



Data Protection Impact Assessment 2024

April 2024

1. Introduction

The National Inpatient Experience Survey is a nationwide survey asking people for feedback about their stay in hospital. 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. All patients aged 16 years and over discharged during the month of May 2024, who spend 24 hours or more in a public acute hospital and have a postal address in the Republic of Ireland are asked to complete the survey.

In preparation for the inaugural survey in 2017, an independent third party was commissioned to carry out a Privacy Impact Assessment (PIA). The findings of this PIA informed the development of security and data protection controls for the implementation of the first survey. This was conducted at a very specific and strategic point in time and the assessment is repeated in advance of each subsequent iteration of the survey, as per HIQA's *Guidance on Privacy Impact Assessment in health and social care* published in 2017¹. The guidance recommends that PIAs should be updated at regular intervals, particularly if projects evolve in a way that introduces new privacy risks. Even if specific processes do not change over a project's lifetime, assessments should be conducted at regular intervals to evaluate the adequacy of security and privacy controls, particularly in light of changes to current legislation or the introduction of new legislation.

Since the introduction of the General Data Protection Regulation (GDPR) (EU) 2016/679, a PIA is now referred to as a Data Protection Impact Assessment (DPIA).

This report presents the findings of the DPIA for the 2024 iteration of the National Inpatient Experience Survey.

2. Why are we updating the DPIA?

In preparation for the survey in 2024, special consideration was given to the following:

- it is important to review and evaluate the adequacy of security controls in mitigating the privacy risks identified in previous DPIAs.
- the National Inpatient Experience Survey underwent review in 2023. The DPIA reflects changes to the survey, arising from the review.

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>.

3. Survey model

3.1. Overview of the National Inpatient Experience Survey model

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

Step 1: Hospital staff provide patients with a letter and a Frequently Asked Questions (FAQ) during their stay in hospital, which informs them that they may be invited to participate in a survey. Patients can opt out of the survey at this stage.

Step 2: Nominated staff within hospitals identify eligible survey participants and collate their contact details for the purposes of administering the survey. This information is quality assured by the HSE prior to sending it to Behaviour & Attitudes, the data processor.

Step 3: The data processor records and manages the list of all eligible participants. It removes the names of patients who have opted out of the survey or who have died since their discharge from hospital. The data processor distributes the survey to all patients who are eligible to participate.

Step 4: Eligible participants receive a survey invitation within one month of their discharge from hospital. They receive two further reminders at two, two-week intervals. Eligible participants respond to the survey either online, using their unique survey code provided in the invitation letter, or by completing the hard copy questionnaire and returning it by post.

Eligible participants can opt out of the survey:

- while they are still in hospital
- on the website www.yourexperience.ie
- by calling 1800 314 093
- by emailing info@yourexperience.ie
- by returning a blank survey questionnaire in the post.

Step 5: The data processor manages the survey responses.

