

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

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Over last years, policies and efforts have been ongoing to encourage the share/reuse of data in a 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/) project. In this regard, it is important to provide principles/guidelines to improve the findability, accessibility, interoperability, and reuse of digital assets. FAIRification of health research data will enable the re-use/share of existing biomedical 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 added-value 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

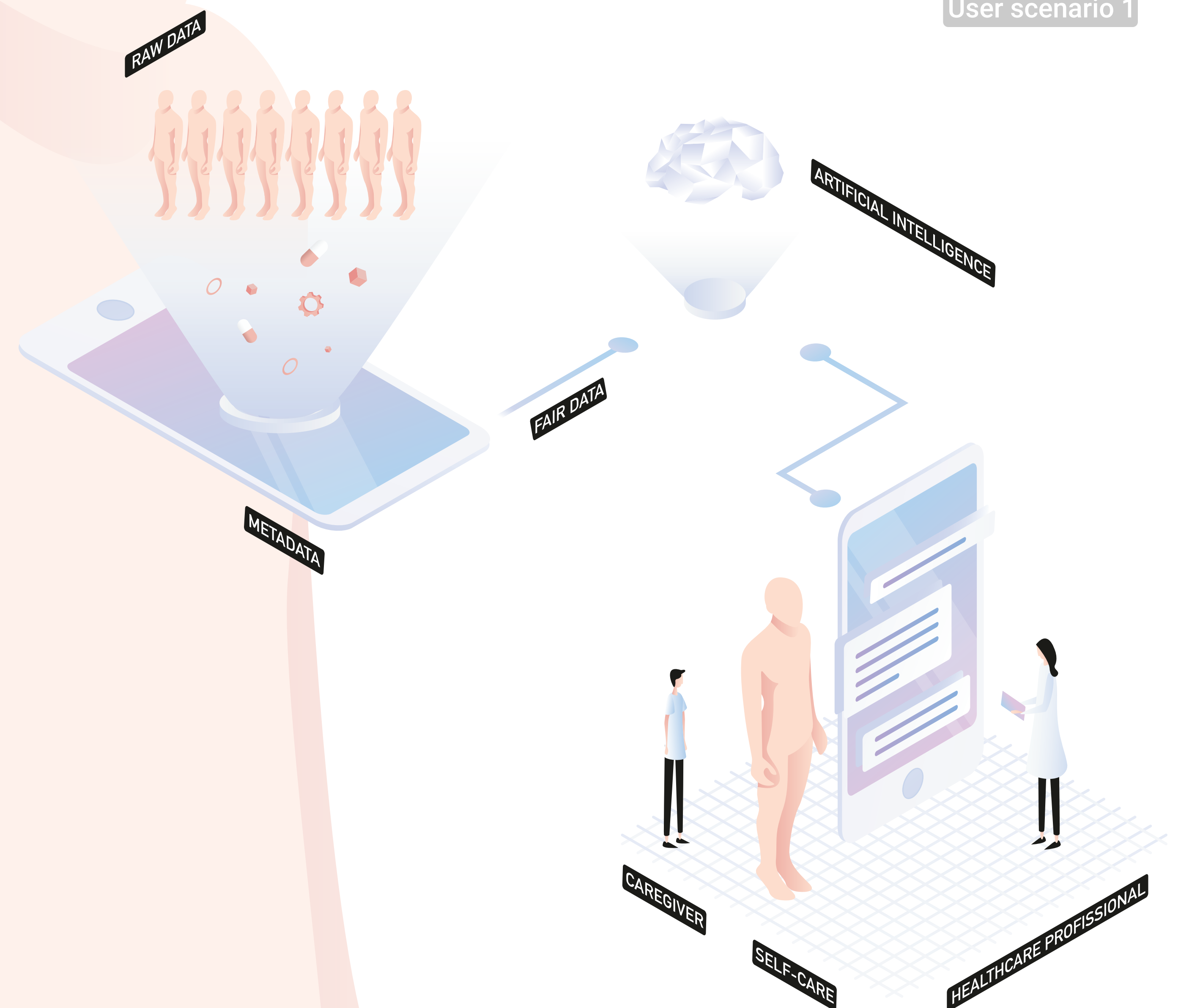
HdataCare is a health start-up founded four years ago by two colleagues in Porto, Portugal. With 20 workers and growing, it recently got a project funded in an international application. Since faculty, the ambition of these colleagues has been to re-use a great amount of real health data generated throughout the years.

