Swiss Personalized Health Network From clinical routine data to FAIR data for research

Dr. sc. ETH Sabine Österle
Lead Semantic Interoperability Strategy and FAIR Data Team,
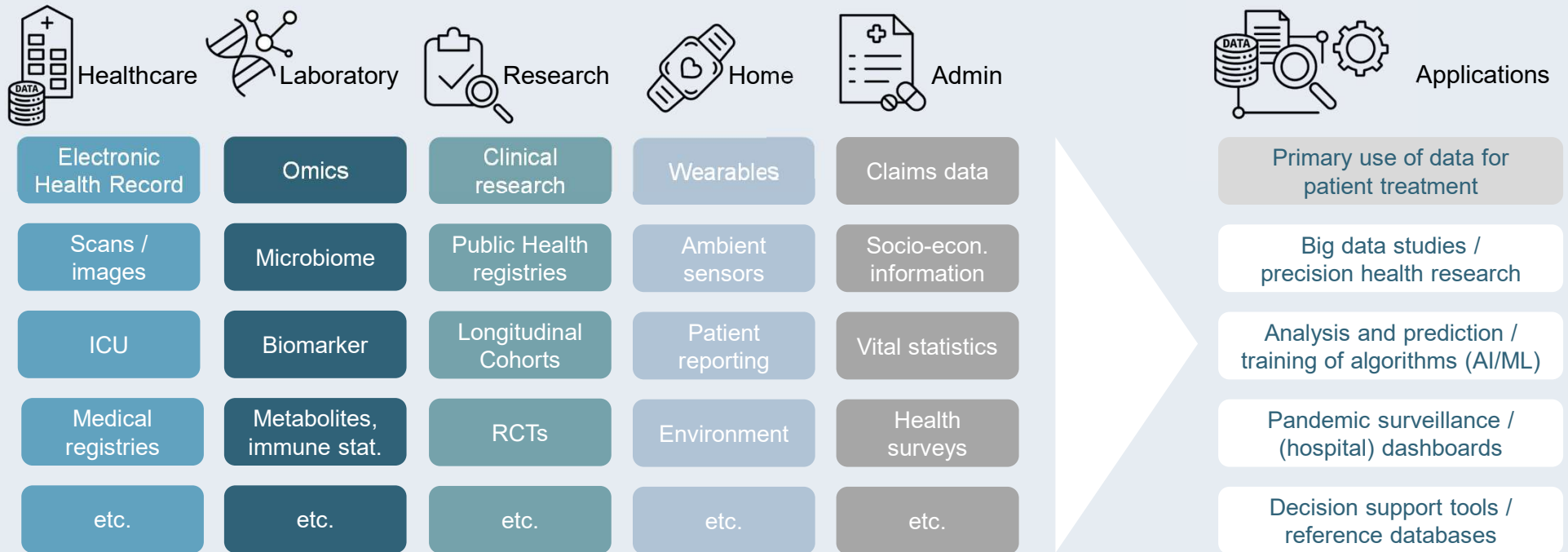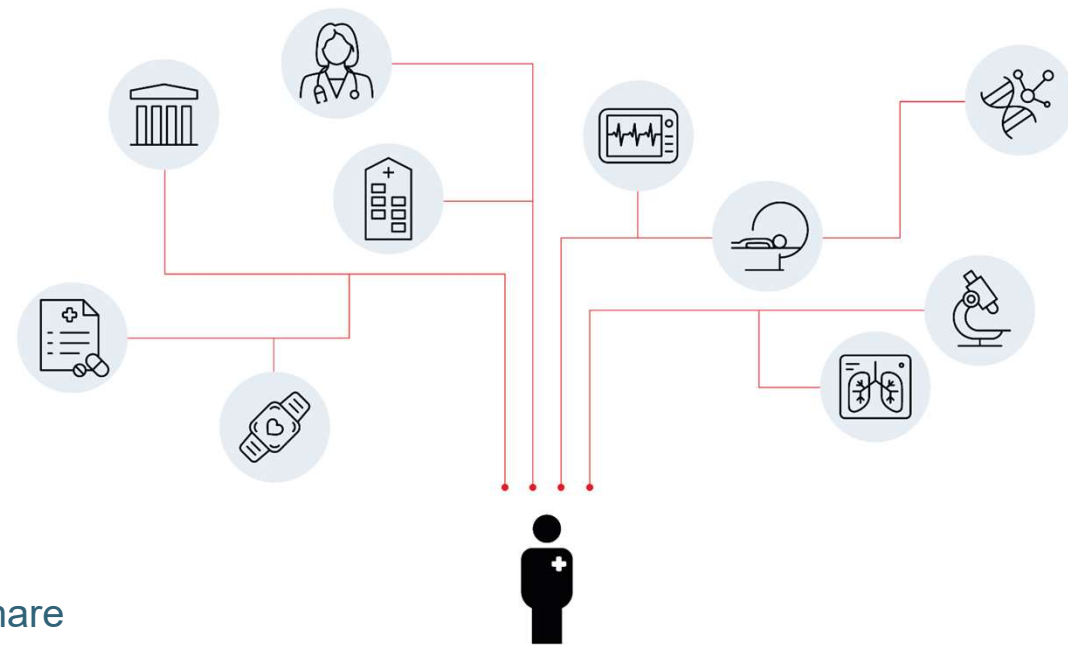Personalized Health Informatics Group, SIB Swiss Institute of Bioinformatics

