

National Patient
Experience Survey
Programme

Statement of
Information Practices



The National Patient Experience Survey Programme

Statement of information practices

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We're committed to excellence in healthcare



1. What is the National Patient Experience Survey Programme?

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.

2. Purpose of this document

This document sets out what information is collected in the course of the National Patient Experience Survey Programme, 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.

The National Patient Experience Survey Programme takes a person-centred approach, which will ensure that the privacy, confidentiality and quality of all the information collected is assured and that all information is collected, used and stored in a safe and effective way.

Our statement of information practices demonstrates our commitment to openness and transparency about the way in which we collect and use information.

This document will be reviewed and revised every three years or in line with changes to the survey programme.

3. What is the purpose of the National Patient Experience Survey Programme?

The purpose of the National Patient Experience Survey Programme is to engage with patients, to hear about their experiences and to use those findings to improve patient experience in Irish hospitals.

4. What information is being collected in the National Patient Experience Survey Programme?

The survey will ask questions about admission to hospital, the ward environment, care and treatment, interaction with staff and the discharge process.

5. Who is collecting this information?

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. The survey programme is governed by a steering group, with representation from the three partner organisations and two patient representatives.

A Memorandum of Understanding between the three partner organisations formalises this partnership.

A cross-partner project team and an advisory group have been formed to support the National Patient Experience Survey Programme team in implementing the survey.

The role of each governance group and team are as follows:

- The **steering group** makes executive decisions on the operational and strategic direction of the survey programme.
- The **project team** is responsible for developing the model and methodology to implement the suite of surveys under the National Patient Experience Survey Programme.
- The **advisory group** provides advice and solutions in relation to the operational and strategic objectives for each of the suite of surveys. It includes patient representatives.
- The **National Patient Experience Team** is responsible for the development and implementation of the operational and strategic objectives on behalf of the partner organisations. The National Patient Experience Team is based in HIQA. HIQA, as lead partner, has contracted an agent, to administer the survey and process the responses received. HIQA (data controller) and HIQA's agent (data processor) are registered with the Office of the Data

Protection Commissioner.¹ The data processor is certified compliant with ISO27001:2013, an international information security standard.

HIQA's agent is responsible for:

- administering the questionnaire
- printing and distributing the questionnaire
- processing the survey responses
- designing and maintaining a public facing website for the survey programme.

HIQA's agent also hosts a secure back-end database to allow hospitals to view the results of their performance in the survey.

Figure 1 below summarises the relationships between the National Patient Experience Survey governance groups, the survey team and HIQA's agent.

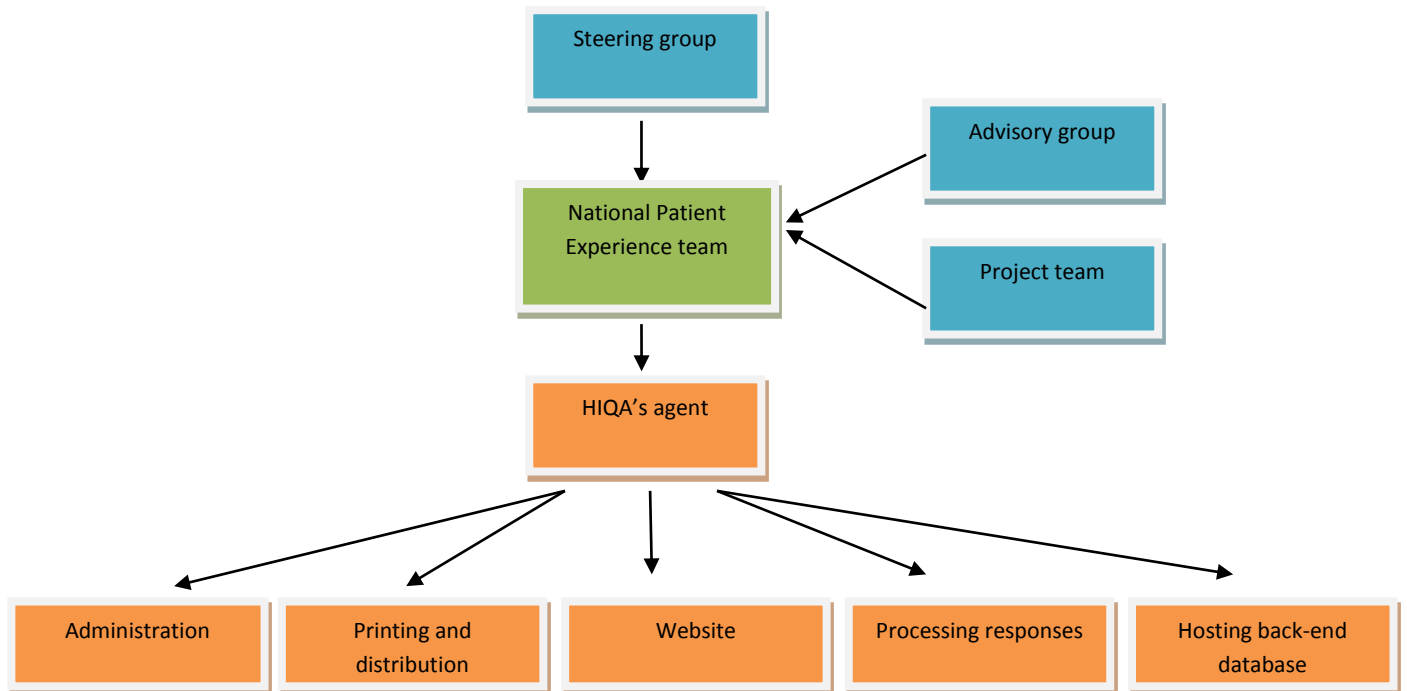


Figure 1: Relationships between the National Patient Experience Survey Programme governance groups, the survey team and HIQA's agent.

