



Irish Institute of Pharmacy Webinar 8th May 2024

Importance of standardisation for digital health initiatives

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Today

- Hi and who I am
- Introduction to digital health
- Why we need to standardise our data
 - The patients, clients and citizens
 - What's happening now and what will be happening in our health system
- Where is the health service now
- What's next



What is digital health

- Refers to the use of information and communication technologies (ICT) in health products, services and processes, combined with organisational **change** in healthcare systems and **new skills** to improve health, efficiency and productivity in healthcare delivery
- It is about the digitalisation of health services and processes so that the right data about the right patient is in the right place and at the right time to ensure safe and efficient provision of care services.

Digital health



Evolve from eHealth to Digital Health

Move from 'Digital Transformation' thinking to healthcare transformation enabled by digital technology

Move the emphasis towards data and data flow rather than the tools



Why standardise our data

The patient





Information at the core of healthcare delivery

Patient journey can be complex

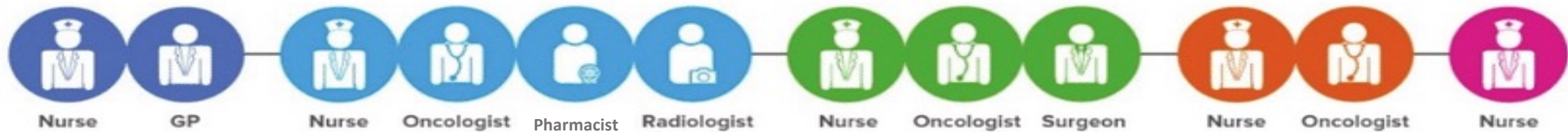




Information follows the patient



Healthcare professionals along the patient journey



IPPOSI citizens jury (2021):

Our patients want us to have good data and



We need a connected, quality, digital health information system

We need citizens to be the owners of their own information

We have a collective responsibility to do the right thing

We need to be supported to grow trust and confidence in the State

We need to partner with citizens to design our health information future

We need to treat data as a national resource

We have to make consent the cornerstone of everything we do

IPPOSI

VERDICT FROM A CITIZENS' JURY ON ACCESS TO HEALTH INFORMATION



This verdict has been prepared by an independent rapporteur and the 25 members of the public who served as jurors during the IPPOSI Citizens' Jury on Access to Health Information in April 2021.

Why standardise our data

Policy and Strategy





Shared Vision



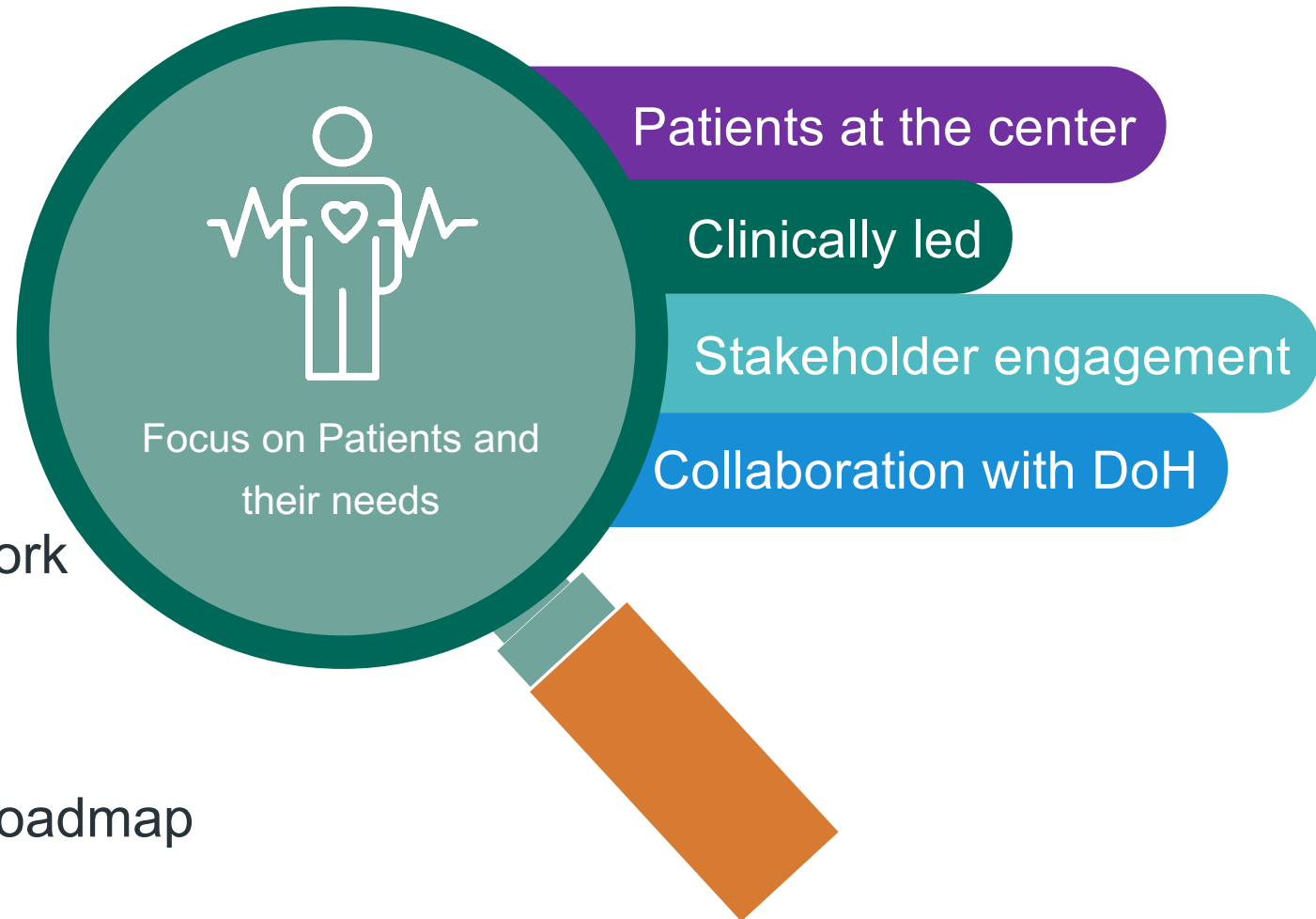
Better Health Outcomes enabled by
Seamless, Safe, Secure, and connected
Digital Health Services which support
Health and Wellbeing for both our
Patients and Providers.

