Swiss Personalized Health Network (SPHN)

Annual report 2024

A project of

SAMW ASSM
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Académie Suisse des Sciences Médicales
Accademia Svizzera delle Scienze Mediche
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1 Executive Summary

During the last year of the initiative, SPHN focused on completing the ecosystem of data infrastructures created over the past eight years and on preparing for its new mandate 2025-2028 in view of the long-term goals. A highlight of 2024 was the “Data for Health” Symposium, jointly organized by SPHN and PHRT at the end of October in Bern, which brought together over 450 stakeholders from health research, hospitals, policymakers, and patients. The joint appearance of State Secretary Martina Hirayama from SERI and FOPH Director Anne Lévy underlined that research and care must go hand in hand and celebrated the achievements made by SPHN and PHRT. National alignment, coordination and collaboration are at the core of SPHN’s mission and will become even more important in the years ahead.

Important progress was made on all aspects of the initiative: the collaboration with university hospitals was expanded, with a focus on streamlining and maturing the infrastructures and processes in a sustainable way. As a proof-of-concept for SPHN’s scalability, five cantonal hospitals and SAKK started to onboard to the network and shall be technically capable of participating in future projects by the end of 2025. The SPHN- and PHRT-funded National Data Streams (NDS) began transferring and integrating data at scale, laying the groundwork for generating insights and research results from the data of hundreds of thousands of Swiss patients. In parallel, the SPHN Data Governance Working Group and the Data Coordination Center (DCC) further developed the data governance framework and adapted the respective legal agreement templates, with a strong focus on the re-use of health data for multi-site data-driven projects. Updated guidelines for de-identifying sensitive health data using a risk-based approach were also elaborated on, and published to support researchers, institutions and ethics committees. To facilitate collaboration with industry partners, a public-private collaboration framework was established and the first pilot project was launched in 2024.

Key to all these activities is the efficient mobilization of routine clinical data from hospitals, provided in an interoperable format to ensure seamless integration with data from other sources. To this end, the SPHN semantic interoperability framework and respective toolstack were enhanced enabling the university hospitals to process billions of data elements from over 700’000 Swiss patients who have consented to the further use of their data for research. To facilitate the exploration of these data assets by researchers, the SPHN Data Exploration and Analysis System (DEAS) project was launched in 2024 in collaboration with six university hospitals and the start-up Tune Insight. This system will complement the findability of health research data sets registered in the new SPHN Meta Data Catalog, which was established in 2024.

Additionally, the BioMedIT federated Trusted Research Environment (TRE) continued to optimize its information security policy and infrastructure, connecting 35 data providers with over 62 national, regional, and international health-related research projects, and more than 1000 users registered on the portal. A white paper published in October 2024 highlights the importance of versatile TREs for health research and discusses the complexities and challenges of providing safe but collaborative data processing environments for sensitive data. As an extension of the BioMedIT network and complementary to the SPHN Metadata Catalog, the buildup of the Swiss Federated European Genome-Phenome Archive (FEGA) node began in earnest in 2024. A consortium comprising SIB, SIS ETH Zurich, the Swiss Data Science Center, Switch, the Health 2030 Genome Center and ETHZ Nexus presented a successful end-to-end demonstrator in December 2024. This is a prerequisite for joining the FEGA network and establishing an operative Swiss genomic data repository by the end of 2025. The first project to deposit whole genome sequence data in the Swiss FEGA will be the Genome of Switzerland (GoS) pilot project. With an adapted project organization

under the leadership of Prof. Didier Trono (EPFL), the complexity of the ongoing pilot project was reduced and more than 400 samples from the CHUV biobank were sequenced by the Health 2030 Genome Center at the end of 2024. PHRT is the primary funder of the GoS pilot, with additional support from SPHN. In view of the future reuse of genomic data from the GoS and other projects, the SPHN ELSI Advisory Group developed a guidance document on ELSI challenges for the further use of genomic data, which was published at the beginning of 2025.

A visit by SPHN leadership to the new Federal Councilor Elisabeth Baume-Schneider in August 2024 highlighted the critical alignment between the DigiSanté program, focused on the digital transformation of the Swiss health system, and SPHN as a national data infrastructure for personalized health research. It was jointly recognized that data standards, infrastructures, and data governance processes must be well coordinated and aligned between healthcare and research to maximize value and avoid unsustainable duplication of efforts. SPHN therefore continued to be actively involved in DigiSanté-related working groups and the FOPH and FSO will be invited to join the new SPHN Steering Board for 2025-2028. SPHN also engaged further in the national Open Research Data (ORD) activities, participating in a national workshop of the health and life science cluster and as a member of the ORD Sounding Board of Service Providers.

