

National Maternity Bereavement Experience Survey

Information leaflet for all appropriate bereavement healthcare providers in maternity units or hospitals, and community settings as well as advocacy/support organisations and other relevant stakeholder individuals or groups.

Q: What is the National Maternity Bereavement Experience Survey?

A: The National Maternity Bereavement Experience Survey is the first Irish maternity bereavement experience survey which aims to capture the experiences of bereaved parents following a second trimester miscarriage, stillborn infant or the early neonatal death of a baby. The purpose of the survey is to learn about the experiences of bereaved parents in order to improve the safety and quality of Ireland's maternity bereavement services.

Q: Who is running the survey?

A: The National Maternity Bereavement Experience Survey is part of the National Care Experience Programme – a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

Q: How was the survey developed?

A: We take a structured, evidence-based approach to developing our surveys. A programme board, made up of representatives from HIQA, the Department of Health and the HSE, as well as bereaved parents, advocacy groups and appropriate clinical care providers, oversee the development and implementation of the National Maternity Bereavement Experience Survey.

To develop the survey, we carried out a review of how bereavement care services in maternity settings throughout the Republic of Ireland are provided. This included identifying and reviewing policies, pathways, guidelines, strategies, and standards related to bereavement and perinatal loss, as well as the national reports and investigations carried out by the HSE and HIQA. Following this, a desktop review of international maternity bereavement care surveys was undertaken. Interviews were held with international survey and research teams.

To develop and inform the survey questionnaire, we engaged with bereaved parents, healthcare professionals, and representatives of bereavement support organisations, special interest groups, and policy-makers through focus groups,

Delphi study and cognitive interviews. Bereaved parents have been involved in all stages of the survey development.

The survey was granted ethical approval by the Royal College of Physicians in Ireland's ethics board.

Q: Who will be invited to participate in the survey?

A: Parents who experienced a second trimester miscarriage, stillborn infant or the early neonatal death of a baby in any of Ireland's maternity units or hospitals between 1 July 2019 and 30 June 2020, who are over 16 years of age and who have a postal address in the Republic of Ireland will be invited to participate in the National Maternity Bereavement Experience Survey. The programme wanted to capture recent experiences of care, while allowing parents a reasonable time period to grieve, being mindful that receiving and completing the survey would be emotional for parents. This follows international best practice.

Q: How do participants take part in the survey?

A: All eligible survey parents will receive a letter of introduction by post from the HSE on the week commencing 10 January 2022. The introductory letter will include an acknowledgement of the loss experienced, an explanation of the survey and the option to opt out of the survey. An eligible person can request to opt out from further correspondence before 30 January 2022.

The survey is carried out by Behaviour and Attitudes (B&A) an independent managed service. The HSE then transfers the contact details of the survey participants to the managed service.

On 7 February 2022, survey participants will receive a postal pack from the managed service which will include:

- a letter of invitation to take part in the survey
- an information leaflet/FAQs
- a paper copy of the survey questionnaire
- details for online completion of the survey
- contact details to opt out of the survey

The survey can be completed and returned in the included Freepost envelope or the survey can also be completed online.

Reminder letters will be sent out to survey participants on 21 February and 7 March if they have not opted out or completed the survey previously. The closing date for the survey is 31 March 2022.

Why should a survey participant complete the survey?

A: All responses will provide us with important information on maternity bereavement care in Ireland. This will help to identify what works well and what needs to be improved.

Q: What happens if a survey participant does not want to participate in the survey?

A: Participation in the survey is voluntary. While we would like to hear about all eligible survey participants' experiences, it is possible to **opt out** of the survey by:

- declining participation at the initial point of contact or at any point after they receive the survey
- calling our Freephone number on 1800 314093
- logging onto www.yourexperience.ie
- emailing us at info@yourexperience.ie
- returning the survey questionnaire blank in the envelope provided.

Q: What type of questions will be asked in the survey?

A: The survey will ask about parents' experiences of maternity bereavement care during their pregnancy journey. The survey questionnaire is structured according to stages of care. These include:

- communication and information at the time of diagnosis
- care during admission
- labour and birth
- care after birth and meeting your baby
- neonatal care
- postnatal care
- bereavement care
- post-mortem examination and investigations
- discharge care
- follow-up care
- and overall care.

The questionnaire has a specific section that a partner or support person accompanying the mother during her experience of pregnancy loss can complete, as well as a number of free text questions where survey participants can record any additional information.

Q: What happens with survey participant answers?

A: The National Care Experience Programme will use the answers provided to find out what is working well and what needs to be improved in maternity bereavement services. All responses to the survey will be anonymised, combined and then reported on www.yourexperience.ie. The HSE will identify areas of quality improvements across all maternity units and hospitals.

Q: If a parent (survey participant) had a good experience of maternity bereavement care — do they still need to take part?

A: Yes, please. We want to hear about all experiences of maternity bereavement care so that we fully understand the experience within maternity bereavement services in Ireland.

Q: Will survey participant answers be treated confidentially?

A: Yes. Participants' answers will be processed in strict confidence and kept separately from their contact details. The hospitals will see anonymous responses only. Participants' answers will be solely used for analysis to improve services; they will not be shared with commercial entities or used for commercial purposes.

Q: Does the National Maternity Bereavement Experience Survey comply with data protection laws?

A: Yes. The National Maternity Bereavement Experience Survey complies with data protection laws including the General Data Protection Regulation (GDPR) and Data Protection Act 2018. Survey participant contact details will be used for the sole purpose of sending them the survey. Further details can be found at www.yourexperience.ie.

Q: Who can survey participants contact if they need support?

A: A list of bereavement support resources are included in the survey questionnaire pack. Resources for parents who have been bereaved by pregnancy and infant loss are also available at <https://pregnancyandinfantloss.ie/>. However, parents may wish to contact their key support person or the primary support accessed by them previously.

Q: Where can survey participants find out more about the survey?

A: More information is available on the National Maternity Bereavement Experience Survey website www.yourexperience.ie.

When the survey is rolled out in February, survey participants can also ring the Freephone number on 1800 314093, or email info@yourexperience.ie or write to the:

The National Maternity Bereavement Experience Survey
C/o Health Information and Quality Authority
George's Court,
George's Lane,
Dublin 7,
D07 E98Y