

Data Quality Strategy 2019 - 2021



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 HSE responds to the results of the National Inpatient Experience Programme by developing quality improvement plans at the national, hospital and hospital group levels. In addition, the results of the inpatient survey inform national policy and HIQA's healthcare monitoring programme.

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.







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Glossary of terms¹



Audit: a systematic, independent and documented process for obtaining evidence and evaluating it objectively to determine the extent to which the audit criteria are met.

Data and information lifecycle: the stages which data goes through to become information, from the point of data collection through to dissemination of information.

Data dictionary: a descriptive list of names (also called representations or displays), definitions and attributes of data elements to be collected in an information system or database. The purpose of the data dictionary is to standardise definitions and ensure consistency of use.

Data quality dimensions: the quality of data and information can be defined and assessed using the following internationally accepted dimensions:

- relevance
- accuracy and reliability
- timeliness and punctuality
- coherence and comparability
- accessibility and clarity.

Data quality framework: a document which outlines the approaches to systematically assess, document and improve data quality. It includes a data quality strategy, data quality assessment methodology, reporting on data quality and data quality improvement cycle.

Data quality statement: a statement prepared to accompany all published outputs from a national health and social care data collection which highlights the dimensions of data quality, including strengths and weaknesses, so that potential data users can make informed judgments about fitness for use.

Data quality strategy: a document outlining an organisation's formalised approach to managing and continuously improving the quality of their data. It outlines the organisation's direction and prioritised initiatives for identifying, documenting and ensuring the implementation of data quality practices.

¹ Health Information and Quality Authority (HIQA). *Guidance on a data quality framework for health and social care*. 2018. Available from: <u>https://www.hiqa.ie/reports-and-publications/health-information/guidance-data-quality-framework-health-and-social-care</u>. Accessed on 15 October, 2019.



Data user: any stakeholder who uses data held by a health or social care organisation or any information outputs from that organisation.

Key performance indicators: specific and measurable elements of practice that are designed to assess key aspects of structures, processes and outcomes.

National health and social care data collections: national repositories of routinely collected health and social care data, including administrative sources, censuses, surveys and national patient registries in the Republic of Ireland.

Policy: a written statement that clearly indicates the position and values of an organisation on a given subject.

Procedure: a written set of instructions that describe the approved and recommended steps for a particular act or sequence of events.

Quality: quality is defined as 'fitness for purpose' to meet the needs of users. Data and information quality encompasses the dimensions of relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; and accessibility and clarity, which need to be balanced against one another to meet users' needs.

Statement of purpose: a publicly available document which succinctly captures why an organisation such as a national health and social care data collection exists and clearly outlines its stated objectives.



1. Introduction

The National Care Experience Programme collects data on the experiences of people using health and social care services in Ireland. This data is used to inform:

- quality improvements by health and social care service providers (the HSE)
- monitoring and regulation by the health and social care regulator (HIQA)
- national policy and legislation (the Department of Health).

1.1 Purpose

The purpose of this strategy is to outline how the National Care Experience Programme formalises the approach it uses to identify, document and implement data and information quality.



1.2 Scope

The collection, processing, dissemination and use of National Care Experience Programme data and information comes under the scope of this data quality strategy. Data and information quality is the responsibility of all those who work for or on behalf of the National Care Experience Programme.

1.3 Who are the National Care Experience Programme stakeholders?

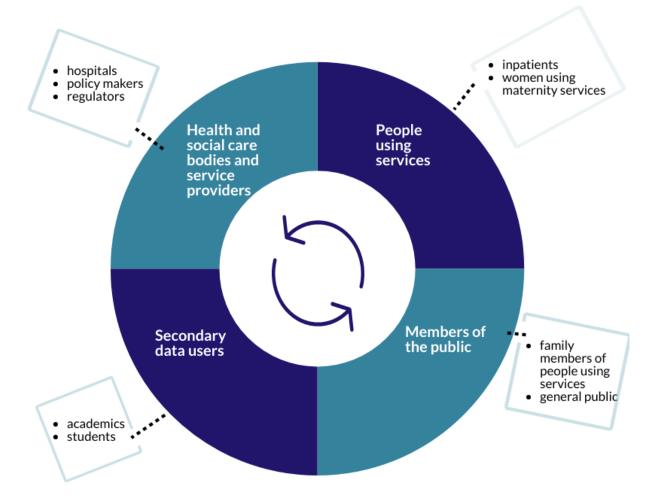
The National Care Experience Programme Data Quality Strategy identifies the following stakeholders:

- health and social care bodies and service providers, for example hospital staff
- people who use health and social care services
- members of the public
- secondary data users.

Figure 1 provides an overview of the main stakeholders in the National Care Experience Programme Data Quality Strategy.





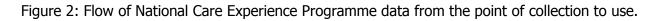


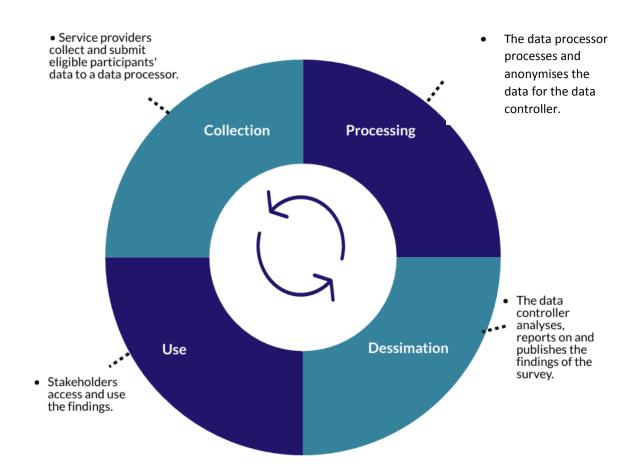


1.4 Flow of data: an overview

The National Care Experience Programme conducts surveys of health and social care services. The details of eligible survey participants are submitted by service providers to a data processor. The data processor distributes surveys to eligible survey participants and processes survey responses. The data controller (HIQA) analyses the responses and reports on the findings. Service providers then use the findings to inform quality improvements.

Figure 2 illustrates the flow of survey data from the point of collection by service providers to its use by stakeholders.







2. Data Quality Objectives

This strategy sets out three data quality objectives, which will be actioned and achieved by 2021.

Objective 1: collect data and produce information that meets the needs of data-users

Over the next three years, the National Care Experience Programme will:

- produce high-quality data and information that is fit for purpose
- continually engage with key stakeholders to ensure that the data it collects and processes and the information it releases meets the needs of data-users
- review the content, layout, format and reporting of results before each iteration of each survey to ensure that they meet the needs of data-users.

By 2021, the National Care Experience Programme will have:

- continued to conduct a survey of inpatient care
- implemented a survey of maternity, older persons and end-of-life care
- conducted Delphi studies on each new survey to ensure surveys solicit data that is of use to stakeholders
- conducted a review of each iteration of each survey. The review will solicit feedback from stakeholders and will inform the development of future surveys, including the collection, use and reporting of data.





Objective 2: using information responsibly to provide assurance in our data

Over the next three years, the National Care Experience Programme will:

- demonstrate compliance with the <u>Information Management Standards for National Health</u> <u>and Social Care Data Collections</u>² and any additional relevant standards introduced before 2021
- demonstrate compliance with all standards and legal requirements, such as data protection legislation.

By 2021, the National Care Experience Programme will have:

- conducted, reviewed and updated privacy impact assessments for each iteration of each survey and published a summary of same
- sought ethical approval of each survey in its first iteration and where relevant, review and update in advance of any subsequent survey
- conducted internal audits of data on an ongoing basis to ensure that they meet national standards and data protection requirements
- developed a quality assurance framework to standardise processes for the collection, dissemination and use of data.



