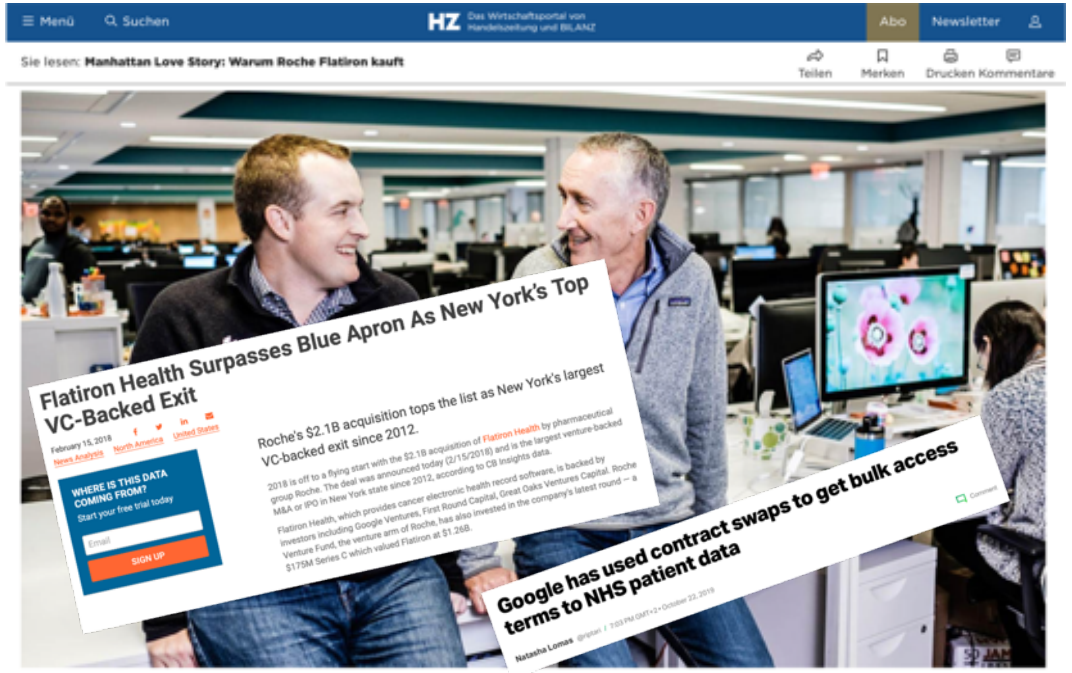
ETH zürich

Data Cooperatives: Shaping Together an Ethical and Social Contribution to the Future of Healthcare

