Suirbhé Náisiúnta ar an Eispéireas Máithreachais | National Maternity Experience Survey

Data Protection Impact Assessment

Summary 2025

About the National Maternity Experience Survey

The National Maternity Experience Survey offers women the opportunity to share their experiences of maternity care in Ireland. The second National Maternity Experience Survey takes place in 2025. Women who give birth in February or March 2025 will be contacted by SMS and invited to take part in the survey three months after they give birth. The survey covers postnatal, intra-partum and antenatal care. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their babies receive. The results of the survey will be made available on www.yourexperience.ie.

The survey is conducted by the National Care Experience Programme, a partnership between the Health Information and Quality Authority (HIQA) as lead partner, the Health Service Executive (HSE) and the Department of Health.

1. Purpose

This document summarises the findings of a Data Protection Impact Assessment (DPIA), which was carried out to identify and mitigate risks to women who will be invited to take part in the National Maternity Experience Survey 2025.

2. Why is it important to do a DPIA?

When personal and sensitive data is processed, a DPIA must be carried out to identify and mitigate risks to the privacy of data subjects.

To carry out the National Maternity Experience Survey, the National Care Experience Programme will process the data of women who give birth in February or March 2025 in Ireland’s 19 maternity units and at home. To take part in the survey, women must provide a mobile telephone number to receive their SMS survey invitation, and be 16 years of age or over. The data to be processed will include the administrative data of eligible women, such as their name and contact details, as well as their date of birth, the hospital in which they give birth and the date they give birth, to ensure that they meet the eligibility criteria. Administrative data will also be used to compare, with the aim of improving, the experiences of women in Ireland based on characteristics such as age and the sociodemographic conditions of the areas where eligible survey participants live.
In responding to the survey, women will provide detailed health information about their experiences of pregnancy, labour, birth, and aftercare, which constitutes sensitive and therefore special category data. Special category data is extremely sensitive data that requires more protection then regular personal data, such as information about people’s health.

Survey responses will be anonymised to ensure that no individuals can be identified from responses to open-ended questions. Once anonymised, survey responses will be retained for additional analyses, including comparisons with future National Maternity Experience Surveys. The data may be analysed by health service researchers, under agreed conditions.

A DPIA is therefore necessary to ensure that all risks to the privacy of eligible participants are identified and appropriate safeguards are put in place.

3. What is the legal basis for processing National Maternity Experience Survey data?

The National Maternity Experience Survey complies with data protection laws, including the General Data Protection Regulation (GDPR) 2016. Under Article 6(1)(e) of the GDPR[1] and Section 38 of the Data Protection Act 2018[2], personal data can be processed where necessary for the performance of a task carried out in the public interest. Article 9(2)(i) of the GDPR and Section 53 of the Data Protection Act 2018 permit the processing of healthcare data, which is special category data under the GDPR, when processed in the public interest.

The National Maternity Experience Survey is conducted in the public interest. The partner organisations of the National Care Experience Programme have committed to using the results of the survey to inform quality improvements in maternity care, policy, legislation and regulation. The processing of personal data is necessary to carry out a survey on the experience of women using maternity services.

4. Overview of the National Maternity Experience Survey - data flow

This section provides an overview of the data flow of the National Maternity Experience Survey.

Step one:	Healthcare providers (19 maternity units and the National Home Births Service) provide women with an information leaflet in antenatal and maternity settings, to inform them that they will be invited to participate in a survey. Women can opt out of the survey at this stage.
Step two:	Healthcare providers identify eligible participants. They transfer this data to the HSE, who quality assure the data and provide it to the National Care Experience Programme.

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[1] European Union, *General Data Protection Regulation (GDPR) [Internet]*. 2016. Available at: https://gdpr-info.eu/art-6-gdpr/

[2] Government of Ireland, *Data Protection Act 2018 [Internet]*. 2018. Available at: http://www.irishstatutebook.ie/eli/2018/act/7/enacted/en/html

Step three:	The National Care Experience Programme oversees the distribution of the survey, through its data processor Ipsos, to eligible participants and enables people to opt out of the survey, where requested.
Step four:	Eligible participants receive an SMS invitation to participate in the survey, with a link to complete the survey online. They receive two further communications by SMS about the survey at two-week intervals.
Step five:	Survey responses are returned by participants to the National Care Experience Programme for processing.
Step six:	Survey responses are uploaded to a secure digital dashboard, where they are anonymised, cleaned, quality assured, analysed and reported on.
Step seven:	The administrative data, for example the contact details of eligible participants, is destroyed within six weeks of the survey closing and the hard-copy survey responses are destroyed within two months of the survey closing, in line with the National Care Experience Programme's Data Retention and Destruction Schedule (please see here). By this stage, the survey responses have been fully anonymised, meaning that the responses cannot be linked back to the person who completed the survey.

