

Swiss Personalized Health Network

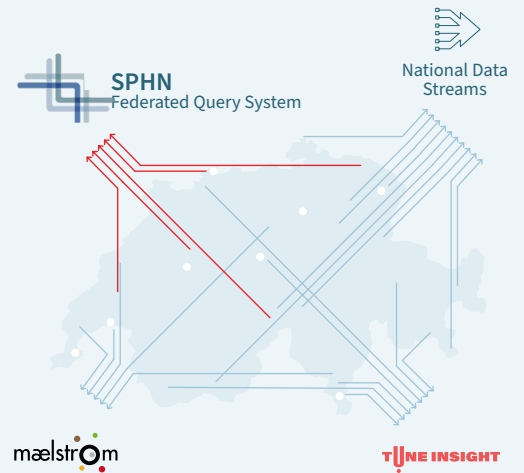
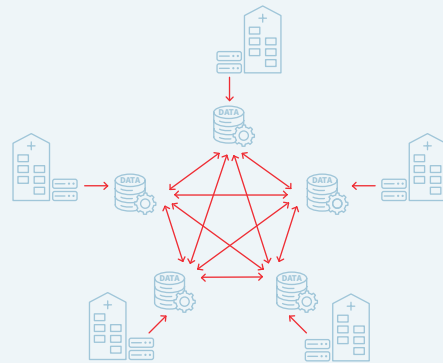


Over the past years, SPHN has made significant contributions to make health data FAIR for secondary use. These accomplishments strengthen Switzerland's position in personalized health research, driving innovation and improving healthcare outcomes.

Key achievements include:

Efficient Data Provision:

SPHN facilitates the efficient provision of interoperable biomedical and clinical routine data to researchers, promoting personalized health research

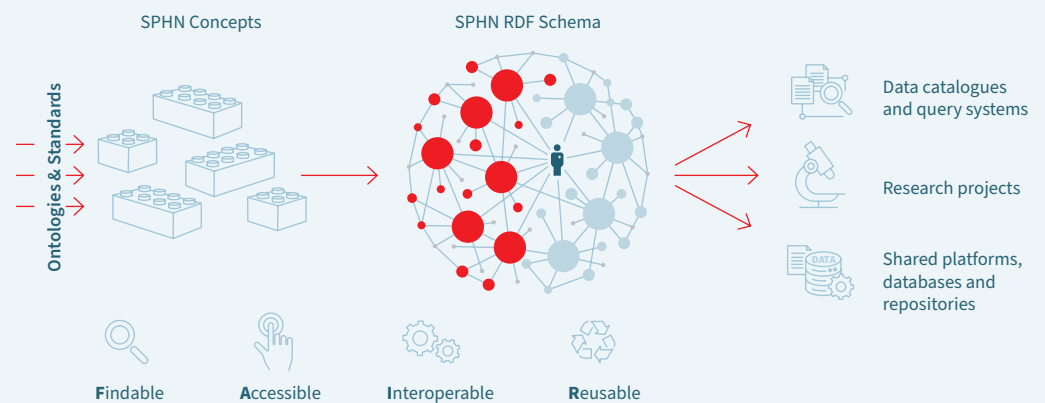


Discoverability of Data:

SPHN enables project feasibility and data exploration by providing different tools, services and data platforms (e.g., Federated Query System, NDS)

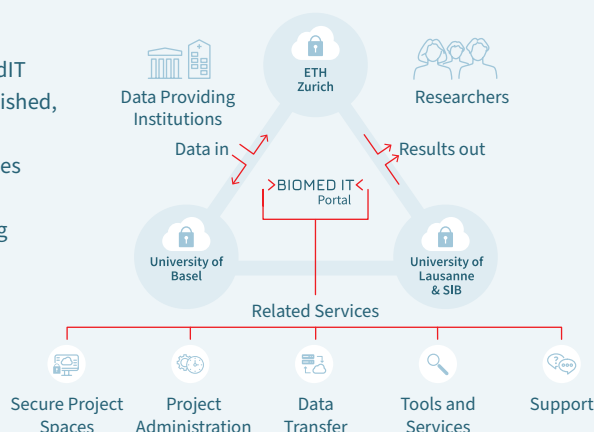
SPHN Semantic Interoperability Framework:

SPHN operates a common data schema, tools and services that make biomedical and health data understandable by humans and machines, enabling seamless data exchange



Trusted Research Environment:

Within SPHN, the BioMedIT network has been established, providing a secure IT infrastructure and services for transferring, storing, processing and analyzing sensitive research data



Compliance:

SPHN ensures the responsible and compliant reuse of sensitive health data, according to ethical guidelines and legal requirements

Collaboration:

SPHN became a trusted partner and integral part of the Swiss health research landscape and data ecosystem, strengthening research capabilities and fostering collaboration

ADDITIONAL ACTIVITIES

- > Outreach and Training
- > Legal Framework and ELSI Helpdesk
- > International alignment and collaborations

The SPHN Connector

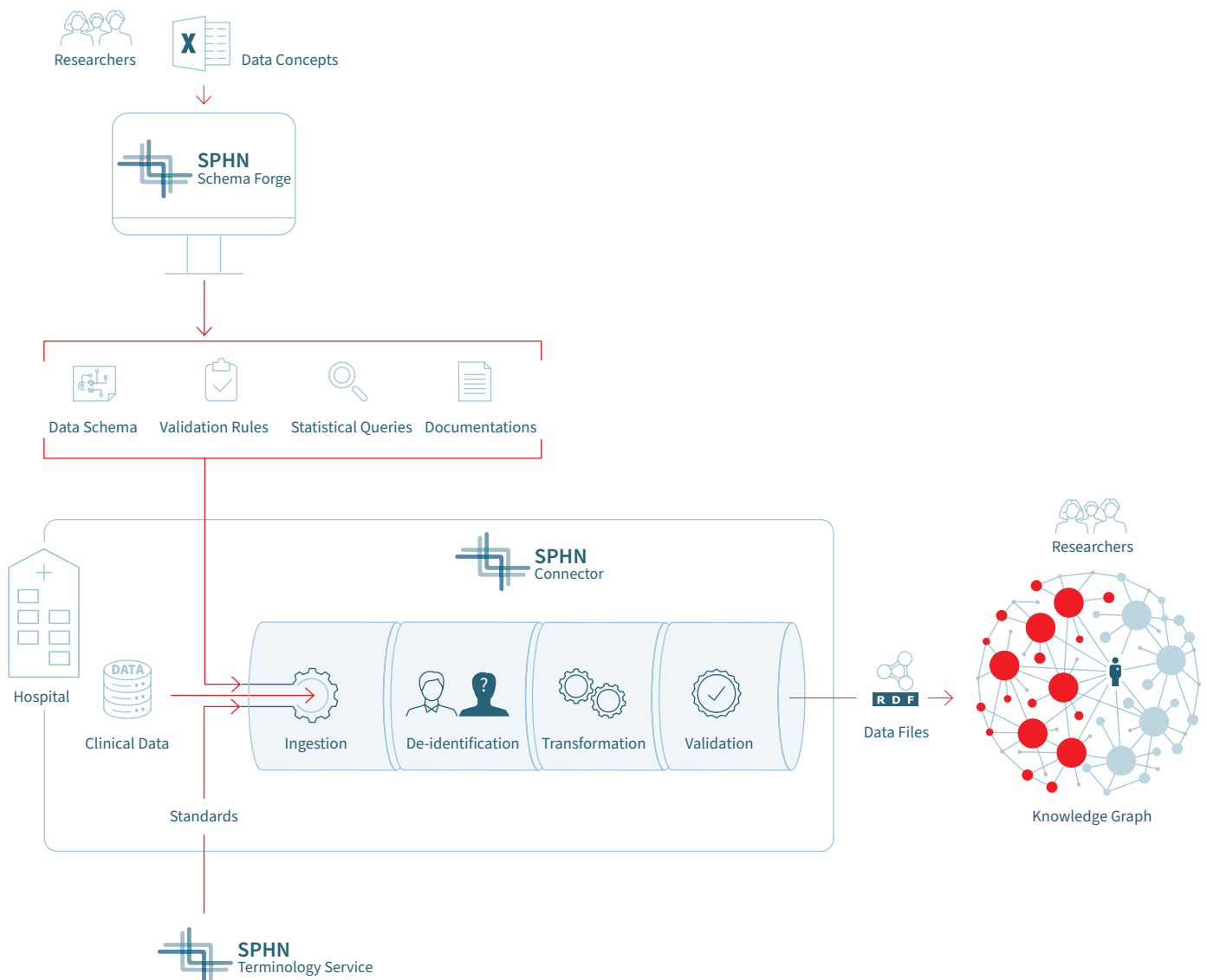
The SPHN Connector serves as a vital tool, facilitating the delivery of interoperable health data from data providers to research projects.

