



**National Care  
Experience  
Programme**

**Impact report  
2020**

## About the National Care Experience Programme

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) 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 NCEP has successfully implemented the National Inpatient Experience Survey for three years, the National Maternity Experience Survey in 2020, and is currently developing three further surveys covering end of life care, nursing home care and maternity bereavement. These surveys will be ready for implementation by the end of 2021.

The National Inpatient Experience Survey is an annual survey providing patients with the opportunity to describe their experiences of public acute hospital care in Ireland. The purpose of this survey is to learn from patients' feedback to find out what is working well in our hospitals, and what needs improvement. The HSE responds to the results of the National Inpatient Experience Programme by developing quality improvement plans at the national, hospital and hospital group levels. In addition, the results of the inpatient survey inform national policy and HIQA's healthcare monitoring programme.

The National Maternity Experience Survey offers women the opportunity to share their experiences of Ireland's maternity services. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their baby receive. The first National Maternity Experience Survey was completed in 2020, with over 3,200 women who gave birth on October and November 2019 sharing their maternity care experiences.

The National Care Experience Programme launched a Survey Hub in 2020, which provides support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.

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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 Strategic Plan (2019-2021) 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.

<b>Outputs</b>	<ul style="list-style-type: none"> <li>• Tangible entities produced from projects</li> <li>• Reports, policies, quality improvements</li> </ul>
<b>Reach</b>	<ul style="list-style-type: none"> <li>• One-way communications about a project</li> <li>• Promotional material, information sessions</li> </ul>
<b>Engagement</b>	<ul style="list-style-type: none"> <li>• Two-way communication about a project</li> <li>• Conferences, training programmes</li> </ul>
<b>Change</b>	<ul style="list-style-type: none"> <li>• Changes in patient experience scores</li> <li>• Changes in practice/policy in response to the survey</li> </ul>

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 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 on an annual basis.

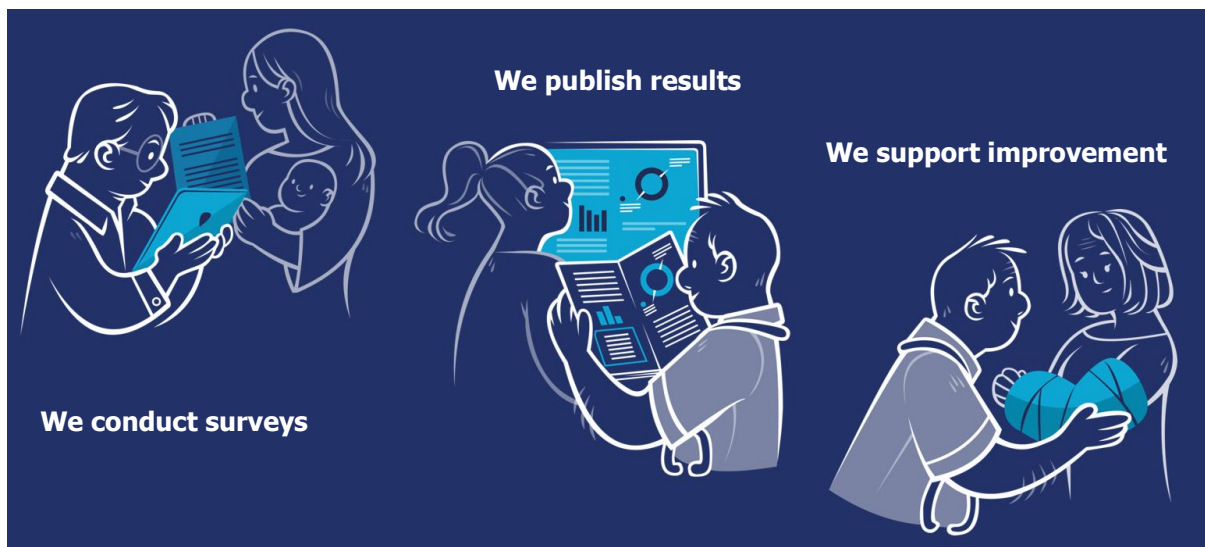
## National Care Experience Programme Objectives 2020

The National Care Experience Programme objectives for 2020 were as follows:

- to implement and report on the National Inpatient Experience Survey (NIES)<sup>1</sup>
- to implement and report on the National Maternity Experience Survey (NMES)
- to commence development of the model and methodology for the:
  - National Maternity Bereavement Experience Survey (NMBES)
  - National End of Life Survey (NELS)
- to develop a competency centre (Survey Hub) of international standing providing expertise and skills to support greater engagement with service providers and NCEP counterparts nationally and internationally.

