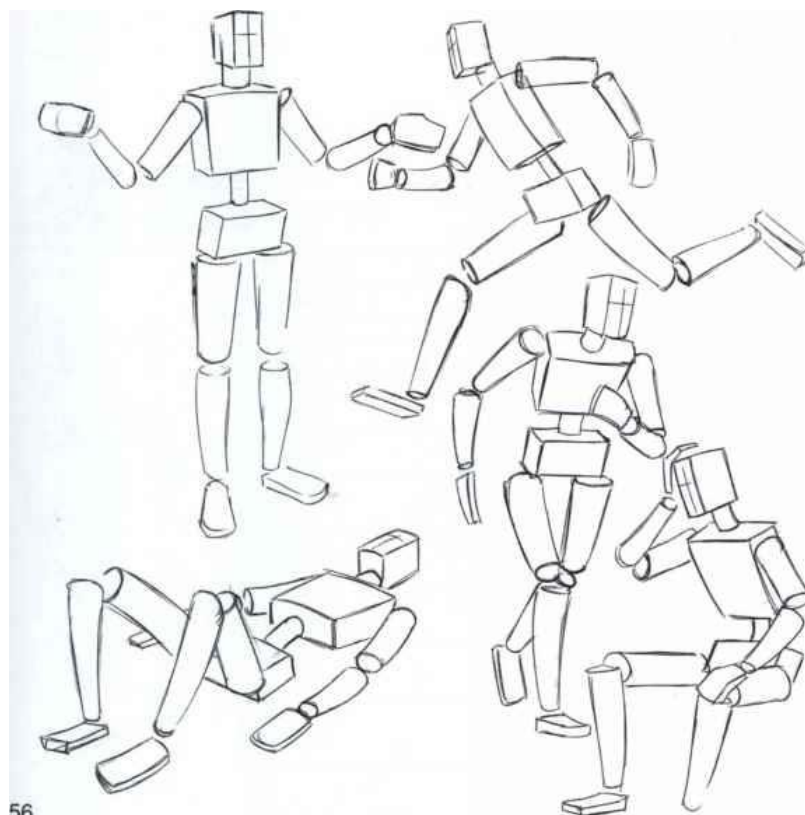


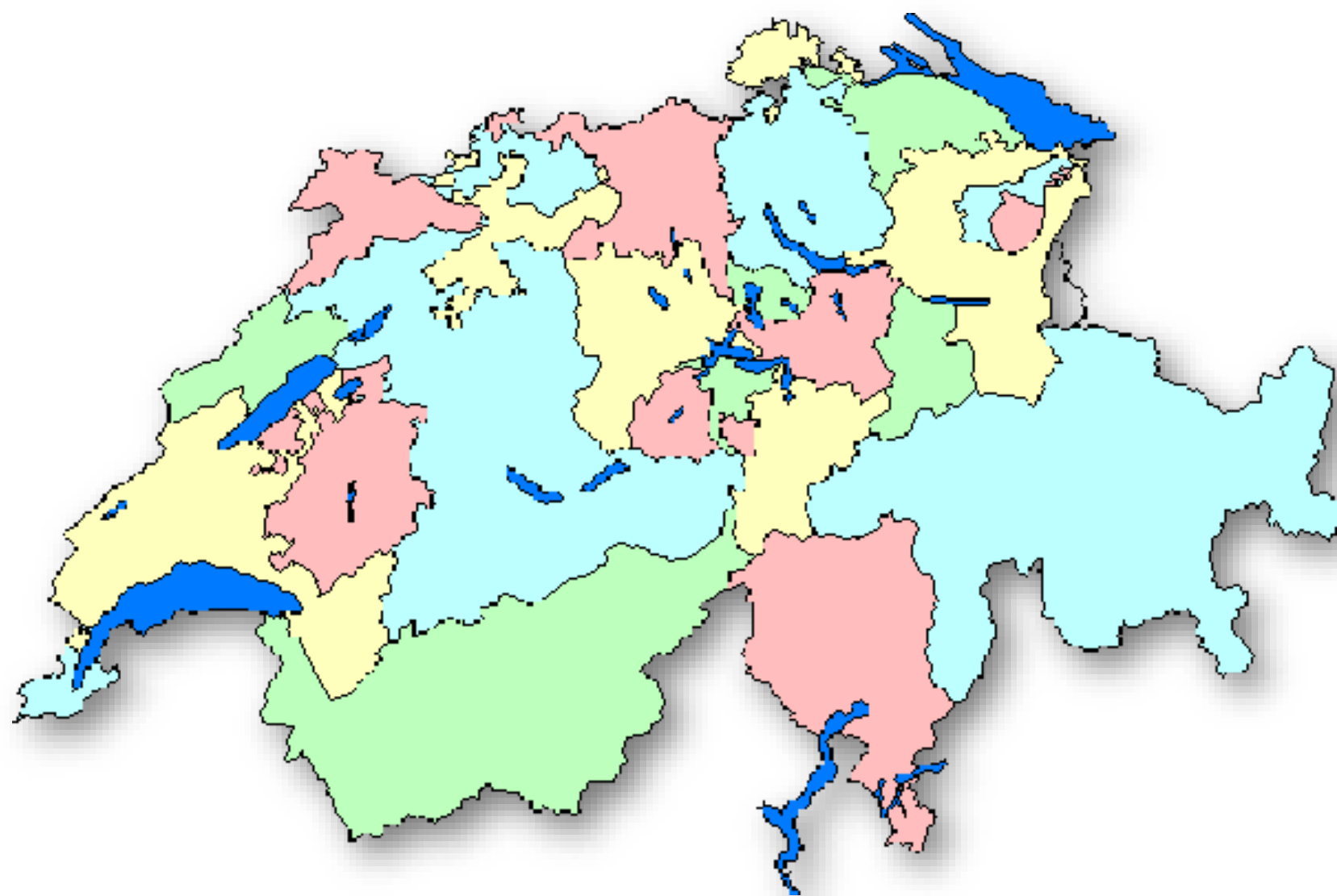
Swiss Personalized Health Network

Swiss care system

Pendant zur MI-I?



Christian Lovis MD MPH FACMI
university of Geneva
University hospitals of Geneva



THE PERSONALIZED HEALTH CHALLENGE

THE DATA DRIVEN SCIENCE



NIH Public Access

Author Manuscript

Hum Mutat. Author manuscript; available in PMC 2013 May 01.

Published in final edited form as:

Hum Mutat. 2012 May ; 33(5): 884–886. doi:10.1002/humu.22048.

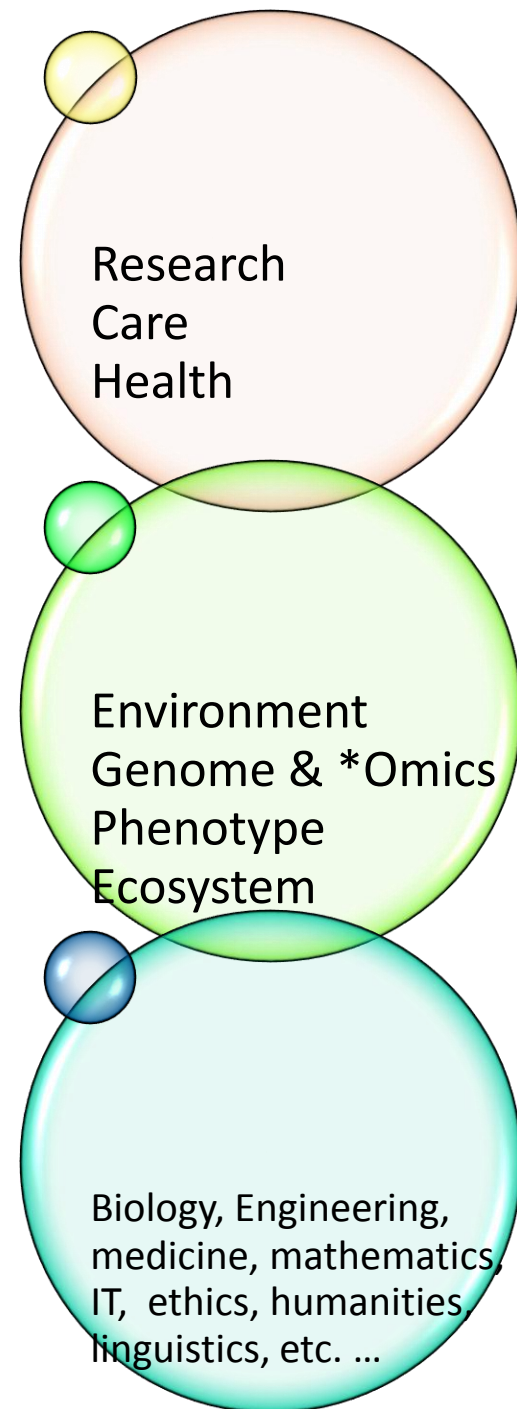
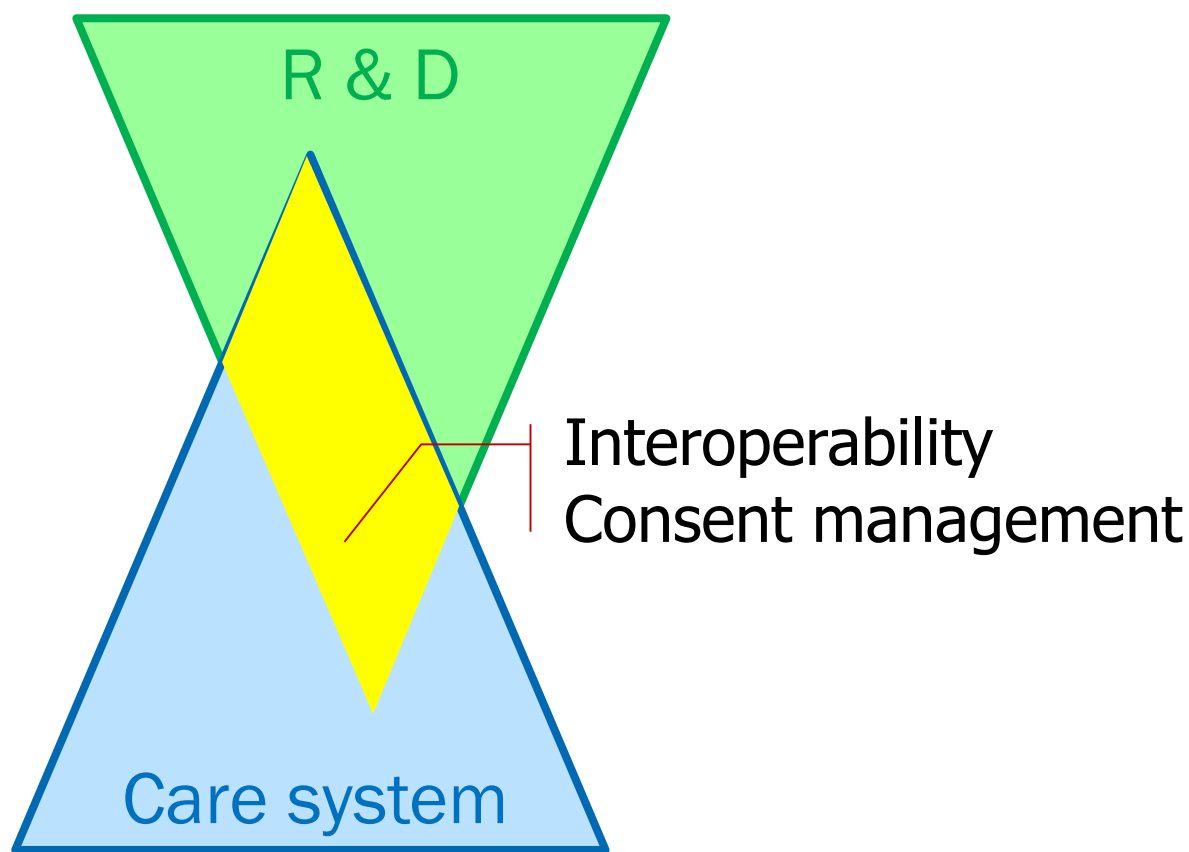
Next Generation Sequencing Demands Next Generation Phenotyping

