



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Knowledge Sharing and Impact Assessment

Health Information and Standards Directorate

2022 REPORT

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory authority established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

HIQA's mandate to date extends across a wide range of public, private and voluntary sector services. Reporting to the Minister for Health and engaging with the Minister for Children, Equality, Disability, Integration and Youth, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services** — Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of health services and children's social services, and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health technology assessment** — Evaluating the clinical and cost-effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.
- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health services, in conjunction with the Department of Health and the HSE.

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Overview of the Health Information and Standards Directorate

The Health Information and Standards (HIS) Directorate aims to support a consistent and standardised approach to health and social care service provision and information in Ireland and bring about effective and sustainable improvements to Irish health and social care services.

The HIS Directorate has three core functions:

1. Development of national health and social care standards and guidance

The Standards Team delivers against this function through the development of evidence-based national standards and implementation support tools for health and social care services in Ireland. The standards setting function operates under the remit of the Health Act 2007 and is guided by a prioritisation process* and a Standards Strategy (2022-2024).†

2. Informing and driving health information quality and eHealth

The Technical Standards Team and the Health Information Quality Team deliver on this function by developing recommendations, national standards and guidance for the Irish eHealth and health information landscape, and assessing against the national standards. These teams operate under the remit of the Health Act 2007 and are guided by the Health Information Strategic Objectives 2020-2022.‡

3. Surveying the experiences of people who use health and social care services

The National Care Experience Programme is responsible for this function which currently includes running national inpatient, the maternity, the maternity bereavement, the end of life and nursing home surveys. The National Care

* The prioritisation process is available at: <https://www.hiqa.ie/reports-and-publications/standard/prioritisation-process-development-national-standards-and>

† The Standards Strategy (2022-2024) is available at: <https://www.hiqa.ie/reports-and-publications/corporate-publication/health-and-social-care-standards-strategy-2022-2024>

‡ The Health Information Strategic Objectives 2020-2022 are available at: <https://www.hiqa.ie/reports-and-publications/health-information/health-information-strategic-objectives-2020-2022>

Experience Programme operates in line with the objectives and remit, as laid out in the National Care Experience Programme Strategy (2022-2024).[§]

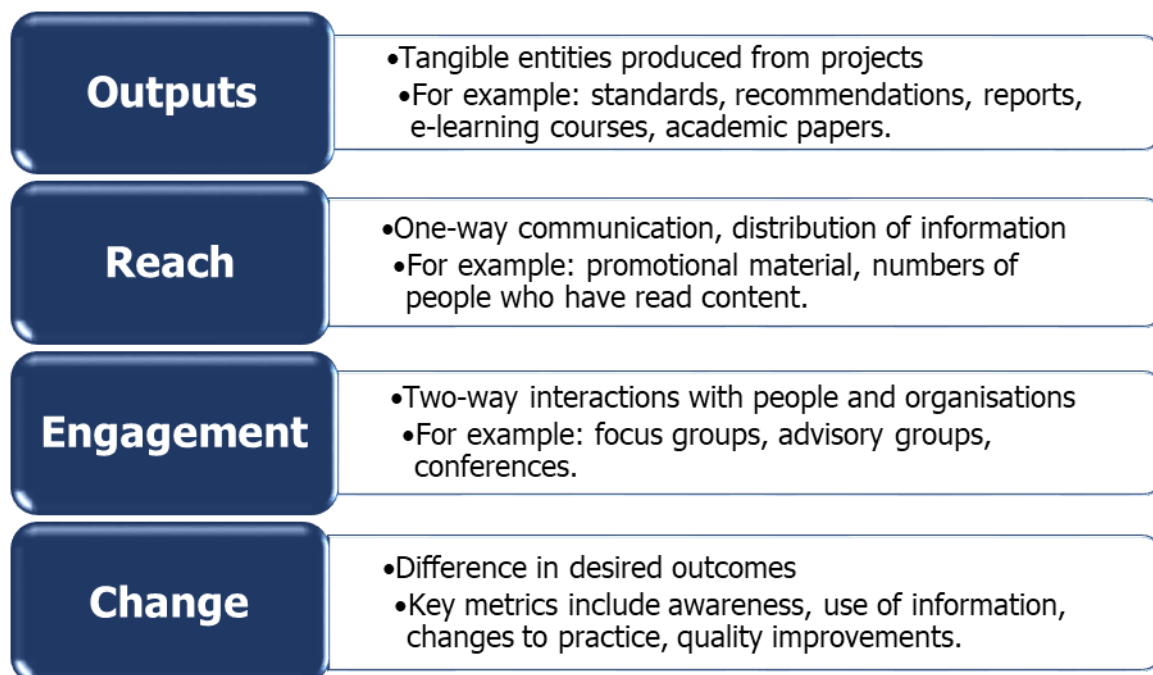
[§] The National Care Experience Programme Strategy (2022-2024) is available at:
https://yourexperience.ie/wp-content/uploads/2022/01/NCEP_Strategy_2022_2024-1.pdf

Introduction

Within the Health Information and Quality Authority's (HIQA's) Health Information and Standards (HIS) Directorate, we have committed to measuring the impact of the work that we do. Measuring and reporting on impact facilitates transparency, allows for the evaluation of our work and demonstrates the effectiveness of our work. It also supports the teams in identifying what worked well, thus informing future work and approaches.

Measuring the impact of the work of the HIS Directorate is difficult as most of our work is at a national level, meaning there is no group unaffected with which to compare outcomes. Many of the projects are expected to instigate change indirectly and slowly, sometimes over years. Furthermore, much of our work is intertwined with the work the Regulation Directorate within HIQA and with other organisations such as the Department of Health, the Department of Children, Equality, Disability, Integration and Youth, and the Health Service Executive (HSE). This can make it difficult to pinpoint the exact contribution of the HIS Directorate. As such, when we report on our impact we do so by creating a portfolio of indirect and direct measures of impact, and through collecting data over a prolonged period of time.

In 2018, we developed a strategic framework to support the measurement of impact (Knowledge sharing and impact strategic framework the HIS Directorate, 2018). The framework supports measuring impact through a combination of measures including: outputs generated, reach and engagement activities with stakeholders, and tangible changes.



Impact measurement involves identifying desired outcomes, embedding impact analytics within the lifecycle of projects and using this information to evaluate and report on whether a project has met its objectives, and the desired outcomes of the work have been achieved.

Purpose of this report

This report contains the findings of the impact evaluation of the work of the standards setting function, the health information function (quality and technical standards teams), and the National Care Experience Programme. Together, these comprise the Health Information and Standards Directorate. The purpose of the report is to demonstrate the effectiveness of our work, ensure transparency and highlight our successes.

This report documents the impact of our 2022 business plan objectives, as outlined in the HIQA Business Plan (2022).** It also reports on the impact of our work as observed during 2022. This is the fourth impact report by the HIS Directorate.

It is intended that the data collected as part of this report, along with the ongoing data collection in relation to the projects outlined herein and other projects, will help inform future work of the directorate and drive improved knowledge sharing and impact as part of the individual team strategies.

** The HIQA Business Plan (2022) is available at: <https://www.hiqa.ie/reports-and-publications/corporate-publication/business-plan-2022>

1. Standards Setting Function

1.1 About

National standards are a set of high-level outcomes that describe how services can achieve safe, quality, person-centred care and support. They are evidence-based and informed by engaging with those who use and provide our health and social care services.

Purpose of national standards

National standards, approved by the Minister for Health, in consultation with the Minister for Children, Equality, Disability, Integration and Youth, where appropriate, aim to promote progressive quality improvements in the care and support provided in health and social care services. The standards give a shared voice to the expectations of the public, people using services, service providers and staff working in health and social care services.

National standards:

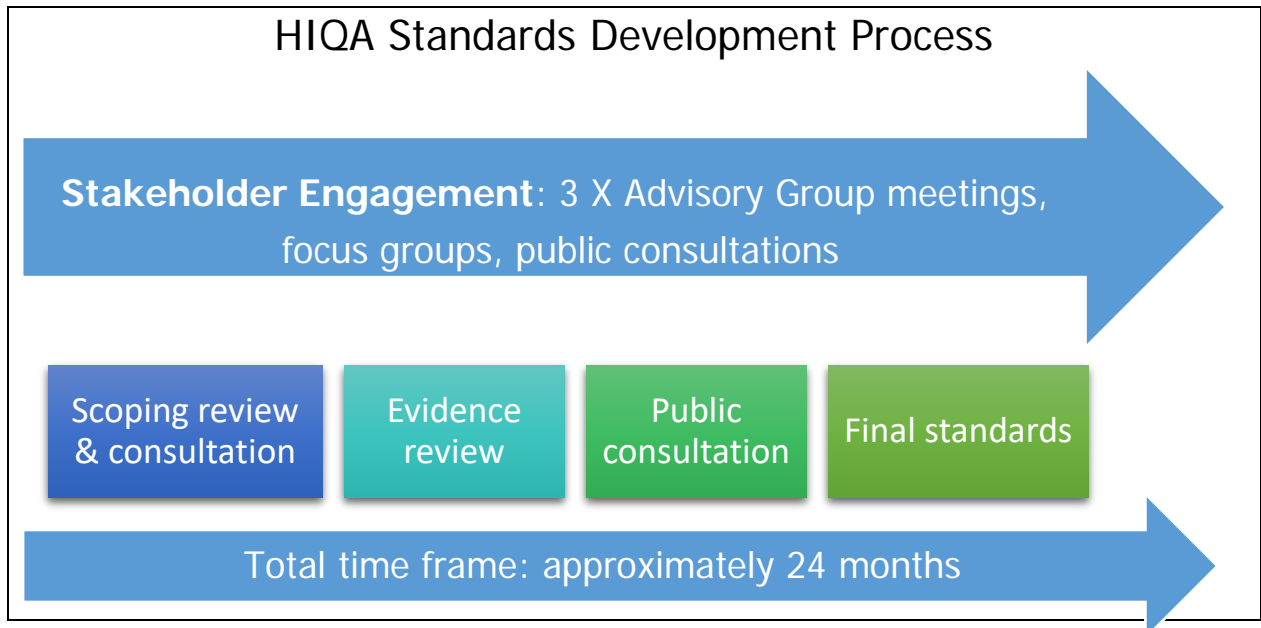
- Offer a common language to describe what high-quality, safe and reliable health and social care services look like.
- Are underpinned by a set of key principles which are used consistently across all national standards (a rights-based approach, responsiveness, safety and wellbeing, accountability, all working together to achieve person-centred care and support).
- Enable a person-centred approach, by focusing on outcomes for people using services and placing them at the centre of all that the service does.
- Can be used by people using services to understand what high-quality, safe health and social care should be and what they should expect from a well-run service.
- Create a basis for services to measure the quality and safety of a service's performance against the standards, by identifying strengths and highlighting areas for improvement.
- Promote day-to-day practice that is up to date, effective, and consistent, and based on the best available evidence.
- Provide a framework for service providers to be accountable to those using their services, the public and funding agencies, by setting out how they should organise, deliver and improve the care and support they provide.

When we finalise national standards, we also develop additional implementation support tools such as guides, leaflets or online learning modules to help staff

working in health and social care services to implement national standards or as a guide to making improvements in a particular area.

How we do it

Working in conjunction with a wide range of stakeholders, we develop standards using the following process.



Once the standards are finalised, implementation support tools are developed to optimise implementation of the standards into practice.

Our vision

To improve the quality and safety of health and social care services by setting national standards. Standards promote practice that is up to date, evidence-based, effective and consistent. Implementation support tools assist service providers and staff to understand and implement national standards in their setting.