To realize 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, anonymised and submitted to FAIRification process. This app uses Data/Metadata from health FAIRified databases (from patients, citizens and health

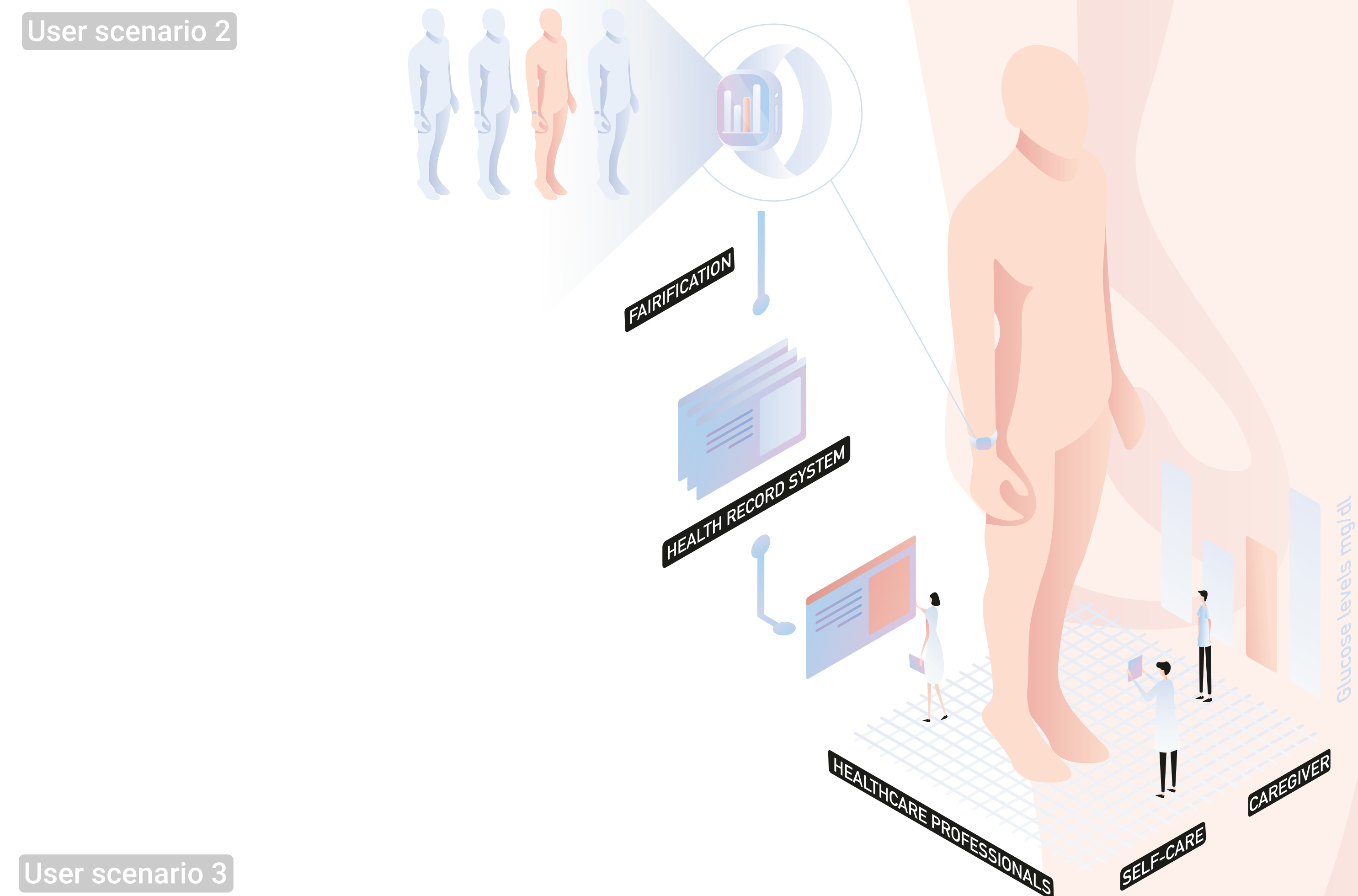
units). Through Artificial Intelligence and Machine Learning algorithms, PerCare integrates this health data into a digital app, which allows the analysis of complex clinical data. Hence, taking into account patients' signs and symptoms, PerCare will propose to healthcare professional differential diagnosis, prognosis, costs, theoretical foundations and treatment guidelines, to support an integrated and personalised healthcare and improve quality/efficacy of health care 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 1



User scenario 2



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 physician, 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 in a regular way that are displayed in the

smartwatch screen. SmartGlu shows and registers glucose history, allowing Maria to follow the trends of her glucose levels at each time and improving her conscious on the impact of actions on her health.

Additionally, SmartGlu indicates the glucose levels of people in surroundings (30 km by default) so Maria can compare her glucose levels/disease control with other patients anonymously, as a way to encourage her to keep DM1 under control in a daily-routine.

After patients' consent, glucose levels and other health data is anonymised, processed and stored at interoperable personal health record system, enabling a repository of FAIRified clinical data, whose access is controlled by patients. Caregivers and healthcare professionals have real-time management to Maria's health status allowing a home-based monitor of the disease.

User scenario 3

FAIR data for health research

Health Data Research Centre

The Health Data Research Centre is based in Porto since 1988. In 2008, it was ranked as exceptional 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.

Health data/metadata is submitted to a FAIRification process to transform raw health data into FAIR data. The

latter is findable, accessible and readable by humans, machines and computers. Health units and research centres may exchange clinical data between them, taking the advantage of interoperability principle of FAIR. Additionally, researchers from the Health Data Research Centre may share and re-use data and provide further information to be integrated in the FAIRification process during their research.

In addition, health companies/start-up, as HdataCare, use FAIR health data to develop solutions or medical devices to improve quality of healthcare services and promote personalized care.

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 explore 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 academia, industry and funding agencies, but also citizens.

User scenario 3

