Swiss
Personalized
Health
Network

SPHN

Steps # 2

June 2017

Getting to know the SPHN Partners

- Prof. Peter Meier-Abt, SAMS, President of the National Steering Board

Dear Personalized Health Community,
since the publication of the previous newsletter, many developments have occurred in SPHN. A consultation of all institutions involved in SPHN was performed until end of 2016 in order to develop the Funding Principles and Funding Regulations. The Swiss Academy of Medical Sciences (SAMS), the State Secretary for Education, Research and Innovation (SERI), and the Federal Office of Public Health (FOPH) have clarified their roles and responsibilities and signed a service contract for the period 2017–2020 in May 2017. SAMS is thus the legal entity responsible for the good governance of SPHN; the service contract together with the Rules of Procedure, the Funding Principles, and the Funding Regulations define the overall framework of the initiative. The Data Expert Group (DEG) has worked extensively on identifying the steps that are required to achieve nationwide interoperability of health-related data. In addition, the Ethical-Legal-Social-Issues Advisory Group (ELSIag) has been constituted and has developed an Ethical Framework for Responsible Data Processing between the SPHN partner institutions (see Textbox).

In April, we published a factsheet about SPHN and in May we launched the SPHN website: www.sphn.ch. This website will be updated regularly and informs about organisation, funding opportunities, and important ongoing activities of SPHN.

In the first period of SPHN (2017–2020), funding priority is given to the development of essential coordinated infrastructures necessary for nationwide interoperability of health-related data generated and managed in local and regional information systems. This will optimize the use of data from both patients as well as healthy citizens for biomedical research.

In this context, collaboration agreements ("Leistungsvereinbarung") are currently prepared with the University Hospitals for the funding instrument "infrastructure implementation" (see factsheet or www.sphn.ch/en/funding). The first call for proposals for "driver projects" and "infrastructure development projects" was published on 16 June 2017. An information session will take place on 29 June 2017 to explain SPHN in general and the various funding opportunities to the scientific community. A second event is planned for beginning of September 2017 with patient's representative and the interested public as target audience.

This newsletter briefly describes the types of projects that will be funded through the competitive call for proposals and presents how SPHN will coordinate with relevant institutions in Personalized Health related research. For further information, please check the SPHN website: www.sphn.ch.
Stay tuned!

Ethical Framework for Responsible Data Processing within SPHN

The Ethical Legal and Social Implications advisory group (ELSIag) of the SPHN was mandated to produce ethical guidance in relation to personal data processing within the SPHN, with particular emphasis on guidance for data sharing. To this aim, the ELSIag has developed an "Ethical Framework for Responsible Data Processing" within SPHN. The framework provides ethical guidance to the partners of the SPHN network as to the collection, storage, analysis and sharing of personal data for research purposes. It is built on four general principles: scientific progress, respect for persons, privacy and accountability. Compliance with this framework is required for participation in the SPHN funding schemes and activities.

The document will be published on the SPHN website: www.sphn.ch.

SPHN will coordinate with relevant institutions for Personalized Health related research in Switzerland

The SPHN aims to bring Switzerland at the forefront of Personalized Health research by developing an interoperable translational research environment for health-related information. The integration of all relevant actors is key to the success of this initiative, in particular in a small country like Switzerland. Only by combining efforts across the country, sufficiently large data sets can be achieved, which allow to perform meaningful, i.e. causally relevant correlation and association studies.

In order to create such a national interoperable research infrastructure ecosystem for competitive personalized health research, SPHN is launching a call for proposals. Grants will be awarded for projects aiming at the development, implementation and validation of data infrastructures that allow connecting research institutions and hospitals in order to share and use health-related data across Switzerland. To this end, SPHN will support two types of projects: "infrastructure development projects" and "driver projects". While "infrastructure development projects" shall thrive to develop and test new technologies, methods and infrastructures which address specific bottlenecks for personalized health related research, "driver

projects" shall demonstrate the value of personalized health research and "push" the development of appropriate research platforms by "test driving" the infrastructures and nation-wide data interoperability mechanisms in a specific area of biomedical research (e.g. cancer research, immunology, etc.). SPHN will fund predominantly the harmonization, interoperability and infrastructure aspects of the "driver project". Adherence to the data processing principles developed by the ELSIag (see Textbox p.1) will be a condition for receiving funding from the SPHN initiative.

In order to make the best use of the available resources, SPHN will coordinate their calls for proposals with the ETH Domain "Strategic Focus Area in Personalized Health and Related Technologies (PHRT)" (see below, p.3). More information on the call for proposal will be published on the website www.sphn.ch/en/funding.

In addition to the ETH Domain, SPHN will coordinate its activities with further relevant partners for Personalized Health related research in Switzerland. Please read about their roles in the following sections.

SIB Swiss Institute for Bioinformatics: Data Coordination Center and BioMedIT

Data interoperability plays a central role for SPHN. The Data Coordination Center (DCC) of the SPHN will deal with data interoperability and data management questions to ensure that research projects can efficiently collaborate nationwide and share information across the various Swiss hospitals and research institutions. It will be coordinating the establishment of standards for data generation and annotation, data quality indicators, semantic interoperability and exchange formats.

