



National
Maternity
Bereavement
Experience
Survey

Data Protection Impact Assessment 2021

May 2021



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 (from 13 to 26 weeks of pregnancy)
- a still birth (from 13 to 40 weeks of pregnancy)
- a perinatal loss, that is the death of a baby within the first week of their 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 2017¹. 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

This section provides an overview of the National Maternity Bereavement Experience Survey model.

Step 1: Maternity units and hospitals participating in the survey compile a list of eligible survey participants, that is the woman who experience a pregnancy loss between 1 July 2019 and 30 June 2020. This will include the names and addresses of eligible survey participants, which are used to administer the survey. It will also include details, such as the dates of birth of the mothers, dates of delivery and where relevant the dates of death of the babies. This data is used to apply the eligibility criteria.

Step 2: The HSE quality assure the data, submitted by maternity hospitals and units. A representative of the HSE contacts eligible survey participants to inform them of their inclusion in the survey and to offer them the opportunity to opt out. Following this, the data is then made available to a data processor.

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>.



Step 3: The data processor manages the distribution and receipt of surveys. This involves sending the survey to eligible survey participants via post, opting women out of the survey upon request and managing survey responses.

Step 4: Eligible survey participants receive the survey, upon which time they may decide to ignore, opt out or complete the survey. If they do not opt out, they will receive two further reminder letters about the survey. Eligible survey participants respond to the survey either online or by completing the paper version of the survey and returning it by post.

If eligible survey participants choose to opt out of the survey, they can do so:

- by calling the helpline on 1800 314 093
- by emailing info@yourexperience.ie
- on the website at www.yourexperience.ie
- by returning a blank survey questionnaire in the post.

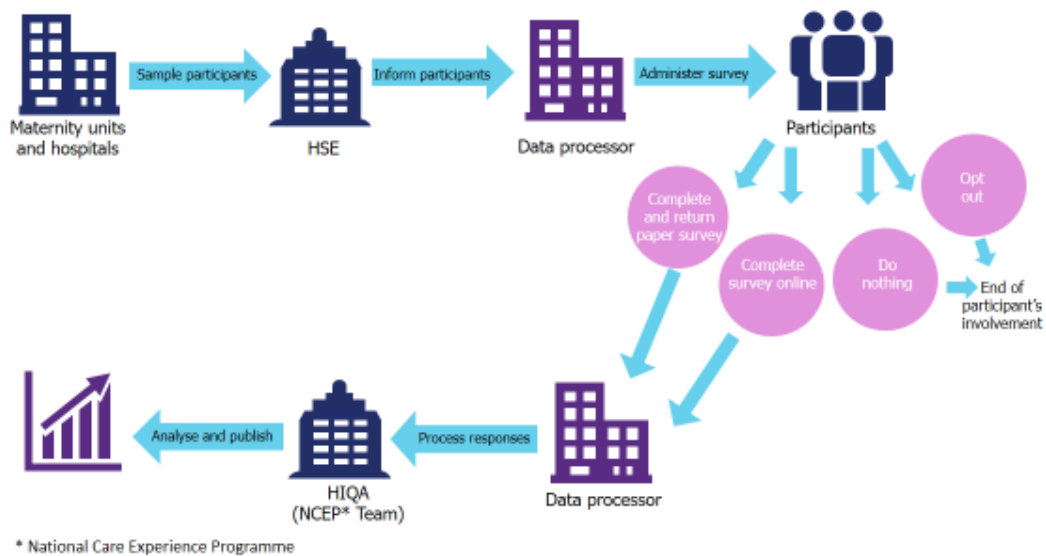
Step 5: The data processor manages the survey responses.

Step 6: The National Care Experience Programme Team analyse the data and report on the findings at www.yourexperience.ie.

Step 7: 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

Likelihood of harm	Severity 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 roles of data controller, data processor, the HSE and maternity hospitals and units are not clearly defined or assigned to the numerous parties involved, 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 put data sharing agreements in place with maternity hospitals and units to ensure the secure transfer of eligible survey participants' data
- 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
- provides training and guidance for the maternity hospitals and units, which outlines all roles and responsibilities in transferring data.

