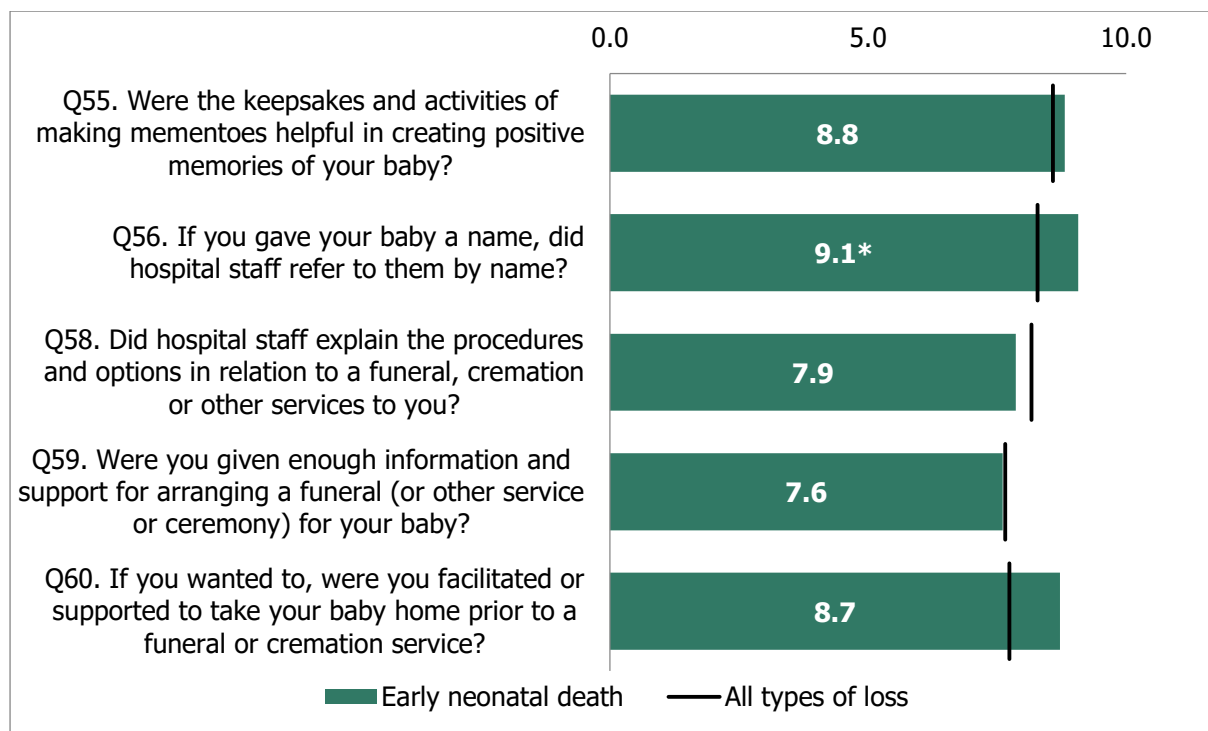
Q54. Were you offered the opportunity to...		
	No.	%
Name your baby	94	95.9%
Spend time with your baby	95	96.9%
Hold your baby	93	94.9%
Dress your baby	61	62.2%
Bath your baby	27	27.6%
Take a lock of your baby's hair	53	54.1%
Have photos with your baby	90	91.8%
Have a copy of your baby's hand print or foot print	92	93.9%
Have a naming or blessing ritual or ceremony	74	75.5%
Create a memory box	84	85.7%
Use a Bereavement alert symbol	42	42.9%
I was not offered any of these	0	0.0%
I did not want any of these	1	1.0%

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	60	61.2%
No, but I would have liked them to	5	5.1%
No, I did not want them to	4	4.1%
Family and friends were not able to visit due to COVID-19 restrictions	27	27.6%
Family and friends were not able to visit for other reasons	2	2.0%

The five other questions in this section asked about emotional and practical support, and the results are shown in Figure 18. The highest-scoring question for this stage related to naming the baby, with 81 participants (84%) saying that staff always referred to their baby by name. This question scored above the average for all types of loss. The lowest-scoring question related to information and support with organising a funeral or other service, with 10 participants (11%) saying that they were not given enough information and support with arranging a funeral or other service for their baby.

