Data Research in Switzerland: Swiss Personalized Health Network (SPHN) Initiative and Data Governance

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Agenda

Overview: Human Research and Data Research in Switzerland

Swiss Personalized Health Network (SPHN) Initiative

Local Implementation of the SPHN Initiative

Data Governance at USZ

Conclusions

Human Research in Switzerland

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Human Research in Switzerland

Switzerland is highly competitive in research and innovation

one of the highest R&D spending of gross domestic product (3% of GDP = around CHF 22 billion)

- 2/3 from private sector; 1/3 public research funding

- Public funding relies on competition and international cooperation

- Division of tasks between public and private sectors:

  based on subsidiarity and a liberal economy.

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Human Research in Switzerland

Comprehensive framework governing research involving humans:

**Swiss Federal Human Research Act (HRA)** and international standards
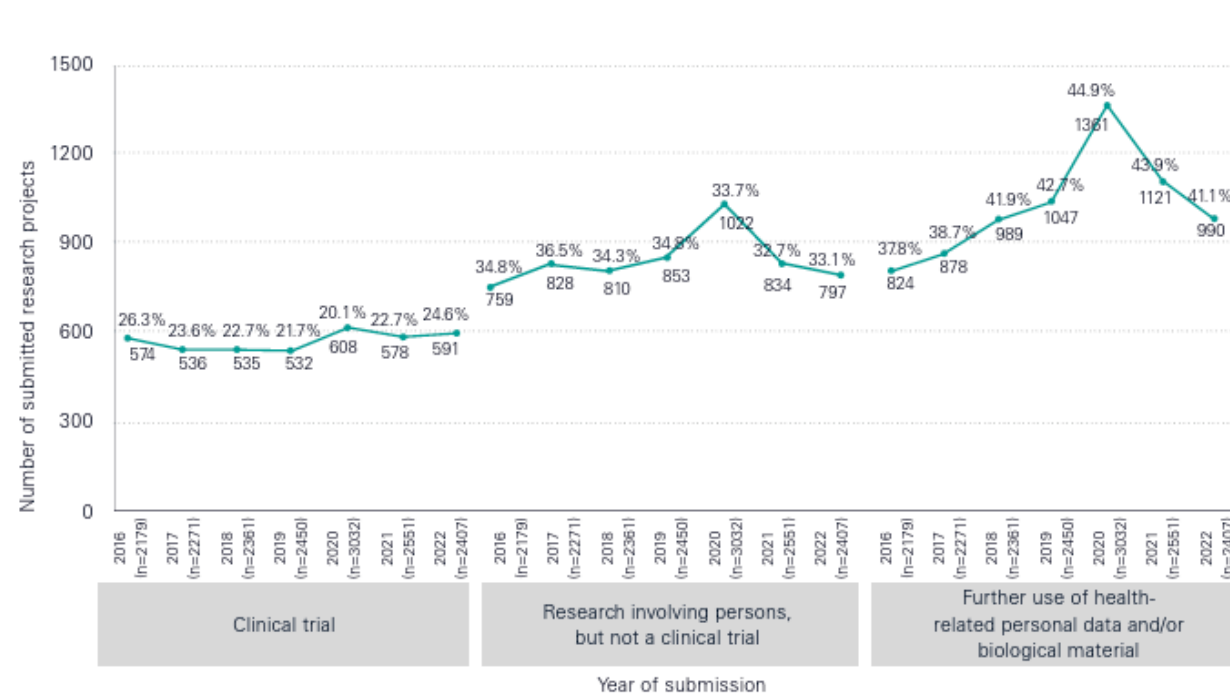
Research permissible only upon prior review and approval by independent body:

- Interventional Research: Clinical Trials (IMP, IMD, other clin. Trials)

- **Research with Data/Samples**

  - Research involving persons

  - Further use of Data/Samples

Human research legislation (admin.ch)

