SPHN International Advisory Board

Summary report of the 19-20 September 2023 meeting

Authors (in alphabetic order): Russ Altman (Chair), Søren Brunak, Iain Buchan, Joan Dzenowagis, Jan Hazelzet, Marie-Christine Jaulent, Paul Klenerman, Oliver Kohlbacher, Dan Roden, Amalio Telenti

Table of Contents

1 Executive summary

The SPHN initiative has made good progress since the last International Advisory Board (IAB) meeting held in May 2022 in Zürich. In particular, the legal and governance aspects of data flow have mostly been resolved, so that all four of the National Data Streams (NDS) projects are now poised to start accepting data from the participating hospitals and conducting their analyses. The coming months will be critical to test the infrastructure and make sure that the data flows as expected, and that the analyses on this data can commence. Now is the time to open the pipes and see how the infrastructure works. In addition to the NDS projects, there has been very good progress in planning for genomics, federated learning, and interactions with other data sources (such as the Federal Statistics Office and the Federal Office of Public Health). The big planning challenge now is for sustainability. There is a need for a national health office that coordinates the collection, governance and use of data. SPHN has laid the groundwork for this type of function. However, SPHN represents an academic effort. Going forward, it is important that academic demonstration projects and proofs of concept continue under a flexible and nimble model. SPHN or its follow-on projects should be careful to coordinate with any new national health office, but should remain independent since the realities of governance, economics, politics, and scale will put considerable constraints on a national office, and an academic SPHN-like functionality will be critical for continued innovation and direction-setting.

Specific advice from the IAB includes:

– As the NDS projects mature and begin to function, it may be useful to extend the type of stakeholders involved in the discussion (patients, physicians, politicians, insurance companies, MedTech etc.).
– SPHN should make sure that it presents itself as a real data authority and make more effort on marketing this expertise to any nascent national health data office, industry and other academic projects.
– Future projects led by academic efforts such as SPHN should focus on two new directions: lifelong longitudinal data and multimorbidity. Both of these are challenging but critical for understanding and personalizing healthcare across the lifespan. Current projects understandably focus on particular moments in the patient trajectory (pediatrics, ICU, oncology, in particular), but there should be focus on the complexities of real medical care: multiple diagnoses evolving over time.
– SPHN should continue its outreach to other Swiss data resources and make appropriate alliances, for example, to include personalized social and economic data, in order to be able to better characterize the social determinants of health.
– Critical to the long-term mission and to the acceptance of the PPI community is that SPHN develops a plan for recording, integrating and analyzing patient reported data (PROMs, including data from wearables).
– SPHN may be in a position to stimulate standardized documentation close to the point of care. This might be done in collaboration with any new national health data office. Relatedly, outpatient

data from all sources is very valuable for personalized health. Once the general data flow is enabled and functioning, it will be important to consider the opportunities for additional outpatient data. The initial experiments should ideally be conducted by academic efforts such as SPHN in order to inform national data priorities and regulations. Again, it is critical to have the SPHN-like academic functionality for testing, prototyping, piloting and learning from mistakes, that cannot be done within a governmental national effort.

– SPHN is quickly becoming a resource that may be attractive for international collaboration. Of course the safety of data, privacy and security are critical. But the expertise of SPHN in federated learning may allow it to lead globally in creating secure networks for data sharing.

– SPHN should emphasize the value to providers of curating data for NDS in terms of the care quality improvement and cost savings achieved – start each data-action example with actions, not data. For instance, for acting to tackle antimicrobial resistance: show how NDS-enabled predictions of resistance can reduce unnecessary lab sensitivity testing, saving time and money.

– SPHN should create and promulgate a national predictive care service, not just a national data service – making it clear that data controllers have a net gain from investment in data capture, curation and providing APIs to decision support systems.

– SPHN should involve patients more as a cooperative of data subjects alongside regional/cantonal cooperatives of data controllers. In this way, generate the social license for streamlined governance and a national mandate for, for instance, opt-out consent to avoid bias that affects the most vulnerable patients more. Use the principle of fairness/justice/equality.

– SPHN should create a national grid of data-action cooperatives running on NDS, where the principle of subsidiarity applies (i.e., one organization may be licensed to act on behalf of others, e.g., with antimicrobial resistance surveillance or a specific national research project).

