swiss clinical trial organisation

HRO Lunch Seminar Series

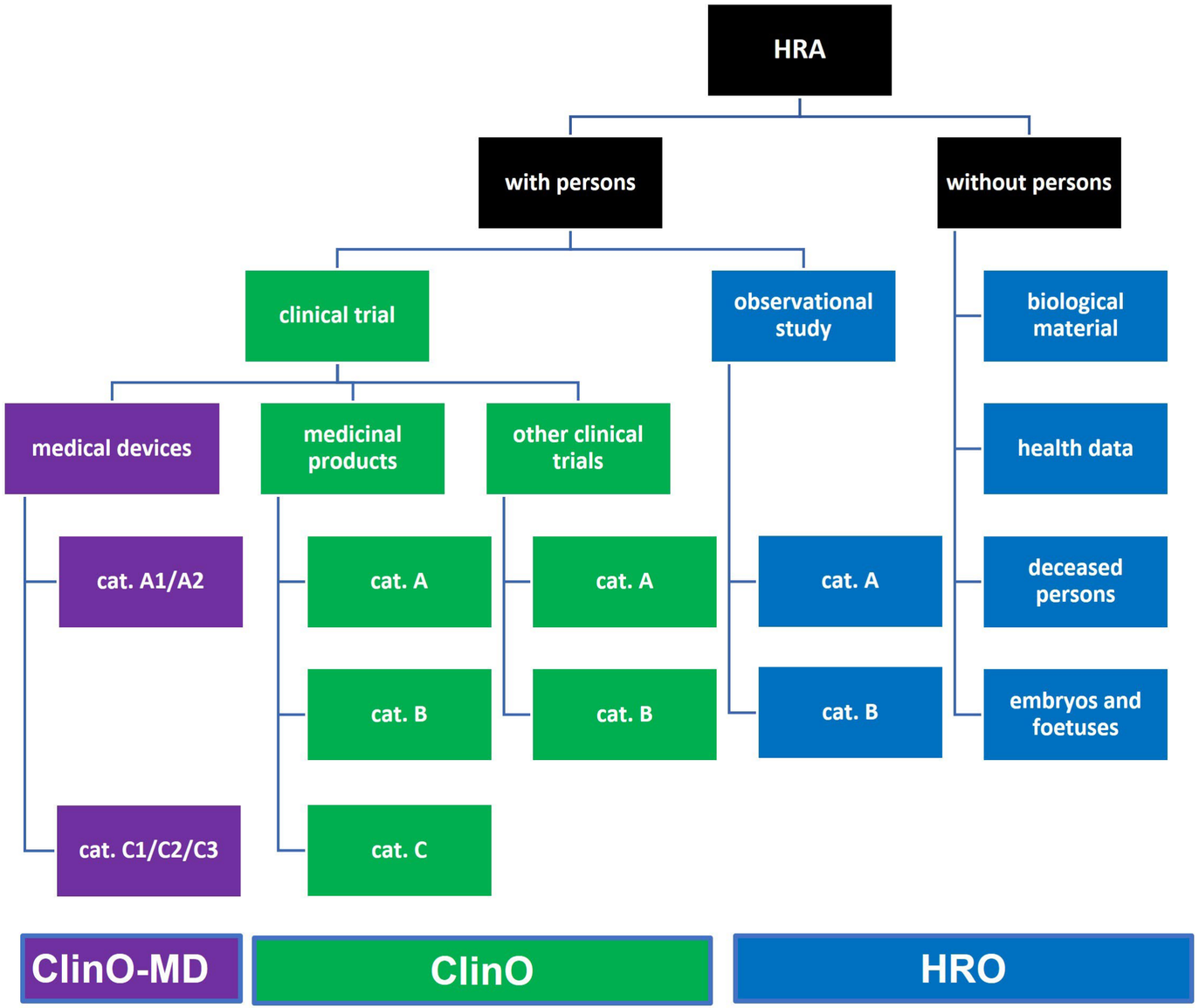
Session 1, 2026

SCTO EDUCATION PLATFORM

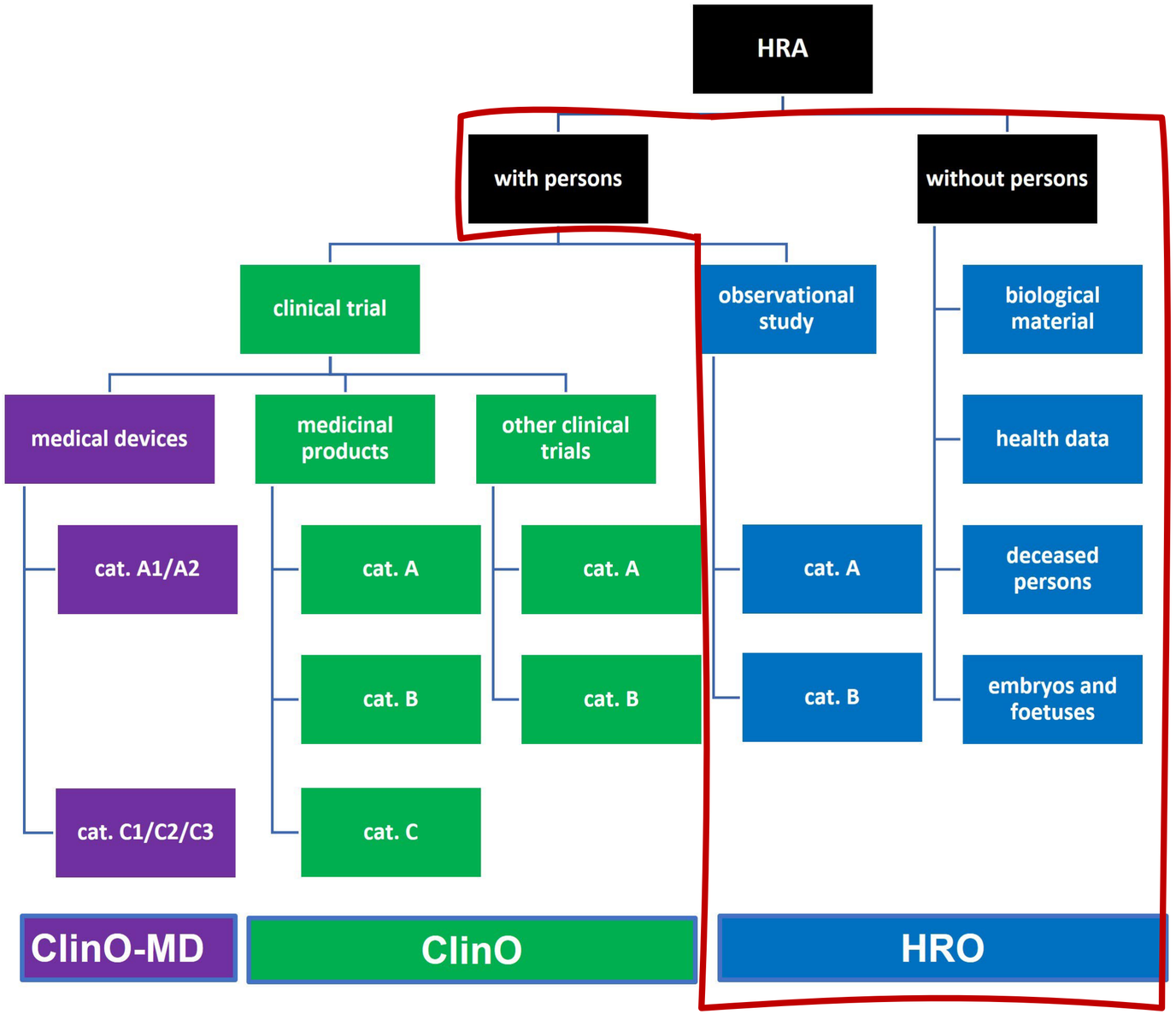
Introduction

swiss clinical trial organisation

Introduction

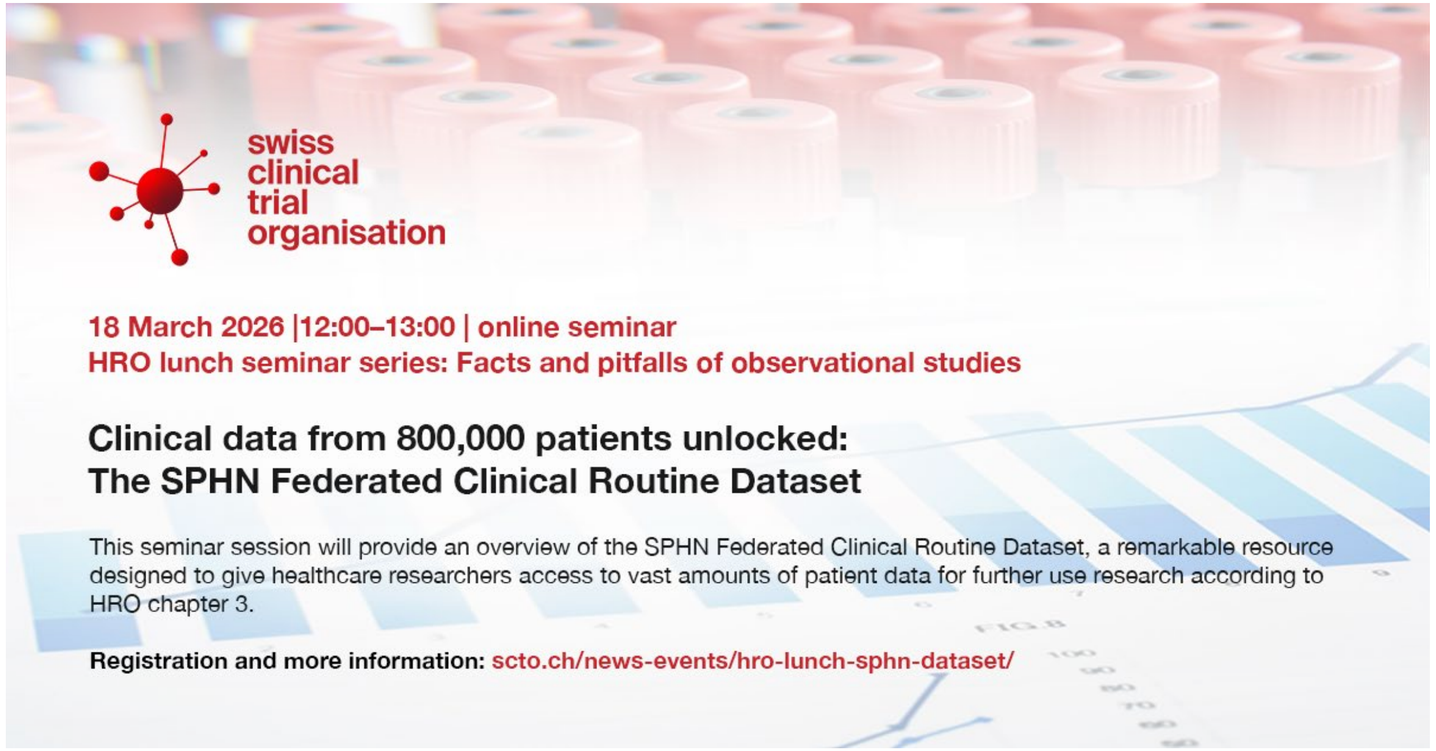


Introduction



General information

- If your require a certificate please login with your correct full name!
- Questions:
  - ➢ during presentation in the chat → for Q&A part at the end
- Presentation recorded
- Video, slides and Q&A document provided after the session on the website
- Feedback poll at end → please fill in!
- HRO lunch project team:
  - Claudia Fila (CTC Zurich)
  - Antoine Poncet (HUG)
