Digital Health and Pharmacy: HIQA’s role in supporting the Irish digital health and health information landscape

Irish Institute of Pharmacy Webinar

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10 September 2025

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Health
Information
and Quality
Authority

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

- The Health Information and Quality Authority (HIQA) is an independent statutory body established under the Health Act 2007 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.

- As an independent statutory body established to promote safety and quality in the provision of health and social care services, HIQA is responsible for developing national standards, recommendations and guidance to support the Irish digital health and health information landscape to ensure safer, better care.

- To do this, HIQA develops person-centred standards, guidance and recommendations that are underpinned by principles of:

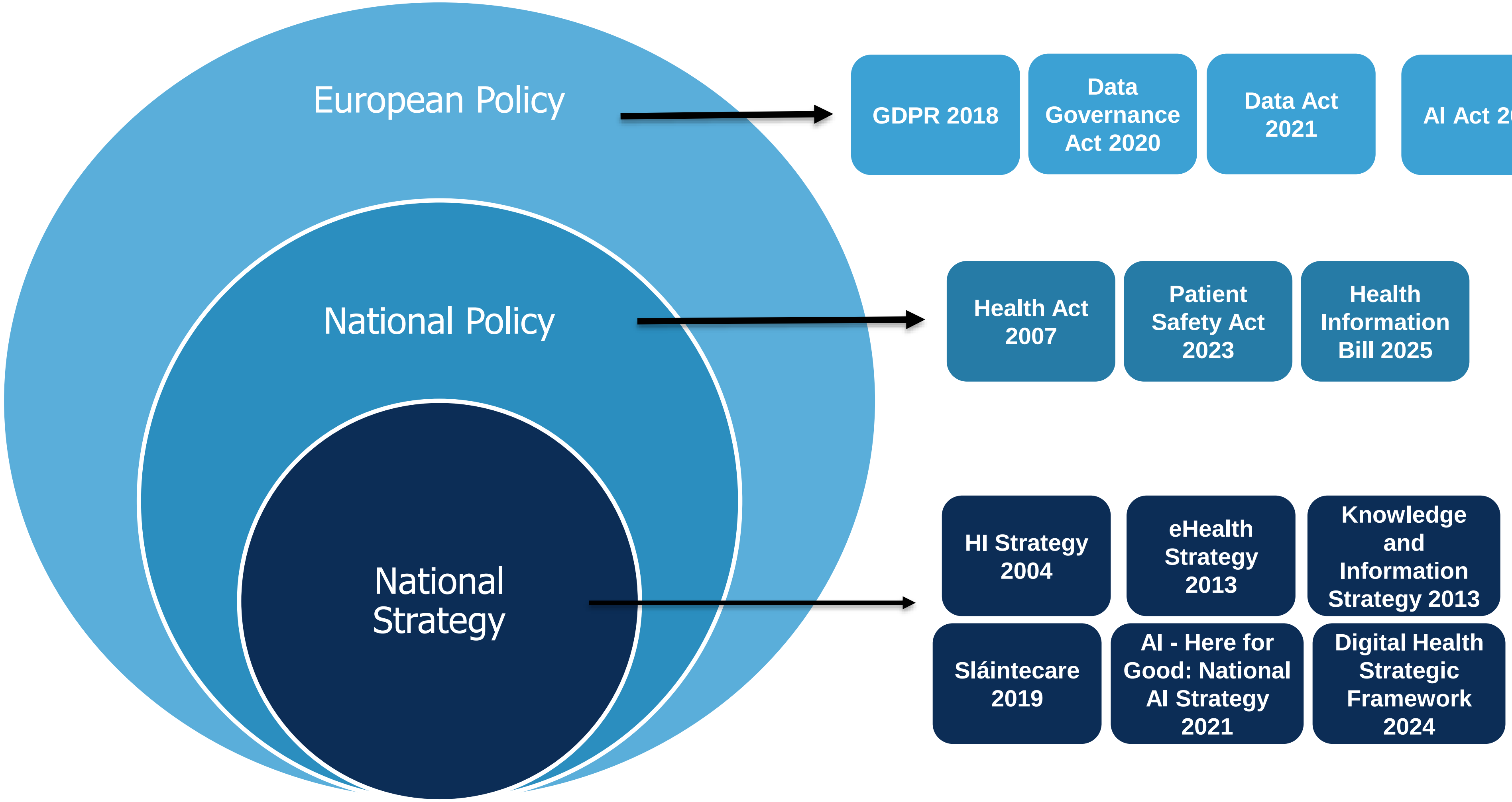
  - a human rights-based approach
  - safety and wellbeing
  - responsiveness
  - accountability

Webinar overview

- Introduction to the Health Information function at HIQA
- Overview of recent and current projects at the Health Information function
  - National Engagement on Digital Health and Social Care
  - National Guidance for the Responsible and Safe Use of Artificial Intelligence in Health and Social Care
  - National Standards for Information Management in Health and Social Care
  - Revision of:
    - (a) National Standard for a Demographic Dataset for Health and Social Care
    - (b) National Standard for Hospital Discharge Information

Introduction to the Health Information function at HIQA

What is the context for our work?



European Policy

- GDPR 2018
- Data Governance Act 2020
- Data Act 2021
- AI Act 2024
- EHDS 2025

Principles and rules to support government to implement goals related to effective and safe collection, use and sharing of data.

National Policy

- Health Act 2007
- Patient Safety Act 2023
- Health Information Bill 2025

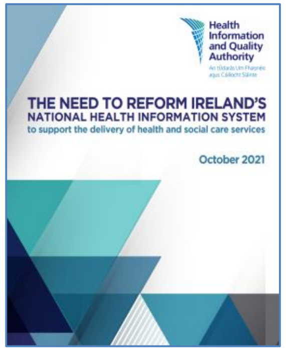
National Strategy

- HI Strategy 2004
- eHealth Strategy 2013
- Knowledge and Information Strategy 2013
- Sláintecare 2019
- AI - Here for Good: National AI Strategy 2021
- Digital Health Strategic Framework 2024

Plans to achieve digital health and integrated care

Key national developments

A Digital Health Framework for Ireland 2024–2030: Six Principles for Digital Care

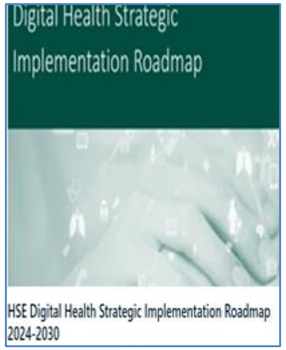


Health Information and Quality Authority

THE NEED TO REFORM IRELAND'S NATIONAL HEALTH INFORMATION SYSTEM
to support the delivery of health and social care services

