

FAIR Health

D7.2. Report on the FAIR4Health open community development

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List of acronyms

F2F	Face to Face
FAIR	Findable, Accessible, Interoperable and Reusable
ICT	Information and Communication Technologies
OSF	Open Science Framework
PE2020	Public Engagement Innovations for Horizon 2020
RDA	Research Data Alliance

1. Executive Summary

This report will outline the methods that will be employed in **fostering open community engagement** and is a living document which will be periodically revised to include the latest outputs and engagements throughout the life of the project. The methodology and rationale for employing the methods will be explored, where public engagement studies, chiefly the PE2020, are the primary source of information. Any new advancements and/or deviations from the original agreed methods will also be documented here.

2. Introduction

2.1. Public engagement strategies

Public engagement (PE) has become a specific field of research that has gained a lot of attention in recent decades with an understanding that embracing and nurturing such methods can have major beneficial effects to research in general. Taking this into account, the following statements define the different levels of engagement:

- ❖ **Debate:** when engaging with the public there is flow of information only in **one direction**. In the present case, this may involve our project producing ideas and results for dissemination with little outside consultation. Although this has its place in the wider research community, FAIR4Health wants to minimise such a form of communication to ensure a collective response to its goals are met. [1]
- ❖ **Dialogue:** in this case there is a flow of information in more than one direction and there is an active interest in learning the views (whether these may be informed from research) of the other side. However, in terms of decision making, no further action is taken and this is purely an exercise in learning. [1]
- ❖ **Deliberation:** in order to take action based on collective reasoning, deliberation must be invoked and which will allow collective action. [1]

Keeping the above definitions in mind, FAIR4Health aims to avoid debate and encourage active participation from target audiences. This introduction will describe the strategies being deployed by FAIR4Health in this context.

2.1.1. PE2020

From Feb 2014 to Jan 2017, the **PE2020** (Public Engagement Innovations for Horizon 2020) project¹ ran as a continuation of the previous **MASIS** (Monitoring Policy and Research Activities on Science in Society in Europe) project with a mission to “identify, analyse and refine innovative public engagement (PE) tools and instruments for dynamic governance in the field of Science in Society (SiS)”. Their WP2 produced deliverable D2.1, “A refined

¹ <https://pe2020.eu/>

typology of PE tools and instruments” and which FAIR4Health is utilising in its bid to explore avenues of engagement with various stakeholders. To this end, PE2020’s D2.1 outlines five distinct modes by which PE should be explored and in the following sections we will summarise each with each of their subcategories. For each category, we show the methods (in bold) that are being employed by FAIR4Health, or those in development, where applicable.

2.1.1.1. Public communication

- ❖ Online communication: **FAIR4Health website; Twitter; Google Docs; YouTube; LinkedIn; Korsakow films; email**
- ❖ Social networking: **Twitter; LinkedIn**
- ❖ Engagement transfers: **health tracking apps**
- ❖ Non-information and communication technology (non-ICT) based communication: **conferences; workshops; peer-reviewed journals**
- ❖ Science education: **workshops; lectures**

2.1.1.2. Public activism

- ❖ Frequency of PE: **increase and sustain PE to maintain interest**
- ❖ Public sensitiveness: **level of engagement with stakeholders directly correlates with level of interest**

2.1.1.3. Public consultation

- ❖ Targeted: **single-disease charities and umbrella groups; researchers**
- ❖ Non-targeted: **non-health/clinical research groups and associations NGOs; patients’ support groups**

2.1.1.4. Public deliberation

- ❖ Deliberative research: **surveys; workshops**
- ❖ Deliberative dialogue: **face-to face engagement, e.g. conferences and workshops**
- ❖ Deliberative decision making: **policy making**

2.1.1.5. Public participation

- ❖ Multiple-engagement: **cross-platform, online and offline presence sustained through course of entire project lifetime**
- ❖ Multiple-partnership: **FAIR4Health is a pan-European project with academic and commercial partners; targeting of stakeholders across the spectrum of health research**
- ❖ Multiple-funding: **n/a**

3. Target areas and stakeholder analysis

3.1. Health and clinical research field

Surveys have been sent out to the health research community across Europe on the subjects of “**Boosting citizen science**” (see 3.4.1.), “**Ethical implications of reusing FAIR data in health research**” and “**Cultural barriers for implementing a FAIR data policy in health research**”. The results of these surveys are all openly available in OSF² under the “Reports” folder.