Raoul CM Hennekam¹ and Leslie G Biesecker²

¹Department of Pediatrics and Translational Genetics, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands ²Genetic Disease Research Branch, National Human Genome Research Institute, NIH, Bethesda, Maryland, USA

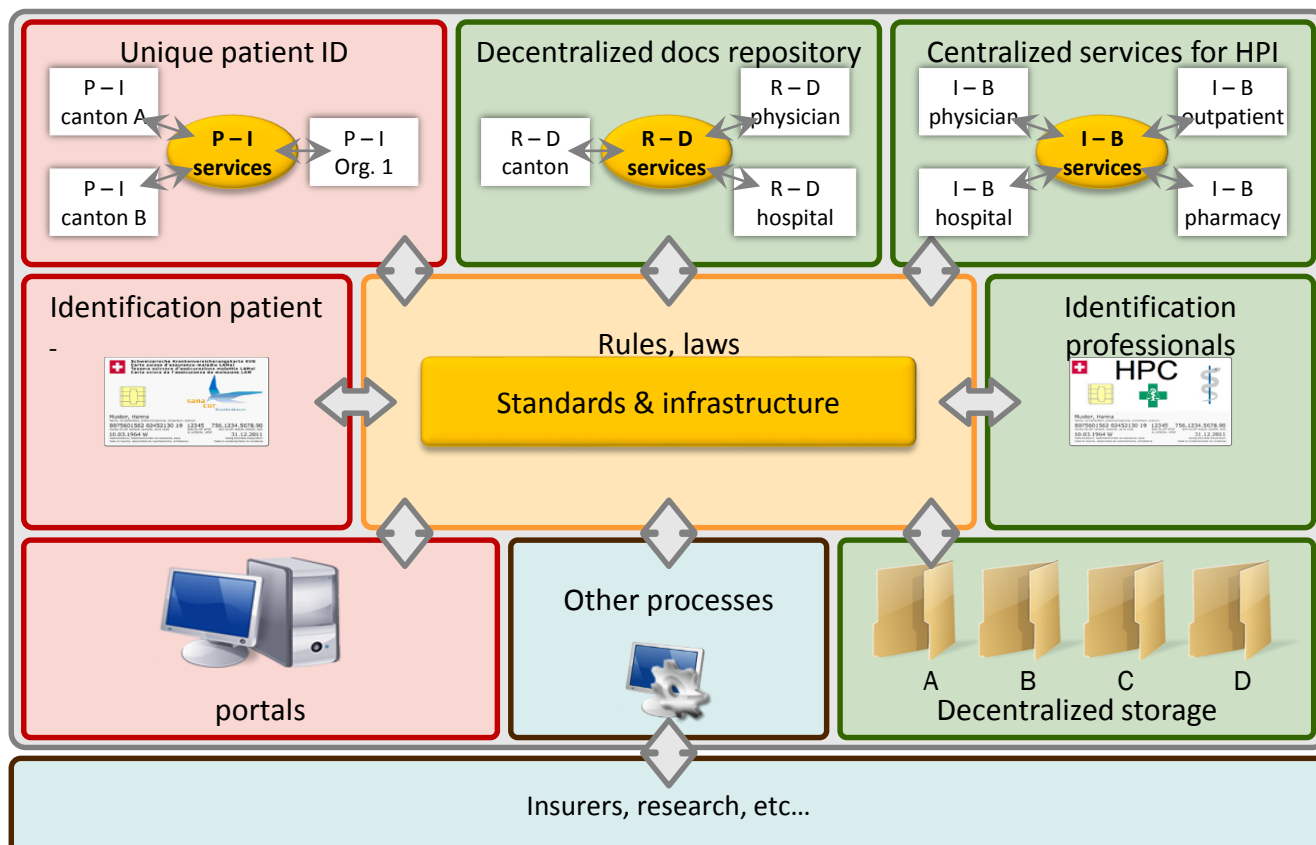
THE PERSONALIZED HEALTH CHALLENGE

CONVERGENCE AND COLLABORATION



NATIONAL REGULATORY FRAMEWORK – CARE SYSTEM

DISTRIBUTED GRID OF CERTIFIED COMMUNITIES OF CARE PROVIDERS





stiftung meineimpfungen
fondation mesvaccins
fondazione mievaccinazioni
foundation myvaccines

Der schweizerische elektronische Impfausweis

Für Alle

Für die Fachpersonen

Benutzeranleitung

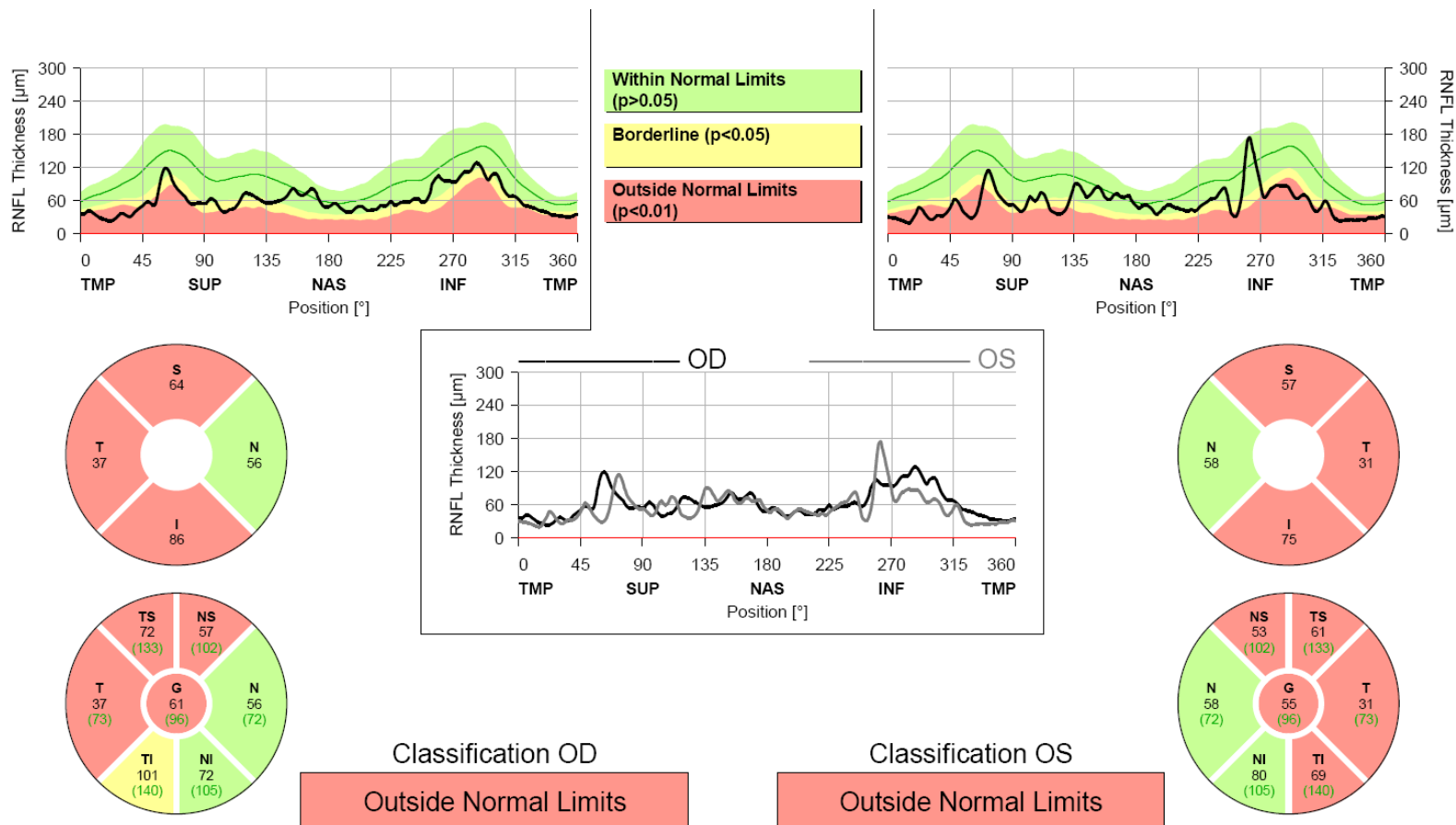
Kostenlos registrieren!

