

FAIR4Health project: Improving Health Research in EU through FAIR Data



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Santiago de Compostela

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Outline

- ❖ Call: SwafS-04-2018
- ❖ Use of FAIR data in Health
- ❖ FAIR4Health Project:

- Consortium
- Objectives
- Implementation
- Pathfinder use cases
- Technological platform
- Open Community

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Call: SwafS-04-2018

TOPIC: 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
<http://ec.europa.eu/research/participants/portal/desktop/en/opportunities/h2020/topics/swafs-04-2018.html>

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Call: SwafS-04-2018

TOPIC: 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

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Call: SwafS-04-2018

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

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.

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Use of FAIR data in Health



Corpas et al. (2018)

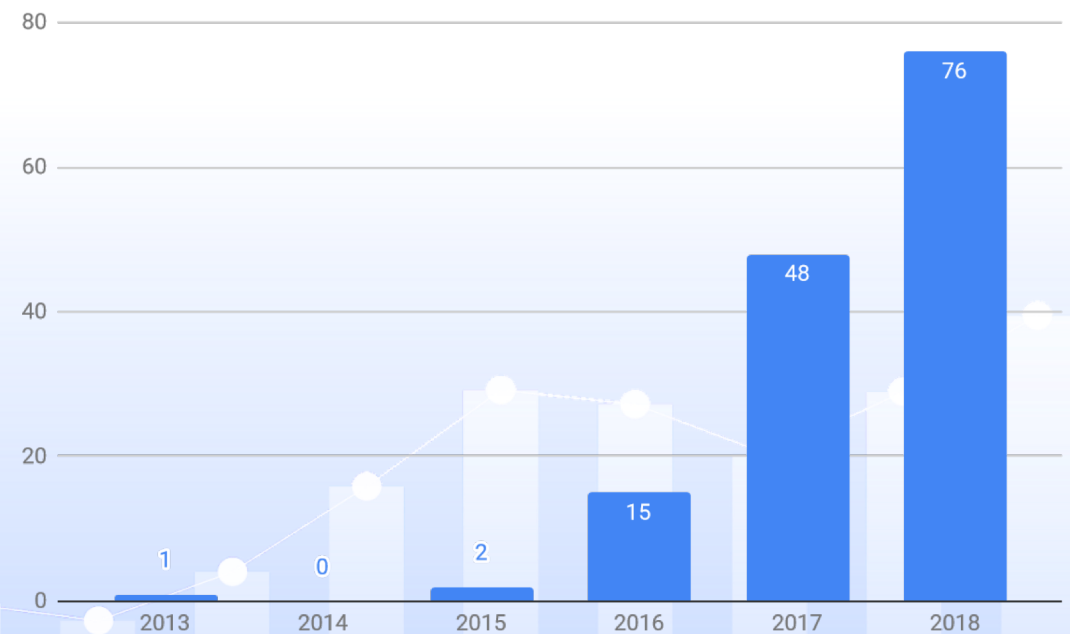


Rare diseases (active IN)
PHT (preparatory IN)
Metabolomics (preparatory IN)

data for better health

A Belgian federal government initiative

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PubMed search of FAIR data in health (8.2.2019)



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FAIR Guiding Principles

(F)INDABLE

- F1. (Meta)data are assigned a globally unique and persistent identifier
- F2. Data are described with rich metadata (defined by R1 below)
- F3. Metadata clearly and explicitly include the identifier of the data they describe
- F4. (Meta)data are registered or indexed in a searchable resource

(A)CCESSIBLE

- A1. (Meta)data are retrievable by their identifier using a standardised communications protocol
 - A1.1 The protocol is open, free, and universally implementable
 - A1.2 The protocol allows for an authentication and authorisation procedure, where necessary
- A2. Metadata are accessible, even when the data are no longer available

(I)NTEROPERABLE

- I1. (Meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
- I2. (Meta)data use vocabularies that follow FAIR principles
- I3. (Meta)data include qualified references to other (meta)data

