



# **Memorandum of Understanding**

### **Between**

Health Information and Quality
Authority, Department of Health, Health
Service Executive, Sage Advocacy CLG and
National Advocacy Service for People with
Disabilities CLG

National Care Experience Programme 2025-2027





#### 1. The Parties

**Health Information and Quality Authority,** having its head office at Unit 1301 City Gate, Mahon, Cork, Ireland.

**Department of Health** having its principal office at Block 1, Miesian Plaza, 50 – 58 Lower Baggot Street, D02 XW14

**Health Service Executive** having its principal office at Dr. Steeven's Hospital, Steeven's Lane, Dublin 8, D08 W2A8

**Sage Advocacy CLG** having its principal office at 24-26 Upper Ormond Quay, Dublin D07 DAV9

National Advocacy Service for People with Disabilities CLG having its principal office at Level 3 Rear Unit, Marshalsea Court, Merchant's Quay, Dublin 8

The Parties agree that the Memorandum of Understanding entered into between the Parties on 22 December 2021 is hereby terminated and replaced with this Memorandum of Understanding which shall come into effect in accordance with Clause 13.

### 2. Interpretation and Definitions

- 2.1 This Memorandum of Understanding means the clauses of and the appendices to this Memorandum of Understanding, all of which shall be read as one document.
- 2.2 In this Memorandum of Understanding, the following definitions shall apply:
  - (i) "2004 Act" means the Health Act 2004 as amended from time to time;
  - (ii) "2007 Act" means the Health Act 2007 as amended from time to time;
  - (iii) Data Protection Law means all applicable laws and regulations relating to the processing of personal data, including, in particular, the GDPR, the Data Protection Acts 1988 to 2018, the Data Sharing and Governance Act 2019 and any statutory instruments, rules, orders or regulations made thereunder as from time to time amended, extended, re-enacted, replaced or consolidated (whether before or, after the date of this Agreement);





- (iv) "Department" means the Department of Health;
- (v) "Funding Principles" means the Funding Principles for the National Care Experience Strategy 2025-2027 as agreed between the Partners. The Funding Principles reflect the commitment of the Partners to funding the delivery of the National Care Experience Programme;
- (vi) "Health and Social Care Services" means services provided within the meaning of Section 8(1) of the Health Act 2007 as amended and services provided by the HSE under the Mental Health Act 1945 to 2009;
- (vii) "HIQA" means the Health Information and Quality Authority, a statutory body established under the Health Act 2007 and the NCEP Lead Partner;
- (viii) "HSE" means the Health Service Executive, a statutory body established under the Health Act 2004;
- (ix) "MOU" means this Memorandum of Understanding;
- "National Advocacy Service" means National Advocacy Service for People with Disabilities CLG and includes the Patient Advocacy Service which is provided by the National Advocacy Service;
- (xi) "NCEP" means the National Care Experience Programme, a joint initiative between HIQA, the Health Service Executive and the Department of Health, which conducts surveys of survey participants in the Irish health and social care system with the aim of improving the quality of health and social care services by asking people about their experiences of care;
- (xii) "NCEP Strategy" means the National Care Experience Programme Strategy 2025-2027 a copy of which is attached to Appendix 2 of this Memorandum of Understanding;
- (xiii) "NCEP Team" means HIQA's Director of Health Information and Standards and National Care Experience Programme and the Deputy Director of the National Care Experience Programme in HIQA and people working in HIQA on the delivery of the National Care Experience Programme Strategy 2025 - 2027 and who report to the persons holding those positions;
- (xiv) "Partners" means the Health Information and Quality Authority, the Department of Health and the Health Service Executive and "Partner" means any of them;
- (xv) "Parties" means the Health Information and Quality Authority, the Department of Health, the Health Service Executive, Sage Advocacy and the National Advocacy Service and "Party" means any of them;
- (xvi) "Personal Data" has the meaning set out under Data Protection Law;
- (xvii) "Sage Advocacy" means Sage Advocacy CLG;





(xviii) "the surveys" means the surveys conducted by the National Care Experience Programme.

