

# MIDATA.coop

Citizen-Controlled Personal Data is  
Essential for Personalised Medicine

Personalised Medicine Conference June 1, 2016

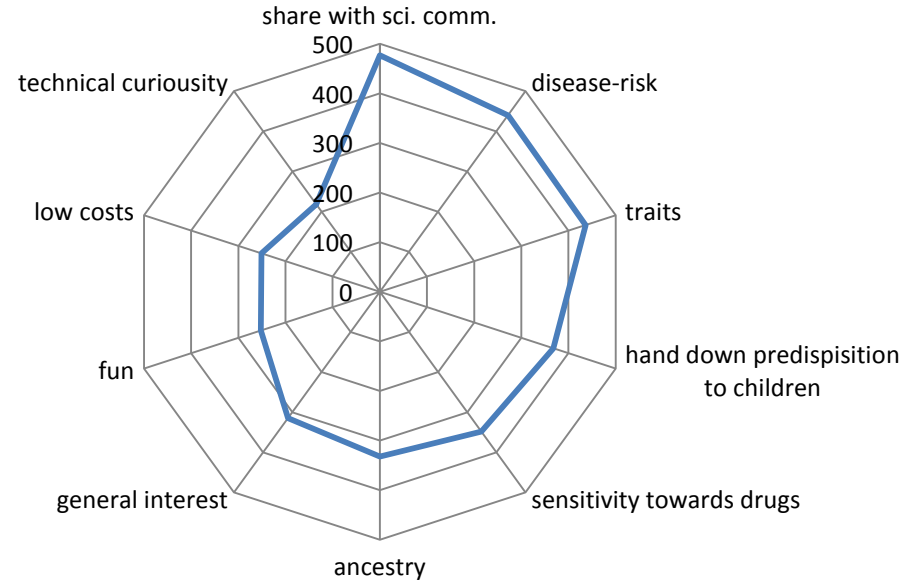
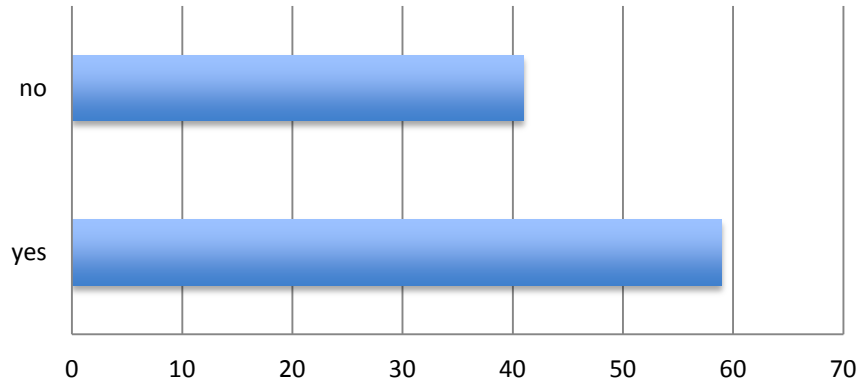
Prof. Ernst Hafen, ETH Zürich

# The Need: Google Maps of Health

- Big Data in health is all about personal data
- Need to integrate diverse data sets from millions of people
- Geographical Information System (GIS): Data integration on longitude and latitude
- Human Information System (HIS): Data integration on the individual
- **The active participation of citizens is essential**

# The Willingness: Student Survey

## hypothetical DTC-GT test taking [%]



Vayena E, Ineichen C, Stoupka E, Hafen E. Public Health Genomics. 2014;17(3):158-68. doi: 10.1159/000360257. Epub 2014 Apr 25.

# The Problem (I): Dwindling trust in data companies



- What data are collected about me?
- Missing transparency
- Dwindling trust

Symantec (2015) State of privacy report 2015.  
[www.symantec.com](http://www.symantec.com)

## Problem (2): Socioeconomic asymmetry



- Global dominance of data companies
- Digital feudalism
- Citizens have little influence

### CHAPTER 1.6

#### Rebalancing Socioeconomic Asymmetry in a Data-Driven Economy

PETER HAYNES, Atlantic Council

M-H. CAROLYN NGUYEN, Microsoft

<http://www.weforum.org/reports/global-information-technology-report-2014>

# The Solution: The need for citizen empowerment

- A **legal right to a digital copy** of all personal data (medical and non-medical) > *Postulate accepted by Federal Council Nov 12 2015*
- A **safe and secure bank account** in which people can store, manage and actively share data on their terms
- A **not-for-profit cooperative** organizational structure of the personal data banks so that they are owned by the citizens
- Revenues from citizen-controlled secondary use of data are invested in projects and services that **benefit members and society at large**

# MIDATA.coop – The basis for a new Trust-promoting Framework

- **Citizen owned**
  - Cooperatives
- **Not for profit**
  - Revenues are reinvested for the benefits of members and society
- **Open source**
  - Code available on Github
- **Transparent**
  - Transparent governance
- **Secure**
  - Data encryption, only members possess key
- **Regional**
  - Promotion of regional linked MIDATA cooperatives

