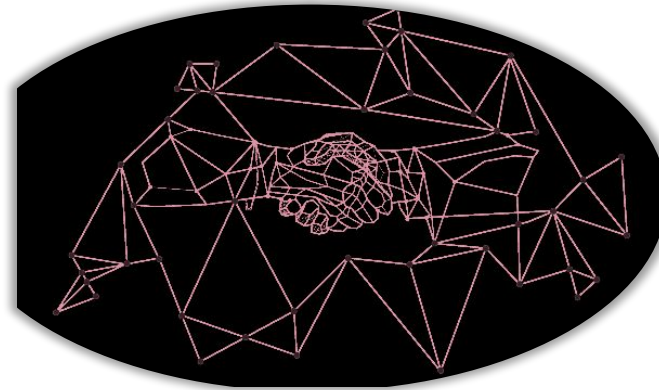


Open Research Data in Health



Prof. Antoine Geissbühler
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United States | Identity medicine

The data hinted at racism among white doctors. Then scholars looked again

Science that fits the zeitgeist sometimes does not fit the data



The Swiss National Open Research Data Strategy (2021)

Vision

- Facilitate **access and reuse** of research data to promote more effective and impactful research for the benefit of society
- Support transparent and **reproducible research** findings
- Foster **collaboration across disciplines**, legal systems and national borders, to enable creativity and innovation

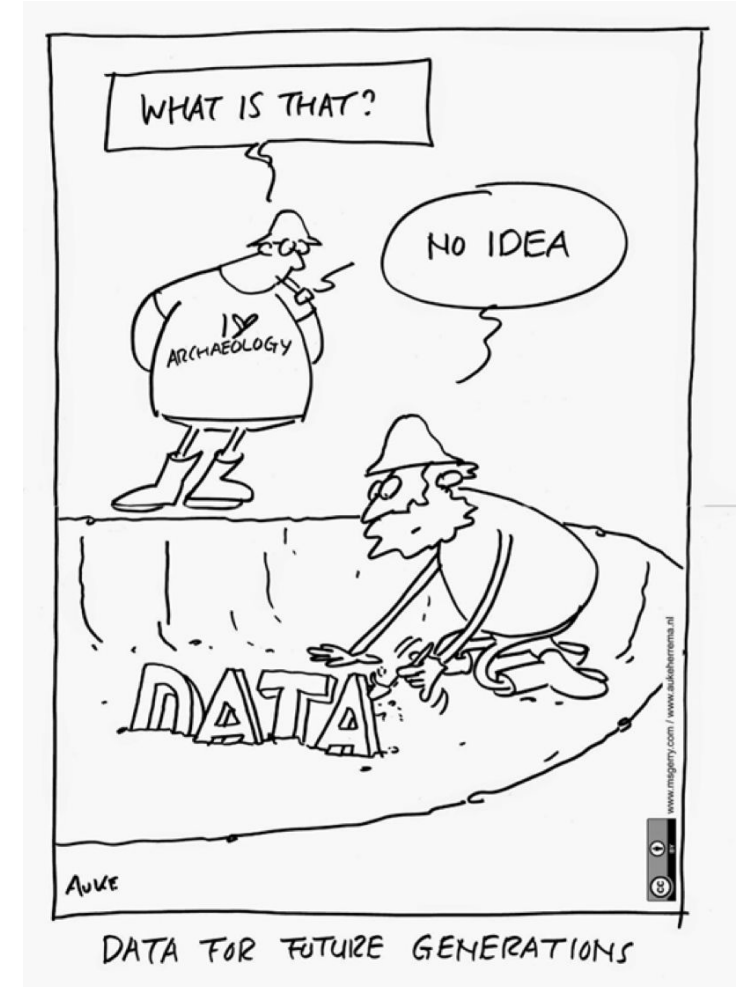


Enable the pooling of data form multiple sources to **increase the sample size** and statistical power of research projects



Guiding principles for the ORD Strategy

1. Upholding **FAIR** principles
2. Good research practice includes **openness**
3. Data should be as **open** as possible, as **protected** as necessary
4. Recognising of the **value** of data
5. Respecting disciplinary **diversity**
6. Connecting to **national and international** ecosystems
7. Pursuing a **sustainable** approach



