D7.4. Report on the FAIRification workshops and tutorials series

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Table of Contents

List of acronyms

BoF	Birds-of-a-Feather
CEN	Centre Européen de Normalisation
CrowdHEALTH	Collective wisdom driving public health policies
DCC	Digital Curation Centre (See. IDCC)
EFMI	European Federation for Medical Informatics
EOSC	European Open Science Cloud
EU	European Union
FAIR	Findable, Accessible, Interoperable and Reusable
HIMSS	Healthcare Information and Management Systems Society
HIT	Health Information Technology
HL7	Health Level 7
ICIMTH	International Conference on Informatics Management and Technology in Healthcare
IDCC	International Digital Curation Conference (See. DCC)
IFIP	International Federation for Information Processing
IMIA	International Medical Informatics Association
IMISE	Universitaet Leipzig
ISO	International Standardization Organization
MIE	Medical Informatics Europe
P13	RDA 13th Plenary (Philadelphia, April 2019)
P14	RDA 14th Plenary (Helsinki, October 2019)
RDA	Research Data Alliance
SAS	Servicio Andaluz de Salud
STC	Special Topic Conference
UC3M	Universidad Carlos III De Madrid
UEDIN	The University of Edinburgh

| **UNIGE** | Université de Genève |
| **WHO** | World Health Organisation |

1. Executive summary

Deliverable D7.4 is a report on some of the **specific outreach activities** pointed out in the previous D7.3, particularly D7.4 focusses in the events (conferences and workshops) and some of the training materials (tutorials) developed within the FAIR4Health project. It describes the implemented strategy, plans and tools used for these particular materials.

Participations in conferences with **oral presentations, posters and workshops**, as well as the involvement in exhibitions and other events have been suggested as the most appropriate dissemination methods for projects like ours. Publications on **scientific journals, articles on newspapers and online communication** (website and social media) have also been considered in FAIR4Health as a means of engaging the public and scientific community with the project and its outcomes. For the activities outlined above all partners are committed to provide sufficient and appropriate material for dissemination purposes and contribute to project's outreach during its life cycle and after its completion.

As far as social media are concerned, a **social media strategy** (Twitter, LinkedIn, etc.) has been established and there are updates on a regular basis to keep the audience informed about FAIR4Health project, its progress and outcomes. Taking into consideration the KPIs it is suggested that the project is making progress towards the achievement of the dissemination goals and communication activities. Future dissemination activities have been planned and communicated with the consortium (Cfr. D7.3).

2. Introduction

All the members of FAIR4Health consortium participate in the project communication and dissemination activities, but in particular **EFMI** and **DCC** have a relevant role due to their long tradition on organizing big conferences and events in the field of FAIR4Health.

2.1. EFMI

The **European Federation for Medical Informatics (EFMI)** [1] is a Federation of National Associations in Medical and Health Informatics in the European Region as defined by the World Health Organization (WHO). EFMI was conceived at a meeting, assisted by the Regional Office for Europe of WHO, in Copenhagen in September 1976. The original declaration says of 11-09-1976 states that "The Federation shall be constituted as a non-profit organization concerned with the theory and practice of Information Science and Technology within Health and Health Science in a European context as defined by WHO.

Nowadays, EFMI has **more than 32 national associations** that span from Iceland to Israel and from Portugal to Armenia within the European Continent and the European Region as defined by WHO. In addition, 12 working groups cover the whole spectrum of the scientific domain of Biomedical Informatics, among those are: Health Records, Information Systems, Data Analytics, Education, Imaging, Evaluation of Health Information Systems, Standards, Nursing Informatics, Translational Bioinformatics. Besides national associations and

working groups EFMI has introduced the notion of institutional membership where academic and corporate organizations may participate in the activities.

The objectives of the EFMI are: to advance international **co-operation and dissemination of information in Medical Informatics on an European basis**; to promote high standards in the application of medical informatics; to promote research and development in medical informatics; to encourage high standards in education in medical informatics; to disseminate knowledge in the field developed within national associations among and to the countries constituting EFMI; to provide guidelines and accreditation on education and training in Biomedical Informatics and Health Informatics; and to function as the autonomous European Regional Council of International Medical Informatics Association (IMIA) [2].

