



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: Colorectal Cancer 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 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 colorectal cancer in Ireland

3.1 Definition

Colorectal cancer, also called bowel cancer, refers to cancer that occurs in the lower part of the bowel, that is; the colon and rectum. Colorectal cancer usually develops from benign polyps (growths of tissue that commonly occur on the mucous membrane) in the lining of the colon or rectum. These polyps, or adenomas, may become cancerous over time.⁽²⁾

This type of cancer represents approximately 10% of all diagnosed cancers worldwide and 900,000 annual deaths.⁽³⁾ Risk factors have been identified as follows:

- increasing age, with 60% occurring in those over 65 years.
- previous bowel cancers.
- family history of bowel cancer.
- inherited bowel conditions (i.e. Lynch syndrome)
- history of other bowel conditions (including benign polyps, Crohn's disease)
- obesity
- poor diet
- alcohol intake
- smoking.⁽³⁾

3.2 Incidence

In Ireland, colorectal cancer is the second most common cause of cancer-related death, with an average of 1,012 deaths per year. This represents 11.2% of cancer-related deaths in males and 9.6% of cancer-related deaths in females.⁽⁴⁾ Colorectal cancer was the second most commonly diagnosed cancer in males (11.2%) and the third in females (9.3%) for the period 2022-2024.⁽⁴⁾ The National Cancer Registry (NCRI) tracks the five year survival rate for those diagnosed with cancer. Data from the 2009 to 2018 period indicates a five year survival rate of 63.5% for those diagnosed with colorectal cancer, with similar rates observed in five of the six Irish health regions. A slightly lower survival rate of 59.4% is reported during this period for the HSE Mid West region.⁽⁴⁾

3.3 Cancer care services in Ireland

Since 2007, the National Cancer Care Programme (NCCP) has been in place within the HSE to coordinate all aspects of cancer care diagnosis and treatment.⁽⁵⁾ The NCCP has identified the following eight locations as regional centres for adult surgical cancer treatment:

- Beaumont Hospital
- Cork University Hospital
- Mater Misericordiae University Hospital
- St. James's Hospital
- St. Vincent's University Hospital
- University Hospital Galway
- University Hospital Limerick
- University Hospital Waterford.⁽⁶⁾

Radiotherapy services are provided in five locations. These are:

- Beaumont Hospital
- St. James's Hospital
- St. Luke's Hospital
- Cork University Hospital
- Galway University Hospital.⁽⁶⁾

There are 17 other locations across the country that provide systemic anti-cancer therapy (chemotherapy and immunotherapy).⁽⁶⁾

In 2017, a national cancer strategy was published by the Department of Health containing over 50 recommendations for improving cancer care in Ireland.⁽⁷⁾ Each year an implementation report is published setting out achievements in relation to this national strategy. In the most recent implementation report, the following updates are most relevant to colorectal cancer:

- The HSE is continuing to expand its endoscopy services to address anticipated demand, with BowelScreen services incrementally broadened to include those aged over 55 years.
- A hereditary cancer model of care was developed by a multi-disciplinary team. This impacts patients with colorectal cancer as it provides a tumour testing pathway for those diagnosed with Lynch syndrome.
- GP access to diagnostic tests for suspected cases of colorectal cancer continues to be enhanced.
- Specific guidance documents have been developed to support the conduct of multi-disciplinary case conferences for cancer patients, including those with colorectal cancer.

- Tumour specific guidance documents for cancers including colorectal cancer have been developed to ensure treatment is informed by international best practice.
- A patient and treatment summary care plan is being introduced for all patients, with a patient passport in use for patients with colorectal cancer at most cancer centres.
- A consensus statement on the standardised follow up and surveillance for colorectal cancer has been completed and published on the NCCP website.⁽⁸⁾

In relation to the key performance indicators tracked as part of the strategy, the following most recent updates are relevant for colorectal cancer:

- The rate of early detection of colorectal cancer has improved from 42.5% in 2013 to 45% in 2017; however, this is below the target increase of 10%.
- The percentage uptake for BowelScreen was 43.2% in 2022, below the target of 60%.
- The patient passport for colorectal cancer has been finalised and introduced to the majority of cancer treatment centres. This document is provided to patients on attendance for treatment. It provides information on what to expect from the various treatment options and how best to manage common side effects. It can be used by patients to record their attendance at clinics and treatment received.⁽⁹⁾
- The five-year survival rate for colorectal cancer remains outside the target of the top quartile for survival across the EU, with survival rates in Ireland ranking 9th out of 24 for rectal cancer and 13th out of 24 for colon cancer.
- There is a 5.4% lower five-year survival rate for colorectal cancer in areas of greater deprivation, higher than the 3% target difference.⁽¹⁰⁾

