So my undergraduate degree was in psychology and my PhD, which [I] have just finished, which was in health sciences, so kind of using like health psychology and health sciences, and behavioral sciences and in cancer research is my area and I have used both quantitative methods using R, and then I've used more qualitative methods where I've done one-to-one interviews with participants.

Yes. I've been using both. For the qualitative. Yes, for [that] I use Nvivo to help me organize the data.

Yeah, SPSS, R

And, so in my PhD, I am used the theoretical domains framework quite a lot to inform my, both, my quantitative studies and my qualitative studies, and for sort of guiding the analysis.

And so, yes, I've done one - recruited participants and done, like, one-to-one interviews, and these were semi-structured interviews and with participants, and I've recorded these interviews, you know, analyzed the data transcriptions and things.

…yeah, I find it really interesting and I do really like working qualitatively, so in quantitative, I think I quite like being mixed-methods so I can change it up quite, and so interesting to read all the quotes, it was probably harder to get my head around quality at first, but now - it's, it's not really easier, it's just more creative I guess.

In general. Um yeah, I'm very for open research in many ways, and I [have] done a lot of work with that with my university, and I've led the [Redacted University club name] journal club. And so, I am very for open research overall, and I'm also very for that quote. Is it from, I can't remember where it's from actually, that quote where it said ‘as open as possible, as closed as necessary’, which I'm also, I think I was really when I first started looking into open researchers, very positive. And now I've got a more critical lens in some aspects that I think is needed.

So I have made some of my qualitative data open access in a sense, so, but it is open access - it's just restricted open access. So when I, so I was really big into sharing quantitative data, anonymous quantitative data. So when I do my qualitative interview study, and I wanted to do the same. So for participants who can send it, and they didn't have to consent. It was optional. But participants who can send it, I put their sort of pseudonymized Interview transcripts into a restricted access repository held by the [Redacted University name]. I find that process. I mean, it's really, it's really good to keep. data, if it's funded by public through charities and public bodies. It is really important to try and keep the long journey of the data, but I guess it's also balancing that with making sure participants can't be identified, and potentially to do that you have to remove quite a substantial amount [of] data to anonymize it And potentially, if you do that is the data reading useful. Once you've done that and put it online, I'm not really sure. And it was very time-consuming to Anonymize and

…so I thought it was a really good experience, that I felt like afterwards I still wasn't sure how, what I felt about it.

Yeah, and I don't know, and I also think it was a lot of work for me. But I think I've seen [Name redacted] say that the future you can cost for maybe helping with things like that, to help project the longevity of the data if you don't have funding though. It's like [a] thing, I spent like a good few days a week just going through and double-checking all the data to anonymize it. So if you're busy it's quite time-consuming.

And so I guess one is what people do with the data. So, will they use that data to add to their date in the future, such as like a big qualitative synthesis, or - and maybe for qualitative meta analysis or for future studies. If they want to collect extra data from a topic, is that how it's going to be used? Maybe that's the best way, because in quantitative research you can do things such as, you know, reproduce the data to insurance accuracy, and it can be used a lot more for other things and checking things like yeah reproducibility and things like reproducibility and reliability. It's not really anything that can be used with qualitative research. That is a lot more inductive. And so, that is the sort of barrier like, what do people - do [they] really understand what is that data going to be used for? Because it's can't always be used the same as quantitative, and the other barriers ar. as I mentioned, anonymizing the data, but then potentially, you could have really good - you've got - have really good consent processes. Participants what their consenting to, but potentially you don't - you can, they could consent to their being this risk of disclosure. I don't know…

…and you put [it] in a really restricted access repository. It's sort of [a] duty of care to participants. I think that's really hard to weigh up. And participants might say that they're fine for their names to be attached to it. But for example, they might think it's fine for learning to be attached to it, but if they talk about people in their interviews, like family members, have they consented to their details being released like that. So, that's really complicated. And the other is continuing consent, because it consented for the research, their data to be used for future research I guess it would be quite heartbreaking to know that your data got used for [a] future study that actually was trying to contribute harm in some way to maybe, whatever population group you're associated with, you can't really necessarily control who uses the data, and what - for outside of things like not in my data. It says, you know, it shouldn't be used for, it should be used non-commercial learning research and teaching purposes. So it's not used for commercial purposes, but past that there's not a lot of control.

