

A large, dark blue circular graphic on the left side of the page. It contains several white, curved, concentric lines and three small white squares, creating a dynamic, abstract design.

**Statement of Information
Practices – Standard
Operating Procedure
January 2022**

National Care Experience Programme

Statement of information practices – Standard Operating Procedure

Reference No: 04-002-00-SOP3

Revision No: 3.0

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Approved by: Rachel Flynn, Director of the National Care Experience Programme

Effective from: August 2022

Review date: December 2024

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 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 is currently developing the National Maternity Bereavement Experience Survey, National Nursing Home Experience Survey and 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 on the findings.

Find out more at www.yourexperience.ie.

1. Purpose of this document

This document outlines what information is collected by the National Care Experience Programme, how it is used, with whom it is shared and for what purpose it is collected, as well as the safeguards that are in place to protect it, and how people can access information held about them.

The National Care Experience Programme takes a person-centred approach, which ensures that:

- the privacy and confidentiality of eligible survey participants is protected
- all data is collected, used and stored in a safe and effective way.

Our Statement of Information Practices demonstrates our commitment to openness and transparency about the way in which we collect and use information.

2. What are the governance structures of the National Care Experience Programme?

A National Care Experience Programme Steering Group provides strategic direction for the programme. The Steering Group is comprised of representatives of the partner organisations and people using health and social care services. The role of the Steering Group is to ensure that:

- the development and expansion of the programme is in line with national policy and legislation
- resources are in place and objectives identified in the National Care Experience Programme Strategy 2022-2024 are met
- survey responses are used at a local, regional and national level to improve the experience of people using services in Ireland.

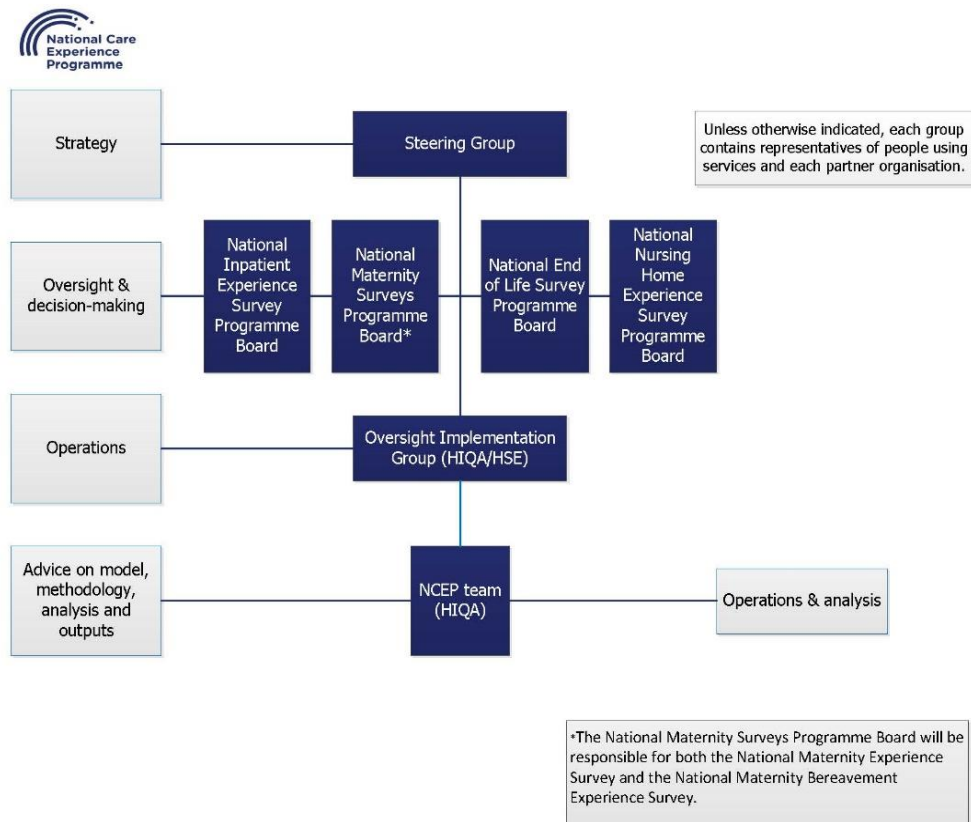
In addition to the Steering Group, each survey has a programme board, which is responsible for operational decision-making in the development, administration and reporting of each survey. Programme boards are composed of representatives from each of the partner organisations, subject matter experts and representatives of people using services.

