

Swiss Personalized Health Network- From clinical (routine) data to FAIR research data

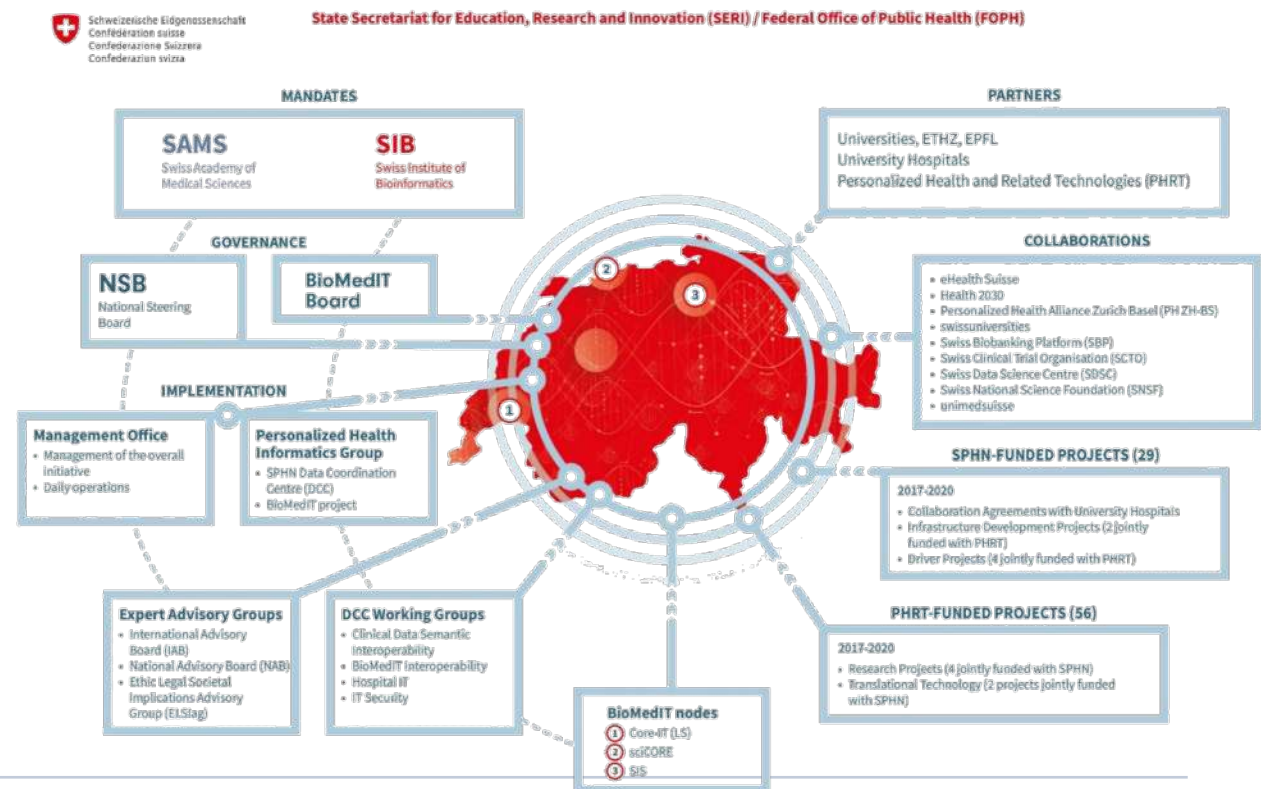
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Personalized health informatics group, SIB Swiss Institute of Bioinformatics

A project of

The Swiss Personalized Health Network

- Government funded infrastructure initiative
- Creation of a scalable and sustainable data-enabling environment
- Enabling researchers to access, integrate, analyze, and share interoperable health data

