National Care Experience Programme

Impact Report
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 has a suite of surveys that capture the experiences of people using our services. The Programme implements the annual National Inpatient Experience Survey, the National Maternity Experience Survey and the National Nursing Home Experience Survey, and is currently developing the National Maternity Bereavement 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.

Contents

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) Strategic Plan 2019-2021, and the new 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 projects • Reports, policies, quality improvements
Reach	• One-way communications about a project • Promotional material, information sessions
Engagement	• Two-way communication about a project • Conferences, training programmes
Change	• Changes in patient experience scores • Changes 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.

The National Care Experience Programme Strategy 2019-2021

The National Care Experience Programme Strategic Plan 2019-2021 set out the programme's objectives for 2019 to 2021. By August 2021, all objectives had been met.

Over the past three years, the programme worked in partnership with key stakeholders using a robust governance structure, which included members of the three partner organisations, representatives of people using services and advocacy groups.

We enhanced our links with academia by offering student placements, giving guest lectures, and facilitating access to care experience data for research projects, as well as collaborating with researchers and academics on a successful grant application.

We also developed the Survey Hub, which offers resources such as e-learning modules to help people develop and implement their own surveys.

An international forum was established to collaborate with international partners involved in care experience surveys, sharing our findings and staying up to date with best practice.

Extensive communication and engagement took place over the past three years with various stakeholders, including the public, survey participants, staff within services, the media and policymakers.

We demonstrated our commitment to ensure that we meet and comply with information management standards and are compliant with all legal requirements, such as carrying out Data Privacy Impact Assessments for each survey.

In response to NCEP survey findings, quality improvement plans were developed at national and service provider level.

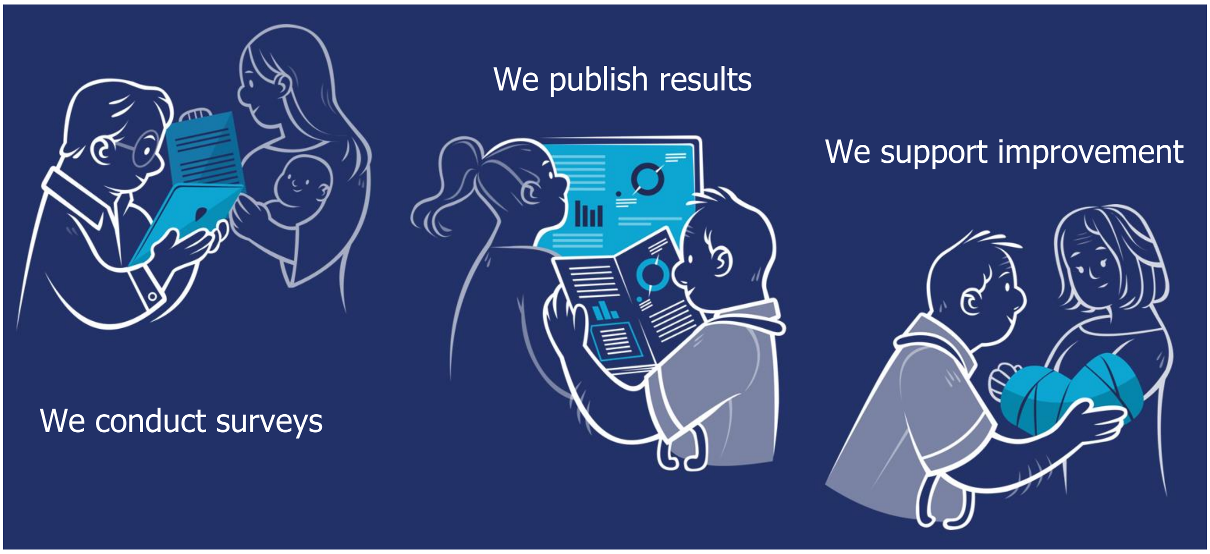
In December 2021, we published a new National Care Experience Programme Strategy for 2022-2024, which will ensure that the National Care Experience Programme continues to have clear objectives with appropriate support from relevant health and social care professionals.