Informed by our horizon scanning, consultation with key stakeholders and what we have learned from our work in recent years in evaluating the impact of our work,

there are four high-level areas for us to work in to support quality and safety in health and social care services in Ireland:

- Developing national standards
- Supporting implementation of standards
- Disseminating standards and implementation tools
- Being a trusted voice relating to health and social care standards.

2022 Objectives

- Develop and update standards based on need, prioritising the use of our resources and maximising the benefits to the health and social care system and the people who use them.
- Support implementation of standards in order to drive improvements and consistent interpretation within health and social care services.
- Enhance dissemination of standards and implementation support tools, increasing reach, understanding and application of standards.
- Establish a centre of excellence for the development of standards, implementation support tools and quality, safety and human rights in health and social care services.

Desired Outcomes

- Increased awareness and understanding of national standards, guidance, tools and resources developed by HIQA through communication and dissemination, promoting our work at conferences and through the publication of academic papers, in order to facilitate implementation.
- Support the development of a culture in health and social care services where the *National Standards for infection prevention and control in community services*, *National Standards for Adult Safeguarding and Guidance on a Human Rights-based Approach in Health and Social Care Services* are embedded into practice.
- Increased engagement with staff working in, and people with experience of using, health and social care services, to raise awareness of and to inform the development of National Standards for Children's Social Services, Overarching National Standards for the Care and Support of Children using Health and Social Care Services and National Standards for Home Support Services.

We have selected three key metrics to measure the change relating to our work:

- 1) Increased awareness
- 2) Level of reach and stakeholder involvement in the development of standards and implementation support tools
- 3) Cultural change.

1.2 2022 impact

Impact in numbers

- **63,965** online learning course completions.
- **One** set of Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services submitted for Ministerial approval in July 2022.
- **One** evidence review to inform the development of the National Standards for Homecare and Support Services published.
- **One** academic paper published entitled *Definitions of health and social care standards used internationally: A narrative review*.
- **Five** video clips recorded of people discussing what advocacy is about and their own experience with advocacy and **one** educational video on advocacy created.
- Met with **25** representatives of advocacy organisations, nursing home staff and relevant units in the HSE to discuss gaps in relation to advocacy in health and social care settings.
- **41** participants took part in **seven** focus groups to inform the development and content of the online learning course *The Fundamentals of Advocacy in Health and Social Care*.
- **49** responses received from participants testing the online learning course *The Fundamentals of Advocacy in Health and Social Care*.
- **8** stakeholder organisations and groups were members of the working group to inform the content and the structure of the online learning course *The Fundamentals of Advocacy in Health and Social Care*.
- **Six** parents and foster carers and **14** children aged five to 11 took part in **five** focus groups to discuss their experiences of children's social services and what an animation on children's services should cover.
- **15** stakeholder organisations and groups were members of the Advisory Group to inform the development of the Draft National Standards for Homecare and Support Services.
- **14** stakeholder organisations and groups were members of either the Children's Reference Group and or Advisory Group to inform the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services.
- **Ten** stakeholder organisations and groups were members of cross-sectoral Working Groups to inform the development of implementation tools and information resources in relation to the Draft National Standards for Children's Social Services.
- **One** workshop held at the Social Care Ireland Annual Conference entitled Advocacy in Health and Social Care.
- **One** workshop on rights-based care held with inspectors from HIQA's Disability Pillar.
- **Four** presentations to Disability Service Providers on the resources developed to support health and social care staff to apply a human rights-based approach.
- **Two** posters presented at the Department of Health National Patient Safety Office Annual Conference.
- **Two** oral presentations delivered at conferences on how children's lived experiences informed the development of the Draft National Standards for Children's Social Services.
- Total of **four** conference presentations, **two** poster presentations, **five** workshops, **three** webinar presentations, **three** lectures and **four** roadshow presentations.

Desired Outcome 1: Increased awareness and understanding

Under the desired outcome, our aim was to increase awareness and understanding of national standards, guidance, tools and resources developed by HIQA through communication and dissemination. We did this by promoting our work at conferences and through the publication of academic papers. Through this, we have had the following impact:

Outputs

- Four presentations were delivered at four separate stakeholder engagement events, held by HIQA Regulation's Disability Pillar. These presentations raised awareness of the *Guidance on a Human Rights-based Approach in Health and Social Care Services* and the broader suite of resources published to support health and social care staff to understand and apply this approach.
- One academic paper published in peer-reviewed journal, Definitions of health and social care standards used internationally: A narrative review. This review informed a standardised definition and purpose of health and social care standards for use across national standards.^{††}
- One evidence review to inform the National Standards for Homecare and Support Services published. This evidence review provides an overview of the current provision of homecare in Ireland and summarises international evidence to identify characteristics of good practices in homecare and support services and will be used to inform the development of national standards.
- Four conference presentations:
 - Factors that influence the implementation of health and social care standards: a systematic review and meta-summary.
 - Developing Draft National Standards for Children's Social Services informed by the lived experiences of children and young people (presented at two separate conferences).
 - Using implementation levers to translate evidence into practice.
- Two poster presentations:
 - Factors that influence the implementation of health and social care standards: a systematic review and meta-summary.
 - Supporting frontline health and social care staff to put advocacy into practice.

^{††} Kelly Y, O'Rourke N, Flynn R, Hegarty J, O'Connor L. Definitions of health and social care standards used internationally: a narrative review. *International Journal of Health Planning and Management*. 2022;1-13. Available from: <https://doi.org/10.1002/hpm.3573>

- One article published in the HSE National Office for Human Rights and Equality Policy newsletter Spring 2022 edition on the online learning course, Applying a Human Rights-based Approach in Health and Social Care: Putting National Standards into Practice and related tools. This aimed to support health and social care staff to put this approach into practice.
- One article by the Director of Health Information and Standards published in Social Care Professional Ireland magazine on embedding a human rights-based approach into everyday care, highlighting the online learning course and other tools to support health and social care staff to understand and apply a human rights-based approach.
- One article published in the European Social Network newsletter on the importance of evidence-based standards that are informed by deep and ongoing engagement both with people using health and social care services, and those involved in their design and delivery.
- One talk delivered to inspectors within the HIQA Disability Pillar on 'Translating a Human Rights-based Approach into Health and Social Care Practice' to raise awareness of the resources we have developed to support staff in health and social care services to understand and apply a rights-based approach to care.
- Delivered five workshops at the Social Care Ireland conference, Patient and Public Involvement summer school and evidence-based practice training courses.
- Delivered six lectures and webinars in universities, HSE Workplace Health and Wellbeing Unit, Age and Opportunity Bealtaine Festival and the Implementation Network of Ireland and Northern Ireland.

Reach

The evidence review to inform the development of National Standards for Homecare and Support Services in Ireland was downloaded 61 times from ResearchGate in 2022. ResearchGate is an online platform that is used to share research and connect with other national and international researchers.

Engagement

We developed an online learning course entitled *The Fundamentals of Advocacy in Health and Social Care* to improve knowledge and understanding of advocacy and to highlight the role of health and social care staff in relation to advocacy. To raise awareness of this work and to inform the content of the online learning course, the team facilitated a World Café-style workshop for social workers titled 'Supporting frontline health and social care staff to put advocacy into practice' at the Social Care Ireland Annual Conference. The workshop introduced participants to the background

of the project, some key definitions of advocacy and the process of developing an online learning module on advocacy. During the session, participants broke into groups and provided their feedback. It was a lively and interactive session that generated an informative discussion. The findings from this session were used to inform the development of the content and the structure of the online learning course.

During 2022, we continued to promote our work on the Draft National Standards for Children's Social Services by sharing with stakeholders what children and young people told us was important to them and the outcomes they expect when they are using services. We presented at the Social Care Ireland Conference in April 2022 and at the European Social Services Conference in June 2022 on how children's lived experiences informed the development of the standards.



Deirdre Connolly, Acting Standards Manager, presenting on how children's views and experience informed the Draft National Standards for Children's Social Services, European Social Services conference, Hamburg, June 2022.

We engaged with external organisations to share our learning and expertise. We met with the Swedish Standards Institute online to present HIQA's approach to developing national standards and our approach to supporting implementation of national standards into practice. We also presented on the work of the Standards Team to a European Social Service Network delegation from the Israeli Ministry of Welfare and Social Affairs.



The Standards Team meeting with a European Social Service Network delegation from the Israeli Ministry of Welfare and Social Affairs in Dublin.

We participated in four stakeholder engagement events held by HIQA Regulation's Disability Pillar in Dublin, Cork, Galway and Cavan, with a total attendance of 528 people. Attendees included registered providers, managers and persons in charge. At these events, members of the team gave presentations to raise awareness of the *Guidance on a Human Rights-based Approach in Health and Social Care Services* and provided information on resources we have published to support health and social care staff to understand and apply a human rights-based approach.

Change

Increased awareness

Awareness of national standards continues to rise. In 2022, there were 63,695 completions of the three online learning courses, bringing the total number of course completions since their launch to the end of 2022 to over 158,500. The number of completions shows the level of awareness of these resources, which we have

optimised through our use of HSeLanD^{‡‡} and social media. These online learning courses help build capacity, and promote sustained quality improvement within health and social care services. The evaluation of the online learning courses has also shown that participants now have a greater awareness and understanding of the standards and how to apply them in practice, with one participant stating:

"Simple and clear learning which is most informative, this course really put me thinking about how I can improve myself on safeguarding in my daily duties."

Greater use of social media, publication in a peer-reviewed journal (one paper), conference presentations (six), lectures (three), workshops (five), webinar presentations (three), Disability Provider roadshow presentations (four) and international collaborations (two) have also increased awareness of the national standards.

^{‡‡} HSeLanD is the Health Service Executive's (HSE) national online learning and development portal.

Desired Outcome 2: Supporting the development of a culture where standards and guidance are embedded in practice

Under the desired outcome, our aim was to support the development of a culture in health and social care services where the *National Standards for infection prevention and control in community services*, *National Standards for Adult Safeguarding* and *Guidance on a Human Rights-based Approach in Health and Social Care Services* are embedded into practice. Through this, we have had the following impact:

Outputs

- One online learning course developed on *The Fundamentals of Advocacy in Health and Social Care*. This course was developed in response to a recommendation from the COVID-19 Nursing Home Expert Panel Report published in 2020 for HIQA to highlight and promote independent advocacy services available to nursing home residents. The online course aims to help health and social care staff implement the advocacy elements of the *National Standards for Adult Safeguarding*, and the *Guidance on Human Rights-Based Approach in Health and Social Care Services*.
- Five video clips recorded of people discussing what advocacy is and their own experience with advocacy for inclusion in the advocacy online learning course. The participants in these videos were:
 - an advocacy expert
 - a patient representative
 - a nursing home resident
 - a nursing home activities manager
 - a nursing home senior care assistant.
- One 11 minute educational video, compiling the five video clips on advocacy, was created, which will be made available on the HIQA website and YouTube.



Reach

In 2022, we continued to promote our popular online learning courses, to assist service providers and staff to understand and implement national standards, and

promote sustained quality improvement within health and social care services. The online learning courses on infection prevention and control, adult safeguarding and a rights-based care approach in health and social care assist service providers and staff to understand and implement national standards in practice.

Please see Table 1 below for the number of people who have completed each of these courses.

Table 1: Online learning course completions

Online learning course	Completions in 2022	Completions since launch
Infection prevention and control	16,269	49,209
Adult Safeguarding	13,074	27,976
Human-rights based care	34,622	81,397
Total	63,965	158,582

The online learning course to support the *Guidance on a Human Rights-based Approach in Health and Social Care Services* includes four modules:

- Module 1: Introduction to Human Rights in Health and Social Care
- Module 2: Role of Good Communication in upholding Human Rights
- Module 3: Putting People at the Centre of Decision-Making
- Module 4: Positive Risk-Taking.

