

# Decisions About Medical Data Disclosure in the Internet: An Age Perspective

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Abstract. In times of the ongoing digitalization in private and public areas, online privacy is a specific good that should be handled with care. This is relevant for many social and economic contexts, but is most sensible in the health and medical sector. On the one hand the sharing of medical data increases public knowledge and enables the development of digital (health) services and innovations, on the other hand the protection of individual privacy is of paramount importance. From a technical perspective, there are approaches to protect privacy, such as differential privacy or privacy-aware recommendation systems. Yet, little is known about the users' willingness to share data, especially against the offering of individual benefits and the perceived risk of identification, but also the impact of data type and data recipients. Taking an age-perspective, focus groups were run first followed by a conjoint-decision study (n = 173), in which we empirically investigated individual decisions to share medical data, exploring the importance and utility of four attributes related to sharing of personal health data. Results show both, age-sensitive as well as age-insensitive findings. Independently disliked of their age, users disagreed to sharing data regarding mental illnesses, also disliked high identification risks and commercial use of the data, but would be willing to share data scientific purposes. The findings might contribute to understanding users' privacy perceptions and to develop information and communication strategies.

**Keywords:** Aging · Attitudes towards online privacy · Privacy trade-off Privacy calculus · Conjoint study · De-anonymization risks

## 1 Introduction

Today's societies are facing enormous challenges: On the one hand, the consequences of the demographic change need to be met—with an increasingly older population that needs medical care in the near future [1, 2]. There are severe bottlenecks in the medical supply chain: overarching economic burden for health suppliers and insurances, as well as an increasing number of solitary living older persons without family support in combination with a low availability of medical care personnel [3]. As a consequence, it is a paramount question how older persons can be adequately cared for, or, supervised in keeping up a healthy and self-determined lifestyle. On the other hand, the overarching digitalization, which enters all private and public fields in society comes with a considerable baggage [4]: The increasing potential of IT solutions for health

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surveillance, medical services, medical treatment and care [5] faces the problem of privacy risks and the fear of patients, family members but also care personnel that medical data might not be safe [5–7] and open to potential malpractice and data misuses by third parties [8, 9].

Thus, there is a critical trade-off between the enormous benefits of (public) digital medical services and the privacy issue and data safety of medical data [10].

## 2 Trade-off Between Benefits of Digital Health Data and Keeping up Individual Privacy

Without any doubt, public health surveillance represents an enormous technical and social benefit for countries, societies and individuals [11, 12]. It profits from the fast developments of information and communication technologies across the Internet and the digitalization of medical data. It allows a fast, seamless and continuous collection, analysis, interpretation as well as dissemination of health data [13]. The benefits of using digital health data are based on advances in terms of time-critical and accurate diagnosis and treatments, the development of novel services which enable, e.g., the fast and area-wide identification of emerging diseases, the identification of patients at risk, the detection of health adverse behaviors, and epidemics [14].

Digitalization in health and medicine and the broad availability of health data is not only helpful for care givers, but also for patients and family members [15]. Digital health services can inform patients about the status of the disease, can support persons to keep up a healthy life style and patients to stick to their medical treatments [16]. In addition, digital health services provide fast access to medical care also from remote places, connect them with other patients and care personnel, and, finally, allow a shared decision making in health issues between patients and medical doctors. Taken together, the overall benefits lie in the increase in patients' safety and the effectiveness of medical treatments. In addition, patients' health awareness and health motivation could be risen by empowering patients to feel responsible for their own health and to be an integral and active part of digitally assisted medical care and treatment [17, 18].

Recent studies show that the acceptance of digital health services is quite high: People, independently of their health status, basically acknowledge the benefits of digital health services, the access to public health data and their potential for a time-critical medical supply and care [6, 10]. From a technological perspective, tremendous efforts are directed to developing mechanisms to protect personal data in the Internet, such as k-anonymity or differential privacy procedures [19, 20], for an overview see [21].

