Knowledge Sharing and Impact Assessment Framework

Health Information and Standards Directorate Report, 2019

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

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 throughout the lifecycle of the project 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 Standards Directorate, we are 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*). The framework supports measuring impact through a combination of measures including outputs generated, reach and engagement activities with stakeholders, and observable changes.

Outputs

- Tangible entities produced from projects – standards, guidance, recommendations, reports, digital learning courses, leaflets and web content.

Reach

- One-way communications, distribution of information.

Engagement

- Interactions with people and organisations. Two-way dialogues, capturing information

Change

- Difference in desired outcomes of a project. Key metrics - awareness, knowledge and use of information, changes to practice and population health and well-being.

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 the Regulation Directorate within HIQA and with other organisations such as the Department of Health (DoH), the Department of Children and Youth Affairs (DCYA), 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.

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 the Health Information and Standards Directorate. The purpose of the report is to demonstrate the effectiveness of our work, promote transparency and highlight our successes.

This report documents the impact of select objectives that were undertaken in 2019. These objectives are as outlined in the HIQA Business Plan (2019) along with outputs, reach, engagement, and change metrics, observed during 2019. Engagement is an ongoing effort and change requires observation over a long period of time. As this is the first report and based on observation over one year only, it is limited in what can be reported on in terms of engagement and change. As such, the impact relating to the projects outlined in this report will be reported on again in later years with 2019 acting as a 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 evaluation 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 the 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.

Health Information Quality

2019 Objectives

- Continue a review programme to assess compliance with information management standards of two national health and social care data collections, publishing two reports by September 2019.
- Commence the preparation of recommendations on a consent model for the collection, use and sharing of health information in Ireland.
- Promote and support the implementation of the Guidance on a Data Quality Framework published in 2018.

Desired outcomes

- improve the quality of health information in national data collections in Ireland
- provide leadership in defining the health information landscape
- 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.

2019 Impact

Against our desired outcome of **improving the quality of health information in national data collections in Ireland** and as part of the ongoing review programme that assess compliance with the Information management standards for national health and social care data collections, we undertook two reviews; Computerised Infectious Disease Reporting (CIDR) and Primary Care Reimbursement Service (PCRS). We also began work on a review of National Incident Management

System (NIMS), which will be completed in 2020. In 2018, we reviewed the Hospital Inpatient Enquiry (HIPE) scheme. Impact of the HIPE review was observed in 2019.

Outputs

- Review of information management practices in HSE PCRS.
- Review of information management practices in the HSE CIDR system.

Reach

- The webpage for the Information Management Standards for National Data Collections (2017) against which the review programme assess compliance, had 603 unique page views in 2019.
- The Irish Medical Times published an article on the CIDR review, reaching a wide audience of medical professionals.

Engagement

- We engaged directly with people at all levels within PCRS itself and also with pharmacists and GPs in relation to the PCRS review and the Health Protection Surveillance Centre (HPSC), public health departments, and clinical laboratories in relation to the CIDR review.
- We visited Cork University Hospital, Cork University Maternity Hospital and University Hospital Kerry in order to learn more about the NIMS system at a local level. We also had two meetings with senior officials in the HSE to inform the NIMS review.
- The review programme was presented internationally at the International Society for Quality in Healthcare conference in Cape Town.
- Three presentations were given at the national Health Informatics Society of Ireland (HISI), National Patient Safety Office (NPSO) and Structured Population and Health Services Research (SPHeRE) conferences.
- We gave two academic lectures in relation to the review programme.

Change

Awareness

In November 2019, we carried out a survey of the health information community to evaluate the Information Management Standards and the Review Programme. Most respondents (95% of 18 responses) said they were familiar with the standards and saw the value of them for their national data collection.

In March 2019, the World Health Organization (WHO) carried out a Health information system and eHealth strengthening assessment in relation to Ireland. As part of this assessment, WHO representatives interviewed staff from the HIS Directorate in relation to our health information function. In their interim final report, they noted the importance of the review programme and commended the work that has been carried out as part of this programme of work in Ireland.

Improvement in information management practices

While a formal evaluation has not been undertaken, changes to practice have been seen since the reviews were completed and the recommendations published in the review programme reports. Specific changes that reflect the recommendations made include:

- HIPE have set up a governance group for their data
- PCRS have set up a governance group to oversee access to data for research
- PCRS have developed a strategy document 2019-2021, this includes many of the recommendations from our review. These recommendations are reflected in one of its overall strategic goals to implement a robust data/information governance framework. They are also reflected in the strategic actions listed in the document including: developing and publishing a data/information management strategy; and continuously reviewing and expanding the range of performance metrics (KPIs), focused on service outcomes for customers and stakeholders.

- Our review highlighted that there was no senior manager dedicated to providing governance, leadership and accountability for HPSC and CIDR. The HSE also identified this as a risk. In response to the identified risk and our recommendations:
    - The HPSC have advertised to appoint a clinical director for Health Protection for the HSE.
    - An interim Director was appointed during the course of the CIDR review.

Over 72% of the 18 organisations surveyed in November 2019 stated that the standards led to changes to information management within their national data collections. 50% of the organisations thought that the publications of the reports from the review programme helped them identify areas where change was necessary to improve information practices in their own national data collections.

In 2019 we began the process of developing recommendations on a model for the collection, use and sharing of health information in Ireland against our desired outcome of **providing leadership in defining the health information landscape**. This work is in its infancy, our impact thus far has been related to engagement and raising awareness.

