

Qualitative Data Sharing: Participant Understanding, Motivation, and Consent

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Abstract

Expectations to share data underlying studies are increasing, but research on how participants, particularly those in qualitative research, respond to requests for data sharing is limited. We studied research participants' willingness to, understanding of, and motivations for data sharing. As part of a larger qualitative study on abortion reporting, we conducted interviews with 64 cisgender women in two states in early 2020 and asked for consent to share de-identified data. At the end of interviews, we asked participants to reflect on their motivations for agreeing or declining to share their data. The vast majority of respondents consented to data sharing and reported that helping others was a primary motivation for agreeing to share their data. However, a substantial number of participants showed a limited understanding of the concept of "data sharing." Additional research is needed on how to improve participants' understanding of data sharing and thus ensure fully informed consent.

Keywords

abortion < reproduction, qualitative, ethics, moral perspectives, confidentiality, privacy

Introduction

Debates about sharing qualitative data in health and social science research go back to at least the 1990s, when efforts by United Kingdom (UK) funding agencies to require sharing data through Qualibank elicited a series of exchanges between proponents and skeptics (see, e.g., Corti et al., 2000; Fielding & Fielding, 2000; Mauthner et al., 1998). Data sharing can refer to data being shared freely without any restrictions ("open data") or, more commonly for qualitative data, using a range of appropriate safeguards such as limiting data access to specific groups (e.g., academic researchers) or specific use (e.g., research or teaching), data use agreements, and virtual or physical safe rooms for accessing highly sensitive contents (Plale et al., 2019). The most common form of shared qualitative data is interview and focus group transcripts, but qualitative data can be shared in a wide range of formats including (but not limited to) images, audio, and audio-visual materials, scanned historical documents, field notes, and observations. The proliferation of shared qualitative data has significant promise for qualitative research, advancing research transparency, methods pedagogy (see DuBois et al., 2018), and new work via secondary analysis of qualitative data (e.g., Phillippi & Lauderdale, 2018,

referring to field notes as shared data). Due to this promise, funding agencies such as the US National Institute for Health (see Mozersky, Walsh, et al., 2020) or the UK's Economic and Social Research Council (see Bishop & Neale, 2011) are increasingly expecting qualitative data resulting from funded research to be shared. As such requirements for data sharing are becoming more common, and with some journals starting to require data sharing as a condition for the publication of qualitative work, the topic is currently receiving significant attention in a wide range of disciplines (e.g., DuBois et al., 2018; Feldman & Shaw, 2019; Jacobs et al., 2021; Tsai et al., 2016).

One key area of contention in such debates is the informed consent process as it applies to sharing data. While there is broad agreement on the need to ask participants' consent for sharing data even when those data are de-identified (Bishop, 2009, p. 260), the feasibility of

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such consent is subject to debate, with three main concerns being raised by researchers. First, participants in qualitative research might be reluctant to give consent knowing their responses will be shared, making the research process significantly more difficult and any data possibly shared highly selective (Jacobs et al., 2021, p. 10; Parry & Mauthner, 2004, p. 147). Additionally, even where participants consent to data sharing, answers they give during subsequent interviews may be less candid because participants are more self-conscious given the prospect of a wider audience, impacting the validity of research particularly on sensitive topics (MacLean et al., 2019, p. 10). Finally, critics question that consent is truly informed. Participants may consent to data sharing without fully understanding the meaning, making their consent poorly informed (Parry & Mauthner, 2004, p. 147) or, particularly in qualitative studies that include multiple interactions over an extended period, the content and focus of the study may change significantly after the initial consent (Lawton, 2001, p. 701–702).

In this article, we share results from one of the first empirical studies of these questions. As part of a qualitative study of abortion reporting in the United States (US), we assessed the willingness of participants to consent to share their data, their understanding of data sharing, and their motivations for consenting or not consenting to data sharing. Due to the continued stigma of abortion reporting (Lindberg et al., 2020), studying data sharing in the context of this study provides insight into data sharing for a range of research topics, including sensitive ones.

