

# Swiss Personalized Health Network



## WHERE DO WE STAND TODAY

*“Medicine is becoming ever more data driven, predictive and tailored to individual characteristics, ranging from genetic and molecular to lifestyle. To support the development of such science-based personalized health care in our country, research and clinical decision-making need to rely on real-world health data. Since 2017, SPHN has developed over 70 infrastructures, technologies and methods enabling researchers and clinicians to safely use large sets of health data in a responsible, ethical, and legal manner.”*

**Prof. Urs Frey, Chairperson National Steering Board SPHN, SAMS**

### IN THIS FACT-SHEET

#### WHO BENEFITS FROM SPHN?

Perspectives of patients and citizens, researchers, pharma industry and hospitals.

#### WHAT HAS BEEN PUT IN PLACE SO FAR?

A global picture of the infrastructure built to last and according to the FAIR principles.

#### WHAT ARE THE KEY CHALLENGES THAT ARE BEING ADDRESSED?

The groundwork that led to achieving interoperability, on the semantic and technical level.

#### WHAT ARE THE PLANS FOR THE FUTURE?

For the next funding period and beyond, consolidating the infrastructure and fostering engagement.

### SPHN IN BRIEF

SPHN is a national initiative under the leadership of the Swiss Academy of Medical Sciences (SAMS), in collaboration with the SIB Swiss Institute of Bioinformatics. It contributes to the development, implementation and validation of coordinated data infrastructures in order to make health-relevant data interoperable and shareable for research in Switzerland.

SPHN’s scale and nature are unprecedented in Switzerland. It is collectively building a sustainable, health-data ecosystem from which citizens, researchers, healthcare providers, authorities and cooperating partners can benefit. SPHN works hand-in-hand with the Personalized Health and Related Technologies program (PHRT) of the ETH Domain, and interacts closely with international data sharing initiatives (e.g. GA4GH, ICPeMed) to ensure lessons learned are shared.

[Find out](#) about the governance of SPHN

### MAKING HEALTH DATA AVAILABLE: WHAT FOR?

Here are some of the questions scientists are able to tackle as a result of this ambitious initiative, directly impacting the way patients are cared for today and in the future.



**Molecular and digital biomarker discovery:** personalized prevention of diseases, prediction of possible treatment outcomes, treatment and intervention strategies



**Hypothesis generation** based on data exploration: identification of otherwise concealed medically relevant associations, changes in disease trajectory



**Drug targeting and efficacy:** earlier detection of drug side-effects, enhancement of therapeutic treatment



**Altogether, improving patients’ and citizens’ healthcare quality,** through a greater understanding of the factors impacting disease prevention and care

*“SPHN enables access to valuable datasets, which are both critical and crucial to current research developments, including AI, in order to better anticipate, diagnose and treat patients.”*

**Prof. Joël Mesot**  
President of ETH Zurich

# BENEFITS FOR ALL

*By collaboratively advancing personalized health research and innovation, the initiative benefits society at large.*

## EXAMPLES OF BENEFITS AND ACTIONS UNDERTAKEN BY SPHN:



### FOR CITIZENS

A safe context for citizens and patients to share their data in an informed way and for a meaningful purpose

- Being able to **give consent in a transparent and dynamic way** thanks to a personalized communication platform: this is the purpose of the citizen-centred consent project (see the C3-STuDY infrastructure development project)
- Benefiting from the **latest advances in precision medicine** through early detection of pathologies and targeted treatment (see the PSSS, SOCIBP-SPO or SFNR driver projects)



### FOR HOSPITALS AND CLINICS

Solutions to improve patient care and to reduce infrastructure costs

- Establishing **research data management systems** at the University Hospitals with the support of SPHN, enabling scalable and sustainable re-use of health-related data for research, care and quality assessment
- By linking to the **BioMedIT network**, benefiting from a trusted, high performance IT environment to outsource data management and analyses, without the need to (re)develop costly in-house infrastructures and know-how



### FOR RESEARCHERS

A streamlined and legally compliant process to conduct research on health-related data

- Through a **federated distributed query system**, finding out, across Swiss University Hospitals, if, where and how many patients present the condition of interest for the study envisaged - a key aspect of the feasibility analysis step
- Following security training, being able to seamlessly access interoperable datasets on the **BioMedIT network** - the platform to process sensitive data in a secure and collaborative way - while benefiting from dedicated data management and analysis support
- Using a comprehensive **legal architecture** with contract templates to manage regulatory requirements in the most efficient way, saving time for research activities



