

# MIDATA.coop

## The Personal Data Economy – A Cooperative Approach

**Prof. Ernst Hafen**

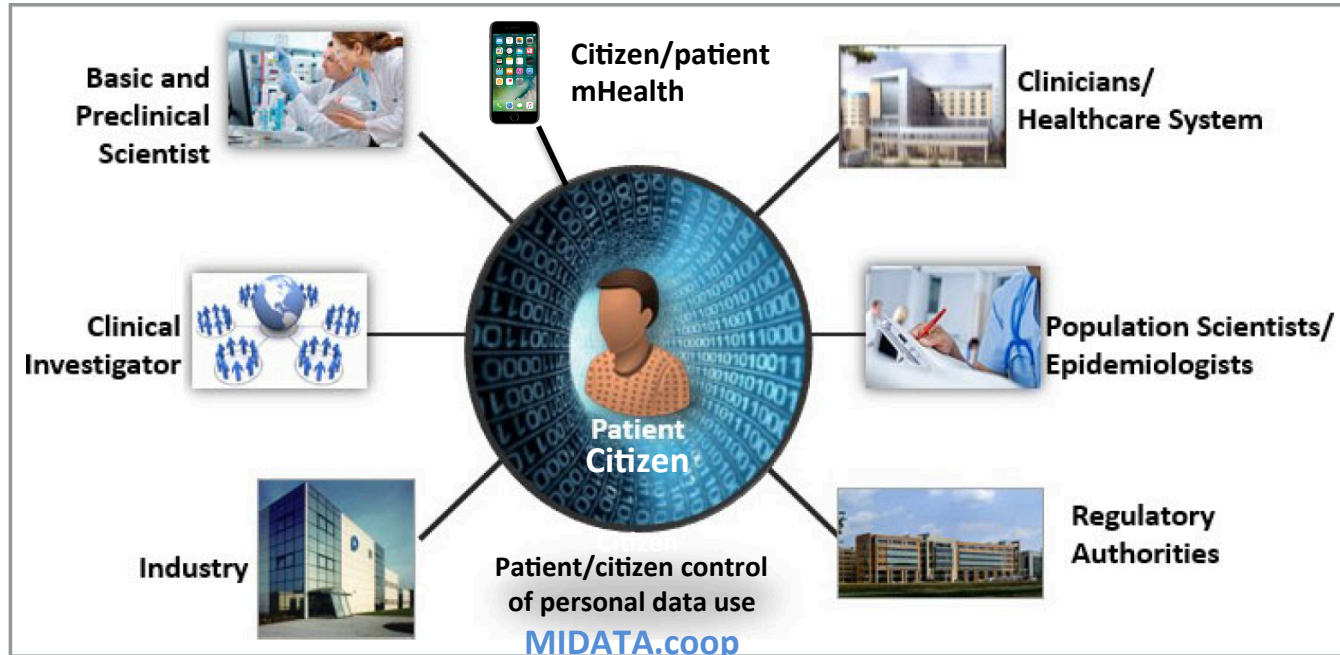
ETH Zurich, Institute of Molecular Systems Biology, MIDATA Cooperative