The Oversight Implementation Group (HIQA/HSE) and the National Care Experience Programme team (HIQA) are responsible for the routine operation of the programme. In addition, the National Care Experience Programme team is responsible for analysing and publically reporting on the responses to surveys as directed and informed by the Steering Group and programme boards.

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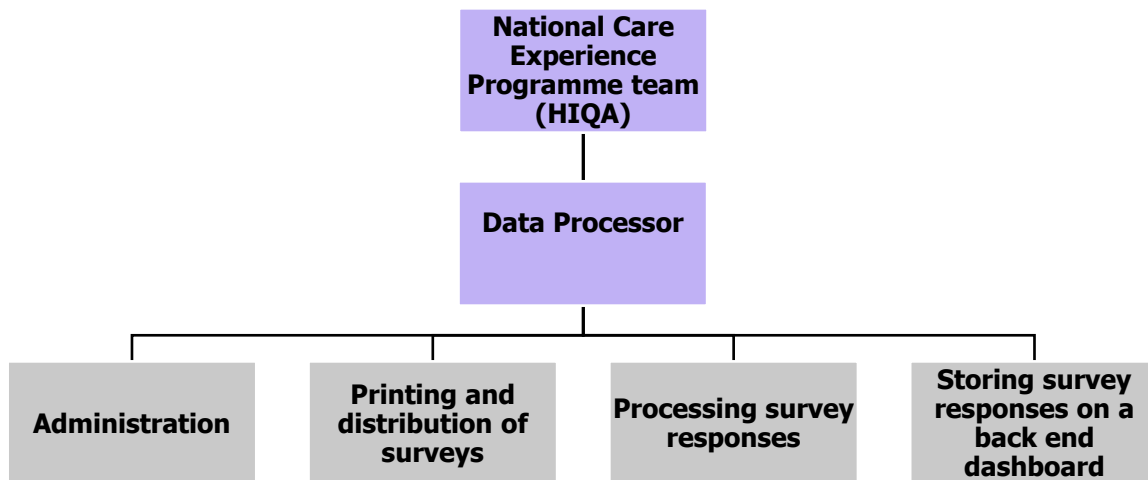
Figure 1 illustrates the roles of the National Care Experience Programme governance groups and team.

Figure 1 Roles of the National Care Experience governance groups and team



HIQA is the lead partner in the National Care Experience Programme and as such, the data controller. HIQA has contracted a data processor, Behaviour and Attitudes, that is responsible for the administration of surveys. Figure 2 outlines the responsibilities of the data processor.

Figure 2: Responsibilities of the data processor



Roles of partner organisations and representatives of people using services

The National Care Experience Programme includes representation from people using services, thereby ensuring that the viewpoints of people using services will be central to decisions and actions taken in the development, implementation and expansion of the National Care Experience Programme.

HIQA is the lead partner in the National Care Experience Programme and is responsible for providing a centralised, coordinated approach to the implementation of the programme. HIQA holds responsibility as data controller under the provisions of the Data Protection Acts 1988 - 2018 and the General Data Protection Regulation (EU) 2016/679, hereafter referred to as the GDPR.

HIQA's primary responsibilities [in implementing National Care Experience Programme surveys and data governance of the programme] are to:

- develop survey models and methodologies
- develop a stakeholder involvement strategy
- develop processes and procedures to support the implementation of surveys
- analyse and report the survey data
- support the HSE in interpreting the data in order to develop and implement quality improvement plans
- develop alternative models, methodologies and tools to capture the experience of people using services, not captured by traditional survey tools
- oversee secondary analysis of the data by academic and other institutions
- use the results to inform monitoring and regulation programmes
- provide support and guidance to health and social care providers to develop surveys of local and specialised care.

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The **HSE** is working with HIQA to ensure successful implementation of the National Care Experience Programme across participating service providers.

The HSE's primary responsibilities [in implementing National Care Experience Programme surveys and data governance of the programme] are to:

- provide national oversight to ensure the project is implemented and delivered in accordance with the scope and timelines across each of the service providers
- drive engagement between staff and people using services to promote the programme
- ensure that appropriate systems and processes are in place to implement surveys
- use the findings to develop quality improvement plans in order to drive improvements across the healthcare sector
- oversee and assist with developing a cohesive approach to the successful delivery of quality improvement plans within agreed timeframes.

The **Department of Health** provides leadership and policy direction for the health sector in order to improve health outcomes and, through effective performance oversight, ensure accountability and high-quality health service delivery.