5. Methodology to conduct the DPIA

The DPIA was conducted as per the stages outlined in the Privacy Impact Assessment toolkit for health and social care (Please see here)[3], developed by HIQA. The stages were as follows:

Stage one:	A threshold assessment was conducted and it was determined that a DPIA was necessary.
Stage two:	The necessity and proportionality of the processing activities were assessed, with regard to their potential impact on the privacy rights of individuals and the right to have their personal data protected. Privacy risks and solutions were identified, in consultation with key stakeholders.
Stage three:	Privacy risks were addressed and appropriate controls were put in place.
Stage four:	A DPIA report was produced, approved and finalised.
Stage five:	The findings of the DPIA were incorporated into processes and procedures.

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[3] Health Information and Quality Authority, *Privacy Impact Assessment toolkit for health and social care Health Information and Quality Authority*. 2016. Available at: https://www.hiqa.ie/sites/default/files/2017-10/Privacy-Impact-Assessment-toolkit-A5.pdf.

6. Overview of risks

The DPIA identified eight risks. The safeguards put in place to mitigate the risks are also summarised in this section. Each risk is assigned a risk rating on the basis of the matrix in Table 1.
This matrix combines the impact of a risk, based on a scale of 1 to 5, with the likelihood of its occurrence, also based on a scale of 1 to 5. For instance, a risk that is almost certain to occur but bears negligible consequences to a data subject's privacy, would be assigned a rating of 5.

Table 1: Risk matrix

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

Low (1-7) **Medium (8-14)** **High (15-25)**

6.1 Summary of risks

Risk 1: Responsibilities are undefined or unclear

There is a risk that the roles and responsibilities for the roles of data controller, data processor and healthcare providers participating in the survey are not clearly defined or assigned to the parties involved. This may result in non-adherence to processes developed to manage the privacy and security of eligible participants' data.

Controls

The data controller has:

- put a contract in place with the data processor(s), which authorises and defines data processing activities necessary to administer the survey. The contract ensures that the data processors equally put agreements in place with any sub-processors
- put a data sharing agreement in place with healthcare providers to ensure the secure transfer of eligible participants' data
- developed an information governance framework
- provided training and a process guide for staff involved in processing data to implement the National Maternity Experience Survey.

Risk-rating: 6 (unlikely/moderate) – this represents a low risk.

Risk 2: Data integrity

There is a risk that the confidentiality, integrity, or availability of personal, sensitive or special category data is jeopardised. This may entail intentional breach and use of data subjects' information for nefarious, fraudulent and unintended purposes.

Controls

The National Care Experience Programme:

- approves the processing of all data
- oversees the secure processing of all survey data, to include transfer, storage, use and destruction, in compliance with the GDPR
- oversees the provision of guidance and training for all staff processing survey data.

Risk-rating: 6 (unlikely/moderate) – this represents a low risk.

Risk 3: Data quality and data breach

There is a risk that ineligible participants may be included in the survey or alternatively eligible participants will not be included in the survey, representing a data breach and misuse of data respectively.

This risk is particularly pertinent, as the collection of eligible participants' data may involve the processing of data from different information systems, as data such as the date women give birth is not normally captured in administrative data.

Consequently, eligible participants may be excluded or conversely, ineligible participants may be included in the survey.

Controls

The National Care Experience Programme:

- oversees the provision of guidance and training for staff responsible for data transfer
- tests the extraction and transfer of data in advance of the survey
- oversees a quality assurance process of the data, to ensure that the eligibility criteria have been applied
- has developed a process to suppress survey responses completed by ineligible participants in the event that they receive and complete the survey.

Risk rating: 6 (possible/minor). This represents a low risk.