National Care Experience Programme Objectives 2021

The National Care Experience Programme objectives for 2021 were as follows:

- to revise, deliver and report on the National Inpatient Experience Survey (NIES)[1]
- to develop a model and methodology and implement the National Maternity Bereavement Experience Survey (NMES)[1]
- to develop a model and methodology to enable the implementation of:
  - the National End of Life Survey (NELS)
  - the National Nursing Home Experience Survey (NNHES)
- to continue to develop a Survey Hub, providing tools and resources to enhance understanding and implementation of surveys by care providers
- to develop the NCEP Strategy for 2022-2024.

This report describes the impact of the National Care Experience Programme in 2021, in accordance with the framework outlined above.



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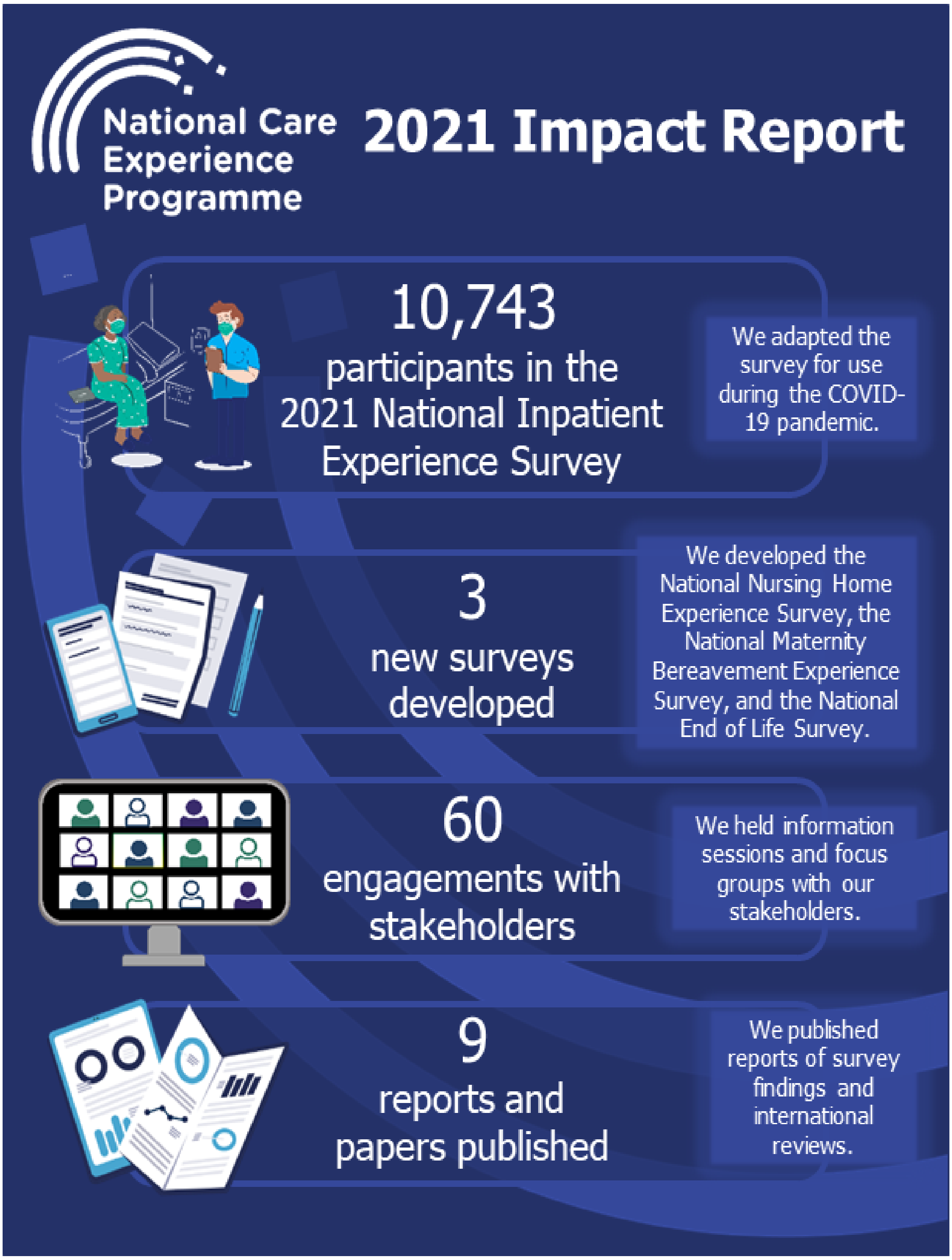
[1] As a result of the cyber attack on the HSE in May 2021, the National Inpatient Experience Survey 2021 was postponed to September 2021, with the survey findings scheduled to be published in April 2022. The National Maternity Bereavement Experience Survey was also postponed.



