

▶ OPEN SCIENCE ▶ FAIR ▶



Landscape Analysis – Initial Findings from FAIR4Health Project

Workshop session: Fostering a FAIR research culture - what works?

Kiko Núñez

Open Science Fair 2019
16-18 Sep 2019, Porto (Portugal)

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



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Outline



1. The FAIR4Health Project
2. The FAIRification workflow
3. Guidelines for HRPOs to implement a FAIR data policy



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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.

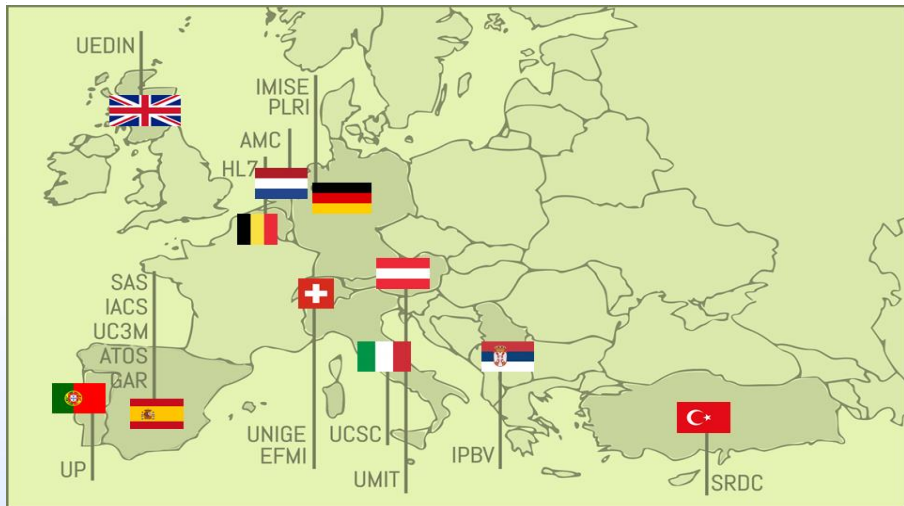
1. OUTREACH STRATEGY AT EU LEVEL

2. FAIR DATA CERTIFICATION ROADMAP

3. TECHNOLOGICAL PLATFORM

4. DEMONSTRATE POTENTIAL IMPACT

EC funding: 2,999,053.75 €



Health Research Organizations



Research Data Management



Health Informatics



Business Actors



Demonstrators

Innovative eHealth 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 **prediction service for 30-days readmission risk** in complex chronic patients








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Datasets

Name	The EpiChron Cohort	
Owner	SHELTER	
Funding Source	DPIData	
Owner	IBENC	
Funding Source	FRAN SURVEY	

Health and social care data from **5 million** of subjects

Owner	Virgen del Rocío University Hospital (SAS)
Funding Source	Public funding for healthcare delivery, not for research
Size	2.32 million EHR with information about 18.83 million clinical episodes.

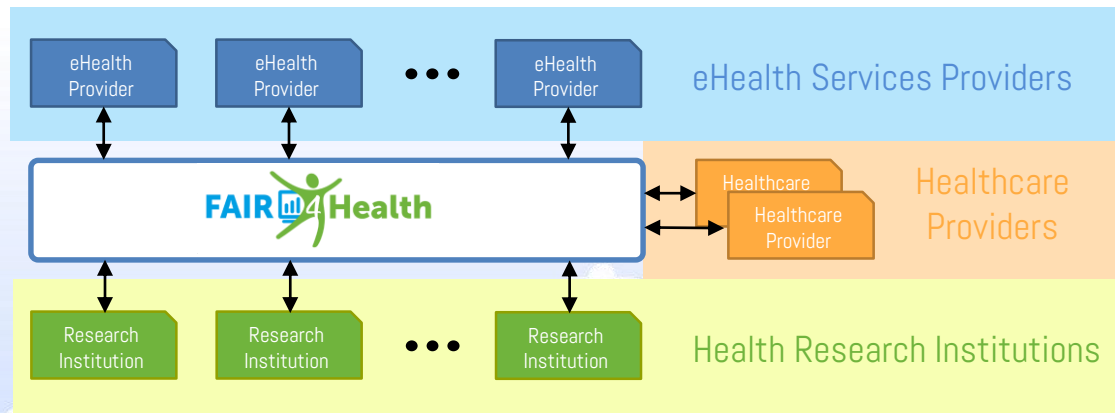
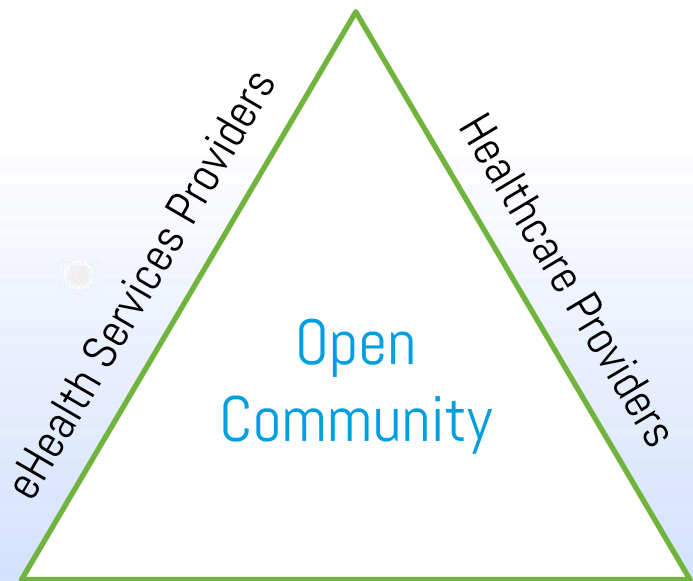
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FAIR4Health Vision