3.4 Screening

The national screening service for colorectal cancer is BowelScreen. This service is currently available across the population to all adults aged between 59 and 74 years.⁽¹¹⁾ Eligible adults receive an invitation to participate and are sent a home faecal immunochemical test (FIT) in the post. Approximately five in 100 people will receive an abnormal test result and be referred for a follow-up colonoscopy in hospital, with screening appointments are offered every two years.⁽³⁾ This programme is being extended incrementally to all adults over 55 years and will be offered for the first time to those over 58 years in 2025.⁽¹²⁾ An evidenced based review is currently underway to explore the benefits of extending this programme to adults over 50 years of age.⁽²⁾

3.5 Treatment

The treatment options for those with colorectal cancer include surgery, chemotherapy, biological therapy and radiotherapy.⁽³⁾ The Department of Health (DOH) has produced separate national clinical guidelines for colon and rectal cancer.^(13, 14) The National Cancer Care Programme (NCCP) has developed GP referral guidelines for cases of suspected colorectal cancer.⁽¹⁵⁾

4 Details of identified data sources

A number of core Irish data sources have been identified for exploration in this use case. This process was informed by the EOSC4Cancer project, which is a Horizon Europe-funded initiative aimed at making diverse types of cancer data accessible. It is currently developing systems for securely identifying, sharing, processing, and applying the FAIR (Findable, Accessible, Interoperable, and Reusable) principles to data across EU Member states.⁽¹⁶⁾ The EOSC4Cancer project is examining five use cases in the area of colorectal cancer aimed at demonstrating the various challenges and opportunities that will present in secondary use of data in this context.⁽¹⁷⁾ Using the EOSC4Cancer project as a guide, the following sources were identified:

- National Cancer Registry of Ireland (NCRI)
- Primary Care Reimbursement Service (PCRS)
- Hospital In-Patient Enquiry (HIPE)
- Vital Statistics – Death Registration
- BowelScreen
- National Cancer Information System
- National Drug Treatment Reporting
- National Drug-Related Deaths
- MedLis
- National Integrated Medical Imaging System (NIMIS).

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

4.1 National Cancer Registry of Ireland

Name of data holder	National Cancer Registry Ireland
Data dictionary publically-available	<input checked="" type="checkbox"/> Yes
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input checked="" type="checkbox"/> Address Line 1 <input checked="" type="checkbox"/> Eircode <input checked="" type="checkbox"/> PPSN <input type="checkbox"/> Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> ▪ basis of diagnosis ▪ mortality status ▪ treatment codes ▪ tumour codes.

4.2 Primary Care Reimbursement Service (PCRS)

Name of data holder	HSE - National Health Schemes Data
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input checked="" type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input checked="" type="checkbox"/> Address Line 1 <input checked="" type="checkbox"/> Eircode <input checked="" type="checkbox"/> PPSN <input type="checkbox"/> Mother's Birth Family Name
List of variables relevant to this use case	<ul style="list-style-type: none"> ▪ health services provided ▪ medications dispensed.

4.3 Vital Statistics - Death Registration

Name of data holder	Central Statistics Office)
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input type="checkbox"/> First Name <input type="checkbox"/> Last Name <input type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input checked="" type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> cause of death.

4.4 BowelScreen

Name of data holder	HSE - National Screening Service
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input type="checkbox"/> Gender <input checked="" type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input checked="" type="checkbox"/> PPSN <input checked="" type="checkbox"/> Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> bowel screening results, colonoscopy attendance treatments biopsy results.

4.5 Hospital In-Patient Enquiry System (HIPE)

Name of data holder	HSE - Healthcare Pricing Office
Data dictionary publicly available	<input checked="" type="checkbox"/> Yes
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input type="checkbox"/> Address Line 1 <input checked="" type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> ▪ 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).

4.6 National Cancer Information System (NCIS)

Name of data holder	HSE – National Cancer Care Programme.
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input type="checkbox"/> Date of Birth <input type="checkbox"/> Gender <input checked="" type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mothers Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> ▪ medical history ▪ cancer diagnosis ▪ treatment possibilities ▪ cancer drug treatment (also known as chemotherapy).

4.7 National Drug Treatment Reporting System (NDTRS)

Name of data holder	Health Research Board (HRB)
Data dictionary publicly available	<input checked="" type="checkbox"/> Yes,
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input type="checkbox"/> First Name <input type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mothers Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> ▪ reason for treatment ▪ source of referral ▪ history of drug use ▪ type of treatment ▪ treatment outcomes.

