Research Participant Views regarding Qualitative Data Sharing

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Abstract

We found no studies in the United States that explored research participants' perspectives about sharing their qualitative data. We present findings from interviews with 30 individuals who participated in sensitive qualitative studies to explore their understanding and concerns regarding qualitative data sharing. The vast majority supported sharing qualitative data so long as their data were deidentified and shared only among researchers. However, they raised concerns about confidentiality if the data were not adequately deidentified and about misuse by secondary users if data were shared beyond the research community. These concerns, though, did not deter them from participating in research. Notably, participants hoped their data would be shared and may have expected or assumed this was already happening. While many could not recollect details about data-sharing plans for studies in which they participated, they trusted researchers and institutions to appropriately handle data sharing. If individuals view data sharing as an extension or integral part of their participation in qualitative research, then researchers may have a stronger obligation to share qualitative data than previously thought. Guidelines and tools to assist researchers and institutional review board members in ethical and responsible qualitative data sharing are urgently needed.

There are a number of benefits to sharing data from various types of research: increasing the transparency of research and enabling the replication of findings, which can foster public trust in science;[1] enabling secondary users to explore new research questions, thereby maximizing the value of data that is often costly and resource intensive to collect; reducing participant burden by using existing data rather than collecting new data; and providing an opportunity for students to learn how to conduct data analysis through examining research questions using real data when they have no funding to gather their own.[2]

While policies that require researchers to share data from qualitative studies have existed for some time outside of the United States, data-sharing policies in the U.S. have focused almost

entirely on quantitative data.[3] However, it is possible that the policies of the National Institutes of Health (NIH), the National Science Foundation, and other entities may be applied to qualitative data in the future, given the increasing trend toward data sharing and open science, and these policies do not explicitly refer to quantitative data. Sharing qualitative data poses unique challenges of which researchers must be aware in order to share such data responsibly. Because qualitative methods are often used to explore highly sensitive or stigmatized issues,[4] a trusting relationship between researchers and participants may be especially important to enable participants to talk openly about issues they might not otherwise reveal.[5] While quantitative research aims to produce generalizable findings abstracted from context, qualitative research is primarily inductive and descriptive, with the aim of producing contextually rich data to better understand lived experiences.[6] As a result, qualitative methods aim to minimize the distance and separation between researchers and participants and often (although not necessarily) involve face-to-face interactions or repeated contact.[7] In contrast, quantitative data collection may not even involve interacting with research participants, for instance, if data are gathered via an online survey, from electronic health records, or passively through wearable devices.[8] While trust and informed consent are essential for all research participants, the way in which qualitative data is "generated" by researchers through interactions with research participants highlights the importance of participants' giving explicit consent for researchers to share data from qualitative studies.[9]

Qualitative researchers have expressed concerns that secondary users who were not involved in data collection—and therefore had no personal contact or relationship with the original participants—will misinterpret the data, potentially generating incorrect or stigmatizing conclusions.[10] This could lead to a breach of trust among research participants who revealed the information within a relationship of trust to a particular researcher.[11] Even for quantitative data, guidelines and data governance about appropriate secondary use, including for commercial purposes, are lacking.[12] Given the newness of qualitative data sharing, no evidence or guidelines regarding appropriate secondary use exist.[13]

Further, in contrast to quantitative data, qualitative data frequently take the form of textual data, such as transcripts, that may be difficult to anonymize.[14] The criteria most health care or academic organizations use for deidentifying quantitative data is the removal of the 18 Health Insurance Portability and Accountability Act (HIPAA) identifiers, such as an individual's name, address, and phone number. However, this approach may be insufficient for qualitative data,[15] which often contain contextual details or specific characteristics (such as race or ethnicity, rare diseases, or details about the research site) that are not considered HIPAA identifiers but, when combined with other details, could identify individuals.[16] While removing this information may ensure privacy and confidentiality, other researchers have cautioned that removing too many contextual details reduces the utility of the data for secondary analysis.[17]

All the above concerns are legitimate and require attention, but they reflect the concerns of researchers. Few studies have explored research participants' perspectives about qualitative data sharing.[18] One Finnish study recontacted 169 participants in qualitative research and found that 98% agreed to have their qualitative data archived and were supportive of data sharing.[19] The main reason individuals agreed to have their data in an archive was to

advance science even though the data contained sensitive and private information.[20] Many individuals in this study presumed that researchers had access to data from other researchers. Participants also perceived their relationship with researchers as more of an institutional arrangement rather than a personal or private relationship with the individual researcher.[21] In a study conducted in the United Kingdom, participants in qualitative research said they trusted institutions and researchers to handle data sharing, lacked understanding about data sharing, emphasized transparency, and often expected that data were already being shared among researchers.[22]

These limited findings about participant support for sharing qualitative data may or may not translate to the U.S. context, where there has often been a high level of mistrust among African Americans and other populations (such as Native Americans) toward research, leading to lower participation rates in various types of studies.[23] Yet sharing data could potentially reduce the burden on participants by eliminating the need to re-contact them for permission to share or collect data a second time. In that sense, data sharing demonstrates respect for participants by maximizing their contributions while minimizing research burdens.[24]

