QR03\_transcript\_deidentified

**SUMMARY KEYWORDS**

people, data, qualitative research, interview, research, publishing, questions, irb, thinking, write, article, person, confidentiality, dissertation, qualitative data, understand, researcher, context

**SPEAKERS**

Sara Mannheimer, QR03

**Sara Mannheimer** 00:00

....conversation. And I did send you the interview guide via email. Do you have it, um, handy?

**QR03** 00:10

No. Um, but I could find it. Um, I can't. Yeah, no, I'm sure I could find I just like closed everything down, because sometimes my Zoom goes out. So I try....

**Sara Mannheimer** 00:22

Well, you don't have to follow along, either or, you know.

**QR03** 00:27

Whatever you want to do I mean, you can also just like ask the question, like, it's fine.

**Sara Mannheimer** 00:32

I think I'll do that. Yeah. Okay. Yeah. All right. Great. So I gave you a little overview of the research. And so I've done a lit review, and identified six issues that are in common between qualitative data sharing and big social research. And those issues are context, data quality, data comparability, informed consent, privacy and confidentiality and intellectual property. And so the interview was structured around each of those issues. And, and so there will be six questions, and then I have some introductory stuff as well, it should take about an hour, sometimes it takes a little longer, which is why I gave us 75 minutes.

**QR03** 01:28

Okay, that's fine. I have to probably at around by 4:20.

**Sara Mannheimer** 01:43

Yeah, we can get done. Yeah.

**QR03** 01:45

Okay.

**Sara Mannheimer** 01:45

For sure. All right, great. So first question, tell me about generally the type of research you do and what type of data you generally produce.

**QR03** 01:55

Okay, so in general, I'm sort of interested in, you know, how social policy unfurls, gets implemented on the ground, right. And so and I'm particularly interested in how people who are charged with implementing social policy, so that could be, you know, the teacher who has to teach to the test, or, you know, a police officer who has to arrest people for... whatever it is, right, like, so how people charged with implementing policy navigate around policies that they think are, you know, don't work well, they're ineffective or are unjust, or both. Right? Not necessarily sometimes they think just one or the other. And I'm also interested in how people who are the targets of policy—and I very purposely used the term targets, because many people are not choosing to be engaged with the policies that engage with them—how those similarly, how those folks also navigate, and then how these two groups sometimes do this together, or, at the same time around the same policies, not always, in the same way. So that's sort of generally. And so a lot of that means that a lot of what I've looked at is process and relationships. And, and people's understandings of what is fair, and what is just and what is effective. And so these are, you know, really questions that are most amenable to answering using qualitative methods. So I'm almost exclusively a qualitative researcher. I mean, I view the value of understanding large trends, even in my areas, but I'm sort of more interested in, you know, the phenomenological perspective, what do people say? How do people understand the work they do? Or what they're asked to do and what it means in their lives? One second, I just have to.... [brief interruption]. Alright, I'm just gonna move to my office. So I have continued electricity. Anyway, um, and so. So that's sort of the general kind of research that I do, and I do research in three substantive areas. So these kinds of questions I look at in [a few different specific areas]. Um, but one is.... oh, did that disconnect? Am I still here?

**Sara Mannheimer** 04:19

I still hear you. Yeah, there was a little hiccup.

**QR03** 04:22

Yeah, [brief interruption]... So I look at [details redacted; legal and government-related programs]. And so that sort of... all of these are areas also where the processes matter. And almost, they're almost epidemiological, in the sense that, you know, you don't really, it's hard to focus in on one cause or an effect. They tend to be intersectional. Interactive, they tend to be in institutions that they themselves interact with other institutions, right. [Details about different stakeholders redacted]. So all my work is kind of like really complex and embedded. And so I when I say qualitative methods, I generally tend to do a combination of focus groups, interviews, sometimes ethnographic that, you know, includes observations, just sort of sitting places. And in qualitative research, we also talk about researcher as instrument. So, you know, if I'm going to have I want to understand [a child welfare issue], like, you know, my experience of trying to get to the office on a bus, and taking two hours to go one mile and not being able to figure out how, how is a parent who is working a low wage job with, you know, so so the experiential part of even getting to an interview, or what does it feel like sitting in a courtroom where I'm hungry, and I wasn't allowed to bring in food. I'm in there for six hours. Well, you know, what, I came from a house with a kitchen, I'm going home, you know, I can eat. What about people who don't have that, you know, I started bringing brownies to court, you know, like, but the experience of doing that tells me something in that sense. So so, so part of my data are also my own experience of being in the settings or getting to the settings. And so that's always an important component of my research as well. So to answer your question of it, but yeah.

**Sara Mannheimer** 07:56

Very interesting. Yeah.

**QR03** 08:03

I mean, if you sort of study... So a core part of qualitative research is the idea of researcher as instrument and that you can find in any qualitative textbook, and so, yeah.

**Sara Mannheimer** 08:35

Cool. All right. So the, what I'm using is called critical incident technique, where we look at one specific time when you either prepared your qualitative data for publication or sharing or reused existing data yourself, or considered sharing your data, even if you ended up not sharing. So you could talk about the study that I had identified or anything else that's on your mind. Relatively recent.

**QR03** 09:06

Okay, yeah. Why don't we talk about that? Because you're familiar with it. So I don't, you know, you can look up more stuff about it. So I have to be the one... what what would you want it like, what would you want? And what, like, what were my considerations about should I or shouldn't I?

**Sara Mannheimer** 09:20

We'll talk through different issues that you may have encountered, but just thinking of that specific example as we go through the questions. We'll use that to inform the specifics. What was your... was this project part of a grant? Was it grant funded? Did the grant require okay...