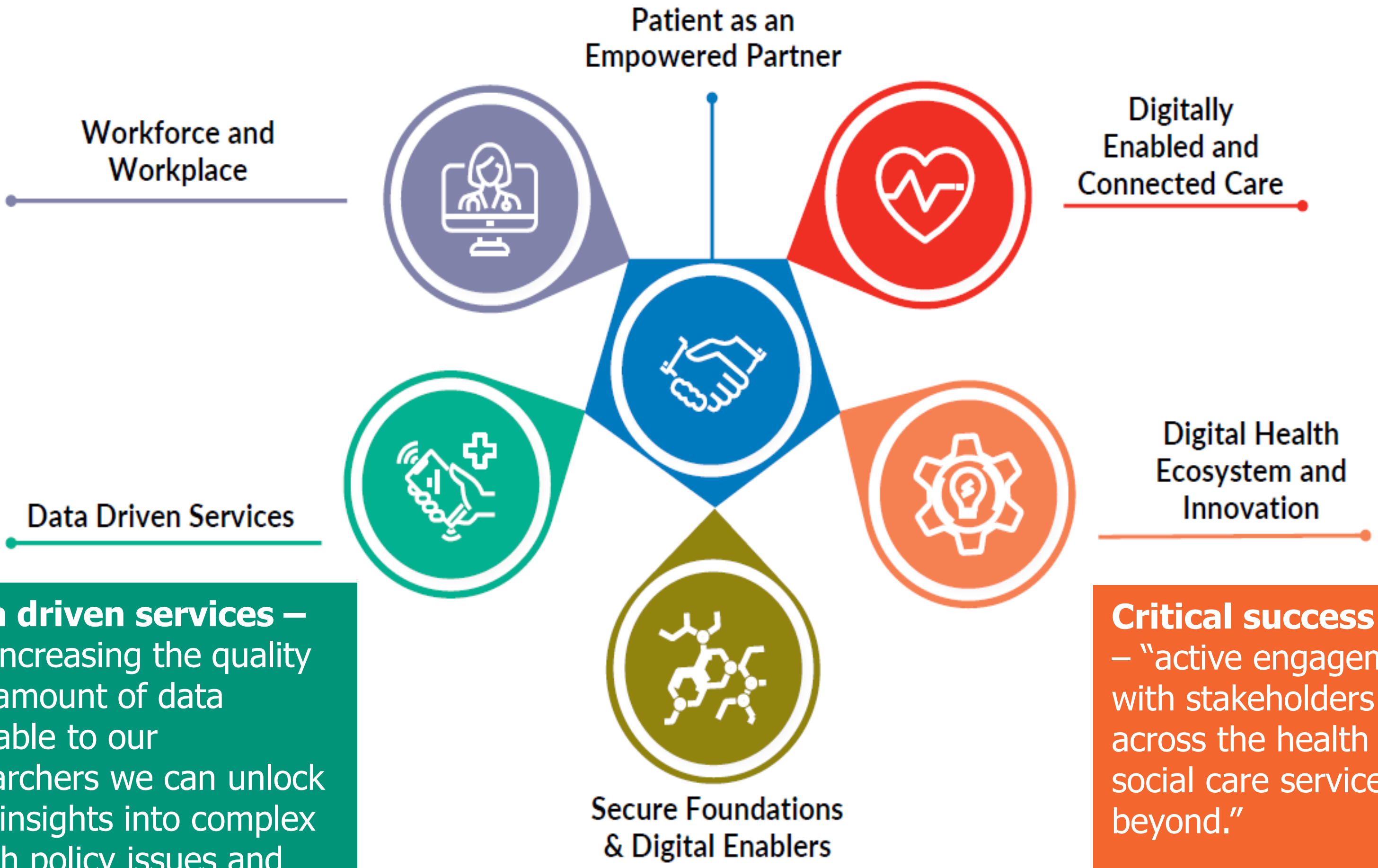
October 2021

Digital for Care — A Digital Health Framework for Ireland
2024-2030



Digital Health Strategic Implementation Roadmap

HSE Digital Health Strategic Implementation Roadmap
2024-2030



Patient as an Empowered Partner

Workforce and Workplace

Digitally Enabled and Connected Care

Data Driven Services

Digital Health Ecosystem and Innovation

Secure Foundations & Digital Enablers

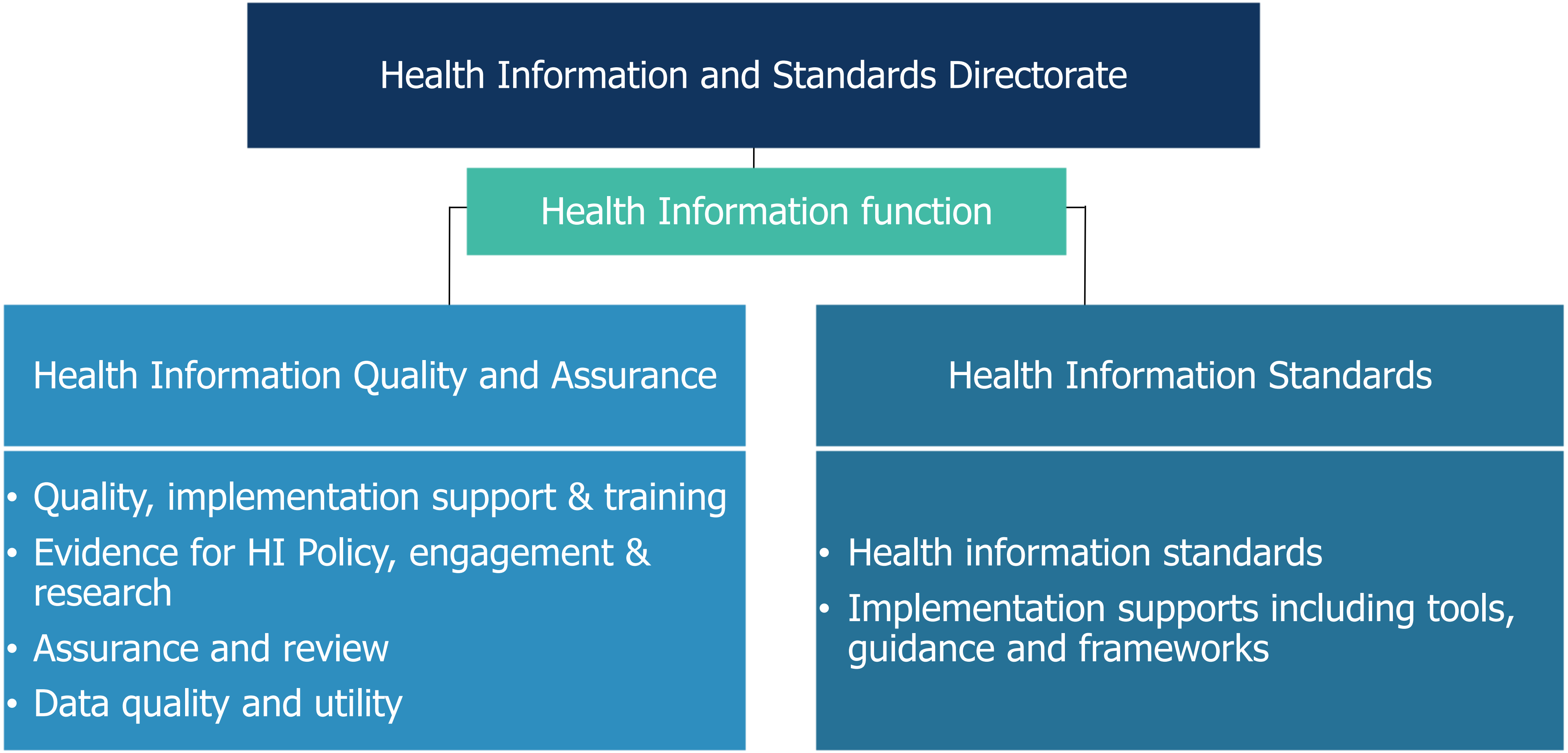
Data driven services – "By increasing the quality and amount of data available to our researchers we can unlock new insights into complex health policy issues and translate this into evidence-informed policy."

Critical success factor – "active engagement with stakeholders from across the health and social care service and beyond."

HIQA’s Health Information function

- Provide **leadership** in defining health information landscape
- Set **standards**, develop **guidance** and make **recommendations** for health information
- Drive **quality improvements** in health information
- Enhance foundations for **eHealth**

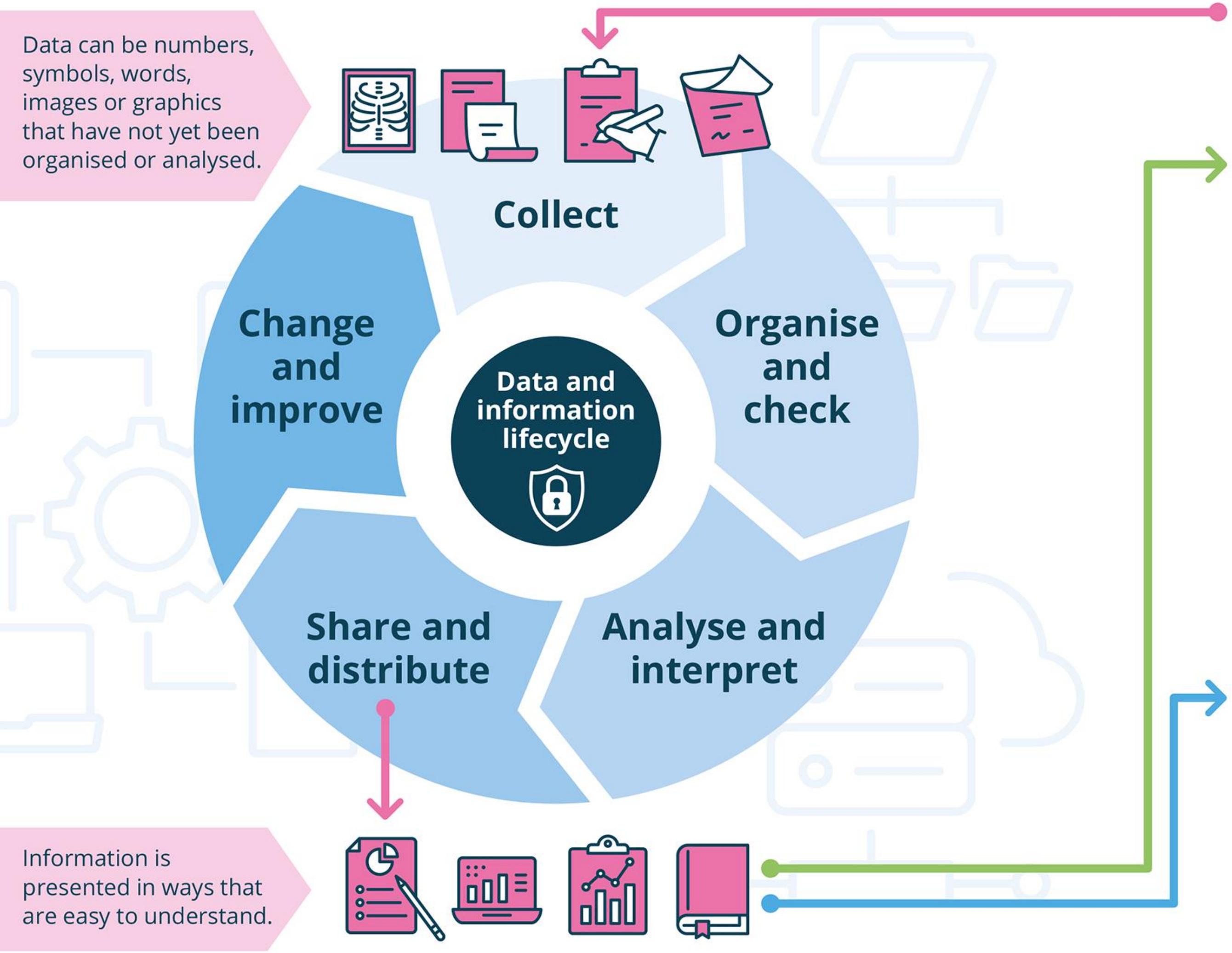
How is the Health Information function at HIQA structured?



- Health Information and Standards Directorate
  - Health Information function
    - Health Information Quality and Assurance
      - Quality, implementation support & training
      - Evidence for HI Policy, engagement & research
      - Assurance and review
      - Data quality and utility
    - Health Information Standards
      - Health information standards
      - Implementation supports including tools, guidance and frameworks

What is health information?

Before data becomes information, it goes through the following lifecycle:



Data can be numbers, symbols, words, images or graphics that have not yet been organised or analysed.

Collect

Organise and check

Analyse and interpret

Share and distribute

Change and improve

Data and information lifecycle

Information is presented in ways that are easy to understand.

Primary use of information:

Use of a person's health information to inform their care.

EXAMPLES:

Individuals use their health information to make decisions on their own health and well-being, for example, managing a chronic (ongoing) condition.

Health and social care professionals use health information to decide on what care, support or treatment is best for the person.

Secondary use of information:

Re-using a person's information to help plan and manage health and social care services, inform public health, guide policy-making, and perform research.

EXAMPLES:

Healthcare organisations, such as hospitals, use information to manage services and plan for future needs with the aim of continuously improving quality of care and achieving better value for money.

National data collections use information to inform policy-making, improve public-health and undertake research to compare treatments and services.

How does the Health Information Standards team support good information collection and management?

Setting **standards** to drive improvements in the standardisation of information across health and social care services

Developing **guidance, frameworks and tools** to help services and organisations implement standards and improve practice

Health Information Standards to date

National Standard for Patient Referral Information (2011)

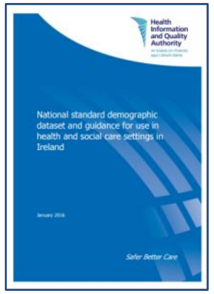

Health Information and Quality Authority

National Standard for Patient Discharge Summary Information

3 July 2013

Safer Better Care

Data model for an electronic medicinal product reference catalogue – a National Standard (2015)

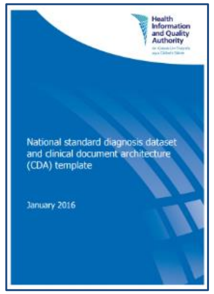

Health Information and Quality Authority

National standard demographic dataset and guidance for use in health and social care settings in Ireland

January 2016

Safer Better Care

General Practice Messaging Standard (Version 4.0) (2016)


Health Information and Quality Authority

National standard diagnosis dataset and clinical document architecture (CDA) template

January 2016

National Standard for national community-based electronic prescribing (2018)


Health Information and Quality Authority

Health Information and Standards

National Standard on information requirements for a national electronic patient summary

December 2018

Safer Better Care

2011 2013 2015 2016 2016 2016 2018 2018

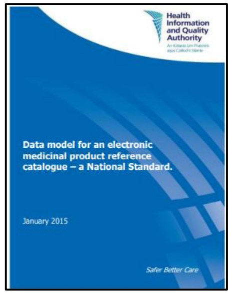

Health Information and Quality Authority

Report and Recommendations on Patient Referrals from General Practice to Outpatient and Radiology Services, including the National Standard for Patient Referral Information

23 March 2011

Safer Better Care

National Standard for a Clinical Summary (Patient Discharge) (2013)


Health Information and Quality Authority

Data model for an electronic medicinal product reference catalogue – a National Standard.

