MIDATA.COOPs –
Personal (Health) Data Cooperatives

Democratizing the Personal Data Economy

Prof. Ernst Hafen
The Personal Data Dilemma

- Personal data is a *New Asset Class* (WEF)
- Missing transparency and trust
- Strong competition by multinational shareholder-driven companies
- *Digital feudalism*
Primary and Secondary Use of Data

• **Primary use**
  • E.g. Patient – physician interaction
  • E.g. Citizen – commercial provider (according to digital agreements with App providers and retail companies (e.g. Migros Cumulus)
  • Limited societal and economic value since value lies in the aggregation of data

• **Secondary use**
  • Value generated through aggregation (e.g. advertising, clinical research, public health)
  • $1tn personal data economy (health data not included) builds on secondary use
  • Currently citizens have not control and little benefit from secondary use
The Personal Health Data Crisis

• Data silos (physician, hospital, mobile Apps, labs)
• Incompatibilities
• Aggregation of data by third parties limited by strong data protection laws
• Citizens have no control over their data and its secondary use (digital feudalism)
  • Empowerment is lacking
• Unnecessary costs and treatments
• Data standardization initiatives failed (i.e. UK’s NHS Connecting for Health)
Digital Serfdom

Personal Data – A €1,000,000,000 Market*

* BCG Study
Digital Self Determination

Trust

Citizen-owned Data Cooperatives

Control of 2nd use
Personal Health Data – Most valuable and most sensitive
EU Citizens …

• Want the best health prevention and treatment available anywhere
• Want access and control over their health data; available anywhere anytime for their own health but NOT for anything AGAINST their will (Control)
• Want to find patients with the same disease anywhere in the world
• Are ready to provide personal health data for research if they and society have clear benefits that outweigh the risks
• Want to profit from the knowledge and the economic value generated by secondary use of their health data
Personalized Medicine…

• Needs aggregation and individualization of large health-related datasets form millions of citizens globally
• Active participation of citizens globally
Technology Generates New Data and Silos

- Genome sequencing
  - Costs in 2-3 years below CHF 500.00
  - Data contain important personal information
    - Effectiveness of drugs
    - Health risks

- Mobile Health
  - > 90’000 health applications
  - Longitudinal health monitoring without a visit to the doctor’s office
  - New data silos, no data integration
Precision Medicine – Need for Aggregation and Integration of Health Data > Google Maps of Health

Ref: Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease National Research Council of the National Academies of Sciences, USA 2012
BUT, healthcare systems …

- Function nationally
- Have national efficiency as their highest priority
- Produce data in incompatible silos
- Secondary use of data is subject to data protection laws
Data Integration Requires the Collaboration of Citizens Globally

Personalized Medicine/Health

Medical Data Silos

Genomic and mHealth Data Silos
How to Empower Millions of Citizens to Contribute to and Benefit from Data Integration and Personalized Health?
The Citizens and their Data are the Third Pillar of Personalized Health

Association Data and Health
Founded July 2012
Aim of the Association Data and Health

To develop the societal, ethical, political and scientific boundary conditions for the creation of a repository for the storage, management, and sharing of personal health data. The repository will be organized as a Swiss cooperative.

Owing to its long lasting democratic tradition, the high quality of its ICT infrastructure and its excellent medical care Switzerland offers an ideal place for a globally active health data repository.
Board

Marco Baggiolini, Präsident
Emeritus Universität Bern, Alt-Rektor Universität della Svizzera Italiana

Vincent Mooser, Vizepräsident
Leiter Pathologie und Labormedizin des CHUV, Universität Lausanne

Mathis Brauchbar, Aktuar
advocacy AG Zürich und Basel

Verena Briner
Kantonsspital Luzern

Ernst Hafen
ETH Zürich, Institut für Molekulare Systembiologie

Donald Kossmann
ETH Zürich, Systems Group, Cloud Computing

Peter Meier-Abt
Präsident SAMW, Universität Basel
Activities
The **Cooperative** – Ideal Corporate Form for Storing and Managing Personal Data

- The cooperative DNA: *“We do it ourselves, on our own terms, self-supporting; rather than depending on government or pure capital investors”*

- One member, one vote
  - Each person has similar amounts of health data (i.e. 6 bn letters in the genome)

- Long tradition in Europe
Why a Cooperative (II)

- Personal data are sensitive and part of one’s digital identity
- Each person should have control over the secondary use of their personal data
- The value of personal data lies in its aggregation
- This value should be returned to the individuals and the community and not third parties (e.g. shareholders)
- The cooperative is owned and controlled by its members and not by shareholders (of Google, Facebook, etc). Profits are invested according to the member’s needs
- Cooperatives cannot be bought
- The ideal corporate form for a sharing economy since all people have similar amounts of personal data
MIDATA.COOPs – Personal Data Cooperatives

