Swiss Personalized Health Network: Report of the International Advisory Board

9 December 2019

1. Introduction

The Swiss Personalized Health Network (SPHN) is a national initiative designed to promote personalized medicine and personalized health in Switzerland. SPHN contributes to the development, implementation, and validation of a nationally coordinated infrastructure as a basis for making health-related data interoperable and exchangeable across Switzerland. A total of CHF 68 million was allocated to the initiative for the first funding period 2017-2020 with special emphasis on developing interoperable clinical data management systems enabling effective exchange of patient data. In the long-term, public health and "healthy citizen" data will also be integrated.

SPHN supports the development and implementation of coordinated infrastructures by means of two funding schemes:

- **Bottom-up:** selection of projects through competitive calls for proposals to lead the development of infrastructures and test them with concrete research projects (Infrastructure development projects and Driver projects);
- **Top-down:** funding of compatible data management systems in the University Hospitals through Collaboration Agreements.

In addition, a secure and cutting-edge IT environment (BioMedIT, a project of SIB Swiss Institute of Bioinformatics) is established to support computational, biomedical research and clinical bioinformatics, ensuring data privacy and technical performance.

In the second funding period (2021-2024), the SPHN initiative shall continue on the path that was paved in the first four years and focus on the consolidation of the developed infrastructure. Preparatory work for extension of its activities to non-University Hospitals, strengthening the empowerment of patients and healthy citizens, as well as addressing the question of public-private partnership are envisaged.

2. Role and activities of the International Advisory Board

2.1 Role of the International Advisory Board

The International Advisory Board (IAB) of SPHN, chaired by Prof. Russ Altman, Stanford University, is composed of 10 international experts who are independent of both the SPHN organization and partner institutions:

- Prof. Russ Altman, Stanford University, USA
- Prof. Søren Brunak, University of Copenhagen, Denmark
- Prof. Iain Buchain, University of Liverpool, United Kingdom
- Joan Dzenowagis, World Health Organization
- Prof. Jan Hazelzet, Erasmus University Rotterdam, The Netherlands

- Dr. Marie-Christine Jaulent, INSERM, France
- Prof. Paul Klenerman, University of Oxford, United Kingdom
- Prof. Oliver Kohlbacher, University of Tübingen, Germany
- Prof. Dan Roden, Vanderbilt University, USA
- Prof. Amalio Telenti, The Scripps Research Institute, USA

Based on its mandate and article 13 of the Rules of Procedure, the Board has the following duties:

1. Review and assess funding proposals submitted to SPHN calls for proposals;
2. Provide advice and expertise on the strategy to the National Steering Board;
   review the initiative as a whole every two to three years.

2.2 Review of proposals submitted to the call for proposals 2017

The first call for proposals launched in June 2017 was open to applications for two types of projects: Infrastructure development projects and Driver projects. For both types of projects, the call was coordinated with the 'Personalized Health and Related Technologies' (PHRT) program of the ETH Domain.

A total of 38 proposals were received by 15 September 2017 (16 Infrastructure development projects, 22 Driver projects including 11 applications requesting co-financing with PHRT) requesting a total amount of CHF 58.6 million. The 38 proposals passed the formal check performed by the SPHN Management Office and were evaluated by the IAB. Each project proposal was reviewed independently by a referee and co-referee and their assessments were used as a basis for discussion during the evaluation meeting that took place in September 2017. Joint SPHN-PHRT proposals were evaluated independently by the IAB and the PHRT Evaluation Committee. At the end of the meeting, the IAB made funding recommendations to the National Steering Board (NSB) of SPHN with respect to the 38 proposals submitted.

Based on the recommendation of the IAB and – for the joint SPHN-PHRT proposals – also the recommendation of the PHRT Evaluation Committee, the NSB decided to support 8 Infrastructure development projects and 7 Driver projects for a total amount of CHF 15.66 million, of which 3 were co-funded by SPHN and PHRT. The remaining CHF 2.84 million budgeted for the call for proposals 2017 was allocated to the budget of the call for proposals 2018.

In addition, the IAB made the following recommendations:

- SPHN governance should ensure the coordination of the three funded SPHN oncology Driver projects;
- A targeted call for proposals in the area of imaging should be organized;
- The area of public health and citizen science should be emphasized;
- SPHN should ensure that project implementation and progress will be evaluated and benchmarked;
- The progress of the projects funded in 2017 should be presented and discussed at the next IAB meeting in 2019.