ETHEL 2021 Symposium, November 30 2021

Prof. Ernst Hafen, @ehafen

Health data save lives and are a valuable commodity today



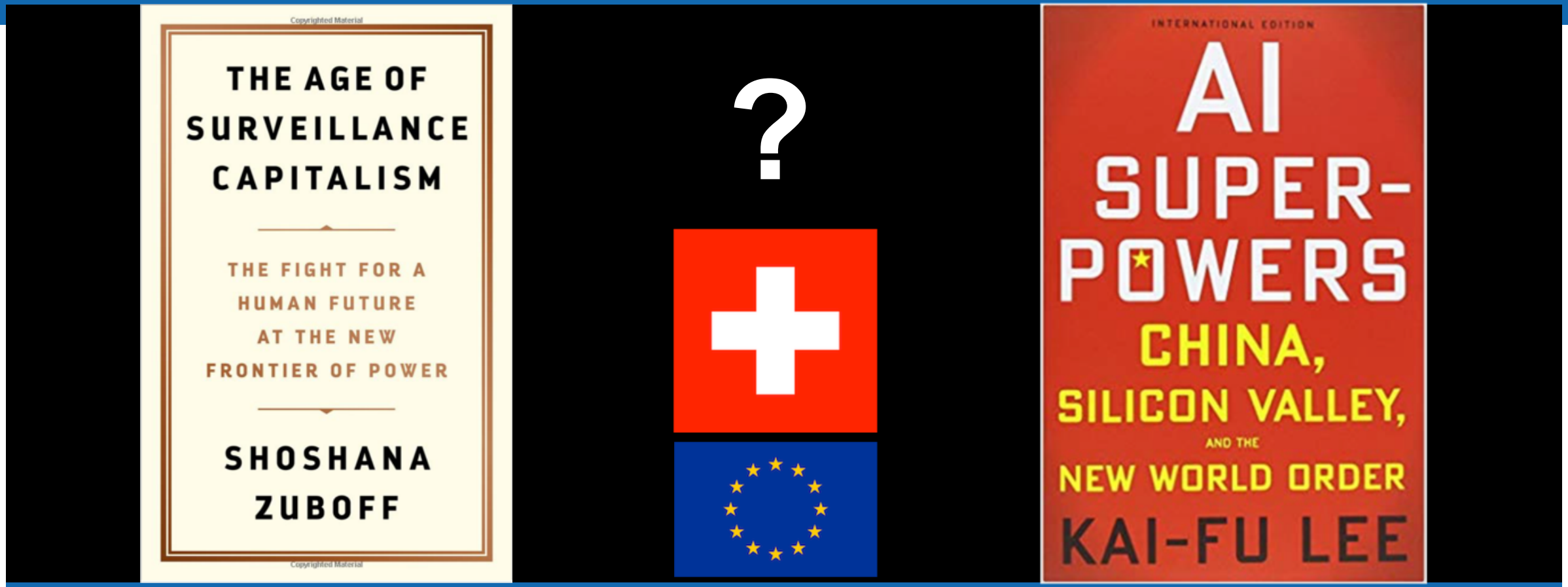
Big Data trifft Big Pharma: Flatiron-Chef Nat Turner (l.) und Roche-Pharmachef Daniel O'Day.

Quelle: Chris Sorensen

Der Basler Pharmakonzern Roche lässt für ein New Yorker Startup mit 500 Mitarbeitern 1,9 Milliarden Dollar springen. Die Hintergründe.

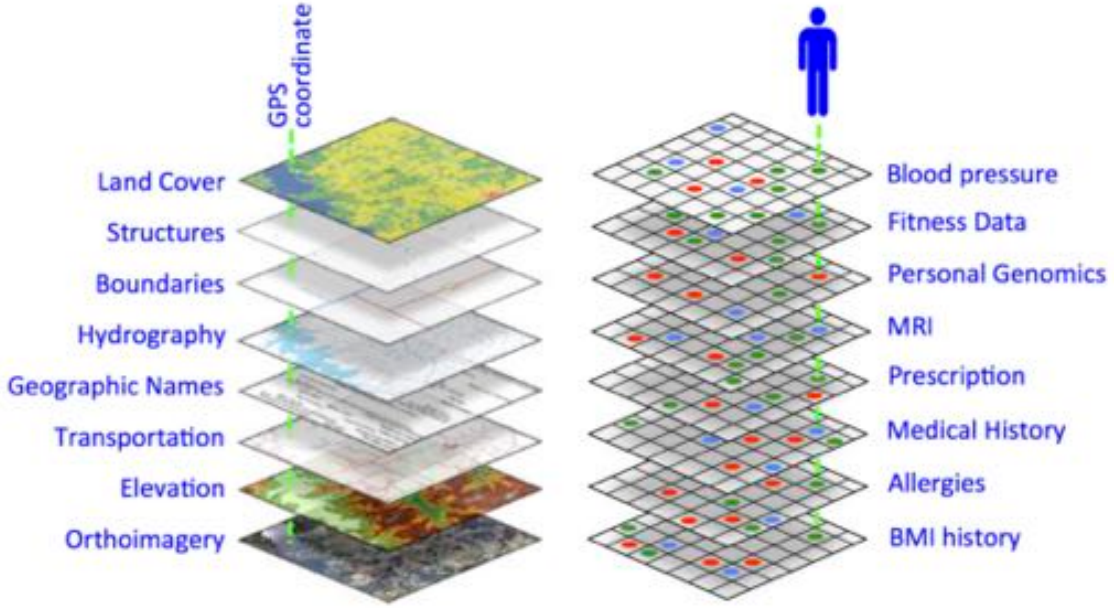
Von Seraina Gross
am 14.05.2018

- Flatiron has clinical data of 2 M cancer patients from 267 US cancer clinics
- Roche acquired Flatiron for $ 1.9 B > each data set ~ $ 1'000
- Data protection laws and fragmentation of healthcare systems in Europe prevent aggregation of data
- Clinical data do not include valuable 24/7 health data from smartphone sensors
- How can Europe compete in data-driven precision healthcare and precision medicine?



