



Junta de Andalucía

Consejería Salud y Familias

Servicio Andaluz de Salud

Carlos Luis Parra-Calderón

FAIR4Health Project Coordinator – Andalusian Health Service



THE FAIR PRINCIPLES AS A GUIDE TO MAKING TRUE THE EUROPEAN HEALTH DATA SPACE.

From Electronic Health Records to Open Health Research in Europe.

ENDORSE.

THE EUROPEAN DATA CONFERENCE ON REFERENCE DATA AND SEMANTICS

Outline

The FAIR4Health Project.

The benefits of applying FAIR principles to health data: Fully Artificial Intelligence Ready.

Hurdles taken: Different data sets and ethical and legal issues.

Remaining challenges: the strong dependence on the semantic domain of Health

Health information standards as a response: The HL7 FAIRness for FHIR (FHIR4FAIR) Implementation Guide.



FAIR4Health project

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 824666

Consortium

Coordinated by **Virgen del Rocío University Hospital, Andalusian Health Service (SAS)**

17 partners from **11 EU and non-EU countries**

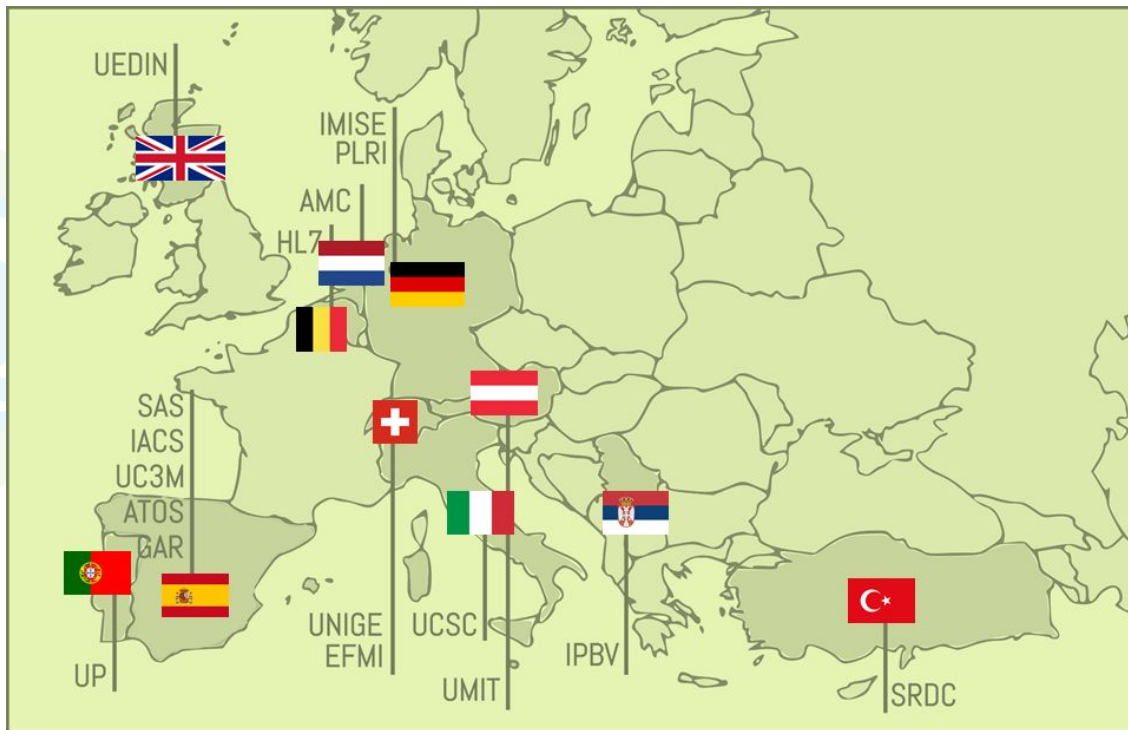
6 health research organisations

2 universities experts in data management

4 academic partners with strong background

on medical informatics

5 business actors



Objectives

To **facilitate and encourage** the EU Health Research community **to FAIRify, share and reuse** their datasets derived from publicly funded research initiatives through the demonstration of the potential impact that such strategy will have on health outcomes and health research.