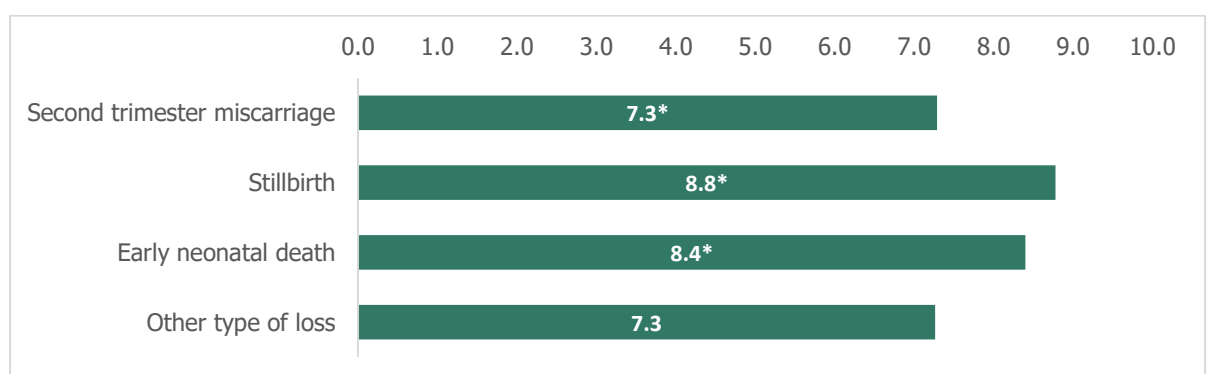
Figure 18. Individual questions for 'Bereavement care'.



* 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 19. 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 19. 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. 13 participants (13%) said that their baby had a consented post-mortem, while 15 participants (15%) said their baby had a coroner's post-mortem.¹⁴

Table 8. Results for question on post-mortem examination

Q61. Did your baby have a post-mortem examination?		
	No.	%
Yes, a consented post-mortem	13	13.3%
Yes, a coroner's post-mortem	15	15.3%
No, I declined a post-mortem examination	42	42.9%
No, I was not offered a post-mortem examination	28	28.6%

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. Ten participants (36%) said that they received the results within one to three months. Two participants said they had waited for longer than 18 months.

¹⁴ 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.

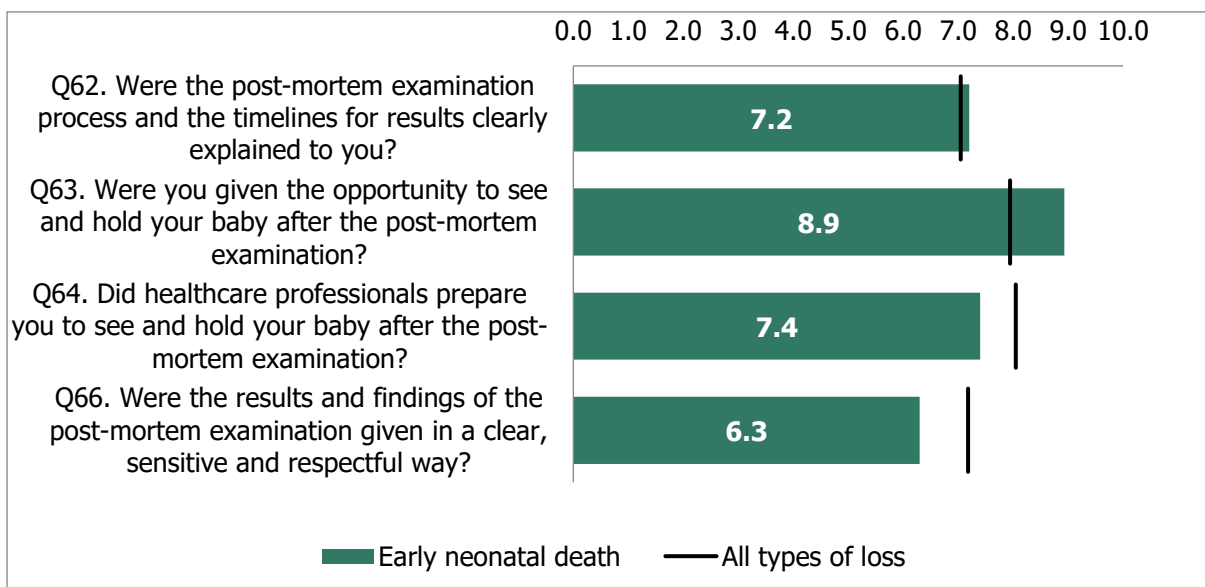
In the case of a coroner's post-mortem examination, parents are informed of the reason for this requirement and the process is explained to the parents along with written information. Parent's consent is not required for a post-mortem examination instigated by a Coroner.