**QR03** 09:39

And no, it wasn't I wanted it to be. That's its own story about qualitative research and grants and like, whatever but yes, I had, yeah, it was not funded. I mean, I got a little bit of in-kind money from my [institution]. So I had applied for a large [funder] grant. And I actually, I didn't know this. I was in pretty new researcher at the time and had gotten I think the equivalent of a revise and resubmit. And I didn't understand it that way. I was like, "Oh, okay, never mind I didn't get it never mind," not knowing that you have to go through two or three times, and then you might get it. But no one told me that and the program officers didn't, like no one told me that I was like, "Oh, well," and the program I was going to study. I mean, that's another problem with these programs is that, you know, sometimes they just stop happening. And the program had been on hiatus, and I was afraid it was going to just disappear. And the funding mechanism every six months, I'm like, I'm like, I can either rewrite this grant or I can get in the field. So I was like, oh, forget this. And I just started doing the research. So I did. So but I was able to, like we had some faculty development, I was able to ask, like my [administrator], and my [institution] was able to provide a little bit of money for interview incentives, and transcription.

**Sara Mannheimer** 10:55

Okay. The main reason I ask is like, is to see whether you had like a data management plan or special treatment plans for the data?

**QR03** 11:03

Yeah, and so, um, yeah, [when I applied for the initial grant, I had] to write a data management plan, it was a long time ago. So I'm trying to remember at the time, I had to, I mean, I was a reviewer for [a funding agency] and so I'm really familiar with those. And I do remember the discussions that people had around, did those [data sharing requirements] apply to qualitative research. And, you know, my initial reaction to those when I saw them as a reviewer, and also as a person applying is like, there's no way I can share my data, like, not even from an IRB, but like, these are people are... you can... the the risk of deductive identification is really too high. And this is not okay. And, you know, and, and as a reviewer for [funder], I do understand that you, we are using public money to fund research and so that that research really should be not just so that I can write a book, you know, or so that you can, you know, get your tenure, but that, you know, that's not really necessarily public good. And so I do understand the rationale behind sharing. And that did speak to me, I just, it wasn't clear to me how one would do that in a way that was really okay. So I'm sort of I was very much aware of those those debates.

**Sara Mannheimer** 12:23

Cool. Um, okay, great.

**QR03** 12:29

And as a reviewer, I would be one of those people saying, you know, this makes sense, like, this person is not just saying this, because they don't want to share that. This is a very real risk.

**Sara Mannheimer** 12:39

Yeah. The I, the qualitative data community, I think, have done a lot of thinking about that, which is part of why I chose qualitative data as the sort of counterpart to social media data, because yeah, the qualitative community and qualitative data curators have done such deep thinking about all these issues that I'm hoping that they will, that will be really helpful to this newer community looking at social media data that hasn't really done as deep as...

**QR03** 13:11

I think that's, that's right on. And I think in terms of the, the arc of, you know, that's... so I conducted that research [a few years ago] I'm still writing from it, and I'm actually doing a follow up study right now. So I'm like, really, in the thick of thinking about it. Um, you know, so the difference between, you know, what I was thinking, when I applied for the grant -- that was [about a decade] ago, there really wasn't a good way of thinking about that. Like, the concern was there. But I think we were just starting to grapple with it. Probably as a community, that's probably that time, really the thinking about what's our responsibility to share this. I mean, the other thing in qualitative, I think that may be important for your project is that, you know, when you are sitting down with someone, and they're telling you a story, that that I mean, that's, that's something that they have, like they're giving you this gift of their knowledge and their experience. And, you know, I think qualitative researchers, as a group have been really thoughtful about acknowledging the value of that right of ideology and respecting respondents, and wanting to do right by them. And by the gift that we've been given is their time and their sharing of knowledge. And so the same instinct that makes us protective, right, we don't want people to be harmed, also makes us want to do the most with the data and make it the most helpful. And so sometimes that's where you end up, you know, being in a place where there's a conflict between those two things. So if we can share it and have broader use of it, and keep people protected, then you resolve that is not a true dilemma, right? It's a true dilemma when you can't solve it completely. But if you can somehow resolve it that that gets you out of the dilemma. It just makes it hard, but it's not a dilemma. And I think as part of where the qualitative research has moved from it being a true dilemma, like as dilemma is defined, we use that casually in the room very bit is true dilemma from from making into something that's resolvable, and so forth. And if you're thoughtful, and if you have a community that can help you be thoughtful like [data repositories that offer curation services] and are like, "Hey, you missed this," like, you need extra eyes, then you're no longer in the dilemma place. You just need to put in more work.

**Sara Mannheimer** 15:27

Yep. Yeah, I hope so.

**QR03** 15:30

I mean, I mean, yeah. And then recognizing where you can't, right? Like, yeah, no, there's no way that people can look at this. And so you know, that that's also legitimate. But yeah, okay.

**Sara Mannheimer** 15:43

Well, this is a great transition to the issues that I've identified here. So the first one is context. So I have a quote, I'll read to you to help frame context, as we're thinking about it here. "Qualitative research is a process that may include deep and prolonged contact and connection with research subjects, attempting to understand the subjects within their own context. Qualitative data are therefore highly context dependent. Context is a source of data meaning and understanding, ignoring context under using it or not recognizing one's own context driven perspective may result in incomplete or missed meaning and a misunderstanding of human phenomena." So that's sort of where I'm coming from here. And so the question is, was there a time during the process of [sharing your data in the repository] when you considered the issue of how you would help future users understand the data in context? How you might communicate context about the community where the data was collected, contextual information about respondents, about you, etc. And so what did you think about there?