See Table 2 below to view the number of people who have completed each of the course modules on a human rights-based approach to care.

Table 2: Human rights-based approach module completions

Human rights-based approach modules	Completions in 2022	Completions since launch in 2021
Module 1	9,724	25,316
Module 2	8,567	21,319
Module 3	8,009	17,967
Module 4	8,322	16,795
Total	34,622	81,397

All of the above courses are available to complete on HSeLanD and the HIQA website.

In terms of the geographical reach of the courses, the majority of respondents who completed the module evaluation surveys did so from Ireland, but the surveys were also completed by participants in other countries including:

- India – 76 completed the course on a Human Rights-Based Approach, 90 completed the course on Safeguarding
- Israel – 262 completed the course in Infection Prevention and Control
- Philippines – 34 completed the course on a Human Rights-Based Approach, 15 completed the course on Safeguarding
- United Kingdom – 101 completed the course on a Human Rights-Based Approach, 31 completed the course on Safeguarding.

HIQA gained international visibility for the online learning courses, securing a nomination for the annual European Social Services Award in the area of Workforce Development. Our submission, entitled *Online Learning Courses to support Health and Social Care Staff to implement National Standards*, was successfully shortlisted for inclusion at the award ceremony that took place in November 2022.



Davina Swan, Shauna McCarthy and Judy Gannon at the European Social Services Award Ceremony.

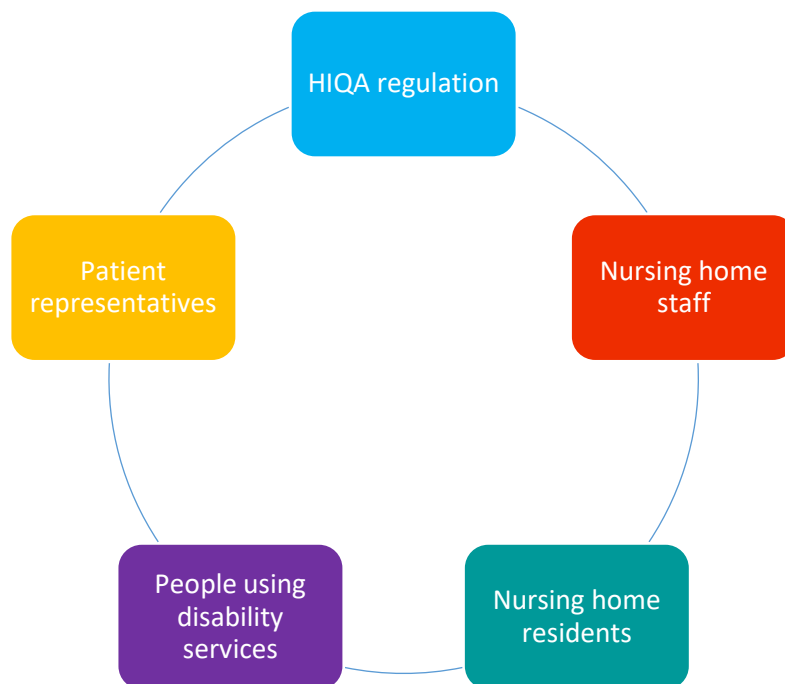
Engagement

In developing the online learning course, *The Fundamentals of Advocacy in Health and Social Care*, we held 16 one-to-one meetings with 25 participants from advocacy organisations, nursing home staff and areas of the HSE. We held seven focus groups with 41 participants (see Figure 1). These meetings and focus groups provided an opportunity for participants and people using services to inform and shape the content of the course.



Members of the Inclusion Ireland Midlands Conversation group attending a focus group to inform the content of the advocacy online learning course.

Figure 1: Focus group participant groups that informed the content of the advocacy online learning course.



We also established a working group of eight members to support and assist us in the development of the course, to inform its content and ensure it was fit for purpose. Organisations represented on the working group include the National Advocacy Service, the Patient Advocacy Service, SAGE Advocacy, Safeguarding Ireland, the HSE, Alliance of Age Sector NGOs, and Nursing Homes Ireland. We held two meetings with group members and worked closely with them throughout the project, gathering their feedback at various stages of the project. Based on this

feedback and the engagements we had with stakeholders, we developed the content and format of the course.

The draft course was circulated for user testing. We collated feedback from 49 participants who were involved in the initial round of focus groups and included nursing home staff, nursing home residents, advocacy organisations, patient representatives and members of staff from HIQA's Regulation and National Care Experience Programme teams. Participants provided feedback on:

- Course content
- Structure
- Length of the course
- What they would like added to the course
- What they would like removed from the course, if anything.

The feedback was applied to the course to enhance features, making it more interactive and user friendly for the learner.

Members of the team delivered a lecture to students on the MSc in Healthcare Infection course in Trinity College Dublin in December 2022. The lecture provided information on the *National Standards for infection prevention and control in community services*, a wider overview of HIQA and HIQA's work in infection prevention and control.

Members of the team delivered a workshop at the three-day training course on evidence-based practice, in collaboration with the HSE, Dublin City University (DCU) and University College Cork (UCC).

Change

Increased awareness

In 2022, there were almost 64,000 completions of the three online learning course on HSeLanD. At the end of each course, we include an evaluation to gather feedback on the course and to assess its impact on learners and how they intend to change or improve their practice.



People who completed online learning courses to support health and social care staff implement the *National Standards for infection prevention and control in community services* course in 2022 stated:

"This course was very informative and I felt very reassured that so many things are taken into consideration, right down to how fabric chairs and carpet in a waiting room are not easy to keep clean and therefore choosing different furniture here would make it easier to keep this area infection free."

"The course gave me a better insight to the use and misuse of antibiotics and the stats of the use of antibiotics in Ireland."



In 2022, people who completed the online learning course to support people who work in health and social care services to implement the *National Standards for Adult Safeguarding* in their service stated:

"Simple and clear learning which is most informative, this course really put me thinking about how I can improve myself on safeguarding in my daily duties."

"I would change my practice in areas I know I was lacking knowledge and apply what I have learned on this course in my practice."

"It helped me to connect practice to policy. It validated what I do in practice and learn the principles behind it and more."

"I have learned how I haven't been doing something correctly, not wrong but I can improve my technique."



In 2022, those who completed the course modules to support the *Guidance on a Human Rights-based Approach in Health and Social Care Services* stated:

Module 1: Introduction to Human Rights in Health and Social Care

"It is really an eye-opener. It has changed my perspective on human rights and health and social care work."

"I find the module very insightful, understandable and realistic. I can easily relate and apply in my daily practice."

Module 2: Role of Good Communication in upholding Human Rights

"Excellent module. That showed me I am on the right path how I am working. But also gave me more ideas that I can bring into my practice to be a better practitioner to the residents under my care."

"This module helped me refresh my skills. It made me aware of the importance of delivering information in an effective way to people who may have various communication difficulties."

Module 3: Putting People at the Centre of Decision-Making

"I found this module beneficial to me in my role as CNM2 Intellectual Disability Services. I feel very strongly about residents' rights and will be recommending to my line manager that training is completed by all staff in our area."

"This course creates such an awareness of empowering people with as much information as possible, to help them make both very simple and huge decisions about their own lives."

Module 4: Positive Risk-Taking

"I found it very informative and gave tools to help me improve the way I support the individual I work with."

"The detail of how the service followed up to support the person is very practical and applicable for the services where this support is mostly required, individuals with intellectual disability and cognitive impairment."

"This course is very helpful and gives you a lot of information as to how to support clients and how important it is to support them to live the life of their choosing."

"All modules have given me a better understanding of the importance of promoting human rights in my workplace."

Desired Outcome 3: Increased engagement with staff and people using services

Under the desired outcome, our aim was to increase engagement with staff working in health and social care services, and also to engage with people with experience of using these services. We wanted to raise awareness about and to inform the development of **National Standards for Children’s Social Services, Overarching National Standards for the Care and Support of Children using Health and Social Care Services** and **National Standards for Homecare and Support Services**. Through this, we have had the following impact:

Outputs

- Draft **Overarching National Standards for the Care and Support of Children using Health and Social Care Services** were developed together with the Mental Health Commission (MHC) and submitted for Ministerial approval in July 2022. These standards cover all health and social care services providing care and support to children and is the first time that a set of national standards has been developed that is focused on the needs of all children across health and social care services. Written in the voice of the child using the service, the standards set out what outcomes a child should expect and what a service needs to do to achieve these outcomes.
- Draft **National Standards for Homecare and Support Services** developed.
- Draft easy-to-read version of the **National Standards for Homecare and Support Services** developed.
- Draft video animation to support the **Draft National Standards for Children’s Social Services** developed.

Reach

Through the use of HSeLanD, we have expanded our reach and potential audience for our online learning programmes. We are also developing an online Learning and Resources hub on the HIQA website to reach a wider audience and profile HIQA as a source of educational material for health and social care staff. We have expanded our knowledge translation mechanisms to include use of sign language and easy-to-read versions of standards for consultation to make our processes more accessible.

Engagement

Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services

These standards aim to drive improvements in the quality and safety of care and support for all children using health and social care services, and to support

organisations and services to work together in an integrated and collaborative way to improve the experiences and outcomes of children and their families.

The standards are informed by a review of national and international literature on children’s health and social care services, as well as extensive engagement with children, young people, families, carers, advocates, staff and policy-makers at every stage of the standards development process, drawing on their expertise and experience to inform the development of the standards.

In 2022, we held the final meetings of the Standards Advisory Group and Children’s Reference Group to discuss the draft standards, before the draft standards were finalised and submitted for Ministerial approval. The Advisory Group is comprised of 15 representatives from a diverse range of stakeholders, including government departments, statutory bodies, advocacy groups, and regulatory bodies (Table 3).

Table 3: Members of the Overarching Children’s Standards Advisory Group

Overarching Children’s Standards Advisory Group
<ul style="list-style-type: none"> ➤ Children’s Health Ireland ➤ Children’s Rights Alliance ➤ Department of Children, Equality, Disability, Integration and Youth ➤ Department of Health ➤ HIQA’s Regulation Directorate ➤ HSE ➤ Mental Health Commission’s Regulatory Team ➤ National Disability Authority ➤ Representatives from the Children’s Reference Group ➤ The Child and Family Agency (Tusla)

The Children’s Reference Group comprises young people and family members with experience of using a range of health and social care services for children. The group gave insight into the issues that are important to children and families using services, so that this was reflected in the content of the standards. It consists of seven people from a range of nominating organisations (Table 4).

Table 4: Members of the Children’s Reference Group

Children’s Reference Group
<ul style="list-style-type: none"> ➤ Children’s Health Ireland ➤ Empowering People in Care ➤ Mental Health Commission ➤ National Patient Forum

- Patients for Patient Safety Ireland
- RehabCare

National Standards for Homecare and Support Services

In 2022, we conducted two additional focus groups to inform the national standards for homecare and support. In the first focus group, we met with a group of self-advocates which was coordinated by Inclusion Ireland. In the second focus group we met with a representative from the Irish Deaf Society which was facilitated by an Irish Sign Language (ISL) interpreter. This means that over the course of the home support standards project to date, there have been 24 focus groups held with 129 participants.

Feedback from participants in these focus groups and the Advisory Group identified the need for an easy-to-read version of the standards to be developed and made available as part of the public consultation. This will make the standards more accessible and enable greater engagement and feedback from all stakeholders. In response to this, the project team has developed a draft easy-to-read version of the standards. A group of self-advocates (co-ordinated by Inclusion Ireland) have reviewed these easy-to-read standards and an accompanying easy-to-read consultation form. Their feedback has been used to improve these documents to ensure accessibility.