  - Stephanie Maissen (SCTO)



Dr. Sabine Österle

Lead of the Semantic Interoperability Strategy & FAIR Data Team,

Swiss Institute of Bioinformatics (SIB) / Swiss Personalized Health Network (SPHN)

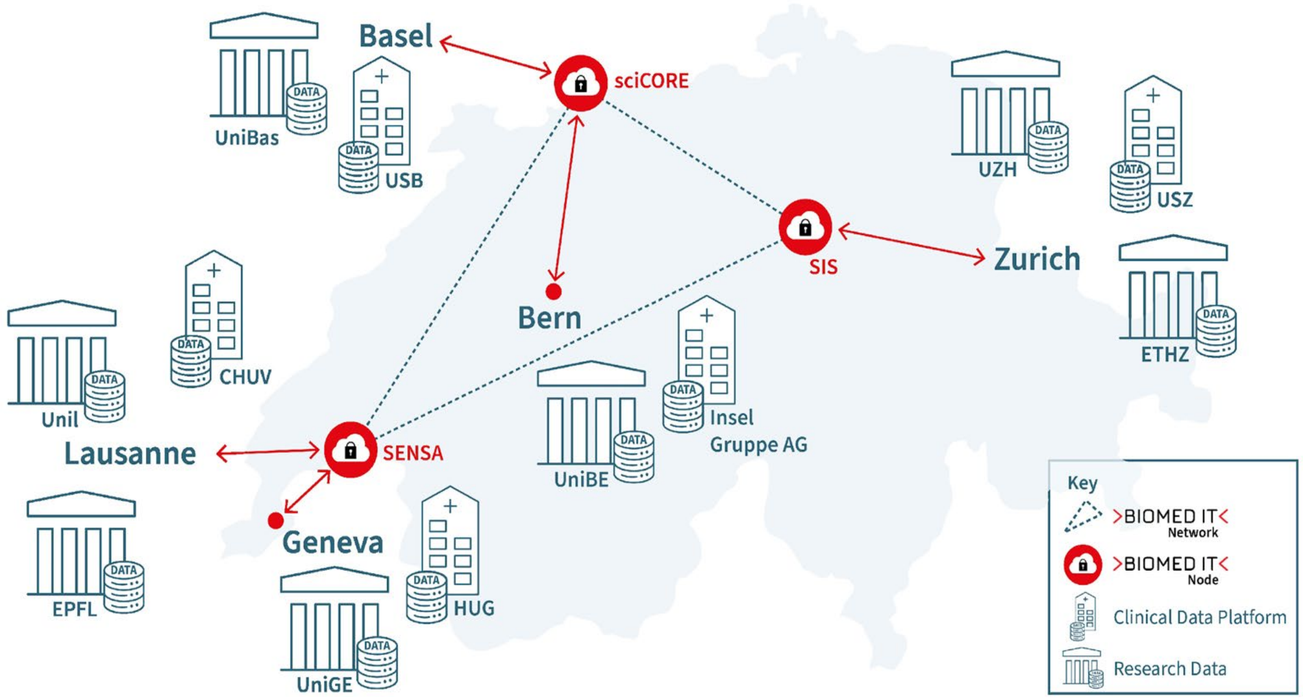
Sabine.Oesterle@sib.swiss

Swiss Personalized Health Network Federated Clinical Routine Dataset

Dr. sc ETH Sabine Österle
Swiss Personalized Health Network (SPHN), SIB Swiss Institute of Bioinformatics

A project of
SAMW ASSM
Schweizerische Akademie der Medizinischen Wissenschaften
Académie Suisse des Sciences Médicales
Accademia Svizzera delle Scienze Mediche
Swiss Academy of Medical Sciences
SIB Swiss Institute of Bioinformatics

