

Harnessing the Power of Data to Transform Cancer Research, Care and Innovation Across the Island of Ireland



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For full acknowledgements, please see page 22

Foreword

Cancer is one of the most pressing challenges in health and wellbeing on the island of Ireland. Planning for and mitigating the impacts of significant rises in cancer incidence and poor outcomes requires robust and timely data, to develop insights to inform care, policy, research and innovation.

Timeliness of data was a critical enabler of the response to the COVID-19 pandemic, empowering the understanding, detection, prevention and treatment of the disease. However, the pandemic also exposed the shortcomings of existing approaches to collecting and using data. Lessons learned (including the need for rapid and linked data) must inform a data-driven strategy to enhance cancer research and care to improve outcomes, while unleashing innovation, both at population and individual patient levels. Making a patient's data available to them also ensures they can be an active decision-maker in their own care.

Cancer Knows No Borders, presenting an opportunity and imperative to unite data to address the cancer challenge across the island of Ireland. With a population of just over 7 million, the island represents an ideal cancer data ecosystem. There is already precedent for cross-border collaboration, with initiatives such as the Ireland – Northern Ireland – US National Cancer Institute Cancer Consortium, which has been active for over 25 years.

However, data challenges are limiting this unrivalled all-island opportunity, including in data governance, digital infrastructure, data linkage and sharing, cancer genomics and digital maturity. We need to solve these challenges to accelerate a data-enabled, research-

informed patient-centred cancer health system.

In this Report, we have analysed the current cancer data landscape in Ireland and Northern Ireland. We have considered in detail the achievements, challenges and opportunities that underpin current activities and further potential of an all-island approach from patient, clinical care, research and innovation perspectives. We articulate our ambition and present our vision to maximise the impact of cancer-relevant data, positioning the island of Ireland at the epicentre of a data-driven cancer research and innovation nexus, through an urgent **All-Island Call to Cancer Data Action**.

We urge all stakeholders – patients, healthcare providers, researchers, policymakers, politicians and the public – to commit to making the island of Ireland a global leader in cancer data and its deployment. This must include delivering on existing commitments, including giving patients access to their own medical records, and ensuring they are embedded in health data strategy going forward. By working together to implement our **7-point Cancer Data Plan**, we can transform oncology research, care, and innovation, ensuring better health outcomes for patients and powering economic growth.

This urgent Call to Cancer Data Action provides the evidence to encourage political leaders to embrace this unrivalled but time-limited opportunity to deliver better health and well-being, greater societal benefit, and enhanced economic value to the island of Ireland and its people.



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Executive Summary

Data save lives. The island of Ireland has an unrivalled opportunity to harness the power of health and care data to deliver an ambitious health and wealth agenda. Together, we can provide the evidence to transform research activity, inform equitable, person-centred care, enhance cancer outcomes, influence cancer-relevant policy and catalyse an innovation agenda that contributes to the island's economic growth. This Report "*Harnessing the Power of Data to Transform Cancer Research, Care and Innovation across the Island of Ireland*," sets out the current cancer data landscape, North and South, articulating progress achieved, significant opportunities that we must grasp and challenges that we must overcome. The aftermath of the global COVID-19 pandemic (which exposed the lack of resilience of health systems and critical gaps in data collection and data processes) represents a critical moment for those who design and deliver policy to agree an ambitious manifesto designed to enhance cancer research and dramatically improve cancer outcomes on the island of Ireland.

This Report brings together and amplifies the views and goals of multiple stakeholders across the cancer community who came together at the **Inaugural All-Island Forum for Cancer Data** held at the University of Limerick on 14th January 2025, hosted by the eHealth Hub for Cancer. Its goal is to inform an urgent **All-Island Call to Cancer Data Action** to ensure timely delivery of a vibrant digital ecosystem that supports and advances data-driven, patient-informed cancer research, care and innovation. Based on current achievements and future ambitions, the Report positions the island of Ireland as an attractive region for oncology innovation, ensuring that cancer research and care advances serve the broadest community, nationally and internationally, while also fostering investment and promoting economic growth.

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The need to address the cancer challenge is immense – cancer is now the biggest killer on the island of Ireland. 1 in 2 people will have a cancer diagnosis on the island during their lifetime. While Ireland and Northern Ireland are improving their outcomes, they can perform better compared to similar countries. At the same time, despite some notable practice-changing trials, we are not attracting as many clinical trials as other similar European countries.

Data can be the catalyst for enhancing cancer research, delivering optimal and equitable clinical care and providing insights to empower patients by supporting data-enabling informed shared decision-making, ensuring that patients are treated as equal partners, with full access to their own data. Data insights are also our North Star to inform cancer policy.

Importantly, there have been significant investments and advances in digital health in both Northern Ireland and Ireland over the past five years including the Encompass digital transformation of health and social care data, the *Northern Ireland Trusted Research Environment (NITRE)* and the *Belfast Region City Deal Innovation Centres* in Northern Ireland and the *Digital for Care 2030* initiative in Ireland.

Additional to country-level activities, there are high-quality all-island oncology data initiatives, such as the eHealth Hub for Cancer, an all-Island Hub of Excellence in digital oncology. A strong emphasis on quality digital skills is also enhancing the research and care workforce.

These investments and advances are particularly welcome, contributing to our international reputation in cancer data research. But key challenges limit the potential for a transformational all-island oncology data agenda. Northern Ireland and Ireland are at different stages of their digital health journeys e.g. in areas such as data infrastructure, data availability and usability, genomic testing capacity, data governance and data sharing. There is also a need to advance the population's overall health data literacy, building on the increased public understanding of the role of health data that emerged during the COVID-19 pandemic.

The challenges outlined in this Report represent areas of significant opportunity, which, if solved, will help position the island of Ireland as a global leader in digital oncology and its applications. As highlighted by the Taoiseach Micheál Martin at the launch of the Economics and Social Research Institute (ESRI) 2025 Report.¹

"We need data to inform all-island investment and cooperation priorities, as we build a shared future together on this island."

An Taoiseach Micheál Martin

Harnessing cancer data represents a largely untapped opportunity for the island of Ireland to present itself internationally as a credible oncology innovation ecosystem, primed to help inspire and nurture an impactful cancer research and innovation agenda. Deployment of a near "real-time" (low latency) data environment and architecture that provides patients with access to their own data, will enable collaborative cancer research and enhance clinical trial activity, including Real World Evidence (RWE) studies on the island. Realising this ambition presents an attractive, achievable opportunity to leverage an all-island economic dividend of health data.

Our Report stresses the pressing urgency of delivering digital oncology transformations at pace, so that patients, health systems, researchers and industry, working together in an equal, respectful and cooperative partnership, will derive both fair benefit and fair and equitable value, for patients, for the health systems in both jurisdictions and to enhance research and innovation that are paramount to success across the island and beyond.

Recognising this urgency, the Report issues an immediate **Call to Cancer Data Action**, urging through a 7-Point Cancer Data Plan that political leaders North and South seize this unique opportunity to improve health and well-being, promote greater societal benefits, and enhance economic value to the island of Ireland.

¹ <https://www.esri.ie/news/taoiseach-launches-esri-overarching-report-sharing-the-island-economic-and-social-challenges>

Call to Cancer Data Action

The 7-Point Cancer Data Plan

Create a robust legislative, regulatory and governance framework

Prioritise **appropriate and proportionate data legislation**, to ensure patient access to medical records, maximise research potential of health data, respect data privacy and embed patients in data governance



Invest in data infrastructure

Enhance **data infrastructure island-wide** to maximise research and innovation delivery, through investment in digital health infrastructure to overcome data fragmentation, streamline data governance processes, and enhance patient data security



Enhance digital skills

Incentivise a **cross-border digital skills agenda**, including federated data solutions, to ensure a vibrant cancer data research and innovation community, in public and private sectors



Ensure equity and inclusion

Provide opportunities for all **patients to benefit from the use of data and digital tools**, ensuring those who can benefit do so, while not leaving behind those who are digitally excluded



1

Power insight generation

Establish an appropriately-resourced **All-Island Cancer Data Innovation Centre** to deliver a patient and public approved data strategy that maximises equitable health and economic dividends. Incorporate a **Cancer Data Research Service (CDRS)**, for secure, timely access to cancer data, with appropriate governance, generating reliable intelligence to inform policymakers; Ensure cancer trend insights are appropriately shared by facilitating closer cooperation between Cancer Registries North and South, informing a **dynamic All-Island Cancer Atlas**



2

3

4

Generate linked data to fill critical gaps

Ensure comprehensive data collection to **address critical gaps in patient data**, such as genomic testing, metastatic disease, cancer inequalities and socio-economic factors. Co-create with **healthcare professionals, patients, policymakers, and data experts** to support timely clinical decisions and real world analyses



5

6



Improve health data literacy

Provide accessible opportunities to **enhance health data literacy**, including understanding cancer genomics. Co-create with stakeholders to enable shared decision-making between patient and their medical teams

7

Introduction

This All-Island Report emphasises the critical importance of data to empower cancer research, improve cancer care and outcomes and drive innovation in Ireland and Northern Ireland. It highlights significant all-island achievements but also flags challenges that are compromising optimal use of data on the island of Ireland. It sets out a vision to transform deployment of these data, and articulates an ambitious but robust roadmap through an All-Island Call to Cancer Data Action and a 7-Point Cancer Data Plan.

Context

The broader policy landscape

Before exploring the role of data in cancer research and care, it is important to understand the broader policy context. Northern Ireland and Ireland share many core principles and values and face similar social, economic, and political pressures. Key common challenges include an ageing and growing population, evolving healthcare needs, workforce planning, rising costs associated with medical technology and increasing expectations.

Sláintecare², Ireland's national ten-year healthcare reform programme aims to transform the country's health and social care system, include provision of a universal health service with equal access for every citizen, reducing waiting lists, lowering healthcare costs, shifting from hospital to community care, and improving eHealth.³ The UK's 10 year plan for the NHS will focus on "Three Shifts": moving from hospital to community care, analogue to digital, and treatment to prevention.⁴

Data have long been seen as a critical enabler of these health policy goals:

The Bengoa Report "Systems, Not Structures" published in October 2016, stressed that effective use of information was crucial for planning and delivering care in Northern Ireland, and for achieving the Quadruple Aim goals: enhancing patient experience, improving population health, reducing costs, and improving the work life of staff.⁵

Lord Darzi's Report "State of the NHS in England"⁶ indicated that data have the potential to transform healthcare. Technology such as artificial intelligence (AI) and digital systems were identified as critical drivers. However, his report notes that the NHS has not yet fully embraced technology's potential. The report calls for a significant "tilt towards technology" to unlock productivity, reduce bureaucratic burdens, and enable preventive care.

"There must be a major tilt towards technology to unlock productivity. In particular, the hundreds of thousands of NHS staff working outside hospitals urgently need the benefits of digital systems. There is enormous potential in AI to transform care and for life sciences breakthroughs to create new treatments."

Lord Darzi Report, September 2024

² <https://about.hse.ie/our-work/slaintecare-our-strategy-for-improving-irelands-healthcare-system/>

³ <https://www.gov.ie/en/department-of-health/publications/sl%C3%A1intecare-action-plan-2023/>

⁴ <https://change.nhs.uk/en-GB/projects/three-shifts>

⁵ Systems, Not Structures - Changing Health and Social Care - Full Report | Department of Health

⁶ <https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england>

The critical importance of a data-informed approach to research, innovation and care was the central pillar of the 2024 Sudlow Review Uniting the UK's Health Data: A Huge Opportunity for Society⁷:

“We are simply not maximising the benefits to society from the rich abundance of health data in the UK. Far too often research about health conditions affecting millions of people across the UK is prevented or delayed by the complexity of our data systems. We are letting patients and their families down as a result...

We need to recognise our national health data for what they are: critical national infrastructure to underpin the health of the nation.”

Professor Cathie Sudlow OBE

The Irish Government's Digital for Care: A Digital Health Framework for Ireland 2024–2030 sets out a future vision, stating that:

“It presents a vision for how we will use data and digital technology to improve our population's health and well-being, enabled by seamless, safe, secure, and connected digital health systems.

Using data and digital, we see a future where our population, our patients and those who care for them — are empowered and better informed about their care.”

Digital for Care: A Digital Health Framework for Ireland 2024–2030

Despite the benefits of data, there is unequal access to the underlying digital technology. Although there is high overall internet penetration in Ireland and Northern Ireland, significant digital inequalities persist. In Ireland, rural communities and lower-income households still face slower broadband speeds and limited access to digital devices.⁹ An estimated 25% of the population experiences some form of digital exclusion, and 27% lack basic digital skills.¹⁰ In Northern Ireland, digital poverty remains a pressing issue, particularly in rural areas and among older or economically disadvantaged groups. Digital exclusion in Northern Ireland is not solely due to infrastructure gaps, but also stems from affordability, lack of digital skills, and limited access to devices.¹¹

⁷ <https://www.hdruc.ac.uk/helping-with-health-data/the-sudlow-review/>

⁸ <https://www.gov.ie/en/department-of-health/publications/digital-for-care-a-digital-health-framework-for-ireland-2024-2030/>

⁹ <https://datareportal.com/reports/digital-2025-ireland>

¹⁰ <https://ec.europa.eu/eurostat/web/interactive-publications/digitalisation-2025>

¹¹ <https://www.nicva.org/article/the-digital-divide-in-northern-ireland-horizon-scan-of-digital-policies>

Efforts are also underway to improve digital skills for health professionals and researchers e.g. Research Ireland's Centre for Research Training in Genomic Data Science¹² and Momentum One Zero's digital skills initiative in Northern Ireland.¹³

Both Northern Ireland and Ireland have an appetite for cross-border care. There is already effective cross-border collaboration through the All-Island Congenital Heart Disease Network, with integrated cardiology and cardiac surgery services to children across the island, demonstrating the value of shared healthcare infrastructure.¹⁴ Additionally, there is provision of certain cancer services to patients in the north-west of Ireland through Altnagelvin hospital.¹⁵

At the launch of the latest Economic and Social Institute Report (ESRI) report, Sharing the Island¹⁶ An Taoiseach Micheal Martin noted that the report:

“...highlights the huge untapped potential of all-island co-operation — reflecting the Government's commitment to deepen collaboration across our island.”

