

HealthData@EU Pilot project Stakeholder forum 2024

Exploring the European Health Data Space:
a journey guided by the HealthData@EU Pilot Project

12 November 2024, 13:30 - 17:00, Lisbon, Portugal

Join us at the pre-conference to embark on an exciting journey through the European Health Data Space (EHDS), guided by the HealthData@EU pilot project!

The EHDS aims to establish a common secure framework across Europe to facilitate the reuse of health data for research, innovation, and public policy purposes. Launched in October 2022 and running over two years, the HealthData@EU pilot initiative, with its 17 partners including national data platforms and research infrastructures, is at the forefront of this transformation.

Their mission? Develop and deploy an EHDS-like IT infrastructure for secondary data use and validate use cases for cross-border research projects. The pilot project addressed every aspect of the user journey for secondary health data use, including data discovery facilitated by a metadata catalogue, the development of a common data access application form for permit requests, setting interoperability and quality control standards for data preparation, and data usage.

During this preconference, the project partners will showcase how this innovative initiative contributes to unlocking EHDS's potential for secondary health data use. They will guide you through your user journey in the new data space to uncover its benefits for you, European citizens, patients, and policy makers. By sharing key achievements, insights, and challenges encountered throughout the project, we aim to pave the way to unleash the potential of health data in Europe!



Preliminary programme

Moderator: Dr. Nienke SCHUTTE, Scientist, Head of Unit, Innovation in Health Information Systems unit, Sciensano (Belgium)

13:30 **Welcome by the HealthData@EU pilot project Coordination Team**

Marianne BENDERRA, European project manager, Health Data Hub (France)

13:40 **Introduction to the European Health Data Space**

Jérôme DE BARROS, Policy officer, DG Sante C1, European Commission

13:55 **Data discovery: Health DCAT-AP for findable health data**

Speakers:

- Pascal DERYCKE, Data engineer, Sciensano (Belgium)
- Truls KORSGAARD, Senior Advisor, Norwegian Institute of Public Health (Norway)
- Charles-Andrew VANDE CATSYNE, Scientist, Sciensano (Belgium)

This session tackles the challenge of locating health data across Europe, particularly during crises like COVID-19. The EHDS aims to streamline health data discovery using FAIR principles. The HealthData@EU pilot introduced HealthDCAT-AP to support these efforts.

Highlights: HealthDCAT-AP demo, metadata record creation, showcasing EU and national health data catalogues.

14:30 **Data preparation to ensure data usability and compliance**

Speakers:

- Eva GARCIA ALVAREZ, IT Scientist and Project Manager, BBMRI-ERIC
- Petr HOLUB, Chief IT Officer, BBMRI-ERIC
- Rachel BEDENIS FORSTER, Researcher, Norwegian Institute of Public Health (Norway)

Preparing health data for cross-border use is a critical step in ensuring that data is both usable and compliant with legal and technical requirements. This session will delve into the strategies developed during the HealthData@EU pilot to optimise data preparation, focusing on aligning with the EHDS framework and enabling seamless cross-border research.

Highlights: a practical example from a use case research team

15:00 *Coffee break*

15:20 **Scaling up the EHDS and closing the loop**

Speakers:

- Katrine HØJEN VAD, Coordinator, Danish Health Data Authority (Denmark)



Building on the outputs of the HealthData@EU Pilot project, this session will focus on defining a scalable model for a well-functioning EHDS node that can be adopted across any EU Member State. These recommendations provide a framework for establishing key services of a Health Data Access Body (HDAB), ensuring alignment with EHDS goals.

Highlights: recommendations and economic scenarios developed through extensive discussions with pilot use cases and technical work packages, focusing on the critical components for establishing a HDAB.

15:35 **Panel discussion: unleashing the potential of health data**

Speakers:

- Dr Mélodie BERNAUX, Policy Officer, Seconded National Expert, DG SANTE, European Commission
- Irene SCHLÜNDER, Senior legal expert, BBMRI-ERIC
- Elina DRAKVIK, Specialist lead, Sitra (Finland)
- Denise UMUHIRE, Pharmacoepidemiology & RWE senior Specialist, European Med

16:25 **Data access: common data application forms to boost cross-border use of electronic health data within the European Union**

Speakers:

- Rosa JUUTI, Senior Specialist, Findata/THL (Finland)
- Emanuel BRAĐAŠEVIĆ MD, Department for medical informatics and biostatistics, Croatian Institute for Public Health (Croatia)
- Pero IVANKO, Department of Data Science and Analytics, Croatian Institute for Public Health (Croatia)

Navigating diverse application processes across Member States complicates cross-border data access. This session presents a standardised data access form, simplifying requests while adhering to EHDS and GDPR requirements.

Highlights: design process insights, lessons from Croatia's experience.

16:55 **Closing words**

Dr. Nienke SCHUTTE, Scientist, Head of Unit, Innovation in Health Information Systems unit, Sciensano (Belgium)