SPHN Short Report (2019)

Yearly update and overview of activities.

1. Editorial

The year 2019 was dedicated to the continuation of the activities initiated during the first two years of SPHN. At the beginning of the year, the main goals and preliminary budget for the next SPHN funding period 2021-2024 were submitted to the SEFRI and were well received. In addition, an on-boarding session was organized for the projects supported by the second Call for proposals so that these could all take up their activities in the first half of the year.

As part of the national harmonization efforts and in order to facilitate research collaboration in Switzerland, SPHN, Swiss Biobanking Platform and representatives of the universities (Basel, Bern, Geneva, Lausanne, Zurich), the institutions of the ETH Domain (EPFL, ETHZ) and the five university hospitals, developed harmonized templates for Data Transfer and Use Agreement (DTUA) and Material Transfer Agreement (MTA) documents. So far, the above-mentioned institutions had been using their own DTUA and MTA models.

Based on the structured information provided in the annual reports submitted by the first 15 granted projects and the Collaboration Agreement works in the University Hospitals, a mapping and gap analysis was performed. This mid-term analysis allowed to measure the progress made and to create a national map, indicating which types of infrastructures (platforms, algorithms, document templates, etc.) are available or under development for personalized health research. In addition to the reports, a review of the overall initiative by the International Advisory Board allowed identify the gaps of the initiative with a particular need for action.

As a major technical milestone in 2019, an agreement on the implementation of the Federated Query System in the five University Hospitals could be concluded with a signature. This system will allow Swiss researcher to assess the amount and type of data available in the University Hospitals and thus conduct feasibility studies. Also, The Clinical Data Semantic Interoperability (CSI) Working group elaborated a semantic strategy and published 3 Dataset releases.

Finally, SPHN's visibility was increased by modernization of the corporate design, the development of an updated fact-sheet as well as the development of a new website for SPHN.

Yours sincerely,

Prof. Urs Frey
Chairperson of the
National Steering Board

Prof. Peter Meier-Abt
Vice-Chairperson of the
National Steering Board

Dr. Adrien Lawrence
Managing Director

2. Activities and achievements in 2019

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 2019, the implementation and management of the funding instruments defined in the Funding Regulations continued (total budget: CHF 46 million):

With respect to the Collaboration agreements, the annual reports were submitted by the five University Hospitals in a timely manner. The Management Office (MO) coordinated the reporting and evaluation process. All milestones defined in the collaboration agreements were achieved. As a feedback to the University Hospitals (UH), the implementation of the general consent model approved by unimedsuisse and swissethics until 31 March 2020 was deemed highly desirable by the National Steering Board (NSB).

Concerning the 25 SPHN-funded projects, the 10 selected projects from the Call 2018 took up their activities and published a non-scientific summary on the SPHN website. During an onboarding meeting in March 2019, the new projects were introduced to the grant management guidelines and expectations from the SPHN governance, Data Coordination Center (DCC) and BioMedIT. Meanwhile, the annual reports of the 15 projects awarded in 2017 were reviewed by the different boards of SPHN and recommendations concerning the continuation of the payment were submitted to the NSB by the NSB Ausschuss. Finally, the 15 Infrastructure Development projects and Drivers projects were asked to present the progress and obstacles encountered to the International Advisory Board (IAB) and peers from the SPHN community in the frame of the SPHN Review Meeting of 5-6.9.2019.

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

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, who is in charge of these two assignments, is the "Personalized Health Informatics" (PHI) Group, based in Basel.

The mandate of the DCC is to promote the development and implementation of nationwide standards for data semantics and exchange mechanisms in order to meet the interoperability goals of the SPHN initiative. Within this scope, the DCC is responsible for the coordination of the SPHN-Driver projects. In addition, the DCC is responsible for the technical implementation (on a national level) of milestones B (Definition of data interoperability standards), C (Clinical research data management at hospitals) and D (Biobanking interoperability) of the collaboration agreements between SAMS/SPHN and the University Hospitals. Further, the DCC has the mandate to assess, if work products of the collaboration agreements meet the relevant criteria. Many activities of the DCC have a direct link to the BioMedIT project, the aim of which is

to establish a coordinated network of ICT core facilities at Swiss universities for secure processing of biomedical data. This network is centered between the University Hospitals and researchers anywhere in Switzerland, thus enabling authorized project members to access and analyze the data with access to this network.

