



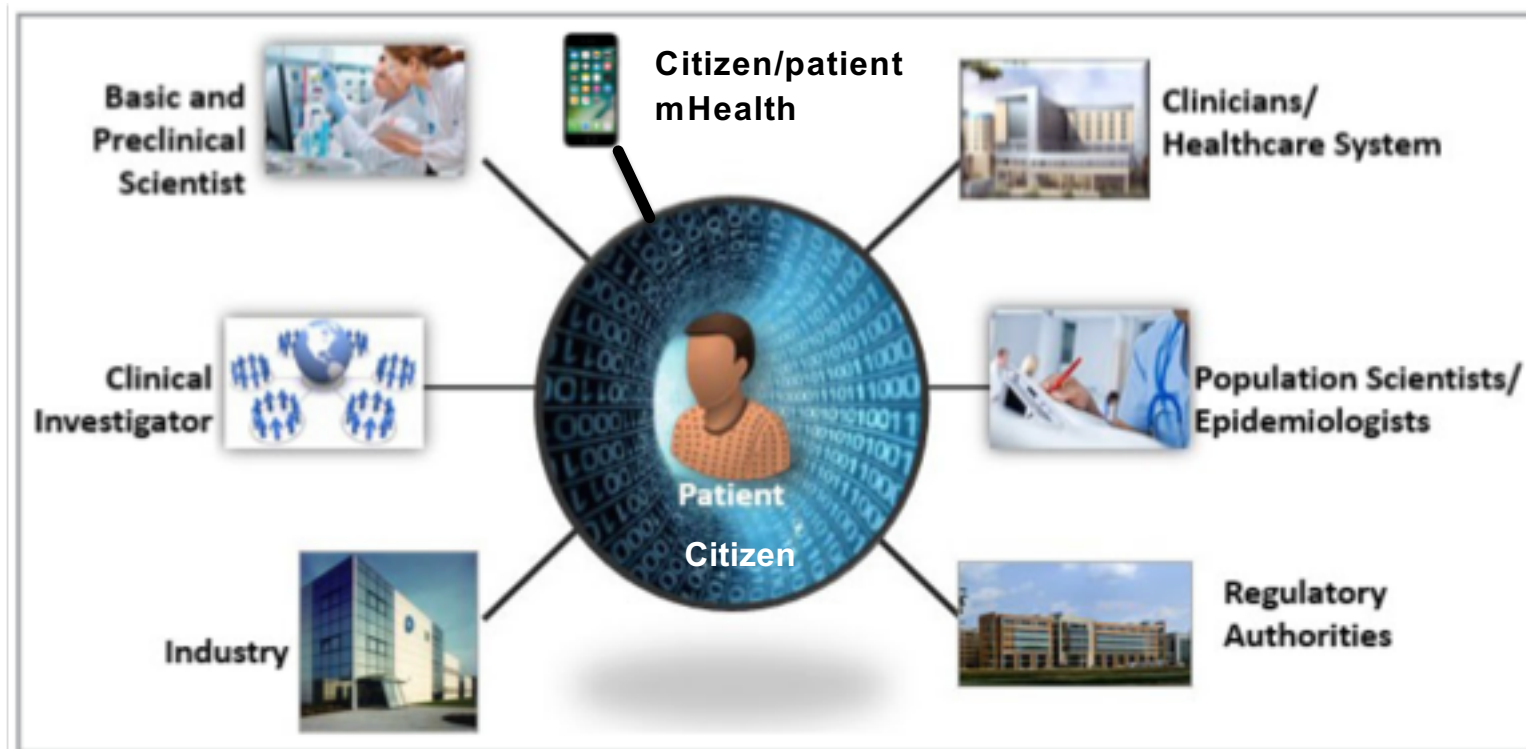
Data to the People – MIDATA Personal Data Cooperatives

