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: Influenza Use Case Overview

April 2025

Co-mhaoinithe ag an Aontas Eorpach
Co-funded by the European Union

Health Information and Quality Authority
An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

An Roinn Sláinte
Department of Health

HRB
An Bord Taighde Sláinte
Health Research Board

Table of Contents

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 Heath 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 Heath 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 placeto 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 Influenza in Ireland

3.1 Definition

Seasonal influenza is an acute respiratory infection, which negatively impacts individuals, the healthcare system and society.[2] It is a preventable infectious disease caused by the influenza virus, which spreads through saliva droplets that are coughed up or sneezed into the air by an infected person.[3] Influenza viruses derive from the Orthomyxoviridae family of virus. Four influenza viruses have been identified, types A, B, C and D, although type D is not usually active in humans.[4] When individuals are exposed to a new version of the virus to which they have no immunity, influenza viruses can lead to pandemics.

Influenza-A viruses are divided into subtypes based on two proteins on the surface of the virus: hemagglutinin (H) and neuraminidase (N). At present, 18 different hemagglutinin subtypes and 11 different neuraminidase subtypes (H1 through H18 and N1 through N11) have been identified. In humans, the most common subtypes of influenza-A viruses in circulation among people are A(H1N1) and A(H3N2).[5] It has been estimated that influenza infects up to a billion people annually, causing severe illness in up to five million cases. Globally, it has also been reported to cause between 290,000 to 650,000 deaths each year.[6]

3.2 Treatment

The symptoms of influenza include fever, cough, sore throat, body aches and fatigue. For most individuals with a mild infection, these symptoms resolve in a number of days. However, in the case of a severe infection, medical intervention may be required.[6] The Health Protection Surveillance Centre (HPSC) have set out treatment guidelines for those infected by influenza. Depending on disease severity, the guidelines indicate the following approach:

- Non severe influenza: Uncomplicated, non-severe, influenza illness is characterised by symptoms which include a sudden onset of cough, headache, muscle and joint pain, severe malaise, sore throat and rhinorrhoea, with or without fever. Most people recover from the fever and other symptoms within a week, without requiring medical attention.

- Severe influenza: Influenza virus can also cause severe illness (such as sepsis, septic shock, severe pneumonia, acute respiratory distress syndrome [ARDS], multi-organ failure, exacerbation of chronic medical conditions) or death. The above severe conditions would normally require hospitalisation and in some critical cases, the provision of oxygen, mechanical ventilation (invasive or non-invasive) and, or vasopressor therapy.[7]

A key consideration in the treatment of influenza is ensuring appropriate medical care is delivered to those at risk of severe disease, including older adults, children aged between six months and four years, pregnant women, individuals with weakened immunity and those with the chronic medical conditions.[6]

3.3 Vaccination

In order to address the risk posed by seasonal influenza, an annual vaccination programme is undertaken aimed at specific at-risk groups with the objective of reducing the impact of the disease.[2] The HSE provide a free flu vaccine to those aged 60 years and older, those aged two to 17 years, to health workers, pregnant women, individuals who live in a nursing or care home and those in regular contact with pigs, poultry or waterfowl.

In addition, a free flu vaccine is available to those who have a health condition, or those who care for or live with an individual with a health condition. The specific health conditions that place individuals at risk of severe infection are defined as:

- chronic heart disease, including acute coronary syndrome
- chronic liver disease
- chronic kidney failure
- chronic respiratory disease, including chronic obstructive pulmonary disease (COPD), cystic fibrosis, moderate or severe asthma, or bronchopulmonary dysplasia
- chronic neurological disease including multiple sclerosis (MS), hereditary and degenerative disorders of the central nervous system
- diabetes
- Down syndrome
- haemoglobinopathies
- a body mass index (BMI) over 40
- metabolic disorders
- immunosuppression due to disease or treatment (including asplenia or hyposplenism, and cancer)
- serious mental health conditions
- children with a moderate to severe neurodevelopmental disorder such as cerebral palsy

- children on long-term aspirin therapy
- any condition that can compromise respiratory function, like spinal cord injury, seizure disorder or other neuromuscular disorder, especially among people attending special schools or day centres.[8]

