The Health Data Hub is a public structure whose mission is to guarantee easy and unified access to health data for projects of general interest, in compliance with regulations and citizens' rights. It provides a highly secure, state-of-the-art technological platform to project leaders who are interested.
Our ambitions for 2022

1. Integrating and enriching the main database and catalog
2. Reducing delays in accessing health data and increase impactful projects
3. Consolidating a technological platform that respects the principle of reversibility and the national strategy for a trusted cloud
4. Being receptive to civil society and co-construct a culture of health data
5. Contributing to the development of a database funding strategy to promote their sharing and development
6. Contributing to the prefiguration of the European Health Data Space
7. Keeping developing the international structure
Integrating and enriching the main database and catalogue
Today, the Health Data Hub provides data on a project-by-project basis...

The Hydro project aims to develop an algorithm for predicting heart failure attacks by cross-referencing hospitalization data with data from connected pacemakers.
... tomorrow, the replication of the main SNDS base and the implementation of the catalog will allow to scale up.
The scalable catalog will allow, starting with its first version, to address many medical issues

- **BNA**: National Alzheimer's Bank
- **Memento**: Cohort of patients with signs suggestive of early Alzheimer's disease or a related disorder
- **E-must**: Prospective collection of information concerning Myocardial Infarction
- **I-Share**: A multidisciplinary study to assess health status and explore risk factors for specific health problems among students
- **OSCOUR**: Organization of coordinated emergency surveillance
- **MDO**: List of mandatory diseases
- **UroCCR**: French Kidney Cancer Research Network
- **ESME**: Epidemiologic-Economic Strategy for Breast Cancer
- **CANTO**: Improve the quality of life of women with breast cancer

**Bases for the Covid-19 epidemic**

- **IPEDS**: Covid-19 National Population Screening Information System
- **SIVIC**: Hospital data for the COVID-19 outbreak
- **ThOracic scan for the diagnosis of Coronavirus 19 pneumonia (STOIC)**
- **French National Database of Rare Diseases (BNDRM)**
- **HEPATHER**: Cohort of patients infected with the hepatitis B or C virus
- **EPICOV**: National survey on the Covid-19 epidemic
- **Base e-sis**: IS for the complete dematerialized management of breast cancer screening
- **Base ATU**: Database collected as part of early access

**2022 Roadmap**

First list of potential bases for the HDH catalog
Reducing delays in accessing health data and expanding impactful projects
In France, a project requiring the use of health data can get long and complex...

In order to support the projects, the Health Data Hub will continue, along with its partners, to create a service offer including:

- Pedagogical documentation for users, a diversified training offer and open-source tools that are constantly being further developed
- Transparency tools for the public
- The implementation of an action plan with the Assurance Maladie in order to accelerate the delivery of SNDS data and to ensure that the Health Data Hub's teams become more competent
- The implementation of a concentrator to industrialise data chaining operations
- The harmonisation of data use contracts, including aspects of economic valuation
... the challenge is all the more strategic as the number of projects keep on increasing

55 projects support by early 2022 and many more to come
Consolidating a technological platform in accordance with a principle of reversibility and the national strategy for a trusted cloud
Prior to the analysis, project leaders must be able to easily identify which data are available...

In 2022, the Health Data Hub will **deploy a metadata catalogue to make it easier for project managers** to explore the available data, its content and its quality.
Once the authorisations are granted and the data prepared, the project managers can analyse the data in the project space.

In 2022, the Health Data Hub will keep on implementing its software offer for project managers and developing functionalities for operators or citizens who would like to exercise their rights.
Continuation of the reversibility action plan for the migration of the technology platform

Construction of the HDH platform according to a logic of reversibility thus facilitating its redeployment to another solution, in particular by its programming in the Terraform language

Continued identification of sovereign solutions meeting security requirements and verifying the trusted cloud label

Action plan to reduce adherence to the current provider's services
Listening to civil society and co-building a health data culture
In 2022, the Health Data Hub expands its actions towards civil society by continuing to listen and dialogue,

“There should be a single platform for all medical data, which authorized researchers should be able to access via anonymization/pseudonymization algorithms.

“What if the massification of public health data was the subject of a practical and educational guide accessible to all?”

Barometer

Consensus conference
... by the creation of content and its diffusion...

"What opportunities for national health data platforms?"
March 31, 2022

"VivreCovid19" seminar: feedback and debate on health data sharing
June 2022

4th edition of our conference "Health data and collective intelligence"
December 2022

5 of these events were awarded the "French Presidency of the Council of the European Union" label

+120 events in which the Health Data Hub participated in 2021
... and by initiating a collective reflection based on the first concrete results

Continuation and expansion of partnerships

Results from the first partnerships

Identification of the most appropriate governance
Contribution to the development of a database funding strategy
Contributing to a permanent funding of databases

The French Law on the Organization and Transformation of the Healthcare System created the Health Data Hub and expanded the SNDS to include all health data associated with a Health Insurance reimbursement.

Therefore, this data can be shared in accordance to national rules. Some of these rules are enshrined in law, such as access governance. Other rules remain to be specified, within the framework of the SNDS Strategic Committee created in July 2021, of which the HDH is a member.

One of the core issues that must be addressed is the national policy for financing health databases. In order to share data as widely as possible, it is necessary to take into account the efforts made by the actors who created the data and to provide a fair return for those efforts.
Contribution to the prefiguration of the European Health Data Space
The pilot of the European Health Data Space (EHDS) will be launched in 2022

1) Exploring and identifying concrete actions within the framework of the Joint Action "Towards a European Health Data Space"

2) Launch of a first test with a Health Data Hub counterpart, FinData, and exploring international standards such as OMOP

3) Scaling up with the European Health Data Space (EHDS): call for applications financed up to 5 million euros for which the HDH is applying as leader of a consortium including 16 European partners
Further internal structuring

By the end of 2022, nearly 100 people will be working within the Health Data Hub to improve access to health data.
Key figures for the Health Data Hub in 2022

- **Platform users**: 90
- **Staff members**: 100
- **Partnerships**: 130
- **Contributions to public debates**: 5000
Health Data Hub - Members of the public interest grouping

The French State

Healthcare insurance funds

Complementary health insurance organizations
Health Data Hub - Members of the public interest grouping

Research and education

Healthcare facilities

Healthcare professionals
Health Data Hub - Members of the public interest grouping

Users

Agencies

Industries
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