



## **D7.4. Report on the FAIRification workshops and tutorials series**

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Project Officer	Katharina BUSE		
Project Coordinator	Carlos Luis Parra Calderón, Andalusian Health Service (P1–SAS)		
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Lead beneficiary	P12-EFMI		
Responsible Author	Patrick Weber		
e-mail	Patrick.weber@nicecomputing.ch	Phone number	+41216410420
Reviewers	Celia Alvarez (SAS)		
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## List of acronyms

BoF	Birds-of-a-Feather
CEN	Centre Européen de Normalisation
CrowdHEALTH	Collective wisdom driving public health policies
DCC	Digital Curation Centre (See. IDCC)
EFMI	European Federation for Medical Informatics
EOSC	European Open Science Cloud
EU	European Union
FAIR	Findable, Accessible, Interoperable and Reusable
HIMSS	Healthcare Information and Management Systems Society
HIT	Health Information Technology
HL7	Health Level 7
HRPO	Health Research Performing Organizations
IACS	Instituto Aragonés de Ciencias de la Salud
ICIMTH	International Conference on Informatics Management and Technology in Healthcare
IDCC	International Digital Curation Conference (See. DCC)
IFIP	International Federation for Information Processing
IMIA	International Medical Informatics Association
IMISE	Universitaet Leipzig
IPBV	Institute of Pulmonary Diseases of Vojvodine
ISO	International Standardization Organization
MIE	Medical Informatics Europe
P13	RDA 13th Plenary (Philadelphia, April 2019)
P14	RDA 14th Plenary (Helsinki, October 2019)
PLRI	Peter L Reichertz Institute
RDA	Research Data Alliance
SAS	Servicio Andaluz de Salud
SRDC	Software Research and Development Consultancy
STC	Special Topic Conference
UC3M	Universidad Carlos III De Madrid
UEDIN	The University of Edinburgh
UNIGE	Université de Genève
UP	University of Porto
WHO	World Health Organisation

## 1. Executive summary

To follow the Deliverable D7.4 made in August 2020 (M21), this report will summarize the activities fulfilled up to November 2021 (M36). Due to the SARS-Cov2 pandemic almost all the conferences was canceled or conducted virtually.

A great effort was done to participate and present the work of FAIR4Health in many available events. For the activities outlined above, all partners are committed to provide sufficient and appropriate material for dissemination purposes and contribute to the project's outreach during its life cycle and after its completion.

## 2. Introduction

This document gives an overview of the activities conducted by the different FAIR4Health partners. Perhaps some events could be reported in other deliverables. The objective is to give an extended chronological view of the dissemination actions performed during the project.

Report on the FAIRification workshops and tutorials series (deliverable D7.4) was presented at month M6 (May 2019), and then updated at months M21 (August 2020) and M36 (November 2021).

## 3. FAIR4Health participation in previous events

### 3.1 Workshop 2020: FAIR Data Infrastructures - The FAIR4Health approach (15.10.2020)

SAS participated at a workshop entitled "FAIR Data Infrastructures". FAIR4Health has designed a workflow to apply the FAIR Principles to health research data, based on the FAIRification process of GO FAIR, but addressing the ethical, legal and technical aspects that health data includes. These aspects have been analysed and FAIRification tools, based on the use of the HL7 FHIR standard, have been developed to obtain FAIR data from data resulting from biomedical research. FAIR4Health platform will be validated with the two pathfinder case:

- 1) Identification of multimorbidity patterns and polypharmacy correlation on the risk of mortality in elderly.
- 2) Early prediction service for 30-days readmission risk in COPD patients.

### 3.2 FAIR Health Data Sets with HL7 FHIR: New Standards to support Health Research (17.10.2020)

SAS, HL7, IMISE and SRDC gave a tutorial at the Tutorial at the 2nd EU-China Health Summit. The tutorial is available on YouTube <https://youtu.be/abGir9sUvAw>

### 3.3 Swiss Research Data Day 2020 (22.10.20)

UNIGE participated at this virtual conference, Switzerland. Conduct a panel "Sharing meaningful data is an important challenge in the field of personalized medicine. Besides legal and ethical aspects, there are technical challenges to be met in order to be able to handle massive amounts of multimodal and heterogeneous distributed data, and semantic challenges in order to build an interoperable framework."