Login



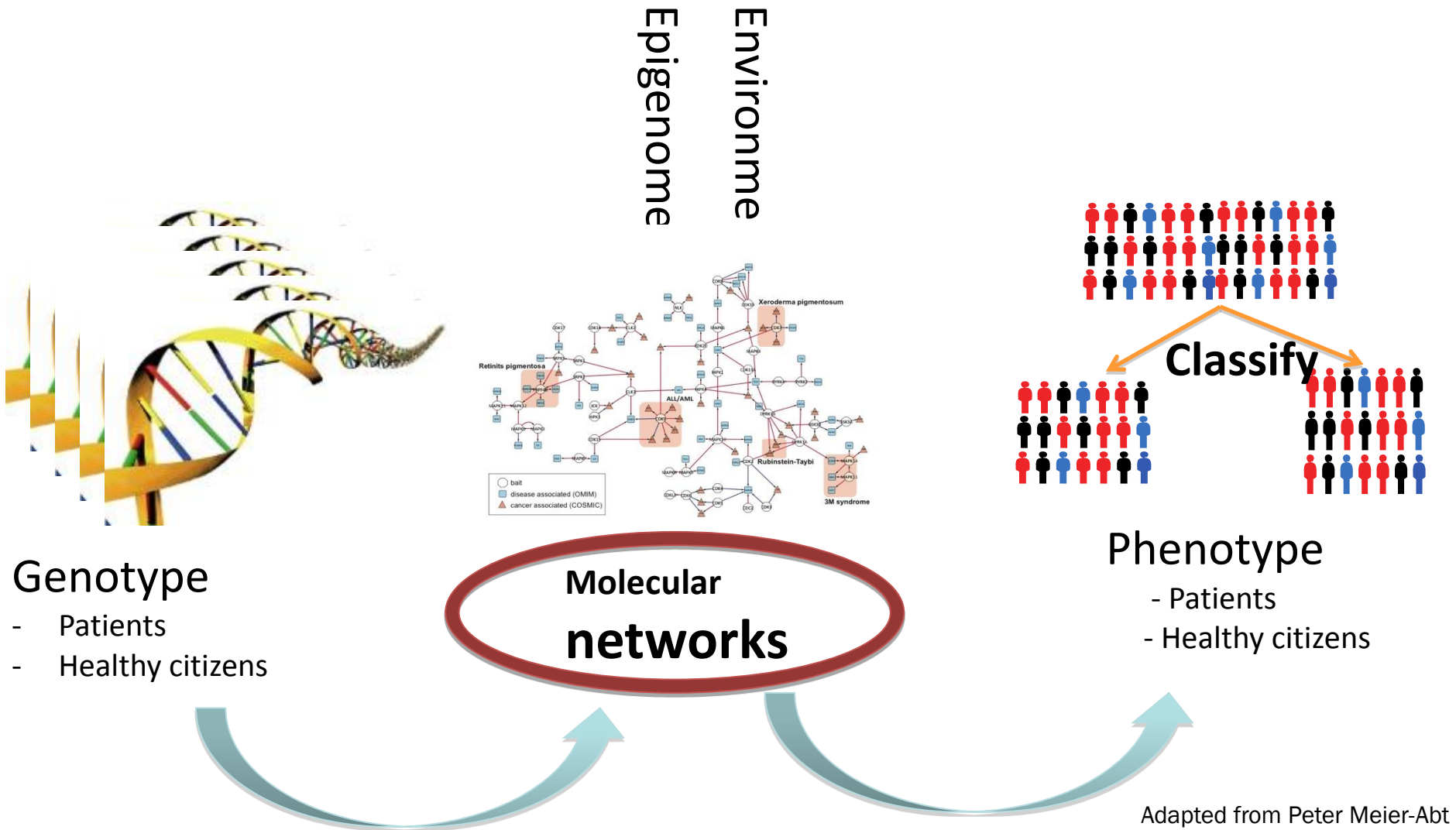
Willkommen auf www.meineimpfungen.ch

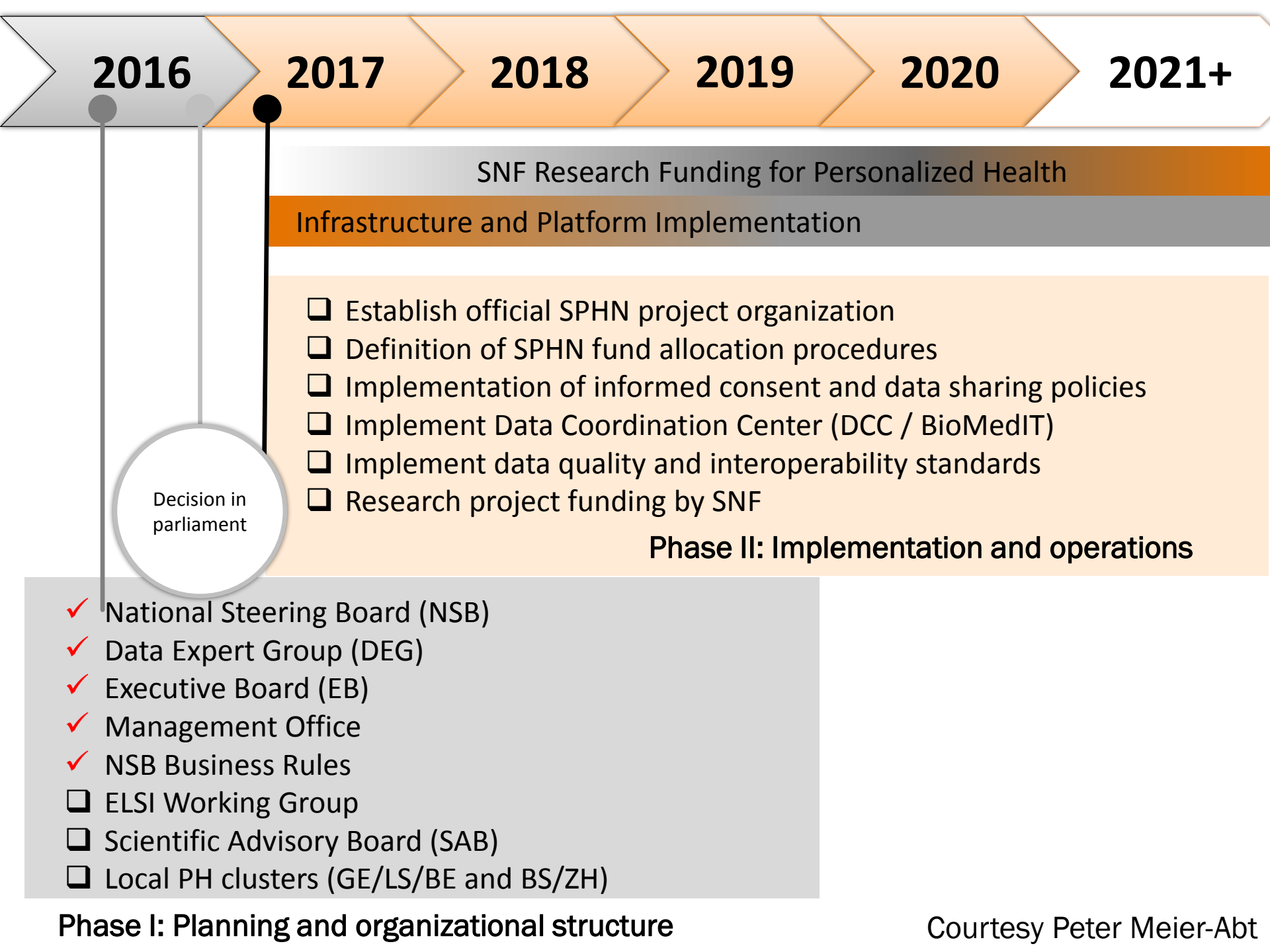




PERSONALIZED HEALTH RESEARCH NETWORK

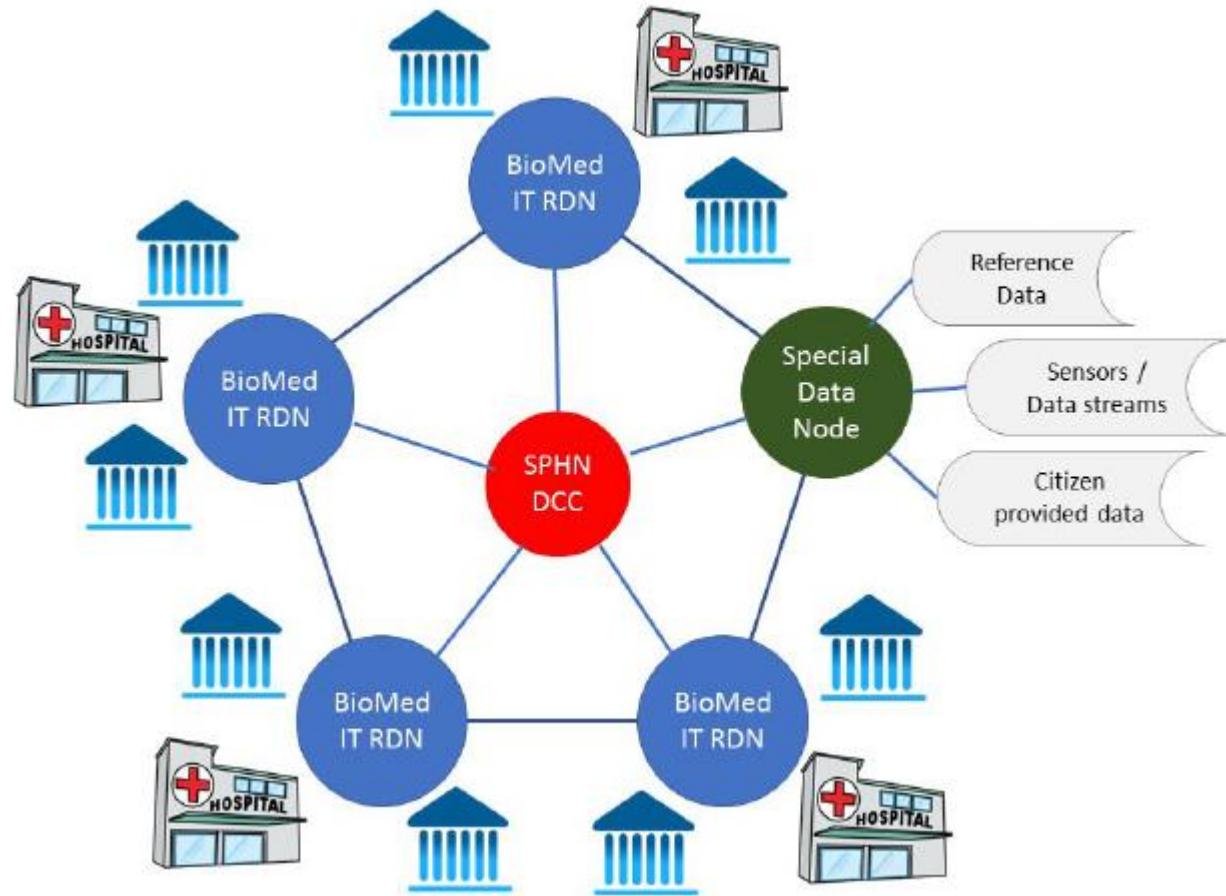
GENOTYPE – NETWORKS - PHENOTYPE





DISTRIBUTED PRIVATE NETWORK OF RESOURCES

COMPETENCES – PEOPLE - DATA – PROCESSING POWER



I2B2/TRANSMART FOUNDATIONS STANDARDS, SHRINE DISTRIBUTED NETWORK OF REGIONAL CLINICAL DATA CLUSTERS

Swiss Personal Health Private Research Cloud - SPH-PRC

i2b2

Informatics for Integrating Biology & the Bedside

A National Center for Biomedical Computing

[About Us](#) | [Software](#) | [NLP Data Sets](#) | [i2b2 tranSMART Foundation](#) |

