



# Data to the People – The Power of Citizen Science in Healthcare

The Swiss Research Data Day – Zürich, June 12 2018

Prof. Ernst Hafen



# The three unique features about personal data

1. Can easily be copied at near zero marginal costs
2. Equally distributed amongst individuals (all people are billionaires in genome data)
3. Individuals are the maximal aggregators of their personal data



# Art 20 in der EU-DSGVO: Right to Data Portability

Art. 20 GDPR

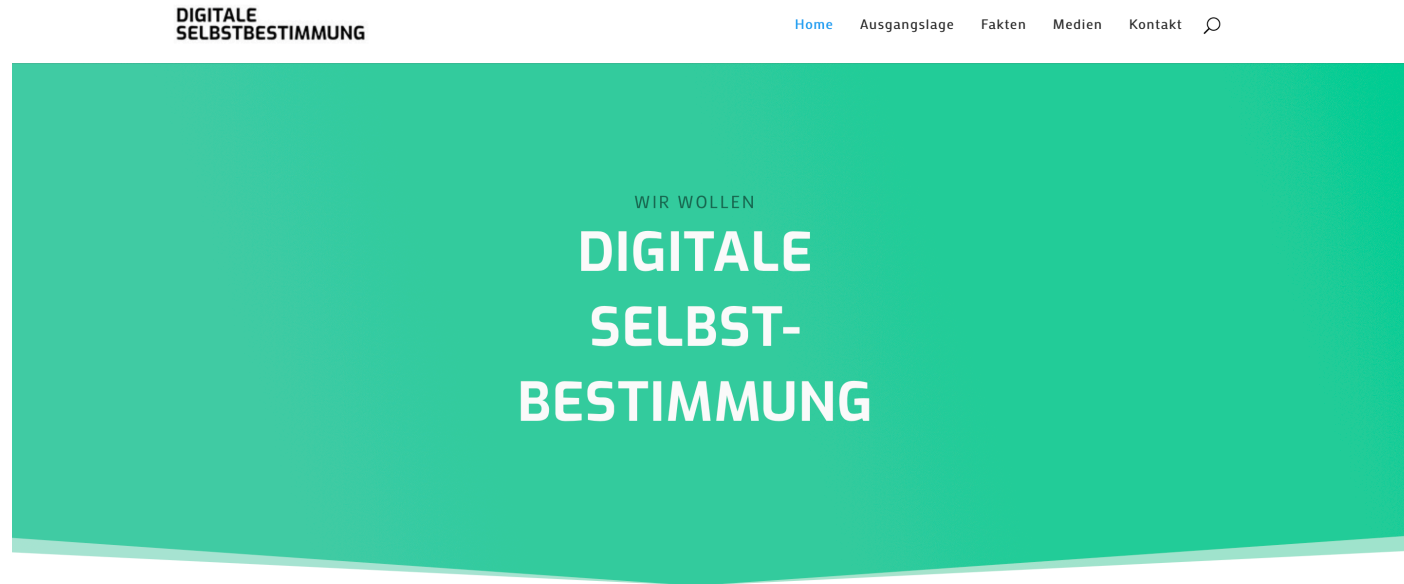
## Right to data portability

- (1) The data subject shall have the right to receive the personal data concerning him or her, which he or she has provided to a controller, in a structured, commonly used and machine-readable format and have the right to transmit those data to another controller without hindrance from the controller to which the personal data have been provided, where:
  - a) the processing is based on consent pursuant to point (a) of [Article 6\(1\)](#) or point (a) of [Article 9\(2\)](#) or on a contract pursuant to point (b) of [Article 6\(1\)](#); and
  - b) the processing is carried out by automated means.
- (2) In exercising his or her right to data portability pursuant to paragraph 1, the data subject shall have the right to have the personal data transmitted directly from one controller to another, where technically feasible.
- (3) The exercise of the right referred to in paragraph 1 of this Article shall be without prejudice to [Article 17](#). That right shall not apply to processing necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.
- (4) The right referred to in paragraph 1 shall not adversely affect the rights and freedoms of others.

- Initially planned to prevent lock-in in data repositories
  - Like portability of mobile phone number
- With a copy of their data citizens can decide about their own secondary use of the data (research, citizen science, data services)



# Data Portability – Not in Switzerland! Help us to change this!



[www.DigitaleSelbstbestimmung.ch](http://www.DigitaleSelbstbestimmung.ch)

