SPHN Short Report (2020)

Yearly update and overview of activities

1. Editorial

The year 2020 was dedicated to the closure of the first SPHN funding period 2017-2020 and the transition to the second funding period 2021-2024. The COVID-19 pandemic obviously had a major impact on SPHN as it had worldwide on society, healthcare, government, research, and economy. Nevertheless, SPHN not only managed to keep up its activities and make important progress towards its goals, the ongoing crisis also clearly showed the importance of rapid accessibility and interoperability of high-quality health data, which are core goals of SPHN.

Measurable progress has been made in 2020 regarding the regulatory framework for SPHN-funded projects. The harmonized templates for Data Transfer and Use Agreements (DTUA) and Material Transfer Agreements (MTA) have been well-received and implemented by the SPHN partner institutions. In combination with the newly established ELSI (Ethical, Legal, Societal Issues) Helpdesk, operated by the SPHN Data Coordination Center (DCC), the time to execute an agreement for sharing sensitive data has been reduced from months to weeks. The SPHN templates are also widely used in the research community.

A number of Infrastructure Development projects reached their goals and were completed in 2020, providing important tools, concepts, and infrastructures from which SPHN will benefit in the next funding period. The Driver projects are still underway and were cost-neutrally extended, mainly because of delays caused by the COVID-19 pandemic. Nevertheless, they have evidently made progress, which is for example illustrated by the transfer of data from more than 6000 intensive care patients from all five university hospital data warehouses via the secure BioMedIT network in 2020.

The governance and organizational structures of SPHN were adapted to address the gaps and increasing complexity identified in 2019. The new National Advisory Board (NAB) has prioritized the issues and, mandated by the National Steering Board (NSB), established dedicated task forces for elaborating proposals for interoperability of cohort data, for a Swiss genomics and multi-omics network, and for data lifecycle management. In addition, the implementation of the semantic strategy and federated query system has successfully started.

Finally, the Swiss parliament approved in December 2020 further financing of the SPHN initiative for 2021-2024. The goals and budget for this second period were defined together with the State Secretariat for Education, Research and Innovation and the Federal Office of Public Health.

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 2020

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

In 2020, the implementation and management of the funding instruments defined in the Funding Regulations continued (total budget: CHF 46 million), albeit with some delays caused by the COVID-19 pandemic.

With respect to the collaboration agreements, the annual reports were submitted by the five university hospitals (UH) in a timely manner, despite being under tremendous strain from the COVID-19 crisis. The Management Office (MO) coordinated the reporting and evaluation process. Since not all milestones defined in the collaboration agreements were achieved, SPHN leadership conducted bilateral meetings with the management of each UH. These high-level talks resulted in very constructive mutual feedback and a pragmatic way forward to achieve the goals of the collaboration agreements. All 5 UHs were asked to present the progress, encountered obstacles, and needs for the future collaboration to the International Advisory Board (IAB) and peers from the SPHN community in the frame of the SPHN Review Meeting held on 16 and 17 November 2020. As a result, the alignment of UH information systems strategies between UHs and with SPHN was subsequently strengthened by the creation of the SPHN Hospital IT Strategy Alignment group (HIT-STAG) with leading IT-representatives from all UHs. They also agreed to participate in the HospFAIR initiative, aiming to elaborate the regulatory, technical and qualitative feasibility to merge 100'000 high quality, de-identified patient-related data sets according to FAIR standards (**F**indable, **A**ccessible, **I**nteroperable and **R**eproducible). This proof of principle project will test and optimize the ability of UH and SPHN-related research infrastructures to share large scale health data in a regulatory, technical and qualitatively appropriate manner.

Of the 25 SPHN-funded projects, four Infrastructure Development projects successfully completed their work and received the final payment. One project had to stop after a successful pilot phase, because the legal basis for a national deployment is currently lacking. All other projects were either granted a cost-neutral extension or have an original runtime beyond 2020. The annual reports of all projects were reviewed by the different boards of SPHN. Recommendations concerning the continuation of payments were submitted to the NSB by the NSB Ausschuss.

