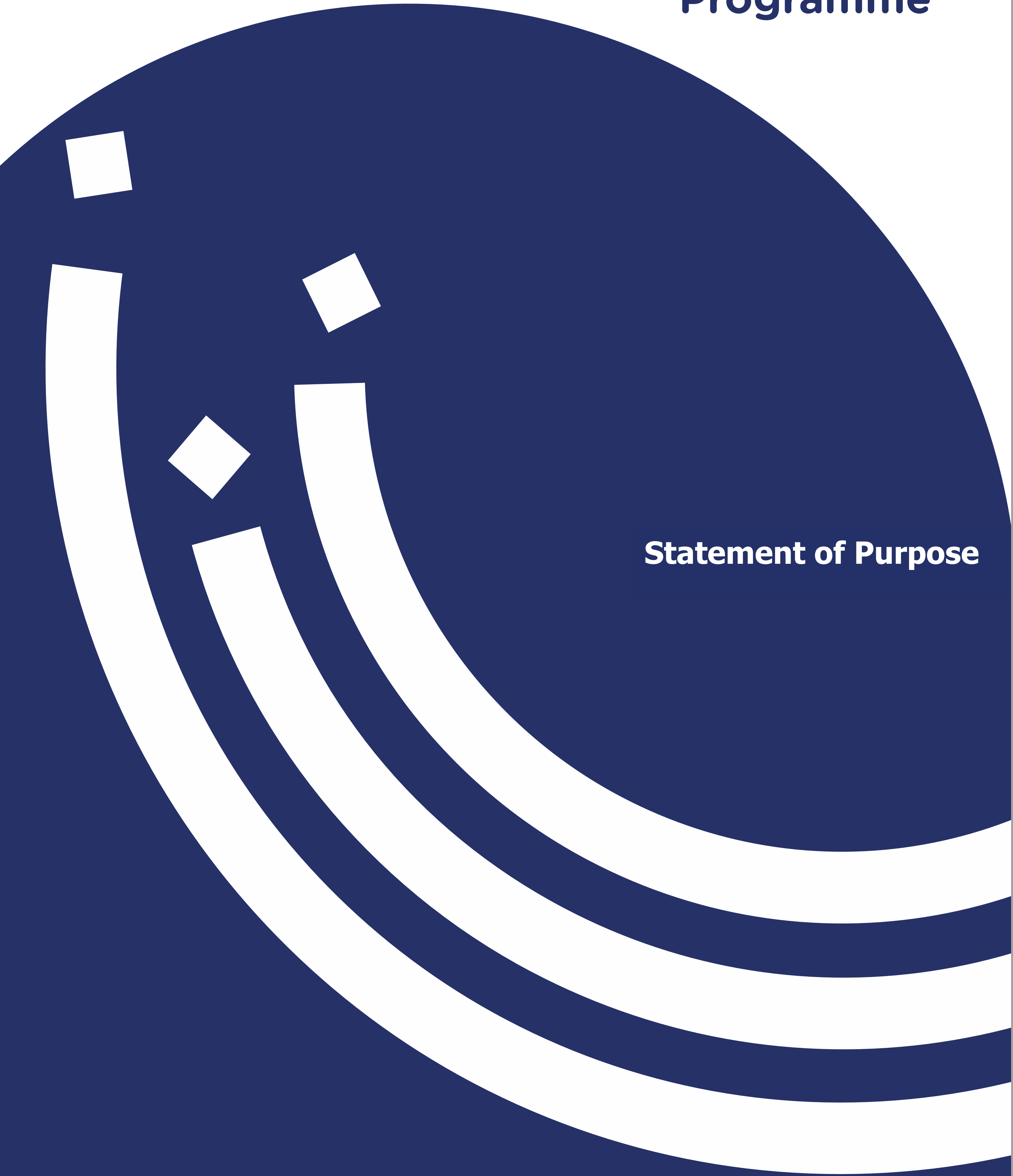
National Care
Experience
Programme



Statement of Purpose

Statement of purpose - policy

Reference No:	04-002-00-SOP2
Revision No:	6.0
Author:	National Care Experience Programme team
Approved by:	Rachel Flynn, Director, National Care Experience Programme, HIQA
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. What is the aim of the National Care Experience Programme?

