National Maternity Bereavement Experience Survey

Findings of the

National Maternity Bereavement Experience Survey 2022

National Maternity Bereavement Experience Survey

Thank you

Thank you to all of the women, partners and support persons who participated in Ireland's first National Maternity Bereavement Experience Survey.

Without your participation and overwhelming generosity and willingness to share your experiences, the survey would not have been possible. We wish to acknowledge your experience of pregnancy loss and we appreciate how difficult it may have been to consider the answers to the questions in the survey. The survey ensures that your voice will be heard by those with responsibility to change and improve maternity bereavement care in Ireland.

Thank you also to the staff working across all maternity care and maternity bereavement care services for contributing to the success of the survey, and in particular for publicising the survey and providing supportive care to those who experienced bereavements while the survey was ongoing.

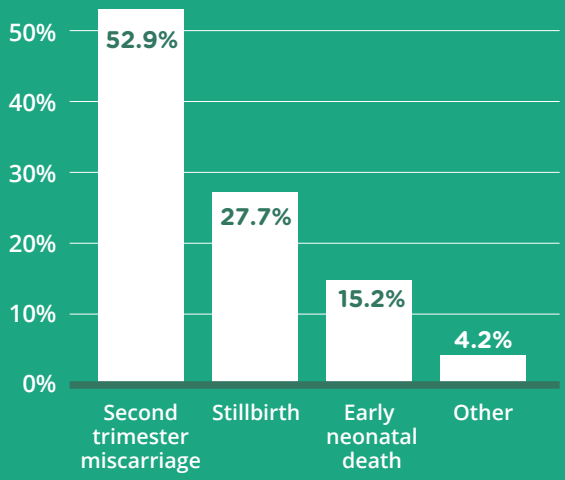
The survey was overseen by a national steering group and a programme board. We acknowledge the direction and guidance provided by these groups. Appendix 1 lists the members of these groups and the core project team.

Participants and key findings

655 **232**

Women and partners responded

Type of loss experienced



Key findings

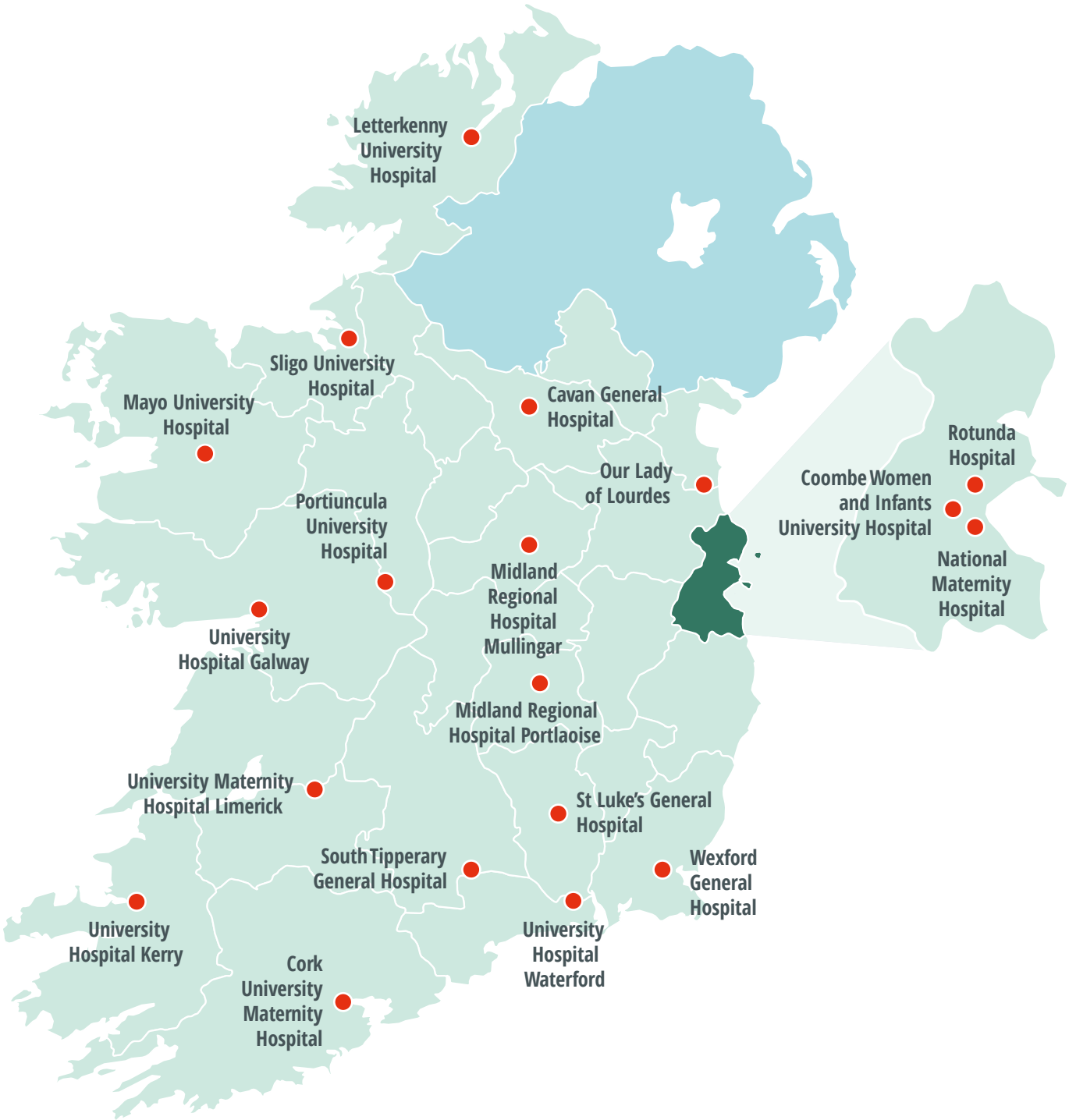
Positive care experiences

- Caring and sensitive attitudes of staff
- Supportive midwives and chaplaincy staff
- Compassionate care provided to parents

Areas for improvement

- Need for dedicated spaces in hospitals for grieving parents
- More consistent communication across services involved in care
- Additional supports for physical and mental health

19 participating maternity hospitals and units



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.

Summary

About the National Maternity Bereavement Experience Survey

The National Maternity Bereavement Experience Survey offered women and their partners the opportunity to share their experiences of Ireland's maternity bereavement care services. The survey is part of the National Care Experience Programme. The survey reflects a commitment made in the National Maternity Strategy 2016-2026 to evaluate maternity care services from the perspectives of the women who use them[1]. The aim of the survey was to learn from the lived experiences of bereaved women to improve the standard and quality of the care that they receive.

Women and their partners who experienced a second trimester miscarriage[2], 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.[3]

The survey questionnaire contained 99 questions which explored the pathway of maternity bereavement care from communication and information at the time of antenatal diagnosis[4], through to maternity hospital care, and follow-up care provided in the community after leaving hospital[5]. Over 180 people, including bereaved parents, healthcare professionals such as clinical midwife/nurse specialists in bereavement and loss, chaplains, social workers, support and advocacy representatives, policymakers, and academic experts were involved in developing and selecting the questions most relevant to the Irish context.

1 Department of Health. Creating a better future together: national maternity strategy 2016-2026. 2016.

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

3 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.

4 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.

5 The full National Maternity Bereavement Experience Survey questionnaire can be found in Appendix 3.

What were the main findings of the 2022 survey?

In total, 655 women and 232 partners or support persons[6] participated in the survey[7]. 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 74% rating their care as 'very good' or 'good', and 26% rating their care as 'fair to poor'.

Areas of good care experience and areas needing improvement

In their responses to the free-text survey questions, participants praised staff for their caring and sensitive attitudes, with numerous comments mentioning midwives and chaplaincy staff in particular. An illustrative comment is provided below.

> **"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."**

When asked to describe in their own words how care could be improved, participants expressed a desire for dedicated spaces in hospitals for grieving parents; more consistent communication across services involved in their care; additional supports for physical and mental health; and more support for partners. Illustrative comments are provided below.

> **"Once discharged any follow-ups were to be instigated by me. I believe the bereavement team should check in on mothers in the early weeks, even just a phone call to see how they're coping."**

> **"Sound proof rooms would have been less traumatic or something to block the sound of other women in labour and babies cries. No one will ever understand the pain unless they have been through something like this."**

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

7 A total of 683 survey responses were received which included feedback from 655 women and 232 partners or support persons.

Using the methodology described in Appendix 2, questions where most participants had positive care experiences and questions where there is the most room for improvement were identified. These questions were also highlighted due to their strong relationship with participants' overall ratings of their maternity bereavement care, as measured by Question 87.

Participants highlighted some areas of positive care received during their experiences of loss. For example, most participants felt treated with respect and dignity both during labour and birth, and after their baby was born. Participants said that staff treated them with kindness and sensitivity, and presented their baby to them in a respectful and sensitive way. In addition, staff members assisted participants when they needed it, and respected their cultural and religious needs.

A number of areas for improvement in maternity bereavement care were also identified using the methodology described in Appendix 2. These included greater parental involvement in decisions about care during labour and birth, and support for physical recovery after birth. In addition, participants identified a need for greater information-provision at discharge, particularly in relation to physical recovery, mental health, grieving, and follow-up care and appointments.

Stages of care covered in the survey

The survey included multiple 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
- Postnatal care
- Bereavement care
- Post-mortem examination and investigations
- Discharge
- Follow-up care
- Overall care
- Partner or support person

The highest-scoring stage of care was 'care after birth and meeting your baby', which scored 8.3 out of 10. This section included four questions on participants' experiences of meeting their baby for the first time. Most participants (82%) said that their baby was 'definitely' presented in a respectful and sensitive manner, and participants felt they could spend as much time as they wanted with their baby.

The lowest-scoring stage of care was 'discharge', which scored 6.1 out of 10.[8] This section included eight questions that asked about the information and support provided prior to being discharged from hospital. Some of the lowest-scoring questions of the survey related to this stage of care. For example, 47% of participants said that they were not given information about changes they might experience to their mental health, before they were discharged from hospital.

Comparisons by age group and type of loss experienced

A number of significant differences between groups of participants were identified. When comparing the experiences of participants from different age groups, the 33 participants aged 16-24 years, on average gave significantly poorer ratings of their overall care experience than the national average. In addition, participants in this age cohort gave significantly lower-ratings of their labour and birth experience, and their postnatal care. On the other hand, these participants gave above-average ratings of their experiences of neonatal care.

Ratings were also compared by the type of loss participants had experienced, with a number of significant differences identified. Most notably, people who experienced a stillbirth gave significantly more positive ratings of their overall experience than the national average. In addition, these participants rated their experiences of most stages of care above the national average.

Experiences of partners

In total, 232 partners responded to the survey, which included nine questions specific to their experiences. The highest-scoring question for partners related to feeling supported to meet their baby, with 174 participants (81%) saying that healthcare staff 'definitely' did enough to support them if they wanted to meet their baby. The joint-lowest scoring questions related to clear explanations, involvement in decisions and needs being acknowledged. 32 participants (14%) said that healthcare professionals did not explain what was happening in a way they could understand, while 44 (20%) felt that they were not involved in decisions about their baby's care. In addition, 39 participants (17%) felt that healthcare professionals did not acknowledge the partner or support person's needs.

8 Information on how scores out of 10 for the stages of care were calculated are provided in Appendix 2.

Impact of the pandemic

The survey period covered the experiences of people who experienced losses both before and during the COVID-19 pandemic. The pandemic affected some aspects of how care was provided, necessitating the introduction of hospital restrictions and limitations on the attendance of partners, among other measures. Comparisons were made between participants who experienced losses prior to the onset of the COVID-19 pandemic in March 2020, and those who experienced losses after that time. Numerous comments made in response to the free-text questions referred to the negative impact of the pandemic, particularly in relation to the impact of restrictions and limitations on the attendance of partners and family members. An illustrative comment is provided below.

> **"I wasn't allowed to be with my wife when she was told our baby had died, she was told this heart-breaking information alone. Due to Covid-19 restrictions. I was brought in shortly afterwards."**

However, when experiences across the stages of care were compared, no significant differences in ratings were found.

Conclusions:

The findings of the National Maternity Bereavement Experience Survey show that most parents were positive about the care they received, particularly the respect and sensitivity shown to them by healthcare professionals and other staff. The willingness of participating parents to share their experiences of such a difficult and painful time has also helped identify areas where care can be improved, particularly in relation to information and support relating to grieving, physical recovery, and mental health after leaving hospital. Participants also noted how difficult it was to receive care in the vicinity of parents who had not experienced a bereavement.

What happens next?

The HSE and the National Women and Infant Health Programme (NWIHP) will use the survey findings 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 of maternity care.

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1

About the National Maternity Bereavement Experience Survey

Who was eligible to take part in the survey?

Women aged 16 or over, and their partners, who experienced a second trimester miscarriage (from 14 weeks of pregnancy[9]), a stillborn infant or the early neonatal death of a baby in one of Ireland's 19 maternity units or hospitals from 1 January 2019 to 31 December 2021[10] were eligible to participate in the National Maternity Bereavement Experience Survey. In this survey round, earlier gestation 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. 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.

How was the survey conducted?

The survey used an online, self-selecting model and was promoted through a comprehensive public awareness and media campaign in order to inform all eligible women and partners of the survey. The media campaign commenced in August 2022, prior to the survey opening. The survey rollout commenced on the 1 September 2022 and remained open for completion for eight weeks. Participation in the survey was voluntary and confidential. The translated questionnaire was available in print format on request in Irish, Polish, Lithuanian and Romanian. No requests were made for translated surveys. The administration and survey fieldwork was carried out by Behaviour & Attitudes[11] on behalf of the partner organisations.

Who participated in the survey?

In total, 655 women and 232 partners or support persons responded to the survey.[12] A breakdown of participants by age group is provided in Figure 1, with over 70% of participants aged between 30 and 39.

9 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.

10 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.*

11 Behaviour & Attitudes is a research agency. More information on the company can be found on their website www.banda.ie.

12 A total of 683 survey responses were received which included feedback from 655 women and 232 partners or support persons. An additional 284 people who did not meet the eligibility criteria were redirected to support resources and a telephone line run by the National Patient Advocacy Service if they wished to avail of their services.

Figure 1: Characteristics of participants by age group.

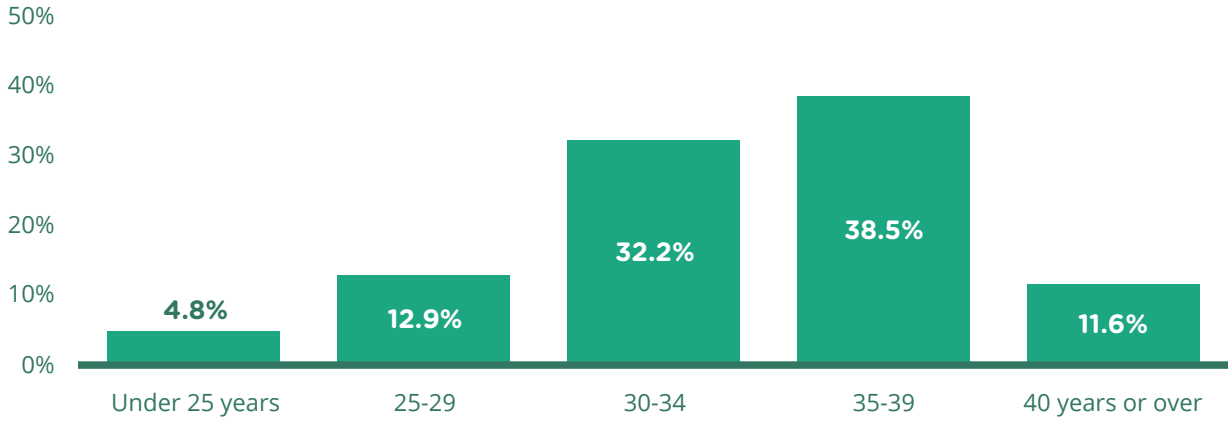


Table 1 outlines the type of loss participants experienced, along with the year in which their loss occurred. Just over half of the 683 participants who answered the question on type of loss (361, 53%), experienced a second trimester miscarriage, with 189 experiencing a stillbirth (28%), and 104 early neonatal deaths (15%). A further 29 participants (4%) said they experienced an 'other' type of loss, with 27 of these relating to medical terminations or compassionate inductions for fatal foetal abnormalities, one unspecified loss, and one participant who experienced multiple losses during the survey period.

Table 1: Details on the type of losses participants experienced and when they occurred.

Type of loss experienced	No.	%
Second trimester miscarriage	361	52.9%
Stillbirth	189	27.7%
Early neonatal death	104	15.2%
Other	29	4.2%
Year loss was experienced		
2019	207	30.3%
2020	228	33.4%
2021	248	36.3%

What questions were asked in the survey?

The survey questionnaire asked about the pathway of maternity bereavement care from communication and information at the time of antenatal diagnosis[13] through to labour and birth, postnatal and bereavement care, neonatal care, investigations, discharge, follow up care and care in the community. The final survey questionnaire can be found in Appendix 3. There were 90 questions for 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.

Over 180 people, including bereaved parents, healthcare professionals such as clinical midwife/nurse specialists in bereavement and loss, chaplains, social workers, support and advocacy representatives, policymakers, and academic experts were involved in developing and selecting the questions most relevant to the Irish context. The development steps are outlined below:

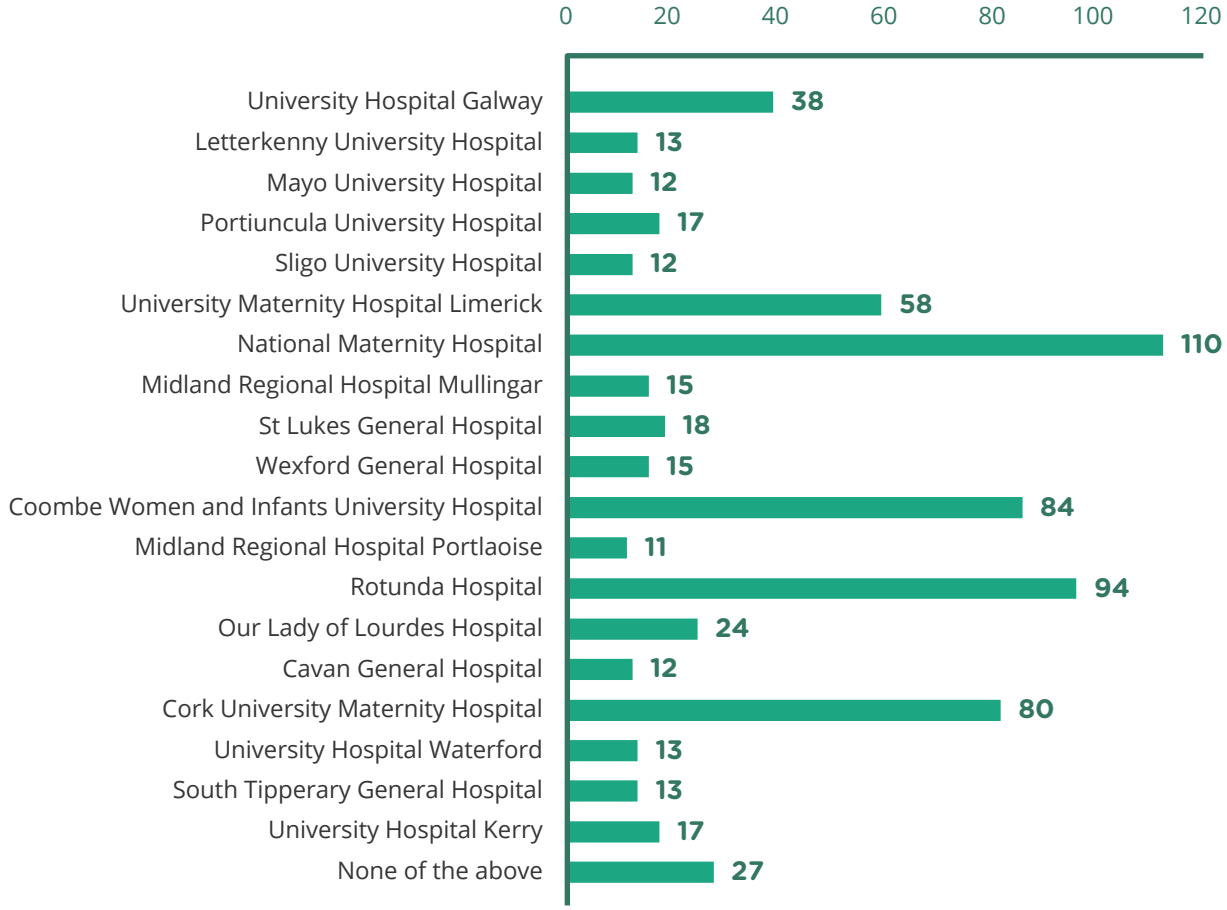
1. A national review of the provision of maternity bereavement care services in Ireland was conducted. This included identifying and reviewing national reports, investigations, policies, pathways, guidelines, strategies and standards related to bereavement and perinatal loss.
2. An international review examined best practice with regard to the models and methodologies employed to inform and deliver a national maternity bereavement experience survey. The review identified six relevant, international maternity bereavement experience surveys.
3. Focus groups, comprising users and providers of maternity bereavement care in Ireland, identified the most important question areas in respect of maternity bereavement care.
4. A gap analysis further identified questions which are relevant to the Irish context of maternity bereavement care.
5. A list of 136 questions was developed from the previous steps, of which a Delphi Study identified 110 priority questions.
6. Picker Institute Europe checked the measurement and analytic quality of the questions.
7. Review by the National Maternity Bereavement Experience Survey Programme Board further prioritised questions.
8. Six cognitive interviews took place with women, and partners/support person who have used maternity bereavement services to assess the clarity and appropriateness of the proposed National Maternity Bereavement Experience Survey questionnaire.

