

# 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](http://www.yourexperience.ie) or email us at [info@yourexperience.ie](mailto:info@yourexperience.ie).

Your answers will remain anonymous and confidential.

Your feedback will not affect your future care in any way.

**Survey Code:**

We're committed to excellence in healthcare



An Roinn Sláinte  
Department of Health

## 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?

- <sup>1</sup> Under 25 years
- <sup>2</sup> 25 to 29 years
- <sup>3</sup> 30 to 34 years
- <sup>4</sup> 35 to 39 years
- <sup>5</sup> 40 years or over

### Q2. What is your ethnic group?

#### White:

- <sup>1</sup> Irish
- <sup>2</sup> Irish Traveller
- <sup>3</sup> Roma
- <sup>4</sup> Any other white background

#### Black or Black Irish:

- <sup>5</sup> African
- <sup>6</sup> Any other black background

#### Asian or Asian Irish:

- <sup>7</sup> Chinese
- <sup>8</sup> Indian/Pakistani/Bangladeshi
- <sup>9</sup> Another Asian background

#### Other, including mixed group/ background:

- <sup>10</sup> Arabian
- <sup>11</sup> Mixed, please specify
- <sup>12</sup> Other, please write your ethnic group here:

### Q3. What type of pregnancy loss did you experience?

- <sup>1</sup> Second trimester miscarriage (a miscarriage that happens when a baby has died between 14 - 24 weeks of pregnancy)
- <sup>2</sup> A stillbirth (baby born after 24 weeks of pregnancy or greater than or equal to 500g, showing no signs of life)
- <sup>3</sup> Early neonatal death (baby born alive but died within first seven days of life)
- <sup>4</sup> Other (please explain):

### Q4. Did you experience the loss of more than one baby?

- <sup>1</sup> No, this was a pregnancy with one baby
- <sup>2</sup> No, this was a twin pregnancy, but one twin died
- <sup>3</sup> Yes, this was a twin pregnancy, both twins died
- <sup>4</sup> 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)**

- January
- February
- March
- April
- May
- June
- July
- August
- September
- October
- November
- December

**(Please write in)**

e.g. 

2	0	2	0
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Y	Y	Y	Y
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**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?**
- <sup>1</sup> During pregnancy, before labour
  - <sup>2</sup> My baby died during labour
  - <sup>3</sup> After delivery in the neonatal period
  - <sup>4</sup> 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)**
- <sup>1</sup> The baby's mother alone
  - <sup>2</sup> The baby's mother and her partner or support person together
  - <sup>3</sup> Partner or support person alone
- SKIP TO **Q91**, STAGE 13. PARTNER OR SUPPORT PERSON

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- 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?**
- <sup>1</sup> Yes
  - <sup>2</sup> 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?**
- <sup>1</sup> Yes, completely
  - <sup>2</sup> Yes, to some extent
  - <sup>3</sup> No
  - <sup>4</sup> Not applicable to my situation

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- Q11. Were you in a suitable private place when you were first told of your baby's diagnosis?**
- <sup>1</sup> Yes
  - <sup>2</sup> No
  - <sup>3</sup> 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?**

- <sup>1</sup> Yes
- <sup>2</sup> No
- <sup>3</sup> I did not want to have someone with me
- <sup>4</sup> I was not able to have someone with me due to COVID-19 restrictions
- <sup>5</sup> I was not able to have someone with me for other reasons
- <sup>6</sup> 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?**

- <sup>1</sup> Yes, completely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q14. Did you have an opportunity to ask questions about your baby's diagnosis?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q16. Were you given written information about your baby's diagnosis?**

- <sup>1</sup> Yes
- <sup>2</sup> No
- <sup>3</sup> 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.)

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes
- <sup>2</sup> No
- <sup>3</sup> 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)

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> 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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> 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)**

- <sup>1</sup> Single room (not shared)
- <sup>2</sup> Shared room
- <sup>3</sup> Labour ward
- <sup>4</sup> Antenatal ward
- <sup>5</sup> Postnatal ward
- <sup>6</sup> General ward
- <sup>7</sup> Emergency ward
- <sup>8</sup> I wasn't admitted overnight → SKIP TO **Q23.**
- <sup>9</sup> Other

**Q22. On your admission to hospital, did you feel your accommodation was sensitive to your needs?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

<sup>4</sup> 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)**

- <sup>1</sup> Yes, by my partner
- <sup>2</sup> Yes, by a support person (such as a family member, friend or doula)
- <sup>3</sup> No, I was alone
- <sup>4</sup> I did not want to have someone with me
- <sup>5</sup> I was not able to have someone with me due to COVID-19 restrictions
- <sup>6</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> It was not possible for me to be involved for medical reasons
- <sup>5</sup> Don't know or can't remember