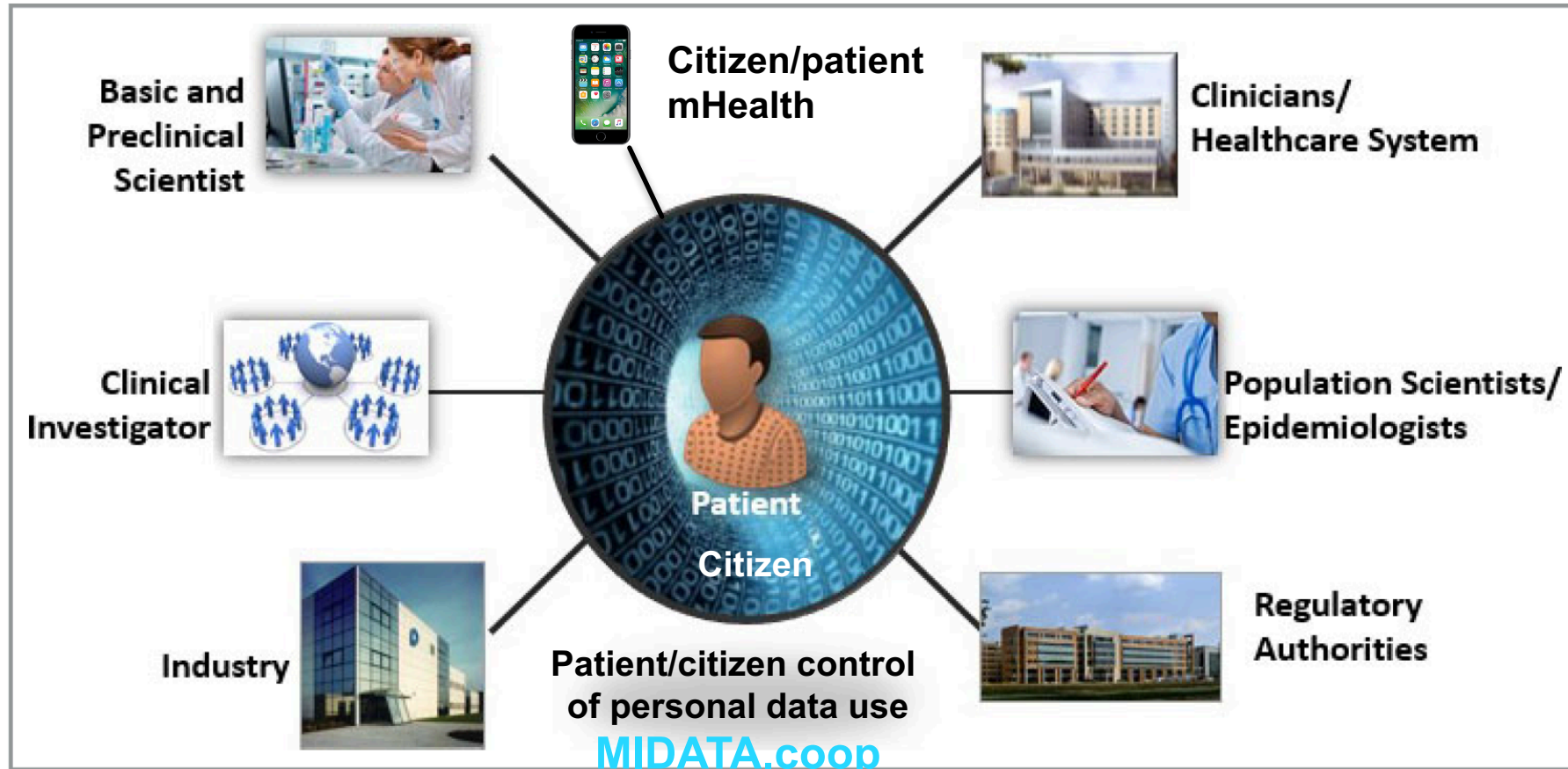
**Digitale Selbstbestimmung**

Wir Bürger fordern, was uns gehört: Das Recht, die eigenen Daten zu kontrollieren. Die digitale Selbstbestimmung muss als grundlegendes Recht verankert werden!

