



# Country visit – Hungary

## 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.

## When did it take place?

The visit to Hungary took place virtually between **14 and 17 February 2022**.

## Who was involved?

Seven stakeholder organisations were interviewed: E-Group, Ministry of Human Capacities, Ministry of Interior, National Health Insurance Fund, Roche, Semmelweis University, State Secretary for Health.

## Any questions?

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Information about all country visits is available on [tehdas.eu/country-visits](http://tehdas.eu/country-visits).

## Hungary in brief

The Hungarian health information system (HIS) has several rich sources of health data. The HIS appears to be mainly focused on healthcare and performance, rather than population health monitoring. The Hungarian healthcare system is funded through a single payer, the National Health Insurance Fund (NEAK). All registered citizens have a social security number, used for healthcare. There is strong political interest in digital health and an ambition for a data-driven health system and decision making. AI and big data analysis are supported and promoted through multiple innovative projects.

## Data collections/sources

- The main health data sources in Hungary are:
  - National E-Health Infrastructure (EESZT): individual-level healthcare data from all healthcare providers
  - NEAK: public healthcare reimbursement data
  - National Public Health Centre: public health data
  - Hungarian Central Statistical Office: demographic data
- There are some patient registries with data on specific diseases (e.g., National Cancer Registry, National Registry of Congenital Disorders).
- Most health data from GPs and hospitals is digitalised. There are 3 to 4 providers of EHR softwares in the hospital sector. Data from all EHRs is collected centrally in the EESZT. Reporting to the EESZT is mandatory.
- National health insurance fund: universal coverage through the single payer of the public healthcare system. Almost all citizens have access to healthcare, providing a wide coverage of structured health insurance data across the population.
- The use of private healthcare is high and growing. Since 2020 private providers must also report to the EESZT, reducing the data gap on private healthcare use.

## Data quality

- Stakeholders note a need for action on data quality.
- NEAK data is optimised for reimbursement purposes. Checks are performed in the context of financial consistency.
- The EESZT infrastructure has some quality assurance mechanisms in the software. Data is updated daily.
- Much of the health data is unstructured, but the proportion of structured data is increasing.

## Data infrastructure

- Health data is stored centrally in two main data collections: the EESZT and the NEAK.
- National Infocommunications Services Company (NISZ) is a state-owned company for public sector ICT services and data storage, including health data.
- The pilot 'data lake' project aims to create a data lake of EHR data to improve access for researchers.
- There is currently no common metadata catalogue. The new National Data Asset Agency is tasked with developing a public data inventory, not limited to health data.
- Data for secondary use is mostly pseudonymised, and data sources do the pseudonymisation in-house.
- Data access procedures vary between data sources:
  - EESZT: reportedly time-consuming access for secondary use.
  - NEAK: clear access procedure on website. Access mainly to aggregated or anonymised data. Individual-level pseudonymised data only accessible on-site. Hourly fee to private sector users, no fees to academic researchers. Time to access is on average 60 days.
- International standards ICD-10 and ATC are used mainly in finance and administration. SNOMED-CT is planned to be introduced in clinical documentation. For data exchange, a national EHR reference model is under development. Ongoing projects use local standards, specific projects use HL7 V3 and FHIR.
- Data linkage is generally project-based.
- Health data can be transferred internationally with explicit consent from the individual.

## Data governance

- A number of legal provisions govern the use of health data.
- There are legal challenges to linking individual level data and a need for clear legal framework on secondary use of health data.
- National Data Asset Agency was established in 2020, with the aim of facilitating access to public data. The planned tasks at its establishment include developing an open data portal, a public data inventory, and supporting analysis of data from public institutions.
- The EESZT has an opt-out mechanism: patients can state that their data should not be viewed by a specific healthcare professional, or can opt out of data use for research.
- Research projects using personal data require ethical approval. There are different levels of ethical committees, depending on the research project.
- A pilot 'data lake' project aims to establish a data board to evaluate research projects on the basis of data protection.
- Citizen empowerment is important: citizens have access to their health data and visibility on who accesses it via e-portal. Trust in data sharing and use increased during the pandemic.
- There is a reported willingness to increase the number of public-private partnerships to promote data sharing.

## Resources (human, technical, financial)

- Human resource capacities for maintaining and operating data collections vary across data sources.
- The NEAK reported a difficulty meeting data requests due to human resource needs.
- There is a need for skilled human resources, particularly data scientists.
- It was reported that there is a need to align the mind-set between healthcare professionals and researchers/data users.
- Technological progress has been seen in Hungary, with an increasing determination for AI tools and data-driven decision-making. There is a reported need for technical and financial resources to support the secondary use of health data.

## Capacity building

- Several trainings needs were identified by stakeholders:
  - Improving data literacy and technical knowledge of healthcare providers
  - Strengthening links between healthcare providers and researchers/data users
  - Strengthening AI capacity
  - Training on data security and data linkage
  - Education of data scientists
  - EU level input and training on semantic interoperability and structured datasets.

## Best practices

- The EESZT connects all healthcare providers into one location and serves as a structural foundation that can be further used beyond primary use of health data.
- Citizens are empowered by having visibility on who accesses their patient files (eID), which contributes significantly to trust of citizens.
- The concept of research rooms where researchers can use already existing anonymised or pseudonymised data, providing more rapid access to data.

## European Health Data Space (EHDS)

- Hungary is active in cross-border research and data sharing initiatives.
- Overall, there is strong political will to become part of a future EHDS. There is a call that the EHDS should provide equal benefit to all countries, and this benefit should be clearly communicated.
- It is currently unclear which entity could play the role of national contact point in Hungary. There could be a potential for the newly established National Data Asset Agency to take on this role. However, the Agency's formal tasks are under development, and it is important to note that its remit is not limited to health.
- There are promising developments in health data use in Hungary. Strategic investments are being made in data-driven tools and artificial intelligence (AI), as well as innovative pilot projects building the technical infrastructure for federated analysis.
- There was a call for a separate infrastructure for the secondary use of health data, so as not to interfere with the primary use.
- The EU data spaces are recognised as a valuable next step for cross-border collaboration and service provision. There was a call for attention to be paid to data protection and privacy concerns.
- Some stakeholders report a preference that access to health data should be conditional and not free, with transparent business models.
- It was noted that the EHDS should focus on cybersecurity, trust, and citizen empowerment.

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