



# Importance of data and information governance to underpin digital transformation in Ireland

Dr Barbara Foley, Health Information Manager, HIQA Better Together for Digital Healthcare - 1<sup>st</sup> December 2023

### **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

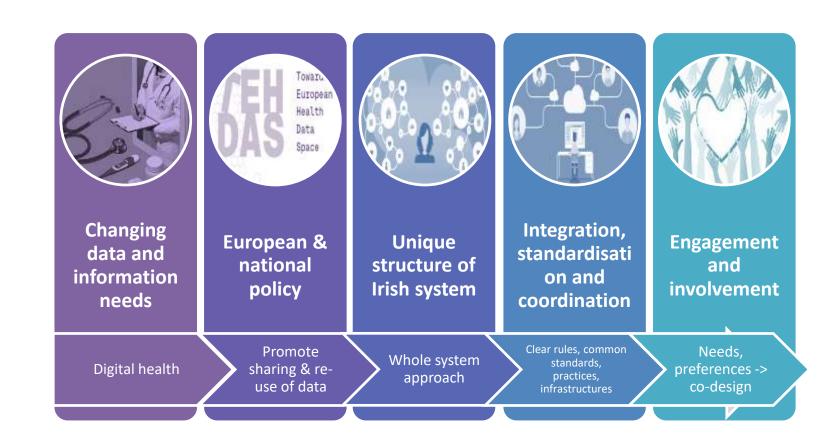


Enhance foundations for eHealth



### **Evolving health information landscape**





## **Context - European and national policy**





- Proposed European Health Data Space (EHDS) Regulation
- **Health Information Bill** 2023 (General Scheme)
- Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023
- Digital Health and Social Care Strategic Framework (2023-2030)
- EU target citizens should have access to digitised personal health information by 2030
- EU TEHDAS-2 Joint Action





## **Impact on Safety and Wellbeing**



An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte





Lack of a strategic approach to information management, quality assurance and risk management that supports continual improvement and good governance



Lack of performance monitoring or effective clinical audit at service level. Lack of agreement on national quality and safety performance measures e.g. maternity outcomes/sepsis



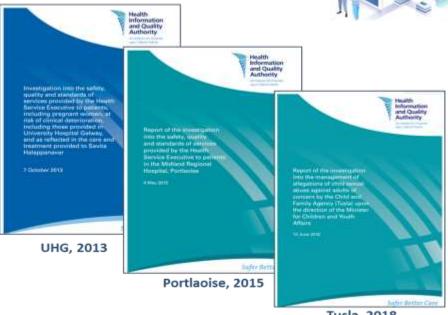
Poor information systems and processes to support the collection and analysis of required data to inform effective practice and clinical governance



Lack of focus on information management within governance structures



Lack of formal data quality policies or procedures to ensure timely, accurate and reliable data to inform decisions.

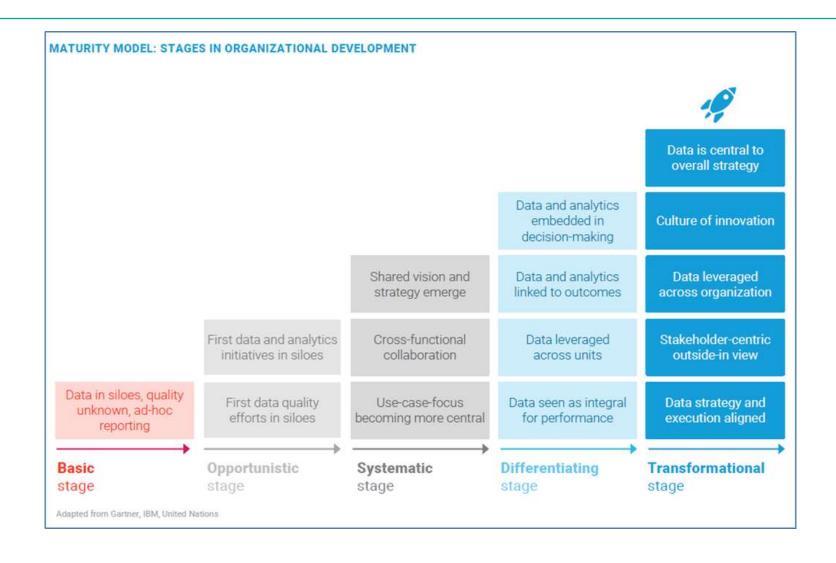


Tusla, 2018

Poor information management resulted in serious failures in the provision of quality and safe care