Finally, much of 2024 was devoted to initiating the organizational changes needed for SPHN's new mandate in the coming years. With the departures of Dr. Katrin Crameri as the head of the Data Coordination Center, and Prof. Urs Frey as chairman of the SPHN National Steering Board, SPHN lost two prominent leaders and key drivers. Going forward, Prof. Matthias Baumgartner will lead the SPHN network in close collaboration with Managing Director Dr. Thomas Geiger, Technical Director Dr. Davide Chiarugi, and the DCC team and SPHN partners, to support the Swiss health research community in the coming years. The Data Coordination Center will continue throughout 2025-2028 as a collaboration of SAMS and SIB, with a focused service portfolio that was presented to the national stakeholders at the SERI Roundtable in June 2024. The close cooperation with the university hospitals and BioMedIT nodes will continue to provide a robust backbone for the SPHN network in the coming years, paving the way for a long-term national health data research infrastructure that is closely embedded in the Swiss ORD landscape and learning healthcare system.

2 Activity report

2.1 Funding activities

Bottom-up funded projects

National Data Streams (NDS)

Co-funded by SPHN and PHRT with up to CHF 5 million per project, four NDS projects were launched in September 2022 in the disciplines 1) infectious diseases in intensive care, 2) oncology, 3) pediatrics, and 4) quality of care research. Each NDS comprises a Switzerland-wide multidisciplinary consortium that invests in the development of sustainable data infrastructures for high-end data-driven personalized health research. Unique is the requirement to enable third-party data reuse beyond the runtime of the project (i.e., from 2026 onwards).

The NDS have made progress throughout the project, such as regarding data deliveries from hospitals, lighthouse and nested research projects, contractual framework for third-party reuse, and Patient and Public Involvement and Engagement (PPIE) activities. Some projects have faced more hurdles than others. SPHN leadership has addressed with swissethics that the ethics approval processes for complex multinational projects need streamlining.

The NDS have presented their activities and conditions for long-term success to the audience of the SPHN & PHRT “Data for Health” event on 31 October. In addition, an NDS leadership meeting was organized on 12 September for the NDS consortia, HIT-STAG, SPHN MO and DCC and PHRT Office to clarify challenges in the complex multistakeholder collaborations. Lastly, an NDS-internal workshop was organized on 1 November, fostering collective problem-solving and exchange of learnings.

Demonstrator projects

The aim of the SPHN Demonstrator projects is 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. Launched in spring 2023, one project was completed in September 2024; the remaining 10 are extended until March 2025.

All Demonstrator project teams collaborate closely with the DCC and provide semi-yearly progress reports. One challenge identified is the request for new data concepts instead of reusing already established ones, which has posed an extra workload on the DCC and hospitals.

Infrastructure implementation projects

Collaboration agreements

As the Collaboration Agreements 2021-2024 with the five university hospitals (UHs) ended in June 2024, an extension was signed for the period 01.07.2024-31.12.2025, financed with unused funds from the period 2021-2024. The focused deliverables of the extension are preparing UHs for the next phase 2025-2028 to continue their activities. Alignment on milestones and deliverables between the UHs occurred monthly in the Hospital IT Strategy Alignment Group with leadership of the UH Clinical Data Platforms.

Phase II of the HospFAIR program was completed on 30 June 2024. The program has helped the five UHs to improve data quality, standardization, and extraction for secondary data use, demonstrating the value of SPHN-funded activities for the hospital systems at large.

SPHN Federated Query System

The SPHN Federated Query System (FQS) remained routinely used by Swiss researchers in 2024. In 2024 the system had over 220 active users, who made over 2000 feasibility queries. By the end of 2024 the data pool reached over 700'000 patients, who signed the general consent, with over 700 Mio data points. As our software partner discontinued the support and development of the software PNEx used for the FQS, the platform was discontinued on 1.12.2024. Together with the hospitals, we have worked on a pilot for the SPHN Data Exploration and Analysis System (DEAS), which will replace the FQS and provide more functionalities.

SPHN Data Exploration and Analysis System

In 2024, SPHN launched a pilot to replace the discontinued Federated Query System with the Data Exploration and Analysis System (DEAS). The new system is being developed by the EPFL spin-off Tune Insight (formerly MedCo). DEAS will allow authorized researchers to conduct feasibility studies, assessing whether sufficient generally consented data is available for a specific research question at the participating hospitals. Additionally, it supports explorative data analyses, such as value distributions and survival curves. The system is based on the SPHN Semantic Interoperability Framework to allow a seamless integration into the hospitals' infrastructure. Patients' privacy is ensured through multiple privacy preserving methods such as homomorphic encryption, secure multi-party computation and k-anonymity.

