National Care
Experience
Programme

Data Subject Access Request Policy

National Care Experience Programme

Data Subject Access Request Policy – Policy

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Author:	National Care Experience Programme Team
Approved by:	Rachel Flynn, Director of the National Care Experience Programme (HIQA)
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About 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 includes the National Inpatient 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 Inpatient Experience Survey inform the development of quality improvement plans at hospital, hospital group and national levels and informs regulation and national legislation.

The National Maternity Experience 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 Experience 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.

1. Purpose of the policy

The purpose of this document is to outline how the National Care Experience Programme manages data subject access requests that are submitted by individuals (data subjects) to the National Care Experience Programme. A data subject access request enables a data subject to gain access to any personal information held about them by the National Care Experience Programme.

The policy covers the collection of all personal information gathered by the National Care Experience Programme. It promotes the right of data subjects to submit a data access request in order to obtain a copy of information held on them, in electronic or hard copy format, by the data controller.

It also outlines the procedure to be followed by data subjects when submitting a data subject access request for data collected by the National Care Experience Programme.

Please refer to Appendix 1 for a step by step procedure on how to submit a data access request.

2. Policy Statement

HIQA, in its capacity as data controller for all data gathered by the National Care Experience Programme, must meet its obligation to provide a data subject with a copy of their personal information upon request.

3. Scope of this document

This policy outlines how the National Care Experience Programme will meet its legal obligations upon receipt of a data subject access request. The scope covers all personal data that is collected for the purpose of administering surveys and in addition responses to surveys, where feasible. For a complete list of information collected by the National Care Experience Programme, please see our Statement of Information Practices at www.yourexperience.ie.

Article 15 of the General Data Protection Regulation (EU) 2016/679 (GDPR) gives data subjects the right to access their personal data. A person has the right to obtain confirmation from the National Care Experience Programme that their data is being processed, and to be provided with certain information about how their data is processed. A person is also entitled to request and obtain a copy of the data being processed by the National Care Experience Programme.

If requested, the National Care Experience Programme must provide a response and copy of the data sought within **one month** of the receipt of the request. No fee applies unless the workload is exceptional.

4. Responsibility

The Director of the National Care Experience Programme in HIQA, has overall responsibility for ensuring the implementation of this policy.

All data subject access requests should be addressed to the Data Protection Officer in HIQA who will ensure that appropriate action is taken. A list of contact details can be found in section 14 of this document.

5. Data controller and data processor roles and responsibilities

HIQA acts in the capacity of data controller for all of the data that it collects as part of the National Care Experience Programme. HIQA has contracted a data processor, Behaviour and Attitudes, who will administer the distribution and receipt of surveys, on its behalf.

6. Legal context

Participation in National Care Experience Programme surveys is voluntary. Participants are informed by service providers that they will be invited to participate in a survey, upon which time, participants can opt out. Eligible participants who do not want to participate can avail of four different options to opt out, upon receipt of the survey.

The National Care Experience Programme has developed a comprehensive information governance framework to ensure that the privacy rights of all participants are upheld. The National Care Experience Programme complies with data protection laws, including the GDPR. Under Article 6(1)(e) of the GDPR and Section 38 of the Data Protection Act 2018, personal data can be collected and processed where necessary for the performance of a task carried out in the public interest. Article 9(2)(i) of the GDPR and Section 53 of the Data Protection Act 2018 permit the processing of healthcare data, which is "special category data", in the public interest, which includes ensuring high standards of quality and safety in healthcare.

The National Care Experience Programme is conducted in the public interest; the partner organisations of the programme have committed to using the results to inform quality improvements across the healthcare system, from policy to planning and service delivery. The collection of personal data is necessary to conduct National Care Experience Programme surveys, which capture feedback on the experience of people using services.

Data collected by the National Care Experience Programme may be used for secondary analysis. A formal request can be made to gain access to anonymised survey responses, in line with the National Care Experience Programme Data Access Request Policy. The request must demonstrate that the secondary analysis of the data is in the public interest.

There is a contract and a Data Processing Agreement in place between HIQA and the data processor to define the arrangements for the secure sharing, storage, handling, processing and destruction of all data processed by the National Care Experience Programme.

