IF PUBLIC ENGAGEMENT IS THE SOLUTION, THEN WHAT IS THE PROBLEM?

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Patient engagement

Growing discussion on the role of patients in biobanking: from being seen simply as donors, to actual collaborators/partners in the design, development and the running of biobanks and related research

Often described as key for the further development of biobanking

However, studies show important differences according to the kind of biobank, the context, ….

publics, patients, healthcare workers, researchers, governmental actors, funders, healthcare providers, ethicists, regulators, …..

kinds of biobank
disease-oriented biobanks
population-wide biobanks
cohorts
project specific biobank collections …

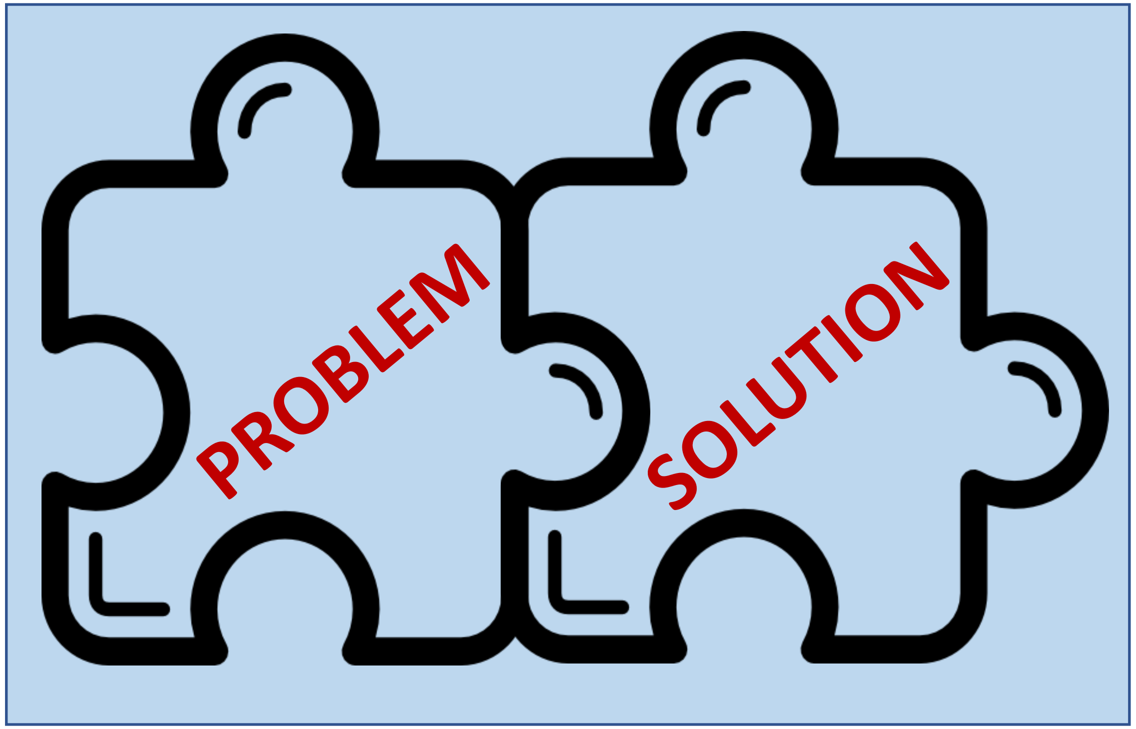
different "stakeholder ecologies"
national/institutional contexts,
(techno)political cultures, disease, …

