

EHDS

HealthData@EU Pilot

External Advisory Board - Call for participation

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Open call for experts to participate in the HealthData@EU pilot External Advisory Board

What is it all about? Building the European Health Data Space

The construction of a European Health Data Space (EHDS), to overcome the barriers to the use and reuse of health data at a European scale, has been identified as a priority of the European Union's health policy.

The draft EHDS regulation, unveiled by the European Commission in May 2022, establishes the core principles for sharing health data at a European scale, covering both the primary and secondary use of health data. For the secondary use of health data, it proposes a governance framework aiming to simplify and harmonise the conditions for accessing the data. This framework includes rules and a data access process with time limits to deliver the authorisation and provide access to the data; it also foresees the establishment of national health data access bodies, with a definition of the roles and responsibilities of all actors in the process. Finally, it sets a framework for the cross-border use of health data with the establishment of a European infrastructure "HealthData@EU" and guides the actors in order to facilitate the identification and reuse of data at European level. The text provides for the establishment of a European governance, through the creation of a "European Health Data Space Board".

In order to bring this framework to life, especially with regards to the European infrastructure HealthData@EU and the associated services, the European Commission has launched a call to build a first test version of HealthData@EU: the resulting project is the HealthData@EU pilot project.

What are the objectives of the project?


The HealthData@EU pilot is a two-year long European project bringing together 17 partners including national health data platforms and permit authorities, European agencies and research infrastructures, co-financed by the EU4Health program.

It will build a pilot version of the European Health Data Space (EHDS) for the secondary use of health data "HealthData@EU" which will serve research, innovation, policy making and regulatory purposes.

The project will connect data platforms in a network infrastructure and develop services supporting the user journey for health data research projects at EU level.

[Learn more about the project](#)

The External Advisory Board will provide additional insight and expertise to the project Work packages, which covers the entire user journey for the EHDS:

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- **Data discovery: Metadata standards** (WP6): develop and implement a descriptive metadata standard for health data (Health DCAT-AP extension) and provide requirements for establishing a search portal at the EU central services level.
 - Data access: **Regulatory and legal compliance** (WP7): function as normative laboratory with main outputs including building a unique data permit request form, providing requirements for the implementation of a request portal at EU central services level and developing general conditions for data use taking into account data protection principles.
 - Data preparation and use: **Data interoperability and quality** (WP8): provide guidelines for data standards and data quality.

The user journey will be supported by the IT infrastructure (WP5) connecting the data platforms involved in the project and the central services. This network infrastructure will enable secure information exchange and serve as the technical backbone for the implementation of services.

In order to illustrate the feasibility and potential of cross-border reuse of health data, the project will run **5 use cases** (WP9) on the following 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 France and Finland)
- Mobilise and chain clinical and genomic data to enhance our understanding of colorectal cancer (led by ELIXIR).

Depending on the application received, there may also be specific interaction on WP4 '**Recommendations for being an EHDS node**', which also include work on the economic model and funding of the EHDS.


Why apply?

By participating in the HealthData@EU Pilot External Advisory Board, you will contribute in shaping the future European Health Data Space for secondary use and in ensuring that it is fit for purpose for all categories of stakeholders.

Who can apply?

Members of the External Advisory Board will be selected according to the following criteria:

- Experience and expertise in areas related to the project activities (see description of activities of the work packages above);
- Representation of the different types of actors with stakes in the future European Health Data Space, e.g. data holders, data users, future European Health Data Space nodes,



health public authorities, patients and citizens organisations, health care professional associations and organisations, health insurance bodies, research and teaching institutions, healthcare facilities, data protection authorities, private sector (pharmaceutical industry, eHealth start-up...)

- Members will be required to declare conflicts of interest as well as a non-disclosure agreement.

Candidates affiliated with an organisation that is already part of the project Consortium will not be eligible, as they can already get involved through their organisation.

What will participation entail?

After the selection process is complete, the External Advisory Board will convene a first time for an online kick-off in February 2023.

Throughout the lifetime of the project, the External Advisory Board members will be invited to review some of the Work packages' key deliverables or to give feedback on specific questions. Depending on the complexity of the questions put forward, the members will debate them in dedicated online meetings or will provide their feedback in writing. Work packages will reach out to the External Advisory Board at least once a year for the duration of the project.

How to apply?

Candidates should fill out the following [form](#) with their information :


- Name
- Organisation
- Email address
- Work package(s) in which they are specifically interested
- Description of their interest in the project and of their expertise in the field(s) covered by the Work package(s) selected

They will also be required to attach their resume.

All candidatures will be reviewed by the project Coordinator to assess their eligibility, by checking that their application is complete, that their expertise on at least one of the fields covered by the Work packages is justified and that the candidates is affiliated to an organisation among those targeted above and not affiliated to one of the project's members; eligible candidates will be selected by the project Steering Committee, taking into consideration the balance between different types of expertise and organisations.

How will your data be handled?

We are committed to the protection of your personal data. The information collected via this call is recorded in a file computerised by the Health Data Hub (hereinafter the "Health Data Hub (HDH)") for the following processing purposes: a) project management (organisation of meetings, steering committee meetings, sharing of information and invitation to events); b) access to the project's encrypted and secure file and folder sharing platform allowing document sharing and collaboration on the documents saved for each Work Package of the EHDS Pilot



project; c) the sharing of your data with all contributors/partners as well as with the collaborators of the European Commission.

The legal basis for processing is your consent.

The following data must be provided in order to apply: your name, first name, organisation, email and resume.

You agree that the data collected will be communicated to the following recipients only: a) HDH employees from the various HDH departments who are involved in the EHDS Pilot project; b) the other contributors/partners of the EHDS pilot project; c) employees of the European Commission.

The data is kept for the duration of the EHDS pilot project, i.e. for a period of 24 months from the date of collection by the HDH.

You can access the data concerning you, rectify it, request its deletion or exercise your rights to limit the processing of your data and to the portability of your data. You can withdraw your consent to the processing of your data at any time.

To exercise these rights or for any questions about the processing of your data, you can contact our data protection officer at the address: dpo@health-data-hub.fr or by post to HDH, at the attention of the Data Protection Officer 9 rue Georges Pitard 75015 PARIS.

If you believe, after contacting us, that your "Data Protection" rights are not respected, you can file a complaint with the CNIL. Visit the [cnil.fr](https://www.cnil.fr) website for more information.

Schedule :

- Deadline for submission of applications: 13 January 2023
- Notification of results: End of January 2023 (approx.)
- External Advisory Board Kick-off meeting: February 2023 (approx.)
- End of the project: October 2024

Contact

For all questions regarding the External Advisory Board and the project in general, you can contact us at ehds2pilot@health-data-hub.fr

Stay up to date on the project's progress by subscribing to the newsletter on the [project website](#).