The aim of the National Care Experience Programme is to encourage people using health and social care services to share their experiences of care and to use this information to improve the quality of health and social care services in Ireland.

2. What are the objectives of the National Care Experience Programme?

The objectives of the National Care Experience Programme are to provide people using health and social services in Ireland with the opportunity to share their experience, which will help the partner organisations to:

- improve the future planning and delivery of health and social care
- develop and build quality improvement initiatives
- improve experience of care at a local and national level
- shape local and national policy as appropriate
- allow comparisons and benchmarking of service delivery, both nationally and internationally.

3. 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:

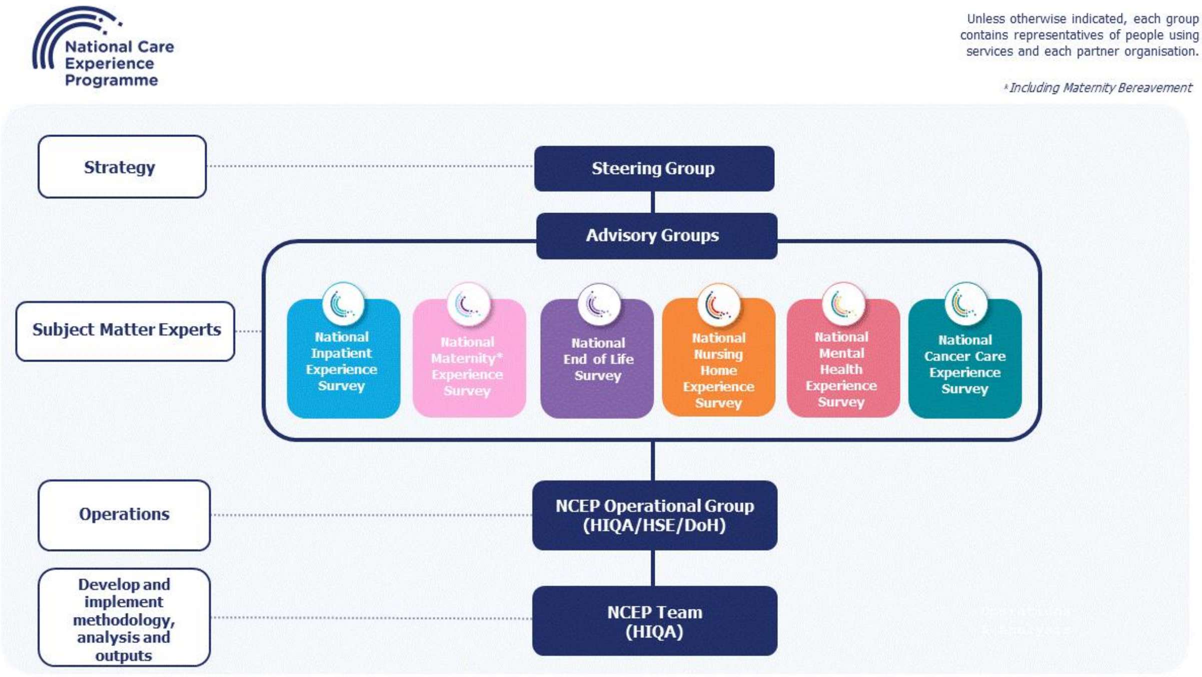
- the development and expansion of the programme is in line with national policy and legislation
- the objectives identified in the National Care Experience Programme Strategy 2025-2027 are met
- survey responses are used at a local, regional and national level to improve the experience of people using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

