



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Knowledge Sharing and Impact Assessment

Health Information and Standards Directorate

2023 REPORT

About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent statutory body 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.

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 of Social Services 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 permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social 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 and social care services, with the Department of Health and the HSE.

Visit www.hiqa.ie for more information.

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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 national standards function develops 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, as amended, and is guided by a prioritisation process* and a Health and Social Care Standards Strategy (2022-2024).†

2. Informing and driving improvements in health information quality and digital health

The health information function develops recommendations, national standards and guidance for the Irish digital health and health information landscape, and assesses against the national standards. These teams operate under the remit of the Health Act 2007, as amended.

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. Two new surveys of mental health services and cancer care services are under development. The National Care Experience Programme operates in line with the objectives and remit, as laid out in the National Care Experience Programme Strategy (2022-2024).‡

* 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>

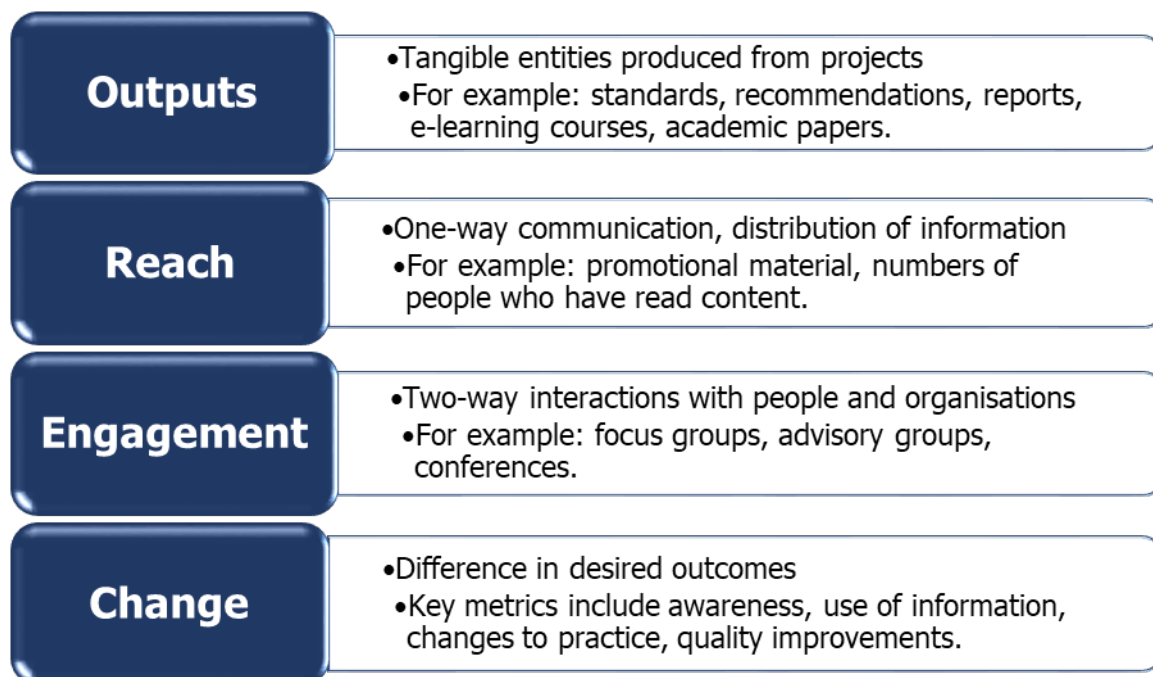
‡ The National Care Experience Programme Strategy (2022-2024) is available at: https://yourexperience.ie/wp-content/uploads/2022/01/NCEP_Strategy_2022_2024-1.pdf

Introduction

The Health Information and Quality Authority's (HIQA's) Health Information and Standards (HIS) Directorate has committed to measuring the impact of the work that it does. Measuring and reporting on impact facilitates transparency, allows for the evaluation of our work and demonstrates the effectiveness of our work. It also supports us to identify what worked well, thus informing future work.

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 within the Irish population unaffected with which to compare outcomes. Many of the projects are expected to instigate change indirectly and slowly, sometimes over years. Much of our work is intertwined with the work of the regulation directorates within HIQA and with other organisations such as the Department of Health, the Department of Children, Equality, Disability, Integration and Youth, the Health Service Executive (HSE) and the Child and Family Agency (Tusla). This can make it difficult to identify the exact contribution of the HIS Directorate. As such, when we report on our impact we create a portfolio of indirect and direct measures of impact, and through collecting data over a prolonged period of time.

In 2019, we developed a strategic framework to inform impact measurement (Knowledge sharing and impact strategic framework for the HIS Directorate, 2019). 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 if the desired outcomes of the work have been achieved. Following the development of the strategic framework, each team in the HIS Directorate identified desired outcomes of key relevance to their function and area of work, and use these desired outcomes to assess and report the impact of their work.

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, and the National Care Experience Programme. Together, these comprise the Health Information and Standards (HIS) Directorate. The purpose of the report is to demonstrate the effectiveness of our work, ensure transparency and highlight our successes. The report presents the impact of our work against selected desired outcomes. This report outlines our impact as observed during 2023 although the impact for some of our outcomes will be measured over a number of years. This is the fifth 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.

Health Information and Standards Impact Report

3,029

Members of public and health and social care professionals took part in National Engagement on Digital Health and Social Care.

94,969

Completions of our online learning modules on advocacy, data quality, infection prevention and control, adult safeguarding and human rights-based care.



4,570

Respondents to first National End of Life Survey on experiences of end-of-life care.



1

Learning Hub launched on www.hiqa.ie.

2023

1. National Standards for Health and Social Care Services

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.

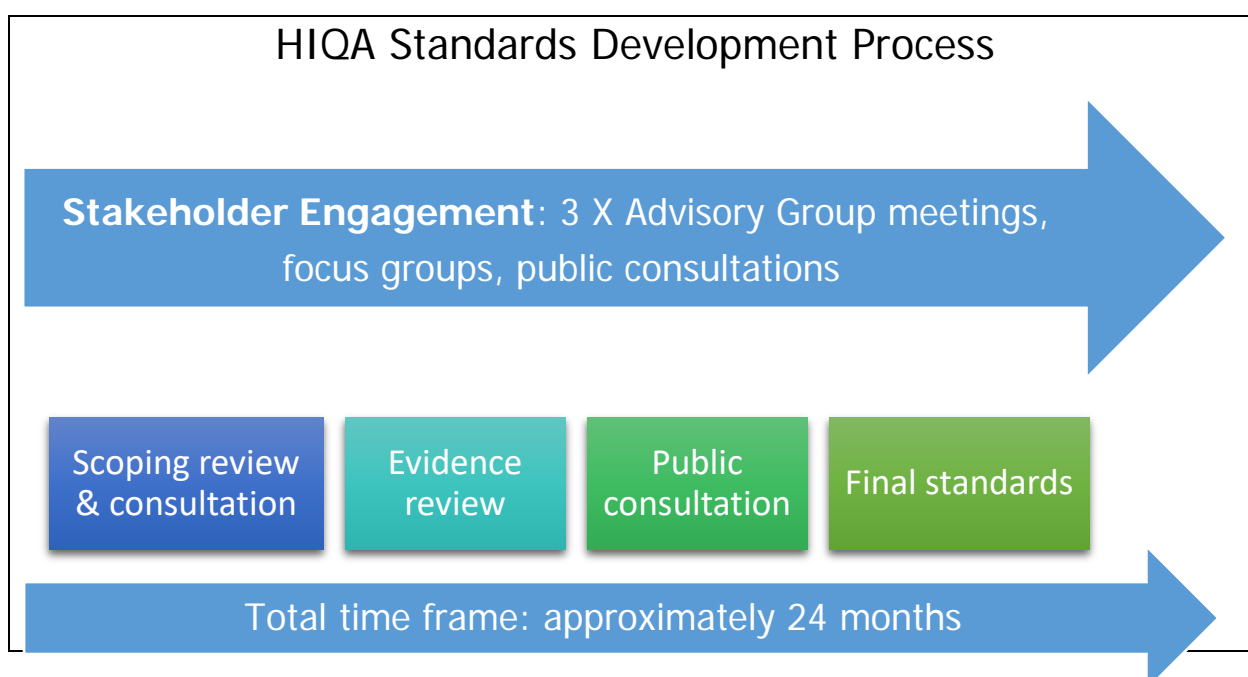
Purpose of national standards

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.

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.



Our vision

Our vision is 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 outlined in our *Health and Social Care Standards Strategy*[§] 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.

2023 objectives of the standards setting function

- Develop and update evidence-based standards in line with the prioritisation process and the standards development framework.
- Implement the 2023 workplan of the Health and Social Care Standards Strategy 2022-2024.
- Develop implementation support tools for national standards in line with the Knowledge Sharing and Impact Strategic Framework.

Desired outcomes for impact

- Increased awareness and understanding of national standards, guidance, and tools developed by HIQA, through communication and dissemination, promoting our work at conferences, publication of policy and academic papers, launch of a Learning Hub, and being shortlisted for awards.
- Support the development of a culture in health and social care services where key elements of national standards, such as advocacy and good communication, are embedded into practice.

[§] Health and Social Care Standards Strategy (2022-2024) is available at:
<https://www.hiqa.ie/sites/default/files/2022-05/HIQA-Standards-Strategy-2022-2024.pdf>

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

- 1) Increased awareness and understanding of national standards and resources
- 2) Positive cultural change within health and social care services embedding key elements of national standards into practice, specifically advocacy.

1.2 2023 impact

Impact in Numbers

- **94,053** online learning course completions in 2023; **252,635** completions since their launch.
- **Two** academic papers published:
 - *Factors that influence the implementation of (inter)nationally endorsed health and social care standards: a systematic review and meta-summary* published in the BMJ Quality and Safety
 - *Using Online Learning Courses as a Tool to Support Implementation of National Standards: A Case Study* published in the Journal of Social Care.
- **One** co-authored chapter published in *Social Care Work: An Introduction for Students in Ireland*.
- **One** policy paper published in collaboration with the Mental Health Commission to inform the new National Policy Framework for Children and Young People 2023-2028.
- **One** online learning course launched on *The Fundamentals of Advocacy in health and social care*.
- **One** booklet published on advocacy; approximately **19,000** copies distributed to health and social care services and professional organisations.
- **One** 11-minute educational video on advocacy launched and viewed **1,727** times.
- **Seven** focus groups with **42** participants to inform the development of a toolkit to support Tusla staff to communicate effectively with children, young people, families and foster carers.
- **Ten** focus groups and two interviews with **68** participants to inform the development of a self-appraisal tool to support services to prepare for and implement national standards.
- **Four** poster presentations at national and international conferences.
- **Six oral** presentations at national and international conferences.
- **Three** lectures, two in-person and one online, delivered to university students.
- **Two** award shortlistings for *The Fundamentals of Advocacy in health and social care*.
- **One** new Learning Hub launched on the HIQA website landing page.
- **One** educational slide deck titled 'National Standards for Health and Social Care Services - An Introduction', launched on the HIQA Learning Hub.