**QR03** 16:52

I mean, I think about that all the time, really, in almost anything that I'm in. But there's no way, I mean, even when we're talking to other humans, and but like, there's no way to give everybody a full context, right. And so even when I just write an article where you don't have a lot, I mean, that's, that's actually one of the problems with publishing qualitative research, especially when you're, let's say, publishing articles, and you have a 20 page page limit. Like I also I'm a proponent, like articles shouldn't be really long, they're hard, they're slogs, or whatever. On the other hand, with qualitative research, in particular, if you want to use quotes, and if you want to provide necessary context, that's actually a bias against qualitative research, it makes it harder to publish, you know, rigorous qualitative research that really conveys what it needs to do. And so I feel like there should be some sort of, you know, it's not a sameness quality. It's like a, you know, a different kind of quality. So there's a, there's a thing with that. So so that problem exists. So I published from this data a lot. And so that's one problem I almost always encounter when I'm publishing an article from this data. And one way I do that is, you know, if I can do the first article that gives a lot more context, then I can say, hey, read over there, if you want to learn about the rules of the program, or what if I don't have space? Now that people necessarily are but they could if they wanted to? You know, another thing I do is if I give pseudonyms, a respondent a pseudonym, you know, that means that people want to read across my articles, they can actually see that, you know, [Name] over here, oh, that's the same [Name] from this article. You know, it would take a lot to reconstruct, but when I was going to [the repository], it was a, it was real hard, because I haven't given them all of my data. It's an enormous data set. And, and even though I cleaned it up for my own purposes, once it was going to go into the world, I was like, I decided I had to re-listen to every single interview and like, double check, and then you know, [have a curator], double check, like the [repository] team, they triple checked. And so it's just been really, it's taken a lot of time. So I only gave them part of the dataset. So one thing I decided to do in order to have as much... so I thought about that a lot, right. So these, the data set is comprised of different elements. But so I interviewed the [redacted] stakeholders, just one time interviews, although now I'm doing actually follow up interviews with them, and hopefully going to be sending that into [the repository] as well. So it's like, [a number of] years later, this is what it looks like. But, um, the participants in the [redacted] program, I interviewed them [multiple] times. And then about halfway through, I got permission to interview them [once more, after additional time had elapsed]. Now, some people dropped out, they were incarcerated, or they went AWOL, and so I lost them. But you know, so I had between one and [several] interviews for all of those folks. So what I decided is if I'm going to give something to [the repository], I'm only going to give sets. So if I interviewed Sara four times, and you know, I wouldn't give them just the first interview. I would give them the set. And so I'm sending them as sets. So that was one way I did it. The other thing is I created... So [the repository] has a place where you can tell somebody like what is there. And I actually decided I wanted to get like the entire, like, the whole story in the sense of this is how I collected data. So I took our IRB process, and applications have a lot of information. So I sort of put all that in there. And then I also gave a little bit of background on the programs, like these are the phases. And so it's almost like, [I want potential users to] read that first, you know. And so I try to give that information like what I did, when I did it, you know what I was... what kind of questions I was asking, I put all of my interview guides into [the repository] so that people would know, you know, what I was asking. I also have a ton of observation data and some of it has been typed up. And then some of it is literally in notebooks. And I have not transcribed them all. I'm not going to give my handwritten stuff. I know I could, but I don't think I'm going to because I have things I need to go through. And there's something called data saturation, like I don't need, like I have enough of the... but no one will ever, I mean, I sat there in court once a month for [a number of] years. And you know, and I had a lot of personal interchanges that don't get written down, and those will never be fully conveyed. But that does not mean that someone can't see something in the data that's real and important. And I think that's where I need to let go of bouncing between: "context is important; I can give people this context," and then I can also let go, and then that will mean that people will bring other understandings. So I don't know if that answers your questions; it's a little bit rambly. But I have since... it's interesting. [Brief interruption. So um, you know, so it's sort of interesting that this morning, actually, I was at a dissertat-, I was on somebody's dissertation committee, and [they] just defended this morning. So yeah, there's a new doctor in the room. But [they] actually used my data. It was sort of serendipitous just at the time that [an employee at the repository] had approached the [institution where I work], and I was like, yeah, I'll be the guinea pig. And so we have a wonderful librarian, [details about the librarian], so I was also working with [them]. [They] came [to talk to me and my colleagues] and like very few people want to go into these things. Like we don't have time, you know, which is unfortunate. So I know one of my colleagues also [shared data through the institution], and I did, and [the librarian] would be like, "Tell your friends to do it." And I would tell them, and nobody does it. They don't take the time. They don't do it. And they're like, "Why should we? what does it give us?" And also people just have demand- demands on their time. And I'm always like, oh, let me try it. This is interesting. So I think part of it is just, you know, so I had to work with [the librarian] and then I said to, I said to [the repository], I said, you know, "I've really been thinking about this issue." [A few details redacted]. It's like, let's just try it. And I'm willing to be a guinea pig. And so I asked [the librarian] also to [attend the meeting] with me, I was like "You're a librarian, you understand this, like, let's meet with [the repository]," and all my questions were really about how are you going to protect the confidentiality? Can I put any safeguards in the data? And [the repository] explained to me that you can't put safeguards-- like you have to pay for it. And I don't have money like that, you know, what, you know, you can't get that kind of, but [they] did say, and this for me was actually, this would have been a no, if like, this would have been a hard line. I asked [them] if we could require that anybody using my data, to show us some sort of like training, like CITI training, some sort of IRB ethics training, and if they had that, then that would be okay. But I wanted that to be a prereq. Because [they] said, "Yes, we can do that, for sure." And I did get some guidance from [the librarian]. Like, they had some questions. Like, they helped me think of what kind of questions. And so we and once I felt comfortable with that, with [the librarian's] help I was like, okay. And what happened is at the same time, I was just, at the same time, and so the person whose dissertation [committee I just served on], so this was an it, [they] came to me, um, how did [they] get to me? So the reason... the places I did research, this was an ethnography that I did in two places. [Locations redacted]. So the PhD student was, a PhD student in the [redacted] department. [They were] taking a class and [they] wanted to do a project where [they] wanted to go and do interviews with people at [a location], which is where I had been. And they said to [the student], "No, no, we already have someone. It's [QR03]." And I wasn't like... but I was the researcher there. So [the PhD student] looked me up. And [they] found an article. And [they] reached out to me, and [they] said, "They're not letting me do interviews, let's talk." And you know, fast forward a bunch. So, as part of [their] dissertation, [the student] ended up using my data set-- my interviews. Now, I didn't give [the student] the whole data set. But I was like, "Yeah, I'm preparing this for [the repository], I'll do it for you and [the repository] at the same time." So it was just a serendipitous coincidence, which I guess that's redundancy, redundancy.

