EHDS
HealthData@EU Pilot

About This Project

The HealthData@EU Pilot project brings together 17 partners including health data access bodies, health data sharing infrastructures and European agencies. It will build a pilot version of the European Health Data Space (EHDS) infrastructure for the secondary use of health data which will serve research, innovation, policy making and regulatory purposes: HealthData@EU

The project will connect data platforms in a network infrastructure and develop services supporting the user journey for research projects using health data from various EU Member States. It will also provide guidelines for data standards, data quality, data security and data transfer to support this cross-border infrastructure.

Priority services include a metadata discovery service and a common health data access request. The consortium will collaborate closely with the European Commission and their team working on developing the central services for HealthData@EU.

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Selected use cases

In order to illustrate the feasibility and the potential of reusing data from several European countries, the project will run five use cases that encompass a wide range of research and policy topics.

- Demonstrate the feasibility of using the EHDS to carry out infectious disease surveillance, focusing on antimicrobial resistance (led by the European Centre for Disease Prevention and Control)

- Foster a better understanding of the risks of thrombosis in COVID-19 patients (led by the European Medicines Agency)

- Compare COVID-19 testing, vaccination and hospitalisation between the general population and vulnerable subpopulations (led by Sciensano - Belgium)

- Compare care pathways for cardiometabolic diseases in European countries and build prediction models, using artificial intelligence (led by the Health Data Hub - France)

- Mobilise and chain clinical and genomic data to enhance our understanding of colorectal cancer (led by ELIXIR)

www.ehds2pilot.eu   @ehds2pilot   ehds2pilot@health-data-hub.fr

WORK PACKAGES

Horizontal work packages

Horizontal work packages to coordinate, communicate and ensure delivery:
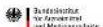
- ☑ WP1 Coordination of the project
- ☑ WP2 Communication and dissemination of the project
- ☑ WP3 Evaluation for the project
- ☑ WP4 Recommendations for becoming a data node in the future European Health Data Space

Project partners

Technical work packages

Technical work packages to build and test the user journey:

- ☑ **WP5 IT Infrastructure:** build an IT infrastructure connecting the health data infrastructures and initiatives involved in the project and the central services. This network infrastructure will enable information exchange and serve as the technical backbone for the implementation of services.

- ☑ **WP6 Metadata standards:** develop and implement a descriptive metadata standard for health data (Health DCAT-AP extension) and provide requirements for establishing a search portal at the central services level.

- ☑ **WP7 Regulatory and legal compliance:** function as normative laboratory to support development of services and use case implementation. Main outputs include building a unique data permit request form, providing requirements for the implementation of a request portal at central services level and developing general conditions of data use.

- ☑ **WP8 Data interoperability, quality and protection:** provide guidelines for data standards, data quality, data security and data transfer.

- ☑ **WP9 Use cases management:** Ensure project management for use cases and implement data standards as well as metadata standards on the databases involved in the use cases.

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