Making *problem-solution packages*

Defining what the problem is means also framing potential solutions

– and the other way round

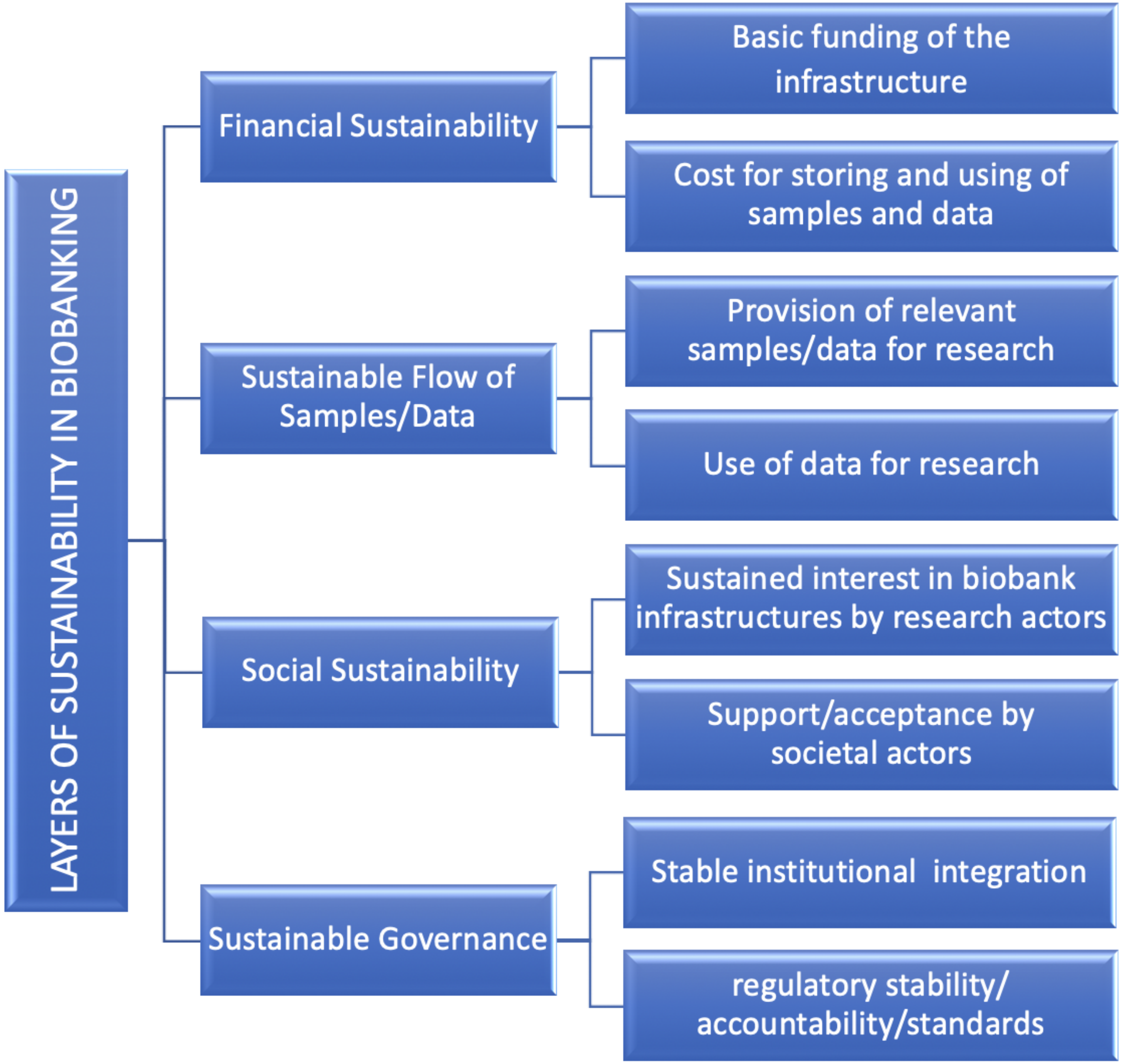
Defining something as the solution also means framing potential problems



Challenge:
Sustainable biobanking

Where, when and how do patients/publics figure if sustainability of the problem?

Felt, Metzler, Ferent 2020; BBMRI.at#2
Layers of sustainability (Fig 3, D4.1.1)



LAYERS OF SUSTAINABILITY IN BIOBANKING

Financial Sustainability
- Basic funding of the infrastructure
- Cost for storing and using of samples and data

Sustainable Flow of Samples/Data
- Provision of relevant samples/data for research
- Use of data for research

Social Sustainability
- Sustained interest in biobank infrastructures by research actors
- Support/acceptance by societal actors

Sustainable Governance
- Stable institutional integration
- regulatory stability/ accountability/standards

BBMRI.at#1

Discussion groups with citizens to get insights into the attitudes and concerns of publics regarding ethical, legal and societal implications of biobanking.

15 discussion groups were held between 2015 and 2018 in Vienna, Graz and Innsbruck.

Each discussion group consisted of a heterogeneous sample of citizens regarding gender, age, educational background and prior experiences with biobanks and/or medical studies.