13 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.

What maternity care services were included in the survey?

Women, partners or support person who attended and received bereavement care in Ireland's 19 maternity units and hospitals from 1 January 2019 to 31 December 2021 were invited to participate in the National Maternity Bereavement Experience Survey. In addition, the survey includes questions on women's maternity bereavement care experiences with public health nursing and GP services across Ireland. Participants were asked about the hospital they gave birth in, and the results are shown in Figure 2[14].

Figure 2: Hospital of birth.



14 27 participants answered 'none of the above'. These participants typically had terminations for medical reasons, which typically did not take place in Ireland. Nevertheless, these participants received aspects of their maternity bereavement care in Irish hospitals.

Why measure experiences of maternity bereavement care?

Feedback from women and their partners on their experiences provides important information about maternity bereavement care in Ireland. This helps to identify where maternity bereavement services are performing well and what is needed to improve the standard and quality of care. Care experience surveys gather feedback in a rigorous and systematic way, and provide a good indicator of healthcare quality and performance.[1-4]

In recent years, several reports and reviews into maternity care including bereavement care have highlighted service deficits and failings in Irish maternity services with a need for significant improvements.[5-9] *The National Maternity Strategy 2016-2026 and the National Standards for Safer Better Maternity Services* were developed as a consequence.[10,11] One of the recommendations made in the Strategy was the improvement of support services for women who experienced the loss of a baby. This recommendation led to the development and publication of the *National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death* in 2016. The purpose of the standards was to improve and standardise bereavement care services for parents, by clearly outlining how hospitals should provide this care.

During the development of the National Maternity Experience Survey in 2019, it was identified that there was a need to develop a dedicated survey for those who had experienced a maternity bereavement.

HIQA, the HSE and the Department of Health have committed to acting on the findings of the National Maternity Bereavement Experience Survey to improve maternity bereavement care services in Ireland.

2

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?[15]

In total, 1,813 comments were made in response to the free-text questions. The results for each question are presented in the following pages.

A framework approach[16] 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 below in Table 2. This framework helped organise and systematically reduce the thousands of comments into manageable segments of information. The framework approach is suited to analysing large volumes of qualitative information and has previously been used to analyse comments made in the National Maternity Experience Survey.

15 This question was specific to partners.

16 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.

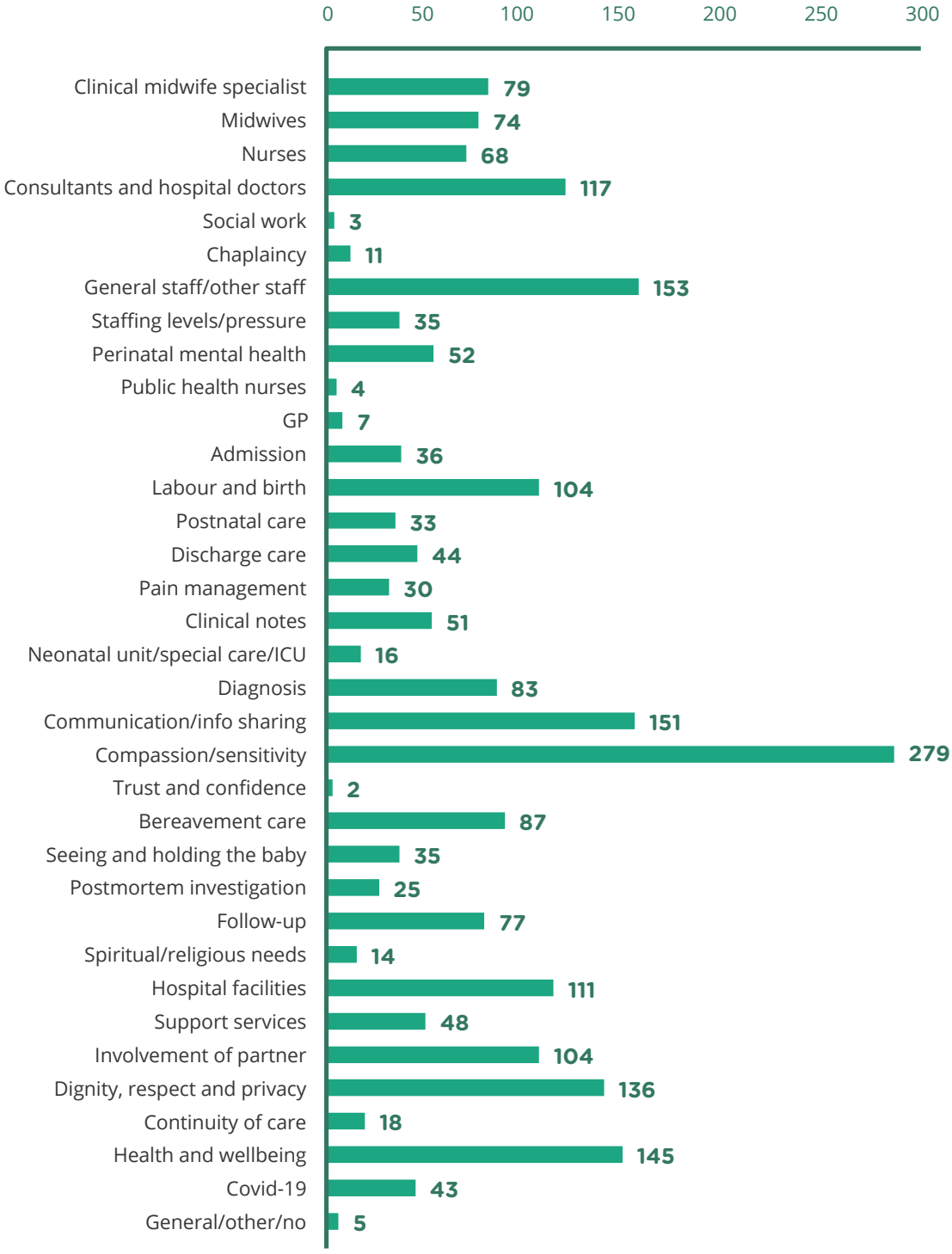
Table 2: List of Comment Themes

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 376 comments in response to this question. Figure 3 shows the breakdown of themes covered within these comments.

Figure 3: Responses to Q.75 broken down by theme.



The most frequently occurring theme was 'Compassion and sensitivity', which appeared in 279 comments. The next most common themes were 'General staff or other staff comments' (153 comments) and 'Communication and information-sharing' (151 comments). A selection of comments illustrating these themes is provided below.

Compassion and sensitivity

"Each and every doctor and midwife we met on our journey spoke to us with such kindness and compassion. They explained everything and gave us so much time."

"Hardest part for me was being told our baby girl had no heartbeat, alone and left in a room to cry alone for a while before being offered a family member was absolutely heart-breaking."

General staff or other staff comments

"The staff were amazing on the bereavement floor from the nurses to the cleaners. They were so caring and kind."

"Everyone was so supportive and I think I got only angels for doctors, nurses and even the cleaner girl who bought me the coffee and brought to my room. In so sad and heart-breaking moment I had a 5 star service, the most gentle and sensitive people around me."

Communication and information-sharing

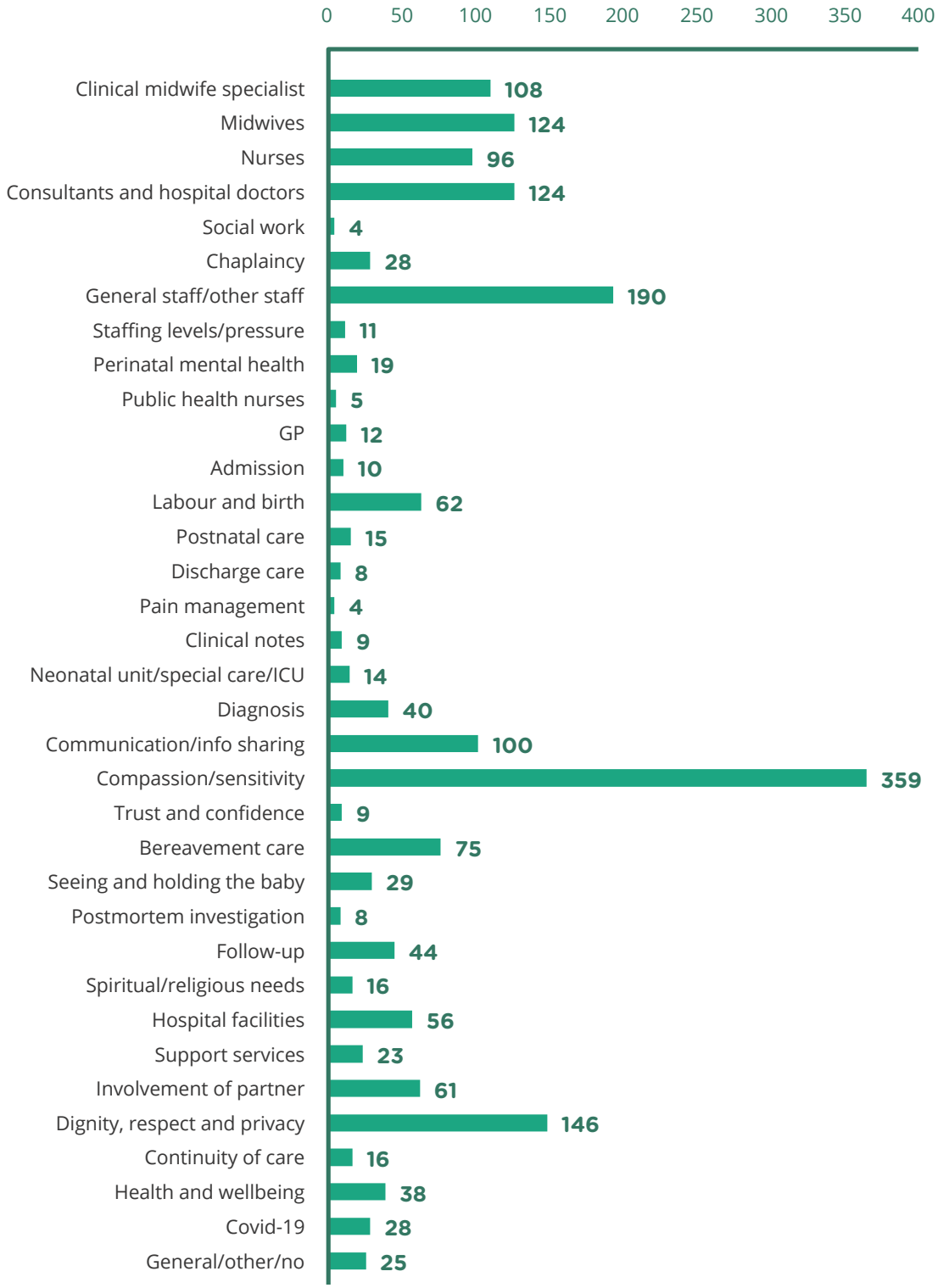
"I cannot commend the nursing staff anymore as they were outstanding in their care. They treated my husband and I and our precious baby with the utmost care and respect and despite being under huge pressure in a busy ward, always made time to look after us and answer our queries."

"My hospital care was excellent but there was a communication breakdown between my GP/primary care centre after discharge, resulting in a lack of physical aftercare, no follow up from GP (when I went about the pains (infection) 6 weeks after he asked how far along I was and claimed to never have received my discharge notes - terrible effect on mental health)"

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

In total, participants made 528 comments in response to this question. Figure 4 shows the breakdown of themes covered within these comments.

Figure 4: Responses to Q.88 broken down by theme.



The most frequently occurring theme was 'Compassion and sensitivity', which appeared in 359 comments. The next most common themes were 'General staff or other staff comments' (190 comments) and 'Dignity respect and privacy' (146 comments). A selection of comments illustrating these themes is provided below.

Compassion and sensitivity

"The nurse I had was amazing, very caring and sensitive. Our consultant doctor was also fantastic and came to check in on me before and after I had my baby. The midwifes in the labour ward were also incredible."

"All the staff were very kind, caring and supportive. My partner was allowed to attend all my appointments and he was well looked after we had our baby. The staff guided us through the most difficult days of our lives and helped us create special memories and made sure we had enough time with our little girl."

General staff or other staff comments

"Our experience during our hospital stay was very good. I had complete trust in the team and everyone was doing their best for us and our boys."

"I was treated with the utmost respect and kindness during the most difficult time of my life. Every staff member in the hospital cared for me to the highest standard."

Dignity, respect and privacy

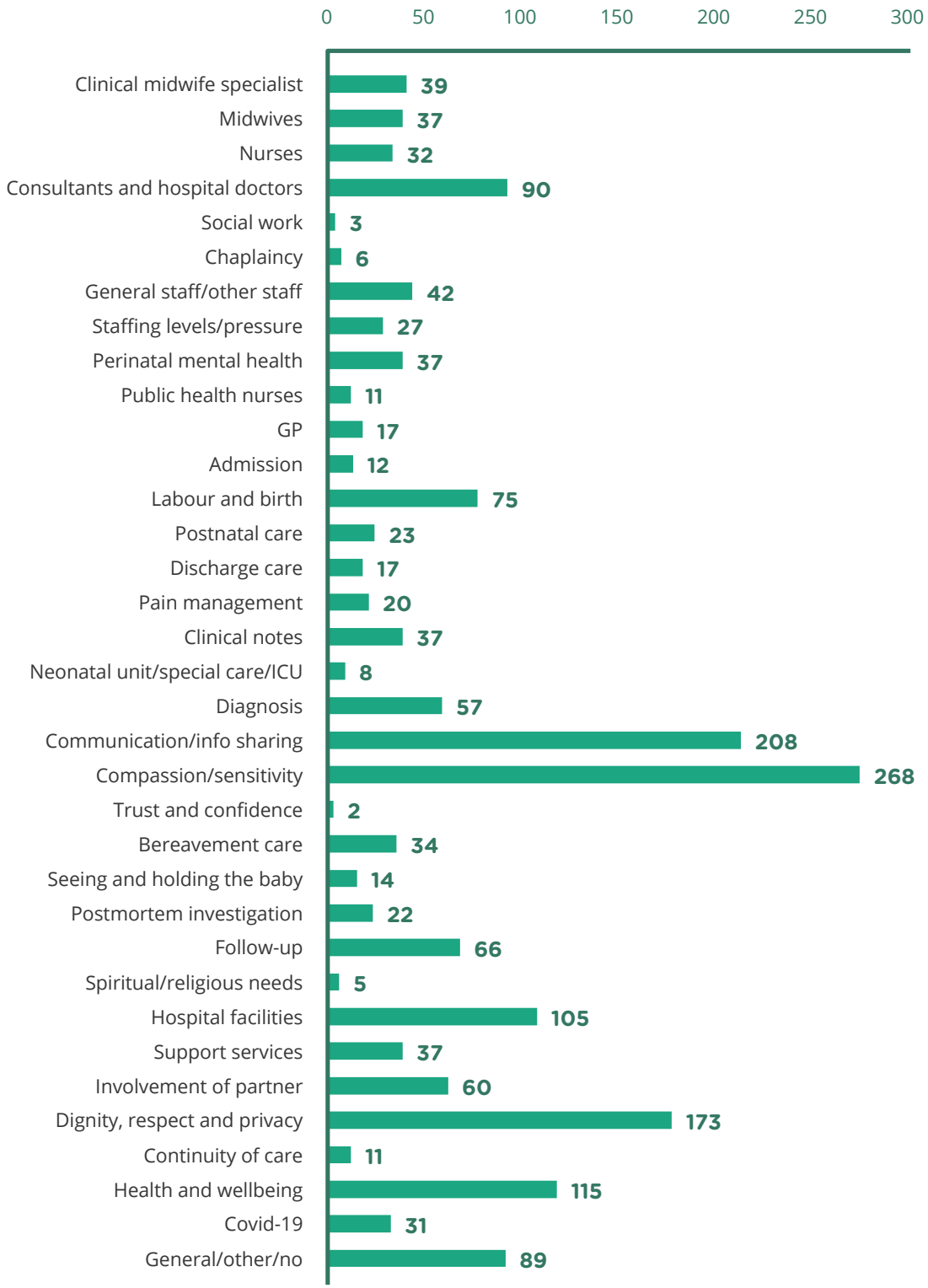
"Of special mention is the fact that they asked during admission if we had a name picked for our little boy and every single member of staff called him by his name from that second on. It made him so real even before he was born, which was especially important as we knew we were going to lose him."

"The kindness, compassion and understanding of the midwives and doctors. They gave us so much of their time, stayed on after their shift, visited myself and my baby in our room the day after delivery, gave words of encouragement which really stuck with me. Nothing we asked for was too much trouble and we had the chaplain's number to call when we sought advice on things related to the funeral."

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

In total, participants made 508 comments in response to this question. Figure 5 shows the breakdown of themes covered within these comments.

Figure 5: Responses to Q.89 broken down by theme.



The most frequently occurring theme was 'Compassion and sensitivity', which appeared in 268 comments. The next most common themes were 'Communication and information-sharing' (208 comments) and 'Dignity respect and privacy' (173 comments). A selection of comments illustrating these themes is provided below.

Compassion and sensitivity

"Some basic kindness understanding and acknowledgment of the extremely difficult time. I felt because I was still only 14 weeks that the situation was belittled a lot."

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

Communication and information-sharing

"I will always struggle with why my child died. The inquest did not help at all - and I was pregnant again when it was held which was very challenging. It's hard to move on with no answers."

"I think patients should have a badge or symbol that hospital staff recognise so they don't have to keep explaining their situation."

