



Statement of Purpose

National Care Experience Programme

Statement of purpose - Policy

Reference No: 04-002-00-SOP2

Revision No: 1.0

Author: National Care Experience Programme Team

Approved by:

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

Phelim Quinn, Chief Executive Officer, HIQA

Patrick Lynch, Director of Quality Assurance and Verification, HSE

Roisin O' Leary, Senior Patient Advocate, Sage Advocacy

Effective from: August 2019

Review date: August 2021

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.

Statement of Purpose

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.

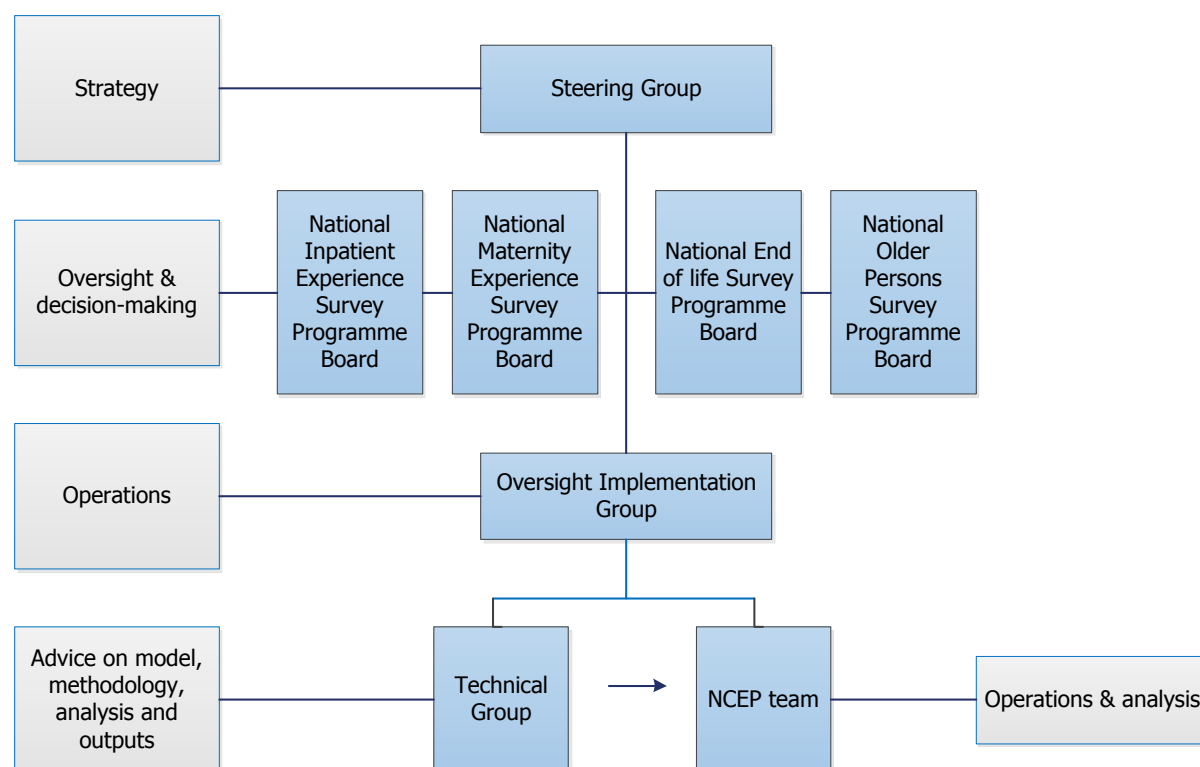


Figure 1 Roles of the National Care Experience Programme governance groups and team

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.

