National
Maternity
Bereavement
Experience
Survey

Data Protection Impact Assessment 2022

May 2022

1. Introduction

The National Maternity Bereavement Experience Survey is a nationwide survey that aims to explore the care delivered by our health and social care services to women who experience a pregnancy loss in Irish maternity settings.

The survey is carried out by 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. The National Care Experience Programme develop and implement a suite of surveys, which includes the:

- National Inpatient Experience Survey
- National Nursing Home Residents Survey
- National End of Life Survey
- National Maternity Experience Survey
- National Maternity Bereavement Experience Survey.

The National Maternity Bereavement Experience Survey will provide a systematic way to gather information on the care provided by health and social care services to women who experience a pregnancy loss. The survey will include all women who experience:

- a loss in the second trimester (for the purpose of this survey, second trimester miscarriage refers to when a baby has died from 14 to 24 weeks of pregnancy)
- a still birth (a baby born weighing 500 grams or more from 24 weeks of pregnancy or more, showing no signs of life)
- an early neonatal death (a baby born alive that dies within the first seven days of life)

The findings of the survey will inform quality improvements in the HSE and service providers who provide care to bereaved mothers. It will also be used to inform the regulation of service providers and the development of national care standards in HIQA, and the development and direction of national policy and legislation in the Department of Health.

1.1 Why do a Data Protection Impact Assessment?

In advance of each of its survey, the National Care Experience Programme carry out a Data Protection Impact Assessment (DPIA). The aim of a DPIA is to identify risks to the privacy of individuals whose data is being processed and in addition to propose and implement controls to mitigate those risks. The findings of DPIAs carried out by the National Care Experience Programme, inform the development of security and data protection controls for the implementation of surveys.

DPIAs are conducted at very specific and strategic points in time and are repeated in advance of each subsequent iteration of a survey, as per HIQA's *Guidance on Privacy Impact Assessment in health and social care* published in 2017[1]. The guidance recommends that DPIAs should be reviewed at regular intervals to evaluate the adequacy of security and privacy controls, particularly in light of changes in how data may be processed or the amendment or introduction of legislation governing data privacy.

This report presents the findings of the DPIA for the first iteration of the National Maternity Bereavement Experience Survey and will be updated in advance of any subsequent survey, to take account of any changes in data protection legislation, best practice and the National Care Experience Programme's data processing activities.

2. Survey model

2.1. Overview of the National Maternity Bereavement Experience Survey model

It is proposed to ask women aged 16 years or older, who received in-patient bereavement care in one of Ireland's 19 maternity hospitals or units, following a second trimester miscarriage, a stillbirth or early neonatal death of a baby, about their experience of maternity care. This will be achieved through a self-selecting online survey model.

This will be a retrospective survey of a sample population covering a three year period from 1 January 2019 to 31 December 2021. Women must be bereaved a minimum of 6 months to be eligible to participate in the survey, being mindful of the time period of their loss and grief process and in keeping with international best practice.

The survey will be rolled out for an 8 week time period, from 1 September to 31 October 2022.

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[1] Health Information and Quality Authority (2017). Guidance on Privacy Impact Assessment in health and social care. Version 2.0. [online]. Available from: https://www.hiqa.ie/sites/default/files/2017-10/Guidance-on-Privacy-Impact-Assessment-in-health-and-social-care.pdf.

All eligible women, partners or support persons are made aware of the survey through an extensive media campaign and are invited to take part and complete the survey questionnaire.
Steps 1 to 5 provide an overview of how the survey will be implemented.

Step 1: Survey participants go to **www.yourexperience.ie** and complete the survey online.

Step 2: Upon request, the data processor sends surveys to eligible survey participants (in English, Irish, Romania or Polish) via post.

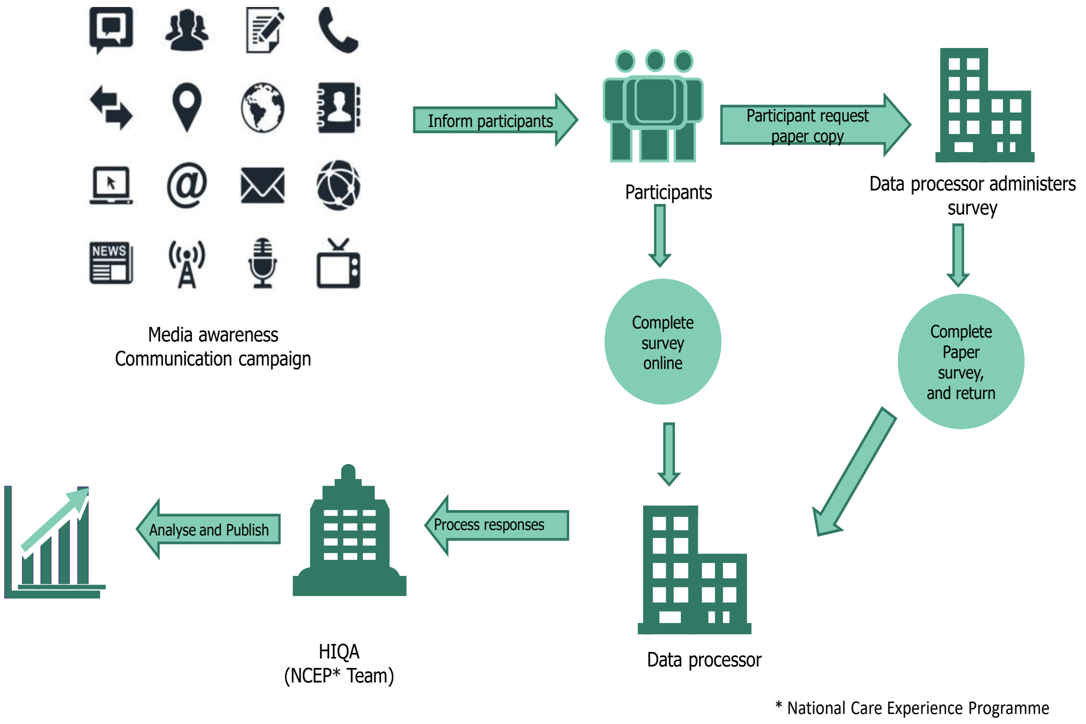
Step 3: The data processor manages the survey responses.

