

Swiss Personalized Health Network

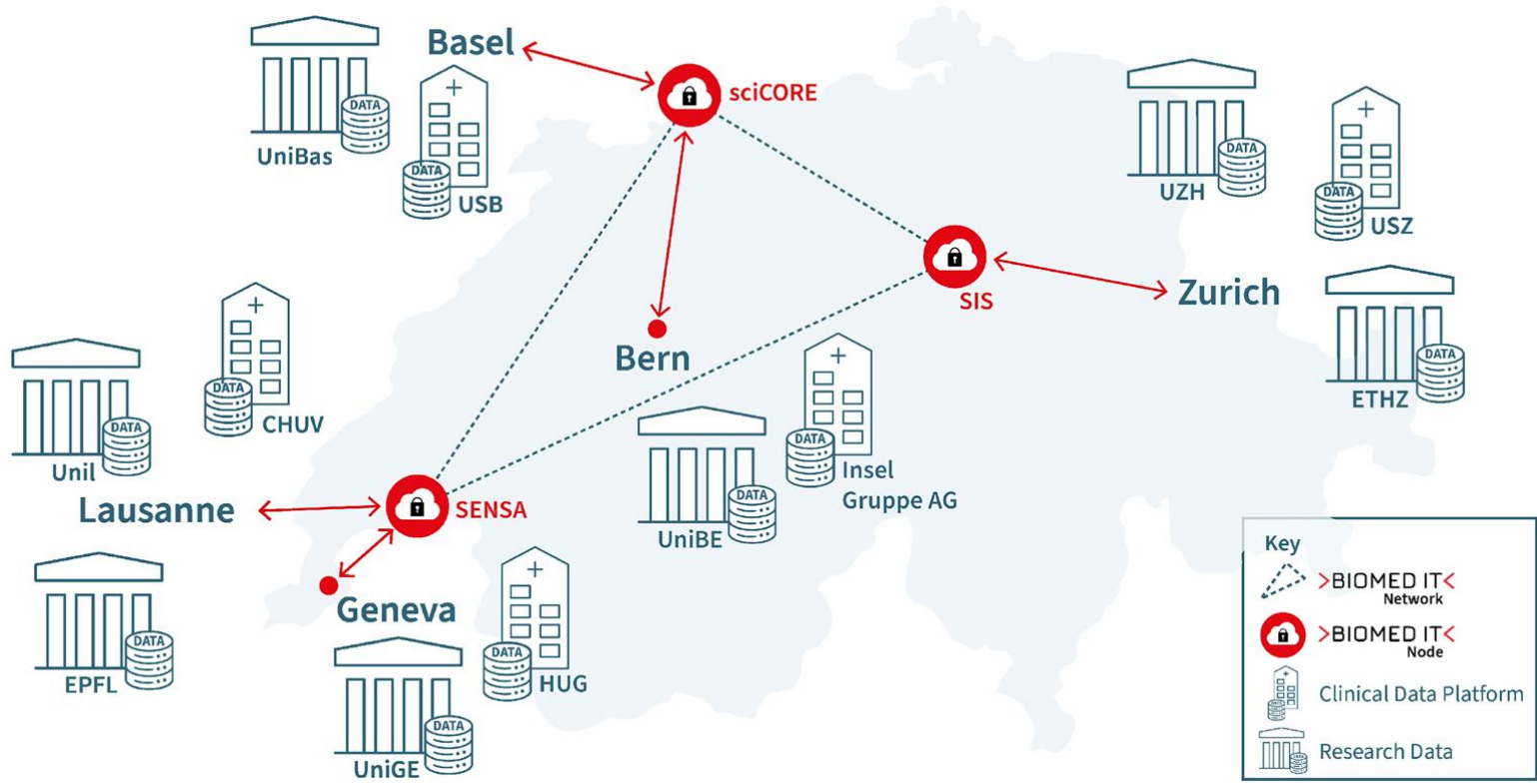
Dr. sc. ETH Sabine Österle

Lead Semantic Interoperability Strategy and FAIR Data Team,
SPHN Data Coordination Center, SIB Swiss Institute of Bioinformatics

A project of



Welcome to SPHN



Key

>BIOMED IT< Network

>BIOMED IT< Node

Clinical Data Platform

Research Data

Data Coordination Center (DCC)