Is there a third way for Switzerland and Europe?

The Need: Data Integration – Google Maps of Health



- **Aggregation** of health data of millions of people
- There is a need for **an active participation** of people in Europe

Europe's third way out of the digital dependency – Citizen-controlled data commons (Data Cooperatives)

Personal Data

1. Can be copied (citizens have a right to obtain a copy of their data (GDPR))
2. Equally distributed amongst individuals (all people are billionaires in genome data)
3. Neither Google nor Facebook, only individuals can aggregate their genome, smartphone and medical data

Personal Data Cooperatives

1. Generation of a parallel personal data ecosystem under the control of the citizens
2. One-member-one-vote – democratic governance of cooperatives
3. Largest knowledge and economic value creation for the benefit of society

MIDATA

Citizen/Patient-Controlled Data Access and Goverance – The Cooperative Approach

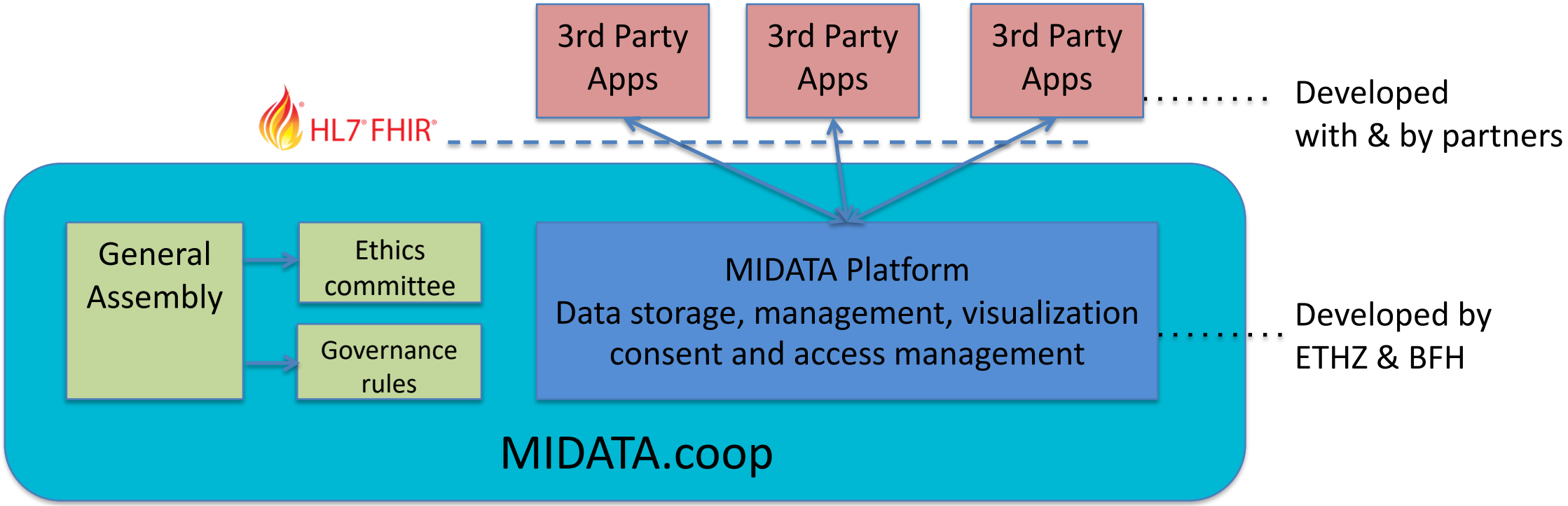
www.midata.coop

Ernst Hafen, Co-Founder of the MIDATA Genossenschaft and Professor at Institute of Molecular Systems Biology, ETH Zürich, ehafen@ethz.ch, @ehafen

