

## German SOLID Symposium

# Session: Health Care

**Place:** To be held in Nürnberg, Fraunhofer [Augustiner Hof](#)<sup>1</sup>

**Date:** 30 March 2023 (From 14:00 to 17:30)

Slot: SOLID for Health Care

### Day 1 (Afternoon): Effects of decentralized health data in society, politics and EU-Data initiatives

	Speaker/organization	Title
14:00	<a href="#">Prof. Dr. J. Hooyberghs</a> / VITO - Flanders	A citizen-driven ecosystem for personal health data
14:45	<a href="#">Tim Schurig</a> / <a href="#">Lehrstuhl Prof. Martin Gersch</a> / Freie Universität, Berlin	Made in and for Europe: Data Spaces, Gaia-X and the EHDS Regulation Proposal
15:30	Coffee Break	
16:00	<a href="#">Prof. Dr. Joachim Schulze</a> / LIMES Institut	Swarm Learning as a new model for decentralized data access, analysis and use in medicine and the healthcare space
16:30	<a href="#">Dr. Henrik Matthies</a> / Honic GmbH	Status Quo of real-world data (RWD) health research in Germany
17:00	<a href="#">Prof. Dr. Karolin Kappler</a> / Professur für Digitalität - Katholische Hochschule NRW	Health - Conventions - Digitization: The trap between market and civic solutions for health data
17:30	End of session	
19:00	Social Event	

## Abstracts

### A citizen-driven ecosystem for personal health data

#### Abstract

In a health sector where personalized products and services are becoming increasingly important, personal data is a necessary prerequisite. The ethical and legal challenges involved raise questions about access to and management of this data. Contradictions seem to be emerging between different trends in our society.

We believe a crucial element is the creation of a level playing field, Flemish and international, through a citizen-driven platform. In 2017, we embarked on a journey through international initiatives and Flemish stakeholders in search of answers to these contradictions. Midway this initiative SOLID appeared in the Flemish landscape.

In this presentation this journey and the current status in Flanders will be outlined.

<https://we-are-health.be/en>



<sup>1</sup> <https://www.iis.fraunhofer.de/en/kontakt/nuernberg-augustinerhof.html>

## Made in and for Europe: Data Spaces, Gaia-X and the EHDS Regulation Proposal

### Abstract

In 2020, the European Union (EU) allocated a budget of up to two billion euros for federated data infrastructures and common data space investments. In May 2022, the Commission published the European Health Data Space (EHDS) proposal. It represents the emergence of the first sector-specific data space in an overarching European digital strategy where other sector-specific data spaces will follow. The strategy frames an emerging data economy that builds on and promotes European values such as citizen-centricity, data sovereignty and transparency. The EU tries to combine previous attempts for regulation and the EHDS further specifies the data holder's and data user's rights, requirements for a fair data exchange, institutional framings, and governance aspects. It prohibits data usage for reasons that are harmful to individuals, such as marketing or increasing insurance premiums. It promotes European citizens to take control of their own health data while enabling a fair and transparent primary and secondary data use. While the EHDS provides a regulatory framework, it is agnostic to the technical implementation that the member states shall build on.

The budget that the European Commission allocated includes cross-domain initiatives such as Gaia-X that develop a specific open-source technical reference architecture for data spaces. Thus, the Gaia-X initiative aims to realize a joint infrastructure for decentralized data spaces. Thereby, the technical, organizational, and regulatory frameworks represent a paradigm-shifting that will shape the European healthcare landscapes but are yet to be implemented on a large scale. Health-X is building on top of Gaia-X to develop a first realization of a currently national, prospectively also EHDS.

## Swarm Learning as a new model for decentralized data access, analysis and use in medicine and the healthcare space

### **Abstract**

With the digitalization of the healthcare space and the ever-increasing amount of health- and disease-related data the potential value of data-enabled precision medicine is similarly increasing. Yet, medical data are inherently decentralized and siloed due to organizational, regulatory, legal, technical, security, privacy and practical reasons. The sheer size of the data and its complexity will require high quality data-centric machine learning and artificial intelligence solutions for which central data storage is not really an option anymore. Therefore, solutions are required that fulfill all the requirements successfully established in medicine (data privacy, protection, regulation, patient physician privilege) and yet allow data-centric ML/AI applications as a prerequisite to reach precision medicine standards. I will discuss Swarm Learning, an ecosystem build on the combination of AI and blockchain technologies that is highly efficient and at the same time fulfills all criteria established for medicine and the healthcare sector.

## Status Quo of real-world data (RWD) health research in Germany

### **Abstract**

Germany has not only missed the digital transformation until recently, it is also lagging in nearly all dimensions to make health data accessible and usable for research and care. Dr. Henrik Matthies gives an overview of the major challenges (regulatory, data privacy, data security, healthcare system etc.), as well as first solutions to overcome these challenges. By starting to enable RWD research, the German healthcare system & lifescience industry can prepare itself for the upcoming European Health Data Space – while exploring various technological solutions such as decentralized data storage.