Dignity, respect and privacy

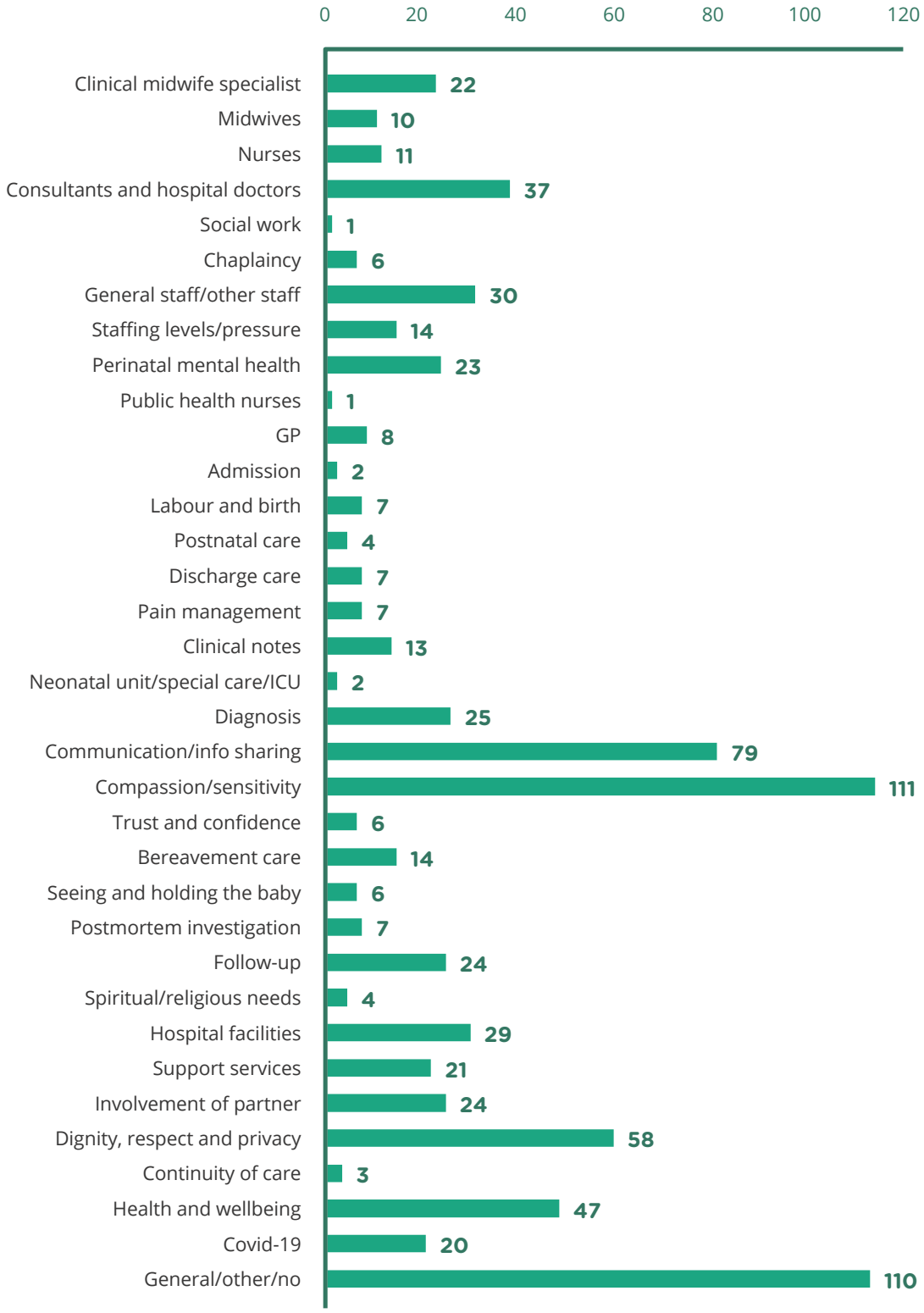
"It was inhumane that my husband was not allowed in with me. I was in a room on my own."

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

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 303 comments in response to this question. Figure 6 shows the breakdown of themes covered within these comments.

Figure 6: Responses to Q.90 broken down by theme.



The most frequently occurring theme was 'Compassion and sensitivity', which appeared in 111 comments. The next most common themes were 'General/other comments' (110 comments) and 'Communication and information-sharing' (79 comments). A selection of comments illustrating these themes is provided below.

Compassion and sensitivity

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

"Doing this survey has made me carefully reflect on my whole experience. I was so distraught and then Covid started, it was a very distressing and frightening time for me and then I was pregnant again. I had to just keep going. I needed counselling which I had to access privately and had to stop after 3 sessions as I couldn't afford any more. This really should be available for free to me...even now 2 years on."

General/other comments

"Losing a baby is the most difficult experience of my life. I am glad surveys like this are being carried out to help improve care for families."

"There isn't enough care available."

Communication and information-sharing

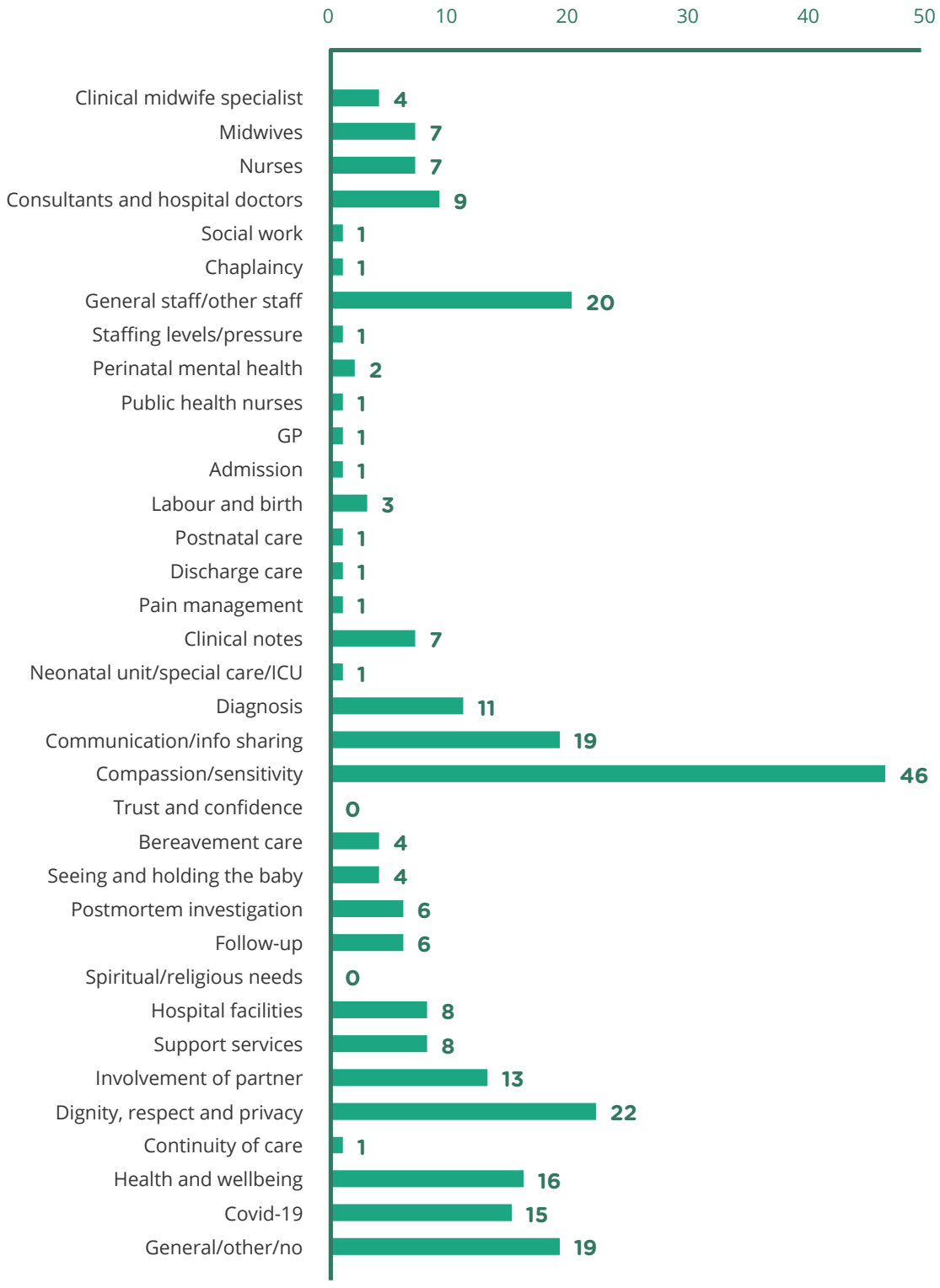
"After my miscarriage I continued to receive phone calls and letters informing me of future antenatal appointments. This was very insensitive to me."

"There are amazing support groups for baby loss out there such as A Little Life Time Foundation that we had no knowledge of except the well-known Feileacain. They really should all be written down on a leaflet and handed to every parent of every baby loss".

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 98 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 46 comments. The next most common themes were 'Dignity, respect and privacy' (22 comments) and 'General or other staff comment' (20 comments). A selection of comments illustrating these themes is provided below.

Compassion and sensitivity

"The care we received was top class in really difficult circumstances. The staff were exceptional and their care, time and effort made a horrible time a little bit easier. So thank you and God bless you."

"There was no support given to me as the father of our stillborn baby, in any way. No information for looking after myself or my wife after labour."

Dignity, respect and privacy

"Everyone directly involved in our son's case was amazing in how caring/ sensitive/ professional and supportive they were."

"I wasn't allowed to be with my wife when she was told our baby had died, she was told this heart-breaking information alone. Due to Covid 19 restrictions. I was brought in shortly afterwards."

General or other staff comments

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

"The one thing that really triggered us / angered us /saddened us was the lack of awareness or sensitivity of other hospital staff not directly involved in our case. I think more could be done to make sure the wider hospital staff aware of people cases."

3

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[17], 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

Experiences of care, support, interactions and provision of information at the time of baby's diagnosis.

10 QUESTIONS

2

Admission care

Experiences of care when admitted for induction of labour or delivery, focusing on admission planning and the hospital environment.

3 QUESTIONS

3

Labour and birth

Experiences of interactions with healthcare professionals, pain management and involvement in decisions while in labour and giving birth.

10 QUESTIONS

4

Care after birth and meeting the baby

Experiences of meeting the baby, and the support and privacy provided.

4 QUESTIONS

5

Neonatal care

Experiences of care in the neonatal unit, including visiting, involvement in decisions and communication.

6 QUESTIONS

6

Postnatal care

Experiences of hospital care after the birth, including physical and emotional support.

11 QUESTIONS

17 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.

7

Bereavement care

Experiences of support with practical and emotional aspects of dealing with the bereavement.

7 QUESTIONS

8

Post-mortem examinations and investigations

Experiences of the post-mortem examination process, including timeframes and communication.

6 QUESTIONS

9

Discharge care

Experiences of preparation for leaving the hospital and provision of information and support for returning home.

5 QUESTIONS

10

Follow-up care

Experiences of care at home after the discharge, including care from a GP or Public Health Nurse.

7 QUESTIONS

11

Overall care

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

8 QUESTIONS

12

Partner or support person

Experiences of a partner or support person, including involvement in decisions and provision of support.

9 QUESTIONS

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 scores for specific groups, for example for people who experience a particular type of loss, and the national average. For further information on the analyses please see Appendix 2.

Appendix 3 provides a list of the questions. Throughout this report, quotations from participants are used to illustrate particular themes. Quotations from participants have been redacted to remove any information that could identify an individual.

Communication and information at the time of diagnosis

"Midwifes were very caring and neonatal specialist clearly explained my baby would not survive and took the time to investigate if they could intervene or not when he was born. He clearly explained all information to me."

"Sonographer and consultant handled telling us the bad news very well, very empathetic and caring."

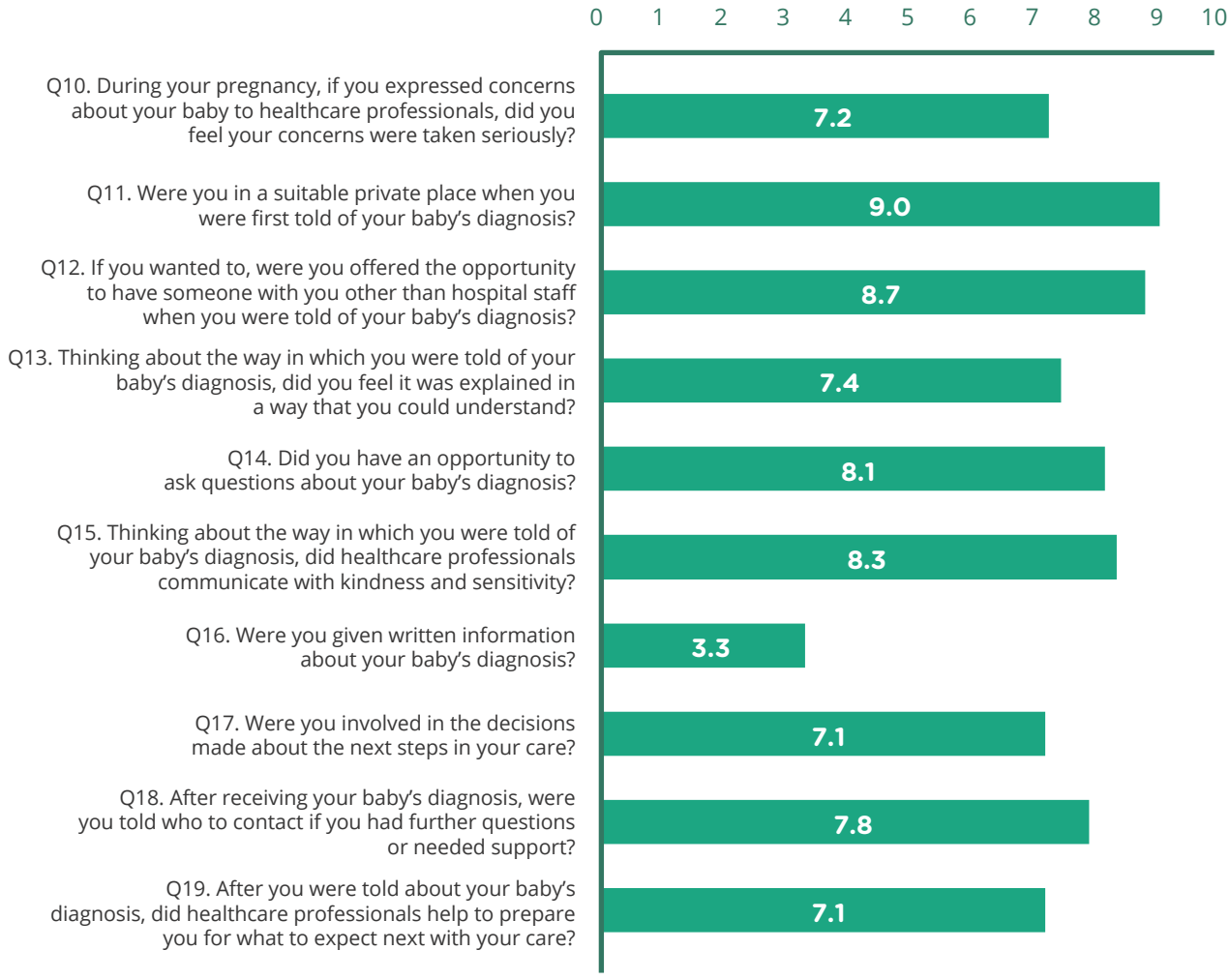
"The doctor who gave me the news about my baby could have been clearer about what was going to happen and what my delivery options were."

"There needs to be a separate section in hospitals for women receiving bad news and not be expected to sit with women with healthy babies."

The questions for this stage of care asked about experiences relating to receiving a diagnosis. It was explained in the survey that diagnosis included a medical condition, which meant that the baby or babies could die before or after they were born or that the baby had no heartbeat. In total, 289 (44%) participants said that they had received such a diagnosis during their pregnancy.

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 259 participants (90%) 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 177 participants (67%) saying they did not receive such information.

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



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 9 and Figure 10 respectively. While younger participants gave lower ratings of this stage of care, the difference from the national average was not statistically significant. In addition, no statistically significant differences from the national average were identified by type of loss for this stage of care.

Figure 9: Comparison of 'Communication and information at the time of diagnosis' by age group.

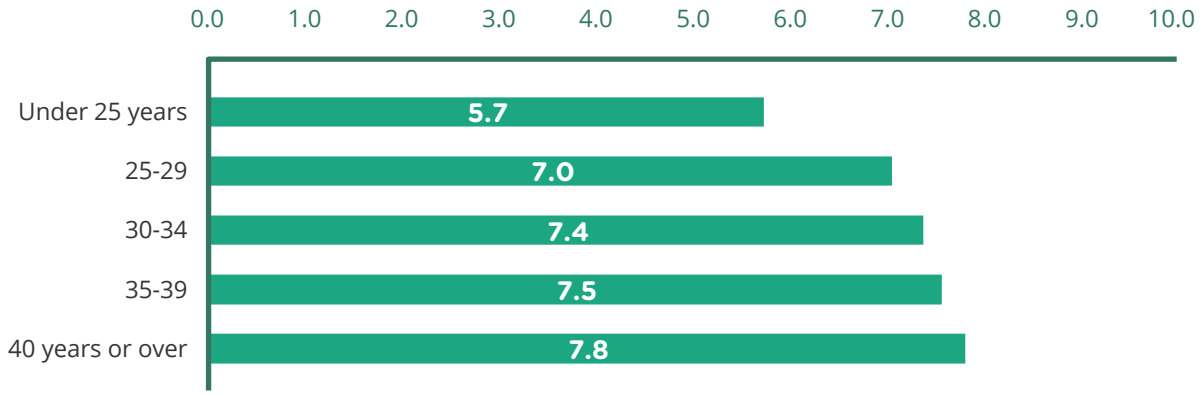


Figure 10: Comparison of 'Communication and information at the time of diagnosis' by type of loss experienced.

Admission care

"From hospital admission to discharge, I was treated with respect and dignity. I feel that the staff walked along with me, they felt my pain and they recognised the love we had for our son. They admired him, they cherished him, they treated him as every newborn deserves to be treated. My husband was equally cared for, and his loss recognised too. I wish that every family who finds themselves in this painful place could have this level of care."

"Prior to admission and delivery we were cared for excellently by the feotal medicine team. And during admission we were treated well."

"When we were admitted maternity ward not aware of us and we had to wait few hours before anything was done."

"The doctor at admissions should have taken the time to read my file properly. Her interactions with me were very inappropriate and ill-informed."

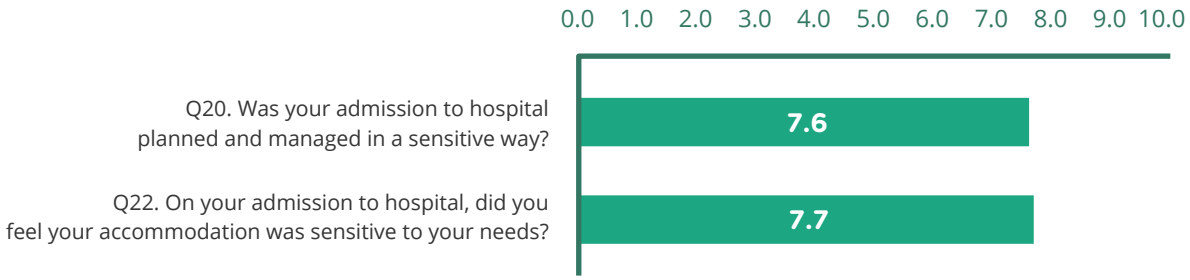
This stage included three questions on experiences of being admitted to hospital. One question asked people to describe the type of room or ward they were admitted to. The results for this question are presented in Table 3. Most participants (241, 84%) said they were admitted to single room.

The two other questions for this stage were scored out of 10 and the results are presented in Figure 11. These questions asked participants if their admission was managed sensitively, and whether their hospital accommodation was sensitive to their needs. For these questions, 155 participants (62%) said that their admission was 'definitely' planned and managed in a sensitive way, while 180 (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? [18]		
	No.	**%**
Single room (not shared)	241	83.7%
Shared room	13	4.5%
Labour ward	15	5.2%
Antenatal ward	15	5.2%
Postnatal ward	3	1.0%
General ward	8	2.8%
Emergency ward	5	1.7%
I wasn't admitted overnight	11	3.8%
Other	11	3.8%

Figure 11: Individual questions for 'Admission care'.