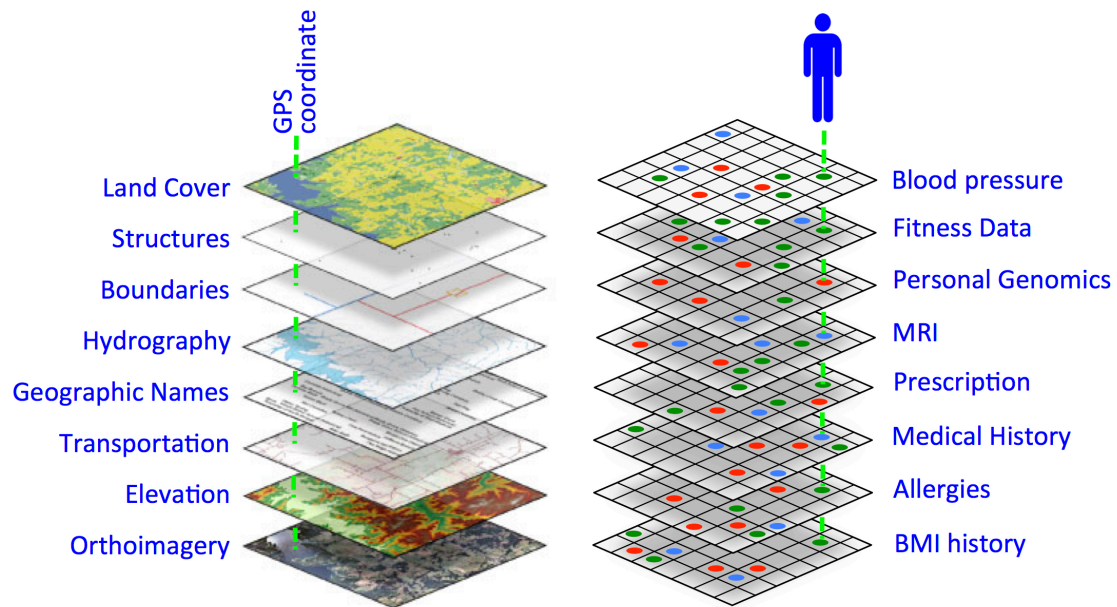




# Personal data are the basis for personalized medicine



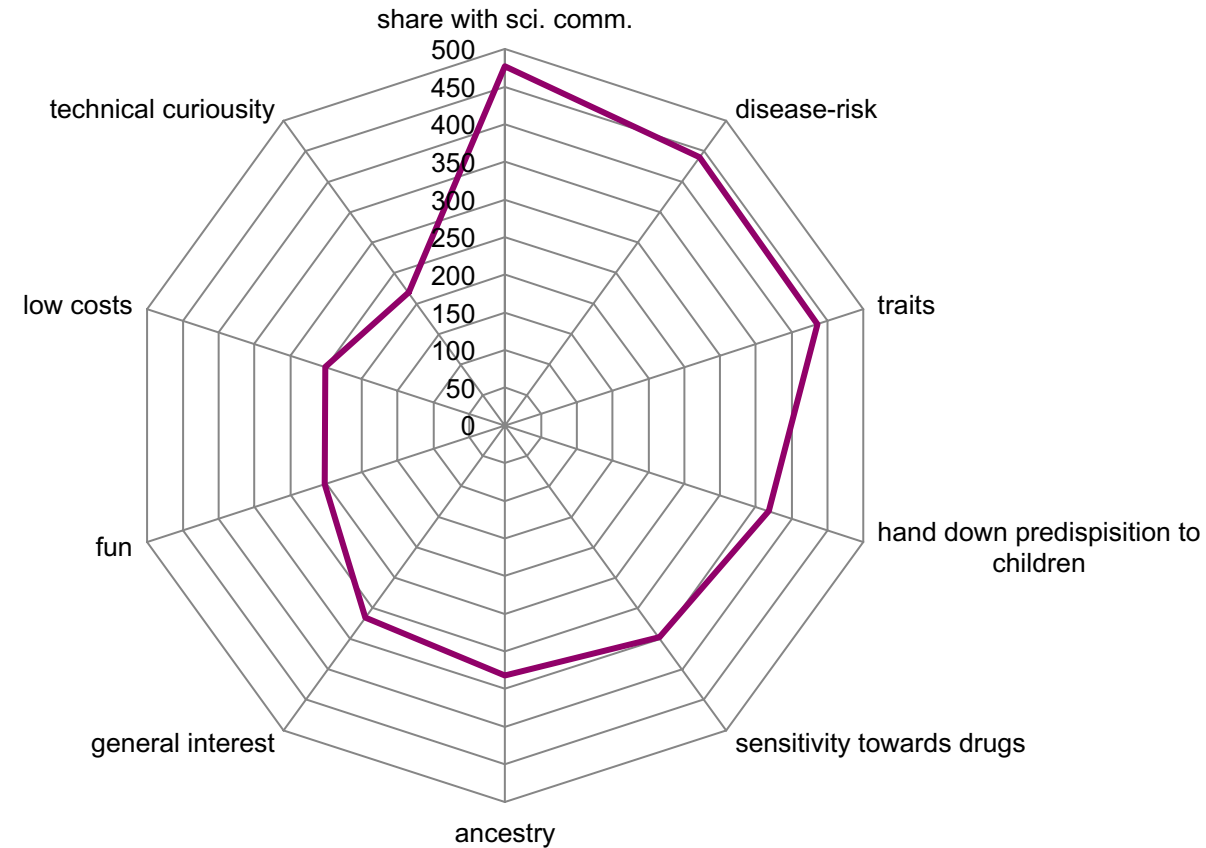
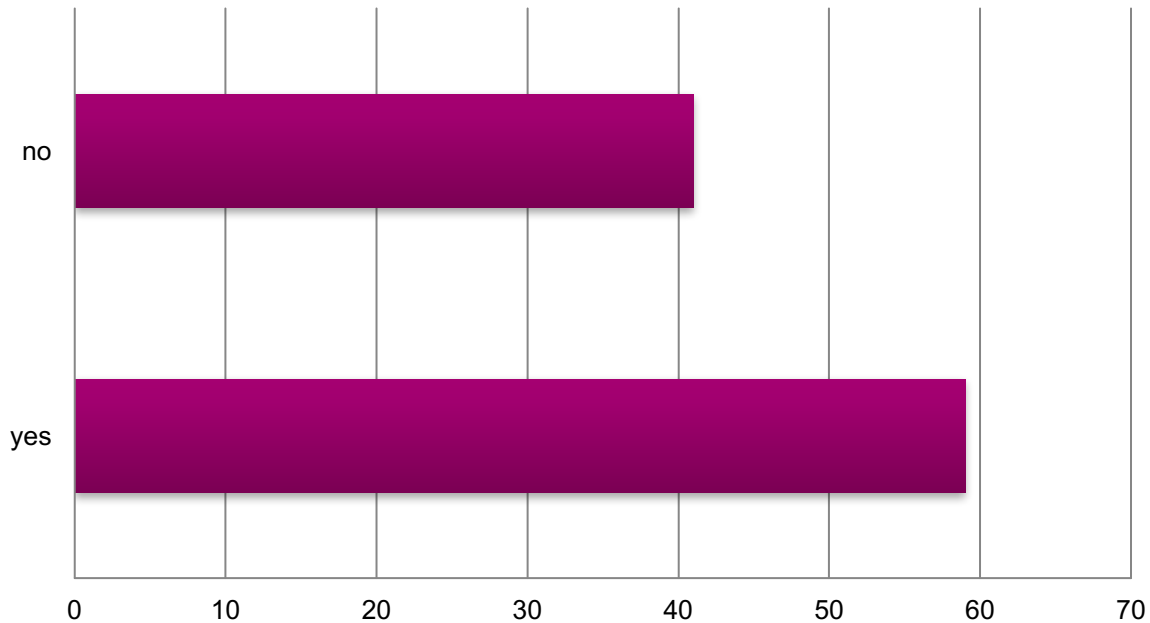
# The Need: Data Integration – Google Maps of Health



- **Aggregation** of health data from millions of people
- **Active participation** of citizens world-wide

## The Opportunity: Student Survey

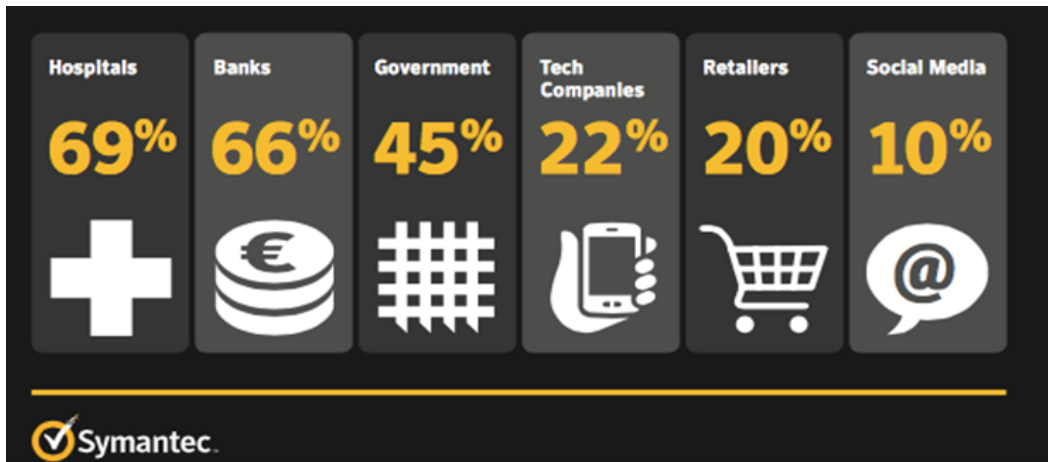
hypothetical DTC-GT test taking [%]



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 Challenge: Missing Trust in the Personal Data Economy



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



# MIDATA

## The Personal Data Management A Cooperative Approach

Prof. Serge Bingens, BFH, Institute for Medical Informatics

Prof. Ernst Hafen, Institute of Molecular Systems Biology, ETH Zürich

# Project Partners

**ETH** zürich



Berner Fachhochschule  
Haute école spécialisée bernoise  
Bern University of Applied Sciences