The BioMedIT project aims to build a coordinated network of secure IT infrastructure core facilities across Swiss universities to enable researchers to efficiently work with confidential data (not only medical data). BioMedIT forms an integral part of SIB's contribution to the SPHN initiative – providing expertise, software workflows, and high-performance storage and computing resources for analysing and interpreting large volumes of omics-, laboratory/imaging-, clinical- and other personal health related data within SPHN. The Personalized Health Informatics Group at SIB is in charge of establishing the Data Coordination Center (DCC) and coordinating the BioMedIT project.

SIB is a non-profit organization federating 65 Swiss research and service groups of experts in bioinformatics. SIB's 800 scientists join forces to advance biomedical research by providing life scientists and clinicians with state-of-the-art bioinformatics resources, services, expertise, and training. SIB acts as the Swiss node of ELIXIR – an intergovernmental organization for coordinating life science data resources across Europe.

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SIB
Swiss Institute of Bioinformatics

ETH Domain Strategic Focus Area in "Personalized Health and Related Technologies": Coordinated calls for project proposals

To take advantage of the entire personalized health ecosystem actually developing in Switzerland, SPHN will closely coordinate with the ETH-Domain Strategic Focus Area (SFA) in "Personalized Health and Related Technologies (PRHT)". As SPHN and PRHT are complementary in their setting, they have similar goals. Exploiting synergies between the two programs represents a unique opportunity to strengthen and accelerate the development of a strong personalized health landscape in Switzerland. In order to facilitate and encourage collaborations between ETH-Domain, Universities and University Hospitals, SPHN and PHRT will coordinate their calls for proposals as well as evaluation procedures for "driver projects" and "infrastructure development projects" (see www.sfa-phrt.ch), but the two initiatives remain independent. While PHRT will focus their funding predominantly on establishing platforms for molecular profiling, biomedical research projects with large-scale data generation, Technology Translation Projects as well as on education, SPHN will concentrate its funding on efforts to enable interoperability and building data infrastructures required for bridging basic and applied research institutions and University Hospitals ensuring effective collaborations between basic and clinical research.

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Strategic Focus Area
**Personalized Health
and Related Technologies**

Swiss National Science Foundation (SNSF): Support of Personalized Health research within existing funding instruments

The SNSF contributes to SPHN mainly through project funding as well as through support to currently running longitudinal studies and the Swiss Biobanking Platform (see below, p. 4). While other stakeholders dispose of additional or earmarked budgets dedicated to the support of SPHN, SNSF was not mandated with a specific budget for SPHN, but will be involved in its support via its already existing funding instruments. Therefore, grant applications will be evaluated in direct competition to all other applications, which have been submitted to the same funding instrument. However, the SNSF invites scientists to submit Personalized Health related research projects and to indicate in their project proposals the concrete interconnections with SPHN. The SNSF will evaluate the projects independently, but If deemed appropriate (e.g. infrastructure building) the SNSF can coordinate its funding with the SPHN initiative.

It should be noted that the SNSF regulations allow researchers to have two independent project grants funded at a time, provided that the two projects are thematically clearly distinct from each other and that the project applications are not submitted together at the same deadline. Besides project funding, researchers also have the option to apply to other funding instruments, e.g. Sinergia or ERA Net programs.

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SWISS NATIONAL SCIENCE FOUNDATION**

Swiss Biobanking Platform (SBP):
Coordination and harmonization of biobanking management systems and clinical research data management platforms

The SBP is the national coordination platform for biobanks in human and non-human domains supported by SNSF. It responds to increasing requests from researchers in terms of quality, access, transparency and interconnectedness of biobanks and their associated data for research purposes.

To foster coordination and harmonization of biobanking and promote competitive research, SBP has been mandated to provide expertise and services to biobanks and their hosting institutions for the period 2016–2020 by:

- Providing biobanks' recommendations and tools to promote harmonization with quality at the centre of a biobank reputation.
- Supporting biobanks in the choice and implementation of a professional biobank information management system (BIMS) favouring sharing and interoperability.
- Developing a one stop shop model at SBP to promote access and create value to existing and future biospecimens through a centralized catalogue of biobanks.
- Developing, implementing and monitoring guidance on biobanks to support policy makers, regulators and institutions.
- Promoting acceptance and participation in biospecimen's research while supporting implementation of patient and population cohorts.
- Engaging public to promote public awareness and foster patient/citizen empowerment in human research.
- Developing governance guidelines for biobanks and their hosting institutions in Switzerland with politics' support to promote the legal and ethical framework.

After a one-year preparation phase, SBP has been created in June 2016 as an independent association regulated by its own bylaws and setting its governance. SBP structure is in place with a governing board composed by the five University Hospitals, the initiating Project Group and a strategic advisory board, whose composition integrates major Swiss stakeholders related to research. SBP is thus leaning on a variety of experts within institutions and is offering in addition to its central office, specialized hubs in Universities to support and implement Biobanking governance and practice.

SPHN and SBP will work together on the implementation of data interoperability mechanisms between the biobanking management systems and clinical research data management platforms to ensure that sample information can be exposed together with the clinical data.

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A project of: **SAMW**ASSM