HEALTH DATA HUB

Health Data Hub

Secondary use of Health Data - European Perspective

The Health Data Hub is a project driven and supported by major public policies

The uses of health data are multiplying and access to data sources in the shortest possible time is essential. The Health Data Hub is a public structure created at the end of 2019 to facilitate access to health data for public interest projects in order to improve the quality of care for patients.

A **unique gateway** to health data in France

A **state-of-the-art and secure** technological platform

A **collection of databases,** including one of the largest medico-administrative database in the world

A project driven and supported by major public policies

Created following the **Villani report** promoting the implementation of large data sharing platforms to foster AI

A flagship project and an active contributor to the **National Strategy for Artificial Intelligence**

One of **FTAP**'s (Public Policy Transformation Fund) major projects

One of the initiatives of the **French Digital Health Roadmap**

The HDH unique gateway for access to health data

1 HDH HEALTH DATA HUB

2 CESREES — Comité Éthique et Scientifique pour les Recherches, les Études et les Évaluations en Santé

3 CNIL. COMMISSION NATIONALE INFORMATIQUE & LIBERTÉS

Health data

without starter kit   with starter kit

The HDH is the one-stop shop for data access. The data access request is submitted online on a dedicated platform. It provides a **starter kit** to guide project leaders through the process.

The HDH verifies the completeness of the file and transmits it, if necessary, to the **Ethic and Scientific Committee** (CESREES) for evaluation.

If the CESREES gives a favourable opinion on the project leader's request, the **Data Protection Agency** (CNIL) assesses the request for access to the data for approval.

Which data is available in the main SNDS database?

✓ The SNDS is a **compilation of pre-existing databases fed by data flows**

✓ **These databases are already linked to each other** to enhance opportunities for research and innovation

✓ **We can link external databases with data from the SNDS**

The SNDS is made available on the National Insurance Fund portal, after a positive opinion from the CESREES scientific and ethics committee and authorisation from the CNIL.

3 main databases

SNIIRAM
DCIR

All data linked to health insurance reimbursement since 2006

PMSI

French hospitals discharge database allows to define the activity of hospitals, both from the public and private sector, for the initial purpose of hospital budget planning allocation