Swiss Data Science Center

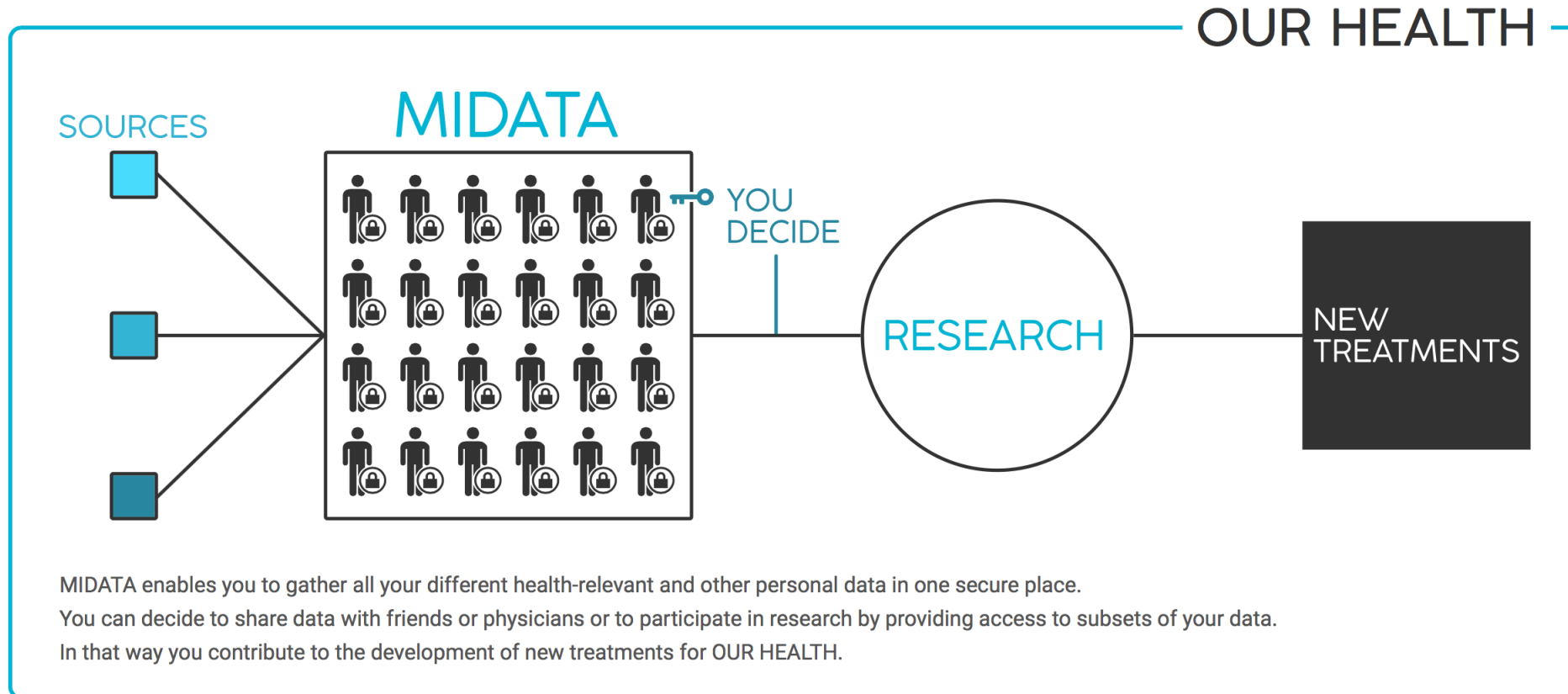


UniversitätsSpital  
Zürich





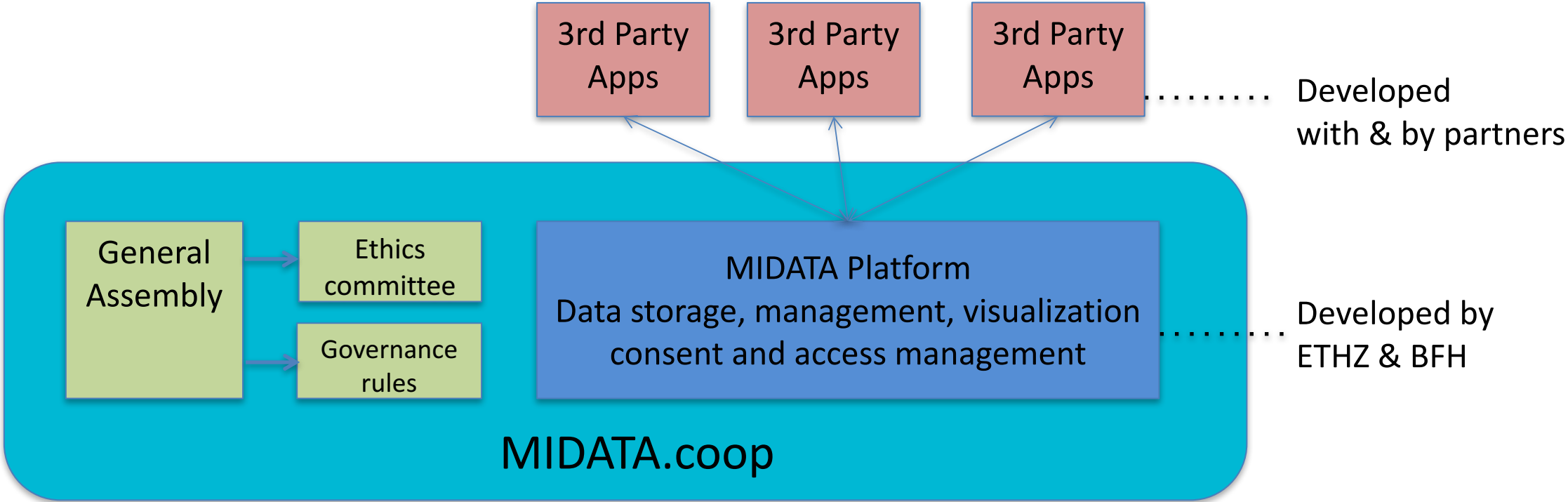
# Citizen-controlled data storage and sharing