To design and implement an effective **outreach strategy at EU level**

To produce a **set of guidelines** to set the foundations for a **FAIR data certification roadmap**

To develop and validate an intuitive, user-centered **FAIR4Health platform and FAIR4Health agents**

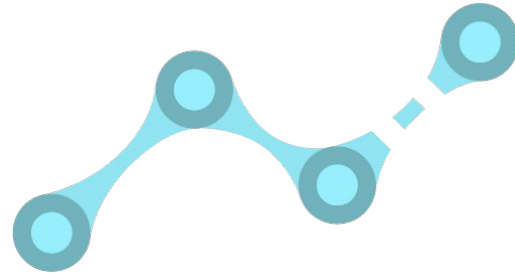
To demonstrate the potential **impact in health research and health outcomes** through the validation of 2 pathfinder case studies

Pathfinder Use Cases: Innovative Digital Health services based on FAIR data reuse

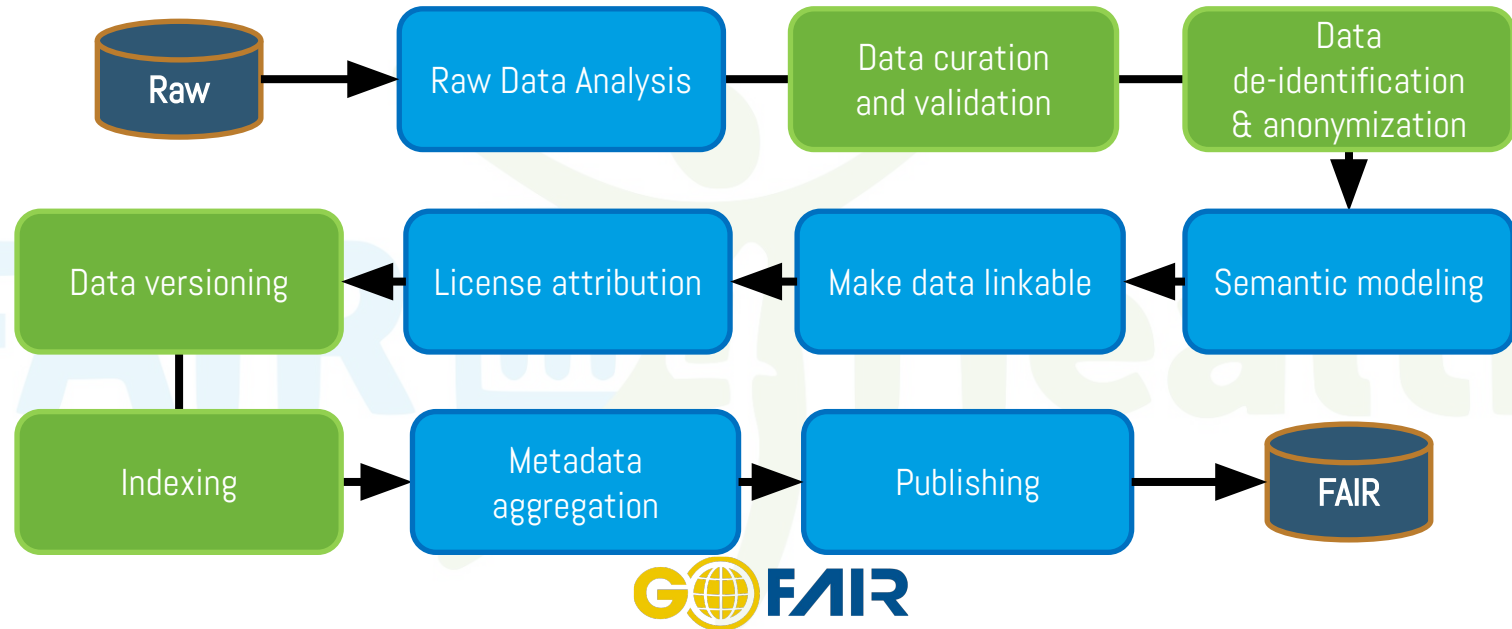
#1 To support the **discovery of disease onset triggers and disease association patterns** in comorbid patients and **demonstrate the reproducibility of research**



#2 To develop and pilot a **Digital Prediction Service for 30-days readmission risk** in patients with COPD.