Health Research Institutions

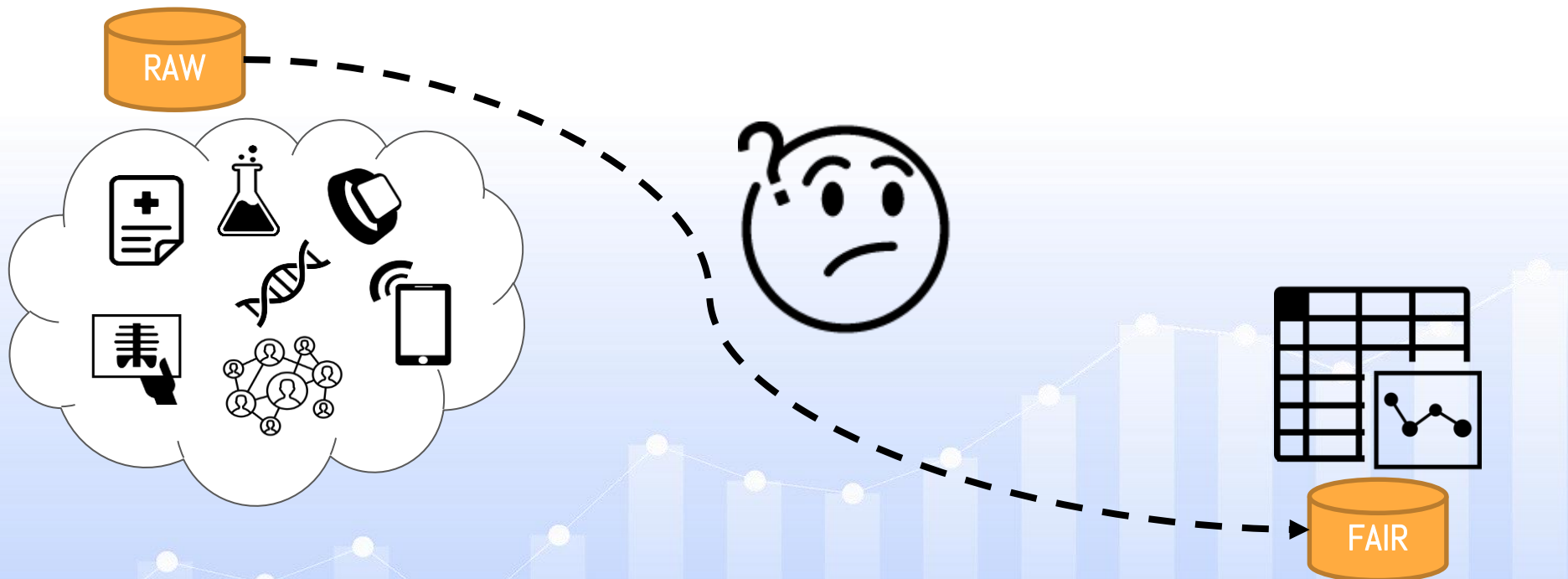
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FAIRification workflow



