

IMI2 Project 802750 - FAIRplus  
FAIRification of IMI and EFPIA data

## **WP4 – Communication and outreach to FAIR data user community**

### **D4.4 FAIRplus Policy Maker Engagement Strategy**

Lead contributor	Alexander Duyndam (13 - Lygature) alexander.duyndam@lygature.org
Other contributors	Andrew Smith (1 - EMBL - ELIXIR Hub) andrew.smith@elixir-europe.org
	Jan-Willem Boiten (13 - Lygature) janwillem.boiten@lygature.org

Due date	31 March 2020
Delivery date	27 March 2020
Deliverable type	R
Dissemination level	PU

Description of Work	Version	Date
	V1.0	27 March 2020

## Document History

Version	Date	Description
V0.1	10 Feb 2020	First Draft Alexander Duyndam
V0.5	26-Feb-2020	Processed comments co-authors
V0.9	10 Mar 2020	Draft for final review
V1.0	27 Mar 2020	Final Version

## Table of Contents

<b>Document History</b>	<b>1</b>
<b>Executive Summary</b>	<b>2</b>
<b>Engagement Strategy</b>	<b>2</b>
#1: Our Priorities	3
#2: Stakeholder mapping	3
#3: Connection with EU Policies	6
#4: Possible campaigns	7
#5: Planning	7

## Executive Summary

The concept of Findable, Accessible, Interoperable and Re-usable (FAIR) data has become widely disseminated since it was first put forward by Wilkinson et. al. in 2016. A recent example of this is the Beijing Declaration of Research Data from the International Science Council.<sup>1</sup>

The FAIRplus project has the aim to improve the FAIRness of at least 20 IMI projects, as well as of internal datasets from EFPIA companies. FAIRification opens up the data for re-use by making them findable and machine-readable under clear governance rules about access to sometimes sensitive data.

Task 4.4 of the FAIRplus project aims to engage with key policy makers in national and European organisations across all relevant sectors to help ensure a conducive environment for the FAIRification of industry and IMI data in general and help academic participants to provide a stable foundation for the long-term storage of these data.

## Engagement Strategy

The following steps have been followed in the development of the engagement strategy for policy makers:

1. Define the advocacy goals and our priorities for the project.
2. Map the relevant stakeholders: both in terms of organisations and individuals.
3. Explore how FAIR data connects with current and future policies of key stakeholders. Identify the arena: where are the important decisions being discussed and decided?
4. Ideate possible campaigns that would advance our advocacy goals, develop convincing key messages for the different key stakeholders.
5. Planning: establish an activity calendar to ensure a concerted effort to engage policy makers.

---

<sup>1</sup><https://www.codata.org/uploads/Beijing%20Declaration-19-11-07-FINAL.pdf>

## #1: Our Priorities

FAIR has become an established concept. Although the concept is clear, its application in practice is perhaps less straightforward. We see many initiatives, such as FAIRplus, that have taken this up. The current status of the FAIR-concept is that in some cases dedicated expertise is needed but in general the tools and teaching materials to make a dataset FAIR are available. With FAIR we seem to enter the scale-up phase where the focus will be on education and establishing common practices, i.e. a compliance framework.

It seems most effective to focus our efforts on the FAIRification of prospective data. The uptake of FAIRification would be greatly helped if we achieve the following:

- A. Policy change: Fixed percentage, say 5%, of any research funding should be reserved to make any data from the research FAIR in a sustainable fashion. The same point is made in a recent Nature editorial by Barend Mons.<sup>2</sup>
- B. Policy change: Make the data management plan part of the evaluation of a project in the proposal phase.
- C. Policy execution: Enforce at the end of large IMI research projects that activities described in the data management plan have resulted in the desired FAIRness of the data.
- D. Additional funding: FAIRplus will only convert 20% of the IMI data at best. Further project funding is needed to unlock the rest of the data, and discussion is needed on finding the most efficient way of enabling current FAIRplus partners to support multiple projects in the future.
- E. Capacity building. An estimate has been published, see reference 2, that 500,000 data stewards are necessary in Europe to support researchers.

## #2: Stakeholder mapping

Many organisations are responsible for creating and implementing policies and decisions relating to FAIR, such as data management policies or funding models that pertain to the sustainability of research data. We want to ensure that we will target the right individuals in the right organisations to get across the key messages from the FAIRPlus project.

