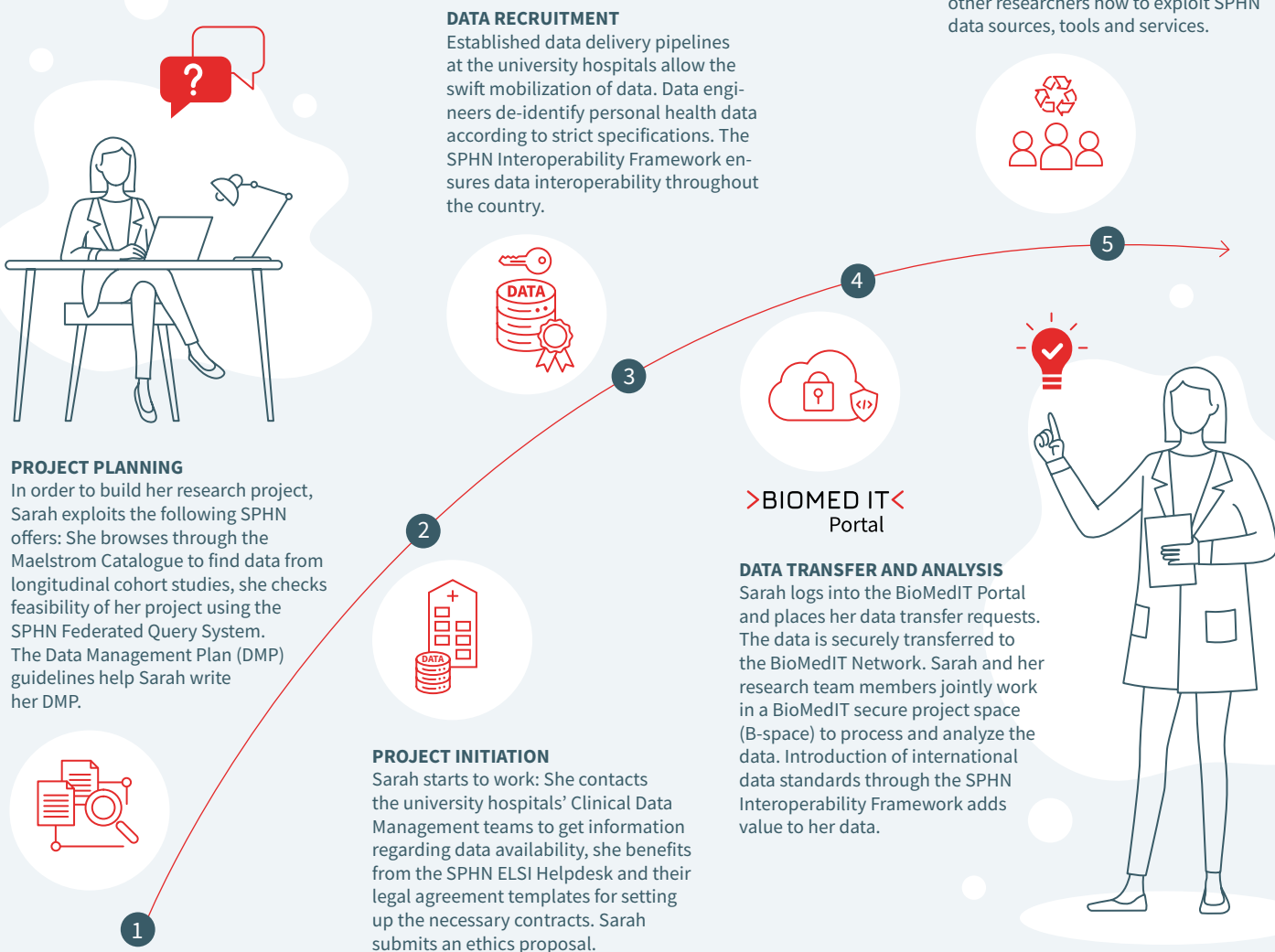# Swiss Personalized Health Network

The goal of the Swiss Personalized Health Network (SPHN) is the establishment of coordinated data infrastructures in order to make health-relevant data available, interoperable and shareable for research in Switzerland.