University Hospital Basel

CHUV Centre hospitalier universitaire vaudois

KSA

ehealthsuisse

ETHZ

FNRS FONDOS NATIONAL SUISSE SCHWEIZERISCHER NATIONALFONDS FONDO NAZIONALE SVIZZERO SWISS NATIONAL SCIENCE FOUNDATION

THE LOOP ZÜRICH MEDICAL RESEARCH CENTER

Personalized Health Alliance Basel-Zurich

SWISS BIOBANKING PLATFORM

SCTO

SSPH+ SWISS SCHOOL OF PUBLIC HEALTH

life sciences cluster basel

SDSC

swissuniversities

Universität Medizin Schweiz Médecine Universitaire Suisse

USZ Universitäts Spital Zürich

HUG Hôpitaux Universitaires Genève

luzerner kantonsspital

INSELSPITAL UNIVERSITÄTSSPITAL BERN HOPITAL UNIVERSITAIRE DE BERNE BERN UNIVERSITY HOSPITAL

KantonsSpital St.Gallen

UNIVERSITÄTS-KINDERSPITAL ZÜRICH

UKBB kompetent & menschlich

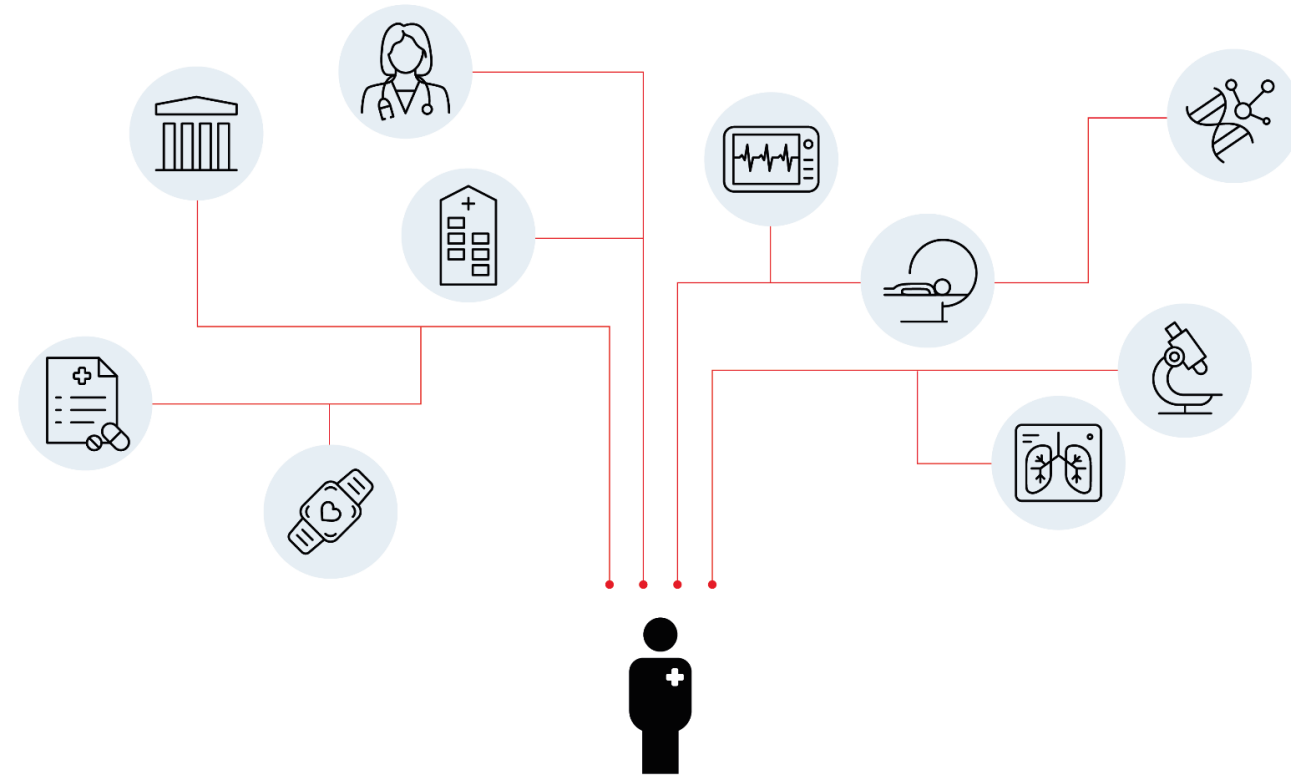
KSB

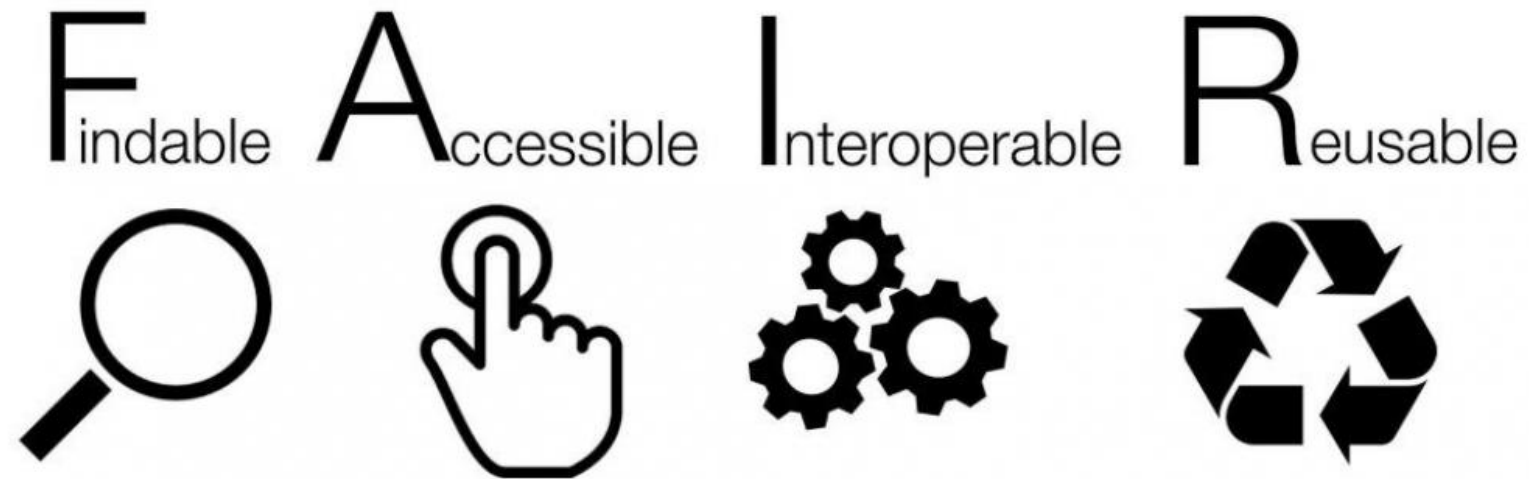
health 2030

SAKK THE BRINGING PROGRESS TO CANCER CARE

Personalized Health (Research): The Challenges

- RWD captured for care, reflect the billing reality rather than the patient reality
- Lots of free text, lack of structured data, local or no standards
- Data quality – sufficient for the purpose?
- Big Data analyses require a critical mass of data to be combined from various scattered sources
- (Gen)omic layer often missing
- Sensitive nature of health data (even if pseudo- or anonymized)
- Data ownership and governance
- Cultural shift

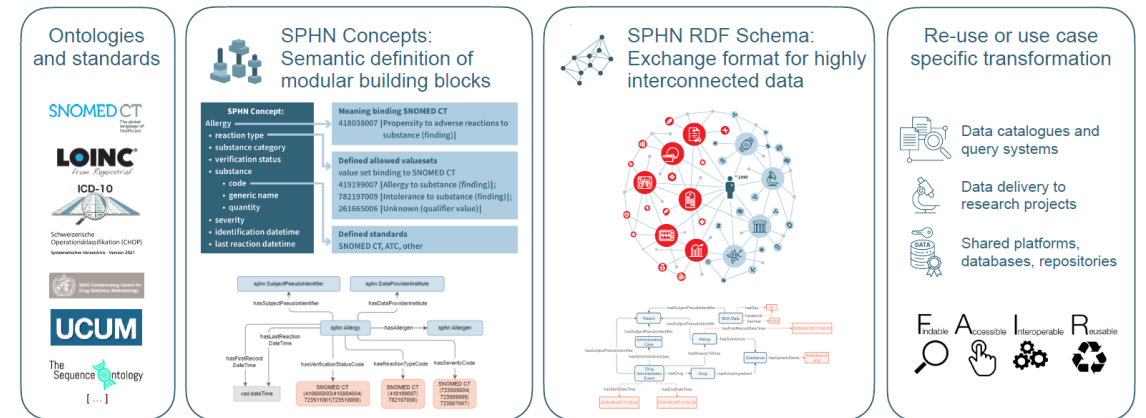




Wilkinson, M., Dumontier, M., Aalbersberg, I. et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci Data 3, 160018 (2016). <https://doi.org/10.1038/sdata.2016.18>