Engagement

- We hosted a meeting with the Chief Privacy Officer from Canadian Institute of Health Information (CIHI), which the Department of Health and the HRB also attended.
- We carried out a scoping exercise to define the scope of this project, this included calls with the HSE and the Department of Health.
- We engaged internationally by holding interviews with experts in 7 countries.
- The findings of the international review were presented at the HISI conference.
- We convened an advisory group that included 23 members from across health and social care in Ireland, including patients. The organisations included were:

  - 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
  - Child and Family Agency (Tusla)
  - Irish Pharmacy Union
  - IPPOSI
  - National Patient Forum
  - Central Statistics Office
  - HSE
  - Department of Health
  - Health Research Board
  - HI Systems Research Centre UCC

To **support those working in health and social care to improve data quality to underpin the delivery of safe care and informed decision-making,** we promoted the Guidance on a Data Quality Framework (2018) and developed two digital learning modules. These were aimed at translating and supporting implementation of the guidance.

Outputs

- Introduction to data quality a digital learning module
- Developing a data quality framework a digital learning module

Reach

- The digital learning modules were published on the 17 October 2019 and were reported on in 11 targeted and relevant media publications.
- Guidance documents were distributed at 5 conferences – NPSO, National Immunisation Office (NIO), National Perinatal Epidemiology Centre (NPEC), SPHeRE and NOCA reaching a wide and varied audience.

Engagement

- We co-developed the digital learning modules with two national data collections (HIPE and NOCA), a patient (MS Ireland) and a clinician (Temple St).
- We engaged with ICGP, GPs from the SPHeRE programme and specific GP practices in relation to holding a webinar on data quality for GPs in 2020.
- We engaged with National Care Experience Programme (NCEP) to support them in developing a Data Quality Strategy.

Change

Awareness

The number of unique page views rose from 294 to 843 when the digital learning modules were launched. There were 93 completions of our two digital learning modules in less than two months. This included people from Ireland, the United Kingdom, the United Arab Emirates and the United States. 43% of completers of the courses were developing a data quality framework for their organisation or were working within a health and social care setting, the remainder was largely teachers, trainers and students.

The following organisations and national data collections are applying the data quality framework:

- NOCA major trauma audit and hip fracture database.
- HIPE
- CIDR
- NPEC
- National Immunisation Office (NIO)

This equates to 4% of the national data collections in Ireland, however, these few are the bigger collections and represent a large percentage of the data in Ireland.

Improvements in data quality practices

77% of the 18 organisations surveyed in November 2019 thought the Guidance on a Data Quality Framework was useful. 93% of people who completed the Introduction to Data Quality module said they planned to make changes to their practice having completed the course.

NOCA is applying the data quality framework to two of their national data collections, the major trauma audit and the national hip fracture database. In 2019, NOCA published the Major Trauma Audit Annual report, citing the data quality framework.

A new project within HIQA, to create an open access dataset of the statutory notifications received by the Chief Inspector has applied the data quality framework in the planning. The project team are working with the health information quality team to ensure the data quality practices applied to this new national data collection are of the highest quality.

Next steps

In 2020, we will continue to progress the review programme of national data collections. We will use the results from the evaluation of the standards and the review programme survey to make improvements and ensure that this programme of work has the maximum impact. Going forward, we will 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.

Due to the positive response, we will continue to develop digital learning tools in order to support national data collections and improve the quality of health data in Ireland. We will also continue to work with specific groups of healthcare professionals, in order to make the data quality guidance more accessible to them. In particular, we will host a webinar aimed at and developed with general practioners (GPs).

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 develop a methodology for an extensive public consultation on this topic that will inform the development of the recommendations and ensure the project has a meaningful impact.

Supporting information

In order to produce this impact report, a database of impact metrics was developed and updated throughout the year. Quarterly impact meetings were held to ensure that all data were correct and up to date. Case studies were recorded as evidence of impact throughout the year. As part of the evaluation of the information management standards and the review programme, in November 2019, an online survey was sent out to 32 managing organisations in relation to health information in Ireland. 18 responses were received. Impact questions were embedded within the digital learning modules. These captured the types and amount of people who completed the course, asked about intention to change practice and included course evaluation questions to allow us tailor the course with further updates to ensure the needs of our audience are met.

Health Information Quality, 2019 Impact Summary

There were **4406** unique page visits to our Health Information Quality content.

100% of people who completed the Introduction to Data Quality digital learning course said it was useful.

94% of people surveyed saw the value in the Information Management Standards for their National Data Collection.

93% of people who completed the Introduction to data quality digital learning course said they plan to change their practice relating to data quality having completed the course.

There were **93** completions of our **2** digital learning modules on data quality in less than **2** months.

16 recommendations aimed at improving the governance and management of information within CIDR and PCRS were published

8 international countries and **23** people from across health and social care services, were engaged with for the development of recommendations on collection, use and sharing of health information.

6 focus groups were undertaken as part of the review programme and the development of recommendations.

5 organisations have implemented the data quality framework within their national data collection.

2 reviews of information management practices completed and reports published.

2 digital learning modules published.

3 national conference presentations.

3 student placements hosted from UCD and UCC.

1 international conference presentation.

Technical Standards

2019 Objectives

- Develop a methodology for assessing compliance of eHealth services within the HSE to underpin the introduction of a review programme.
- Develop Recommendations related to the development and implementation of National electronic Patient Summaries.

