



SPHN after 2 years, where do we stand?

Urs Frey, MD PhD

Chairperson of the National Steering Board

SPHN Review Meeting, 5 September 2019

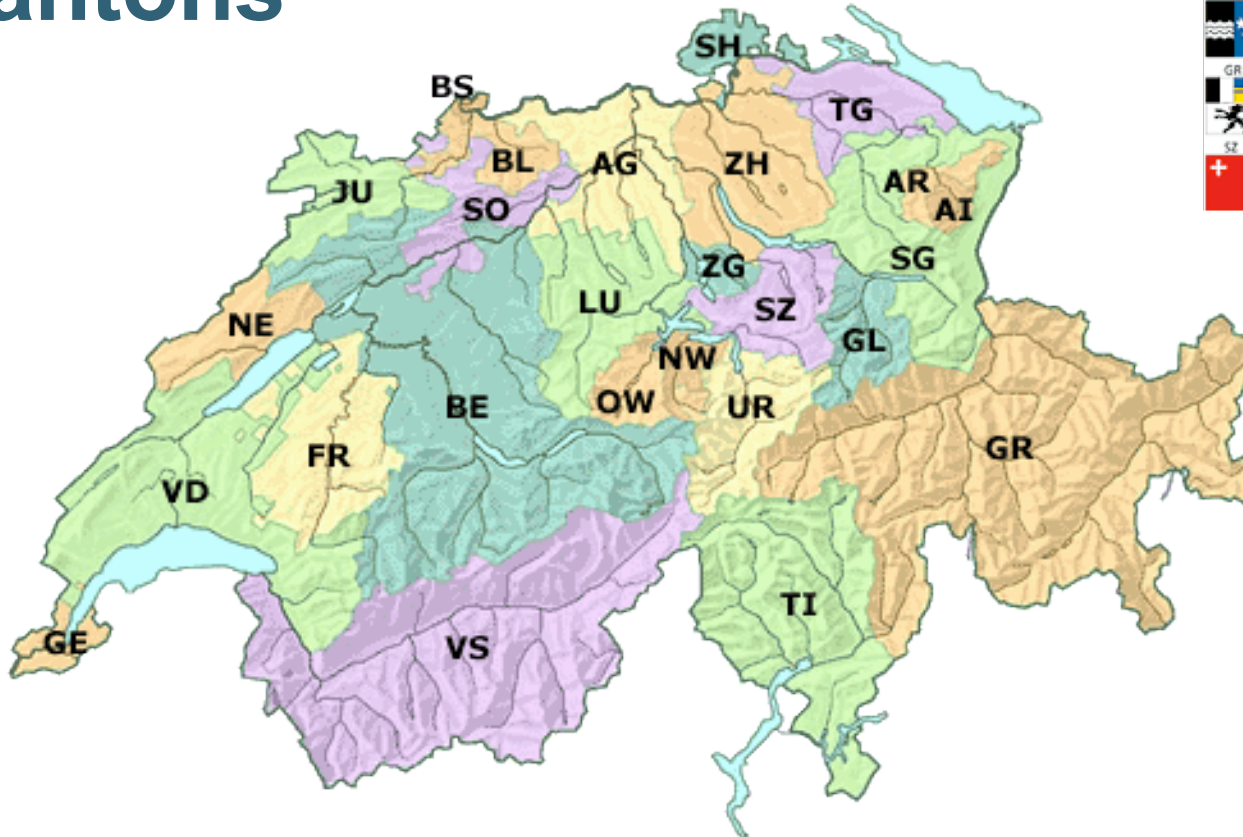
A project of



Prerequisites: 'Precision Medicine'

- Standardized, analytical methods (-omics technologies);
- Accurate clinical phenotyping of patients;
- Standardized assessment of clinical and analytical data in research networks;
- Large datasets of patient data;
- Legal, safe and ethically appropriate data sampling and storage;
- Interoperability of data, standardized semantics, bioinformatics for big-data analysis, quality standards;
- Communication (patients, clinicians, basic scientists, population, politics, government);
- Good research concepts with stringent verification of generated hypotheses.

Switzerland: a federal state of 26 cantons

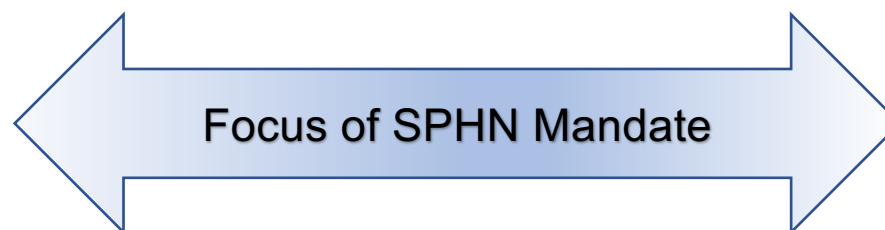
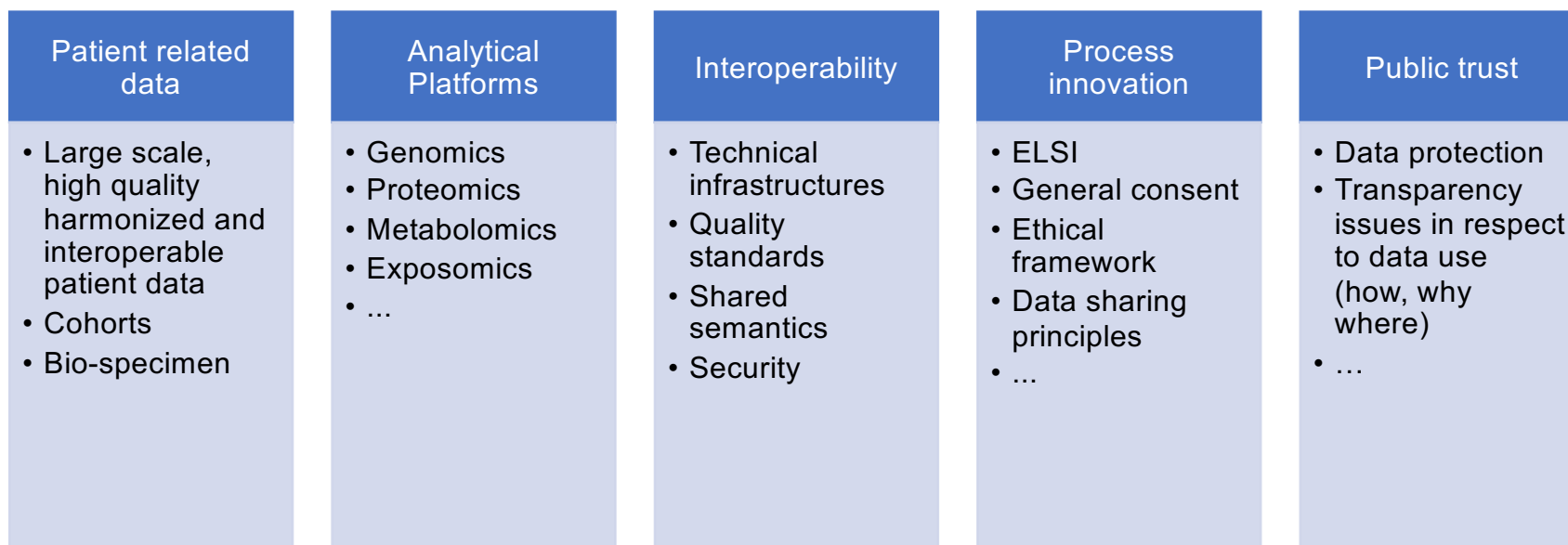