**Sara Mannheimer** 25:30

That is really delightful. Like, yes, getting an immediate, positive response to your published data, like someone who wants to actually you know....

**QR03** 25:37

No, no, no, [they] didn't know that wasn't it. I was preparing it for [the repository], it wasn't published yet.

**Sara Mannheimer** 25:42

Right. Right. Yes. But your data.

**QR03** 25:44

But it reinforced that, "oh, this is useful." It was like the universe telling me like... And so what ended up happening is I only shared the participant interviews with [the PhD student]. Right, which is what I ended up, you know, sharing that batch with [the repository]. And I'm still working. I mean, I'm doing it in batches, I just did another thing. And I sent [them] another bunch. It's just taking me forever, but you know, we're publishing it as it goes. And so when... so [the PhD student is] working with my data, and it ended up really informing [their] thinking on [their] dissertation. [They] ended up doing [their] own original interviews, and then [they] did a quantitative technique. But [they] drew on my data as sort of a, you know, comparison sample. And then we ended up, we just, we ended up writing an article using my data, which just it's going to be published in [a journal in my field]; we just got the acceptance after it being rejected [several] times, like it was just the weirdest... But anyway, but what I learned from that, too, and working with [the student] is [they] brought fresh eyes to my data. I had been sitting with this data for [a number of] years. It's not like I, you know, I've been publishing a lot, there's so much to see in it. But having [the student] look at my data, and having me... I learned from [them] too, right. And it's my data, but [they were] saying things that I wasn't seeing because [they] had [their] own lens. And that was really fruitful for me. And it was exciting for me. And it also felt good, because because, you know, and of course [they would] say to me, "Well, wait a minute, am I understanding-?" So, so that's... when you ask about context, also. So [the student] would periodically check with me, even not for our article, which was really [they're] like, "I'm thinking this, is that your read too?" And I'd be like, "No, no, no, this actually..." so there were some things that I could see that [the student] wasn't getting and that could be misunderstood. So I do think that it also confirmed that that can be a problem. And so I think what you're looking at is, that's a very long way of like, you know, risks and benefits. It's a real risk. But does that mean you shouldn't share it? You know, I don't think so.

**Sara Mannheimer** 27:43

Yeah, yeah. That's such an interesting case study. Cool. Thank you. Alright, let's move to data quality. During this example, when you were publishing this data, what quality issues or concerns arose? For example, like missing data, or communicating the quality of your methods? Sort of like how did you think about communicating the quality of your data to future users so that they could know that they could trust your data?

**QR03** 28:13

Yeah, that part actually, it's almost the same answer as the first one. So what I did when I wrote the IRB thing, I actually was able to write like, these are my methods, these are my interview guides. These are the steps that I took to enhance rigor, right? So I wrote about, you know, using member checking with subsequent interviews, I told them I had, I don't remember if I used all the... but triangulation of data, I was doing observations and interviews. I also told people there how things unfolded. So for example, while I was doing research [in one location], [a stakeholder] said, "Oh, you should come with me to like, when I introduce people, you know, come with me to [a location] when I'm telling them about the program" and I was like yes. And so I added that on, you know, so those were the kind of things that, even as a reviewer of an article, what I'm trying to figure out, like, it's the same kind of stuff that you would want to know, if you're reading somebody's published article: can you rely on their study? So I gave very detailed information about that in the hopes of communicating. That's something that I think qualitative researchers often have to do anyway. Because our data are not generalizable. We often... I try, you know, again, space limitations notwithstanding, or withstanding, okay, I tried to give as much context as possible so people can say "Hmm, well, [QR03], [QR03] was talking to people in a [redacted] setting, if I was looking, you know, at [a different, but related setting], could I..." you know. So I might tell them, okay, they're in this program. So you give people a bit detail, so they can sort of see whether, you know, it makes sense to think about it. So as a qualitative researcher, I'm always doing that and so in, in [the repository], that's why I put in my entire IRB protocol. And then I added wherever it wasn't clear, like these are the steps I did to protect confidentiality. This is what I did to protect privacy. You know, this is what I did to, you know, what what what I told people in terms of if you tell me x, I'm going to have to report, and so that... so that way they would be able to say, "Oh, you know, if people were going to talk about [an issue that requires mandatory reporting], they probably didn't, because [QR03] told them not to." So that's that would be potentially, well, they did tell me a lot about that. But that potentially is the kind of thing that could be missing data, right. And so I shared a lot, as much as possible. I tried to be as detailed as possible. I also give people my contact information, like you can tell, you can probably tell by the things I told you, I responded, like, if anybody emails me, I'm like, "yeah let's talk!" You know, um, and I just try and do that. So if anybody were to ask me questions, I want to be reachable, and I would be happy to talk to people, I'd rather people ask questions, than misread my data. So you know, so I wanted to put... because I asked [the repository], you know, what, what kind of background... [they were] like, "you can put whatever you want. People do a little, people do a lot." I was like, I want to do a lot. So I actually did one for precisely the reasons you're asking about. I wanted to put a lot of information there because I wanted people to be able to assess the quality to understand the context. Yeah, and maybe replicate, like, you know, here, take my interview guides, I don't care use the same interview guides, like go ahead.