Swiss Personalized Health Network

SPHN

DATA REUSE
Sarah has completed her research project. She deposits the dataset in a FAIR repository in order to make it reusable for others. SPHN training modules help other researchers how to exploit SPHN data sources, tools and services.

DATA RECRUITMENT
Established data delivery pipelines at the university hospitals allow the swift mobilization of data. Data engineers de-identify personal health data according to strict specifications. The SPHN Interoperability Framework ensures data interoperability throughout the country.

PROJECT PLANNING
In order to build her research project, Sarah exploits the following SPHN offers: She browses through the Maelstrom Catalogue to find data from longitudinal cohort studies, she checks feasibility of her project using the SPHN Federated Query System. The Data Management Plan (DMP) guidelines help Sarah write her DMP.

PROJECT INITIATION
Sarah starts to work: She contacts the university hospitals' Clinical Data Management teams to get information regarding data availability, she benefits from the SPHN ELSI Helpdesk and their legal agreement templates for setting up the necessary contracts. Sarah submits an ethics proposal.

>BIOMED IT<
Portal

DATA TRANSFER AND ANALYSIS
Sarah logs into the BioMedIT Portal and places her data transfer requests. The data is securely transferred to the BioMedIT Network. Sarah and her research team members jointly work in a BioMedIT secure project space (B-space) to process and analyze the data. Introduction of international data standards through the SPHN Interoperability Framework adds value to her data.

SPHN is important to researchers because …

› It establishes a **data ecosystem** to overcome the hurdles of using data for research purposes, and enables the (re)use and exchange of health data for research.

› It provides an **Interoperability Framework** enabling collaborative research by turning (routine) health data into FAIR research data, understandable to humans and machines.

› Researchers can assess the **feasibility of projects** by browsing through over 90 million anonymized data elements across all Swiss university hospitals.

› It provides the necessary **secure IT environment BioMedIT**, a platform to process sensitive data while benefiting from secure connections to relevant Swiss data providers, dedicated compute resources, as well as data management and analysis support.

› The ELSI helpdesk of SPHN **supports researchers to comply with the necessary ethical and legal requirements** for complex, mulit-site research projects, saving them time for their research activities.

Feasibility of projects and discoverability of data

Exploring feasibility and identifying data sources are the first steps in planning a research project. To support both the feasibility analysis for the use of routine health data from the five Swiss university hospitals and the discoverability of existing clinical research data from Swiss cohort studies, SPHN has developed the following two solutions for researchers:
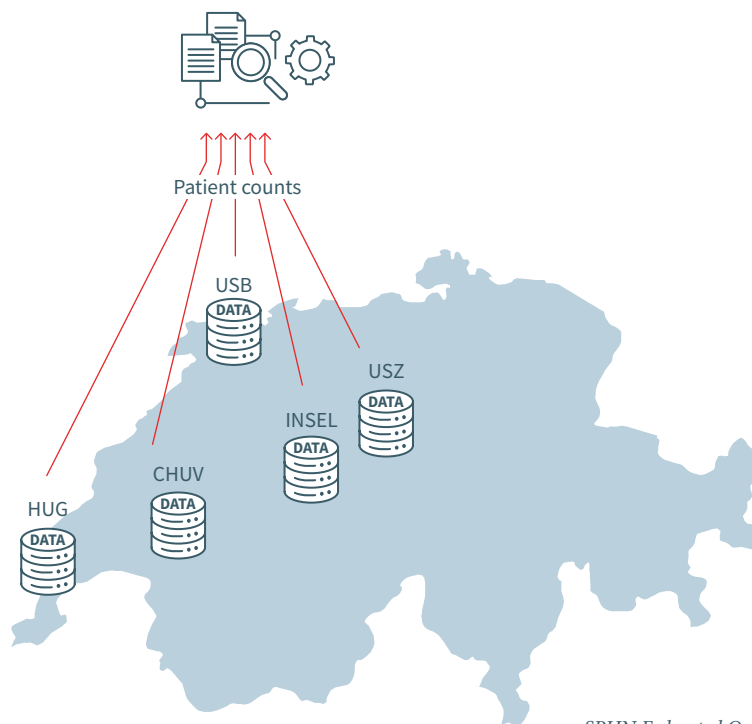
SPHN Federated Query System

