Beyond Informed Consent

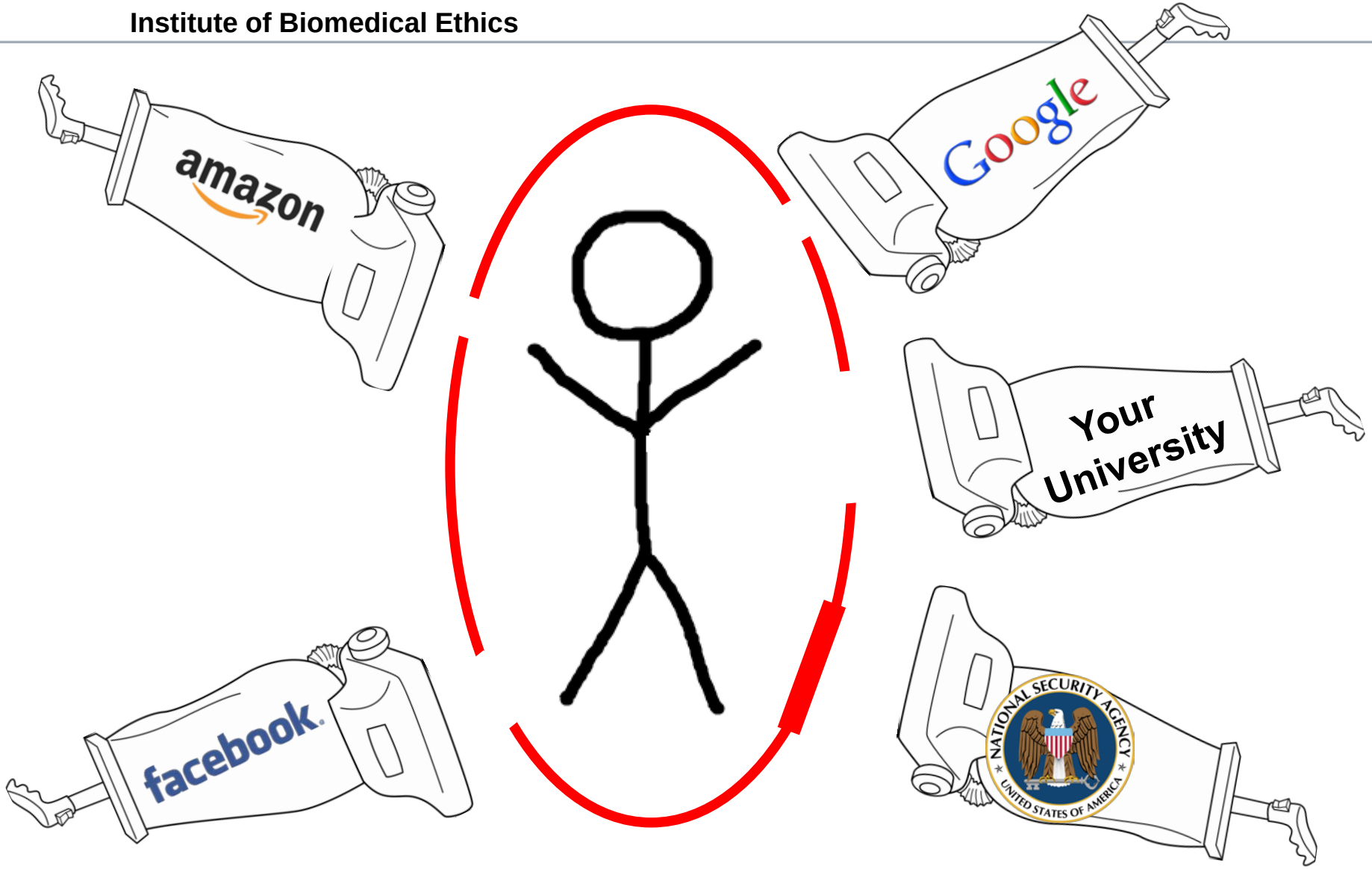
Investigating Ethical Justifications for Disclosing, Donating or Sharing Personal Data in Research

