



D7.2. Open community engagement strategy

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Document Information

GRANT AGREEMENT NUMBER 824666		ACRONYM: FAIR4Health	
Full title	Improving Health Research in EU through FAIR Data		
Horizon 2020 Call	SwafS-04-2018: Encouraging the re-use of research data generated by publically funded research projects		
Type of action	Research and Innovation Action		
Start Date	1 st December 2018	Duration	36 months
Website	www.fair4health.eu		
Project Officer	Katharina BUSE		
Project Coordinator	Carlos Luis Parra Calderón, Andalusian Health Service (P1–SAS)		
Deliverable	D7.2 Open community engagement strategy		
Work Package	WP7 Strategies to widespread the use of FAIR data in Health research in at EU level		
Date of delivery	Contractual	M36	Actual November 2021
Nature	Report	Dissemination Level	Public
Lead beneficiary	P13-UEDIN		
Responsible Author	Laurence Horton		
e-mail	Laurence.Horton@glasgow.ac.uk	Phone number	
Reviewers	SAS		
Keywords	Community engagement, outreach, FAIR, strategy, citizen science, open community		

Document history

Version	Issue Date	Stage	Changes	Contributor(s)
1.0		Draft		
1.1	31/05/2019	Final		S. Venkataraman
2.0	27/01/2020	Draft	Survey results	S. Venkataraman
2.1	13/02/2020	Review		Celia Alvarez
3.0	29/05/2020	Draft	RDA, FAIR4Health	S. Venkataraman, T.

			membership	Sveinsdottir, Celia Alvarez
4.0	26/06/2020	Draft	Surveys, FAIR4Health membership	S. Venkataraman, T. Sveinsdottir, Ronald Cornet, Catherine Chronaki, Celia Alvarez, Carlos Caverro, Anil Sinaci, Alicia Martínez-García
5.0	01/09/2021	Final	Update	S. Venkataraman, Celia Alvarez
6.0	11/11/2021	Update M36	Update M36	S. Venkataraman, Celia Alvarez, Laurence Horton
7.0	18/11/2021	Update M36	Update M36	Celia Alvarez, Laurence Horton

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List of acronyms

AMED	Agency for Medical Research and Development
AMRC	Association of Medical Research Charities
BoF	Birds-of-a-feather group
EFMI	European Federation for Medical Informatics
EJP RD	European Joint Programme on Rare Diseases
EOSC	European Open Science Cloud
EPF	European Patients' Forum
F2F	Face to Face
FAIR	Findable, Accessible, Interoperable and Reusable
HRPO	Health Research Performing Organizations
ICT	Information and Communication Technologies
IG	Interest group
KPI	Key Performance Indicator
MASIS	Monitoring Policy and Research Activities on Science in Society in Europe
MRC	Medical Research Council
NIH	National Institutes of Health
OSF	Open Science Framework
PE2020	Public Engagement Innovations for Horizon 2020
PPDDM	Privacy-Preserving Distributed Data Mining
RDA	Research Data Alliance
RDM	Research data management
RFO	Research Funding Organisation
RPO	Research Performing Organisation
WG	Working group

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, which will activate 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

¹ <https://pe2020.eu/>

in the field of Science in Society (SiS)". Their WP2 produced deliverable D2.1, "A refined 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. In the following sections, we summarise each with each of their subcategories. For each category, we show the methods (in bold) employed by FAIR4Health, or those in development, as 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**

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; standards groups**
- ❖ Non-targeted: **non-health/clinical research groups and associations?**

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"**.

3.1.1. Survey results (see also D2.3.3.)

Initial results from the surveys **"Boosting citizen science"**, **"Ethical implications of reusing FAIR data in health research"** and **"Cultural barriers for implementing a FAIR data policy in health research"** have now been collated. The results of these surveys are all openly available in OSF² under the "Reports" folder. The following charts show results from each, where those that have scales from 1-5 refer to how strongly the respondent interprets the statement presented, from strongly disagree (1) to strongly agree (5).

² <https://osf.io/ubvsh/>

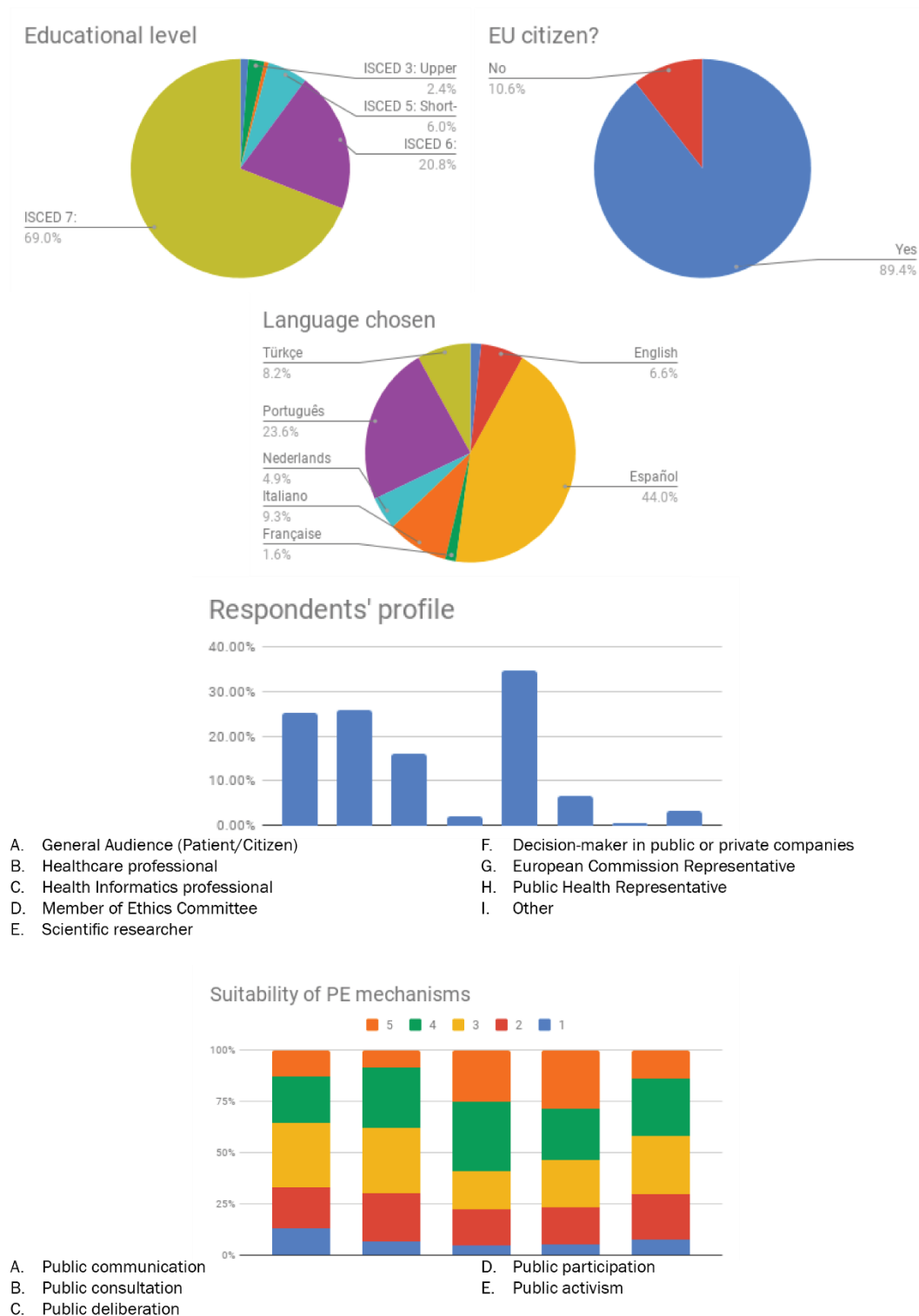
3.1.1.1. Boosting citizen science ($n = 182$)

Figure 1 Results from "Citizen Science" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.

