

Barcamp Sessions @ Verpackungshalle, 12.00-12.45

	Session V1	Session V2	Session V3	Session V4	Session V5	Session V6
Title	NephroCAGE: Real-world Experiences from the German-Canadian Consortium on AI for Improved Kidney Transplantation Outcome.	What Can Germany learn from the Canadian Province of Alberta running one of the world's largest digital health systems and their open data culture?	Data Sharing: only consent will work. It must be designed so that it can work.	Accelerating Medical Progress with Large Language Models: A Brainstorming Session.	Privacy Preserving Data Analysis - Code2Data Approaches	How to bring people living with diseases / citizens on board of the digital train to understand health data sharing across borders.
Your Host	Matthieu Schapranow & Klemens Budde	Daniel C. Baumgart	Stefanie Brückner	Nils Krüger	Hannes Wünsche, Florian Schwarz, Toralf Kirsten, Sofia Maria Siampani	Birgit Bauer & Ihno Fokken

Barcamp Sessions @ Zählhalle, 2.00-02.45

	Session Z1	Session Z2	Session Z3	Session Z4	Session Z5	Session Z6
Title	Solidarity principle 2.0 – Data governance for health.	Reimagining Health Data Sharing: Innovating Beyond HIPAA and GDPR for a Global Framework.	Interoperability of primary data collection and its impact on secondary data use.	Real-Time Healthcare capacity Monitoring: Hospitals, Emergency Service and beyond	Regulation of large language models - the most important health data question of the next 5 years?	How to operate international research projects GDPR-compliant with German data?
Your Host	Lutz Hager	Jason Crites	Stefanie Weber	Christian Karagiannidis	Stephen Gilbert	Henrik Matthies & Jamie Blackport

Barcamp Sessions @ Verpackungshalle 12.00-12.45

Session V1	
Title	NephroCAGE: Real-world Experiences from the German-Canadian Consortium on AI for Improved Kidney Transplantation Outcome.
Teaser	The NephroCAGE consortium combines multi-dimensional kidney transplant data from leading nephrology centers in Germany and Canada to build high-quality clinical prediction models using latest artificial intelligence algorithms. The dedicated NephroCAGE Federated Learning Infrastructure was developed upon blockchain technology to enable use of clinical data in a highly protected and privacy-preserving way. In this session, we will share real-world experiences of our cooperation work from the clinical and technical perspective to discuss innovative ways of using historic data for building high-quality AI models for improving healthcare.
Session Host	Matthieu-P. Schapranow , NephroCAGE consortium leader and research group leader at Hasso Plattner Institute in Potsdam, Germany. Klemens Budde , senior physician at the department of nephrology, Charité – University Medicine Berlin
Session V2	
Title	What Can Germany learn from the Canadian Province of Alberta running one of the world’s largest digital health systems and their open data culture?
Teaser	Precision health means the right treatment, for the right person, at the right time, in the right place. It requires a learning health system framework, one that digitally integrates and conceptually aligns medicine with science, economic viability, distinct social and physical environments, cultural diversity and patient preferences to deliver data driven healthcare that empowers patients to improve and maintain their health and wellbeing. In this session we interactively discuss how access to a population-wide electronic health record launched 25 years ago and other data of all citizens, a diverse team of basic, social, clinical and computing scientists, support from patient advocates and citizen groups embedded within a national strategy create a unique environment to realize the opportunities and overcome the challenges of precision health.
Session Host	Daniel C. Baumgart , Professor of Medicine and Adjunct Professor of Computing Science, Director NSERC CREATE “From Data to Decision - Digital Transformation and Artificial Intelligence from Data Value Chain to Human Value” (https://fd2d.org), University of Alberta, Edmonton, AB, Canada