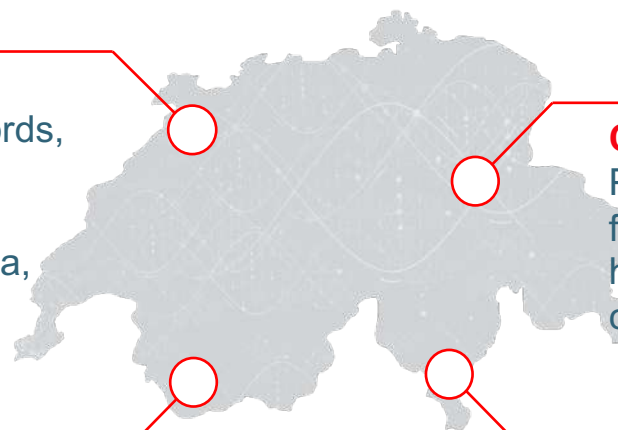


Data types and data sources



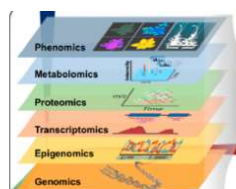
Clinical (routine) data (RWD)

Data from electronic health records, e.g., diagnosis medication, vital signs, procedures, lab values, imaging data, administrative data, etc.



Clinical research data

Patient-oriented study data, e.g., from RCTs, medical and public health registries, longitudinal cohort studies, etc.



Molecular and *omics data

e.g., Genomics, epigenomics, transcriptomics, proteomics, metabolomics, Biomarker, etc.

Healthy citizen data

Tracking apps, wearables, Sensors, life-style data, social media data, etc.



Personal data

Personal data refers to "*all information relating to an identified or identifiable person*" (FADP Art 3)

A person is

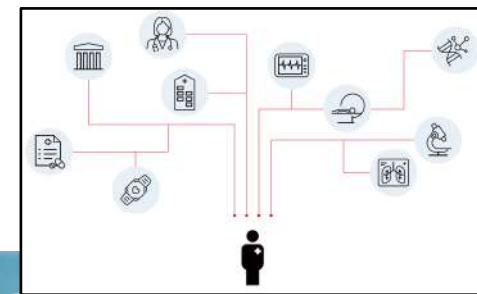
- **identified** → from the information clear that this is the person concerned (e.g., ID document)*
- **identifiable** → can be identified from the circumstances, i.e., **from the context of the information or on the basis of additional information****

*ATF 138 II 346 para. 6.1 = JdT 2013 I p. 71, 77; Swiss Federal Tribunal 4A_365/2017 (n 26) 2018, para. 5; Philippe Meier, Protection des données. Fondements, principes généraux et droit privé, Bern 2011, N 431 p. 201.

**ATF 138 II 346.

Systematic use of large amounts of health data in multi-site research projects: What does it take?

- Detailed legal-architecture and clear responsibilities
- FAIR data
- Strong capabilities in clinical bioinformatics, computational biology, and computational service infrastructure
- High-performance IT infrastructures for big data computing and storage
- Security measures for ICT systems to protect confidential information from unauthorized access, unauthorized use, etc.

