

SPHN Short Report (2022)

Yearly update and overview of activities

1 Editorial

The second year of the second SPHN funding period 2021-2024 was marked by important achievements for the further consolidation of the SPHN infrastructures and services in view of a scalable and sustainable FAIR health research data ecosystem for Switzerland.

First and foremost, the year was dedicated to in-depth reflections and discussions on the consolidation of the SPHN Data Coordination Center (SPHN-DCC) beyond 2024. By mandate of the State Secretariat for Education, Research and Innovation (SERI), SPHN elaborated a pragmatic concept for continuing the essential services and core infrastructures of the SPHN-DCC after 2024, when the initiative ends. Comprehensive discussions, consultations and bilateral meetings with the numerous partners of SPHN helped clarify the expectations and needs regarding the roles and responsibilities of the future SPHN-DCC, its activity portfolio, governance and financing model and – importantly – how the many interfaces with the other ongoing complementary national initiatives (e.g. Swiss National Open Research Data (ORD) Strategy) can be seamlessly organized. In view of this, stakeholders from research, care and public health expressed a strong positive opinion towards establishing a sustainable and empowered structure for Switzerland in the long term, in the form of a ‘National Center for Health and Research (NCHR)’. This larger vision shall be pursued by the national Coordination Platform Clinical Research (CPCR), while the continuation of the SPHN-DCC in 2025-28 will be part of the respective ERI-Dispatch.

Particularly intensified in 2022 were the interactions of SPHN with the Federal Office of Public Health (FOPH). Starting with a meeting of the “Beirat Digitale Schweiz”, hosted by Federal Councilor Alain Berset in April 2022, SPHN has since been a member of the FOPH Expert Group Data Management to help create a common understanding of the architecture and standards, and to elaborate national recommendations for improving the collaboration and exchange of data between the actors in the health system.

A legacy of SPHN and its partner program from the ETH Domain strategic focus area “Personalized Health and Related Technologies” (PHRT) will be the four National Data Streams (NDS) that are jointly funded starting in 2022. These data-rich health research platforms in the areas of infectious diseases in intensive care medicine, oncology, pediatrics, and health services research will be central pillars of the future health research data ecosystem and serve as models and crystallization points for future research programs and clinical applications of personalized health. Complementary to the NDS, SPHN launched in 2022 a Call for Demonstrator projects to test and validate the established infrastructure components and leverage the use of SPHN data resources from clinical routine. Out of 30 applications, 11 Demonstrator projects were selected for funding.

Further important progress was made on the harmonization of the SPHN IT architecture with the development and deployment of the SPHN Connector across all five university hospitals and the university children’s hospital Zurich. Likewise, the HospFAIR program provided a strong push for the implementation of common data standards and the systematic monitoring of data quality within university hospitals. To further evaluate

the possibilities of federated exploration of data through ‘sharing without sharing’, a pilot project with the TI4Health (formerly MedCo) distributed data analytics platform from Tune Insight SA and two previously funded SPHN projects (SPO and SwissBioRef) was conducted in 2022.

Finally, following two years of pandemic-related physical distance, SPHN and PHRT jointly organized the second Personalized Health Day at the Casino Bern in August 2022. Over 200 participants attended the event, aimed at researchers from clinical research, data science and laboratory-based research and which revealed the great spirit of community, mutual trust of the partners and a shared vision on data-driven biomedical research in Switzerland established over the last years in the realm of SPHN and PHRT. Given this fundamental work and achievements, SPHN continues its commitment to improve the interface with other research stakeholders (e.g. Swiss National Science Foundation, Swiss Biobanking Platform, Swiss Clinical Trial Organisation, Schweizerische Arbeitsgemeinschaft für Klinische Krebsforschung, patient organizations) and data sources (Federal Office of Public Health, Federal Statistical Office, Swiss Data Science Center, registries, Swiss Multi-Omics Centers) help shaping the national health research landscape in Switzerland.

Yours sincerely,

Prof. Dr. Urs Frey

Chairperson of the National
Steering Board

Prof. Dr. Beatrice Beck Schimmer

Vice-Chairperson of the National
Steering Board

Dr. Thomas Geiger

Managing Director

2 Activities and achievements in 2022

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

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

2.1 Funding activities and collaborative projects

A major milestone in 2022 was the conclusion of the joint Call for National Data Streams (NDS), launched in collaboration with the ETH Domain strategic focus area Personalized Health and Related Technologies (PHRT), in spring 2022. After a two-step evaluation procedure, 4 NDS projects covering the fields of infectious diseases in intensive care medicine, oncology, pediatrics, and health services research were selected for funding. Each of them comprises a Switzerland-wide multidisciplinary consortium that invests in the development of a sustainable data infrastructure for high-end data-driven and personalized health research. The four NDS will constitute central pillars of the SPHN health research data ecosystem and the PHRT research platforms. In the long term, they shall serve as models and crystallization points for future research programs and clinical applications of personalized health. NDS include clinical, analytical (such as multi-omics) and other data that will be enriched and made available to the research community. In addition, all NDS include patient and public involvement (PPI) in their projects. The 4 NDS started in September 2022 with a maximal support of CHF 5 million per project and a runtime of 3 years.