Still however, it has been also shown that people are basically concerned about privacy issues sharing data on the Internet, especially when it is not clear how the data are handled, stored and who actually is using those data [9, 22, 23]. This is true for all personal data but might be still more relevant in health-related and medical data [24–26]. In addition, recent studies revealed that user diversity plays an important role in the perception of privacy issues [27, 28]. This especially regards older adults [7, 29], which are—due to their lower experience in Internet usage and their lower openness to digital services—might be regarded as a special user group in this regard. However, only

sparse knowledge is prevailing regarding older adults' perspectives on the trade-off between the perceived utility from sharing medical data and potential benefits arising from health surveillance against the drawbacks in terms of perceived privacy losses. Also, it is unclear yet which data types are perceived as most personal—and thus should not be shared—and which reasons for sharing medical data might be regarded as so useful that potential risks of privacy losses might be accepted.

## **3** Research Questions and Purpose of the Study

The aim of this study was to investigate acceptance-relevant criteria that people apply to the vision of sharing their medical data on the Internet.

In a first step, focus groups were undertaken in which participants discussed freely about potential benefits and drawbacks of sharing data on the Internet, thereby also elaborating on different data types as well as on the specific conditions which should be given before they would agree to share data. Arguments and conditions served as a base for the development of the subsequent conjoint study, which was run in a second step, in which participants evaluated different decision scenarios in terms of willingness to share their medical data. In Fig. 1, the schematic procedure of both empirical parts is depicted.



Fig. 1. Overview of the two-tier methodological approach

For the analysis, we took an aging perspective, thereby determining if users of different ages and technology education might have a different perspective regarding their willingness to share medical data on the Internet. The following research questions guided this research.

- (1) What are the most important factors for Internet usage and willingness to share data?
- (2) Do persons of different ages apply different sharing preferences?
- (3) What is the worst-case scenario under which respondents would not share their medical data at all and which is the best-case scenario?

# 4 What People Think About Sharing of Medical Data: Focus Groups

Overall, three focus groups were carried out, in which 19 participants in a wide age range (22–65 years of age, 52% women, 48% men) volunteered to take part. They were all frequent Internet users and were introduced in the topic. It was stressed that the sharing of data might have many benefits for users as well as for the society in terms of gaining public knowledge, but at the same time potential barriers could show up. This might be especially relevant for the medical context, in which data refer to sensitive and, highly intimate, contexts. Participants were informed that the focus groups should give them the possibility to participate in this timely topic and elaborate freely on the topic.

Overall, the discussion was vivid, revealing both, positive as well as negative aspects. Participants' actively shared their views which were quite diverse. The perception of privacy and the openness to share data on the Internet was not age-sensitive, revealing similar benefits and barriers across ages. It became obvious that people do see the general benefit of the availability of public health data for the society, the public education as well as for medical science and the development of novel treatments and care. However, the idea that private companies would benefit from their data was clearly disliked. In addition, a paramount barrier was referred to the fear of losing individuality, intimacy and privacy in line with the fear of being transparent patients especially as they do usually not know who actually might be the usufructuary from third party side.

On the base of argumentation lines, four most important and controversially discussed factors to share medical data on the Internet were extracted:

- (1) the type of data, distinguishing between general health data, (temporary) physical illnesses, chronic diseases, mental illnesses)
- (2) the probability of being identifiable
- (3) The role and importance of exchange values (benefits) from sharing the data (personal, financial and general benefit) and
- (4) the data receiver, thus those entities which receive or use the data. Regarding the latter, we identified three relevant major receivers: science, health insurances or commercial use of the data (private companies).

Out of the four attributes and their variations we developed an experimental design in which different scenarios were formed that had to be evaluated by participants. For this, we chose the conjoint analysis, a quantitative experimental procedure which allows to decompose participants' decisions of sharing data or not is accomplished according to the underlying single factors.

# 5 Evaluation of Decision Scenarios: Conjoint Analyses

Human decisions are complex by nature. In the context here, people need to decide under which circumstances they would be willing to share data and, also, under which conditions they would not do so. Thus, they weight the positive aspects and the negative aspects against each other. Users could refuse to share their data when private companies might benefit from it. On the other hand, users could decide to share data when data might contribute to a public understanding of diseases and allow the development of novel treatments, even though an element of risk to be identifiable remains. In addition, different data types could also lead to different decision patterns, especially depending on user factors, like age. To uncover those decision patterns and to identify the trade-offs between perceived benefits form sharing data and barriers that prevent users doing so, we used the choice-based conjoint analysis approach (Luce and Tukey [30]).