Following the publication of the COVID-19 Expert Panel Final Report by the Expert Panel on Nursing Homes in July 2020, a recommendation was also made to expedite the expansion of the National Care Experience Programme to nursing home residents. In response, the NCEP commenced the development of the model and methodology for the National Nursing Home Experience Survey (NNHES).

This report describes the impact of the National Care Experience Programme in 2020, in accordance with the framework outlined above.



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<sup>1</sup> In light of the COVID-19 pandemic, the National Inpatient Experience Survey 2020 was cancelled.

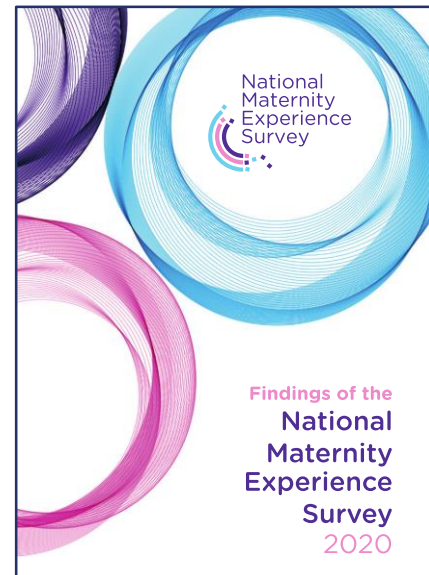
## Outputs

### Reports

#### National Maternity Experience Survey 2020

The National Care Experience Programme produced a number of reports in order to disseminate the findings of the National Maternity Experience Survey 2020:

- one national report
- 19 maternity hospital/unit reports
- one National Home Births Service report
- one technical report, which provides a technical description of the model, methodology and procedures implemented during the maternity experience survey.



#### National Inpatient Experience Survey 2019

The National Care Experience Programme produced a number of reports in order to further disseminate the findings of the National Inpatient Experience Survey 2019:

- Six hospital group reports
- One technical report, which provides a technical description of the model, methodology and procedures implemented during the maternity experience survey
- One review of processes, which reports on the findings of a public consultation of key stakeholders to determine which processes worked well and what can be improved.



### Survey Hub

In 2020, the National Care Experience Programme developed a Survey Hub to provide expertise and skills and support greater engagement with stakeholders, both nationally and internationally. The Survey Hub offers a suite of resources for anyone

aiming to capture the experiences of people who use health and social care services, and provides advice on how to develop and implement a survey, interpret the findings, and make improvements based on the results.

## Training and support resources



### Survey design modules

As part of the new Survey Hub, the National Care Experience Programme developed a series of five online modules in 2020. These modules provide advice on how to develop and implement a survey and cover a range of topics.

### Information governance podcast

The National Care Experience Programme produced a podcast on information governance, which describes the importance of Data Protection Impact Assessments (DPIAs) for surveys, as well as the steps involved in their development. A series of podcasts is planned for 2021.



*Survey Hub podcast: Donnacha O' Ceallaigh discusses information governance*

The Survey Hub launched on 14 October 2020 and features the following content:

- a survey development roadmap
- five **Survey design** e-learning modules
- one **Interactive dashboards** e-learning module
- one podcast on **Information governance**
- list of academic publications and presentations.