Desired Outcomes

- promote compliance of eHealth services with National Standards
- support the sharing of patient information in the health and social care sector
- progressing the implementation of national priorities within the eHealth landscape.

We selected one key outcome in order to measure the change relating to our work:

- Adoption of Recommendations and National Standards.

2019 Impact

To **promote compliance of eHealth services within the HSE against supporting National Standards,** we developed 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, 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

- Guidance on eHealth Review Programme
- A Prioritisation, Assessment and Judgement Framework for eHealth services.

Reach

- The guide to the Review Programme was viewed 274 separate times and downloaded on 159 occasions.

Engagement

- We engaged with the following organisations in developing the methodology for the Review Programme:
  - **MedCom** in Denmark, who are providing an subject matter expert to lend expertise and for site visits
  - The **Norwegian Directorate of eHealth**.
  - The **Office of the Chief Information Officer.** The National Electronic Referrals Service is the first eHealth service to be reviewed. They have returned a self-assessment and provided extensive documentation.
- We presented on the review programme at the 2019 Health Informatics Society of Ireland (HISI) Conference, reaching a targeted audience of key stakeholders.

An 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. In our aim of **supporting the sharing of patient information in the health and social care sector** in Ireland we developed National Standards on Information Requirements for a National Electronic Patient Summary and an information leaflet that explains what patient summaries are. The target audience are individuals who can adopt the Standard and use it in the development of electronic patient summaries. In line with HIQA's public service remit, we developed a short animation and a brochure, to promote understanding of patient summaries and of this work among a wider audience. We also undertook preliminary work on the development of Recommendations on the implementation of a national patient summary in Ireland.

Outputs

- National Standard: The *National Standard on Information Requirements for a National, Electronic Patient Summary in Ireland* (2019).
- A5 brochure: titled *What is a national, electronic patient summary?*
- Short animation: explaining what an electronic patient summary is, disseminated on Twitter and through the HIQA website.

Reach

- The HIQA Communications Department launched the Standard by
  - sending a press release to tech, medical and national press
  - posting updates on Twitter and LinkedIn
  - posting the animation, A5 brochure, and National Standard on the website.
  - printing 500 copies of the A5 brochure.
- The following reach was recorded, though full statistics for Twitter and LinkedIn were not available.
  - national Standard was viewed 407 times on the Website
  - A5 brochure was viewed 136 times on the Website

  - estimate 250 of 500 printed A5 brochure were distributed to visitors to the HIQA office and at health and social care conferences
  - the animation was viewed as follows:
    - Website: 377 times
    - YouTube: 385
    - Facebook: 934.
- In April 2019, the Minister for Health approved the *National Standard on Information Requirements for a National, Electronic Patient Summary.*

Engagement

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

- Department of Health – eHealth and Information Policy
- Enterprise Ireland
- General Practice Information Technology Group
- Health Service Executive
- Irish Association of Directors of Nursing and Midwifery
- Irish Pharmaceutical Union
- National Standards Authority of Ireland
- Patient Representative
- Royal College of Physicians of Ireland
- Royal College of Surgeons in Ireland
- Irish College of General Practitioners
- Irish Medical Organisation.

We engaged International experts from the following countries to develop a Best Practice Review of Summary Care Records (Patient Summaries):

- Andalucía, Spain – Servicio Andaluz de Salud (Andalucian Health Service), Andalucian Regional Government
- Austria – ELGA GMBH (Austrian Electronic Health Record)
- Denmark – Medcom

- England – NHS Digital
- Estonia – former CEO, Estonian eHealth Foundation
- Finland – National institute of Health and Welfare
- New Zealand – Data and Digital Directorate, Ministry for Health
- Northern Ireland – Health and Social Care Northern Ireland
- Norway – eHealth Directorate
- Scotland – NHS National Services Scotland.

We presented on early findings from the Best Practice Review of Summary Care Records, to the annual *Health Informatics Society of Ireland Conference 2019*. The Conference is the largest health informatics conference in the country by far, with over 600 attendees, 14 conference tracks, 120 speakers and 25 exhibitors.

A new collaboration has been established with the Irish Platform for Patient Organisations, Science and Industry, to define several key terms used in the *Recommendations on the Implementation of a National, Electronic Patient Summary* project.

Change

Adoption of Recommendations and National Standards

- The information requirements for a national electronic patient summary as outlined in the National Standards were included in the new Terms of Agreement between the DoH, the HSE and the Irish Medical Organisation (IMO) regarding GP contractual reform and service development.

Against our desired outcome of **progressing the implementation of national priorities within the eHealth landscape** we continue to promote Standards and Recommendations relating to eHealth and engage with key stakeholders after the publication of these documents. The General Practice Message Standard was first published in 2010. We are currently on version 4. Healthlink, the national message broker, informed HIQA that it had adopted the General Practice Message Standard as its standard, laying the foundations for interoperability. As this is now a well-established project in 2019, we evaluate the use of the General Practice Message Standard to assess the long term impact of our work.