18 Participants could select more than one option in response to this question.

Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 12 and Figure 13 respectively. While younger participants gave lower ratings of this stage of care, the difference from the national average was not statistically significant. Participants who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 12: Comparison of 'Admission care' by age group.

Figure 13: Comparison of 'Admission care' by type of loss experienced.

* indicates a significant difference from the national average.

Labour and birth

"When I went into Labour, the hospital were expecting my arrival and even with high Covid restrictions, there was a bed in my room for my husband which I can't imagine going through everything without. I wasn't ever around normal maternity patients or healthy babies. Everything was handled with sensitivity and compassion."

"The midwife with me when I delivered was simply amazing. The bereavement midwife I trusted so much, she was compassionate and professional and never assumed she knew what I was going through, spoke to me so well."

"During my time in labour in the emergency room I was often left on my own. These times were very scary. As my loss was early on a Sunday morning I had to wait for the bereavement team on Monday."

"Improved information and communication on birth would have been helpful when in the hospital."

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 (533, 82%) said that their partner accompanied them during labour and birth. Notably, 32 women (5%) said that they were not able to be accompanied due to COVID-19 restrictions, with a further 16 (2.5%) unable to be accompanied for other reasons.

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 14.

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

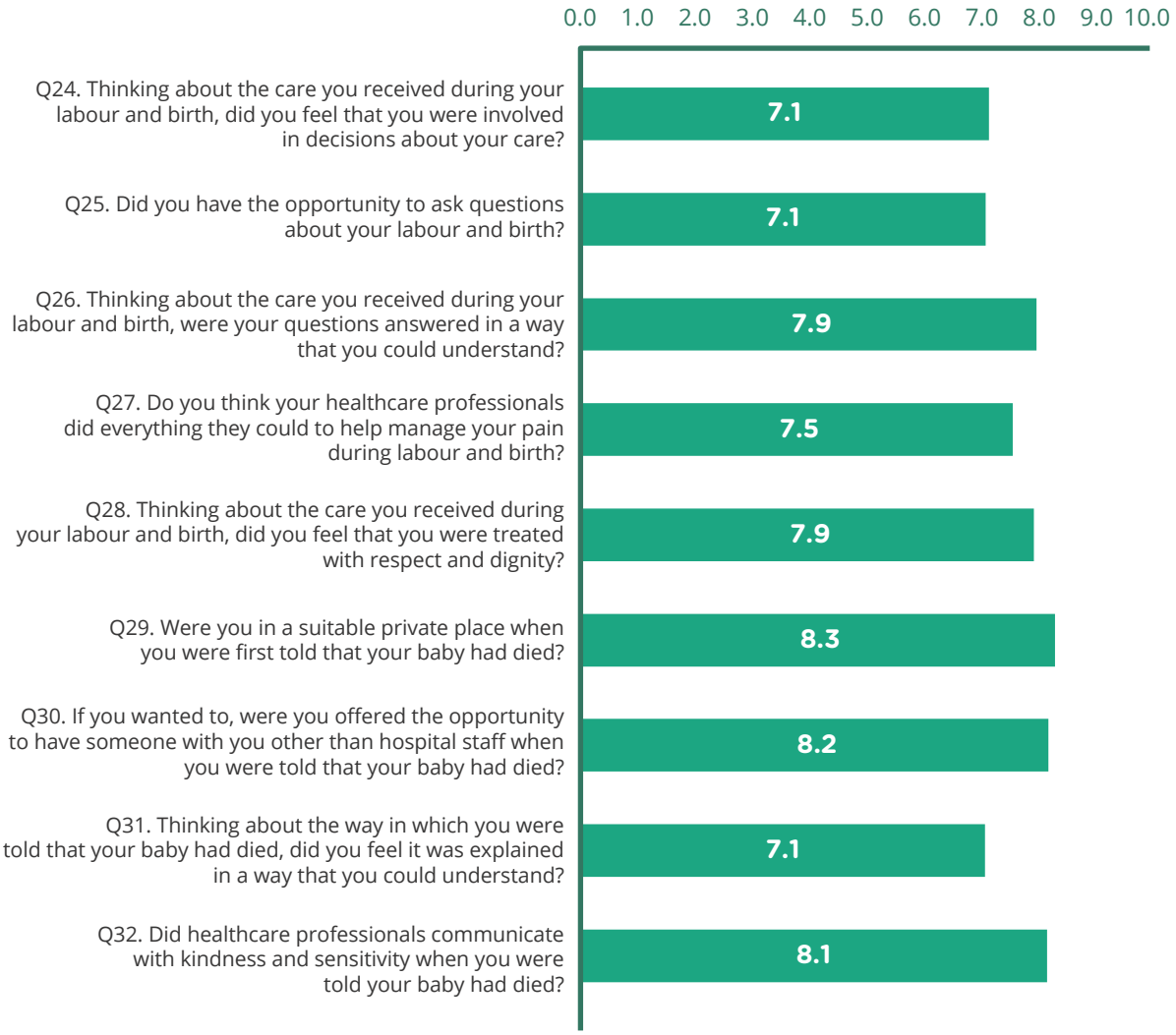
Q23. Were you accompanied by anyone other than healthcare professionals during the labour and birth of your baby? [19]		
	No.	**%**
Yes, by my partner	533	81.7%
Yes, by a support person (such as a family member, friend or doula)	28	4.3%
No, I was alone	46	7.1%
I did not want to have someone with me	4	0.6%
I was not able to have someone with me due to COVID-19 restrictions	32	4.9%
I was not able to have someone with me for other reasons	16	2.5%

The highest-scoring question for this stage related to privacy, with 343 participants (83%) saying they were in a suitable private place when they were first told that their baby had died.

The joint-lowest scoring questions for this stage related to involvement in decisions, opportunities to ask questions, and clear explanations. 95 participants (16%) felt that they weren't involved in decisions about their care during labour and birth, while 73 (12%) said that they did not have the opportunity to ask questions. In addition, 55 participants (13%) felt that their baby's death was not explained to them in a way that they could understand.

19 Participants could select more than one option in response to this question.

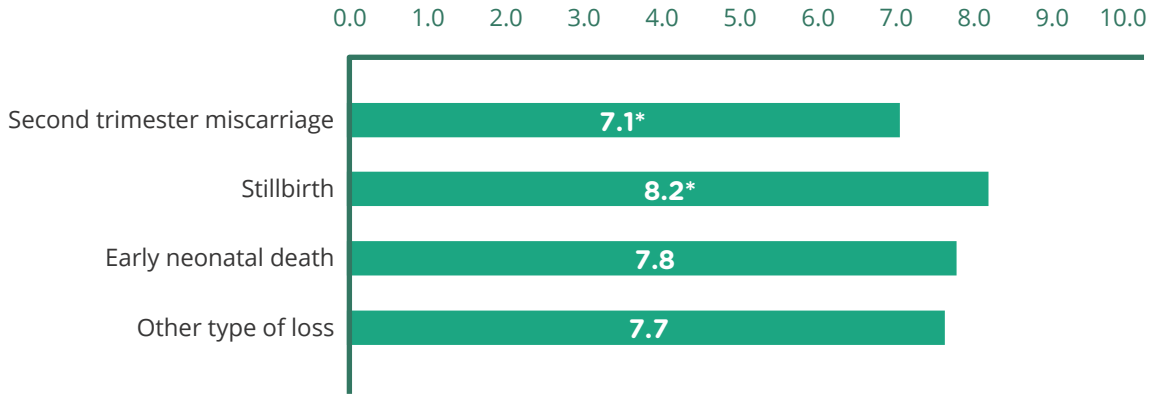
Figure 14: Individual questions for 'Labour and birth'.



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 15 and Figure 16 respectively. Participants aged between 16 and 24 years gave significantly lower ratings of this stage of care than the national average. Participants who experienced a stillbirth rated this stage of care more positively than the national average, while those who experienced a second trimester miscarriage gave significantly below-average ratings.

Figure 15: Comparison of 'Labour and birth' by age group.

Figure 16: 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

"The kindness and sensitivity that was shown to us... we were expecting our baby to be stillborn and when he was born the doctors first words were "He's beautiful"... we appreciated those words so, so much."

"I delivered at 20 weeks and was unprepared for the experience of giving birth (waters breaking/after birth etc). I wasn't prepared to make decisions like naming him, holding him and burying him. I don't know what I was expecting but I didn't think I'd have to do that."

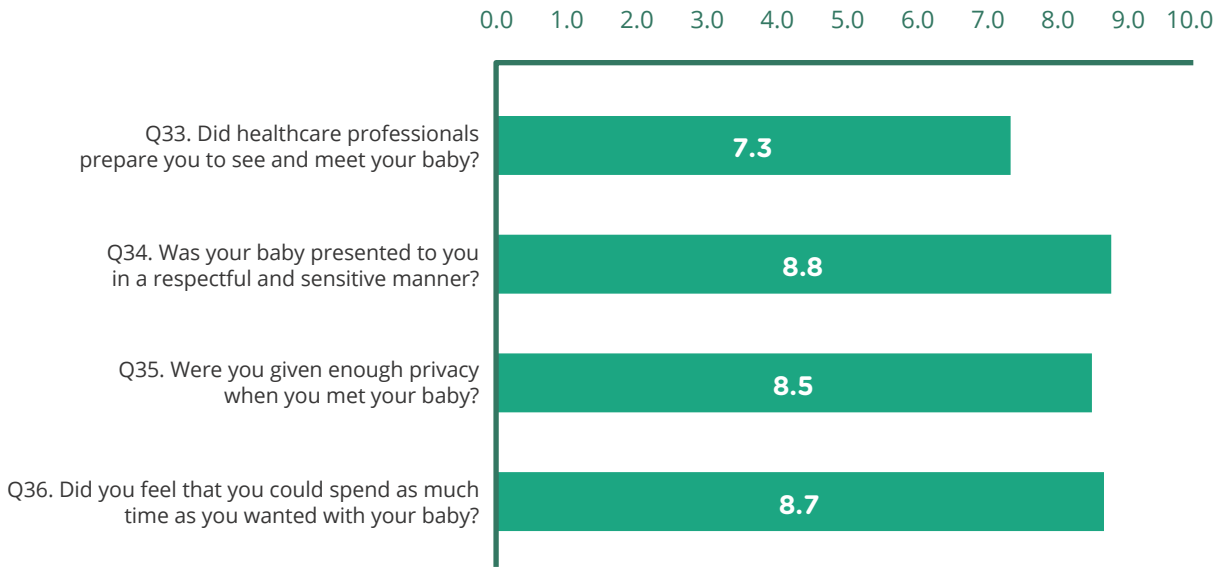
"Having the single special room to ourselves with the beautiful pictures on the wall was a comfort and also we couldn't hear other babies crying which would have been very difficult. Being able to take pictures and receiving the Feileacain and Little Lifetime information and memory box were so helpful at such a difficult time for us."

"I would have loved the opportunity to bath and dress my baby instead of having the midwives do it."

Each of the four questions for this stage of care were given a score out of 10 and the results are shown in Figure 17.

The highest-scoring question for this stage asked participants if their baby was presented to them in a respectful and sensitive manner, with 474 participants (82%) answering 'yes, definitely'. The lowest-scoring question for this stage related to how healthcare professionals prepared participants to see and meet their baby. 80 participants (14%) said that healthcare professionals did not prepare them for this.

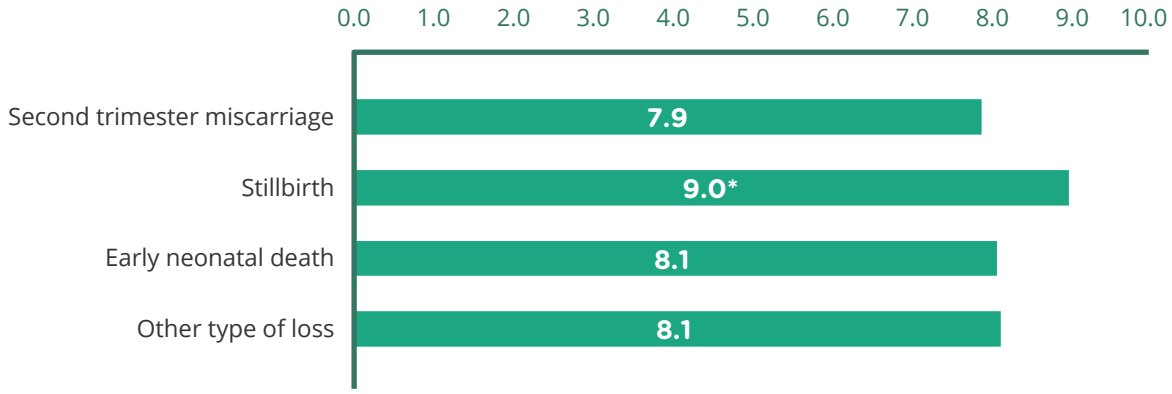
Figure 17: Individual questions for 'Care after birth'.



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 18 and Figure 19 respectively. While younger participants gave lower ratings of this stage of care, the difference from the national average was not statistically significant. Participants who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 18: Comparison of 'Care after birth' by age group.

Figure 19: Comparison of 'Care after birth' by type of loss experienced.



* indicates a significant difference from the national average.

Neonatal care

"People were very respectful of the situation. The NICU unit care was second to none. The staff are just so kind and caring. I will never forget these people."

"The doctors, nurses and staff of NICU were so nice and caring, absolute angels."

"We were asked to leave NICU each time bloods had to be drawn or bed linens changed for our baby, we would have loved to be present or involved while our baby was being cared for."

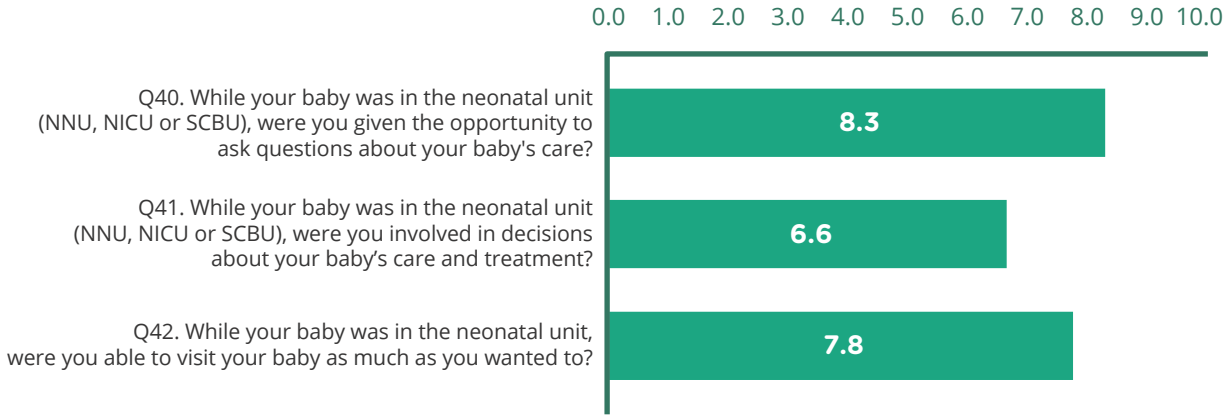
"I think there should be a separate part of the maternity hospital for women who have lost their babies. It was horrific to listen to other babies crying while my baby was in the NICU and after she has passed away."

Six questions explored experiences of care in a neonatal unit.[20] 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 this section explored experiences of communication, decision-making and visiting the neonatal unit. The results for these questions are shown in Figure 20. 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 20: Individual questions for 'Neonatal care'.



Comparisons of ratings for this stage of care by age group in Figure 21. Participants aged 16 to 24 years gave the most positive ratings of the stage of care, significantly above the national average.

Figure 21: Comparison of 'Neonatal care' by age group.

* indicates a significant difference from the national average.

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

Postnatal care

"The midwives in the labour ward were fantastic as were the staff in the postnatal ward. The Bereavement team were very supportive and helpful. The Doctors we spoke to after our baby was born listened to our concerns and we felt heard."

"Postnatal ward staff were very kind and supportive also the bereavement midwife was a lovely lady."

"As it was my first child I was unaware of what happens after birth e.g. breast having milk, loss of hair and depression. I needed more help and knowledge on this end of things."

"I wasn't given any follow-up appointments or told about any. I know family and friends who have also had stillbirths in other hospitals had a six week check-up but I didn't get any of this. The only contact we had was with our bereavement midwife who would check in regularly and our post mortem appointment with our consultant."

This section included 11 questions that asked about 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 show in Table 5. In total, 392 participants (60%) said that they were accommodated in a single room, with a further 215 (33%) accommodated in a designated bereavement room.

Participants who experienced an early neonatal loss were asked where their baby had died, with the results are shown in Table 6. The other nine questions for this section were scored out of 10 and the results are shown in Figure 22.

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)	392	60.1%
Bereavement room (designated facility for bereaved families)	215	33.0%
Shared room	18	2.8%
Labour ward	17	2.6%
Antenatal ward	10	1.5%
Postnatal ward	12	1.8%
General ward	23	3.5%
Emergency ward	9	1.4%
I wasn't admitted overnight	40	6.1%
Other	17	2.6%

Table 6: Results for question on where baby died in the postnatal period.

Q52. If your baby was born alive and subsequently died in the postnatal period, did your baby die:		
	No.	**%**
At home	6	5.3%
In the labour ward	27	23.7%
In the postnatal ward	6	5.3%
In the neonatal unit	48	42.1%
Other	27	23.7%
Don’t know or can’t remember	0	0.0%

The highest-scoring question for this stage related to kindness and sensitivity, with 456 participants (71%) saying that they were 'always' treated with kindness and sensitivity. The lowest-scoring question for this stage asked about breast care and lactation, with 124 participants (34%) saying that they were not given information and support relating to breast care and lactation.

Figure 22: Individual questions for 'Postnatal care'.

Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 23 and Figure 24 respectively. Participants aged between 16 and 24 years gave significantly lower ratings of this stage of care than the national average. Participants who experienced a stillbirth rated this stage of care more positively than the national average, while those who experienced a second trimester miscarriage gave significantly below-average ratings.

Figure 23: Comparison of 'Postnatal care' by age group.

Figure 24: Comparison of 'Postnatal care' by type of loss experienced.

* indicates a significant difference from the national average.

Bereavement care

"The nurses and doctors were very respectful and supportive through my c section experience I couldn't have asked for better I got to hold my son straight away and was given as much time as possible with him. I was never rushed to do anything."

"Although I'm not very religious I found the pastoral care I received very comforting. Midwives also encouraged me to hold my baby and take care of him. The hospital let my husband stay overnight with us which really helped me and also him as we got to spend time together as a family."

"I wish I could have bathed and dressed my baby and I feel I was encouraged to use to cool cot and I didn't hold my baby enough."

"More effort should have been made to encourage me to meet with a bereavement midwife, memory box was never offered, and we should have been put in a private room."

This section asked seven questions about bereavement care and supports provided to parents. The first question asked whether parents 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 7. 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. 49 participants (7.5%) 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 8. 258 participants (40%) said that their family or friends were offered the opportunity to meet their baby, while 212 (33%) said that this was not possible due to COVID-19 restrictions.

Table 7: Results for question on opportunities to interact and make memories with the baby.

