Country visit – Belgium

Objectives of the country visits

The objective of the TEHDAS country visits is to provide an overview of the status of national health data management in different European countries. This mapping exercise takes place in the form of country visits in which national stakeholders working with health data or exchanging health data are interviewed.

The Joint Action Towards the European Health Data Space (TEHDAS) supports EU member states and the European Commission in developing and promoting concepts for the secondary use of health data to benefit public health and health research and innovation in Europe.

Any questions?

Contact us at
TEHDAS.sciensano@sciensano.be
Information about all country visits is available on tehdas.eu/country-visits.

When did it take place?

The visit to Belgium took place virtually between **31 January and 4 February 2022.**

Who was involved?

14 stakeholder organisations were interviewed: Belgian Cancer Registry (BCR), Belgian Data Protection Authority, Belgian Health Care Knowledge Centre (KCE), Cabinet of Minister of Health and Social Affairs Vandenbroucke, Common Sickness Funds Agency (IMA-AIM), Consultants for the Health Data Authority, Crossroads Bank for Social Security (CBSS) and e-Health platform, Federal Agency for Medicines and Health Products (FAMHP), FPS Public Health, Food Chain Safety and Environment, Healthdata.be, INTEGO, National Institute for Health and Disability Insurance (NIHDI), Sciensano, Statbel – Belgian Statistical Office.

Belgium in brief

The Belgian Health Information System has rich health data of high quality. However, the data landscape remains fragmented across multiple data holders, on different federal and regional layers. In Belgium, the health system is primarily funded through social security contributions and taxation. All registered citizens have a social security number making linkage possible, however not across all sources due to legal and organisational difficulties. Linkage is often allowed only in ad hoc project based manner. An important initiative is Belgium's national initiative towards establishing the Belgian Health Data Authority was highlighted as the next steps to facilitate the use of health data for secondary use.

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Data collections/sources

- Primary health care providers use multiple electronic health records (EHR) systems. The EHRs are mostly digitalised using a unique national identifier that is also used by general practitioners (GP).
- Secure exchange of EHRs between health care providers and patients is possible through the national eHealth platform.
- Citizens can access most of their data through the online platform www.mijngezondheid.be/ www.masante.belgique.be.
- Belgium has over 150 clinical registries containing health data.
- The Belgian Cancer Registry (BCR), a national, population-based registry collecting data on cancer incidence since 2004.
- The Belgian institute for health (Sciensano) manages surveillance systems, part of the clinical registries (e.g. Central Rare Disease Registry), and health surveys (e.g. the Health Interview Survey).
- The Belgian statistical office (Statbel) mainly collects sociodemographic data.
- The Common Sickness Funds Agency (AIM-IMA) collects data on reimbursed healthcare services and prescription medication from the 7 Belgian sickness funds.
- The INTEGO project is based on an automated data collection of EHRs of patients from Flemish GP practices.

Data quality

- In general, data updates are infrequent and not in real time, which can hinder policy making.
- For the purposes of healthcare delivery, the patient information is updated weekly on the online platform.
- Data from the sickness funds is updated regularly.
- There are various quality control mechanisms in place, including: cross checks with feedback loops, data validation, and verification at data source level.

Data infrastructure

- In Belgium, there is no central storage of patient data.
- The platform healthdata.be includes copies of data sets from different data sources including hospital data, patient data, pharmaceutical data, and research labs data.
- A common metadata catalogue is under development.
- There is a general agreement about aligning all health data sources (laboratories and GP practices) to use CDA/HL7-FHIR as the data exchange standard.
- Stakeholders aim for full standardisation using SNOMED-CT for semantic interoperability by 2027.
- The national e-Health platform for primary use uses SNOMED-CT and ICD-10 standards.
- There is no common access procedure to the different data sources.
- Access to individual level data generally requires Information Security Committee (ISC) approval.
- Linkage among datasets is potentially possible through the social security number, however, difficulties were reported due to legal barriers.
- Pseudonymisation is done by a trusted third party, such as the eHealth platform.
- The fees to access data differ and vary between being free of charge to stakeholders that request a fee for service.
- The time to access data depends on the complexity of the request, but is often reported to be long (6 to 18 months).

Data governance

- Belgium is characterised by decentralised management procedures, spread across the different federal and regional governments.
- There is a need for more transparency on roles of the data holders and access procedures to health data for secondary use.
- Belgium is setting up a Health Data Authority (HDA), an infrastructure to improve findability of data collections by establishing a metadata catalogue and streamline and harmonise data access procedures and governance.
- Multiple national acts are under revision in preparation for the HDA and EHDS: Patients' Rights Act, The Health Care Quality of Practice Act, and The Belgian Privacy Act.
- Research projects that require access to data generally need ethical approval, and approval from the Information Security Committee.

Resources (human, technical, financial)

- Human resource:
    - For maintenance and operating of data collections.
    - More data analysts and data scientists, which was reported as a highly solicited and rare profession.
    - For administrative and scientific support with application processes (including for health data access) for researchers.
    - More experts for the development of ICT solutions.
    - More experts in the use of artificial intelligence.

- Financial resources are needed across all stakeholders. It was reported that to facilitate this, Belgium is using multiple EU funds towards the setup of a new legislative framework for data sharing and operational agreements between communities and regions.

Capacity building

- Training and skills development needs:
    - Data literacy of healthcare providers.
    - Training and knowledge exchange among registries on novel techniques, to promote common advancements among registries.
    - Training on all aspects of data privacy.
    - Training in statistical tools for data analysis
    - Training on the use of standards, such as SNOMED-CT and HL7-FHIR.

- Available training opportunities:
    - Some data holders are investing in dedicated user access support services and provide data management software and privacy training.

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Best practices

- In Belgium there is an initiative called DPO Connect that brings together national data protection officers to discuss challenges and exchange experiences.
- The common sickness funds agency (IMA-AIM) has a permanent sample of socially insured people that includes individual level pseudonymised data, and is readily accessible to governmental agencies for the purpose of policymaking.
- Belgium has multiple open data platforms, for example the HISIA platform for survey data in Sciensano, and the IMA-AIM Atlas for indicators on socio-demographic characteristics and the use of health care. These platforms provide interactive tools that enable the analysis of publicly available, anonymised datasets.

European Health Data Space (EHDS)

- There is a national ambition in setting up a Health Data Authority (HDA) which is aligned with the EHDS. A proposed legislation was published in July 2022.
- There is high involvement in international collaborations. Belgium coordinates or takes part in multiple health data related international projects (TEHDAS, PHIRI, B1MG, HealthyCloud, EHDS2 pilot, ELIXIR, BBMRI and many more).
- It has not been decided who the EHDS national contact will be yet, however, preparatory work is ongoing through the development of the Belgian HDA. There is potential for it to be the national contact point for secondary use of health data.

- Some of the reported expectations for the EHDS:
    - It is seen as an opportunity for international comparisons and research exchange.
    - It should provide academic incentives for training of data analysts.
    - It should improve transparency in access decisions (by publishing evaluations) and transparency towards citizens.
    - It could potentially develop a European level platform for Data Protection Officers discussion.

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