Desired Outcome 1: Increased awareness and understanding

Under the desired outcome of increasing awareness and understanding of national standards, guidance, and tools developed by HIQA through communication and dissemination, we have had the following impact:

Outputs

- One new Learning Hub accessible on the HIQA website landing page. The hub provides links to a range of learning resources and materials that support front-line staff to put national standards into practice. It is a quick and easy way for front-line staff, as well as students, third-level lecturers/educators and people using health and social care services, to access HIQA's range of online learning courses, guides and videos. In 2024, we aim to measure the extent to which these resources have been accessed and downloaded.
- Two academic papers published:
 - *Factors that influence the implementation of (inter)nationally endorsed health and social care standards: a systematic review and meta-summary*** published in BMJ Quality and Safety. This review identifies and describes the most frequently reported enablers and barriers to implementing health and social care standards based on international evidence.
 - *Using Online Learning Courses as a Tool to Support Implementation of National Standards: A Case Study*†† published in the Journal of Social Care. This paper describes the evaluation of the development, dissemination and analysis of three online learning courses. The results indicate that online learning courses are an effective tool and support the adoption of standards in health and social care services where knowledge and understanding is a barrier.
- One co-authored academic chapter published in *Social Care Work: An Introduction for Students in Ireland*. The chapter 'Standards, regulation and quality improvement in health and social care services', explores HIQA's role

** Kelly Y, O'Rourke N, Flynn R, O'Connor L, Hegarty J. Factors that influence the implementation of (inter)nationally endorsed health and social care standards: a systematic review and meta-summary. BMJ Quality & Safety Published Online First: 08 June 2023. <https://doi.org/10.1136/bmjqs-2022-015287>

†† McCarthy S, Connolly D, Weir L, O'Connor L, and O'Rourke N. Using Online Learning Courses as a Tool to Support Implementation of National Standards: A Case Study. *Journal of Social Care*. 2023;3(9)

in the sector, including the interdependent roles of standards, regulations and inspection to drive improvement in the quality of health and social care services. It sits alongside contributions from academics and practitioners from across a wide range of social care settings to inform undergraduate social care work students at the formative stage of their practice development.

- One published policy paper titled *Key considerations to inform the National Policy Framework for Children and Young People 2023-2028* shared with the Department of Children, Equality, Disability, Integration and Youth. This paper drew on extensive research and stakeholder engagement conducted by HIQA and the Mental Health Commission in preparation for the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services.
- One best-practice case study on children's participation in the development of national standards included in the Department of Children, Equality, Disability, Integration and Youth report: Final Review of the National Strategy on Children and Young People's Participation in Decision-making 2015–2020.
- One contribution to the United Nations Economic Commission for Europe (UNECE), Older Persons in Vulnerable Situations, UNECE Policy Brief on Ageing No. 28 June 2023 and subsequent online seminar, at the request of the Department of Health.
- One educational slide deck entitled 'National Standards for Health and Social Care Services - An Introduction', developed to provide a teaching resource on the development of evidence-based national standards for health and social care services in Ireland. The slide deck is aimed at those teaching health and social care students, such as third-level lecturers/educators, and those providing training for health and social care staff.
- Two published articles in the National Office for Human Rights and Equality Policy Newsletter and the Quality and Patient Safety Matters #AllThingsQuality quarterly newsletters, to raise awareness of the launch of the advocacy online learning course.
- One national and one international award shortlisting on the work carried out to inform and develop the advocacy online learning course *The Fundamentals of Advocacy in health and social care*.
- Five poster presentations:
 - A qualitative exploration of experiences, enablers and barriers from stakeholders implementing health and social care standards in Ireland presented at the 23rd International Conference on Integrated Care (ICIC) 2023
 - A qualitative analysis of experiences, enablers and barriers to implementing nationally endorsed health and social care standards in

Ireland presented at the 6th UK and Ireland Implementation Science Research Conference

- The Fundamentals of Advocacy in health and social care: Designing an online learning course for health and social care staff presented at the European Public Health Conference 2023
- Development of a digital intervention for Selecting Implementation Tools and Actions for Standards (SITAS) presented at the National Patient Safety Office Conference 2023
- The Fundamentals of Advocacy in health and social care: Improving knowledge and understanding of advocacy among health and social care staff presented at the National Patient Safety Office Conference 2023.

Reach

The academic paper, *Factors that influence the implementation of (inter)nationally endorsed health and social care standards: a systematic review and meta-summary* has been downloaded 4,702 times from the BMJ Quality and Safety website.



Engagement

In April 2023, we launched the online learning course *The Fundamentals of Advocacy in Health and Social Care*. The aim of the course is to improve knowledge and understanding of advocacy and to highlight the role of health and social care staff in relation to advocacy. We facilitated a workshop for social workers at the Social Care Ireland Annual Conference 2023 titled 'The Fundamentals of Advocacy in health and social care' to raise awareness of the course and participants provided feedback on various topics related to advocacy in their service.

In June 2023, we presented at the European Social Services Conference (ESSC) 2023 held in Malmo, Sweden. The ESSC is the annual flagship event of the European Social Network (ESN), the leading network for public social services in Europe. The theme of the conference was, 'Advancing social services. The role of technology in promoting autonomy and inclusion'. We presented on 'A collaborative approach to developing online learning courses to support health and social care staff to put national standards into practice' and aimed to raise awareness of the collaborative

work carried out in developing the advocacy course. The conference, attended by almost 700 people from 40 different countries, provided an opportunity to highlight the work of HIQA and to meet others working to improve social services.



Cathy Duggan, Standards Development Lead, presenting at the European Social Services Conference 2023 held in Malmo, Sweden.



We continued to raise awareness of the advocacy resources throughout 2023, both nationally and internationally. *The Fundamentals of Advocacy in health and social care*, was shortlisted in the category of ‘Workforce Support’ at the European Social Services (ESS) Awards 2023. The Fundamentals of Advocacy in health and social care: Resources to address a crisis highlighted during the COVID-19 pandemic, was also shortlisted for the Irish Healthcare Awards 2023 under the category ‘Crisis Management Response of the Year’ where our work was highly commended.

During 2023, we delivered a number of presentations at conferences across a range of topics:

- ‘A qualitative exploration of experiences, enablers and barriers from multilevel stakeholders implementing health and social care standards’ - SPHeRE Network 9th Annual Conference

- 'How to achieve person-centred care in homecare services: a systematic narrative review' - SPHeRE Network 9th Annual Conference
- 'Driving improvements in the quality, safety, consistency and coordination of care and support for children: a collaborative approach' - 2nd All-Ireland Conference on Integrated Care
- Translating a Human Rights-based Approach into Health and Social Care Practice - UCD School of Medicine Roundtable Discussion on Human Rights and Medical Law
- 'Driving improvements in the quality, safety, consistency and coordination of care and support of children using health and social care services, through the collaborative development of national standards for health and social care services working with children' - 23rd International Conference on Integrated Care (ICIC) 2023
- 'A collaborative approach to developing online learning courses to support health and social care staff to put national standards into practice' - European Social Services Conference 2023.



Left: Davina Swan, Standards Development Lead, presenting at the 23rd ICIC in Belgium. Right: Linda Weir, Programme Manager, contributing to a panel discussion at the ESS awards in Croatia.

Research conducted by a PhD student on the team on the factors influencing implementation of national standards was presented at national and international conferences, including the National Patient Safety conference and SPHeRE conference held in Dublin, the European Implementation Collaborative conference in Switzerland and the 6th UK & Ireland Implementation Science Research Conference 2023 held in Limerick. This research identified the key enablers and barriers to implementing health and social care standards into practice. The findings will inform strategies that the standards team can develop to assist implementation of national

standards within health and social care, and to improve the outcomes and experiences of people using health and social care services. The academic paper, *Factors that influence the implementation of (inter)nationally endorsed health and social care standards: a systematic review and meta-summary* published in BMJ Quality and Safety Journal was shortlisted at the HSE Open Access Research Awards 2023. The awards recognise health and social care professionals and those conducting research in the Irish health system. It promotes research activity that improves the evidence and knowledge base underpinning our health services.



Yvonne Kelly presenting at the SPHeRE Network 9th Annual Conference in Dublin and at the European Implementation Collaborative conference in Switzerland.



In order to promote the HIQA Learning Hub and the new educational slide deck, we engaged with over 200 course coordinators for all health and social care qualifications in third-level institutions in Ireland. We also engaged with CORU, the body responsible for regulating health and social care professionals, where we promoted the HIQA Learning Hub and how it can support continuous professional development for health and social care professionals.

In 2023, we participated in four stakeholder engagement events held by HIQA for providers of designated centres for older persons in Dublin, Cork, Galway and Mullingar. A total of 678 people attended the events, including registered providers, managers and persons in charge. At these events, we engaged with attendees to raise awareness of our work and provide information on our resources that support health and social care staff to understand adult safeguarding and how to apply a human rights-based approach to their work.

The team also delivered three lectures and engaged with students in a number of universities:

- Developing national standards for health and social care services to improve quality and safety – BA in Social Care, Technological University Dublin
- Health Information and Standards Directorate and overview of HIQA's work in infection prevention and control - MSc in Healthcare Infection, Trinity College Dublin
- National Standards for health and social care - MSc in Healthcare Management, Royal College of Surgeons Ireland.

Change

Increased awareness and understanding of national standards and resources

A number of the considerations set out in the policy paper, *Key considerations to inform the National Policy Framework for Children and Young People 2023-2028*, have been reflected in the final national strategy, *Young Ireland: National Policy Framework for Children and Young People 2023-2028*. This includes reference to the need to improve interagency working, better planning for transitions from child to adult services for key groups, and a more systemised approach to resource and workforce planning.

The addition of the Learning Hub and the educational slide deck to the HIQA website allows for easier access for trainers and educators, students and academics, front-line staff and people using services to the national standards and resources developed by HIQA. Feedback to date has been positive with many course coordinators and lecturers advising that it has increased their awareness and understanding of national standards and that they plan to use the resources in their work. Many have also indicated that they would like to engage further with HIQA in this regard.