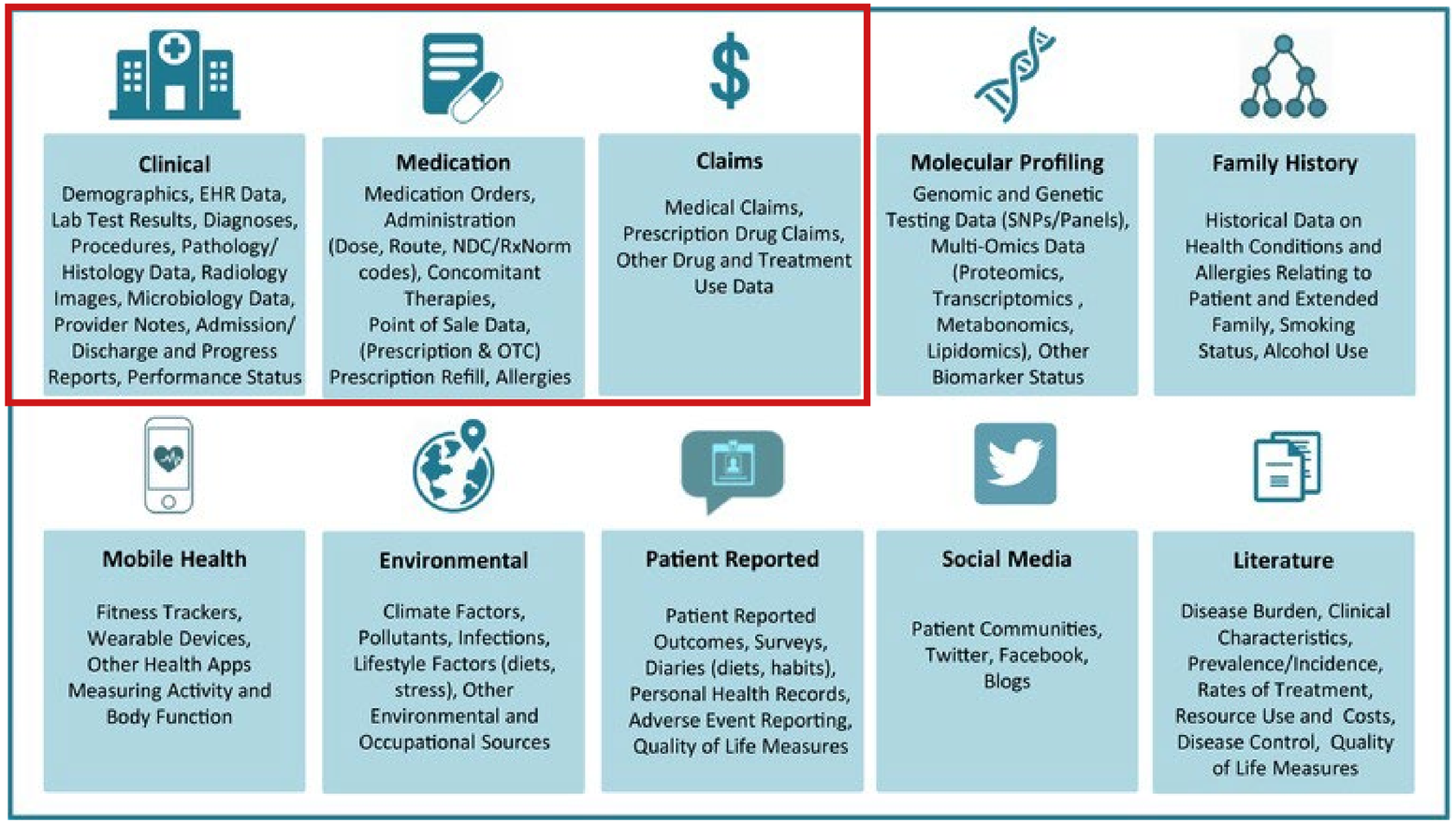
Welcome to SPHN



https://sphn.ch/

Real-world data in research

Clinical Routine Data



Swift B, et al. Innovation at the Intersection of Clinical Trials and Real-World Data Science to Advance Patient Care. Clin Transl Sci. 2018 Sep;11(5):450-460. doi: 10.1111/cts.12559. Epub 2018 May 16.

Data landscape

Data Elements

Clinical research

- 3% of patients
- Set of features defined (small)
- Low missing data

Clinical registries

- 100% of patients targeted
- Set of features defined (small)
- Moderate missing data

Clinical routine

- 100% of patients which were at hospital
- 100% features
- High rate of missing

Challenges related to clinical routine data

1. Bias & Representativeness

- Data reflect healthcare use and billing, not actual health status
- Over-/under-representation of certain population groups
- Healthy reference populations often missing

2. Heterogeneity of Data Sources

- Data from different hospitals and systems
- Different coding standards, formats, and granularity

3. Data Quality Issues

- Missing values and measurement errors
- Data often incomplete or inconsistently documented

4. Temporal & Longitudinal Complexity

- Irregular observation intervals
- Changing treatments & guidelines over time

5. Patient Tracking Limitations

- Difficult to follow patients across institutions
- No universal patient ID for data linkage in Switzerland

Benefits of clinical routine data

1. Large Sample Sizes

- Data from large patient populations
- Enables research on rare conditions and small effects

2. Real-World Evidence

- Reflects actual clinical practice
- Includes diverse and heterogeneous patient populations

3. Cost Efficiency

- Data are already collected during care
- Reduces time and costs of data collection

4. Faster Research

- Existing data enable quicker analyses
- Supports insights for healthcare improvements

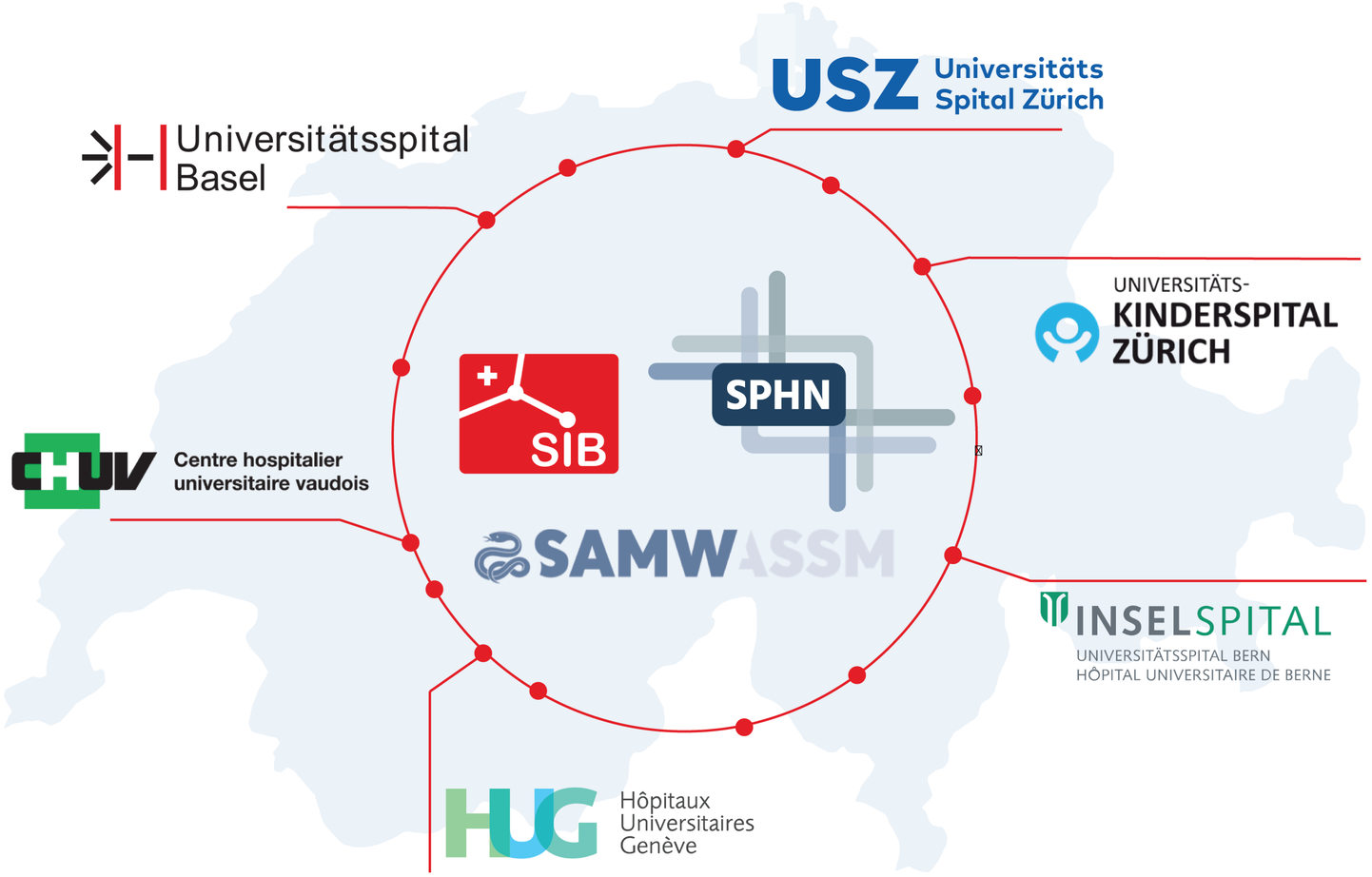
5. Hypothesis Generation

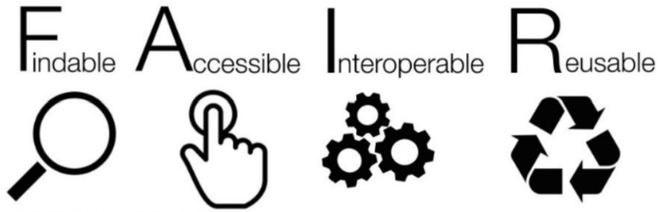
- Can identify new patterns, correlations, or risk factors
- Helps guide future clinical trials or studies