CépiDc

Medical Cause of Death Database to be matched with SNIIRAM. *The database does not contain any name.*
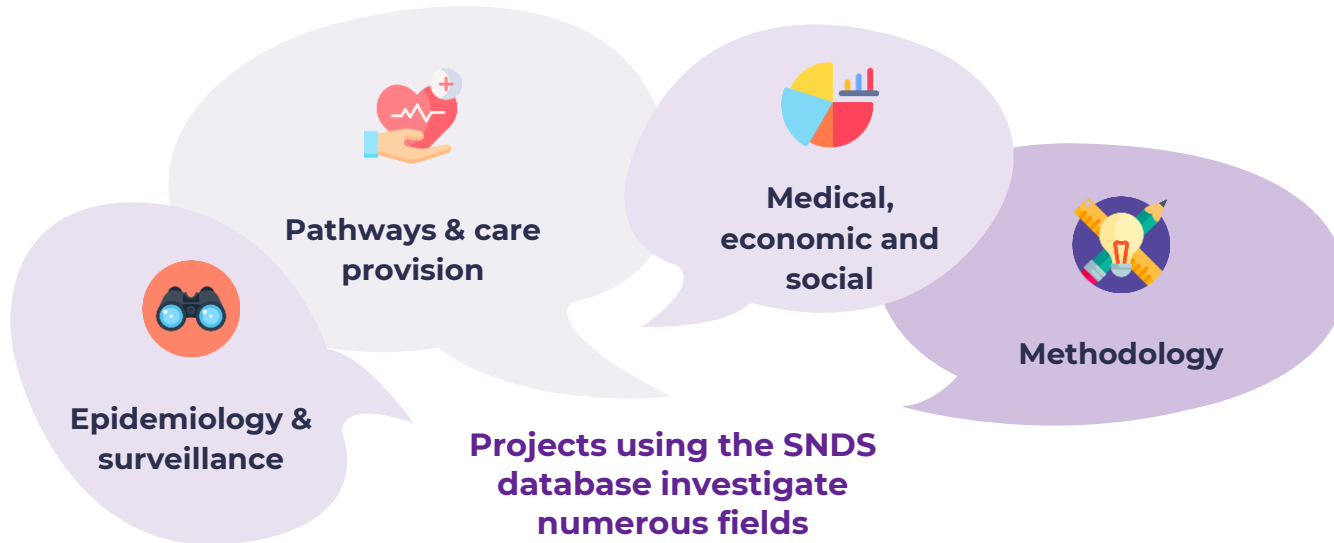
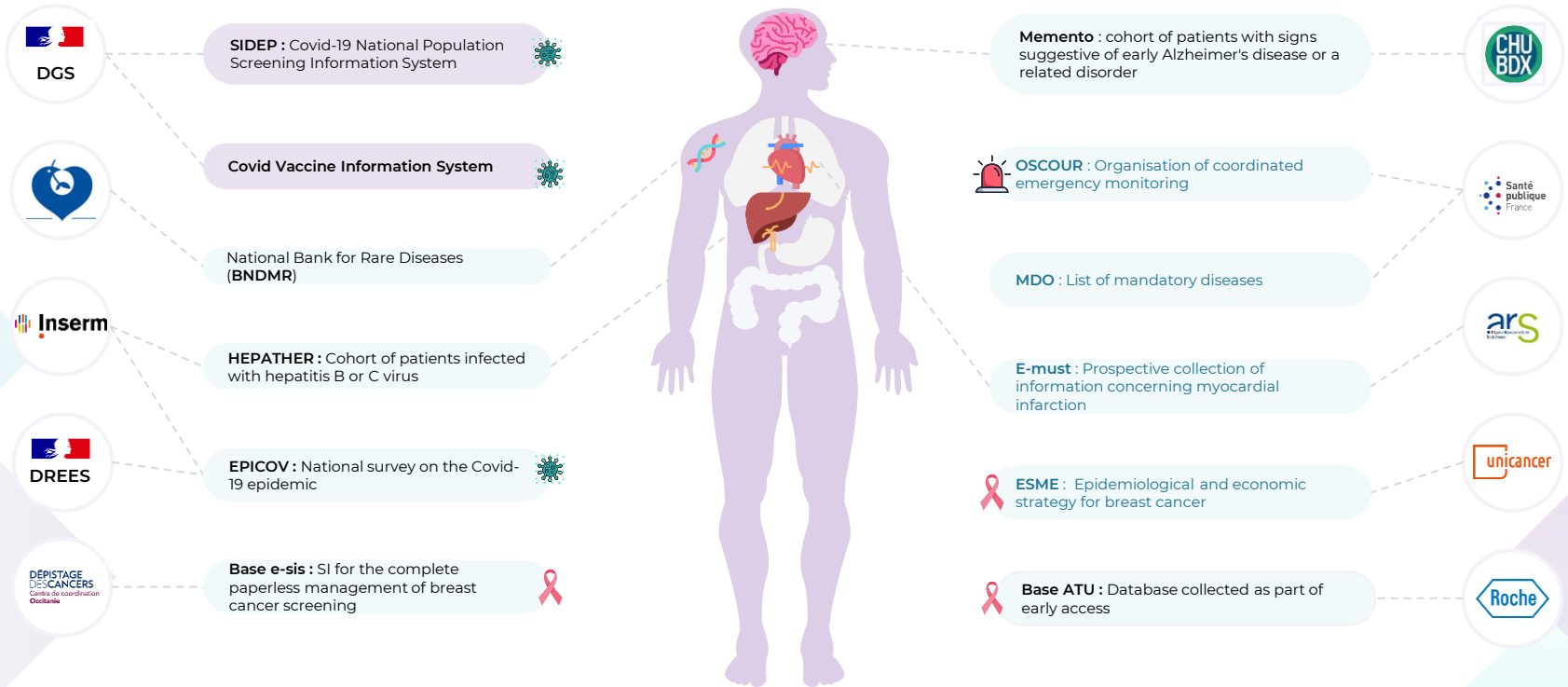# The use of the SNDS database by type of project as of today