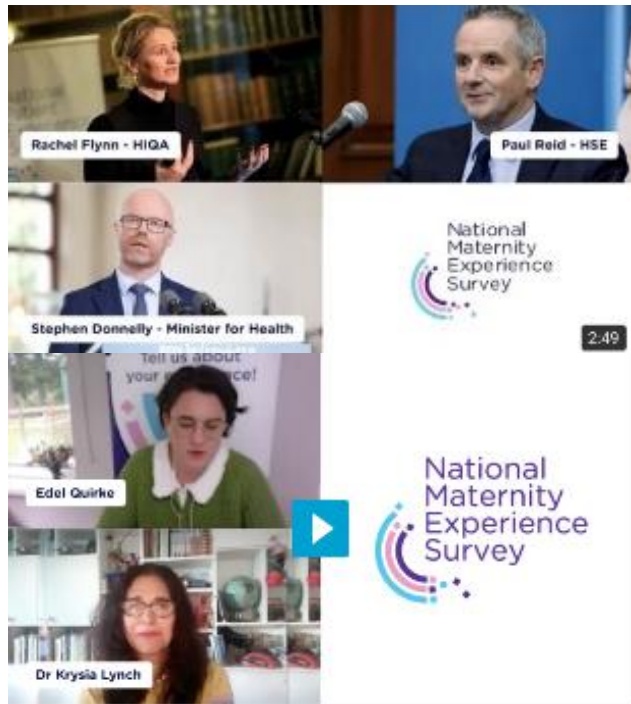
The survey design e-learning modules can be found [here](#).



## Reach

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

- 3,204 participants in the National Maternity Experience Survey 2020
- one webinar to launch the results of the National Maternity Experience Survey, with 269 attendees
- 20 Zoom townhall sessions to discuss the local results of the survey, with 250 attendees from maternity hospitals and units, the National Home Births Services and community care across the 20 sessions
- five conferences<sup>2</sup> attended by members of the team
- two information stands hosted by the programme at national conferences
- one poster and 2 oral presentations accepted at conferences in Ireland
- two promotional videos
- one video animation.



*Virtual launch of the National Maternity Experience Survey 2020*

The results of the National Maternity Experience Survey 2020 were launched on 1 October 2020. The survey results were quoted in a number of articles and media outlets:

- 20 hospital (and National Home Births Services) infographics designed
- 16 national print articles
- 20 online media articles
- 35 broadcast pieces
- three promotional campaigns with online parenting websites.



<sup>2</sup> Due to the COVID-19 pandemic, the majority of conferences in 2020 were cancelled or postponed

## Website and social media

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

In 2020, there were:

- 236 downloads of the National Maternity Experience Survey National Report
- 312 downloads of local hospital reports from the National Maternity Experience Survey
- 8,862 visitors to <https://yourexperience.ie>
- 3,223 followers across Facebook, Twitter and Instagram
- 429,700 Twitter impressions
- 54,634 Facebook post reach<sup>3</sup>
- 1,143 Facebook engagements<sup>4</sup>
- 8,128 views of the interactive results across all surveys.



The screenshot shows the Twitter profile for the National Care Experience Programme (@careexperience). The profile includes a header with the programme's logo and a navigation bar with 70 Posts, 258 Followers, and 32 Following. The bio states: "We are the National Care Experience Programme, asking people about their experience of care." It lists the website as [linkin.bio/careexperience](https://linkin.bio/careexperience) and the address as George's Court, George's Lane, Dublin, Ireland. The profile also shows 185 Following and 2,539 Followers. A grid of featured tweets is visible at the bottom, including posts about maternity, inpatient care, and a 2019 review.

<sup>3</sup> Post reach refers to the number of people who saw a particular post.

<sup>4</sup> Engagement refers to any action taken in response to a page or post, such as liking, commenting or sharing.

## Engagement

### Hospital and community visits

Hospital and community visits form an important part of the National Care Experience Programme's engagement with healthcare staff and providers.

In order to promote the National Maternity Experience Survey, in 2020 the team undertook<sup>5</sup>:

- 19 maternity hospital and unit visits to promote the National Maternity Experience Survey
- 16 Public Health Nursing forums, which reached 200 Public Health Nurses
- one General Practitioner (GP) Study Day, which reached 250 GPs.



*The Coombe Women & Infants University Hospital visit*

### Virtual hospital and local community townhall sessions

In order to discuss the local results of the National Maternity Experience Survey 2020, the team organised virtual townhall sessions with each of the 19 participating maternity hospitals and units, the corresponding local community services, and the National Home Births Services. The team also held six townhall sessions with acute hospitals to discuss the National Inpatient Experience Survey.