We found no studies in the U.S. that explored research participants' perspectives about sharing their qualitative data. Research in the U.S. and other countries regarding views about sharing *quantitative* data derived from biospecimens or clinical trials reveal that respondents are generally supportive of sharing their deidentified research data to benefit themselves, their immediate community, the public, or science as a whole. Respondents in those studies did express concerns regarding privacy and confidentiality, discrimination, or misuse of data by secondary users, but overall, they were widely supportive of data sharing.[25] Nonetheless, many reported being unaware of quantitative data-sharing plans, which address how data will be shared and with whom.[26]

In this article, we report findings from semistructured, in-depth qualitative interviews with individuals who participated in sensitive qualitative research studies to explore their understanding, experience, and concerns regarding qualitative data sharing. The data were collected as part of the NIH-funded R01 Sharing Qualitative Research Data: Identifying and Addressing Ethical and Practical Barriers (grant 5R01HG009351–02, with DuBois as the principal investigator). The larger project involves engaging several stakeholder groups. We report the views of other stakeholder groups—institutional review board (IRB) members, qualitative researchers, and data repository curators—elsewhere.[27] Understanding participants' views about sharing their qualitative data may ensure that consent forms and data-sharing plans are devised in ways that are consistent with participant wishes. This is important for its own sake but also in order to avoid breaching trust in the research enterprise and potentially reducing individuals' willingness to share their data or take part in research.

STUDY METHODS

We recruited participants (n = 30) through the Washington University School of Medicine Volunteer for Health Research Participant Registry. The registry maintains a list of over 7,000 members who have agreed to be contacted about participating in research studies.

Volunteer for Health posted recruitment flyers in their offices and posted information about our study on social media platforms that their members use (Facebook and Twitter). Volunteer for Health also posted our study information on a website that members could access. Interested individuals then contacted our study team directly. To be eligible to participate, individuals had to be 18 years of age or older and must have participated in at least one qualitative research study concerning their health or sensitive health behaviors such as substance abuse or sexual behavior. We defined qualitative research as research involving interviews or focus groups in which a researcher—whether over the telephone or in person—asks an individual or group questions and records what they say. Participants were recruited over a two-week period, on a first-come, first-served basis. Given African Americans' history of mistrust about research[28] and the fact that the population of African Americans is higher in the city where we conducted our study than in the general population nationwide (47.6% in St. Louis, Missouri, compared to 13.4% among the U.S. population), [29] we purposely oversampled African Americans during the recruitment process to ensure that they comprised half of the respondents in our study. The Washington University School of Medicine's IRB approved the study under its expedited review process.

All eligible participants provided informed consent online before completing a brief preinterview demographic survey administered via Qualtrics. The preinterview survey collected information about prior research experience, whether prior studies involved data sharing, reasons for taking part in research, and demographic characteristics. The research team developed the interview guide after conducting a review of the literature to determine key issues related to research participants' views of qualitative data sharing. Although there is limited empirical data on this topic from research participants, areas of concern cited in the literature relate to maintaining confidentiality, secondary analyses, informed consent, and breaching trust.[30] The interview guide was then reviewed by our stakeholder advisory board, which included qualitative data repository directors, qualitative researchers, IRB members, and bioethicists. We incorporated their feedback and then conducted a mock interview using the guide before finalizing it.

Using the final interview guide (see the appendix, which follows the endnotes), we asked participants open-ended questions exploring their prior research experience and their knowledge about qualitative data sharing. We then provided a brief explanation of qualitative data sharing followed by the open-ended question, "What is your reaction to the idea of sharing qualitative research data about you with other researchers who were not part of the original study team?" This question was followed by a series of prompted questions about the potential benefits of qualitative data sharing, such as secondary analyses and verification of findings. The remainder of the interview probed participants about specific areas of concern described in the literature: privacy and confidentiality, secondary analyses, and consent preferences. Interviews were conducted by trained interviewers who had conducted a mock interview (MP, HW, and KB). Participants were given a $30 gift card following completion of the interview.

Audio recordings from interviews were transcribed verbatim by a professional transcription company and cleaned before they were uploaded to Dedoose, a HIPAA-compliant online software for qualitative data analysis.[31] Survey data was exported from Qualtrics and

uploaded into Dedoose, where responses were linked to the corresponding transcript. The principal investigator, the coinvestigator, and the project manager (JMD, JM, and HW, respectively) led codebook development with input from all interviewers. The codebook was refined as coding proceeded. We coded using a combination of inductive and deductive codes, which reflected the nature of our interview guide. Inductive coding allowed us to capture unprompted views that arose spontaneously, usually in response to our open-ended questions (for example, "Tell me what you know about how researchers share data they collect.") Deductive coding was driven by the topics we specifically asked about regarding qualitative data sharing, including benefits, concerns about confidentiality and secondary use, and consent preferences. Inductive codes were applied anywhere in the transcript that the particular themes arose, but our questions themselves prompted individuals to consider these issues. This coding strategy allowed us to examine whether concerns described in the literature were present while also determining if new or unexpected themes arose from the data itself.