Human Research in Switzerland
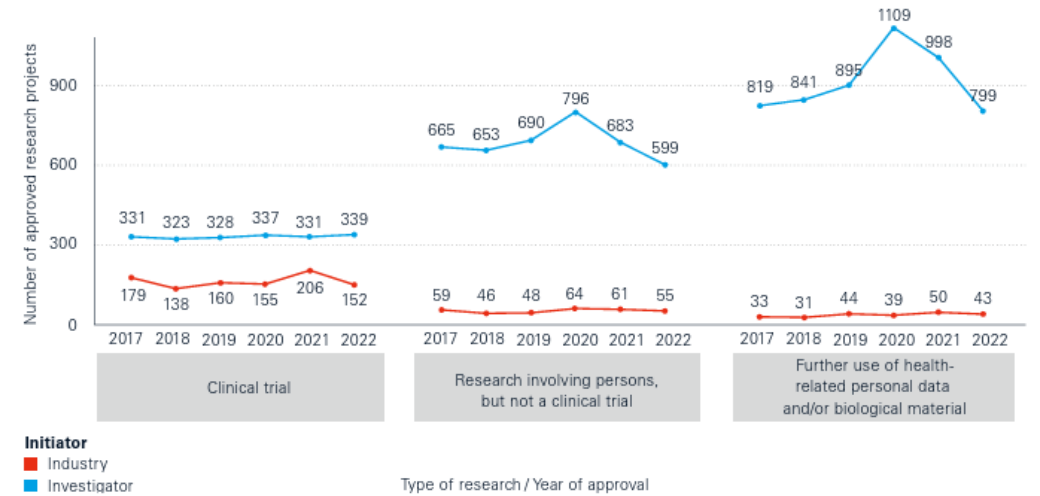
- 25% interventional clinical trials; 75% research with data/samples

- 90% academic; 10% Industry-sponsored (clin trials 70/30)

Human Research in Switzerland

various agencies and initiatives support research and innovation

Swiss Personalized Health Initiative (SPHN) enables nation-wide use and exchange of health data for research

Swiss Personalized Health Network SPHN Initiative

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Swiss Personalized Health Network SPHN

national initiative, start in 2017

Goals:

- develop, implement, and validate data infrastructures in Switzerland.

- ensure interoperability, accessibility, shareability of health-related data.

- Bring together decision-makers from clinics, research, support

  institutions, and patient organizations.

Budget: over 150mio CHF
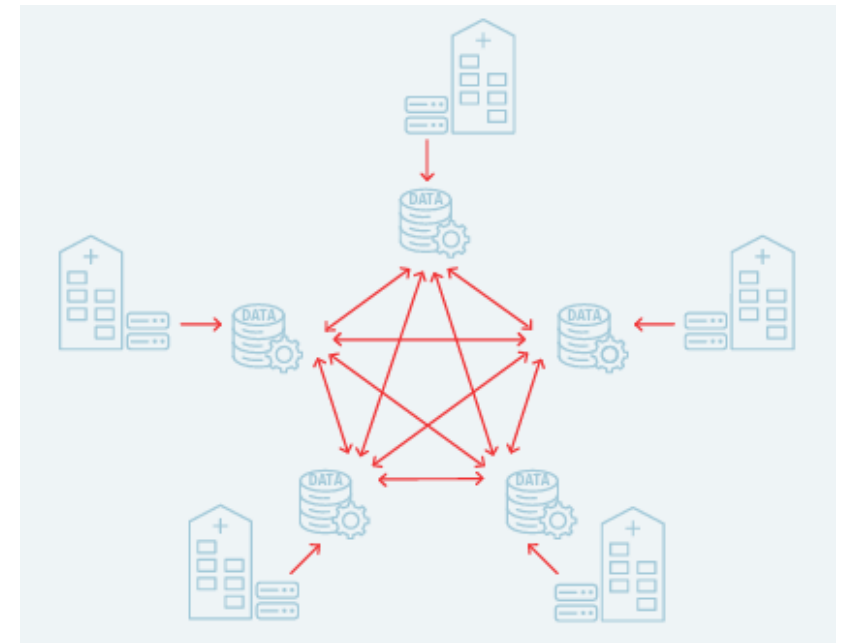
Swiss Personalized Health Network SPHN

Efficient Data Provision:

- efficient provision of interoperable biomedical and clinical routine data

- National Data Streams

Discoverability and Exploration of Data:

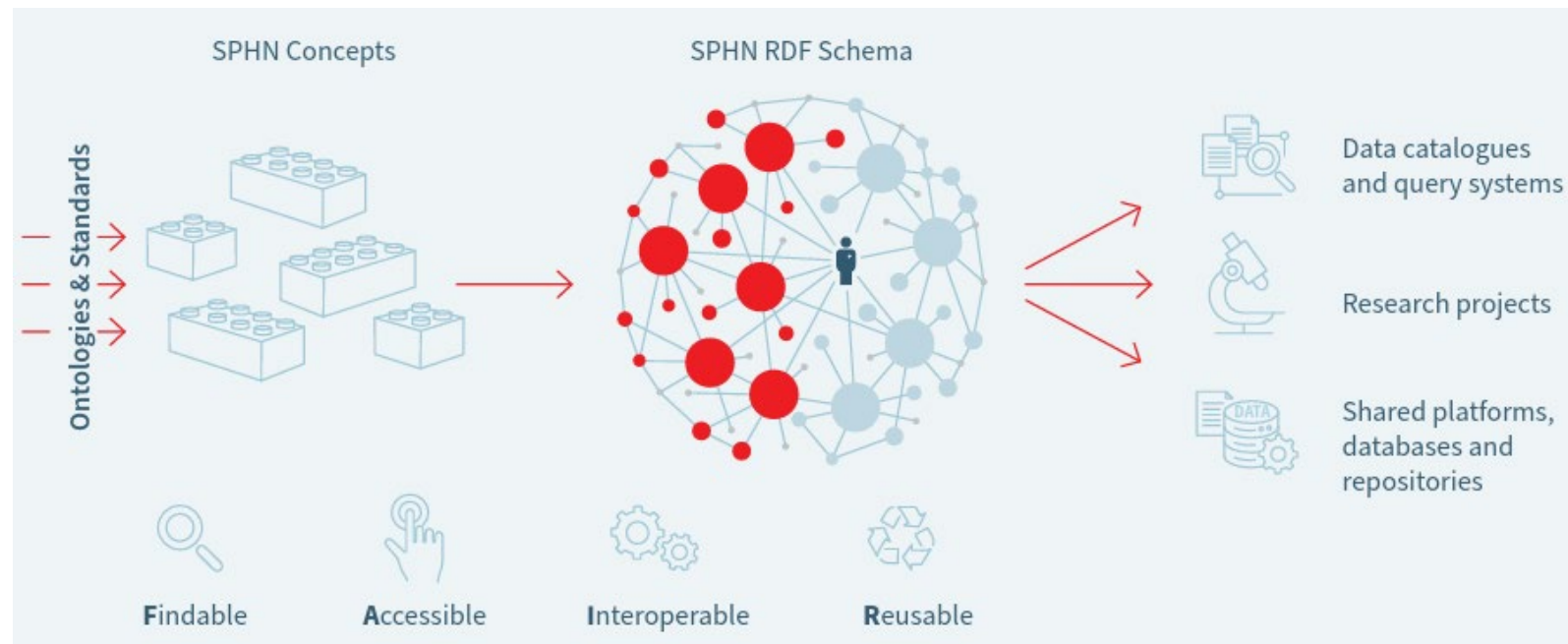- SPHN provides different tools, services and platforms

Swiss Personalized Health Network SPHN

FAIR principles and Data Interoperability

- standardized data schema (resource description framework, tools, services)

- makes biomedical and health data understandable by humans and machines
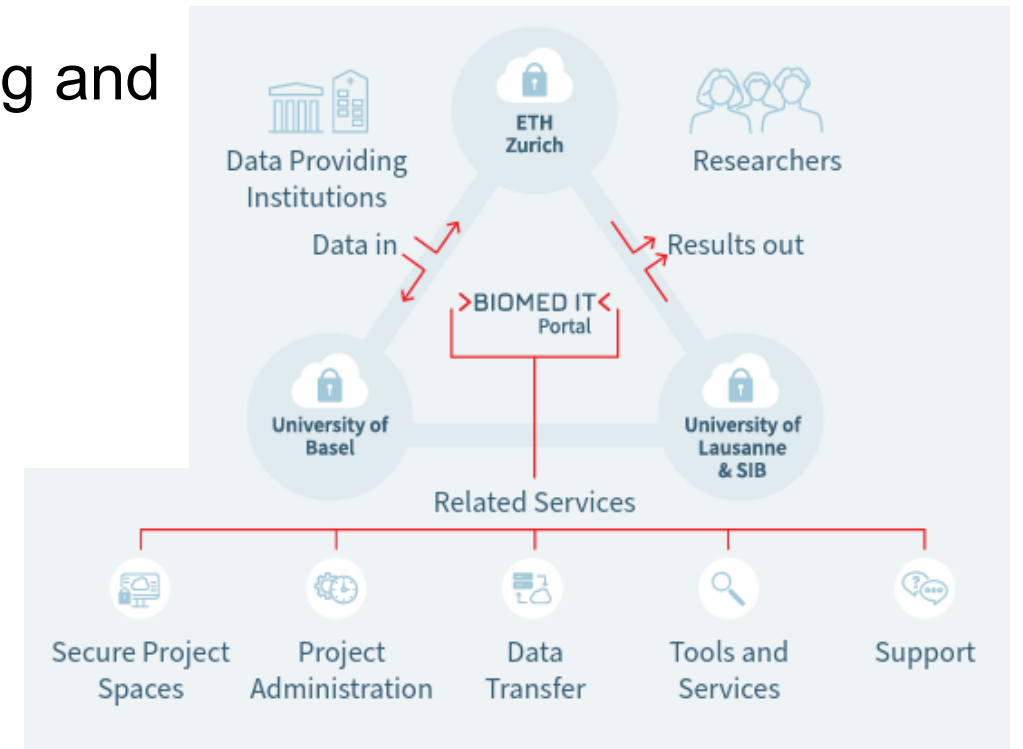
Swiss Personalized Health Network SPHN

