

# National Care Experience Programme: Datasets and research priorities

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# About HIQA and the NCEP

- The Health Information and Quality Authority is an independent authority established to drive high-quality and safe care for people using our health and social care services in Ireland.
- The National Care Experience Programme is a partnership between HIQA, the HSE and the Department of Health

## **Mission**

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

## **Vision**

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

# NCEP Strategy 2025-2027

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

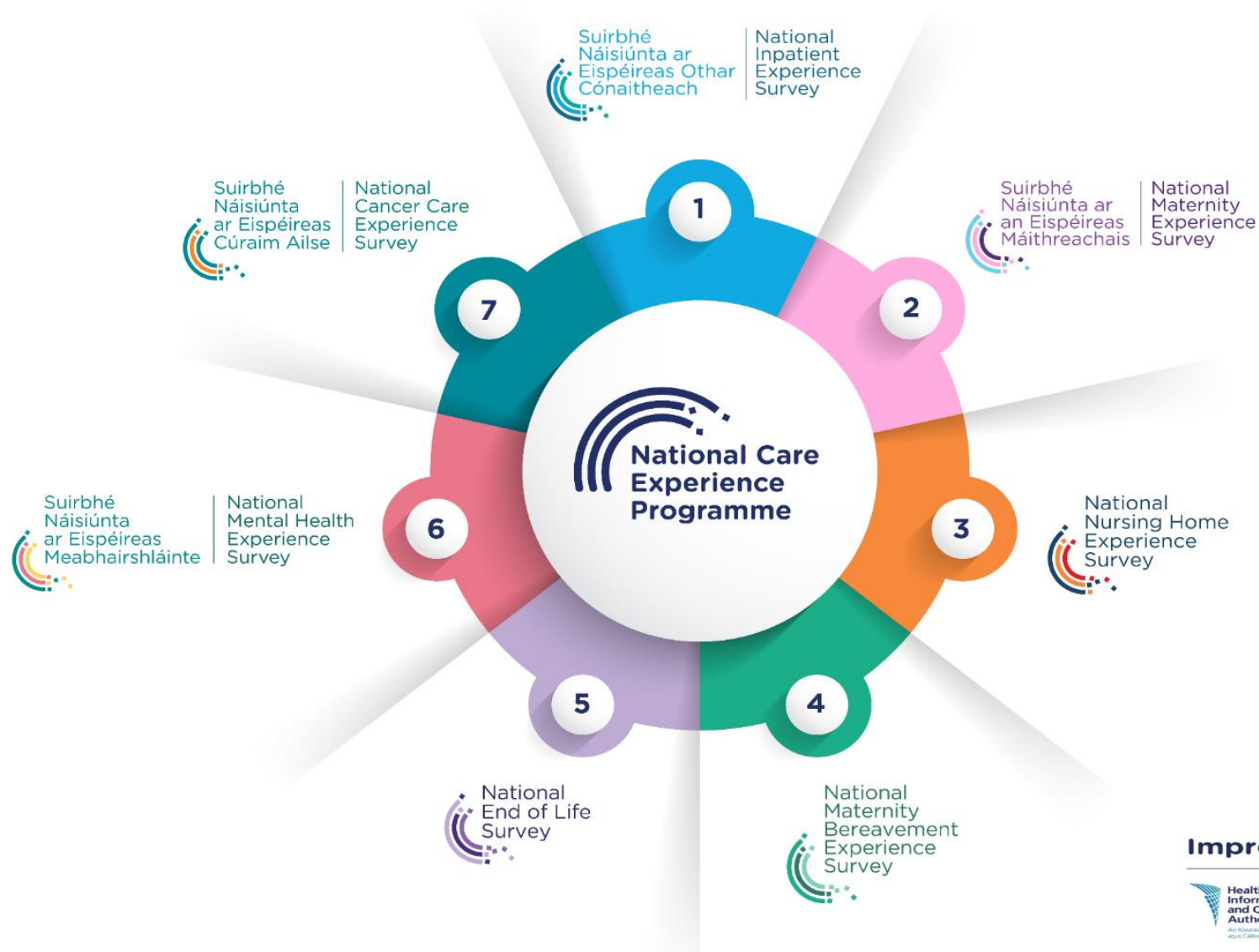
**Objective 2:** Provide actionable insights to drive improvements in health and social care