Markus Christen, University of Zurich, Switzerland

Josep Domingo-Ferrer, Universitat Rovira i Virgili, Catalonia

Dominik Herrmann, University of Hamburg, Germany

Jeroen van den Hoven, Delft University of Technology, Netherlands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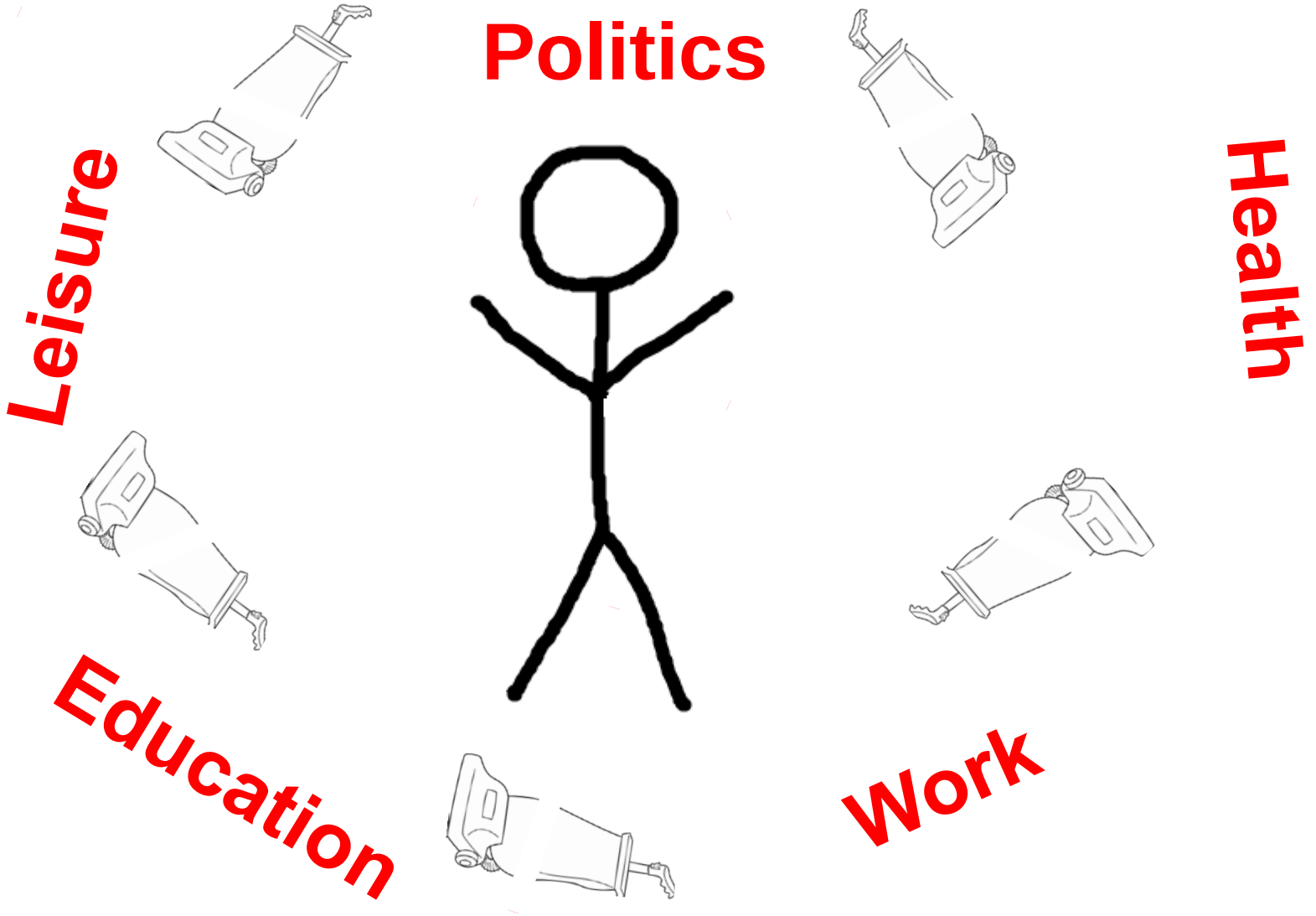
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How to tackle these problems?