**Inspire2live**

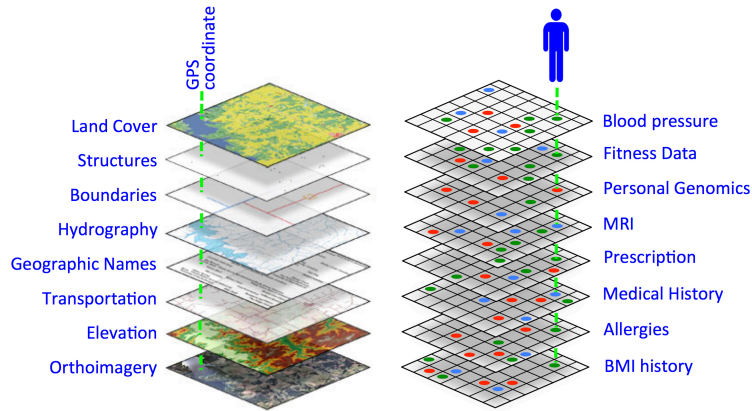
**Amsterdam, February 3 2017**



# Personal data are the basis for precision medicine and precision public health



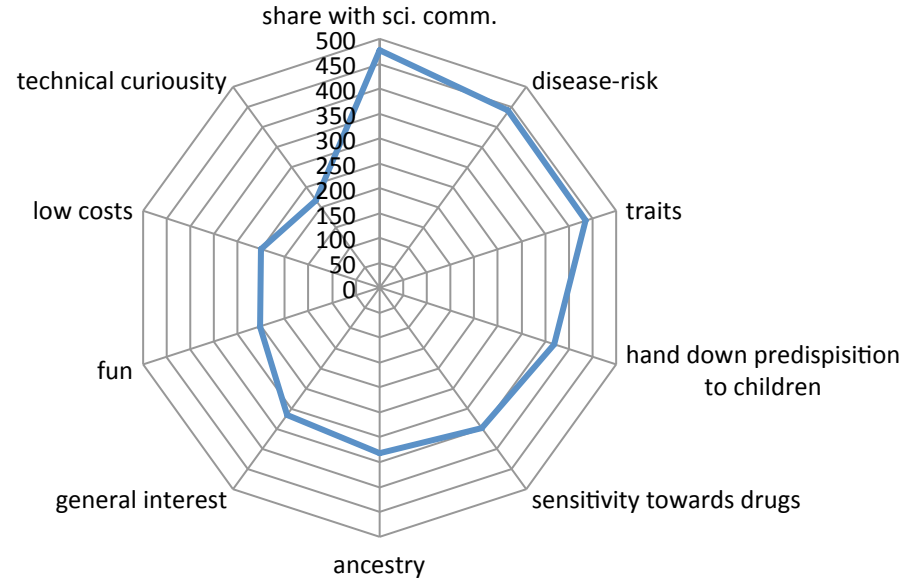
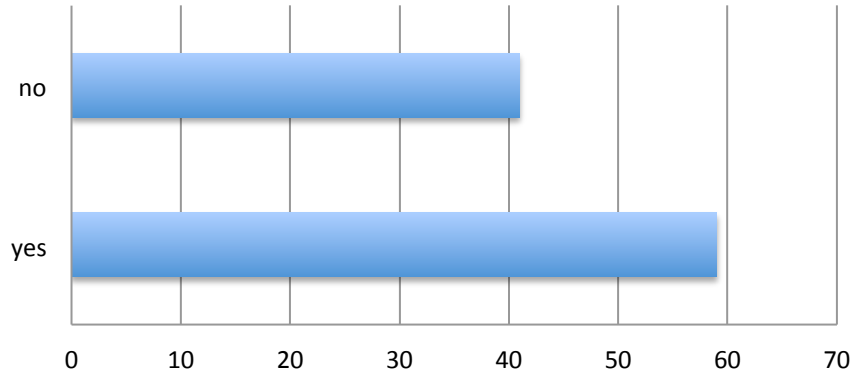
# The Needs for Personalized Health



- Data integration – *Google Maps of Health*
- Aggregation of health related data from millions of people.
- Active participation of citizens is essential.