3.2. Non-clinical research

Lessons can be learnt from the non-clinical research domain too and FAIR4Health will explore any such possibilities. For example, although no patient data may be involved, there are frequently other types of data that have a sensitive nature such as geospatial tracking of individuals and which have had to be treated with care. The **research communities involved** in research of such data may have a common interest in the methodologies used and *vice versa* and engagement with such communities may have value.

3.3. Publishers and peer reviewed publications

Dissemination of outputs and to achieve the wider aims of informing the general public and stakeholders will require FAIR4Health to produce written documents that will undergo peer review. On this basis some possibilities are already being investigated with a call for papers in **Methods of Information in Medicine**³ and other outputs will also be sought.

3.4. General public

Targeting participation of the general public is a key objective of FAIR4Health. As well as enriching and enhancing the research being carried out, engagement of the general public will increase visibility and transparency of the project.

3.4.1. Citizen science [2-4]

In recent years, with increasing computing power and accessibility, there has been a movement to make science more inclusive and open to people not directly involved in a project and beyond, **including lay persons**. Some individuals, whether knowledgeable of the subject matter or not, go beyond having a passing interest in some projects and these people are of particular interest to many scientific projects around the world as well as

² <https://osf.io/ubvsh/>

³ DOI: <https://doi.org/10.1055/s-00035037>

FAIR4Health, and these members of the public have been labelled *citizen scientists*: "a member of the general public who engages in scientific work, often in collaboration with or under the direction of professional scientists and scientific institutions; an amateur scientist"⁴. Muki Haklay, a geographer at University College London, has outlined a taxonomy of involvement, from 'crowdsourced' citizen science, in which lay people contribute data or volunteer computing power, to 'co-created' and 'collegial' research, in which members of the public actively engage in most aspects of a project, or even conduct research on their own. [5]

As a result of this growing trend, many countries have sought to leverage the potential offered by this pool of interested third parties through establishing formalised communities. The following table from Wikipedia⁵ lists some of the national level initiatives to harness citizen science.

Nation or region	Portal
Australia	Australian Citizen Science Association
Australia	Australian Citizen Science Project Finder
Austria	Österreich Forscht
Belgium (Flanders)	Citizen Science Vlaanderen
Canada	Citizen science portal
Denmark	Citizen Science Portalen
France	Open
Germany	Bürger schaffen Wissen
Global	Scistarter
Global	Zooniverse: People-powered research
Ireland	Environmental Protection Agency
Netherlands and Flanders	EOS Wetenschap
Scotland	Citizen Science with TCV.
Spain	Observatorio De La Ciencia Ciudadana
Sweden	Arenas for co-operation through citizen science
Switzerland	Schweiz Forscht
United Kingdom	UK Environment Observation Framework
United States	USA Government Official Website

Active engagement and participation in some or all of these citizen science initiatives by FAIR4Health will be sought, especially since these platforms are well established in many cases.

⁴ <https://daily.zooniverse.org/2014/09/16/citizen-science-in-dictionary/>

⁵ https://en.wikipedia.org/wiki/List_of_citizen_science_projects

3.4.2. Lay persons

As well as engaging with members of the general public that may want to participate in the process of scientific enquiry, it will be necessary to develop methods to engage with those that do not, and which will typically take the form of reports and announcements. The FAIR4Health website will be the primary portal to achieve this as before but active contribution to peer reviewed journals and other publications will also be required.

