





## **Opening Remarks**

Speaker:



Theresa Barry
Data & Clinical Terminology
Architecture Lead, HSE





## Inputs from the Audience: March Playback session

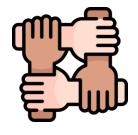
Q1 – What would you like to know more about? (Top 6)

- Data Quality
- Data Standards
- Data Governance
- Health Information Bill
- Data Dictionary
- > EHDS



Q2 – Would you like more information on HSE specific projects? (Top 3)

- Shared Care Records
- Community Connect
- HSE Health App



Q3 – Is there any other topic or project you would like more information on? (Top 6)

- > Al
- Data Harmonisation
- Data Governance
- Incorporating IHI in pre-existing systems
- > PPS requirement for hospitals
- Data Quality





## Agenda for July Playback Webinar





Session duration: 1 hr, 10 AM-11AM

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Session	Duration	Speakers
Hear from CDAO 1. Data Strategy & Al Strategy	15 mins	Tom Laffan
EHDS and MyHealth@EU	15 mins	Eamonn Coyne
MyHealth@IE: HSE App & NSCR	15 mins	Kathryn Kissane
Central Terminology Service & Data Dictionary Update	10 mins	Theresa Barry
Closing Remarks	5 mins	Theresa Barry



## Hear from CDAO

**Data Strategy & Al Strategy** 

Speaker:



Tom Laffan
Chief Data and Analytics Officer
(CDAO) , HSE



#### Digital For Care for Ireland 2030 – Data Strategy and Artificial Intelligence (AI) Strategy Updates



The framework sets out how the future of healthcare will harness the power of data, digital technology, future technologies, and innovation, to widen access to health and social care services, provide improved, affordable, and equitable care, better patient safety and boost productivity.

In **development** this Data Strategy will position Data as the cornerstone of our operations, empowering us to make informed decisions, optimise patient care, and drive innovation across our services.

In **Draft**, the DoH and HSE have jointly commissioned AI for Care which outlines the vision for AI in the health service and opportunities for AI deployment over the next five years.

In **Draft**, an AI implementation framework for implementing AI projects with robust governance and regulatory adherence specifically to the EU AI Act.

## HE Data Strategy - DRAFT

#### Approach:

- A use-case based approach has been taken: stakeholders have outlined strategic objectives and priorities where data-related challenges have impacted the ability to achieve these.
- Stakeholders consulted to date have included Regional leadership at REO and IHA level, leadership across central enabling functions, leadership of selected digital programmes, teams across a broad range of focus areas for the HSE such as workforce planning, disability services and organisational culture, and HSE teams that have a current role in data management. External bodies such as DoH, DCEDIY, HIQA, HRB, MHC, IPPOSI and NOCA have also been engaged.
- A review of legislation has been completed to assess the impacts of current and planned legislation

The current draft of the strategy outlines four strategic pillars focussed on:

Data Governance and Management

**Culture and Capability** 

Insights, Efficiency and Productivity

**Research and Innovation** 

- For each pillar, a set of use-cases are outlined, in addition to a **set of commitments** that will be delivered to simultaneously develop the capability of the CDAO office and address these use cases.
- An indicative timeline for delivery of the commitments is outlined in the strategy showing delivery in year 1 to 2, year 3 to 4, and from year 5 onwards.
- A data management plan is being developed in parallel with the data strategy to outline how these commitments can be met, and an analytics operating model will be created to ensure effective governance, resources and processes are in place.
- A data architecture design is being developed in parallel with the Data Strategy



## Data Strategy – Patient Journey (DRAFT)

The **patient** journey illustrated below demonstrates the future state data-driven and supported management of patient care, highlighting some of the ways this Data Strategy's commitments will enable and improve integrated care delivery. Improved data integration, interoperability and multidisciplinary care collaboration are enhanced by technology and patient self-management using digital tools.

#### **Patient Journey**



 Mary attends her GP with abdominal pain  Mary provides her Personal Public Service Number (PPSN)  Mary's GP orders diagnostic imaging and blood tests, tagging her order to her IHI Mary provides her PPSN on arrival to the ED, which allows the hospital staff to access all of her medical history

 All documentation related to Mary's care journey is stored in her Electronic Healthcare Record (EHR)

 Mary is discharged home and her GP and the National Shared Care Record (NSCR) supports the continuity of her care in the community



Strategic Pillar

**Culture and Capability** 

Governance and Management Governance and Management Governance and Management Insights, Efficiency and Productivity

HSE Data Strategy Enabler

Strive to develop a culture in which everyone takes ownership of the quality of the data they record, such as the PPSN Collaborate with national programmes to identify and support data requirements (e.g. integration of the IHI) Transitions of care are supported by the collection of the PPSN between care settings, building trust in data and supporting patient safety

Large transformative programmes such as the EHR are engaged with to identify and support data requirements Leverage the standardised data that will become available as national digital programmes progress

Impact on Patient Outcomes and Experience

Using the PPSN to accurately locate an IHI ensures the correct assignment with the correct IHI, promoting patient safety IHI integration improves patient safety through improved accuracy in patient identification.

improved patient care and reduced duplication Enhanced integration leads to reduced manual efforts/workarounds, which facilitates improved decision making The EHR improves the quality and efficiency of care, reduces medical errors, enhancing patient safety. It streamlines workflows, improve communication, and facilitate improved data management

A centralised data model with agreed interoperability standards to support integration of patient records across care settings will enable better patient care and ultimately outcomes



## Data Strategy – Healthcare Professional Journey (DRAFT)

The illustration below captures some of the ways in which a digital enabled healthcare service allows staff to provide high quality care services to patients in an efficient and holistic manner by leveraging a data driven approach to healthcare delivery. Information is shared between care providers in various settings, leading to better informed decisions, improved patient outcomes and the ability to build trust in the quality of our data.

#### **HCP Journey**



- Mark is a cardiologist, reviewing a patient at the local Chronic Disease Integrated Care Hub
- Upon presentation, the patient registers their details including their PPSN
- 3. Mark accesses the patient's medical history and notes via the NSCR
- 4. Mark refers the patient for diagnostic investigations
- 5. Upon return to the Integrated Care Hub the patient provides their PPSN and all patient information can be viewed on the NSCR
- 6. Mark is empowered to utilise cardiovascular registries to enhance clinical decision making and enable personalised care

#### Strategic Pillar

**HSE Data** Strategy Enabler

**Culture and Capability** 

Governance and Management

Governance and Management

Insights, Efficiency and Productivity

Research and Innovation

Strive to develop a culture in which evervone takes ownership of the quality of the data they record, such as the PPSN

Design and implement a centralised data model with interoperability standards

Collaborate with national programmes to identify and support data requirements (e.g. integration of the IHI)

The ability to analyse integrated data sets is available, increasing productivity and efficiency across the system

Identify and establish the data capabilities required to support development and management of registries

Impact staff experience

Using the PPSN to identify a patient. healthcare providers can accurately match information across different systems and services, improving efficiency and reducing errors

Integrated platforms lead to improved communication and coordination. streamlined workflows. enhanced patient outcomes, and greater iob satisfaction for **HCPs** 

Integrated IHI allows for seamless referrals and consultations between different providers, simplifying the process for both the HCP and the patient

Integrated systems optimise the use of system resources by improving patient flow and reducing unnecessary administrative burden

Facilitate improved management and care for patients with Chronic Diseases via proactive management



## Al Strategy and Implementation Framework



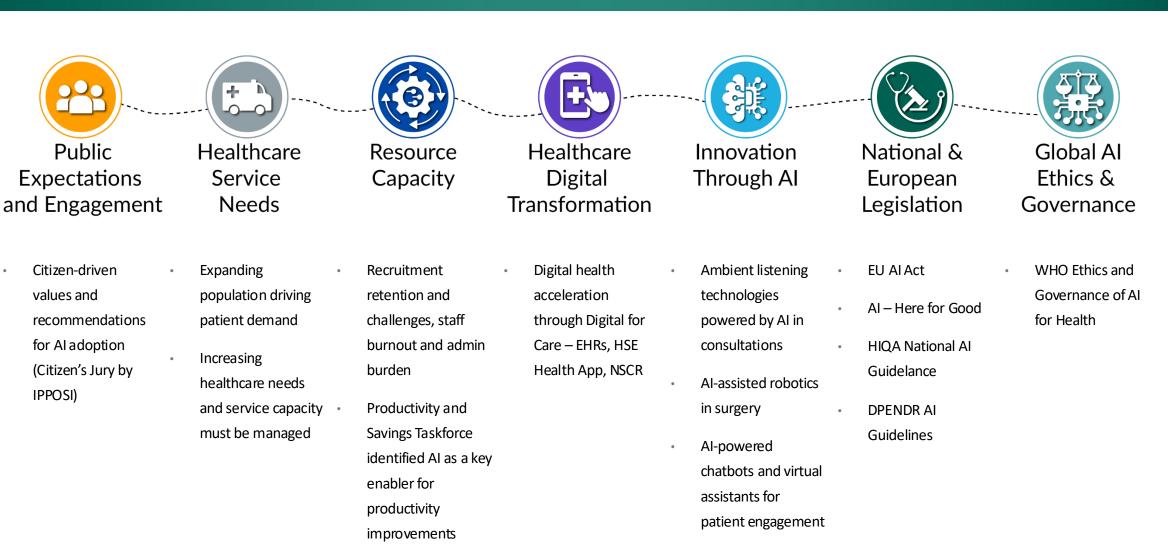
The development of an Al Strategy that sets the vision for Al and strategic priorities, the strategic roadmap of opportunities for Al deployment across the health service over the next five years, and critical success factors to activate and achieve our vision.



The development of a supporting AI Implementation
Framework to outline how to execute the AI Strategy and provide a framework for implementing AI projects with robust governance and regulatory adherence specifically to the EU AI Act.



## Healthcare Drivers for Artificial Intelligence (AI)





#### Al for Care Strategic Pillars

A shared set of objectives to achieve our Al Vision and focus areas of Al deployment opportunities that build the AI Strategic guide all stakeholders



#### Al for Clinical

We will use AI to enhance the quality of clinical care, empowering clinicians so that patients receive faster treatment, and care that meets their needs



#### Al for Operations

We will use AI to improve system efficiencies and boost productivity: helping to shorten wait times, streamline patient pathways, and ensure coordinated and responsive care



#### Al for Research & Innovation

We will use AI to advance research and innovation and develop targeted insights; supporting the development of new treatments, diagnostics, and therapies that lead to better health outcomes. We will also leverage Al to provide insights to drive service improvements



#### Al for **Public Health**

We will use Al to strengthen public health initiatives; helping to detect health risks earlier. support healthier lifestyles, and deliver more targeted prevention efforts that improve wellbeing across communities

#### Al for Care Guiding **Principles**

Fundamental guardrails throughout the AI Strategy and any future Al initiatives

## Person-

Centric



Transparent & Trustworthy

## 3

Human in the Loop

Lived Experience



Governance & Safety



Proven Benefits

#### **Al Strategic Outcomes**

The best practice for healthcare improvement

Enhanced care experience



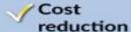
Better staff experience



Advanced health equity



Improved population health





## **Al Implementation Framework**

#### A Responsible and Safe AI Implementation Framework

To ensure the safe and responsible implementation of AI projects, the framework sets out requirements for compliance with the EU AI Act, clinical safety, trustworthiness, and risk management. The framework outlines the compliance steps, which include evaluating AI use based on risk categories, conducting fundamental rights impact assessments, and registering AI solutions in an AI inventory.