Finally, five representative Infrastructure Development projects presented the progress and potential of SPHN-developed infrastructures to the IAB during the SPHN Review Meeting, along with presentations by the chairpersons of three SPHN task forces. The feedback from the IAB members will be integrated into the planning activities for the second phase of SPHN.

A lay summary of each project is available on the SPHN website: www.sphn.ch/en/projects.html

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2.2 Data Coordination Center & BioMedIT

Within SPHN, the SIB Swiss Institute of Bioinformatics is responsible for two assignments: the management of the SPHN Data Coordination Center (DCC) and the BioMedIT project. The SIB group in charge of these two assignments is the Personalized Health Informatics (PHI) group, based in Basel.

The DCC is responsible for the coordination and the technical implementation of key milestones of the SPHN initiative, as well as for promoting harmonization efforts and process innovation throughout the Swiss health data ecosystem. Its mandate further covers the promotion of the development and implementation of nationwide standards for data semantics and exchange mechanisms to reach the interoperability goals of SPHN. The DCC closely collaborates with the university hospitals and other data providers, various expert working groups and task forces, and the BioMedIT network partners. The DCC furthermore takes a lead on education and training across the network, and provides helpdesk functions regarding technical as well as ELSI matters that arise in the community.

Given the sensitive nature of health-related information, research using patient data calls for high levels of security and data protection in Information and Communication Technology (ICT) infrastructures, processes and expertise to fulfil stringent legal, regulatory, and ethical requirements. The key challenge here is to provide researchers with an integrated solution. The PHI group, in close collaboration with the network partners, has set up the BioMedIT network as part of SPHN to provide all authorized researchers in Switzerland with easy access to collaborative analysis of confidential data without compromising data privacy. Under the umbrella of the DCC, the PHI group operates a central service layer and is responsible for the coordination, management, and direction of the implementation of the BioMedIT Network project.

2.2.1 DCC activities and achievements in 2020

In the last year of the first SPHN funding phase, important progress was made regarding the SPHN interoperability framework: A substantial number of new concepts have been semantically defined and a FAIR data framework based on RDF (resource description framework) has been developed to define, represent and store clinical data using common semantics. Health-related data from any source can be expressed within this framework and semantically annotated. The encoded data are referenced by standard uniform resource identifiers (URIs) that allow direct linking to common ontologies (such as SNOMED CT). This is enabled by the flexibility of RDF, allowing easy extension and merging of data, empowering researchers to harness the relations between concepts in a terminology together with the collected data to derive new knowledge. In a workshop in June, SPHN brought together key players from academia and pharma industry to agree on common foundations to jointly improve technical and semantical data interoperability in Switzerland.

To enable researchers to verify the feasibility of a project, SPHN is putting in place a federated query system allowing simple counting queries against a subset of clinical data from all five university hospitals. At the end of 2020, a total of 385'000 patients and over 130 Mio data elements have been included in the system, which is planned to be opened to researchers in the course of 2021.

SPHN has widened its focus to datatypes beyond clinical routine data that are important for personalized health research with the kick-off of three new SPHN task forces for genomics, cohorts and registries, and data life cycle management, which are closely supported by the DCC. First milestones regarding the FAIRification of cohort data could already be achieved: In November 2020, PHI signed a contract with the

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international Maelstrom catalogue to bring harmonized meta-data of large Swiss cohorts to the catalogue, giving these high-quality and rich data sets the appropriate exposure.

In December, with the help of SIB legal and in close collaboration with hospital representatives, the DCC published a modular set of legal agreement templates that can be used for collaborative research projects within SPHN and beyond. The new templates build on the SPHN DTUA (version 1.0) developed in 2019 and establish the contractual framework necessary to conduct a multicenter research project involving the exchange of health-related data. These agreements settle the issues that need to be legally addressed and define the rights, obligations, and responsibilities of all parties involved. For projects running over the BioMedIT network infrastructure, the templates also provide controller-processor amendments. The general acceptance of these templates by all partners significantly reduced the waiting time for individual projects for the consortial contracts to be signed.