MIDATA Governance Principles

- Non-profit citizen-owned cooperative structure
- Citizens fully control access to their data (including "anonymized" data).
- No financial incentives for data sharing
- Storage of any data types HL7® FHIR®
- Tested, secure and scalable cloud-based open source IT platform hosted in Switzerland

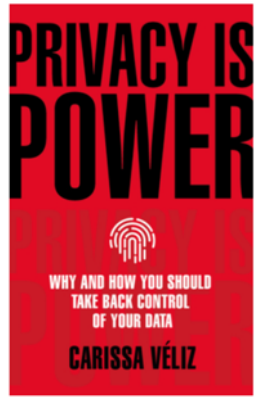
The MIDATA ecosystem for innovation



Lessons from the MIDATA Cooperative Model

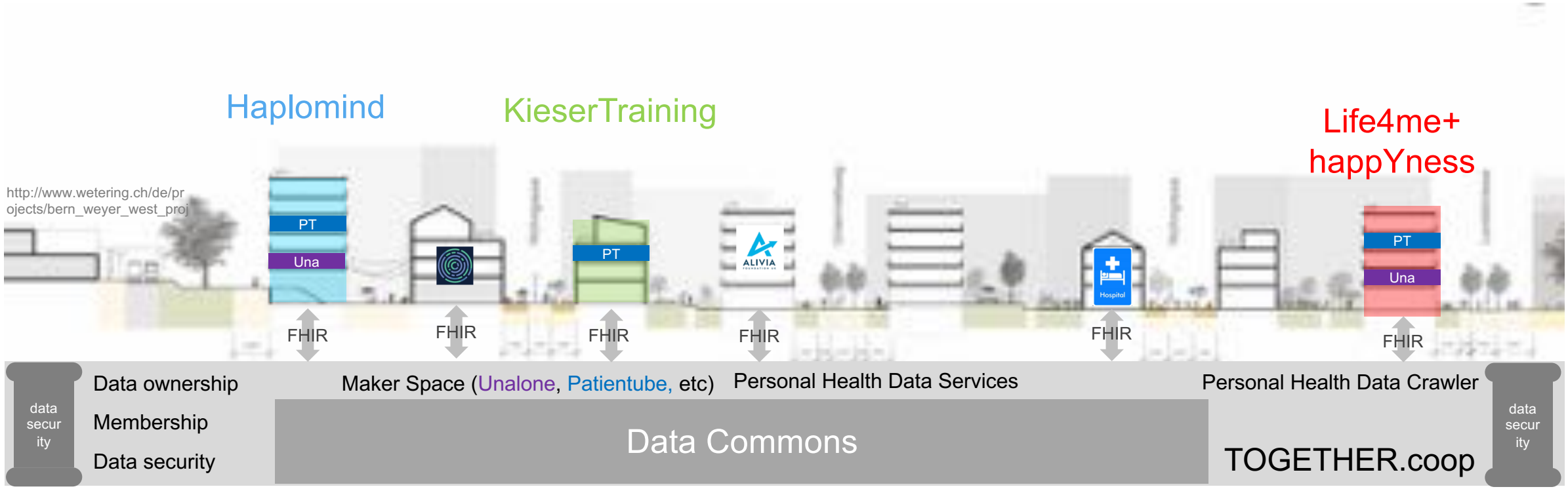
- Positive
  - Governance
  - Secure, cloud-based open source platform developed with top experts at ETH
- Negative
  - There is no sense of joint self help.
  - No coherent data sets
  - No personal benefit (no short term feedback, no long term financial benefits).

