

# SPHN Short Report (2023)

Yearly update and overview of activities

## 1 Editorial

Over the past seven years, the SPHN initiative has established a comprehensive framework for the exploration, transformation and use of routine patient data from university hospitals for personalized health research in Switzerland. The SPHN framework closely follows the FAIR principles to make data findable, accessible, interoperable, and reusable for research, benefitting also other secondary use. It is in accordance with all applicable regulatory and legal requirements, including the revised Federal Data Protection Act. The close collaboration between the central coordination services, university hospitals, higher education institutions and partner organizations has been key to progress towards the envisioned health research data ecosystem.

In 2023, SPHN achieved important milestones such as the expansion of the SPHN Semantic Interoperability Framework, which now incorporates more than 160 clinical concepts providing a holistic view of patient data from domains including cardiology, oncology, microbiology, and intensive care. The existing tool stack was revamped, and new tools were introduced to provide an end-to-end service for researchers and data providers. An important legacy of SPHN, the SPHN Connector, is now offering data providers a versatile data generation pipeline producing de-identified RDF graph data from diverse input formats, validation tools and extensive statistics on the generated data.

Another major milestone was achieved over the past year with the signing of the consortium and data transfer and use agreements for the four National Data Streams (NDS). These comprehensive, multi-center digital cohorts will exchange and analyze data with a strong view to interoperability and further data sharing. Concurrently with the progress of the NDS, 11 Demonstrator projects started in 2023 to test, challenge and further inform and develop the SPHN ecosystem. To further streamline the processes for accessing data in multisite research projects in a responsible and legally compliant manner, the SPHN Data Governance Working Group was established to jointly tackle recurring data governance issues. Its first work package is to develop an overarching contractual framework for third-party use of sensitive data – with harmonized processes and templates endorsed by all involved institutions and in line with national and international standards.

Facilitating exploration and discoverability of clinical data available for research has been a core mission of SPHN since the beginning. The SPHN Federated Query System (FQS) currently holds over 650 million data elements from more than 0.6 Mio patients who gave general consent to further use their data for research. In the past year, we have completed a successful pilot project in collaboration with Tune Insight SA and university hospitals to increase security and enhance federated analytics features of a future SPHN data catalog towards a federated Data Exploration and Analytics System (DEAS).

The interactions with partners of SPHN further increased in 2023, strengthening the interfaces of SPHN with the ETH-domain, hospitals, industry and, last but not least, the federal administration – most notably the Federal Office of Public Health (FOPH) and the Federal Statistics Office (FSO). The approval of the DigiSanté program by the Federal Council in November 2023 promises a strong push for the digital transformation of the healthcare system. SPHN strongly supports this program, recognizing it as a pivotal step towards implementing a Swiss Health Data Space. The frameworks and insights developed in the context of SPHN can thereby serve

as a model, contributing to the development of a comprehensive national health data strategy and ecosystem for Switzerland. SPHN is committed to exploring synergies with DigiSanté and further work towards realizing its vision to enable personalized health in Switzerland.

The SPHN National Steering Board published in 2023 its report on the continuation of the SPHN data infrastructures after the completion of the initiative in 2024. The State Secretariat for Education, Research and Innovation (SERI) committed to the consolidation of the SPHN Data Coordination Center (SPHN-DCC) as a national competence and coordination center in the area of health data, in coordination with decentralized infrastructure from the university hospitals, the BioMedIT infrastructure and the National Data Streams. The ERI Dispatch 2025-2028 outlines a basic financial contribution by the Confederation of CHF 20.7 million over four years. While securing the maintenance of the core services and infrastructures of SPHN in the coming years is a major success, it is not sufficient to enable the expansion and further development of the network for the future. This will have to be financed by additional income generated through services, mandates and project-related funds. Negotiations on the operationalization of the future SPHN-DCC in a currently very challenging financial environment have been a major focus of SPHN leadership in the past year and will continue to be in 2024. The strong commitment of the partners for collaborating and sharing the responsibilities and benefits for the common goal is of utmost importance.

Yours sincerely,

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## 2 Activities and achievements in 2023

SPHN's activities are outlined according to four main categories:

- Funding activities and collaborative projects;
- Data Coordination Center & BioMedIT;
- National and international collaboration;
- Events & communication.

### 2.1 Funding activities and collaborative projects

Given the conclusion of the initiative in 2024, no new Calls for proposals were launched in 2023.

#### **National Data Streams (NDS)**

Four NDS projects covering the fields of infectious diseases in intensive care medicine, oncology, paediatrics, and health services research were jointly selected for funding by SPHN and the ETH-Domain program Personalized Health and Related Technologies (PHRT). Each of the NDS comprises a Switzerland-wide multidisciplinary consortium that invests in the development of sustainable data infrastructures for high-end data-driven and personalized health research. In the long term, the NDS shall serve as models and crystallization points for future research programs and clinical applications of personalized health. All NDS started in September 2022 with a support of up to CHF 5 million per project and a runtime of 3 years. After intense negotiations in 2023, the contractual framework for all four NDS was signed by the beginning of 2024. Thanks to these agreements, the projects are now able to exchange and analyze data with a strong view to interoperability and further data sharing in the future. In September 2023, all NDS presented their progress to the SPHN International Advisory Board and their specific NDS Monitoring Boards in the context of a mini-symposium. By the end of October, NDS had communicated their detailed data needs and first data transfers from the university hospital Clinical Data Warehouses/Platforms (CDWs) to the projects have been executed. The majority of data transfers will take place in 2024.

#### **Demonstrator projects**

SPHN Demonstrator projects were selected for funding to test the infrastructures, processes, and data resources established in the realm of SPHN, to demonstrate their added value for the network and to identify remaining gaps. The 11 funded Demonstrator projects started their work in spring 2023 and are planned to end in September 2024. For 9 of the 11 projects, legal agreements such as Consortium Agreements, ethics approval and DTUA/DTPAs had to be set up. Despite the smaller size of the Demonstrator project consortia, for some projects the finalization of the legal framework took more time than expected and therefore only 50% of the first instalment was released upfront. Approximately six months after the start of the projects, a first intermediary report was submitted by the project PIs to assess the launch of the projects and difficulties encountered.

