Researcher BN: There we go. So, I hoped we could start with kind of how you came, did you mention erm, you’ve accessed (name of organisation) and..

SU3: (name of organsiation), yeah.

Researcher BN: (name of organization) so erm, maybe if we could just start with how you came to find them and access them, things like that.

SU3: Erm, the (name of organisation) was good few years ago. And I was searching, I can't exactly how I got told about them, but because I had a social worker and I was trying to find groups in the local area. Erm, and no one was really coming up with anything but then I mentioned that I wanted to start my own business and it was like oh well (name of organisation) can help with that

Researcher BN: Ah okay.

SU3: Turns out, well, no, not really, (laughs) but. Erm, so I reached out through their website and never heard anything again because the website didn't work. Erm, but eventually, somehow I got put back in touch with them. But knowing that I'd already tried to reach out with them, I was like, yes, I'm going to do that. I can't exactly remember how I ended up going to an open day kind of thing

Researcher BN: Okay.

SU3: Erm, that was like joint (name of organisation) and (name of organisation), it's both run by the same woman, erm.

Researcher BN: Ah, OK.

SU3: So it was a few things to get me there, but eventually I got there, and started, supposed to be having mentoring sessions, and had a few, and then everything shut down. (laughs)

Researcher BN: Yeah (laughs)

SU3: Yeah, and (name of organisation) erm, I've seen posts about them on Facebook.

Researcher BN: Ah OK.

SU3: Erm, and I think (name of organisation) mentioned them a couple of times because (name of organisation) are trying to work with as many groups in the area, and link up with many groups in the area as possible, because there's not really a directory, sorry there’s a wasp and I’m just like conscious of it, so if I’m staring off to the side that’s why, sorry, erm, yeah so erm, I was just kind of keeping an eye on it because it seemed like a good thing. And then they said that they did, they’d started a fibromyalgia support group, and I was like, oh great, I've got that, I'll go.

Researcher BN: Yeah.

SU3: And that's how I got involved with them.

Researcher BN: Through both of those yeah. So, and what goes on at each one of those?

SU3: Erm, I've only been to the fibro support group for (name of organisation). Erm, so that's, but they do board game nights, they do a load of other things, but that's all I'm focused on,

Researcher BN: Yeah.

SU3: ..and we just kind of sit in a room and, not just have a whinge (laughs), it's more than that but there's a certain amount of whinging that goes on. Erm, you know share how our week’s been, erm, anything that we found that helps or makes our fibro worse we share, and often they bring in people that do, like the one I saw, somebody came in and was talking about erm kind of trauma informed yoga that they do,

Researcher BN: Oh wow.

SU3: ..and saying you know, if anybody wants to sign up to that. Sorry, I really don’t like wasps.

(removes wasp)

SU3: Yeah erm, so that’s what I do, that what I do for (name of organisation) group erm, and it’s quite social, and then for (name of organisation), they have like a, each week they kind of e-mail us like what's going on that week, and they do a wide range of things and each month they have a theme.

Researcher BN: Oh, oh wow.

SU3: Erm, so they do mindful Mondays, so in the morning there's like a mindful exercise session, erm, kind of do whatever you feel you can manage. But it's very gentle, erm, most things they do are on zoom.

Researcher BN: OK.

SU3: Which is an issue. Erm, they've got an allotment, so they do a session with, where people come in, well women come and tend to the allotment. Erm, they sometimes link up with other organisations like I was part of a violence against women and girls seminar like awareness training thing.

Researcher BN: Ah okay.

SU3: Erm, and they brought in somebody from grace, you know rape crisis Northumberland.

Researcher BN: Oh yeah.

SU3: Erm, to be, to like to watch that and so they could kind of be aware of what courses are going on and various different things. They've teamed up with worky ticket in Newcastle to put on plays and stuff. So it’s quite a wide range of stuff generally.

Researcher BN: Yeah.

SU3: Erm, but at the moment it's mostly on zoom.

Researcher BN: Ah OK. Has it always been on zoom ever since you started going there?

SU3: Erm, no not before everything shut down. There was a lot more in person stuff, hands on stuff, and that has really dialled back since the pandemic,

Researcher BN: Yeah.

SU3: Erm, but their premises are quite small.

Researcher BN: Right.

SU3: So I get that they can't have many people in person, but they never used to have loads of people in person, so, yeah (laughs).

Researcher BN: Yeah, okay (laughs). That sounds good though. Erm, and so have you accessed any other kind of voluntary and community groups before?

SU3: Erm, I'm trying to think (laughs). Erm, kind of, erm I don't know if it counts as a community group, but there's a group I go to in Newcastle erm, weekly, that’s run for autistic people, but you have to be referred by a social worker so I don't know if that counts?

Researcher BN: Ah okay. Yeah.

