Suirbhé Náisiúnta ar Eispéireas Cúraim Ailse | National Cancer Care Experience Survey

# Data Protection Impact Assessment

## Summary 2026

## The National Cancer Care Experience Survey

The National Cancer Care Experience Survey (NCCES) is a nationwide survey of people aged 16 years or older who received cancer care in one of Ireland's 25 public hospitals that deliver cancer services.

People aged 16 years and older who received cancer care as an inpatient or day case, during October, November and December 2026, will be invited by text message (SMS) and postal invitation to take part in the survey.

The survey covers all areas of cancer care, from receiving a diagnosis and treatment to living with and beyond cancer. The aim of the survey is to learn from the experiences of people to improve the safety and quality of the care that they receive. The results of the survey will be made available on www.yourexperience.ie.

The survey is carried out by the National Care Experience Programme (NCEP), a shared initiative between the Health Information and Quality Authority (HIQA) as lead partner, the Health Service Executive (HSE), the Mental Health Commission (MHC) and the Department of Health, supported by the National Cancer Control Programme (NCCP).

The findings of the survey will inform quality improvements, policy, legislation, regulation and standards. The results of the survey will be made available on www.yourexperience.ie.

## 1. Purpose of this document

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

## 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.

## 3. What personal data is collected and how will it be used?

To carry out the National Cancer Care Experience Survey, the National Care Experience Programme will process the data of people (aged 16 years and older) who received cancer care during October, November and December 2026, in Ireland's 25 public hospitals that deliver cancer services.

The data that is being processed will include the administrative data of eligible participants ( such as their name and contact details) to enable text message (SMS) and postal contact, their

date of birth, the hospital in which they had their care, their date of discharge and their length of stay to ensure they meet the eligibility criteria. The data processed will also include the person's diagnosis and procedure received during the sampling period, to ensure they are correctly identified to receive the survey invitation. In responding to the survey, participants will provide detailed information about their experiences of cancer care, which constitutes personal and special-category data.

Survey responses will be anonymised by applying a code to each survey response. Six weeks after the survey closes, the datasets of the names and contact details of participants will be deleted, ensuring survey data is fully anonymised and the privacy of participants protected. Anonymised survey responses will be retained for additional analysis, including comparisons with future National Cancer Care Experience Surveys.

Reports will be generated at an aggregated or summary level from the response data and this will be used by service providers and NCEP partners to acknowledge what is working well in Ireland's cancer care services and hospitals, and to inform quality improvements in cancer care, policy, legislation and regulation.

The data may be analysed by health service researchers, under agreed conditions.

## 4. What is the legal basis for processing National Cancer Care Experience Survey data?

The National Cancer Care Experience Survey complies with data protection laws, including the General Data Protection Regulation (GDPR)[1]. Under Article 6(1)(e) of the GDPR 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 permits the processing of healthcare data, which is "special category data" under the GDPR, when processed in the public interest.
The legal basis for processing is that it is necessary for the performance of the statutory function of the HSE and HIQA.

[1] General Data Protection Regulation (GDPR) [Internet]. 2016. Available at: https://gdpr-info.eu/art-6-gdpr/
[2] Data Protection Act 2018 [Internet]. 2018. Available at: http://www.irishstatutebook.ie/eli/2018/act/7/enacted/en/html

## 5. Overview of the National Cancer Care Experience Survey - data flow

This section provides an overview of the data flow of the Cancer Care Experience Survey.

**Step one:** hospital staff (personnel from 25 public HSE and voluntary hospitals delivering cancer care) provide eligible participants with an information booklet in day oncology and radiation therapy departments, surgical waiting rooms and inpatient wards to inform them about the survey and that they may be invited to participate.

**Step two:** hospital staff identify eligible survey participants. They transfer this data to the National Care Experience Programme Managed Service, who quality assures the data and distributes the survey.

**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 survey participants receive a text message (SMS) invitation to participate in the survey, with a link to complete the survey online. They receive two further communications by text message (SMS) and post about the survey at one-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, are 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. You can find out more about our survey information governance here.

## 6. 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:

**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.

## 7. Overview of risks

The DPIA identified 10 risks. The safeguards put in place to mitigate the risks are also summarised in this section. Each risk is assigned a risk rating, based on the matrix in Table 1 below. 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 on 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)**

## 7.1 Summary of risks

### Risk 1. Person incorrectly sent the survey

There is a risk that a person may be incorrectly sent the survey.

#### Controls

The National Care Experience Programme will:

- provide appropriate guidance and resources to hospitals to identify people to be included in the patient contact list and to ensure they meet the eligibility criteria (including sample eligibility checks)
- provide training to all staff who will be supporting data extraction
- develop survey related materials, with professional guidance, to reflect the survey population receiving cancer care
- provide information and supports through a patient information booklet, Freephone helpline, email and website.

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

### Risk 2. 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 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 Cancer Care Experience Survey.

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

## Risk 3. Data integrity

There is a risk that the confidentiality, integrity, or availability of personal, sensitive or special category data is jeopardised.