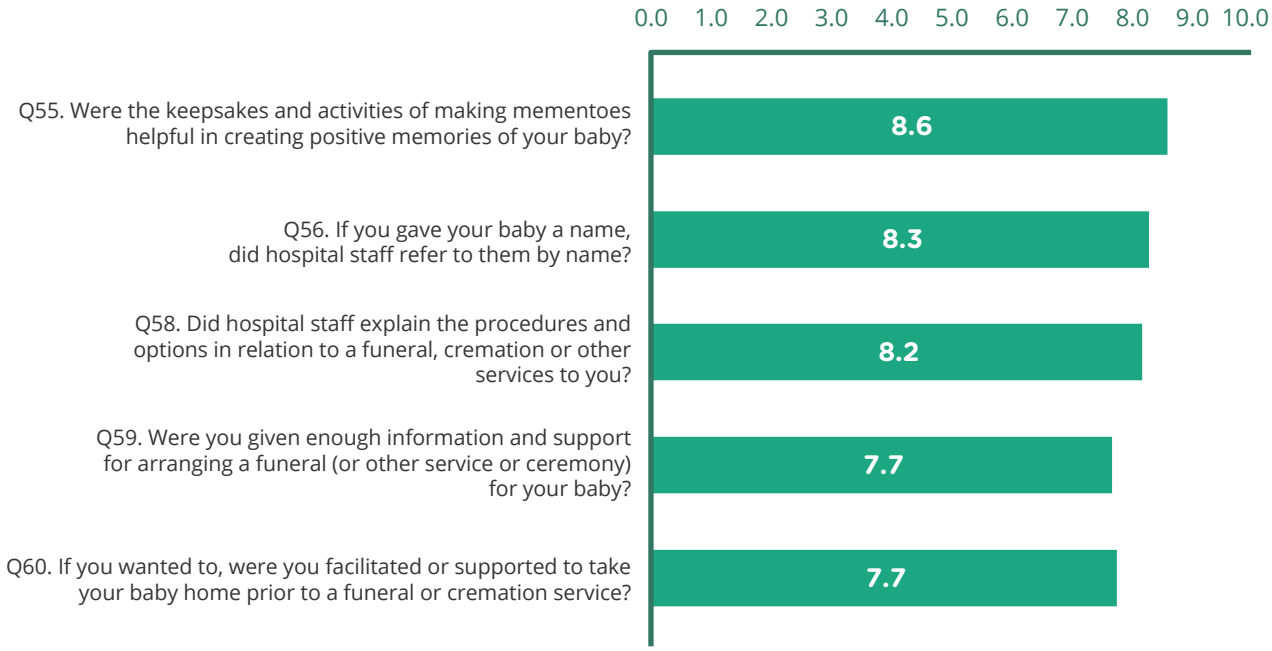
Q54. Were you offered the opportunity to...		
	No.	%
Name your baby	551	84.5%
Spend time with your baby	552	84.7%
Hold your baby	518	79.4%
Dress your baby	253	38.8%
Bath your baby	71	10.9%
Take a lock of your baby's hair	188	28.8%
Have photos with your baby	443	67.9%
Have a copy of your baby's hand print or foot print	449	68.9%
Have a naming or blessing ritual or ceremony	374	57.4%
Create a memory box	478	73.3%
Use a Bereavement alert symbol	279	42.8%
I was not offered any of these	49	7.5%
I did not want any of these	19	2.9%

Table 8: 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	258	39.6%
No, but I would have liked them to	37	5.7%
No, I did not want them to	105	16.1%
Family and friends were not able to visit due to COVID-19 restrictions	212	32.5%
Family and friends were not able to visit for other reasons	40	6.1%

The five other questions in this section asked about emotional and practical support, and the results are shown in Figure 25. The highest-scoring question for this stage related to memory-making, with 444 participants (76%) saying that the keepsake and activities of making mementoes were 'definitely' helpful in creating positive memories of their baby. The joint-lowest scoring questions related to information and support for arranging a funeral, and being supported to take the baby home prior to the funeral. In total, 79 participants (13%) said that they were not given enough information and support for arranging a funeral or other service, with 89 participants (18%) saying that they were not facilitated or supported to take their baby home prior to the funeral or cremation.

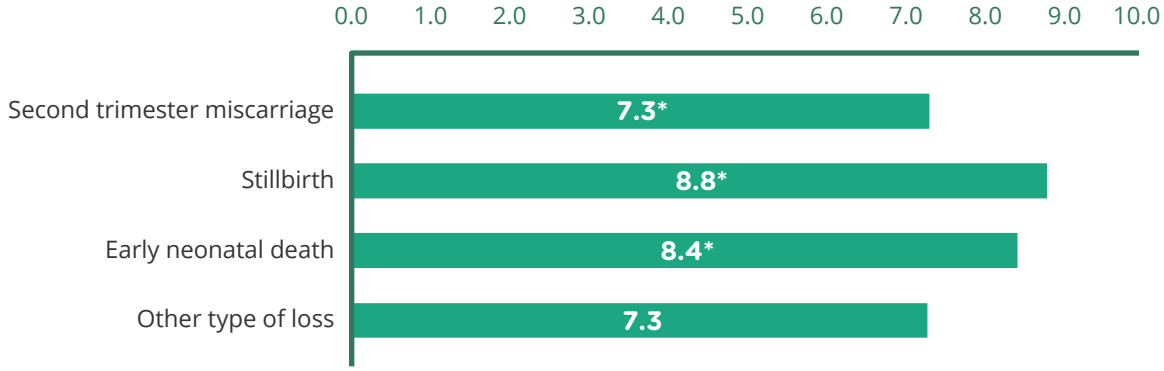
Figure 25: Individual questions for 'Bereavement care'.



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 26 and Figure 27 respectively. There were no statistically significant differences by age group for this stage of care. 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 26: Comparison of 'Bereavement care' by age group.

Figure 27: Comparison of 'Bereavement care' by type of loss experienced.



* indicates a significant difference from the national average.

Post-mortem examination and investigations

"We were offered to take home our baby, offered post-mortem, offered to stay as long as we wanted in hospital."

"My bereavement midwife has supported me since day one and continues to touch base with me to keep me updated on our son's post-mortem."

"Although a post-mortem was carried out, no one from the hospital sat down with me to understand and hear from me my experience of the pregnancy and see if there were any red flags in hindsight."

"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."

The six questions in this section asked about experiences of post-mortem examinations. 208 people (32%) said that their baby had a consented post-mortem, while 60 people (9.2%) said their baby had a coroner's post-mortem.[21]

Table 9: Results for question on post-mortem examination.

Q61. Did your baby have a post-mortem examination?		
	No.	%
Yes, a consented post-mortem	208	31.8%
Yes, a coroner's post-mortem	60	9.2%
No, I declined a post-mortem examination	186	28.4%
No, I was not offered a post-mortem examination	201	30.7%

Participants were asked when they had received the results of the tests and investigations. Findings for this question are shown in Table 10. Most participants (52%) said that they received the results within one to three months, while eight (3%) said they had waited for longer than 18 months.

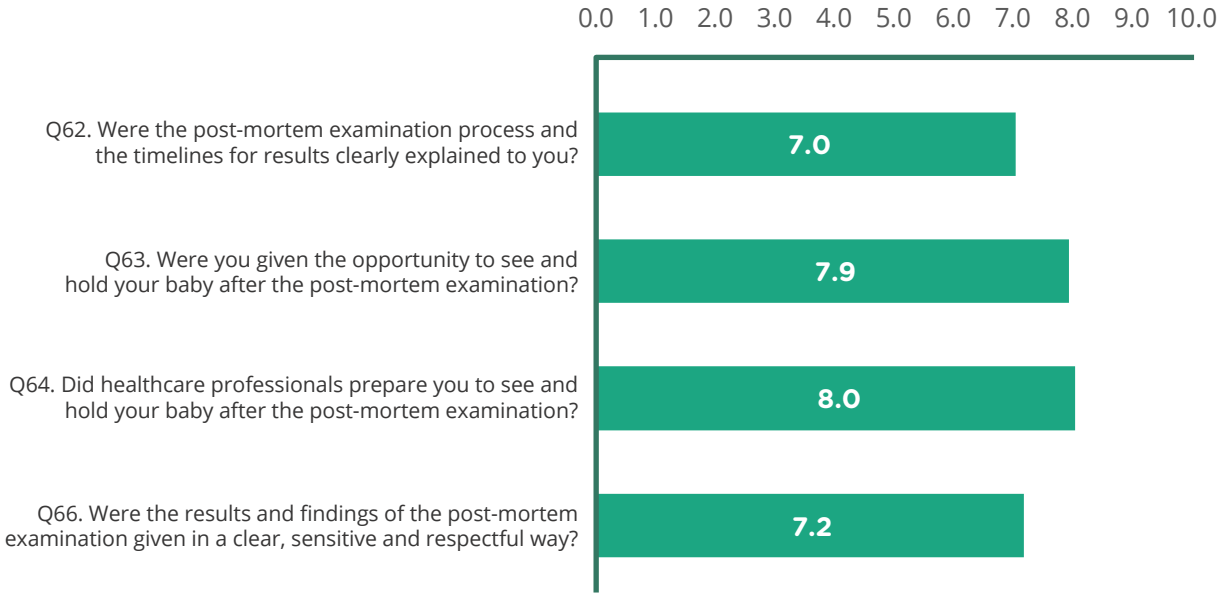
Table 10: Results for question on follow-up appointment.

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	18	6.7%
1 to 3 months	140	52.2%
4 to 6 months	64	23.9%
7 to 11 months	29	10.8%
12 to 18 months	9	3.4%
Longer than 18 months	8	3.0%

21 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 requirement and the process is explained to the parents along with written information. Parental consent is not required.

The results for the four other questions in this section are shown in Figure 28. The highest-scoring question for this stage related to being prepared to see and hold the baby after the post-mortem examination. 113 participants (67%) said that they were 'definitely' prepared to see and hold their baby after post-mortem examination. The lowest-scoring question related to explanations of the process, with 32 participants (12%) saying that the process and timelines for results were not explained clearly to them.

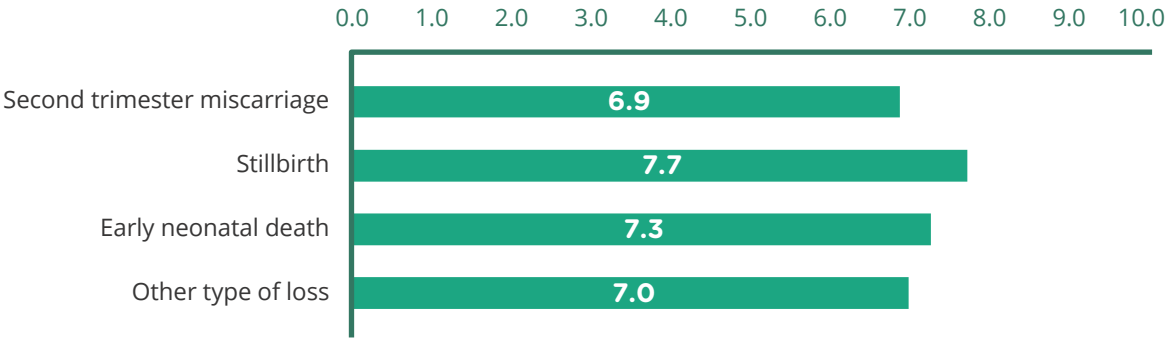
Figure 28: Individual questions for 'Post-mortem examination and investigations'.



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 29 and Figure 30 respectively. There were no significant differences from the national average by age group or type of loss.

Figure 29: Comparison of 'Post-mortem examination and investigations' by age group.

Figure 30: Comparison of 'Post-mortem examination and investigations' by type of loss experienced.



Discharge

"They organised an easy and as private as can be discharge, from a nurse waiting at the lift so no waiting, to 2 security guards standing either side of a private door away from public, and had our car waiting."

"My voice was listened to, my many questions answered from hospital admission to discharge, I was treated with respect and dignity. I feel that the staff walked along with me, they felt my pain and they recognised the love we had for our son."

"Leaving the hospital, I felt this could have been dealt with much more sensitively, private door, private exit etc, it was heart-breaking passing expectant mothers and couples leaving the hospital with their newborns, all the while carrying our deceased angel baby in a basket covered in a blanket, it broke our hearts and is something that really stands out in our story when we speak about our experience."

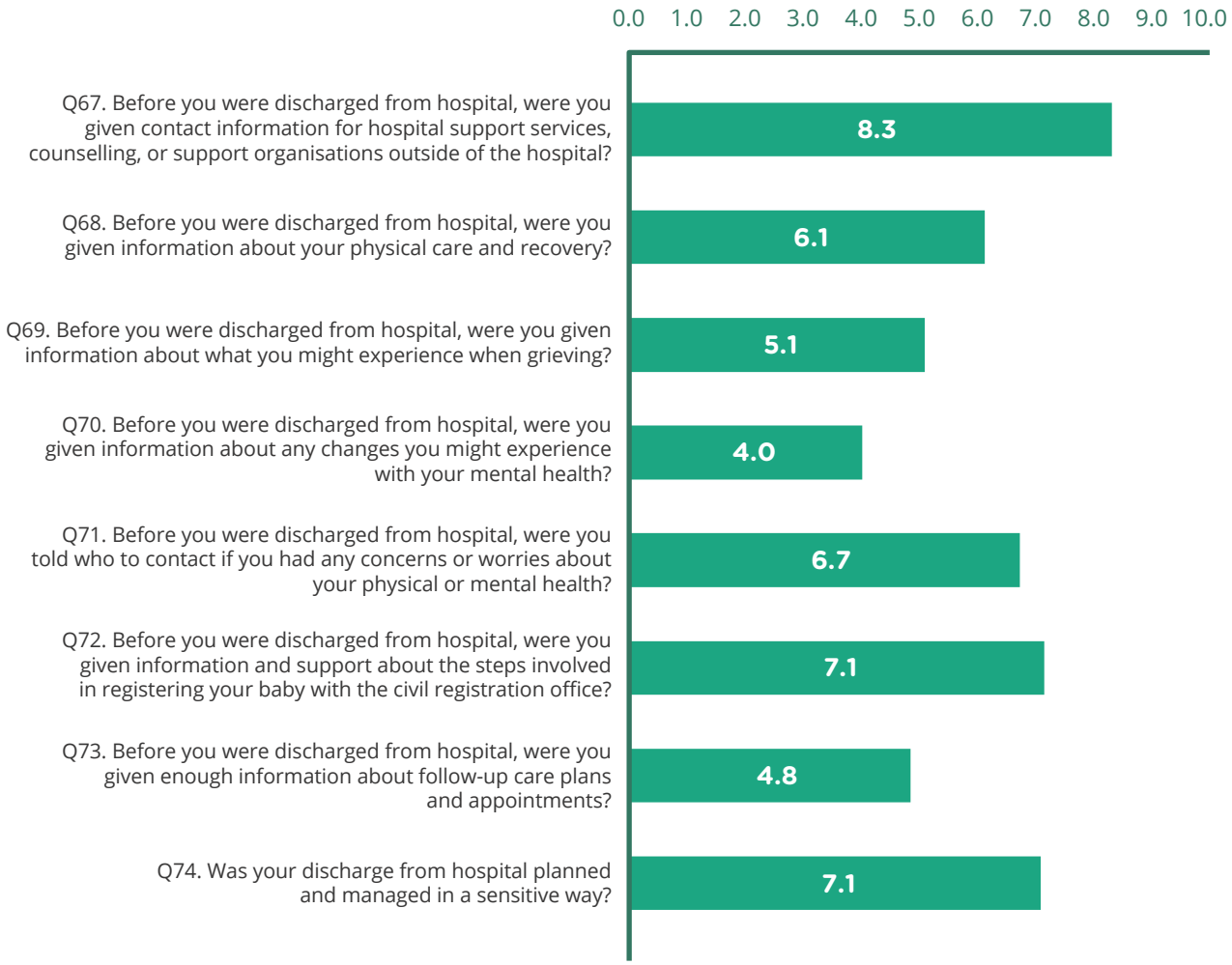
"I was discharged with no support or information on emotional supports, grief or bereavement."

This section included eight questions that asked about the information and support provided prior to being discharged from hospital.

Seven questions for this section were scored out of 10 and the results are shown in Figure 31. 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 results for this question are provided in Chapter 2.

The highest-scoring question for this stage related to provision of information for support services, with 514 participants (83%) 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 282 participants (47%) saying that they were not given information about changes they might experience with their mental health.

Figure 31: Individual questions for 'Discharge'.



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 32 and Figure 33 respectively. While younger participants gave lower ratings of this stage of care, the difference from the national average was not statistically significant. Participants who experienced a stillbirth rated this stage of care more positively than the national average.

Figure 32: Comparison of 'Discharge' by age group.

Figure 33: Comparison of 'Discharge' by type of loss experienced.

* indicates a significant difference from the national average.

Follow-up care

"My GP was made aware of our loss immediately and they made an effort to call and express their personal sympathies."

"Although the bereavement team were excellent in my baby's funeral arrangements and gave me a booklet on aftercare etc. I only received a call to follow up on my baby's diagnosis, there was no follow up regarding counselling or any mental health support that wasn't off your own back."

"My GP and PHN were amazing. My GP rang me and spoke at length about any supports I needed. He made sure that both me and my husband were ok and always (and still does) ask about our emotional well-being anytime any family member has a reason to be in clinic. PHN was also very available. She was sensitive and caring. She made herself available without intruding."

"I feel that more information relating to follow on services, support groups could have been given."

This section asked participants 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 show in Table 11. 320 participants (49%) said that they saw a GP, while significant numbers also saw a bereavement midwife or obstetrician. On the other hand, 100 participants (15%) 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 12. The most common source of support accessed by participants were partners, family and friends. Seventeen participants (3%) had not accessed any supports.

The remaining five questions for this section were scored out of 10 and the results are shown in Figure 34.

Table 11: Results for question on follow-up care providers.

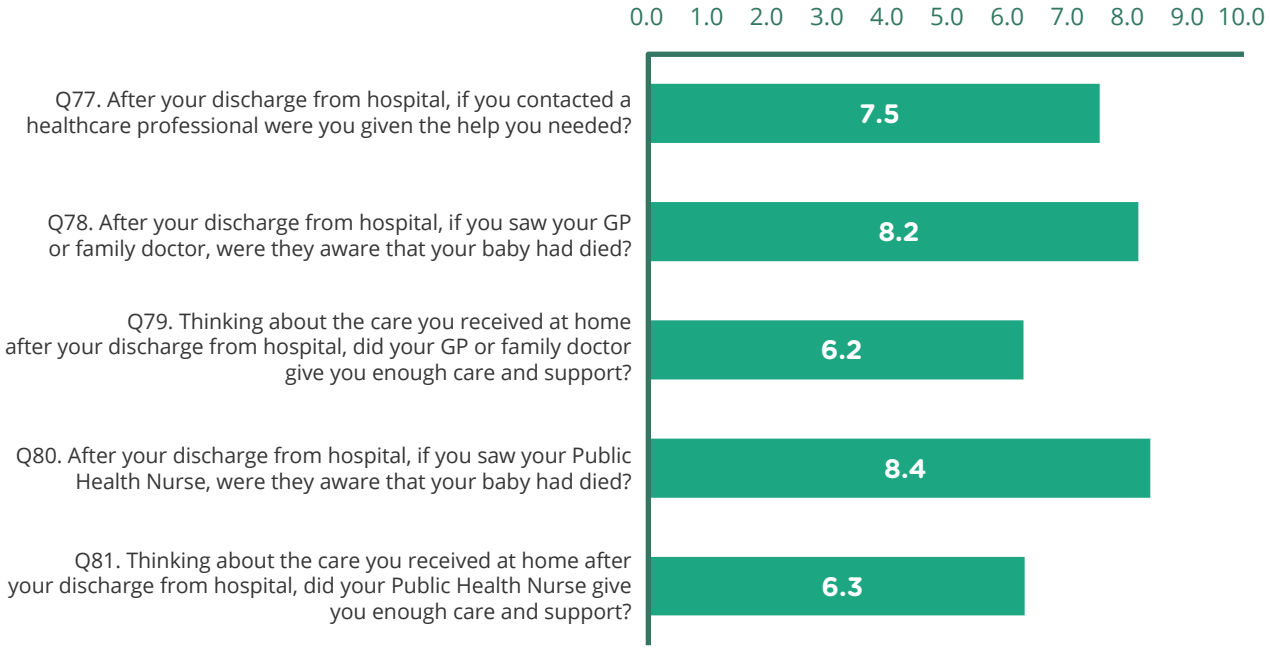
Q76. After your discharge from hospital, who did you see as part of your follow-up care?		
	No.	**%**
Family doctor (GP)	320	48.9%
Public Health Nurse (PHN)	147	22.5%
Bereavement midwife or nurse specialist in the hospital	283	43.3%
Mental health services	58	8.9%
Obstetrician or gynaecologist after discharge	205	31.3%
Consultant paediatrician or neonatologist	33	5.0%
Other	41	6.3%
I had to attend the hospital emergency department because of complications	48	7.3%
I had a follow-up appointment at the hospital but I declined to attend	6	0.9%
I haven't had any follow-up care since my discharge from hospital	100	15.3%

Table 12: Results for question on supports accessed after discharge.

