



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Knowledge Sharing and Impact Assessment

Health Information and Standards Directorate

2021 REPORT

About the Health Information and Quality Authority

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

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

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

Contents

About the Health Information and Quality Authority	2
Overview of the Health Information and Standards Directorate	4
Introduction	5
1. Standards Setting Function	7
1.1 About.....	7
1.2 2021 impact	10
Impact in numbers	10
Desired Outcome 1: Increased awareness and understanding	11
Desired Outcome 2: Supporting the development of a culture where standards and guidance are embedded in practice.....	15
Desired Outcome 3: Increased engagement with staff and people using services.....	23
1.3 Next steps	28
2. Health Information Function	29
2.1 About.....	29
2.2 2021 impact	31
Impact in Numbers.....	31
Desired Outcome 1: Providing thought leadership	32
Desired Outcome 2: Supporting the sharing of patient information	38
Desired Outcome 3: Progressing the implementation of national eHealth priorities.....	40
Desired Outcome 4: Ensuring the public voice is heard	45
Desired Outcome 5: Improving the quality of health information in national data collections.....	49
Desired Outcome 6: Supporting those working in services to improve data quality	51
2.3 Next steps	53
3. National Care Experience Programme	55
3.1 About.....	55
3.2 2021 impact	57
Impact in numbers	57
Desired Outcome 1: Expanding to new areas to capture people’s experiences of care .58	
Desired Outcome 2: Developing research, academic and international partnerships and links with key stakeholders.....	63
3.3 Next steps	68
4. Conclusions and next steps	69

Overview of the Health Information and Standards Directorate

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

The HIS Directorate has three core functions:

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

The Standards Team delivers against this function through the development of national standards and implementation supports for health and social care services in Ireland. The standards setting function operates under the remit of the Health Act 2007 and is guided by a prioritisation process* and is in line with HIQA's Corporate Plan 2019-2021.

2. Informing and driving health information quality and eHealth

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

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

The National Care Experience Programme is responsible for this function which currently includes running national inpatient, the maternity, the maternity bereavement, the end of life and nursing home surveys. The National Care Experience Programme operates in line with the objectives and remit, as laid out in the National Care Experience Programme Strategic Plan (2019-2021).‡

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

† Available at: <https://www.hiqa.ie/reports-and-publications/health-information/health-information-strategic-objectives-2020-2022>

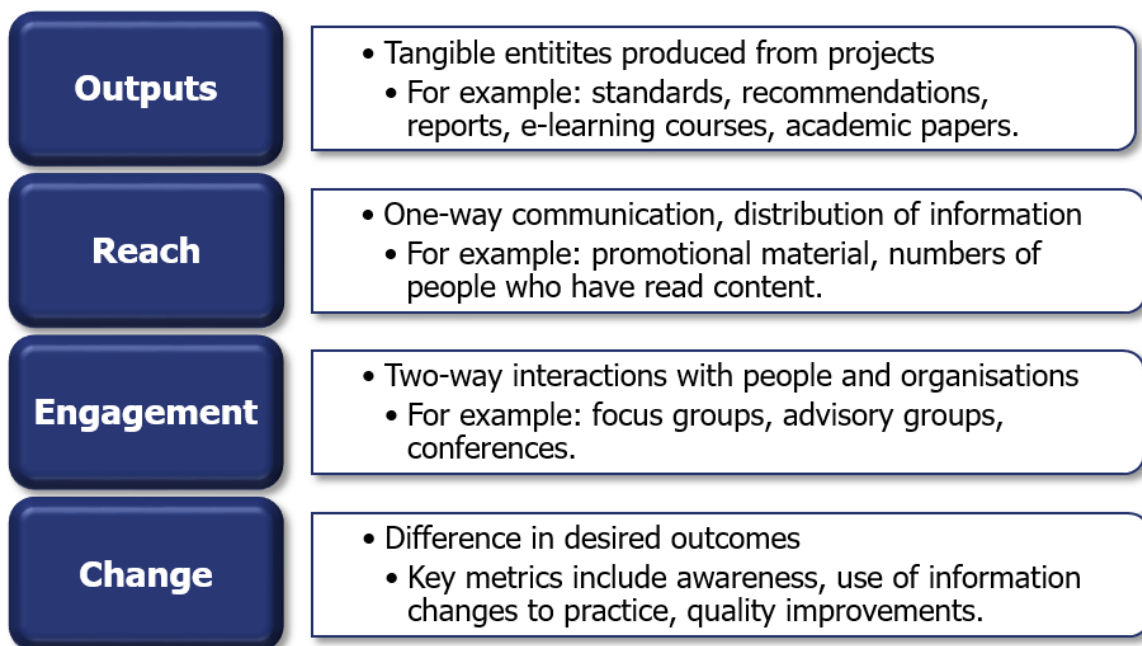
‡ Available at: <https://yourexperience.ie/about/news/national-care-experience-programme-strategic-plan-2019-2021/>

Introduction

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

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

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



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

Purpose of this report

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

This report documents the impact of our 2021 business plan objectives, as outlined in the HIQA Business Plan (2021).[§] It also reports on the impact of our work as observed during 2021. This is the third 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.

[§] Available at: <https://www.hiqa.ie/reports-and-publications/corporate-publication/business-plan-2021>

1. Standards Setting Function

1.1 About

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

Purpose of national standards

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

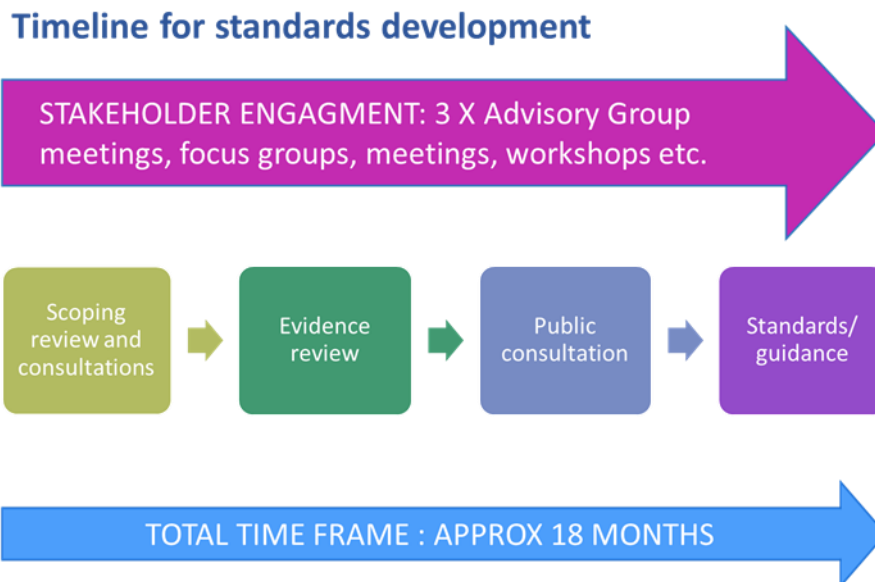
National standards:

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

When we finalise national standards, we also develop additional implementation support tools such as guides, leaflets or online learning modules to help staff working in health and social care services to implement national standards or as a guide to making improvements in a particular area.

How we do it

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



Our vision

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

2021 objectives

- Develop National Standards for Children's Social Services.
- Identify and commence the development of targeted support tools to assist the implementation of the National Standards for Children's Social Services.
- In partnership with the Mental Health Commission, develop Overarching National Standards for the Care and Support of Children using Health and Social Care Services.
- Conduct an international review, public scoping consultation and evidence review to underpin the development of National Standards for Home Support Services.
- Deliver a set of principles to underpin all future standards and guidance for health and social care services.

- Develop support tools to assist in the implementation of the *National Standards for Infection Prevention and Control in Community Services*.
- Review the implementation of the *National Standards for Adult Safeguarding and Guidance on a Human Rights-based Approach in Health and Social Care Services* to identify support tools required in relation to advocacy.
- Develop e-learning modules for service providers and staff, and a video animation for people using services to help raise awareness of, and support, a human rights-based approach in health and social care services.

Desired outcomes

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

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

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

1.2 2021 impact

Impact in numbers

- Undertook a six-week public consultation on the Draft National Standards for Children’s Social Services, in March, with **81** submissions received.
- **Ten** focus groups, engaging with **56** participants, were held to inform the development of Draft National Standards for Children’s Social Services (over the course of the project, there were **71** focus groups held with **395** participants).
- **Three** focus groups with **12** Advisory Group members to explore the requirements to support the implementation of the Draft National Standards for Children’s Social Services.
- **One** set of Draft National Standards for Children’s Social Services submitted for Ministerial approval in December 2021.
- **39** focus groups and **three** telephone consultations with **217** participants to inform the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services.
- **One** set of Draft Overarching Standards for the Care and Support of Children using Health and Social Care Services developed.
- **A six**-week public consultation on the draft overarching standards for all health and social care services working with children launched in September, with **58** submissions.
- **Three** focus groups with **13** advisory group members to explore the requirements to support the implementation of the overarching standards for all health and social care services working with children.
- **One** online learning course of **four** modules to support the understanding and application of a human rights-based approach was launched, with over **46,000** course completions.
- Total of **71,907** module completions across **three** e-learning courses.
- Launched **one** video animation on a human rights-based approach, with over **4,690** views.
- A **four** week public scoping consultation held to inform draft National Standards for Homecare and Support Services, with **182** submissions.
- **22** focus groups held with **122** participants to inform draft National Standards for Homecare and Support Services.
- Published **two** evidence reviews and **three** academic papers.
- Hosted **four** workshops, delivered **four** lectures, **four** online conference presentations and **one** poster presentation.
- Published **one** framework to underpin all health and social care standards, based on principles.
- Developed a **three**-year Standards Strategy.

Desired Outcome 1: Increased awareness and understanding

Under the desired outcome of increased awareness and understanding of national standards, guidance, tools and resources developed by HIQA through communication and dissemination, promoting our work at conferences and through the publication of academic papers, and in order to facilitate implementation, we have had the following impact:

Outputs

- Three academic papers published in peer-reviewed journals:
 - ‘Translating a Human Rights-based Approach into Health and Social Care Practice’, Journal of Social Care.
 - ‘What Underpins Good Child-centred Practices in Children’s Social Services?’ Journal of Social Care.
 - ‘Factors that influence the implementation of health and social care Standards: a systematic review and meta-summary protocol’, HRB Open Research.
- Two evidence reviews published:
 - Evidence review to inform the development of Overarching National Standards for the Care and Support of Children using Health and Social Care Services.
 - Evidence review to inform the development of a set of principles to underpin future national standards for health and social care services.
- Four e-learning modules developed to support the *Guidance on a Human Rights-based Approach in Health and Social Care Services*.
- Standards framework published based on principles to underpin all health and social care standards.
- Hosted four workshops, delivered four lectures, four online conference presentations and one poster presentation.
- Video animation developed on a human rights-based approach.

The *Applying a Human Rights-Based Approach in Health and Social Care: Putting National Standards into Practice* e-learning course was launched as a series of four modules between 24 March and 12 May 2021. To help raise awareness of the course, each of the four modules were publicised on HIQA’s social media platforms, including Instagram, Facebook, Twitter and LinkedIn.

In June 2021, to improve an understanding of a Human Rights-based Approach for Health and Social Care staff, a paper titled *Translating a Human Rights-based Approach into Health and Social Care Practice* was published in the Journal of Social Care. On 10 December 2021, for International Human Rights Day, content was

published across our social media platforms (Twitter, LinkedIn, Instagram and Facebook) to raise awareness of the guidance, the e-learning course, and the suite of resources to support a human rights-based approach.

A paper called '*What Underpins Good Child-centred Practices in Children's Social Services?*', published in the Journal of Social Care in June 2021, highlighted the new Draft National Standards for Children's Social Services. Social media activity on UN International Children's Day, as well as a press release, aimed to raise awareness of the draft standards. In addition, the public consultation on the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services was widely publicised across social media.

Reach

The published paper, titled *Translating a Human Rights-based Approach into Health and Social Care Practice*, has been downloaded 241 times (at the time of writing) since publication in June 2021.

The public consultation on the draft standards was widely publicised on Twitter, Instagram, Facebook and LinkedIn and a press release was issued to promote awareness of the standards and their purpose. This included:

- 12 tweets
- three posts on LinkedIn
- one post on Instagram
- one post on Facebook
- 300 stakeholders notified of the public consultation via email.