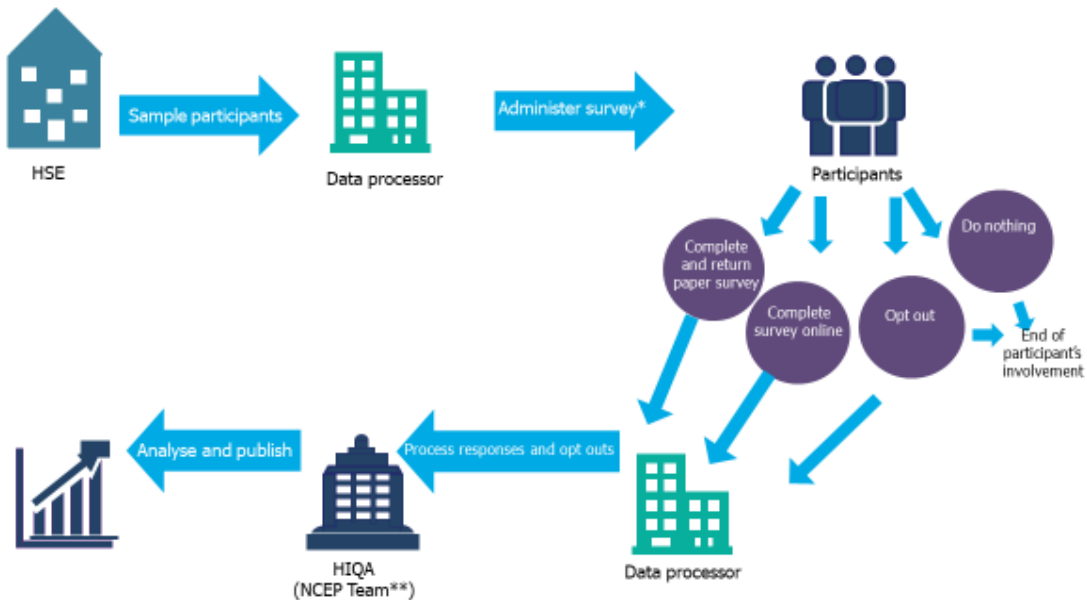
Step 6: The National Care Experience Programme Team analyses the data and reports on the findings at www.yourexperience.ie.

Step 7: The contact details of eligible participants and survey responses are destroyed in line with a retention and destruction schedule. The names and contact details of eligible participants are destroyed within three weeks of the survey closing. The hard copy and original online survey responses are destroyed within two months of the survey closing.

Anonymised survey responses are retained indefinitely. For more information on the schedule and the survey's information governance, please see [here](#).

Figure 1 depicts the National Inpatient Experience Survey model.

Figure 1: National Inpatient Experience Survey model



* Administer survey includes application of eligibility criteria, distribution of survey to eligible participants, application of HP Deprivation Index and management of survey responses and opt outs.

** National Care Experience Programme

4. Methodology to update the 2022 DPIA

Risk assessment process

The input of key stakeholders was sought in identifying risks and the necessary controls to mitigate risks. The National Inpatient Experience Survey Advisory Group was consulted, which includes patient representatives, HIQA, the HSE and the Department of Health. The input of the data processor, the National Care Experience Programme Team, the National Care Experience Programme Director and the data controller's Data Protection Officer was also sought. All existing risks (identified in the 2022 DPIA) were reviewed and the risk register was updated. Security and privacy controls were also reviewed. Risks were subsequently assigned a risk rating, ranging from 1 to 25.

Risk ratings were assigned 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 only bears negligible consequences to an eligible participant’s privacy, would be assigned a rating of 5.

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	Minor	Moderate	Significant	Substantial
Likelihood of harm		1	2	3	4	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	

5. Data privacy risk register

This section provides an overview of the risks identified to the privacy of eligible participants and the controls that have been put in place to reduce and 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 (HIQA), data processor (Behaviour and Attitudes) and any sub-processors it contracts, and data provider (HSE) 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 survey participants' data. This may include non-application of agreed processes and procedures, such as those outlined in the security policy, the data retention and destruction schedule or the access request policy

This risk is particularly pertinent in the case of the novel use of technology and additional element of data processing as of 2024, through the use of the HP Deprivation Index². Index numbers will be applied to the participant data based on coordinate and geo-code information and will inform and facilitate targeted, evidenced-based quality improvements in care based on location. The HP Deprivation Index is currently used across the public service.

Controls

The data controller has:

- developed an information governance framework, outlining data protection and security specifications agreed with and implemented by the data processor.
- put a contract in place with the data processor, which authorises and defines data processing activities necessary to administer the survey. The contract ensures that the data processor equally puts agreements in place with any sub-processors.
- has a data sharing agreement in place with hospitals and hospital groups to ensure the secure transfer of eligible participants' data.
- provided training and a process guide for staff involved in processing data to implement the National Inpatient Experience Survey.
- developed and implemented a process to ensure the secure processing of data in the application of the HP Deprivation Index.

Risk-rating: 9 (possible/moderate) – this represents a **medium** risk.