(R)EUSABLE

- R1. Meta(data) are richly described with a plurality of accurate and relevant attributes
 - R1.1. (Meta)data are released with a clear and accessible data usage license
 - R1.2. (Meta)data are associated with detailed provenance
 - R1.3. (Meta)data meet domain-relevant community standards

Wilkinson, M. D., et al. (2016). The FAIR Guiding Principles for scientific data management and stewardship. *Scientific data*, 3

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FAIR4Health

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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**

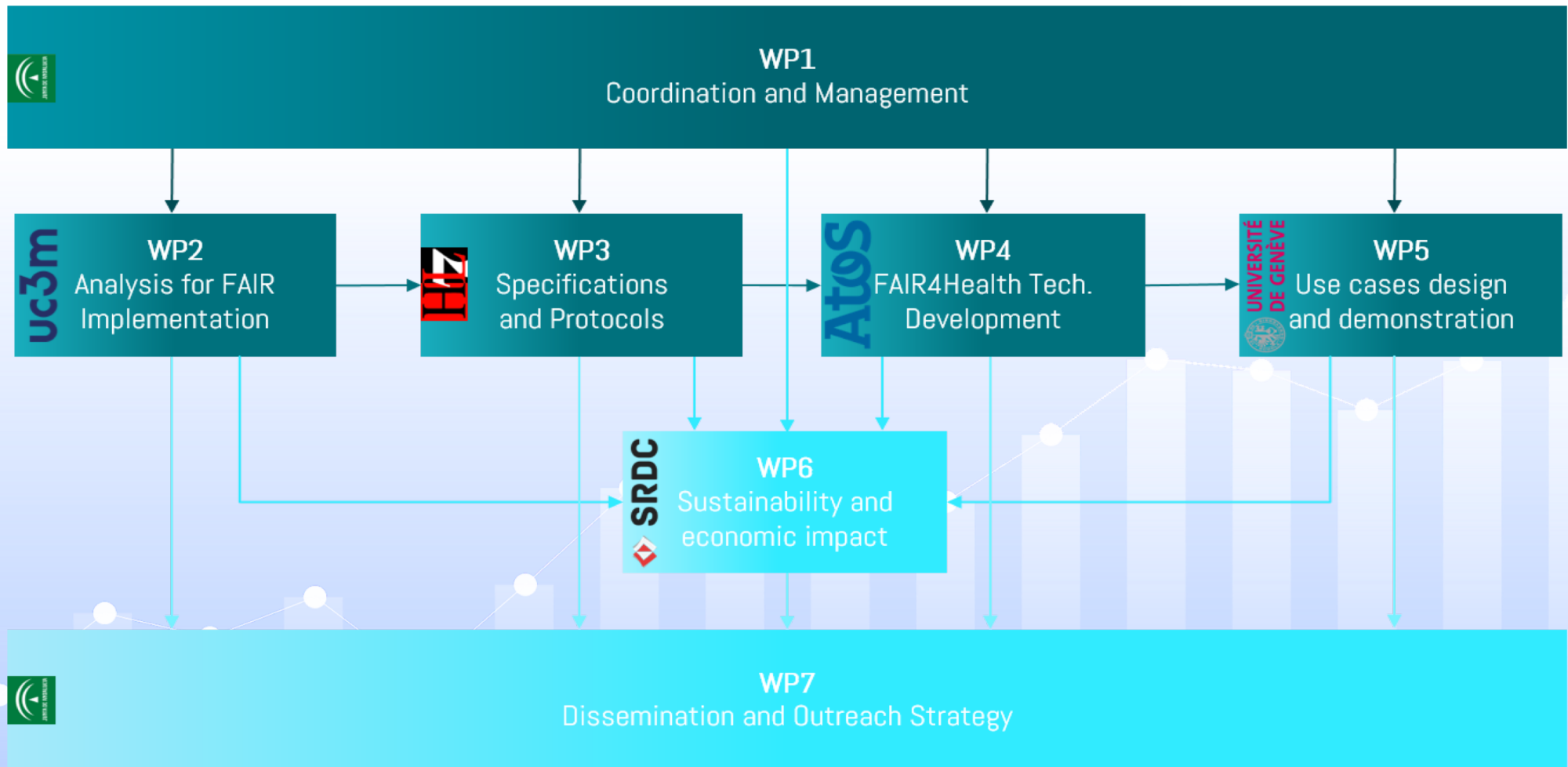
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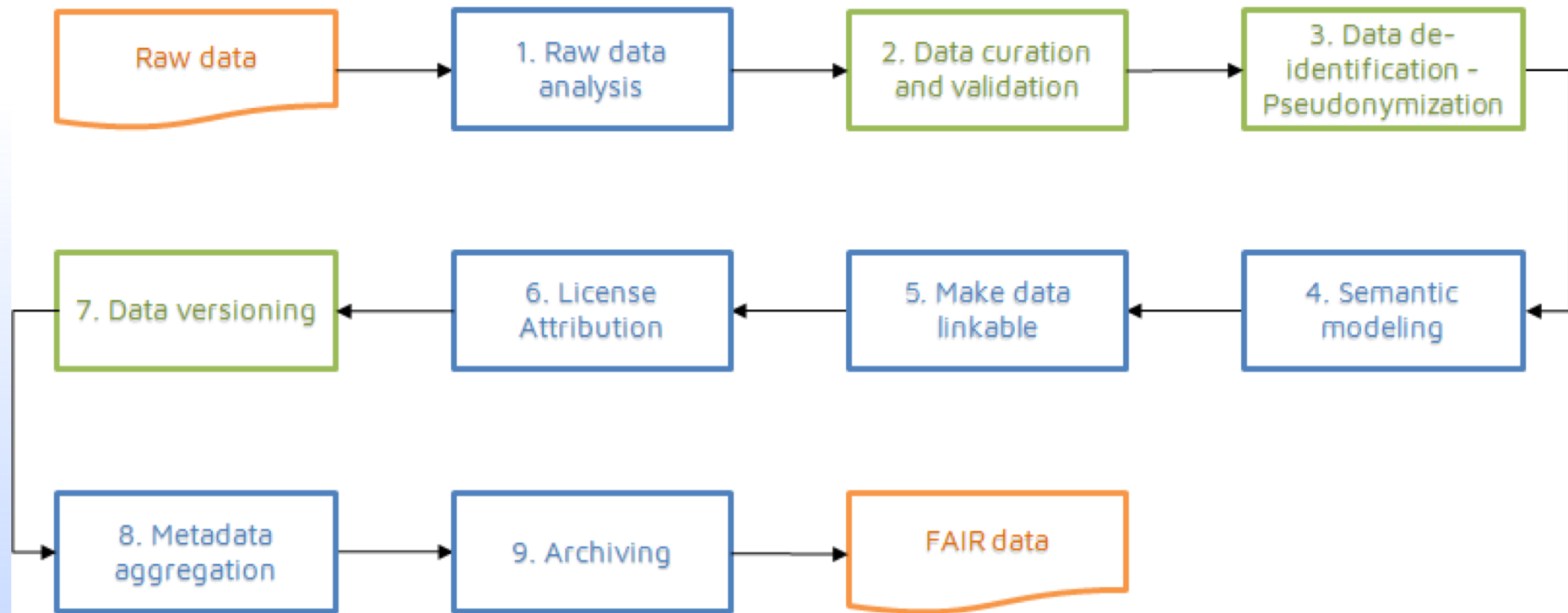
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Implementation



