CASE STUDY
DENMARK
Digital-first is business as usual

Strengths

Ranked #2 in eHealth maturity by the EU Digital Decade study, data and digital is firmly embedded in the Danish health system, enabled by high levels of trust among members of the public and confidence in using technology such as the national patient portal sundhed.dk where patients can see their data and manage their care, all connected to their Central Person Register number as a unique identifier enabling linkage across data sources and for research.

Challenges

- Some data is still not available to patients in the portal due to ongoing conversations about patient confidentiality - with the entire GP record expected to be made available by 2026.
- Researchers or others wanting access to data have to apply separately to each individual data controller.
- Whilst there is some data sharing with providers of elderly care, this is primarily for medication records.

BEST PRACTICE EXAMPLES

National Patient Registry

Data has been collected in the National Patient Registry since 1977, making it one of the world's oldest data registries. The Registry holds data for all hospital treatments and has a large cohort of 13 million (including the deceased) enabling research spanning decades with a whole-population cohort. There are also other registries (over 350 of them) and the use of the Central Person Register number enables effective linkage across different data sources.

Secure processing environment

When accessing data for research or other secondary uses, data users use a secure processing environment enabling secure access to the data for analysis without any data having to leave the environment.

"Interoperability is not an end goal, but something you work on continuously and develop and improve.

The important thing is to work incrementally. Denmark has made steady progress since the 1990s."

DANISH HEALTH DATA EXPERT

Understanding Patient Data

CASE STUDY
ESTONIA:
Longstanding leader with nationwide system

Strengths

A highly mature system, Estonia is consistently ranked as a leader in health data and electronic health records (EHRs) in Europe and internationally. The Health Information System (HIS) stores all digitised patient data in one national platform, available to healthcare professionals and patients, with patients able to extert signicant control over their data.

Challenges

- The structure of the system - wherein each result or encounter is uploaded manually as a document - means that data is not always updated in a timely manner.
- To date, data is available to patients via an online portal, but there is not yet an app.
- Areas for future improvement include structuring of data and using data to improve outcomes (e.g. patient recorded outcome measures).

BEST PRACTICE EXAMPLES

Patient control
Patients have the ability to hide certain information or restrict information to only a certain type of healthcare professional or to a particular individual. However, they cannot edit data in their record.

Publicly available health statistics
Some health data is publicly available in aggregate form for analysis. For instance, you can run analyses in an online dashboard about presciptions.

Genomics
Over 200,000 Estonians have contributed their genomic data to the Estonian Genome Centre to make it available for research- more than 14% of the entire population.

"At the end of the day, health data is a collection of documents, what you do with it is another thing.

We start thinking what kind of data we should collect in addition [to what we have]. Instead we should think about how to use the data that we already have."

ESTONIAN HEALTH DATA EXPERT

CASE STUDY
SPAIN
A regional system trialling new approaches

Strengths

Recgnised as a "fast tracker" country on eHealth in the European Union's Digital Decade study, Spain provides an example of where national infrastructure has effectively linked data at the regional level. With each of the 17 autonomous communities responsible for health data, there is a lot of innovation with new approaches to infrastructure and patient-facing technology. Apps for patients are commonplace, enabling easy access to their records.

BEST PRACTICE EXAMPLES

Health Record of the National Health System

Launched in July 2023 to provide a national solution for overcoming regional silos in data, the Health Record of the National Health System (HCDSNS) was introduced, enabling access to patients' records across different autonomous communities, improving continuity of care and providing an example of how existing regional records can be connected at the point of the user. Patients can restrict access to parts of their record and see who has accessed their data.

Innovation and new initiatives

Due to the regional system and relatively little national guidance, autonomous communities are able to try new things on a smaller scale. For instance, the region of Catalonia is moving towards an open-platform EHR, and Spain is an early adopter of EU initiatives like cross-border ePrescriptions, the European Patient Summary and the EHDEN Project.

Challenges

- Due to the regional system, there are differences in health data maturity across the country, with some regions (particularly wealthier ones) providing better patient portals for patients and a more joined-up regional record compared to slower adopting regions.
- Different EHRs in place across providers (especially primary vs secondary care) and different coding systems create silos.
- Private providers do not share data with public electronic health records.

"Despite a relative lack of central coordination and regulation, the regions have innovated a lot and have put in a lot of effort to come up with different solutions and learn from one another, innovating in the region to fill the gaps of national regulation."

SPANISH HEALTH DATA EXPERT