## **Data to the People – A Solution to Healthcare?**

Date & Time: Wednesday 1-3pm, Jan 18th 2017

Location: Promenade 73, Davos Dorf; 'Caspian Week' caspianweek.com

Two factors challenge the current healthcare space: The quest for better diagnostics and treatment options to increase the precision of healthcare services and its related socio-economic cost do so. Data, and all its aspects; from generation of data, complex data processing and its adequate distribution, affect above challenges structurally.

Present panel members are at the forefront of leading the healthcare space into the next phase of integrated data management and utilization. They support the concept of citizen-controlled data access pioneered by MIDATA.coop, which enables citizens to securely store, manage and control access to their personal data by helping them to establish and own national and 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. The MIDATA cooperatives act as the fiduciaries of their members' data. MIDATA members can visualize and analyze their personal data and can actively contribute to medical research and clinical trials by providing access to their sets of personal data. MIDATA cooperatives provide novel and fair platforms for commercial partners to develop personal data services and tools.

### This panel addresses fundamental questions of:

- What kind of data does healthcare and precision public health need?
- What hinders health data integration?
- What is the economic value of personal data?
- How can a right to a digital copy of personal data help?
- How can not-for-profit data cooperatives contribute to a new sustainable personal data economy?
- Why should the individual not obtain financial incentives to share data?

The moderators are: Prof. Ernst Hafen and Dr. Kaspar Bänziger

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We are honored to present the following panelists:

# Prof. Ernst Hafen, ETH Zurich Prof. Effy Vayena ETH Zurich & Harvard Prof. Marcel Tanner

Ernst Hafen is a leading geneticist and a promoter of the democratization of a personal data economy. He holds a professorship at ETH Zürich and served as its President<sup>1</sup>. He is a co-founder of the Association Data and Health and the personal data cooperative MIDATA.coop<sup>ii</sup>.

Effy Vayena is a leading expert in digital health ethics and policies. She has a professorship at the University of Zurich and a teaching affiliation with Harvard Medical School at the center for Bioethics<sup>iiiiv</sup>. She is the lead consultant to the WHO for ethical and policy issues relating to reproductive health, and assisted reproduction as well as on health research ethics. Effy was a Fellow at the Berkman Center for Internet and Society at Harvard Law School.

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Marcel Tanner is a global leader in public health research and epidemiology in low and middle income countries. President of Swiss Academy of Sciences and Emeritus Director of the Swiss Institute for Tropical and Public Health, University Basel and EPF Lausanne<sup>v</sup>. He is the co-founder and former president of the Board of INDEPTH-Network.org<sup>vi</sup>. Honorary Prof. University of Queensland Medical School, Brisbane, Australia and University of Neuchâtel, Switzerland

Dr. Klaas Zuideveld , Caris Lifesciences, Dallas



Klaas Zuideveld is an expert in clinical drug development. At Roche, he transitioned from being responsible for the clinical development of Avastin, to leadership roles setting the strategic agenda in Oncology Diagnostics. He is currently leading efforts at Caris Life Sciences<sup>vii</sup> to develop the next generation of Companion Diagnostics.

David Haerry, EUPATI-IMI



David Haerry is the work package co-leader and member of the Executive Committee in the EUPATI-IMI patient project<sup>viii</sup>. He has been involved in the working group updating the CIOMS International Ethical Guidelines for Health-Related Research involving Humans and in several European and global research networks and research collaborations<sup>ix</sup>. David's interests are in the areas of Personalized Medicine, Risk Communication, Pharmacovigilance, Observational Studies, Biomedical Prevention and HIV Eradication Research. He is living with HIV since 1986.

## For further enquiries: Prof. Ernst Hafen hafen@imsb.biol.ethz.ch

i http://www.imsb.ethz.ch/research/hafen/people/ernst-hafen.html

<sup>&</sup>quot;www.midata.coop

iii https://www.ebpi.uzh.ch/en/aboutus/departments/publichealth/healthpol/teamhealthethpol/vayena.html

iv http://bioethics.hms.harvard.edu/

v http://www.naturalsciences.ch/organisations/scnat/portrait/executive\_board

vi http://indepth-network.org/

https://www.carislifesciences.com/

https://www.imi.europa.eu/content/eupati

ix http://www.cioms.ch/