In the course of the year, the DCC organized 10 SPHN webinars and 9 national and international expert talks aiming to build competences and share know-how and best practices within the SPHN community.

2.2.2 BioMedIT activities and achievements in 2020

In 2020, the two essential BioMedIT tools for data transfer (sett) and project/user management (BioMedIT portal) have been officially released. sett, the secure encryption and transfer tool, is an easy-to-use, open-source tool to support the full process of complex data packaging and secure data transfer between data providers and destination project spaces on BioMedIT. The BioMedIT portal is the one-stop entry to BioMedIT (https://portal.dcc.sib.swiss/). After logging in with a SWITCH edu-ID account, users see an overview of their BioMedIT resources – no matter which BioMedIT node their data is stored on – and can easily access their projects via a virtual desktop or a virtual terminal session from the portal, view their data transfers, handle their keys, as well as manage the user permission to their projects.

In summer 2020, first sets of pseudonymized patient data for an SPHN funded project were successfully transferred over the BioMedIT Network (in the realm of the SPHN PSSS Driver Project). Automated data transfer logging and validation has been implemented, and a first research article on BioMedIT has been published in Studies in Health Technology and Informatics (DOI 10.3233/SHTI200348), describing the aims, the architecture and the functionalities of the BioMedIT network.

A comprehensive security report on BioMedIT central services and the three BioMedIT Nodes has been approved by security experts of university hospitals, bringing BioMedIT closer to the goal of establishing itself as a trusted partner in the system. In addition, substantial progress has been made regarding the technical documentation, process definition, and the production of SOPs, work instructions and user guides.

In December 2020, a project running on BioMedIT using the central services and tools, has produced initial results and published a pre-print. At the end of 2020, a total of 44 projects were running on the secure BioMedIT infrastructure, 17 in the framework of SPHN and PHRT, and over 150 users were registered in the portal. In addition, 16 data providers have been onboarded to the network. PHI answered over 140 helpdesk tickets and signed over 70 keys for data en- and decryption. Moreover, international collaborations, especially in the area of privacy preserving computation (e.g., Personal Health Train, ELIXIR, EOSC, 1+MG, GA4GH, etc.) have been strengthened.

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2.3 National and international collaborations

The SPHN Management Office (MO) underwent personnel changes in 2020, most notably with a new Managing Director. In August 2020, Dr. Myriam Tapernoux ad interim took over the lead of the MO from Dr. Adrien Lawrence and guided the transition from the first to the second funding period of SPHN. Two months later, Dr. Thomas Geiger joined the MO as scientific coordinator.

2.3.1 National collaboration

Throughout the year, SPHN has further strengthened the collaborations with the relevant national partners such as the ETH Domain program Personalized Health and Related Technologies (PHRT), Swiss Biobanking Platform (SBP), Swiss Clinical Trial Organisation (SCTO), Swiss National Science Foundation (SNSF), and the Schweizerische Arbeitsgemeinschaft für Klinische Krebsforschung (SAKK) by organizing several coordination meetings with their respective directors, to better define the roles and responsibilities for overlapping topics that are relevant for all stakeholders. A number of shared and aligned task forces and working groups have been mandated to elaborate concepts and guidelines for specific technical, regulatory or policy aspects of specific topics, as described in www.sphn.ch/task-forces and www.sphn.ch/working-groups. The coordination of such efforts is in line with the SERI mandate.

Unimedsuisse agreed to facilitate the negotiation of the new collaboration agreements between SPHN and university hospitals.

