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

ETHEL 2021 Symposium, November 30 2021
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Health data save lives and are a valuable commodity today

- 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)

<table>
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<tr>
<th>Personal Data</th>
<th>Personal Data Cooperatives</th>
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<td>1. Can be copied (citizens have a right to obtain a copy of their data (GDPR))</td>
<td>1. Generation of a parallel personal data ecosystem under the control of the citizens</td>
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<td>2. Equally distributed amongst individuals (all people are billionaires in genome data)</td>
<td>2. One-member-one-vote – democratic governance of cooperatives</td>
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<td>3. Neither Google nor Facebook, only individuals can aggregate their genome, smartphone and medical data</td>
<td>3. Largest knowledge and economic value creation for the benefit of society</td>
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Citizen/Patient-Controlled Data Access and Governance – 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
- Tested, secure and scalable cloud-based open source IT platform hosted in Switzerland
The MIDATA ecosystem for innovation

MIDATA.coop

General Assembly

Ethics committee

Governance rules

MIDATA Platform
Data storage, management, visualization
consent and access management

3rd Party Apps

3rd Party Apps

3rd Party Apps

Developed
with & by partners

Developed by
ETHZ & BFH

Developed with & by partners

Developed by
ETHZ & BFH

HL7 FHIR
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 controlling data commons provide the secure citizen-centered infrastructure for fair, connected and efficient health systems.
Secure and fair services from other cooperatives
- Messaging
- Social network
- Video conferencing
- Decision tools
- Liquid democracy

TOGETHER* Data Cooperative of Cooperatives

• Messaging
• Social network
• Video conferencing
• Decision tools
• Liquid democracy

Citizens in control of their digital footprint

Patient Organizations

Citizen Science Healthy Aging

Industry Academia

*) Name tentative
TOGETHER.coop reserved
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

- **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)!