Another important milestone was achieved with the Call for Demonstrator projects in 2022. These projects will 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. From a total of 30 project applications, 11 Demonstrator projects were selected for funding. Two types of Demonstrator projects are supported: On the one hand, projects that test the practical application of SPHN infrastructure components in medical research and/or expand their use in the network. On the other hand, projects that demonstrate the added value of SPHN-compliant data resources from the university hospitals for personalized health research. Each Demonstrator project is supported with up to CHF 500'000 and has a maximum duration of 18 months. The projects are expected to start by 1 April 2023.

In 2022, SPHN also launched a second Call for Swiss cohorts to join the Maelstrom catalogue as part of the efforts towards a sustainable re-use of health research data. In the context of a pilot study and as a result from the first Call for cohorts launched in 2021, a total of 10 Swiss cohorts had already joined the SPHN Cohort Consortium network on the Maelstrom catalogue and successfully integrated their metadata with over 120'000 variables from more than 80'000 cohort participants. From the second Call, the Swiss Multiple Sclerosis Cohort was selected and gets supported by the SPHN Data Coordination Center (DCC) during the process of metadata integration.

In the frame of the renewed collaboration agreements 2021-2024 (CA) between SPHN and the five Swiss university hospitals (UH), the institutions took up their works of the second year with full speed. Similar to previous years, bilateral so-called 'Friendly Talks' between SPHN and UH leadership at the beginning of the year helped to establish common ground on the most pressing issues. Common data standards, scalability

and producing high-quality data close to the point of care were identified as key success factors. 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 for the second year of the agreement, which were jointly monitored by the UHs and SPHN throughout the year.

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 in the participating hospitals through the implementation of streamlined processes at the Clinical Data Platforms of the UH. At the end of the first phase of the program, there shall be a sustainable and scalable data extraction pipeline in place to efficiently produce a federated volume of data according to the SPHN interoperability framework. With the joining of the HospFAIR program, the UH have shown another important commitment towards the FAIRification efforts of SPHN to establish nationwide interoperability of health-related information.

The SPHN IT Architecture Working Group is responsible for elaborating a sustainable, service-oriented IT architecture framework for data providers, and for developing components enabling standardized data provisioning to SPHN and other research projects. In 2022, the National Steering Board of SPHN mandated the development of the first common infrastructure component: the SPHN Connector. This tool connects internal data provider infrastructures with SPHN research services. Data providers are able to ingest data in different technical formats to the SPHN connector, which will then validate the data for specification compliance, de-identify the data and transform it into SPHN RDF format. The development of the SPHN Connector was led by the University Hospital Zurich and deployed for testing in early 2023 at all UHs and the University Children's Hospital Zurich.

In 2022, a pilot/proof-of concept project for distributed and privacy-preserving cohort exploration and analytics was conducted under the management of the DCC, aiming at investigating and documenting the deployment and use of the TI4Health platform (formerly 'MedCo') in a real-world setting. This platform resulted from the Infrastructure Development project 'MedCo' by the EPFL Laboratory for Data Security and the CHUV Clinical Data Science Center, jointly funded by SPHN and PHRT. It is now run by Tune Insight SA, a start-up from EPFL. The platform was tested in the context of the two SPHN projects "Swiss Personalized Oncology (SPO)" and "Swiss BioRef" in collaboration with Tune Insight, the university hospitals in Zurich, Lausanne and Geneva, and the BioMedIT node SIS at ETH Zurich. The evaluation will be completed in early 2023.

Finally, the last running Infrastructure Development projects from the 2018 Call were completed in 2022 and another 5 Driver projects came to an end and delivered their final reports. Information about the developed and reusable infrastructure components and resources of the completed projects, including access information and contact persons, can be found on the SPHN website (<https://sphn.ch/network/projects/>). The annual reports of ongoing SPHN projects and collaboration agreements were reviewed by different boards and recommendations concerning the continuation of funding were made to the SPHN National Steering Board (NSB). In 2022, 4 Driver projects from the Call 2018 were still ongoing and will be completed in summer 2023.

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 and the management of the BioMedIT Network.

