

Country visit – Netherlands

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 the Netherlands took place virtually between **29 and 31 March 2022**.

Who was involved?

16 stakeholder organisations were interviewed: CBS-NL – Central Statistics Office; CIBG – National Contact Point for eHealth NL (NCPeH-NL); Erasmus MC; Health Insurance Company Cooperation; Health-RI; HL7 Netherlands; Ministry of Health Welfare and Sport (VWS) – Directorate of Information Policy / Cluster (Interoperability & Information Security), Directorate of Innovation and Healthcare Renewal, Directorate of Public Health, Division of Medical Ethics; Netherlands Comprehensive Cancer Organisation (IKNL); NEN (Dutch Normalisation Institute); Nictiz; Nivel; Ondernemers in de Zorg (Dutch ICT providers in the Netherlands); PALGA (Dutch Nationwide Pathology Databank); RIVM (Public Health Institute); VNO-NCW (Dutch Association of employers and entrepreneurs); Zorginstituut NL (Healthcare Institute).

Netherlands in brief

The Dutch Health Information System is rich and digitalised but fragmented, with decentralised management. In general, health data is stored in a structured manner. There are multiple initiatives aiming to standardise data and ensure quality. In the near future, citizens will be able to access their health data through the Personal Health Environment (PHE); a nation-wide program to implement this, is currently running. The burgerservicenummer (BSN) is the citizen number used as a unique personal identifier for health, covering all registered citizens and allowing individual level data linkage across data sources. In the Netherlands there is a distinction between secondary use of health data for scientific research and the use for innovation. Scientific research refers to studies conducted for the public good, whilst innovation refers to studies for commercial purposes.

Data collections/sources

- Electronic health records (EHRs) are digitalised but decentralised. There are two main providers.
- Upcoming PHEs allow patients to access a copy of their data from all their healthcare providers.
- Dutch Hospital Data (DHD) is a central collection of hospital data. Nivel and the Integrated Primary Care Information (ICPI) database have primary care data.
- Obligatory insurance provided by private not-for-profit companies. Central pool of health insurance data (Vektis).
- Statistics Netherlands (CBS) has several health-related registries, with mandatory reporting. CBS also carries out the Health Interview Survey.
- National Institute for Public Health and the Environment (RIVM) collects, stores, receives and re-uses data for research and policymaking. RIVM has its own datasets, and hosts screening programme data.
- >100 national quality registries. Dutch Cancer Registry has 2.3 million patients.
- Biobanks are decentralised in hospitals and other organisations. There is no plan to create a central biobank. PALGA is the national pathology register, with data from all pathology laboratories.

Data quality

- Quality control mechanisms in place: most registries in the Netherlands have quality validation processes and long feedback loops to healthcare providers to fix input errors and ensure proper registration at the source (e.g., validity checks on the data by quality departments and medical professionals).
- Health-RI: defines quality standards for research. In the future, possibility to have a data quality train checking consistency of data.
- Pathology data in PALGA are updated nightly.

Data infrastructure

- Decentralised storage of mostly digitalised and structured health data.
- Currently, there is no centralised metadata catalogue providing a general overview of health-related data collections and access procedures. RIVM and the Health-RI have developed metadata catalogues that could be combined to create the common metadata catalogue for the Netherlands. DCAT-AP standard is used by Health-RI.
- Pseudonymisation is done by CBS and the Zorg Trusted Third Party (based on BSN, name, date of birth, and postcode).
- The nationally developed Zibs common data model is the most used standard. Nictiz and HL7-NL promote the use of SNOMED-CT and HL7 FHIR, respectively. Some data collections (Nivel and Erasmus MC) are transferring their data to the OMOP common data model.
- Data access procedure:
 1. Obtain necessary (ethical) approvals
 2. Describe the research project protocol
 3. Apply to the different data holders separately
- Time and fees for accessing data vary between data holders. Same access procedure and fees apply for foreign researchers.
- Data linkage is possible but not always using the BSN number.
- CBS have a secure processing environment where they give access to data for analysis. Most university medical centres are also implementing such an environment.
- Personal Health Train (PHT) proof of concept for federated analysis by the Health-RI.