Session V3	
Title	Data Sharing: only consent will work. It must be designed so that it can work
Teaser	<p>In this session, I will briefly introduce a concept for standardised consent for health data sharing and discuss the potential and challenges of this process with regard to a global data market. This will then be opened up for discussion.</p> <p>Health data is increasingly connected data that tracks every moment. Legal frameworks for health data sharing will only sustain if consent-based and designed for the citizen and the world we now live in.</p> <p>The increasing popularity of health and wellness apps has led to a new category of citizen-generated health data. This data is collected through sensors and simple user inputs. As more parameters are measured over longer periods, this data will become more critical for disease prevention, prediction, prognosis, treatment and research than classical clinic-generated health data. Policymakers have recognised the value of both data types for patient care and research, and international health data spaces for data sharing, including US concepts and the European Health Data Space, are now in development. While it could be argued that clinic-generated data comes from public-funded health systems and should therefore be sharable, after depersonalisation, for public service, this 'social contract' argument extends poorly to data from wearables and apps. We propose a new approach for standardised and inheritable health consent to tackle the fragmented and confusing process for consent. In this participative healthcare model, physicians and researchers can trust that the data is shared on the correct legal basis, which enables the safe usage of citizen-generated health data as international medical guidelines recommend.</p> <p>Will the large tech giants be the mediators and arbiters of citizen consent? Is that the best solution or is it unacceptable? What is the role of the state/independent bodies?</p>
Session Host	Stefanie Brückner , Research Associate Medical Device Regulatory Science, TU Dresden, Dresden, Germany
Session V4	
Title	Accelerating Medical Progress with Large Language Models: A Brainstorming Session
Teaser	In this rapid ideation, I will share insights on how LLMs can be leveraged in medical research and clinical practice based on several interdisciplinary projects. Next, we'll engage in innovative brainstorming activities to inspire fresh thoughts on potential applications of LLMs and formulate strategies for successful integration.
Session Host	Nils Krüger , Physician Scientist, German Heart Center Munich / TUM Klinikum

Session V5	
Title	Privacy Preserving Data Analysis - Code2Data Approaches
Teaser	<p>The availability of personal health data for research purposes is a cornerstone for advancing public and personal health research and further improving health outcomes. However, privacy and data protection regulations pose challenges to sharing and analyzing sensitive health data, in order to prevent the misuse of personal data.</p> <p>Innovative approaches such as Code2Data-Technologies have emerged to address these challenges. Bringing code to the data fosters collaborative research environments, in which federated data analysis can be conducted while maintaining privacy and data security. By utilizing a secure computation framework, individual-level data remains confidential throughout the analysis process.</p> <p>Using DataSHIELD and Personal Health Train as examples of federated data analysis platforms, supported by the NFDI4Health Consortia, we will discuss practical and technical aspects of Code2Data Technologies and explore their implications for public health research and practice.</p> <p>By attending this session, participants will gain an understanding of Code2Data-Technologies and their potential for public health research. The barcamp opens the discussion of benefits and limitations associated with these innovative approaches, ensuring that the responsible use of personal health data remains at the forefront.</p>
Session Host	<p>Hannes Wünsche, Robert Koch Institute Florian Schwarz, German Institute of Human Nutrition Potsdam-Rehbruecke Toralf Kirsten, Leipzig University Sofia Maria Siampani, Max Delbrück Center for Molecular Medicine</p>
Session V6	
Title	How to bring people living with diseases / citizens on board of the digital train to understand health data sharing across borders
Teaser	<p>As a patient-led project called Data Saves Lives Germany we are sharing information, inform our target group (mostly patients, patient organisation) and interested citizens about health data sharing. We know it is not very known in that groups and we do our best to provide information, discussion and also the option to ask experts in different formats. We are 7 months on the market, the only project what discusses health data sharing across borders in the public and try to inform people more and more. We are not there to convince people to share their data, but we want to inform and educate to enable them to make an informed decision. We are looking for experiences, ideas and new formats to share the information, grow our reach and also to engage more and more with the target groups. We also look for potential partners to support the work we do. And want to brainstorm with other attendees to find new ways to reach out to the german audience.</p>
Session Host	<p>Birgit Bauer, Founder and Project Coordinator of Data Saves Lives Germany Ihno Fokken, Communication Expert of Data Saves Lives Germany</p>