The Federated Query System combines consented health data from five Swiss university hospitals and allows researchers to query a large number of patient records that might be relevant for their research project. Using the drag-and-drop function on the Federated Query System's online interface, researchers can evaluate the feasibility of their study using the parameters they are interested in. The information is fully standardized and the data is anonymized, ensuring patients' privacy.

The searchable data include demographic information (age and gender), diagnoses, procedures, medications, and laboratory test results. By spring 2022, the system included over 90 million data elements from over 490,000 patients; additional data elements are added on a monthly basis.

In just a few clicks, these combined sources play a key role in determining the availability of data for research and ensuring statistical power for research projects. For more information: www.sphn.ch/fqs

SPHN Federated Query System

Swiss Cohort Consortium on Maelstrom

Switzerland has a long tradition of high-quality population-based and disease-specific cohort studies encompassing a large variety of health data. To promote the discoverability of these cost-intensive data collections, SPHN supported the integration of the metadata of Swiss cohort studies into the internationally renowned Maelstrom Catalogue (managed at McGill University Health Centre, Canada). The catalog relies on a powerful toolkit to improve documenting study metadata from around the world. It already serves to promote the dissemination of more than 310 individual studies and 23 international networks covering a wide range of research areas.

The SPHN Cohort and Registry Task Force together with the SPHN's Cohort and Registry Task Force and Data Coordination Center (DCC)

have worked closely with Maelstrom Research to build the SPHN Cohort Consortium. The integration of 10 large Swiss cohorts into the catalog is underway and allows researchers create queries on more than 120,000 annotated variables. For more information: www.maelstrom-research.org/network/sphn-cc

Clinical data management at the Swiss university hospitals

During healthcare processes, the patient story is spread over multiple applications and the data is stored in various systems or databases. In order to be able to leverage the potential of healthcare data through research projects, it is necessary to obtain an overall view of a patient's data across the various systems, and to ensure the availability of data for repeated and continuous use.
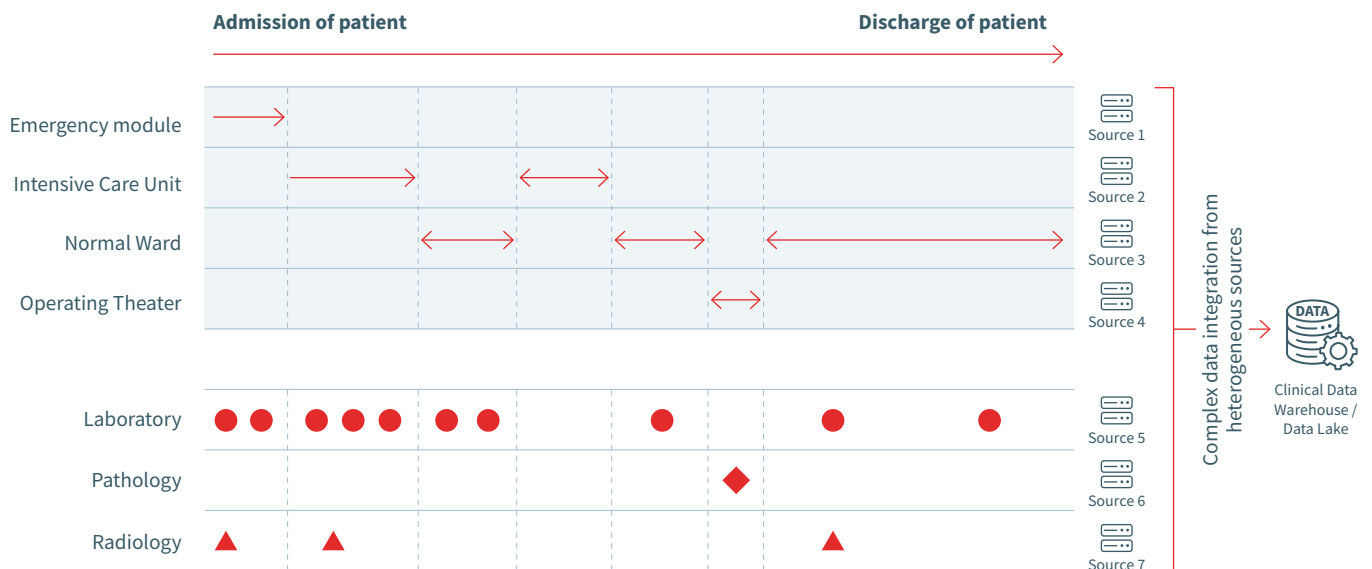
In the course of the past years, the five Swiss university hospitals with support from SPHN have built up clinical data management systems (i.e. Clinical Data Warehouses and/or Data Lakes) to ensure sustainable data availability for secondary usage. The SPHN-funded projects helped driving the infrastructure development and populating the clinical data management systems.