Population: 8.48 mio
4 national languages:
 German, French, Italian,
 Romanch

Healthcare and education system is administered largely by the individual cantons. Within a canton there is a mix of private, semi-private and public healthcare providers competing against each other.

→ *No uniform system, heterogeneity of health data infrastructures.*

Personalised Health Research

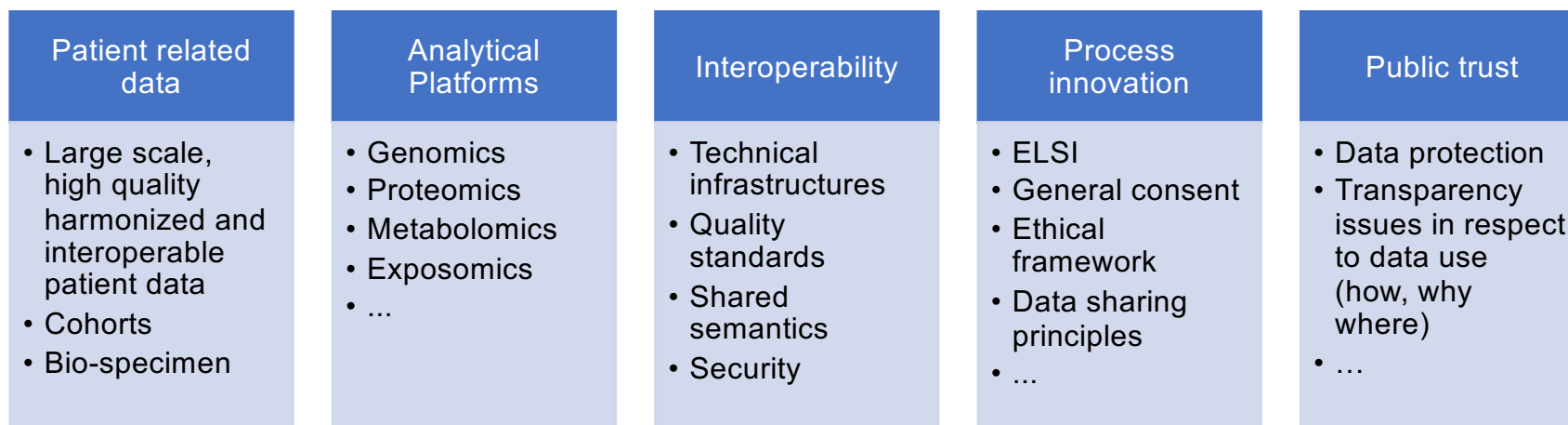


Vision and Mission of SPHN

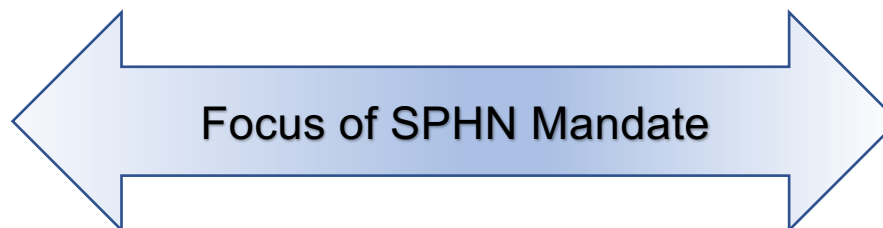
*‘Mit der SPHN-Initiative wird langfristig das Ziel verfolgt, ein **Schweizerisches Netzwerk in personalisierter Medizin zu etablieren**, in welchem alle in diesem Bereich relevanten Forschungsinstitutionen sowie der Schweizerische Nationalfonds SNF involviert sind.’*

*‘In der Periode 2017-2020 steht zwecks optimierter Nutzung für die Forschung im Bereich der personalisierten Medizin der Aufbau einer **national koordinierten Dateninfrastruktur im Zentrum**, einschliesslich der Sicherung der angestrebten **Interoperabilität** von lokalen/regionalen Informationssystemen.’*

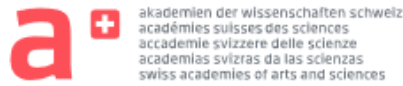
Personalised Health Research



SPHN is an infrastructure development program for patient oriented research allowing large scale high quality national projects