Background

Informed consent is at the heart of procedures for ethical research. By ensuring that participants understand and agree to the details of a study, researchers demonstrate their respect for persons, one of the three tenets of ethical research (together with beneficence and justice, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, pp. 4–6). Informed consent, however, is not without its critics. For decades, practitioners and ethicists have noted that participants may not properly understand study protocols they are consenting to, including critical components such as randomization. In systematic reviews of studies of informed consent, typically only about half of the studies find adequate (defined as >80%) understanding of key concepts such as risks and randomization by participants (Falagas et al., 2009; Sherlock & Brownie, 2014; Tam et al., 2015). In order to assess and improve the effectiveness of consent, several different strategies have been developed and tested. In a systematic review, Nishimura et al. (2013) find that improved consent forms (focusing on brevity and simple language) and extended discussion

have the strongest effect on improving participant understandings, whereas alternative multi-media consent processes (videos and computer-guided consent) have no demonstrated effect across studies.

Informed consent for data sharing has only recently started to be the subject of systematic study. Most existing studies of consent to data sharing have been conducted around data collection in the biosciences, mainly biobanks (i.e., collections of specimens such as tissue, blood samples, and cells) and genome databases. These studies find similar issues with participants' understandings of informed consent. Eisenhauer et al. (2019) report levels of understanding of biobank-specific content of informed consent to be under 80% for most quantitative studies reviewed, with similar assessments across eight of nine qualitative studies. A significant number of studies have investigated participants' attitudes towards data sharing in biomedical research, finding that between 65% and 90% of participants agree to data sharing with researchers (De Vries et al., 2019, p. 1942; Garrison et al., 2016, p. 668). A significant number of participants across studies also express a strong preference to be contacted and re-consented for future use of their data (which may not always be feasible for de-identified data). Given the heterogeneity of views among participants, many studies suggest flexible and/or tiered consent agreements that allow for participants to opt out of data sharing or only allow for sharing data as restricted data, accessible only by researchers whose applications have been reviewed (see, e.g., Joly et al., 2015).

Perhaps unsurprisingly, given the relative novelty of sharing qualitative data, there is little research on the views of participants towards data sharing. Two existing studies (Kuula, 2011; Mozersky, Parsons, et al., 2020) find largely positive views of participants to data sharing, whereas one study (Yardley et al., 2014) reports more skeptical reactions. Kuula (2011) collaborated with authors of four qualitative studies in Finland to contact participants and seek their consent for sharing de-identified transcripts, obtaining permission from 165 out of 169 contacted participants (p. 15). In a recent, qualitative health research study with 30 past participants in the US, Mozersky, Parsons, et al. (2020) report 28 out of 30 participants favoring sharing de-identified qualitative data (p. 16), citing advancing science as a principal motivation for them to participate in research in the first place (p. 16–18). They also report that participants often do not recall the content of consent given in past research in which they participated (p. 21), in line with similar findings for consent in other settings. Yardley et al. (2014) present results from discussion groups of researchers and research participants in the UK, reporting significant skepticism about data sharing by participants. Research participants in this study expressed reluctance to give

broad consent for future use of shared data since they do not know or trust secondary users (p. 106).

Despite the differences in overall respondent views on data sharing, some common themes emerge from these studies on sharing qualitative data. All three studies report that participants were motivated significantly by a desire to advance science and viewed that as a motivation for data sharing. Both Mozersky et al. and Yardley et al. found similar concerns about the ability of secondary users to properly understand the data: “What my concern would be [is] that you wouldn’t get the right answer from analyzing what I’d said about one question to get [to] the next question” (Yardley et al., 2014, p. 109), and participants in both studies indicated that checks on research plans and researcher credentials could be appropriate to mitigate such a risk (Mozersky, Parsons, et al., 2020, p. 20; Yardley et al., 2014, p. 108). All three studies also report participant concerns about confidentiality, especially for sensitive information, but also general trust that researchers and research institutions will appropriately safeguard confidential information.