2.2.1 DCC activities and achievements in 2019

Following Prof. Torsten Schwede's appointment to the Vice Rectorship of the University of Basel in 2018, Dr. Katrin Crameri was installed as the Director of the PHI Group in March 2019.

In 2019, PHI also recruited two Clinical Data Specialists to support the Clinical Data Semantics Interoperability Working Group and core DCC functions. Both have been instrumental in advancing one of PHI's mandates: to promote the development and implementation of nationwide standards for data semantics and exchange mechanisms. Concerning semantic interoperability, the PHI group together with the expert working group completed the definition of the basic routine data, as required in the collaboration agreements between SPHN and the university hospitals, and most of the specific routine data, which is needed to support the SPHN projects of the first funding round. The group published three releases of the SPHN dataset in 2019. Concerning the choice of transport and storage format within SPHN, different possibilities were evaluated, implying that the format allows transport of data without affecting the semantic meanings and the highest degree of flexibility when it comes to data reuse. This evaluation revealed RDF as a potential format of choice. A two-day hackathon in November 2019 resulted in the successful integration of mock data form all five hospitals in RDF.

The setup of a federated query system over all five university hospitals enabling feasibility studies for researchers took an important step forward in 2019: all involved parties approved the collaboration agreement, and the PHI group started the detailed planning concerning the adaptation of the data model and GUI of the product of choice, and regarding the specifications for the ETL process – in close collaboration with the responsible technical experts at the University Hospitals.

Another important mandate of the DCC is to contribute to overcoming silos and facilitating cross-domain, cross-institutional research, resulting in sustainable infrastructures for data sharing and further use of health and health-related data. With the contribution of the PHI group, the SPHN Driver Projects and, to an extent the SPHN Infrastructure development projects, drive the development of clinical data management systems in all University Hospitals by challenging data interoperability and data sharing principles within the entire network. In March 2019, the PHI group successfully on-boarded the second round of SPHN funded projects, jointly determining the necessary steps to be taken in order to get the projects started.

After two years of development work, the PHI Group's communication activities increased substantially in 2019: In preparation for the International Advisory Board Meeting in October, the PHI group in collaboration with the SPHN Management Office produced a first comprehensive SPHN Fact Sheet, outlining the mandate, goals, governance, partners, planned infrastructure, and projects of the initiative. Over the course of the year, 16 DCC seminar and training webinars were organized aiming to build competences and share know-how and best-practices within the SPHN network. In addition, SPHN was presented in 2019 by the PHI Director and DCC representatives at numerous national and international events. Moreover, a new website was set up, combining the former websites of the PHI Data Coordination Centre and SPHN, and therefore functioning as a one-stop-shop for all the stakeholders and contributors in the realm of the SPHN Initiative. The DCC collaborated and exchanged actively with numerous national key organization in the

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field of biomedical and clinical research, and with relevant actors involved in personalized health and data-driven medicine.

A close dialogue was also maintained with similar international initiatives in the framework of the national initiative network. SPHN was selected in 2019 by the Global Alliance for Genomics and Health (GA4GH) to join an international group of leading initiatives. This group works collaboratively to create frameworks and standards to enable responsible research in the field of genomics and personalized health. Representatives of the DCC were actively engaged in the GA4GH Connect Implementation Meeting in the UK in spring 2019 and in the GA4GH 7th Plenary Meeting in Boston, USA, in October. This collaboration allows SPHN to align with GA4GH's global efforts, contributing to the development of international frameworks and standards, and at the same time import international knowledge and expertise to the biomedical community in Switzerland.

