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: Diabetes Use Case Overview

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1   Purpose statement

As part of the HealthData@IE project, HIQA is undertaking a readiness assessment. To conduct the assessment, HIQA has selected three use cases comprising influenza, diabetes and colorectal cancer, to understand the readiness and preparedness of the Irish health system to access data for secondary purposes in the context of these three diseases. By carrying out this readiness assessment, HIQA will explore if adequate structures are in place to enable the secondary use of data, using the examples of influenza, diabetes, and colorectal cancer to further our understanding of these important diseases. The key data sources and the associated data holders for each use case will be identified and selected for inclusion in the various stages of the readiness assessment which comprises a desktop review of available evidence, a survey, focus groups and interviews.

> The overarching aim of this readiness assessment is to obtain a baseline view of data holders' levels of preparedness for the establishment of Health Data Access Body (HDAB) services in Ireland across multiple areas, and to identify where gaps exist and what steps need to be taken to ensure Irish data holders can meet future obligations under the European Health Data Space (EHDS) Regulation.

The specific objectives of the readiness assessment are:

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 data sources.

2. To identify whether there is capability and 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 discovery of their data, coding of data and the exchange of data with a future HDAB service.

4. To raise awareness among data holders about what their obligations will be under the EHDS, and explore perceived barriers and facilitators to the implementation of the EHDS and the establishment of HDAB services in Ireland.

5. To identify and prioritise data holders' data quality guidance and training needs.

6. To identify the steps required, and outline a pathway to support data holders to make the required changes to ensure compliance with the EHDS Regulation.

The findings of this readiness assessment will inform many of the HealthData@IE deliverables, including the development of data quality guidance and training for data holders, a national interoperability framework as part of Work Package 8, and the development of a national health dataset catalogue (NHDsC) as part of Work Package 6.

2   Methodology

2.1   Selection of use cases

The topics of the three use cases topics were selected to align with those included in the HealthData@EU Pilot, chosen by the European Commission, and the minimum categories of electronic data for secondary use, as outlined in the EHDS Regulation. The topics of the Data Access Sharing Storage Linkage (DASSL) project case studies were also taken into consideration.[1] See **Table 1** for an overview of the three use cases.

Table 1. HealthData@IE use cases

Use case one: Influenza The aim of this use case is 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 (for example older adults). **Use case two: Diabetes** The aim of this use case is to demonstrate the feasibility of using available data to enhance our understanding of diabetes (type 1 and type 2), to compare care pathways, measure clinical outcomes, costs of care, and enable better planning of services. **Use case three: Colorectal Cancer** The aim of this use case is to demonstrate the feasibility of linking clinical and genomic data to enhance our understanding of colorectal cancer, including incidence, risk factors (for example lifestyle, environment and genetic factors), aetiology, and long-term outcomes.

2.2   Approval

This use case overview has been reviewed by project governance structures in place to guide and support the work of WP8. Approval was provided by HIQA's internal grant oversight group, chaired by HIQA's Director of Health Information and Standards.

3   Overview of diabetes in Ireland

3.1   Definition

Diabetes mellitus is a lifelong condition caused by a lack or insufficiency of insulin.[1] The two main types of diabetes are:

- Type 1 diabetes: an autoimmune condition that causes destruction of the insulin-producing cells in the pancreas. As a result of the loss of insulin production, people with type 1 diabetes must administer subcutaneous insulin in order to manage their blood glucose.[2]
- Type 2 diabetes: a common metabolic disorder characterized by chronic hyperglycaemia.[3]

3.2   Incidence

Accurate determination of diabetes prevalence in Ireland would be enhanced through the introduction of a national diabetes registry, which could track the pervasiveness of the condition, measuring outcomes, determine cost of care and planning for future services.[2][3] The current estimate is that anywhere between 20,000 to 30,000 individuals live with type 1 diabetes, in Ireland.[4] Approximately 272,904 individuals have been estimated to have type 2 diabetes.[5] In total, it is believed that there are over 300,000 people diagnosed with diabetes across the country.[6] According to Irish Longitudinal Study on Aging (TILDA) data, 10% of those over the age of 50 have type 2 diabetes, with a higher prevalence of the disease in men as opposed to women.[7] Levels of childhood diabetes in Ireland are found to be among the top 25% of countries internationally, with the highest rates in the 10 to 14 year group.[8] According to a Global Burden of Disease study, in 2021 there were approximately 428 deaths attributable to diabetes mellitus in Ireland.[9]

3.3   Diabetes services in Ireland

A National Clinical Programme was established in 2010 to oversee the provision of health services to individuals living with diabetes. This programme is run in collaboration with the Health Services Executive (HSE) and the Royal College of Physicians of Ireland (RCPI). A national working group was set up to inform the development of this programme, comprising representatives from those living with

diabetes, health service professionals and academic experts in the study of diabetes.[2] The programme has published a clinical guideline setting out the recommended model of care for adults with type 1 diabetes.[4] It has also published a report setting out best practice in the care of individuals with type 2 diabetes.

