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Public views on open data health research in Switzerland : Implications for research and policy

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public trust, assessing public perceptions of open data research in healthcare is crucial.

Methods: We conducted 10 focus groups across the German, French, and Italian-speaking regions of Switzerland. We presented participants with real-world examples of open data research in healthcare and guided discussions using a semi-structured format. The topic areas were: (1) using Twitter data to assess public opinion on gene-editing technology, (2) assessment of health policy documents, (3) using Twitter data to predict individual health status and (4) using YouTube data to assess public sentiment on health policies. We assessed our findings using a thematic analysis approach.

Results: Gathering insights from 75 citizens, four major themes emerged: (1) Expectations towards actors and open data research, such as using research findings for societal benefit, and ensuring transparency in data use through informed consent; (2) Supportive measures including communication strategies to raise awareness and inform the public about the use of publicly available data for health research; (3) Concerns about data reuse for purposes beyond the study's objectives, especially for financial gain, and about data validity and privacy, particularly for sensitive health data; and (4) Mitigative measures to minimize harm, such as through the involvement of external oversight committees.

Conclusions: Our findings indicate public support for open data research in healthcare, provided that specific expectations are met. Developing a guiding framework for legitimate open data research in healthcare is a valuable next step, with a focus on enhancing public awareness through communication campaigns and providing oversight measures to foster public trust.

Key messages:

- Open data research in healthcare relies on public data use without explicit consent, which can disconnect the research community from society.
- We found that public support for open data research in healthcare is generally present, however it is also conditional on communication and policy efforts addressing their concerns.

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Public views on open data health research in Switzerland: Implications for research and policy

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Background: The increasing volume of publicly available data offers health researchers opportunities to explore public sentiment through open data research on issues such as vaccination hesitancy and fake news propagation. To ensure ethical conduct and maintain