## **Context - Data Maturity**





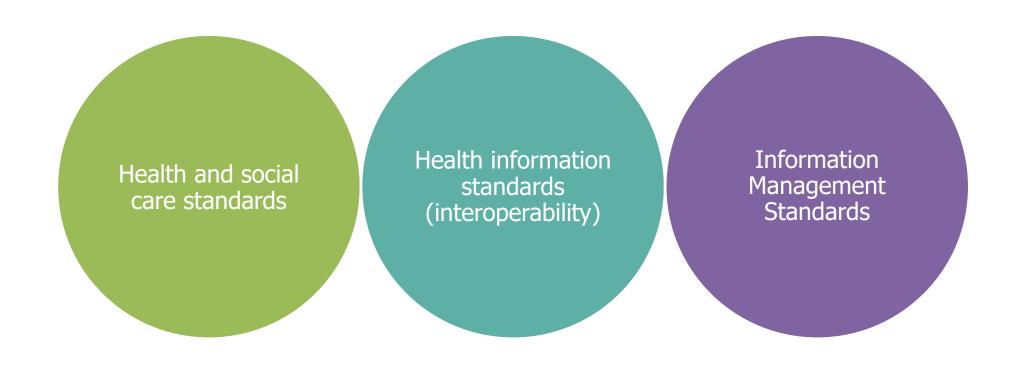


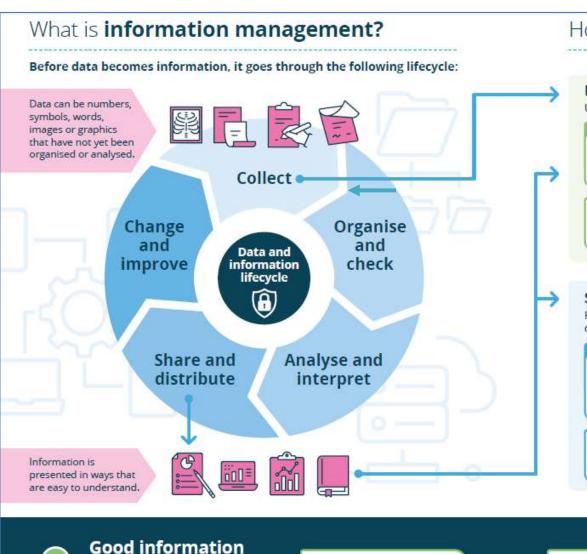


# Draft National Standards for Information Management in health and social care

## Standards developed by HIQA







### How data and information is used?

#### Primary use of information:

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



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 policymaking, improve public-health and undertake research to compare treatments and services.



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



#### Improve safety and wellbeing

- promoting the use of accurate, relevant and timely data to inform good decisionmaking for both primary and secondary use.







Build trust - 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.









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



### V1.0 (2017)

## **Draft National Standards for Information Management in Health and Social Care**

 All services and organisations that collect, use or share health and social care information.



V2.0 (2023)

## **Principles underpinning standards**





## **Information Management Standards** (2023)





**Principle 1: Human rights-based approach** 

**Standard 1.1 Uphold people's rights relating to information** 

Standard 1.2 Protect privacy and confidentiality



### **Principle 2: Safety and wellbeing**

Standard 2.1 Optimise the accessibility, use and value of information

**Standard 2.2 Undertake effective stakeholder engagement** 



### **Principle 3: Responsiveness**

Standard 3.1 Align with national & international standards & best practice

Standard 3.2 Enhance data quality

Standard 3.3 Ensure data security

**Standard 3.4 Develop staff capability and capacity for information management** 



### **Principle 4: Accountability**

Standard 4.1 Develop strong organisational governance, leadership and management

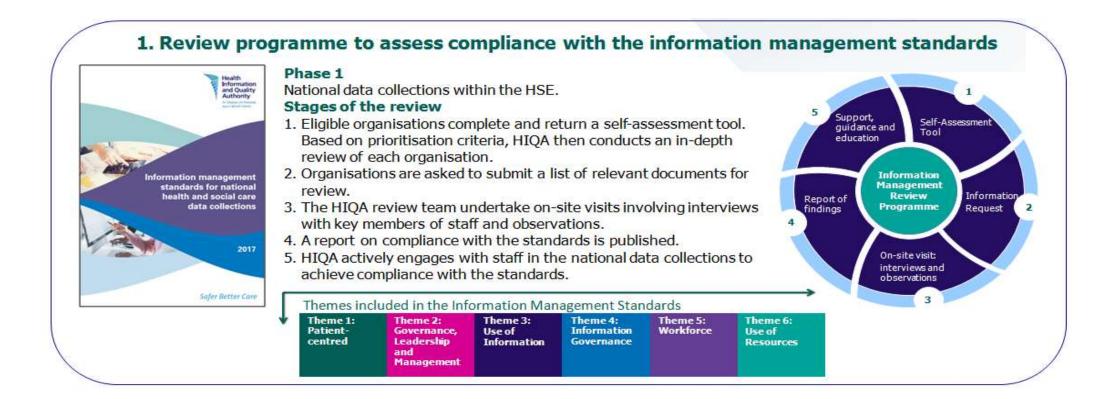
Standard 4.2 Implement strategy for information management

Standard 4.3 Promote effective performance assurance and risk management

Standard 4.4 Ensure compliance with relevant legislation and codes of practice

## Information management - Review programme





## Impact – driving improvements in information management



### Long term

Evidence of improvements in the quality of national health information, safety and wellbeing.

