



How do unknown people take agency over their data?

Introduction to the “Beginners Minds &
Experienced hands” sessions

Inspire2Live Annual Congress, Amsterdam, 9 Feb 2018



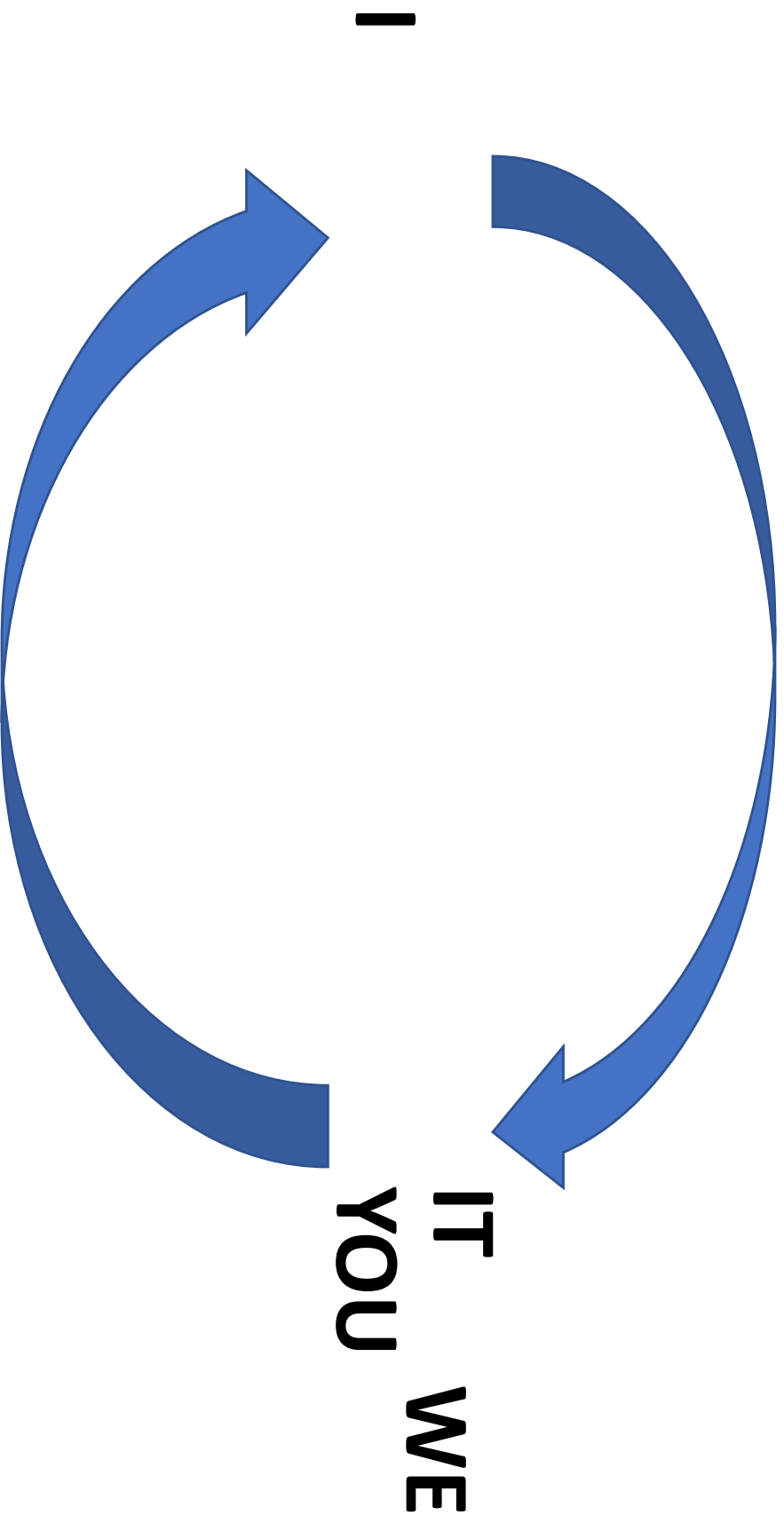
mijn data
onze gezondheid



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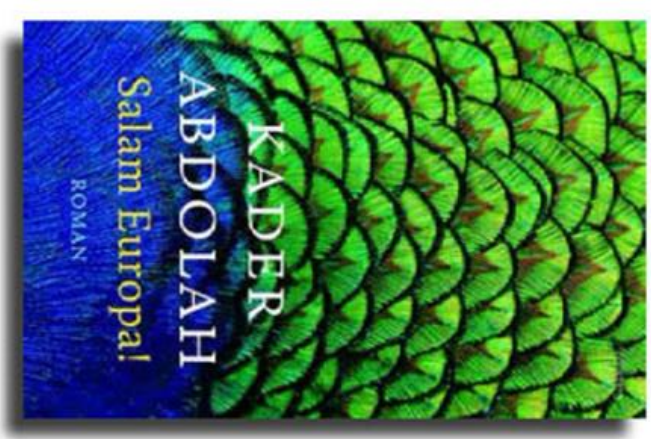
Reciprocity



Reciprocity

- **Proportionality**
- **Power**
- **Control**
- **Knowledge about the value of the data**