A project by members of the Association Data and Health
# The MIDATA.COOP Team

<table>
<thead>
<tr>
<th>Name</th>
<th>Role and Experience</th>
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<tbody>
<tr>
<td>Doris Alisser</td>
<td>Entrepreneur and Founder. Group Vice Chairman of CLS Communication AG.</td>
</tr>
<tr>
<td>Silvio Frey</td>
<td>exec. MBA HSG, Healthcare Consultant, former Head of Sales at InterComponentWare</td>
</tr>
<tr>
<td>Ulrich Genick</td>
<td>Ph.D. Life science researcher (Genomics, Metabolomics, Biochemistry, Bioinformatics)</td>
</tr>
<tr>
<td>Andre Golliez</td>
<td>IT Exert and Entrepreneur. Governance of public institutions, Opendata.ch President</td>
</tr>
<tr>
<td>Peter Grolimund</td>
<td>Dr. phys. ETH data specialist. Data Expert, Taradata.com</td>
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<tr>
<td><strong>Ernst Hafen</strong></td>
<td>Geneticists, former president of ETH Zürich</td>
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<tr>
<td><strong>Donald Kossmann</strong></td>
<td>Professor for Computer Science at ETH Zurich. Database and cloud computing exert.</td>
</tr>
<tr>
<td><strong>Christian Lovis</strong></td>
<td>Professor of Medical Informatics, Hôspitaux Universitaires de Genève, Member of the Board of HIMMS Global</td>
</tr>
<tr>
<td><strong>Andreas Marfurt</strong></td>
<td>Computer Scientist, ETH Zürich</td>
</tr>
<tr>
<td><strong>Thomas Ruddy</strong></td>
<td>Political scientist, privacy activist.</td>
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<tr>
<td><strong>Beat Widler</strong></td>
<td>Clinical research exert, Consultant. Member of the Board of ACRES (Alliance for Clinical Research Excellence and Safety)</td>
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# MIDATA.COOP Advisors

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<th>Advisor</th>
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<tbody>
<tr>
<td>Michael Ambühl</td>
<td>Prof. ETH Zürich, Former State Secretary of Finance</td>
</tr>
<tr>
<td>Barbara Biedermann</td>
<td>MD in private practice, Co-Founder of COBEDIIX AG</td>
</tr>
<tr>
<td>Angela Brand</td>
<td>Prof. of Public Health in Maastricht</td>
</tr>
<tr>
<td>Helmut Brand</td>
<td>Prof. of Health Policy in Maastricht and president of the European Health Forum Gastein and Co-chair of EAPM</td>
</tr>
<tr>
<td>Mathis Brauchbar</td>
<td>Communication Expert, Founder of advocacy AG, Member of the Board of Data and Health</td>
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# MIDATA.COOP Advisors (II)

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
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<tbody>
<tr>
<td>Martin Denz</td>
<td>Martin Denz ist Präsident von EHTEL und Präsident der Schweizerischen Gesellschaft für Telemedizin und eHealth.</td>
</tr>
<tr>
<td>Steven Friend</td>
<td>Founder and president of Sagebionetwork.org</td>
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<tr>
<td>Jakob Kellenberger</td>
<td>Former President of the International Red Cross</td>
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<tr>
<td>Stefan Knoth</td>
<td>Founder and CEO of Curanovis AG, Healthcare Expert</td>
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<tr>
<td>Gordon McVie</td>
<td>Prof. MD and Founder of ecancer.org, Board Member of EAPM</td>
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# MIDATA.COOP Advisors (III)

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<tbody>
<tr>
<td>Alexander Rittweger</td>
<td>Chief Executive Officer (CEO) der Loyalty Partner GmbH, Founder of Payback GmbH, a loyalty card program sold to American Express in 2013</td>
</tr>
<tr>
<td>Amnon Shabo</td>
<td>Amnon Shabo (Shvo), PhD, a specialist in health informatics. The initiator of the Health Record Bank Alliance. He holds leading positions in HL7 (Health Level 7 - a major standards developing organization dedicated to health information):</td>
</tr>
<tr>
<td>John Tasioulas</td>
<td>Prof. in Law and Philosophy and specialist in Human Rights</td>
</tr>
<tr>
<td>Sharon Terry</td>
<td>President and CEO of Genetic Alliance</td>
</tr>
<tr>
<td>Effy Vayena</td>
<td>Dr. in Public Health and Ethics, Expert in Biomedical Ethics</td>
</tr>
<tr>
<td>John Willbanks</td>
<td>Founder of Creative Commons</td>
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Personal (Health) Data Cooperatives – MIDATA.COOPs

- Citizen-owned, citizen-centered
- Secure storage, management and sharing
- Citizens decide what data to share with whom (doctors, friends, research) > Active informed layered consent
- Members decide how to invest revenues in research, education or information platforms
“Secondary Use”
- New Personal data based services (e.g. personal choice engines)
- New Personal data based research (privacy protected!)

