



National Patient
Experience Survey
Programme

Statement of
Purpose

National Patient Experience Survey Programme

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1. Introduction

The National Patient Experience Survey Programme conducts 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.

All patients aged 16 and over who are discharged from participating hospitals during designated survey sample periods will be invited to participate in a survey.

Participants will be asked questions on topics such as confidence and trust in hospital staff, hospital food, care and treatment, and whether their medications and possible side-effects were explained before discharge from hospital.

As a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health, the National Patient Experience Survey Programme will use data collected from surveys to shape 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.

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

The role of each partner organisation within Ireland's healthcare system is as follows:

HIQA is an independent authority which was established to drive high quality health and social care services in Ireland. Its function is to develop standards, inspect and review health and social care services and support informed decisions on how services are delivered.

The HSE is the statutory body with responsibility for the management and delivery of health and social care services in Ireland.

The Department of Health provides leadership and policy direction for the health sector in order to improve health outcomes and, through effective performance oversight, ensure accountability and high-quality health service delivery. The overall aim of the Department is to improve the health and wellbeing of people in Ireland.

2. What is the aim of the National Patient Experience Survey programme?

The **aim** of the National Patient Experience Survey Programme is to engage with and understand the experience of patients and use this feedback to inform future development, planning, design and delivery of improved patient-centred care.

3. What are the objectives of the National Patient Experience Survey Programme?

The **objectives** of the National Patient Experience Survey Programme are to provide patients with the opportunity to share their experience, which will help the partner organisations to:

- improve future planning and delivery of healthcare
- develop and build quality and safety improvement initiatives
- improve patient experience at local and national level
- shape national and local policy as appropriate
- allow comparisons and benchmarking of service delivery, both nationally and internationally
- collaborate with academic institutions to facilitate further analysis of patient experience
- build a competency centre that will provide expertise nationally in the development and delivery of surveys.

4. What is the governance and management structure of the National Patient Experience Survey Programme?

HIQA is the lead partner for the National Patient Experience Survey Programme and is responsible for providing a centralised, coordinated approach for the implementation of the survey programme. HIQA holds responsibility as data controller under the provisions of the Data Protection Act 1988 and 2003 and the European Union General Data Protection Regulation 2016.

HIQA's primary responsibilities are to:

- develop survey models and methodologies
- develop a communications strategy
- develop processes and procedures to support the implementation of surveys
- analyse and report the survey data
- support the HSE in the development of quality improvement plans
- oversee secondary analysis of the data by academic institutions.

The HSE is working with HIQA to ensure successful implementation of the National Patient Experience Survey Programme across the participating hospitals.

The HSE's primary responsibilities are to:

- provide national oversight to ensure the project is implemented and delivered in accordance with the scope and timelines across each of the hospitals
- drive engagement between staff and patients to promote the survey programme
- ensure the appropriate systems and processes are in place to implement surveys
- use the findings of surveys to develop quality improvement plans in order to drive improvements across the healthcare sector
- oversee and assist with developing a cohesive approach to the successful delivery of quality improvement plans within agreed timeframes.

The Department of Health provides leadership and policy direction for the health sector in order to improve health outcomes and, through effective performance oversight, ensure accountability and high-quality health service delivery. The overall aim of the Department is to improve the health and wellbeing of people in Ireland by:

- keeping people healthy
- providing the healthcare people need
- delivering high quality services
- getting the best value from health system resources.

The Department of Health recognises patient safety as the cornerstone to quality healthcare. In December 2016, the Department of Health established the National Patient Safety Office (NPSO) to progress a policy programme of patient safety legislation, patient safety and the national clinical effectiveness framework.

5. How is the National Patient Experience Survey Programme governed?

The survey programme is governed by a Steering Group, which makes executive decisions on all proposals put forward by the project team. The Steering Group comprises of representatives from HIQA, the HSE and the Department of Health, in addition to two patient representatives.

The National Patient Experience Team is responsible for the development and implementation of surveys on behalf of the partner organisations. The team is also responsible for analysing and publically reporting on the responses to surveys.

In addition, further guidance on the model and methodology of surveys is provided by the Project Team and the Advisory Group