Those diagnosed with diabetes receive multi-disciplinary team interventions delivered in a range of settings from local GP clinics to outpatient and in-patient hospital contexts depending on clinical need. Guidance regarding diabetes technologies such as insulin pumps, continuous glucose monitors (CGM) and flash glucose monitors (FGM) or smart pens is also provided as required. These devices are prescribed by the relevant medical professional and supplied through the reimbursement scheme.[10]

In 2024, the Diabetes Policy and Services Review Group was established by the Department of Health to consider the current status of services for individuals with diabetes and to make recommendations for future service provision. The group comprises of stakeholders from the Department of Health, the HSE and Diabetes Ireland; they are expected to set out a strategic direction for service provision in the area of diabetes.[6]

4　Details of identified data sources

A number of core Irish data sources have been identified to be explored in this use case. This process was informed by a study which explored available data that might facilitate the development of a national diabetes register. This research concluded that the Medical Card Prescriptions (MCP) Scheme and the Long Term Illness (LTI) Scheme data sources formed the most reliable sources of data for individuals with diabetes.[11] These data sources are now incorporated into the Primary Care Reimbursement Service. A feasibility study was also undertaken to identify sources of data that might be used to audit paediatric service provision in Ireland.[12] Findings from both these studies informed the inclusion of the data sources as follows:

- Primary Care Reimbursement Service (PCRS)
- Chronic Disease Management programme
- Hospital In-Patient Enquiry (HIPE)
- Irish Childhood Diabetes National Register
- Diabetic RetinaScreen programme
- Irish National ICU Audit
- Vital Statistics – Death Registration
- National Paediatric Mortality Register
- MedLis.

A full overview of each data source is set out below.

4.1   Primary Care Reimbursement Service (PCRS)

Name of data holder	HSE – National Health Schemes Data
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☒ Individual Health Identifier ☒ First Name ☒ Last Name ☒ Date of Birth ☒ Gender ☒ Address Line 1 ☒ Eircode ☒ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case	▪ health services provided ▪ medications dispensed ▪ diabetes-related medical devices dispensed.

4.2   Chronic Disease Management Programme (CDMP)

Name of data holder	HSE – National Health Schemes Data
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☐ Individual Health Identifier ☒ First Name ☒ Last Name ☐ Date of Birth ☐ Gender ☒ Address Line 1 ☐ Eircode ☐ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case	▪ diagnoses ▪ risk factor data ▪ investigations data.

4.3   Hospital In-Patient Enquiry (HIPE)

Name of data holder	HSE – Healthcare Pricing Office
Data dictionary publicly available	☒ Yes
Identifier variables included in the dataset	☐ Individual Health Identifier ☒ First Name ☒ Last Name ☒ Date of Birth ☒ Gender ☐ Address Line 1 ☒ Eircode ☐ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	▪ principal diagnosis (DIAG1) ▪ additional diagnosis (DIAG2-DIAG30) ▪ hospital acquired diagnosis 1 (HADX1) ▪ hospital acquired diagnosis 2-30 (HADX2-HADX30) ▪ number of days in intensive care environment (ITUDAYS) ▪ admission type (ADMTYPE).

4.4   Irish Childhood Diabetes National Register (ICDNR)

Name of data holder	Children's Health Ireland (CHI)
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☐ Individual Health Identifier ☐ First Name ☐ Last Name ☒ Date of Birth ☒ Gender ☐ Address Line 1 ☐ Eircode ☐ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	▪ date of first insulin injection ▪ symptoms and duration of symptoms (in days/weeks) ▪ blood results at diagnosis ▪ associated conditions/autoimmune disease.

4.5   Diabetic RetinaScreen

Name of data holder	HSE – National Screening Service
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☐ Individual Health Identifier ☒ First Name ☒ Last Name ☒ Date of Birth ☐ Gender ☒ Address Line 1 ☐ Eircode ☒ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	▪ diabetic retina screening history.

4.6   Irish National ICU Audit

Name of data holder	HSE – National Office of Clinical Audit
Data dictionary publicly available	☒ Yes
Identifier variables included in the dataset	☐ Individual Health Identifier ☒ First Name ☒ Last Name ☒ Date of Birth ☒ Gender ☐ Address Line 1 ☐ Eircode ☐ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case	▪ past medical history ▪ clinical diagnosis ▪ ICU and hospital discharge data.

