PRESS RELEASE

Paris, November 17th 2022

Official kick-off event for the European health data space pilot project

After being selected by the European Commission this summer, the consortium that aims to implement the European Health Data Space (EHDS) pilot project launched its work. During two days, the 17 members discussed the project priorities and participated in working groups to launch the planned work and selected use cases of the pilot project. The grant agreement with the Health and Digital Executive Agency (Hadea) was also signed, fully initiating the consortium's momentum.

Since 2019, the European Health Data Space (EHDS) is identified as a one of the EU health policy priorities. By facilitating access to European health data, its enforcement will help to develop research and improve citizen's health.

"*With the EHDS, the EU can become the major player in digital health that it needs to be internationally - for the benefit of every citizen. This is an important issue for the consortium, with many challenges to be met in order to make it a success. These two days of work allowed partners to share a common vision and created a positive dynamic for the project*"
- Emmanuel Bacry, scientific director of the French Health Data Hub.

In July 2022, the European consortium led by the Health Data Hub was selected to carry out the EHDS pilot project "HealthData@EU pilot". The 17-member consortium gathers amongst others several Member States health data platforms, the European Medicines Agency (EMA) and the European Centre for Disease Prevention and Control (ECDC), as well as European research infrastructures BBMRI, ELIXIR and eBrains.

Although the actors have been cooperating together since the launch of the European Commission call for tenders in 2021, the 11 and 12 October kick-off event marked the first general assembly of the consortium, held in person at PariSanté Campus.

Bringing together 77 people, these two days of work marked the effective launch of the pilot project. Underlining the importance of the event, the introductory session allowed national and European actors to highlight the project's stakes:

"*It is vital, in order to improve research, to promote scientific exchanges at the level of the European Union. The EHDS aims to handle issues on quality, standards and more broadly the openness of health data*", emphasised Member of French Parliament Éric Bothorel, in introduction to the event. Priorities which echoed Fulvia Raffelli, Head of Unit "digital health" at the European Commission DG SANTE : "*Health data represent the future of research, and in light of the need for common infrastructure, we are counting on you to help make the EHDS a reality*".

The pilot project, co-financed with €5 million over 2 years by the European Commission's health programme EU4Health, is divided in nine working groups (5 technical, 4 transversal) aiming to build the network that will interconnect health data platforms at EU level. The project will also develop services to support the conduct of European research projects, such as a common metadata catalogue or a single data access request form; the experience of these works will be valuable feedback for the prefiguration of the European Health Data Space.

The EHDS pilot will test the network, as well as the first user journey, thanks to 5 use cases focusing on antimicrobial resistance, cancer or coagulation disorders, for instance. The use cases will help determine both the feasibility of European research projects, as well as the EHDS added value regarding research, innovation and public policies.

The event demonstrated the consortium's full commitment and determination to this major project. As such, on October 27th, the Health Data Hub signed a grant agreement with the European Health and Digital Executive Agency (Hadea), taking a step further in structuring the work of the consortium, which is ongoing in a collegial manner and at a sustained pace.

Stay tuned to follow the consortium progress !

ABOUT THE FRENCH HEALTH DATA HUB

Health data are essential for research and innovation in health, yet these data are often under-used because they remain too scattered. The French Health Data Hub (HDH) was hence conceived as the unique gateway to health data in France. Implemented in November 2019, it interacts with a variety of actors within the health ecosystem. The Health Data Hub has set up a highly efficient technological platform enabling public interest project leaders to mobilise very large data sources, to cross-reference them, and to use enough computing power to run complex search algorithms. In a word, the HDH supports ambitious project leaders who contribute to finding tomorrow's solutions to improve all citizens' health.

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ABOUT THE HEALTH DATA@EU PILOT

The HealthData@EU Pilot project brings together 17 partners including national health data platforms and permit authorities, European agencies and research infrastructures. It will build a pilot version of the European Health Data Space (EHDS) for the secondary use of health data, by connecting existing data platforms in a network infrastructure and developing services supporting the user journey for health data research projects at the European Union level. Priority services include a metadata discovery service and a common data permit request form. In addition, the project will run five use cases to illustrate the feasibility and the potential of reusing data from several European countries for research, innovation, policy making and regulatory purposes. These use cases will also serve as a learning source for the creation of services at node and central service level. 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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