

Joining Forces for a Swiss Health Research Data Ecosystem

SPHN | Swiss Personalized Health Network

PHRT | Personalized Health and Related Technologies

Prof. Dr. med. Urs Frey, Chair SPHN National Steering Board

Prof. Dr. Christian Wolfrum, Chair PHRT Strategic Committee

SPHN | Swiss Personalized Health Network
www.sphn.ch | nds@sphn

A project of



PHRT | Personalized Health and Related Technologies
www.sfa-phrt.ch | phrt-office@ethz.ch



31.10.24

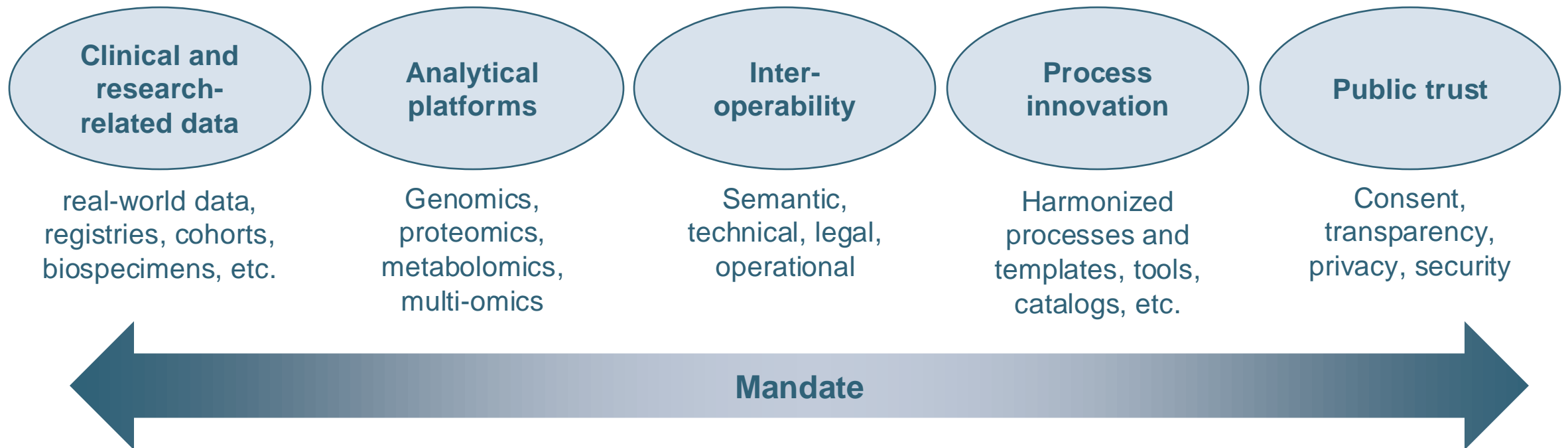


Where did we start...?

In 2016, Switzerland had...

- **No national platform** for data-driven medicine
- Ad-hoc collaborations with **no institutional frameworks** for sharing data at scale
- **Fragmented understanding** of the requirements for sharing data (governance)
- **No national interoperability strategy** for health data
- Compliance with **data privacy and security left to individual researchers**, no national data infrastructure for secure processing of sensitive health data
- Findability and extraction of routine clinical data in university hospitals hampered by **silos with low transparency** on data availability and access requirements
- **Rapid change in data protection regulation** framework, large regional heterogeneity in processes
- **Limited data sharing culture**

Personalized health research to improve health data research infrastructure building



SPHN and PHRT – two complementary federal initiatives

SPHN

- Mandate by SERI to SAMS and SIB
- 2017-2024: CHF 134 Mio. plus matching funds
- Goal: Coordinate the establishment of an infrastructure for the nation-wide use of health data for research



Peter Meier-Abt

PHRT

- Strategic Focus Area of the ETH/EPF Domain
- 2017-2024: CHF 100 Mio.
- Goal: pushing the frontiers of knowledge on the mechanisms of diseases and opening the door to new treatments and technologies improving health

SPHN & PHRT approach for infrastructure building

Mandated and coordinated by SPHN National Steering board

‘Top Down’ Coordination

(SPHN working groups, aligned with hospitals, universities, ETH domain, SIB, PHRT, SCTO, SBP, SAKK etc.)