### FOR PARTNERS

Improve efficiency to develop new drugs faster and more tailored to patient needs, by accessing previously unavailable routine data

- Jointly develop and improve technical and semantical data interoperability in Switzerland through **common foundations**. [Watch](#) the presentations at the inaugural interdisciplinary workshop on this theme
- Clear conditions and mechanisms to ensure **fair collaborations** between SPHN partners, commercial entities and international consortia

*“We need an open ecosystem on the basis of which all actors can develop patient-centric offers and services focusing on the various medical needs.”*

**Dr René Buholzer**  
CEO and Delegate of the Board,  
Interpharma

# OVERCOMING KEY CHALLENGES

To move from fragmented, heterogeneous data to a harmonized pool of quality health information, two kinds of bottlenecks need to be addressed, in addition to increasing data findability and accessibility and complying with regulatory requirements pertaining to the sensitive nature of health data.

## SEMANTIC INTEROPERABILITY

Bridging the world of healthcare and the world of research in a sustainable way calls for solutions to transport not just data (i.e. texts from medical reports, numeric data from laboratory results, or images), but also the metadata that will enable researchers to properly interpret them (i.e. type of analyzer or kit used, the clinical context of the patient, etc.).

→ SPHN has developed a semantic interoperability framework, including the use of standards and ontologies to describe the data (i.e. LOINC or SNOMED-CT), and a flexible transport and storage format (i.e. Resource Description Framework RDF), to allow convenient data representation and linkage.