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<sup>5</sup> Due to the COVID-19 pandemic, hospital and community visits ceased in March 2020

## **National Maternity Bereavement Experience Survey**

During the development of the National Maternity Experience Survey, it was identified that a dedicated survey was required to explore the experiences of bereaved parents, to capture meaningful information on their experiences of care in a sensitive and appropriate manner. The National Maternity Bereavement Experience Survey (NMBES) aims to learn from parents and families about their care experience and perceptions of care following a pregnancy or perinatal loss. The survey findings will help to offer assurance in the care being provided and identify areas for improvement in all maternity hospitals and units in Ireland. The findings will also inform existing national standards for bereavement care, in addition to informing regulation programmes for maternity care services.

A project lead was appointed in July 2020 for an 18 month period, and is currently developing the model and methodology to implement the National Maternity Bereavement Experience Survey. As part of the development of the survey, engagement with international counterparts who have conducted similar work in this area was undertaken to learn from their experiences and to inform the development of a suitable approach for the Irish context. This included five video conference calls and 52 email correspondences with nine international counterparts from six countries recognised for their work in highlighting and supporting perinatal bereavement, including Australia, England, the US, Canada, Italy and Spain. Extensive engagement with national stakeholders also took place. A communications and stakeholder engagement plan is in development to support the delivery of the survey, ensuring that the views of all relevant stakeholders are represented throughout the survey development process.

## **National Nursing Home Experience Survey**

Following the publication of the COVID-19 Expert Panel Final Report by the Expert Panel on Nursing Homes in July 2020, a recommendation was made to expedite the expansion of the National Care Experience Programme to nursing home residents. The National Nursing Home Experience Survey (NNHES) will capture the care experiences of older people in nursing homes across Ireland in a structured and systematic manner. The survey aims to inform quality improvement within service provision, support the development of future policies and standards and to inform monitoring programmes to support the regulation of older persons' health and social care services.

As part of the development of the National Nursing Home Experience Survey, engagement with international counterparts who have conducted similar work in this area has taken place to learn from their experiences and to inform the development of a suitable approach for the Irish context. In 2020, four international calls were held with eight representatives from Australia, the Netherlands, the US and Canada.

An extensive communications and stakeholder engagement plan is also in development to support the delivery of the survey, ensuring that the views of all relevant stakeholders are represented throughout the survey development process.

## **National End of Life Survey**

In response to the COVID-19 Expert Panel Final Report, the National Care Experience Programme is also progressing work on the development of the National End of Life Survey (NELS), to include people who were cared for and died in nursing homes. The National End of Life Survey aims to capture the experience of care of adults who are at end of life from the perspective of bereaved relatives, to establish the quality of healthcare delivered by health and social care services. 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.

As part of the development of the National End of Life Survey, engagement with international counterparts who have conducted similar work in this area has taken place to learn from their experiences and to inform the development of a suitable approach for the Irish context. In 2020, four international calls were held with international counterparts who have undertaken similar work, including six representatives from Japan, the US, England and New Zealand. In addition, 14 teleconference calls were held with stakeholders in Ireland to discuss access to the survey sample.

## **Collaboration**

In 2020, the NCEP continued to engage with professional bodies and educational institutions to support and demonstrate use of the survey findings.

