

Data Size Matters: The Impact of Message Framing in Different Health Scenarios on the Donation of Personal Health Information

Julia Klein
University of Goettingen
julia.klein@uni-goettingen.de

Kristin Masuch
University of Goettingen
kristin.masuch@wiwi.uni-goettingen.de

Laura Schulze
University of Goettingen
laura.schulze@uni-goettingen.de

Simon Trang
University of Paderborn
simon.trang@uni-paderborn.de

Abstract

Health data donation allows individuals to share their personal health information for the greater good. As privacy concerns hinder many individuals from disclosing such sensitive information, this study investigates how benefit appeals, attribute framing, and health conditions can influence the intention to donate personal health information. We conduct a scenario-based online experiment and answer our research question using data from a German sample (n=208). We use a vignette design with a 2 (benefit appeal) x 2 (attribute framing) x 2 (health condition) mixed-subject design. Our results indicate that benefit appeals, attribute framing, and health condition statistically significantly influence the intention to donate personal health information. Our findings contribute to health information systems and the privacy literature stream by extending knowledge regarding phenomena with multi-layered benefit structures and by opening future research possibilities in the context of health data donation.

Keywords: health data donation, benefit appeal, attribute framing, personal health information

1. Introduction

Through the digitalization in health care and the creation of precious behavioral and health data, it is possible to realize value for all kinds of population groups (Ibrahim et al., 2021), including those with rare diseases (Fürstenau et al., 2021) or those currently underrepresented in clinical trials and medical research such as women, people of color, or immigrants (Renault, 2021; Vitale et al., 2017). Health data donation has been introduced as a relatively new way to increase the available data set while still protecting the individuals' data sovereignty (Bietz et al., 2019; Spajić, 2021). However, to realize their full potential, individuals must

be willing to voluntarily donate their personal health information – despite potential privacy concerns (Fox, 2020).

In the past, research has identified many factors influencing the willingness to adopt new health technologies, including anticipated personal benefits such as personalized medicine suggestions or more efficiency at the physicians' practice (Angst & Agarwal, 2009; Bohr & Memarzadeh, 2020; Gonçalves & de Figueiredo, 2022), and privacy concerns such as the fear of health data loss which is associated with severe consequences such as financial discrimination (e.g., by the health insurance), stigmatization or fraud (Bridges, 2011). As personal health data are generated with wearables, sensors, or during treatment in hospitals or at the health practitioner's office daily, the benefit of using these vast amounts of data would be tremendous. For example, analyzing health data stored in electronic health records could contribute to the safety of medicines and prevent drug interactions (Kohli & Tan, 2016), which would not only result in personal benefits but also societal benefits through savings for the health system and increased drug effectiveness (Bates et al., 1997).

Indeed, in the past years, many new health data donation initiatives have aimed to accelerate research regarding disease transmission and vaccination (Spajić, 2021). These ambitions realize not only personal benefits for the individual but also societal benefits (Trang et al., 2020). Although only a little attention has been paid to the so-called societal benefits in information systems so far, the need for more research involving societal benefits in privacy decision-making has been identified (Nabity-Grover et al., 2020).

At the same time, privacy research has identified that biases, heuristics, and personal experiences influence the decision to perform a certain behavior (Anderson & Agarwal, 2011; Dinev et al., 2015). For example, positively framed messages have positively altered attitudes toward adopting electronic health records despite prevalent privacy concerns (Angst &

Agarwal, 2009). Further, individuals who perceive a rather severe health condition are more likely to disclose personal health information (Cherif et al., 2021; Zhang et al., 2018).

Health data donation differs from general health data disclosure, as the individual may not receive immediate gratification, which is often a primary driver for disclosing private information even when privacy risks are perceived as significant (Acquisti, 2004). However, it is also possible that non-tangible benefits and motives from donation literature apply, such as 'egoism' (concerns about reputation) or 'warm glow' (Sisco & Weber, 2019).

So far, only a little attention has been paid to the influences of individuals' decision to donate personal health information and, especially, what kind of message strategies may increase the donation of personal health information.

Accordingly, we would like to shed light on the drivers of the decision to donate personal health information by investigating the role of benefit appeals and message framing in the presence of different health conditions. We pose the following research question:

When do individuals donate health data when confronted with different types of messages and different health conditions?

In this study, we aim to investigate the role of benefit appeals, attribute framing, and health conditions on the intention to donate personal health information. We develop our hypotheses from the basic understanding of privacy calculus and prospect theory. For this purpose, we deployed a scenario-based online experiment and collected survey data from 208 individuals. We used a vignette design with a 2 (benefit appeals: personal vs. societal benefit) x 2 (attribute framing: positive vs. negative framed message) x 2 (health condition: mild vs. severe) mixed-subject design whereby benefit appeals and attribute framing were served as between-subject factors and health condition as a within-subject factor.

The results of this study support evidence for the influence of benefit appeals, attribute framing, and health conditions on the intention to donate personal health information. We found that personal benefits (self-benefitting appeals) drive individuals to donate personal health information more than societal benefits. Further, we found that positively framed messages and a more severe health condition positively influence the intention to donate personal health information.

