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Romero, Romina A
Young, Sean D

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Ethical Perspectives in Sharing Digital Data for Public Health Surveillance Before and Shortly After the Onset of the COVID-19 Pandemic

Romina A. Romero, PhD, MPH⁺, Sean D. Young, PhD, MS⁺*

⁺Department of Emergency Medicine, University of California, Irvine, California, United States of America

Abstract

Data from digital technologies are increasingly integrated in public health research. In April of 2020, we interviewed a subset of participants (N=25) who completed a survey approximately one month earlier (just prior to the declaration of the COVID-19 pandemic in the United States). Using the survey, we contacted and interviewed participants who had expressed their willingness or unwillingness to share digital data (e.g., from contact tracing apps) for use in public health. We followed a directed content analysis approach for the analysis of the interview data. Among participants who had reported being unwilling to share data, concerns about privacy, confidentiality, and the purpose of the research were cited. During the interviews, 76.9% of the participants who had previously indicated that they were unwilling to share their data, expressed willingness to share data in order to assist with COVID-19 prevention. Our results contribute to our understanding of people's perspectives on sharing personal data and of the way their perspectives can vary as a function of potential uses of their personal information (e.g., prevention of COVID-19).

Keywords

data privacy; contact tracing; social media; digital tools; COVID-19

Introduction

The COVID-19 pandemic is rapidly changing the way public health research is being conducted. Daily increases in cases and deaths worldwide have prompted changes in travel (Updated WHO Recommendations for International Traffic in Relation to COVID-19 Outbreak, 2020) and movement, with many countries and municipalities having implemented stay-at-home orders (McFall-Johnsen, 2020). Such policies have also affected scientific research. In some clinical trials, aspects of the study such as recruiting new participants, follow-up visits, and providing treatment, have been paused or diminished (Servick, 2020). Scientists have navigated social distancing in laboratories by having only a

*University of California Institute for Prediction Technology, Department of Informatics, University of California, Irvine, California, United States of America Romina A. Romero, rromero5@hs.uci.edu, Sean D. Young, syoung5@hs.uci.edu.

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few people in the lab or opting to work from home (Weise, 2020). Other researchers have shifted in-person interventions to online visits using platforms such as Zoom (Telemedicine for Substance Use Disorders, 2020). New tools and approaches continue to be needed to allow health researchers to remotely (from home) continue to conduct their research, including studying ways to prevent the growing COVID-19 pandemic.

Data from digital platforms, such as social media, contact tracing applications (apps), and electronic health records, are increasingly being considered for integration into public health research for near-real time remote monitoring of public health outcomes. Studies using these data were occurring prior to the COVID-19 pandemic, but during the pandemic, data from digital platforms are of even greater importance due to their adaptability to the stay-at-home climate. Additionally, their usefulness for studying ways of preventing COVID-19, such as by analyzing data collected from COVID-19-related social media and contact tracing apps, warrants attention. For example, investigators have previously examined the predictive effects of Twitter posts in the rise of syphilis cases (Young et al., 2018) and asthma-related emergency department visits (Ram et al., 2015), as well as their potential use in HIV (Young et al., 2014) and influenza (Allen et al., 2016; Broniatowski et al., 2013; Gesualdo et al., 2013) surveillance. Integration of these types of models and approaches into public health policy and practice has rapidly increased due to the need for infection control in light of the recent pandemic. For example, digital contact tracing has successfully been implemented in several Asian countries (Abeler et al., 2020; Huang et al., 2020) and Australia (Whitley & Withers, 2020). In South Korea, a digital contact tracing app that alerted the user if they were within 100 meters from an infected individual was recently downloaded over one million times (Dujmovic, 2020). Several websites that publish travel logs of infected individuals were also very popular in South Korea (Kim & Denyer, 2020). In the US, Apple and Google have partnered to create contact tracing technology with the aim of helping public health agencies reduce and contain viral spread (Sainz, 2020). In summary, collection and analysis of data from technologies have shown promise in assisting public health surveillance for various diseases, and have utility in the surveillance and preventive efforts for COVID-19.

