Country visit – Finland

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
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Information about all country visits is available on tehdas.eu/country-visits.

When did it take place?

The visit to Finland took place face to face in Helsinki between **8 and 10 June 2022**.

Who was involved?

23 stakeholder organisations were interviewed: Finnish Institute for Health and Welfare (THL); Kela; Hospital District of Helsinki and Uusimaa (HUS); Findata; IT Centre for Science (CSC); Technical Research Centre Finland (VTT); University of Helsinki; Turku University Hospital; University of Oulu; Sitra; Ministry of Social Affairs and Health (STM); Eksote; Biobank of Eastern Finland; Helsinki Biobank; FinBB; Pharma Industry Finland; Healthtech Finland; Business Finland; Roche; Medaffcon; Esior; Veil.ai; BC Platforms.

Finland in brief

Finland has a tax funded healthcare system. It is characterised by a fully digitalised and rich health data landscape. All residents have a social security number, which is used as personal unique identifier for linking individual-level health data. Finland is the first European country to set up a specific legal act on the secondary use of health and social data in 2019. Its recently established data permit authority, Findata, facilitates the access to health data for research and policy making. The Finnish Institute for Health and Welfare (THL) and the Social Insurance Institution of Finland (Kela) are the main data holders for most of the national registries. Finland has almost all elements in place for joining the EHDS. However, resources will be needed in expand the capacity of the national infrastructure to answer to the increased demand for data sharing as a result of the EHDS.

Co-funded by
The Health Programme
of the European Union

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Data collections/sources

- The Finnish national eHealth infrastructure Kanta is a centralised patient data repository for health, wellbeing and social welfare information. Kanta is maintained by the Social Insurance Institution of Finland (Kela). Kela also holds drug reimbursement, prescriptions data, and social benefits data.
- Cross-border ePrescription service has been running through the Kanta platform since 2019. Work for developing the digital patient summary exchange system with other MS is ongoing.
- Districts have their own data lakes where data is available for secondary use, located at university hospitals. HUS is the largest healthcare provider in Finland and operates a data lake for the Helsinki region containing decades of clinical information.
- The Finnish Institute of Health and Welfare (THL) has comprehensive datasets in the social welfare and healthcare sector. It contains population monitoring data in the form of national registers, population surveys and biobanks. THL has 16 social and healthcare registers.
- Biobanks are distributed across 11 hospital biobanks, six of which are hospital biobanks linked to the hospital data lakes.
- The Finnish Biobank Cooperative FinBB was established to provide a centralised access to collections and services of the Finnish biobanks through their [Fingenious gateway](#) service.

Data quality

- In general, there is ongoing work on data quality and structuring of data across Finland. Stakeholders noted a need for incentives for healthcare providers to improve data quality at the hospital level.
- Registry data at THL are validated and checked through basic automated checks, manual checks, comparison to previous years and feedback loops. More automated checks are being developed.
- Hospital data lakes implement data quality standards.

Data infrastructure

- A copy of patient health data is stored centrally in the Kanta Data Platform. The original data remains at the data holders: the separate registers of health and social care service providers, and data lakes.
- Findata only temporarily stores data during the permit request process. Ready-made datasets are under development.
- Biobanks have no centralised storage.
- The Fingenious gateway offers a metadata catalogue presenting all available samples in biobanks, and streamlines access to these samples.
- The [Aineistokatalogi](#) is a common metadata catalogue, and currently includes structured information on data from more than 35 data holders. It is established on a national standard based on DDI lifecycle and GSIM.
- Access to data is mainly requested via Findata (e.g. to Kanta and THL data). When data is needed from only one data holder and linkage is not required, access to data may be requested and provided from the individual data holders directly.
- The IT Centre for Science (CSC) provides the secure processing environment (SPE) and additional technical support to Findata. At the time of country visit, Finland has 7 audited SPEs (three of which are hosted by CSC). More are under development.
- Time to access data through Findata has decreased from 2019 to 2022. Previous waiting times for Findata were reported to be up to 14 months. Applications are now checked within one week, with an average time until decision of 3-4 months. Access from single data holders takes about 2-3 months.
- Access fees vary and are split between data holders (~87%) and Findata (~13%). Findata charges a fixed fee for the permit process and an hourly fee for data management. Data holders charge for data extraction and delivery.
- In general, national and international researchers have the same rights to data access.
- All individual-level data is shared/provided in a pseudonymised way.
- THL updates and publishes international and national classifications and terminologies for eHealth.
- Hospitals and biobanks use ICD10 and HL7 versions for data exchange. In general, the OMOP common data model is widely used, and an increase use of SNOMED-CT was reported for semantic interoperability.

