

Impact Report 2022

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 five surveys that capture the experiences of people using Ireland's health and social care services: the National Inpatient Experience Survey, the National Maternity Experience Survey, the National Maternity Bereavement Experience Survey, the National Nursing Home Experience Survey, and the 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 upon the findings.









2022 Impact Report



3 surveys implemented We implemented the first National Nursing Home Experience Survey, the first National Maternity Bereavement Experience Survey, and the fifth National Inpatient Experience Survey.



13,452 survey participants Nursing home residents, their relatives and friends, bereaved parents and people admitted to public acute hospitals told us about their experiences of care.



47 reports published

We published national, local and themed reports of survey findings.



60⁺ engagements with stakeholders

We held information sessions and calls with our stakeholders.



18 lectures, presentations and posters

We delivered guest lectures, facilitated workshops and presented at national and international conferences.



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Improving care experiences together

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Introduction

Measuring and reporting on the impact of projects promotes transparency, allows for evaluation of a project against its stated objectives and demonstrates the effectiveness of a programme.

A commitment was made as part of the National Care Experience Programme's (NCEP) Strategy 2022-2024, to measure its impact on healthcare policy, practice and regulation. HIQA has developed a framework to support the measurement of impact through a combination of measures, including:

- the generation of outputs
- reach and engagement with stakeholders
- changes in practice.

Outputs	Tangible entitites produced from projectsReports, policies, quality improvements
Reach	One-way communications about a projectPromotional material, information sessions
Engagement	Two-way communication about a projectConferences, training programmes
Change	Changes in patient experience scoresChanges in practice/policy in response to the survey

The use of a consistent methodology for measuring impact will facilitate evaluation of the programme across the Irish health and social care system. As the programme progresses, it will be possible to examine longer-term trends in care experience of health and social care services. The National Care Experience Programme's approach to measuring impact is a new process that will evolve over time.









National Care Experience Programme Objectives 2022

The National Care Experience Programme objectives for 2022 were as follows:

- to report on the National Inpatient Experience Survey (NIES) 2021 and develop, implement and report on the NIES 2022¹
- to deliver and report on the National Maternity Bereavement Experience Survey²
- to deliver and report on National Nursing Home Experience Survey
- to commence the National End of Life Survey
- to develop the analytical and research function of the NCEP, strengthening links with academic and other partners to maximise the value, usage and understanding of survey data and findings.

This report describes the impact of the National Care Experience Programme in 2022, in accordance with the framework outlined above.







¹ As a result of the cyber attack on the HSE in May 2021, the National Inpatient Experience Survey 2021 was postponed to September 2021, with the survey findings published in May 2022.

² As a result of the cyber attack on the HSE in May 2021, the National Maternity Bereavement Experience Survey was postponed to September and October 2022, with the survey findings due to be published in 2023.



Outputs

Reports

The National Care Experience Programme published a number of reports in 2022:

National Inpatient Experience Survey 2021

- Findings of the 2021 Inpatient Survey (National Report)
- Experiences of a human rights-based approach to care in hospital
- Experiences of discharge or transfer from hospital
- National Inpatient Experience Survey 2021 Technical Report

National Inpatient Experience Survey 2022

- Findings for the 2022 Inpatient Survey (National Report)
- 39 local hospital reports

National Nursing Home Experience Survey 2022

- Overview of Findings 2022
- Experiences of Residents 2022
- Experiences of Relatives and Friends 2022

Academic publications

The National Care Experience Programme published one paper based on secondary analysis of data from the 2020 National Maternity Experience Survey in the journal *Midwifery*: '*Women's experiences of initiating feeding shortly after birth in Ireland: A secondary analysis of quantitative and qualitative data from the National Maternity Experience Survey'*.