3.1.1.2. Ethical implications of reusing FAIR data in health Research ($n = 170$)

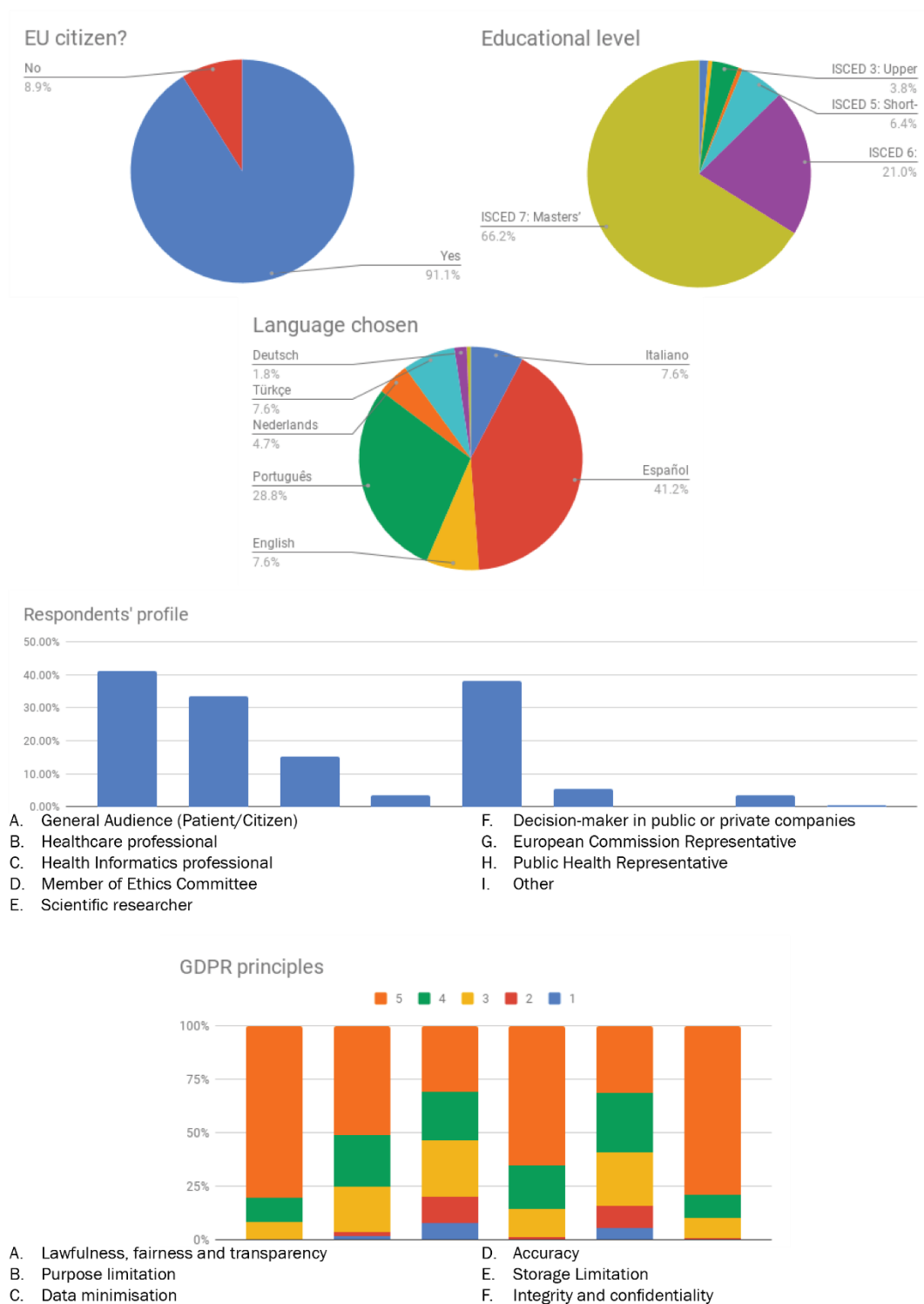


Figure 2 Results from "Ethics" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.



Figure 2 (cont'd) Results from "Ethics" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.

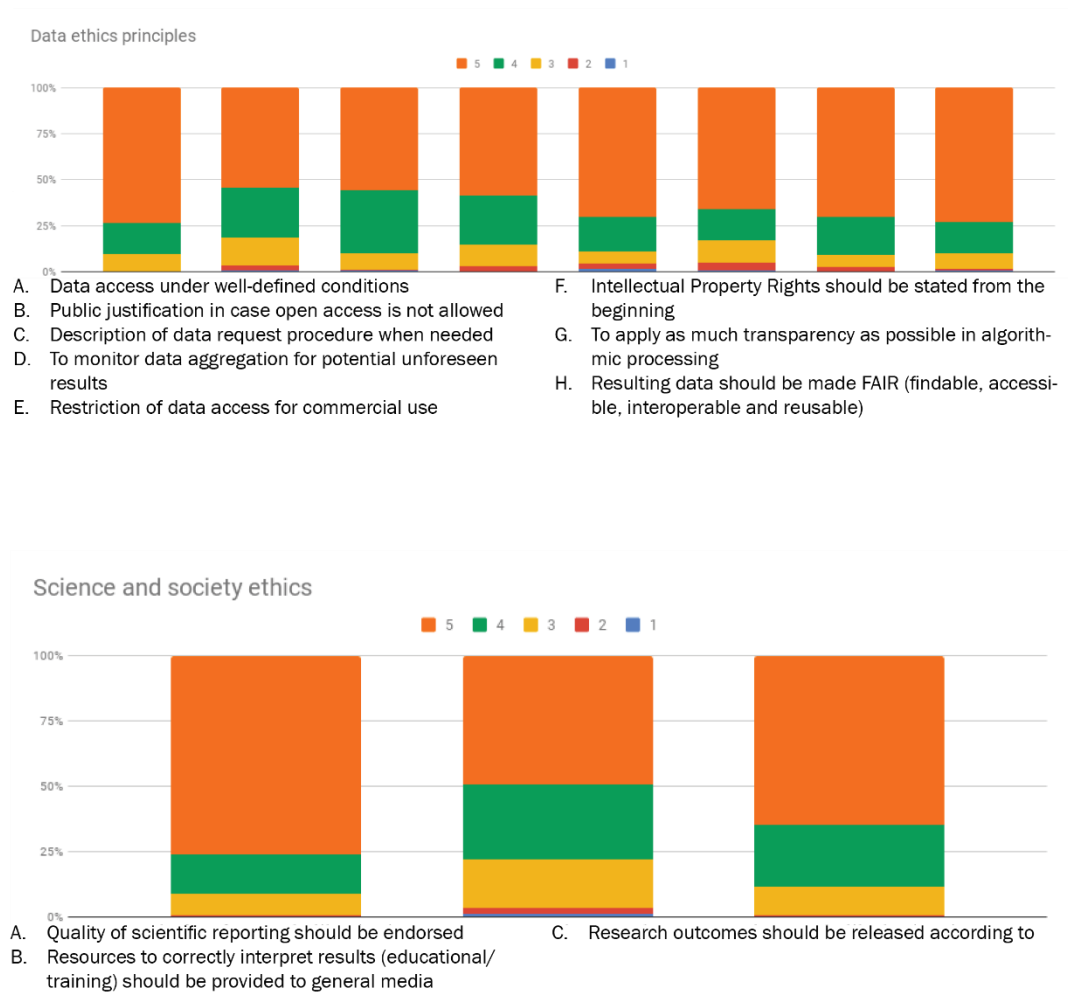


Figure 2 (cont'd) Results from "Ethics" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.