Our study adds to this growing evidence on participants’ views on data sharing in qualitative research. It also adds an important new angle: whereas previous studies queried participants about past participation, we were able to discuss consent and data sharing with participants at the time of the interview. This research provides additional insight into participants’ willingness to agree to qualitative data sharing, their understanding of data sharing, and their motivations for sharing data.

Methods

The data presented here are part of a larger study in which the research team conducted cognitive interviews to iteratively assess new question wording and introductions designed to improve the accuracy of abortion reporting in response to a survey question; these results are not included here.

During the informed consent process prior to starting the interview, we explained to potential participants that they could opt-in to data sharing and included an optional consent to data sharing section using the following language: “If you agree, the transcript of your interview may be shared with researchers at other organizations in the future. We will take out or change any information that could identify you before sharing. You can be in the study whether you agree to data sharing or not” (see Figure 1). Respondents could participate in the study regardless of whether they consented to data sharing. At the end of the interview, we asked participants to reflect on data sharing and their motivations for agreeing or declining to share their data.

Potential for Data Sharing: If you agree, the transcript of your interview may be shared with researchers at other organizations in the future. We will take out or change any information that could identify you before sharing. You can be in the study whether you agree to data sharing or not (see *Optional Consent* below).

Optional consent to data-sharing:

Do you agree to allow a written copy of your interview to be shared with other researchers in the future?

Yes _____

No _____

Participant ID: _____

Figure 1. Consent form data sharing language.

The research team conducted 64 cognitive interviews with cisgender women.¹ Interviews were conducted in Wisconsin in January 2020 and in New Jersey in February 2020; these states were selected with regard to variations in policies and legal restrictions on abortion in order to make findings less geographically specific. Participants were recruited by a third-party recruiting firm to take part in a cognitive interview about sexual and reproductive health. Individuals were eligible to participate if they were between the ages of 18 and 49, spoke English, and had ever had penile-vaginal sex. Respondents were asked about their abortion history at screening, and we purposively sampled respondents so that roughly half the sample reported an abortion and half did not.

In-person interviews were conducted in English by authors (Jennifer Mueller and Alicia VandeVusse), lasted between 60 and 90 minutes, and took place in private rooms at conference and market research locations. All interviews were audio recorded. We designed the two-page informed consent document to be at an eighth-grade reading level. We obtained verbal consent from all participants, and they completed a short sociodemographic questionnaire at the conclusion of the interview. Participants received \$150 cash as a token of appreciation for their time. This amount was cited by the third-party recruiting firm as the going rate for studies involving the level of effort, time, and sensitivity associated with our planned data collection activities. The study was reviewed and approved by the Guttmacher Institute’s Institutional Review Board (protocol 00002197).

We had the audio recordings transcribed and stripped identifying information from the transcripts. We developed a coding scheme for the sections of the interview related to the data sharing component using both inductive

and deductive coding (Saldaña, 2016). We employed structural deductive coding to classify responses to our interview questions regarding participant understanding of and motivation for data sharing, while we used inductive concept coding to examine nuances in respondents' levels of understanding and motivations. Using NVivo 12, we coded the transcripts using this coding scheme. Upon completion of coding, we generated node reports and developed matrices to identify themes.

Results

Slightly more interviews took place in Wisconsin ($n = 35$) than New Jersey ($n = 29$), and slightly more respondents reported abortions than did not (Table 1). Almost half of all participants were non-Hispanic White. The majority of respondents reported household income levels of 200% of the federal poverty level (FPL) or above and almost half reported that they had completed college. All of the respondents identified as heterosexual/straight. Over three-quarters of respondents were over the age of 27.

