

User perspectives on sharing self-generated health data

Preliminary findings from the PreNUDGE project

Michael Schön¹, Mona Dür¹

¹Duervation GmbH



Background

Self-generated health data from apps and wearables can support prevention, research and personalised care. Integrating these data into prevention-oriented data infrastructures requires attention to acceptable data use, governance and user participation. PreNUDGE explores how a national platform for the secure use of self-generated health data can be designed in a trustworthy and user-centred way.

Aim

To explore barriers, motivators and acceptance conditions for sharing self-generated health data across different population groups in Austria.

Methods

Design: Qualitative study

Data collection: Focus groups and individual interviews

Groups: Employed adults, patients, students, long-term unemployed persons

Analysis: Meaning condensation according to Kvale

Focus: Barriers, motivators and conditions for acceptance of data sharing

Discussion

The findings indicate that acceptance of self-generated health data sharing is shaped not only by privacy concerns, but also by the anticipated consequences of data use. Different groups may associate different harms with data sharing. Therefore, prevention-oriented data infrastructures should focus less on incentives and more on trustworthy governance, clear communication, granular consent and protection against unwanted secondary use.

Preliminary results

Willingness to share data was conditional and purpose-dependent.

A Perceived legitimacy of data use

Viewed as legitimate

- Medical use
- Scientific research
- Support for prevention

Viewed critically

- Private-sector use
- Profit motives
- Advertisement
- Risk for financial disadvantages



B Key conditions for acceptance across groups

Transparency	Clear information about who uses the data and why
Active consent	Data sharing should require explicit permission
User control	Participants want to decide what is shared
Personal benefit	Sharing should be meaningful or useful
Support for research	Scientific use was often seen as legitimate

Student-specific concerns

Students placed greater emphasis on social risks, including negative comparisons, stigma, and potential exclusion associated with perceived poor performance or behaviour.



Trust matters more than incentives.

People are more likely to share self-generated health data when data use is transparent, purpose-bound, controllable, and protected against misuse.

Implications for platform design



Trustworthy governance



Clear communication



Granular consent



Safeguards against misuse

Project partners



i Preliminary findings – patient data collection still ongoing



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