FEAM Conference, Sept 28 2018

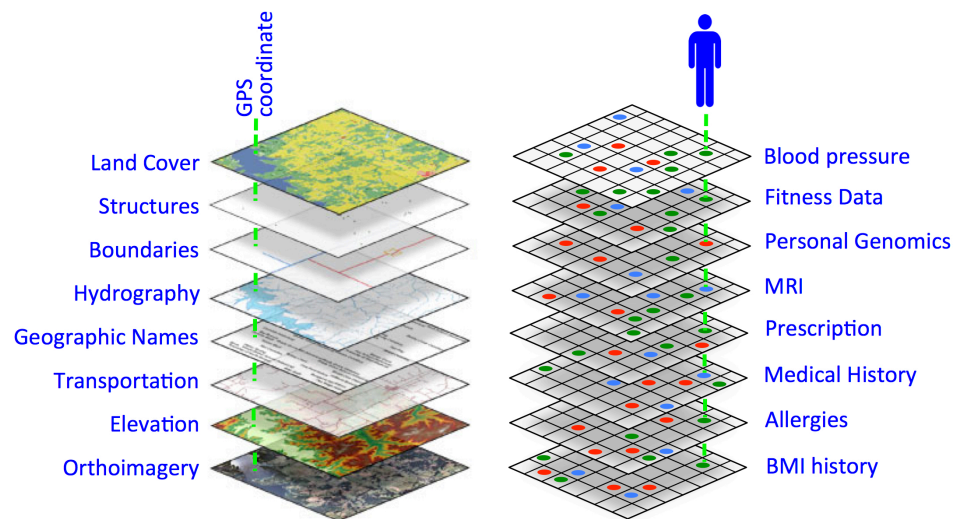
Prof. Ernst Hafen



Personal data are the basis for personalized medicine



The Need: Data Integration – Google Maps of Health



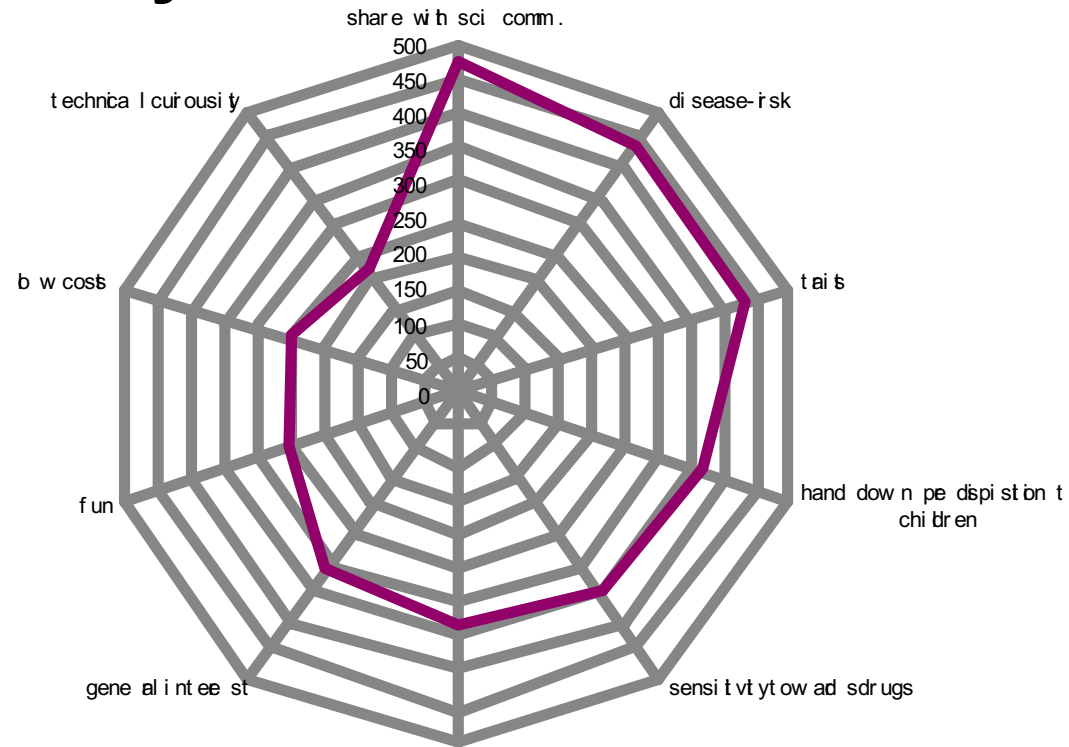
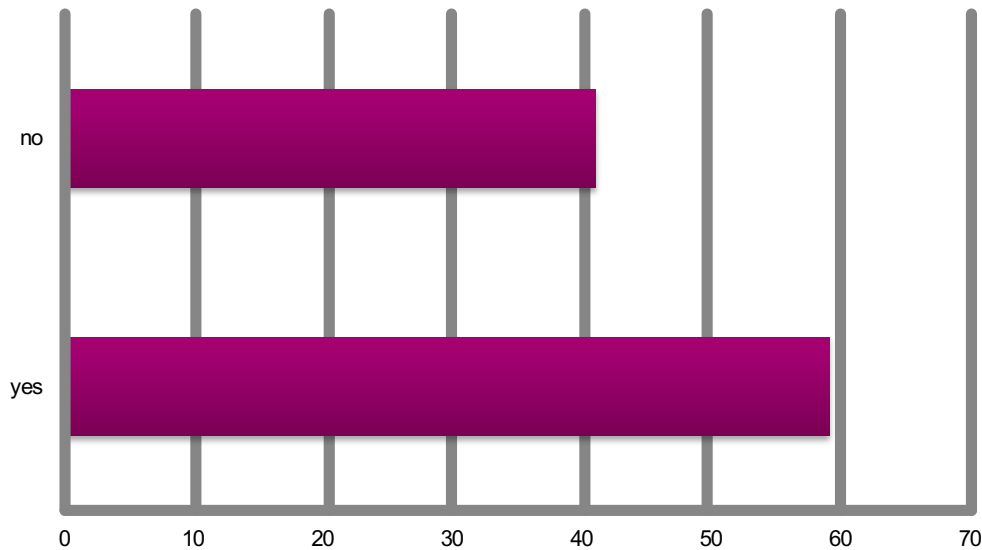
- **Aggregation** of health data from millions of people
- **Active participation** of citizens world-wide

