

# Electronic health records and citizen access to health information



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Ireland is considered a laggard in terms of citizen access to electronic health records. Enacting new legislation would provide the legal basis to share health information for patient care and treatment.

Electronic health records (EHRs) are a key element of the digital transformation of healthcare. Replacing traditional paper records with records in electronic form, EHRs are designed to be shared across healthcare professionals and settings.

Access to EHRs at a national level, however, has been limited, with the Health Information and Quality Authority (HIQA) (2022) describing healthcare information systems in Ireland as “immature, under-developed, and lagging behind other European countries”. A recent review of the national landscape found that digital maturity is low, with paper records “the norm”. **Just five out of 47 public hospitals in Ireland had implemented their own EHRs.** In terms of citizen access to EHRs across the EU, Ireland has been classed as a ‘beginner’ (European Commission, 2024) or a ‘clear outlier’ (Department of Health, 2024).



EHRs are a digital record of a patient's medical information. They can include everything from diagnoses, medical history, medications, and immunisations, to X-rays, laboratory results and clinical notes.

**Harnessing Digital:** The Digital Ireland Framework committed to pursuing a work programme to meet the eHealth target of all EU citizens being able to access their EHRs by 2030.

## Potential offered by EHRs

EHRs can provide various benefits for healthcare systems. For instance, the Health Service Executive (HSE) advises that EHRs can help reduce medical errors by allowing better tracking and more standardised documentation of patient interactions. EHRs can also help streamline workflows by cutting down on paperwork, as well as improving communication and collaboration between healthcare professionals.

A recent HIQA ‘national engagement’ on digital health found that people are willing to engage with EHRs. For instance, approximately nine out of every 10 respondents would like EHRs to help them understand and manage their health, track the progress of tests, and renew prescriptions. Overall, almost three-quarters of people said that they would access their EHR.

Data privacy and security, however, were of concern to the public. Additionally, an earlier ‘national engagement’ found that most people felt it important to know which healthcare professionals had viewed their EHR (82%).

## Access to EHRs internationally

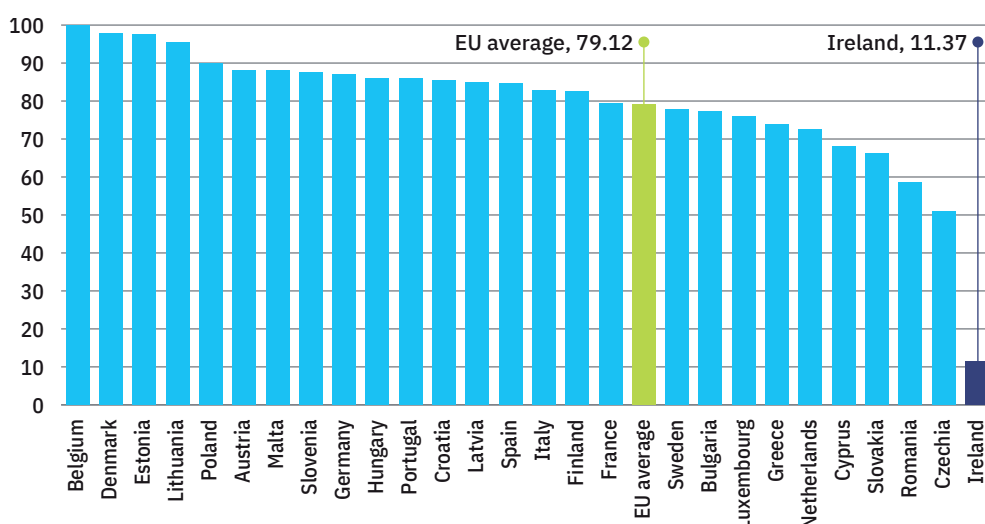
Key comparative data stems from Europe’s Digital Decade. Initial benchmarking on citizen access to electronic medical records found that all responding countries, except Ireland, had some form of access (reference year, 2022). **Ireland was the lowest-ranked EU country in terms of citizen access to their eHealth records, with a score of 0%.** A follow-up study found that the average overall eHealth score in the EU increased to 79% (up from 72%) (reference year, 2023). Ireland’s score increased to 11% (up from 0%). However, it remained the lowest score in the EU (see Figure 1 below).

**Europe’s Digital Decade** seeks to ensure that digital transformation across the EU benefits all. A key target under digital government is that 100% of citizens have access to medical records online by 2030.

**Figure 1**

**eHealth scores in the EU: access to eHealth records. Scores relative to the EU27**

Source: European Commission (2024)



Countries like Belgium, Denmark, and Estonia, by contrast, have been described as ‘trendsetters’. Estonia, for instance, has provided citizen access to EHRs since 2008. A Health Portal enables Estonians to access information such as appointments/referrals, prescriptions, vaccinations, health history, and health certificates. There is also a log of who has accessed information.