Engagement

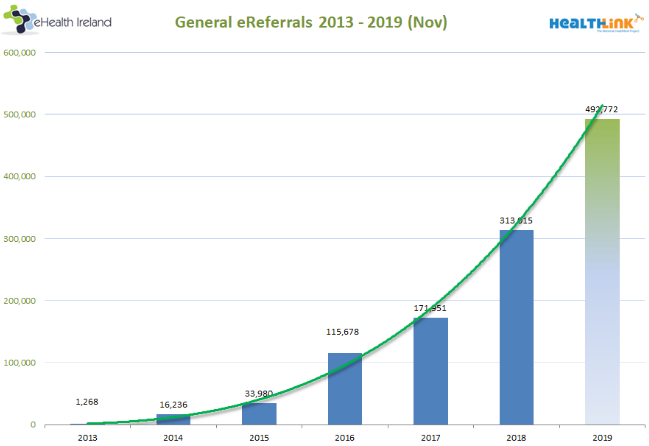
- Healthlink proactively communicated requirements to the Technical Standards team over the life course of this project and three subsequent versions of the General Practice Message Standard were published in response to their needs.

Change

Adoption of Recommendations, Standards

- In 2019, 19,707,626 electronic referral messages were sent through Healthlink, including all types of senders. By November 2019, 90% of Irish GPs had used the electronic referral service.
- Healthlink statistics show that, by November 2019, the following referrals were exchanged electronically:
  - 35% referrals to hospitals
  - 2% discharge summaries.

There has been substantial growth in the number of hospital eReferrals from general practice made since the inception of the service, as highlighted in the following graph:



Next steps

As soon possible, given the restrictions in place to limit the spread of COVID-19, we will undertake our first review of an eHealth service, namely 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 continue to engage with key stakeholders to support the introduction of electronic patient summaries. We will further support this programme in 2020 by undertaking:

- A Best Practice Review of Summary Care Records
- As Is Review of the Irish eHealth landscape.

and developing:

- Recommendations on the Implementation of a National, Electronic Patient Summary
- Commence the development of recommendations on a National Patient Portal for Ireland
- Educational materials for key terms relating to the standards and recommendations.

We will continue to work with the Sláintecare Programme Office on the roll out of an ePrescribing Programme in Ireland, as required.

Technical Standards, 2019 Impact Summary

19,707,626 electronic referral messages sent through Healthlink, which has adopted the General Practice Messaging Standard.

90% of Irish GPs had used the electronic referral service.

35% of referrals to hospital and **2%** of discharge summaries were sent using the electronic referrals service and Healthlink.

51 stakeholder groups from across health and social care in Ireland, including patient representatives, along with 10 international experts were engaged with as part of our work.

2 clinical leads for the ePrescribing Programme are being recruited, in response to the Recommendations on ePrescribing.

2 new academic collaborations were set up.

2 international student interns were hosted.

1 new PhD student commenced with the Technical Standards team, in collaboration with Trinity College Dublin.

2 new Standard was approved by the Minister for Health.

1 new set of Recommendations on implementation of an electronic patient summary in Ireland was commenced.

1 new Review Programme was launched.

Standards and Guidance Setting Function

What we do

The Standards team sets national standards for health and social care services to:

- provide a common language to describe what high quality, safe, person-centred care looks like
- create a basis for services to improve the quality and safety of the care they deliver by identifying strengths and highlighting areas for improvement
- assist people using services to understand what they should expect from a service
- promote practice that is up to date, effective and consistent.

When we finalise national standards, we also publish additional implementation support tools such as guidance or leaflets 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.

2019 Objectives

- Develop National Standards for Adult Safeguarding and a toolkit of resources to assist services to implement the Standards in their setting.
- Develop guidance, awareness and training materials for service providers and staff to support a rights-based approach to care in health and social care services.

Desired Outcomes

- Support the development of a culture in health and social care services where safeguarding is embedded into practice.
- Assist health and social care staff to apply a human rights-based approach in their work.

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

- increased awareness
- cultural change.

2019 Impact

Under our desired outcome of **supporting the development of a culture in health and social care services where safeguarding is embedded into practice**, we developed National Standards for Adult Safeguarding and a suite of resources to support people in understanding safeguarding and implementing the standards. An evidence review to inform the development of the Standards was published in 2018. The Standards were published in December 2019, as such we do not expect there to have been a change before the end of 2019. Therefore, here, we focus on the outputs, reach and engagement we have had so far.

Outputs

- National Standards for Adult Safeguarding, Dec 2019.
- Statement of Outcomes report outlining the feedback that was received during focus group discussions with people using health and social care services, people supporting and caring for them, as well advocates, and through the public consultation and how this feedback informed the development of the National Standards for Adult Safeguarding, Sept 2019.
- A set of FAQs on the National Standards for Adult Safeguarding.
- 1 page summary of the National Standards for Adult Safeguarding.
- Leaflet for people using services: Your guide to the National Standards for Adult Safeguarding.
- Video animation on the National Standards for Adult Safeguarding

Reach

- The Minister for Health launched the National Standards for Adult Safeguarding Standards on 4th December 2019.
- Over 550 stakeholders were notified when the National Standards for Adult Safeguarding were launched.
- There were 560 unique views of the HIQA webpage on adult safeguarding.
- Over 2000 copies of the National Standards for Adult Safeguarding disseminated to health and social care services.
- In excess of 2000 people watched our video animation on Adult Safeguarding which was circulated on Twitter and through the HIQA website.

Engagement

The National Standards for Adult Safeguarding were jointly developed with the Mental Health Commission (MHC). An advisory group was convened to develop the Standards comprising of interested and informed parties, including representatives from the following organisations:

- Mental Health Commission

- Third Age Ireland
- Irish Association of Social Workers
- The Office of the Ombudsman
- Family Carers Ireland
- Social Care Ireland
- HIQA
- Health Service Executive
- Department of Health
- Private Hospitals Association
- IHREC
- An Garda Síochána
- The Law Society
- Department of Social Protection
- Sage
- National Disability Authority
- Inclusion Ireland
- Nursing Homes Ireland.