January 2015

Safer Better Care

National demographic dataset Standard and guidance (2016)


Health Information and Quality Authority

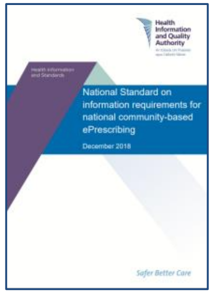
General Practice Messaging Standard

Version 4.0

September 2017

Safer Better Care

National Standard for a Procedure Dataset, Adverse reaction, Diagnosis dataset including clinical document architecture (CDA) template (2016)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Health Information and Standards

National Standard on information requirements for national community-based ePrescribing

December 2018

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National Standard for a electronic patient summary (2018)

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https://www.hiqa.ie/reports-and-publications/health-information

Recommendations to date

2009

Recommendations for a Unique Health Identifier for Individuals in Ireland (2009)

Recommendations for a Unique Health Identifier for Individuals in Ireland

2011

Recommendations for Unique Health Identifiers for Healthcare Practitioners and Organisations (2011)

Recommendations for Health Identifiers for Healthcare Practitioners and Organisations

July 2011

Safer Better Care

2014

Recommendations on SNOMED CT terminology (2014)

Recommendations regarding the adoption of SNOMED Clinical Terms as the Clinical Terminology for Ireland

May 2014

Safer Better Care

2014

Recommendations on National Data Collections (2014)

Recommendations for a more integrated approach to National Health and Social Care Data Collections in Ireland

November 2014

Safer Better Care

2016

Recommendations on the coordination of patient safety intelligence in Ireland (2016)

Recommendations on the coordination of patient safety intelligence in Ireland

January 2016

2018

Recommendations on community-based ePrescribing (2018)

Health Information and Standards

Recommendations for the national, community-based ePrescribing programme in Ireland

September 2018

Safer Better Care

2021

Recommendations on the Implementation of a National Electronic Patient Summary in Ireland (2021)

Health Information and Standards

Recommendations on the Implementation of a National Electronic Patient Summary in Ireland

December 2020

Safer Better Care

2022

Recommendations on the ICT enablement of older persons services (2022)

RECOMMENDATIONS ON

ICT Enablement of Older Persons Services

November 2022

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https://www.hiqa.ie/reports-and-publications/health-information

EU regulations: European Health Data Space and Primary Data

Aims to improve individuals' access to, and control over, their personal electronic health data, from anywhere within the EU; and facilitate secondary use of large anonymised datasets for specified purposes, including for research, innovation, policy-making and regulatory activities

Better diagnosis and treatment, improved patient safety, continuity of care and improved healthcare efficiency

Empower **individuals** to have control over their health data

Enable **health professionals** to have access to relevant health data

Electronic health records

Health data from apps and medical devices

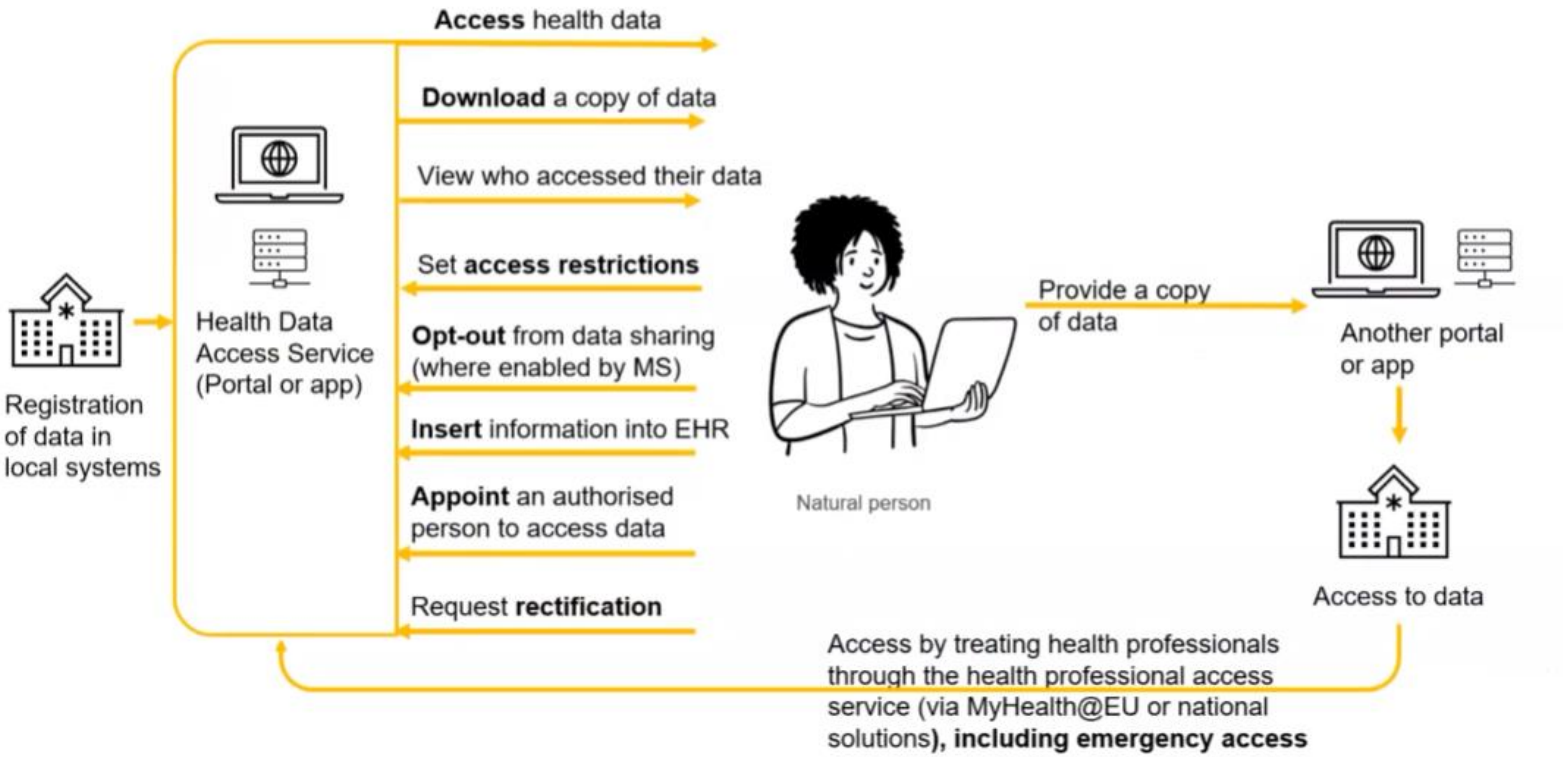
Health data in registries

Assist **policy makers and regulators** in accessing relevant non-identifiable health data

Facilitate access to non-identifiable health data for **researchers and innovators**

Better health policy, greater opportunities for research and innovation

What it means for natural persons



Registration of data in local systems

Health Data Access Service (Portal or app)

Access health data

Download a copy of data

View who accessed their data

Set **access restrictions**

Opt-out from data sharing (where enabled by MS)

Insert information into EHR

Appoint an authorised person to access data

Request **rectification**

Natural person

Provide a copy of data

Another portal or app

Access to data

Access by treating health professionals through the health professional access service (via MyHealth@EU or national solutions), **including emergency access**

Priority categories of data

The EHDS Regulation mandates a **phased** approach for integrating **six priority data categories of electronic health data** into **national health information systems**.

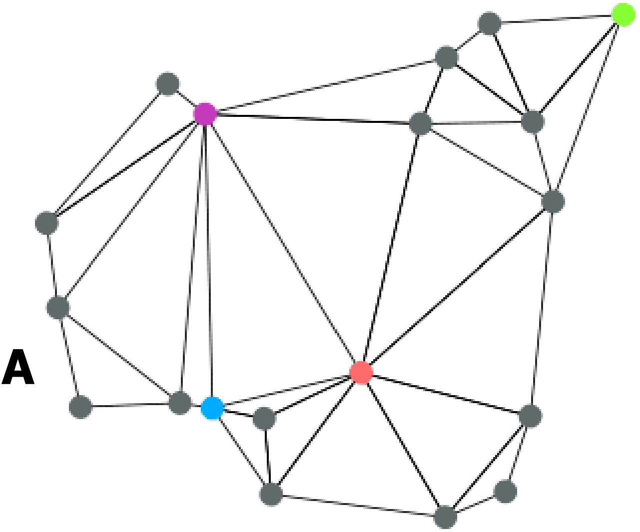
- **By 26 March 2029**: Member States are required to ensure that the first group of priority data categories are integrated into their national health information systems.
  - *patient summaries*
  - *electronic prescriptions*
  - *electronic dispensation*

- **By 26 March 2031**: The remaining priority data categories must be incorporated into national systems.
  - *laboratory results*
  - *medical imaging and reports*
  - *hospital discharge reports*

HealthData@IE Project (2024-2027)

Establishing the services of a Health Data Access Body (HDAB) in Ireland

- Funding from EU Commission to establish health data access services for Ireland
- Collaborative approach - DoH, HIQA, HRB, HSE and key stakeholders



Key areas for advancement for Ireland:

- **Programme of engagement, dissemination, training and support - HIQA**
- **National dataset catalogue - HIQA**
- National data access application management system (DAAMS) - HRB
- Secure processing environments (SPE)
- **Data quality enhancement - HIQA**

What is the Health Information Standards team doing to support these developments?

Recent projects

- National Engagement on Digital Health and Social Care
- Information Management Standards

Current projects

- Development of National Guidance for the Responsible and Safe Use of AI in Health and Social Care
- National Standard for Demographic Dataset
- National Standard for Hospital Discharge Information

Overview of recent and current digital and health information standards projects

1

National Engagement on Digital Health and Social Care

National Engagement on Digital Health and Social Care

- HIQA, HSE and Department of Health partnership
- Built on the work of the National Public Engagement Survey to gather the attitudes and opinions of the public in relation to the collection, use and sharing of health information
- Findings report, and a range of additional assets published September 2024

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An Roinn Sláinte
Department of Health

Background and aim

- The WHO promotes the importance of assessing local needs and context before the development of new digital health and social care systems.
- The European Commission has set goals to support Europe's digital transformation, one of which is to provide access to electronic health records for all European Union (EU) citizens by 2030. The EC has recently adopted the European Health Data Space Regulation which will enable people to access their electronic health data nationally and across borders.
- The Health Information Bill 2024 makes provisions for information to be collected and shared within the electronic health record.
- The Digital Health Framework for Ireland 2024-2030 and the HSE's corresponding implementation roadmap set out a vision to digitally transform health services with a focus on empowering patients.

The aim of the National Engagement on Digital Health and Social Care was **to understand the opinions and attitudes of the Irish public and professionals in relation to the digitalisation** of health and social care services.

Approach

Phase 1
Engagement to inform design of surveys

Phase 2
Conduct surveys

Phase 3
Conduct focus groups

Phase 4
Report on findings

Who participated in the survey?

