

Our contribution to health data governance

1/ The creation and rationale of the Health Data Hub

France has very rich health databases, including one of the largest health claims databases in the world. These databases have for long been under-exploited.

The Health Data Hub (HDH) was created by a [French Law on July 24, 2019](#) and officially established by order of [November 30, 2019](#), following the Villani report "[AI for humanity](#)".

The HDH ensures easy and unified, transparent and secure access to health data for public interest research projects, aimed at improving the quality of care and patient support.

The HDH is a "public interest group" of 56 stakeholders, gathered in its General Assembly and divided into 9 colleges representing the entire health data ecosystem in France.

2/ The Health Data Hub's missions and initial achievements

The HDH's missions are based on 4 main activities:

1. **A unique gateway:** assist project coordinators in their administrative procedures. It also provides the secretariat of the national ethics and scientific committee (CESREES), which evaluates projects before they are sent to the National Data Protection Agency (CNIL) for authorization;
2. **Upon authorization,** project coordinators can choose the HDH which provides the necessary data for their study through a state-of-the-art secure platform offering advanced storage, processing, combining and data analysis capabilities;
3. **To facilitate data availability,** a collection of strategic databases referred to as "data catalogue" are replicated on the technological platform and, in agreement with the data holders, updated regularly.
4. **Federate and maintain strong links with the health data ecosystem** to encourage the sharing of knowledge and best practices between key actors, thereby fostering innovation.

The HDH's service offer is crucial mainly for two types of projects:

- Projects aiming at combining different data sources
- Projects requiring large volumes of data, for example for the training of artificial intelligence algorithms and therefore need to benefit from a technological infrastructure with large storage and computing capacities.

To date, the HDH is supporting 27 pilot projects and 15 projects contributing to managing the pandemic. 25 priority databases are expected to be included in the first version of the "catalogue".

In addition, the HDH has organized several key health data events, including a Data challenge, an "[AI and Medicine](#)" Symposium with the MIT and the French National Academy of Medicine and the "[AI4Health](#)" Winter School. The HDH is also the French competent authority and a major contributor to the European Health Data Space Joint Action ([TEHDaS](#)) and linked activities.

3/ The Health Data Hub's commitment towards citizens

The 2019 Law also entrusted the HDH with the mission to inform citizens. Therefore, key actions have been implemented by the [HDH's Citizenship Directorate](#), in close consultation with civil society and patient associations, such as:

1. The HDH's [commitments towards citizens](#) and their health data, including public interest, data protection, respect for individual rights and transparency;

2. The provision of [educational tools](#) to enable them to gain knowledge about health data, and even to develop health data use;
3. Effective listening to consider citizens' perspectives: European e-consultation, focus groups, individual interviews, "consensus conferences" ...;
4. A public directory with the list of projects using health data, clearly presented and accessible;
5. The support of patient associations to become health data actors, i.e. how to deploy study projects, access indicators...

Since citizens and healthcare users are not only interested in data-driven research projects but also wish themselves to become actors of innovation, the HDH implements its actions by systematically integrating citizens and involving them in its governance. This represents the foundation for trust and acceptability of this large-scale project both at the national and European level.