An Taoiseach Micheal Martin

In both Ireland and Northern Ireland, health policy is increasingly shaped by a shared commitment to equity, innovation, and sustainability. Despite differences in structure, both systems are converging on similar goals: shifting care closer to communities, embracing digital transformation, and prioritising prevention. Central to achieving these ambitions is the effective use of health data—an enabler of smarter decision-making, better outcomes, and more responsive services. As these strategic frameworks take shape, they lay the groundwork for addressing complex and evolving health challenges including the growing burden of cancer.

The growing challenge of cancer on the island of Ireland

The island of Ireland faces a mounting cancer crisis, with incidence rates among the highest in Europe and projected to rise sharply in the coming decades. In Ireland, the number of cancer cases is projected to increase by 47% between 2022 and 2040, representing the second-highest EU growth rate (EU average growth is 18%).¹⁷ Northern Ireland is expected to experience a similar trajectory, with a 51% projected rise by 2040. This surge in both countries is attributed to demographic changes, increased life expectancy, and lifestyle factors.¹⁸ While Ireland and Northern Ireland are improving their outcomes, International Cancer Benchmarking Partnership (ICBP) analysis indicates they are doing so at a slower rate than similar countries.¹⁹

¹² SFI Centre for Research Training in Genomics Data Science

¹³ Queen's joins innovative partnership to develop future leaders in Big Data

¹⁴ [https://www.childrenshealthireland.ie/list-of-services/all-island-congenital-heart-disease-network/#:~:text=Our%20network%20provides%20Cardiology%20services,and%20Northern%20Ireland%20\(NI\).](https://www.childrenshealthireland.ie/list-of-services/all-island-congenital-heart-disease-network/#:~:text=Our%20network%20provides%20Cardiology%20services,and%20Northern%20Ireland%20(NI).)

¹⁵ <https://www.hse.ie/eng/about/who/national-services/eu-and-north-south-unit/#:~:text=People%20from%20both%20sides%20of,their%20radiotherapy%20treatment%20at%20Altnagelvin.>

¹⁶ <https://www.esri.ie/news/taoiseach-launches-esri-overarching-report-sharing-the-island-economic-and-socialchallenges#:~:text=The%20ESRI%20report%2C%20Sharing%20the,the%20Sharing%20the%20Island%20series>

¹⁷ EU Country Cancer Profiles Synthesis Report 2025

¹⁸ https://ecis.jrc.ec.europa.eu/sites/default/files/2024-09/2024_08_Factsheet_2040CancerEstimates.pdf

¹⁹ <https://www.cancerresearchuk.org/health-professional/data-and-statistics/international-cancer-benchmarking-partnership-icbp>

Cancer is also the leading cause of death in Ireland, responsible for approximately 30% of all deaths. On average, 9,800 people die from cancer annually, with, for example lung cancer responsible for one in five of these deaths. In Northern Ireland, cancer is also the leading cause of death at 28%.²⁰ 4,520 people die from cancer annually, with lung cancer being responsible for 1,033 deaths, slightly more than one in five.²¹

There are significant inequalities in cancer diagnosis, care and outcomes

The European Cancer Pulse report for Ireland highlights significant cancer inequalities, noting that individuals from the most deprived areas face higher incidence of certain cancers—such as lung and cervical—and poorer survival rates.^{22,23} Cancer death rates are ~45% higher for people living in the most deprived areas in Northern Ireland, with 630 extra cancer deaths linked to socio-economic inequality.²⁴ Research has suggested that women in Northern Ireland may be at a particularly high risk of experiencing health inequalities due to relatively high rates of poverty, deprivation, mental illness, combined with very long waiting lists compared to the rest of the UK, impacting negatively on breast cancer diagnosis and treatment.²⁵ Lower screening uptake

among deprived populations is a key driver of cancer inequalities, particularly for colorectal, breast, and cervical cancers in Northern Ireland.²⁶

People across Ireland have poor access to clinical trials

The benefits of improving patient access to clinical trials, include direct health benefits and significant economic dividends.²⁷ For example, Spain has become the leading country for clinical trial starts in Europe. Industry investment in clinical trials has risen at an average annual rate of 5.7%, climbing from EUR 479 million in 2012 to EUR 834 million in 2022.²⁸ However, while we have delivered some landmark clinical trials in both Ireland (e.g. in early breast cancer²⁹) and Northern Ireland (e.g. in metastatic prostate cancer³⁰), according to Cancer Trials Ireland, <3% of cancer patients take part in cancer trials in Ireland³¹, falling significantly short of the National Cancer Strategy’s 6% target.³² Reasons include: shortfall in attracting clinical trials; low rates of patients being asked to participate in trials. Logistical challenges with accessing and working with the data needed to identify patients and run trials efficiently³³ (see Appendix B).

²⁰ <https://www.nisra.gov.uk/publications/registrar-general-annual-report-2023-cause-death>

²¹ EU Country Cancer Profiles Synthesis Report 2025

²² The European Cancer Pulse: tracking inequalities in cancer control for citizen benefit - PubMed

²³ Cancer Inequalities in Ireland | National Cancer Registry Ireland

²⁴ https://www.cancerresearchuk.org/sites/default/files/cancer_in_the_uk_2025_socioeconomic_deprivation.pdf?_gl=1*2x9xut*_gcl_au*MTk1MTE3OTgyOS4xNzQ0NzMzMjY0*_ga*MTQyNDM2MDQ2NS4xNzI2ODQ2MjIx*_ga_58736Z2GNN*cZ3NDYzNzM5NDUKbzEwJGcwJHxNzQ2MzcOTQ1JGo2MCRsMCRoMA..

²⁵ Investigating breast cancer health inequalities in Northern Ireland | Breast Cancer Now

²⁶ Health inequalities in cancer care: a literature review of pathways to diagnosis in the United Kingdom - eClinicalMedicine

²⁷ Selby P, Popescu R, Lawler M, Butcher H, Costa A. The Value and Future Developments of Multidisciplinary Team Cancer Care. J Clin Oncol Am Soc Clin Oncol Educ Book. 2019; 39:332-340. DOI: 10.1200/EDBK_236857 PMID: 31099640

²⁸ <https://www.efpia.eu/media/0ipkatpg/efpia-ct-report-embargoed-221024-final.pdf>

²⁹ Adjuvant Chemotherapy Guided by a 21-Gene Expression Assay in Breast Cancer - PubMed

³⁰ Radium-223 and concomitant therapies in patients with metastatic castration-resistant prostate cancer: an international, early access, open-label, single-arm phase 3b trial - PubMed

³¹ <https://www.cancertrials.ie/medical-community/accruals/>

³² <https://www.cancertrials.ie/wp-content/uploads/2024/12/Cancer-Trials-Ireland-Annual-Review-2023.pdf>

³³ <https://www.cancertrials.ie/wp-content/uploads/2024/11/CTI-Clinical-Trials-Manifesto-Call-to-Action-for-print-1.pdf>

The economic burden of cancer

The economic burden of cancer was highlighted in a recent OECD Report, *“Tackling the Impact of Cancer on Health, the Economy and Society”*.³⁴ The direct healthcare cost of cancer in Ireland was estimated at €1.14 billion in 2018, with over €100 million allocated annually to cancer services through the National Cancer Control Programme (NCCP). However, these figures likely underestimate the total economic burden, as they do not account for indirect costs such as lost productivity and workforce participation. Cancer has a significant impact on the workforce. Nearly half of cancer survivors report negative effects on their career prospects, particularly among younger workers, women, and the self-employed.^{35,36} The increasing incidence rates of cancers including colorectal cancer in younger adults intensifies the economic and social consequences, as these individuals are often in their prime working years.

Learning lessons from the COVID-19 pandemic that can inform our cancer data strategy

Early in the COVID-19 pandemic, researchers globally shared and used data to first understand the disease and how it affected the population, then leveraged those insights to develop diagnostic tests and to inform design and production of vaccines and medicines to prevent COVID-19 infection or treat its consequences. Data also shone a spotlight on the disastrous knock-on effects of the pandemic on cancer health systems and cancer patients. The pandemic highlighted the urgent need for timely, reliable, and interoperable health data to inform public health measures, coordinate responses, and support research. Incomplete and incompatible datasets limited policy makers’ ability to make informed, evidence-based decisions.³⁷

The Health Foundation identified four lessons from the pandemic³⁸ that are highly relevant as we consider a cancer data strategy:

- 1. Don’t let missing data render some experiences invisible** – Health systems struggle to address everyone’s needs, partly due to missing data from certain groups, influenced by practical, economic, political, and social factors, highlighting the need for inclusive digital system design.
- 2. Include public and patient involvement as standard in health data projects** – builds trust and improves outcomes
- 3. Make open analytics the norm** – Where data was shared transparently during the pandemic, significant progress was made
- 4. Address the unequal benefits of data and technology** – There are insufficient data on how technology impacts health inequalities; evidence suggests that minorities and lower paid workers may be disadvantaged by new technologies, potentially exacerbating health disparities.

In the UK, the pandemic drove development and adoption of new data infrastructures, such as Trusted Research Environments (TREs), streamlined data curation and access processes, and promoted open sharing of research tools and outputs, acting as a catalyst for new data. While Health Data Research UK (HDR UK), the UK’s Health Data Science Institute was already in place, it pivoted rapidly to support delivery of academic-led data informed approaches³⁹ that delivered novel diagnostics and pivotal COVID-19 clinical trials.

HDR Northern Ireland became a key driver of health data science in Northern Ireland. Northern Ireland had also established its own data infrastructure, including the Honest Broker Service (HBS) and the Northern Ireland Trusted Research Environment (NITRE), supporting secure research access to health care data. These approaches not only transformed

³⁴ https://www.oecd.org/en/publications/tackling-the-impact-of-cancer-on-health-the-economy-and-society_85e7c3ba-en.html

³⁵ <https://www.cancer.ie/sites/default/files/2020-01/Real%20Cost%20of%20Cancer%202019%20report.pdf>

³⁶ <https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/14614-10061/cured-but-at-what-cost-summary-report-july-2013#:~:text=Not%20being%20able%20to%20work,of%20C2%A3860%20a%20month>

³⁷ [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(22\)00540-X/abstract](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(22)00540-X/abstract)

³⁸ <https://www.health.org.uk/features-and-opinion/blogs/four-lessons-the-pandemic-has-taught-us-about-health-data>

³⁹ <https://www.hdruk.ac.uk/covid-19-data-and-connectivity/#:~:text=Co%2Dordinate%20and%20connect%20national,to%20COVID%2D19%20for%20research>

COVID-19 research and its application, but also created a blueprint for using large-scale health data to tackle other diseases, including cancer.

The COVID-19 pandemic also exposed significant gaps in European health data systems, including fragmented and non-standardised data, underscoring the urgent need for a unified European approach to health data. This drove establishment of the European Health Data Space (EHDS). In line with EHDS requirements, Ireland is setting up a Health Data Access Body (HDAB) to enable secure data access for research and policy, aligning with the statutory requirements of the EHDS, set to be operational by 2029-2031.

These developments ensure that our data are standardised, AI-ready, and can be securely shared and analysed with European data, benefiting both population-level research and individual patient care. Integration with European data promotes benchmarking, enhancing the robustness and inclusivity of cancer research while ensuring that insights/innovations generated globally can directly benefit patients on the island of Ireland.

Building on a legacy of North/South cooperation

Co-operation in cancer research and care on the island of Ireland has a rich and distinguished history. In 1999, as a direct result of the Good Friday Agreement, a Memorandum of Understanding was signed between Ireland, Northern Ireland, and the US National Cancer Institute (NCI)⁴⁰, giving rise to the All-Ireland Cancer Consortium (AICC). The NCI's former Clinical Director Dr Bill Dahut emphasised the overall success of the Consortium when he said,

“Ireland and Northern Ireland together are now firmly embedded on the global cancer research map.”

Dr Bill Dahut

Data on the impact of the Consortium were presented at the Science Summit of the UN General Assembly at the United Nations in New York in September 2023, where the work of the Consortium was recognised as a global exemplar of the health dividend of peace.⁴¹

European Health Data Space

The European Health Data Space (EHDS) is a flagship EU initiative to create a unified framework for secure exchange and use of health data across Europe. It is the first common EU data space under the European strategy for data and a key pillar of the European Health Union. The EHDS will enable secure, standardised, and efficient sharing and use of electronic health data, both for healthcare delivery and for research, innovation, and policy-making.

- Ireland's HDAB will enable secure data access in line with EHDS.
- Supports cross-border initiatives like the eHealth Hub for Cancer on the island of Ireland.

Enhances integration with EU projects such as:

- 1+ Million Genomes (1+MG) and Genomic Data Infrastructure (GDI) – enabling federated, secure genomic data sharing.
- European Open Science Cloud (EOSC) – providing infrastructure for large-scale health data analysis.