**Sara Mannheimer** 31:18

Yeah. I wish that there was more like credit and benefit to the researcher for doing all that work. You know, it's like, it's good for science, but you know.

**QR03** 31:30

Yeah, but you do it anyway. I mean, I think in that way, I mean, I had to do it with my IRB. I copied and pasted, and then I made it coherent. Like, you know, I it's not like I was inventing the interview guides for [the repository], like, I had them. And so it's not like anybody's gonna take anything away from me if they use my interview guides. I mean, would it be nice if they said, these are based on [QR03's] interview guides? Yeah. Do I care that much? I'm still gonna do my stuff.

**Sara Mannheimer** 31:55

Yeah.

**QR03** 31:56

And I've always had people be very generous with me. I did my dissertation. My dissertation research was [topic redacted]. And I was very generously given interview guides, there was a book written about [topic and author redacted]. [The authors of the book are] like wonderful human beings. And [they] said, you know, and I basically said, "Hey, can I look at your interview guides? I want to use them." And they sent me their, their interview guides, and that was what I just used. So my models have been, in general, of generosity. I mean, no, I don't want... that's another thing about [sharing data in a repository], you don't want to be scooped. So like, if [the PhD student] were to say, "Should I put my dissert-," I said, "You know, you can wait a year or two, you know, write when you want to and put them in here." But as far as sharing those kinds of things, and then eventually sharing when you, you know. No one's going to write what you're gonna write, exactly, anyway, from qualitative data.

**Sara Mannheimer** 32:50

Yeah, true. Okay, let's move on to the third issue, which is data comparability. During this research, did you compare or combine multiple qualitative data sets? Or did you think about comparability and interoperability of your data set? And if yes, tell me more.

**QR03** 33:09

Okay, so well, first of all, the research itself was in some ways, you know, I don't want to call it exactly comparative research, but I was doing research in two different programs. And they were very different, very differently structured. [Details redacted]. You know, so very different programs. So it was already a little bit comparative in nature, but because they were so different, you know, the data from the [the one program] was so much richer than the data from [the other program], you know. I mean, I use them both. But really, it feels like it was much more influenced by the other. They were, you know, reinforcing. And so the fact that I was hearing some similar things, where there was a chance for similar things [between the two programs]. But then [there were other key differences between the programs]. And [sometimes they were not] comparable. So even within the data set, they were, you know, it was built as almost like a comparison. Although I never actually wrote about that comparison, I wrote more like shared strains kind of, but then most of the articles and I can't remember how many there have been so far. One, two, there's been probably [several] articles that I wrote. So I have a collaborator, [details redacted]. And very early on, I started having conversations with [them. They] did a study of... [a program similar to the ones studied by QR03]. Um, and [they were] doing almost like a sort of a needs assessment, you know, or, and, you know, should they start a [redacted] program. And so [they] had data from that. And [they] and I combined our data of the nonexistent, you know, but it was also similar stakeholders. [Stakeholder details redacted]. And so we actually combined our data, and we have written the... We have one that right now is in page proofs. I mean, we're still writing together. [They] did [their] research at the time. And so we combine those. And then the other thing is, I have one other. I have an article, I think it came out and I can send you these if you just want to see like how we described that.

**Sara Mannheimer** 36:06

Yeah. I'm also curious about like, what challenges you encountered when trying to combine them?

**QR03** 36:11

So the so the other the other thing, project I did where we combined data, or that was so for something I we combined data, so you'd ask that combined data, we really combined it, and then we analyzed it together.

**Sara Mannheimer** 36:23

Okay, nice.

**QR03** 36:25

The thing I did with [name redacted -- a different collaborator], is we actually, we compared our data, which is a little bit different. So [they] had data from a project looking at [a topic related to QR03's research area]. And so what happened is [they] and I were doing really the equivalent of peer debriefing for each other's data, right? Like I would talk to [them] about my emerging analysis. It's a qualitative technique, right? Where you peer debrief with somebody else who might be outside your, you know, not part of the research, but you're trying to it's a it's a rigor technique. And as we were talking, we discovered, actually, that the language the way that [participants in these similar programs] were assessed was very similar. And so we combined our data, we analyze them to look at [research question redacted]. They're actually the same, they use the same mechanisms. And we something... We encountered many challenges, different kinds of... how can you combine these, you know, how can you add to... starting from with Rose, how can you talk about [one type of participant] in the same breath as talking about [a different type of participant]? Are you saying that, you know, [these participants are the same?] Like no, you know, like... And we're saying no, conceptually, and isn't it interesting and what does it say about the way we view [the two different types of participants]. Right? So those kinds of so we got a lot of those kinds of questions. The other challenge when you're combining is you have to explain, you have to give context, speaking to your first question about both, do you have room. [Collaborator] and I ended up publishing in a [redacted] journal, where they didn't have page limitations And they do footnotes. No, I'm serious. This sounds like a minor thing. You can be digressive in a [redacted] journal. In fact, you have to, and it's a pain but like, so you could put in a footnote, if you want to see more about [the program investigated in the research], then you can go to this publication where you can say... this isn't, you know, you can give your caveats, you know, without having a comprehensive article, but you have the caveats. We tried. We tried publishing in social science journals, and we just kept getting dinged. Like, what about this? Why are you doing this? And then you don't have room to explain and it doesn't make sense. So it's really hard to combine these, why you're saying you can combine these what is the same you have to explain enough about how they're similar or different on something I do every article, we have to put something in there. And so we always do have had the challenge of explaining enough about each of the data sets so that people understand. And then people get confused, like, people get confused, and then they go off on, like, you send it out, and reviewers are like, and then they get stuck on the weird question that really has nothing to do with like the substance of the article. But yeah, so all those were problems that we had.

**Sara Mannheimer** 39:40

Okay. That's perfect. That's really helpful. All right, let's move to informed consent.

