

PRESS KIT

April 11, 2022. Paris

Conference : "The creation of national health data hubs: what lessons can be learned?"

Following the French Presidency of the Council of the European Union (PFUE), which runs from 1 January to 30 June 2022, a limited number of events will benefit from visibility at national and European level thanks to an official PFUE label.

On **May 11, 2022 at 2pm (CEST)**, The French National Health Insurance Fund (**Cnam**) and the Directorate for Research, Studies, Evaluation and Statistics (**Drees**), in collaboration with **Findata** and the **Health Data Hub** organised a **conference on: "The creation of national health data hubs: what lessons can be learned?"**.

During this half-day event, **the national stakeholders at the initiative of these national platform projects in France and Finland have gathered to exchange on the challenges of their implementation.** This was also an opportunity for various French and European health data stakeholders to **share their perspectives and expectations on the eve of the creation of the European Health Data Space.**

14h00-14h15 - Introduction - The possibilities offered by national health data platforms

- **Bruno Maquart**, President of the Health Data Hub
- **Dominique Polton**, Health economist, President of the Health Accounts Commission and of the Scientific Council of the École des Hautes Études en Santé Publique (EHESP)

A few months after the signature of the partnership agreement between Findata and the Health Data Hub, **Bruno Maquart**, President of the Health Data Hub and CEO of Universcience, will introduce this half-day event dedicated to national platforms for access to health data, alongside **Dominique Polton**, health economist, President of the Commission des comptes de la santé and of the Scientific Council of the École des Hautes Études en Santé Publique (EHESP), who will recall the history of the opening up of health data in France and the context of the creation of the one-stop shop in France.

"The main challenge in transforming an administrative management tool into a tool for research is, of course, that data sharing accelerates the production of knowledge. The opening of a joint call for projects by the Ministry of Solidarity and Health and France 2030, endowed with 50 million euros, to support the constitution of hospital health data warehouses will enable better patient care and the development of new medical research projects."

Bruno Maquart, President of the Health Data Hub and Universcience

"The tipping point was the Mediator® affair. We sensed that these databases could bring a lot of things to the table, especially when we managed to link reimbursement data with hospital data from the PMSI, because we had the complete care pathways of patients. And with Mediator, we saw indeed that it was an extremely powerful tool."

Dominique Polton, Health Economist, President of the Health Accounts Commission and the Scientific Council of the École des Hautes Études en Santé Publique (EHESP)

14h15-15h15 - Implementing national data platforms

- **Océane Xayakhom-Dauvergne**, International project lead at Health Data Hub (**Panel Moderator**)
- **Stéphanie Combes**, Director at Health Data Hub
- **Johanna Seppänen**, Director at Findata (Finnish Social and Health Data Permit Authority)
- **Fabrice Lenglard**, Director at DREES (Directorate for Research, Studies, Evaluation and Statistics)
- **Damien Vergé**, Director of Strategy, Studies and Statistics at Cnam (French National Health Insurance Fund)
- **Joni Komulainen**, **Speaker**, Senior Ministerial Advisor at Finnish Ministry of Social Affairs and Health

This first round table has allowed the national stakeholders behind the creation of health data platforms to discuss the issues related to their implementation as well as the expectations and challenges they are facing at the moment.

Johanna Seppänen, Director of Findata, will introduce the context in which the Findata project was born in Finland and the path taken since its creation in 2020. **Stéphanie Combes**, Director of the Health Data Hub, will talk about how the Health Data Hub fits into the national strategy for Artificial Intelligence. Together, they will discuss the major challenges facing the two national platforms in the context of the increasing use of health data.

Damien Vergé, Director of Strategy, Studies and Statistics (Cnam), will address the broader issues that accompany open access to health data, such as the need for specific expertise.

Finally, the discussions will also address the associated governance issues and, more broadly, the potential of using health data to improve public policy. To enrich the debate on these topics, **Fabrice Lenglard** and **Joni Komulainen** will speak, as representatives of the French and Finnish Ministries of Health respectively.