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

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Health data and its areas of application

Healthcare	Laboratory	Research	Home	Admin		Applications
Electronic Health Record	Omics	Clinical research	Wearables	Claims data		Primary use of data for patient treatment
Scans / images	Microbiome	Public Health registries	Ambient sensors	Socio-econ. information		Big data studies / precision health research
ICU	Biomarker	Longitudinal Cohorts	Patient reporting	Vital statistics		Analysis and prediction / training of algorithms (AI/ML)
Medical registries	Metabolites, immune stat.	RCTs	Environment	Health surveys		Pandemic surveillance / (hospital) dashboards
etc.	etc.	etc.	etc.	etc.		Decision support tools / reference databases

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: a nightmare

- Cultural shift

The Swiss Personalized Health Network

SPHN infrastructures, services and support

Core infrastructures at Swiss University Hospitals
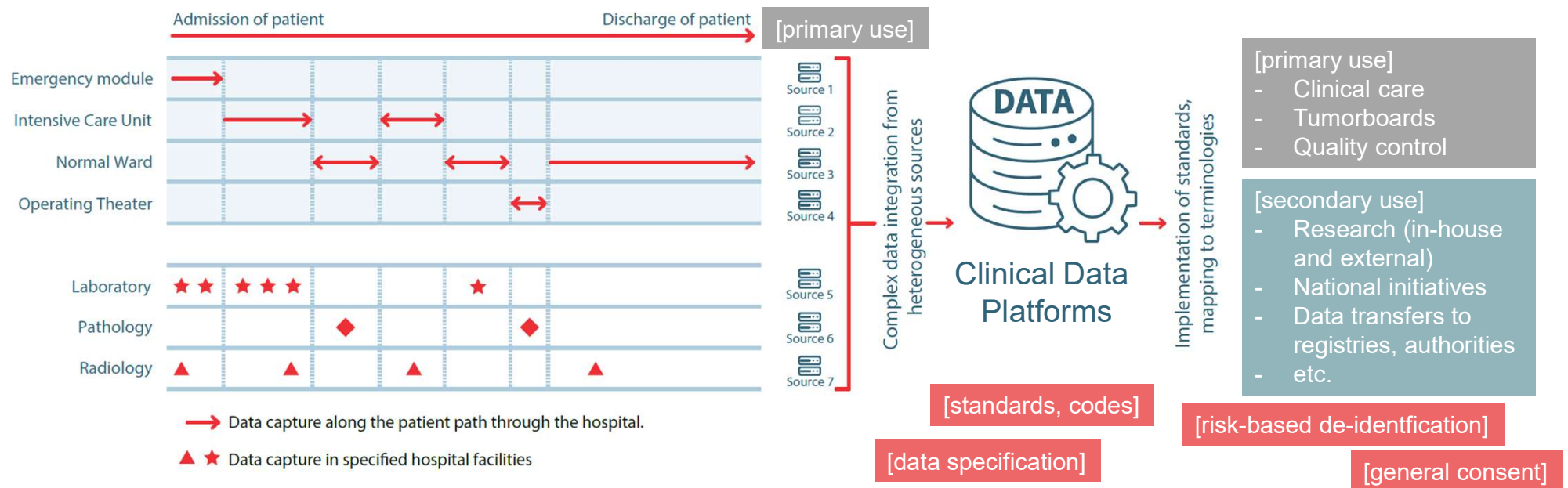
The need for data interoperability [at the source]