**Q25. Did you have the opportunity to ask questions about your labour and birth?**

- Yes, definitely
- Yes, to some extent
- No → SKIP TO Q27.
- It was not possible for me to ask questions for medical reasons → SKIP TO Q27.
- 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?**

- Yes, always
- Yes, sometimes
- No
- 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?**

- Yes, definitely
- Yes, to some extent
- No
- I did not need any help
- 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?**

- Yes, always
- Yes, sometimes
- No
- 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?**

- Yes
- No
- Don't know or can't remember
- 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?**

- Yes
- No
- I did not want to have someone with me
- I was not able to have someone with me due to COVID-19 restrictions
- I was not able to have someone with me for other reasons
- 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?**

- Yes, completely

- <sup>2</sup> Yes, to some extent  
<sup>3</sup> No

**Q32. Did healthcare professionals communicate with kindness and**

## 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?**

- <sup>1</sup> Yes, definitely  
<sup>2</sup> Yes, to some extent  
<sup>3</sup> No  
<sup>4</sup> I chose not to see my baby → SKIP TO **Q37.**  
<sup>5</sup> 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?**

- <sup>1</sup> Yes, definitely  
<sup>2</sup> Yes, to some extent  
<sup>3</sup> No

**Q35. Were you given enough privacy when you met your baby?**

- <sup>1</sup> Yes, definitely  
<sup>2</sup> Yes, to some extent  
<sup>3</sup> No

**sensitivity when you were told your baby had died?**

- <sup>1</sup> Yes, definitely  
<sup>2</sup> Yes, to some extent  
<sup>3</sup> No

**Q36. Did you feel that you could spend as much time as you wanted with your baby?**

- <sup>1</sup> Yes, definitely  
<sup>2</sup> Yes, to some extent  
<sup>3</sup> No  
<sup>4</sup> 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)**

- <sup>1</sup> Yes  
<sup>2</sup> 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)**

- <sup>1</sup> Yes  
<sup>2</sup> No → SKIP TO **Q40.**



**Q39. Following your baby's transfer, were you admitted to the same hospital as your baby?**

- <sup>1</sup> Yes
- <sup>2</sup> No, I was discharged home
- <sup>3</sup> 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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q42. While your baby was in the neonatal unit, were you able to visit your baby as much as you wanted to?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> 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)**

- <sup>1</sup> Single room (not shared)
- <sup>2</sup> Bereavement room (a specific family room designed to facilitate bereaved families)
- <sup>3</sup> Shared room
- <sup>4</sup> Labour ward
- <sup>5</sup> Antenatal ward
- <sup>6</sup> Postnatal ward
- <sup>7</sup> General ward
- <sup>8</sup> Emergency ward
- <sup>9</sup> I wasn't admitted overnight
- <sup>10</sup> Other

**Q44. After your baby was born, was your postnatal accommodation sensitive to your needs?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q45. While you were in hospital, were you given enough care and support with your physical recovery after the birth of your baby?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q46. While you were in hospital, were you given information and support with breast care and lactation?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No, but I would have liked this information
- <sup>4</sup> No, but I did not need this information
- <sup>5</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> I did not have any questions

- <sup>5</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No
- <sup>4</sup> I did not need any assistance
- <sup>5</sup> 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:**

- <sup>1</sup> At home
- <sup>2</sup> In the Labour ward → SKIP TO Q54.
- <sup>3</sup> In the Postnatal Ward → SKIP TO Q54.
- <sup>4</sup> In the Neonatal Unit → SKIP TO Q54.

Other (please explain): → SKIP TO Q54.

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?**

- Yes, completely
- Yes, to some extent
- 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)

- Name your baby
- Spend time with your baby
- Hold your baby
- Dress your baby
- Bath your baby
- Take a lock of your baby's hair
- Have photos with your baby

- Have a copy of your baby's hand print or foot print
- Have a naming or blessing ritual or ceremony
- Create a memory box
- Use a Bereavement alert symbol
- I was not offered any of these → SKIP TO Q57.
- 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?**

- Yes, definitely
- Yes, to some extent
- No

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

- Yes, always
- Yes, sometimes
- No
- I did not give my baby a name

**Q57. Were your family or friends offered the opportunity to meet your baby?**

- Yes
- No, but I would have liked them to
- No, I did not want them to
- Family and friends were not able to visit due to COVID-19 restrictions
- 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?**

- Yes, definitely

- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, completely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