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

Under the desired outcome of supporting the development of a culture in health and social care services where key elements of national standards, such as good governance, interagency working, service-user feedback, advocacy and good communication are embedded into practice and accessible to a wide range of audiences, we have had the following impact:

Outputs

- One online learning course entitled, *The Fundamentals of advocacy in health and social care*, launched to support staff working in health and social care to improve their knowledge and understanding of advocacy. This course was developed in response to a recommendation of the COVID-19 Nursing Homes Expert Panel Report that HIQA 'continue to highlight and promote independent advocacy services to residents', and that the rights of residents, in terms of dignity, freedom, choice and equality, need to be respected and at the forefront of policy. This was also highlighted as a gap in the National Nursing Home Experience Survey.
- One booklet developed to enhance understanding of advocacy and enable staff to better support people using services to advocate for themselves and to access advocacy services. This booklet describes what advocacy is, the different types of advocacy, and the role of people working in health and social care in relation to advocacy and how they can support person-centred care within their service.
- One educational video on advocacy developed to support those working in health and social care services to understand advocacy and to improve access to advocacy for people using services. The video features an advocacy expert, nursing home staff, a nursing home resident, a patient representative and members of the Brothers of Charity advocacy group, discussing what advocacy means to them and why it is important.
- One poster developed to promote the online learning course, *The Fundamentals of Advocacy in health and social care*.

Reach

The online learning course, *The Fundamentals of Advocacy in health and social care*, was launched in April 2023. Advocacy is central to person-centred care and support, and a key element of national standards. The advocacy course is available on HSeLanD and the HIQA website. Since its launch, the course has been completed on HSeLanD over 12,000 times. As part of the launch, 38 key stakeholders including members of the working group and focus groups involved in the development of the course were contacted by email to promote and inform their organisations of the course.



An accompanying booklet was launched alongside the online course and approximately 19,000 booklets have been distributed so far. A total of 16,735 booklets were distributed to 2,332 health and social care services and professional organisations, including residential services for older people, residential services for children and adults with disabilities, small and large public and private hospitals, advocacy services, public bodies and academic institutions. Services also received a poster to be used as an aid to promote the online learning course. Follow-up requests for booklets resulted in approximately 1,000 additional booklets being distributed to nursing homes, hospitals, advocacy services, colleges, universities and disability services. Another 1,200 booklets were distributed to service providers at four HIQA stakeholder events for providers of designated centres for older persons.



An educational video was launched with the online learning course and booklet, and aims to support those working in health and social care services. It has been viewed 1,727 times since its launch.

In 2023, we continued to promote our other 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. Since their launch there have been a total of 252,635 completions of these courses on HSeLanD, with close to 100,000 completions in 2023 alone. See Table 1 for the number of people who have completed each course.

Table 1. Online learning course completions

Online learning course	Completions in 2023	Completions since launch
Infection prevention and control	15,823	65,032 (launched in 2020)
Adult Safeguarding	11,459	39,435 (launched in 2020)
Human-rights based care (4 modules)	54,479	135,876 (launched in 2021)
Fundamentals of Advocacy	12,292	12,292 (launched in 2023)
Total	94,053	252,635

All of the online learning courses developed by HIQA are available to complete on [HSeLanD](#) and on the [HIQA website](#).

Engagement

Following the launch of the online learning course, The Fundamentals of Advocacy in health and social care, we commenced a Learning Impact Study to assess the medium to long-term impact of the course on the knowledge and behaviour change

of health and social care staff. We also sought feedback on the booklet and educational video that were developed alongside the course. The secondary aims of the learning impact study are to explore the effectiveness of online learning courses in supporting the implementation of standards, and to develop a framework for measuring the medium- to long-term impact of implementation support tools. In conducting the Learning Impact Study, we engaged with key stakeholders to compile baseline data on advocacy, including the National Care Experience Programme, HIQA's regulation directorates, HIQA's Disability Provider Representative Forum, and advocacy organisations.

As part of the PhD studentship, focus groups were held with 38 health and social care staff to discuss perceived enablers and barriers to implementing health and social care standards and real-world experiences of implementing health and social care standards into practice. The findings will be used to develop tools to assist implementation of national standards within health and social care services.

Change

Positive cultural change within health and social care services embedding key elements of national standards into practice

In the initial phase of the Learning Impact Study, the team conducted a review of the baseline data relating to advocacy in acute hospitals, nursing homes and residential services for people with disabilities. As part of this review, a discussion on advocacy in disability services took place at a meeting of the Disability Provider Representative Forum, at which six provider representatives contributed feedback. The majority of responses provided positive feedback on the advocacy online learning course and booklet, finding them "very informative and very relatable to our work", "excellent," and that the advocacy resources have "improved how they [staff] work in relation to advocacy." Most stated that the HIQA resources are being circulated and used in their service.

Six months after the launch of the course, a survey was distributed to 745 people who had completed the course and agreed to be contacted at a later date. Of those contacted, 155 (21%) people provided feedback on the advocacy course and related materials. Some of the survey findings are displayed in Figure 1. Additionally, 60 (48%) participants reported that they had referred back to the online course since first completing the course and 51 (41%) had referred back to the advocacy booklet.

Figure 1: Learning Impact Study survey findings



Some of those who had completed the course between April and October 2023 provided their feedback on how the course has positively impacted their work. In terms of changes in their work practice, participants stated:

"It helps me to support people and help them to express their views and wishes, also to stand up for their rights." - *Older persons residential worker*

"I have made changes to my communication skills to ensure all patients' rights and needs are met in terms of advocacy..." - *Older persons residential worker*

"I listen more to what people are saying so that I can help them in every way that is possible." - *Disability residential worker*

On changes in their workplace, participants stated:

"More awareness around what advocacy means, how it's different for everyone and how as an organisation we can promote all forms of advocacy." - *Disability community worker*

"Increased confidence in advocating for service users or team members." - *Home support or care service worker*

Providing feedback on the online learning course, participants stated:

"...a really good refresher and reminder
what advocacy is and should be." –
Disability community worker

"A valuable resource for all staff
working in support." – *Disability
residential worker*

1.3 Next steps

In 2024, we will plan to deliver impact through the following areas of our work:

- Conduct focus groups with key stakeholders, including HIQA's regulation teams, service providers and advocacy organisations, and compare baseline data with updated data from HIQA inspection reports and advocacy organisations to measure the impact of the advocacy resources.
- Complete a pre-implementation test phase of the communication toolkit, *Fundamentals of good communication: How to have effective everyday conversations*, to assess usability and its acceptability by Tusla staff. We will revise the toolkit as necessary and will support Tusla to develop a framework for implementation of the toolkit.
- Continue to work in collaboration with the Mental Health Commission to develop a self-appraisal tool to support services to prepare for and implement national standards. We will incorporate findings from stakeholder engagements in conjunction with working group members and commence user-testing of the tool before being finalised.
- Continue to engage with children, young people and families to inform the style and content of the resource for children to explain the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, draft the resource and seek feedback from key stakeholders.
- Undertake a public consultation on the Draft National Standards for Home Support and amend the draft standards to ensure they are fit for purpose and can help improve the experiences of people using home support services. The final draft standards will be submitted to the Minister for Health for approval, following approval by HIQA's Board.

2. Health Information Function

2.1 About

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

- Providing evidence to inform national health information policy
- Developing national health information standards and guidance
- Monitoring compliance against national health information standards.

What we do

We work collaboratively, using best available evidence, to develop recommendations to support decision-making for the Irish digital health and health information landscape. We drive improvements in the quality of data and information by developing national standards and guidance and monitoring 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 synthesise national and international evidence on best practice. We consult with experts, stakeholders, service providers and people that use health and social care services. 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 digital health 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

2023 objectives

- 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.
- Continue to drive improvements to national health information by developing National Standards for Information Management in Health and Social Care.
- 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.
- Through the National Engagement on Digital Health and Social Care, collaborate with the Department of Health and the HSE to 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.
- Participate in international collaborations to facilitate shared learning in Health Information.
- Facilitate fellowship and internship 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.

Desired outcomes for impact

- Provide thought leadership in defining the health information landscape in Ireland by developing recommendations and engagement with stakeholders.
- Support the sharing of standardised health information in the health and social care sector.
- Progress the implementation of national priorities within the digital health 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 three key metrics to measure the change relating to our work:

- Evidence of improvements in practice
- Increased awareness
- Adoption of recommendations and standards.

2.2 2023 impact

Impact in Numbers

- **13,816** unique page visits to the Health Information content on our website.
- **916** people completed our online learning module 'How to Improve Data Quality for Health and Social Care Services'.
- **Three** national standards adopted by national digital health solutions.
- As part of the National Engagement on Digital Health and Social Care:
 - **2,009** members of the public participated in a telephone survey
 - **1,020** professionals in health and social care responded to an online survey
 - **50 participants** took part in nine focus groups.
- Over **600** stakeholders emailed to promote the online survey of the National Engagement on Digital Health and Social Care.
- **11** articles published in professional newsletters and websites on the National Engagement on Digital Health and Social Care.
- **One** new methodology developed to conduct the National Engagement on Digital Health and Social Care based on a review of national and international engagement activities and policies.
- **One** Data Protection Impact Assessment (DPIA) undertaken and a Summary DPIA published for the National Engagement on Digital Health and Social Care.
- **Four** stakeholder organisations and groups were members of the Steering Group for the National Engagement on Digital Health and Social Care.
- **One** article in the Irish Medical Times and **two** radio interviews discussing the National Engagement on Digital Health and Social Care.
- Participated in **five panel discussions** at four national conferences.
- **Six posters** presented at national and international conferences.
- **Six oral presentations** at national conferences discussing our work in relation to health information standards, key considerations for health information policy, and our National Engagement on Digital Health and Social Care.
- **Two webinars** delivered as part of the online SPHeRE Symposium series.
- **Two lectures** delivered to students completing a Masters in Public Health and to those completing the SPHeRE PhD programme.

