

Social Dimensions of Health Data Sharing

Attitudes, Influencing Factors, Motives, and Incentives

Elias Kühnel¹, Felix Wilke^{1*}, Sven Bock^{2*}

¹Chair of Sociology in Social Work, Ernst-Abbe University of Applied Sciences Jena, ²Institute of Data Science, German Aerospace Center (DLR) Jena

*Contact: felix.wilke@eah-jena.de; sven.bock@dlr.de

1 Introduction & Background

- **Health data** is becoming **increasingly important** for **medical progress**, but it is also a subject of contentious public debate.
- A **vast amount of data** is available but remains **untapped**, especially in the healthcare sector, due to a lack of secure infrastructures to share health data.
- In order to fully realize the potential of health data, technical solutions must be supported by **public acceptance**.
- This project explores **people's willingness** to share health data depending on their **social background, motives, and perceived risks and benefits**.

2 Methods

Survey: public attitudes

- Germany-wide cross-sectional survey
- Computer Assisted **Telephone Interview (CATI)**
- Stratified random sample
- Field phase: **December 2023**
- **Participants:**
 - Persons residing in **Germany** with an age varying from **18 – 60** years
- **Statistical Analysis:**
 - successive multiple linear regression
 - cluster analysis

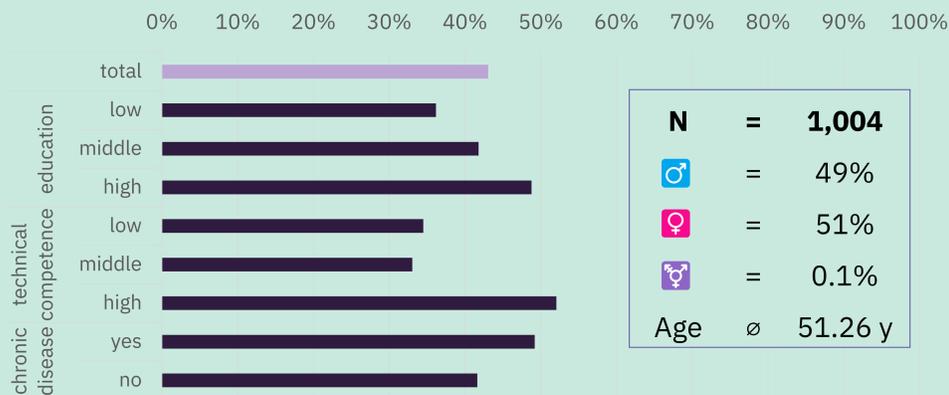
Workshop: Incentives

- Goals**
 - Verifying incentives collected from the survey & obtaining **feedback** about the app demonstrator
- Participants**
 - ♂ = 3 ♀ = 3
- Professions**
 - mechanic, student, engineer, OKR social scientist, nursing assistant
- Group Discussion
- Introduction Application
- Structuring of Risks and Incentives

3 Willingness of Health Data Sharing

- about **43%** are (rather) willing to share their health data with **public research institutions**; about **29.5%** with **private research institutions**
- low willingness to share health data with commercial companies (**small and medium-sized companies: 23.5%; technology companies: 17.5%**)

Willingness to share health data with public research institutions by individual characteristics (%; yes definitely / rather yes)



*data weighted by age group, gender, region (East/West Germany), country of birth, education, and municipality size

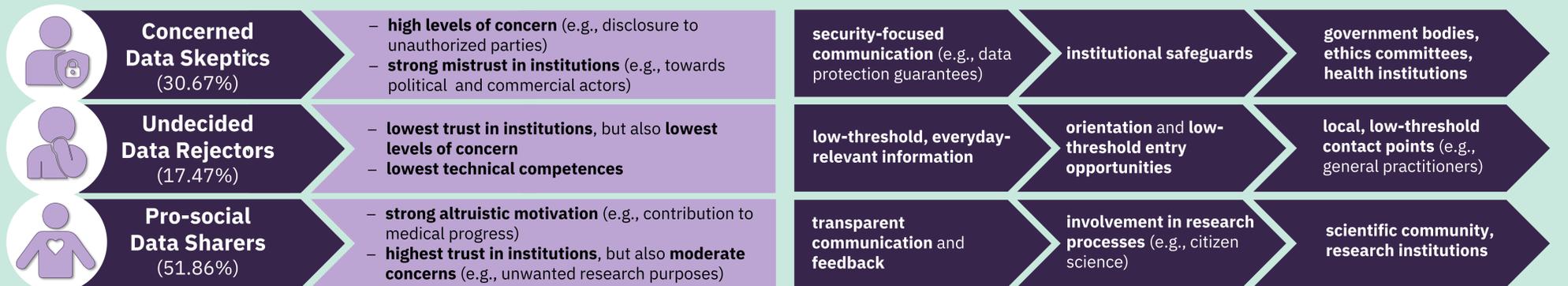
4 Influencing Factors

... on the Willingness to Share Health Data



5 Factors Matter Differently

Appropriate Framework Conditions for Different Types of People



6 Example: How to Turn Enabling Factors into Incentives