Our research contributes not only to the field of information systems in health but also to the privacy literature stream by extending knowledge regarding phenomena with multi-layered benefit structures and the relatively new direction in information systems of citizen- and society-centric technological advancements

that require the mobilization of mass acceptance (Trang et al., 2020) within the outstanding context of personal health information (Anderson & Agarwal, 2011).

The structure of the paper is as follows. First, we describe the conceptual background of our paper by describing the theoretical foundation. Here, we introduce the theories of our study: privacy calculus theory and prospect theory. This is followed by a summary of the knowledge regarding individuals' personal health information disclosure and by the hypothesis derivation and our proposed research model. We then describe our research methodology and introduce our experimental design before describing the results. The paper concludes with a discussion of the results in the merit of its limitations, implications, and possibilities for future research directions.

2. Conceptual Background and Hypotheses Development

2.1. Privacy Calculus and Prospect Theory

When assessing the health donation behavior of individuals, it is first necessary to understand the willingness to disclose personal health information in general. In this context, prior research has often used the privacy calculus theory, which describes the cost-benefit assessment of privacy costs (i.e., privacy risks) and anticipated benefits individuals undertake before disclosing personal information (Dinev et al., 2006). The basic assumption of the privacy calculus is that individuals compare the risks and benefits before engaging in a behavior and only adopt new technologies or disclose personal information when the benefits outweigh the risks (Culnan & Armstrong, 1999).

However, it has been found that the willingness to disclose personal information changes across different contexts and situations. For example, biases, heuristics, and misattributions may directly influence (privacy-related) attitudes and behaviors (Dinev et al., 2015; Thaler & Sunstein, 2021).

This finding can be supported by the prospect theory. The prospect theory describes that positive (gain-framed) and negative (loss-framed) messages have different effects on behaviors, although the message's content remains the same (Kahneman & Tversky, 1979). When faced with two choices with different degrees of risk- a person's preference will be influenced by how the choices are framed. If the choices emphasize potential losses, individuals are likely to choose a risky option to prevent those losses. However, if the choices emphasize potential gains, individuals are generally less inclined to select options involving risk to secure those gains (Kahneman & Tversky, 1979).

Positively framed messages emphasize the advantages, whereas negatively framed statements emphasize the disadvantages of a particular behavior. The literature shows that this kind of *attribute framing* should be used depending on the situation. For example, to strengthen health prevention behavior, gain-framed messages (i.e., ‘Exercising regularly can help you lose weight’) are more successful than loss-framed statements (i.e., ‘Not exercising regularly can make you gain weight’) (Gallagher & Updegraff, 2012). On the other side, there are indications that loss-framed messages are more likely to increase detection behavior (i.e., security technology adoption or screening) (Shropshire et al., 2010).

In the health context, gain-framed messages positively altered attitudes toward adopting electronic health records despite the perception of high privacy concerns (Angst & Agarwal, 2009) and positively influenced the disclosure of personal health information (Becker et al., 2020). This indicates that attribute framing can be applied in scenarios where privacy concerns may be prevalent, such as in the context of donating personal health information for medical research.

In summary, multiple factors influence individuals' privacy behavior, including the perception of perceived benefits and risks and biases, heuristics, and personal perceptions.

2.2. Personal Health Information Disclosure

In the context of healthcare, prior research has used the theory of the privacy calculus to assess the role of anticipated benefits and perceived privacy concerns on the acceptance of health technologies (Fox, 2020), the intention to opt-in to an electronic health record (Angst & Agarwal, 2009), and the willingness to disclose personal health information (Kordzadeh & Warren, 2017; Zhang et al., 2018). The results suggest that health information privacy concerns can impact the intention to use and how individuals use different health technologies (Fox, 2020). For example, individuals may not share personal health information when they fear that a potential loss or misuse of their information may have severe consequences such as economic discrimination (i.e., insurance providers), stigmatization, or fraud (Bridges, 2011).

At the same time, it has been found that perceived benefits increased the intention to disclose health information and adopt health technologies (Fox, 2020; Liang et al., 2017). In this context, benefits have been operationalized as positive personal outcomes (Kordzadeh & Warren, 2017), such as improved diagnosis, access to information at any time, and improved efficiency with electronic health records (Fox,

2020), and perceived benefits of wearables (Zhao et al., 2018) and personal health tips and advice based on artificial intelligence (Bohr & Memarzadeh, 2020).

In addition, many factors such as emotion (Anderson & Agarwal, 2011), age (Zhao et al., 2018), perceived health status (Zhang et al., 2018), and health information security awareness (Park et al., 2019) have been found to directly or indirectly influence the intention to disclose personal health information and to adopt health technologies. This indicates that both the enhanced privacy theory model and the prospect theory apply to the context of health information disclosure.

In summary, current research indicates that perceived privacy risks may negatively, and anticipated benefits positively influence the intention to disclose personal health information and that individual factors such as the perceived health severity are relevant when using the privacy calculus theory and examining the privacy behavior of individuals.