(Coffees arrive)

Researcher BN: And so what kind of interactions do you have with the staff and volunteers? We can do one at a time if that would be easier, if we start with erm (name of organisation)

SU3: Erm, to, well it's all voluntary run,

Researcher BN: Ah okay.

SU3: Erm, but two of the women that kind of I guess work there, run the fibro group because they saw a need for it. Erm, so they run it, so they're part of the group, and they've also erm, 'cause I've talked about like I'm trying to find as many things as possible because there is like no support at all round here. It is shockingly bad, there’s nothing.

Researcher BN: Yeah.

SU3: Erm, so they've erm, I’ve had conversations with them where they’ve tried to let me know what's available, and what they’re working on, and how I can be a part of what various different things there are, which is really great.

Researcher BN: Yeah, ah that's good, so that's a positive

SU3: Yes.

Researcher BN: (illegible) And what about (name of organisation)?

SU3: Erm, I’ve had a few complicated experiences with them, so I was supposed to be getting mentoring, and I was from this one person and it was going great and I had like four sessions and then everything shut down because of COVID. She left and never told me.

Researcher BN: Oh.

SU3: So erm the woman that runs everything tried to take over my mentoring sessions, but didn't let me know that that was happening

Researcher BN: Right.

SU3: So that was a bit confusing for me.

Researcher BN: Yeah.

SU3: Erm, and there's, we're quite different people in a number of ways, erm, and she's lovely, but not exactly what I was hoping for of a mentor

Researcher BN: Yeah.

SU3: ..and I’d like to talk about my abuse with someone a bit closer to my own age,

Researcher BN: Yeah.

SU3: Like no, no offence but, yeah, and I think she took a bit of offense to it, apparently I wasn’t the only one that had asked for someone, for a mentor closer to our own age, erm, because it used to be, there used to be two halves to erm, the young women’s, (name of organisation), and there was young women up to about 30 I think it was, and then everyone else. And, since the person that was mentoring me left, and the other person that was helping running the young woman women’s bit went on maternity leave, they just dissolved that, and there's been nothing at all.

Researcher BN: Right.

SU3: So it's just been me and one other person that I don't know for the young women and that was it.

Researcher BN: Ah okay.

SU3: And it’s all seemed to be very focused on older women and what they might want to do, and there’s really not much insight into what me and this other person might wan to do at all. Erm, which isn't great, and I know they're trying but, it's still not brilliant, and the person that runs is, promises a lot, but she was very forgetful, I know she's doing like 6 jobs so I get why, though she could be quite forgetful,

Researcher BN: Yeah.

SU3: ..which can be quite frustrating, erm, because there's lots of promise and then very little follow through, or she'll describe something and it won't quite be as described, and I get it that she’s probably getting it confused with something else, but that’s routine (laughs).

Researcher BN: Yeah.

SU3: Like most recently, I was promised to help, erm, to pay for my vets bills. And I haven’t had it. And then, so my counsellor is trying to kind of, talk to this woman and get it. But there's, there's a lot of this and then it's all, oh you need to contact me. But she know full well that I’ve got memory problems and I’m incredibly anxious, and she's very busy. And she knows that there are those barriers there and still expects me to do the legwork, to get the support. I’m pretty sure that’s not how it should be working.

Researcher BN: Yeah.

SU3: I don't know if it’s deliberate but, erm, any in person thing, almost, yeah, any in person thing that's being held since the pandemic, it's all been completely wheelchair inaccessible.

Researcher BN: Right.

SU3: We know that I'm in a wheelchair, and I'm not the only person that's ever been to (name of organisation) that's ever been in a wheelchair, either. Erm, so that’s not good.

Researcher BN: Slightly more negative, yeah. And so do you tend to have conversations with the volunteers there, kind of everyday rather, other than the mentoring?

SU3: Erm, no not really, no it’s, I don’t even have that anymore, it’s just stopped. Erm, 'cause I was another, they got another person in and then she's left to do another job now so, or something

Researcher BN: Okay.

SU3: So it's very sporadic that I have a conversation with anyone, so I, I technically still go, like I'll turn up to something that sounds interesting, if I can somehow get there.

Researcher BN: Yeah.

SU3: Erm, but I don't really have conversations with staff members anymore.

Researcher BN: And what, what, at what point did everything change?

SU3: Erm, well things started changing in lockdown,

Researcher BN: Right.

SU3: ..which it's understandable, erm, but they haven't really improved since then, and a lot has changed since then, and they still haven't improved. Which isn’t great (laughs).

Researcher BN: Yeah, so kind of would you COVID was the kind of started the changes?

SU3: Yeah definitely.

Researcher BN: Yeah. So what in, in, maybe focusing on (name of organisation) and when you do have conversations with volunteers, people that work there, what do you tend to talk about? Is there any kind of themes in, that you talk about?

