

Data Protection Impact Assessment:  
Summary Report  
(January 2020)

## 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 first National Maternity Experience Survey takes place in early 2020. Women who gave birth in October and November 2019 will be contacted by post and invited to take part in the survey, which 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](http://www.yourexperience.ie) in summer 2020.

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 2020.

### 2. Why is it important to do a DPIA?

When personal, sensitive and special category 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 October and November 2019 in Ireland's 19 maternity units and at home. To take part in the survey, women must be 16 years of age or over and have a postal address in the Republic of Ireland. The data that is being processed will include the administrative data of women, such as their name and contact details, to enable postal contact with eligible women; and their date of birth, the hospital in which they gave birth and the date of delivery, to ensure that they meet the eligibility criteria. In responding to the survey, women will provide detailed information about their experiences of pregnancy, labour, birth, and aftercare, which constitutes personal and potentially special-category data.

A DPIA is therefore necessary to ensure that all risks to the privacy of eligible survey 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<sup>1</sup> and Section 38 of the Data Protection Act 2018<sup>2</sup>, 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 letter and a frequently asked questions (FAQ) flyer upon discharge, 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 survey participants during October in the larger maternity units, and October and November in the smaller units and the National Home Births Service. They transfer this data to the National Care Experience Programme.

**Step three:** the National Care Experience Programme oversees the distribution of the survey to eligible survey participants and where requested, opts people out of the survey.

**Step four:** eligible survey participants receive a postal invitation to participate in the survey, with a link to complete the survey online. They receive two further communications about the survey at two-week intervals, a paper copy of the survey, and a final reminder.

**Step five:** survey responses are returned by participants to the National Care Experience Programme for processing.

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<sup>1</sup> General Data Protection Regulation (GDPR) [Internet]. 2016. Available at: <https://gdpr-info.eu/art-6-gdpr/>

<sup>2</sup> Data Protection Act 2018 [Internet]. 2018. Available at: <http://www.irishstatutebook.ie/eli/2018/act/7/enacted/en/html>

**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 [Data Retention and Destruction Schedule](#). 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](#), developed by HIQA. The stages were as follows:

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|---------------------|---|
| <b>Stage one:</b>   | A threshold assessment was conducted and it was determined that a DPIA was necessary.   |
| <b>Stage two:</b>   | 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. |
| <b>Stage three:</b> | Privacy risks were addressed and appropriate controls were put in place.  |
| <b>Stage four:</b>  | A DPIA report was produced, approved and finalised.   |
| <b>Stage five:</b>  | The findings of the DPIA were incorporated into processes and procedures.   |

## 6. Overview of risks

The DPIA identified 13 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 2 on page 6. 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 only bears negligible consequences to a data subject's privacy would be assigned a rating of 5.

Table 1: Risk matrix

Impact ↓	Likelihood →				
	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
<div>Low (1-7)</div> <div>Medium (8-14)</div> <div>High (15-25)</div>					

## 6.1 Summary of risks

### Risk 1: 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 last women have been sampled. 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](#) 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. Hard-copy data, for example hard-copy survey responses, is stored in a locked room. All access to the data is managed on a role basis and access rights are reviewed regularly
- stores administrative data separately to survey response data
- has formalised roles and responsibilities for all parties processing survey data, such as data processors and healthcare providers, through data processing and data sharing agreements.

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

## Risk 2: 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 survey participants through their qualitative survey responses, if information disclosed by survey 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 30 responses from survey participants
- extended the survey sample period from one to two months in smaller maternity units and the National Home Births Service to ensure a larger sample size and therefore minimise the risk of participants being identified in their responses.

**Risk-rating:** 5 (rare/negligible) – this represents a **low** risk.

## Risk 3: Retention of personal data

There is a risk that participants' data is retained for a period beyond that which is required for the completion of the survey's objectives. This risk is greater in situations where:

- data is collected and stored manually
- personal data is collected in a way or in a system that is new and potentially 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 data retention and destruction policy and a data retention and destruction schedule, which covers data processed for the National Maternity Experience Survey
- put data sharing and or processing agreements in place with all parties processing data
- provided training and a process guide for staff involved in processing data for the National Maternity Experience Survey.

**Risk rating:** 8 (unlikely/substantial) – this represents a **medium** risk.

#### **Risk 4: Responsibilities are undefined or unclear**

There is a risk that the responsibilities and boundaries 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 participants' data.

##### **Controls**

The data controller has:

- put a contract, non-disclosure agreement and a data processing agreement in place with the data processor(s), which authorise and define data-processing activities necessary to administer the survey. The contract ensures that the data processors equally put agreements in place with any sub-processors
- agreed to a data sharing agreement with healthcare providers to ensure the secure transfer of eligible survey 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:** 8 (unlikely/significant) – this represents a **medium** risk.

#### **Risk 5: Transparency**

There is a risk that eligible survey participants may not be fully aware that their data will be shared, processed and potentially used for secondary analysis.

##### **Controls**

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

- implements national and local media campaigns during survey sample and distribution periods
- has developed material, such as an information letter and an FAQ, to be given to eligible survey participants at key points of interaction with healthcare providers
- ensures that communication with the public is accessible
- provides details of its data-processing activities on [www.yourexperience.ie](http://www.yourexperience.ie)
- anonymises all survey responses before any secondary analysis of responses is conducted.