However, a number of ethical concerns exist in using digital tools for surveillance and epidemiology efforts, including questions around the public's willingness to share this information. In addition to privacy issues with location-based tools, Gasser et al (2020) identified infringement of personal autonomy, discrimination and stigmatization, and repurposing data outside the scope of surveillance as inherent risks in data collection. Wang and Loui (2009) argued, that with respect to location data, it's the centralization of aggregate data in combination with personal information that threatens individual privacy. In South Korea, despite the positive response contact tracing apps and websites received from the populace, concerns over privacy, especially from infected individuals, were rising. Kim and Denyer (2020) reported that although efforts to anonymize infected persons were taken, enough data were provided on websites which allowed the public to identify and harass them. In a Facebook study, investigators released Facebook profile data about a cohort of students. Although attempts were made to secure the information published, the identity of the university was discovered putting the students' privacy at risk (Zimmer, 2010). Participants in social media research have voiced concerns over (1) privacy, confidentiality

and anonymity, (2) their data taken out of context, and (3) risks to users such as online judgement and harassment (Golder et al., 2017).

Hunter and colleagues (2018) discussed key ethical issues when conducting public health research in social media/digital technologies and acknowledged the challenges that researchers and institutional review boards face in the constantly evolving field. At the core, these investigators reported that researchers need to adapt to the ever-changing technologies while still abiding by the principles set forth by the Declaration of Helsinki in protecting participants (Hunter et al., 2018). Chui et al (2016) looked at the ethical considerations of conducting HIV research on social media. Participants were asked about the informed consent process, comfort with engaging with others in the study, and benefits gained during the study. Compared to younger participants, older participants reported having a higher understanding of the consent process, trusted the veracity of other participants in the study, but felt less likely to benefit from the study (Chiu et al., 2016).

For this research we conducted follow-up interviews with patients with a diagnosed medical condition who had taken a prior survey on ethics (Romero & Young, 2020). Because the COVID-19 pandemic began in the United States approximately one month after the survey had been completed, the purpose of this follow-up interview was to assess ethical perspectives on sharing personal information with researchers and the type of information they were willing to provide in light of the onset of the COVID-19 pandemic. These interviews were especially relevant during the current COVID-19 pandemic as technologies such as social media, internet search, and digital contact tracing apps and their data, may be highly impactful in COVID-19 prevention efforts. However, it is unknown whether and how people might be willing to share these data in general, as well as how their data sharing views might be affected by a pandemic. This is especially true among medical patients, who might be less willing to share data due to privacy and confidentiality concerns around the medical issues.

Method

Recruitment

Twenty-five participants for this study were chosen from the larger ethics survey of approximately 175 individuals recruited online from February through March 2020. This number was chosen as it is a commonly-used number of participants needed for recruitment in qualitative research/interviews (Raffe et al., 2020; van der Velden & El Emam, 2013; Young & Heinzerling, 2017). We also left open the possibility to recruit additional participants if saturation of responses had not been achieved within this initial group of 25 participants.

The two primary methods of recruitment for the original study were through Facebook advertisements or through referral from [Moshemu.com](https://moshemu.com), an online website for posting research studies designed to help researchers find research participants. Participants for the survey who clicked on a Facebook online advertisement were routed to an online interest form for initial screening. After participants submitted the online interest form, research staff called participants to verify information and obtain informed consent. Moshemu website

staff also provided study research staff with a list of participants meeting eligibility criteria. Participants were then contacted by email and sent the study information sheet. Research staff followed up the email with a phone call to screen participants and obtain verbal consent. Eligible participants were adults 18 years old and older, living in the US, who had self-reported having been diagnosed by a physician with a medical condition. As we were interested in examining the willingness of individuals to share their medical records, we specifically recruited people with medical records.

During phone screening for the larger survey questionnaire, participants were informed that they might be selected to participate in a 30-minute phone interview. For the present study, we selected participants based on their responses to a survey item on their willingness to share social media and location data. Participants were stratified into two categories: (1) those who had reported being willing to share social media and location data (listing a 4 or 5 on a 5-point scale from very unwilling to very willing) and (2) those who had reported being unwilling to share social media and location data (listing a 1 or 2 on the 5-point scale from very unwilling to very willing). Within each category, participants were then given a sequential number. Research staff used [random.org](https://www.random.org) to populate random numbers that corresponded to participants and those were then invited for the interview. A total of 49 survey participants were sent an email invitation and 25 participants were interviewed for the current study, 12 who were willing to share social media and location data and 13 who were unwilling to share social media and location data. Recruitment ended once information saturation for each category was filled (Assarroudi et al., 2018). Participants were informed that all interviews would be recorded and that once the recording was transcribed, the recordings were deleted. They were assured that no personal identifying information would be kept in the transcript. Once participants provided a time they were available for the interview, research staff scheduled the Zoom call. Institutional Review Board approval was obtained to conduct both the online survey and phone interview.