A public consultation was undertaken which had 79 detailed submissions. Of these 79 responses, 31 people (41%) responded in a personal capacity, with 44 people (59%) responding on behalf of an organisation. The submissions represented a variety of advocacy organisations, nursing homes, hospitals, professional bodies, disability organisations, support services, and mental health organisations,

During the development of these standards, 17 focus groups and two one-to-one interviews were conducted with a total of 147 participants.

A wide range of health, mental health and social care services contacted the Standards team directly to provide their organisations with printed material to support staff to implement the standards, including organisations working with people with physical, sensory and intellectual disabilities, organisations working with older people, adult safeguarding services and healthcare providers

Members of the Standards Team gave a number of presentations at conferences on how HIQA used research, evidence and stakeholder engagement to inform the development of National standards for Adult Safeguarding. This included presentations at the SPHeRE Network 6th annual conference, 25 February 2019, the Social Care Ireland Conference, 27 and 28 March 2019 and at the European Social Network Co-Production Forum, 14 and 15 November 2019.

As part of the public consultation on the draft standards, we asked respondents what impact the standards will have on adult safeguarding in health and social care services. 71% provided feedback on this question and generally agreed that standards will have a positive impact when implemented in services.

In 2019 we aimed to **assist health and social care staff to uphold human rights in their work**. Against this desired outcome, we developed Guidance on a Human Rights-based Approach in Health and Social Care Services, an evidence base to support the guidance and a range of printed or downloadable tools to support staff and ensure that the human rights of people using health and social care services are protected, promoted and supported in practice, and embedded in the culture of a service.

Outputs

In 2019, we published the following documents and printable or downloadable tools on a human rights-based approach in health and social care services:

- Guidance on a Human Rights-based Approach in Health and Social Care Services, Nov 2019.
- Background document of the supporting evidence, June 2019.
- Statement of Outcomes report on public engagement on draft Guidance on a Human Rights-based Approach in Health and Social Care Services, Nov 2019.
- An FAQ about the Guidance and how it can help staff in their work.
- Legal framework document which outlines the key national and international legislation underpinning a human rights-based approach to care and support in Ireland.
- Decision-making flow chart that uses a human rights-based approach to care and support. This is a helpful tool for staff when making decisions in relation to a person's care.
- The FAIR approach to decision-making, which is a resource that was developed by the Scottish Human Rights Commission. It has been designed to help staff consider their actions when faced with a decision that may restrict the rights of a person using a service.

Reach

- Awarded grants from the Irish Human Rights and Equality Commission for:

  - Developing and applying an evidence base for a rights based approach to service provision.
  - Development of awareness and training materials for providers of services (Public, Private and Voluntary) that promote the principles and practices of rights based care provision.
- The Guidance was launched in November 2019 at the National Patient Safety Office (NPSO) Conference, which was attended by over 200 representatives from community healthcare organisations, acute hospitals, academics and key professional bodies who represent those operating in the health and social care sector in Ireland.
- Every registered centre for older persons and people with disabilities in Ireland, community healthcare organisations, acute hospitals, academic schools and departments, and health and social care professional bodies received notice of the launch and publication of the Guidance.
- 22 tweets were posted on the HIQA account highlighting the Guidance on a Human Rights-based Approach in Health and Social Care Services to 12.7K followers.
- 400 copies of the Guidance were circulated at the National Patient Safety Office Conference and the Nursing Homes Ireland Conference, to organisations and individuals working in health and social care services.
- There were 3831 unique visits to the Guidance on a Human Rights-based Approach in Health and Social Care Services page on the HIQA website.

Engagement

The guidance was developed in conjunction with Safeguarding Ireland, and part-funded by the Irish Human Rights and Equality Commission under the Human Rights and Equality Grant Scheme 2017, key stakeholders with the capacity to promote and use this work.

An advisory group was convened to develop the Guidance and included the following organisations:

- Decision Support Service

- The Office of the Ombudsman
- Third Age
- Irish Association of Social Workers
- UCD School of Medicine
- Family Carers Ireland
- Social Care Ireland
- HIQA
- Health Service Executive
- Department of Justice and Equality
- Department of Health
- Private Hospitals Association
- IHREC
- Irish Council for Civil Liberties
- The Law Society
- Inclusion Ireland
- Department of Social Protection
- Sage
- Mental Health Commission
- National Disability Authority
- Nursing Homes Ireland.

Scoping focus groups were held with six groups comprising 39 participants in total to inform the development of the guidance. The participants represented a variety of service users and service providers, for example disability, mental health, advocacy, older persons, physiotherapy, primary care, rehab care and speech and language.

A scoping consultation was undertaken at the outset of the guidance development process which had 51 submissions. Of the 51 responses, 22 people (43%) responded in a personal capacity and 29 people (57%) responded on behalf of an organisation. The submissions represented a variety of organisations, including advocacy organisations, nursing homes, hospitals, support services for people with intellectual disabilities, disability organisations, support services for older people, mental health organisations, addiction services, rehabilitation services, a professional body and a university.