2.3. Hypotheses Development and Proposed Model

Although it is possible to realize both personal and societal benefits, only a few studies distinguish between these benefit types (Fernandes & Costa, 2021; Kordzadeh & Warren, 2017). Nonetheless, in the context of health, it may be important to investigate the influence of societal benefits on the intention to donate personal health information, as it is possible that other motivations, such as social norms and altruism (White & Peloza, 2009; White & Simpson, 2013), have a more substantial impact on the behavior than self-benefitting motives. On the other side, it has been found that the strongest predictor of *not* donating personal data was the lack of direct benefits (Skatova & Goulding, 2019). This would contribute to the role of immediate gratification when deciding to disclose personal information (Acquisti, 2004).

Health data donation has by nature the unique characteristic that in the moment of donation, it is not known whether possible benefits will be achieved at all. Accordingly, when deciding to donate health information, individuals must overcome their privacy concerns and the uncertainty of benefit realization (McCarter et al., 2010). We believe that altruistic motives are not strong enough to override both, and accordingly, we propose the following hypothesis:

H1: Self-benefitting appeals are more successful in increasing the intention to donate personal health information than societal-benefitting appeals.

We believe that in the context of health data donation, the decision can also be altered by the

mechanisms of framing, as the mere presentation of information with a positive or negative framing can already change individuals' perceptions and awareness when deciding to disclose information (Acquisti et al., 2013). In the context of electronic health records, it could be found that a pre-manipulation attitude can be altered by argument framing even despite high privacy concerns (Angst & Agarwal, 2009). They argue that message content is more likely to positively influence behaviors if the attribute framing leads to positive thoughts. Further, individuals who received positively framed messages tend to disclose more personal health information (Becker et al., 2020). We think that the same mechanisms apply to health data donation and that these findings support the following hypotheses:

H2: Positively framed messages are more successful in increasing the intention to donate personal health information than negatively framed messages.

From everyday life, we know that when something matters to us, we may behave differently or even irrationally than in other situations - even when it may contradict our beliefs. For example, although some individuals have healthy habits and take preventive measures to maintain good health when being confronted with a deadline, they override their usual rational self-care behavior and prioritize work over leisure and sleep.

For many individuals, their health is very important to them, and, if possible, they would like to protect it at all costs. We believe that when confronted with a health condition that may have a negative influence on their (perceived) quality of life, individuals tend to be more likely to engage in behavior that helps to minimize negative consequences. For example, one study found that physical disability strengthens the effect of perceived benefits on information use (Liang et al., 2017).

We believe that individuals tend to be more open about donating personal health information when they are confronted with a severe health condition as the possible anticipated benefits outweigh the risks. Accordingly, we propose the following hypotheses:

H3: A severe health condition has a greater positive influence on the intention to donate personal health information than a mild health condition.

The proposed research model is summarized in Figure 1 according to the aforementioned hypotheses.

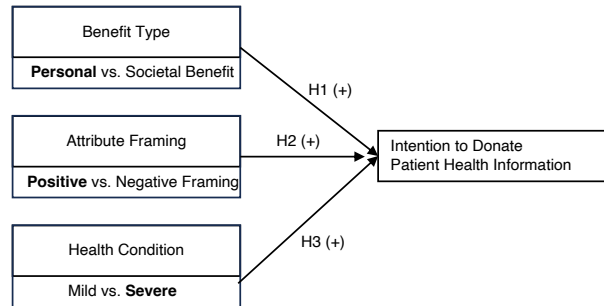


Figure 1 Proposed research model

3. Research Methodology

3.1. Experimental Design

A scenario-based online experiment was conducted to test our hypotheses and proposed research model. The scenario describes a fictitious event in which the participants are asked if they would be willing to donate their personal health information to medical research.

For setting the stage, we asked survey participants to imagine that they use a health app that allows them to save all kinds of personal health information including steps, sleep activity, symptoms, disease development, and adverse drug effects. Afterward, each study participant was randomly assigned to one of two health condition scenarios. The individuals received the information that they visited a health practitioner as they experienced symptoms of a mild cold (mild health condition scenario) or of chronic obstructive lung disease (COPD) (severe health condition scenario). We chose the health condition COPD as it is commonly known as *smoker's cough* and is characterized by a severe cough and a decreasing quality of life (World Health Organization, 2022).

After the randomization of health conditions, all participants received the information, that after visiting the health practitioner, they would open the health app intending to save the health information. Before being able to do so, the individuals receive a pop-up notification.

Each study participant was randomly assigned to one of the four scenario messages (personal benefit x positive framing, personal benefit x negative framing, societal benefit x positive framing, societal benefit x negative framing). The benefit appeal was manipulated by highlighting the benefit for the person or the society 'you yourself can (*not*) profit' in the personal benefit scenario and 'the society can (*not*) profit' in the societal benefit scenario. The attribute framing was manipulated by saying that 'if you agree to donate, you accelerate medical research' in the positively framed message and

'if you do not agree to donate, you slow down medical research' in the negatively framed message.

