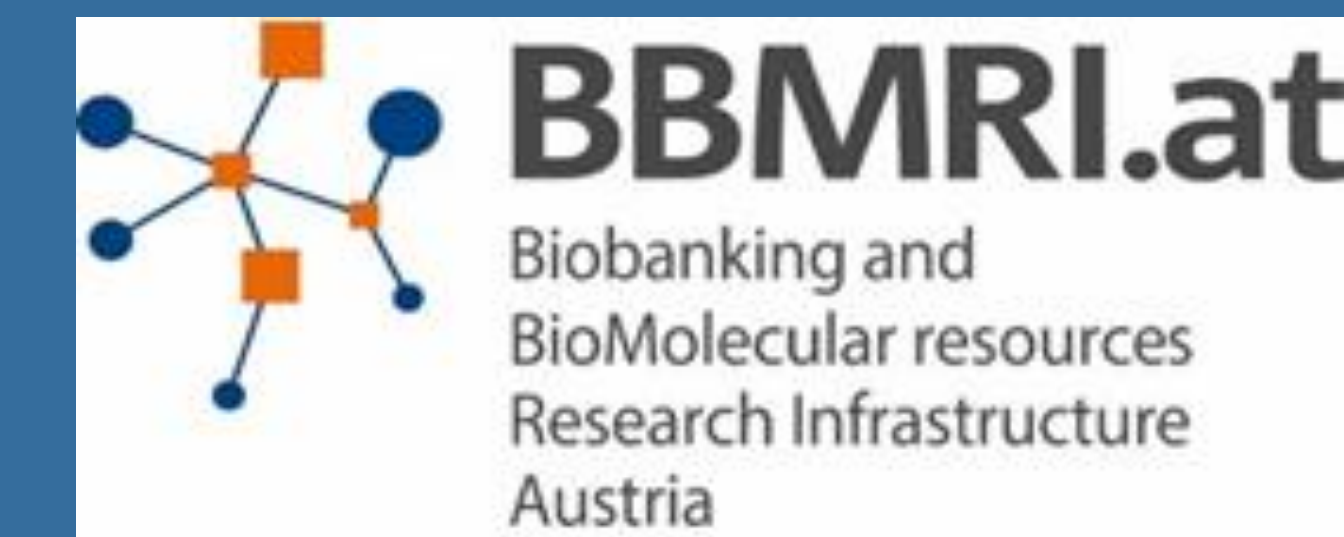# REQUIREMENTS FOR A BIOBANK PORTAL TO COMMUNICATE WITH DONORS

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INTRODUCTION

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.