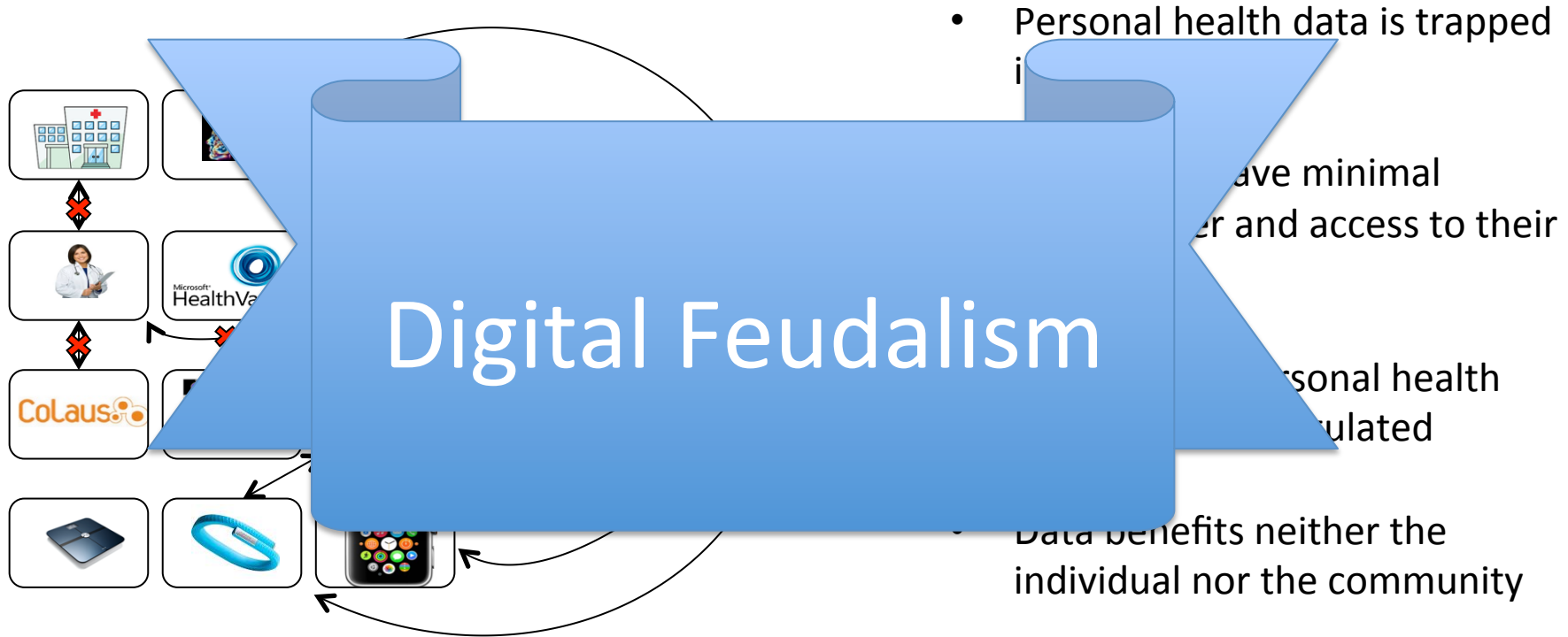
# The Opportunity: Citizen Science

## 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 Challenge: The challenge of personal health-relevant data



# The Challenge: Rebalancing the socioeconomic asymmetry in a data-driven economy

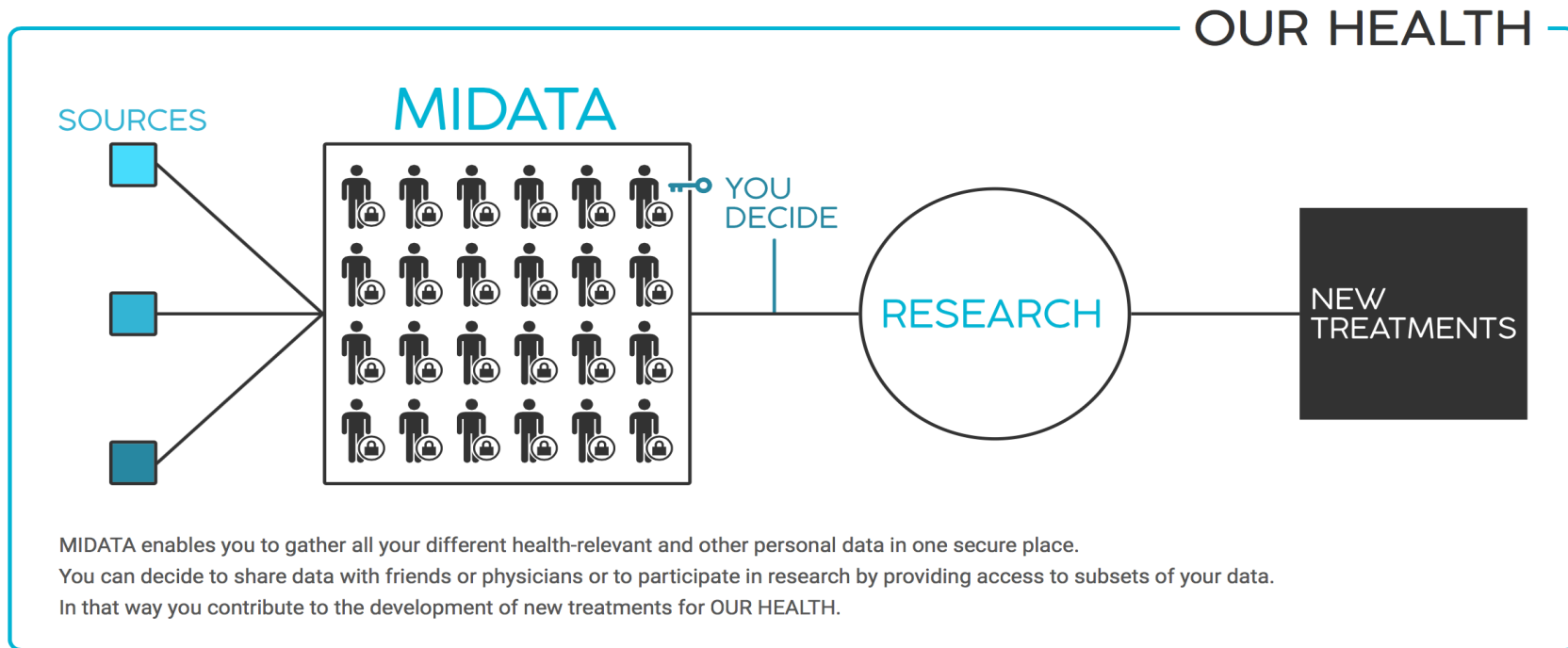


# The Solution: Data to the people – citizen empowerment

- 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 platform** on which people can store, manage and actively share data on their terms