The European Commission identified eHealth as a main area for improvement for Ireland in meeting 2030 Digital Decade targets. It recommended that Ireland:

- ▶ expand access so that all citizens can access their EHRs;
- ▶ ensure that all data types are available;
- ▶ increase the supply of data by onboarding more types of healthcare providers.

## Progressing patient access to EHRs in Ireland

EHRs have been a national policy concern for some time. Patients' ability to access their own health records was seen as a key outcome of the eHealth Strategy for Ireland (2013). EHRs were a key capability in the Knowledge & Information Strategy (2015), whilst Sláintecare saw their integration into service provision as 'paramount'. Additionally, a key principle underpinning Digital for Care: A Digital Health Framework for Ireland 2024–2030 is 'patient as an empowered partner'.

Some recent digitalisation projects in the health service include:

- ▶ The National Integrated Medical Imaging System (NIMIS): aims to capture/store diagnostic images electronically. Sligo Regional Hospital was the first site to go live with the system in June 2011. As of November 2020, it is in use in 74 sites across the country (including almost all public hospitals and many satellite imaging centres).
- ▶ Maternal & Newborn Clinical Management System (MN-CMS): seeks to provide a single EHR for all women and infants in maternity, gynaecology and neonatal services. Phase 1 saw deployment in Cork University Maternity Hospital (2016), University Hospital Kerry (2017), the Rotunda (2017) and the National Maternity Hospital (2018). With the completion of Phase 1, 40% of births are covered annually. Phase 2 has commenced.
- ▶ Project Ogham: includes Epic – the new EHR – which will go live with the opening of the new children's hospital. A key element is the MyChart: Epic's Patient Portal, which will allow patients (from 13+ years) and their parents/guardians to access patient healthcare information (for example, medications, appointments, and hospital visit summaries).

In September 2024 a phased approach for the eventual rollout of EHRs was announced, to include a new patient app. Its initial release (expected 2025) is set to include functions for appointments for maternity patients, self-declared medications, prescriptions and referrals.

A roadmap for the deployment of EHRs is a key initiative of the Sláintecare Action Plan 2023. However, the HSE's Digital Health Strategic Implementation Roadmap highlights deployment challenges. For instance, even where electronic data currently exists (such as in pharmacies, laboratories, and primary care clinics), systems are often not interoperable meaning they are not able to talk to each other and share data. A single, comprehensive EHR requires legacy systems to be replaced and the gradual integration of all databases.

## Upcoming EU developments

The European Health Data Space (EHDS) seeks to empower individuals through better access to their personal health data. It also establishes a framework for the secondary use of anonymised/pseudonymised health data for purposes such as research and innovation, public health, and policymaking. Various implementation deadlines are expected to fall between 2026 and 2030.

The EU aims to digitalise all medical records as part of the EHDS and help individuals access/share their health data with medical professionals across the EU. Citizens will be able to access various services via MyHealth@EU. For instance, ePrescriptions will allow patients to obtain their medication in another EU country.

Ireland's National Strategic Roadmap set a target of 80% of citizens having access to core elements of their digital health record. Significantly, the European Commission highlighted that this is not in line with requirements under the upcoming EHDS Regulation. Digital for Care: A Digital Health Framework for Ireland 2024–2030 however, states that Ireland's digital health strategy aligns fully with EU's overarching ambition.

## Operational and legislative opportunities

Various operational developments are anticipated over the course of the new parliament, including ePharmacy and Project Ogham in 2026. More broadly, the HSE has outlined that EHRs will roll-out on a regional basis over the next seven to eight years, with a business case currently in train for the first region.

Legislation will also be needed to ensure that Ireland can meet its obligations under the EHDS Regulation. As a first step, the Health Information Bill 2024 sought to provide, amongst other things, a legal basis for EHRs and a 'duty to share' health information for patient care and treatment. It completed Second Stage in Dáil Éireann but fell with the dissolution of the 33<sup>rd</sup> Dáil. It will need to be restored to the Order Paper of the new parliament to progress these measures. Additionally, the Department of Health advises that legislative provisions will be required regarding the secondary use of health data, including provisions for a national health data access body and a permit-system for wider secondary use.

According to the Department of Health (2024), Ireland's healthcare information systems lacks coherence, coordination, and digital maturity. In the absence of operational and legislative developments, this will remain the case.



Legislation will be needed to ensure that Ireland can meet its obligations under the European Health Data Space Regulation.