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	1	3.6%
1 to 3 months	10	35.7%
4 to 6 months	5	17.9%
7 to 11 months	7	25.0%
12 to 18 months	3	10.7%
Longer than 18 months	2	7.1%

The results for the four other questions in this section are shown in Figure 20. The highest-scoring question for this stage related to having the opportunity to see and hold their baby after the post-mortem examination. 25 participants (89%) said that they were given this opportunity. The lowest-scoring question related to explanations, with seven participants (26%) saying that the post-mortem examination results and findings were not given to them in a clear, sensitive and respectful way.

Figure 20. Individual questions for 'Post-mortem examination and investigations'.



Comparisons of ratings for this stage of care by the type of loss participants experienced are provided in Figure 21. There were no significant differences from the national average by type of loss.

Figure 21. Comparison of 'Post-mortem examination and investigations' by type of loss experienced.



Discharge

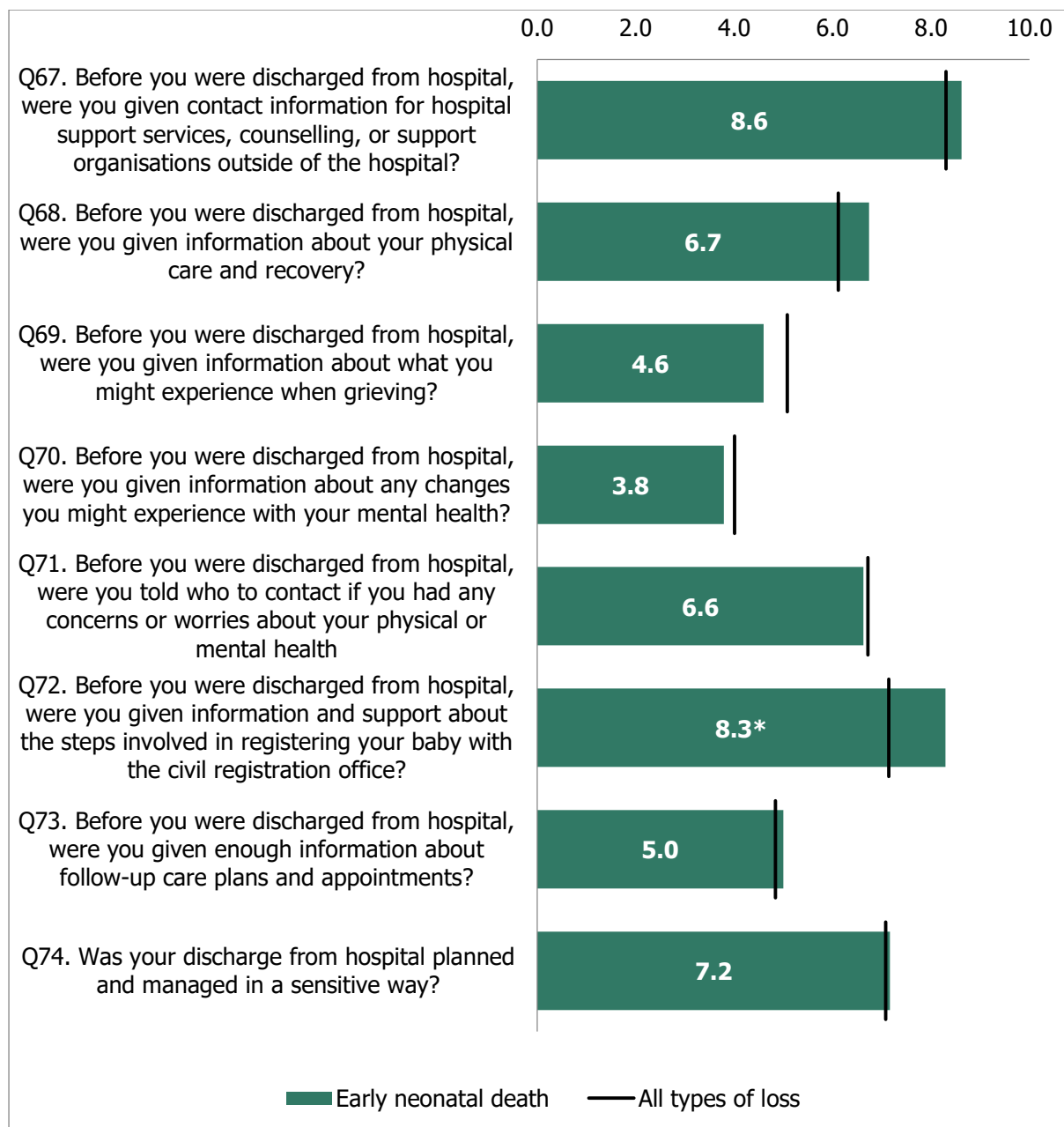
This section included eight questions that asked participants who experienced an early neonatal death about the information and support provided to them prior to being discharged from hospital.