Collaborations

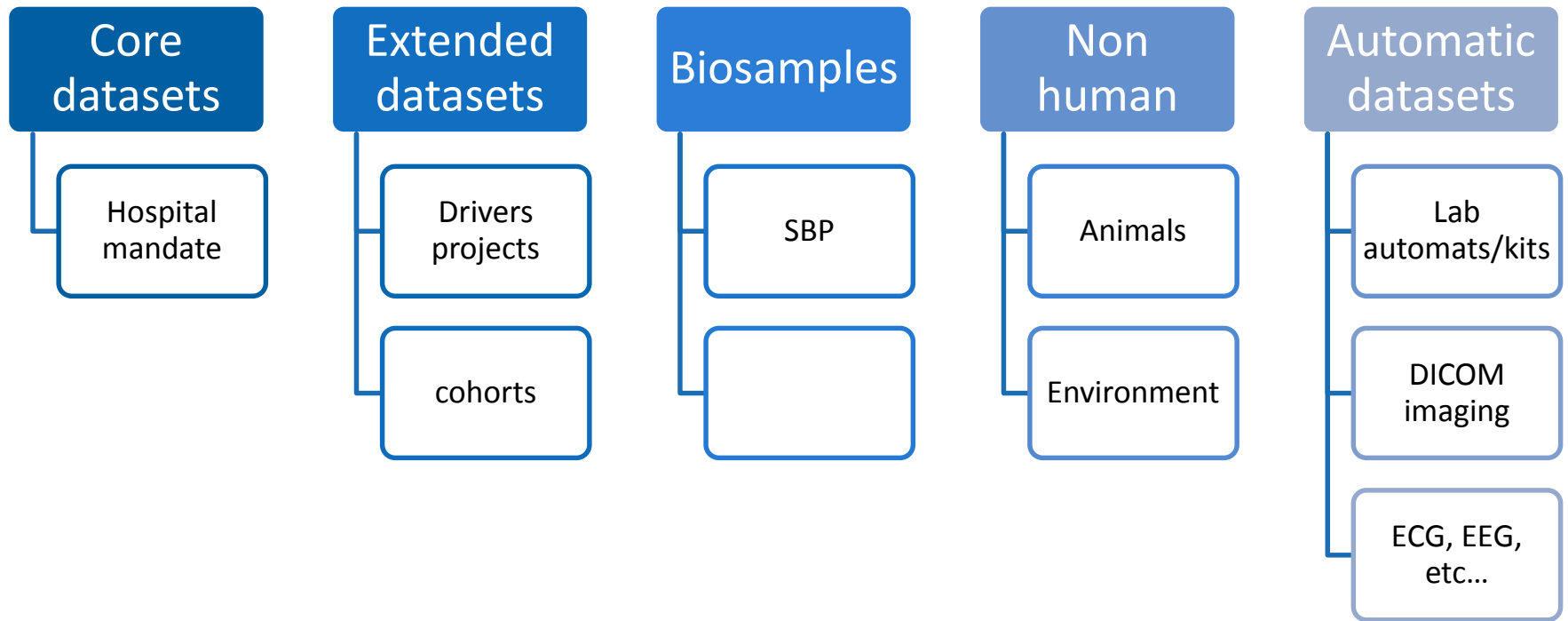
- Scientific Collaborations
- i2b2 Installations
- Academic Users' Group
- Data Sharing Network (SHRINE)
- Use of our Software
- Data Sharing Policy

Data Sharing Network (SHRINE)

In their application for CTSA status, Harvard Medical School (HMS) proposed creating a web-based software network (based on the prototype model SPIN, Shared Pathology Informatics Network) that would allow the participating Harvard hospitals to link their respective i2b2 instances for the sharing of obfuscated, aggregated counts of patients meeting selected inclusion and exclusion criteria for demographics, diagnoses, medications, and labs. It was envisioned that this network, called SHRINE (Shared Health Research Informatics NEtwork), would greatly enable population-based research, assessment of potential clinical trials cohorts, and hypothesis formation for followup study by combining the EHR assets across the hospital system.

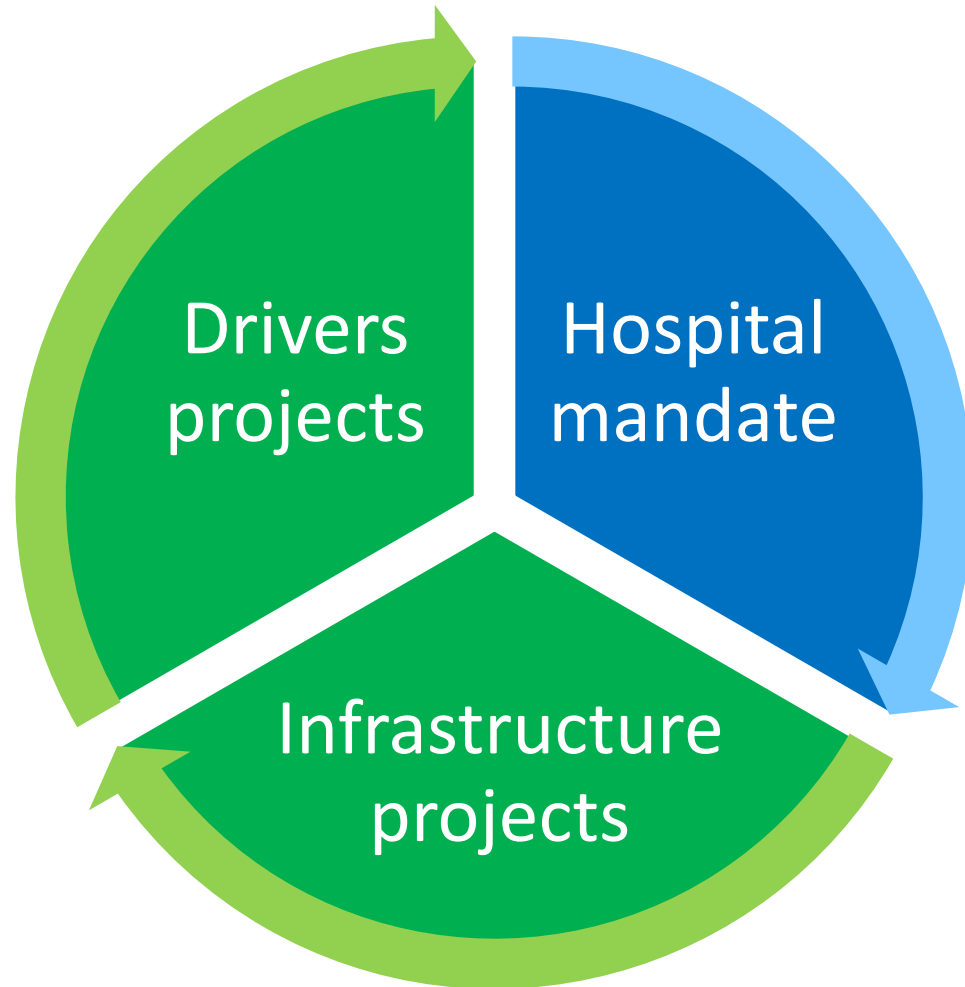
SWISS PERSONALIZED HEALTH NETWORK INITIATIVE

DCC – DCS-IOP DATA STRATEGY



SWISS PERSONALIZED HEALTH NETWORK INITIATIVE

FUNDING STRATEGY



SWISS PERSONALIZED HEALTH NETWORK INITIATIVE

HOSPITAL MANDATE

Expose >80% patients to General Consent

Adopt SPHN standards for data

Implement i2b2/tranSMART endpoint

Implement BioMedIT endpoints

ALIGNED VERSION (after Feedback Unimed Suisse) | 4 December 2017

Collaboration Agreement („Leistungsvereinbarung“) (hereinafter “the Collaboration Agreement”)

between

the Swiss Academy of Medical Sciences, Laupenstrasse 7, 3001 Bern (hereinafter referred to as **SAMW**) represented by Prof. Dr. Daniel Scheidegger, Valérie Clerc, and Prof. Dr. Peter Meier-Abt,

on behalf of the Swiss Personalized Health Network initiative (hereinafter referred to as **SPHN**),

and

Hôpitaux Universitaires de Genève (HUG), Rue Gabrielle-Perret-Gentil 4, 1211 Genève 14 (hereinafter referred to as the **UH**) represented by Bertrand Levrat and Prof. Dr. Amaud Perrier.

SAMW and the UH each are a **Party**, and are jointly referred to as the **Parties**.