#### **Driver projects**

In 2023, the four remaining ongoing Driver projects from the Call 2018 were completed (SOIN, IMAGINE, SACR, SHFN). The final reports were reviewed and outcomes of the projects were published on the SPHN website.

### **Collaboration agreements with university hospitals and HospFAIR program**

In the frame of the renewed collaboration agreements 2021-2024 (CA) between SPHN and the five Swiss university hospitals (UH), the institutions continued their works in 2023. Similar to previous years, bilateral so-called 'Friendly Talks' between SPHN and UH leadership were held during the year to foster a common understanding on the most pressing issues. Common data standards between research and healthcare, scalability and producing high-quality data close to the point of care were identified as key success factors in an increasingly challenging financial environment. A joint workshop between SPHN and the UH was organized in January 2023 to exchange learnings and jointly identify priorities for the third year of the renewed CA. In close collaboration with the SPHN Hospital IT Strategy Alignment Group (HIT-STAG) and the unimeduisse-SPHN Working Group, the hospitals defined common as well as UH-specific objectives and deliverables, which were jointly monitored by the UHs and SPHN throughout the year. Notably, a sustainability concept for the SPHN-related infrastructures and services at the UHs is a deliverable of the third year of the CA.

Complementary to the work of the CA, all five Swiss UH participated in the HospFAIR program. This program aims to improve the quality of data and to systematize data standardization and extraction through the implementation of streamlined processes at the Clinical Data Platforms of the participating UH. In 2023, the first phase of the program came to an end with all five UH showing various levels of progress on the data standardization goals. As concluded at the joint workshop between SPHN and UH representatives, the main outcome of the HospFAIR phase I is an increased awareness of data quality issues in all institutions, which are now being addressed more systematically. Monitoring and improving data quality remain more complex tasks than anticipated. The goals of phase II of HospFAIR were reviewed during the joint SPHN-UH workshop and approved by the NSB in May 2023. Specifically, during the second phase, the UHs shall focus on systematically monitoring and improving real-world data quality, on efficiently and sustainably providing data for research and other secondary usages and on demonstrating the added value of data platforms beyond SPHN-funded use cases.

### **TI4Health proof of concept project (formerly, MedCo)**

Following a successful initial pilot project for distributed and privacy-preserving cohort exploration and analysis based on two limited datasets, the TI4Health platform (developed by Tune Insight SA, a spin-off from EPFL) is now being tested to act as an integral part of the SPHN infrastructure portfolio for exploring and analysing the full SPHN Dataset. TI4Health emerged from the MedCo Infrastructure Development project funded by SPHN and PHRT in 2017. In order to minimize additional work for the hospitals participating in the distributed network and to embed the new Federated Data Exploration and Analysis (DEAS) tool as organically as possible in the SPHN tool landscape requiring only one type of data integration, the DCC is developing a component using a graph database as part of the pilot, which should also enable a correct representation of external terminologies and improve query functionality and performance. Various clinical use-cases will be included into the DEAS pilot in order to drive the infrastructure development and especially also the elaboration of the User Interface (UI). First results of the DEAS pilot, in which all five university hospitals and the Children's University Hospital Zurich participate, will be presented to the SPHN National Steering Board in November 2024.

## 2.2 Data Coordination Center & BioMedIT Network

Within SPHN, the Personalized Health Informatics Group (PHI) of the SIB Swiss Institute of Bioinformatics is responsible for running the SPHN Data Coordination Center (DCC) and the management of the BioMedIT Network.

### 2.2.1 DCC activities and achievements in 2023

#### **Data interoperability**

In 2023, the DCC with support of the network experts made significant progress in advancing the FAIR Swiss health data ecosystem. The 2023 releases encompass blueprints, templates, tools, and services dedicated to realizing FAIR research data and now incorporate diverse clinical concepts from domains such as cardiology, oncology, microbiology, and intensive care, providing a comprehensive perspective on patient data.

In addition, an omics layer has been added to the framework, introducing concepts for omics results, sample information and data processing. The introduction of the data file concept allows seamless linking of graph data with raw files from imaging (e.g. DICOM files) or genomic data (e.g. FASTQ files). Moreover, a set of data provenance concepts was integrated, enhancing researchers' confidence in the validity of the research data being provided. This collaborative effort extended beyond borders, involving German colleagues from the Medical Informatics Initiative (MII) and contributing to the MIRAPIE project of the University of Greifswald for defining minimal requirements in automated provenance information enrichment.

To offer an end-to-end service for researchers and data providers, the DCC team revised the existing tool stack and introduced new tools. The [SPHN Schema Scope](#) web service facilitates the navigation of the SPHN Schema, enabling researchers to interactively explore its connections. The [SPHN Schema Forge](#) web service empowers researchers to generate semantic artifacts from an Excel file in minutes. The DCC Terminology Service expanded its offerings with 10 new external terminologies, including the Orphanet Rare Disease Ontology (ORDO) and Genomic Epidemiology Ontology (GenEpiO). A versioning strategy for ATC, ICD-10-GM, and CHOP was implemented, facilitating data integration over time and across different terminology versions. Collaborating with the BioMedIT RDF Support Working Group, a Mock Data Generator was created for training, testing, and tool validation purposes.