The key stakeholders are categorised into the following groups:

---

<sup>2</sup><https://www.nature.com/articles/d41586-020-00505-7>

## Funding agencies

Dual role: 1) funders of research that generates data, 2) issuer of guidelines and policies on data management)

- [IMI](#): Executive Director, Scientific Project Manager for FAIRplus, Adviser to the Executive Director, Member States Representatives Group and Scientific Advisory Board.
- European Commission's DG RTD (Research and Innovation) and DG CONNECT - especially those units responsible for open science and planning for data management plans in Horizon Europe
- US National Institute of Health ([NIH](#)): Data Commons Project + Strategic Plan for Data Science (2018).<sup>3</sup>
- Charitable foundations ([Bill & Melinda Gates Foundation](#), [Chan Zuckerberg Initiative](#), [LifeArc](#) and [Wellcome Trust](#))
- National funders, in particular those represented through [ScienceEurope](#)

## Industry

- [EFPIA](#): Director General, Head of Policy
- Senior decision makers on data management in EFPIA member companies
- [EIT Health](#): Director of Strategy - ad interim
- [Pistoia Alliance](#), a not-for-profit collaboration of life sciences companies, vendors, publishers and academic groups working to lower barriers to innovation in life science and healthcare R&D through pre-competitive collaboration
- Other associations like [Medtech Europe](#) which represents the medtech industry in Europe
- European Federation [EUROM](#) represents the interests of manufacturers in the European precision mechanical and optical industries - ensuring that data is 'FAIR at source'
- IT providers which deliver computing and storage facilities for FAIR data management. Commercial cloud computing services such as Google Cloud, Amazon Web Services and Microsoft Azure.

## Patient organisations

---

<sup>3</sup>[https://datascience.nih.gov/sites/default/files/NIH\\_Strategic\\_Plan\\_for\\_Data\\_Science\\_Final\\_508.pdf](https://datascience.nih.gov/sites/default/files/NIH_Strategic_Plan_for_Data_Science_Final_508.pdf)

- European Patients Forum: <https://www.eu-patient.eu/>. Contact: coordinator of the IMI-funded PARADIGM project.
- [Data Saves Lives](#) initiative together with [The European Institute for Innovation through Health Data \(i~HD\)](#).

## Publishers

- [Elsevier](#), [Springer Nature](#): Ethics and data management statements. Elsevier published in November 2019 a white paper entitled '[Potential of FAIR data for pharmaceutical R&D](#)'.
- Society publishing houses like [ACS Publications](#) (American Chemical Society)
- [PLOS](#) (Public Library Of Science)

## FAIR and Open Science Initiatives

Of the extensive number of FAIR-initiatives, identified by the project<sup>4</sup>, several also employ public affairs activities. It is crucial for us to align and make sure we speak with one voice. Working jointly with these other FAIR-related initiatives, with coordinated messaging, helps to ensure the message can go further. We are certain the following initiatives engage with policy makers:

- [OpenAIRE](#) Open AIRE is a large scale initiative set out to engage with all stakeholders for an effective Open Science implementation
- [GO-FAIR](#) GO FAIR is a bottom-up, stakeholder-driven and self-governed initiative that aims to implement the FAIR data principles
- [FAIRsFAIR](#) Another EU funded project that recently provided an analysis of European funder policies and their compliance with FAIR<sup>5</sup>
- [Research Data Alliance](#) RDA builds the social and technical bridges that enable open sharing and re-use of data
- [European Open Science Cloud](#) EOSC is an initiative by the European Commission to build a competitive data and knowledge economy in Europe
- [cOAlition S](#) Plan S is an initiative for Open Access publishing

<sup>4</sup><https://docs.google.com/document/d/1LwFJBqU1F3JgWrfQbZEjg9ivi6jpaYa-FZG-huR2dPg/edit#heading=h.v6artwgtbe3k>

<sup>5</sup><https://sparceurope.org/highlights-of-an-analysis-of-european-funder-policies-and-their-compliance-with-fair/>

### #3: Connection with EU Policies

Current EU policies provide many touchpoints with FAIR. A first, not exhaustive, exploration gives:

- Horizon Europe: the upcoming research program of the European Commission, due to start in 2021. This will replace the current Horizon2020 and IMI2-funding. Currently consultations are underway about the budget and scope of this new program.<sup>6</sup> As and when appropriate, FAIRplus partners will seek to engage through for example submitting consultation responses or position papers or meeting staff responsible for developing plans and proposals.
- EU Open Science.<sup>7</sup>
- FAIR data is a crucial boundary condition for any artificial intelligence applications. The European Commission has put forward a European approach to artificial intelligence.<sup>8</sup>
- EU Beat Cancer Strategy.<sup>9</sup>
- Six preparatory actions for Horizon Europe.<sup>10</sup>
- EU Digital Single Market Strategy<sup>11</sup>: part of this is the 'Towards a common European data space'.<sup>12</sup>
- Panel for the Future of Science and Technology (STOA).<sup>13</sup>
- A European strategy for data.<sup>14</sup>

A more extensive analysis of the different policies and future scenarios is necessary before engaging with policy makers. A further scan of opportunities to increase our exposure or impact decision making will help in refining our timing of activities. Currently, for example, the European Commission holds two public consultations on the European Data Strategy and Artificial Intelligence.

### #4: Possible campaigns

A further exploration of the interests and positions of the different stakeholders is necessary in order to develop a value proposition of FAIR for them. These value propositions need to be translated into key messages and

<sup>6</sup>[https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme\\_en](https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme_en)

<sup>7</sup><https://ec.europa.eu/research/openscience/index.cfm>

<sup>8</sup><https://ec.europa.eu/digital-single-market/en/artificial-intelligence>

<sup>9</sup>[https://ec.europa.eu/health/non\\_communicable\\_diseases/cancer\\_en](https://ec.europa.eu/health/non_communicable_diseases/cancer_en)

<sup>10</sup><https://ec.europa.eu/digital-single-market/en/news/launch-six-european-initiatives-potential-transformational-impact-society-and-economy>

<sup>11</sup><https://ec.europa.eu/digital-single-market/en/policies/shaping-digital-single-market>

<sup>12</sup><https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52018DC0232&from=EN>

<sup>13</sup><https://www.europarl.europa.eu/stoa/en/home/highlights>

<sup>14</sup>[https://ec.europa.eu/info/sites/info/files/communication-european-strategy-data-19feb2020\\_en.pdf](https://ec.europa.eu/info/sites/info/files/communication-european-strategy-data-19feb2020_en.pdf)

talking points so that we are able to advance our cause in meetings and communication materials. The values of FAIR-document that was produced by the consortium provides an excellent starting point for this.<sup>15</sup>

A brainstorm during the break-out session at the General Assembly in January 2020 provided the following campaign-ideas:

1. An ideal platform to engage with policy makers would be an event 'Toward a FAIR future' in Brussels aimed at policy makers.
2. In order to prepare for this event, both in terms of relation building and exploring where interests overlap or collide we propose one or more face-to-face meetings with key people in the Brussels arena.
3. Separately it is clear the scientific publishers are very aware of the value of data as it provides a possible extension/renewal of their business model. The suggested action would be to reach out to Springer Nature, Elsevier and a publisher connected with a scientific society.

## #5: Planning

- Q2&Q3: Face to face-meetings with 5 key stakeholders. Present should be WP4-lead, expert on FAIR and public affairs support from ELIXIR or Lygature.
- Q4: A policy maker event in the fourth quarter of 2020 in Brussels, preferably co-located with the FAIRPlus mid-term review.

We established the following longlist of potential candidates for face to face-meetings:

#	Persons <sup>16</sup>	Organisation	Remarks	Meeting scheduled
1		MEP	Member STOA panel: Future of Science & Technology	

<sup>15</sup>[https://docs.google.com/document/d/1UTbN\\_mN4gSFZufCXD6xkKlaqaLtuOPZZg43BbNKKu30/edit](https://docs.google.com/document/d/1UTbN_mN4gSFZufCXD6xkKlaqaLtuOPZZg43BbNKKu30/edit)

<sup>16</sup> The actual names of the persons have been identified but removed from the public document for privacy reasons



2	Executive Director, Scientific Project Manager, Adviser to the Executive Director	IMI		
3		Head of Unit Open Science (DG R&I)		
4	Head of Policy	EFPIA		
5	Director Digital Health	Medtech Europe		
6	Head of Open Research	Wellcome Trust	Charity	
7	Vice-President of Research Data Management Solutions	Elsevier		
8	Data Saves Lives Coordinator	Data Save Lives	Patient Organisation	
9	President	Science Europe	Funder	
10	Director for Science, Technology and Innovation	OECD	US Citizen	