EXPLORE DELIVER DEPLOY



#### Opportunity Identification & Prioritisation

In the lifecycle refers to opportunity identification and prioritisation. This includes defining the opportunity for which AI will be used for, assessing that the problem is a suitable use case for AI and complies with existing data protection, clinical safety, ethical and EU AI act requirements.



#### Planning & Approval

In the lifecycle refers
to the planning and
approval process.
During this stage,
the project team will
perform an evaluation
around building an Al
solution for the specific
use case or buying an
existing available Al
product. The project
will then be approved
using the agreed
governance structure.



#### **Design & Readiness**

In the lifecycle refers to the creation of detailed plans around solution design, integration into existing systems, data collection, update of compliance documentation and change management plan creation.



#### Integration & Deployment

In the lifecycle refers to integration & deployment. This phase relates to the integration of an AI solution into relevant systems.



#### Operation & Monitoring

This is the final stage in the Al lifecycle and refers to the launch of the Al solution, benefits management and realisation, post market surveillance (for clinical projects) and ultimately potentially solution decommissioning.

RISK MANAGEMENT

GOVERNANCE



### Al Strategy and Framework - Partnerships

Partnerships are vital for the successful implementation of AI in healthcare. They bring together diverse expertise, resources, and perspectives, fostering innovation and ensuring comprehensive solutions.

#### Vendors

- The HSE will seek to leverage its existing partners' Al capabilities where appropriate and go-to-market to secure Al best-of-breed solutions where gaps are identified.
- Al vendors deliver advanced platforms that analyse healthcare data for actionable insights, improve diagnostics, personalise care, and ensure effective, secure solutions with ongoing support and updates.
- They provide advanced AI and machine learning platforms that can analyse vast amounts of healthcare data to generate insights, improve diagnostics, and personalise patient care.

#### Academic Partners

- The HSE will continue to partner with academic institutions and seek to publish academic papers on the outcomes achieved as part of individual healthcare. All projects to ensure the knowledge can be dispersed to other healthcare systems.
- Academic institutions and researchers drive innovation and provide foundational knowledge for developing advanced, evidence-based Al solutions, ensuring they are scientifically validated and enhance patient care and operational efficiency.



#### **Patient Advocacy**

- The HSE will continue to leverage its partnerships with patient advocacy and have patients with lived experience form part of AI project teams.
- Patient advocacy groups ensure patient needs and perspectives are central to Al solution development and implementation.
- Patient advocacy groups work with healthcare providers and AI vendors, and identify key areas for AI impact for patient journeys. Their involvement fosters trust and acceptance of AI technologies among patients, ensuring patientcentric solutions and successful adoption.

#### Regulatory Bodies

- The HSE will work closely with regulatory bodies to ensure that AI tools developed and deployed comply with healthcare standards and regulations.
- The regulatory bodies will provide regulatory oversight to ensure AI solutions and their deployment within the healthcare system meet legal requirements, fostering trust and reliability in AI technologies.







## EHDS and MyHealth@EU Digital for Care Webinar 16<sup>th</sup> of July 2025

Presenter:

Eamonn Coyne

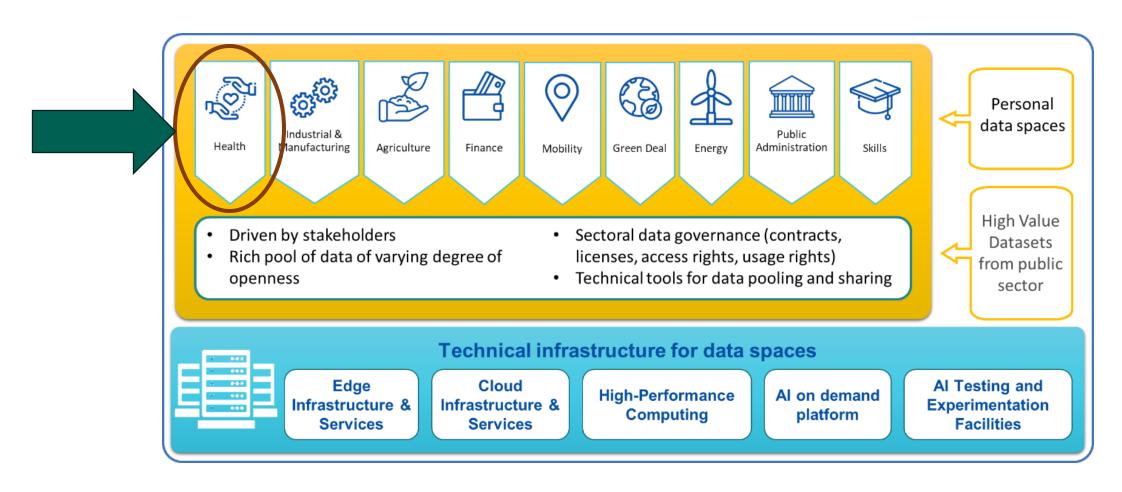
Role:

Digital Health Specialist, Assistant Principal, eHealth Unit DOH

Current MyHealth@EU eHealth Member State Expert Group Chair

## The vision: Common EU Data Spaces

 The Common European Data Spaces will help unleash the enormous potential of data-driven innovation. Common European Data Spaces will enhance the development of new datadriven products and services in the EU, forming the core tissue of an interconnected and competitive European data economy. Health is the first of these sectors to be delivered.



### The legal enablement:

## What is the European Health Data Space Regulation?

#### EHDS in a Nutshell –what is it about?

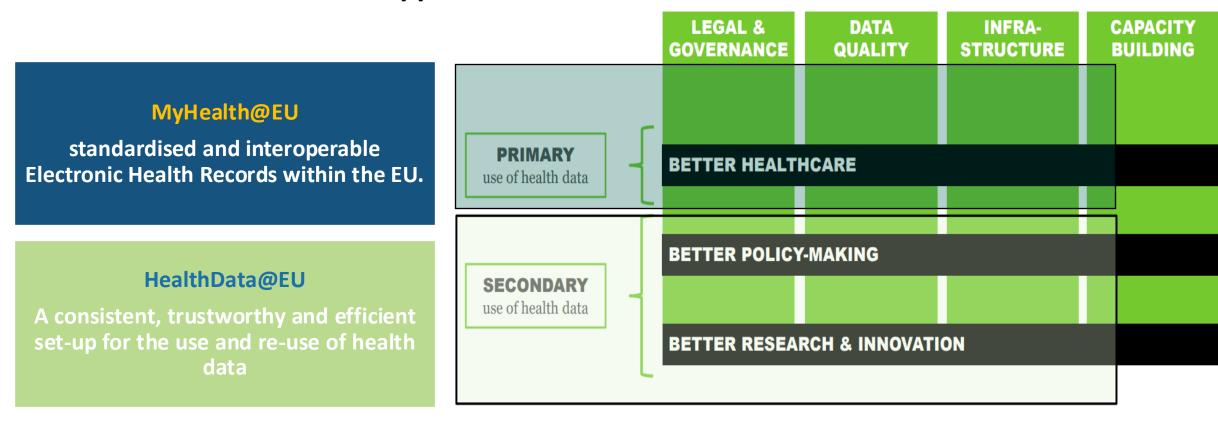
- 1. Primary use = use of data for the delivery of healthcare
  - \* Improving patients' access to their health data;
  - \* Ensuring seamless exchanges for continuity of healthcare.
- 2. Secondary use = use of data for research and public interest purposes

  \* Making data available for research, policy-making etc. in a safe and secure way.
- 3. Requirements for electronic health record (EHR) systems
  - \* Creating a single market for electronic health records systems, supporting both primary and secondary use.



# The building blocks: *How will EHDS be supported?*

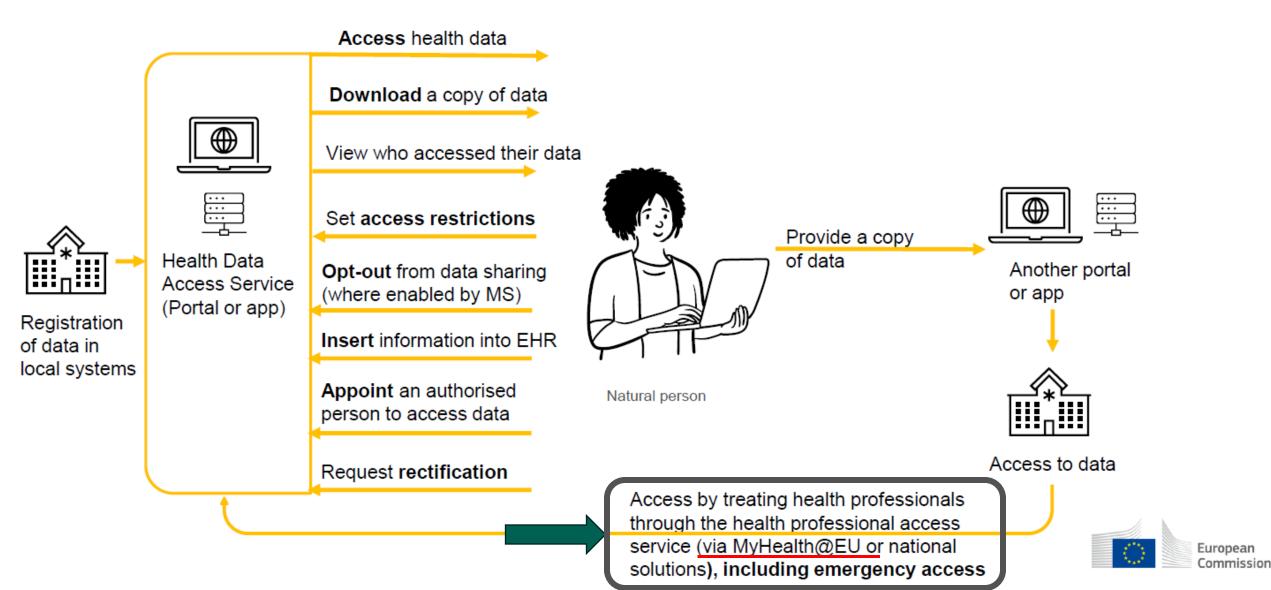
Two infrastructures will support access to electronic health information



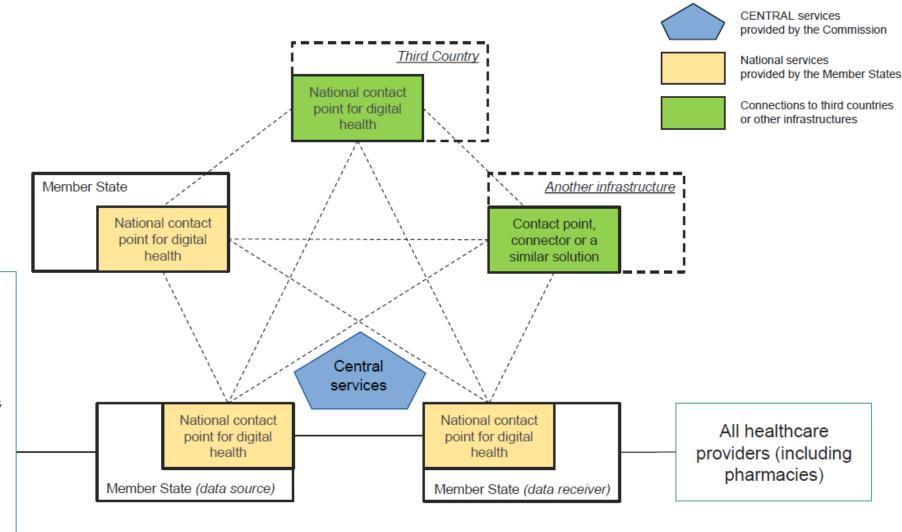
Through MyHealth@EU – each person will have access to their personal health records for medical treatment (in Ireland and the EU).