**QR03** 39:47

They all got successfully published, by the way like, you know, that's fine.

**Sara Mannheimer** 39:52

Nice. Yeah. I mean, that's a huge challenge that I've seen throughout the literature. So it's interesting, to hear your specific challenges, too. So can you tell me about a time during the publication process of your data set when you consider the idea of consent, particularly the idea of consent for future use of the data? Like, did you? Yeah. Did you have that in your original consent form these transcripts will be published, did you consult with people to think about it? How did you think about that idea of like publishing the data and how consent would work in the future?

**QR03** 40:34

So when I did this original research, I never considered publishing the transcript, it was like considered taboo, by my mentors, right? This was not, so it was not in the original ones. You know, once transcripts are de-, I mean, I consulted with my IRB, and they're kind of like, "What's the problem? They're deidentified," you know, like, they don't get qualitative research really like no offense. But anyway, like, so sometimes there'll be like, I just got a question like, "What data are you collecting with your interviews?" And I was like, "The interviews are the data." No, "Can you summarize the data that you'll get?" So I said, you know, I didn't even know how to answer like, so sometimes, like, that was like, you know, yesterday's question. And but, but on the other hand, like this, or like, they should have been, there's a problem. Let's think about it. They're like, no, it's deidentified like, so the idea of deductive identification was not even on their radar. So the IRB, so I guess that to say that I don't I didn't find the IRB very helpful in, in thinking through this question from an ethics perspective, they did let me know that I was off the hook in terms of an IRB. But I still had an ethical question with myself, that wasn't resolved. I talked to [an employee at the repository], [they were] sort of helpful. [They] told me that this is part of the service that they provide with the curation service, that they look at consent forms. So I sent the original consent forms, for [them] to see and see what they thought about the consent forms. [They] thought they were okay. And, um, I mean, it was also helpful that a lot of time had passed, I think, [several] years that I thought that, you know, the people in the program might be able to identify each other, but like, you know, as the program stuff changed over, as maybe some of the people in the program, things got a little bit blurrier. So that assuaged my concerns a little bit. I think it was the follow up study that I'm doing right now, in the consent form, I said that I might want to put it in there [the data in a repository]. And so I asked people, so that's in the current consent. So moving forward. With my IRB, my IRB is like, "Are you sure?" Like they have not been wanting to approve studies that have that in there? Like, they want me to be more... And so, you know, path of least resistance I just pull it off and say no, and then I figure I can go back after it's deidentified and ask [the data curator].

**Sara Mannheimer** 43:07

Oh, they don't want to approve it again?

**QR03** 43:11

I think I've had a little pushback, because they don't really understand. And then I'm like, I don't really have time to deal with you guys. And then it's a different person every time and it just there's like this, you know, you get so many questions like this question of like, "What are the data that you get from a qualitative interview" like, like, those kinds of things, like when you're at that level. The idea of having to have this back and forth sometimes like you try once or twice, and it just doesn't sink in, then then I just let it go. Yeah, yeah. So So I do think that there is a kind of a lack of understanding of how this works.

**Sara Mannheimer** 43:46

This is definitely an issue. Yeah, that IRB is like, don't exactly know how to treat secondary use of data. They'll just say, "Oh, that's like exempt, because it's existing data." But yeah, so yeah.

**QR03** 43:57

But then if you want to actually say it's in there, like, which is, which is the better way to do it you can't, but you can after the fact, even if you didn't ask in the first place, it seems to me like the way I'm being pushed to go with it doesn't seem the right way to go.

**Sara Mannheimer** 44:12

Do, did, did you make? Like, did you make any considerations based on your knowledge of the respondents like the community, like how you would seen them respond to the research or their ideas about like, whether they would be okay with sharing, you know, did you make any? Did you have any thoughts about that community how you thought the community would respond to data sharing?

**QR03** 44:38

Yeah, um, I mean, I think about that a lot. I think when I was talking about the idea of, you know, people share, like their story as a gift, you know, and so a lot of the people that I talked to are like, "Oh, you can use my real name like, I want people to know my story."

**Sara Mannheimer** 44:59

Yeah.

**QR03** 44:59

And a lot of people think you aren't allowed to. But yeah, so I actually think that, you know, one of my impetus for wanting to share is I do believe that the, and a lot of people in my study also like, they want to help other people like that's, you know, maybe they don't want to help other people through research, but they, many of them said, "I want to help other people I want, you know, people to learn from my experience, I want to share this." And so I do have that in mind, both in terms of when I said to you, why shouldn't other people do more with this, you know, as long as they're going to be responsible and respectful. I feel like that's making more use of it. I also am very attuned to some of the critiques about researchers who sort of go in and take and take and take. There's a wonderful piece by [a researcher], it's like a finger with... a good finger, in the good sense-- of finger wagging researchers who are coming into communities, working with [vulnerable communities], this is what you should be considering. And so part of the idea is you're respectful people's time, don't go ask more people, when you can ask fewer people don't ask the same people twice, don't overburden communities. And so if that means that someone can make use of my data without going and wasting somebody's time, so I do think about that a lot. And I appreciate that suggestion. And so for me sharing the data is is, you know, putting my money where my mouth is with the suggestion.

**Sara Mannheimer** 46:41

Yeah.

**QR03** 46:42

So why wouldn't we want to create less burden? Again, you know, it's a little bit balanced, like, sometimes people like to tell their stories, you know, it's not always a burden. But really thinking of sort of the research burden, particularly when you're talking about populations who might have been marginalized, and who are overburdened by researchers, you know, shouldn't be using this data, and bugging people, you know, less.

**Sara Mannheimer** 47:06

Yeah. I like that. You're very, you're very focused on the benefits. And I really like, you're like, we're on the same page there. Okay, let's take....