4.7 Vital Statistics – Death Registration

Name of data holder	Central Statistics Office
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☐ Individual Health Identifier ☐ First Name ☐ Last Name ☐ Date of Birth ☒ Gender ☒ Address Line 1 ☐ Eircode ☐ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	▪ cause of death.

4.8 National Paediatric Mortality Register (NPMR)

Name of data holder	HSE – National Office of Clinical Audit
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☐ Individual Health Identifier ☐ First Name ☐ Last Name ☒ Date of Birth ☒ Gender ☐ Address Line 1 ☐ Eircode ☐ PPSN ☐ Mothers Birth Family Name
List of variables relevant to this use case (not exhaustive)	▪ cause of death.

4.9 MedLis

Name of data holder	HSE – Technology and Transformation
Data dictionary publicly available	☒ No
Identifier variables included in the dataset	☐ Individual Health Identifier ☒ First Name ☒ Last Name ☒ Date of Birth ☒ Gender ☒ Address Line 1 ☐ Eircode ☐ PPSN ☐ Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	▪ hospital medical record number (MRN) ▪ tests carried out.

5   Details of other potential data sources

There are a number of other potential data sources that will be explored in this use case. These are as follows:

- Hospital records: A hospital patient administration system (PAS) contains patient demographics and tracks all patient contact with the hospital. All hospitals have some system in place, but many use outdated technology.[13] Follow-up is needed to identify specific data variables and the issues to be addressed in making these data available for secondary use.

- Community Care Services: Given the range of community care services engaging with individuals at different stages of their illness, it is likely that there will be relevant data sources across a range of community-based initiatives. The East Coast Area Diabetes Programme is an example of such a project and may provide insight into the types of data sources collected by a range of community service providers.[14] A further example is a project which investigated the feasibility of collecting information on those at risk of foot issues due to diabetes in one community service area.[15] Other information held locally are registers of those attending training courses to support them in the management of their diabetes.[16] The national Community Healthcare Visualisation project which aims to streamline data collection and sharing processes across all community healthcare organisations will be an important source of information in exploring how these data sources might be accessible for secondary use.[17]

- Clinical trials data: The HRB Diabetes Collaborative Clinical Trial Network has been established to support the conduct of clinical trials in the study of diabetes.[18] This network may be able to provide insight on the availability of data on clinical trials for secondary analysis.

- Medical Devices: The Primary Care Reimbursement Service (PCRS) contains records of medical devices prescribed for individuals with diabetes.[10] This will include insulin pumps, continuous glucose monitors (CGM), flash glucose monitors (FGM) and smart pens. Additional suppliers and sources of data on the use of devices in the treatment of diabetes will also need to be explored in this use case.

6 International examples of diabetes data linkage studies

6.1 Causes of mortality in patients with diabetes

Welsh researchers explored patterns and causes of mortality in patients diagnosed with diabetes for the period 1991 to 1997.[19]

The study involved linking mortality records with inpatient data, outpatient data, a diabetes outpatient database and an audit of GP practice databases. Data of a total of 1,694 individuals was linked in this process and indicated that 38% of patients with diabetes had this identified as their immediate cause of death, while 49.1% of patients with diabetes had cardiovascular disease listed as cause of death. The authors concluded that reliance on mortality data alone was not sufficient in understanding patient outcomes and made recommendations to enhance data systems in order to facilitate further data linkage capacity.

6.2 Impact of deprivation on patient outcomes

In Scotland, researchers explored the association between living in an area identified as geographically deprived and developing complications as a result of a diagnosis of diabetes.[20]

Records of 112,231 individuals diagnosed with diabetes were extracted from the Scottish Care Information - Diabetes Collaboration (SCI-DC) database. These were then linked to mortality records, data on diabetic foot ulceration and lower extremity amputation. Results were then mapped to NHS deprivation maps. The results indicated that diabetic foot ulceration, lower extremity amputation and mortality are linked to multiple deprivations and form geographically neighbouring clusters.

6.3   Relationship between attendance at primary care and hospitalisation rates

An Australian data linkage study was undertaken to explore the relationship between attendance at primary care services and subsequent hospitalisation rates for individuals diagnosed with diabetes.[21]

Data on 20,433 patients' care was extracted from a Medicare database. Specific variables explored were continuity of primary care, completion of an annual programme of care, having a GP management plan, the review of a GP management plan and the tests carried out. These datasets were linked for each individual to the New South Wales administrative data for hospital admissions. Results indicated the importance of strengthening attendance at primary care for reducing levels of hospitalisation.

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