



# HealthData@IE – setting up health data access body services in Ireland

## Preparing for the establishment of health data access body services in Ireland under the European Health Data Space Regulation:

### Readiness Assessment Survey

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Có-mhaoinithe ag ar  
Aontas Eorpach

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**Health  
Information  
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## Information for participants

As part of the HealthData@IE project, HIQA is undertaking a readiness assessment to obtain a baseline view of data holders' preparedness for the implementation of the European Health Data Space (EHDS) Regulation, and the establishment of health data access body (HDAB) services in Ireland across multiple areas, with a particular focus on data quality and interoperability.

HIQA has developed a guidance document for data holders outlining what the EHDS means for the secondary use of data and what data holders' obligations will be once this regulation is fully implemented. This survey is one part of the readiness assessment. It has been purposefully designed to ensure it is appropriate and fit-for-purpose for evaluating how prepared Irish data holders are for the implementation of the EHDS and the establishment of HDAB services across multiple areas.

The survey is broken into six sections, as set out in Table 1 below.

**Table 1: Survey Sections**

Section	Scope of questions	Purpose
<b>1</b>	Details of the data holder and their dataset	To obtain an overview of the characteristics of the survey respondents.
<b>2</b>	General EHDS preparedness and information management maturity	To assess overall preparedness for the implementation of the EHDS and the establishment of HDAB services in Ireland, as well as information management maturity to support such practices.
<b>3</b>	Data linkage and anonymisation	To ascertain if potential linkage variables are present across datasets, and assess current practices with regard to data linkage and anonymisation methods.
<b>4</b>	Data quality	To explore current data quality practices and levels of data quality expertise among staff.
<b>5</b>	Standards	To explore readiness to support and implement data discovery standards, standards for semantic interoperability and data exchange standards.
<b>6</b>	Data quality training and guidance	To assess preferences and priorities for future data quality training and guidance.

The following documents will be of benefit to you in preparing and providing your response to the survey:

- [Frequently Asked Questions on the European Health Data Space \(European Commission\)](#)
- [Guidance for data holders \(HIQA\)](#)
- [National Standards for Information Management in Health and Social Care \(HIQA\)](#)
- [HealthDCAT Ap specification – \(European Health Information Portal\)](#)

Findings of this survey and the overall readiness assessment will be published in multiple reports and will inform subsequent work streams of the HealthData@IE project, centred on improving Ireland's preparedness for the EHDS. The output from the readiness assessment will be treated confidentially. Points made will be summarised and will not be attributed to any individual or organisation.

### Instructions for completing the survey

Please note that when you were invited to complete this survey, **a specific dataset** was identified. **Questions in sections 3, 4 and 5 relate specifically to the data set and responses should be provided pertaining to the identified dataset.**

Please provide your name and contact details so that we can contact you in order to verify your responses, if required.

### Data Protection and Freedom of Information (FOI)

HIQA will only collect personal information through this survey for the purposes of verifying your response. If you have any concerns regarding your data, please contact HIQA's Information Governance and Assurance Manager at [infogovernance@hiqa.ie](mailto:infogovernance@hiqa.ie).

HIQA is subject to the Freedom of Information (FOI) Act and the statutory Code of Practice in relation to FOI. Following the readiness assessment, the survey data will be analysed and the findings will be published in multiple reports summarising the responses received. Findings from reports may include the names and types of organisations that completed the survey. For that reason, it would be helpful if you could note any information you provide in this survey that is confidential or commercially sensitive.

If we receive a request for disclosure of information under FOI, we will take full account of your explanation but we cannot give you an assurance that confidentiality will be maintained in all circumstances due to the requirements of the FOI Act.

## Section 1 Questions about the respondent

Please provide the following details for the dataset pertaining to your response.

**Q1A.** Name of person responsible for the survey response:

**Q1B.** Organisation:

**Q1C.** Current role:

**Q1D.** Name of dataset pertaining to your survey response:

**Q1E.** Contact email address:

## Section 2 Preparedness for EHDS and information management maturity

When the EHDS Regulation is fully implemented and HDAB services are established in Ireland, data holders will be required to have appropriate structures in place, including policies and procedures for sharing their metadata and data for secondary use purposes with the HDAB services. There is a need for all data holders to be aware of their obligations and what will be required of them under the regulation once it is fully implemented.

