



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

Health Information  
and Standards

# Knowledge Sharing and Impact Assessment

Health Information and Standards  
Directorate Report 2020

*Safer Better Care*

## 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

Introduction.....	5
Health Information Function .....	9
Health Information Quality .....	10
Technical Standards.....	20
Standards and Guidance Setting Function.....	34
The National Care Experience Programme .....	58
Conclusion and next steps .....	72

## Introduction

*Impact can be defined as the measure of change or difference that is attributable to a definable action.*

Measuring and reporting on the impact of our work promotes transparency, allows for evaluation of our work against our stated aims and objectives and, in turn demonstrates the effectiveness of our work. The measurement of impact is a way of judging the success of a project and identifying areas which need improvement.

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

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. In 2018, we developed a strategic framework to support the measurement of impact within our teams (*Knowledge sharing and impact strategic framework for the HIS Directorate, 2018*).

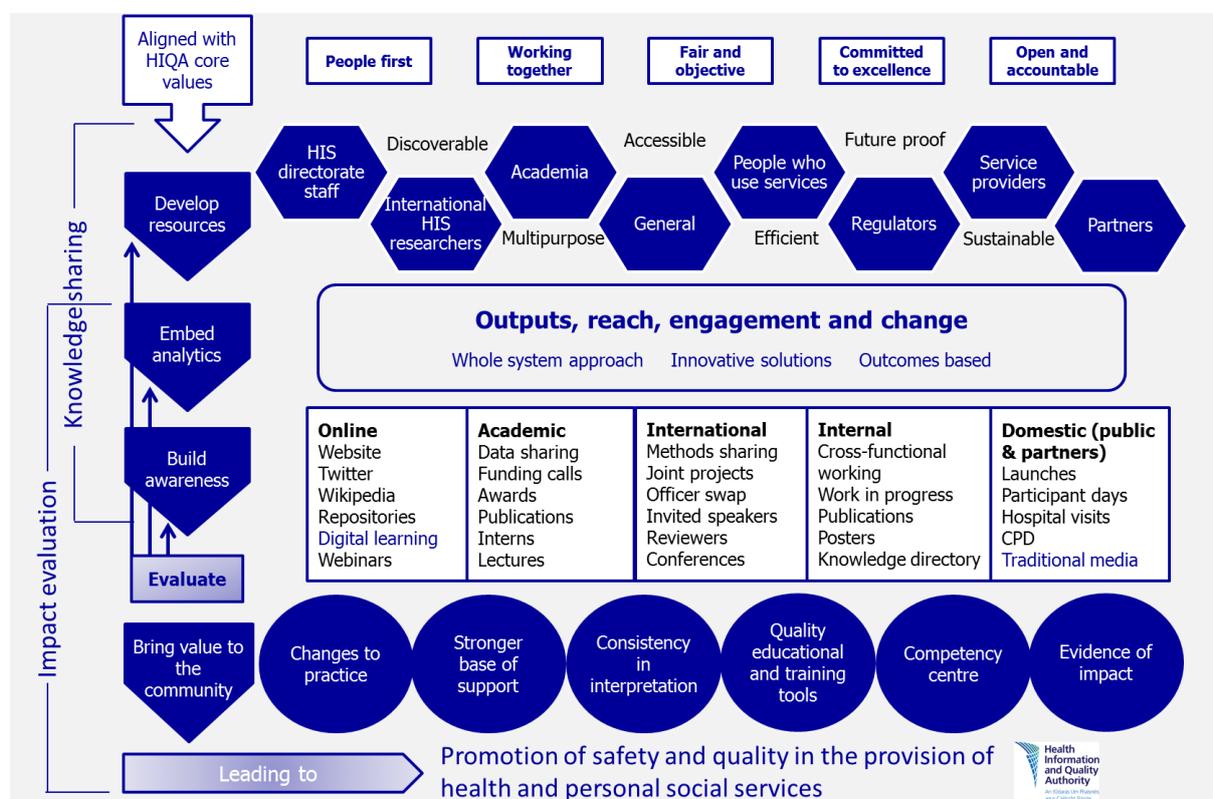
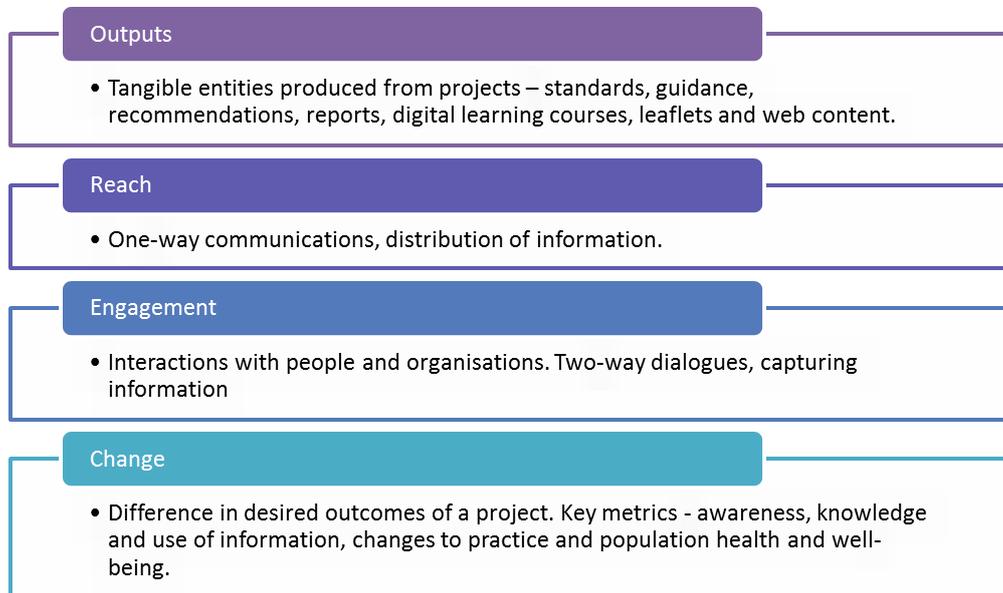


Figure. Overview Knowledge sharing and impact strategic framework, 2018

The framework supports measuring impact through a combination of measures including outputs generated, reach and engagement activities with stakeholders, and observable changes.



*Figure. Measure of impact*

The HIS Directorate has the following functions:

1. Health Information Function
  - The Health Information Function operates under the remit of the Health Act 2007 and is guided by the [Health Information Strategic Objectives, 2019](#).
2. Standards and Guidance Setting Function
  - The Standards and Guidance Setting Function operates under the remit of the Health Act 2007 and is guided by a [prioritisation process](#).
3. National Care Experience Programme
  - The National Care Experience Programme operates in line with the objectives and remit, as laid out in the [National Care Experience Programme Strategic Plan \(2019-2021\)](#).

The projects undertaken within the HIS Directorate do not usually have one easily measureable desired outcome. Many of our projects are expected to elicit change indirectly and slowly, in some cases it may take years before we see the full impact of a project. Furthermore, the impact of the work is intertwined with the work of the Regulation Directorate within HIQA , as well as with other organisations such as the

Department of Health, the Department of Children, Equality, Disability, Integration and Youth, and the Health Service Executive (HSE). The framework was therefore developed to support the creation of a portfolio of impact evidence, bringing together indirect and direct measures of impact, and collecting data over a prolonged period of time. The measurement of impact is, as such, an ongoing endeavour. This document describes the outputs, reach, engagement and change against business plan objectives. Change can be somewhat difficult to measure and where evidence of change exists, it is included. However, an organisational approach to measuring long-term change for all HIQA's functions is being considered.

## COVID-19

HIQA's business plan objectives for 2020 were initially developed at the end of 2019. The objectives were revised in light of the impact of COVID-19 on our priorities as an organisation and on our ability to engage in planned work, such as face-to-face stakeholder engagement and hospital visits. As such, this impact report is written against our revised objectives.

There were a number of temporary redeployments of staff from within the Directorate to COVID-19 related work. From April to July 2020, two members of the Health Information Quality Team were redeployed to the Health Protection Surveillance Centre (HPSC) South region in the HSE to assist with COVID-19 epidemiology and surveillance. From March to July 2020, four members of the HIS Directorate were redeployed to work with the COVID-19 Evidence Synthesis Team within HIQA's Health Technology Assessment (HTA) Directorate. They conducted evidence synthesis at the request of the National Public Health Emergency Team (NPHE) and of related groups tasked with the national COVID-19 response, to inform national strategic decision-making. One member of the Standards Team was redeployed to COVID-19 projects from March to August and worked with the NPHE subgroup on vulnerable groups to develop guidance and materials on cocooning and, following this, was redeployed to HPSC for development of public health guidance. She worked with the NPHE subgroup on evidence synthesis and guidance development to provide up-to-date, evidence-based and accessible guidance for COVID-19. Five members of the HIS Directorate assisted with contact tracing for the HSE.

The nature of our stakeholder engagement changed. In lieu of face-to-face meetings we held virtual meetings, workshops and townhalls. This proved successful in maintaining our ability to engage with target stakeholders, but it also extended our reach and engagement as virtual sessions were more accessible for many.

## Purpose of this report

This report contains the findings of the impact evaluation of the work of the Health Information Function (Quality and Technical Standards), the Standards and Guidance Development Function and the National Care Experience Programme. Together, these comprise HIQA's 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 2020 business plan objectives, as outlined in the [HIQA Business Plan \(2020\)](#). It also reports on the impact of our work as observed during 2020. This is the second such report by the HIS Directorate. Our first [report](#) based on 2019 impact acts as baseline.

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

## **Health Information Function**

The Health Information Function is comprised of two teams: Health Information Quality and Technical Standards.

### **What we do**

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

### **Why we do it:**

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

### **How we do it**

Working collaboratively with key stakeholders, we gather national and international evidence on best practice. We consult with experts, stakeholders, service providers and service users. We report on the implementation of our national standards and guidance, and supports 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*

## Health Information Quality

### 2020 Objectives

- Commence the development of recommendations on a model for the collection, use and sharing of health information in Ireland.
- Develop a methodology for a public consultation in relation to the collection, use and sharing of health information in Ireland.
- Complete 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.

### Desired outcomes

- Provide thought leadership in defining the health information landscape in Ireland by using best available evidence and engagement with stakeholders.
- Develop a consultation methodology to enable meaningful engagement with the wider public in order to inform national health information policy in Ireland.
- Ensure that the public voice is heard by listening to and learning from people's opinions and attitudes and incorporating this into our work.
- 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 selected two key outcomes in order to measure the change relating to this our work:

- Awareness
- Improvements in practices.

## 2020 Impact

Against our desired outcomes of **providing thought leadership in defining the health information landscape in Ireland by using best available evidence and engagement with stakeholders**, in 2020 we continued to develop recommendations on a model for the collection, use and sharing of health information in Ireland. This is a new project and as such is evaluated for impact under reach and engagement only.

### Outputs

- International review of consent models for the collection, use and sharing of health information published in February 2020.

