National
Nursing Home
Experience
Survey

Data Protection Impact Assessment 2022: Summary Report

January 2022

1. Introduction

The National Nursing Home Experience Survey aims to explore the care provided to nursing home residents in Ireland.

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

The National Nursing Home Experience Survey will gather information on the care provided to nursing home residents in a structured and systematic way. Residents from a representative sample of nursing homes in Ireland will be asked to participate in the survey, as will a nominated family member or friend of each resident. Residents must have the ability[1] to take part in the survey.

The findings of the survey will inform quality improvements in the provision of nursing home care in Ireland. They will also be used to inform the regulation of nursing homes and the development of relevant national standards by HIQA, and the development and direction of national policy and legislation by the Department of Health.

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 is 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[2].

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[1] The functional ability of residents to participate will be based on their physical, psychological, cognitive, and social ability to perform normal daily activities required to meet basic needs, and maintain health and wellbeing.

[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/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 Nursing Home Experience 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 Nursing Home Experience Survey model

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

Step 1: Nursing homes participating in the survey compile one dataset of eligible survey participants, that is, residents who have the ability to take part and a separate dataset, containing the names and contact details of one nominated family member or friend for each resident. The datasets, hereafter referred to as the contact datasets, will include the names and addresses of eligible survey participants, which are used to administer the survey.

Step 2: Nursing homes will inform eligible survey participants about the survey. Information packs will be sent to each participating nursing home and will be distributed to residents and their nominated family members and friends. Residents and their nominated family members and friends will be asked if they want to participate in the survey and if not, provided with the option to opt out.

Step 3: Nursing homes securely send the contact datasets of eligible survey participants to a data processor, Behaviour and Attitudes. The details of residents and their family members or friends who do not want to participate in the survey are not included in the contact datasets.

Step 4: The data processor manages the implementation of the survey. This involves:

- setting up interviews with residents
- sending the survey by post to the nominated family member or friend of each resident.

Step 5: Each resident will be offered an opportunity to take part in an interview. The data processor carries out interviews with residents using trained interviewers. Interviews take place in private. Residents' survey responses are uploaded to the National Care Experience Programme Dashboard[3], using a secure, encrypted portable device. Residents can opt out of the interview at any point, up to and including the end of the survey.

Step 6: Each resident's nominated family member or friend will receive a survey in the post, upon which time they may decide to ignore, opt out or complete the survey. If they do not opt out, they will receive two further reminder letters about the survey. Nominated family members or friends respond to the survey either online or by completing the paper version of the survey and returning it by post.

If eligible survey participants choose to opt out of the survey, they can do so:

- by informing the nursing home upon receipt of their information pack
- by calling the Freephone helpline on 1800 314 093
- by emailing info@yourexperience.ie
- on the National Care Experience Programme's website: www.yourexperience.ie
- by returning a blank survey questionnaire in the post.

Step 7: The data processor manages the survey responses and any opt outs. Survey responses are stored separately to the contact dataset. The data held in survey responses and the contact dataset are never directly matched. Survey responses and opt outs are managed using a unique survey code, which the data processor assigns to each eligible survey participant.

Step 8: The National Care Experience Programme Team in HIQA anonymises and analyses the survey responses on the National Care Experience Programme Dashboard. Survey responses are made available to nominated healthcare professionals in HIQA, the Department of Health, the HSE and participating nursing homes at an aggregated national level. The findings of the survey are published on www.yourexperience.ie.

Step 9: The contact details of eligible survey participants and survey responses are destroyed once they have served their purpose, in line with the National Care Experience Programme Data Retention and Destruction Schedule. For more information on the schedule and the National Care Experience Programme's Information Governance Framework, please see www.yourexperience.ie.

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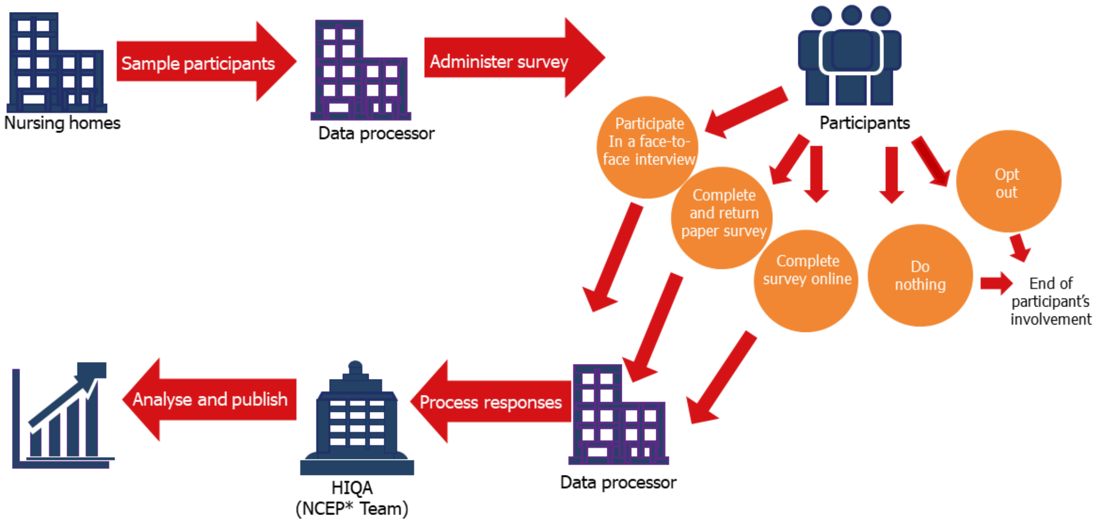
[3] The National Care Experience Programme Dashboard is an online repository of anonymised survey responses. Nominated individuals in HIQA, the Department of Health, the HSE and participating nursing homes are granted access to the dashboard. The data is used to inform quality improvements in the HSE and nursing homes, regulation and standards in HIQA and legislation and policy in the Department of Health.

