

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 is 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.