

Publication

Sensing the (digital) pulse. Future steps for improving the secondary use of data for research in Switzerland.

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Ensuring that the health data infrastructure and governance permits an efficient secondary use of data for research is a policy priority for many countries. Switzerland is no exception and many initiatives have been launched to improve its health data landscape. The country now stands at an important crossroad, debating the right way forward. We aimed to explore which specific elements of data governance can facilitate - from ethico-legal and socio-cultural perspectives - the sharing and reuse of data for research purposes in Switzerland.; A modified Delphi methodology was used to collect and structure input from a panel of experts via successive rounds of mediated interaction on the topic of health data governance in Switzerland.; First, we suggested techniques to facilitate data sharing practices, especially when data are shared between researchers or from healthcare institutions to researchers. Second, we identified ways to improve the interaction between data protection law and the reuse of data for research, and the ways of implementing informed consent in this context. Third, we put forth ideas on policy changes, such as the steps necessary to improve coordination between different actors of the data landscape and to win the defensive and risk-adverse attitudes widespread when it comes to health data.; After having engaged with these topics, we highlighted the importance of focusing on non-technical aspects to improve the data-readiness of a country (e.g., attitudes of stakeholders involved) and of having a pro-active debate between the different institutional actors, ethico-legal experts and society at large.

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