2.2.1 DCC activities and achievements in 2022

In 2022, the DCC made significant advancements in the creation and improvement of the FAIR Swiss health data ecosystem – a compilation of blueprints, templates, tools and services for the achievement of FAIR research data. The 2022 release of the [SPHN Semantic Interoperability Framework](#) marked an important step in promoting data interoperability and expanding the types of data that can be shared in a semantically consistent manner. A total of 33 new concepts were developed in 2022, with 10 published in 2022 and the remaining ones set to be released in early 2023. The [SPHN RDF schema](#) was updated to improve consistency and simplicity, making use of more ontological features. Together with the SPHN Dataset and RDF Schema release 2022, the DCC also included new services for data providers, such as quality control tools and a migration path to easily update from the previous versions of the RDF schema. To ensure that these services are provided in an automated fashion for future releases and project-specific extensions, [a tool stack](#) (SPARQLer, SHACLer and Visualization Tool) was developed to generate all additional services on the basis of the SPHN RDF Schema. In order to maintain backwards compatibility with the external terminologies used in the SPHN interoperability framework, the DCC developed a strategy for the versioning of these terminologies. This strategy will be put into action in 2023 and cross-versioned terminologies will be accessible through the SPHN Terminology Service.

The [SPHN Federated Query System](#) is now routinely used by researchers from several Swiss universities, including the 5 university hospitals, ETH, and universities of Bern, Zurich and Basel, with the option for other interested institutions to join. In the course of the year 2022, the amount of available, fully anonymized health data in the system was expanded from 75 million data elements to over 140 million elements, covering nearly 0.6 million patients from all five university hospitals. In addition to the original data elements such as age, gender, procedures, diagnoses, and lab test results, the system now includes information on the amount of medication administered to patients. 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.

In 2022, the ELSI Helpdesk of the DCC, in close cooperation with SIB legal developed the SPHN legal agreement templates further with a view to the reuse possibility by third parties, as required for the SPHN National Data Streams. The helpdesk advised 22 projects (12 SPHN and 4 PHRT-funded projects, 4 external research projects, and 2 SPHN-internal infrastructure projects) and supported them in drafting the required legal contracts on the basis of the [SPHN templates](#) for multicenter research projects. In close collaboration with international and national experts, a hands-on [guidance for de-identifying data](#) has been developed and published in May 2022, outlining the legal context of de-identifying data in compliance with Swiss law and elaborating in three phases the de-identification process following a risk-based procedure. A template use case evaluation and risk assessment allows researchers to define project specific de-identification rules and re-identification risk.

2.2.2 BioMedIT Network activities and achievements in 2022

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 the work on the central BioMedIT level in the past year was on the further development, coordination and implementation of the strategic roadmaps for advanced interoperability, IT security, technical core infrastructures and service management in the network. These roadmaps ensure that nationally funded secure IT services from BioMedIT for data-driven, biomedical research projects are being delivered at scale to SPHN and PHRT-funded projects, in particular to the new National Data Streams, as well as to other interested clients. In addition, the central BioMedIT team's effort in the DCC was dedicated to development, operations and first line support for central BioMedIT services such as the secure transfer of data (utilizing the secure encryption and transfer tool, [sett](#)), the central entry point and one-stop shop of the network – the [BioMedIT portal](#), as well as related services such as the [DCC container registry](#), [DCC terminology services](#), [DCC WebProtégé](#), [FQS registration](#), and others. With the start of the four large National Data Streams, the teams were also busy with onboarding new data providers and project partners to the network.

One major milestone reached in 2022 was the release of a new version of the [BioMedIT Information Security Training](#), replacing the old SPHN Information Security Training and exam, and a new [Getting Started with BioMedIT](#) -training. The new training models contain self-assessment sections for a better learning outcome. In addition, a variety of modular training courses on how to use, deploy and manage the central tools for the data providers, data managers, and users of BioMedIT were produced and are available online through the edu.sib.swiss platform (edu-ID login required).

Furthermore, a new [BioMedIT website](#) was launched in March 2022 for better visibility and community engagement, and providing a single source of truth regarding all DCC and [BioMedIT tools and resources](#).

The technical core infrastructure at the nodes has been further developed to provide users with a flexible platform configured to meet the researcher's computational needs. At the end of 2022, 2.5 PB of secure storage, and more than 5000 CPUs and 450 GPUs were available for research projects at the three nodes. A selected interoperable software and analysis tools portfolio has been implemented as well as workflow systems, allowing researchers to independently manage their projects and carry out scientific tasks. A [BioMedIT base package](#) was determined in the network for the default project's service provisioning. A new GDPR compliant GPG Keyserver was also introduced in the network for researchers to manage their GPG keys securely and use them on the BioMedIT nodes. The process of DTR authorization was automated giving BioMedIT nodes and data providers the flexibility to authorize production data transfers at scale. In addition to the technical and operational support, BioMedIT further developed the portfolio of scientific user support to help projects with regard to active and FAIR data management, Semantic Web Technology, and the amendment of their data schema according to the project needs.