Yeah, so with mine, it's in a restricted access repository, where it has an end user license. And someone would have to apply to [Redacted University name], and they have this whole massive contract license that I didn't write the [Redacted University name], for it, it's very solid and, and they apply for that. And that will have terms and conditions such as where the date is stored, how long for, and why they use it and so that in that way is…

I've seen now that a lot of grant funders wanted to it be the norm, including the UKRI and to have a really good reason for opting out. So, I guess grant funders, are require, sort of requiring it is sort of changing, potentially, a culture and - then, I think what I mentioned earlier, if there's a potential for grant funders to allow costing, so the things that are time-consuming to a sort of allow costing for things like maybe studentizing days to make sure it's really, really, and I have heard people use companies for things like that. I think that does exist, I'm not sure. I didn't use it, and if there's a way for grants to make sure there is funding for that, and that's not something they have to. If you want them to deposit data, then you have money for this. It shouldn't really be something they have to fight for. And that would make that easier but it's training as well. And it's not going to quantitative data training. It needs a whole thing. And potentially. It needs to be implemented quite university. Wise. So even if it's like a national funding, the training, it gets like advertising at universities and quite regular chain training for when people want to go to it to find out actually how they do it because I didn't know that there were things such as restricting access repositories, until I spoke to my university library team and don't know, you don't know. So how do you find out? Basically, I had to find out just working, you know, like really, like, interoperator research, and just chatting [with the] library team. Otherwise. It's really hard to navigate data and sharing, I think, if you've never done it before,

Yeah. So what I thought of the ethical steps item for [undecipherable]. So, I explained in the particular information sheets and consent form about that the data could be stored in a restricted access repository, and that people will have access to data for non-commercial learning research into teaching purposes, and participants consented. For this, it was optional. So I put it at the bottom, and I said you don't have to consent this. Take part in this, you can opt out and you can still take part, but really the vast majority of people opted in - and even though they could opt out [were] very happy to share their data, and I yeah. So that was the sort of procedure things but I had seen my data from when I conducted, sort of conducted the interviews and I sent the transcripts to a transcription company, they sent me back the pseudomized data with things like locations removed. But what I did was I went through again, when I wanted to upload it to the restricted access repository, I went through it all again, and double checked everyone's consent form. They definitely can send it for the data being used. And then I removed absolutely anything I felt that could be identifiable and especially because I was researching quite a niche population, like quite a niche genetic population. and it just meant things like, they said, “I had two sisters” and they each had bowel cancer, womb, cancer, and even stuff like that. I tried to keep it quite vague and say, family members and cancer. So it kind of ends removing interesting data, but then I was using quite a niche pool of people that even though they have high risk of cancer in these families, sort of saying, how many sisters and brothers they had - and which can family members - have cancer could be identifiable. And so it's just removing sort of anything and everything; accents, expressions that could hint an accent. And so it was quite time-consuming, and so, yes, and then uploading to the restricted access repository.

Yeah, I would be like, a those brackets, those square brackets.

They and I would not say removed, I would just say They said “Sister, I say [Family member] they said they have this many cancers...

..I just put number of cancers, just to get rid of the little specific details.

But hopefully someone [will] understand it, and I also had a data user guide that sort of describes how I anonymized for people. I just remembered that, and so have this guide, and that really helped. So hopefully people come back to it. They can be like, that's what I'm anonymized. That's why I've changed this, and hopefully it's easier for them to read and that was on the guidance of my university library team.

And so, what was that my [undecipherable] at this week?

Yeah, so epistemology is funny because we don't really talk about [it] in health research so often, yeah, where what position I come from, but I definitely come from much more preposition of trying to make qualitative research much more inductive rather than being led by quantitative deductive measures - such as when I used extra coders to help me analyze my data. I've not thought about it as reliability checking, I thought of it as wanting to hear other people's opinions, and discuss together collaboratively. And so, it is tension in a sense, because opens, like research and quantitative is a much more positivism deductive framework. And I think that's why, I think the tension comes from that, we are a big part of the sort of open science, open research movements, what open science and originally what it was called because it is very much the quantitative science is coming from a very positive as a quantitative respective and sort of adapting things to meet qualitative research, but maybe in some times it's not as simple as adapting. It sort of needs a whole massive overhaul, and doesn't dismantle, put back together from the ground up, with like qualitative researchers, and that leads them to tensions. I think where there's like a lot of things coming through like grant funders and hiring criteria, is that talking about open science and things and open research practices and there's attention to that. If you are purely conducting qualitative research, especially in areas of high risk populations who really can't risk any disclosure, then you're going to be left behind by grant funders and hiring criteria. And it's, things [are] going to be sort of against you because the system sort of built up for a very positive open science structure.