– SPHN should exploit the national BioMedIT query interface to ground large language models (LLMs) that augment both curation (e.g., adaptive code-concept mapping), query building and curation of predictive models (elements of a national clinical epidemiological knowledge graph – orthogonal to bio-mechanism graphs).

– SPHN should exploit population health management and predictive care efforts. For example, in North-West England (7.4m population), three health systems are converging their multi-purpose (care, planning and research) intelligence systems to interoperate as part of England's NHS Secure Data Environments program. Data-sharing is supported by the public through popular approaches such as the Civic Data Cooperative (www.civicdatacooperative.com). This health system level data fluidity has thrived while national programs such as Care.Data, HDRUK and Federated Data Platform have faced challenges. It seems clearly better to create efforts that pull participation from health systems with useful tools and collaborative relationships rather than push with high-level national mandates about data flow for predictive care.

– SPHN should invest in enabling methodology at national level, in the underpinning data science and informatics, without duplicating the data research that is just 'research' from usual sources, and incentivize a national grid of nodes of that Swiss Federation of Data Science for Health to embed in constituent universities and hospitals – co-investing in a sustainable enterprise. Note

lessons from HDRUK, which has not taken root in health systems and relies mostly on Medical Research Council (MRC) funding (not sustainable).

– To highlight NDS impact, it would be worthwhile to define key performance indicators (KPIs) that summarize data flow, project progress, PPI progress that serve to illustrate current, as well as potential future NDS impact.

– It will be very important to document victories of SPHN as the NDS projects mature. This could be science victory, engineering victory, or even stories about individual patients or groups of patients who benefitted from the infrastructure. These stories resonate with policy makers and the public and should be curated.

– The potential for collaboration with industry in Switzerland should be explored. A strategy for consultation to examine shared interests and find out how the SPHN infrastructure may be attractive to them should be developed. Of course, all appropriate boundaries should be maintained, but this could be a source of revenue if appropriate data can be prepared for use by industry, and also protected. This would be part of PPI to make sure it was done in acceptable ways.

– As SPHN plans for the future, it is absolutely critical that they maintain at least a minimal flow of support so that the software and infrastructure that has been created is maintained. Any gap in funding and staffing could quickly lead to stale and unusable code. The code must be maintained and nurtured so that its value can be realized in the future. This is a critical point to make during negotiations about “next steps.”

– Progress in all of the above issues could be accelerated by the creation of a national health data science initiative. That could provide/support common legal and data science frameworks for data and specimen collection and storage, common consent mechanisms, methods and rules for return of data, coordination of deployment, policy recommendations and pilot projects to demonstrate new capabilities for future initiatives.

2 General comments on the overall progress of NDS projects

Are NDS projects on track? Are any interventions required?

After one year, there appears to be still much difficulty to address the approvals and requirements - each group seems to be approaching the ethics commissions and institutions separately. Regarding progress, there is a general lack of representation/descriptive statistics of what has been accomplished, what is available in the current existing database of the SPHN (~100 variables) and accurate projections.

The overall impression is good – the projects are progressing well (with some exceptions discussed above). As usual, it is clear that the projects are not hampered by technical hurdles, but mostly by legal

and organizational issues. The focus should be on this and most likely only a certain degree of legal centralization will solve this issue.

Are adaptations needed to the NDS projects?
As mentioned, data-based projects should be mandated to provide comprehensive descriptive statistics (past and present).

How can we make governance more efficient?
There is a tension between the “hard” regulatory constraints, the technical solutions that would theoretical diminish the risks of data access and usage (e.g., federated learning, encrypted solutions), and the ambiguity of researchers on who should have access to “their” data. Easy to say, but we would lobby for the most open and technically advanced access to the data - somehow imitating the UK Biobank philosophy.

How should use of the NDS be promoted?
SPHN should actively promote academic use, as well as socializing the content and potential across potential users, be it public health, insurers and industry. SPHN should present a roadmap to include conditions for broader (international researchers, paying industrial users) engagement.

SPHN could ramp up its outreach activities. Patient engagement seems to be going well, but ultimately, it will be critical that clinicians also recognize that some of their newly established routine care came/comes from SPHN.