Clinical routine data

Other health-related data

– Clinical Trial Data
– Registry Data
– Patient Reported Outcomes
– Sensor Data
– Medical Imaging
– etc.
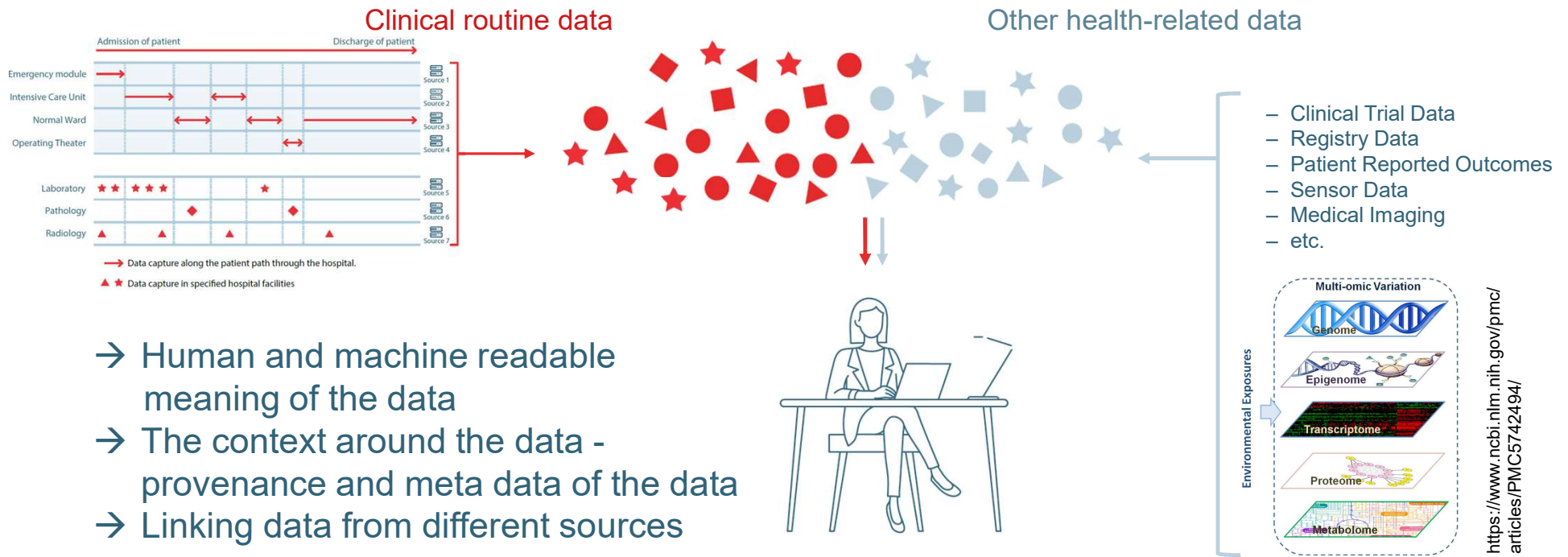
→ Human and machine readable meaning of the data

→ The context around the data - provenance and meta data of the data

→ Linking data from different sources

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5742494/

The SPHN Interoperability Framework: Why a knowledge graph (KG)?

– **Semantic representation of the data** rather than harmonization to fit in one data model

– **Flexibility**: Allows representation of complex, interrelated data and integration of multimodal data from different sources

– **Scalability**: KGs can handle large amounts of data and are designed to be scalable

– **Intuitive and visual** presentation of relationships and connections between data elements, allowing researchers to easily explore relationships, and to identify new signals

– **Linked data**: seamless use of data and semantic standards

– **Knowledge inference**

– **FAIR principles** implementation

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 I 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 I More information

SwissPed Health

Pediatric personalized research network Switzerland (SwissPedHealth) – a Joint Pediatric National Data Stream

Main PIs: Prof. Dr. Luregn 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 I 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

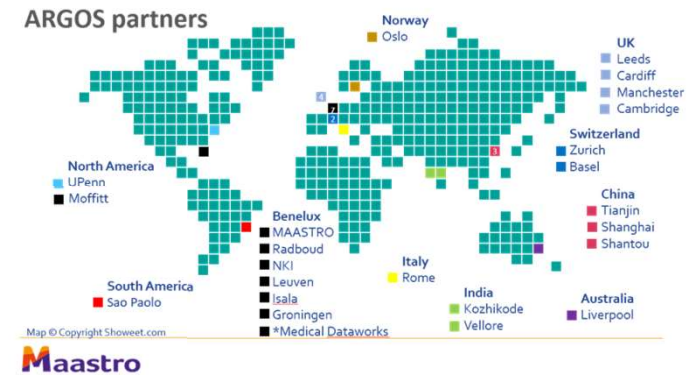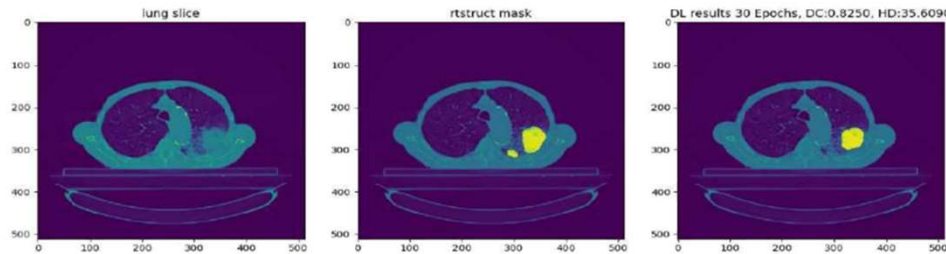**Lay summary I More information**

