



Data Protection Impact Assessment:  
Summary Report

March 2023



## 1. Introduction

The National End of Life Survey aims to understand the experience of our health and social care services for people approaching the end of their life and their relatives.

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 develops and implements a suite of surveys, which includes the:

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

The National End of Life Survey will provide a systematic way of gathering information on end-of-life care provided by health and social care providers, which will be used to inform quality improvements in care.

The survey will inform quality improvements within service provision in the HSE, national standards and regulation in HIQA, and national policy and legislation in the Department of Health. There is no standardised national approach in Ireland for capturing the experience of end-of-life care from the perspective of bereaved relatives.

### 1.1. Why do a Data Protection Impact Assessment?

In advance of each of its surveys, the National Care Experience Programme carries out a Data Protection Impact Assessment (DPIA). The aim of a DPIA is to identify risks to the privacy of individuals whose data are 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<sup>1</sup>.

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<sup>1</sup> 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/reports-and-publications/health-information/guidance-privacy-impact-assessment-pia-health-and>.



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 protection.

This report presents the findings of the DPIA for the first iteration of the National End of Life 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 End of Life Survey model

This section provides an overview of the National End of Life Survey model.

HIQA requires data from the General Register Office (GRO) in order to administer the National End of Life Survey. The GRO is the central repository for records relating to births, stillbirths, adoptions, marriages, civil partnerships and deaths in Ireland. The data required relate to eligible participants, which includes individuals who register the death of a family member or friend that occurred between 1 September and 31 December 2022, officially referred to as "qualified informants". The data will also contain minimal information on deceased individuals. (a full list of categories of qualified informants can be found [here](#)).

**Step 1:** Posters and FAQs will be displayed in Civil Registration Offices between 1 September 2022 and 31 March 2023<sup>2</sup>, to sensitively inform eligible participants about the survey, when registering a death.

**Step 2:** The GRO will identify eligible participants (qualified informants) and transfer their contact data to HIQA, the data controller.

**Step 3:** HIQA is responsible for cleaning the contact dataset, to ensure that the data are accurate and complete. It then transfers the contact dataset to the data processor.

**Step 4:** The data processor distributes the survey to the eligible participants.

**Step 5:** Eligible participants receive the survey within three to six months of the death of their relative/friend. They may complete the survey themselves or, in the event that the eligible participant is not a bereaved family member or friend, they may pass it to

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<sup>2</sup> The survey sample period is 1 September to 31 December 2022. As qualified informants have up to three months to register a death, information will be made available in Civil Registration Offices until 31 March 2023.



the most relevant person. They may respond to the survey either online or by completing the hard copy questionnaire and returning it by post.

If eligible participants do not want to participate in the survey, they can opt out:

- by calling the Freephone helpline on 1800 314 093
- by emailing [info@yourexperience.ie](mailto:info@yourexperience.ie)
- by visiting the National Care Experience Programme's website: [www.yourexperience.ie](http://www.yourexperience.ie)
- by returning a blank survey questionnaire in the post.

**Step 6:** The data processor manages the survey responses and any opt outs.

**Step 7:** The National Care Experience Programme Team in HIQA analyse the data and report on the findings at [www.yourexperience.ie](http://www.yourexperience.ie).

**Step 8:** In line with the National Care Experience Programme Data Retention and Destruction Schedule, the contact details of eligible participants and the information on deceased individuals are destroyed within six weeks of the survey closing. The original, ineligible anonymised survey responses are destroyed within two months of the survey closing. For more information on the schedule and the National Care Experience Programme's Information Governance Framework, please see [www.yourexperience.ie](http://www.yourexperience.ie).

### 3. Methodology to conduct the DPIA for the National End of Life 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, HIQA’s Data Protection Officer, the National Care Experience Programme Team and Director and the National End of Life Survey Programme Board. The Programme Board contains representatives for end-of-life care.

Once risks and controls were identified, a risk rating was assigned to each risk on the basis of the matrix in Table 1. 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 participant (the person that registers the death, the majority of whom are bereaved relatives), 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 |            |               |                  |                  |
|--------------------|---------------------|------------------|------------|---------------|------------------|------------------|
|                    |                     | Negligible<br>1  | Minor<br>2 | Moderate<br>3 | Significant<br>4 | Substantial<br>5 |
| Likelihood of harm | 1<br>Rare           | 1                | 2          | 3             | 4                | 5                |
|                    | 2<br>Unlikely       | 2                | 4          | 6             | 8                | 10               |
|                    | 3<br>Possible       | 3                | 6          | 9             | 12               | 15               |
|                    | 4<br>Likely         | 4                | 8          | 12            | 16               | 20               |
|                    | 5<br>Almost certain | 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: Data quality and potential data breach**

There is a risk that the eligibility criteria are not applied correctly and that ineligible survey participants subsequently receive, complete and return a survey questionnaire, which would represent a data breach.

