

# The willingness to share patient-reported measures 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, 2017a, 2017b, 2019b, 2019c). While administrative health data is collected automatically – e.g. when the social health insurance card (eCard) is used – the routine collection of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), i.e. people's subjective health state and experiences used as quality indicators, relies heavily on voluntary participation in self-administrated 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. The research questions are: **1) What differences exist between the willingness to share patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) regarding recipients and the purpose of data collection? 2) What are potential reasons for these differences?**

To this end, problem-centered interviews were combined with survey data to provide a deeper understanding of in what scenarios people in Austria would share their health data, what factors play a role in reaching a decision, and what interventions could possibly increase the willingness to share health data. 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 (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, providers, 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 displays the methodological model and the relationship between the data sources.

### 2.1 Ethics

An approval for this study was obtained in 2023 as part of the PRÖMs-project from the Ethics Committee at the Vienna University of Economics and Business (REF: WU-RP-2023-015). No personal data was collected, and all participants took part voluntarily. All interviewees provided written informed consent about the recording of the interview, data use, and storage.

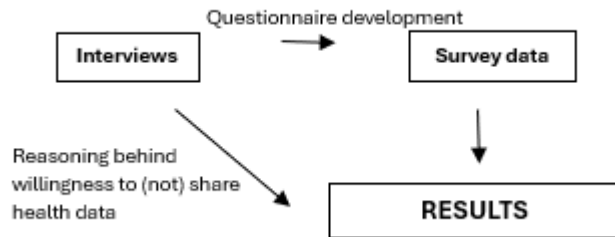


Figure 1: Methodological model

## 2.2 Problem-centered interviews

An interview guide was developed containing open-ended questions about experiences with and opinions and attitudes towards sharing of health data, and closed ended questions containing the same questions that were later on used in the questionnaire (Scheibelhofer 2008). For the second part, participants were shown examples of PREMs and PROMs and later asked to answer the questions about whether they would be willing to share them. In addition, they were asked to provide their reasoning behind their answer.

Maximal variation sampling was used to capture opinions of people that differ in age, education, gender, and type of stakeholder (i.e. patient, provider, or system representative). The recruitment process for the qualitative interviews was conducted through the personal and professional networks of the researchers, with a minimum of two degrees of separation between each participant and the interviewer. Additionally, the interviewer and interviewee were required to have no prior contact prior to the interview. New participants were recruited until different viewpoints were represented, i.e. a point of saturation or redundancy was reached to ensure all the information was covered, and that contradicting opinions are represented.

Participants were contacted to schedule an appointment for a personal meeting at a place of their choice (e.g. a café or a meeting room at the Vienna University of Economics and Business) or an online video call to conduct the interview. Interviews were conducted between myself and the interview partner and lasted 40-60 minutes. The recordings were password-protected and stored on a secure drive. Any information that could lead to identification of the participants such as the interviewee's name were replaced with a pseudonym during transcription. Participants that took part in the interview outside their working hours were given EUR 20 as compensation. Handwritten notes were taken during the interview to capture any additional thoughts and impressions to the transcribed interview. The transcripts and notes were compiled in Microsoft Word.

The unit of analysis is the individual participant. First, attribute coding was used to map characteristics of the participants. Second, the Framework Method (Ritchie and Lewis, 2003; Gale et al. 2013) was used to compare and contrast reasons for and against health data sharing across and within recipients and interviewees.

## 2.3 Questionnaire

The questionnaire was an online self-reporting instrument facilitated by the ISO 20252- certified recruitment service marketagent ([Marketagent.com - online Marktforschung](https://www.marketagent.com)). 1260 observations were gathered from a pool of 170.000 people using quota sampling for the Austrian population aged 18-70 in terms of age, gender, region, and educational background.

As there was no existing validated questionnaire fitting the study's purpose, I created a new one by conducting a literature search and using the information gathered during the narrative interviews. The questionnaire was tested among experts in the field of Socioeconomics and Health Economics to ascertain face validity and objectivity. The questionnaire was further tested through seven cognitive interviews with people of various age, gender, educational background, and levels of German to ensure that the length was appropriate and the structure and questions easy to understand and fill out.