Through HealthData@EU – access to health datasets for public interest uses.

# EHDS: Rights of natural person in Primary Use



## MyHealth@EU High level architecture



#### Data categories

#### Priority group 1:

- Patient summaries
- ePrescriptions and eDispensations

#### Priority group 2:

- Medical test results: laboratory, other diagnostics, related reports
- Medical imaging: studies and reports
- Discharge reports

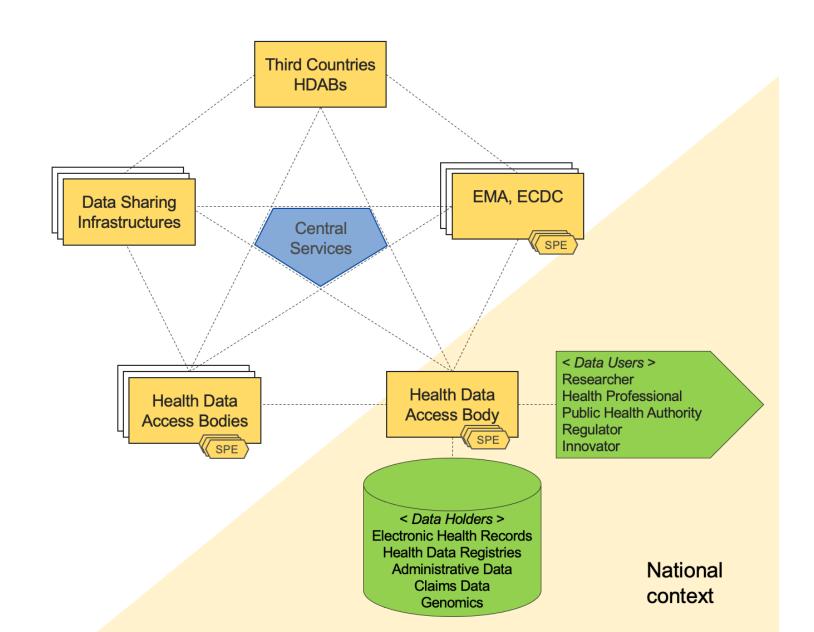
#### Additional data categories:

May be exchanged where supported

#### Data suppliers:

all healthcare providers.

## HealthData@EU High level architecture



Is MyHealth@EU being used now?:

Collaborative work, years in the making!

MyHealth@EU under Cross-border Healthcare Directive

 Voluntary system for exchanging patient summaries, prescriptions and dispensations (= first group of priority categories)

 15 countries live with at least one service, up to 10 more expected to go live with first service(s) this year

Evolution of MyHealth@EU for the EHDS

- Voluntary => mandatory
- New services
- New data categories

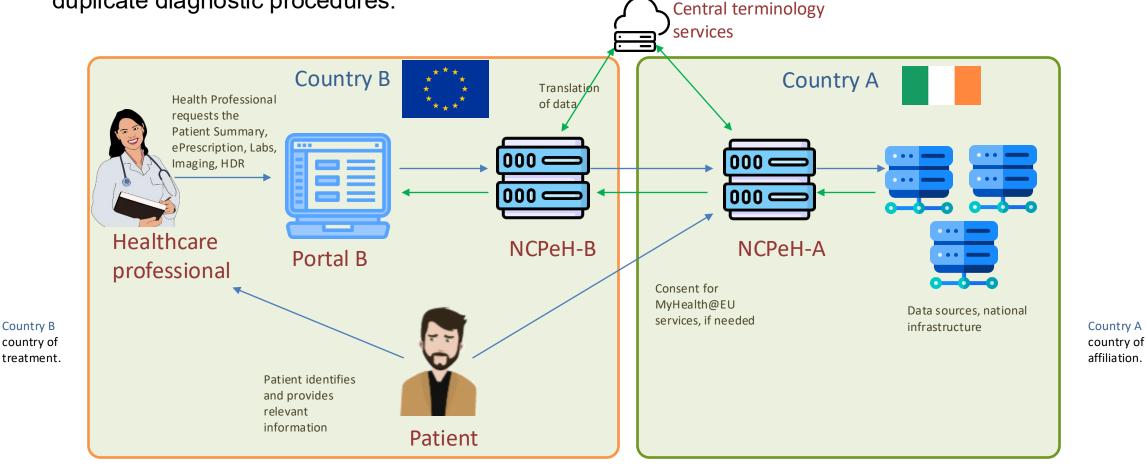


## How MyHealth@EU works: MyHealth@EU built on eHDSI



 The current MyHealth@EU infrastructure connects Member States National Contact Points for eHealth (NCPeH) giving healthcare professionals access to the patient's data via a Portal.

The health data is returned and displayed in the portal to the healthcare professional in their own
language thereby enhancing the patient's treatment. Reducing the potential for clinical errors and
duplicate diagnostic procedures.

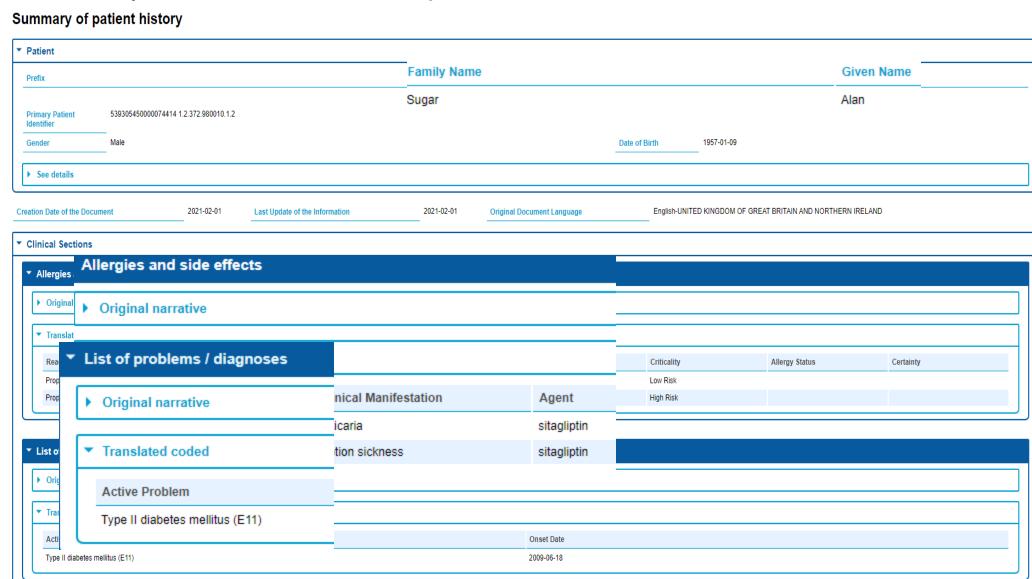


## How MyHealth@EU works: MyHealth@EU built on eHDSI

Here you can see how a healthcare professional can access healthcare data in real time.

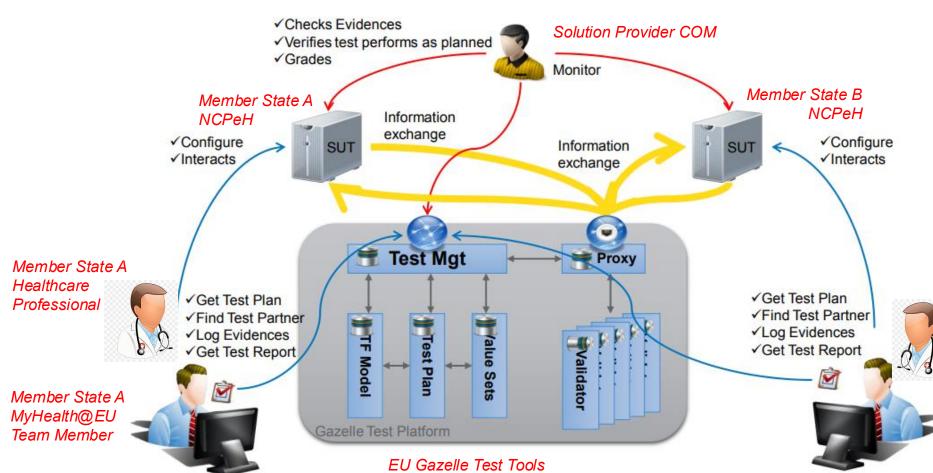
The Patient Summary Gives the Healthcare professional access to:-

- ✓ Patient Demographics.
- ✓ Allergies
- ✓ A List of Current Medical Conditions
- ✓ A History of Medication
- ✓ Implanted Medical Devices
- ✓ Surgical History



# MyHealth@EU: How do we know it works?

**Projectathon (interoperability) Testing Sessions!** 

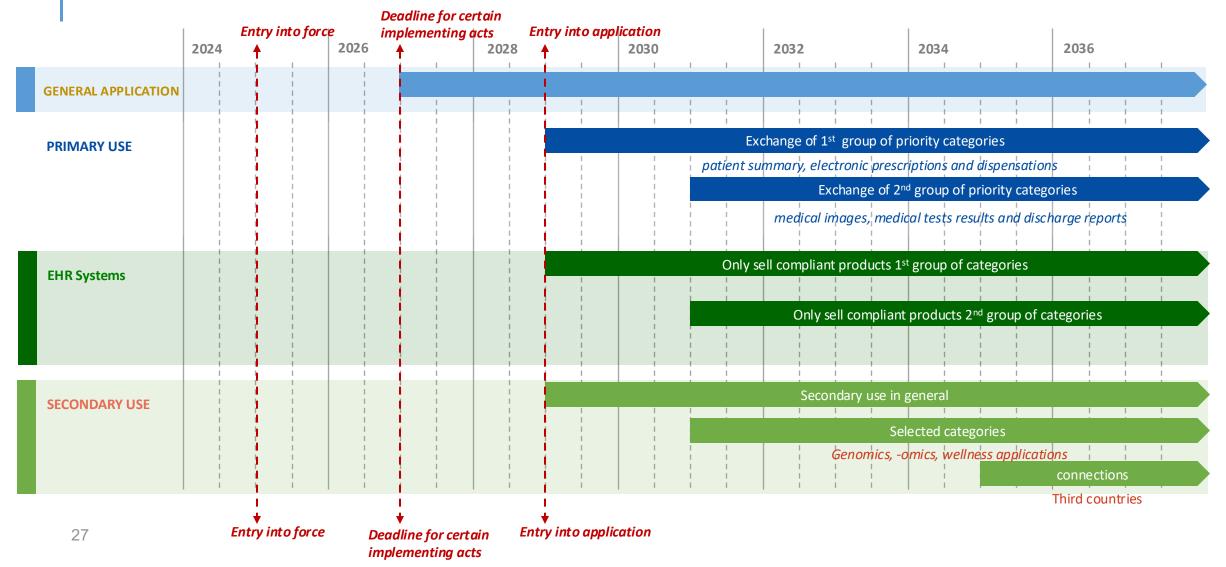


- √ Three test sessions per year
- ✓ Run for 5 weeks
  1. Registration and
  Connectivity 2/3.
  Conformance Testing
  4/5. Functional E2E Testing
- ✓ Continuous improvement and testing of Open NCP
   Artefacts and Member States
   NCPeH
- ✓ Member States working collaboratively to deploy the MyHealth@EU services