### Medium term

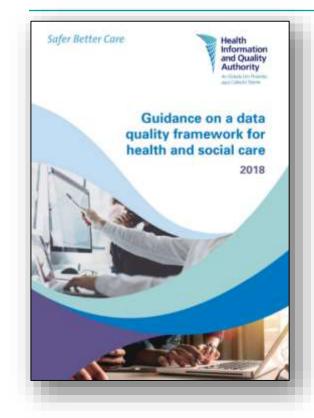
Evidence of improvements to information management practices.

### Short term

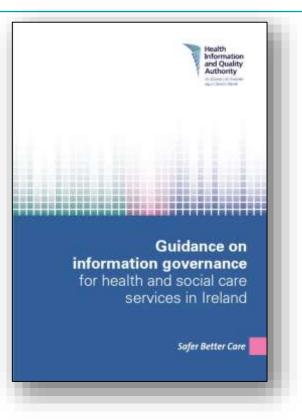
Improved awareness of information management standards, associated guidance - assessment of compliance and education.

## HIQA guidance to support information management and governance











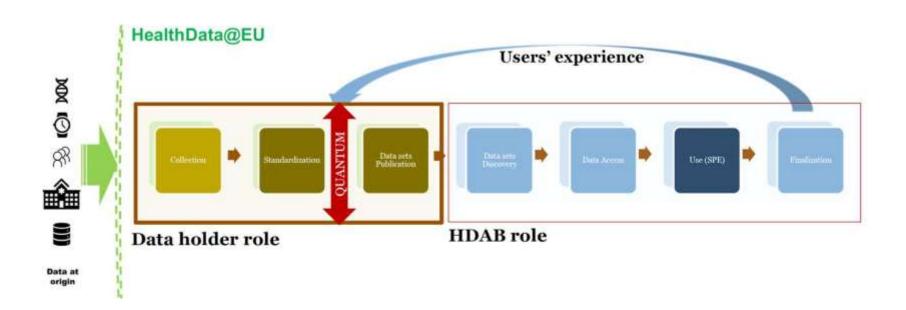
## **Importance of Data Quality - EHDS**





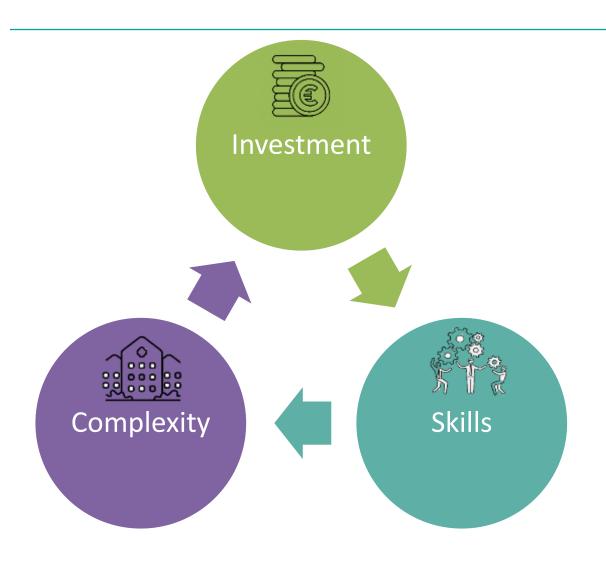
### **EU Horizon Grant - QUANTUM Project**

Developing a Data Quality and Utility Label for the European Health Data Space



## Staff capability and capacity





### **Developing capability and capacity**

- General knowledge for all health and social care professionals (information management standards)
- Undergraduate/post graduate reform
- Development specialist roles and career pathways



## **Challenges bring opportunities!**





Key considerations/reform	Challenges	Opportunities
Technical infrastructure (primary use)	Reliance on paper records	eHealth initiatives – shared care record, EHRs, portal, IHI
Technical infrastructure (secondary use)	Underdeveloped infrastructure for re-using and sharing data	National data sharing and linkage service, IHI
Effective governance (national strategy)	Fragmented systems and landscape – whole system approach public, private, voluntary, national data collections	National strategic approach to health information
Operational capacity	Foundation - health information standards, data quality standards and security standards.	National information governance framework and national strategy for training and education
Engagement	Acceptance and buy-in public and professionals	National engagement strategy & co-design

## Thank You

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