Step 4: The National Care Experience Programme Team analyse the data and report on the findings at www.yourexperience.ie.

Step 5: The contact details of eligible survey participants and hard-copy and online survey responses are destroyed in line with the National Care Experience Programme Data Retention and Destruction Schedule. For more information on the schedule and the National Care Experience Programme's Information Governance Framework, please see www.yourexperience.ie.

Figure 1 depicts the National Maternity Bereavement Experience Survey model.

Figure 1: National Maternity Bereavement Experience Survey model



3. Methodology to conduct the DPIA for the National Maternity Bereavement Experience Survey

Risk assessment process

Key stakeholders were identified and consulted on the possibility of data privacy risks and the controls necessary to put in place to mitigate those risks. This included the data processor, the Project Lead developing the survey, the National Care Experience Programme Team and Director and the National Maternity Surveys Programme Board. The Programme Board contains representatives of women using maternity bereavement services.

Once risks and controls were identified, a risk rating was assigned to each risk on the basis of the matrix in Table 2. This matrix combines the likelihood of harm with the severity of harm. For instance, a risk that is very likely to occur but which only bears negligible consequences to an individual's privacy, would be assigned a rating of 5. Individuals whose data privacy rights were considered were the eligible survey participants (women who experienced a pregnancy loss), staff working in healthcare providers and any other individual whose data may be processed as part of the survey, for example a partner or family member, who may be mentioned by name in a survey participant's response to the survey.

Risks with higher ratings are prioritised during the project implementation phase and are monitored closely by the wider project team.

Table 1: Risk matrix

	Severity of harm				
Likelihood of harm	Negligible 1	Minor 2	Moderate 3	Significant 4	Substantial 5
Rare 1	1	2	3	4	5
Unlikely 2	2	4	6	8	10
Possible 3	3	6	9	12	15
Likely 4	4	8	12	16	20
Almost certain 5	5	10	15	20	25

4. Data protection risk register

This section outlines the data privacy risks that were identified and the controls that were put in place to mitigate those risks.

Risk 1: Responsibilities are undefined or unclear

There is a risk that the responsibilities and boundaries for the role of data processor are not clearly defined or assigned, which may result in non-adherence to processes to manage the privacy and security of eligible survey participants' data.

Controls

The National Care Experience Programme:

- has put a contract in place with the data processor. The contract authorises and defines data processing activities necessary to administer the survey
- has developed an information governance framework, outlining data protection and security specifications agreed with and implemented by the data processor
- provides training on information governance to the data processor

Risk rating: 6 (unlikely/moderate). This represents a low risk.

Risk 2: Data quality and potential data breach

There is a risk that during the survey completion, individuals who do not meet the eligibility criteria complete the survey and are included in the survey data. For example, women who experienced a first trimester miscarriage, who are not eligible to participate in the survey, may complete the survey, in error.

There is a risk that the data processor will mistakenly include the survey responses from ineligible survey participants.

Controls

The National Care Experience Programme:

- ensures that the eligibility criteria of eligible survey participants is clearly defined and displayed on the survey landing page and within the survey questionnaire. Multiple controls will be included in the questionnaire and analysis of responses to remove ineligible responses. Respondents will be

asked to specify the type of loss they experienced, the hospital where they received care, and the month/year they experienced their loss before completing the survey questionnaire
- has a data breach management procedure in place to manage data breaches and other security incidents in line with the General Data Protection Regulation (GDPR) 2016 and the Data Protection Act 2018.

Risk rating: 6 (unlikely/moderate). This represents a low risk.

Risk 3: Retention of personal data

There is a risk that eligible survey participant's data is retained for a period beyond that which is required for the completion of the survey's objectives, which would constitute a data hotspot[2]. This risk is accentuated in situations where personal data is collected in a way or in a system that is new or that could be vulnerable to an unauthorised disclosure, data breach or security infringement.

