A Privacy Paradox? Impact of Privacy Concerns on Willingness to Disclose COVID-19 Health Status in the United States

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ABSTRACT

Privacy concerns around sharing personal health information are frequently cited as hindering COVID-19 contact tracing app adoption. We conducted a nationally representative survey of 304 adults in the United States to investigate their attitudes towards sharing two types of COVID-19 health status (COVID-19 Diagnosis, Exposure to COVID-19) with three different audiences (Anyone, Frequent Contacts, Occasional Contacts). Using the Internet User's Information Privacy Concern (IUIPC) scale, we were able to identify the effect of different types of privacy concerns on sharing this information with various audiences. We found that privacy concerns around data Collection predicted lower willingness to share either type of health status to all of these audiences. However, desire for Control and for Awareness of data practices increased willingness to share health information with certain audiences. We discuss the implications of our findings.

CCS CONCEPTS

• **Security and privacy → Usability in security and privacy**; **Social aspects of security and privacy**.

KEYWORDS

Privacy Pardox; IUIPC; Information Disclosure; COVID-19

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1 INTRODUCTION

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" [11]. However, privacy concerns have acted as a hindrance for contact tracing app adoption. Altmann et al. found that "privacy and security seem to be an important impediment to the adoption of the app, particularly in Germany and the United States" [1]. Thus, understanding how people's privacy concerns affect the usage of these apps is paramount. Further studies have also shown the negative effects which privacy concerns can have on willingness to share COVID-19 related information. One such study found that individuals were unwilling to share their diagnosis because of the potential workplace discrimination they would face [7]. Consequently, understanding the relationship between privacy concerns and willingness to share is important in developing these apps.

On the other hand, some research suggests that stated privacy concerns do not necessarily impact adoption [9]. When expressed privacy concerns are contrary to an individual's actions, it is known as a privacy paradox [16]. Given these contradictory results from prior research, there may be multiple factors at play. A nuanced understanding of people's attitudes and behaviors is needed to unpack any potential privacy paradox.

Thus our research investigates whether privacy concerns actually do effect people's willingness to share certain types of COVID-19 health status data. We also recognize that willingness to share may vary based on the audience. Thus our research question is:
How do privacy concerns affect willingness to share COVID-19 health-related status with different audiences?

We conducted a nationally representative survey study (N=304) in the United States about COVID-19 attitudes and behaviors. We chose to initially focus on the U.S. as it is a highly individualistic country where privacy is heavily debated. This work draws on a subset of the survey questions to answer our research question. We use Malholtra et al.'s IUIPC subscales [10] to measure respondents' privacy concerns. We also measured their willingness to share if they were Diagnosed with COVID-19 (Diagnosis) or Exposed to COVID-19 (Exposure) with people of varying degrees of regular contact (Frequent, Occasional, Anyone).

We report on our findings that privacy concerns around each dimension of privacy measured by IUIPC does impact willingness to share to some extent, but the effect differs greatly by information type and audience.

2 BACKGROUND

In the surge of studies looking at attitudes and behaviors around COVID-19, some highlight the role of privacy in contact tracing app adoption. Duan et al. studied contact tracing apps in Australia and found that adoption was hindered by perceived privacy risks, but driven by perceived benefits to society and individuals [4]. Lin et al. also studied willingness to adopt the COVIDSafe contact tracing app in Australia and used the widely accepted IUIPC sub-scales developed by Malholtra et al. to measure privacy concerns. They found that increased privacy concerns do increase risk beliefs, but that risk beliefs do not predict intention to adopt contact tracing apps [9, 10]. Jamieson et al. studied willingness to install contact tracing apps in the United States and also found there to be a privacy paradox. This paradox occurred among individuals who had apprehensions regarding "information leakage" yet were still willing to install a contact tracing app. They surmised that this might be due to "knowledge gaps about how their information is used in digital systems", a desire to "self-sacrifice", and herding effects [6].

These latter studies illustrate the privacy paradox where attitudes regarding privacy do not align with disclosure behaviors [16] or technology adoption [12]. Studies on the privacy paradox have come opposite conclusions, with studies that both support and challenge its existence [8]. For instance, Schubert et al. studied possible explanations for the privacy paradox in the context of social media and found lack of privacy literacy to be the catalyst [13]. In contrast, Barth et al.'s research found that "technically savvy" university students exhibited behavior aligning with the privacy paradox [2]. The lack of consensus surrounding the topic has led scholars to assert that"no comprehensive explanation for the privacy paradox has been found so far" [5]. Dienlin et al. has demonstrated that focusing on different facets of privacy, rather than treating it as one monolithic concept, can overcome the privacy paradox [3].