Department of Health

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

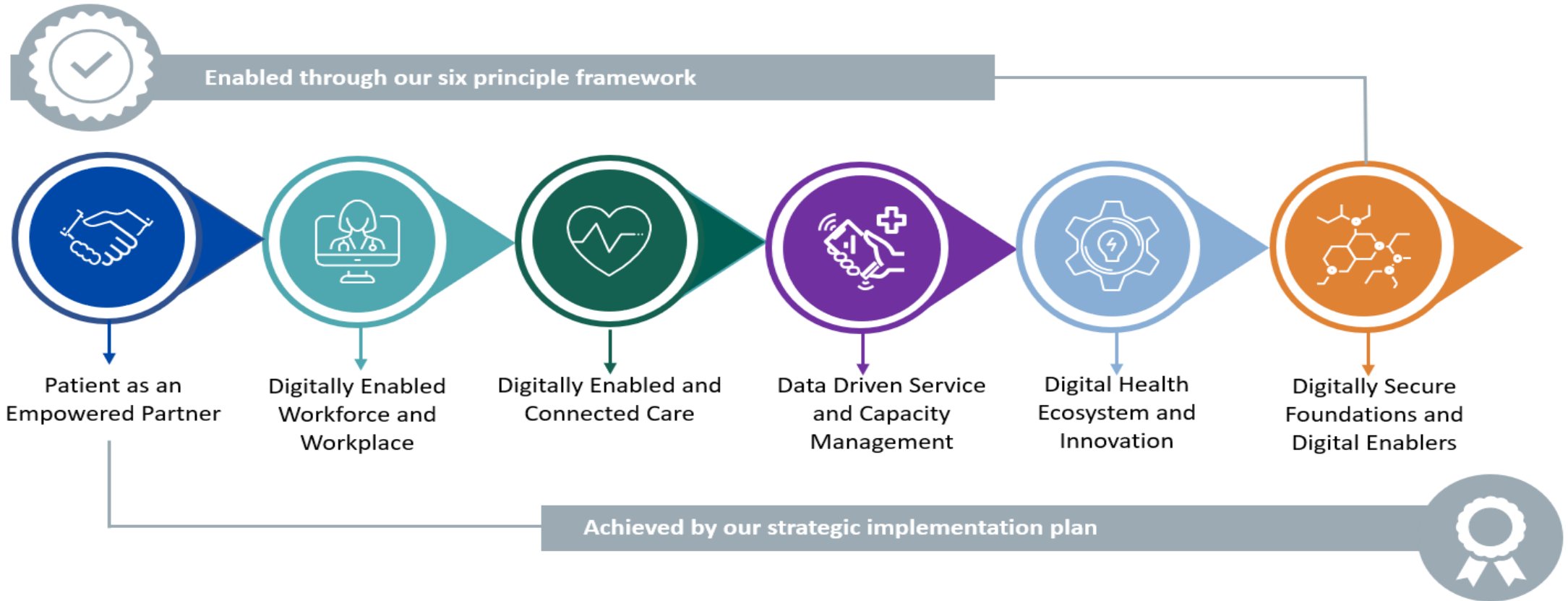
HSE

Digital Health Strategic Implementation Roadmap





Six Strategic Guiding Principles



Patient as an Empowered Partner

Digitally Enabled Workforce and Workplace

Digitally Enabled and Connected Care

Data Driven Service and Capacity Management

Digital Health Ecosystem and Innovation

Digitally Secure Foundations and Digital Enablers

Achieved by our strategic implementation plan

The HSE Digital Health Strategic Implementation Roadmap will be presented through the perspective of the single vision, 6 principles & defined initiatives.

The focus of the Roadmap is to commence initiatives that underpin empowering patients, establishing the foundations to enable the transformation, and leveraging the potential of EHRs.

The initial focus will lay the groundwork for a patient-centred care ecosystem that prioritises the patient.



Digital Health Strategic Implementation Roadmap: 48 Initiatives

The initiatives which form the basis of the HSE Strategic Implementation Plan are aligned to the Department of Health Digital Health & Social Care Framework vision and principles.

1 Vision
6 Principles
48 Initiatives*

**This includes the current in flight initiatives funded via the ICT Capital Funding*

Our Vision

‘Better health outcomes enabled by seamless, safe, secure and connected digital health services and which support health and wellbeing for both our patients and providers.’



Patient as an Empowered Partner



Digitally Enabled Workforce & Workplace



Digitally Enabled & Connected Care



Data Driven Service & Capacity Management

10 Key Initiatives

- Patient Portal
- Patient App
- HSELive - Contact Centre
- Patient Feedback Platform
- Remote Care/Monitoring/Digital Therapeutics
- Benefits & Schemes Access
- Public Facing Engagement & Digital Literacy Development Programmes
- Public Website Content Management
- Open Health API Framework
- Contact Care Platform
- Telehealth



5 Key Initiatives

- Reliable Secure Connectivity
- Modern Workspace & Productivity Tools
- Improve Employee Experience
- Mobile Ecosystem for Front Line
- Employee Feedback Platform
- Digital Finance and HR

12 Key Initiatives

- Shared Care Record
- Population Health Management
- Patient Administration & Care Coordination
- Medication Management
- Diagnostics
- Order Comms & Care Delivery
- Patient Safety & Quality of Care
- EHR Procurement & Delivery
- Digitisation of Health Care Records
- National Clinical Information Systems
- Medical Device Integration

4 Key Initiatives

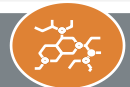
- Patient Journey Analytics
- Healthcare Data Analytics
- Integrated Referral Management
- Scheduling, Rostering & Resource Management



Digital Health Ecosystem & Innovation

5 Key Initiatives

- Precision Medicine Support
- Healthcare Research
- AI in Healthcare
- Open Innovation & Ecosystem



Digitally Secure Foundations & Digital Enablers

12 Key Initiatives

- Legislation, Regulation, Standards, Governance & Guidelines
- Patient Identity Management
- Healthcare Worker Identity & Access Mgt
- Architecture, Service Design & Knowledge Mgt
- Culture, Change and Agile Delivery
- Talent Identification & Development
- Integration, Interoperability & Data Engineering
- Crisis-Responsive Healthcare
- ICT Cyber Programme
- Foundational Infrastructure
- Regional Strategic Implementation
- 24/7 Support Function

Health Information Policy and European Health Data Space



What is changing for health information?

European Union - The European Data Strategy (2020)

- Path to Digital Decade 2030' - transformation of society and economy across the EU
- European Health Data Space (EHDS) will be the first EU sectoral data space and regulation with direct effect



National Policy in Ireland

- Health Information Bill (General Scheme approved April 2023)
- National Digital Strategy, 'Harnessing Digital' (2022)
- Digital health and social care strategic framework and HSE roadmap



An Roinn Sláinte
Department of Health

An **integrated health information** system that supports the delivery of integrated care and ensures the **efficient, secure sharing of health information for care and treatment, and for 'relevant' purposes**



Ensuring a **standards-based approach** to health information and the interoperability of health information systems



Strengthening our national **health data collections and infrastructure**



Improving **access, sharing and use of health information** for care and treatment and relevant purposes



Identity management of health information as part of the digitalisation of public services



Building **trust** in our national health information system through **engagement**

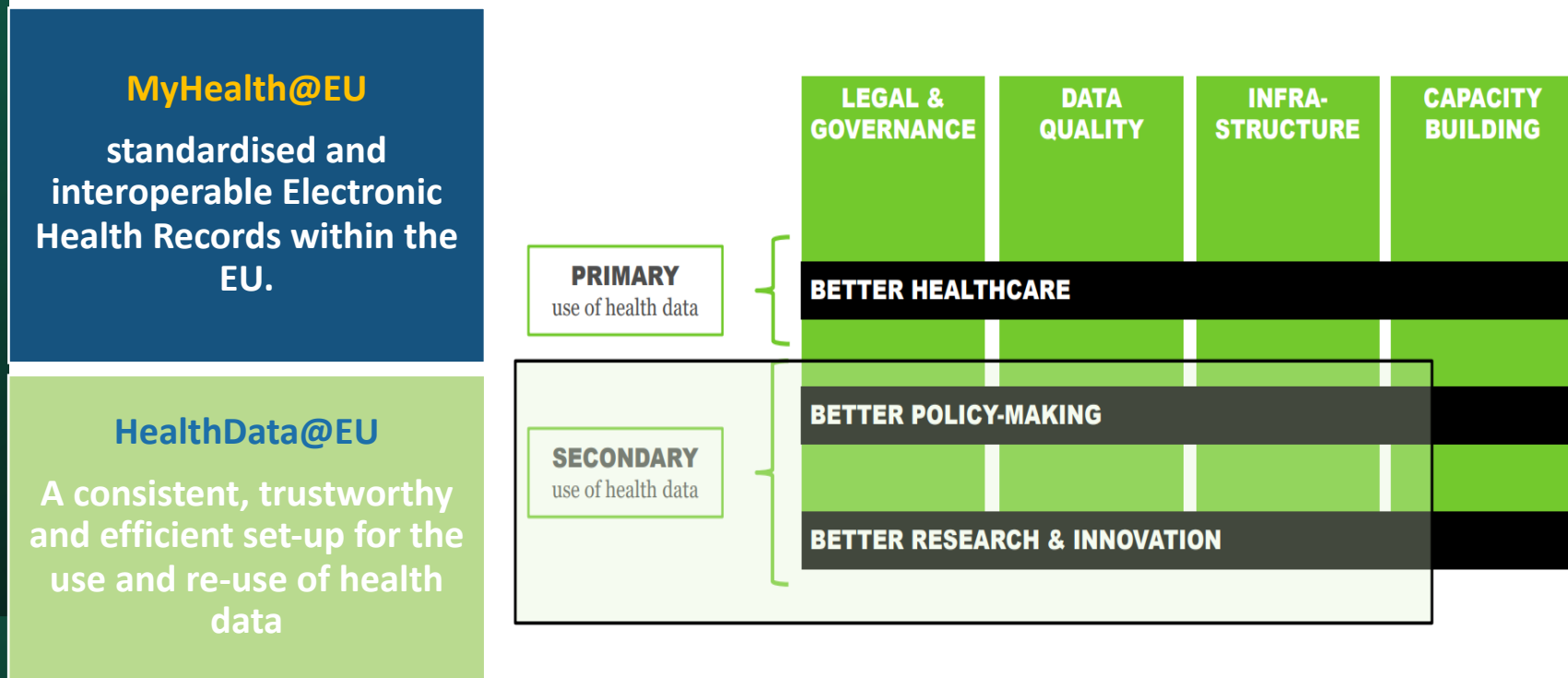


Empowering patients and services providers with greater access to health information