The participating hospitals are CHUV, HUG, Insel Group, USB, USZ, and University Children's Hospital Zurich (Kispi). At the end of 2024, all of them have installed the system and have started loading data from over 700'000 patients who signed the general consent.

The pilot, originally planned for 2024, has been cost-neutrally extended into 2025. In the contractual framework of DEAS, SAMS has joined the contract and is authorized to negotiate licensing conditions with Tune Insight. In 2025, the system will be further refined, and we will start the testing phase.

SPHN Connector

The SPHN Connector is an open-source tool that hospitals can install locally, enabling them to convert data in various formats into SPHN-compliant RDF data. In addition, hospitals can de-identify data and perform

quality checks with this tool. The SPHN Connector was developed by the DCC and University Hospital Zurich (USZ).

In 2024, interfaces were developed between the SPHN Connector and the data managing solution Einstein of DEAS. Furthermore, the tool was updated with no less than 10 releases, improving its performance to support SPHN and project-specific data and schemas and enhancing user experience with new features. This includes: two times faster validation, data migration between minor releases, backup and restore functions, and support for RDF Quads. The SPHN Connector now enables seamless and automated patient data loading into Einstein. It is widely adopted to transform and validate hospital data, not only by the five Swiss university hospitals but also by newly onboarded cantonal hospitals (see section on onboarding of cantonal hospital program). It is also installed by other initiatives such as the LOOP Zurich, where both the Balgrist University Hospital and Psychiatric University Hospital Zurich (PUK) used it. Additionally, researchers in National Data Stream projects process non-hospital data, including omics data, with the SPHN Connector.

Public-private collaboration: first industry pilot

The aim of the public-private collaboration program is to enable collaboration between private industry and public organizations in a scalable way. In the context of the first pilot, the DCC has acted as a service partner and will analyse data from two hospitals to answer a specific research question on behalf of an industry partner. No patient data will be shared with the industry partner, the partner will only receive aggregated results.

The contractual framework for the pilot was signed in 2024. It includes a Service Level Agreement between the industry partner and SIB (on behalf of SPHN), a Collaboration Agreement between the data-providing institutions, and a Data Transfer and Processing Agreement between SIB and BioMedIT. In parallel, the industry partner submitted a research question and developed an analysis plan with the DCC. The completion of the pilot is expected in the first half of 2025. Several more pharma companies have expressed interest in collaborating with SPHN. Further pilots and an extension of the data-providing network are planned for 2025.

Cantonal hospital onboarding program

To extend the network, SPHN launched a proof-of-principle infrastructure implementation project in 2024, onboarding additional data providers to SPHN. Data providers were selected based on their IT readiness and their involvement in ongoing SPHN/PHRT projects or other collaborations.

The project includes the cantonal hospitals of Ticino (EOC), Aarau (KSA), Baden (KSB), St.Gallen (KSSG), and Luzern (LUKS), and the Swiss Group for Clinical Cancer Research (“Schweizerische Arbeitsgesellschaft für Krebsforschung”, SAKK).

These institutions have worked on four work packages, including coding data coding to the data standards LOINC and SNOMED CT, setting up the SPHN/BioMedIT toolstack in the hospitals, and transferring a test dataset of 50 patients to a specific BioMedIT B-space for quality control purposes. To regulate the data sharing of personal data, a Data Transfer and Use Agreement was set up and signed with the EOC, KSA, LUKS and KSB in 2024. The program will be concluded in 2025.

2.2 Activities of the Data Coordination Center (DCC) & BioMedIT Network

Data Coordination Center activities in 2024

FAIR Data

In 2024, with support of the network experts, the FAIR Data Team made significant progress in advancing the FAIR Swiss health data ecosystem.

The **2024 release of the SPHN Semantic Interoperability Framework** includes blueprints, templates, tools, and services designed to enable FAIR research data. This release now also covers oncology, intensive care, and a set of omics concepts. Moreover, concepts related to data provenance now enable tracking data origins and transformation steps, such as semantic mappings. SPHN collaborated closely with eHealth Suisse and SNOMED CT international to introduce 50 new SNOMED CT codes, which have been incorporated into the international standard, and will be used in the 2025.1 release. The SPHN RDF Schema is also gaining international recognition and is being adopted by multiple consortia and projects beyond Switzerland, e.g., AIDAVA, Semantifying Genomic Variant Data, and NeuroVasc.

The **SPHN Schema Forge** web service empowers researchers to generate semantic artifacts from an Excel file in minutes. In 2024, this tool was further improved based on user feedback to enhance performance, maintainability and user experience.