MIDATA.COOP
- Citizen controls data ingest and access
- Global data sharing (“smart disclosure”)
- Aggregation possible
- MIDATA.COOP participate in personal data market (€ €)

“Primary Use”
- Provider controls data management
- Data silos
- Data protection law
- Individual privacy regulation
- No aggregation
MIDATA.COOP – A Federation of National Personal Data Cooperatives

- Federation of national PDCs
- Common IT structure
- Data storage in countries with strong data protection laws
- Adapted to national healthcare systems
- Profits stay in national PDCs
- A truly European solution
Project Status

- 3 year effort
- Broad support from Swiss stakeholders (politics, academies, physicians, cooperatives) in over 380 personal meetings
- IT platform prototype build by ETH Computer Science
- H2020 proposal submitted (Lead in Maastricht)
- Preparing a political motion to include *Digital Self Determination* in the Swiss constitution (by Association Data and Health)
- EU level support (e.g. DG Connect, DG Sanco, European Health Forum Gastein)
- European Alliance of Personalised Medicine (EAPM)
- INDEPTH Network for Data Research in LMICs
- Alliance of Clinical Research Excellence and Safety (ACRES)
- Business plan > seeking CHF 3.5 Mio in venture philanthropy, crowd funding and projects
- Incorporation of MIDATA.COOP in Switzerland in Q4 2014
- Pilots will start in Q1 2015 in Switzerland and the Netherlands
MIDATA IT Platform

Open and Secure
Structure of the MIDATA IT Platform

- Data Sharing in Circles
  - Friends
  - Research
  - Patient group

- Data Storage in Spaces
  - Dashboards – Data Visualization, Annotation (App marketplace)
  - Check-ups
  - Fitness
  - Knee Injury
  - Cancer data

- Swiss Cloud
  - Apps
    - Lab
    - Hospital
    - Apps
    - Doctor
    - Clinic

- Data Providers
  - 23andme
  - Apps
  - Drugs
  - Histology
  - Vaccinations
  - Organ donor, patient will

- Data Storage in Spaces
  - Blood: Genome – 23andme, Colonoscopy
  - Dacadoo: Runkeeper, X-ray, Surgery
  - Physiotherapy: CT Scans, Drugs
  - Histology: Cancer data

- Apps API

- Data Providers
  - Lab: 23andme
  - Hospital: Apps
  - Apps
  - Doctor: Clinic
  - Clinic

- Swiss Cloud
Architecture of the MIDATA Platform

- web-based & user controlled
- all data-types accepted
- App / Core / Visualization structure:
  - Core handles Data storage and access controls (by HDC)
  - “Apps” handle data import (by HDC, users & 3rd parties)
  - Visualizations allow browsing and analysis of data (by HDC, users & 3rd parties)

Prof. Donald Kossmann  
Andreas Marfurt
Philosophy of MIDATA Platform Design

**Transparency:**
Platform, apps and visualization written by team are open source (code available on github.com)

**Portability:**
Widely-used, open source, free, public license components enable no-cost cloning of platform.

**Openness generates innovation ecosystem:**
Anyone can contribute new Apps and Visualizations.
Development kit in preparation.
Revenue-share model

**Focus on HDC-specific tasks:**
Outsource hardware and system maintenance, crowd source
Swisscom Cloud as Backend for MIDATA

- Data Storage and CPU physically located in Switzerland under Swiss legislation
- Swisscom is familiar with health data (e.g. Evita)
- Scalability
- Outsourcing of non-core functions
**MIDATA Platform Security**

- Data in / Visualizations out.
- Visualization server not connected to web.
  - Data passed to visualization DB reference not as raw data.
  - Visualizations served to web application in iFrame
  - Local copies of web-resource provided by local node server.
- Hardware (physical access), Firewall and Backup outsourced to experienced provider.
- Use of standard, open source building blocks monitored by large user community
Current Status of MIDATA platform

- MIDATA platform software ready for beta testing
- Installation on Swisscom cloud ongoing
- Apps for Fitness Bands and Text data
- First visualization for Fitness and Genetic data
- Discussions with SMEs to develop new Apps and Visualizations for medical applications.
Join us and start
MIDATA.YOURCOUNTRY.COOP

• Promote bottom-up citizen empowerment in health
• Be a pioneer in a global initiative towards *Digital Self Determination*
• Help to change health and the personal data economy
Contact Information

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