Health Information Policy – Vision and Mission

Two new infrastructures will support access to electronic health information

What is the European Health Data Space



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

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



Accessing Electronic Health Data for Care and Treatment (Primary Uses)

- **What will be in the MyHealth@EU EHR? (Art 5)**
 - patient summaries*
 - electronic prescriptions
 - electronic dispensations
 - medical images and related image reports
 - laboratory results and related laboratory reports
 - hospital discharge reports
- **Who will have access to and the ability to input/edit an EHR?**
 - healthcare professionals (Art 7a)
 - natural persons (Art 8)
 - a representative of a natural person (Art 8g)
- **Can access to an EHR be restricted?**
 - Yes, under Art 8e, a person can restrict parts of their EHR record, however, in cases of critical need this can be unlocked
 - If an individual exercises a right to restrict their data, data must still be recorded to reverse any restrictions if required*

Accessing Electronic Health Data for Care and Treatment (Primary Uses)

Items for Inclusion in the EHDS Patient Summary (Annex I)

1. Personal details
2. Contact information
3. Information on insurance
4. Allergies
5. Medical alerts
6. Vaccination/prophylaxis information, possibly in the form of a vaccination card
7. Current, resolved, closed or inactive problems
8. Textual information related to medical history
9. Medical devices and implants
10. Procedures
11. Functional status
12. Current and relevant past medicines
13. Social history observations related to health
14. Pregnancy history
15. Patient provided data
16. Observation results pertaining to the health condition
17. Plan of care
18. Information on a rare disease such as details about the impact or characteristics of the disease

Electronic
health
datasets that
can be
accessed for
**Secondary
Purposes**

What datasets can be accessed under the EHDS? (Art 33)

Examples include, but are not limited to:

- Data contained in **Electronic Health Records**
- Healthcare-related **administrative data** (insurance status or reimbursements)
- **Biobanks and databases**
- **Health survey-related data**
- **Genetic and genomic data**
- Other **human molecular data**
- **Registry data** (e.g. the National Cancer Registry)
- **Clinical trial data** (after completion)
- **Medical device-generated data**

MyHealth@IE Programme

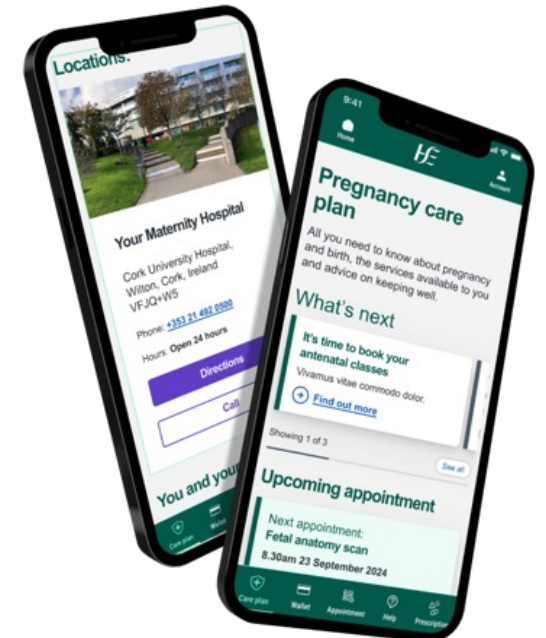
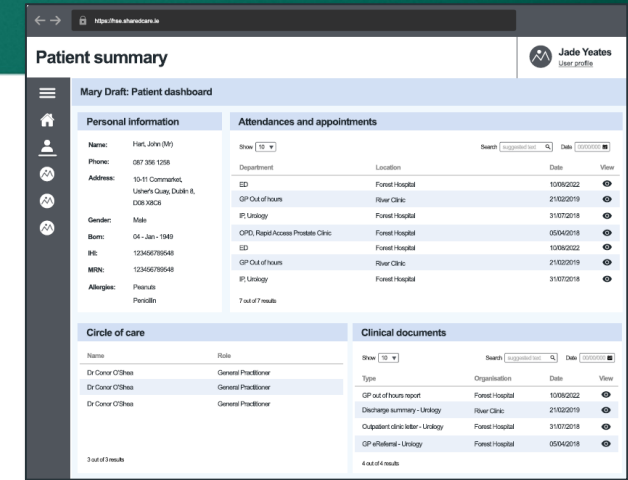




MyHealth@IE Programme

The MyHealth@IE Programme will deliver three important things:

- **National Shared Care Record** – A new system to bring together health information from lots of different Health Service IT systems, GPs, Hospitals, Community Services, Primary Care Reimbursement Service (Medical Cards), Pharmacies.
- **HSE App** – Giving patients access to their health information and making it easier to manage your health care through a secure mobile app
- **Open NCP/MyHealth@EU** – Making the shared care record and HSE App work with other health service systems across Europe. Good for patients when you travel and good for people when they visit Ireland.



A secure mobile app to give patients access to their own health information and to make it easier to manage their own health care. The HSE App will enable the whole population to access information, advice and support, and healthcare in the way they want.

Your Health Credentials:

- Health Identity
- Medical Card
- EHIC
- Proof of vaccination



An easier way to manage and carry your health access credentials - EHIC, Medical Card

Your Health Data:

- Appointments
- Prescriptions
- Test results, scans



Empower Patients with available information about their health & planned care

Your Personalised Health service:

- Signposting
- Personalised communication
- Self-care advice and information



Access useful, timely care information, find services, and self-care advice

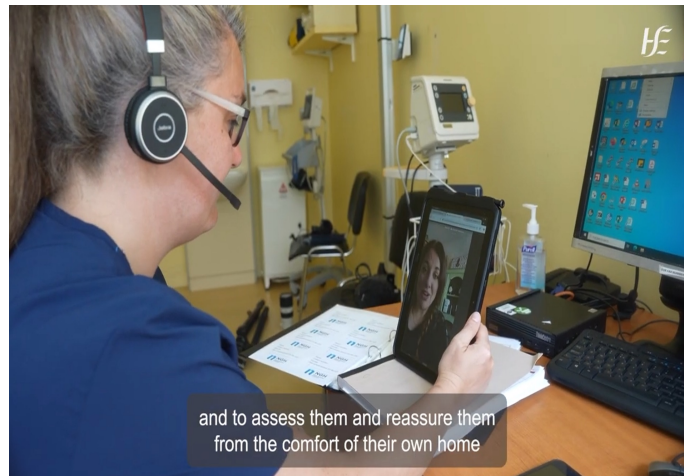
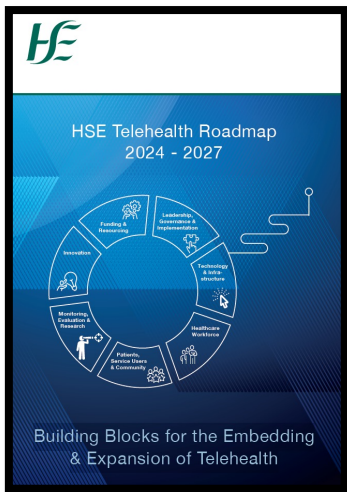


