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 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 simple 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 challenges and shortages of using these data are the following:

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 embraced 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 heavy meningococcal meningitis project, the establishment of a favor has directly impacted the care provided to patients. Often, difficulties are discussed, with all centers sharing their experience and giving crucial feedback on the treatment.

Secondary use of health data

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:

- Healthcare providers for, e.g., value-based healthcare, quality improvement, and regulators for, e.g., policy making, public health initiatives, monitoring and steering, market authorization, and/or research.
- Researchers for, e.g., feasibility studies, research (clinical, public health) and re-use of health data in Switzerland.

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

- Large administrative burdens on medical personnel
- The same data are collected multiple times in different systems
- Lack of organization and automation in the healthcare systems
- Data are stored in specialized clinical information systems within the same hospital
- Large administrative burden on medical personnel
- Lack of data sharing and interoperability

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
- Data are stored in silos and therefore highly fragmented
- Data reflect billing reality rather than medical reality
- Data are siloed in specialized clinical information systems within the same hospital
- Data are stored in silos and therefore highly fragmented
- Lack of a ‘unique patient identifier’ for research hinders data linkage
- Data are unstructured and insufficiently described with contextual metadata
- Data reflect billing reality rather than medical reality
- Data are siloed in specialized clinical information systems within the same hospital
- Lack of organization and automation in the healthcare systems
- Large administrative burden on medical personnel

The primary use of health data in the domain of health research is interdisciplinary, involving services and tools that enable the validation and cross-check of data across the country. Its development is part of a broader research landscape towards Open Research Data. The careful embedding of the SPHN-DCC is in the national data strategies and its interface with key partners in the system is an important prerequisite for the success of the opened health data space. A responsible and efficient secondary use of health data, as promoted by the SPHN-DCC, will only be effective when combined with adequate intervention policies, governance, technology and infrastructure.

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 FOPH has announced that the SPHN-DCC will be consolidated and continued to be funded during the next ER period 2025-2028.

The SPHN-DCC will continue to be at the heart of SPHN data in the domain of health research in Switzerland, providing services and tools that enable the validation and cross-check of data across the country. Its development is part of a broader research landscape towards Open Research Data. The careful embedding of the SPHN-DCC is in the national data strategies and its interface with key partners in the system is an important prerequisite for the success of the opened health data space. A responsible and efficient secondary use of health data, as promoted by the SPHN-DCC, will only be effective when combined with adequate intervention policies, governance, technology and infrastructure.

SPHN’s key contributions

- Communication and legislation of health data sharing and management facilitate the access to and the exchange of data
- A set of legal agreements supports research with inter-institutional data sharing and processing
- Communication based on dedicated rules support data providers in ensuring data privacy

Interoperability

- Communication standards and protocols defined by the SPHN imprint ensure interoperability, making the linking of data coming from different sources possible
- Tools and services automate and standardize the compliance with interoperability requirements

Process improvement

- Tools and procedures allow the systematic monitoring and improvement of data quality
- Free and cost-efficient provision of interoperable data through the National Contact Data
- Education and training for researchers

Infrastructures

- SPHN linked the establishment of clinical data platforms in two university hospitals
- A model based query system allows for highly anonymized clinical information access in university hospitals for feasibility studies
- SPHN provides the technical backbone, related services and toolkits in order to deploy tools, processing, visualization and analysis solutions
- Provision of primary preserving and federated analytics technologies
- SPHN data discovery tools provide access to fully anonymized data for high-end data-driven and personalized health research
- SPHN’s key contributions

External contributions

- The SPHN-DCC interacts with a number of other research initiatives and organizations to shape the evolving research landscape in Switzerland:
  - Swiss Data Infrastructure for Health and Life Sciences (SDI-LS)
  - Swiss Scientific Computer Center (SCC"
  - European Open Science Cloud (EOSC)
  - Open Science in Medicine (OSiM)
  - European Research Area (ERA)
  - Swiss Research and Technology Foundation (SRTF)
  - Swiss Data Initiative (SDI)

- Beyond research, the SPHN-DCC interfaces with the federal administration (e.g., FOPH, FAL), cantons and the health industry to accelerate the digital transformation in the healthcare system and to build or integrate new health data space.

- Beyond national, the SPHN-DCC collaborates and aligns with international initiatives, research and standardization initiatives promoting the secondary use of health data.
A quantitative insight into the progress and impact of the Swiss Personalized Health Network.

**SPHN in Numbers**

- **138+** PIs and Co-PIs supported by competitive SPHN project grants
- **130+** experts contributing to SPHN Boards, Working Groups and Task Forces
- **683+** users of the BioMedIT Network
- **25+** data providers onboarded to BiomedIT, including international ones
- **176 million +** data elements included in the Federated Query System from 615'494 patients who gave their general consent
- **961+** hours of SPHN training videos watched on our Youtube Channel
- **5** office plants have not survived the home office in the SPHN implementation offices
- **86+** presentations on SPHN were given by the SPHN Implementation Teams at national and international meetings since 2017

< 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. >

Solang Zoergiebel, 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

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A project of:

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