2009 members of the public surveyed:

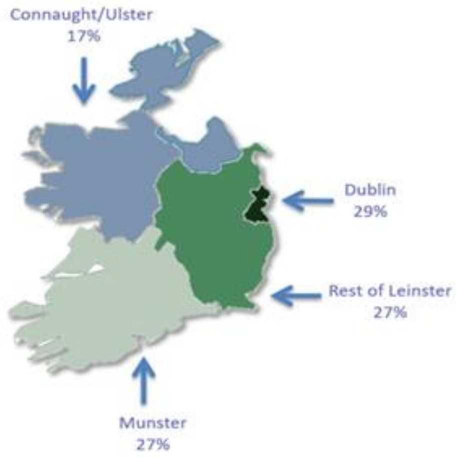
Male 49%

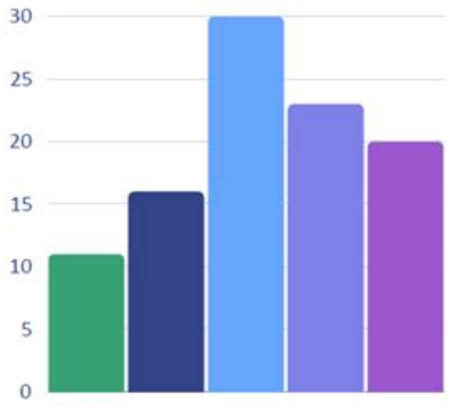
Other 0.1%

Female 51%

Age of public participants:

- 🟩 18 to 24 - 11%
- 🟦 25 to 34 - 16%
- 🟦 35 to 49 - 30%
- 🟪 50 to 64 - 23%
- 🟪 65 or older 20%



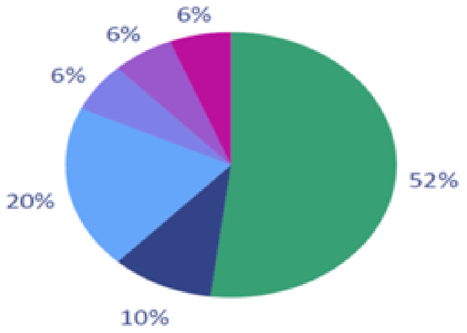


1020 professionals surveyed:

Male 21%

Other 1%

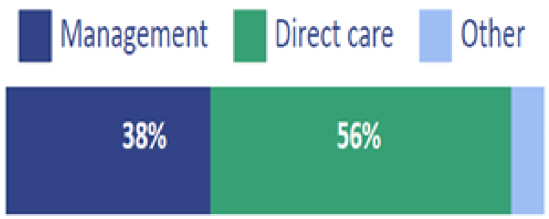
Female 78%



Professional roles:

- 🟩 Nurses and midwives– 52%
- 🟦 Doctors – 10%
- 🟦 CORU* Registered professionals – 20%
- 🟪 Pre-hospital Emergency Care – 6%
- 🟪 Pharmacists – 6%
- 🟪 Other - 6%

Management vs direct care:



*CORU - Ireland's multi-profession health regulator that includes speech and language therapists, social workers, physiotherapists etc.

Key findings – public

What did the public tell us?

The public feel ready to engage digitally with health and social care services.

74% said that they would access their online health record when it is available online.

95% of people said they are comfortable getting text and email reminders.

55% said that they would access digital health services if available.

Key findings – public

The public want their online health record for practical tasks to manage their health.

90% want to use it to contact professionals about mistakes or missing information.

90% want to use it to renew prescriptions for regular medications.

89% want to use it to track progress of tests.

> “you remember to tell one doctor [your family history] but possibly not the next..having that readily available to anyone reading your [online record] would be really nice.”

Key findings – public

The public need an online record to have more autonomy and to actively participate in decisions around their care.

91% think it will help them understand their health.

90% think it will help them manage their health between visits.

88% think it will help them talk to a professional about their health.

> Everybody would have the same view that the more information you can get about your own care and your own records the more it puts things in your own control to a certain extent. And that you are effectively managing your own health.

Key findings – professionals

What did the professionals tell us?

Professionals think that online records will empower people to be more in control of their health.

88% think the public will be better informed about their health.

88% think the public will be better prepared to ask questions.

> “[when people readily have access to their health information] I think people’s outcomes are way better, they have more choice, they feel freer and it improves the relationship because you know they know what you are saying about them.”

Key findings – professionals

Professionals need technical support and training in place prior to feeling comfortable interacting digitally with the public.

92% want clarity on who to contact for technical support.

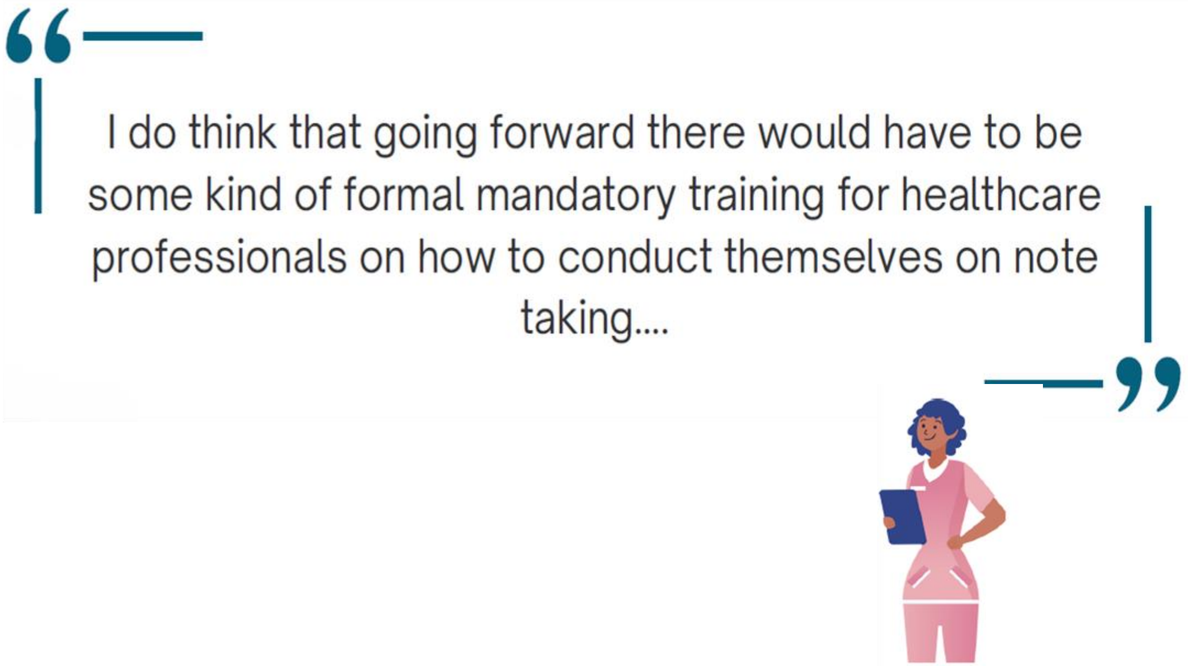
83% want training in digital tools.

79% want protocols in place on providing services or information digitally.

Key findings – professionals

Professionals need policy direction and guidance on clinical note taking prior to feeling comfortable sharing their clinical notes.

66% of professionals are comfortable sharing clinical notes but professionals need policy direction and guidance on clinical note taking.



> I do think that going forward there would have to be some kind of formal mandatory training for healthcare professionals on how to conduct themselves on note taking....

Pharmacy perspectives on digital care

Professionals want decisions around digital delivery to be person centred and informed by the healthcare need and patient's choice:

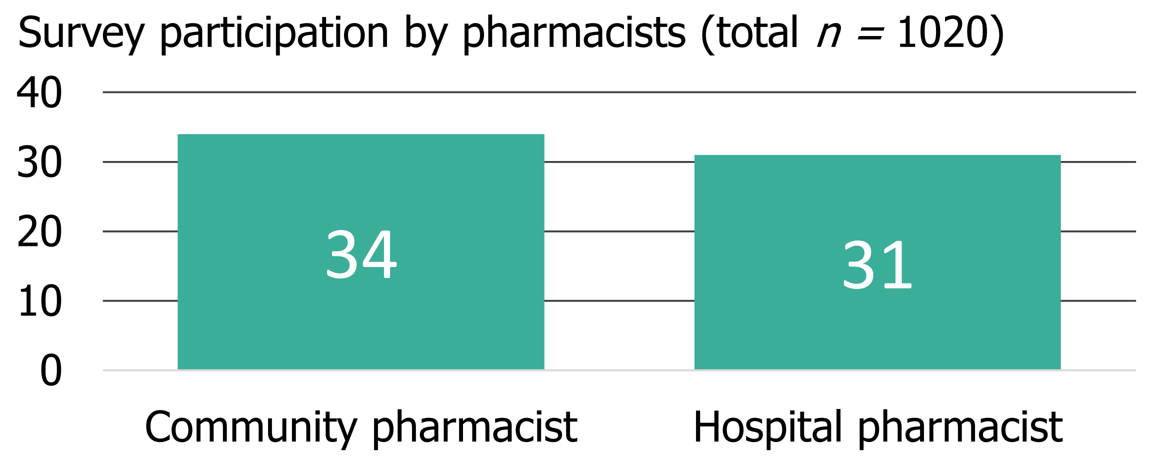
"it is always about the patient and the personal interaction, it's important not to lose that in the rush to digitise." (Pharmacist)

Professionals feel that digital access to healthcare records will improve transparency and trust in the system:

"I think there needs to be some degree of informed consent with the patient and it has to be voluntary. It should never be mandatory that you must allow your data to be aggregated across multiple sources, or if it is, that they are in plain language told why that is being done and how that helps." (Pharmacist)

