

THE VALUE(S) OF/IN INFRASTRUCTURING THE BIOSCIENCES REFLECTING BIOBANKING FROM A SOCIAL SCIENCE PERSPECTIVE

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ABSTRACT

This social science (science and technology studies) research project aims at

- (1) providing a better understanding of how biobanks as an infrastructural resource are valued (and used) by different kinds of actors;
- (2) developing insights into the changing relations of citizens to their biological data collected in biobanks – in terms of rights, expectations and self-understandings; and
- (3) investigating how the new data protection regulation impacts biobanking, the use and sharing of material and data as well as the process of donating.

This research is pursued in order to support a responsible and sustainable development of biobanks while engaging with societal actors, their values and concerns.

BUILDING RESPONSIBLE AND SUSTAINABLE BIOBANKS

Biobanks as Infrastructures

Biobanks are core infrastructures for research and innovation in the biomedical sciences; they impact the ways how the biosciences are and can be done – therefore we speak of **infrastructuring the biosciences**. Biobanks

- have a strong future orientation, as they pool resources to advance research into new territories;
- bring donors, research communities, actors in the health industry, policy makers, bioethicists and biomedical objects into interaction (Larkin, 2013);
- are the expression of specific values and expectations and reflect new distributions of responsibilities (Akrich, 1992).

General Data Protection Regulation

Opens new questions and debates on

- the relationship of biobanks to citizens and donors,
- the ownership of data, and
- practices of collecting, storing and making available data.

Responsible Research and Innovation (RRI)

Using the RRI approach (Felt, 2018; Stilgoe et al., 2013) in our research means

- being attentive to values and diverse understandings in/of biobanking
- caring for and being responsive to societal concerns
- engaging with forward-looking dimensions of biobanking, considering aspects of uncertainty and non-knowledge.

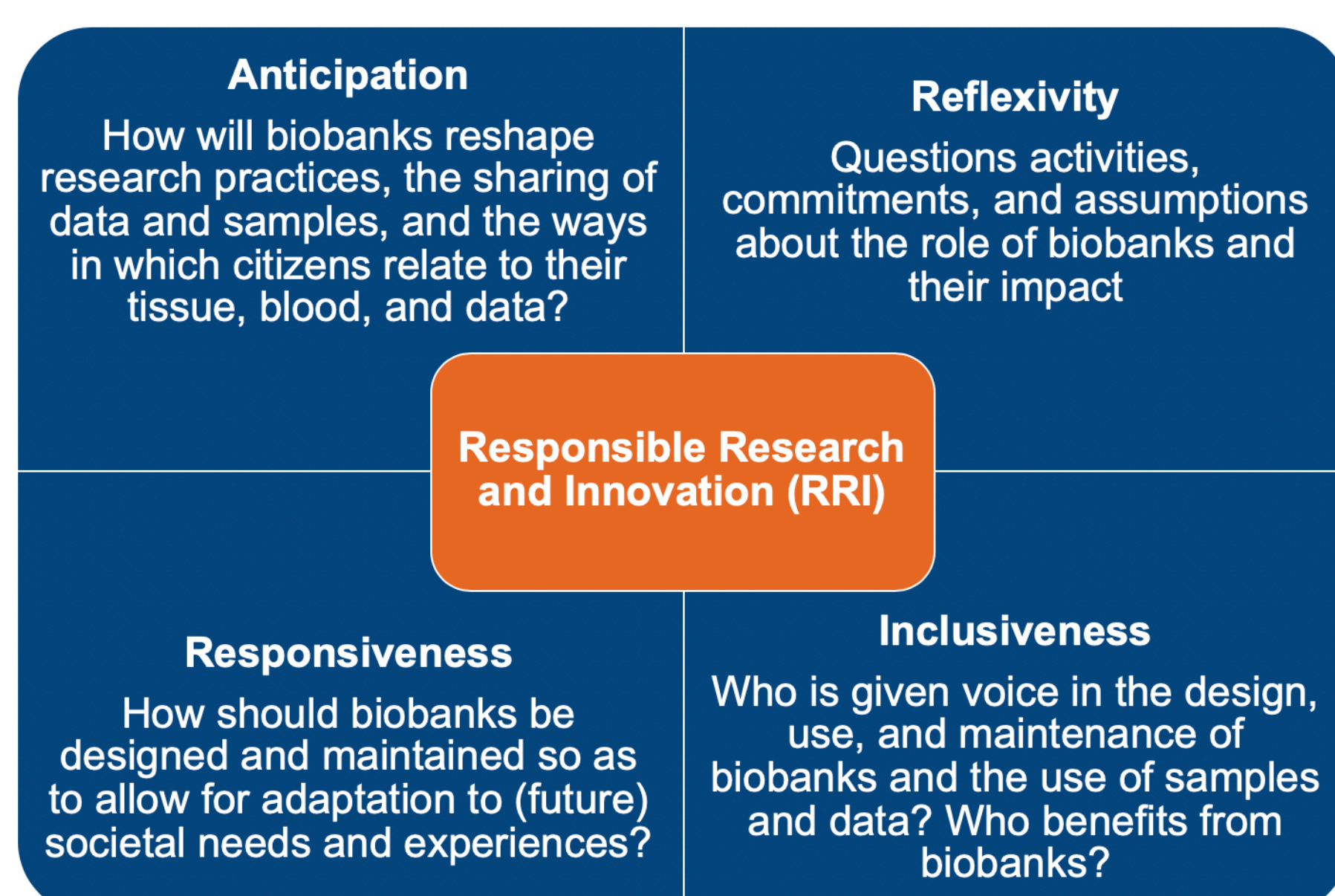


Figure 1 The four dimensions of RRI (Stilgoe et al., 2013)

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VALUE(S) AND VALUING

In this part of our project we aim at developing deeper insights into practices and processes of valuing (i.e. creating, inscribing and assessing value(s)) in the context of biobanks.