A new collaboration was established with the Swiss Biobanking Platform (SBP) in 2022 by providing an identity and access management service for the smooth integration of SPHN and BioMedIT services with SBP services such as SBP Next, SBP SQAN and others. In the area of international collaboration, a new research project from the University of California at San Francisco was successfully onboarded to the BioMedIT node SIS at ETHZ. The ARGOS project, in which the University Hospitals Basel (USB), Zurich (USZ) and sciCOREmed of the University of Basel form the Swiss node of the international Personal Health Train, has also been running successfully since mid-2021. As part of this project, a neural network is being trained with Deep Learning at

more than 20 sites worldwide to automatically segment CTs of lung cancer. The Personal Health Train is designed to enable healthcare innovators and researchers to work with distributed health data from multiple sources using federated learning techniques. In addition, international collaborations were further strengthened with ELIXIR, EOSC, 1+MG, and GA4GH, among others.

At the end of 2022, over 65 national and international health-related research projects were running on the platform and over 520 users were registered in the portal. In addition, a total of 25 Swiss data providers and 1 international data provider have been onboarded to the network.

2.3 National and international collaborations

In 2022, Cédric Petter left the SPHN Management Office and was succeeded by Christine Remund, joining the team in September 2022 as project administration specialist with a focus on the financial aspects of the initiative.

Due to the medical leave of Nicolas Rosat, chair of the Hospital IT and Strategy Alignment Group (HIT-STAG), Solange Zoergiebel took up her role as chair ad interim of the group.

2.3.1 National collaboration

At the end of 2020, the federal government had extended the mandate to a second SPHN funding period until 2024. In view of permanently sustaining the consolidated data infrastructures and services of the SPHN Data Coordination Centre (SPHN-DCC) after the initiative has wound down, the mandate also included the task to elaborate a report for SERI by the end of 2022 outlining the activity portfolio, governance structure, financing model, and interfaces of the future SPHN-DCC. The year 2022 was thus marked by numerous discussions, consultations and meetings to create this 'SPHN-DCC (2024++) report'. Based on an outline analysis from wide-range stakeholder interviews conducted by advocacy AG in 2021, a dedicated SPHN Working Group iteratively elaborated the report throughout the year in close collaboration with the stakeholders, NSB, and SERI. Those discussions helped to further clarify the expectations regarding the roles and responsibilities of the future SPHN-DCC and how the various interfaces with ongoing complementary national initiatives for health and research data (e.g., by the Open Research Data (ORD) Strategy Council, Federal Office of Public Health (FOPH), or the ETH-Domain) could be seamlessly organized. It became evident that the governance of the SPHN-DCC must reflect the multi-stakeholder network and be strategically, financially, and operationally independent of a single stakeholder and particular interests. Furthermore, to guarantee long-term sustainability, robust core financing ('Sockelfinanzierung') for the SPHN-DCC needs to be ensured by the Confederation and matching contributions from the participating partners.

The final report was submitted in December 2022 to SERI, which will include the further consolidation of the SPHN-DCC in the ERI-Dispatch 2025-28. Most of the key stakeholders consulted during the preparation of the report shared the vision that - in the long run - a 'National Center for Health and Research' should be established in Switzerland in order to bundle up existing institutions and foster data-based health research and secondary health data use in general, promoting personalized medicine and health. The national Coordination Platform Clinical Research (CPCR), established in 2021 based on a mandate from SERI in response to the White Paper: Clinical Research is the ideal platform to pursue such a vision.

In the aftermath of the Covid-19 pandemic, the digital transformation of the health system and respective data management processes have gained much traction through multiple initiatives by the parliament,

administration (e.g., FOPH), and industry. It has been increasingly recognized that the learnings and groundwork concepts and frameworks of SPHN can make a valuable contribution to the establishment of a coherent health data strategy and ecosystem in Switzerland. SPHN has therefore been actively participating in the FOPH Expert Group Data Management (“Fachgruppe Datenmanagement / “groupe spécialisée gestion des données”) and several of its working groups, leading the working group on promoting efficiency and ROI in healthcare data collection. Similarly, SPHN has been consulting FOPH about researchers’ needs related to the use of electronic patient records data for research purposes, envisioned for the upcoming revision of the Electronic Patient Record Act. The increasingly data-driven approaches applied across domains make it of utmost importance that research and healthcare go ‘hand in hand’, applying the same principles and standards.