The mission of the Department of Health is to improve the health and wellbeing of people in Ireland by:

- supporting people to lead healthy and independent lives
- ensuring the delivery of high-quality and safe health and social care
- creating a more responsive, integrated and people-centred health and social care service
- promoting effective and efficient management of health and social care services and ensuring best value from health system resources.

The Department recognises patient safety as the cornerstone to quality healthcare. The National Patient Safety Office (NPSO) at the Department of Health was established by the Government in December 2016 to strengthen the patient safety role of the Department. The NPSO provides leadership and direction with regard to embedding a national framework for clinical effectiveness and clinical audit, developing patient safety policy and legislation and progressing patient safety priorities and initiatives through enhancing patient safety surveillance and evidence-based policy-making. The NPSO team engages with stakeholders to ensure that there is a dedicated focus on patient safety and quality in the achievement of broader health policy goals, in particular, the Sláintecare programme of health service reform. From the Department, both the NPSO and the relevant policy units participate in furthering the objectives of the National Care Experience Programme.

3. What personal information is collected to distribute surveys?

Personal data, such as the contact details of people using services, is collected from all participating service providers during survey sample periods. It is collected for the sole purpose of administering national surveys on the experience of people using services in the Irish health and social care system.

Limited data relating to the health of service users, such as the date of delivery of people using maternity services, is also collected. This data is collected to apply the eligibility criteria. The processing of this data is subject to the safeguards provided for in the Data Protection Acts 1988 - 2018 and the GDPR. The information collected includes:

| National Inpatient Experience Survey | |
|---|--|
| Data of patient | <ul style="list-style-type: none"> first name surname address date of birth gender date of admission source of admission date of discharge discharge destination length of stay hospital name hospital group name hospital code |
| National Maternity Experience Survey | |
| Data of mother | <ul style="list-style-type: none"> first name surname address date of birth date of delivery date of discharge hospital group hospital name hospital code |
| National Maternity Bereavement Experience Survey | |
| Data of mother | Data of deceased baby |
| <ul style="list-style-type: none"> first name surname address date of birth of mother date of delivery hospital group hospital name hospital code | <ul style="list-style-type: none"> date of death gestational age at diagnosis/death |

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| National End of Life Survey | |
|---|---|
| <p>Data of bereaved individual</p> <ul style="list-style-type: none"> ▪ first name ▪ surname ▪ address ▪ qualification of information ▪ relationship of bereaved to deceased | <p>Data of deceased individual</p> <ul style="list-style-type: none"> ▪ first name ▪ surname ▪ gender ▪ date of death ▪ International Statistical Classification (ICD 10 Code) ▪ Cause(s) of death ▪ coroner status (certified/uncertified)* ▪ certified cause of death ▪ post-mortem held ▪ inquest held ▪ place of death |
| National Nursing Home Experience Survey | |
| <p>Data of nursing home resident</p> <ul style="list-style-type: none"> ▪ first name ▪ surname ▪ nursing home details | <p>Data of family member/friend</p> <ul style="list-style-type: none"> ▪ first name ▪ surname ▪ address ▪ relationship to resident ▪ nursing home details |

During the survey sample period, service providers extract eligible participants' data and, following a series of data quality checks, exchange this information with the data processor. The contact details of people using services who are eligible to participate are used to distribute the questionnaire to participants' addresses. Information such as date of birth is collected to help us get a more detailed picture of who will be invited to take the survey and to ensure that they are eligible to participate in the survey. All information will be deleted within six weeks of the closure of the survey cycle.

Data sharing agreements have been signed between HIQA and representatives of all participating hospitals. These agreements formally authorise the sharing of information.

4. What information is collected on the experience of people using services?

Information on the experience of people using services is collected through structured survey questionnaires. Surveys ask questions about admission, environment, care and treatment, interaction with staff and the discharge process and may also ask about care delivered in the community. Surveys ask structured tick-box questions as well as open-ended questions for comments. The survey can be completed online or by returning the questionnaire via freepost. In certain cases, surveys may be carried out by interview, such as the National Nursing Home Experience Survey. Anonymisation criteria are consistently applied to survey responses upon receipt to ensure that an individual cannot be identified in a survey participant's response. This includes the survey participant, healthcare staff and any other individuals who may be identifiable in survey responses.

A detailed information governance framework has been developed to ensure that all data, including personal information, is handled in line with all relevant legislation, guidance and evidence-based practices.