Interview

At the beginning of the interview, research staff reminded participants that the interview was being recorded. Research staff then proceeded with the semi-structured interview. The interview guide included questions about their medical diagnosis, use of social media and digital technologies, and willingness to share data with researchers and for-profit organizations. Based on participant responses, follow up questions were asked to allow participants to clarify and further describe answers. For example, participants were asked about their willingness to share social media data, internet search data, and mobile phone data (including text and mobility data). They were asked whether they would share this information with researchers seeking to use it for public health research, as well as separately whether they would be willing to share it with corporations using it for business purposes. They were further asked to expand on their responses (i.e., “Please tell us more about why you expressed willingness to share with researchers but not corporations.”) Research staff took notes during the interview in addition to the recording. Participants were interviewed between April 22 and April 29, 2020. Twenty-four participants agreed to be interviewed by Zoom. One participant preferred to be interviewed by phone.

Data analysis

We followed a directed content analysis approach in analyzing interview data (Hsieh & Shannon, 2005). Based on findings from the larger survey data, predetermined themes were used to guide analysis. The three broad themes were: (1) general willingness to share data with researchers, (2) willingness to share with for profit organizations, and (3) willingness to share data for COVID-19 purposes. Research staff perused hand-typed notes and observed responses that echoed across participants to develop a coding system. Another investigator independently reviewed these codes to reach a consensus. Codes were then used to review interview transcripts. Each code was assigned a color, and transcripts were color-coded to highlight specific codes. Once the transcript was coded, related codes were aggregated to create broad categories. Participant demographic data were obtained from the online survey.

Results

Participant demographics and characteristics are shown in Table 1. [Table 1 near here.] Most participants were females (n=18), White (n=19), between 26 to 35 years old (n=11), and at least college-educated (n=13). Participants reported a variety of medical conditions that were diagnosed by a physician, including chronic pain, mental health, substance use disorder, and HIV. Participants who were willing to share data (based on their survey responses) appeared more likely than those unwilling to share their data to spend five or more hours on social media each day (6 out of 12 versus 1 out 13).

Table 2 displays interview data about participant comfort level in sharing specific types of data with researchers, including comfort and willingness to share data with for-profit organizations such as Google, Facebook, and Amazon. [Table 2 near here.] Generally, participants who had indicated in the survey that they were willing to share data stated that they were comfortable sharing digital information with researchers during the interview as well. Of participants who stated in the online survey they were not willing to share data, upon further discussion during the interview, expressed comfort in disclosing certain types of data more than others (23.1% for both social media and search history, 38.5% for medical records), with location data the most likely type to share (46.2%). Over two thirds of both groups were not comfortable providing these same data to Google, Facebook, and Amazon.

Participants were also asked during the interview how willing they would be to download an application that tracked their location and movement. Two applications were specified: (1) specifically to track COVID-19 and (2) a general health app. With respect to the general health app, the two groups differed in willingness to download the app. Although, all participants who were willing to share their data stated they would be willing to download a general health app, less than half (46.2%) of the other group expressed willingness to do so. As for willingness to download an app specifically for COVID-19, 72% of all participants interviewed stated they were willing to download an app to allow researchers to track their location and movement.

Sharing data and type of data shared

Several notable codes were observed from participant transcripts regarding their willingness to share their data and the type of data they were willing to share. From these codes, two broad categories emerged: security (i.e., safety, privacy, confidentiality, anonymity, protection of information) and beneficence (i.e., benefit, treatment, help, purpose, label, against). Total codes for each category were $n=18$ for security and $n=20$ for beneficence.