The **DCC Terminology Service** expanded its offerings with two **new external terminologies**, including the International Classification of Diseases for Oncology (ICD-O3) and OncoTree. Additionally, improvements in version comparison for ATC, CHOP, and ICD-10-GM codes resulted in a more refined historized file, reducing the number of false positives.

Collaborating with the BioMedIT RDF Support Working Group, the **SPHN Mocker** was further developed to generate mock data for training, testing, and tool validation purposes. Its code is open-source, so it can be freely used by the community.

To improve the visibility of the datasets produced in the realm of SPHN, the **SPHN Metadata Catalog** was published online, hosting descriptive metadata of NDS and DEM projects on a FAIR data point, as well as visualizations of the corresponding project schemas in the **SPHN Schema Scope**.

The FAIR Data Team played a key role in operating FQS, developing DEAS, managing the cantonal hospital onboarding program and enhancing the SPHN Connector, as outlined in section 2.1 on Funding Activities.

Ethical, and legal support services

In 2024, the ELSI Helpdesk of the DCC, in close cooperation with the SIB Legal and Technology Transfer Office, further developed the SPHN legal agreement templates with a view to the reuse possibility by third parties, as required for the NDS. A fully revised version based on the feedback of Data Governance Working Group members was published. Multi-site consortium agreements with integrated Data Transfer and Use Agreements (DTUAs) have been set-up and negotiated for the NDSs and their Nested Projects and successfully signed by all participating parties. Further support was given for continuing SPHN funded

projects. In addition, the ELSI Helpdesk advised several external projects that required assistance for governance related issues or data sharing with multiple parties.

Data Governance Frameworks

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 continued its work in 2024. A comprehensive data de-identification guidance on how to de-identify data in compliance with Swiss legislation and data protection regulations was revised and published in close collaboration with national experts from CHUV and USZ who were already part of the task force in 2022. This template provides hands-on guidance for assessing the re-identification risk and documenting the process of de-identification as requested in the revised Human Research Ordinance.

A Registry Regulation Template was developed through the initiative of swissethics and the combined expertise of several key partners. The purpose of this template is to serve as guidance for the creation and management of health-related registries. The template provides a comprehensive framework addressing key aspects like purpose, governance, data access protocols, and quality management systems, ensuring compliance with ethical principles.

Genome of Switzerland (GoS)

The GoS project is part of the Swiss Federated Genomics Network and mainly funded through PHRT, in collaboration with SPHN. 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 current pilot project 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 is foreseen, thus creating direct added value for the research community.

In spring 2024, the PHRT Executive Committee and the SPHN NSB approved an adapted project organization to reduce complexity and clarify roles in this, so far, slowly progressing project. EPFL offered to take on the Sponsor role with Prof. Didier Trono as the main PI for the GoS Pilot project. The DCC offered to continue supporting the project regarding ethics application, contractual frameworks and information to patients. The approval from the cantonal ethics committee Vaud was received in summer 2024 and all necessary contracts were signed. By the end of 2024/early 2025, all 1000 samples from the CHUV biobank were received and an initial set of 440 samples were sequenced and preliminarily analysed. Sequencing shall be completed by summer 2025 for first-line analysis and the data will be stored in the new Swiss FEGA repository. The GoS pilot project is scheduled to be completed by the end of 2025 and the project team is actively pursuing options to realize the subsequent scale-up for the full GoS.

BioMedIT Network activities and achievements in 2024

BioMedIT services

Connecting researchers from across Switzerland with biomedical data to foster personalized health: this is the aim of the national Trusted Research Environment (TRE) 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 focus of work of the central team in 2024 was the successful **operational support** for the ongoing SPHN funded projects (including NDS and the Demonstrator projects) into the BioMedIT network. As part of this support, the team played a key role in running the BioMedIT helpdesk which serves as the single point of contact for the projects in the network facing any technical, operational or data delivery issues. The central team also played a key role in establishing secure data transfer pipelines to the BioMedIT nodes, with new cantonal hospitals and private clinics providing personalized health data to researchers participating in these projects.

The central team played a key role in leading **BioMedIT working groups** for further development of BioMedIT secure services, efficient procedures, and the security policy. These efforts ensure the successful delivery of nationally funded BioMedIT services to local & national data-driven biomedical research projects running on BioMedIT at scale.

The central team was instrumental in the development, operation, and first-line support of **BioMedIT Central Services and Tools**, including sett (the Secure Encryption and Transfer Tool), the BioMedIT Portal – the network's central entry point and one-stop shop – as well as key infrastructure such as the BioMedIT Identity and Access Management (IAM) system, the DCC Container Registry, DCC Terminology Services, central logging & monitoring systems. In 2024, the BioMedIT Central Services and Tools were continuously enhanced with new features based upon features requested by stakeholders and evolving compliance requirements such as the new Federal Act on Data Protection (nFADP).