### Engagement

- We held a meeting of the Advisory Group in relation to developing recommendations to provide an update on the national survey aspect of the public engagement project. The organisations represented on the committee are:
  - Royal College of Surgeons Ireland
  - Irish College of General Practitioners
  - HISI
  - Institute of Community Health Nursing
  - Nursing and Midwifery Board of Ireland
  - The College of Psychiatrists of Ireland
  - HI Systems Research Centre UCC
  - Child and Family Agency (Tusla)
  - Irish Pharmacy Union
  - The Irish Platform for Patient Organisations, Science and Industry (IPPOSI)
  - National Patient Forum
  - Central Statistics Office
  - HSE
  - Department of Health
  - Health Research Board.

In 2020, against our desired outcomes of **developing a consultation methodology to enable meaningful engagement with the wider public in order to inform national health information policy in Ireland; and ensuring that the public voice is heard by listening to and learning from people's opinions and attitudes and incorporating this into our work**, we carried out a public engagement survey on the collection, use and sharing of health information in Ireland with members of the population of Ireland.

### **Outputs**

- Developed a review of public engagement activities and policy in other countries
- Methodology developed for a public consultation on the collection, use and sharing of health information
- Survey tool — scenario-based Computer-Assisted Telephone Interviewing tool using scenarios based on the Irish healthcare system.

### **Reach**

- 1,200 randomly selected adult members of the public in Ireland were contacted and completed the national telephone survey.

The survey was launched on the HIQA website and social media outlets. A press release was sent to national and regional broadcast and print news desks across the country, as well as targeted emails to the medical press. This resulted in:

- 189 engagements on Twitter
- 59 clicks on LinkedIn
- 23 engagements on Facebook
- 341 reached on Instagram
- An article published in the Medical Independent
- An article published in the Irish Medical Times.

### **Engagement**

- We completed a national telephone survey, engaging with a representative sample of 1,200 members of the population of Ireland.
- As part of the governance structure for the survey, we engaged with the Department of Health, the HSE and patient representatives, members of which formed the project's Steering Committee and the partnership project team.
- We engaged with the Royal College of Physicians of Ireland's Research Ethics Committee which granted ethical approval for the survey and focus groups

- We held focus groups with HIQA staff in relation to attitudes and opinions on the collection, use and sharing of personal health information.
- We carried out 21 interviews with selected healthcare professionals to discuss the barriers and facilitators in relation to the collection, use and sharing of personal health information in Ireland.
- We undertook cognitive testing of the survey tool with nine patient representatives and members of the public.
- There was ongoing engagement with the National Steering Group on the development of the survey methodology.
- As part of planning for focus groups due to be held in 2021 in relation to this project, organisations representing special interest groups such as people experiencing homelessness, drug users and sexual health service users were engaged with during 2020.
- A pilot of the survey was conducted with 10 participants.
- A Data Protection Impact Assessment was completed in relation to the National Public Engagement Survey on Health Information and focus groups.

## **Change**

### *Awareness*

The National Public Engagement Survey on Health Information was conducted with 1,200 participants in 2020. Awareness of this topic will therefore have increased among those who took part. Interviews were also held with 21 healthcare professionals from across health and social care disciplines, thus increasing awareness among those who were interviewed. In addition, the survey was launched on the HIQA website and social media outlets. This promotion of the survey on national platforms raises awareness of the topic among the public.

Against our desired outcome of **improve the quality of health information in national data collections in Ireland**, as part of the ongoing review programme that assesses compliance with the *Information management standards for national health and social care data collections*, we undertook a review of information management practices of the National Incident Management System (NIMS) within the HSE.

### Outputs

- Final draft report was prepared and sent for factual accuracy review in 2020.

### Engagement

- A review of international evidence was carried out and teleconferences were held with subject matter experts to identify and understand best practice models for incident management within health systems in other jurisdictions.
- In 2020, governance meetings were held with directors and senior management team members in:
  - HSE Quality and Verification Ream
  - State Claims Agency
  - HSE Acute Operations
  - HSE Community Operations
  - National Patient Safety Office (NPSO), Department of Health
  - Office of the Chief Executive Officer, Cork University Hospital.

These interviews were held to inform HIQA's review of information management practices for NIMS in the HSE.

- Site visits and focus groups were conducted with:
  - Risk Managers
  - QPS lead
  - Directors of Nursing
  - Clinical Care Coordinator
  - Clinical Nurse Manager
  - Area administrator and reps from different disciplines within primary care services.
- The review programme and information management standards for national data collections were presented internationally at the international HealthInf Conference (both oral and poster presentation) in Malta in February 2020.
- The webpage for the [Information Management Standards for National Data Collections](#) (2017) against which the review programme assesses compliance, had 282 unique page views in 2020 and the document itself was downloaded 239 times.

## **Change**

### *Awareness*

NIMS interviews have highlighted important topics like information governance, use of information and governance to end user, project leads and directors of the HSE and State Claims Agency and this should have a positive impact on use and future strategic planning for NIMS. In addition, meetings with stakeholders (for example, NPSO) have promoted the use of NIMS for future projects while also highlighting existing and potential challenges facing the use of the system.

From April to July 2020, two members of the HI Quality Team were redeployed to the HPSC South region in the HSE to assist with COVID-19 epidemiology and surveillance.

### *Improvement in information management practices*

In relation to the 2019 review of information management practices in the HSE CIDR system, although no formal evaluation has been undertaken, CIDR's Information Security and IT Manager has noted that recommendations made in the review undertaken in 2019, for example the use of Data Sharing Agreements, are being implemented in the organisation. Details of these changes are due to be presented by staff from the HPSC at the national Health Informatics Society of Ireland (HISI) conference in 2021.

Due to redeployment and loss of core team members, work in relation to data quality modules against our objective to **support those working in health and social care to improve data quality to underpin the delivery of safe care and informed decision-making** was paused. However, progress was made in relation to a background document to inform the development of guidance on developing an Information Management Strategy for national data collections.

### Outputs

- Draft background document on national and international information management strategies.

### Engagement

- Interviews with four international stakeholders and three national stakeholders were held in relation to their respective information management strategies.
- One meeting was held with an international healthcare consultancy organisation in relation to developing an information management strategy, including the sharing of useful resources.
- The HI Quality Team and National Care Experience Programme undertook this work as a joint initiative with continuous engagement during interview stage and drafting of background document.
- We engaged with the National Care Experience Programme and the LENS Project (development of an open access database of statutory notifications from social care) providing advice and support in the implementation of information management standards and guidance.
- There were 3,345 unique page visits to HI Quality content.
- There were 349 downloads of the *Guidance on a data quality framework for health and social care* and 83 downloads of the *Five quality improvement tools for national data collections* during 2020.

### Change

#### *Awareness*

112 people completed our two digital learning modules in 2020. These included people from Ireland, the UK, Canada, United Arab Emirates, Australia and Kenya. 62% of those who had completed the course were working within a health and social care setting, or were developing a data quality framework for their organisation. The remainder largely comprised teachers, trainers and students.

*Improvement in information management practices*

Findings from the background document and the final guidance tool for national data collections, due to be developed and published in 2021, will inform the development of the National Care Experience Programme's own Information Management Strategy. The digital learning modules and tools for national data collections were used by HIQA's LENS Project Team in the development of a data dictionary and statement of purpose for the new Database of Statutory Notifications from Social Care in Ireland, underpinning the development of this newly available database.

## **Next steps**

In 2021, we will continue to work on the national public engagement project for health information and conduct follow-up focus groups with members of special interest groups whose views were not fully represented through the public engagement survey. These will include harder to reach groups including people experiencing homelessness, people with disabilities, drug users and sexual health services users. The full findings from this project will be published in Quarter 2 of 2021. Educational tools will be developed to promote the findings and the benefits of data sharing.

We will publish the review of information management practices of the National Incident Management System (NIMS) within the HSE and continue to progress the review programme of national data collections. We will also conduct a follow-up with organisations that have previously been reviewed under the review programme. This will allow us to evaluate the actions taken by the organisations against the recommendations made in the review. It will also facilitate us in evaluating longer term change stimulated by the review programme.

We will publish the background document on national and international information management strategies. Findings from this document will inform the development of a guidance document for national data collections on how to develop an Information Management Strategy. We will continue to update and develop digital learning tools in order to support the national data collections and improve the quality of health data in Ireland.

We will continue to engage with patients, the public and key stakeholders to support the development of recommendations on a model for the collection, use and sharing of personal health information. We will hold a public consultation on this topic and publish a draft report outlining recommendations which will reflect findings from the international review on consent models and the public engagement project and feedback from the public consultation.

## Health Information Quality, 2020 Impact Summary

There were **3,345** unique page visits to our Health Information Quality content.

**1,200** members of the Irish public were surveyed in relation to their views on the collection, use and sharing of their health information.

**21** healthcare professionals were interviewed in relation to their views on the collection, use and sharing of health information.

**8** national and international organisations were interviewed in relation to their approach to information management.

There were **112** completions of our **2** digital learning modules on data quality in 2020.

**100%** of the 74 people who completed an evaluation of the Introduction to Data Quality digital learning course said it was useful and 95% said they plan to change their practice relating to data quality having completed the course.

**100%** of the 20 people who completed an evaluation of the Implementing a Data Quality Framework digital learning course said they were confident that they could now develop a data quality framework having completed the course.

**3** lectures were delivered to students completing Public Health and Digital Health Masters and to those completing the Sphere PhD programme.

**2** national data collections – National Care Experience Programme and the Database of Statutory Notifications from Social Care in Ireland - actively engaged with the team and with the published tools in the development of their data quality frameworks and information governance structures.

## Technical Standards

### 2020 Objectives

- Begin assessing compliance of eHealth services within the HSE against supporting national standards
- Support the introduction of a national, electronic patient summary, compliant with the existing national standard, published in 2018
- Support the introduction of a national health information model.

We also continued to support the following programmes of work, each of which is based on previously-published national standards, recommendations, and guidance:

- National community-based eprescribing service, supported by recommendations and a national standard
- Automation of key services in general practice through use of the national messaging broker, supported by a national standard
- National eReferral service, supported by a national standard
- National terminology standard, supported by recommendations
- National information model for a national electronic medicinal products catalogue, supported by a national standard.

### Desired Outcomes

- Promote compliance of eHealth services within the HSE with national standards
- Support the sharing of patient information in the health and social care sector
- Progress the implementation of national priorities within the eHealth landscape.

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

- Involvement of key national stakeholders in development of national standards, recommendations, and guidance (new projects)
- Adoption of national standards, recommendations, and guidance (previously published work).

## 2020 Impact

Against our desired outcome of **promoting compliance of eHealth services within the HSE with national standards**, we developed the methodology and launched a new review programme that aims to drive quality improvements by identifying areas of good practice and areas where improvements are necessary across eHealth services. This programme is in its infancy, and as such our focus has been on outputs, reach and engagement. We will evaluate change in response to the programme in the coming years.

### Outputs and Reach

- [Guidance on eHealth Review Programme](#) has been viewed 215 times in 2020, similar to the viewing level in 2019 demonstrating maintained interest since its publication.

### Engagement

- We engaged with the following organisations in developing the methodology for the review programme:
  - **MedCom in Denmark:** a subject matter expert to lend expertise and visits would be involved in all stages of the review including on-site visits, report writing and a lessons learned workshop which is planned post-review.
  - National eReferrals Service, the first eHealth service to be reviewed, returned a self-assessment and provided extensive documentation as part of a document request.