Seven questions for this section were scored out of 10 and the results are shown in Figure 22. 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 81 participants (86%) 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 42 participants (48%) saying that they were not given information about changes they might experience with their mental health.

Participants who experienced an early neonatal death gave higher than average ratings on the question relating to information and support on the steps relating to registering their baby with the civil registration office.

Figure 22. 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 23. Participants who experienced an early neonatal death 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 23. 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 an early neonatal death 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. 55 participants (57%) said that they saw a GP, while significant numbers also saw a bereavement midwife or obstetrician. On the other hand, 11 participants (11%) 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 sources of support accessed by participants were partners, family and friends. Two 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 24.

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

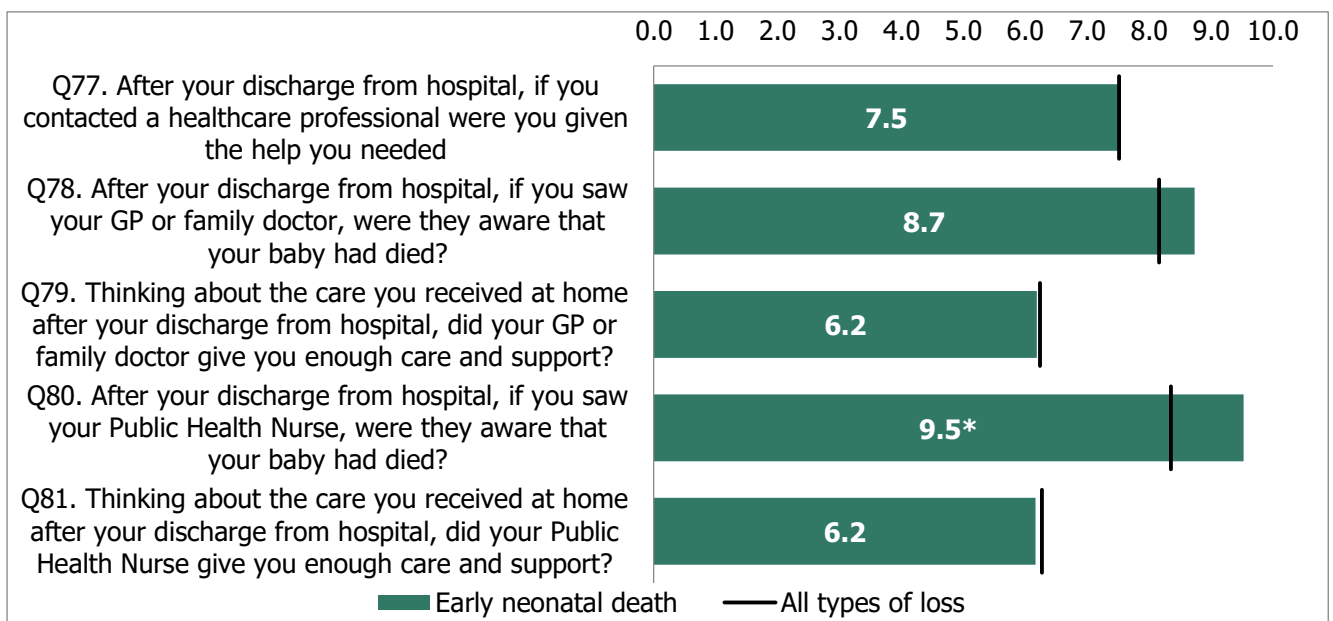
Q76. After your discharge from hospital, who did you see as part of your follow-up care?		
	No.	%
Family doctor (GP)	55	56.7%
Public Health Nurse (PHN)	44	45.4%
Bereavement midwife or nurse specialist in the hospital	42	43.3%
Mental health services	8	8.2%
Obstetrician or gynaecologist after discharge	26	26.8%
Consultant paediatrician or neonatologist	15	15.5%
Other	5	5.2%
I had to attend the hospital emergency department because of complications	6	6.2%
I had a follow-up appointment at the hospital but I declined to attend	1	1.0%
I haven't had any follow-up care since my discharge from hospital	11	11.3%