SU3: Erm, because it's mostly, the, because it’s the fibro group, erm, that, erm, what kind of things help, we all share what helps you, erm so things that can help each other, I've told them, talked to them about erm other services that I've used, an alternative health thing that I've attempted, and it might be helpful because they're looking to bring other people in to do things in the workshops, we were talking about for example, erm, Bowen therapy, that powerful and that it might be helpful to, for them to get Bowen therapy because it might be useful. Erm, that kind of thing mostly.

Researcher BN: Yeah.

SU3: And then also what other groups are on.

Researcher BN: Yeah.

SU3: Is pretty much it.

Researcher BN: Yeah (laughs), so quite brief would you say?

SU3: Yeah.

Researcher BN: Okay. And erm, can, can you describe any differences in what you've talked about with volunteers, before and after COVID?

SU3: Erm, I've only been to (name of organisation) over the last few months, so,

Researcher BN: Ah okay.

SU3: ..I don't really have that, any comparison.

Researcher BN: Yeah.

SU3: But for (name of organisation) erm, there was a lot more on before COVID, so I was talking about what was on, how can I get there, is it accessible and being told lots of, about lots of workshops and since COVID there is far less on, and often it's me going I can’t do that, it would be great if you could make it more accessible. Is there anything not on zoom? Could you maybe hold it in a wheelchair accessible building? It's lots of me being like you need to make this more accessible, and kind of feeling like I’m hitting a brick wall.

Researcher BN: Yeah. Sounds frustrating.

SU3: It is, because there's, they claim that it's disability accessible because there's other women there with other disabilities, but it's accessible to a very small type, group, types of disabilities

Researcher BN: Okay.

SU3: ..and not much beyond that. And the won’t go (laughs).

Researcher BN: Yeah.

SU3: Erm, so that, that's kind of it. And me going this isn’t, this isn't good enough. Oh, and also me telling the person that runs it that she needs to make her language more inclusive.

Researcher BN: Right.

SU3: Because you're not being trans inclusive (name) you need to improve (laughs). And she seemed shocked. Like, but it's a women's group, I’m like, yeah, that, that's a big umbrella term.

Researcher BN: Yeah, uhuhh. I agree. And so, in these quite rare conversations with staff, do you ever talk about health in any of way kind of physical activity..?

SU3: Yeah, we have.

Researcher BN: … and things like that?

SU3: We talked about health,

Researcher BN: Okay.

SU3: ..because she was trying to help me find a job and erm, when that started I didn't have all of the disabilities I have now to the same extent, and erm since a while after, everything got a lot worse. And I was saying I cant really use my hands properly anymore. Erm, I can't do this, I can't do that. And she actually got quite annoyed that she’d gone through all that trouble to find these things for me, and now it wasn't any good. So that was a discussion on my illnesses getting worse.

Researcher BN: Okay.

SU3: Erm, various different things like that. Again, me going I can't do that because, erm, I’m in a wheelchair. But often it’s, the discussions around health are why I can no longer do something. And, yeah.

Researcher BN: Yeah.

SU3: More than anything else.

Researcher BN: So not, nothing around kind of alcohol, smoking, erm, mental health or anything like that?

SU3: We've talked about mental health, erm, like one of the reasons I can't do video calls because of past trauma, and erm it’s, kind of partnered with the splinter group, which is an autism group, so there's a bit of overlap there and we’ve talked about erm her daughter, and her daughter’s disabilities. Erm, talked about me and my partner and our relationship due to erm my mental health problems and being autistic and various things like that. Erm, so there's been a bit

Researcher BN: Okay.

SU3: Erm, but not lots.

Researcher BN: And was that at the (name of organisation)?

SU3: Sorry, that's at the, not the (name of organisation), the (name of organisation)

Researcher BN: Sorry, the (name of organisation). And who, who initiated those kind of conversations?

SU3: Erm, either of us at any time. Erm, at (name of organisation) we've also talked about mental health that comes into the whole fibro support group thing as well. So we've talked about mental health there. Erm, and I've also said that they could probably, I think that's, there’s a need for erm, a group for abuse survivors. 'cause I haven't found any support groups anywhere, erm so there probably should be one (laughs). If I think there’s a need, everyone else, other people are going to think there’s a need.

Researcher BN: Yeah.

SU3: So I guess we do talk about mental health in that respect as well, in like, the lack of resources, and what, what they could do.

Researcher BN: Yeah. And how, how did you find those conversations? Did you find them useful, helpful?

SU3: Yeah quite productive.

Researcher BN: Okay that’s good.

SU3: Yeah erm, they're going to try and see what they can set up which if good. Also, you know, the more people know what there isn't, the more likely something is going to be done about it. So I always feel like it's useful to, to talk to people about that kind of thing.

Researcher BN: Yeah.

SU3: But if people don't know then nothing is going to change.