Methodologically, the given decision scenarios and tradeoffs consist of variations of the four attributes and which differ from each other in the attribute levels. As a result, the relative importance of attributes deliver information about which attribute influences the respondents' choice the most. Part-worth utilities reflect which attribute level is valued the highest.

For the experimental design, we used a  $4 \times 4$  matrix (*type of data, identification probability*) respective a  $4 \times 3$  factors matrix (*Benefits of sharing medical data, data receiver*). In Table 1, the experimental factors and attribute levels are detailed.

Attributes	Levels					
Type of data	General	Р	hysical	Chronic		Mental
	health data	illnesses		illnesses		illnesses
Identification probability	100%	50%		25%		10%
Benefits of sharing medical data	personal		financial		general	
Data receiver	science		health		commercial use	
			insurance			

Table 1. Attributes and their levels in the conjoint analysis

#### 5.1 Experimental Design and Instruction

Decision scenarios were provided using an online questionnaire. The questionnaire was composed using the SSI Web Software (Luce and Tukey [30]) and consisted of three major parts. First, participants were introduced into the topic and the reason for the questionnaire, using the following instruction.

Patients do have a right to decide what is going to happen with their data. Principally, the society as a whole and every single individual can profit from public health data that are generated on the Internet. What is important is an approach that satisfies the interests of all parties concerned. Here, privacy preserving technologies can step in as they anonymize data and thereby detach them from one's person. Though, this procedure also reduces the usability of that data as one cannot, for example, link a gender to a person anymore. Thus, a complete anonymization might not be reasonable in every case. The study aim is to find a solution that adheres to the interests of the data owners (i.e., you as patient) and the ones utilizing the data.

In this questionnaire, we ask for your personal evaluation of different scenarios. Please envision that you have the possibility to share your medical data and have advantage out of the sharing. At the same time, you may decide in which scenario you want to be private (not sharing the data).

In a second part, demographic data was assessed, e.g., age, gender, health status and profession. Also, participants' attitudes towards using the Internet and their privacy concerns were surveyed (Table 2).

Table 2.	Items regarding privacy attitudes when using the Internet. Items had to be answered on
a 6-point	Likert scale (1 = I completely agree; $6 = I$ do not at all agree).

Statements			
positive	"Due to the multitude of safety precautions I can use Internet ser-		
	vices and offers unscrupulously"		
	"Regulatory framework will protect me against misuse in the Inter-		
	net"		
	"Technical security procedures will protect me against misuse in the		
	Internet"		
	"Overall, the Internet is a stable and secure environment in which		
	services can be made use of"		
negative	"I am concerned about my privacy when using the Internet"		
	"I am concerned that online vendors pretend something which is		
	untrue"		
	"I am concerned about my personal data when I am registering as a		
	user in the Internet"		
	"I am concerned that my data are misused by third parties"		

The privacy statements were summed up to positive attitude score (positive items 1-4) and a negative attitude score (negative items 1-4).

Finally, the attributes and their levels were carefully described and instructed, followed by the decision scenarios which were formed out of different levels of the attributes described. In Fig. 2, an exemplary scenario choice is illustrated.

As decision tasks are quite demanding the number of choice tasks was limited to 10 random tasks. A test of design efficiency confirmed that the reduced test design was

comparable to the hypothetical orthogonal design. Each choice task consisted of three different combinations of the attributes *types of data, extent of anonymization*, types of *benefits* and *type of data receiver*.

In addition, a "none" option was available in case that none of the scenarios seemed appropriate. Participants were instructed to select the scenario they preferred the most. In order to improve comprehensibility, attribute levels were presented by pictograms in addition to written information.



Fig. 2. Exemplary decision scenario. Participants had to choose the scenario in which they would be willing to share medical data.

#### 5.2 Sample Description

Overall, 173 participants volunteered to take part. Survey data was collected via an online panel and was checked for completeness and quality by excluding speeders and internally inconsistent answering patterns. Participation was financially rewarded. Respondents had different education levels and came from all regions in Germany. According to quota setting in the data collection process, the sample was approximately representative in terms of age, region, and education.