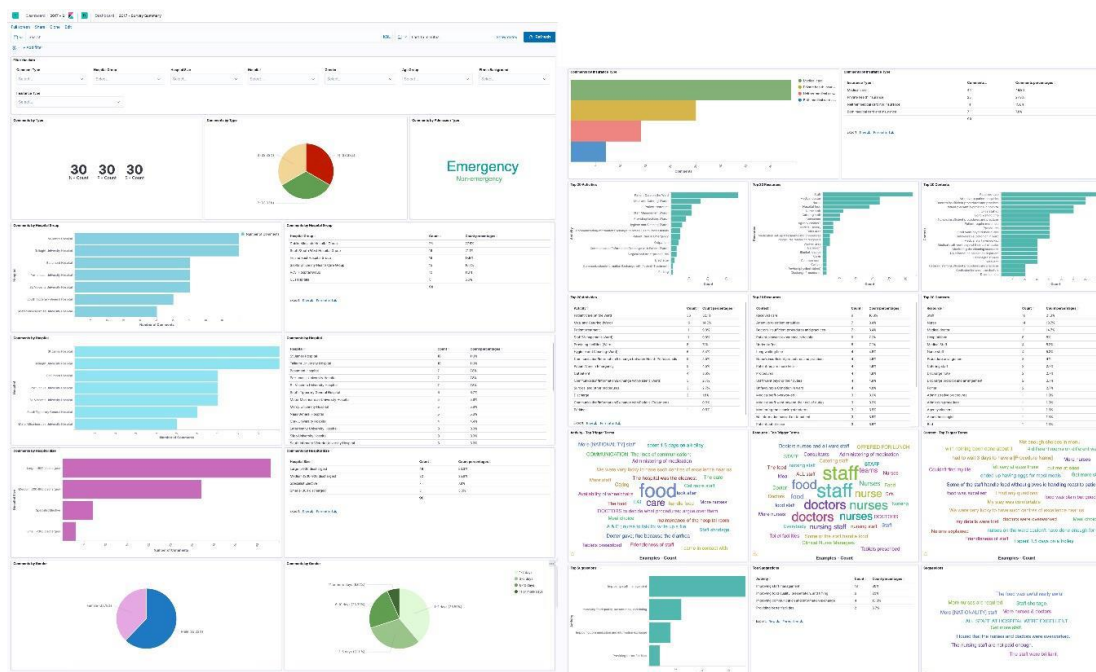
### **NUI Galway analysis of qualitative comments from the National Inpatient Experience Survey**

Over 40,000 qualitative comments were received in response to the 2017 and 2018 National Inpatient Experience Surveys. These comments contained rich information on how patients perceived the care they received in hospital and where they felt it could be improved. In order to get a deeper understanding of these comments and how they could be used to improve care, the National Care Experience Programme worked with a team based in the Insight Centre for Data Analytics, Data Science Institute, NUI Galway (NUIG), led by Prof. Adegboyega Ojo. The NUIG team used a combination of traditional qualitative analysis methods, as well as data mining and machine learning techniques to identify the key activities, resources and contexts within the comments. The team then used complex statistical models to quantify how

each of these factors were associated with positive and negative patient experiences. The findings of the NUIG analysis will be published in early 2021.

The team also developed an interactive dashboard, which allows users to explore a detailed analysis and visualisation of the comments. Access to the interactive dashboard will be provided by the NCEP to allow hospital personnel to work with data relevant to their specific hospital.

## NUIG interactive dashboard



## Student work placements

In 2020, the programme supported an eight-week work placement for a student of the Masters in Applied Social Research in Trinity College Dublin. The work placement resulted in:

- a literature review
- coding of qualitative data from the National Inpatient Experience Survey
- an MSc dissertation based on secondary analysis of data from the National Inpatient Experience Survey 2019.

## Data access requests

The National Care Experience Programme promotes a culture of making data available, with reports and interactive online reporting platforms available on the yourexperience.ie website. 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 2020, the programme received and granted eight data access requests, compared with five requests per year in 2018 and 2019. The majority of requests received in 2020 were from students or staff in academic institutions, including Trinity College Dublin, University College Cork, University College Dublin, University of Limerick, NUI Galway and Dublin Business School.

### International networks

In addition to engagement with national and international stakeholders as part of the development of the model and methodology for the three new surveys, the programme organised one international patient experience Zoom call in 2020. The purpose of this call was to strengthen links with international counterparts, and to discuss international patient experience survey developments, including:

- COVID-19-specific surveys and questions
- analysis of qualitative survey data
- the Survey Hub.



**14 calls**



**32 international counterparts**



**10 countries**

Nine representatives from England, Scotland, Australia and New Zealand attended the call. Discussions helped to inform the development of new questions for the National Inpatient Experience Survey 2021, specific to the COVID-19 pandemic.

In total, the NCEP team engaged with 32 international counterparts from 10 countries in 2020.

### Information governance

In addition to producing an information governance podcast for the Survey Hub, the National Care Experience Programme engaged and collaborated with other teams within HIQA on information governance. The Data Protection Impact Assessment (DPIA) conducted for the National Maternity Experience Survey served as a reference point for the development of DPIAs across the Health Information & Standards Directorate, as well as the wider organisation. The team's work also informed guidance for the development of Information Management Strategies for national data collections.