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

**Objective 4:** Building a high performing and innovative research offering to provide actionable insights and guidance to health and social care services

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# National Care Experience Programme



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# National Care Experience Programme

Each NCEP survey is developed using a defined multistage process and collects closed and open-ended responses

- National Inpatient Experience Survey
  - 6 iterations since 2017, over 70,000 respondents to date
- National Maternity Experience Survey
  - Conducted in 2019 (3,204 respondents), with 2<sup>nd</sup> iteration to commence in 2025.
- National Maternity Bereavement Experience Survey
  - Conducted in 2022, with 655 women who experienced a loss and 232 partners responding.
- National Nursing Home Experience Survey
  - Conducted in 2022, with 718 residents and 943 family members responding across a selection of 53 nursing homes, reflective of the national profile.
- National End of Life Survey
  - Conducted in 2023, 4,570 bereaved relatives responded, giving feedback on EOL care in nursing homes, at home, in a hospice and in hospital.

# Accessing NCEP data

- Data access requests
  - Form accessible via [yourexperience.ie](https://yourexperience.ie)
  - 53 access requests fulfilled to date
- Interactive dashboards
  - Tableau and PowerBI for survey results
- Online repositories
  - ISSDA
- Grant-specific arrangements

The image shows two overlapping documents from The National Care Experience Programme. The left document is the 'Data Access Requests Policy' and the right document is the 'Data Access Request Form'.

**The National Care Experience Programme**  
Data Access Requests Policy

Reference No: 04-002-POL11  
Revision No: 02  
Author: National Care Experience Programme team  
Approved by: Rachel Flynn, Director of Health Information and t (HIQA)  
Date: 2 January 2023  
Effective from: June 2023  
Review date: June 2025

**The National Care Experience Programme**  
Data Access Request Form

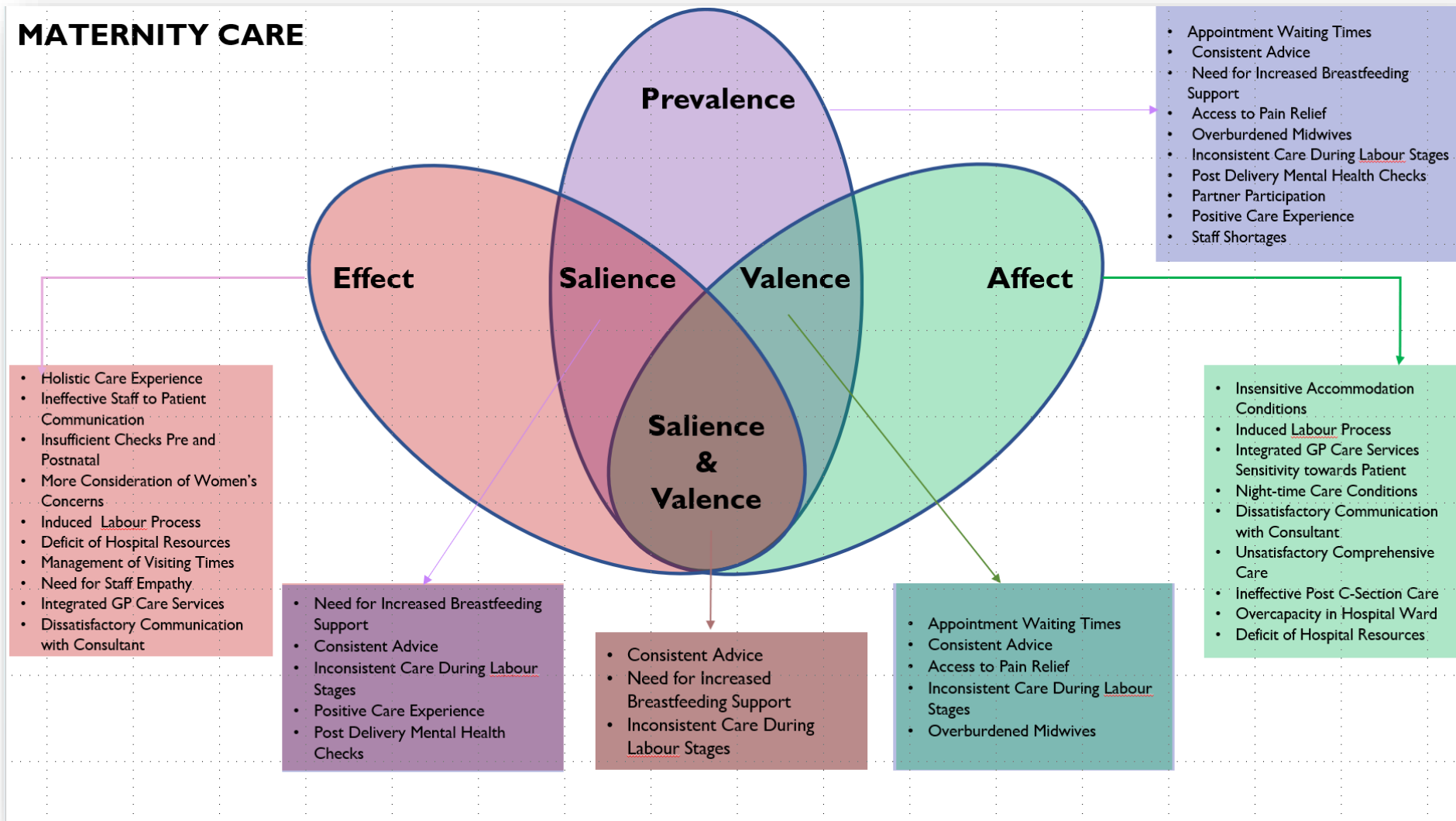
Note: Before completing this form please read the information governance policies and procedures, available from [www.yourexperience.ie](https://www.yourexperience.ie).