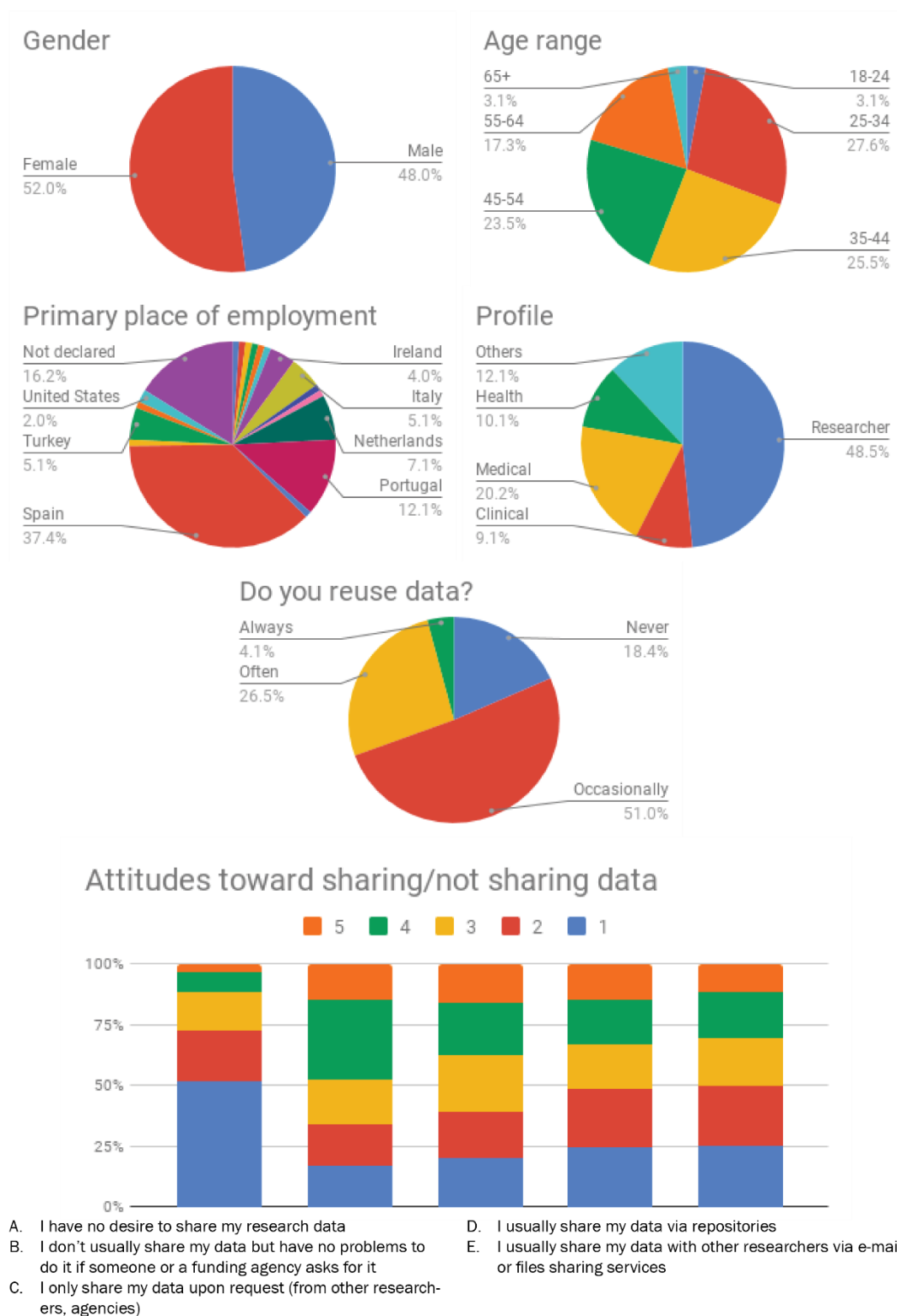
3.1.1.3. Cultural barriers for implementing a FAIR data policy in health research ($n = 99$)

Figure 3 Results from "Cultural Barriers" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.



Figure 3 (cont'd) Results from "Cultural Barriers" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.

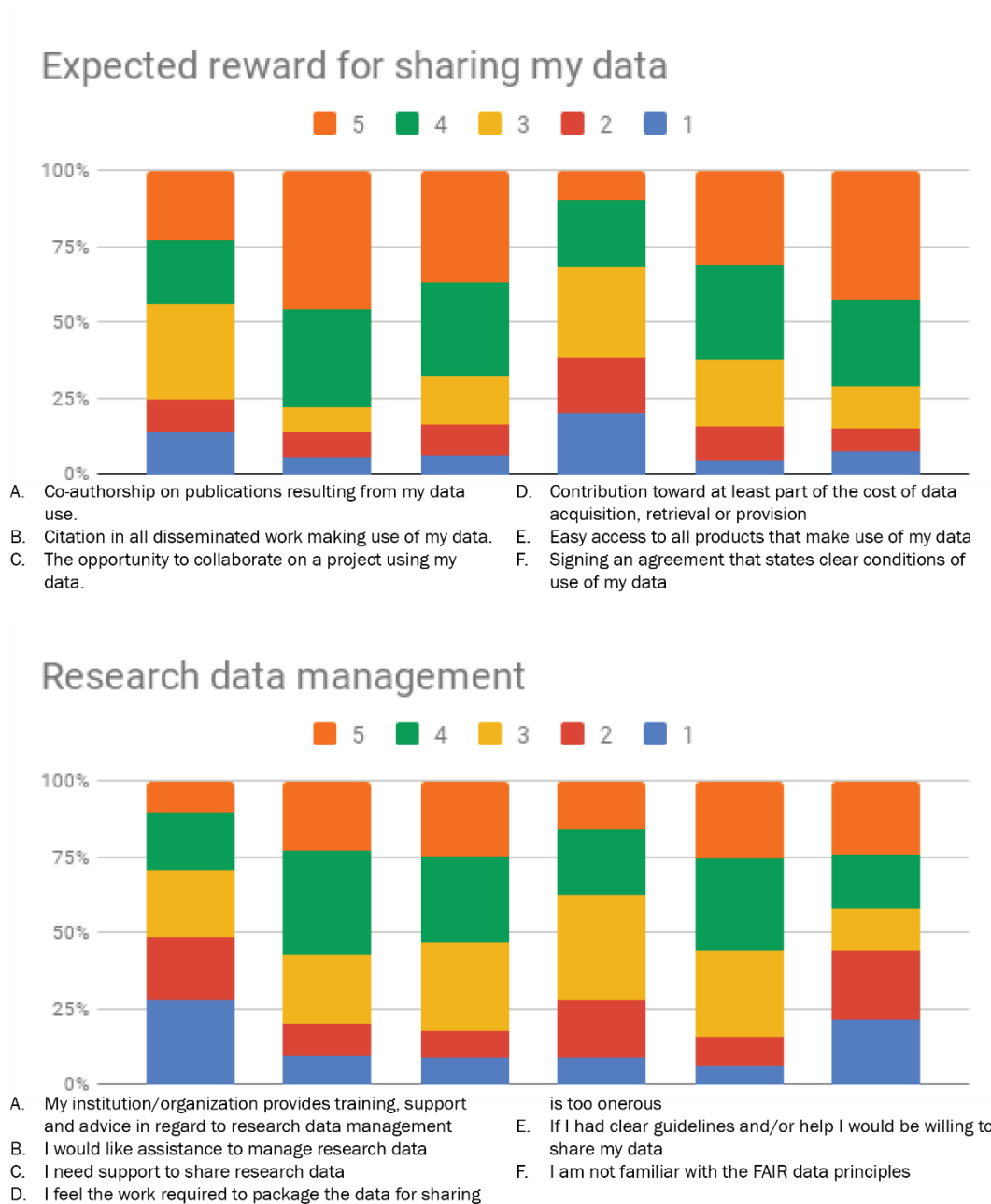


Figure 3 (cont'd) Results from "Cultural Barriers" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.

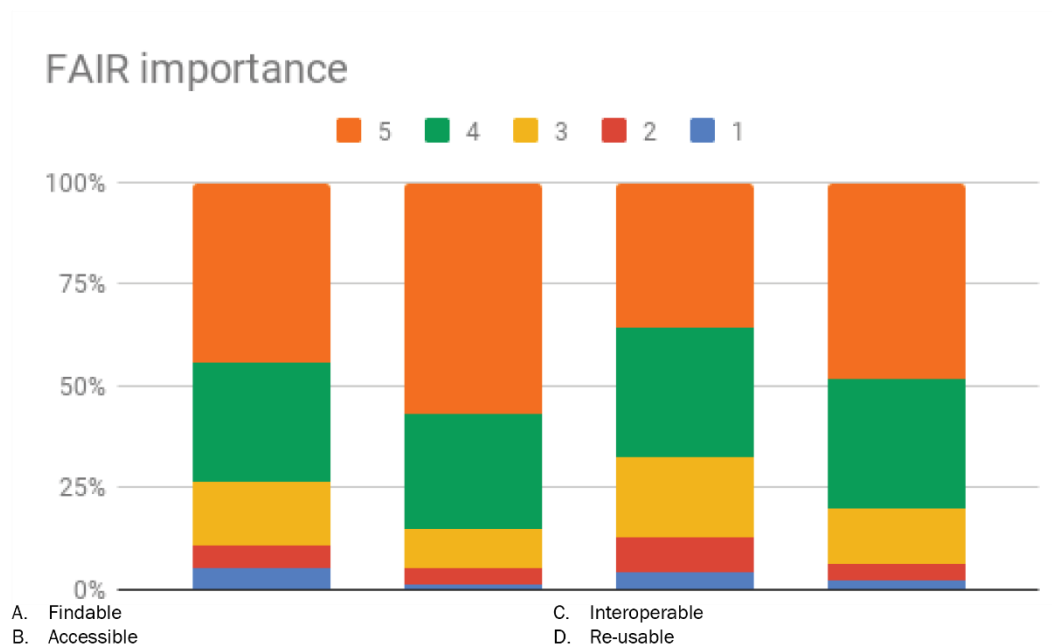


Figure 3 (cont'd) Results from "Cultural Barriers" survey. Bar charts which have alphabetical labels relate to the x-axis from left to right.