The published paper in the Journal of Social Care titled '*What Underpins Good Child-centred Practices in Children's Social Services?*' was downloaded 105 times (at the time of writing). In 2020, members of the team published a paper titled *Translating national standards into practice: Supporting social care professionals* in the Journal of Social Care. Over the course of 2021, this paper was downloaded 296 times by government departments, academic institutions and commercial entities. The paper has had international reach, with readers downloading the paper across the United States of America as well as some European, Asian and African countries.

Engagement

In June 2021, the Standards Team was invited to deliver an online workshop to lecturers on the Social Care Degree programme in the Atlantic Technological University Sligo. This workshop, on the resources we have published to support a human rights-based approach (HRBA) in health and social care services, was to

inform their five-yearly review of the Social Care Degree programme to ensure that it meets with current standards of education for social care. This interactive workshop introduced lecturers to the academic slide deck on a HRBA which HIQA developed in 2020 for third-level educators of health and social care students. The slide deck was developed to support educators in providing a foundation to students on the relevance of human rights to their future work and how they can apply a HRBA in practice. In addition, we introduced them to the guidance and e-learning course on a HRBA as well as the broader suite of resources that HIQA has published to support health and social care practitioners and students to understand and apply this approach. In October 2021, the *Guidance on a Human Rights-based Approach in Health and Social Care Services*, the e-learning course and a suite of additional resources were also promoted at an online workshop that the team delivered to social care practitioners and students at the Social Care Ireland Annual Conference.

On 22 October 2021, to promote our work on the Draft National Standards for Children's Social Services, a presentation on the development of the standards was delivered at the National Child Protection and Welfare Social Work conference, which was attended by 300 people. This presentation focused on how the lived experiences of children and young people informed the standards. A similar presentation was also given to HIQA colleagues at an internal lunchtime talk in March 2021.

In January and December 2021, two lectures were given to students completing the Masters in Healthcare Infection at Trinity College Dublin. These included details on the function of the HIS Directorate and the Standards Team with a focus on the development and content of the *National Standards for infection prevention and control in community services* and supporting implementation tools. The lectures also included details on the wider work of HIQA in supporting infection prevention and control through its regulation and HTA Directorate.

Change

Increased awareness

Awareness of national standards continues to rise. The number of course completions of the e-learning modules (71,907 in 2021) shows the level of awareness of these resources, which we have optimised through our use of HSELand. Evaluation of the e-learning modules has also shown that participants now have a greater awareness and understanding of the standards and how to apply them in practice. 99% of respondents of the evaluation of the Adult Safeguarding e-learning module felt they now have a better understanding of adult safeguarding.

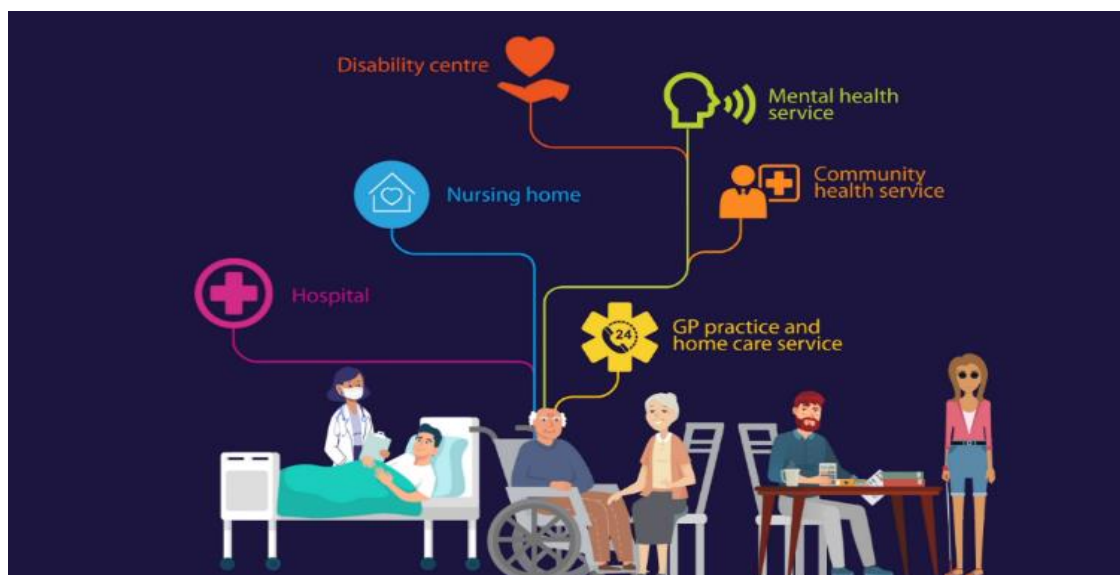
Greater use of social media, publication in peer-reviewed journals (three papers), conference presentations (four), lectures and workshops (eight) and collaboration with the academic sector has also increased awareness of the national standards.

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 the *National Standards for infection prevention and control in community services*, *National Standards for Adult Safeguarding and Guidance on a Human Rights-based Approach in Health and Social Care Services* are embedded into practice, we have had the following impact:

Outputs

- A video animation was produced to raise awareness of promoting human rights in health and social care settings.
- An e-learning course to support the understanding and application of a human rights-based approach was launched.
- Content was published across social media for Ireland's first Adult Safeguarding Day.



In March 2021, a short video animation was published to raise awareness among people using services of what they should expect from a health or social care service that is committed to respecting, protecting and promoting their human rights.

An online learning course to support health and social care staff to understand and apply a human rights-based approach in their work was launched on HSELand between 24 March and 12 May 2021. The *Applying a Human Rights-Based Approach in Health and Social Care: Putting National Standards into Practice* e-learning course consists of a series of four modules:

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

The course builds upon the *Guidance on a Human Rights-based Approach in Health and Social Care Services*, published by HIQA in November 2019. The course delves further into key elements of the guidance to further support staff to understand and implement a human rights-based approach in their work. In addition to promoting and supporting good practice in this area, the course aims to address knowledge and skills gaps that were identified through extensive stakeholder engagement. The course contains practical scenarios describing real-life examples of good and poor practice, self-reflection questions and links to additional resources to extend learning. Each module can be completed separately and the learner receives a certificate of completion at the end of each module. The course is hosted on HSELand to maximise reach and ensure it is accessible to front-line staff.

To promote the *National Standards for Adult Safeguarding*, content was published across social media platforms on Ireland's first Adult Safeguarding Day on 19 November 2021.

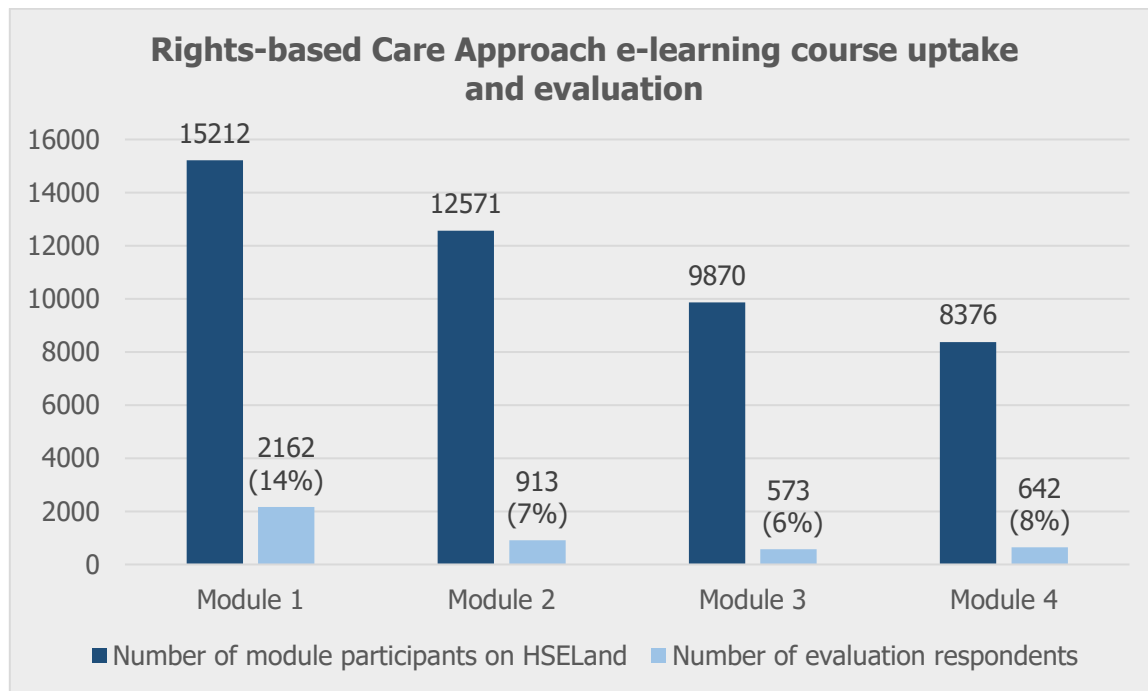
Reach

The *Applying a Human Rights-Based Approach in Health and Social Care: Putting National Standards into Practice* e-learning course was launched as a series of four modules. Upon publication of each module, members of the team contacted large numbers of people and organisations who may have been interested in the module, such as registered providers of residential settings as well as professional bodies. These specifically included designated centres for older people and centres for people with a disability, in order to raise awareness of the modules among their staff members. In terms of the geographical reach of the course, the majority of respondents who completed the module evaluation surveys did so from Ireland, but the surveys were also completed by participants in:

- The UK (102)
- India (5)
- United States (4)
- Jamaica (1)
- Other European countries (6).

Due to the level of interest in the e-learning courses developed by the team, HIQA also made all e-learning courses available on the HIQA website from June 2021. The

short video animation, *Human Rights in Health and Social Care Services*, created for people using services, has also been viewed 4,690 times on YouTube (at the time of writing).



The number of people who completed the e-learning modules in 2021 and since their launch in 2020 are as follows:

Module	Launched	Completions in 2021	Completions since launch
Human-rights based care	24 March 2021	46,000	46,000
Infection prevention and control	18 August 2020	16,170	32,523
Adult Safeguarding	05 November 2020	9,962	14,329

Engagement

At key stages of the development of the *Guidance on a Human Rights-based Approach in Health and Social Care Services*, the team engaged with stakeholders in order to identify the areas where health and social care staff needed further support to put a HRBA into practice.

Feedback from stakeholders in focus groups and public consultation indicated that staff wanted to learn more about the following aspects of a HRBA:

- Effective communication with people using services
- Building people's capacity to make informed decisions about their care and support
- How to manage situations involving competing human rights
- How to support people using services in positive risk-taking.

Subsequent to the publication of the guidance, we undertook a targeted survey of a sample of HIQA inspectors working in the areas of older persons, disability, and healthcare, and convened a workshop with subject-matter experts in the area of human rights across the health and social care sector to agree the key messages and further inform the content of this online course. A draft version of the course was reviewed by the workshop participants and inspectors from HIQA. We also engaged with representatives from the Brothers of Charity Service in Galway to develop a video for the e-learning course. Galway Advocacy Council, a self-advocacy group within the Brothers of Charity in Galway, created a video with advocates explaining what being at the centre of decision-making means to them. The video was published on the HIQA website as a perpetual resource, and widely publicised on social media to raise awareness of this important topic. The video produced by people using services generated a large amount of interest and positive feedback with:

- 133 likes on LinkedIn
- 63 likes on Facebook
- 32 shares on Facebook
- two reels from the video on Instagram had 1,245 and 1,308 views respectively.

Comments on social media demonstrated the learning and motivation achieved by the video. For example, one comment noted:

"What a fantastic video. Lots in that for us all to consider about decision making autonomy. And not for the first time, a woman declaring the she 'doesn't need to be rescued'. Well done to all involved."

To address the recommendations of the COVID-19 Expert Panel for Nursing Homes, the team has initiated a project to develop implementation support tools for the

advocacy elements of the *National Standards for Adult Safeguarding* and the *Guidance on a Human Rights-based Approach in Health and Social Care Services*. To inform this work, meetings have been held with:

- The Regulation Directorate in HIQA
- The National Advocacy Service
- The Patient Advocacy Service
- Sage Advocacy
- The Decision Support Service
- HSE National Office for Human Rights and Equality Policy
- Youth Advocate Programmes (YAP) Ireland.

