

Shared-Access Platforms for Behavioural and Affective Data: Requirements and Open Challenges

Giovanna N. Vilaza and Jakob E. Bardram

Department of Health Technology, Technical University of Denmark, Lyngby, Denmark

Research Focus

- **Behavioural and affective data:** personal and physiological data collected passively and actively from smartphones and wearables
- Data can be used for personal self-tracking, but it can also be **shared** with circles of support, clinicians and researchers
- What new dilemmas, opportunities, risks and requirements do shared-access platforms create?



Providing open-access to self-tracked data may bring benefits but may also disclose sensitive and intimate details of users' lives

Findings

Requirements:

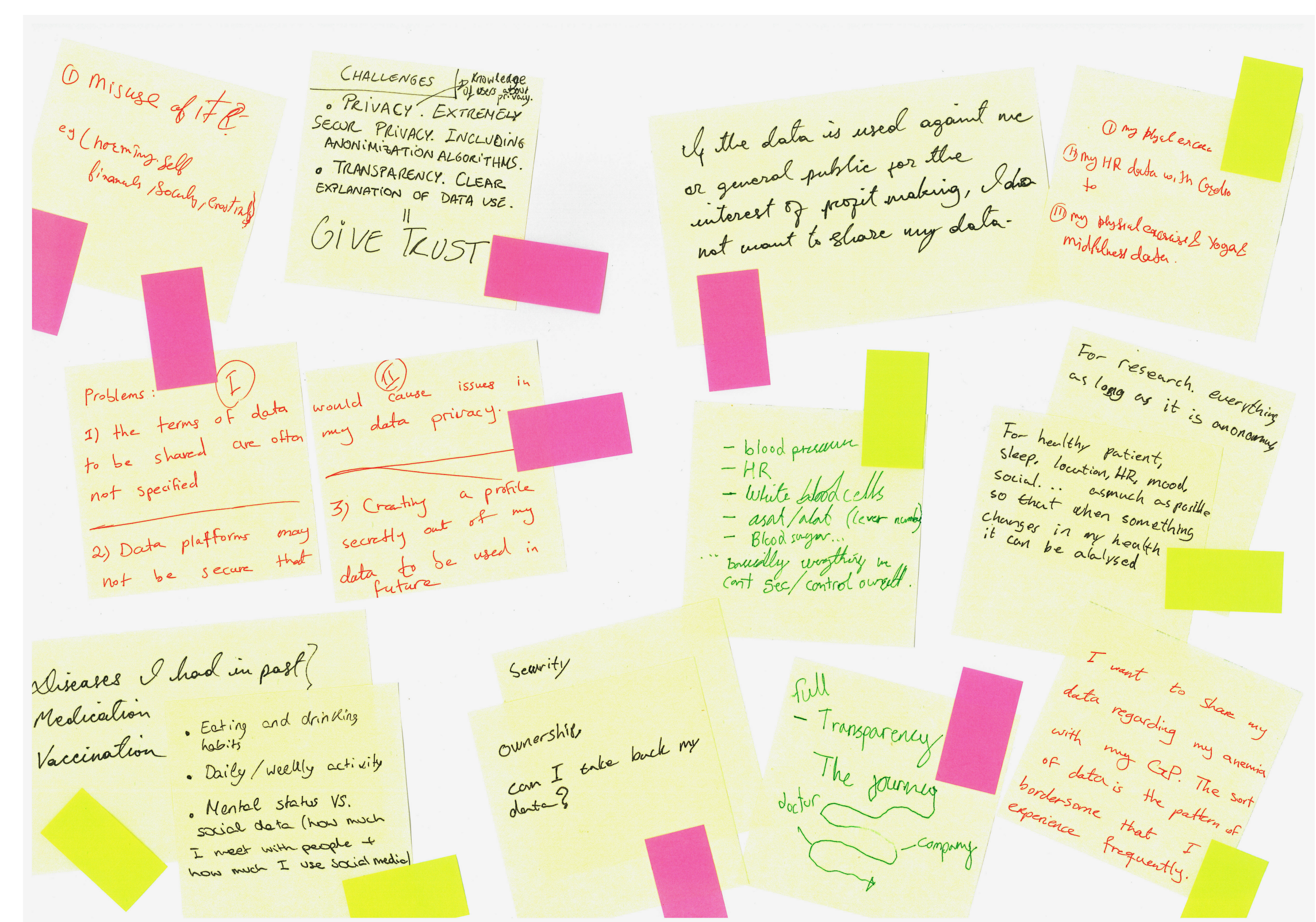
- Sharing has to be beneficial for individuals or society
- More transparency and control over how the data is used now and in the future
- A relationship of trust with those who access the data is required
- Better data protection mechanisms and better communication with users are needed

Open Challenges:

- Data can be misused (for profit of third-parties)
- Some data can bring social stigma (diagnosis)
- Users do not trust current privacy approaches
- Users do not understand the consent terms
- Sharing some data types is not common yet

Previous Research

- It is difficult for users to foresee all the **risks** before sharing data [2]
- The willingness to share data challenges the **needs** of clinicians and researchers [4]
- Issues on how to adequately provide **visual representations** of the data to each user group [1]



Participants' notes during the focus group

Methods

- Focus Group + Future Thinking workshop
- Six participants: developers and designers of smartphone sensing platforms for healthcare
- Semi-structured questions/tasks
- Data Analysis: Thematic Analysis [3]

Future Work

- To investigate how users perceive different **data types**: risks and acceptability
- To review **existing data sharing** applications and practices

References

1. Amid Ayobi, Tobias Sonne, Paul Marshall, and Anna L Cox. *Flexible and mindful self-tracking: Design implications from paper bullet journals*. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*, page 28. ACM, 2018.
2. Jaspreet Bhatia and Travis D Breaux. *Empirical measurement of perceived privacy risk*. *ACM Transactions on Computer-Human Interaction (TOCHI)*, 25(6):34, 2018.
3. Virginia Braun and Victoria Clarke. *Using thematic analysis in psychology*. *Qualitative research in psychology*, 3(2):77–101, 2006.
4. Christina Kelley, Bongshin Lee, and Lauren Wilcox. *Self-tracking for mental wellness: understanding expert perspectives and student experiences*. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, pages 629–641. ACM, 2017.