FAIR4Health platform: a distributed Learning Health System FAIR-based

GO FAIR PHT Implementation Network German Chapter

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Outline

❖ Call: SwafS-04-2018 (“Science with and for the Society”) in H2020

❖ Use of FAIR data in Health

❖ FAIR4Health Project:
  ➢ Consortium
  ➢ Objectives
  ➢ Implementation
  ➢ Pathfinder use cases
  ➢ Technological platform
  ➢ Open Community

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 824666
Call: SwafS-04-2018

Encouraging the re-use of research data generated by publically funded research projects

Specific Challenge:
All research builds on former work and depends on scientists’ possibilities to access and share scientific information. In the context of Open Science and Responsible Research and Innovation the European Commission therefore strongly supports the optimal open access to and re-use of research data (considering e.g. robust opt-outs). As a concrete action the EC has extended the Open Research Data Pilot to cover all areas of Horizon 2020 (as of the 2017 Work Programme). This will result in more data becoming available for re-use. However, it is necessary to adopt further actions to reach the Commission’s overall objective of findable, accessible, interoperable and re-usable (FAIR) data by 2020.

SwafS-04-2018: Encouraging the re-use of research data generated by publically funded research projects


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Encouraging the re-use of research data generated by publically funded research projects

Scope:
1. To support the FAIRification of data, stressing on data quality (certification), their interoperability and reproducibility of research
2. To generate pathfinder use cases to demonstrate how data sharing and re-use can generate a groundbreaking innovative product, service, or treatment
3. To generate a prototype of such innovative product, service, or treatment
4. To include at least 10 different EU countries in the consortium

SwafS-04-2018: Encouraging the re-use of research data generated by publically funded research projects

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Expected impacts:

1. To increase the visibility of the Commission’s open FAIR data policy through dedicated communication activities, and networking of relevant actors including industry.

2. To generate a beneficial impact for science, the economy and society by means of:
   a. Increasing the reproducibility of research.
   b. Cross-fertilisation of interdisciplinary research.
   c. Boosting citizen science.
   d. Generating added value for innovative companies (including SMEs and start-ups) in the EU DSM.

Key Performance Indicators:

1. Increase in FAIR data in those domains identified by the beneficiaries for action.
2. Contribution of the pathfinder case studies to innovative data sharing and re-use.
Example: problems with closed data

- In June 2016 a Tesla S in autopilot mode hits a semitrailer truck
- Neither autopilot nor automatic braking system nor the "driver" applied the brake
- The Road Safety Authority then investigated this and other accidents

Result:

5.4 Crash rates. ODI analyzed mileage and airbag deployment data supplied by Tesla for all MY 2014 through 2016 Model S and 2016 Model X vehicles equipped with the Autopilot Technology Package, either installed in the vehicle when sold or through an OTA update, to calculate crash rates by miles travelled prior to\textsuperscript{21} and after Autopilot installation.\textsuperscript{22} Figure 11 shows the rates calculated by ODI for airbag deployment crashes in the subject Tesla vehicles before and after Autosteer installation. The data show that the Tesla vehicles crash rate dropped by almost 40 percent after Autosteer installation.
News from yesterday

- A company called Quality Control Systems Corporation wanted to know on which data and calculations the alleged security improvement was based
- The Road Safety Authority refused to release the information
- QCS sued and won. Result of the recalculation:
  - Only 5,714 of 43,781 vehicles showed when Autosteer was installed and how much was driven before and after the installation
  - In this group, a **59 percent increase** in airbag deployments is evident
  - Alleged accident reduction was gross miscalculation
Use of FAIR data in Health

Corpas et al. (2018)

PubMed search of FAIR data in health (8.2.2019)

Rare diseases (active IN)
PHT (preparatory IN)
Metabolomics (preparatory IN)
The FAIR4Health Project
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

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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.

**SO 1.** To design and implement an effective outreach strategy at EU level

**SO 2.** To produce a set of guidelines to set the foundations for a FAIR data certification roadmap

**SO 3.** To develop and validate an intuitive, user-centered FAIR4Health platform and FAIR4Health agents

**SO 4.** To demonstrate the potential impact in health research and health outcomes
Implementation

WP1 Coordination and Management

WP2 Analysis for FAIR Implementation

WP3 Specifications and Protocols

WP4 FAIR4Health Tech. Development

WP5 Use cases design and demonstration

WP6 Sustainability and economic impact

WP7 Dissemination and Outreach Strategy
Pathfinder Use Cases

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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**Technological Platform**

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<thead>
<tr>
<th>FAIR4Health Agents</th>
<th>User Interface</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication Interface with FAIR4Health Platform</td>
<td></td>
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<tr>
<td>PPDDM Agent</td>
<td></td>
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<td>Curation, Normalization and Mapping</td>
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<tr>
<td>ETL</td>
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## Technological Platform

### FAIR4Health Platform

<table>
<thead>
<tr>
<th>Comm. Interface PPDDM services</th>
<th>Security Layer for P2P Comm.</th>
<th>Actionable PPDDM repository</th>
<th>User Interface</th>
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</thead>
<tbody>
<tr>
<td>PPDDM Manager</td>
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<td>Federated Query Manager</td>
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<tr>
<td>Comm. Interface Agents</td>
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**FAIR4Health Platform**

[Image of FAIR4Health Platform diagram]

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