Personalized Health in Switzerland



Personalized Health Alliance Zurich Basel

ehealthsuisse



swissethics

Schweizerische Ethikkommissionen für die Forschung am Menschen
 Commissions d'éthique suisses relative à la recherche sur l'être humain
 Commissioni etiche svizzere per la ricerca sull'essere umano
 Swiss Ethics Committees on research involving humans



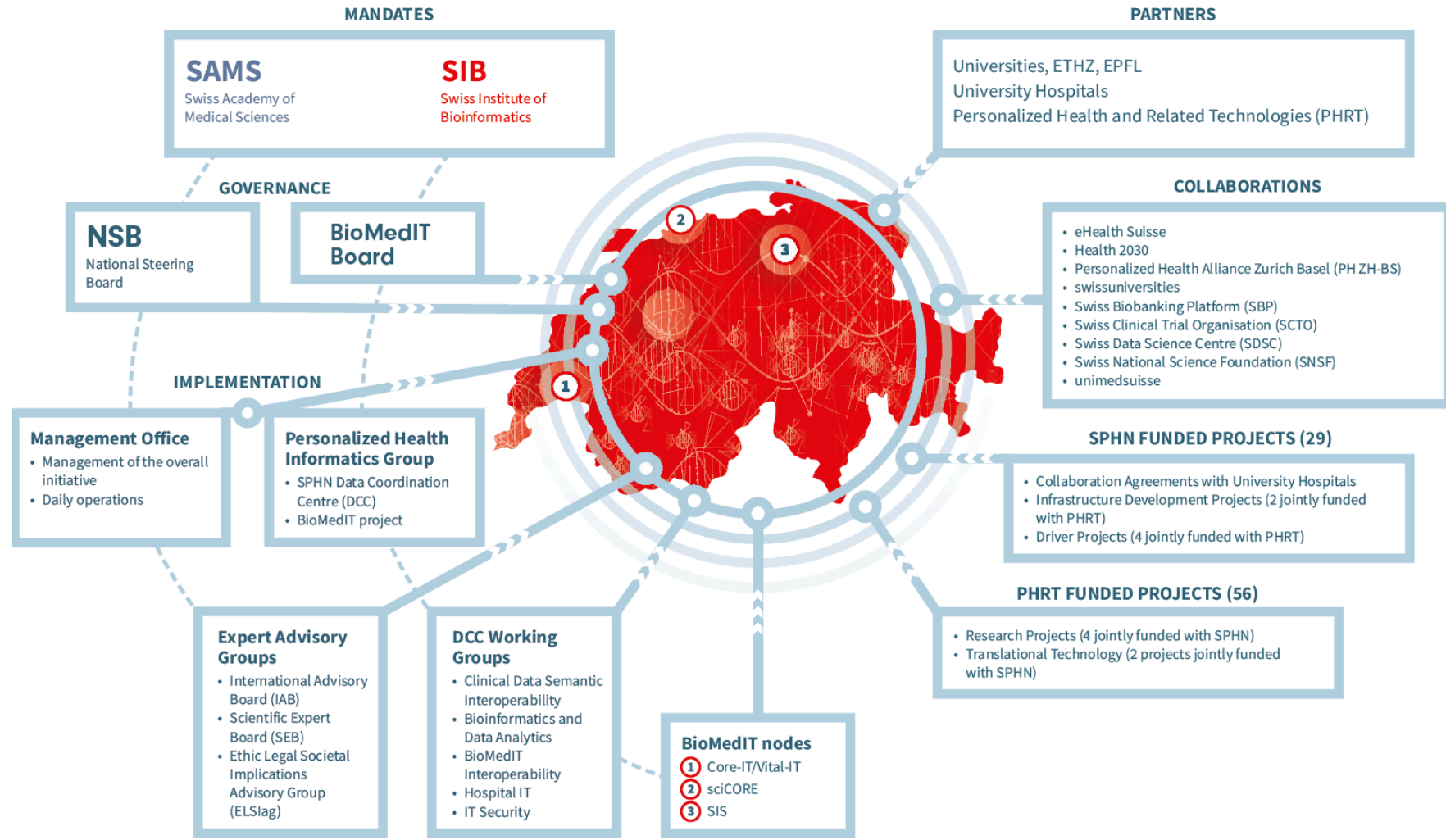
A project of



SPHN Governance

Schweizerische Eidgenossenschaft
Confédération suisse
Confederazione Svizzera
Confederaziun svizra

State Secretariat for Education, Research and Innovation (SERI) / Federal Office of Public Health (FOPH)