___

What is now possible that hasn't been possible before?
› Gain easy and fast access to an enormous breadth and depth of patient data.
› Make data quality visible and measurable.

› Ensure data availability for a wide variety of purposes also outside of research, such as business intelligence, process analysis, quality management, data deliveries for medical registries and authorities (reporting obligation), etc.
› Standardized de-identification of structured clinical data, images and genomic files.
› Professionalized data delivery pipelines that enable fast export of data in different formats.

For researchers, this means that the effort required to obtain data can be significantly reduced, as data availability has been greatly simplified. Due to the semantic integration of the data (according to the SPHN Interoperability Framework), it is now possible to exchange data across centers without generating further effort for the researcher. In addition, standardized preparation of data in full breadth and depth makes the same data (re)usable for different research purposes. Thanks to SPHN's efforts, patients are also being asked more systematically if they would like to provide their data for research purposes, which has significantly increased the amount of patient data usable for research in Switzerland.

Arrows represent data capture along the patient path through the hospital.

Symbols represent time points of data capture in specified facilities of the hospitals.

Turning health data into FAIR research data

Personalized health research relies on large amounts of structured and well-standardized clinical (routine) data. Combining these with results from modern analytical approaches, such as genomics, proteomics, or metabolomics, enables new insights for the development of innovative diagnostic and therapeutic approaches that take into account the unique characteristics of individuals.
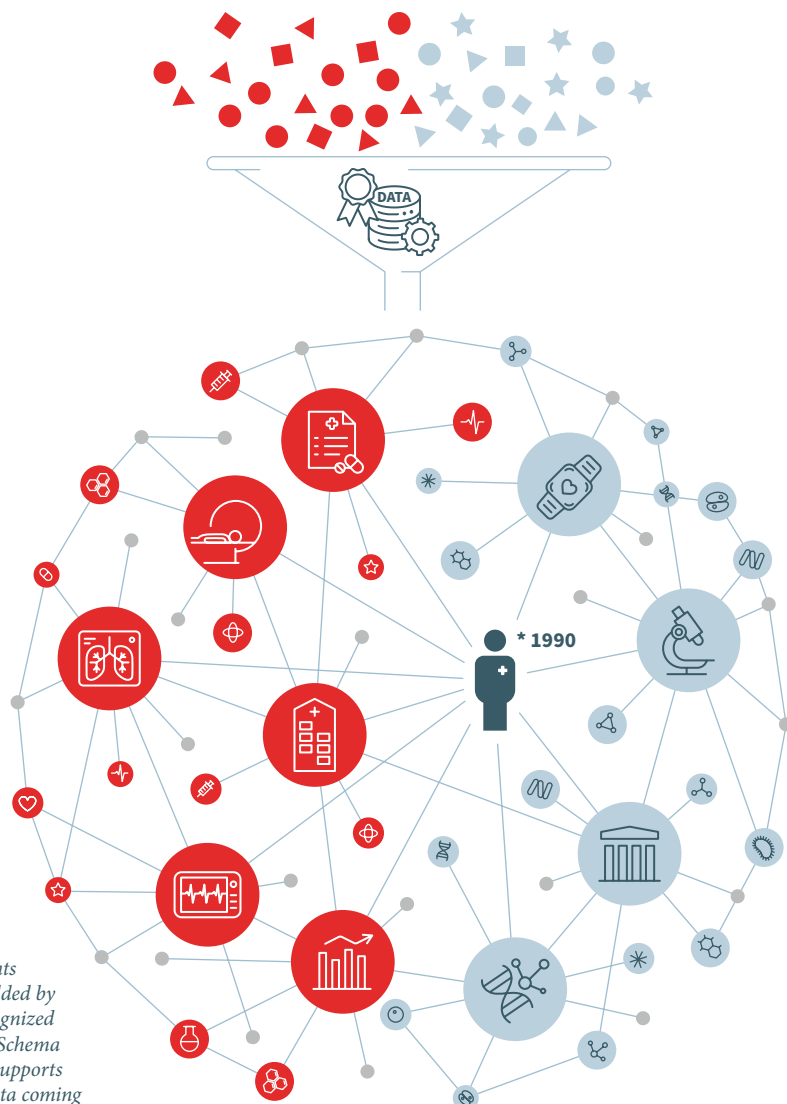
Meaningful merging of diverse data from different sources, however, is only possible if local differences and specific coding are replaced by the use of international terminologies. For researchers to be able to use (routine) health data for their projects, it is also important that data is findable and accessible.

Following the FAIR principles[1], the SPHN Data Coordination Center (DCC) in collaboration with its partners developed the SPHN Interoperability Framework, building on a strong semantic concept layer using international standard vocabulary and references. The syntax that links the semantic concepts is expressed via the Resource Description Framework (RDF), a semantic web standard.