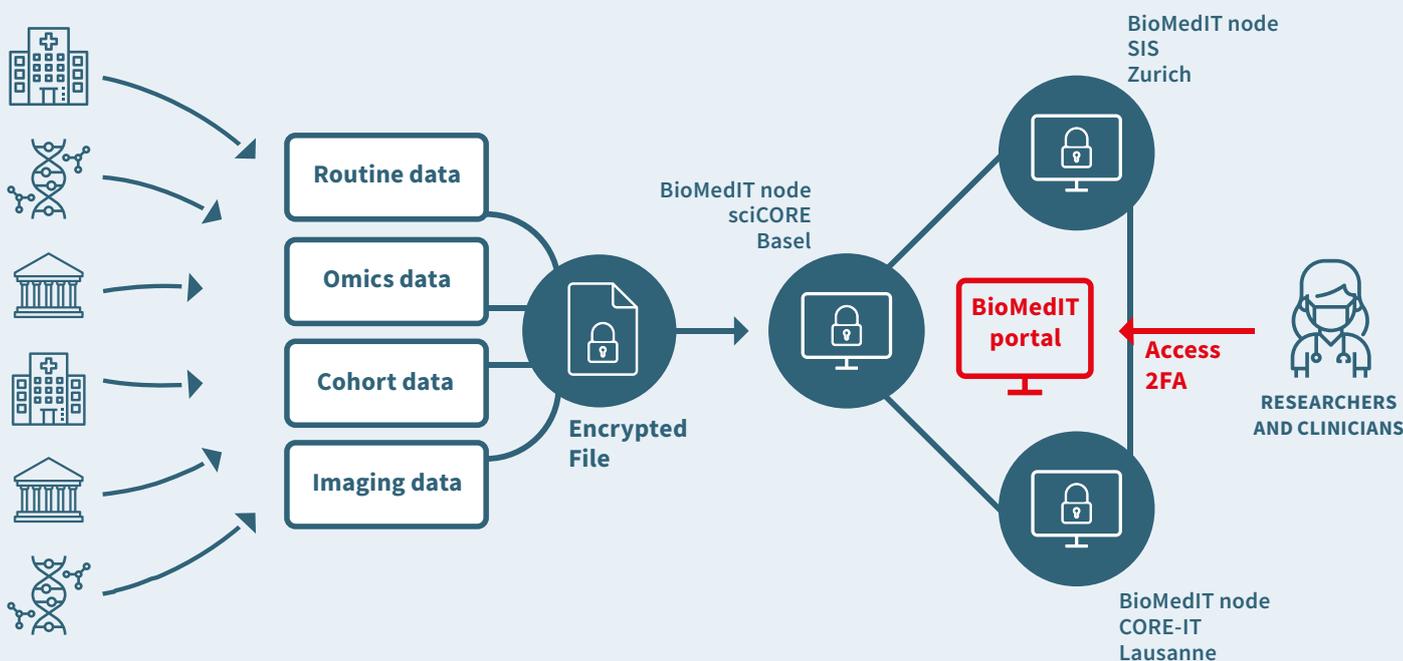
## SECURE NATIONWIDE INFRASTRUCTURE

Given the sensitive nature of health-related information, research using patient data calls for high levels of security and data protection in Information and Communication Technology (ICT) infrastructures, processes and expertise, in order to fulfil stringent legal, regulatory and ethical requirements. The key challenge here is to provide researchers with an integrated solution.

→ SIB has setup the BioMedIT network (see below) as part of SPHN to provide all authorized researchers in Switzerland with easy access to collaborative analysis of confidential data without compromising data privacy. The network is operational today at all three nodes based in Basel (sciCORE, operated by the University of Basel), Lausanne (Core-IT, operated by SIB) and Zurich (SIS, operated by ETHZ).  
Read the paper: [doi:10.3233/SHTI200348](https://doi.org/10.3233/SHTI200348)

## THE BIOMEDIT NETWORK

The BioMedIT network allows secure and standardized data transfer from data providers to researchers. This includes shared controlled access to datasets across different teams across the country, as well as cutting-edge technology for data analysis.



# SETTING UP A SCALABLE AND SUSTAINABLE INFRASTRUCTURE

## MAKING HEALTH DATA FAIR...

Health-related data are of different kinds, stored in different places, in different formats, and standards are often lacking. Making them Findable, Accessible, Interoperable, Reusable (FAIR) for the research community is part of SPHN's mission. By doing so, the initiative is unlocking the potential of combined data sources to deliver insights for personalized health.



### MOLECULAR / OMICS DATA

Genomics, transcriptomics, proteomics, metabolomics, etc.

#### SPHN IS:

- fostering the creation of data and meta-data standards in the Swiss omics landscape in close cooperation with PHRT and international initiatives such as the Global Alliance for Genomics and Health (GA4GH)
- examining the option of establishing a local European Genome-phenome Archive<sup>1</sup> (EGA) for data from projects inside and outside the network
- establishing a federated network enabling sharing and processing of genomic, transcriptomic, proteomic, and metabolomic data for research

**The aim? To enable researchers relying on biobank samples (tissue, blood, etc.) to know if associated omics data are available, and use them in their research**



### DATA FROM HOSPITALS AND CLINICS

Routine data incl. medical analysis results, diagnosis, medication, demographics, imaging

#### SPHN IS:

- promoting and supporting the implementation of data standards in hospitals
- setting-up a Semantic Interoperability Framework, including a strong semantic definition and a formal descriptive language for exchanges
- running experimental Natural Language Processing projects to map information from free-text reports onto adopted terminology

**The aim? To ensure that when a patient enters a hospital anywhere in Switzerland, routine data are captured in primary systems in a way that allows re-usability**



### CLINICAL RESEARCH DATA

High-quality patient-oriented health data from clinical trials, cohorts<sup>2</sup> and medical registries<sup>3</sup>

#### SPHN IS:

- connecting large-scale Swiss cohorts to a metadata catalogue to increase findability
- fostering interoperability of clinical research data
- promoting the use of routine data for clinical studies, cohort and registries

**The aim? To enable the re-use of clinical research data from one project to another, and thus unlock new knowledge on disease prevention, diagnosis and treatment**

<sup>1</sup> A service for permanent archiving and controlled sharing of personally identifiable genetic and phenotypic data from biomedical research projects

<sup>2</sup> Data on groups of people that are part of a clinical study, observed over many years

<sup>3</sup> A collection of information about individuals, usually focused around a specific diagnosis or condition

## ... WHILE CREATING INFRASTRUCTURE WITH CONCRETE PROJECTS

To ensure the steps to make all these data sources FAIR offer realistic solutions to current and future research needs, the *implementation teams* work in close collaboration with infrastructure projects selected and funded by SPHN. Covering the full spectrum of topics and issues relating to health data digitalization, these 24 projects act as 'pilots' to create and validate new infrastructures.