Figure 1 depicts the National Nursing Home Experience Survey model.

Figure 1: National Nursing Home Experience Survey model



* National Care Experience Programme

3. Methodology to conduct the DPIA for the National Nursing Home Experience 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, the National Care Experience Programme Team and Director, and the National Nursing Home Experience Survey Programme Board, who oversee the implementation of the survey. The Programme Board contains representatives from organisations that represent the interests of and advocate for nursing home residents.

Once risks and controls were identified, a risk rating was assigned to each risk on the basis of the matrix in Table 2. This matrix combines the likelihood of harm with the severity of harm. For instance, a risk that is very likely to cause harm but that only bears negligible consequences to an individual's privacy, would be assigned a rating of 5. Individuals whose data privacy rights were considered include the eligible survey participants (residents and their nominated family members and friends), staff working in healthcare providers and any other individuals 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. 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				
Likelihood of harm	Negligible 1	Minor 2	Moderate 3	Significant 4	Substantial 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

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: Responsibilities are undefined or unclear

There is a risk that the roles and responsibilities of data controller, data processor and nursing homes 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 eligible survey participants’ data.

Controls

The National Care Experience Programme:

- has put a contract in place with the data processor. The contract authorises and defines the data processing activities necessary to administer the survey
- has put data sharing agreements in place with nursing homes to ensure the secure transfer of eligible survey participants’ data

- has developed an information governance framework, outlining data protection and security specifications agreed with and implemented by the data processor
- provides training on information governance to the National Care Experience Programme Team in HIQA and the project team in the data processor
- provides training and guidance for the nursing homes, which outlines all roles and responsibilities in transferring data.

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

Risk 2: Data quality and potential 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 this data is transferred to the data processor. Alternatively, there is a risk that a person who is eligible to take the survey is not included in the list of eligible survey participants.

In cases where nursing homes send the data of ineligible survey participants to the data processor, there is an additional risk that the data processor will distribute the survey to ineligible survey participants mistakenly included in the survey sample. This would constitute an additional data breach.

Controls

The National Care Experience Programme:

- provides training and guidance for staff in nursing homes, who create the contact dataset of eligible survey participants
- arranges for the secure transfer of eligible survey participants' data from the nursing homes to the data processor. All data transfers will be subject to a data sharing agreement
- arranges for the reporting of the numbers of resident opt-outs, exclusions and reasons for exclusion by nursing homes
- minimises the data it processes to what is necessary and proportionate to the aim of the survey. The National Care Experience Programme only process the names and contact details of eligible survey participants to administer the National Nursing Home Experience Survey. No sensitive or special category data is processed as part of the contact dataset
- has a data breach management procedure in place to manage data breaches and other security incidents in line with the General Data Protection Regulation (GDPR) 2016 and the Data Protection Act 2018.

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

Risk 3: Re-identification using pseudonymised data

The contact dataset (personal data collected to administer the survey, which includes the names and contact details of eligible survey participants) is retained until the last pseudonymised survey responses have been processed — within three weeks of the close of the survey. There is a risk that eligible survey participants' contact details could be linked with their pseudonymised survey responses.

The severity of this risk is accentuated by the fact that certain survey participants will be in receipt of continuing and long-term care and therefore still dependent on the nursing home.

Controls

The National Care Experience Programme:

- has a contract in place with the data processor, which stipulates data processing measures to ensure that the data is treated in compliance with the GDPR
- ensures that the data is pseudonymised. This means that the contact dataset, containing eligible survey participants' names and addresses are stored separately to survey responses
- has an Access Control Policy in place. Access to any data held by the National Care Experience Programme is managed on a role and 'a need-to-know' basis and access rights are reviewed on a regular basis
- ensures the secure processing of survey responses:
    - Residents take part in the survey by agreeing to partipate in an interview. Interviews are conducted in private in nursing homes with trained interviewers from the data processor. Nursing home staff are not present during the interview. Interviewers are under contractual obligation not to disclose any information they process as part of the interview. Interview responses are directly uploaded to the dashboard via secure, encrypted portable devices
    - Nominated family members and friends can log on to www.yourexperience.ie and complete the survey online or by completing and returning the paper copy of the survey in the post. Online survey responses are directly uploaded to the dashboard. Postal survey responses are manually uploaded to the dashboard

- ensures that the survey responses are anonymised, by assigning anonymisation criteria to data deemed to be personally identifiable. This means that any information contained in survey responses that could identify a survey participant, a staff member or any other individual is removed. Examples include names, physical characteristics and job titles

- has developed a data retention and destruction policy and schedule, to ensure that the contact dataset that contains the details of eligible survey participants are destroyed within three weeks of the survey closing and the hard copy and original online survey responses are destroyed within two months of the survey closing. After this point, only anonymised survey responses remain, which removes the possibility of identifying eligible survey participants and any other individuals
- supervises the destruction of the data in line with the schedule.