Representing the used terminologies and the data itself as linked data allows researchers to easily combine subsets of data from different sources facilitating their use and exploration. In addition, it enables researchers to leverage the (clinical) knowledge of the integrated ontologies within their research projects.

The framework adds greater value to data and ensures that researchers (and their machines) can interpret the provided data consistently – across projects, systems, countries, and over time. For more information: sphn.ch/network/data-coordination-center/the-sphn-semantic-interoperability-framework/

---

[1] The FAIR principles require that data are Findable, Accessible, Interoperable, and Reusable. Sensitive health data cannot be openly accessible to third parties, but taking regulatory requirements into account, the data should be FAIR – also with reproducibility and sustainability in mind. The main goal of the FAIR principles is the optimal preparation of research data for reuse by humans and machines.

Relationships between data elements (red and blue) and information added by coding data in internationally recognized standards (grey). The SPHN RDF Schema provides a systematic syntax that supports a harmonized representation of data coming from different data sources.

Additional resources and services for researchers

Data Management Plan

For researchers who have received or will apply for SPHN funding, the new Data Management Plan guidelines outline recommendations for the use of sensitive biomedical data, help researchers to plan the entire data lifecycle, and highlight the SPHN and BioMedIT standards and services. The guidelines have been developed by the SIB's Personalized Health Informatics group and are available on sphn.ch/document/sphn-data-management-plan-dmp-guidelines/

Ethical and legal compliance support

To support researchers with the establishment of a contractual framework for the collaborative use of health-related data for research, the SIB has elaborated a new, modular set of legal agreement templates. These agreements settle the important issues that need to be legally addressed and define the rights, obligations and responsibilities of all parties involved. For projects running over the BioMedIT network infrastructure, the templates also provide for controller-processor amendments. The ELSI helpdesk from the Personalized Health Informatics (PHI) Group further provides essential help in choosing the right document and creating a first draft according to the needs of the respective institutional legal departments. For more information: sphn.ch/services/dtua/