Table 11. Results for question on supports accessed after discharge

Q82. After your discharge from hospital, what supports did you access?		
	No.	%
Partner	78	89.7%
Family	71	81.6%
Friends	60	69.0%
Bereavement support organisations/advocacy groups	42	48.3%
Hospital support services	17	19.5%
Professional counselling	25	28.7%
Other	0	0.0%
I did not access any supports	2	2.3%

Question 80 was the highest-scoring for this stage, with 60 participants (95%) saying that their Public Health Nurse was aware their baby had died. This question scored significantly above the national average. The joint-lowest scoring questions related to GPs and Public Health Nurses. 17 participants (22%) said that their GP did not give them enough care and support, with 13 (22%) saying that the Public Health Nurse did not give them enough care and support.

Figure 24. 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 25. There were no significant differences from the national average by type of loss.

Figure 25. 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 an early neonatal death. 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 26. These questions asked participants about their experiences of communication and involvement.

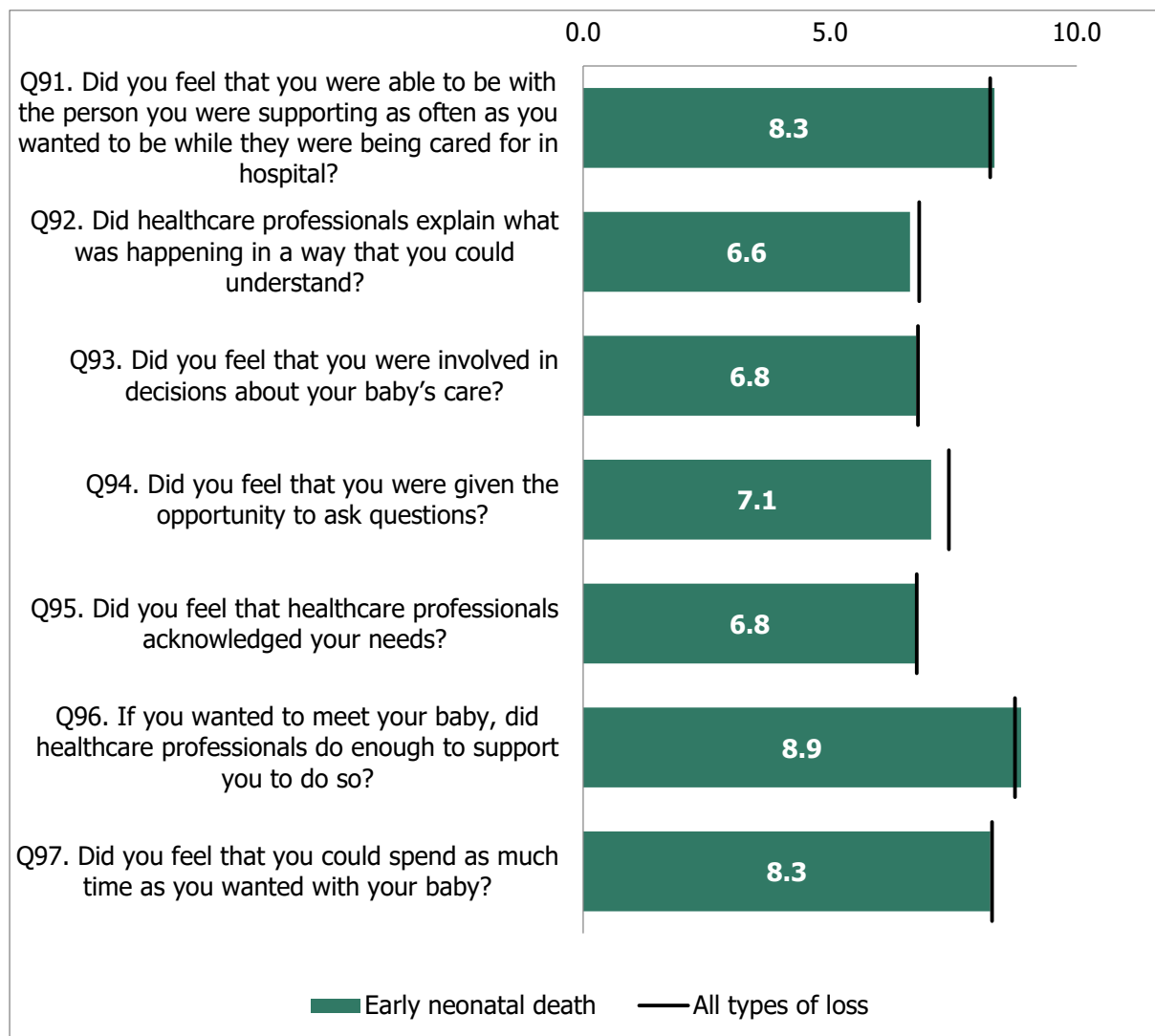
Participants were also asked about the supports they accessed and the results for this question are shown in Table 12. The most common sources of support were partners, family and friends. Four participants (10%) said that they did not access any supports.