### EXAMPLES OF PROJECTS (EXPLORE THE COMPLETE LIST AND ABSTRACTS):

#### INFRASTRUCTURE DEVELOPMENT PROJECTS

Software, databases, and methods developed at single or joint sites

- **Collective protection of medical data: MedCo**  
Software using a combination of advanced cryptographic approaches to enable the collective analysis of data stored at different sites
- **Harmonizing cancer variant interpretation: SVIP-O**  
An expertly curated collaborative platform providing clinical interpretation of somatic variants identified in cancer patients from routine diagnostics in Swiss hospitals
- **A new approach to consent management: C3-STuDY**  
Towards a citizen-centred, transparent, dynamic, and sharable consent solution, to address the challenges posed by consent management in the era of precision medicine

#### DRIVER PROJECTS

'Test driving' the infrastructures and interoperability for multi-site research in a specific area

- **Detecting and predicting sepsis in individual patients: PSSS**  
Infrastructure and research framework to gather and analyse complex information on patients and pathogens during the entire course of a sepsis, and enable its early detection through personalized biomarkers
- **Improving precision oncology care and therapy development: SOCIBP - SPO**  
A platform to manage and share oncology data across Switzerland with a focus on melanoma, breast, lung and prostate cancer, as well as a national molecular tumour board and standardized molecular profiling procedures of tumour biopsies
- **Swiss Frailty Network and Repository: SFNR**  
Overcoming the bottleneck of diagnosing frailty and laying the ground for personalized frailty prevention and treatment strategies

*"Ethical and legal issues including approval of research projects, consent procedures and data protection are given high priority within SPHN: this is instrumental in fostering trust, from patients and society."*

**Dr Susanne Driessen**  
President, swissethics

*"Thanks to SPHN, researchers will soon be able to use valuable consented data from Swiss healthcare institutions. This strengthens SNSF's efforts to facilitate high-quality, reproducible and accessible research data."*

**PD Dr Irène Knüsel**  
Head, Division of Biology and Medicine, SNSF

## LOOKING AHEAD

*“In tomorrow’s digital, learning healthcare system, healthcare and research must go hand in hand. Interoperable, high-quality data are useful not only for research, but also for hospital internal processes as well as procedures all along the patient’s pathway. The network we are collectively building to empower data-driven medicine and research in Switzerland is therefore designed to last. And thanks to the efforts of all partners across the ecosystem, we are on the right path to ensuring its long-term sustainability.”*

**Dr Katrin Cramer, Director, Personalized Health Informatics Group, SIB**

### KEY ACHIEVEMENTS OF FIRST FUNDING PERIOD 2017-2020

**Nationwide coordinated infrastructures** were set up to efficiently manage, exchange and process consented health data in accordance with ethical and legal requirements;

**24 health data projects** were selected and supported to develop and validate infrastructure, new technologies and methods in collaboration with PHRT, as well as multi-site research on specific health issues;

**A semantic strategy** was established to ensure the common basis for a clear and shared understanding of the meaning of the data to be used;

**Dedicated data warehouses**, as well as associated infrastructures and processes, are now in place in the five Swiss University Hospitals.

### PERSPECTIVES FOR THE NEXT FUNDING PERIOD 2021-2024

First, the existing infrastructure will be consolidated, and the initiative will pursue efforts to expand the scope of clinical variables and accessible data sources. This will enable the progressive inclusion of additional hospitals. Second, while the first period focused on technical and legal feasibility, as well as on infrastructure building, in the next phase engagement with patients and citizens will be strengthened.

**All these efforts will ultimately converge in a long-term, independent national centre for health-data coordination and infrastructure for research from 2024 onwards.**

### STAY CONNECTED

**in** [linkedin.com/groups/8579798](https://www.linkedin.com/groups/8579798)

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SPHN Data Coordination Center (DCC) & BioMedIT

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### ALLOCATION OF FUNDS

- During the first phase 2017-2020, CHF 58.3 million have been invested into research infrastructure projects
- 13 infrastructure development projects: CHF 3.7 million
- 11 driver projects: CHF 21.6 million
- 5 infrastructure implementation projects at the University Hospitals: CHF 15 million
- BioMedIT project: CHF 18 million

*“Making sense of and using the full potential of digital data are significant challenges for hospitals. SPHN has triggered the creation of an infrastructure of direct relevance to us, whether to allow the scaling up of clinical research projects or to support our diagnostic activities.”*

**Prof. Arnaud Perrier**  
Chief Medical Officer, HUG