3.1.2. Analysis and summary of survey results

Most of the respondents to the surveys were either Spanish (~40%) or Portuguese (~25%) with only ~7% being English speakers, and similar low percentages for other languages including French, Italian, Dutch and German. Although the respondents were mostly scientific researchers or healthcare professionals, there was a strong representation from a general audience, matching those of the former two.

- ❖ **Citizen science results ($n = 182$):** Public deliberation and participation were the most popular choices for the manner in which public engagement should be implemented and these methods for engaging the FAIR4Health audience should be investigated further.
- ❖ **Ethics results ($n = 170$):** "Lawfulness, fairness and transparency" and "Integrity and confidentiality" were the highest scoring statements relating to GDPR, while all other statements had a high degree of agreement showing that respondents were in tune with the principles of fair ethics and research integrity that should be strived for.
- ❖ **Cultural barriers results ($n = 99$):** More than three quarters of respondents indicated that they had at least reused data occasionally, while nearly three quarters agreed to share their data. However, the manner in which data is shared, either through repositories or peer-to-peer, shows fewer clear-cut results with more varied responses. Meanwhile, concerns over reuse showed broad disagreement and rewards for sharing showed broad agreement with the statements. However, research data management (RDM) and institutional support appears to be an issue and respondents also showed that they require assistance, mostly not being familiar with the FAIR principles and that the tasks required for RDM can be regarded as time consuming. Finally, when asked about the importance

of each of the FAIR principles, the vast majority of respondents strongly agreed with each, with accessibility and reuse showing the most agreement and interoperability the least.

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. FAIR4Health Open Community Membership

One of the key drivers for the project is to facilitate researchers' skills to reuse and share health research data and to make that data FAIR compliant. To this end, FAIR4Health is building a platform upon which this can be achieved and provides other tools such as the *data-privacy-tool* and the *data-curation-tool* to manage datasets specifically aimed at the health research domain. We have also devised a FAIRification workflow, that has undergone revisions through the course of the project so far, and which provides a set of instructions for researchers to follow when thinking about their health research data.

Until now, in the project, some relationships and synergies have been created informally, with participation of some people external to the FAIR4Health consortium through workshops and other dissemination activities. To allow the relevant stakeholders to derive the maximum benefit from the tools developed by FAIR4Health, and the knowledge gained, we are setting up the **FAIR4Health Open Community Membership**, aiming to create the FAIR4Health Open Community formally. The general public will be able to use the open source software published in the FAIR4Health GitHub repository (under Apache 2.0 license) to directly use the tools or to make their own platform that can be tailored to their own use/purpose. Apart from that, the FAIR4Health Open Community Members are going to be able to access the Privacy-Preserving Distributed Data Mining (PPDDM) models developed and trained within the project. To access this material, interested parties must register as a member of the FAIR4Health open community.

We anticipate that the best way to allow access for researchers who are interested in FAIR4Health, and to exploit the tools that are being developed by the consortium will be through a membership scheme involving the access and reuse of the PPDDM models generated in the project. Consequently, using the FAIR4Health open source code software will facilitate the secure sharing of any health research data therein. This could take the form of established sensitive data handling workflows and technological platforms in various institutions around the world (for example, data safe havens such as the one in the

University of Edinburgh³), with the key differentiator of our platform being the emphasis on ensuring FAIRification of data, thus addressing legal and ethical aspects. A membership scheme will also allow the FAIR4Health consortium to better understand and monitor the interest in FAIR4Health results by relevant stakeholders.

There will be an onus to increase membership, but increasing the number of users will in and of itself drive further memberships: there need to be incentives to attract initial recruit members since they will need to be reassured that disclosing members' personal data (i.e. names and affiliations in the list of FAIR4Health members) will have benefits to them. We anticipate the Membership will have threefold benefits to initial users: firstly, to allow enhancement of the collaborative use of FAIR4Health's tools and workflows; secondly, to improve reuse of the FAIR4Health source code published on GitHub to make their own platform that can be tailored to their own use/purpose; and third, to have priority in receiving all public dissemination materials generated in the context of the project.

With respect to the technological resources, the FAIR4Health open community membership should provide new members access to:

- ❖ the PPDDM models generated in the project.
- ❖ the documents related to the HL7 FHIR Implementation Guidelines that are being developed for FAIR4Health, and the possibility to participate in their development.

Meanwhile, with respect to the dissemination materials, the FAIR4Health open community membership should provide new members:

- ❖ "priority" access: they will be primary contacts.
- ❖ invitations to the initiatives that arise from FAIR4Health in the RDA.
- ❖ invitations to workshops and other events, especially those organized by EFMI (European Federation for Medical Informatics).
- ❖ invitations to the final plenary of the project at the end of 2021 in Seville.
- ❖ newsletters providing periodic news about the status of the project.

By meeting these requirements, a membership to the FAIR4Health platform will be more attractive to users and will lay the foundation for more users to join and increase the value of the FAIR4Health project.

3.3.1. Strategies for attracting members

In the first instance, for the purpose of validation and feedback, as well as for underpinning the desired network effect, the FAIR4Health consortium will engage in targeted communication to select individuals who represent entities and organisations within the relevant stakeholder groups that FAIR4Health communicates with (see D7.3 and former versions of D7.2):

- ❖ Researchers (FAIR data and Health)
- ❖ Medical doctors and students
- ❖ Patient Associations
- ❖ RFOs and RPOs
- ❖ Biomedical Institutions – Hospitals
- ❖ General public

³<https://www.ed.ac.uk/information-services/research-support/research-data-service/during/data-safe-haven/intro-data-safe-haven>

We will seek to communicate specifically with individuals and organisations, which we have engaged previously and are aware of the FAIR4Health project and its objectives. We will also target umbrella organisations, which can cascade the FAIR4Health message to their partners and or members. We will also leverage the FAIR4Health partners extensive contact networks for this purpose.

Any communication about the Open Community Membership will highlight the message of the FAIR4Health project and will emphasize the security of the platform as well as the benefits it brings to FAIR management of health research data.

3.3.2. Impact of the FAIR4Health membership

This membership will have a major impact in the following aspects:

- ❖ Improved trust in science through increased openness and quality of scientific research in Europe.
- ❖ Stimulate the development of innovative services and products in Europe.
- ❖ Better quality and more productive research and innovation, addressing societal challenges.
- ❖ Contribution to European and global policies and the realisation of Horizon Europe's objectives.
- ❖ building a knowledgebase through dissemination materials generated in the context of the project:
 - FAIR4Health tools technical guidance.
 - FAIR4Health tools training.
 - Drive communication with the EC and EOSC with respect to FAIR compliance.

3.3.3. Commitments of FAIR4Health members

The FAIR4Health Open Community members will have the following commitments:

- ❖ Promote and incentivise open data sharing.
- ❖ Promote the FAIR principles.
- ❖ Develop standardised FAIRification tools.
- ❖ Promote FAIR certification mechanisms.
- ❖ Contribute FAIR research digital objects (data, publications, software, tools, services, etc.) and practices.
- ❖ Give insights into data citation in order to provide proper acknowledgement of researchers
- ❖ Share expertise with other members.

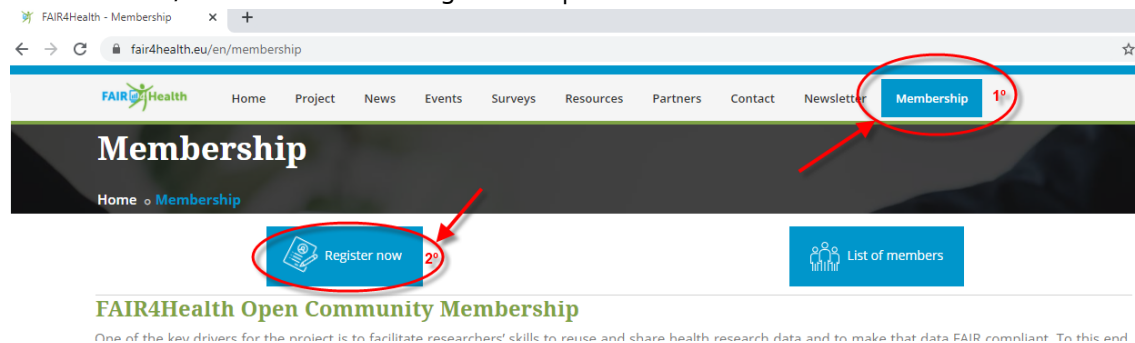
3.3.4. Open Community Membership Update

Open community engagement since the last version of D7.2 has built the number of members to over 80 and whose names can be openly viewed from the project website: <https://www.fair4health.eu/en/news/list-of-fair4health-members>

The last update of deliverable D7.2 was in M18, and subsequently the FAIR4Health consortium worked on including the relevant information of the FAIR4Health open community on the FAIR4Health website. That section of the website includes the

Membership definition, as well as the list of members and a button to register as a new member: <https://www.fair4health.eu/en/membership>

The FAIR4Health Open Community members have joined through a combination of active recruitment as well as finding the project through various channels such as participation in conferences, where the following slide is presented:



This cohort forms a group that fulfils many of the stated goals in sections 3.3.2. and 3.3.3, with the majority coming from higher education and research institutions who are located in Europe. We have also attracted a handful of members that represent North and South America, Asia and Australia, while also there are a handful of members that are not strictly associated with any educational institution and are independent or work for a commercial entity. This cohort is also distinct to the RDA WG membership but has some overlap. We aim to build the community further and anticipate that by the end of the project it will have grown in size. Please see the Annex for a list of current members, and see [here](#) for latest version of this list as we expect it to grow over time.

