



**National Care
Experience
Programme**

A large, dark blue circular graphic occupies the lower two-thirds of the page. Inside this circle, there are several white, thick, curved lines that sweep across the space. Interspersed among these lines are four small white squares, some of which are slightly rotated. The overall effect is a dynamic, abstract pattern.

**Data Protection and
Confidentiality Policy**

National Care Experience Programme

Data Protection and Confidentiality Policy – Policy

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Author:	National Care Experience Programme Team
Approved by:	Rachel Flynn, Director of the National Care Experience Programme
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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 includes the National Inpatient Experience Survey — an annual survey providing patients with the opportunity to describe their experiences of public acute hospital care in Ireland. The purpose of this survey is to learn from patients' feedback to find out what is working well in our hospitals, and what needs improvement. The results of the National Inpatient Experience Survey inform the development of quality improvement plans at hospital, hospital group and national levels and informs regulation and national legislation.

The National Maternity Experience Survey offers women the opportunity to share their experiences of Ireland's maternity services. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their baby receive. The first National Maternity Experience Survey will be carried out in early 2020.

A National Care Experience Programme competency centre is currently under development in order to provide support, guidance, information and leadership on the appropriate collection and use of care experience data for all engagement programmes in the health and social care services.

The National Care Experience Programme will expand to include two further surveys of health or social care services by 2021.

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 data subjects when collecting, processing and managing personal data. The Data Protection Acts 1988 to 2018 and the General Data Protection Regulation (EU) 2016/679 (GDPR) confer rights on individuals as data subjects, and responsibilities on HIQA as a data controller.

2. Policy statement

The National Care Experience Programme will process personal data in accordance with the Data Protection Acts 1988 to 2018 and the GDPR. Personal data collected is used fairly, stored safely and securely and not disclosed unlawfully.

Maintaining the security, confidentiality and integrity of data is a responsibility shared by all persons working on the National Care Experience Programme for or on behalf of HIQA.

3. Scope

This policy outlines the arrangements made by the National Care Experience Programme to meet its legal obligations in relation to the Data Protection Acts 1988 to 2018 and the GDPR.

This policy relates uniquely to the National Care Experience Programme. It applies to all persons working on the National Care Experience Programme for or on behalf of HIQA. All information relating to an individual, held in electronic or in paper format, collected by the National Care Experience Programme, preserved in the form of records, is covered by this policy.

Categories of data covered under this policy

Two categories of information are collected in the course of the National Patient Experience Survey Programme.

The first of these is administrative data which includes personally identifiable and sensitive information such as the contact details of people using health and social care services. This data is only used for the purpose of administering the survey to potential participants, and is managed in line with the National Care Experience Programme's information governance framework. The following information is collected to administer surveys:

- name
- address
- date of birth
- gender
- date of admission
- source of admission

- date of delivery (in the case of people using maternity services)
- date of discharge
- discharge destination
- length of stay
- hospital name
- hospital group.

Information on the experience of people using services will be sought through responses to surveys.

Participation in National Care Experience Programme surveys is voluntary and anonymous. Potential participants who meet the eligibility criteria are assigned a unique code. This code, rather than participants' names, is used to track survey responses. The codes do not contain personally identifiable information.

4. Legal context

Participation in the National Care Experience Programme is voluntary. Participants are informed by service providers that they will be invited to participate in a survey, at which time participants can opt out. Eligible participants who do not want to participate can also opt out, upon receipt of the survey.

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 laws, 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 is "special category data", in the public interest, which includes ensuring high standards of quality and safety in healthcare.

The National Care Experience Programme is conducted in the public interest; the partner organisations of the programme have committed to using the results to inform quality improvements across the health care system, from policy to planning and service delivery. The collection of personal data is a necessary step to administer surveys capturing feedback on 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 Requests Policy. The request must demonstrate that the secondary analysis of the data is in the public interest.

There is a contract and a Data Processing Agreement in place between HIQA and the data processor to define the arrangements for the secure sharing, storage, handling, processing and destruction of all data collected by the National Care Experience Programme.

5. Responsibilities under this policy

Data controller and data processor roles and responsibilities

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

Corporate responsibilities:

Director of the National Care Experience Programme

The Director of the National Care Experience Programme (HIQA):

- has overall responsibility for data protection activities in the context of the National Care Experience Programme
- shall provide all the necessary resources to ensure that personal, confidential and sensitive data is maintained in a secure manner.

Data Protection Officer's (HIQA) responsibilities

The Data Protection Officer in HIQA is responsible for:

- assisting the National Care Experience Programme in complying with data protection legislation
- co-ordinating internal audit activities related to data protection
- ensuring compliance with legislative requirements and consulting with legal advisors where necessary
- co-ordinating activities in relation to data protection breaches
- co-ordinating data subject "access request" activities
- providing training programmes as required for staff
- reviewing information distributed to stakeholders, such as service provider staff and the general public, on information governance.