After the randomization, we measured the intention to donate personal health information. In the second part of the experiment, the participants received the other health condition scenario with the same scenario message which was again followed by measuring the intention to donate personal health information.

benefit appeal (between-subject)		
attribute framing (between-subject)	<p>personal benefit x positive framing "you yourself can profit" "if you agree to donate, you accelerate medical research"</p>	<p>societal benefit x positive framing "the society can profit" "if you agree to donate, you accelerate medical research"</p>
	<p>personal benefit x negative framing "you yourself can not profit" "if you do not agree to donate, you slow down medical research"</p>	<p>societal benefit x negative framing "the society can not profit" "if you do not agree to donate, you slow down medical research"</p>
health condition (within-subject)		

Table 1 Experimental Design

Accordingly, we used a vignette design with a 2 (personal vs. societal benefit) x 2 (positively vs. negatively framed message) x 2 (mild vs. severe health condition) mixed-subject design (Table 1). The health condition served as a within-subject factor, whereas the benefit appeal and the attribute framing served as between-subject factors. To ensure that the random distribution is balanced, we implemented randomization through the functionality of the Qualtrics questionnaire tool. Further, we included attention checks before the experiment and manipulation checks for all manipulated variables.

3.2. Data Collection and Sampling

Three experts from the research fields of privacy and health in information systems reviewed the questionnaire before the survey to ensure the impact of our treatment and the cleanliness of the questionnaire. Further, we performed a pre-study, which led to a revision of the treatments. We generated data through the panel data provider Prolific. We used the balanced sample function to obtain a balanced sample of female and male participants. For the sample, we used individuals living in Germany who are fluent in the German language and at least 18 years old. We decided to focus on one country to reduce biases due to different healthcare systems or levels of digitalization.

3.3. Measurement Validation

The variables were measured based on previously validated scales. The dependent variable, intention to donate personal health information, has been adapted from Bansal et al., (2010) and Venkatesh et al., (2013). Further, we adapted the control variable altruism (ALTRU) from Anderson and Agarwal, (2011) and included age and gender as control variables. The full instrument is available upon request.

In our measurement model, the standardized factor loadings for our dependent variable are above the threshold of 0.7 and Cronbach's alpha is 0.97. The values indicate adequate individual indicator validity and reliability (Hulland, 1999). To ensure construct reliability, the composite reliability must be higher than 0.7 (Fornell & Larcker, 1981). Out of our model, the construct for the dependent variable achieved composite reliability above 0.9.

3.4. Data Analysis

Due to the mixed-subjects design and the use of health condition as a within-subject factor and benefit appeal and attribute framing as between-subject factors, we utilized a mixed ANOVA. A mixed ANOVA is the preferred analysis method for a mixed-subjects design, as it compares several means when there are two or more independent variables, with at least one being a within-subject factor and one a between-subject factor. We performed the analysis using the *R Studio Version 2023.03.0+386* statistics software and the package *lmerTest*. We then used the Type III Analysis of Variance Table with Satterthwaite's method to obtain the results of the ANOVA (Kuznetsova et al., 2017).

To account for fixed and random effects, we used the benefit appeal, attribute framing, health condition, altruism, gender, and age as fixed effects and included the subject and health condition as random effects.

4. Analysis and Results

4.1. Descriptive Statistics

In total, 216 participants took part in our study. We excluded 8 participants because data was missing, or the attention check was not passed. For our analysis, we included a sample size of n=208, with 105 individuals identified as male, 99 as female, and four as divers. Of all participants, 79.4% were between 18 and 34 years old, and 45% indicated a high school diploma as the highest level of education. 34.4% of the individuals use a health app that allows them to save personal health information, 19.6% donated at least once health data,

and 23.9% any other data. Furthermore, 76.1% of all surveyed individuals are at least partly satisfied with the German healthcare system. As for the experiment, each session and resulting questionnaire lasted about ten minutes per individual.

The size of each condition can be found in Table 2.

	Personal Benefit	Societal Benefit
Positive Framing	n = 52	n = 52
Negative Framing	n = 51	n = 53

Table 2 Treatment Overview

We analyzed the differences in the different conditions. Personal benefit x positively framed messages lead on average to a higher intention to donate personal health information ($M = 5.20, SD = 1.68$) than individuals in the other-oriented x positively framed message condition ($M = 4.41, SD = 1.97$), and then individuals in the negatively framed message conditions (personal x negative: $M = 4.67, SD = 1.74$, societal x negative: $M = 4.26, SD = 1.80$). Further, the severe health condition led on average to a higher intention to donate personal health information ($M = 4.80, SD = 1.77$) than the mild health condition ($M = 4.45, SD = 1.88$).

The results indicate that the manipulations worked as expected for benefit appeal $t(201.24) = -2.44, p = .01$, and for attribute framing $t(193.05) = -9.09, p < .000$. Further, there is a difference in the mean for the manipulation of health condition ($M_{mild} = 6.08, SD = 1.04; M_{sev} = 1.64, SD = 0.82$). Therefore, we assume that all manipulations worked as planned.

4.2. Results of Mixed ANOVA

A Levene's test was conducted to check for homogeneity of variance ($F = 1.1774, p = .31$). We found no evidence for heteroscedasticity in our data. Before conducting the mixed ANOVA, we deployed a box plot diagram to visualize the data distribution of the single groups for benefit appeal and health condition (Figure 2) and attribute framing and health condition (Figure 3). In the boxplots, personal benefit and positively framed messages are coded as 0 and societal benefit and negatively framed messages as 1.