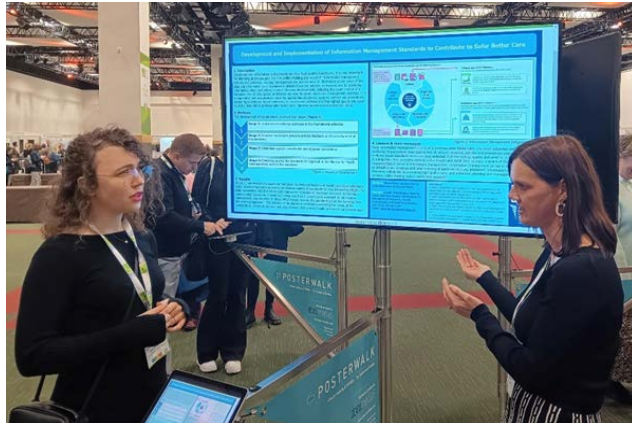
Desired Outcome 1: Providing thought leadership

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

- We contributed to a report led by EIT Health on 'Implementing the European Health Data Space in Ireland'. The report outlines a new framework intending to make it easier for different groups to access and use information about the health of citizens across the European Union (EU) and presents a series of recommendations to implement the framework.^{††}
- Two knowledge-sharing resources, published on our website, outlining examples of challenges and opportunities for health information in Ireland from the perspective of researchers and health and social care professionals. These resources were developed based on our engagement with patient representatives, members of the public and people that use different health and social care services as part of the development of *Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland*.
- Resources developed to support the planning and facilitation of a national workshop, led by the Department of Health, on policy proposals to strengthen national standards setting in Ireland, including participant information packs, discussion questions and presentation.
- Four poster presentations:
 - Irish people's views on electronic health records (EHRs) and data security: findings from a national survey presented at the 16th European Public Health Conference
 - Development and implementation of Information Management Standards to contribute to safer better care presented at the 16th European Public Health Conference
 - 'Facilitating patient safety through effective health information management' presented at the National Patient Safety Office Annual Conference
 - 'Importance of Information Management Standards to Underpin Digital Transformation in Ireland' presented at the HSE Better Together for Digital Healthcare conference.

^{††} Report available at <https://eithealth.eu/wp-content/uploads/2023/11/Implementing-the-European-Health-Data-Space-in-Ireland-EIT-Health-report-1.pdf>



Dr Sarah Jane Flaherty, Health Information Programme Lead, and Dr Barbara Foley, Health Information Quality Manager, presenting their posters at the European Public Health Conference.

Reach

Our work has been cited and referenced on a number of platforms such as:

- An article published in the Irish Medical Times highlighting that 'Technology and eHealth solutions must be radically overhauled' references the findings of the public engagement survey.
- The *Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland* was referenced in a keynote presentation delivered by the Chief Clinical Information Officer of the HSE at the Irish Platform for Patient Organisations, Science and Industry (IPPOSI) conference.
- Our work in relation to developing Draft National Standards for Information Management and the *Key considerations to inform policy for the collection, use and sharing of health and social care information in Ireland* was referenced at the launch of the HSE National Policy for Consent in Health and Social Care Research.

Engagement

Throughout 2023, members of the Health Information Team met regularly with colleagues from the Department of Health to share expertise and relevant national and international evidence to inform national legislation and strategy, specifically in relation to the Health Information Bill, Digital Health Strategic Framework, implementation of the European Health Data Space Regulation and strengthening national standards setting functions. We also engaged directly with the HSE's Chief Clinical Information Officer and Chief Clinical Information Officer for Nursing and

with the National Standards Authority of Ireland to discuss policy proposals in relation to national standards setting functions.

In order to understand approaches being taken in other jurisdictions in relation to the proposed regulation on the European Health Data Space, interviews were held with:

- European Projects Lead, Health Data Hub, France
- Europe & International Director for Digital Health, Délégation Ministérielle du Numérique en Santé, France
- Special Advisor from Federal Ministry of Social Affairs, Health, Care and Consumer Protection, Austria
- Special Advisor to the Cabinet of Minister of Public Health and Social Affairs, Belgium
- Chief Consultant, Unit for Strategy and Analysis, Danish Health Data Agency.

The Health Information Team was a successful co-applicant on two EU grants in 2023. Under the Setting up services by Health Data Access Bodies grant, HIQA is engaging with the Department of Health to put in place resources to support the health information system in Ireland and ensure readiness for implementation of the European Health Data Space Regulation. Our work will specifically focus on engagement and training, developing a national dataset catalogue for health data, and health data quality enhancement. As part of a second grant, HIQA is one of 39 partners across 16 European countries in the QUANTUM consortium including data holders, research and academic institutions, data access bodies, and patient and public representatives. The QUANTUM project aims to develop guidance on the implementation of a data quality, utility and maturity labelling mechanism to meet requirements laid out in the European Health Data Space Regulation. Our involvement in these grants will extend HIQA's network in the area of health information and data quality and build knowledge and skills to support the Department of Health in the future implementation of the European Health Data Space Regulation in Ireland.

Conferences

At the 2023 IPPOSI conference 'Building a Data-Sharing Enabled Health Sector in Ireland', members of the team were invited to participate in two panel discussions. Our Health Information Quality Manager discussed the importance of a rights-based approach to health data sharing in the first panel discussing data sharing across institutions and borders. In the second panel on building our health data future, our Health Information Programme Lead discussed the importance of engagement and a national engagement strategy relating to health data sharing.



Members from the IPPOSI conference panel (L-R) Dr Markus Hesseling, Dr Sarah Craig, Muiris O'Connor, Dr Sarah Barry, Bernard Gloster, Dr Derick Mitchell, Barry Lowry and Dr Maria Ryan.

We were invited to participate in the HSE 'Better Together for Digital Healthcare conference' where we presented on the 'Importance of data and information governance to underpin digital transformation in Ireland. Members of the team also took part in the National Patient Registry Conference 2023 hosted by Health Research Charities Ireland (HCRI) and the Cystic Fibrosis Registry. Our Health Information Quality Manager, took part in a panel discussion which discussed the 'Future of Patient Registries in Ireland' and the supports required to ensure sustainability and value in the future. Our Health Information Programme Lead presented an overview of the Draft National Standards for Information Management in Health and Social Care and discussed the implications for registries.



Dr Barbara Foley, Health Information Quality Manager and Dr Maria Ryan, Health Information Programme Lead, from the Health Information Quality team pictured with fellow speakers and panel members at the Future of Patient Registries in Ireland conference.

Members of the team delivered two presentations at the SPHeRE^{SS} Network 9th Annual Conference 'Population Health: Future Directions and Challenges':

- 'Irish people's views on the collection, use and sharing of health information – opportunities to inform future policy'
- 'Four key policy considerations to improve health information and support safer care and better population health in Ireland'.

Following on from the SPHeRE Annual Conference, we were invited to present as part of the SPHeRE Symposium webinar series. The first webinar held in April 2023 presented 'Irish people's views on the collection, use, and sharing of health information'. The second webinar, held in June 2023, presented the 'Key policy considerations for health information – What's next? Current and future developments'.

In a seminar focused on 'Ireland's preparedness for the European Health Data Space (EHDS)', led by EIT Health Ireland, we participated in a roundtable discussion titled 'Vision and preparedness: What is the potential for the European Health Data Space

^{SS} Structured Population Health, Policy, and Health Services Research Education

and how prepared is Ireland to realise the benefits?' We further contributed to a report, based on the discussions of the seminar, titled 'Implementing the European Health Data Space in Ireland'.



Health Information Quality Manager, Dr Barbara Foley with members from the EIT Roundtable discussion on 'Vision and preparedness: What is the potential for the European Health Data Space and how prepared is Ireland to realise the benefits?'

Additional engagement

Members of the team met with colleagues from the Singapore Ministry of Health, which had representation from its health regulation, cybersecurity, engagement and strategy and regulatory policy and legislation teams. We discussed HIQA's work in relation to health information, some of the challenges and opportunities for health information in Ireland, forthcoming changes to national and European policy, and potential opportunities for future collaboration and knowledge sharing.

Change

Increased awareness

The Department of Health published the Draft General Scheme for the Health Information Bill 2023 in April 2023 with the work of HIQA's health information function referenced in a number of sections. Our *Recommendations on the Implementation of a National Electronic Patient Summary in Ireland* and *What is a National Patient Summary?* were directly cited as informing decision-making in relation to the design of summary care records. Additional aspects of the Bill show alignment with recommendations proposed in our *Key considerations to inform policy for the collection, use and sharing of health and social care information* and our position paper on *The need to reform Ireland's national health information system to support the delivery of health and social care services*. These include the establishment of a national data sharing and linkage service, development of an information governance protocol, greater emphasis on engagement and building

public trust, appointment of a national health information guardian, and enhanced information rights for individuals.

Desired Outcome 2: Supporting the sharing of standardised health information

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

Engagement

Members of the Health Information Team engaged with multiple external committees and initiatives in 2023:

National ePrescribing Project Board

The Health Information Technical Standards Lead participates as an observer on this board, which is overseeing procurement and implementation of a national ePrescribing solution.

National Medicinal Product File Project Board

The Health Information Technology and Standards Manager participates as an observer on this board, which is overseeing procurement and implementation of a national medicinal product solution.

National Standards Association of Ireland (NSAI)

The Health Information Technical Standards Lead participates as an observer in National Standard Authorities in Ireland (NSAI) meetings with an aim of disseminating relevant standards within HIQA.

SNOMED Ireland Governance Board

The Health Information Standards and Technology Manager chairs the SNOMED Ireland governance board, which oversees the SNOMED CT National Release Centre.

Health Service Executive Data Set Management Process Board

The Health Information Technical Standards Lead participates as an observer on this board and provides information about relevant national standards, recommendations and guidance.

Change

Adoption of recommendations and standards

Three national standards, previously developed by HIQA in collaboration with stakeholders, have been adopted by national digital health solutions and programmes this year:

- The National Shared Care Record Programme has adopted the *National Standard on information requirements for a national electronic patient summary* (HIQA 2018).^{***} This means that every National Shared Care Record will comply with the national standard, and provide the essential information required to treat a patient safely during unscheduled care, in a consistent way.
- The National Medicinal Product File has adopted the *Data model for an electronic medicinal product reference catalogue – a National Standard* (HIQA 2015)^{†††} National electronic prescribing and dispensation services require a standardised national list of medications that is updated and maintained appropriately. This means that all national eHealth solutions that use the National Medicinal Product File will have access to that standardised national list of medications.
- The National ePrescribing Project has adopted the *National Standard on information requirements for national community-based ePrescribing* (HIQA 2018)^{†††} The information systems supporting national electronic prescribing and dispensation services require a minimum set of data items and this data set is outlined in the national standard.