Change

When giving feedback on the e-learning modules, respondents were asked:

- If they felt they had a better understanding of the subject
- If they intended to change their practices
- If they would recommend the course to a colleague
- If they had suggestions for any other tools that would help them implement what they had learned.

Of those who completed the *National Standards for infection prevention and control in community services: Putting the standards into practice* module,

6,372 of 6,760 (94%) indicated that they felt they had a better

understanding of infection prevention

and control (IPC). Some respondents answered that after completing the module,

they felt that IPC was a shared responsibility for both staff and the public. Out of

6,760 respondents, 5,362 (79%) indicated that they intended to change their

practices. Those who expressed an intention to change answered that they intended

to be more cautious and thorough in their practices. Others said that they would

strive to educate others and remind their colleagues of best practice in the

workplace. Meanwhile, the respondents who indicated that they did not intend to

change their practice explained that they felt they were already using best practice.

Additionally, 6,436 of 6,760 (95%) respondents answered that they would

recommend the module to a colleague. Respondents felt that the content was highly

relevant, especially during a global pandemic. Several people with responsibility for a

team of staff stated that they would be arranging for their staff to take this training

also.



Respondents of the evaluation survey on the *National Standards for Adult Safeguarding: Putting the Standards into Practice* module were asked if they felt they had a better understanding of adult safeguarding and 2,558 of 2,588 (99%) answered positively.

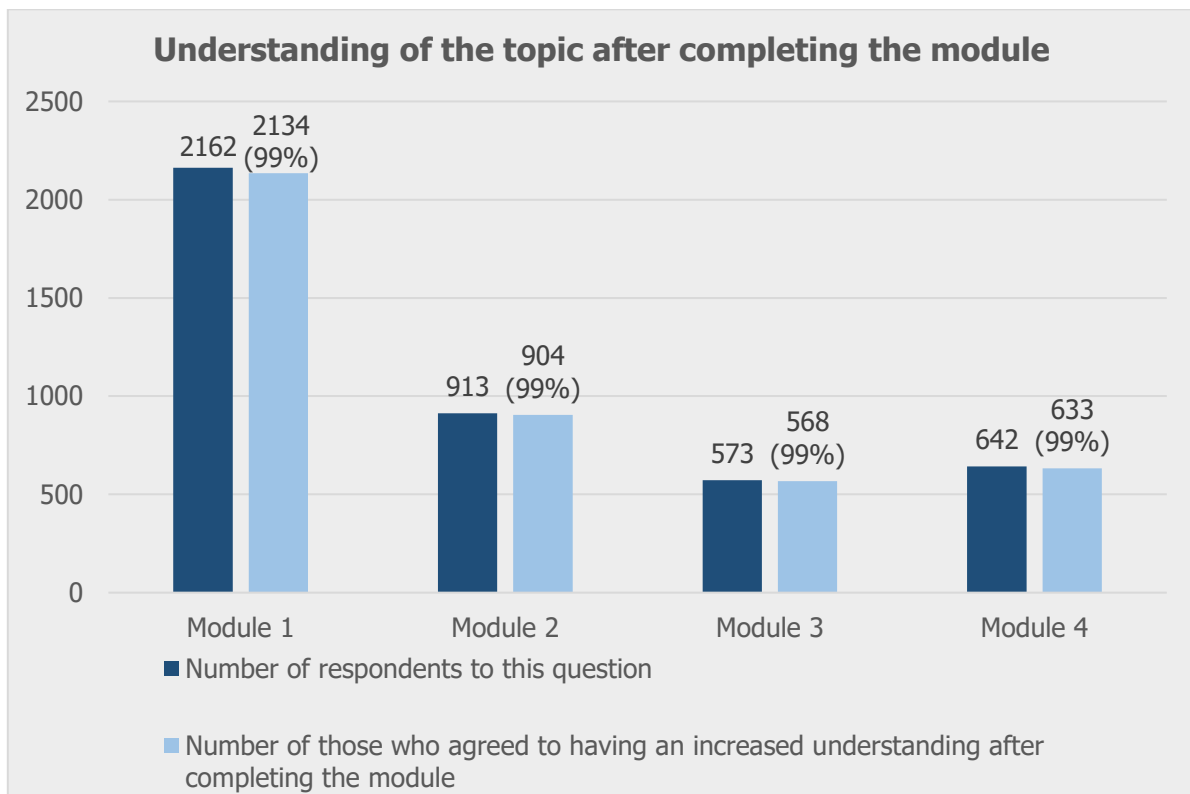


Respondents commonly expressed that the module had caused them to think about adult safeguarding in a new light, and that they were now more aware of the nuances of rights-based care. Feedback indicated that the module had highlighted to respondents that safeguarding is more than simply protecting people from harm; it is also important that people feel respected and that they have input into their care.

Of those who responded, 1,938 of 2,492 (78%) people indicated that they intended to change their practices in relation to adult safeguarding. In line with the above feedback, many respondents stated that they intended to use their new understanding to improve the quality of care that the people in their care receive. For example, some respondents said they would take more care to consider the opinion of the person receiving care when creating their care plan. In addition, 2,228 of 2,596 (85%) respondents answered that they intended to recommend the module to their colleagues. When asked to explain why they had answered in this way, many respondents answered that they felt it was important that their colleagues learn the importance of safeguarding, and how to implement it in their work. Respondents felt that the content was highly relevant and even staff who were trained on this topic required refresher training.

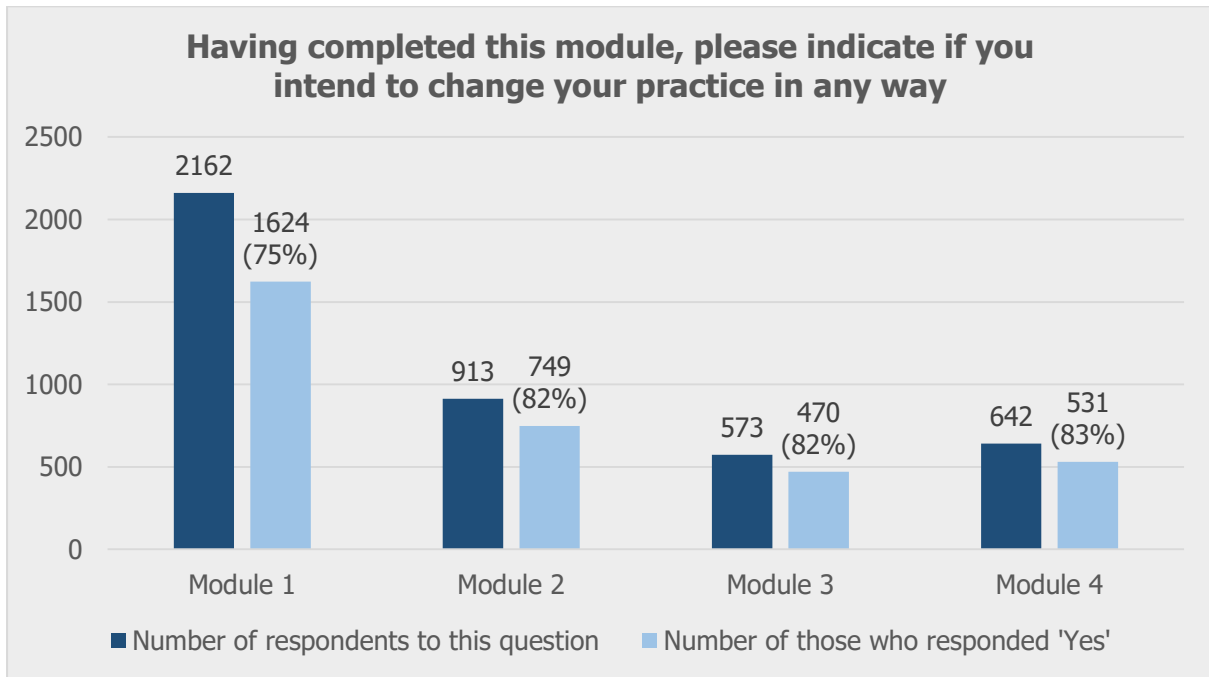
Increased awareness

The *Applying a Human Rights-Based Approach in Health and Social Care: Putting National Standards into Practice* online course aimed to address the knowledge and skills gaps identified through the guidance development process, the survey of HIQA inspectors and the workshop with subject-matter experts. The evaluation survey at the end of each module asked, if having completed the module, the respondent had a better understanding of the topic. The figure below shows the number of respondents who answered this question for each module and that 99% of respondents answered positively.

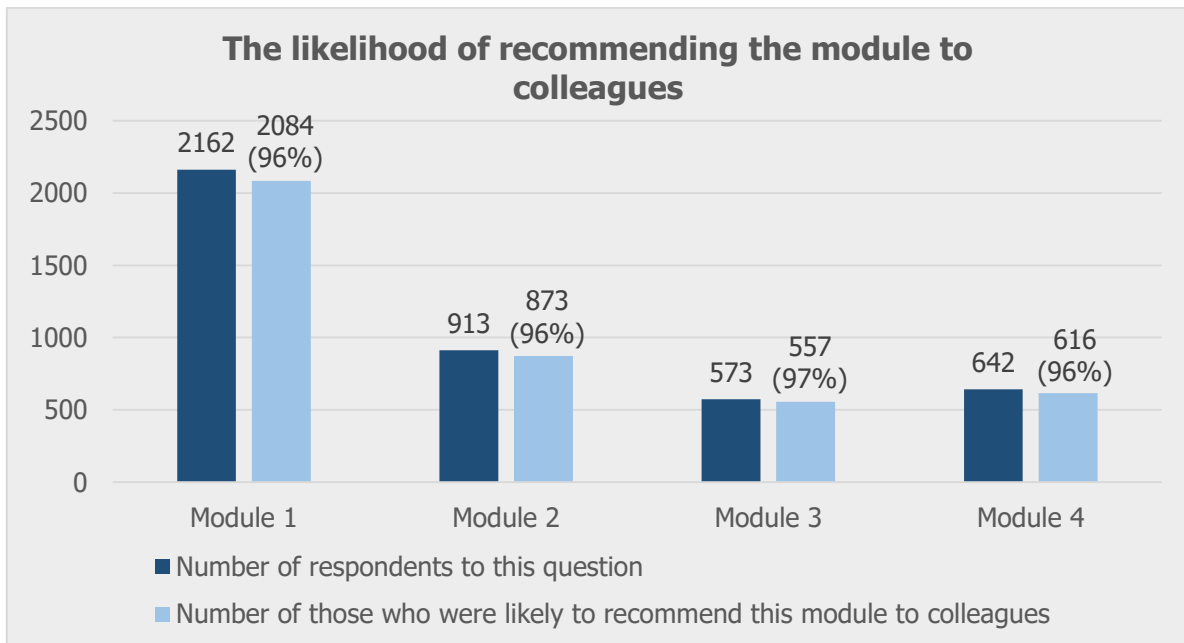


Cultural change

The evaluation survey at the end of each module in the *Applying a Human Rights-Based Approach in Health and Social Care: Putting National Standards into Practice* online course asked "Having completed this module, please indicate if you intend to change your practice in any way." The figure below shows the numbers of respondents who answered each question and that 75-83% of respondents indicated that they intended to change their practice. Those who intended to change their practice noted they would be more mindful of people's human rights when caring for and supporting them and would apply what they had learned from the modules to enable them to do this. For example, one participant wrote they intended to be "mindful of allowing people choice and treating everyone with dignity and respect and always discuss treatment, plans etc. with the individual no matter what." Another noted "I will change my practice because I was not really implementing human rights in full in my practice. So with the training, I will be more cautious."



Respondents were also asked “Having completed the module, please indicate how likely you are to recommend it to a colleague.” The figure below shows the number of respondents who answered this question, with 96% of people answering positively.

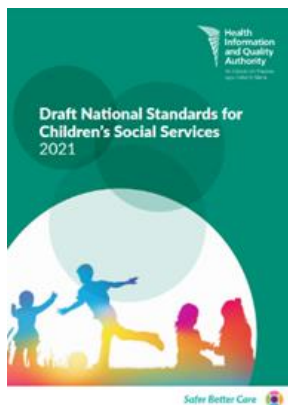


Desired Outcome 3: Increased engagement with staff and people using services

Under the desired outcome of increased engagement with staff working in, and people with experience of, using health and social care services to raise awareness about and to inform the development of National Standards for Children's Social Services, Overarching National Standards for the Care and Support of Children using Health and Social Care Services and National Standards for Homecare and Support Services, we have had the following impact:

Outputs

- Two public consultations launched to inform
 - Draft National Standards for Children's Social Services
 - Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services
- An evidence review was published and publicised on social media
- Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services were developed.