The findings from the 24 focus groups, along with the 182 submissions to the public-scoping consultation and findings from the evidence review were used by the Standards Team to inform the development of a draft set of standards for homecare and support services. These draft standards were presented to the Homecare and Support Standards Advisory Group in March 2022 for their feedback. The Advisory Group is made up of 20 members as outlined below in Table 5. Throughout 2022, the project team, alongside our colleagues in Regulation, continued to engage and work closely with the Department of Health to support the development of the primary legislation and regulations for home support.

Table 5: Members of the Advisory Group to inform the development of National Standards for Homecare and Support Services

Homecare and Support Standards Advisory Group Members
<ul style="list-style-type: none">➤ Advocacy groups➤ CORU (Health and Social Care Professionals Council)➤ Department of Children, Equality, Disability, Integration and Youth Affairs➤ Department of Health➤ Family and informal carer representative

- Home support service providers
- Home support worker
- HIQA Regulation Directorate
- HSE
- Irish College of General Practitioners
- Mental Health Commission
- National Disability Authority
- National Health and Social Care Professions Office
- Office of the Ombudsman
- People who use home support services

Draft National Standards for Children’s Social Services

We have continued to engage extensively with key stakeholders to develop additional tools and materials to support services to fully implement the Draft National Standards for Children’s Social Services. We met with Tusla and the Department of Children, Equality, Disability, Integration and Youth to discuss requirements for these additional tools and materials, and it was agreed that HIQA would work with key stakeholders to collaboratively develop tools to support effective communication and information-sharing. To ensure that any tools developed are relevant and fit for purpose, we established a high-level Steering Group, with senior representatives from Tusla and the Children’s Rights Alliance, to oversee this collaborative project. Four meetings of the Steering Group were held in 2022.

We also established a cross-sectoral Working Group to co-produce the tools and further ensure these tools are assistive and will be adopted by frontline staff. Members of the Working Group are outlined in Table 6.

Three Working Group meetings were held in 2022. During these initial exploratory meetings, the Working Group co-produced a charter to guide the collaborative project. The charter sets out the purpose, principles, practices and processes of the Working Group, as agreed by the members and will guide the work over 2023. The Working Group also identified the priority areas that the group can address in terms of improving communication and information sharing. There has been strong engagement and support from all members towards this collaborative approach for the development of the tool.

Table 6: Members of the Working Group to inform the development of communication and information-sharing tools to support the implementation of Draft National Standards for Children’s Social Services Group

Working Group to inform the development of Communication and Information-Sharing Tools
<ul style="list-style-type: none">➤ Foster carers➤ HIQA’s Children’s Regulation team➤ Irish Association for Social Care Managers➤ Irish Association of Social Workers➤ Irish Foster Care Association➤ Tusla➤ Young people with experience of children’s social services

Throughout 2022, we have been working collaboratively with key stakeholders to develop a video animation for young children to help support them understand what the standards mean for them, as they journey through children’s social services. We established a cross-sectoral Working Group to collaboratively develop the video animation. This Working Group comprises representatives from HIQA’s Children’s Regulation Team, HIQA’s Communication and Stakeholder Engagement Team, Tusla, Barnardos, and Empowering People in Care (EPIC). We held two collaborative Working Group meetings in 2022 to agree appropriate methods to engage with key stakeholders including children and parents with experience of children’s social services and foster carers, to develop the content for the video animation. Facilitated by Barnardos, we engaged with 14 children aged five to 11 and three parents to hear their views on what is important to them and what should be in the video. We also held a focus group with three foster carers to hear what they thought the video should cover. Feedback from the cross-sectoral Working Group and the focus groups informed the development of a draft video animation. We are also using the feedback to inform the development of a flyer which will accompany the video animation as a further resource for young children who are being cared for and supported by children’s social services.

1.3 Next Steps

In order to address the areas identified through our standards prioritisation process and the recommendations of the COVID-19 Expert Panel for Nursing Homes, key areas of work for 2023 include:

- Completion, launch and dissemination of the advocacy online learning course *The Fundamentals of Advocacy in Health and Social Care*.
- Promote the online learning course *The Fundamentals of Advocacy in Health and Social Care* to support implementation of National Standards and optimise access and reach.
- Conduct a public consultation on the Draft National Standards for Homecare and Support Services and an easy-to-read version of the standards. Feedback from the public consultation and Advisory Group will be used to finalise the national standards which will then be submitted to the Minister for approval.
- Commence updating the suite of existing national standards in accordance with prioritisation process.
- Develop a process for updating existing implementation support tools and guidance.

We will support services to implement the Draft National Standards for Children's Social Services, and will continue to work collaboratively with our cross-sectoral Working Group to co-produce a user-friendly tool(s) to support Tusla staff to communicate and share information effectively with children, families and foster carers. We will also continue the collaborative development of the video animation and accompanying flyer which will help young children understand what the standards mean for them as they journey through social services. These tools and resources will be published on the HIQA website, subject to the approval of the standards.

From the outset of the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, it was recognised that additional supports would be required to assist services to fully implement the standards. To this end, throughout the standards development process we asked stakeholders what was needed to support services and staff to implement the standards into practice in their work settings, for example, any additional tools and materials. Respondents provided a wide range of suggestions in this area. In order to support services to put the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services into practice, we will work collaboratively with stakeholders in 2023 to develop implementation support tools that will have the greatest impact, including:

- a paper outlining key considerations for policy development in the area of children's health and social care services
- a guide to support health and social care services to implement national standards
- materials for children of different ages, needs and abilities, to help them to understand what the standards mean for them.

We will conduct a Learning Impact Study to measure the impact of the advocacy online learning course, *The Fundamentals of Advocacy in Health and Social Care*. This study will enable us to assess if the course is increasing knowledge and understanding of advocacy among health and social care staff and if it is creating positive change to practice. The study will be conducted in 2023 and will include surveys, focus groups and interviews with health and social care staff who have completed the course, and members of staff from HIQA's Regulation Team. The findings from the study will be used to ensure the course is fit for purpose and will inform the development of other online learning courses in the future.

2. Health Information Function

2.1 About

The Health Information Function works in three high-level areas, to support the national eHealth agenda. These include:

- Evidence to inform national health information policy
- Developing national standards and guidance
- Reviewing against national standards.

What we do

We work collaboratively, using best available evidence, to develop recommendations to support decision-making for the Irish eHealth and health information landscape. We drive improvements in the quality of data and information by developing national standards and guidance and assessing compliance with these national standards.

Why we do it

HIQA works independently to gather the best available evidence to inform policy, legislation and service provision in the area of health information. The ultimate aim is to have quality data and information to support individual care, planning and management of services, policy-making and research.

How we do it

Working collaboratively with key stakeholders, we gather national and international evidence on best practice. We consult with experts, stakeholders, service providers and service users. We report on the implementation of our national standards and guidance, and support organisations to improve health information.

Our vision

To build and consolidate our position as a centre of excellence to support and facilitate decision-making for national eHealth and health information programmes and to drive the collection, use and sharing of high-quality data across health and social care to ensure more efficient services, more effective care and better outcomes.

Better data, Better decisions, Better care

2022 Objectives

- Finalise recommendations for a health information standards model for Ireland's health information system to support the delivery of health and social care services in Ireland.
- Continue to develop recommendations on the implementation of a national portal for health and social care.
- Finalise recommendations on the ICT enablement of older persons' services.
- Commence the review of Health Identifiers eHealth service.
- Engage with key stakeholders to advance the recommendations set out in The Need to Reform Ireland's National Health Information System and inform national health information policy.
- Participate in international collaborations to facilitate shared learning in Health Information, Standards, National Care Experience Programme, and Health Technology Assessment, including supporting the implementation of the forthcoming EC Regulation on HTA.
- Complete a review to assess compliance with information management standards for national waiting list data within the HSE.
- Publish recommendations on a model for the collection, use and sharing of health information in Ireland.
- Publish revised Information Management Standards for National health and social care Data Collections.
- Publish revised Catalogue of national health and social care data collections in Ireland.

Desired outcomes

- Provide thought leadership in defining the health information landscape in Ireland by developing recommendations and engagement with stakeholders.
- Support the sharing of patient information in the health and social care sector.
- Progress the implementation of national priorities within the eHealth landscape.
- Support those working in health and social care to improve the quality of health information to underpin the delivery of safe care, informed decision-making, monitoring and planning.

We have selected four key metrics in order to measure the change relating to our work:

- Evidence of improvements in practice

- Increased awareness
- Involvement of key national stakeholders in development of our work
- Adoption of recommendations and standards.

2.2 2022 impact

Impact in Numbers

- There were **40,403** unique page visits to our Health Information content.
- **Three** reports published in relation to the Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland.
- **Two** examples published of the challenges and opportunities in the area of health information in Ireland.
- **Three** reports published in relation to the Recommendations on the ICT enablement of older persons' services was submitted to the Minister for Health and published on our website.
- **Two** persona developed to explain what the Recommendations on the ICT enablement of older persons' services will mean for patients and health and social care professionals.
- **Four** videos, recorded by the Director of Health Information and Standards, promoting the position paper on the need to reform Ireland's national health information system shared across HIQA's social media accounts.
- **More than 9 million referrals** were sent electronically between medical practitioners and hospitals in compliance with the *National Standards for Messaging and eReferrals*.
- **51** submissions received as part of the public consultation on the draft National Standards for Information Management in Health and Social Care.
- **29** submissions received in relation to the public consultation on draft recommendations on a Model for Health Information Standards.
- **23** submissions received in relation to the public consultation on draft recommendations on the ICT enablement of older persons' services
- **32** stakeholder organisations and groups were members of the Advisory Group in the development of recommendations on ICT enablement of older persons' services.
- **Five** Irish and **two** international stakeholder organisations engaged in the development of Recommendations for Implementation of a National Portal for Health and Social Care.
- **39** professionals took part in **four** focus groups in relation to their views on the draft National Standards for Information Management in Health and Social Care.
- **42** professionals involved in the management of acute and community waiting list in the HSE were interviewed as part of a review of information practices for national waiting list data within the HSE.
- **Eight** interviews held with key national stakeholders within the HSE and the National Treatment Purchase Fund (NTPF) as part of a review of information practices for national waiting list data within the HSE.
- **1,075** people completed Introduction to Data Quality e-learning module; **98%** reported that they feel they have a better understanding of data quality, having completed the module.
- **300** people completed Developing a Data Quality Framework e-learning module; **99%** reported that they feel they have a better understanding of data quality, having completed the module.
- Participated in **one** panel discussion at the Smart Health Summit 2022.
- Participated in **two** EU-level reviews: Joint Action Towards the European Health Data Space (TEHDAS) review assessing national health data management systems and Population Health Information Research Infrastructure (PHIRI) review assessing health information systems that monitor the wider effects of COVID-19 on population health.
- **Four** posters presented at the National Patient Safety Conference.
- **Two** academic papers published in peer-reviewed journals.
- **Three** lectures delivered to students completing Public Health and Digital Health Masters and to those completing the SPHeRE PhD programme.

Desired Outcome 1: Providing thought leadership

Under the desired outcome of providing thought leadership in defining the health information landscape in Ireland by developing recommendations and engagement with stakeholders, we have had the following impact:

Outputs

- Three reports published in relation to the Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland:
 - Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland.
 - Summary of Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland.
 - Summary of Stakeholder Involvement for key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland.
- Three knowledge sharing resources published in relation to the Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland:
 - Two examples of challenges and opportunities for health information.
 - One infographic displaying the key messages for policy.
- Four separate videos recorded by the Director of Health Information and Standards promoting the Position paper on the need to reform Ireland's national health information system shared across HIQA's social media accounts.
- Draft recommendations on a model for health information standards to support the delivery of health and social care services in Ireland published for public consultation.
- One video recorded by the Director of Health Information and Standards promoting the draft recommendations on a model for health information standards shared across HIQA's social media accounts.