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Figure 1: Statistics of the call for proposals 2017

Call 2017	Total Applications received	Joint SPHN-PHRT proposal	Budget		
			Requested	Available	Difference
Infrastructure development projects	16	0	5'729'427		
Driver projects	22	11	52'705'667		
Total	38	11	58'435'094	18'500'000	39'935'094

2.3 Review of proposals submitted to the call for proposals 2018

The second call for proposals 2018 was also open to Infrastructure development projects and Driver projects and was again coordinated with the 'Personalized Health and Related Technologies' (PHRT) program of the ETH Domain.

Funding applications could be submitted from all research areas; however, in order to address gaps identified by the IAB in the previous year, priority would be given to projects in the following three areas:

1. Imaging and radiology interoperability;
2. Public health and healthy citizens;
3. Nationwide interoperability of cohorts and registries.

Thirty-eight proposals were received by 30 June 2018 (18 Infrastructure development projects, 20 Driver projects, including 11 requesting co-financing with PHRT) requesting a total amount of CHF 31.8 million. All proposals passed the formal check performed by the SPHN Management Office and were evaluated by the IAB according to the same review procedures as for the first call for proposals. Again, joint SPHN-PHRT proposals were evaluated independently by the different evaluation committees.

Based on the recommendation of the IAB and the recommendation of the PHRT Evaluation Committee, the NSB decided to support 5 Infrastructure developments projects and 5 Driver projects for a total amount of CHF 9.65 million, of which 3 were co-funded by SPHN and PHRT.

At the end of the evaluation, the IAB gave the following recommendations:

- An event should be organized in early September 2019 where the grantees of the projects funded in 2017 would present their progress to the IAB;
- Grantees of projects awarded in 2018 should also attend the event to hear from their peers and learn from their experience.

Figure 2: Statistics of the call for proposals 2018

Call 2018	Total Applications received	Joint SPHN-PHRT proposal	Budget		
			Requested	Available	Difference
Infrastructure development projects	20	2	7'197'996		
Driver projects	18	4	24'661'869		
Total	38	6	31'859'865	9'300'000	22'559'865

2.4   SPHN Review Meeting 2019

As per the Funding Regulations, projects funded through SPHN calls for proposals report on their activities to the SPHN Management Office and to the IAB.

In 2018, the 15 projects funded within the call for proposals 2017 as well as the 5 University Hospitals had initiated their activities in the form of projects or Collaboration Agreements respectively. The project leaders submitted their annual activity reports by 31 March 2019, summarizing the progress and challenges encountered in 2018. Following the review of the reports by different SPHN bodies (Scientific Expert Board, ELSI advisory group [ELSIag] and Data Coordination Center [DCC]), recommendations with respect to funding continuation were made to the NSB. The NSB then decided whether the Driver projects would receive a full or partial second installment, or whether the second installment was retained until issues had been resolved.

In September 2019, both the PIs and the representatives of the University Hospitals were invited to present the progress of their work in the frame of a 2-day SPHN Review Meeting to the IAB and project peers. The first part of the meeting provided an overview of the current state of the initiative, core activities such as the ELSI, DCC and BioMedIT projects, and on the synergies with the ETH Domain partner initiative PHRT. In the subsequent project review sessions, the IAB had the opportunity to hear not only about the achievements, but also about the various challenges and hurdles encountered. Following each project presentation the IAB and the audience had the opportunity to clarify open questions and/or to provide advice and input to the project leaders.

In addition to the project review sessions, a panel discussion focused on the future directions of the initiative and a roundtable on the works done within the frame of the Collaboration Agreements.

The comprehensive program of the Review Meeting provided the IAB with a broad overview as well as an in-depth look at SPHN's core activities. The reports on the current status, challenges and gaps identified by the first 15 funded projects, as well as in the University Hospitals facilitated the Board's first review of the initiative, almost three years after its operational launch.

2.5 Feedback on the Review Meeting

Overall, the IAB was positive about the progress of the initiative, noting the achievements as well as identifying opportunities and areas for further action. The challenges of SPHN and its projects were considered complex. Nevertheless, the Board found it encouraging to see the progress and momentum of this new initiative, as after only 2 years a fledgling program has been established with early accomplishments and identification of the key challenges.