A project of



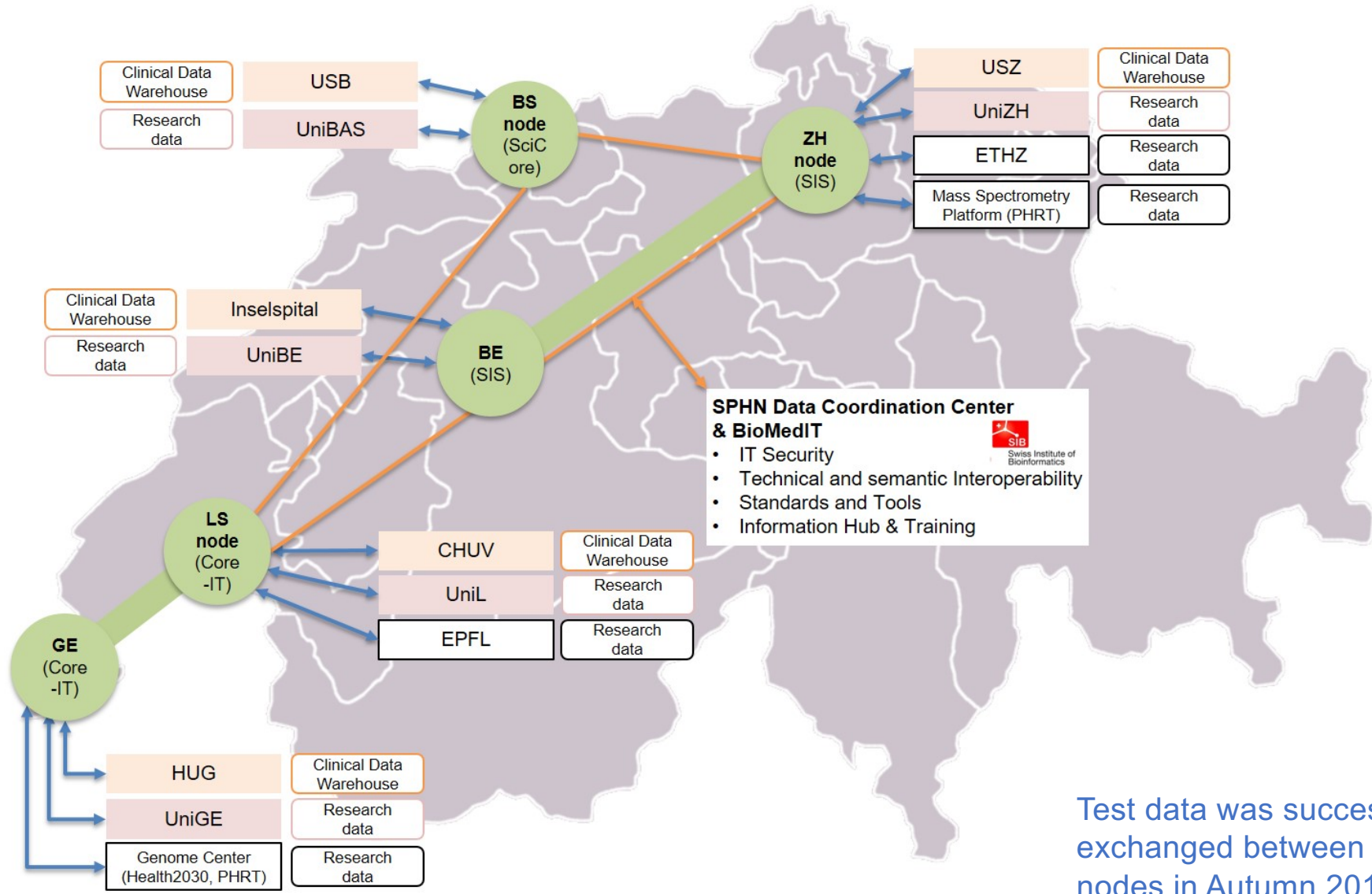
Milestones overview



Content

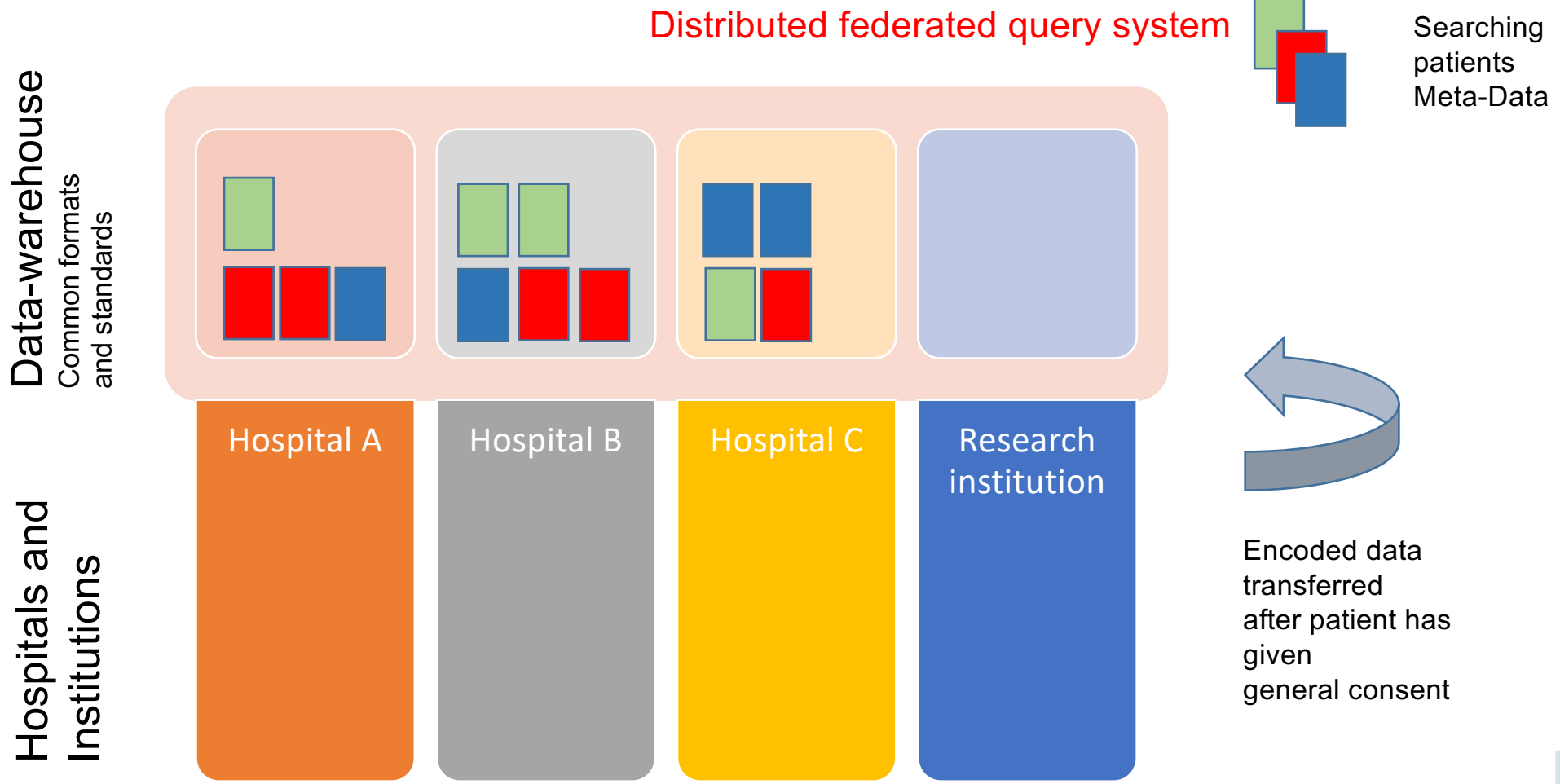
1. **Building up of technical infrastructure 2016-19;**
2. Process innovation 2016-2019;
3. Specific projects (calls 2017-19);
4. Create landscape of newly built research infrastructures (visibility transparency, gap analysis);
5. ELSI, patient perspective and involvement (patient and citizen), public trust and security, accountability;
6. Strong focus on linking and coordination with partners (PHRT, SNSF, SCTO, SBP, Universities, ETH-Domain, Hospitals, BAG etc.);
7. Outlook 21-24