One coder (MP) was responsible for coding the research participant interviews, with JM serving as the second gold-standard coder. During the first phase of coding, both coders blind coded a single transcript and then discussed and resolved differences in coding. The two repeated this process until codes were consistently applied to transcripts without major discrepancies between the raters. The primary coder (MP) kept detailed notes about coding decisions and questions while coding data. The primary coder proceeded to code with blind coding checks by the gold-standard coder (JM) to ensure ongoing agreement. Random blind coding occurred for approximately 15% of interviews. After each blind coding check, both coders met to discuss questions or discrepancies. Coders resolved differences in coding during consensus meetings and revised the codebook accordingly.

STUDY RESULTS

Table 1 provides demographic characteristics about participants and about their prior research experience derived from the preinterview online survey. Table 2 reports racial differences in the code counts reported in this article. As we discuss in our conclusion, we did not find major differences by race for most codes. Four major themes emerged from the interviews: broad support for data sharing, concerns about confidentiality and secondary use, trust in the research process and in institutions, and the importance of transparency.

Broad support for data sharing.

Participants said that they generally wanted their qualitative data to be shared among researchers. In response to our initial open-ended question, 28 out of 30 supported data sharing so long as their data was deidentified and shared with other researchers rather than the public. The vast majority viewed sharing deidentified data as a way to advance science and research. In the early stages of analysis, we created a code called "hope data is reused" to capture positive expressions of participants' hope or assumptions that their data will be shared with or reused by other researchers. This code was the one most frequently applied (it was applied in 23/30 interviews). This hope was not something we explicitly asked participants about; rather, expression of it arose inductively from their initial reactions to our

question about data sharing. The most common reason for wanting data shared was to help others and to advance science. As one participant explained, "If I'm going for research, or someone is doing research on me and gathering information, then I actually want that information to be shared so everybody will know the information and everybody can put their dots together to come up with the solution" (Participant 25, female, African American, age 40–49). In reference to qualitative data sharing, another said, "I think it's a good idea, because there's a lot of things going on that need to be researched, and if I can help, I'm glad to help" (Participant 20, female, African American, age 60 or older).

These findings are consistent with the demographic survey data we collected, in which, alongside payment, advancing science was one of the most cited reasons participants provided for enrolling in research (see table 1). When asked their thoughts about potential benefits of sharing qualitative data (such as training or verification of findings), participants said they viewed sharing qualitative data among researchers as a way to accelerate scientific breakthroughs, leading to the development of new treatments or cures that could benefit themselves, future generations, or their community. In the words of one participant, "Make sure that you leave no stone un-turned, and you do a good job, as much research as you can" (Participant 1, male, white, age 50–59). Another said, "That would be very blessed for me because that's the reason why I participate in the study, so they can understand exactly what they need to know and to learn and be able to progress that understanding [of] the data in the study (Participant 30, male, Hispanic/Latino and African American, age 50–59). Others emphasized the value of transparency in science and agreed that data sharing enables other researchers to check the accuracy of findings, generating higher-quality scientific outputs. As one participant noted, "Well, I guess the more input that you have—having more input [than] based on just one particular, say, researcher—say if you've got three or four because everybody might come up with something different, they might find something that another researcher overlooked" (Participant 3, female, African American, age 60 or older).

When asked about benefits, several participants also cited cost saving and efficiency as a benefit of data sharing. Several noted that sharing qualitative data reduces participant burden, preventing similar data from being collected from the same participants over and over. They also cited the importance of preserving researcher time and resources for novel research or saving taxpayer dollars. Along these lines, one participant said, "As a taxpayer, like, I'd rather the dollars get spent once to collect the data, rather than more dollars being spent to collect another set of data when a perfectly valid set of data already exists" (Participant 10, female, white, age 50–59). As to reducing participant burden, one participant suggested that sharing data in a responsible manner could help reduce "additional phone calls … just to keep other researchers from calling me and asking me the same questions" (Participant 16, female, African American, age 50–59).

Notably, participants often expected or assumed that their data would be shared when a study was completed and saw data sharing as maximizing their contribution to research. Even when participants could not recall if they had been explicitly told their data would be shared, they still expected that it would be shared with other researchers. This exchange between the interviewer and a few participants illustrates this point:

Interviewer: Okay, and do you know if any of the studies you've participated in involved sharing data collected about you with other researchers, not part of the original study team?

Interviewee: I'm not sure, to be honest. They possibly—I just—I don't have, like, a firm yes or no on that one. I'm assuming that some studies I've done in the past have done that. (Participant 8, female, white, age 30–39)

Interviewee: It doesn't matter to me what they do. It's whatever they wanna do; it's up to them. I mean I have no difficulty with it. In fact, I expect it because it's part of the researcher information that's collected. (Participant 12, male, white, 60 or older)

Interviewee: Well, I'm not sure how it would be shared, but I thought—initially I thought it would just be used at [the institution] … but there were a couple thousand people in this study, and I just presumed it would be shared for the better good of people to improve future generations is kind of my opinion about all this … and how, you know, if it will help people to understand how the mind works and why people do the things they do and how they feel about it, I'm okay with that. I'm a little concerned about the sensitive information, but, you know, I don't think it's gonna have my exact name on it. I'm probably just a number. (Participant 14, female, white, age 60 or older)

Participants also supported sharing their qualitative data with government agencies that funded the original project, with other researchers to enable new analysis or check the validity of the original findings, and with students for training purposes. However, they wanted their data to be deidentified and to remain within the research ecosystem. Many said they were not comfortable with their identifiable data being available to the general public. One participant said, for example, that she was open to the sharing of her data "only if it was a part of the research team, but not just the general public" (Participant 9, female, African American, age 40–49).