6. Support for Personalized Medicine

- Data can help to identify subgroups that respond differently to treatments

SPHN Federated Clinical Routine Dataset

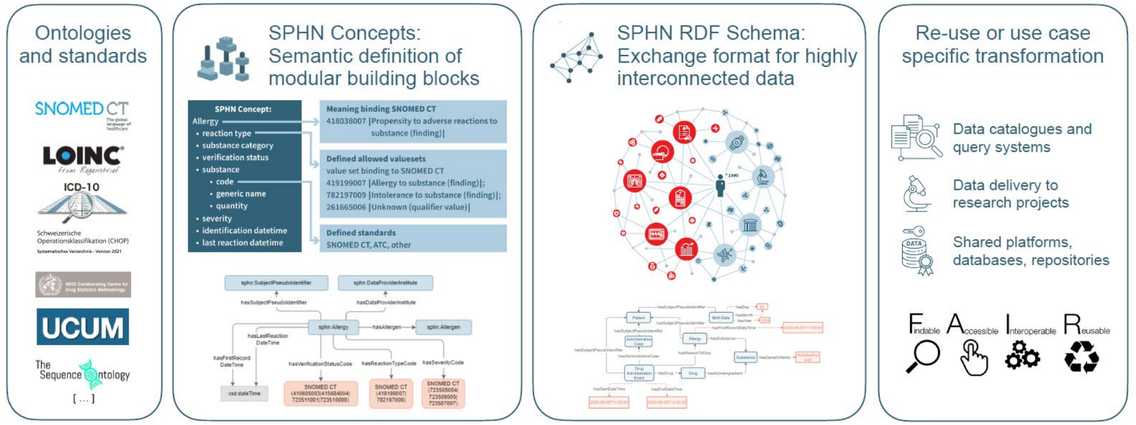




SPHN Semantic Interoperability Framework

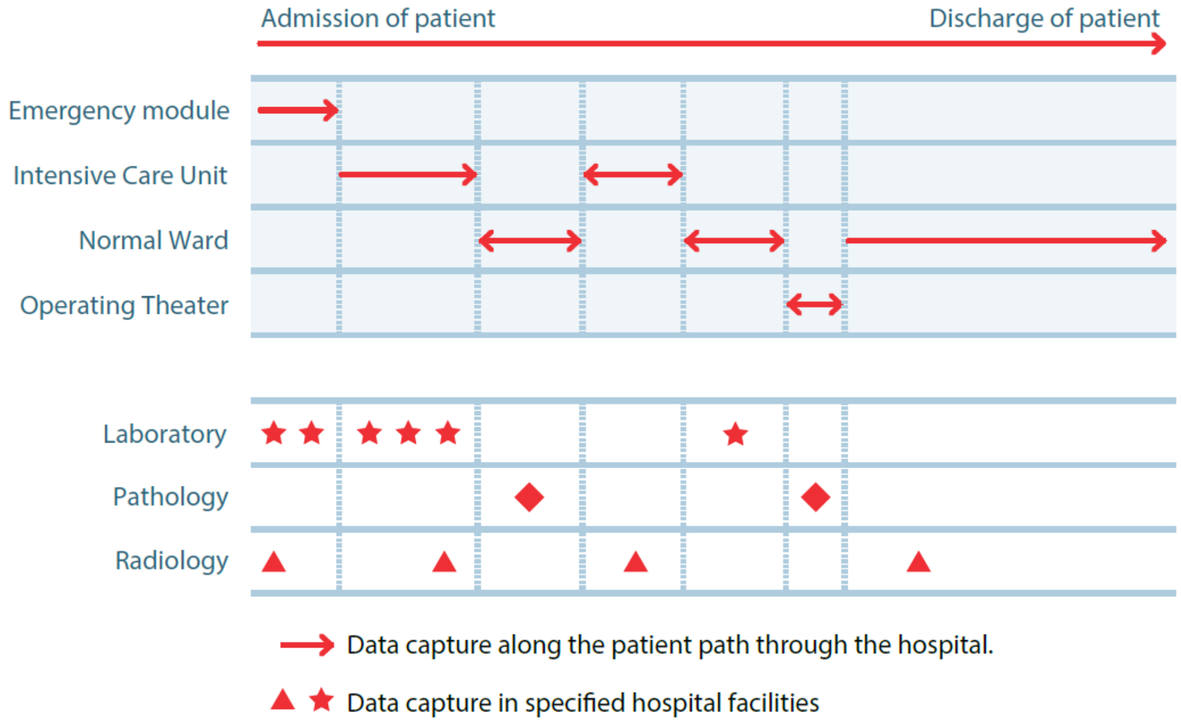
- **Real world data** is complex and diverse level of context of the data is available
- **Biological data** adds a layer of complicity
- World Wide Web Consortium standards and data standards (SNOMED CT and LOINC) allow to **speak a common language**
- **Semantic representation** of the data enables a better understanding of the data

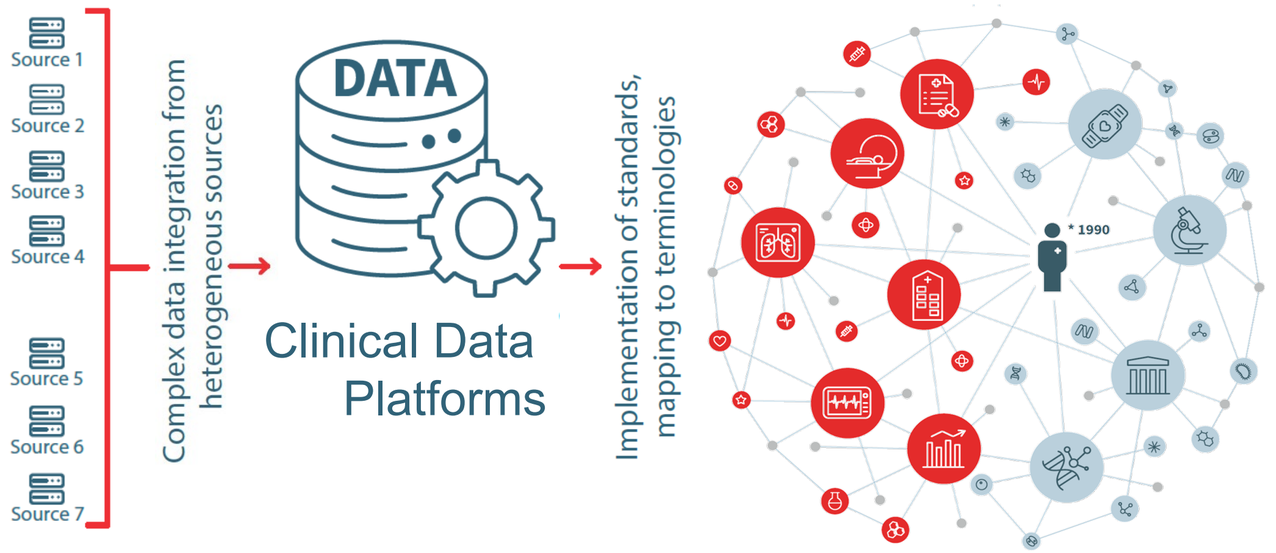
Multi-layered **data integration** into a knowledge graph enables a comprehensive view of the patient



https://sphn-semantic-framework.readthedocs.io/

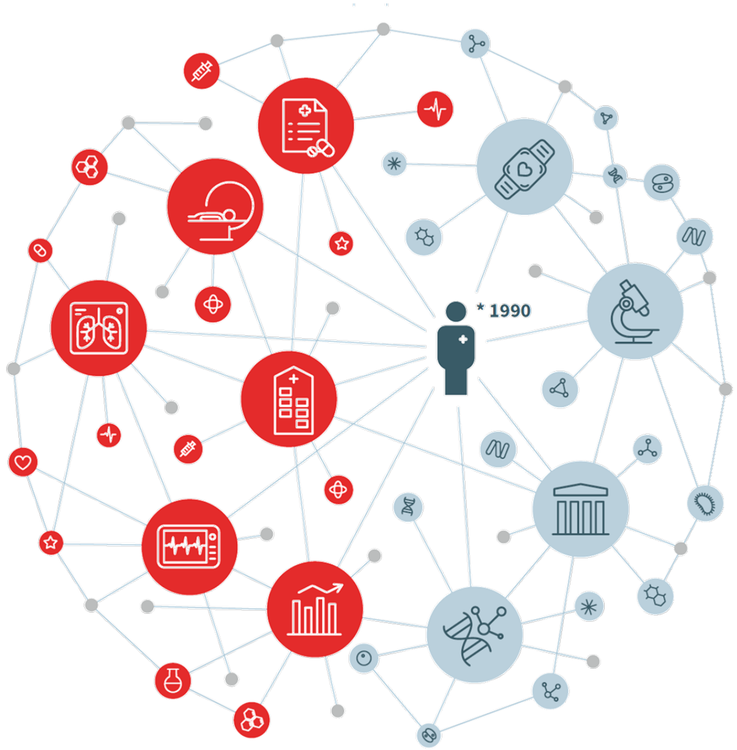
Core infrastructures at Swiss University Hospitals





- → Human and machine-readable meaning of the data
- → Context - provenance and metadata
- → Linking data from different sources

The SPHN Schema to generate knowledge graphs



210 SPHN concepts (2026.1)

– Nationally aligned

– Meaning defined once

Domains covered

– Administrative items (administrative case, consent)

– Demographics, medications, procedures, diagnosis, lab, measurements (vital signs)

– Medical Imaging, Sample and biobanks

– Special concept for oncology, intensive care, microbiology

– Omics results and processing

– Data provenance

https://www.biomedit.ch/rdf/sphn-schema/sphn
https://git.dcc.sib.swiss/sphn-semantic-framework/sphn-schema

SPHN Federated Clinical Routine Dataset

Data stays in the hospital

- Hospitals are in control of the data
  (also for subsequent data sharing)
- Ownership of the platform
- Security and data privacy
- Data follows SPHN schema
- Easier processes for
  - Data updates
  - Consent revocation
- Detailed metadata exposed on the SPHN Metadata Catalog