FAIRificación process




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Data sets I

Name	The EpiChron Cohort 
Owner	Instituto Aragonés de Ciencias de la Salud (IACS)
Funding Source	Institute of Health Carlos III for Strategic Actions in Health (Grant Number PI11/1126), the Program INTERREG V-A Spain-France-Andorra of the European Commission (POCTEFA) and private funds.
Size	1.3 million inhabitants approx.

Name	SHELTER 
Owner	Università Cattolica del Sacro Cuore (UCSC)
Funding Source	7 th Framework Programme of the EU
Size	4156 nursing home residents followed for 1 year (Follow up at 6 and 12 months)

Name	DPIData 
Owner	Hôpitaux Universitaires de Genève (UNIGE)
Funding Source	Public funding for healthcare delivery, not for research
Size	1.3 Mill. patients, 90 Mill. encounters, 40 Mill. order entries, 400 Mill. acts scheduled, 120 Mill. lab results, 30 Mill. documents, 200 Mill. structured clinical facts.

Name	IBENC 
Owner	Università Cattolica del Sacro Cuore (UCSC)
Funding Source	7 th Framework Programme of the EU
Size	2884 home care clients followed for 1 year


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Data sets II

Name	FRAILSURVEY	
Owner	Porto4Ageing / Elisio Costa (UPorto)	
Funding Source	Scale AHA - Support to scaling up of innovations in Active and Healthy Ageing. European Commission	
Size	34 x 1500 + 39 x 500	

Name	SPRINTT	
Owner	Università Cattolica del Sacro Cuore (UCSC)	
Funding Source	Innovative Medicine Initiative (IMI)	
Size	1500 older adults followed for 1 year	

Name	Diraya AE HUVR	
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.	

Name	SmokeFreeBrain	
Owner	Institute for Pulmonary Diseases of Vojvodine (IPBV)	
Funding Source	SmokeFreeBrain project (GA 681120), H2020, European Commission	
Size	60 patients x 53 observations with follow-up until 6 months.	

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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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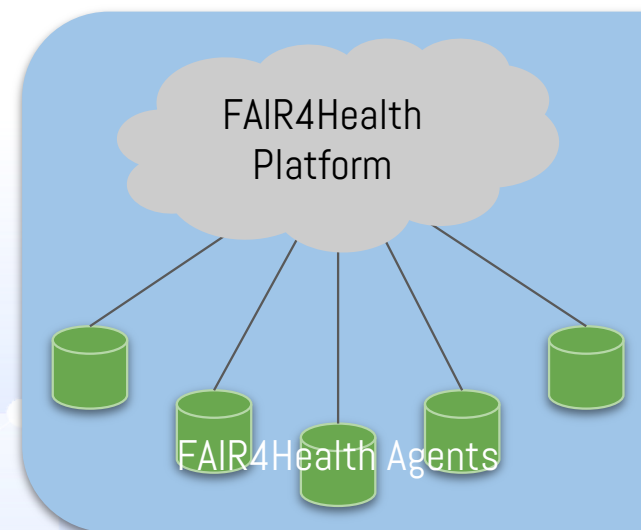


Technological Platform



FAIR4Health Agents

Communication Interface with FAIR4Health Platform	User Interface
PPDDM Agent	
Curation, Normalization and Mapping	
ETL	



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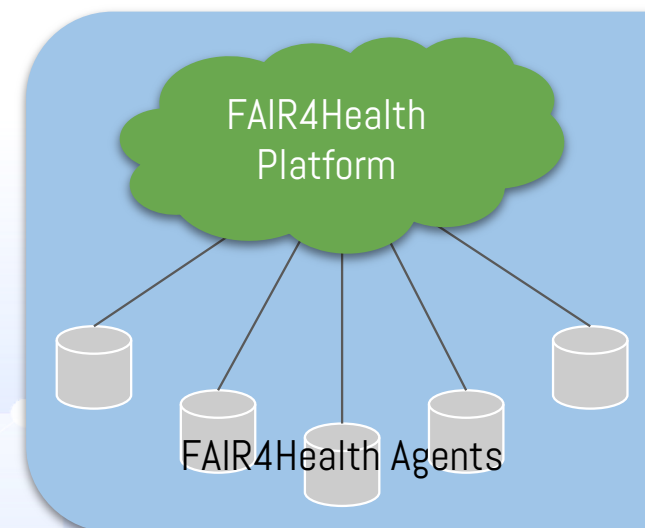


Technological Platform



FAIR4Health Platform

Comm. Interface PPDDM services	Security Layer for P2P Comm.	Actionable PPDDM repository	User Interface
PPDDM Manager			
Federated Query Manager			
Comm. Interface Agents			