- **Note.** Following the outbreak of COVID-19 in March 2020, work on the eHealth review programme was suspended for 2020.

A national electronic patient summary is a relevant set of information needed to treat a patient in unplanned care, such as emergency or out-of-hours treatment. Against our desired outcome of **supporting the sharing of patient information in the health and social care sector**, we developed recommendations outlining international best practices in the establishment of a national programme for the introduction of a national, electronic patient summary in Ireland, ensuring compliance with the related *National Standard on Information Requirements of a National Electronic Patient Summary* (2018). Our aim was to reach key individuals who will set up the national implementation programme for the implementation of a national electronic patient summary. Therefore, our metric for change is the involvement of stakeholder organisations in the development of the recommendations and supporting evidence. In line with HIQA's public service remit, we developed an online brochure, to promote understanding of the patient summary and of this work among a wider audience, and an FAQ guide for the health informatics audience. The launch of the recommendations is scheduled for January 2021.

## Outputs

- Best Practice Review of Summary Care Records (2020)
- As Is Analysis of the Irish eHealth Landscape (2020)
- Draft Recommendations to the Minister for Health on the Implementation of a National, Electronic Patient Summary in Ireland (2020)

## Reach

- In developing the recommendations, we undertook a six-week public consultation. As part of the public consultation, we published the Best Practice Review of Summary Care Records and an As Is Analysis of the Irish eHealth Landscape on the HIQA website. As a result, the following reach was recorded in website statistics:

Publication	Number of website views
<b>Best practice review</b>	255
<b>As Is Analysis</b>	276
<b>National Standard on Information Requirements on a National Electronic Patient Summary <sup>1</sup></b>	360

<sup>1</sup> Referenced throughout the Recommendations, this National Standard was published in 2018.

## Engagement

To develop the recommendations, we convened an Expert Advisory Group, which met three times in 2020. We also engaged with international organisations to inform the development of the Best Practice Review and with national programmes and services to inform the development of the As Is Analysis.

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

- Cairde
- Department of Health
- General Practice Information Technology,
- Irish College of General Practitioners
- Health Service Executive
- Irish Association of Directors of Nursing and Midwifery
- Irish Medical Organisation
- Irish Medication Safety Network
- Irish Pharmacy Union
- National Standards Authority of Ireland
- Royal College of Physicians of Ireland
- Royal College of Surgeons of Ireland
- Irish Platform for Patient Organisations, Science and Industry

**International organisations** Representatives of the following international organisations provided guidance and expertise that informs the *Best Practice Review of Summary Care Records*:

- ELGA, Austria
- Medcom, Denmark
- Summary Care Record Programme, NHS Digital, England
- Estonian eHealth Foundation (former CEO)

- National Institute of Health and Welfare, Finland
- Health and Social Care Northern Ireland
- Norwegian Directorate of eHealth
- NHS National Services Scotland
- Andalusian Health Service, Andalusia, Spain.

**National organisations** The following organisations and programmes provided submissions to the *As Is Analysis of the Irish eHealth Landscape*:

- Acute Floor Information System
- Department of Health
- Digital Academy
- eHealth Ireland
- GP IT Group
- HSE Access to Information – Individual Health Identifier, and others
- HSE Maternal and Newborn Clinical Information System (MNCIS)
- HSE Medical Laboratory Information System (MEDLIS)
- HSE National Data Dictionary
- HSE National Electronic Health Record
- HSE National Integrated Medical Imaging System (NIMIS)
- HSE Patient Forum
- HSE Primary Care and Eligibility Reimbursement Service (PCERS)
- Irish Medical Organisation
- Irish Pharmacy Union
- Irish Platform for Patient Organisations, Science, and Industry
- National Ambulance Service
- National Immunisation Office
- OpenNCP

- Pharmaceutical Society of Ireland
- SláinteCare
- SNOMED CT National Release Centre for Ireland
- Vendors-GP.

In developing the recommendations, we undertook a six-week public consultation, with emails sent to more than 400 individuals and organisations. The following organisations made submissions to the public consultation:

- Article Eight Advocacy
- Cantillons Solicitors, Cork
- Caredoc, Carlow
- Citizens Information Board
- Data Protection Commission
- Department of Health
- Digital Rights Ireland
- Enterprise Technical Architecture, HSE Office of the CIO
- GS1 Ireland
- Health Research Board
- HRB Primary Care Research Centre
- HSE Access to Information Programme
- HSE eHealth HSCP Advisory Group
- HSE National Quality Improvement Team
- HSE Primary Care Eligibility Reimbursement Service
- Information Architecture, HSE Office of the CIO
- InterSystems Corp
- Irish College of General Practitioners, GPIT Group
- Irish Lung Fibrosis Association
- Irish Medical Council
- Irish Medical Organisation
- Irish Medication Safety Network
- Irish Platform for Patient Organisations, Science and Industry
- Irish Society of Chartered Physiotherapists
- Mental Health Commission
- National Cancer Control Programme
- National Rare Diseases Office
- National Release Centre for SNOMED CT
- NSAI HISC Committee
- Pre-Hospital Emergency Care Council
- Private Hospitals Association
- St Patrick's Mental Health Services
- Takeda (Shire) Pharmaceuticals

In the context of healthcare, an information model identifies the information that can be included when collecting and sharing clinical and administrative information. It allows key stakeholders, including clinicians, to identify the common categories of information that can be grouped together in a logical way (known as concepts) — such as patient, medications, diagnosis — and which computer systems need to support. Recommendations on a national information model for health information in Ireland will support the collection, use and sharing of information across health information systems including eHealth systems and national data collections (patient registries).

Against our desired outcomes of **supporting the sharing of patient information in the health and social care sector and progressing the implementation of national priorities within the eHealth landscape**, we aimed to reach key individuals who will support the recommendations on health information modelling in Ireland. Therefore, the metric for change is the involvement of stakeholder organisations in the development of the recommendations and supporting evidence. In line with HIQA's public service remit, a best practice review and a supporting FAQ will be developed, to promote understanding of this work for the health informatics audience.

## **Engagement**

To develop the Recommendations, 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 the Best Practice Review.

**Advisory Group Membership** 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
- Department of Health – Sláintecare Division/Programme Implementation Office
- Health Service Executive – Office of the Chief Clinical Information Officer
- Health Service Executive (OCIO) – Digital Nursing and Midwifery
- Health Service Executive (OCIO) – Enterprise Architecture
- Health Service Executive (OCIO) – Integrated Information Division
- Health Service Executive (OCIO) – Access to Information

- Health Service Executive (OCIO – Engagement & Delivery EHR programme)
- Health Service Executive (OCIO) – 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 Pharmacy Union
- Irish Medical Organisation
- National Haemophilia Register
- Irish Epilepsy and Pregnancy Register
- Academia

**International organisations** Representatives of the following international organisations provided guidance and expertise that informs the *Best Practice Review of Health Information Modelling in Ireland*:

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

Owing to the nature of our published work, which is developed in collaboration with the small groups of critical stakeholders that will implement the work, large scale reach and engagement activities are not usually appropriate. For published work, we therefore assess the resulting change in terms of the adoption. In 2020, we aimed to **evaluate the adoption of published national standards, recommendations, and guidance** including:

- National standards for messaging (version 4.0, 2017) and eReferrals (2011), supporting the automation of key GP services
- Recommendations in respect of the adoption of Systematized Nomenclature of Medicine (2014) as the clinical terminology standard for Ireland
- National standard on a data model for a national electronic medicinal product catalogue (2015).

### **National Standards for messaging and eReferrals, supporting the automation of key GP services**

First published in 2010, the General Practice Message Standard supports a range of key GP services, including the ordering of laboratory tests and return of the test results, the return of results of radiological investigations, management of ante-natal care visits, and others. Now in its fourth version, it is a well-established project with long-term impact. Healthlink, the national message broker, also adopted the General Practice Message Standard as their standard, laying the foundations for interoperability. All health services wishing to exchange messages through Healthlink, must comply with the standard. The National Standard for Patient Referral Information (2011) supports improved delivery of care through the automation of a range of referrals, including general referrals and cancer referrals, again using the national health message broker. There has been substantial growth in the number of hospital eReferrals from general practice made, in compliance with the General Practice Messaging Standard, since the inception of the service, as highlighted in the following graph.



General eReferrals Sept 2018 - Nov 2020

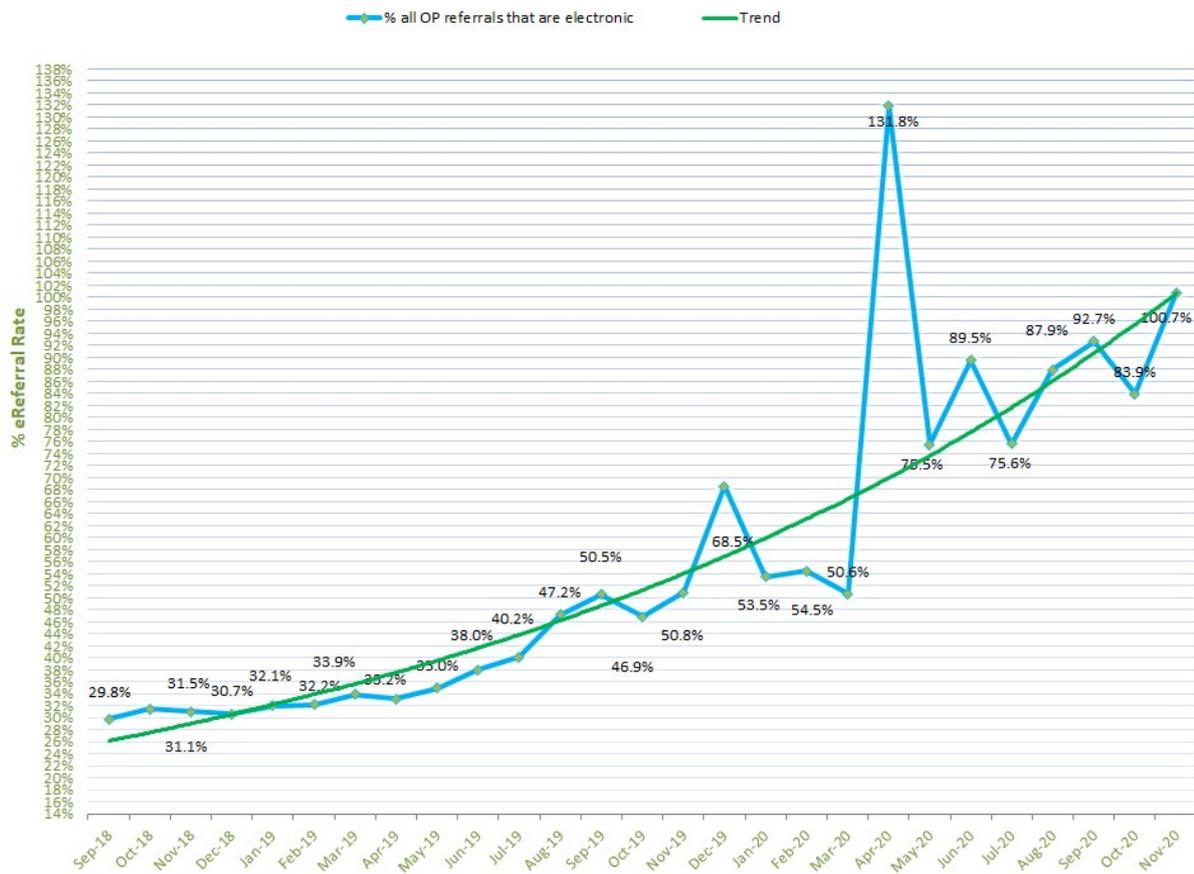


Figure. General eReferrals September 2018-November 2020, Healthlink Data

By 2020, more than 23 million electronic referral messages had been sent through Healthlink – indicating compliance with the General Practice Messaging Standard.