Concerns about confidentiality and secondary use.

While participants had positive attitudes about data sharing overall when asked our initial open-ended questions, they also expressed concerns about the risks of data sharing when prompted to consider those risks. Participants conveyed concerns about confidentiality (the code was applied in 20/30 interviews) and secondary use (the code was applied in 16/30 interviews). Notably, participants simultaneously conveyed that risks to confidentiality were unlikely or were not great enough to deter them from participating in research, so we created a code called "no privacy and confidentiality concerns" to capture these sentiments that arose during interviews (the code was applied in 18/30 interviews).

With respect to confidentiality, participants expressed worries that harm could come to them or their loved ones if, after study participation, their confidential information was not protected. Perceived harms included both psychological harms (such as judgment from others) and economic harms (becoming a victim of identity theft, for example, or difficulties finding employment or insurance). As one participant explained,

Well, you know, again, depending on where we're headed with the world of insurance and stuff like that, anything that could potentially compromise your

ability to get insurance because it identifies a preexisting condition of some kind or reveals, you know, criminal activity or illegal activity of some kind, or you know, substance abuse, or anything like that that you've told someone in confidence, and you don't want it getting out there in a way that other people could find out it's you.

(Participant 10, female, white, age 50–59)

Another participant put it more succinctly: "I just think that my privacy is sacred, because, if certain information was exposed to certain people—I wouldn't say it would put me in danger, but it might—ya know, there's information out there, information I don't want everybody to know, or certain people to know"(Participant 7, female, white, age 30–39).

Participant concerns about confidentiality depended on the nature and sensitivity of the data. Participants generally agreed that sharing data about nonsensitive topics such as exercise or diet was unlikely to lead to any harms. However, concerns were raised about ensuring confidentiality of sensitive information regarding their children or other family members, sexual behavior, potentially embarrassing health information (such as urinary incontinence), or their opinions about controversial subjects (such as politics). As one participant pointed out, "[T]he only question is, if it's really personal, like, sometimes, I participated in studies where they got into very intricate details about sexual behavior … I mean, you really wouldn't want that broadcasted with your name, and address, and phone number, you know" (Participant 12, male, white, age 60 or older).

Even when participants expressed concerns about the risks of sharing sensitive data, they were not necessarily opposed to sharing it, so long as it was anonymized and there were adequate protections to prevent reidentification. For example, one participant said the nature of the study could make a difference to her: "If it's like my asthma, I wouldn't mind if my information was not deidentified, but if it was maybe about, like, sex or alcohol or more stuff like that, I think I probably would still want it deidentified" (Participant 17, female, white, age 20–29).

Several participants also said that, while they were aware of the risks to confidentiality when they agreed to participate in a study, the risks were not significant enough to deter them from participating in research. One explained, "I guess to a certain extent I think about it, but I am okay with it overall. Like I said, I don't spend too much time on it. I kinda weigh the advantages and disadvantages and end up with it's okay" (Participant 26, male, African American, age 40–49). A second said, "I believe that my information will stay under lock and key and—or at least you hope. I've never had reason to doubt that that won't happen, and I don't have anything to hide so I guess it's never really bothered me too much" (Participant 17, female, white, age 20–29). Another participant noted that people could choose to filter themselves or to skip certain questions to ensure privacy: "I mean, if the person doesn't wanna answer certain questions or doesn't wanna let people know too much, I guess they could not choose to do so" (Participant 1, male, white, age 50–59).

And several participants described being confident that the risks of being identified were low because they trusted that the data were adequately deidentified, or they were unable to

imagine why anyone would care to reidentify them. For example, one participant said she thought that identifying her would be hard to do: "I don't think you can pinpoint one particular person, saying so and so said that—I think that would be kind of difficult" (Participant 3, female, African American, age 60 or older), and another pointed out that "I would just kind of be, like, a study number or an object." This participant went on to say, "I don't think anyone would really pay attention to me in particular because I think it would be a group of just, like, numbers. And since we're all deidentified, it can be, like, a group of 30 females or—you know, I don't think anyone would be focusing on just one person, unless the research study was on just, like, me (Participant 17, female, white, age 20–29).

Some participants did not describe risks specific to qualitative research but, rather, described risks of data breaches more broadly and the risks to privacy and confidentiality as a result of the amount of data collected on people and the potential for systems to be hacked both inside and outside medical research settings. In the words of one participant,

> So I would say, you know, if it's done honestly, I'm okay with it, if that's the case, if it's done in a way that my individual information is not shared. You know, with so many hackings and so much information being stolen one way or another, I'm not giving it away freely, but I just don't spend a lot of time worrying about it. I think we're in an age where it's become commonplace, unfortunately. So as long as the agencies are, you know, doing their due diligence and being honest. But, you know, tonight someone could come in and hack the information … . But, like I said, I just think there's so many hacking incidents that due diligence is about all that I think anyone can do anymore.
>
> <div align="right">(Participant 26, male, African American, age 40–49)</div>