### 3. Background

- 3.1 The NCEP 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.
- 3.2 The NCEP is a partnership between the Department, HIQA and the HSE. The NCEP is established to develop the care experience model and to develop and implement the most appropriate methodologies to capture the experience of people using health and social care services in Ireland in order to identify areas for improvement and drive improvements in care at local and national level. It has been agreed between the Partners that HIQA will be the lead Partner for the NCEP. The NCEP Team will lead on providing a centralised, coordinated approach to implement the NCEP Strategy. This will be done in collaboration with Sage Advocacy and the National Advocacy Service who will be consulted for the purpose of seeking support and advice where relevant and appropriate.
- 3.3 The NCEP captures patient experiences of health and social care services through the development and implementation of the surveys. The surveys aim to elicit feedback from people about the care received in health and social care services. The aim of the surveys is to find out what is working well, and what needs to be improved. The NCEP Research and Analysis team publishes survey findings and data, engages in academic research, and develops educational material to help people understand care experience surveys.
- 3.4 A NCEP Steering Group is in place to oversee the successful implementation of the NCEP Strategy 2025-2027 which sets out the objectives of the NCEP for 2025-2027 which the Partners commit to and agree and to implement.

The NCEP Steering Group is responsible for:

- Agreeing the terms of reference for the NCEP Steering Group and providing oversight of NCEP advisory groups which may be established from time to time to support the delivery of the NCEP Strategy
- Development, oversight and delivery of the NCEP Strategy





- Reviewing the effectiveness of this MOU for the purpose of ensuring that it remains fit for purpose to ensure delivery of the NCEP Strategy
- Providing governance for the NCEP including governance regarding the processing of personal data for the purpose of implementation of the surveys
- Risk management in relation to survey design, delivery, implementation and evaluation of results
- Prioritising programmes of work to achieve the objectives outlined in the NCEP Strategy
- Ensuring the funding and resources required are in place to implement the NCEP
- Engaging with relevant health and social care providers at, regional and national level, to ensure they are acting upon the survey findings to improve services
- Providing regular reports on plans and actions based on survey findings published on www.yourexperience.ie.

### 4. Mandate

### **Health Information and Quality Authority**

4.1 HIQA, having been established under the 2007 Act, is an independent statutory body established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public. HIQA's mandate to date extends across a wide range of public, private and voluntary health and social care sector services.

Reporting to the Minister for Health and engaging with relevant government Ministers and departments, HIQA has responsibility for the following:

- National Care Experience Programme Carrying out national service-user experience surveys across a range of health and social care services, with the Department of Health and the HSE.
- Setting standards for health and social care services —
   Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.





- Regulating social care services The Chief Inspector of Social Services within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- Regulating health services Regulating medical exposure to ionising radiation.
- Monitoring services Monitoring the safety and quality of permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social services.
- Health technology assessment Evaluating the clinical and cost effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- Health information Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.

Under Section 8(2)(b) of the 2007 Act, in carrying out its functions, HIQA shall have regard to the need to co-operate with and co-ordinate its activities with public authorities, the performance of whose functions affect or relate to the functions of HIQA, other than those functions described in section 8(1)(c), (d) and (l) of the 2007 Act.

Under Section 38 of the 2007 Act, HIQA may, subject to any directions given by the Minister for Health under Section 29 of the 2007 Act, and on the terms and conditions HIQA sees fit to impose, give assistance to a body which performs or proposes to perform a function similar or ancillary to a function that HIQA may perform.

Section 8(3) of the 2007 Act provides that HIQA has all the powers as are necessary or expedient for the performance by it of its functions.





### **Department of Health**

- 4.2 The Department, having been established under the Ministers and Secretaries Act 1924 as amended in 2011, has an overall mission to improve the health and wellbeing of people in Ireland by delivering high quality health services and getting best value from health system resources. The Department's role is to provide strategic leadership for the health service and to ensure that government policies are translated into actions and implemented effectively. The Department supports the Minister for Health and Ministers of State in their implementation of government policy and in discharging their governmental, parliamentary and departmental duties. This includes:
  - leadership and policy direction for the health sector to improve health outcomes
  - governance and performance oversight to ensure accountable and high quality services
  - collaboration to achieve health priorities and contribute to wider social and economic goals
  - an organisational environment where, on an ongoing basis, high performance is achieved, collaborative working is valued and the knowledge and skills of staff are developed.

