Swiss Personalized Health Network

International Advisory Board (IAB) meeting 2020 – Summary report

Meeting: 16 & 17 November 2020

IAB members: Russ Altman (Chair), Soren Brunak, Joan Dzenowagis, Jan Hazelzet, Marie-Christine Jaulent, Paul Klenerman, Oliver Kohlbacher, Dan Roden, Amalio Telenti,
(not present: Iain Buchan)

1 General feedback

The SPHN International Advisory Board (IAB) met with SPHN leadership by videoconference for two half-days on November 16 and 17, 2020 to discuss together with representatives from the five university hospitals, Principal Investigators of several SPHN Infrastructure Development Projects, and the chairs of three SPHN Task Forces, the progress made during the first SPHN funding period 2017-2020 with regard to the future direction of SPHN for the second phase 2021-2024.

In preparation for the meeting, the IAB members received a set of materials, including the **SPHN report from the National Steering Board 2016-2019**. The IAB found the gap analysis presented in the report particularly useful and accurate at identifying the key challenges to SPHN that would require special attention going forward from 2020. Overall, **the IAB was impressed to see progress in all areas of SPHN, including the serious uptake of the infrastructure challenges by the university hospitals, the technical progress on the projects presented, and the creation of task forces to support SPHN decision makers.** The IAB was also happy to learn that funding for another four years would provide resources for SPHN to focus on the most important elements of the infrastructure and prepare for a sustainable system, likely supported by several sources. For this reason**, impact and sustainability must be the primary drivers of SPHN decisions in the next period**. The impact must include examples of clinical implementation to show that personalized health is a coming reality in Switzerland. The clinical impact demonstrations would ideally involve more than one hospital to show the value and importance of a national (vs. regional) network. Sustainability is critical because the investments of SPHN must be recognized as valuable and ongoing resources must be identified (likely from a combination of hospital/health system, university, and local/federal governmental support, perhaps with some philanthropy and industrial support) to maintain momentum in building a fully functional personalized health system.

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The IAB noted that after four years, **SPHN has gone from an initial vision to a set of tangible infrastructures, clinical and scientific projects that are moving towards a truly personalized health network for Switzerland.**

2 Infrastructure implementation at the University Hospitals (UHs)

The progress made over the past four years is encouraging, as is the common identification of needs and expectations from SPHN. Consent processes are far along, data warehouses are at a good level of maturity and the priority now should be on the sustainability of funding and centralized and distributed systems for the network. **Coordination and harmonization are critical in a number of areas**.

Moving forward, building on what has been done, will require making some choices as to the focus over the next four years, for example identifying at the national level what is most important to achieve collectively and ensuring those objectives are met. **Making the best impact for the country requires a community that wants to develop together** and, given the heterogeneity of projects, an immediate effort on joint planning is required. A high-level IT leadership committee could consolidate gains and ensure that everyone's efforts contribute to the overall goal. The **comprehensive assessment of the strategic potential of SPHN's work not only for research, but also for clinical care as well as for managerial purposes such as planning for emergencies and quality assurance monitoring should be undertaken**. This should not only illustrate, but also quantify, the tangible expected outcomes and benefits to stakeholders. The COVID-19 crisis could be a compelling starting point for a number of demonstrations highlighting the practical and social benefit of this work.

One area for improvement is potentially aligning the activities in the different university hospitals to avoid developing solutions in parallel. A **much stronger focus on harmonization would add value to the program and save effort in the long term**. In considering the sustainability of such infrastructure in the long term it will be important to consider this as a group to maximize the overall value of the current projects and ensure that the university hospitals and funders can together prioritize the key platforms together.

In the next four years it will be critical to **create effective incentives and financial models to make the ongoing investment in infrastructure for precision medicine sustainable.** This must be a constant priority for the university hospitals and SPHN should work with the them to develop models based on precise goals, reasonable expectations for interoperability, specification of a useful national data catalog, engagement of patients and demonstrations of scientific and clinical value. There will likely be

opportunities for joint support from the hospitals, their associated university, as well as state and federal sources.

