



How to improve access to sensitive data at the national level

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Changes in the way research is done



Increasing use of data not collected by researchers for research but that already exists (administration, interactions with the Internet, etc.)

Data has to be FAIR

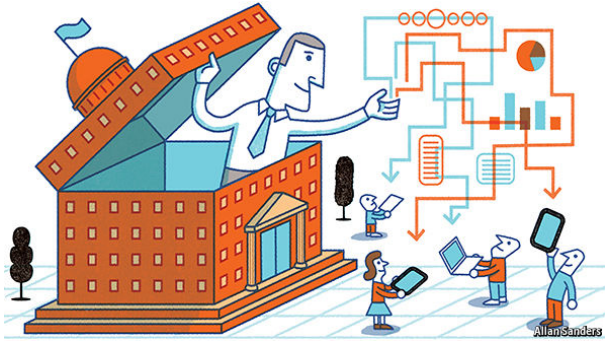


In order to maintain the competitiveness of Switzerland in research, a data policy is needed that,

- Enables the use of administrative data for research;
- If necessary, also regulates access to company data for research;
- Creates the possibility to link and use data in a secure framework.

The current legal situation at the national level

- New **data protection law**, to be in place in 2023. In principle more data protection, definition of highly sensitive data expanded, however some exemptions for research still in place (like in GDPR). How this will influence research in practice needs to be seen.
- **Federal law on statistics and national regulation on data linking**: allows data linking also of sensitive data, conducted by the Swiss Federal Statistical Office. However: must include data from the SFSO, rather complicated procedures especially for data linking.
- New „**Bundesgesetz über den Einsatz elektronischer Mittel zur Erfüllung von Behördenaufgaben (EMBAG)**„.
 - Regulates among other topics open government data: “The administrative units [...] shall make their data [...] which are stored electronically and structured in collections, publicly accessible.” However:
 - “The following shall not be made publicly accessible: a. Personal data and data of legal persons;”
- -> Currently in the parliamentary debate.



Elements of a new (research) data policy



Institutional framework

- Metadata provision;
- Organizations that link and make data usable and provide data protection;
- As well as regulating various other processes (permissions, ethics reviews if necessary, data contracts, re-use, etc.).



Legal framework,

that comprehensively regulates data use and data linkage, e.g. in the form of a research data or digitization law.

Political will



New efforts to improve access to (sensitive) data

- SFSO: “Nationale Datenbewirtschaftung”; New metadata platform for government data <https://www.i14y.admin.ch/>, data linking services.
- Various proposals from the parliament, many in the health sector to get better access to administrative data.
- New motion „Kommission für Wissenschaft, Bildung und Kultur, Ständerat“ for a new „Rahmengesetz für die Sekundärnutzung von Daten“: “The Federal Council is instructed to create the basis in a framework law so that specific infrastructures for the secondary use of data in strategically relevant areas can be quickly initialized and can be set up.” -> Federal Council decided 23 November to support this motion! -> Discussion in the Council of States 14.12.2022.

Possible next steps in Switzerland

- Continue cooperation, especially with the SFSO on how to make data usable for research and how to link data step by step;
- Continue the conceptual work from a research perspective how to link and access sensitive data (existing work “Accessing and linking data for research in Switzerland» November 2020: <https://linkhub.ch/report/>):
 - Institutional models;
 - Legal framework;
 - Possible processes;
 - Funding and governance models.
- Contribute to the public debate especially in the preparation for the implementation of a new “Rahmengesetz” also in the framework of “Netzwerk Future”.



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