## Health - Conventions - Digitization: The trap between market and civic solutions for health data

### **Abstract**

The digitization of health is spreading widely, coming along with buzzwords such as telemedicine, e-health, digital health, smart health, big data, or robotics. An overview of the theoretical and empirical research about the role

of datafication in health will emphasize the dynamics of datafication and valorization of health from a social science perspective and highlight the meaning and social relevance of health as a plural social institution that is enforced by ongoing digital transformations. Using the Economy of Conventions as a theoretical lens, the plurality of logics in different health-related fields will be shown: be it health as a commodity, the introduction of economic policy attempts disguised as patients' empowerment to give them market-power and thus make the field of health accessible as a market through quantitative, predictive, and preventive aspects, or the institutional approach understanding health as a standard and the effort to quantify health outcomes. These logics describe a shift from welfare-state-organizational principles to market-economic-organizational principles, particularly in European health systems. After mapping the tensions between market logics and civic developments in the EU Health Data Space, the Economy of Convention with its theoretical concepts and tools to study digital health technologies and practices offers pragmatic perspectives and new insights into emerging and ongoing conflicts and possibilities of cooperation in the field of datafication and health.

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## Speakers Bio

### Prof. Dr. Karolin Kappler



Dr. Karolin Kappler holds the Chair of Digitality at the Catholic University of Applied Sciences NRW and is senior researcher at the research cluster "Arbeit-Bildung-Digitalisierung" (Work-Education-Digitization) at the University of Hagen. Her work focusses on digital transformation in the social and health services from a valuation and convention theory perspective. With her interdisciplinary background in political science, sociology and information systems, Karolin Kappler has published numerous articles in journals and books on the topics of social media, self-tracking, big data, calculative practices, digitization and health. She has recently edited a book (in cooperation with Valeska Cappel) on Health-Conventions-Digitization (open access: [Gesundheit – Konventionen – Digitalisierung | SpringerLink](#)) and written on telemedical approaches in hospitals ([Expertise in die Fläche bringen: Analyse der Covid-19-Telekonsile und szenariobasierte Handlungsempfehlungen | SpringerLink](#)).

For more information: [Kappler, Karolin, Dr.: katho \(katho-nrw.de\)](mailto:kappler.karolin@katho-nrw.de)

### Dr. Henrik Matthies



Dr Henrik Matthies is CEO and co-founder of Honic, the sovereign, DSGVO-compliant research platform for German health data. He is primarily concerned with how the fourth industrial revolution will also massively change healthcare in Germany, and how we can create European independent, value-based solutions, platforms and framework conditions for this. Dr. Henrik Matthies studied at the WHU – Otto Beisheim School of Management in Koblenz and worked for five years as an executive assistant and site manager for the Bertelsmann Group. For five years he was for example co-founder and managing director of the Berlin-based Mimi Hearing Technologies GmbH, pioneer of digital medicine and digital prevention in Germany, Mimi's sound personalisation technology is now widely incorporated into consumer electronics products (headphones, TVs, smartphones) and won the CES Innovation Award in Las Vegas, USA, in 2018 and 2019. Until the end of 2021, Henrik Matthies served as Managing Director of the health innovation hub (hih), think tank and sparring partner of the Federal Ministry of Health for the digital transformation of the German healthcare system, which helped shape Jens Spahn's reform agenda<sup>2</sup>.

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<sup>2</sup> <https://coveredspeakers.com/topical-keynote-speakers-and-experts/dr-henrik-matthies/>

### Prof. Dr. Joachim Schultze



neurobiology worldwide<sup>3</sup>.

He is director of the department of Genomics & Immunoregulation at the LIMES Institute in Bonn. **Innovations** arise at the interfaces of different scientific fields. We have dedicated ourselves to the interface between immunology, metabolism research and neurobiology on the one hand and genomics and bioinformatics on the other. **High-throughput sequencing down to the single-cell level** plays a decisive role for us. Our research group is therefore also heavily involved in the new **platform for Single Cell Genomics and Epigenomics** at the University of Bonn and the German Center for Neurodegenerative Diseases. Our research includes laboratory experimental areas as well as computer-aided analysis. We are thus excellently positioned to answer **systems biology questions**. With our expertise, we also help many other scientists in the fields of immunology and

### Prof. Dr. Jef Hooyberghs



Jef Hooyberghs is a professor theoretical biophysics at the University of Hasselt, affiliated to its Data Science Institute and Theory Lab. He is strategic consultant at VITO, the strategic Flemish research organisation in the area of cleantech and sustainable development. He has 20 years of experience in both fundamental and applied research at the interface of Physics, Life Sciences and Data Science. Recently, Jef Hooyberghs, contributed to the creation of a broad base of stakeholders around preventive health and SOLID in Flanders.

### Tim Schurig



Tim Schurig is a PhD Candidate at the Department of Information Systems at Freie Universität Berlin and a Research Assistant in the Health-X project funded by the German Federal Ministry of Economics and Climate Affairs. His research interest involves Data Spaces, Digital Platform Ecosystems, and Digital Health. He holds master's degree in Data Science and Business Administration from Copenhagen Business School, where he simultaneously worked as a Student Research Assistant within Natural Language Processing and Learning Analytics, as well as a Teaching Assistant for the Courses Visual Analytics and Machine Learning. Prior to his employment in academia, he worked in the banking, auditing, eCommerce and consulting industry.

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<sup>3</sup> <https://www.limes-institut-bonn.de/forschung/arbeitsgruppen/unit-2/abteilung-schultze/abt-schultze-startseite/>