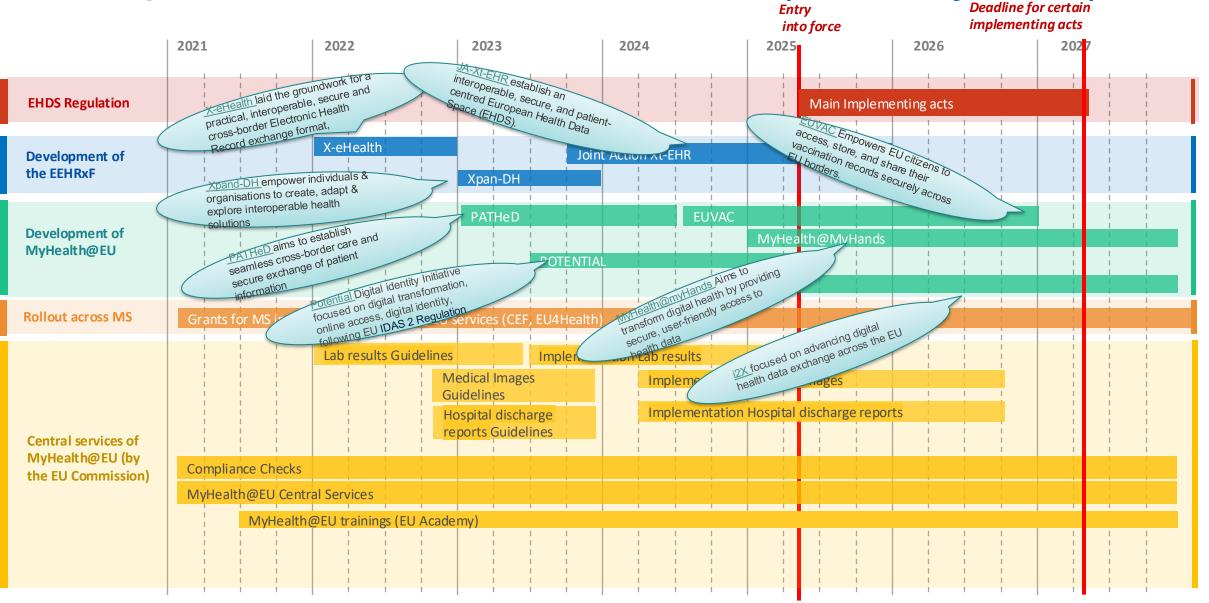
Member State B Healthcare Professional

Member State B MyHealth@EU Team Member

## EHDS – Overall timeline for application



## Implementation of the EHDS (Primary Use)



## Xt-EHR Expected Outcomes

(WP6)

**Patient Summary** 

(WP6)

New Services for

**EHR Systems** 

towards EHDS:

Discharge reports,

Medical test results and imaging studies

(WP7)

Current status of play in EHR and interoperability requirements



Services for the Electronic Health Record (EHR)

Implementation guides on EEHRxF, functional and technical requirements and specifications for EHR systems ePrescriptions and eDispensations

Sustainability and cross-border interoperability (WP4)

General, security and logging requirements for EHR systems, System Interfaces (WP5)



Classification and functional profiles of EHR systems guidelines (WP8)

EHR Conformity Assessment Scheme assertion document (WP8) EHDS guidelines for app developers of wellness applications in Europe (WP8) Cross-border telemedicine services under MyHealth@EU (WP9)

> Requirements for Large-Scale Uptake of Telemedicine Service (WP9)

Cross-border telemedicine services

Requirements, use cases and technical specifications on the availability of health data

Certification and labelling network

## Xt-EHR deliverables consultation periods

#### Tentative timeline for announcement and consultation phases per deliverable Announcement phase D9.1 Consultation phase D9.1 2025 Compilation of comments\* D9.1 Feb Oct Jan Mar Apr May Jun Jul Aug Sep Nov Dec D9.1 D9.1 D9.1 D8.3 D8.3 D8.3 D5.1 D5.1 D5.1 D5.2 D5.2 D5.2 D9.3 D9.3 D9.3 D9.2 D9.2 D9.2 D6.1 D6.1 D6.1 D6.2 D6.2 D6.2 \* After compilation of comments, D7.3 D7.3 D7.3 comments are shared with WP5-9. D8.1/8.2 D8.1/8.2 D8.1/2

D7.1

D7.2

D7.1

D7.1

D7.2

D7.2

WP5-9 address comments received

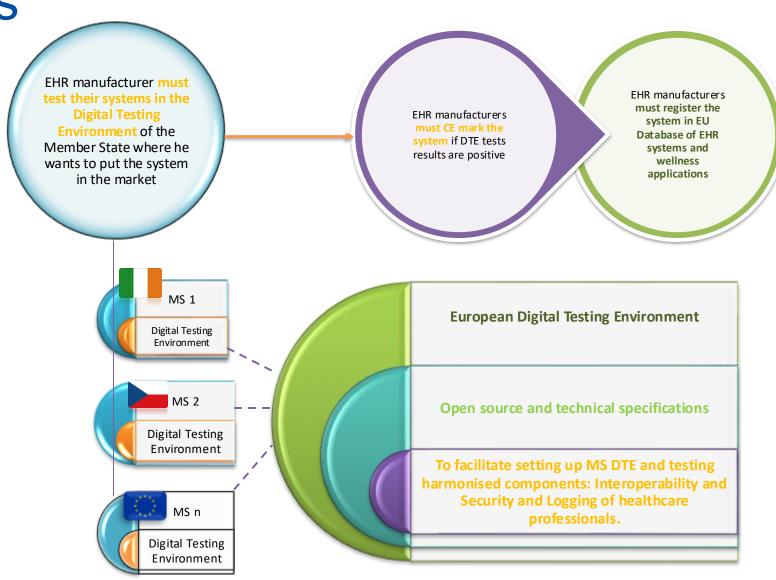
consolidated version of deliverable

on respective deliverable,

submitted to EC

New responsibilities of the EHR systems manufacturers

EHR manufacturer wants to put on EU market an EHR system which process data from one of the priority categories: ePrescription, Patient Summary, eDispensation, Discharge Letter, Medical images, Lab results



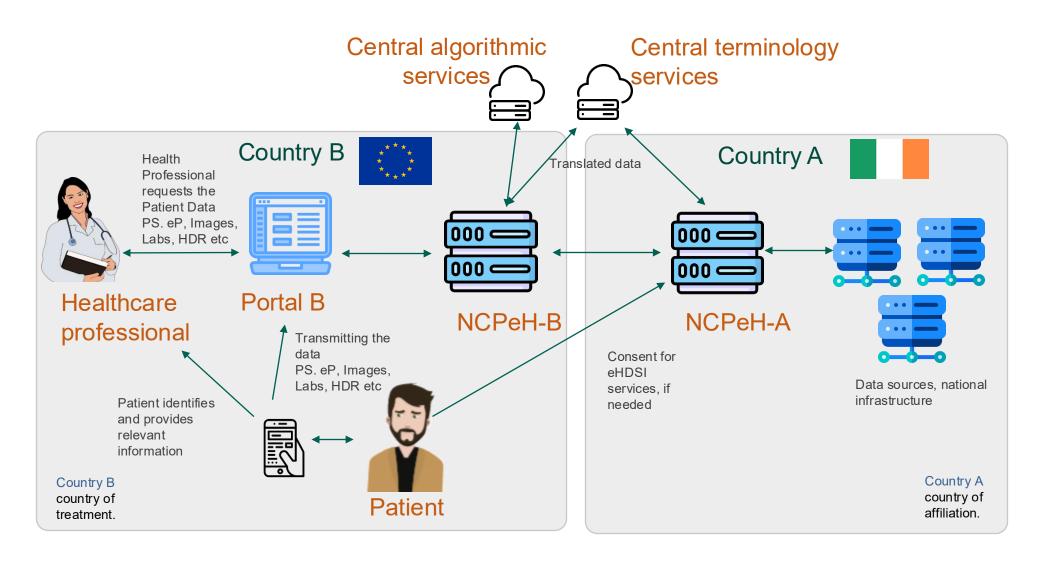
## Next steps...

 Ensure the Irish feedback and comments captured are included during the consultation period of these Xt-EHR deliverables which will be used to inform the Implementing Acts.

Currently this is being done with targeted Irish stakeholder consultation based on the relevant stakeholders identified through the Digital for Care conference/webinars lists...

## MyHealth@EU: Future State

A fully interoperable future state MyHealth@EU landscape.



# Future state: When we do!

Data travels with the patient for the patient

In line with EU Digital Decade Enhanced continuity of care

Moving to
Patient
Participatory
Care



Less clinical risk (duplicate tests and so forth)

Increased eHealth digital literacy of EU Citizens Access and control over their own health data

## Additional practical EHDS information...

 https://health.ec.europa.eu/latest-updates/frequently-askedquestions-european-health-data-space-2025-03-05\_en



## Thank you / Go raibh maith agat!

• eamonn\_coyne@health.gov.ie



## MyHealth@IE: HSE App & NSCR

Speaker:

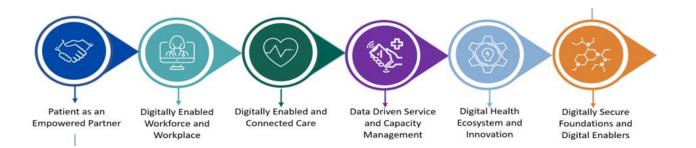


Kathryn Kissane
Deputy Delivery Director,
Engagement & Delivery,
Standards & Shared Care Records,
HSE





## MyHealth@IE Programme



Vision

To enable the sharing of standardised, interoperable digital health records for both healthcare professionals and citizens, nationally and across borders. We aim to enhance the clinician and patient experience to enable improved clinical decision-making and self-management of healthcare.

### **Products**

#### **HSE App**

A secure mobile App to give patients access to their own health information and to make it easier to manage their own health care.

#### **National Shared Care Record**

A digital record of a patient's key healthcare data aggregated from various electronic data sources and settings and presented to clinicians, patients and carers in a secure and structured way.

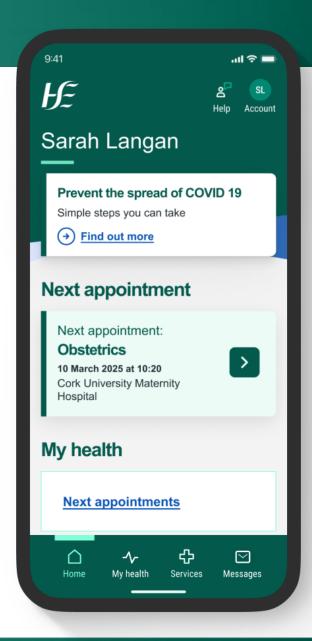
#### MyHealth@EU

Enabling exchange of digital health records between EU member states.



## One of the key initiatives under the Digital for Care Framework is the delivery of the HSE Health App

- The first version of the App gives users secure access to certain health information, COVID-19 and flu vaccination records, digital medications lists, medical cards and EHIC cards, all in one place.
- Expectant mothers are now also able to see some of their antenatal hospital appointment information in the App:
  - Appointment date and time
  - Clinic speciality
  - Clinic name, address and eircode
  - Clinic phone number and email address (where available)
- A target for 2025 is to display all Acute and Community Patient-Facing outpatient appointments made in iPMS in the App.