##### Controls:

The National Care Experience Programme

- provides the GRO with required data fields to apply the eligibility criteria and ensure that unnecessary data are not included in the contact dataset
- arranges for the secure transfer of the data
- cleans the contact dataset
- has developed a process to suppress survey responses completed by ineligible participants in the event that they receive, complete and return the survey
- has a data breach management procedure in place.

Risk rating: 9 (possible/moderate). This represents a **medium** risk.

##### **Risk 2: Retention of personal data**

There is a risk that a survey participant's data are retained for a period beyond that which is required for the completion of the survey's objectives. This risk is accentuated in situations where personal data are 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, or where creation of a dataset requires the involvement of different roles and departments.



#### 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, as per the National Care Experience Programme Retention and Destruction Policy and Schedule
- has a data sharing agreement in place with the GRO, which underwent a public consultation through the Office of the Government Chief Information Officer, in compliance with the Data Sharing and Governance Act 2019
- arranges for the secure transfer of eligible participant data from the GRO to the data processor.

**Risk rating:** 8 (unlikely/significant). This represents a **medium** risk.

### **Risk 3: Responsibilities are undefined or unclear**

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

#### Controls:

The National Care Experience Programme:

- has put in place a contract with the data processor, which authorises and defines data-processing activities necessary to administer the survey
- has put in place a data sharing agreement with the GRO to ensure the secure transfer of eligible participants' data
- has developed an information governance framework, outlining data protection and security specifications agreed with and implemented by the data processor
- has provided training on information governance to the data processor.

**Risk rating:** 4 (negligible/significant). This represents a **low** risk.

#### **Risk 4: Re-identification using pseudonymised data**

Administrative data (personal information collected to administer the survey, including the contact details of eligible participants and deceased people) is retained until the last pseudonymised survey responses have been processed — within six weeks of the closure of the survey. There is a risk that eligible participants' contact details 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 contact datasets and survey responses are stored separately and hence pseudonymised
- ensures that survey responses are anonymised, by assigning anonymisation criteria
- ensures that all personal data are stored in password-protected, encrypted environments. All access to the data are managed on a role basis and access rights are reviewed regularly
- 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. For more information, please see [here](#).

**Risk rating:** 9 (possible/moderate). This represents a **medium** risk.

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

There is a risk that eligible participants will not know that they are being included in the survey and may want to opt out of the survey before their data are processed.

##### **Controls:**

The National Care Experience Programme:

- has put a process in place to ensure that eligible participants are sensitively informed about the survey, when registering the death
- facilitates eligible participants in opting out of the survey, if they do not wish to participate
- implements a national media campaign, to ensure that eligible participants are duly informed about the survey



- facilitates eligible participants in enacting their rights under the GDPR, such as submitting a data subject access request and having their data destroyed
- 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, including cognitively testing the survey tool
- provides details of its data-processing activities and information governance on [www.yourexperience.ie](http://www.yourexperience.ie)
- publishes the results of the survey and corresponding quality improvement plans on [www.yourexperience.ie](http://www.yourexperience.ie).

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

### **Risk 6: Participants' self-disclosure of sensitive information**

There is a risk that, in answering qualitative, open-ended questions, eligible participants voluntarily disclose personal and or sensitive data which is not required or sought by the survey, which may directly or indirectly identify them. For example, an eligible 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 response data 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:

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

**Risk rating:** 5 (Almost certain/Negligible). This represents a **low** risk.

**Risk 7: Personal, sensitive and or special category data received through the Freephone helpline number and [info@yourexperience.ie](mailto: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 participant or member of 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. Operators only take personal data if a specific action is required, for example to opt an eligible participant out of the survey
- Any data collected is stored securely and destroyed within six weeks of the survey closing
- 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. 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.

## **5. Next steps**

The controls identified in the DPIA will be integrated into the End of Life Survey project plan and actioned. This summary will be published on [www.yourexperience.ie](http://www.yourexperience.ie).