Legal & Ethical Framework: EHDS builds on existing frameworks such as the General Data Protection Regulation (GDPR), the Data Governance Act, and the Network and Information Systems Directive. It includes specific sectoral rules considering the sensitivity of health data and provides opt-out rules for both primary and secondary use of data.

⁴⁰ <https://academic.oup.com/jnci/article/91/22/1921/2606585>

⁴¹ <https://www.qub.ac.uk/News/Allnews/2023/all-island-cancer-initiative-science-summit-un-general-assembly.html#:~:text=Professor%20Lawler%20presented%20%E2%80%9CThe%20Legacy%20of%20the,achieve%2C%20in%20research%20recently%20published%20in%20the>

Complementing this “top-down” was a “bottom-up” approach from the cancer community on the island, first articulated publicly at the Biopharma Ambition 2020, an all-island event, in March 2020⁴², leading to development of the All-Island Cancer Research Institute (AICRI).⁴³

More recently, the Shared Island initiative, launched by the Taoiseach, was created to enhance cooperation, connection, and mutual understanding on the island of Ireland, fostering reconciliation and building a shared future.⁴⁴ Its inaugural Research Funding Call recognised the quality of the cancer research on the island of Ireland, providing over one third of the funding to cancer research projects.⁴⁵ In April 2025, the Taoiseach Micheal Martin announced that the Irish Government was adding an additional €1 billion to the Shared Island Fund in the next decade,⁴⁶ delivering the largest ever programme of North/South investment.

Key drivers of innovation in healthcare and cancer

The pace of innovation offers transformative potential for prevention, detection, diagnosis, treatment and better outcomes. Some key enablers include: digital transformation; the potential of AI; the rise of precision oncology and a growing understanding of the drivers of cancer risk (Appendix C). Data underpin all of these domains, enabling us to harness the potential of these transformative capabilities.

*In April 2025, the Taoiseach Micheal Martin announced that the Irish Government was adding an additional €1 billion to the Shared Island Fund in the next decade, a significant portion of which will be dedicated to research and innovation.*⁴⁶

Data play a central role in helping improve cancer care and outcomes

Up-to-date and reliable data from clinical trials and studies incorporating “real world data” (RWD), intelligence routinely collected during the patient’s cancer journey (primary diagnosis, remission, relapse etc) are transformative. They provide valuable and actionable insights into treatment effectiveness, disease progression and outcomes, promoting more personalised treatment plans. They also delineate healthcare trends and resource utilisation, underpinning better policy decisions.

The critical role of data in cancer was highlighted in Cancer Research UK’s 2022 Cancer Data Strategy Paper⁴⁷ which emphasised a unique opportunity to leverage the collective Northern Ireland/Ireland knowledge and resources, fostering collaboration, driving research & innovation, and accelerating progress against cancer. (Refer to Appendix D for further details on initiatives ongoing in Ireland, Northern Ireland and an all-island basis.) A 2021 study on healthcare collaboration on an all-island basis identified data limitations as key barriers to progress.⁴⁸ Another study noted that lack of current data collection on cancer treatment and outcomes in Northern Ireland makes assessment, and therefore improvement to service difficult.⁴⁹ The inability to benchmark against cancer outcomes elsewhere in the UK hinders regional improvements.

⁴² <https://www.ipha.ie/wp-content/uploads/2020/05/BPA-Report-Final.pdf>

⁴³ www.AICRI.org

⁴⁴ <https://www.gov.ie/en/department-of-the-taoiseach/campaigns/shared-island/>

⁴⁵ Changing the Landscape of Cancer Research across the Island of Ireland through Collaboration - Irish Pharmacy News

⁴⁶ Keynote address by Taoiseach Micheál Martin: A new phase of the Shared Island Initiative

⁴⁷ https://www.cancerresearchuk.org/sites/default/files/cancer_research_uk_-_research_data_strategy.pdf <https://news.cancerresearchuk.org/2022/07/07/joining-the-dots-how-our-new-research-data-strategy-will-unlock-the-power-of-big-data/#:~:text=The%20foundations%20of%20our%20Research%20Data%20Strategy%20are%20to%3A&text=Make%20research%20data%20more%20findable,supportive%20cancer%20data%20science%20community.>

⁴⁸ [https://www.newrymournedown.org/media/uploads/collaborating_on_healthcare_on_an_all-island_basis_-_a_scoping_study\(1\).pdf](https://www.newrymournedown.org/media/uploads/collaborating_on_healthcare_on_an_all-island_basis_-_a_scoping_study(1).pdf)

⁴⁹ Cancer in Northern Ireland: Strategy and beyond - Research Matters

The critical role of data in cancer was highlighted in Cancer Research UK's 2022 CancerData Strategy Paper⁴⁷ which emphasised a unique opportunity to leverage the collective Northern Ireland/Ireland knowledge and resources, fostering collaboration.

According to the Cancer Strategy for Northern Ireland 2022–2032, enhancing cross-border collaboration in health data can drive also substantial economic dividends.⁵⁰ The transformative economic impact that a well-functioning oncology and digital health ecosystem could have on the island of Ireland is a key conclusion of the All-Island Oncology Industry

Report,⁵¹ commissioned by AICRI and supported by InterTrade Ireland's Synergy programme. The Report recommended creation of an All-Island Oncology Innovation Cluster to foster collaboration, fast-track new business opportunities, and attract investment, island-wide.

Key international data standards, principles and initiatives

It is also important to position within the wider international context. A list of key international data standards and initiatives which include the following: (see more in Appendix E)

- **OMOP** (Observational Medical Outcomes Partnership): A common data model that standardises health data for large-scale, reproducible research.
- **MEDOC** (Minimal Essential Description of Cancer): A core dataset to improve cancer care by capturing key clinical, demographic, and treatment data.
- **FHIR** (Fast Healthcare Interoperability Resources): A standard for flexible, electronic exchange of healthcare information to support interoperability.
- **GA4GH** (Global Alliance for Genomics and Health) Standards: Frameworks that enable secure, federated sharing of genomic and clinical data.
- **DICOM** (Digital Imaging and Communications in Medicine): The global standard for storing and sharing medical imaging, now extended to digital pathology.

Key principles governing the use of data assets:

- **FAIR** (Findable, Accessible, Interoperable, Reusable) Principles: Guidelines to make data more usable by both humans and machines through better stewardship.
- **Five Safes Framework**: A model ensuring safe access to data by focusing on people, projects, settings, data, and outputs.
- **Data Observability**: Practices to monitor data quality, freshness, structure, and lineage to ensure reliability.
- **TREs** (Trusted Research Environments): Highly secure platforms that allow researchers to analyse sensitive data without compromising privacy.
- **Federated Data Models**: Systems that allow decentralised data analysis while keeping data under local control and governance.
- **OpenSAFELY**: A secure, open-source platform for analysing health data at scale without exposing raw patient information.

⁵⁰ [doh-cancer-data-moving-forward.PDF](#)

⁵¹ https://intertradeireland.com/assets/files/All-Island-Oncology-Industry-Report_FINAL.pdf

Key enablers to harness the power of data

Strong governance: Establish robust governance structures that prioritise patient rights and data privacy. Include clear policies, procedures, and oversight mechanisms to guide collection, storage, and sharing of data. Build/maintain trust through patient involvement, transparency and accountability.

Efficient, low-latency, patient privacy-protecting data infrastructure: Develop secure, scalable data infrastructure that ensures patient privacy and complies with data protection regulations. Ensure Low latency (minimal delay in processing and providing data), to deliver operational efficiency, inform decision-making and enhance outcomes.

Data integration: Cancer data intelligence is inherently complex, involving multi-modal, multisector and longitudinal data. Integrate patient data, from various sources, including primary and secondary care, patient-reported data and wearable technologies, to ensure a comprehensive understanding of a patient's journey and optimising care pathways. Explore federated solutions, reducing the need for data transfer.

Data interoperability: Establish interoperable data systems, allowing seamless and rapid data exchange across healthcare providers to improve care coordination and decision-making. Facilitate interoperability to enable insight generation. Deliver "one source of the truth" that is accessible (with appropriate governance) by health professionals, researchers and patients⁵²

Data quality: Implement quality assurance and testing protocols to ensure data reliability and integrity.

Training and education for the public, patients, and health professions: Empower patients to play an active role in contributing their data and supporting their appropriate use. Enhance health data literacy among stakeholders. Involve patients in education programs to build trust. Train healthcare professionals on data advances relevant to cancer care

Patient access to their own data: Ensure patients have access to their own records for direct care, as recommended in the Scally Report (2018).⁵³

Dedicated resources and appropriately skilled staff: Dedicate sufficient trained staff for data collection, analysis, skill development, and translating research into policy/guidelines.

Stakeholder engagement: Involve patients, healthcare providers, researchers, and policymakers in co-creation processes. Establish patient and public advisory panels. Maintain regular communication on data activities. Implement feedback mechanisms

⁵² A patient-led survey on information and communication needs of patients with metastatic breast cancer in Ireland and Northern Ireland (CTRIAL-IE 23-05) - PubMed

⁵³ <https://assets.gov.ie/static/documents/scoping-inquiry-into-cervicalcheck.pdf>

...but significant challenges remain

Despite significant progress, the island of Ireland still faces certain challenges in advancing data-informed cancer research, clinical trials, patient care, and innovation. Some of these challenges are highlighted below: (For detailed description of challenges, please refer to Appendix F)

Legislative and regulatory frameworks:

Ireland lacks a unified digital health system and a single patient identifier, hindering efficient data sharing. The introduction of the Individual Health Identifier (IHI), the Digital for Care 2030 strategy, and the Health Information Bill aim to address this. Diverging data governance frameworks between Ireland (strict GDPR interpretation) and Northern Ireland (UK Data Protection Act) complicate cross-border collaboration.

Policy and strategy coordination:

Ireland needs better alignment with European standards, particularly the European Health Data Space (EHDS), to standardize data practices. Coordination with the UK's Health Data Research Space (HDRS) is also essential for North-South joint initiatives.

Data infrastructure investment:

Ireland lags in Electronic Health Record (EHR) adoption, with cancer EHRs urgently needed. Both jurisdictions face challenges in secure data access, standardization, and infrastructure scalability. Cancer registries use international standards but converting data to formats like Observational Medical Outcomes Partnership (OMOP) is resource-intensive. Although Health Information and Quality Authority (HIQA), The National Genetics and Genomics Office (NGGO) can define standards and support clinical data use and the National Cancer Registry Ireland (NCRI) can provide data, there is a lack of national health or cancer research data entity with a legal mandate to define data standards, store and archive data. Environmental sustainability must also be considered due to the energy demands of data processing.

Data sharing:

Data silos between hospitals in Ireland limit comprehensive patient views. Governance issues and the absence of a common data model hinder cross-border data sharing, affecting research on cancer trends and treatment outcomes.

Digital skills enhancement:

A cross-border digital skills agenda is needed, including integrating data science into health education. Public understanding of genomics must improve to support informed health decisions and foster a robust research community.

Critical data gaps:

Suboptimal clinical genomic testing capacity, especially in Ireland, poses a significant challenge to harnessing genomic insights for personalised cancer care. Socioeconomic data gaps hinder efforts to address cancer disparities.

Challenges in using data to drive and deliver research:

The lack of up-to-date, patient data from across their diagnosis and treatment journey and mechanisms to appropriately access these data has a major impact on research. It also places an increased administrative burden on clinicians who are participating in these studies.

Health data literacy:

Enhancing health data literacy across the island is crucial to ensure that patients, health professionals, policymakers, and the public, are equipped with the necessary skills to engage with health data effectively – understanding how data are generated, governed, accessed and used.

Patient involvement:

While patient advocacy is strong in both jurisdictions, there is no unified mechanism to embed patient voices in shaping an all-island cancer data strategy.

5. Our Vision

With a population of just over 7.0 million and a strong history of all-island cancer collaboration, the island of Ireland is uniquely positioned to become a leader in data-driven cancer innovation. With cancer incidence expected to double in the coming years, now is the time for both jurisdictions to align in adoption of international standards, build secure, cross-border, AI-ready federated data research infrastructure, and support academic-industry partnerships.

Our vision is to transform oncology research, care, and innovation on the island of Ireland by harnessing the power of data, including Real World Data (RWD). By deploying data to turbo-charge cancer research, empower clinical trials and real world studies, enhance clinical care, and inform cancer policy, we can also help secure economic benefit. This will be achieved by:

Figure 1: Both clinical trials and Real World Evidence (RWE) play a critical role in informing a learning health care system

Clinical trial data inform clinical practice



Real World Evidence helps optimise patient care and informs future research

5.1. Optimising patient care

Data play a pivotal role in supporting the earlier detection, diagnosis, identification of optimal treatments, coordination of their delivery for individual patients and providing longer term insights which feed-back into optimal care for all patients. The Hereditary Cancer Model of Care initiative recently launched by Ireland's National Cancer Control Programme is an exemplar of using genetic insights to improve identification and management of people with inherited cancer predisposition.⁵⁴ By adopting new approaches such as precision oncology, the island of Ireland can help optimise patient care by providing more effective and targeted treatments. Two critical enablers are availability of tissue/blood samples, through an integrated biobank, and deployment of genomics and digital pathology to interrogate those samples and make decisions in relation to diagnosis, prognosis and the monitoring of patients both during and following therapy. Northern Ireland has a national biobank <https://nibiobank.org.uk/> whereas in Ireland biobanking is somewhat fragmented.⁵⁵

By integrating genomic data with RWD, healthcare providers can identify genomic markers for early detection, accurate diagnosis and treatment optimisation, predicting patient response and develop targeted therapies, with fewer side effects. Additionally, leveraging data can help identify opportunities for prevention-focused initiatives, improving overall health outcomes. The report Sequencing Success: Genomics for Cancer Research and Care⁵⁶ (Cancer Research UK) highlights the transformative potential of genomic sequencing in cancer research and care, leading to personalised treatment and improved patient outcomes.