Researcher BN: Uhumm. Yeah. And did you feel like it was an appropriate environment to talk about health and wellbeing?

SU3: Yeah, yeah.

Researcher BN: Yeah. Okay, that's good. And did you make any change, did, did you make any changes following these conversations?

SU3: No.

Researcher BN: OK.

SU3: Erm, but I’m kind of already doing everything I possibly could.

Researcher BN: Yeah.

SU3: So there's not really much I could change really. It's kind of more about what they could change that I talk to them about,

Researcher BN: Yeah.

SU3: ..be like hey, you're not good enough, but I'm willing to help (laughs).

Researcher BN: Yeah (laughs). So it’s actually the other way around.

SU3: Yeah.

Researcher BN: Yeah.

SU3: (laughs) I think telling the what I think they should be doing. Like in in a polite way, because if they don't get told, then they're not going to know.

Researcher BN: Yeah, yeah, no exactly. And is there anything that might stop you from talking about health and wellbeing erm, with volunteers at both groups?

SU3: Erm, I suppose really at (name of organisation) it’s kind of the attitude of the person that runs it. Erm, yeah, I know she's trying to help everybody, but sometimes she can come across as quite judgmental.

Researcher BN: OK.

SU3: Erm, so if I'm not having a good day, I’m just not going to talk to her about anything (laughs). Because I don't have the will, like the strength for that. Erm, so yeah, sometimes her demeanour is, can be off-putting.

Researcher BN: Okay.

SU3: Scary, really (laughs). And I know it's all from like a good place, but she's can still be quite scary.

Researcher BN: And scary in what, in what way? Kind of unpick that a little bit more?

SU3: Like, quite brisk in the way that she talks, like harsh, I always, I often come away from a conversation with her feeling like, like she thinks that I should be doing more, but like I can’t, that’s why I’m asking for help. Erm, so I come away feeling quite upset and angry, and I don't want to feel like that. And I know that that's what's going to happen. So I guess the anticipation of like I know I’m going to feel bad at the end of this.

Researcher BN: Yeah, and so what might help do you think?

SU3: Erm, I think she needs to adjust her expectations of people. Again, she seems to have experience of certain types of disabilities. And has her expectations built around that, and there’s an awful lot more. I think she does need to adjust her world view a bit. Erm also she’s quite out of touch, like so I didn't realise erm that apparently she's queer, and I've been talking about the need for a queer specific group in (name of location) for, when we had one pride, and the it was shut down and moved away. And so as I say like there needs to be something here, there is no community, we need a community. Erm, and I've been talking about erm support for trans people. And she seems to be completely forgetting that queer and trans people exist and she is gay, like.

Researcher BN: So kind of her attitude would help?

SU3: Yeah, well, even just her demeanour, I mean her attitude might be good (laughs) but if, maybe it's just the way she says things. It might just be the way she comes across, but definitely that needs working on.

Researcher BN: Yeah. And what about in the other group, what might help in that group to talk about health and wellbeing more?

SU3: I think there needs to be more frequent meet-ups because the fibro groups are once a month, and they only, either you have to be at the, at the previous group to, when they decide the date of the next one to know when it is, or you have to watch on Facebook and they don't always post it on Facebook in time. So erm, this is stopping people going, so I feel like if they have more frequent groups, then that wouldn't be an issue, and if I could go more often then I'd feel more comfortable with them, so I think it’s frequency.

Researcher BN: Okay.

SU3: Of being able to be there.

Researcher BN: Okay so quite different between the two groups. Yeah.

SU3: Yeah. Yeah because one of the people that runs the (name of organisation) has endometriosis, so she's got very similar experiences, even if it's not the same. So, I know that I'm not going to get judged, like she's been through all the same bullshit as me (laughs).

Researcher BN: So that’s not a problem.

SU3: That's not a problem at all. Which is good.

Researcher BN: So, yeah, is there anything else that's a barrier in that group, in the other group?

SU3: Erm, it's not wheelchair accessible the building so I can only go if I can get a lift to the building.

Researcher BN: Yeah.

SU3: And I can’t always because my boyfriend, I don’t have a car, he drives his parents’ car. So if they’re using it, I can't go. Or if I’m not in (name of location), I can’t go. Erm, they said they are working, they're trying to work on it and they're aware that it’s a problem, okay so buy a ramp then.

Researcher BN: Yeah (laughs).

SU3: Sorry, the pub up the road has done it.

Researcher BN: Yeah, (laughs) yeah you’re right. And so do you think it's inappropriate, kind of these two settings if you think of both of them, do you think it's an appropriate environment to talk health and wellbeing?

SU3: Yeah, I think they are. I think (name of organisation) could be better at it. But yeah, I think they're both appropriate settings. 'cause (name of organisation) does aspire, that's kind of one of the things that they want to support people with as well so.

Researcher BN: Yeah, and what, what makes you think that it is appropriate?

