Suirbhé Náisiúnta ar Eispéireas Meabhairshláinte | National Mental Health Experience Survey

Data Protection Impact Assessment: Summary Report 2025

June 2025

About the National Mental Health Experience Survey

The National Mental Health Experience Survey is a nationwide survey offering adults who have been discharged from acute inpatient mental health care, the opportunity to share their experiences of care in Ireland.

People discharged from inpatient care, including from public, **voluntary and independent providers**, will be contacted by post and invited to take part in the survey. The survey covers inpatient mental health care and services, from admission through to discharge and follow-up. The aim of the survey is to understand and learn from people's experiences 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 conducted by the National Care Experience Programme, a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE), the Department of Health and in collaboration with the **Mental Health Commission**.

Learning from people who have received inpatient mental health care will help to acknowledge what is working well in Ireland's mental health units and hospitals, and identify areas of improvement to enhance future care. 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 the participants who will be invited to take part in the National Mental Health Experience Survey. A glossary of terms is provided at the end of this document, where explanation for the words in bold can be found.

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 the data subjects.

To carry out the National Mental Health Experience Survey, the National Care Experience Programme will process the data of people (aged 18 years and older) who have been admitted to and discharged from participating inpatient mental health units and hospitals on the Register for **Approved Centres** under the Mental Health Act 2001. The data that is being processed will include the administrative data of participants, such as their name and contact details, to enable postal contact with eligible participants; along with their date of birth, and the unit or hospital which they were discharged from, to ensure that they meet the eligibility criteria. In responding to the survey, participants will provide information about their experiences of admission, inpatient care, discharge and follow-up care, which constitutes personal and potentially, special-category data.

Survey responses will be anonymised to ensure that no individuals can be identified from responses to open-ended questions. Once anonymised, survey responses will be retained for additional analysis, including comparisons with future National Mental Health Experience Surveys. The data will also be used to acknowledge what is working well in Ireland's mental health units and hospitals, and identify areas of improvement to enhance future care. The data may be analysed by health service researchers, under agreed conditions.

A DPIA is therefore necessary to ensure that all risks to the privacy of eligible survey participants are identified and appropriate safeguards are put in place.

3. What is the legal basis for processing National Mental Health Experience Survey data?

The National Mental Health Experience Survey complies with data protection laws, including the **General Data Protection Regulation (GDPR)** 2016. Under Article 6(1) (e) of the GDPR[1] 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 processing of personal data is necessary to carry out a survey on the experience of participants who have received inpatient mental health care and services. The National Mental Health Experience Survey is conducted in the public interest; the partner organisations of the National Care Experience Programme have committed to using the results of the survey to inform quality improvements in mental health care, policy, legislation and regulation.

4. Overview of the National Mental Health Experience Survey - data flow

This section provides an overview of the data flow of the National Mental Health Experience Survey.

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[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

Step 1: Unit or hospital staff provide patients with an information booklet prior to their discharge from the unit or hospital, which informs them that they may be invited to participate in a survey. Service users and or patients can opt out of the survey at this stage.

Step 2: Nominated staff within units or hospitals identify eligible survey participants from the sampling period and collate their contact details for the purposes of administering the survey. This information is **quality assured** by the HSE and the other participating mental health units or hospitals (voluntary and independent providers) prior to sending it to the **data processor**.

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

Step 4: Eligible participants receive a survey invitation between two to five months following their discharge from the unit or hospital. They receive two further reminders which will be sent at two-week intervals. Eligible participants respond to the survey either by completing the hard copy questionnaire and returning it by post or online, using their unique survey code provided in the invitation letter.

Eligible participants can opt out of the survey:

- while they are still in the unit or hospital
- through the website www.yourexperience.ie
- by calling 1800 314 093
- by emailing info@yourexperience.ie
- by returning a blank survey questionnaire in the free post envelope provided.

