



National Patient  
Experience Survey  
Programme

Data Protection and  
Confidentiality Policy



# National Patient Experience Survey Programme

## Data protection and confidentiality policy

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**Author:** National Patient Experience Survey Team

**Approved by:** Rachel Flynn, Director of Health Information and Standards (HIQA)

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## 1. Background

The National Patient Experience Survey Programme conducts annual surveys of patients in the Irish public healthcare system. It gives patients an opportunity to describe their experiences during their stay in hospital through the completion of a survey. The data collected from the survey will inform future healthcare policy and improve outcomes for patients. It will be a key building block in the creation of a strong patient safety culture in our health service.

The National Patient Experience Survey Programme is a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. HIQA, as the lead partner in this initiative, is responsible for the implementation of the survey programme.

HIQA has contracted an agent, which is responsible for the administration of the National Patient Experience Survey Programme. A contract, in addition to a Data Sharing Agreement, has been signed between both parties and outlines the roles and responsibilities of the third party, in its capacity as data processor on behalf of HIQA.

### Data controller and data processor roles and responsibilities

HIQA acts in the capacity of the data controller for all of the data that it or its agents collect as part the National Patient Experience Survey Programme.

HIQA's agent acts in the capacity of data processor on behalf of HIQA for all of the data that it collects as part of the National Patient Experience Survey Programme.

### 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 personal and personally identifiable information such as patients' contact details. This data will only be used for the purpose of administering the survey to participants, and will be managed in line with the National Patient Experience Survey Programme's information governance framework.

The following information will be collected to administer the survey:

- name
- address
- date of birth
- gender
- date of admission
- source of admission
- date of discharge
- discharge destination
- length of stay
- hospital group
- hospital name.

Information on patient experience will be sought through patients' responses to the survey.

Participation in National Patient Experience surveys is voluntary and anonymous. 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.

## Legal context

The National Patient Experience Survey Programme has developed a comprehensive information governance framework to ensure that the privacy rights of all participants are upheld.

The National Patient Experience Survey complies with data protection laws. Under Article 6 (1) (e) of the European Union (EU) General Data Protection Regulation (GDPR) 2016, individuals' information can be collected and processed for a task carried out in the public interest. The survey is equally conducted in accordance with Section 2 (A) of the Data Protection Act 1988 and 2003. According to this section, the processing of data is permissible if it is necessary for the performance of a function of a public nature performed in the public interest.

The National Patient Experience Survey Programme is conducted in the public interest. The partner organisations have committed to using the results of the survey to inform quality improvement across the health care system, either through

- a) direct quality improvement initiatives within each hospital and hospital group
- b) using the findings to inform policy, regulation programmes and service delivery planning.

The collection of personal data for the purpose of administering the survey is a necessary step to understand patients' perspectives of the care they receive and use that experience to drive improvements in that experience.

Data collected by the National Patient Experience Survey Programme may be used for secondary analysis by academic institutions. To gain access to the anonymised survey responses, academic institutes will have to

- make a formal request, in line with the Data Subject Access Request Policy (Reference: 04a-NPE-POL-05.18)
- demonstrate that any analysis is in the public interest
- have gained ethical approval from their academic institution

There is a contract and a data sharing agreement in place between HIQA and their agent that define the arrangements for the secure sharing, storage, handling and processing of all data collected by the National Patient Experience Survey Programme.

## 2. Purpose of this policy

The purpose of this document is to outline the National Patient Experience Survey Programme's policy in relation to the protection and safeguarding of the privacy rights of individuals when collecting, processing and managing personal data. The Data Protection Act 1988 and 2003 and the European Union General Data Protection Regulation 2016 confer rights on individuals as data subjects, and responsibilities on HIQA as a data controller.

### Policy statement

The National Patient Experience Survey Programme will process personal data in accordance with the Data Protection Act 1988 and 2003 and the European Union General Data Protection Regulation 2016. Personal data collected, will be 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 Patient Experience Survey Programme for or on behalf of HIQA.

## Scope

This policy outlines the arrangements made by the National Patient Experience Survey Programme to meet its legal obligations in relation to the Data Protection Act 1988 and 2003 and the European Union General Data Protection Regulation 2016.

This policy relates uniquely to the National Patient Experience Survey Programme. It applies to all persons working on the National Patient Experience Survey Programme for or on behalf of HIQA.

All information relating to an individual, held in electronic or in paper format, collected by the National Patient Experience Survey Programme, preserved in the form of records, is covered by this policy.