The H2020 FAIR4Health project aims at facilitating and encouraging the European Union Health Research community to FAIRify, i.e. make data findable, accessible, interoperable and re-usable, share and reuse datasets derived from publicly funded research initiatives. A user-centered FAIR4Health platform and FAIR4Health agents are being developed to enable the translation from raw (meta) data to FAIR (meta) data. To validate the FAIR4Health platform and demonstrate the feasibility of FAIRifying medical research data, two pathfinder case studies prototypes will be performed on real medical data. The FAIR4Health consortium consists of 17 partners from both public and private entities".

### 3.4 FAIR Health Data Sets with HL7 FHIR: New Standards to support Health Research(22.10.2020)

SAS presented virtually a poster entitle "Tools for the support of workflow with data in Health Research to make them Findable, Accessible, Interoperable and Reusable" during the the 2nd EU-China Health Summit.

### 3.5 XIV Jornadas APDIS Associação Portuguesa de Informação e Documentação em Saúde (29.10.2020)

UPorto conducted an oral presentation entitled "User scenarios no contexto de investigação em saúde e dados FAIR" at the Centro Hospitalar Universitário do Porto (CHUP), Porto, Portugal.

### 3.6 RDA P16 Plenary Meeting (10.11.2020)

SAS and UEDIN presented a poster viritually entitled "Improving Health Research in EU through FAIR Data".

### 3.7 RDA P16 Plenary Meeting (12.11.2020)

SAS and UEDIN conducted a virtual workshop at WG on Guidelines for Health Research Performing Organizations to implement FAIR Data Policy, entitled "Raising FAIRness in health data and health research performing organisations (HRPOs) WG".

The main objective of this meeting is to build upon the previous three BoFs (P13 Philadelphia, P14 Helsinki and VP15 Melbourne), consolidating what those meetings established and formally inaugurate this new WG. This meeting will also review in depth the key principles that will inform the RDA output and form the basis for the guidelines: a unifying and globally applicable FAIR data policy for HRPOs. Participants will be polled to gather feedback and we will also identify volunteers to undertake specific tasks (see the section on activities), at least in the short to medium term. Specifically, this will take the form of gathering the requisite information to create a global landscape analysis of FAIR data policies in the health research field.

### 3.8 EOSC Projects EXPO (16.11.2020)

SAS organized a virtual booth at EOSC called "FAIR For Health Research".

### 3.9 Higher Health School of Porto - Seminários MBBAS - Escola Superior de Saúde (18.12.2020)

UPorto organized a workshop for the master students of health and care, bioinformatics, medical informatic areas and Professors. The title of the workshop is "FAIR4Health: Improving Health Research in EU through FAIR Data".

### 3.10 FHIR Confluence Connectathon 26 (13.01.2021)

SAS, HL7, IMISE and SRDC participated to this connectathon organized by FHIR. The intent of this track is to engage the FHIR and FAIR communities on the implementation of the FAIR (Findability, Accessibility, Interoperability, and Reuse) principles and FAIR health data objects by using HL7 FHIR. This objective will be pursued by leveraging on existing HL7 FHIR implementation experiences.

### 3.11 ENDORSE - The European Data Conference on Reference Data and Semantics (19.03.2021)

SAS and UC3M participated to a round table having the objectives described by "The linking and re-using of data has been recognized as a common goal across different data communities that work on different topics (data spaces) in different sectors (public sector, industry and research). Nevertheless, it has been difficult to practically align different approaches towards handling data. This round table aims to concretize how different data communities can cooperate to apply FAIR principles. We will start with

concrete use cases in which cooperation between different data communities has been successful. Speakers will reflect on their approach to FAIR practices, its benefits and remaining challenges. A panel composed of representatives of research, industry and public sector will elaborate on these findings to induce policy priorities and concrete actions for sharing knowledge, expertise and technology. (Results of the round table will be documented in a position paper)".

