Landscape Analysis – Initial Findings from FAIR4Health Project

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

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Outline

1. The FAIR4Health Project
2. The FAIRification workflow
3. Guidelines for HRPOs to implement a FAIR data policy
Improving Health Research in EU through FAIR data

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 €

www.fair4health.eu @FAIR4Health
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.
Datasets

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

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 824666
FAIR4Health Vision

Open Community

Health Research Institutions
FAIRification workflow

1. RAW → Raw data analysis
2. Raw data analysis → Curation and validation
3. Curation and validation → Anonymisation
4. Anonymisation → Semantic modeling
5. Semantic modeling → Make data linkable
6. Make data linkable → License attribution
7. License attribution → Data versioning
8. Data versioning → Metadata aggregation
9. Metadata aggregation → Archiving
10. Archiving → FAIR
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.
THANK YOU!