The vaccine is designed to target the outer protein coating of influenza virus. However, this outer coating of the virus is regularly changing, therefore it is necessary to update the flu vaccine in response.[9] In practice, this requires health services to fund and implement an annual vaccination programme. Recent analysis indicates that for people aged 65 years and older, there is merit in considering the introduction of a more enhanced vaccine, given its potential to be more effective than the current programme.[2]

During flu season, the HPSC publishes weekly reports on vaccination rates across the Irish population. Data on the 2024-2025 season indicates that 20.2% of children between the ages of two and 17 years had received a flu vaccine. This is below the 50% target rate for this group. However, the data also indicates that 74.3% of older adults had received a flu vaccine, which is line with the target rate of 75% for this population.[10]

The rate of vaccine uptake among health care professionals is also monitored. Data for the 2023-2024 season indicates that there was a take up of 50.8% uptake among hospital healthcare staff, a slight decrease from 54.4% the previous season. (2022-2023). Healthcare staff working in long term care facilities had a 42.2% uptake rate for the 2023-2024 season, a slight decrease from 53.5% from the previous year.[11]

3.4 Incidence

Influenza has been classed as a notifiable disease in Ireland, placing a duty on medical practitioners to notify cases of the disease to the HSPC.[12] Information is submitted to the HSPC using the Computerised Infection Disease Reporting system (CIDR). This system is used to record all notifications of infectious diseases in Ireland. Using submitted data, the HSPC regularly publishes updates on the level of influenza circulating in the community throughout the flu season, which runs from October to May each year. [13] Current data indicates that for the 2024-2025 season, the HSPC were notified of 20,750 cases of influenza at a weekly rate of 20.9 per 100,000.[14]

Between 2010 and 2020, adults aged 65 years and older stayed in hospital for an average of nine days when diagnosed with influenza, using approximately 3,853 hospital bed days per year. The cost of hospital care for those aged 65 years and older has been estimated at approximately €6.03 million per annum. It has also

been estimated that during the 2022-2023 season, patients aged 65 years and older presenting with influenza type illness accounted for 899.6 per 100,000 consultations in primary care.[2]

4 Details of identified datasets

HIQA conducted a desktop review of data sources in the area of influenza in Ireland. Analysis indicated that there are a number of core data sources across a range of public service bodies. These sources are:

- Primary Care Reimbursement Service (PCRS)
- Hospital In-Patient Enquiry (HIPE)
- Irish National ICU Audit
- Computerised Infectious Disease Reporting (CIDR)
- COVAX - National COVID-19 Immunisation System
- Vital Statistics – Death Registration
- The Irish Longitudinal Study on Aging (TILDA).

A full overview of each data source is outlined in sections 4.1 to 4.7.

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.

4.2 Hospital In-Patient Enquiry (HIPE)

Name of data holder	**HSE – Healthcare Pricing Office (HPO)**
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).

4.3 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.

4.4 Computerised Infectious Disease Reporting (CIDR)

Name of data holder	**HSE – Health Protection Surveillance Centre (HPSC)**
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	▪ positive laboratory results (organism, type, specimen and test details ▪ onset and diagnosis dates ▪ hospitalisation status ▪ outcome.

4.5 COVAX - National COVID-19 Immunisation System

Name of data holder	**HSE – Office of the Chief Clinical Officer and the National Immunisation 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	▪ influenza vaccination records.

4.6 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.

4.7 The Irish Longitudinal Study on Ageing (TILDA)

Name of data holder	**Trinity College Dublin**
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)	▪ health assessment measures.

5 Details of other potential data sources

There are a number of other potential data sources that will be explored in this use case, including:

- Hospital records: A hospital patient administration system (PAS) contains patient demographics and tracks all patient contacts with the hospital. All hospitals have some system in place but many use outdated technology.[15] Follow-up is needed to identify specific data variables and the issues to be addressed in making these data available for secondary use.

- Regional immunisation records: As part of the HSE's national immunisation programme, local health offices maintain records of children's vaccinations received.[16] This use case will facilitate an exploration into how these data might be utilised for secondary analysis.[17]

6 International examples of influenza data linkage studies

6.1 Risk from COVID-19 and influenza on patients with cancer

This research explored whether cancer survivors and patients who were cancer-free differed in the development of complications arising from COVID-19 and from severe influenza.[18]

Data was linked for individuals who had survived cancer for more than one year. The linked data sets were primary care data, cancer registry data, hospital admission data and death registrations. In total, data from 108,215 patients who had survived cancer was included, alongside 523,541 individuals who were cancer-free.