### Controls

The National Care Experience Programme:

- approves the processing of all data
- oversees the secure processing of all NCEP data, to include transfer, storage, use and destruction, in compliance with the GDPR
- oversees the provision of guidance and training for all staff processing National Cancer Care Experience Survey data.

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

## Risk 4. 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.

### 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
- arranges for the secure transfer of data through a pre-approved secure file-sharing service.

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

## Risk 5. Participants' self-disclosure of sensitive information

There is a risk that, in answering qualitative, open-ended questions in the survey, participants may voluntarily disclose personal or sensitive information, which is not required or sought by the survey, which may directly or indirectly identify them.

### Controls

The National Care Experience Programme:

- has developed anonymisation criteria for qualitative survey responses to remove data that personally identify individuals
- has a process in place to review 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 survey participants.

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

## Risk 6. Re-identification using pseudonymised data

There is a risk that 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. The contract ensures that:
  - All parties' processing survey data have formalised roles and responsibilities through data processing and data sharing agreements.
  - The contact dataset and survey responses are pseudonymised and stored securely and separately.
  - All personal data is stored in password-protected, encrypted environments.
  - All access to data is managed on the basis of roles, and access rights are regularly reviewed.
  - Administrative data is stored separately to survey response data. The survey responses are anonymised within six weeks of the survey's closure, when the personal information collected to administer the survey is deleted.
  - Has developed a data retention and destruction policy and schedule to ensure secure and timely destruction of all personal data.
- supervises and records the destruction of the data, in line with the schedule.

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

## Risk 7. Personal, sensitive and special category data received by helpdesk

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

### Controls

The National Care Experience Programme:

- does not record calls
- has developed training and a process guide for helpline operators to ensure that they do not unnecessarily seek personal data
- does not seek personal data from individuals who make contact by phone or email, until required to action the request
- receives emails on secure, encrypted, password-protected devices and deletes them when the survey closes.

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

## Risk 8. Unauthorised disclosure of a participant's hospital stay

There is a risk that the distribution of the survey may be accessed by other individuals, disclosing the fact that the intended recipient recently received cancer care.
For example, this may happen where the number provided is not for the participant but for another individual, such as a partner, friend or family member.

There is a risk that family members may not be aware of a respondent's cancer diagnosis, and the survey delivered through post or text inadvertently impacts the privacy rights of the individual.

### Controls

The National Care Experience Programme:

- arranges for the distribution of all communication by text message (SMS) and post. Eligible participants will be informed about the survey distribution method and will be asked to confirm their number while in hospital.
- where it is known that the telephone belongs to another individual, an SMS invitation will not be sent.
- ensures that eligible telephone numbers are processed securely, in compliance with the GDPR.
- ensures that there will be no National Cancer Care Experience Survey-identifiable information on the text message (SMS) or postal envelopes sent to eligible participants, to ensure privacy is maintained.

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

## Risk 9. Transparency

There is a risk that eligible survey 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 survey participants are informed about the survey, the National Care Experience Programme:

- Provides eligible survey participants with an information booklet about the survey during episodes of care. The information booklet contains frequently asked questions and information about the survey and specifies who is running the survey, what their data is used for, and the legal basis of processing and compliance with GDPR.
- Transparency around the use of third-party processors is provided on the National Care Experience Programme's publicly available Statement of Purpose and Statement of Information Practices and Privacy Notice.
- Uses posters and digital signage (where available) in hospitals during the survey sample and distribution period, to inform eligible survey participants about the survey.
- Implements a national media campaign, to ensure that eligible survey participants are duly informed about the survey.

- Provides details of its data-processing activities and information governance on www.yourexperience.ie.
- Ensures that all communication for public dissemination is accessible and adheres to National Adult Literacy Agency (NALA) guidelines.
- Has a process in place to allow eligible survey participants to opt out of the survey, before their data is processed.
- Facilitates eligible survey participants in opting out of the survey through five different mechanisms.
- Facilitates eligible survey participants in enacting their rights under the GDPR.
- Publishes the results of the survey and corresponding quality improvement plans on www.yourexperience.ie.

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

### Risk 10. Opt-out process

There is a risk that if survey participants receive care in more than one hospital, and request to opt out of the survey at a hospital level, they could still receive the survey.

#### Controls

To ensure that eligible survey participants are informed about the survey and the ability to opt out of it, the National Care Experience Programme:

- provides eligible survey participants with information booklets at key points of interaction with healthcare providers, informing them that they will be invited to take part in the survey and outlining how they can opt out of participating
- arranges for the display of posters, banners and digital signage in cancer services during the survey cycle
- implements national and local media campaigns during survey sample and distribution periods
- ensures that communication with the public is accessible
- provides details of its data-processing activities on www.yourexperience.ie.

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

## 8. Next steps

The controls identified in the DPIA will be integrated into the National Cancer Care Experience Survey project plan and actioned. This summary will be published on www.yourexperience.ie

Suirbhé Náisiúnta ar Eispéireas Cúraim Ailse

National Cancer Care Experience Survey

**Improving care experiences together**

Health Information and Quality Authority

HSE

mhc mental health commission

An Roinn Sláinte Department of Health

nccp National Cancer Control Programme