² Health Information and Quality Authority (HIQA). Information Management Standards for National Health and Social Care Data Collections. 2017. Available from: <u>https://www.hiqa.ie/reports-and-publications/health-information/information-management-standards-national-health-and</u>. Accessed on 15 October, 2019.



Objective 3: maximise use of data and information

Over the next three years, the National Care Experience Programme will:

- ensure that data is accessible to all stakeholders
- measure the impact of collecting and releasing quality data.

By 2021, the National Care Experience Programme will have:

- publicly reported on acute inpatient care, maternity services, older persons and end-of-life care, through online reporting portals and the publication of traditional, standalone reports. In addition, data will be made available on Ireland's Open Data Portal and the European Union's Open Data Portal.
- engaged with providers of education to ensure that the survey findings inform the training of healthcare professionals
- encouraged use of the data in research and academia by facilitating data access requests and developing academic collaborations for secondary analysis and use of the data
- tracked, recorded and reported on the direct use and impact of the data.

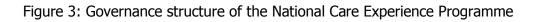


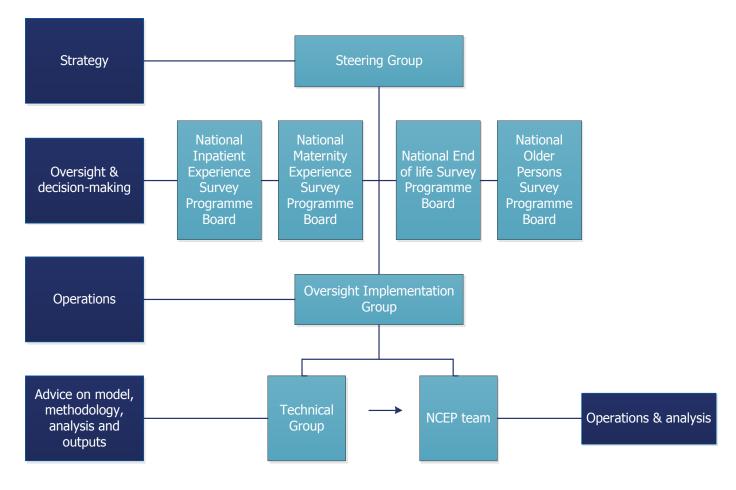
3. Governance Structure

The National Care Experience Programme is a partnership between HIQA, the HSE and the Department of Health. The National Care Experience Programme governance structure consists of the:

- Steering Group
- Programme Boards
- Technical Group
- Implementation Oversight Group
- National Care Experience Programme Team.

The remit of each group is outlined in figure 3.







4. Standardisation

The use of standards supports comparability and consistency of data and information. This section details the standards that the National Care Experience Programme adheres to in relation to data quality.



4.1 Information Management

The National Care Experience Programme is a national data collection. The design and delivery of the programme is aligned to the ten standards of the *Information Management Standards for National Health and Social Care Data Collections*. Compliance with these standards ensures that data is processed, disseminated and used transparently and securely and that resulting quality improvements in health and social care are based on high-quality information.

The National Care Experience Programme has a comprehensive information governance framework in place. This framework includes a statement of purpose, a statement of information practices and a record retention and destruction schedule, which are available at <u>www.yourexperience.ie</u>.

A data protection impact assessment (DPIA) is conducted prior to each survey to outline how risks identified in the collection and processing of personal data have been mitigated or removed. The DPIA is updated annually and informs the development of security and data protection controls for the secure processing of eligible survey participants' data.

In line with the General Data Protection Regulation (GDPR) 2016², the National Care Experience Programme adheres to the principal of data minimisation and only collects the most relevant data necessary to administer surveys, meaning that no extraneous or unnecessary data is collected.

Further information on how the National Care Experience Programme manages the data and information it processes is available at <u>www.yourexperience.ie</u>.



4.2 Survey questions

Where possible, the National Care Experience Programme sources its questions from standardised, international question banks. The most appropriate questions are selected and adapted for an Irish context and inform the collection of data that is relevant to people using and providing services in Ireland.

