

Statement of Purpose Policy
January 2022



National Care Experience Programme

Statement of purpose - policy

Reference No: 04-002-00-SOP2

Revision No: 4.0

Author: National Care Experience Programme team

Approved by:

Phelim Quinn, Chief Executive Officer, HIQA

Marita Kinsella, National Director: Patient Safety Office, Department of Health

Joe Ryan, National Director, Operational Performance and Integration, HSE

Louise Loughlin, National Manager, National Advocacy Service

Roisin O' Leary, Senior Patient Advocate, Sage Advocacy

Effective from: January 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. 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 services 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?

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 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 2022-2024 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.

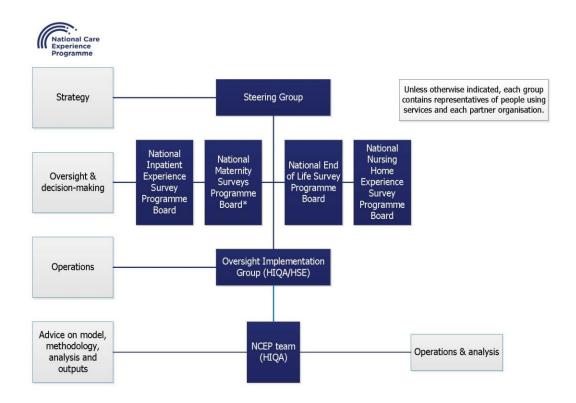
In addition to the Steering Group, each survey has a programme board, which is responsible for operational decision-making in the development, implementation and reporting of each survey. Programme boards are composed of representatives from each of the partner organisations, subject matter experts and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

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

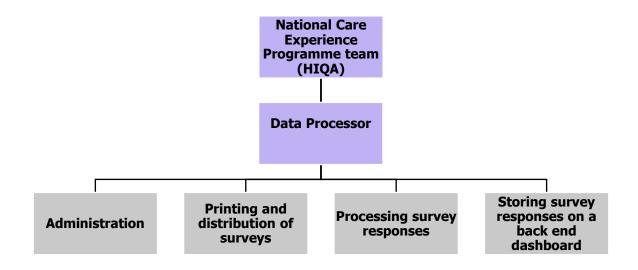


*The National Maternity Surveys Programme Board will be responsible for both the National Maternity Experience Survey and the National Maternity Bereavement Experience Survey.



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: 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.

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 findings of 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 resources to health and social care providers to develop and implement surveys of local and specialised care.

The **HSE** is working with HIQA to ensure the 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.

4. Who are the data providers?

Personal data such as the contact details of people using services, is 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 sole purpose of administering national surveys to engage with people using Irish health and social care services.

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 administer surveys of care experience

National Inpatient Experience Surve	y	
Data of patient		
 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		
 first name surname address date of birth date of delivery 	 date of discharge hospital group hospital name hospital code 	



National End of Life Survey			
Data of bereaved individual	Data of deceased individual		
 first name surname address qualification of informant relationship of bereaved to deceased 	 first name surname gender date of death cause(s) of death place of death 		
National Nursing Home Experience Survey			
Data of nursing home resident	Data of family member/friend		
first namesurnamenursing home details	 first name surname address relationship to resident nursing home details 		

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 administering 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. If eligible participants request to take the survey in Irish or Polish, the National Care Experience Programme will process their name and address for the sole purpose of distributing the survey to them.

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.

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'. 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

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



Data Sharing and Governance Act 2019. Under Article 6 (1) (e) of the GDPR² and Section 38 of the Data Protection Act 2018³, 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 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, at which time, participants can opt out. Eligible participants who do not want to participate can avail of four different options to opt out, upon receipt of the survey.

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 Subject 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 sharing, storage, handling, processing and destruction of all data processed by the National Care Experience Programme.

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/charity organisations.

² General Data Protection Regulation (EU) 2016/679, European Union. 2016. Available from: https://gdprinfo.eu/.

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



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:

- 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).

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

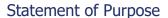
This policy will be reviewed every three years or alternatively in light of any legislative or other relevant programme requirements.





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 January 2022	Review in advance of the National Maternity Bereavement Experience Survey and the National End of Life Survey





13. Signatories of the Statement of Purpose

Signed on this 22 day of December 2021

Phelim Quinn

Chief Executive Officer

for and on behalf of the Health Information and Quality Authority

by Marita Kinsella

Director of the National Patient Safety Office

for and on behalf of the **Department of Health**

by -

Joe Ryan

National Director, Operational Performance and Integration

for and on behalf of the **Health Service Executive**

bv

Louise Loughlin National Manager

for and on behalf of the National Advocacy Service

by Com

Roisin O' Leary

Senior Patient Advocate

for and on behalf of Sage Advocacy