Confirmed High Impact Services Phase 1: Public Release Q4 '24

Service	Included	Data Source	Coverage
Health cards and credentials	<ul style="list-style-type: none">• Medical card• GP visit card• Drug Payment Scheme, LTI• EHIC• Proof of vaccination	<ul style="list-style-type: none">• PCRS	100% card holders
Public Hospital Appointments	<ul style="list-style-type: none">• Appointments• Notifications• Reminders	<ul style="list-style-type: none">• IPMS	Maternity Pathway, with review of other publicly funded hospitals
My Medication	<ul style="list-style-type: none">• Reimbursed medication• Self-declared medication	<ul style="list-style-type: none">• PCRS	All Medical Card, DPS & LTI patients Self-declared 100% app users, engage with IMO on GP data
Enhanced care pathway services	<ul style="list-style-type: none">• Maternity patients• Smoking Cessation Patients• Cancer patients on self-care pathway• COVID and Flu vaccination communication	<ul style="list-style-type: none">• MN-CMS• COVAX	100% coverage for all eligible patients
Services and signposting	<ul style="list-style-type: none">• Urgent and emergency care• EDs, Injury Units, GP out of hours• Services near me	<ul style="list-style-type: none">• HSE.ie Service Directory	100% app users <i>ED waiting times as available site-by-site</i>
HSELive support	<ul style="list-style-type: none">• App support• Data Quality issue & resolution management• Health Services signposting and queries		100% app users

Telehealth

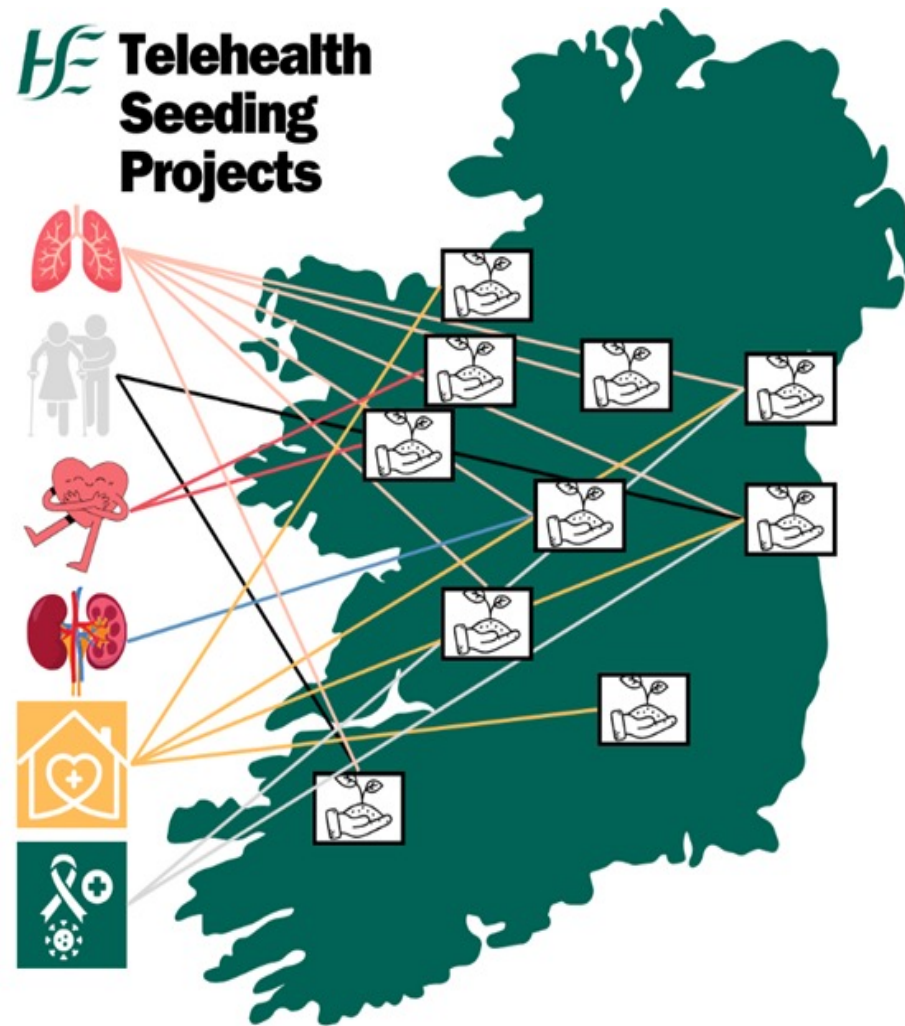




and to assess them and reassure them from the comfort of their own home

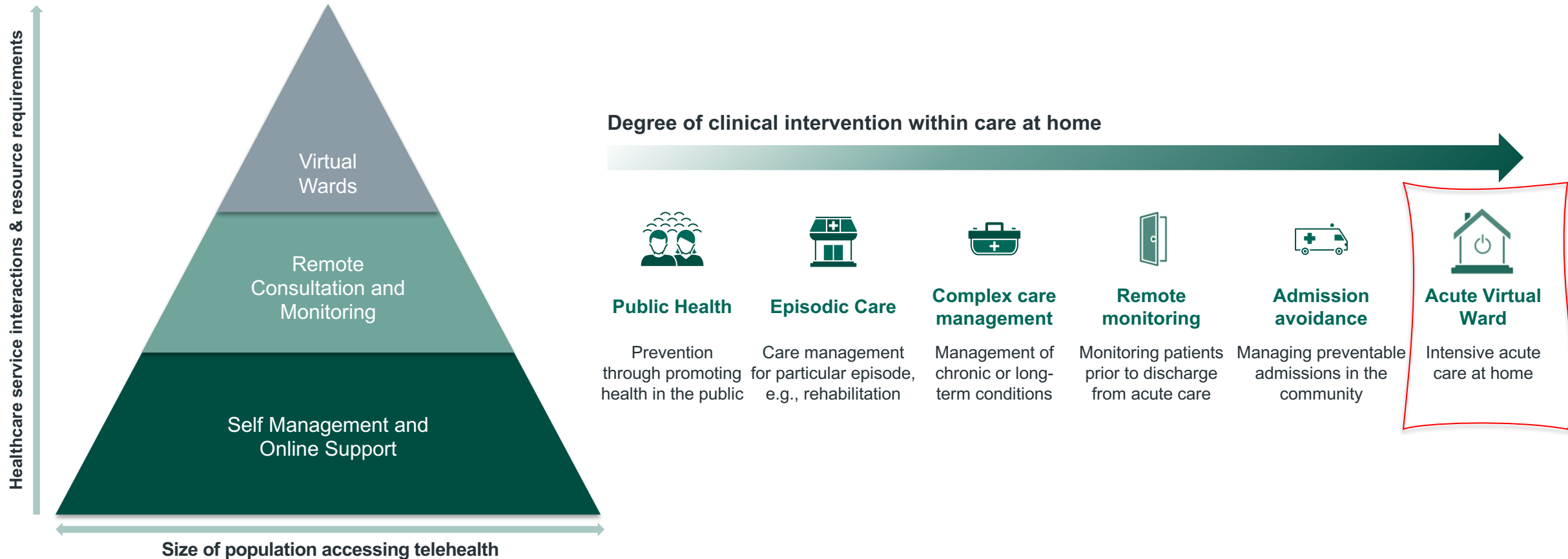


HSE Telehealth Seeding Projects



What are Acute Virtual Wards?

Acute virtual wards (AVWs) support patients who would otherwise be in a hospital bed, to be remotely monitored and receive treatment in their homes. Internationally, AVWs have emerged as a viable clinical intervention, enabled by technology, that is a safe and efficient alternative to HSE bedded care.

