



Data Protection Impact Assessment 2021

September 2021

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 and over discharged during the month of September 2021¹, 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 2017². 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 a Data Protection Impact Assessment (DPIA).

This report presents the findings of the DPIA for the 2021 iteration of the National Inpatient Experience Survey.

2. Why are we updating the DPIA?

In preparation for the survey in 2021, 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

¹ In 2017, 2018 and 2019, the National Inpatient Experience Survey took place in May. The survey was cancelled in 2020 due to the Covid-19 Pandemic and was postponed from May to September in 2021 due to the cyber attack on the Irish health service in May 2021.

² 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>.

- processes to conduct the survey may be affected by the COVID-19 Pandemic and a cyber attack on the Irish health service in May 2021.

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) flyer upon discharge, 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: Each of the 40 participating hospitals identify eligible participants' contact data during the month of September and provide Behaviour and Attitudes, the data processor, with this information.

Step 3: The data processor records and manages the list of all eligible participants for the 40 participating hospitals. 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, via post.

Step 4: Eligible survey participants receive the survey approximately four to seven weeks after their discharge from hospital. They receive two further reminders (including a second survey) at two three-week intervals. Eligible survey participants respond to the survey either online or by completing the hard copy questionnaire and returning it by post.

Eligible survey participants can opt out of the survey:

- while they are still in hospital
- by calling the Freephone number
- by email
- on the website www.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 analyse the data and report on the findings at www.yourexperience.ie.

Step 7: The contact details of the eligible survey participants and survey responses are destroyed in line with a retention and destruction schedule. The names and contact details of eligible survey 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.

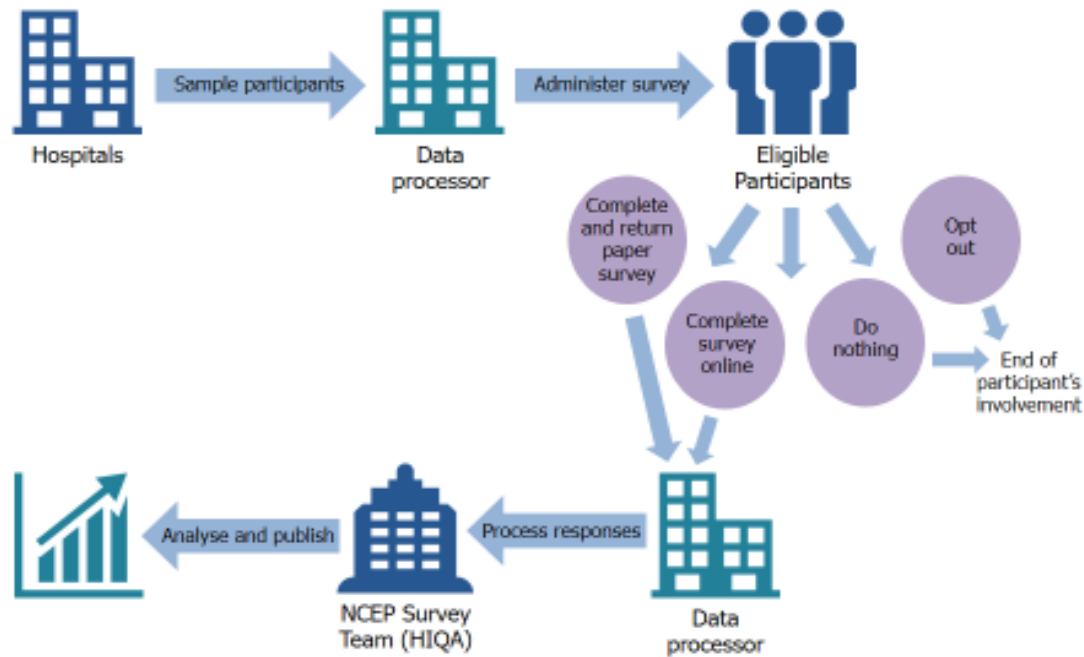


Figure 1: National Inpatient Experience Survey model

4. Methodology to update the 2021 DPIA

Risk assessment process

The input of the data processor, the National Care Experience Programme Team and the National Care Experience Programme Director was sought. All existing risks (identified in the 2019 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 survey 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.

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

Table 1: Risk matrix

5. Data privacy risk register

This section provides an overview of the risks identified to the privacy of eligible survey participants and the controls that have been put in place to reduce and mitigate those risks.

Appendix 1 provides an overview of risks that were removed, amalgamated or amended in the previous DPIA, carried out in 2019.

Risk 1: Responsibilities are undefined or unclear

There is a risk that the responsibilities and boundaries for the roles of data controller, data processor and service provider (hospital) 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.

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, which contains a confidentiality agreement and a data processing agreement, 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 put agreements in place with any sub-processors
- put in place a data sharing agreement with hospitals and hospital groups to ensure the secure transfer of eligible survey participants' data
- provided training and a process guide for staff involved in processing data to implement the National Inpatient Experience Survey.

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

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 from hospitals 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 a risk that the data processor will distribute the survey to ineligible survey 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 survey participants are processed
- has tested 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 survey participants in the event that they receive, complete and return the survey.