The value of Data

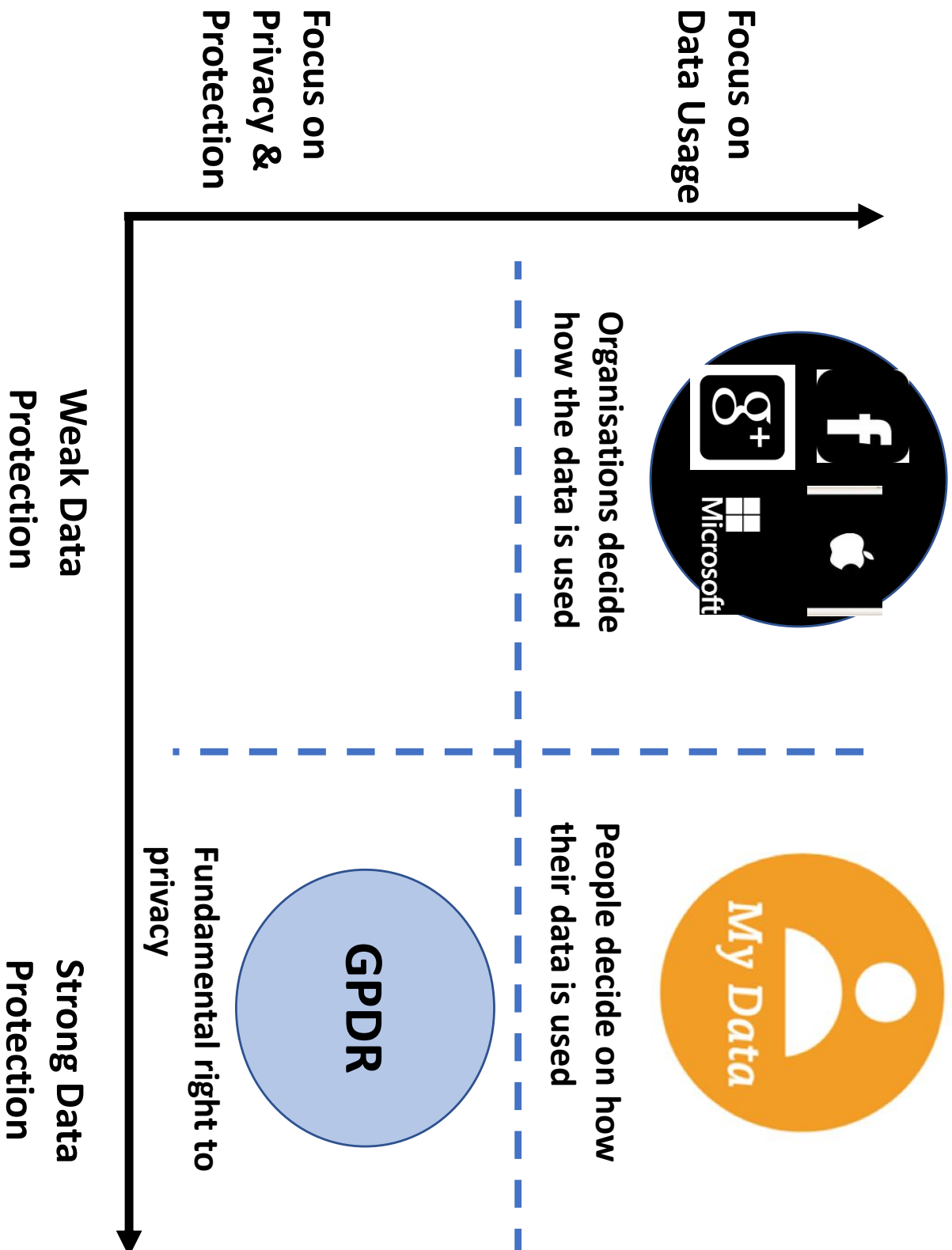


Back to Reciprocity

- Proportionality
- Power
- Control
- Knowledge about the value of the data
- **Data sharing is about organizing relationships**
- **Hence about trust**
- Privacy-by-design, security-by-design, trust-by-design?
- Let it not only be ICT technology. Let us focus on the **social design**.

Usability 'versus' Privacy

From Data protection to data empowerment



Borrowed from
Antti Poikola,
MyData.org



Data: what do we do as Patient Advocates

- Foundation **Mijn Data Onze Gezondheid** (MD|OG): making the value of cooperative citizen science tangible
 - BeyondRCT-2: towards Cooperative Citizen Science in food and health – 17 may 2018
 - n=1 validated tool for self-monitoring (call ‘BeterGezond’ – SGF, Topsector Life S& H)
 - Holland Health Data Coop: data cooperative stimulating a new health economy



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- Hackaton ‘BeyondBanking’ (Tjebbe Tauber)
 - on data sets of Dr. Jules Meijerink (Princess Maxima Center for pediatric oncology) to explore differences between sick (leukemia) and healthy people’s cells at the genomic level

In short, we need fresh views

**Beginners Minds &
Experienced hands**

Beginners Minds and Experienced hands

Data and reciprocity

- What practices do you see/dream/hope within your field of expertise and within your geographical area, as key examples of **engaging the public on data**, that impulse a movement that will **create a shift from the current focus of disease into health societies?**
- What **new combinations** of citizen-driven data generation, data governance, research and responsible business are emerging or needed?
- What are **steps that can be taken**, and by who, that will make these practices applicable, in a way that **citizens and patients remain in the driver's seat?**

Beginners Minds and Experienced hands

4 teams:

- Ernst Hafen (ETH, Zurich) - Data co-operativism & data portability: a new health economy
- James N'Dow (Univ. Aberdeen) - Development of guidelines
- Dik van Gent (ErasmusMC, R'dam) - Fundamental research
- Parag Mankeekar (Neeti Solutions, Mumbay) - The importance of empathy