The SPHN Federated Query System (FQS) remains routinely used by Swiss researchers. In addition to the existing five university hospitals, ETH, and universities of Bern, Zurich and Basel, the system is now available for the universities of Geneva, Lausanne, and EPFL, with the option for other interested academic institutions to join. In the course of the year 2023, the amount of available, fully anonymized health data in the system was expanded from 140 million to over 650 million data elements, highlighting a substantial effort to provide access to an ever-growing pool of valuable data resources. A lot of work has been put into quality improvements of the data loaded (e.g. regarding units, removal of negative values where not feasible). The system now houses data covering over 0.6 Mio patients from all five university hospitals and were queried by more than 200 different users, generating a total of 2000 queries and yielding valuable results. In 2023, the SPHN FQS industry collaboration pilot was successfully initiated, engaging selected users from Novartis, Roche, Bristol Myers Squibb, and Johnson & Johnson. The establishment and expansion of the FQS represents an important achievement for SPHN, as it enables researchers to query data to assess the feasibility of their planned research projects on a Switzerland-wide scale and across institutions, without compromising data privacy and security.

## **SPHN Connector**

To enable hospitals to generate medical knowledge graphs and produce valid RDF data, the DCC in joint leadership with University Hospital Zurich (USZ) provides services and a tool stack for the easy design, generation, and validation of RDF graph data from multiple sources. At its core, the SPHN Connector, an open-source pipeline tool, has been designed to facilitate the generation of de-identified graph data according to a well-defined RDF schema. On the basis of an SPHN-compliant RDF schema, an on-the-fly generation of the full pipeline and thus a versatile data handling is granted. This includes the generation of the ingestion interfaces in JSON, database, or CSV, the transformation to RDF, the SHACL queries for quality control, as well as the SPARQL queries for statistics. The SPHN Connector allows data providers to deliver data defined in the SPHN RDF Schema as well as additional data specifically needed for the individual projects. Integrated de-identification functions enable hospitals to replace internal patient IDs (which are considered sensitive information) with a pseudonymized project-specific ID. Additionally, all dates in the dataset are shifted by a random number within a defined range to minimize the risk of re-identification of an individual. The required external terminologies can be easily retrieved from the DCC Terminology Service, providing external national and international standards like SNOMED CT, LOINC, CHOP, and ATC in a compatible form. The SPHN Connector has been successfully deployed and used for data provisioning in the five university hospitals. The onboarding process of additional data providers is currently ongoing.

## **Ethical and legal support**

In 2023, the ELSI Helpdesk of the DCC, in close cooperation with SIB LTTO, further developed the SPHN legal agreement templates with a view to the reuse possibility by third parties, as required for the NDS. Multi-site consortium agreements with integrated Data Transfer and Use Agreements (DTUAs) have been set-up and negotiated for the NDSs and successfully signed by all participating parties. Further support was given for the 11 funded Demonstrator projects for which 9 contracts were set up, negotiated and successfully signed. In addition to the projects funded by SPHN, the ELSI Helpdesk advised several external projects that required data sharing with multiple parties and the creation or review of legal agreements.

To further streamline processes related to the contractual framework setup and data sharing approval for multi-site large scaling projects, the SPHN Data Governance Working Group was established and began its work in February 2023. The group consists of legal and governance board representatives of the main data providing and using institutions in Switzerland. Four work packages were created based on identified topics of most important relevance and interest that concern the further development of the legal agreement templates, open data and open access requirements, expanding the contractual framework for further collaborations with private partners and investigating the requirements and practice for using health data for non-research purposes.

A revision process for the guidelines of how to de-identify data in compliance with Swiss legislation and data protection regulations has been initiated in close collaboration with national experts from CHUV and USZ who were already part of the task force in 2022. Publication of the revised de-identification guidelines will be reviewed by numerous stakeholders and published in Q2 2024.

## **Genome of Switzerland (GoS)**

The GoS project is part of the Swiss Federated Genomics Network and mainly funded through PHRT. It aims to demonstrate the feasibility of recruiting biosamples for Whole Genome Sequencing (WGS), producing standardized genomic data and sharing data for research purposes in Switzerland. The project is a driving force for the development of infrastructure and processes to help advance genomic research in Switzerland, in alignment with efforts at the European level under the 1+MG program and the European Genomic Data Infrastructure (GDI) project. The added value of the project is therefore clearly of an infrastructural nature and



an investment in the future of targeted and efficient genomic research in this country and should not be evaluated in terms of direct benefits for the current research community - at least with regard to the GoS pilot phase.

The outcome of the GoS pilot is (i) a genomic reference dataset consisting of full human sequences and variant calls derived from 1'000 pseudonymized human samples (the “WGS reference dataset”) and (ii) first-line analysis, interpretation and a thorough description of this dataset. This pilot is intended to lay the foundation for a later scale-up, in which – given additional funding can be recruited – up to 15,000 samples will be sequenced and a multi-omics project part will be realized, thus creating direct added value for the research community. During 2023, a comprehensive project plan for the GoS was developed and presented to the PHRT Board in early 2024. The Swiss Biobanking Platform (SBP) launched a call for biobanks and conducted a thorough assessment for potential sample recruitment, resulting in the inclusion of 1,000 samples from the CHUV biobank in the pilot project. Additional clarifications with the ethics committee of the Canton of Vaud were necessary to allow the samples to be used for the pilot. An initial draft of a consortium agreement for the cooperation partners was drawn up by the SIB legal team and the preparatory work for submitting the application to the ethics committee was completed. The pilot project is to be carried out during 2024 and completed in 2025.

### 2.2.2 BioMedIT Network activities and achievements in 2023

#### **BioMedIT services**

Connecting researchers from across Switzerland with biomedical data to foster personalized health: this is the aim of the national secure computing network BioMedIT, operated by the SIB Swiss Institute of Bioinformatics in close collaboration with ETH Zurich, the University of Basel and the University of Lausanne.

The main focus of work at the central BioMedIT level in 2023 was the successful onboarding of the NDS and the Demonstrator projects into the BioMedIT network. As part of this integration, new cantonal hospitals and private clinics were also included so that these institutions can securely provide personalized health data to researchers in Switzerland accessing the BioMedIT platform. During 2023, the BioMedIT central team, together with the BioMedIT security officers, revised the existing BioMedIT information security policy and created an updated version that takes into account the latest security threats and the state-of-the-art security controls required to mitigate these threats.

