

The National Patient Experience Survey Programme

Data Access Requests Policy

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What is the National Patient Experience Survey?

The National Patient Experience Survey Programme is the first of its kind in Ireland. It gives patients an opportunity to describe their experiences during their stay in hospital and this information will be used to improve our health service.

The target population for the survey includes all adult patients aged 16 and over¹, who have spent a minimum of 24 hours in a public acute hospital, have been discharged during a specific month and who hold a postal address in the Republic of Ireland.

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 the survey 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.

Purpose of this document

Due to the sensitive and personal nature of the data collected in the survey, defined procedures must be followed with regard to the release of information. These procedures apply both to the supply of data by the National Patient Experience Survey Programme and to its subsequent analysis and publication. This document sets out the guidelines for the release of National Patient Experience Survey data.

General guidelines on information release

As a general principle stated under Article 5 of the General Data Protection Regulation, the processing of personal data for purposes other than those for which the personal data were initially collected should only be allowed where the new purpose of the processing is compatible with the purposes for which the personal data were initially collected.

In supplying data, the National Patient Experience Survey must comply with its obligations of confidentiality under the Data Protection Acts, 1988 and 2003. The use of the data by the applicant must also be consistent with the Data Protection Acts.

¹ The 2017 survey did not include patients under the age of 18.

Individuals or groups requesting information will be asked to complete a request form to ascertain the nature of information sought, its intended purpose and provisions for secure storage and destruction of data. Further information may be found in the Data Access Request Form. All data requests will be reviewed at an appropriate level, depending on the nature of the information requested.

Types of information which may be requested

General information:

This information is at the same level of detail as that which is published in the hospital, hospital group and national reports. Examples include stage of care scores and frequencies of themes for qualitative comments, broken down by age, sex or admission type. Requesters are encouraged to check if the information sought has already been made available in National Patient Experience Survey reports before making a request.

Aggregate information:

Aggregate information is that which is analysed in greater detail than general information, at a level which is not routinely produced and published by the National Patient Experience Survey, but does not allow the direct identification of individuals or hospitals. Aggregate information may, for example, include stage of care scores with additional filtering by demographic variables not already reported upon.

Individual-level data:

The National Patient Experience Survey does not hold personal data such as names and addresses, however the nature of conditions described, hospitals attended and other participant-provided information could potentially be identifiable.

Fully anonymised individual-level survey response data which carries no risk of identification may be provided if reviewers are satisfied that the request complies with ethical and legal obligations and is scientifically sound and feasible.

Requesting data

All data applicants are required to complete a request form. All data requests will be reviewed on receipt and assessed at an appropriate level. Requests for data with no potential to identify an individual will be assessed by the National Patient Experience Survey Project Team.

Requests for data where there is a risk of identifying individuals will require further scrutiny and will thus be assessed by the National Patient Experience Survey Steering Group. Such requests will take longer to process and may be subject to modification and restrictions in terms of use.

Conditions of use for National Patient Experience Survey data

The following conditions apply to the release of National Patient Experience Survey data:

1. The likely benefits of releasing the data must outweigh potential damage.
2. Requesters must undertake:
 - a. to use the data only for the purposes specified
 - b. not to pass it on to anyone else
 - c. not to link it to other data unless this was specified in the original request
 - d. not to attempt to identify any individual, hospital, family or dwelling, or to publish the data in a way which would allow any individual, hospital, family or dwelling to be identified, either directly or by linkage with other data.
 - e. to take every precaution to avoid the identification of individuals in any publication
 - f. users of the data must ensure that, in complying with the above conditions, they observe the relevant provisions of the Data Protection Acts, General Data Protection Regulation and the Freedom of Information Act
 - g. data should not be released to users outside the state without express permission from the National Patient Experience Survey Steering Group.
3. Individual-level data will be provided only when no alternative method of investigation is possible and if the Steering Group deem the benefits to accrue from the data to outweigh any potential risks. Aggregated or cross-tabulated data will always be offered in preference to individual data.

4. The data user must work within a recognised institution of some standing (e.g. third level institution, health service organisation). All individuals who will have access to the data must be named.
5. Data will only be released subject to a provision of a data processing agreement which indicates that the data will be stored in a secure manner and used in a way which complies with the conditions outlined above.

Further information on National Patient Experience Survey 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.

Alternatively, you can write to us at info@patientexperience.ie

or

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