**Gender.** The sample consisted of 50.3% male respondents (N = 87) and 49.7% female respondents (N = 86).

Age. The age range was wide, with participants from 18–65 years of age (M = 43.5 years, SD = 12.8). In order to analyze age effects on the willingness to share medical data, three age groups were formed. Age group 1 – the youngest age group – was, on average 24.4 years of age (SD = 2.8; N = 32). Age group 2 – the middle-aged persons – was 39.6 years (SD = 5.5; N = 73) and age group 3—the oldest age group—was on average 56.6 (SD = 4.3, N = 68) years of age.

**Health Status.** With regard to health status, 63% (N = 109) reported to be of good health (age range, 18–64 years, M = 41.8; SD = 12.9), while 37% (N = 64) reported to suffer from a chronical disease (age range 21–65 years, M = 46.5; SD = 12.4).

**Participants' Privacy Concerns.** Regarding participants' privacy attitudes towards using the Internet and their privacy concerns, age did not significantly impact the participants' attitudes, neither for the positive privacy attitudes (younger: M = 3.3 (SD = 1), middle-aged: M = 3.0 (SD = 0.84); older: M = 3.3 (SD = 1), nor for the negative privacy attitudes (younger: M = 2.6 (SD = 0.78); older: M = 2.5 (SD = 1).

#### 5.3 Results on Decisions to Share Medical Data

The data analysis and the estimation of part-worth utilities was done with the Sawtooth Software (SSI Web, HB, SMRT). First, the relative importance of each attribute was calculated in order to determine the main impact factors on users' decision to share their medical data. Second, we analyzed part-worth utilities (on the basis of Hierarchical Bayes). Part worth utilities show which of the attributes is most relevant across all decisions and in relation to other attributes. As this paper takes an age-perspective, we compared three age groups regarding their willingness to share medical data.

**Relative Importance of Attributes.** In Fig. 3, the relative importance of attributes is depicted.



Fig. 3. Relative importance of attributes in the three age groups. Error bars denote standard errors.

The most important attribute for all age groups is the identification probability with a share over 30% (younger adults: 36%, middle-aged 32%; older adults: 34%). The type of benefit is the next important criterion though importance scores differ depending on the age groups. For older adults, the benefit is slightly more important (26%) in comparison to middle-aged (25%) and younger users (24%). The data recipient—the entity which is utilizing the data—is more important for the middle-aged group (24%) compared to the younger (21%) and the older users (22%). The least important criterion is—overall—the data type with a share of, on average, of 19%. Overall, the analysis of attributes' relative important criterion, thus showing that medical data privacy is a general issue among Internet users. In the next analysis, we look at the part worth utilities of the attributes.

**Part-Worth Utilities – The Value of Attribute Levels.** In order to show positive and negative preferences across attribute levels, data are visualized as zero-centered scores. In Fig. 4, part-worth utilities are depicted.

As can be seen, *identification probability* is the criterion which is most relevant and which shows quite extreme results. All age groups show negative part worth utilities for an identification probability of 100% even though the older age group is not that critical in comparison to the younger age groups (young: -19.6; middle-aged: -23.4; old -17.9). Also, the 50% identification probability is seen critical revealing negative utility scores (young: -10.5; middle-aged: -3; old -7). A probability to be identifiable of 25% yields quite different outcomes. While younger (13) and middle-aged adults (15.3) show a slightly positive evaluation of this identification level, the older age group is still declining to share their medical data (-15). The picture changes when the probability of being identified is 10%. Here, all age groups would be willing to share medical data, however to a much higher extent by older age group persons (39.6) in contrast to middle-aged (11) and younger Internet users (16.3).

Regarding the attribute *data recipient*, clear cut outcomes showed up. If data are to be used for science and the development of novel care and treatments, all respondents consistently agree to share the data (young: 35.1; middle-aged: 20.9; old 29.9). However, whenever data recipients are perceived as commercial or as profiting from the medical data for their personal benefit, participants decline to share their medical. All participants refuse to share their medical data with health insurance companies, however, the age groups reacted differently in this regard. Younger persons (-20.6) and middle-aged adults (-15.1) are more negative in comparison to older adults (-3.2). Whenever medical data are to be used for commercial use, the most negative are the results. Especially older adults see a commercial use of their medical data as most critical (-26.7), followed by the younger (-14.8) and the middle-aged users (-15.1).