Based on the

- “Zusatzprotokoll zur Leistungsvereinbarung 2017-2020 zwischen der Schweizerischen Eidgenossenschaft und der Akademie der Medizinischen Wissenschaften Schweiz (SAMW)”
- Swiss Personalized Health Network: Funding Principles (1.3.2017)
- Swiss Personalized Health Network: Funding Regulations (1.3.2017), hereinafter “the Funding Regulations”
- Ethical Framework for Responsible Data Processing in the Swiss Personalized Health Network (12.6.2017), hereinafter “the Ethical Framework”
- the “SPHN – Data Strategy” dated 22 June 2017 (and approved during the National Steering Board (NSB) meeting dated 29 June 2017)

which documents are to be seen as an integral part of this Collaboration Agreement, the Parties agree on the following:

Article 1. Purpose and Scope

1. As defined in the “Zusatzprotokoll zur Leistungsvereinbarung 2017-2020 zwischen der Schweizerischen Eidgenossenschaft (represented by SERI) und der Akademie der Medizinischen Wissenschaften Schweiz (SAMW)”, the aim of the SPHN initiative is to establish a Swiss network in personalized medicine in which all research institutes relevant to this area as well as the Swiss National Science Foundation are involved. This network of actors will be established and developed further in consultation with the Swiss federal health authorities, i.e. the Federal Office of Public Health. In the period 2017-2020, the focus is on the development of a nationally coordinated data infrastructure for the purposes of optimized use of data collected by the network's participants for research in the field of personalized medicine, including securing the desired interoperability of local / regional information systems, while respecting the appropriate legal and ethical frameworks.
2. This Collaboration Agreement sets out overarching goals and conditions that the UH has to fulfill in exchange for the SPHN funds made available by SAMW.
3. This Collaboration Agreement between SAMW and the UH aims at supporting the development of an interoperable clinical data management system (clinical data warehouse) at the UH. Clinical Data shall mean data that have been created in the context of a health care provider's (such as the UH's) process of treating patients.

Appendix 1: List of Milestones for the Collaboration Agreement (Leistungsvereinbarung)

This Appendix sets out the Milestones to be achieved by the UH. References to the contract years are expressed by Y1 (for contract year 1), Y2 (for contract year 2) and Y3 (for contract year).

For the purposes of this Appendix 1, the contract years are defined as follows: Y1 shall last from 1 January 2018 until 31 December 2018, Y2 shall last from 1 January 2019 until 31 December 2019 and Y3 shall last from 1 January 2020 until 31 December 2020.

Where a milestone is declared to be relevant for a contract year the respective requirement must have been achieved on the last date of the relevant contract year and must be upheld during the contract that follow. Once a requirement has been met the UH shall continue to meet the respective requirement(s) until 31 December 2021.

This Appendix has been agreed by the National Steering Board on 2 June 2017. – Modified as per recommendations of the SPHN-Task Force Collaboration Agreements in its session of 23 October 2017. – Approved (as modified) by the National Steering Board on 14 December 2017.

A. Consent Management and Legal Framework	Assessment/deadline
<p>A1. Milestone A1 is a hard milestone. Milestone A1 is met if the following aspects (i) and (ii) and (iii) are met:</p> <p>(i) UH has formally submitted a commitment to SAMW to participate in the development of a "harmonized consent" and to use it if the content is formally accepted by the UH;</p> <p>(ii) UH has implemented a formal and documented process to continuously increase the proportion of patients who are informed about the existence of a "general consent" or a harmonized consent (if available¹). On 31 December 2020, the following information level should be reached for each of the following groups for Year 3:²</p> <ul style="list-style-type: none"> • ≥85% of adult DRG domain patients • ≥50% of Tarmed domain patients • ≥50% of pediatric DRG domain patients <p>(iii) Patients must have the possibility to choose whether to "sign" a consent.</p>	<p>Milestone A1 to be met at the end of Y3.</p>
<p>A2. Milestone A2 is a soft milestone. It is met if the UH, during the relevant contractual year, has actively contributed to clarify and document the relationship between SPHN and the UH with respect to the legal framework and the procedures in place within the UH that relate to the sharing of consent information and the sharing of patient data (including governance, mechanisms to ensure proper implementation of consent revocation, adherence to the applicable data protection law, Human Research Act (HRA), law on public organizations and public archive laws, etc.). The documentation must cover at least (but shall not be limited to) governance aspects, procedures and other mechanisms to ensure the proper implementation of consent revocation and adherence to laws, such as: the applicable data protection act as well as the General Data Protection Regulation (GDPR) (to the extent the GDPR actually applies or has effects), the Human Research Act (HRA), the law on public organizations, public archive laws, etc.</p>	<p>Milestone A2 to be met at the end of Y1, Y2 and Y3.</p>
B. Definition of Data Interoperability Standards*	Assessment/deadline
<p>B1. Milestone B1 is a soft milestone. Milestone B1 is met if the following aspects (i) and (ii) are met:</p> <p>(i) During the relevant contractual year the UH must have actively participated in defining the initial SPHN data encoding and exchange standards.</p> <p>(ii) During the third contract year, the UH must have actively participated to progress on standards for data model and semantics to enable interoperability and according to scientific needs; compatible with relevant national and international standards, reporting to FOPH, and additional international standards if possible, etc.</p>	<p>Milestone B1(i) to be met at the end of Y1.</p> <p>Milestone B1(ii) to be met at the end of Y2 and Y3.</p>

<p>B2. Milestone B2 is a soft milestone. During the contract year preceding the milestone the UH must have actively participated in defining a horizontal data set (DS) to enable feasibility studies and contributed to a SPHN catalog of available data.</p>	<p>Milestone B2 to be met at the end of Y1, Y2 and Y3.</p>
<p>B3. Milestone B3 is a hard milestone. Milestone B3 is met if the following aspects (i) and (ii) and (iii) are fully met:</p> <p>(i) The UH provides a unique patient centered de-identified ID according to the Human Research Act (HRA);</p> <p>(ii) During the contract year preceding the milestone, the UH must technically be able to provide data in an encoded shareable way according to Appendix 2 and applicable law;</p> <p>(iii) During the contract year preceding the milestone, the UH must have participated in the development of deduplication mechanisms with SPHN.</p>	<p>Milestone B3(i) to be met at the end of Y1.</p> <p>Milestone B3(ii) to be met at the end of Y1, Y2 and Y3.</p> <p>Milestone B3(iii) to be met at the end of the years Y2 and Y3.</p>
<p>B4. Milestone B4 is a soft milestone. Milestone B4 is met if, during the period preceding the milestone, the UH has actively participated in defining the technical requirements to ensure access to shareable unstructured data (e.g. medical images, text, genomics, electrophysiological data, longitudinal observational data, etc.).</p>	<p>Milestone B4 to be met at the end of the years Y1, Y2 and Y3.</p>
C. Clinical Research Data Management at Hospitals (CDW)	Assessment/deadline
<p>C1. Milestone C1 is a soft milestone. Milestone C1 is met if, until the end of the third contract year, the UH has implemented and deployed internal clinical research data management systems (e.g. a data lake or Clinical Data Warehouse) at hospitals for integrating patient data in order to be able to provide data for research (including quality and security requirements).</p>	<p>Milestone C1 to be met at the end of the year Y3.</p>
<p>C2. Milestone C2 is a hard milestone. Milestone C2 is met if, at the end of each relevant contract year, the UH is technically able to harvest a horizontal data set according to B2 [as set out in Appendix 2].</p>	<p>Milestone C2 to be met at the end of the years Y1, Y2 and Y3.</p>
<p>C3. Milestone C3 is a hard milestone. Milestone C3 is met if, after the third contract year, the UH has implemented:</p> <p>(i) SPHN data encoding for clinical research data and;</p> <p>(ii) transcoding resources for clinical data.</p>	<p>Milestone C3 to be met at the end of the year Y3.</p>
<p>C4. Milestone C4 is a hard milestone, staggered by contractual year. Milestone C4 is met (tested on a per year-basis) if the UH has provided certain defined data sets (DS). Such data sets must use an i2b2/shrine-compatible mechanism, i.e. query endpoint or data export, to establish an interface to the SPHN distributed query architecture.</p> <p>(i) Implement an i2b2/shrine compatible mechanism - i.e. query endpoint or data export - to establish an interface to the SPHN distributed query architecture (using test or real data).</p> <p>(ii) The UH must technically be able to use the i2b2/shrine compatible mechanism to provide defined data sets (DS) as defined in B2.</p>	<p>Milestone C4 (i) to be met at the end of the year Y1.</p> <p>Milestone C4 (ii) to be met at the end of the years Y2 and Y3.</p>
D. Biobanking Interoperability	Assessment/deadline
<p>D1. Milestone D1 is a soft milestone. Milestone D1 is met if, at the end of the third contract year, the following goals are met: In collaboration with the Swiss Biobanking Platform, implementation of 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.</p>	<p>Milestone D1 to be met at the end of the year Y3.</p>

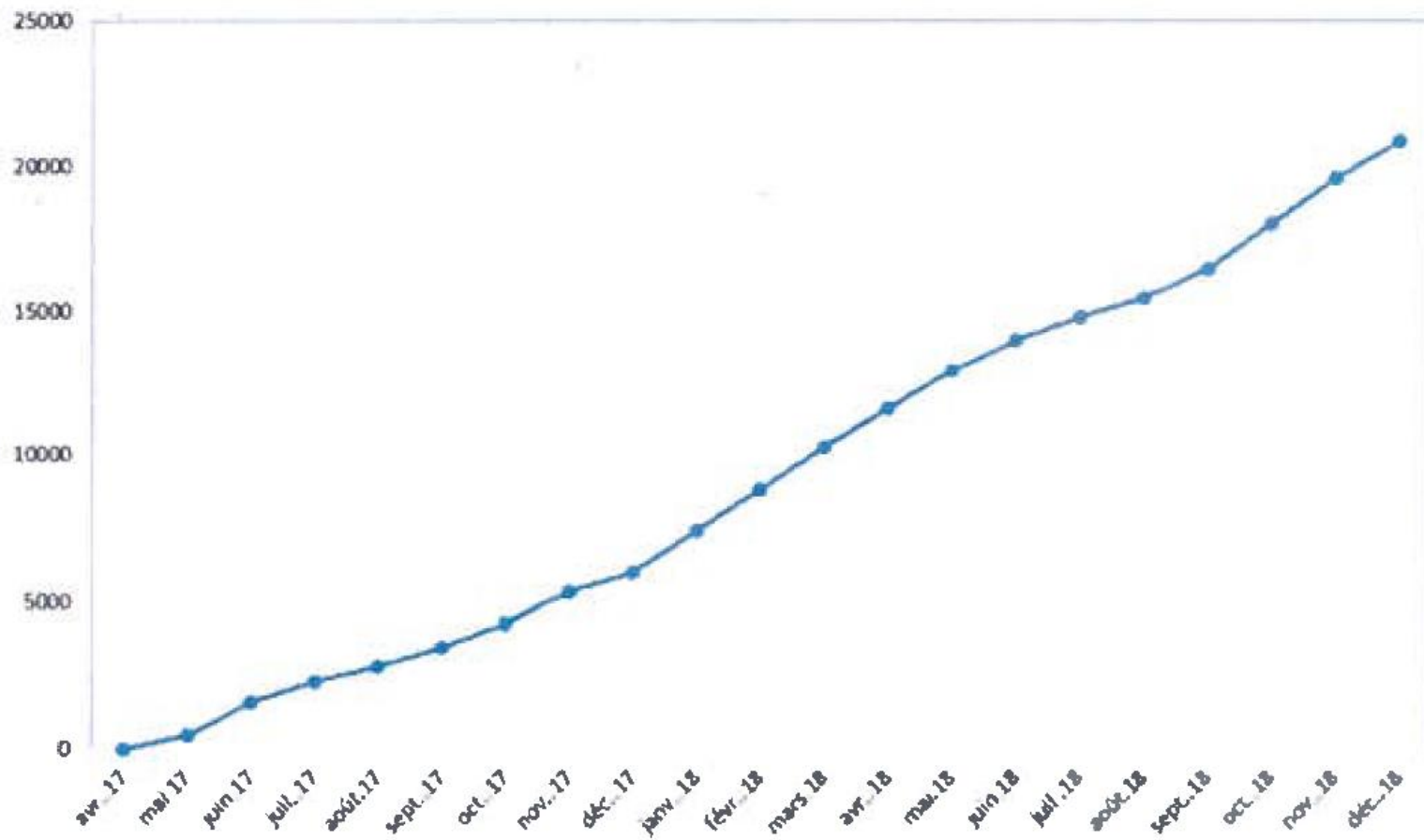
*The implementation of programmatic access mechanisms to specific data types shall be funded by driver projects.