National Care Experience Programme

2021 Impact Report

10,743

participants in the 2021 National Inpatient Experience Survey

We adapted the survey for use during the COVID-19 pandemic.

3

new surveys developed

We developed the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey, and the National End of Life Survey.

60

engagements with stakeholders

We held information sessions and focus groups with our stakeholders.

9

reports and papers published

We published reports of survey findings and international reviews.

Outputs

Reports

The National Care Experience Programme published a number of reports in 2021:

- Report on maternity care provided in the community by general practitioners, practice nurses and midwives

  This report focused on women's experiences of maternity care provided outside of hospital by general practitioners (GPs), practice nurses and midwives in the 2020 National Maternity Experience Survey.

- Experiences of patients admitted for a tumour or cancer

  This report focused on the experiences of the 1,100 participants in the National Inpatient Experience Survey 2019 who stated that the main reason for their stay in hospital was a tumour or cancer.

- Final Summary Report on Secondary Analysis of 2017 & 2018 Qualitative Survey Responses

  This report presents the results of an in-depth secondary analysis of free-text survey responses from the 2017 and 2018 National Inpatient Experience Survey. This analysis was conducted in partnership with a team based at the Insight Centre for Data Analytics at the National University of Ireland, Galway.

- International Review of Maternity Bereavement Experience Surveys

  This review identified how international organisations and agencies collect and use maternity bereavement care experience data.

- Early pregnancy loss: A scoping review of research in Ireland

  This report provided an overview of Irish research on early pregnancy losses, including first trimester miscarriage, ectopic and molar pregnancies.

- International Review of National End of Life Surveys
  This review identified how organisations and agencies internationally collect and use bereaved relatives' experience data, associated with the death of an adult.

- International Review of Nursing Home Experience Surveys
  This review identified how international organisations and agencies collect and use nursing home residents' care experience data.

The National Disability Authority published a report using data from the National Maternity Experience Survey:

- Experiences of Women with Disabilities in their Journey through Maternity Services in Ireland

  This report focused on the maternity care experiences of women with long-term disabilities, illnesses or conditions.

Academic publications

The National Care Experience Programme published one paper based on secondary analysis of data from the 2019 National Inpatient Experience Survey in the *Journal of Patient Experience*:

- Care Experiences of Older People in the Emergency Department: A Concurrent Mixed-Methods Study

  This study explored the experiences of people aged 65 years and above in Irish emergency departments, and was led by one of our former work placement students as part of the Masters in Applied Social Research in Trinity College Dublin.

Reports and papers published by the National Care Experience Programme in 2021

Training and support documents

To support interviewers who will be conducting interviews with nursing home residents as part of the National Nursing Home Experience Survey, we developed training that covers information governance, adult safeguarding and managing adverse events. We published Data Protection Impact Assessments (DPIAs) for the National Inpatient Experience Survey 2021 and the National End of Life Survey, and developed four process documents to support hospitals involved in the National Inpatient Experience Survey, the National Maternity Bereavement Experience Survey, the National End of Life Survey and the National Nursing Home Experience Survey. We developed the NCEP Strategy for 2022-2024, as well as a Communications and Stakeholder Engagement Strategy 2022-2024 and an Information Management Strategy. These strategies ensure that the National Care Experience Programme has clear objectives with appropriate support from relevant health and social care professionals.

Survey development

In the Department of Health Statement of Strategy 2021-2023, the Department of Health highlighted the promotion of 'initiatives for patient engagement and advocacy, improved patient experience and open disclosure, complaints and incidents policy', assessed through performance metrics that include 'improved patient experience measured through National Care Experience Programme and other channels'. The Sláintecare Implementation Strategy and Action Plan 2021-2023 explicitly highlighted the National Care Experience Programme as one of the patient safety initiatives that will support and enable the reforms outlined in the action plan.

In 2021, we continued work to expand the National Care Experience Programme to three new areas of care, and revised the National Inpatient Experience Survey for use during the COVID-19 pandemic. The aim of the National Care Experience Programme surveys is to find out about people's experiences of care and to use this feedback to acknowledge areas of good experience and to identify areas needing improvement. The findings will be used to improve services and to inform national policies, regulatory programmes and standards.