435 **projects submitted to CESREES requested access to the SNDS database** since the start of HDH

more than #100 publications related to SNDS studies in 2020

Pathways & care provision

Medical, economic and social

Epidemiology & surveillance

Methodology

Projects using the SNDS database investigate numerous fields

Go beyond the use of the SNDS by making available existing databases of interest available to project leaders

DGS

SIDEP : Covid-19 National Population Screening Information System

Covid Vaccine Information System

National Bank for Rare Diseases (**BNDMR**)

Inserm

HEPATHER : Cohort of patients infected with hepatitis B or C virus

DREES

EPICOV : National survey on the Covid-19 epidemic

DÉPISTAGE DES CANCERS
Centre de coordination Occitanie

Base e-sis : SI for the complete paperless management of breast cancer screening

Memento : cohort of patients with signs suggestive of early Alzheimer's disease or a related disorder

CHU BDX

OSCOUR : Organisation of coordinated emergency monitoring

Santé publique France

MDO : List of mandatory diseases

ars

E-must : Prospective collection of information concerning myocardial infarction

ESME : Epidemiological and economic strategy for breast cancer

unicancer

Base ATU : Database collected as part of early access

Roche

Catalogue · HEALTH DATA HUB

Core database · l'Assurance Maladie · HEALTH DATA HUB

Why is the Health Data Hub a *game changer* in research for health improvements?

Le Health Data Hub is the only french **cloud technological platform** providing health data projects with :

- providing health data projects with **elastic storage and computing capacities**

- offering **the ability to link multiple different data sources**

- **suitable for a large number of users**

- meeting the **highest safety requirements**

Supporting the health professional in an increasingly complex clinical context with use cases like characterising alerts in case of drug interactions from the main SNDS database

Save time, improve screening, and reduce delays in diagnosis with projects like the one developing diagnostic tool for 10,000 MRI scans

Early warning systems for patient management with projects like the one developing an alert tool for medical professionals based on data from connected medical devices annotated with medical and administrative data

Offer patients the best long-term treatments with use cases using comparison of healthcare using cohort data enriched with medical and administrative data when clinical trials are not possible

The HDH supports a wide variety of projects...

#74 projects HDH

Spontaneous arrivals

12 COVID projects as of today

... and tomorrow any project leader will be able to submit a project

Laureates of call for projects launched in collaboration with partners

either generalist...

bpifrance   DataLab NORMANDIE

...or thematic

BOAS   unicancer

Projects directly scouted by the HDH for their strategic interest and carried out with its partners

... such as patient associations, other data platforms, European and international actors, hospitals

EHDEN EUROPEAN HEALTH DATA & EVIDENCE NETWORK   European Commission

FINDATA Social and Health Data Permit Authority

RÉPUBLIQUE FRANÇAISE Ministère de l'Environnement, de l'Énergie et de la Mer

Fédération Française des Diabétiques Des patients solidaires contre le diabète   INRAE

The HDH is animating the health data ecosystem by creating meaningful contents and events and disseminate them

"Health data interoperability : A european challenge for impactful research project"

