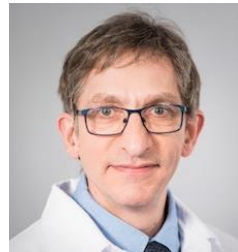


DCC Seminar and Training Series

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C3-STUDY Citizen Centered Consent: A comprehensive approach for national consent management



Consent management is becoming a central challenge in the era of data-driven science and precision medicine. This project is focusing on building a new approach for consent management in proposing a broad vision that goes beyond the traditional boundaries of the broad/general or specific research-driven consent.

A consent should be:

Citizen-centered: The citizen is placed at the center of consent management. Citizens must be able to see and manage all their consents, independently from their status of being a patient, and the domain of the consent, be it for research, health care, or other intentions.

Dynamic and proactive: Consent builders, consent users, and citizens must be able to act on consents, consenting and revoking, at any time, from anywhere. Creation, modifications, and suspensions of consents, as well as publishing consents for enrolling, must be doable at any time.

Interoperable: Consents must be sharable and interoperable, despite the fact that there are a) numerous types of consents and b) evolution of consents in time, including the Swiss General Consent.

Shared: Consents must be sharable. Consents do neither belong to institutions, nor to care providers or researchers. Consent must comply with the intention of their purpose to which the citizens have consented for.

Transparency and auditability: The process of consent management, creation, modifications and suspension, must be traced. All consents and revocations given by citizens must be traced.

Privacy and security: Only those granted must be able to act. Actions must be revocable but not retractable.

Trust: The citizen centered consent management infrastructure must be built in such a way that it builds trust for all stakeholders involved.

Date: Monday, 14 January, 2019

Time: 16:00 – 17:00

Room: Hörsaal 2, Klingelbergstrasse 70, Basel

Contact: Silvia Schaub (dcc@sib.swiss)