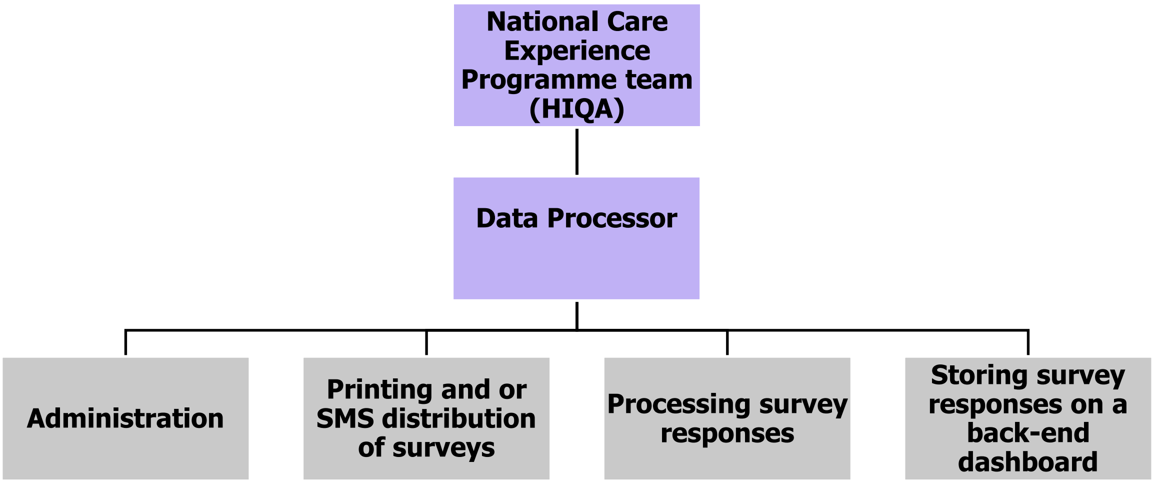
Figure 1 illustrates the roles of the National Care Experience Programme governance groups and team.

Figure 1: Roles and responsibilities of the National Care Experience Programme 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, Ipsos Limited, which is responsible for the administration of surveys. Figure 2 outlines the responsibilities of the data processor.

Figure 2: Roles and 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 datasets
- 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 carry out 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 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.

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 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 of Health 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 of Health 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 and to identify areas of priority for health services in Ireland, where it deems it appropriate to do so.

4. Who are the data providers?

Personal data such as the contact details of people using services, are collected from participating service providers during survey sample periods. Each service provider is a data provider and the sharing of such data is governed by a formal data sharing agreement between service providers participating in surveys and HIQA.

The personal data is collected for the purpose of engaging with people using Irish health and social care services to carry out surveys of care.

5. What personal data is collected by the National Care Experience Programme?

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 carry out 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	▪ source of admission category ▪ date of discharge ▪ discharge destination ▪ length of stay

▪ mobile telephone number ▪ date of birth ▪ gender ▪ date of admission	▪ hospital name ▪ hospital code ▪ health region

Service providers collect this data and share it with the data processor who carries out 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 for the purpose of carrying out surveys. 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.

6. 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 length of stay and 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.

7. 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 quality 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 in a survey. Eligible participants who do not want to participate can opt out of the

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[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/

survey by telephone, by email, online at www.yourexperience.ie or by returning a blank questionnaire in the post.

Data collected by the National Care Experience Programme is used for analysis by the National Care Experience Programme and may be made available for secondary analysis for research purposes. 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.

8. What is the source of funding?

As with other resource allocation in the Irish public health and social care system, resourcing for the National Care Experience Programme is provided each year through the annual estimates process for each of the partner organisations. This is also described in a memorandum of understanding between the partner organisations. Certain surveys are supported, in part, by relevant professional and charity organisations.

9. 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 the:

- 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

10. Further information on information handling practices

Further details on information handling practices can be found at 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 by the National Care Experience Programme.

Alternatively, you can also email us at info@yourexperience.ie or write to us at:

The National Care Experience Programme team
C/o Health Information and Quality Authority
George's Court, George's Lane
Smithfield, Dublin 7
D07 E98Y

11. Review

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

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
3.0	1 January 2022	Periodic review
4.0	1 August 2022	Review in advance of the National Maternity Bereavement

		Experience Survey and the National End of Life Survey
5.0	06 October 2023	Version history corrected no change to content and no change to dates
6.0	10 March 2025	Periodic review

National Care
Experience
Programme

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

Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service

An Roinn Sláinte
Department of Health