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

### **Risk 6: Personal information solicited by helpdesk**

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

#### **Controls**

The National Care Experience Programme:

- does not record calls
- does not request personal data from individuals who make contact by phone or email
- receives emails on secure, encrypted, password-protected devices and deletes them when the survey closes
- 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: Right to object to processing**

There is a risk that the survey opt-out process on discharge from hospital does not facilitate an eligible survey participant to object to their personal data being processed. In addition, eligible survey participants may not be fully aware that their personal data will be processed for the purposes of the survey.

#### **Controls**

The National Care Experience Programme:

- has developed a process to allow women to opt out of the survey while they are still in the maternity unit or in the care of the National Home Births Service, that is, before their data has been processed
- has included the in-hospital opt-out process in the process guide and training for healthcare staff
- provides four additional opt-out methods: by phone, by email, via the website or by returning the survey in the Freepost envelope.

**Risk-rating:** 1 (rare/negligible) – this represents a **low** risk.



### **Risk 8: Data breach during data extraction**

There is a risk that women who do not meet the eligibility criteria are included in the survey sample and their data is therefore processed. There is a further risk that, upon receipt of the survey, women who are not eligible to participate may complete and return a survey questionnaire.

#### **Controls**

The National Care Experience Programme:

- has provided a process guide and training for staff responsible for data transfer
- has tested the extraction and transfer of data in advance of the survey
- oversees a quality assurance process of the data
- oversees the retention of a list of ineligible survey participants and women who have opted out with their healthcare providers to quality assure the list of potentially eligible survey participants.
- has developed a process to suppress survey responses completed by ineligible survey participants in the event that they receive and complete the survey.

**Risk rating:** 12 (possible/significant). This represents a **medium** risk.

### **Risk 9: Collection of data from different systems**

There is a risk that the collection of data from two different information systems may result in a data breach. This risk concerns the date of delivery, which informs the main eligibility criteria and which is not collected in the same information system as the administrative data of women. Consequently, eligible survey participants may be excluded or, conversely, ineligible survey participants may be included in the survey, which would constitute a data breach.

#### **Controls**

The National Care Experience Programme has:

- provided training and a process guide for healthcare staff involved in transferring data
- tested the data extraction and transfer process in advance of any data transfer.

**Risk-rating:** 4 (unlikely/minor). This presents a **low** risk.

### **Risk 10: Unauthorised disclosure of a participant's recent hospital visit**

There is a risk that surveys issued to participants (via post) may be accessed by unauthorised individuals, disclosing the fact that the intended recipient was recently discharged from maternity care. This may be due to the survey being issued to an incorrect or previous address.

#### **Controls**

The National Care Experience Programme:

- sends all communication by post, which is governed by the Communications Regulation (Postal Services) Act 2011, whereby it is illegal to open, interfere with, use or disclose another individual's post
- sends all post to eligible survey participants in discrete, white, non-branded envelopes to deflect interest of third party individuals.

Risk-rating: 1 (rare/negligible). This represents a **low** risk.

### **Risk 11: Temporary addresses**

There is a risk that surveys will be sent to women who no longer reside at the address provided upon discharge. The non-branded envelopes will not be possible to track or return and eligible survey participants' personal information (for example their name, given address and their status as a new mother) will be lost within the postal system.

#### **Controls**

The National Care Experience Programme:

- has developed process guides for hospitals participating in the National Maternity Experience Survey to ensure that the correct data is extracted and transferred
- conducts an extensive communications campaign to encourage woman to participate. The campaign covers the survey sample and survey distribution periods and targets key interactions and points of care in the antenatal, intra partum and postnatal period
- facilitates requests from eligible survey participants who do not receive the postal survey, for an additional hard-copy postal survey, or provides them with their survey code by email or telephone, which they can use to complete the survey online.

Risk-rating: 6 (possible/minor) – this represents a **low** risk

## Risk 12: Translation of surveys

There is a risk that participants who opt for a translated version of the survey may be identified in their response by a translator from within their linguistic community, and additionally by any acknowledgement of their language or their use of a translation service in the reporting process.

### Controls

The National Care Experience Programme:

- has put non-disclosure agreements in place with staff who translate survey responses to ensure that all data is handled in the strictest confidence
- does not disclose that a survey was translated
- anonymises the language of origin of participants, as language is a potential identifier.

**Risk-rating:** 1 (rare/negligible). This represents a **low** risk.

## Risk 13: Indirect impact on vulnerable individual

There is a 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:

- processes the data of the mother only. No information on the infant is directly sought
- arranges for communication with eligible survey participants in non-branded envelopes, thereby not disclosing the possible location of, or any other information on, a potentially vulnerable individual, for example the infant
- restricts access to eligible survey participants' data and survey response data
- oversees the destruction of eligible participants' data six weeks after the closure of the survey, thereby removing the possibility of identifying the mother and or infant.

**Risk-rating:** 4 (rare/substantial). 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 2020 and will be published on [www.yourexperience.ie](http://www.yourexperience.ie).