Across the data set, the risk of influenza hospitalisation or death was higher in cancer survivors compared to those with no history of cancer. The risks of severe COVID-19 outcomes were also found to be increased for cancer survivors. These findings support efforts to prioritise both influenza and COVID-19 vaccination programmes for those living with a cancer diagnosis.

6.2 Streptococcal disease and incidence of influenza

A study in Victoria, Australia explored the association between invasive group A streptococcal disease (iGAS) and incidence of influenza, varicella and chronic hepatitis C virus (HCV).[19] The researchers were able to link data of individuals who had a diagnosis with iGAS using data from the Victoria Hospital Pathogen Surveillance Scheme (VHPSS). This linkage of 1,949 individuals was facilitated by a diagnostic code in a dataset for all hospital admissions.

The study found that the relative risk of iGAS increased following an infection with influenza. The rates of iGAS was also higher for those who inject non prescribed drugs. These findings were useful to public health officials in tracking the incidence and follow-up of iGAS disease in the community.

6.3 Effectiveness of the influenza vaccine

A linked data research design was used by a team of researchers in England to investigate the effectiveness of the influenza vaccine among children aged one to 17 years and in adults over 50 years, during the 2021-2022 flu season.[20] Vaccination records were obtained from the National Immunisation Management Service (NIMS). Data were linked to records of emergency department presentation with respiratory swab results within a defined period of the presentation.

Using this method, it was possible to link records of 33,340 adults and 6,583 children. Results indicated good protection against emergency presentation of children with modest protection against emergency presentation for adults. The data also indicated increased effectiveness for vaccine against the A(H1N1) virus as opposed to the A(H3N2) virus circulating in that flu season.

7 References

1. Fennelly O, Moriarty F, Corrigan D, Grogan L, Wong SS. *Proof of concept: Technical prototype for Data Access, Storage, Sharing and Linkage (DASSL) to support research and innovation in Ireland*. Dublin: Health Research Board; 2022.
2. Health Information and Quality Authority. *Health technology assessment of use of an enhanced inactivated influenza vaccine for those aged 65 years and older in the HSE Seasonal Influenza Vaccination Programme.* Dublin: 2024. Available from: https://www.hiqa.ie/sites/default/files/2024-10/HTA_Enhanced-inactivated-influenza-vaccines-for-over-65s.pdf. Accessed on: 07 February 2025.
3. Irish Thoraic Society. *Influenza* [Online]. Available from: https://irishthoracicsociety.com/lung-disease/influenza/. Accessed on: 07 February 2025.
4. European Centre for Disease Prevention and Control. *Factsheet about seasonal influenza* [Online]. Available from: https://www.ecdc.europa.eu/en/seasonal-influenza/facts/factsheet#the-pathogen. Accessed on: 07 February 2025.
5. Centers for Disease Control and Prevention. *Types of Influenza Viruses* [Online]. Available from: https://www.cdc.gov/flu/about/viruses-types.html. Accessed on: 07 February 2025.
6. World Health Organisation. *Influenza (seasonal)* [Online]. Available from: https://www.who.int/en/news-room/fact-sheets/detail/influenza. Accessed on: 07 February 2025.
7. Health Protection Surveillence Centre. *Guidance on the use of antiviral agents for the treatment and prophylaxis of Influenza.* Dublin: 2024. Available from: https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/guidance/antiviraltreatmentandprophylaxisguidance/Antivirals%20guidance%20for%20treatment%20and%20prophylaxis%20of%20%20influenza.pdf. Accessed on: 07 February 2025.
8. Health Service Executive. *Flu vaccine overview* [Online]. Available from: https://www2.hse.ie/conditions/flu/vaccine/. Accessed on: 07 February 2025.
9. European Centre for Disease Prevention and Control. *Why do I need a flu vaccine every year?* Dublin: 2016. Available from: https://www.ecdc.europa.eu/sites/default/files/documents/influenza-why-do-I-need-flu-vaccine-every-year-infographic.pdf. Accessed on: 07 February 2025.
10. Health Protection Surveillence Centre. *Influenza Vaccine Uptake in Ireland in 2024-2025 season* Dublin: 2025. Available from: https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/vaccination/Seasonal%20Influenza%20Vaccine%20Uptake%20in%20Ireland%20Week%203%202025.pdf. Accessed on: 07 February 2025.