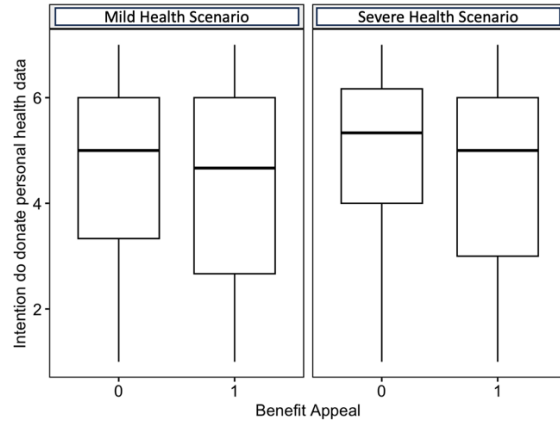


Figure 2 Box plot for intention to donate based on benefit appeal scenario

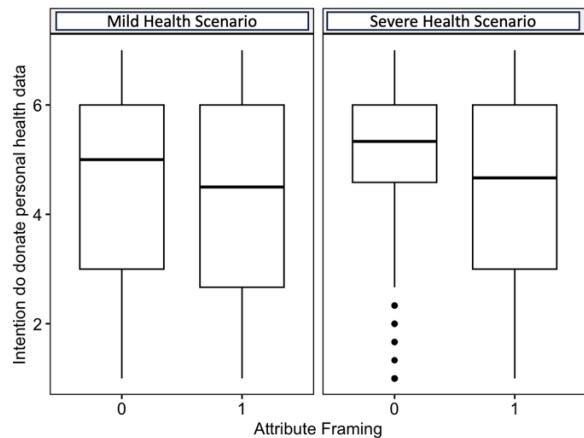


Figure 3 Box plot on intention to donate based on attribute framing scenario

Variables	df	SS	F	p
BEN	1	9.72	8.65	.00**
ATT	1	4.85	4.32	.04*
HC	1	12.23	10.89	.00**
AGE	1	2.16	1.92	.17
GEN	1	6.05	5.39	.02*
ALTRU	1	8.98	7.99	.00**

Notes: df = degrees of freedom, SS = Sum of Squares, F = F-statistic, p = p-value
 BEN = Benefit Appeal (0 = Personal, 1 = Societal); ATT = Attribute Framing (0 = Positive, 1 = Negative); HC = Health Condition (0 = Mild, 1 = Severe); GEN = Gender, ALTRU = Altruism
 Signif. Codes: ** <.01; * <.05

Table 3 Mixed ANOVA

Based on Satterthwaite's method, we identified three main effects, one for each independent variable. The results are depicted in Table 3. Further, we checked

for possible interactions between the independent variables but found no statistically significant interactions. The results for each hypothesis are described in the following.

Hypothesis 1: Based on the analysis, we found a statistically significant main effect of benefit appeal on the intention to donate personal health information, ($M_{per} = 4.49$, $SD = 1.73$, $M_{soc} = 4.32$, $SD = 1.88$; $F(1,202) = 8.65$, $p < .01$). It can be concluded that appeals which highlight the personal benefit, lead to a significantly higher intention to donate personal health information. Therefore, H1 can be confirmed.

Hypothesis 2: Regarding our second hypothesis, the analysis demonstrated that the effect of attribute framing was significant for the intention to donate personal health information ($M_{pos} = 4.81$, $SD = 1.87$, $M_{neg} = 4.44$, $SD = 1.78$; $F(1,202) = 4.32$, $p = .04$.) Accordingly, the H2 can also be confirmed.

Hypothesis 3: Finally, H3 can be confirmed as well, as we found a significant effect for the health condition on the intention to donate personal health information ($M_{mild} = 4.45$, $SD = 1.88$, $M_{sev} = 4.80$, $SD = 1.78$; $F(1,202) = 10.89$, $p < .01$).

5. Discussion

5.1. Summary of Findings

The study investigates the role of benefit appeals, attribute framing, and health conditions on the intention to donate personal health information. The basic assumption of this study is that the privacy calculus theory, meaning that individuals weigh benefits and perceived risks, can be altered by external factors, including the framing of messages.

Our findings support evidence of the influence of message framing on the intention to donate personal health information, suggesting that depending on the design of the message (attribute framing) and the highlighted benefit (benefit appeal), the intention to donate personal health information can be increased. We found that positively framed messages are more likely to increase the intention to donate personal health information than negatively framed messages. These results support the current literature (Acquisti et al., 2013; Becker et al., 2020; Gallagher & Updegraff, 2012).