Trusted Research Environment:

- SPHN-BioMedIT network (secure IT infrastructure)

- Services for transferring, storing, processing and analyzing sensitive data

Compliance Structures:

- Harmonized ethical guidelines and legal requirements
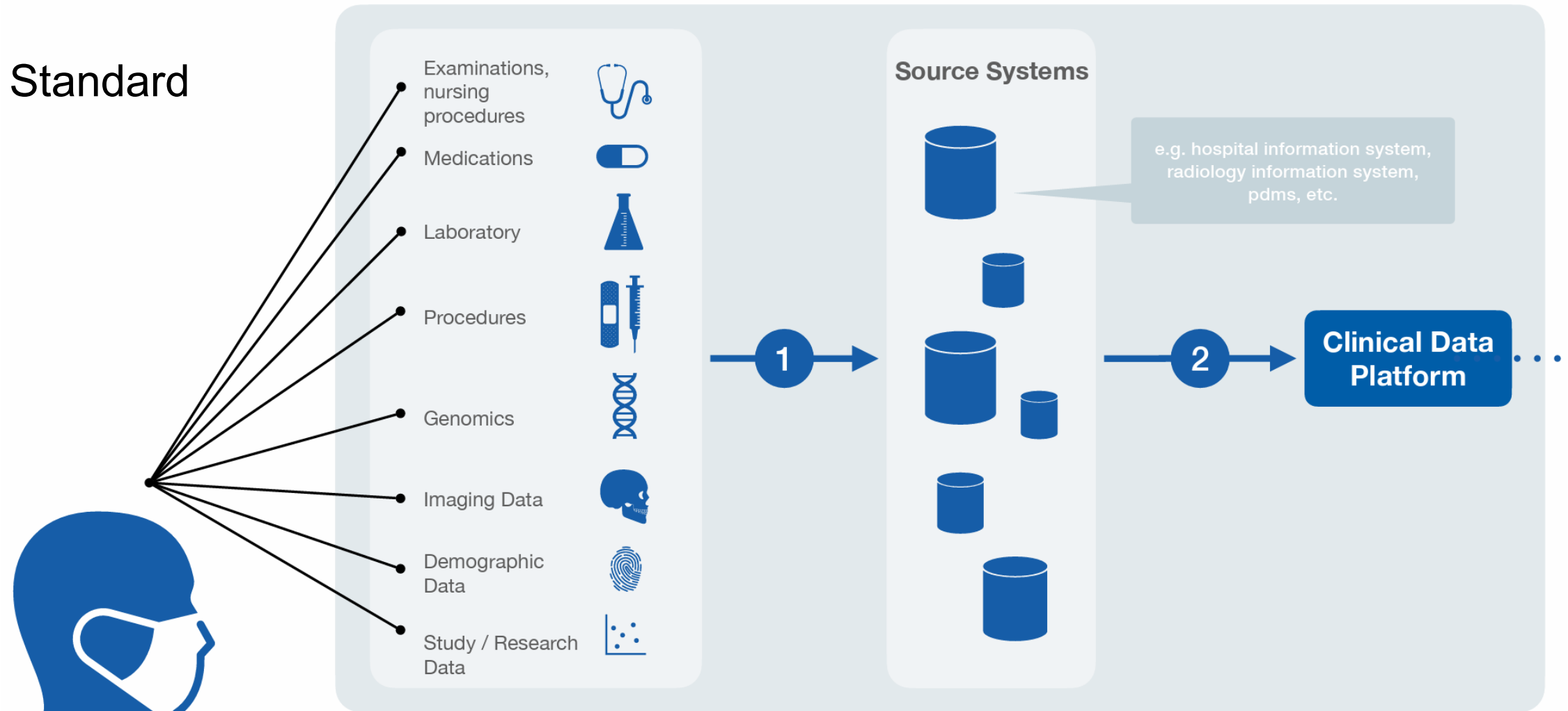
- Local Data Governance Boards