## Change

### Quality improvement

The National Maternity Experience Survey local Zoom townhall sessions brought together staff from both hospital and community services for the first time, to discuss the results of the survey and quality improvement initiatives.

#### Examples of quality improvement initiatives



##### Hospital and community maternity services working together

Whilst many hospital and community maternity service providers already work in tandem to provide continuity of care to new mothers, the extent of communication and liaison between both is not consistent across the country. The NMES individual hospital Zoom sessions, in which the affiliated public health nursing services were in attendance, highlighted the potential for synergy in the provision of postnatal care. This was particularly evident in the context of breastfeeding support, following breastfeeding initiation in hospitals and subsequent continuation of support at home.

Similarly, the introduction of the Perinatal Mental Health Model of Care has led to an increase in diagnoses and heightened vigilance for mental health issues throughout the pregnancy, birth and postnatal periods. Communication between healthcare providers throughout the maternity journey is required to ensure continuity and consistency of care for women's perinatal mental health. Our Lady of Lourdes Hospital and Community Healthcare Organisation (CHO) 8 have endeavored to strengthen their interactions in order to facilitate continuity of care for women.

##### Specialist Perinatal Mental Health Services Model of Care

The National Maternity Experience Survey highlighted perinatal mental health as a key area for improvement. These findings have served to reinforce the importance of the implementation of the perinatal mental health model of care. Questions relating to mental health were some of the lowest-scoring questions across the survey. The requirement for improvement in the care of women's mental health during pregnancy, birth and the postnatal periods was thus underscored and so too, the requirement for the implementation of the Specialist Perinatal Mental Health Services Model of Care.

The Rotunda Hospital has expanded its mental health team and now has a staff of 11 perinatal mental health professionals in place, including some in postnatal community outreach posts. Additionally, it has recruited a Birth Reflections Midwife who acts a link person between women and mental health services. Based on the results of the survey, Cork University Maternity Hospital is offering debriefing and mental health support to women who have experienced any type of birth trauma. This includes those who have had a 'normal' birth, as well as those who have poor outcomes or morbidities.



In light of the COVID-19 pandemic, the National Inpatient Experience Survey 2020 was cancelled. Calls with the six hospital groups, however, highlighted the ongoing quality improvement initiatives being undertaken by the hospitals.

### Examples of quality improvement initiatives



#### Medication safety

Beaumont Hospital provides a medication safety counselling service for patients on discharge from hospital.

#### Emergency department volunteers

St Luke's Hospital Kilkenny utilises community volunteers to sit and wait with patients in the Emergency Department at weekends.

#### Emergency department waiting times

St James's Hospital has reduced its waiting times in the Emergency Department by 13% as a result of the recruitment of two additional registrars in emergency medicine.

### 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 annually 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*. In the NHQRS 2020 Annual Report<sup>6</sup> a total of 21 indicators from the National Inpatient Experience Survey 2019 and the National Maternity Experience Survey 2020 were included. 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.

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<sup>6</sup> National Healthcare Quality Reporting System Annual Report 2020. Available from: <https://www.gov.ie/en/collection/5fd4f6-national-healthcare-quality-reporting-system-reports/#2020>

## Regulation

Findings from the National Inpatient 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.

## Policy and practice

### Communication and shared learning

To facilitate shared learning on the evidence of best practice and to inform future quality improvement initiatives for maternity services, the HSE response to the National Maternity Experience Survey highlighted areas of existing best practice across Ireland's hospital and community maternity services, with a focus on areas identified as requiring improvement nationally. Examples include the Birth Reflections service in the Coombe Women & Infants University Hospital, which 'aims to give women a chance to explore their birth experience and ask questions that they may not have previously asked',<sup>7</sup> and local support and breastfeeding groups run by Public Health Nurses in Dublin and Kerry.