Another participant made similar points while noting how much data people share on social media:

> I think the thing is you hear so much about how much information anybody can have on you, almost at any time anyway … [W]hen people get upset about … the security breaches and stuff, it's like, do you people realize how much information you've shared about yourself on Facebook already that anybody can access? … People know where you live. People know what you eat.
>
> <div align="right">(Participant 10, female, white, age 50–59)</div>

When asked about secondary-use concerns, participants expressed worry that secondary users of qualitative data could misinterpret, misuse, or be biased when handling their data (the code was applied in 16/30 interviews). While participants acknowledged that misinterpretation, misuse, and bias are all risks that exist when the original researcher collects and analyzes their qualitative data, some worried that other researchers interpreting their data could amplify these risks, potentially spreading misunderstanding of a disease or characteristics of certain vulnerable populations. With regard to a secondary researcher, one participant observed,

> [H]e might have a skewed version of what was initially introduced to the first researcher, like that first researcher got a face-to-face, hands-on look at the results of what was going on, whereas a guy looking at it on a piece of paper doesn't have

your facial reactions, doesn't have your tone of voice, for instance. He doesn't have your—you know, your physical presence to formulate his own opinion, so it could be partially biased if he has any other, you know, additional information to add to that, especially if it isn't congruent with what the initial researcher jotted down.

(Participant 27, male, white, age 30–39)

Another participant asked about a secondary researcher said, "I'm not so sure about that one, because if they were not the original researcher, the one who was there to, you know … I'm not sure if they would get the information correct, so I'm not sure if I agree with that one" (Participant 2, female, African American, age 30–39).

To prevent the misinterpretation or misuse of their data, participants preferred it to be shared for research that was generally similar to its original purpose. According to one participant, "I think that they need to have a guideline on what they can and can't do with information" (Participant 5, female, white, age 50–59). Another participant said, "I mean, as long as they're not doing, you know, anything that they're not supposed to do with the research, if they're only using it for that specific purpose, then, no, I don't see a problem" (Participant 2, female, African American, age 30–39). Participants emphasized that those requesting the data should meet specific criteria before accessing it (such as having adequate expertise or supervision or maintaining contact with the original researcher to ensure the interpretation of data is appropriate and accurate). One participant explained, "So, if one researcher collected the data, and then someone else was interpreting it, I would just be concerned about how that second researcher was trained, you know, onboarded on the study, or the project, because if it is different, then obviously, those results are gonna be reviewed differently, so there may be some variance there" (Participant 8, female, white, age 30–39). "Well, I don't know if a researcher is trained not to be biased… . But they may bring their own biases to the study because they weren't the original interviewer and don't know all the ins and outs," another said (Participant 24, female, white, age 40–49).

Trust in the research process and in institutions.

Participants often did not recall the specific details of prior studies they participated in beyond the broad subject matter of questions they were asked. On the preinterview survey, 22 out of 30 participants reported taking part in studies that involved data sharing (see table 1). However, when asked during the interviews, many participants generally did not remember if the informed consent document for the qualitative studies they had completed mentioned data-sharing plans. We created a "lack of recall/knowledge" code to capture expressions of not remembering details about prior research or about how data sharing works (the code was applied in 18/30 interviews). Several described being generally unaware of the research process and knew very little about the lifecycle of their qualitative data after their participation was complete. For example, one participant said, "When I did the one on my brain, I don't know what they did with it … . [A]fter I finished and completed it, they was like, thank you, and I never heard from them again, like, nothing" (Participant 6, male, African American, age 30–39). Participants also said they were often unaware of the details of deidentification and assumed information like their name or Social Security number would be removed from the data before sharing. "I really don't know a whole lot," a

participant said. "Only thing is, like, they said, your name is never used, or your personal information is never used. That's the only thing I really know about it" (Participant 4, female, African American, age 40–49).

Participants' responses also indicated that they trusted researchers to appropriately handle their data. We created a "trust in research process" code to capture these sentiments (the code was applied in 18/30 interviews). Participants deferred to the original researcher about how data should be anonymized and with whom they should be shared; assumed that researchers have the knowledge, skills, and available regulatory or policy guidance to make those decisions; and trusted the researchers because of their level of education and expertise. They also trusted the institutions that employ researchers because they assumed that reputable institutions provide their researchers with appropriate guidance. As one participant explained, "Well, once I participate in the study, I don't really feel like I have a lot of control as to how it will be used. In fact, a lot of times, I don't know. So, again, it comes back to trust. It comes back to me working with an agency that seem reputable and actually who I have a history with. So, I'm okay with however they deem the information be used" (Participant 26, male, African American, age 40–49). Another participant said, "Well, I trust that when they said they were going to protect it, the personal part of it, I trust that. I don't have any concerns" (Participant 19, female, African American, age 50–59).

Transparency.

Finally, while participants trusted researchers to share their data appropriately, when asked about their preferences for consent, they also expected that researchers would communicate any data-sharing plans during the informed consent process so that individuals could make an educated decision about whether to participate in the study. To capture this sentiment, we created a "just ask me/transparency" code (which was applied in 17/30 interviews).

