Health Data Hub & TEHDaS

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Health Data Hub

Key figures on the Joint Action Towards the European Health Data Space - TEHDaS
An important role for France

A key role for France which occupies the 4th place in this Joint Action

The Joint Action started in February 2021 but preparation has been ongoing since mid-2020, including a series of French actors.

France along with Finland, Belgium, Spain and 20 other countries has a key role in this Joint Action.

France represented through the HDH and its affiliated entities

France is represented by the HDH as competent authority and five affiliated entities from a diversified ecosystem, including the research, hospital and government sector:

- French eHealth Agency (ANS)
- French National Institute for Health and Medical Research (INSERM): Service Units 14 (Orphanet) and 47 (France Cohortes)
- Lyon Hospitals (HCL)
- Aix-Marseille University
- Toulouse III University

Other national structures are associated to the working groups as experts.

Participation in strategic deliverables

The recommendations expected to be produced during the Joint Action will be used for the future legislative or non-legislative framework of the European health data space.
France actively participates in the thematic Work packages (WP) 5 (governance), 6 (data quality), 7 (architecture) and 8 (citizens).
A restitution of the first results may take place during the French presidency at the European Union during the first semester of 2022.

The French affiliated entities involved in the thematic work packages (WP5-8)

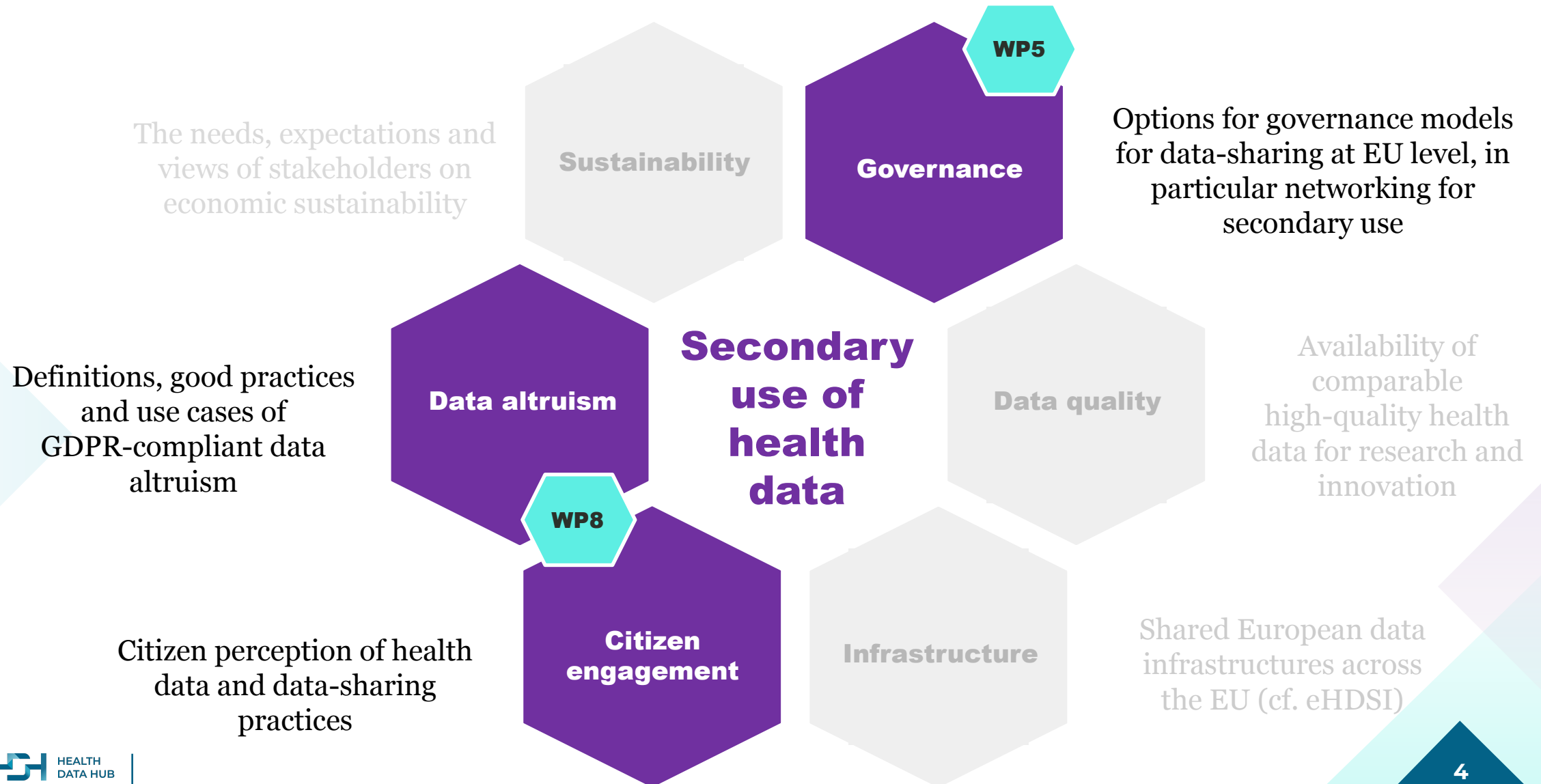

French affiliated entities

Experts

French partners involved in the Joint Action Towards a European Health Data Space

HDH working with European partners involved in WP5.3 and WP8

The Health Data Hub is actively involved in work around gouvernance and citizens within TEHDaS

The needs, expectations and views of stakeholders on economic sustainability

Sustainability

WP5

Governance

Options for governance models for data-sharing at EU level, in particular networking for secondary use

Definitions, good practices and use cases of GDPR-compliant data altruism

Data altruism

Secondary use of health data

Data quality

Availability of comparable high-quality health data for research and innovation

WP8

Citizen perception of health data and data-sharing practices

Citizen engagement

Infrastructure

Shared European data infrastructures across the EU (cf. eHDSI)

HDH HEALTH DATA HUB

Overview of WP5

Governance

OBJECTIVES

Setting options for the **operational framework** and **governance models for the exchange and secondary use of health data between European countries,** respecting the principles of transparency, trust, fairness, citizen empowerment and common good

TASKS

5.1 Define and develop the evidence base for the secondary use of health data in EHDS, user perspectives

5.2 Enabling the secondary use of data by aligning the interpretation of GDPR

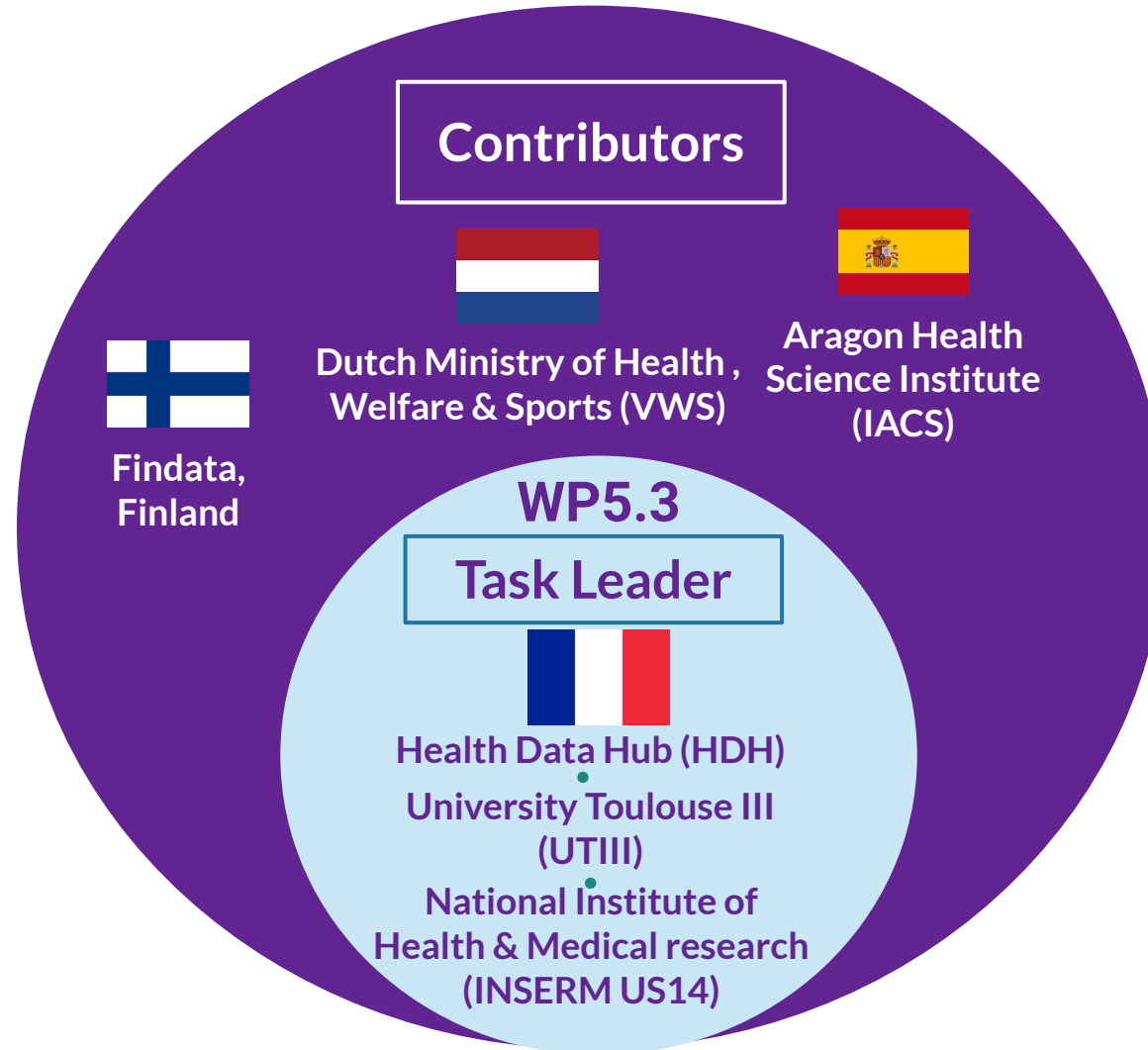**5.3** Best practices for EU-cross border sharing of personal health data