All reports sent through the national messaging broker, Healthlink, must comply with the *General Practice Messaging Standard* Version 4.0 (HIQA, 2017). The national standard supports the electronic sharing of health information for a range of typical interactions between general practice (GP) systems and secondary care including ordering laboratory tests or radiological investigations; and the patient. More than two million patient referrals were made through Healthlink in 2023.

^{***} The National Standard on Information Requirements is available at: https://www.hiqa.ie/sites/default/files/2019-01/PatientSummary_InfoReqs.pdf

^{†††} The Data model for an electronic medicinal product reference catalogue is available at: https://www.hiqa.ie/sites/default/files/2017-01/Data_model_for_an_electronic_medicinal_product_reference_catalogue.pdf

^{†††} The National Standard on information requirements for national community-based ePrescribing is available at: <https://www.hiqa.ie/reports-and-publications/health-information/national-standard-information-requirements-national>

Desired Outcome 3: Inform policy and implementation of national digital health priorities

Under the desired outcome of progressing the implementation of national digital health priorities, we progressed the National Engagement on Digital Health and Social Care in 2023. The national engagement is a collaboration between HIQA, the Department of Health, the HSE, and patient representatives. It aims to investigate the attitudes of the public and professionals across health and social care towards the digitisation of services and their attitudes to digital access to information.

Outputs

In 2023, we successfully implemented two national surveys and commenced the focus groups for the national engagement. The following resources were developed to support survey preparation and implementation:

- National engagement methodology based on a review of national and international engagement activities and policies
- Data Protection Impact Assessment (DPIA) to identify and mitigate risks that participants who will be invited to take part may encounter
- Summary DPIA published on the HIQA website to provide potential participants with key information from the DPIA.

In collaboration with our Project Steering Group and the Project Partnership Team, and to support implementation of the surveys and focus groups and help potential participants make an informed decision about taking part, we developed the following outputs:

- Public Telephone Survey Tool
- Public consultation webpage on the HIQA website
- Public FAQs
- Public Participant Information Leaflet
- Suirbhé Poiblí Teileafóin - Ceisteanna Coitianta
- Suirbhé Poiblí Teileafóin - Bileog Faisnéise do Rannpháirtithe
- Public survey infographic
- Professional Online Survey Tool
- Professional Consultation Webpage on the HIQA website
- Professional Online Survey – FAQs
- Professional Online Survey – Participant Information Leaflet
- Suirbhé Ar Líne le haghaidh Gairmithe - Ceisteanna Coitianta
- Suirbhé Ar Líne le haghaidh Gairmithe - Bileog Faisnéise do Rannpháirtithe
- Professional survey infographic.

NATIONAL ENGAGEMENT ON Digital Health & Social Care
An tAidéalán um Thrialláin agus Calabairt Shóiseara
Health Information and Quality Authority

In partnership with the Department of Health and the Health Service Executive.
We want to hear the public's views.

We are doing a telephone survey with the public on digital health and social care.

We want to know what you think of having digital access to your own health and social care information.

We also want to know what you think of using digital tools in health and social care to communicate with and receive care from professionals.

If you are contacted, please complete the survey.

NATIONAL ENGAGEMENT ON Digital Health & Social Care
An tAidéalán um Thrialláin agus Calabairt Shóiseara
Health Information and Quality Authority

In partnership with the Department of Health and the Health Service Executive.
We want to hear the views of professionals in health and social care.

Professionals from dentistry, medicine, midwifery, nursing, pharmacy, pre-hospital emergency care, psychology, or CORU are invited to complete the online survey.

What do you think of the public having digital access to their own health and social care information?

We also want to know what you think of using digital tools in health and social care to communicate with and provide care to people.

Please complete the 15-minute online survey.

Infographics used to promote the National Engagement on Digital Health and Social Care surveys.

We presented two posters at the project at national conferences:

- National Engagement on Digital Health and Social Care presented at the National Patient Safety Office Annual Conference.
- Attitudes of the Public and Professionals to Digital Health and Social Care presented at the HSE Better Together for Digital Healthcare conference. This poster is published on the eHealth Ireland website.

National Engagement on Digital Health and Social Care
Marie Higgins¹, Emma Burke¹, Kevin O'Carroll¹, Rachel Flynn¹
¹ Health Information and Quality Authority (HIQA)

Background

- The EU has set targets where the public will have electronic access to their medical records by 2020. It has also developed the proposal for a regulation on the European Health Data Space (EHDS).¹
- EHDS aims to support individuals to take control of their own health data and supports the use of data for better healthcare.
- In Ireland, the Sustainable Health Reform programme has goals aimed at using digital technologies in health and social care.²
- The Department of Health has published the General Scheme for the Health Information Bill 2023.³
- We have also seen the impacts of the COVID-19 pandemic which brought many accelerated changes in how people interact with health and social care services.
- For example, the public booked vaccination appointments online. Health professionals carried out consultations by video or telephone rather than having in-person appointments.
- In addition, the experience in the HSE brought about potential changes in attitudes to health information technologies.

Aims

- The Health Information and Quality Authority (HIQA), in partnership with the Department of Health and the Health Service Executive (HSE), has commenced a National Engagement on Digital Health and Social Care.
- The aim of the engagement is to listen to, engage with, and understand the opinions, attitudes, and current needs of the public and professionals around the digitalisation of health and social care.
- The engagement will seek opinions on the public having digital access to their own health and social care information.
- It will also investigate the digital provision of care and what this means to the public and professionals.
- In addition, the engagement will identify gaps, and will look at potential benefits, challenges, and impacts for both the public and professionals across health and social care.

Main Themes

The National Engagement on Digital Health and Social Care covers the following themes:

- Information Access and Sharing Information
- Digital Care
- Benefits, Challenges, and Impacts

Methods

The National Engagement on Digital Health and Social Care involves 5 stages (Figure 1):

1. Review of national and international engagements on digitalisation of health and social care, consultation with relevant stakeholders, management advice, and HIQA colleagues
2. Undertake a national telephone survey with the public on digital health and social care (n=200)
3. Undertake a national online survey with professionals in health and social care (dentistry, medicine, midwifery, nursing, pharmacy, and hospital emergency care) (n=200)
4. Focus groups with both the public (n=7) and professionals (n=22)
5. Analyse the evidence, prepare the findings, and publish the report to inform policy plans, and recommendation projects

Discussion

- The engagement will look at what digital access to information and digital services mean to the Irish public and professionals, people's expectations, how they would like to use digital information and services, and where the public and professionals are in terms of readiness for digitalisation.
- The engagement findings will provide evidence and valuable insights to help inform national policy and legislation, future plans in health, technology, and recommendations for the use of digital tools.
- HIQA, the Department of Health, and the HSE will use the findings to help progress digital health and social care in Ireland.

NATIONAL ENGAGEMENT ON Digital Health & Social Care

We want to hear from professionals in dentistry, medicine, midwifery, nursing, pharmacy, pre-hospital emergency care, psychology, or equivalent with GPs.

Please complete the 15-minute online survey.

We would like to hear from professionals in dentistry, medicine, midwifery, nursing, pharmacy, pre-hospital emergency care, psychology, or equivalent with GPs.

Please scan our QR code to complete a 15 minute survey and have your voice heard. The survey is live until 23 October.

References

1. European Commission. Sustainable Digital Health. Digital Targets for 2020.
2. European Commission. Sustainable Digital Health. Digital Targets for 2020.
3. Department of Health. Sustainable Health Reform Programme. Report 2021.
4. Department of Health. Sustainable Health Reform Programme. Report 2021.
5. Department of Health. Sustainable Health Reform Programme. Report 2021.

Attitudes of the Public and Professionals to Digital Health and Social Care
Emma Burke¹, Marie Higgins¹, Kevin O'Carroll¹, Rachel Flynn¹
¹ Health Information and Quality Authority (HIQA)

Background

- The EU has set targets where the public will have electronic access to their medical records by 2020.¹
- The European Health Data Space (EHDS) aims to support individuals to take control of their own health data and supports the use of data for better healthcare.²
- In Ireland, the Sustainable Health Reform programme has goals aimed at using digital technologies in health and social care.³
- The Department of Health has published the General Scheme for the Health Information Bill 2023.⁴
- The impact of the cyber attack in the Health Service Executive (HSE) and the COVID-19 pandemic have brought about potential changes in attitudes to health information technologies.

Aims

- The Health Information and Quality Authority (HIQA), in partnership with the Department of Health and the HSE, is undertaking a National Engagement on Digital Health and Social Care.
- Evidence is being gathered on the attitudes, opinions, and comfort levels of the public and professionals around the digitalisation of health and social care.
- The engagement will identify potential benefits, challenges, and impacts of digitalisation for both the public and professionals across health and social care.

Methods

The National Engagement on Digital Health and Social Care involves five stages:

1. Review of national and international engagements on digitalisation of health and social care consultation with relevant stakeholders, management advice, and HIQA colleagues
2. Undertake a national telephone survey with the public on digital health and social care (n=200)
3. Undertake a national online survey with professionals in health and social care (dentistry, medicine, midwifery, nursing, pharmacy, and hospital emergency care) (n=200)
4. Focus groups with both the public (n=7) and professionals (n=22)
5. Analyse the evidence, prepare the findings, and publish the report to inform policy plans, and recommendation projects.

Discussion

- The engagement will look at what digital access to information and digital services mean to the Irish public and professionals, people's expectations, how they would like to use digital information and services, and where the public and professionals are in terms of readiness for digitalisation.
- The engagement findings will provide evidence and valuable insights to help inform national policy and legislation, future plans in health technology, and recommendations on the use of digital tools.
- HIQA, the Department of Health, and the HSE will use the findings to help progress digital health and social care in Ireland.

Main Themes of the Surveys and Focus Groups for both the Public and Professionals

Information Access, Working Information, Digital Care, Benefits, Challenges, Impacts

References

1. European Commission. Sustainable Digital Health. Digital Targets for 2020.
2. European Commission. Sustainable Digital Health. Digital Targets for 2020.
3. Department of Health. Sustainable Health Reform Programme. Report 2021.
4. Department of Health. Sustainable Health Reform Programme. Report 2021.

Reach

The Health Information Team was directly responsible for promoting the online survey among health and social care professionals. This had multiple phases where we promoted the survey before its launch, again on its opening, and finally, prior to closure. This resulted in approximately 700 stakeholders being directly contacted. Emails were sent to regulatory bodies, unions, and organisations as follows:

- dentistry, medicine, nursing and midwifery, pharmacy, pre-hospital emergency care, psychology, CORU, and other health and social care professional bodies
- HSE national clinical programmes
- hospital groups
- senior managers in the HSE and the Department of Health
- public and patient representatives
- senior and general managers in acute and community healthcare

- universities and colleges, including schools of nursing and midwifery and dentistry
- urban and rural dentists across Ireland
- urban and rural community pharmacies across Ireland.