The use of questions from international question banks allows the findings of the National Care Experience Programme to be compared internationally, on a question-by-question basis.

4.3 Data Dictionary

A data dictionary has been developed and is available at <u>www.yourexperience.ie</u>. The data dictionary provides a descriptive list of the variables used in each National Care Experience Programme survey and is updated with each iteration of a survey, when necessary.



4.4 Release of data

The National Care Experience Programme has developed a data release policy to formalise the release of its data to key stakeholders. Findings of surveys are published:

- on an online reporting tool for nominated staff in service providers
- in traditional report formats at <u>www.yourexperience.ie</u>
- on an online reporting portal at <u>www.yourexperience.ie</u>.

4.5 Plain English Guidelines

The National Care Experience Programme adheres to the National Adult Literacy Agency's (NALA) Plain English Guidelines to ensure that the information it disseminates is clear and accessible to stakeholders.



5. Policies and procedures

The National Care Experience Programme has developed policies and procedures to ensure the collection, processing and dissemination of good-quality data.

5.1 Policies

Data quality policies outline the National Care Experience Programme's approach to collecting and processing good-quality data. The National Care Experience Programme has a:

- data quality policy, which outlines how data quality is ensured in the collection and processing of data.
- quality assurance framework, which directs and controls the quality of National Care Experience Programme outputs, from the point of data collection to the production of information.
- documents and records management policy, which standardises how documents are created, approved and stored, ensuring consistency in content and layout.



5.2 Procedures

Procedures detail the processes in place to support the achievement of good-quality data throughout the data and information lifecycle. This section outlines the procedures followed by the service providers, the data processor and the data controller to ensure data quality.

Service providers

Data is collected by service providers and submitted securely to the data processor. Process guides are developed for each survey type, providing guidance and support on extracting and quality assuring the data, which contains the names and addresses of eligible survey participants. Quality assurance guarantees, as far as is feasibly possible, that the data is:

- relevant (containing only the details of eligible survey participants)
- timely (submitted at agreed timelines during the survey sample period)
- accessible and clear (must be submitted in the standardised format as prescribed by National Care Experience Programme).



Data Processors

The National Care Experience Programme contracts a data processor to process the data on its behalf. The data processor follows these procedures to ensure the collection and processing of high-quality data. This entails:

- distributing surveys to eligible survey participants in a timely manner
- anonymising paper-based survey responses to ensure that the most relevant data is presented in an accessible manner
- providing nominated stakeholders with access to the data to ensure its accessibility and facilitating data subject access requests for eligible survey participants
- making survey responses available to services providers in a timely manner, ensuring the data's point-in-time relevance
- categorising and theming qualitative data to ensure the clarity, coherence and comparability of the data
- retaining and destroying the data, in line with the National Care Experience Programme Record Retention and Destruction Policy, to ensure that only the most relevant data is held indefinitely.



Data controller

The data controller (HIQA) has access to the survey responses via an online platform (managed by the data processor). HIQA manages and processes the data by:

- quality assuring survey responses
- anonymising online survey responses
- making survey responses available to service providers in a timely manner
- developing report templates to ensure that survey findings are reported on in a consistent manner and are therefore comparable
- producing reports on the findings of surveys in a timely manner to ensure their continued relevance to both service providers and people using services.



6. Data Quality Assurance

This section details how the National Care Experience Programme is assured that the data it collects, processes and disseminates is of good quality.



6.1 Training on data and information quality

The National Care Experience Programme recognises the importance of training. Training needs are pro-actively identified and met. This may include training on any process from the point of data collection through to dissemination and use of data.

