Committee Approval Date:
SOA WG - 03 Jun 2021

Publishing Lead:
Giorgio Cangioli

Contribution or Reviewing Work Groups:
- BR&R would like to be kept informed of progress, particularly to ensure the relevance of FAIR principles in Clinical Research are taken account of.
- CDS wishes to be an Interested Party, given that we are interested in applying the same FAIR principles to the creation, management, and access of knowledge artifacts.
- FHIR-I would like to be kept informed of progress.

FHIR Development Project Insight ID:
1651

Scope of coverage:
The main goal of this guide is to enable a cooperative usage of the HL7 FHIR and FAIR paradigms, that is a quite new area for HL7.

In this version of the guide conformance resources are limited to Study level (Data collection) and - where applicable - subject level FAIR data object metadata.

This guide is and will not attempt to define any domain specific FHIR profile (e.g how to represent genetic data) for describing the subject level FAIR data objects; but it will rely on existing Igs for the representation of such a data.

Target Audience of this guide are: Researchers; Health Data Providers; Technical Implementers; Government agencies

Content location:
https://github.com/HL7/fhir-for-fair

Proposed IG Title:
FHIR for FAIR Implementation Guide
Proposed IG realm and code:
UV fhir-for-fair

FHIR Core version(s):
FHIR Release #R4B (4.1.0)

Maintenance Plan:
The IG will be continuously maintained by the FAIRness for FHIR project team currently established under the SOA WG

Short Description:
The FHIR for FAIR Implementation Guide provides guidance on how the HL7 FHIR standard can be used for supporting the implementation and the assessment of the FAIR principles for health data.

Long Description:
The FAIR principles define a minimal set of community-agreed guiding principles and practices that allow both machines and humans to find, access, inter operate and re-use research data.

This guide explains, starting from a set of selected representative real word cases, how the HL7 FHIR standard can contribute in:
- the implementation of the FAIR principles, in particular of the interoperability and reusability dimensions;
- the FAIRness assessment, by using the RDA FAIR Data Maturity Model;
- the improvement of the FAIR maturity

The guide is composed by an informative part addressing the above mentioned points and by a set of FHIR conformance resources and examples for these selected cases.

Other kinds of health-related artefacts, as clinical guidelines, algorithms, software, models are out of scope.

Involved parties:
no external agencies

Expected implementations:
The FAIR4Health Project; SRDC; ATOS

Content sources:
FAIR Data Maturity Model Specification and Guidelines 2020 - DOI: 10.15497/rda00050
The FAIR Guiding Principles for scientific data management and stewardship - DOI: https://doi.org/10.1038/sdata.2016.18

Example Scenarios:
A set of data (e.g. a set of ECG Multimodal Foetal ECG-Doppler) is published as part of a publication. This data set is made available to other researchers, under well defined conditions of use. A rich description of the data set content (study level metadata) and of each set of measures (subject level metadata /data) is provided to enable the discovery, the retrieval and the re use of such a data, by applying the FAIR data principles.

A repository aims to be a trustworthy data resources and an essential component of the research enterprise focusing on immunological research. It offers support to the community by providing data sets and data types in specific domains and across clinical, laboratory and computational areas. Data sharing, management, and dissemination is planned to be realized by following the FAIR Data Principles and by adopting appropriate standard as HL7 FHIR to improve data reusability and interoperability.

IG Relationships:
No direct dependencies

Timelines:
STU ballot: September 2021