

P139: Sample Index: A tool for searching in biobank data taking into account privacy restrictions

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Introduction

To provide material and data to researchers efficiently, biobanks have to implement means of searching for collections that contain the data needed for research. The problem with such a search is that direct access to the sample data may be subject to privacy restrictions. One solution is to search in a central repository of quality annotated metadata augmented with indexes.

Methods

As part of BBMRI.at research, in addition to metadata-based search, we propose to design and implement a sample index tool supporting the search for suitable collections within preprocessed non-sensitive data. It consists of the data anonymization component converting the biobank data into a non-sensitive form, the repository storage component holding metadata, quality data, and index data, and the search component running queries against the repository and returning requested collections.

Results

The concept of a sample index was implemented as a software tool that supports a search within the repository storing biobank data after its K-anonymization, aggregation, and annotation with OMOP CDM concepts. It was validated with data from the BBMRI Colorectal Cancer Cohort.

Discussion

We address compliance with the accessibility principle for biobank data by opening the possibility to search within non-sensitive data when the original data is not accessible. The novelty of the tool lies in its support for semantic data annotation together with its aggregation and anonymization such that the central repository can offer rather fine grain information about collections and their associated data sets without any potential compromise of the privacy of the donors.

Keywords

biobank search, repository, data quality, anonymization, data aggregation