Modified from: National Research Council. (2011). *Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease* (pp. 1–143). National Academic Press.



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



The Challenge: Rebalancing Socioeconomic Asymmetry in a Data-driven Economy



CHAPTER 1.6

Rebalancing Socioeconomic Asymmetry in a Data-Driven Economy

PETER HAYNES, Atlantic Council
M-H. CAROLYN NGUYEN, Microsoft

<http://www.weforum.org/reports/global-information-technology-report-2014>



The three unique features about personal data

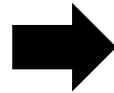
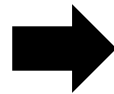
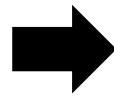
1. Can easily be copied
2. Equally distributed amongst individuals (all people are billionaires in genome data)
3. Individuals are the maximal aggregators of their personal data



Our Solution: Control over personal data access in citizen-owned non-profit personal data cooperatives

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

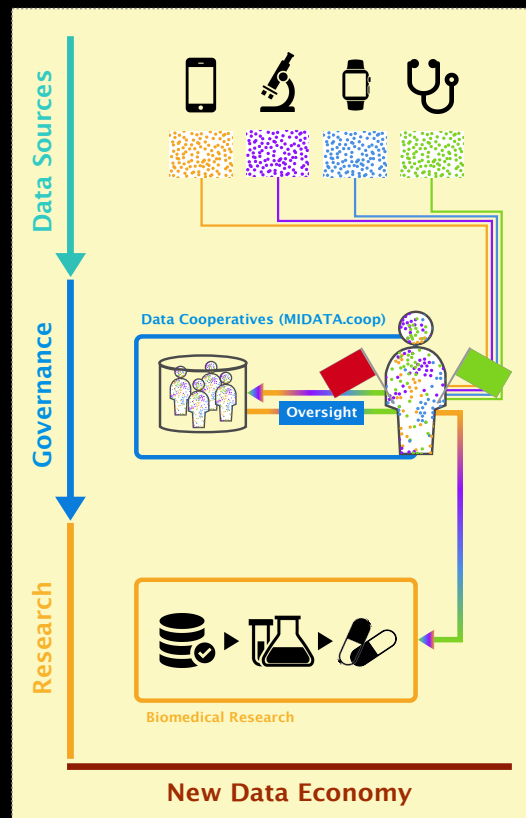


Personal Data Cooperatives

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



Data Cooperatives – Citizen-controlled Data Access and Governance



Blasimme, A., Vayena, E & Hafen, E. (2018). Democratizing health research through data cooperatives. *Philosophy and Technology*.