Another important milestone in 2024 was the **retirement of BioMedIT snowflake architecture (based on SFTP)** and replacing it with modern, scalable, performant & secure data transfer architecture based on S3/HTTPs. This new setup enables data providers to transfer data directly to the BioMedIT Node hosting the respective research project and eliminates the need for an intermediary BioMedIT transfer node. The streamlined architecture not only enhances efficiency and performance but also simplifies legal efforts needed by reducing the number of signing organizations involved and easing the operational workload for technical teams involved at both Data Providers and BioMedIT Nodes.

The **core infrastructure at BioMedIT** nodes was further developed to support modern state of the art computing technologies to help researchers. These improvements included for example, easier to use secure remote access technologies (Open on Demand) and flexible service deployment & scaling of pipelines using secure Kubernetes. Onboarding process for Data providers & Projects was further streamlined to be more consistent, sustainable & scalable.

The BioMedIT central team was also involved in advising and supporting **new regional TRE collaborations** that are being set up in the Romandie part of Switzerland (SENSA 2.0: UNIL, SIB, SWITCH, SDSC & CHUV), and in the Bern region Forschungsplattform Standort Bern (FpBe) with UniBE, Inselspital & SWITCH.

Along with key stakeholders, the central team further revised & published a **newer version of BioMedIT Information Security policy,** accommodating changes to clarify definitive responsibilities of different stakeholders, and the latest CIS controls and changes proposed by nFADP. New security controls were implemented for BioMedIT central services to increase compliance with BioMedIT security standards. New collaborations with SWITCH were started to support them with their new secure cloud implementation.

Along with BioMedIT nodes, central team published a new **BioMedIT white paper,** which highlights the need for trusted research environments in Switzerland, as well as how BioMedIT balances data access and security, offering trusted and scalable services to the research community in Switzerland who are working with highly sensitive data.

By the end of 2024, 62 national, regional and international health related research projects were running on the BioMedIT network and over 1000 users were registered on the BioMedIT portal. In addition, a total of 35 data providers (including all Swiss university hospitals, major cantonal hospitals and technological platforms) have been securely onboarded to the BioMedIT network enabling them to securely share human health related data to research projects hosted in BioMedIT.

Swiss federated EGA (European Phenome-Genome Archive)

This project is setting up a Swiss node of the Federated European Genome Archive (FEGA) in order to provide a safe and legally compliant repository for genomic data used for research. It enables both publication through generating accession numbers for submission to journals, and also supports reuse through ensuring datasets can be searched and access can be requested.

Following the successful proof-of-concept work in late 2023 and the ELIXIR supported workshops in Helsinki with the Finnish node and Barcelona with the Spanish node and Central EGA, a more formal project plan was assembled in spring 2024 and was approved by the BioMedIT board in June 2024. This project includes SIB, ETH (thorough the Scientific IT Services/SIS and Nexus), SDSC, Health2030 Genome Centre and Switch and began in July, although a lot of the active work started in September 2025.

Work in late 2024 focussed on the requirements of joining FEGA, and the end-to-end demo of the FEGA technology stack as deployed by the Swiss team. In parallel the team worked on developing a Swiss portal for metadata submission and exploration, planning for a Swiss portal for managing Data Access Committees and setting up a Swiss FEGA partnership to manage the service in the long term.

The team performed the end-to-end demo successfully in December 2024, which lead to a presentation to the FEGA Strategic Committee in January and a formal invitation for Switzerland to join FEGA. Work in 2025 will then proceed to work on a minimum viable product in the first half of the year, and a full production service by the end of 2025.

2.3 Events & communication

Events

In 2024, in collaboration with PHRT, SPHN organized the **symposium «Data for Health»,** celebrating eight years of the initiative and its transition to a permanent national data infrastructure. The event welcomed over 450 participants and over 30 speakers, policy-makers, clinicians and data scientists.

SPHN furthermore was represented at the following national and international events:

- Academies of Arts and Sciences events: Science After Noon
- Workshops: Provenance Workshop with German colleagues (online - Berlin)
- NDS Day 1.11.2024 & workshop
- NZZ Podium on personalized medicine
- Knowledge Graph Forum
- SNOMED CT Expo 2024
- Data for Health: Joining Forces for a Swiss Health Research Data Ecosystem
- Maximizing the Potential of Data in Shaping Personalized Healthcare
- SCTO platform lunch series – Data sharing and open research dataSCTO platform lunch series – Data sharing and open research data SWAT4HCLS 2024 Panel discussions (“10 Years of FAIR Principles”)
- Data Science for the Sciences
- Nordic Precision Medicine Forum 2024
- Linked Data Day 2024
- Webinar: santeneXt-Webinar – Digitalisierung in der Praxis: Lösungen für die digitale Erneuerung des GesundheitswesenssanteneXt-Webinar – Digitalisierung in der Praxis: Lösungen für die digitale Erneuerung des Gesundheitswesens
- Personalized Health Technologies 2024 – Workshop “Unlocking the full potential of health data for research: A hands-on exploration of a toolstack for FAIR knowledge graphs”
- SCTO Platform Event 2024
- Semantics@Roche 2024 - Panel discussions
- Geneva symposium - Talk
- Workshop on Open Research Data in Cancer in Zurich - Talk
- Joint Annual Meeting 2024 of the Swiss Society of Neurosurgery (SSNS) and Swiss Society of Neuroradiology (SSNR) -Talk
- Clinics Meets Data Science -Poster

Communication

SPHN communicated via the following channels in 2024:

- Publications:
  - Factsheet 2024: Overview of SPHN's tools and services for researchers and data providers
- Digital Channels:
  - Website (www.sphn.ch)
  - Social media (X, LinkedIn)
  - SPHN newsletter (four editions)
  - SAMS newsletters (four editions) and SAMS Bulletin (four editions)
- Audiovisual Formats:
  - SPHN YouTube channel, 4 new training videos:
    - How to fill the Dataset Template
    - Querying versioned terminologies
    - Advanced SPARQL queries and best practices
    - SPHN Connector installation guide
  - Contributions to various CAS courses at ETH Zurich, University of Basel, University of Bern, and Unisanté
- SPHN was further featured in the following outlets:
  - NZZ Newspaper article on risks and benefits of personalized health
  - Health Terminal Podcast – contribution on healthcare digitalization

2.4 National and international collaborations

National collaborations

In preparation for SPHN's consolidation (2025–2028), key interfaces with unimedsuisse, swissuniversities, the ORD Strategy Council, the ETH domain and the emerging DigiSanté program were a focus in 2024.

- **State Secretariat for Education, Research and Innovation:** SPHN participated in the SERI Roundtable on 3rd June 2024 in Bern and presented the concept for 2025-2028, which was supported by all representatives.
- **Unimedsuisse & university hospitals:** SPHN met with the unimedsuisse executive board and several times with representatives from the university hospitals agreeing on the cornerstones of the further collaboration 2025-2026. Sustainability and financial challenges were furthermore discussed with the Collège des Doyens.
- **ETH Domain (PHRT & SDSC**) SPHN and PHRT co-lead four National Data Streams (NDS) and fund the Genome of Switzerland project. The SDSC supported NDS "LUCID" with data science expertise, leveraging SPHN's FAIR infrastructure.

- **CPCR:** SPHN contributed to the mapping and visualization of services of the national research support organizations SCTO, SAKK, and SBP.
- **FOPH, FSO, DigiSanté:** SPHN continued to contribute to the Fachgruppe Datenmanagement and its working groups. SPHN also met with Federal Councilor Elisabeth Baume-Schneider to discuss the alingment and synergies between DigiSanté and SPHN. The SPHN FAIR Data Team worked closely with the Federal office of public health to deliver a Training for FAIR data on the basis of a Swiss cancer registry dataset in 2025.
- **National Open Research Data (ORD) Strategy:**
  SPHN provided input to the ORD Strategy Council's Task Force Health and Life Sciences' report published in 2024. SPHN is also a member of the ORD StraCo's Sounding Board of Service Providers and co-authored the respective "Recommendations on Data Archiving & Sharing, User Access, Technical Interoperability, Reuse and the European Open Science Cloud"
- **Patient & Public Involvement and Engagement (PPIE):**
  All NDS projects included patient advocates and engaged patient organizations. A panel comprised of patient partners discussed questions of patient engagement and data sharing at the SPHN-SPHN Data for Health Symposium 2024. SPHN is also active in the SCTO PPI Working Group, supporting patient involvement in all stages of clinical research.
- **Swiss Digital Pathology Initiative (SDPI):** A strategic collaboration between SPHN and the SDPI was established with the goal to reuse the SPHN toolstack and consult the ELSI Team.
- **European Open Science Cloud Swiss Forum:** SPHN took part in the EOSC Swiss Taskforce, where Swiss members of EOSC working groups aligned.
- **A joint workshop with the GEMINI project (HUG, Geneva)** was organised in Bern to explore the use of the SPHN Framework for the GEMINI project
- Participated in the **Federal Chancelleries' Professional/Technical Community of Practice for the Swiss Data Ecosystem**

International collaborations

SPHN continued engagements in the Dutch-Swiss Collaboration on Health Data, and the Beyond 1 Million Genomes Initiative (B1MG), among others. SPHN initiated a collaboration with colleagues of the Berlin Institute of Health to work on SPHN FHIR profiles.