Secure data **infrastructure**

SIB, universities, ETH

BioMed IT Network

Health data **standardization** and
 access, de-identification

University hospitals
 2024: Cantonal Hosp.

Clinical data platforms
 (Data warehouse/lake)

Data findability, accessibility, interoperability,
 reusability, **FAIR**

SIB, SAMS

Data Coordination Center
 (DCC)

Frameworks and policies for ELSI,
 interoperability information security

NSB, NAB, HIT-STAG
 ELSI, working groups

Standards, processes,
 guidelines, templates

SPHN & PHRT approach for infrastructure building

**Evaluated by SPHN International Advisory Board
 PHRT Scientific Board**

‘Bottom up’ real world experience: SPHN + PHRT Research Projects
 Development, Driver, Research, Demonstrator Projects
 National Data Streams and Lighthouse Projects

Building field-specific infrastructures

Universities, SPHN,
 ETH

Specific data pipelines

Real-world experience in health data
 research and processes

SPHN, PHRT
 Gap-analysis

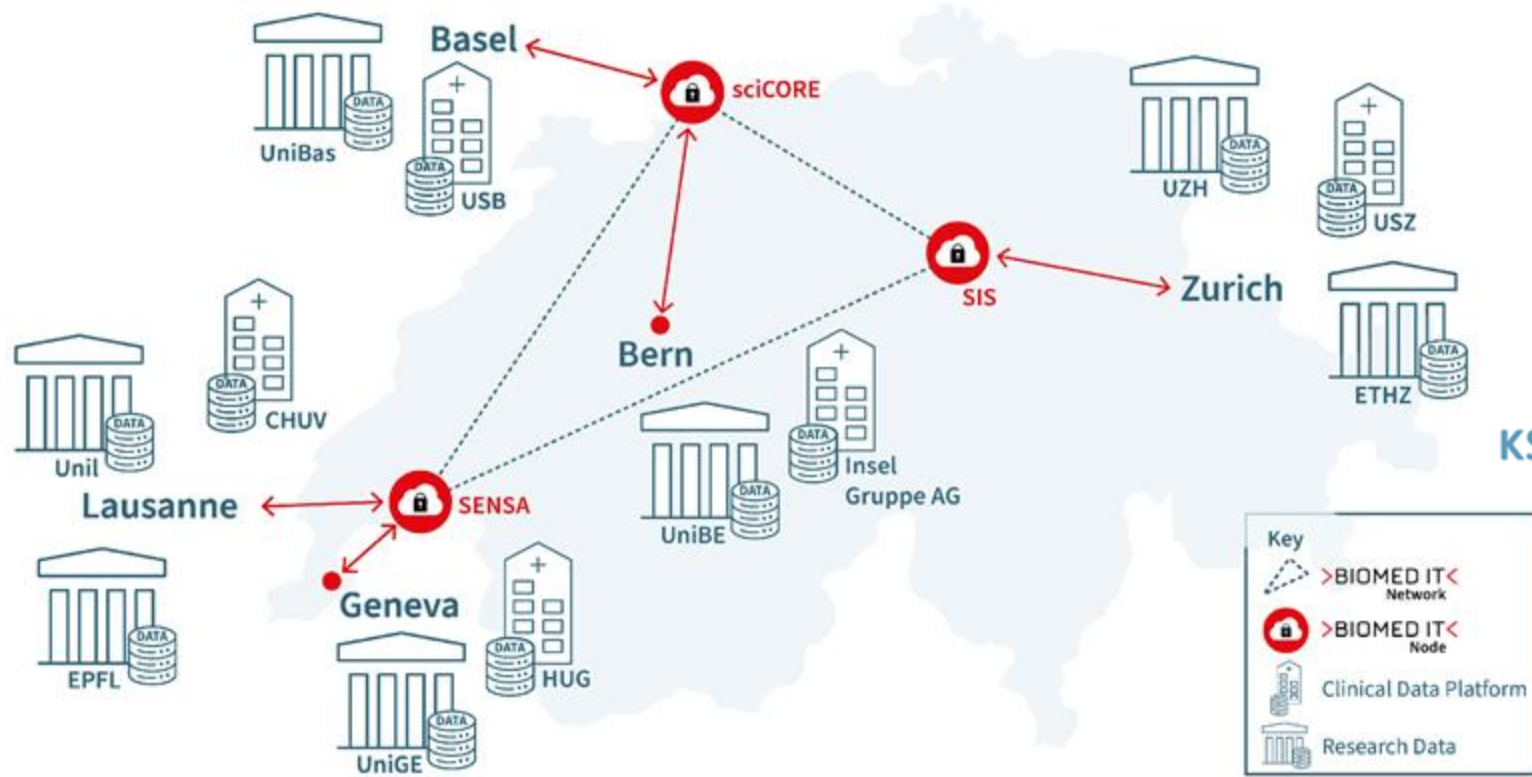
Process optimization
 Identification of gaps