7. Timeframe for request submission and response

An individual can make a formal request to know if the National Care Experience Programme holds information on them. This request must be processed without delay. If the National Care Experience Programme does hold data or information on an individual, they as a data subject, can request a copy of the data.

To make a request under Article 15 of the GDPR and **gain access to** personal data held by the National Care Experience Programme, a Data Subject Access Request Form can be downloaded from www.yourexperience.ie and can be used to submit a request. Requests can also be submitted and processed by phone.

A one month time frame applies in situations whereby a data subject requests a copy of their personal data. This time frame begins upon receipt of the request for proof of identification and other supporting documentation by HIQA.

Once the relevant information has been retrieved by the data controller, a response will be compiled for the data subject.

Please note that all participant contact details are deleted at the end of a survey cycle. For example, if a survey runs for the month of May in a given year, all administrative data, including potential participants' names and contact details, will be deleted by 31 July which means that requests must be received by 17 July to allow a minimum of 10 days to process the request.

8. Right to complain

If HIQA fails to comply with a valid data subject access request, or if the data subject is dissatisfied with the response to a request, they may lodge a formal complaint with the Data Protection Commission. The Data Protection Commission may then investigate the complaint, with consideration to the rights of the data subject.
For more information, please see the Data Protection Commission's website at www.dataprotection.ie.

9. Training and awareness

Relevant employees of HIQA, including the Data Protection Officer, and the data processor receive training on this policy. Training on this policy is provided, and repeated as required.

10. Review

This policy will be reviewed every three years or alternatively in light of any legislative changes or other relevant programme requirements.

11. Legislation

This policy is informed by the:

- General Data Protection Regulation (EU) 2016/679 (GDPR)
- Data Protection Acts 1988 - 2018

12. Revision history

Number	Effective date	Reason for update
1.0	1 August 2019	Original document release
2.0	6 August 2021	Review in advance of National Inpatient Experience Survey

13. Individuals with responsibilities under this policy

Data Controller
Rachel Flynn Director of the National Care Experience Programme Health Information and Quality Authority Unit 1301, City Gate, Mahon, Cork 021 240 9691 087 922 1938 rflynn@hiqa.ie **Data Protection Officer** Health Information and Quality Authority Unit 1301, City Gate, Mahon, Cork 021-4547722 dpo@hiqa.ie **Tracy O'Carroll** Senior Programme Manager National Care Experience Programme Health Information and Quality Authority Georges Court, Georges Lane, Smithfield Dublin 7, D07 E9Y 01-8147684 0873666778 tocarroll@hiqa.ie

Data Processor
Elaine Sloan Project Director Behaviour and Attitudes Milltown House Milltown Dublin 6 Ireland Tel: 01 2057500 Email: elaine@banda.ie

Appendix 1

Procedure for submitting a data subject access request

1. Making an access request

All data subject access requests must be submitted to the Data Protection Officer in HIQA, by email, post or telephone.

- If you would like to request a copy of your personal data or obtain information about how your data is being processed, please download the data access request form from www.yourexperience.ie.
- You will need to provide us with your name and address as well as a copy of a form of identification.
- When filling in the form, please be as specific as possible about the information you wish to access; include any additional details which may help to locate the information you are seeking, such as the hospital you attended, date of admission, date of discharge and so on.
- If a third party (for example, a family member) is submitting a data subject access request on behalf of a data subject, written authorisation is required from the data subject in order for the data controller to disclose any personal data to the relevant third party.

2. Identification

The data controller is entitled to request evidence of identity from the individual in order to check that the request is valid and to ensure the information is not disclosed to the wrong person, in order to safeguard the privacy of a data subject.

Therefore, we would ask that you include a copy of a form of identification. Acceptable forms of identification include a copy of a passport, driving licence or birth certificate. All copies of identification documents that accompany your requests will be securely destroyed once your identity has been verified.

3. Submitting the request

If you would like to submit a request or if you have a query on how to make a data subject access request, please contact us at dpo@hiqa.ie or alternatively you can write to us at the address below:

Data Protection Officer
Health Information and Quality Authority
Unit 1301
City Gate
Mahon
Cork
T12 Y2XT.

National Care
Experience
Programme

Health
Information
and Quality
Authority
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agus Cáilíocht Sláinte

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