¹ The "harmonized consent" is deemed to be available if the form was developed and approved by the relevant authorities (Ethics committees) and the UH.

² European patients can be excluded to make sure that we are not exposing ourselves to the new European framework on data protection.

GENERAL CONSENT EVOLUTION

GENEVA UNIVERSITY HOSPITALS 2017/04 – 2018/12



SWISS PERSONALIZED HEALTH NETWORK INITIATIVE

DRIVER PROJECTS

Match funding principle

Competitive call

Large consortium

Address an important aspect of medicine

Implement sustainable infrastructure

Driver Projects

Project title	Institutions	Main applicant
Swiss Frailty Network and Repository.	USZ, Inselspital, Felix Platter Spital, CHUV, HUG	Heike Bischoff-Ferrari (USZ)
Population-wide screens of the human immune repertoire: a reverse personalized-medicine approach. Adriano Aguzzi	USZ, UZH, ETHZ, PSI, UniBS, SIB	Adriano Aguzzi (USZ/UZH)
Swiss Personalized Oncology Driver (SPOD).	CHUV, HUG, Inselspital, UniGE, EPFL-SDCD, HES-SO, SAKK	Olivier Michiélín (CHUV)
Multidisciplinary Multicentre Molecular and Cellular Cancer Consortium (M3C3.CH).	USB, UniBS, USZ, UZH, ETHZ, UniGE, IOR, SIB, Kantonsspital Aarau, Kantonsspital Winterthur, Stadtsptal Triemli, Kantonsspital St. Gallen, SICHH, Oncology Institute of Southern Switzerland	Mohamed Bentires-Alj (USB/UniBS)

Driver Projects jointly with PHRT

PRECISE: Identification of biomarkers and therapeutic targets in inflammatory disease immunotherapy by high-dimensional single cell analysis and cluster proteomics	ETHZ, CHUV, Inselspital, USB, USZ, UZH	Manfred Claassen (ETHZ)
Swiss Molecular Pathology Breakthrough Platform (SOCIBP)	Inselspital, UniBE, ETHZ, HUG, CHUV, USZ	Mark Rubin (Insel, UniBE)
Personalized Swiss Sepsis Study (PSSS): Detection and modelling of sepsis using machine learning to analyse continuous ICU monitoring, laboratory, microbiology, and -omics data for personalized sepsis management.	UniBS, USB, USZ, CHUV, HUG, ETHZ, Inselspital, UniBE	Adrian Egli (USB/UniBS)

SWISS PERSONALIZED HEALTH NETWORK INITIATIVE

INFRASTRUCTURE PROJECTS

Match funding principle

Competitive call

No need for a consortium

Implement sustainable infrastructure

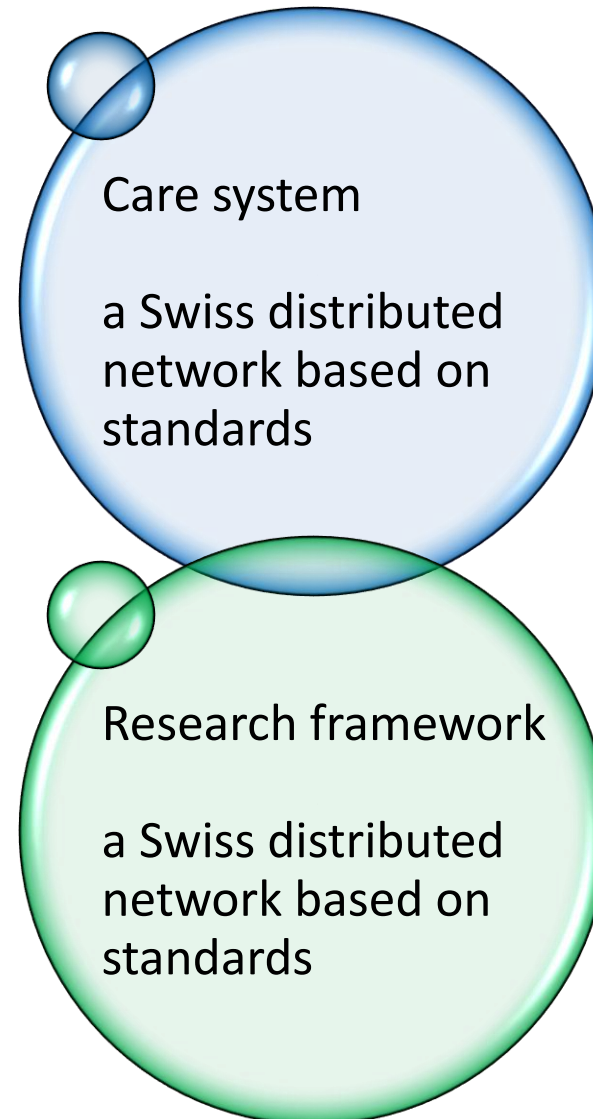
SPHN Call for Proposals 2017: List of awarded projects

Infrastructure Development Projects

Project title	Institutions	Main applicant
Development of a governance and quality management system for exchange of patient related data for research purposes	USB, UniBS, USZ, UniBE, SCTO	Joerg Willers (USB/UniBS)
E-General-Consent: Development and Implementation of a Nationwide Harmonized Interactive Electronic General Consent.	USB, UniBS, UKBB, Inselspital, HUG, CHUV, USZ, SCTO, SBP, SwissPedNet	Christiane Pauli-Magnus (USB/UniBS)
C3-STuDY: Citizen Centered Consent: Shared, Transparent and Dynamic.	HUG, UniGE, CHUV, SBP	Christian Lovis (HUG/UniGE)
LOINC for Swiss Laboratories (L4CHLAB).	HUG, UniGE, Inselspital, CHUV, Hôpital du Valais, SICHH	Christian Lovis (HUG/UniGE)
DeID/De-identification of clinical narrative data in French, German and Italian.	HUG, UniGE, UZH	Christian Lovis (HUG/UniGE)
NLP-powered mapping of clinical reports onto SNOMED-CT concepts for tumour classification (NLPforTC).	USB, UniBS, USZ	Thomas Fabbro (USB/UniBS)
Swiss Variant Interpretation Platform for Oncology (SVIP-O).	ETHZ, HES-SO, SIB	Daniel Stekhoven (ETHZ)
Harmonising the collection of health-related data and biospecimens in paediatric hospitals throughout Switzerland.	UniBE, Inselspital, UZH, UKBB, HUG, CHUV, Cantonal Hospital Aarau, Children's Hospital of Eastern Switzerland, Ente Ospedaliero Cantonale	Claudia Kuehni (UniBE)

THE PERSONALIZED HEALTH CHALLENGE

CONVERGENCE AND COLLABORATION



L4CHLAB

LOINC FOR SWISS LABORATORIES



A	B	C	D	E	F	G	H	I	J	K	L	M	N
LOINC	HUG	Analyse	Materiel	OFAS	Labo HUG	ICHV	Analyse	Materiel	OFAS	INSEL	Nr. Ana.	Kbz. Ana.	Analyse
10333-3	ok	Aspect (LCR)	LCR	1766 LIQBIO	ok	Aspect (LCR)	LCR	1766	ok	249 BESVZ	VOR Zentrifugation		
10501-5	ok	LH (Lutrophine)	Sang	1542 CHIMURG	ok	LH (Lutrophine)	Sang	1542	ok	2130 LH	LH		
11580-8	ok	TSH	Sang	1718 CHIMURG	ok	TSH	Sang	1718	ok	2005 TSH	TSH		
12736-5	ok	Acide hyaluronique	Sang	Hors liste	RQUAL	ok	Acide hyaluronique	Sang	Hors liste	ok	2970 HYA	Hyaluronat	
13539-2	ok	Phosphate (Urine)	Urine, récolte	1602 CHIMURG	ok	Phosphate (Urine)	Urine, récolte	1602	ok	323 PI-U	Anorg. Phosphat		
14566-4	ok	Calcitriol (Vitamine D 1,25-OH)	Sang	1000 RQUAL	ok	Calcitriol (Vitamine D 1,25-OH)	Sang	1000	ok	2430 1.25D	1,25-Dihydroxy-Vit		
14590-4	ok	Vitamine E (alpha tocophérol)	Sang	1755 TOX	ok	Vitamine E (alpha tocophérol)	Sang	1755	ok	3517 Vit-E	Vitamin E (D a-Tocc		
14631-6	ok	Bilirubine totale	Sang	1207 CHIMURG	ok	Bilirubine totale	Sang	1207	ok	69 Blg	Bilirubin gesamt		
14646-4	ok	HDL-Cholestérol	Sang	1410 CHIMURG	ok	HDL-Cholestérol	Sang	1410	ok	629 HDL	HDL-Cholesterin		
14647-2	ok	Cholestérol total	Sang	1230 CHIMURG	ok	Cholestérol total	Sang	1230	ok	74 CH	Cholesterin		
14665-4	ok	Cuivre	Sang	1515 TOX	ok	Cuivre	Sang	1515	ok	203 CU	Kupfer		