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Strategic Focus Area
Personalized Health and Related Technologies

Data exploration and analysis system (DEAS)
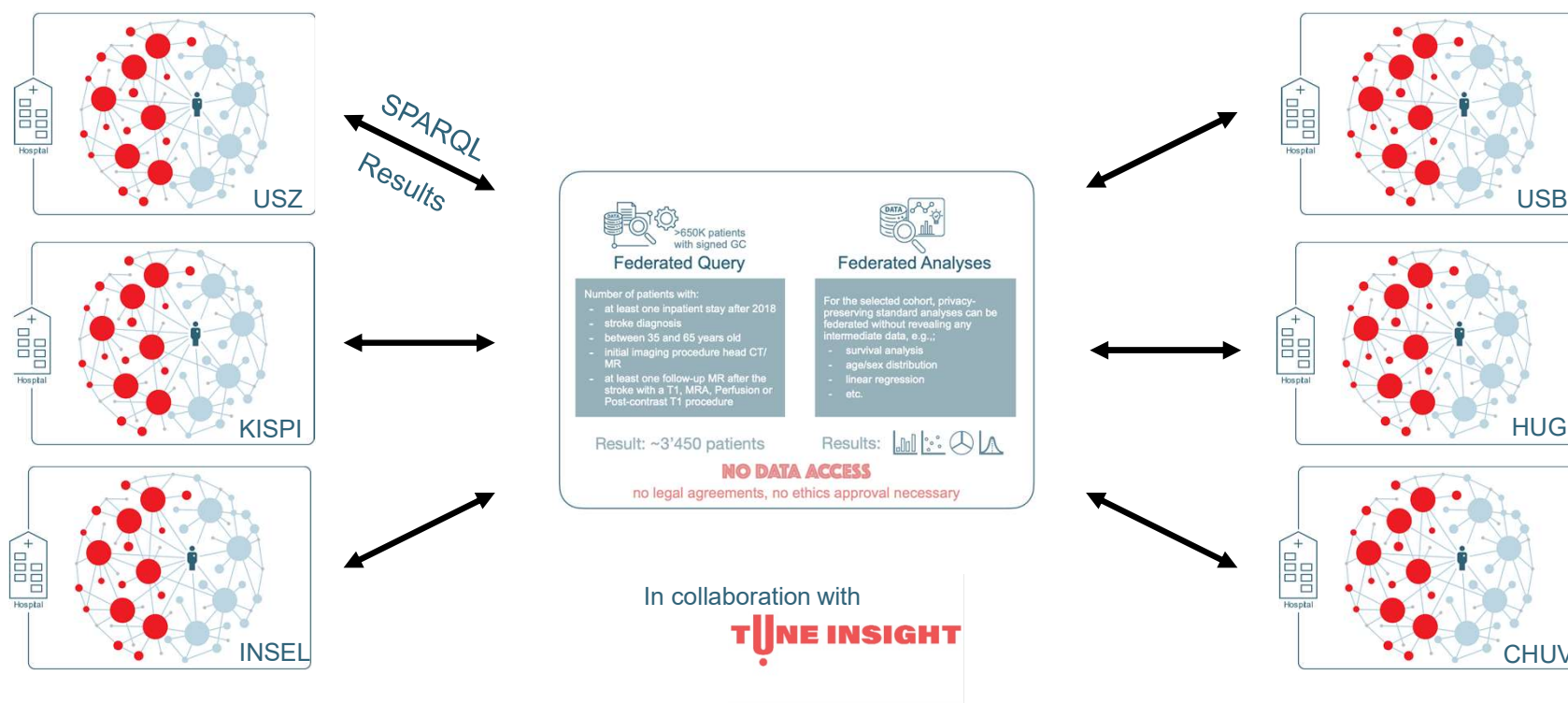
International Federated Compute ARGOS

(AR)tificial intelligence for (G)ross tumour v(O)lume (S)egmentation

- Fully open-sourced code for federated deep learning
- 22 institutional partners across 10 countries
- Executed **legal agreements in multiple jurisdictions** incl EU, Switzerland, US, China and India
- **Inclusivity and diversity** – low resource threshold for small clinics and LMICs; each contributes 200+ cases
- **In-kind funding** from participants

Credit for slides to Leonhard Wee, Maastro

Data alone is not enough

For a functioning data ecosystem and broad use of health data in research and innovation, there is a need for:

- Domain knowledge

- Scalable and sustainable infrastructures

- A smart governance framework

- Close coordination at national and international level

- A change in research culture, to foster collaboration, transparency, and to ensure responsible data practices

- Public acceptability

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