SU3: Erm, that both places they're just trying to help people, like that's what it's for.

Researcher BN: Yeah.

SU3: So, and I know that everything is going to be treated sensitively, it's all going to be confidential. If not, then it's going to be shared for a good reason.

Researcher BN: Yeah. And, erm, did you, with the, was it (name of organisation) that you’ve been to before and after COVID, so did you notice any differences in the conversations about say mental health you had?

SU3: Erm, I had a few more conversations, because after COVID I made friends with somebody that goes who actually lives on my street, which I had no idea, especially because there's like five houses on my street. I'm in the middle of nowhere. I had no idea. And she's got some of the same mental illnesses as me. Erm, so we've connected in a way that she's also part of one of the staff now and helps run it. So I've had quite a few more conversations specifically with her.

Researcher BN: OK.

SU3: Erm, than before.

Researcher BN: Okay. And so what about kind of the wider determinants of health like housing, finance, things like that, do you ever have conversations about those kind of topics at the groups you go to?

SU3: Yeah, I’ve talked about housing specific-, especially.

Researcher BN: Okay.

SU3: A lot with, erm (name of organisation), and they're trying to help me, but again, I think a lot has changed in the last few years and I think some of the information they have through experience might be outdated now. There's so much which was stopped and then cut during COVID, really the council used it as an excuse to take away as many services as possible. And, but I’ve talked about housing and finance a lot, talked about, you know, I desperately need money and trying to help me find a job a lot, and in the fibro group as well

Researcher BN: Yeah.

SU3: ..I've talked about finances and housing quite a lot. A lot of, I think I'm one of the youngest people that goes. And everyone else has a job and family and a house, and I'm like, I have no income, I can't work, I’m, I've got the most illnesses out of everybody there, it turns out, (laughs) which was not fun to find out.

Researcher BN: Yeah.

SU3: ..erm, I've got no house, I can't afford to do anything, and I've gotta pay my parents bills 'cause they haven’t got any money either, so I’m in quite a different position. So when we were talking about barriers to healthcare and like, living in poverty is a big one, guys.

Researcher BN: Yeah.

SU3: Erm, 'cause a lot of people weren't diagnosed until later life and I've known since I was about 16.

Researcher BN: Oh OK.

SU3: I only got a diagnosis in the last few years, but I’ve know, I’ve been visibly, well no, visibly to me, ill for my whole life, I've had illnesses from birth, that have only recently been picked up and when everyone else has been diagnosed after the menopause it's quite different. So I've been talking about the barriers I face, my age, with living with fibro because it's quite different.

Researcher BN: Yeah. And so initiated the conversation with, so with (name of organisation), who initiated those conversations?

SU3: Erm, both me and the person that runs it.

Researcher BN: OK.

SU3: Erm, and other people sometimes. Like erm, at one point we had sort of like a local politician come in and talk to us about various things and then afterwards I was talking to her about how like my water is not safe to drink, I think maybe you should get involved (laughs). My landlord’s breaking the law maybe, maybe help (laughs)? Erm, and you know, it was kind of a group discussion, so sometimes no one in particular.

Researcher BN: Uhuhh.

SU3: Erm, sometimes me, sometimes the people that run it.

Researcher BN: So a mixture.

SU3: Yeah.

Researcher BN: Yeah. And how did they go did you feel?

SU3: Erm, sometimes I kind of come away with there's still no answer but I already knew that, so nothing has been lost, sometimes I come away kind of hopeful because it seems like there might be progress being made somewhere, there is no progress that has been made yet (laughs), but yeah, I keep trying.

Researcher BN: Yeah.

SU3: Erm, sometimes it's like, well there's nothing. And mmm I feel rubbish but, that's because there is nothing, there is no help so. That's kind of normal and to be expected.

Researcher BN: Yeah, yeah.

SU3: It's a mixed bag.

Researcher BN: And what about (name of organisation), how, who initiated those conversations?

SU3: Erm, generally, when conversation runs dry, run a bead or those who run it will, you know, be asking you questions prompting a new point of discussion, so often it starts with them and then it kind of goes from there.

Researcher BN: OK. And do you think those conversations go well in that context?

SU3: Yeah, ‘cause it, it’s good to hear different perspectives, erm, and also I think it's good to let each other know that like, we all live, have huge differences in our conditions, but there’s still shared bits and you know, eventually maybe one day down the line, it might get better.

Researcher BN: So (name of organisation) is that always group conversations?

SU3: Yeah.

Researcher BN: Always?

SU3: I've only had two one-on-one conversations with staff members and it was after the group ended when I came back to talk to them. And it was to ask about like what other things are there?

Researcher BN: Ah OK.

SU3: Can I get extra help.

Researcher BN: Yeah. And so do you think it's an appropriate environment to talk about the social determinants of health?