We found that the vast majority of participants agreed to potential data sharing ($n = 59$). Respondents who did not

agree to data sharing were from both states, and included those who reported abortions ($n = 3$) and those who did not ($n = 2$) (see Table 2). These respondents were all over the age of 27 ($n = 5$), and the majority had completed college ($n = 4$) and reported household income levels of 300+% FPL ($n = 3$). Notable differences between the responses of participants from New Jersey and Wisconsin were not apparent.

Understanding of data sharing

At the end of the interview process, we reminded respondents of the optional consent for data sharing in the consent process, and we asked what data sharing meant to them and what they were thinking when data sharing was mentioned. In response, some participants described their understanding of "data sharing." Respondents' descriptions were deemed accurate when they explicitly mentioned data being shared with other researchers or for other studies.

That my answers could be used for other studies, not just this one, and I don't have any concerns with that. (prior abortion, consented to data sharing)

Table 1. Respondents by Demographic Characteristics ($N = 64$).

Characteristic		<i>n</i>	%
State	New Jersey	29	45
	Wisconsin	35	55
Abortion	Yes	33	52
	No	31	48
Data sharing	Yes	59	92
	No	5	8
Age	18–27	14	22
	28–38	23	36
	39–49	27	42
Poverty status	<100% FPL	1	2
	100–199% FPL	11	17
	200–299% FPL	29	45
	300+% FPL	23	36
Race/ethnicity	Non-Hispanic White	26	41
	Non-Hispanic Black	11	17
	Hispanic	16	25
	Other/multiple	10	16
Relationship status	Living with partner	8	13
	Married	28	44
	Other	28	44
Education	High school graduate or GED	3	5
	Some college or associate degree	34	53
	College graduate or above	27	42
Sexual orientation	Heterosexual or straight	64	100
	Gay or lesbian/Bisexual/Other ^a	0	0
Previous births	None	21	33
	One or more	43	67

^aPercentages may not add up to 100% due to rounding.

Table 2. Respondents by abortion report and consent to data sharing ($N = 64$).

		Consent to data sharing	
		Yes	No
Abortion report	Yes	30	3
	No	29	2

Among those whose responses included a sufficient description of data sharing ($n = 34$), over half of respondents provided answers that demonstrated accurate understanding of the concept ($n = 18$).

That other people may be interested in the survey process that you guys did and could be helpful to them. So that's what I got from it, that it would be shared to other research people that need answers to the questions that maybe they didn't do, but they would like the data, I guess, from it. (prior abortion, consented to data sharing)

Similar numbers of respondents provided accurate descriptions among the respondents who reported an abortion ($n = 9$) and those who did not ($n = 9$). Of the respondents who described data sharing accurately ($n = 18$), the vast majority ($n = 16$) consented to share their data and a small number did not ($n = 2$).

Because the prompt in our interview guide regarding respondents' understanding of data sharing did not explicitly ask for a definition, many respondents did not provide sufficient detail for the research team to assess the accuracy of their interpretation ($n = 30$). For some respondents, their answers focused only on their motivation for sharing or declining to share their data, which we describe in more detail below. Other respondents reflected on related issues, such as their expectations of the study itself, rather than elaborating on their understanding of the concept of data sharing.

However, still other respondents provided answers that demonstrated an incomplete or inaccurate understanding of data sharing ($n = 16$), despite our attempt to describe the process during informed consent. Among these respondents, many interpreted "data sharing" as participating in research, although we attempted to distinguish research from data sharing during the consent process.

I guess it's pretty much giving my opinion that was set and compare it to other opinions that other people have given, I guess to see what's the best option to make people feel comfortable. That's how I saw it. That's what you're going to use it for. (no prior abortion, consented to data sharing)

Other respondents seemed to view data sharing as equivalent to disseminating findings from a research study rather than making their responses available to other researchers.