This study explored women's experiences of initiating and continuing breast or formula feeding shortly after birth in Ireland's maternity hospitals and units, as well as at home after birth.³

Academic slide deck

The National Care Experience Programme developed and published an academic slide deck. The slide deck provides a teaching resource on national care experience surveys for people teaching health and social care students, and or providing training to health and social care staff. The slide deck includes material on healthcare quality and safety, patient experience, survey development, the surveys carried out by the National Care





³ Murphy R, Foley C, Verling AM, O'Carroll T, Flynn R, Rohde D. Women's experiences of initiating feeding shortly after birth in Ireland: A secondary analysis of quantitative and qualitative data from the National Maternity Experience Survey. Midwifery. 2022:103263. doi: 10.1016/j.midw.2022.103263

Experience Programme, and the impact of the programme, and is available from: <u>https://yourexperience.ie/about/about-the-programme/#academic_slide_deck</u>.



Reports and other outputs published by the National Care Experience Programme in 2022

Interactive findings

An interactive dashboard for each survey, available on <u>www.yourexperience.ie</u>, allows interested stakeholders to further explore the survey results in an understandable, interactive way.

Training and support documents

The National Care Experience Programme is committed to using the information that it collects in a manner that is fair, secure and respects the privacy of the survey participants. In 2022, we published our Data Quality Strategy 2022-2024, which outlines how the National Care Experience Programme formalises the approach it uses to identify, document and implement data and information quality. We updated our Statement of







Information Practices, which explains why we collect information and how we process and handle data. We updated our Data Protection and Confidentiality Policy, which describes how we protect survey respondents' privacy. We also published data protection impact assessment summary reports for the National End of Life Survey, the National Inpatient Experience Survey, the National Nursing Home Experience Survey and the National Maternity Bereavement Experience Survey.

Survey development and implementation



National Inpatient Experience Survey

The fifth National Inpatient Experience Survey took place in 2022. The aim of the survey was to find out about patients' experiences in public acute hospitals and to use their feedback to identify areas of good experience, and areas requiring

improvement. A total of 10,904 patients took part (44% response rate), the majority of whom (82%) said they had a good to very good overall experience in hospital. The HSE responded to the results of the survey by producing detailed quality improvement plans at local and national levels (available from <u>www.yourexperience.ie</u>). These initiatives build on the work conducted since 2017, which has included programmes to improve admissions, hospital food and nutrition, and discharge information for patients, as well as clearer medication instructions, the rollout of activity programmes for older patients, and a programme of support and training for staff on communication skills.

The National Inpatient Experience Survey will be reviewed throughout 2023, with a view to ensuring that it continues to meet the needs of its various stakeholders. The sixth iteration of the survey is planned to be undertaken in 2024.

National Nursing Home Experience Survey

We implemented the first National Nursing Home Experience Survey in 2022. The survey asked nursing home residents and their relatives or friends about their experiences of nursing home care in



Ireland. The survey aimed to learn from and understand these experiences in order to improve the care provided in Irish nursing homes.

In total, 718 residents and 943 family members and friends from 53 nursing homes participated in the survey. Most residents (90%) and most family members and friends (87%) said they had a good or a very good overall experience with their nursing home.

Nursing homes can use the survey results to develop plans on how they will respond to the findings. The Department of Health will use the findings to help inform the







development of policy and strategy in relation to nursing home care as appropriate. The findings of the survey will also inform national standards and HIQA's regulation of nursing homes.

National Maternity Bereavement Experience Survey

The first National Maternity Bereavement Experience Survey was implemented in 2022. Women and their partners who experienced a second trimester miscarriage, a stillbirth or an early neonatal death and received inpatient care in one of Ireland's 19



maternity units or hospitals between 1 January 2019 and 31 December 2021, were invited to participate in the survey. The online survey was open to all eligible participants for an eight week period from 1 September to 31 October 2022.

In total, 655 women and 232 partners or support persons participated in the survey. Participants shared their stories of the care they received from when they first found out that their baby had died, through to the care they received while in hospital, and the follow-up care they received once they returned home. Participants were asked to rate their overall care, and 74% said that they had received good or very good care.

The results of the survey will be published in early 2023, and will help to provide assurance in the care being provided and identify areas for improvement in all maternity hospitals and units in Ireland. The survey findings will also help inform the existing national standards for bereavement care in addition to informing regulation programmes for maternity care services.