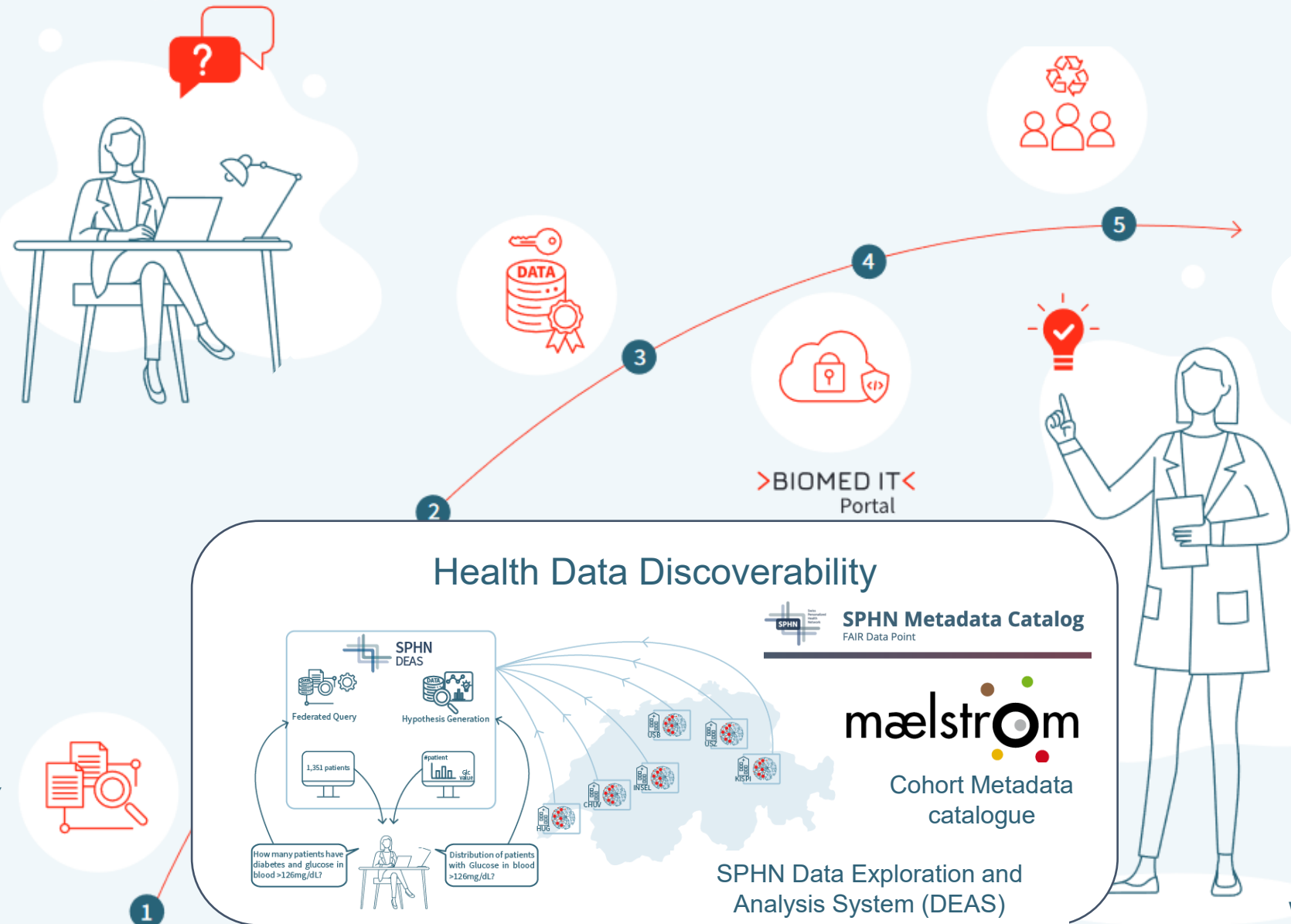
SPHN Semantic Interoperability Framework

- **Real world data** is complex, diverse level of context of the data is available
- **Biological data** (e.g. omics) adds an additional layer of information
- W3C (RDF and OWL) and data (SNOMED CT and LOINC) standards allow to **speak a common language**
- **Semantic representation** of the data enables a better understanding of the data

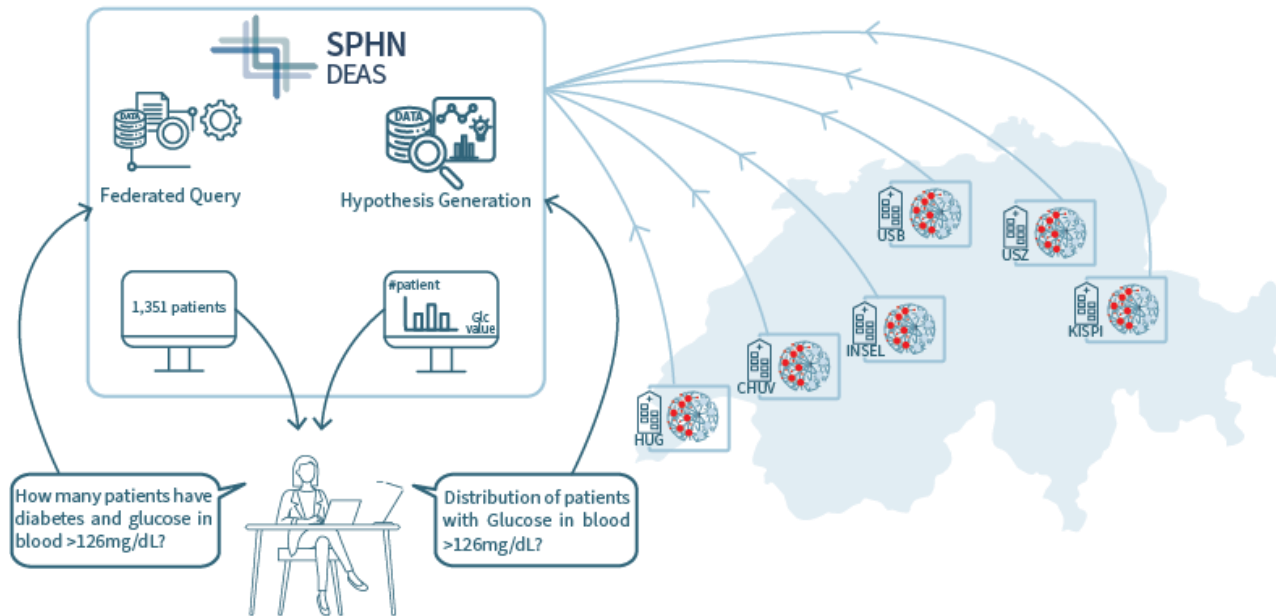


Multi-layered data integration into a knowledge graph enables a comprehensive view of the patient