Previous studies have identified a number of barriers and facilitators to health data sharing (e.g. Cumyn et al. 2023; Kalkman et al. 2022; Naeem et al. 2022). In addition to the problem-centered interviews, the questionnaire was thus informed by similar studies, including surveys of the public and patients' perspectives on health data sharing. Some questions were directly taken from other surveys, while others were informed by similar studies and adapted to the Austrian context. The result was a list of different scenarios by varying recipients, the type of data and differences in benefits (i.e. direct, indirect, and no benefit) arising for the person sharing the data (see Box 1). To provide a better

**Question 20: With whom would you share the answers given above about your state of health and well-being?**

- a) With family and/or friends to inform them about my state of health.
- b) With my general practitioner to support him/her in my treatment/diagnosis etc.
- c) With doctors in public or religious hospitals to support them with my treatment/diagnosis etc.
- d) With doctors in private hospitals to support them with my treatment/diagnosis etc.
- e) With doctors to help other patients with similar complaints.
- f) With other healthcare staff (e.g. nurses, paramedics) to support them with my treatment.
- g) With social health insurances (ÖGK, BVAEB, SVA, etc.) so that they can improve the planning, quality and efficiency of the healthcare system.
- h) With researchers from public universities/research institutes so that they can improve healthcare and medical care.
- i) With private companies (e.g. insurance companies, Google, Apple, etc.) so that I can use their products (e.g. life insurance, apps, smart watch).
- j) With private pharmaceutical companies so that they can develop and improve medicines.

**Question 29: With whom would you share the answers given above about your experiences with doctors and the health system?**

- a) With my general practitioner so that he/she can improve the planning, quality and efficiency.
- b) With doctors in public or religious hospitals so that they can improve the planning, quality and efficiency.
- c) With doctors in private so that they can improve the planning, quality and efficiency
- d) With social health insurances (ÖGK, BVAEB, SVA, etc.) so that they can improve the planning, quality and efficiency of the healthcare system.
- e) With researchers from public universities/research institutes so that they can improve healthcare and medical care.

*Box 1: List of scenarios with varying recipients, type of data, and benefits arising for the data sharer.*

understanding of the type of data that is investigated, the participants were asked to fill out PROMs before answering question 20 and PREMs before answering question 29.

To ensure consistency in the responses, a four-item Likert scale was employed to assess the respondents' willingness to share data (no, rather no, rather yes, yes). This is an adaptation of the 5-point Likert scale used in similar studies (Shah et al. 2019; Patil et al. 2016; O'Brien et al. 2019). To

assess willingness to share, the neutral or middle point was excluded as previous studies have demonstrated that including a neutral point can influence people’s answers. Consequently, a neutral position should only be included if a neutral position exists (Faulbaum et al. 2009). In this case, one cannot share or not share at the same time.

Rstudio version 2023.09.0 was used for all quantitative data analysis. Descriptive tables of non-responses to PREMs and PROMs were used to provide an insight into revealed preferences for sharing, and graphs were used to describe stated preferences for sharing PROEMS. A Wilcoxon rank test was used to assess whether the differences in willingness to share PROMs and PREMs differ significantly between recipient and purpose of data collection.

### 3. Quantitative Results

#### 3.1 Willingness to share patient-reported outcome measures

As shown in Figure 2, willingness to share patient-reported outcome measures varied by recipient and type of service. Most participants (81%) said they would be willing to share PROMs with their GP to improve their own treatment and diagnosis, and 69% would share PROMs with their GP to help others. The willingness to share PROMs with public universities or research institutes (49% 'yes' or 'rather yes') and social health insurance (47% 'yes' or 'rather yes') was split between recipients. The majority of participants would not or would not share their PROMs with a pharmaceutical company (73%) or with private companies (85%).