3.5. Single-disease charities

This will be a targeted approach where single-disease charities will have access to a cohort of individuals (*i.e.* patients) that can be engaged in our wider goals.

3.6. Umbrella groups

As well as single-disease charities, more generalised groups bringing together various single disease and other groups will also be invited to participate. These organisations have an outreach capability which will be invaluable in our stated goals of reaching as many participants as possible.

3.6.1. Association of Medical Research Charities (AMRC UK)

Established in 1987, the Association of Medical Research Charities (AMRC)⁶ is the UK's national membership organisation for health and medical research charities.

3.6.2. European Patients' Forum (EPF)

This is an EU level organisation with a mission to "be the collective influential patient voice in European health and related policies and a driving force to advance patient empowerment and equitable patient access to care in Europe." EPF⁷ has a scope beyond that in the UK alone and therefore adds further engagement opportunities.

3.6.3. Medical Research Council (MRC), UK

Since the MRC⁸ is government funded, it is not a member of the AMRC, and yet is one of the major funding bodies in the UK, and therefore its engagement in the FAIR4Health would be beneficial.

⁶ <https://www.amrc.org.uk/>

⁷ <http://www.eu-patient.eu/>

⁸ <https://mrc.ukri.org/>

3.6.4. National Institutes of Health (NIH), USA

As a non-EU organisation, and one of the major world funding bodies, engagement with the NIH⁹ would dramatically increase the scope of FAIR4Health.

3.6.5. Agency for Medical Research and Development (AMED), Japan

Another non-EU organisation, and which is the major funding body in Japan, engagement with the AMED¹⁰ would also dramatically increase the scope of FAIR4Health.

3.7. Research Data Alliance (RDA)

The Research Data Alliance¹¹ is a global community that was established in 2013 and describes itself thus:

“With more than 8,100 members from 137 countries (March 2019), RDA provides a neutral space where its members can come together through focused global Working and Interest Groups to develop and adopt infrastructure that promotes data-sharing and data-driven research, and accelerate the growth of a cohesive data community that integrates contributors across domain, research, national, geographical and generational boundaries.”¹²

It was formed from a collaboration between European Commission, the United States Government's National Science Foundation and National Institute of Standards and Technology, and the Australian Government's Department of Innovation. Due to the Digital Curation Centre's active participation in RDA and its organisation, FAIR4Health will benefit from the networks that can be accessed through RDA membership and participation.

4. Mode of engagement

4.1. Digital media

4.1.1. Project website

One of the first objectives of FAIR4Health was to create its own project website¹³ and which has now been created. This is a focal point for all FAIR4Health outputs that will be made

⁹ <https://www.nih.gov/>

¹⁰ <https://www.amed.go.jp/en/>

¹¹ <https://www.rd-alliance.org/>

¹² <https://www.rd-alliance.org/about-rda>

¹³ <https://www.fair4health.eu/>

publicly available and also from where surveys and other forms of public input can be accessed. Please see D7.1 and D7.3 for further information.

4.1.2. Korsakow films

A further identified method of engaging the public's attention to FAIR4Health is to produce Korsakow films¹⁴. By interviewing various individuals, both from the general public and those that come from health research, non-linear films can be created to tell a story of the project. Please see D7.3 for further information.

4.2. Active F2F engagement, conferences and workshops

Deliverable 7.4 reports on conferences and workshops where past and future events are described.

5. References

- [1] O Escobar (2012). Public Dialogue and Deliberation: A communication perspective for public engagement practitioners. *Edinburgh Beltane*
- [2] <http://theconversation.com/explainer-what-is-citizen-science-16487>
- [3] <https://www.bbc.co.uk/programmes/articles/4BZZdHm64S051q2lnZ1Nr7p/citizen-science>
- [4] https://en.wikipedia.org/wiki/Citizen_science
- [5] A Irwin (2018). No PhDs needed: how citizen science is transforming research. *Nature* 562:480-82. doi: <https://doi.org/10.1038/d41586-018-07106-5>

¹⁴ <http://korsakow.com/>