Further, our results indicate that, despite the potential societal benefit, individuals are more likely to donate their personal health information when the framed message highlights self-benefits. Prior research has led to mixed results regarding the potential of benefit appeals. For example, one study found that benefit appeals are effective if they appeal to the citizens' altruistic and collective effort-oriented

concerns for the use of disease tracing applications in times of pandemics (Trang et al., 2020). One explanation for this mixed finding could be that during times of pandemics or other health emergencies, individuals feel that providing health data might lead to a faster benefit as society focuses on resolving the situation. This would not necessarily mean that individuals themselves would benefit, but that a direct benefit to society can be seen relatively fast or at least anticipated.

Our findings indicate that individuals are more likely to disclose personal health information when confronted with a rather severe health condition than compared to a rather mild health condition in the context of health data donation. This finding supports the literature on the general influence of health on the disclosure of personal health information (Kordzadeh & Warren, 2017; Liang et al., 2017; Zhang et al., 2018).

In current data donation ambitions, donated health data is mostly from individuals who may already be sick. However, for medical research and the health care system, it would be interesting to have more data on individuals who are healthy and only become sick in the future. This would allow us to identify why individuals may experience a severe health condition in the first place and what secondary prevention measures should be applied to reduce costs and the burden on the healthcare system. Therefore, it is crucial to identify factors influencing healthy individuals to donate personal health information.

5.2. Implications, Limitations, and Future Research Directions

This study contributes to information system research in multiple ways.

First, from a theoretical standpoint, this study theorizes on the privacy calculus from the benefit perspective by identifying the role of benefit types – namely, societal and personal benefits for donating personal health information. By doing so, we follow a recent call to move away from only a self-centered privacy calculus (Nabity-Grover et al., 2020).

Further, we contribute to the privacy literature stream by extending knowledge regarding phenomena with multi-layered benefit structures in general and the relatively new direction in information systems of citizen- and society-centric technological advancements that require the mobilization of mass acceptance (Trang et al., 2020) within the outstanding context of personal health information (Anderson & Agarwal, 2011).

In addition to the theoretical contribution, our results offer implications for practitioners.

First, the study suggests that benefit appeals and attribute framing can effectively influence individuals'

intention to donate their health information. Organizations and policymakers can design persuasive campaigns to encourage more individuals to contribute their health information for the greater good by highlighting the potential personal benefits and positive outcomes of sharing such data.

Secondly, the study recognizes that the severity of health conditions can influence the decision to donate personal health information. Understanding this influence can help organizations and researchers design strategies sensitive to the specific needs and concerns of individuals with different health conditions.

Nonetheless, three limitations merit further consideration. Our online experiment is based on a fictitious scenario in which participants are supposed to imagine a situation. As we aimed to maximize internal validity in a randomized controlled trial, this reduced external validity and realism. Furthermore, the study relied on self-reported data, including participants' intentions to donate personal health information. Self-reported measures are subject to biases, such as social desirability bias, which can influence participants' responses. Accordingly, it would be interesting for future research to investigate the willingness to donate personal health information in a real-life scenario. This could, for example, include active users of an electronic health record or other health apps.

For the sake of comparability, we decided to focus on one country to reduce biases due to external factors such as the health system, or the degree of digitization. Accordingly, the results of this study may not apply to other cultural and geographical contexts. To accelerate medical research and create value for all, collecting more data from culturally diverse groups is necessary. Future research could include individuals who are currently underrepresented in medical trials, such as individuals from the global south or minority groups.

Furthermore, this study focused on investigating the influence of benefit appeals, attribute framing, and health condition, while other factors may also impact the intention to donate personal health information.

6. Conclusion

In conclusion, we demonstrated that positively framed messages highlighting a personal benefit positively influence the intention to donate personal health information. Further, individuals who are confronted with a more severe health condition are more likely to donate their personal health information.

Based on our results, which were obtained from a fictitious online experiment with 208 participants, we can conclude that the long-standing theory of prospect theory can also be connected to today's digital health era. Accordingly, both researchers and practitioners

should be aware of the possibilities of prospect theory when developing persuasive campaigns to encourage individuals to contribute to the greater good, and when investigating the influence of external factors on data donation behavior.

Our research contributes to the fields of information systems in health and privacy by extending knowledge regarding the decision-making of individuals in the context of multi-layered benefit structures and the relatively new direction in information systems of citizen- and society-centric technological advancements that require the mobilization of mass acceptance within the context of personal health information.