graphic credit Manuel Schneider



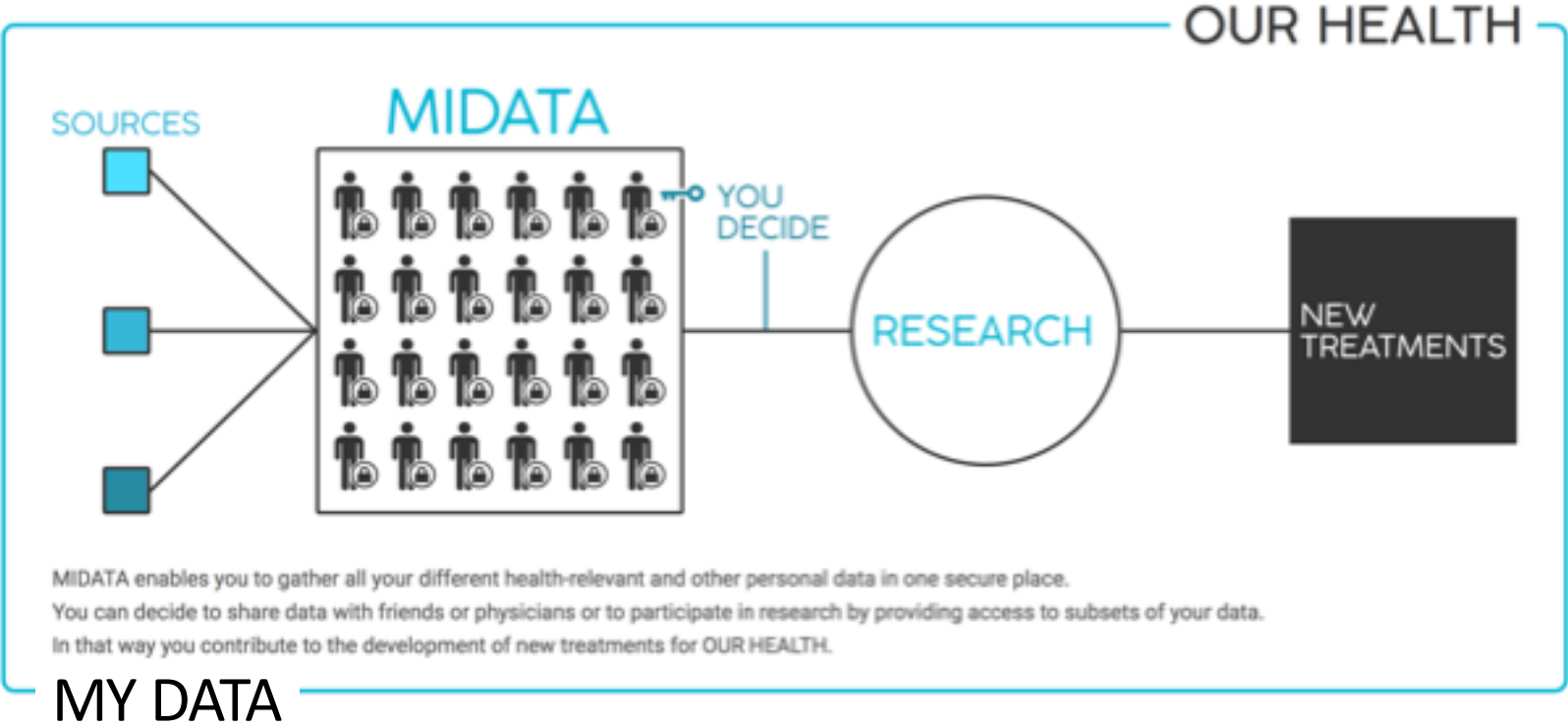


The Personal Data Management A Cooperative Approach

Ernst Hafen, Institute of Molecular Systems Biology, ETH Zürich

Serge Bignens, Institute for Medical Informatics, BFH, Biel

Citizen-controlled data storage and sharing



Project Partners

ETH zürich



Berner Fachhochschule
Haute école spécialisée bernoise
Bern University of Applied Sciences