Guidelines for sharing data with private parties

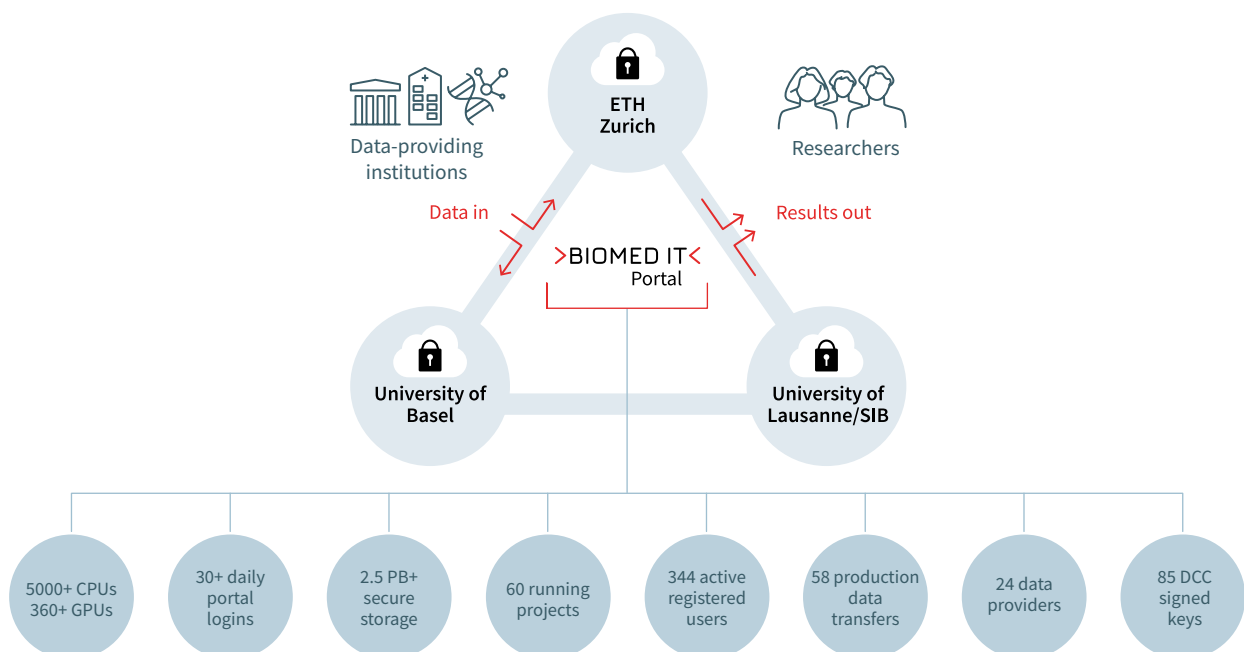For researchers envisioning collaborations with private companies such as the pharma industry, the ELSI Advisory Group of SPHN has developed guidelines for Public-Private Partnerships (PPP). These practical guidelines help researchers to process data in a responsible, transparent, ethically and legally sound way. For more information: sphn.ch/document/guidance-on-ethical-health-data-sharing-in-public-private-partnerships/

DCC training

DCC training modules and the SPHN Webinar series cover a wide range of subjects, from responsible use of health-related data for research, to the use and implementation of the SPHN Interoperability Framework components, and security trainings. Recordings are available on YouTube. Register for new webinars and training sessions on sphn.ch/services/sphn-webinars/

BioMedIT: The national infrastructure to boost personalized health research

Connecting researchers from across Switzerland with biomedical data to foster personalized health: this is the aim of the national secure computing network BioMedIT, set up by the SIB Swiss Institute of Bioinformatics in collaboration with ETH Zurich and the University of Basel. Launched in 2017 as part of the Swiss Personalized Health Network (SPHN) initiative, the network is now fully operational with over 60 national and international health-related research projects running, from infection prediction to precision oncology. This represents a major step forward in empowering personalized health research in Switzerland. For more information: www.biomedit.ch

The BioMedIT Network in numbers (Status: April 2022)

Outlook

National Data Streams

With the National Data Streams (NDS) program, SPHN and PHRT have funded multidisciplinary consortia that invest in the development of sustainable health-related data infrastructures for high-end personalized health research. External researchers will be able to benefit from the NDS thanks to streamlined third-party reuse processes. NDS projects have been launched in summer 2022 and have a runtime of 3 years.