This policy will be reviewed every year or alternatively in light of any changes to the survey programme and or data protection legislation.

## 3. Responsibilities under this policy

### Corporate responsibilities:

- The Director of Health Information and Standards (HIQA) has overall responsibility for data protection activities in the context of the National Patient Experience Survey Programme and has delegated this responsibility to the Data Protection Officer in HIQA.
- The Director of Health Information and Standards (HIQA) shall provide all the necessary resources to ensure that personal, confidential and sensitive data is maintained in a secure manner.

### **Data Protection Officer's responsibilities:**

- Assist the National Patient Experience Survey Programme in complying with data protection legislation.
- Co-ordinate internal audit activities related to data protection.
- Ensure compliance with legislative requirements and consult with legal advisors where necessary.
- Co-ordinate activities in relation to breaches of data protection.
- Co-ordinate all 'access request' activities.
- Ensure annual registration is kept up to date with the Office of the Information Commissioner.
- Provide training programmes as required for staff.
- Prepare and distribute information for both staff and the general public.
- Register the categories of personal data the National Patient Experience Survey Programme holds with the Office of the Data Protection Commissioner.

### **Managers' responsibilities:**

- The National Patient Experience Survey Programme's Programme Manager in HIQA and the programme manager in HIQA's agent are required to ensure that appropriate resources are made available within their teams to ensure that the survey programme can meet its legal obligation in relation to the Data Protection Act 1988 and 2003 and the European Union General Data Protection Regulation 2016, in the context of the survey programme's information governance framework. It is the responsibility of the aforementioned managers to organise training sessions on this policy for all persons working on the National Patient Experience Survey Programme.

## 4. Individual Rights

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

- to have their personal data obtained and processed fairly, kept securely and not illegitimately disclosed to others
- to be informed of the identity of the data controller and of the purpose for which the information is held
- to get a copy of their personal data upon request
- to have their personal data corrected or deleted if inaccurate
- to prevent their personal data from being used for purposes other than the administration of the National Patient Experience Survey Programme.

### 4.1 Right to opt out

Participation in the National Patient Experience Survey Programme is voluntary. Prior to leaving hospital, all patients discharged from participating hospitals, who meet the survey eligibility criteria will be 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 Patient Experience survey. The patient information leaflet further outlines how survey responses will be used and reassures participants that all survey responses will be processed in confidence.

Eligible participants who may want to opt-out of the survey, can avail of one of the 5 different opt out mechanisms available:

- i. opt out while still in hospital and prior to their data being processed (that is the personal information required to administer the survey)
- ii. over the phone, on the website, by email, or by returning a blank questionnaire after they have received a survey pack in the post or by simply not participating in the survey.

By participating in the National Patient Experience Survey Programme, respondents willingly consent to providing information on their experience in hospital.



## 5. The National Patient Experience Survey Programme administrative and operational activities in response to the principles of the data protection legislation

### Data Protection Acts 1988 and 2003

The National Patient Experience Survey Programme will administer its responsibilities under the legislation in accordance with the eight stated data protection principles outlined in the Data Protection Acts 1988 and 2003<sup>1</sup>, which are as follows:

**1. Obtain and process information fairly.**

The National Patient Experience Survey Programme will obtain and process personal data fairly and in accordance with the fulfilment of its function, that is to conduct a national survey of patient experience in public hospitals.

**2. Keep data only for one or more specified, explicit and lawful purposes.**

The National Patient Experience Survey Programme will keep data for purposes that are specific, lawful and clearly stated and the data will only be processed in a manner compatible with these purposes.

**3. Use and disclose data only in ways compatible with these purposes.**

The National Patient Experience Survey Programme collects personal data for the sole purpose of administering the survey. It does not use or disclose personal information in a manner incompatible with the former.

**4. Keep data safe and secure.**

The National Patient Experience Survey Programme realises that high standards of security are essential for all personal data. The programme will take appropriate security measures against unauthorised access to, or alteration, disclosure or destruction of, the data and against their accidental loss or destruction.

<sup>1</sup> Data Protection (Amendment) Act 2003, 2003. Available from:  
<http://www.irishstatutebook.ie/eli/2003/act/6/enacted/en/html>

**5. Keep data accurate, complete and up-to-date.**

The National Patient Experience Survey Programme has developed procedures that are adequate to ensure high levels of data accuracy and completeness.

**6. Ensure that data are adequate, relevant and not excessive.** Personal data held by the National Patient Experience Survey Programme will be adequate, relevant and not excessive in relation to the purpose for which it is collected.