5.4 Developing options for governance models for the EHDS

France is leading Task 5.3

Task 5.3 : Stakeholders

Contributors

Findata, Finland

Dutch Ministry of Health, Welfare & Sports (VWS)

Aragon Health Science Institute (IACS)

WP5.3

Task Leader

Health Data Hub (HDH)

University Toulouse III (UTIII)

National Institute of Health & Medical research (INSERM US14)

Overview of WP8

Citizen engagement & Data altruism

OBJECTIVES

- Citizens' understanding and **trust in, health data sharing and its secondary use**

- **Empower citizens around health data** and enable them to become actors of innovation as part of the future EHDS, including through enhanced data altruism practices.

TOOLS

D8.1 Recommendations to ensure citizen sensitization and engagement with their health data in the future EHDS (Feb.2023)

D8.2 Recommendations to foster data altruism practices in the implementation of construction of national and European health data spaces (Feb. 2023)

France is leading tasks related to Deliverable D8.1

HEALTH DATA HUB

WP8 Stakeholders

D8.1 - CITIZEN ENGAGEMENT

TASK LEADER

Health Data Hub

Affiliated Entity : Université Toulouse III

TASK PARTNERS

Sciensano

NHS Confederation

Affiliated Entity : Wellcome Sanger Institute

D8.2 - DATA ALTRUISM

TASK LEADER

ÖKFO

Affiliated Entity : Semmelweis University

TASK PARTNER

Norwegian Ministry of Health

Affiliated Entity : NOR Health Directorate

SITRA Innovation Fund Finland

Croatian Health Insurance Fund

Affiliated Entity: Croatian Institute of Public Health

NHS Confederation

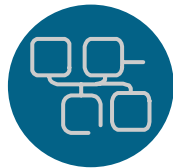*Affiliated Entity : Wellcome Sanger Institute*

Czech Ministry of Health

The EHDS pilot project : presentation & objectives

**The HDH seeks to be part of the European Health Data Space (EHDS) pilot project.
The pilot contributes to the construction of the future European Health Data Space (EHDS).**

OBJECTIVES

Demonstrate the potential and feasibility of a pan-European infrastructure for the secondary use of health data through :

Building a pilot infrastructure to share health data

The identification of "node" structures in the architecture of this space.

Collaborative use-cases between multiple data holders, national data systems/platforms

Next steps for the European Health Data Space

Some ideas for next steps to get data moving cross-border in the EU for the benefit of European citizens, communities and companies:

- ☐ At national level, **promote the emergence of national policies to foster the secondary use of health data and create national data gateways and improved health data gouvernance**

- ☐ At the EU level, **harmonize regulatory rules across the EU,** including scientific, ethics and data protection rules to access individual-level health data

- ☐ Adopt **common data standards and terminologies for the EU**

- ☐ Create **common security standards**

- ☐ **Provide significant and continuous funding** for cross border research projects for public interest and national health databases

- ☐ **Promote data sharing practices between public and private sector**

- ☐ Ensure that **EHDS principles are accepted and shared by citizens**

HEALTH DATA HUB

TRUST

Societal participation and acceptability

Contacts

Link to our website

Our engagement with civil society

Candidate

Our news