The main activities of EFMI are the organization of the **annual conferences MIE (Medical Informatics in Europe) and the EFMI-STC (Special Topic Conference)**. Besides those main events EFMI promotes national conferences and workshops organized by its national associations, and initiatives such as special meetings and **advanced workshops** organized by its Working Groups. EFMI participated in international Conferences and Exhibitions such as Medinfos, eHealth Forums, and HIMSS Europe events. The main means of dissemination of its developed knowledge is through the above-mentioned events and conferences and through white papers, and peer-reviewed articles and high-impact papers. Moreover, EFMI seeks to be linked with international organizations, such as, WHO, IMIA, IFIP, ISO and CEN, European Commission, and EFMI's expertise is part of any high-level initiative European and International. EFMI will enable wide communication and dissemination of FAIR4Health outcomes by engaging and interacting with stakeholder across the complete health care ecosystem. EFMI, being able to address more than 5000 health institutions / entities, provides a significant added-value to FAIR4Health. Finally, EFMI will incorporate recommendations and feedback from external stakeholders.

2.2. DCC

The **Digital Curation Centre (DCC)** [3] is an internationally-recognized centre of expertise in digital curation with a focus on building capability and skills for research data management. It provides expert advice and practical help to research organizations wanting to store, manage, protect and share digital research data. The DCC runs an annual International Digital Curation Conference (IDCC). The conference is now in its 15th year and attracts around 250 delegates representing researchers, research support, funders, publishers and cultural heritage. Ethics and data security are common topics which align well with the FAIR4Health agenda.

The DCC is also a partner in the **Research Data Alliance Europe** [4] project. It contributes to the RDA Secretariat and is involved in running the bi-annual plenaries. Plenary 14 will take place in Helsinki in October 2019, where FAIR4Health will be present. An EOSC stakeholder forum event will be co-located and presents a good opportunity to engage with international collaborators working on FAIR practices in health research. Indeed, the last plenary saw a BoF session and joint Interest Group.

3. Main regular conferences, workshops and tutorials within FAIR4Health

3.1. Objectives of FAIR4Health workshops and tutorials as a dissemination and communication mechanism

The main objective of this activity is **to inform and engage the target audience** (European Institutions, public bodies, broad business, academic and research communities, healthcare professionals, hospitals and other healthcare facilities and the general public) about the FAIR4Health project and its outputs. All efforts take the following into consideration:

1. Establishing **cooperation among the consortium partners** to guarantee effective communication inside the project and facilitate interaction with external stakeholders.
2. **Implementing efficient activities** regarding the outputs of the project to reach the audience outlined above.
3. **Interacting with other EU initiatives** and European funded projects to foster synergies regarding common dissemination activities (e.g. FAIRPlus, FAIRsFAIR, etc.).
4. Actively **contributing to the standardization community** in the Health research domain.
5. **Accepting feedback** in order to improve the FAIR4Health project and enhance its exploitation.

3.2. Regular conferences organized by EFMI

EFMI organizes mostly **two conferences per year**: Medical Informatics Europe (MIE) and Special Topic Conference (STC). MIE is the main event and STC is the conference for the working groups in a smaller size. Both **proceedings are published in open access and indexed in Medline**. Some of the working groups inside the organization are also organizing European conferences to promote their own topic.

3.2.1. Medical Informatics Europe (MIE)

FAIR4Health will profit from the big experience and community expansion activities that EFMI has. Twenty-four MIE congresses have been organized so far by the national members and EFMI with **up to more than 1000 participants**. The concept includes peer-reviewed presentations according to the type of paper as oral or poster presentation. Workshops and tutorials prepared or supported by EFMI working groups are an essential part of EFMI MIE conferences that could also benefit the impact of FAIR4Health. MIE conference alternates with another big conference in the field (MedInfo) in Europe, so during the time of FAIR4Health those are the targeted conferences in Europe where we plan to present out outcomes and enlarge the community:

❖ MedInfo 2019 in Lyon (France) from August 25 to 30, 2019 (see 4.3)

❖ MIE 2020 will be held in Geneva (Switzerland) from April 28 to May 1, 2020 [5]
❖ MIE 2021 will be in Athens (Greece) in April 2021
❖ MedInfo 2021 is organized in Sydney (Australia) in July 2021 [6]