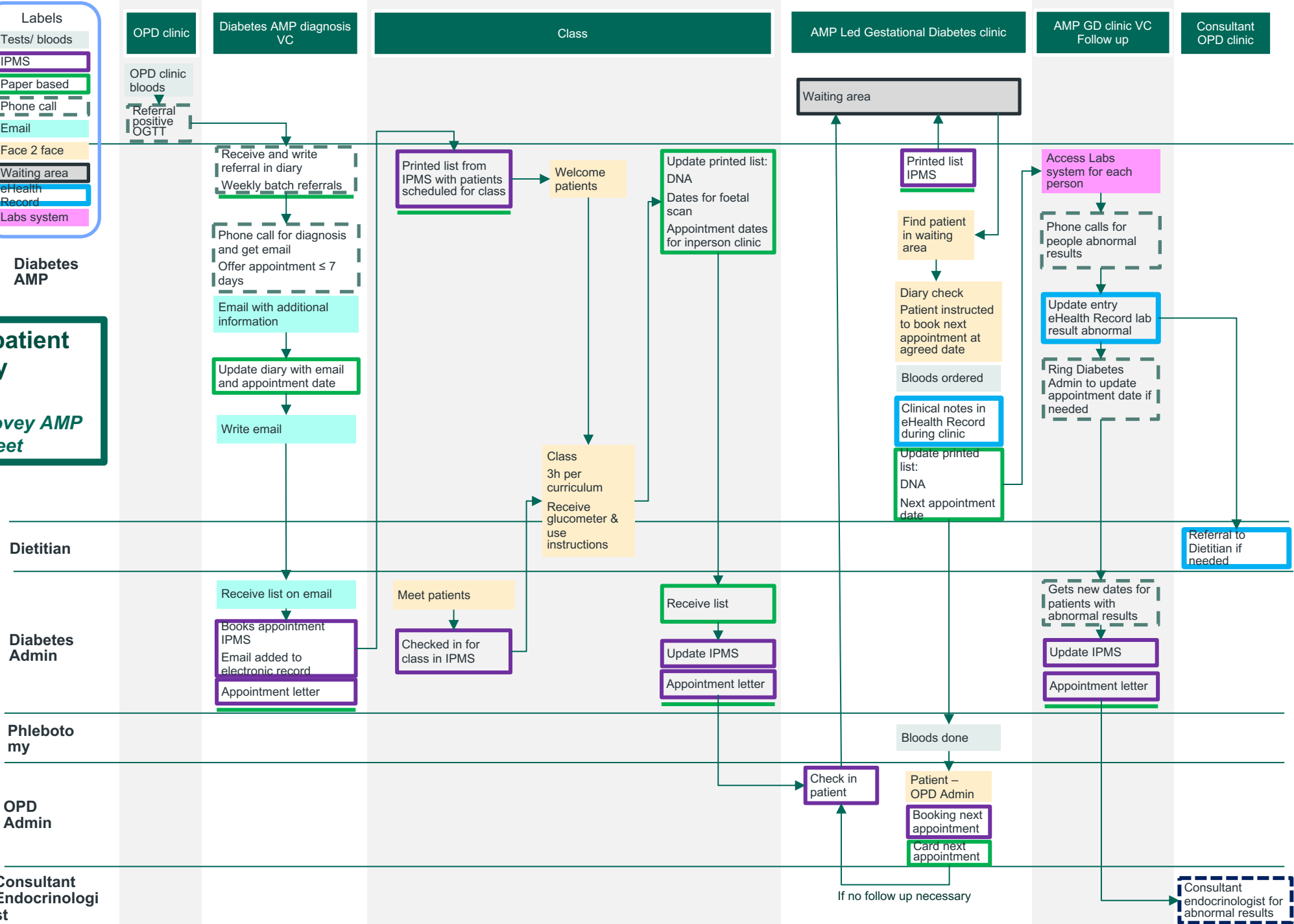


- Labels
- Tests/ bloods
- IPMS
- Paper based
- Phone call
- Email
- Face 2 face
- Waiting area
- eHealth Record
- Labs system