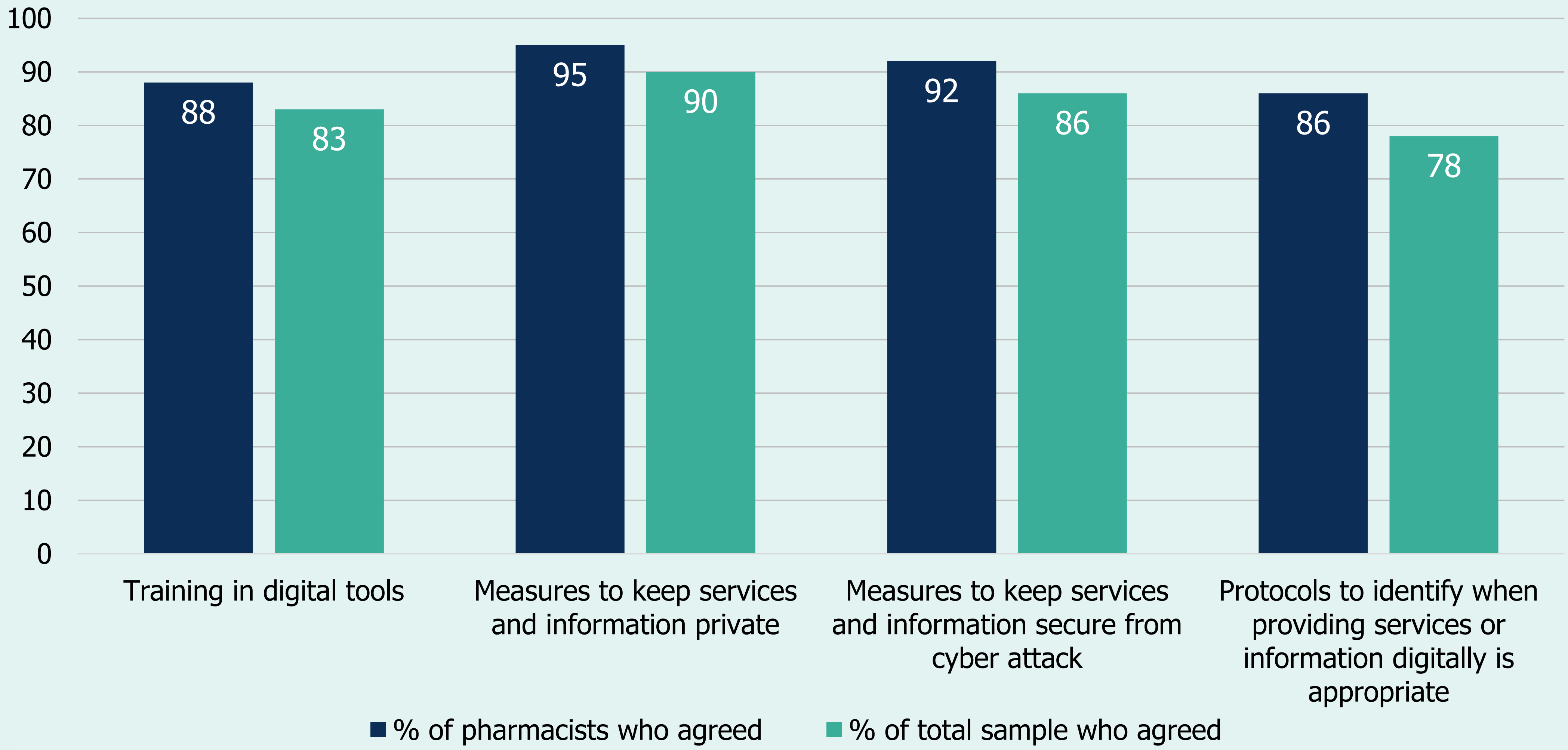
Professionals think that online records will empower people to be more in control of their health:

"We have seen in community pharmacy sometimes the way in which the vaccination record for example is presented that the person may not actually realise that they received a flu vaccine for example, because it might be the generic name of the flu vaccine. Then they go to their GP to seek the flu vaccine again" (Pharmacist)



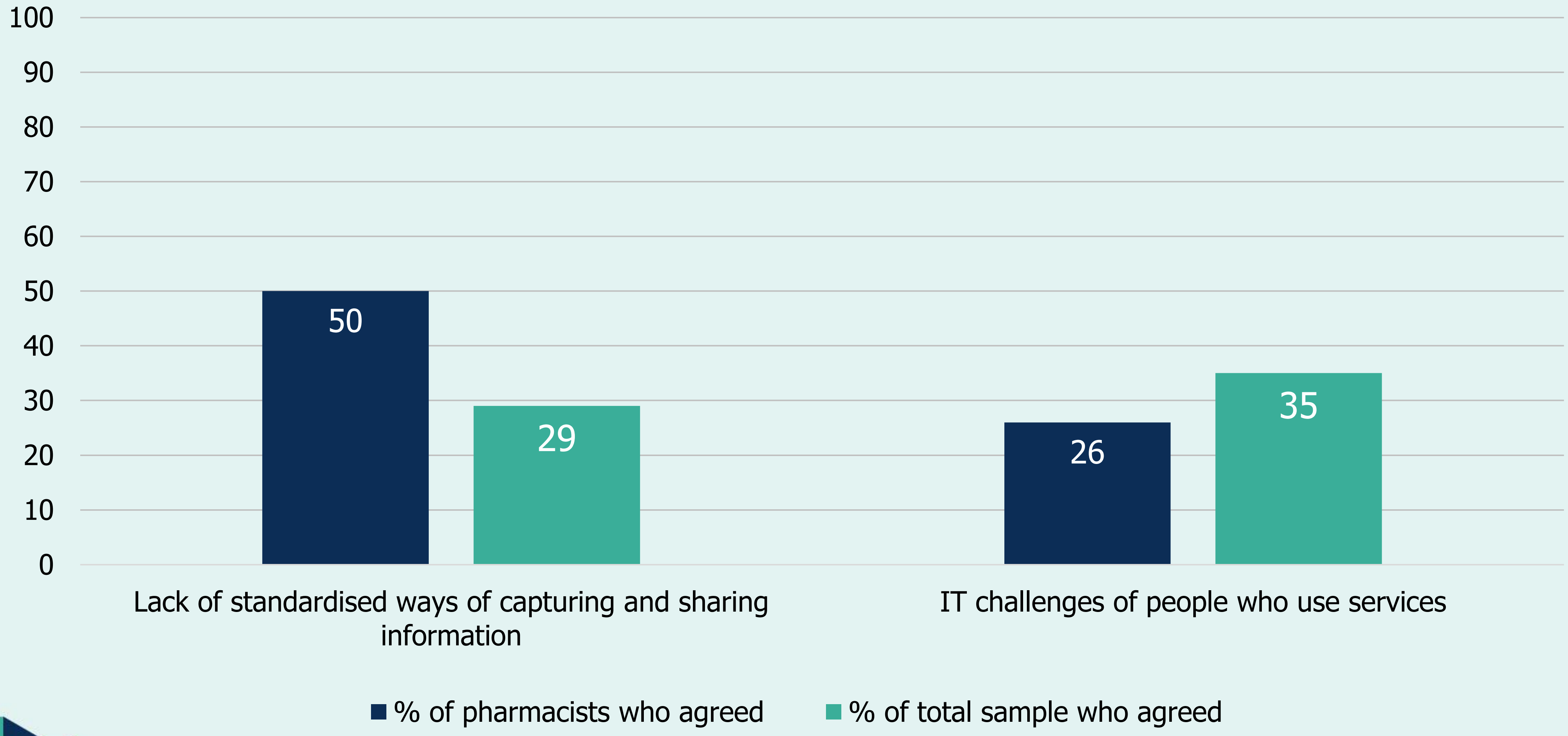
Pharmacy perspectives on digital care

Supports that would increase comfort providing care digitally



Pharmacy perspectives on digital care

Challenges to delivering care digitally



Translating the findings into action

An Roinn Sláinte
Department of Health

Department of Health is using the findings to inform legislation, national policy in digital health and social care being progressed under the Health Information Bill 2024 and the National Digital Health Framework 2024-2030.

HSE

The **HSE** is using the findings to inform the delivery of key elements of the National Digital Health Strategic Implementation Framework 2024-2030 and Sláintecare vision including the patient app, patient feedback platform, digital health capacity building and electronic health record.

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HIQA is using the findings to inform their programme of work in relation to health information including:

- development of national health information standards
- promotion and implementation of the National Standards for Information Management in Health and Social Care (6)
- the dissemination, training and support to progress goals to inform the establishment of a data access body.

2

National Guidance for the Responsible and Safe Use of Artificial Intelligence (AI) in Health and Social Care

What is Artificial Intelligence (AI)?

Artificial Intelligence (AI) is defined as the ability of machines or systems to perform activities that mimic human intelligence such as recognising patterns or making decisions based on data. Artificial Intelligence already plays a role in our day to day lives.

Below are some examples of how AI is currently used:

- **Interact:** When you speak to Siri or Alexa, you're using an AI-powered voice assistant. These systems rely on speech recognition and natural language processing to interpret your request and respond appropriately.
- **Recommend:** Recommendation systems, like those on Netflix and Amazon, use AI to analyse your past behaviour and suggest content or products tailored to you.
- **Optimisation:** AI can predict traffic patterns to optimise routes in navigation systems.

Context: EU AI Act 2024

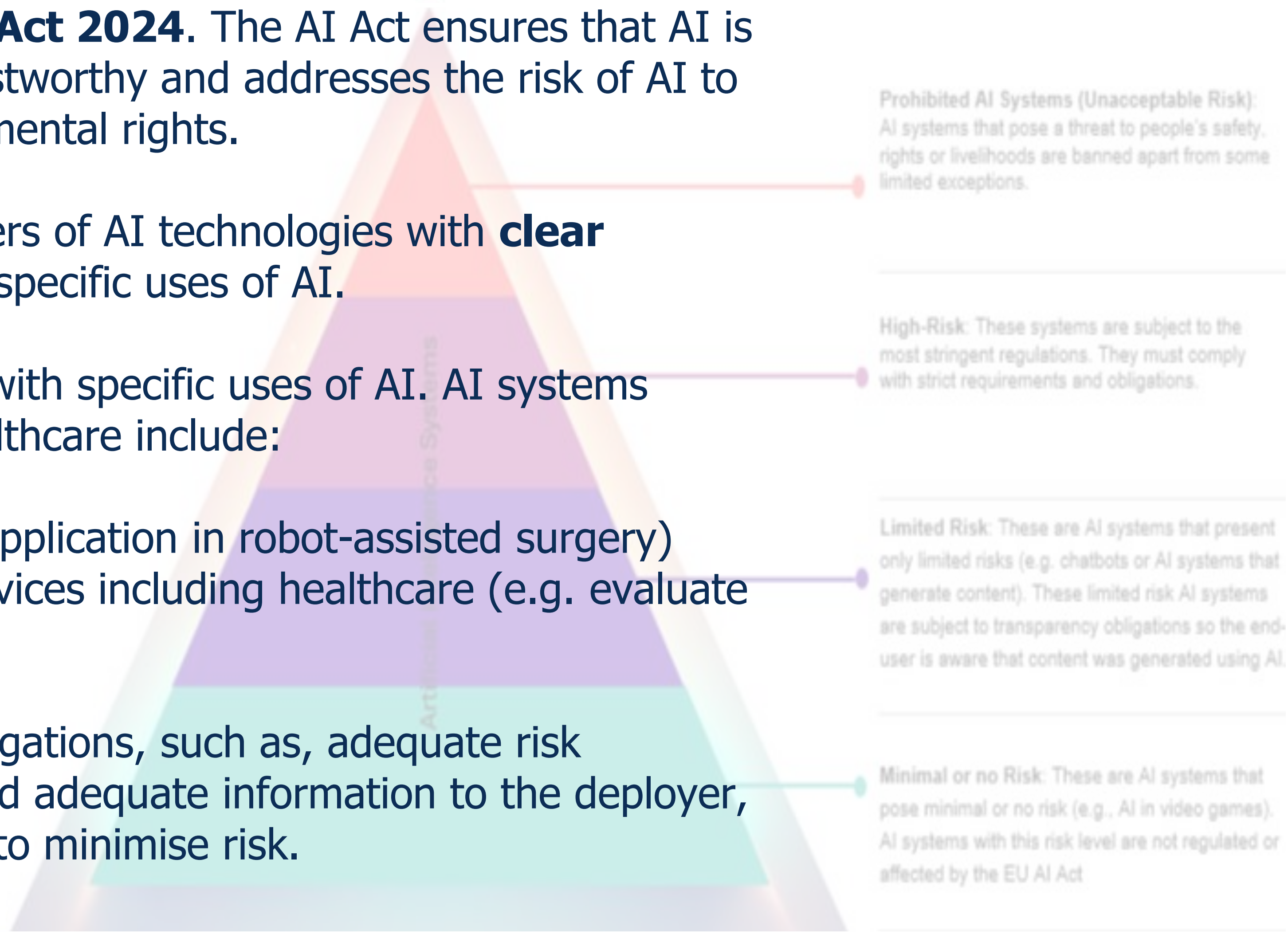
- AI in Ireland will be governed by the **EU AI Act 2024**. The AI Act ensures that AI is developed and deployed in a way that is trustworthy and addresses the risk of AI to citizens' health, safety, wellbeing and fundamental rights.