Q82. After your discharge from hospital, what supports did you access?	No.	%
Partner	484	87.4%
Family	420	75.8%
Friends	358	64.6%
Bereavement support organisations/advocacy groups	237	42.8%
Hospital support services	119	21.5%
Professional counselling	175	31.6%
Other	19	3.4%
I did not access any supports	17	3.1%

Question 80 was the highest-scoring question for this stage, with 198 participants (84%) saying that the public health nurse was aware that their baby had died. The lowest-scoring question related to GP care, with 105 participants (22%) saying that their GP or family doctor did not give them enough care and support.

Figure 34: Individual questions for 'Follow-up care'.



Comparisons of ratings for this stage of care by age group and the type of loss participants experienced are provided in Figure 35 and Figure 36 respectively. There were no significant differences from the national average by age group or type of loss.

Figure 35: Comparison of 'Follow-up care' by age group.

Figure 36: Comparison of 'Follow-up care' by type of loss experienced.

Experiences of partner or support person

"I think the hospital did as much as they possibly could have for us, staff were compassionate towards us and helped us through a tough time."

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

"The support we received after losing our baby was exemplary. We knew before the birth that we would lose our baby. We were put in contact with a social worker who was very kind and supportive. The midwives and bereavement midwives were phenomenal. They were such a calm presence in a time of total devastation."

"There was no grief counselling offered to me or my partner after the loss of our baby."

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 pregnancy loss. There were nine questions in this section, including one free-text question. The results for the free-text question are provided in Chapter 2.

The first eight questions in this section were scored out of 10 and the results are shown in Figure 37. 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 13. The most common sources of support were partners, family and friends. However, 47 participants (21%) said that they did not access any supports.

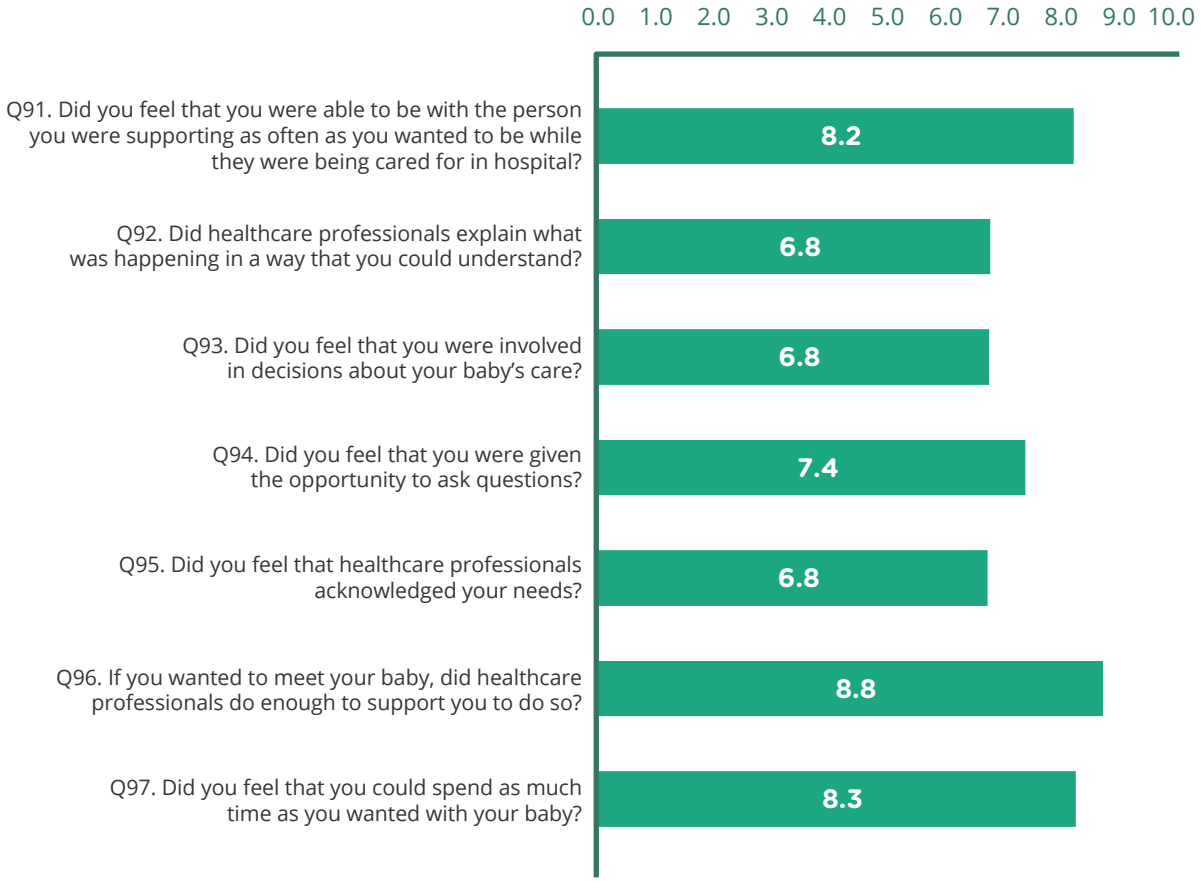
Table 13: Results for question on supports accessed by partner or support person.

Q98. If you sought support after the loss of your baby, what supports did you access? [22]		
	No.	**%**
Partner	161	70.3%
Family	117	51.1%
Friends	94	41.0%
Family doctor or GP	27	11.8%
Bereavement support organisations/advocacy groups	49	21.4%
Hospital support services	20	8.7%
Professional counselling	25	10.9%
Other	2	0.9%
I did not access any supports	47	20.5%

22 Partners could select more than one answer to this question.

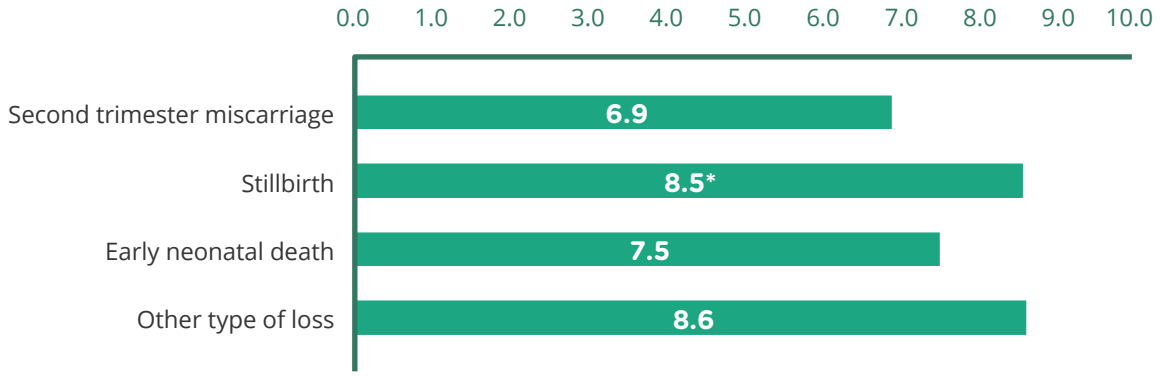
The highest-scoring question for this stage related to feeling supported to meet the baby, with 174 of the 230 participants who answered this question (81%), saying that healthcare staff 'definitely' did enough to support them if they wanted to meet their baby. The joint-lowest scoring questions related to clear explanations, involvement in decisions and needs being acknowledged. 32 participants (14%) said that healthcare professionals did not explain what was happening in a way they could understand, while 44 (20%) felt that they were not involved in decisions about their baby's care. In addition, 39 participants (17%) felt that healthcare professionals did not acknowledge the partner or support person's needs.

Figure 37: 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 38.[23] Partners who experienced a stillbirth rated their experience significantly more positively than the national average.

Figure 38: Comparison of 'Experiences of partner or support person' by type of loss experienced.



* indicates a significant difference from the national average.

23 No comparisons by age group is made for this stage as partners were not asked to indicate their age.

4

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 39. The highest-scoring of these questions related to respect for cultural needs, with 367 of the 618 participants who answered this question (81%), saying that healthcare professionals 'definitely' respected and facilitated their cultural, spiritual and religious needs. The lowest-scoring question related to confidence and trust, with 76 participants (12%) saying that they did not have confidence and trust in the staff that treated them. In response to the other question in this section, 406 participants (62%) said that they were always treated with respect and dignity.

Figure 39: 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 14. The most commonly offered support was a bereavement midwife or nurse specialist, with 517 participants (80%) saying they were offered this service. In total, 60 participants (9%) said that they were not offered any hospital support services, with six (1%) saying that no hospital support services were available.

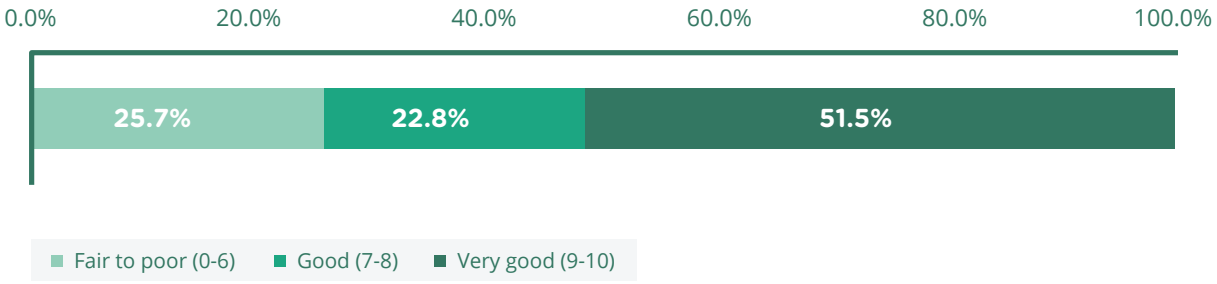
Table 14: Results for question on hospital supports offered to participant.

Q86. Were you offered any of the following hospital support services?	No.	%
Chaplaincy or pastoral care	368	57.0%
Social Work	90	13.9%
Bereavement midwife or nurse specialist	517	80.0%
Perinatal (pregnancy-related) Mental health service	78	12.1%
Perinatal (pregnancy-related) Palliative Care team	14	2.2%
Paediatrician/Neonatologist	44	6.8%
Other	11	1.7%
I wasn't offered any hospital support services	60	9.3%
No hospital support services were available	6	0.9%
Don't know or can't remember	22	3.4%

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. The average overall rating of care was 7.6 out of 10. In total, 318 participants (52%) rated their care as 'very good', 141 (23%) as 'good' and 159 (26%) rated it as 'fair to poor'.

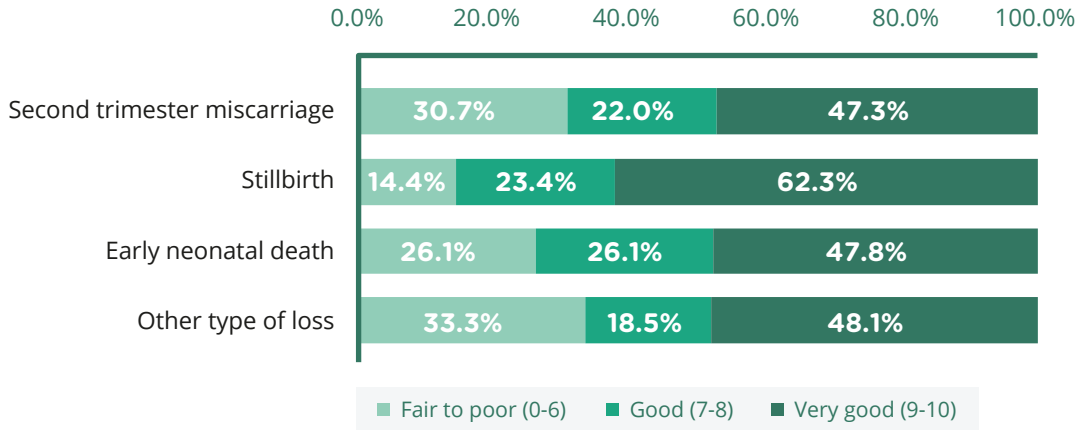
Figure 40: Overall ratings of care.



Overall care by type of loss experienced

There were differences in participants' overall ratings of their care, when comparing by the type of losses they experienced, with the results shown in Figure 41. Participants whose baby was stillborn were significantly more likely to give a positive overall rating of the care they received than participants who experienced a second trimester loss, early neonatal death or any other type of loss.

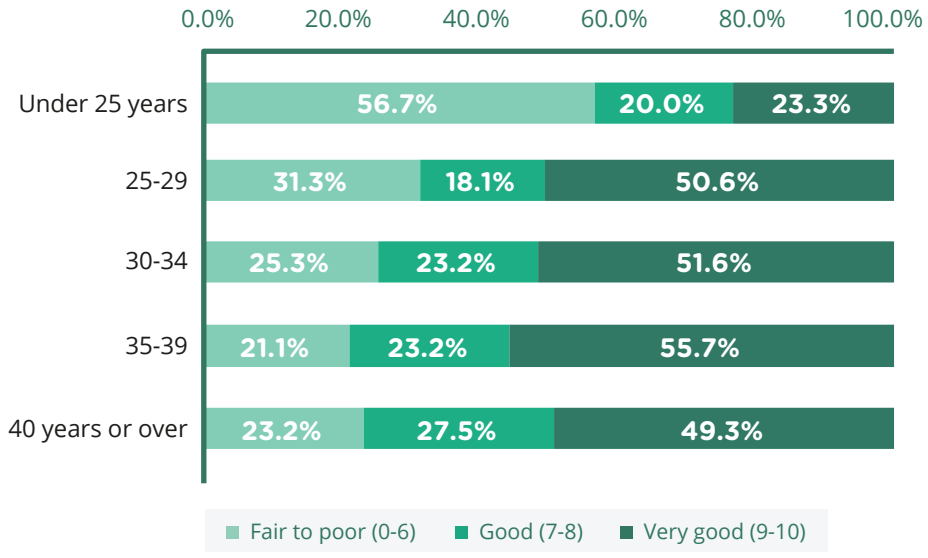
Figure 41: Overall ratings of care by type of loss experienced.



Overall care by age group

Participants aged 24 or younger were less likely to report positive ratings of the overall care they received than those in other age groups. The full findings for this comparison are shown in Figure 42. Participants aged 16 to 24 years were significantly more likely to rate their overall care as fair to poor than other age groups.

Figure 42: Overall ratings of care by age group.



5

Impact of the COVID-19 pandemic on care experiences

Maternity bereavement care during the pandemic

The survey period covered experiences of losses both before and during the COVID-19 pandemic. The pandemic affected some aspects of how care was provided, necessitating the introduction of hospital restrictions on visitors among other measures. This section of the report explores the impact of the pandemic on experiences of maternity bereavement care. In total, 247 participants experienced loss between January 2019 and February 2020, with 436 participants experiencing a loss from March 2020 to December 2021. The results are shown in Table 15.

Table 15: Results for question on when participants experienced loss.

	No.	%
January 2019 – February 2020	247	36.2
March 2020 – December 2021	436	63.8

Comments about the impact of the pandemic on experiences of care

In total 137 comments highlighted the impact of COVID-19, in response to the five free-text survey questions, with a breakdown provided in Table 16. The comments typically referred to the impact of restrictions on partners and family members. Examples of relevant comments are presented below.

Table 16: Number of COVID-related comments by question.

Question	No. of COVID-related comments
Q75. Is there anything else you would like to tell us about the care you received in hospital?	43
Q88. What was good about your care?	28
Q89. Was there anything that could be improved about your care?	31
Q90. Do you have anything else you wish to tell us about your experience?	20
Q99. (Partner) Is there anything else that you would like to tell us about your experience?	15

Examples of COVID-19 related comments

Q75. Is there anything else you would like to tell us about the care you received in hospital?

"Even though there were COVID restrictions my husband was allowed to stay with me all the time."

"The only thing we wished different is the restrictions that were put in place because of COVID-19. It was difficult for both of us, getting bad news without my partner there."

Q88. What was good about your care?

"The staff on maternity ward were very kind and caring, and supportive. I felt cared for as I was on my own and it was during lockdown."

"Considering that I was alone due to COVID - I never felt alone! I had a very positive, non-traumatic experience during a very upsetting time."

Q89. Was there anything that could be improved about your care?

"Partner should've been allowed to wait with me, he should have been with me when I got the bad news. COVID-19 meant nothing once we learned we lost our child."

"The COVID restrictions were the only problem but that wasn't the hospital's fault. Having to find out I was in labour and give birth to my first baby alone was awful, even though the staff were fantastic."

Q90. Do you have anything else you wish to tell us about your experience?

"Having to do everything alone during the pandemic was incredibly difficult. I don't think my husband will ever understand what I went through as he was not allowed to be present for anything."

"It was hard because of lockdown, but the other side, I wouldn't have wanted too many visitors because I wasn't able and I had sepsis and was very sick for over a week."

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

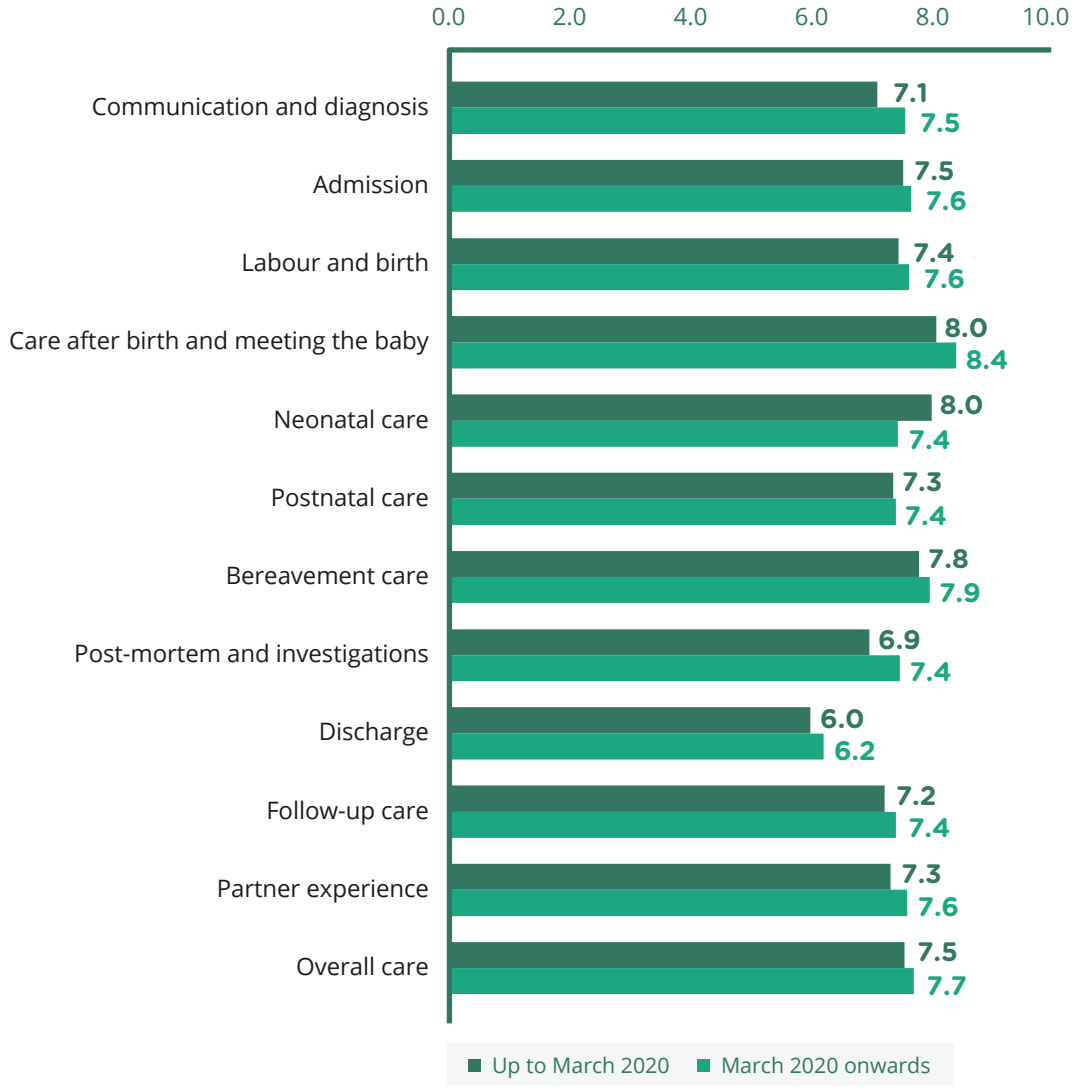
"I wasn't allowed to be with my wife when she was told our baby had died, she was told this heart-breaking information alone. Due to COVID-19 restrictions. I was brought in shortly afterwards."

