National Care Experience Programme

Data Access Requests Policy

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Improving care experiences together

About the National Care Experience Programme

The National Care Experience Programme (NCEP) engages with people who use health and social care services, and their families, to learn about their experiences of care. It is a shared initiative of the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE), the Mental Health Commission and the Department of Health, with representatives of people using services providing their input at each stage of the programme.

The NCEP implements programmes of engagement across a range of care areas. Feedback is gathered at each stage of the care journey - from the community, through to hospital admission and post-discharge - to better understand the continuity of care from the perspectives of people using these services. This approach also allows for targeted improvements in communication, coordination, and overall care by identifying gaps or inefficiencies that exist in how people move between settings.

The NCEP currently operates programmes of engagement in the following areas of care:

- Inpatient
- Maternity
- Maternity bereavement
- Nursing homes
- End of life
- Mental health
- Cancer care (in development).

The aim of each programme of engagement is to learn from people's feedback on their care experiences, to identify what is working well and what needs to be improved in that particular area of care. The findings are published and widely disseminated to support and enable sustained improvements in people's care experiences. Service providers are supported to understand what the survey findings mean for them and to identify priority areas for quality improvement initiatives.

The NCEP team actively engages in academic research and develops educational material to further disseminate key findings and to help people understand experiences of care across Ireland's health and social care system. All NCEP publications and academic papers are published here. A key priority of the NCEP is to facilitate secondary use of the data by researchers, healthcare staff, policy makers and other data users to further our understanding of people's care experiences and inform improvements across the system. Find out more at 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 survey data to data users. These procedures apply both to the supply of data by the NCEP and to its subsequent analysis and publication. This document sets out the guidelines for the release of NCEP data.

The NCEP promotes a culture of making anonymised data available, with reports and interactive online reporting platforms available on the NCEP website. If these do not meet your requirements, anonymised aggregated or individual-level data may be requested in line with this policy.

General guidelines on data 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 NCEP must comply with its obligations of confidentiality under the Data Protection Acts, 1988 – 2018.

Individuals or groups requesting data 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 requests

The type of NCEP data that is made available can be classified as follows:

1. Anonymised aggregated data that is made publicly available in reports and interactive dashboards on the NCEP website
2. Anonymised aggregated data or statistics that is not publicly available on the NCEP website
3. Anonymised individual-level data.

When considering applying for access to NCEP survey data, data users are encouraged to investigate if the required data is available from the published survey reports and the interactive dashboards available on the NCEP website (option 1 above). If the data available in the reports or dashboards isn't sufficient, a data user can submit a request to the NCEP team for anonymised aggregated or individual-level data. Both types of request are described below.

1. Requests for anonymised aggregated data or statistics

Aggregated data refers to data that has been compiled by combining individual-level data. Aggregated data may, for example, include stage of care scores with additional filtering by demographic variables not already reported upon. There is no risk of individuals or care providers (e.g. hospitals, nursing homes, etc) being identified from anonymised aggregated data or statistics provided by the NCEP to data users.

For these types of requests, the NCEP team remains responsible for the processing of the individual-level data and provides only anonymised aggregated data or statistics to the applicant, without disclosing any individual-level data. Applicants should choose this option if anonymised aggregated data is sufficient to meet their objectives.

2. Requests for anonymised individual-level data

Individual-level data refers to data that represents individual participants' survey responses. All NCEP survey data is fully anonymised two months after the closure of each survey when participants' names and addresses are deleted. Therefore, there is no way of directly identifying any individuals. Participants' responses to the open-ended questions (ie qualitative data) are redacted in line with the NCEP's redaction policy; however, the in-depth nature of the qualitative data provided by some participants, such as people's in-depth accounts about their experiences of care, can increase the risk of individuals being identified.

Fully anonymised individual-level survey response data which carries no risk of identification may be provided if the NCEP team is satisfied that the request complies with ethical and legal obligations and is scientifically sound and feasible. Applicants must explain why the individual-level data that is being applied for is necessary for their purpose and demonstrate compliance with data minimisation principles. These applications will be evaluated for both compliance and necessity. Applicants should only select this option when aggregated data would be insufficient to meet their needs.

Requesting data

When considering requests for data access, the NCEP applies the following risk rating to all requests depending on the nature of the request:

Type of request		Risk of identification
Anonymised aggregated data or statistics		No risk
Anonymised individual-level data	Quantitative data only	No risk
	Qualitative data	Low risk

Based on this risk rating, the following steps outline the process followed by the NCEP team to manage data access requests:

1. Data applicants must complete a Data Access Request Form. An online form can be completed on the NCEP website (yourexperience.ie). Alternatively, a Microsoft Word version of the form can be completed and returned to the NCEP team by email or post.
2. All data requests will be reviewed and assessed by an NCEP Programme Manager.
    a. All requests for anonymised aggregated data or statistics and requests for individual-level data where there is no risk of identifying participants can be approved by an NCEP Programme Manager.
    b. In the case of requests for individual-level data where the Programme Manager identifies a risk of identifying participants or has concerns about the suitability of the request, the request will be submitted to the NCEP Director for review and approval.
3. The applicant will be informed of the decision within two weeks of submitting the request. For approved requests, data will be released to the data applicant within four weeks of receipt of the request. The data applicant will be informed of any delays to these timelines.

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. Data users 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. Anonymised 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. Anonymised aggregated data or statistics will always be offered in preference to individual-level data.
4. 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. 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 or:

The National Care Experience Programme

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