The SPHN value chain

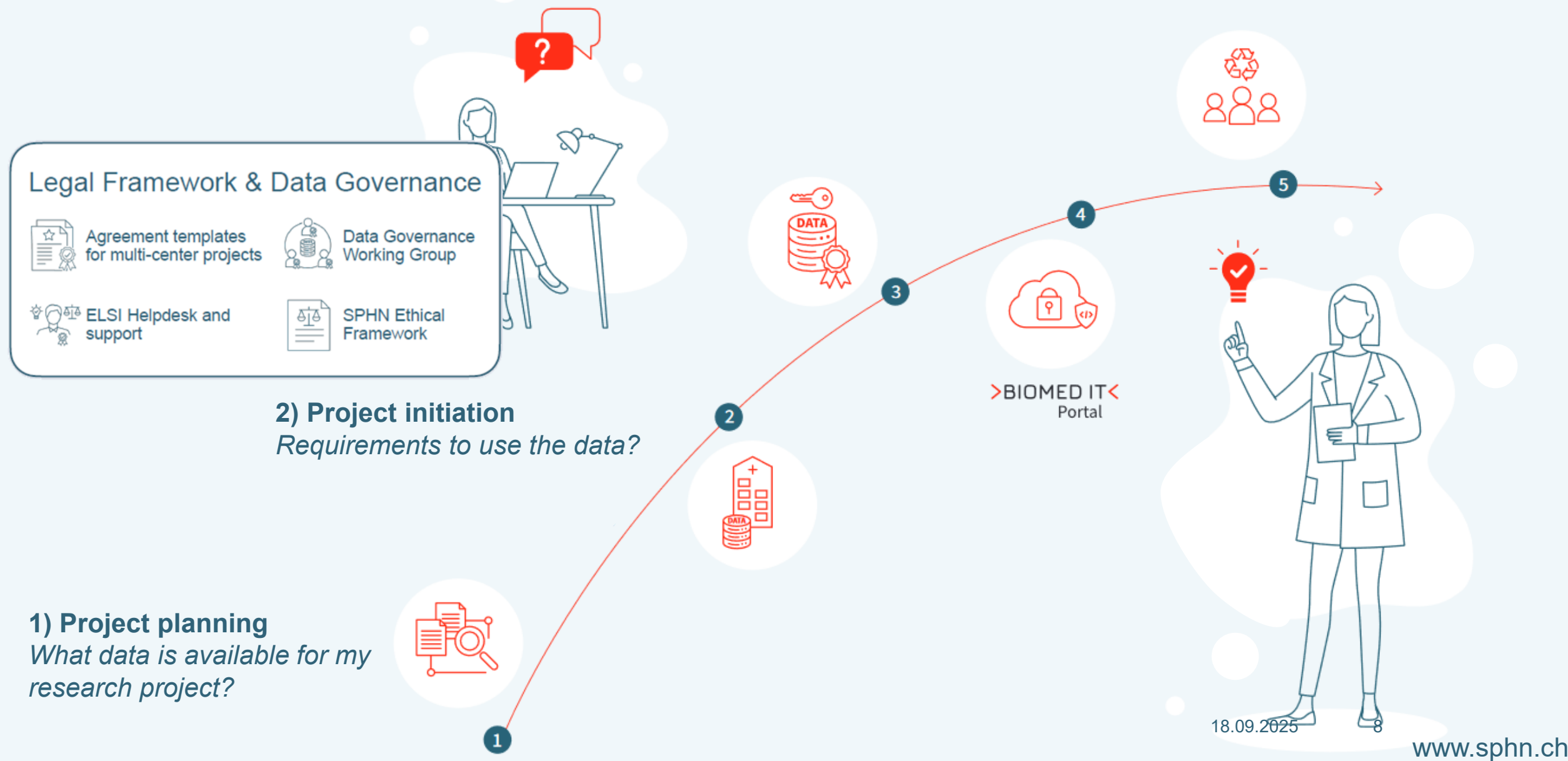


SPHN DEAS (Data Exploration and Analysis System)



- Feasibility queries, value distribution and survival curves of patient cohorts
- Full SPHN Dataset (>165 clinical parameters)
- All patients with General Consent since 2018 from 6 hospitals
- 0.7 Mio patients
- Local triple store at each hospital with over 12 Bn triples
- Fully privacy preserving, in collaboration with **TU NE INSIGHT**
- Plan to go live in 2026

The SPHN value chain



The SPHN value chain

1) Project planning

What data is available for my research project?



1

2) Project initiation

Requirements to use the data?



2



3) Data preparation

Is the data available and interoperable?