3.2.2. Special Topic Conference (STC)

STC is the other main event organized by EFMI. They are conferences specialized in current topics, which follow a successful concept organized by a member society in combination with its annual meeting. The topic is defined to the needs of the member society, the relevant EFMI working groups are engaged with the content of the contributions mostly on the invitation and it is **a small 2-day conference with 100+ participants**:

❖ STC 2019 was held in Hanover (Germany) April 8 to 10, 2019 (see 5.3)
❖ STC 2020 a proposal was made by Slovenia in Autumn
❖ STC 2021 call for proposal is open

3.2.3. Other EFMI conferences

EFMI is supporting several conferences along the year. These conferences are organized either by EFMI working groups or by entities strongly related to EFMI. The **national conferences** are also important to promote FAIR4Health activities, news, etc. The next important conference for the purpose of FAIR4Health dissemination and community engagement is:

International Conference on Informatics Management and Technology in Healthcare (**ICIMTH**) in Athens (Greece) July 5 to 7, 2019 (see 6.3)

3.3. Regular conferences organized by DCC

The DCC runs its own **annual conference** each February and it is also involved in delivering the RDA plenaries each Spring and Autumn. Both of these events focus on research data management and curation practices so are very relevant to the FAIR4Health project. The incoming events, in this sense are:

❖ Research Data Alliance plenary on "Data Makes the Difference" in Helsinki, Finland, 23-25 October 2019 (see 6.6)
❖ International Digital Curation Conference on "Collective Curation: the many hands that make data work" in Dublin Ireland, 17 - 20 February 2020 [7]
❖ Research Data Alliance plenary, Australia, c. April 2020, exact location & dates tbc

4. FAIR4Health participation in dissemination events

As described in the Outreach strategy (Cf. D7.3) members of the consortium are encouraged to **attend and present the progress of the project**. As we have stated above, main dissemination stream is to be present and active in each conference and international

meetings. Scientific papers, posters, workshops or panels can be proposed to each of the conferences. In general terms the targeted outcomes in this context are:

- ❖ A **scientific paper** is an original publication presented during a conference, published in the proceedings and indexed in Pubmed. The usual length is 5 to max 10 pages. The presentation lasts for 15 to 20 minutes.
- ❖ A **poster** is described in 1 to 2 pages published in the proceeding and the poster is shown at the conference. A poster template should be prepared to be updated following the development made in FAIR4Health. This poster could be proposed as a scientific poster or an information poster showed in the booth of EFMI and IMIA, as well as in other events.
- ❖ A **workshop** or a **panel** is a presentation from 2 to 4 people and last 60 to 90 minutes during the conference. It is described in a three pages paper not published in the proceeding nor in Pubmed. Workshops should be proposed as often as possible to raise awareness and share the concept of FAIRification.
- ❖ A **tutorial** is a course or any other training action given mostly before the beginning of the conference. It is a half or a full day course. It is described in 3 pages not published in the proceeding nor in Pubmed. A standard FAIRification tutorial will be prepared in the context of WP7, and also ideally recorded in video to be integrated in MOOC-like material. Nevertheless, particular or intended tutorials can be planned in specific conferences and contexts.

Any other kind of contribution in different events is also encouraged. E.g. **BoF** (Birds-of-a-Feather). A BoF is an informal discussion group. Unlike special Interest Groups, Working Groups, Task Forces, etc. a BoF are informal and often formed in an ad hoc proposition. BoFs are very common modality to start a work in the context of RDA and FAIR4Health have already organized one (P13) (see 5.2) and will organize a new one in the next plenary (P14 in Finland) (see 6.6).

5. FAIR4Health participation in previous events

5.1. Inforsalud 2019

An **oral communication** was given by SAS at Inforsalud 2019 in Madrid March 6 under the title "FAIR4Health: Mejorando la investigación en salud gracias al uso de datos FAIR" this session was attended by 43 participants from Spain.