A similar transformation in research is ongoing nationally and internationally in the realm of ORD and several research and funding organizations are currently actively shaping the evolving research landscape in Switzerland towards such a vision. SPHN has been closely aligning itself with the partners and initiatives relevant for health research to build a common understanding of the requirements and to coordinate and align on data strategies and processes. These interfaces between SPHN and, e.g., the ORD Strategy Council, PHRT, unimeduisse, swissuniversities, Swiss Biobanking Platform (SBP), Swiss Clinical Trial Organisation (SCTO), Schweizerische Arbeitsgemeinschaft für Klinische Krebsforschung (SAKK), Swiss School for Public Health (SSPH+), Swiss National Science Foundation (SNSF), FOPH, Federal Statistics Office (FSO), and the Swiss Data Science Center (SDSC) of the ETH-Domain will be a strong focus of SPHN also in 2023.

In 2022, the National Advisory Board took up its mandate to implement the concept of a national strategy to facilitate genomic research and to accelerate the integration of genomics into healthcare, e.g. by assembling data and knowledge about the genetic structure of the Swiss population. The Swiss Federated Genomics Network (SFGN) launched in close collaboration with PHRT and the Health 2030 Genome center builds on two complementary pillars: first, an infrastructure backbone to support and coordinate genomic data generation/processing/exchange in a scalable and sustainable manner, including a FAIR data repository allowing reuse of genomic data, and second, a national reference genomic dataset “Genome of Switzerland” (GoS) to demonstrate the feasibility of genome data production and sharing at scale. As part of this effort, the establishment of a Swiss Federated European Genome-phenome Archive (EGA), or similar infrastructure, is envisaged and needs further exploration in 2023.

The SERI ‘Zusatzprotokoll’ 2021-24 includes the mandate to develop also strategies for public-private partnerships in SPHN. In this context, the ELSlag has developed a SPHN Guideline for the Ethical Sharing of Health Data in Public-Private Partnerships. Moreover, the DCC participated in workshops with Interpharma and individual industry representatives to identify the feasibility, needs and requirements from the industry regarding real-world clinical data. Given the interest from industry in observational studies based on routine primary care data, the NSB mandated the DCC to develop a blueprint for streamlined collaboration and time-efficient services in the context of a pilot study between Novartis, University Hospital Basel and University Hospital Zurich.

Finally, SPHN is an active member of the 2022 initiated Patient and Public Involvement (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, by providing for example template agreements for researchers to implement PPI in their studies/initiatives, monitoring templates or match-making activities.

2.3.2 International collaboration

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 2022, SPHN continued its membership in the ICPerMed Working Group on Personalized Medicine in Healthcare and joined the ICPerMed Conference entitled 'Prelude to the Future of Medicine' (5-6 October, Paris). Furthermore, SPHN was featured as 'ICPerMed Best Practice Example', as a successful approach to personalized medicine.

The SPHN-DCC continued its collaboration with the Global Alliance for Genomics and Health (GA4GH) also in 2022. GA4GH is an international, nonprofit alliance to accelerate the potential of research and medicine to advance human health. The collaboration with GA4GH allows SPHN to align with GA4GH's global efforts, contributing to the development of international frameworks and standards. SPHN further continued to participate in the regular meetings of the Dutch-Swiss Collaboration on Health Data, took part in the European Open Science Cloud (EOSC) Swiss Taskforce Exchange Group, and had exchange meetings with consortium members from the German Medizininformatik Initiative (MII) and the German Human Genome-Phenome Archive (EGA). SPHN representatives further take part in the Beyond 1 Million Genomes (B1MG) Initiative, benefiting from international experience and knowledge for the development of a Swiss Federated Genomic Network. International collaborations represent a small but important part of SPHN's work. Exchanges of knowledge, experiences and best practices are beneficial to the SPHN initiative, as well as its partners and the research location Switzerland in general. With the maturation of the SPHN initiative over the years, it has also become an example for and advisor to health data research initiatives from other countries.

2.4 Events & Communications

In 2022, SPHN focused its communication and community building activities on the researchers as target group. In this context, SPHN and PHRT organized the second Personalized Health Day (PH-Day) at the Casino Bern in August 2022. Over 200 participants attended the event, which was aimed at researchers from clinical research, data science and laboratory-based research. The main goal of the PH-Day was to offer the community the opportunity for direct exchange after two years of pandemic-related physical distance.

The morning program provided an overview of the status of the initiatives, the infrastructures and services that SPHN and PHRT have built for researchers, and included the perspectives of the federal government and industry. A panel discussion with experts from the Confederation, industry, the ETH domain and university hospitals addressed the successes achieved so far, but also the challenges still to be faced in the coming years. The afternoon of the event was dedicated to networking: a poster session allowed in-depth discussions and during workshops and a round table, the four newly launched National Data Streams were discussed.