As a consequence of the Open Community Membership, we have been contacted by members of the Wellcome Trust and National Institute of Health Research (NIHR) in the UK who represent the FAIRware project and who are interested in a possible collaboration. Previously, at the 5th FAIR4Health GA, another member of the FAIRware project, Mark Musen, had provided a presentation on other related work, and we are exploring the possibility of further work.

3.3.5. FAIR4Health Open Community: Update M36

At month M36, the Open Community members listed on the website comprise of 81 members, from 22 different countries, with 63 unique affiliations. Their roles are drawn from a range of researcher, medical, patient, RFO and RPO, biomedical institution, hospital, and public positions.

The FAIR4Health Final Assembly involves 16 partners from 10 different countries and will celebrate the end of the FAIR4Health project, gathering the main conclusions, outputs and considerations. And the members of the FAIR4Health Open Community are invited to participate in the project's Final Assembly, to be held in Seville on 24 November 2021. Concretely, they are invited to join a virtual demonstration of the functioning of the tools developed in the project, as well as an overview of the final architecture of the FAIR4Health solution.

Paths for future contact and engagement include the project's fair4health google group as well as through the Research Data Alliance.

3.3.6. RDA Engagement Update

After the previously established BoFs, we have successfully created a WG that was fully endorsed in August 2020: [RDA WG on Raising FAIRness in health data and health research performing organizations \(HRPOs\)](#). This was accomplished after a period of public, RDA TAB and RDA Council consultation whereby a case statement that we wrote was evaluated and reviewed. Membership of the RDA WG since its inception has grown to 45 members, as of November 2021. Some of these members were already actively participating in our previous BoF group but have now become formal members of the WG. Several others are new and have joined as a result of word of mouth and through participation in other related projects and WGs. During this time, we also successfully recruited a fourth and final co-chair, Anupama Gururaj from the National Institutes of Health (NIH) and National Institute of Allergy and Infectious Diseases (NIAID), and together the co-chairs have done the bulk of the work described here.

Since the last version of D7.2, we have delivered breakout sessions at three more RDA plenaries with as full WG status. RDA VP16 in Costa Rica (November 2020) was our first opportunity to showcase our work as a fully endorsed WG and where we launched the tasks set out in the case statement. The milestones that we set out in that document are the following:

- Review of the current landscape for FAIR adoption of health research data taking into consideration levels of privacy and ethical considerations granted to such data in regions around the world. This will be based on existing and recently completed work done by F4H in the EU context and the EOSC Landscaping Work currently being carried out. [M1-3]
- Assessing the impact of such restrictions in terms of research, as well as financial and societal impacts, drawing on previously mentioned work by F4H, EOSC and others. [M2-6]
- Analysis of national and international guidelines and policies, and their enforcement to compare and contrast and provide a foundation for the WG's own recommendations. [M3-9]
- Implementation of draft guidelines at 4-5 HRPOs to test feasibility. [M9-12]
- Community surveys to gauge requirements and assess proposed deliverables of the WG. [M1-12]
- Deliver final output as a written set of principles to be adopted by the HRPO community, with care to be taken that these should not be seen as rules that need to be strictly followed depending on the particular regional and local contexts. [M12]

The proposed outputs from this work will include the following:

- Guidelines for HRPO senior managers on how to write a FAIR aligned data policy for their organization, to enable the reuse of health research data.
- Guidelines for health researchers working within HRPOs on publicly funded research on how to make their data FAIR in a practical sense. This will be a longer document with links to supporting resources and references to best practice examples of FAIR health data.

- A checklist and/or rubric that can assist data creators within HRPOs to make their data FAIR. This will be a short and concise document that will allow researchers to quickly check their data against a specific FAIR checklist.
- Training documents aimed primarily at early career health researchers. This will include an introduction to the FAIR principles and how these can be implemented without risking privacy of human research participants.

Due to the nature of RDA WGs, the suggestions by the RDA TAB and the timeframes involved, the above timeline has changed since it was proposed and there has been a revision to lengthen the lifetime of the WG by a further 6 months to make it a total of 18 months, with a projected end time of RDA VP19 (expected in June 2022). This means that the RDA WG will be operational beyond the lifetime of the FAIR4Health project. We see this not to be a problem since we have deliberately established the RDA WG as a separate entity to the FAIR4Health project, and that the former is more an offshoot of the latter. However, this should be factored into the sustainability goals and planning of the FAIR4Health project since any work beyond the lifetime of the FAIR4Health project will be unfunded.

Currently, we have finalized a first version of the landscape document that is the first task after leaving it open for public consultation and review. The document was presented at RDA VP17 (April 2021) in a breakout session at which participants were largely in agreement with what had been written. It is the intention of the WG to maintain this document as much as possible by periodic revisions to reflect the changing landscape. Furthermore, we have now established a scheduled time at which any interested parties (mainly WG members) can join the co-chairs in a teleconference to discuss progress and next steps. Through this, we have been able to delegate some writing and research duties and are currently putting together an impact assessment of the restrictions or barriers included in the landscape document which is the second deliverable of the WG and was presented and discussed in RDA VP18 (November 2021). Concurrently, we have also started making a list of possible targets to approach for validating the draft guidelines and which we hope to be able to test beyond Europe. To this end, we have been successful in recruiting WG members from Latin America and Africa who have the potential to provide us with the necessary contacts to achieve this goal. We are actively sourcing other contacts that can cover other regions such as Asia and also contacts that could provide further coverage to existing regions.

3.4. Publishers and peer reviewed publications

Dissemination of outputs and to achieve the wider aims of informing the general public and stakeholders required FAIR4Health to produce written documents that underwent peer review. The main scientific open access papers that were developed to present the results of the project were as follows:

- Sinaci, A. A., Núñez-Benjumea, F. J., Gencturk, M., Jauer, M. L., Deserno, T., Chronaki, C., ... & Parra-Calderón, C. L. (2020). From raw data to FAIR data: the FAIRification workflow for health research. *Methods of Information in Medicine*, 59(S 01), e21-e32. DOI: [10.1055/s-0040-1713684](https://doi.org/10.1055/s-0040-1713684)

- Parra-Calderón, C. L., Sanz, F., & McIntosh, L. D. (2020). The Challenge of the Effective Implementation of FAIR Principles in Biomedical Research. *Methods of Information in Medicine*, 59(04/05), 117-118. DOI: [10.1055/s-0040-1721726](https://doi.org/10.1055/s-0040-1721726)
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In addition, in the previous months, the FAIR4Health consortium has been working on the preparation of scientific papers to disseminate the results of the project. They are currently under review by the following open access journals:

- 'Towards FAIR data in healthcare: A data curation tool to transform health data into HL7 FHIR', submitted to Journal of the American Medical Informatics Association.
- 'Boosting-based Federated Random Forest Methodology on Horizontally Distributed Data for Privacy-Concerned Environments', submitted to ACM Transactions on Intelligent Systems and Technology - Special Issue on Federated Learning: Algorithms, Systems, and Applications.
- 'FAIR4Health: Findable, Accessible, Interoperable and Reusable data to foster Health Research', submitted to Open Research Europe (European Commission scientific publishing service: <https://open-research-europe.ec.europa.eu/>).
- 'Predicting 30-days Readmission Risk for COPD Patients Care through a Federated Machine Learning Architecture on FAIR Data: Development and Validation Study', submitted to Journal of Medical Internet Research (JMIR).
- 'Impact of the FAIR4Health Solution on Health Care and Health Research outcomes', submitted to Digital Health journal.
- 'Applying the FAIR4Health Solution to Identify Multimorbidity Patterns and their Association with Mortality through a Frequent Pattern Growth Association Algorithm: Validation Study', submitted to Journal of Medical Internet Research (JMIR).