"Findata's goal is to enable and increase the use of publicly collected data by producing diverse and rich data sets for data users. We operate on a one-stop-shop basis: we issue permits, collect and link data, and submit it to researchers for analysis in a secure environment. Findata is authorized for all data that is collected in Finnish health care systems and social services. In addition, we issue permits to Finland's extensive national health registries".

Johanna Seppänen, Director of Findata

"The ambition of the Health Data Hub is to facilitate access to data in order to respond to the growing use of health data for innovation in health and in particular for artificial solutions for the benefit of patients. This entails providing project leaders with a secure technological platform enabling them to cross-link large sources of data, as well as identifying databases of interest in France and Europe".

Stéphanie Combes, Director of the Health Data Hub

"The SNDS (National health data system) is the culmination of a gradual construction of the National Health Insurance Information System, which was not initially designed for the myriad of uses that have now been developed by mobilising the wealth of these databases. The opening up of health data, the dissemination of skills and expertise, and the emergence of new technologies and analytical capabilities should enable us to take a further step in the collective exploitation of this unique heritage".

Damien Vergé, Director of Strategy, Studies and Statistics, Cnam

"Using the high quality social and healthcare and socioeconomic registers and databanks is nothing new in Finland as such. We have had legislation enabling this for a long long time and those high quality registers and databanks even since the 1950 's. The revolutionary Act on the secondary use

of social and health data has made using these registers a lot easier and especially helped us drafting new legislations and enabling the large-scale social and healthcare reform that is happening in Finland as of 2023. In the Finnish legislation there are several purposes that enable us to improve public policy. Policy making and the needs of the legislator is just one of them. Development, innovation activities and knowledge management will further help policy makers."

Joni Komulainen, Senior Ministerial Advisor at Finnish Ministry of Social Affairs and Health

16h00-17h00 - European perspectives on health data sharing

- **Markus Kalliola**, Project Director at Sitra (Panel Moderator)
- **Ioana Maria Gligor**, Head of Unit, Digital Health, European Reference Networks, DG Santé
- **Peija Haaramo**, Chief Metadata Specialist at Findata
- **Emmanuel Bacry**, Scientific Director du Health Data Hub
- **Irène Kesisoglou**, Researcher at the EU Health Information System Unit, Sciensano
- **Bernard Hamelin**, Member of the Scientific Advisory Board at Health Data Hub
- **Ségolène Aymé**, Vice President of the Scientific Advisory board at Health Data Hub - Founder of ORPHANET (INSERM)

The second round table has focused on the integration of these national platforms into the European dynamic. Indeed, in order to facilitate access to the different types of data available in the Member States, the European Commission has identified the creation of a European Health Data Space (EHDS) as one of its priorities in health policy. **Markus Kalliola**, Project Director at Sitra, the Finnish innovation agency, and coordinator of the TEHDAS (Towards the European Health Data Space) joint action, will invite stakeholders from research, industry, national platforms and European projects to share their perspectives and expectations of this future EHDS.

Iona Maria Gligor, Head of Unit at DG Health (the European Commission's unit responsible for health and food safety policies) outlined the European challenges of cross-border health data sharing and the European Commission's ambitions in the context of the draft European Health Data Space legislation. The EHDS aims to facilitate this sharing by interconnecting the different data accesses of the Member States in a network of nodes, whether they are national platforms, European agencies or research infrastructures.

Emmanuel Bacry, Scientific Director at the Health Data Hub, presented the project of the candidate consortium for the implementation of a pilot version of EHDS, of which the Health Data Hub is the leader alongside its 14 partners. He will invite two of the consortium partners - **Peija Haaramo from Findata** and **Irene Kesisoglou** from Sciensano - to share their vision and expectations for the future EHDS.

Finally, two members of the Health Data Hub's Scientific Advisory Board, **Ségolène Aymé** and **Bernard Hamelin**, enriched this discussion by addressing the challenges and benefits of opening up health data for research and industry.

"The challenges we face in France in terms of opening up and sharing health data are even greater at European level. It is therefore to help remove the obstacles to sharing that the Health Data Hub has agreed to take the lead in a candidate consortium to build and test a first version of a European Health Data Space."

