National Care
Experience
Programme

Statement of Information Practices

National Care Experience Programme

Statement of information practices – Standard Operating Procedure

Reference No:	04-002-00-SOP3
Revision No:	5.0
Author:	National Care Experience Programme team
Approved by:	Rachel Flynn, Director of the National Care Experience Programme
Effective from:	March 2025
Review date:	February 2028

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 National Inpatient Experience Survey, National Maternity Experience Survey, National Maternity Bereavement Experience Survey, National Nursing Home Experience Survey, National End of Life Survey, National Mental Health Experience Survey and the National Cancer Care Experience 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?

The 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 services. The role of the Steering Group is to ensure that:

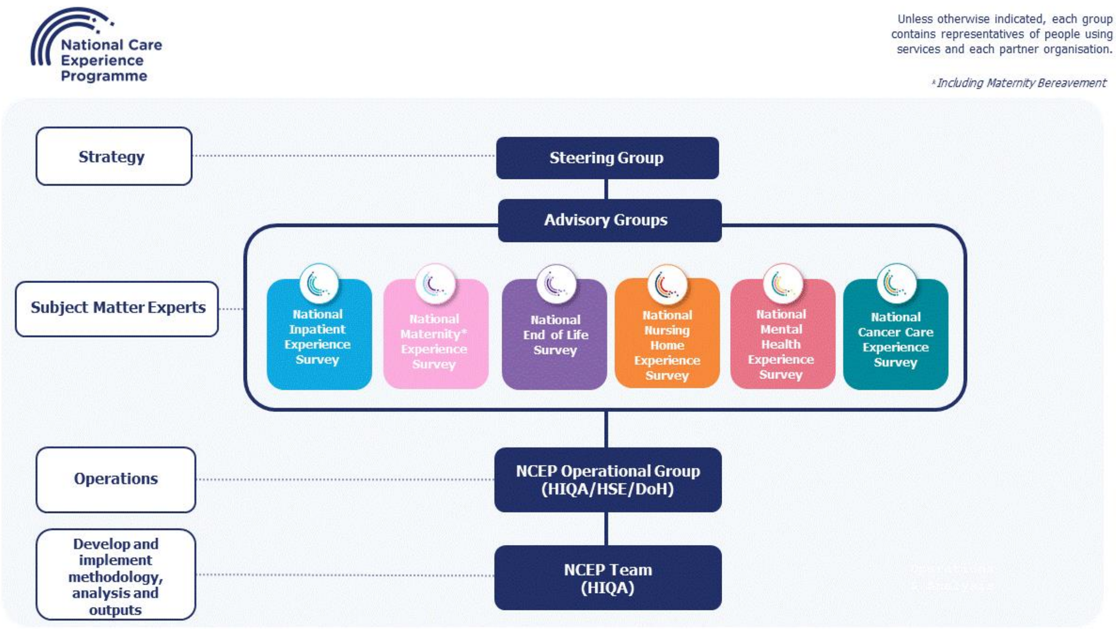
- the development and expansion of the programme is in line with national policy and legislation
- the objectives identified in the National Care Experience Programme Strategy 2025-2027 are met
- survey responses are used at a local, regional and national level to improve the experience of people using health and social care services in Ireland.

In addition to the Steering Group, each survey has an advisory group, which provides expert advice on the development, implementation and reporting of each survey. Advisory groups are composed of representatives from each of the partner organisations, subject matter experts and representatives of people using services.

The Oversight Implementation Group (HIQA and 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 advisory groups.

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

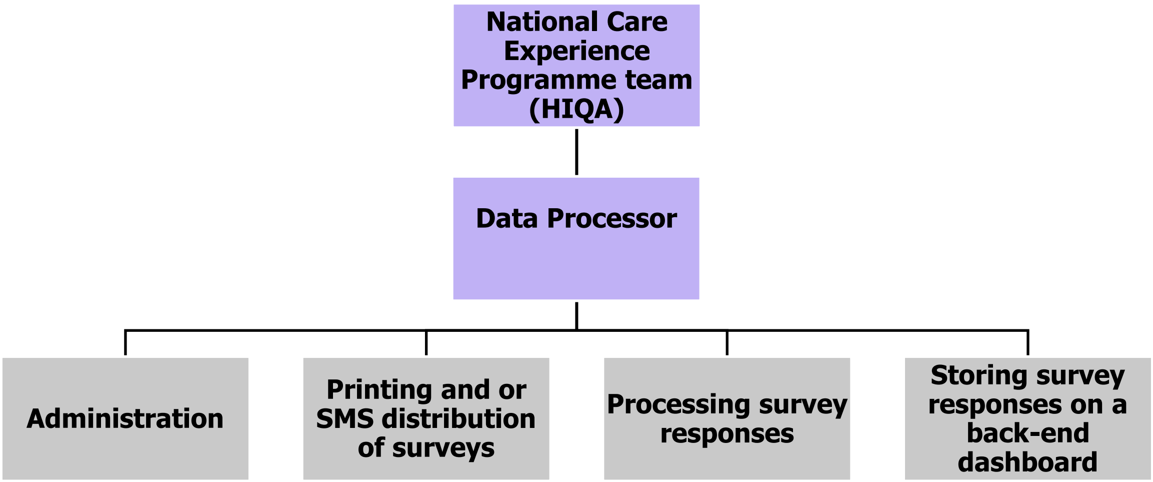


Unless otherwise indicated, each group contains representatives of people using services and each partner organisation.