3 Infrastructure Development Projects (5 projects were presented to the IAB)

The presented Infrastructure Development projects already show a high level of maturity, and those that can **demonstrate clinical impact and use of the hospital infrastructure** in the most compelling ways should be prioritized. This may require SPHN leadership to only support a subset of projects that are already aligned with the goals of impact and sustainability. Some may spin out as companies, which would also be a good sign of value. The range of the projects, some close to clinical applications, some more focused on technological developments, represents a challenge when it comes to ensuring lasting value. In particular with the technological developments, **a business model for the adoption of the technologies needs to be found, that incentivizes the university hospitals to build on these developments**. It is apparent that the projects need to converge with the strong development of infrastructure at university hospitals at the risk of otherwise failing implementation once the current cycle of funding ends. In the spirit of SPHN to build coordinated data infrastructures in order to make health-relevant data interoperable and shareable for personalized healthcare and research in Switzerland, projects should emphasize their connection to FAIR data. For all projects data should be kept separate from application (no embedded data within applications), in order to facilitate portability of the applications. Ideally, these developments would be aligned with similar initiatives in other European countries to ensure interoperability and sustainability.

The selection of Infrastructure Development projects that were discussed offer a glimpse into how the systems built nationwide will maintain competitive edge and evolve through innovation. Current challenges are that as individual projects reach maturity, there is not yet an established vehicle or path for piloting or formally implementing the solutions that they offer into the national infrastructures. **Projects would need a strategic partnership to extend to other fields within the SPHN, and eventually attract academic or corporate investment to support the development once the SPHN funding ceases**. SPHN may want to consider creating methods for connecting the project leaders with private/public funders who have an interest in supporting these tools. In that case, **demonstrations of real-world effectiveness will be critical, along with a strategy for estimating the potential value of the tools** to these funders. The market of health data is complex and divided between opensource and proprietary tools - both are acceptable options depending on the funding scheme.

While the IAB was unable to hear updates from all SPHN Infrastructure Development projects, the discussed issues may be pertinent to these as well.

4 Task Forces (Genomics, Data Lifecycle Management, Cohorts & Registries)

The IAB judged the creation of the task forces as a strong step forward towards a **long-lived national network of scientists and clinicians devoted to infrastructure for precision medicine**. The IAB reviewed the mandates of the task forces (available on the SPHN website) and found them to be good for helping to define solutions to the technical issues identified in the gap analysis. The IAB concluded that the task forces have kicked off successfully, and will likely create proposals for the attention of the SPHN National Steering Board that will require refinement, review and implementation—**the same criteria of impact and sustainability as for the Infrastructure Development projects should be applied to these proposals**.

The challenge for each of the three task forces is to assess existing resources, and advise SPHN leadership on how to have them work together in a functional and harmonious manner.

The discussion of the **data lifecycle management** taskforce highlighted the formidable challenge of creating a FAIR infrastructure from an existing rich set of data sources. The IAB was impressed with the complexity of the challenges associated with data lifecycle management and **endorsed the approach of finding specific use cases (as pilots) to ensure that there is tangible progress in this challenge on focused examples that show the way to others**.

The discussion of the **cohorts and registries** proved challenging in a different way since cohorts and registries, by their very nature and definition, tend to be well-defined and well-documented. **The challenge here will be that it is unclear how much overlap in relevant information there is between cohorts and so how much can be gained in integrating them and making them FAIR**. Thus, the IAB recommended (like for the data life cycle management task force) that this group **identify some use examples where there is strong evidence that the interoperation of two or more registries or cohorts will create clear scientific opportunity**.

In the discussion of the **genomics network** task force, the potential of building a new national cohort versus aggregating existing cohorts was the main discussion point. **The IAB believed that a critical component to personalized medicine is genomic discovery and implementation, and so SPHN should ensure that the likely benefits of genomics are implemented for the health of the Swiss population**. The discovery effort will be difficult with a small national cohort, but the cohort, once

developed, could contribute to international efforts that are increasingly recognizing the value of diversity across multiple local ancestries. Inclusion of a primary focus on metabolomics and/or proteomics might catapult a Swiss cohort to a leadership position in these areas, but the key is excellent clinical phenotyping regardless of which omics is the focus. There is no doubt that a new biobank cohort is expensive and perhaps out of the remit of SPHN, but the genomics task force should articulate how such a cohort would benefit the health of Swiss citizens by advancing personalized health. It is critical to recognize that Switzerland is a bit behind in joining the "club" of regions with biobanking and genomics efforts, combining available tissue and electronic clinical data. The IAB strongly recommended developing a strategy for joining this group. It can be through aggregation of existing cohorts or creation of a new one. Because genomics is so commonly considered part of personalized health, it is **critical that the infrastructure of the hospitals and the outputs of the SPHN projects be at least in part used to advance the implementation of genomic medicine.**