The mission of the Department 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 the 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) within 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 NCEP Strategy.

### **Health Service Executive**

4.3 The HSE was established by Ministerial Order on 1 January 2005 in accordance with the provisions of the 2004 Act. It is the single body with statutory responsibility for the management and delivery of health and personal social services to the population of Ireland. Section 7 of the 2004 Act states that the objective of the HSE is to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public.

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 personcentred care, and to measure people's experience of care in a real and meaningful way. The NCEP 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.

### Sage Advocacy

4.4 Sage Advocacy is a company limited by guarantee (Registered Company Number 610824) which is regulated by the Charities Regulator (Registered Charity Number 20162221). Sage Advocacy's mission statement is to promote, protect & safeguard the rights and dignity of older people, vulnerable adults and healthcare patients through individual and systemic advocacy. Representatives of Sage Advocacy will act in an advisory capacity to the Partners to ensure that the viewpoints of people using services are central to the strategic direction and decision-making process of the NCEP.

### **National Advocacy Service**

4.5 The National Advocacy Service is a company limited by guarantee (Registered Company Number 535779) which is regulated by the Charities Regulator (Registered Charity Number 20141332). The National Advocacy Service





provides an independent, confidential and free advocacy service that works exclusively for adults with disabilities. Its role is to work with those who may be isolated from their community of choice or mainstream society, may communicate differently and who may have limited informal or natural supports. The National Advocacy Service acts as a catalyst for change through collaboration, capacity building and representation to make the rights of people with disabilities a reality. It provides an independent, confidential and free Patient Advocacy Service that works to support and empower patients in public acute hospitals and residents in nursing homes who wish to make a formal complaint about the care they have received. The Patient Advocacy Service also provides support in the aftermath of a patient safety incident.

### 5. Purpose and Objectives

The purpose and objectives of this MOU are to:

- 5.1 Provide a framework for effective co-operation and communication to ensure implementation of the NCEP Strategy.
- To cover areas of common interest where cooperation will lead to improved health and social care services in Ireland by asking people about their experiences of care and acting on the feedback.
- 5.3 To clearly outline the roles and responsibilities of the Partners to ensure effective delivery of the NCEP Strategy. Oversight and strategic leadership of the NCEP Strategy will be provided by the NCEP Steering Group.
- To establish an appropriate funding mechanism which adheres to the Funding Principles as agreed between the Partners and which will contribute to the successful delivery of the NCEP Strategy within agreed timelines and objectives.
- To review existing Data Sharing Agreements in place between HIQA and various HSE Hospitals with a view to establishing an overarching Data Sharing Agreement between HIQA and the HSE which will ensure effective and transparent processing of personal data for the surveys at HSE national level.
- 5.6 Where appropriate, to enter into collaboration arrangements, with professional bodies, academic institutions or subject matter expert





organisations to leverage their networks or resources with the aim of supporting and informing the development of surveys and for the purpose of driving the use of survey data to promote improvements in health and social care services.

### 6. Primary Areas of Cooperation

The Partners, having agreed the primary areas of cooperation under NCEP Strategy will be:

- 6.1 Undertake to communicate as appropriate on all matters of strategic, mutual and operational interest in relation to the NCEP. Communication will be conducted on both a formal basis through scheduled meetings, and informally on an ad hoc basis as required.
- 6.2 Agree an annual business plan that is achievable and adheres to the agreed Funding Principles.
- 6.3 Support communication and awareness of the surveys in line with NCEP Communications and Stakeholder Engagement Plan.
- 6.4 Leverage networks to build awareness and amplify the impact of the NCEP Strategy.
- 6.5 Integrate survey findings in their work to drive improvements in practice, inform the development and implementation of policy and legislation, and support the development of person-centred standards and guidance for health and social care services.
- 6.6 Support data and digital evolutions to ensure the NCEP remains agile and responsive to the public and health and social care services needs.