National End of Life Survey

The National End of Life Survey will be the first national survey asking bereaved relatives about the care provided to a family member or friend in the last months and days of their life. The purpose of the survey is to learn

from people's experiences of end-of-life care in order to improve the services provided both to people who are dying, and to their loved ones.

The survey will be implemented in 2023. We continued to work on the development of the survey and engaged with our stakeholders throughout 2022. Individuals who registered the death of a family member or friend that occurred between 1 September and 31 December 2022, will be invited to participate in the survey and will receive a survey pack in the post between March and May 2023.







The findings will build on existing good practice and inform quality improvements within services, national standards and monitoring programmes within the Health Information and Quality Authority, and national policy and legislation in the Department of Health.

Reach

The National Care Experience Programme employed a number of methods and resources to reach a wide range of stakeholders:

- 10,904 participants in the National Inpatient Experience Survey 2022
- 718 nursing home residents and 943 designated representatives participated in the National Nursing Home Experience Survey
- 655 women and 232 partners participated in the National Maternity Bereavement Experience Survey
- 1,324 downloads of reports of survey findings
- Nine conferences attended by members of the team
- Four poster presentations at conferences
- 10 oral presentations at conferences, including one invited presentation
- One opening plenary conference presentation
- Four invited guest lectures and workshops.

Poster presentations at national and international conferences









Website and social media

The National Care Experience Programme uses its website (<u>www.yourexperience.ie</u>), Twitter, Facebook and Instagram to communicate with stakeholders across the health and social care system in Ireland and beyond. In 2022, there were:

- 11,482 visitors to <u>www.yourexperience.ie</u>
- 3,229 followers on Twitter
- 456,900 Twitter impressions
- 15,360 Facebook page reach⁴
- 22,878 Instagram reach
- 2,939 views of the interactive results across all surveys
- 377 people who accessed our e-learning modules
- 392 people who subscribed to our email alerts.

Podcast



The National Care Experience Programme launched a new podcast series, 'Let's Talk Care Experience', in 2021. This podcast discusses all aspects of people's experiences of Ireland's health and social care services. The podcast features people who use services, staff within services, as well as leading health and social care experts. To date, 'Let's Talk Care Experience' podcast episodes have been downloaded over 600 times.

Three episodes of `Let's Talk Care Experience' were released in 2022 and covered the following subjects:

- the importance of effective communication between hospital staff and patients
- the importance of supporting patients while in hospital
- the importance of listening to experiences of maternity bereavement care.



⁴ Page reach refers to the number of people who saw any content from the NCEP Facebook pages.







Engagement

Engagement with stakeholders

Information sessions and presentations

Hospital and community information sessions form an important part of the National Care Experience Programme's engagement with healthcare staff, providers and other stakeholders. In order to engage with stakeholders and promote the National Care Experience Programme surveys, in 2022, the team held the following engagement events:

- One National Inpatient Experience Survey workshop on discharge from hospital
- Eight hospital visits
- Six hospital group visits
- Eight dashboard training sessions
- Two information sessions with HSE Patient Administration System staff
- Four information sessions with Directors of Midwifery Clinical Nurse/Midwife Specialists
- Two information sessions and three individual calls with advocacy and support organisations
- 10 data extract support sessions with nursing homes
- Two information sessions with nursing homes to discuss use of survey findings
- Three information sessions with Civil Registration Service staff
- Four information sessions with health and social care staff
- Three information sessions with HIQA staff.

We attended information sessions and delivered presentations for:

- Residents' Rights: Listening to Drive Improvement engagement events
- National Women & Infants Health Programme webinar series
- Bereavement Standard Oversight Group meetings.

We also attended events and meetings organised by:

- Women's Health Taskforce
- All Ireland Institute of Hospice and Palliative Care
- Palliative Care Week
- Carú
- Tipperary University Hospital Quality Day
- Pregnancy Loss Research Group.







Members of the National Care Experience Programme team at conferences and stakeholder engagement events in 2022



From left to right: Dr Conor Foley, Roisin Murphy; Siobhan Morrisson; Donnacha O'Ceallaigh, Karen Charnley; Linda Drummond, Trudi Mason; Tadhg Daly, Anton Savage, Tina Boland, Brent Pope; Dr Daniela Rohde, Anna Maria Verling, Roisin Murphy; Alice Reetham; Tracy O'Carroll, Angela Dunne; Dr Lisa Ann Kennedy; Mary McGowen, Deirdre Hyland, Tracy O'Carroll, Maura Grogan.

