

2021-01 FAIR

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Short Description	The intent of this track is to engage the FHIR and FAIR communities on the implementation of the FAIR (Findability, Accessibility, Interoperability, and Reuse) principles and FAIR health data objects by using HL7 FHIR. This objective will be pursued by leveraging on existing HL7 FHIR implementation experiences.
Long Description	<p>There is a growing interest, above all in the research communities, on FAIR data. The aspirational nature of principles however led to a wide range of interpretations of FAIRness. The FAIR principles by itself in fact do not strictly define how to achieve a state of FAIRness.</p> <p>To facilitate the implementation and the assessment of FAIR health data by using HL7 FHIR, a new HL7 project (called FAIRness for FHIR) is going to be started: the first objective of this project is the development of a new FHIR IG (FHIR4FAIR) to support social and health data FAIRness.</p> <p>This first edition of the FAIR track aims to engage the FHIR and FAIR communities on the implementation of the FAIR principles and the assessment of the FAIR indicators, by collecting and discussing implementation experiences, known challenges, and proposed solutions,..... This also by testing and supporting the refinement of existing project specific FHIR IGs as the EU funded FAIR4Health project.</p> <p>The outcomes of this track will be used as first input for the development of the FHIR4FAIR FHIR IG.</p>
Agenda	Proposed Scheduling (the schedule may change, the latest agenda is available on Whova) Wednesday 13th

- Kick-off FAIR Track - Wed - 8 am PT / 11 am ET / 17 CET



20210113 17h Kick...ff FAIR track.pdf

- Educational session: FAIR principles - *Catherine Chronaki* - Wed - 9 am PT / 12 am ET / 18 CET



20210113 Educatio...IR principles.pdf

Thursday 14th

- Break-out session: Sharing experiences - The FAIR4Health project - *Alicia Martínez-García; Mert Gencturk; Anil*



20210114 15h Brea...ealth project.pdf

Sinaci - Thursday - 6 am PT / 9 am ET / 15 CET (1h)

- Break out session: What are the main challenges to be addressed ? - Thursday - 8 am PT / 11 am ET / 17 CET (1h)
- Educational session: RDA FAIR metrics - *Oya Beyan* - Thursday - 10 am PT / 13 ET / 19 CET

Friday 15th

	<ul style="list-style-type: none"> • Break-out session: Sharing experiences - Making Biomedical Research Informatics Computing System (BRICS) data FAIR - Olga Vovk - Fri - 6 am PT / 9 am ET / 15 CET (1h) • Break-out session: FAIR principles in the development of Evidence-related FHIR Resources - <i>Brian S. Alper</i> - Fri - 8 am PT / 11 am ET / 17 CET (1h) • FAIR track highlights Friday Fri - 9 am PT / 12 am ET / 18 CET (15 min) • FAIR track wrap-up Fri - 12 am PT / 15 ET / 21 CET
Type	Educate on the use of a FHIR technology/IG (Test a FHIR-associated specification)
Submitting Work Group/Project /Accelerator /Affiliate /Implementer Group	FAIRness for FHIR HL7 project (SOA WG) / FAIR4Health (EU funded project)
Proposed Track Lead	Alicia Martínez-García, alicia.martinez.garcia@juntadeandalucia.es Giorgio Cangioli, giorgio.cangioli@hl7europe.org
Related Tracks	
FHIR Version	FHIR R4
Specification(s) this track uses	
Artifacts of focus	
Clinical input requested (if any)	N/A
Patient input requested (if any)	N/A
Expected participants	<p>Expected participants:</p> <ul style="list-style-type: none"> • Scientific community <ul style="list-style-type: none"> • FAIR researchers <ul style="list-style-type: none"> • FAIR projects • FAIR-connected organizations (e.g. EOSC; RDA;..) • Data science researchers • Software engineering researchers • University community • Health providers <ul style="list-style-type: none"> • Health data owners • Health policy makers • Health data stewards • Health data curators • Developers and/or integrators • EHR-S vendors • Pharma organizations <p>We expect to have at least 5-10 participants.</p>
Zulip stream	https://chat.fhir.org/#narrow/stream/267332-FAIR
Zoom Link	TBD
Track Orientation Date	December 17th 11:00 ET // 17:00 CET https://global.gotomeeting.com/join/421902093

**Track Orientation
Details**

Slides



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Presentation (mp4)



2020-12-1...ation.mp4

Track Details

As described in the introduction, this first edition of the FAIR track aims to engage the HL7 FHIR community on the implementation of the FAIR principles and the assessment of the FAIR indicators, by collecting and discussing implementation experiences, known challenges, proposed solutions, etc.

Type of systems (system roles) that could participate in this track:

1. Data source system: system from which original data (raw data) are provided, and FAIR data are obtained / generated. Original data can be provided in different formats.
2. Data analysis, curator and validator system: FHIR-based system allowing the selection of data, analysis, the authoring of metadata, the validation of FAIR data. This actor provides also capabilities for aggregating metadata such as provenance information, licences, versions, indexes, and/or other local metadata. (to be evaluated if these capabilities might be provided by a distinct Metadata curation system)
3. Data de-identification & anonymization system: FHIR-based system responsible for applying the requested procedure of de-identification & anonymization of data before their publication.
4. Data Semantic mapping system: FHIR-based system supporting model and terminology mapping.
5. FAIR data registry/repository system: FHIR-based system supporting the consultation and the retrieval of FAIR data, in conformance with their conditions of use.
6. FAIR data consumer system: system consulting and retrieving FAIR data, in conformance with their conditions of use.

The following described **scenarios** participating systems can engage in during the connectathon, are provided for exemplification purposes; also others, realized by existing implementations, can be evaluated and discussed.

Technical scenarios:

1. An agreed raw dataset are collected from data source systems and made available for analysis, curation, validation, semantic modeling, and/or metadata aggregation.
2. Curated, validated, with appropriate metadata (including the condition of use), and semantic model data, are de-identified & anonymized as needed.
3. Processed FAIR data are published in a FHIR-based FAIR repository.
4. FAIR data are queried and retrieved by authorized consumers, in accordance with their conditions of use.

Functional scenarios:

- (example) FAIR4Health use case #1: Characterization of multi-morbidity patterns and association with health outcomes in the elderly.
- (example) FAIR4Health use case #2: Early prediction service for 30-days readmission risk in COPD patients.
- (example) Sharing of COVID-19 patients dataset.

Security and Privacy Considerations:

Taking into account we are going to perform testing using anonymized data from real patients, participants undertake to:

- Do not use the testing datasets for any other purpose than the Connectathon
 - Remove the testing datasets at the end of the Connectathon.
 - Do not make any attempt to re-identify patients.
- More information [here](#).

References

- Wilkinson, M. D., Dumontier, M., Aalbersberg, I. J., Appleton, G., Axton, M., Baak, A., ... & Bouwman, J. (2016). The FAIR Guiding Principles for scientific data management and stewardship. *Scientific data*, 3(1), 1-9.
- Sinaci, A. A., Núñez-Benjumea, F. J., Gencturk, M., Jauer, M. L., Deserno, T., Chronaki, C., ... & Erturkmen, G. B. L. (2020). From Raw Data to FAIR Data: The FAIRification Workflow for Health Research. *Methods of Information in Medicine*, 59(S 01), e21-e32.
- FAIR4Health project. Deliverable D2.1. Technical recommendations for the FAIR4Health platform and agents implementation. <https://osf.io/huy9r/>