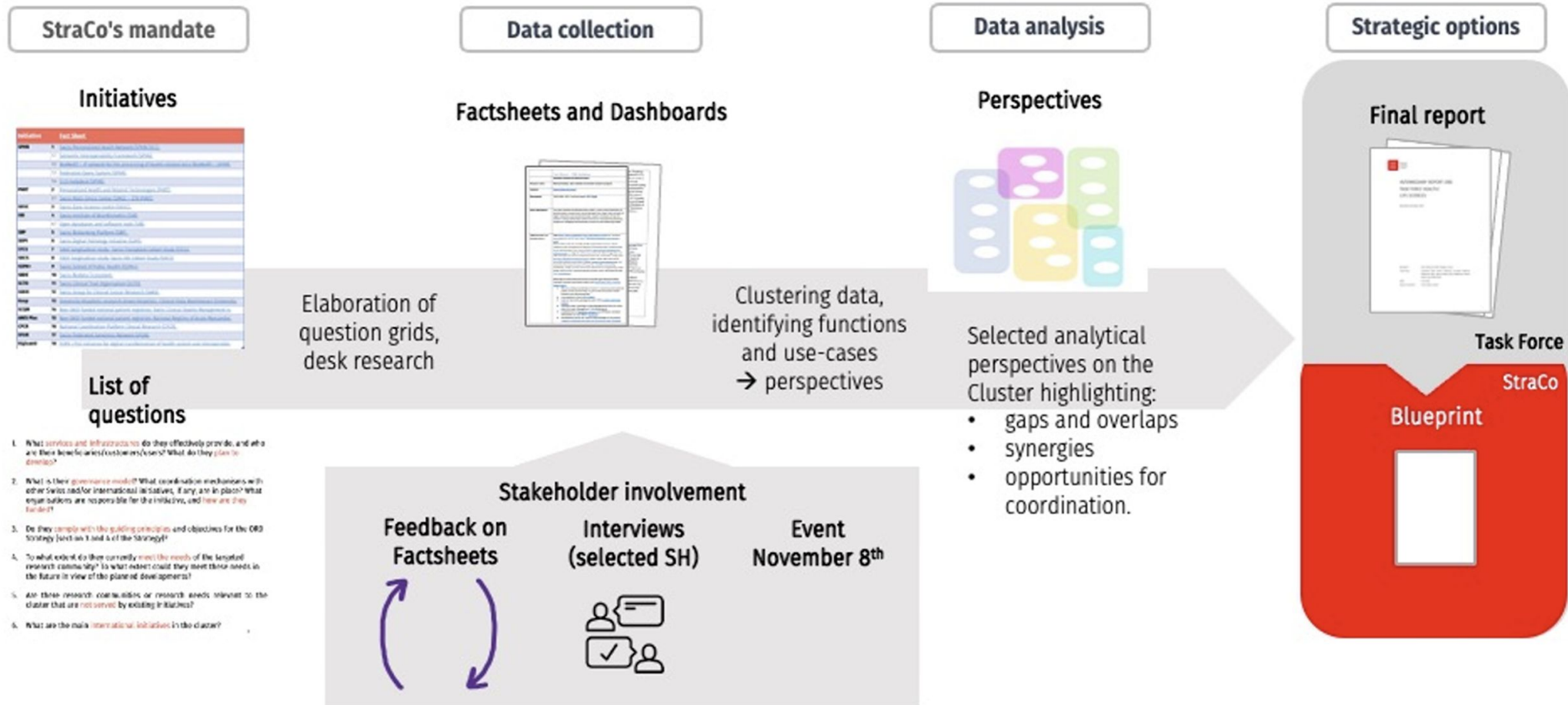
Objectives of the ORD Strategy

- **Support** researchers and research communities in **imagining and adopting** ORD practices
- Develop, promote, and maintain **financially sustainable basic infrastructures and services** for all researchers
- Equip researchers for ORD – **skills development** and exchange of best practices
- Build up **systemic und supportive conditions** for institutions and research communities
- **Govern** the ORD Strategy: ORD StraCo