Since many data providers face difficulties in meeting the criteria for generating graph data that is both semantically accurate and compliant with SPHN standards, we created a central tool. The SPHN Connector not only reduces the workload associated with data pipelines for university hospitals, but also streamlines the process of integrating new hospitals into the network.

The Connector has been developed as part of the SPHN IT architecture strategy led by University Hospital Zurich and the SPHN-DCC. It interfaces with the other components of the SPHN ecosystem and services for FAIR data. Its flexibility allows users to derive data from a sim-

ple project-specific input using the SPHN Schema Forge Web Service. The Schema Forge generates a project schema, validation rules, and statistical queries that are then ingested into the SPHN Connector to produce valid RDF graph data for use in the study.

The SPHN Connector also facilitates validation, quality checks and de-identification procedures during the transformation process. The standardized output can be transformed back into other exchange formats (e.g., csv or json) at any time. The presented features of the SPHN Connector are a prerequisite for participating data providers to efficiently and sustainably operate their data platforms.



Current state of health data in Switzerland

Data sources

Health data are collected in a wide variety of settings, such as routine clinical practice, clinical research, registries and cohorts, or public health surveillance. The major challenges and shortcomings of using these data are the following:

- › The data is stored in silos and therefore highly fragmented
- › The formats, standards and quality of data vary greatly depending on the data source
- › Institution-specific governance processes provide additional challenges for sharing, access and use of health data
- › Data volumes from single institutions are too small to enable big data analyses

Primary use of health data

The primary use of health data is to support the delivery of care to the individual patient and improve the quality of diagnosis and treatment.

SPHN has enhanced the primary use of health data by developing infrastructures, services and processes that improve the cost- and time efficiency, and ultimately, the quality of clinical care. For example within the SPHN Swiss Personalized Oncology project, the establishment of tumor boards has directly impacted the care provided to cancer patients: difficult cases are discussed, with all centers sharing their experience and giving crucial feedback on treatment opportunities, including information on active clinical trials.

Among the obstacles and gaps for an efficient primary use of health data are the following:

- › Large administrative burden on medical personnel
- › The same data are collected multiple times and in different systems during a patient's treatment
- › The lack of digitalization and automatization in the healthcare system
- › The data are siloed in specialized clinical information systems within the same hospital

Secondary use of health data

The secondary use of health data refers to using the data beyond its original purpose of delivering care to the individual patient. Aggregated health data can be used by:

- › Researchers for, e.g., feasibility studies, research (clinical, public health, care or personalized health) and for research within public-private partnerships
- › Administration and regulators for, e.g., policy making, public health initiatives, monitoring and steering, market authorization, and surveillance (e.g. epidemics)
- › Healthcare providers for, e.g., value-based healthcare, quality control, safety monitoring, process improvement and reporting

Among the obstacles and gaps for an efficient secondary use of health data are the following:

- › Data are unstructured and insufficiently described with contextual metadata
- › Lack of data interoperability hinders data integration
- › Data reflect billing reality rather than medical reality
- › Lack of 'e-Consent' solutions impedes consent management
- › Lack of a 'unique patient identifier' for research hinders data linkage
- › Unclear legal basis for secondary use of health data beyond the Human Research Act

< *From admission to diagnosis, treatment and outpatient care, the FOPH recognizes the critical role of interoperable and meaningful health data. A dedicated unit at the national level - as envisioned for the SPHN-DCC - will be instrumental in efficiently coordinating and streamlining processes for the use and re-use of health data in Switzerland.* >



Nassima Wyss-Mehira
Head of Digital Transformation and Steering Directorate,
Vice Director Federal Office of Public Health

Interfaces of the SPHN Data Coordination Center with the developing Swiss Health Data Space

In light of the successes of the SPHN initiative and the critical role that the SPHN Data Coordination Center (SPHN-DCC) plays, the SERI has announced that the SPHN-DCC will be consolidated and continued to be funded during the next ERI period 2025-2028.

The SPHN-DCC will continue to be at the heart of FAIR data in the domain of health research in Switzerland, providing services and tools that enable the exchange and use of such data across the country. Its development is part of an evolving research landscape towards 'Open Research Data' and a functional and efficient health data ecosystem. The careful embedding of the SPHN-DCC in the national data strategies

and its interfaces with key partners in the system is an important prerequisite for the success of the desired Swiss Health Data Space. A responsible and efficient secondary use of health data, as promoted by the SPHN-DCC, will not only better serve research, but also advance healthcare processes, policy making, and ultimately benefit patients and the Swiss population at large.



SPHN's key contributions

Governance

- › Common ethical and legal standards and processes for data sharing and management facilitate the access to and the exchange of data
- › A set of legal agreement templates supports researchers with inter-institutional data transfer, access and processing
- › Common risk-based de-identification rules support data providers in ensuring data privacy

Interoperability

- › Common data standards and formats defined by the SPHN Semantic Interoperability Framework enable the linking of data coming from different sources
- › Tools and services facilitate and automatize the compliance with interoperability requirements

Process improvement

- › Tools and procedures allow the systematic monitoring and improvement of data quality
- › Time and cost efficient provision of interoperable data through the SPHN Connector
- › Education and training for researchers