7. References

- Acquisti, A. (2004). Privacy in electronic commerce and the economics of immediate gratification. *Proceedings of the 5th ACM Conference on Electronic Commerce*, 21–29. <https://doi.org/10.1145/988772.988777>
- Acquisti, A., Adjerid, I., & Brandimarte, L. (2013). Gone in 15 Seconds: The Limits of Privacy Transparency and Control. *IEEE Security & Privacy*, 11(4), 72–74. <https://doi.org/10.1109/MSP.2013.86>
- Anderson, C. L., & Agarwal, R. (2011). The Digitization of Healthcare: Boundary Risks, Emotion, and Consumer Willingness to Disclose Personal Health Information. *Information Systems Research*, 22(3), 469–490. <https://doi.org/10.1287/isre.1100.0335>
- Angst, C., & Agarwal, R. (2009). Adoption of Electronic Health Records in the Presence of Privacy Concerns: The Elaboration Likelihood Model and Individual Persuasion. *MIS Quarterly*, 33, 339–370. <https://doi.org/10.2307/20650295>
- Bates, D. W., Spell, N., Cullen, D. J., Burdick, E., Laird, N., Petersen, L. A., Small, S. D., Sweitzer, B. J., & Leape, L. L. (1997). The costs of adverse drug events in hospitalized patients. Adverse Drug Events Prevention Study Group. *JAMA*, 277(4), 307–311.
- Becker, M., Matt, C., & Hess, T. (2020). It's Not Just About the Product: How Persuasive Communication Affects the Disclosure of Personal Health Information. *ACM SIGMIS Database: The DATABASE for Advances in Information Systems*, 51(1), 37–50. <https://doi.org/10.1145/3380799.3380804>
- Bietz, M., Patrick, K., & Bloss, C. (2019). Data Donation as a Model for Citizen Science Health Research. *Citizen Science: Theory and Practice*, 4(1), 6. <https://doi.org/10.5334/cstp.178>
- Bohr, A., & Memarzadeh, K. (2020). The rise of artificial intelligence in healthcare applications. *Artificial Intelligence in Healthcare*, 25–60. <https://doi.org/10.1016/B978-0-12-818438-7.00002-2>
- Bridges, J. (2011). *The privacy risks of sharing health info online*. ReputationDefender. <https://www.reputationdefender.com/blog/privacy/privacy-risks-sharing-health-info-online>
- Cherif, E., Bezaz, N., & Mzoughi, M. (2021). Do personal health concerns and trust in healthcare providers

- mitigate privacy concerns? Effects on patients' intention to share personal health data on electronic health records. *Social Science & Medicine*, 283, 114146. <https://doi.org/10.1016/j.socscimed.2021.114146>
- Culnan, M. J., & Armstrong, P. K. (1999). Information Privacy Concerns, Procedural Fairness, and Impersonal Trust: An Empirical Investigation. *Organization Science*, 10(1), 104–115. <https://doi.org/10.1287/orsc.10.1.104>
- Dinev, T., Bellotto, M., Hart, P., Russo, V., Serra, I., & Colautti, C. (2006). Privacy calculus model in e-commerce – a study of Italy and the United States. *European Journal of Information Systems*, 15(4), 389–402. <https://doi.org/10.1057/palgrave.ejis.3000590>
- Dinev, T., McConnell, A. R., & Smith, H. J. (2015). Research Commentary—Informing Privacy Research Through Information Systems, Psychology, and Behavioral Economics: Thinking Outside the “APCO” Box. *Information Systems Research*, 26(4), 639–655. <https://doi.org/10.1287/isre.2015.0600>
- Fernandes, T., & Costa, M. (2021). Privacy concerns with COVID-19 tracking apps: A privacy calculus approach. *Journal of Consumer Marketing*, 40(2), 181–192. <https://doi.org/10.1108/JCM-03-2021-4510>
- Fornell, C., & Larcker, D. F. (1981). Evaluating Structural Equation Models with Unobservable Variables and Measurement Error. *Journal of Marketing Research*, 18(1), 39–50. <https://doi.org/10.2307/3151312>
- Fox, G. (2020). “To protect my health or to protect my health privacy?” A mixed-methods investigation of the privacy paradox. *Journal of the Association for Information Science and Technology*, 71(9), 1015–1029. <https://doi.org/10.1002/asi.24369>
- Fürstenau, D., Klein, S., Vogel, A., & Auschra, C. (2021). Multi-sided platform and data-driven care research. *Electronic Markets*, 31(4), 811–828. <https://doi.org/10.1007/s12525-021-00461-8>
- Gallagher, K. M., & Updegraff, J. A. (2012). Health Message Framing Effects on Attitudes, Intentions, and Behavior: A Meta-analytic Review. *Annals of Behavioral Medicine*, 43(1), 101–116. <https://doi.org/10.1007/s12160-011-9308-7>
- Gonçalves, R. B., & de Figueiredo, J. C. B. (2022). Effects of perceived risks and benefits in the formation of the consumption privacy paradox: A study of the use of wearables in people practicing physical activities. *Electronic Markets*, 32(3), 1485–1499. <https://doi.org/10.1007/s12525-022-00541-3>
- Hulland, J. (1999). Use of partial least squares (PLS) in strategic management research: A review of four recent studies. *Strategic Management Journal*, 20(2), 195–204. [https://doi.org/10.1002/\(SICI\)1097-0266\(199902\)20:2<195::AID-SMJ13>3.0.CO;2-7](https://doi.org/10.1002/(SICI)1097-0266(199902)20:2<195::AID-SMJ13>3.0.CO;2-7)
- Ibrahim, H., Liu, X., Zariffa, N., Morris, A. D., & Denniston, A. K. (2021). Health data poverty: An assailable barrier to equitable digital health care. *The Lancet Digital Health*, 3(4), e260–e265. [https://doi.org/10.1016/S2589-7500\(20\)30317-4](https://doi.org/10.1016/S2589-7500(20)30317-4)
- Kahneman, D., & Tversky, A. (1979). Prospect Theory: An Analysis of Decision under Risk. *Econometrica*, 47(2), 263–291. <https://doi.org/10.2307/1914185>
- Kohli, R., & Tan, S. S.-L. (2016). Electronic Health Records: How Can IS Researchers Contribute to Transforming Healthcare? *MIS Quarterly*, 40(3), 553–573.
- Kordzadeh, N., & Warren, J. (2017). Communicating Personal Health Information in Virtual Health Communities: An Integration of Privacy Calculus Model and Affective Commitment. *Journal of the Association for Information Systems*, 18, 45–81. <https://doi.org/10.17705/1jais.00446>
- Kuznetsova, A., Brockhoff, P. B., & Christensen, R. H. B. (2017). lmerTest Package: Tests in Linear Mixed Effects Models. *Journal of Statistical Software*, 82, 1–26. <https://doi.org/10.18637/jss.v082.i13>
- Liang, H., Xue, Y., East Carolina University, Zhang, Z., & Shanghai Jiao Tong University, China. (2017). Understanding Online Health Information Use: The Case of People with Physical Disabilities. *Journal of the Association for Information Systems*, 18(6), 433–460. <https://doi.org/10.17705/1jais.00461>
- McCarter, M. W., Rockmann, K. W., & Northcraft, G. B. (2010). Is it even worth it? The effect of loss prospects in the outcome distribution of a public goods dilemma. *Organizational Behavior and Human Decision Processes*, 111(1), 1–12. <https://doi.org/10.1016/j.obhdp.2009.06.003>
- Nabity-Grover, T., Cheung, C. M. K., & Thatcher, J. B. (2020). Inside out and outside in: How the COVID-19 pandemic affects self-disclosure on social media. *International Journal of Information Management*, 55, 102188. <https://doi.org/10.1016/j.ijinfomgt.2020.102188>
- Park, E. H., Kim, J., Wiles, L. L., & Park, Y. S. (2019). Factors affecting intention to disclose patients' health information. *Computers & Security*, 87, 101340. <https://doi.org/10.1016/j.cose.2018.05.003>
- Renault, M. (2021). How patient data underpin COVID-19 research. *Nature Medicine*, 27(9), Article 9. <https://doi.org/10.1038/s41591-021-01493-5>
- Shropshire, J. D., Warkentin, M., & Johnston, A. C. (2010). Impact of Negative Message Framing on Security Adoption. *Journal of Computer Information Systems*, 51(1), 41–51. <https://doi.org/10.1080/08874417.2010.11645448>
- Sisco, M. R., & Weber, E. U. (2019). Examining charitable giving in real-world online donations. *Nature Communications*, 10(1), Article 1. <https://doi.org/10.1038/s41467-019-11852-z>
- Skatova, A., & Goulding, J. (2019). Psychology of personal data donation. *PloS One*, 14(11), e0224240. <https://doi.org/10.1371/journal.pone.0224240>
- Spajić, D. (2021). *The German corona-data-donation-app as an example of the concept of data donation*. CITIP Blog. <https://www.law.kuleuven.be/citip/blog/the-german-corona-data-donation-app-as-an-example-of-the-concept-of-data-donation/>
- Thaler, R. H., & Sunstein, C. R. (2021). *Nudge: The Final Edition*. Yale University Press.
- Trang, S., Trenz, M., Weiger, W. H., Tarafdar, M., & Cheung, C. M. K. (2020). One app to trace them all? Examining app specifications for mass acceptance of contact-tracing apps. *European Journal of Information*