The central team also worked with the BioMedIT nodes to develop strategic roadmaps for advanced interoperability, IT security, core technical infrastructure and service management across the network to ensure that nationally funded, secure BioMedIT IT services for data-driven, biomedical research projects are delivered at scale to SPHN and PHRT funded projects. In addition, the central team was dedicated to the development, operation and first-line support for central BioMedIT services such as secure data transfer (using sett, the secure encryption and transfer tool), the network's central entry point and one-stop shop - the BioMedIT portal - and related services such as the DCC container registry, DCC terminology services, FQS registration, central monitoring and others. Another important milestone in 2023 was the consolidation of BioMedIT documentation (SOPs, WIs, GLs and user manuals) on the new documentation platform. BioMedIT information security training, which provides BioMedIT users with an awareness of data protection, relevant legislation and information security, was also migrated to Adam's more advanced, user-friendly and GDPR-compliant training platform (hosted by the University of Basel).

The core technical infrastructure at the nodes was further developed to provide users with a flexible platform configured to meet the computing needs of researchers. By the end of 2023, the three nodes had 5.3 PB of secure storage and more than 9000 CPUs and 400 GPUs available for research projects. A selected portfolio

of interoperable software and analysis tools was implemented, as well as workflow systems that enable researchers to manage their projects independently and perform scientific tasks. In addition to technical and operational support, BioMedIT further developed the scientific user support portfolio to support projects in terms of active and FAIR data management, semantic web technology and the customization of their data schema to project needs.

As part of the DCC, the BioMedIT central team was also involved in advising and supporting new collaborations that are being set up in the French-speaking part of Switzerland (UNIL, SIB, SWITCH, SDSC & CHUV), in the Bern (UniBE, Inselspital, SWITCH) and on the Balgrist campus to establish local secure platforms for processing sensitive data.

In the area of international collaboration, the ARGOS project, in which the University Hospitals of Basel (USB), Zurich (USZ) and sciCOREmed at the University of Basel form the Swiss hub of the international Personal Health Train, was successfully completed in 2023. As part of this project, a neural network was trained at more than 20 locations worldwide using deep learning to automatically segment CT scans of lung cancer. The Personal Health Train developed as part of this project enables healthcare innovators and researchers to work with distributed health data from different sources using federated learning techniques. In addition, international collaboration was further expanded with ELIXIR, EOSC, 1+MG and GA4GH, among others.

At the end of 2023, over 46 national and international health-related research projects were running on the platform and over 843 users were registered in the portal. In addition, a total of 30 Swiss data providers and 1 international data provider have been onboarded to the network.

### **Swiss federated EGA (European Phenome-Genome Archive)**

This project entails a repository and associated services for genomic data so that genomic data can be reused in a federated approach and their metadata can be found over the international EGA catalogue. The SIB/Vital-IT has been mandated to run and manage a PoC (proof of concept) project collaborating with other Swiss institutions to assess the challenges and capabilities in Switzerland in order to develop and deploy a Swiss FEGA infrastructure.

This PoC project was kicked off in June 2023, focusing on several axes:

- Learning from other FEGA nodes and their implementation. Over 7 local FEGA nodes (Finland, Norway, Germany, Spain, Portugal, Estonia and Poland) as well as the 2 Central EGA (Spain & UK) have been engaged remotely to gather their experience and challenges. 2 on site workshops in Helsinki (Finland) and Barcelona (Spain) partly funded by Elixir offered hands-on experience to our collaborators.
- Assessing the technical requirements for a Minimum Viable Product (MVP) based on currently available software and the need for further development.
- Assessing the needs of the Swiss user community through direct interviews, both as data submitters and as data requesters, in order to gather their expectations and accommodate their requirements in future developments.
- Finally, investigating the legal requirements under Swiss law and the potential governance framework most appropriate to run the infrastructure.

The PoC work brought in experts and professionals from several partners working together from September 2023 to May 2024. A summary report is expected by mid-May 2024, proposing a way forward to the end of 2024 and covering 2025, that will be assessed by the BioMedIT Board before the end of May 2025.



## 2.3 National and international collaboration

### 2.3.1 National collaboration

In view of the planned consolidation during 2025-2028 of the SPHN data infrastructures into a national competence and coordination center of health data, the interfaces of the SPHN-DCC with its main stakeholders—in particular unimedsuisse, swissuniversities, the ORD Strategy Council and the ETH domain—were in the focus of 2023.

#### **Unimedsuisse and university hospitals**

Also in 2023, SPHN leadership met bilaterally with the CEOs and CMOs of the five university hospitals for informal 'Friendly Talks'. Besides discussing the particular strengths, opportunities, but also gaps of the UH within the SPHN network, these meetings focused on the questions of sustainability of the central and local infrastructures and services developed in the context of the SPHN initiative. There was unanimous agreement about the importance of continuing and stabilizing the national health data infrastructure established through SPHN. However, all hospitals are currently under great financial constraints in the aftermath of the Covid-19 pandemic. Unimedsuisse has been providing a platform for exchange and negotiation between SPHN and the university hospitals for the present and future collaboration. The Collège des Doyens of the medical faculties has also been getting more closely involved in the discussions about the future SPHN-DCC.

#### **ETH Domain (PHRT and SDSC)**

Throughout the years, the ETH Strategic Focus Area "Personalized Health and Related Technologies" (PHRT) has been the primary partner of SPHN in advancing personalized health research in Switzerland. In 2023, two joint programs were in the focus: Firstly, the four co-funded NDS were jointly guided and monitored by SPHN and PHRT through regular meetings with the principal investigators and project managers. A joint mini-symposium in September 2023 further included our national and international advisors and patient advocates. Secondly, the Genome of Switzerland project has been jointly advanced by PHRT and SPHN. Another strategic focus area of the ETH Domain, the Swiss Data Science Center (SDSC) is closely involved in the NDS "LUCID" supporting this data stream with data science expertise. SDSC thereby leverages the FAIR data infrastructures and services of SPHN and the of the PHRT Swiss Molecular Omics Center (SMOC), paving the way for future collaborations.

