Luxembourg National Data Service
Bert Verdonck

CEO Luxemburg National Data Service

1993 MSc Engineering, KULeuven, Belgium
1996 PhD Medical image processing, ENST Paris, France
1996-2022 Healthcare informatics, Philips, Netherlands
Since 2020 Gaia-X
Since 2022 Data Space Support Centre
Since 2022 Luxemburg National Data Service
Luxembourg National Data Service

- A national organisation providing services for value creation from public sector data.
- Focusing on enabling sharing and re-use of data for public and private data partners.
- Offering technology and data services, know-how, capabilities, platform, and infrastructure.
- Developing and supporting solutions for responsible secondary use.

Note: The Luxembourg National Data Service is a brand of PNED G.I.E, an economic interest group established on 28 July 2022 by the Luxembourg government and public institutes.
LNDS will design and build a service portfolio

MATCH
Animate a match making environment between data owners/providers and data consumers/users.

INNOVATE
Learn, code and publish about the soft and hard infrastructure to enable data exchange.

CONSULT
Educate and guide participants of the data economy. Join data trusts as an experienced advisor. Co-design data spaces.

SERVE
Provide data services to enable data intermediaries, brokers, clearing house, identity and trusted third party services.

Note: this includes the tasks of a competent body that assists public sector bodies to grant access for the re-use of specific categories of data, as defined in article 7 of the Data Governance Act (EU regulation 2022/868).
Engagement on national and EU level

• Potential role as competent body as defined under the EU Data Governance Act (no permit authority)
• Potential role in a health data access body (EHDS), taking over some functionalities in data management (no permit authority)
• Consultancy role in the definition of a European Digital Infrastructure Consortium (EDIC)
• Infrastructure provider within the future 1+MG EDIC, potentially EHDS, Gaia-X clearing house, Clinvova, e.a.
• Trusted third party for Luxembourgish data space needs
European Health Data Space (EHDS)

OBJECTIVES

Effective use of health data

SCOPE & EXPECTED IMPACT

Use of health data (primary, MyHealth@EU)

- Empower individuals to control their data
- Standardization and mandatory certification of EHR systems
- Voluntary labelling of wellness apps
- European Electronic Health Record Exchange Format

Re-use of health data (secondary, HealthData@EU)

- Health data access bodies
- Purposes for use and forbidden use
- Data permits, secure environments, no identification

Single market for health data, data protection, free movement of people, digital goods and services

Facilitated Research & Innovation
Better Policy Making

MEANS

Legal / Governance
Quality of data
Infrastructure
Capacity building/digitalisation

European Commission
Chapter IV Secondary use of health data

- Set up a health data access body/bodies for secondary use of electronic health data (Art. 36) – building upon the Data Governance Act

- Development of the new decentralised EU cross-border infrastructure for secondary use (HealthData@EU) (Art. 52)

- Setting up and fostering cross-border access to electronic health data and mutual recognition (Art 53, 54)

- Foresees further legislative developments for the implementation of common measures enabling the secondary use of health data in the proposed EHDS related to several aspects of the proposal (implementing acts, delegated acts).
EHDS Proposal - Negotiations

2. European Council
   - Swedish Presidency (Jan-June 2023)
   - Spain (Jul-Dec 2023)

3. European Parliament
   - Rapporteurs: Tomislav Sokol, Annalisa Tardino
   - Responsible Committees: ENVI, LIBE

Starting point: EC proposal, adopted in May 2022
## Draft timeline for some actions on secondary use

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- **EHDS Reg. proposal**: Negotiation, entry into force, entry into application, applicability
- **TEHDAS**: 28 months
- **HealthData@EU Pilot**: 24 months
- **HDABs grants**: 36 to 48 months
- **TEHDAS II**: 24 months
- **CSA on data quality**: 24 months
- **Capacity Building on 2U**: 24 months
- **HealthData@EU Scale-UP**: 36 months
- **Simpl**: 36 months
The HDH, leader of a European consortium to build and operate a first version of the EHDS

Create and test a beta version of the European Health Data Space

17 partners, 9 countries
2 years
5 million euros of European fundings

Build a network of data platforms on a European scale...

...tested by concrete cross-border use cases
The project will cover important pieces of the overall EHDS user journey

... building on the IT infrastructure connecting the data platforms and EU central services in a network allowing information exchange (WP5)
5 cross-border use cases will show the added value of HealthData@EU
One of the use cases focuses on linking genomic and clinical data

1. Antimicrobial resistance surveillance
   led by ecoEC

2. Identifying the risks of coagulation disorders in patients with Covid-19
   led by European Medicines Agency

3. Test use, hospitalizations and vaccination adherence in vulnerable sub-populations
   led by sciensano

4. Project to anticipate care pathways in cardio-metabolic diseases using AI
   led by HSH Health Data Hub

5. Identify genomic signatures characteristic of different types of colorectal cancers
   led by BBMRI-ERIC
Direct grant to Member States: for setting up services by Health Data Access Bodies - Secondary use of health data (DI-g-22-22.01)

- Objectives
  - Support Member States in establishing and strengthening health data access bodies with a view to preparing, ensuring readiness and using a common approach for the secondary use of health data in the EHDS.

- Activities to be funded:
  a) Design, establishment and deployment of national services and infrastructures for secondary uses
  b) Design, establishment and deployment of cross-border services and infrastructures
  c) Improvement of data quality

Budget: EUR 30 million