

# The National Care Experience Programme

## Data Access Requests Policy

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**Author: National Care Experience Programme team**

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

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## What is the National Care Experience Programme?

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

A Steering Group was established to oversee the National Care Experience Programme and the implementation of the programme's Strategic Plan (2019 – 2021). The group is chaired by Phelim Quinn (Chief Executive Officer, HIQA) and includes representatives from each of the partner organisations as well as people using services.

The National Care Experience Programme includes the National Patient Experience Survey — an annual survey providing patients with the opportunity to describe their experiences of public acute hospital care in Ireland. The purpose of this survey is to learn from patients' feedback to find out what is working well in our hospitals, and what needs improvement. The results of the National Patient Experience Survey inform the development of quality improvement plans at hospital, hospital group and national levels, informs regulation and national legislation.

The National Maternity Survey offers women the opportunity to share their experiences of Ireland's maternity services. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their baby receive. The first National Maternity Survey will be carried out in early 2020.

A National Care Experience Programme competency centre is currently under development in order to provide support, guidance, information and leadership on the appropriate collection and use of care experience data for all engagement programmes in the health and social care services.

The National Care Experience Programme will expand to include two further surveys of health or social care services by 2021.

## **Purpose of this document**

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

The National Care Experience Programme promotes a culture of making data available, with reports and interactive online reporting platforms available [on our website](#). If these do not meet your requirements, data may be requested as per this policy.

## **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 Care Experience Programme must comply with its obligations of confidentiality under the Data Protection Acts, 1988 – 2018.

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 Care Experience Programme 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 Care Experience Programme, 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 Care Experience Programme does not hold personal data such as names and addresses following the closure of the survey, 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 Care Experience Programme Project Team.

Requests for data where there is a risk of identifying individuals will require further scrutiny and will thus be assessed by the relevant NCEP Programme Board. Such requests will take longer to process and may be subject to modification and restrictions in terms of use.

## **Conditions of use for National Care Experience Programme data**

The following conditions apply to the release of National Care Experience Programme 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 relevant NCEP programme board.
3. Individual-level data will be provided only when no alternative method of investigation is possible and if the relevant programme board 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 Care Experience Programme information handling practices**

Further details on information handling practices can be found on [www.yourexperience.ie](http://www.yourexperience.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 Care Experience Programme.

Alternatively, you can write to us at [info@yourexperience.ie](mailto:info@yourexperience.ie)

or

The National Care Experience Programme  
c/o Health Information and Quality Authority  
George's Court,  
George's Lane  
Smithfield  
Dublin 7.