#### **Coordination Platform Clinical Research (CPCR)**

SPHN is a member of the CPCR and has been actively contributing to the work package on mapping and aligning the mandates of the various national research support organizations. A detailed description of the services and infrastructures of SPHN has been assembled and can now be used to identify synergies, potential for collaboration and areas in need for coordination between SPHN and partners like SCTO, SAKK and SBP.

#### **National Open Research Data (ORD) strategy**

The national ORD Strategy Council (StraCo) further strengthened its efforts to develop a coherent national strategy for Open Research Data based on the FAIR principles. In 2023, it extended its Task Force Health and Life Sciences to perform a landscape analysis of the Swiss health and life sciences cluster as a basis to address the technical, legislative, coordination, and support needs for health data towards strategic solutions and impactful outcomes. SPHN has been providing input and feedback to the task force which published its final [report](#) in February 2024, recognizing SPHN's efforts for functional interfaces and cross-coordination between data producers and implementors.

SPHN furthermore participated in the new Sounding Board of ORD Service Providers, established to facilitate the deliberations and decisions of the StraCo. The Sounding Board provides expertise and brings together specialists from service providers involved in the operational implementation and provision of ORD services.

### **Federal Office of Public Health, Federal Statistics Office, DigiSanté**

The federal government has recognized the need for accelerating the digital transformation of the healthcare system in Switzerland and the respective data management processes. In this context, Prof. Urs Frey, President of the SPHN National Steering Board, was invited to give an input presentation at the 'Beiratstreffen Digitalisierung Gesundheitswesen' in August 2023 led by Federal Councillor Alain Berset. In November 2023, the Federal Council approved the 'DigiSanté' program to promote the digital transformation of the healthcare system over the coming 10 years and requested a corresponding commitment credit (Verpflichtungskredit) of CHF 392 million.

Since 2022, SPHN has been contributing a research-oriented perspective to the FOPH Expert Group Data Management ("Fachgruppe Datenmanagement / "groupe spécialisée gestion des données") and several of its working groups. This expert group aims to develop and implement national standards for the exchange of data in the healthcare sector. SPHN is committed to explore synergies with DigiSanté and is willing to share its expertise on data interoperability, infrastructures and sharing for further use.

As a trusted partner, SPHN has been further consulted to provide feedback on the revision of the Electronic Patient Record Act. A major novelty in the revised law is that EPD data will also be made accessible for research, if people consent.

The goals of SPHN are well aligned with the national strategies of FOPH, FSO and the Federal Chancellery. Important issues for collaboration include:

- Once-only principle: the same data standards should be applied in care, research, quality assurance and also aligned with data of registries and the Electronic Patient Dossier
- Regulatory challenges: need for a unique patient identifier, need for a national trust center for data linkage, need for an electronic dynamic consent management
- Sustainability: financing models need to be developed that reward adherence to national standards and data reuse; large up-front investments are needed to establish interoperability

### **Industry collaboration**

In the SPHN Guidelines for the Ethical Sharing of Health Data in Public-Private Partnerships, SPHN calls on partners and projects to share routinely collected health data made accessible through SPHN with other organizations and especially encourages collaboration between private and public entities. This includes further academic partners but also non-academic and private partner, such as industry partners. To enable such projects, a contractual framework with data providing Institutions, private partners and the SPHN Data Coordination Center, Swiss Institute of Bioinformatics (SIB) was developed, the Private Public (P2) Collaboration program. A first pilot project under this new framework is planned for 2024.

### **Patient and Public Involvement (PPI)**

The active engagement of patients is an integral part of the four NDS projects. Each NDS reached out to patient organizations and communities and involves patient advocates in their activities. The NDS monitoring boards also include patient experts and accompany and evaluate the NDS consortia on patient-related aspects. Since 2022, SPHN is an active member of the PPI Working Group launched by the SCTO. This

working group aims to share information on PPI activities and lessons learnt among the network partners and to support and strengthen PPI in clinical research.

### 2.3.2 International collaboration

In June 2023, SPHN was invited by the German Medical Informatics Initiative (MII) to participate in a joined workshop in Berlin including the three national initiatives for health data infrastructures from Germany, Switzerland and the Netherlands. Representatives from MII, SPHN and Health-RI discussed the current status of infrastructure development in the three countries in various workshop sessions and addressed similarities and differences. The topics of consent, interoperability, data sharing, legal framework, financing and follow-up were discussed. Furthermore, the challenges and perspectives of a common European Health Data Space (EHDS) were presented by Licínio Kustra Mano, advisor for the EHDS at the EU Commission.

Since 2017, SPHN is a member of the International Consortium for Personalized Medicine (ICPerMed) and participates in the Executive Committee meetings that take place twice per year. In 2023, SPHN continued its membership in the ICPerMed Working Group on Personalized Medicine in Healthcare. In 2023, the Working Group conducted a study on "Challenges, Opportunities, and Facilitators in Implementing Personalised Medicine" that outlines strategies for integrating personalised medicine into healthcare systems, aiming to improve health outcomes and create sustainable healthcare systems through research, development, innovation, and implementation. Several experts from the SPHN network provided input on the infrastructural aspects of implementing personalized medicine into healthcare. The outcomes of the study are summarized in the ICPerMed publication entitled "Challenges, Opportunities and Facilitators in Implementing Personalized Medicine".

SPHN further continued to participate in the regular meetings of the Dutch-Swiss Collaboration on Health Data, the European Open Science Cloud (EOSC) Swiss Taskforce Exchange Group, the Beyond 1 Million Genomes Initiative (B1MG), and other national and international groups.