3.5. 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.

3.5.1. 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 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”⁵. 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 Wikipedia⁶ 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.

3.5.2. 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.

⁵ <https://daily.zooniverse.org/2014/09/16/citizen-science-in-dictionary/>

⁶ https://en.wikipedia.org/wiki/List_of_citizen_science_projects

3.6. 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.

3.7. 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.

3.7.1. Association of Medical Research Charities (AMRC), UK

Established in 1987, the Association of Medical Research Charities (AMRC)⁷ is the UK's national membership organisation for health and medical research charities. AMRC brings together 149 organisations, which together eclipse the spending from the publicly funded MRC (see 3.6.2.) and also surpasses the NIH in the USA. We will contact the AMRC to encourage engagement with FAIR4Health's objectives and help shape its policies especially with respect to privacy and ethical issues.

3.7.2. 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." EPF⁸ has a scope beyond that in the UK alone and therefore adds further engagement opportunities.

3.7.3. Medical Research Council (MRC), UK

Since the MRC⁹ 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.

3.7.4. National Institutes of Health (NIH), USA

As a non-EU organisation, and one of the major world funding bodies, engagement with the NIH¹⁰ would dramatically increase the scope of FAIR4Health.

⁷ <https://www.amrc.org.uk/>

⁸ <http://www.eu-patient.eu/>

⁹ <https://mrc.ukri.org/>

¹⁰ <https://www.nih.gov/>

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

Another non-EU organisation, and which is the major funding body in Japan, engagement with the AMED¹¹ would also dramatically increase the scope of FAIR4Health.

3.7.6. EOSC-Life

As part of the wider European Open Science Cloud (EOSC^{12,13}) project, EOSC-Life¹⁴ specifically focuses on infrastructure in the biomedical sciences domain. FAIR4Health has contacted EOSC-Life to form alliances with this far reaching project. In November 2019, FAIR4Health joined an initial meeting "Turning FAIR into Reality 01" which involved discussion from other EU funded FAIR related projects: FAIRsFAIR¹⁵, FAIRplus¹⁶, EOSC-Hub¹⁷, as well as GO FAIR¹⁸, and this will be followed up further.

3.7.7. European Joint Programme on Rare Diseases (EJP RD)

This¹⁹ is another H2020 funded project that started in January 2019 and which brings together over 130 institutions from 35 countries, mostly represented by the EU and Europe, but also Israel, Turkey and Canada. Its stated mission is to *"create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care and medical innovation"*.

3.8. Research Data Alliance (RDA)

The Research Data Alliance²⁰ 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."*²¹

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

¹¹ <https://www.amed.go.jp/en/>

¹² <https://ec.europa.eu/research/openscience/index.cfm?pg=open-science-cloud>

¹³ <https://www.eosc-portal.eu/>

¹⁴ <https://www.eosc-life.eu/>

¹⁵ <https://www.fairsfair.eu/>

¹⁶ <https://fairplus-project.eu/>

¹⁷ <https://www.eosc-hub.eu/>

¹⁸ <https://www.go-fair.org/>

¹⁹ <https://www.ejprarediseases.org/>

²⁰ <https://www.rd-alliance.org/>

²¹ <https://www.rd-alliance.org/about-rda>

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.

3.8.1. RDA Engagement in 2019

One key aspect of RDA is its endeavours to establish standards that can be adopted by the wider research community and beyond. To do this, RDA works by enabling collaboration between members through **interest** and **working groups** (IGs and WGs, respectively), where the latter can produce **RDA endorsed outputs**. To this end, FAIR4Health engaged with the RDA community and other established RDA groups to produce an RDA output based on FAIR4Health's objectives.

Through the existing work was conducted at the European level (gathered in the [FAIR4Health deliverable D2.3. Guidelines for implementing FAIR open data policy in health research](#)), and which differences in policies within that region were identified, some FAIR4Health partners worked on the creation of a RDA WG on the need of the FAIR adoption in the health research domain. The aim was to expand on that FAIR4Health work to create a global analysis of policies and to subsequently draw on commonalities to propose a set of guidelines (RDA outputs or recommendations) that can be utilised by HRPOs in their local contexts to address FAIRification of their research data.

Concretely, the RDA [WG on Raising FAIRness in health data and health research performing organisations \(HRPOs\)](#) builds upon previous Birds-of-a-Feather (BoF) sessions. BoFs are typically prerequisites to establishing IGs or WGs, and a method to test community interest in the proposed objective. At the RDA Plenary 13, we managed to attract 30 members from RDA, while in the RDA Plenary 14 BoF there were 15 in attendance, some overlapping with the previous meeting. These participants have given permission to be contacted and form a core of individuals that can be engaged further to advise on FAIR4Health's objectives. In addition to these BoFs, we also identified one key already established RDA group that was of particular relevance to FAIR4Health, the Health Data IG, and actively sought their advice and cooperation. This is ongoing and the current status is that we may look to establish our own WG to produce an RDA output or to align ourselves with some of the objectives from a proposed WG from the Health Data IG. The following is a compiled list of the attendees from both BoF sessions with any individuals that attended both sessions only marked once and not including any members of FAIR4Health that were present:

	Affiliation / FAIR Project
1	Centre for Biomedical Informatics and Systems Biology, University of Khartoum, SD
2	RWTH Aachen University, DE
3	NIEHS, USA
4	Drexel, USA
5	Universite Laval, CA
6	Universite Laval, CA
7	Universite de Montreal, CA
8	SHARC group RDA IG co-leader; in charge of ethical aspects in the IMI FAIRplus project (EU funded), FR
9	CIHR, CA

10	Yale, USA
11	Drexel, USA
12	RDC, CA
13	GO FAIR, Europe
14	NIH NIDDK, USA
15	MIT, USA
16	DANS, NL
17	Children's Hospital of Philadelphia, USA
18	Wellcome Trust, UK
19	Johns Hopkins Medical Institute, USA
20	American Society of Clinical Oncology, USA
21	NBDC, JP
22	INIST CNRS, FR
23	WUR, NL
24	ARDC, AUS
25	UPC/BSC, ES
26	Drexel, USA
27	EGI Foundation, Europe
28	Goettingen, DE
29	Rutgers, USA
30	AARNet, AUS
31	ARDC, AUS
32	VU Amsterdam, NL
33	RDA, USA
34	ECRIN-ERIC, Europe
35	ECRIN-ERIC, Europe
36	RDA North America, USA
37	WUSTL, USA
38	NIST, USA
39	NLM/NIH, USA
40	INESC-ID, PT

The cohort represents individuals from the following countries/territories: 16 USA, 5 Canada, 3 Australia, 1 Japan, 1 Sudan, 4 Europe, 2 Germany, 2 France, 3 Netherlands, 1 Spain, 1 UK, and 1 Portugal. Names and email addresses for these individuals have been collected and will be used for correspondence in advising FAIR4Health decisions and for any potential RDA output. Some specific individuals are already known to be particularly useful as contacts and will be engaged more than others.

3.8.2. RDA Engagement: May 2020 Update

Due to the global Covid-19 crisis, the RDA Plenary 15 that was scheduled to take place in Melbourne, Australia was cancelled. FAIR4Health was due to attend this conference and presented the proposals for a working group that would aim to produce recommendations and/or guidelines that could be adopted by the HRPO community to FAIRify their datasets, whether retro- or prospectively. The in-person meeting would have built upon the previous

two RDA plenaries that FAIR4Health has attended and at which interest in such a proposal was gauged and a list of interested parties was gathered.

Instead, the organisers of the RDA Plenary 15 created a Virtual Plenary 15 (VP15) using Zoom teleconferencing software to provide virtual rooms for those breakout sessions that were due to take place. The programme for the VP15 was spread out over three weeks and individual breakout session organisers were allowed to improvise virtual sessions within this framework. FAIR4Health took advantage of this opportunity and held its own virtual session on 8th April 2020 and at which we accommodated over 50 participants and several unique registrants compared to the previous two sessions that we hosted.

The main aim of the meeting was to invite assessment of the case statement that had been written and which is part of the process for applying for establishing an RDA working group. To move towards ratification, the case statement was written in Google Docs²² and made open for review. Several comments were made in the document by community members and these were in turn reviewed by the original writers of the document and edits made where necessary.

Another aim of the VP15 was to gauge interest by any individuals to become a co-chair of the proposed WG. To this end, we welcomed one person, Dr. Kristan Kang, from the Australian Research Data Commons ADRC to co-chair. We are in the process of identifying and inviting at least one other person to co-chair that can represent North America and possibly one further individual from another geographical territory. The case statement was submitted to the RDA for review by its technical advisory board (TAB) on 1st June 2020 and we are awaiting its outcome.