### Highlighting areas requiring improvement

An important, unexpected finding from The National Maternity Experience Survey was the identification of variation in access to GP care across different parts of Ireland. A 2-week postnatal check-up with a GP is a standard part of the Maternity and Infant Care Scheme. Nationally, 85% of women said that their baby received the 2-week check-up with a GP. However, there was significant variation in attendance across the country, with particularly low attendance in the North West. In Donegal, 44.4% of mothers attended, whilst in Leitrim, 46.3% attended and in Sligo, 47.1% attended. In Cork and Cavan, on the other hand, 97.5% of women attended a 2-week check-up with a GP, while in Louth, 98.4% of women attended their GP at 2-weeks. Of those who did not attend the 2-week check-up, most said it was because they did not know about it.

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<sup>7</sup> Listening, Responding and Improving: The HSE response to the findings of the National Maternity Experience Survey. Available from: <https://yourexperience.ie/wp-content/uploads/2020/10/HSE-RESPONSE-TO-NMES-2020.pdf>

## **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 follows a recommendation from the Scoping Inquiry into the CervicalCheck Screening Programme,<sup>8</sup> 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 has been used by the Department of Health to inform the work of the Women's Health Taskforce. Results from the National Inpatient Experience Survey helped inform the initial stages of the Women's Health Taskforce work, while results from the National Maternity Experience Survey have informed the taskforce's mental health workstream.

## **Informing Ireland's new Health Systems Performance Assessment Framework**

The Health System Performance Assessment Framework (HSPA) for Ireland aims to identify appropriate health system domains, made up of performance indicators relevant to those domains, in order to move towards a measurable and quantifiable outcome-based model. Developmental work was undertaken in 2020 and Phase 1 of the project is now complete. The HSPA for Ireland includes five clearly defined domains with 260 indicators and 3 cross-cutting themes to be used to develop policy, measure service delivery, and for public-facing communications. National Care Experience Programme survey data have been identified as a key data source for indicators under the person-centredness domain in the HSPA. Inclusion of NCEP survey data will ensure that the experiences of service users are central to the measurement of health system performance in Ireland.

## **Implementation of the National Maternity Strategy**

The National Maternity Experience Survey was a key recommendation in the National Maternity Strategy 2016-2026.<sup>9</sup> The strategy recognises 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

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<sup>8</sup> Scoping Inquiry into the CervicalCheck Screening Programme. Available from: <https://assets.gov.ie/9785/9134120f5b2c441c81eed06808351c7.pdf>

<sup>9</sup> Creating a better future together: National Maternity Strategy 2016-2026. Available from: <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>

purpose of gathering women's views through the National Maternity Experience Survey is to improve the quality and safety of maternity care. Findings from the survey identified areas where improvements are required. The results directly informed the allocation of funding in 2021, including funding targeted at improving post-natal supports. The additional funding provided for maternity services in 2021 will facilitate the implementation of quality improvement plans that were developed in response to the survey.

### **Raising awareness of the Independent Patient Advocacy Service**

The Independent Patient Advocacy Service was commissioned by the National Patient Safety Office in the Department of Health following a recommendation in the Health Information and Quality Authority's (HIQA) 2015 report on the investigation into maternity care in Midland Regional Hospital Portlaoise.<sup>10</sup> The service, which was launched in November 2019, is aimed at supporting patients who wish to make a complaint about care received in a public hospital. The National Maternity Experience Survey was used as a channel to build awareness regarding the Patient Advocacy Service for women who wish to make a complaint about the maternity care they have received.

### **What's next for the programme in 2021?**

The National Care Experience Programme Strategic Plan (2019-2021) sets out how the partnership plans to develop and diversify its programme of work up to 2021, listening to the experiences of people using health and social care services in Ireland and ensuring appropriate actions are taken in response.

In 2021, the programme will:

- implement and report on the National Inpatient Experience Survey
- implement the National Maternity Bereavement Experience Survey
- continue the development of the model and methodology of two new surveys:
  - National End of Life Survey
  - National Nursing Home Experience Survey
- continue to develop resources for the Survey Hub.

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<sup>10</sup> Report of the investigation into the safety, quality and standards of services provided by the Health Service Executive to patients in the Midland Regional Hospital, Portlaoise. Available from: <https://www.hiqa.ie/sites/default/files/2017-01/Portlaoise-Investigation-Report.pdf>



# National Care Experience Programme