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Collaboration

Academic partnerships

In 2022, we continued to engage with professional bodies and educational institutions to support and demonstrate the use of the National Care Experience Programme survey findings. We supported two student placements and two internships:

- One student from the BSc in Public Health Sciences, University College Cork
- One student from the MSc in Applied Social Research, Trinity College Dublin
- Two EUSA academic internships.

We supervised an MSc in Applied Social Research dissertation:

• *"Difficult times, difficult decisions": The impact of visiting restrictions on the inpatient experience in acute hospitals in Ireland during the COVID-19 pandemic. A Mixed-Method Study'.*

We engaged with colleagues at Trinity College Dublin, the Royal College of Surgeons in Ireland and University College Dublin in the development of our academic slide deck, and delivered invited guest lectures and workshops as part of a number of academic programmes, including:

- BSc Physiotherapy, Trinity College Dublin
- Promoting Quality and Safety in Healthcare (MSc nursing programmes), University of Limerick
- MSc Health Services Management, Trinity College Dublin
- MSc Healthcare Management, Royal College of Surgeons in Ireland.

Secondary analysis projects

We continued working with researchers and academics at Maynooth University on a Health Research Board-funded secondary analysis project titled *'Generating actionable insights from the analysis of free-text comments from the National Care Experience Programme using qualitative and computational text analytics methods'*. This project involves a detailed analysis of over 70,000 free-text comments received in response to our surveys, as well as the development of a tool that will facilitate more efficient and standardised analysis of qualitative data received in response to future surveys. The project is led by Prof. Adegboyega Ojo at Maynooth University, with support from coapplicants Dr. Conor Foley and Dr. Daniela Rohde from the National Care Experience Programme.

Data access requests

The National Care Experience Programme promotes a culture of data transparency, with reports and interactive online reporting platforms available on <u>www.yourexperience.ie</u>. Data can also be requested by individuals working in academic or healthcare settings, for research or quality improvement purposes. Data access requests are reviewed by the







NCEP team and or the relevant programme board, depending on the nature and purpose of the request. In 2022, the programme received and granted three data access requests from students and staff in academic institutions and hospitals.

Pilot project to inform the centralisation of bespoke, local surveys of public acute hospitals

The National Inpatient Experience Survey has provided hospitals and the HSE with survey findings to make evidence-based improvements in care since 2017. Hospitals have indicated that they would like access to additional information and survey options that are not included within the current approach; for example, a consistent method of surveying patients who fall outside of the survey's inclusion criteria such as patients discharged outside of the survey month, outpatients, or patients who spend less than 24 hours in hospital.

Since the programme's inception in 2017, the NCEP has received requests from across the healthcare system to carry out additional surveys of care. Acute care providers have also indicated their need for a facility that would allow them to capture patient experiences at a local level, with the flexibility to focus on different areas of care within a hospital.

In 2022, two pilot survey projects were completed in conjunction with two hospital sites, in order to evaluate the feasibility of the NCEP facilitating hospitals to carry out bespoke, local surveys. The first pilot engaged with all eligible patients throughout a five-month survey period, providing flexibility to capture experiences at a micro-level and reflect seasonal variations, which is not currently possible under the national programme. A total of 1,401 patients participated in the pilot Patient Experience Survey, with a response rate of 29%. The second pilot, the Haematology Experience Survey, allowed the pilot hospital to explore an area of care not currently covered by the NCEP's suite of surveys. In total, 41 patients participated in the pilot sites had the flexibility to develop and customise surveys and reports through the provision of cognitively tested, internationally validated question banks and an efficient and effective survey distribution method. Based on the demonstrable feasibility and effectiveness of the survey pilots, a set of recommendations were made on how to progress the model of local survey implementation.