4

From raw data to FAIR data



Finds Accesses Interoperates Reuses

W3C[®]
LOINC[™]
From Regenstrief
SNOMED CT
The global language of healthcare



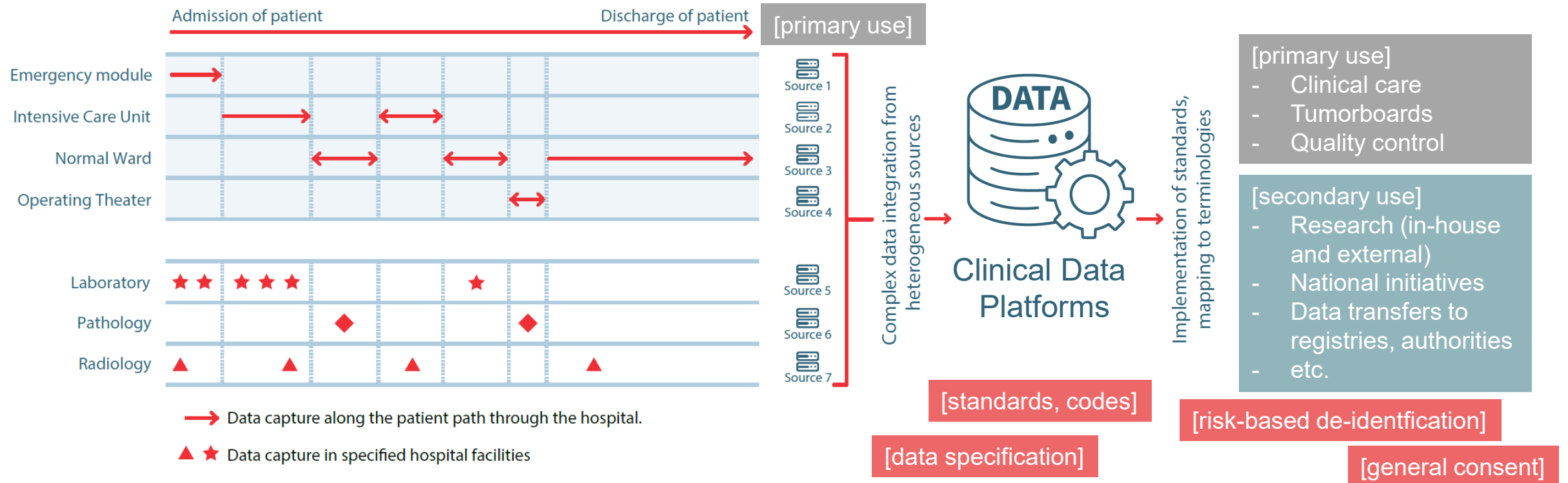
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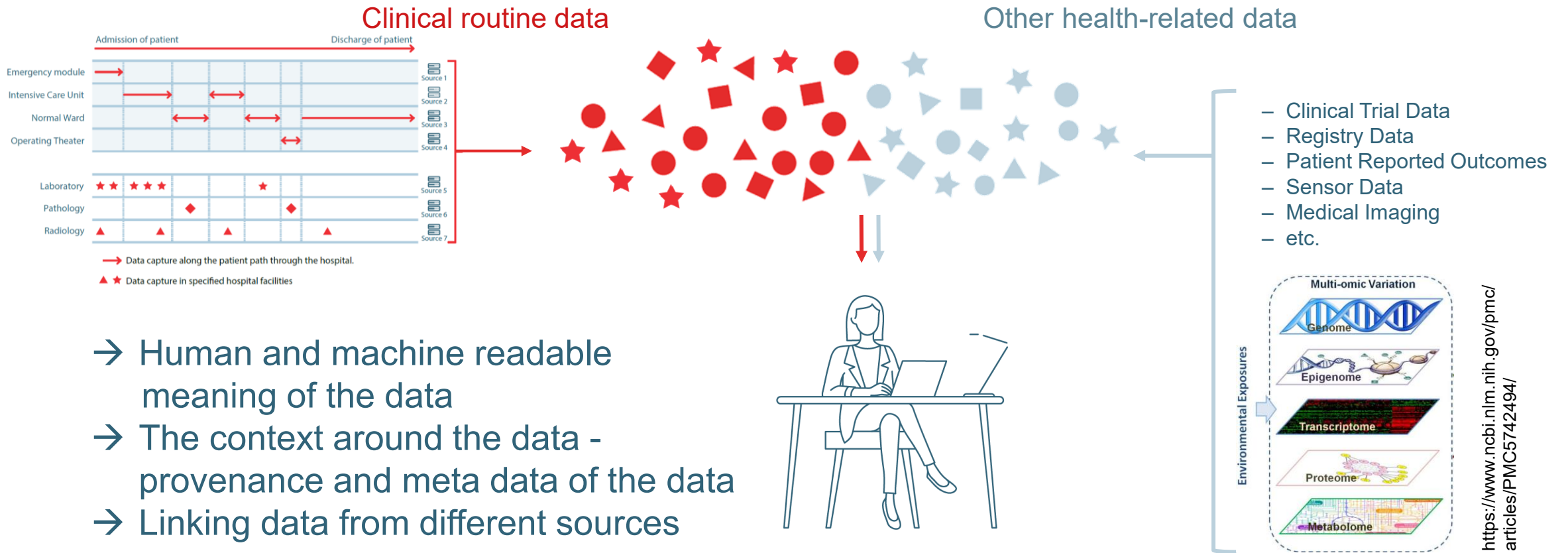
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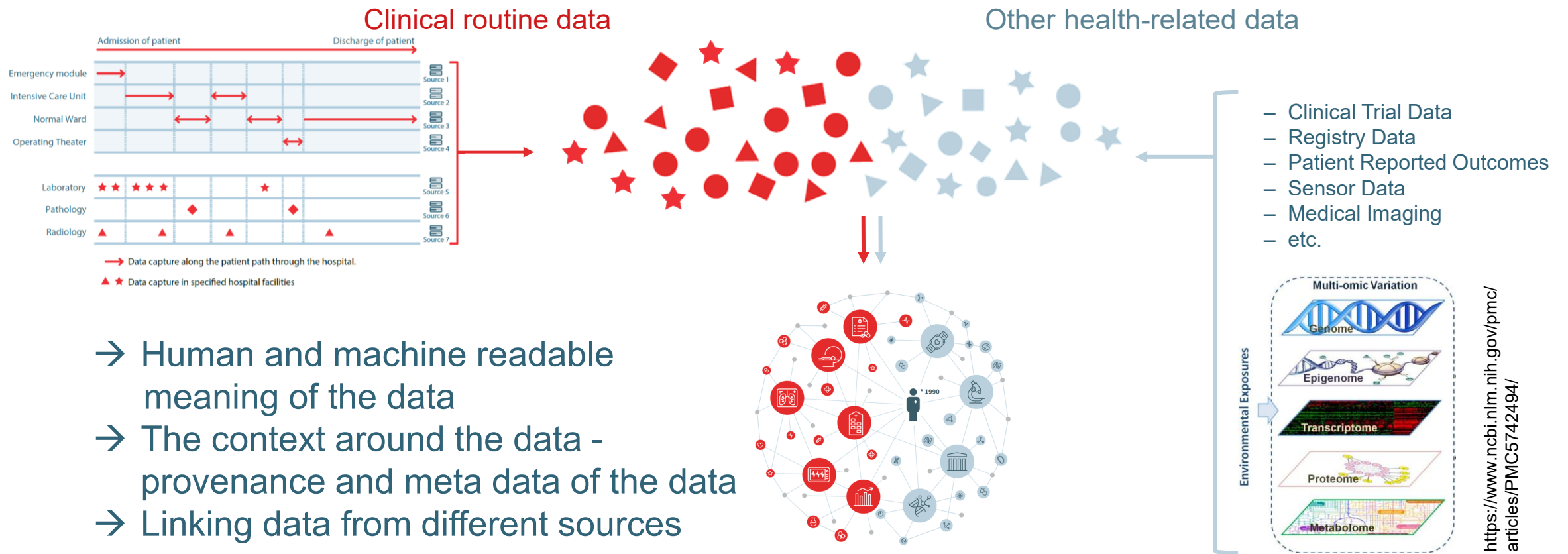
Core infrastructures at Swiss University Hospitals



The need for data linkage



The need for data linkage



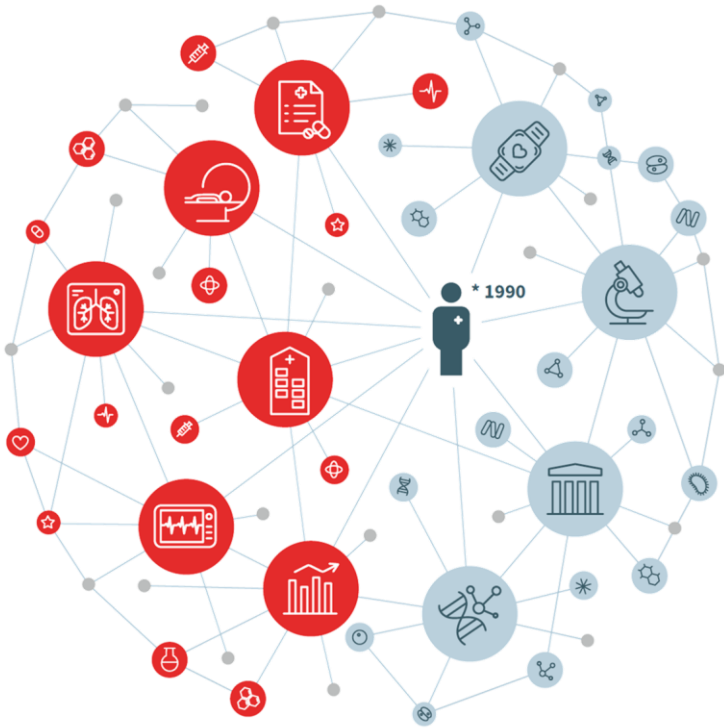
The SPHN Schema to generate knowledge graphs