In 2024, HIQA published the *National Standards for Information Management in Health and Social Care*. These national standards can be used by data holders as a tool to enhance information management maturity and to assist with preparations for the implementation of the EHDS Regulation and the establishment of HDAB services in Ireland.

With this in mind, please provide a response to the following statements.

**Q2A.** Please indicate the level of knowledge in your organisation of the secondary use of data under EHDS with, 1 being very low and 5 being very high.

1 Very low	2 Low	3 Average	4 High	5 Very High
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q2B.** Please indicate your organisation's level of preparedness for the EHDS, with 1 being very low and 5 being very high.

1 Very low	2 Low	3 Average	4 High	5 Very High
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q2C.** Is your organisation currently taking steps to prepare for the EHDS?

☐ Yes

☐ No

Please provide further detail on your answer. (Word count 400)

**Q2D.** Is there an individual with responsibility for ensuring your organisation takes the steps necessary to prepare for the EHDS?

☐ Yes

☐ No

**Q2E.** Please indicate the level of knowledge in your organisation of the *National Standards for Information Management in Health and Social Care*, with 1 being very low and 5 being very high.

1	2	3	4	5
Very low	Low	Average	High	Very High
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q2F.** Have the *National Standards for Information Management in Health and Social Care* been implemented in your organisation?

☐ Yes, fully implemented

☐ Yes, partially implemented

☐ No

☐ Don't know

Please provide further detail on your answer. (Word count 400)

**Q2G.** Overall, how would you indicate the level of maturity of your organisation with regard to information management?

- ☐ Initial – little coordination, and practices remain ad hoc.
- ☐ Repeatable – basic practices are in place, but variation exists between people and teams.
- ☐ Defined – standardised practices are documented and in place but there is still room for improvement.
- ☐ Managed – practices are established and controlled, and regularly monitored.
- ☐ Optimised – practices are continuously monitored to enable optimisation and improvement.

## Section 3 Data linkage and anonymisation

The EHDS will create new potential for the linkage of individuals' health data from different sources safely and securely using established techniques. In order to facilitate data linkage, the use of consistent identifier variables across datasets is essential, as are appropriate methods for anonymisation of datasets, as well as the secure and controlled access to datasets through a Secure Processing Environment (SPE). An SPE is a highly-secure platform and isolated environment that allows all data processing activities to take place under supervised conditions, which will allow the HDAB control over how the data is accessed, used and processed.

With this in mind, please answer the following questions for the dataset pertaining to your survey response.

### Section 3a: Identifier variables

**Q3A.** Is there a way of uniquely identifying individuals in the dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

**Q3B.** If yes, please indicate which variable(s) are used to uniquely identify individuals. Select all that apply.

- ☐ Personal Public Service number (PPSN)
- ☐ Individual Health Identifier (IHI)
- ☐ First Name
- ☐ Last Name
- ☐ Date of Birth
- ☐ Gender
- ☐ Sex
- ☐ Address Line 1
- ☐ Eircode
- ☐ Mother's Birth Family Name
- ☐ Other



If other, please describe:

**Q3C.** Is this dataset ever linked to other datasets?

- ☐ Yes, routinely.
- ☐ Yes, on an ad hoc basis
- ☐ No
- ☐ Don't know

If yes, please describe, including the type of data linkage undertaken. (Word count 400)

**Q3D.** Is there a mechanism for recording an individual's preference regarding the processing of their data for secondary use (for example if they can opt out)?

- ☐ Yes
- ☐ No
- ☐ Don't know

Please provide further detail on your response. (Word count 400)

**Section 3b: Anonymisation**

**Q3E.** Are anonymisation techniques used on this dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please describe the anonymisation techniques used, including *how* and *when* they are used. (Word count 400)

**Q3F.** Are pseudonymisation techniques used on this dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please describe the pseudonymisation techniques used, including *how* and *when* they are used. (Word count 400)

**Q3G.** Are any other anonymisation techniques used on this dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please describe the techniques used, including *how* and *when* they are used. (Word count 400)

## Section 4. Data quality

High-quality data is data which is fit-for-purpose; that is, it meets the needs of data users. Within the context of the EHDS, assurances with regard to the quality of available data are essential to facilitate the reliable secondary use of health data. The assessment of health data quality is commonly undertaken through consideration of a number of dimensions including relevance; accuracy and reliability; timeliness and punctuality; coherence and comparability; accessibility and clarity. As set out in HIQA's *National Standards for Information Management in Health and Social Care*, organisations striving to ensure data quality should develop a data quality framework. Essential elements of a data framework include a data quality strategy, a data quality assessment tool, data quality reports and a data quality improvement cycle.

