

# The National Care Experience Programme

## Programme

### Data Access Requests Policy

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**Author: National Care Experience Programme team**

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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.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The programme implements the annual National Inpatient Experience Survey, the National Maternity Experience Survey and the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey and the National End of Life Survey

The surveys aim to learn from people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.

A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

Find out more at [www.yourexperience.ie](http://www.yourexperience.ie).

## **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 published reports for each survey. Examples include stage of care scores and frequencies of themes for qualitative comments, broken down by age, sex or other categorical variables. 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 care providers (e.g. hospitals, nursing homes, etc). 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, services 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 advisory 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 Care Experience Programme data**

The following conditions apply to the release of National Care Experience Programme data:

1. The purpose and necessity of releasing the data must be clearly articulated.
2. Requesters must undertake:
  - a. to use the data only for the purposes specified
  - b. not to pass it on to anyone other than individuals named in the data access request
  - c. not to link it to other data unless this was specified in the original request
  - d. not to attempt to identify any individual, service, family or dwelling, or to publish the data in a way which would allow any individual, service, 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 advisory group.
3. Individual-level data will be provided only when reviewers are satisfied that the request complies with ethical and legal obligations and is scientifically sound and feasible. 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.
6. Data will only be made available once the results have been officially published on the NCEP website.

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  
Unit 1301, City Gate  
Mahon  
Cork  
T12 Y2XT