In March 2021, a six-week public consultation was launched on the Draft National Standards for Children's Social Services, along with associated public-facing documents and social media content. A series of focus groups was also undertaken during this time, re-engaging with participants who informed the development stage of the standards. Focus groups with Advisory Group members were also held to explore what is required to support the implementation of the standards. This informed a plan for implementation support tools, submitted along with the Draft National Standards for Children's Social Services for Ministerial approval in December 2021.

In conjunction with the Mental Health Commission, the team published an evidence review to inform the development of Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. The evidence review was publicised on social media to build awareness of the development of these standards. Between March and May 2021, the team undertook a series of focus groups and telephone consultations with stakeholders to inform the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services. A six-week public consultation on the draft standards was undertaken from 16 September to 28 October 2021, and included focus group and individual stakeholder meetings. Working with the Mental Health Commission, the draft overarching national standards were developed.

From 9 September to 1 October 2021, the team undertook a scoping consultation to inform the development of Draft National Standards for Homecare and Support Services. In addition, between October and December 2021, focus groups and online meetings were conducted with key stakeholders to inform the development of these draft national standards. An advisory group with Terms of Reference was also been convened, with the first meeting of this group taking place in November 2021.

Reach

Throughout 2021, the project team working on the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services met with key stakeholders in the healthcare sector to raise awareness of the draft standards. Key stakeholders included:

- Senior representatives from the HSE
- The Pharmaceutical Society of Ireland
- The Irish College of General Practitioners.

The public consultation on the draft standards was widely publicised on social media and a press release was issued to promote awareness of the standards and their purpose. In addition, over 300 stakeholders were notified about the public consultation to inform the development of the standards.

Engagement

In March 2021, the public consultation on the Draft National Standards for Children's Social Services and what was required to support their implementation in practice received 81 submissions from a wide range of organisations and individuals. The 10 focus groups undertaken re-engaged with 56 participants and facilitators from the focus groups conducted during the development stage of the standards. The team engaged extensively with key stakeholders throughout 2021 to ensure the standards were fit for purpose. Key stakeholders included:

- The Child and Family Agency (Tusla)
- The Irish Foster Care Association
- The Department of Children, Equality, Disability, Integration and Youth.

Focus groups with advisory group members were also held, meeting with 12 members to explore what is required to support the implementation of the standards.

To inform the development of the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, the team held 25 focus groups and three telephone consultations, engaging with 156 people. The team engaged extensively with a range of organisations and networks to include

young people, family members, advocates, and staff from a wide range of health and social care services.

Organisations engaged with to inform the development of standards

- Jigsaw
- Spunout
- Comhairle na nOg
- Children in Hospital Ireland
- Tusla
- Youth Advocate Programmes (YAP) Ireland
- HSE Office of Nursing and Midwifery Services Director (ONMSD)
- Senior Children’s Nursing Network
- Community Healthcare Organisations
- Child and Adolescent Mental Health Services (CAMHS)
- a range of professional representative bodies

One meeting of the Advisory Group (21 June 2021) and two meetings of the Children’s Reference Group (28 January and 14 June 2021) were also held to inform the development of the draft standards.

A six-week public consultation was held on the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, with 58 submissions received as depicted below.



As part of the public consultation, the team also conducted 14 focus groups with 61 young people, family members, foster carers, advocates, and staff from a wide range of health and social care services. In addition, the Youth Advocate

Programmes (YAP) Ireland conducted consultation sessions with their YAP Ireland Parents Forum and YAP Ireland Youth Forum to discuss the draft standards.

Three focus groups with 13 Advisory Group members explored what is required to support the implementation of these draft standards. This will contribute to a plan for implementation support tools by HIQA and the MHC to assist services to put these standards into practice. The team also held individual stakeholder meetings with senior representatives from the Department of Health and the HSE's National Clinical Programme for Paediatrics and Neonatology to inform the development of the standards.

A scoping consultation to inform the development of Draft National Standards for Homecare and Support Services received 182 responses from a wide range of stakeholders including:

- People using services
- Family carers
- Advocacy groups
- Homecare workers
- Health and social care professionals
- Service providers.

The 22 focus groups and online meetings undertaken to inform the development of draft National Standards for Homecare and Support Services engaged 122 participants. The Advisory Group convened for the development of draft National Standards for Homecare and Support is made up of 20 members, including representation from: the Department of Health; the Department of Children, Equality, Disability, Integration and Youth; the HSE; people using services; service providers; and advocacy bodies.

Change

Increased awareness

Of the 58 responses to the public consultation on the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services, 39 (67%) responded on behalf of an organisation and 19 (33%) responded in a personal capacity. A wide range of organisations across the healthcare, mental health, disability and children's social services sectors made a submission to the consultation, which would indicate an increase in awareness and knowledge about the standards.

Respondents to the public consultation were asked if they had a better understanding of how services can provide high-quality, safe, consistent and

coordinated care and support to children using health and social services after reading these draft standards. Forty-three of the 58 respondents answered this question, with 34 (79%) answering that they did have a better understanding.

Cultural change

Respondents to the public consultation on the Draft Overarching National Standards for the Care and Support of Children using Health and Social Care Services were asked to indicate if they intended to change their practice after reviewing the draft national standards. This was relevant to respondents working in a health or social care service with children. Twenty-five of the 58 respondents answered this question, with 20 (80%) answering that they intended to change their practice in some way. Most commonly, people planned to change their practice by using the standards for quality improvement purposes and to improve communication and collaboration with children and families using the service.

1.3 Next steps

We shall continue our development of evidence-based standards, ensuring that we are prioritising areas of need, reaching our target audiences and having an impact on the quality and safety of health and social care services in Ireland, ultimately improving the experience of people using health and social care services.

We will also develop implementation support tools 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.

In line with the HIQA Corporate Plan and the Standards Strategy, we will:

- Ensure that standards are underpinned by principles of equality and human rights, to increase awareness and understanding of human rights and equality in the services, and among stakeholders, that we engage with.
- Develop and update standards, and support their implementation and dissemination, prioritising the use of our resources and maximising the benefits to the health and social care system.
- Continue to position HIQA as thought leaders and key influencers in the development of policy in its areas of expertise.

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 we will 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 support tools
- Being a trusted voice relating to health and social care standards.

To address the areas identified through our standards prioritisation process and the recommendations of the COVID-19 Expert Panel for Nursing Homes, key areas of work for 2022 include:

- National Standards for Children's Social Services
- Overarching National Standards for the Care and Support of Children using Health and Social Care Services
- Development of tools and resources to support the implementation of both sets of children's standards
- National Standards for Homecare and Support Services
- Development of an e-learning module on advocacy in health and social care.

2. Health Information Function

2.1 About

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

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

What we do

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

Why we do it

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

How we do it

Working collaboratively with key stakeholders, we gather national and international evidence on best practice. We consult with experts, stakeholders, service providers and people using 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 eHealth and health information programmes and to drive the collection, use and sharing of high-quality data across health and social care to ensure more efficient services, more effective care and better outcomes.

Better data, Better decisions, Better care

2021 objectives

- Develop recommendations on a model for the collection, use and sharing of health information in Ireland.
- Complete a public engagement project on the collection, use and sharing of health information in Ireland.
- Publish a review of information management practices of the National Incident Management System (NIMS) within the HSE.
- Develop guidance and digital learning tools to support the national data collections and data quality.
- Commence a review to assess compliance with information management standards for the Patient Treatment Register within the National Treatment Purchase Fund.
- Complete recommendations on an integrated information technology system for older persons' services.
- Recommence the review programme for the eHealth service.
- Complete recommendations on health information modelling.
- Commence recommendations on a national patient portal project.

Desired outcomes

- Provide thought leadership in defining the health information landscape in Ireland by developing recommendations and engagement with stakeholders.
- Support the sharing of patient information in the health and social care sector.
- Progress the implementation of national priorities within the eHealth landscape.
- Ensure that the public voice is heard by undertaking meaningful engagement, and listening to and learning from people's opinions and attitudes to inform national health information policy in Ireland.
- Improve the quality of health information in national data collections in Ireland.
- Support those working in health and social care to improve data quality to underpin the delivery of safe care and informed decision-making.

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

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

2.2 2021 impact

Impact in Numbers

- There were **2,488** unique page visits to our Health Information Quality content.
- **One** review of the National Incident Management System within the HSE was published.
- **Three** reports published in relation to the National Public Engagement on Health Information.
- **85** members of the public took part in **14** focus groups for public engagement on health information in relation to views on the collection, use and sharing of their health information.
- **17** healthcare professionals were interviewed in relation to their views on the draft recommendations on a consent model for the collection, use and sharing of health information.
- **22** members of the public took part in **four** focus groups to share their views on draft recommendations on a model for the collection, use and sharing of health information.
- **123** learners completed the Introduction to Data Quality e-learning module, prior to its re-launch on HSeLanD.
- **98%** of the 65 people who completed an evaluation of the Introduction to Data Quality digital learning module, said they have a better understanding of data quality, having completed the module and **95%** said they would recommend the module to a colleague.
- **Three** lectures were delivered to students completing Public Health and Digital Health Masters and to those completing the SPHeRE PhD programme.
- **One** panel workshop was facilitated at the 14th European Public Health Conference.
- **Two** student placements were hosted: one undergraduate public health student from University College Cork and one undergraduate medicine student from University College Dublin.
- **More than 3.7 million** COVID-19 tests were requested, and results returned, electronically in compliance with the *National Standards for Messaging and eReferrals*.
- **One** new position paper on the Need for Reform of Ireland's Health Information System.
- The communications campaign on the Need for Reform of Ireland's Health Information System resulted in significant reach, including over **1,300** views across YouTube, LinkedIn, Facebook, Twitter and Instagram and **563** views on HIQA's website
- **32** stakeholder organisations and groups involved in the delivery of older persons services, including patient representatives, and **24** international experts, engaged in the development of recommendations on ICT enablement of older persons' services.
- **One** Best Practice Review on ICT enablement of older persons' services published and had **32** views and **23** downloads.
- **18** stakeholder organisations and groups involved in the health information modelling domain, and **six** international organisations, engaged in the development of recommendations on health information modelling. **One** Best Practice Review on health information modelling had **168** views and **109** downloads.
- **Four** Irish and **10** international stakeholder organisations engaged in the development of Recommendations for Implementation of a National Portal for Health and Social Care.

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

- Position paper on the need to reform Ireland's national health information system published.
- Evidence Synthesis: Recommendations on a consent model for the collection, use and sharing of health information in Ireland published.
- Draft recommendations on a consent model for the collection, use and sharing of health information in Ireland were published for public consultation.
- Two separate videos recorded by the CEO of HIQA and the Director of Health Information and Standards promoting the position paper on the need to reform Ireland's national health information system were shared across HIQA's social media accounts.
- A video recorded by the Director of Health Information and Standards, promoting the public consultation on the draft recommendations on a model on the collection, use and sharing of information was shared across HIQA's social media accounts.

Reach

Position paper on the Need for Reform of Ireland's Health Information System

The position paper on the Need for Reform of Ireland's Health Information System has reached a broad range of senior leaders across the Department of Health, the HSE, the Department of Public Expenditure and Reform, regulatory authorities, and a wide range of professional representative bodies.

Prior to publication, the draft paper was sent directly to the following individuals:

- Secretary General, and selected members of the Department of Health
- Director General, HSE
- Chief Information Officer and Head of Operations, Department of Public Expenditure and Reform
- Assistant Secretary - Central Expenditure Policy and Reporting Division (including Justice and Health Vote) Department of Public Expenditure and Reform
- Chief Executive Officer, Tusla.