- The Act provides the developers and deployers of AI technologies with **clear requirements and obligations** regarding specific uses of AI.

- The EU Act categorises the risks associated with specific uses of AI. AI systems identified as high-risk that may relate to healthcare include:

    - Safety components of products (e.g. AI application in robot-assisted surgery)
    - Access to essential private and public services including healthcare (e.g. evaluate eligibility)

- High risk AI systems are subject to strict obligations, such as, adequate risk assessment and mitigation systems, clear and adequate information to the deployer, appropriate human oversight and measures to minimise risk.



Prohibited AI Systems (Unacceptable Risk): AI systems that pose a threat to people's safety, rights or livelihoods are banned apart from some limited exceptions.

High-Risk: These systems are subject to the most stringent regulations. They must comply with strict requirements and obligations.

Limited Risk: These are AI systems that present only limited risks (e.g. chatbots or AI systems that generate content). These limited risk AI systems are subject to transparency obligations so the end-user is aware that content was generated using AI.

Minimal or no Risk: These are AI systems that pose minimal or no risk (e.g., AI in video games). AI systems with this risk level are not regulated or affected by the EU AI Act

What work is being done to support the responsible and safe use of AI in health and social care?

Department of Health and HSE:

The Department of Health and the HSE are developing an AI in Health Strategy, as committed to in the Programme for Government 2025, to promote and support innovation and digital transformation in health and the responsible and safe use of AI in health and social care services.

HIQA:

The Department of Health commissioned HIQA to develop national guidance to promote and drive the responsible and safe use of Artificial Intelligence (AI) in health and social care services to ensure safer, better care for people using health and social care services.

The guidance will sit within the wider context of legislative, policy and service delivery requirements and initiatives.

What is the purpose of HIQA’s National Guidance?

- The national guidance will support services to promote and drive a responsible and safe approach to the use of AI in the health and social sector in Ireland, underpinned by the principles of:
  - a human rights-based approach
  - safety and wellbeing
  - responsiveness
  - accountability.

- All services and organisations that provide health and social care services can use this guidance to develop and embed good practice to ensure safer better care for people using health and social care services.

- The guidance will be used to promote awareness and build good practice among service providers and staff about the responsible and safe use of AI in health and social care services.

- The guidance will also be of use to people using services by educating and empowering them on what their expectations should be, in respect of the responsible and safe use of AI while engaging with health and social care services.

Approach to developing the National Guidance

Public Scoping Consultation

- Provided people an opportunity to give their initial input on the development of a guidance for the responsible and safe use of AI.

Co-production Working Group

- Working collaboratively on the development of the guidance to support the responsible and safe use of AI in health and social care.
- Facilitating engagement with stakeholders during focus groups, stakeholder meetings and public consultation.

Evidence Review

- Synthesised available international literature on the safe and responsible use of AI in health and social care to inform national guidance.
- Identified what guidance, frameworks, and principles are available to facilitate responsible and safe use of AI in health and social care services.

Focus Groups and Interviews

- Conducted focus groups and interviews with stakeholders including public and patient representatives, people who deliver care and people who manage services, exploring their perspectives on the guidance.

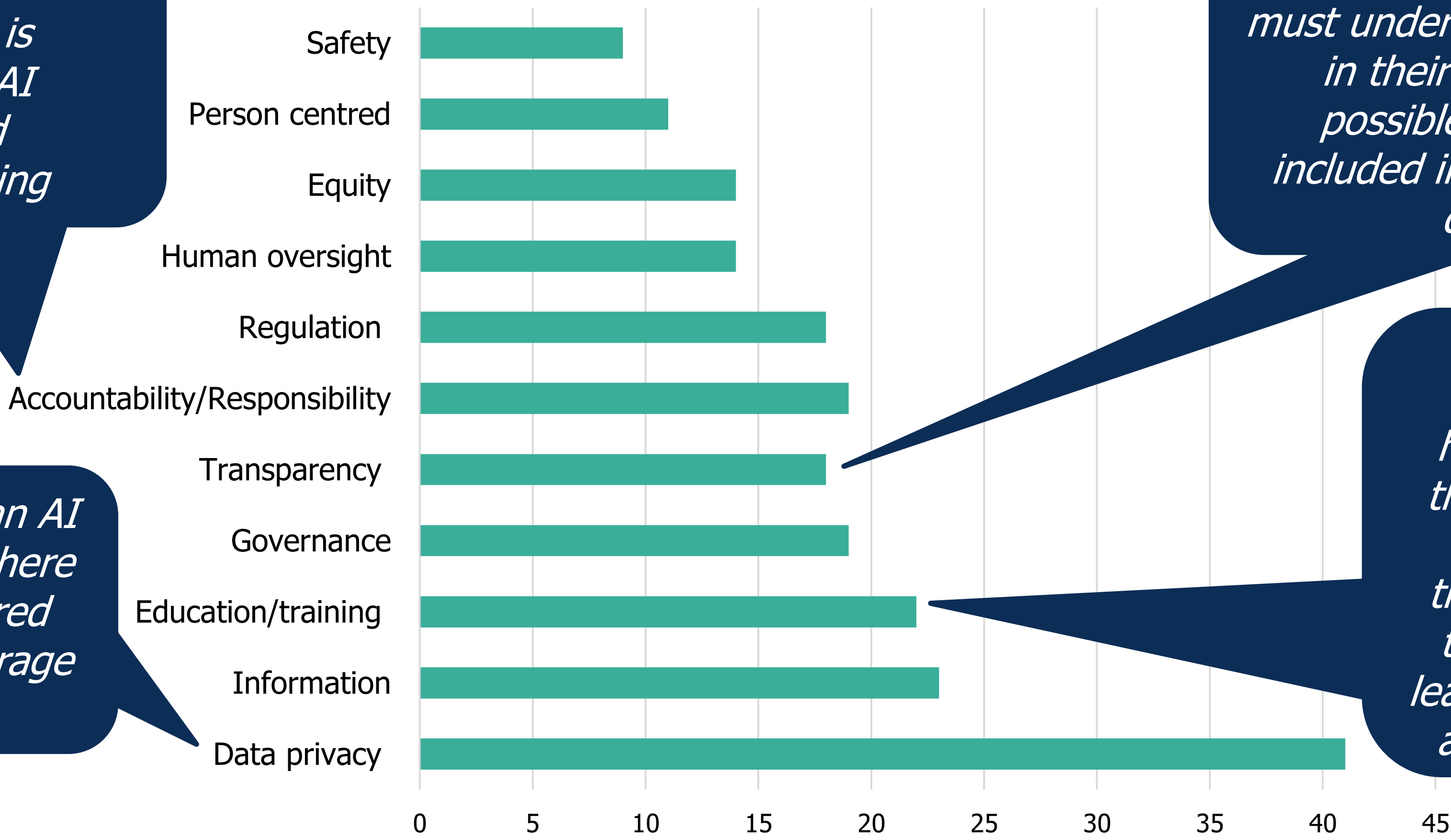
Public Consultation

- A public consultation will be undertaken to invite all interested parties to make submissions on the draft guidance document.

Evidence-based and collaborative approach

Scoping consultation:
Key areas the guidance should address

Roles and responsibilities - *particularly who is accountable for AI monitoring and adjustment/learning*



"At an individual level, people must understand how AI is used in their care and, where possible, they should be included in conversations and decisions."

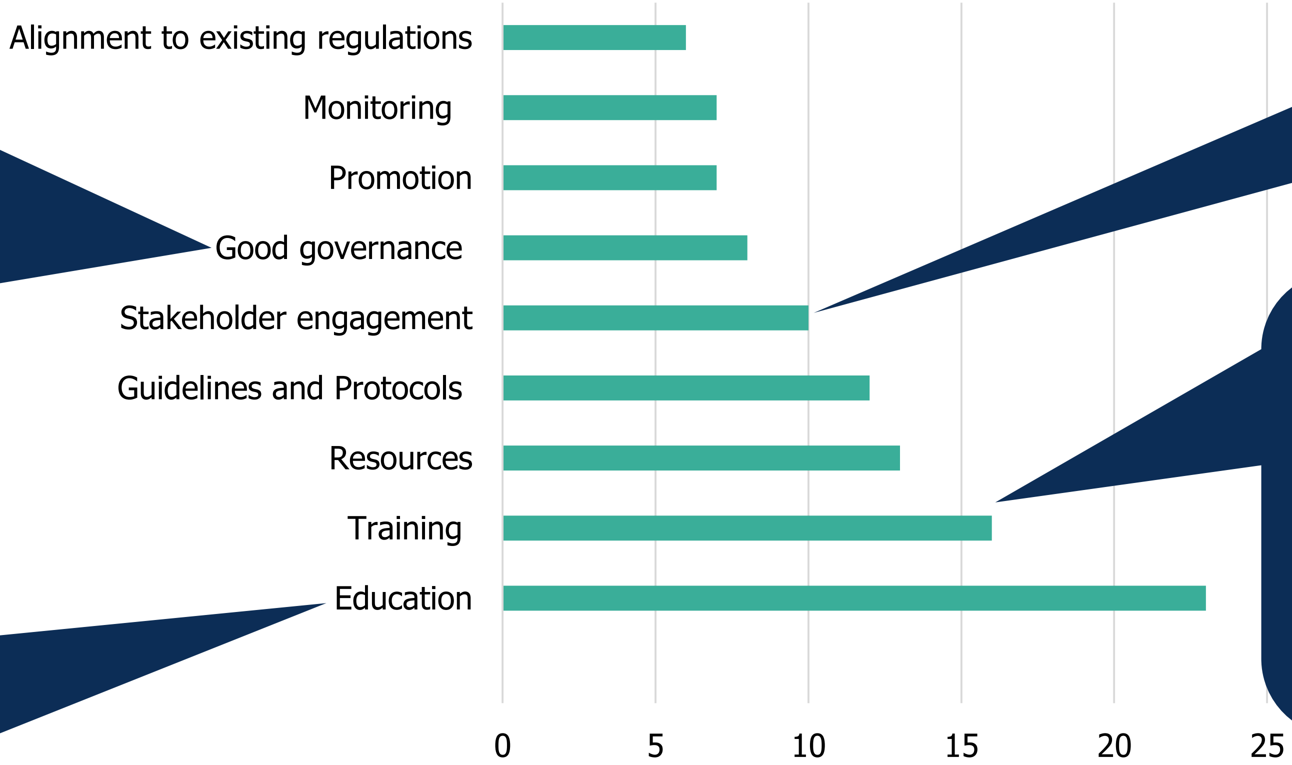
"Provide comprehensive training programmes for healthcare staff to ensure they are proficient in using AI technologies. Proper training will empower staff to leverage AI effectively, leading to more efficient and accurate service delivery."