Barcamp Sessions @ Zählhalle, 2.00-2.45

Session Z1	
Title	Solidarity principle 2.0 - Data governance for health
Teaser	Protection of personal data is a fundamental value that underpins the digital transformation in free societies. At the same time, the use of data has the potential to contribute to significant improvements in care. Under universal healthcare, it is in the public interest to work toward such improvements. A “solidarity principle 2.0” would comprise laws and practices that enable and encourage such uses while at the same time protecting rights of the individual. In this session we want to discuss how data protection laws can be thus developed further.
Session Host	Lutz Hager , Chairman of the Board, Bundesverband Managed Care e.V.
Session Z2	
Title	Reimagining Health Data Sharing: Innovating Beyond HIPAA and GDPR for a Global Framework
Teaser	Join us in exploring the challenges of creating a global health data framework that enables exponential data sharing while preserving privacy and rights. Delve into the delicate balance between collective and individual patient rights and the societal 'social good.' Uncover the ethical, legal, and technical considerations crucial for data sharing, protection and privacy. Together, we will drive tangible outcomes for the EU and US, shaping a concrete roadmap that meets their evolving needs.
Session Host	Jason R. Crites , Citizen scientist, Patient Advocate, and Founder, CEO of Assurance Health Data
Session Z3	
Title	Interoperability of primary data collection and its impact on secondary data use
Teaser	Interoperability of multiple data sources collected for different purposes and in different settings can be impaired. Discussions often do not consider secondary data use in the first place and existing ways of data capture often focus on a single use case. In a Brainstorming Session ideas should be collected to enhance the joint thinking on data capture and consecutive use of the data for research. What should policy makers know and consider when setting the standards for primary data collection? What can they learn from secondary data use? And what should secondary data users consider concerning the primary data collection use case, when evaluating results of data analysis? The Brainstorming session could result in a few key messages for policy makers as well as for researches
Session Host	Stefanie Weber , Head of Division Code Systems and Registries at BfArM (German Federal Institute for Drugs and Medical Devices)

Session Z4	
Title	Real-Time Healthcare capacity Monitoring: Hospitals, Emergency Service and beyond
Teaser	Healthcare capacity will decrease over the next few years for a variety of reasons. The pandemic has shown that real-time monitoring of capacity for patient allocation needs to be improved. This capacity monitoring will be discussed technically but also in its impact on public perception.
Session Host	Christian Karagiannidis , Chair German ICU registry

Session Z5	
Title	Regulation of large language models - the most important health data question of the next 5 years?
Teaser	LLMs and generative dialogue models have the potential to be transformative in health care. The possibilities are endless but the risks are enormous. I will briefly introduce the challenges in the frame of a paper I just authored for one of the top international science journals. The theme will then be opened up for discussion. Are LLMs relevant for health data? Yes - they may well turn out to be the conductors of the health data orchestra, acting as: (i) citizen and care provider health data gathering tools, for data processing and structuring, for information integration, alignment and summary generation (primary use); (ii) decision support tools (primary use); (iii) data unification and merging tools for generating multi patient insights into summaries, for secondary use in research. The debate for how to regulate LLMs is the hot topic of spring/summer 2023 and has been addressed in speeches and articles by the German Health Minister, the CEOs of Google, OpenAI and Nuance, the FDA Commissioner and debated in the EU parliament and the US Congress. Will the large tech giants themselves draw up the defining regulatory frameworks? What is the balance between enabling transformation through LLMs vs controlling their potential for irresponsible data capture? Can a central role of LLMs in the data ecosystem be permitted or are the risks too high? Limitations and potential guardrails for LLMs in health and health data will be discussed.
Session Host	Stephen Gilbert , Professor of Medical Device Regulatory Science TU Dresden. Coordinator: BMBF data sharing project PATH.

Session Z6	
Title	How to operate international research projects GDPR-compliant with German data?
Teaser	In this session, Honic (sovereign EU health data platform) and Datavant (US market leader for health data pseudonymization) will present their joint, scalable, standardized solution to link EU health data with US & international health data for research, and discuss best practices with the participants.
Session Host	Henrik Matthies , CEO & Co-Founder Honic Jamie Blackport , Head of International Strategy Datavant