



Symposium about Ethics and Data Exchange in Precision Medicine

Wednesday, 24 November 2021, 9-12.30h CET

Online via Zoom (a partial participation is also welcome)



The symposium is organized by the Bern Center for Precision Medicine (BCPM), it will address ethical and legal issues with respect to the exchange and use of clinical and omics data for research purposes. It is centered on the new research methodologies as they are being used in Precision Medicine (PM), such as data research and machine learning within bigger pools of anonymized and/or encoded genomic data coming from several clinics.

The subject matter focus lies on the facilitation of research, and the practical issues encountered in Switzerland.

<https://unibe-ch.zoom.us/j/61926860993?pwd=WEtHK0llaWZmTWtmTnhPUlVqRmlGUT09>



Program

Time	Description	Presenter
09:00-09:30h	Welcome and opening address	Prof. Dr. Samia Hurst Majno, physician bioethicist, director, editor, board member and chair. University of Geneva, National Covid-19 Task force, SPHN ELSI Board.
09:30-10:00h	How the DLF supports ethics, data governance and data exchange	Dr. Danielle Krebs, head of research at DLF (Learning and Research), representing Prof. Dr. Thomas Geiser, Director DLF, both Bern University Hospital.
10:00-10:30h	Tools to facilitate sample exchange: the example of Swiss Biobanking Platform	Dr. Christine Currat, Executive Director of Swiss Biobanking Platform.
10:30-10:45h	Short break	
10:45-11:30h	Data sharing: The legal framework proposed by the Swiss Personalized Health Network (SPHN), and further ideas for the future	Dr. Julia Maurer, Lead ELSI Helpdesk at SIB PHI Group, responsible for the national data sharing frameworks SPHN
11:30-11.45h	Experiences when establishing a multicenter research project with the exchange of genomic cancer data	Dr. Senija Selimovic-Hamza, Coordinator of the SPHN SOCIBP project.
11:45-12:30h	Podium discussion: How can we foster multicenter medical research in a legal and ethical way, without burdening researchers with overly bureaucratic or complex rules and procedures?	The discussion will focus on ideas for improvement, which might include: -> <i>best practices</i> (as seen in registries and the Swiss biobanks) -> <i>new ideas</i> (e.g., mutual accreditation of research teams among the hospitals, or common signature rules among the hospitals) -> <i>existing ideas</i> (e.g., the ideas proposed by SPHN).