"the exact data that an AI system will collect, where this data will be stored and how safe the storage of this data is."

Scoping consultation:
What will support implementation of the guidance?

"The guidance must outline clear lines of responsibility for AI decision-making. There should be robust governance mechanisms, including a national AI oversight body to handle audits, safety reviews, and ethics compliance."

"Building public confidence in AI's ability to enhance the provision of high-quality and timely care is crucial before it can be introduced across health and social care services."



"Stakeholders need to be involved in the process of implementing the guidance."

"Clinical and non-clinical staff need to be adequately equipped with the knowledge and skills to integrate AI into their workflows before it can be rolled out across health and social care services."

Scoping consultation:
Feedback from pharmacy perspective

AI-enabled clinical decision support systems are being used in pharmacies to *"identify potential drug-drug interactions, dosing errors, and contradictions".*

Automated dispensing robots are being used in pharmacies *"a proven example of how AI can support safe and efficient medicine supply. These systems reduce the risk of human error, improve stock rotation, and streamline daily operations"*

Submissions from:
- Irish Institute of Pharmacy
- Irish Pharmacy Union

- Areas the guidance should cover included:
  - Patient safety and clinical governance
  - Professional oversight and accountability
  - Data privacy and security
  - Bias and Equity
  - Education, Training and AI literacy

- What will support implementation of the guidance:
  - Continuous evaluation
  - Public and professional trust
  - Education, training and workforce upskilling

Some pharmacies have implemented AI-enabled messaging platforms or chatbots to provide patients with reminders, basic service information, or refill alerts. Where these tools are implemented ethically with clear consent and transparency they have been shown to enhance service accessibility and improve medicine adherence. Human pharmacist intervention is always available for more complex queries, ensuring safe patient triage.

Evidence review

- 55 sources
- Mix of academic papers, frameworks, guidance documents and position papers from a range of international bodies including public and patient representative bodies
- Key findings:

HIQA principle	Key themes to uphold the principle in relation to the responsible and safe use of AI in health and social care
Human Rights-Based Care	Inclusivity, Upholding Human Rights, Human Connection, Data Privacy, AI Literacy
Safety and Well-being	Safe care, Security, Trust
Responsiveness	System Responsiveness, Education and Training, Eco-responsibility, Research
Accountability	Oversight, Responsibility, Transparency, Human-in-the-loop, Compliance

Focus groups and interviews
Key stakeholders

Focus groups and individual interviews were conducted with 29 participants to gather perspectives on guidance for the responsible and safe use of AI in the delivery of health and social care services.

Qualitative data analysis using thematic analysis, guided by the four HIQA principles:

- a human rights-based approach
- safety and wellbeing
- responsiveness
- accountability

People who use health and social care services	Professionals working in direct care roles	Professionals working in management and administration
• Experience using health and social care services • Experience using mental health services • Living with a long-term condition • Living with a rare disease • Experience caring for a child living with a long-term condition • Experience as a young person	• Assistant director of nursing • Clinical nurse specialist • Clinical psychologist • Community pharmacist • Dermatologist • General practitioner • Laboratory manager • Medical student • Senior staff nurse • Social worker	• Chief information officer • Clinical information manager • Corporate governance • Data and analytics • Data protection officer • Director of nursing • Patient safety strategy manager • Professional regulation • Service feedback manager (+ academic researcher)

Next steps

Prepare draft National Guidance in collaboration with co-production working group

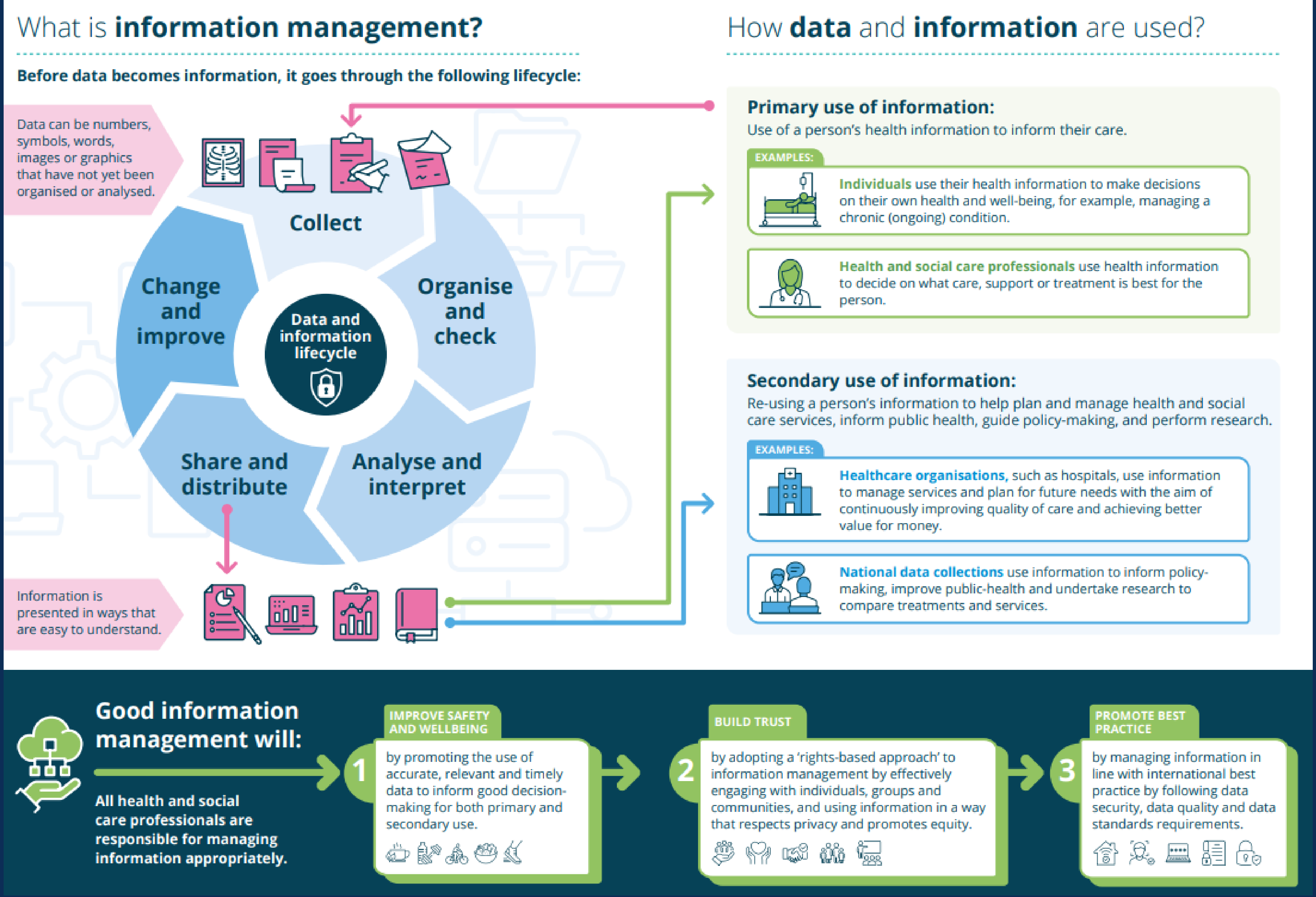
Conduct public consultation and further stakeholder engagement on draft National Guidance (due to commence in early November)

–> **key opportunity for pharmacists to contribute your views**

Finalise National Guidance in response to stakeholder feedback

3

National Standards for Information Management in Health and Social Care



What is **information management?**

Before data becomes information, it goes through the following lifecycle:

Data can be numbers, symbols, words, images or graphics that have not yet been organised or analysed.

Information is presented in ways that are easy to understand.

How **data** and **information** are used?

Primary use of information:

Use of a person's health information to inform their care.

EXAMPLES:

Individuals use their health information to make decisions on their own health and well-being, for example, managing a chronic (ongoing) condition.

Health and social care professionals use health information to decide on what care, support or treatment is best for the person.

Secondary use of information:

Re-using a person's information to help plan and manage health and social care services, inform public health, guide policy-making, and perform research.

EXAMPLES:

Healthcare organisations, such as hospitals, use information to manage services and plan for future needs with the aim of continuously improving quality of care and achieving better value for money.

National data collections use information to inform policy-making, improve public-health and undertake research to compare treatments and services.

Good information management will:

All health and social care professionals are responsible for managing information appropriately.

1. **IMPROVE SAFETY AND WELLBEING** by promoting the use of accurate, relevant and timely data to inform good decision-making for both primary and secondary use.
2. **BUILD TRUST** by adopting a 'rights-based approach' to information management by effectively engaging with individuals, groups and communities, and using information in a way that respects privacy and promotes equity.
3. **PROMOTE BEST PRACTICE** by managing information in line with international best practice by following data security, data quality and data standards requirements.

Information Management Standards

Information Management Standards for National Health and Social Care Data Collections

- National health and social care data collections/national repositories of health and social care data

National Standards for Information Management in Health and Social Care

- All services and organisations that collect, use or share health and social care information (within HIQA remit, excluding designated centres)

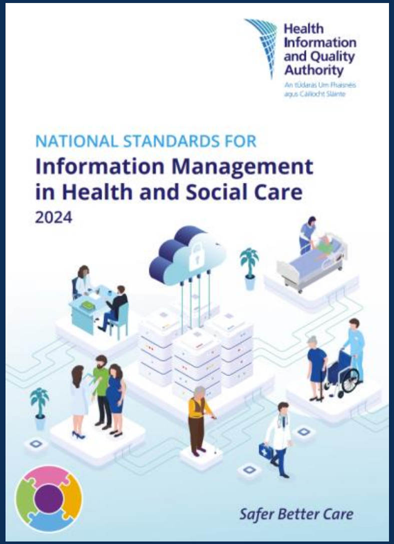
Health Information and Quality Authority

Information management standards for national health and social care data collections

2017

Safer Better Care

V1.0 (2017)



Health Information and Quality Authority

NATIONAL STANDARDS FOR

Information Management in Health and Social Care

2024

Safer Better Care

V2.0 (2024)

Approach

Undertake an **evidence synthesis** of arrangements in place for national health and social care data collections.