Metadata

SPHN Metadata Catalog

SPHN Federated Clinical Routine Dataset

Data context

- 6 hospitals
- Cases from 2018 to current

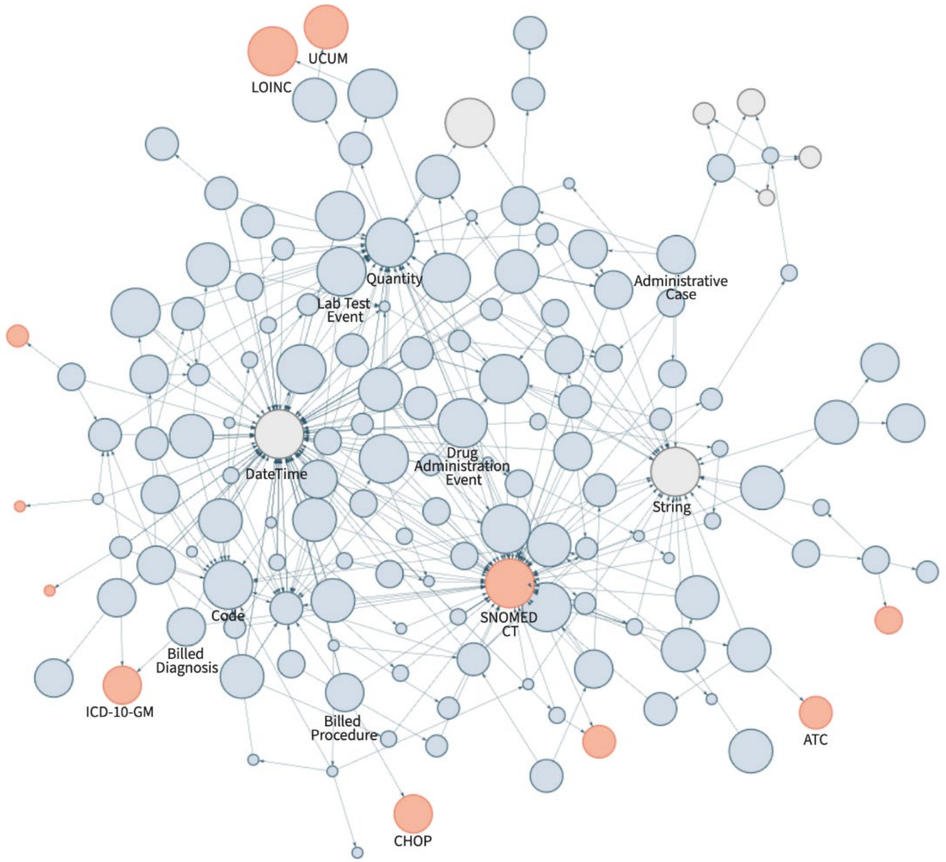
Data numbers

> 800 000 patients (broad consent)

> 12 billion triples

> 6 500 SNOMED CT codes

> 3 600 LOINC codes



Armida et al. (2025); https://doi.org/10.21203/rs.3.rs-8250886/v1

SPHN Federated Clinical Routine Dataset

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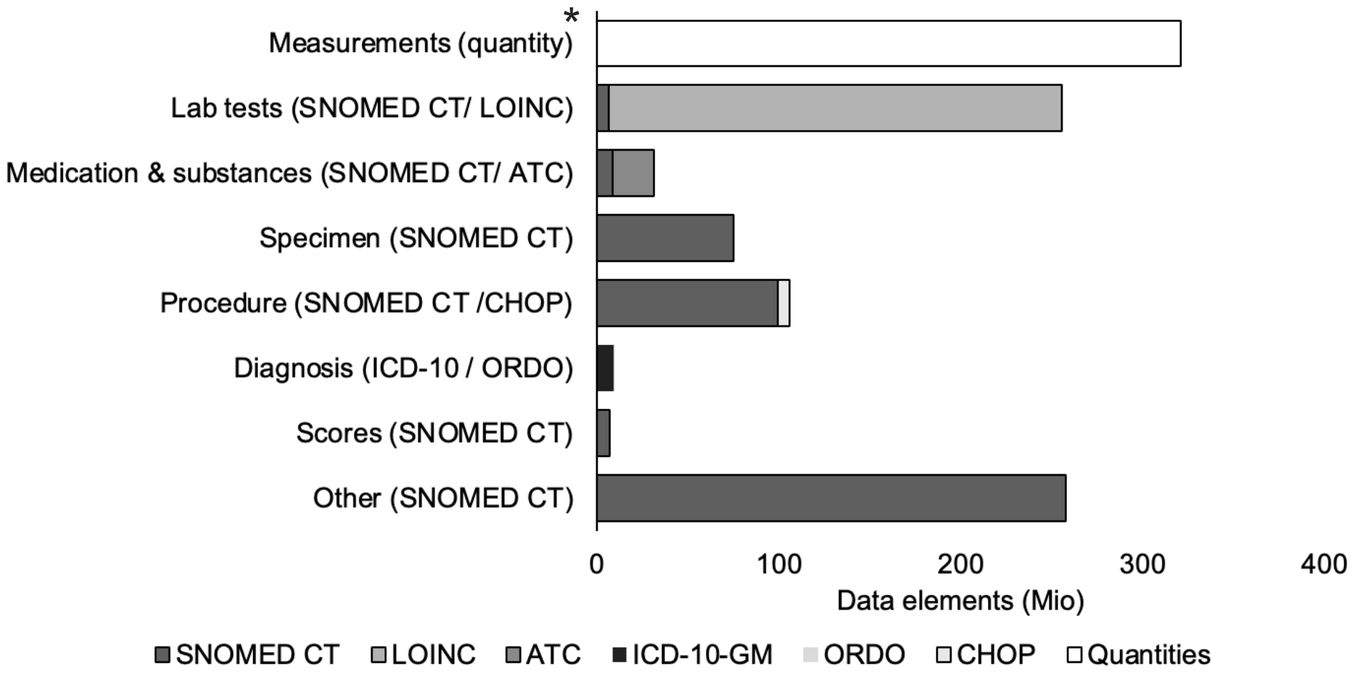
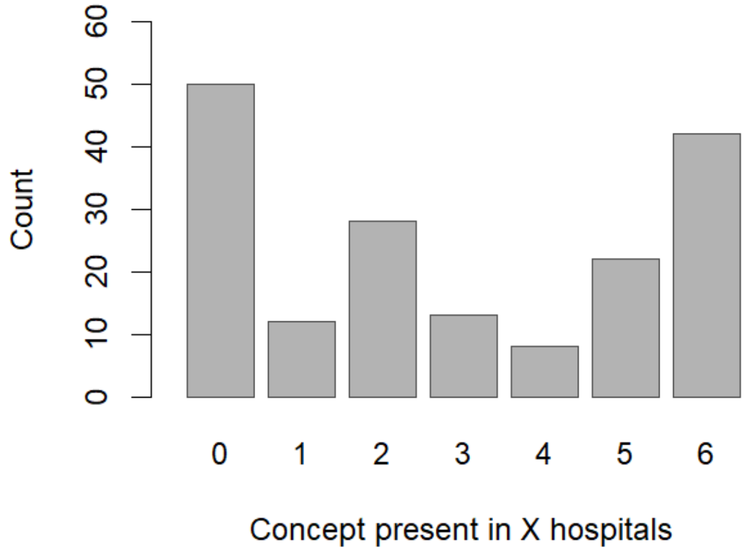


* excluding timeseries (PDMS)

Data completeness



All hospitals: Administrative, Medication, Diagnosis, Procedure, Lab, Sample, Oxygen Administration, Scores

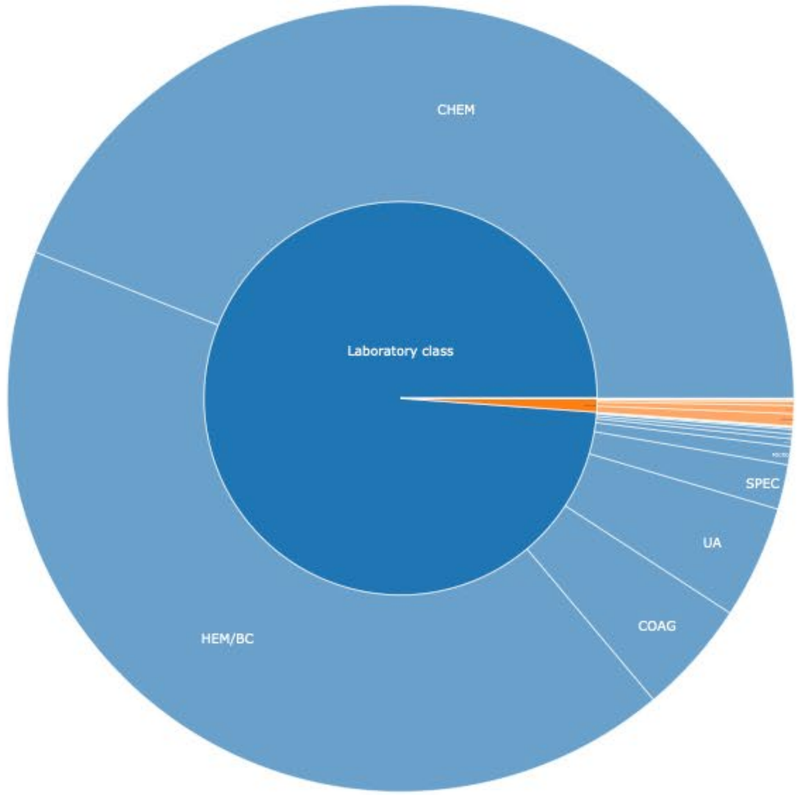
Most hospitals: Allergy, BMI, Body Weight, Civil Status, Imaging procedure, Vital signs, Circumference, Country, Isolate, Nationality, Pharmaceutical Dose Form, Access Device, Insurance Status, Oncology Diagnosis, Organ Support