National Inpatient Experience Survey

The National Inpatient Experience Survey was cancelled in 2020 due to concerns over the capacity of services to support the execution of the survey and to implement quality improvement plans in response to the findings.

The survey resumed in 2021,[2] presenting an important opportunity for patients to provide feedback on their experiences of care during the pandemic.

A series of new questions were included to address specific aspects of inpatient experiences during the pandemic, such as questions on communication with staff who were wearing personal protective equipment (PPE), and contact with family and friends given visitor restrictions.

National Maternity Bereavement Experience Survey

In 2021, the National Care Experience Programme continued to develop the National Maternity Bereavement Experience Survey. This survey will provide an opportunity for parents who have experienced a second trimester miscarriage, a stillborn infant or the early neonatal death of a baby to describe their experiences of care.

National End of Life Survey

We continued to develop the first National End of Life Survey, with the aim of surveying bereaved relatives in 2022. This will be the first time that Ireland will hear about the experiences of care in a person's last months of life. Bereaved relatives, which can include the closest relatives or friends of those who have died, will be invited to tell us about the experience of end-of-life care from their perspective.

National Nursing Home Experience Survey

The National Care Experience Programme continued to develop the first National Nursing Home Experience Survey, which commenced in March 2022.

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[2] As a result of the cyberattack on the HSE in May 2021, the National Inpatient Experience Survey was postponed from May to September 2021.

Reach

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

- 10,743 participants in the National Inpatient Experience Survey 2021
- 5 conferences attended by members of the team
- 4 poster presentations at conferences
- 3 oral presentations at conferences
- 2 poster presentations at the UCD School of Medicine Summer Student Research Awards, 2021.

Presentations at the International Society for Quality in Health Care Conference

National Maternity Experience Survey

Developing, implementing and responding to a survey of women's experiences of maternity care in Ireland: The National Maternity Experience Survey

9 July 2021

Conor Foley
Senior Analyst

National Inpatient Experience Survey

The role of mixed sex wards in women's experiences of acute hospital care

9 July 2021

Tracy O'Carroll
Senior Programme Manager

Poster presentations at various national and international conferences

National Maternity Experience Survey

Women's views and experiences of infant feeding practices in Ireland – findings from the National Maternity Experience Survey

Roisin Murphy, Daniela Rohde, Conor Foley, Tracy O'Carroll, Rachel Flynn.
Health Information and Quality Authority , Unit 1301, City Gate, Mahon, Cork.

Introduction
Breastfeeding is one of the most effective ways to ensure child health and survival.[1] An international report on the rates of infants who were ever breastfed found that Ireland ranked the lowest out of 121 countries, with 55%.[2] It is important to understand women's experiences of infant feeding, including the reasons why women may choose not to breastfeed.

Aim
This study aimed to explore women's experiences of infant feeding in Ireland.

The comments revealed that some women would have liked additional support, regardless of their chosen feeding method.

National Inpatient Experience Survey

The impact of mixed sex wards on patient experiences of acute hospital care: A mixed-methods analysis of the National Inpatient Experience Survey

Daniela Rohde, Magreth Thadei Mwakilasa, Conor Foley, Tracy O'Carroll, Rachel Flynn
Health Information and Quality Authority, George's Court, Smithfield, Dublin 7

Introduction
Rising patient numbers, bed shortages and pressures to reduce emergency department waiting times have led to an increased use of mixed sex wards in hospitals.[1] It is important to consider the impact of this practice on patient experiences, which are central to the delivery of quality, person-centred care and an important predictor of outcomes.[2,3]

Aim
To explore the impact of mixed sex wards on the experiences of patients in acute hospitals in Ireland.

The comments revealed that both sexes felt unhappy, uncomfortable and embarrassed in mixed sex wards, with concerns over privacy and dignity, and dissatisfaction with shared bathroom facilities.