ORD StraCo Health and Life Sciences Task Force

HLS Landscape Analysis – updated report published in July 2024



ORD StraCo Health and Life Sciences Task Force

HLS Blueprint - consolidate and improve the ecosystem of research infrastructures and services

- **Empower an initiative of national relevance** to operationalize the existing data interoperability framework (DCC) and further develop it for health-related clinical and non-clinical data, in alignment with international standards.
- **Mandate as few as possible key data portals** of national relevance that cover the need for findability of and accessibility to most data in the cluster, driving the federation and improving the quality of HLS repositories.
- **Initiate a national drive for the integration of AI and data science tools** in the HLS cluster, connecting dedicated initiatives of national importance and fostering innovation across existing initiatives.
- **Reinforce the international dimension** in the development of the HLS cluster, promoting international partnerships and attractiveness to global researchers, over the development of local-for-local resources.

ORD StraCo Health and Life Sciences Task Force

HLS Blueprint – propose a governance model that promotes collaboration within the intended strategic framework

- **Establish an HLS ORD Charter/Pact** that defines an overarching vision for the development of the cluster in reference to the StraCo Blueprint and the ORD national strategy, as a tool to facilitate the engagement of HLS actors
- **Organize multilateral governance in the cluster** with research data infrastructures committing to one another on certain services and responsibilities, endorsed by the StraCo and under the common strategic framework of the Charter/Pact

ORD StraCo Health and Life Sciences Task Force

Next steps: from strategy to operationalization of the HLS Blueprint

- Co-develop the strategic orientations **with stakeholders**
- Finalize a vision for the cluster in time for input to be **integrated into the 2029-2032 ERI period**
- Kick-off the **stakeholder engagement process** with an event at the end of 2024 or by early 2025. This event will introduce the Blueprint, gather initial feedback, and form expert groups to further develop the six strategic options over the following months, leading to the creation of the Level B (Operational Level) Blueprint.



Ongoing initiatives:

DigiSanté (FOPH/FSO)

SERI working group on clinical data

Electronic Patient Record (EPD)

SPHN-DCC and the Swiss Health Data Space

Current state of health data in Switzerland

Data sources

Health data are collected in a wide variety of settings, such as routine clinical practice, clinical research, registries and cohorts, or public health surveillance. The major challenges and shortcomings of using these data are the following:

- › The data is stored in silos and therefore highly fragmented
- › The formats, standards and quality of data vary greatly depending on the data source
- › Institution-specific governance processes provide additional challenges for sharing, access and use of health data
- › Data volumes from single institutions are too small to enable big data analyses

Primary use of health data

The primary use of health data is to support the delivery of care to the individual patient and improve the quality of diagnosis and treatment.

Among the obstacles and gaps for an efficient primary use of health data are the following:

- › Large administrative burden on medical personnel
- › The same data are collected multiple times and in different systems during a patient's treatment
- › The lack of digitalization and automatization in the healthcare system
- › The data are siloed in specialized clinical information systems within the same hospital

Secondary use of health data

The secondary use of health data refers to using the data beyond its original purpose of delivering care to the individual patient. Aggregated health data can be used by:

Among the obstacles and gaps for an efficient secondary use of health data are the following:

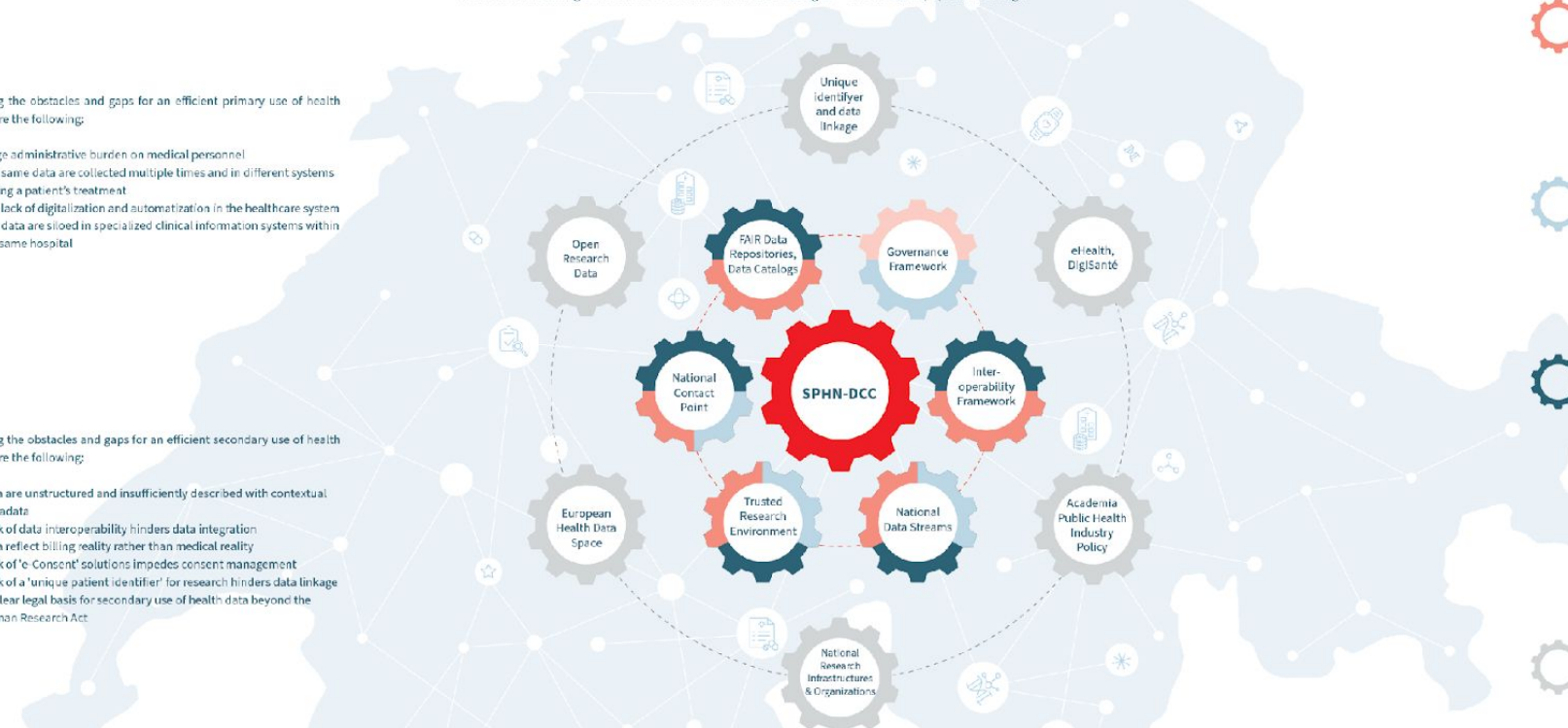
- › Researchers for, e.g., feasibility studies, research (clinical, public health, care or personalized health) and for research within public-private partnerships
- › Administration and regulators for, e.g., policy making, public health initiatives, monitoring and steering, market authorization, and surveillance (e.g. epidemics)
- › Healthcare providers for, e.g., value-based healthcare, quality control, safety monitoring, process improvement and reporting

Interfaces of the SPHN Data Coordination Center with the developing Swiss Health Data Space

In light of the successes of the SPHN initiative and the critical role that the SPHN Data Coordination Center (SPHN-DCC) plays, the SERI has announced that the SPHN-DCC will be consolidated and continued to be funded during the next ERI period 2025-2028.

The SPHN-DCC will continue to be at the heart of FAIR data in the domain of health research in Switzerland, providing services and tools that enable the exchange and use of such data across the country. Its development is part of an evolving research landscape towards 'Open Research Data' and a functional and efficient health data ecosystem. The careful embedding of the SPHN-DCC in the national data strategies

and its interfaces with key partners in the system is an important prerequisite for the success of the desired Swiss Health Data Space. A responsible and efficient secondary use of health data, as promoted by the SPHN-DCC, will not only better serve research, but also advance healthcare processes, policy making, and ultimately benefit patients and the Swiss population at large.



