



Statement of Purpose

National Care Experience Programme

Statement of purpose - Policy

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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 results of the National Inpatient Experience Survey inform the development of quality improvement plans at hospital, hospital group and national levels and informs regulation and national legislation.

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.

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 and safety 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 and safety 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
- resources are in place and objectives identified in the National Care Experience Programme Strategic Plan 2019-2021 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, 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.

A National Care Experience Programme Technical Group provides statistical expertise on the development and implementation of surveys and includes representation from the three partner organisations.

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, Programme Boards and the Technical Group.

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

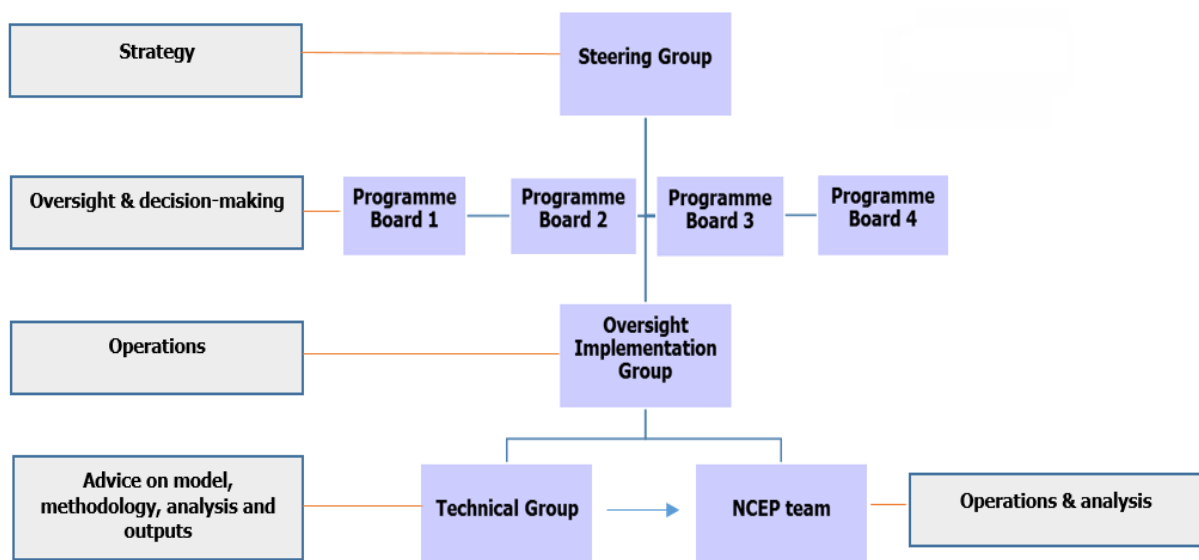


Figure 1 Roles of the National Care Experience Programme governance groups and team

HIQA has contracted a data processor, Behaviour and Attitudes. The data processor is responsible for the administration of surveys. Figure 2 outlines the responsibilities of the data processor.

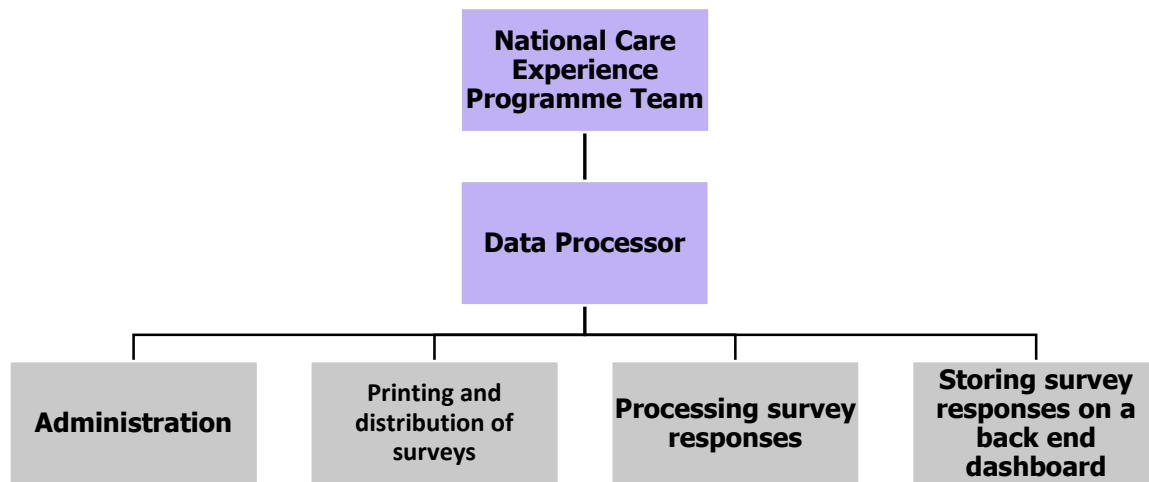


Figure 2 Responsibilities of the data processor

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 for 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 communications and stakeholder engagement 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.

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 overall aim of the Department is to improve the health and wellbeing of people in Ireland by:

- keeping people healthy
- providing the healthcare people need
- delivering high quality services
- getting the best value from health system resources.

The Department recognises patient safety as the cornerstone to quality healthcare. In December 2016, the Department established a National Patient Safety Office (NPSO) to progress a policy programme of patient safety legislation, patient safety surveillance, patient safety policy initiatives as well as the National Clinical Effectiveness Framework. Learning from patient experience, promoting a problem-sensing culture through patient safety surveillance, as well as establishing a robust clinical effectiveness framework contribute to the continuous development of national patient safety policy and legislation. From the Department, both the NPSO and the relevant policy unit (such as Acute Hospitals and Maternity Services) participate in furthering the objectives of the National Care Experience Programme.

4. Who are the data providers?

Personal information, including personally identifiable information 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 participating hospitals and HIQA.

Personal information 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:

- name
- address
- date of birth
- gender
- date of admission
- source of admission
- date of delivery (in the case of people using maternity services)
- date of discharge
- discharge destination
- length of stay
- hospital name
- hospital group name.

Service providers collect this information 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.

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 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. The survey can be completed online or by returning the questionnaire via freepost. 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

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, upon 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.

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 laws, including the GDPR. 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 Care Experience Programme surveys, which capture feedback on the experience of people using health and social care 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.

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.

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 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

13. Signatories of the Statement of Purpose

Signed:

on this 6 day of November 2019
by Marita Kinsella


National Director of the Patient Safety Office
for and on behalf of the Department of Health

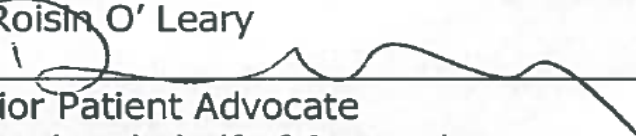
on this 19th day of November 2019
by Phelim Quinn


Chief Executive Officer
for and on behalf of the Health Information and Quality Authority

on this 19 day of Nov 2018
by Patrick Lynch


National Director of Quality Assurance and Verification
for and on behalf of the Health Service Executive

on this 30 day of October 2019
by Roisin O' Leary


Senior Patient Advocate
for and on behalf of Sage Advocacy

