National Care
Experience
Programme

Data Protection and Confidentiality Policy

National Care Experience Programme

Data Protection and Confidentiality Policy – Policy

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About the National Care Experience Programme

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The Programme implements the National Inpatient Experience Survey, National Maternity Experience Survey, National Maternity Bereavement Experience Survey, National Nursing Home Experience Survey, National End of Life Survey, National Mental Health Experience Survey and the National Cancer Care Experience Survey.

The surveys aim to learn through people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.
A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

Find out more at www.yourexperience.ie.

1. Purpose of this policy

The purpose of this policy is to outline how the National Care Experience Programme protects and safeguards the privacy rights of individuals, whose data it processes.

2. Policy statement

The National Care Experience Programme processes personal, sensitive and special category data in accordance with data protection legislation. This includes the General Data Protection Regulation (GDPR) 2016, the Data Protection Acts 1988 to 2018 and the Data Sharing and Governance Act 2019.

3. Scope

This policy covers data processed as part of National Care Experience Programme surveys. The policy covers data held in electronic or paper format, and preserved in the form of records.

This policy outlines the procedures the National Care Experience Programme have put in place to ensure the confidentiality of the data it processes.

Categories of data covered under this policy

Two categories of information are collected in the course of the National Care Experience Programme; contact datasets and survey responses.

The first type of data processed by the National Care Experience Programme are contact datasets, which contain the personal data of eligible survey participants. Contact datasets include names and contact details, which are processed to administer the survey. Contact datasets also include other basic health information such as admission and discharge dates, which are processed to apply the eligibility criteria. Data may also be used to compare, with the aim of improving, the experiences of different communities in Ireland based on demographic conditions, such as age, length of stay in a healthcare facility and the areas where participants live. A full list of the data collected for each survey can be found in the Statement of Purpose here.

The second type of data processed by the National Care Experience Programme are survey responses, provided directly by survey participants.

4. Legal context

HIQA as data controller has a remit under Article 8 (1) (g) of the Health Act 2007 ‘to operate such other schemes aimed at ensuring safety and quality in the provision of the services as the Authority considers appropriate’. Survey responses are used to inform quality improvements in healthcare, ensuring quality and safety in the provision of services.

The National Care Experience Programme has developed a comprehensive information governance framework to ensure that the privacy rights of all participants are upheld. The National Care Experience Programme complies with data protection legislation, including the GDPR. Under Article 6 (1) (e) of the GDPR and Section 38 of the Data Protection Act 2018, personal data can be collected and 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 permit the processing of healthcare data, which are “special category data”, in the public interest, which includes ensuring high standards of quality and safety in healthcare.

The National Care Experience Programme complies with the Data Sharing and Governance Act 2019, where it applies to the sharing of information between public bodies for the purposes of conducting the surveys. Section 13 (2) (a) (ii) (V), (VI) and (VII) provide a legal basis to process data collected by the National Care Experience Programme for the purposes of service administration and supervision and facilitating the improvement of a service and evaluating a service.

The National Care Experience Programme is conducted in the public interest; the partner organisations of the programme have committed to using the results of surveys to inform quality improvements across health and social care, from policy and planning to service delivery. The collection of personal data is a necessary step to carry out surveys that capture the experience of people using health and social care services.

Data collected by the National Care Experience Programme may be used for secondary analysis. A formal request can be made to gain access to anonymised survey responses, in line with the National Care Experience Programme Data Access Request Policy. The request must demonstrate that the secondary analysis of the data is in the public interest.

5. Responsibilities under this policy

HIQA acts in the capacity of the data controller for all of the data that it collects as part of the National Care Experience Programme. HIQA has contracted a data processor, Ipsos Limited[*], which is responsible for administering surveys.

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[*] Ipsos Limited is a market research agency. More information on the company can be found on their website www.banda.ie.

6. Data Protection Principles

Article 5 of the GDPR sets out seven data protection principles. These are:

- lawfulness, fairness and transparency
- purpose limitation
- data minimisation
- accuracy
- storage limitation
- integrity and confidentiality
- accountability.

Section 6.1 outlines how the National Care Experience Programme complies with the data protection principles.

6.1 Data protection principles

a) Data must be processed lawfully, fairly and transparently.

- The National Care Experience Programme complies with data protection legislation, including the GDPR 2016, the Data Protection Acts 1988 — 2018 and the Data Governance and Sharing Act 2019.

- A data protection impact assessment (DPIA) is completed in advance of each survey, to firstly identify data privacy risks and then identify and implement controls to reduce risks and protect the confidentiality of data subjects. A summary of the DPIA is published on the National Care Experience Programme's website to enable survey participants to access information regarding how the data protection rights of individuals included as survey participants are considered and safeguarded. DPIA summaries can be found here.

- Stakeholder engagement plans are developed and implemented for each survey to ensure that complete transparency is provided around the purpose of the survey and the eligibility criteria. This includes providing information about the survey in healthcare settings in the form of posters, information leaflets and other communication tools as well as directly providing eligible survey participants with information about the survey. An example of this is providing inpatients with an information pack about the National Inpatient Experience Survey on discharge from hospital during survey sample periods. The information pack contains a letter and an FAQ, which informs patients about the survey and provides them with the option to opt out.

- Participation in National Care Experience Programme surveys is voluntary. Eligible survey participants are provided with the option to opt out when informed about the survey and can opt out at any point during a live survey cycle.

b) Purpose limitation: data must be collected for specified, explicit and legitimate purposes.