Some hospitals: Biobanksample, Body Surface Area, Cardiac Index, Cardiac Output, Microbiology, Resuscitation Directive, Tumor grade, Tumor stage, Fluid Balance, Gene, Implant, Medical Device, Oncology surgery, Transplant

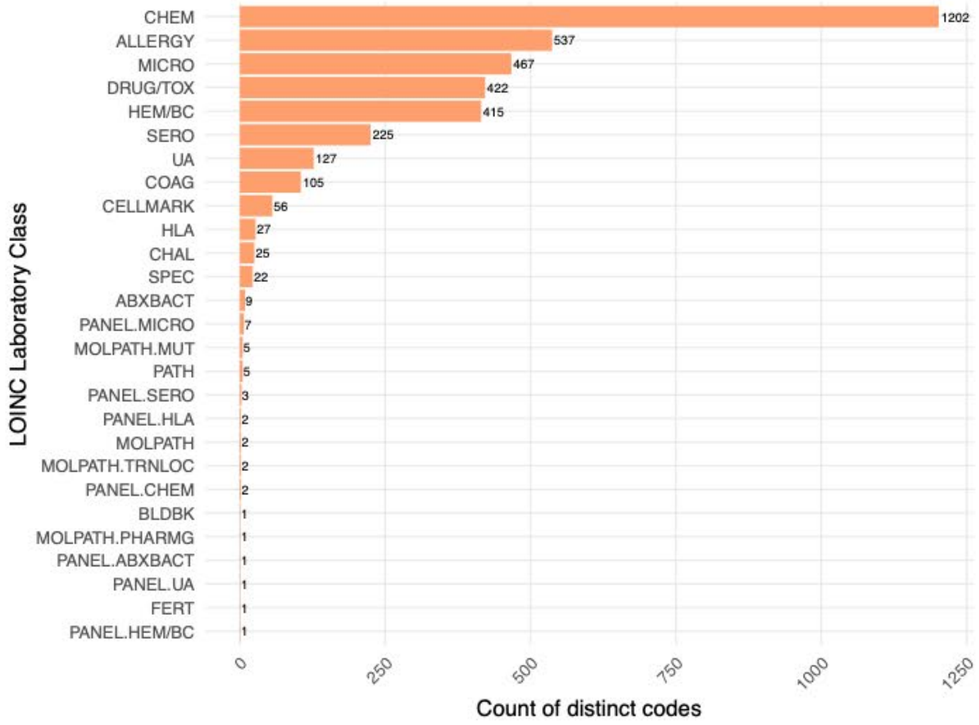
No hospital: Non clinical routine concepts or data not structured at scale at the hospitals

Data coding (LOINC)

Data Instances (12-122 Mio)

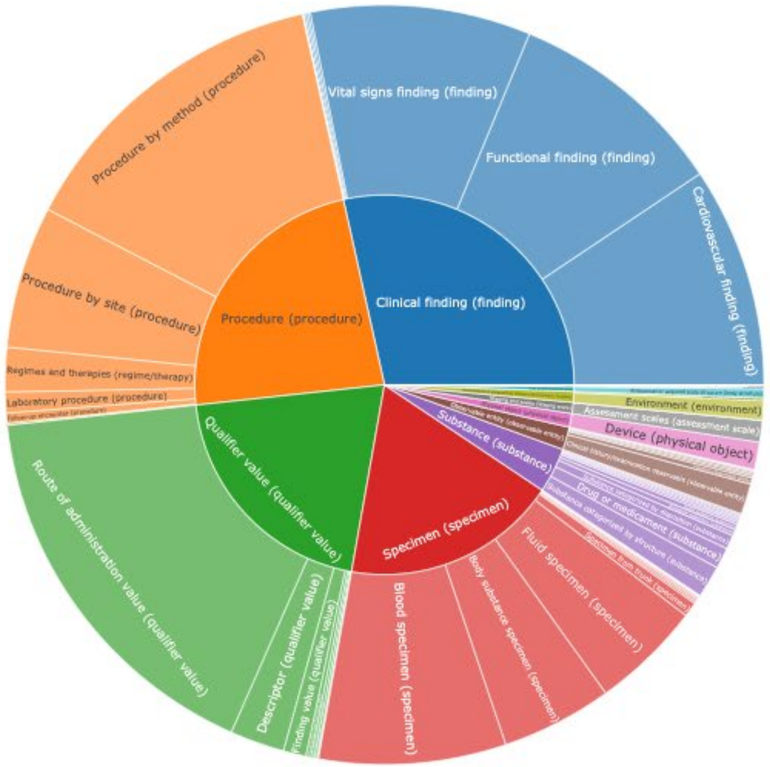


Codes (220 to 1 426 codes) per hospital

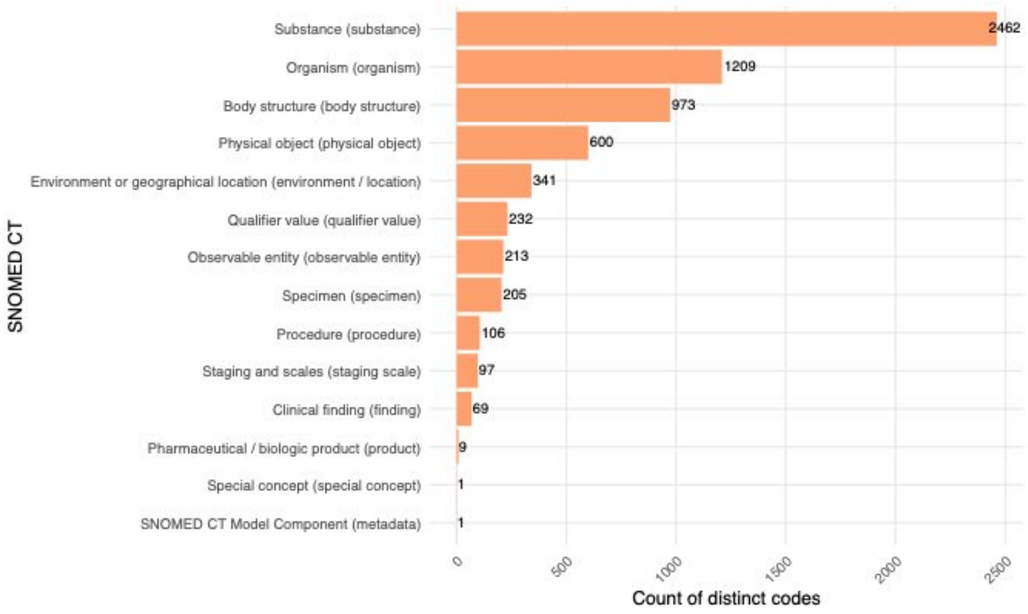


Data coding (SNOMED CT)

Data Instances (17-56 Mio)

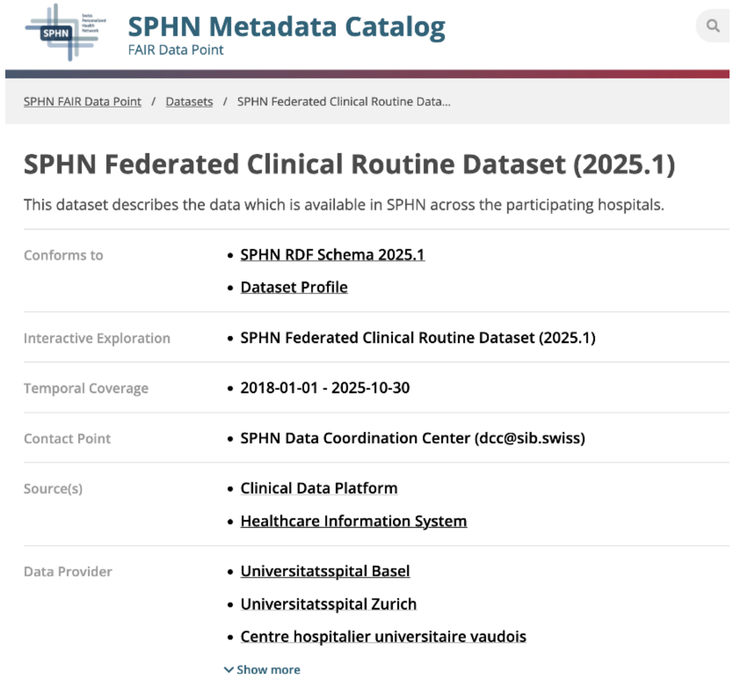


Codes (669 to 3 077 codes) per hospital



SPHN Federated Clinical Routine Dataset on the SPHN SPHN Metadata Catalog

Explore online (HealthDCAT of European Health Data Space and VOID - Vocabulary of interlinked datasets)