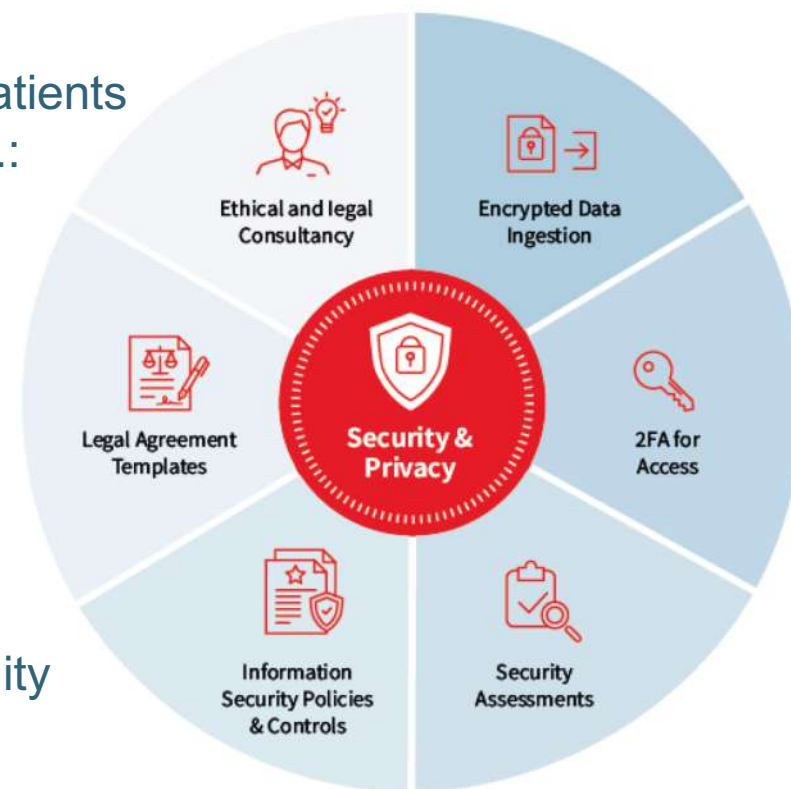


What does security mean?

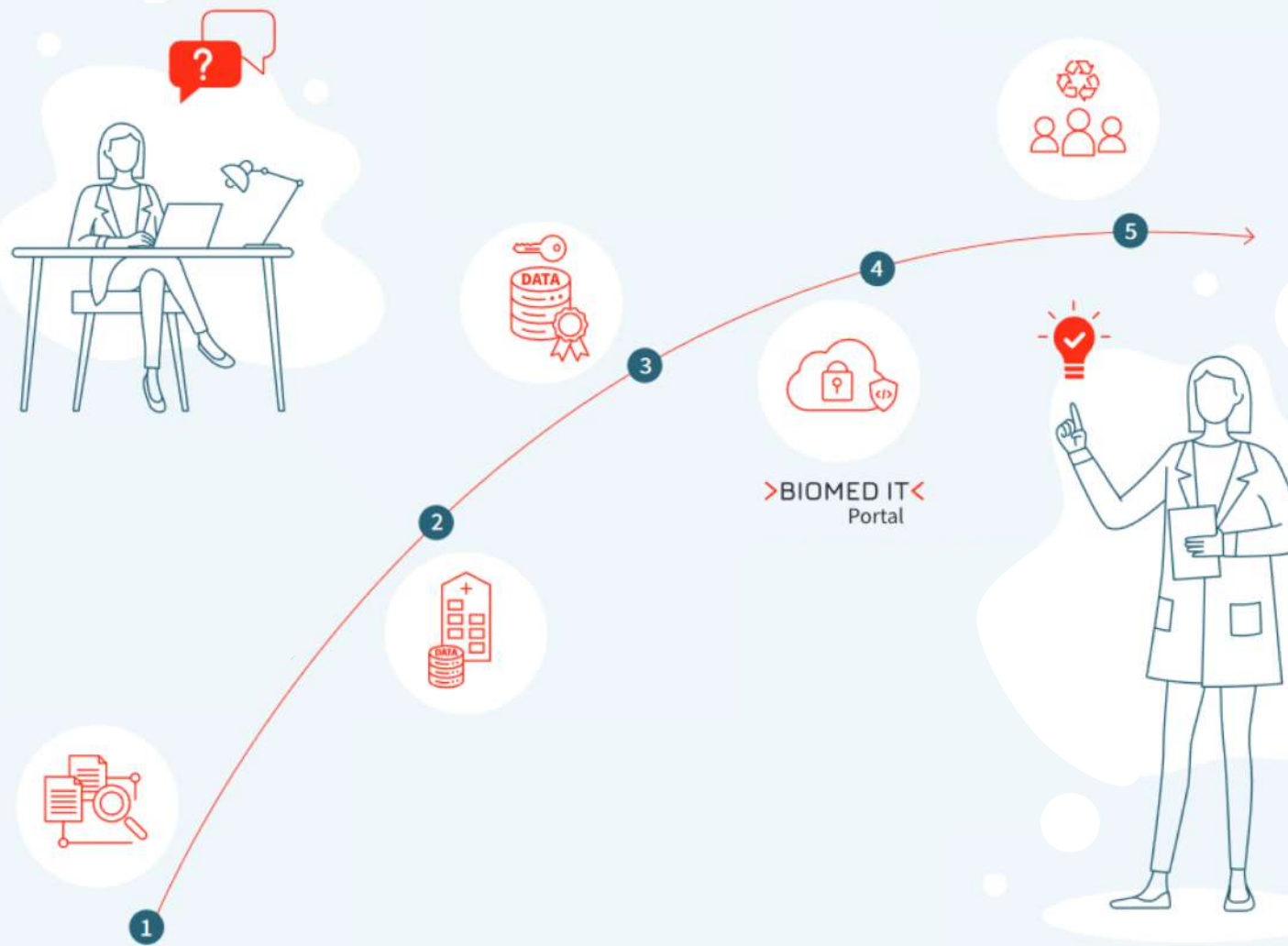
Ensure that data processing protects the privacy of patients and complies with ethical and legal requirements, e.g.:

- Confidentiality: Ensure only permitted people can access data
- Integrity: Prevent unauthorized deletion, modification, combination of data
- Accessibility: Ensure data can be safely and securely accessed when it is needed

→ Implementation needs to be compatible with usability for researchers and trust of data providers

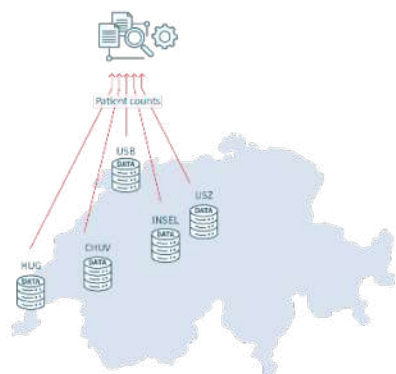


The SPHN value chain



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

Findability and discoverability of data



SPHN Federated Query System:

- Project feasibility, data from all 5 UH searchable with one tool
- > 0.5 million patients (consented data); > 100 million data elements



Swiss cohort **meta-data** in the international Maelstrom Catalogue:

- Metadata of 10 Swiss population-based and disease-specific cohorts
- Full study descriptions searchable with > 145'000 annotated variables

The SPHN value chain



2) Project initiation
Requirements to use the data?

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



1



2



3



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Portal

4



5



Key elements of Data Transfer and Use Agreement

The Data Transfer and Use Agreement (DTUA) is the main written control on how sensitive health data is transferred, processed and exploited in SPHN and BioMedIT.

Elements to be addressed in a data transfer and use agreement



Security measures



No attempt at re-identification



Limitation of the data processing purpose (no use for purposes other than research)



Data subject rights: right of access to data...



Applicable rules to international data transfers



Liability for non-compliance

<https://sphn.ch/services/dtua/>

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?