Furthermore, SPHN/BioMedIT participated in several national and international events, such as the Digital-ID Conference (20-21/01/2020), which was also financially supported by SPHN, the Clinerion webinar "Benefits of a Federated Research Network/Ecosystem" (20/05/2020), the Roche Tower Talk series (27/05/2020), the Elixir Bioinformatics Industry Forum (23/06/2020), the Policy Kitchen workshop on "My Data - My Health" (26/08/2020), a "Parlamentarieranlass" on "The added value of health data for strong research and a healthy society", the Future Labs Live conference (28-29/09/2020), and the SAPHIRe webinar on "Access to health data" (29/10/2020).

2.3.2 International collaboration

SPHN is a member of the International Consortium for Personalized Medicine (ICPerMed) since July 2017 and attends the Executive Committee meetings that take place twice per year. In 2020, SPHN continued its collaboration with the Global Alliance for Genomics and Health (GA4GH). GA4GH is an international, nonprofit alliance to accelerate the potential of research and medicine to advance human health. While the participation in ICPerMed allows SPHN to coordinate its efforts with other funding bodies, this additional collaboration allows SPHN to align with GA4GH's global efforts, contributing to the development of international frameworks and standards. Given that the exchange of knowledge and expertise at the international level is essential, such a collaboration will be beneficial to the SPHN initiative, as well as its partners and the biomedical community in general.

Representatives of SPHN furthermore presented SPHN at numerous international conferences and meetings.

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2.4 Events & Communications

SPHN has continuously made a mapping and gap analysis of their efforts and openly presents the degree of implementation of the various projects in the Swiss landscape. Interested citizens and patients, researchers and clinicians can find these overviews on www.sphn.ch and in the SAMW report (www.samw.ch/en/Publications/Proceedings).

In 2020, SPHN organized and co-organized the following events:

− Strengthening the health data-driven ecosystem in Switzerland: academia and pharma industry agree on common foundations to jointly improve technical and semantical data interoperability in Switzerland 15/06/2020;
− The SPHN Review Meeting on 16 and 17/11/2020. A new SPHN fact sheet was produced for this occasion.

SPHN communicates continuously via its website (www.sphn.ch; available in English, French, and German), Twitter, LinkedIn, and punctual newsletters. SPHN articles have also appeared in several SAMS newsletters and the SAMS bulletin.

3. Finance

The payments of the third installments related to the collaboration agreements with the university hospitals and the projects awarded in the frame of the 2017 call were made in 2020 and beginning of 2021, as well as the second installments to the projects awarded in the 2018 call for proposals.

The initial business plan of 2 June 2017, from which all the activities of SPHN are derived, was modified in 2018 and again in 2019 because the operating expenses of the Data Coordination Center and Management Office were found to be lower than initially planned and because some completed projects returned unused funds. The NSB decided in September 2020 to allocate the positive balance of the 2017-2020 period to the planned HospFAIR project and the SERI approved the respective carryover of funds to the second SPHN period 2021-2024. Table 1 summaries how the SERI funds were used between 2017 and 2020 and how the remaining liquidities will be used over the next years to projects supported during the 1st phase.

Using the same format as Table 1, Table 2 shows an overview of the usage of funds allocated to the BioMedIT Network during the 2017-2020 period. Not all funds provided by the SERI for phase I were spent during the first four years. The remaining funds have been transferred to phase II as provisions with specific allocation.

Table 1: First SPHN funding period funds usage

Funding period 2017-2020 SERI funds usage

All amounts in kCHF

Accounts description	Cash flow	Cash flow forecast			TOTAL
	2017-2020	2021	2022	2023	
Incomes					
SERI Contribution - SAMW	30 000				**30 000**
SERI Contribution - SIB	19 702				**19 702**
TOTAL INCOMES	**49 702**	**0**	**0**	**0**	**49 702**
Infrastructure implementation projects					
ELSI projects (including project support staff)	260				**260**
Data Coordination Center	2 822				**2 822**
Collaboration agreements with University Hospitals	12 750	2 250			**15 000**
HospFAIR		1 250	3 810		**5 060**
Projects : call 2017					
Infrastructure development projects	2 290	82			**2 372**
Driver projects	11 000	323	1 141		**12 464**
Refund finished projects	-150				**-150**
Projects : call 2018					
Infrastructure development projects	1 842	375	48		**2 265**
Driver projects	5 213	528	1 204	296	**7 240**
Cash flow Management Office and Bodies	2 354	14			**2 368**
TOTAL EXPENSES	**38 382**	**4 822**	**6 202**	**296**	**49 702**
Cash available end of year (2017-2020 funding)	**11 321**	**6 498**	**296**	**0**	**0**

