





Dear readers,

The #5 Newsletter of the Project CONNECT eHealth Community brings you the issues related with health data.

We hope that you find it interesting.

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Community

The Project

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What is health data?

Health data refers to any data describing a person's health, their healthcare or anything affecting any health issues or diseases they may have. This includes information created by health and care professionals, information generated by patients; from illnesses monitored through mobile applications and smart devices, to screening tests and also nutritional data.

Why is health data important?

Healthcare systems are being challenged by growing and aging populations living with more chronic diseases. More effective and smarter medicine is urgently needed to provide better care for patients. Learning from health data can help contribute to innovations that reveal how to make these improvements.

The effective and efficient use of data has the potential to create the transformative step change needed through targeting health and care improvement.

What is FAIR data?

A group of scientists published in 2016 a paper in Nature magazine, the "FAIR Guiding Principles for scientific data management and stewardship", discussing the need for a set of principles to govern the discovery, management and reuse of scientific data. Dozens of prominent scientists who contributed to the paper came up with the FAIR Data concept of describing the principles that make data valuable to researchers and scientists.

The authors of the paper, Wilkinson et al. (2016), intended to provide guidelines to improve the Findability, Accessibility, Interoperability, and Reuse of digital assets. The principles emphasise machine-actionability (i.e., the capacity of computational systems to find, access, interoperate, and reuse data with none or minimal human intervention) because humans increasingly rely on computational support to deal with data as a result of the increase in volume, complexity, and creation speed of data.

The four fundamental principles



Findable - The first step in (re)using data is to find them. Metadata and data should be easy to find for both humans and computers. Machine-readable metadata are essential for automatic discovery of datasets and services.



Accessible - Once the user finds the required data, they need to know how they can be accessed, possibly including authentication and authorisation



Interoperable - The data usually need to be integrated with other data. In addition, the data need to interoperate with applications or workflows for analysis, storage, and processing.



Reusable - The ultimate goal of FAIR is to optimise the reuse of data. To achieve this, metadata and data should be well-described so that they can be replicated and/or combined in different settings.

Why are FAIR principles useful?

The FAIR principles:

- ·support knowledge discovery and innovation
- ·support data and knowledge integration
- ·promote sharing and reuse of data
- ·are discipline independent and allow for differences in disciplines
- ·move beyond high level guidance, containing detailed advice on activities that can be undertaken to make data more FAIR
- ·help data and metadata to be 'machine readable', supporting new discoveries through the harvest and analysis of multiple datasets.

Technological advancements have made research and science more data intensive and interconnected, with researchers producing and sharing increasing volumes of data. In their effort to produce high health quality data, researchers have to follow good data management and data stewardship practices such as the FAIR principles.

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