Step 1: Outlining the basis: Contextual integrity, autonomy and informed consent.

Step 2: An appropriate “minimal morality”

Step 3: Outline of an infrastructure for responsible online research

Contextual integrity (in a nutshell)

- **Contextual integrity** is inspired by the idea of *spheres of justice* (Walzer 1983): societies consist of different social spheres each defined by different types of goods, distribution mechanisms of goods as well as relevant values and principles that justify allocations etc.

- The major **ethical challenge** is to prevent the domination of a single good, distribution mechanism, principle etc. *across spheres*.

- "Translating" this idea to the **information sphere** (Nissenbaum 2004) means that the type of information that is revealed and the flows between different spheres have to be *appropriate for the context*.

A problem with this conception is ethical pluralism, i.e. even within a single sphere, people may disagree on what exactly the relevant values and principles are.

The two sides of autonomy and informed consent

Due to ethical pluralism, **autonomy** has become a “meta value” in the sense that it justifies the acceptance of ethical pluralism (within some boundaries) and the right of the individual to act according to own (interpretations of) moral values within the different social spheres.

Autonomy furthermore provides the moral foundation of the idea that an individual executes **control** over relevant decisions, actions etc. within social spheres. This goes along with abilities to execute autonomy (and missing abilities may justify bypassing decisions made by the individual).

In this framework, **informed consent** becomes the key requisite when the individual is involved in activities which are outside of its direct control, but it involves the notion of “indirect control” (some prediction regarding the consequences of consenting)

In this picture, contextual integrity is likely to be the precondition for the “empirical” part of autonomy/informed consent: control & prediction

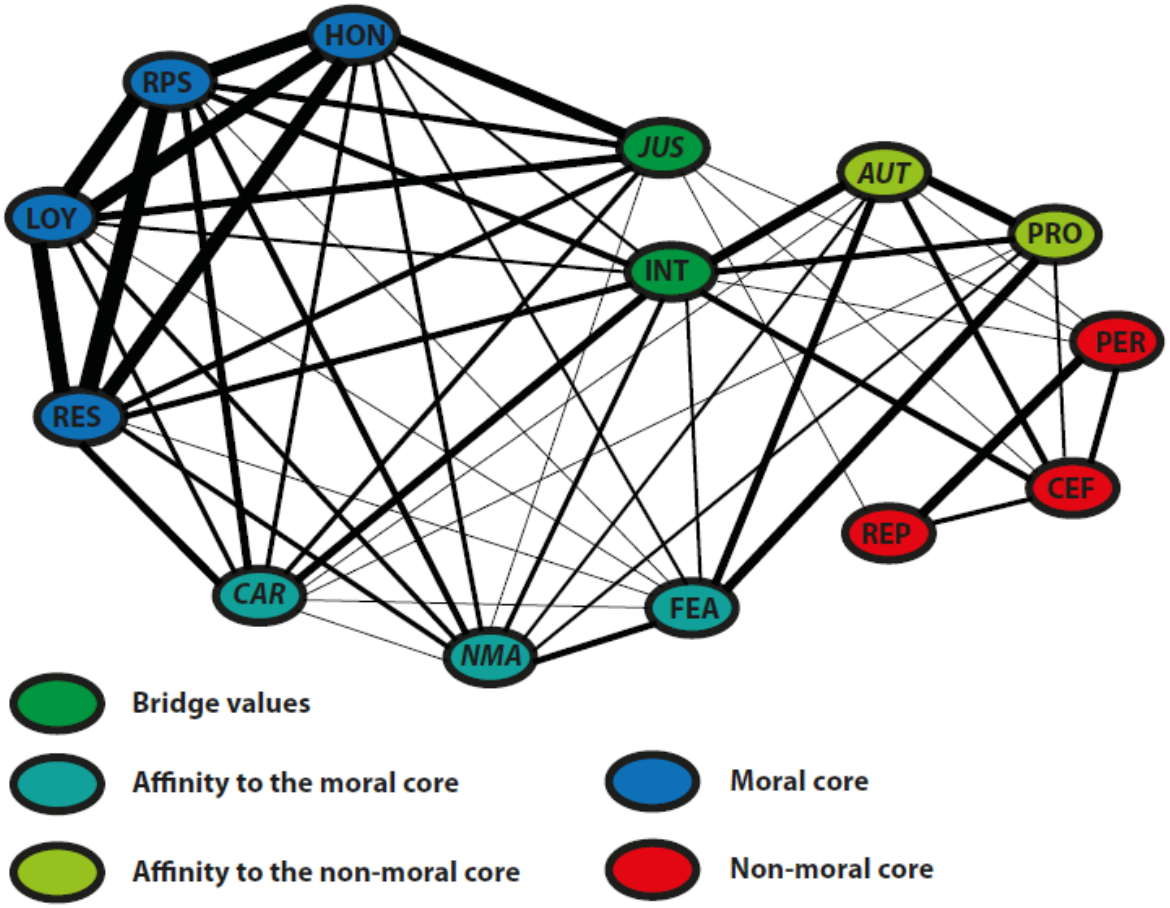
Well-known problems of autonomy & consent