It is in this spirit that we decided to consider privacy as a multi-faceted construct and to investigate its effect on willingness to share various types of data shared with various audiences. Thus, we draw on Malholtra et al.'s IUIPC which conceptualizes privacy as consisting of three dimensions: concern about data collection (Collection), awareness of data practices (Awareness), and control over data disclosure (Control). Furthermore, willingness to disclose information is known to vary widely depending on the audience [15]. Thus, we focused on several different relevant audiences in our study. Next, we looked at two different types of health status that could be useful for contact tracing and helping slow the spread of the disease: exposure to COVID-19 and diagnosis of having COVID-19. We expected that exposure status may pose less risk for stigmatization than diagnosis. Research has pointed out how individuals can face a high level of stigmatization for having COVID-19 and experience discrimination in the workplace as a result of their diagnosis [7]. Thus, we focus on these two different types of data. Lastly, we focus on one country, the United States, since privacy is a culturally-dependant construct which varies country to country, culture to culture [14].

3 METHODOLOGY

Survey. This study was IRB approved. We used the Internet Users' Information Privacy Concerns (IUIPC) sub-scales to measure privacy concerns (Collection, Control, Awareness) [10]. Collection refers to individuals' concerns regarding their data being collected. Control refers to people having control over sharing their data. Awareness has to do with whether they understand what is being done with their data. For example, "It usually bothers me when online companies ask me for personal information" is one of the survey items used to measure concerns about data collection. "Companies seeking information online should disclose the way the data are collected, processed, and used." is a survey item used to measure concerns around being aware of data collection practices. We also developed survey items to capture respondents' willingness to share two types of COVID-19 related health status:

1. (Exposure Status) "If I became exposed to the disease I would be comfortable sharing my exposure status with..."
2. (Diagnosis) "If I was diagnosed with the disease I would be comfortable anonymously sharing my diagnosis with..."

Note that while the diagnosis sharing is anonymous (in keeping with existing contact tracing practices), the exposure data is not. This keeps the exposure data more useful for app users to access risk or take more measures to protect their health, but does increase the privacy sensitivity to some extent. We had participants answer each of these two questions for three different audiences:

1. (Frequent) "...people who I have frequent contact with."
2. (Occasional) "...people who I have occasional contact with."
3. (Anyone) "...anybody."

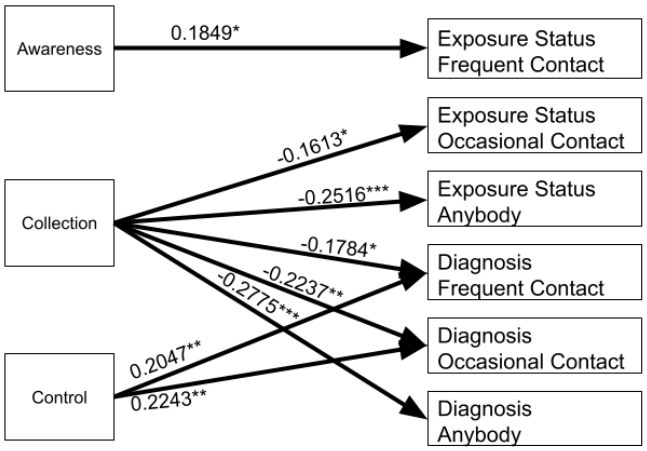
Recruitment. We deployed our US-based survey using Prolific, a third-party recruitment service. Participants took an average of 14.84 minutes to complete the survey and were compensated $2.50 for their time. We surveyed a nationally representative sample of the U.S. population (N=304) matched with US census data on age, sex, and ethnicity. Of our participants, 146 were male, 151 were female, and 5 were non-binary. Because COVID-19-related attitudes have been largely politicized in the US, we also collected information on participants' political opinions. We received more responses from individuals who identified as politically liberal or very liberal (N=177) than individuals who identified as moderate (N=74) or as conservative or very conservative (N=46). Respondents indicated their age bracket which ranged from age 18 to 65+ with the median age bracket of 35–44.

Analysis. We performed a multiple linear regression with Control, Collection, and Awareness as explanatory variables. The six Willingness to Share questions were used as our outcome variables. Participants answered on 5-point likert scales with 1 being "strongly disagree" and 5 being "strongly agree". All values were standardized before formulating the model. Our results are presented in table 1.