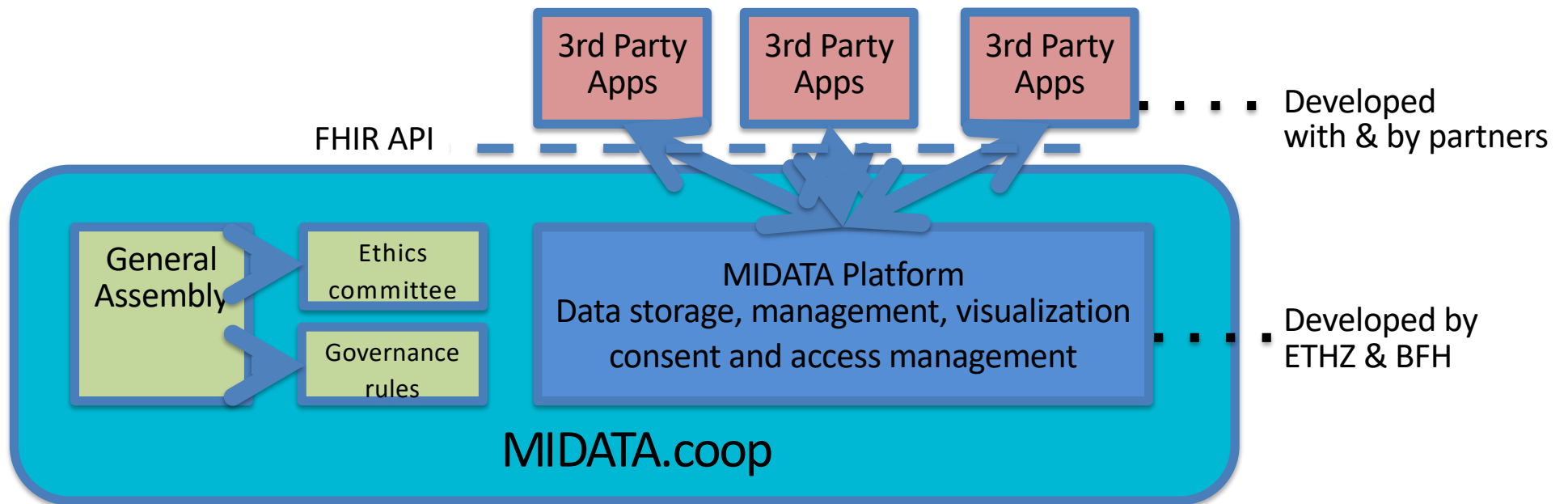
Swiss Data Science Center



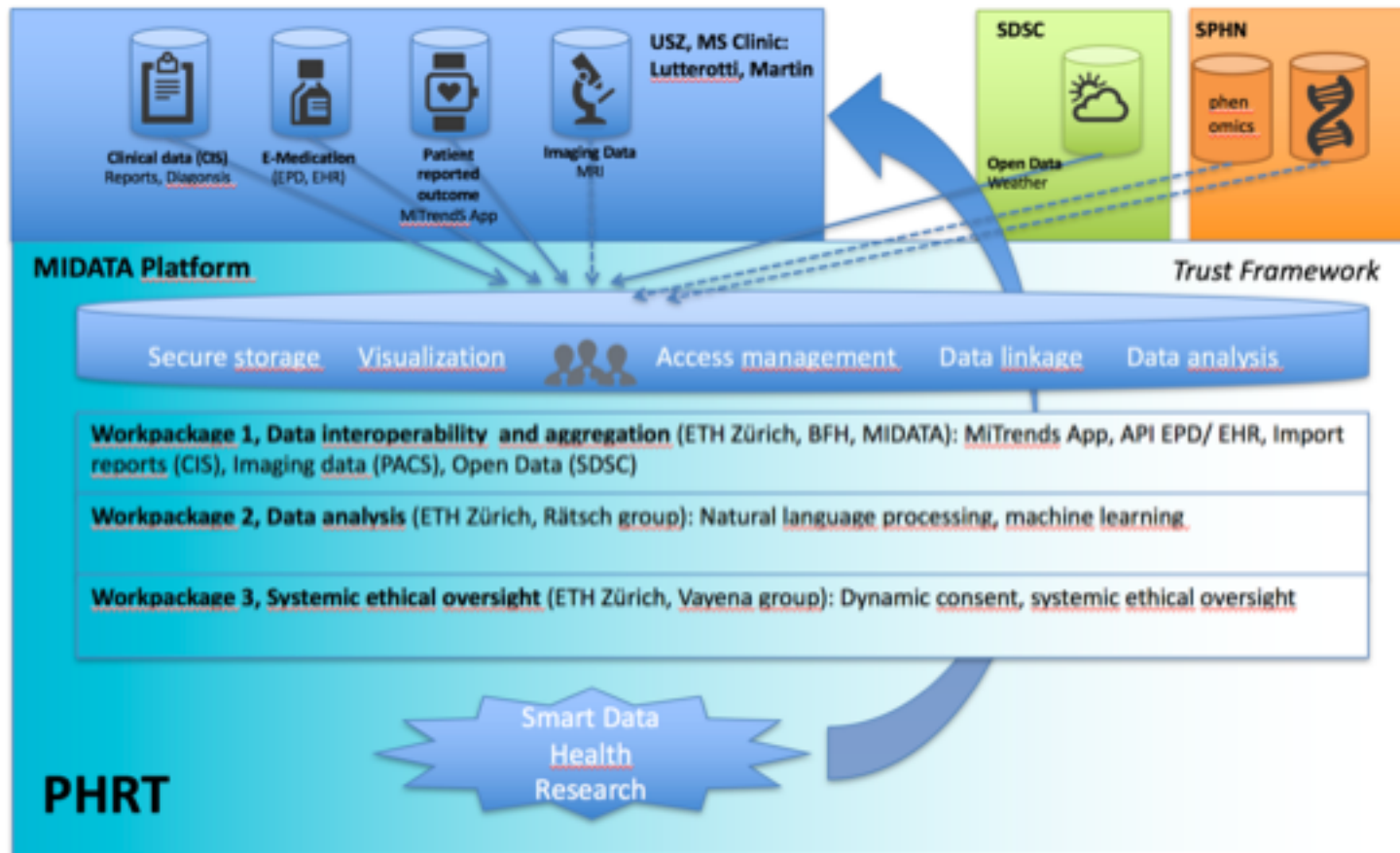
**UniversitätsSpital
Zürich**



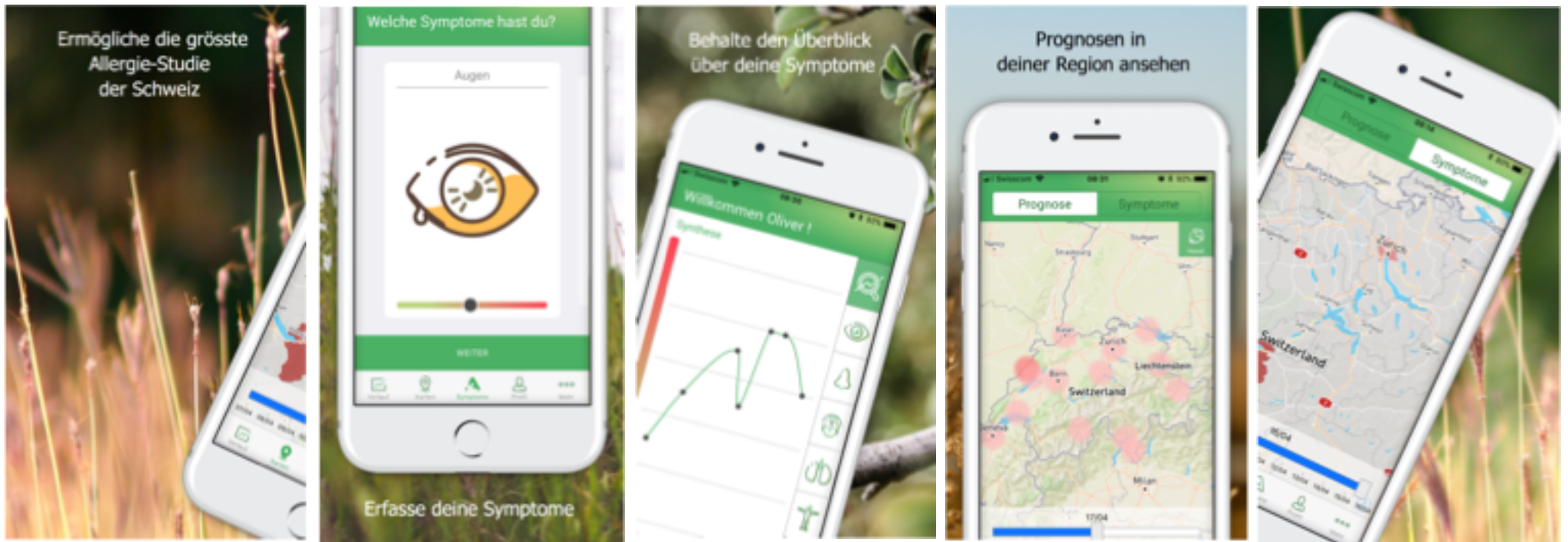
The MIDATA ecosystem for innovation



PHRT Grant: MIDATA Platform and Swiss Personalized Health Network (SPHN) – Citizen-controlled data aggregation



Citizen Science to map pollen allergies in Switzerland



Fakten und Zahlen zu «Ally Science»

Kick-Off: 15. Nov. 2017

MIDATA – BFH – USZ – ELCA – DYSON – AHA! – METEOSWISS

Go-Live: 24. April 2018

Präsenz und Nutzer-Zahlen 24. April bis 2. Mai 2018 (10 Tage)

- Website: 49'000 Visits aus der Schweiz und 3'500 Visits EU & USA
- App: 10'020 Downloads
- Studie: 6'387 registrierte Teilnehmer
- Records: 184'934
- Video: 625 Views

>> Per Juli 2018: 8'100 Teilnehmer

Presse- und Lancierungskampagne 24. April 2018:

Adressiert: Medien, Fachmedien, Partner-Kontakte und Interessen-Verbände, in allen Sprachregionen

Publikationen bis und mit 02. Mai

- Print-Presse und Newsportale: 38 Presse-Artikel
- Radio-Stationen: 9 Audio-Beiträge
- Fernsehen: 2 TV-Sendungen

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

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
- Low and Middle Income Countries; INDEPTH-Network.org

The democratization of the personal data economy

The Democratization of the Personal Data Economy

Present



Artificial Intelligence

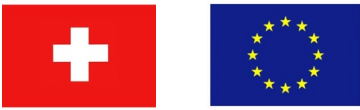


Global Dominance

Future



Artificial Intelligence + Human Intelligence



Fair democratic governance
Property owning democracy



Contact information

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serge.bignens@bfh.ch