National Inpatient Experience Survey

Patient experience research during a pandemic: Adapting the National Inpatient Experience Survey in the context of COVID-19

Daniela Rohde, Conor Foley, Linda Drummond, Tracy O'Carroll, Rachel Flynn
Health Information and Quality Authority, George's Court, Smithfield, Dublin 7

Background
The COVID-19 pandemic has significantly impacted healthcare services, including the cancellation of procedures and a move to virtual appointments. Patient experiences are central to the delivery of quality healthcare; therefore, it is important to understand how the pandemic has affected all aspects of patient care, including experiences in acute hospitals.(1) In Ireland, the National Inpatient Experience Survey was cancelled in 2020, as a result of concerns over the capacity of services to support the conduct of the survey and implement quality improvement plans in response to the findings. The National Inpatient Experience Survey will resume in 2021, presenting an important opportunity for patients to provide feedback on their experiences of care during the pandemic.

Website and social media

The National Care Experience Programme uses its website (www.yourexperience.ie), Twitter, Facebook and Instagram to communicate with stakeholders across the health and social care system in Ireland and beyond. In 2021, there were:

- 6,116 visitors to www.yourexperience.ie
- 372 new followers on Twitter
- 638k+ Twitter impressions
- 31,000+ Facebook page reach[3]
- 2,000 Instagram reach
- 7,943 views of the interactive results across all surveys
- 603 people who accessed our e-learning modules.

Podcast

The National Care Experience Programme launched a new podcast series, Let's Talk Care Experience, on 16 November 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.

The first two episodes of Let's Talk Care Experience were released in 2021 and covered the following subjects:

1. The importance of listening to the voice of patients
2. The impact of food and nutrition on patients' experiences.

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[3] 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 2021, the team undertook the following online engagement sessions:

- Eight information sessions with HSE Patient Administration System (PAS) staff
- Workshops with physiotherapy students at Trinity College Dublin and midwifery students at University College Cork
- Six hospital presentations
- Six hospital group presentations
- 10 introductory and training sessions with nursing homes
- Information sessions and presentations for the:
    - Irish Hospice Foundation Bereavement Network
    - Clinical Midwife Specialist Group
    - National Women & Infants Health Programme webinar series
    - Compassionate End of Life (CEOL) Network
    - HSE and Hospice Friendly Hospitals (HFH) Network of Adult Acute Hospitals
    - Irish Hospice Foundation (IHF)
    - National Palliative Care Service Providers
    - HSE National Clinical Care Programme
    - HSE and Hospice Friendly Hospitals (HFH) National Oversight Committee

In total, the team held 40 information sessions or presentations for national stakeholders in 2021 with over 565 attendees.

Focus groups

As part of the development of the National Maternity Bereavement Experience Survey, the National End of Life Survey and the National Nursing Home Experience Survey, we conducted 29 focus groups and held one individual meeting with a total of 188 participants to identify the most important areas of experience to be included in each of the new surveys. A wide range of stakeholders participated in these focus groups and shared their experiences and expertise, including bereaved parents and families, nursing home residents and their families, healthcare professionals, managers and service providers, policy makers, researchers and advocacy organisations.

Delphi studies

In order to identify the most important questions for inclusion in each of the new surveys, the team conducted two rounds of Delphi studies[4] for each survey, with a total of 227 participants. The Delphi studies involved a wide range of stakeholders, including bereaved parents and families, nursing home residents, healthcare professionals and managers, policy makers, researchers and advocacy organisations.

Cognitive testing

The team cognitively tested[5] each of the newly developed survey questionnaires with 24 bereaved parents and families and nursing home residents and their relatives in order to assess the clarity and appropriateness of the questions and response options. Cognitive interviews were also held with four patient representatives to assess the clarity and appropriateness of seven new COVID-19 questions for inclusion in the National Inpatient Experience Survey 2021.

Engagement with international care experience survey programmes

We continued to engage and collaborate with our international networks in 2021. As part of the development of the National Nursing Home Experience Survey, we held four calls with international experts, including attendees from the Netherlands, Australia, the US and Canada. We engaged with Picker Institute Europe on the finalisation of our new survey questions. An informal network has been created with counterparts from national care experience survey programmes in Scotland, England, Australia and New Zealand. Several engagements were held in 2021 to share ideas and experiences of data analysis, the implications of COVID-19, and explore opportunities for further collaboration.

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[4] A Delphi study is a consensus-building technique used to refine the selection of questions to be included in each survey questionnaire.

[5] Cognitive testing involves exploring how participants interpret and understand survey questions and response options.