3.8.3. RDA Engagement: November 2020 Update

In the beginning of June 2020, the case statement prepared for this WG was submitted for review by the RDA Technical Advisory Board (TAB) and finally this WG was endorsed by the RDA Council in August 2020.

In RDA Plenary 16 (November 2020, Virtual), the launch of this WG was formalized, and the over 15 attendees performed a review in depth of the principles and steps to guide HRPOs to create a policy (internationally valid) for FAIR data. The WG targeted researchers, HRPOs, clinicians and healthcare professionals, hospitals, research institutes, and funders, for membership. At the first WG meeting it reviewed the principles informing the group's output and began discussing the establishment of the basis for a globally applicable FAIR data policy for HRPO. It also introduced a work plan including reviewing the landscape for FAIR adoption of health research data, assessing impact of research restrictions, analyzing national and international guidelines and policies, a community survey, and scoping a final set of written principles for community adoption.

²²https://docs.google.com/document/d/15mxia8Y_wsllp1a_IDhseYz8ACrvaodGdw4L-VID9ww/edit?usp=sharing

3.8.4. RDA Engagement: April 2021 Update

Due to the COVID-19 pandemic, RDA plenaries switched to online events and another formal working group session at RDA Plenary 17 (April 2021, Virtual) was held to discuss the global landscape analysis of FAIR adoption which was initiated by the Chairs of this WG. In addition, at RDA Plenary 17, Alicia Martínez-García who is a member of the [‘FAIRness for FHIR’ HL7 project](#) participated to introduce the work done related to the [‘FHIR4FAIR’ HL7 FHIR Implementation Guide](#), aiming to establish synergies between both working groups. The working group sessions at RDA Plenary 17 attracted over 60 people and it focused on an initial impact assessment of identified barriers, and work on analyzing national and international level policies and guidelines, with an invitation to contribute. Initial results from a community survey that polled requirements from the community were also presented.

3.8.5. RDA Engagement: November 2021 Update.

WG sessions were previously held in which the WG Chairs solicited feedback on the WG activities from the broader community. Additionally, this WG has regularly scheduled monthly meetings (both with the WG members and the Chairs’ meetings) which enabled the Global Landscape Analysis that is the focus of this WG to be conducted and completed that is a goal of this WG, collecting legal and ethical considerations and national and international guidelines and policies.

Another WG group meetings were held at RDA Plenary 18 in November 2021 which attracted 18 people to the initial session, and over 10 people to the repeat session scheduled. Results of the landscape analysis and impact assessment were introduced, and the [community survey](#) on policies and data sharing requirements was launched. This session included a presentation on the FAIR Data Cookbook²³ with a view as to how members of the WG could contribute their expertise with health data to the endeavor.

A significant progress has been achieved by this RDA WG that expects to present the draft guidelines at [RDA Plenary 19](#) (June 2022) that is currently planned to be in person meeting, allowing for better participation that we have had in the last virtual plenaries due to the pandemic.

²³ <https://fairplus.github.io/the-fair-cookbook/content/home.html>

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 website²⁴ and which has now been created. This is a focal point for all FAIR4Health outputs that will be made 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 films²⁵. 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 on this.

4.1.2.1. Korsakow films results (see also D7.3)

At the 13th RDA Plenary, as well as holding a BoF session (see 3.7), FAIR4Health actively sought engagement with other attendees by asking willing individuals to give a filmed interview to produce short pieces of footage that could then be used in FAIR4Health's Korsakow films. Other footage was also filmed in other locations.

4.1.3. Twitter

Active engagement via a dedicated FAIR4Health Twitter account will be pursued to allow a user-friendly method for the health research community to interact with the project (see D7.3).

4.1.3.1. Twitter results

The Twitter handle @Fair4Health²⁶ and hashtag #FAIR4Health have been created and used since the start of the project to help disseminate news and updates on the projects and has garnered 404 followers. The account has tweeted and retweeted 232 times so far and its

²⁴ <https://www.fair4health.eu/>

²⁵ <http://korsakow.com/>

²⁶ <https://twitter.com/fair4health?lang=en>

impact is being analysed through cataloguing of the data and visualisation through software such as TAGSExplorer²⁷ (see D7.3).

4.1.4. YouTube

This platform can create “channels”, and FAIR4Health aims to use this functionality to disseminate video content relating to the project and to further community building (see D7.3).

4.1.4.1. YouTube results

We have established a YouTube Channel²⁸ and started to upload content. This is ongoing and still in its early stages but will allow the wider community to view any relevant content published by FAIR4Health and, importantly, to allow feedback (see D7.3).

4.2. Active F2F engagement, conferences and workshops

Deliverable D7.4 reports on conferences and workshops where past and future events are described.

²⁷ <https://tags.hawksey.info/tagsexplorer/>

²⁸ <https://www.youtube.com/channel/UCpycUlqaXMAJCZPatqcm4cg>

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/4BZZdHm64S051q2InZ1Nr7p/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>

6. Annex I - Survey questions

6.1. Open survey on boosting citizen science

1. Please, choose your language
2. Are you a citizen of the European Union?
3. Please, indicate your educational level (using ISCED scale)
4. Please, indicate which of the following roles best defines you (choose all that apply)
5. Public communication: The aim is to inform and/or educate citizens. The flow of information constitutes one-way communication from sponsors to public representatives, and no specific mechanisms exist to handle public feedback (examples include public hearings, public meetings and awareness raising activities). [Suitability of public communication] [Scale 1(strongly disagree) - 5(strongly agree)]
6. Public consultation: The aim is to inform decision-makers of public opinions on certain topics. These opinions are sought from the sponsors of the PE initiative and no prescribed dialogue is implemented. Thus, in this case, the one-way communication is conveyed from citizens to sponsors (examples include citizens' panels, planning for real and focus groups). [Suitability of public consultation] [Scale 1(strongly disagree) -5(strongly agree)]
7. Public deliberation: The aim is to facilitate group deliberation on policy issues of where the outcome may have an impact on decision-making. Information is exchanged between sponsors and public representatives and a certain degree of dialogue is facilitated. The flow of information constitutes two-way communication (examples include 'mini publics' such as consensus conferences, citizen juries, deliberative opinion polling). [Suitability of public deliberation] [Scale 1(strongly disagree) -5(strongly agree)]
8. Public participation: The aim is to assign part or full decision-making-power to citizens on policy issues. Information is exchanged between sponsors and public representatives and a certain degree of dialogue is facilitated. The flow of information constitutes two-way communication (examples include co-governance and direct democracy mechanisms such as participatory budgeting, youth councils and binding referendums). [Suitability of public participation] [Scale 1(strongly disagree) -5(strongly agree)]
9. Public activism: The aim is to inform decision-makers and create awareness in order to influence decision-making processes. The information flow is conveyed in one-way communication from citizens to sponsors but not on the initiative of the sponsors as characterises the 'public consultation' category. (Examples include demonstrations and protests). [Suitability of public activism] [Scale 1(strongly disagree) -5(strongly agree)]

6.2. Open survey on ethical implications

1. Are you a citizen of the European Union?
2. Please, indicate your educational level (Using ISCED scale)
3. Please, indicate which of the following roles best defines you (choose all that apply)
4. Please, choose your language
5. When processing sensitive personal data, Research Performing Organizations (RPOs) must consider the following principles as stated in the General Data Protection Regulation (GDPR):
 - a. Lawfulness, fairness and transparency
 - b. Purpose limitation
 - c. Data minimisation
 - d. Accuracy
 - e. Storage Limitation
 - f. Integrity and confidentiality
6. RPOs must put in place the following measures to comply with the accountability principle under the GDPR:
 - a. To implement data protection policies and security mechanisms
 - b. To agree data protection contracts with third-party processors
 - c. To document any processing activity
 - d. To record and report, where necessary, any personal data breaches
 - e. To carry out data protection impact assessments
 - f. To appoint a data protection officer
7. From research integrity and good practices point of view, RPOs must demonstrate:
 - a. Honesty
 - b. Reliability
 - c. Objectivity
 - d. Impartiality and independence
 - e. Open communication
 - f. Duty of care
 - g. Fairness
 - h. Responsibility for future science generations
8. Regarding science and society ethics, RPOs must consider the following issues:
 - a. Quality of scientific reporting should be endorsed
 - b. Resources to correctly interpret results (educational/training) should be provided to general media
 - c. Research outcomes should be released according to guidelines for incorporating scientific progress into policy-making