Infrastructures

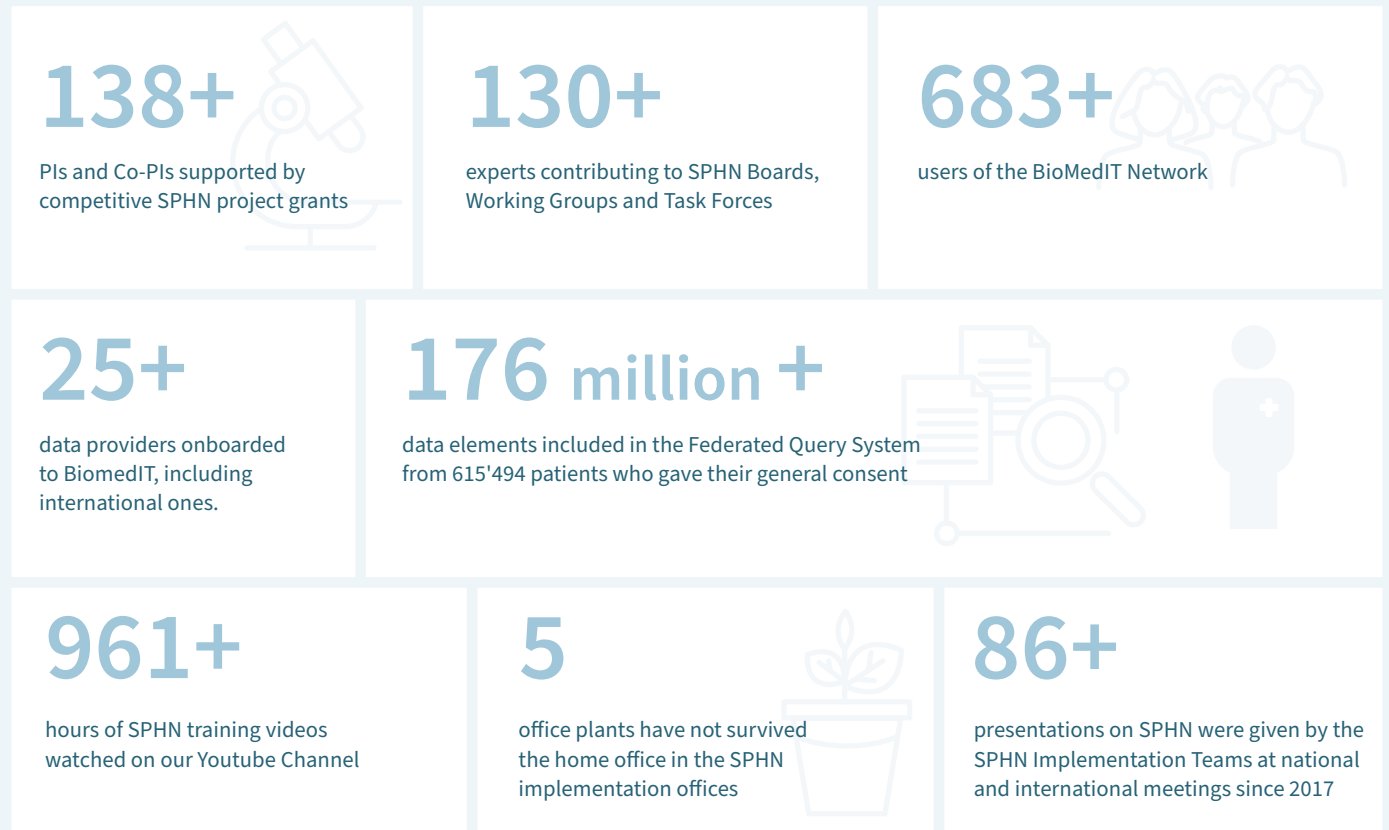
- › SPHN funded the establishment of clinical data platforms in 5 Swiss university hospitals
- › A Federated Query System allows the search for fully anonymized clinical information across 5 university hospitals for feasibility studies
- › BioMedIT provides the technical backbone, related services and information security for data transfers, processing, analysis and storage
- › Provision of privacy preserving and federated analytics technologies
- › National Data Streams build sustainable data infrastructures for high-end data-driven and personalized health research

External contributions

- › The SPHN-DCC interfaces with a number of other research initiatives and organizations to shape the evolving research landscape in Switzerland towards Open Research Data
- › Beyond research, the SPHN-DCC interfaces with the federal administration (e.g., FOPH, FSO), cantons and the health industry to accelerate the digital transformation in the healthcare system and to build an integrated Swiss Health Data Space
- › Beyond Switzerland, the SPHN-DCC collaborates and aligns with international infrastructure, research and standardization initiatives promoting the secondary use of health data

SPHN in Numbers

A quantitative insight into the progress and impact of the Swiss Personalized Health Network.



< As data is becoming instrumental for medical research and patient care, SPHN has created a real data mind-shift within the university hospitals. Improving data access, data quality, standardization and interoperability has significantly gained importance on the hospitals' agenda. >

Solange Zoergibel,
Chair Hospital IT Strategy Alignment Group



< By valuing and incorporating the authentic voices of patients, we can establish these data-rich research platforms as sustainable entities that yield substantial, enduring benefits for patient care. >

Larisa Aragon
PPI expert National Data Streams

A project of:



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



Swiss Institute of
Bioinformatics

🐦 @SPHN_ch

🌐 SPHN – Swiss Personalized Health Network

www.sphn.ch www.biomedit.ch