- One academic paper published in peer-reviewed journal: 'What influences a person's willingness to share health information for both direct care and uses beyond direct care? Findings from a focus group study in Ireland'. This examines the factors that influence the Irish public's willingness to share their health information using data collected as part of a national public engagement.^{§§}
- Four poster presentations at the National Patient Safety Office Annual Conference:
 - Engaging the Irish public to improve and enhance the collection, use and sharing of health information in Ireland.
 - Enhancing quality health systems using quality data sources
 - Four key policy considerations essential to improve health information and support better patient safety and care in Ireland.
 - Working together to improve patient safety by driving improvements in the management, quality and use of data and information for the National Incident Management System within the HSE.

Reach

Position paper on the need to reform Ireland's national Health Information System to support the delivery of health and social care services

In October 2021, HIQA published a landmark position paper on the need to reform Ireland's health information system. To bring this message to a wider audience, the team also developed and published four videos, in which the Director discussed the three key enablers and the reforms needed in governance and leadership, national strategy and legislation. Table 7 outlines the reach of these four videos across HIQA's social media accounts.

Table 7: Reach achieved for four videos published in relation to the position paper.

Channel	Position Paper videos (Oct 2021)
Website downloads	313
YouTube views	67
Facebook people	700

^{§§} Flaherty SJ, Duggan C, O'Connor L, Foley B, Flynn R. What influences a person's willingness to share health information for both direct care and uses beyond direct care? Findings from a focus group study in Ireland. *HRB Open Research*. 2022 Oct 24; 5:36. Available from: <https://hrbopenresearch.org/articles/5-36>

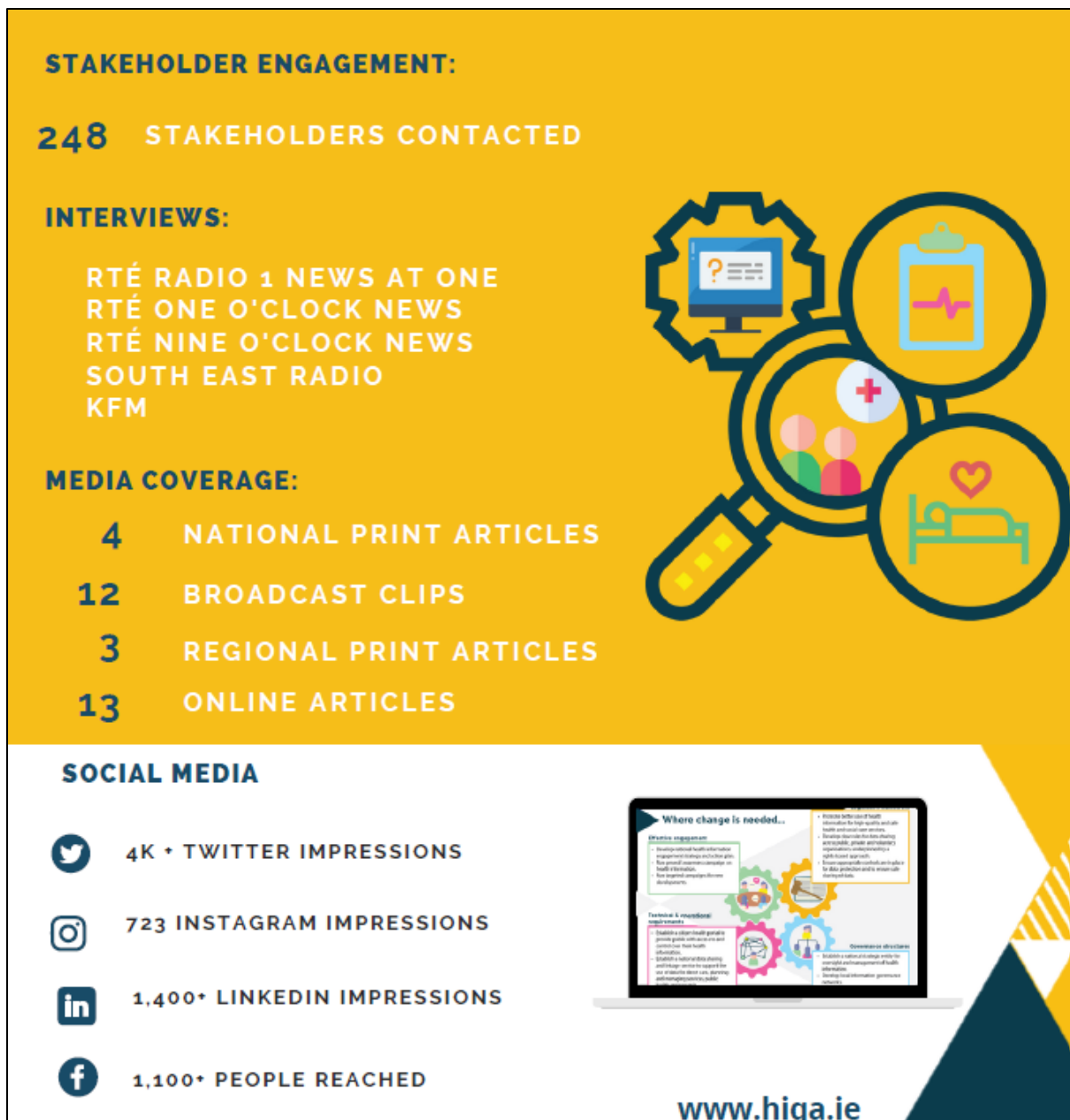
Instagram impressions	800
LinkedIn impressions	15,000+
Twitter impressions	7,000+

Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland

The findings of the Key considerations report were publicised on the HIQA website and social media outlets, and had 267 unique downloads in 2022. On the day of publication, over 200 stakeholders were notified of the publication of the report, via email, including senior managers in the HSE, Department of Health, Department of Public Expenditure and Reform, hospital groups, community health care organisations, patient advocacy groups, professional representative bodies and major national data collections.

The press release was sent to national and regional broadcast outlets and print news desks across the country, as well as targeted emails to the medical press. In the two weeks following publication, this resulted in:

- Two TV interviews, including RTÉ One O’Clock News and RTÉ Nine O’Clock News
- Three radio interviews, including RTÉ Radio 1 News at One, South East Radio and KFM
- 13 online articles
- Four national print articles
- Three regional print articles
- Twelve broadcast clips
- Over 1,100 people reached on Facebook
- 723 Instagram impressions
- Over 1,400 LinkedIn impressions
- Over 4,000 Twitter impressions
- 927 unique page views of the webpage for the Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland.



Recommendations on a model for health information standards to support the delivery of health and social care services in Ireland

Health Information is developing recommendations on a model for health information standards and, as part of that process, published a draft for public consultation, together with the international evidence base (Best Practice Review). Both documents were promoted widely on HIQA's social media channels and more than 150 organisations were invited directly, by email to participate.

Engagement

Position paper on the need to reform Ireland's national Health Information System to support the delivery of health and social care services

In order to advance the recommendations set out in the position paper, we engaged with key stakeholders in the Department of Health, including the Research and Development, Health Analytics and Health Information Structure Divisions. We also met with key senior representatives from the HSE, such as the Chief Clinical Information Officer, Chief Information Officer, Chief Strategy Officer and the National Clinical Information Officer for Nursing and Midwifery.

Key considerations to inform policy for the collection, use and sharing of health and social care information

At the Smart Health Summit 2022, we were invited to take part in a panel discussion entitled "Getting the Basics in place - what are the key enablers needed to drive improvements in eHealth and health information?" Our Health Information Quality Manager spoke about our work in health information, focusing on the key considerations to inform policy for the collection, use and sharing of health information. Members of the team presented their work at the National Patient Safety Office Annual Conference where they presented posters on engaging the Irish public to improve and enhance the collection, use and sharing of health information in Ireland, and on four key policy considerations essential to improve health information and support better patient safety and care in Ireland.



Dr Barbara Foley, Health Information Quality Manager, discussed the key considerations as part of a panel discussion on the key enablers needed to drive improvements in eHealth and health information at the Smart Health Summit in Dublin in September 2022.

We held one meeting of the Advisory Group in 2022. The organisations represented on the Advisory Group are detailed in Table 8.

Table 8: Members of the Advisory Group for the Key considerations to inform health information policy

Advisory Group: Key considerations to inform policy for the collection, use and sharing of health and social care information
<ul style="list-style-type: none">➤ Central Statistics Office➤ College of Psychiatrists of Ireland➤ Department of Health➤ Health Informatics Society of Ireland (HISI)➤ Health Information Systems Research Centre, UCC➤ Health Research Board➤ HSE – Office of the Chief Information Officer; Operational Performance & Integration➤ Institute of Community Health Nursing➤ Irish College of General Practitioners➤ Irish Pharmacy Union

- Irish Platform for Patients' Organisations, Science and Industry (IPPOSI)
- National Patient Forum
- Nursing and Midwifery Board of Ireland
- Royal College of Surgeons Ireland
- Tusla

We received 32 responses as part of the public consultation for the Key considerations to inform policy for the collection, use and sharing of health and social care information. Eight responses were received from members of the public and health and social care professionals. We received 24 responses from a range of organisations, including health and social care professional representative organisations, national data collections, human rights groups, health researchers, patient advocacy groups, health and social care service providers, and the HSE.

As part of the public consultation, we also engaged with national stakeholders with specific expertise in this area, including the Central Statistics Office, the Data Access, Storage, Sharing and Linkage (DASSL) group, Health Research Board, Tusla, and representatives from the HSE, including those in the area of eHealth, data protection and strategy and planning.

Recommendations on a model for health information standards to support the delivery of health and social care services in Ireland

During the six-week public consultation (June to August 2022), 29 responses were received. Nine responses were from individuals, while the remaining 20 came from: health and social care professional representative organisations, national data collections, national regulatory bodies, health researchers, advocacy groups, health and social care service providers, the Department of Public Expenditure, and the HSE.

As part of the public consultation we engaged with National Patient Forum, Health Information Society Ireland, academics in UCC and Trinity College Dublin (TCD), HSE CHO Digital Health Managers, HSE eHealth Directors, and stakeholders in the Department of Health, the HSE and the National Standards Authority Ireland.

During the development of Recommendations on a model for health information standards, we also convened a special Advisory Group with representatives from the Department of Health, the patient representative organisations, professional representative organisations, as well senior technical leaders in the HSE and other stakeholders.



Sepideh Hooshafza attending the National Patient Safety Office Annual Conference where she presented her poster on enhancing quality health systems using quality data sources.

EU reviews

We participated in two EU-level reviews:

- Joint Action Towards the European Health Data Space (TEHDAS) review which assessed the state of play of health data management systems at a national level
- Population Health Information Research Infrastructure (PHIRI) review which assessed the state of play of European countries' health information systems that monitor the wider effects of COVID-19 on population health.

For each review, we provided input through presenting to the assessment team, participating in semi-structured interviews, participating in multi-stakeholder engagement meetings and providing feedback on draft reports.