- A **not-for-profit cooperative** organizational structure of the personal data platforms 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**



# Citizen-controlled data storage and sharing



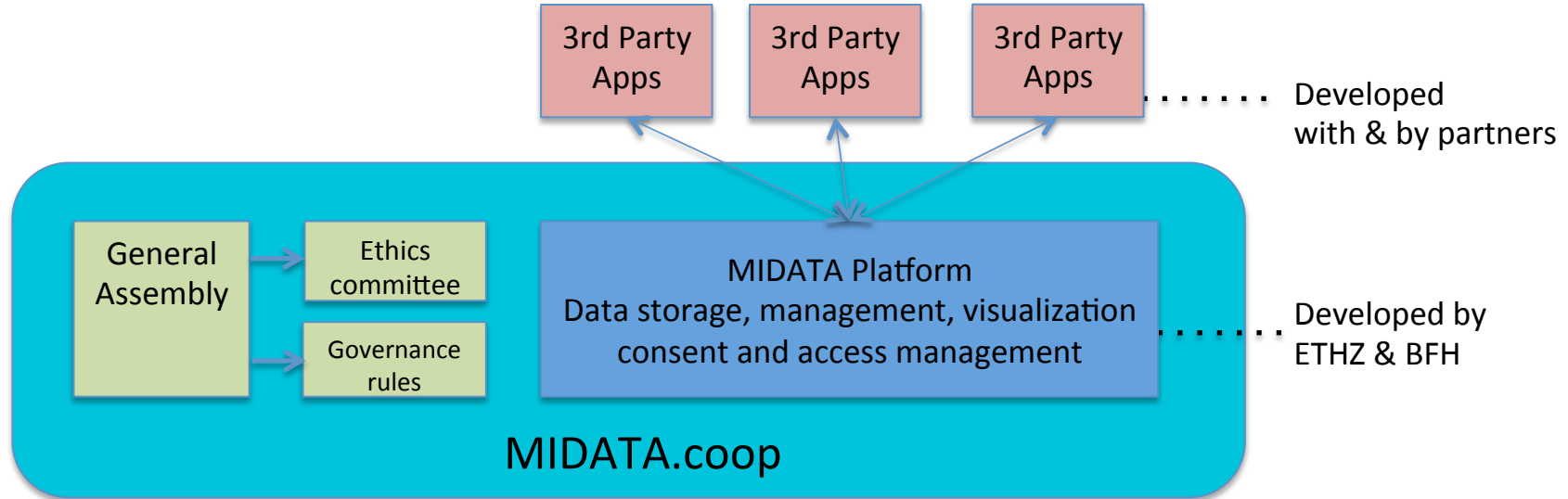
# The basis for a new trust-promoting framework – The personal data platform cooperatives

- **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 Platform 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

# MIDATA ecosystem for innovation



# Project partners



Berner Fachhochschule  
Haute école spécialisée bernoise  
Bern University of Applied Sciences