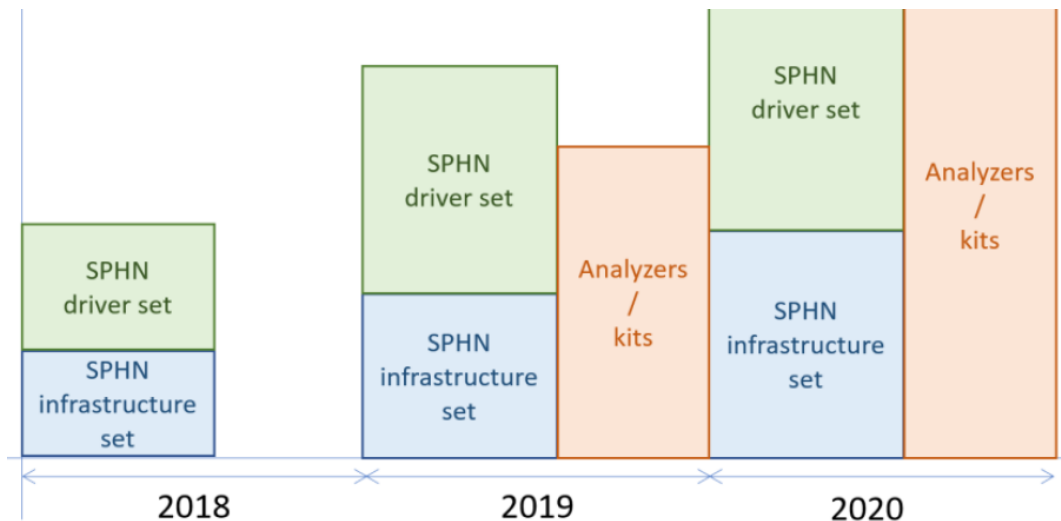
Common mapping > 1'000 analysis – LOINC & BAG/OFSP LA

SPHN DCC Strategy paper and milestones for laboratory

L4CHLAB

LOINC FOR SWISS LABORATORIES

- 1) Enforce LOINC as a common language
- 2) Use LOINC for identifying analysis, not results
- 3) Enforce the classifications, not specific encoding
- 4) Stepwise introduction based on commercially available analyzers/assays kits
- 5) Converging approach between the major SPHN supported initiative
- 6) Accept alternatives encoding when required
- 7) Alignment between care system requirements and R&D bodies and needs
- 8) Governance and sustainability



DE-ID

DEIDENTIFICATION FOR MEDICAL DOCUMENTS



UniversityHospital
Zurich

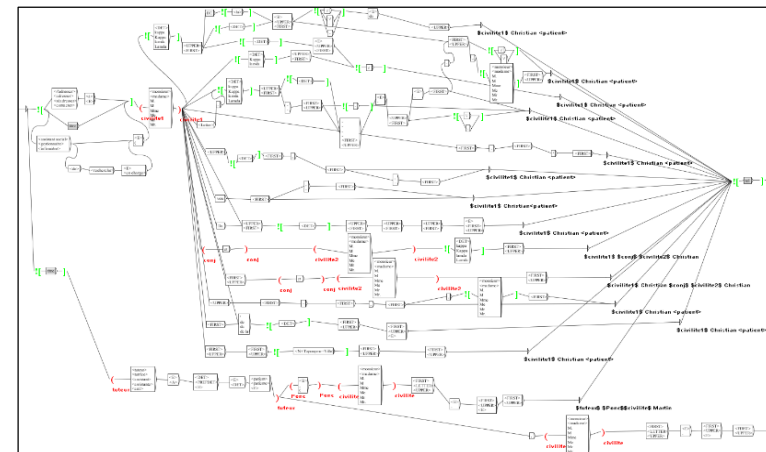
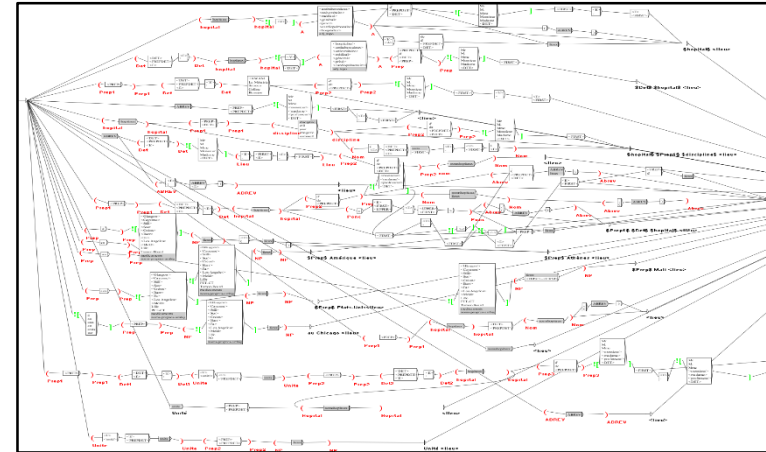


Hospital adoption friendly strategy for deidentification
explainable
correctable
commitable
Based on finite state automata

DE-ID

DEIDENTIFICATION FOR MEDICAL DOCUMENTS

- Protected Health Information
- (HIPAA) Privacy Rules:
 - Names (patients, doctors, nurses)
 - Dates
 - Locations (hospitals, clinics, towns, countries)
 - Telephone and fax numbers
 - Names of health insurance companies
- 29 finite state automata delivered to CHUV, USB, USZ, ETHZ