11. Health Protection Surveillence Centre. *Influenza vaccine uptake in healthcare workers and residents of long term care facilities.* Dublin: 2025. Available from: https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/vaccination/vaccineuptakeinhcwsandresidentsofltcfs/Seasonal%20Flu%20Vaccine%20Uptake%20in%20Hospitals%20LTCFs-2023-2024-July%202024_Final_1.pdf. Accessed on: 07 February 2025.
12. S.I. No. 528/2024 - Infectious Diseases (Amendment) (No. 2) Regulations Dublin: Government of Ireland; 2024. Available from: https://www.irishstatutebook.ie/eli/2024/si/528/made/en/print. Accessed on: 14 February 2025.
13. Health Protection Surveillence Centre. *Influenza Season 2023 - 2024* [Online]. Available from: https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzasurveillancereports/previousinfluenzaseasonssurveillancereports/20232024season/#:~:text=During%20the%20flu%20season%2C%20which,season%20in%20April%20and%20May. Accessed on: 07 February 2025.
14. Health Protection Surveillence Centre. *Integrated Respiratory Virus Bulletin, Ireland -Week 5 2025 (26/01/2025 - 02/02/2025).* Dublin: 2025. Available from: https://www.hpsc.ie/a-z/respiratory/acuterespiratoryinfection/surveillance/integratedreports/IRV_bulletin_week_05_2025.html#1_Key_messages. Accessed on: 07 February 2025.
15. Health Service Executive. *National Electronic Health Record - Strategic Business Case.* 2016. Available from: https://www.ehealthireland.ie/media/uwbdglci/national-ehr-strategic-business-case-appendices.pdf. Accessed on: 10 December 2024.
16. Health Service Executive. *Request my vaccine records* [Online]. Available from: https://www.hse.ie/eng/health/immunisation/whoweare/requestrecord.html#:~:text=You%20will%20need%20to%20contact%20your%20local%20health%20office%20to,contact%20them%20for%20your%20record. Accessed on: 07 March 2025.
17. Health Service Executive. *National Immunisation Office Strategic Plan 2024-2027.* 2024. Available from: https://www.hse.ie/eng/health/immunisation/infomaterials/niostrategy.pdf. Accessed on: 10 December 2024.
18. Carreira H, Strongman H, Peppa M, McDonald HI, Dos-Santos-Silva I, Stanway S, et al. Prevalence of COVID-19-related risk factors and risk of severe influenza outcomes in cancer survivors: A matched cohort study using linked English electronic health records data. *EClinicalMedicine*. 2020; 29-30:100656. Available from: https://doi.org/10.1016/j.eclinm.2020.100656. Accessed on: 10 February 2025.
19. Goldsmith JJ, Vu C, Zhu Z, MacLachlan JH, Thomson TN, Campbell PT, et al. The associations between invasive group A streptococcal disease and infection

with influenza, varicella, or hepatitis C viruses: A data linkage study, Victoria, Australia. *Int J Infect Dis*. 2024; 141:106969. Available from: https://doi.org/10.1016/j.ijid.2024.02.012. Accessed on: 10 February 2025.

20. Whitaker HJ, Hassell K, Hoschler K, Power L, Stowe J, Boddington NL, et al. Influenza vaccination during the 2021/22 season: A data-linkage test-negative case-control study of effectiveness against influenza requiring emergency care in England and serological analysis of primary care patients. *Vaccine*. 2024; 42(7):1656-64. Available from: https://doi.org/10.1016/j.vaccine.2024.02.006. Accessed on: 20 February 2025.

Published by the Health Information and Quality Authority (HIQA).

For further information, please contact:

Health Information and Quality Authority

George's Court

George's Lane

Smithfield

Dublin 7

D07 E98Y

+353 (0)1 814 7400

info@hiqa.ie

www.hiqa.ie

© Health Information and Quality Authority 2025