SPHN and PHRT draw a very positive conclusion of the event: The sense of community created in recent years, the strengthened mutual trust of the partners and the shared vision on data-driven medical research in Switzerland was clearly noticeable at this second PH-Day. The day was characterized by lively discussions and the participants greatly appreciated the personal exchange.

Following the Factsheet 2020, the DCC, together with the MO published an updated Factsheet 2022. Written with a researcher's perspective in mind, this new edition highlights the various tools, services and resources that SPHN offers in the field of data-driven and personalized health research and their added value. From project planning, to data acquisition and processing through to the re-use of data by third parties, researchers

learn about the new opportunities that are opening up, e.g., in terms of data availability in the clinical data warehouses or data lakes of the university hospitals. In addition, the Factsheet 2022 contains an outlook on the future developments of the SPHN ecosystem and its important partnerships.

SPHN communicates continuously via its website (www.sphn.ch; available in English, French, and German), Twitter, LinkedIn, and punctual newsletters. The DCC, together with the MO, continues to develop SPHN's social media presence, where collective posts have gained over 155'000 impressions in 2022, a rise of over 280% on 2021. SPHN articles have also appeared in several SAMS newsletters and the SAMS Bulletin.

In 2022, the SIB Personalized Health Informatics Group produced 5 editions of the SPHN Technical Newsletter addressed to the community. This newsletter periodically updates on news, developments and technical details in SPHN, the Data Coordination Center (DCC) and BioMedIT. The technical newsletter continues to see high levels of engagement and a growing mailing list.

In addition to the joint PH Day, SPHN in 2022 supported the Symposium in memoriam of Prof. Peter Meier Abt entitled 'A culture of collaboration' (19 July 2022, Basel). The aim of the event was to discuss how scientists, clinicians, regulators, research ethics committees, academic institutions, and funding agencies share responsibilities to enhance value and progress in science and medicine. This was a key concern of Prof. Meier-Abt as a researcher, former vice-rector of the University of Basel and former president of the Swiss Academy of Medical Sciences and first president of the SPHN National Steering Board.

With the conclusion of SPHN webinars by the SPHN funded projects in the first phase, the DCC focused on hosting webinars by international experts in topics relevant to the SPHN community in 2022. The webinars, along with training developed by the DCC are available on the [SPHN YouTube channel](#), which amassed 8239 unique views in 2022, with a total of 762 hours of content viewed. The most watched video on the channel in 2022 was "Querying Data with SPARQL", a training video delivered by PHI's Data Interoperability team published in 2021, which was viewed 1299 times in 2022.

In 2022 the DCC produced a total of 4 new training modules, also available on the SPHN YouTube channel and in the international Elixir [TeSS training catalogue](#):

- FAIR principles in practice for health data
- How to create a concept for the SPHN Dataset
- Extended Training SPHN Federated Query System (FQS)
- Responsible Data Sharing – Legal agreements for using health-related data in multi-center projects
- BioMedIT: Information Security Awareness Training (revision)

Further, members of the DCC contributed to the following further education 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.

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):

- Databits, Basel, CH
- FORS Workshop on safe access to sensitive data, Bern, CH
- BioDataWorld, Basel, CH
- LOINC Conference 2022, Annecy, F
- SNOMED CT Expo, Lisbon, PT

- Semantics@Roche, Basel, CH
- Ontotext Forum, Basel, CH
- ICPeMed Conference 2022 'Prelude to the Future of Medicine', Paris, F
- Life science cluster, HKBB, Basel, CH
- The Data Warehousing Institute (TDWI), online, Basel, CH
- SWAT4HCLS, Leiden, NL
- MILA Seminar, Greifswald, DE
- Medizininformatik Initiative, Berlin, DE
- HealthCom, Rüslikon, CH
- Cutting-Edge Implementation of Precision Medicine in Europe, Stockholm, SE
- General Assembly of the IG eHealth, Basel, CH
- Personalized Health Technologies 2022, Zurich, CH
- GHGA Mini-symposium 'FAIR Sharing Approaches for Human Omics Data, Tübingen, DE
- Schulthess Forum Life Science Day, Basel, CH
- Oncosuisse Forum "Data and Registries" Bern, CH
- Schulthess Forum Legal Aspects in Life Sciences, online, CH
- 1st International Workshop on Patient and Public involvement in cancer research, Lausanne, CH

3 Finance

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

During the year 2022, first instalments were released for the National Data Streams as well as for the Hosp-FAIR agreements. The payments for the 2021-2024 collaboration agreements were released according to the planned payment schedule. Some projects of the first phase of SPHN (calls 2017 and 2018) requested and received cost-neutral extensions and are thus still ongoing. Final payments were released for five Driver projects (from the Call 2017) and one Infrastructure Development project (from the Call 2018), that ended in the course of 2022. Further, funds for two MedCo pilot projects were released in 2022. All payments in 2022 related to these projects were deducted from provisions created in 2020 and approved by the SERI. Negative interest rates on the SPHN bank accounts continued to have an impact, albeit less so than in previous years (CHF 50k in 2022). As from the 4th quarter of 2022, interests on the bank accounts have turned positive again.

