

Publication

Systemic Fairness for Sharing Health Data: Perspectives From Swiss Stakeholders

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)**ID** 4627451**Author(s)** Geneviève, Lester Darryl; Martani, Andrea; Perneger, Thomas; Wangmo, Tenzin; Elger, Bernice Simone**Author(s) at UniBasel** [Elger, Bernice Simone](#) ; [Geneviève, Lester](#) ; [Martani, Andrea](#) ; [Perneger, Thomas](#) ; [Wangmo, Tenzin](#) ;**Year** 2021**Title** Systemic Fairness for Sharing Health Data: Perspectives From Swiss Stakeholders**Journal** Frontiers in Public Health**Volume** 9**Pages / Article-Number** 669463**Keywords** attribution mechanisms; data sharing; health data; health policy; legislation; systemic fairness**Mesh terms** Hospitals; Humans; Policy Making; Qualitative Research; Research Personnel; Switzerland

Introduction:; Health research is gradually embracing a more collectivist approach, fueled by a new movement of open science, data sharing and collaborative partnerships. However, the existence of systemic contradictions hinders the sharing of health data and such collectivist endeavor. Therefore, this qualitative study explores these systemic barriers to a fair sharing of health data from the perspectives of Swiss stakeholders.; Methods:; Purposive and snowball sampling were used to recruit 48 experts active in the Swiss healthcare domain, from the research/policy-making field and those having a high position in a health data enterprise (e.g., health register, hospital IT data infrastructure or a national health data initiative). Semi-structured interviews were then conducted, audio-recorded, verbatim transcribed with identifying information removed to guarantee the anonymity of participants. A theoretical thematic analysis was then carried out to identify themes and subthemes related to the topic of systemic fairness for sharing health data.; Results:; Two themes related to the topic of systemic fairness for sharing health data were identified, namely (i) the hypercompetitive environment and (ii) the legal uncertainty blocking data sharing. The theme, hypercompetitive environment was further divided into two subthemes, (i) systemic contradictions to fair data sharing and the (ii) need of fair systemic attribution mechanisms.; Discussion:; From the perspectives of Swiss stakeholders, hypercompetition in the Swiss academic system is hindering the sharing of health data for secondary research purposes, with the downside effect of influencing researchers to embrace individualism for career opportunities, thereby opposing the data sharing movement. In addition, there was a perceived sense of legal uncertainty from legislations governing the sharing of health data, which adds unreasonable burdens on individual researchers, who are often unequipped to deal with such facets of their data sharing activities.

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