

"Others Have the Right to Know": Determinants of Willingness to Share COVID-19-Related Health Symptoms

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Abstract

Consideration for data privacy is a potentially significant factor behind user-apprehension regarding sharing personal medical information (e.g., disease symptoms), even during the COVID-19 pandemic. In this study, we set out to unpack the extent to which privacy (and related) factors influence people's perceptions of data sharing. Specifically, we designed and deployed a survey (N=304) with both qualitative and quantitative questions concerning willingness to share COVID-19 related medical information with others. Our findings indicate that although an individual might feel strongly about maintaining their privacy in general, in context of a global pandemic, altruism may outweigh these concerns. This may be especially true for others who are frequent contacts. We discuss the implications of societal duty having a stronger effect on willingness to disclose medical information than privacy amidst a pandemic.

1 Introduction

The disclosure of medical information during a pandemic has the potential to help slow the spread of the disease. According to the World Health Organization, "when systematically applied, contact-tracing will break the chains of transmission of an infectious disease and is thus an essential public health tool" [1]. Moreover, concealment of a positive diagnosis has been shown to result in negative health outcomes [10]. Consequently, it is important to consider attitudes towards sharing potentially sensitive medical information that would be beneficial from a public health standpoint.

Many studies have found that a majority of U.S. citizens consider their personal health information to be "very sensitive" [6]. However, recent studies have uncovered possible ways in which the COVID-19 pandemic has altered individuals' perceptions of sharing personal information and digital data [6, 11]. Past studies have primarily looked at privacy attitudes towards contact tracing and willingness to disclose health and COVID-19 status to various organizations. However, taking a more proactive approach to prevent contact and transmission before one has even been diagnosed could more effectively prevent the spread of disease. Thus, we investigate people's attitudes about sharing COVID-related symptoms regardless of diagnosis. Understanding people's attitudes about sharing this information will allow us to better design proactive contact tracing apps that might share this type of information. To that end, this poster will look into the following research question: *How do privacy concerns affect willingness to disclose one's COVID-related symptoms to various audiences?*

To answer this question, we deployed a nationally representative survey in the U.S. consisting of 304 respondents. Our analysis of the survey data suggests that participants actively perform a *privacy calculus* when deciding to share COVID-19 related health symptoms. Altruism was the primary benefit which participants considered whereas privacy concerns were the main risks. When frequency of contact is higher, individuals feel a stronger sense of altruism. Despite being worried that companies can access their online data, participants found it acceptable, and even essential, to share symptoms with those closest to them. However, when frequency of contact is lower, privacy concerns are more integral to shaping participants' willingness to share.

2 Background and Related Work

We introduce our theoretical framework, Privacy Calculus, and then review literature on health information-sharing as well as privacy concerns in context of the COVID-19 pandemic.

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Privacy calculus: Individuals often weigh perceived risks against the benefits they could gain from sharing private information or engaging in other online activities. This behavior is known as privacy calculus [13]. The privacy calculus model has proven useful for understanding decisions in a broad range of domains from understanding social networking services to contact tracing apps [5, 14]. For example, in the context of social networking platforms, Trepte et al. showed the positive impact that peer sharing (i.e., similarity to peer and how frequently peers share) has on the amount an individual is willing to disclose, while unmet “expectations of support” and privacy concerns decrease willingness to share information [14]. Drawing from the perspective of the privacy calculus framework, our study reveals that people do consider both benefits and drawbacks to sharing medical information at the time of COVID-19.

Factors shaping health information disclosure decisions:

Use of contact tracing apps in a global pandemic is a quintessential example of a privacy trade-off between “expected loss of privacy” and the “potential gain of disclosure” [8]. There are many factors that play a role in shaping both risks and benefits. For example, Fernandes et al. studied willingness to use contact tracing apps and found that younger people do so in favor of societal benefit, whereas the older generations are more motivated by personal benefit and are more wary of privacy concerns. This was due to younger individuals being more familiar with technology, feeling a greater sense of control over their information, as well as believing themselves less affected by the virus. Because of this, societal benefit was found to be the primary determining factor of usage for the younger population. Meanwhile, the risks were weighed more heavily by their older counterparts [5]. Our research complements these earlier findings about contact tracing app adoption by exploring the privacy-related and societal factors that affect health-related disclosures beyond what is typically shared in contact tracing apps.

Privacy concerns amidst the COVID-19 pandemic: Much research has been done in regard to the effects of the COVID-19 pandemic on shaping privacy attitudes, and vice versa [4, 6]. A study by Milsom et al. showed that “concerns about privacy and a lack of trust in government [are] two key variables that hinder adoption” of contact tracing apps [2]. Following the COVID-19 outbreak, it has also been shown that privacy concerns have increased in regards to government use of data and decreased with respect to medical uses such as research [6]. Participants in a study by Biddle et al. became “less concerned about the use of their personal data by organizations broadly, compared to their sentiments before the pandemic” [3, 6].