When asked about their preferences for recontact, participants greatly preferred to be asked to consent to a data-sharing plan just once at the beginning of a study as opposed to providing consent every time their data was to be shared with a secondary user. In the view of one participant whose sentiment was expressed by several others, "I mean, it should just be—they should always ask me when I'm signing up if they can have permission to share it with other researchers, and I'll probably always say yes, but that should just be part of the process" (Participant 15, female, white, age 40–49). Another participant stated, "So … I'm okay with the agency sharing with other research. It's nice to know up front, if that's part of the consent process, they say that somewhere so that I have a choice one way or the other" (Participant 26, male, African American, age 40–49).

If a researcher did not disclose plans to share qualitative data but wanted to share the data after the study was completed, participants also felt that being recontacted and asked to consent to sharing was a reasonable compromise, but they noted it would be more burdensome than being asked just once at the beginning of the original study. This finding is notable given that participants were also often unsure if consent forms they had previously signed included permission to share data, yet they still trusted that researchers or institutions knew how to handle data sharing appropriately.

DISCUSSION

Nearly all participants in our study (28/30) supported qualitative data sharing as long as the data were deidentified and shared among researchers, though some participants expressed concerns about privacy and confidentiality (20/30) and secondary use (16/30) if the data were not appropriately deidentified or if the data were shared beyond the research community. We purposely ensured that half of our sample was African American to enable us to explore whether perspectives differed by race. During analysis, we looked for differences in themes arising or types of concerns conveyed, and we found only a few minor differences (Table 2). Where there were differences in code counts, it is not possible to determine if they are due to race or to other factors such as socioeconomic status or education level.

For many participants, sharing data is a way to amplify the societal benefits of participating in research and to maximize their contribution to the research enterprise at large. An unexpected finding is that participants hoped their data would be reused and expected or assumed that this was already happening. Even when participants were unclear as to whether they had taken part in studies that involved data sharing, they frequently described the importance of facilitating research and saw data sharing as part of this broader commitment to research. Participants articulated benefits to themselves, their communities, the public, or science as a whole as the key reasons that they participated in research. For many, data sharing was assumed to be part of this process. These findings are consistent with the limited prior studies exploring participant views of qualitative data sharing that found broad support, along with the expectation that data was already being shared.[32]

Although individuals were broadly supportive of sharing deidentified data among researchers, they did convey concerns about risks to confidentiality and the potential misuse of data by secondary users when asked about these issues. Participants recognized that the risks posed by data sharing varied depending on the sensitivity of the data, and many were still willing to share their data so long as their identities were protected. Participants trusted that researchers handled removing individual identifiers and data sharing appropriately. Importantly, there are no standards for safely and ethically anonymizing qualitative data that do not involve "manual context-driven procedures,"[33] and there are no guidelines on appropriate secondary use.[34] In the current environment, we lack resources, tools, or guidelines specifically for sharing qualitative data to mitigate the confidentiality and secondary-use concerns that participants conveyed.

Participants deferred to the expertise of researchers and institutional policies for keeping their data secure. It is essential to maintain this trust, and participants clearly conveyed that transparency about what would happen to data after a study was complete was essential to whether they would agree to have their data shared in the first place. Participants want to be told up front about plans to share data; ensuring that participants are aware of these plans is important for maintaining trust and engagement. Kirilova and Karcher suggest that qualitative researchers can leverage their relationships and contextual knowledge of participants to tailor details of their consent forms to the participants' population and the potential for harms specific to them. For instance, researchers can directly explain to

participants the "nature, purpose, and benefits"[35] of data sharing and ask participants what risks they are most concerned about (for example, by offering choices of what materials would be shared). It is imperative that we do not breach trust and potentially discourage people from participating in research by not communicating plans appropriately. The onus is on researchers and policy makers to ensure that the risks and protections in place are conveyed clearly to participants. Questions to explore in future studies include how to best deliver information to potential participants about data-sharing plans and whether data sharing has an impact on individuals' willingness to take part in research. In addition, participant concerns may vary depending on the data type and collection method (qualitative versus quantitative, for example), a question that also warrants further research. Future research should also explore what counts as appropriate or inappropriate secondary use from the perspective of participants, whose views may not align with those of researchers.

Participants are the foundation of research, and they place a great deal of trust in the research process.[36] They rely on researchers and institutions to responsibly handle their data. Our findings suggest that sharing data with permission and with safeguards in place is one way to respect participants and recognize their contributions. At a minimum, researchers should provide prospective research participants with information about data-sharing plans during the informed consent process. The overall willingness of participants in our study to have their deidentified data shared among researchers suggests that, with appropriate information provided in the consent form, most would agree to have their data shared. If participants view data sharing as an extension or integral part of their participation, then researchers may have a stronger obligation to share than previously thought.[37] Developing guidelines and standards for responsible and ethical qualitative data sharing is essential going forward.

STRENGTHS, LIMITS, AND NEXT STEPS

To our knowledge, this study provides the first account of views of research participants in the U.S. about sharing qualitative data. One limitation of our study is ascertainment bias on the part of study participants. Because they were recruited from a registry of research participants willing to be informed about ongoing research studies, they likely had positive attitudes about taking part in research. Future studies should explore the views of those who have not participated in qualitative research to learn about whether they view data sharing as a deterrent to participating or as an incentive or benefit.