¹ The Health Information and Quality Authority is registered with the Office of the Data Protection Commissioner (Ref 9768). HIQA's agent is registered with the Office of the Data Protection Commissioner (Ref 6745/A).

6. What personal information is collected to distribute surveys?

Personal data, including personally identifiable information such as patient contact details, is collected from all participating hospitals during survey sample periods. This information is administrative data and non-sensitive. It is collected for the sole purpose of administering national surveys of patient experience in the Irish health system.

The information collected relates to participants' names, addresses, date of birth, gender, date of admission, source of admission, date of discharge, discharge destination, length of stay, hospital group and hospital name details.

During the survey sample period, hospitals extract patient information on a weekly basis and, following a series of data quality checks, exchange this information with HIQA's agent. Patients' contact details are used to distribute the questionnaire to participants' home addresses. Information on date of birth, gender and so forth is collected to help us get a more detailed picture of who will be invited to take the survey. All information will be deleted at the close of the survey cycle.

Data Sharing Agreements have been signed between HIQA and representatives of all participating hospitals. These agreements formally authorise the sharing of information.

7. How is the information on patient experience collected, recorded and stored?

Information on patient experience is collected through structured survey questionnaires. The survey asks structured tick-box questions as well as open-ended questions for comments. The survey can be completed online or by returning the questionnaire via freepost.

A detailed information governance framework has been developed to ensure that all data, including personal information, is handled in line with all relevant legislation, guidance and evidence-based practices.

8. What is the legal basis for processing eligible participants' information?

Participation in National Patient Experience surveys is voluntary. Prior to leaving hospital, all patients discharged from hospital, who meet the respective 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 are anonymous.

Eligible participants who do not want to partake 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 or by simply not participating in the survey.

By participating in a National Patient Experience survey, respondents willingly consent to providing information on their experience in hospital.

9. What is patient experience information used for?

The National Patient Experience Survey Programme will help to determine the quality and safety of healthcare services provided and to inform a system-wide quality improvement initiative in Ireland.

The information on patient experience will be used by the three partner organisations to support a variety of activities:

- the Health Service Executive (HSE) will use the results to develop and implement quality improvement plans at both hospital group and hospital level. As National Patient Experience surveys are repeated over time, it will become possible to monitor and evaluate quality improvements.
- HIQA oversees and manages the analysis, as well as the reporting of the data. It will provide an objective overview of the results, and support the HSE in translating these results into quality improvements. HIQA will also use the survey results to support and inform its monitoring and regulatory programmes of work.
- the Department of Health will use the data to inform national health policy and planning.

10. Who sees the survey results?

The results of surveys will be published and made available to the public on www.patientexperience.ie a few months after the survey has ended. The survey results will be anonymous and will be reported in summary form.

Once a hospital has received more than 30 responses, a select number of hospital personnel can access a facility to review anonymous survey responses.

11. How is the privacy of personal information protected?

A Privacy Impact Assessment was conducted to identify all privacy risks associated with the National Patient Experience Survey Programme. The Privacy Impact Assessment recommended that a number of additional controls be put in place to minimise identified risks. As a result of this Privacy Impact Assessment, the National Patient Experience Survey Programme has developed a comprehensive information governance framework to protect the privacy of all information collected.

This information governance framework outlines:

- how the personal data is used (that is, for the purpose of administering the survey)
- the necessary precautions that are in place to protect personal information from loss, unauthorised access, modification, use, disclosure and disposal
- how data protection breaches are managed
- the retention and destruction schedule for any personal data collected in the administration of the survey.

The National Patient Experience Survey Programme does not store personal data for any longer than is required beyond the administration of the survey.

Anonymity is integral to the survey design:

- participant names will not be linked with their responses
- participant contact details will be electronically shredded once the survey is complete
- all hardcopy survey responses will be shredded at the end of the survey cycle

- survey results for hospitals with less than 30 respondents will not be published to ensure that there is no risk of identification for participants.

12. How can people access personal information held about them?

Under data protection legislation, individuals have a number of rights which a data controller is obliged to respect. At a most fundamental level, individuals have the right to have their details used in line with data protection regulations. They have the right to know if an organisation or individual is holding information on their person, and to access this information. They also have the right to have their information changed or removed by a data controller. A complete [guide to your rights](#) is available on website of the Data Protection Commissioner.

The National Patient Experience Survey Programme has a data subject access request policy, which outlines how a data access request can be submitted. This policy is available to download at www.patientexperience.ie.

13. Further information on information handling practices

Further details on information handling practices can be found on www.patientexperience.ie.

Our website has a dedicated section on information governance, where you can find out more about our information governance framework designed to protect and safeguard all information collected in the course of the National Patient Experience Survey Programme.

Alternatively, you can write to us at

info@patientexperience.ie

or

The National Patient Experience Survey
 c/o Health Information and Quality Authority
 George’s Court
 George’s Lane
 Smithfield
 Dublin 7.

14. Review

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

15. Revision History

Number	Effective date	Reason for update
01	1 May 2017	Original document release
02	1 May 2018	Updated due to 1) introduction of data protection legislation 2) extension of survey programme

16. Signatures of all parties responsible:



_____ **Rachel Flynn** _____

Director of Health Information and Standards, Health Information and Quality
Authority



_____ **Brian Ahern** _____

Data Protection Officer, Health Information and Quality Authority