Um, I think the experience made me feel like it depends. I will try where I can, but I don't think of it as a priority in comparison to quantitative. and I will try and always get consent for it, where possible, because if you don't get consent and you've blocked yourself in later, And so it's trying to get consent things. But it is a lot of work. I have another data set from a PhD - that - I need to do that with some time, but I don't know when I'll find time, and trying to balance that publishing and yeah, I don't think I left the experience fully convinced that qualitative open data is completely the way forward. At least without instructions there to make it easier, just because it's so time-consuming. AndI'm not sure, I'm not sure on the benefits I guess, because I'm, I don't really know what the benefits are of longitudinal qualitative data. I wonder if there's any really interesting best practice examples, because I don't really know what people use the data for, might be really interesting. I think maybe people do, or maybe it's only hypothetical speculation, but [it would] be quite interesting to know - that zombies things may be to make me feel that.

The time I put in anonymizing, it is worth it.

Yeah, existing, was yeah, because I just don't know. So I don't know how to use, or what it's useful, and yeah. And I know a lot of data probably isn't useful stuff, but just especially qualitative data, I've seen people talk about how it can be used, but how has it actually been used?

I can see it working really well for a qualitative synthesis of existing data, because it could be a lot more helpful if you could access the actual transcripts rather than just the review data that could be really handy potentially. Past that, it could be. It could be useful. I work in such a niche area to be honest, I haven't seen anyone do research that I do in the UK, so. But if more people did, it would be interesting potentially, but I can't see me using it any time soon, but I could see how it could have worked. When I did a systematic review for my PhD, I tried to look for quality to research and we didn't find any if I had fan qualitative research and I could see where having that existing data would have been useful.

So there's one thing I'm aware of from our unit [at Redacted University name] And so I did a reproducibility session, and there was a qualitative researcher. He came to speak at the session and they talked about timescapes, which is a longitudinal, qualitative research data storage projects, and that was a project. I can't think how long it ran, but that was yeah, really interesting. A study where these sort of, they actually did it without actually, saw a lot of longitudinal qualitative data and they really looked at what consent processes would be, and sort of looked at troubleshooting, those sort of ideas. So I know of that [at Redacted University name] and I know a lot of open researchers who talk about it in qualitative research, and sort of written papers express things like that. And so, accessing a lot of like, discussions actually. And maybe less practice in the past, I've seen apart from timescapes, It's very much in practice and it's really interesting. That's what's called [indecipherable] archive, most, so talking about it, and sort of the barriers and challenges, and Yyah, be interesting to know how people do it. More in practice, I guess it comes back to my earlier point.

Yeah, so, with the research in general, you know, is that - there's loads of things such as like publishing protocols. And I'm pre-registering in qualitative research, and which is also a contentious issue because it's much more quantitative. I've pre-registered my qualitative research on open science framework, I did find it really helpful to sort of link to say this is what I was originally gonna do, and this sort of how the study evolved, and quality to research can change. And that's like, fine, it's [an] evolving process. And, but it's also how do you know the resources are there? So I pre-registered on open science framework, which is kind of funny, because it's called open science framework. So originally, I think, imagine qualitative researchers would think, well that's not for me because it's something very science, quantitative research. And with the data, this is, but I’m sorry - the question would you repeat the question? That's okay.

Yeah. Yeah, the data needs to be, increase awareness of resources - including, like, restricted access repositories, which would make people probably feel a lot better. Increase awareness of the consent process participants understand what they're consenting to and that this is really factored in as early as possible from the study. and again, that's also training and awareness and, and

The understanding processes. For, if you say subsistence of data is going to be sort of pseudonymized and anonymized, and identifiable data is going to be removed. They're actually - how that actually is done in practice and what is identifiable. What is considered identified? Well, that's quite, that's not exactly black and white, that can be quite difficult to work out. And then you could go to your library university. Libraries sometimes have resources in this area like experts, like the [ Redacted University name], but I guess if everyone did that and the library would never be able to support them because they're just would not be enough people. Not enough library staff with all the questions.

yeah, and more support roles that are funded that can help this so increasing awareness, but making sure the other end of the spectrum, when you've increased awareness, you have the structures there and support staff.