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Change

This section outlines examples of quality improvement initiatives and policy developments by our partner organisations, the HSE and Department of Health, which have been informed by findings from our surveys. It is important to note that while National Care Experience Programme survey data contribute to these developments, it is not the only source of information acted on by the HSE or Department of Health. Any changes or developments are likely to be the result of multiple factors.

Quality improvements



As in previous years, the HSE published quality improvement plans in response to the National Inpatient Experience Survey 2022 findings (available from <u>www.yourexperience.ie</u>). The HSE coordinates its response to the survey through a national oversight group, with local implementation of quality improvement initiatives led by personnel from hospitals and hospital groups. These initiatives build on the work conducted since 2017, which has included programmes to improve admissions, hospital food and nutrition, and discharge information for patients, as well as clearer medication instructions and the roll out of activity programmes for older patients. A programme of support and training for staff on communication skills has also been implemented.

Examples of quality improvement initiatives developed in response to the National Inpatient Experience Survey 2021 and 2022

Patient Advice and Liaison Service (PALS)

The importance of a patient advice and liaison service (PALS) was identified as part of national quality improvement plans for the 2021 National Inpatient Experience Survey. The PALS team acts as a point of contact for patients and their families and or carers, and provides them with the necessary advice and support and advocates on their behalf. One example is the re-establishment of the patient 'Protected Meal Time' in Portiuncula University Hospital. This is a period of time set aside for breakfast, dinner and evening tea when all non-essential activities on the wards stop. Nurses and healthcare assistants are available to give help to patients who may need it, while family members who wish to provide assistance at these times are also welcome to do so.







Communication between patients and family

In order to improve communication with patients' families during visiting restrictions, Cavan Monaghan Hospitals commenced a pilot quality improvement initiative, whereby each patient's designated contact person would be contacted by a member of nursing staff on the ward within 24 hours of the patient's admission, and informed of their clinical status, plan of care, relevant information regarding ward visiting and contact numbers.

Patient information folder

In response to patients highlighting issues around discharge, communication and medication safety, St Columcille's Hospital introduced a patient information folder. This folder is provided to each patient on admission and includes hospital information on who to contact if patients have worries or concerns. The information in the folder encourages patients and their families to ask about their care and plan for discharge, and also includes safety socks to reduce patient falls and medication advice leaflets to inform patients of any changes before they are discharged home.

Tallaght University Hospital created an inpatient guide for patients that includes information on nutrition and meal times, an illustrated guide of uniforms introducing the different staff a patient may come across during their stay, and facilities and supports that are available within the hospital. The information is designed to help patients take a greater part in their health and healthcare.

Policy

Department of Health National Healthcare Quality Reporting System

The National Healthcare Quality Reporting System (NHQRS) is the Irish health quality indicator framework. The NHQRS Report is published by the Department of Health. It provides information on a broad range of measures of health service structures, processes and outcomes with the purpose of providing a means of comparison against international data and internationally accepted best practice. It allows data on the health service to be transparently shared with patients, service providers and policy-makers.

In recognition of evidence confirming links between patient experience and clinical safety and effectiveness data, National Care Experience Programme survey data are included under Domain 4: Supporting people to have positive experiences of healthcare. Inclusion of NCEP data in the NHQRS highlights that the service user's voice is a key input for quality improvement of health service provision. In the NHQRS Report 2021/2022, a total of 12 indicators from the National Inpatient Experience Survey 2021 were included under Domain 4: <u>https://www.gov.ie/en/collection/5fd4f6-national-healthcare-quality-reportingsystem-reports/#20212022</u>. Survey data were also used in a dedicated chapter on women's health to highlight different experiences reported by sex.







COVID-19 Nursing Homes Expert Panel Report

The COVID-19 Nursing Homes Expert Panel Report, published in August 2020, highlighted the importance of providing nursing home residents with an opportunity to have their voice and experience heard in a structured manner, with a view to improving services and the lived experiences of nursing home residents. The panel recommended that the expansion of the National Care Experience Programme to nursing homes residents be progressed at pace. The implementation of the first National Nursing Home Experience Survey as part of the National Care Experience Programme realised this important recommendation.