**MIDATA**  
**Genossenschaft**

Manage your health data

 **INSELSPITAL**

UNIVERSITÄTSSPITAL BERN  
HOPITAL UNIVERSITAIRE DE BERNE  
BERN UNIVERSITY HOSPITAL

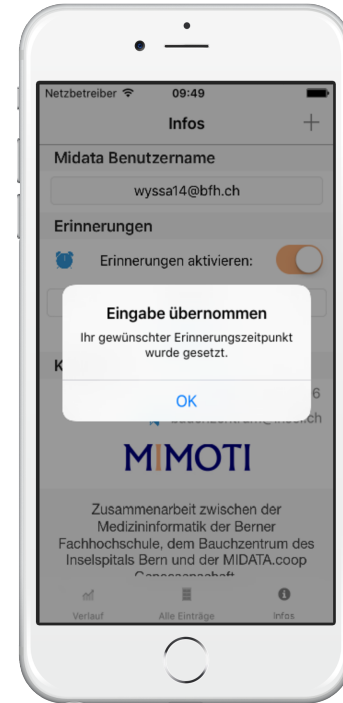


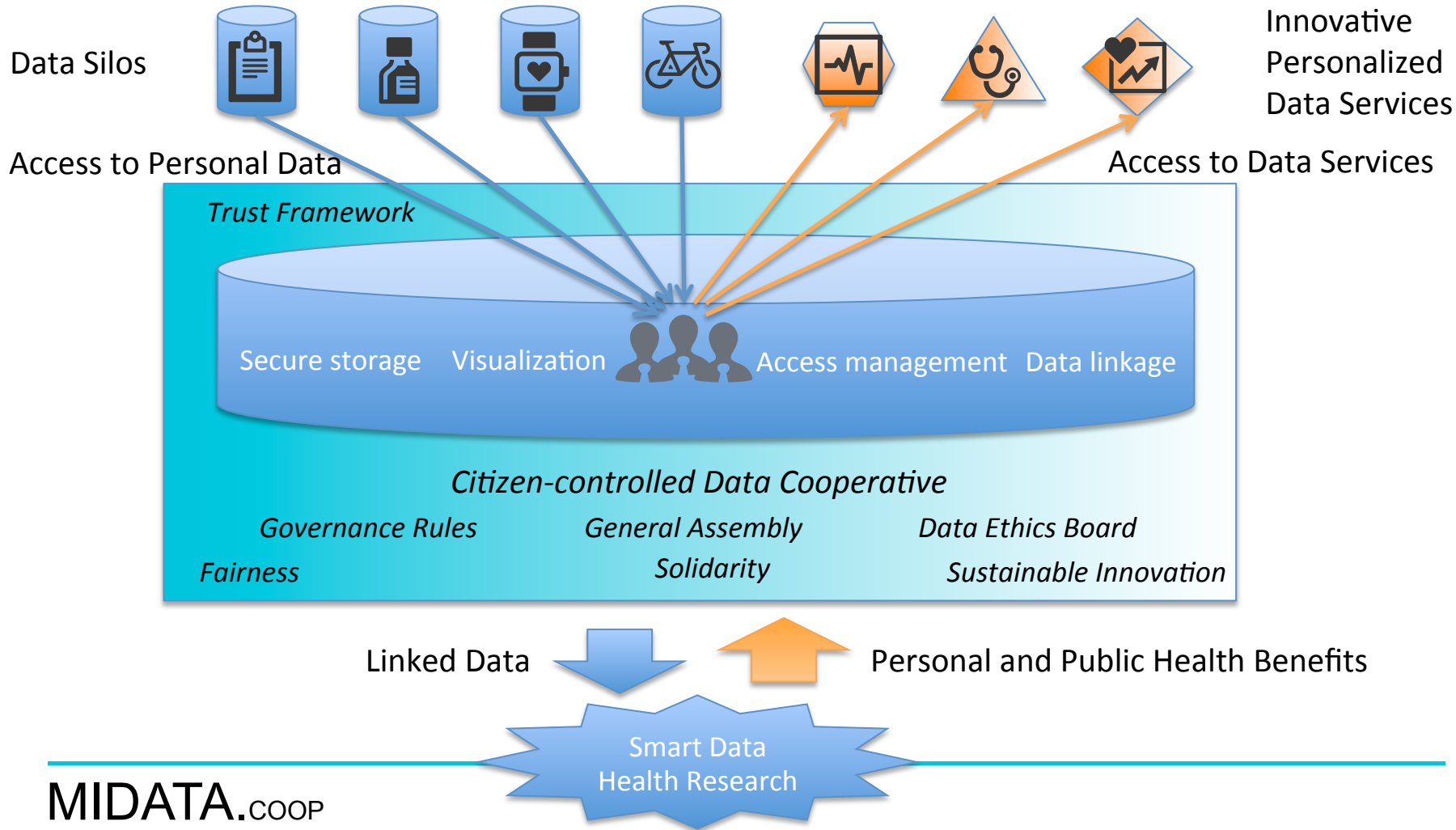
# Use case 1: MIDATA for Patient follow-up