Data governance

- Long-standing national strategies and legislation support the use of IT for health and social services in Finland. The eHealth strategy in 2013 defined the task to create new legislation on the secondary use of health data. The Isaacus project in 2016 laid the foundations for the establishment of Findata.
- THL is the main institute that informs policy makers and implements evidence-based studies to support decision making.
- A multi-member sanction board is set up to control data privacy breaches. This includes the data protection ombudsman and its deputies.
- The main laws governing health data use include: The Medical Research Act (updated in 2021); Statistics Act (2004); Act on the Finnish Institute of Health and Welfare (THL) (2008); Biobank Act (2013); Act on Secondary Use of Health and Social Data (2019); Client Data Act (2021).
- Currently, a Health and Social Services Reform will become effective at the start of 2023, aiming to improve the availability and quality of basic public services by combining multiple municipalities into 21 self-governing wellbeing counties.
- The Toivo Programme is reported to be the structural implementation for this reform. It focuses on developing the knowledge-based management capacity of the counties.
- Ethical approval is required only when there is an intervention involved in the research project, such as in clinical trials and in surveys.
- Surveys are based on informed consent for data collection as well as for further linkage with registry data. Using and accessing register data does not require ethical approval nor consent.
- On citizen engagement, citizens have access to their Kanta data through 'My Kanta Pages' where they can provide or withdraw consent for sharing their data as needed, to provide them health and social care services. They can also upload their wellbeing wearables data.

Resources (human, technical, financial)

- The overall need for skilled human resources in the public sector reported includes data analysts and IT professionals.
- Most of the resource needs relate to Findata becoming the national contact point for the EHDS and the resources needed to improve time for receiving access to the data.
- Stakeholders expressed the need to improve technical capabilities and human resources for registry owners.
- Financial needs were reported for the transition from ICD10 to ICD11 in hospitals.

Capacity building

- Findata offers the following opportunities:
    - Data access application clinics to researchers to help them with their data access procedure
    - Free courses for data holders on using data description tools (in cooperation with THL)
    - Free half-day courses to the data holders several times a year, to help them get started with metadata descriptions to the Aineistokatalogi
    - Helpdesk: one national contact point to ask about availability of the data, quality, etc.
    - Universities and university hospitals provide training on tools for health data analysis
    - Biobank course on data and sample handling to healthcare providers

- Needs:
    - Training on data literacy for healthcare providers, to demonstrate the value of good quality data input for research

Best practices

- Finland established streamlined access procedures to data through Findata for health and social data, and Fingenious gateway for biobanks.
- The work towards the Act on Secondary Use of Health and Social Data provides the legal foundation for the EHDS. The development was reported to be based on transparency and trust in the government and the public authorities.
- Biobanks allow for enrichment of their data sets from external research projects that used biobanks data. The enriched data is then used to improve healthcare, such as screening projects.
- In general, there is strong interest in AI for health, for example using AI applications to improve healthcare, and the use of high quality, row-level anonymised and synthetic data for many secondary use cases by university hospitals and global pharma companies

European Health Data Space (EHDS)

- Finland is prepared to join the EHDS, and there is strong political will and agreements with the overall legislative proposal for the EHDS. Similarities are noted with the Act for Secondary Use.
- Most elements are already in place and it is likely that Findata would be the national contact point for secondary use and one of the health data access bodies.
- In general, there is willingness for Finnish data to be sent to and shared with other countries, but under the condition that the SPEs would have to meet the same requirements in accordance to the Regulation on secure operating environments.

- Needs for joining the EHDS:
  - Stakeholders report that resources will be needed to expand the national infrastructure and Findata specifically, including funding, staff and skills

- Expectations from the EHDS:
  - Finnish researchers will have access to more data across Europe.
  - An established network, peer to peer support between Findata and the other health data access bodies.
  - Clear concept of mutual recognition in case of a multi-country application procedure
  - Better interaction with relevant research infrastructures, and co-creation.
  - Private sector involvement, for dynamic technical solutions.
  - Create standard procedures on how to handle personal data across borders.
  - EHDS and EU should define requirements for trusted research environments, and clear legislation for federated analysis.