

# On the Importance of Context: Privacy Perceptions of General vs. Health-specific Data in Health Recommender Systems

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## ABSTRACT

Recommender systems are essential to reduce complexity on the web due to the plethora of available content. However, depending on design choices they require a lot of (potentially personal) data to work, raising the issue of privacy and acceptance of such systems. This is particularly true when they are used in sensitive matters such as health. We addressed these issues in a survey of 163 participants in which we presented three different health-related contexts where recommender systems can be used: 1) desire for better nutrition and more exercise, 2) information about causes and treatment of headaches and nausea, and 3) information about side effects of a medication prescribed by a doctor. We found that participants are generally more willing to disclose their general data than their specifically health-related data. The more health-critical the context of use was, the more willing they were to disclose health-related data.

## CCS CONCEPTS

• **Human-centered computing** → *Human computer interaction (HCI)*; **Collaborative and social computing**; Empirical studies in collaborative and social computing; • **Security and privacy** → **Social aspects of security and privacy**.

## KEYWORDS

Health Recommender Systems; Privacy; User Perceptions; Trust; Acceptance; Application contexts

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## 1 INTRODUCTION

Many people use the Internet to seek health-related information before or after a doctor's appointment [1]. However, such information is often complex and contradictory which makes it difficult for users to assess it along with its relevance to their personal situation [26]. Recommender systems tackle this issue by filtering information and offering personalized recommendations to users [6]. Such system can also be used in the healthcare sector to recommend information, therapies, or side-effect free medicine [9]. While recommender systems are already more established and accepted in many other areas of application, (potential) users of health recommender systems are even more concerned about privacy and security. User acceptance is hampered by technical aspects such as data ownership or privacy and security, as well as user diversity aspects such as data and health literacy [8, 29].

## 2 RELATED WORK

Health recommender systems can improve the quality of preventive health care [24]. Nonetheless, when asked about their inclination to disclose data to these systems, users are often concerned about their privacy and these concerns must be taken into account when considering acceptability [18].

Li et al. investigated the acceptance of wearables in the health sector and found that users conduct a risk-benefit analysis to decide whether to use wearables: If the perceived benefit outweighs the perceived risk, they are more likely to use them [15]. The phenomenon of users performing a risk-benefit analysis to decide which of their personal information they want to disclose is called *Privacy Calculus* [3, 14]. For this risk-benefit analysis, it has been shown that patients who use computers more frequently [21], use the Internet more often, or have a higher level of education are more willing to disclose data to obtain a benefit.

Caine and Hanania have investigated which type of health data users voluntarily disclose [7]. They found that users are less willing to disclose more sensitive health data such as information on their mental and sexual health. In contrast, Frost et al.'s analysis of online cancer communities found that patients affected by poorer health were more willing to disclose their private data [12].

In addition to the sensitivity of the data itself, it has been shown that other experiences on the Internet affect the willingness to disclose data as well. Awad and Krishnan found that a previous invasion of privacy decreased the respondents' willingness to be profiled for personalized advertising [3]. Similarly, Frost et al. found that patients who previously had bad experiences on the Internet were less willing to disclose their data [12].

When considering user preferences, technology acceptance models are also relevant. Research of technology acceptance has shown an influence of user factors such as gender, age, and technology self-efficacy on the willingness to use a technology [27]. Further, when asked to provide personal data to an Internet service provider [23], users differ in their perceptions of trust [17] and privacy concerns [16, 20, 32].

Some studies have shown that a majority of respondents (patients and doctors) gave positive ratings to the use of computers for patient health. For them, the advantages outweigh the disadvantages in terms of confidentiality [15, 21].

Nevertheless, the decision to use a health recommendation system remains a balance between benefit and concern. Different usage contexts may provide different benefits and result in different concerns. Much of previous research has looked at specific illness-related contexts (e.g., smoking cessation, weight loss, sports) or specific privacy concerns in isolation.

**Our Contribution.** The objective of this study is to consider the privacy concerns (potential) users have when using recommendation systems in different health application contexts, and the extent to which they are willing to disclose different general and health data. In this study, we identify what general and health data the participants consider to be sensitive and whether there are differences in the willingness of participants to disclose more sensitive data. We also consider whether different user factors influence the willingness to disclose the aforementioned data.

