How do unknown people take agency over their data?

Inspire2Live Annual Congress, Amsterdam, 9 Feb 2018
Reciprocity

• Knowledge about the value of the data
• Control
• Power
• Proportionality
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

Focus on Data Usage

Focus on Privacy & Protection

Weak Data Protection

Organisations decide how the data is used

Strong Data Protection

People decide on how their data is used

Fundamental right to privacy

Borrowed from
Antti Poikola,
MyData.org
Advocates

Data: what do we do as Patient Advocates

Foundation Mijn Data: making the value of cooperative citizen science tangible

MijnGezondheid (MD|OG): making health economy

Holland Health Data Coop: data cooperative stimulating a new Topsector Life (SG H)

n=1 validated tool for self-monitoring (call, betregezond – SGF, health – 17 May 2018

BeyondRCT-2: towards Cooperative Citizen Science in food and

the value of cooperative citizen science tangible

Foundation Mijn Data: what do we do as Patient Advocates
In short, we need fresh views

Beginners Minds & Experienced hands
Beginners Minds and Experienced hands

Data and reciprocity

• 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?

• What are new combinations of citizen-driven data generation, data governance, research and responsible generation, data governance, research and responsible business are emerging or needed?

• What new combinations of citizen-driven data generation, data governance, research and responsible business are emerging or needed?

• What are 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 of health into disease societies?

• What practices do you see/dream/hope within your geographical area, as key 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?

Data and reciprocity

Experienced hands
Beginners Minds and Experienced hands

4 teams:

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

Experienced hands and Beginners Minds