

# Attitudes and opinions towards health data sharing in the Austrian population: a mixed-methods study

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## 1. Introduction

Routine health data collection is indispensable for sustainable, efficient, and acceptable health systems (OECD 2019a, op. 2017, 2017, 2019b, 2019c). While administrative health data are collected automatically - for example, through the use of the social health insurance card (eCard) - the routine collection of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), i.e. people's subjective health status and experiences used as quality indicators, relies heavily on voluntary participation in self-administered surveys. Successful data collection depends therefore on social acceptability, which can go both beyond or below of what is legally possible (Taylor und Taylor 2014; Kalkman et al. 2022; Carter et al. 2015).

Previous research has shown that the Austrian population is more reluctant to share their health data compared to other European countries (Patil et al. 2016), and that among those who a priori prefer not to share their data, the reason for data use was rated the most important attribute to data collection (Biasiotto et al. 2023). In this study, I will thus investigate preferences regarding the sharing of PROMs and PREMs in Austria. The research question is: **How does the purpose of data collection influence the willingness to share patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) in Austria?**

To this end, I will combine qualitative narrative interviews with quantitative survey data to provide a deeper understanding of why people in Austria may be reluctant to share their health data and what interventions may alleviate their hesitancy. The aim of this paper is to contribute to the current discussion about preferences for digital health data sharing (Kalkman et al. 2022; Biasiotto et al. 2023) and to potentially inform policymakers in effectively implementing future policies, such as the European Health Data Space (European Commission 2023), or achieving national goals, such as the use of PROMs and PREMs as health system performance indicators (Jillian Oderkirk 2021; OECD 2019b).

## 2. Methods

This is a mixed-methods study using survey data collected in Austria (N=1260) and 15 narrative interviews with representatives of the public and health data experts. The methodological model is a combination of an instrument development design and a follow-up explanations variant (Creswell et al. 2004; Creswell und Plano Clark 2018; Creswell 2014; Enosh et al. 2015; Ivankova et al. 2006):

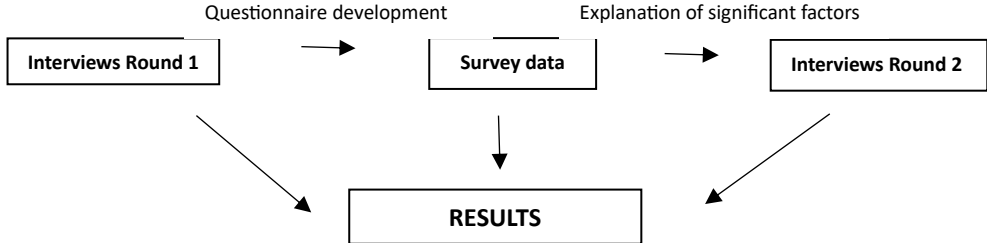


Figure 1: Methodological mixed- methods model

15 semi-structured, narrative interviews were conducted using maximal variation sampling according to age, education, gender, and knowledge about health data. Recruitment for the qualitative interviews occurs through the personal and professional network, with always at least two degrees of separation.

The survey data was collected from the Austrian population aged 18-70 in 2024 via an online survey by the recruitment service marketagent. Participants were sampled to represent the Austrian population in terms of age, gender, educational status, and region.

Survey participants were shown examples of PREMs and PROMs and then asked to indicate with which recipient and for what purpose they would share their answer with. After answering some open questions about their opinions and experience with health data, interviewees were given the same questions as the survey respondents, with the possibility to indicate their reasoning behind their answers. Thematic analysis was applied on the qualitative data to extract experiences and opinions that motivates people's willingness to share self-reported health data, and Wilcoxon rank-sum tests were used on the quantitative data to estimate differences of willingness to share between various recipients and usage of data.

### 3. Preliminary results

Respondents were more willing to share PREMs than PROMs ("rather yes" vs. "rather no",  $p < 0.001$ ). One explanation given in the interviews is that since PROMs capture people's health state, they are more personal and convey sensitive information, so a personal relationship and trust with the recipient is important. In contrast, PREMs were compared with administrative data because sharing what experiences were made with the healthcare system and providers would provide information about them, not about the person responding to the survey.

In terms of sharing PROMs, people were most likely to share with their general practitioner (81%) and least likely to share with private companies (7%). Purposes of self-reported health data collection that were identified as facilitators in the interviews were improving personal care and the health system, while barriers were use for profit and fear of negative consequences for the person sharing.

### 4. Discussion

The results suggest that the reason for data collection and analysis is essential to motivate people to share self-reported data. Therefore, to increase social acceptability, the purpose of data collection should be clearly communicated. In addition, the collection of PROMs needs to be handled with more care and sensitivity than the collection of PREMs, as in addition to the reason for data collection, the recipient is also important in motivating people to share.

## 5. Literature

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