Local Implementation of SPHN

Local Implementation of SPHN: Data Availability at USZ

Standard

Examinations, nursing procedures

Medications

Laboratory

Procedures

Genomics

Imaging Data

Demographic Data

Study / Research Data

Source Systems

e.g. hospital information system, radiology information system, pdms, etc.

1

2

Clinical Data Platform
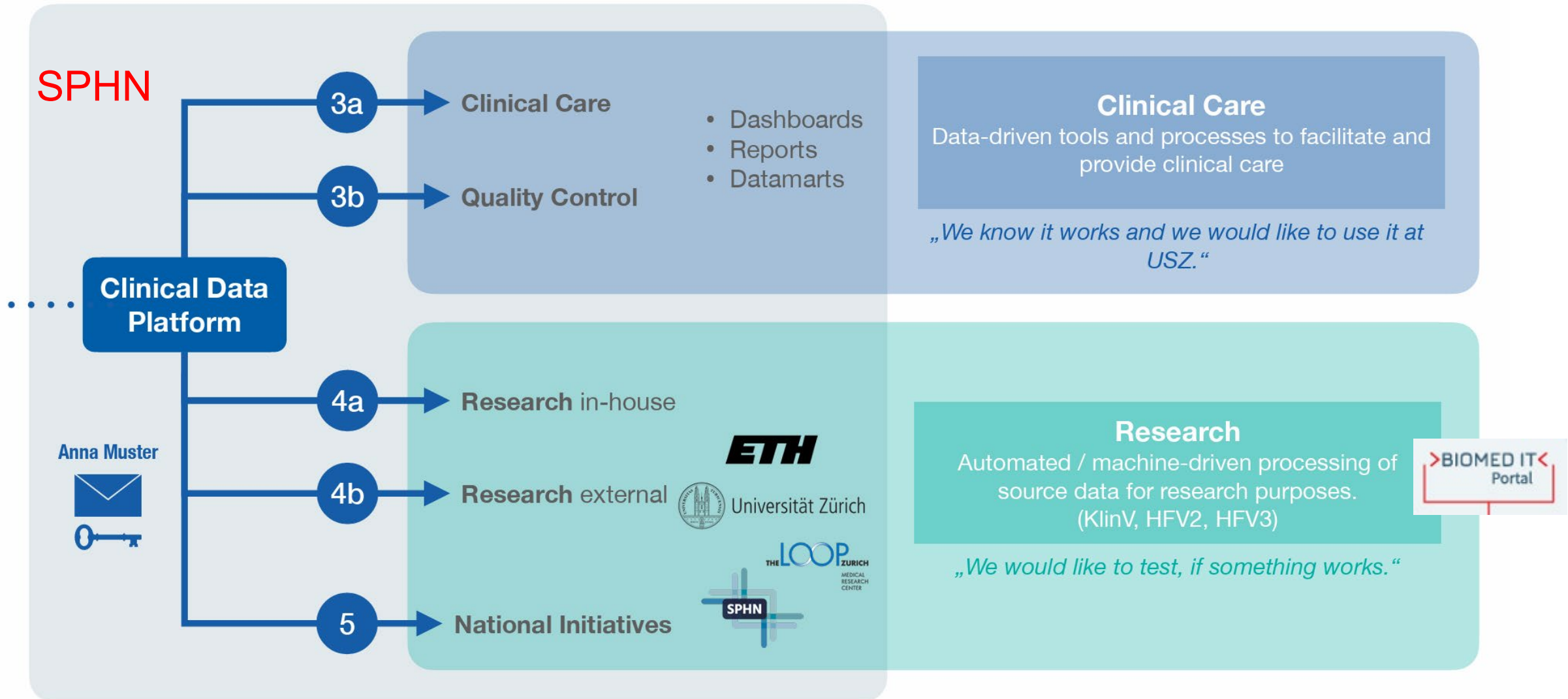
Local Implementation of SPHN: Data Availability at USZ