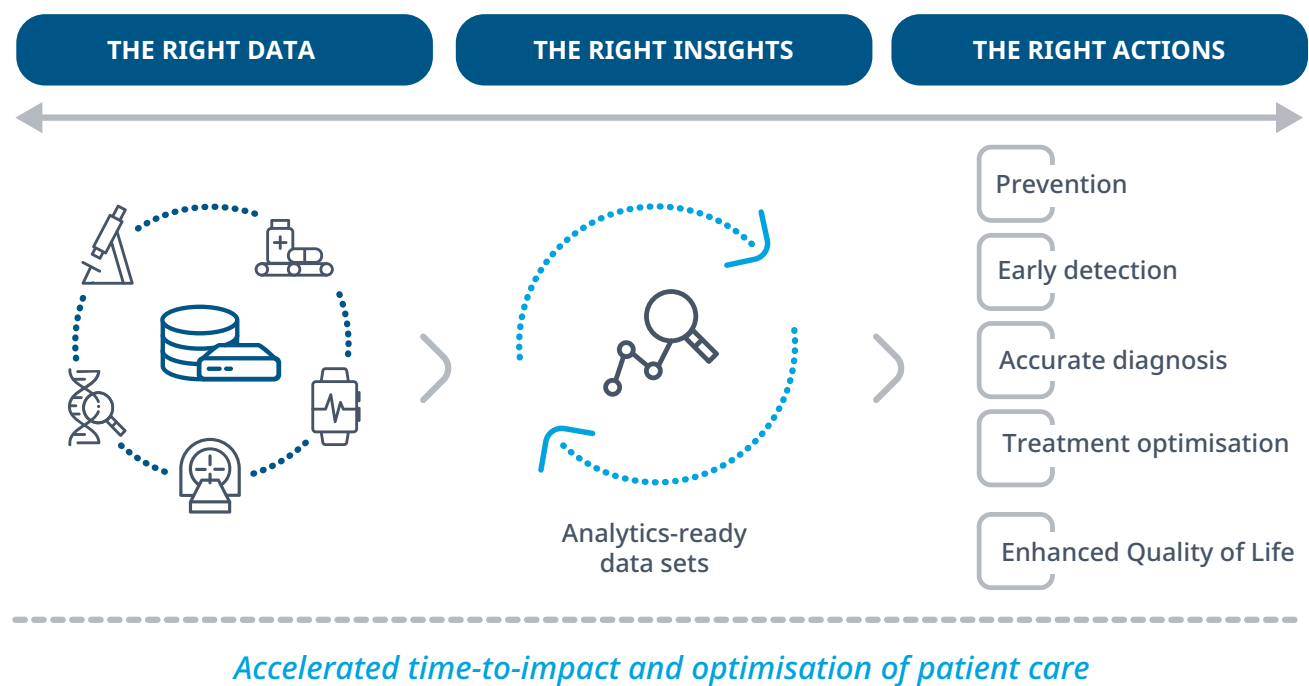
Integrating health data with data on socio-economic status, gender, age and ethnicity) will help identify inequities for timely intervention, ensuring equitable care for all.

⁵⁴ <https://www.hse.ie/eng/services/list/5/cancer/news/launch-of-hereditary-cancer-model-of-care.html>

⁵⁵ Building a 'Repository of Science': The importance of integrating biobanks within molecular pathology programmes - PubMed

⁵⁶ https://www.cancerresearchuk.org/sites/default/files/sequencing_success_-_genomics_for_cancer_research_and_care_-_full_report_november_2024.pdf?11

Figure 2: Integrating genomic data with real world data enables healthcare providers to identify genomic markers, personalise care, and improve health outcomes



Increasing patient access to clinical trials

Data must play a critical role in improving access to clinical trials on the island of Ireland. In July 2024, the Minister of Health established the National Clinical Trials Oversight Group (NCTOG) to enhance access to clinical trials and increase the number of trials conducted in Ireland. One of NCTOG’s objectives was to identify and optimise use of data, metrics, and KPIs related to clinical trials, aiming to provide a comprehensive view of the clinical trials landscape, including research infrastructure.

Data must play a critical role in improving access to clinical trials on the island of Ireland.

This would support the Department of Health in policymaking and improving national performance in research and innovation. The group’s draft recommendations focus on streamlining contracts with pre-arranged templates and standardising cost frameworks. Additionally, they emphasised the need for a clear national policy to address the complexities of ensuring compliance with data protection regulations.

Ways in which data play a critical role in clinical trials include:

- **Integration of Real World Data (RWD):** RWD can streamline clinical trial processes, informing trial design⁵⁷, leading to faster approvals and more efficient use of resources.
- **Rapid patient identification:** Harnessing data to support rapid patient identification and accelerate clinical trial recruitment ensures that the right patients benefit. This also allows life science companies to complete trials more efficiently, enabling all patients with the relevant profiles to access innovative therapies in a timely fashion.
- **Electronic Data Capture (EDC):** Efficient systems to support electronic data capture during clinical trials improve efficiency, attracting of the latest, most innovative trials to the island.
- **Addressing slow recruitment challenges:** Utilising AI to analyse health records, data, and RWD can enhance patient identification and recruitment processes, delivering more timely and effective clinical trials.

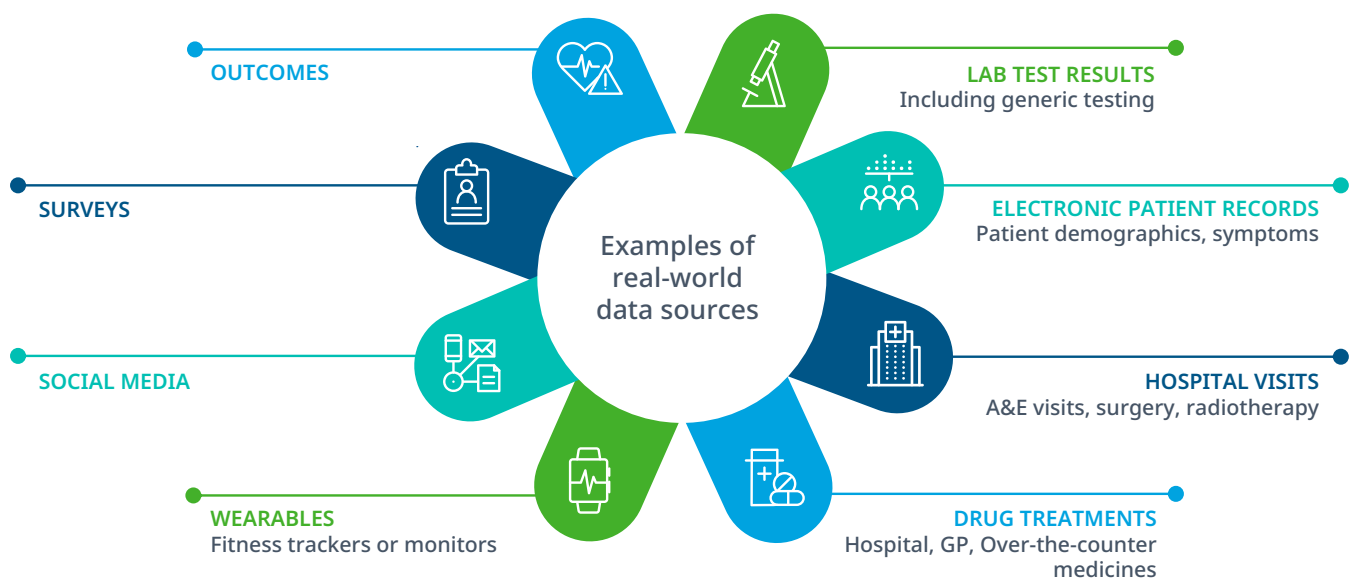
Attracting Real World Evidence (RWE) studies

RWE is the clinical evidence about benefits or risks of medical products derived from analysing real world data (RWD). These are data collected through routine clinical practice (see figure 3).

RWE studies offer significant benefits as an adjunct to clinical trials. They provide insights into how treatments perform in diverse, real world populations, beyond the controlled settings of clinical trials. This can help identify long-term safety and effectiveness, uncover rare adverse events, and understand treatment adherence and patient outcomes in routine clinical practice. Additionally, RWE can support regulatory and reimbursement decisions, inform clinical guidelines, and enhance the generalisability of clinical trial findings, ultimately leading to more informed healthcare decisions and improved patient outcomes.

Robust mechanisms to capture RWD and make it appropriately available for analysis would enable the island of Ireland to participate in RWE national and multi-country studies, ensuring that relevant insights are generated and economic benefits are delivered.

Figure 3: Real world data is any information captured in day-to-day healthcare – it can come from a wide variety of sources



⁵⁷ <https://joppp.biomedcentral.com/articles/10.1186/s40545-023-00590-9>

Prioritisation and fast tracking new drug approvals

Ireland has faced challenges in the timely approval and reimbursement of EMA-approved cancer medicines.⁵⁸ This lag is partly due to complex health technology assessment (HTA) processes and the need for robust evidence to support reimbursement decisions. Most new therapies – over 80% – are now genomically indicated. A national somatic variant database would be increasingly important for genomically-indicated cancer medicines, supplementing clinical trial data and inform reimbursement decisions. Further investment in data infrastructure, standardisation, and regulatory frameworks is needed to fully realize their potential.

Most new therapies – over 80% – are now genomically indicated.

Maximising the economic dividends of cancer data for the island of Ireland

The economic dividends of investing in oncology data are substantial, as set out in the Cancer Strategy for Northern Ireland 2022–2032.⁵⁹ It also fosters development of small and medium-sized enterprises (SMEs) and university spinouts on the island. Integration of digital health technologies and RWD can create significant innovation and entrepreneurship opportunities.⁶¹

The direct burden of cancer on the economy is also significant. A study into the economic burden in colorectal cancer across Europe revealed that it had an economic impact of €19.1 billion.⁶² This figure includes

non-healthcare costs from loss of productivity due to disability, premature death, and opportunity costs for informal carers, and direct healthcare costs from hospital care, systemic anti-cancer treatment, primary care and emergency care. Addressing these costs through improved cancer care and outcomes can attract further investment in healthcare infrastructure, create high-value jobs and stimulate economic activity,⁶³ a key conclusion of the All-Island Oncology Industry Report.⁶⁴

Involvement of initiatives like *Momentum One Zero* will be crucial in this regard.⁶⁵ *Momentum One Zero* is a business-led innovation centre at Queen's University Belfast, that aims to transform Northern Ireland's digital economy and enhance its digital one health footprint, by substantially increasing digital innovation activities, through a "secure connected intelligence" approach that maximises the power of data.

Ensuring unwavering support and resources for delivering best practices in oversight and regulation are essential. Collaboration with healthcare providers, researchers, policymakers, regulators, and industry partners will drive adoption of RWE studies. Transparency in data practices and involving patient representatives in governance will build and maintain trust.

A study into the economic burden of just one type of cancer, colorectal cancer across Europe revealed that it had an economic impact of €19.1 billion.⁶²

⁵⁸ <https://link.springer.com/article/10.1007/s11845-025-03930-7>

⁵⁹ <https://nican.hscni.net/2022/04/01/a-cancer-strategy-for-northern-ireland-2022-2032/>

⁶⁰ https://pureadmin.qub.ac.uk/ws/portalfiles/portal/148196922/Lawler_et_al_2016_Cancer.pdf

⁶¹ <https://www.epo.org/en/news-events/news/new-case-studies-highlight-how-innovation-fights-cancer>

⁶² <https://pubmed.ncbi.nlm.nih.gov/34329626/>

⁶³ <https://pubmed.ncbi.nlm.nih.gov/34329626/>

⁶⁴ https://static1.squarespace.com/static/62ff577d16a2401d731b1772/t/66438cdb6ba4b64564fbca3d/1715703027064/All+Island+Oncology+Industry+Report_FINAL.pdf

⁶⁵ <https://www.qub.ac.uk/about/belfast-region-city-deal/momentum-one-zero/>

Moving Forward: A 7-Point Plan to harness the power of cancer data

Our Call to Cancer Data Action is designed to ensure that data are a key enabler of transformation, such that the island of Ireland assumes a leading role in data-informed cancer research, healthcare innovation and treatment optimisation, and that the economic dividend of data and their deployment are fully realised.

1 Create robust legislative, regulatory and governance framework

Prioritise delivery of appropriate and proportionate data legislation to maximise the research and innovation potential of health-relevant data, both within and across jurisdictions, while respecting data privacy. Ensure patients and the public are embedded in governance of data-related initiatives.

Compliance with national and international regulations and standards for data protection and privacy will safeguard patient information and foster trust in data-driven initiatives. These efforts will establish a robust legislative and regulatory framework that prioritises the delivery of appropriate and proportionate data legislation, maximising the research and innovation potential of health-relevant data while respecting data privacy. DATA-CAN's approach serves as an example of good practice in public and patient involvement and engagement (PPIE) in governance. By involving patient representatives in its key governance structures, DATA-CAN ensures transparency and trust in the use of health data. Both the Patients Voice in Cancer Research (Ireland) and the Northern Ireland Cancer Research Consumer Forum are also delivering robust and innovative PPIE in cancer overall.