1

Complete **gap analysis to identify where changes** to the standards are required.

2

Convene an **Advisory Group** to provide feedback on the evidence synthesis and draft standards.

3

Undertake a **Public consultation and target consultation.**

4

Send national standards to **minister for approval.**

5

Principles underpinning the National Standards

- HIQA’s principles-based framework is used for the development of all national standards.

- Standards are presented under the four principles:
  - a human rights-based approach
  - safety and wellbeing
  - responsiveness
  - accountability

Overview of information management standards

1.1 Uphold people’s rights relating to information

1.2 Protect privacy and confidentiality

2.1 Optimise the accessibility, use and value of information

2.2 Undertake effective stakeholder engagement

3.1 Align with best practice regarding standards and agreed definitions

3.2 Enhance data quality

3.3 Ensure data security

3.4 Develop staff capability and capacity for information management

4.1 Develop strong organisational governance, leadership and management

4.2 Implement strategy for information management

4.3 Promote effective performance assurance and risk management

4.4 Ensure compliance with relevant legislation and codes of practice

Supporting documents x3

Self-Assessment Tool

1.

Self-Assessment Tool

Health Information and Quality Authority

DRAFT NATIONAL STANDARDS FOR
Information Management
in Health and Social Care

Safer Better Care

Purpose: To determine the extent to which organisations are in compliance with the standards and identify areas of good practice and where improvement is needed

Assessment and Judgement Framework (AJF)

2.

Assessment and Judgement Framework

Health Information and Quality Authority

DRAFT NATIONAL STANDARDS FOR
Information Management
in Health and Social Care

Safer Better Care

Purpose: To set out **lines of enquiry** to assist organisations and reviewers in assessing compliance with the standards

Guide to AJF

3.

Guide to Assessment and Judgement Framework

Health Information and Quality Authority

DRAFT NATIONAL STANDARDS FOR
Information Management
in Health and Social Care

Safer Better Care

Purpose: To set out how compliance will be assessed and provide detailed guidance on on how organisations can achieve compliance to the standards

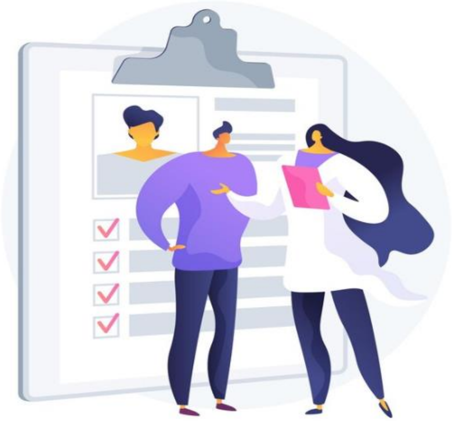
4

Revision of:

- National Standard for a Demographic Dataset for Health and Social Care
- National Standard for Hospital Discharge Information

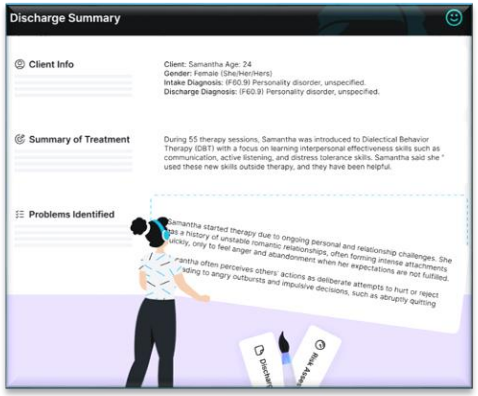
National Health Information Standards

- For information to flow in and between health and social care systems, it needs to be collected, organised and recorded in a consistent way every time.
- We are working collaboratively to set health information standards that outline what information needs to be gathered in a particular situation, or 'use case' (e.g. GP referral to outpatient department) and a standardised way to record this information.
- These standards are fundamental to support the move from fragmented, often paper-based systems to seamless interoperable digital systems.
- Work programme will be informed by engagement with stakeholders, the EHDS regulation and relevant legislation and strategies developed by the Department of Health in order for Ireland to meet the requirements of the EHDS regulation.



National Standard for a Demographic Dataset

National Standard for Hospital Discharge Information



Discharge Summary

Client Info

Client: Samantha Age: 24
Gender: Female (She/Her/Hers)
Intake Diagnosis: (F60.9) Personality disorder, unspecified.
Discharge Diagnosis: (F60.9) Personality disorder, unspecified.

Summary of Treatment

During 55 therapy sessions, Samantha was introduced to Dialectical Behavior Therapy (DBT) with a focus on learning interpersonal effectiveness skills such as communication, active listening, and distress tolerance skills. Samantha said she " used these new skills outside therapy, and they have been helpful.

Problems Identified

Samantha started therapy due to ongoing personal and relationship challenges. She as a history of unstable romantic relationships, often forming intense attachments uickly, only to feel anger and abandonment when her expectations are not fulfilled.

antha often perceives others' actions as deliberate attempts to hurt or reject ading to angry outbursts and impulsive decisions, such as abruptly quitting

Revised Draft National Standard for a Demographic Dataset
Aim, purpose and composition

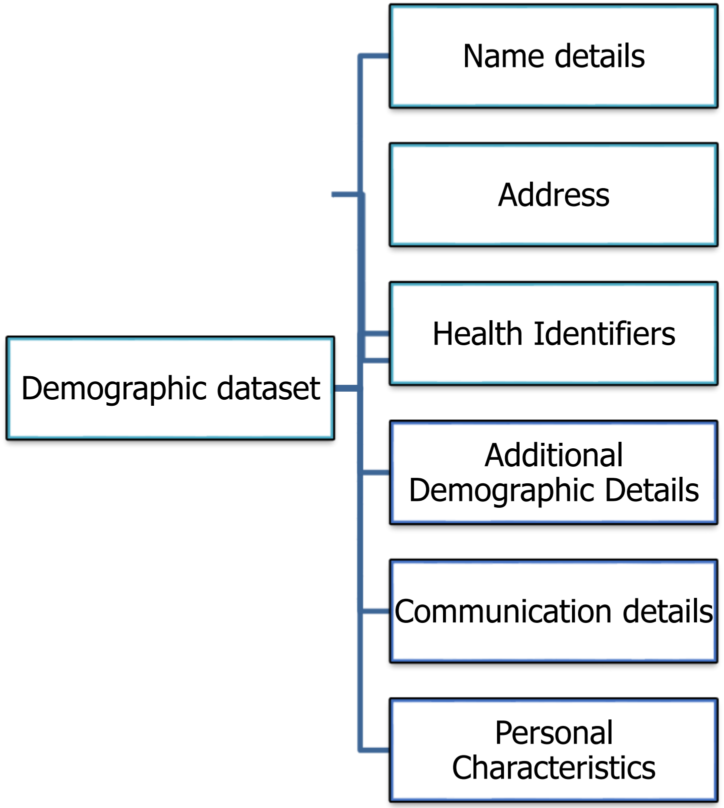
Aim:

The National Standard for a Demographic Dataset for Health and Social Care defines the core set of data elements required to identify an individual uniquely, in order to provide safe, quality care and support.

Purpose:

The standard aims to promote safe, quality care and support by:

- ensuring that an individual using services is identified correctly, and all of their health information is correctly associated with them.
- assisting service providers to collect standard core demographic data about individuals using their services for:
  - Administrative functions
  - Service planning
  - Clinical purposes
  - Secondary use


Demographic dataset

Name details

Address

Health Identifiers

Additional Demographic Details

Communication details

Personal Characteristics

Health information standards
Structure and content

- **Data elements**
- **Description**
- **Conformance or optionality** (identifying whether data elements are mandatory, required if available or options)
- **Cardinality** (the number of instances)
- **Value sets** (identifying existing international standards such as ISO and SNOMED standards and defining how data should be captured if no international standard exists)
- **Guidance for use** (providing examples or how to use the standard in practice in an Irish context)

Revised Draft National Standard for a Demographic Dataset Stakeholder input

- 6-week public consultation in June - July
- 46 responses
- Submission from **Pharmaceutical Society of Ireland**
  - Positive regarding guidance, conformance and cardinality
  - Potential challenges regarding implementation:
    - Legislative misalignment – pharmacies are subject to multiple legislative requirements
  - What will support the standard in practice?
    - Education and training
    - Practical resources for example case studies

Draft Revised National Standard for a Demographic Dataset Next steps

- Refine draft standard based on stakeholder feedback
- Bring updated draft standard back to Standards Working Group
- Testing of standard
- Final standard submitted to Minister for Health for approval

Revised Draft National Standard for Hospital Discharge Information

Aim, purpose and composition

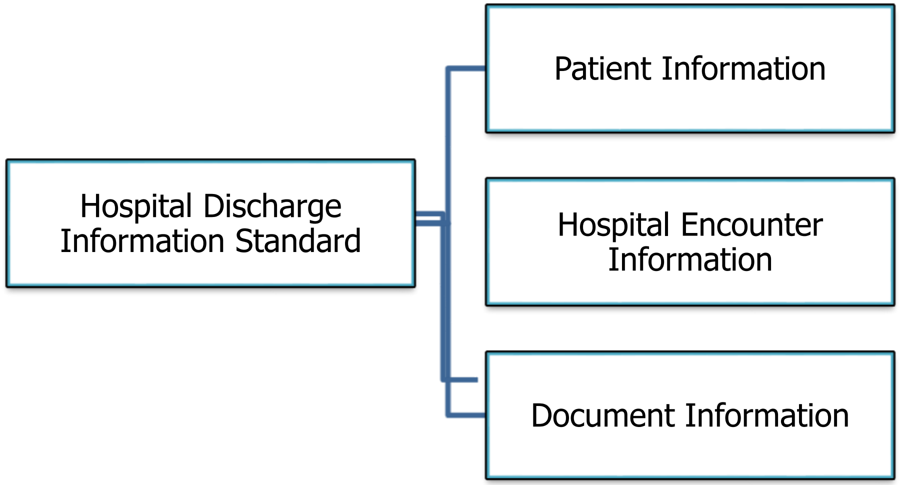
Aim:

The National Standard for Hospital Discharge Summary Information defines the core set of data elements, required when a person is discharged from an acute hospital back to the care of their primary healthcare professionals, in order to provide continued safe quality care and support.

Purpose:

The standard aims to promote safe, quality care and support by:

- Ensuring the relevant and appropriate data elements are included in a hospital discharge dataset to ensure the correct information about the person is shared in a safe, appropriate and timely manner in order for ongoing care be provided.
- Providing guidance on how data elements should be defined, structured and documented.



Hospital Discharge Information Standard

Patient Information

Hospital Encounter Information

Document Information

Revised Draft National Standard for Hospital Discharge Information

Next steps

6-week public consultation due to commence at the end of September

Refine draft standard based on stakeholder feedback

Bring updated draft standard back to Standards Working Group

Testing of standard

Final standard submitted to Minister for Health for approval

Questions?

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Thank you

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Information
and Quality
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