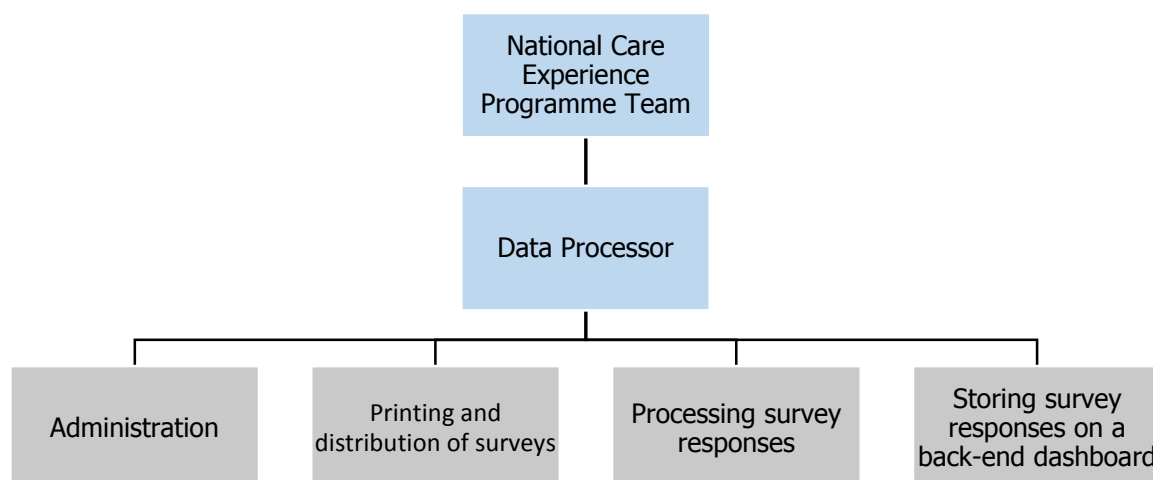


Figure 2 Responsibilities of the data processor

Roles of partner organisations and representatives of people using services

a. Department of Health

It is the role of the Department of Health to:

- ensure that the National Care Experience Programme is in line with current national policy and 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's element of the Communication Plan
- 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 prioritisation process for the programme's expansion into two others sectors of health and social care
- support the creation of a competency centre of international standing with the capacity, skills and expertise to extend the National Care Experience Programme to other areas of health and social care. This may include supporting academic or international collaboration and showcasing survey findings and resulting improvements as appropriate.

Throughout the programme, the Department'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

Statement of Purpose

Care Experience Programme Strategic Plan through representation on Programme Boards and the Technical Group, 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 and to identify areas of priority for health services in Ireland, where it deems it appropriate to do so.

b. Health Information and Quality Authority

It is the role of HIQA to:

- develop the annual business plans for the National Care Experience Programme, which reflect and lead to the delivery of the National Care Experience Programme Strategic Plan 2019-2021
- implement the agreed strategic plan for the National Care Experience Programme, which will include a prioritisation process for the programme's expansion into other sectors of health and social care
- implement the element of the annual business plans that fall under HIQA's remit
- develop and implement a communication framework supported by a Communication Plan in order to increase public awareness and maximise engagement with the National Care Experience Programme
- respond to and mitigate identified risks as appropriate
- be responsible for operational and resource management, including management of all third parties
- ensure confidence and trust in the collection, use and dissemination of data
- conduct primary and secondary analysis of survey data and report on the findings in accordance with the National Care Experience Programme Strategic Plan 2019 – 2021 as well as the policy and direction of the Steering Group
- support the creation of a competency centre of international standing with the capacity, skills and expertise to extend the National Care Experience Programme to other areas of health and social care.

Information from the National Care Experience Programme will be a key enabler to assist HIQA in its role of promoting sustainable quality improvements, safeguarding people using services, and promoting person-centred care for the benefit of the public.

c. Health Service Executive

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

- implement the agreed strategic plan for the National Care Experience Programme, which will include a prioritisation process for the programme's expansion to two new sectors of health and social care
- 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.
- 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 Plan for the National Care Experience Programme
- 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 the creation of a competency centre of international standing with the capacity, skills and expertise to extend the National Care Experience Programme to other areas of health and social care. This may include supporting academic or international collaboration and showcasing survey findings and resulting improvements as appropriate
- 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, as described in the National Service Plan 2019. 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.

d. Sage Advocacy

Sage Advocacy promotes, protects and defends the rights and dignity of vulnerable adults, older people and healthcare patients. Representatives of Sage Advocacy will act in an advisory capacity to the partner organisations to ensure that the viewpoints of people using services are central to the strategic direction and decision making process 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(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	15 November 2019	Original document release

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

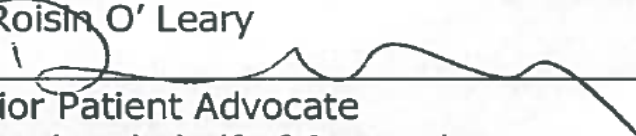
on this 19th day of November 2019
by Phelim Quinn


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