** Including Maternity Bereavement*

HIQA is the lead partner in the National Care Experience Programme and as such, the data controller. HIQA has contracted a data processor, Ipsos Limited, which 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.

It is the role of **HIQA** to:

- lead on governance requirements for the National Care Experience Programme, including chairing the Steering Group and advisory groups
- draft annual business plans for the National Care Experience Programme aligned with the agreed strategic objectives
- be responsible for all procedural aspects of developing, implementing and reporting on national survey
- identify and review survey methodologies to ensure they remain fit for purpose
- lead on the delivery of the Communications and Stakeholder Engagement Plans for each survey with input from all partner organisations, to increase awareness and maximise survey participation

- act as the primary point of contact for key stakeholders including the Department of Health, participating services, public and patient representatives and advocacy groups
- identify, respond to and mitigate risks as appropriate
- be responsible for identifying, implementing and managing information governance requirements for data processed as part of National Care Experience Programme surveys
- be responsible for managing resources within the National Care Experience Programme team to meet the delivery of the strategy
- manage all third parties including external contractors, grantees and funders
- ensure programmes of work are delivered within the agreed funding model
- build confidence and trust in the collection, use and dissemination of data
- build the research and analytical function to enhance secondary use of survey data, optimising usage of the programme's dataset
- support and drive delivery of survey capability at service provider level
- build a collaborative model with academia, professionals and charity organisations to drive the secondary use of the data and overall impact of the programme
- provide appropriate training to promote the use of survey data in health and social care services
- further enhance a data and digital solution to ensure survey findings are accessible to all stakeholders.

The **HSE** National Care Experience Programme Steering Group representatives will champion any changes necessary within the HSE and promote the initiatives to ensure full engagement.

It is the role of the HSE to:

- implement the agreed strategy for the National Care Experience Programme within the HSE including the necessary structures, processes and policies to support consistent implementation within and across services
- respond to and mitigate identified risks, as appropriate
- provide the supports necessary to deliver on models and methodologies including people, training, information technology and amendment to existing practices and processes if appropriate
- provide data required to administer surveys such as names and contact details, as per the data sharing agreement between HIQA and the HSE
- deliver on the HSE's element of the annual business plans for the National Care Experience Programme

- deliver on the HSE's element of the communication and stakeholder engagement plans
- lead on facilitating the National Care Experience Programme's contact with key HSE stakeholders, responsible for supporting implementation of surveys
- provide the necessary support to the service providers to deliver on processes and procedures, to effectively administer and implement the survey methodologies and respective quality improvement initiatives
- ensure that responses to National Care Experience Programme findings, and an update on progress of same are published on the National Care Experience Programme website within an appropriate timeframe
- ensure that the findings from the National Care Experience Programme are acted on to inform quality improvements, policy and work programmes at local, regional and national levels
- support academic and international collaboration
- engage with all relevant stakeholders to inform and contribute toward the maintenance and expansion of the National Care Experience Programme.

The measurement of people's experience of care is a foremost priority on the HSE's agenda. The HSE is committed to implementing a plan, to build the capacity and infrastructure that is needed to promote a culture of person-centred care, and to measure people's experience of care in a real and meaningful way. The National Care Experience Programme results in increased information to inform and support processes to improve the experience for all those that use health and social care services in Ireland.

It is the role of the **Department of Health** to:

- ensure that the National Care Experience Programme operates in line with current national policy, remains informed and responds as appropriate to any changes in the national direction of health and social care, healthcare legislation and national policy
- respond to and mitigate identified risks as appropriate
- deliver on the Department of Health's element of the National Care Experience Programme Communications and Stakeholder Engagement Plans
- proactively use the findings of the National Care Experience Programme to inform the development and implementation of policy and legislation as appropriate
- inform and support the identification of further areas of health and social care to survey, based on national priority.

Throughout the programme, the Department of Health's Steering Group representatives will provide vision and leadership to ensure the success of the National Care Experience Programme. The Department will also participate in the advancement of the National Care Experience Programme Strategy though representation on advisory groups, and through participation in stakeholder feedback, as appropriate.

The Department will promote and expand care experience insights across the healthcare sector using the findings from the National Care Experience Programme to inform and improve national healthcare policy, legislation and vision, as well as identify areas of priority for health services in Ireland, where it deems it appropriate to do so.