SU3: Yeah, definitely. Erm again, you know we kind of talk about how like it's important, for everyone, especially in the fibro group, for everyone to be aware of all of the different things that impacts on our conditions. It's so important, and for us to like share that information. Erm, because again, if it's not shared, then no one is going to do anything about it, and we’ve all had awful experiences, especially with doctors trying to get a diagnosis. And the doctors don't often realise that housing and finances impact on health, which is shockingly bad.

Researcher BN: Yeah it is (laughs)

SU3: So we're trying to, and (name of organisation) are actually trying to team up with the (name of location) GPs, and the (name of location) GPs won’t recognise them.

Researcher BN: Wow.

SU3: (laughs) Erm, so it's important to have all these conversation so we can be aware of it tell other people,

Researcher BN: Yeah.

SU3: ..be like don’t go to your doctors, go to a support group (laughs). doctors. The doctors are going to offer you nothing helpful I can guarantee it (laughs), so go to the support group.

Researcher BN: (laughs) And so is there anything that would help you have conversations about the social determinants of health? In these settings?

SU3: Erm, it, I mean the (name of organisation) group, I mean it's, erm, it's fairly good already because I know there's going to be no judgement and there have been times where somebody said something and I'm like, I hugely have a different experience. You know, yours has been mostly positive, mine has been overwhelmingly negative with this particular thing, and there's no well, I'm right you're wrong. It's just like oh, it's really interesting to hear that perspective, you know thank you for sharing and that's it. There's no judgments at all, erm, about anything, so they're pretty great already,

Researcher BN: Yeah.

SU3: ..I think with (name of organisation) it would help if there were a few more younger people. Because again, they're quite out of touch with like what there is in terms of housing, and what there is in terms of support for disabled people. What there is if you're living in poverty, how to get a job if you haven't worked and you're now past 24, there's no help. If you're past 24, really,

Researcher BN: Oh wow.

SU3: ..not from the government, that’s it. I mean, I mean, you can sign on to job seekers, but there's no actual help, sorry, there's no jobs designed, you know like erm, if you're in Universal Credit and you're under 24th then I can't remember what they call them, but there's like specific roles for people in that situation to help them get into work

Researcher BN: Ah okay.

SU3: If you're after, if you’re over 24 there's nothing for you. And erm, I think it would help if there were a few younger people. Or at least people that were a bit more aware of the variety of experiences and what little help there is for everyone,

Researcher BN: Yeah.

SU3: ..and not just like one group of people.

Researcher BN: Yeah, yeah. And so, in terms of what might stop you from talking about the social determinants of health, what would you say?

SU3: Erm, if I felt like it was going to fall on deaf ears, erm, I probably wouldn’t waste my breath.

Researcher BN: Yeah (laughs).

SU3: Erm, it generally doesn't, but sometimes it's like, yeah, that sucks, anyway. So if I felt like it wasn't going to go anywhere, I probably would bother, if I just wasn't feeling up to talking about it that day.

Researcher BN: Yeah.

SU3: Because it’s a lot. And it's such a big thing to talk about as well, if, there's like no one tiny part that you can focus on really, everything is connected so, if I I didn't have the energy.

Researcher BN: Yeah.

SU3: I wouldn’t.

Researcher BN: Yeah. That’s fair enough. Anything on, on their side that stops you?

SU3: Erm, I guess a lack of knowledge and it’s like, if I have that conversation I'm going to have to explain actually I've been through all of that, I've tried all those routes and they're not available anymore. Yes, they were last year, they're not now. And knowing that like they don't know that, would probably stop me because like I don’t want to have to teach a lesson at the same time as reaching out for help.

Researcher BN: Yeah, yeah. No I can see that. And so what about, maybe this might be a little bit more positive for you (laughs) what about the other people that come so, first of all with the (name of organisation) group, the fibro group, do you tend to talk about health with people who attend?

SU3: Yeah, a lot, you know, there's big group discussions, but often we kind of chat amongst ourselves in groups of two or three as well at the same time. Erm, and we've all shared various different things that help, like we've all discovered the cannabis. We all use it and we all (laughs) it helps everyone realise that we’re a bit of an appreciation society.

Researcher BN: (laughs) Yeah.

SU3: Nobody knew until I started that conversation. Because everyone else was like, oh what else helps. Oh my God, I know what helps! So we’ve talked about things like that erm, you know, differences in condition, different other conditions that we've got. Erm so there's one person that's gone erm, and she can't keep a job because of some of her conditions. And so she’s shared that being like yeah, I can't get a job because of my conditions, and a lot of us had to move a lot. You know, how being around family impacts all of that. Yeah a lot (laughs).

Researcher BN: Yeah, so would you say more so than with other volunteers or..?

SU3: Yeah, probably more so with the service users than with the staff.

Researcher BN: Yeah. And who tends to initiate, how do they kind of come about those conversations?