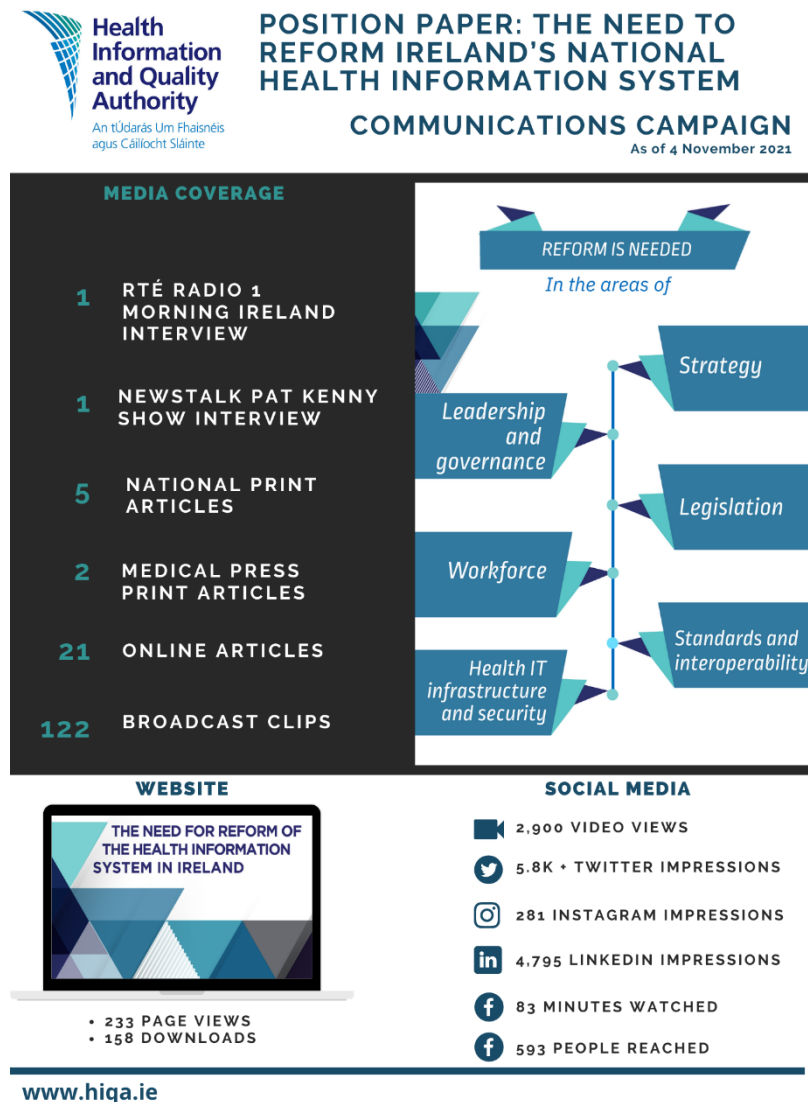
On the day of publication, the paper was sent directly to the following individuals and groups:

- Department of Health Senior Management Team
- Department of Public Expenditure and Reform Senior Management Team
- Health Service Executive, Office of the Chief Clinical Information Officer Team
- Chief Executive Officers of the hospital groups and individual hospitals
- Chief Executive Officers of the Community Health care organisations
- Chief Executive Officers of key organisations with an interest in Health Information and Major National Data Collections
- HSE Assistant National Directors
- Others including representative bodies, academia, health informatics community and Patient Advocacy groups.

Additionally, a communications campaign achieved significant reach. For example, on launch day this included:

- coverage by the following media outlets:
 - RTÉ Radio 1 - Morning Ireland interview
 - Newstalk - The Pat Kenny Show interview
- 5 National print articles
- 2 Medical press articles
- 21 Online articles
- 122 Broadcast clips.

In addition, the infographic below provides information on social media reach in the two weeks following the launch of the position paper.



Draft recommendations on a consent model for the collection, use and sharing of health information in Ireland

Two online articles about the open consultation on the draft recommendations on a model for the collection, use and sharing of health information in Ireland were published:

- *Irish Tech News* online article: "HIQA asks public to give feedback on a consent model for the collection, use and sharing of health information"
- *TechCentral* online article: "Public asked for feedback on collection, use and sharing of health information"

Two radio interviews took place with South East Radio and Kildare FM.

In 2021, there were 131 unique page views of the International review of consent models for the collection, use and sharing of health information and 68 unique page views of the Evidence Synthesis: Recommendations on a consent model for the collection, use and sharing of health information in Ireland.

Engagement

Position paper on the Need for Reform of Ireland's Health Information System

Since the publication of the position paper, we have engaged with senior leaders from the Department of Health, with the Office of the Government Chief Information Officer (OGCIO) in the Department of Public Expenditure and Reform, and senior leaders in the HSE including:

- Chief Information Officer of the Health Service Executive (HSE)
- National Clinical Information Officer for Nursing & Midwifery (ONMSD)
- HSE Chief Clinical Information Officer.

Draft recommendations on a consent model for the collection, use and sharing of health information in Ireland

A total of 15 experts from across the eight jurisdictions included in the international review for recommendations on a consent model for the collection, use and sharing of health information in Ireland, were contacted to validate information, and five teleconferences were held throughout the year with subject matter experts to better understand best practice in defining models for the collection, use and sharing of health information in other jurisdictions.

Meetings were held with:

- Australia: Data Governance Division, Australian Institute of Health and Welfare (AIHW)
- Canada: Public Health Agency of Canada
- Finland: Findata
- New Zealand: Data and Digital, Ministry of Health
- Northern Ireland: eHealth Business management team, Health and Social Care Northern Ireland (HSCNI).

We held nine teleconferences with subject matter experts within the following organisations in Ireland:

- Data Access, Storage, Sharing and Linkage (DASSL) group.
- Data Protection Commission - Health, Voluntary and Public Sector Group

- Department of Health - Assistant Secretary (Health Infrastructure) and Assistant Secretary (Research & Development and Health Analytics Division)
- Department of Public Expenditure and Reform Office of the Government Chief Information Officer - Chief Information Officer and Head of Operations
- Digital Rights Ireland
- Health Research Consent Declaration Committee – Programme Manager
- HSE - National Director, Operational Performance and Integration.

We held two advisory group meetings in March and September 2021. The organisations represented on the Advisory Group were:

- Central Statistics Office
- College of Psychiatrists of Ireland
- Department of Health
- Health Informatics Society of Ireland (HISI)
- Health Information Systems Research Centre, UCC
- Health Research Board
- HSE
- Institute of Community Health Nursing
- Irish College of General Practitioners
- Irish Pharmacy Union
- Irish Platform for Patients' Organisations, Science and Industry (IPPOSI)
- National Patient Forum
- Nursing and Midwifery Board of Ireland
- Royal College of Surgeons Ireland
- Tusla.

In March, a member of the UK's National Data Guardian Steering Group attended and presented at our Advisory Group meeting.

A public consultation on the draft recommendations on a consent model for the collection, use and sharing of health information was open from November 2021 until January 2022. In addition to the online public consultation, a focus group on the draft recommendations was held with health professionals. Four focus groups with members of the public were also held in collaboration with IPPOSI at an online workshop in December 2021.

Change

Increased awareness

Position paper on the Need for Reform of Ireland's Health Information System

Publication of the position paper is seen as the first step in raising awareness around the urgent need for reform, and towards the longer term objective to influence policy and effect long term change. Upon publication, the position paper was shared with senior management teams in the Department of Health and in the HSE, as well as with HSE Assistant National Directors. It was also shared with key executives in the Department of Health, the HSE, community healthcare organisations, hospital groups and individual hospitals, and in other organisations with an interest in health information and major national data collections. It was also shared with a wide range of representative bodies, stakeholders in academia, the health informatics community and patient advocacy groups.

The paper has started a national conversation on health information, with interviews on flagship national radio shows and in national print media, and over 1,300 views on social media channels. The paper outlines the key enablers at national level for the success of national eHealth priorities, and, as such, informs the other desired outcomes for Technical Standards.

Draft recommendations on a consent model for the collection, use and sharing of health information in Ireland

The draft recommendations have been informed by international evidence, a review of the current situation in Ireland, and engagement with a broad range of national and international stakeholders through the advisory group, public engagement on health information, contact with internal experts, focus groups, one-to-one meetings and the public consultation. The engagement with key stakeholders as part of the targeted consultation raised awareness of the considerations needed to inform national legislation, policy and strategy for health information in Ireland. The focus groups with healthcare professionals and members of the public also highlighted the need to engage effectively with these groups to gain an understanding of their views and opinions on the collection, use and sharing of health information. Involving people in important decisions about their health information will ensure that new technologies and initiatives, such as electronic health records and a citizen's portal, are implemented in a way that is acceptable. Furthermore, the public consultation also initiated a national conversation on the importance of ensuring that individuals are informed about how their information might be used, as well as the choices they have around this.

Desired Outcome 2: Supporting the sharing of patient information

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

Engagement

In relation to the development of recommendations on the implementation of a national portal for health and social care, we engaged with subject matter experts from the following international organisations to inform the international review of best practice:

- Australia: Australian Digital Health Agency
- Denmark: Sundhed.dk
- England: NHSX and NHS Digital
- Estonia: Estonian eHealth Foundation (former CEO)
- Finland: Finnish Institute for Health and Welfare and Kela, the Social Insurance Institute
- New Zealand: Ministry of Health, Data and Digital Directorate
- Norway: Norwegian Health Network
- Scotland: Digital Health and Care Directorate.

We also engaged with subject matter experts from the following national organisations to inform the 'As-is' review and development of draft recommendations:

- MyPatientSpace
- PiSCES Epilepsy Portal
- St. James's Hospital
- Wexford Living Lab MyMobile App/Tunstall.

We engage with external committees including the SINC Group, an informal group of members drawn from health and social care regulators across Europe and beyond, and the EU X-eHealth project which aims to lay the foundations to advance the eHealth services across the EU to improve the quality and safety of healthcare for citizens.

Change

Adoption of Recommendations and Standards

We have previously developed numerous standards and recommendations aimed at supporting the sharing of patient information in the health and social care sector including standards for the sharing of information and recommendations on national eHealth initiatives.

Our General Practice Messaging Standard was the first standard developed and has been revised on a number of occasions most recently in 2017. It aims to standardise the transmission of these electronic messages between general practices, hospitals and out-of-hours care, making accurate information available in a more timely manner to healthcare practitioners providing patient care, leading to safer better care for patients.

Healthlink's (national electronic messaging service) core remit is to provide a messaging service that allows patient information to be securely transferred between hospitals and medical practitioners. Healthlink is fully compliant with the HIQA National General Practice Messaging Standard, and IT systems wishing to exchange messages with Healthlink adhere to the standards.

Over 200 million messages containing patient information have been shared through Healthlink services to date, including over 3.7 million referrals for COVID-19 testing. Additionally, over 4 million referrals for appointments have been sent to hospitals, and over 1.8 million tests have been ordered electronically, compliant with the messaging standard.

Desired Outcome 3: Progressing the implementation of national eHealth priorities

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

Outputs

- Best Practice Review of ICT Enablement of Older Persons Services, outlining best practices and lessons learned internationally.
- Best Practice Review on Health Information Modelling in Ireland.
- Modelling temporal data in knowledge graphs: a systematic review protocol. A systematic review protocol published on the Health Research Board's open access platform, HRB Open Research.
- Framework to assess the quality of data sources in healthcare. This research paper was submitted to the reputable international health information journal, the Journal of the American Medical Informatics Association (JAMIA).

Reach

- Best Practice Review of ICT Enablement of Older Persons Services had 32 website views and 23 downloads.
- Best Practice Review on Health Information Modelling in Ireland had 189 website views and 109 downloads.

Engagement

Recommendations on ICT enablement of older persons' services

To date, we have engaged with experts from the following international organisations, to inform development of the Best Practice Review of ICT Enablement of Older Persons' Services, which collates evidence of international best practices to inform the recommendations:

- Australia: Department of Health
- Canada:
 - Canadian Institute of Health Information,
 - Provincial Seniors Health and Continuing Care, Alberta Health Services
 - Continuing Care Branch, Alberta Health
 - Government of Alberta
- Denmark: Medcom
- Estonia: Estonian eHealth Foundation
- Finland: Finnish Institute for Health and Welfare

- New Zealand: the Ministry of Health, and the Data and Digital Directorate
- Northern Ireland: Health & Social Care Business Services Organisation
- Norway: Norwegian SCR Programme
- Scotland:
 - NHS Healthcare Improvement Scotland
 - Digital Health and Care
 - Scottish Government.