2.2.2 BioMedIT activities and achievements in 2019

In parallel of the elaboration of the SPHN initiative, the BioMedIT network project was funded as part of the Swiss Roadmap for Research Infrastructures. The aim of the BioMedIT network is to provide all researchers in Switzerland with access to a service infrastructure for collaborative analysis of confidential data without compromising data privacy. Security measures for Information and Communications Technology (ICT) systems are necessary to protect confidential information from unauthorized use, modification, loss or release. Therefore, the BioMedIT network architecture includes key elements of an effective ICT security system, such as (i) Monitoring and controlling access to confidential information; (ii) Safe transmission of data, and (iii) Secure storage and disposal of data.

In the course of 2019, all three BioMedIT nodes (SIS/Leonhard Med of the ETHZ, sciCOREmed of the University of Basel, and Core-IT of SIB) established multi-tenant high performance storage and compute resources providing a broad range of secure services to store, manage, process and share biomedical data. At the end of 2019, the BioMedIT infrastructure featured data storage capacity approaching in total 5 PB, support for data encryption, secure backup, private-cloud and high performance computing (HPC) leveraging more than 3000 CPU cores and 324 GPUs. In all three nodes, virtualization technologies have been applied to establish private-cloud environments in which each scientific project is completely isolated from other projects with respect to data and compute resources. In order to ensure a standardized and secure data transfer, an end-to-end encryption process from the data source through the BioMedIT network to the designated project space has been developed, based on public-key cryptography. Key management was set up, which is provided as a central service to users of the network. A global ID management has been put in place in two of the three nodes, allowing a single sign-on using the SWITCH edu-ID. A central project and user database has been developed in 2019 and will be implemented as part of a full featured BioMedIT information management system.

An online on-demand community Data Privacy and IT Security Training as well as an online exam have also been developed in 2019. The establishment of the legal framework for data sharing in collaborative research projects using the BioMedIT infrastructure was one of the main challenges in 2019. With the contribution of BioMedIT network members, a joint template for a Data Transfer and Use Agreement for SPHN was published in spring 2019. The BioMedIT network was presented and discussed at over 20 national and international events in 2019.

2.3 National and international collaborations

2.3.1 National collaboration

In 2019, SPHN has been re-enforced the collaboration with the relevant national partners such as the ETH Domain program PHRT, Swiss Biobanking Platform (SBP), Swiss Clinical Trial Organisation (SCTO) by organizing several coordination meetings among the directors of the different organizations, with the aim to better define the roles and responsibilities for overlapping topics that are relevant for all stakeholders. Informal friendly chats were further organized with FMH, SNSF, Science et Cité, unimedsuisse and EPFL in order to strengthen the national collaboration.

Furthermore, SPHN participated at several national events, such as the national conference Santé2020 (31.1.2019), the inauguration of the Bern Precision Medicine Center (20.5.2019), the workshop santéneXt in Zurich (14.11.2019), DayOne Experts (3.12.2019), Workshop «Clinical routine data in paediatric research: The Swiss approach» (5-6.12.2019). The latter event and the [BC]² Conference 2019 (10-11.9.2019) were furthermore financially supported by SPHN.

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 addition, the Managing Director participated in the writing group who developed the « ICPerMed Vision Paper », which was published on 25.9.3019.

At the beginning of 2019, SPHN was selected to join an international group of 22 leading initiatives coordinated by the Global Alliance for Genomics and Health (GA4GH). GA4GH is an international, nonprofit alliance formed in 2013 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 new collaboration will allow 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.

SPHN was further presented by Representatives of SPHN at numerous international conferences and meetings.

2.4 Events & Communications

In 2019, SPHN organized and co-organized the following events:

– Onboarding information for projects awarded in the Call 2018, Bern, 1.3.2019;
– The SPHN Review Meeting was co-organized with the PHI group from 5 to 6.9.2019 in Basel with the support of the Personalized Health Basel team. A new fact sheet was produced on this occasion;
– The MO and the PHI Group worked closely together to modernise SPHN's corporate design with the aim of having a common identity for the MO and the PHI Group. A new website integrating the content of sphn.ch and dcc.sib.swiss was launched in January 2020;
– Publication of articles in the SAMS newsletter, newsletters and a flyer on SPHN.

