

The Project Context



Vision: RDA and HL7 cooperate to promote **FAIR data** by using **HL7 standards**.



Goal: jointly **develop HL7 Guides** enabling **FAIRness**.




Objective: start an **HL7 Project** providing guidance on how to use HL7 FHIR for data FAIRness.

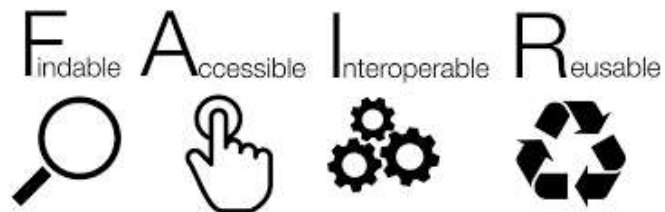
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 824666

Why I'm here..

- Seek for the Security WG support for the «FAIRness for FHIR» (<https://jira.hl7.org/browse/PSS-1657>) project proposal , as
 - project co-sponsor or
 - Interested party
 - Informal colaboration



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- The FAIR principles – first introduced in 2014 – (<https://www.go-fair.org/fair-principles/>) intend to **define a minimal set of community-agreed guiding principles** and practices that allow both machines and humans to find, access, interoperate and re-use research data.
- Principles by itself **do not strictly define how to achieve a state of FAIRness** but describes desired features for digital objects.
- The FAIR principles are well received in international community and rapidly adopted by researcher.
- The aspirational nature of principles led to a **wide range of interpretations of FAIRness**
- **FAIR data ≠ Data freely accessible by everyone**

FAIR in the Health Care Context

Achieving FAIRness by using HL7 FHIR

- 1) Explore at which degree FHIR standards leverage us to comply with FAIR:
 - How HL7 FHIR standards can help our community in FAIR maturation?
 - How much of essential, important and useful indicators can be fulfilled by applying FHIR standards ?

- 2) How FHIR can be used to support FAIR data:
 - What are the unaddressed FAIR indicators after complying with FHIR standards?
 - How FHIR can be used to ensure FAIR compliance ?

Courtesy of Oya Beyan, Fraunhofer, RDA DE

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FAIR Facets and Principles

- Accessible.
 - Once the user finds the required data, she/he needs to know how can they be accessed, possibly including authentication and authorisation.
- Reusable.
 - R1.1. (Meta)data are released with a clear and accessible data usage license.
 - R1.2. (Meta)data are associated with detailed provenance

FAIR Data Maturity Working Group

Home » Working and Interest Groups » Working Group » FAIR Data Maturity Model WG

FAIR Data Maturity Model WG

WG

Taxonomy:

- Posts
- Create Wiki Index
- Events
- Repository
- Outputs
- Case Statements
- Plenaries
- Members

create new content

Group Status: WGs Maintaining deliverables (maintenance group) [Join Group](#)

Status: Recognised & Endorsed
Chair (s): Edit Herczog, Keith Russell, Shelley Stall
Secretariat Liaison: Stefanie Kethers
TAB Liaison: Jane Wyngaard

FAIR Data Maturity Model: core criteria to assess the implementation level of the FAIR data principles

The RDA FAIR Data Maturity Model Working Group develops as an RDA Recommendation a common set of core assessment criteria for FAIRness and a generic and expandable self-assessment model for measuring the maturity level of a dataset. The aim is not to develop yet another FAIR assessment approach but to build on existing initiatives, looking at common elements and allowing the group to identify core elements for the evaluation of FAIRness. That will increase the coherence

https://www.rda-consortium.org/rdm-looked.html ... of existing or upcoming FAIR assessment frameworks, and it will ensure the combination and consistency of their results in a meaningful way.

Specification and Guidelines: DOI: 10.15497/rda00050

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FAIR Data Maturity Model Specification and Guidelines 2020

A1	RDA-A1-04M	Metadata is accessed through standardised protocol	●●●	Essential
A1	RDA-A1-04D	Data is accessible through standardised protocol	●●●	Essential
A1	RDA-A1-05D	Data can be accessed automatically (i.e. by a computer program)	●●	Important
A1.1	RDA-A1.1-01M	Metadata is accessible through a free access protocol	●●●	Essential
A1.1	RDA-A1.1-01D	Data is accessible through a free access protocol	●●	Important
A1.2	RDA-A1.2-01D	Data is accessible through an access protocol that supports authentication and authorisation	●	Useful
A2	RDA-A2-01M	Metadata is guaranteed to remain available after data is no longer available	●●●	Essential
I1	RDA-I1-01M	Metadata uses knowledge representation expressed in standardised format	●●	Important
I1	RDA-I1-01D	Data uses knowledge representation expressed in standardised format	●●	Important
I1	RDA-I1-02M	Metadata uses machine-understandable knowledge representation	●●	Important