Other targeted emails comprised:

- one email from HIQA's Chief Inspector to 364 disability and older persons' services
- one email from HIQA's Deputy Chief Inspector of Social Services to its Disability Provider Representative Forum of approximately 90 providers
- 30 public health nurses and non-consultant hospital doctors (NCHDs) were contacted by HIQA's Health Technology Assessment Directorate.

HIQA's Chief Inspector of Social Services also helped to promote the professional survey by publishing a notice on HIQA's Provider Portal, for health and social care providers.

Promotion to stakeholders resulted in 11 articles being published on the following professional newsletters and websites:

- Medical Council Newsletter
- CORU (regulator for health and social care professionals)
- The Irish Computer Society
- The Irish Chartered Physiotherapist
- Association of Occupational Therapists of Ireland
- The Irish Pharmacy Union online and print editions (two articles)
- The Healthcare Informatics Society of Ireland
- The National Lead NCHDs newsletter (two articles)
- The National Medicines Information Centre newsletter, Therapeutics Today.

A press release calling on professionals across health and social care to share their views on the future of digital health and social care in Ireland, was issued to national and regional media, and targeted emails were sent to the medical press. This resulted in:

- one article in the Irish Medical Times
- two radio interviews; one with Tipp MidWest FM and one with Galway Bay FM.

Social media and the HIQA website were used to increase awareness of the national engagement. It was promoted in the internal staff e-zine and through six news articles in HIQA News which is disseminated to over 3,000 people. These resulted in widespread online activity as outlined below.

Social Media

- 32,829 X (Twitter) interactions
- 12,134 LinkedIn interactions
- 2,733 Facebook interactions
- 1,500 Instagram impressions.

HIQA Website

- 258 website views
- 69 press release views
- 57 document downloads (FAQs, PILs, summary DPIA, and infographics).

Engagement

We engaged with the Department of Health, the HSE, and patient representatives to form the National Engagement Steering Group. Five meetings of the Steering Group were held during the year. A Partnership Project Team (PPT) was also formed with representatives from of the Department of Health and the HSE. Ten meetings of the PPT were held. The membership of both groups is detailed in Tables 2 and 3.

Table 2. 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 - Health Information Policy Unit
- HSE – eHealth and Disruptive Technologies
- HSE – Office of Chief Clinical Officer
- National Patient Forum - Patients for Patient Safety Ireland
- National Patient Forum - Pavee Point

Table 3. Members of the Project Partnership Team for the National Engagement on Digital Health and Social Care

Project Partnership Team: National Engagement on Digital Health and Social Care

- Department of Health - Health Information Policy Unit
- Department of Health - Health Information Policy Unit
- HSE – eHealth and Disruptive Technologies

We conducted two focus groups with 12 professionals from across health and social care to inform the development of the national engagement survey tools. These focus groups included representatives from dentistry, medicine, nursing, pharmacy, pre-hospital emergency care, CORU registrants, and members of the Psychological Society of Ireland.

We successfully submitted for ethics approval for the national engagement from the Royal College of Physicians in Ireland (RCPI) Research Ethics Committee. There was ongoing consultation with the RCPI and HIQA's Data Protection Officer.

Through the implementation of an extensive stakeholder engagement plan, we surpassed our minimum numbers for each survey. For our telephone survey with members of the public, there were 2,009 participants, exceeding our minimum number of 1,920 people. For the survey with professionals across health and social care, the minimum sample size required was 672 people and there were 1,020 final respondents.

For the online survey with professionals across health and social care, we engaged with the following organisations to promote the survey among their members or registrants:

- CORU (Ireland's multi-profession health regulator)
- Dental Council
- Medical Council
- Nursing and Midwifery Board of Ireland
- Pharmaceutical Society of Ireland
- Pre-Hospital Emergency Care Council
- Psychological Society of Ireland.

Focus groups with members of the public are currently ongoing with seven groups taking place in 2023. Table 4 outlines the groups represented to date.

Table 4. Groups that participated in the focus groups as part of the National Engagement on Digital Health and Social Care

Participant Group	Number of participants
Members of the Traveller and Roma Communities	Six people
Family carers	Three people
Members of the public who are more likely to use digital health and social care services	Five people

Members of the public who are less likely to use digital health and social care services	Five people
Members of the public who are neutral towards digital health and social care services	Six people
Young people aged 16 and 17 (rural school)	Six people
People with intellectual disabilities	Eight people

Conferences

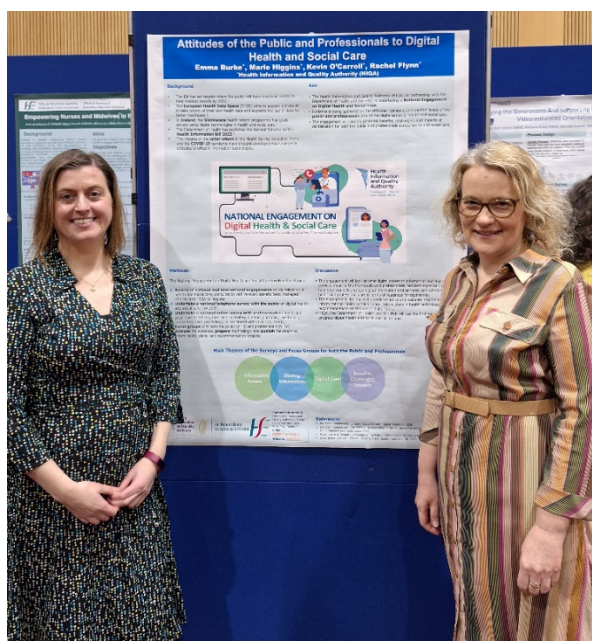
Our Health Information Standards and Technology Manager took part in the opening panel discussion at the Smart Health Summit. The theme was 'Unlocking the Full Value of our Investment in eHealth' and focused on future ehealth strategy, the Digital Health and Social Care Strategic Framework 2023-2030, progress with the electronic health record (EHR) and shared care record programme, and the roadmap and investment case for EHR deployment.



Dr Kevin O'Carroll, Standards and Technology Manager (middle), discussed the national engagement as part of a panel discussion at the Smart Health Summit.



Marie Higgins, Programme Lead, Technical Standards, presenting the poster to Colm Henry, the Chief Clinical Officer of the HSE, at the National Patient Safety Office Annual Conference.



Emma Burke, Research Officer, and Marie Higgins, Programme Lead, Technical Standards, with their poster at the Better Together for Digital Healthcare Conference 2023.

Additional Engagement

Members of the team also engaged with the following groups to promote the National Engagement on Digital Health and Social Care:

- SOLAS, the national state agency for further education and training
- Expert Review Body for Nursing and Midwifery Implementation Action Group 3 (IAG3) Digital Health meeting
- Pharmacy eHealth Group meeting
- School of Linguistic, Speech & Communication Sciences, Trinity College Dublin
- Care Alliance Ireland
- Structured Population Health, Policy and Health-Services Research Education (SPHeRE)
- National Mirror Group for the 1+ Million Genomes for Europe.

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

- An update to *the Information Management Arrangements for National Health and Social Care Data Collections: Evidence Synthesis* (Version 2) was published.
- A link to a searchable Microsoft Excel file was added to the Catalogue of National Health and Social Care Data Collections webpages on the HIQA website in 2023. This Excel file will make it easier for all stakeholders, including healthcare professionals, people using services, researchers, policy-makers, service-users and members of the general public, to search catalogue entries for information specific to their needs.

Reach

Online learning modules and guidance resources

Our *Guidance on a data quality framework* was published in 2018 and was downloaded 45 times in 2023.^{§§§} The Health Information Team's two-module online learning course on 'How to Improve Data Quality for Health and Social Care Services' has been available on HSEland and the HIQA website since its launch in 2022. Table 5 below shows the number of people who have completed each of the two modules this year.

Table 5: Online learning course completions

Online learning course	Completions in 2023	Completions since launch
Introduction to Data Quality	703	1,576
Developing a Data Quality Framework	213	508
Total	916	2,084

- The Introduction to Data Quality module is included in the training schedule for staff working with national community waiting list data.

^{§§§} Our *Guidance on a data quality framework* is available at: <https://www.hiqa.ie/reports-and-publications/health-information/guidance-data-quality-framework-health-and-social-care>

- Aspects of HIQA's 'Introduction to Data Quality' module have been incorporated into the 'Making use of information and data quality' training for all new regulation staff in HIQA. The training is carried out three times per year and the slides used include links where the online learning course can be completed on the HIQA website and on HSELand.
- The Healthcare Pricing Office (HPO) used HIQA's *Guidance on developing a data quality framework* to develop a data quality framework for their organisation which was published in January 2023. The HPO is the managing organisation for four national data collections - Speciality Costing Data, Patient Level Costing Data, Hospital In-Patient Enquiry (HIPE) and National Perinatal Reporting System (NPRS).
- The HPO also used HIQA's *Data Quality Assessment Tool for health and social care* to inform the development of a data quality assessment tool for their organisation. ****

Catalogue of national health and social care data collections

- The Catalogue is included on the HSE Research and Development website as part of a list of frequently used sources of data for health research in Ireland.†††
- HSE Social Inclusion utilised the Catalogue excel file to help establish a baseline of health and social care data systems that collect ethnicity data.

Engagement

Draft 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 6.

**** The HPO data quality assessment tool is available here: http://download.hpo.ie/DQ/HPO_Data_Quality_Assessment_Tool.xlsx

††† The HSE Research and Development website can be accessed here: <https://hseresearch.ie/data-sources/>

Table 6: 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 ➤ Health Informatics Society of Ireland (HISI) ➤ Healthcare Pricing Office ➤ Health Protection Surveillance Centre ➤ Health Research Board ➤ 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 ➤ Tusla

As part of the public consultation on the Draft National Standards for Information Management in Health and Social Care, we held the final focus group with eight representatives from private hospitals. We also engaged with the following stakeholders to inform the development of the standards:

- Policy Unit and Health System Performance Management Unit, Department of Health
- Department of Children, Equality, Disability, Integration and Youth
- Private Hospitals Association
- National Cancer Control Programme (NCCP).

To assess the readability and interpretation of the standards and features from different perspectives we conducted three think-out loud sessions with representatives from the National Office of Clinical Audit (NOCA), the National Screening Service and HIQA's health and social care standards function.