### 7. Roles and Responsibilities under this MOU

### **Department of Health**

- 7.1 It is the role of the Department to:
  - ensure that the NCEP 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's element of the NCEP Communications and Stakeholder Engagement Plans 2025-2027
- proactively use the findings of the NCEP 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 NCEP, the Department's NCEP Steering Group representatives will provide vision and leadership to ensure the success of the NCEP Strategy. The Department will also participate in the advancement of the NCEP Strategy though representation on NCEP Advisory Groups, and through participation in stakeholder feedback as appropriate.

The Department will promote and expand care experience insights across the health and social care sector using the findings from the NCEP 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.

### **Health Information and Quality Authority**

- 7.2 As lead Partner, the role of HIQA is to:
  - lead on governance requirements for the NCEP, including chairing the NCEP Steering Group and Advisory Groups
  - draft annual business plans for the NCEP aligned with the agreed strategic objectives
  - be responsible for all procedural aspects of developing, implementing and reporting on national survey programmes
  - 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 Partners to increase awareness and maximise survey participation
  - act as the primary point of contact for key stakeholders including the Department, 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 NCEP surveys
- be responsible for managing resources within the NCEP team to meet the delivery of the NCEP Strategy
- manage all third parties including external contractors, grantees and funders and enter into contracts and agreements, including data sharing agreements and ensuring lawful transparent processing of data, where necessary on behalf of the NCEP in order to successfully implement the NCEP Strategy
- ensure programmes of work are delivered within the agreed Funding Principles
- 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 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 NCEP
- 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
- develop and implement an appropriate funding mechanism, which may include a funding agreement/s, between HIQA and the HSE to govern effective and timey transfer of funding to HIQA for the successful delivery of the NCEP Strategy.
- Oversee all aspects of the design, development and operational aspects for the NCEP Website www.yourexperience.ie.

### **HSE**

### 7.3 It is the role of the HSE to:

- implement the agreed NCEP Strategy 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/processes if appropriate
- provide data required to administer surveys such as names and contact details, as per the NCEP HSE Data Sharing Agreement
- deliver on the HSE's element of the Annual Business Plans for the NCEP
- deliver on the HSE's element of the Communication Stakeholder Engagement Plans
- lead on facilitating the NCEP'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 NCEP findings, and an update on progress of same are published on the NCEP website within an appropriate timeframe
- ensure that the findings from the NCEP are acted on to inform quality improvements, policy and work programmes at local, regional and national levels
- support academic, professional or international collaboration
- engage with all relevant stakeholders to inform and contribute toward the maintenance and expansion of the NCEP
- make a financial contribution on an annual basis in the terms as set out in the Funding Principles and to enter into a funding agreement/s with HIQA to govern effective and timey transfer of funding to HIQA for the successful delivery of the NCEP Strategy.

### Sage Advocacy

7.4 Sage Advocacy promotes, protects and safeguards the rights and dignity of, older people, vulnerable adults and healthcare patients. Representatives of Sage Advocacy will attend meetings and act in an advisory capacity to the Partners based on their expertise to ensure that the viewpoints of people using services are central to the strategic direction and decision-making process of the NCEP.

### **National Advocacy Service**

7.5 Representatives of the National Advocacy Service and the Patient Advocacy





Service will attend meetings and act in an advisory capacity to the Partners based on their expertise to ensure that the viewpoints of adults with disabilities and patients of public acute hospitals and residents' of nursing homes are central to the strategic direction and decision-making process of the NCEP.