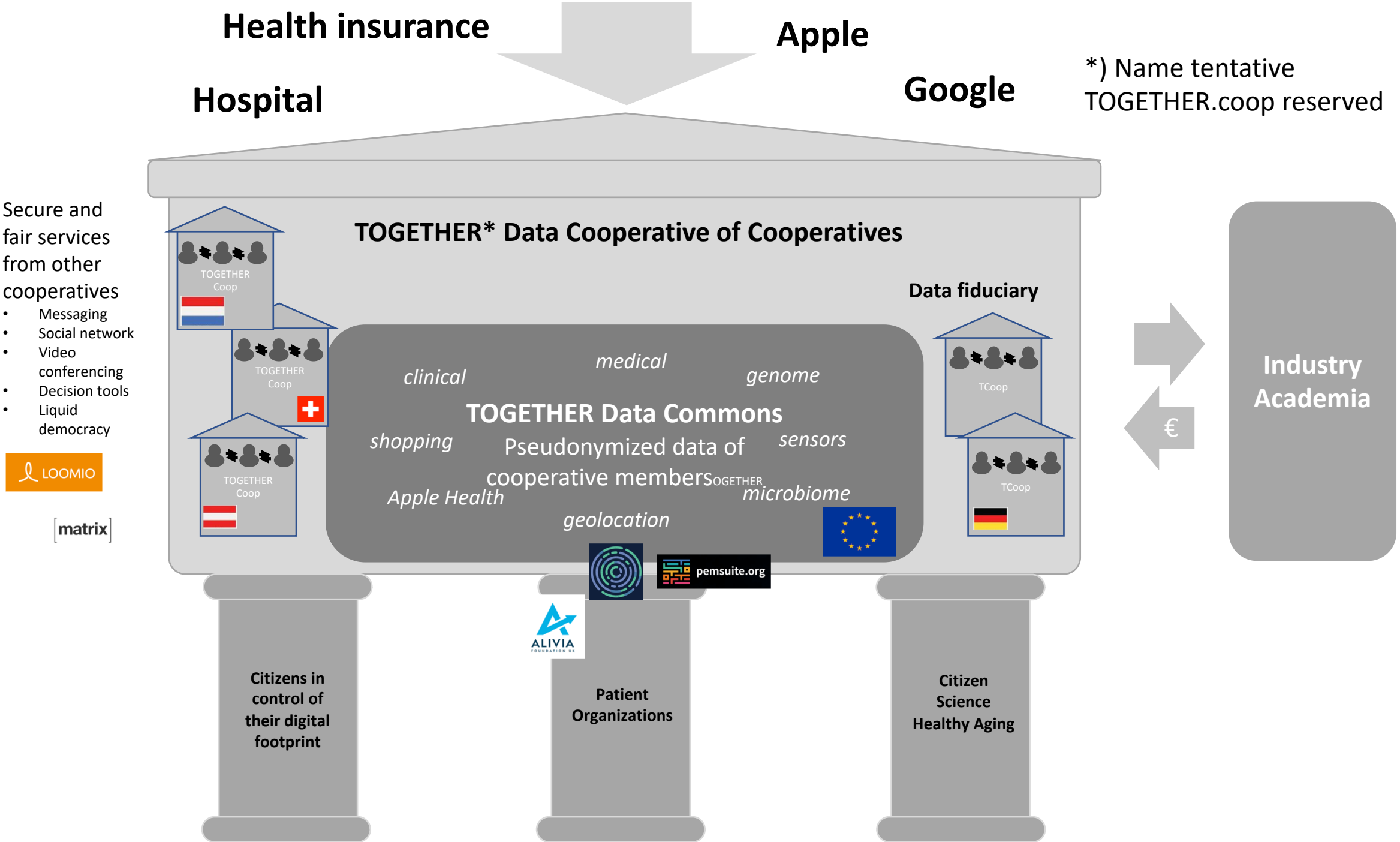
Success factors for data cooperatives controlling personal data commons



- Trust
  - Cooperative governance
- Personal utility and benefit for participants
  - Direct and immediate personal feedback (e.g. blood glucose, nutritional recommendations)
    - My health graph (timeline)
  - Use of fair and safe digital services run by cooperatives
  - Data fiduciary > mandate to collect (and possibly delete) copies of personal data of members
  - Financial benefit proportional to the amount of data sharing
- Economic benefit for society (possible value creation >>> Google, Facebook et al)
- New data services, new jobs (in analogy to the financial service industry)
- Europe as a forerunner of a fair digital future