Diabetes AMP

End to end patient journey

Slide by Ciara Covey AMP Holles Street

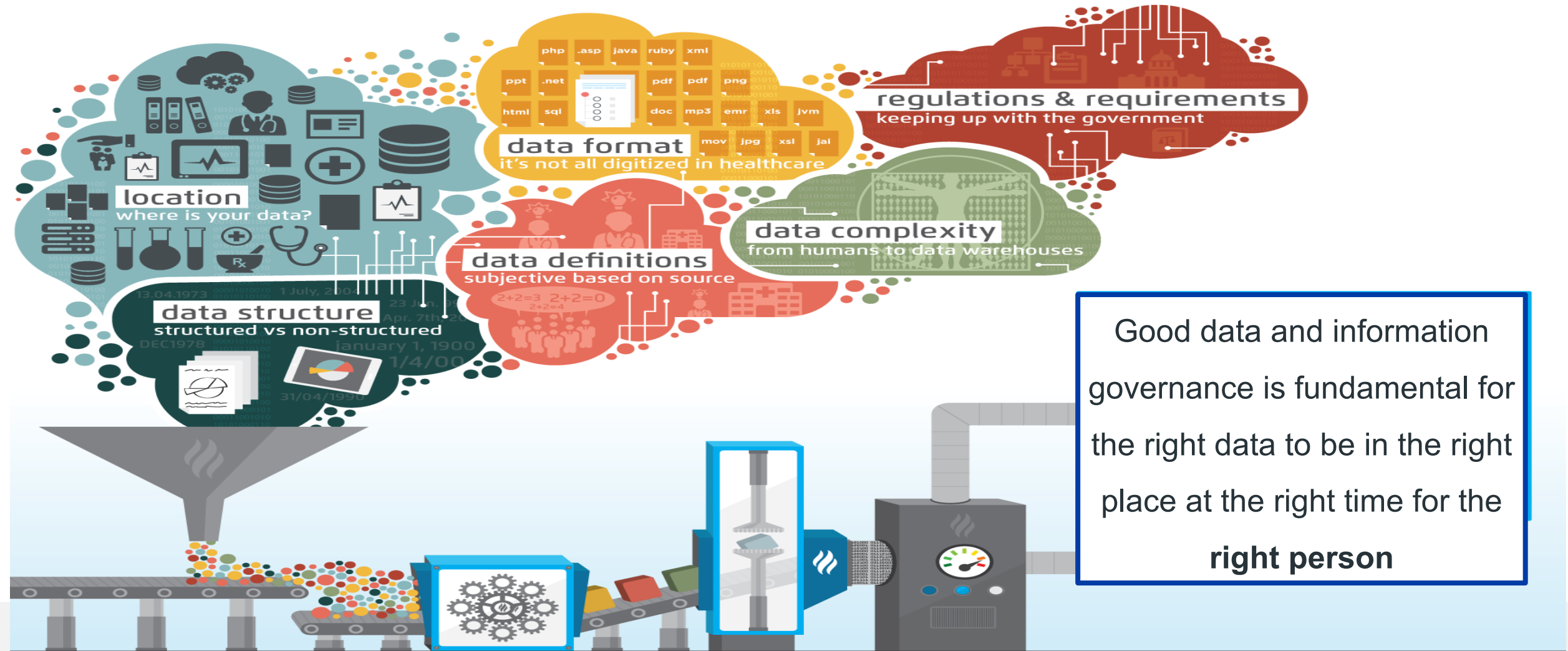


Where are we now

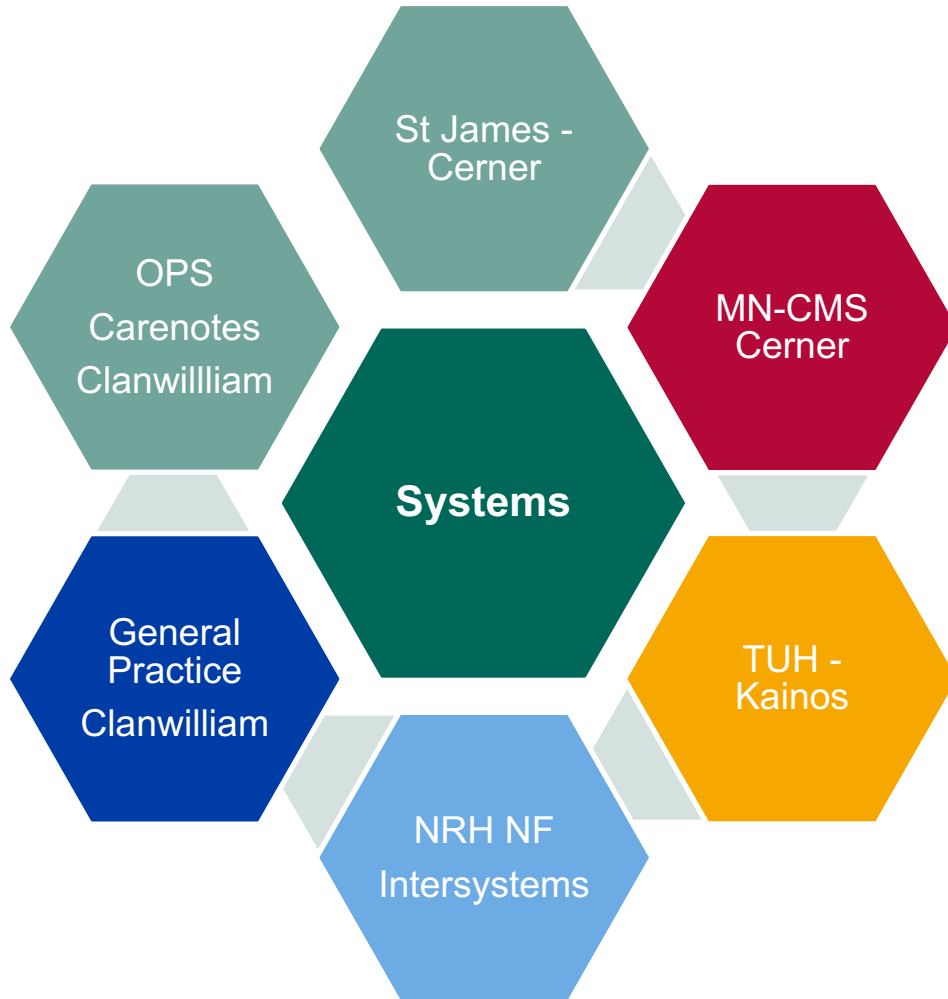


Health data

WHY HEALTHCARE DATA IS DIFFICULT



Health data and information



Health Data

- Administration Data
- Clinical Data
- Laboratory Data
- Imaging Data
- Medication Data
- Audit Data
- Metrics
- Research Data
- Paper/Electronic/Mixture/ Human

Every day we collect vast quantities of data on individuals

Issues

- Working in silos
- Duplication of data, laboratory tests, radiological studies, medical prescriptions
- Poor Value
- Poor Service – repeated request for information
- Poor access

Every day we spend a lot of time collecting, handling, looking for, storing and analysing information

Facts

- ✓ 2000 Standalone ICT Systems approx
- ✗ Data Standardisation
- ✗ National & EU Regulatory Compliance
- ✗ No Data Quality Assurance
- ✗ No Governance of Datasets
- ✓ Incomparable and Inconsistent Data



Reduce complexity and simplify

10 systems to get to here



Healthcare professionals along the patient journey

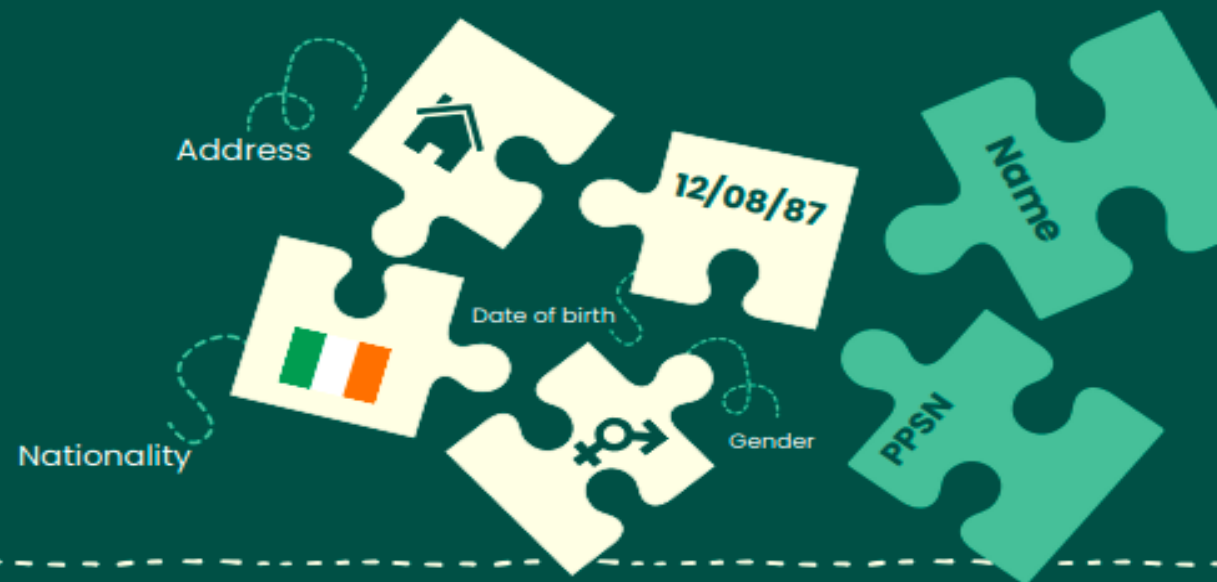


Integrated Care

Functioning and scalable identification programme

What is an Individual Health Identifier (IHI)

An individual health identifier or IHI is a number that uniquely and safely identifies each person that has used, is using or may use a health or social care service in Ireland.



How does IHI help me? What are the benefits?



Safest possible care

Improved accuracy in identifying you.

The key to link your health records

Your records across different healthcare organisations more accurately associated with you.

Connected care

Your health information can be shared safely and seamlessly between health care providers via Electronic transfer.



Interoperability

Standardisation of documentation is a basic requirement for interoperability



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How does IHI help me? What are the benefits?

- Safest possible care**
Improved accuracy in identifying you.
- The key to link your health records**
Your records across different healthcare organisations more accurately associated with you.
- Connected care**
Your health information can be shared safely and seamlessly between health care providers via Electronic transfer.

The infographic also features a puzzle graphic with pieces labeled: Address, 12/08/87 (Date of birth), Name, Nationality, Gender, and PPSN.



Background for the assessment



Digitisation and our efforts to ensure that the right data about the right patient is available in the right place at the right time.



Ensuring that data is **trustable**, standardised and interoperable would require **embedding mature data management (DM)** across the system.



We need to **baseline** our capabilities, prior to initiating work on this and publishing the data strategy in 2024.



As a best practice, we used Data Management Capability Assessment Model (DCAM) to baseline and **plan for gap closure** initiatives.



Outcomes from the assessment



Measure of our data management maturity



Understanding of our current strengths



Data management areas to focus initially



Broader capabilities we need to build



Required standards and processes



Required technology solutions



How we can plan to increase our maturity



How we plan use the outcomes



Plan a stream of work based on the feedback from survey participants on our current state and pressing DM gaps.



Define DM objectives and prioritise initiatives to close critical gaps.

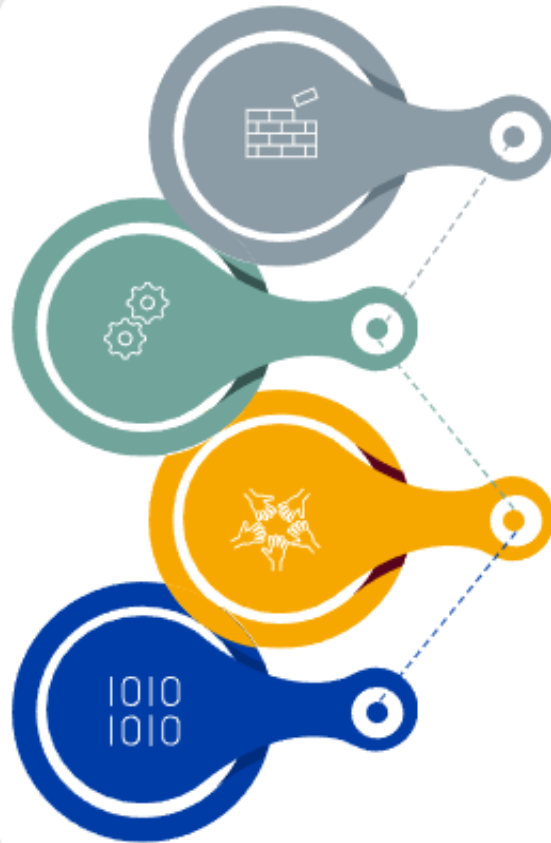


Use the DCAM report as a baseline for the data management program.



A roadmap for implementing DM in the organisation and accelerating the data management journey.