Following the outbreak of COVID-19 in March 2020, the national eReferral service was quickly identified as a fast, safe, and efficient means of expediting Covid-19 test requests and of receiving those test results. Healthlink has been instrumental in enabling referrals for patients who need a COVID-19 test or who need to be seen at a Community Assessment Hub. It is also instrumental in returning laboratory results for COVID-19 to referring clinicians, including GPs.

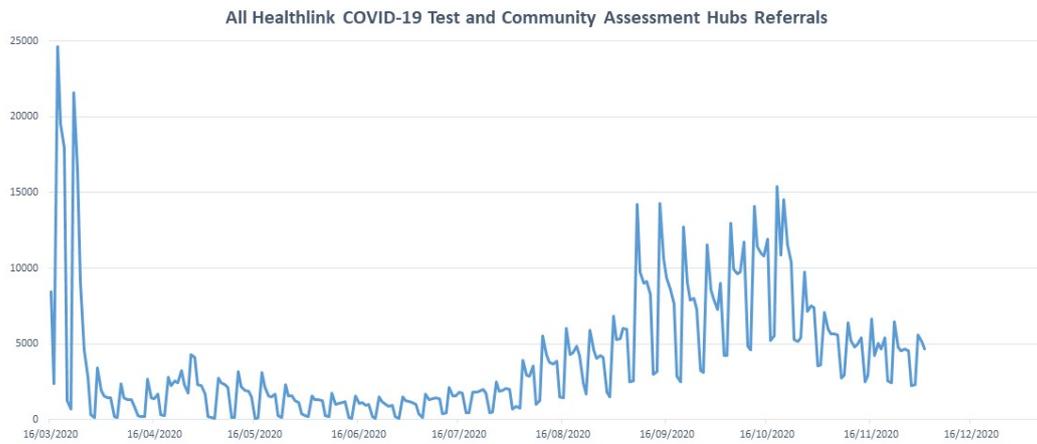


Figure. COVID-19 test and Community Assessment eReferrals, Healthlink Data

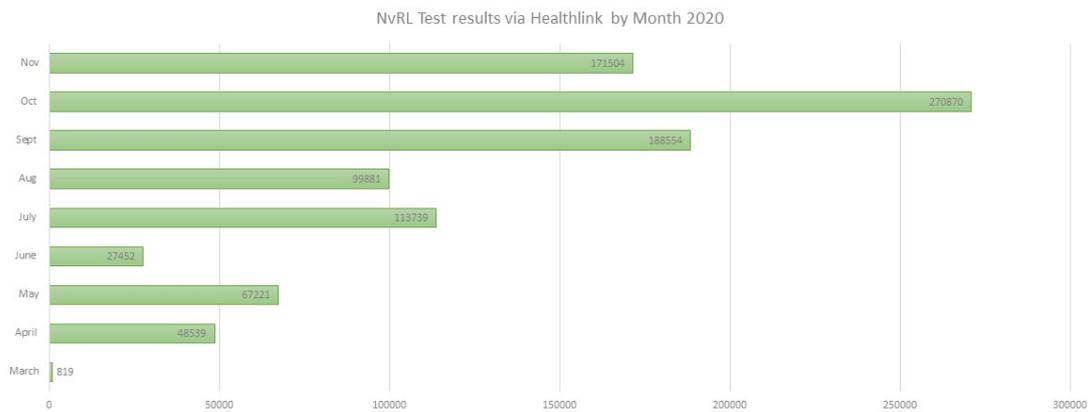


Figure. COVID-19 test results via eReferral System, Healthlink Data

## **National Terminology Standard**

In 2014, we made recommendations in respect of the adoption of Systematized Nomenclature of Medicine (SNOMED CT) as the clinical terminology standard for Ireland. Following the adoption of SNOMED CT in 2016, the SNOMED CT National Release Centre for Ireland was established. The SNOMED CT Governance Group was also convened, which continues to be chaired by Dr Kevin O'Carroll, HIQA's Technology and Standards Manager. In 2020, the fourth edition of SNOMED CT Ireland edition was released.

A SNOMED CT dataset was developed for the assessment, testing, contact tracing and management of COVID-19 cases in Ireland and is currently being implemented in information systems used for the management of COVID-19 in community and hospital settings. The National Release Centre has also worked with the National Immunisation Office, public health and systems suppliers to ensure that SNOMED CT is incorporated into the IT systems developed to support the national COVID-19 vaccination programme. SNOMED CT will improve data quality, allow for interoperability between information systems, allow for internationally comparable data and allow for good recording and retrieval data.

## **National standard on a data model for a national electronic medicinal product reference catalogue**

The *Data model for an electronic medicinal product reference catalogue – a National Standard* defines the data model required to support the implementation of an electronic medicinal product reference catalogue. An electronic medicinal product reference catalogue is an electronic dictionary of medications available for prescribing and dispensing. The key aim of the catalogue is to provide a consistent approach to the identification and naming of medicines prescribed and dispensed.

In 2020, the National Health Products Catalogue announced that it and all its catalogues are compliant with the national standard.

## Next steps

In 2021, we will address one of the highest national eHealth priorities for 2021 — **an integrated IT system for older persons** services including residential, home support, day care, needs assessment and care planning, so as to support the provision, management, delivery and reporting of services, and especially for planning alternative service provision and planned capacity development in the event of evolving public health measures. We will do this by developing a set of recommendations and the subsequent development of national standards.

We will complete the **recommendations on health information modelling**, which will support the collection, use and sharing of information across health information systems including eHealth systems and national data collections (patient registries).

We will resume our first **review of an eHealth service**, the National Electronic Referrals Service. We will work with the service to make improvements based on our findings and recommendations. We will also publish our recommendations so that other eHealth services can use them as a learning resource.

We will publish **recommendations on the implementation of a national electronic patient summary**, scheduled for January 2021, to support the implementation of the patient summary defined in the *National Standard on Information Requirements for a National Electronic Patient Summary*. Educational materials for key terms relating to both the standard and the recommendations will also be published.

Finally, we will also continue to support the wider adoption of previously-published national standards, recommendations, and guidance.

## Technical Standards, 2020 Impact Summary

COVID-19 tests were requested, and results returned, electronically in compliance with the National Standard for messaging and eReferrals.

Fourth release of Irish SNOMED CT edition, a national terminology standard supporting clinical coding and interoperability of systems used:

- for assessment, testing, contact tracing and management of COVID-19 cases, and,
- for the national Covid-19 vaccination programme.

**69** stakeholder organisations and groups from across health and social care in Ireland, including patient representatives, and **10** international experts, engaged in the development of Recommendations on the Implementation of a National Electronic Patient Summary.

**1** new Review Programme was launched.

**1** National Health Products Catalogue, and all associated catalogues, now compliant with the National Standard on a Data Model for a National Electronic Medical Product Catalogue (2015).

## Standards and Guidance Setting Function

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.

## 2020 Objectives

- Complete the development of an online learning module to aid understanding and support implementation of the *National Standards for infection Prevention and control in community services*.
- Complete the development of an online learning module to aid understanding and support implementation of the *National Standards for Adult Safeguarding*.
- Develop awareness and training materials for service providers and staff to support a rights-based approach in health and social care services.
- Continue the development of National Standards for Children's Social Services.
- Commence the development of Overarching National Standards for the care and support of children using health and social care services.

- Improve the processes used in developing Standards and translating these into practice.

## Desired Outcomes

- Increase awareness and understanding of the *National Standards for infection prevention and control in community services* in order to facilitate implementation.
- Support the development of a culture in health and social care services where safeguarding and a human rights-based approach to care and support are embedded into practice.
- Engage with staff working in, and people with experience of using, health and social care services for children to raise awareness about and to engage with staff to inform the development of two sets of children's standards.
- Ensure the processes applied to the development of Standards are in line with best practice and result in translation of Standards into practice.

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

- Increased awareness
- Cultural change.

## 2020 Impact

The *National Standards for infection prevention and control in community services* were published in 2018. To achieve our desired outcome of **increasing awareness and understanding of the National Standards for infection prevention and control in community services in order to facilitate implementation**, we developed an online learning module on infection prevention and control, which was launched on 18 August, 2020.

This module was developed for the purpose of supporting health and social care staff to implement the standards. By the end of the year, it was completed by 16,362 people, the majority of whom are front-line staff working in health and social care community services. An online evaluation was designed to gather feedback on the module and assess the module's impact, with 3,781 respondents (23% of completers) completing the survey. Based on the evaluation forms, 93% of people said the course gave them a better understanding of what the national standards look like in practice, 78% intend to change their practice having completed the course and 95% would recommend the course to a colleague.

### Outputs

The output from this is a perpetual resource — the online learning module “National Standards in Infection prevention and control in community services: Putting the standards into practice”. The online module aims to support front-line staff to understand and implement the *National Standards for infection prevention and control in community services*, which were launched in 2018. It contains practical examples, real-life scenarios and day-to-day practice tips for staff across a range of health and social care settings in the community, such as residential services for older people and people with a disability, day care services, GP practices, dental services and care delivered in the home.

The module aims to promote good practice in the area, while also addressing knowledge and skills gaps identified through extensive stakeholder engagement. It contains self-reflection questions to help staff to think about how they are already applying the standards, identify areas they may be able to improve and how they might set about doing that.

### Reach

The online learning module was publicised on many social media platforms including Instagram, Facebook, Twitter and LinkedIn to raise awareness that it had been published. The module is hosted on HSEland to maximise reach and ensure it is accessible to frontline staff. Hosting the module on this platform also facilitates

participants to download and save certificates of completion in their learning and development portfolios. Members of the team contacted large numbers of people and organisations who may be interested in the module such as registered providers and residential settings as well as professional bodies. These specifically include designated centres for older people and for people with a disability in order to publicise the module among their staff members. The large number of people working in these services that have completed the module reflects this dissemination effort.

The national Antimicrobial Resistance and Infection Control (AMRIC) Team in the HSE included details of the module in their August 2020 newsletter. This newsletter is issued across the HSE to all staff on the broadcast email system (over 70,000 people). The Pharmaceutical Society of Ireland (the pharmacy regulator) also included details of the online module in its November 2020 newsletter.

In terms of geographical reach of the module, the majority of respondents who completed the evaluation survey did so from Ireland, but the survey was also completed by participants in the UK (19), India (3), United States (2) and other European jurisdictions (6).

We plan to continue to publicise the module further in 2021 including to academic institutions and professional bodies' newsletters, where relevant.