206 SPHN concepts

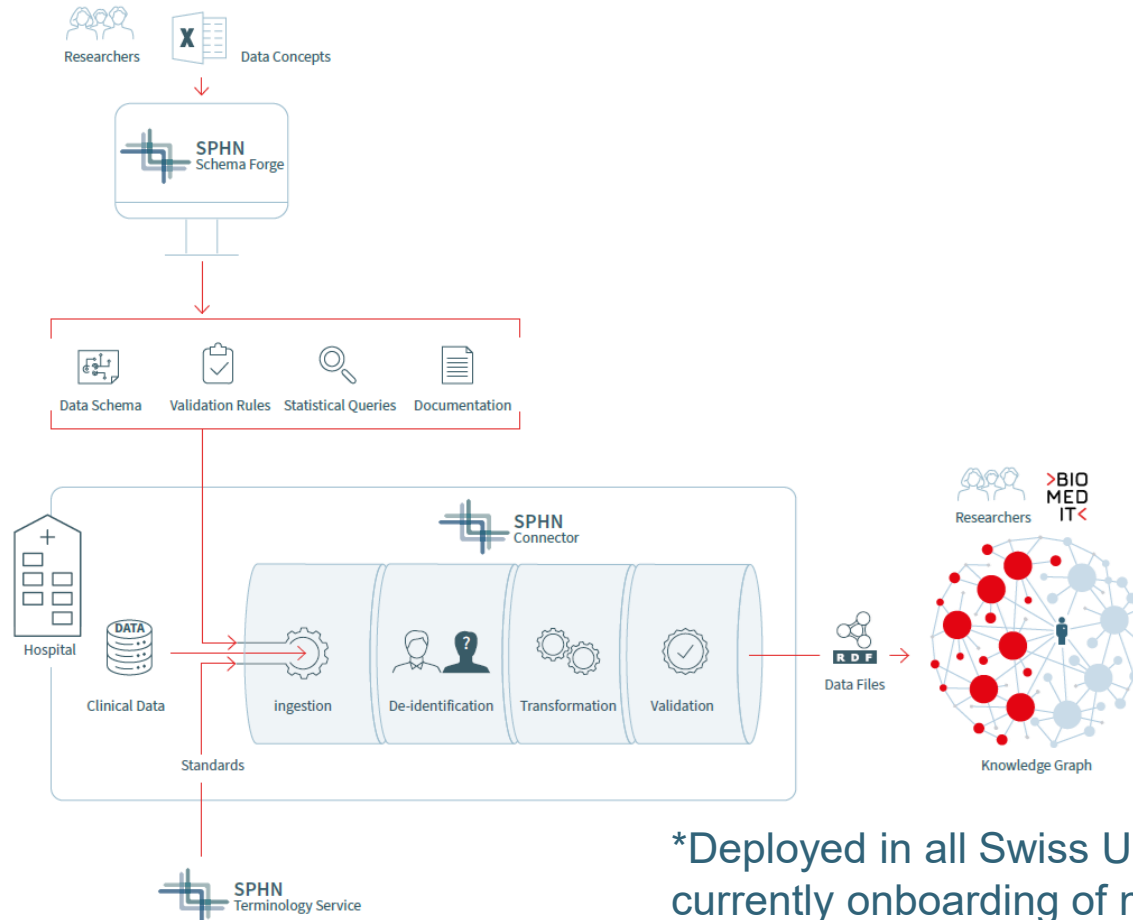
- Nationally aligned
- Meaning defined once

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



SPHN Toolstack to generate knowledge graphs



SPHN Schema Forge – Web service for the generation of semantic artefacts

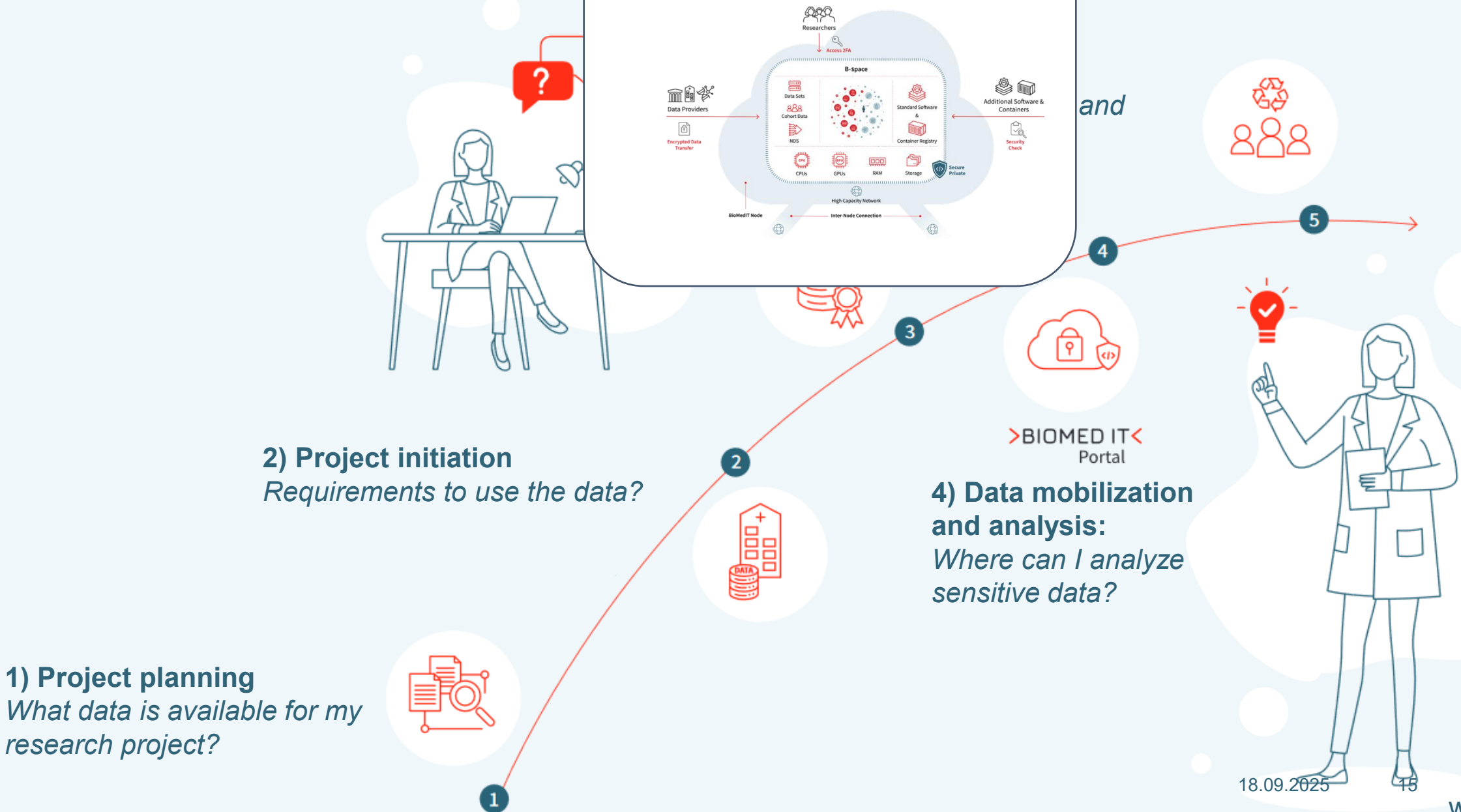
SPHN Connector – RDF data generation on the data provider side

SPHN Terminology Service – FAIR and versioned terminologies in RDF

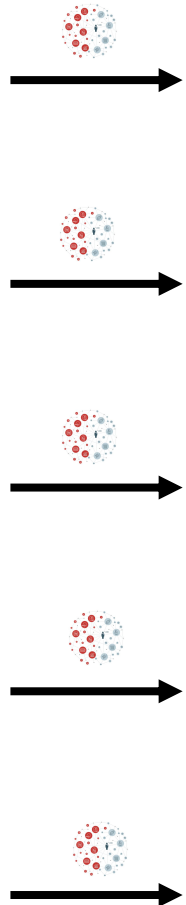
SPHN Mock Data Generator – Large scale production of Mock Knowledge Graphs for training or testing

*Deployed in all Swiss University hospitals, currently onboarding of multiple cantonal hospitals