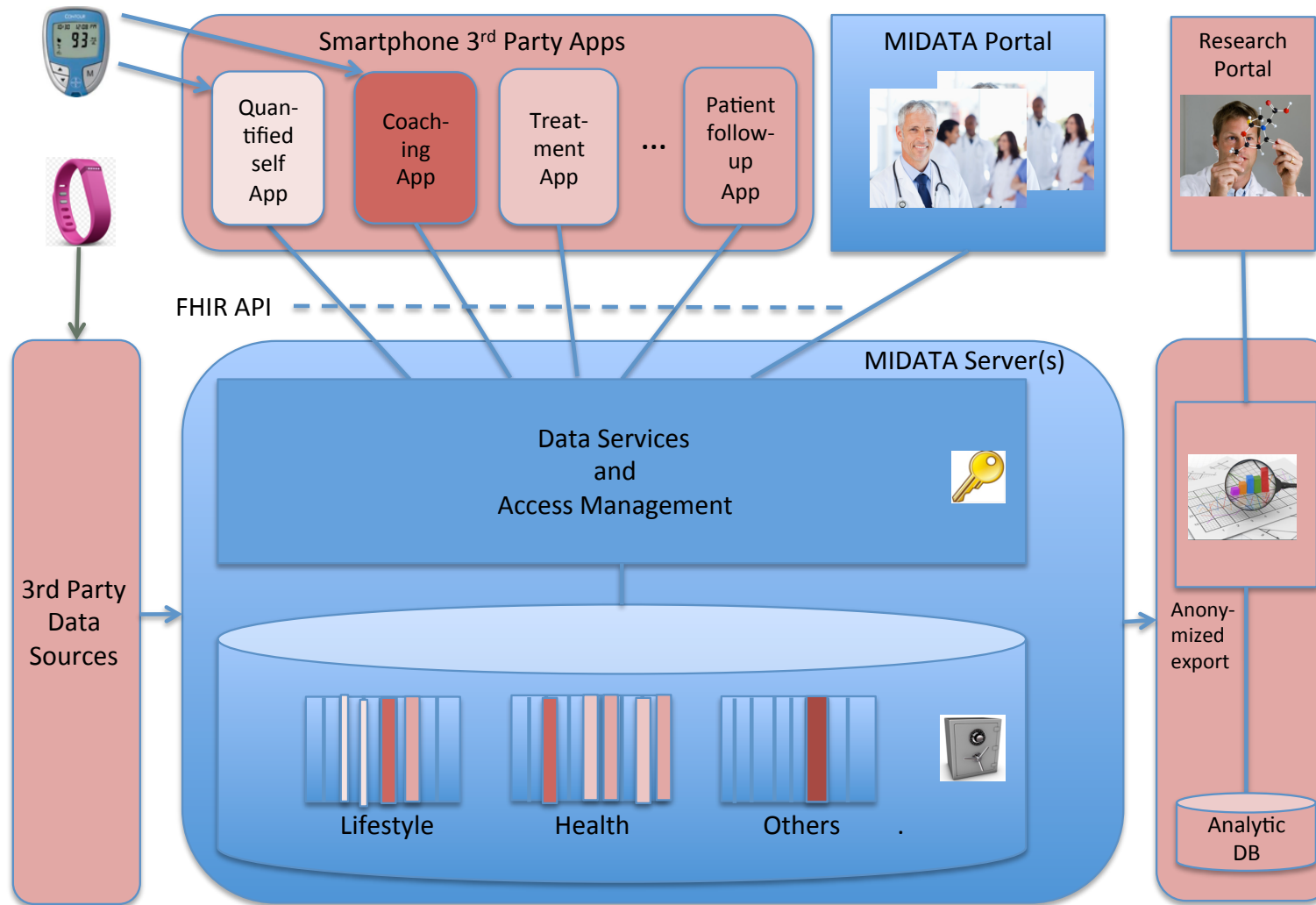
# A new trust promoting framework

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

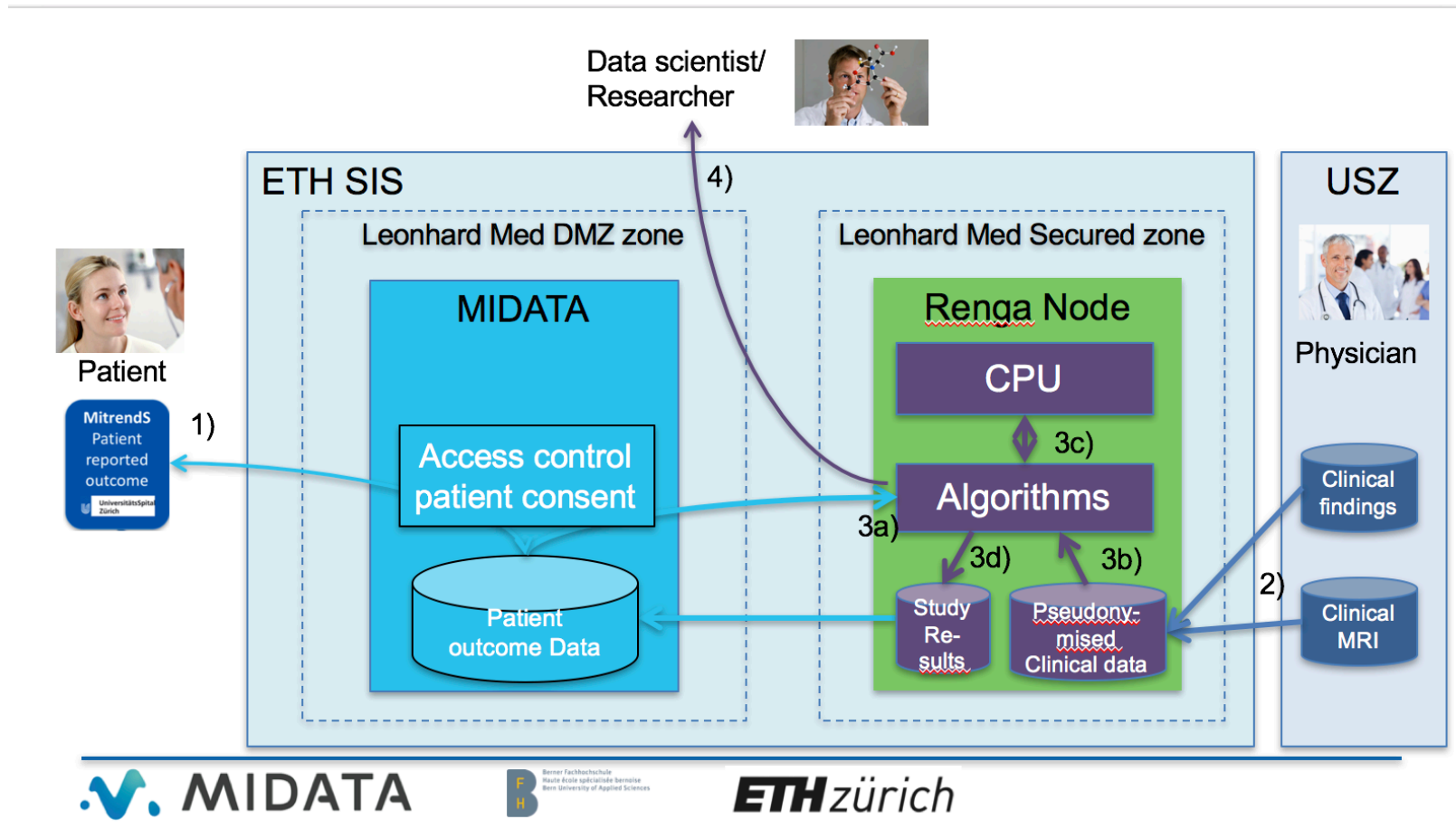
# The MIDATA ecosystem for innovation



# MIDATA platform architecture



# In-platform computing – Research grant from the Swiss Data Science Center



## Partners

- G. Rätsch, ETH D-INFK
- O. Vescheure, SDSC
- B. Rinn, ETH SIS
- S. Bignens, BFH Med Info
- A. Lutterotti, USZ Neurology