The Board recognized that the projects have been successful in defining technical and other roadblocks as well as in identifying the solutions required in order to scale to a national infrastructure. The project presentations revealed that the majority of the projects face and/or had faced similar challenges. Unexpectedly, these challenges are mainly related to organizational/governance issues (e.g. institutional commitment) or culture (e.g. hurdles with respect to data sharing) rather than technical issues. In addition, some project leaders seemed to be new to the clinical hospital environment and had underestimated the various governance, legal and administrative issues they would encounter. At the same time, the University Hospitals are challenged when it comes to dealing with large sets of variables collected and requested by the SPHN Driver projects. In fact, the Driver projects are actually serving their purpose of 'driving' the development of appropriate infrastructures and nationwide data

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interoperability mechanisms, by revealing the local barriers and gaps with respect to processes, services and infrastructure.

It was noted that the various project teams are investing considerable efforts in solving downstream tasks (e.g. semantic integration, modeling etc.) which in some cases might to lead to a duplication of efforts. If each group needs to solve repeatedly the same issues for its specific institution, there is an additional risk that projects develop ad hoc/one-off solutions rather than global ones. As an example, an impressive series of documents (guidelines, considerations, and templates) was developed in the context of the Infrastructure development project titled '*Development of a governance and quality management system for the exchange of patient-data for research purposes*' (PI Jörg Willers, February 2018 - July 2019), which could provide valuable solutions and guidance to other SPHN projects if implemented by their institutions.

3. Recommendations

Based on the overall impressions of the status and progress of the initiative, the IAB formulated a set of recommendations for the next phase(s) of SPHN (in order of priority):

– The infrastructure that SPHN aims to develop to make health-related data interoperable and accessible across the country, may be key not only for research, but also to the future applications and practice of medicine - and thus for operations of the University Hospitals in general. It may be that the organizational, financial, and logistical challenges of linking the Hospitals with the Driver projects (and ultimately into the routine investigation of personalized medicine) are more substantial than some expected, and so an assessment of the best way forward with the Hospital Leadership seems critical. As a consequence, a meeting between the SPHN leadership and the University Hospital leadership would be valuable to come to an understanding of the utility of this national infrastructure program and to agree on a common long-term vision, beyond the duration of the funded projects. It would also be important to identify and agree on the support the University Hospitals are able to provide to the overall initiative.

– A radical consolidation of procedures and processes at all levels - from consent, creation, management and access to data - is needed from the data controllers. It is critical to establish appropriate incentives and education so that those with the data understand the importance of their role in the future SPHN infrastructure, and engage the Driver projects to create sustainable methods for data sharing and access. This is non-trivial and requires deeper discussions, creation of consensus and institutional will, across all data controllers.

– Partner institutions should create a prioritized list of shared digital services for which there are clear economies of scale that each network node benefits from in terms of quality/functionality/cost. This will require concrete planning around open and common standards for capturing the various streams of medical data and assuring sustainable storage. The Driver projects may extend such services competitively but they would build from a common and evolving base.

– In general, each project should remember that it is a prototype and that lessons learned and associated documentation, good practices, and protocols should be maintained and shared.

– SPHN needs to consider how to support and engage the private sector e.g. at which stage, on which terms and how these can be developed to benefit all parties. The transfer to professional solutions

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in terms of software and tools is essential for scalability of the network. The development of a guidance framework on this topic would be valuable. It is already clear that some projects are thinking about translation to industry, whereas it is not on the horizon for other projects. Academic institutions are rarely the right place to scale and make "professional" critical algorithms, decision-support software and other artifacts and products related to precision medicine.

− Support for the projects and PIs should be strengthened by the host institutions, as they develop best practices and local expertise in solving logistical and other challenges: Ideally, there should be one or several points of contact, who acquire the institutional knowledge required to provide guidance and knowledge to SPHN grantees with respect to internal and external processes and procedures including at the level of governance, ethics, legal and hospital IT systems.

− Fostering public awareness, engagement (and even excitement) about the SPHN is essential for the next phase. Patients and healthy citizens will need to be involved in SPHN's activities, in order for SPHN to hear their expectations and opinions. From SPHN side, there should be clarity in the national message addressed to the public.

− It is essential to think beyond the next funding period 2021-2024. It is critical to evaluate whether and how the developed infrastructures and products have actually caused a change in personalized medicine. A set of downstream metrics (beyond publication, creation of infrastructure and good working relationships) that focus on the impact on patient care and health services delivery should be developed as a priority for evaluating outcomes and impact.

In summary, SPHN has made a good start, and none of the challenges are particularly surprising or insoluble. However, the challenges are real and require a focused and sustained effort to solve them. The IAB is confident that the talented participants in the program will be able to overcome the barriers to bringing personalized medicine to the people of Switzerland.

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