Health data research, personalized
 health research projects

PHRT
 SPHN

Research output

Creating a scalable network



Key

- >BIOMED IT< Network
- >BIOMED IT< Node
- Clinical Data Platform
- Research Data

Personalized Health Informatics Group

SPHN Data Coordination Center (DCC)
BioMedIT Network

University Hospital Basel

USZ Universitäts Spital Zürich

HUG Hôpitaux Universitaires Genève

KSB

Kantonsspital St. Gallen

luzerner kantonsspital

health 2030

SDSC

CHUV Centre hospitalier universitaire vaudois

INSELSPITAL
UNIVERSITÄTSSPITAL BERN
HOPITAL UNIVERSITAIRE DE BERNE
BERN UNIVERSITY HOSPITAL

KINDERSPITAL ZÜRICH

UKBB
kompetenz & innovation

swissuniversities

Université de médecine
Université de médecine
Université de médecine
Université de médecine

ehealthsuisse

FN-NF
FONDS NATIONAL SUISSE
SCHWEIZERISCHER NATIONALFONDS
FONDO NAZIONALE SVIZZERO
SWISS NATIONAL SCIENCE FOUNDATION

THE LOOP
ZÜRICH
MEDICAL RESEARCH CENTER

KSA

Personalized Health Alliance
Basel-Zürich

EOC

SWISS BIOBANKING PLATFORM

SCTO

SAKK
KANTONSSPITAL BASEL STADT

SIB

SSPH+
SWISS SCHOOL OF PUBLIC HEALTH

life sciences cluster basel

Achievements of SPHN and PHRT for research

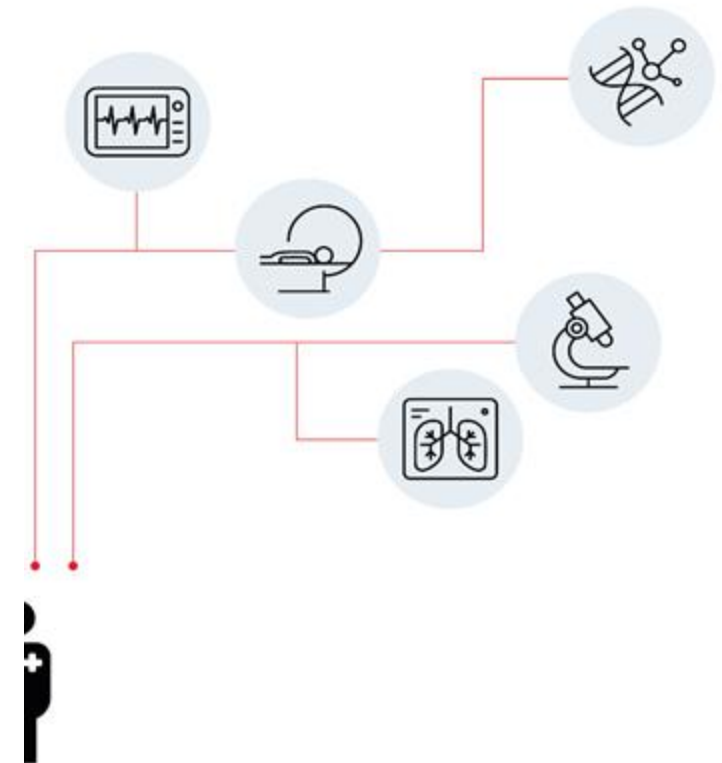
Development, implementation and validation of coordinated data infrastructures to make health-relevant data **interoperable and shareable for research** in Switzerland