Grant received Jan 2018

# Use Cases

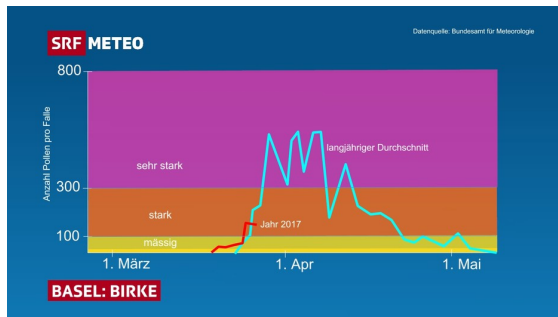
- **Mimoti:** Patient Reported Outcome (PRO) study after bariatric surgery, Insel Hospital (May 2016)
- **MitrendS:** PRO study in multiple sclerosis, USZ, (April 2017)
- **Miwado:** Secure communication between patients and healthcare providers, Insel (July 2017)
- **Evoli:** PRO study after chemotherapy, Insel Hospital (Oct 2017)
- **Ally Science:** Swiss Hay Fever Cohort, USZ, (April 2018)



# Ally Science – The Swiss Allergy Study



- Allergy mapping over all parts of Switzerland using citizen science
- Start version 1 April 24, 2018
  - V2 May 22 2018
- 4.5 months from project start to launch
- After three weeks: > 7'500 users and > 60 press and media coverage



# Project Partners



**UniversitätsSpital Zürich, Dermatologische Klinik, Allergiestation :**  
Studiendesign, Auswertung der Forschungsergebnisse



**MIDATA, genossenschaftliche, sichere Datenverwaltung:**  
Verwaltung & Sicherung der Nutzerdaten, Steuerung der Zugriffsrechte,



**Berner Fachhochschule, Abteilung für Medizininformatik:**  
Fach- und Technologie Partner, App-Konzeption, Design & Entwicklung



**ETH Zürich, Institute for Molecular Systems Biology:**  
Studiensupport und Begleitung im Citizen-Science-Prozess



**Dyson Schweiz SA & Dyson Ltd.,** Forschung und Entwicklung Raumklima-Geräte  
Kompetenz- und Finanzierungspartnerschaft