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	32	80.0%
Family	21	52.5%
Friends	18	45.0%
Family doctor or GP	10	25.0%
Bereavement support organisations/advocacy groups	12	30.0%
Hospital support services	3	7.5%
Professional counselling	7	17.5%
Other	0	0.0%
I did not access any supports	4	10.0%

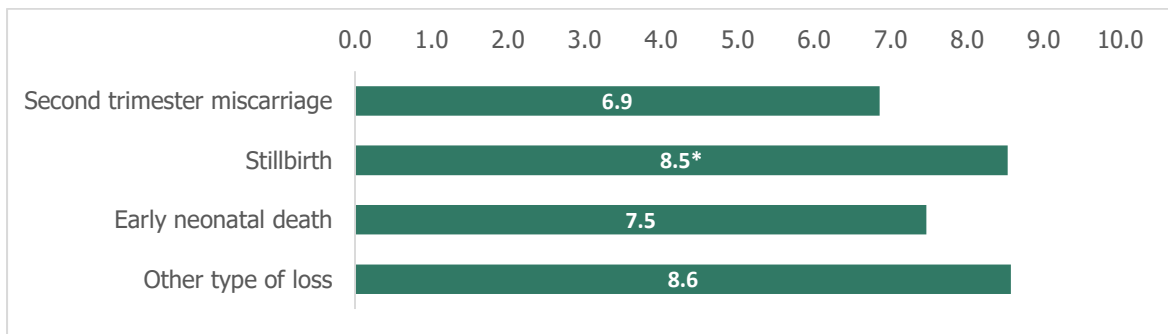
The highest-scoring question for this stage related to feeling supported to meet the baby, with 32 participants (80%) saying that healthcare staff 'definitely' did enough to support them if they wanted to meet their baby. The lowest scoring question related to clear explanations, with five participants (13%) saying that healthcare professionals did not explain what was happening in a way they could understand.

Figure 26. 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 27. Participants who experienced an early neonatal death 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 27. Comparison of 'Experiences of partner or support person' by type of loss experienced



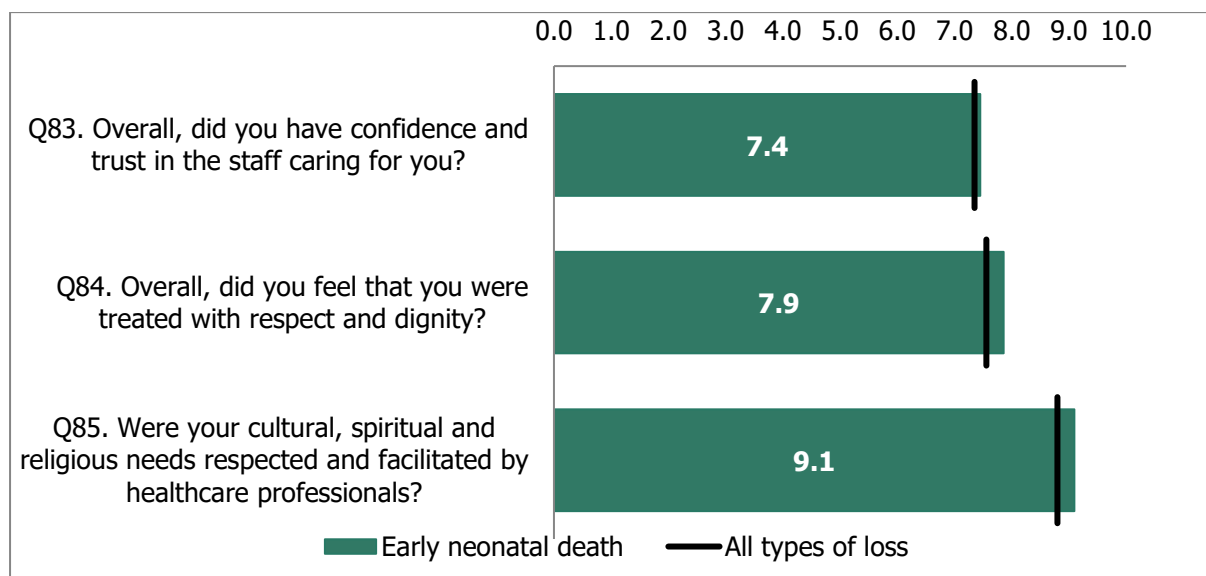
* indicates a significant difference from the national average

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 28. The highest-scoring of these questions related to respect for cultural needs, with 61 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 (10%) saying that they did not have confidence and trust in the staff that treated them. In response to the other question in this section, 63 participants (64%) said that they were always treated with respect and dignity.