One study found that pre-pandemic, a majority of individuals were wary of sharing social media, search history, location, and medical records with for-profit companies, and that many were hesitant to share with anyone. However, following the pandemic, the greater portion of participants were willing to

share in the “interest of public health and safety” [11]. Understanding the purpose of their data was paramount in their willingness to disclose. Utz et al. noted how the difference in data sharing norms between countries (e.g., mistrust in government backed apps in the U.S. and Germany, concerns of potential stressors in China) affected their willingness to share information and participate in contact tracing, symptom checks, quarantine enforcement, and health certificates [15]. For example, Trang et al. studied determining factors in usage of contact tracing apps in Germany and identified “social benefits and convenience” as more important than privacy [12]. Another study noted that general willingness to share in a variety of settings (e.g., with government, apps, social media) in 2019 was dictated by an assortment of variables, such as gender, age, and education. In 2021, it was primarily determined by political party and Hispanic ethnicity [6].

In a recent study, a group of participants were asked immediately before the pandemic began whether they would be willing to share their recent contacts and health status with public health researchers. The same participants were asked once again after the pandemic had begun. It was found that a majority (76.9%) of the participants who initially were unwilling to share this data were now willing [11]. A possible reason for this phenomena is that collective-good appeals have been found to be an effective motivator for “pro-social COVID-19 behavior”, such as “adoption of an exposure notification app” [4]. Howe et al. found that, overall, participants are willing to share data from clinical trials or public health interventions for secondary research use if it benefits society [7]. Our findings on the interaction of privacy and altruism in context of COVID-19 symptom data-sharing adds to this literature.

3 Methodology

To assess how privacy concerns affect willingness to disclose COVID-related symptoms we designed and deployed a survey. Our responses revealed attitudes towards the COVID-19 pandemic and inform the data presented in this poster. IRB approval was obtained for this study.

Survey instrument: In our survey we inquired about the preferences about sharing symptoms of COVID-19. For example, we asked: “You experience some symptoms of the disease, but you are not sure whether or not what you have is the disease from the pandemic. Would you be willing to share this information with others, why or why not?” Additionally, we asked them rate their comfort (using a 5-point likert scale) with sharing this information to the following audiences: “people I have frequent contact with”, “people I have occasional contact with”, and “anybody”.

Recruitment and demographics: We used a third-party survey recruitment service, Prolific, to deploy our survey. Participants were compensated \$2.50 for their time and on average

it took 14.84 minutes to complete. We then ran quality checks (e.g., checking reverse-coded items) to ensure all responses were legitimate. In total, there were 304 survey respondents in this US-based survey. We sought to ensure a representative sample of the U.S. population so that our results can be representative of current attitudes. In order to do this, we matched our participants against U.S. census data on the dimensions of age, sex, and ethnicity. The gender breakdown of our participants were 146 male, 151 female, and 5 non-binary. We received more responses from individuals who identified as liberal or very liberal (177 responses) than individuals who identified as conservative or very conservative (46 responses). There were also 74 individuals who identified as moderate. The age range of respondents was 18 to 65+ with a median age group of 35–44.

Analysis plan: In order to analyze our open-ended responses, we performed a content analysis as to why or why not participants would be willing to share their medical information with others. Two coders engaged in open coding and reconciled discrepancies through discussion.

To analyze the quantitative data, we calculated the means for each of the willingness to disclose variables. Next, we performed paired t-tests between each pair of variables to see if there was a significant difference in willingness to disclose to different audiences.

4 Limitations

We rely on self-reports rather than behavioral data. However, this allowed us to probe on hypothetical situations and future possibilities without actually disclosing potentially sensitive data.

5 Results

In this section, we will present our results regarding the factors affecting the willingness to share COVID-related symptoms. We specifically focus on two dimensions that factored into people’s disclosure decisions: The audience and altruistic attitudes about social duty.

5.1 Willing to Share COVID-19 Related Health Data Depends on Data-recipient

We found that a participant’s desire to share their COVID-19-related health symptoms differed greatly depending on audience. The result is presented in Figure 1. Participants were the most comfortable sharing their exposure status with both those they saw the most frequently and those they saw occasionally. They were the least willing to share their data with “anybody” (i.e., a random person), especially when anonymity was not guaranteed. We observed significant differences in willingness to share between an audience of “anybody” and