- Systems*, 29(4), 415–428.
<https://doi.org/10.1080/0960085X.2020.1784046>
- Vitale, C., Fini, M., Spoletini, I., Lainscak, M., Seferovic, P., & Rosano, G. M. (2017). Under-representation of elderly and women in clinical trials. *International Journal of Cardiology*, 232, 216–221.
<https://doi.org/10.1016/j.ijcard.2017.01.018>
- White, K., & Peloza, J. (2009). *Self-Benefit versus Other-Benefit Marketing Appeals: Their Effectiveness in Generating Charitable Support*.
<https://doi.org/10.1509/jmkg.73.4.109>
- White, K., & Simpson, B. (2013). When Do (and Don't) Normative Appeals Influence Sustainable Consumer Behaviors? *Journal of Marketing*, 77(2), 78–95.
<https://doi.org/10.1509/jm.11.0278>
- World Health Organization. (2022). *Chronic obstructive pulmonary disease (COPD)*. [https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-\(copd\)](https://www.who.int/news-room/fact-sheets/detail/chronic-obstructive-pulmonary-disease-(copd))
- Zhang, X., Liu, S., Chen, X., Wang, L., Gao, B., & Zhu, Q. (2018). Health information privacy concerns, antecedents, and information disclosure intention in online health communities. *Information & Management*, 55(4), 482–493.
<https://doi.org/10.1016/j.im.2017.11.003>
- Zhao, Y., Ni, Q., & Zhou, R. (2018). What factors influence the mobile health service adoption? A meta-analysis and the moderating role of age. *International Journal of Information Management*, 43, 342–350.
<https://doi.org/10.1016/j.ijinfomgt.2017.08.006>