Data cooperatives controling data commons provide the secure citizen-centered infrastructure for fair, connected and efficient health systems




Health insurance
Apple
Hospital
Google
*) Name tentative
TOGETHER.coop reserved
Secure and fair services from other cooperatives
• Messaging
• Social network
• Video conferencing
• Decision tools
• Liquid democracy
LOOMIO
matrix
TOGETHER* Data Cooperative of Cooperatives
TOGETHER Coop
TOGETHER Coop
TOGETHER Coop
Data fiduciary
TCoop
TCoop
clinical
medical
genome
TOGETHER Data Commons
Pseudonymized data of cooperative members
shopping
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Apple Health
microbiome
geolocation
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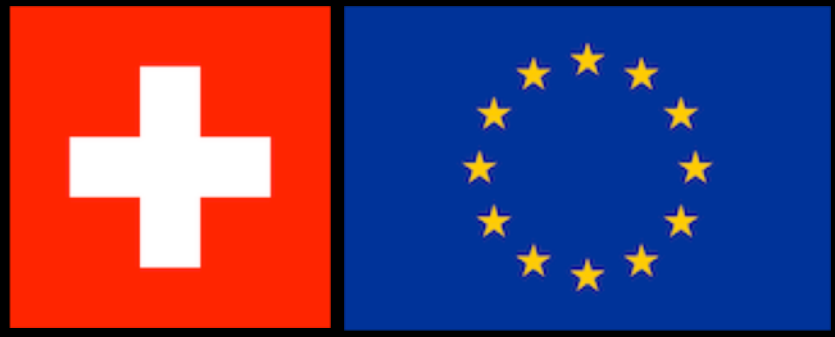
Academia
Citizens in control of their digital footprint
Patient Organizations
Citizen Science Healthy Aging

Data to the People! – Data Democracy



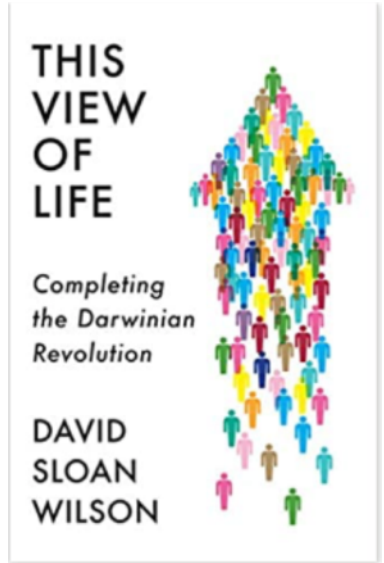
Citizen Movement, Data Commons, Data Cooperatives

Elinor Ostrom's Core Design Principles (CDP) of Commons applied to the TOGETHER Cooperative

Elinor Ostrom (Nobel Laureate)
"Governing the Commons"

- CDP1: **Strong Group Identity**
  - Digital democracy movement
  - Patient organizations as "data unions"
  - Cause of Health Cohort
  - Academic leadership for the benefit of society
- CDP2: **Proportional Equivalence Between Benefits and Costs**
  - Financial benefits proportional to the amount of data sharing
- CDP3: **Fair and Inclusive Decision-Making**
  - Democratic governance with online decision making tools (e.g. Loomio)
- CDP4: **Monitoring Agreed-Upon Behaviors**
  - Independent ethics board
  - Randomly selected regular members serve on the board
- CDP5: **Graduated Sanctions**
  - There is little chance for members to misbehave, e.g. not to share data
  - Sanctions could be directed towards third parties that misuse the accessed data
- CDP6: **Fast and Fair Conflict Resolution**
  - Open communications with members

Elinor Ostrom's Core Design Principles of Commons (CDP) (II)

- CDP7: **Local Autonomy**
  - Independent governance of cooperatives
- CDP8: **Polycentric Governance**
  - Cooperative of Cooperatives

DS Wilson shows how evolutionary thinking is important in policy making. E Ostrom came with the CDPs to evolutionary thinking (without being a biologist)!