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

Risk 3: Retention of personal data

There is a risk that eligible survey participant's data is retained for a period beyond that which is required for the completion of the survey's objectives. This risk is particular to situations where personal data is 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 data retention and destruction policy and a data retention and destruction schedule, which covers data processed for the National Inpatient Experience Survey
- put 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
- put data sharing agreements in place with hospitals participating in the survey
- provides training and a process guide for hospital staff involved in extracting and transferring data for the National Inpatient Experience Survey.

Risk rating: 6 (unlikely/moderate) – 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 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 survey participants' contact details could be linked with their pseudonymised survey responses.

Controls

The National Care Experience Programme:

- ensures that the contact dataset and surveys responses are pseudonymised, that is, stored securely and separately
- ensures that survey responses are anonymised, by assigning anonymisation criteria
- 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, 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 5: Participants' self-disclosure of sensitive information

There is a risk that, in answering qualitative, open-ended questions, survey participants voluntarily disclose personal and or sensitive data which is not required or 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 30 responses from survey participants.

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

Risk 6: 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 at discharge 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 survey participants with a participant information leaflet and FAQ upon discharge from the hospital to inform them about the survey
- uses posters and digital signage in hospitals during the survey sample and distribution period to inform eligible survey participants about the survey
- facilitates eligible survey participants to opt out of the survey, if they do not wish to participate. Eligible survey 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 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.

Risk 7: 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 survey participant and 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: 3 (possible/negligible). This represents a **low** risk.

Risk 8: Unauthorised disclosure of participants' recent hospital visit

There is a risk that the distribution of the survey to eligible survey participants may be intercepted and or accessed by another individual, therefore disclosing personal and potentially special category data about a person.

This risk also applies to the return of completed surveys in the post, which contain survey participants' responses.

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: 3 (rare/moderate). 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 2021 and actioned. This summary will be published on www.yourexperience.ie.

Appendix 1

1. Changes to the risk register

This section provides an overview of the risks that were identified in the 2019 DPIA that have been removed, amalgamated or amended.

1.2 Risks that have been removed, amalgamated and or amended

Risk numbers 4, 5, 8, 11 and 12, as outlined below, were removed from the DPIA 2019 risk register and were amalgamated into the DPIA 2021 risk register under risk numbers 3, 4 and 7. Risk number 9 from the DPIA 2019 risk register was removed from the DPIA 2021 risk register.

Risk 4: Creation of new data hotspots

There is a risk that several new data hotspots are created within different organisation's technical environments during the survey period.

Data hotspots may be defined as instances where personally identifiable information (PII) or sensitive PII is 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.

Reason for update in 2021

This risk was removed as it is covered under risk number 3 of the DPIA 2021, entitled 'Retention of data'.

Risk 5: Security controls

There is a risk that the controls, processes, procedures and training required by the data controller (HIQA) for managing the security of survey participants' data are not consistently applied within the third parties that make up the data processor's environment (the primary data processor, Behaviour & Attitudes, and its sub processors).

Reason for update in 2021

This risk was removed as it is now covered by risk 4 of the DPIA 2021, entitled 'Responsibilities are undefined or unclear'.

Risk 8: Right to object to processing

There is a risk that the survey opt-out process does not adequately facilitate the patient in objecting to their personal data being processed (i.e. opting out) when being discharged from hospital. Additionally, participants may not be fully aware of, or consent to, their personal data being uploaded from hospitals to the data processor for the purposes of the survey.

Reason for update in 2021

This risk was removed as it is now covered by risk 7 of the DPIA 2021, entitled 'Transparency'.

Risk 9: Changes to anonymisation criteria

Hospital staff have access to the qualitative survey responses for their hospital via a reporting platform. In 2018, the anonymisation guidelines for the redaction of qualitative comments were amended — ward names and specific healthcare professions (for example, physiotherapists, speech therapists and occupational therapists) are no longer anonymised. The decision to 'relax' anonymisation criteria was made following feedback from hospital staff who said that they often could not action patient suggestions for improvement due to a lack of important contextual details.

There is a risk that hospital personnel will be able to identify specific patients or hospital staff on the basis of responses to questions 59, 60 and 61. This risk is disproportionately higher in smaller hospitals who employ fewer staff and who have less than 30 discharges per month.

Reason for update in 2021

This risk was removed as the anonymisation criteria have been in place since 2018.

Risk 11: Secondary processing

There is a risk that participants are unclear about the fact that their survey responses may be used for secondary research purposes (for example publication in scientific journals and presentation at conferences).

Reason for update in 2021

This risk was removed as it is now covered by Risk 7 of the DPIA 2021, entitled 'Transparency'.

Risk 12: Non-processing of in-hospital opt-outs

There is a risk that even though a mechanism is in place to facilitate patients to opt out of the survey while they are still in hospital (and before their data is processed), hospital staff receiving the request may not relay the request to the nominated individual within the hospital. There is a possibility that patients may receive a survey pack in the post despite their explicit objection to the processing of their contact details.

**Reason for
update in
2021**

This risk was removed as it is now covered by Risk 7 of the DPIA 2021, entitled 'Transparency'.



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