Risk rating: 5 (rare/substantial). This represents a low risk.

Risk 4: 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, which may directly or indirectly identify them or other individuals. For example, an eligible survey participant may provide their name and contact details in their survey response and ask to be contacted.

In addition, eligible survey participants may be directly or indirectly identified through their participation in the survey, if:

a) their response to the survey is combined with previous or ongoing complaints with the nursing home
b) their response refers to an incident where there is a high level of risk to the survey participant, in this case the resident, and will therefore require further action and follow up.

This risk is particularly pertinent in nursing homes with lower numbers of residents, which may make it easier to identify a survey participant by their response.

Controls

The National Care Experience Programme:

- develops anonymisation criteria, which are then applied to qualitative survey responses. The criteria ensure that personal identifiers relating to an eligible survey participant and any other individual are removed and their privacy is protected
- reviews survey responses on the dashboard before making them available to service providers
- only makes the data available on the dashboard to nominated staff within HIQA, the Department of Health, the HSE and nursing homes at an aggregate, national level. This means that nursing homes will receive access to the combined survey responses of all participating nursing homes as opposed to survey responses for their nursing homes only. This will prevent the identification of survey participants within a local nursing home

- processes any information of concern that a resident discloses during the course of an interview in line with HIQA's Adult Safeguarding – Standard Operating Procedure. Information of concern refers to any information that pertains to a risk to a resident's safety, health and wellbeing.

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

Risk 5: Retention of personal data

There is a risk that a 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 accentuated in 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 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 data sharing agreements in place with nursing homes providing the data to ensure the secure processing of eligible survey participants' data
- arranges for the secure transfer of eligible survey participants' data from the nursing homes to the data processor
- has contractual agreements in place with the data processor to ensure the secure retention and destruction of data, in line with the National Care Experience Programme Data Retention and Destruction Policy and Schedule. For further information on the National Care Experience Programme's Retention and Destruction Schedule, please see here
- has contractual agreements in place with the data processor to ensure that the data controller can audit sub processors
- supervises the destruction of the data in line with the Retention and Destruction Schedule.

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

Risk 6: Transparency

There is a risk that eligible survey participants may not know about the survey until they receive a survey pack in the post and may not want their data processed for the purposes of the survey.

Controls

The National Care Experience Programme:

- carries out the survey in the public interest, in accordance with Article 6 (1) (e) and 9 (2) (i) of the GDPR and uses the results of the survey to inform quality improvements in nursing home care
- has put a process in place to ensure that all eligible survey participants are informed about the survey by participating nursing homes and provided with the option to opt out of the survey. Information packs, which contain a letter and a Frequently Asked Questions leaflet, will be distributed to each resident and the nominated family members or friends of residents in advance of the survey period by the nursing homes. Residents and their nominated family members or friends will therefore be directly informed about the survey and provided with the opportunity to take part or opt out, if they wish
- implements a targeted awareness campaign to ensure that all stakeholders are aware of the survey, to include information sessions and the display of promotional materials in participating nursing homes
- has developed promotional material, such as an information letter and participant information leaflet to be given to eligible survey participants to provide further information on the survey and allow them to make an informed decision about taking part
- ensures that all communication for public dissemination is accessible and adheres to NALA (National Adult Literacy Agency) guidelines. This includes cognitively testing the survey tool, to ensure that it is accessible to eligible survey participants
- facilitates eligible survey participants to opt out upon receipt of the survey, if they do not wish to participate. This can be done by informing the nursing home, or by contacting the National Care Experience Programme by telephone, email, on www.yourexperience.ie or by returning a blank survey in the post
- facilitates eligible survey participants in enacting their rights under the GDPR, such as submitting a data subject access request and having their data destroyed, upon request
- provides details of its data processing activities and information governance on www.yourexperience.ie
- publishes the results of the survey and corresponding quality improvement plans on www.yourexperience.ie.

Risk rating: 3 (rare/moderate). 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 or member of the public.

Controls

The National Care Experience Programme:

- does not record calls it receives in relation to the survey
- receives and stores emails on password-protected, encrypted devices and deletes them at the end of the survey cycle
- has developed training and a helpline script for the Freephone number to ensure that no personal information is requested or processed unnecessarily. Phone operators use an eligible survey participants' unique survey code to manage queries and only take personal information if the code is not available
- only records type of calls received by the Freephone helpline and other non-personal, operational data. This data is deleted and shredded at the end of the survey.

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

5. Next steps

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

National
Nursing Home
Experience
Survey

Health
Information
and Quality
Authority
An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health