SPHN's key contributions

Governance

- › Common ethical and legal standards and processes for data sharing and management facilitate the access to and the exchange of data
- › A set of legal agreement templates supports researchers with inter-institutional data transfer, access and processing
- › Common risk based de-identification rules support data providers in ensuring data privacy

Interoperability

- › Common data standards and formats defined by the SPHN Semantic Interoperability Framework enable the linking of data coming from different sources
- › Tools and services facilitate and automatize the compliance with interoperability requirements

Process improvement

- › Tools and procedures allow the systematic monitoring and improvement of data quality
- › Time and cost efficient provision of interoperable data through the SPHN Connector
- › Education and training for researchers

Infrastructures

- › SPHN funded the establishment of clinical data platforms in 5 Swiss university hospitals
- › A Federated Query System allows the search for fully anonymized clinical information across 5 university hospitals for feasibility studies
- › BioMedIT provides the technical backbone, related services and information security for data transfers, processing, analysis and storage
- › Provision of privacy preserving and federated analytics technologies
- › National Data Streams build sustainable data infrastructures for high-end data-driven and personalized health research

External contributions

- › The SPHN-DCC interfaces with a number of other research initiatives and organizations to shape the evolving research landscape in Switzerland towards Open Research Data
- › Beyond research, the SPHN-DCC interfaces with the federal administration (e.g., FOPI, FSO), cantons and the health industry

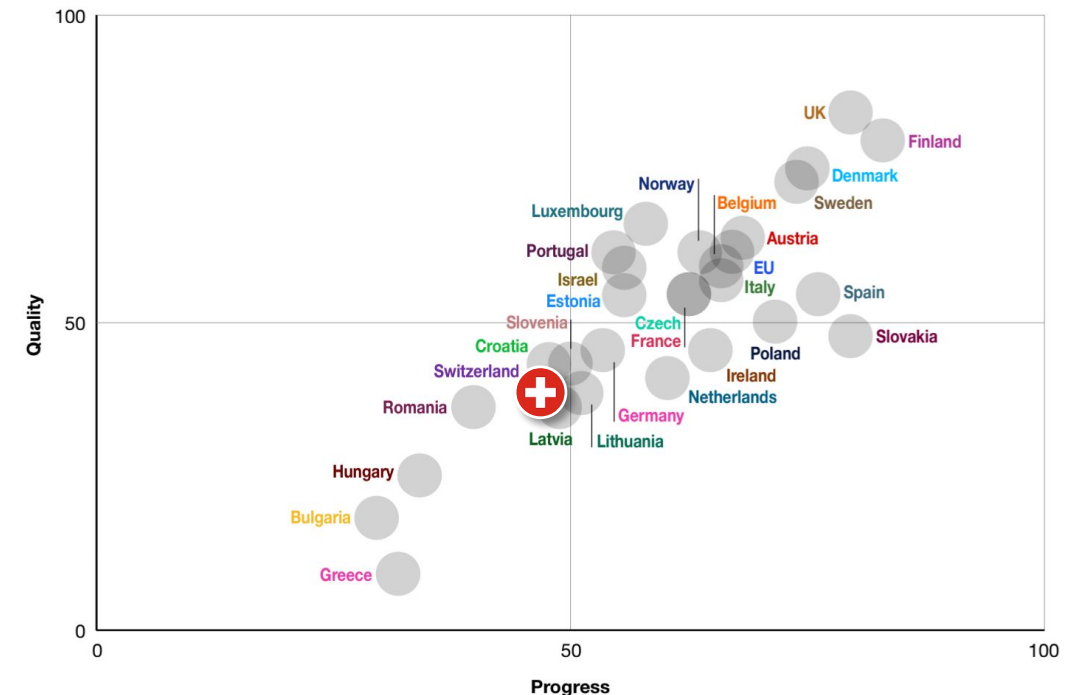
Areas of ORD StraCo – SPHN/PHRT collaboration

Common challenges

- **FAIRification of clinical data** – interoperability framework – data exchange processes – DCC – engagement of data producers
- **Data portals:**
 - Distributed exploration and analysis
 - Swiss Federated Genomics Network & FEQA
 - Swiss Biobanking Platform's NExT
- **Architecture** for integrating data producers, data/AI services and trusted research environments
- **International collaborations**
- **Multilateral governance**

Existing interfaces

- ORD HLS Task Force – SPHN NSB links
- Stakeholder group



Country policy rankings for the secondary use of health data in Europe (Open Data Institute 2021)

towards a positive societal impact