Data Challenges for health

4th edition of our "Health data and collective intelligence" colloquium
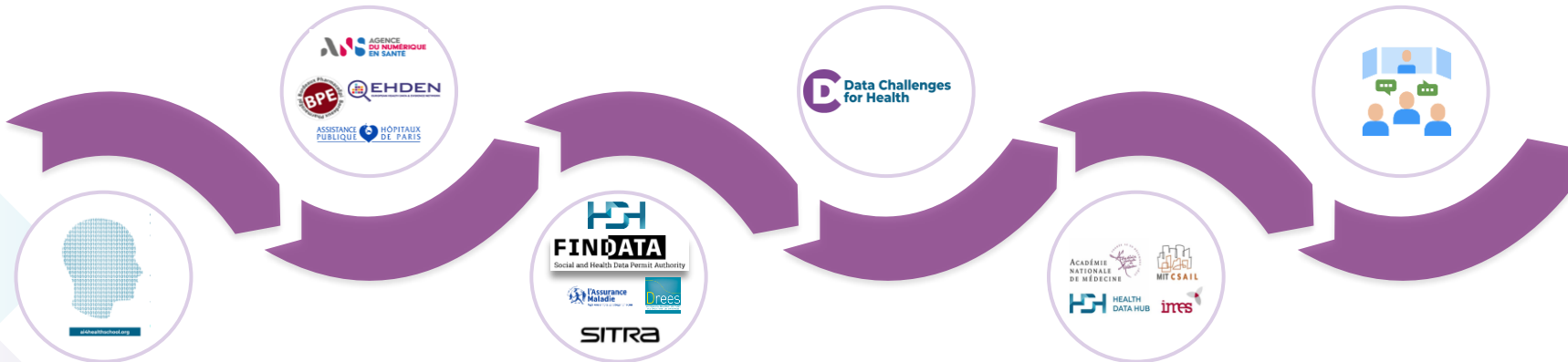
"AI4Health" Winter School

"What opportunities for national health data platforms?
in partnership with Findata

Symposium "AI and medicine"
in partnership with MIT

+120 events in which the Health Data Hub participated

#5 events supported by the French Presidency of the Council of Europe with the "PFUE" label

Health data sharing, a major priority for the European Commission and European health policy

Objective
remove obstacles to the smooth functioning of the data economy

Health data fragmentation

Multiple conditions for data use

Diversity of access governance models

Solutions
create an EU-wide governance framework for data access and use

2020 — **Data Governance Act** proposal

2021 — **Joint Action TEHDAS** "Towards a European Health Data Space"

2021 — **Pilot version of European Health Data Space**: call for proposals financed up to 5m€

2022 — Proposed **European Health Data Space** legislation

The HDH, leader of a European consortium to build and operate a first version of the EHDS

HealthData@EUpilot

17 partners, **9** countries

2 years

5 million euros of European fundings

HEALTH DATA HUB

Create and test a beta version of the European Health Data Space

Build a network of data platforms on a European scale...

...tested by concrete cross-border use cases

Bundesinstitut für Arzneimittel und Medizinprodukte

DANISH HEALTH DATA AUTHORITY

BBMRI-ERIC

CROATIAN INSTITUTE OF PUBLIC HEALTH

EBRAINS

EUROPEAN MEDICINES AGENCY

ecdc

Instituto Aragonés de Ciencias de la Salud

elixir

FINDATA

EUPHA

orphanet

The Norwegian Directorate of eHealth

sciensano

The HDH, leader of a European consortium to build and operate a first version of the EHDS

Create a first **user experience of the European Health Data Space...**

Single access application form and conditions of use

Data transfer protocol (if applicable)

Informing citizens and respecting **RGPD** rights

Data permit request

Use of data

Data discovery

Data preparation

Finalisation

Metadata standards (Health DCAT-AP)