**ELCA Informatique SA,** IT-Dienstleistungen. Beratung, Entwicklung, Betrieb und Unterhalt  
IT-Entwicklungspartner



**Superhuit Sàrl,**  
Partner für Grafik und Design

**Weitere Partner:**



Christine Kühne – Center for Allergy  
Research and Education

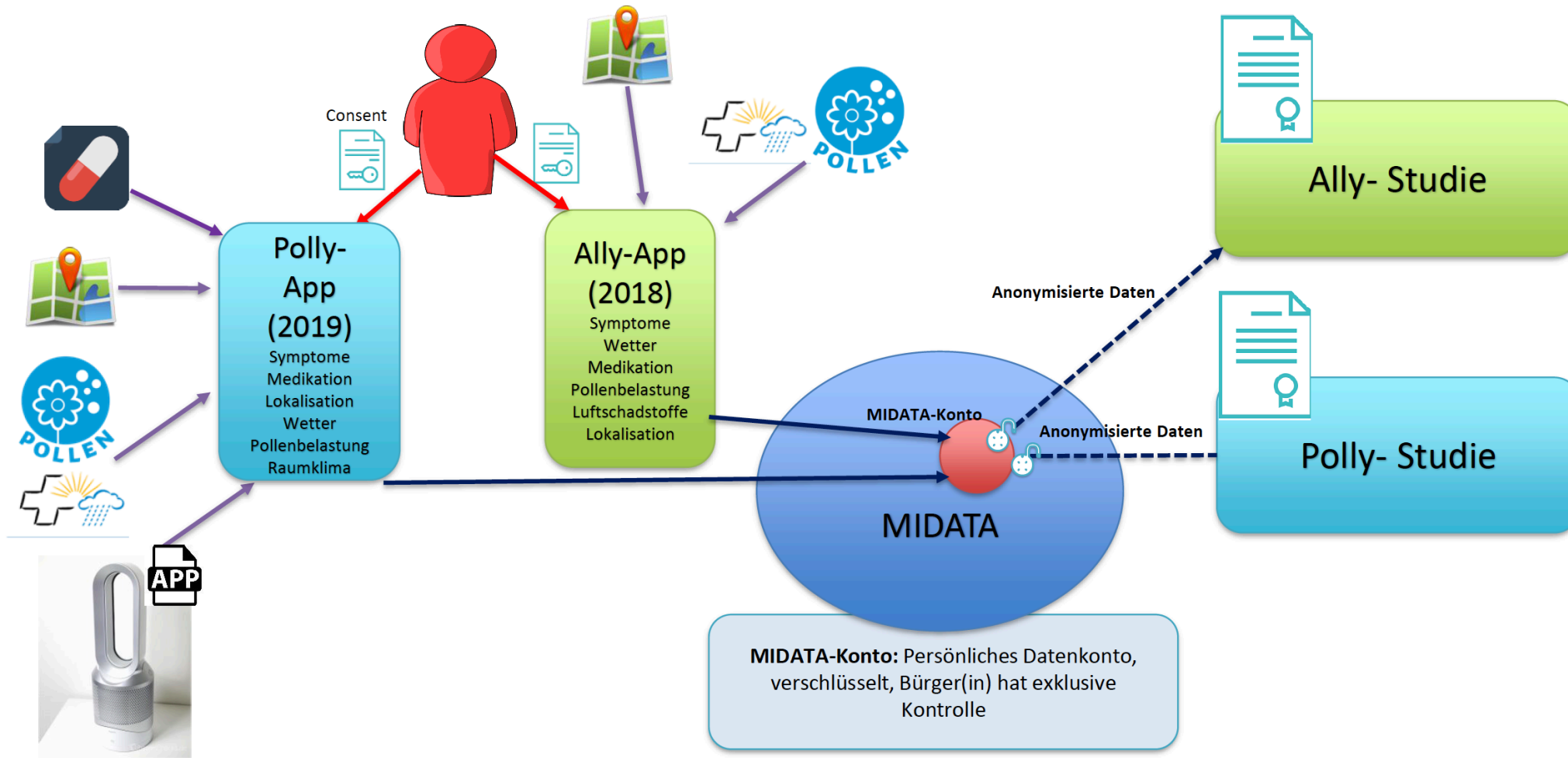


Das Bundesamt für Meteorologie und  
Klimatologie

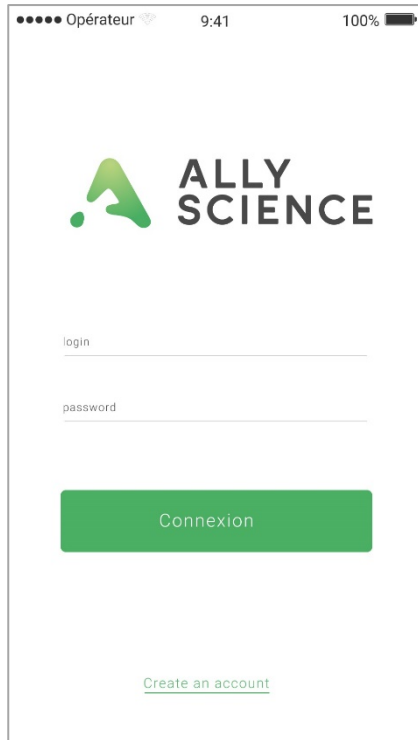


Allergiezentrum Schweiz

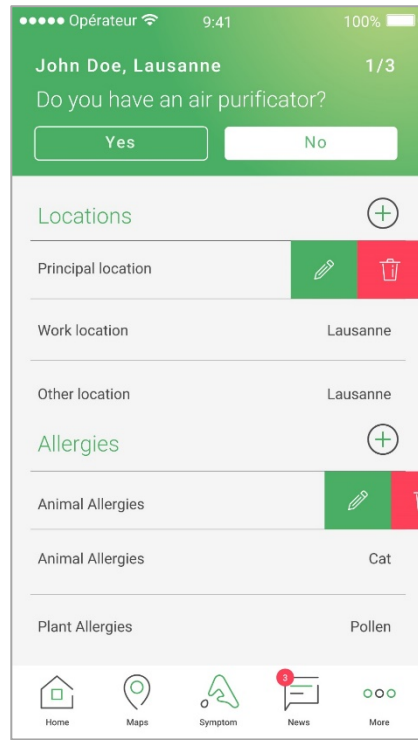
# Processes in the ecosystem of Ally Science



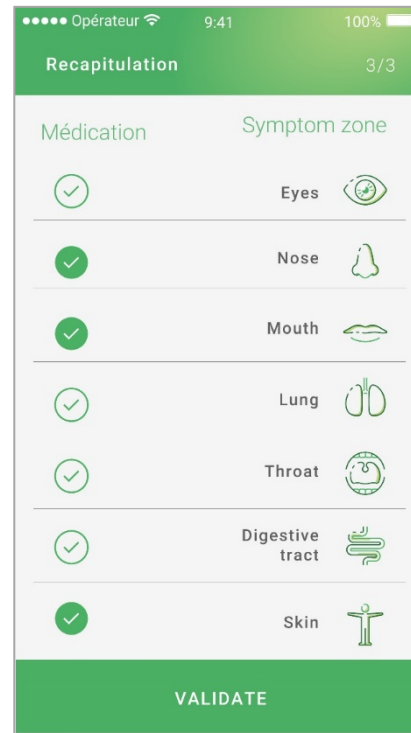
# Ally Science App (I)



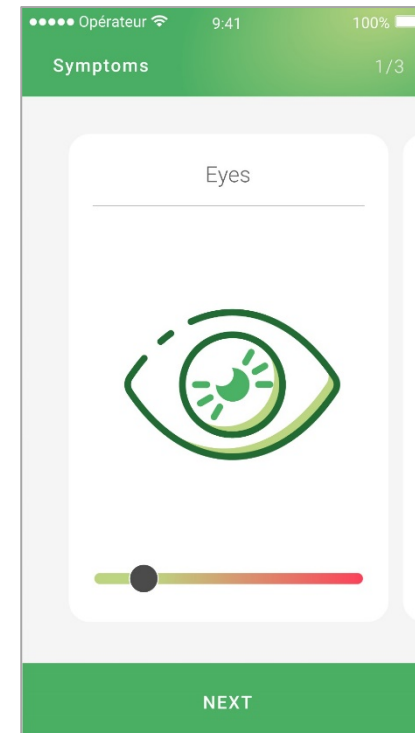
Ja, ich mache mit!