5.2. Research Data Alliance 13th Plenary

As part of the RDA's mission, it holds a plenary meeting twice annually and the latest was held in Philadelphia on 2-4 April 2019. [8] FAIR4Health identified the RDA as a key target for its own mission of community engagement and building and therefore UC3M and UEDIN attended the plenary. The structure of the plenary meeting takes the form of breakout parallel sessions interspersed with plenary sessions. The former is composed of *"birds-of-*

a-feather" (BoF), interest and working groups, and which increase in the level of formal participation respectively such that once a group becomes a working group it can create outputs and recommendations. The breakout sessions were deemed to be most useful in our requirements and to this end we proposed active participation by **establishing a new BoF group** and which was accepted by the RDA organising committee. This new group, "Assessing FAIR Data Policy Implementation in Health Research", attracted participation from **30 attendees** from across a spectrum of disciplines and technical backgrounds and this will form the basis for a community from which FAIR4Health can build upon.

Moreover, another previously established interest group, "Health Data Brokerage and Reproducibility", was actively engaged to **forge a collaboration**. This interest group has moved forward through past engagement activities through the RDA and has a more generalised remit than that proposed by FAIR4Health and there is overlap in membership and goals and therefore it is envisaged that this group will act as an umbrella for the FAIR4Health BoF group.

The RDA plenary was also an opportunity for FAIR4Health to recruit participants for the Korsakow films that are being developed

5.3. EFMI Special Topic Conference 2019

The EFMI STC was held in Hanover, Germany April 7 to 10 2019. [9] A **workshop** was conducted by SAS Carlos Luis Parra Calderón and Francisco J. Núñez Benjumea. Under the title "The European FAIR4Health Initiative" they engaged the assistance to reach following objectives:

Goals: To engage stakeholders by providing training and awareness raising on the FAIR data principles and its potential impact in the Health research domain.

- ❖ To **receive feedback** from key stakeholders regarding the challenges posed in the application of the FAIR data principles in Health research and how to overcome them.
- ❖ To **gather expressions of interest** for FAIRification of Health research datasets beyond the FAIR4Health partnership.

Expected Impacts: The session impacted on the following points related to the strategy to adopt the FAIR data policy at EU level:

- ❖ **Increase in the awareness** of the potential benefits in adopting this strategy among key involved stakeholders
- ❖ Contribution to the **definition of the overcoming mechanisms** for tackling the challenges posed by the adoption of the FAIR data policy, and in the definition of the policy guidelines in the long term.

This workshop was followed by **39 participants** and an online questionnaire was conducted to improve and measure the goals.

5.4. Porto4Ageing Networking Event

The project was presented in Porto (Portugal) during the Porto4Aging Networking Event (**23-24 May 2019**) [10] hosted by the University of Porto, partners of FAIR4Health consortium. The project was introduced to more than 30 attendees, including researchers and healthcare managers, as part of the initiatives in which Porto4Ageing, a two-stars reference site of the European Innovation Partnership on Active and Healthy Ageing, is involved. During the presentation, Francisco J. Núñez (SAS) stressed on the importance of translating raw research data to FAIR data in the European research landscape. A primer of the FAIRification workflow developed by FAIR4Health, which is one of the main outcomes of the project at this point, was also presented in this event. The Porto4Ageing Networking Event also gathered experts in artificial intelligence for health sciences, innovators specialized in co-creation and hosted the presentation of the Portuguese node of Research Data Alliance (RDA-pt).

6. FAIR4Health participation in future events

6.1. 2nd Big Data for Precision Medicine Symposium

June 4, 2019 SAS will present in this event in Cordoba (Spain) under the title "FAIR4Health: Improving Health Research in EU Through FAIR Data". The program is available at: https://medal.ctb.upm.es/bdpm2019/programme/. It is held one day ahead of the IEEE Symposium CBMS 2019. It will share session with other EU projects such as CrowdHealth [11], iASiS [12], MIDAS [13] and PULSE [14], among others

6.2. HIMSS Europe

June 11 to 13, 2019 HIMSS Europe proposes a big event in Helsinki. https://www.himsseuropeconference.eu/helsinki/2019/collaboration. As our partner HL7 Europe is an official partner in this event, we will work together to promote our work. A poster could be presented at the booth, and flyers will be distributed.

6.3. ICIMTH

July 5 to 7, 2019 The International Conference on Informatics, Management, and Technology in Healthcare http://www.icimth.com/ It will attract on more than 150 participants. A scientific poster could be presented and a workshop with our partners IMISE, HL7, UNIGE, EFMI.