SPHN – A decentralised approach

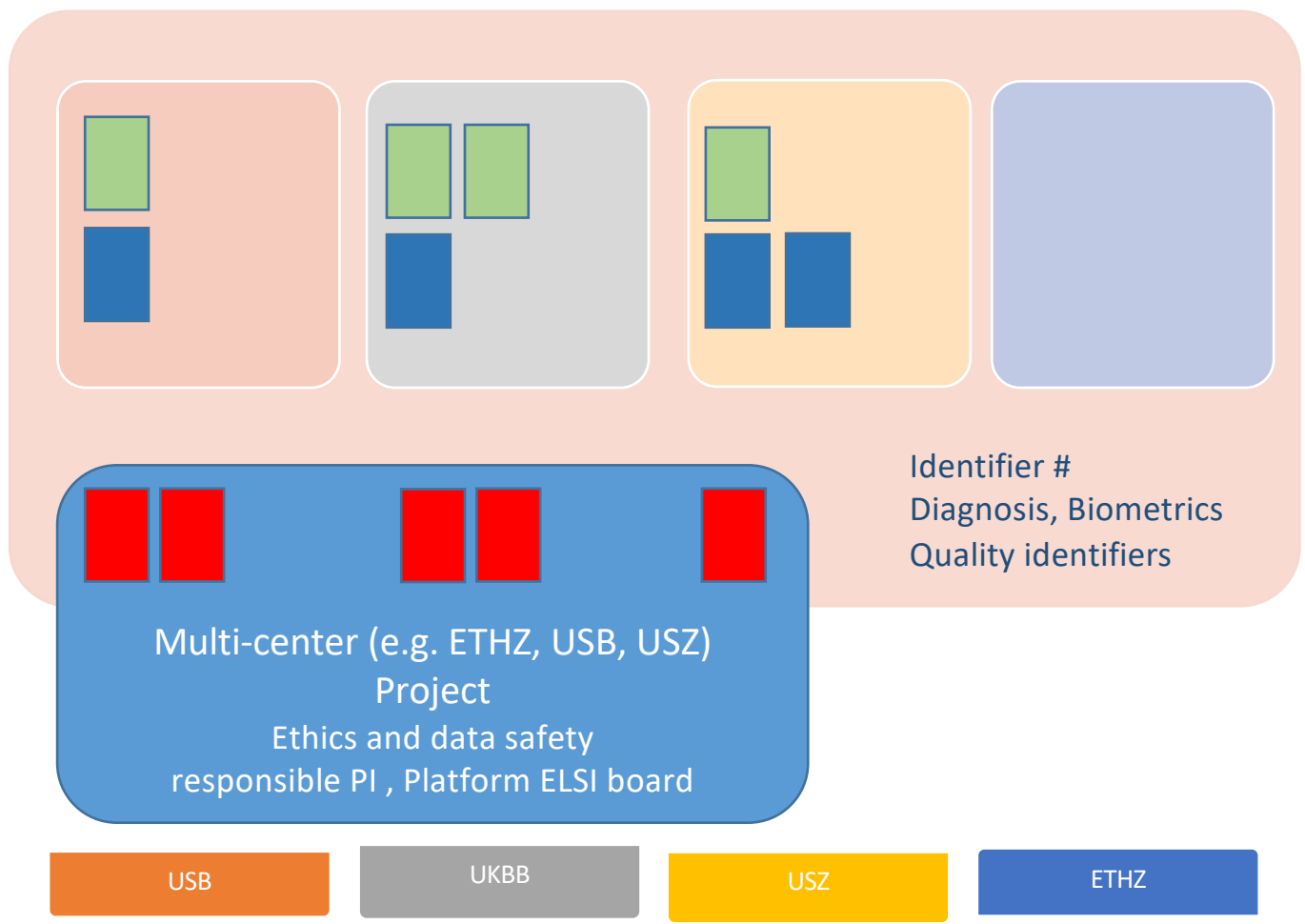


Test data was successfully exchanged between the 3 nodes in Autumn 2018.

Collaboration agreements: information about patient clinical data



Research projects using hospital data



Content

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Process innovation: Guidelines, SOPs and recommendations

Ethical-legal-social implications (ELSI)

- Ethical Framework (including data sharing principles)
- Guidance on the Return of Actionable Clinical Findings (exp. 2019)
- Data Transfer and Use Agreement (Template)
- Material Transfer Agreements (Template) (Swiss Biobanking Platform)
- General Consent (unimedsuisse, swissethics, SAMS)
- SPHN Glossary

Technical

- Infrastructure Roadmap (BioMedIT network)
- IT Information Security Policy (DCC/SIB)
- Data Semantic Interoperability Strategy (DCC)
- Hospital IT Strategy (DCC)
- Distributed federated query system (exp. 2020, DCC/SIB, Hospital IT)

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Project funding: review overview

Projects	Infrastructure milestones	Coord. with DCC	ELSI aspects
DEV-1	●	n/a	●
DEV-2	●	n/a	●
DEV-3	●	n/a	●
DEV-4	●	n/a	●
DRI-1	●	●	●
DRI-2	●	●	●
DRI-3	●	●	●
DRI-4	●	●	●
DRI-5	●	●	●
DRI-6	●	●	●
UH-1	●	●	●
UH-2	●	●	●
UH-3	●	●	●
UH-4	●	●	●
UH-5	●	●	●