- Every biobank stands for particular values and expectations, carries visions of potential future use(s), and contains specific ideas about who has to take care of issues of ethics and responsibility — we investigate ‘values **IN** biobanking’.
- Actors – from donors, over sponsors, to biobankers and researchers – hold particular understandings of what makes biobanks particularly valuable, or what needs to be done to increase the value of samples and data – we create insights into the ‘value **OF** biobanking’.
- Biobanks are not merely based on a predefined set of ethical/value related principles to be followed; as infrastructures they also shape and realize them, and take part in generating value and values.

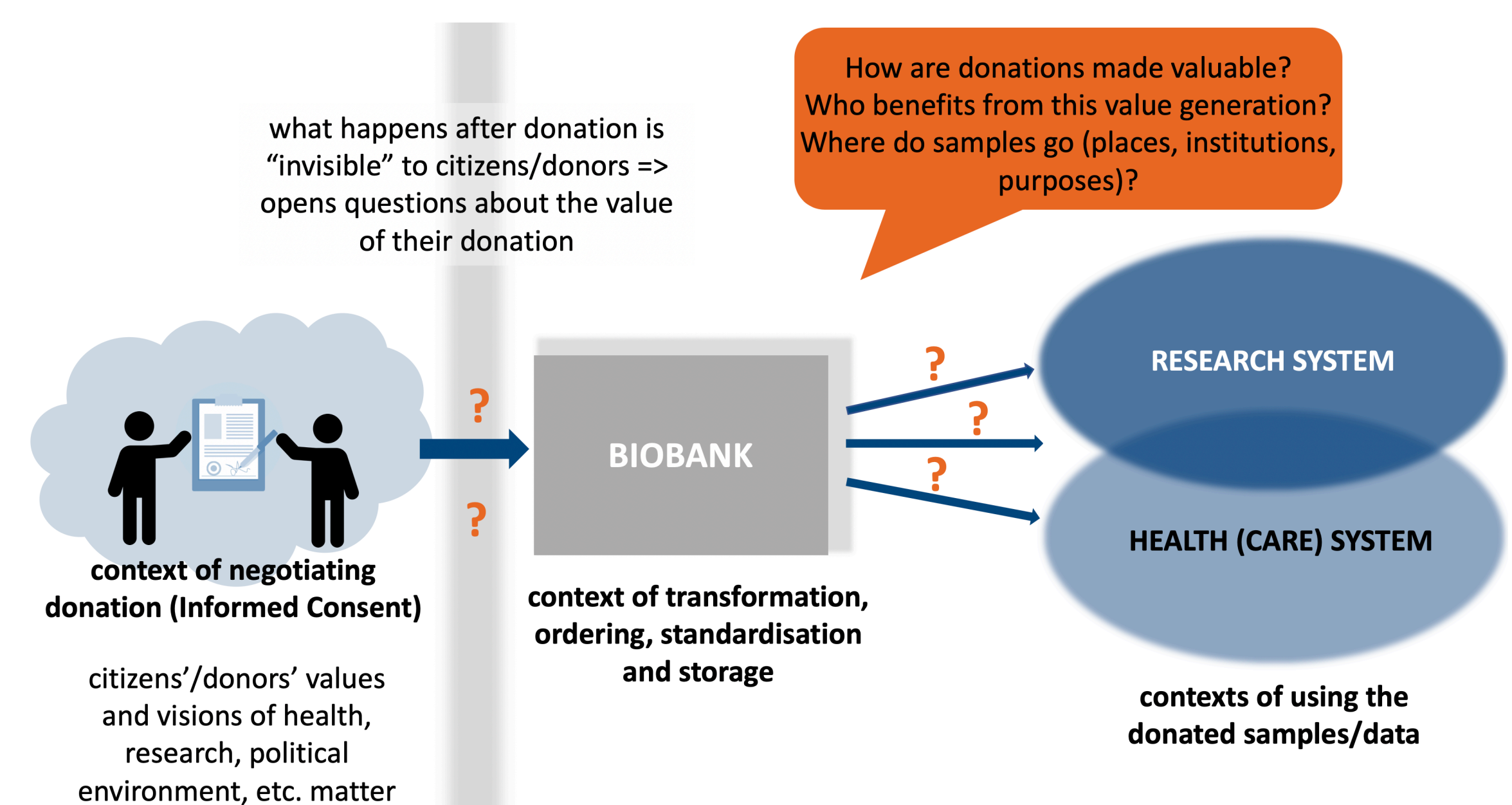


Figure 2 Biobanking – processes and practices of valuing

BIO-DATA AND CITIZENSHIP

We explore the relationship between biological data and being a citizen with rights and obligations in the wider context of ‘big data’ becoming an important matter of concern in public debates. The objective is to explore individual and collective imaginations around the relation of citizens and researchers to “their” data.

Specifically, we engage with:

- how different actors understand the relation of data and human identity;
- how the human/data relationship is perceived in the wake of the GDPR; and
- how data protection is enacted by both donors and researchers.

Across all investigations, we seek to understand what issues of responsibility are addressed, how they are seen as resolved in current biobanking systems and what changes would be needed.

METHODS

1 Data Collection and Analysis

We will use a set of different methods (including document analysis, semi-structured interviews, ‘walk-shops’ in biobanks, and group discussions with citizens/donors) to investigate the understandings, experiences, and practices of a diverse set of actors — citizens/donors, researchers/biobankers, regulators, economic actors, policy makers and ethics board members — in the field of biobanks. We use situational analysis to analyze the collected data (Clarke, 2005).



2 Integration

Continuous engagement with and feedback from members of the BBMRI.at consortium through regular workshops.