We have convened a special Advisory Group, with representatives nominated by the following stakeholder organisations and programmes:

- Age Friendly Ireland
- All Ireland Gerontological Nursing Association
- CORU
- Department of Health
 - Older Persons Strategy
 - Sláintecare Programme Office
 - National Patient Safety Office
 - eHealth and Health Information Systems
- HIQA Regulation Inspectorate (Older Persons Services)
- Health Service Executive
 - Acute Operations
 - Community ICT
 - Community Operations
 - Community Strategy and Planning
 - EHR/Shared Record
 - Integrated Care Programme for Older Persons
 - National Clinical Programme for Older Persons
 - Office of the Chief Information Officer
 - Office of Nursing and Midwifery
 - Primary Care Operations
 - Primary Care ICT
 - Public Health Nursing
 - Social Care Directorate Services for Older People
- Irish College of General Practitioners, General Practice IT Group (GPIT)
- Irish College of General Practitioners
- Irish Medical Organisation
- Mental Health Commission

- Nursing Homes Ireland
- Royal College of Physicians of Ireland.

Recommendations on Health Information Modelling

To develop the *Recommendations on Health Information Modelling*, we convened an expert Advisory Group, which met for the first time in November 2020. We also engaged with international organisations and with national programmes and services, to inform the development of a best practice review.

In developing the recommendations, we involved all key stakeholders in Ireland as part of our advisory group. These included representatives from the following organisations:

- Department of Health
 - R&D and Health Analytics Division
 - Sláintecare Division/Programme Implementation Office
- Dublin City University
- Health Service Executive – Office of the Chief Clinical Information Officer
 - Digital Nursing and Midwifery
 - Enterprise Architecture
 - Integrated Information Division
 - Access to Information
 - Engagement & Delivery EHR programme
 - ePharmacy Programme
- Health Service Executive – eHealth and Social Care Professionals Group
- Health Service Executive – National Patient and Service User Forum
- Health Service Executive – National Screening Service
- Irish College of General Practitioners
- Irish Epilepsy and Pregnancy Register
- Irish Medical Organisation
- Irish Pharmacy Union
- National Haemophilia Register.

We also engaged with representatives of the following international organisations who provided guidance and expertise to inform the *Best Practice Review of Health Information Modelling in Ireland*:

- Australia:
 - Australian Institute of Health and Welfare
 - Digital Health Australia
- Canada: Canadian Institute for Health Information
- England: FreshEHR Clinical Informatics/UCL
- New Zealand: Health Information Standards Organisation, Ministry of Health
- Wales: NWIS Applications Design, NHS Wales.

Change

Increased awareness

Our work continues to progress the implementation of national priorities within the eHealth landscape.

Following on from our recommendation regarding the adoption of SNOMED CT as a national terminology for Ireland, we continue to work with the HSE to progress the implementation of SNOMED CT in Ireland through chairing of the SNOMED CT Governance Group.

The implementation of SNOMED CT Strategy (2020 - 2022) in Ireland progresses under the direction of the SNOMED CT Governance Group. The main goals of the strategy are to develop expertise in SNOMED CT, focus on quality and ensure SNOMED CT adoption.

The Irish National Release of SNOMED CT is maintained by the National Release Centre and continues to be updated twice yearly. Reference sets that have been developed include Chronic Disease Management, Gynaecology Discharge Summary, Irish National Early Warning System, Coronavirus Reference Set Ireland, Ireland Nursing and Midwifery Quality Care Metrics Dataset, Make Every Contact Count Ireland, and Safeguarding Ireland.

Multiple webinars were held by the National Release Centre in 2021 including Back to Basics - How to engage with SNOMED CT education and training, Data Analytics and SNOMED CT - How to derive information to make decisions based on clinical terminology, and Understanding SNOMED CT in The Irish Healthcare setting.

In 2013, the National eHealth Strategy identified electronic prescribing as a priority initiative and in 2015 the national ePharmacy programme identified eight key

national projects to progress in this area. We previously developed standards for the electronic exchange or prescription in Ireland and recommendations in relation to the community based electronic prescribing in Ireland. In addition, we previously developed standards for a national medicinal product catalogue. While progress on these national programmes has been slow, change has commenced with the appointment of leads to two national projects to progress the implementation of a national medicinal product file and community based electronic prescribing. This will progress the implementation of standards and recommendations previously developed by HIQA in this area.

Our PhD research on the utility of knowledge graphs for modelling temporal data in healthcare has raised the profile of HIQA and of technical standards in the health research community, through the publication of the systematic review protocol on the HRB Open Research website. Publication of a research paper on the framework to assess the quality of data sources in healthcare, which has been submitted to the Journal of the American Medical Informatics Association, is expected to raise the profile of HIQA's role in technical standards in the wider international health informatics research community.

Undertaking the process of gaining ethical approval from a university for the PhD research has strengthened relationships with external academic institutions. Presenting this research as part of the HIQA PhD showcase event also raised the profile of technical standards profile among HIQA staff and with external audiences, including from academia and in the health service.

Desired Outcome 4: Ensuring the public voice is heard

Under the desired outcome of ensuring that the public voice is heard by undertaking meaningful engagement, and listening to and learning from people's opinions and attitudes to inform national health information policy in Ireland, we have had the following impact:

Outputs

- We published three reports in relation to the National Public Engagement on Health Information:
 - Findings of the National Public Engagement on Health Information
 - Technical report for the National Public Engagement on Health Information
 - Responding to the National Public Engagement on Health Information.
- We also developed and published three knowledge sharing resources:
 - An anonymised data file from the national public engagement survey
 - An infographic
 - An animation of the key findings.
- A blog post on the National Public Engagement on Health Information was published on the SPHeRE website and shared via the SPHeRE Network newsletter. The SPHeRE Network is Ireland's largest population and health services research network connecting individuals working in research, policy and practice.

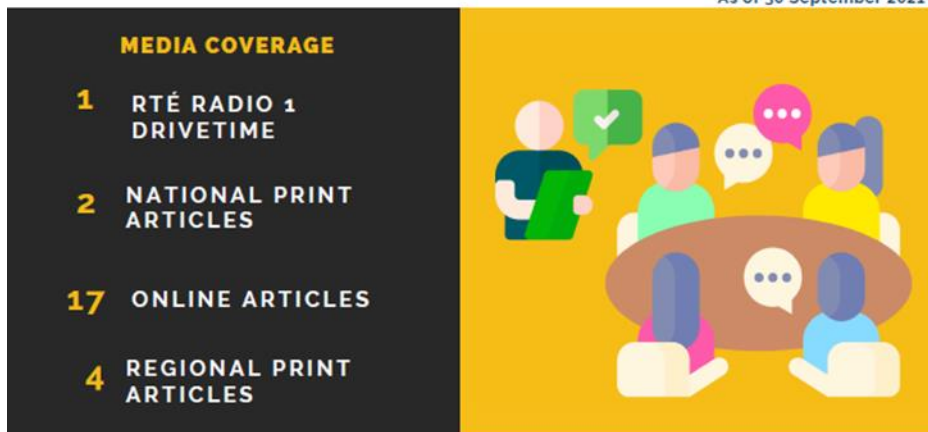
Reach

- The findings were published on the HIQA website and on social media (see infographic below). A press release was issued to national and regional media, and targeted emails were sent to medical press. This resulted in:
 - One RTÉ Radio 1 Drivetime interview
 - Two national print articles and four regional print articles
 - 17 online articles
 - 281 impressions on Instagram
 - Approximately 2,695 LinkedIn impressions
 - Reached 621 people on Facebook
 - Over 12,000 Twitter impressions
 - 2,900 animation views
 - 216 unique page views of the webpage for the Findings of the National Public Engagement on Health Information.

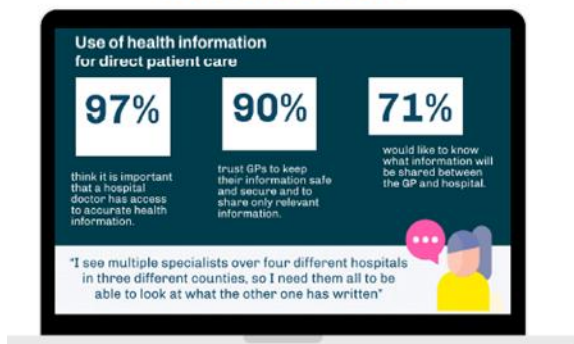


COMMUNICATIONS CAMPAIGN

As of 30 September 2021



PUBLICATION



- 3 REPORTS
- 1 SURVEY DATA FILE
- 1 INFOGRAPHIC

SOCIAL MEDIA

- 2,900 ANIMATION VIEWS
- 12K + TWITTER IMPRESSIONS
- 281 INSTAGRAM IMPRESSIONS
- 2,695 LINKEDIN IMPRESSIONS
- 621 PEOPLE REACHED

Engagement

- Two videos were recorded to welcome the launch of the public engagement findings on social media. These were recorded by Dr Abigail Collins, Consultant in Public Health Medicine, HSE, and Muiris O'Connor, Assistant Secretary, Department of Health.
- 14 focus groups were held to inform the findings of the public engagement – Three groups with members of the public, two groups with patient representatives, two groups with 16-17 year olds, one group with representatives of migrant and asylum seeker communities, one group with people from the Traveller community, one group with people using addiction services, one group with people using disability services, one group with people using homeless services, one group with people using mental health services and one group with people using sexual health services.
- Two Partnership Project Team Meetings were held with representatives from the HSE and the Department of Health.
- Two Steering Group Meetings were held with representatives from the HSE, the Department of Health, and patient advocacy groups.
- One presentation was delivered to IPPOSI's Citizen's Jury which is available to view on YouTube.** A written response to the Citizen's Jury was also provided following questions on presentation from members and feedback to IPPOSI.

External meetings were held regarding the public engagement:

- Four meetings were held with IPPOSI Citizen's Jury oversight group
- One meeting with the UK National Data Guardian.

Change

Evidence of improvements in practice

The National Public Engagement on Health Information was discussed in the Digital Futures in Healthcare Diploma (organised by Dell and HSE Digital Transformation).

The National Public Engagement on Health Information was discussed at the ADAPT Online "Think-In" which invited the public to a conversation on personal health information.

The co-ordinator of Homeless Services Cork/Kerry, HSE stated that the launch of the findings will help to review and inform current and future data sharing/consent processes.

** Available at: <https://www.youtube.com/watch?v=SKCqE8dIIFA>

Increased awareness

The findings of the national public engagement on health information and evidence gathered from meetings with key stakeholders (including patient representatives, the HSE and the Department of Health) as part of this national engagement have demonstrated that there is an increased awareness for the importance of public involvement in decision making in relation to their health information. It has been recognised that it will be important to continue this national conversation on the importance of ensuring that individuals are informed about how their information might be used, as well as the choices they have around this.

Involvement of key national stakeholders in development of our work

Key meetings were held with representatives from the HSE, Department of Health and patient advocacy groups, throughout the development of the survey and focus groups. These representatives provided expert advice for the National Public Engagement on Health Information.

Meetings and focus groups were held with patient representatives, members of the public, people that use addiction services, people that use mental health services, people that use homeless services, members of the Traveller community, people that use disability services, people that use sexual health services, 16-17 year olds, and representatives of migrant and asylum seeker communities; their feedback informed the findings of the National Public Engagement on Health Information.

Desired Outcome 5: Improving the quality of health information in national data collections

Under the desired outcome of improving the quality of health information in national data collections in Ireland, we have had the following impact:

Outputs

- We published a review of information management practices for the National Incident Management System (NIMS) within the HSE.

Reach

- The preliminary findings of NIMS Review were presented to the National Patient Safety Office (NPSO).
- The findings of the published NIMS report were presented to the Board, the Regulation SMT, Healthcare and SIRT.
- The findings of the NIMS review were also presented to the Department of Health in the context of the forthcoming patient safety legislation.
- One article was published on the RTÉ website and three in the Irish Mail on Sunday referring to the 2019 HIQA CIDR report.
- At a webinar for the National Office of Clinical Audit (NOCA), Chair of HIQA's Board referenced the review programme in his keynote speech.
- HIQA's review of the Hospital Inpatient Enquiry Scheme (HIPE) was referenced in the new strategy for HIPE being developed by the Healthcare Pricing Office.
- There were 356 unique webpage views of the review of information management practices for the National Incident Management System (NIMS) within the HSE which was published in May 2021.
- The webpage for the Information Management Standards for National Data Collections (2017) against which the review programme assess compliance, had 227 unique page views in 2021. This is similar to the number of views in 2020 (282 unique page views). The webpage for the Self-assessment tool for national data collections (2017) which is based on the Information Management Standards had 101 unique page views. This decreased from 315 unique page views in 2020.
- In 2021, the webpage for the Catalogue of national health and social care data collections had 1,041 unique page views. In 2020, there were 1,935 unique page views of the catalogue.