With this in mind, and considering the dataset in question, please provide responses to the following questions.

### Section 4a: Current practices

**Q4A.** Are there processes in place to improve and maintain data quality for this dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please describe. (Word count 400)

**Q4B.** Is there a data quality framework in place for the dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

**Q4C.** If yes, select which of the following components of a data quality framework are in place for the dataset. (Select all that apply)

- ☐ Data quality strategy (follow-on question below)
- ☐ Data quality assessment methods

- ☐ Data quality reports
- ☐ Data quality improvement cycle

**Q4D.** If you selected yes to having a data quality strategy in place for the dataset, please indicate which of the following components are included in the strategy. (Select all that apply)

- ☐ Governance, leadership and management structures in relation to data quality
- ☐ Data quality policies and procedures
- ☐ Training, education and development programme for data quality
- ☐ Data quality audits
- ☐ Standards for data quality

**Q4E.** Overall, how would you indicate the level of maturity of data quality practices for this dataset?

- ☐ Initial – little coordination and practices remain ad hoc.
- ☐ Repeatable – basic practices are in place, but variation exists between people and teams.
- ☐ Defined – standardised practices are documented and in place but there is still room for improvement.
- ☐ Managed – practices are established and controlled, and regularly monitored.
- ☐ Optimised – practices are continuously monitored to enable optimisation and improvement.

**Q4F.** Overall, how effective do you find current data quality policies and procedures in meeting your organisation's needs with regard to producing data that is fit-for-purpose?

- ☐ Not effective at all
- ☐ Slightly effective
- ☐ Moderately effective
- ☐ Very effective

☐ Extremely effective

#### Section 4b: Current expertise

**Q4G.** Is data quality training and education available for relevant staff members to assist them in meeting their responsibilities with regard to data quality?

☐ Yes

☐ No

☐ Don't know

If yes, please describe the data quality training and education opportunities that are currently available to staff members. (Word count 400)

**Q4H.** Overall, how would you assess current levels of data quality expertise and the ability to manage data quality amongst staff with data quality responsibilities?

☐ No expertise

☐ Little expertise

☐ Some expertise

☐ Good Expertise

☐ Extensive expertise

☐ Don't know

**Q4I.** Please indicate your perception of the current levels of expertise among staff with data quality responsibilities, across each of the following specific areas of data quality management:

	No expertise	Little expertise	Some expertise	Good expertise	Extensive expertise
<b>Metadata management and documentation</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Using relevant data quality standards</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Data cleaning techniques</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Data quality auditing and reporting</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Data integration and consolidation methods</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Developing and applying data quality metrics</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Using data quality improvement software</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Communicating data quality issues to stakeholders</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Section 5 Standards for data discoverability, semantic interoperability and interoperable communication

### Section 5a. Data discoverability standards

When HDAB services are established in Ireland, data holders will be required to use the HealthDCAT AP specification to submit metadata describing their health-related datasets for inclusion in a national health dataset catalogue (nHDsC). With this in mind, please answer the following questions for the dataset you are completing this survey on.

**Q5A.** Do you currently use a specific descriptive metadata standard to describe the dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please describe what metadata standard is currently in use. (Word count 400)

**Q5B.** Have you used the general DCAT-AP specification (not HealthDCAT-AP) to describe the dataset?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please provide further details on your answer. (Word count 400)

**Q5C.** Do you currently have plans in place to use the Health DCAT-AP (health-related extension of DCAT-AP) to describe the dataset, in preparation for the EHDS?

- ☐ Yes
- ☐ No
- ☐ Don't know

If yes, please provide further details on your answer. (Word count 400)

**Q5D.** Are details about your dataset currently discoverable by data users through any of the following? (Select all that apply)

- ☐ Search engine
- ☐ Browsing catalogue
- ☐ Viewing metadata
- ☐ Other

Please provide details on how your datasets are discoverable. (Word count 400)

**Q5E.** Does your organisation currently share descriptive **metadata** (from the dataset you are providing a response on) with other systems?

- ☐ Yes
- ☐ No

If yes, please provide information on the methods you utilise to share your data.