Collaboration

Academic partnerships

In 2021, 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 four student work placements from three universities:

- Two undergraduate medical students from University College Dublin
- One undergraduate public health student from University College Cork
- One postgraduate masters in applied social research student from Trinity College Dublin.

Funding applications

Generating actionable insights from the analysis of free-text comments from the National Care Experience Programme using qualitative and computational text analytics methods.

We worked with researchers and academics at Maynooth University on a successful grant application for funding from the Health Research Board under the Secondary Data Analysis Projects (SDAP 2021) funding scheme, with co-applicants from the HSE, Department of Health, and patient representatives. The grant will support a project involving 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 co-applicants 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 www.yourexperience.ie. 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 2021, the programme received and granted four data access requests. The majority of requests received in 2021 were from students or staff in academic institutions, including Trinity College Dublin, University College Dublin, and the Mater Hospital.

Change

Policy and practice

Medicines A-Z

One of the areas for improvement identified by the National Inpatient Experience Survey included information on medications. Across the first three years of the survey (2017 to 2019), 11.0% of patients (n=3,360) said that the purpose of medicines they were to take at home were not explained to them in a way that they could understand. In addition, 38.5% (n=10,291) reported that they were not told about the side effects of medications to watch out for when they went home.

The findings of the National Inpatient Experience Survey suggested that one of the reasons for re-admission to hospital may be related to medication, including medication side effects and patients not remembering their correct dosage. The HSE's Medicines A-Z resource was developed in response to these findings. Medicines A-Z, which is available at https://www2.hse.ie/conditions/medicines/, launched in October 2021 and was developed in collaboration with general practitioners, the Royal College of Surgeons in Ireland, SaferMeds and the Health Products Regulatory Authority (HPRA).

Implementation of the National Maternity Strategy

The National Maternity Experience Survey was a key recommendation in the National Maternity Strategy. The Strategy recognises that we need to listen to women, and notes that the woman's voice is essential to evaluate and inform the care given, to guide quality improvements, and to inform quality improvement initiatives at a local and national level.

The ultimate purpose of gathering women's views through the National Maternity Experience Survey is to improve the quality and safety of the maternity care provided. The results 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 in 2021, including funding targeted at improving post-natal supports and new lactation consultant posts. The significant additional funding provided for maternity services in 2021 and 2022 will facilitate the implementation of quality improvement plans that were developed in response to the survey.

Informing Ireland's Health Systems Performance Assessment Framework

The Health Systems Performance Assessment Framework (HSPA) will deliver a reliable framework for assessing the overall performance of the health system in Ireland. Measurable and quantifiable outcomes-based indicators identified in the framework will inform evidence-based health policies and strategies, including Sláintecare. The National Care Experience Programme and the suite of surveys that capture the experience of people using our health and social care services will be an important input into the Health System Performance Assessment Framework.

Phase 1 of the project, which involved the development of a conceptual framework, was completed in 2021. Within this framework, the domain of person centeredness is a central pillar connecting access and quality, with National Care Experience Programme survey data utilised as a key data source under this domain.

Phase 2 of the project, which focuses on implementation of the framework, is currently underway and is expected to last between 18 to 24 months. As further surveys are developed as part of the National Care Experience Programme, it is envisaged that additional input will be reviewed as part of the wider management of indicators included in the framework.

Informing the Women's Health Taskforce

A Women's Health Taskforce was established by the Department of Health to improve women's health outcomes and experiences of healthcare in September 2019. 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. Informed by women's voices, the taskforce chose four initial priorities: improve gynaecological health, improve supports for menopause, improve physical activity, and improve mental health among women and girls.

Data from the National Care Experience Programme, including the National Inpatient Experience Survey and the National Maternity Experience Survey, has been used by the Department of Health to inform the work of the Women's Health Taskforce and specifically the Women's Health Action plan developed in 2021. Specific initiatives supported by the Taskforce, such as provision of additional staffing in perinatal mental health, were informed by the findings of the National Maternity Experience Survey.

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.

What’s next for the programme in 2022?

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 2022, the programme will:

- Report on the National Inpatient Experience Survey 2021 and develop, implement and report on the 2022 survey
- Deliver and report on the National Maternity Bereavement Experience Survey
- Deliver and report on National Nursing Home Experience Survey
- Commence the National End of Life 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.

National Care
Experience
Programme

Health
Information
and Quality
Authority
An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health