Title:

Selection of Collections Based on Available Data and Their Quality

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Problem:

When biomedical researchers require material and data for their studies they search samples and collections in biobanks. This search can be based on phenotypical or genotypical data of donors, therapeutical data, lifestyle data, etc. Increasingly, this search does not only aim at pointers to samples but also to available data associated with the samples, which can be used in the studies. Here data quality is of essential importance and support for the specification of quality requirements is needed.

Solution:

We present a metadata model which captures the data available for collections in biobanks in a generic and semantic way based on reference ontologies to overcome the problem of different data representation formats and encodings. The prototype implementation used LOINC Codes as reference ontology. This representation is augmented with a representation of essential data quality characteristics on the sample and on the collection level. Search in this metamodel yields which collections contain the specified data in the requested quality.

Discussion:

The metamodel provides an infrastructure for search for appropriate biobanks and collections for a specified requirement data and data quality requirements. It is by far more expressive than biobank directories and does not require nor is it restricted to a minimal data model. It is very flexible and allows to use ontological hierarchies to extend and/or restrict the search. The explicit inclusion of data quality allows to avoid to chase collections which are ultimately not usable. Empirical evaluations of the efficiency of the metamodel for study preparations are planned.

Requirements for a Biobank Portal to Communicate with Donors

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Abstract:

Background:

Communication with donors is essential for biobanks to establish trust, motivate donations of biological material and data, and support necessary processes. A portal where stake holders receive specific and personalized information considered as a tool to facilitate this communication. The goal of this study was to explore the requirements for such a portal, elicit which information should be provided, and which processes could be supported.

Method:

A first set of requirements was collected in interviews and a workshop. Then a mock-up portal was produced, presented to stake-holders who were then asked to comment on the mock-up and provide additional information requirements, respectively, provide arguments for and against the inclusion of the presented information items. The results led to a cycle of implementing, presenting, and discussing versions of the mock-up. The final version was then presented to a larger audience and the comments were collected in a questionnaire.

Results:

The result is a collection of information requirements for a donor portal including managing of donor profile data, of informed consents, of information about donations, and about the usage of donations in projects.

Discussion:

The resulting list of requirements is complemented with arguments for the inclusion or exclusion of certain information items, discussions for the appropriate level of granularity for some information items and arguments about the efforts required by biobanks to provide the information items on a personalized basis. We expect the final mock-up to be a generic blueprint for biobanks considering to develop such a portal.