- ☐ Manual submission through file uploads (for example, CSV)
- ☐ Manual submission through form-based user interface (UI)
- ☐ Uploading data via an application programming interface (API) (push)
- ☐ HDAB service harvests data via an API (pull)

If yes, please provide information on the metadata you currently share with other systems. (Word count 400)



## Section 5b Standards for semantic interoperability and interoperable communication

When the EHDS is fully implemented and HDAB services are established in Ireland, data holders will be required to provide data to the HDAB service in response to permit requests being granted. With this in mind, please provide a response to the following questions.

**Q5F.** Does your organisation currently share **aggregated** data (from the dataset pertaining to your survey response) with other systems?

☐ Yes

☐ No

If yes, please provide information on the data you currently share with other systems, and the systems and methods you utilise to share your data. (Word count 400)

**Q5G.** Does your organisation currently share **individual-level** data (from the dataset pertaining to your survey response) with other systems?

☐ Yes

☐ No

If yes, please provide information on the methods you utilise to share your data.

- ☐ Manual submission through file uploads (for example, CSV)
- ☐ Manual submission through form-based user interface (UI)
- ☐ Uploading data via an application programming interface (API) (push)
- ☐ HDAB service harvests data via an API (pull)

If yes, please provide information on the data you currently share with other systems. (Word count 400)

**Q5H.** Please indicate your organisation's level of preparedness for providing data to a HDAB service, with 1 being very low and 5 being very high.

1	2	3	4	5
Very low	Low	Average	High	Very High
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Q5I.** Does your organisation have a plan in place for providing data to the HDAB service using the standards for interoperability identified at the European level?

- ☐ Yes
- ☐ No
- ☐ Don't know

**Q5J.** Overall, how would you indicate the level of maturity of this dataset with regard to the implementation of standards for semantic interoperability and interoperable communication?

- ☐ Initial – little coordination and practices remain ad hoc.
- ☐ Repeatable – basic practices are in place, but variation exists between people and teams.
- ☐ Defined – standardised practices are documented and in place but there is still room for improvement.
- ☐ Managed – practices are established and controlled, and regularly monitored.
- ☐ Optimised – practices are continuously monitored to enable optimisation and improvement.

**Q5K.** What standards for semantic interoperability are implemented in the dataset pertaining to your survey response? Please select all that apply.

- ☐ LOINC
- ☐ SNOMED CT
- ☐ Orphanet codes
- ☐ ICD-10-AM

☐ Other

If other, please describe. (Word count 400)

**Q5L.** What standards for data exchange are implemented in the dataset pertaining to your survey response? Please select all that apply.

☐ HL7 version 2.x

☐ HL7 FHIR

☐ DICOM

☐ Other

If other, please describe. (Word count 400)

## Section 6 Preferences and priorities for future training and guidance

As part of the HealthData@IE project, HIQA will be developing a range of data quality guidance and training materials for data holders. With this in mind, please provide a response to the following questions.

**Q6A.** Which of the following topics do you believe is most critical to include in data quality guidance and training to support you in becoming prepared to meet data holders' obligations with regard to data quality under the EHDS regulation. (Select all that apply)

- ☐ Key data quality criteria and indicators
- ☐ Applying a data quality label to datasets
- ☐ Metadata management and documentation
- ☐ Data quality standards
- ☐ Data maturity assessment
- ☐ Effective data quality tools and technologies
- ☐ Data quality audit and reporting
- ☐ Data quality metrics
- ☐ Data governance strategy and policy development
- ☐ Data quality improvement strategies
- ☐ Standards for semantic interoperability
- ☐ Standards for data exchange

**Q6B.** Are there any additional topics or skills related to data quality that you would like to see included in future training and guidance developed by HIQA? (Word count 400)

**Q6C.** What format of data quality education would you find most suitable? Please rank your top three in order of preference (1 being the most preferred).

- \_\_\_ In-person workshops
- \_\_\_ Live webinars
- \_\_\_ Self-paced online courses
- \_\_\_ Reading materials, including process guides, guidance documents
- \_\_\_ Short informative videos
- \_\_\_ Checklists

- \_\_\_ Peer-to-peer learning opportunities
- \_\_\_ Other (please specify) (Word count 400)

**Q6D.** If you have used any particular data quality guidance or resources that you have found useful, please provide the names and links in the box below.



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