

# SPHN – The Swiss Personalized Health Network Initiative

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**Abstract.** The Swiss Personalized Health Network (SPHN) is a national initiative designed to promote the development of personalized medicine and personalized health in Switzerland. SPHN contributes to the development, the implementation, and the validation of coordinated infrastructures in order to make health-relevant data interoperable and shareable for research in Switzerland. To this end, SPHN rallies all decision-makers from key clinical, research-, research support institutions and patient organizations around the same table.

**Keywords.** SPHN, personalized health

## 1. Introduction

Given the tremendous amount of health data available, health care and medical decisions should no longer be solely based on population averages, but take into account individual patient characteristics, including the variability in genes, molecular biomarkers, environment and lifestyle. To leverage the immense potential of these data for better prevention, improved medical practice and the development of innovative treatments, transdisciplinary scientific research, as well as specific infrastructural efforts are necessary: Health data need to be interoperable and broadly accessible for research according to the FAIR principles [1]. Additionally, research involving sensitive human data demands potent IT infrastructures that permit the collection, storage and analysis of high quality data, adequately link to biobank samples and, at the same time, fulfill stringent data protection and information security requirements. Furthermore, patients and citizens have to be included, not only for consent to release their data or samples for use in research, but also as active partners supporting research and helping to advance medical knowledge. These issues raise unprecedented ethical and legal (e.g., data protection) questions that must be considered even more within an extended personalised health ecosystem [2].

Although the public Swiss healthcare system is universal, healthcare is provided by a combination of public, subsidized private and totally private systems, and is organized largely on the level of individual cantons. To a large extent, this federalist principle until now prevented a nationwide coordination and/or harmonisation of

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biobanks, electronic clinical information systems and clinical data management infrastructures and created a heterogeneity of health data infrastructures which has retarded the development of a nationwide personalised health ecosystem as compared to countries with more homogenous national health systems. These deficiencies have been realised early- on and appropriate initiatives have been undertaken on local and regional levels. In order to expand the local initiatives to the whole of Switzerland and complement them with nationwide efforts for making health data findable, accessible, interoperable and usable for research (FAIR) on a national scale, the Swiss Government launched the Swiss Personalized Health Network (SPHN) initiative in 2017. The mission of the initiative is to contribute to the development, the implementation, and the validation of nationally coordinated infrastructures which are required to make health-related data interoperable and shareable for research in Switzerland. Given its high quality health care network and excellence in research and technologies, Switzerland has the potential to *become one of the European leaders in health and medical science*, although the regulatory aspects of the federated health system are a major challenge for big data research. The initiative shall thus help to push Switzerland to the international forefront of personalised health-related research and health care.

## 2. Mandate and governance

The Swiss Personalized Health Network (SPHN) is an initiative of the Swiss federal government, namely the State Secretariat for Education, Research and Innovation (SERI) and the Federal Office of Public Health (FOPH). SPHN is led by the Swiss Academy of Medical Sciences (SAMS) in collaboration with the Swiss Institute of Bioinformatics (SIB). A total of CHF 68 million was allocated to the initiative for the first funding period 2017-2020. As defined in the corresponding mandate, the long-term goal of the SPHN initiative is to establish a Swiss network in personalized medicine, in which all relevant research institutions and hospitals in this field are involved. The development of a nationally coordinated data infrastructure including interoperability of local and regional information systems in order to optimize the use of primarily clinical but also other health-related data for research in the field of personalized medicine, is the central focus of the first funding phase. Rather than building a new centralized database, SPHN adopts a decentralized approach and aims to establish interoperability of health-related information by building a dynamic scalable network of data providers based on common standards for formats, semantics, governance, and exchange mechanisms. It is therefore our mission to lay the foundations needed to establish a nationwide exchange of health-related data for better disease prevention, improved medical practice and ground-breaking innovative treatments, transdisciplinary scientific research, as well as specific infrastructural efforts.

The SPHN project organization involves partners at national level, at technical level, and at institutional level (Figure 1). SPHN rallies all decision makers from key clinical, research and research support institutions around the same table. The combined knowhow, experience and commitment of the numerous partners and experts of the SPHN Boards and Working Groups enable discussion, collaborations and progress.

The National Steering Board (NSB) is the highest body of SPHN and is responsible for the overall strategy, for maintaining regular contacts to the superordinate political authorities and for external communications in coordination with the Swiss Academy of Medical Sciences (SAMS). The NSB includes representatives from key institutions in

Switzerland (e.g. University Hospitals, universities, ETH-Domain, swissuniversities, FOPH, SNSF, patient organisation). In addition to the NSB, SPHN is composed of the following Expert Advisory Groups/Bodies:

- ELSI Advisory Group (ELSIag).
- National Advisory Board (NAB, foreseen in 2020).
- International Advisory Board (IAB).
- Data Coordination Center (DCC) including several technical Working Groups (operated by the Personalized Health Informatics Group of SIB).

SPHN is further supported by the expert knowledge of several mandated SPHN *ad hoc* Working Groups, which are responsible for solving specific issues related to infrastructure development. SPHN has put very strong efforts into close collaboration with other stakeholders from the biomedical research landscape. This includes funders such as the Swiss National Science Foundation (SAKK) or the ETH Domain Personalized Health and Related Technologies Program (PHRT), and also research networks such as the Swiss Group for Clinical Cancer Research (SAKK), the Swiss Biobanking Platform (SBP), the Swiss Clinical Trial Organization (SCTO), as well as patient organizations (e.g. ProRaris, for rare disease). During the last years, these organizations managed to identify common issues and obstacles, which need to be addressed. Typically, the above-mentioned Working Groups are now highly coordinated within these stakeholder groups.

