The National Patient Experience Survey Programme

Data protection and confidentiality policy

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Author: National Patient Experience Survey team
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1. Background

The National Patient Experience Survey is a nationwide survey asking patients about their experience in hospitals in Ireland. The survey 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 National Patient Experience Survey.

HIQA has contracted a third party, Behaviour & Attitudes, which is responsible for the administration of the National Patient Experience Survey. 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 Behaviour & Attitudes collects as part the National Patient Experience Survey.

Behaviour & Attitudes 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.

Categories of data covered under this policy

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

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 information governance framework.

The information necessary for the administration of the survey includes:

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

Secondly, information on patient experience will be sought through the completion of the survey. Patients are asked to answer a total of 61 structured questions, 58 of which are quantitative and three of which are qualitative.

Participation in the National Patient Experience Survey is voluntary and anonymous. Participants who meet the eligibility criteria are assigned a unique code. This code, rather than participant names, is used to track survey responses. The codes do not contain personally identifiable information.

Legal context

The Data Protection Act 1988 and the Data Protection (Amendment) Act 2003 outline the roles and responsibilities of data controllers, those organisations or individuals who hold and process personal information. The Data Protection Acts lay down strict rules to safeguard the privacy rights of all individuals who have their personal data stored by data controllers, in this case, HIQA.

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 processing and managing personal data. The Data Protection Act 1988 and the Data Protection (Amendment) Act 2003 confer rights on individuals as well as responsibilities on those persons processing personal data.

The purpose of this document is to outline how the National Patient Experience Survey Programme ensures the protection and safeguarding of the privacy rights of individuals when collecting, processing and managing personal data.

Policy statement

The National Patient Experience Survey Programme will process personal data in accordance with the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003. 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 for or on behalf of HIQA and Behaviour & Attitudes.

**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 the Data Protection (Amendment) Act 2003.

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 and Behaviour & Attitudes.

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

This policy will be reviewed on an annual basis or in light of any legislative changes.

**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 Project Manager in HIQA and the Project Director in Behaviour & Attitudes 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 the Data Protection (Amendment) Act 2003 in the context of the Programme’s information governance framework. It is the responsibility of the National Patient Experience Survey Project Manager in HIQA and the Project Director in Behaviour & Attitudes to organise training sessions on this policy for all persons working on the National Patient Experience Survey.

**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.

5. Consent

Participation in the National Patient Experience Survey is voluntary. Prior to leaving hospital, all patients discharged from a public acute hospital and 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 the 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 do not want to partake can opt-out of the survey:

i. 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, online, 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, respondents willingly consent to providing information on their experience in hospital.

6. The National Patient Experience Survey Programme administrative and operational activities in response to the principles of the Data Protection Acts

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 Act as follows:

**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 acute hospitals.
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.

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.

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.

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.

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.

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.

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 to ensure that data subjects can exercise their rights under data protection legislation.
7. Data protection security

The National Patient Experience Survey Programme consulted with the Office of the Data Protection Commissioner. In addition, a Privacy Impact Assessment was carried out which recommended that a number of additional controls are put in place to minimise risks to the privacy of survey respondents. 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.

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

**Extraction of data from participating hospitals:** data are extracted at hospital level and transferred to Behaviour & Attitudes via secure file transfer protocol.

**Opt out at hospital level:** patients can request that their data not be transferred to Behaviour & Attitudes. This can be done upon discharge.

**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 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 by Behaviour & Attitudes. The Health Information and Quality Authority (HIQA), as data controller, will witness the destruction of this data.

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

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

8. 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, approved by the Data Protection Commissioner under Section 13 (2) (b) of the Data Protection Acts, 1988 and 2003. This Code of Practice addresses situations where personal data has been put at risk of unauthorised disclosure, loss, destruction or alteration.

9. Statement of information practices

The National Patient Experience Survey Programme shall generate a statement of information practices on an annual basis. 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 Programme makes use of such personal information.

10. 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.

11. Training and awareness

All persons working on the National Patient Experience Survey for or on behalf of HIQA and Behaviour & Attitudes will receive training on this policy.
12. Breach of this policy

Breaches to this policy may be considered in line with HIQA’s and Behaviour & Attitudes’ 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 up to and including dismissal.

13. 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.

14. Review

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

15. Revision History

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<th>Reason for update</th>
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16. Individuals with responsibilities under this policy

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