

"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. To that end, 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 304 participant survey with both qualitative and quantitative questions concerning willingness to share medical information with others. Our findings indicate that although an individual might generally feel strongly about maintaining their privacy, in the scope of a global pandemic, they value altruism more, specially when they are in frequent contact with others. Thus a sense of societal duty potentially plays a larger role in determining disclosure of medical information than privacy does in times of COVID-19.

1 Introduction

The disclosure of medical information during the COVID-19 pandemic has been essential in slowing 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.

Many studies have found that a majority of U.S. citizens consider their personal health information to be "very sensi-

tive" [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]. COVID-19 tracing largely focuses on sharing diagnosed COVID-19 cases and contact tracing. 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 will 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 developed and deployed a 304 participant survey. Our analysis of the survey data suggest that participants actively use *privacy calculus* in their decision 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, in the scope of a global pandemic, 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 control participants' willingness to share.

2 Background and Related Work

Privacy calculus: Individuals often weigh the potential risk against the benefits they could gain While sharing private information or engaging in activities with a possible privacy risk. This behavior is known as privacy calculus [13]. The privacy calculus model has broad applications in the human

computer interaction community with uses in studying social networking services and contact tracing apps [5, 14]. In the context of social networking platforms Trepte et al. showed the positive impact that peer sharing (similarity to peer, and how frequently they 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]. We built on this body of work—our study uncovered the intrinsic usage of privacy calculus regarding medical information sharing at the time of COVID-19.

Factors affecting health information-sharing decision: Use of contact tracing apps in a global pandemic is a quintessential example of a privacy tradeoff between “expected loss of privacy” and the “potential gain of disclosure” [8]. There are many possible contributors to the consideration of both risks and benefits, one such being age. Fernandes et al. studied willingness to use contact tracing apps and have found that younger people do so in favor of societal benefit, whereas the older generation are more motivated by personal benefit and wary of privacy concerns. This is because younger individuals are more familiar with technology and feel a greater sense of control over their information as well as believe themselves less effected by the virus. Because of this, societal benefit is the only relevant determining factor of usage for the younger population, meanwhile the risks have more weight with their older counterparts [5]. We complemented this earlier research by exploring the privacy-related as well as societal factors that affect medical data-sharing.

Privacy concerns at the time of COVID-19: Much research has been done in regard to the effects of COVID-19 on privacy, and vice versa [4, 6]. A study by Altman et al. has shown 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 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 many of sharing with anyone. However, following the pandemic, the greater part 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 US 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 found additional support in 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.

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: “an online company”, “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, Prolificity 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 conflicting answer quality checks 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 US population. In order to do this we matched our participants with US census data on age, sex, and ethnicity. In our participants 146 were male, 151 were female, and 5 were non-binary. We received more responses from individuals who identified as liberal or very liberal (177 responses) than individuals who

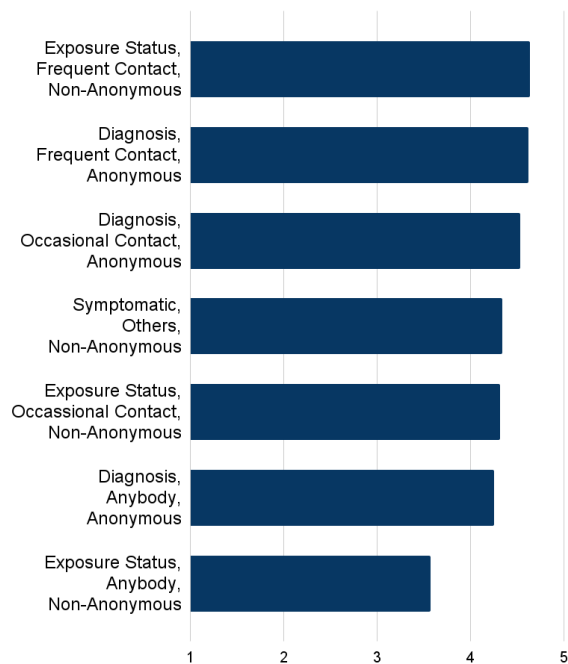


Figure 1: Average willingness to share (five is most-willing) for different <data type, data recipient, anonymity> combination.

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 coded the responses and reconciled discrepancies through discussion.

To analyze the quantitative data, We performed paired t-tests between all willingness to disclose variables.

4 Results

In this section, we will present our results regarding the factors affecting the willingness to share COVID-related symptoms. Specifically we will focus on two dimensions.

4.1 Willing to Share COVID-related Health-data Depends on Data-recipient

We found that the 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 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 learn how they use privacy calculus to justify sharing or withholding their symptoms. 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.”

4.2 Role of Social Duty and Altruism in Sharing COVID-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 is seen as one's duty to society as a whole, or your fellow man. "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 as well as the other's right to protect themselves and to knowledge pertaining to their person. There was often an element of obligation in these responses, as in, "I would feel obligated to do so in order to protect those around me" and "others have the right to know". These individuals within the context of a global pandemic adhered to a greater disclosure of personal information and less regard for privacy. Consequently, our results hint at the positive impact of social responsibility of sharing symptoms compared to social pressure. Under social pressure people might be not disclose information about the symptom; however with a feeling of social responsibility intrinsically our participants felt they are obligated to share the information to help others. Consequently social responsibility results in a privacy paradox which is unique for sharing COVID-19 symptoms.

5 Discussion

Our findings indicate that while a majority of people are willing to disclose medical information, they don't trust online companies with said information. In the case of medical disclosure for use in the COVID-19 context, the benefits outweigh this mistrust. The benefit which was a key determinant to many participants was a sense of altruism. Of the qualitative responses which we analyzed, 196 explicitly mentioned concern for others while only 18 mentioned privacy concerns.

The sense of altruism was stronger amongst close, frequent contacts, while it lessened the more distant the contact (including the broad term "anybody"). This remained true for both sharing anonymously as well as being identified. Among frequent contacts, participants were about equally willing to share diagnosis and exposure status, both anonymously and known. However, the differences between sharing anonymously and without that guarantee became greater with each further contact, occasional and anybody.

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.

Since technology is a global tool, we believe that it is important to understand opinions not just in the US, but also abroad. There have been previous studies which have shown that cultures differing in levels of collectivism or individuality had distinct privacy concerns towards technology [13]. It would be informative to see if countries with differing privacy concerns share the thought that societal duty outweighs privacy in the decision to share personal medical information. We are in the process of deploying the survey across multiple countries like United Kingdom and India. As an immediate future work, we will move forward to analyze the survey responses from different countries. We will check if the current US-based findings generalize to other cultures or there are additional factors impacting willingness to share symptom data across cultures.

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