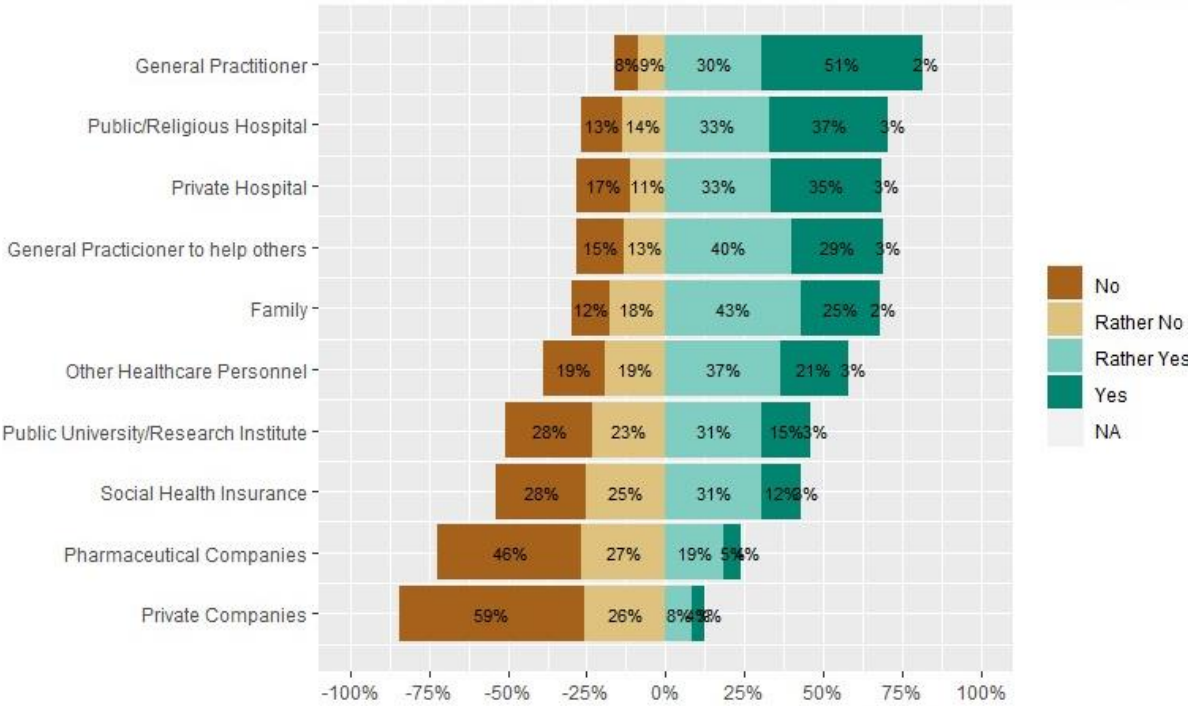


Figure 2: Willingness to share patient-reported outcome measures

#### 3.2 Willingness to share patient-reported experience measures

As visible in Figure 3, the willingness to share patient-reported experience measures varied between the recipients. Most participants (81%) said they would be willing to share PREMs with their GP, but compared to PROMs, more people said they would be somewhat rather than fully willing to share PREMs (35% compared to 30%). The majority of participants would share their PREMs with both public and private hospitals, but public hospitals were preferred. Compared to PROMs, fewer people said they were fully willing to share PREMs with hospitals. The willingness to share PREMs with public universities or research institutes (53% 'yes' or 'rather yes') and social health insurance (55% 'yes' or 'rather yes')

was again split between recipients, but overall more people were willing to share PREMs with these institutions compared to PROMs. The majority of participants would not or would not share their PROMs with a pharmaceutical company (73%) or with private companies (85%).