- National Care Experience Programme data are collected for specified purposes and only used for those purposes.
    - The contact datasets, which contain the names and contact details are processed to apply eligibility criteria and administer the survey – that is sending out surveys, organising interviews and managing survey responses. Data may also be used to compare, with the aim of improving, the experiences of different communities in Ireland based on demographic conditions, such as age, length in stay in a healthcare facility and the areas where participants live.
    - Survey responses are used to identify what works well in care and where improvements are needed.
    - Survey responses may be made available for secondary analysis and research, once anonymised.

c) Data minimisation: NCEP data are adequate, relevant and limited to what is necessary.

- To ensure that the National Care Experience Programme only collect the minimal amount of data necessary to carry out a survey, two steps are taken:
    - The contact datasets that contain the names, mobile numbers, addresses and other data of eligible survey participants are reviewed by key stakeholders[†] to ensure that only data that are necessary and proportionate to the aims of the survey are processed. No additional or extraneous data are collected.
    - Survey questionnaires are reviewed by key stakeholders[‡] to ensure that surveys only elicit responses that provide data proportionate to the aims of the survey and therefore fulfil its purpose, which is to identify what works well and what can be improved in care.

[†] Stakeholders involved in reviewing the contact datasets collected to administer the survey include the project team, Data Protection Officer(s) and the Director of the National Care Experience Programme.

[‡] Stakeholders involved in reviewing survey questionnaires include the project team, the Data Protection Officer, the Director of the National Care Experience Programme and the survey's main governance group, the advisory group. The advisory group provides direction on the development and implementation of surveys and includes representation from HIQA, the Department of Health, the HSE and groups that represent the interests of survey populations, such as patient advocacy groups.

d) Accuracy: NCEP data are accurate and, where necessary kept up to date.

- Contact datasets provided by service providers to carry out surveys are quality assured, to ensure that only eligible survey participants are included in the survey. Eligible survey participants who do not want to participate are opted out, upon request. Mortality checks are carried out to ensure that surveys are not sent to deceased individuals.

- Hard copy survey responses are audited against their online version to ensure that survey responses returned by post are transcribed accurately.

e) Storage limitation: NCEP data are kept in a form which permits identification of data subjects for no longer than is necessary, for the purposes for which the personal data are processed.

- National Care Experience Programme data are pseudonymised — the National Care Experience Programme contact datasets used to carry out surveys are stored separately to survey responses and the data in both files are not matched. A survey code is assigned to each survey participant to manage responses and avoid matching survey participants' personal information with their responses.

- Survey responses are anonymised — survey responses are anonymised to protect the identity of survey participants and ensure confidentiality. Information that may identify an individual, including survey participants, their friends or family and healthcare staff are removed from survey responses, to ensure confidentiality and to protect their identity.

- Shortly after the last surveys have been returned to the data processor by survey participants, contact datasets and the original un-anonymised survey responses are destroyed. HIQA, as data controller, oversees the destruction of this data.

f) Integrity and confidentiality: NCEP data are processed in a manner that ensures appropriate security of the personal data

- National Care Experience Programme data are:
  - transferred securely using secure file sharing software, as data is never shared by email
  - encrypted while in transfer and at rest
  - password protected. All passwords used to access survey data must be stored securely and cannot be saved to web browsers. Audit logging and account lockout is enforced on devices used to access National Care Experience Programme data, via local security settings on servers and firewalls, to restrict unauthorised and or

  nefarious access to National Care Experience Programme data
  - processed in compliance with the GDPR
  - only accessed on devices that are protected by anti-virus software
  - subject to restricted access. The National Care Experience Programme has an access control policy. Access to data is limited to the minimum number of people necessary to carry out surveys and manage survey responses
  - subject to the National Care Experience Programme Data Breach Management Procedure. All suspected data breaches must be reported to the Data Protection Officer in HIQA
  - destroyed once they have served their purpose. The Data Retention and Destruction Schedule can be found here.

g) Accountability: a data controller must be able to demonstrate compliance with the aforementioned principles.

  - HIQA as the data controller has a contract in place with its data processor to ensure that data processing activities comply with data protection legislation. In addition, HIQA has oversight of any contracts in place between its data processor and any sub-processors.
  - HIQA ensures that data sharing agreements are put in place between it and any entity it shares data with, such as hospitals and other healthcare settings, in line with any legal requirements including the GDPR, Data Protection Acts 1988 – 2018 and the Data Sharing and Governance Act 2019.
  - HIQA carries out a DPIA in advance of each survey to identify risks and put controls in place to reduce those risks. DPIAs are updated in advance of future iterations of a survey and a summary of the DPIA is published on the National Care Experience Programme website.
  - HIQA has developed an Information Governance Framework, which consists of policies, processes and procedures. All staff involved in processing data, in HIQA and any data processor, are provided with training on this policy.
  - HIQA carries out audits of its processes to ensure compliance with data protection legislation.

7. Review

This policy will be reviewed every three years or alternatively in light of any legislative or other relevant programme requirements.

8. Revision History

Number	Effective date	Reason for update
1.0	1 August 2019	Original document release
2.0	6 August 2021	Review in advance of National Inpatient Experience Survey
3.0	01 May 2022	Periodic review
4.0	06 October 2023	Correction of version history. No change to content or dates
5.0	10 March 2025	Periodic review

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

An Roinn Sláinte
Department of Health