3



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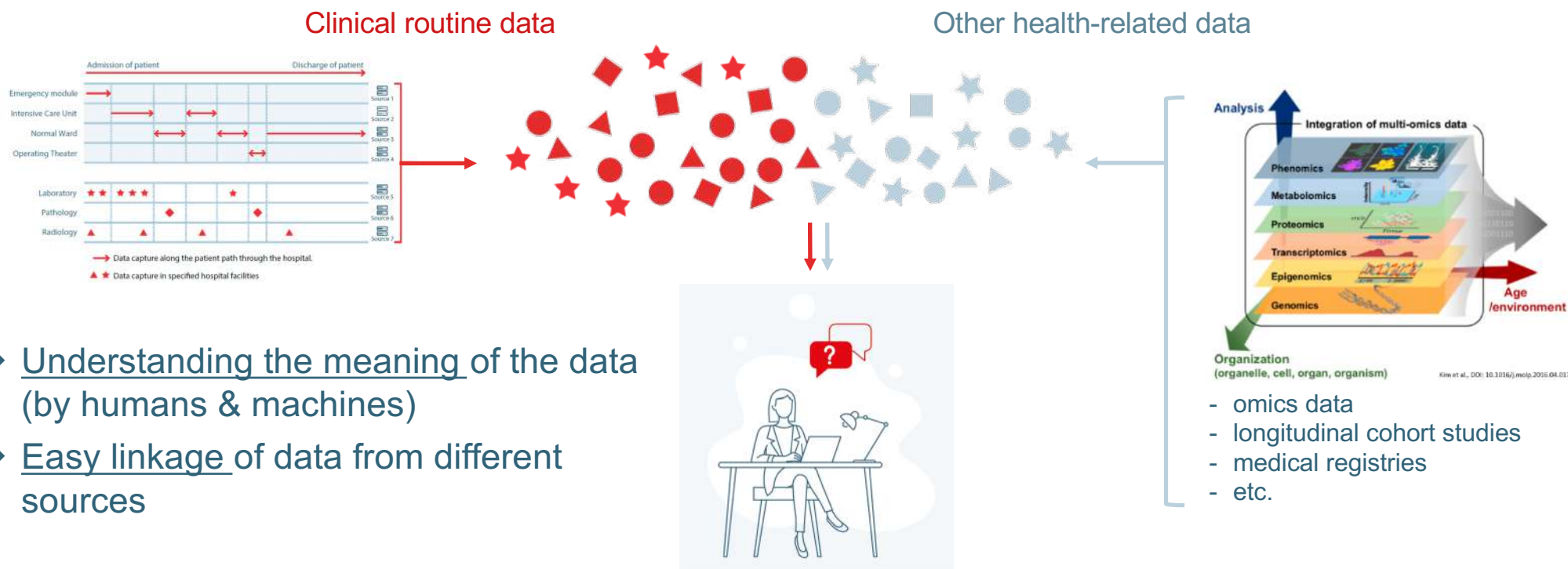
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Diversity of health-related data



- Understanding the meaning of the data (by humans & machines)
- Easy linkage of data from different sources

The SPHN Interoperability Framework: Making sense of data and adding value

Data semantics

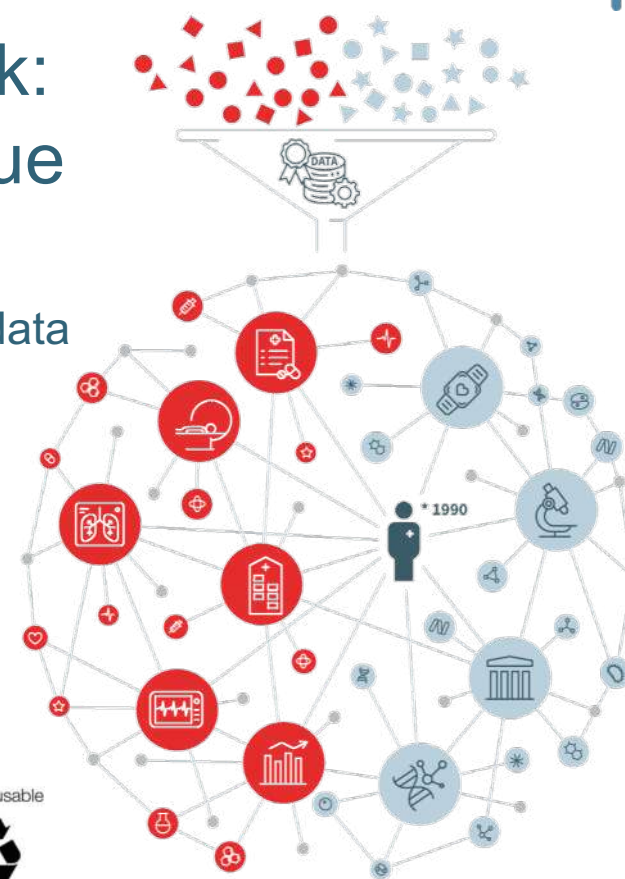
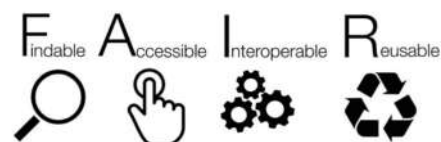
- Use of **controlled vocabulary** for concepts, valuesets and data
- **Data standards**: ATC, SNOMED CT, ICD-10-GM, CHOP, UCUM, LOINC, NANDA, ICD-O,...
- Multi-level coding and mappings