Citizen/Patients:	Adepositas, stomach bypass
Health Professionals:	Bariatric surgery, University Hospital Bern
Functions:	Patients document and share their activity and well-being after surgery
Data:	Activity tracking, weight, well-being
Added value:	Outcome measure, patient empowerment, risk reduction
Status:	Started May 1 2016



# MIMOTI – „Mini Motivation“





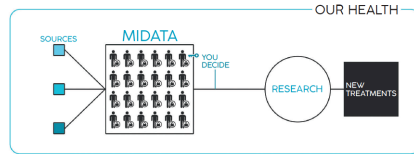


Use case	Disease/ treatment	Institution	Physician/Researcher	Data types	Status
1	Obesity	<u>Inselgruppe</u>	Dr. Philip Nett Dr. Dino Kröll	Steps, Weight, Wellbeing, Diary notes	Ongoing
2	Multiple Sclerosis	USZ	Prof. Dr. Roland Martin, Dr. Andreas Lutterotti	Steps, Wellbeing, cognition tests Hand-eye coordination	Development and validation of a app for health status assessment
3	Oncology	<u>Inselgruppe</u>	Prof. Dr. Thomas Pabst	Steps, Weight, Wellbeing, Blood lab results	Realization of a proof of concept
4	Type 2 Diabetes	<u>Inselgruppe</u>	Prof. Dr. Christophe Stettler Dr Markus Laimer	Glycemic index, Calendar, Patient/physician communication	Realization of a proof of concept
5	Drug Rehab	<u>Suchtbehandlung im Frankental</u>	Dr Urs Vontobel Fr Nicole Schmid	Steps, anxiety level, craving scale, therapies	Development and Test
6	COPD	<u>Inselgruppe</u>	Prof. Dr. Christophe von Garnier	Lungs function	Definition of a study perimeter
7	Type 1 Diabetes	Potentially CHUV, USB and <u>Inselgruppe</u>	Contacts will be shortly confirmed	Glucose level, Stress level, <u>electrodermal</u> activity	Building of partnership for a multi-centric study
8	Drug dependence	PUK	Prof. Dr. Boris Quednow Prof. Dr. Erich Seifritz	Steps, craving scale, self reported drug consumption	Definition of a study perimeter
9	Genetics of Sensory Perception	ETH	Prof. Hafen Dr. Ulrich Genick Citizen scientists	Whole genome genotyping, Sensory perception, Food intake	Pilot testing
10	Metabolic Syndrom / <u>PersonalizeNutrition</u>	ETH, EPFL	Prof. Michael Ristow, Prof. Marcel Salathe Citizen scientists	Nutrition, Glycemic Response, mobile health	Development
11	Cancer	ETH, USZ, UZH	Prof. Bernd Wollscheid Cancer Hub Team	Genomics, Metabolomics, mobile health	Building of partnership to integrate patient-generated data into ongoing project
12	Sleep	ETH, USZ, <u>Kispi</u> , UZH	Profs. Walter Karlen, Christian Baumann, <u>Reto Huber</u>	Sleep behaviour and electrophysiology, <u>mHealth</u>	Development
13	Low back pain	ETH, UZH	Prof. Walter <u>Karlen</u>	Pain, EMA, <u>mHealth</u>	Development
14	Breast cancer	ETH, UZH, USZ, <u>brcaexchange.org</u> consortium	Prof. Gunnar Rätsch Prof. Anita Rauch (tbc) Citizen scientists, patient groups	Genome, <u>mHealth</u> , patient feedback	Development

# We are looking for partners and supporters to build a global MIDATA platform cooperative ecosystem

## MIDATA.coop

MIDATA Cooperatives:  
Citizens take control of their  
personal data



### Mission

MIDATA cooperatives enable citizens to securely store, manage and control access to their personal data by helping them to establish and own national/regional not-for-profit MIDATA cooperatives.