Figure 28. Individual questions for 'Overall experience'.



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 82 participants (84%) saying they were offered this service. Five participants (5%) said that they weren't offered any hospital support services.

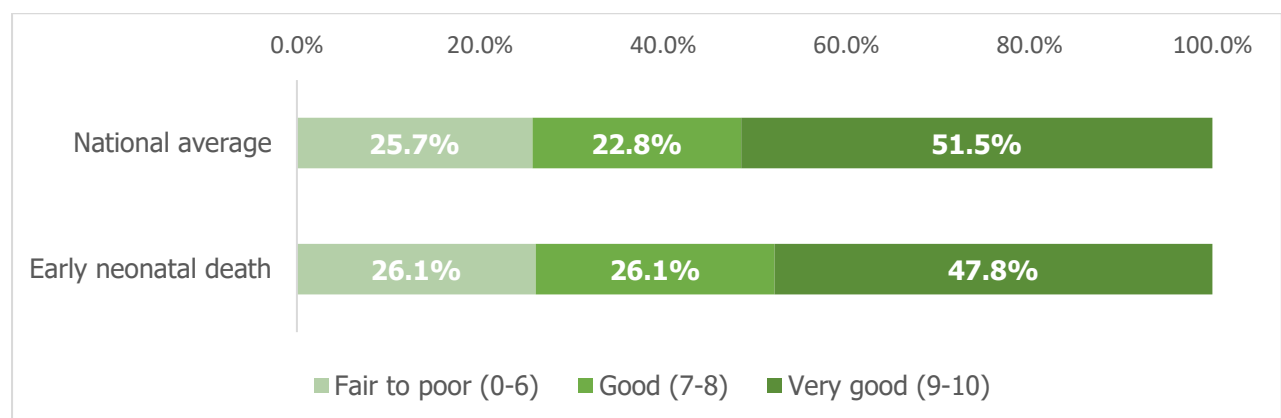
Table 13. Results for question on hospital supports offered to participant

Q86. Were you offered any of the following hospital support services?		
	No.	%
Chaplaincy or pastoral care	66	67.3%
Social Work	32	32.7%
Bereavement midwife or nurse specialist	82	83.7%
Perinatal (pregnancy-related) Mental health service	20	20.4%
Perinatal (pregnancy-related) Palliative Care team	8	8.2%
Paediatrician/Neonatologist	31	31.6%
Other	1	1.0%
I wasn't offered any hospital support services	5	5.1%
No hospital support services were available	0	0.0%
Don't know or can't remember	3	3.1%

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, 44 participants (48%) rated their care as 'very good', 24 (26%) as 'good' and 24 rated it as 'fair to poor' (26%).

Figure 29. Overall ratings of care



Conclusion

Experiences of maternity bereavement care for an early neonatal death between 2019 and 2021

In total, 98 women and 40 partners or support persons generously shared their experiences of an early neonatal death through the National Maternity Bereavement Experience Survey. Participants described all aspects of their experiences of maternity bereavement care.

While 74% 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 grieving, mental health, 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, noting that they were predominantly treated with compassion and respect. Participants also said that most staff referred to their baby by name, and that staff members respected their cultural and religious needs. In addition, Public Health Nurses and GPs were aware that they had experienced a loss.

The experiences of partners of those who experienced an early neonatal death were also explored. Most partners felt that they were treated with compassion and support, however they highlighted a need for clearer explanations by healthcare professionals, 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 'bereavement care', with 'discharge' the lowest-scoring stage. Participants who experienced an early neonatal death gave more positive ratings than those who had a different type of loss for the 'bereavement care' stage. Ratings for all other stages were similar to the average for all types of loss.

In conclusion, the findings of the National Maternity Bereavement Experience Survey show that most parents who experienced an early neonatal death 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 grieving.

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.¹⁵

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.

¹⁵ 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.