## **Engagement**

The national standards on which the course is based were developed in collaboration with a standards advisory group, which was comprised of key stakeholders in this area. Topics identified by the advisory group during the development of standards as requiring additional support to implement were included in the content of the online module. Thirteen focus groups with people working in, or with experience of, community services were also conducted during the standards development process to discuss their experiences and inform the content. A public consultation on the draft national standards was also conducted. Barriers to implementation and suggestions for guidance and implementation tools were identified during focus groups and detailed in the submissions from the public consultation. This feedback was used to inform the development of the online module.

Two workshops, with wide representation from front-line staff and management working in community services, were conducted to further inform the content of this online module and identify barriers to implementation. These were conducted 10 months after the publication of the national standards to allow time for their implementation to commence.

Subject matter experts working in the HSE were also consulted to agree the key messages of the online learning module during the initial phase of module development. These subject matter experts also reviewed a working and final draft of the online module and provided feedback on both.

Staff working in HIQA's Regulation Directorate also reviewed the module and provided feedback at various stages of its development.

## **Change**

### *Increased awareness*

The online learning module aimed to address the knowledge, skills and motivation gaps identified through public consultation, focus groups, advisory group and workshops.

As of 31 December 2020, 16,362 people completed the online learning module, while 3,781 people completed the evaluation form (23% of completers). This provided insight into how participants felt they could improve infection prevention and control in their day-to-day practice.

The evaluation survey asked *'Having completed the course, do you have a better understanding of what the National Standards for infection prevention and control in community services look like in practice?'* 93% of people responded positively and indicated that they felt they had a better understanding of what the standards look like in practice. Participants felt the online learning module supported standards already in place, while providing clear and concise information. For example, one respondent reported "I had an idea from reading the standards, but like all documents sometimes what you absorb isn't sufficient, this method of information highlighted the important/key aspects of the standards and made it easier to understand and retain".

### *Cultural change*

The evaluation survey asked *'Having completed the course, do you intend to change your practice in any way?'* 78% of respondents indicated that they intended to change their practice in some way after completing the course. People responded that they plan to change their practice by taking more time to consider infection threats and being more proactive to eliminate risks. Some highlighted that the self-reflection element was beneficial in this regard and others reported that they would be discussing learning from the module at their team meetings.

Of those who responded that they did not intend to change, many explained that they were already compliant with infection prevention and control practices and

already carrying it out in their service. For example one respondent wrote “I am working in dentistry and we are already big into cross infection control. We also are careful about prescribing and would do a lot on that. It does help my general knowledge though.”

95% of respondents who answered the question *'Having completed the course, how likely you are to recommend it to a colleague?'* would recommend the course to a colleague. Some participants who were managing services stated that they were ensuring all staff working in their service complete the module. In addition, within days of the module being launched the team was contacted by management in a number of older persons and disability services advising that they would be requiring all staff to complete it.

Other people working within the services said they would recommend it to their colleagues to ensure there was greater team work in relation to infection prevention and control.

Under our desired outcome of **supporting the development of a culture in health and social care services where safeguarding and a human rights-based approach to care and support are embedded into practice**, in partnership with the Mental Health Commission we developed an online learning module 'National Standards for Adult Safeguarding: Putting the standards into practice'. The module was launched on 5 November and by the end of 2020, 4,842 people had completed the module, the majority of whom are front-line staff working in health and social care community services. Of the 4,842 people who completed the online learning module, 994 completed an evaluation form on the course (20% of completers). Of the respondents answered the question '*Having completed the course, do you intend to change your practice in any way?*', 79% indicated that they intended to change their practice in some way after completing the course.

We contributed to HIQA's submission on the Law Reform (LRC) Commission Issues Paper 'A Regulatory Framework for Adult Safeguarding', setting out the guiding principles for inclusion in any regulatory framework, as well as defining key terms for adult safeguarding.

## **Outputs**

The online learning module to support front-line staff to understand and implement the *National Standards for Adult Safeguarding* was launched in October 2020. These standards apply to all health and social care services, including designated centres. The module aims to promote good practice in the area, while also addressing knowledge and skills gaps identified through extensive stakeholder engagement throughout the standards development process. It contains self-reflection questions to help staff think about how they are already applying the standards, identify areas they may be able to improve and how they might set about doing that.

## **Reach**

The online learning module was publicised on many social media platforms including Instagram, Facebook, Twitter and LinkedIn to spread awareness that it had been published. The module is hosted on HSELand to maximise reach and ensure it is accessible to frontline staff. Hosting the module on this platform also facilitates participants to download and save certificates of completion in their learning and development portfolios. Members of the team contacted large numbers of people and organisations who may be interested in the module, such as registered providers and residential settings as well as professional bodies. These specifically include designated centres for older people and for people with a disability in order to publicise the module among their staff members. This engagement resulted in the online learning module reaching a wide range of front-line staff, as can be seen in

Figure 1, below, which provides a breakdown of where participants who responded to the evaluation work.

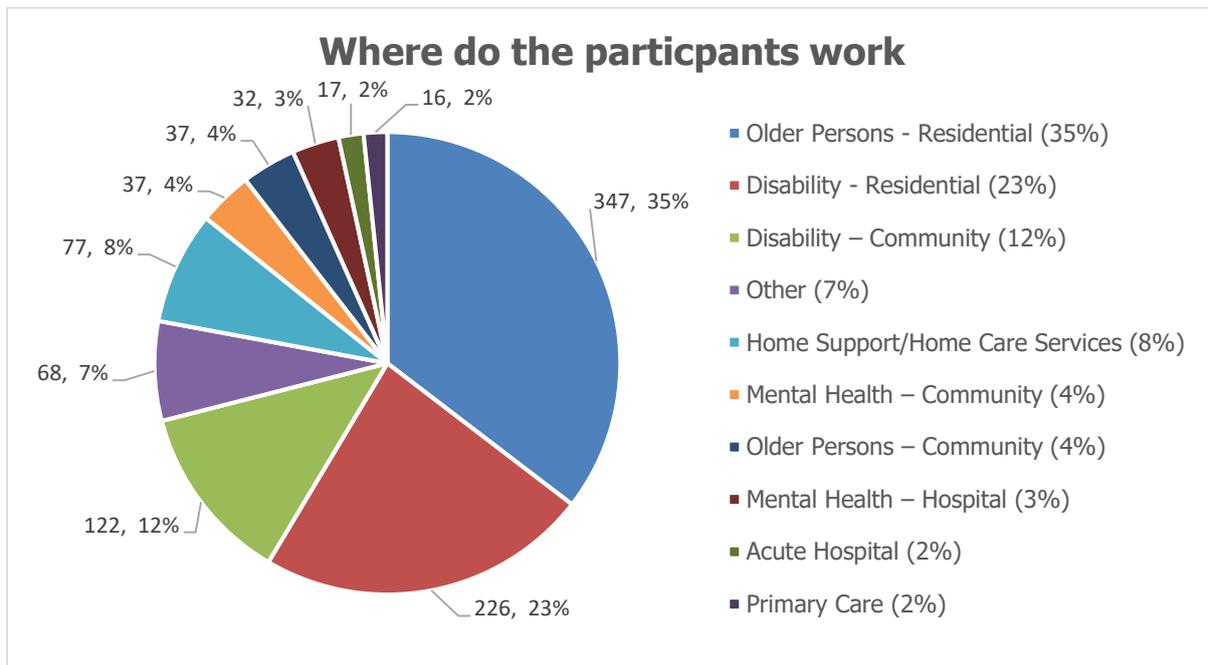


Figure. Breakdown of areas participants work in

In terms of geographical reach of the module, the majority of respondents who completed the evaluation survey did so from Ireland, but the survey was also completed by participants in the UK (13), India (1), and the United States (1). The team will continue to promote awareness of the online learning module in 2021 through social media, online fora, conferences and by targeting sector-specific newsletters and information hubs.

## Engagement

At key stages of development of the *National Standards for Adult Safeguarding* we engaged with stakeholders in order to identify the areas where health and social care staff needed support in order to implement the standards. Feedback from stakeholders in focus groups and through the public consultation indicated that staff needed clarity around what adult safeguarding is, who has responsibility to address safeguarding issues and how to work in a proportionate and empowering way when safeguarding concerns arise. The team engaged with colleagues in the Department of Health and the HSE to inform the development of the online learning module to support staff to understand what adult safeguarding is and their role in responding to it. A draft version of the module was reviewed by a subject matter expert, HIQA

inspectors working in the areas of older persons, disability, as well as inspectors from the Mental Health Commission.

In May, we contributed to HIQA's submission on the Law Reform (LRC) Commission Issues Paper 'A Regulatory Framework for Adult Safeguarding' setting out the guiding principles for inclusion in any regulatory framework, as well as defining key terms for adult safeguarding.

## **Change**

### *Increased awareness*

The online learning module aimed to address the knowledge, skills and motivation gaps identified throughout the standards development process.

As of the 31 December 2020, 4,842 people completed the online learning module, and 994 people (20% of completers) completed the evaluation form at the end of the online learning module. This gave us insight into how participants felt they could improve their adult safeguarding practice.

976 respondents answered the question '*Having completed the course, do you have a better understanding of what the National Standards for Adult Safeguarding look like in practice?*' Of these, 98% responded positively and indicated that they felt they had a better understanding of what the standards would look like in practice.

### *Cultural change*

880 respondents answered the question '*Having completed the course, do you intend to change your practice in any way?*' with 79% indicating that they intended to change their practice in some way after completing the course. Of those who responded that they did not intend to change, many explained that they felt they were already carrying out best practice. For example, one community disability services worker explained that '*This is how I work in my practice, the course highlighted that my practice was in line with standards*'.

Of the 984 participants who answered the question '*Having completed the course, how likely you are to recommend it to a colleague?*', 87% answered positively.

In 2019, we published *Guidance on a Human Rights-based Approach in Health and Social Care Services* and a range of printed or downloadable tools to support health and social care service providers and staff to uphold the human rights of people using services. In 2020, we continued to develop awareness and training materials for service providers and staff to ensure that the rights of people using health and social care services are protected, promoted and supported in practice, and embedded in the culture of a service.

Under our desired outcome of **supporting the development of a culture in health and social care services where safeguarding and a human rights-based approach to care and support are embedded into practice**, we published an academic slide deck for those teaching health and social care students and those providing training for health and social care staff. This was developed to address a large number of requests from academic institutions to deliver modules to their students in this area. In addition, we have developed a number of online learning modules for staff in health and social care services and a video animation for people using services, which will be launched in early 2021.

## Outputs

An academic slide deck on 'A Human Rights-based Approach for Health and Social Care Services' was launched on 31 August 2020. The slide deck is intended as a resource for those teaching health and social care students and those providing training for health and social care staff and is available on the HIQA website. The slide deck has been divided into a number of different sections, which can be delivered together or separately as individual modules. It includes material on human rights within an international and Irish context, the legal framework relevant to human rights in health and social care in Ireland, and the application of human rights principles in day-to-day practice.