Engagement

- Preliminary and full feedback was received from HSE Quality Assurance and Verification Division and the State Claims Agency regarding factual accuracy of the draft review of NIMS.
- A meeting in relation to the design and configuration of the new Quality and Patient Safety (QPS) Directorate in the HSE outlined that one of the functions of this new Directorate, under the pillar of Incident Management, will be the “Governance and Administration of NIMS within the HSE”.
- Preliminary meetings to explain the review of national waiting list data within the HSE and encourage engagement in the process were held with key stakeholders in:
 - HSE Acute Operations
 - HSE Community Operations
 - National Treatment Purchase Fund.
- Site visits and focus groups have been carried out at two of the seven hospital sites to be visited as part of the review. Senior management, scheduled care leads, waiting list managers and team staff, data protection officers, clinical directors and IT staff members were met with during the visits.
- As part of the international review of waiting list data management in other jurisdictions, a meeting was held with a senior manager in NHS England and NHS Improvement to further understand practices in this jurisdiction and enable comparisons with the Irish context.

Change

Evidence of improvements in practice

- At the meeting held in relation to the design and configuration of the new QPS Directorate in the HSE, it was stated that the Directorate would be taking the review recommendations on board.
- The HSE advertised a post for Assistant National Director for Incident Management which included the role of supporting the implementation of the findings from HIQA’s Review of information management practices for the National Incident Management System.

Desired Outcome 6: Supporting those working in services to improve data quality

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

Outputs

- We published an updated e-learning module on the HSE's learning and development platform HSeLanD and on the HIQA website.

Reach

- At the launch of the National Database of Statutory Notifications from Social Care, the Guidance on a Data Quality Framework and Information Management Standards were referred to in a presentation.
- Irish Tech News posted a tweet about the launch of *the Introduction to Data Quality* e-learning module.
- Three online articles about the launch of the *Introduction to Data Quality* eLearning module were published by media. The articles were published in Health Manager Journal, Hospital Professional News and Irish Tech News.
- Learners (approximately 50 persons in charge from Nursing Home settings each year) completing the Leadership and Management of Infection Prevention and Control module in UCC are directed to *the Introduction to Data Quality* module as a learning resource.
- The Health Protection Surveillance Centre (HPSC) welcomed the launch of *Introduction to Data Quality* module and circulated information about the module within its organisation.
- The webpage for the Guidance on a data quality framework (2018) had 363 unique page views in 2021. This represents a slight increase from 349 in 2020.
- The webpage for the Five quality improvement tools (2017) document which sets out tools and supports for national data collections to use to improve their information management practices, had 221 unique page views in 2021. This is similar to the number of unique page views in 2020 (229 views).

Engagement

- We held meetings with a patient representative and a representative from National Office of Clinical Audit (NOCA) about capturing their perspectives on data quality in health and social care in a video learning resource.
- We engaged with external stakeholders for feedback on both modules. We received feedback from five organisations for Module 1: *Introduction to Data Quality* and from two organisations for Module 2: *Developing a Data Quality Framework*.
- A meeting was held with the author of a research paper published in BMC Public Health entitled: "A review of the inclusion of equity stratifiers for the measurement of health inequalities within health and social care data collections in Ireland". The paper investigates the inclusion of equity stratifiers in routine health and social care data collections. This meeting informed updates to the metadata template for the revision of HIQA's Catalogue of National Data Collections.

Change

Evidence of improvements in practice

NOCA demonstrated changes to data quality practices informed by the guidance and requested feedback from us on templates on a data quality framework developed as part of their implementation of the guidance. NOCA also demonstrated use of the HIQA Self-Assessment Tool (SAT) to inform their approach to managing data quality.

We were informed by the National Screening Service that the Data Quality Manager for BreastCheck and BowelScreen is currently implementing a data quality framework in those programmes.

The Guidance on a data quality framework and Information Management Standards were used by the National Database of Statutory Notifications from Social Care to inform its development providing evidence of a shift in thinking and practice for new data collections.

The National Care Experience Programme has also engaged with the Guidance on a data quality framework and Information Management Standards to inform the development of its database and data management practices.

The student placements hosted by the Health Information Quality Team have helped build academic relationships and promote our work in the next generation of health and social care professionals.

2.3 Next steps

In 2022, we plan to deliver impact through our work in the following areas:

- Develop a strategic plan for health information to include the health information quality aspects of the health information function of HIQA. This strategy will incorporate learnings to date, identify gaps and drive further improvements in relation to the impact on our work.
- The second module of the e-learning course *How to Improve Data Quality* will be launched on the HSeLanD platform and on the HIQA website. This module will further support the implementation of good data quality practices in health and social care.
- Increase the reach of our work programme by targeting key stakeholders.
- Continue to drive improvements in the quality of health information by progressing the review of information management practices for national waiting list data within the HSE and completing a draft report by the end of the year.
- Revise and update the current version of the Catalogue of National Data Collections. This will include a revision of the current metadata template, engagement with national data collections and publication of a new version of the Catalogue this year.
- Continue to drive improvements to national health information by publishing a revision of information management standards for national health and social care data collections.
- Inform and influence national health information policy and legislation by publishing recommendations on a model for the collection, use and sharing of health information in Ireland.
- We will continue to engage with senior decision-makers and leaders at national level to influence thought and policy regarding current deficiencies in the national health information system and the measures needed for reform.
- Under the desired outcome of supporting the sharing of patient information in the health and social care sector, we will finalise recommendations in relation to a national health and social care portal in Ireland.
- Under the desired outcome of progressing the implementation of national priorities within the eHealth landscape, we will undertake a full public consultation on the Draft Recommendations for Consultation on ICT Enablement of Older Persons' Services. Following this we will finalise our Recommendations and submit them to the Minister for Health. We will also develop recommendations on a model for health information standards in Ireland.

- We will continue to progress PhD fellowship work on a framework for quality assessment of data sources to inform strategy, through:
 - development of a tool to assess the quality of data sources in healthcare settings
 - modelling temporal data in knowledge graphs: a systematic review
 - modelling temporal data in healthcare: A narrative literature review.
- In line with our objective of beginning to assess compliance of eHealth services within the HSE against supporting national standards, we have developed the methodology and commenced a new Review Programme of eHealth services. This project was deferred in 2020 with the intention of recommencing the project in 2021. The project did not recommence in 2021 due to the deployment of resources to develop the Need for Reform of Ireland’s Health Information System position paper. The project will recommence in 2022.

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 National Care Experience Programme is a joint initiative by HIQA, the HSE and the Department of Health.

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

The surveys aim to learn from people's feedback about the care received in health and social care services to find out what is working well, and what needs to be improved.

A National Care Experience Programme Survey Hub is available to provide support, guidance, information and resources to assist providers to develop, conduct and analyse their own surveys, and act upon the findings.



2021 objectives

- Revise, deliver and report^{††} on the National Inpatient Experience Survey.
- Develop a model and methodology to enable implementation of the National End of Life Survey, the National Maternity Bereavement Experience Survey and the National Nursing Home Experience Survey.
- Continue to develop a Survey Hub of international standing, providing tools and resources to enhance understanding and implementation of surveys by care providers.
- Develop the NCEP Strategy for 2022–2024 and a Communications Strategy for 2022–2024 to ensure the National Care Experience Programme has clear objectives with appropriate support from relevant health and social care professionals.

Desired outcomes

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

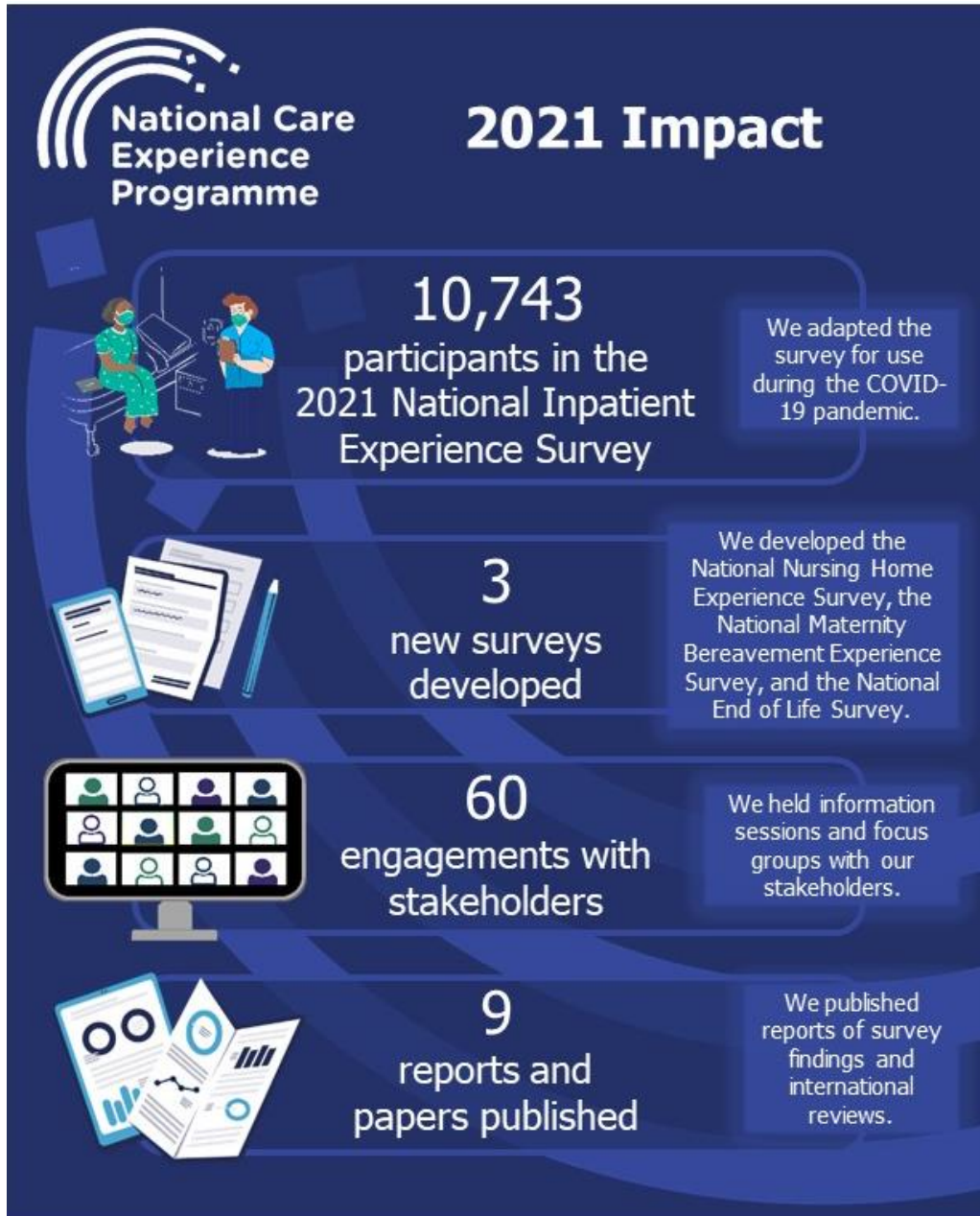
We have selected two key metrics in order to measure the change relating to our work:

- Involvement of key stakeholders
- Use of survey data.

^{††} As a result of the cyber-attack on HSE systems in May 2021, the National Inpatient Experience Survey was postponed to September 2021, with findings to be published in 2022.

3.2 2021 impact

Impact in numbers



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

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

Outputs

Reports

We published four reports to inform the development of the National Maternity Bereavement Experience Survey, National End of Life Survey and National Nursing Home Experience Survey:

- International Review of National End of Life Surveys
- International Review of Nursing Home Experience Surveys
- International Review of Maternity Bereavement Experience Surveys
- Early pregnancy loss: A scoping review of research in Ireland.