MIDATA's initial focus will be on health related data since these are most sensitive and valuable for one's personal health.

MIDATA cooperatives act as the fiduciaries of their account holders' data. As MIDATA account holders, citizens can visualize and analyze their personal data. As cooperative members, they govern the cooperative. They can actively contribute to medical research and to clinical trials by providing access to sets of their personal data across cooperatives.

### First MIDATA cooperative in Switzerland

The first MIDATA cooperative was founded in Switzerland, in 2015. It already runs several pilot projects with Swiss university hospitals, supporting patient outcomes research and clinical trials.

## Current partners:

- Germany: Berlin Institute of Health, Charité
- The Netherlands: TNO, Medical Delta
- Ethiopia, Kersa INDEPTH HDSS
- Vietnam, Filabavi INDEPTH HDSS
- Ghana, INDEPTH-Network

Take a Flyer

MIDATA.coop

# Contact information

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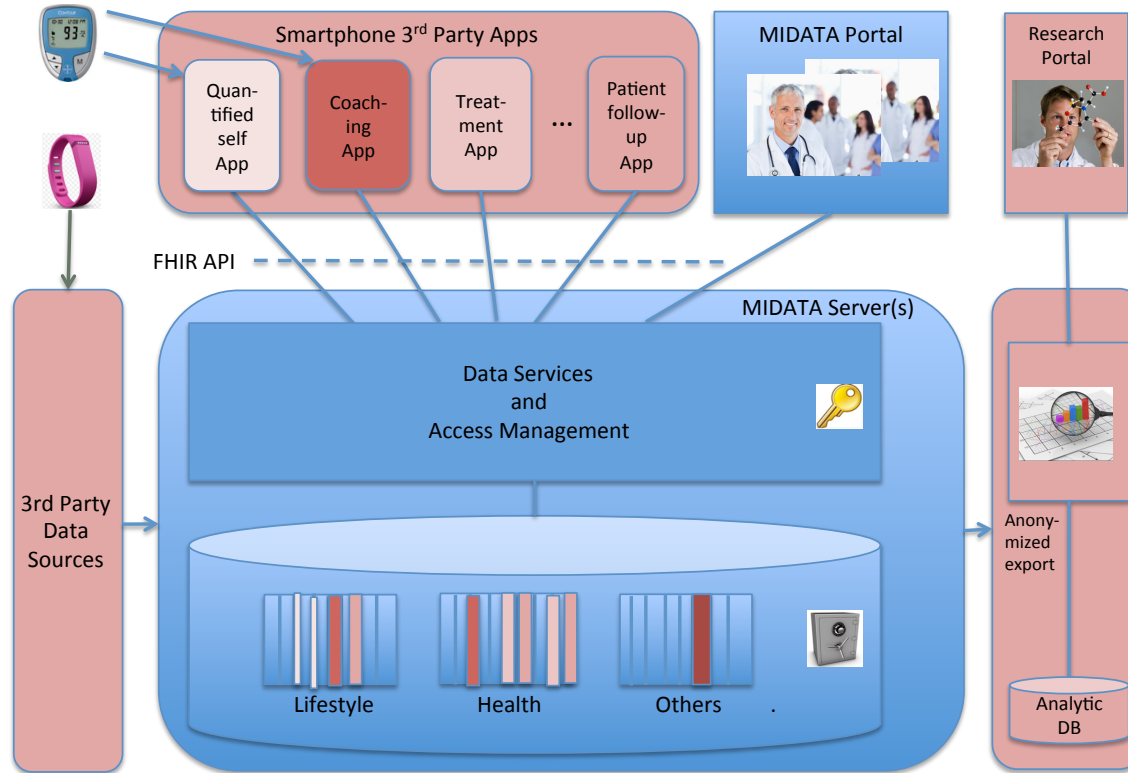
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# MIDATA platform architecture



# MIDATA security through cryptography