Change

Increased awareness

Our work on the Key Considerations report and the position paper has raised awareness of important policy considerations in the area of health information and influenced key policy decisions in this regard. The Department of Health is currently revising and updating the national eHealth Strategy, which was recommended in the position paper as a key strategic element of reforming Ireland's health information system. Both the Key Considerations report and the position paper highlighted the need for a legislative framework specific to health information. In April 2022, initial plans for the Health Information legislation, announced by the Minister for Health, show alignment with recommendations from our work, including the appointment of a National Health Information Guardian, who will be an independent champion for the public in how the health system intends to use their health information. The

plans also signal the introduction of a National Health Information Centre with clearly specified governance rules in relation to the collection and processing of health information for population health purposes and research and innovation.

Desired Outcome 2: Supporting the sharing of patient information

Under the desired outcome of supporting the sharing of patient information in the health and social care sector, we have had the following impact:

Engagement

Recommendations on the implementation of a national portal for health and social care

As part of the evidence-gathering phase to inform the development of recommendations, we engaged with national and international stakeholders from organisations that have developed portals or made advances in the area. We met with Maccabi Healthcare Services from Israel, Health and Social Care Northern Ireland, and representatives from Beth Israel Deaconess Medical Center/Harvard Medical School, and the University of Manchester. In Ireland, we met with representatives from the Office of the Chief Information Officer at the HSE, private hospital providers, digital health developers, and academics.

Feedback received as part of this engagement process was to identify what a portal would mean to the public and health and social care professionals. Therefore, a national engagement is being undertaken to inform the development of purposeful digital health systems that meet the needs of the public and health and social care professionals.

The National Engagement on Digital Health and Social Care is a collaboration between HIQA, the Department of Health, the HSE, and patient representatives. A Steering Group was convened and two meetings were held in 2022. Members of the Steering Group were engaged to inform the aims, objectives, and project governance, and also to inform the themes for the research being conducted. The members are detailed in Table 9.

Table 9: Members of the Steering Group for the National Engagement on Digital Health and Social Care

Steering Group: National Engagement on Digital Health and Social Care
➤ Department of Health - Health Infrastructure Division
➤ Department of Health - Research & Development and Health Analytics Division
➤ HSE – eHealth and Disruptive Technologies
➤ HSE – Office of Chief Clinical Officer
➤ National Patient Forum - Patients for Patient Safety Ireland
➤ National Patient Forum - Pavee Point

In addition, two focus groups were held with seven staff members from across HIOA which helped to further inform the overarching project themes. The themes include attitudes to and readiness for digital access to information, sharing information digitally, and digital care as well as challenges and opportunities.

Change

Adoption of Recommendations and Standards

We have previously developed standards and recommendations to support the sharing of patient information in the health and social care sector, including standards for the sharing of information and recommendations on national eHealth initiatives. Our General Practice (GP) messaging standard was the first standard that we developed and was revised most recently in 2017. It aims to standardise the transmission of electronic messages between general practices, hospitals and out-of-hours care, making accurate information available in a more timely manner to healthcare practitioners providing patient care, leading to safer better care for patients. Healthlink, the national electronic messaging service, provides a messaging service that allows patient information to be securely transferred between hospitals and medical practitioners. Healthlink informed HIOA that they adopted the General Practice Messaging Standard (GPMS) v4 as their standard and that Healthlink is fully compliant with this standard, and IT systems wishing to exchange messages with Healthlink adhere to the standards. To date, over 240 million messages containing patient information have been shared through Healthlink services, including almost 10 million referral messages, over 170 million laboratory results, over 7 million radiology reports and over 2 million laboratory tests have been requested.

Desired Outcome 3: Progressing the implementation of national eHealth priorities

Under the desired outcome of progressing the implementation of national priorities within the eHealth landscape, we have had the following impact:

Outputs

- Three reports published in relation to the Recommendations on the ICT enablement of older persons' services
 - Recommendations on the ICT enablement of older persons' services, which were also submitted to the Minister for Health.
 - ICT Enablement of Older Persons' Services: As Is Analysis
 - Stakeholder Involvement Report: Recommendations on the ICT enablement of older persons' services.
- Two personas were published which explain what these recommendations will mean for patients and health and social care professionals.
- One video recorded by the Director of Health Information and Standards promoting the public consultation on the draft Recommendations on the ICT enablement of older persons service was shared across HIQA's social media accounts.
- One academic paper published in peer-reviewed journal: 'Development of a framework to assess the quality of data sources in healthcare settings'. The framework can assist those using healthcare data sources to identify and assess the quality of a data source and inform whether the data sources used are fit for their intended use.***

Reach

The draft Recommendations on the ICT Enablement of Older Persons' Services were published for public consultation along with a related Best Practice Review and As Is Analysis. Over 150 stakeholder organisations and individuals were notified, via email, of the public consultation, inviting them directly to respond to the consultation. A press release was issued to promote awareness of the public consultation, and the public consultation was widely publicised across HIQA's social media channels which continued throughout the duration of the public consultation, which ran for six weeks from 16 March to 29 April 2022. The webpage for the public consultation for

*** Hooshafza S, McQuaid L, Stephens G, Flynn R & O'Connor L. Development of a framework to assess the quality of data sources in healthcare settings. *Journal of the American Medical Informatics Association*. 2022; ocac017. Available from: <https://academic.oup.com/jamia/article-abstract/29/5/944/6534111?login=false>

the draft Recommendations had 987 unique page views. The final Recommendations were submitted to the Minister for Health in November, published on HIQA's website and publicised through HIQA's social media platforms. Two personas have been developed, to explain what these recommendations mean for patients and health and social care professionals. The webpage for the final Recommendations on the ICT Enablement of Older Persons' Services had 197 unique page views.

Engagement

During the development of the Recommendations on the ICT Enablement of Older Persons' Services, we convened a special Advisory Group with members drawn from the domains of health and social care and of ICT. Members represented Department of Health units for eHealth, National Patient Safety Office, Older Persons' Strategy, and Sláintecare.

Members represented HSE Offices of the Chief Information Officer and of the Chief Clinical Officer, as well as several HSE functions (eHealth, Operations, Change and Innovation, Digital Transformation, Older Persons' Programmes, Pricing Office, and the National InterRAI Office). Representatives of Gerontological nurses, GPs, health and social care professions, and of directors of nursing and midwifery also took part.

Age Friendly Ireland, through its older persons' councils, represented the authentic voice of the older person.



To drive participation in the public consultation, we engaged with three networks: Age Friendly Ireland (older persons), HSE CHO Managers (digital health leads), and HSE Health and Social Care Professions Office (health and social care professionals). 23 responses were made to the public consultation. Eight submissions were made in a personal capacity and 15 submissions were made on behalf of organisations, including health and social care professional representative organisations, health researchers, advocacy groups, and units within the HSE that are working in the area of digital health, health information and older persons' services.

Other projects

In order to inform the implementation of national eHealth priorities, members of the Health Information team engaged with multiple external committees and initiatives during 2022 including:

- National Standards Authority of Ireland Health Informatics Standards Consultative Committee TC 21 (HISC)
- SNOMED CT Governance Board
- International Network for Innovation in Regulation and Supervision of Care (SINC) Group
- X-eHealth
- HSE - National ePrescribing Project Board
- HSE National Medicinal Product File Project Board
- HSE Dataset Specification Management Process.

Our Technical Standards Manager participated in a panel at the Symposium on Digitalisation in Healthcare, Interoperability and Standards, hosted by the Centre for eIntegrated Care at Dublin City University. He also participated in a webinar hosted by IPPOSI discussing a human rights approach to patients accessing their own health information.



Dr Kevin O'Carroll attending the Symposium on Digitalisation in Healthcare, Interoperability and Standards, hosted by the Centre for eIntegrated Care at Dublin City University.

Change

Adoption of Recommendations and Standards

We have previously developed numerous standards and recommendations aimed at progressing the implementation of national eHealth initiatives.

The national standard for a national medicinal product file (2015) has been adopted by the National Medicinal Product File Project Board as the standard that will be used to support the implementation of a national medicinal product file in Ireland. HIQA is sitting on the Project Board in an observer capacity.

Our Recommendations on community-based ePrescribing (2018) and National Standard on information requirements for national community-based ePrescribing

(2018) are being progressed through the National ePrescribing Project Board convened by the HSE. HIQA is sitting on that Project Board in an observer capacity.

Following on from our recommendation regarding the adoption of SNOMED CT as a national terminology for Ireland, we continue to work with the HSE to progress the implementation of SNOMED CT in Ireland through chairing of the SNOMED CT Governance Group. The implementation of SNOMED CT Strategy (2020 - 2022) in Ireland progresses under the direction of the SNOMED CT Governance Group. The main goals of the strategy are to develop expertise in SNOMED CT, focus on quality and ensure SNOMED CT adoption. A subgroup was established in 2022 to support IT projects that are planning on or are implementing SNOMED CT in their information systems. Two meetings of this group took place in 2022.

The SNOMED CT National Release Centre of Ireland has been set up to meet Ireland's responsibilities to administer the national license for SNOMED CT, as outlined by the International Health Terminology Standards Development Organisation (IHTSDO), which trades as SNOMED International. An Irish National Release of SNOMED CT is maintained by the National Release Centre and continues to be updated twice yearly. Reference sets that have been developed to support eHealth systems covering areas such as the National Ambulance Service, Dentistry, BreastCheck Screening Service, and adult oncology day care nursing discharge.

- **National Ambulance Service reference set:** Dataset over 5,000 terms, first release April 2022, 111 terms in reference set, second phase, October 2022, had 971 terms.
- **Dentistry Ireland reference set:** April 2022, 671 terms were published which were existing concepts in SNOMED. Additional 111 newly authored concepts in October 2022.
- **National Breastcheck Screening Service reference set:** 726 terms published in Oct 2022.
- **Adult oncology day care nursing discharge reference set:** 107 concepts added to reference set for October 2022 release.

Desired Outcome 4: Supporting those working in services to improve the quality of health information

Under the desired outcome of supporting those working in health and social care services to improve the quality of health information to underpin the delivery of safe care, informed decision-making, monitoring and planning, we have had the following impact:

Outputs

- Draft National Standards for Information Management in Health and Social Care published for public consultation.
- Evidence synthesis of international evidence on governance structures and information management arrangements in place for national health and social care data collections published.
- An updated e-learning module, Developing a Data Quality Framework published on the HIQA website and also on HSeLanD.
- Version four of the Catalogue of National Health and Social Care Data Collections in Ireland published which helps to continue to promote the maximum use of existing national data collections and drive improvements in the quality and safety of health and social care services in Ireland.
- In October 2022, a flyer outlining key HIQA health information publications and resources including information on accessing our online learning modules, Introduction to Data Quality, and Developing a Data Quality Framework, was made available to interested delegates of the National Patient Safety Annual Conference.

Reach

National Standards for Information Management in Health and Social Care

The Draft National Standards for Information Management in Health and Social Care were published for public consultation in October 2022. Over 360 stakeholder organisations and individuals were notified, via email, of the public consultation, inviting them directly to respond to the consultation. The webpage for the public consultation for the Draft National Standards for Information Management had 1,382 unique page views. The public consultation on the draft recommendations was widely publicised across HIQA's social media channels and a press release was issued to promote awareness of the public consultation which continued throughout the duration of the public consultation.

Online learning modules and guidance resources

Our online learning module, Introduction to Data Quality, was launched on HSeLand in November 2021 and our online learning module, Developing a Data Quality Framework was launched in January 2022.

Please see Table 10 below for the number of people who have completed each of these courses. The Introduction to Data Quality module is included in the training schedule for staff working with national community waiting list data.