**QR03** 47:17

I just think what, what and one other thing, actually, which I think is really interesting. I mean, I think when we think of costs, you know, the fact that if we go back to the funding, you asked was I funded, most people don't get [funding from big federal agencies]. So if I'm on [the repository], and it's freely accessible, and a person who is not an academic wants to do some research. And maybe they don't have the time, they can go get my data, like, I mean, that's another thing. So the idea of breaking down barriers for people who were able to make use of the research, there was one or only one person who actually asked to use my data from [the repository]. And I think it was either I can't remember was either a master's student, or it wasn't a doc student, it was somebody who would not have had the wherewithal to collect their own data, [they were] gonna use it, like, why not? So yeah, that's down the costs. And to the extent that cost is a barrier to people being able to do research, like, I got money, you know, from [an administrator], and for my [institution] to pay and give people incentives, what if you don't have money? What if you don't have money for transcription? You know, so this allows people with less, you know, resources, including time, you have less time, less money, maybe you don't have access. So this removes secondary data removes an access barrier.

**Sara Mannheimer** 48:32

Yeah.

**QR03** 48:33

I mean, I took me [several] years to do my, my dissertation, well not my diss-, my entire doctoral program, you know, and, and that was okay, I had part time work, I had a partner who had a lower paying job, you know, what if I needed to do my, my program in four years or five years, it's also a hurdle for people doing original qualitative research, the data collection is really, really long. And they're disadvantaged, you know, as compared to folks who can use secondary data sets. So both gathering the data, and then of course, like secondary data analysis for quant is like, you set it up and push a button, which I know that, but you don't have to engage as much. And so it reduces the the cost. Also, I think the time cost, even for, you know, PhD students.

**Sara Mannheimer** 49:19

Yeah, for sure. Okay, I want to be aware of your time here. But um, let's, you've talked a little bit about privacy and confidentiality already, like with the requirement that people who use the data have density training or ethics training, and that you talk your librarian a little. What... do you have any other like challenges or issues that you encountered around privacy, the deidentification process, anything like that as you publish this data?

**QR03** 49:48

Well, I feel like privacy isn't really an issue once you've collected the data, right? Because privacy is like, you know, it's been years. It's not like anybody was like walking by while I was doing data collection. So I don't think privacy privacy sort of ends when you're done with data collection from my understanding.

**Sara Mannheimer** 50:01

Yeah.

**QR03** 50:01

And so it's really a confidentiality issue kind of at this point. And that's mostly with the de-, deidentification.

**Sara Mannheimer** 50:08

Yeah.

**QR03** 50:09

So no, I mean, I don't know, you know, I mean, I definitely think for example, with the IRB, there was some back and forth about what kind of data we're collecting, because these were [vulnerable communities]. And that was sort of interesting. My IRB was all concerned of like, what if I learned that somebody is engaging in [illegal behavior]? I'm like, "Yeah, what if? I don't have to report that. Like, okay," but so but but that to be said, I, so I did actually write to ask if I could apply for a certificate of confidentiality. And so there's a mechanism to do that, and you do it through the federal government. And that means if you're subpoenaed, you can even get a waiver for that. I don't know how much you know about that process. But I did for this data set, I did do that. So that was another reason I wasn't so worried about the confidentiality, I had written to them. You, you have to figure out depending on what you're doing, which agency you go to, and then if you don't fit, like different federal agencies can give that to you. And then there's like, if you don't belong anywhere, this is where you go. And I don't remember where it was, it could have been [federal agency] or something. And I wrote to the person there. And they said, "You do not need this, because you are not collecting data..." that you know, so they sort of said kind of what I said, but an official way. And so I sent that to my IRB, I was like, see, I don't, it's okay. So so I didn't know that. And that reduced some of my own anxiety about confidentiality, right, like this is not. And so I did not ask specific questions about things that I thought would put people in danger. You know, people, and I have people have pseudonyms, too. And so so so I guess I wasn't so worried about that.

**Sara Mannheimer** 51:56

And the data in [the repository]. It's, it is restricted?

**QR03** 52:02

It's deidentified. And it's restricted to people who... it's only, well, but that's the only restriction is that people have to have had ethics training. So it's the kind of thing where I would want people that do that, and to, you know, know that they handle it carefully that I mean, and also no one can take my transcripts and publish them. Like, it's not like I'm publishing the transcript like they are available for somebody to read through [the repository]. And you can't access them unless you've had the CITI training, in which case, you know, you're using it for for those purposes, you know, you can't use it for purposes of prosecuting people or whatever you have to. And so it's not like, so it's restricted access, and it's to people who are I don't know, you're actually raising a good question. I feel like I'm going to ask [the data curator QR03 worked with], this. Like, even if someone had CITI training, I'm not giving them access to use it for like [purposes that could hurt participants]. I'm giving the right to use it for research purposes. And I don't know if they say like, you know, "I swear I'm only using this for like," I don't know, I will now I'm going to check with [the data curator], because...

**Sara Mannheimer** 52:56

I'm, I think they have a standard agreement of some kind that they use, but I'm not sure if it...

**QR03** 53:03

I think, so I think so because and that was the other the other thing that allayed my concern is that that they had clearly thought about this. And they looked at my like I said, they they offer you these services in the curation. So they would say things to me, like, you know, I was deidenti-, but I'd be like, you know, a person would say something like, "I have five children, their age 3, 5, 7," whatever. And [the data curator] would come back and say, "Well, why don't you just say I have multiple children; don't say how many children they have?" Or I said this person [did something in] May of 2013. He'd be like, "Can you just say spring?" And so they did take it a step further. And so I did have concerns, but the curation process that they provided me, allayed those concerns, and that included this curation that I'm describing the review of the consent form, and their willingness to put a restriction on access to the data for people who had had training around ethics and confidentiality, and privacy. Right. So if you do like that, you've done the confidentiality of privacy that, you know, all that kind of stuff.