We published two reports to further disseminate the findings from the National Inpatient Experience Survey and National Maternity Experience Survey:

- Report on maternity care provided in the community by general practitioners, practice nurses and midwives
- Experiences of patients admitted for a tumour or cancer.



Training and support documents

To support interviewers who will be conducting interviews with nursing home residents as part of the National Nursing Home Experience Survey, we developed training that covers information governance, adult safeguarding and managing adverse events. We published Data Protection Impact Assessments (DPIAs) for the National Inpatient Experience Survey 2021 and the National End of Life Survey, and developed four process documents to support hospitals involved in the National Inpatient Experience Survey, National Maternity Bereavement Experience Survey, National End of Life Survey and National Nursing Home Experience Survey.

Reach

A total of 10,743 people participated in the 2021 National Inpatient Experience Survey.

The National Care Experience Programme communicates with stakeholders across the health and social care system in Ireland and beyond through the website www.yourexperience.ie, social media platforms. In 2021, there were:

- 6,116 visitors to www.yourexperience.ie
- 638k+ Twitter impressions
- 31,000+ Facebook post reach^{††}
- 7,943 views of the interactive results across all surveys
- 603 people who accessed our e-learning modules.

Engagement

As part of the development of the National Maternity Bereavement Experience Survey, the National End of Life Survey and the National Nursing Home Experience Survey, we conducted focus groups to identify the most important areas of experience to be included in each of the new surveys. A wide range of stakeholders, including bereaved parents and families, nursing home residents and their families, healthcare professionals, managers and service providers, policy-makers, researchers and advocacy organisations, participated in these focus groups and shared their experiences and expertise. In order to identify the most important questions for inclusion in each of the new surveys, we conducted two rounds of Delphi studies^{§§} for each survey, which included bereaved parents and families, healthcare professionals and managers, policy makers, researchers and advocacy

^{††} Post reach refers to the number of people who saw a particular post.

^{§§} A Delphi study is a consensus-building technique used to refine the selection of questions to be included in each survey questionnaire.

organisations. We cognitively tested^{***} each of the newly-developed survey questionnaires with bereaved parents and families, and nursing home residents and their relatives, in order to assess the clarity and appropriateness of the questions and response options. Cognitive interviews were also held with patient representatives to assess the clarity and appropriateness of seven new COVID-19 questions that were included in the 2021 National Inpatient Experience Survey.

In 2021, we held:

- 29 focus groups and one individual meeting with a total of 188 participants
- Three Delphi studies, consisting of two rounds each, with a total of 227 participants
- Cognitive testing with 28 participants, including bereaved parents and relatives, patient representatives, nursing home residents and designated representatives
- 40 information sessions or presentations for national stakeholders with over 565 attendees.

Change

Involvement of key stakeholders

In its Statement Strategy 2021-2023, the Department of Health highlighted the promotion of 'initiatives for patient engagement and advocacy, improved patient experience and open disclosure, complaints and incidents policy', assessed through performance metrics that include 'improved patient experience measured through National Care Experience Programme and other channels'. The Sláintecare Implementation Strategy and Action Plan 2021-2023 explicitly highlighted the National Care Experience Programme as one of the patient safety initiatives that will support and enable the reforms outlined in the action plan. In 2021, we continued work to expand the National Care Experience Programme to three new areas of care, and revised the National Inpatient Experience Survey for use during the COVID-19 pandemic.



National End of Life Survey

In 2021, we continued to develop the National End of Life Survey, with a view to surveying bereaved relatives in 2023. The National End of Life Survey will provide an opportunity for bereaved relatives, including the closest relatives or friends of those who have died, to tell us about the experience of end-of-life care

^{***} Cognitive testing involves exploring how participants interpret and understand survey questions and response options.

from their perspective. For the first time in Ireland, we will hear about the experience of care in a person's last months of life. The findings of the survey will be used to improve care services and to inform regulation, national policies and standards.



National Maternity Bereavement Experience Survey

We developed the National Maternity Bereavement Experience Survey to give parents who experienced a second trimester miscarriage, a stillborn infant or the early neonatal death of a baby, an opportunity to share their experience of care. This will be the first national survey of maternity bereavement experiences in Ireland. The feedback that parents provide will be used to acknowledge areas of good experience and identify areas needing improvement. The findings will be used to improve care services and to inform regulation, national policies and standards.



National Nursing Home Experience Survey

We continued development of the National Nursing Home Experience Survey, with a view to surveying nursing home residents and their designated representatives (such as a family member or friend) in 2022. The National Nursing Home Experience Survey will be the first national survey to give nursing home residents an opportunity to share their lived experiences of nursing home care in Ireland. The findings of this national survey will drive improvements in nursing home care provision, acknowledging what is working well and also identifying areas where improvements are needed. The findings will also be used to inform national policies, regulatory programmes and standards.



National Inpatient Experience Survey

In 2021, we adapted the survey model and questionnaire for the National Inpatient Experience Survey for use during the COVID-19 pandemic. A series of new questions were included to address specific aspects of inpatient experiences during the pandemic that were not captured by the existing survey, such as staff communication while wearing Personal Protective Equipment (PPE) and contact with family and friends given visitor restrictions. The National Inpatient Experience Survey 2021 presented an important opportunity for patients to provide feedback on their experiences of care during the pandemic. As a result of the cyber-attack on the HSE IT systems in May 2021, the survey month was postponed from

May to September 2021. The findings from the survey and quality improvement plans will be published in 2022.

Desired Outcome 2: Developing research, academic and international 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

Reports

We published a *Final Summary Report on Secondary Analysis of 2017 & 2018 Qualitative Survey Responses*, which presented the results of an in-depth secondary analysis of free-text survey responses from the 2017 and 2018 National Inpatient Experience Survey. This analysis was conducted in partnership with a team based at the Insight Centre for Data Analytics at the National University of Ireland, Galway.

We also published a paper on *Care Experiences of Older People in the Emergency Department: A Concurrent Mixed-Methods Study*, based on secondary analysis of data from the 2019 National Inpatient Experience Survey, in the *Journal of Patient Experience*. This study was led by one of our former work placement students as part of the Masters in Applied Social Research in Trinity College Dublin.

The National Disability Authority published a report on the *Experiences of Women with Disabilities in their Journey through Maternity Services in Ireland*, using data from the National Maternity Experience Survey.

Podcast



We launched a new podcast series, *Let's Talk Care Experience*, on 16 November 2021. This podcast discusses all aspects of people's experiences using 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.

Two episodes of *Let's Talk Care Experience* were released in 2021:

- The importance of listening to the voice of patients. This episode features Paul Reid, CEO of the HSE; Phelim Quinn, CEO of HIQA; Karen Green, Deputy Chief Nursing Officer in the Department of Health; and Phyllis McNamara, patient representative with the Saolta University Healthcare group, who spoke about the importance of listening to people using healthcare services in Ireland.
- The impact of food and nutrition on patients' experiences. This episode features Jennifer Feighan, CEO of the Irish Nutrition and Dietetic Institute,

and Laura Brennan, Senior Dietitian in St. James's Hospital, who spoke about the impact of food and nutrition on patients' experiences.

Reach

Members of the team attended five conferences in 2021 to disseminate the work of the National Care Experience Programme and build understanding of people's experiences of health and social care. We presented four posters and gave three oral presentations at national and international conferences.

Engagement

Academic partnerships

In 2021, we continued to engage with professional bodies and educational institutions to support and demonstrate use of the National Care Experience Programme survey findings. We supported four student work placements from three universities:

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

Generating actionable insights from the analysis of free-text comments from the National Care Experience Programme using Qualitative and Computational Text Analytics methods

We worked with researchers and academics at Maynooth University on a successful grant application for funding from the Health Research Board under the Secondary Data Analysis Projects (SDAP 2021) funding scheme, with co-applicants from the HSE, Department of Health, and patient representatives. The grant will support a project involving a detailed analysis of over 70,000 free-text comments received in response to our surveys, as well as 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 Professor Adegboyega Ojo at Maynooth University, with support from co-applicants Dr Conor Foley and Dr Daniela Rohde from the National Care Experience Programme.

International networks and collaboration

We continued to engage and collaborate with our international networks in 2021. As part of the development of the National Nursing Home Experience Survey, we held four calls with international experts, including attendees from the Netherlands, Australia, the USA and Canada. We engaged with Picker Institute Europe on finalising our new survey questions. An informal network has been created with

counterparts from national care experience survey programmes in Scotland, England, Australia and New Zealand. Several engagements were held in 2021 to share ideas and experiences of data analysis, the implications of COVID-19, and explore opportunities for further collaboration.

Change

Use of survey data

The National Care Experience Programme promotes a culture of making data available, with reports and interactive online reporting platforms available on the www.yourexperience.ie website. Data can also be requested by individuals working in academic or healthcare settings, for research or quality improvement purposes. Data access requests are reviewed by the NCEP team and or the relevant programme board, depending on the nature and purpose of the request. In 2021, the programme received and granted four data access requests. The majority of requests received in 2021 were from students or staff in academic institutions, including Trinity College Dublin, University College Dublin, and the Mater Hospital.

Medicines A-Z

One of the areas for improvement identified by the National Inpatient Experience Survey included information on medications. Across the first three years of the survey (2017 to 2019), 11% of patients (n=3,360) said that the purpose of medicines they were to take at home was not explained to them in a way that they could understand, while 38.5% (n=10,291) reported that they were not told about medication side effects to watch for when they went home.

Findings from the National Inpatient Experience Survey suggested that one of the reasons for readmission to hospital may be related to medication, including medication side effects and patients not remembering their correct dosage. The HSE's Medicines A-Z resource was developed in response to these findings. Medicines A-Z⁺⁺⁺ launched in October 2021 and was developed in collaboration with general practitioners, the Royal College of Surgeons in Ireland, SaferMeds and the Health Products Regulatory Authority (HPRA).

Implementation of the National Maternity Strategy

The National Maternity Experience Survey was a key recommendation in the National Maternity Strategy – Creating a Better Future Together 2016-2026. This strategy recognises that we need to listen to women, and notes that the woman's voice is essential to evaluate and inform the care given, to guide quality

⁺⁺⁺ Available at: <https://www2.hse.ie/conditions/medicines/>

improvements, and to inform quality improvement initiatives at a local and national level.

The ultimate purpose of gathering women's views through the National Maternity Experience Survey is to improve the quality and safety of the maternity care provided. The results of the first National Maternity Experience Survey, published in 2020, were used to identify areas where improvements are required. The results directly informed the allocation of funding in 2021, including funding targeted at improving post-natal supports and new lactation consultant posts. The significant additional funding provided for maternity services in 2021 and 2022 will facilitate the implementation of quality improvement plans that were developed in response to the survey.

Informing Ireland's Health Systems Performance Assessment Framework

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

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

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

Informing the Women's Health Taskforce

A Women's Health Taskforce was established in September 2019 by the Department of Health to improve women's health outcomes and experiences of healthcare. The Taskforce followed a recommendation from the Scoping Inquiry into the CervicalCheck Screening Programme, that women's health issues be given more consistent, expert and committed attention. Informed by women's voices, the taskforce chose four initial priorities: improve gynaecological health, improve

supports for menopause, improve physical activity, and improve mental health among women and girls.

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

3.3 Next steps

In 2021, we developed the National Care Experience Programme Strategy 2022-2024, as well as a Communications Strategy and Information Management Strategy. These strategies ensure that the National Care Experience Programme has clear objectives with appropriate support from relevant health and social care professionals.

In 2022, we will report on the findings from the 2021 National Inpatient Experience Survey, deliver and report on the 2022 National Inpatient Experience Survey, the National Nursing Home Experience Survey, the National Maternity Bereavement Experience Survey, and commence the National End of Life Survey. We will continue to develop our Survey Hub, providing tools and resources to enhance understanding and implementation of surveys by care providers. We will also continue to foster partnerships with academic institutions and other stakeholders, to encourage secondary use of our data, increase our reach and engagement, and demonstrate how use of our data can drive changes in health and social care provision. The experience of evaluating our impact has informed the National Care Experience Programme Strategy for 2022-2024, and we will continue to strengthen relationships with our partner organisations to ensure we track policy and practice changes across health and social care settings.

4. Conclusions and next steps

The impact that our work has had against our desired outcomes as outlined in this 2021 report for the HIS Directorate is the result of effort over the last three 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 to ensure the work we do has the desired effect. It allows us to see where we are having 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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