### 3 METHODS

To find out whether the application context of health recommendation systems influences the users' willingness to disclose their data, we conducted an online survey in German. Participants were acquired using convenience sampling between July and August 2018 and March and April 2019. The survey was distributed via the social network Facebook using snowball-sampling.

The survey consisted of three parts: First, we asked the participants for demographic factors (*age* and *gender*), perceived health, and smoking habits. Next, we measured *technology self-efficacy*, *health concerns*, *privacy concerns*, *institution-based (dis)trust* and *disposition to trust*. Lastly, we assessed the participants willingness to disclose personal and health data for three different application contexts.

**Technology Self-Efficacy (TSE).** We used eight items of Beier's scale for measuring *technology self-efficacy* (TSE) [4], extended by two additional items to account for the shift in answering tendency. Internal reliability was good according to DeVellis [11] (Cronbach's  $\alpha = .82$ ).

**Health concerns.** To assess participants' general health concerns, we asked them four questions about whether they were worried about their general health status, that they might develop

a chronic disease, that they might fall in with a serious illness or that they get infected when sick people are in their environment (Cronbach's  $\alpha = .807$ ).

**Privacy concerns.** Perceived privacy while using Internet services was assessed with seven items from Xu et al., Li et al. and Morton et al. [16, 20, 32]. The items measure generalized fear that general data stored online could be "insecure" and concerns about misuse of personal data (Cronbach's  $\alpha = .777$ ).

**Trust.** To assess *institution-based trust*, we used six items from McKnight et al. [17]. Through principal component analysis we discovered that the scale breaks down into two dimensions. The first dimension depicts users' trust in online services concerning the handling of their (*personal data*) (Cronbach's  $\alpha = .617$ ). The second dimension assesses how much users trust the technical infrastructure to ensure privacy on the Internet (*technical*) (Cronbach's  $\alpha = .862$ ). In addition, we measured general *disposition to trust* using six items by McKnight [17] (Cronbach's  $\alpha = .732$ ).

**Application contexts.** In the last part of the survey we presented three different application contexts of recommendation algorithms in health settings to the participants. For twelve different types of data, such as date of birth or medication currently being taken, we asked whether the participants would disclose these in each application context.

First, the participants should imagine that they committed to a healthier lifestyle (context *healthy life*). We explained that the health recommendation system is a mobile app that provides nutritional recommendations and encourages users to be more active.

For the second application context (*complaints*) the participants should imagine that they feel headaches and nausea and therefore use an app to find out about the causes and treatment options. They were told that the more data they would enter, the more reliable the diagnosis would be.

In the last application context (*drugs*) the participants should imagine that the doctor prescribes a medication for them and they would like to check with an app which side effects can occur. They were told at this point that the more data the app receives, the more reliably it can assess the risks.

For all three contexts, we performed a factor analysis with the 12 different data items, resulting in two scales, general data (Date of Birth, Gender, height, weight) and health data (preexisting conditions, chronic illnesses, illnesses of family members, allergies, current medication, information about diet, alcohol consumption, smoking behavior). We then tested the reliability of the two scales for each context individually as shown in table 1.

**Table 1: Scales, items and reliability as Cronbach's  $\alpha$ .**

Context	Scale	Items	$\alpha$
healthy life	general data	4	.89
healthy life	health data	8	.95
complaints	general data	4	.91
complaints	health data	8	.96
drugs	general data	4	.94
drugs	health data	8	.96

### 3.1 Hypotheses

Following the results of the study of Caine and Hanania (see section 2), we assume for all contexts that the participants are less willing to disclose *health data*, which should be more sensitive to them than *general data* ( $H_1$ ). We also assume that, according to the risk-benefit analysis, participants distinguish between the three application contexts and are more willing to disclose their data for the context *drugs*, as this is where they could see the strongest benefit—preventing potentially dangerous side-effects( $H_2$ ).