2 Power insight generation

Establish an appropriately resourced All-Island Cancer Data Innovation Centre to deliver a patient and public approved data research and innovation strategy that maximises health and economic dividends.

This would include a **Cancer Data Research Service (CDRS)**, a secure portal for secure, accountable and timely access to cancer data and research, with appropriate governance respecting privacy and the public good, with patient and public members as gatekeepers, aligning with the activities of MITRE. As part of its remit it would generate appropriate, reliable and timely insights to inform governments North and South on cancer-relevant issues, challenges and opportunities. Ensure data insights can be appropriately shared and analysed to derive advanced analytics, AI-empowered learnings and insights on cancer trends by facilitating closer cooperation between Cancer Registries North and South, informing a **dynamic All-Island Cancer Atlas**, that is AI-ready, multi-modal and longitudinal.

Setting up a Cancer Data Research Service, ideally within the All-Island Cancer Data Innovation Centre, can help to leverage data from clinical trials and RWD to enhance the understanding of treatment efficacy, safety, and long-term impacts. Emphasising rapid testing for genomic profiling and capturing data promptly will help support personalised care and insight generation from the data, deliver a patient and public approved R&I strategy that maximises both health and economic dividends of cancer data on the island of Ireland.

Coordinating a strategy to make health data a critical national infrastructure will facilitate closer cooperation between NICR and NCRI. Implementing a CDM for the two registries ensures data consistency and accuracy, enabling effective data sharing and collaboration. Combining data to create a unified dataset supports sharing data intelligence and capturing relevant learnings on cancer trends. These efforts will inform a dynamic All-Island Cancer Atlas, ensuring comprehensive and coordinated data-informed collaborative efforts across the island.

Other areas of focus include the need for socio-economic data to inform understanding of inequalities in access to and experience of care. These data are generated by the Administrative Data Research Centres in Northern Ireland and by the CSO in Ireland.

3 Invest in data infrastructure

Enhance secure data infrastructure island-wide, so as to maximise the delivery of clinical trials and digital technologies studies, with an emphasis on investigator-led studies and Real World Evidence initiatives.

Implementing robust security measures to protect sensitive health data from unauthorised access and breaches is crucial. Developing interoperable data systems and fostering collaboration will enhance data infrastructure island-wide. A TRE like NITRE to facilitate the safe and efficient use of health data will ensure data security, accessibility, and integration, building on the work of the Data Institute. To ensure effective data exchange and integration, both regions should actively support adoption of common international data standards, such as FHIR (Fast Healthcare Interoperability Resources). Considering federated analysis of health data as an alternative to a centralised TRE would ensure a flexible and robust infrastructure for advancing data-enabled cancer research and care. Robust data infrastructure will maximise delivery of clinical trials and digital technologies studies, with an emphasis on investigator-led studies and RWE initiatives.

4 Generate data to fill critical gaps

Ensure comprehensive data collection to address critical gaps in patient data, focusing on domains such as genomic testing capacity, data on cancer recurrence and the influence of socio-economic and environmental factors. This initiative should be co-designed with healthcare professionals, patients, policymakers, and data experts to support timely clinical decisions and real world analyses.

Focused attention is needed to fill critical gaps in the data generated and gathered about patients. In particular, this Report highlights issues with genomic testing capacity across the island. Northern Ireland has

already made significant progress in this regard with the establishment of the Personalised Medicine Centre of Excellence at Queen's University Belfast.^{66,67} As part of deploying this capability, digital infrastructure needs to be in place to ensure clinicians treating individual patients have rapid access to the data to make timely clinical decisions, but also that data are made appropriately available to understand adoption of innovative diagnostic tests and support RW analyses. Another critical gap is the absence of data on recurrence /metastasis – 90% of deaths in patients with solid tumours are as a result of metastasis.⁶⁸

5 Enhance digital skills

Incentivise a cross-border digital skills agenda, to ensure productive cancer data research and innovation communities, maximising the island's digital potential.

A skills assessment undertaken by the Belfast Region City Deal partnership has identified significant increased demand for digital skills at various levels. This includes addressing skills imbalances across the region through socially inclusive progression pathways that maximise inclusion and diversity and supporting the drive for increased innovation capability to help achieve world-leading advantage in the digital sector. Under the Digital One Health Hub of Impact, Momentum One Zero will promote the development of skills in building AI models and exposure to real world challenges and environments, through project-based learning.

6 Improve health data literacy

Provide accessible opportunities to enhance health data literacy across the island, (including cancer genomics), appropriately co-designed with and for different stakeholders including patients health professionals, policy makers, and the public.

Initiatives like the Northern Ireland Cancer Research Consumer Forum (NICRCF)⁶⁹, NITRE⁷⁰, the Patient Voice

⁶⁶ Integrated molecular pathology: the Belfast model - PubMed

⁶⁷ Multimodal analysis and the oncology patient: Creating a hospital system for integrated diagnostics and discovery - PubMed

⁶⁸ The lingering mysteries of metastatic recurrence in breast cancer - PubMed

in Cancer Research (PVCR)⁷, IPPOSI⁷² and UseMyData⁷³ will engage patients and the public, ensuring their perspectives are central to data governance and usage.

Bridging the digital health divide is also crucial to prevent exacerbation of existing health inequalities. We want to ensure that all individuals on the island of Ireland benefit from the transformative potential of data in improving cancer prevention, detection, treatment, and long-term outcomes. Simultaneously, public awareness campaigns across the island will improve overall digital health literacy of patients, empowering confidence in engagement with digital health services, accessing their own health information, and actively participating in their care. By improving health data literacy, we can ensure data intelligence is a key enabler of transformation.

7 Equity and inclusion

Provide opportunities for all patients to benefit from the use of data and digital tools, ensuring those who can benefit do so, while not leaving behind those who are digitally excluded.

Ensure all patients have access to the benefits of data and digital tools by creating inclusive opportunities. This involves reaching to those who are digitally excluded, providing education and training programs to improve digital literacy. Policies that guarantee equitable access to digital health resources, regardless of socioeconomic status, geographic location, or other barriers are needed. By doing so, we can ensure that everyone can benefit from advancements in digital health, fostering a more inclusive and equitable healthcare system.

Concluding remarks

The island of Ireland has an unparalleled opportunity to position itself as a world-leader in cancer innovation and patient care and outcomes by achieving all-island cancer data excellence. This Report outlines the current cancer data landscape and achievements to date, emphasises the challenges that must be addressed and sets out the significant opportunities that can be realised for people North and South including:

- **Enhancing Equitable Care:** Data-driven insights can help address disparities in cancer care, ensuring that all patient groups receive equitable treatment and support
- **Transforming Research Activity:** By leveraging health and care data, the island of Ireland can significantly enhance cancer research, leading to more effective treatments and better patient outcomes from insights from both trials and real world studies
- **Empowering data-driven Policy:** Comprehensive data can inform cancer-relevant policies, leading to more effective and targeted healthcare strategies
- **Catalysing Innovation:** The development of a vibrant digital ecosystem on the island of Ireland can attract investment from the private sector, fostering innovation and contributing to economic growth

By focusing on our 7-point strategic framework, the island of Ireland can leverage its strengths to position itself as a global leader in digital oncology, fostering investment, promoting economic growth, and ensuring equitable care and outcomes for all.

⁶⁹ <https://cancertrials.hscni.net/about-us/ni-cancer-research-consumer-forum/about-us/>

⁷⁰ <https://dhcni.hscni.net/digital-strategy/data/>

⁷¹ <https://www.ucd.ie/patientvoicecancer/>

⁷² <https://ipposi.ie/>

⁷³ <https://www.usemydata.org/>

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Authorship contribution statement

The concept of the Report was developed by Professor Mark Lawler (Queen's University Belfast (QUB) and eHealth Hub for Cancer) and Professor Aedin Culhane (University of Limerick and eHealth Hub for Cancer). All authors, Professor Mark Lawler, Professor Aedin Culhane, Professor Deirdre Heenan (Ulster University), Debbie Keatley (Patient Advocate and Northern Ireland Cancer Research Consumer Forum), Doctor Damien Bennett (Northern Ireland Cancer Registry (NICR) and QUB), Siobhan Gaynor (Patient Advocate and Cancer Trials Ireland (CTI)), Professor Maeve Lowery (Trinity College Dublin), and Doctor Stephen McCabe (Momentum One Zero and QUB), contributed to the writing of this report. All authors reviewed this report.

Disclosure/conflict of interest statement

All authors have declared that they have no conflicts of interest.

Contributors

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Methodology

Overview

The process of developing this paper involved initial concept creation, early and ongoing stakeholder engagement, draft development, intelligence collection, analysis, iterative refinement, and finalisation:

Initial Concept Creation

Strategic Framework Development:

- Created a strategic framework, outlining challenges and opportunities in data utilisation for cancer research, care and innovation.

Literature Review:

- Reviewed existing literature and data sources to identify key themes and best practices.

Stakeholder Engagement and Draft Report Creation

Core Working Group Formation:

- Formed core working group with healthcare providers, researchers, and patient representatives.
- Developed an initial draft document
- Held regular meetings for progress updates and feedback.

Outreach and Collaboration:

- Engaged a wider group of stakeholders to gather diverse perspectives.

All-Island Forum on Cancer Data:

- Conducted consultation session to collect intelligence on challenges and opportunities at the All-Island Forum on Cancer Data hosted by the e-Health Hub for Cancer (University of Limerick, January 14th 2025).
- There were over 250 attendees

Data Collection and Analysis

Consultation Feedback:

- Collected and analysed data from consultation sessions to identify common themes.

Real World Evidence Discussion:

- A facilitated discussion at the All-Island Forum on Cancer Data highlighted the importance of real world evidence in improving cancer treatments.

Iterative Refinement

Draft Review and Feedback:

- Shared draft document with stakeholders for review and incorporated feedback.

Continuous Improvement:

- Conducted regular reviews to ensure relevance and alignment with stakeholder needs.

Finalisation and Dissemination

Report Finalisation:

- Finalised Report to provide a roadmap for enhancing data-informed cancer research, care and innovation on the island of Ireland

Dissemination:

- Launched Final Report at Inaugural All Island Cancer Summit (Croke Park, 14th May 2025)
- Disseminated Final Report widely to relevant stakeholders using various channels.

Appendices

Appendix A: Collaboration partners involved in creating this paper

The eHealth Hub for Cancer (www.ehealth4cancer.ie)

The eHealth Hub for Cancer is an emerging hub of excellence funded by the Irish Higher Education Authority (HEA) Shared Island North-South Research Programme. It is dedicated to enhancing the use of data (including RWD) across the island of Ireland, through a collaborative approach involving researchers, patients, clinicians and allied health professionals, academic institutions, clinical centres, and research organisations. The Hub aims to unlock and share health data, to inform a digital oncology approach to enhance cancer research, deliver data-informed insights, and improve cancer care.

Cancer Knows No Borders project⁷⁴

The “Cancer Knows No Borders” project is supported by the Keough-Naughton Institute for Irish Studies at the University of Notre Dame and its collaborative project with the Royal Irish Academy – Analysing and Researching Ireland North and South (ARINS).

The All-Island Cancer Research Institute (AICRI) (www.aicri.org)

AICRI unites 11 universities and their associated hospitals, together with cancer charities, patient advocacy groups and industry. Its mission is to provide an overarching framework for cancer research across the island of Ireland, from discovery to implementation, for the benefit of cancer patients and wider society. AICRI will also help deepen North/South collaboration and strengthen social, economic and political links on the island of Ireland. Progressing the vision of AICRI, its ethos is “With the patient; around the patient; for the patient”.

Momentum One Zero, an Innovation Centre of the Belfast Region City Deal

(www.momentumonezero.com)

Momentum One Zero is a Queen’s University Belfast led £70 million Digital Innovation Centre, located close to Catalyst, the Northern Ireland Science Park. It aims to transform Northern Ireland’s digital economy and enhance its digital one health footprint, by substantially increasing digital innovation activities, through a “secure connected intelligence” approach that maximises the power of data. Momentum One Zero will enhance economic growth and help deliver both health and societal value. Momentum One Zero’s Digital One Health Hub is at the forefront of transforming health and life sciences in NI, combining AI, data science, and health and life sciences expertise, to address the most pressing health challenges, while also delivering on its innovation and business credentials.

Appendix B: Reasons for low rate of clinical trial participation across the island of Ireland

Reasons for low rate of participation in clinical trials include:

- The island of Ireland currently faces a shortfall in attracting clinical trials, initiating only one-third of interventional cancer trials compared to Denmark over a six-year period. Other EU countries, e.g. Germany, France, Spain, also conduct a higher number of interventional cancer trials.⁷⁵
- The 2018 Cancer Patient Experience Survey showed that only 15% of Northern Ireland patients were being asked to take part in cancer research/clinical trials compared to 31% for England.⁷⁶
- Fragmented healthcare systems, capacity issues inconsistency and misunderstanding in application of legislation (GDPR) and poor availability of and access to patient data, making it harder to identify eligible patients in a timely fashion.