### 8. Exchange of Information

- 8.1 The Partners will ensure that any disclosure of information in furtherance of the NCEP Strategy and particularly for the purpose of the surveys is carried out in a manner that is prompt, efficient, proportionate and fully in compliance with Data Protection Law, the 2004 Act, the 2007 Act, the Ministers and Secretaries Act 1924 to 2011, the Protected Disclosures Act 2014 and any amendments to this legislation.
- 8.2 The Partners will, where appropriate, anonymise information or personal data before it is transferred to the other Party.
- 8.3 Any sharing of information or personal data undertaken for the purpose of the NCEP Strategy will be appropriately documented and will be subject to strict access and security controls and will ensure secure disposal of shared data.
- 8.4 HIQA, in its role as the lead Partner, may enter into Data Sharing Agreements, where appropriate, for successful delivery of the NCEP Strategy and to ensure transparent, lawful and proportionate processing of personal data for the purpose of the surveys. The Partners agree that no personal data shall be processed unless there is a lawful basis and it is necessary and proportionate to do so.
- 8.5 The Partners agree not to use any information or personal data disclosed under this MOU for any purpose other than the purpose of performing their statutory obligations.
- 8.6 Without prejudice to any obligations under the Freedom of Information Act 2014, Data Protection Law or any other statutory obligations requiring the release of information or personal data, the Partners will not disclose any information or personal data received by any third party without first obtaining the consent of the Party that provided such information.
- 8.7 Nothing in this MOU requires the Partners to disclose personal data or





information except in accordance with law.

### 9. Liaison and Communication

- 9.1 The Parties agree to meet regularly as required and in accordance with the governance arrangements agreed by the NCEP Steering Group.
- 9.2 Strategic, policy and operational matters and all communication required for the purpose of this MOU will be conducted between the designated contact persons as set out in Appendix 1 of this MOU. This is in order to ensure that matters are dealt with by the appropriate person.
- 9.3 Upon signing of this MOU, the Parties will ensure that the identity and contact details (name, email and telephone number) of the designated contact person as set out in Appendix 1 of this MOU will be exchanged with the other Parties. In the event of a change in a designated contact person during the term of this MOU, it is the responsibility of each Party to update the other Parties with the identity and contact details of the appropriate designated contact person.
- 9.4 The Partners agree to publish this MOU on their respective websites in addition to it being published on yourexperience.ie.

### 10. Funding

- The Partners agree that funding for the NCEP will be provided in accordance with the Funding Principles as agreed by the Partners. The Funding Principles outline the sources and allocation of funds necessary to deliver the NCEP Strategy and reflects a commitment of the Partners to funding the delivery of the NCEP Strategy.
- 10.2 Any adjustments to the Funding Principles must be mutually agreed upon in writing by all Partners in advance of such adjustments taking place.
- 10.3 In order to ensure adherence to the Funding Principles, the Partners commit to develop and implement a binding funding agreement between HIQA and the HSE as soon as practicable following signing of this MOU. The funding agreement will set out the legal parameters for the HSE to contribute towards NCEP's consolidated funding model. The Partners acknowledge and





accept that the entry into force of a funding agreement may require a review of this MOU and the Funding Principles to ensure it remains effective and fit for purpose.

### 11. Ethical Approval

11.1 To ensure that the programme of work set out in the NCEP Strategy is held to the highest ethical standards, ethical approval will be sought by HIQA from the Royal College of Physicians of Ireland as deemed appropriate on behalf of the Partners. The Partners commit to seeking ethical approval for every survey that is carried by the NCEP.

### 12. Miscellaneous Matters

### **Legal Status of MOU**

12.1. This MOU does not create any legally binding obligations of any nature. This MOU reflects the intentions of the Parties who will in good faith observe and give due respect to the agreed terms of the MOU including the confidentiality undertakings set out herein.

#### Variation

12.2 Any provision of this MOU may be amended at any time by the mutual consent in writing of the Parties via the respective signatories.

### **Effective date**

12.3 This MOU will come into effect upon the date of signature of the Parties and will continue in effect until its termination.

### Review

12.4. This MOU will be subject to a formal review every three years from the date of its signing or otherwise as requested by a Party to this MOU. The content of this MOU will be reviewed to ensure that it remains relevant, fit for purpose and up to date.

### **Termination**

12.5 Each Party may at any time give written notice of termination of this MOU to the other Party. This MOU will terminate three months after the date of receipt of the notice of termination. The termination of this MOU will not affect the confidentiality undertakings expressed by the Parties in this MOU or any





commitments given under, or as a consequence of, this MOU in respect of any arrangements or action taken during the period before the termination takes effect.