SPHN Metadata Catalog
FAIR Data Point

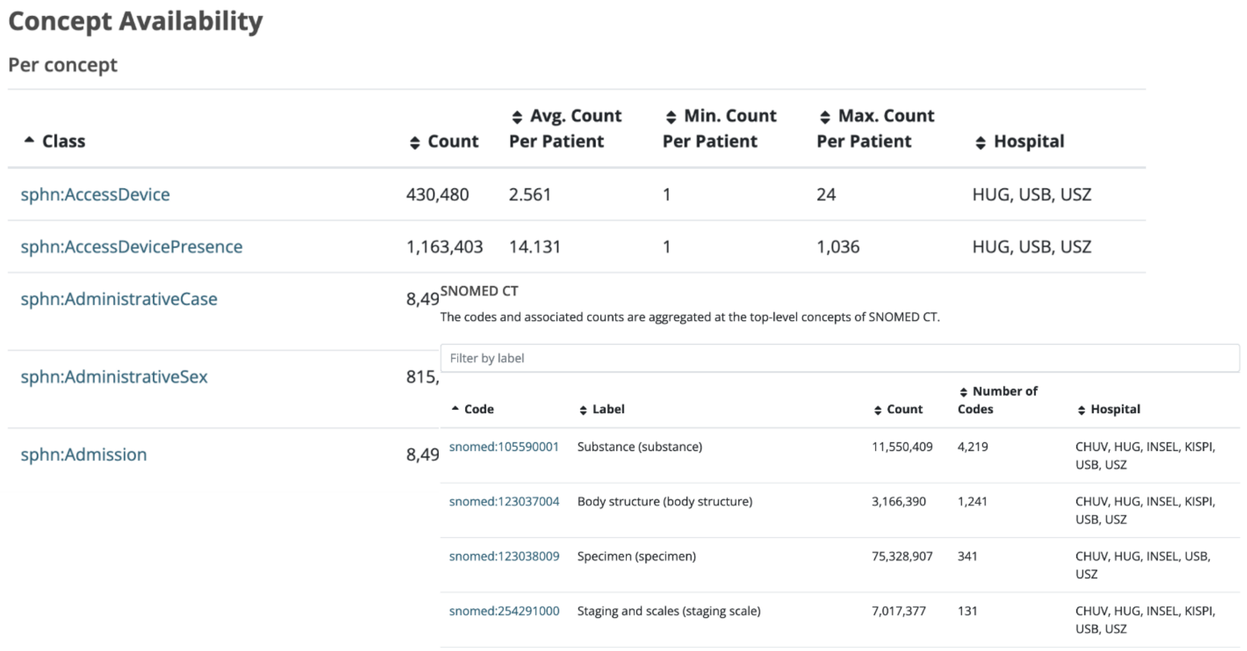
SPHN FAIR Data Point / Datasets / SPHN Federated Clinical Routine Data...

SPHN Federated Clinical Routine Dataset (2025.1)

This dataset describes the data which is available in SPHN across the participating hospitals.

Conforms to	• SPHN RDF Schema 2025.1 • Dataset Profile
Interactive Exploration	• SPHN Federated Clinical Routine Dataset (2025.1)
Temporal Coverage	• 2018-01-01 - 2025-10-30
Contact Point	• SPHN Data Coordination Center (dcc@sib.swiss)
Source(s)	• Clinical Data Platform • Healthcare Information System
Data Provider	• Universitatsspital Basel • Universitatsspital Zurich • Centre hospitalier universitaire vaudois

Show more



Concept Availability

Per concept

Class	Count	Avg. Count Per Patient	Min. Count Per Patient	Max. Count Per Patient	Hospital
sphn:AccessDevice	430,480	2.561	1	24	HUG, USB, USZ
sphn:AccessDevicePresence	1,163,403	14.131	1	1,036	HUG, USB, USZ
sphn:AdministrativeCase	8,49				
sphn:AdministrativeSex	815,				
sphn:Admission	8,49				

SNOMED CT
The codes and associated counts are aggregated at the top-level concepts of SNOMED CT.

Filter by label

Code	Label	Count	Number of Codes	Hospital
snomed:105590001	Substance (substance)	11,550,409	4,219	CHUV, HUG, INSEL, KISPI, USB, USZ
snomed:123037004	Body structure (body structure)	3,166,390	1,241	CHUV, HUG, INSEL, KISPI, USB, USZ
snomed:123038009	Specimen (specimen)	75,328,907	341	CHUV, HUG, INSEL, USB, USZ
snomed:254291000	Staging and scales (staging scale)	7,017,377	131	CHUV, HUG, INSEL, KISPI, USB, USZ

https://fdp.dcc.sib.swiss/catalog/fc6e936d-ad4b-5b21-b8a4-8c7826bbec99

SPHN Metadata Catalog – Browsing the graph

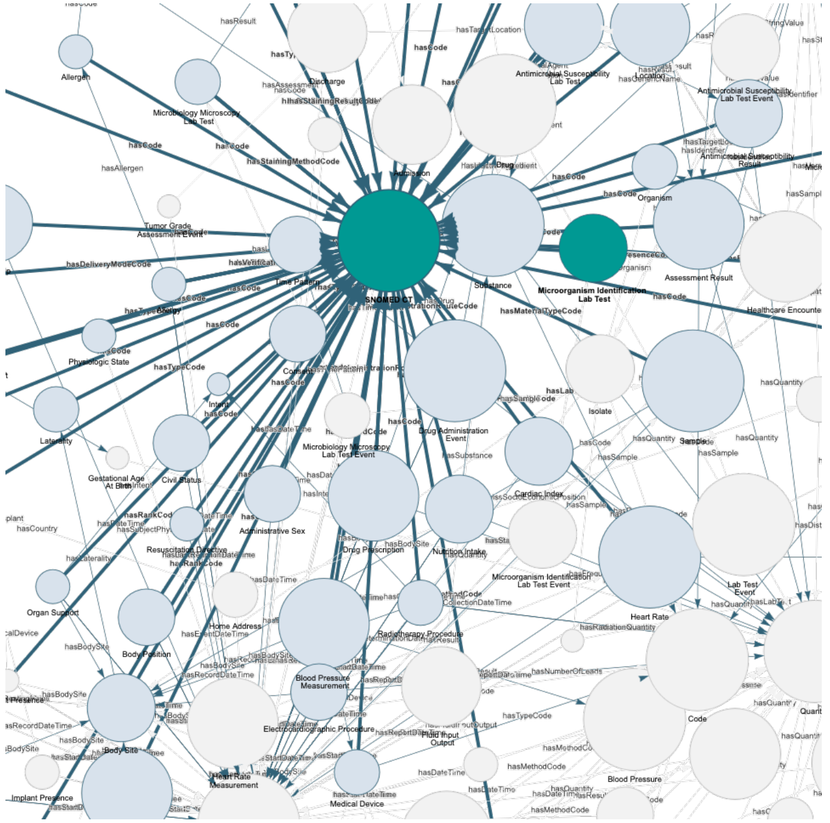
Explore graph structure online (SPHN Schema Scope)

Concepts (e.g. Lab Test, Diagnosis)

- Instance counts
- Availability per hospital

Code systems (e.g. SNOMED CT, ICD-10)

- Instance counts
- Number of different codes
- Availability per hospital



https://schemascope.dcc.sib.swiss/?project=SPHN-Federated-Clinical-Routine-Data&version=2025.1

SPHN Metadata Catalog – Querying datasets

SPHN FDP SPARQL endpoint **https://fdp.dcc.sib.swiss/store/fdp/sparql**

```
SELECT DISTINCT ?class
WHERE {
?distribution dcterms:isPartOf fdp-dataset:58cd4839-
          5821-5dee-a859-72e4462c3659 .

   ?concepts dcterms:isPartOf ?distribution .
   ?concepts a void:Dataset .
   ?concepts void:classPartition/void:class ?class .

   ?class rdfs:subClassOf sphn:Measurement .
}
```

Which SPHN measurements concepts are available in the FedData?

?measurements
sphn:BodyWeightMeasurement
sphn:HeartRateMeasurement
sphn:BodyTemperatureMeasurement
sphn:BodyHeightMeasurement
sphn:BloodPressureMeasurement
sphn:OxygenSaturationMeasurement
sphn:RespiratoryRateMeasurement
sphn:CircumferenceMeasurement
sphn:CardiacOutputMeasurement

SPHN Metadata Catalog – Querying datasets

SPHN FDP SPARQL endpoint **https://fdp.dcc.sib.swiss/store/fdp/sparql**

```
SELECT ?class (COUNT(DISTINCT ?hosp) AS ?count_hospital)
WHERE {
          ?code_frequency a sphn-metacat:DetailedCodeFrequency .
          ?code_frequency void:classPartition ?classSet .
          ?classSet void:class ?class .

FILTER (?class = snomed:459231000124102)
```

SOFA Score code

```
?classSet sphn-metacat:hasHospital ?hosp .
?classSet void:entities ?instance .
          }
GROUP BY ?class
```

How many hospitals deliver the SOFA scores?