## 2.4 Events & Communications

### Communications

Based on the “Future SPHN-DCC report” that was elaborated in the course of 2022 and submitted to SERI at the of 2022, the Management Office (MO) together with the Swiss Academy of Medical Sciences (SAMS), published in 2023 the Swiss Academies Communications entitled “The SPHN Data Coordination Center: Consolidating the SPHN infrastructures beyond 2024”. This publication shows how the continuation of the SPHN Data Coordination Center (SPHN-DCC) can be ensured beyond 2024, including the non-central support structures at the university hospitals and universities. The report summarizes the expectations and needs of the Swiss research community regarding the activities of the SPHN-DCC and describes the technical, organizational and financial requirements that the future network should meet to enable the responsible use of health-related data in research. Special attention is paid to the numerous interfaces with partners from research, health care and administration, as well as to the context of the evolving Swiss research landscape. This includes the national Open Research Data Strategy, efforts to create a national health data space by the federal government and the cantons, and coordination with other national research organizations. The careful embedding of the SPHN-DCC in this dynamic landscape is of great importance for the future of Switzerland as a research location.

In 2023, the SPHN-DCC together with the MO developed a new Factsheet 2023. While the 2022 edition focused on the various tools, services and resources that SPHN offers to the research community in the field of data-driven and personalized health, the new factsheet illustrates the important hub function of the SPHN-DCC in the evolving Swiss health data space. It also highlights the various SPHN key elements that have been established over the past years to make health-related data FAIR and usable for Swiss research and beyond. The factsheet further outlines the baseline situation of health data management in Switzerland, as well as the challenges and hurdles associated with the primary and secondary use of these data.

SPHN communicates continuously via its website ([www.sphn.ch](http://www.sphn.ch); available in English, French, and German), and social media (Twitter and LinkedIn). SPHN articles have also appeared in several SAMS newsletters and the SAMS Bulletin. Four SPHN Technical Newsletter were published to update the community on news, developments and technical details in SPHN, the DCC and BioMedIT.

The Schweizerische Ärztezeitung (SAEZ) and Swiss Medical Forum further published a series of articles (in German and French) dedicated to the developments of personalized medicine in Switzerland. In this series, several articles featured representatives of SPHN and project PIs and provided valuable information on SPHN’s efforts to harness health data from routine care for research purposes and further secondary use.

Finally, SPHN was invited for a contribution to the Health Terminal Podcast ([www.healthinal.com](http://www.healthinal.com)). The podcast provides relevant information on the digitalization of the healthcare system and informs about tools, developments and visions through interviews with relevant stakeholders.

After the conclusion of the webinar series with international experts focusing on topics relevant to the SPHN community, the DCC launched the hospital IT webinar series. In these webinars, representatives from the IT Departments of the five university hospitals, presented the progress made within their hospital IT department thanks to the support of SPHN. The Webinars, along with training developed by the DCC are available on the SPHN YouTube channel, which amassed 9925 unique views in 2023, with a total of 999.6 hours of content viewed. The most watched video on the channel in 2023 was “Validate Graph Data with SHACL”, a training video delivered by PHI’s Data Interoperability team first published in 2021, which was viewed 1496 times in 2023.

In 2023 the DCC produced 2 new training modules, also available on the SPHN YouTube channel and in the international Elixir TeSS training catalogue:

- FAIRification of Terminologies
- How to fill the Dataset Templates

Further, members of the SPHN-DCC contributed to the following further educations courses: CAS Modern concepts in clinical research, Real World Data, ETH Zurich; CAS Ethics and Legal in Clinical Trials, EPCM, University of Basel; CAS Healthcare Management, University of Bern; CAS in Health Systems Governance, Unisanté; Health Data and AI: Responsible Innovations, Ethics and Regulatory Strategies, ETH.

## Events

In January 2023, the MO presented at the 'Smart Break' organized by the Swiss Academies of Sciences on Open Research Data, with a focus on SPHN's framework for responsible secondary use of health data. Additionally, in May 2023, SPHN was featured at the PHRT Edu Community Retreat in Thun, specifically for PhDs and postdocs from the PHRT community.

In September 2023, SPHN and PHRT held an NDS mini-symposium in Lausanne, in conjunction with the annual SPHN International Advisory Board (IAB) review meeting. The event featured overview presentations from the four NDS and provided a platform for members of the IAB, the NDS and Demonstrator consortia to exchange on common gaps and hurdles and to explore synergies for further collaboration. Over 70 participants joined the meeting which received overall very positive feedback. The IAB further summarized its impression on the overall progress of the initiative in the IAB report 2023 published on the SPHN website.

Finally, SPHN was invited to discuss how the digital transformation of healthcare in Switzerland can be made a success, in the frame of the "Science et Politique à table!" event for members of Parliament, organized by the Swiss Academies of Arts and Sciences in December 2023. Short input presentations by Prof. Torsten Schwede (University of Basel), Prof. Murielle Bochud (Unisanté) and Prof. Urs Frey (University Children's Hospital Basel), complemented with expert opinions by Prof. Beatrice Beck Schimmer (University of Zurich), Prof. Manuela Eicher (University of Lausanne) and Prof. Catherine Jutzeler (ETH Zurich) were discussed with interested members of Parliament.

SPHN was also represented by members of the SIB PHI Group and the SPHN MO at a number of national and international events and conferences (selection):

- SWAT4HCLS, Basel, CH
- SCTO Forum, Bern, CH
- A+ Smart Break, Bern, CH
- EOSC National Event Switzerland, Bern, CH
- DACH Healthcare Innovation Summit, München, Germany
- UK Deep Tech Delegation, Bern, CH
- NRP 75 Workshop, Bern, CH
- Generalversammlung Schweizerische Gesellschaft für Biomedizinische Ethik, Bern, CH
- Swiss Medical Student Convention, Bern, CH
- PHRT edu community retreat, Thun, CH
- LSZ Impact conference, Zurich, CH
- Joint workshop SPHN – Health RI – MII, Berlin, Germany
- Beiratstreffen Digitalisierung Gesundheitswesen, Bern, CH
- NDS mini-symposium, Lausanne, CH
- [BC]2 conference 2023, Basel, CH