R1	RDA-R1-01M	Plurality of accurate and relevant attributes are provided to allow reuse	●●●	Essential
R1.1	RDA-R1.1-01M	Metadata includes information about the licence under which the data can be reused	●●●	Essential
R1.1	RDA-R1.1-02M	Metadata refers to a standard reuse licence	●●	Important
R1.1	RDA-R1.1-03M	Metadata refers to a machine-understandable reuse licence	●●	Important
R1.2	RDA-R1.2-01M	Metadata includes provenance information according to community-specific standards	●●	Important
R1.2	RDA-R1.2-02M	Metadata includes provenance information according to a cross-community language	●	Useful

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FAIR Data Maturity Model Specification and Guidelines 2020

RDA-R1.1-01M Metadata includes information about the licence under which the data can be reused

●●● Essential

Principle to which the indicator relates

This indicator is linked to the following principle: *R1.1: (Meta)data are released with a clear and accessible data usage licence*. More information about that principle can be found [here](#).

Description of the indicator RDA-R1.1-01M

This indicator is about the information that is provided in the metadata related to the conditions (e.g. obligations, restrictions) under which data can be reused. In the absence of [licence](#) information, data cannot be reused.

Assessment details

This indicator can be evaluated by looking in the metadata for licence information. This information may be in human-readable text; machine-understandability of the information is covered in indicator RDA-R1.1-03M.

RDA-R1.1-02M Metadata refers to a standard reuse licence

●● Important

Principle to which the indicator relates

This indicator is linked to the following principle: *R1.1: (Meta)data are released with a clear and accessible data usage licence*.

Description of the indicator RDA-R1.1-02M

This indicator requires the reference to the conditions of reuse to be a [standard licence](#), rather than a locally defined licence.

Assessment details

The indicator can be evaluated by verifying that the licence is indeed a standard licence. Examples of standard licences are: [Creative Commons licences](#), [Open Data Commons](#).



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Goal of the proposal

- To provide **guidance on supporting FAIRness with HL7 FHIR** and specifically:
 - the FAIR (Findability, Accessibility, Interoperability and Reusability) principles and
 - the proposed RDA (Research Data Alliance) recommendations on FAIR data maturity model, providing indicators for assessing adherence to the FAIR principles.
 - the recommendations of RDA Reproducible Health Services Working Group for describing, documenting, and sharing metadata for health data curation workflows

Scope of the guide

- Identify how **HL7 FHIR** standard fulfils data **FAIRness maturity indicators**
 - analyse relationship between FAIR data object conceptual components (e.g. data, metadata, provenance, identifiers) and HL7 FHIR resources
 - analyze how RDA FAIR Maturity indicators are supported by specific HL7 FHIR resources
 - analyze how RDA Reproducible Health Data Services recommendations can be supported by HL7 FHIR
 - identify a minimum set of metadata to be fulfilled for specific sets of RDA FAIRness maturity indicators extended for health-related research data sets.
 - provide examples of best practices from EOSC or NIH.
- Suggest an assessment methodology/checklist, exploring machine readable and manual assessment methods.

How the FHIR4FAIR IG should look like ...

- a large informative part explaining how
 - FAIR principles can be supported by using HL7 FHIR;
 - conceptual components of the FAIR data objects maps into FHIR;
 - data FAIRness maturity indicators may be assessed by using FHIR;
 - and so on.
- a set of FHIR conformance resources and examples that provide, for selected case(s), a practical example of how it should be realized.

HL7 FHIR an enabling factor for FAIRness

FAIR4Health

evaluated if and how the **HL7 FHIR** standard can support the data FAIRification;



highlighting the relationships between **FAIR data object conceptual components** and HL7 FHIR

assessing the **Force11 Facets and Principles** and the **FAIRPorts requirements** as described by Force11 community;



FAIR data doesn't imply FAIR data...

...but FHIR may help the FAIRness.