?hospital_count	4

Metadata Catalog – Querying Datasets

Federated querying: SPHN, HealthRI and Data.Norge catalogs

How many 'health' datasets are available?

```
SELECT ?source (COUNT(?dataset) AS ?count)
WHERE {
  VALUES (?service ?source) {
    (<https://fdp.dcc.sib.swiss/store/fdp/sparql> 'SPHN')
    (<https://sparql.healthdata.nl/repositories/fdp> 'HealthRI')
    (<https://sparql.fellesdatakatalog.digdir.no> 'Data.Norge')
  }

  SERVICE ?service {
    ?dataset a dcat:Dataset .
    ?dataset dcat:theme data-theme:HEAL .
  }

} GROUP BY ?source
```

?source	?count
SPHN	30
HealthRI	23
Data.Norge	144

From Querying Metadata to Querying Data

Is it possible to build an application layer on top of the Federated Clinical Routine Dataset?

What would be needed?

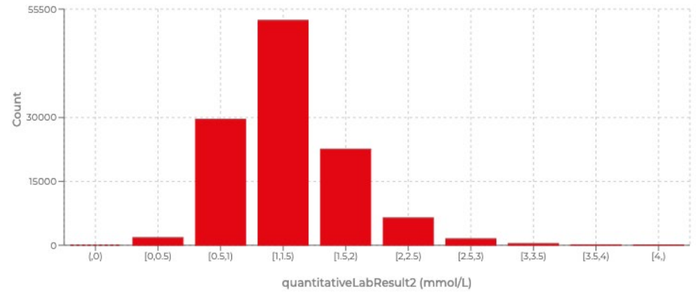
Application

- Way to control the queries (content and performance)
- Query and result federation

Use cases

Use case 1: Feasibility

User case 2: Value distribution



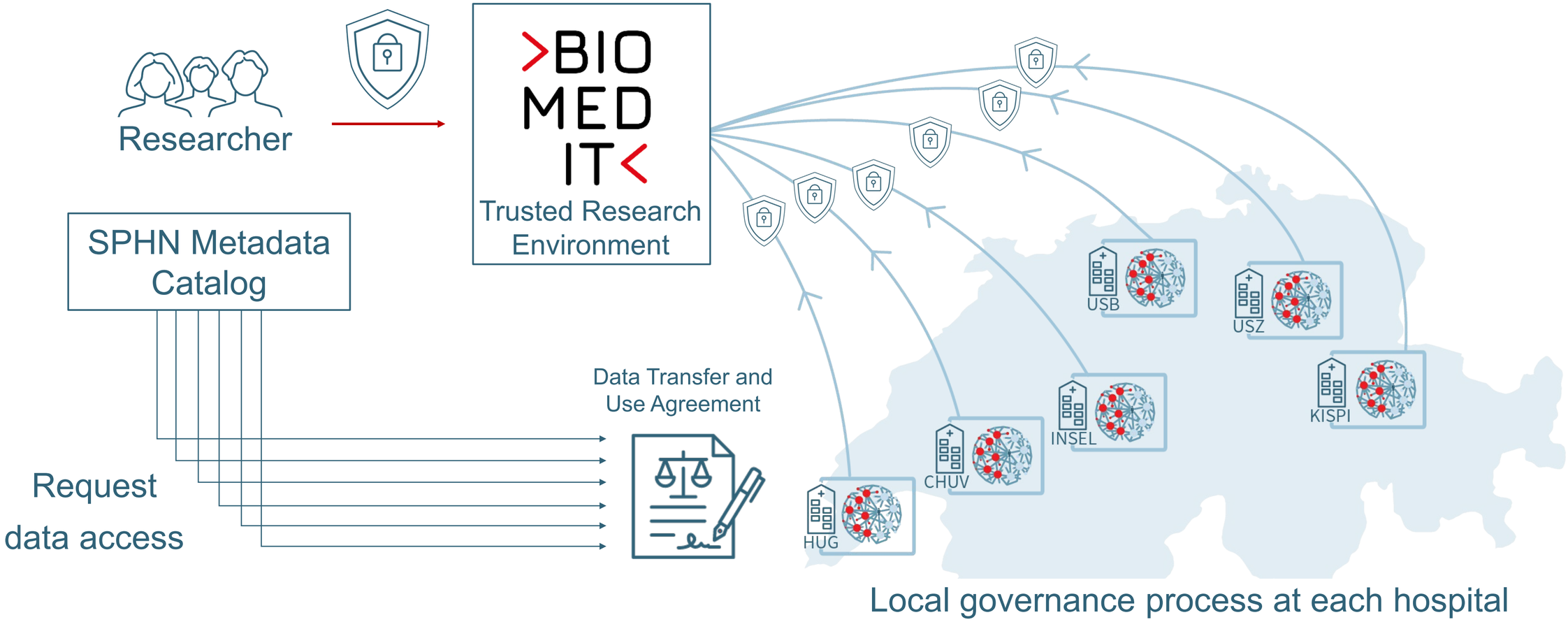
Use case 3: Means

Mean	Standard Deviation
29.01	16.05

→ User only see anonymized aggregated patient counts and statistics
→ Currently in the pilot phase
→ Go live planned mid 2026

In collaboration with TUNE INSIGHT

Accessing the SPHN Federated Clinical Routine Dataset



Contact points for each hospital can be found on the SPHN Metadata Catalog
For more information contract: elsi@sphn.ch

Next steps

Data

- Migrate to 2026.1 Schema
- Close the gaps (missing concepts and properties)
- Improve data quality
- Expand the SNOMED CT and LOINC coding

SPHN Data Explorer (query system)

- Go live summer 2026 for university hospital users, then extend the users groups

Acknowledgments

Everyone in the Swiss Personalized Health Network, especially the SPHN Implementation Teams:

Thomas Geiger, Christine Remund, Davide Chiarugi, **Deepak Unni**, Harald Witte, **Jan Armida**, Judit Kiss Blind, Julia Maurer, Manuela Paganini, Michaela Egli, Owen Appleton, **Andrea Brites Marto**, Patricia Fernandez Pinilla, Regan Geissmann, Sabine Österle, Sarah Vermij, Shubham Kapoor, Sergio Guarino, Simone Guzzi, **Vasundra Touré**, **Philip Krauss**

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https://doi.org/10.21203/rs.3.rs-8250886/v1

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http://bit.ly/4bsBpO2

Q&A part – Questions?

Sabine Österle

Thank you for participating!

Further questions to:

Sabine.Oesterle@sib.swiss

HRO lunch session 2

- 20 May 2026 –

Speaker: Swiss PedNet

Registration possible soon under:

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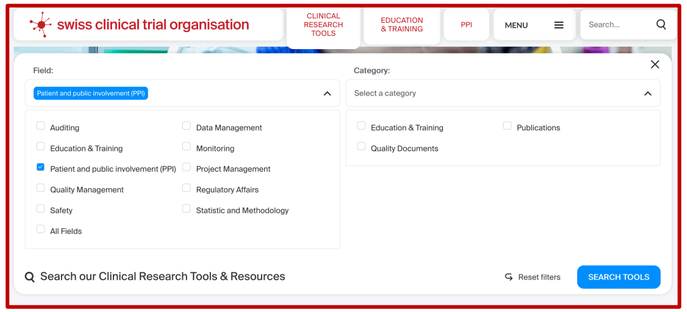
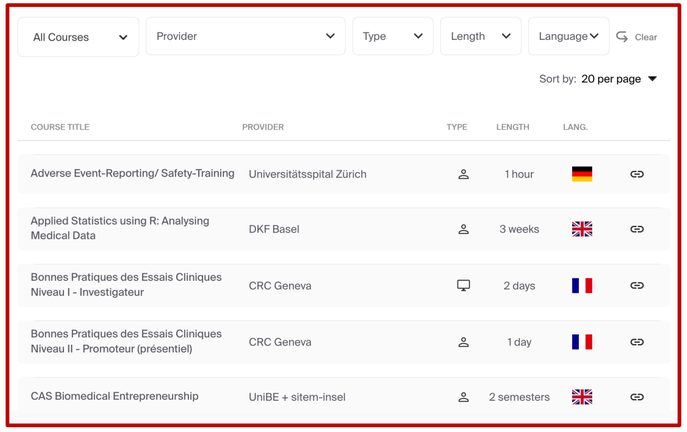


Course Finder: To discover courses for clincial reserachers

www.scto.ch/education-and-training/clinical-research-training/



Thank you!

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