SU3: Erm, sometimes as like a staff member will be like, well what about this? And it introduces a talking point and it'll go from, kind of spiral on from there, sometimes somebody might ask me something or vice versa. Erm, at one point one of the staff, because there's another young person that goes, I think they’re younger than me, who is also autistic, who also has some of the same mental health problems as me, erm, and I'm several years into my kind of diagnostic journey, and they've only just begun, so they'll say oh, why don't you talk about that, erm, since you've got similar experiences you might be able to share. Erm but yeah, but there's still more things for us (laughs) (illegible)

Researcher BN: Yeah.

SU3: But yeah, like there's still, so things like that, where they might go, oh, you know, you have got something in common. Why don’t you talk about that?

Researcher BN: Yeah. And so how do those conversations go with..?

SU3: Erm, I find them helpful, interesting, good. It’s nice to know that I’m not alone. We're all suffering together (laughs). That sounds really awful but like, there are other people that get it. And like we can all have go and have a big moan about our families and like how, sometimes people trying to help is just as bad as people, trying to help and it not working is just as bad as people not trying to help, things like that. Whereas if you talk about people that maybe don't have chronic health issues, they can't wrap their head around it, my mum for one. It’s like ‘they're just trying to help’ but I’m like, yeah, but their good intentions have resulted in my pain, so please don't (laughs)!

Researcher BN: And what about for like the social determinants of health, like housing, finance.

SU3: Yeah, we've talked about that quite a bit erm, again, generally I seem to be sharing information that no one else seems to be aware of, but none of them had to house hunt in the past 30 years, so.

Researcher BN: Yeah (laughs).

SU3: Yeah. Or none of them have ever had to apply for social housing or, if they're on benefits, their partner also has an income and things like that. And like, I'm the cause of my partner's income. He's my carer, he gets 50 pence an hour for looking after me. That's what the government thinks is appropriate. That's our income.

Researcher BN: Right.

SU3: And they’re like, ohh uhumm, it's quite easy saying why didn't you do this, why didn't you do that, this product really helps me, I'm like yeah I've got no money (laughs) like I get 500 pound a month and that’s it. And they expect me to pay for rent, bills, food, health care, everything, with that.

Researcher BN: Yeah.

SU3: No, no that covers my pets vet bills, bills and insurance and that is it.

Researcher BN: Yeah.

SU3: Yeah. No, it's, it's interesting to hear that people aren't aware of it. But it's good. Because then they become aware of it,

Researcher BN: Yeah.

SU3: And, you know, again, the more people that know, the better.

Researcher BN: Yeah.

SU3: So I think that they are always worthwhile conversations to have, especially with other service users. Sometimes the staff, you know, are kind of limited in what they can do about it. But if I talk to other service users, we might be able to get together and do something about it.

Researcher BN: So it's kind of, that you can do something together,

SU3: Yeah.

Researcher BN: ..be active together, yeah.

SU3: Yeah, and if not, then at least we can all get together and have a good moan about it first.

Researcher BN: Yeah (laughs) And is there anything that would stop you from talking about health and the wider social determinants of health with other people who go to these groups?

SU3: Again, if I think it's gonna fall on deaf ears. Or, if I think it's going to upset someone then I'm not going to talk about it, 'cause I don't want to upset people.

Researcher BN: Yeah.

SU3: Like there's one person that goes to (name of organisation) group and she's really into yoga and mindfulness and she finds it incredibly helpful. And she's got kids, like grown up children that help her out and, a doting partner and they're quite financially secure, and I'm like that's great, that is the polar opposite of my life. But that's so great for you. I'm just gonna let you live in your bubble, because I don't want to burst that for you because she's, she's coping. So I don't wanna, I don't wanna bring her down. So people like that I'm like, you know what, you’ve got a good thing going on, I think I'm just going to leave all of that alone (laughs). It's tempting to be like actually like it’s shit but I’m like no, no, no, no, don't bring her down to my level, don't do that (laughs). Be nice, be kind, move on (laughs). Do I tell her that mindfulness is bullshit, no don’t do it, it works for her.

Researcher BN: (laughs) And so what do you expect from, we’ll kind of do them one at a time, what do you expect from like the volunteers at (name of organisation)? In their role?

SU3: I expected mentoring because that's what I was promised, and they pay, they still offer it, but I haven't had that. Erm so kind of that. Erm, I er, honestly, these days they've lifted my expectations so that I expect only zoom or wheelchair accessible workshops. You know, maybe once every three months there might be something interesting. And that's it, I don't really expect them to be very flexible.

Researcher BN: Yeah.

SU3: Unfortunately.

Researcher BN: And is that the same with (name of organisation)?

SU3: Erm no, they seem to genuinely take things on board. Erm, yeah I kind of expect them to, to listen, to try and be helpful, and they, they are.