Federated queries

Interoperability standards, quality control and data preparation

Publication of the study and valorisation
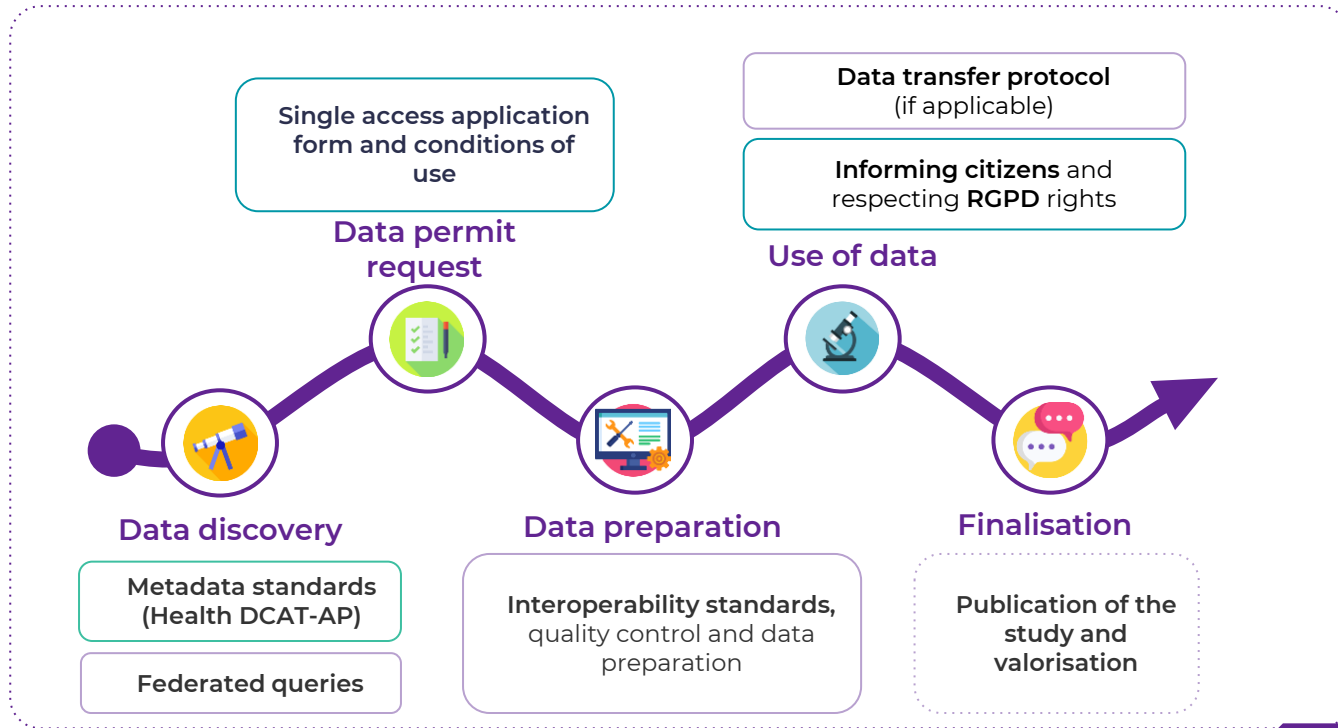
The HDH, leader of a European consortium to build and operate a first version of the EHDS

... based on a **technical infrastructure** allowing the exchange of information between nodes

- ✔ Design and deploy a **technical infrastructure** for the **network of nodes** and the link with **central services**

- ✔ Use European building blocks (eDelivery), open source standards and establish **security standards**

- ✔ After a **scoping phase**, development of a **POC**, then **MVP** and **deployment** of the network