We further assume that negative experiences with the Internet and thus higher *privacy concerns* ( $H_3$ ) and lower *institution-based trust* ( $H_4$ ) inhibit the willingness to disclose data, while the *disposition to trust* boosts it ( $H_5$ ). Lastly, we assume that higher *age* ( $H_6$ ), lower *Technology Self Efficacy* ( $H_7$ ), and being female ( $H_8$ ) correlate with a lower willingness to disclose data.

### 3.2 Statistical Procedures

To analyze our descriptive results we used means, standard deviations, and 95% within-subject confidence intervals [19]. We ensured sampling adequacy by using the Kaiser-Meyer Olkin criterion. With Bartlett's  $\chi^2$  test we tested the sphericity of our data. We further looked at associations between variables using Pearson correlations. We report the correlation coefficient  $r$  and an asymmetric 95% confidence interval that is generated by population bootstrapping [10]. Finally, we used MANOVA repeated measurements to analyze differences between the contexts.

All study materials, data, and analysis code are available online at the Open Science Foundation.<sup>1</sup>

## 4 RESULTS

We analyzed the data using R version 3.6.2 and several packages [2, 22, 25, 28, 30, 31]. Analyses were run on Mojave 10.14.6 MacOS (system x86 64, darwin 15.6.0). Our data showed good sampling adequacy using the Kaiser-Meyer Olkin criterion ( $MSA > 0.8$  for all items) and showed sufficient sphericity. With Bartlett's  $\chi^2$  test we tested the sphericity of our data ( $\chi^2(630) = 7008.197, p < .001$ ), which was present. Next, we will describe our sample and then present the findings of our analyses.

### 4.1 Description of the sample

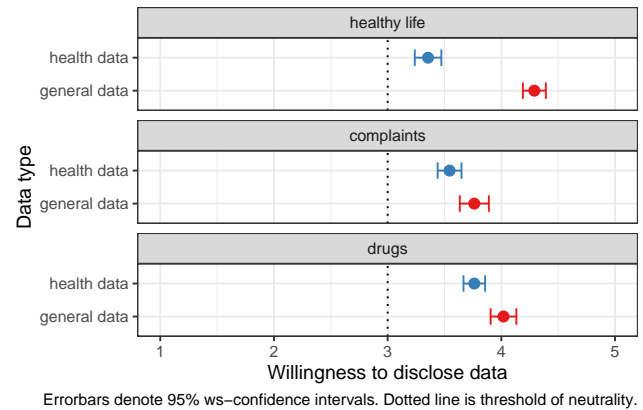
Of the 163 participants 108 (66%) were female and 55 (34%) were male. The participants were on average  $M = 28.8$  years old ( $SD = 11.1$ ). Most participants in our sample did not smoke (145, 89%). Men and women were about the same age on average ( $t(161) = -0.695, p = .488$ ). The participants showed a rather low *technology self-efficacy* ( $M = 3.20, SD = 0.80$ ) and rather low *health concerns* ( $M = 3.14, SD = 1.18$ ). They showed an even lower *institution-based trust technical* ( $M = 2.74, SD = 1.06$ ) and matching this rather high *privacy concerns* ( $M = 4.21, SD = 0.06$ ) and a rather high *institution-based distrust personal data* ( $M = 4.41, SD = 1.08$ ). Interestingly they showed a rather high *disposition to trust* ( $M = 3.89, SD = 0.70$ ).

**Correlations of independent variables** To get a more accurate impression of our sample, we can look at the Pearson correlations of our independent variables (see Table 2). Older people have a

lower general *disposition to trust* as well as a higher *institution-based distrust personal data*. Participants with a higher *computer self-efficacy* have also higher *privacy concerns*. Higher *computer self-efficacy* and higher *privacy concerns* also correlate positively with a higher *institution-based distrust personal data*. Interestingly, participants with higher *privacy concerns* have also more *institution-based trust technical*. Participants with a higher *institution-based trust technical* tend to have a lower *disposition to trust*.

**Application contexts** As described in section 3, we presented three application contexts of health recommendation systems to the participants and asked if the participants would disclose their *personal* and *health data*. Figure 1 shows, that the participants indicated for each context a higher willingness to share their *general data* than their *health data*. The highest difference occurs for a *healthy life*.