CITIZEN CENTERED CONSENT (C3) MANAGEMENT SYSTEM



transparent



dynamic



shared



revocable



auditable

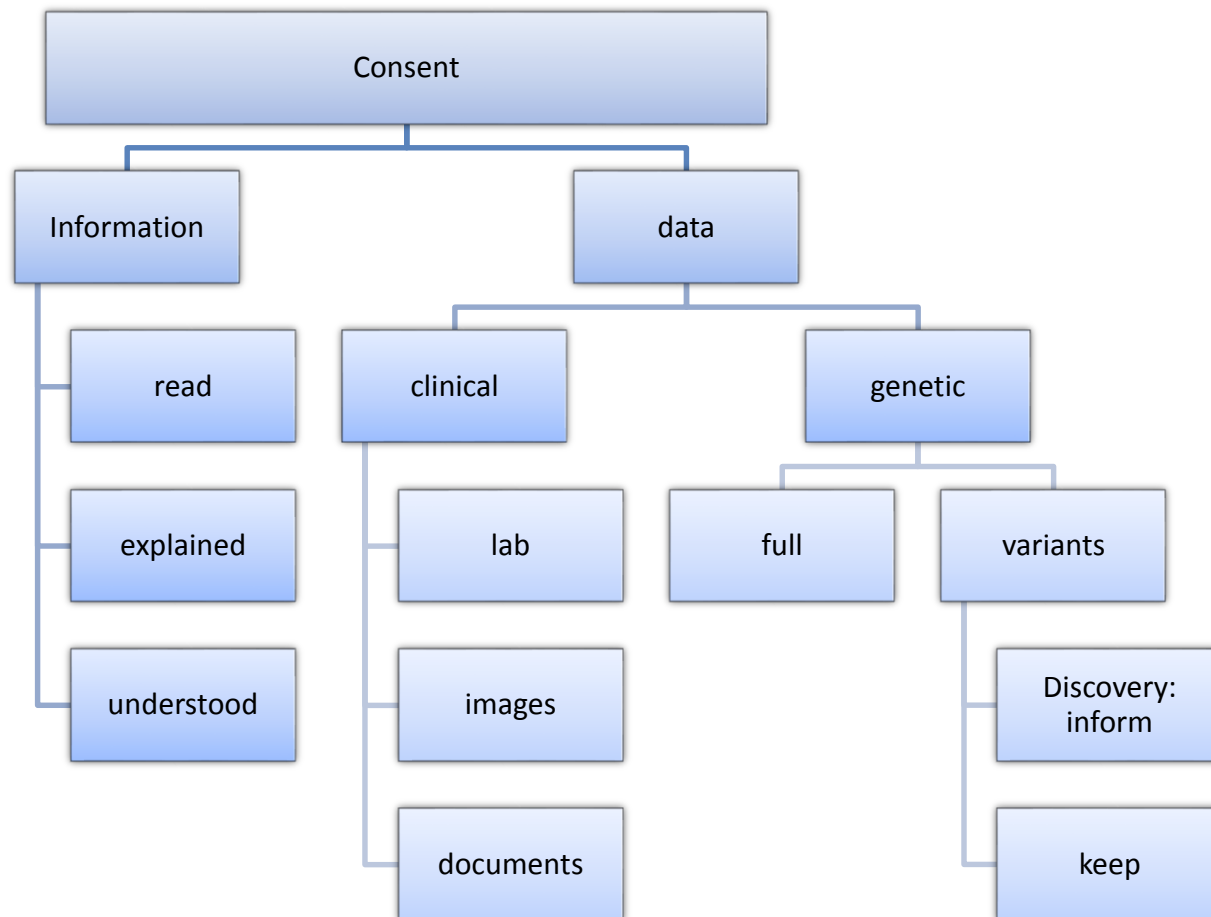


Non retractable

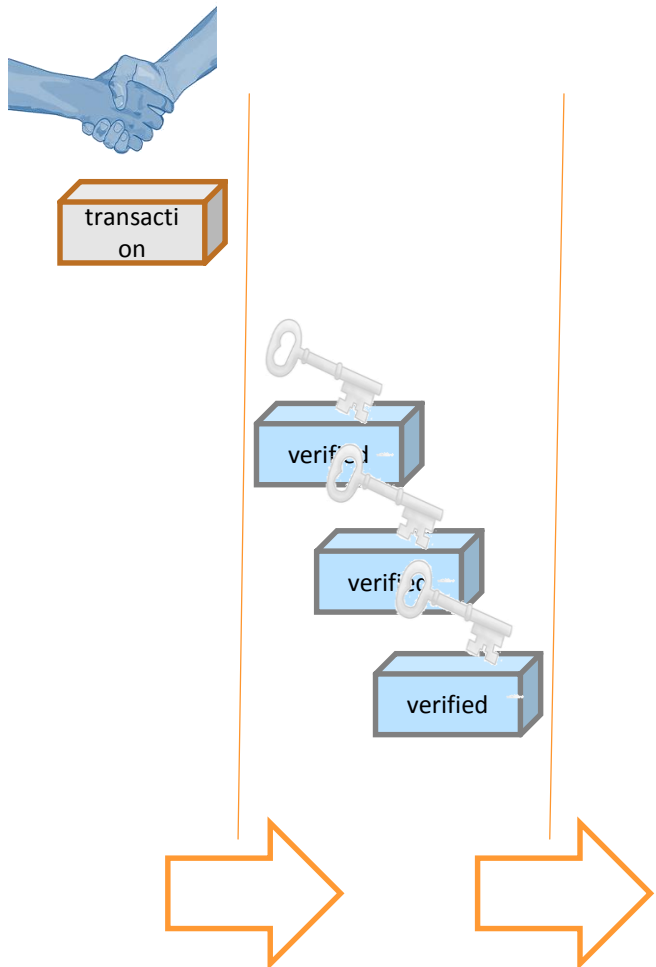
building

trust

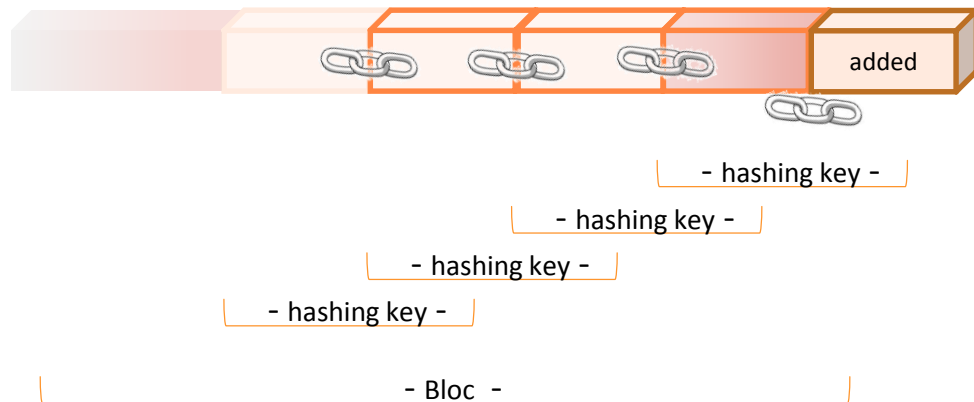
CITIZEN CENTERED CONSENT (C3) MANAGEMENT SYSTEM



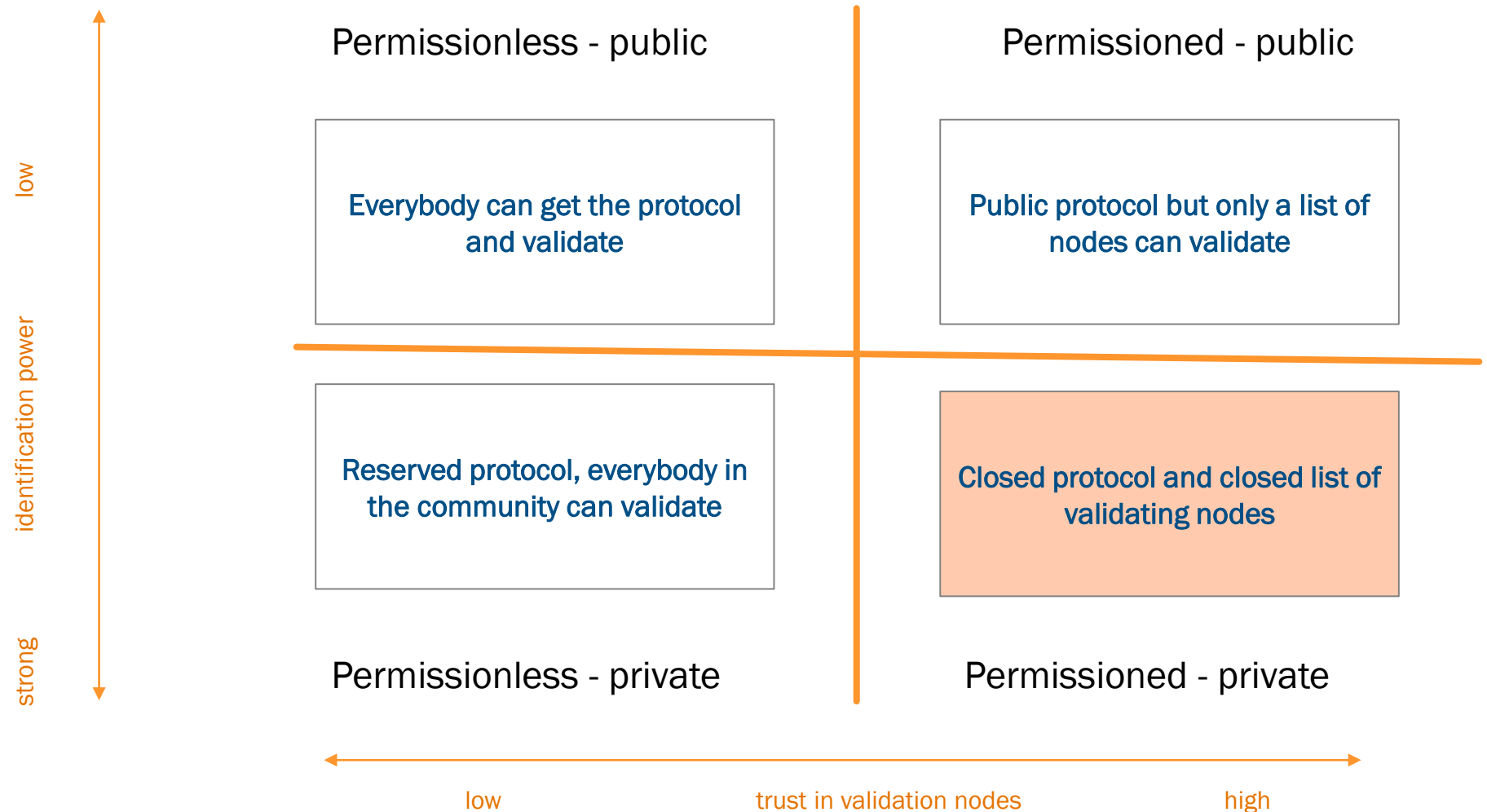
CITIZEN CENTERED CONSENT (C3) MANAGEMENT SYSTEM



BLOCKCHAIN

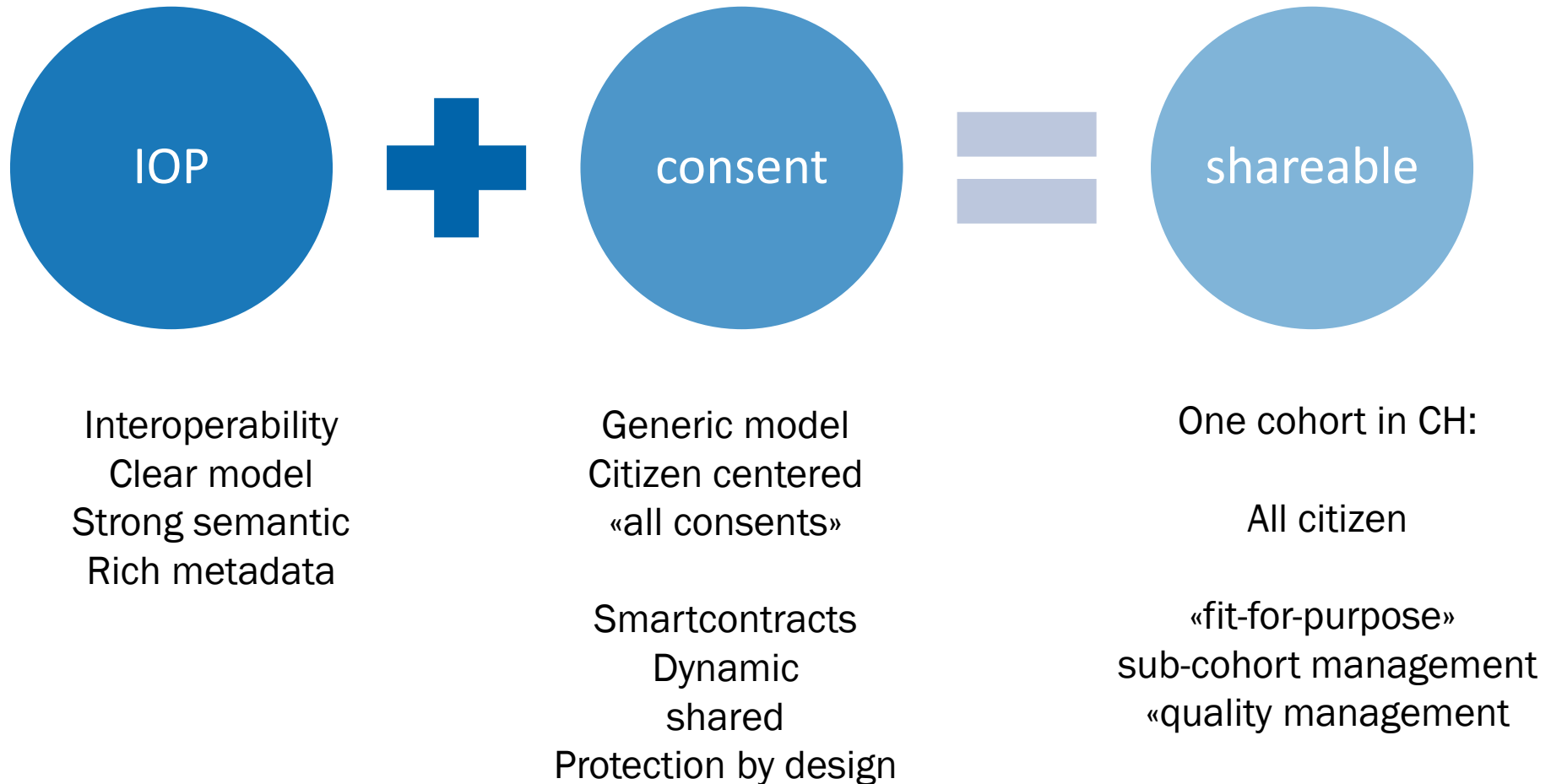


CITIZEN CENTERED CONSENT (C3) MANAGEMENT SYSTEM



SWISS PERSONALIZED HEALTH NETWORK INITIATIVE

DCC - DATA STRATEGY



DATA DRIVEN ECOSYSTEM