The SPHN value chain



SPHN National Data Streams



B-Space per project
Secure data processing
Triplestore and
terminology server



>BIOMED IT<

Project-specific infrastructure development,
data management and data-driven research

 IICU Personalized, data-driven prediction and assessment of infection-related outcomes in Swiss ICUs (IICU) Main PIs: Prof. Dr. Adrian Egli (UZH) & Prof. Dr. Catherine Jutzeler (ETHZ) Duration: 01.09.2022 - 31.08.2025 (36 months) Award: CHF 5 Mio Lay summary More information	 SPO-NDS Swiss Personalized Oncology National Data Stream (SPO-NDS) Main PIs: Prof. Dr. Olivier Michielin (CHUV) & Prof. Dr. Bernd Bodenmiller (ETHZ) Duration: 01.09.2022 - 31.08.2025 (36 months) Award: CHF 5 Mio Lay summary More information	 SwissPed Health Pediatric personalized research network Switzerland (SwissPedHealth) – a Joint Pediatric National Data Stream Main PIs: Prof. Dr. Luegn Schlapbach (University Children's Hospital Zurich) & Prof. Dr. Julia Vogt (ETHZ) Duration: 01.09.2022 - 31.08.2025 (36 months) Award: CHF 5 Mio Lay summary More information	 LUCID LUCID, Low Value of Care in Hospitalized Patients, a National Data Stream on Quality of Care in Swiss university hospitals Main PIs: Dr. Marie Méan (CHUV) & Dr. Guillaume Obozinski (EPFL) Duration: 01.09.2022 - 31.08.2025 (36 months) Award: CHF 5 Mio Lay summary More information
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>BIOMED IT<



Strategic Focus Area
**Personalized Health
and Related Technologies**

The SPHN value chain

1) Project planning
What data is available for my research project?

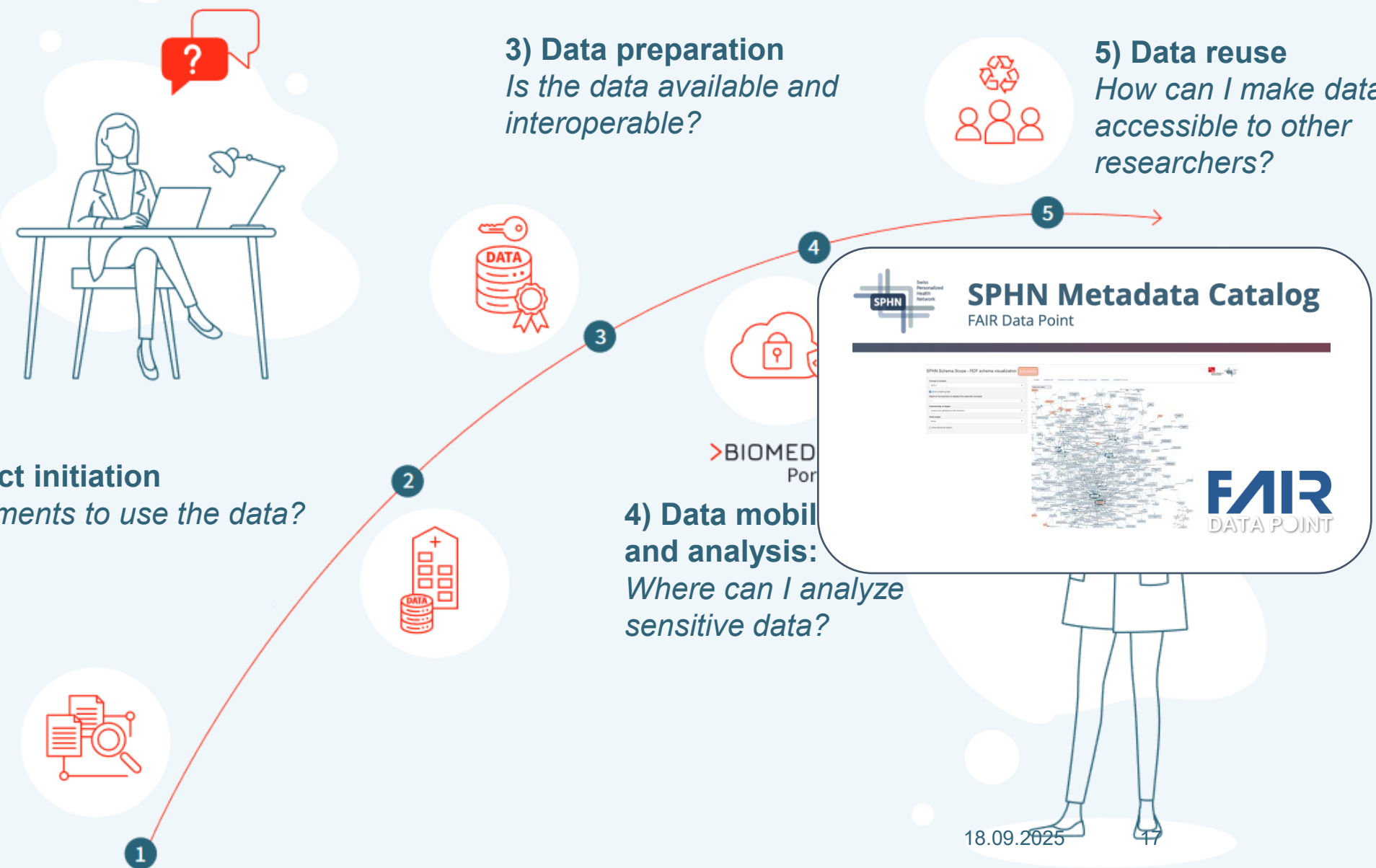
SPHN - Sabine Österle

2) Project initiation
Requirements to use the data?

3) Data preparation
Is the data available and interoperable?

4) Data mobil and analysis:
Where can I analyze sensitive data?

5) Data reuse
How can I make data accessible to other researchers?



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SPHN Metadata Catalog (FAIR Data Point)

- Title (*dcterms:title*)
- Abstract (*dcterms:abstract*)
- Version (*dcat:version*)
- Sources (*dcterms:source*)
- Data schema / Data model used (*dcterms:conformsTo*)
- Language (*dcterms:language*)
- Creation datetime (*dcterms:issued*)
- Coding systems (*healthdcatap:hasCodingSystem*)
- Health data access body (*healthdcatap:hdab*)