⁷⁴ <https://www.ucd.ie/research/news/2024/cancerexpertssupporttanaistescallforestablishmentofall-islandcancerinstitute/body,750148,en.html>

⁷⁵ <https://www.cancer.ie/about-us/news/press-release-report-reveals-ireland-initiates-one-third-of-the-interventional-clinical-trials>

⁷⁶ <https://www.publichealth.hscni.net/publications/northern-ireland-cancer-patient-experience-survey-2018>

- Patients may not be aware of their right to participate in clinical trials or may not be told about them by their clinicians.⁷⁷

Appendix C: Key drivers of innovation in healthcare and cancer

The pace of innovation in healthcare and cancer offers transformative potential for prevention, detection, diagnosis, treatment and outcomes. Key drivers of innovation include:

- 1. Digital Transformation:** Increased adoption of digital technologies, including telemedicine, electronic health records (EHRs), and mobile health apps, is revolutionising how healthcare is delivered and managed.⁷⁸ Patients increasingly use apps and digital tools to monitor and improve their own health.⁷⁹
- 2. Potential of AI and Deep Tech:** Artificial Intelligence (AI) and other technology innovations e.g. neural networks/quantum computing, under the umbrella of “Deep Tech” can generate important insights such as enhancing cancer screening/earlier diagnosis, delivering more effective treatments and ultimately improving patient outcomes.⁸⁰ However, they require high quality, low latency, complete data.
- 3. Rise of Precision Oncology:** Data-informed precision oncology is significantly impacting cancer care, tailoring treatments to individual genomic profiles, leading to more effective and personalised care. Precision oncology also has the potential to reduce R&D costs and improve return on investment for new medicines.⁸¹

- 4. Drivers of Cancer Risk:** Greater understanding of the drivers of cancer risk such as smoking, diet, or occupational exposures and their impact on genomics (mutational signatures). Comprehensive collection and analysis of genomics data could inform targeted public health campaigns, guide personalised prevention strategies, and empower individuals to make lifestyle changes that reduce their cancer risk.

Appendix D: Progress in realising the potential of data

Northern Ireland

The Northern Ireland Cancer Registry (NICR)⁸² provides official statistics on cancer incidence, prevalence and survival, delivering intelligence to inform cancer service planning, support research and improve patient outcomes. NICR is defining better methods for capturing cancer recurrences. The Northern Ireland Cancer Strategy 2022–2032⁸³ outlines a comprehensive plan for improving cancer outcomes through collaborative approaches. Health and social care services are integrated, with initiatives such as the GPIP (General Practice Information Platform)⁸⁴, which extracts confidential patient information from GP systems to support primary care data analysis, being an important enabler to link primary and secondary care.⁸⁵

The Northern Ireland Biobank (NIB) supports high calibre translational research by enabling access to collections of quality-assured biological samples linked to well-defined data sets.⁸⁶ NICR has well established links with NIB, with a NICR staff member dedicated to providing high quality clinical data to link with approved NIB studies.

⁷⁷ Lawler M, Prue G, Banks I, Law K, Selby P, McVie G, Sullivan R Mapping the cancer patient information landscape: A comparative analysis of patient groups across Europe and North America. Eur J Cancer. 2018; 92:88-95. doi: 10.1016/j.ejca.2018.01.074 . PMID: 29428868

⁷⁸ <https://www.iqvia.com/-/media/iqvia/pdfs/asia-pacific/white-papers/digital-transformation-for-medtech.pdf>

⁷⁹ <https://www.nhsconfed.org/news/majority-public-happy-use-health-technology-avoid-going-hospital-new-research-shows>

⁸⁰ https://reports.weforum.org/docs/WEF_The_Future_of_AI_Enabled_Health_2025.pdf

⁸¹ [iqvia-institute-global-oncology-trends-2024.pdf](https://www.iqvia.com/-/media/iqvia/pdfs/global-oncology-trends-2024.pdf)

⁸² <https://www.qub.ac.uk/research-centres/nicr/>

⁸³ <https://nican.hscni.net/2022/04/01/a-cancer-strategy-for-northern-ireland-2022-2032/>

⁸⁴ https://dhcni.hscni.net/digital-strategy/data/analytics_insight/

⁸⁵ Analytics & Insight – DHCNI

⁸⁶ <https://nibiobank.org.uk/>

The most significant data development in Northern Ireland has been the partnership with EPIC, a comprehensive electronic secondary care medical record system used by healthcare organisations, to implement the Encompass⁸⁷ digital transformation programme, creating a single, integrated electronic health record (EHR) for every citizen. It is being rolled-out in all 5 Hospital Trusts in Northern Ireland, with full implementation by May 2025.⁸⁸

EPIC will digitise health and care records, reducing the need for paper records and improving efficiency and accuracy of patient care. It will enable healthcare staff to access real-time patient information, enhance continuity of care, reduce duplication of services, and facilitate research and innovation. However, it is crucial to ensure that EPIC is truly interoperable across health systems.⁸⁹

The Data Institute, as outlined in the Digital Health and Care Northern Ireland (DHCNI)⁹⁰ strategy, aims to harness the power of data to improve health and care services. Through its Northern Ireland Trusted Research Environment (NITRE⁹¹), the institute focuses on developing data and connectivity infrastructure to enable collaborative data research, innovation, and evaluation, thereby improving insights into health and social care.⁹²

Although it is more digitally mature than Ireland, Northern Ireland has a particular challenge in the secondary use of data for research; while the requisite legislation has been passed (Health and Social Care (Control of Data Processing) Act (Northern Ireland)

2016⁹³ - it has yet to be enacted, representing a significant bottleneck to data-driven research and innovation; this is currently being addressed through the Data Institute. Leveraging the Northern Ireland Health Analytics Platform (NIHAP)⁹⁴ and NITRE will facilitate secure and efficient data sharing and analysis, key to ensuring enhanced research, care and innovation.^{95,96}

From a Research and Innovation perspective, Northern Ireland has recently established the Future Medicines Institute (FMI)⁹⁷, an academia-industry partnership in advanced diagnostics and therapeutics, aligning with the digital activities of Momentum One Zero. Potential for all-island activities include FMI linking with Research Ireland's Accelerating Research to Commercialisation (ARC) centres, Enterprise Ireland/ IDA funded centres e.g. National Institute for Bioprocessing Research and Training (NIBRT), Centre for Applied Data Analytics Research (CeADAR). These are essentially "Research Hotels" where academia and industry can gain access to technologies, insights and promote either academic-business or business-business joint partnerships.

Ireland

In Ireland, the healthcare system will undergo a significant digital transformation through delivery of the Digital for Care 2024–2030 Framework⁹⁸ to modernise health and social care. Ireland is in the early stages of transitioning to digital EHRs, with significant gaps remaining in digital and AI-readiness. Although rollout of the National Cancer Information

⁸⁷ <https://dhcni.hscni.net/digital-portfolio/encompass/>

⁸⁸ encompass – DHCNI

⁸⁹ doh-cancer-data-moving-forward.pdf

⁹⁰ <https://dhcni.hscni.net/digital-strategy/overview/>

⁹¹ https://dhcni.hscni.net/digital-strategy/data/analytics_insight/

⁹² <https://dhcni.hscni.net/digital-strategy/data/>

⁹³ <https://www.legislation.gov.uk/nia/2016/12/notes#:~:text=This%20Act%20will%20allow%20the,the%20Human%20Rights%20Act%201998.>

⁹⁴ https://dhcni.hscni.net/digital-strategy/data/analytics_insight/

⁹⁵ Health and Social Care (Control of Data Processing) Act (Northern Ireland) 2016 - Explanatory Notes

⁹⁶ Analytics & Insight – DHCNI

⁹⁷ <https://www.qub.ac.uk/Business/futuremedicines/>

⁹⁸ <https://www.gov.ie/en/department-of-health/publications/digital-for-care-a-digital-health-framework-for-ireland-2024-2030/>

System (NCIS)⁹⁹, and Medical Laboratory Information System (MedLis)¹⁰⁰ are key components in cancer data digitalisation, reliance on paper records means that health care providers often lack direct access to key patient information, leading to fragmented care and data silos. Among the eight National Cancer Control Programme (NCCP) designated adult cancer centres in Ireland, only St. James's Hospital Dublin has a fully integrated electronic health record (EHR) system.

The National Cancer Registry Ireland (NCRI)¹⁰¹ provides a population-based registry, under a strong legal mandate, to collect high-quality cancer incidence, treatment, and survival data from all Irish hospitals since 1994. NCRI operates within a highly fragmented Irish health data environment, recently reporting at least 896 data systems¹⁰² in Ireland. While some information, such as histopathology reports, are shared electronically, the majority of data collection relies on manual reporting. NCRI has prioritised digital health integration through its Strategic Plan 2024–2026¹⁰³, focusing on capturing a holistic view of the patient's cancer journey, leveraging digital tools for research, and actively participating in digital health initiatives.

Establishment of the National Genetics and Genomics Office (NGGO) and recent publication of the National Strategy for Accelerating Genetic and Genomic Medicine in Ireland¹⁰⁴, is a significant development in mainstreaming genomics across the health system, ensuring patients benefit from advances in precision medicine. However, while NGGO is tasked with improving clinical genomics infrastructure, it is not mandated to serve as a data repository or to facilitate secondary use of genomic data for research. In contrast to the UK, Ireland lacks a trusted research

environment for health data research, or a health data research service.

The introduction of the new Health Information Bill 2024 aims to establish a legal framework for digital health records, facilitating easier access for patients to their health information and enabling more efficient data sharing among healthcare providers. By setting clear guidelines for data sharing, the Bill seeks to balance the need for data protection with the practical requirements of modern healthcare, whilst aligning with EHDS to ensure Ireland meets EU obligations for both primary and secondary uses of health data, and addressing concerns regarding GDPR application in Ireland, which is considered overly restrictive. The importance of addressing the restrictions of GDPR application are also highlighted by Clinical Trials Ireland which states that *"The government must underpin exceptions 9(2)(g) and 9(2)(i) of Article 9 of the GDPR by enacting Member State Law that provides for the processing of personal health data for health research including clinical trials and compatible secondary research."*¹⁰⁵

Ireland has also taken steps to develop research programmes focused on developing new diagnostics and therapeutics. Precision Oncology Ireland (POI)¹⁰⁶, is a national Research Ireland Strategic partnership, focussed on delivering precision oncology. **Blood Cancer Network Ireland (BCNI)**¹⁰⁷ is a cross-border clinical research network on blood cancer. MAGIC-I (Molecular and Genomic Interrogation of Childhood Cancer – Ireland)¹⁰⁸ launched in April 2025, is a national five-year study aiming to optimise treatments for childhood cancers using genomics and big data; potentially poised to expand all-island as collaboration with Northern Ireland grows.

⁹⁹ <https://www.hse.ie/eng/services/list/5/cancer/profinfo/medonc/projects/mocisproject.html>

¹⁰⁰ <https://www.hse.ie/eng/services/news/newsfeatures/medlis-the-national-laboratory-information-system/#:~:text=MedLIS%20is%20a%20new%20electronic,where%20your%20test%20was%20done.>

¹⁰¹ <https://www.ncri.ie/>

¹⁰² <https://www.irishexaminer.com/news/arid-41553964.html>

¹⁰³ https://www.ncri.ie/sites/ncri/files/pubs/strategic-plans/2024-2026%20NCRI%20Strategic%20Plan_1.pdf

¹⁰⁴ <https://www.hse.ie/eng/about/who/national-genetics-and-genomics/about-the-national-strategy-for-accelerating-genetic-and-genomic-medicine-in-ireland/>

¹⁰⁵ <https://www.cancertrials.ie/wp-content/uploads/2024/10/Digital-Use-GPDR-Position-Paper-FINAL.pdf>

¹⁰⁶ <https://www.precisiononcology.ie/about/>

¹⁰⁷ <https://www.cancer.ie/cancer-research/about-our-cancer-research/our-cancer-research-networks/blood-cancer-network-ireland-bcni>

¹⁰⁸ <https://www.ucd.ie/sbi/research/projectsprogrammes/magic-i/>

All island

Significant efforts are being made to harmonise deployment of cancer data through the eHealth Hub for Cancer¹⁰⁹, with cross-border collaboration between Ireland and Northern Ireland in a joint research programme. The Hub is building expertise in OMOP-based analytics and data harmonisation, supporting integration of Irish cancer data within European and global research efforts. By adopting OHDSI tools and standards, the Hub enhances connectivity across healthcare systems, positioning participation in pan-European projects. OMOP CDM is recognised globally for enabling federated analytics, large-scale observational studies, and improved data quality in cancer research.¹¹⁰ The work of the eHealth Hub for Cancer and its inaugural All Ireland Forum on Cancer Data were the genesis of this report.¹¹¹

The **HRB-funded All Ireland Cancer Consortium (AICC)** initiative, in partnership with HSC Public Health Agency and US National Cancer Institute, supports collaborative research across the island. Recent projects include a TransAtlantic Cancer Alliance for Liquid Biopsy Research, a genomics education network (GENE-ONC), development of an All-Island Cancer Atlas (between NCRI and NICR), research on lung cancer screening and on cancer-associated genetic variants.

The **All-Ireland Cancer Networks (AllCan)** supported by Breakthrough Cancer Research is a collaborative All-Ireland research network involving leading scientists and researchers at institutions across Ireland, tackling cancers with low survival rates and high unmet including oesophageal and pancreatic cancer.¹¹²

The **All-Ireland Cancer Liquid Biopsies Consortium (CLuB)** is a collaborative, all-island initiative focused

on developing minimally invasive, cost-effective blood tests (liquid biopsies) for cancer diagnosis and treatment selection.¹¹³

Several Irish institutions and researchers are actively involved in major EU cross-border initiatives for sharing of cancer data. GDI-Ireland¹¹⁴ (Genomics Data Infrastructure Ireland) is a collaborative, multi-institutional effort (led by Royal College of Surgeons in Ireland) that is developing secure, ethical, and effective management of genomic data in Ireland as part of the European 1+ Million Genomes Programme, enabling federated cross-border genomic analysis.

