SPHN Data Governance Working Group Updated Mandate

January 2025

The Data Governance Working Group (DGWG) was constituted in February 2023 as part of the SPHN initiative with the aim of developing a nationally harmonized contractual framework for the further use of health data in multi-centric projects and to align on a joint data sharing and data governance strategy in such projects. Since the constitution of the working group, the contractual framework has been revised and a nationally harmonized legal agreement template regulating data sharing and use in multi-centric projects has been published. Moreover, controversial topics of national interest, such as "open research data" and effective data sharing models with third parties facilitating "data as product", have been put on the agenda.

Vision and Mission

For the current period of SPHN (2025-2028), the group's efforts will continue with a focus on governance aspects for effective data sharing with third parties. **The group's mission is to promote harmonized governance frameworks for data access, enabling equitable and trustworthy further use of routine health data throughout its entire lifecycle.** The goal of a harmonized health data governance is to drive collaboration across the Swiss research landscape to create lasting value for both science and society.

Composition

The following institutions are represented in the DGWG. The institutions can nominate group members with legal or data governance expertise, like legal professionals, data protection officers, data governance managers or representatives in an institutional data governance board.

Members
- Inselgruppe AG
- Hôpitaux universitaires de Genève (HUG)
- Centre hospitalier universitaire vaudois (CHUV)
- Universitätsspital Zürich (USZ)
- Universitätsspital Basel (USB)
- Universität Basel (Unibas)
- Eidgenössische Technische Hochschule Zürich (ETHZ)
- École polytechnique fédérale de Lausanne (EPFL)
- Université Lausanne (UNIL)
- Université Genève (UNIGE)
- Universität Zürich (UZH)
- Universität Bern (UniBe)
- Swiss Institute of Bioinformatics (SIB)

Observing stakeholders
- Unitectra

- swissethics
- Interpharma
- SAKK
- Patient representatives, patient advocacy group
- Swiss Clinical Trial Organization
- Swiss Biobanking Platform

Ex officio members:
- Julia Maurer, SPHN DCC
- Michaela Egli, SPHN DCC
- Judit Kiss Blind, SPHN DCC

Work packages

Work package 1: Documentation of data access governance at university hospitals.

WP1 aims to share among stakeholders know-how about data governance practices in university hospitals and universities/ETH/EPF, and to prepare the ground to further align governance practices and promote a common vision for the role and responsibilities of data governance bodies in the Swiss data ecosystem.

Work package 2: Establishing common policies for data access governance

Work Package 2 aims to develop common policies for data governance bodies within DGWG institutions to facilitate data access in underregulated areas, that often lead to fragmented decision-making and delays in granting data access. These areas include the sharing of anonymized data, complex quality projects, exploratory or AI projects.

Work package 3: Develop effective data governance models for equitable access and multiple-use of health data

WP3 aims to advance data governance models for complex multiple-reuse scenarios (e.g. governance of health data made available in scientific repositories) and scenarios without involving a local Principle Investigator.