General willingness to share data with researchers—Overall, participants were comfortable sharing their data with researchers to help them gain knowledge that could be beneficial to individuals with medical conditions and to society. Of all participants, 32% ($n=8$) were open to disclosing private information with researchers whose purpose was to help advance public health. Participants who were willing to share data had very little concern sharing their social media data, search history, location, and medical records with researchers. Only twenty five percent of those willing to share data ($n=3$) had concerns regarding confidentiality. On the other hand, of the 13 participants not willing to share, nine (69.2%) had concerns about privacy and confidentiality. Of participants not willing to share data, 46.2% were willing to share with researchers depending on the type of data researchers were asking for and the purpose of the research ($n=6$). Table 3 provides examples of participant quotes for each of the study themes. [Table 3 near here.]

Willingness to share with for-profit organizations—Participants in both groups were more hesitant to share their data with for-profit organizations. They acknowledged that organizations such as Google, Facebook, and Amazon already track consumer behavior while on their platforms, and each of these organizations have some private information about them. With respect to providing the same types of data (social media, search history, location, and medical records) to these organizations, participants had some concerns. Of all participants, 40% cited concern about purpose of data collection and storage ($n=10$), 28% were concerned about the potential sale of data for profit ($n=7$), 24% mentioned security and confidentiality ($n=6$), and 8% had hesitation depending on the type of data collected ($n=2$), as well as about the possibility having the data be used against them ($n=2$).

Willingness to share data for COVID-19 purposes—The purpose of data collection was important to participants in determining their action and willingness to download an application that tracked their location and movement. All participants willing to share data said they would download a general health app that tracks their location and all but one said they would do the same for a COVID-19 specific app. The one participant expressed a lack of trust on the media and the way they were handling number of COVID-19 cases reported as a reason for not downloading the app. On the other hand, among participants who expressed being unwilling to share data on the initial survey just prior to the COVID-19 pandemic, 76.9% were willing to download a COVID-19 specific contact tracking/tracking app ($n=10$). Approximately half of these participants also now expressed willingness to download a general health-tracking app (not specific to COVID-19) ($n=6$). In addition, almost half (46.2%) of these participants now expressed willingness to share their location data, with greater willingness to share if sharing for a very specific reason, such as COVID-19 prevention.

Discussion

Ethical conduct of research is a concern of research participants and the responsibility of researchers (WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects, 2018). New opportunities to use more recent technologies in research, such as social media and digital tools, are becoming increasingly available. In this study, we sought to explore the comfort level and willingness of participants to share confidential digital data with researchers and the type of data they were willing to share. We interviewed two types of participants with medical diagnosis, (1) those who had initially reported being willing to share data on a survey approximately one month earlier, and (2) those who had reported being unwilling to share data, to examine concerns and hesitations regarding sharing data with researchers. In this follow-up interview, approximately one month after the initial survey, we also ascertained their willingness to share data with for-profit organizations. Overall, both groups of participants interviewed reported being generally willing to share data about their social media, search history, location, and medical records with researchers, though those not willing to share their data in the earlier survey still had reservations. Participants in the group of those willing to share their data had very little qualms about providing personal data to researchers; they were more concerned with providing data to corporations. This finding supported those of other investigators who found that only few participants were concerned with university research using social media data (Williams, 2015). Upon further discussion during the interview with participants who were not willing to share their data with researchers, a little more than half stated they would be comfortable sharing certain data with researchers depending on the purpose of the research. Additionally, similar to the study by Rendina and Mustankaski (2018), our participants had concerns about what would happen to their data once collected. Interestingly, we found that the majority of participants who had expressed being unwilling to share data on the survey approximately one month prior to the COVID-19 pandemic in the United States (February and early March, 2020), during the interviews reported being willing to share digital data, especially if being used for specific purposes such as COVID-19 prevention.

With respect to sharing data with for-profit companies, participants in both groups concurred that they would not feel comfortable sharing their data with for-profit companies. The finding echoes other studies that examined participant attitudes about companies having access to social media data. Williams and colleagues (2015) found that a little over half of survey respondents were concerned with for-profit companies having access to social media data. Evans and colleagues (2015) found a higher proportion of participants who thought that social media data should not be used for marketing or provided to government or companies for research. Similar to Evans et al (2015), we found that context of the data, anonymity, purpose of the data collection, and type of data collected were key concerns for participants in both groups.