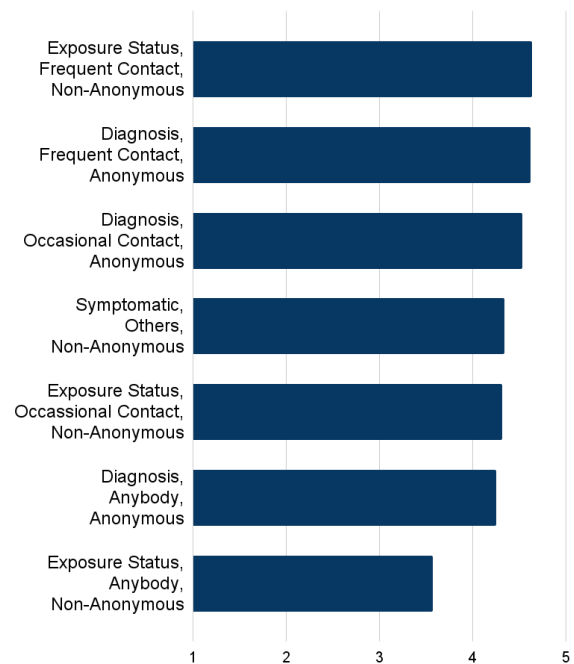


Figure 1: Average willingness to share (five is most-willing) for different <data type, data recipient, anonymity> combination.

an audience of those seen occasionally ($Z=-8.06$, $p<0.001$, 95% CI 0.09, 0.56 on a 5-point Likert scale) as well as between an audience of “anybody” and an audience of those seen frequently ($Z=-12.10$, $p<0.0001$, 95% CI -1.24, -0.89 on a 5-point Likert scale). Interestingly, anonymity did not seem to make a difference in terms of willingness to share personal information with those they saw frequently ($p = .81$, 95% CI -0.18, 0.15).

Note that willingness to share with “anybody” was statistically significantly lower than the other categories, especially without guarantees of anonymity. The open-ended responses shed light into potential reasons of this finding. Fear of potential backlash was a sentiment which some participants held, with one participant noting, “I would [share] to protect people but in the world we now live in, I would be afraid of backlash for myself”. We found another apprehension among participants: by sharing their information indiscriminately, the government would impose new restrictions or mandates. One individual stated that while this information would allow them to protect those in close contact, they would be worried about possible interference from the government, “It would let people I could have exposed know to isolate. I would be somewhat worried about being forcibly quarantined, though”. Participants were also concerned that private technology companies would misappropriate their data: “I would be willing to

share information to get a better determination on my symptoms, but I would be wary of sharing information with tech companies, who often operate unscrupulously with regard to privacy concerns”.

Thirty participants explained their willingness to share symptoms with specific situations and people. From their responses, we learned about the benefits that they feel justify sharing and thus, this suggests that people’s privacy decisions could be well represented through a privacy calculus model where people are weighing risks of sharing against benefits gained. One participant said, “I would be willing to share with close family and friends, but not just anyone”. Many respondents felt similarly, stating that they were more likely to disclose medical information to close friends, family, or those they are in most frequent contact with. This illustrated a balancing act between two goals: minimizing backlash and panic versus protecting those who were most likely to have been exposed. As multiple participants explained, “I’d tell the people I am commonly around, to let them take precautions”, and “I would share it if relevant, but also not want to generate panic.”

5.2 Role of Social Duty and Altruism in Sharing COVID-19 symptoms

In our open-ended responses, we overwhelmingly saw that people weighed the societal benefit as important enough to overcome the perceived drawbacks of sharing such information. Social responsibility was seen as one’s duty to those around us and to society as a whole. “Duty is associated primarily with constraint and is seen as coming into play in compelling individuals to perform behaviors that they would not be inclined to undertake spontaneously” [9]. Twenty-three participants explicitly mentioned that they felt this duty compelled them to disclose their symptoms. One stated, “well it’d be my moral duty to protect others from the disease”. Those who quoted this social or ethical duty noted personal feelings of accountability to protect others. Namely, supporting others’ rights to protect themselves through knowledge about potential exposure. There was often an element of obligation in these responses: “I would feel obligated to do so in order to protect those around me” and “others have the right to know”. Within the context of a global pandemic, these individuals valued greater disclosure of their personal information over their own privacy. Consequently, our results hint at the positive impact of social responsibility on sharing symptoms compared, in contrast with the impact of social pressure. Under social pressure, people might not disclose information about their symptoms; However, intrinsic feelings of social responsibility led participants to feel obligated to share their health information in order to help others. Consequently, social responsibility may overcome privacy concerns when people undertake privacy calculus in deciding to share their COVID-19 symptoms.

Our findings also indicate that while a majority of people are willing to disclose medical information, they don’t trust online companies with said information. However, the benefit and sense of altruism was much more tangible than this mistrust. Of the qualitative responses which we analyzed, 196 explicitly mentioned concern for others, while only 18 mentioned privacy concerns.