For our problem – information sharing in the context of digitally blurred social spheres – we see the following problems:

- When individuals use digital platforms, they are often in a position of **informational asymmetry**: they are not aware of the informational links between social spheres that are generated in this way.
- In the context of Big Data, the amount of information extracted from data might **exceed ex-ante expectations** of both users and platform administrators.
- The orientation on autonomy puts the focus on the individual and **disregards the moral obligations of the other players** involved in Big Data.

A “minimal ethics” focusing on autonomy and informed consent disregards the “empirical undermining” of autonomy and consent capacity and neglects other morally relevant values. Autonomy might even be “too lean” as a moral value (see next slide).

How rich is the “moral ontology”? An example:



Christen M, Ineichen C, Tanner C: How “moral” are the principles of biomedical ethics? – A cross-domain evaluation of the common morality hypothesis. BMC Medical Ethics 15: 47

Autonomy, informed consent and its problems

In the following, it is proposed that the following three values provide a better outline of the moral landscape:

Autonomy: Users ought to be aware of how their data records are used in order to promote their values and gain control over privacy-related choices.

Responsibility: Users (both researchers and data providing research subjects) should be held responsible and accountable for the ways in which they use their personal information and the information about other people. If some subjects are wronged, it must be possible to attribute personal responsibility for the wrongs in question.

Fairness: The benefits of knowledge and information ought to be fairly apportioned to all participants in interactions, so as to rule out inequality of opportunity and exploitation by some at the expense of others.

Autonomy in a online research infrastructure

- Enable research participants to gain awareness on what guides their choices (privacy preferences), e.g. through a privacy preferences self-assessment tool that will provide a value profile that outlines the privacy preferences of participants with respect to their participation in research or data donation.

- Provide information (to participants and researchers) on what they potentially may disclose when providing certain types of data. This may include a security issues taxonomy; i.e. forensic and security assessment of relevant risks when using the platform, including the generation of operational security guidelines on (technology and non-technology related) behavioral and tool usage rules for researchers and participants.

The goal is to shift away the focus from (mere) informed consent towards empowering research participants and data donators.

Responsibility in a online research infrastructure

- Ensure longer-term relations between participants and researchers through an infrastructure (social network) that allows for bidirectional relations (e.g., for suggesting new research questions by participants).