4.8 National Drug-Related Deaths Index (NDRDI)

Name of data holder	Health Research Board (HRB)
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input type="checkbox"/> First Name <input type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mothers Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> ▪ drug use at time of death ▪ other risk behaviours ▪ drug treatment history ▪ toxicology ▪ manner and cause of death.

4.9 MedLis

Name of data holder	HSE – Technology and Transformation
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input checked="" type="checkbox"/> Gender <input checked="" type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mothers Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> hospital medical record number (MRN) tests carried out.

4.10 National Integrated Medical Imaging System (NIMIS)

Name of data holder	HSE – Technology and Transformation
Data dictionary publicly available	<input checked="" type="checkbox"/> No
Identifier variables included in the dataset	<input type="checkbox"/> Individual Health Identifier <input checked="" type="checkbox"/> First Name <input checked="" type="checkbox"/> Last Name <input checked="" type="checkbox"/> Date of Birth <input type="checkbox"/> Gender <input type="checkbox"/> Address Line 1 <input type="checkbox"/> Eircode <input type="checkbox"/> PPSN <input type="checkbox"/> Mother's Birth Family Name
List of variables relevant to this use case (not exhaustive)	<ul style="list-style-type: none"> hospital medical record number (MRN) diagnostic images.

5 Details of 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.⁽¹⁸⁾ Follow-up is needed to identify specific data variables and the issues to be addressed in making these data available for secondary use.
- Genomics and other -omic data: This field of study is an evolving one in Ireland. The Genomic Data Infrastructure (GDI) project is exploring how this type of data use can be established in Ireland. Follow-up is needed to also explore the issues in accessing these data for secondary use.⁽¹⁹⁾
- Clinical trials data: Specific follow up is needed with the Irish cancer research community to identify data sources in the area of clinical trials that may be available for data linkage and to set out the issues to be addressed in order to facilitate this. Further information on this may be available from Cancer Trials Ireland.⁽²⁰⁾ Another potential data source in this area is the Health Research Board National Clinical Trials Office (NCTO).⁽²¹⁾ Work is also ongoing in the field of digital cancer research and there are a number of Irish projects which may provide additional context on the secondary use of data in their field of study.^(22, 23)

6 International examples of colorectal cancer data linkage studies

6.1 Impact of hospital care processes

In New South Wales, researchers used a population-based dataset to explore the differences in hospital care processes and outcomes of patients with colorectal cancer.⁽²⁴⁾

Data from 6,890 patients across 105 hospitals was statistically analysed to explore differences in their care and outcomes. In conducting this study, 10 data sources were linked, these were the NSW Central Cancer Registry (CCCR), the NSW Admitted Patient Data Collection, the NSW Registry of Birth Deaths and Marriages and six Area Health Service Clinical Cancer Registries (ClinCrS). The outcome measures tracked were; 30-day mortality, 28-day emergency readmission, prolonged length of stay, 30-day wound infection, 90-day venous thromboembolism, and 1-year mortality.

The five care processes tracked were; discussion at a multi-disciplinary team meeting, documented cancer stage, recorded pathological stage, treatment within 31 days of decision to treat, and treatment within 62 days of referral. The study found that there were significant differences in care processes for older adults leading to poorer outcomes.

6.2 Influence of sociodemographic characteristics on survival rates

A study was carried out to explore the association between sociodemographic characteristics and survival rates for colorectal cancer by researchers in South Australia.⁽²⁵⁾

A sample of 4,641 patients who had been diagnosed with colorectal cancer during the five-year period of 2003-2008 were identified. A linked dataset was created using data from three data sources; the central cancer registry, hospital data and radiotherapy data. Discrepancies in survival were explored using statistical techniques. The findings indicated that patients living in more remote locations had poorer outcomes not explained by differences in disease stage at diagnosis, tumour characteristics or treatments provided.

6.3 Comparison of emergency versus non-emergency diagnoses

Researchers in England used a data linkage study design to explore if there were pre-diagnostic differences in the presenting symptoms and care provided for patients diagnosed with colorectal cancer following presentation at emergency services as opposed to those diagnosed in non-emergency settings.⁽²⁶⁾

The study linked data from GP records to hospital records for 1,606 patients. The results indicated that while over 95% of both groups of patients had consulted their doctor in the year prior to diagnosis, the emergency group had less relevant symptoms at these appointments and had less “alarm” symptoms. However, 20% of emergency patients did have significant symptoms during their primary care appointments, indicating that an earlier and non-emergency diagnosis may have been possible.

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