### 3.12 AMIA 2021 Virtual Informatics Summit Digital Collection (23.03.2021)

SAS and HL7 organized a workshop entitled "Common Approaches to FAIR Data Policy in the US and Europe: key issue to accelerate science in times of Covid-19 Pandemic" with this description "We are living in a historic time worldwide caused by the coronavirus pandemic. The challenge is enormous worldwide and is testing the health systems and the economy of the affected countries themselves, the regions even globally. It is also seriously challenging the capacity of the world's nations to collaborate in science to know and combat this enemy of Humanity. Therefore, the international dimension of knowledge and information exchange as well as the acceleration of evidence generation should be a central concern. At this time, the FAIR principles are positioned as the pillar on which to base this necessary alignment of policies for managing data and health research results, now more essential than ever. This panel will present an approach to the common components that should govern these FAIR policies between the US and Europe as well as the key aspects of their effective application".

### 3.13 First SWForum Workshop on Trustworthy Software and Open Source (24.03.2021)

EFMI and SAS organized a workshop at European Forum of Software Research Community SWForum.eu entitled "Approaches to the integration of TRUST and FAIR principle" FAIR4Health, an EU's funded project, promotes the application of FAIR principles (Findable, Accessible, Interoperable, Reusable) in data derived from publicly funded health research initiatives to share and reuse them in the European Union Health Research community, defining an effective EU-wide strategy for the use of FAIR in Health. This paper analyses how to apply FAIR principles to "trust" in the context of the open-source software development of FAIR4Health. The FAIRification process and TRUST principles are discussed and related. The paper tries to open a new view on the trustworthiness of data access using open-source software.

### 3.14 Student Association of the Faculty of Medicine of the University of Porto AEFMPU (15.04.2021)

UPorto conducted in the Health Innovation Program a transversal training program, about Fair Health Data Science.

### 3.15 16th International Digital Curation Conference IDCC 2021 (19.04.2021)

SAS gave a presentation at this conference entitled "FAIR4Health FAIRification Tools".

### 3.16 Universidad Europea de Madrid (19.04.2021)

SAS gave a masterclass in bioinformatics entitled Digitization of biomedical data within healthcare systems this masterclass is available on youtube.

### 3.17 RDA Plenary 17 & Colocated events (20.4.2021 & 23.04.2021)

SAS and UEDIN organized a workshop entitled Raising FAIRness in Health Data and Health Research Performing Organisations (HRPOs) this session was presented in a second time 23.04.2021.

SAS, HL7 and IMISE had a poster entitled FAIRness for FHIR project: Making Health Datasets FAIR using HL7 FHIR.

### 3.18 Faculty of Pharmacy University of Porto (07.05.2021)

UPorto had a poster within the tutorial class Digital Health entitled Data base FAIR a Project FAIR4Health.

### 3.19 AMIA Clinical Research Informatics Working Group (18.05.2021)

SAS made a presentation in the working group entitled Experience with Applying FAIR principles for secondary use on health data in Europe, the FAIR4Health Project.

### 3.20 Medical Informatics Europe MIE 2021 (31.05.2021)

SAS, HL7 and IMISE organized a workshop entitled FAIRness for FHIR project: making the Covid-19 Datasets FAIR with HL7 FHIR.

EFMI set up a booth FAIR4Health.

SRDC presented a paper entitled "End User Evaluation of the FAIR4Health Data Curation Tool" The aim of this study is to build an evaluation framework for the usercentric testing of the Data Curation Tool. The tool was developed in the scope of the FAIR4Health project to make health data FAIR by transforming them from legacy formats into a Common Data Model based on HL7 FHIR. The end user evaluation framework was built by following a methodology inspired from the Delphi method. We applied a series of questionnaires to a group of experts not only in different roles and skills, but also from various parts of Europe. Overall, 26 questions were formulated for 16 participants. The results showed that the users are satisfied with the capabilities and performance of the tool. The feedbacks were considered as recommendations for technical improvement and fed back into the software development cycle of the Data Curation Tool.