The eight components of DCAM belong to four groups

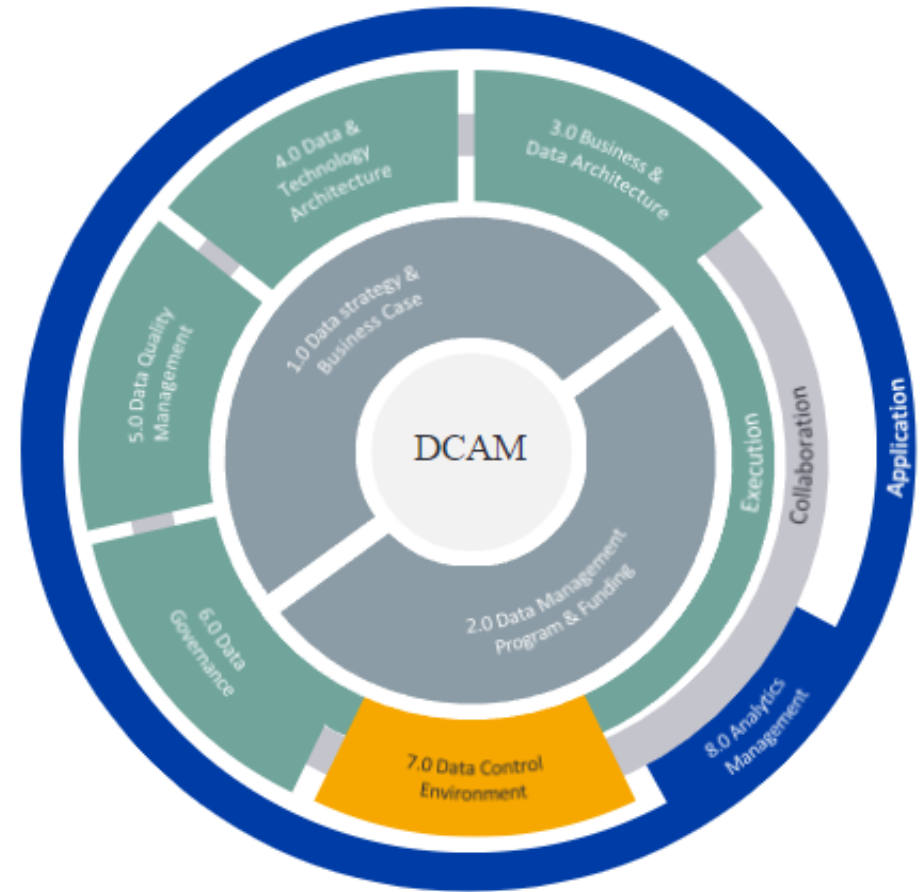


Foundational Components: Defines the data management strategy and vision, build the team and put the roadmap in place.

Execution Components: Capabilities to execute and deliver the data management strategy. These components are the work engine of an organisation's data management program.

Collaboration Component: Ensure teams across the organisation work together to manage, protect and leverage data.

Application Component: Capabilities to build innovative and robust advanced analytics.



The DCAM maturity scale has six capability levels

Increasing maturity levels

Enhanced: Data management capabilities **fully** integrated or **embedded** in the operational culture of the organisation with the goal of continuous improvement.

Achieved: Data management capabilities **adopted**, compliance **enforced** and sanctioned by executive management, activity and responsibilities coordinated, adherence audited, strategic funding, data harmonised across repositories. policy and standards implemented; lineage verified.

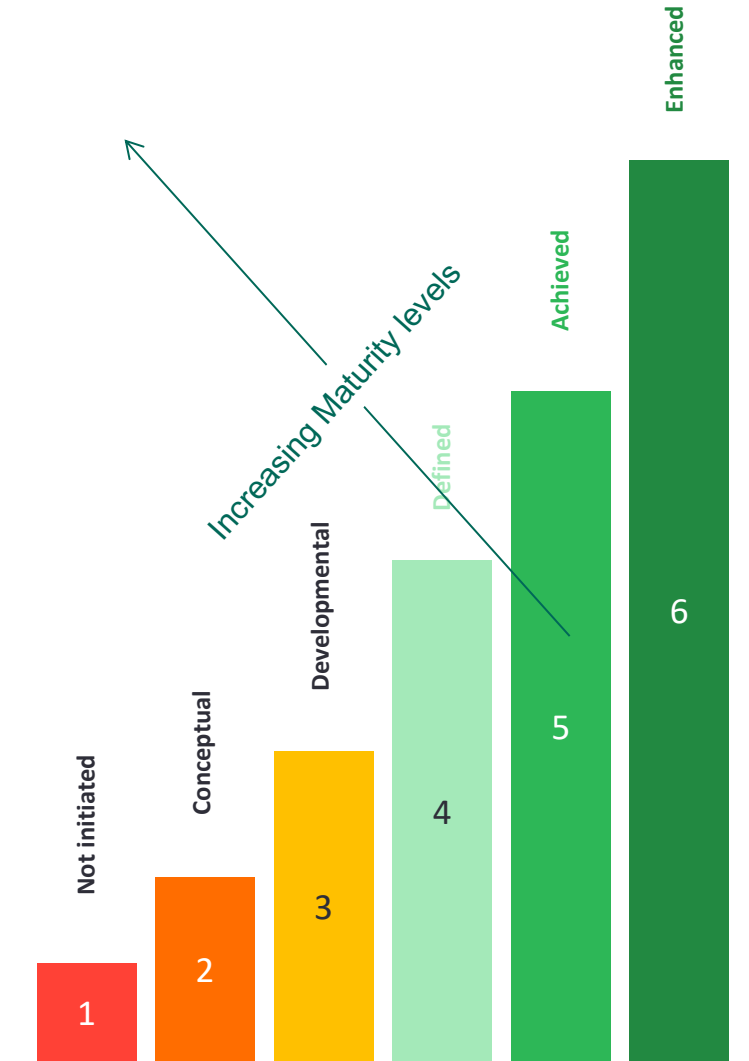
Defined: Capabilities **defined, established and verified** by stakeholders. Roles and responsibilities structured, policy and standards implemented, glossaries and identifiers established. Business users active; senior management is engaged.

Developmental: Stakeholders **being identified and initial discussions** about roles, responsibilities, standards and processes. Workstreams are defined; meetings underway; participation growing; policies, roles, and operating procedures being established.

Conceptual: **Initial planning activities** and ongoing discussions to agree on required data management efforts.

Not Initiated: Data Management **not performed or ad hoc** efforts by some individuals or functions.

Unaware of the requirement (for this survey an additional option “0” has been added as a potential response for survey respondents who are not familiar with some capabilities).