Risk 4: Participants' self-disclosure of sensitive information

There is a risk that, in answering qualitative, open-ended questions in the survey, participants voluntarily disclose personal or sensitive information not required or sought by the survey, which may directly or indirectly identify them to healthcare staff. There is also a risk that service providers may be able to identify participants through their qualitative survey responses, if information disclosed by participants pertains to a specific complaint they raised with the service provider.

Controls

The National Care Experience Programme:

- has developed anonymisation criteria for qualitative survey responses to remove data that personally identifies individuals
- has put a process in place to review and risk-rate all qualitative survey responses before making them available to healthcare providers
- will only give healthcare providers access to the data when they have a minimum of five responses from participants.

Risk-rating: 4 (likely/negligible) – this represents a low risk.

Risk 5: Re-identification using pseudonymised data

Administrative data (personal information collected to administer the survey, including the contact details of women) is retained until the last pseudonymised survey responses have been processed — approximately six weeks after the survey closes. There is a risk that participants' contact details could be linked with their pseudonymised survey responses.

Controls
The National Care Experience Programme:

- has developed a data retention and destruction policy and schedule (please see here) to ensure secure and timely destruction of all personal data, and supervises and records data destruction practices
- ensures that all personal data is stored in password-protected, encrypted environments. All access to data is role-based and access rights are reviewed regularly
- stores administrative data separately to survey responses
- ensures that the contact dataset and survey responses are pseudonymised and stored securely and separately
- ensures the survey responses are anonymised, by assigning anonymisation criteria to information that may identify survey participants
- has formalised roles and responsibilities for all parties processing survey data, such as data processors and healthcare providers, through contracts and data sharing agreements.

Risk-rating: 4 (unlikely/minor) – this represents a low risk.

Risk 6: Personal, sensitive and special category data received by the helpdesk

There is a risk that staff operating the Freephone helpline and email inbox may unnecessarily request personal or sensitive data when dealing with queries from the public.

Controls
The National Care Experience Programme:

- does not record calls
- receives emails on secure, encrypted, password-protected devices and deletes them when the survey closes
- does not request personal data from individuals who make contact by phone or email
- has developed training and a process guide for helpline operators to ensure that they do not unnecessarily solicit personal data. Operators only take personal data if a specific action is required, for example to opt an eligible participant out of the survey. Training includes a testing period to ensure that operators use the processes as outlined in the process guide.

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

Risk 7: Unauthorised disclosure of a participant's hospital stay

There is a risk that surveys issued to eligible participants (via SMS) may be accessed by unauthorised individuals, disclosing the fact that the intended recipient was recently discharged from maternity care. For example, this may happen where the telephone number provided is not for the eligible participant but for another individual, such as a partner, friend or family member.

There is an associated risk that the privacy rights of a vulnerable individual, namely the new-born infant, may be impacted through their mother's inclusion and participation in the survey.

Controls

The National Care Experience Programme:

- arranges for the distribution of all communication by SMS. Eligible participants will be informed about the survey distribution method and will be asked to confirm their telephone number while in hospital
- does not send out invitations where it is known that the telephone number belongs to another individual
- ensures that telephone numbers are processed securely, in compliance with the GDPR
- ensures that the rights of the new-born infant are considered, when determining the data to be processed as part of the survey, such as the questions asked in the questionnaire, to limit any potential impact on the new-born infant.

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

Risk 8: Transparency

There is a risk that eligible participants may not be fully aware that their data will be shared, processed and potentially used to invite them to take part in the survey and for analysis.

Controls

To ensure that eligible participants are informed about the survey, the National Care Experience Programme:

- implements national and local media campaigns during the survey cycle
- provides eligible participants with information leaflets at key points of interaction with healthcare providers, informing them that they will be invited to take the survey
- arranges for the display of posters, banners and digital signage in antenatal and maternity settings
- ensures that communication with the public is accessible
- provides details of its data processing activities on www.yourexperience.ie
- anonymises all survey responses before any secondary analysis of responses is conducted.

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

7. Next steps

This document reflects the feedback from all stakeholders in relation to identified risks for the National Maternity Experience Survey 2025 and will be published on www.yourexperience.ie.

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an Eispéireas
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National
Maternity
Experience
Survey

Health
Information
and Quality
Authority
An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health