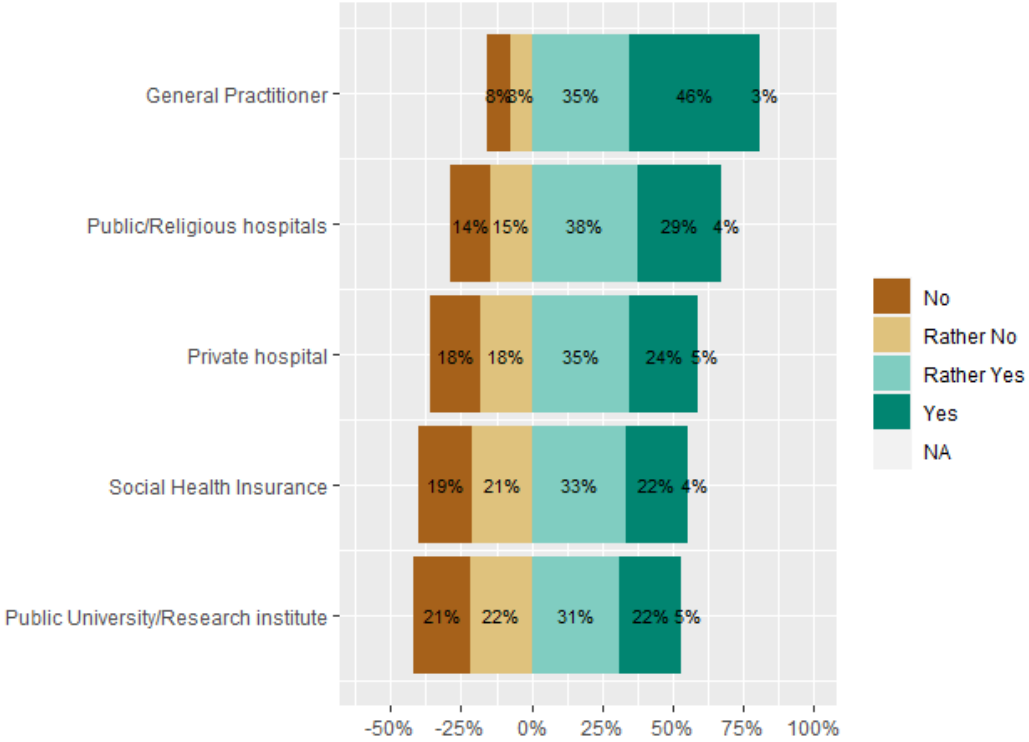


Figure 3: Willingness to share patient-reported experience measures

### 3.3 Comparison of PROMs and PREMs

As can be seen in Table 1, the willingness to share PREMs and PROMs varies significantly across all recipients at the 95% significance level. There are medium effect sizes for the difference between sharing PROMs or PREMs with the general practitioner and with public and private hospitals. Participants were significantly less willing to share PREMs with healthcare providers compared to PROMs. However, they were significantly more willing to share PREMs than PROMs with public universities and social health insurance. The effect sizes for the difference between sharing PROMs and PREMs with the university and social health insurance were large.

Table 1: Wilcoxon Signed-rank tests

	Wilcoxon Signed Rank Test	Median
<b>General Practitioner</b> W p-value Effect size	782814 0.06113 0.49	PROMs: Yes (1) PREMs: Rather yes (2)
<b>Public/ Religious Hospital</b> W p-value Effect size	687082 <0.001 0.43	PROMs: Rather yes (2) PREMs: Rather yes (2)
<b>Private Hospital</b> W p-value Effect size	641166 <0.001 0.40	PROMs: Rather yes (2) PREMs: Rather yes (2)
<b>Public University/ Research Institute</b> W p-value Effect size	818669 <0.001 0.52	PROMs: Rather no (3) PREMs: Rather yes (2)
<b>Social Health Insurance</b> W p-value Effect size	862540 <0.001 0.54	PROMs: Rather no (3) PREMs: Rather yes (2)

#### 4. Qualitative Results

##### 4.1 Framework

Applying the framework to the qualitative data revealed that respondents weighed several factors. The decision to share or not share health data was discussed along the following dimensions: data recipient, purpose of data collection, type of data shared, usefulness of data collection, benefits, risks, and mode of data collection. In addition, personal traits such as the readiness to reveal personal data were mentioned as reasons for or against sharing (see Table 2). No respondent used all dimensions, but often several dimensions were used simultaneously and weighted against each other. An example of this argumentation process is illustrated by interviewee 15, who argues that he would share the number of steps taken during the day, because it is not sensitive, unlike medical records (type of data), he does not see how the data can be misused (no risk), and if it is useful:

**Interviewee 15:** *“So I have less of a problem with the pedometer, yes, that's information, um, I wouldn't know how you can do anything bad with it. If it's useful, you're welcome to use it. Um, it would be different if, as I said, my blood results were accessed, or my medical records.”*

Interviewee 6 discusses whether he would share his health data with the social health insurances and pharmaceutical companies. He assumes that the data would not be anonymized when pharmaceutical companies use it (risk of identification) and considers people working at the Austrian social health insurance as incompetent (recipient), but considers sharing data with this recipient as purposeful:

**Interviewee 6:** *“I'd be a little more uneasy about pharmaceutical companies. And with social insurance, it's a political story. The way it is now with the ÖGK and the incompetent people they've put in there, partly, and I find that a bit more difficult because on the whole I take it as a good thing, let's put it that way, because I suspect that it's going to be sorted out. But with pharmaceutical*

companies...yes...actually too. I assume that they don't come to pharmaceutical companies completely anonymised...otherwise it wouldn't matter at all. But if they get my address or telephone number, I'm not happy, for example."