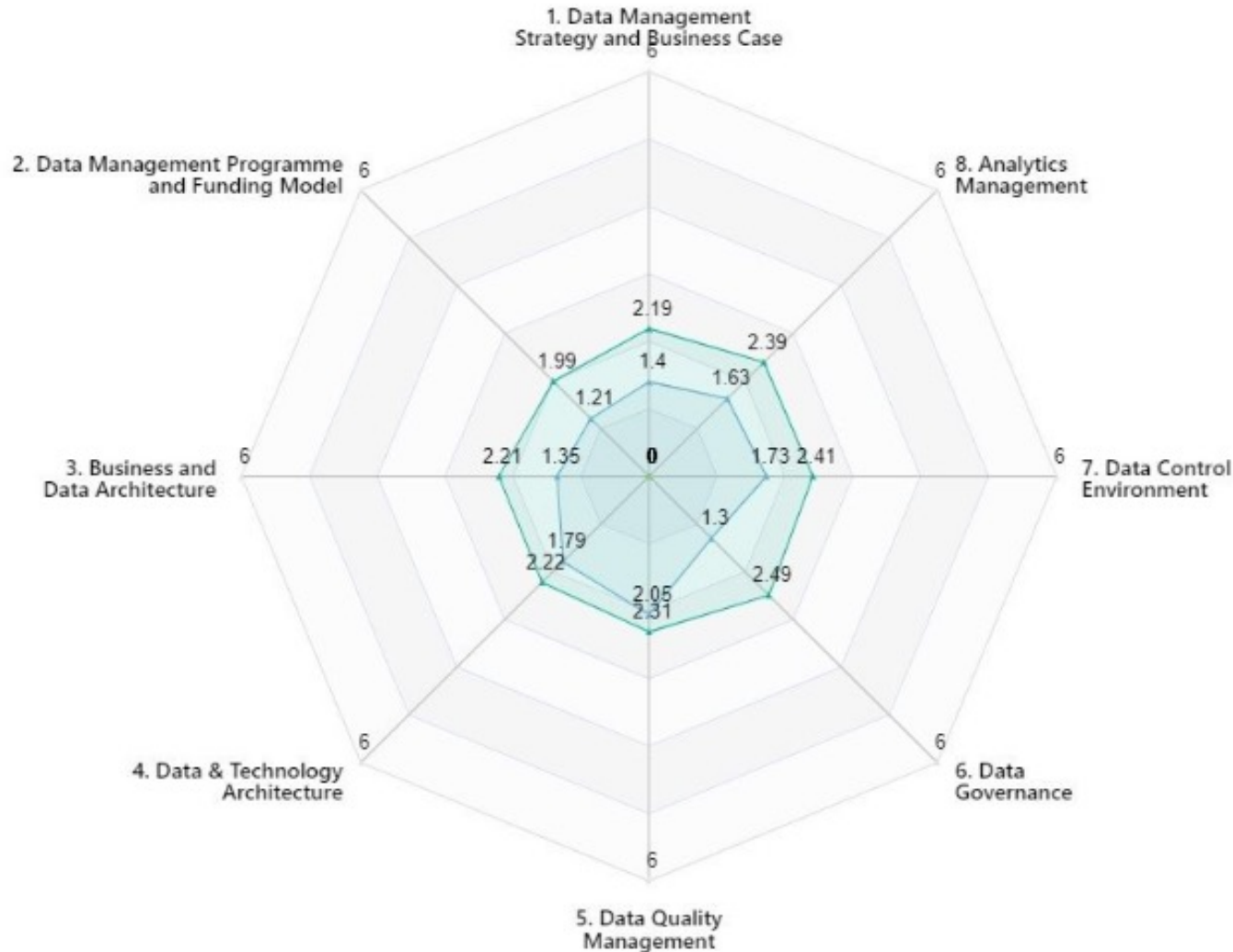


DCAM score from survey

2.27

DCAM score after workshops

1.61



Survey

- Most services have no DM initiatives in place or in the early 'conceptual' stages of establishing a limited set of capabilities.
- There are some services where efforts are in the 'developmental' stage for some key data management areas.
- Most of the survey comments indicate critical data management gaps and its impacts and risks for the HSE.



Consensus Workshops

- Workshop participants agree that there is no DM efforts centrally and this is a significant gap.
- The scores observed as part of the survey has been consistently seen as higher, when considering organisation level maturity for capabilities.
- There is a need for joined up thinking and efforts to initiate DM across the organisation.

Next



OUR BIGGEST ASSET

Associated key activities that the standardisation workstream is supporting includes:

HSE Data Maturity Assessment

- A data management maturity assessment (DCAM) is nearing completion, baselining current data management practices across the organisation and identifying areas of focus. The assessment will also assist with the development of the Data Strategy. The HSE Data Maturity assessment is now complete and outputs and next steps are being documented.

Standard Setting

- *Strengthening Standards Setting and Implementation*
Engaging with the Department and HIQA to co-design the national standards setting function; governance structures; stakeholder engagement and standards development process; and prioritisation.

Alignment and support of existing programmes of work

- Alignment with Virtual Wards Programme team to define standards and undertake a mapping exercise of the patient journey.
- Engage and support related ongoing eHealth initiatives, including ICCMS and ePrescribing.

Clinical Data and Clinical Document Standardisation

- Development of the Clinical Data and Clinical Document Standardisation (CDCDS) discussion paper outlining the clinical need, rationale and proposed approach for CDCDS within the Irish healthcare service.



Clinical Data and Clinical Documentation

Patients' clinical needs enabled by Clinical Data & Clinical Documentation Standardisation (CDCDS) – a national approach



HSE Position Paper
January 2024

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 Governance of CDCDS project..... 6

Vision Statement

For every healthcare service and site in the Republic of Ireland to use the same standard of clinical data and clinical documentation in order to meet the needs of service users and patients in an evolving, integrated landscape of healthcare delivery, enhance the quality of care provided, optimise patient safety and facilitate the implementation of national digital health transformation strategies.

Executive Summary

The purpose of this document is to outline the identified clinical need, rationale, and proposed solution for **Clinical Data and Clinical Document Standardisation (CDCDS)** within the Irish healthcare service, governed, coordinated and systematised from a national perspective.

Healthcare delivery is evolving to health regions, with the integration of public health, primary and community care and acute care as an essential requirement. The HSE needs to ensure our future health model is driven by the model of care outlined in [Sláintecare](#) with integrated care at its core.

National and international evidence demonstrates that integrated care requires integrated teams and integrated information to be truly effective. Clinical data and clinical document standardisation (CDCDS) is core to quality, safe patient care provision and HSE clinical initiatives including integrated care pathways and population-based funding, while also enabling patient empowerment and a desire for increased ownership – essentially, the fundamental pillars around which [Sláintecare](#) is built.

To enable this, CDCDS and its supporting infrastructure is a key requirement of the HSE to allow clinical and administrative information to flow and be available at each point of care with the patient on their care delivery journey.

Informed by learning from other countries, this paper outlines the clear and pressing need to standardise clinical data and clinical documentation from a national perspective.

The desired outcome is agreement to proceed and mobilise the strategic and operational planning phase of this CDCDS initiative, supported with the required resourcing. This approach will ensure the development of robust national clinical data and clinical



Strengthening Standards and Implementation



Next steps

The Department of Health will lead on setting up a core interim working group comprising of the Department, the Health Information and Quality Authority (HIQA) and the Health Service Executive (HSE), to advance work on the next phase.

As part of that next phase, the lead agencies will undertake the following:

Governance structures:

- The Department will lead on the establishment of a national governance committee on standards.
- The HSE will lead on establishing a HSE Standards Implementation Office, as outlined in the policy proposals.

National Roadmap for standards development:

- The National Governance Committee will set the strategic direction and lead on the development of a national roadmap for HI Standards development.
- As part of this process, HIQA will lead on developing and enhancing the national standards development process, in collaboration with the Department and the HSE.
- As part of this process, HIQA will lead on developing a prioritization process for national standards, in collaboration with the Department and the HSE.



Getting our data right

IMPACT OF NOT STANDARDISING



- **Significantly impact successful implementation of our national health policies** – Slaintecare, Health Regions - Integrated care requires integrated information
- **Patient safety** - clinical documentation and the data it is based on are foundational for successful clinical interactions and outcomes
- **Overwhelm – too much data in too many different places**
- **Different ways of representing what we do**
- **Documentation burden**
- **Decreased efficiency and accuracy**
- **Poor reporting, analytical and visualisation capability**
- **Poor research capability, quality measurement and performance benchmarking**
- **Interoperability problems**
- **Professional risk to clinicians**
- **Higher operational costs resulting in financial loss**



Digital Health Leadership – its everyone’s business



- **The exponential growth of the digital economy means that leaders who don’t develop a digital mindset will soon no longer be able to lead their organisation effectively**
- **Leaders who wish to thrive in organisations need to upgrade their skills and become digitally literate or they will get left behind (Harvard Business School, 2022)**

“It’s about things like understanding how to do collaboration differently in a digital world, how to think about data and security and how to make decisions around data, and finally how to think about change at a time of rapid transformation that requires a continuous learning loop to order to continue to innovate and make good decisions.”

One of the ways that getting a better understanding of digital informs better decision-making is that leaders gain a better appreciation not only about the many benefits digital offers, but also about its limitations and deficits and the ways in which humans should best interact with it.

“You can no longer survive with low literacy levels about digital technology. You need to understand the language of digital in terms of how it impacts on strategy, operating models, employees, retention and recruitment, stakeholders, products and services – and if you don’t understand it, you will not be able to participate in the digital transformation that is now taking place.”



Information at the core of healthcare delivery



**Data right
at capture**

Thank you