AIM

- 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.
- The goal is not a general (software) solution for all biobanks but rather a framework which can then be instantiated by each biobanks according to the local situation and possibilities.
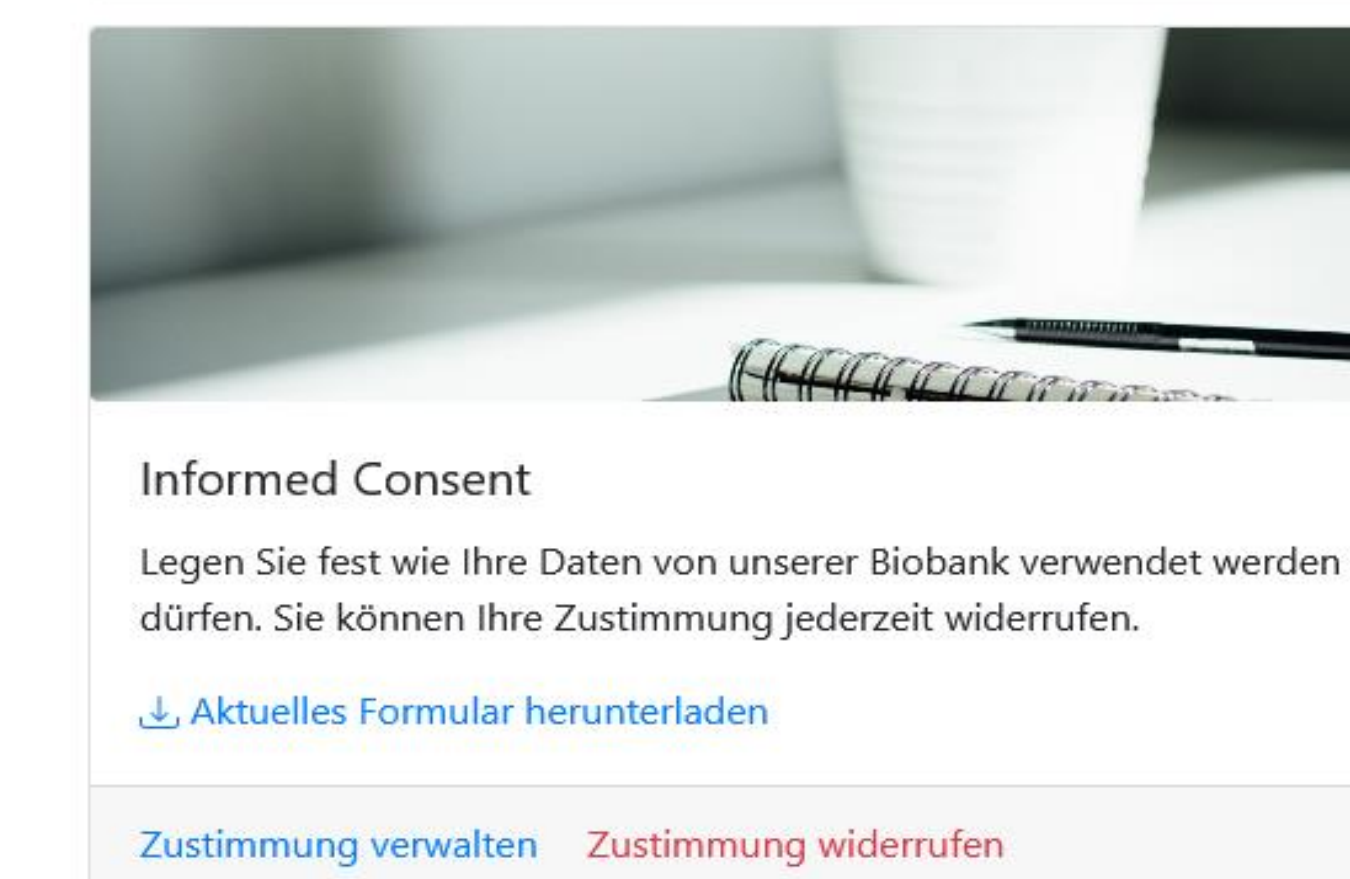
RESULTS

1. It was generally considered as valuable and useful to have a portal for communicating with donors.

2. The portal should enable donors to gather overview about their relationship with the biobank, should link to relevant information about biobanks in general and about the contacted biobank in particular.

3. Donors should be offered a communication channel with the biobank through the portal.

4. The details of information about donations and their use has to be extremely carefully designed to avoid any problematic inferences by the donors and great care is necessary to avoid misunderstandings.

5. The level of detail of information about donations and their use depends heavily on the information systems of the individual biobanks and which information in which granularity they can reasonably produce.

Information items and service stubs:

1. Donor profile
   - Login information
   - Contact details

2. Informed consent
   - List of signed informed consents
   - Adjustment of informed consents
   - Opt-out information
   - Reconsenting

3. Donations
   - List of donations
   - Collections containing donations
   - Data donations
   - Consent for follow-up examinations

4. Usage of donations
   - Projects using collections including donor's samples
   - General list of projects

5. General information
   - Information about biobank
   - Information about biobanking in general
   - Educational Material (articles, videos, etc.)

6. Contact information
   - Contact form
   - Email, address, phone

MOCK-UP

METHOD

For eliciting the we followed an iterative approach using horizontal prototyping.

- 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 comments were collected in a questionnaire.

CONCLUSIONS

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.

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