User scenarios to promote the use of FAIR data on health research

Marta Almada¹, Inês Dias¹, Diana Portela², Luís Midão¹, Anil A. Sinaci³, Francisco J. Núñez-Benjumea⁴, Carlos L. Parra-Calderón⁵, Elíssio Costa¹

¹ UCIBIO, REQUIMTE, University of Porto, Portugal
² Ageing Research Group of Research and Innovation in Biomedical Informatics, Biomedical Engineering and Health Economy. Institute of Biomedicine of Seville, IBiS / Virgen del Rocío University Hospital / CSIC / University of Seville, Spain.
³ SRDC Software Research, Development and Consultancy Corp, Ankara, Turkey.

Over last years, policies and efforts have been ongoing to encourage the share/reuse of data in different research disciplines. Recently, an urgent need to FAIRify data from health research has emerged and this is one of the aims of FAIR4Health (www.fair4health.eu). In this regard, it is important to provide principled guidelines to improve the findability, accessibility, interoperability, and reuse of digital assets. FAIRification of health research data will enable the re-use/sharing of existing biomedial data to improve research into personalised care, preventive medicine, and value-based healthcare. Nevertheless, this FAIRification process brings novel challenges, such as the use of personal and sensitive data, and currently, there is a lack of knowledge among the use of FAIR data on health. In parallel, the digital transformation of health/care in the Digital Single Market aims to empower citizens, to generate applications for innovative companies and provide wider suggestions to stakeholders on the path towards optimal use of scientific data. In this work, we aimed to demonstrate the potential impact of FAIR data strategy on health outcomes, innovation/research, and on boosting citizen science. For this, we will present four user scenarios and provide evidence-based representations of the benefits of the use FAIR on health.

User scenario 1
FAIR data for development of digital solutions by start-ups

PerCare
A digital tool for healthcare

HdataCare is a health start-up founded four years ago by two colleagues in Porto, Portugal. With 20 workers and growing, it recently got a project funded in an international application. Since then, the ambition of these colleagues has been to reuse a great amount of health data generated throughout the years. To realise their vision, they developed the digital tool PerCare mainly directed to healthcare professionals, caregivers, and patients. Clinical databases consist in large amount of raw data, which after patient consent is collected, preprocessed and submitted to FAIRification process. This app uses Data/Metadata from health FAIRified Databases (from patients, citizens and health units) through Artificial Intelligence and Machine Learning algorithms. PerCare integrates the health data into a digital app, which allows the analysis of complex clinical data. Hence, taking into account patient's signs and symptoms, PerCare will propose to healthcare professional differential diagnosis, prognosis, costs, theoretical foundations and treatment guidelines, to support an integrated and personalized health care and improve quality/effectiveness of healthcare services.

Currently, HdataCare start-up is developing new services for patients/caregivers to improve self-management of disease and to empower citizens through enhanced health literacy.

User scenario 2
FAIR to improve self-management /self-care and citizen science

SmartGlu
An health device for disease management

Maria Silva, 67 years old, is a waitress in a famous restaurant in Faro, Portugal. She lives with her husband, children and her elderly mother. At age of 5 years old, she was diagnosed with Diabetes Mellitus type 1 (DM1). Recently, Maria’s mother moved into her house due to an advanced stage chronic disease, and since then Maria was having problems controlling her glucose levels.

HdataCare start-up developed SmartGlu, an health device (smartwatch) to help patients and caregivers to manage disease. Encouraged by her family and health providers, Maria started to use the smartwatch. This device works as a sensor when applied on the wrist, that contains a thin, sterile and painless needle inserted under the skin that measures glucose levels.

After patients’ consent, glucose levels and other health data are accumulated, processed and stored at a secure personal health record system, enabling a repository of FAIRified clinical data, whose access is controlled by patients, caregivers and healthcare professionals.

User scenario 3
FAIR data for health research

Health Data Research Centre

The Health Data Research Centre is based in Porto since 1988. In 2006, it was ranked as an exceptionality by the European Science Foundation evaluation, and gathers a team of 127 integrated researchers from Bioinformatics, Chemistry to Biological Sciences backgrounds.

This research centre uses raw data from health units databases, health research, and citizens/patients clinical data, which after consent, is collected and stored in an interoperable personal health record system.

This approach enabled the design of representative user scenarios with related needs to different segment of populations: a start-up, citizen, health unit/hospital and a research centre. These user scenarios highlight specific aspects of healthcare products/services, or needs, and ultimately generate innovative services based on sharing/reuse of FAIR datasets.

In overall, this work will allow us to identify technical hurdles and overcome challenges that will emerge from the FAIRification process, but foremost to show the impact of using FAIR data on health research, to not only researchers and stakeholders representing academic, industry and funding agencies, but also citizens.