Contact details	
Requester's full name	
Title (Mr/Mrs/Di/Prof/Other)	
Job title	
Organisation name and sector (government, private company, etc.)	
Address	
Telephone number	
Email address	
Names of other persons who will have access to the data requested	

# Successful grants

- 2 x SDAP and 1 x APA as knowledge user co-applicant. Academic partners from Maynooth, Galway and TUD
  - Exploring the demographic and healthcare factors associated with breastfeeding in Ireland; a gap analysis to develop a national infant-feeding survey tool (SDAP-2023-035).
    - Awarded €205,000, due for completion in 2026.
  - No data about us without us: Co-designing the Integration of Health Inequalities into the National Inpatient Experience Survey to Enhance the Participation of and Data about Marginalised Communities (APA-2022-022).
    - Awarded €234,000 (with co-fund), due for completion in 2026.
  - Generating actionable insights from the analysis of free-text comments from the National Care Experience Programme using Qualitative and Computational Text Analytics methods (SDAP-2021-012).
    - Awarded €348,000 (with co-fund), completed in 2024.

# HRB-SDAP Maynooth Project Excerpt





# Nature of the partnerships

- In all cases, academic PI with all funding going to university. PI led on all dealings with HRB
  - Co-funding provided by HIQA in some cases
  - Creating research agreements to govern working relationship
- Building on existing governance structures, as well as creating project-specific structures
- Time taken to work together to clearly define the problem, linking it to policy objectives
  - Setting clear and feasible objectives with very specific deliverables
  - Clear roles and responsibilities regarding which sections of applications to complete
- Broad range of co-applicants and collaborators
  - Policymakers, healthcare managers, inspectors, international counterparts, advocacy groups
  - NCEP as a stable partnership programme between HSE, HIQA and DOH
- NCEP and HIQA staff with experience of working on grants and funded projects

# Example areas of interest for future research

- Triangulation of survey data with data on outcomes, process measures, regulatory compliance, etc?
  - Fitting care experience data into a bigger picture
- Looking across the full suite of surveys – what can we learn?
  - Coordination of care, transitions between services/sites
- Developing a toolkit, creating a community of practice and catalogue to assist providers to respond to survey findings effectively
- Exploring perceived/self-reported patient safety incidents and how they compare to notified patient safety incidents

**THANK YOU**

**QUESTIONS**

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