- World of Data 2023, Basel, CH
- 1st National Symposium on Data-Driven Approaches in Sepsis and Infectiology: "From Bits to Breakthroughs", Bern, CH
- Swiss Public Health Conference, Lausanne, CH
- Data Science Speaker series, Toronto, Canada
- Life science cluster, HKBB, Basel, CH
- Miracum DIFUTURE symposium, Erlangen, Germany
- Scientifica 2023, Zürich, CH
- 16<sup>th</sup> Annual International Biocuration Conference, Padua, Italy
- Swissnex Day 2023, Lugano, CH
- Sidley/ISS/SwissMedtech Life Sciences Event, Bern, CH
- Science et Politique à table!, Bern, CH
- FORS Workshop on safe access to sensitive research data, CH
- Annual SASRO Meeting, Bern
- SGMI ehealth summit, Aarau, CH
- Second Data ethics Multiplier Event, Eurolife, Strasbourg
- Bits to breakthroughs Symposium on Data-driven Approaches in Sepsis and Infectiology, Bern, CH
- Intelligent Health Conference, Basel CH
- Life Science Cluster, Basel CH
- Oncosuisse network event "Research", Bern CH



### 3 Finance

Table 1 provides a summary of how the funds allocated by the SERI were used so far.

During the year 2023, first instalments were released for the Demonstrator projects. Conversely, several projects ended this year: The Driver and Infrastructure Development projects (from the Call 2018), the MedCo pilots and HospFAIR Phase 1. For most of these projects, final payments were released, whereas for those which ended later in the year, the corresponding funds will be released at the beginning of 2024. For HospFAIR Phase 1, the NSB approved to transfer part of the unused funds from Phase 1 to Phase 2, which started in April and thus first instalments were paid. As for the Collaboration Agreements with university hospitals and the National Data Streams, funds have been released according to the planned payment schedule.

The major part of the payments in 2023 related to projects were deducted from provisions made in previous years and approved by the SERI. As some of the provisions had been placed on the Swiss money market, the interests have positive influence on the management costs.

Since 2021, the expenses of the Data Coordination Center are no longer reported under Infrastructure Implementation projects, but separately (Table 2).

Table 1: 2017-2023 SERI funds usage

### 2017-2023 SERI funds usage

All amounts in kCHF

Accounts description	Cash flow				TOTAL
	2017-2020	2021	2022	2023	
<b>INCOMES</b>					
SERI Contribution - SAMS	30'000	7'332	7'353	7'404	<b>52'088</b>
SERI Contribution - SIB	19'702	2'907	2'915	2'935	<b>28'459</b>
<b>TOTAL INCOMES</b>	<b>49'702</b>	<b>10'238</b>	<b>10'268</b>	<b>10'339</b>	<b>80'547</b>
<b>EXPENSES</b>					
<b>Infrastructure implementation projects</b>					
ELSI support staff	260	100			<b>360</b>
Reimbursement unused funds			-25		<b>-25</b>
Data Coordination Center	2'822				<b>2'822</b>
Collaboration agreements with University Hospitals	12'750	4'850	7'400	3'000	<b>28'000</b>
HospFAIR			1'150	1'207	<b>2'357</b>
Other projects (MedCo Pilot, GoS)			380	231	<b>611</b>
<b>Projects : call 2017</b>					
Infrastructure development projects	2'290	14	7		<b>2'311</b>
Driver projects	11'000	871	459	638	<b>12'968</b>
Reimbursement unused funds	-150	-4			<b>-153</b>
<b>Projects : call 2018</b>					
Infrastructure development projects	1'842	231	81		<b>2'153</b>
Driver projects	5'213	471	453	498	<b>6'635</b>
Reimbursement unused funds				-161	<b>-161</b>
<b>National Data Streams</b>		75	908	2'194	<b>3'177</b>
Reimbursement unused funds			-7	-3	<b>-10</b>
<b>Demonstrator Projects</b>				2'420	<b>2'420</b>
<b>Cash flow Management Office and Bodies*</b>	2'354	731	762	635	<b>4'483</b>
<b>TOTAL EXPENSES</b>	<b>38'382</b>	<b>7'339</b>	<b>11'567</b>	<b>10'660</b>	<b>67'949</b>
<b>Cash available end of year</b>	<b>11'321</b>	<b>14'219</b>	<b>12'920</b>	<b>12'599</b>	<b>12'599</b>

\*incl. financial result (bank fees, interests)

Table 2: Data Coordination Center cash-flow statement 2017-2023

## Data Coordination Center : Cash flow 2017-2023

All amounts in kCHF

Accounts description	Cash flow				TOTAL
	2017-2020	2021	2022	2023	
<b>INCOMES</b>					
SPHN contributions	2'822				<b>2'822</b>
SERI contributions		1'715	1'720	1'732	<b>5'167</b>
Various incomes	28	03	16	39	<b>87</b>
<b>TOTAL INCOMES</b>	<b>2'850</b>	<b>1'718</b>	<b>1'736</b>	<b>1'771</b>	<b>8'076</b>
<b>EXPENSES</b>					
<b>PHI Projects portofolio</b>					
Implementation RDF	31	158	236	314	<b>739</b>
De-Identification project	32	41	03	0	<b>75</b>
<b>SPHN Project Portfolio covered by PHI*</b>					
Federated Query System	112	262	124	133	<b>632</b>
SPHN Connector			483	855	<b>1'339</b>
MedCo			295	59	<b>354</b>
HospFAIR			27	89	<b>116</b>
Maelstrom			21	42	<b>63</b>
SPHN IT Architecture		43	79	59	<b>180</b>
NDS support on the nodes				269	<b>269</b>
<b>Consultancy costs</b>					
other consultancy costs	144	43	07	145	<b>339</b>
<b>Personnel costs</b>	<b>1'903</b>	<b>831</b>	<b>1'004</b>	<b>1'251</b>	<b>4'989</b>
<b>Operating costs</b>	<b>463</b>	<b>131</b>	<b>132</b>	<b>177</b>	<b>902</b>
<b>TOTAL EXPENSES</b>	<b>2'685</b>	<b>1'508</b>	<b>2'410</b>	<b>3'393</b>	<b>9'997</b>
<b>Cash available end of year</b>	<b>166</b>	<b>375</b>	<b>-299</b>	<b>-1'920</b>	<b>-1'920</b>

\*Since the DCC has taken over additional mandates and implementation tasks on behalf of SPHN, the Leistungsvereinbarung shall be amended and respective funds be re-categorized to the DCC budget.