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

Table 1: 2017-2022 SERI funds usage

2017-2022 SERI funds usage

All amounts in kCHF

Accounts description	Cash flow			TOTAL
	2017-2020	2021	2022	
INCOMES				
SERI Contribution - SAMS	30'000	7'332	7'353	44'684
SERI Contribution - SIB	19'702	2'907	2'915	25'524
TOTAL INCOMES	49'702	10'238	10'268	70'208
EXPENSES				
Infrastructure implementation projects				
ELSI support staff	260	100		360
Reimbursement unused funds			-25	-25
Data Coordination Center	2'822			2'822
Collaboration agreements with University Hospitals	12'750	4'850	7'400	25'000
HospFAIR			1'150	1'150
MedCo Pilot			380	380
Projects : call 2017				
Infrastructure development projects	2'290	14	7	2'311
Driver projects	11'000	871	459	12'330
Reimbursement unused funds	-150	-4		-153
Projects : call 2018				
Infrastructure development projects	1'842	231	81	2'153
Driver projects	5'213	471	453	6'137
National Data Streams		75	908	983
Reimbursement unused funds			-7	-7
Cash flow Management Office and Bodies	2'354	731	762	3'848
TOTAL EXPENSES	38'382	7'339	11'592	57'313
Cash available end of year	11'321	14'219	12'895	12'895

Table 2: Data Coordination Center cash-flow statement 2017-2022

Data Coordination Center : Cash flow 2017-2022

All amounts in kCHF

Accounts description	Cash flow			TOTAL
	2017-2020	2021	2022	
INCOMES				
SPHN contributions	2'822		5	2'827
SERI contributions		1'715	1'720	3'435
Various incomes	28	3		32
TOTAL INCOMES	2'850	1'718	1'725	6'294
EXPENSES				
PHI Projects portfolio				
Implementation RDF	31	158	236	425
De-Identification project	32	41	3	75
SPHN Project Portfolio covered by PHI*				
Federated Query System	112	262	124	499
SPHN Connector			483	483
MedCo			295	295
HospFAIR			27	27
Maelstrom			27	27
SPHN IT Architecture		43	79	121
Consultancy costs				
other consultancy costs	144	43	7	194
Personnel costs	1'903	831	993	3'726
Operating costs	463	131	128	721
TOTAL EXPENSES	2'685	1'508	2'402	6'595
Cash available end of year	166	375	-301	-301

*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 2017-2022 period.

Table 3: BioMedIT Network SERI funds usage 2017-2022

BioMedIT Network project: SERI funds usage

All amounts in kCHF

Accounts description	Cash flow			TOTAL
	2017-2020	2021	2022	
INCOMES				
SERI Contribution - SIB BioMedIT Network	17'732	4'592	4'606	26'930
Other incomes		20	9	29
TOTAL INCOMES	17'732	4'612	4'615	26'959
EXPENSES				
Node funding				
SIB / Core-IT/SENSA	1'400	606	394	2'400
ETHZ / SIS	700	300	500	1'500
Unibas /sciCORE	700	307	327	1'333
Addition support node security MS	340	71	0	411
Node security officers		382	745	1'127
Interoperability WG				
SIB / Vital-IT	450	-34	147	564
ETHZ / SIS	450	69	179	699
Unibas /sciCORE	450	100	150	700
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	86	228
Methodology Development		5	7	12
IDEAL project	500			500
Personnel, consultancy and operating costs	2'678	1'555	1'299	5'531
TOTAL EXPENSES	10'167	3'879	3'834	17'879
Cash available end of year	7'566	8'299	9'080	9'080

Table 4 shows the cash flow statement 2022 of the Management Office compared with 2021. The main costs of the Management Office were salaries and working groups (remuneration of board members). The increased amounts paid for funding activities as compared to 2021 reflect the beginning of several projects of the second SPHN phase 2021 – 2024.