When you mentioned the word data sharing, it could be an article with different points of views. No names, no nothing, but different points of view of the people that you've interviewed. So, that's what I thought about. A magazine, a book, or what do you call those that they give you sometimes? Pamphlet, I think it's called. Something like that with opinions of women. (prior abortion, consented to data sharing)

When I take surveys, I just automatically think that it's going to be shared with somebody. That's what surveys usually are going to be shared with somebody. So, this is research and research is going to be shared, and there is going to be some kind of an outcome. (prior abortion, consented to data sharing)

Responses such as these demonstrate that several participants were unclear as to the distinction between how their data would be used as a result of their participation in the study and as a result of agreeing to data sharing.

Although most of our respondents agreed to data sharing ($n = 59$), five did not. Some of these respondents described data sharing in accurate terms ($n = 2$), understanding that data sharing entailed responses being available to people beyond the research team. The remainder ($n = 3$) did not provide sufficient detail to assess their understanding of data sharing.

I was thinking, sharing this with yourself, obviously, and the team, whoever will be typing up what we're talking about, and then there was the additional part with other researchers, and I was like, I don't know if I consent to that, just because you took the time, your team took the time. Let the other groups find me or find a recruiter or whoever that called me about it to take that time. (no prior abortion, did not consent to data sharing)

Given that abortion is a stigmatized medical procedure in the United States, one might expect to see more hesitance regarding data sharing among respondents who reported an abortion than those who did not. However, the responses received were very similar across both groups; three respondents declined data sharing among the 33 respondents who reported an abortion, compared to two respondents who declined data sharing among the 31 who reported no prior abortion.

We also asked respondents if they thought about data sharing during the interview; of those who provided a response on this ($n = 38$), most respondents ($n = 33$)

reported not thinking about this “at all,” with a few saying that they had “forgotten about it.” Responses were similar between those who consented to data sharing and those who did not.

Motivation for data sharing

At the end of the interview, we asked respondents how they decided to consent to share their data or not. Respondents described a variety of reasons they were motivated to participate in data sharing.

The majority of respondents were motivated to agree to data sharing in order to help other people and/or improve research ($n = 47$). Among those who wanted to help other people and/or improve research, some respondents ($n = 24$) described wanting to contribute to the research field, citing that reusing their data could “save money,” “improve health care,” or “help people understand more about abortions.”

So that’s why I really don’t care if my interview is shared, I think [it] would be helpful for future purposes, so like improving on how to get people to say truthfully how many abortions they’ve had, how to make them feel comfortable and things like that. (no prior abortion, consented to data sharing)

Some of these respondents described that they hoped their participation would improve the survey questions that might be used in future studies (the original purpose of the overall study) or the experience of participating in research for future respondents.

My information could maybe help them to better ask other people. Maybe my responses could make it a better experience for someone else to answer a question. (prior abortion, consented to data sharing)

Many respondents ($n = 27$) wanted their responses to “help somebody else” or “help other women and girls.”

Even if I had had an abortion, I would feel like, if it’s benefitting or someone’s taking information that could be helpful to the next person, my mistake or me learning, then I feel I can help and share. (no prior abortion, consented to data sharing)

A subset of those who wanted to help other people wanted to bring awareness about or provide information to those interested in pregnancy prevention and abortion.

Anything to bring awareness to this—this, you know. There’s a lot of teenagers out there. They don’t, you know, they don’t have the proper guidance and stuff like that. They might not

know a lot of this information so, you know, all this information is going to be readily available or it’s going to be on the internet. (prior abortion, consented to data sharing)

Additionally, a few of these respondents felt that they could help others by sharing their experience with abortion to encourage other women to not seek abortions themselves.

So, if I can help somebody else, while I’m still living, not organ donors, I don’t mind sharing the information. Maybe what I say can help somebody else, like don’t get an abortion. (prior abortion, consented to data sharing)

Aside from the desire to help others or improve research, one third of participants who agreed to data sharing felt comfortable doing so as long as their name or other identifying information was not included ($n = 22$).