5. Legal context

HIQA as data controller has a remit under Article 8 (1) (g) of the Health Act 2007 'to operate such other schemes aimed at ensuring safety and quality in the provision of the services as the Authority considers appropriate'.¹

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 law, including the GDPR, the Data Protection Act 2018 and the Data Sharing and Governance Act 2019. 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

¹ Health Act 2007, Ireland. 2007. Available from:
<http://www.irishstatutebook.ie/eli/2007/act/23/enacted/en/html>.

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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.

6. Right to opt out

Participation in National Care Experience Programme surveys is voluntary. Potential participants are provided with a participant information leaflet and an invitation letter at the point of discharge. This will allow potential participants to make an informed decision about whether or not to take part in a National Care Experience Programme survey. The participant information leaflet further outlines how survey responses will be used and reassures participants that all survey responses are anonymous.

Eligible participants who do not want to partake can opt out of the survey:

- upon discharge, prior to their data being processed
- by calling 1800 314 093
- by emailing info@yourexperience.ie
- online at www.yourexperience.ie
- by returning a blank questionnaire after they have received a survey pack in the post.

7. What are survey responses used for?

Survey responses will help to determine the quality and safety of health and social care services provided and to inform system-wide quality improvement initiatives in Ireland.

Survey responses will be used by the three partner organisations to support a variety of activities:

- The HSE will use the results to develop and implement quality improvement plans. As National Care Experience Programme surveys are repeated over time, it will become possible to monitor and evaluate quality improvements.

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- HIQA oversees and manages the analysis, as well as the reporting of the data. It will provide an objective overview of the results, and support the HSE in translating these results into quality improvements. HIQA will also use the survey results to support and inform its regulation of service providers and development of standards.
- The Department of Health will use the data to inform national health policy and planning.

8. Who sees the survey results?

The results of surveys will be published and made available to the public on www.yourexperience.ie within four months of the closure of a survey. The survey results will be anonymous and will be reported in summary form.

Service providers may receive access to anonymised survey responses, if they have received a minimum number of responses.

9. How is the privacy of personal information protected?

A data privacy impact assessment is conducted and updated in advance of each survey. The data privacy impact assessment identifies and rates all privacy risks associated with the National Care Experience Programme and recommends the controls to be put in place to minimise identified risks. In addition, the National Care Experience Programme has a comprehensive information governance framework to protect the privacy of all information collected.

This information governance framework outlines:

- how the personal data is used (that is, for the purpose of administering the survey)
- the necessary precautions that are in place to protect personal information from loss, unauthorised access, modification, use, disclosure and disposal
- how data protection breaches are managed
- the retention and destruction schedule for any personal data collected in the administration of the survey.

The National Care Experience Programme does not store personal data for any longer than is required beyond the administration of a survey.

Anonymity is integral to the survey design in the following ways:

- eligible participants' names will not be linked with their responses
- eligible participants' contact details will be electronically shredded once the survey is complete

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- all hardcopy survey responses will be shredded at the end of the survey cycle
- all survey responses are reviewed, risk rated and anonymised
- survey results will not be published if service providers do not meet a minimum threshold of responses to ensure that there is no risk of identification for participants.

10. What national legislation and standards must the National Care Experience Programme adhere to?

The National Care Experience Programme is aligned with national legislation and standards including:

- Data Sharing and Governance Act 2019
- Data Protection Acts 1988 – 2018
- General Data Protection Regulation (EU) 2016/679
- Freedom of Information Act 2014
- Information Management Standards for National Health and Social Care Data Collections (2017).

11. How can people access personal information held about them?

Under data protection legislation, individuals have a number of rights that a data controller is obliged to respect. At a most fundamental level, individuals have the right to have their details used in line with data protection regulations. They have the right to know if an organisation or individual is holding information on their person, and to access this information. They also have the right to object to the processing of their information, or have their information changed, removed or corrected by a data controller. A complete [guide to your rights](#) is available on the website of the Data Protection Commission.

The National Care Experience Programme has a data subject access request policy, which outlines how a data subject access request can be submitted. This policy is available to download at www.yourexperience.ie.

12. Further details on information handling practices

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.

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Alternatively, you can write to us at

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

13. Review

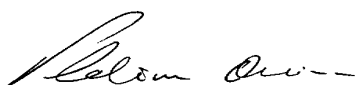
This policy will be reviewed every three years or alternatively in light of any legislative or other relevant project requirements.

14. 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 |
| 3.0 | 1 January 2022 | Periodic review |

15. Signatories to this document:

Signed on this 22 day of December 2021, by:



Phelim Quinn
Chief Executive Officer
Health Information and Quality Authority