Infrastructure mapping: infrastructure domains

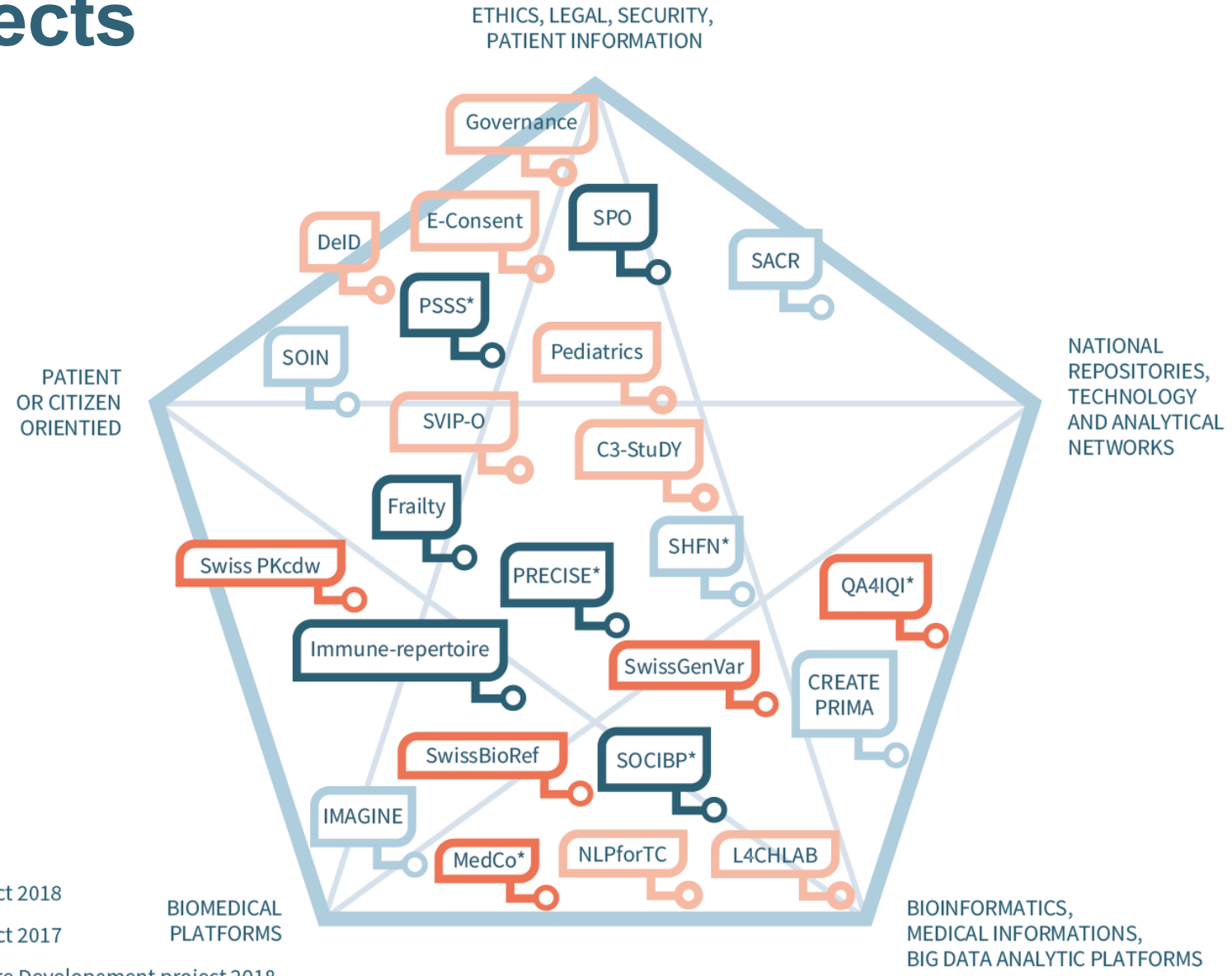
Step 1: Each consortium was asked to select 3 domains

- Patient or citizen oriented
- Ethics, legal domain, data protection, patient information
- Analytical platforms (e.g. genomics, metabolomics,..)
- Bioinformatics, medical informatics, big data analytic platforms
- National registries, technology, and analytical networks

Step 2: Within the domains, newly built infrastructure and their degree of implementation was reported

1. *Concept established*
2. *Infrastructure built and tested*
3. *First scientific study successfully performed on the described infrastructure*
4. *Infrastructure tested with multiple studies*
5. *Infrastructure available for projects outside the project consortium*
6. *Infrastructure used for clinical diagnostic or therapeutic applications*

SPHN portfolio: 24 bottom-up projects



- Driver project 2018
- Driver project 2017
- Infrastructure Development project 2018
- Infrastructure Development project 2017