### **Execution**

12.6 This MOU may be executed in two or more counterparts, each of which shall be deemed to be an original, but all of which together shall constitute one and the same instrument. The Parties have the option to execute this MOU by means of a simple electronic signature which shall be considered as an original signature and shall have the same validity, enforceability and permissibility as the original signature for the purpose of this MOU.

### No Disclosure if prohibited

12.7 This MOU does not operate to require any Party to disclose information to any other Party if the disclosure of that information by the Party concerned is prohibited by law.

### **Exceptional cases**

While it is intended that the arrangements in this MOU should apply generally, it is recognised that some circumstances will require special handling. Nothing in this MOU prevents the making of arrangements to meet specific exceptional circumstances.

### **Disputes**

12.9 The designated contact persons agree to act in good faith and to make efforts to resolve any dispute arising on foot of this MOU amicably. In the event, that the designated contact persons cannot resolve the matter, it will be referred to the Chief Executive Officer or person with equivalent title of each Party who will endeavour to resolve the matter.





# **IN WITNESS** where of this *Memorandum of Understanding* has been entered into on the 24 March 2025

	For and on behalf of	Signed by	Position	Signature
Health Information and Quality Authority An ubdate the Planes Just Callothi Stinio	Health Information and Quality Authority	Angela Fitzgerald	Chief Executive Officer	Arg to Signed by Date 06/03/2025
An Roinn Sláinte Department of Health	Department of Health	Kate O'Flaherty	Director of the National Patient Safety Office	Kate O'Flaherty Signed by Date 28/02/2025
FE	Health Service Executive	Joe Ryan	National Director Public Involvement, Culture and Risk	Signed by Date 24/3/2025
Sage	SAGE Advocacy	Rebecca Carolan	Regional Advocate North East	Signed by  Date 27/02/2025
NATIONAL ADVOCACY SERVICE FOR RECOVERY WITH ORSCHUME	National Advocacy Service	Joanne Condon	National Manager	Signed by  Date 25/02/2025





# **Appendix 1 - Designated Contact Persons**

Rachel Flynn	Elaine Newell	
Director of Health Information and Standards	Operations Manager	
for and on behalf of <b>Health Information</b>	for and on behalf of the <b>Health Service</b>	
and Quality Authority	Executive	
Gavin O' Dowd	Rebecca Carolan	
Assistant Principal Officer	Regional Advocate North East	
for and on behalf of the <b>Department of</b>	for and on behalf of SAGE Advocacy	
Health		
Joanne Condon	Georgina Cruise	
National Manager	National Manager	
for and on behalf of National Advocacy	for and on behalf of Patient Advocacy	
Service	Service	





# Appendix 2

NCEP Strategy 2025-2027







## **Background**

The National Care Experience Programme (NCEP) 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), the Department of Health and patient and or service-user partners.

The NCEP undertakes surveys in a range of care areas, seeking to capture the experiences of people using services and publish the results. Surveys are designed to capture people's experiences across both community and a variety of acute settings and to provide a holistic understanding of people using these services. The NCEP gathers feedback at each stage of the care journey from the community to hospital admission and post discharge to better understand the continuity of care from the perspective of people using these services. This approach also allows for targeted improvements in communication, coordination, and overall care by identifying gaps or inefficiencies that exist in the transition between settings. A comprehensive survey strategy ensures that people's experiences are captured, enhancing both quality of care and service user experience, in diverse healthcare environments.

The NCEP operates the following surveys:

- National Inpatient Experience Survey
- National Maternity Experience Survey
- National Nursing Home Experience Survey
- National Maternity Bereavement Experience Survey
- National End of Life Survey
- National Mental Health Experience Survey (in development)
- National Cancer Care Experience Survey (in development).