Future DCC

The SPHN Data Coordination Center (DCC) is at the heart of the initiative and tasked with the technical implementation of key SPHN milestones such as the FAIR data framework and semantic strategy, the secure BioMedIT Network, and numerous central services and support. The continuation of the data coordination activities as well as a national support of the further development, maintenance, operation, and support regarding these infrastructure components beyond 2024 are of central importance. Discussions with the State Secretariat of Education, Research and Innovation (SERI) and all SPHN stakeholders how to sustain the established infrastructures and services and bring them to the national scale are currently ongoing. A decision is expected in 2023.

Collaboration with private industry

Health data research has the potential to transform healthcare delivery and is a key element in strengthening Switzerland's biomedical research base in the long term. Following the publication of the SPHN guidelines to Public-Private Partnerships, SPHN now aims to develop a better understanding of the needs and expectations of private-sector partners in relation to the health data mobilized through SPHN and to develop concrete use cases for collaboration with the pharmaceutical industry.

Swiss Federated Genomics Network (Swiss FGN)

The use of genomic data in healthcare is increasing and genome analysis will soon be considered an integral part of advanced healthcare systems. To fully benefit from emerging opportunities in this area, it is crucial to rapidly initiate coordinated efforts:

› to collect data and knowledge about the genetic structure of the Swiss population;
› to develop a streamlined infrastructure supporting collaborative genomic research;
› to provide researchers and clinicians with secure and efficient access to genomic information.

A Swiss Federated Genomics Network Strategy is currently being elaborated by SPHN consisting of two complementary pillars: an infrastructure backbone to support and coordinate genomic data generation, processing, and exchange in a scalable and sustainable manner, including a FAIR data repository allowing reuse of data, and a national reference genomic dataset (Genome of Switzerland) to demonstrate the feasibility of genome data production and sharing at scale.

Call for Demonstrator projects

Demonstrator projects illustrate the added value of SPHN data resources and infrastructure elements for data-driven personalized health research, clinical and public health research, and clinical use. Projects are launched from 1 December 2022.

A project of:

SAMW ASSM
Schweizerische Akademie der Medizinischen Wissenschaften
Académie Suisse des Sciences Médicales
Accademia Svizzera delle Scienze Mediche
Swiss Academy of Medical Sciences

SIB
Swiss Institute of Bioinformatics

Address:

Swiss Personalized Health Network
Haus der Akademien
Laupenstrasse 7
CH-3001 Bern

✉ info@sphn.ch

SIB Swiss Institute of Bioinformatics
Personalized Health Informatics Group
Elisabethenstrasse 43
CH-4051 Basel

✉ dcc@sib.swiss

Collaboratively implementing the mandate of SPHN

The Swiss Academy of Medical Sciences (SAMS) and the SIB Swiss Institute of Bioinformatics are co-responsible for the implementation of the SPHN mandate. The SPHN Management Office (MO) works together with the SIB's Personalized Health Informatics (PHI) Group to coordinate the funding and drive the development of harmonized infrastructures, compatible data management systems, interoperability of data and cutting-edge, multi-site research in personalized health.

The MO is in charge of the financial administration and the daily operation of the initiative, and coordinates the SPHN Governance bodies. It also supports the SPHN board chairs at the interface with the funders and political stakeholders.

The PHI Group is responsible for the SPHN Data Coordination Center (DCC) and thus in charge of the technical implementation of key milestones of the initiative, including the SPHN Interoperability Strategy, the required infrastructure components, the ELSI helpdesk, and the BioMedIT Network coordination.

Social media links:

🐦 @SPHN_ch   in SPHN – Swiss Personalized Health Network   www.sphn.ch