Additional engagement

Additional engagement undertaken included presentations at:

- 2023 HSE Data Collaborathon discussing 'The importance of high-quality data and how to achieve it'.
- 2023 HealthTech Conference on the 'Importance of good information management practices to underpin digital transformation in Ireland'.

Members of the team delivered lectures on HIQA's health information work to candidates from the SPHeRE PhD programme at Trinity College Dublin in February 2023 and to Masters of Public Health students at University College Cork in November 2023.

At the 16th European Public Health Conference 2023, our Health Information Quality Manager was invited to act as Chair of an oral presentation session that focused on digital health in practice. The session included presentations from researchers across Europe discussing topics such as co-designing summary formats of evidence synthesis with end users, and use of telemedicine in the management of heart failure during COVID-19 period.



Health Information Quality Manager, Dr Barbara Foley as Chair for the Digital Health in Practice oral presentation session at the 16th European Public Health Conference 2023.

Members of the Health Information Team met with members of a working group from the HSE South - Department of Public Health leading on the development of the new Outbreak Case and Incident Management system (OCIMS). We described the significance of the Draft National Standards for Information Management for the new system, as well as noting key contacts for the working group in terms of current developments within the health information landscape.



Health Information Programme Lead, Suzanne Barror at the 2023 HSE Data Collaborathon.

Our team represents HIQA on Europe's 1+ Million Genome Initiative with a Technical Standards Programme Lead participating in the Department of Health's National Mirror Group and two EU working groups, one on Data and Metadata Standards and one on Quality Standards.

Our Programme Lead participated in a Collective Intelligence session as part of the TRAUMA Study and shared relevant findings of our work in relation to public and patient engagement, information standards and data quality. The TRAUMA Study is a collaboration between the Royal College of Surgeons Ireland, the National Office of Clinical Audit (NOCA) and the National Ambulance Service (NAS) and involves joining the electronic patient care record of the NAS and the Major Trauma Audit of NOCA to create a complete database of the patient journey from incident to recovery.

Student Placements

The Health Information Team supported four student placements in 2023:

- two undergraduate students from the School of Medicine, University College Dublin (UCD) as part of the Student Summer Research Awards (SSRA)
- two undergraduate students in Health Sciences as part of the EUSA academic internship.

These placements have helped advance academic relationships and build skills and knowledge in relation to health information in the next generation of health and social care professionals.

Change

Evidence of improvements in practice

In 2023, there were over 916 completions of our online learning course, How to Improve Data Quality for Health and Social Care Services, 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. 99% of those who completed an evaluation for the module on Introduction to Data Quality in 2023 reported that they feel they have a better understanding of data quality having completed the module.

The National Screening Service (NSS) has used our *Information management standards for national health and social care data collections* and related guidance material to develop an Information Governance Framework to support quality and patient safety at the NSS. The framework is relevant for all national data collections managed by the organisation: BreastCheck, BowelScreen, CervicalCheck and Diabetic RetinaScreen. The framework has not yet been published but this work was shortlisted for the Excellence in Healthcare Management award in the Irish Healthcare Awards 2023.

2.3 Next steps

In 2024, 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 the delivery of an EU grant in relation to setting up services by health data access bodies.
- Collaborate with European colleagues as part of the QUANTUM consortium to deliver the EU Horizon grant in relation to the development of guidance on a data quality and utility label as set out in the European Health Data Space regulation.
- Continue to drive improvements to national health information by publishing *National Standards for Information Management in Health and Social Care*, once approved by the Minister for Health, and associated self-assessment tool, assessment and judgment framework, and relevant guidance.
- Undertake an evidence review to support national policy for registries and national data collections.
- Complete the National Engagement on Digital Health and Social Care.
- Advance the digital health goals of Sláintecare, the European Commission's Europe's Digital Decade: digital targets for 2030, and the European Health Data Space through the promotion of the findings from the National Engagement on Digital Health and Social Care.
- Work collaboratively with the Department of Health and the HSE in relation to the development and implementation of national health information standards.

3. National Care Experience Programme

3.1 About

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The Programme is a joint initiative 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. Two new surveys of mental health care and cancer care are under development. 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.



⁺⁺⁺ The Survey Hub is accessible here: <https://yourexperience.ie/survey-hub/>

2023 objectives

- Conduct a review of the model and methodology of the National Inpatient Experience Survey.
- Implement and report on the National End of Life Survey.
- Report on the findings of the National Maternity Bereavement Experience 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.
- Commence development of a model and methodology to enable implementation of a survey of people who use mental health services.
- Commence development of a cancer care survey.

Desired outcomes for impact

- Drive the use of survey findings to inform quality improvement, policy initiatives, monitoring and standard-setting activities.
- 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:

- Quality improvement responses to survey findings
- Use of survey data.

3.2 2023 impact

Impact in numbers

- **4,570** respondents to the National End of Life Survey. These were the bereaved relatives and friends of people who died between September and December 2022.
- **Five** reports published
 - Findings of the National Maternity Bereavement Experience Survey (One national report and three loss-specific reports)
 - Technical report of the National Inpatient Experience Survey 2022.
- **Three** published journal articles on the topics of shared decision-making, development of the National End of Life Survey, and factors influencing confidence and trust in maternity staff.
- **12** dashboard training sessions with **86** participants accessing the National End of Life Survey findings.
- **19** international calls with national and regional survey organisations on the development of the cancer and mental health surveys, as well as the international review of the National Inpatient Experience Survey.
- **Eight** focus groups with 64 participants as part of the revision of the National Inpatient Experience Survey.
- **11** information sessions held with care providers on the National Inpatient Experience Survey, National End of Life Survey and the mental health survey.
- **Two** active Health Research Board grants – Ongoing Secondary Data Analysis Project with Maynooth University and recently-awarded Applied Partnership Award with University of Galway.
- **Eight** data access requests for research purposes granted.
- **12** oral and **five** poster presentations at national and international conferences.
- **One** workshop at the European Public Health conference, with **five** presentations on key findings and insights from the National Care Experience Programme.

Desired Outcome 1: Drive the use of survey findings to inform quality improvement, policy initiatives, monitoring and standard-setting activities.

Under the desired outcome of driving the use of survey findings to inform quality improvement, policy initiatives, monitoring and standard-setting activities, we have had the following impact:

Outputs

- Four reports were published to disseminate the findings of the National Maternity Bereavement Experience Survey:
 - Findings of the National Maternity Bereavement Experience Survey 2022
 - Report on experiences of second trimester miscarriage
 - Report on experiences of stillbirth
 - Report on experiences of the early neonatal death of a baby.
- A response document addressing the findings of the National Maternity Bereavement Experience Survey was published by the HSE outlining national and local-level plans to improve maternity bereavement care.
- National Care Experience Programme results were included as key indicators of care quality in the National Healthcare Quality Reporting System and the Health System Performance Assessment framework, published by the Department of Health.
- Interactive dashboard for the National Maternity Bereavement Experience Survey was made available on www.yourexperience.ie, which allows interested stakeholders to further explore the survey results in an understandable, interactive way.
- A report outlining recommended revisions to the National Inpatient Experience Survey was presented to the Programme's Steering Group. The report was developed based on extensive research and engagement with stakeholders.



Reach

Between March and May 2023, 9,446 people were invited to participate in the National End of Life Survey. Individuals who registered the death of a family member or friend (aged 18 or over) between 1 September and 31 December 2022, were eligible to participate in the survey. Maternal, sudden or accidental deaths were outside the scope of the survey. The survey is the first to cover a range of settings including care at home, in hospices, hospitals, nursing homes and other residential care settings. The findings will be published in April 2024, with a quality improvement response document due to be published by the HSE concurrently. Five meetings with representative bodies of private care providers from the nursing home and hospital sectors, as well GPs, have been held to encourage the development of sectoral quality improvement initiatives in response to the findings of the survey.





The National Care Experience Programme launched a 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. The purpose of the podcast is to raise awareness of the surveys and how they will contribute to improving care.

Two episodes of *Let's Talk Care Experience* were released in 2023 and covered the following subjects:

- Ireland's first National End of Life Survey. In this episode Donnacha O'Ceallaigh, Project Lead, provided information on the new survey, including what questions were asked, how the survey will contribute towards quality improvements, who was eligible and how people could take part.
- The importance of supporting women during their infant feeding journeys. We spoke with two of Ireland's lactation and infant feeding experts, Dr Krysia Lynch, Maternity Care Expert, Association for Improvements in the Maternity Services Ireland, and Claire Bulfin, clinical midwife specialist lactation consultant, University Hospital Waterford. Krysia and Claire talked about the importance of information and the supports available to women before birth and during infant feeding. The guests discussed the importance of support not only from professionals but also from support groups, family and friends. The podcast also covered the experiences of new mothers, as documented in the results from the National Maternity Experience Survey, which took place in October and November 2019.

Engagement

Information sessions, focus groups, presentations and training sessions with healthcare staff, providers and other stakeholders are an important part of the National Care Experience Programme engagement activities. In 2023, the following engagement activities were undertaken:

- 12 National End of Life Survey dashboard training sessions were held, with 86 participants in total. The sessions were designed to assist users to engage with survey findings with a view to developing quality improvement responses.
- 188 people signed up to the National End of Life Survey, logging in a total of 7,654 times. The dashboard is available to care providers, policy-makers and

regulatory staff. It allows users to engage with the survey results and use them to identify improvement initiatives and areas of good practice.

- 92 people signed up to the National Maternity Experience Survey, logging in a total of 5,479 times. The results on the dashboard informed the creation of the HSE response document, outlining the measures taken to address the findings of the survey.
- 19 international calls with national and regional survey organisations were conducted on the development of the cancer and mental health surveys, as well as the international review of the National Inpatient Experience Survey. The team spoke with counterparts from numerous countries including Switzerland, Australia, Norway, Canada, and United States of America.
- Eight focus groups with 64 participants as part of the revision of the National Inpatient Experience Survey. The purpose of the focus groups was to invite reflections on all aspects of the existing survey and identify areas for improvement. Participants included patient representatives, clinicians, policy makers and other stakeholders.
- 11 information sessions held with care providers on the National Inpatient Experience Survey, National End of Life Survey and the mental health survey. The purpose of the sessions was to inform attendees on various aspects of the survey programmes, including their implementation and objectives.
- An internal presentation on the National Maternity Bereavement Experience Survey results was given to members of HIQA staff in September. Anna Maria Verling, Project Lead, and Conor Foley, Senior Analyst, presented on the results of the survey.