Each survey aims to learn from peoples' feedback to identify what is working well and what needs to be improved when it comes to care in health and social services. The findings are published to support and enable sustained improvements in overall care experiences. The NCEP Research and Analysis team publishes survey findings and data, engages in academic research, and develops educational material to help people understand care experience surveys. All NCEP publications and academic papers are published <a href="here">here</a>.

Find out more about the NCEP at www.yourexperience.ie.



# National Care Experience Programme Strategy 2025-2027

### Mission:

To gather comprehensive feedback from people using services across health and social care; improving quality, patient experience and outcomes through data-driven insights.

### Vision:

To empower service providers with insights that drive continuous improvement, enhance service user experience and ensure optimal care outcomes.

### Values:

Human Rights	We promote and champion human rights
People Centred	We value and respect the needs of the people we work with and for
Fair, Objective & Equitable	We are fair, objective and proportionate in our work
Open & Accountable	We communicate how we work and the outcomes of what we do
Excellence	We strive to constantly innovate and seek to improve the quality of our work
Quality	We support continual quality improvement for people who use services
Collaborative	We work in partnership with all colleagues and stakeholders



## **Objectives and Priorities:**

The National Care Experience Programme will achieve its vision by delivering on its key objectives by December 2027.

# Objective 1: To capture the voice of people using health and social care services

The National Care Experience Programme will ask people about their care experiences to maximise the understanding of what works well and what can be improved in health and social care services in Ireland.

### **Priorities**

### By 2027, the National Care Experience Programme will have:

- conducted national surveys to capture experiences in the following areas of care;
   inpatient acute, maternity, nursing homes, end of life, mental health and cancer<sup>1</sup>
- identified key areas for new care experience surveys through the NCEP prioritisation process
- reviewed survey methodologies to ensure they remain fit for purpose, inclusive
  of diverse populations and marginalised communities, and aligned with current
  legislation, national standards, relevant national policies, and strategies
- assessed the implications of the Patient Safety Act 2024 by determining whether it is appropriate and feasible to include Ireland's private hospitals in the National Care Experience Programme
- reviewed the feasibility and readiness of the infrastructure to implement locally run surveys in the HSE Health Regions by conducting a readiness assessment in one Health Region to identify the capacity and capabilities required.

# Objective 2: Provide insights to drive improvements in health and social care

Working in partnership with key stakeholders and service providers, both public and private, the National Care Experience Programme will seek to optimise access to care experience data across multiple platforms, providing contextual information and analysis as well as equipping health and social care services (in both acute and

<sup>&</sup>lt;sup>1</sup> All surveys will be carried out during this strategic period based on the achievement of a consolidated funding model for the NCEP



community settings) with critical insights to support evidence-informed decision making.

#### **Priorities**

### By 2027, the National Care Experience Programme will have:

- provided key stakeholders with platforms to interrogate survey findings within and across survey themes and questions to assist with identifying and supporting key areas for improvement across all health and social care services
- reported and acknowledged the service user experience across surveys over a 10 year period
- integrated survey data into decision-making frameworks to inform and influence practice, national policy and legislation in line with the NCEP's Memorandum of Understanding (MOU)
- collated and published the NCEP's impact report to demonstrate the effectiveness of the programme
- further developed and enhanced the capability for all users of the data by providing appropriate training to promote the use of survey data in health and social care services
- continue to publish academic papers to elevate the voice of people using services at national and international level.

In keeping with the terms of the NCEP's MOU, all parties are committed to addressing the survey findings. By 2027:

- HIQA will have considered the use of the findings to inform the development of HIQA national standards, guidelines, guidance and recommendations
- The Department of Health will have provided leadership and policy direction for the health sector to improve health outcomes and quality of services
- The HSE will have published action plans for each survey aligned with the reporting plan, and follow up with assurance reviews assessing the delivery and effectiveness of the action plans.
- Advocacy Groups, that is National Advocacy Service and SAGE
   Advocacy will provide education and support to patient's caregivers and
   members of the public to support a patient centred and culturally sensitive
   approach.



# Objective 3: Strengthen stakeholder involvement through building a collaborative model

The National Care Experience Programme will amplify the impact of the programme by fostering stronger collaboration and partnerships with key stakeholders.