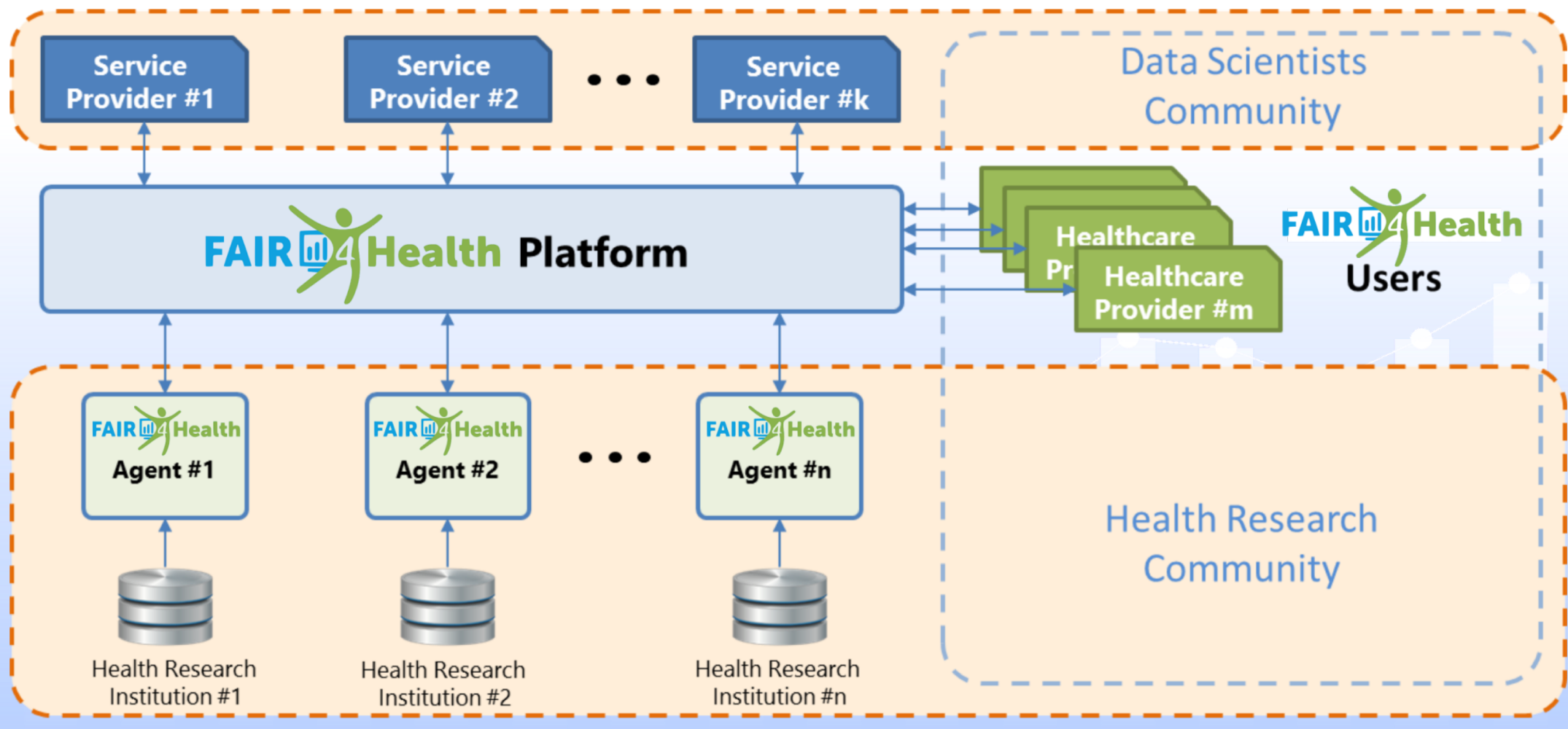
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FAIR4Health Community



Relevant links:



<https://www.fair4health.eu/en/contact>

<https://www.fair4health.eu/en/newsletter>

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MUITO
OBRIGADO!

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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www.FAIR4Health.eu

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