Table 2: Overview of dimensions considered when deciding whether to share health data - derived from problem-centered interviews

<b>Dimensions</b>	<b>Considerations</b>	<b>Examples</b>
<b>Recipient</b>	Who collects the data?	<ul style="list-style-type: none"> <li>• Public/private institution</li> <li>• What kind of company/university</li> </ul>
	What is my attitude towards them?	<ul style="list-style-type: none"> <li>• Intentions</li> <li>• Competence</li> <li>• Data usage</li> <li>• Relationship with recipient</li> <li>• Trust</li> </ul>
<b>Purpose</b>	What is the data collection for?	<ul style="list-style-type: none"> <li>• Improving my diagnosis/treatment</li> <li>• Improving healthcare system</li> <li>• Profit generation</li> </ul>
	Do I agree with the purpose?	
<b>Type of data</b>	What kind of information is disclosed?	<ul style="list-style-type: none"> <li>• Personal</li> <li>• Sensitive</li> <li>• Level of detail</li> <li>• Type of experience made</li> </ul>
<b>Usefulness</b>	Can the purpose be fulfilled given the data and the recipient?	
<b>Benefits</b>	Do I benefit?	<ul style="list-style-type: none"> <li>• Directly</li> <li>• Indirectly</li> <li>• Not at all</li> </ul>
	Do I agree with this?	
<b>Risks</b>	Are there any risks connected to sharing this information?	<ul style="list-style-type: none"> <li>• Data leakage</li> <li>• Data is passed on</li> <li>• Data used against sharer</li> <li>• Identification</li> </ul>
<b>Mode</b>	What do I have to do?	<ul style="list-style-type: none"> <li>• Time</li> <li>• Effort</li> </ul>
<b>Personal traits</b>	How willing am I to share data?	<ul style="list-style-type: none"> <li>• Openness</li> <li>• Readiness to take part in surveys</li> </ul>

#### 4.1 Reasons for differences between the willingness to share PREMs and PROMs

In both the quantitative survey and the problem-centred interviews, respondents indicated their willingness to share PREMs and PROMs with a number of different stakeholders, including their general practitioner, hospital doctors, their social health insurance provider, and universities. This implies that when contrasting these two scenarios, the recipients remain constant, but that the type of data and, in the case of general practitioners and hospitals, also the purpose, benefit and usefulness of the data collection may undergo a transformation.

There are several potential explanations for the significant discrepancy in willingness to share PREMs and PROMs with universities and social health insurance providers. In terms of the nature of the data, the interviewees perceived PREMs to be less personal and less sensitive, given that they regarded such information as pertaining to the delivery of health services, rather than to themselves. The collection of less personal and sensitive data also diminished the perceived significance of certain risks, such as data leakage or identification. Additionally, interviewees cited a lack of perceived utility as a reason for not sharing PROMs with universities and social health insurance providers. They expressed uncertainty about how PROMs could be used to improve healthcare or the healthcare system, whereas they perceived PREMs to have a more evident potential for such improvements. An illustrative example is provided by interviewee 13, who posited that the data was of a less sensitive nature (in terms of its intrinsic value), thereby reducing the potential risks associated with its dissemination. Additionally, he articulated a perception of benefit in terms of the enhancement of the healthcare system as a whole, and asserted that the utility of data collection is more evident in the context of PREMs.

**Interviewee 13:** *“I didn't actually discover anything in the questions that you showed me that was somehow highly sensitive or personal for me, because it's only about experiences and not,... I don't have to talk about my state of health or complaints, but simply how I felt treated by the doctor in this practice. Yes, so that's what I would say, yes the same with public hospitals and religious hospitals yes, because for me that actually goes in the direction of a feedback questionnaire. I don't see any risk here for me personally if I share these answers, yes. Also with social insurance, also with researchers. I would say yes to all of these, because in contrast to the others, I don't see any risk here for me and I see the benefit behind it in order to improve it in general, which I simply predominantly see here.”*

The Wilcoxon signed-rank tests demonstrated that individuals exhibited a notable reluctance to share PREMs with general practitioners and hospital doctors. This may be attributed to the fact that, in addition to the type of data, the purpose and the benefit underwent a transformation. The data was initially collected with the objective of enhancing practices and service delivery, rather than for the purpose of personal treatment and diagnosis. Consequently, the benefit shifted from a direct to an indirect one. A change in the purpose and type of data collected may impact the perceived usefulness of the data collection process.