3. What personal information is collected to distribute surveys?

The National Care Experience Programme only collects the data of people who are eligible to participate in surveys. The information collected includes:

Table 1: Data processed by the National Care Experience Programme to administer surveys of care experience

National Inpatient Experience Survey	
Data of patient ▪ first name ▪ surname ▪ address ▪ Eircode ▪ mobile phone number ▪ date of birth ▪ gender ▪ date of admission	▪ source of admission category ▪ date of discharge ▪ discharge destination ▪ length of stay ▪ hospital name ▪ hospital code ▪ health region
National Maternity Experience Survey	
Data of mother ▪ first name ▪ surname ▪ address ▪ Eircode ▪ mobile phone number ▪ date of birth of mother	▪ date of delivery ▪ date of discharge ▪ home birth ▪ hospital name ▪ hospital code ▪ health region

National End of Life Survey	
Data of bereaved individual ▪ first name ▪ surname ▪ address ▪ qualification of informant ▪ relationship of bereaved to deceased	Data of deceased individual ▪ first name ▪ surname ▪ gender ▪ date of death ▪ cause(s) of death ▪ place of death
National Nursing Home Experience Survey	
Data of nursing home resident ▪ first name ▪ surname ▪ nursing home name ▪ health region	Data of family member/friend ▪ first name ▪ surname ▪ address ▪ Eircode ▪ telephone number ▪ nursing home name
National Mental Health Experience Survey	
▪ first name ▪ surname ▪ address ▪ Eircode ▪ telephone number ▪ date of birth ▪ gender ▪ date of admission	▪ source of admission category ▪ date of discharge ▪ discharge destination ▪ length of stay ▪ hospital name ▪ hospital code ▪ health region
National Cancer Care Experience Survey	
▪ first name ▪ surname ▪ address ▪ Eircode ▪ mobile telephone number ▪ date of birth ▪ gender ▪ date of admission	▪ source of admission category ▪ date of discharge ▪ discharge destination ▪ length of stay ▪ hospital name ▪ hospital code ▪ health region

Service providers collect this data and share it with the data processor who administers surveys on behalf of the National Care Experience Programme. Access to this data is restricted to pre-defined persons. The data is handled in complete confidence, transferred and stored securely, and used uniquely for the purpose of carrying out surveys of care. It is held for the duration of the respective survey and deleted within six weeks of the closure of the survey cycle.

The National Maternity Bereavement Experience Survey will be carried out through a self-selecting online survey model. Eligible participants' data such as names, addresses and dates of birth will therefore not be processed as part of the survey.

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, the discharge process and care delivered in the community. Surveys ask structured tick-box questions as well as open-ended questions. Surveys can be completed online, by returning the questionnaire via freepost or in certain cases by interview. Anonymisation criteria are consistently applied to survey responses upon receipt, to ensure that no personally identifiable information is retained.

Once anonymised, survey responses will be retained for additional analysis, including comparisons with future surveys. The data will also be used to compare, with the aim of improving, the experiences of different communities in Ireland based on data such as age, length of stay or the sociodemographic conditions of the areas where participants live.

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] Survey responses are used to inform improvements in the quality and safety of health and social care.

The National Care Experience Programme has developed a comprehensive information governance framework to ensure that the privacy rights of all eligible survey 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[2] and Section 38 of the Data Protection Act 2018[3], 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 complies with the Data Sharing and Governance Act 2019, where it applies to the sharing of information between public bodies for the purposes of conducting the surveys. Section 13 (2) (a) (ii) (V), (VI) and (VII) provide a legal basis to process data collected by the National Care Experience Programme for the purposes of service administration and supervision and facilitating the improvement of a service and evaluating a service.

The National Care Experience Programme is conducted in the public interest; the partner organisations of the programme have committed to using the results of surveys to inform quality improvements across the health and social care 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.

Participation in National Care Experience Programme surveys is voluntary. Participants are informed by service providers that they will be invited to participate

---

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

[2] General Data Protection Regulation (EU) 2016/679, European Union. 2016. Available from: https://gdpr-info.eu/.

[3] Data Protection Act 2018, Ireland. 2018. Available from: https://www.gov.ie/en/publication/65865-data-protection-act-2018/

in a survey, at which time, participants can opt out. Upon receipt of the survey, eligible participants who do not want to participate can opt out by email, by phone, online at www.yourexperience.ie or by returning a blank questionnaire in the post.

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 in place between HIQA and the data processor, which sets out the requirements for the secure processing of all data processed by the National Care Experience Programme to include sharing, storage, handling and destruction.

6. Right to opt out

Participation in National Care Experience Programme surveys is voluntary. Potential participants are provided with a participant information leaflet at the point of data collection, for example hospitals in the National Inpatient Experience Survey and the National Maternity Experience Survey. 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 information 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:

- by calling 1800 314 093
- by emailing info@yourexperience.ie
- by selecting the opt-out option provided 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.
- 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.
- 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 six 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 carrying out surveys)
- 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 deleted once the survey is complete
- 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:

- National Standards for Information Management in Health and Social Care (2024)
- Data Sharing and Governance Act 2019
- Data Protection Acts 1988 – 2018
- General Data Protection Regulation (EU) 2016/679
- Freedom of Information Act 2014.

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 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.

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
4.0	1 August 2022	Review in advance of the National Maternity

		Bereavement Survey and the End of Life Survey
5.0	10 March 2025	Periodic review

National Care
Experience
Programme

Health
Information
and Quality
Authority
An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health