## 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?**

- <sup>1</sup> Yes, a consented post-mortem
- <sup>2</sup> Yes, a coroners post-mortem
- <sup>3</sup> No, I declined a post-mortem examination → SKIP TO Q67.
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, completely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> Don't know or can't remember

- <sup>4</sup> 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?**

- <sup>1</sup> Yes, completely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> I did not wish to take my baby home

**Q63. Were you given the opportunity to see and hold your baby after the post-mortem examination?**

- <sup>1</sup> Yes
- <sup>2</sup> No → SKIP TO Q65.
- <sup>3</sup> I didn't wish to see and hold my baby → SKIP TO Q65.
- <sup>4</sup> 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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> 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?**

- <sup>1</sup> I haven't received the results → SKIP TO Q67.
- <sup>2</sup> 1 to 3 months
- <sup>3</sup> 4 to 6 months
- <sup>4</sup> 7 to 11 months

- 5 12 to 18 months
- 6 Longer than 18 months

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**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

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**Q69. Before you were discharged from hospital, were you given information**

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**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

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**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

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**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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No
- <sup>4</sup> Don't know or can't remember

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q74. Was your discharge from hospital planned and managed in a sensitive way?**

**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)**

- <sup>1</sup> Family doctor (GP)

- <sup>2</sup> Public Health Nurse (PHN)
- <sup>3</sup> Bereavement midwife or nurse specialist in the hospital
- <sup>4</sup> Mental health services
- <sup>5</sup> Obstetrician or gynaecologist after discharge
- <sup>6</sup> Consultant paediatrician or neonatologist
- <sup>7</sup> Other
- <sup>8</sup> I had to attend the hospital emergency department because of complications

- I had a follow-up appointment at the hospital but I declined to attend
- 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?**

- Yes, always
- Yes, sometimes
- No
- I was unable to reach the healthcare professional
- 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?**

- Yes
- No
- I did not need or want to see a GP → SKIP TO Q80.
- I did not see a GP but I would have like to → SKIP TO Q80.
- 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?**

- Yes, definitely
- Yes, to some extent

- No
- I did not need any care and support
- 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?**

- Yes
- No
- I did not need or want to see a Public Health Nurse → SKIP TO Q82.
- I did not see a Public Health Nurse but I would have liked to → SKIP TO Q82.
- 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?**

- Yes, definitely
- Yes, to some extent
- No
- I did not need or want to see a Public Health Nurse
- Don't know or can't remember

**Q82. After your discharge from hospital, what support did you access? (tick all that apply)**

- Partner
- Family
- Friends

- <sup>4</sup> Bereavement support organisations/advocacy groups
- <sup>5</sup> Hospital support services
- <sup>6</sup> Professional counselling
- <sup>7</sup> Other
- <sup>8</sup> 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?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No

**Q84. Overall, did you feel that you were treated with respect and dignity?**

- <sup>1</sup> Yes, always
- <sup>2</sup> Yes, sometimes
- <sup>3</sup> No

**Q85. Were your cultural, spiritual and religious needs respected and facilitated by healthcare professionals?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent

- <sup>3</sup> No
- <sup>4</sup> 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)**

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



Empty rectangular box for reflection or notes.

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

Large empty rectangular box for the answer to Q88.

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

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

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**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?**

- Yes, always
- Yes, sometimes
- No

I was not able to be with the person I was supporting due to COVID-19 restrictions

I was not able to be with the person I was supporting for other reasons

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?**

- Yes, completely
- Yes, to some extent
- No
- Don't know or can't remember

**Q93. Did you feel that you were involved in decisions about your baby's care?**

- Yes, definitely
- Yes, to some extent
- No
- Don't know or can't remember

**Q94. Did you feel that you were given the opportunity to ask questions?**

- Yes, definitely
- Yes, to some extent
- No
- I did not have any questions
- Don't know or can't remember

**Q95. Did you feel that healthcare professionals acknowledged your needs?**

- Yes, definitely
- Yes, to some extent
- No
- 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?**

- Yes, definitely
- Yes, to some extent
- No
- I chose not to meet my baby → SKIP TO Q98.
- 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?**

- <sup>1</sup> Yes, definitely
- <sup>2</sup> Yes, to some extent
- <sup>3</sup> No

**Q98. If you sought support after the loss of your baby, what support did you access?**

*(Tick all that apply)*

- <sup>1</sup> Partner
- <sup>2</sup> Family
- <sup>3</sup> Friends
- <sup>4</sup> Family doctor or GP
- <sup>5</sup> Bereavement support organisations/advocacy groups
- <sup>6</sup> Hospital support services
- <sup>7</sup> Professional counselling
- <sup>8</sup> Other
- <sup>9</sup> I did not access any supports

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

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**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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