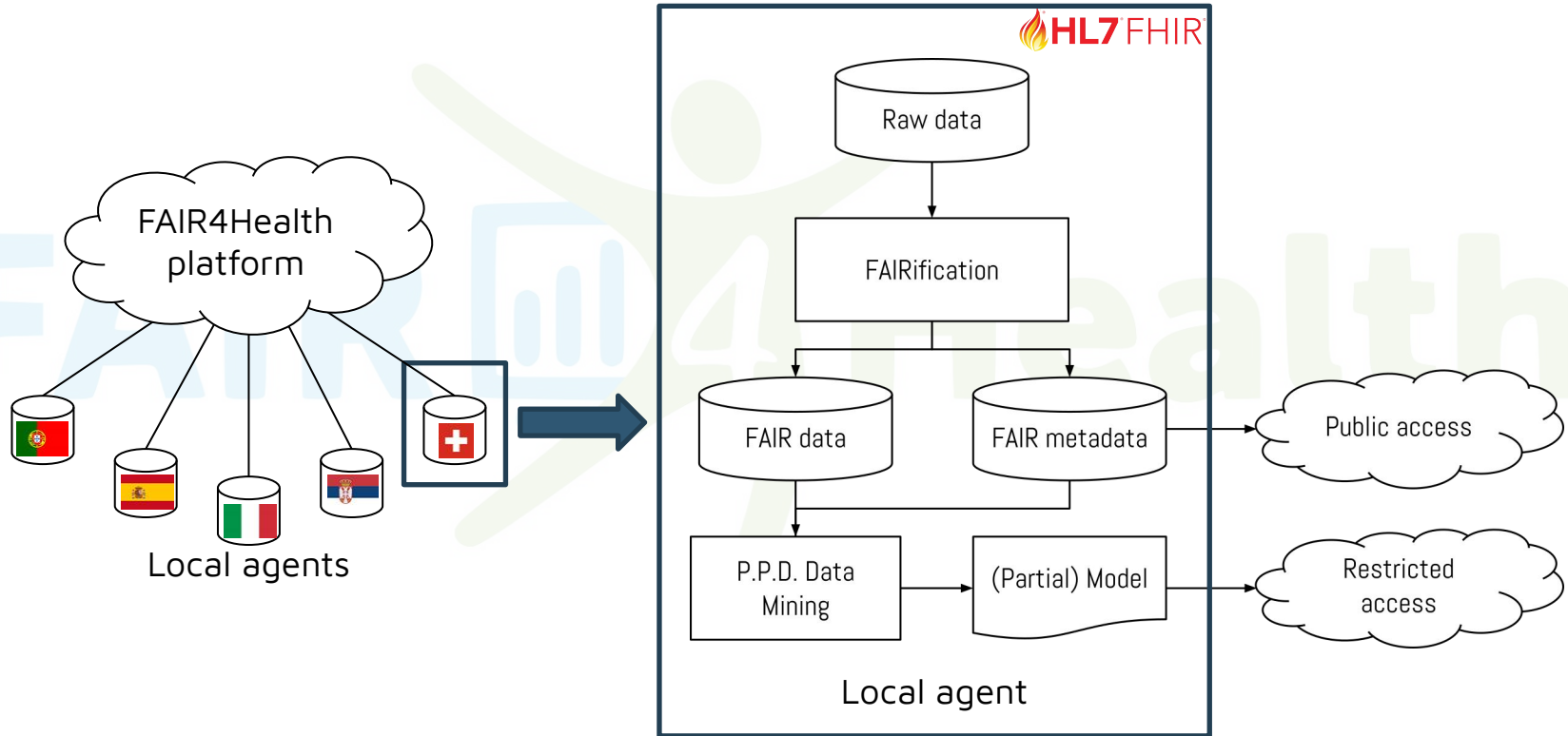


Technological solution I



Sinaci AA, Núñez-Benjumea FJ, Gencturk M, Jauer ML, Deserno T, Chronaki C, Cangilioli G, Cavero-Barca C, Rodríguez-Pérez JM, Pérez-Pérez MM, Laleci Erturkmen GB, Hernández-Pérez T, Méndez-Rodríguez E, Parra-Calderón CL. From Raw Data to FAIR Data: The FAIRification Workflow for Health Research. *Methods Inf Med*. 2020 Jun;59(S 01):e21-e32. doi: 10.1055/s-0040-1713684. Epub 2020 Jul 3. PMID: 32620019.

Technological solution II



Relationships



The benefits of applying FAIR principles to health data: “Federate Artificial Intelligence-Ready.”¹

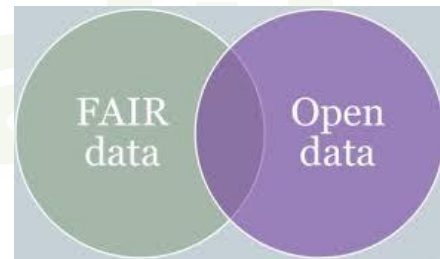
- An essential source of health research information is the information collected by healthcare providers for individuals' health care throughout their lives.
- This information is collected in Electronic Health Records (EHR). Although these data are not collected for research, they are collected to care for each patient.
- There is a long experience in research on methods to convert care information into actionable information for research at different levels: translational, clinical, and population.
- Enormous efforts are made to collect specific health research information when most of the data is already available in EHRs.
- Artificial Intelligence applied to large amounts of data brings exponential capabilities to accelerate health research but requires quality, consistent and standardized data.
- A practical application of FAIR principles with tools that support this process allows AI algorithms to be trained uniformly with data collections that are very different from each other in origin.



1. <https://www.eoscsecretariat.eu/news-opinion/eosc-podcast-episode-2-learning-international-fair-practices-bert-meerman>