² The Pobal HP Deprivation Index shows the level of overall affluence and deprivation of areas, and is updated for each census. For more information, please see <https://www.pobal.ie/pobal-hp-deprivation-index/>.

Risk 2: Data quality and 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 that their data will be transferred to the data processor. For example, women using maternity services who are not eligible to participate, could be mistakenly included in the contact dataset.

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

Controls

The National Care Experience Programme:

- has provided a process guide and training for staff responsible for extracting and transferring the data. This is to ensure that eligibility criteria are applied and that only the data of eligible participants are processed.
- tests the extraction and transfer of data in advance of the survey.
- arranges for the secure transfer of all data.
- oversees a quality assurance process of the data.
- has a data breach management procedure in place.
- has developed a process to suppress survey responses completed by ineligible participants in the event that they receive, complete and return the survey.

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

Risk 3: Re-identification using pseudonymised data

Administrative data (personal information collected to administer the survey, including the contact details of eligible survey participants) is retained until the last pseudonymised survey responses have been processed, which is within three weeks of the closure of the survey. There is a risk that participants' contact details could be linked with their pseudonymised survey responses.

Controls

The National Care Experience Programme:

- ensures that the contact dataset and survey responses are pseudonymised, that is, stored securely and separately. Pseudonymisation is maintained in the application of the HP Deprivation Index.
- ensures that survey responses are anonymised.

- ensures that all personal data is stored in password-protected, encrypted environments. All access to the data is 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](#).
- has formalised roles and responsibilities for all parties processing survey data, through data processing and data sharing agreements.

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

Risk 4: Participants' self-disclosure of sensitive information

There is a risk that, in answering open-ended questions, participants voluntarily disclose personal or sensitive data that is not sought by the survey and 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 response data may be combined with complaints received by hospitals at a local level, which may intentionally or unintentionally lead to the identification of survey participants. This risk is particularly pertinent in hospitals with lower numbers of admissions.

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 healthcare providers.
- will only give healthcare providers access to the data when they have a minimum of 5 responses from survey participants.

Risk-rating: 5 (almost certain/negligible). This represents a **low** risk.

Risk 5: 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 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 three 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: 4 (unlikely/minor). This represents a **low** risk.

Risk 6: Unauthorised disclosure of participants' recent hospital visit

There is a risk that survey invitations and responses may be intercepted or accessed by another individual in the post, therefore disclosing personal data about a person.

This risk also applies to the return of completed surveys in the post.

Controls

The National Care Experience Programme:

- sends and receives 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.
- encourages eligible survey participants not to include directly identifiable personal information in their survey returns, such as their names and addresses.

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

Risk 7: Transparency

There is a risk that, despite significant efforts (including a national media campaign, information leaflets, information sessions with hospital staff, information packs handed to patients during their stay in hospital and a dedicated website), survey participants may not be fully aware of who will process or have access to their data or survey responses.

Controls

The National Care Experience Programme:

- carries the survey out in the public interest, in accordance with Art. 6 (1) (e) and 9 (2) (i) of the General Data Protection Regulation (GDPR) and uses the results of the survey to inform quality improvements in public acute hospital care.
- provides eligible participants with a participant information leaflet and FAQ during their stay in hospital to inform them about the survey.
- uses posters and digital signage in hospitals during the survey sample and distribution periods to inform eligible participants about the survey.
- facilitates eligible participants to opt out of the survey, if they do not wish to participate. Eligible participants can opt out in hospital upon discharge or upon receipt of the survey pack by telephone, email or by returning the survey unanswered.
- implements national and local media campaigns during survey sample and distribution periods.
- ensures that all communication with eligible survey participants and the public is accessible.
- cognitively tests the survey tool to ensure that it is accessible to eligible survey participants, aged 16 years and above.
- 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.

6. Next steps

The controls identified in the DPIA will be integrated into the National Inpatient Experience Survey Project Plan for 2024 and actioned. This summary will be published on www.yourexperience.ie.



National
Inpatient
Experience
Survey