* Project co-funded by SPHN and PHRT

Projects average degree of implementation

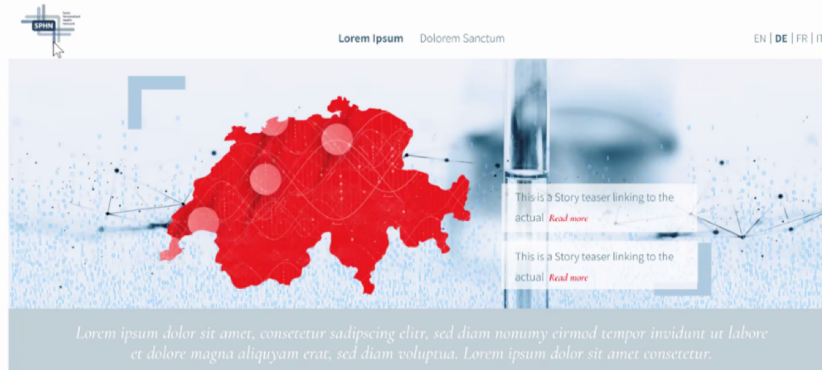
Infrastructure Development projects (*co-funded SPHN-PHRT)	Average degree of implementation [°]
Development of a governance and quality management system for exchange of patient related data for research purposes	n/a
E-General Consent	3.67
Citizen Centered Consent: Shared, Transparent and Dynamic	4.75
De-identification of clinical narrative data in French, German and Italian	3
LOINC for Swiss labs	5
Swiss Variant Interpretation Platform for Oncology	1.67
Natural Language processing [...] for Tumour Classification	3
Harmonising the collection of health-related data and biospecimens in paediatric hospitals throughout Switzerland	1
Driver projects (*co-funded SPHN-PHRT)	Average degree of implementation [°]
Swiss Frailty Network and Repository (SFNR)	1.67
Population-wide screens of the human immune repertoire	2.33
Swiss Molecular Pathology Breakthrough Platform (SOCIBP)*	3.17
Swiss Personalized Oncology Driver (SPO)	1
Identification of biomarkers and therapeutic targets in inflammatory disease immunotherapy by high-dimensional single cell analysis and cluster proteomics (PRECISE)*	1.5
Personalized Swiss Sepsis Study (PSSS)*	3.5

[°]Calculated Based on self-reported values (Annual report 2018)

Newly built infrastructures (Year 2018)

	Infra. dev. projects		Driver projects		Overall	
	# newly built infra.	average level of imp.	# newly built infra.	average level of imp.	# newly built infra.	average level of imp.
A: Patient or citizen oriented	9	2.4	5	1.8	14	2.2
B: Ethics, legal, data protection, patient information	6	2.8	3	2.5	9	2.7
C: Analytical platforms	2	3.5	3	2.8	5	3.1
D: Bioinformatics, medical informatics, big data analytic platforms	2	3.8	4	2.4	6	2.8
E: National registries, technology, and analytical networks	5	2	3	1	8	1.6
Overall	24	2.6	18	2.1	42	2.4

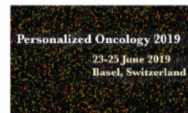
Visualizing analytic platforms and networks finding partners



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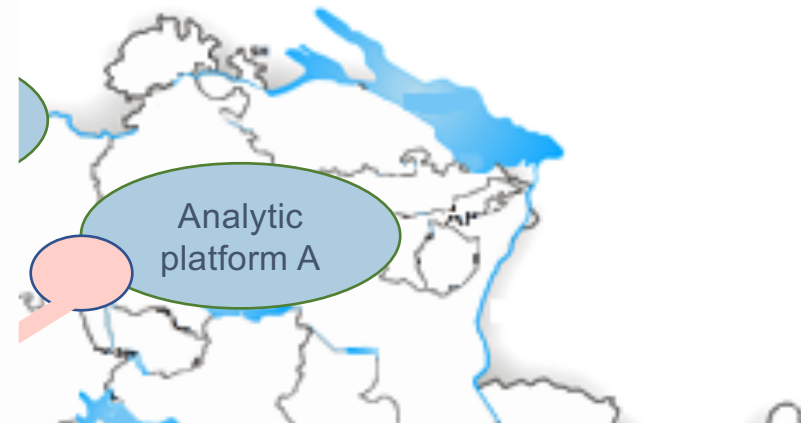
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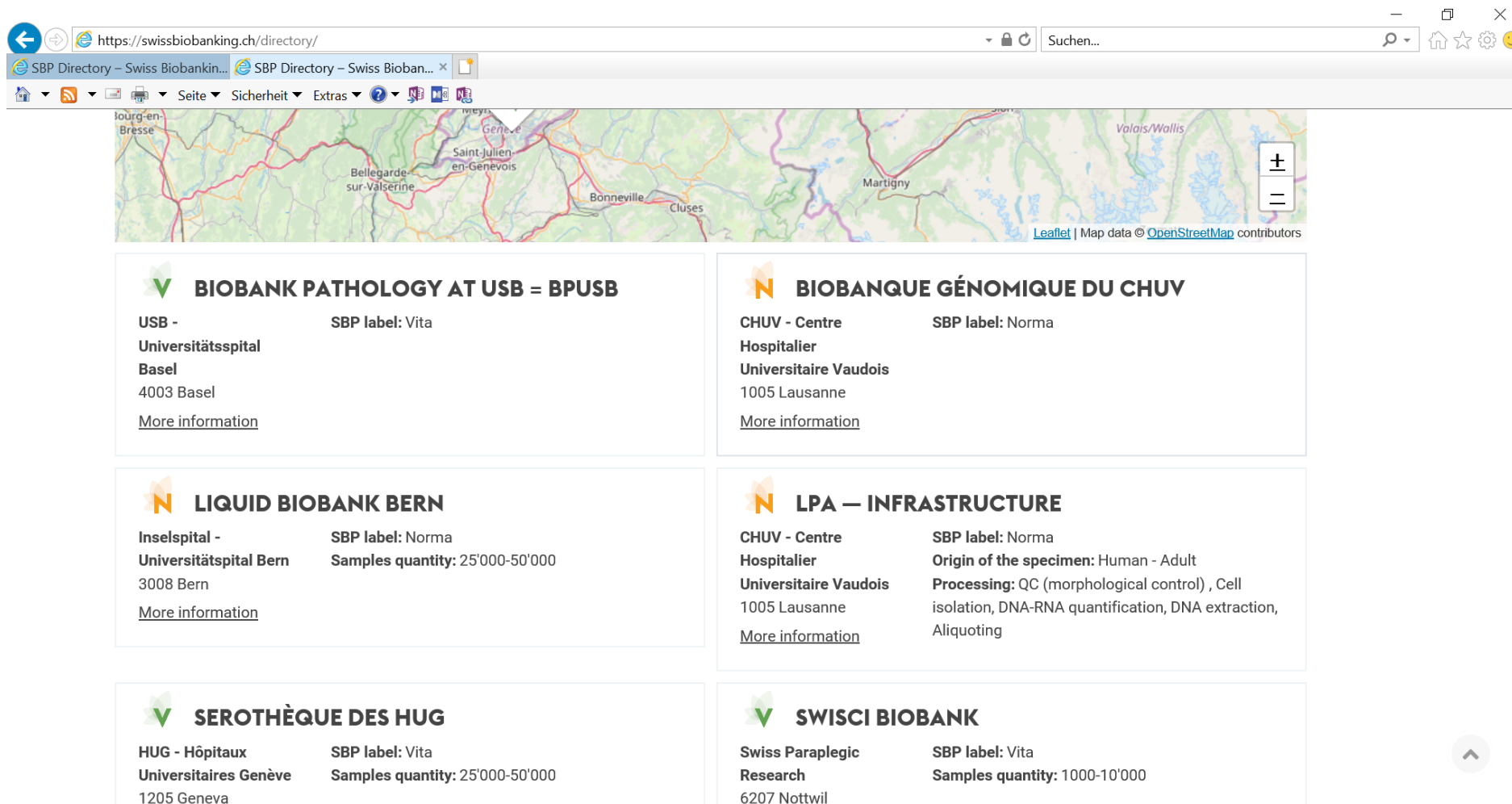
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- Defining common research use cases (e.g. Testing of new biomarker, ...)
- Finding collaborators and network partners
- Aggregate or compare study cohorts and samples in a safe IT environment
- Access to analytical platforms and existing consortia
- Process innovation (e.g. data transfer agreement)
- ELSI Support, e-learning facilities
- Access to bioinformatic analysis expertise