The University of Limerick is a partner in CANDLE, an initiative to map national infrastructures and develop European Federated Cancer Research Data Hubs, connecting national data to central UNCAN.eu platform, supporting cross-border, AI-ready research.

Appendix E: Relevant international data standards initiatives

The international community has developed international data standards including:

- **OMOP (Observational Medicinal Outcomes Partnership):** OMOP standardises the structure and content of observational health data, enabling systematic analysis and generating real world evidence to improve healthcare outcomes.¹¹⁵
- **MEDOC (Minimal Essential Description of Cancer):** MEDOC is a dataset designed to improve cancer care delivery and quality by covering key demographic, clinical phenotype, biomarker, treatment, and pragmatic outcomes. The eHealth-Hub for Cancer is part of the 1+MG GDI project that produced an extended data model.¹¹⁶

¹⁰⁹ <https://www.ehealth4cancer.ie/>

¹¹⁰ <https://www.openaccessgovernment.org/wp-content/uploads/2024/06/openaccessgovernment.org-From-selfish-silo-to-collaborative-culture-embracing-data-enabled-cancer-research.pdf>

¹¹¹ Ireland's 900 health data systems a barrier to positive patients outcomes, cancer conference told

¹¹² <https://allcan.ie/>

¹¹³ <https://www.clubcancer.ie/>

¹¹⁴ <https://genomicdata.ie/>

¹¹⁵ <https://www.ohdsi.org/data-standardization/>

¹¹⁶ <https://pure.ul.ie/en/publications/the-1million-genomes-minimal-dataset-for-cancer>

- **FHIR (Fast Healthcare Interoperability Resources):** FHIR is a standard for exchanging healthcare information electronically, developed by HL7 to support interoperability between different healthcare systems.¹¹⁷ It enables efficient and flexible data exchange, facilitating improved health outcomes and innovative healthcare solutions.
 - **Global Alliance for Genomics and Health (GA4GH)** standards enable responsible, federated, and interoperable sharing and analysis of genomic and clinical data. They are designed to be interoperable with health data standards, e.g. HL7 FHIR.
 - **DICOM** (Digital Imaging and Communications in Medicine) - international standard for storing, transmitting, and managing medical images. Originally developed for radiology, EUCAIM (European Cancer Imaging Initiative) are extending DICOM to digital pathology.
- In addition, common principles have been developed for governing use of data assets:
- **FAIR (Findable, Accessible, Interoperable, Reusable):** The FAIR principles aim to enhance management and stewardship of scientific data by ensuring it is findable, accessible, interoperable, and reusable.¹¹⁸
 - **Five Safes:** The Five Safes framework ensures safe and secure access to data for researchers by focusing on five key areas: safe people, safe projects, safe settings, safe data, and safe outputs.¹¹⁹ This framework helps data providers deliver controlled access to data while maintaining privacy and security.
 - **Data Observability:** To ensure data reliability, it's crucial to monitor aspects like freshness, quality, volume, structure, and origin, maintaining a clear view of data's usefulness. These principles keep data accurate, up-to-date, and well-organised.
 - **TREs:** TREs are secure platforms designed to provide controlled access to sensitive data for research purposes.¹²⁰ They ensure data privacy and security by de-identifying data prior to access and allowing researchers to analyse data within a highly secure environment. The HDR UK OMOP initiative exemplifies the importance of standardisation. Healthcare Trusts in HDR UK are harmonising data in each TRE to the OMOP Common Data Model, to enable interoperability and federated analytics.
 - **Federated data models** enable multiple standalone systems to share insights from data without it moving location.¹²¹ In a federated network, each system maintains control over its own data while participating in a broader, unified network, enhancing efficiency, scalability, and data privacy by design.
 - **OpenSAFELY model:** A secure, open-source platform that enables large-scale analysis of data without exposing raw patient information.¹²² Researchers develop and test code on synthetic data, which is then run within secure NHS environments, ensuring data remain protected while supporting transparent, reproducible research at national scale.
- Federated approaches provide a solution for cross-border all island Ireland initiatives.

¹¹⁷ <https://fhir.org/>

¹¹⁸ <https://www.go-fair.org/fair-principles/>

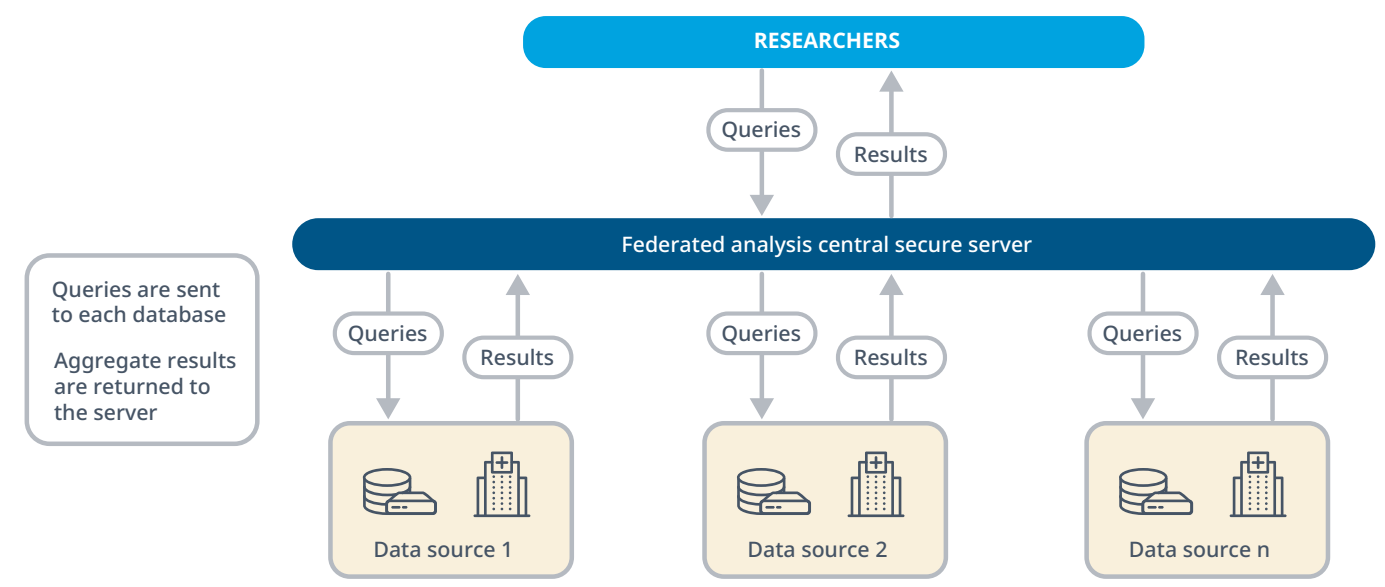
¹¹⁹ <https://www.gov.uk/data-ethics-guidance/the-five-safes-framework>

¹²⁰ Trusted Research Environments - HDR UK

¹²¹ Federated Analytics | Federated Analytics

¹²² <https://www.opensafely.org/>

Figure 4: Federated analysis allows one to get to pooled, centralised data equivalent to insights from de-centralised data



Appendix F: Challenges

This section lays out in greater detail the challenges faced across the island of Ireland in advancing data-informed cancer research, clinical trials, patient care, and innovation:

1. Legislative and regulatory framework challenges

Ireland: Lack of a single patient identifier and digitalised system hinders seamless sharing of data between healthcare providers, impacting efficiency, quality of patient care and research. Introduction of the Individual Health Identifier (IHI)¹²³, implementation of the Digital for Care 2030 strategy¹²⁴ and passing of the Health Information Bill will help will help address this lack of interconnectedness

Ireland and Northern Ireland’s divergence in governance frameworks (e.g., GDPR vs. UK Data Protection Act) impacts all-island collaboration. Ireland has among the strictest interpretation of the EU General Data Protection Regulation (GDPR) of any country in the EU. This limits access to health data more than in other European countries.

2. Policy and strategy coordination challenges

Ireland: There is a need for better alignment with European Standards, particularly EHDS. EHDS is creating a common framework for the secure exchange and use of health data across Europe. By leveraging EHDS guidelines, research processes and data collection practices can be standardised on the island, promoting more robust and comprehensive data-informed research and innovation. Alignment with the recently announced UK Health Data Research Space (HDRS)¹²⁵ will also be an important enabler in North-South joint initiatives.

3. Data infrastructure investment challenges

Ireland: Ireland is still behind many of its peers in the use of EHRs. Adopting an EHR, as has been done with EPIC in Northern Ireland, its selection and implementation in Ireland may be another five years away. There is an urgent need to create a cancer EHR solution to enable establishment of clinical network for care and treatment of patients, clinical trials¹²⁶ and research. Cancer should be prioritised for EHR roll out.

¹²³ <https://www.hse.ie/eng/about/who/national-services/individual-health-identifier/>
¹²⁴ <https://about.hse.ie/our-work/digital-for-care-2030/>
¹²⁵ <https://www.gov.uk/government/news/prime-minister-turbocharges-medical-research>
¹²⁶ <https://www.cancertrials.ie/wp-content/uploads/2024/11/CTI-Clinical-Trials-Manifesto-Call-to-Action-for-print-1.pdf>

Ireland and Northern Ireland: Lack of infrastructure for secure data access and standardisation across the island of Ireland is hampering the ability to efficiently and securely collect, store, manage, and share data, crucial for advancing cancer research, clinical care and innovation.^{127,128} Robust and scalable infrastructure is needed, including common data standards, and advanced analytical tools

Ireland and Northern Ireland: Cancer registries already record data to international standards (ENCR) and use international coding e.g. ICDO. Converting cancer registry data to OMOP and MEDOC to facilitate data sharing presents a significant challenge due to resource constraints and varying data formats across different systems.

Ireland: Although HIQA, NGGO can define standards and support clinical data use and NCRI can provide data, there is a lack of national health or cancer research data entity with a legal mandate to define data standards, store and archive data. No archive exists for sensitive clinical genomics data; it is often siloed within a clinical or academic institution. NCRI has a strong legal mandate to develop as a national cancer data node, although data, capacity and expansion might be challenging.

Ireland and Northern Ireland: Energy needs associated with significant data storage/ processing capacity required to deliver data insights can have a major environmental impact. Consideration of energy sources and efficiency gains such as optimising software, minimising memory over-allocation, and using green-certified data centres to mitigate this potential impact are needed to ensure environmental sustainability.¹²⁹

4. Data sharing challenges

Ireland: Challenges in data access and sharing between hospitals create silos of information, limiting the comprehensive view of patient health records and hindering collaborative efforts in cancer research and treatment.

Ireland and Northern Ireland: There are difficulties in sharing data due mainly to governance issues as well as a lack of a common data model (CDM). This restricts comprehensive understanding of differences in cancer trends/ treatment outcomes, missing opportunities for joint research and insights e.g. comparing screening activities, medicines utilisation, economic burden of cancer etc.

5. Digital skills enhancement challenges

Ireland and Northern Ireland: Incentivising a cross-border digital skills agenda including ensuring that data science is part of the health professional's curriculum is essential to empower a vibrant and productive cancer data R&I community and deliver health and economic dividends in both the public and private sectors. Increasing public and patient understanding of somatic genomics can empower individuals to make informed, modifiable lifestyle choices that may reduce cancer risk and improve health outcomes.

6. Critical data gaps

Ireland and Northern Ireland: Suboptimal clinical genomic testing capacity, especially in Ireland, poses a significant challenge to harnessing genomic insights for personalised cancer care. Northern Ireland has already made significant progress in this regard with the establishment of the Personalised Medicine Centre of Excellence at Queen's University Belfast.^{130,131}

¹²⁷ doh-cancer-data-moving-forward.pdf

¹²⁸ doh-cancer-data-moving-forward.pdf

¹²⁹ Green Algorithms: Quantifying the Carbon Footprint of Computation - Lannelongue - 2021 - Advanced Science - Wiley Online Library

¹³⁰ Integrated molecular pathology: the Belfast model - PubMed

¹³¹ Multimodal analysis and the oncology patient: Creating a hospital system for integrated diagnostics and discovery - PubMed

This needs to be combined with an all-island cancer genomic data infrastructure enabling rapid access for clinicians to patients’ data. This would support clinical trials, Molecular Tumour Boards, where patients’ care and treatment decisions are made, and inform incidence of somatic mutational signatures associated with cancer exposures, informing screening and preventative health and supporting real world studies.