Managers' responsibilities:

The Senior Programme Manager of the National Care Experience Programme in HIQA and the Project Director within the data processor are required to ensure that appropriate resources are made available within their teams to ensure that the programme can meet its legal obligations in relation to the Data Protection Acts 1988 to 2018 and the GDPR, in the context of the programme's information governance framework. It is the responsibility of the Senior Programme Manager and Project Director to ensure that staff:

- understand their roles and responsibilities in relation to data protection
- ensure policies are adhered to
- ensure policies are up to date and fit for purpose
- escalate data breaches, as per the Data Breach Management Policy.

6. Individual Rights

The individuals for whom the National Care Experience Programme stores personal data have the following rights:

- 1) to be informed of the identity of the data controller and of the purpose for which the information is held, and other relevant information
- 2) to object to the processing of their data or restriction of the processing in certain instances
- 3) to have their personal data obtained and processed fairly and transparently, kept securely, and not illegitimately disclosed to others
- 4) to get a copy of their personal data upon request
- 5) to have their personal data corrected or deleted if inaccurate
- 6) to not have their personal data used for purposes other than the administration of the National Care Experience Programme

6.1 Right to opt out

Participation in National Care Experience Programme surveys is voluntary. Potential participants are provided with a participant information leaflet and an invitation letter at the point of discharge. This will allow potential participants to make an informed decision about whether or not to take part in a National Care Experience Programme survey. The participant information leaflet further outlines how survey responses are used and reassures participants that all survey responses are treated anonymously.

Eligible participants who do not want to take part can opt out of the survey:

- while still in hospital and prior to their data being processed
- over the phone, online, or by returning a blank questionnaire after they have received a survey pack in the post.

7. Data Protection Principles

The National Care Experience Programme will administer its responsibilities in line with the principles outlined in Article 5 of the GDPR. Under Article 5, personal data processed by the National Care Experience Programme must be:

- processed lawfully, fairly and transparently
- collected for specified, explicit and legitimate purposes and not further processed (Further processing for research or statistical purposes in the public interest shall not be considered to be incompatible with this principle, as any further processing concerns anonymized survey response data and not personally identifiable information)
- adequate, relevant and limited to what is necessary in relation to the purposes for which data are processed
- accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate are erased or rectified without delay

- 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; personal data can be stored for longer periods insofar as the personal data will be processed solely for research or statistical purposes in the public interest
- processed in a manner that ensures appropriate security of the personal data.

In line with Article 5(2), HIQA shall be responsible for and able to demonstrate compliance with the aforementioned principles.

8. Data protection security

A Data Privacy Impact Assessment is conducted and updated annually for each survey. The Data Privacy Impact Assessment identifies all privacy risks associated with the National Care Experience Programme and recommends the controls to be put in place to minimise identified risks. In addition, the National Care Experience Programme has a comprehensive information governance framework to protect the privacy of all information collected. Furthermore, the processes detailed below are in place to ensure the security of data collected:

Extraction of data from participating hospitals: data extracted at hospital level is transferred via secure File Transfer Protocol (sFTP) to the data processor.

Encryption of contact details: once received from service providers, the administrative data of potential participants is encrypted and access to it will be limited to pre-identified individuals.

Storage of data: participant contact details and survey responses will be stored on separate servers to ensure that the databases cannot be linked.

Destruction and retention of data: shortly after the last surveys have been returned to the data processor by survey participants, the contact details of participants are electronically shredded. HIQA, as data controller, oversees the destruction of this data.

Securing survey responses: all hard copy survey responses are anonymised. Access to the survey responses is limited to pre-identified individuals.

Low responses numbers at hospital level: to ensure full anonymity, the National Care Experience Programme Team will not reveal survey findings to service providers, if they receive less than 30 responses.

Data sharing agreements: data sharing agreements are in place between HIQA and all participating service providers and a data processing agreement is in place between HIQA and the data processor. This ensures that all organisations involved in the National Care Experience Programme understand their roles and responsibilities in the area of information governance.

9. Breach of data protection security

The National Care Experience Programme will manage any data protection breaches in line with the National Care Experience Programme Data Breach Management Procedure. This procedure addresses situations where personal data has been put at risk of unauthorised disclosure, loss, destruction or alteration.

10. Statement of information practices

The National Care Experience Programme has a Statement of Information Practices, which is publically available on www.yourexperience.ie.

This statement provides the general public with an overview of the types of information collected by the National Care Experience Programme and how the programme makes use of such personal information.

11. Data Privacy Impact Assessment

A Data Privacy Impact Assessment is a process that facilitates the protection and enhancement of individuals' privacy. The National Care Experience Programme completes a Data Privacy Impact Assessment for each survey and commits to conducting repeat assessments for surveys, should this be warranted by changes to survey methodology, processes or the legislative environment. The findings of Data Privacy Impact Assessments are made available on www.yourexperience.ie.

12. Training and awareness

All persons working on the National Care Experience Programme for or on behalf of HIQA will receive training on this policy.

13. Breach of this policy

Breaches to this policy may be considered in line with HIQA's disciplinary policies (as the case may be). Wrongful or deliberate disclosure of personal or confidential data will be considered as an act of gross misconduct.

14. Information governance auditing

The Data Protection and Confidentiality Policy is subject to ongoing internal audit.

15. Review

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

16. 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

17. Individuals with responsibilities under this policy

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