Participants, including those who were not willing to share their location data, appeared to understand the need to provide certain personal and private information in the interest of public health and safety. We found that participants were somewhat willing to sacrifice privacy during this pandemic. Of participants who were unwilling to share data prior to

pandemic policies on the initial survey, 46.2% stated during the interview they would be willing to share their location data. However, this proportion increased to 76.9% when asked if they would download an app that tracks their location specifically for COVID-19. Abeler et al (2020) conducted a multi-country survey asking participants if they would be willing to install a contact tracing app. Their findings revealed that about 70% of their respondent would download an app that tracked their movement while keeping their identity secure.

This study has limitations. We interviewed a sample of only 25 people, specifically, those with medical conditions. Although we reached saturation of topics, the data do not necessarily generalize across all patients. Additionally, our sample consisted of mostly females and there may be a gender difference in comfort and willingness to share data with researchers and for-profit organizations. Although small, our sample does reflect opinions across different age groups and different parts of the country (data not shown). Our advertisement was limited to social media paid ads, in particular, Facebook. The number of US adults who have Facebook accounts number in the millions; these adults are current social media users who are aware of the risks involved with social media exposure. By recruiting on Facebook, we may have missed other individuals who would potentially participate in a research study about ethics and technology but who are not on social media and may have concerns about ethics in collecting social media data. Lastly, the participants who were willing to download the COVID-19 app may be biased given the situation of the current pandemic and its impact on mobility, the economy, and relationships. It would be interesting to study the acceptance of a similar contact-tracing app during a time when its need is not urgent. Although we inquired about a general health app that would track their location and movement, we did not ask if they would be willing to download a contact-tracing app if we were not in a pandemic.

In this study, we sought to determine how comfortable participants were with sharing their data to researchers and whether their ethical perspectives can be affected by the COVID-19 pandemic. Even participants with concerns about privacy and confidentiality were likely to be interested in working with scientists to benefit themselves and society. Results from our study on technology data build on previous more broad ethics research showing that informed consent, communication of the purpose of the research, and transparency are important factors in helping participants decide whether to volunteer for studies. Additionally, reassuring participants that all data will be anonymized may help encourage participation knowing that the data cannot be traced back to them.

An interesting point is that these interview participants were recruited from a survey on ethics and technology conducted in March, just prior to the COVID-19 policies and related pandemic growth in the United States. During interviews that occurred after the onset of the COVID-19 pandemic, we explored willingness to share digital data to help with the prevention of COVID-19 and found that the context of COVID-19 prevention appeared to increase willingness to share personal information.

Conclusion

Participants are guided by the desire to further science in the hope of benefiting society when volunteering for research studies. Furthermore, attitudes against disclosing data may vary depending on context (e.g., the presence or absence of a pandemic).

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Table 1.

Participant Characteristics (Based on Online Survey).

| Characteristics | Willing n=12 | Not willing n=13 |
|--------------------------------------|--------------|------------------|
| <i>Gender</i> | | |
| Male | 2 (16.7%) | 4 (30.8%) |
| Female | 10 (83.3%) | 8 (61.5%) |
| Transgender | | 1 (7.7%) |
| <i>Race/Ethnicity</i> | | |
| White | 8 (66.7%) | 11 (84.6%) |
| Asian | 4 (33.3%) | 2 (15.4%) |
| <i>Age</i> | | |
| 18–25 | 2 (16.7%) | 3 (23.1%) |
| 26–35 | 5 (41.7%) | 6 (46.2%) |
| 36–45 | 2 (16.7%) | 1 (7.7%) |
| 46–55 | 2 (16.7%) | 1 (7.7%) |
| 56–65 | 1 (8.3%) | 2 (15.4%) |
| <i>Education</i> | | |
| <High School | | 1 (7.7%) |
| High School | 2 (16.7%) | 2 (15.4%) |
| Associate's Degree | 1 (8.3%) | 2 (15.4%) |
| College Graduate | 8 (66.7%) | 5 (38.5%) |
| Graduate School | 1 (8.3%) | 3 (23.1%) |
| <i>Medical Condition^a</i> | | |
| HIV/AIDS | 1 (4.0%) | |
| Mental Health | 6 (24.0%) | 5 (2.8%) |
| Substance Use Disorder | 2 (8.0%) | |
| Autoimmune Disease | 3 (12.0%) | 1 (5.6%) |
| Cardiovascular Disease | 1 (4.0%) | 1 (5.6%) |
| Chronic Pain | 5 (20.0%) | 2 (11.1%) |
| Cancer | | |
| Diabetes | 5 (20.0%) | 1 (5.6%) |
| Other | 2 (8.0%) | 8 (44.4%) |
| <i>Hours per day on Social Media</i> | | |
| 0–1 | | 1 (7.7%) |
| 1–2 | 1 (8.3%) | 1 (7.7%) |
| 2–3 | 3 (25.0%) | 6 (46.2%) |
| 3–5 | 2 (16.7%) | 4 (30.8%) |
| 5+ | 6 (50.0%) | 1 (7.7%) |

^aParticipants were asked to select all medical conditions that applied to them.