Tracy O'Carroll, Head of the National Care Experience Programme, speaking with delegates at the National Patient Safety Office Annual Conference.

Change

Quality improvement responses to survey findings

National Maternity Bereavement Experience Survey

The results of the first National Maternity Bereavement Experience Survey were published in April 2023.

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.

In response to the findings, the HSE published *The HSE response to the findings of the National Maternity Bereavement Experience Survey*^{§§§§} outlining the measures it will take to address the findings of the survey at local and national levels. The response document was coordinated by the National Women and Infants Health Programme and published on the same day as the main findings report.

The actions outlined in the HSE response document aligned with the core pillars of the *National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death*. Examples of initiatives undertaken include the appointment of clinical leads for pregnancy loss in maternity hospitals and units; investment in dedicated bereavement rooms in maternity hospitals and units; and provision of specialised communications training for all staff.



Rachel Flynn, Director of Health Information and Standards, Anna Maria Verling, Project Lead, and Dr Conor Foley, Senior Analyst at the launch of the findings for the National Maternity Bereavement Experience Survey.

National End of Life Survey

In 2023, we successfully implemented the National End of Life Survey which is the first national survey to ask 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

^{§§§§} Report available here: <https://yourexperience.ie/wp-content/uploads/2023/05/HSE-Response-Report-NMBES-2022.pdf>

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

The HSE has committed to publishing a quality improvement response document outlining actions to be taken to address the findings across all services under its remit. In addition, five meetings have been held with representative bodies of private care providers to encourage the development of sectoral responses to the survey findings. The survey findings will also inform national standards and monitoring programmes within HIQA, and national policy and legislation in the Department of Health.

New surveys and review of the National Inpatient Experience Survey

Work commenced on the development of new surveys of mental health services and cancer care. National and international reviews were carried out to inform the development of an appropriate and actionable model and methodology for carrying out each survey.

In addition, a major project was undertaken to review and revise the National Inpatient Experience Survey. The purpose was to ensure that the survey remains fit for purpose and reflects changes since its original development that was completed in 2016. The review process reflects a strategic commitment to agility and continual improvement. The findings of the review were collated into a series of recommendations for amendments to the survey tool, model and methodology for consideration by the National Care Experience Programme Steering Group.



Tina Boland, Project Lead for the National Inpatient Experience Survey, in Dublin City University.

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

- Three academic papers were published in high-quality journals:
 - Adegboyega Ojo, Nina Rizun, Grace S. Walsh, Wojciech Przychodzen, Mona Isazad Mashinchi, Conor Foley, Daniela Rohde, Building confidence and trust in Ireland's National Maternity Services Workforce –What matters most and how?, Health Policy, Volume 138, 2023, 104947, <https://doi.org/10.1016/j.healthpol.2023.104947>.
 - Linda Drummond, Sarah Jayne Guiney, David Connolly, Conor Foley, Laura O'Connor, Tracy O'Carroll, Rachel Flynn, Daniela Rohde, Experiences of shared decision making in acute hospitals: A mixed methods secondary analysis of the Irish National Inpatient Experience Survey, Patient Education and Counseling, Volume 113, 2023, 107755, <https://doi.org/10.1016/j.pec.2023.107755>.
 - Diarmuid Ó Coimín, Daniela Rohde, Conor Foley, Tracy O'Carroll, Rachel Flynn. Dying, death and bereavement: developing a national survey of bereaved relatives. BMC Palliative Care 22, 14 (2023). <https://doi.org/10.1186/s12904-023-01135-2>.
- The academic slide deck originally published in 2022 was updated in 2023. The slide deck is available on the Survey Hub, **** and 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.
- Five poster presentations were delivered, including:
 - 'Applying a human-rights based approach in the development and implementation of The National End of Life Survey' presented at the North West Hospice Explorations National Palliative Care Conference and at A Human Rights based approach for Palliative Care Conference

**** The Survey Hub is accessible here: <https://yourexperience.ie/survey-hub/>

- ‘National Maternity Bereavement Experience Survey 2022’ presented at the NHS Bereavement Conference and at the UCC College of Medicine and Health Future Research Conference
- ‘Channelling experiences of end-of-life care into better services in Ireland: The National End of Life Survey’ presented at the 9th SPHeRE Network Annual Conference.
- One best poster award received at the 9th SPHeRE Network Annual Conference for our poster on the National End of Life Survey.

Reach

The National Care Experience Programme uses its website (www.yourexperience.ie), X (Twitter), Facebook and Instagram to communicate with stakeholders across the health and social care system in Ireland and beyond. In 2023, there were:

- 5,382 visitors to www.yourexperience.ie
- 2,023 downloads of reports
- 3,360 followers on X
- 128k X impressions
- 973 Facebook page reach⁺⁺⁺⁺
- 679 Instagram reach
- 1,733 views of the interactive results across all surveys.

Engagement

Presentations

Members of the team attended 29 conferences and events in 2023 to present survey findings and promote awareness and participation of ongoing and upcoming surveys.

The National Care Experience Programme successfully delivered a workshop entitled Developments in Patient Experience Surveys at the 16th European Public Health conference in Dublin. The workshop included five presentations by team members, HIQA and HSE partners, and academic collaborators covering multiple topics:

- Adapting to changing healthcare landscapes: International trends and practices in inpatient experience surveys

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

- “The worst has already happened”: Communicating sensitively with bereaved survey participants
- Generating actionable evidence from free-text feedback to improve maternity and acute hospital experiences: A computational text analytics & predictive modelling approach
- Learning from experience: Integrating patient experience survey responses with other key metrics to understand and improve care quality and patient safety
- How do patient and care experience data inform policy and practice? Insights from the Irish National Care Experience Programme.

The team also delivered 12 oral presentations at conferences, with examples including:

- ‘Patient experiences of hospital care during the COVID-19 pandemic in Ireland’ presented at the 9th SPHeRE Network Annual Conference
- ‘Listening to the voice of nursing home residents and their family members; insights from the National Nursing Home Experience Survey’ presented at the Irish Gerontological Society, 70th Annual Scientific Meeting
- ‘The National End of Life Survey’ presented at Marymount International Conference.

We participated in four stakeholder engagement events held by HIQA for providers of designated centres for older persons in Dublin, Cork, Galway and Mullingar. A total of 678 people attended the events, including registered providers, managers and persons in charge. At these events, we engaged with attendees to raise awareness of the National Nursing Home Experience Survey and the National End of Life Survey.

Academic partnerships

In 2023, 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 one student placement and one internship:

- One student completing the MSc in Applied Social Research, Trinity College Dublin
- Two undergraduate students in nursing and health sciences as part of the EUSA academic internship programme.

We delivered lectures and workshops on the work of the Programme to students of the following courses:

- BSc in Physiotherapy in Trinity College Dublin

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

Health Research Board-funded 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 the analyst team in the National Care Experience Programme. In 2023, multiple engagement events were held with relevant stakeholders including hospital quality and safety personnel, patients, clinical staff and others to explore preliminary analyses and shape potential project outputs including dashboards and reports.

The National Care Experience Programme was a successful co-applicant with the University of Galway on the Health Research Board's Applied Partnership Awards grant scheme. This project is entitled 'No data about us without us: Co-designing the Integration of Health Inequalities into the National Inpatient Experience Survey to Enhance the Participation of and Data about Marginalised Communities'. The aim is to investigate how the National Inpatient Experience Survey could be redesigned to make it better at identifying inequalities in hospital care. The first objective of this project is to analyse how patient experience surveys in other countries address health inequalities. The second objective is to engage communities that are often affected by health inequalities, such as women, people from working class backgrounds, the LGBT+ community, people who experience racism, to discuss inequalities in hospital care which will allow us to identify priority issues for the survey. The third objective is to facilitate participatory workshops in which people affected by health inequality, healthcare practitioners and health policy-makers will co-design potential new questions for the National Inpatient Experience Survey. These will feed into the survey redesign process which will improve data collection on inequalities in patient experiences of hospital care in Ireland. The project is led by Dr Chris Noone at University of Galway, with support from analysts on the National Care Experience Programme.

International engagement

The team demonstrated its strategic commitment to international engagement by holding 19 calls with counterparts in other jurisdictions. The team spoke with counterparts from numerous countries including Switzerland, Australia, Norway, Canada, the United States, and others. In November, further contact was made with representatives from these and other jurisdictions to establish a forum for more regular engagement among agencies conducting care experience surveys.



Donnacha O'Ceallaigh, Project Lead for the National End of Life Survey, presenting at the Scottish Partnership for Palliative Care's Annual Conference in Edinburgh.

Change

Data access requests

The National Care Experience Programme promotes a culture of data transparency, with reports and interactive online reporting platforms available on our website, 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 team and or the relevant programme board, depending on the nature and purpose of the request. In 2023, the programme received and granted eight data access requests from students and staff in academic institutions and hospitals.

Informing Ireland's Health Systems Performance Assessment Framework and the HSE Quality and Safety Signals system

The Health Systems Performance Assessment (HSPA) Framework 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. The HSPA online interactive tool was launched in June 2023.

The HSE is in the process of developing the Quality and Safety Signals system. The purpose of this Sláintecare-funded project is to provide an online system that optimises the use of available data for patient safety surveillance and quality improvement. The National Care Experience Programme provided anonymised data from the National Maternity Experience Survey in the development of a prototype system.

3.3 Next steps

In 2024, the ongoing work on developing surveys of mental health services and cancer care will continue. We are working closely with the Mental Health Commission and the National Cancer Control Programme to inform the development of these surveys.

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

In 2024, we plan to deliver impact through our work in the following areas:

- Report on the findings of the National End of Life Survey.
- Implement and report on the findings of the revised National Inpatient Experience Survey.
- Develop the analytical and research function of the Programme, strengthening links with academic and other partners to maximise the value, use and understanding of survey data and findings.
- Deliver the procurement competitions for the data and digital requirements that includes commencing two new contracts. This will ensure the continued maintenance, hosting and support of the programme's website, as well as the provision of services supporting administration of national surveys as well as delivery of the digital solution that offers an online survey platform as well as a data visualisation platform that will facilitate analysis of survey data.
- Advance development of a model and methodology to enable implementation of a survey of cancer service users.
- Advance development of a model and methodology to enable implementation of a survey of mental health service users.

4. Conclusions and next steps

The impact that our work has had against our desired outcomes outlined in this 2023 report for HIQA's HIS Directorate is the result of effort over the last five 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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