In the next phase of our project, we will develop guidelines for ethical and responsible qualitative data sharing and software to support researchers in anonymizing qualitative data.[38] We will then recruit qualitative researchers to pilot our anonymization software and to deposit anonymized data for archiving with our project partners at the Inter-university Consortium for Political and Social Research at the University of Michigan, which is the largest social science data repository in the U.S. Working with a professional data repository helps ensure that confidentiality is protected, as repositories can provide varying levels of access control for secondary users, including restricted access.[39] We will also create a toolkit containing our anonymization support software and guidelines for sharing qualitative data that can be used by all stakeholders. These are essential steps to ensure that privacy concerns

can be addressed while data is made available for secondary use or educational purposes.[40] Our goal is to facilitate ethical qualitative data sharing that minimizes risk and maximizes benefits for participants and researchers.

ACKNOWLEDGMENTS

Appendix 1.: Semistructured, In-Depth Interview Guide: Participants

INTRODUCTION

Thank you for agreeing to take part in this interview. This study is conducted by the Washington University School of Medicine and funded by the National Institutes of Health.

Throughout this interview, I will speak a lot about qualitative research data. Researchers call the things you say during an interview qualitative research data. They usually record what you say. Then they type the recording so they can analyze what was said. Sometimes other researchers not involved in the original study want to see the data so they can analyze it themselves. But right now, it is not very common for researchers to share qualitative research data—or the information you share during interviews—so that other researchers who are not part of the original research team can see it. We want to talk to you today about your attitudes toward researchers sharing their data with other researchers.

[Make sure to review the demographic survey first. The purpose of question 1. below is to clarify the types of research participated in and what knowledge they have about prior studies.]

1. Based on your survey, it looks like you have participated in XXXXXXXX types of studies *[review demographic answers]*. I'd like to ask you a little bit more about the research studies you have participated in.

    - Do you remember why they wanted to talk to you? *[If participant has taken part in more than one study, ask them why for the studies they can remember taking part in. This list does not have to be exhaustive. The point is to get a sense of why they were eligible and if they have participated in many or just one prior study.]*

    - Did any of the studies involve collecting sensitive information, for instance, about your health or other private information about you? *[This will also be answered in the demographic survey unless the participant chooses not to answer, so you can begin by saying, "Based on your survey, it looks like the study(ies) involved collecting health or sensitive information. Can you tell me a little bit more about why the information was sensitive?]*

    - Were you interviewed—either by yourself or with a group—by a researcher?

- Do you remember if the interview was recorded?

THIS SECTION EXPLORES OBTAINING INFORMATION ON WHAT PARTICIPANT KNOWS ABOUT DATA SHARING

2. Next, I'd like to ask you to tell me what you know about how researchers share research data they collect. *[See if respondent has any spontaneous response to this open-ended question but move to bullet below if subject does not have a lot to say or is uncertain how to answer or says I don't know anything about that.]*

    - Do you know if any studies you participated in involved sharing data collected about you with other researchers?

    - *If yes*, what did you understand about how your data would be shared with other researchers?

3. Before we continue, let me share a few more details about how data sharing works. Before data is shared, researchers remove from the research data any information that would directly identify you, such as your name or address or telephone number. The amount of details that are removed from data that could identify you can be different depending on the situation. For example, sometimes researchers will remove a lot of other information from the research data to make it very difficult or impossible for another person looking at the data to identify you. Or sometimes researchers leave in information such as your age, job, race, or the city you live in. In this case, any researchers who want to use the data need to get special permission and approvals, and they need to promise to protect the data and to never try to identify participants.

    - Now that you have a bit more information about data sharing, what is your reaction to the idea of sharing qualitative research data about you with researchers who were not part of the original study team?

    - Anything else—positive or negative? *[Repeat probe until they have nothing further to add.]*

4. Let me share with you some of the reasons researchers share their data with other researchers. I want to know what you think of these reasons.

    - Sometimes researchers share data because the government paid for the research, and the government wants other researchers to be able to analyze the data to discover new things. What do you think of this reason?

    - Some people want researchers to share their data so that other researchers can check their work—make sure that they are not cheating or making things up. What do you think of this reason?

    - Sometimes researchers share data so that college students, or other people training to be researchers, can learn how to do research by analyzing real data. What do you think of this reason?

- Some people think that sharing data helps members of the public have more trust in research. What do you think of this reason?

- Do you have any other thoughts about researchers sharing data collected about you?

THIS SECTION EXPLORES PRIVACY ISSUES AND CONCERNS

5. We have talked about your views of sharing qualitative data. Next, I would like to ask you a few more specific questions about sharing qualitative data.

- Do you have any concerns about privacy and the confidentiality of your data if it was shared? For example, that it would be possible for other people who looked at the data to tell who you are by your answers.

- *[If participant has no concerns and you feel they understood the question and had the chance to consider their concerns, it may not be necessary to ask the following probes, but these might still be useful to help draw out concerns.]* Tell me whether you think any of the following would help address your concerns:

- What do you think about removing your name and replacing details about you with more general information? For example, instead of saying someone is a "3rd grade teacher in St. Louis," we could say that person is a "schoolteacher in the Midwest."

- What do you think about requiring any additional researchers who want to use the data to get special permission and approval to use the data and make sure they protect privacy and confidentiality?

