



# Country visit – Estonia

## 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?

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

## When did it take place?

The visit to Estonia took place virtually between **11 and 14 April 2022**.

## Who was involved?

15 stakeholder organisations were interviewed: Biobank, Connected Health Cluster, Data Protection Inspectorate, Estonian Health Insurance Fund (EHIF, written input), Estonian State Agency for Medicines, Health Board, Health and Welfare Information Systems Centre (TEHIK), Ministry of Social Affairs (MoSA), National Institute for Health Development (NIHD), North Estonia Medical Centre, Roche, Statistics Estonia, TalTech, Tartu University Hospital, University of Tartu.

## Estonia in brief

The Estonian health information system has been digitalised since 2009. The Estonian X-road allows data sharing on all administrative levels in a secure way. The Estonian healthcare is mainly funded by the Estonian Health Insurance Fund (EHIF). All registered citizens have a national ID number making linkage possible. A Next Generation HIS is in progress to rethink all aspects of Estonian health information, including the type documents and data exchange standards used, new governance and funding models.

## Data collections/sources

- The national electronic health information system is a fully digitalised e-health system that centralises patient data from all healthcare providers.
- This data is accessible for both healthcare providers and the patients through the national eHealth Portal. All transactions are logged and visible to the patient.
- The Estonian Health Insurance Fund (EHIF) database contains claims data from Estonian healthcare providers with whom they have contracts.
- The National Institute for Health Development (NIHD) holds 6 medical registries, fully digitalised and include individual level data, and health statistics.
- The Health Board is the competent authority for surveillance, prevention and control of communicable diseases. It has several information systems, including the Communicable Diseases Register.
- Statistics Estonia collects socio-demographic data. It owns the national census.
- The Estonian State Agency for Medicines owns data regarding Medicinal products, and pharmacovigilance data.
- The Estonian Biobank is a population-based biobank of the Estonian Genome Center at the University of Tartu and collects genetic information about 20% of the adult Estonian population.

## Data quality

- The national HIS data is logged and quality checks are implemented both manually and automatic.
- The claims data of EHIF implement automatic control checks for mistakes.
- Data in the NIHD have both automatic and manual checks.
- Data at the Health Board is checked and sent back to disease register in case errors are detected.
- The Biobank implements data cleaning and quality checks by a quality control team.

## Data infrastructure

- The national HIS has a centralised storage for a part of the EHR data from all healthcare providers.
- The data in the EHIF is stored in one central data warehouse that pools together data from different operational systems.
- In addition to the biological samples, the Estonian Biobank stores descriptive phenotype data and genetic data.
- No common metadata catalogue. There is a register of registers (RIHA) that is a non-standardised catalogue of state-based data and 1200 registries.
- NIHD, Statistics Estonia and EHIF have individual available metadata catalogues.
- There is no trusted third party (TTP) that deals with the pseudonymisation of the data, each source has in-house anonymization and/or pseudonymisation, and linkage processes.
- Access is mostly given to pseudonymised data. If identifiable data is needed, an ethical approval specifying it, is required.
- Mostly, there is no fee for access. Some stakeholders charge a fee for the working time to prepare the datasets.
- Time to access data varies, can reach up to 6 months for complex requests.
- The same process applies for national and EU researchers, and for industry. Data is not shared with third countries where GDPR does not apply.
- The Biobank and Statistics Estonia each have a secure processing environment.
- All e-Government data is exchanged through the x-road system using blockchain technology.
- TEHIK, the health and welfare information systems center promotes and provides guidance on the implementation of standards: LOINC and ICD-10.
- The health information system is using CDA and HL7 V3 standards for data exchange and aims to integrate SNOMED and HL7 FHIR standards.

## Data governance

- Data protection is primarily governed by the GDPR, but interpretations differ.
- There is a Data Protection Act that allows to use personal data for scientific research and policy. This act is supervised by the Data Protection Inspectorate (DPI).
- Secondary use of data does not require patient's consent. Except for the Biobanks.
- The NIHD collects data for the registries and for health statistics based on EU and state legislation and other public interest.
- A new consent management tool is under development which will be launched by the Ministry of Economic Affairs and Communication

## Resources (human, technical, financial)

- Due to its small size, Estonia has limited resources.
- Human resources needed across stakeholders:
  - Legal specialists
  - IT specialists
  - Statisticians
  - Data analysts
  - Data stewards
- Financial resources are mainly needed to fund and hire more personnel
- For hospitals, more funding is needed for IT services

## Capacity building

- Several trainings are currently provided by the different stakeholders, such as:
  - Statistics Estonia provides courses on statistical programmes (e.g. R, STATA).
  - Tallinn University provides training for physicians on data privacy and security.
  - The Ministry of Economics Affairs and Communications provides a 2-day course on data stewardship and data quality control.
- Some training needs that were reported were for improving data literacy, and on data analysis tools.
- Stakeholders also reported that there is more need to share best practices at an EU level to learn from the different skills and experience across EU countries.

## Best practices

- A big strength in Estonia is its X-road software-based solution that allows Estonia's e-Government services information to be shared and linked across administrations.
- Another aspect to be considered, is that even though there is no common metadata yet, there are individual user-friendly metadata catalogues (NIHD, and Statistics Estonia) that are also available in English.
- In general, the health sector provides a lot of open data for research and policy making (e.g., the COVID data portal).
- Citizens have a high level of control over the access to their data through the eHealth Portal.
- Researchers receive a lot of support, such as implementing data quality checks and providing advice on the use of data from the different data holders, the preparation of data proposals, analysis, and secure processing environments.

## European Health Data Space (EHDS)

- Estonia has reported high interest in cross-border sharing of health data for research, and a positive approach towards the EHDS.
- At this moment, the national competent body roles and structure related to the EHDS are still to be decided upon. There is a possibility that a new body would be set up for this purpose.
- Estonia participates in different EU networks and initiatives dealing with health data such as BBMRI, B1MG (for biobanks), TEHDAS, X-eHealth.
- Needs for EHDS:
  - There should be EU financial resources to join the EHDS.
  - There is a need for common guidelines on the interpretations of GDPR.
  - There should be training provided and sharing of best practices at EU level, for example sharing of open-source software components as building blocks for health research.
- Expectations from the EHDS:
  - Easier exchange and better pan-European analysis of data, specifically useful in the area or rare diseases.
  - EU wide standardisation and harmonisation of data which will bring great benefits for research.
  - Harmonised copy rights agreements on the results of data analyses and publications.
  - Speed up common taxonomy or standards of data collection.

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