Ireland and Northern Ireland: There is a lack of systematic data on cancer recurrence and metastasis. Despite metastasis accounting for approximately 90% of deaths in patients with solid tumours, current clinical tools and cancer registries often lack the data needed to track, predict, or understand metastatic recurrence, limiting the ability to improve outcomes and develop targeted interventions.¹³² Capturing other measures of disease progression e.g. identifying recurrence and metrics such as molecular residual disease (MRD) is also important and must be facilitated

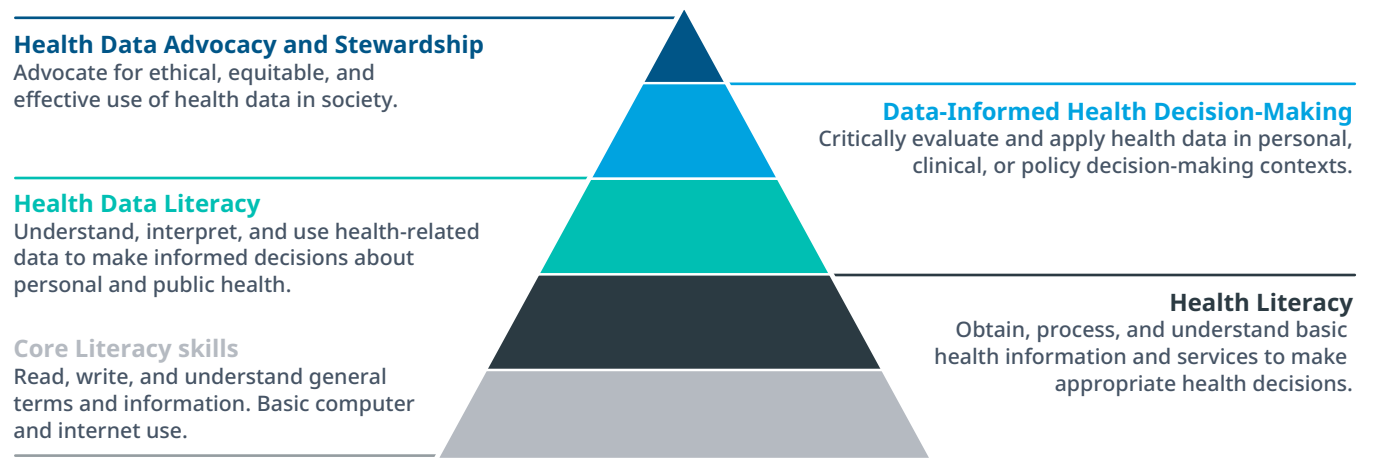
A wider dataset needs to be collected, which combines treatments (both medical – medicines, surgery, radiotherapy) and psychosocial (mental health, exercise, nutrition, counselling, symptom control) and efficiency of care delivery e.g. waiting times. Quality of life indicators and patient reported outcomes would also provide valuable insights

Ireland and Northern Ireland: There is significant impact of socio-economic factors on cancer outcomes; patients from lower socioeconomic backgrounds often experience worse cancer prognosis/higher mortality.¹³³ Without robust socioeconomic and environmental data, policymakers lack data-driven evidence to reduce disparities.¹³⁴ Data are generated by the Administrative Data Research Centre (Northern Ireland) and Central Statistics Office (Ireland) but are not linked to patient data, severely limiting the insights that can be generated.

7. Health data literacy challenges

Ireland and Northern Ireland: Enhancing health data literacy across the island is crucial to ensure that patients, health professionals, policymakers, and the public, are equipped with the necessary skills to engage with health data effectively – understanding how data are generated, governed, accessed and used. Low health literacy is linked to poorer outcomes, increased costs, and reduced life expectancy. However, there is currently a lack of investment in developing tailored opportunities to enhance health data literacy.

Figure 5: Harnessing the power of health data must build on strong foundations starting with core literacy skills



¹³³ The lingering mysteries of metastatic recurrence in breast cancer - PubMed
¹³⁴ The European Cancer Pulse: tracking inequalities in cancer control for citizen benefit - PubMed

Patients and data: The DATA-CAN example

Patients play a crucial role in harnessing the power of data. DATA-CAN is the UK's Health Data Research Hub for Cancer, making high-quality health data more accessible for cancer researchers, clinicians and industry. DATA-CAN has made a significant commitment to putting PPIE at the heart of every aspect of their work.

DATA-CAN's overarching philosophy, is one of Fair Value for all stakeholders. Patients, health services, researchers and industry all derive fair value from the use of patient data. Patients are embedded within DATA-CAN – co-applicants in the original funding bid; equal partners on all steering, management and project committees; present for all discussions, including those with industry.

DATA-CAN is an exemplar of PPIE¹³⁶ best captured in the words of DATA-CAN's PPIE group member and breast cancer survivor Jacqui Gath.

“Patients want their data to be used to improve care and enhance research. In fact, they're often surprised it's not used already.”

Jacqui's words need to be heard more clearly in the debate on balancing data privacy and trust in the use of data, with the need to deploy data to help enhance human health.

8. Patient involvement challenges

Ireland and Northern Ireland: As DATA-CAN demonstrated, embedding patients as equal partners in data-enabled cancer research and ensuring their voices are integral to decision-making is a blueprint for success. Excellent work in patient advocacy has been achieved in both Ireland, e.g. Patient Voice in Cancer Research, and Northern Ireland Northern Ireland Cancer Research Consumer Forum. However, there is not yet an equivalent mechanism across the island of Ireland to ensure that the patient voice is an integral part of defining and delivering an All-Island Cancer Data Strategy. There are increasingly strong voices such as the recently launched United Cancer Advocates Network (Ucan) Ireland¹³⁵ who could contribute to this debate.

9. Challenges in using data to drive and deliver research

Ireland and Northern Ireland: The lack of up-to-date, patient data from across their diagnosis and treatment journey and mechanisms to appropriately access these data has a major impact on research. AI tools can now massively accelerate efficient identification of suitable patients for clinical trial recruitment, while access to relevant data can enable insights into mechanisms of response and resistance. Lack of longitudinal data and governance and technical challenges with accessing data make the process unwieldy. It also places an increased administrative burden on clinicians who are participating in these studies. Ultimately, patients are less likely to participate in available trials and RW studies. This slows down development and availability of new treatments and renders the island of Ireland a less attractive place to do research.

Overcoming the challenges presented above is essential to harness the full potential of data-driven cancer research, care, and innovation on the island of Ireland. The potential impact of overcoming such challenges is exemplified by the insights generated during the pandemic.

¹³⁵ <https://www.ucanireland.ie/>

¹³⁶ <https://blogs.bmj.com/bmj/2021/08/11/data-can-a-co-created-cancer-data-knowledge-network-to-deliver-better-outcomes-and-higher-societal-value/>

Appendix G: Glossary of terms and organisations

ACRONYM/TERM	MEANING/DEFINITION	URL
1+MG	1+ Million Genomes initiative	https://digital-strategy.ec.europa.eu/en/policies/1-million-genomes
AI	Artificial Intelligence	
AICC	All-Ireland Cancer Consortium	https://www.aicri.org/
ARC	Accelerating Research to Commercialisation	https://www.sfi.ie/funding/funding-calls/sfi-arc-hub-programme/
ARINS	Analysing and Researching Ireland North and South	https://www.ria.ie/research-programmes/arins/
AllCaN	All-Ireland Cancer Networks	https://allcan.ie/
BCNI	Blood Cancer Network Ireland	https://www.bloodcancers.ie/
BRCD	Belfast Region City Deal	https://www.belfastcity.gov.uk/regeneration/belfastregioncitydeal
CANDLE	Cancer Data Learning Environment	https://computational.cancer.gov/software/cancer-distributed-learning-environment
CDPU	Cancer Data Policy Unit	
CDRS	Cancer Data Research Service	
CLuB	All-Ireland Cancer Liquid Biopsies Consortium	https://www.clubcancer.ie/
CSO	Central Statistics Office	https://www.cso.ie/en/index.html
CeADAR	Centre for Applied Data Analytics Research	https://ceadar.ie/
DATA-CAN	The UK's Health Data Research Hub for Cancer	https://www.data-can.org.uk/
DHCNI	Digital Health and Care Northern Ireland	https://dhcni.hscni.net/
DICOM	Digital Imaging and Communications in Medicine	https://www.dicomstandard.org/
Data Governance	The policies and practices that ensure data is managed properly	
Data Infrastructure	The systems and technologies used to collect, store, and manage data	
Data Sharing	The exchange of data between different entities	
Digital Health	The use of digital technologies to improve health and healthcare services	
Digital for Care 2030	An initiative in Ireland aimed at transforming healthcare delivery through digital innovation	https://www.gov.ie/en/publication/2f07e-digital-health-strategy/

ACRONYM/TERM	MEANING/DEFINITION	URL
eHealth Hub for Cancer	An all-Island Hub of Excellence in digital oncology	http://www.ehealth4cancer.ie
EDC	Electronic Data Capture	
EHDS	European Health Data Space	https://ec.europa.eu/health/ehealth-digital-health-and-care/european-health-data-space_en
EHR	Electronic Health Record	
ENCR	European Network of Cancer Registries	https://www.encr.eu/
EOSC	European Open Science Cloud	https://research-and-innovation.ec.europa.eu/strategy/strategy-research-and-innovation/our-digital-future/open-science/european-open-science-cloud-eosc_en
ESRI	Economic and Social Research Institute	https://www.esri.ie/
EUCAIM	European Cancer Imaging Initiative	https://www.egi.eu/project/eucaim/
Economic Dividend	The economic benefits derived from health data initiatives	
Encompass	A digital transformation initiative linking health and social care data in NI	https://www.health-ni.gov.uk/encompass
FAIR Principles	A set of guidelines for making data Findable, Accessible, Interoperable, Reusable	https://www.go-fair.org/fair-principles/
FHIR	Fast Healthcare Interoperability Resources	https://www.hl7.org/fhir/overview.html
FMI	Future Medicines Institute	https://www.qub.ac.uk/Business/futuremedicines/
Five Safes Framework	A model ensuring safe access to sensitive data	https://ukdataservice.ac.uk/help/secure-lab/what-is-the-five-safes-framework/
GA4GH	Global Alliance for Genomics and Health	https://www.ga4gh.org/
GDI-Ireland	Genomics Data Infrastructure Ireland	https://genomicdata.ie/
GDPR	General Data Protection Regulation	https://gdpr-info.eu/
GPIP	General Practice Information Platform	https://dhcni.hscni.net/digital-strategy/data/analytics_insight/
Genomic Testing	Testing that examines a person's genes to identify mutations that may cause cancer	
HDR UK	Health Data Research UK	https://www.hdruk.ac.uk/
HDRS	UK Health Data Research Space	https://www.hdruk.ac.uk/
HEA	Irish Higher Education Authority	https://hea.ie/
HIQA	Health Information and Quality Authority	https://www.hiqa.ie/

ACRONYM/TERM	MEANING/DEFINITION	URL
HTA	Health Technology Assessment	
Health Data Literacy	The ability to understand and use health data effectively	https://www.healthit.gov/topic/health-data-literacy
European Health Data Space	A framework for managing health data across borders	https://ec.europa.eu/health/ehealth-digital-health-and-care/european-health-data-space_en
ICBP	International Cancer Benchmarking Partnership	https://www.icbp.org.uk/
ICDO	International Classification of Diseases for Oncology	https://www.who.int/standards/classifications/other-classifications/international-classification-of-diseases-for-oncology
IHI	Individual Health Identifier	
IPPOSI	Irish Platform for Patient Organisations, Science and Industry	https://ipposi.ie/
MAGIC-I	Molecular and Genomic Interrogation of Childhood Cancer – Ireland	https://www.ucd.ie/sbi/research/projectsprogrammes/magic-i/
MEDOC	Minimal Essential Description of Cancer	https://oeci.eu/Attachments/Paris_23/State_of_play_on_DigiONE.pdf
MRD	Molecular Residual Disease	
MedLis	Medical Laboratory Information System	https://www.hse.ie/eng/services/news/newsfeatures/medlis-the-national-laboratory-information-system/
Momentum One Zero	A Queen's University Belfast led Digital Innovation Centre	http://www.momentumonezero.com
NCCP	National Cancer Control Programme	https://www.hse.ie/eng/services/list/5/cancer/
NCI	US National Cancer Institute	https://www.cancer.gov/
NCRI	National Cancer Registry Ireland	https://www.ncri.ie/
NCTOG	National Clinical Trials Oversight Group	
NHS	National Health Service	https://www.nhs.uk/
NIB	Northern Ireland Biobank	https://nibiobank.org.uk/
NIBRT	National Institute for Bioprocessing Research and Training	https://www.nibrt.ie/
NICR	Northern Ireland Cancer Registry	https://www.qub.ac.uk/research-centres/nicr/
NICRCF	Northern Ireland Cancer Research Consumer Forum	https://cancertrials.hscni.net/about-us/ni-cancer-research-consumer-forum/about-us/

ACRONYM/TERM	MEANING/DEFINITION	URL
NIHAP	Northern Ireland Health Analytics Platform	https://dhcni.hscni.net/digital-strategy/data/analytics_insight/
NITRE	Northern Ireland Trusted Research Environment	https://dhcni.hscni.net/digital-strategy/data/
OHDSI	Observational Health Data Sciences and Informatics	https://ohdsi.org/
OMOP	Observational Medical Outcomes Partnership	https://www.ohdsi.org/data-standardization/
Oncology	The study and treatment of cancer	https://www.cancer.org/
OpenSAFELY	A secure, open-source platform for analysing health data	https://www.opensafely.org/
POI	Precision Oncology Ireland	https://www.precisiononcology.ie/
PPIE	Public and Patient Involvement and Engagement	
PVCR	Patients Voice in Cancer Research	https://www.ucd.ie/patientvoicecancer/
Precision oncology	The use of genetic, molecular, and other detailed information about a person's cancer to tailor treatment specifically to their tumour's characteristics	https://www.cancer.org/
RWD	Real World Data	
RWE	Real World Evidence	https://www.fda.gov/science-research/science-and-research-special-topics/real-world-evidence
SMEs	Small and Medium-sized Enterprises	
Shared Island Fund	A fund supporting collaborative initiatives between IE and NI	https://www.gov.ie/en/publication/3c5d0-shared-island-fund/
Sláintecare	Ireland's national ten-year healthcare reform programme	https://www.gov.ie/en/department-of-health/campaigns/sl%c3%a1intecare/
TREs	Trusted Research Environments	
UNCAN.eu	A European Federated Cancer Research Data Hubs platform	https://uncan.eu/a-european-research-data-hub/
Ucan Ireland	United Cancer Advocates Network Ireland	
UseMyData	A patient engagement initiative	https://usemydata.org/

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