## Services in the App now, and Services to come

3 Major Releases yearly, with additional functionality added in each

#### 2025 - First public release

- myGovID integration
- IHI integration
- Certain Maternity appointments
- Self-declared medications
- European Health Insurance Card,
   Medical Card, Long-term Illness Card,
   Drug Payment Card, GP Visit Card
- Covid and flu vaccinations
- Urgent and emergency care signposting
- Health A to Z
- Support from HSE Live

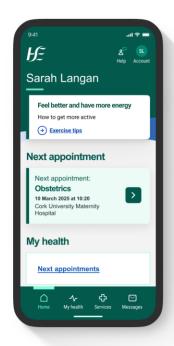
#### Sample future features

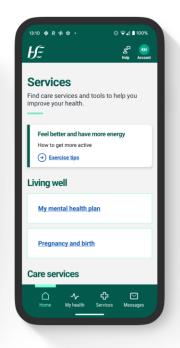
- Rollout of other appointments
- Telehealth appointments
- Notifications, alerts and reminders
- Chat with HSE Live
- Maternity care support
- Pre and post-appointment advice information and support

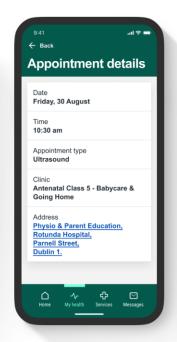
- Quit (smoking cessation) service
- Chronic disease management
- · Cancer self-care recovery support
- Diabetes self-care support
- Physical activity self-care service
- Wait times for urgent care
- · Wait times for scheduled care

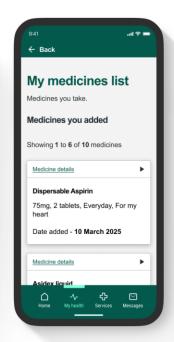


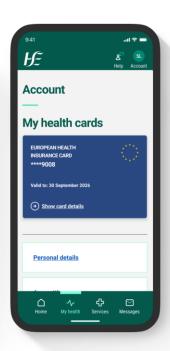
## **Screenshots of Current App Features**

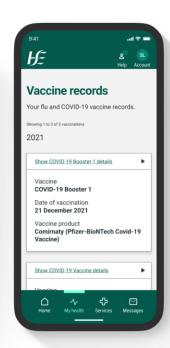












Easy to use, all your information in one place

Health, wellbeing and services information

Appointments, starting with maternity

Self declared and reimbursed medications

Digital cards like the EHIC and Medical Card Covid and Flu vaccine records



## Security and Privacy by Design

Security and privacy have been at the centre of all design decisions throughout the development of the app

- Access using verified MyGovID to make sure the right person gets the right information;
- Data protection and privacy best practice, including consultation with Data Protection Commission;
- Continuous security testing, auditing, monitoring and assurance.

#### Trusted content

We heard often that the information provided was valued because the HSE is a trusted source of public health information.

"It's accurate information because it's from the HSE"

"The biggest value of the app to me is having all my health information in one place and being able to access it easily"

9:41





### **HSE** health app

To log in to this app you need a verified MyGovID. This means we can securely share personal health information with you.

If you do not have a verified MyGovID, you will need to apply for one. Applications can take a number of days to process.

How to get a MyGovID - mygovid.ie

If you continue without logging in, you can use the app to find information about conditions and services.

Continue



## National Shared Care Record (NSCR) Update

- A Shared Care Record brings together healthcare information from various sources such as hospitals, GP practices, and Community care into a single place, making them available at the point of care and self-care.
- The result is a longitudinal record of key data covering the provision of care from primary to secondary and community care.
- The NSCR will help support compliance with the EHDS Regulation, and to meet Ireland's obligations under the EU Digital Decade.

#### "Patient at the centre"



A Shared Care Record is NOT an Electronic Health Record (EHR). It does not allow for adding or editing healthcare data, nor provide the level of detail that would be in a patient's paper chart.

## HE NSCR Discovery Phase

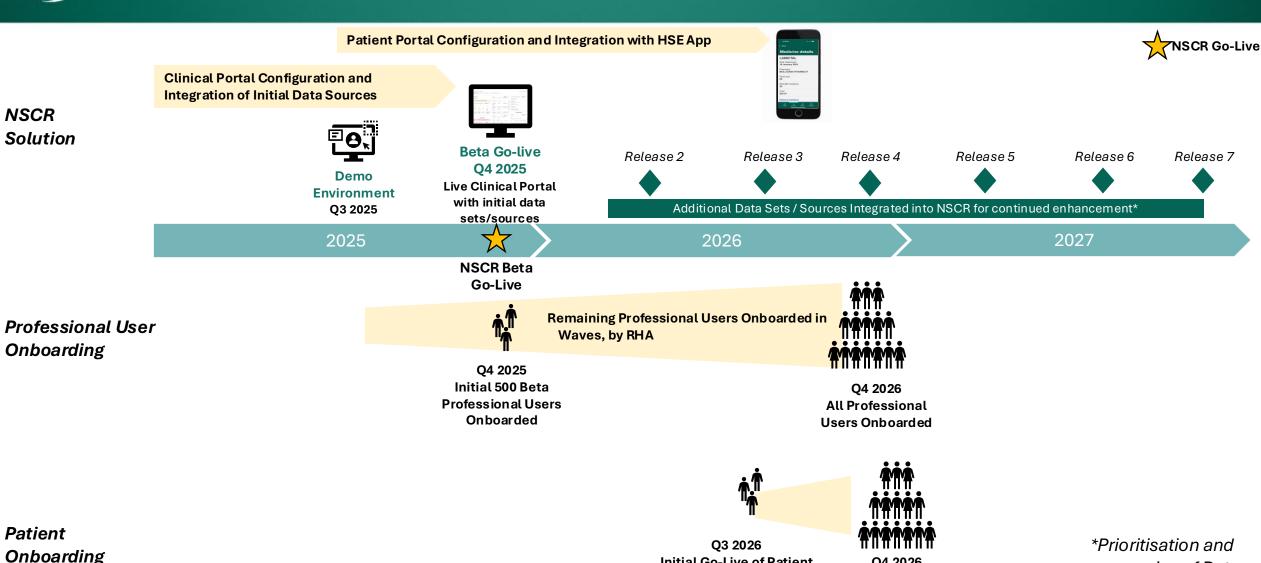
- 6 week Discovery Phase completed across four key workstreams: User and Service Blueprint, Technology, Data, and Programme.
- Broad range of representatives including clinical (medical, nursing, HSCP, CCIOs etc.), National functions (including multiple Technology and Transformation teams) and patient representatives.



- The **Programme has now moved to the delivery phase**, with further engagement continuing to understand key changes, prepare locations for implementation and proactively support staff to adopt and benefit from the NSCR.
- As the first location, Waterford and Wexford will be the key focus for this engagement, training and implementation preparation.



## **Draft High-Level NSCR Roadmap 2025 - 2027**



**Initial Go-Live of Patient** 

Portal including

integration with HSE App

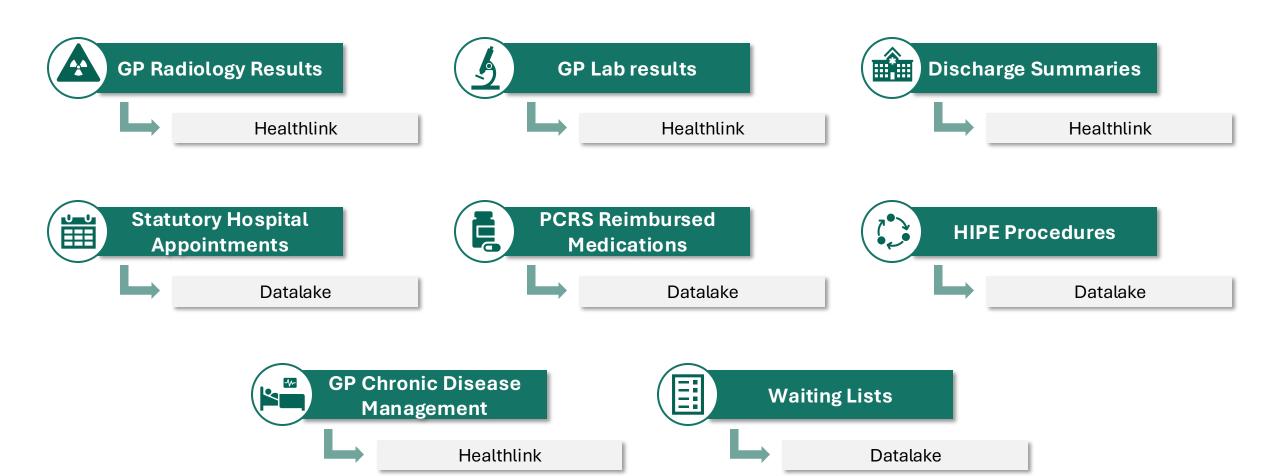
Q4 2026

**Complete National** 

**Go-Live** 

sequencing of Data Sets subject to change

## HE Target Data Sets & Sources for 2025





- IHA Waterford Wexford has been identified as the initial site for the roll-out of the National Shared Care Record (NSCR)
- We will invite 500 Healthcare Practitioners to have early access to the NSCR, providing training and support
- We will also identify local Change Champions to advocate, drive engagement, and support their peers
- Our goal is to gather feedback and learnings for our roll out at scale nationally in 2026





For further information about the App, please see the <u>HSE</u> <u>Health App</u> pages on the HSE website. The App can be downloaded from the App Store or Google Play.

For any queries on the National Shared Care Record, please contact <a href="https://www.nscalenesses.new.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalenesses.new.nscalene









# Central Terminology Service Data Dictionary

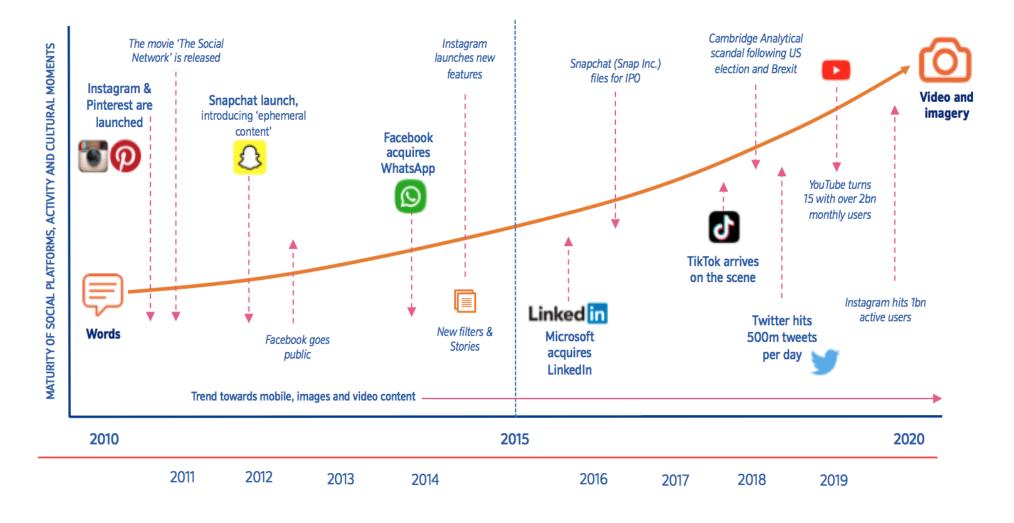


Theresa Barry
Data & Clinical Terminology
Architecture Lead, HSE





# HE The evolution of digital

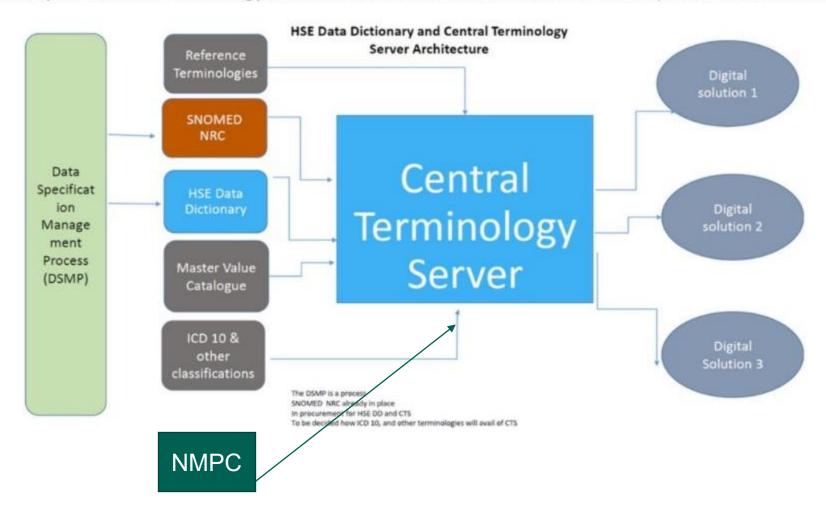


Healthcare is also changing rapidly



### **Planned Architecture**

There is currently no Central Terminology Service within the HSE. The future state is depicted within this diagram below:





# Standardised uniform process that facilitates new and existing dataset specification

Quality assurance process for new and existing dataset specifications

Opportunity for early input from downstream functions to enhance service planning, analytics and reporting

Reduction in re-work and costs due to errors and omissions in dataset specifications

## **Data Principles**

- •Data is an asset that has value to the enterprise and is managed accordingly.
- •Users have access to data necessary to perform their duties; therefore, data is shared across enterprise functions and organisations in accordance with legislation.
- •Data should be accessible for all users to perform their work. Users should have access to local and core national records relevant to their role and within legislative parameters.
- •Data is defined consistently throughout the enterprise, and the definitions are understandable and available to all users.
- •Each data element has a trustee accountable for data quality.
- •Semantic interoperability is achieved through the use of SNOMED CT in all clinical information systems.



## **LE** Key aspects of data standards in healthcare





# **SNOMED CT-Ireland and other terminologies**

Clinical Situations, Family histories & Lifestyle/Environmental Factors

ICD-10 Z Codes - Family history & social determinants of health ICD-10-AM - Used for disease classification in Ireland UMLS (Unified Medical Language System) -Integrates various health terminologies OPCS-4 (Office of Population Censuses and Surveys, 4th Edition) -Used for coding hospital procedures in Ireland SNOMED CT - Systematized Nomenclature of Medicine -Clinical Terms MedDRA (Medical Dictionary for Regulatory Activities) - Drug safety & adverse event tracking

Anatomy & Abnormal Body Structure

MeSH - Biomedical subject headings for anatomy ICD-10-Q Codes -Congenital malformations and abnormalities DICOM - Imaging for structural abnormalities OMIM (Online Mendelian Inheritance in Man) -Genetic disorder database SNOMED CT -Systematized Nomenclature of Medicine - Clinical Terms MedDRA (Medical Dictionary for Regulatory Activities) - Drug safety & adverse event tracking

Medical devices and Physical Objects

> **UDI (Unique Device** Identification) - Device tracking and safety GMDN (Global Medical Device Nomenclature) - Device classification system ISO 13485 - Medical device quality management standard **EUDAMED** (European Database on Medical Devices) - EU-wide device tracking **HPRA** (Health Products Regulatory Authority) -Irish regulatory body SNOMED CT -Systematized Nomenclature of Medicine - Clinical Terms

Medications & Substances

EMA (European Medicines Agency) -EU-wide drug regulation IMT (Irish Medicines Terminology) -Standardized medication terminology ATC (Anatomical Therapeutic Chemical Classification System) - Drug classification RxNorm - Standardized drug names and interoperability **HPRA** (Health Products Regulatory Authority) -Irish regulatory body SNOMED CT -Systematized Nomenclature of Medicine - Clinical Terms

Procedures & Interventions

CPT (Current Procedural Terminology) -Procedure billing and documentation DICOM - Imagingrelated procedures **HCPCS** (Healthcare Common Procedure Coding System) -Medical billing and reimbursement codes ICD-10-PCS (Procedure Coding System) - Hospital intervention coding SNOMED CT -Systematized Nomenclature of Medicine - Clinical Terms

Laboratory test & Specimen

LONIC (logical Observation Identifiers Names and codes) -Standardized lab test codes EQA (External Quality Assessment) - Ensures lab test accuracy LIMS (Laboratory Information Management System) - Pathology and lab management NHSN (National Healthcare Safety Network) - Surveillance for infections SNOMED CT -Systematized Nomenclature of Medicine - Clinical Terms

Diseases, Signs & Symptoms

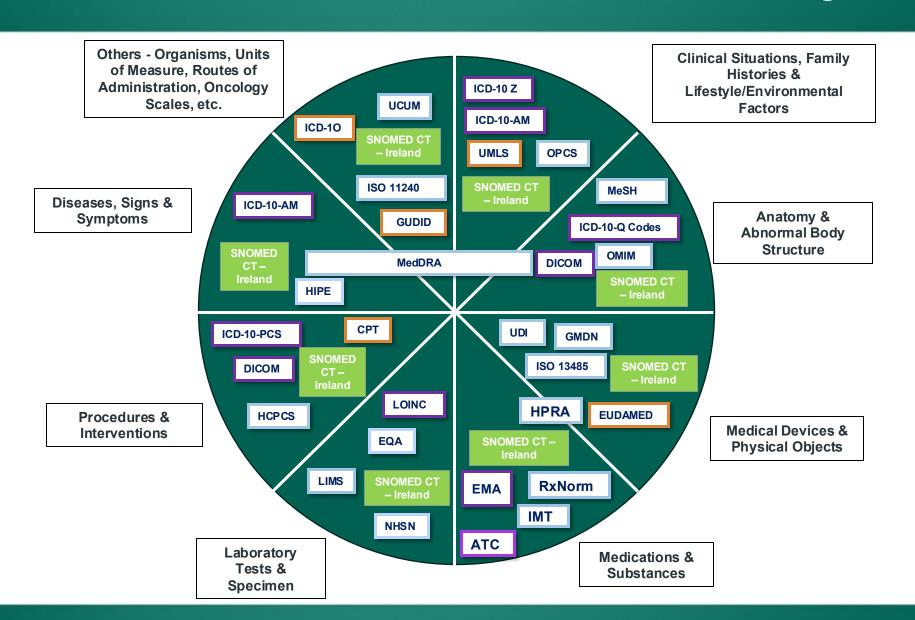
> MedDRA (Medical Dictionary for Regulatory Activities) - Drug safety & adverse event tracking HIPE (Hospital In-Patient Enquiry System) - Disease tracking in Irish hospitals ICD-10-AM -Disease classification system in Ireland SNOMED CT -Systematized Nomenclature of Medicine - Clinical Terms

thers

UCUM (Unified Code for Units of Measure) – Standardized measurement units ICD-O (International Classification of Diseases for Oncology) – Cancer classification ISO-11240 – Standards for medicinal product units of measure GUDID (Global Unique Device Identification Database) – Medical device classification SNOMED CT - Systematized Nomenclature of Medicine – Clinical Terms MedDRA (Medical Dictionary for Regulatory Activities) – Drug safety & adverse event tracking



### **SNOMED CT – Ireland and other Clinical Terminologies**



SNOMED CT
Collaboration
Partner

Agreement
in Progress

No
Agreements
in Place



**Data Quality** 





### Data Quality Dimensions (i~HD)



### A Harmonized Data Quality Assessment Terminology and Framework

- ▶ The assessment of data quality is divided into two primary techniques.
- Verification
  - ▶ Ensuring that the data values conform to internal expectations, metadata constraints, system assumptions, and local knowledge without relying on external benchmarks.
- Validation
  - Comparing data values against external benchmarks or gold standards to confirm their accuracy and reliability.
  - Accepted with external references or standards, providing a higher level of confidence in data quality.



Artificial Intelligence, research and analytics



## HE Al, research and analytics

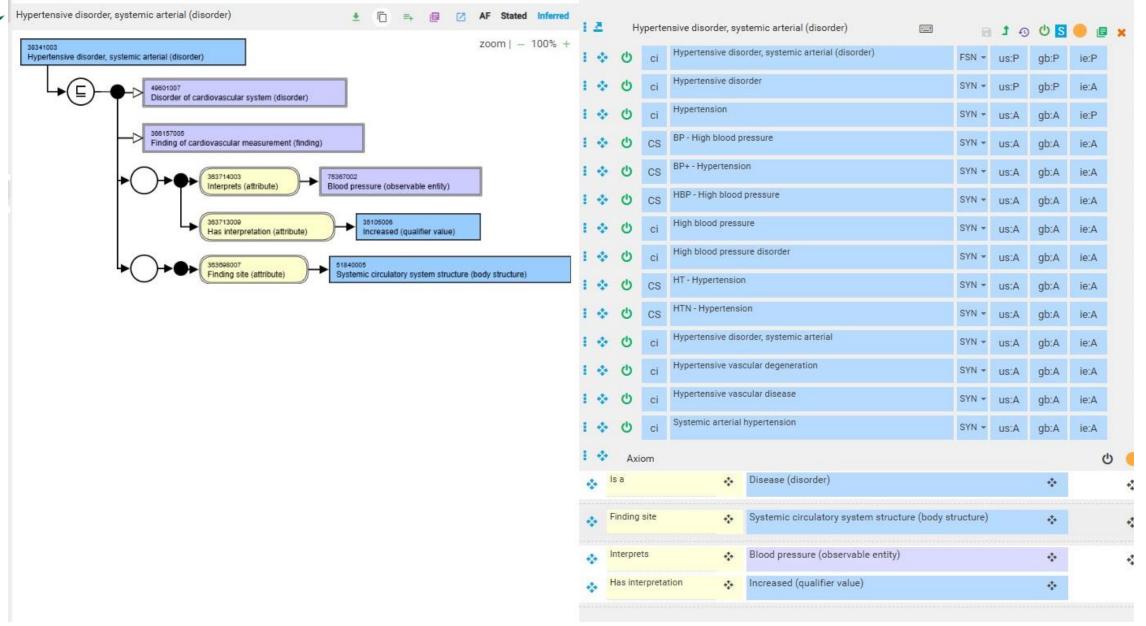
One way to tame a mess, whether it is a child's room, a woodshop or a swamp of data, is to have a place to put everything. **Data standards do this for data.** More importantly, they can do this for generative AI systems, allowing us human beings to address many of the legitimate concerns that have arisen since the widespread release of large language models (LLMs) and their host generative AI (Gen AI) systems like OpenAI ChatGPT, Microsoft Copilot<sup>™</sup>, and Google Bard<sup>™</sup>.

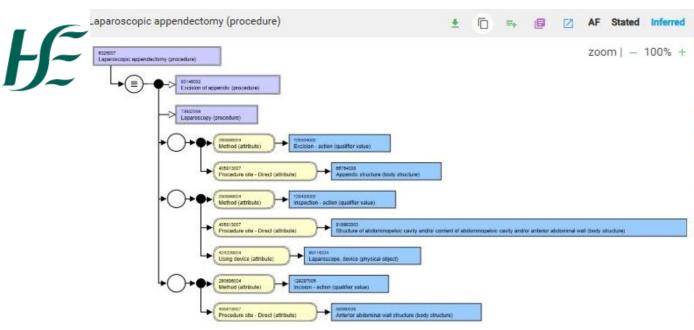
As we step into the era of advanced artificial intelligence, the question arises: do we still need data standards? With the advent of Gen AI, some have speculated that AI systems can make sense of virtually anything, rendering data standards and tagging of data in compliance reports obsolete. This alluring notion, however, does not hold true. In fact, the Age of AI makes data standards more critical than ever before.