When you said that my name wouldn’t be attached to it, that made me more comfortable sharing my data, if it’s gonna, you know, help people understand more about abortions, why people do it and stuff like that. I would be happy to share. I would say, even if my name was attached, I would maybe still share if it were to help, but the fact that it’s not attached made it easier to be like, okay, yeah, to say yes. (prior abortion, consented to data sharing)

Several respondents ($n = 6$) described themselves as an “open book,” meaning that they had no concerns about sharing their personal experiences with others. For respondents who had had abortions, this idea overlapped with participants stating that they were not “ashamed” to share their abortion experiences.

The small number of respondents who did not agree to data sharing ($n = 5$) were concerned about the overall confidentiality of their responses, stating that they consented to research with our team but that this consent did not extend to other researchers.

I just don’t like data sharing in general. If I tell you something or give you access to something, I don’t want you to give it to somebody else. (prior abortion, did not consent to data sharing)

Respondents who did not agree to data sharing and reported an abortion(s) were also concerned because they were uncertain how the data would be used.

I’m in the middle of [...] wanting to share it and not wanting to share it. And I just don’t, you know, I don’t know how the data is going to be used, and I just probably wouldn’t want in the long-term scenario having it come back at me. (prior abortion, did not consent to data sharing)

Discussion

The overwhelming majority of our respondents agreed to data sharing, which aligns with results from prior studies (Cummings et al., 2015; Kuula, 2011; Mozersky, Parsons, et al., 2020). Similarly, our respondents expressed that a desire to help and improve research were primary motivations for agreeing to data sharing, which mirrors the results of other research, both for qualitative and quantitative data (Mozersky, Parsons, et al., 2020; Shah et al., 2019). Among the small number of respondents who did not consent to data sharing, concern about confidentiality and how secondary researchers might use their data arose as major barriers to sharing, as Yardley et al. (2014) found. Thus, our findings provide additional support to the growing body of literature suggesting that requests for participation in qualitative data sharing are likely to be met with agreement, although these findings are tempered by the number of participants who did not fully understand what data sharing entails, discussed below.

Our respondents, both those who did and did not consent to data sharing, indicated that they did not think about data sharing during interviews beyond the initial informed consent process. These findings provide some initial evidence that data sharing does not reduce the candidness of, or otherwise affect, participants' responses during qualitative interviews. Given that the overall study was focused on a sensitive topic (abortion), and over half of our respondents reported prior abortions, it is particularly notable that respondents indicated that they did not think about data sharing during the interview itself. This suggests that participants in studies of less sensitive topics are likely to agree to data sharing.

Our findings suggest that respondents are likely to consent to data sharing and not to dwell on their consent during a subsequent interview. Yet questions about the ethics of data sharing remain: Qualitative researchers have voiced strong objections to relying on a purely "procedural" model of research ethics, describing it as inadequate for ensuring ethical research in the types of close, often personal, interactions involved in qualitative works (Guillemin & Gillam, 2004; Lawton, 2001; Pollock, 2012). As qualitative researchers frequently build on trust and rapport built with participants, they have especially strong ethical imperatives to not violate this relationship of trust. Ensuring that the consent process is embedded into the study in such a way as to not merely be performative "empty ethics" (Corrigan, 2003), but does, in fact, respect the autonomy of participants is therefore essential to conducting ethical qualitative research. To achieve this, qualitative researchers must take additional steps to ensure that participants fully understand what "data sharing" entails when seeking consent.

The need to ensure fully informed consent is particularly important given our findings regarding participants' lack of understanding of data sharing. Many participants conflated the dissemination of research findings with data sharing, indicating that they did not fully understand the distinction between research participation and additional sharing of their responses. This is despite our efforts to describe data sharing accurately, concisely, and simply in the consent form. These results align with those of prior research on participant misunderstanding of informed consent (Falagas et al., 2009; Sherlock & Brownie, 2014; Tam et al., 2015) and suggest that it may be valuable to develop a semi-structured script for discussing data sharing with participants to explore whether that improves comprehension, aligning with Nishimura et al.'s findings that extended discussion of consent is beneficial. In addition, the tiered consent approach that we employed allowed participants to decline data sharing while still participating in the study, and we recommend other studies employ a similar approach to data sharing consent.