Data quality training

- Training is provided for all staff who extract and transfer data for the National Care Experience Programme. In addition, process guides are provided for service providers, which set out how to extract and transfer eligible survey participants' contact data, an example of which is the National Inpatient Experience Survey <u>Process Guide³</u>. This training ensures that data collected for the National Care Experience Programme is relevant, coherent, accurate, accessible and submitted to the data processor in a timely manner.
- Guidance is provided on the anonymisation of qualitative survey data for the data processors to ensure that anonymisation criteria are consistently applied and the data is clear and comparable.
- Training is provided for the data processor on National Care Experience Programme information governance.

Information quality training

- To ensure the consistency and accessibility of information produced and disseminated, training is provided to the National Care Experience Programme Team to ensure the consistent application of:
 - HIQA's house style
 - NALA (National Adult Literacy Agency) standards
 - National Care Experience Programme information governance, including the National Care Experience Programme Data Quality Policy.

³ Health Information and Quality Authority (HIQA). *National Inpatient Experience Survey: Process Guide for Hospitals*. (2019). Available from: <u>https://yourexperience.ie/inpatient/about-the-survey/resources-for-hospital/</u>. Accessed on 15 October, 2019.



 Training is provided for service providers on how to interpret and analyse National Care Experience Programme data and information to ensure its accessibility, clarity and comparability.

6.2 Audits of survey data

A series of targeted audits are conducted to ensure the quality of data collected in the conduct of National Care Experience Programme surveys.

- The contact data of eligible survey participants' is quality assured by service providers before it is transferred to the data processor. Service providers must ensure that the data is accessible and relevant, for example the data required to administer the survey must be complete and of eligible survey participants only.
- During the implementation of the survey, the data processor audits data extracts submitted by service providers to ensure that the data submitted is accessible and clear, to facilitate the effective distribution of the survey to eligible survey participants.
- During the implementation of the survey, the data controller conducts audits to ensure that data processed by data processors is fit for purpose. An example of this is when original hard-copy survey responses are compared to their online version, which has been processed and uploaded to an online platform. This is to ensure that the data is accurate and reliable.



6.3 Risk Management

Risks to the quality of National Care Experience Programme data and information are identified, assessed and mitigated in line with HIQA's risk management procedure, and recorded in the National Care Experience Programme Risk Register. Risks are continuously reviewed to ensure that they are appropriately managed. The National Care Experience Programme has developed an information governance framework, as outlined in section 4.1, which determines internal controls to identify and mitigate risks to the quality of the data and information it processes. In addition, the National Care Experience Programme conducts Data Protection Impact Assessments on all its surveys to identify and mitigate risks in the processing of personal data. This includes risks to the quality of National Care Experience Programme data and information.



6.4 Information quality assessment

To ensure the quality of information produced by the National Care Experience Programme, all informational outputs go through a series of formal reviews until they have been accepted and approved. Reviews ensure that the information produced is relevant, accessible and clear, in terms of content, layout, scope and objective.

Peer Review

Peer reviews of initial drafts occur frequently and may occur before a document is complete. All peer reviewers are identified and are given an opportunity to contribute to the document's content before it is approved. This process may involve a variety of stakeholders, including the National Care Experience Programme Team and Senior Programme Manager.



Final review

Final approval is obtained via the appropriate channel, namely the National Care Experience Programme Senior Programme Manager, Director and the appropriate governance group. For example, the National Inpatient Experience Survey annual report is reviewed and approved by the National Inpatient Experience Survey Programme Board.



6.5 Dissemination

To ensure the accessibility of National Care Experience Programme informational outputs, documents are made available on:

- HIQA's information management and sharing systems (internal)
- National Care Experience Programme website (<u>www.yourexperience.ie</u>)
- Lenus (the Irish Health Repository)
- <u>Ireland's Open Data Portal</u>
- <u>European Union Open Data Portal</u>.



7. Commitment

The National Care Experience Programme is committed to continually improving the quality of its data and information. This strategy will be reviewed on an annual basis within its lifetime (2019 – 2021) and updated to include any changes to National Care Experience Programme collection, processing, dissemination and use of data.







Seirbhís Sláinte Níos Fearr á Forbairt



Service

An Roinn Sláinte Department of Health