6.3. Open survey on cultural barriers

1. Gender
2. Age range
3. Which of the following countries is your primary place of employment?
4. What is your profile?

5. Do you reuse data shared from others?
6. Attitudes toward sharing/not sharing data:
 - a. I have no desire to share my research data
 - b. I don't usually share my data but have no problems to do it if someone or a funding agency asks for it
 - c. I only share my data upon request (from other researchers, agencies)
 - d. I usually share my data via repositories
 - e. I usually share my data with other researchers via e-mail or files sharing services
7. Barriers for sharing data:
 - a. I do not have time to share my data
 - b. My research data are too small or unimportant
 - c. Too costly. I do not have funds to support sharing data
 - d. I do not know how to package/manage/share my research data appropriately
 - e. I am not sure about which repository to use
 - f. I am not sure about the correct license to apply
 - g. My research data are too large to share
8. Concerns for data sharing and reuse:
 - a. My research data might be misused by companies (laboratories, insurance companies, etc.)
 - b. My research data might be misused for political proposals (intentional abuse of data)
 - c. My research data might be misinterpreted due to their complexity
 - d. My research data might be misinterpreted due to their poor quality
 - e. My research data might be criticized for errors found during secondary use
 - f. Secondary use of my research data might be detrimental to me
 - g. Secondary use of my research data might benefit me
 - h. I would be willing to reuse open data for my own research in the future
 - i. My research data would not get proper credit when shared
 - j. Others with more resources might be able to do more with my research data
 - k. There is no reward of any kind for sharing data
9. For others to use my data, I would expect the following in exchange:
 - a. Co-authorship on publications resulting from my data use
 - b. Citation in all disseminated work making use of my data
 - c. The opportunity to collaborate on a project using my data
 - d. Contribution toward at least part of the cost of data acquisition, retrieval or provision
 - e. Easy access to all products that make use of my data
 - f. Signing an agreement that states clear conditions of use of my data
10. Data management:
 - a. My institution/organization provides training, support and advice in regard to research data management
 - b. I would like assistance to manage research data
 - c. I need support to share research data

- d. I feel the work required to package the data for sharing is too onerous
 - e. If I had clear guidelines and/or help I would be willing to share my data
 - f. I am not familiar with the FAIR data principles
11. Which of the FAIR data principles do you think are more important for Research Data
- a. Findable
 - b. Accessible
 - c. Interoperable
 - d. Re-usable
12. Any other comment will be appreciated and welcome

7. Annex II: Open Community Membership

(weekly update: <https://www.fair4health.eu/en/news/list-of-fair4health-members>)

- A. Anil Sinaci (SRDC Software Research & Development and Consultancy Corp.). Turkey.
- Alfred Winter (Universität Leipzig). Germany.
- Alicia Martínez-García (SAS). Spain.
- Alper Teoman (SRDC Software Research & Development and Consultancy Corp.). Turkey.
- Amandeep Kaur (Indira Gandhi Delhi Technical University For Women). India
- Andreas Panayides (3aHealth). Cyprus.
- Angèle Bénard-Sankaran (VHIR). Spain.
- Angus Whyte (Digital Curation Centre). United Kingdom.
- Antonio Gimeno Miguel (Instituto Aragonés de Ciencias de la Salud (IACS)). Spain.
- Avril Palmeri (Newcastle University). United Kingdom.
- Beatriz Poblador-Plou (Instituto Aragonés de Ciencias de la Salud). Spain.
- Bojan Zaric (Institute for Pulmonary Diseases of Vojvodina, Faculty of Medicine, University of Novi Sad). Serbia.
- Brendan Dunphy (C-BIA Consulting Ltd). United Kingdom.
- Brian Alper (Computable Publishing LLC). United States.
- Carlos Caverio Barca (Atos Spain SA). Spain.
- Carlos Lemos (Lisbon Medical School). Portugal.
- Carlos Luis Parra-Calderón (Andalusian Health Service). Spain.
- Carmen Angioletti (Università cattolica del Sacro Cuore). Italy.
- Catherine Chronaki (HL7 Foundation). Greece.
- Celia Alvarez-Romero (SAS - FISEVI). Spain.
- Constantinos Pattichis (University of Cyprus). Cyprus.
- David Rodríguez-Mateos (Universidad Carlos III de Madrid). Spain.
- Diana Portela (Public Health Unit). Portugal.
- Eduard Jacob (Retired neuropsychiatrist). Netherlands.
- Elísio Costa (UCIBIO, REQIMTE, Faculty of Pharmacy, University of Porto). Portugal.
- Esther Inau (Uni- Greifswald). Germany.
- Esther Román (SAS). Spain.
- Ezelsu Şimşek (SRDC). Turkey.

- Fabrizio Pecoraro (National Research Council - Institute for Research on Population and Social Policies). Italy.
- Francisco Novillo Pérez (Orion Health). Spain.
- Franz Matthies (Institute for Medical Informatics, Statistics and Epidemiology (IMISE) Leipzig). Germany.
- Giorgio Cangioli (HL7 Europe). Italy.
- Harshana Liyanage (University of Oxford). United Kingdom.
- Ian Harrow (Ian Harrow Consulting). United Kingdom.
- Jean-Philippe Goldman (Hôpitaux Universitaires de Genève). Switzerland.
- Jessica Rochat (University of Geneva). Switzerland.
- Jiban K. Pal (Indian Statistical Institute). India.
- João Almeida (FMUP). Portugal.
- Joao Moreira (U.Twente). Netherlands.
- Jochen Knaus (Institute of Medical Biometry and Statistics, Faculty of Medicine and Medical Center, University of Freiburg). Germany.
- Jose Emilio Labra Gayo (WESO - Web Semantics Research Group, University of Oviedo). Spain.
- Kerolyn Garcia (Brasilia University). Brazil.
- Laurence Horton (Digital Curation Centre). United Kingdom.
- Li Hui Lee (National Taipei University of Nursing and Health Sciences). Taiwan.
- Lukas Huber (FH Kufstein Tirol). Austria.
- Malin Sandström (INCF). Sweden.
- Manuel Perez Perez (Atos Spain SA). Spain.
- Marek Matejak (Charles University in Prague). Czech Republic.
- Maria Luiza Campos (Federal University of Rio de Janeiro). Brazil.
- Mario Rodriguez (Atos Spain SA). Spain.
- Marta Almada (University of Porto). Portugal.
- Matthias Löbe (Institute for Medical Informatics, Statistics and Epidemiology (IMISE) Leipzig). Germany.
- Mert Gencturk (SRDC Corp.). Turkey.
- Michelle Barker (Research Software Alliance). Australia.
- Miriam Quintero (Atos Spain SA). Spain.
- Na Li (University of Amsterdam). Netherlands.
- Nagarajan Ganapathy (PLRI, TU Braunschweig). Germany.
- Natacha Santos (Centro Hospitalar Universitário do Algarve). Portugal.
- Nick Lynch (Curlew Research). United Kingdom.
- Patrick Weber (European Federation for Medical Informatics). Switzerland.
- Philip van Damme (Amsterdam UMC). Netherlands.
- Priyanka O (UMC). Netherlands.
- Rebeca Isabel (AETSA). Spain.
- Rebecca Leary (Newcastle University). United Kingdom.
- Reme Melero (CSIC). Spain.
- Ricard Martínez Martínez (University of Valencia). Spain.
- Ricardo Cruz Correia (Faculty of Medicine of University of Porto). Portugal.
- Rita Silva (University of Porto). Portugal.

- Romain David (ERINHA AISBL - European Research Infrastructure on Highly Pathogenic Agents). France.
- Romaric Marcilly (Lille Academic Hospital). France.
- Ronald Cornet (Amsterdam UMC). Netherlands.
- Rosa Liperoti (Università cattolica del Sacro Cuore). Italy.
- Sanja Hromis (Institute for Pulmonary Diseases of Vojvodina). Serbia.
- Santiago Aso (Atos Spain SA). Spain.
- Shanmugasundaram Venkataraman (University of Edinburgh/ DCC). United Kingdom.
- Sorana Bolboacă (Iuliu Hatieganu University of Medicine and Pharmacy Cluj-Napoca). Romania.
- Thomas M. Deserno (Peter L. Reichertz Institute for Medical Informatics). Germany.
- Tomi Kovacevic (Institute for Pulmonary Diseases of Vojvodina). Serbia.
- Tony Hernández-Pérez (Universidad Carlos III de Madrid). Spain.
- Vasiliki Foufi (Division of Medical Information Sciences, Geneva University Hospitals & University of Geneva). Switzerland.
- Yuandou Wang (University of Amsterdam). Netherlands.