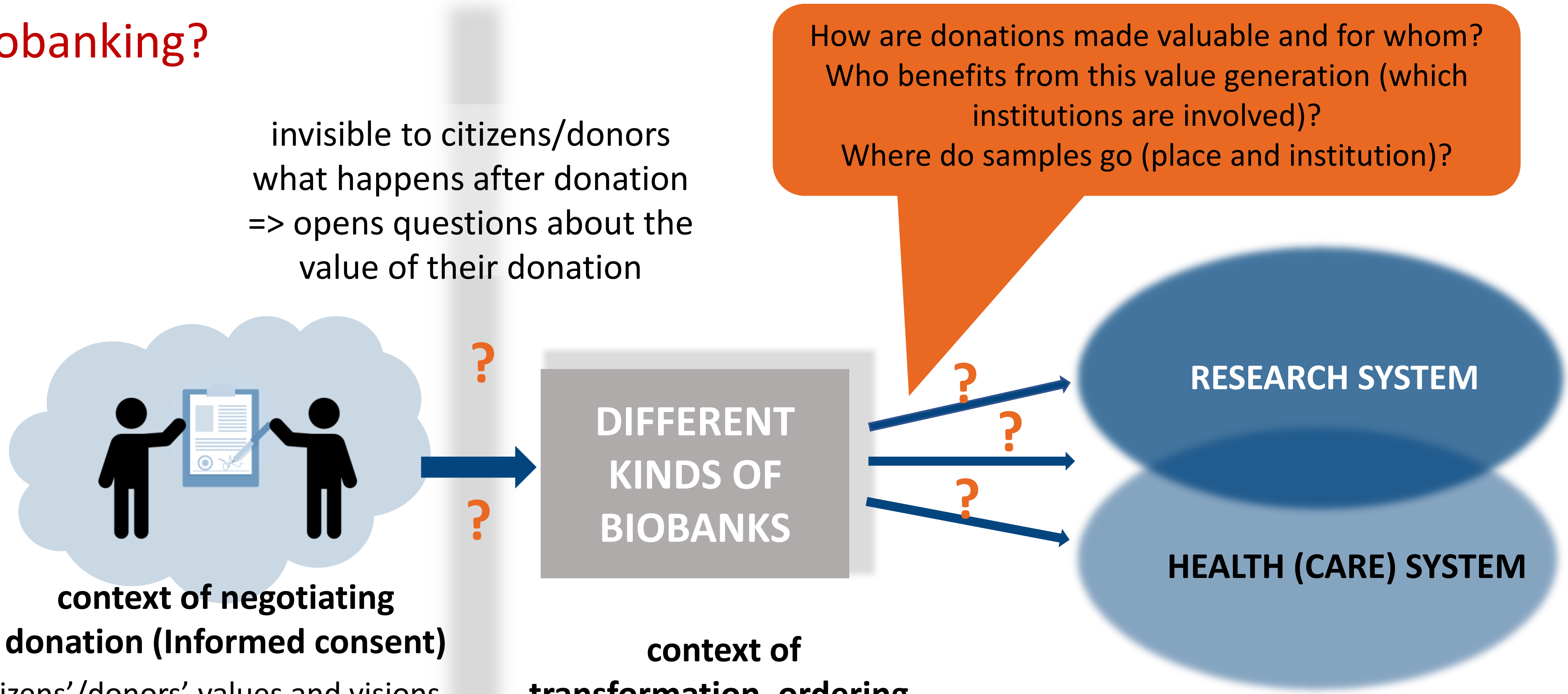
BBMRI.at#2

Interviews and discussions with a broad set of stakeholders around biobanks discussion

Discussion groups with citizens and patients are in the planning

Aim: understand values in/of biobanking; bio-data citizenship

How do citizens understand biobanking?



invisible to citizens/donors what happens after donation => opens questions about the value of their donation

How are donations made valuable and for whom?
Who benefits from this value generation (which institutions are involved)?
Where do samples go (place and institution)?

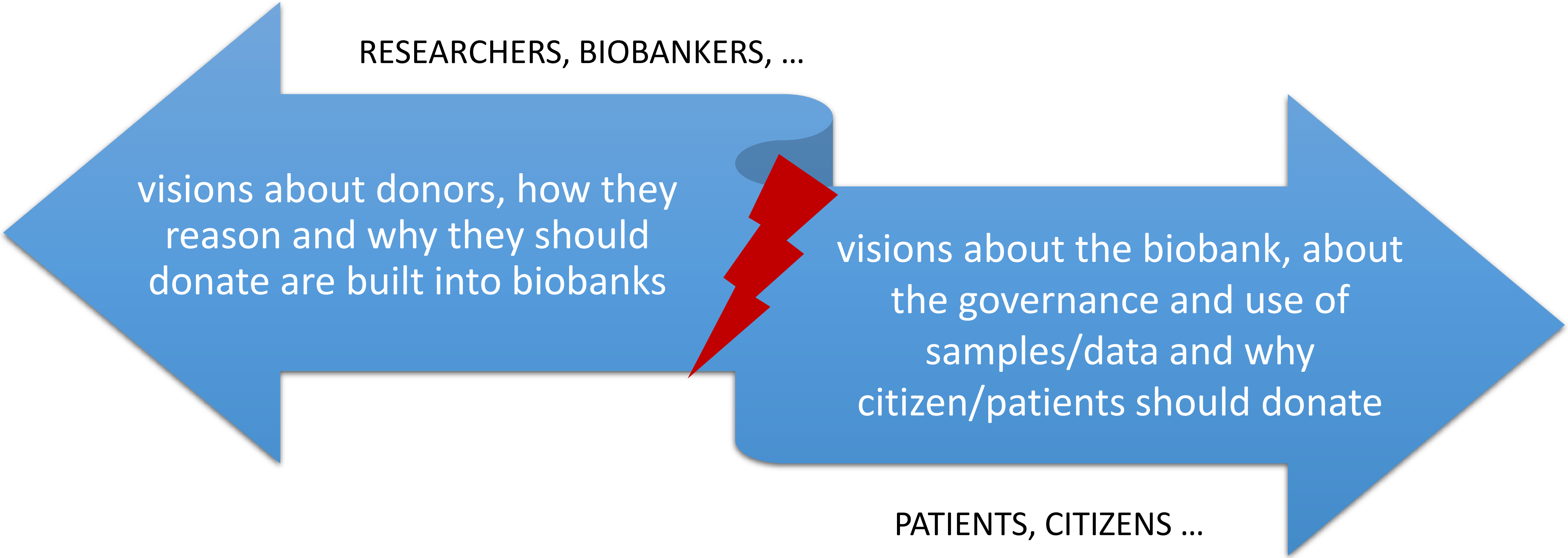
context of negotiating donation (Informed consent)