Emmanuel Bacry, Scientific Director of the Health Data Hub

"Mapping the health data management systems in EU member states has revealed an important diversity in terms of governance, infrastructure and especially with regards to their preparedness to join the European Health Data Space. This event is a great opportunity to discuss the capacity building needs, identified during this mapping exercise, as well as barriers to the secondary use of health data in Europe and how the European Health Data Space legislative proposal will address those."

Irène Kesisoglou, Researcher at the EU Health Information System Unit, Sciensano

"Over the last decade, the growth and application of secondary use of health data has expanded exponentially. Its transformative impact touches many aspects of medicine and spans from research, clinical care, and pharmaceutical applications. The clinical use of Real World data to advance precision health is one of the most dynamic and promising. However, an efficient European Health Data Space can only be realized if Member States agree on shared EU approaches to access and use of health data when public confidence and awareness of the value of sharing health data is ensured."

Bernard Hamelin, Member of the Scientific Advisory Board at Health Data Hub

17h00-17h15 - Conclusion

Isabelle Zablitz-SCHMITZ, eHealth Europe & International Director at the eHealth ministerial delegation

ABOUT THE HEALTH DATA HUB

Health data are essential for research and innovation in health, yet these data are often under-used because they remain too scattered. The HDH was hence conceived as the unique gateway to health data in France. Implemented in November 2019, it interacts with a variety of actors within the health ecosystem. The Health Data Hub has set up a highly efficient technological platform enabling public interest project leaders to mobilise very large data sources, to cross-reference them, and to use enough computing power to run complex search algorithms. In a word, the HDH supports ambitious project leaders who contribute to finding tomorrow's solutions to improve all citizens' health.

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ABOUT THE CNAM (French National Health insurance Fund)

For the past 75 years, the Health Insurance has played a key role at the service of national solidarity by managing the disease and work-related accidents branches of the general Social Security system. In order to protect the health of each individual in the long term, at every stage of life, it works closely with all stakeholders, including insured persons, healthcare professionals, companies and institutions, and creates the conditions to ensure the system's long-term survival. Key player in the system, it works on a daily basis to ensure universal access to rights and to care, to support each insured person in preserving his or her health, and to continuously improve the system's efficiency. To do this, it relies on the expertise of its more than 80,000 employees, spread throughout the country and the 102 primary health insurance funds, the 16 regional medical service departments the four general social security funds (CGSS) and the social security fund (CSS) in Mayotte, the 20 retirement and occupational health insurance funds (Carsat) and the 13 management unions of health insurance fund establishments (Ugecam), all of which share the same motto in the service of everyone's health: ACTING TOGETHER, PROTECTING EVERYONE.

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ABOUT THE DREES (Directorate for Research, Studies, Evaluation and Statistics)

Established by the decree of November 30, 1998, the Directorate for Research, Studies, Evaluation and Statistics (Drees) is part of the official statistical service (SSP), along with INSEE and the other ministerial statistical services. Its role is to provide reliable information and analyses in the social and health sectors. For more than 20 years, DREES' work has been based on a commitment to ethics, the principles of which are codified and shared at the European level: professional independence, commitment to quality, respect for statistical confidentiality, impartiality and objectivity. DREES is also a ministerial statistical service whose priority mission is to support and evaluate public social and health policies.

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ABOUT FINDATA

The Finnish Social and Health Data Permit Authority Findata is a one-stop shop for the secondary use of social and health care register data in Finland. Findata was established in 2019, started operations in 2020 and currently has 22 employees. The main objectives of Findata are to improve data security and streamline the utilisation of social and health care data resources. Findata grants permits for the secondary use of data when it is needed from several public data controllers, the private sector or Kanta services. After granting the permit it compiles, combines and pre-process the data and offers Kapseli – a secure remote access system with tools

for analysing. Findata works in conjunction with Finnish Institute for Health and Welfare, under the performance guidance of the Ministry of Social Affairs and Health.

Find out more information on our [website](#)
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