

French Health Data Hub

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Health Data in France

Administrative
HealthCare Data

SNDS
Système National des Données de Santé

Cohorts

Registers

Regional pathways
data

Town practitioners
data

Pharmaceutical
data

Online Shared
Medical Record
(DMP)

Work Medicine
Data

EMR

Biology
laboratories data

Town imagery

Genomic data

Medico-Social
Data

PROM's

IOT, Telemedicine

Contextual data

DATA
HUB



The Health Data Hub : A national project

- Pitched in 2018 by Member of Parliament (and Fields Medal) Cédric Villani in his report on AI
- D... the law "My Health 2022" voted in July





« My Health 2022 » in 3 points

1. The Hub shall be the platform functioning as a **unique desk** to access SNDS for public interest research (operated by public or private groups)



« My Health 2022 » in 3 points

2. SNDS has been extended to all the health data that are coming from cares partially reimbursed by the national solidarity (almost all french health data !)



« My Health 2022 » in 3 points

3. The Health Data Hub will set up a unified governance for SNDS access for public interest research.

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**DATA
HUB**



The Health Data Hub : A national project

Main ambition : *Health data financed by the national solidarity is a common heritage. It should profit the greatest number, in the respect of the ethics and fundamental rights of our fellow citizens.*

Some Facts

- Work started in January 2019
- Budget : 80m € for the first 4 years
- The Health Data Hub structure will open on December 1st 2019



3 CHALLENGES FOR THE HDH

1. Consolidate massive and heterogeneous health data

- Massive data :
 - SNDS, public/private hospitals, city medicine, cohorts, private companies, . .
- Heterogeneous data :
 - Health records, images, genomic, biological data, survey data, . . .
- Ensure data quality and reusability (FAIR)
- Identify the first databases to be included in the catalogue
 - Only pseudonymise data will be stored in the HDH
 - Databases will be uploaded on demand
- Define a data valorization strategy



2. Share data with very various entities (private/public) + Facilitate cutting-edge research

- Offer a secured yet easy to use platform
 - Users are not allowed to download data
 - Modern/various tools and frameworks available
- Define a unified governance pipeline
- All nationalities may access data



3. Animation

- Become the main actor in the development of the Data/Health ecosystem
- Offer open source software + Market place
- Become a referenced platform for matching skills and interests
- Promote innovation (test data samples, API developments, . . .)
- Bring national and international visibility

January 2019 : Defining use-cases for identifying potential bottlenecks = **Call for projects**

189 answers !

- 10 were selected following the criteria
 - Important potential societal impact
 - High quality of the databases brought in the Hub (for future sharing)
 - Acceptation (in principle) of a unified governance on these databases

The selected projects at a glance (10 out of ... 189)

- **DeepSarc** : Almost **complete database on sarcoma** in France
- **NS-Park** : Cohort of **20k Parkinson patients** (clinical, genomic, ...)
- **Rexetris** : Renal transplant patients (Cristal ABM database)
- **Deep.Piste** : **250k annotated mamography**
- **Hydro** : **Pacemaker data of more than 8000 patients**

The selected projects at a glance (10 out of ... 189)

- **Oscour** : Exhaustive databases of **emergency services** in France
- **Pimpon** : Vidal database
- **Ordei** : ANSM Pharmacovigilance database
- **Parcours IDM en IDF** : SAMU database in IdF
- **ARAC** : Full data from the Malakoff Mederic (French health mutual company) (several million people)



Some future important actions

- First pilot projects working on the HDH platform starting from January 2020
- HDH services should open mid 2020
- Imminent launch of an affiliation program for researchers (doctors, biologists, economists, computer scientists, mathematicians, sociologists, . . .)
 - "Light affiliation" : no obligation
 - Matching (depending on skills) with specific institutional or business demands received by the HDH

Some future important actions

- Participate to European project calls related to health
- Develop links with other foreign national health platform projects
- Co-organization of a summer/winter school "AI for health"
- Organize some more Call for Projects/Challenges, . . .
 - December 16th 2019 : Call for projects SGI + Hub End March 31st 2020
 - AI based 4P medicine projects with prototype ready to be experimented after 24 months
 - Up to 300k euros subvention
 - Help of the hub for collecting data Hub infrastructure at disposal

THANKS FOR YOUR ATTENTION

HEALTH DATA HUB

MAKE FRANCE A LEADER IN HEALTH DATA USE