Linking to partner organisations (e.g. SBP)



https://swissbiobanking.ch/directory/

Suchen...

SBP Directory – Swiss Biobankin... SBP Directory – Swiss Bioban...

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<p>BIOBANK PATHOLOGY AT USB = BPUSB</p> <p>USB - SBP label: Vita Universitätsspital Basel 4003 Basel More information</p>	<p>BIOBANQUE GÉNOMIQUE DU CHUV</p> <p>CHUV - Centre SBP label: Norma Hospitalier Universitaire Vaudois 1005 Lausanne More information</p>
<p>LIQUID BIOBANK BERN</p> <p>Inselspital - SBP label: Norma Universitätsspital Bern 3008 Bern More information</p>	<p>LPA – INFRASTRUCTURE</p> <p>CHUV - Centre SBP label: Norma Hospitalier Universitaire Vaudois 1005 Lausanne More information</p> <p>Origin of the specimen: Human - Adult Processing: QC (morphological control) , Cell isolation, DNA-RNA quantification, DNA extraction, Aliquoting</p>
<p>SEROTHÈQUE DES HUG</p> <p>HUG - Hôpitaux SBP label: Vita Universitaires Genève 1205 Geneva Samples quantity: 25'000-50'000</p>	<p>SWISCI BIOBANK</p> <p>Swiss Paraplegic SBP label: Vita Research 6207 Nottwil Samples quantity: 1000-10'000</p>

Services and products: gaps

SERVICES		
Gaps	Infra. domains	Potential partners?
➤ Data linkage center	D, E	BAG, BFS, SNSF, PHRT SCTO, SBP, institutions
➤ Patient & citizen involvement, dialogue	A, B	SBP, SCTO
➤ ELSI helpdesk	B	SBP, SCTO, swissethics
➤ Harmonization of *omics (standards, quality)	C, D, E	PHRT
➤ Inventory/catalogue of research infrastructure	C, D, E	SBP, SCTO, PHRT, SNSF
➤ Long-term and sustainable funding strategy of infra.	C, D, E	SBP, SCTO, PHRT, SNSF
PRODUCTS		
Gaps	Infra. domains	Potential partners?
➤ Implementation of E-consent, citizen-centered consent	A, B	SBP, SCTO, swissethics, unimeduisse
➤ *Omics harmonization concept	C, D, E	PHRT
➤ Unique patient ID	A, B, E	BAG, FMH, SCTO, FORS
➤ Data sharing principles and associated usage procedures, Data and IT Strategy 2.0	D	SBP, SCTO, PHRT
➤ IP guidelines	B	SBP, SCTO, PHRT
➤ Guidelines on engagement with the corporate world	A, B	SBP , SCTO, PHRT, + swissuniversites, swissethics, unimedsuisse
➤ Map of research infrastructure	C, D, E	SBP, SCTO, PHRT SBP, SCTO, PHRT, SNSF

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A project of

Outlook, phase 2021-2024 (decision pending)

1. To consolidate the existing infrastructure and prepare the network to include additional hospitals (scalability) and, ultimately, general practitioners.
2. To pursue efforts with respect to expanding the scope of clinical and health-related variables (multiomics in collaboration with PHRT) as well as expanding the network with additional data sources, such as cohorts, registries and biobanks (in collaboration with SBP) as well as epidemiologic and statistical data.
3. To develop procedures to increase usage of data from healthy citizens as well as citizen-controlled data and to establish interoperability of such data within the network.
4. To strengthen the SPHN ELSIag in its function as a sounding board for the SPHN, and with respect to its role in the implementation of guidelines in the research settings, and in fostering engagement with patients and citizens.
5. To develop a strategy for engagement with the corporate world (e.g. projects with industry involvement) and international consortia.
6. To establish the concept, governance and technical platform for a long-term, independent national center for health data coordination and infrastructure for research from 2024 on. This platform will provide a technical solution to allow the hosting of encoded hospital, citizen centered and cohort data in a interoperable, legal, safe and semantically harmonized form.

The Swiss Personalized Health Network in a nutshell

- Federated, distributed network of interoperable resources;
- Feasible within the Swiss federal legal system;
- Sustainable, safe and ethical, legal research environment even for large dataset;
- Access to analytical platforms and bioinformatics computational facilities;
- Predefined processes and standards (quality, data exchange, semantics);
- Facilitates collaboration and use of resources;
- Scalable (international and other partners).

Similar SPHN infrastructures can ultimately be used for clinical diagnostics and therapy

Thank you for your attention

www.sphn.ch

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