Table 10: Online learning course completions

Online learning course	Completions in 2022	Completions since launch
Introduction to Data Quality	1,075	1,823
Developing a Data Quality Framework	300	300
Total	1,375	2,123

- The data quality dimensions and evaluation questions from our *Guidance on a data quality* framework was reproduced as a table in an international handbook chapter on Risk & Regulation following a request from the Regulation and Quality Improvement Authority (RQIA) and Mary McColgan (Emerita Professor of Social Work, Ulster University).
- An academic publication 'Development of a framework to assess the quality of data sources in healthcare settings' published in the Journal of American Medical Informatics Association references our guidance documents: 'Guidance on a data quality framework', and 'What you should know about data quality'.
- Our 'Guidance on a data quality framework' was referenced in the Severe Maternal Morbidity in Ireland Annual Report 2020.

Catalogue of national health and social care data collections

Version four of the Catalogue of National Health and Social Care Data Collections in Ireland was launched on the HIQA website and social media outlets. On the day of publication, key stakeholders who were notified of the publication of the Catalogue, via email, including senior management in the Department of Health, Department of Children, Equality, Diversity, Integration and Youth, HSE, and national data collections.

The press release was sent to national and regional broadcast and print news desks across the country, as well as targeted emails to the medical press. This resulted in:

- Two radio interviews with South East Radio and Live 95FM
- One article in the Medical Independent
- Two articles on Irish technology news sites - Irish Tech News and Tech Central.

Between its launch in October 2022 and the end of December 2022, the webpage for version four of the Catalogue of National Health and Social Care Data Collections had 742 unique page views. In 2021, there were a total of 1,041 unique page views for version three of the Catalogue.

The Catalogue and its importance is highlighted in a methodological report on the development of the Irish Health System Performance Assessment Framework (HSPA). HIQA was informed by the Healthcare Pricing Office in the HSE that the Catalogue and other key HIQA resources would be included in ongoing data users training that is carried out several times per year. At an EU level, the Catalogue is mentioned in a *Country Factsheet* about Ireland produced by the Joint Action Towards a European Health Data Space (TEHDAS) project.

Engagement

National Standards for Information Management in Health and Social Care

We held one meeting of the Advisory Group for the National Standards for Information Management in Health and Social Care. The organisations represented on the Advisory Group are detailed in Table 11.

Table 11: Members of the Advisory Group for the National Standards for Information Management in Health and Social Care

Advisory Group: National Standards for Information Management in Health and Social Care
<ul style="list-style-type: none">➤ Central Statistics Office➤ CORU (Health and Social Care Professionals Council)➤ Department of Health➤ Healthcare Pricing Office➤ Health Informatics Society of Ireland (HISI)➤ Health Research Board➤ Health Protection Surveillance Centre➤ HSE – Operations: Office of the Chief Information Officer, Quality and Safety Directorate➤ Irish College of General Practitioners

- Mental Health Commission
- National Cancer Registry Ireland
- National Office for Clinical Audit
- National Screening Service
- Patient Representatives
- Primary Care Reimbursement Service
- Royal College of Physicians in Ireland
- Royal College of Surgeons in Ireland
- Tusla
- University College Cork

As part of the development of the evidence synthesis of international evidence, we engaged with key international stakeholders: Australian Institute of Health and Welfare (Australia); Canadian Institute for Health Information (Canada); Ministry of Health (New Zealand); Ministry of Health (Singapore); NHS Digital/NHSX and Data Alliance Partnership Board (England); Public Health Agency of Canada (Canada); and Socialstyrelsen (Sweden).

As part of the public consultation on the Draft National Standards for Information Management in Health and Social Care, we received 51 responses. We received 16 responses from members of the public and health and social care professionals and 35 responses were received from a range of health and social care organisations, including professional representative organisations, national data collections, digital health developers, health researchers, patient advocacy groups, disability representative groups, health and social care service providers, the HSE, and Tusla.

During the public consultation, we held four focus groups with 41 participants. The focus groups included representatives from key national data collections, inspectors from HIQA's Regulation Directorate, health and social care professionals and staff working in the area of information governance in health and social care settings.

We met with representatives from key organisations during the public consultation, including the Mental Health Commission, to discuss the scope of the revised information management standards. We also met with members of HIQA's Healthcare Inspectorate Team to discuss the implications of the change of scope of the revised information management standards on services and inspection models.

During the public consultation, we also contacted members of the Advisory Group directly via telephone to discuss the change of scope of the Draft National Standards for Information Management and asked them to highlight the ongoing public consultation through their own networks.

Review of information management practices for acute and community waiting list data within the HSE

During the evidence gathering stage of the review programme, we engaged with key stakeholders in the HSE and the National Treatment Purchase Fund. We also held 11 virtual site visits including seven visits to randomly selected hospital sites and four visits to community services (Ophthalmology, Speech and Language, Physiotherapy and Assessment of Need) within one randomly selected Community Health Organisation. In total, we held 42 interviews and focus groups during these visits with a range of staff involved in information management for acute and community waiting list data. Members of the team also engaged with the Corporate Affairs section at the Department of Health to provide an overview of preliminary findings.

Catalogue of national health and social care data collections

We held three scoping interviews with key national stakeholders within managing organisations for large national data collections, which included the National Office of Clinical Audit, the Healthcare Pricing Office, and the Health Research Board. The aim of these interviews was to gather their views in relation to the development of an online self-service portal solution for the ongoing update of the Catalogue of National Health and Social Care Data Collections in Ireland.

Additional engagement

We engaged with representatives from the National Office of Clinical Audit (NOCA) to provide feedback on their draft data quality procedure. The purpose of the procedure is to guide NOCA staff on the effective management of data quality using the five stages of the data and information lifecycle and the five dimensions of data quality set out in HIQA's Guidance on a Data Quality Framework for Health and Social Care (2018).

Members of the team delivered lectures on HIQA's health information work to candidates from the SPHeRE PhD programme in February 2022, to students on the MSc Health Informatics course in UCD in April 2022, and to students from the UCC Masters in Public Health course in November 2022.

Change

Evidence of improvements in Practice

In 2022, there were over 1,000 completions of the two online-learning courses on HSeLanD. At the end of each course, we include an evaluation to gather feedback on the course and to assess its impact on learners and how they intend to change or improve their practice.

Over 98% of people who completed an evaluation for the module on Introduction to Data Quality in 2022 reported that they feel they have a better understanding of data quality, having completed the module. In addition, 89% of people reported that they found the module 'very useful' or 'extremely useful'.

People who completed Introduction to Data Quality in 2022 said:

"Good module to cover. Informed information on how quality data empowers the health service and patients using our health system."

"It is a useful springboard for future study and training in the area of data quality."

"HSE captures a lot of data each day and we as its members need to improve ourselves at collecting accurate good quality data for better care for everyone. It has added a new dimension insight to my job."

Over 99% of people who completed an evaluation for the module, Developing a Data Quality Framework, in 2022 reported that they feel they have a better understanding of data quality, having completed the module. In addition, 80% of people who completed an evaluation reported that they found the module 'very useful' or 'extremely useful'.

People who completed Developing a Data Quality Framework module in 2022 said:

"I have a clearer understanding of data, information and the need for a data quality framework."

"Completing the module made me reflect on practices in own service."

"Helped me understand my role better in why data is important to the organisation."

Our guidance on a data quality framework and our work in this area was used as a case study in a TEHDAS report called European Health Data Space Data Quality Framework.

Our guidance on a data quality framework was applied in practice as part of a PhD thesis where it was applied to the Maternal & Newborn Clinical Management system (MN-CMS) in one maternity setting. It was used as part of an audit to identify where improvements were required in relation to data quality and outlined specific actions to address existing gaps.

Involvement of key national stakeholders in our work

As part of planning for the future development of an online self-service portal for national data collections to update catalogue entries on an ongoing basis, we held initial scoping interviews with the following key stakeholders that have responsibility for large national data collections: National Office of Clinical Audit, Healthcare Pricing Office, Health Research Board.

The aim of these interviews was to understand the views of managing organisations on the benefits of developing an online self-service catalogue, the support tools the national data collection would require in order to effectively use the online catalogue, potential barriers to its use and to gain insights into how HIQA could promote use of the online catalogue and encourage new data collections to register and use it. Future stakeholder engagement for this project will incorporate and build on the findings from these initial interviews.

2.3 Next Steps

In 2023, we plan to deliver impact through our work in the following areas:

- Continue to engage with senior decision-makers and leaders at national level to contribute to the strategic development of the Health Information System in Ireland and to inform associated policy and legislation.
- Collaborate with the Department of Health in relation to EU Grant applications for implementation of aspects of the European Health Data Space Regulation.
- Develop a strategic plan for health information to include the health information quality aspects of the health information function of HIQA. This strategy will incorporate learnings to date, identify gaps and drive further improvements in relation to the impact on our work.
- Continue to drive improvements in the quality of health information by progressing the review of information management practices for national waiting list data within the HSE and publishing the final report by the end of the year.
- Continue to drive improvements to national health information by developing and publishing National Standards for Information Management in Health and Social Care.
- Through the National Engagement on Digital Health and Social Care, continue to give a voice to the public and health and social care professionals and enable them to have a meaningful influence on the future development of digital health and social care systems
- The national engagement will also advance the eHealth goals of Sláintecare and the aims of the European Commission's Europe's Digital Decade: digital targets for 2030 and the European Health Data Space
- Participate in international collaborations to facilitate shared learning in Health Information
- Facilitate fellowship, internship and PhD opportunities and undertake collaborative projects and grant applications that complement our programmes of work in partnership with academic bodies.
- Increase the reach of our work programme by targeting key stakeholders.

3. National Care Experience Programme

3.1 About

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 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 Objectives

- Report on the National Inpatient Experience Survey 2021, and develop, implement and report on the National Inpatient Experience Survey 2022.⁺⁺⁺
- Deliver and report on the National Maternity Bereavement Experience Survey⁺⁺⁺, and the National Nursing Home Experience Survey.
- Commence the National End of Life Survey.
- Develop the analytical and research function of the National Care Experience Programme, strengthening links with academic and other partners to maximise the value, usage and understanding of survey data and findings.

Desired outcomes

- Expand the programme to new areas to capture people's experiences of health and social care services and report the findings to the public and service providers.
- Develop research, academic and international links with key stakeholders to build capacity and understanding of people's experiences of health and social care services.