"COVID made the process incredibly difficult."

Impact of the COVID-19 pandemic on ratings of overall care and stages of care

A comparison of experiences for each stage of care and overall care is shown in Figure 43. While some small differences were found between ratings of care for those who experienced losses before the onset of the pandemic and those who experienced a loss during the pandemic, none of these differences were statistically significant.

Figure 43: Comparison of stages of care and overall care by time of loss.



6

Conclusion

Experiences of maternity bereavement care between 2019 and 2021

In total, 655 women and 232 partners or support persons generously shared their experiences 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 dedicated spaces in hospitals for grieving parents; more consistent communication across services involved in their care; additional supports at discharge for physical and mental health; and more support for partners. Other areas for improvement included a desire for greater involvement in decisions about care during labour and birth, and support for physical recovery after birth. In addition, participants identified a need for greater information-provision at discharge, particularly in relation to physical recovery, mental health, grieving, and follow-up care and appointments.

Participants also highlighted multiple areas where they had positive care experiences. In their responses to the free-text survey questions, participants praised staff for their caring and sensitive attitudes, with numerous comments mentioning midwives and chaplaincy staff in particular. In addition, most participants felt treated with respect and dignity both during labour and birth, and after their baby was born. Participants said that staff treated them with kindness and sensitivity, and presented their baby to them in a respectful and sensitive way. In addition, staff members assisted participants when they needed it, and respected their cultural and religious needs.

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.

When comparing the experiences of age groups and those who had experienced different types of loss, it was clear that participants aged between 16 and 24 years had poorer experiences overall and across several stages of care than older respondents. On the other hand, participants who had a stillbirth typically gave more positive ratings of their care experiences than those who experienced a second trimester loss, early neonatal death or any other types of loss.

The experience of partners was explored in the survey, with 232 partners responding. It was evident that in some cases, partners felt that they were not as involved as they should be, and were not supported sufficiently. Free-text comments also outlined how COVID-19 restrictions and limitations on their attendance at the hospital affected their ability to support their partners when they needed it.

Comparisons were made between participants who experienced losses prior to the onset of the COVID-19 pandemic in March 2020, as well as losses experienced after that time. Numerous comments made in response to the free-text questions referred to the impact of the pandemic. However, when experiences across the stages of care were compared, no significant differences in ratings were found.

In conclusion, the findings of the National Maternity Bereavement Experience Survey show that most parents were positive about the care they received. The willingness of participating parents to share their experiences of such a difficult and painful time has also helped identify areas where care can be improved, particularly in relation to supports for grieving and physical and mental health after leaving hospital.

What happens next?

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

The Department of Health will use the findings to help inform the development of policy in relation to maternity bereavement care as appropriate.

Finally, the findings of the survey will inform national standards and HIQA's monitoring of maternity care services.

Appendices

Appendix 1

Membership of the National Maternity Bereavement Experience Survey Governance Groups

National Care Experience Programme Steering Group

Angela Fitzgerald (Chair)[24]	Chief Executive Officer, HIQA (Chair from March 1, 2022)
Phelim Quinn[25]	Chief Executive Office, HIQA
Rachel Flynn	Director of Health Information and Standards, HIQA
Niamh Bernard	Principal Officer, Department of Health
Patrick Creedon[25]	Principal Officer — Blood & Organ Transplant and Acute Hospital Service Planning Policy, Department of Health
Marita Kinsella[25]	Director, National Patient Safety Office, Department of Health
Louise Loughlin[26]	National Manager, National Advocacy Service
Joanne Condon	National Manager, National Advocacy Service
Mary McGeown	Head of Patient Safety Surveillance & Performance Unit, National Patient Safety Office, Department of Health
Brian Place[27]	Patient representative
Joe Ryan	National Director of Operational Performance, HSE
Sean Egan	Director of Healthcare Regulation, HIQA
Marty Whelan	Head of Communications, HIQA
Orla Healy	National Clinical Director, Quality and Patient Safety, HSE
Yvonne O'Neill	National Director Community Operations, HSE
Mary Day	Interim National Director Acute Operations, HSE
Laura Casey	Principal Officer, Older Persons Policy Development, Department of Health
Roisin O'Leary[28]	Senior Patient Advocate, Sage Advocacy
Mervyn Taylor[29]	Chief Executive Officer, Sage Advocacy
Fidelma Browne	Assistant National Director, Communications, HSE

24 Appointed CEO of HIQA and Chair of the Steering Committee in March 2022.

25 Until December 2021.

26 Until December 2022.

27 The late Dr Brian Place was a patient representative on the steering group since its inception in 2017. He sadly passed away in November 2021.

28 Until January 2022.

29 From January 2022.

National Maternity Bereavement Experience Survey, Programme Board

Rachel Flynn	Director of Health Information and Standards, HIQA (Chairperson)
Tracy O'Carroll	Head, National Care Experience Programme, HIQA
Conor Foley	Senior Analyst, National Care Experience Programme, HIQA
Anna Maria Verling	Project Lead, National Maternity Bereavement Experience Survey, HIQA
Deirdre Hyland	Patient Safety Surveillance Officer, Department of Health
Laura Mangan	Assistant Principal Officer, Patient Safety Surveillance and Performance Unit, National Patient Safety Office, Department of Health
Cliona Murphy	Clinical Director, National Women and Infants Health Programme, HSE
Angela Dunne	National Lead Midwife, National Women and Infants Health Programme, HSE
Prof Keelin O'Donoghue	National Clinical Lead for the Implementation of Bereavement Standards in Pregnancy Loss & Perinatal Death, HSE
Krysia Lynch	Womens' Representative, AIMS Ireland
Rachel Rice	Parent Representative - Parent Forum, Implementation of National Standards for Bereavement Care
Louise Cooke	Clinical Nurse Specialist Bereavement & Loss Maternity Services, Midlands Regional Hospital, Portlaoise
Gavin Ashe	Administration Officer, Maternity & Gynaecology Policy Unit, Department of Health
June Boulger[30]	National Lead for Patient and Public Partnership, HSE
Fiona Mulligan[31]	Clinical Midwife Specialist
Peter McKenna[32]	Clinical Director, National Women and Infants Health Programme, HSE
Cara Regan Downey[33]	Business Manager, Operations, Performance and Integration, HSE
Denise Lawler	Regional Manager, Healthcare Regulation HIQA
Danny Smith	Assistant Principal, Maternity and Gynaecology Policy Unit, Department of Health
Mairie Cregan	Chairperson, Feileacain
Aileen Killeen[34]	Senior Operations Manager, Partnering with Patients, Office of the National Director Operational Performance & Integration, HSE

30 Until August 2021.
31 Until March 2022.
32 Until April 2022.
33 Until August 2022.
34 From September 2022.

National Maternity Bereavement Experience Survey Team

Tracy O' Carroll	Head, National Care Experience Programme, HIQA
Anna Maria Verling	Project Lead, National Care Experience Programme, HIQA
Conor Foley	Senior Analyst, National Care Experience Programme, HIQA
Daniela Rohde	Analyst, National Care Experience Programme, HIQA
Trudi Mason	Project Officer, National Care Experience Programme, HIQA
Róisín Murphy[33]	Research Officer, National Care Experience Programme, HIQA
Donnacha O'Ceallaigh	Project Officer, Information management, National Care Experience Programme, HIQA

33 Until November 2022.

Appendix 2

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.[34]

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

Example of a scored question

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

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

The 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.

34 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 stages 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.

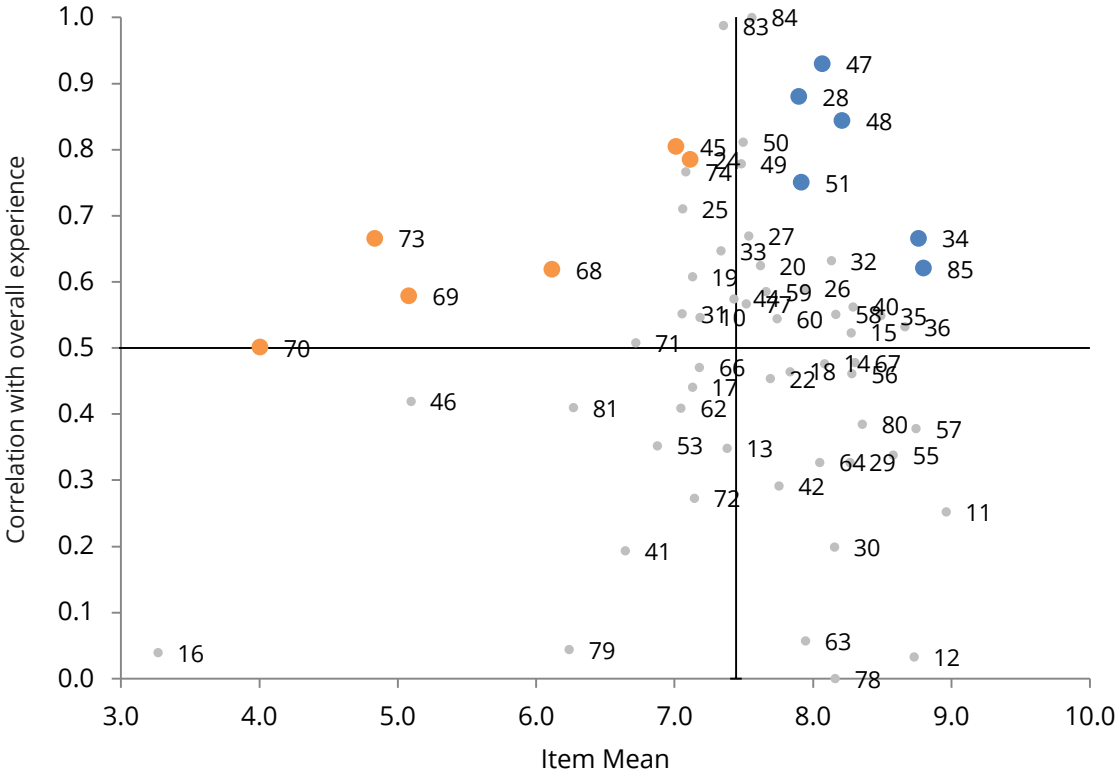
Results on questions comparing two groups of residents (e.g., those who share a bedroom and those who do not) were compared using a 't-test' at the 99% confidence level. A t-test is a statistical test used to compare the average scores of two groups. A statistically significant difference means it is 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 44 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 44: 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. 446 participants (69.4%) said that they were 'always' treated with respect and dignity during labour and birth.
2. Q34. Was your baby presented to you in a respectful and sensitive manner?
    a. 474 participants (81.9%) said that their baby was 'definitely' presented to them in a respectful and sensitive manner.
3. 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. 454 participants (70.4%) said that they were 'always' treated with respect and dignity after the birth of their baby.
4. Q48. Thinking about the care you received after the birth of your baby while you were in hospital, did you feel you were treated with kindness and sensitivity?
    a. 456 participants (70.8%) said that they were 'always' treated with kindness and sensitivity after the birth of their baby.
5. Q51. If you needed assistance while you were in hospital after the birth of your baby, were you able to get healthcare professionals to assist you when you needed it?
    a. 354 participants (67.6%) said that they were 'always' able to get assistance from healthcare professionals when they needed it.
6. Q85. Were your cultural, spiritual and religious needs respected and facilitated by healthcare professionals?
    a. 367 participants (80.8%) said that their cultural, spiritual and religious needs were 'definitely' respected and facilitated by healthcare professionals.

Areas needing improvement

1. Q24. Thinking about the care you received during your labour and birth, did you feel that you were involved in decisions about your care?
    a. 95 participants (15.9%) said that they did not feel involved in decisions about their care during labour and birth.
2. Q45. While you were in hospital, were you given enough care and support with your physical recovery after the birth of your baby?
    a. 116 participants (17.8%) said that they were not given enough care and support with their physical recovery after the birth of their baby.
3. Q68. Before you were discharged from hospital, were you given information about your physical care and recovery?
    a. 159 participants (25.8%) said that they were not given information about their physical care and recovery before they were discharged from hospital.
4. Q69. Before you were discharged from hospital, were you given information about what you might experience when grieving?
    a. 198 participants (32.6%) said that they were not given information about what they might experience when grieving before they were discharged from hospital.
5. Q70. Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?
    a. 282 participants (47.4%) said that they were not given information about changes they might experience with their mental health before they were discharged from hospital.
6. Q73. Before you were discharged from hospital, were you given enough information about follow-up care plans and appointments?
    a. 234 participants (38%) said that they were not given information about 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.

Appendix 3

Questions and Response Options from the National Maternity Bereavement Experience Survey Questionnaire

MATERNITY BEREAVEMENT EXPERIENCE SURVEY

National Maternity Bereavement Experience Survey

What is the survey about?

The National Maternity Bereavement Experience Survey is the first national survey to ask women about their experience of bereavement care in Ireland's maternity units or hospitals. We appreciate how painful it may be to consider the answers to the questions in the survey, but your feedback will provide us with valuable information on the standard of maternity bereavement care in Ireland and help us to identify areas for improvement. If you had a partner or support person with you during your experience of pregnancy loss, there is an optional section in the questionnaire that asks about their experiences.

Who should respond to this survey?

This survey is aimed at women aged 16 or older who experienced a second trimester miscarriage from 14 weeks of pregnancy, the stillbirth of a baby or the early neonatal death of a baby, and who were admitted to one of Ireland's 19 maternity units or hospitals between 1 January 2019 to 31 December 2021. Your feedback will help to improve the safety and quality of Ireland's maternity bereavement services.

Can I ask someone to help me fill in the survey?

Yes, you can ask someone to help you fill in the survey. You may also ask someone to fill in the survey on your behalf. However, please make sure that the answers given reflect your experience of care.

How to complete the survey questionnaire

- Please read the information in the boxes that accompany some of the questions as these provide important information to help you complete the questionnaire.
- **We have included free-text boxes towards the end of the questionnaire to provide you with an opportunity to include additional information in your own words about anything you feel is not covered or adequately included in the survey questions. Please tell us as much or as little as you like.**
- Some questions may not be relevant to your experience. The survey includes instructions to skip past questions if they are not relevant to you.
- If you experienced more than one second trimester miscarriage, stillbirth or early neonatal death between 1 January 2019 and 31 December 2021, and you wish to complete a questionnaire for each of these losses please contact us at **1800 314 093**.
- Please do not type your name or address anywhere on the questionnaire.
- **The survey takes approximately 30 to 40 minutes to complete.**

If you have any questions about the survey, please call our Freephone number on 1800 314 093 (Monday-Friday, 9am-5pm), visit **www.yourexperience.ie** or email us at **info@yourexperience.ie**.

Your answers will remain anonymous and confidential.
Your feedback will not affect your future care in any way.

1. Opening questions

The following section asks about your background and overall details of your pregnancy loss. This will help us to describe the participants in the survey.

Q1.	What is your age?	
	1☐	Under 25 years
	2☐	25 to 29 years
	3☐	30 to 34 years
	4☐	35 to 39 years
	5☐	40 years or over

Q2.	What is your ethnic group?	
	White:	
	1☐	Irish
	2☐	Irish Traveller
	3☐	Roma
	4☐	Any other white background
	Black or Black Irish:	
	5☐	African
	6☐	Any other black background
	Asian or Asian Irish:	
	7☐	Chinese
	8☐	Indian/Pakistani/Bangladeshi
	9☐	Another Asian background
	Other, including mixed group/ background:	
	10☐	Arabian
	11☐	Mixed, please specify
	12☐	Other, please write your ethnic group here:

Q3.	What type of pregnancy loss did you experience?	
	1☐	Second trimester miscarriage (a miscarriage that happens when a baby has died between 14 - 24 weeks of pregnancy)
	2☐	A stillbirth (baby born after 24 weeks of pregnancy or greater than or equal to 500g, showing no signs of life)
	3☐	Early neonatal death (baby born alive but died within first seven days of life)
	4☐	Other (please explain):

Q4.	Did you experience the loss of more than one baby?	
	1☐	No, this was a pregnancy with one baby
	2☐	No, this was a twin pregnancy, but one twin died
	3☐	Yes, this was a twin pregnancy, both twins died
	4☐	Yes, I had triplets or more, and more than one died

Q5.	In what month and year was your baby born (please tick the month and write the year)	
	1☐	January
	2☐	February
	3☐	March
	4☐	April
	5☐	May
	6☐	June
	7☐	July
	8☐	August
	9☐	September
	10☐	October
	11☐	November
	12☐	December
	(Please write in) e.g. 2 0 2 0	
	Y Y Y Y	

Q6.	In which hospital was your baby born?	
	1☐	University Hospital Galway
	2☐	Letterkenny University Hospital
	3☐	Mayo University Hospital
	4☐	Portiuncula University Hospital
	5☐	Sligo University Hospital
	6☐	University Maternity Hospital Limerick
	7☐	National Maternity Hospital
	8☐	Midland Regional Hospital Mullingar
	9☐	St Lukes General Hospital
	10☐	Wexford General Hospital
	11☐	Coombe Women and Infants University Hospital
	12☐	Midland Regional Hospital Portlaoise
	13☐	Rotunda Hospital
	14☐	Our Lady of Lourdes Hospital
	15☐	Cavan General Hospital
	16☐	Cork University Maternity Hospital
	17☐	University Hospital Waterford
	18☐	South Tipperary General Hospital
	19☐	University Hospital Kerry
	20☐	None of the above

Q7.	When did you first find out that your baby had died?	
	1☐	During pregnancy, before labour
	2☐	My baby died during labour
	3☐	After delivery in the neonatal period
	4☐	Don't know or can't remember

Q8.	Who's filling in this questionnaire? (This information will help us direct you to the correct section of the survey)		
	1☐	The baby's mother alone	
	2☐	The baby's mother and her partner or support person together	
	3☐	Partner or support person alone	→ SKIP TO **Q91**, STAGE 13. PARTNER OR SUPPORT PERSON

Q9.	During your pregnancy, were you informed that your baby had a medical condition, which meant that they could die before or after they were born, or that your baby had no heartbeat?		
	1☐	Yes	
	2☐	No	→ SKIP TO **Q23**, STAGE 4. LABOUR AND BIRTH

2. Communication and information at the time of diagnosis

The following section asks about your experience of care, communication and information at the time of your baby's or babies' diagnosis.