Table 2.

Interview Data: Participant Comfort in Sharing Data.

| Type of Data | Willing n=12 | Not willing n=13 |
|---|--------------|------------------|
| <i>Social Media</i> | | |
| Yes | 11 (91.7%) | 3 (23.1%) |
| No | | 6 (46.2%) |
| Maybe/Depends | 1 (8.3%) | 4 (30.8%) |
| <i>Search History</i> | | |
| Yes | 10 (83.3%) | 3 (23.1%) |
| No | 1 (8.3%) | 5 (38.5%) |
| Maybe/Depends | 1 (8.3%) | 5 (38.5%) |
| <i>Location</i> | | |
| Yes | 12 (100%) | 6 (46.2%) |
| No | | 5 (38.5%) |
| Maybe/Depends | | 2 (15.4%) |
| <i>Medical Records</i> | | |
| Yes | 12 (100%) | 5 (38.5%) |
| No | | 3 (23.1%) |
| Maybe/Depends | | 5 (38.5%) |
| <i>For profit organizations^a</i> | | |
| Yes | 4 (33.3%) | |
| No | 8 (66.7%) | 11 (84.6%) |
| Maybe/Depends | | 2 (15.4%) |
| <i>General health app^b</i> | | |
| Yes | 12 (100%) | 6 (46.2%) |
| No | | 5 (38.5%) |
| Maybe/Depends | | 3 (23.1%) |
| <i>COVID-19 specific app^b</i> | | |
| Yes | 11 (91.7%) | 10 (76.9%) |
| No | 1 (8.3%) | 1 (7.7%) |
| Maybe/Depends | | 2 (15.4%) |

^aParticipants were asked if they were willing to share social media, search history, location, and medical records with for-profit organizations such as Facebook, Google, and Amazon.

^bParticipants were asked how willing they were to download an application that tracked their location.

Table 3.

Sample Quotes About Willingness to Share Data with Researchers and For-Profit Organizations.

| Themes | Participant quote |
|--|--|
| General willingness to share data with researchers | <i>Well, anything that could help find treatment or cure for my diseases would be good. I would just be concerned with privacy. But I mean, if it's not direct messages, I don't see a problem with it really.</i> |
| | <i>As long as I am confident that the research, that I will be anonymous and it will not come back to me, I am pretty comfortable sharing information with researchers, because I think that they're trying to help and if I don't share it, how can they help me? So I want to be able to get that help just as long as I know that it's confidential.</i> |
| | <i>I think it's more data breaches and making sure my information stays safe. Besides that, I don't really have any more problems with sharing all that.</i> |
| | <i>I guess it depends on the records. If it was something like pathology reports for an endoscopy for (condition), that would be used to further research and development of medications to treat it, if it would be, yeah, I've taken the biopsies and the information that I'm using that to further treatments, I think I'd be okay with that. I think some other things, maybe not. I think it really just depends on the type of health data. It wouldn't be an all or nothing. It wouldn't be yes or no. It'd be this specifically yes, this no.</i> |
| Lack of willingness to share with for profit organizations | <i>I see researchers using it for a purpose to potentially benefit people; assuming you guys would be using this information to find something out. And I guess that would be like Amazon or Google or corporation like that to do it just for the purpose of making money and where's the data going? It's not necessarily confidential and I don't necessarily trust that.</i> |
| | <i>I would be a little hesitant sharing to Google just because, you don't know what they're doing with that information. As opposed to if it's for research then yeah, I would a hundred percent give my consent. But what is Facebook and Google and Amazon doing with my information. That's what I would want to know before I could give consent.</i> |
| Willingness to share data for COVID-19 purposes | <i>Yeah, I think the more narrow your scope is, the more willing I would be. I think just saying, let's have access to all your stuff, I'd be, no, thank you.</i> |