Means of the willingness to disclose data for the three contexts



**Figure 1: Relative comparison of the willingness to disclose different types of data in our three contexts.**

Comparing the three contexts, we found that participants are less willing to disclose their *general data* for *complaints* and most willing to disclose their *general data* for a *healthy life*. In contrast, they are less willing to disclose their *health data* for a *healthy life* and most willing to disclose their *health data* to find side-effects of *drugs*. The more sensitive the use context (most to less sensitive: *drugs*, *complaints*, *healthy life*), the more willing they are to disclose *health data*.

A computed MANOVA for repeated measurements with the three contexts and the general data showed a significant overall effect of the contexts ( $Wilks\Lambda = .754, F(2, 143) = 23.33, p < .001$ ) with a large effect ( $\text{Partial}\eta^2 = .246$ ). *Gender* is not related to *willingness to disclose general data* ( $\tilde{\chi}^2 = 31.68 - 34.66, p > .05$ ). We also found a significant overall effect of the contexts for *health data* ( $Wilks\Lambda = .807, F(2, 143) = 17.08, p < .001$ ) with a large effect ( $\text{Partial}\eta^2 = .193$ ). The  $\tilde{\chi}^2$ -Test showed a small effect of *gender* on the *drugs* context ( $\tilde{\chi}^2(16) = 26.40 - 18.00, p = .049$ ), females are more willing to disclose their health data ( $M = 3.92, SD = 1.01$ ) than males ( $M = 3.46, SD = .20$ ). *Gender* did not relate to the other contexts ( $\tilde{\chi}^2 = 11.27 - 18.00, p > .05$ ).

So far, we looked at the overall willingness to disclose both general and health data in the three contexts. Following, we look

<sup>1</sup>Link to the OSF Repository: <https://osf.io/5f6jy/>

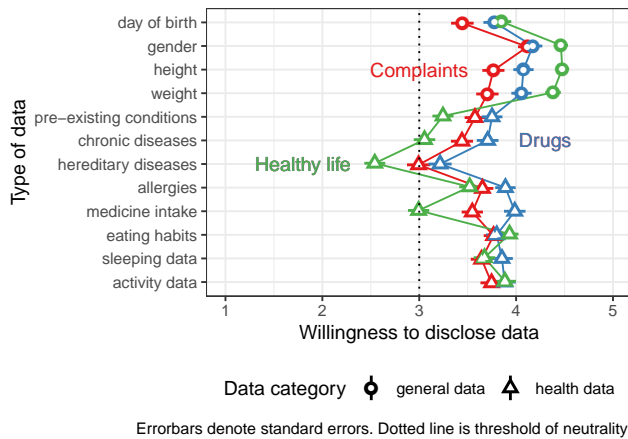
**Table 2: Correlation table of our independent variables**

Variable	1	2	3	4	5	6	7
1. Age					.212**		-.207**
2. Computer self-efficacy				.242**	.203*		
3. Health concerns							
4. Privacy concerns					.437**	.224**	
5. Institution-based distrust personal data							
6. Institution-based trust technical							-.231**
7. Disposition to trust							

Note. \* indicates  $p < .05$ . \*\* indicates  $p < .01$ .

at the willingness to disclose the (12) individual data types. As mentioned before and as can be seen in Figure 2, the participants' willingness to disclose data is higher for *general data* than for *health data*. From the *general data*, the participants are less willing to disclose their day of birth. This applies to all contexts, but for a *healthy life* the contrast between the participants' willingness to disclose their *personal* and *health data* is clearer. In particular, the participants are less willing to disclose hereditary diseases and medicine intake for a *healthy life*, whereas they are willing to disclose their medicine intake for the *drugs* context. Looking at the *health data*, the participants are for all contexts more willing to disclose eating habits, sleeping data and activity data. In contrast, they distinguish between the contexts for pre-existing conditions, chronic diseases, hereditary diseases, allergies and medicine intake. For the context *drugs*, they are strongest inclined to disclose the most types of *health data*, followed by the context *complaints* and they are least willing to disclose the data for a *healthy life*.