When it comes to *potential benefits*, which the participants could gain from sharing their medical data, a quite diverse result emerges. The most accepted benefit is the financial one. Again, it is the older age group which shows a different behavior in comparison to younger adults. While financial benefits are accepted by younger and middle-aged users (20.4 and 13.3, respectively), older adults show the highest acceptance with a share of 33.2. Personal and global benefits are seen negative by nearly all age groups.



Fig. 4. Part-worth utilities across attributes and levels across the three age groups. Part-worth utilities add up to zero for each attribute. Error bars denote standard errors.

Finally, the findings with respect to the *data type* are reported. On a first sight, there is one paramount No-Go condition. Data on mental illnesses are generally not to be shared; this is even more the case for the oldest age group (-28.2), followed by the younger adults (-29) and the middle-aged persons (-15.8).

Data on chronic illnesses, in contrast, might be shared, however, the willingness to share chronical illness data is age-sensitive. While the younger age group is clearly willing to share them (19.9), the middle-aged users are more reluctant in this regard (-5.9). Strikingly, the oldest group is rather neutral than positive (1.7), what might be surprising. On the one hand, one could assume that older adults would be more willing to share their data in order to improve medical treatments, especially as chronic illness is a frequent concomitant of older age. On the other hand, this result might reflect the higher serenity towards chronic illness and a solid habituation in handling chronic illnesses. With respect to general health data and data on physical illnesses a mixed picture emerged regarding age groups. While older adults would be willing to share both, physical illness data (16.7), and general health data (7.8), younger adults were willing to share physical illness data (15.5), but declined to share general health data (-14). Conversely, middle-aged persons would rather share general data (15.7), but were not willing to do so for their physical illness data (6).

**Best-Case and Worst-Case Scenarios.** On the base of these findings, now best- and worst-case scenarios of the consent to share medical data can be derived. In order to be specific, the best- and worst-case scenarios are analyzed separately for the oldest and the youngest age group (the middle-aged are ignored out of space restrictions). In Fig. 5, the best-case scenarios for the willingness to share medical data are depicted for both age groups (old: Fig. 5, left side; young: Fig. 5, right side).



Fig. 5. Best-case conditions under which older adults (left) and younger adults (right) respondents would be willing to share medical data

The attribute levels in the **best-case scenario** show structurally similar patterns for both age groups and, still, reveal differences in the order of relevance.

Overall, the older persons show basically a higher willingness to share their data in comparison to the younger adult group, as taken from the higher part-worth utilities. To share the data for *science* and for the sake of gaining medical knowledge that benefits the public is a clear "go" condition for all participants, even though the relative share is higher in the younger group (35.1) vs. 29.9 in the older group). Also, the *10*%

*probability of being identified* is quite accepted by all participants, however to a much higher extent by older persons (39.6%) in contrast to younger Internet users (16.3%). From all the *benefits* offered when sharing the medical data, participants chose the financial benefits, though older adults to a higher degree (33.2) than younger users (20.5). So far, the same criteria—even though in a different order- formed the best-case scenarios for both age groups. The *data type* is now age-sensitive, revealing different data that are acceptable to be shared in the Internet. For older adults, physical illness data might be shared (16.7), for the younger group it is chronic illness data (19.8) which they would be willing to share.

Finally, the **worst-case scenarios** are depicted for both age groups separately (Fig. 6). On the left side, the "No-Go" conditions are visualized for the older adults' group, on the right side the worst-case conditions can be seen for the younger user group. On a first sight, age-sensitive (differences between age groups) and age-insensitive (same preference pattern) were found (Fig. 6).



Fig. 6. Worst-case conditions under which older users (left) and younger (right) respondents would be declining to share medical data

On a first sight, the *anonymization extent* is a highly critical factor. The probability of being 100% identifiable is no option for respondents, interestingly stronger for the younger group in comparison to the older persons. The same applies for the *data type*, another highly critical criterion. Both, older and younger respondents clearly declined to share their data on mental illnesses, which need to be protected and kept in privacy for all respondents. Apparently, the concern that the public gets to know about mental illnesses is still much more sensible in comparison to general health data or data on physical illnesses.