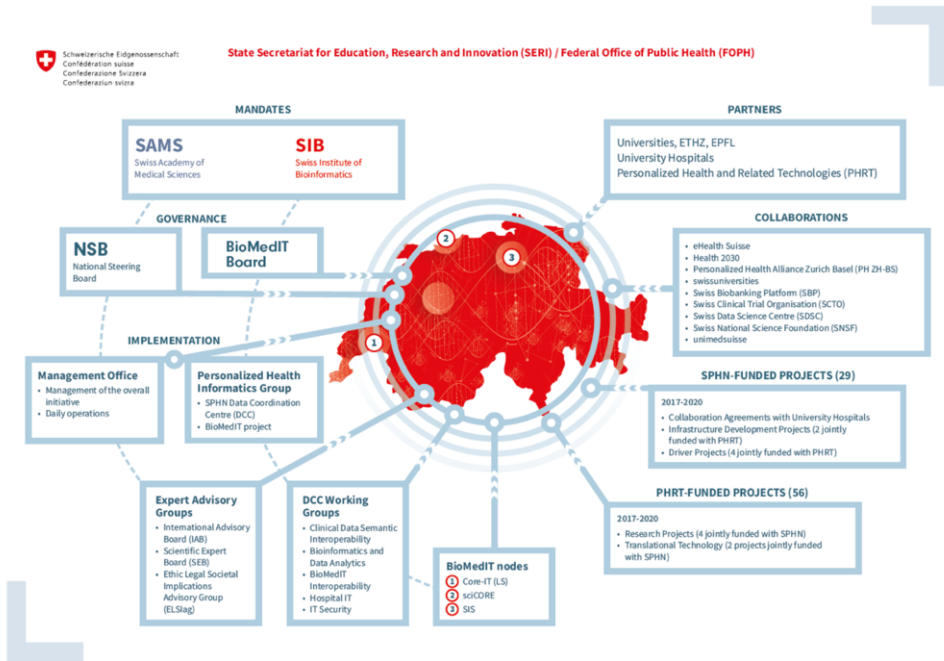


Figure 1. SPHN Governance.

### 3. Implementation

The SPHN initiative supports the development and implementation of coordinated infrastructures by means of a 3-pillar funding strategy:

1. **Top-down:** funding of compatible data management systems in the University Hospitals through Collaboration Agreements, as well as the SPHN Data Coordination Center (DCC) and ELSI projects.
2. **Bottom-up:** selection of projects through competitive Calls for Proposals to lead the development of infrastructures and test it with concrete research questions (Infrastructure Development Projects and Driver Projects). In 2017 and 2018, two SPHN Calls for Proposals were organized in close coordination with the Strategic Focus Area 'Personalized Health and Related Technologies' (PHRT) of the ETH Domain. Selected from a total of 76 proposals requesting CHF 90.4 million, SPHN funded 24 projects (incl. 6 co-funded by PHRT) for a total amount of CHF 25.3 million during this funding period.
3. **IT infrastructure networks:**, a secure and cutting-edge IT environment (BioMedIT, a project of SIB) is established to support computational, biomedical research and clinical bioinformatics, ensuring data privacy [3].

Further information on the projects is available on the SPHN website ([www.sphn.ch](http://www.sphn.ch)).

The SPHN Management Office (MO) together with the SIB Personalized Health Informatics Group (PHI) are responsible for successfully implementing the mandate of

SPHN. The MO manages the daily operations of the initiative, coordinates the funding and ensures a good governance. The PHI group is in charge of the Data Coordination Center and the BioMedIT project.

To ensure nationwide interoperability of biomedical data, a variety of technical, ethical and legal issues have to be tackled. The ELSIag is responsible for the ethical and legal questions related to SPHN activities. The technical aspects related to the development of coordinated infrastructures, compatible data management systems, interoperability of data, and governance of guidelines, are tackled by the Working Groups of the Data Coordination Center in collaboration with the University Hospital IT teams.

#### 4. Conclusion and Outlook

The SPHN funded projects involve 35 Swiss organizations and institutions which demonstrate the magnitude of this national endeavor. Over the past years, we have identified several key success factors for the development of a nationwide network such as i) the need for a common understanding of the vision and scope; ii) commitment of all players to share health data for the benefit of society (citizens, patients, hospitals, research institutes, etc.); iii) a transdisciplinary approach between clinicians, researchers, bioinformaticians, machine learning experts, etc.; iv) nationwide interoperability of health data and nationally coordinated data infrastructures; v) process innovation in research and health care; vi) dialogue with citizens and patient groups; and vii) transparent communication concepts to enhance public trust.

A review of the overall progress of the initiative and gap analysis was performed in 2019 based on the first project progress reports and an external international review by the SPHN International Advisory Board (IAB). As a result from this first evaluation, the biggest achievement of SPHN during the past years is probably the increasing awareness of the systemic gaps and problems related to the field. Though the initiative is overall on a good track and has made significant progress, the gap analysis revealed significant obstacles and hurdles. Most of them related to the federated health care system and the strong local awareness and particularities of data protection issues as well as ethical and legal priorities. In order to achieve interoperability, these issues, priorities and policies need to be coordinated on a national level. Here, the willingness of the stakeholders to agree and implement common strategies, standards and guidelines is a prerequisite. The political discussion needs to be initiated whether or not this should be enforced.

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