National platforms - POC nodes

National platforms - other nodes

Central services

Metadata   Access form

eDelivery

Research infrastructure nodes

European agencies nodes

BBMRI-ERIC®

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH
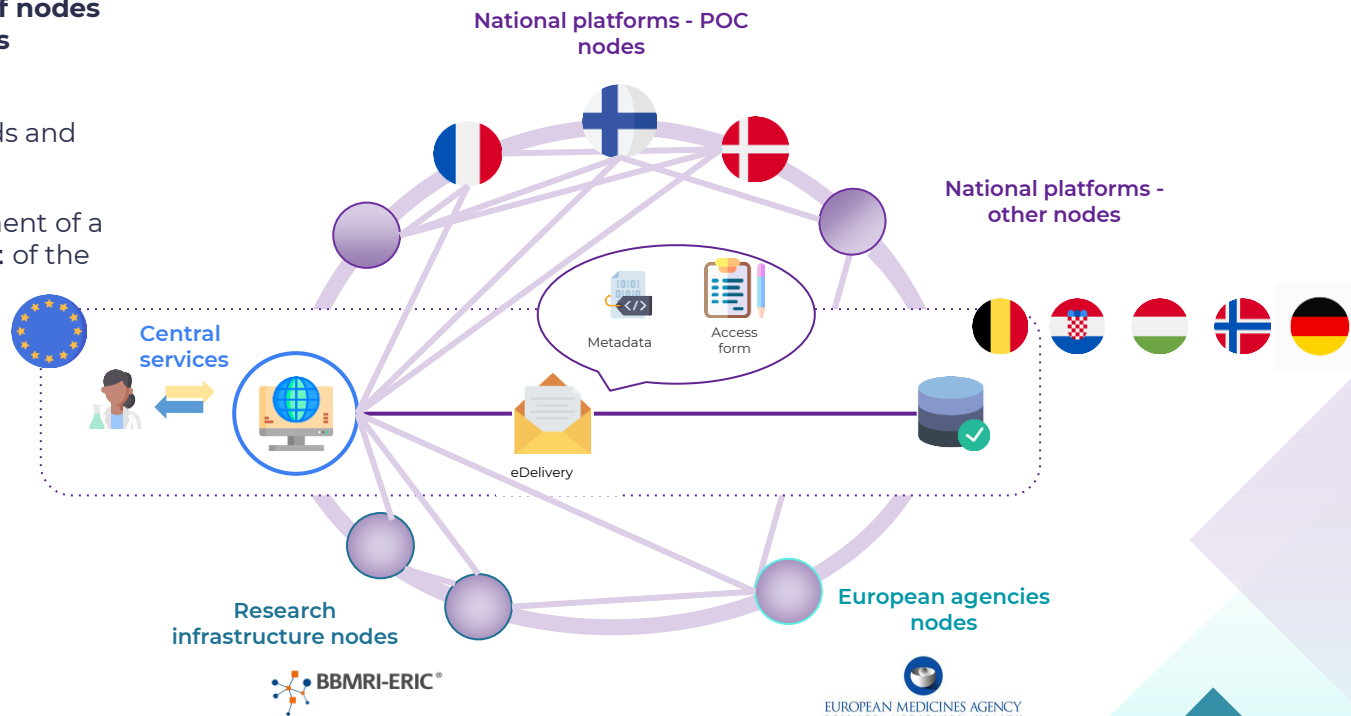
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1 Antimicrobial resistance surveillance

led by **ecdc**

2 Identifying the risks of coagulation disorders in patients with Covid-19

led by **EUROPEAN MEDICINES AGENCY** SCIENCE MEDICINES HEALTH

3 Test use, hospitalizations and vaccination adherence in vulnerable sub-populations

led by **sciensano**

4 Project to anticipate care pathways in cardio-metabolic diseases using AI

led by **HEALTH DATA HUB**

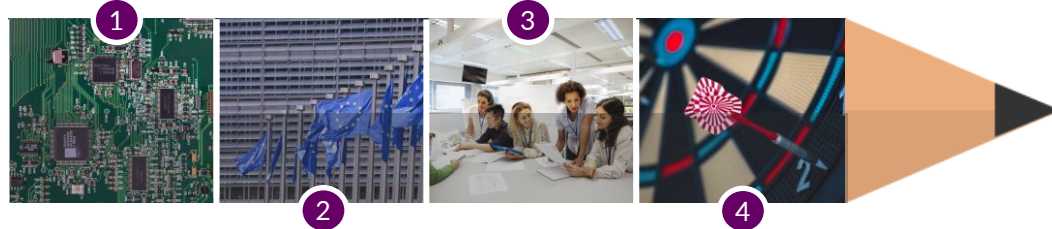**5** Identify genomic signatures characteristic of different types of colorectal cancers

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led by **elixir**

A broader strategy: building international partnerships with major actors

Joining impactful networks

Engaging in concrete partnerships

Answering to international and European calls for projects

Identifying new partners

HEALTH DATA HUB

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