## Reach

The academic slide deck was widely disseminated to targeted groups of stakeholders, including:

- A total of 19 professional bodies for health and social care practitioners, including the Irish College of General Practitioners (ICGP), the Irish Nurses and Midwives Organisation (INMO), CORU, and the Pharmaceutical Society of Ireland (PSI).
- A total of 81 academic schools and departments in Ireland who provide courses in medicine, nursing, health sciences, allied health sciences, public health, social care and social sciences.

The slide deck was also promoted on a number of HIQA's social media accounts, including Twitter, LinkedIn and Instagram.

The draft guidance on a human rights-based approach to care and support in health and social care settings was cited in the following academic publication: Murphy K, Bantry-White E. Behind closed doors: human rights in residential care for people with an intellectual disability in Ireland. *Disability & Society*. 2020.

We also disseminated 3,700 copies of the published guidance w to health and social care services, academic schools and departments and health and social care professional bodies in early 2020.

## Engagement

- To inform the development of the academic slide-deck, we engaged with a number of academics from the medico-legal and social work disciplines to ensure the content, flow and format was useful and appropriate. To inform the development of the online learning modules for health and social care staff, we sought the input and feedback of a range of key external stakeholders, including senior representatives from the Irish Human Rights and Equality Commission, the Decision Support Service, the National Advocacy Service for People with Disabilities, the Office of the Ombudsman and Saolta University Hospital Group. Many of these stakeholders also gave input to the development of the video animation for people using services. The online learning modules and video animation will be launched early in 2021.
- In February 2020, the *Guidance on a Human Rights-based approach in Health and Social Care Services* and the suite of additional resources were promoted at the 6<sup>th</sup> Annual SPHeRE Network Conference which was held in the RCSI, Dublin. An oral presentation titled 'Using data to inform Guidance on a human rights-based approach in health and social care practice' was also delivered.
- In March 2020, we delivered an interactive workshop to over 50 social work students in University College Cork. The session introduced the students to the *Guidance on a Human Rights-based Approach in Health and Social Care Services* and the broader suite of resources. This session also helped to inform the development of the slide deck on rights-based care.
- In July 2020, we delivered an interactive workshop on the guidance and additional resources to the Healthcare Team in HIQA's Regulation Directorate to support their development of a human rights-based approach when monitoring against the national standards.

## Change

### *Increased awareness and cultural change*

The slide deck was published on 31 August 2020, just ahead of the 2020/2021 academic year and positive feedback was received from a number of academics who indicated that they planned to use the slide deck in their teaching, for example to students in medical law in the University of Limerick and to social work students in University College Cork. Feedback from one academic noted:

*"Many thanks for this excellent resource. I will definitely promote this onwards and will also be utilising this within our own courses in UCD and elsewhere. This is an excellent pathway to learning and hopefully, will prove to be very useful. My congratulations to the entire team on this effort."*

In March 2020, the guidance and one of the decision-making aids were promoted and used as part of a pilot training workshop hosted and delivered by the All Ireland Institute for Hospice and Palliative Care (AIHPC) in Limerick. The theme of the workshop was human rights challenges associated with palliative care and its aim was to pilot a training approach promoting good practice. The guidance was included in the content of the workshop and given to participants within their resource pack. The decision-making aid was promoted and used within a small group exercise to structure participants' consideration of human rights issues in practice. Participants included health and social care staff and academics.

Under our desired outcome of **engaging with staff working in, and people with experience of using health and social care services for children to raise awareness about and to engage with staff to inform the development of two sets of children's standards**, we have engaged extensively with a wide range of stakeholders, including seldom-heard children, young people and families with experience of children's social services to inform the development of a draft National Standards for Children's Social Services which will go out for public consultation in early 2021. We published the evidence review to inform the development of the standards and also made a submission to the Department of Children, Equality, Disability, Integration and Youth on the review of the Child Care Act 1991.

## **Outputs**

In July, we published an evidence review to inform the development of National Standards for Children's Social Services. It summarises international, national and academic evidence to identify characteristics of good child-centred practices for children engaged in children's social services. Key themes emerged over the course of the review in relation to best practice for effective child services, which included the importance of participation, of safety and wellbeing, of strengthening families, and of accountable and responsive services.

In July, we contributed to HIQA's submission on the review of the Child Care Act 1991, setting out guiding principles for inclusion in the act, as well as observations on the Department's proposals to address the shortcomings in the Act and a number of suggestions where further improvements could be made.

## **Reach**

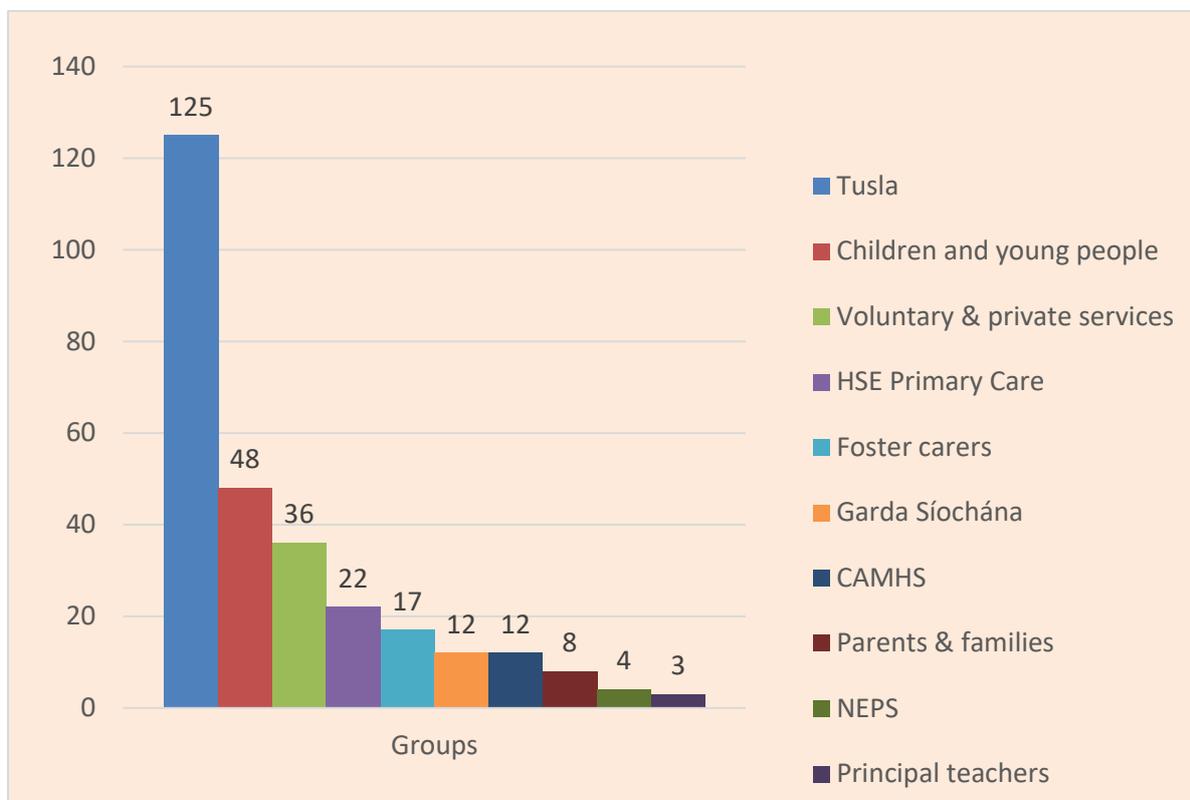
The development of the standards was widely publicised on Twitter, Facebook and LinkedIn to raise awareness of the work. Members of the team engaged extensively with Tusla, HSE, Child and Adolescent Mental Health Services (CAMHS), National Educational Psychology Services (NEPS), Barnardos and Empowering People in Care (EPIC) to engage staff, children, young people and family members in focus groups to inform the development of the standards. Throughout the year there were meetings with key stakeholders in Tusla and the Department of Children, Equality, Disability, Integration and Youth, as well as with the Office of Children's Ombudsman to raise awareness of the work.

The evidence review to inform the development of the standards was well received by academics and practitioners. The Scottish Care Inspectorate, whom the Standards Team has engaged with extensively over the course of the development of the evidence-base to inform the standards, indicated that they plan to include it in

their course materials for their Professional Development Award (PDA) in Scrutiny and Improvement Practice. This principal aim of the PDA is to provide a qualification that will enable a wide range of professionals involved in assessing, monitoring and regulating social care services to demonstrate the knowledge, skills and values needed to ensure positive outcomes for people using services.

## Engagement

We met with 285 children, young people, family members, advocates, and staff members in a diverse range of locations to inform the development of the standards. See Figure 2 below, for a breakdown of the participants.



*Figure. Breakdown of focus group participants*

One meeting of the Advisory Group was held, in November 2020. Representatives from relevant stakeholders included in the Advisory Group are set out below:

- Children’s advocacy groups
- Tusla, the Child and Family Agency
- Department of Children, Equality, Disability, Integration and Youth

- An Garda Síochána
- HIQA's Regulation Directorate – Children's Services
- Coru
- Professional representative bodies
- Service provider organisations
- Academic representation.

## **Change**

As the national standards are still in development it is not yet possible to measure change, however there will be an opportunity to measure intention to change during the public consultation stage, and as the project evolves. The team's ability to measure change will be assisted by the scale and depth of the engagement to date with a wide range of stakeholders with experience of children's social services, which includes children, young people, families, foster carers, advocates, front-line staff, and policy-makers. This engagement has helped to raise awareness of the new standards and to build buy-in that will support their implementation in practice.

The Overarching National Standards for the Care and Support of Children using Health and Social Care Services are being jointly developed with the Mental Health Commission. Under the desired outcome of **engaging with staff working in, and people with experience of using health and social care services for children to raise awareness about and to engage with staff to inform the development of two sets of children's standards** we have engaged with a range of key stakeholders through an Advisory Group, a Children's Reference Group, a scoping consultation on these overarching standards, and meetings with senior representatives from key government departments and organisations. We have completed an evidence review to inform the development of the standards. The evidence review will be published on the HIQA website early in 2021.

## **Outputs**

We have completed an evidence review to inform the development of the standards. The aim of the Overarching National Standards for the Care and Support of Children using Health and Social Care Services is to ensure that no matter what health or social care service a child is using, that there is a consistent response to their needs, and that services will work together to support children in an integrated way. The evidence review to inform the standards summarises international, national and academic evidence to identify characteristics of good child-centred practices for children engaged in children's health and social care services. The key themes which emerged over the course of the review have been structured under the four draft principles which are currently being developed to underpin all future health and social care standards, namely: a human rights-based approach, safety and wellbeing, responsiveness and accountability.

The evidence review will be published on the HIQA website in early 2021.

## **Reach**

The development of the overarching national standards for health and social care services working with children was widely publicised on Twitter, Instagram, Facebook and LinkedIn and a press release was issued to promote awareness of the project and its purpose. Throughout 2020, the project team met with key stakeholders from the Department of Children, Equality, Disability, Integration and Youth, the Department of Health, Tusla, the HSE, the Ombudsman for Children's Office and Children's Health Ireland to raise awareness about the standards.

In addition, over 450 stakeholders were notified about the launch of the scoping consultation to inform the development of the standards, and five tweets were posted on the HIQA Twitter account highlighting the consultation to over 14,700 followers.