### 3.21 Computer in Cardiology CINC 2021 (12.09.2021)

HL7 and SAS presented a paper entitled "FAIRness for HL7 FHIR: supporting interoperability of health datasets". The FAIR (Findable Accessible Interoperable Reusable) principles have been established as best practice in the generation of health datasets for open science, research, and innovation. The FAIR4Health project ([fair4health.eu](http://fair4health.eu)) aims to encourage FAIRification and reuse of research data generated by publicly funded research projects. The Research Data Alliance (RDA) research community organization aims at building the social and technical infrastructure to enable open sharing and re-use of data. FAIR4Health and the RDA FAIR data maturity model WG initiated the HL7 FAIRness for FHIR implementation guide (IG) project to provide guidance on how to assess the FAIRness of health data sets with the RDA FAIR Data Maturity Model and support delivery of FAIR health datasets using the HL7 FHIR standard. In this paper, we present how we applied the guidance of the HL7 FAIRness for FHIR IG on selected PhysioNet datasets and reflect on the experience gained by discussing the recommendations of the IG on how to use HL7 FHIR resources to advance the FAIRness of health data sets.

### 3.22 MedInfo 2021 (02.10.2021)

SAS, HL7 and IMISE presented a paper entitled "FAIRness for FHIR: Towards Making Health Datasets FAIR using HL7 FHIR" this presentation is on YouTube.

### 3.23 Bioinformatics (FISEVI) (15.10.2021)

SAS organized a training program entitled "FAIR principles applied to omics data".

### 3.24 RDA Plenary 18 (03.11.2021 & 09.11.2021)

SAS and UEDIN organized twice a workshop entitled "Raising FAIRness in Health Data and Health Research Performing Organisations (HRPOs)".

The objective of these sessions planned for RDA Plenary 18 was mainly to demonstrate the ongoing tasks that were outlined in the WG case statement. Specifically, the impact assessment of FAIR adoption initiated by the Chairs and requires input and review by the WG and the community was discussed. In addition, a survey has been designed to collect information on the national and international policies and requirements for health research data sharing (including FAIR data) mandated by various countries and research funders has been performed and was disseminated during RDA Plenary 18 (November 2021, Virtual).

### 3.25 EFMI STC 2021 (22 & 23 11.2021)

This Special Topic Conference was dedicated to FAIR4Health with the theme title "Applying the FAIR principles to accelerate health research in Europe in the post-COVID19 Era".

SAS, HL7, IMISE, UMC and SRDC participated with several workshops and papers. Finally, SAS, ATOS and SRDC organized a virtual free demonstration of the FAIRHealth solution, composed by: 1) The FAIRification tools: The Data Curation Tool, and the Data Privacy Tool; and 2) The FAIR4Health portal. This demonstration was performed as part of the FAIR4Health Final Assembly, on Wednesday 24th November, from 14:30 to 17:15 CET.

## 4. YouTube

FAIR Health Data Sets with HL7 FHIR: New Standards to support Health Research  
<https://youtu.be/abGir9sUvAw>

Masterclass Bioinformática - Digitalización de datos biomédicos dentro de los sistemas sanitarios [https://www.youtube.com/watch?v=\\_o6qvkyf-Wk](https://www.youtube.com/watch?v=_o6qvkyf-Wk)

FAIRness for FHIR project: making the Covid-19 Datasets FAIR with HL7 FHIR  
<https://www.youtube.com/watch?v=dZjyitA8-bk>

FAIRness for FHIR: Towards Making Health Datasets FAIR using HL7 FHIR  
[https://www.youtube.com/watch?v=U\\_vNP48hThs](https://www.youtube.com/watch?v=U_vNP48hThs)

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