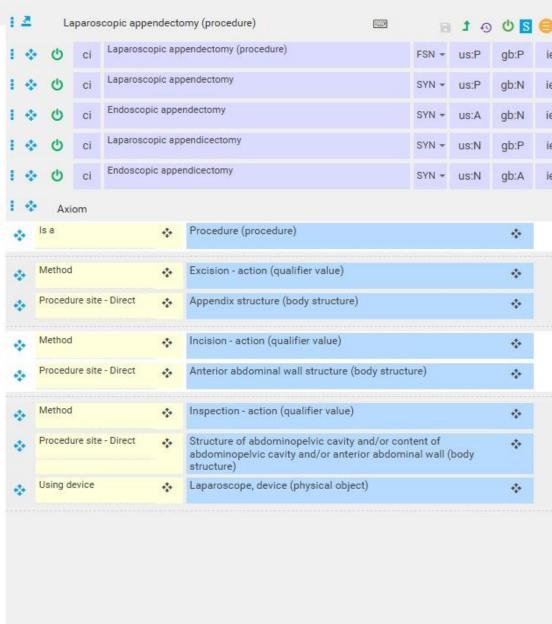
Data Foundation link





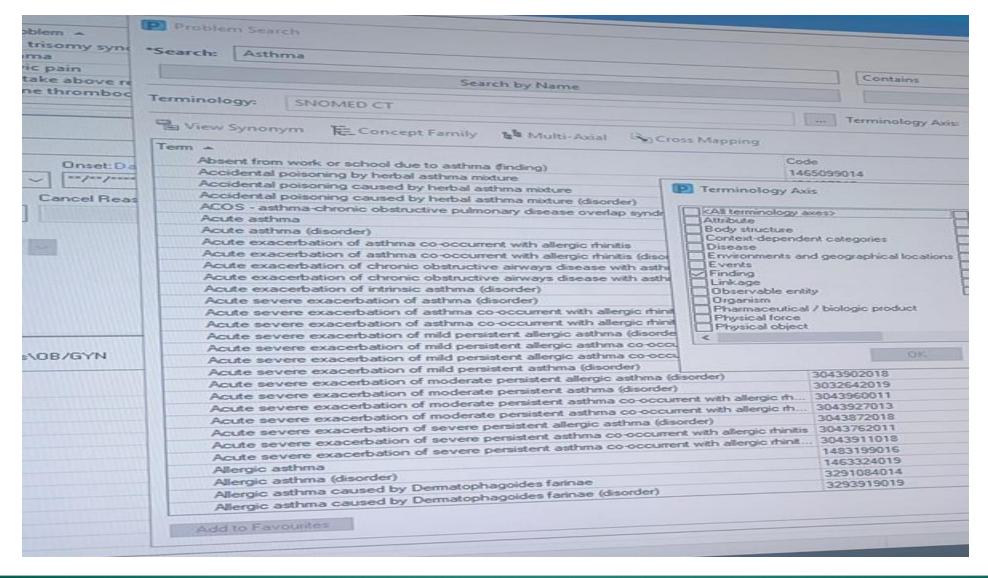








# Current User Interface in EHRs



**Vendor Specification** 

# Benefits of a Central Terminology service

**Enables Interoperability.** 

Centralizes Access to Standardized Health Terminologies.

Provides Pathways for Advanced Use of Terminologies

Supports Improved Collaboration

Information Modeling and Specification Development.

Fully Enabled FHIR Terminology Capabilities.

# **H** Central Terminology Server

- •Simplify the use of clinical terminology by addressing the key challenges faced by implementers.
- •Encourage vendors, jurisdictions, and other organisations to adopt terminology products and services in their solutions.
- •Provide a "one stop shop" for national specification code systems, and enable enterprises to create their own "one stop shop"
- •Improve collaboration between producers and consumers of terminology products and services.
- •Enable the realisation of the benefits of clinical terminology adoption

An API, or Application Programming Interface, is a set of rules and specifications that allow different software systems to communicate and interact with each other. It acts as a bridge, enabling one application to request and receive data or functionality from another application without needing to know the underlying details of how the other application works.

Instead (or as well as) delivering SNOMED CT as RF2 files; APIs, services and software are required as building blocks for implementers

- Lower the entry bar and learning curve, particularly for simple use cases
- Update process is simpler
- Less time working on boilerplate, more time to focus on the product
- Complex/powerful features enabled with little effort required



Fully Enabled FHIR Terminology Capabilities. Includes broad support for the <u>standard FHIR terminology</u> resources and operations. These capabilities include Search, Create, Read, Update, and Delete operations on ValueSet, ConceptMap, CodeSystem, NamingSystem, and StructureDefinition; as well as other terminology-specific operations such as \$expand, \$validate-code, \$lookup, \$subsumes, \$find-matches, \$closure, \$translate, and \$validate.

The Terminology Server provides access to CodeSystems, ValueSets, and other Terminology artifacts for International and Irish Terminologies, and Classifications, such as:

SNOMED CT
ICD-10

Others yet to be decided i.e

National Medicinal Product Catalogue

LOINC

DICOM

Orphanet



## Well-known Terminologies: SNOMED-CT & LOINC

- http://snomed.info/sct (/[edition](/version/[date])?)?
- Properties: all relationships, normalForm, moduleId ...
- Filters: relationships, subsumption, refset, ECL expressions
- Implicit ValueSets
  - All codes: http://snomed.info/sct?fhir\_vs
  - By subsumption: http://snomed.info/sct?fhir\_vs=isa/404684003
  - · List of refsets: http://snomed.info/sct?fhir\_vs=refset
  - All codes in a refset: http://snomed.info/sct?fhir\_vs=refset/734138000
  - All codes that match an ECL expression: http://snomed.info/sct?fhir\_vs=ecl/\*: 363698007 | Finding site | = 85562004 | Hand structure |
- Implicit ConceptMaps
  - Historical associations: http://snomed.info/sct?fhir\_cm=90000000000527005

- http://loinc.org(/[version])?
- · Properties: axes, STATUS, ...
- Filters: by multi-axial hierarchy, by part, ...
- Implicit ValueSets
  - All codes: http://loinc.org/vs
  - By multi-axial hierarchy: http://loinc.org/vs/LP14635-4
  - By Answer List: http://loinc.org/vs/LL715-4



What is included in the procurement





### Solution Overview

Framework requirements exceed Ontoserver alone, components include:

#### Ontoserver

- Indexing
- Authoring
- Staging
- Production

#### Snapper

- Lightweight FHIR authoring
- · FHIR security label aware

#### **OntoCommand**

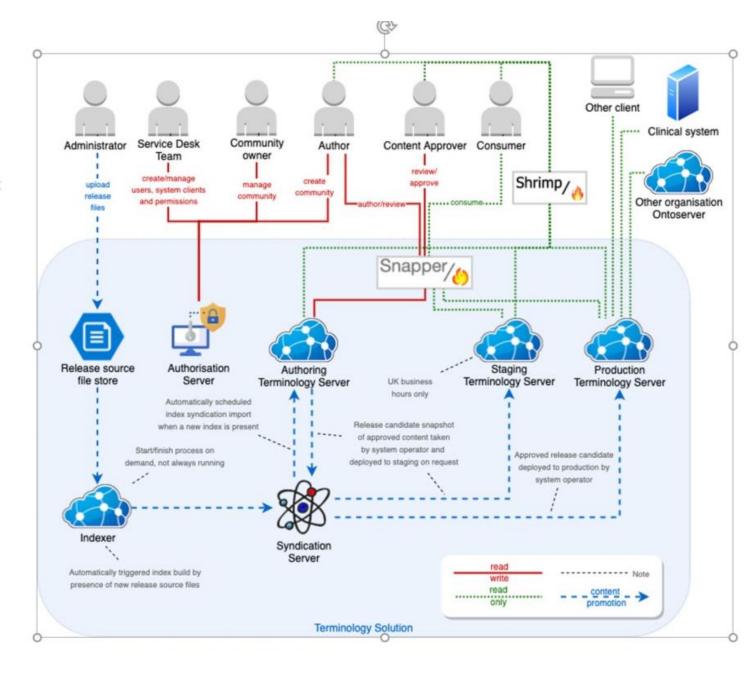
Administration UI

#### Ontocloak

- Authorisation
- Delegated and local authentication

#### **Atomio**

· Syndication server and store



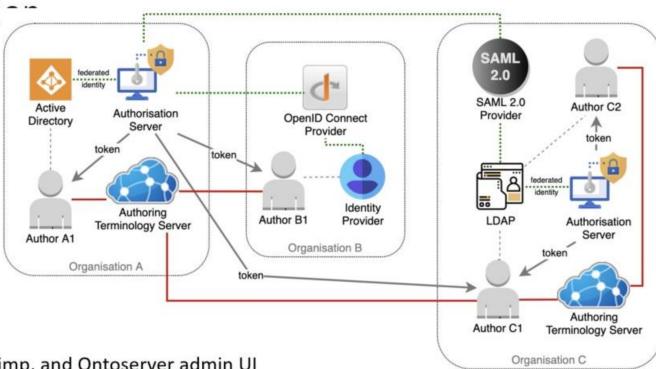


Identity and Authorisati

SMART on FHIR - OAuth 2.0

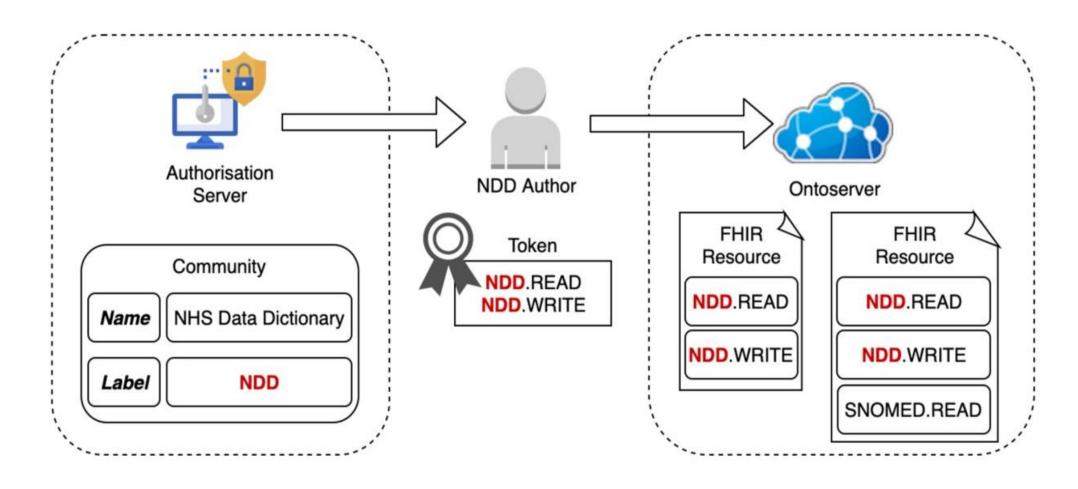
#### Ontocloak supplies

- Authorisation
- Delegated and/or local authentication
  - Open ID Conenct
  - SAML 2.0
  - AD/LDAP
- · Configured for SMART on FHIR with
  - Ontoserver, and
  - associated clients Snapper, Shrimp, and <u>Ontoserver</u> admin UI
- Built on <u>Keycloak</u> with extensions to
  - Present/record user terms acceptance
  - Manage "communities" aligning to FHIR security labels