Table 4: Cash flow statement 2022 compared to 2021

Cash flow statement (direct method)	2022 in CHF	2021 in CHF
+ Cash received from SERI contribution - SAMS	7'352'900	7'331'500
+ Cash received from SERI contribution - SIB	2'915'154	2'906'580
Total cash received from SERI contributions	10'268'054	10'238'080
- Cash paid for Collaboration agreements	-7'400'000	-4'850'000
- Cash paid to Infrastructure dev. & Driver projects	-998'935	-1'586'980
+ Refund unused funds from finished Infrastructure dev. & Driver projects	0	3'573
- Cash paid to National Data Streams	-996'367	-75'000
+ Refund participation PHRT for National Data Streams applications	96'362	0
+ Refund unused funds ELSI support staff	25'000	-100'000
- Cash paid for HospFAIR	-1'150'000	0
- Cash paid for MedCo Pilot	-380'000	0
Total cash paid for funding activities	-10'803'940	-6'608'407
- Cash paid for personnel expenses	-462'913	-469'147
- Cash paid for operating expenses	-141'806	-184'532
- Cash paid related to activities of bodies and experts	-157'741	-105'072
+ Cash received miscellaneous	0	27'659
Total cash paid related to management expenses	-762'460	-731'092
Cash flow from operating activities	-1'298'346	2'898'581
Net increase/decrease in cash	-1'298'346	2'898'581
Cash on 1.1	12'997'244	10'098'663
Cash on 31.12	11'698'898	12'997'244

4 Board Members

National Steering Board

Prof. Urs Frey, Basel
Chairperson

Prof. Effy Vayena, Zürich
Chair SPHN ELSI advisory group, ex officio

Nicolas Rosat, Lausanne
Chair SPHN Hospital IT Alignment Group, ex officio

Solange Zoergiebel, Lausanne, *new*
Ad interim Chair SPHN Hospital IT Alignment Group, ex officio

Dr. Thomas Geiger, Bern
Managing Director, ex officio

Dr. Benedikt Knüsel, Bern, *resigned*
State Secretary for Research and Innovation, ex officio

Dr. Stéphane Berthet, Genève

Prof. Christophe Dessimoz, Lausanne, *new*

Prof. Thomas Geiser, Bern

Prof. Claudia Kuehni, Bern

Dr. Olivier Menzel, Vuarrens

Prof. Falko Schlottig, MuttENZ

Prof. Gabriela Senti, Zürich

Prof. Jürg Steiger, Basel

Dr. Roger von Moos, Chur, *resigned*
Swiss Group for Clinical Cancer Researcher (SAKK), Guest

Dr. Ulf Petrusch, Bern, *new*
Swiss Group for Clinical Cancer Researcher (SAKK), Guest

Prof. Nicole Probst-Hensch, Basel

Prof. Beatrice Beck Schimmer, Zürich
Vice-Chairperson

Prof. Antoine Geissbühler, Genève
Chair SPHN National Advisory Board

Dr. Katrin Cramer, Basel
Director of the SIB Personalized Health Informatics Group, ex officio

Victoria Sarraf, Bern
FOPH, ex officio

Prof. Ron Appel, Lausanne, *resigned*

Prof. Detlef Günther, Zürich

Prof. Christian Leumann, Bern

Prof. Anita Rauch, Schlieren

Prof. Manuel Pascual, Lausanne, *resigned*

Prof. Mauro Oddo, Lausanne *new*

Prof. Didier Trono, Lausanne

Prof. Bernd Wollscheid, Zürich
PHRT, Guest

Dr. Simona Berardi Vilei, Bern, *new*
SNSF, Guest

Dr. Irene Knuesel, Bern, *resigned*
SNSF, Guest

Dr. Stéphanie Wyss, Bern
SNSF, Guest

Annette Magnin
Swiss Clinical Trial Organisation, Guest

Dr. Christine Currat, Lausanne
Swiss Biobanking Platform, Guest

Swiss School of Public Health, Guest

International Advisory Board

Prof. Russ Altman, USA
Chairperson

Prof. Iain Buchan, UK

Prof. Jan Hazelzet, The Netherlands

Prof. Paul Klenerman, UK

Prof. Dan Roden, USA

Prof. Søren Brunak, Denmark

Dr. Joan Dzenowagis, WHO

Prof. Marie-Christine Jaulent, France

Prof. Oliver Kohlbacher, Germany

Prof. Amalio Telenti, USA

Imprint

Editor

Swiss Personalized Health Network (SPHN)

Swiss Academy of Medical Sciences (SAMS)

Haus der Akademien, Laupenstrasse 7

3001 Bern, Switzerland

+41 31 306 92 95 | info@sphn.ch | www.sphn.ch

Authors

SPHN Management Office

- Thomas Geiger
- Liselotte Selter
- Christine Remund

Personalized Health Informatics group

- Katrin Cramer
- Michael Müller-Breckenridge
- Sabine Oesterle
- Julia Maurer
- Shubham Kapoor
- Patricia Fernandez Pinilla