Means of the willingness to disclose data for all data types



**Figure 2: Individual comparison of the willingness to disclose different types of data in our three contexts.**

Beyond the effect of the different application contexts and different types of data we found that higher *health concerns* are associated with a higher willingness to disclose *general data* for all three contexts (*healthy life*:  $r = -.19$ ,  $p = .018$ ; *complaints*:  $r = .20$ ,  $p = .018$ ; *drugs*:  $r = .19$ ,  $p = .019$ ) and their *health data* for context *healthy*

*life* ( $r = .18$ ,  $p = .028$ ). Further, *disposition to trust* causes the participants to be more willing to disclose their *health data* for a *healthy life* ( $r = .22$ ,  $p = .007$ ). We did not find an influence of *age*, *computer self-efficacy*, *privacy concerns* and *institution-based trust* on the willingness to disclose any data (all  $p > .05$ ). Looking at the different data types in the three contexts, participants that are more willing to disclose any data for any context are also more willing to disclose other data or for other contexts (all  $r_s > .47$ ,  $p < .001$ ).

## 5 DISCUSSION

In this study, we investigated the effects of three different application contexts for health recommendation systems and the effect of user diversity factors on the willingness to disclose personal and health data. We first state, that participants differentiate between personal and health data and are more willing to disclose their general data ( $H_1 \checkmark$ ). Furthermore, the different contexts had a significant influence on the willingness to disclose. For health data, our results show that the more sensitive the application context is, the more willing the participants are to disclose their health data ( $H_2 \checkmark$ ). For general data, the participants prefer to disclose their data for a *healthy life*, whereas they are least willing to disclose data for *complaints* ( $H_2 \times$ ).

From the investigated user-factors only health concerns and disposition to trust ( $H_5 \checkmark$ ) seem to influence the willingness to disclose data. At this point, the increased concern about health seems to increase the participants' willingness to disclose their data. People with better health status may expect fewer personal benefits from disclosing their data [13]. We did not see a strong effect of previous experience ( $H_3$  and  $H_4 \times$ ), age ( $H_6 \times$ ), gender ( $H_7 \times$ ) or technology self-efficacy ( $H_8 \times$ ).

Participants had to think of a fictitious situation which can lead to reports revealing less or more data than they would actually reveal. Besides, it is conceivable that users of health recommendation systems would change their initial willingness after experiencing the benefits of the recommendation systems. Nevertheless, studies in technology acceptance showed that preferences are at least to some degree stable over time [27].

In reality, users often do not consciously decide whether they want to disclose their data but disclose their data unconsciously or inadvertently. Nevertheless, our study shows that different application contexts of health recommendation systems have an impact on what data users want to disclose. In future research, we would like to take up this point and use experiments to examine how users

actually perceive the recommendation systems in the respective context.

## 5.1 Does only the application context influence the acceptance of recommendation systems?

Of course, more aspects that may influence the acceptance of recommendation systems than the application context. Burbach et al. [5] for example investigated, if individuals accept five different recommendation algorithms (content-based recommendation, collaborative filtering, hybrid recommendation, social-, trust-based recommendation) for three different product categories (books, mobiles, and contraceptives). Critically, not only the purpose of the recommendation but also the use of data inside of different algorithms seems to play a role in the acceptance of recommendation systems. Here, algorithms that are able to create a more accurate picture of the users, were less likely to be accepted [5].

## 6 CONCLUSION

Concluding, many aspects determine how much individuals accept recommendation systems. The acceptance of different recommendation systems depends among other things on the application context of the recommendations, but also on the product type that is recommended. Our research has shown, that the users have a very distinct idea of what type of data should be used in what type of context and show decreased willingness if the data seems unnecessary for a health-related decision. Accordingly, there is not a one-size-fits-all recommendation system, but the acceptance of the recommendation system is always determined by a combination of different contexts and users.

## 7 OUTLOOK

In the future, we will conduct additional studies on the user acceptance of recommendation systems. We will consider different aspects in one study. For example, it would be interesting to consider whether the application context or the recommended item have a greater influence on the acceptance of different recommendation systems and how these two aspects influence each other. A particularly suitable method for this would be a conjoint analysis, in which different aspects of a recommendation system could be weighed against each other.

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