Supporting FAIR data discoverability in clinical research: Building an object metadata repository (MDR) of clinical study objects

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Background:

Data and documents generated in a clinical study (*study protocol, statistical analysis plan, case report form, analysis data set, publication, etc.*) is collected and stored in a wide variety of different locations (*e.g. data repositories, institutional repositories, trial registries, publications, web pages, etc.*). To maximize the **discoverability** of all these data objects, it is necessary to collect the **metadata** about them, including object provenance, location and access details, into a single system (Figure 1).

Fig. 1 - MDR schema: Collection, storage and linkage of clinical trial studies and related data objects from different locations

Target:

In the EU H2020 funded XDC project (<http://www.extreme-datacloud.eu/>) we developed an **MDR** (MetaData Repository) to standardise, assemble and display the metadata about clinical studies and related data objects and provide access to them through a web portal.

Conclusion:

A demonstrator MDR has been successfully developed and tested. Next steps will be to integrate further data sources and to increase functionality. It is planned to provide the MDR as open service in the European Open Science Cloud (EOSC).

References:

- Canham, Steve. (2019). ECRIN Clinical Research Metadata Schema Version 3.0 (November 2019) (Version 3.0). Zenodo.
- Goryanin et al.: Supporting FAIR data discoverability with a metadata repository for clinical study objects. EOSC-hub Week 2019

Implementation:

The implementation process is presented in Figure 2. Metadata of clinical studies and related data objects were collected from 4 sources, processed, stored and mapped to a common metadata schema by ECRIN (Table 1). The metadata were converted into JSON format and transferred and injected into the Onedata environment. A harvester built upon Elastic search was developed by INFN and implemented as plugin into OneData. The web portal for searches of studies and metadata of associated data objects was provided by Onedata (Figure 2,3).

Source	Extraction Method	Study Records	Data Object Records	Study-object links
Clinical Trials.gov	Bulk download of xml files, extraction from the xml	325,352	389,665	389,665
PubMed	Filtered download of xml files via API, extraction from the xml	0	79,392	85,855
BioLINCC	Web scraping from the BioLINCC web site	203	1337	1337
Yoda	Web scraping from the Yoda web site	376	2544	2544
Total		325,931	472,938	479,401

Table 1 – Records downloaded and extracted

Fig. 2 – Current architecture of MDR demonstrator

Fig. 3 – Screenshot of MDR portal