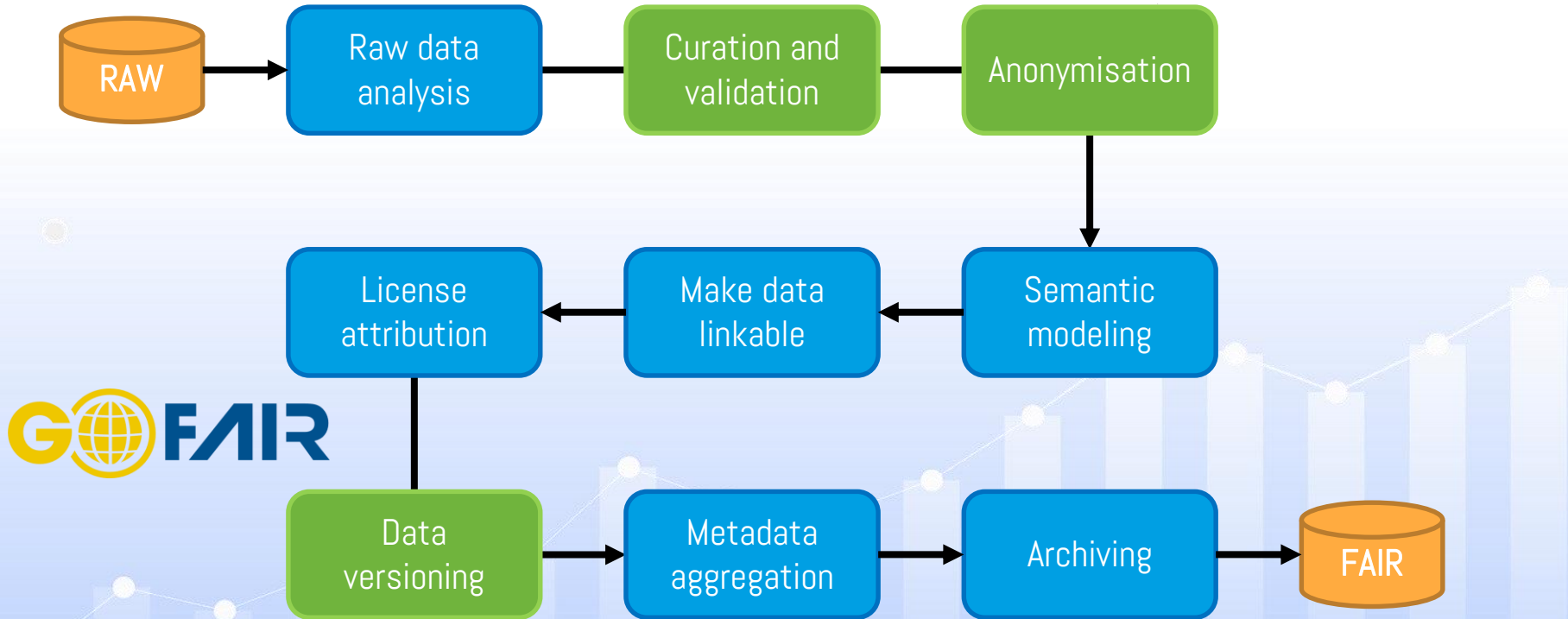
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FAIRification workflow



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Guidelines: 5 principles

01	Strategic Vision	The implementation of FAIR policy implies to manage a complex change
02	Resources	There are no policies without resources and incentives supported by the needed infrastructure
03	Skills	Need to count with right knowledge and skills about FAIR data and research data management
04	Action Plan	The FAIR policy implementation must follow a clear action plan , identifying main actors and a credible timeline
05	Approval	The FAIR policy must be written down and approved by the institution

Guidelines: 10 Steps

1. Vision and Objectives

Describe current research, funders and their policies, research outcomes and infrastructure.
Define the **objectives** of the policy.
Adoption of **overcoming mechanisms** to enhance data sharing

2. Responsible Team

Design an **action plan**
State **resources** and a feasible **timeline**

3. Raise Awareness

Provide training and **assistance** to researchers.
Definition of **skills** and a **training programme**

4. Data Infrastructure

Identify and describe **data storage** and architecture.
Provision of **tools** to make data FAIR.
Research outcomes should be deposited in **trustworthy** repos.

5. Good Practices

Establish responsible **RDM** practices.
Define FAIR for **implementation**.
Creation of standard institutional template for **DMP**

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Guidelines: 10 Steps

6. Openness

Determine the level of **openness**, **transparency and re-usability** of research outputs, including **licensing**, **provenance** and mechanisms for **data protection**

7. Standards

Technical decisions must be adopted regarding **persistent IDs** and **metadata schemas** for accessibility and interoperability. Include a technical analysis of **domain-specific standards**

8. Incentivize

Devise **credit** and **reward** mechanisms to encourage **researchers** to apply the FAIR data policy

9. Implement

1. Write the policy
2. Submit for approval
3. Disseminate

10. Assess

Provide mechanisms for **FAIR data assessment** within the institution. **Re-align and consolidate** with funders.

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THANK YOU!



Improving Health Research in EU through Health Data
WP6 - Sustainability, Economic Impact
and Digital Single Market
SRDC - A. Anil Sinaci, PhD

Kick-off Meeting - General Assembly
28-29 Jan 2020 - Madrid (Spain)

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