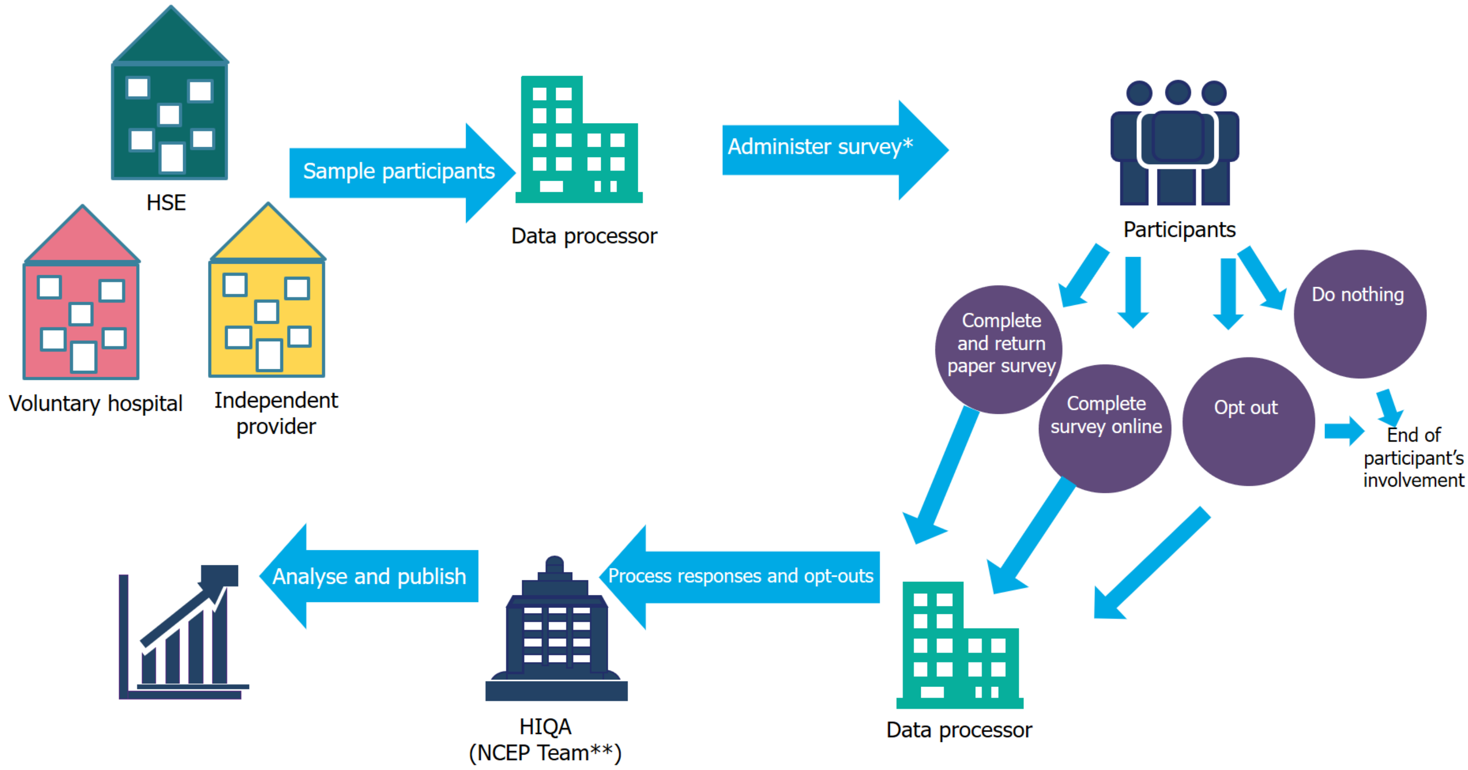
Step 5: The data processor manages the survey responses.

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 six 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.

You can find out more about our survey information governance here.

Figure 1 depicts the National Mental Health 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

Figure 1: National Mental Health Experience Survey Model

5. 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.

6. Overview of risks

The DPIA identified eight risks. The safeguards put in place to mitigate the risks are also summarised in this section. Each risk is assigned a risk-rating on the basis of the matrix in Table 2 on page 6. 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 to a data subject's privacy, would be assigned a rating of 5.

	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)**

Table 1: ***Risk matrix***

6.1 Summary of risks

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 data provider 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 National Care Experience Programme:

- Implemented a contract (which contains a confidentiality agreement), which authorises and defines the data-processing activities necessary to administer the survey.
- Implemented a data-sharing agreement with the HSE, voluntary hospitals and independent providers, to ensure the secure transfer of eligible survey participants' data.
- Developed an **Information Governance Framework**, outlining data protection and security specifications agreed with and implemented by the data processor and **sub-processors**.
- Provided training on information governance to the National Care Experience Programme Team and the data processor.
- Provided training and guidance for staff in the approved centres who are responsible for creating and transferring the dataset.
- Arranges an information session with inpatient mental health settings, to ensure that all parties are aware of the data to be collected as part of the survey.

Risk-rating: 6 (unlikely/moderate) – this represents a low 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 their data will be passed over from participating mental health units or hospitals to the data controller and or processor.
For example, someone discharged outside the survey sampling period may be mistakenly included in the contact dataset.

Controls

The National Care Experience Programme:

- Provides participating units or hospitals providing the data with training on data collection and a process guide outlining the data fields required and the process for transferring data.
- Arranges for the secure transfer of data using a secure file-sharing service.

Risk-rating: 6 (possible/minor) – this represents a low 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 — within six weeks of the hard closure of the survey. There is a risk that survey participant's identifiable details, that is the name and contact information 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.
- Ensures that the contact dataset and the survey responses are pseudonymised and stored securely and separately.
- Ensures the survey responses are anonymised, by assigning anonymisation criteria.
- Has developed a retention and destruction policy and schedule.
- Supervises and records the destruction of the data in line with the schedule.

Risk rating: 3 (rare/moderate). 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 data and or sensitive information which is not required or sought by the survey, 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 units or hospitals at a local level, which may intentionally or unintentionally lead to the identification of survey participants. This risk is particularly pertinent in units or hospitals with lower numbers of admissions, discharges and eligible survey participants.