**Sara Mannheimer** 54:10

Great. Perfect. All right, on to our last question. Intellectual property, so was there a time during the process of publishing this data when you considered intellectual property concerns like for the participants or your organization, or anything like that?

**QR03** 54:32

So participants know because like, what would it be? I mean, you know, if you use an in vivo phrase, like should I be giving people credit? I usually say that it comes from in vivo so I would be giving credit that they would know who the person is, but that's not like yeah, I didn't really worry about myself. But But like I said, I mean, you know, by the time I published... I gave it to to [the repository, I had already published quite a number of publications myself. [Details redacted] I have, I don't want to say squeezed these data. But I, because there's so much in it. I mean, I can I can keep working on it the rest of my life, and I wouldn't be done. But that's actually part of it. Like, you know, it continues to be there for me. But I had published so much, it's not like someone was going to scoop me on [the program] or whatever. But I do. I do a lot of advising to, you know, PhD students and junior faculty. And I think I would say to them, and it's not official intellectual property, but I think I would say to them, you know, "Publish your important pieces from it first, you know, make sure you get out there, and then you can let it be available." So I probably would say that they should get people should get a couple publications out before they put it in there. That's what I would advise like, junior folks to be doing. By the time I gave it to [the repository], I was already... [was well established in my career]. And I think that's a consideration, you know, where you're at. On the other hand, if it's in there, and you get cited, it gives you citation. So for people who have encountered that, so I think that there's a balance, like maybe you want to do a little bit, get one or two articles out, then you put it out, you could keep publishing for it with it. Especially if it's unique, like if people are not writing on that so much. But then all the more reason to share it at some point, right? Because then people will use it, they'll cite you and...

**Sara Mannheimer** 56:27

And people collaborate with you.

**QR03** 56:29

Yeah, exactly.

**Sara Mannheimer** 56:32

Great. Okay. That's the last question. I guess. I do have like, is that is there anything, any challenge or issue that arose that I didn't ask you about that is on your mind?

**QR03** 56:50

No, I don't think so. I mean, it you know, this was this was fun, it was thought provoking. It's really making me think, I think kind of in a renewed way about just giving me a little more impetus to try to get my IRB to like, and reminding me of my current study. You know, what did I say it was going to do? And should I be? Because I'm currently collecting data from this, and I'm thinking, wait, I think I should have pointed this out to the people as I'm collecting data from, you know. Another hesitancy and I'm not sure I have an answer to this, but just to throw out, I do do a lot of work for [government-related institutions]. And so that's a different kind of research when I'm under contract from a government agency, and they've come to me. So I have a project right now, [details redacted]. So they came to me, and I have an ongoing relationship with the [government institution]. And so they periodically come to me with qualitative projects. And they came to me and so, you know, it's there. It's not even it's non-human subjects review, because it's, it's for them to improve their purposes. Um, and usually, I end up publishing something, it's a secondary piece, I give them, you know, the data that I publish, and that's been my pattern. But I wonder, like, you know, I think my contract with my [academic institution] is that I own the data. But, but is that data that I can give, you know, to [the repository]? I think it could be really valuable. I mean, I've gotten some really good data. Um, and I'm not sure. So that's another conversation. And I mean, I guess I would throw that out to you. Maybe that might be an interesting area to research. You know, so people who were doing it's not just grant funded, but people who are doing, you know, research projects that are evaluation for others, you know, is kind of data shareable. You know, and if, though, if so, are they so context dependent? I mean, you know, those questions are very, very specific. But if you do any kind of qualitative research, you know, you know, that we just have this interview, right, I probably gave you lots of information that wasn't exactly what you asked for. And you could potentially write articles from all those things.

**Sara Mannheimer** 59:13

Right.

**QR03** 59:13

So I think, you know, I have quite a bit of those kind of data. And it would be even if you put it all together, like I've combined it myself, I was like, oh, I'll take [data from two different types of participants]. Let's see what happens. You know, so I can do that myself. Can I share it? So I haven't resolved that question. And that's rattling around my brain. And I have a good relationship with the folks in the [government institution] who normally asked me to do this and so that's something I'm thinking of raising with them. Yeah, I fear what's gonna happen they're gonna be like, "Oh, we have to talk to me" right but you know, like, it may never get an answer it might just get lost in the bureaucratic you know, sandstorm, but, but that's another place. I'm thinking about that. I'd be curious.

**Sara Mannheimer** 59:55

Yeah, that is really interesting. Yeah, data like ownership is, is very what's the word I'm looking for? It's different from institution to institution and project to project. So it is a, it's a big question right now.

**QR03** 1:00:12

I mean, I think I own the data. I mean, it's like, according to that, I could probably check on that with the univ-, university? I probably do. But then there's a difference between so I guess it's both ownership. But then if you have relationship with an agency, maybe you own it, but should you? And so that's how we've already, I'm not sure. But my understanding is that our university requires that we retain ownership in the sense of the ability to keep using the data. But I don't know whether we can pass it on. Usually what happens is the articles they put a clause in where we say we'll share it with them, I'm going to write an article, I sent it to them, I said, "Have a look at this, let me know, within 30 days, if you've been changes or issues, otherwise, I'm sending it out." And usually then come back to me or they'll be like, "Oh, this is great," you know, and then I always say thank you and I whenever and I imagine we could do the same thing with with this. Whether they're comfortable with that is something else that I would want to know. So there's both there's the ownership. There's the comfort level, particularly, it's an ongoing relationship that you have with, uh...

**Sara Mannheimer** 1:01:13

Definitely, yeah. Great. Okay. Well, thanks so much for talking. This was really fun.

**QR03** 1:07:10

Okay. All right. Thanks so much. Have a great day.

**Sara Mannheimer** 1:07:14

Okay, you too.

**QR03** 1:07:14

Bye bye.

**Sara Mannheimer** 1:07:15

Bye.