A public consultation was undertaken on the draft guidance which had 75 detailed submissions from 51 organisations and 23 individuals. The submissions represented a variety of organisations, including advocacy organisations, nursing homes, hospitals, NGOs, support services for people with intellectual disabilities, professional bodies, disability organisations, educational centres, support services for older people, mental health organisations, a research institute, domestic abuse and homelessness support services, an end of life charity and government bodies. Three review focus groups were also undertaken during the public consultation with a total of 20 participants to seek feedback on the draft guidance. Participants were invited from those who attended the scoping focus groups.

We collaborated with international experts from Healthcare Improvement Scotland, Scottish Human Rights Commission, Care Quality Commission, The British Institute of Human Rights, Mersey Care NHS Foundation Trust, Icelandic Human Rights Centre, Directorate of Health Iceland, Johannes Wier Stichting and the Netherland's Institute for Human Rights.

We presented on the Guidance to more than 1000 providers of older persons and disability centres in Ireland at ten separate events across Ireland.

We promoted the Guidance at four National Conferences – Nursing Homes Ireland Annual Conference, Conference on the Assisted Decision-Making (Capacity) Act 2015, Disability Special Interest Group Annual Conference, and the Irish Association of Social Workers National Conference.

We gave conference and poster presentations at two National Conferences - 2019 State Claims Agency Quality, Clinical Risk & Patient Safety Conference and 2019 National Patient Safety Office Conference, Dublin – and a workshop at the 2019 Irish Street Medicine Symposium, Cork.

3,700 copies of the Guidance were disseminated to health and social care services, academic schools and departments and health and social care professional bodies.

Change

Increased awareness

As part of our public consultation on the draft Guidance we asked respondents if they had a better understanding of human rights and how they apply to their work. 91% (of the 75 respondents) stated that they had a better understanding and 96% stated that the guidance will be a useful resource for those working in health and social care services.

Cultural change

76% of the 75 respondents to our public consultation on the draft Guidance stated that they intended to make changes to their own work practice or to the work practices within their organisations. Respondents intended to make changes by incorporating the guidance as part of staff induction and training, using the guidance to inform team meetings and to raise awareness among people using services, and changing the way risk assessments are conducted.

Next steps

In 2020, we will progress other projects commenced in 2019, such as the standards for children's services, including the development of National Standards for Children's Services and begin new projects including the development of a set of principles to underpin all future standards and guidance for health and social care services.

We will continue to support cultural change within services. One way in which we will endeavour to do this is expanding our work in developing supports for the implementation of Standards. The Standards Development team has developed three digital learning modules to support staff in health and social care services to implement National Standards. These Standards include National Standards for infection prevention and control in community services, National Standards for Adult Safeguarding and Guidance on a Human Rights-based Approach in Health and Social care Services. All three modules will be launched in 2020. A systematic review of the international literature on enablers and barriers to the implementation of Standards in Health and Social Care settings will be undertaken as part of a PhD thesis and create part of the evidence base for the development of a framework and tools, to support implementation of Standards in the future.

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

Standards and Guidance Development Function, 2019 Impact Summary

In 2019 there were **60,766** unique visits to the Standards web pages.

383 requests were made to the Health and Social Care Standards team for a printed copy of the standards, guides or implementation resources that we produced.

Stakeholder groups from across health and social care, including patient representatives were engaged with.

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

2 international student interns were hosted.

2 undergraduate student placements were hosted from University College Cork.

1 set of National Standards was approved by the Minister for Health.

1 new Guidance was published.

1 new PhD student commenced within the Health and Social Care team and in collaboration with University College Cork.

The National Care Experience Programme

What we do:

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 HSE 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.

2019 objectives

- conduct the 2019 National Inpatient Experience Survey and work in partnership to respond to the findings
- commence the development of the National Maternity Experience Survey
- commence the development of a competency centre to enhance the use of survey data and an understanding of survey methods.

Desired outcomes

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

- improvement in reported patient experience

- use of survey findings
- quality improvement initiatives taken in response to survey findings.

2019 impact

Outputs

In 2019, the National Care Experience Programme produced a number of reports in order to disseminate the findings of this year's **National Inpatient Experience Survey**.

- **1** national report
- **39** hospital reports
- **6** hospital group reports
- **1** technical report, which provides a technical description of the model, methodology and procedures implemented during the inpatient survey.

The *National Care Experience Programme Strategic Plan (2019 – 2021)* was published in 2019 and sets out the plan to support the expansion of the programme into new survey areas across health and social care, including end of life, maternity bereavement and older person care experience.

This year, the programme commenced the development of the **National Maternity Experience Survey.** As part of this, the following background documents were generated to support the development and implementation of a robust survey model to capture maternity care experiences:

- an international review of maternity care experience surveys to identify international experience and best practice in this area
- a concept analysis of women's experiences of maternity care and a systematic review of maternity experience survey instruments were undertaken by the National University of Ireland, Galway (NUIG).
- a validated survey tool was developed in collaboration with the National University of Ireland, Galway (NUIG) to capture the experiences of women.

Reach

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

- **12,343** participants in the 2019 inpatient survey
- **3** information sessions held to inform hospital staff of the National Maternity Experience Survey, with **80** attendees registered across the three sessions
- **20** conferences attended by members of the team
- **8** information stands hosted by the programme at national conferences
- **6** posters and **6** presentations accepted at major conferences in Ireland
- **1** presentation at the International Society for Quality in Healthcare (ISQUa) Conference 2019 in Cape Town, South Africa
- **3 week** radio advertising campaign on national and local stations.

The results of the National Inpatient Experience Survey 2019 were launched on 2 November 2019.