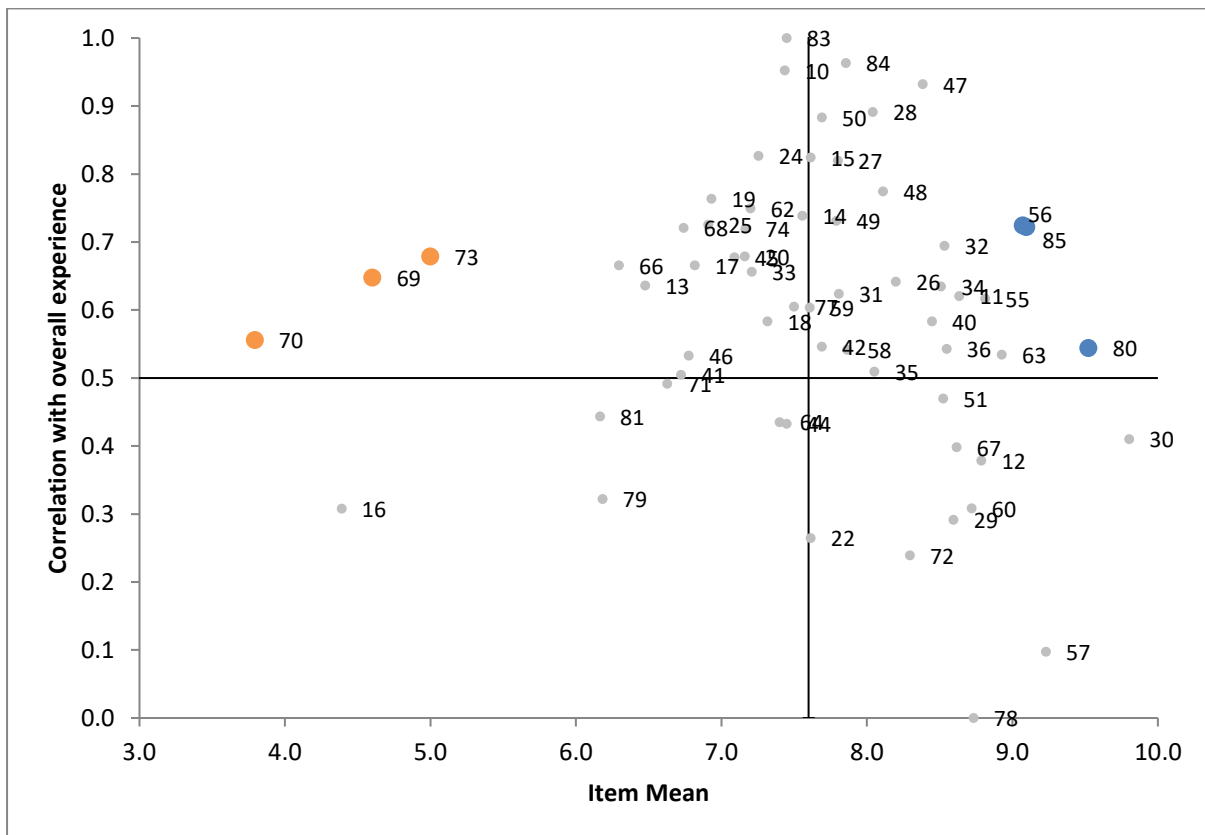
Results on questions comparing two groups of residents (e.g., those who share a bedroom and those who do not) were compared using a ‘t-test’ at the 99% confidence level. A t-test is a statistical test used to compare the average scores of two groups. A statistically significant difference means it is 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 30 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 30. Overall participant experience map



Areas of good care experience

1. Q56. If you gave your baby a name, did hospital staff refer to them by name?
 - a. 81 participants (83.5%) said that hospital staff 'always' referred to their baby by name.
2. Q80. After your discharge from hospital, if you saw your Public Health Nurse, were they aware that your baby had died?
 - a. 60 participants (95.2%) said that their Public Health Nurse was aware that their baby had died.

3. Q85. Were your cultural, spiritual and religious needs respected and facilitated by healthcare professionals?
 - a. 61 participants (84.7%) said that their cultural, spiritual and religious needs were 'definitely' respected and facilitated by healthcare professionals.

Areas needing improvement

1. Q69. Before you were discharged from hospital, were you given information about what you might experience when grieving?
 - a. 34 participants (38.6%) said that they were not given information what they might experience when grieving, before they were discharged from hospital.
2. Q70. Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?
 - a. 42 participants (48.3%) said that they were not given 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. 32 participants (35.2%) 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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