Table 3 shows an overview of the usage of funds allocated to the BioMedIT Network during the 2017-2023 period. As not all the allocated funds will be used until the end of the initiative in 2024, it is planned to carry over 5.2 Mio of BioMedIT funds to SPHN projects in accordance with the Leistungsvereinbarung.

**Table 3: BioMedIT Network SERI funds usage 2017-2023**

**BioMedIT Network project: SERI funds usage**

All amounts in kCHF

Accounts description	Cash flow				TOTAL
	2017-2020	2021	2022	2023	
<b>INCOMES</b>					
SERI Contribution - SIB BioMedIT Network	17'732	4'592	4'606	4'639	<b>31'569</b>
Other incomes		20	09	08	<b>37</b>
<b>TOTAL INCOMES</b>	<b>17'732</b>	<b>4'612</b>	<b>4'615</b>	<b>4'647</b>	<b>31'606</b>
<b>EXPENSES</b>					
<b>Node funding</b>					
SIB / Core-IT/SENSA	1'400	606	394	297	<b>2'697</b>
ETHZ / SIS	700	300	500	333	<b>1'833</b>
Unibas /sciCORE	700	307	327	395	<b>1'729</b>
Addition support node security MS	340	71	0		<b>411</b>
Node security officers		382	346	461	<b>1'188</b>
<b>Interoperability WG</b>					
SIB / Vital-IT	450	-34	147	141	<b>705</b>
ETHZ / SIS	450	69	0	179	<b>699</b>
Unibas /sciCORE	450	100	150	150	<b>850</b>
<b>PHRT Platforms</b>					
Mass Spectrometric P. in Zurich	900				<b>900</b>
Genome Center in Geneva	525	375	0		<b>900</b>
<b>Projects funded</b>					
SVIP O	949				<b>949</b>
Driver project GA4CH - M.Baudis	125				<b>125</b>
RDF / Data management		142	180	424	<b>746</b>
Methodology Development		05	07	43	<b>55</b>
IDEAL project	500				<b>500</b>
FEGA project					<b>0</b>
<b>Personnel, consultancy and operating costs</b>	<b>2'678</b>	<b>1'555</b>	<b>1'385</b>	<b>1'702</b>	<b>7'319</b>
<b>TOTAL EXPENSES</b>	<b>10'167</b>	<b>3'879</b>	<b>3'435</b>	<b>4'125</b>	<b>21'606</b>
<b>Cash available end of year</b>	<b>7'566</b>	<b>8'299</b>	<b>9'479</b>	<b>10'001</b>	<b>10'001</b>

The funds needed to pay the remaining amounts of the ongoing projects are currently remaining on the bank accounts of SPHN and will be distributed until 2025. As interests on the accounts are positive again, the financial result is much better than in 2022.

Table 4 shows the cash flow statement 2023 of the Management Office compared with 2022. The main costs of the Management Office were salaries and working groups (remuneration of board members). The funds needed to pay the remaining amounts of the ongoing projects are currently remaining on the bank accounts of SPHN and will be distributed until 2025. As interests on the accounts are positive again, the financial result is much better than in 2022.

Table 4: Cash flow statement 2023 compared to 2022

<b>Cash flow statement (direct method)</b>	<b>2023 in CHF</b>	<b>2022 in CHF</b>
+ Cash received from SERI contribution - SAMS	7'403'700	7'352'900
+ Cash received from SERI contribution - SIB	2'935'250	2'915'154
<b>Total cash received from SERI contributions</b>	<b>10'338'950</b>	<b>10'268'054</b>
- Cash paid for Collaboration agreements	-3'000'000	-7'400'000
- Cash paid for HospFAIR	-1'206'984	-1'150'000
- Cash paid to Infrastructure dev. & Driver projects	-1'136'056	-998'935
+ Refund unused funds from finished Infrastructure dev. & Driver projects	160'720	0
- Cash paid to National Data Streams	-2'194'001	-996'367
+ Refund participation PHRT for National Data Streams applications	0	95'362
+ Refund unused funds NDS Application allowance	2'918	0
- Cash paid to Demonstrator Projects	-2'420'435	0
- Cash paid for other projects (MedCo Pilot, GoS)	-231'158	-380'000
+ Refund unused funds ELSI support staff	0	25'000
<b>Total cash paid for funding activities</b>	<b>-10'024'996</b>	<b>-10'804'940</b>
- Cash paid for personnel expenses	-492'343	-462'904
- Cash paid for operating expenses	-73'625	-91'850
- Cash paid related to activities of bodies and experts	-121'834	-157'483
<b>Total cash paid related to management expenses</b>	<b>-687'802</b>	<b>-712'237</b>
<b>Total financial result (bank fees, interests)</b>	<b>52'639</b>	<b>-50'214</b>
<b>Cash flow from operating activities</b>	<b>-321'209</b>	<b>-1'299'337</b>
<b>Net increase/decrease in cash</b>	<b>-321'209</b>	<b>-1'299'337</b>
Cash on 1.1	12'920'634	14'219'971
<b>Cash on 31.12</b>	<b>12'599'425</b>	<b>12'920'634</b>

## 4 Board Members

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*Swiss Clinical Trial Organisation, Guest*

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*Swiss Clinical Trial Organisation, Guest*

Dr. Christine Currat, Lausanne  
*Swiss Biobanking Platform, Guest*



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