Controls
The National Care Experience Programme:

- Has developed and continually reviews anonymisation criteria for qualitative survey responses. The criteria ensure that personal identifiers relating to a survey participant and any other individual are removed and their privacy is protected.
- Applies the anonymisation criteria to all survey responses to remove data that personally identifies individuals.
- Reviews survey response data before making them available to units or hospitals
- Only makes the data available at a national, regional and local level, when a minimum of five responses have been received at that level.

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

Risk 5: Personal, sensitive and or special-category data received through the National Care Experience Programme Helpdesk

There is a risk that staff operating the National Care Experience Programme Helpdesk, which includes a 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:

- Receives emails on encrypted, password-protected devices, stored on the data controller's network.
- Does not request personal data from members of the public who contact them.
- Deletes all emails at the end of the survey cycle.
- Has developed training and a helpline script for the Freephone number to ensure that the data processor's helpline staff do not accept or request personal information unnecessarily, to support staff with responding to queries or questions regarding the administration of the survey and to provide staff with the resources to manage difficult questions.

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

Risk 6: Unauthorised disclosure of participants' recent stay in an inpatient mental health unit or hospital

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 or potentially special-category data about a person.

This risk also applies to the return of surveys, which have been completed by survey participants and may contain personal and special category data, if intercepted or accessed by another individual.

Controls

The National Care Experience Programme:

- Arranges for the distribution of all communication by post, which is governed by the Communications Regulation (Postal Services) Act 2011.

- Arranges for discreet, white, non-branded envelopes to be used in all postal communication with eligible survey participants, 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 (possible/negligible). This represents a low risk.

Risk 7: Transparency

There is a risk that, despite significant efforts (including a national media campaign, information leaflets, the provision of information sessions with staff, information booklets given to service users during their stay 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 out the survey in the public interest, in accordance with Article 6 (1) (e) and 9 (2) (g) of GDPR and uses the results of the survey to inform quality improvements in inpatient mental health care.
- Provides eligible survey participants with an information booklet about the survey prior to their discharge from unit or hospital care. The information booklet contains an FAQ and information about the survey.
- 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**.
- 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 in the approved centre, before their data is processed.
- Provides training and a process guide for approved centre staff, which includes an in-hospital, opt-out process.
- 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.
- Provides eligible survey participants with information booklets prior to their discharge from unit or hospital care to inform them about the survey.
- Informs eligible survey participants about the survey through the display of posters and digital signage.

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

7. Next Steps

The controls identified in the DPIA will be integrated into the Mental Health Survey project plan and actioned. This summary will be published on www.yourexperience.ie.

Glossary of Terms

Approved Centre	An approved centre is a service (unit or hospital) registered by the Mental Health Commission to provide inpatient treatment to people experiencing from mental illness.
Data Controller	Determines the purposes for which and the means by which personal data is processed, In the case of the National Mental Health Experience Survey, the data controller is HIQA and NCEP.
Data Processor	The data processor processes personal data only on behalf of the controller. The data processor is usually a third party external to the company.
Data Protection Impact Assessment (DPIA)	Describes a process designed to identify risks arising from the processing of personal data and to minimise these risks as far and as early as possible.
General Data Protection Regulation (GDPR)	The General Data Protection Regulation EU 2016/679 is a regulation on data protection and privacy for all individuals within the European Union.
Information Governance Framework	An information governance framework provides a structured approach to ensuring that data is handled effectively, securely, and in compliance with relevant regulations.
Independent Provider	Also known as private hospitals, they operate independently of state health services in Ireland.
Mental Health Commission (MHC)	Is an independent body established by the Mental Health Act 2001 to regulate and inspect mental health services in Ireland. It is also the facilitator of the Mental health tribunal system in Ireland.
National Adult Literacy Agency (NALA)	An organisation providing professional services to help organisations to be more accessible to people with unmet literacy, numeracy or digital literacy needs.
Privacy Impact Assessment (PIA)	A privacy impact assessment is a way for organisations to assess and address privacy risks when they are collecting, using, or sharing personal information for health and social care.
Privacy Notice	A privacy notice identifies who the data controller is, with contact details for its Data Protection Officer. It also explains the purposes for which personal data are collected and used, how the data are used and disclosed, how long it is kept,

	and the controller's legal basis for processing this data.
Quality Assured (QA)	Quality assurance is any systematic process of determining whether a product or service meets specified requirements.
Risk Matrix	Is a tool that helps visualise the probability versus the severity of a potential risk. That is, the likelihood the risk event will occur and the potential impact the risk event will have.
Statement of Information Practices	Outlines what information is collected by the NCEP, how it is used, with whom it is shared and for what purpose it is collected, as well as the safeguards that are in place to protect it, and how people can access information held about them.
Statement of Purpose	Describes the purpose and function of the NCEP, and the work it carries out.
Sub-processor	A sub-processor acts under the instructions of the processor, meaning that they may process individuals' personal data on behalf of the processor.
Voluntary Provider	Refers to public hospitals, which can be state-funded but are sometimes owned by private bodies. For example, religious orders. Other voluntary public hospitals are run by boards often appointed by the Minister for Health.

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