Yeah. so yeah, I was as aware of pre-registering quantitative research and open science framework anyway, and I was aware that templates have been adapted for qualitative research so I knew I wanted to try and use these sort of open science practices in my qualitative study. So once I wrote the ethics application, and then I took in key information from the ethics application, so expanded upon it and created a pre-registration protocol. And that was really helpful, because it helped me think about things like analysis as well. And what I was planning to do and and then I put that on open science framework and timestamped it pre-registered it. And Oh, and as I mentioned as well, I factor in data collection data, open access data, really early into this process. I got in contact with the [Redacted University name].

Library teams discuss their restricted access repository and to understand what this sort of user license agreement was. So I could sort of take that tax to put into the participant information sheet in the consent form and I'm making that optional. So it was not sure first I sort of had it as it was partake as part taking part in the study and my supervisor felt that it should be optional because it shouldn't really filter out everyone who doesn't want to do that and, you know, recruit qualitative recruitment is hard enough, as is to sort of just heard people away. We didn't really know if people gonna like that or not. It was really unknown. It turns actually, most people are very happy for it, but we didn't really know beforehand. So, yes, and then Sort of started the city. And yeah, everything kind of went from there. And then when I published a study before, I published a study, I put the data in the restricted access repository, and in the publication, it's linked. Both the pre-registration and the restricted access repository and I didn't describe what changed from the, I don't think there were many changes from the pre-registration, I didn't really describe. I didn't describe what changes were either. I mean I think that could, it could be done in some qualitative studies to sort of discuss your process and your thoughts and changes. But I don't think this is a necessity compared to quantitative research where you need to be like, we were going to do this and we did this. I think it's not, it could be interesting qualitative research, but it would be written in a different way to sort of talk about your journey and process. And then I published the paper Open Access, which I was lucky to do, because I have UKRI funding, so I was able to get it published through the library open access, and that was really great because the patient group I was interviewing were really interested in the research. So when I published it, I could give it to them and the community I recruited from, they have this sort of Facebook support network, and they could read the paper as opposed to it being behind a paywall.

Yeah. Yeah, I think people don't, I think how much patients probably do want to read their cites, especially if [they’re] in like a niche pop population group. Like if you're diagnosed with [a] genetic, condition you might want to look at these papers. Yes, and the trials are really hard to understand, but it's just like everything kind of being behind a paywall, that they, they did fund the research in some, most of the research if it's from charities and UKRI, so they should be able to read it.

No, I guess. So, there's a lot of repositories. So, you have to try and search the repositories. I wonder, I'm because I've not done this, and this sounds really naive because I've mostly deposited data. I don't know how this works the other way. So do you like, let's just search in a sense, to find the data - and can you search across multiple databases? Do you have to go across individual ones? Do you find the papers, and see if they have the data? So, I don't know, actually, don't know. I don't know how to do anything the other way, or any mostly done it from depositing, so I, if I was gonna go search and try and find qualitative data, I don't know how I would search for it unless researching for the publications wouldn't know how to search multiple repositories, and I don't know a lot of repositories. I know the UK Data Service for UKRI, and I know my university one, and I'm sure other universities have data repositories, and that's all I really know. So, Yeah, I just yeah, I can't even really help with that question. I just realized, I don't really know how to do the other way.

where we lost. I don't think I know how to do it. I go back to my library team to be honest as for their help, I would actually know the first steps and I'm not sure I've seen. Training in that area. Training on, not how to deposit, how to use secondary qualities of dates and how to find it.

Yeah. Otherwise, it's like that, back to what I said before, it's like we're posting a lot of data but what's it being used for? Because no one knows how to use it.

Yes, exactly. So yeah, I mean unless you have funding it is not really a Maybe, it's not really beneficial for the researcher or not possible to do it. And also, while the barriers, of course, anonymizing also the consent process. It also could be seen as a barrier because you have to ensure participants know what they are consenting. And and…

…also like this, well, the duty of greater participants because sometimes they disclose information that might be sensitive, maybe not about them, but other people and…

…and just have to be very careful and what they do make available. And, and also this part of continuous consent because a, you know, you cannot control who uses that, that the data and why, and