6.4. MedInfo Lyon

August 25 to 30, 2019 This is the biggest scientific international conference on Medical Informatics**.** http://www.medinfo-lyon.org/en/

The workshop "FAIR Health Data Sharing Initiatives in Europe: Opportunities and Challenges for international cooperation (U Prokosch, T Ganslandt, U Sax, C Lovis, CL Parra Calderón, PR Rijnbeek, N Hughes, W Niessen, B Mons, K Van Bochove" is accepted.

This workshop "FHIR for FAIR: Advancing interoperability for health data (C Chronaki, G Cangioli, A Moen, CL Parra Calderón)" is also scheduled.

6.5. Porto Open Science FAIR

September 16 to 18, **2019.** Porto, Portugal. 2nd Open Science FAIR. *Synergies for Sustainable, Open & Responsible Research*: https://www.opensciencefair.eu. The Open Science FAIR is organized as an emblematic initiative of OpenAIRE, but this year is co-organized by 3 other EU projects in the area of Open Science: FIT4RRI, EOSC Secretariat and FAIRsFAIR. It is locally curated by the University of Minho. And it is the perfect context for FAIR4Health to align with already existing projects in FAIR data, as well as with the so relevant EOSC (European Open Science Cloud) initiative. FAIR4Health is part of a workshop proposal and also supports a poster, and in case both submissions are accepted, about 3-5 members of the consortium will participate in the whole event.

6.6. Research Data Alliance 14th Plenary

October 23-25, 2019. Helsinki, Finland RDA's 14th Plenary. *Data Makes the Difference.* https://www.rd-alliance.org/rda-14th-plenary-helsinki-espoo The plenary meetings of RDA are held twice a year and there are the most important events around research data management in general, where the RDA community evolves and creates recommendations and other outputs. One of the milestones foreseen in FAIR4Health is work within this community in the final statement of the Guidelines for implementing FAIR open data policy in Health Research.

We have now established a group of interested individuals and parties and will progress the agenda further in coming months. Principally among these efforts will be continued face-to-face meetings at the plenaries and we anticipate attendance at the next RDA plenary (RDA 14th Plenary) and beyond since these are typically the only opportunities to do so. The aim will be to hopefully progress the BoF group towards a more formalised Interest Group, and from there a Working Group that can generate RDA approved outputs that can then lead to community adoption.

7. Future events

❖ September 7 – 10, 2019 in Barcelona (Spain): IASLC 2019 World Conference on Lung Cancer https://www.iaslc.org/events/iaslc-2019-world-conference-lung-cancer-wclc19
❖ September 27 - October 1, 2019 in Barcelona (Spain): European Society For Medical Oncology (ESMO) Translating science into better cancer patient care. https://www.esmo.org/Conferences/ESMO-Congress-2019

- ❖ September 28 – October 2, 2019 in Madrid (Spain): European Respiratory Science ERS http://erscongress.org/about-ers-2019.html
- ❖ November: 40th congress of SEMI (Spanish Society of Internal Medicine) (Barcelona, Spain) https://www.congresosemi.org/
- ❖ November 21 – 23, 2019 in Budapest (Hungary): Central European Lung Cancer Conference http://celcc2019-budapest.hu/

8. References

1. The European Federation for Medical Informatics https://www.efmi.org/

2. The International Medical Informatics Association https://imia-medinfo.org/wp/

3. The Digital Curation Center http://www.dcc.ac.uk/

4. The Research Data Alliance Europe https://www.rd-alliance.org/rda-europe

5. Medical Informatics Europe 2020 http://mie2020.org/en/

6. MedInfo 2021 https://medinfo2021.org/

7. 15th International Digital Curation Conference http://www.dcc.ac.uk/events/international-digital-curation-conference-idcc

8. Research Data Alliance 13th Plenary https://www.rd-alliance.org/rda-13th-plenary-programme

9. EFMI Special Topic Conference https://stc2019.plri.de/program/workshop-1

10. Porto4Aging Networking https://techtour.com/events/2019/5/event-digital-health-venture-forum-2019.html?pageId=3088789

11. Collective Wisdom Driving Public Health Policies https://www.crowdhealth.eu/

12. Big Data for Precision Medicine http://project-iasis.eu/

13. Meaningful Integration of Data, Analytics and Services http://www.midasproject.eu/

14. Participatory Urban Living for Sustainable Environments http://www.project-pulse.eu/