## Engagement

- An advisory group has been convened to inform the development of the standards. The first meeting of the Advisory Group was held in October 2020 and includes representation from the following organisations:
  - Department of Health
  - Department of Children, Disability, Equality, Integration and Youth
  - Health Service Executive
  - Tusla – Child and Family Agency
  - HIQA’s Regulation Directorate – Children’s Team
  - Children’s Health Ireland
  - Children’s Rights Alliance
  - National Disability Authority
  - Representatives of children and families with experience of health and social care services.
- A Children’s Reference Group has also been convened to inform the development of the standards. This group will run in parallel to the Advisory Group and is comprised of young people and family members with experience of using a range of health and social care services for children. Their role is to give insight into the issues that are important to children and families using health and social care services, so that this is reflected in the content of the standards. The first meeting of the Children’s Reference Group took place in November 2020.
- A scoping consultation was undertaken in September 2020 to inform the development of the standards, which had 71 responses. Of the 71 responses, 29 people (41%) responded in a personal capacity and 42 people (59%) responded on behalf of an organisation. The submissions represented a variety of organisations including advocacy bodies, professional representative bodies, statutory and voluntary organisations and frontline services. One of the key questions asked in the scoping consultation was “What are the key areas that the overarching national standards should address?” Five high-level themes were identified from the responses to this question, which were: the need for the standards to be underpinned by the rights of the child and a rights-based approach, the

need for integrated working across health and social care services and disciplines, the importance of prevention and early intervention to ensure that children can reach their full potential, working in partnership with families and communities, and the need for good governance in services. Another key question asked "What key organisations or individuals, within the sector, should we engage with when developing the overarching national standards?" The project team conducted a comparison between the organisations and individuals suggested by respondents and the stakeholders included in the stakeholder engagement plan for developing the standards. Where it was noted that there was a lack of representation from key groups or organisations, these were added to the stakeholder engagement plan.

- Throughout the year, the project team held individual stakeholder meetings with senior representatives from key government departments and organisations to inform the development of the standards, including the Department of Children, Equality, Disability, Integration and Youth, and the Ombudsman for Children's Office.
- We engaged with a number of experts from key organisations internationally to inform the evidence review, including: Families Australia; the Council for Disabled Children, England; The Care Inspectorate, Scotland; and the Northern Ireland Commissioner for Children and Young People.

## **Change**

As the overarching national standards are still in development it is not yet possible to measure change; however, there will be an opportunity to measure intention to change during the public consultation stage and as the project evolves. In early 2021, the project team will engage more widely with stakeholders in the sector through focus groups with front-line staff and children, young people and families with experience of health and social care services, as well as with advocates and other key stakeholders to inform the development of the standards. This engagement will help to raise awareness of the new standards and to build buy-in to support their implementation in practice. There has been a high level of interest and engagement to date from key stakeholders within the health and social care sector in relation to the development of the standards, signifying that endeavours to raise awareness and knowledge about the standards is being achieved. This was evidenced via the high level of interest in joining the Advisory Group and the Children's Reference Group, as well as by the high number of responses to the scoping consultation and the content of the responses, which broadly welcomed the

development of an overarching set of standards for health and social care services working with children.

Against our desired outcome of **ensuring the processes applied to the development of Standards are in line with best practice and result in translation of Standards into practice**, we have developed a prioritisation process to determine the team's work programme for the next two-to-three year period, drafted a set of principles to underpin all future national standards for health and social care services and hosted a PhD student whose research focus is on the implementation of health and social care Standards, the identification of enablers and barriers and development of support tools. The outputs from this PhD research will contribute towards developing an innovative implementation framework that can be applied by HIQA in future Standards projects and will also support the broader implementation of Standards in health and social care.

### **Outputs**

Members of the team have published a paper in the Journal of Social Care. The paper is titled *Translating national standards into practice: Supporting social care professionals*. Since publication in March 2020 the paper has been downloaded over 200 times by government departments, academic institutions and commercial entities. The paper has had international reach with readers downloading the paper in a number of European and Asian countries, as well as in the United States.

In 2020, we implemented a prioritisation process to determine the team's work programme for the next two-to-three year period. The prioritisation process assists the identification of priority areas for potential national standards and guidance that best address the health and social care needs of the Irish population and which have the greatest impact in improving the outcomes of people using health and social care services. It also ensures that requests for national standards are reviewed, assessed and progressed, in a transparent and consistent manner; the process was published on the HIQA website in October 2020.

### **Engagement**

The team developed a draft set of principles to underpin all future national standards for health and social care services. In 2020 the team completed an evidence review to inform adopting a principles-based approach and to inform the development of the principles. The evidence review will be published early in 2021. The draft principles will be tested in practice through the Draft National Standards for Children's Social Services in 2021. A public consultation will be held on these draft standards and feedback will be sought in the principles underpinning them. Following this testing of the principles and once feedback has been reviewed and incorporated as appropriate, the principles will be finalised and used for all future national standards for health and social care services.

These principles, once finalised, will be used as HIQA's standards development framework, instead of the eight-theme framework which HIQA has used to develop standards since 2012.

## Next steps

In 2021, we will continue to progress the development of National Standards for Children's Social Services and Overarching National Standards for the Care and Support of Children using Health and Social Care Services.

We will continue to support change within services by expanding our work in developing tools and supports for the implementation of national standards. We are developing four online learning modules to assist health and social care staff to implement key elements of a human rights-based approach in their work. These will be launched as a series of modules in 2021. In addition, we are developing an animated video 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.

In 2021, we will commence the development of additional support tools to further assist the implementation of the *National Standards for infection prevention and control in community services*. We will also identify the most appropriate awareness raising materials and tools to support services to implement components of existing national standards that relate to advocacy, and commence the development of these resources. These objectives will be undertaken in response to the recommendations made by the COVID-19 Nursing Homes Expert Panel.

We will evaluate change brought about by our work by continuing to monitor and embed impact-related questions in the public consultations we undertake as part of our core work and online learning modules that support the standards that we develop.

## **Standards and Guidance Development Function, 2020 Impact Summary**

Published **2** online learning modules in infection prevention and control and adult safeguarding.

Published **1** evidence review to inform the development of Draft National Standards for Children's Social Services.

Consulted and engaged with stakeholder groups from across health and social care, including patient representatives and children and families.

A wide range of international experts were engaged with to inform the development of each core project.

A prioritisation process has been developed and implemented.

A draft set of principles to underpin all future national standards for health and social care services has been developed.

**1** set of draft standards on Children's social Services developed.

Ran **4** interactive workshops.

Published **1** academic slide-deck on a rights-based approach to care and support.

**1** conference presentation to 6<sup>th</sup> SPHeRE Annual Conference.

**1** academic paper - *Translating national standards into practice: Supporting social care professionals* - published in the Journal of Social Care and downloaded 200 times.

## The National Care Experience Programme

The National Care Experience Programme was established in 2019 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. It is a partnership between HIQA, the Health Service Executive and the Department of Health.

### How we do it:

We ask people about their experiences of care in order to improve the quality of health and social care services in Ireland by conducting surveys, publishing results and supporting improvement.

The National Care Experience Programme has a suite of surveys that capture the experiences of people using our services. The NCEP has successfully implemented the National Inpatient Experience Survey for three years, the National Maternity Experience Survey in 2020, and is currently developing three further surveys covering end-of-life care, older persons' care and maternity bereavement. These surveys will be ready for implementation by the end of 2021.



## 2020 objectives

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

## Desired outcomes

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

- Use of survey findings
- Quality improvement initiatives taken in response to survey findings

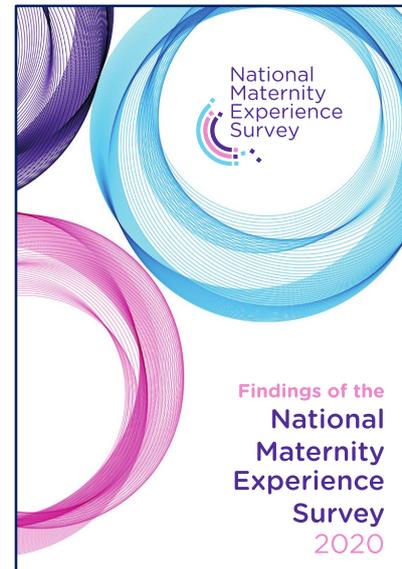
## 2020 impact

### Outputs

#### *National Maternity Experience Survey 2020*

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

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



#### *National Inpatient Experience Survey 2019*

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

- 6 hospital group reports
- 1 technical report, which provides a technical description of the model, methodology and procedures implemented during the maternity experience survey.



#### *Training and support resources*

##### *Survey Hub*

In 2020, the National Care Experience Programme developed a Survey Hub to provide expertise and skills and support greater engagement with stakeholders, both nationally and internationally. The Survey Hub offers a suite of resources for anyone aiming to capture the experiences of people who use health and social care services, and provides advice on how to develop and implement a survey, interpret the findings, and make improvements based on the results.

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

- A survey development roadmap
- Five **Survey design** e-learning modules
- One **Interactive dashboards** e-learning module
- One podcast on **Information governance**
- List of academic publications and presentations.



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

#### *Information governance audio clip*

The National Care Experience Programme produced an audio clip on information governance, which describes the importance of Data Protection Impact Assessments (DPIAs) for surveys, as well as the steps involved in their development.



*Image. Survey Hub audio clip: Donnacha O' Ceallaigh discusses information governance*

## Reach

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

- 3,204 participants in the National Maternity Experience Survey 2020
- 1 webinar to launch the results of the National Maternity Experience Survey, with 269 attendees
- 20 Zoom townhall sessions to discuss the local results of the National Maternity Experience Survey, with 250 attendees across the sessions
- 5 conferences<sup>2</sup> attended by members of the team
- 2 information stands hosted by the programme at national conferences
- 1 poster and 1 oral presentation accepted at conferences in Ireland
- 20 hospital (and home birth service) infographics designed
- Numerous promotional videos
- 1 video animation.

The results of the National Maternity Experience Survey 2020 were launched on 1 October 2020.

The survey results were quoted in a number of articles and media outlets:

- 16 national print articles
- 20 online media articles
- 35 broadcast pieces
- 3 promotional campaigns with online parenting websites.

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

In 2020, there were:

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

---

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

- 8,128 views of the interactive results across all surveys.

## Engagement

### *Hospital and community visits*

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

In order to promote the National Maternity Experience Survey, in 2020 the team undertook<sup>3</sup>:

- 19 maternity hospital and unit visits to promote the National Maternity Experience Survey, which included visits to various community-based healthcare professionals
- 16 public health nursing forums, which reached 200 public health nurses
- 1 General Practitioner (GP) Study Day, which reached 20 GPs.

### *Virtual hospital and local community townhall sessions*

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

### *National Maternity Bereavement Experience Survey*

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

A project lead was appointed in July 2020 for an 18 month period, and is currently developing the model and methodology to implement the National Maternity Bereavement Experience Survey. As part of the development of the survey, engagement with international counterparts who have conducted similar work in this

---

<sup>3</sup> Due to the COVID-19 pandemic, hospital and community visits ceased in March 2020.

area was undertaken to learn from their experiences and to inform the development of a suitable approach for the Irish context. This included five video conference calls and 52 email correspondences with nine international counterparts from six countries recognised for their work in highlighting and supporting perinatal bereavement, including Australia, England, the US, Canada, Italy and Spain. Extensive engagement with national stakeholders also took place. A communications and stakeholder engagement plan is in development to support the delivery of the survey, ensuring that the views of all relevant stakeholders are represented throughout the survey development process.