- Establishment of **partnerships** and **collaborations**
- **Secure** and **ethically/legally compliant** data and technology platforms
- **Coordination** of all data aspects
- **Interoperability** framework according to FAIR Principles
- Pipeline of **tools and services** for data production and delivery in hospitals
- **> 710'000 patients** with General Consent for research and de-identified, interoperable real-world health data
- **Central** and **federated** analyses
- Identified **systemic bottlenecks** to data sharing and tested solutions
- **Gap Analysis**

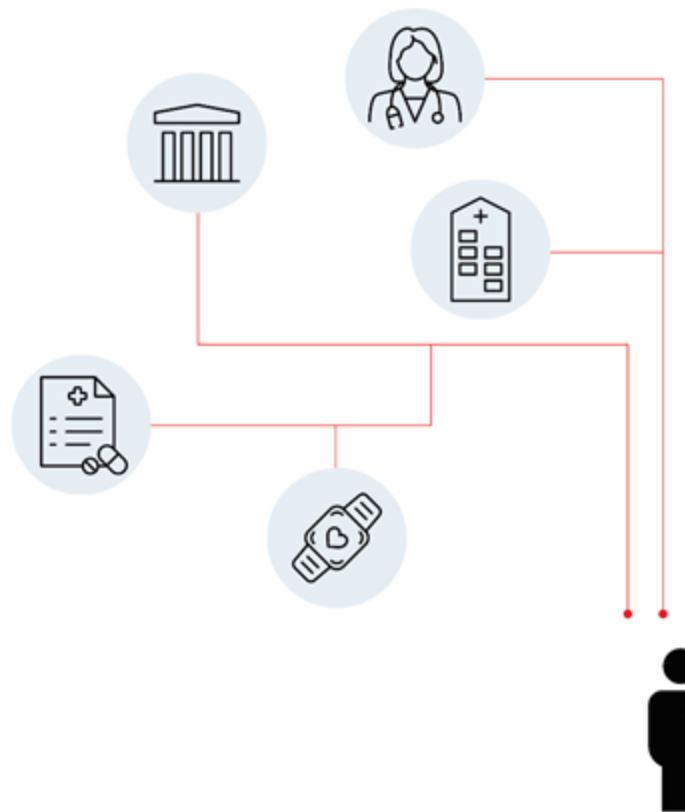


Bringing to light the Challenges (Gap analysis: Data)

- Unclear or untransparent **data access**
- **Fragmentation** requires critical mass of data to be combined from various **scattered sources**
- **Low visibility** of available data and data properties (fit-for-purpose)
- **Redundant research facilities** and infrastructures with poor interoperability
- **Local data needed**, international data cannot fully substitute



Bringing to light the Challenges (Gap analysis hospitals)



- Well annotated, **structured data are missing** (prerequisite)
- Lack of mandatory **interoperability standards**
- Need for similar data standards and interoperability for **health care, research, quality and processes**
- **Heterogeneity** in the existing infrastructure basis
- **Data privacy and security** make processes complex
- Health system provides **few incentives** for meaningful, standardized data (e.g. finances)

Lessons learned from SPHN and PHRT

- Efforts, time and costs get **underestimated**
- **Implementation** of standardization is demanding: «the devil is in the details», structuring comes before automatization, once-only principle
- **SPHN and PHRT as model** that can be built on
 - Multi-stakeholder **governance**
 - National **coordination** combined with local implementation
 - Consolidation of **central services** complemented by **local support** structures
- Agile planning considering a dynamically **developing environment** (Open Research Data)
- Need for a facilitated and nationally **harmonized regulatory framework** (secondary use)
- Must create **sustainable financing models** and incentives