- Empower the researcher both regarding legal / ethical requirements and technical instruments (e.g. for data anonymization) for doing responsible research with personal data. This may include profile anonymisation tools, including masking and synthetic data methods used in statistical disclosure control (micro-aggregation, noise addition, etc.).

- Empower the participant with the ability to verify how safe is the anonymization performed by the data collector/researcher.

The goal is to provide both the infrastructure and tools for stable relations between researchers and participants as a prerequisite for responsible research.

Fairness in a online research infrastructure

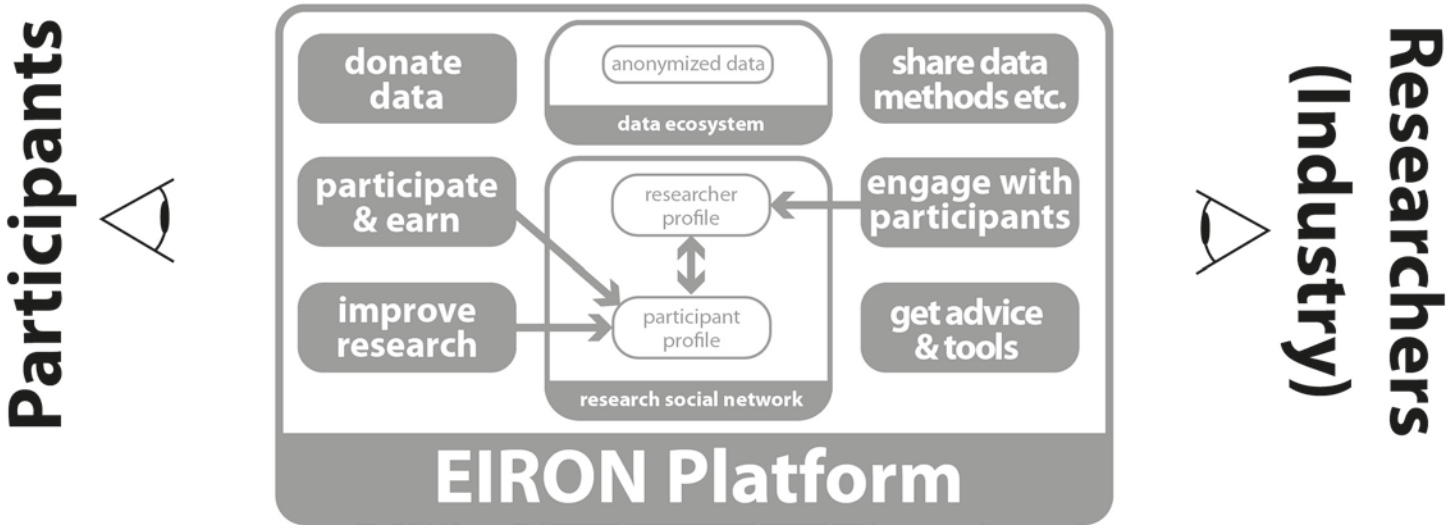
- Provide a broader set of utilities (not only monetary compensation) like visualizing the contribution of research participants, e.g. through donated data, to certain scientific results.

- Create novel types of interactions (using, e.g., co-private protocols, Domingo-Ferrer 2011, and, more generally, co-utile protocols, Domingo-Ferrer et al. 2015) that allow collaborative contribution to a common good (like ensuring each other's privacy).

- Provide anti-discrimination tools, i.e. models and protocols of data acquisition and analysis for quantifying the risk of discriminatory decisions as a (possibly unwanted) consequence of data profiling and data mining.

The goal is to demonstrate that contributing to research is based on a fair exchange and mutual respect of the involved parties.

Outlook


Participants
donate data
anonymized data
data ecosystem
share data methods etc.
participate & earn
researcher profile
engage with participants
improve research
participant profile
get advice & tools
research social network
EIRON Platform
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