The fact that a sizeable group of our respondents misunderstood data sharing to mean disseminating research findings, rather than making their interview transcripts available to other researchers, raises ethical questions regarding their agreement. Because we are unable to determine if they intended for their consent to extend to the sharing of de-identified transcripts with other researchers, we decided that we will not make de-identified transcripts from participants who did not provide an accurate description of data sharing available to other researchers. Another potential mechanism to address participant misunderstandings might be to adopt a more targeted term than data sharing, such as "allowing other researchers to access interview transcripts." These approaches could be used in tandem with a comprehension check at the end of the interview, in which respondents provide a definition of data sharing in their own words and researchers probe on their consent to data sharing if the provided definitions do not clearly include sharing transcripts with other researchers. Such a conversation could also explore how respondents understand research more generally, namely how their data will be used as a result of participating in the study. This would allow for crucial disambiguation of research and data sharing. Furthermore, such an approach would allow the interviewer to revisit each participant's consent to data sharing, in which they are able to revoke their consent for any reason, including discomfort with data sharing given the content of the interview. This would address both potential misunderstanding of data sharing as well as ensure that participants did not change their mind on data sharing based on the content of the interview. A

related approach might be to request consent for data sharing only at the conclusion of an interview, thus ensuring participants know the content of their responses that will be shared. This, however, raises questions about participants potentially consenting out of a sense of obligation to the researchers after rapport has been established. Future research should examine respondents' preferences for when to have consent to data sharing raised during the research encounter.

This study provides initial insight into qualitative research participants' agreement to, understanding of, and motivation for data sharing. While a few other studies have explored these topics, we believe ours is the first to do so in the context of another empirical study. Our study therefore offers real-life insights into the process of consenting for data sharing in qualitative research. However, it is not without limitations. This work was embedded in a larger study with separate research goals, and thus our discussion of data sharing with participants was brief and came at the end of an extensive (60–90 min) interview on unrelated topics. Because of this design, we did not engage in extensive probing of responses, and as a result our data are less rich than those of interviews and focus groups focused on data sharing as used in other studies. Similarly, we did not explicitly ask participants to define data sharing, nor did we return to the consent form when discussing data sharing at the close of the interview. Thus, we are unable to determine the extent to which misunderstandings of data sharing resulted from our consent form and process. While we tried to ensure the consent form language was at an eighth-grade reading level, further research on participant understandings of consent to data sharing is necessary. Our results suggest that there is an urgent need for additional research exploring participant understandings of data sharing and developing consent processes that ensure understanding of that element and thereby genuinely informed consent.

Conclusion

The vast majority of our respondents agreed to share their data with other researchers for unspecified future use, and most also reported that they did not consider their agreement to data sharing during the remainder of the interview. These findings are promising for the future of qualitative data sharing. However, our findings that many respondents conflated participation in research with data sharing are concerning, as they indicate that respondents' consent may not be fully informed. Additional research is needed to explore how participants' willingness to consent to data sharing is impacted by deeper understanding of these differences.

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Data Accessibility Statement

The data generated and analyzed during the current study are available in the Qualitative Data Repository at <https://doi.org/10.5064/F6YYA3O3>.

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Notes

1. Transgender men, gender-non-binary, and gender-non-conforming people also become pregnant and need and have abortions. However, they were not included in this study because of the small sample size, which would not allow for comparisons by gender identity. Furthermore, we expect the issues examined in this study (stigma, sensitivity, and abortion reporting) are influenced by gender identity. We would like to expand this study to examine abortion reporting among trans and non-binary respondents in future work.
2. Participants were asked about their sexual orientation and provided with the following response categories: Heterosexual or straight; Gay or lesbian; Bisexual; Other (please specify). The latter three choices were collapsed in Table 1 as no respondents selected these categories.

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