### **Priorities**

### By 2027, the National Care Experience Programme will have:

- ensured that the data from the NCEP is fit for purpose for the six HSE Health Regions within the programme
- established clear communication channels, fostered collaboration and agreed roles and responsibilities
- enhanced inclusivity by amplifying the voices of marginalised groups through an integrated, culturally sensitive approach that promotes health equity through collaboration and partnership
- explored the potential of establishing a partnership for public and patient involvement in the NCEP
- established a minimum of two or more agreements with professional bodies in health, mental health and social care to incorporate use of findings within their programme of work.

# Objective 4: Build a high-performing and innovative research offering to provide insights and guidance to health and social care services

The National Care Experience Programme will drive the use of survey data to enhance the overall impact of the programme.

### **Priorities**

### By 2027, the National Care Experience Programme will have:

- worked with academic partners to provide insights across the seven survey settings
- identified and exported NCEP data to open access repositories to promote awareness and facilitate access to data
- improved accessibility of data through upgrading reporting tools, outputs and website



- provided statistical tools and training to service providers and researchers to support cross-survey analysis
- established formal student placements opportunities and sponsored PhD programmes in collaboration with academic institutions and professional bodies
- extended the NCEP reach and impact across Europe, identifying opportunities and grants to build a Europe-wide community.

### **Enablers**

The National Care Experience Programme requires the following to enable us to achieve our strategic objectives:

### **Committed Partnerships**

By 2027, the National Care Experience Programme will have:

- continued to foster and build on existing relationships with key stakeholders including patient and public involvement groups
- created communities and networks to facilitate and drive improvements in care promoting knowledge sharing across all service providers
- collaborated with academic partners and stakeholders to establish research agreements, grant application and European grants
- created communication plans based on collaboration, transparency and continuous engagement.

### **Effective Governance Structures**

Appropriate governance structures will be established to support and achieve NCEP's strategic objectives. By 2027, the National Care Experience Programme will have:

- ensured appropriate NCEP governance structures are in place, including NCEP Steering Group and advisory groups for each survey to oversee and ensure delivery of the NCEP Strategy 2025-2027
- established a consolidated funding model and its associated governance structures to deliver the suite of national surveys
- ensured all survey programmes are aligned with the NCEP's Information Governance Framework
- adhered to the NCEP prioritisation process in making decisions relating to the implementation of new care experience surveys.



### Legislative and strategic remit

All programmes of work will be implemented in compliance with existing and new legislation while driving initiatives to support long-term strategic objectives.

By 2027, the National Care Experience Programme will have:

- developed and implemented national survey programmes in alignment with national priorities and legislation
- adhered to and adapted rigorous data privacy protection and ethical standards adhering to current and any forthcoming legislation
- reflected the impact of new legislation and policy on the NCEP
- reviewed and updated the NCEP Information Management Framework to ensure compliance and alignment with National Standards for Information Management in Health and Social Care, HIQA.

### Data and digital ability

The National Care Experience Programme data and digital capabilities will be advanced to effectively deliver the strategic objectives.

By 2027, the National Care Experience Programme will have:

- created a NCEP digital solution in partnership with stakeholders to maximise the use of survey findings driving improvements in care and informing policy
- enhanced the public facing data visualisation platform to ensure it is userfriendly and makes the findings accessible
- improved the NCEP website to support programme expansion by developing a user-friendly interface that enables stakeholders, including the public and health and social care professionals, to find the information they require
- leveraged data and digital technologies to maximise survey participation and data analysis
- established frameworks and infrastructure to inform and influence the development of a data warehouse which will enable a centralised repository to enhance reporting, analysis and decision-making.

## **Implementation and Monitoring**

The implementation of this strategy will be monitored and reviewed by the NCEP Steering Group. The objectives set out in this strategy, together with national priorities and external factors, will inform the NCEP annual business plans. The



delivery of these business plans will ensure that the objectives are achieved over the three years of this strategy.





# Appendix 3 – Funding Principles for the National Care Experience Programme 2025-2027

[To be inserted when finalised]