Data governance

- Wegig legislative proposal drafted in 2021 to improve interoperability for primary use and normalisation of EHRs. In parliament for adoption (at time of writing).
- Ministry of Health, Welfare and Sport developing a roadmap for secondary use of health data.
- RIVM and CBS access aggregated data and perform studies to inform policy makers.
- The legal basis for use of health data for research and innovation is fragmented and on certain points unclear (Executive Act of the GDPR, UAVG).
- Consent is the common legal basis to use personal health data. Lexis specialis mentions that under certain conditions, when consent is not possible, opt-out mechanisms can be used. Due to differing interpretations of the legislation, continuous discussions and different procedures exist.
- Citizens use a two-factor authentication log-in, Mijn DigiD, to access a copy of their health data through the PHE, or directly from their healthcare provider. Medmij manages a set of data exchange standards ensuring that health data is transferred securely.
- There are some pilot initiatives where citizens can also input data from wearables into their PHE.
- Discussion to implement an opt-in and opt-out system for citizens through their Personal Health Environment.

Resources (human, technical, financial)

- Human resources needs:
 - Maintenance and operation of health data collections.
 - Data analysts, scientists etc.
 - ICT experts
 - Legal experts
 - Data stewards (new job profile)
- Technical resources needs:
 - Transformation of health data into the OMOP common data model, or other standardised data models.
- Financial resources needs and status quo:
 - General need for financial incentives to maintain skilled staff, such as data analysts, data stewards and ICT experts.
 - Ministry of Health, Welfare and Sports finances the PHE, PALGA and the IKNL. Healthcare providers and hospitals in general are financed by health insurances.
 - Ministry of Economy provides a Growth Fund that financed the Health-RI and the Dutch Artificial Intelligence Coalition.

Capacity building

- Training needs:
 - Need for training on how to input data in a structured manner and data literacy to healthcare providers.
- Training opportunities:
 - Nictiz provides communication, trainings and podcasts on terminology and how to use standards. It also provides the AMIGO tool, amongst other tools, for assistance to implement standards.
 - HL7 NL has launched an eLearning course for the HL7-FHIR starter code. Potential to become a European course. HL7 NL also provides training in collaboration with Firely.
 - RIVM provide services to researchers internally, on statistical modelling and general support to access and analyse health data.
 - RIVM occasionally also provides external trainings on high performance computing, R, machine learning and data management procedures.
 - Dutch Techcentre for Lifesciences (DTL) in collaboration with Health-RI already provides training for data stewards.

Best practices

- The PHT, the implementation of use cases piloting the federated analysis technology to create a proof of concept.
- Projects applying Privacy Preserving Technologies in order to perform federated analysis while ensuring patient privacy.
- Investment in the development of technical and procedural standards, including the involvement of healthcare professionals in the creation and deployment of these standards.
- The support and expertise provided by HL7-NL in the translation and transfer of health data from a local, national, standard to the HL7-FHIR model.

European Health Data Space (EHDS)

- General will to participate in the EHDS for secondary use but not yet decided who would take the role of the national contact point. Ongoing work on setting up the roadmap for the legislation on the secondary use of health data in the so called data reuse obstacle removal trajectory initiated by the Ministry of Health, Economic Affairs, Education and Health-RI.
- Cross-border sharing of health data is very important and is happening, as foreign researchers have the same access rights to health data as Dutch researchers.
- There is support for a system of federated collection, storage and analysis of health data, in particular through the regional health data nodes coordinated by Health-RI. Ongoing pilots on federated analysis through the PHT at Health-RI.
- The Netherlands is part of multiple international initiatives, such as BBMRI, ELIXIR, EATRIS, B1-MG, TEHDAS, EHDEN, DARWIN, ODISSEI, HL7 Netherlands, and many others.
- Needs to join the EHDS:
 - Need to have a harmonised network of hospitals and general practitioners, standardised electronic patient summary exchange and EHRs.
 - Need to have a common descriptive metadata catalogue for the Netherlands.
 - Need to transfer health data from nationally developed standards to internationally recognized common data models.
 - Need to have an integrated sectoral legal framework for healthcare data usage.
- Stakeholders highlighted the importance of introducing health and lifestyle data (e.g., from wearables, behavioural data) for research and innovation.
- Stakeholders highlighted the need for clarifications of certain definitions and the GDPR. Proposal to create a platform within the EHDS where healthcare providers, citizens, patients, data protection officers and legal officers can interact and share best practices.

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