	Exposure Status Frequent Contact	Exposure Status Occasional Contact	Exposure Status Anybody	Diagnosis Frequent Contact	Diagnosis Occasional Contact	Diagnosis Anybody
Coefficient	Std Coeff (std. error)	Std Coeff (std. error)	Std Coeff (std. error)	Std Coeff (std. error)	Std Coeff (std. error)	Std Coeff (std. error)
Control	0.01374 (0.0779)	0.0533 (0.0790)	0.0921 (0.0769)	0.2047** (0.0757)	0.2243** (0.0750)	0.1499 (0.0763)
Awareness	0.1849* (0.0827)	0.1568 (0.0839)	0.1135 (0.0817)	0.0441 (0.0803)	0.0773 (0.0796)	0.0614 (0.0810)
Collection	-0.1047 (0.0739)	-0.1613* (0.0749)	-0.2516*** (0.0729)	-0.1784* (0.0718)	-0.2237** (0.0711)	-0.2775*** (0.0723)

Table 1: Multiple regression results with standardized coefficients. * <0.001, ** <0.01, and * <0.05**

Figure 1: Model showing the effect of privacy concerns on willingness to disclose COVID-19 Health Status



4 RESULTS

Our results reveal that those who highly valued Awareness were more willing to share their exposure status with frequent contacts, but were not significantly more willing to share anything else to any other audiences. On the other hand, those with a higher desire for Control were more willing to share their diagnosis with frequent or occasional contacts. On the opposite end of the spectrum, respondents with higher concerns about data Collection were significantly less likely to share across the board. The one exception was that there was no effect on Collection attitudes and sharing exposure status with frequent contacts. The model is depicted in Fig. 1, and the regression results are listed in Table 1.

On the five-point likert scale, with one being disagree and five being agree, the average response from participants about sharing exposure status with those in most frequent contact was 4.6379. Sharing exposure status with individuals in occasional contact was 4.3151 and sharing with anybody was 3.5714. When asked about willingness to share diagnosis, the average response from sharing with those in frequent contact was 4.6213, those in occasional contact was 4.5316, and sharing with anybody was 4.2558.

5 DISCUSSION

Our survey looked at attitudes towards sharing both exposure status and diagnosis. Overall, it seemed privacy attitudes are tied to attitudes towards sharing diagnosis as well as exposure status. Surprisingly, some privacy attitudes actually increase willingness to disclose while others decrease that willingness.

Our findings showed that Collection concerns significantly lowered willingness to share both exposure status and diagnosis with all audiences. The one exception was that Collection concerns had no impact on a person's willingness to share exposure status with frequent contacts. One possible explanation is that those who are in most frequent contact with the individual are also likely to be a closer relationships where there may be fewer privacy concerns. Exposure status also may be seen as less risky information to share than diagnosis.

Interestingly, participants who value Control were significantly more likely to share diagnosis with both frequent and occasional contacts. One possible reason for this is that since these individuals value being in control of their information, they want the same ability afforded to those closest to them. This would result in them being more willing to share diagnosis status with those with which they are in frequent contact despite this being highly sensitive information.

On the other hand, individuals that put a higher value on Awareness of privacy practices were significantly more likely to share their exposure status with those they have frequent contact with. A possible reason for this is that they want those they have frequent contact with to also be able to be aware of exposure. While exposure status is less sensitive than diagnosis, perhaps the value of awareness makes them more likely to value exposure status as important information to share than those who do not see as much value in awareness.

The results of our study indeed point to a sort of privacy paradox where some facets of privacy decrease willingness to disclose while others actually seem to increase willingness. However, this reveals the complexities of privacy and suggests how people's privacy values shape their willingness to share with those who are most likely to be impacted and closest to them.

6 CONCLUSION AND FUTURE WORK

The impact of the COVID-19 pandemic is global, making it vital to understand the role of privacy concerns on willingness to disclose health information that can be important to fighting the spread

of the disease. Understanding whether people are willing to share certain types of health status can guide the design of contact tracing apps to minimize privacy concerns over the type of information shared and increase willingness to adopt them. Given the culturally-dependant nature of privacy, it is important to extend this research to other countries. We have deployed surveys in other countries where adoption of contact tracing is also optional and we are now in the process of analyzing that data. The results of this research can help us better inform the design of contact tracing apps and take into account the impact of privacy concerns on willingness to disclose health status.

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