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Enhancing precision medicine: sharing and reusing data

The FAIR4Health project supports wider publicly-funded health data use

How FAIR4Health aims to enable safe and ethical sharing of all data and metadata derived from publicly-funded research



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The FAIR principles are intended to ensure that people and machines can reuse data. These principles are designed to be applied to data and metadata across all scientific disciplines and has been taken over by the OECD for Access to Publicly Funded Research Data and by the European Commission's initiative in the framework of the European Open Science Cloud (EOSC).

The overall objective of FAIR4Health is to facilitate and encourage the European health research community to FAIR and share and reuse their data sets derived from publicly-funded research initiatives by demonstrating the potential impact that such a strategy will have on health research and health outcomes.

FAIR4Health will focus on the area of Health. According to FAIRsharing statistics, life sciences and biomedical sciences are one of the top five domains in the standards, databases, and policies development regarding FAIR.

Nonetheless, this is not a common practice for the vast majority of health research institutions. Health data is particularly sensitive for reuse since such a strategy is a key enabler to develop Learning Health-care Systems and Real-World Data (RWD) for precision medicine and healthcare delivery, and further analysis and prototyping of reuse is required.

The pillars of FAIR4Health

- Development of an open community of health research institutions and data scientists in synergy with related national and international initiatives and projects and based on innovative public participation strategies.

- Effective dissemination strategy at European level. This will include awareness raising and training on the exchange and re-use of health research data, including web and social network visibility, scientific publications and dissemination activities targeting both stakeholders and the general public.

“THESE PRINCIPLES ARE DESIGNED TO BE APPLIED TO DATA AND METADATA ACROSS ALL SCIENTIFIC DISCIPLINES”

- Improving the quality of health research data. This is a result of the implementation of FAIR data certification preparation developed in conjunction with international initiatives leading the management of FAIR data based on a thorough analysis of all relevant aspects related to FAIRification, exchange and reuse of health research data. The purpose is to develop a set of recommendations on how to effectively implement a FAIR health data policy.
- A set of technological tools (FAIR4Health platform and agents), developed in a secure and reliable framework that supports and facilitates the implementation of FAIR data policy in health research institutions, while enabling the development of innovative new data-based services

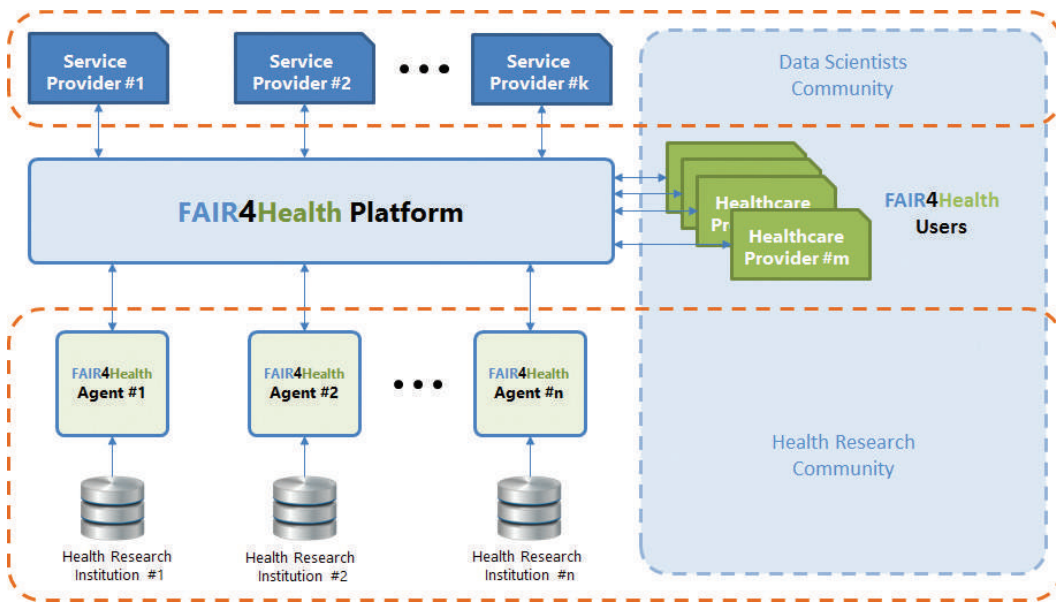


Figure 1. Interactions among FAIR4Health community users

while preserving privacy in a federated data environment.

- Demonstrating the potential impact that the implementation of a FAIR data policy can have for health and health research in real environments that will serve as a lever for the sustainability of FAIR4Health beyond the duration of the project.

Health researchers contribute new FAIRified data and can access other datasets with information relevant to their research, thanks to the use of standard ontologies and vocabularies of each specific domain. Data-based service providers can develop innovative eHealth services based on FAIR information, while healthcare providers can access this innovative set of services through the platform.

FAIR4Health will trigger a step forward to advance the overcoming of one of the major challenges in the health of our time: Precision Health. This will be made possible thanks to the increase in the availability of high-quality health research data provided by FAIR4Health. In this sense, data science research will be able to face theoretical and practical challenges related to the advanced exploitation and

knowledge extraction from federated, heterogeneous resources while preserving the privacy of the data subjects in order to develop the necessary computational tools to address this major challenge. Moreover, health research will benefit from the multiplier effect of aggregating cohorts when testing hypotheses on larger stratified cohorts of subjects to produce unbiased and stronger evidence.

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KEY POINTS

- ✓ The FAIR principles are designed to ensure that people and machines can reuse data
- ✓ FAIR4Health will help overcome the challenge of Precision Health.
- ✓ FAIR4Health will encourage the European health research community to share and reuse their data



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