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

Q10.	During your pregnancy, if you expressed concerns about your baby to healthcare professionals, did you feel your concerns were taken seriously?	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No
	4☐	Not applicable to my situation

Q11.	Were you in a suitable private place when you were first told of your baby's diagnosis?	
	1☐	Yes
	2☐	No
	3☐	Don't know or can't remember

Q12.	**If you wanted to, were you offered the opportunity to have someone with you other than hospital staff when you were told of your baby's diagnosis?**	
	1☐	Yes
	2☐	No
	3☐	I did not want to have someone with me
	4☐	I was not able to have someone with me due to COVID-19 restrictions
	5☐	I was not able to have someone with me for other reasons
	6☐	Don't know or can't remember

Q13.	**Thinking about the way in which you were told of your baby's diagnosis, did you feel it was explained in a way that you could understand?**	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No

Q14.	**Did you have an opportunity to ask questions about your baby's diagnosis?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not have any questions

Q15.	**Thinking about the way in which you were told of your baby's diagnosis, did healthcare professionals communicate with kindness and sensitivity?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q16.	**Were you given written information about your baby's diagnosis?**	
	1☐	Yes
	2☐	No
	3☐	Don't know or can't remember

Q17.	**Were you involved in the decisions made about the next steps in your care?** (For example your treatment options, admission plan, birth plan, pain relief, postnatal care, etc.)	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	It was not possible for me to be involved

Q18.	**After receiving your baby's diagnosis, were you told who to contact if you had further questions or needed support?**	
	1☐	Yes
	2☐	No
	3☐	Don't know or can't remember

Q19.	**After you were told about your baby's diagnosis, did healthcare professionals help to prepare you for what to expect next with your care?** (admission to hospital, labour, birth, postnatal care)	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

3. Admission care

The following section asks about your experiences of care when you were admitted for induction of labour or delivery, after your baby was diagnosed with a medical condition, which meant that they could die before or after they were born, or that your baby had no heartbeat.

Q20.	Was your admission to hospital planned and managed in a sensitive way?	
	1 ☐	Yes, definitely
	2 ☐	Yes, to some extent
	3 ☐	No
	4 ☐	My admission was not planned

Q21.	On your admission to hospital, which of the following best describes your accommodation where you spent most of your time? *(tick all that apply)*	
	1 ☐	Single room (not shared)
	2 ☐	Shared room
	3 ☐	Labour ward
	4 ☐	Antenatal ward
	5 ☐	Postnatal ward
	6 ☐	General ward
	7 ☐	Emergency ward
	8 ☐	I wasn't admitted overnight → SKIP TO **Q23.**
	9 ☐	Other

Q22.	On your admission to hospital, did you feel your accommodation was sensitive to your needs?	
	1 ☐	Yes, definitely
	2 ☐	Yes, to some extent
	3 ☐	No
	4 ☐	Not applicable to my situation

4. Labour and birth

The following section asks about the care you received during the labour and the birth of your baby.

Q23.	Were you accompanied by anyone other than healthcare professionals during the labour and birth of your baby? *(tick all that apply)*	
	1 ☐	Yes, by my partner
	2 ☐	Yes, by a support person (such as a family member, friend or doula)
	3 ☐	No, I was alone
	4 ☐	I did not want to have someone with me
	5 ☐	I was not able to have someone with me due to COVID-19 restrictions
	6 ☐	I was not able to have someone with me for other reasons

Q24.	Thinking about the care you received during your labour and birth, did you feel that you were involved in decisions about your care?	
	1 ☐	Yes, always
	2 ☐	Yes, sometimes
	3 ☐	No
	4 ☐	It was not possible for me to be involved for medical reasons
	5 ☐	Don't know or can't remember

Q25.	Did you have the opportunity to ask questions about your labour and birth?	
	1 ☐	Yes, definitely
	2 ☐	Yes, to some extent
	3 ☐	No → SKIP TO **Q27.**
	4 ☐	It was not possible for me to ask questions for medical reasons → SKIP TO **Q27.**
	5 ☐	I did not have any questions → SKIP TO **Q27.**

Q26.	Thinking about the care you received during your labour and birth, were your questions answered in a way that you could understand?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	Don't know or can't remember

Q27.	Do you think your healthcare professionals did everything they could to help manage your pain during labour and birth?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not need any help
	5☐	Don't know or can't remember

Q28.	Thinking about the care you received during your labour and birth, did you feel that you were treated with respect and dignity?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	Don't know or can't remember

The following questions ask about the care you received if your baby died during labour or at the time of delivery. If this does not apply to you, please skip to Q33.

Q29.	Were you in a suitable private place when you were first told that your baby had died?		
	1☐	Yes	
	2☐	No	
	3☐	Don't know or can't remember	
	4☐	Not applicable to my situation	→ SKIP TO **Q33.**

Q30.	If you wanted to, were you offered the opportunity to have someone with you other than hospital staff when you were told that your baby had died?	
	1☐	Yes
	2☐	No
	3☐	I did not want to have someone with me
	4☐	I was not able to have someone with me due to COVID-19 restrictions
	5☐	I was not able to have someone with me for other reasons
	6☐	Don't know or can't remember

Q31.	Thinking about the way in which you were told that your baby had died, did you feel it was explained in a way that you could understand?	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No

Q32.	Did healthcare professionals communicate with kindness and sensitivity when you were told your baby had died?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

5. Care after birth and meeting your baby

The following section asks about when you met your baby for the first time after they were born.

Q33.	**Did healthcare professionals prepare you to see and meet your baby?**		
	1☐	Yes, definitely	
	2☐	Yes, to some extent	
	3☐	No	
	4☐	I chose not to see my baby	→ SKIP TO **Q37.**
	5☐	It was not possible for medical reasons to see my baby	→ SKIP TO **Q37.**

Q34.	**Was your baby presented to you in a respectful and sensitive manner?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q35.	**Were you given enough privacy when you met your baby?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q36.	**Did you feel that you could spend as much time as you wanted with your baby?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	It was not possible for me to spend time with my baby for medical reasons

6. Neonatal care

After birth, some babies need specialist care and are admitted or transferred to a neonatal unit (NNU). When referring to neonatal care the terms neonatal intensive care unit (NICU), or special care baby unit (SCBU) may also be used. The following section asks about your experience of care while your baby was in the NNU, NICU or SCBU.

Q37.	**Was your baby or one of your babies admitted to a neonatal unit?** (NNU, NICU or SCBU)		
	1☐	Yes	
	2☐	No	→ SKIP TO **Q43.**

Q38.	**Was your baby transferred from one hospital to another for specialised care in a neonatal unit?** (NNU, NICU or SCBU)		
	1☐	Yes	
	2☐	No	→ SKIP TO **Q40.**

Q39.	**Following your baby's transfer, were you admitted to the same hospital as your baby?**	
	1☐	Yes
	2☐	No, I was discharged home
	3☐	No, I was not transferred for other reasons

Q40.	**While your baby was in the neonatal unit (NNU, NICU or SCBU), were you given the opportunity to ask questions about your baby's care?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not have any questions

Q41.	**While your baby was in the neonatal unit (NNU, NICU or SCBU), were you involved in decisions about your baby's care and treatment?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q42.	While your baby was in the neonatal unit, were you able to visit your baby as much as you wanted to?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	No, I was not physically well enough

7. Postnatal care

The following section asks about your postnatal maternity hospital or unit stay and care following the birth of your baby.

Q43.	After your baby was born, which of the following best describes your postnatal accommodation? *(tick all that apply)*	
	1☐	Single room (not shared)
	2☐	Bereavement room (a specific family room designed to facilitate bereaved families)
	3☐	Shared room
	4☐	Labour ward
	5☐	Antenatal ward
	6☐	Postnatal ward
	7☐	General ward
	8☐	Emergency ward
	9☐	I wasn't admitted overnight
	10☐	Other

Q44.	After your baby was born, was your postnatal accommodation sensitive to your needs?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q45.	While you were in hospital, were you given enough care and support with your physical recovery after the birth of your baby?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q46.	While you were in hospital, were you given information and support with breast care and lactation?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No, but I would have liked this information
	4☐	No, but I did not need this information
	5☐	Not applicable to my situation

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?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	Don't know or can't remember

Q48.	Thinking about the care you received after the birth of your baby while you were in hospital, did you feel you were treated with kindness and sensitivity?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	Don't know or can't remember

Q49.	Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that your questions were answered in a way that you could understand?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	I did not have any questions
	5☐	Don't know or can't remember

Q50.	**Thinking about the care you received after the birth of your baby while you were in hospital, did you feel that you were involved in decisions about your care?**	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	Don't know or can't remember

Q51.	**If you needed assistance while you were in hospital after the birth of your baby, were you able to get healthcare professionals to assist you when you needed it?**	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	I did not need any assistance
	5☐	Don't know or can't remember

If your baby was born alive and subsequently died in the postnatal period, the following questions may be relevant to you.

If not, please skip to Q54 (Stage 8. Bereavement care).

Q52.	**If your baby was born alive and subsequently died in the postnatal period, did your baby die:**		
	1☐	At home	
	2☐	In the Labour ward	→ SKIP TO **Q54.**
	3☐	In the Postnatal Ward	→ SKIP TO **Q54.**
	4☐	In the Neonatal Unit	→ SKIP TO **Q54.**
	5☐	Other (please explain):	→ SKIP TO **Q54.**
	6☐	Don't know or can't remember	→ SKIP TO **Q54.**

Q53.	**Did you feel supported by healthcare professionals to take your baby home before they died?**	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No

8. Bereavement care

The following section asks about your experience of maternity unit or hospital bereavement care and your time in hospital.

Q54.	**Were you offered the opportunity to...** *(tick all that apply)*		
	1☐	Name your baby	
	2☐	Spend time with your baby	
	3☐	Hold your baby	
	4☐	Dress your baby	
	5☐	Bath your baby	
	6☐	Take a lock of your baby's hair	
	7☐	Have photos with your baby	
	8☐	Have a copy of your baby's hand print or foot print	
	9☐	Have a naming or blessing ritual or ceremony	
	10☐	Create a memory box	
	11☐	Use a Bereavement alert symbol	
	12☐	I was not offered any of these	→ SKIP TO **Q57.**
	13☐	I did not want any of these	→ SKIP TO **Q57.**

Q55.	**Were the keepsakes and activities of making mementoes helpful in creating positive memories of your baby?**	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q56.	If you gave your baby a name, did hospital staff refer to them by name?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	I did not give my baby a name

Q57.	Were your family or friends offered the opportunity to meet your baby?	
	1☐	Yes
	2☐	No, but I would have liked them to
	3☐	No, I did not want them to
	4☐	Family and friends were not able to visit due to COVID-19 restrictions
	5☐	Family and friends were not able to visit for other reasons

Q58.	Did hospital staff explain the procedures and options in relation to a funeral, cremation or other services to you?		
	1☐	Yes, definitely	
	2☐	Yes, to some extent	
	3☐	No	
	4☐	I did not want or need this information	→ SKIP TO **Q61.**

Q59.	Were you given enough information and support for arranging a funeral (or other service or ceremony) for your baby?	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not want or need this information

Q60.	If you wanted to, were you facilitated or supported to take your baby home prior to a funeral or cremation service?	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not wish to take my baby home

9. Post-mortem examination and investigations

The following section asks about your experience of care if your baby had a post-mortem examination.

Q61.	Did your baby have a post-mortem examination?		
	1☐	Yes, a consented post-mortem	
	2☐	Yes, a coroners post-mortem	
	3☐	No, I declined a post-mortem examination	→ SKIP TO **Q67.**
	4☐	No, I was not offered a post-mortem examination	→ SKIP TO **Q67.**

Q62.	Were the post-mortem examination process and the timelines for results clearly explained to you?	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No
	4☐	Don't know or can't remember

Q63.	Were you given the opportunity to see and hold your baby after the post-mortem examination?		
	1☐	Yes	
	2☐	No → SKIP TO **Q65.**	
	3☐	I didn't wish to see and hold my baby	→ SKIP TO **Q65.**
	4☐	It wasn't possible to see and hold my baby	→ SKIP TO **Q65.**

Q64.	Did healthcare professionals prepare you to see and hold your baby after the post-mortem examination?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

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?	
1 ☐	I haven't received the results	→ SKIP TO **Q67.**
2 ☐	1 to 3 months	
3 ☐	4 to 6 months	
4 ☐	7 to 11 months	
5 ☐	12 to 18 months	
6 ☐	Longer than 18 months	

Q66.	Were the results and findings of the post-mortem examination given in a clear, sensitive and respectful way?
1 ☐	Yes, definitely
2 ☐	Yes, to some extent
3 ☐	No

10. Discharge care

The following section asks about your experience of care around your preparation for discharge home from the maternity hospital or unit following your pregnancy loss.

Q67.	Before you were discharged from hospital, were you given contact information for hospital support services, counselling, or support organisations outside of the hospital?
1 ☐	Yes
2 ☐	No
3 ☐	Don't know or can't remember

Q68.	Before you were discharged from hospital, were you given information about your physical care and recovery?
1 ☐	Yes, definitely
2 ☐	Yes, to some extent
3 ☐	No
4 ☐	I did not want or need this information
5 ☐	Don't know or can't remember

Q69.	Before you were discharged from hospital, were you given information about what you might experience when grieving?
1 ☐	Yes, definitely
2 ☐	Yes, to some extent
3 ☐	No
4 ☐	I did not want or need this information
5 ☐	Don't know or can't remember

Q70.	Before you were discharged from hospital, were you given information about any changes you might experience with your mental health?
1 ☐	Yes, definitely
2 ☐	Yes, to some extent
3 ☐	No
4 ☐	I did not want or need this information
5 ☐	Don't know or can't remember

Q71.	Before you were discharged from hospital, were you told who to contact if you had any concerns or worries about your physical or mental health?
1 ☐	Yes
2 ☐	No
3 ☐	Don't know or can't remember

Q72.	Before you were discharged from hospital, were you given information and support about the steps involved in registering your baby with the civil registration office?
1 ☐	Yes
2 ☐	No
3 ☐	This was not relevant as I experienced a second trimester miscarriage and could not legally register my baby
4 ☐	Don't know or can't remember

Q73.	Before you were discharged from hospital, were you given enough information about follow-up care plans and appointments?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	Don't know or can't remember

Q74.	Was your discharge from hospital planned and managed in a sensitive way?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

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?

11. Follow-up care

The following section asks about your experience of care at home after your discharge from hospital following the loss of your baby and about your follow-up care with your healthcare provider at the maternity hospital or unit.

Q76.	After your discharge from hospital, who did you see as part of your follow-up care? *(tick all that apply)*		
	1☐	Family doctor (GP)	
	2☐	Public Health Nurse (PHN)	
	3☐	Bereavement midwife or nurse specialist in the hospital	
	4☐	Mental health services	
	5☐	Obstetrician or gynaecologist after discharge	
	6☐	Consultant paediatrician or neonatologist	
	7☐	Other	
	8☐	I had to attend the hospital emergency department because of complications	
	9☐	I had a follow-up appointment at the hospital but I declined to attend	
	10☐	I haven't had any follow-up care since my discharge from hospital	→ SKIP TO **Q83.**

Q77.	After your discharge from hospital, if you contacted a healthcare professional were you given the help you needed?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	I was unable to reach the healthcare professional
	5☐	I didn't contact any healthcare professionals

Q78.	After your discharge from hospital, if you saw your GP or family doctor, were they aware that your baby had died?		
	1☐	Yes	
	2☐	No	
	3☐	I did not need or want to see a GP	→ SKIP TO **Q80.**
	4☐	I did not see a GP but I would have like to	→ SKIP TO **Q80.**
	5☐	Don't know or can't remember	

Q79.	Thinking about the care you received at home after your discharge from hospital, did your GP or family doctor give you enough care and support?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not need any care and support
	5☐	Don't know or can't remember

Q80.	After your discharge from hospital, if you saw your Public Health Nurse, were they aware that your baby had died?		
	1☐	Yes	
	2☐	No	
	3☐	I did not need or want to see a Public Health Nurse	→ SKIP TO **Q82.**
	4☐	I did not see a Public Health Nurse but I would have liked to	→ SKIP TO **Q82.**
	5☐	Don't know or can't remember	

Q81.	Thinking about the care you received at home after your discharge from hospital, did your Public Health Nurse give you enough care and support?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not need or want to see a Public Health Nurse
	5☐	Don't know or can't remember

Q82.	After your discharge from hospital, what support did you access? *(tick all that apply)*	
	1☐	Partner
	2☐	Family
	3☐	Friends
	4☐	Bereavement support organisations/advocacy groups
	5☐	Hospital support services
	6☐	Professional counselling
	7☐	Other
	8☐	I did not access any supports

12. Overall care

The following section asks about your overall experience of care and if there is anything else you would like to tell us about your care since your baby died or that we have not asked about in the survey.

Q83.	Overall, did you have confidence and trust in the staff caring for you?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No

Q84.	Overall, did you feel that you were treated with respect and dignity?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No

Q85.	Were your cultural, spiritual and religious needs respected and facilitated by healthcare professionals?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not have any specific cultural, spiritual or religious needs

Q86. **Were you offered any of the following hospital support services?** *(tick all that apply)*

1☐	Chaplaincy or pastoral care
2☐	Social Work
3☐	Bereavement midwife or nurse specialist
4☐	Perinatal (pregnancy-related) Mental health service
5☐	Perinatal (pregnancy-related) Palliative Care team
6☐	Paediatrician/Neonatologist
7☐	Other
8☐	I wasn't offered any hospital support services
9☐	No hospital support services were available
10☐	Don't know or can't remember

Q87. **Overall, how would you rate the care that you received (0 to 10)?** *(please circle a number)*

I had **very poor** care — I had **excellent** care

0	1	2	3	4	5	6	7	8	9	10

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?**

We appreciate and value the time you have taken to share your thoughts and experiences with us.

If you had a partner or support person with you, the next section will ask them to recall their experience.

Thank you

13. Partner or support person

The following section is to be completed by the partner or support person present with the mother during her experience of pregnancy loss, and asks them to reflect and recall their experience.

The term partner or support person includes the main person that was with the mother and provided support to her during her hospital experience of pregnancy loss. This could be a husband, partner, birth partner, family member or a friend.

Q91.	Did you feel that you were able to be with the person you were supporting as often as you wanted to be while they were being cared for in hospital?	
	1☐	Yes, always
	2☐	Yes, sometimes
	3☐	No
	4☐	I was not able to be with the person I was supporting due to COVID-19 restrictions
	5☐	I was not able to be with the person I was supporting for other reasons
	6☐	The person I was supporting did not want me to be there

Q92.	Did healthcare professionals explain what was happening in a way that you could understand?	
	1☐	Yes, completely
	2☐	Yes, to some extent
	3☐	No
	4☐	Don't know or can't remember

Q93.	Did you feel that you were involved in decisions about your baby's care?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	Don't know or can't remember

Q94.	Did you feel that you were given the opportunity to ask questions?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	I did not have any questions
	5☐	Don't know or can't remember

Q95.	Did you feel that healthcare professionals acknowledged your needs?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No
	4☐	Don't know or can't remember

Q96.	If you wanted to meet your baby, did healthcare professionals do enough to support you to do so?		
	1☐	Yes, definitely	
	2☐	Yes, to some extent	
	3☐	No	
	4☐	I chose not to meet my baby	→ SKIP TO **Q98.**
	5☐	It was not possible for medical reasons for me to meet my baby	→ SKIP TO **Q98.**

Q97.	Did you feel that you could spend as much time as you wanted with your baby?	
	1☐	Yes, definitely
	2☐	Yes, to some extent
	3☐	No

Q98.	If you sought support after the loss of your baby, what support did you access? *(Tick all that apply)*	
	1☐	Partner
	2☐	Family
	3☐	Friends
	4☐	Family doctor or GP
	5☐	Bereavement support organisations/advocacy groups
	6☐	Hospital support services
	7☐	Professional counselling
	8☐	Other
	9☐	I did not access any supports

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

We appreciate and value the time you have taken to share your thoughts and experiences with us.

Thank you.

Once you submit your survey answers, we will not be able to identify or change any of the information you have provided.

For this reason, please ensure that you are satisfied with all of the details you have provided in your answers to the questions asked before returning the survey questionnaire in the free post envelope provided.

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