- *[Skip this question if the person did not have any concerns about privacy and confidentiality.]* Do you have any other thoughts about how your concerns about privacy and confidentiality might be addressed?

- What do you think about how another researcher who is not the original researcher might interpret the data and present the information to the public?

6. Have you ever wanted to be identified in a study you have taken part in? By this we mean that you would want your name to be included with the research data or study results.

- *If yes*, can you tell me a little bit more about why you wanted to be identified?

- *If no*, can you tell me a little bit more about why you do not want to be identified?

7. How do you feel about the idea of researchers sharing your data without your permission? By this we mean that you gave permission to a researcher to take part in an interview or focus group study, but that the researcher did not ask your permission to share the data with other researchers. *[Let participant answer this*

open-ended question before using prompts below. If participant struggles to answer open-ended question, you can turn to bullet and begin by saying: "Okay, so let me ask how would you feel … ?"]

- How would you feel if you were contacted each time a new researcher wanted to use your data and asked to give your permission?

- How would you feel if you were asked just once at the beginning of a research project if other researchers could see your data after your name and identifying information were removed? By this we mean that you would not be contacted and asked each time the data was used, but would agree to it only once at the start of the study. *[If participant does not mention this spontaneously, prompt to see if they have a preference for either of the 2 options described above.]*

THIS SECTION EXPLORES RESOURCES WE PLAN TO DEVELOP

8. We are nearing the end of my questions. As part of this study, we are planning to develop tools and guidelines to help researchers share qualitative data. I am going to list them. Please tell me what you think about each. [A useful prompt if you want to get more information after the bullet, you can say, "Can you tell me a little bit about why you think that?" or, "Why is that?"]:

   - What do you think about detailed guidelines for researchers on how to share data in a responsible manner?

   - What do you think about software that would electronically scan the data for any potential identifiers and replace them?

   - What do you think about the idea of a specific person who has special training and is available to help researchers prepare the data before sharing?

   - Are there any other tools that you think should be made available to help researchers share data in a responsible way? *[This might be hard for participants to answer, which is okay; it is an opportunity to let them think of anything else. You can reassure them there are no right or wrong answers here.]*

9. When we make the tools, like guidelines or software that we just discussed, to help researchers share qualitative research data, what groups or people who have an interest in this topic should provide input into the development of resources and guidelines? *[If participant is not sure how to answer this, you can prompt by saying: "Whose views are important to consider when developing guidelines to help researchers share qualitative data?"]*

10. Is there anything else you wish to share with us that you think is important about sharing qualitative research data that we didn't talk about?

That is the end of my questions. Thank you very much for taking part in the interview. We are grateful to hear your views and for the time you took to take part. As a thank you, you will receive a $30 gift card from Amazon. I am going to turn the recorder off and discuss any details I need for your gift card to be processed.

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31. Verbatim quotations have been edited to remove nonlanguage text such as stutters, ums, and ahhs to facilitate reading.

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Table 1.

Participant Characteristics

Demographics	Frequency	Percent
Age		
20–29	3	10
30–39	6	20
40–49	5	17
50–59	9	30
60 or older	7	23
Sex		
Female	22	73
Male	8	27
Race		
Black or African American	15	50
White	15	50
Ethnicity		
Hispanic or Latino	1	3
Not Hispanic or Latino	29	97
Education		
Less than high school	1	3
High school	8	27
Some college	7	23
Associate's degree	2	7
Bachelor's degree	4	13
Master's degree	5	17
Doctoral degree	2	7
Other	1	3
Employment[1]		
Employed part-time	7	23
Employed full-time	11	37
Self-employed	1	3

Demographics	Frequency	Percent
Retired	6	20
Unemployed	4	13
Other	1	3
Number of studies participated in		
1–5	14	47
6–10	6	20
11–15	4	13
15 or more	6	20
Types of studies participated in[2]		
Clinical trial	13	43
Survey	23	77
Focus group	21	70
Interview study	20	67
Biobank	10	33
Observational	6	20
Studies participated in involved sharing		
Yes	22	73
No	5	17
Do not remember	3	10
Sensitivity of studies participated in[2]		
Protected health information	28	93
Drug/substance	7	23
Sexual history	11	37
Illegal behavior	1	3
Financial history	7	23
Other	1	3
Prefer not to answer	2	7
Motivation for participating in research[2]		
Advance research	24	80
Benefit society	17	57

Demographics	Frequency	Percent
Access to latest treatments	14	47
I enjoy it	18	60
Payments	24	80
Family suffered from disease	2	7

[1] Percentages were rounded off and thus do not total 100%.

[2] Participants were asked to check all that applied, so percentages do not total 100%.

Table 2.

Counts of Codes Reported in This Article by Racial Group

Code	Applied among African Americans	Applied among whites	Total code count
Support for data sharing	14/15	14/15	28/30
Hope data is reused	12/15	11/15	23/30
Confidentiality concerns	10/15	10/15	20/30
Secondary-use concerns	7/15	9/15	16/30
No confidentiality concerns	7/15	11/15	18/30
Lack of recall/knowledge	7/15	11/15	18/30
Trust in research process	9/15	9/15	18/30
Just ask me/transparency	6/15	11/15	17/30