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

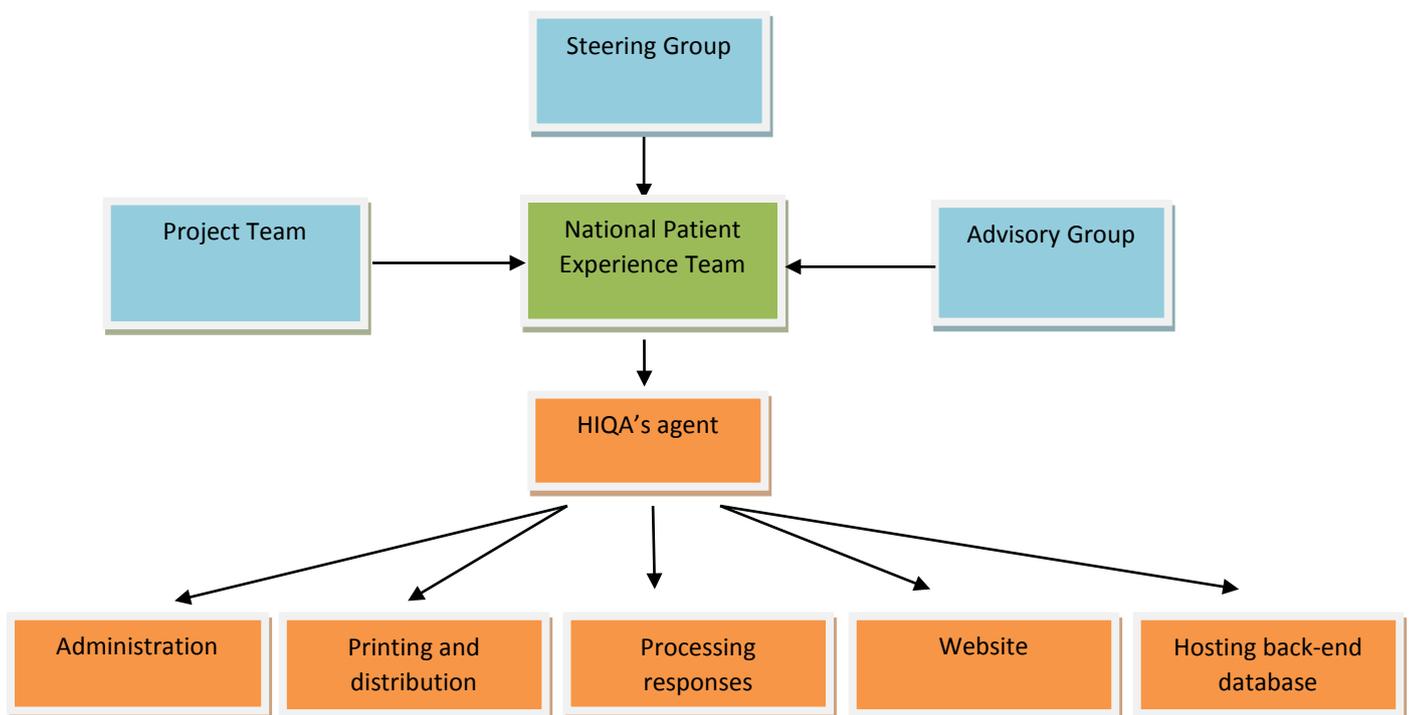


Figure 1: Relationships between the National Patient Experience Survey Programme governance groups, the National Patient Experience Team and HIQA's agent.

6. Who are the data providers?

Personal information, including personally identifiable information such as patient contact details, is collected from participating hospitals during survey sample periods. Each hospital is a data provider and the sharing of such data is governed by a formal Data Sharing Agreement between participating hospitals and HIQA.

Personal information is collected for the sole purpose of administering national surveys of patient experience in the Irish health system.

7. What personal data is collected during the survey?

Personal data is collected for eligible participants only.

The information collected includes:

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

Participating hospitals collect this information during the survey month and share it with HIQA's agent who administer the survey on HIQA's behalf.

Access to this data is restricted to pre-defined persons and the information is handled in complete confidence and stored securely. It is held for a period of three months for the purposes of administering the corresponding survey, after which time it is destroyed.

8. What is the legal basis underpinning the programme?

The National Patient Experience Survey Programme complies with data protection laws. Under Article 6 (1) (e) of the European Union General Data Protection Regulation 2016¹, individuals' information can be collected and processed for a task carried out in the public interest. Surveys are 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' (Data Protection (Amendment) Act 2003).²

The National Patient Experience Survey Programme is conducted in the public interest; the partner organisations of the survey programme have committed to using the survey results to inform quality improvements across the health care system, from policy to planning and service delivery. The collection of personal data for the purpose of administering the survey is thus a necessary step to conduct surveys capturing feedback about patient experience in the Irish health system.

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 institutions 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 previously gained ethical approval from their academic institution

There is a contract and a Data Sharing Agreement in place between HIQA and HIQA's agent to define the arrangements for the secure sharing, storage, handling, processing and destruction of all data collected by the National Patient Experience Survey Programme.

¹ European Union General Data Protection Regulation 2016. 2016. Available from: <https://gdpr-info.eu/>

² Data Protection (Amendment) Act 2003, 2003. Available from: <http://www.irishstatutebook.ie/eli/2003/act/6/enacted/en/html>

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

9. What is the source of funding?

The National Patient Experience Survey Programme is funded by the three partner organisations, HIQA, the HSE and the Department of Health; this is underpinned by the Memorandum of Understanding, signed by each of the partner organisations.

10. What national legislation and standards must the National Patient Experience Survey Programme adhere to?

The National Patient Experience Survey Programme is aligned with national legislation and standards including:

- the European Union General Data Protection Regulation 2016
- the Data Protection Act 1988 and the Data Protection (Amendment) Act 2003
- Information Management Standards for National Health and Social Care Data Collections (2017).

11. Further information on information handling practices

Further details on information handling practices can be found at 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 also email us at info@patientexperience.ie or write to us at:

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12. Review

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

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

13. Signatories of the three partner organisations



_____Phelim Quinn_____

on behalf of the Health Information and Quality Authority



_____Kathleen Mac Lellan_____

On behalf of the Department of Health



_____Patrick Lynch_____

On behalf of the Health Service Executive

