Lightening session

Advancing Health Information Standards

Speakers:

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Advancing secondary use of data in Ireland under the EHDS Regulation – *readiness assessment and preparedness*

Dr Barbara Foley

HIQA

Data Discovery

Project Design

Ethics Approval

(if required)

Data Permit Application Submission to HDAB

Access Committee Review

*HDABs have **3 months** to issue decision (potential additional 3-month ext)*

Data Permit/Request Issued

Permits can issue for up to **10yrs** and be renewed once

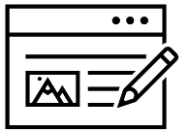
Request to Data Holder(s) Issued

***3-month** timeline (potential additional 3 months)*

Data shared with HDAB

Data access given in SPE

Research published

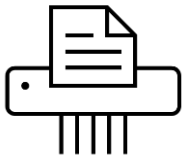


***18 months** to share research with HDAB*

HDAB shares research on website

Data in SPE must be destroyed **6 months** after permit expiry

HDAB destroys data in SPE



EHDS Regulation

Categories of electronic data for secondary use

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a) Electronic Health Record (EHR) data
b) Data impacting on health
c) Data on healthcare needs, resourcing, access, expenditure and financing
d) Pathogen genomic data
e) Healthcare-related administrative data
f) Human genetic and genomic data
g) Other human molecular data
h) Person-generated medical device data
i) Wellness app generated data
j) Identification data on health professionals
k) Population-wide health data registries
l) Data from medical and mortality registries
m) Clinical trial data (after completion)
n) Medical device-generated data
o) Data from product and device registries
p) Health research cohorts/questionnaires/surveys
q) Biobanks and databases

Articles of the European Health Data Space (EHDS), Article 33, Minimum categories of electronic data for secondary use

EHDS Regulation
Potential secondary uses of data

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- Public Health interests, including patient safety
- Policy making and regulatory activities
- Developing statistics at national or multi-national levels
- Educational or teaching activities
- Scientific research
- Innovation contributing to health or social care (incl. medicinal products, medical devices or AI systems)
- Personalised healthcare for patients

How is HIQA supporting these developments? - HealthData@IE project (2023-2027)

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- Grant funding from EU Commission to establish health data access services (HDAB) for Ireland
- Collaborative approach - DoH, HIQA, HRB, HSE and key stakeholders
- National Steering Committee – HealthData@IE
- 3 Working Groups Established – WP2, WP6 and WP8

- **Key areas for advancement :**
  - Programme of engagement, education and training (WP2)
  - National dataset catalogue (WP6)
  - Data quality enhancement (WP8)
  - National data access application management system
  - Secure processing environments

HealthData@IE Work Package 8
Why focus on data quality?

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- For data holders, there are several requirements relating to data quality and utility set out in the EHDS regulation, including:
  - The need to apply a **data quality and utility label** to datasets to demonstrate the quality and usefulness of the data for being used for secondary purposes before they can be made available through the HDAB (currently being developed by the QUANTUM project)
  - The need to use **data standards** to enable data discovery, semantic interoperability, and interoperable communications
- There will also be requirements for organisations to assess levels of **compliance** among data holders with the various requirements set out under the EHDS

HealthData@IE
Readiness assessment: aims

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1. To explore the **feasibility of reusing and linking** health and social care data from different sources for secondary use purposes in Ireland by assessing if potential linkage variables are present across datasets
2. To identify whether there is **capacity** among data holders to provide metadata and data in the necessary formats to a future HDAB service
3. To determine the strengths and weaknesses of data holders' existing ICT systems **interoperability** and their ability to support the exchange of data with a future HDAB service
4. To explore perceived **barriers and facilitators** to the implementation of the EHDS and the establishment of HDAB services in Ireland from the perspectives of data holders
5. To identify and prioritise data holders' **data quality guidance and training needs**.

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Readiness assessment: use cases

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Influenza

- To demonstrate the feasibility of using available data to carry out surveillance of **influenza** and explore rates of influenza testing, vaccination and hospitalisation in vulnerable groups.

Type-1 diabetes

- To demonstrate the feasibility of using available data to enhance our understanding of **Type-1 diabetes**, to compare care pathways, measure clinical outcomes and costs of care, and enable better planning of services.

Colorectal cancer

- To demonstrate the feasibility of linking **clinical and genomic data** to enhance our understanding of **colorectal cancer**, including incidence, risk factors, causes, and long-term outcomes.

HealthData@IE
Readiness assessment: methodology

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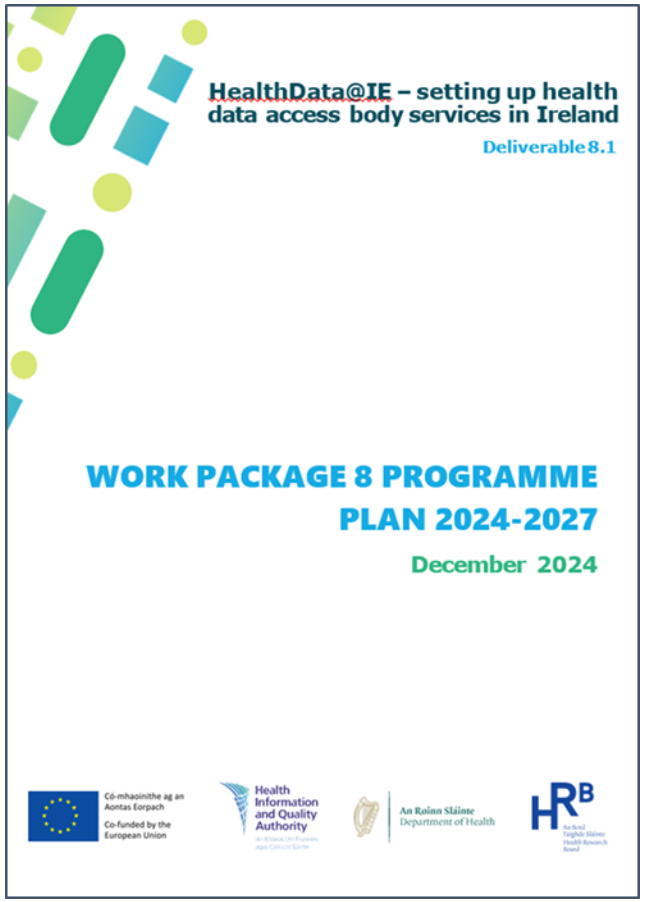
- Through the process of developing the three use cases, the key datasets and the associated data holders will be identified and selected for inclusion in the various stages of the readiness assessment in 2025, via:
  - Online survey
  - Focus groups
  - Interviews
- Key questions will be explored with data holders, particularly whether key linkage variables are present across datasets and whether there is capacity among the data holders to provide metadata and data in the necessary format to a future HDAB service.
- Perceived barriers and facilitators to the establishment of HDAB services will also be explored



Thank you

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