We have selected two key metrics in order to measure the change relating to our work:

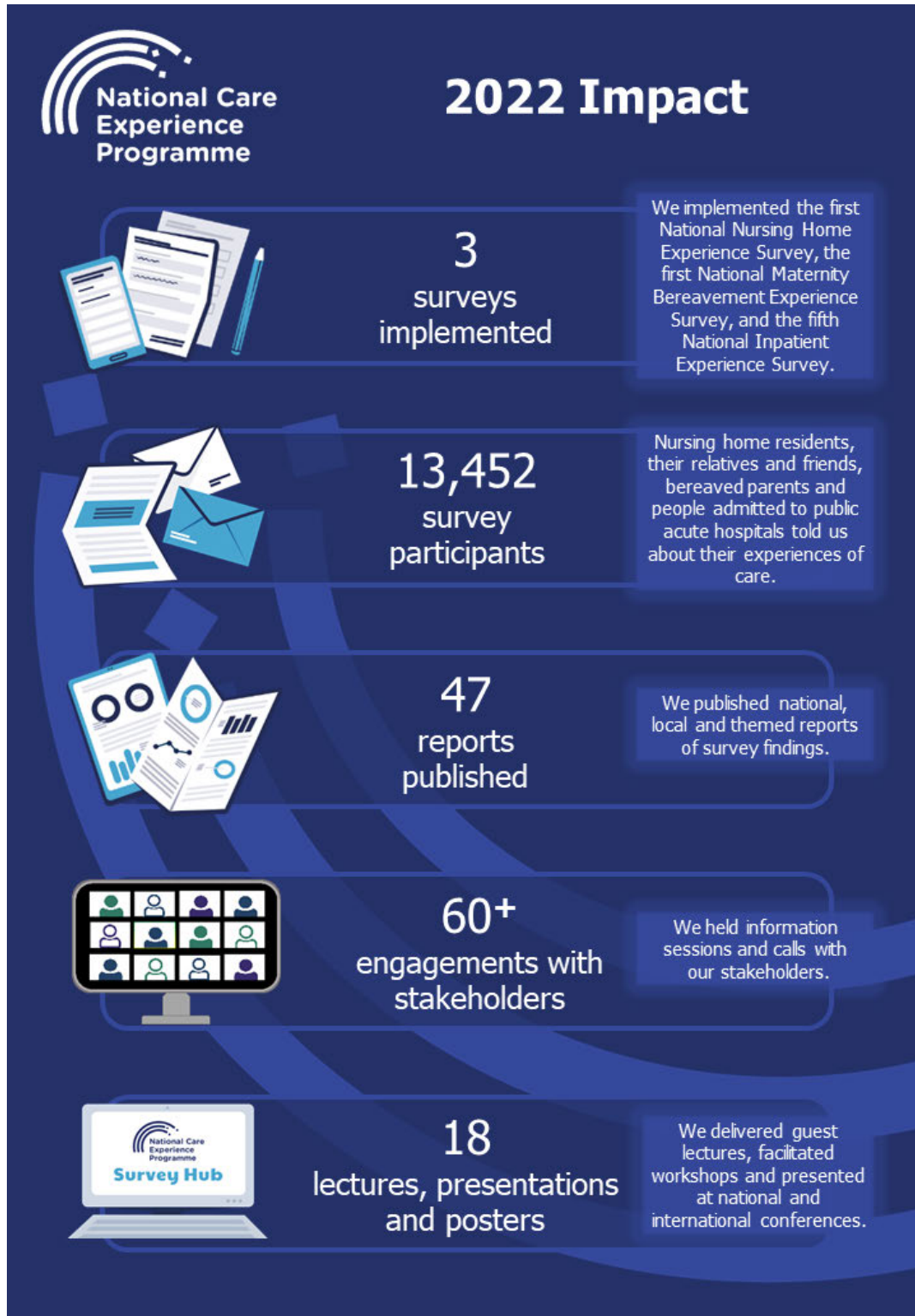
- Expansion of the programme
- Use of survey data.

⁺⁺⁺ 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.

⁺⁺⁺ 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.

3.2 2022 Impact

Impact in numbers



Desired Outcome 1: Expanding to new areas to capture people's experiences of care

Under the desired outcome of expanding the programme to new areas to capture people's experiences of health and social care services and report the findings to the public and service providers, we have had the following impact:

Outputs

- Forty-six reports published to disseminate the findings of the first National Nursing Home Experience Survey, and the fourth and fifth National Inpatient Experience Surveys:
 - 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 2022
 - Findings of 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.



- Interactive dashboard for each survey made available on www.youexperience.ie, which allows interested stakeholders to further explore the survey results in an understandable, interactive way.

- Data Quality Strategy 2022-2024 published which outlines how the National Care Experience Programme formalises the approach it uses to identify, document and implement data and information quality.
- Statement of Information Practices updated, which explains why we collect information, and how we process and handle this data.
- Data Protection and Confidentiality Policy updated, which describes how we protect survey respondents' privacy.
- Data Protection Impact Assessment summary reports published 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.

Reach

In 2022, 718 nursing home residents and 943 designated representatives participated in the first National Nursing Home Experience Survey, and 683 women and 232 partners participated in the first National Maternity Bereavement Experience Survey. Additionally, 10,904 people participated in the National Inpatient Experience Survey 2022, and told us about their experiences of care. Reports of our survey findings were downloaded a total of 1,324 times.

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 2022, there were:

- 11,482 visitors to www.yourexperience.ie
- 3,229 followers on Twitter
- 456.9k Twitter impressions
- 15,360 Facebook page reach^{§§§}
- 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.

^{§§§} Page reach refers to the number of people who saw any content from the NCEP Facebook pages.

Engagement

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 support the expansion of National Care Experience Programme, we held the following engagement events:

- Eight hospital visits to engage with hospital staff
- Six hospital group visits
- One National Inpatient Experience Survey workshop on discharge from hospital
- Eight dashboard training sessions with hospital and nursing home staff
- Two information sessions with HSE Patient Administration System staff
- Four information sessions with Directors of Midwifery and Clinical Nurse/Midwife Specialists
- Two information sessions and three individual calls with advocacy and support organisations
- 10 data extract support sessions with nursing home staff
- Two information sessions with nursing home residents 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 to stay up to date with new developments, including:

- 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.

Change

Expansion of the programme

National Nursing Home Experience Survey

In 2022, we successfully implemented the first National Nursing Home Experience Survey. 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.

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 HIQA, and national policy and legislation in the Department of Health.

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. There are some limitations to the current approach, including the lack of 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. The second pilot, a Haematology Experience Survey, allowed the pilot hospital to explore an area of care not currently covered by the NCEP's suite of surveys. Hospital staff at 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.

Use of survey data

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 home 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.

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.**** Survey data were also used in a dedicated chapter on women's health to highlight different experiences reported by sex.

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 post-natal hubs to deliver improved care to women in the post-natal 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.

**** Available at: <https://www.gov.ie/en/collection/5fd4f6-national-healthcare-quality-reporting-system-reports/#20212022>.

Desired Outcome 2: Developing research, partnerships and links with key stakeholders

Under the desired outcome of developing research, academic and international partnerships and links with key stakeholders to build capacity and understanding of people's experiences of health and social care services, we have had the following impact:

Outputs

- One academic paper published entitled '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 based on secondary analysis of data from the 2020 National Maternity Experience Survey.
- One academic slide deck published which 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 Experience Programme, and the impact of the programme.^{****}

Reach

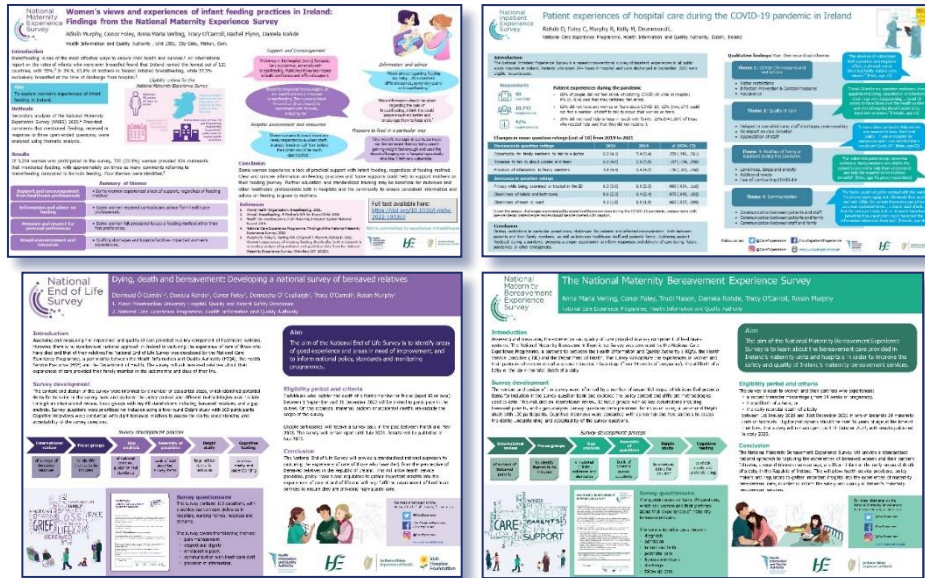
Members of the team attended nine conferences in 2022 to disseminate the work of the National Care Experience Programme and build understanding of people's experiences of health and social care. We presented four posters and gave 10 oral presentations at national and international conferences, including an open plenary presentation at the All Ireland Maternity & Midwifery Festival on the development of the National Maternity Bereavement Experience Survey, and an invited oral presentation on the National Inpatient Experience Survey at the RCSI Medical Professionalism Conference. We delivered invited guest lectures and workshops for students of the BSc in Physiotherapy in TCD, the MSc in Health Services

^{****} 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

^{****} The academic slide deck is available at: https://yourexperience.ie/about/about-the-programme/#academic_slide_deck

Management in TCD, the MSc in Healthcare Management in RCSI, and Promoting Quality and Safety in Healthcare (MSc Nursing programmes) in UL.

Poster presentations at national and international conferences



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.

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. This episode features Professor Peter Gillen (RCSI) who is a clinical advisor to the National Healthcare Communications Programme and Wini Ryan (HSE) who is the National Lead for Patient and Service User Feedback in the HSE. They speak about the importance of effective communications within a healthcare environment, and the National Healthcare Communications Programme, which was developed in response to the findings of the National Inpatient Experience Survey.
- The importance of supporting patients while in hospital. This episode features Carol Mullins, Patient Advice and Liaisons (PALs) Manager in

Tallaght University Hospital, and Fran Kane, who has used the patient advocacy services in the hospital. They discuss the importance of providing supports to patients while in hospital and the different initiatives in Tallaght University Hospital that aim to improve patient experience.

- The importance of listening to experiences of maternity bereavement care. This episode features Mairie Cregan, Co-founder of Féileacáin, the Stillbirth and Neonatal Death Association of Ireland, and Anna Maria Verling, Clinical Midwife Specialist in Bereavement and Loss and Project Lead, National Maternity Bereavement Experience Survey. They discuss the importance of listening to experiences of maternity bereavement care in Ireland to help improve future care provided.

To date, [Let's Talk Care Experience](#) podcast episodes have been downloaded over 600 times.

Engagement

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 a student completing their dissertation as part of the MSc in Applied Social Research, Trinity College Dublin. Their dissertation was titled:

- *“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:

- 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 co-applicants Dr Conor Foley and Dr Daniela Rohde from the National Care Experience Programme.

Change

Use of survey data

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 National Care Experience Programme 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.

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.^{§§§§} 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. 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 the first quarter of 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

^{§§§§} The Women's Health Action Plan 2022-2023 is available from <https://www.gov.ie/en/publication/232af-womens-health-action-plan-2022-2023>

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.

3.3 Next Steps

In 2019, a horizon-scanning and prioritisation process was undertaken by the National Care Experience Programme Steering Group to identify areas for development of new surveys. Surveys of maternity bereavement care, end of life care and nursing home care were prioritised and have now been developed and implemented. Commitments were also made to develop surveys of cancer care and mental health services. The programme has worked closely with the Mental Health Commission and the National Cancer Control Programme in setting up these surveys.

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 cancer care survey. Development of the cancer care survey, in line with the NCEP's Quality Assurance Framework, is expected to commence in Q3 2023.
- Commence development of a model and methodology to enable implementation of a survey of mental health service-users. Specifically, in 2023, a national and international review of similar surveys and extensive stakeholder engagement will be undertaken.
- 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.

4. Conclusions and Next Steps

The impact that our work has had against our desired outcomes outlined in this 2022 report for the HIS Directorate is the result of effort over the last four years to integrate impact evaluation into our work. The continuous feedback loop of identifying what we want to achieve from a project and evaluating the benefits of a project against outputs, reach, engagement and change, has helped us ensure that the work we do has the desired effect. It allows us to see where we are having the most impact, to identify gaps and plan how we will close those gaps with future projects.

Many of the projects undertaken by the HIS Directorate have a long lead-in time in terms of visible change in the health and social care system. As such, we will continue to monitor, evaluate and report on impact over the coming years, each year building on what has come before.

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