citizens'/donors' values and visions of health, research, political environment, … matter

context of transformation, ordering, standardisation and storage

contexts of using the donated samples

Biobank-donor relations



RESEARCHERS, BIOBANKERS, …

visions about donors, how they reason and why they should donate are built into biobanks

visions about the biobank, about the governance and use of samples/data and why citizen/patients should donate

PATIENTS, CITIZENS …

‚Inscribing' donor roles/visions of donors into biobanking

Depending on the kind of biobank and its context, donors are envisioned differently => identities of donors are constructed together with the biobank

- **autonomous citizens** with basic rights and freedoms visible in
  - regulations and biobank governance
  - in the practice of informed consent
  - GDPR
- **embracing certain values,** such as solidarity or altruism when it comes to sharing data and samples (support a specific model of medical developments)
- citizens as **entrepreneurs of/responsible for their own health** – showing readiness to engage in data labour/clinical labour
- for specific kinds of biobanks (e.g. commercial biobanks), citizens are imagined as **customers** – genetic information in exchange for data

Felt, Goisauf, Öchsner 2018 D4.5 BBMRI.at#1; Felt, Metzler, Ferent 2020; BBMRI.at#2

‚Inscribing' donor roles/visions of donors into biobanking

Limitations:

- often informed consent is the only moment where rights can be exercised => yet, this is often seen as a formal procedure
- **trust** assumed as default
- little reflection on the broader experiences of citizens with data, economic actors around health care, and many more

Citizens speak back - Imagining users (researchers) of samples/data

- Sensing a **tension** between discourse on “the value of data” and “simple donation” narrative
- Expectations in exchange for their support
  - Benefits must be accessible to many, i.e. be shared
  - Problematic overpromising what research can achieve
  - Having a bigger say on how, where and by whom samples are used (vision of control behind the smokescreen)
  - Partially, expect a personal return from the research as direct benefits

Citizens speak back - Imagining users (researchers) of samples/data

3 elephants in the room

- Data
  - Data/samples – inseparable entities
  - Data can travel much more easily, can be duplicated easily and thus control/oversight is lacking (reference to data scandals)
  - Promises of protection seem always under threat
- **Commercial actors** – pharma as disrupting the imagination of just return
- **Regional actors** – concern about the places where data could easily travel to

=> Trust relations need transparency and at least in principle the possibility to see where data/samples go

Concluding observations

- If public engagement is the solution, then what is the problem?
- Patient engagement as progress
- Yet, simultaneously: narrow framing of the problem of biobanking and the vision of donors as more or less coherent group of patients
  - Donors can be patients
  - But: not all donors are patients
  - Moreover: different kinds of biobanks
  - Biobanks also needs the support and trust of citizens
- **notion of participation needs** context sensitivity => consider different situated visions of what constitutes a robust trust relationship; changes over time

Concluding observations

- consider the (situated) environments (cultural, experiential, …) in which assessments are made – will be key for our work in BBMRI.at#2
- move away from a too strong promissory discourse; what can 'public benefit' mean in practice? => encourage and enable discussions on the inherent values and tradeoffs
- Reflect and make transparent future data/sample uses (speak to potential data journeys)
- Once arrived at the informed consent moment: essential — whatever form it precisely takes — to use it not solely as an obligatory hurdle but as a moment of mutual learning and engagement with donors and the different value systems involved