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

- **206** downloads of the national inpatient survey 2019 report
- **557** downloads of local hospital reports from the inpatient survey 2019
- **15** national press releases
- **39** hospital infographics designed
- **32** national print articles
- **52** online media articles
- **39** broadcast pieces.

In September 2019, a new dedicated website yourexperience.ie was launched for the National Care Experience Programme in order to make it easier to learn about the various surveys and find out how service providers are improving care, based on survey feedback. Since September 2019 **4378** people have visited to yourexperience.ie.

- since

In 2019, the programme used Twitter, Facebook and Instagram to communicate and interact with stakeholders and build foundations across the health and social care system in Ireland and beyond.

- **2,772** followers across the three social media platforms

Engagement

Hospital and community visits

Hospital and community visits form an important part of each survey; they promote engagement with patients and hospital staff when surveys are live.

- **40** hospital visits undertaken to promote the inpatient survey in 2019.
- **19** hospital visits undertaken to promote the maternity survey, which included visits to various community-based healthcare professionals.
- **20** Public Health Nursing forums were attended in order to promote the maternity survey to **220** Public Health Nurses
- **1** General Practitioner (GP) Study Day attended to promote the maternity survey, which reached **250** GPs.

Training and support resources

The online training programme was developed to support individuals in understanding and navigating the survey dashboards; it reached a range of users, including healthcare professionals, researchers and members of the public.

Survey methodology

As part of the development of the maternity survey in 2019, extensive stakeholder engagement took place to promote consistency and quality:

- **7** focus groups were held in 2019 to hear the views of various stakeholders

- **149** responses received during the Delphi Study[1]
- **14** people took part in cognitive testing of the survey questionnaire
- **20** people took part in the pilot study for online questionnaire functionality.

National Inpatient Experience Survey Conference 2019

The inaugural National Inpatient Experience Survey Conference was held in February 2019. The theme of the conference, 'Knowing what matters to you and doing something about it', focused on the implementation of quality improvement initiatives across participating hospitals. It highlighted key findings from previous inpatient surveys and showcased how healthcare professionals, stakeholders and patients can work together to improve experiences for all.

- **300** conference attendees
- **56** abstracts submitted
- **20** abstracts selected to be presented at the conference
- **9** presentations by various stakeholders, including patient representatives
- **9** exhibition stands representing health and social care services in Ireland
- **Closing address** by Minister for Health Simon Harris TD

Change

As part of the NCEP partnership, this responsibility of implementing change falls to the HSE and service providers and not specifically to HIQA. Below are examples of change observed since the programme was established.

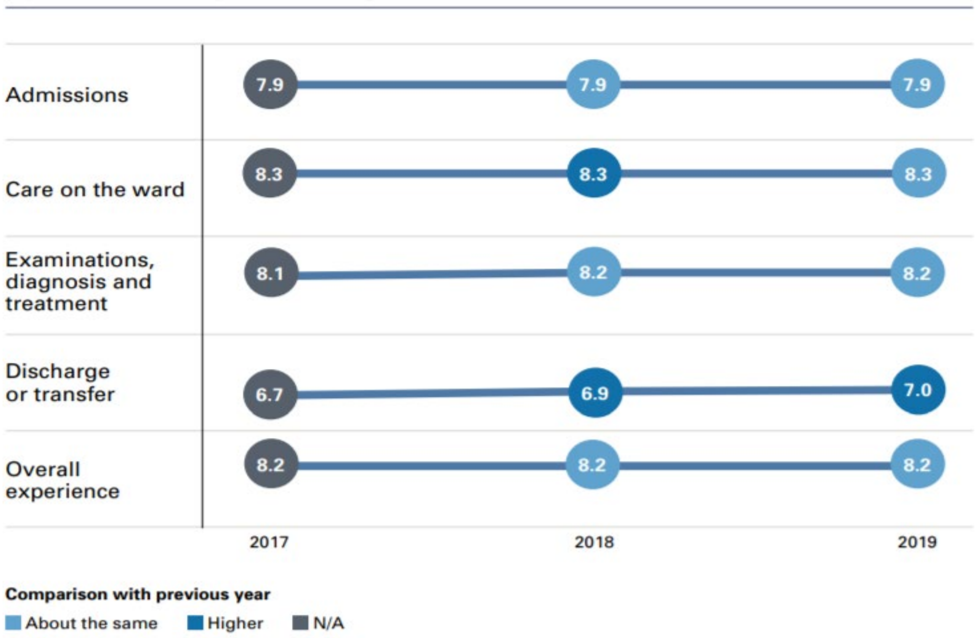
Improvements in reported patient experience

- Participant ratings of their overall experience have remained consistent since 2017. The greatest improvement in patient experience nationally has

---

[1] A Delphi Study is a type of methodology which is used to achieve consensus across a variety of stakeholders; in this case, it was undertaken to help identify priority questions for inclusion in the survey.

been achieved in the area of discharge or transfer, as shown in the figure below.



- In the National Inpatient Experience Survey 2017, **44%** of participants said that they were given written or printed information on what they should or should not do after leaving hospital. In the 2019 survey, **57%** of participants said that they received written information prior to discharge.

