HEALTH DATA HUB

Overview, strategy and lessons learned

June 2020

Health Data Hub : overview, strategy and lessons learned

1 Introduce the context of the creation and the missions given to the Health Data Hub by the French government

2 Provide a focus on the Health Data Hub's strategic roadmap

3 Discuss lessons learned & ongoing challenges

A key component of President Macron's AI strategy, the Health Data Hub, since its recent creation, has published an ambitious roadmap, launched its platform and became a key stakeholder in the Covid-19 response

AI **FOR** HUMANITY

The President of the French Republic presented his vision and strategy to make France a leader in artificial intelligence (AI) , based on Cédric Villani's underline report

29 March 2018

The Minister of Health asks the DREES (Directorate for Research, Studies and Evaluation), and the INDS (National Institute for Health Data) to prefigure the Health Data Hub

November 2018

The Hub is created. This structure replaces the INDS by taking over and expanding its missions.

29 November 2019

Launch of the technological platform

April 2020

Mar	May	July	Sept	Nov	Jan	Mar	May	July	Sept	Nov	Jan	April	May

June-October 2018

A mission, driven by 3 experts explores the obstacles to the reuse of health data by means of a wide consultation and suggests a roadmap to the Minister of Health on October 12

January 2019

The DREES launches a call for projects, 189 projects apply and 10 are selected to help the project team build the Hub's services for researchers

July 2019

Article 41 of the Organization and Transformation for the Health System law provides for the creation of the Health Data Hub
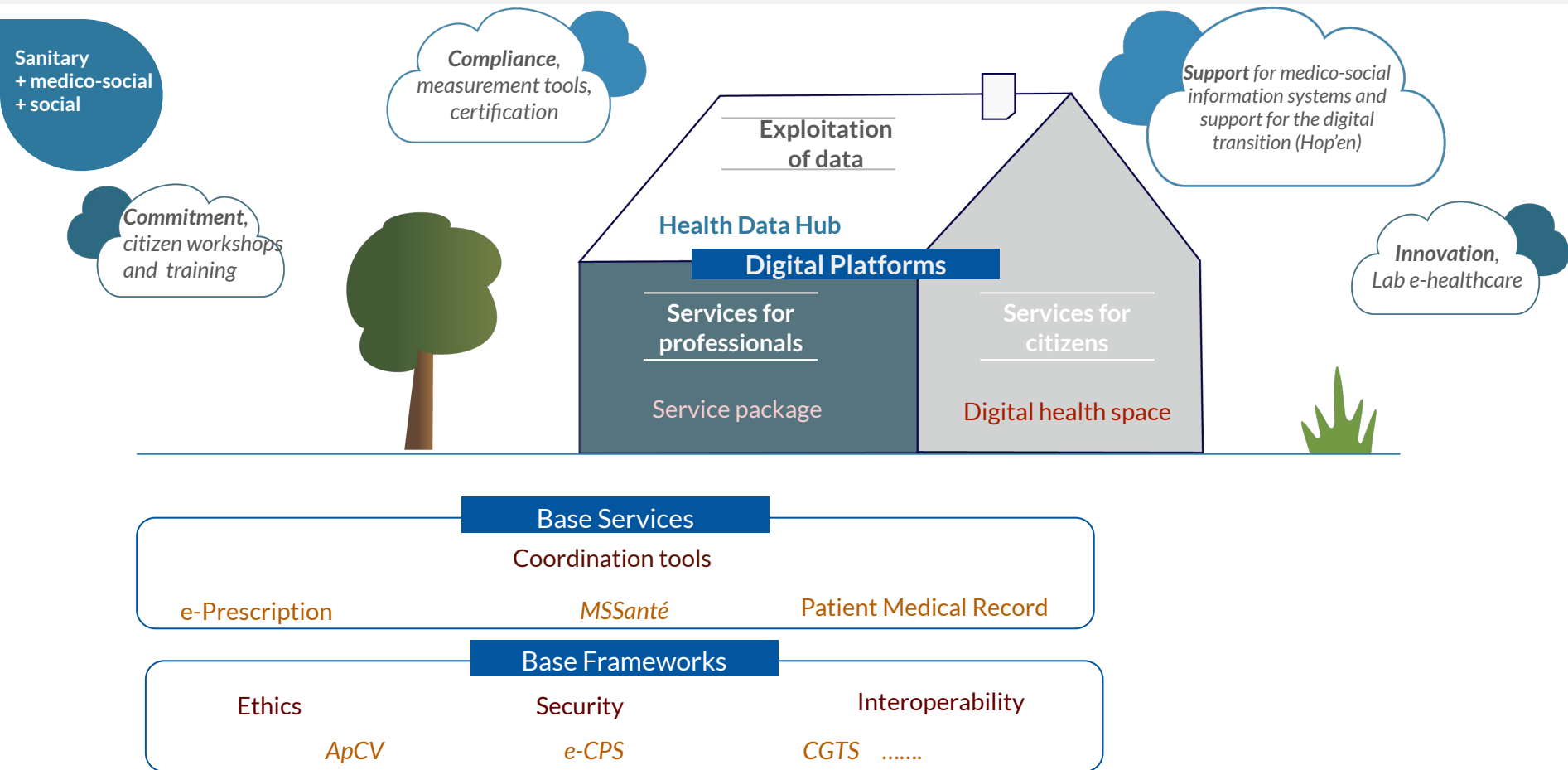
16 December 2019

The first version of the technological platform is homologated

21 April 2020

A ministerial decree allows the Hub to receive all data for the purpose of public interest research in response to the sanitary crisis

3

The Health Data Hub is part and parcel of the French government's strategy to accelerate the 'Digital Health Strategy' and the National Plan for Artificial Intelligence

Sanitary + medico-social + social

Compliance, measurement tools, certification

Commitment, citizen workshops and training

Support for medico-social information systems and support for the digital transition (Hop'en)

Innovation, Lab e-healthcare

Exploitation of data

Health Data Hub

Digital Platforms

Services for professionals

Services for citizens

Service package

Digital health space

Base Services

Coordination tools

e-Prescription   MSSanté   Patient Medical Record

Base Frameworks

Ethics   Security   Interoperability

ApCV   e-CPS   CGTS   ....