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In addition, SPHN communicates continuously via its website (www.sphn.ch; available in English, French, and German), Twitter, LinkedIn, and punctual newsletters.

3. Finance

The payments of the second installments related to the collaboration agreements with the University Hospitals and the projects awarded in the frame of the 2017 call were made in 2019, as well as the first payments 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 slightly modified a first time in 2018 as the Management Office's operating costs were lower than expected. The resulting surplus was used to increase the funds allocated to the call for proposals 2018.

A second adaptation was decided on 21 November 2019 because the operating expenses of the Data Coordination Center were found to be lower than initially planned. Since this meeting, the SERI announced that the cuts announced on the 2020 contributions would not be applied. This represents another positive effect on the finances of the initiative (Table 1).

The gap analysis done after the 2018 reporting process and the SPHN Review Meeting 2019 with the International Advisory Board (IAB) helped to identify certain points on which the generated surplus should be used.

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Table 1: Initial business plan of the initiative for the 2017-2020 period compared to actual business plan after the different modifications

Description [M CHF]	Budget according to the inital business plan	SERI cuts	Reallocations /adaptations	Budget after cuts and reallocations	Difference with initial plan
Incomes					
SERI - SAMW contribution	30.0			30.0	
SERI - SIB contribution	20.0	-0.3		19.7	
Total incomes	**50.0**			**49.7**	**-0.3**
Expenses					
Infrastructure implementation					
Collaboration agreements	15.0			15.0	
ELSI support staff	0.2		0.1	0.3	
DCC	5.8		-3.0	2.8	
HospFAIR			*3.0*	*3.0*	
Total	**21.0**			**21.1**	**0.1**
Driver and infra. Development projects					
Call 2017	18.5		-2.8	15.7	
Call 2018	6.5		3.2	9.7	
Total	**25.0**			**25.3**	**0.3**
Total projects contributions	**46.0**			**46.4**	**0.4**
Operating costs					
Management Office	4.0		-1.4	2.6	
Reserve			0.1	0.1	
Total	**4.0**			**2.7**	**-1.3**
Total expenses	**50.0**			**49.1**	**-0.9**
Difference between incomes and expenses	**0.0**			**0.6**	

The main costs of the Management Office were salaries, working groups (travel expenses, remuneration of group leaders), communication and events. The burden resulting from the banks' passing on the costs of negative interests rates adopted by the Swiss National Bank to customers are still high in 2019 (21 kCHF in 2019 and 2018) (Table 2).

Table 2: Cash flow statement 2019 compared to 2018

Cash flow statement (direct method)	2019 in CHF	2018 in CHF
+ Cash received from SERI contribution - SAMS	7 447 900	7 453 600
+ Cash received from SERI contribution - SIB	5 000 000	4 850 000
Total cash received from SERI contributions	**12 447 900**	**12 303 600**
- Cash paid for Collaboration agreements	-5 000 000	-5 000 000
- Cash paid to Data Coordination Center	-509 000	-2 313 000
- Cash paid to Infrastructure dev. & Driver projects	-8 626 890	-6 664 904
- Cash paid for ELSI support staff	-40 000	-80 000
Total cash paid for funding activities	**-14 175 890**	**-14 057 904**
- Cash paid for personnel expenses	-446 990	-301 102
- Cash paid for operating expenses	-114 820	-199 010
- Cash paid related to activities of bodies	-80 097	-128 600
+ Cash received miscellaneous	10 777	
Total cash paid related to management expenses	**-631 130**	**-628 712**
Cash flow from operating activities	**-2 359 120**	**-2 383 016**
Variation of SAMS current account	0	6 978 096
Cash flow from financing activities	**0**	**6 978 096**
Net increase/decrease in cash	**-2 359 120**	**4 595 080**
Cash on 1.1	9 559 202	4 964 122
Cash on 31.12	**7 200 082**	**9 559 202**

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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

Katrin Crameri, Adrien Lawrence, Liselotte Selter, Cédric Petter