Hurdles taken: Different data sets and ethical and legal issues.

- Our FAIRification workflow anonymizes and aggregates data collections for analysis.
- The application of Privacy-Preserving Distributed Data Mining (PPDDM) methods enable federated data analysis that avoids moving data from the original repositories, and **facilitates the acceptance of secondary use of the health data by the stewards of that data**, typically healthcare providers, in addition to complying with European Personal Data Protection regulation and beyond.
- This architecture provides relevant **building blocks for a European Health Data Space**.



Remaining challenges: the strong dependence on the semantic domain of Health

F2. data are described with rich metadata (defined by R1)

I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.

R1. meta(data) are richly described with a plurality of accurate and relevant attributes

R1.3. (meta)data meet domain-relevant community standards

Ontologies to provide controlled Terms

Standardized guides for uniform structures.



Leading healthcare terminology, worldwide



The HL7 FAIRness for FHIR (FHIR4FAIR) Implementation Guide.

Goals

- Facilitate the collaboration between the FAIR and the FHIR communities.
- Enable a cooperative usage of the FHIR and FAIR paradigms.
- Support the health data FAIRness assessment by using HL7 FHIR conformance resources.

Objective

- Develop a HL7 FHIR Implementation guide - called FHIR4FAIR FHIR IG - providing guidance on how HL7 FHIR can be used for supporting FAIR health data implementation and assessment.
- <https://build.fhir.org/ig/HL7/fhir-forfair/>
- <https://confluence.hl7.org/pages/viewpage.action?pageId=91991234>





Thank you!

carlos.parra.sspa@juntadeandalucia.es

ENDORSE.
THE EUROPEAN DATA CONFERENCE ON REFERENCE DATA AND SEMANTICS