## 4. Discussion

The findings indicate that the type of data, the recipient, and the objective of data collection are pivotal factors in encouraging individuals to share self-reported data. However, the significance of these elements may fluctuate. The qualitative data indicated that risks, benefits, the usefulness of data collection, and the mode of data collection are also taken into account when making the decision to share data. It should be noted that not all factors are considered simultaneously; rather, multiple factors are often weighted against each other during the decision-making process. Furthermore, individual characteristics, such as an individual's propensity for openness or willingness to complete questionnaires, can serve as either facilitators or impediments to the sharing of health data.

In general, individuals are more inclined to divulge patient-reported measures to healthcare professionals than to public institutions or private companies. The qualitative data indicated that individuals or entities perceived as trustworthy, competent, and with benevolent intentions towards the sharer were more likely to be favored. However, there are significant differences between the willingness to share PREMs and PROMs, even when the recipient and the objective remain unchanged.

The findings of this study diverge from those of Biasotto et al. (2023), in which the purpose was identified as the primary determinant in the decision to share health data. This study proposes that the purpose is an important element when deciding whether to share health data. However, it also suggests that the importance of a factor may differ between scenarios, as it is often the case that several factors are weighted against each other. To illustrate, individuals may elect to share health data despite disagreement with the stated purpose when they perceive the recipient as trustworthy, the data as not particularly sensitive and the potential benefit to be high.

### 4.1 Strengths and Limitations

This study's strength lies in its mixed-methods approach, which enabled the quantification of willingness to share health data in specific scenarios while also facilitating an in-depth exploration of the underlying reasons and the collection of information regarding individuals' preferences regarding the sharing of their health data, even in the absence of participation in survey studies. Another strength of the study is the design of the questionnaire, which first required participants to complete PREMs and PROMs before indicating their willingness to share them. This reduced the risk of hypothetical bias, as it provided a situation where participants had full information about the data being shared, as opposed to other studies (e.g. Patil et al., 2016), where data sharing scenarios were more general and less feasible (e.g. "Would you share your genomic data?" is less understandable than "Would you share the answers that you just gave?").

A potential limitation of this study is the possibility of self-selection bias in the quantitative survey, as participants were selected from a pool of individuals registered with the survey company. This indicates that the individuals who participated in the study already exhibited a more favourable attitude towards the disclosure of opinions and participation in surveys. To address this issue, individuals were queried in problem-centred interviews as to whether they would complete a survey if it were to be mailed to them, thus identifying those who would be unlikely to participate in such studies.

With regard to the collection of qualitative data, problem-centred interviews are susceptible to the potential for bias when the interviewer influences the content in addition to the narration. Additionally, the use of both open and closed questions during the course of an interview may prove challenging (Scheibelhofer, 2008). This potential issue was mitigated through the incorporation of two key strategies. Firstly, interviewees were prompted to elaborate or confirm their stance when it became

evident that the interview was veering towards a particular direction. Secondly, the interview guideline was subjected to peer review, and a practice interview was conducted to ensure the consistency and rigor of the process.

## 5. Conclusion

The collection of PROMs (patient-reported outcome measures) requires greater care and sensitivity than the collection of PREMs (patient-reported experience measures) due to the inherently more personal and sensitive nature of PROMs data, which carries a higher risk for the individual providing the information. Additionally, the perceived utility of the collection of PREMs and PROMs differed between recipients and purposes. It is therefore recommended that efforts be made to increase social acceptability in the collection of both PREMs and PROMs. This may be achieved by ensuring that the type of data collected, the data recipient, and the purpose of data collection are clearly communicated. This will support the sharer in judging the usefulness of the data collection. Furthermore, disclosing the anticipated benefits, the manner and time frame of data collection, and the measures taken to mitigate risks can assist the sharer in making informed decisions about health data sharing.

## 5. Literature

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