**7. Retain data for no longer than is necessary for the purpose or purposes for which they are kept.**

The National Patient Experience Survey Programme has a policy on retention periods for personal data. It has developed a retention and destruction schedule for personal information collected as part of the National Patient Experience Survey Programme.

**8. Give a copy of his/her personal data to that individual, on request.**

The National Patient Experience Survey Programme developed a Data Subject Access Request Policy (Reference: 04a-NPE-POL-05.18) to ensure that data subjects can exercise their rights under data protection legislation.

**European Union General Data Protection Regulation 2016**

The National Patient Experience Survey Programme will administer its responsibilities in line with the principles outlined in Article 5 of the European Union General Data Protection Regulation 2016. Under article 5, information collected by the National Patient Experience Survey Programme must be:

1. 'processed lawfully, fairly and transparently
2. 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
3. adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed

4. 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
5. 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
6. processed in a manner that ensures appropriate security of the personal data' (GDPR, 2016)<sup>2</sup>

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

## 6. Data protection security

The National Patient Experience Survey Programme has taken a number of steps to ensure the security of participants' data. A Privacy Impact Assessment was carried out, which recommended that a number of additional controls be put in place to minimise risks to the privacy of survey participants. As a result of this Privacy Impact Assessment, the National Patient Experience Survey Programme has developed a comprehensive information governance framework to protect all information collected. The programme has also been presented to the Office of the Data Protection Commissioner on a number of occasions.

Furthermore, the processes detailed below are in place to ensure security of information collected:

**Extraction of data from participating hospitals:** data extracted at hospital level is transferred via secure File Transfer Protocol (SFTP) to HIQA's agent.

**Opt out at hospital level:** patients can request that their data not be transferred to HIQA's agent. This can be done in line with the National Patient Experience Survey Programme opt-out process.

<sup>2</sup> European Union General Data Protection Regulation 2016. 2016. Available from: <https://gdpr-info.eu/>

**Encryption of contact details:** once received from hospitals, patient data is encrypted and access to it will be limited to pre-identified individuals.

**National Patient Experience Survey Programme responses:** all survey responses are securely stored and anonymised. Access to the survey responses is 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, the contact details of sampled patients are electronically shredded. HIQA, as data controller, will oversee the destruction of this data.

**Low responses numbers at hospital level:** to ensure full anonymity, the National Patient Experience Survey Programme team will not reveal survey findings for hospitals with less than 30 responses.

**Data sharing agreements:** data sharing agreements are in place between HIQA and all participating hospitals and also between HIQA and its agent. This ensures that all organisations involved in the National Patient Experience Survey Programme understand their roles and responsibilities in the area of information governance.

## 7. Breach of data protection security

The National Patient Experience Survey Programme will handle any data protection breaches in line with the Personal Data Security Breach Code of Practice<sup>3</sup>, approved by the Data Protection Commissioner. This code of practice addresses situations where personal data has been put at risk of unauthorised disclosure, loss, destruction or alteration.

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<sup>3</sup> Personal Data Security Breach Code of Practice, Section 13 (2) (b), Data Protection Acts, 1998 and 2003. Available from: <https://www.dataprotection.ie/docs/Data-Security-Breach-Code-of-Practice/y/1082.htm>

## **8. Statement of information practices**

The National Patient Experience Survey Programme shall generate a Statement of Information Practices every year or alternatively in light of changes in the survey programme or data protection legislation.

This statement will provide the general public with information on the types of information collected by the National Patient Experience Survey Programme and how the survey programme makes use of such personal information.

## **9. Privacy Impact Assessment**

A Privacy Impact Assessment is a process that facilitates the protection and enhancement of individuals' privacy. The National Patient Experience Survey Programme completed a Privacy Impact Assessment and commits to conducting repeat assessments for future surveys, should this be warranted by changes to survey methodology, processes or the legislative environment.

## **10. Training and awareness**

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

## **11. 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 and may be treated as a disciplinary offence.

## **12. Information governance auditing**

This data protection and confidentiality policy is subject to ongoing internal audit as required by the National Patient Experience Survey Programme Steering Group.

### 13. Review

This policy will be reviewed every year or alternatively in light of any legislative or other relevant project requirements.

### 14. Revision History

Number	Effective date	Reason for update
01	1 May 2017	Original document release
02	1 May 2018	Revised in line with 1)introduction of GDPR 2)changes in survey programme

### 15. Individuals with responsibilities under this policy

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