#### *National Older Persons Experience Survey*

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

As part of the development of the National Older Persons Experience Survey, engagement with international counterparts who have conducted similar work in this area has taken place to learn from their experiences and to inform the development of a suitable approach for the Irish context. In 2020, four international calls were held with eight representatives from Australia, the Netherlands, the US and Canada. An extensive communications and stakeholder engagement plan is also in development to support the delivery of the survey, ensuring that the views of all relevant stakeholders are represented throughout the survey development process.

#### *National End of Life Survey*

In response to the COVID-19 Expert Panel Final Report, the National Care Experience Programme is also progressing work on the development of the National End of Life Survey, to include people who were cared for and died in nursing homes. The National End of Life Survey aims to capture the experience of care of adults who are at end of life from the perspective of bereaved relatives, to establish the quality of healthcare delivered by health and social care services. The findings will build on existing good practice and inform quality improvements within services, national standards and monitoring programmes within HIQA, and national policy and legislation in the Department of Health.

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

### *Collaboration*

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

Over 40,000 qualitative comments were received in response to the 2017 and 2018 National Inpatient Experience Surveys. These comments contained rich information on how patients perceived the care they received in hospital and where they felt it could be improved. In order to get a deeper understanding of these comments and how they could be used to improve care, the National Care Experience Programme worked with a team based in the Insight Centre for Data Analytics, Data Science Institute, NUI Galway, led by Dr Adegboyega Ojo. The NUIG Team used a combination of traditional qualitative analysis methods, as well as data mining and machine learning techniques to identify the key activities, resources, contexts within the comments. They then used complex statistical models to quantify how each of these factors were associated with positive and negative patient experiences. The findings of the NUIG analysis will be published in early 2021.

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

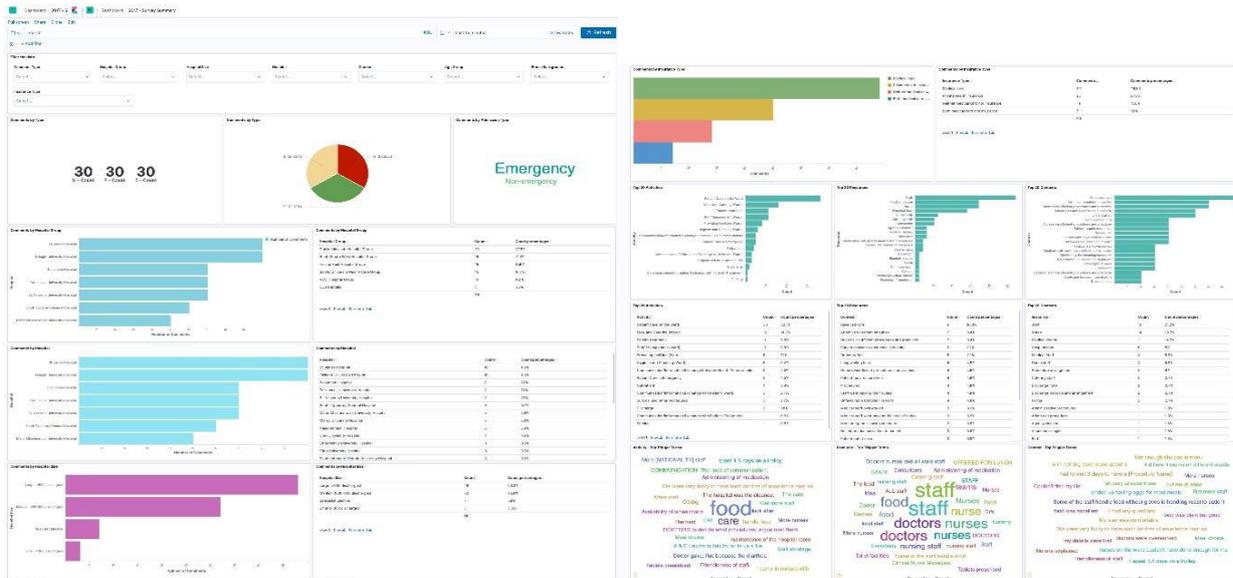


Figure. NUIG interactive dashboard

### Student work placements

In 2020, the programme supported an eight-week work placement for a student of the Masters in Applied Social Research in Trinity College Dublin. The work placement resulted in a literature review coding of qualitative data from the National Inpatient Experience Survey and an MSc dissertation based on secondary analysis of data from the National Inpatient Experience Survey 2019.

### Data access requests

The National Care Experience Programme promotes a culture of making data available, with reports and interactive online reporting platforms available on [www.yourexperience.ie](http://www.yourexperience.ie). Data can also be requested by individuals working in academic or healthcare settings, for research or quality improvement purposes. Data access requests are reviewed by the NCEP Team and or the relevant programme board, depending on the nature and purpose of the request. In 2020, the programme received and granted eight data access requests, compared with five requests per year in 2018 and 2019. The majority of requests received in 2020 were from students or staff in academic institutions, including Trinity College Dublin, University College Cork, University College Dublin, University of Limerick, NUI Galway and Dublin Business School.

### *International networks*

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

- COVID-19-specific surveys and questions
- Analysis of qualitative survey data
- The Survey Hub.



**14 calls**



**32 international counterparts**



**10 countries**

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

In total, the NCEP Team organised 14 calls and engaged with 32 international counterparts from 10 countries in 2020.

## Change

### *Use of survey findings and quality improvement initiatives*

In light of the COVID-19 pandemic, the National Inpatient Experience Survey did not go ahead in 2020. Calls with the six hospital groups, however, highlighted the ongoing quality improvement initiatives being undertaken by the hospitals.

#### Examples of quality improvement initiatives



##### Medication safety

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

##### Emergency department volunteers

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

##### Emergency department waiting times

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

### *Regulation*

Findings from the National Inpatient Experience Survey inform the healthcare regulation and monitoring programme within HIQA. Analysis is underway to align survey questions with standards, which will aid the regulation and monitoring teams to monitor against healthcare standards.

### *Policy and practice*

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

#### **Examples of quality improvement initiatives**



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

Whilst many hospital and community maternity service providers already work in tandem to provide continuity of care to new mothers, the extent of communication and liaison between both is not consistent across the country. The NMES individual hospital Zoom sessions, in which the affiliated public health nursing services were in attendance, highlighted the potential for synergy in the provision of postnatal care. This was particularly evident in the context of breastfeeding support, following breastfeeding initiation in hospitals and subsequent continuation of support at home. Similarly, the introduction of the Perinatal Mental Health Model of Care has led to an increase in diagnoses and heightened vigilance for mental health issues throughout the pregnancy, birth and postnatal periods. Communication between health care providers throughout the maternity journey is required to ensure continuity and consistency of care for women's perinatal mental health. Our Lady of Lourdes Hospital and Community Healthcare Organisation (CHO) 8 have endeavored to strengthen their interactions in order to facilitate continuity of care for women.

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

The National Maternity Experience Survey highlighted perinatal mental health as a key area for improvement. These findings have served to reinforce the importance of the implementation of the perinatal mental health model of care. Questions relating to mental health were some of the lowest-scoring questions across the survey. The requirement for improvement in the care of women's mental health during pregnancy, birth and the postnatal periods was thus underscored and so too, the requirement for the implementation of the Specialist Perinatal Mental Health Services Model of Care. The Rotunda Hospital has expanded its mental health team on foot of the survey. It now has a staff of 11 perinatal mental health professionals in place, including some in postnatal community outreach posts. Additionally, it has recruited a Birth Reflections Midwife who acts a link person between women and mental health services. Based on the results of the survey, Cork University Maternity Hospital is offering debriefing and mental health support to women who have experienced any type of birth trauma. This includes those who have had a 'normal' birth, as well as those who have poor outcomes or morbidities.

### *Communication and shared learning*

To facilitate shared learning on the evidence of best practice and to inform future quality improvement initiatives for maternity services, the HSE response to the National Maternity Experience Survey highlighted areas of existing best practice across Ireland's hospital and community maternity services, with a focus on areas identified as requiring improvement nationally. Examples include the birth reflections service in the Coombe Women & Infants University Hospital, which 'aims to give women a chance to explore their birth experience and ask questions that they may not have previously asked',<sup>4</sup> and local support and breastfeeding groups run by public health nurses in Dublin and Kerry.

### *Highlighting areas requiring improvement*

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

---

<sup>4</sup> Listening, Responding and Improving: The HSE response to the findings of the National Maternity Experience Survey. Available from: <https://yourexperience.ie/wp-content/uploads/2020/10/HSE-RESPONSE-TO-NMES-2020.pdf>

## **Next steps**

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

In 2021, the programme will:

- Implement and report on the National Inpatient Experience Survey.
- Implement the National Maternity Bereavement Experience Survey
- Continue the development of the model and methodology of two new surveys:
  - National End of Life Survey
  - National Older Persons Experience Survey
- Continue to develop resources for the Survey Hub.

## Conclusion and next steps

The impact of the work that HIQA's Health Information and Standards (HIS) Directorate undertakes is difficult to measure as our work can have indirect effects, take time (sometimes years) to have its desired effect and is intertwined with the work of other organisations. As most of our work applies nationally, there are no comparative services where we do not work, with which to compare and isolate the impact that our work has.

We are proactively taking steps to evaluate our impact in a systematic and robust manner, in order to:

- demonstrate our impact in delivering against our remit,
- identify areas where we can be more effective and inform where we should target resources and,
- support transparent decision-making.

Learning from 2020, we will continue to use virtual meeting platforms to engage with stakeholders to complement our traditional face-to-face interactions, as this extends our reach and engagement.

We will continue to embed methods to evaluate impact into our programmes of work. In order to evaluate change, we must monitor the impact of our work over time. We will do this by actively following our projects and capturing metrics and examples of change relating to our work as they arise. Given our integration within the health and social care system in Ireland, we are well positioned to identify impact in this manner. To complement this approach, we will also continue to embed impact-related questions in consultations undertaken, in digital learning modules developed and at other select opportunities that form part of our ongoing work.

The herein report is the second report from the HIS Directorate under the *Knowledge Sharing and Impact Strategic Framework*. The findings have already informed on which activities are having most impact, allowed us evaluate our reach to stakeholders and prompted extra efforts to reaching under-represented groups. They have also helped us better understand learning and implementation barriers of our target audiences for our standards and recommendations.

The findings of this report and future work undertaken to evaluate impact, will help drive improved knowledge sharing and impact and inform the strategic direction of our work against our primary aim of improving health and social care services in Ireland.



**Published by the Health Information and Quality Authority (HIQA).**

**For further information please contact:**

**Health Information and Quality Authority**

**George's Court**

**George's Lane**

**Smithfield**

**Dublin 7**

**D07 E98Y**

**+353 (0)1 8147400**

**info@hiqa.ie**

**www.hiqa.ie**

**© Health Information and Quality Authority 2021**