When it comes to the *type of benefit* which is disliked and which is the reason for not sharing the data, differences between age groups were found. While for the younger group personal benefits (in terms of timely appointments at the doctors' office without waiting or individually tailored treatments) are seen negative. For older adults, general benefits are the No-Go criterion in this regard. Finally, the *data recipient* is also age-sensitive. The older group declines to share data when a commercial use of the data is intended. Here, it becomes obvious how large the distrust in commercial authorities

is and the general doubt what could happen with the data. In the younger group, data should not to be shared with health insurances, obviously because respondents fear negative consequences and disadvantages from health insurance companies.

#### 6 Discussion, Conclusion and Future Research

In this study, we have looked at users' preferences to share medical data, taking an age perspective into account. Empirically, we investigated individual decisions to share medical data in the Internet, exploring the importance and utility of four attributes related to sharing of personal health data. Relevant attributes in this context have been were identified in focus groups which had been carried out in a first step. As found critical factors discussed among users were the type of data, the data recipient, the probability of being identified and potential benefits that users would accept as counter values for sharing their data. To uncover the trade-offs between the seen benefits (e.g., exchange values) and perceived drawbacks (high identifiability, or the discomfort when third parties might make profit out of the data) we used an experimental procedure— choice-based conjoint analysis—which allows the simulation of users' decisions depending on the respective factor combinations.

The research was guided by three major questions: One is the determination of the most important decision criteria (main effects that motivate or hinder users to share their data), the second regards the question whether decisions might be age-sensitive and, finally, the best and worst-case scenarios under which persons are willing or declining to share medical data on the Internet.

The results showed that there is a clear order of importance. The most critical attribute is the identification probability. Apparently, users are well-informed about drawbacks of data sharing and are very aware about the risk of privacy losses. However, the openness to share data is modulated by the type of benefit: Especially financial rewards are perceived as an attractive exchange value for sharing the data, hinting at a high awareness of respondents that their data are precious and valuable for others. The entity which is finally profiting from the data is another major factor. Health insurances and companies that use the data are disliked by participants. From the focus study the reasoning behind this perspective was uncovered: On the one hand, people do not value that third parties alone profit without sharing this profit with them, the data owners. This is in line with the high openness of participants to financial benefits and the selling of the data. On the other hand, they reported to be highly clairvoyant to what happens with the data. Especially, when health insurances might use the data, participants fear negative consequences for them or their families, especially when identification probability is high. Compared to the other attributes, the least important factor was the data type in terms of relative importance. However, a closer look into the attribute levels (part worth utilities) show that there is a clear "No-Go" among data types. Whenever data on mental illnesses are to be shared, respondents-independently of their age—decline to do this. In contrast, respondents would be willing to share data on chronic or general illness, especially when data are used for science and the development of novel treatment and care.

When looking into age effects, we found both age-insensitive patterns as well as some age-specific decisions. Basically, the order of importance among the attributes is not changing depending on the respondents' age. Thus, we received a quite homogenous response pattern hinting at a blueprint of user perceptions towards medical data usage in the Internet, at least in Germany. Results were age-specific in two respects: One is that older users are generally more willing to share their medical data (compared to the other age groups), and, second, with some special characteristics: Older users are most willing to sell their data, thus receiving to financial exchange values compared to middle-aged and younger participants. Also, they prefer to share data on physical illnesses, followed by general health data. Data on chronic illness received only neutral evaluations-which is quite surprising as age is related to the emergence of chronic illness and therefore a highly frequent category which is important for public health surveillance services. Here, one could speculate that older adults might be highly accustomed to having chronic diseases which could be the reason that they underestimate the value and the importance of sharing the data. On the other hand, having a chronic disease could be attributed to negative consequences, and stigma in terms of ageism [31-33].

The results can be used to inform either public information and communication strategies or technical designers of recommender systems in terms of user perceptions on privacy. Future studies will have to broaden the focus. Here different approaches could be valuable extensions of this research. One is to take other countries and cultures into account. As cultures and countries differ with respect to socio-economic perspectives on medical treatment, digital health and aging, this could be very insightful to get the full picture. Also, it should be explored, in how far the health status of respondents and the type and severity of chronic illness might modulate the perspectives on sharing medical data in the Internet.

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