How can we make the NDS sustainable?
Certainly by demonstrating usage across various fields and partners (as above). There should also be a consideration for the value of training a new generation of biomedical researchers that go to influence their peers. In particular there should be an effort to show the on-going value to hospital systems, in exploring SPHN resources to assess quality, economics, and care.

Only by maintaining a minimum funding level for an extended period of time. It will simply not fund itself in the current shape for the foreseeable future, as the financial pressure in healthcare will otherwise grind it down to the bare essentials. Central institutional funding appears to be the most reliable way to achieve that, as structures are harder to kill than projects.

A sort of “mandatory” coordination between the 4 NDS might be helpful, not only technical but also data definitions (such as Open EHR).

3 Swiss Federated Genomics Network

It is impressive to see progress in planning for genomics since our last meeting. The plan for 1000 pilot genomes and then 14K more is reasonable. Alignment with other national initiatives are crucial at this

point (in particular the Nordic countries are quite far ahead). Swiss infrastructure is further developed than in most European countries, so you will actually have a head start in this once you fully engage.

It is critical to maintain and expand the capability of genomics in Switzerland. Currently, emphasis is on the “Swiss genome” rather than on the systems to support registry and research on available genomic information generated across medical use and research projects. However, the project may require strategic thinking on what is at risk in terms of competitiveness of Swiss research and preparedness for clinical use of genome information. It is possible that there may be a need for an adjustment in what is intended and go towards a true genomics research center, or a true central clinical laboratory service - as it stands, the plan does not include either as an outcome.

4 Federated learning (TI4Health)

The IAB is fully in support of this advanced technology, both to promote it internationally and as a true solution to many of the hiccups of the NDS projects. The federated learning capabilities seem to be high quality and unique, and so will provide a large competitive advantage and leadership position to Switzerland. For these reasons, progress in demonstrating the scalability and utility of the federated learning capabilities is critical. A connection to the NDS could be advantageous.

5 Idea of a National Health Data Office

This is an exciting but difficult and complex issue - it would need a charter and a solid basis as to what it will provide and to whom. There is a risk and ambiguity of building a center that is not fully academic research or teaching/training institution, nor an official platform of public health or of hospitals. There is no doubt that SPHN or some new academic research effort to prototype, pilot and test new capabilities and ideas would be required even with a National Office, which would be much more limited in its ability to do these sorts of projects. However, it could be a close collaborator and funder of SPHN-like efforts.

6 Sustainability

The above discussions are the basis of sustainability. Consultation with potential financing partners, who will opt in or not depending on the actual charter, would seem to be essential. For example, a lack of clarity or technology to support access would logically limit the interest by researchers, or by insurers, or pharma. And thus, to participate in costs.

There may be synergies for SPHN to support: e.g., regulatory, coordination role, etc. Towards overcoming institutional resistance, one approach is that “this is Swiss data so must cooperate”- but Swiss law is not positive on the reuse of data, so it will require an important lobbying effort if this is a goal.

Overall, the programs have generated momentum to allow national-level data-driven research using currently available tools. There is much future potential in this and the emergence of newer tools offers new opportunities. In particular for diseases where tissue sampling is a critical part of the clinical pathway, the development of digital pathology approaches and (as is already included in the cancer studies) spatial transcriptomics should provide important data streams. Building on the existing networks and agreements to facilitate data integration for additional modalities will continue to enhance the value of the program.

There have been obstacles identified and lessons learned that will be important to consider in any future incarnation of a Swiss Precision Medicine program.

– Work on common data use agreements, perhaps by establishing a central legal office that will provide rules (or guidance) and an institutional memory for individual participating sites. The issues should be generic, not medial central specific.
– The Oncology project and others are collecting biospecimens. Some thought should be given to mechanisms to store these, connected to target or broader phenotypes, particularly if they may have values across phenotypes (e.g., germline genomes).
– The NDS projects are establishing infrastructure to collect target phenotypes. SPHN needs to think further about mechanisms to evaluate outcomes when those technologies are deployed.
– Progress in all of the above issues would be accelerated by the creation of a national health data science initiative. That could provide/support common legal and data science frameworks for data and specimen collection and storage, common consent mechanisms, consideration of a program of return of data, etc.