Use of survey findings

- In April 2019, the HSE published the Food, Nutrition and Hydration Policy for Adult Patients in Acute Hospitals Policy in response to the survey findings; this policy aims to improve the patient’s experience of hospital food.
- The National Healthcare Communication Programme was established in response to the survey findings to guide and support staff to develop and maintain effective skills when communicating with patients.
- As part of an academic collaboration with NUIG, secondary analysis is underway to explore the qualitative questions, with a view to understanding insights to enhance hospital quality improvements. A dashboard has been developed, enabling sensitivity analysis of

approximately 60,000 qualitative comments; this dashboard will inform and support targeted quality improvement across the health system.

- The regulation and monitoring teams within HIQA utilise the findings from the inpatient survey to inform their inspections in healthcare regulation and monitoring programmes. The Medication Monitoring Programme Guide and the Medication Safety Overview Report have been informed by the inpatient survey.

Quality improvement initiatives taken in response to survey findings

- Quality improvement theme: Communication with patients
    - In direct response to the inpatient survey findings, the HSE developed and implemented the National Healthcare Communication Programme. The programme uses a skills-based approach to provide leadership and support healthcare professionals can communicate with patients and families.
- Quality improvement theme: Hospital food and nutrition
    - St. James's Hospital created menu cards which were distributed to patients prior to mealtimes. A review identified that 64% of patients reported receiving a menu before this initiative, while 94% reported receiving a menu afterwards. Survey results show that ratings of hospital food have increased significantly in the hospital since 2017. In 2017, 56% of participants said that the food was 'good' or 'very good', compared with 67% in 2019.
- Quality improvement theme: Discharge or transfer
    - The discharge or transfer stage of care remains an area for improvement for the majority of hospitals. In response to the findings, Beaumont Hospital developed an information leaflet for patients to inform them about the discharge or transfer process. Since 2017, the hospital has seen a significant improvement in this stage, with 54% of participants reporting they were given written information on their care in 2017, compared with 63% in 2019.

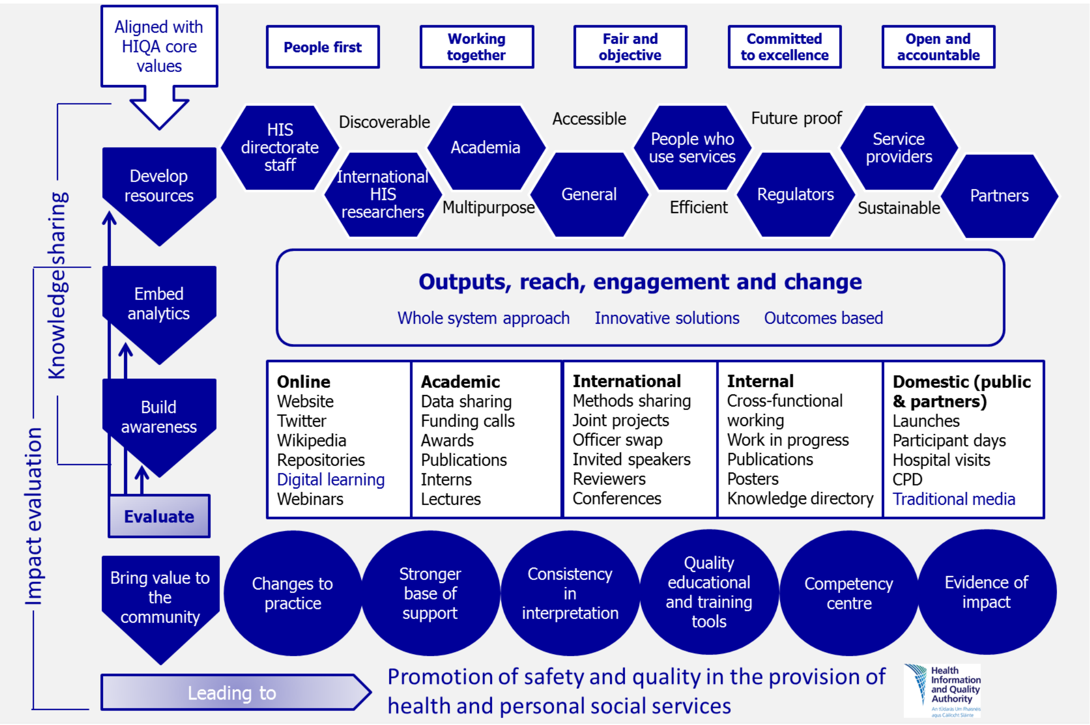
Conclusion and next steps

The impact of the work that the 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. It is further complicated in that most of our work applies nationally, meaning there are no comparative services where we do not work, with which to compare, in order to 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.

In 2018, we developed a framework for the evaluation of the impact of discrete projects and individual teams within HIQA (*Knowledge Sharing and Impact Strategic Framework, 2018*).



This is based on desired outcomes and evaluates impact under the themes of outputs, reach, engagement and change. We will continue to embed methods to evaluate impact, under these themes, 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 first 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.

However, there is still a need to assess organisational level impact. In order to achieve this we need to gather evidence from multiple sources and create a picture of how and where HIQA are having impact on improving health and social care services in Ireland. This requires the development of an impact assessment model and survey tools tailored for each of our key stakeholder groups; policy makers, service providers, service users and the public. Preliminary work with the Care Quality Commission, England has been undertaken to understand how they evaluate impact at an organisational level. This work has produced a preliminary list of topics for inclusion an organisational level impact evaluation:

- awareness of our activities and outputs
- delivering against our remit and strategy
- our presence, engagement and reach
- the quality of our outputs
- observed attributable change

- our work in informing decision-making.

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