A number of findings from the survey supported amendments to the Health Act (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013, which includes provision for the delivery of in-person advocacy awareness campaigns and the strengthening of complaints processes. The findings from the survey will form part of the Department of Health's consideration in relation to future policy development and legislative reform across the older persons sector.

National Maternity Strategy (2016-2026)

The purpose of listening to women's experiences of maternity services in Ireland, through the National Maternity Experience Survey, is to improve the quality and safety of the care provided. The findings of the first National Maternity Experience Survey, published in 2020, were used to identify areas where improvements are required. The results directly informed the allocation of funding for maternity services in 2022, including funding targeted at establishing a number of postnatal hubs to deliver improved care to women in the postnatal period. The significant additional funding provided for maternity services in 2022, including funding for new lactation consultant posts, continues to facilitate the implementation of local and national quality improvement plans that were developed in response to the survey.

Informing the Women's Health Taskforce and Department of Health Women's Health Action Plan 2022-2023

A Women's Health Taskforce was established by the Department of Health in September 2019 to improve women's health outcomes and experiences of healthcare. The taskforce followed a recommendation from the Scoping Inquiry into the CervicalCheck Screening Programme, that women's health issues be given more consistent, expert and committed attention.

Data from the National Care Experience Programme, including the National Inpatient Experience Survey and the National Maternity Experience Survey, were used to inform the work of the Women's Health Taskforce, including the development of the Women's Health Action Plan 2022-2023 (available from https://www.gov.ie/en/publication/232af-womens-health-action-plan-2022-2023). The Action Plan, which was published by the Department of Health in March 2022, sets out an ambitious programme of work to







improve women's health experiences and outcomes in Ireland. It is supported by the voices and perspectives of women, their representatives and women's health professionals, who provided their insights and experiences through a range of listening projects and participations undertaken by the Women's Health Task Force in 2020-2021.

Informing Ireland's Health Systems Performance Assessment Framework

The Health Systems Performance Assessment Framework (HSPA) is a measurement tool for assessing the overall performance of the health system in Ireland. The HSPA covers not only the traditional metrics of resources and workforce invested within the health sector, but also focuses on the equity and level of access to health services, affordability, the quality of the care provided, the efficiency of the health services and the information systems in place for better coordination and continuity of the health service.

Within the current suite of indicators, the National Care Experience Programme and the range of surveys that capture the experience of people using our health and social services is an important input into the domain of person-centredness. This ensures that data on important areas in the treatment of patients, for example whether patients in hospital are treated with dignity and respect or are involved in decisions about their care and treatment, are captured as part of the framework. It is envisaged that the current suite of indicators will be expanded as further surveys are introduced as part of the National Care Experience Programme.

A prototype visualisation platform has been developed which will provide a visual dashboard for the HSPA Framework. Currently, over 270 indicators are included in the framework, and the prototype platform has now been populated with data for over 70% of the indicators. A consultation on the prototype has been completed and following evaluation and review of the feedback, it is proposed that the platform will be released publicly in 2023 on the www.gov.ie website.

Regulation

The findings of the National Inpatient Experience Survey and National Maternity Experience Survey inform the healthcare regulation and monitoring programme within HIQA. Analysis is underway to align survey questions with standards, which will aid the regulation and monitoring teams to monitor against healthcare standards. Members of the National Care Experience Programme team presented on the National Nursing Home Experience Survey at four Residents' Rights: Listening to Drive Improvement engagement events, with HIQA inspectors outlining how the survey findings relate to their inspection findings.







What's next for the programme in 2023?

The National Care Experience Programme Strategy (2022-2024) sets out a plan to develop and expand the NCEP's programme of work over the next three years.

In 2023, the programme will:

- conduct a review of the model and methodology of the National Inpatient Experience Survey
- report on the findings of the National Maternity Bereavement Experience Survey
- implement the National End of Life Survey
- commence development of a model and methodology to enable implementation of a survey of mental health service users
- commence the development of a cancer care survey
- develop the analytical and research function of the NCEP, strengthening links with academic and other partners to maximise the value, use and understanding of survey data and findings.

















An Roinn Sláinte Department of Health