6 Discussion and Conclusion

Willingness to share was stronger towards frequent contacts, and diminished the more distant the contact (including the broad term “anybody”). This remained true for both sharing anonymously as well as being identified. Interestingly, among frequent contacts, participants were just as willing to share diagnosis as their exposure status, both anonymously and known. However, the difference between sharing anonymously and non anonymously became a wider gap with occasional contacts, and even wider gap for sharing with anybody. This could be that being anonymous becomes more important as privacy concerns become more salient for less frequent contacts. Willingness to share anonymously is likely a result of seeing great benefits for others.

When creating technologies which require the disclosure of private information, our results indicate that it is essential to be cognizant of the user’s sense of altruism. Especially in the case of matters of public health, people have the desire to protect those closest to them or society as a whole. This information can serve as a guiding factor when designing interfaces and technologies in which sensitive medical information is shared.

Because privacy is culturally dependant, it is important to understand how and whether the privacy calculus is applied in countries beyond the U.S. Previous studies show that cultural differences lead to differing privacy concerns towards technology [13]. We are in the process of deploying the survey across multiple countries including the United Kingdom and India. As an immediate future work, we will move forward to analyze the survey responses from these different countries. We will determine if the current US-based findings generalize to other cultures or if there are additional factors impacting willingness to share health data.

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References

- [1] Contact tracing in the context of covid-19: interim guidance. *World Health Organization*, 2020.

- <https://www.who.int/publications/i/item/contact-tracing-in-the-context-of-covid-19>.
- [2] Milsom L. Zillesen-H. Blason R. Gerdon F. Bach R. Kreuter F. Nosenzo D. Toussaert S. Abeler J. Altmann, S. Acceptability of app-based contact tracing for covid-19: Cross-country survey study. *JMIR mHealth and uHealth*, 2020. <https://doi.org/10.2196/19857>.
- [3] Edwards B. Gray-M. Hiscox M. McEachern S. Sollis K. Biddle, N. Data trust and data privacy in the covid-19 period. *Data & Policy*, 2022. <https://doi.org/10.1017/dap.2021.36>.
- [4] Turjeman D. Dickerson-J.P. Redmiles E.M. Dooley, S. Field evidence of the effects of privacy, data transparency, and pro-social appeals on covid-19 app attractiveness. *SocArXiv*, 2021. <https://doi.org/10.31235/osf.io/gm6js>.
- [5] Costa M. Fernandes, T. Privacy concerns with covid-19 tracking apps: a privacy calculus approach. *Journal of Consumer Marketing*, 2021. <https://doi.org/10.1108/JCM-03-2021-4510>.
- [6] Dooley S. Redemiles-E.M. Goetzen, A. Ctrl-shift: How privacy sentiment changed from 2019 to 2021. *SocArXiv*, 2022. <https://doi.org/10.48550/arXiv.2110.09437>.
- [7] Giles E. Newbury-Birch D. McColl E. Howe, N. Systematic review of participants' attitudes towards data sharing: A thematic synthesis. *Journal of Health Services Research & Policy*, 2018. <https://doi.org/10.1177/1355819617751555>.
- [8] S. Kokolakis. Privacy attitudes and privacy behaviour: A review of current research on the privacy paradox phenomenon. *Computers & Security*, 2017. <https://doi.org/10.1016/j.cose.2015.07.002>.
- [9] J. Miller. In *Motivation and Culture*, page 178, 1997. ISBN-13: 978-0-415-91509-0.
- [10] Evans A. O'Connor, A. Dishonest during a pandemic: The concealment of covid-19 information. *Journal of Health Psychology*, 2020. <https://doi.org/10.1177/1359105320951603>.
- [11] Young S Romero, R. Ethical perspectives in sharing digital data for public health surveillance before and shortly after the onset of the covid-19 pandemic. *Ethics & Behavior*, 2021. <https://doi.org/10.1080/10508422.2021.1884079>.
- [12] Trezn M. Weiger-W.H. Tarafdar M. Cheung C.M.K. Trang, S. One app to trace them all? examining app specifications for mass acceptance of contact-tracing apps. *European Journal of Information Systems*, 2020. <https://doi.org/10.1080/0960085X.2020.1784046>.
- [13] Reinecke L. Ellison-N. Yao M. Ziegele M. Trepte, S. A cross-cultural perspective on the privacy calculus. *Sage Journals*, 2017. <https://doi.org/10.1177/2056305116688035>.
- [14] Scharkow M. Dienlin-T. Trepte, S. The privacy calculus contextualized: The influence of affordances. *Computers in Human Behavior*, 2019. <https://doi.org/10.1016/j.chb.2019.08.022>.
- [15] Becker S. Schnitzler-T. Farke F.M. Herbert F. Schae-witz L. Degeling M. Dürmuth M. Utz, C. Apps against the spread: Privacy implications and user acceptance of covid-19-related smartphone apps on three continents. *arXiv*, 2021. <https://doi.org/10.48550/arXiv.2010.14245>.