## Communities and FHIR security labels





## Example from SCR in Australia

### Core Data Model and Value Sets

#### Release 1- Clinical

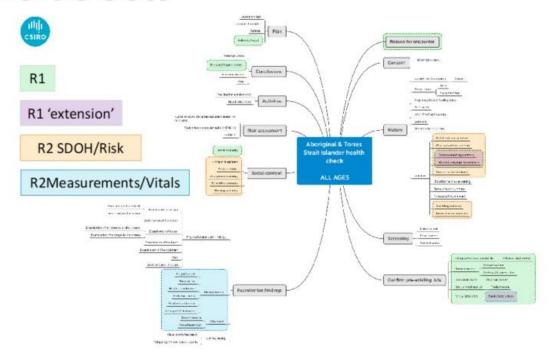
- Demographics
- Medications
- Presenting Problem/Reason for Visit
- Problems/Diagnosis
- Procedures
- Adverse reactions

#### Release 2

- Family history
- Lifestyle factors
- Social Determinants of Health

#### Important for

- Identification of risk factors, risk prediction
- · Social determinants of health
- · Pro-active intervention and care delivery
- · Preventive health programs
- Healthcare Assessments



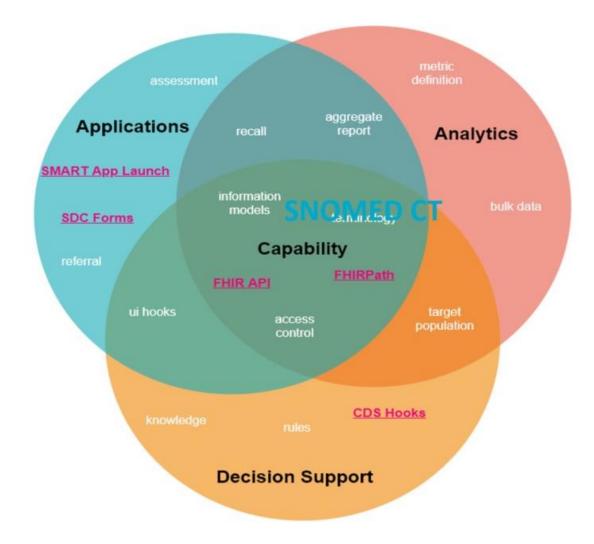
#### Release 3- What we are working on now

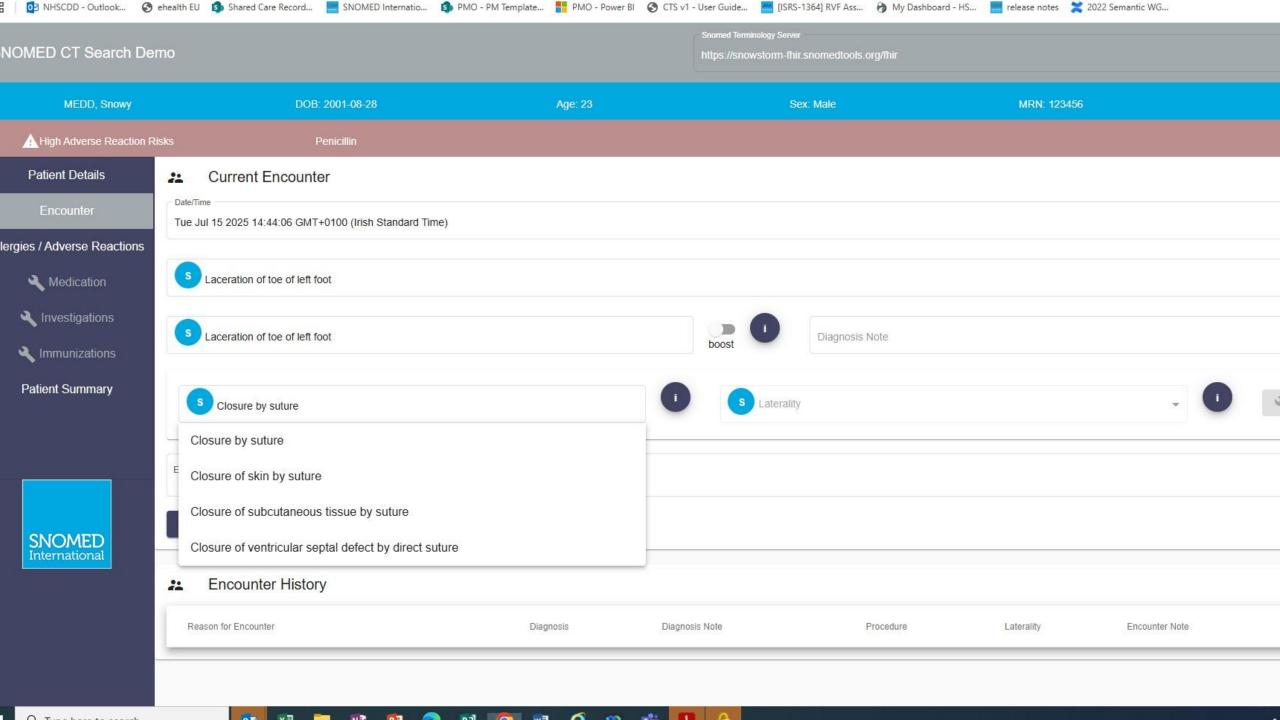
Functional assessments, Activities of Daily Living



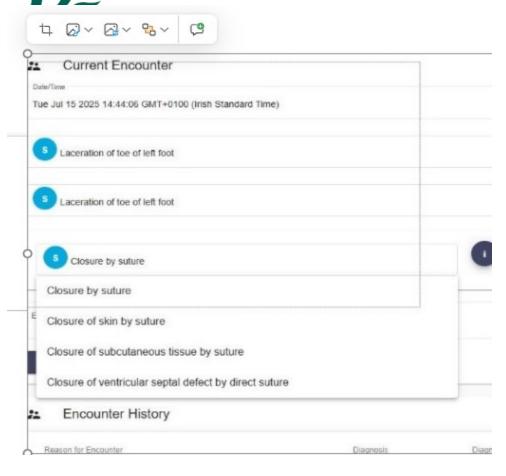
# Interplay of Use Cases, FHIR and SNOMED CT

Standards combine to support a set of use cases with SNOMED CT & FHIR® at its core





# LC Demonstrator



Closure by suture

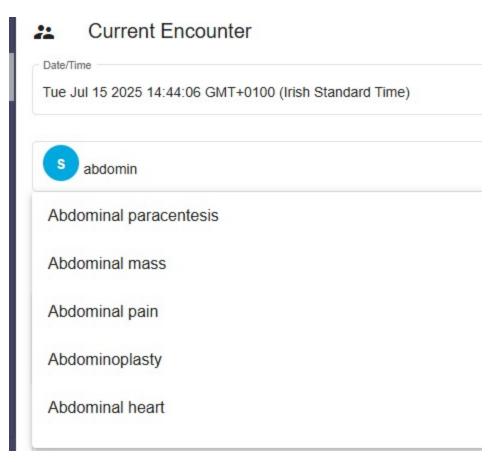
Closure of skin by suture

Closure of subcutaneous tissue by suture

Closure of ventricular septal defect by direct suture

S Closure by suture of toe







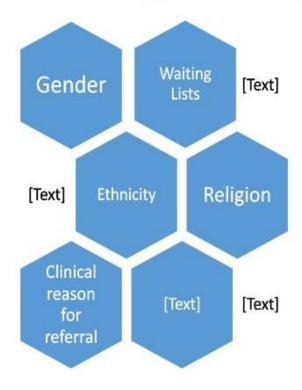
### Link to CTS demonstrator



## **Use Cases**

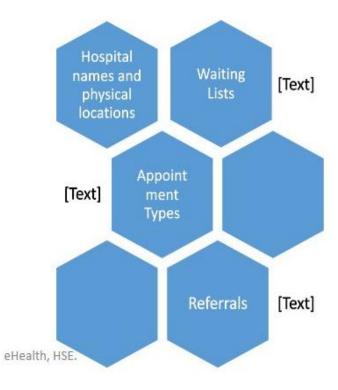
### **Central Terminology Server**

Shared Care Record
Care Connect (Community)



### **Data Dictionary**

- Shared Care Record
- Care Connect (Community)





# Other refsets currently under construction

### **Current Projects for October 2025 Release**

Euroheart TAVI- approx. 200 terms

CHI Child and Young Adult Mental Health- first draft approx. 200 terms

National Sepsis Programme – approx. 50 terms

OCIMS- Outbreak, Case, Incident & Surveillance Information Management System- approx. 1001 terms

NICOR Codes- National institute for Cardiovascular Outcomes Research – approx. 400 terms

OMNSD- Nurse Specialist Register- first phase approx 10 terms

National Ambulance Service – approx. 500 terms

Precision ALS- MS Dataset for Europe



Data Dictionary and Metadata Registry





The **Mauro Data Mapper** is a web based tool which stores and manages descriptions of data. These can be descriptions of data already collected, such as databases or csv files. Or these can be descriptions of data you wish to collect or transfer between organisations, such as a specification for a webform or an XML schema.

Data Dictionary and Metadata Registry

Is defined by national standards





# Included in procurement

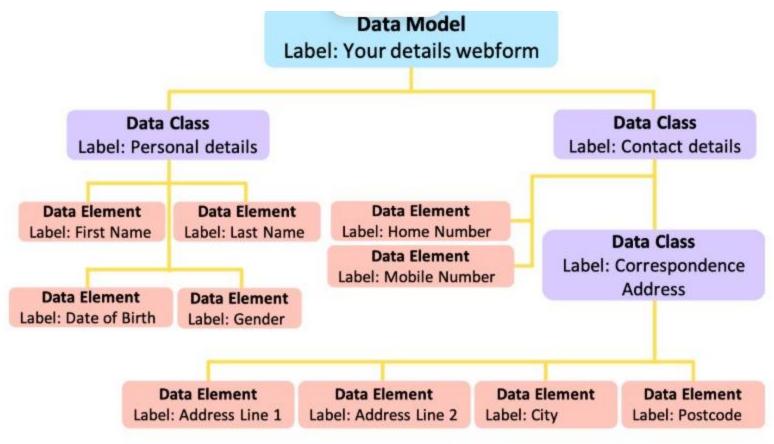
Each **Data Model** consists of several **Data Classes** , which are groups of data that are related in some way. For example, a group of data that appears in the same table of a database or the same section of a form. **Data Classes** can sometimes also contain **Nested Data Classes**.

An open-sc Support

Within each **Data Class** is then a number of **Data Elements** which are the descriptions of an individual field or variable.

For example, a webform where patients enter their details would be a **Data Model**. This form could consist of two separate sections such as **'Personal details'** and **'Contact details'** which would each be a **Data Class**. The individual entries within each of these sections, such as **'First Name'**, **'Last Name'**, **'Date of Birth'** etc, would each be a **Data Element**.

'Correspondence Address' which lies within 'Contact details'. In this case, 'Correspondence Address' would become a Nested Data Class, where the 'Contact details' Data Class would be the parent.



By organising metadata in this way, **Mauro Data Mapper** allows users to easily search data but also automatically import database schemas and export forms; helping to record data in standardised formats.

You	r details
Personal details:	
First Name	Last Name
Date of Birth	Gender
DD / MM / YYYY	M/F
Contact details:	
Home Number	Mobile Number
Correspond Address Line 1	lence Address:
Address Line 2	
City	
Postcode	
rostcode	

HE

Q & A









# **Closing Remarks**

Speaker:



Theresa Barry
Data & Clinical Terminology
Architecture Lead, HSE