The collaboration of SPHN with the German colleagues around the MIRAPIE project was strengthened and the joint provenance model finalized. A publication was written, which will be published in 2025. Additionally, a workshop at the BC2 conference is planned to present these results.

3 Finances

3.1 Financial statement

3.1.1 Overview

As outlined in the Zusatzprotokoll, all funds allocated by SERI for the initiative were fully allocated by mid-2024, with the first instalments already released for the DEAS Pilot and the onboarding of Cantonal hospitals.

Final instalments were paid for the HospFAIR agreement and the Collaboration Agreement 2021-2024. However, the Collaboration Agreement has been extended until the end of 2025, as per the decision of the SPHN National Steering Board, with an additional allocation of 1 million per University Hospital. The first instalments for this extension were released in the second half of the year.

Additionally, the National Steering Board approved the carry-over of unused funds from the Collaboration Agreement, contingent on a detailed action plan submitted by the relevant institutions. As a result, final payments for the Collaboration Agreement 2021-2024 will be made in 2025.

The funds for the Demonstrator projects and National Data Streams have been disbursed according to the established payment schedule.

Table 1 shows the total funds received by SERI by the end of 2024 and the projects they were used for.

Table 1: SERI funds usage 2017-2024

2017-2024 SERI funds usage

All amounts in kCHF

Accounts description	Cash flow					TOTAL
	2017-2020	2021	2022	2023	2024	
INCOMES						
SERI Contribution - SAMS	30'000	7'332	7'353	7'404	7'400	**59'488**
SERI Contribution - SIB	19'702	2'907	2'915	2'935	2'895	**31'354**
Other income					06	**06**
TOTAL INCOMES	**49'702**	**10'238**	**10'268**	**10'339**	**10'301**	**90'848**
EXPENSES						
Infrastructure implementation projects						
ELSI support staff	260	100				**360**
Reimbursment unused funds			-25			**-25**
Data Coordination Center	2'822					**2'822**
Collaboration agreements with University Hospitals	12'750	4'850	7'400	3'000	750	**28'750**
HospFAIR			1'150	1'207	912	**3'269**
Other projects (MedCo Pilot, GoS)			380	231	175	**786**
Projects : call 2017						
Infrastructure development projects	2'290	14	7			**2'305**
Driver projects	11'000	871	459	638		**12'968**
Reimbursment unused funds	-150	-4				**-153**
Projects : call 2018						
Infrastructure development projects	1'842	231	81			**2'153**
Driver projects	5'213	471	453	498	590	**7'225**
Reimbursment unused funds				-161		**-161**
National Data Streams		75	908	2'194	4'296	**7'472**
Reimbursment unused funds			-7	-3		**-10**
Demonstrator Projects				2'420	1'552	**3'972**
Cash flow Management Office and Bodies*	2'354	731	762	635	836	**5'319**
TOTAL EXPENSES	**38'382**	**7'339**	**11'561**	**10'660**	**9'111**	**77'053**
Cash available end of year	**11'321**	**14'219**	**12'927**	**12'606**	**13'795**	**13'795**

*incl. financial result (bank fees, interests)

Table 2: Cash flow Data Coordination Center, 2017-2023

Data Coordination Center : Cash flow 2017-2023

All amounts in kCHF

Accounts description	Cash flow					TOTAL
	2017-2020	2021	2022	2023	2024	
INCOMES						
SPHN contributions	2'822					**2'822**
SERI contributions		1'715	1'720	1'732	1'707	**6'875**
Various incomes	28	03	16	39	12	**99**
TOTAL INCOMES	**2'850**	**1'718**	**1'736**	**1'771**	**1'719**	**9'796**
EXPENSES						
PHI Projects portofolio						
Implementation RDF	31	158	236	314	272	**1'011**
De-Identification project	32	41	03	0	0	**75**
SPHN Project Portfolio covered by PHI*						
Federated Query System	112	262	124	133	519	**1'151**
SPHN Connector			483	855	426	**1'765**
MedCo			295	59	487	**842**
HospFAIR			27	89	0	**116**
Maelstrom			21	42	50	**113**
SPHN IT Architecture		43	79	59	64	**245**
Genome of Switzerland (GOS)					101	**101**
NDS support on the nodes				269	540	**809**
Consultancy costs						
other consultancy costs	144	43	07	145	125	**464**
Personnel costs	1'903	831	1'004	1'251	1'109	**6'098**
Operating costs	463	131	132	177	120	**1'022**
TOTAL EXPENSES	**2'685**	**1'508**	**2'410**	**3'393**	**3'814**	**13'810**
Cash available end of year	**166**	**375**	**-299**	**-1'920**	**-4'014**	**-4'014**

*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 how the funds allocated to the BioMedIT Network were used during the 2017-2024 period. As not all allocated funds have been used in this period, 5.2 Mio CHF has been transferred to SPHN projects in accordance with the Leistungsvereinbarung and the SERI.