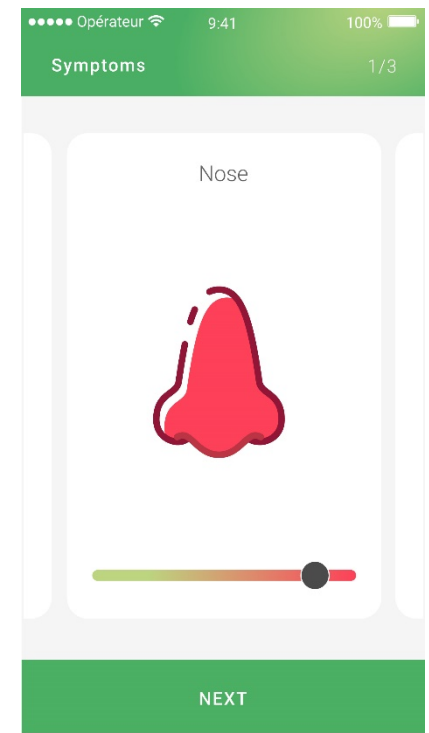
Das sind meine Orte



Gegen das Leiden dieser Organe nutze ich ein Medikament

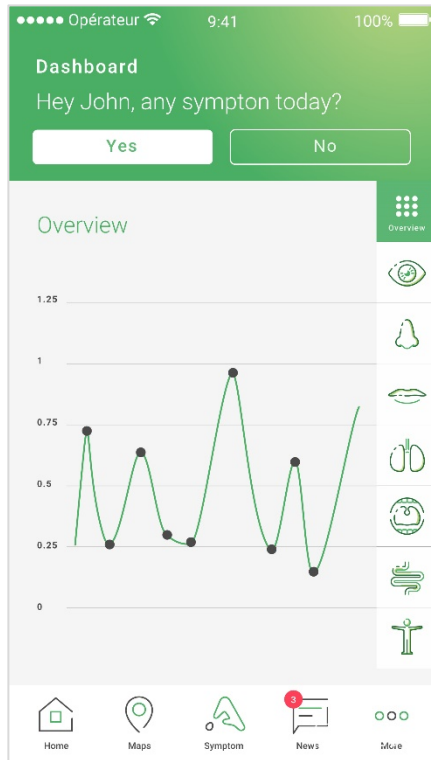


So stark leiden meine Augen heute

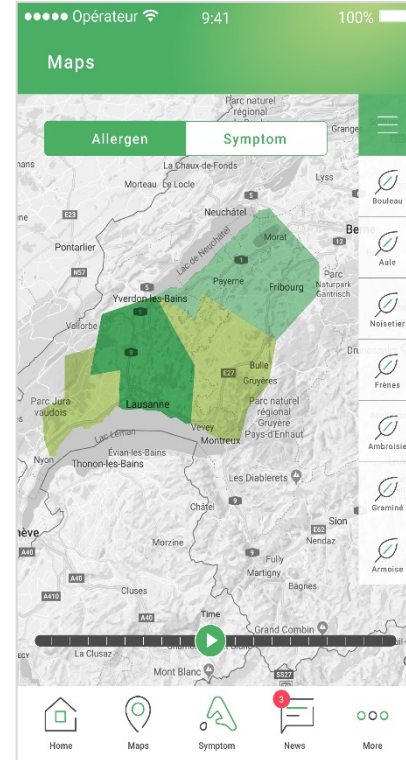


So stark leidet meine Nase heute

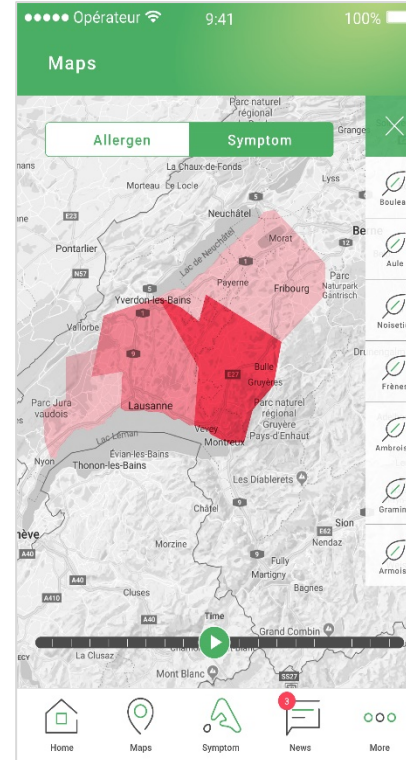
# Ally Science App (II)



Mein Symptom-Verlauf



Die Pollenbelastung an meinen Orten



So leidet die Ally-Community in meiner Region – ich bin nicht alleine



Nützliche Tipps der Meteorologen

# Internationalization – The needs of patients are the same everywhere

**We partner to build a global MIDATA platform cooperative ecosystem**

**Current partners:**

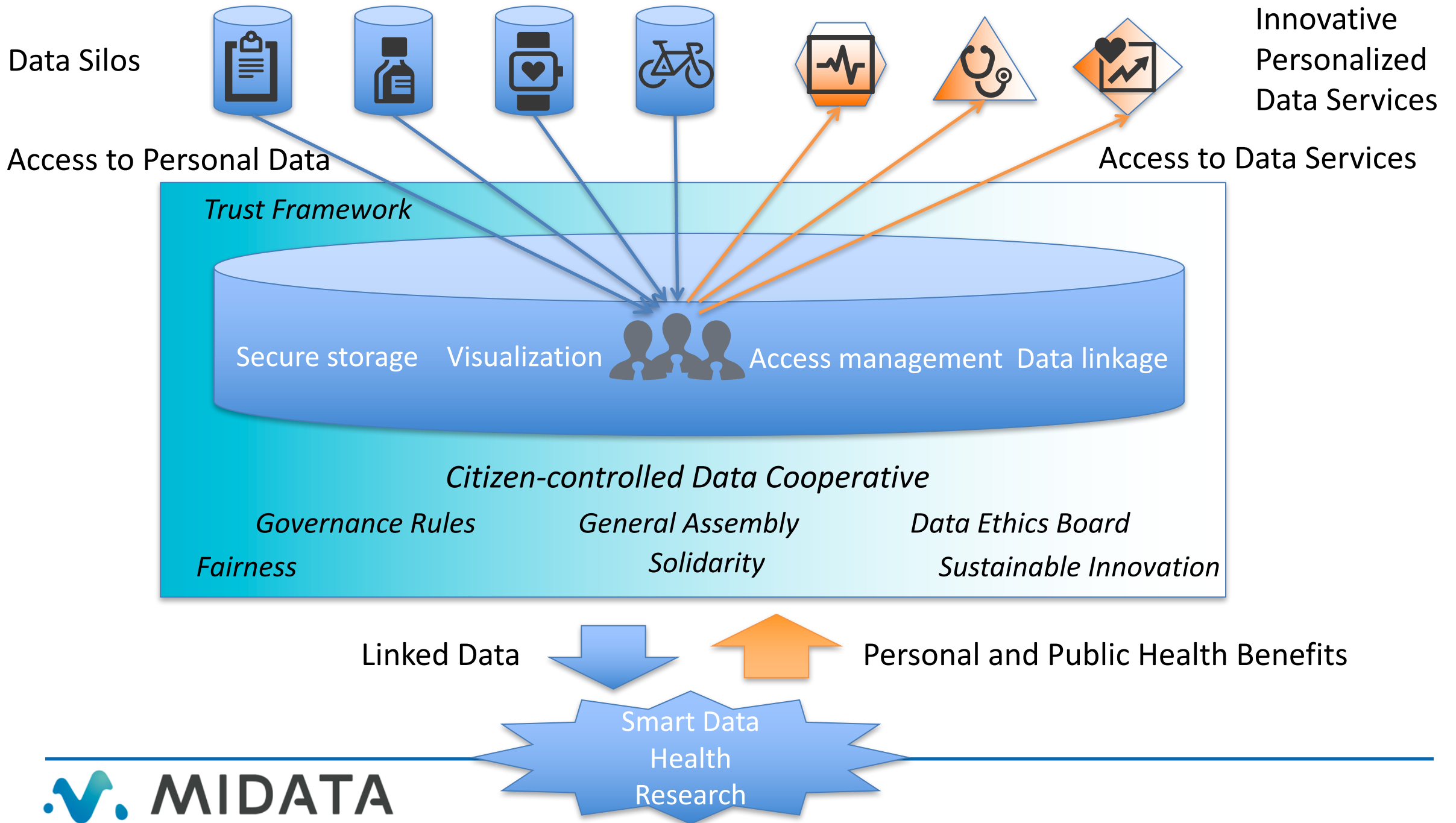
- Germany: Berlin Institute of Health, Charité
- The Netherlands: TNO, Medical Delta, City of Rotterdam
- Belgium: Vito Research Institute
- UK: Oxford University Hospital Foundation Trust

**The democratization of the personal data economy**



# A revolution in Patient Reported Outcome studies

- Entirely based on smartphone sensors and apps
- Dedicated app for each condition
- Fair citizen-controlled data governance
- Branding by hospitals and clinics
- Ready internationalization through MIDATA partners
- Transparency and patient engagement



# The Democratization of the Personal Data Economy

**Present**



**Artificial Intelligence**



**Global Dominance**

**Future**



**Artificial Intelligence + Human Intelligence**



**Fair democratic governance  
Property owning democracy**

# Contact information

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