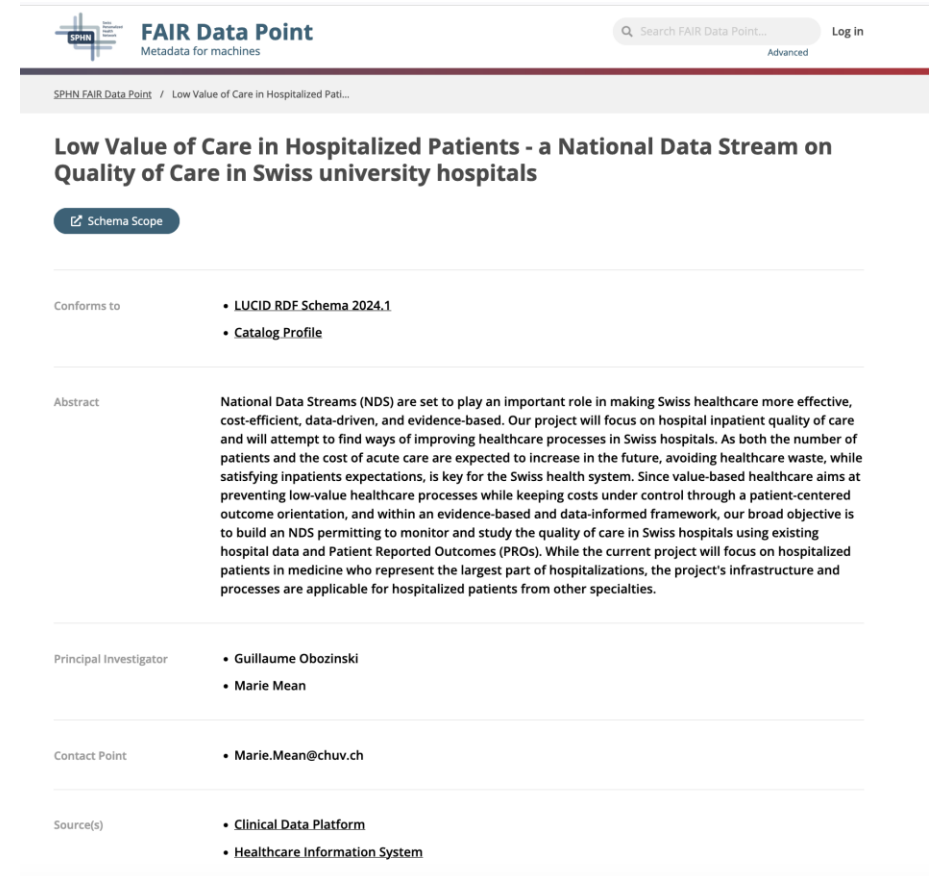
...

→ HealthDCAT (European health data space compliant)

→ FAIR Data Point (human and machine readable)

<https://specs.fairdatapoint.org/fdp-specs-v1.2.html>

<https://healthdcat-ap.github.io/>

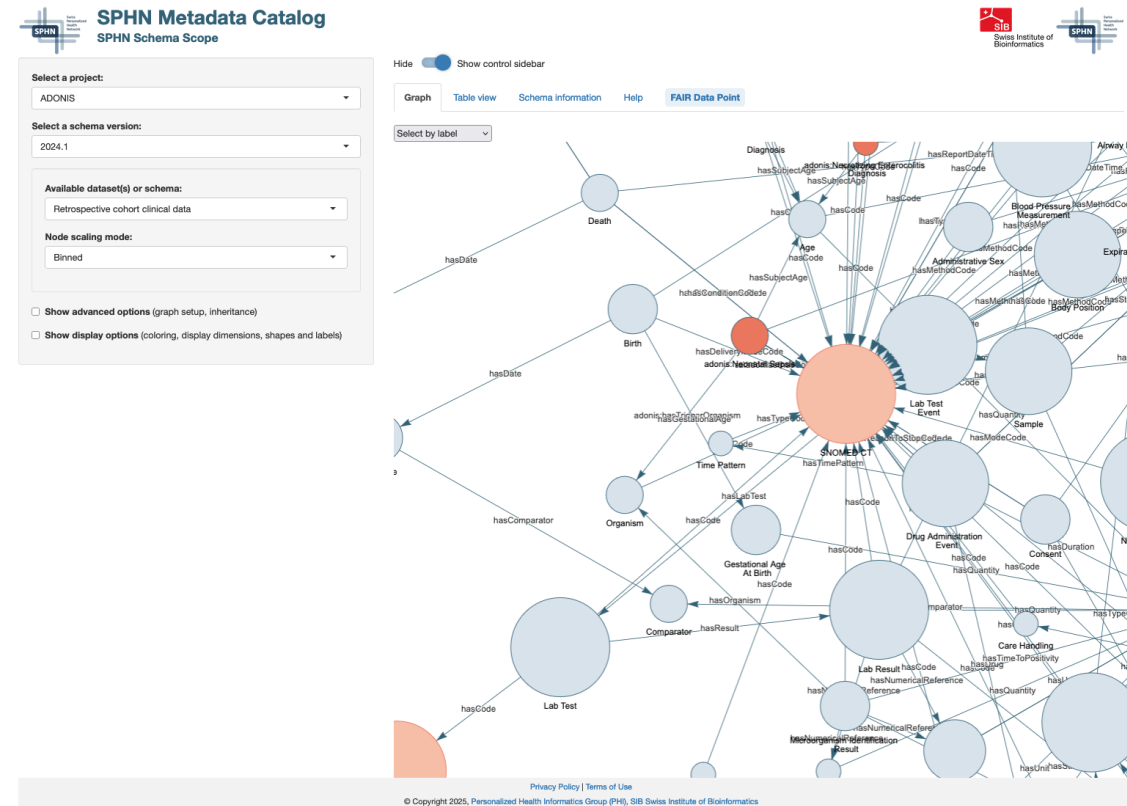


The screenshot shows the FAIR Data Point Metadata Catalog interface. At the top, there is a search bar with the text "Search FAIR Data Point..." and a "Log in" button. Below the search bar, the title "FAIR Data Point" is displayed, followed by the subtitle "Metadata for machines". The main content area shows a search result for "Low Value of Care in Hospitalized Patients - a National Data Stream on Quality of Care in Swiss university hospitals". The result includes a "Schema Scope" button, a list of "Conforms to" (LUCID RDF Schema 2024.1, Catalog Profile), an "Abstract" section with a detailed description of the National Data Streams (NDS) project, a "Principal Investigator" section listing Guillaume Obozinski and Marie Mean, a "Contact Point" section listing Marie.Mean@chuv.ch, and a "Source(s)" section listing Clinical Data Platform and Healthcare Information System.

SPHN Metadata Catalog (SPHN Schema Scope)

Human visualization of the

- SPHN Schema
- Projects (reuse of SPHN concepts plus own concept)
- Counts of instances
- Coding system used (total instance, counts of different codes)



<https://schemascope.dcc.sib.swiss/>

Selected SPHN use cases

12 catalogs with 11 dataset from SPHN Projects (more to come)

LUCID (Low value care in Hospitalized Patients)	SPO (melanoma cohort)	ADONIS
• 0.1 Mio patient • Administrative data, clinical routine data, PROMS • 2.55 Bn triples	• 431 patients • Administrative data, clinical routine data, oncology data, omics • 7 Mio triples	• 15 k patients • Administrative data, clinical routine, ICU data, timeseries • 400 Mio triples

→ Explore more datasets: <https://fdp.dcc.sib.swiss/>

Acknowledgements

The SPHN Implementation Teams (MO and DCC):

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The **SPHN NSB** and **NAB**, **Task Forces & WGs**

The **BioMedIT Board** and **workforces @** ETHZ, Unibas, Unil/SIB

The **Hospital workforces @** USZ, USB, CHUV, Insel, HUG



<https://git.dcc.sib.swiss/sphn-semantic-framework>



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



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www.sphn.ch