Language for knowledge representation

- **Semantic Web** (RDF Schema)

Quality control framework

- **Semantic Web** (SHACL, SPARQL)



The SPHN value chain

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



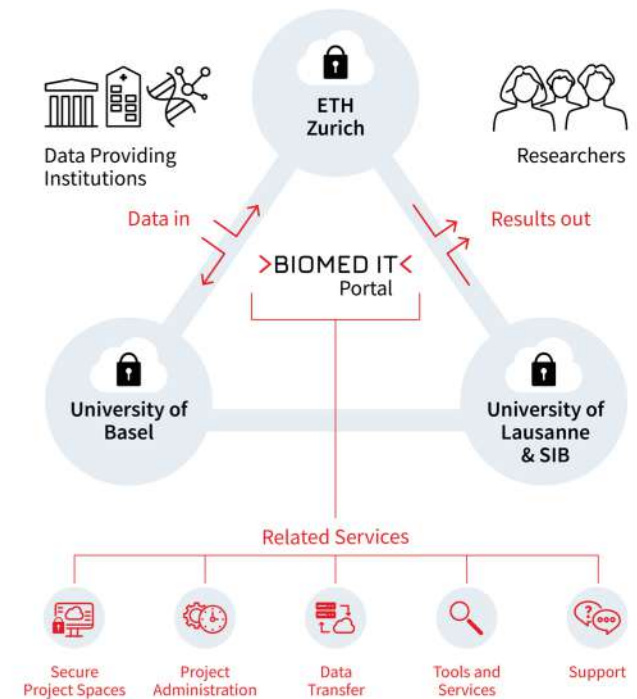
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BioMedIT: Switzerland's Trusted Research Environment

- Secure cloud & HPC: 3 nodes, hosted in CH
- Security by design
- One Information Security Policy
- Allows for the secure mobilization, processing and storage of sensitive research data
- End-to-end encrypted data transfers (via sett)
- Remote access via BioMedIT Portal
- Obligatory training on data protection and IT security



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Federated Compute Projects



Federated confidential data exploration and computing (pilot phase):

- TI4Health in Swiss BioRef: Personalized lab reference ranges
- TI4Health in SPO: Oncology data exploration and survival analysis



Federated machine learning across country borders

- Federated Deep Learning project for Lung GTV automatic segmentation (ARGOS)

Lessons learned and remaining challenges

There are many challenges to face, most are not technical

- Tools and technologies (and money) help, but they only *support* solving problems
- Greater challenges are humans, cultural & organisational habits, particular interests, compliance, etc.

Data harmonization and interoperability is crucial

- Health data is too diverse, cannot automate the problem away
- Standardisation is a slow process, involves all stakeholders of care and research

Federated approaches are required, many groups to align

- Big data means multiple providers (hospitals, tech. platforms, other data sources)
- Modern science means multidisciplinary, collaborating research teams
- Trust is the most important currency in achieving harmonization and collaboration

Lessons learned and remaining challenges

Legal requirements are strict but vague

- Many restrictions, instructions, requirements, interpretations
- No actual guidance and many opinions on *how* to achieve them

– Art. 7 Data security

¹ Personal data must be protected against unauthorised processing through adequate technical and organisational measures.

Security harmonization creates complex engagement between partners

- Technical alignment touches many internal parts of organizations, not just the surface
- Ensure compatibility of policies and day-to-day procedures without central control
- Developing a shared understanding of risks, the means to control them, and the tolerance to accept them in certain cases

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