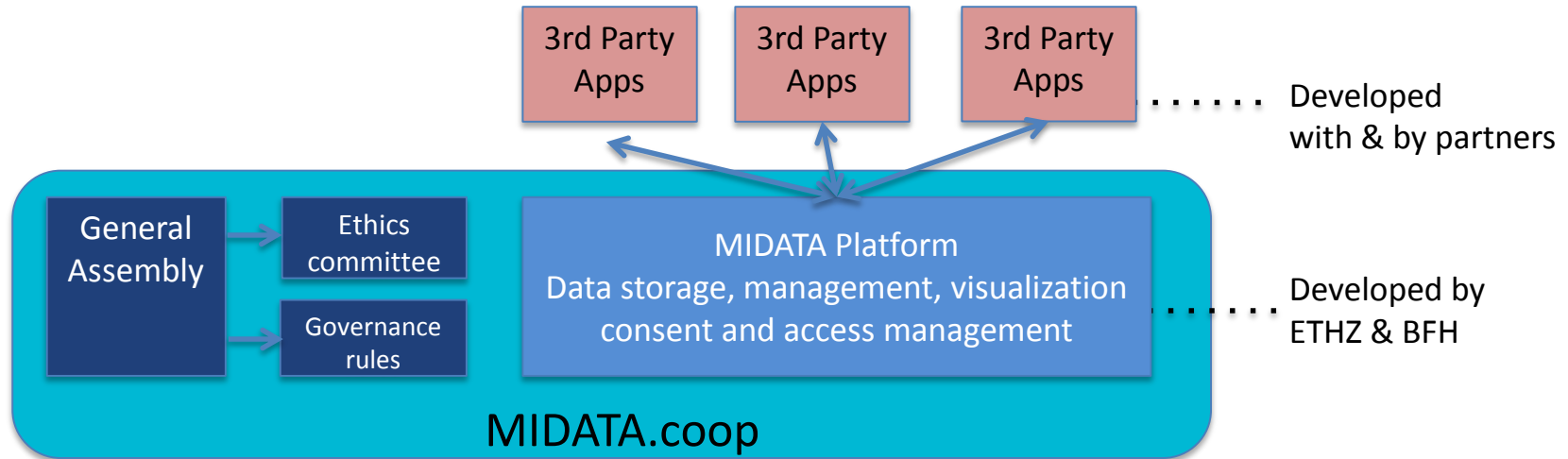
# MIDATA.coop – A Federation of National Personal Data Cooperatives



- Federation of national MIDATA cooperatives
- Common IT structure and data exchange platform (like SWIFT)
- Profits stay in national MIDATA cooperatives (> LMICs)
- A truly European solution with a global reach
- Sustainable personal data economy by democratization



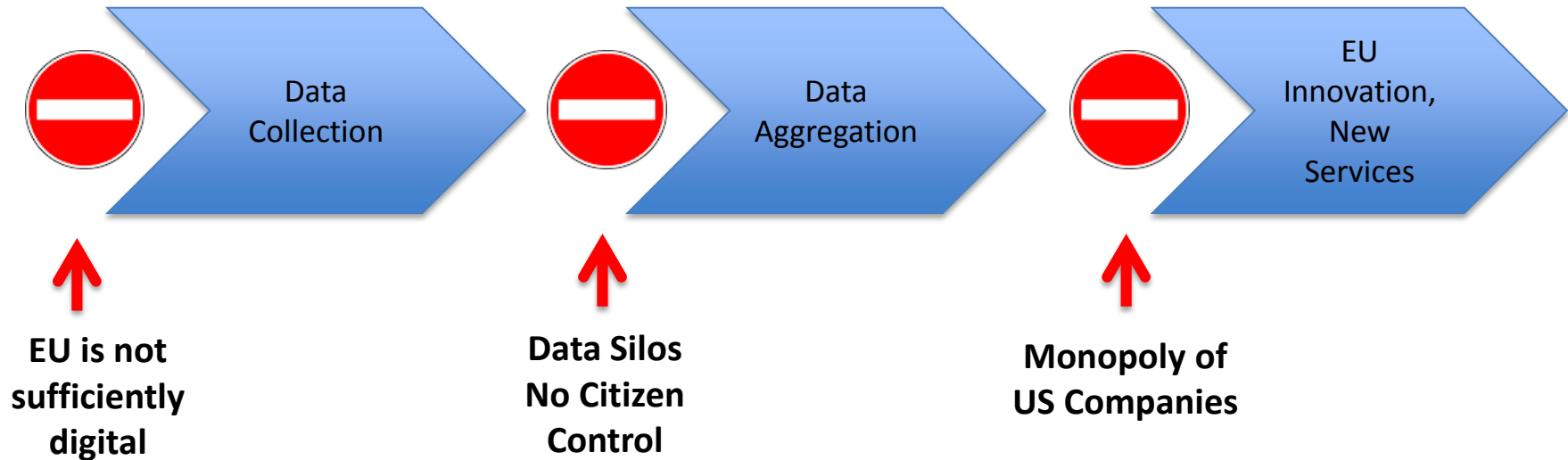
# Das MIDATA Innovationssystem



# MIDATA – The Flipped Clinical Trial

- Patient shares data and signals interest to participate in clinical trials
- Patient recruit their treating physician
- MIDATA represents patients towards sponsors

# Die European data value chain urgently needs a new framework



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