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 data-extraction phase, individuals who do not meet the eligibility criteria are included in the survey sample and their data is transferred from maternity hospitals and units to the data processor. For example, women who experienced a first trimester miscarriage, who are not eligible to participate in the survey, may be included in the dataset, in error.

Upon receipt of this data, there is a risk that the data processor will distribute the survey to ineligible survey participants mistakenly included in the survey sample.

Controls

The National Care Experience Programme:

- provides training and guidance for staff in maternity hospitals and units, who create the contact dataset of eligible survey participants
- arranges for the secure transfer of eligible survey participants' data from the maternity hospitals and units to the data processor. All data transfers will be subject to a data sharing agreement
- ensures that the eligibility criteria of eligible survey participants is verified before sending out the survey. Eligible survey participants will be contacted by telephone by the HSE to inform them about the survey, upon which time they will be asked to confirm their postal address
- 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 hotspot². 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](#)
- arranges for the secure transfer of eligible survey participants' data from the maternity hospitals and units to the data processor

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

- has data sharing agreements in place with maternity hospitals and units providing the data to ensure the secure processing of eligible survey participants' data
- 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 the data controller can audit sub processors
- 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: Re-identification using pseudonymised data

The data used to administer the survey, such as the names and contact details of eligible survey participants, is retained until the last pseudonymised survey responses have been processed — this data is then destroyed within three weeks of the closure of the survey. There is a risk that prior to being destroyed, survey participants' names could be linked with their pseudonymised survey responses.

Controls

The National Care Experience Programme:

- has a contract in place with the data processor, which stipulates data processing measures, including the pseudonymisation of data
- ensures that the contact dataset and survey responses are stored separately and hence pseudonymised
- has an Access Control Policy in place. Access to any data held by the National Care Experience Programme is managed on a role and 'a need-to-know basis' and access rights are reviewed on a regular basis
- ensures the survey responses are anonymised, by assigning anonymisation criteria to data deemed to be personally identifiable
- has developed a retention and destruction policy and schedule, to ensure that the contact dataset that contains the details of eligible survey participants are destroyed within three weeks of the survey closing and the hard copy and original online survey responses are destroyed within two months of the survey closing. After this point, only anonymised survey responses remain,

which removes the possibility of identifying eligible survey participants and any other individuals

- supervises the destruction of the data in line with the schedule.

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

Risk 5: Non-receipt of surveys by intended participants

There is a risk that surveys will be distributed to women who no longer reside at the address provided upon discharge, due to the retrospective nature of the survey and the time elapsed between the delivery of care and the distribution of the survey. This risk is accentuated by the fact that any receipt and or interception of the survey by an unauthorised individual discloses extremely sensitive healthcare information about an individual. In addition, the use of non-branded envelopes, with no return address, sent to survey participants, means that it will not be possible to track or request for the survey to be returned to the data processor.

The National Care Experience Programme:

- has put a process in place to inform eligible survey participants about the survey and confirm their address. A designated staff member in the HSE will make contact with eligible survey participants and while informing them about the survey, will verify their address
- has put a process in place whereby survey participants who do not receive the postal survey due to a change in address or for any other reason, can request another hard copy survey to be delivered to a new address or alternatively request their survey code by email or telephone, which they can use to complete the survey online.

Risk rating: 5 (rare/substantial). This represents a **low** risk.

Risk 6: 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 Dashboard³ 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 7: Transparency

There is a risk that eligible survey participants may not know about the survey and may not want their data processed for the purposes of 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 process is in place to inform eligible survey participants about the survey. Eligible survey participants will be contacted by phone whereby they will be informed about the survey and provided with the opportunity to opt out

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.

- facilitates eligible survey participants to opt out upon receipt of the survey, if they do not wish to participate. This can be done by telephone, email, on www.yourexperience.ie or by returning a blank survey in the post
- 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 an information letter and participant information leaflet to be included with the postal survey invitation
- 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 8: 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 may receive and or unnecessarily solicit personal, 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:

- 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. Operators only take the personal information of people if a specific action is required, however unless callers seek to explicitly opt out of the survey or ask for a new questionnaire or freepost envelope, helpline operators do not request personal data
- only records type of calls received by the helpline and other non-personal, operational data. This data is deleted and shredded at the end of the survey.

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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