Controls

The National Care Experience Programme:

- has developed a comprehensive information governance framework, which includes a public-facing Privacy Notice, Statement of Purpose and Statement of Information Practices, to provide transparency around data processing activities. In addition, the framework includes a Security Policy, Data Breach Management Procedure and a Data Retention and Destruction Policy and Schedule. Further information can be found here
- has contractual agreements in place with the data processor to ensure the secure retention and destruction of data, in line with the National Care Experience Programme Retention and Destruction Policy and Schedule. For further information on the National Care Experience Programme's Retention and Destruction Schedule, please see here
- has contractual agreements in place with the data processor to ensure that it can audit sub processes
- supervises the destruction of the data in line with the Retention and Destruction Schedule.

Risk rating: 6 (unlikely/moderate). This represents a low risk.

Risk 4: Transparency

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[2] A data hotspot in the context of the survey refers to data that is retained unknowingly and indefinitely.

There is a risk that eligible bereaved parents may not know about the survey and as a result may not have the opportunity to take part in the survey. The National Care Experience Programme will promote and increase awareness of the survey, through a targated, extensive media campaign which will take place with the support of advocacy organisations, healthcare providers, healthcare professionals, policy makers, and various other stakeholder groups.

Multiple media platforms will be utilised to sensitively provide information on the purpose and aims of the survey, when it is taking place, how and when it will be conducted, the value of completing the survey, and encourage support and participation in the survey.

Controls

The National Care Experience Programme:

- carries out the survey in the public interest, in accordance with Article 6 (1) (e) and 9 (2) (i) of the GDPR and uses the results of the survey to inform quality improvements in maternity bereavement care
- ensures that a robust, extensive media awareness campaign process is in place to inform eligible survey participants about the survey in advance of survey rollout.
- facilitates eligible survey participants in enacting their rights under the GDPR, such as submitting a data subject access request and having their data destroyed, upon request
- has developed material, such as survey information, press releases, posters, and video content to be included in the media campaign.
- ensures that all communication for public dissemination is accessible and adheres to NALA guidelines. This includes cognitively testing the survey tool, to ensure that it is accessible to eligible survey participants
- provides details of its data processing activities and information governance on www.yourexperience.ie
- publishes the results of the survey and corresponding quality improvement plans on www.yourexperience.ie.

Risk rating: 3 (rare/moderate). This represents a low risk.

Risk 5: Participants' self-disclosure of sensitive information

There is a risk that, in answering qualitative, open-ended questions, survey participants voluntarily disclose personal and or sensitive data that is not required or sought by the survey, which may directly or indirectly identify them. For example, a survey participant may provide their name and contact details in their survey response and ask to be contacted.

In addition, there is a risk that survey responses may be combined with complaints received by service providers, which may intentionally or unintentionally lead to the identification of survey participants and or others.

This risk is particularly pertinent in service providers with lower numbers of admissions and discharges.

Controls

The National Care Experience Programme:

- develops anonymisation criteria, which are then applied to qualitative survey responses. The criteria ensure that personal identifiers relating to an eligible survey participant and any other individual are removed and their privacy is protected
- reviews survey responses on the National Care Experience Programme Dashboard[3] before making it available to service providers
- only makes the data available on the National Care Experience Programme Dashboard at an aggregate, national level to prevent the identification of survey participants at a local maternity hospital and unit level.

Risk rating: 5 (almost certain/negligible). This represents a low risk.

Risk 6: Personal, sensitive and or special category data received through the Freephone helpline number and info@yourexperience.ie

There is a risk that staff operating the Freephone helpline and inbox and the staff operating the HSE support helpline may receive and or unnecessarily solicit personal,

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[3] The National Care Experience Programme Dashboard is an online repository of anonymised survey responses. Nominated individuals in the HSE and service providers, the Department of Health and HIQA are granted access to the dashboard. The data is used to inform quality improvements in the HSE and service providers, regulation and standards in HIQA and legislation and policy in the Department of Health.

sensitive and or special category data when dealing with queries from an eligible survey participant and or member of the public.

Controls

The National Care Experience Programme:

- makes a HSE-helpline available for eligible participants if they require psychological support. This should reduce the volume of potentially personal and special category data processed by the survey helpline
- does not record calls it receives in relation to the survey
- deletes all emails received in relation to the survey at the end of the survey cycle. Emails are received on encrypted, password-protected devices
- has developed training and a helpline script for the Freephone number to ensure that no personal information is requested or processed unnecessarily
- does not request personal data from individuals who make contact by phone or email. Operators only take personal data if a specific action is required, for example to send a paper questionniare. Any data collected is stored securely and destroyed within three weeks of the survey closing.

Risk rating: 3 (possible/negligible). This represents a low risk.

5. Next steps

The controls identified in the DPIA will be integrated into the National Maternity Bereavement Experience Survey Project Plan and actioned. This summary will be published on www.yourexperience.ie.

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