Table 3: BioMedIT Network project: SERI funds usage, 2017-2024

BioMedIT Network project: SERI funds usage

All amounts in kCHF

Accounts description	Cash flow					TOTAL
	2017-2020	2021	2022	2023	2024	
INCOMES						
SERI Contribution - SIB BioMedIT Network	17'732	4'592	4'606	4'639	4'572	**36'141**
Other incomes		20	09	08	09	**47**
TOTAL INCOMES	**17'732**	**4'612**	**4'615**	**4'647**	**4'581**	**36'187**
EXPENSES						
Node funding						
SIB / Core-IT/SENSA	1'400	606	394	297	300	**2'997**
ETHZ / SIS	700	300	500	333	302	**2'135**
Unibas /sciCORE	700	307	327	395	353	**2'081**
Addition support node security MS	340	71	0		0	**411**
Node security officers		382	346	461	576	**1'765**
Interoperability WG						
SIB / Vital-IT	450	-34	147	141	143	**881**
ETHZ / SIS	450	69	0	179	359	**1'058**
Unibas /sciCORE	450	100	150	150	130	**980**
PHRT Platforms						
Mass Spectrometric P. in Zurich	900					**900**
Genome Center in Geneva	525	375	0			**900**
Projects funded						
SVIP O	949					**949**
Driver project GA4CH - M.Baudis	125					**125**
RDF / Data management		142	180	424	467	**1'213**
Methodology Development		05	07	43		**55**
IDEAL project	500					**500**
FEGA project					833	**833**
Personnel, consultancy and operating costs	2'678	1'555	1'385	1'702	1'384	**8'703**
TOTAL EXPENSES	**10'167**	**3'879**	**3'435**	**4'125**	**4'846**	**26'486**
Cash available end of year	**7'566**	**8'299**	**9'479**	**10'001**	**9'735**	**9'702**

The cash flow statement (Table 4) shows that the available cash slightly increased during the year 2024. This was caused by some delays, mainly in the National Data Streams projects, which received their third instalments at the beginning of 2025 instead of in 2024 as initially planned. For the Implementation projects and Demonstrator projects, funds were released according to the payment plan.

Table 4: Cash flow statement for2024 compared to 2023

Cash flow statement (direct method)	**2024 in CHF**	**2023 in CHF**
+ Cash received from SERI contribution - SAMS	7'400'000	7'403'700
+ Cash received from SERI contribution - SIB	2'894'838	2'935'250
+ Income external mandates	6'000	0
Total cash received from SERI contributions	**10'300'838**	**10'338'950**
- Cash paid for Collaboration agreements	-750'000	-3'000'000
- Cash paid for HospFAIR	-911'971	-1'206'984
- Cash paid to Infrastructure dev. & Driver projects	-590'480	-1'136'056
+ Refund unused funds from finished Infrastructure dev. & Driver projects	0	160'720
- Cash paid to National Data Streams	-4'295'832	-2'194'001
+ Refund unused funds NDS Application allowance	0	2'918
- Cash paid to Demonstrator Projects	-1'551'611	-2'420'435
- Cash paid for other projects (MedCo Pilot, GoS, DEAS, Cant. hospitals)	-375'000	-231'158
+ Refund GoS Pilot ETH	200'000	0
Total cash paid for funding activities	**-8'274'894**	**-10'024'996**
- Cash paid for personnel expenses	-766'472	-492'343
- Cash paid for operating expenses	-43'571	-73'625
- Cash paid related to activities of bodies and experts	-91'171	-121'834
Total cash paid related to management expenses	**-901'214**	**-687'802**
Total financial result (bank fees, interests)	**65'156**	**52'639**
Cash flow from operating activities	**1'189'885**	**-321'209**
Net increase/decrease in cash	1'189'885	-321'209
Cash on 1.1	12'599'801	12'921'010
Cash on 31.12	**13'789'687**	**12'599'801**

4 Outlook 2025

The ERI Dispatch 2025-2028 outlines a 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 sustainable and scalable expansion of the network for the future. In 2025, SPHN will continue the negotiations with its main stakeholders on the operationalization of the future SPHN and develop models for how to generate additional income (e.g. through services, mandates and project-related funds). The strong commitment of the partners for collaborating and sharing the responsibilities and benefits for the common goal is of utmost importance.

5 Imprint

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