Table 2 BioMedIT Network SERI funds usage (Phase I)

Funding period 2017-2020 SERI funds usage: BioMedIT Network project

All amounts in kCHF

Accounts description	Cash flow 2017-2020	Cash flow forecast				TOTAL
		2021	2022	2023	2024	
Incomes						
SERI Contribution - SIB BioMedIT Network	17 732					**17 732**
TOTAL INCOMES	**17 732**	**0**	**0**	**0**	**0**	**17 732**
Hardware & Personnel						
SIB / Core-IT	1 400					**1 400**
ETHZ / SIS	700					**700**
Unibas /sciCORE	700					**700**
Addition support node securtiy MS	340	710				**1 050**
Node security officer	0	600	600	600	600	**2 400**
Interoperability WG						
SIB / Vital-IT	450					**450**
ETHZ / SIS	450					**450**
Unibas /sciCORE	450					**450**
PHRT Platforms						
Mass Spectrometric P. in Zurich	900					**900**
Genome Center in Geneva	525	375				**900**
Projects funded						
SVIP O	949					**949**
Driver project GA4CH - M.Baudis	125					**125**
RDF / Data management		450	450	450	450	**1 800**
Metadata catalogue / Repositories		500	1 000	531	250	**2 281**
IDEAL project	500					**500**
Personnel and operating costs	2 678					**2 678**
TOTAL EXPENSES	**10 167**	**2 635**	**2 050**	**1 581**	**1 300**	**17 732**
Cash available end of year (2017-2020 funding)	**7 566**	**4 931**	**2 881**	**1 300**	**0**	**0**

The main costs of the Management Office were salaries, working groups (travel expenses, remuneration of group leaders), communication and events.

The funds needed to pay the remaining amounts of the projects selected during the period 2017-2020 are currently remaining on the bank accounts of SPHN and will be distributed until 2023 as described in Table 1. As a consequence, the amount paid for negative interests for the year 2020 is higher than last year (41 kCHF for 2020 vs 21 kCHF for 2019). Over the entire 1st financing period, the negative interests paid represent approximately 108 kCHF (**Erreur ! Source du renvoi introuvable.**).

Table 3: Cash flow statement 2020 compared to 2019

Cash flow statement (direct method)	2020 in CHF	2019 in CHF
+ Cash received from SERI contribution - SAMS	7 598 500	7 447 900
+ Cash received from SERI contribution - SIB	4 852 150	5 000 000
Total cash received from SERI contributions	**12 450 650**	**12 447 900**
- Cash paid for Collaboration agreements	-2 750 000	-5 000 000
- Cash paid to Data Coordination Center	0	-509 000
- Cash paid to Infrastructure dev. & Driver projects	-5 052 986	-8 626 890
+ Refund unused funds from finished Infrastructure dev. & Driver projects	150 609	
- Cash paid for ELSI support staff	-100 000	-40 000
Total cash paid for funding activities	**-7 752 377**	**-14 175 890**
- Cash paid for personnel expenses	-387 515	-446 990
- Cash paid for operating expenses	-137 060	-114 820
- Cash paid related to activities of bodies	-67 190	-80 097
+ Cash received miscellaneous	14 800	10 777
Total cash paid related to management expenses	**-576 965**	**-631 130**
Cash flow from operating activities	**4 121 308**	**-2 359 120**
Net increase/decrease in cash	4 121 308	-2 359 120
Cash on 1.1	7 200 082	9 559 202
Cash on 31.12	**11 321 390**	**7 200 082**

4. Board Members

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