Adapted from French Ministry of Health

Vision :

Guaranteeing a transparent, easy and unified access to health data to improve the quality of care and patient support

A **unique entry point** facilitating access to health data for research projects contributing to public interest respecting patient rights and ensuring transparency with civil society

A state-of-the-art **platform at the highest level of security**, offering storage, computing, reconciliation and data analysis capacities allowing the development of innovative research projects

A **documented data catalogue built in a progressive manner** to make priority data (historic SNDS, cohorts, registers, hospital data, …) available to the scientific community

A range of tools to **promote networking and to bring together key stakeholders**

Structure and governance of the Health Data Hub

The Health Data Hub is a **public interest group** created by the law. It is established between **56 actors**, as set out by [ministerial decree](#), mostly from the public sector.
Its funding of this initiative is mainly public : around 80M euros for a timeframe of 4 years.

The members of the platform are from 9 types of entities

- The State
- Health insurance funds
- Complementary health insurance organisms
- Research and teaching
- Health structures

- Health professionals
- Users
- Independent agencies, operating entities and public authorities
- Life science industry

These entities represent the diversity of the health data ecosystem.

Their representatives are part of the executive board.

1 — Introduce the context of the creation and the missions given to the Health Data Hub by the French government

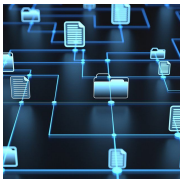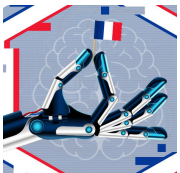**2** — Provide a focus on the Health Data Hub's strategic roadmap

3 — Discuss lessons learned & ongoing challenges

The Health Data Hub published its **strategic roadmap** in January 2020

1. Decompartmentalize the health data heritage and improve its quality

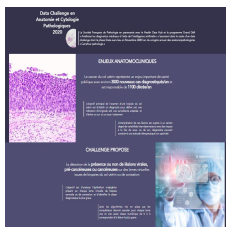2. Reinforce the use of data with an attractive service offer

3. Position France as one of the leaders in the use of health data

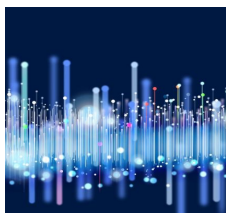4. Guarantee the participation of civil society and promote the use of health data

✓ **Organization of a data challenge**

HDH is hosting a data challenge in anatomocytopathology. The challenge will take place from September to November 2020. Participants will have to train algorithms on anatomocytopathology blades to diagnose cervical cancer and winners of the challenge will share a 25 000€ prize.

✓ **Organization of a Winter School**

HDH is organizing a Winter School, which will take place on Jan. 4-8, 2021 in Paris. The Winter School will welcome PhD students, academics and private-sector professionals to attend lectures by renowned speakers such as Adrian Weller (Turing Institute & University of Cambridge) and Susan Murphy (Harvard University) and engage in day-long practical sessions.

✓ **EU Commission Joint Action European Health Data Space (2020-2022/3)**

The Health Data Hub has been nominated competent authority for France, representing around 10 national actors, along with 25 other countries, to work on recommendations for the creation of a European health data space, aiming to use health data for better healthcare, policy making and research and innovation, around areas such as data governance and rules, data quality and interoperability and infrastructure and technology.

Objectives : *Establish and drive high level scientific collaborations with our European and international partners*

Public Interest

➔ An independent Ethics and Scientific Committee, which includes two representatives of the National Union of Approved Health System Users' Associations, validates the contribution of research projects to the public interest
➔ The use of data for commercial promotion purposes is prohibited
➔ The data cannot be sold

Data Protection

➔ All data collected by HDH has been pseudonymized by third parties
➔ The data will never be accessible freely - specific "project spaces" will be set up and the data available on them is strictly limited to the data necessary for project completion, as validated by the National Committee on Data Protection (CNIL)
➔ Technical security on the platform is of the highest level and maintained as such through regular audits
➔ Platform users are contractually bound to respect its terms and conditions

Respect of Individual Rights

➔ All laws and rules on data protection are enforced, under the Data Protection Officer's authority
➔ The website gives citizens clear and comprehensive information on their rights and how to exercise them
➔ HDH will support individuals who wish to exercise their rights in the procedures

Transparency

➔ The HDH website gives complete and updated information on available databases
➔ The updated list of projects involved in the secondary use of health data is public and results will be communicated granted the respect of rules of academic competition
➔ Regular external communication and a new FAQ

1

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Discuss lessons learned & ongoing challenges

Lessons learned and ongoing challenges

✔ Choosing the right gouvernance model

✔ Technical/ security/ platform-related issues

✔ Relationships with data controllers (including valorization,…)

✔ Standardization of data/ interoperability issues

✔ Relationships with national and international academic ecosystem

✔ Implication of civil society

✔ Choosing a business model

✔ ….

Thank you

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