Data Research and Data Governance at USZ

Preparation of Research Project	Approval by Ethics Committee / IRB	Acceptance by local Data Governance Board	Data Delivery and conduct of Project

Preparation of Research Project

Hypothesis
Study plan

Specify Data

(General) Consent of study participants

Contracts with involved parties

Acceptance by local Data Governance Board

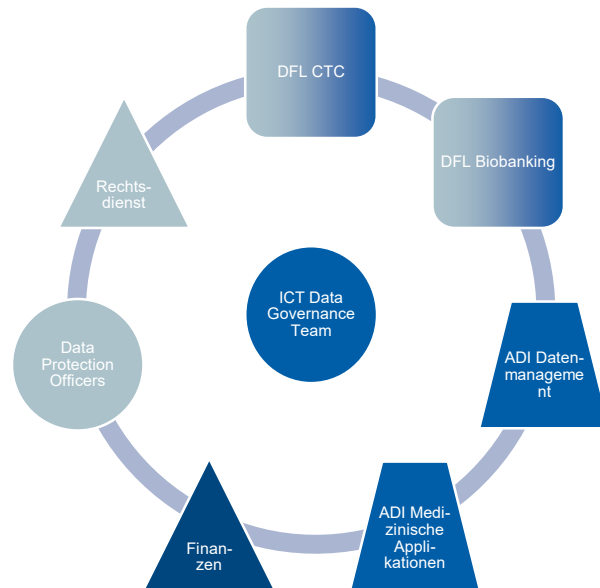Data Governance Board checks:

Regulatory Affairs / Regulatory Compliance
Data Protection
Data Transfer and Security
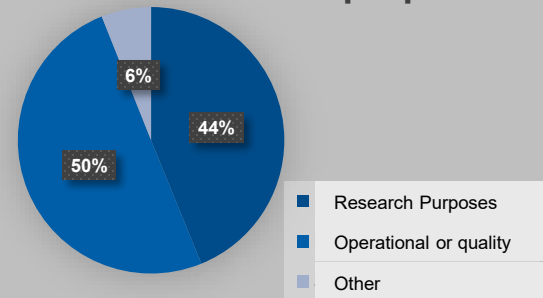Legal Agreements
Others

>BIOMED IT< Portal
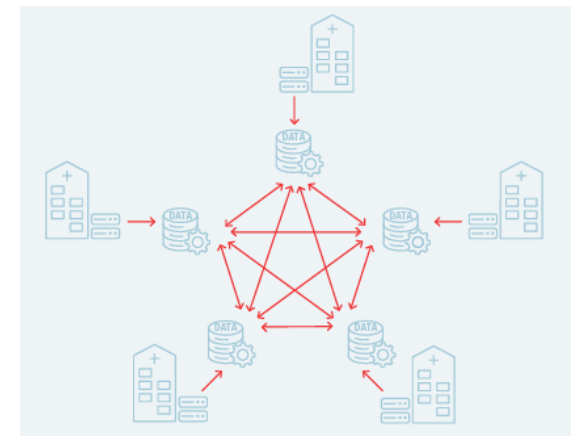
Data Governance Board (DGB) at USZ

Mandate
- Approve requests for reuse of data/ samples
- Assess requests from strategic, ethical, and legal perspectives

Distribution of applications for reuse purposes

6% 44% 50%

- Research Purposes
- Operational or quality
- Other

Circle diagram labels:
- DFL CTC
- DFL Biobanking
- Rechts- dienst
- ICT Data Governance Team
- ADI Daten- managem ent
- Data Protection Officers
- Finan- zen
- ADI Medi- zinische Appli- kationen

DGB **monthly** meetings to:

- discuss complex requests
- harmonize rules (internal/external)

Topics:
- data storage and transfers
- data quality
- data protection issues
- de-identification of data
- General (informed) Consent

Added value of DGB

- Single contact point
- Pannel of experts (regulatory, data protection, legal, data security)
- Comprehensive USZ strategy for reuse of data
- Increased reliability and reproducibility of research
- Central overview and control leads to more transparency

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Conclusions

Conclusions

Responsible/compliant reuse of sensitive health data needs harmonized legal/ethical standards

Secure infrastructure and processes increase data quality and data security

➢ Enhanced Research Credibility, Validity and Reliability

➢ Transparency Boost

Ongoing Challenges:

▪ Dynamic nature of research and innovation: Integration of big data and AI in healthcare

▪ Forward Focus: Continuous adaptation and vigilance

▪ local, national and international perspective

Thank you for your attention

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