Researcher BN: Yeah.

SU3: And to try and keep me in the loop and, it's amazing I've been like three times and they've actually remembered me, like without the wheelchair (laughs), they remembered me, normally that's the most erm, you know, distinctive thing that people remember. 'cause I was, they do a lot, so I wasn't really expecting that which was nice.

Researcher BN: Yeah.

SU3: I expect them to be friendly and to remember me and to, kind of remember what we've talked about.

Researcher BN: Mmmm. And do you feel like volunteers in kind of both of these settings, do you think their role is just to stick to their role, or to do things outside of that, like support with extra, anything extra?

SU3: Erm, a bit of both. I know that there's limits to what people can do and there should be limits. You know, these people are volunteers and they can't be expected to bend over backwards and donate their whole life to other people. But at the same time, if they think that something else is going to be helpful, I think maybe they should make a referral or at least give you the contact details so that you could do it yourself. I think there needs to be a bit of flexibility between the two really,

Researcher BN: Yeah.

SU3: ..but obviously I completely respect that they have their own lives that they need to need to lead (laughs) and I’m not expecting them to donate all of their time to, you know, doing everything they can, because that's unrealistic.

Researcher BN: Yeah.

SU3: And they’re not getting paid.

Researcher BN: And do you expect them to talk about your health and wellbeing?

SU3: Erm, yeah to, to a degree. I think it would be useful if with (name of organisation), if they checked in with me, like when they put out like, oh this might, you might want to come to this thing, there's no, you know, do you feel up to it, are you able to? I think that might be helpful, might be nice, might be good for them to get a picture of like, how I'm doing so when I do turn up to something, they're not suddenly shocked. Like, there was a big gap in between me seeing anybody and then me going to a thing, and when I'd said yes, I wasn't in the wheelchair. Erm, and my hands were better, and then when I, when it came to actually going, I was in an ambulatory, you know I'm, I'm an ambulatory wheelchair user so I was, at that point I could use my hands properly and the expectations gap was because they were expecting me to come up and help and I'm like I can't do anything, and I kind of let them know like I can't do anything but I don't think they really grasped it, because there was such a big gap in time between them seeing me, and me turning up and you know seeing how I was, if they’d checked in that would be, that would be good. So yeah.

Researcher BN: Yeah.

SU3: I think they should. And they don't as much they, they don't as much as they should.

Researcher BN: Okay. And what, is that the same with the social determinants of health?

SU3: Yeah again erm, they don’t check in every now and then, although not much changes really, my situation just stays the same while the world burns around me (laughs). Erm, but I think it would, you know, it would be useful to have a, a regular check-in I think erm, I guess they check-in with me more on that than my physical health.

Researcher BN: Okay.

SU3: Because the person that runs it is trying to kind of, kind of trying to help me find somewhere to live and things like that so.

Researcher BN: Yeah. And so how do you, how involved do you think volunteers should be in your health and wellbeing?

SU3: Erm, I guess it depends on the person and how much the person needs them to be involved, but again, I think there should be a limit. Don’t be nosey (laughs). Yeah, I think as long as they're trying to help and, but again, you know, checking in, seeing what they can do realistically to help in these volunteer settings. But again, I don't think that erm, you know they're not my doctor, and I don't want them to try to be.

Researcher BN: Yeah.

SU3: And erm, and while I think they should be mindful of people’s health and wellbeing and, and ask about it, and be aware of all of these things that impacts on it. At the same time, they shouldn't be giving unsolicited advice.

Researcher BN: Okay.

SU3: So there's a fine line, I think.

Researcher BN: Yeah. Yeah, that's interesting. And where do you think that line is, what would be appropriate for you and not appropriate?

SU3: Erm, see that's a difficult one because like, if I feel like I'm kind of friends with, you know the volunteer, then I'm probably gonna say a lot more is appropriate than if I'm not really friends with them. So again, I think it depends on the person, erm, your relationship with them, what specifically their role is within the organisation as well. So like if somebody was giving me mentoring, I would expect them to be, I think a lot more would be appropriate than just somebody just running the whole thing.

Researcher BN: Yeah, uhuhh. It's very context dependent.

SU3: Yeah.

Researcher BN: Yeah. And is there anything that you would like to talk more about with the volunteer, volunteers at both groups?

SU3: Erm, I'm not sure really. Yeah I’m not sure. I'm just surprised that there is a fibro support at all, to be honest.

Researcher BN: Yeah.

SU3: And I think I would like to talk more with the people at (name of organisation) about accessibility because they really are falling short on that and,

Researcher BN: Yeah.

SU3: ..unless I bully them into it, I feel like nothing is going to change. So I think er I I'd like to talk more to them about that, but it's erm, it's complicated. And as the person who runs it has disabled children, erm, I feel like there's a, a bit of butting heads sometimes. So it's difficult, it’s not easy.

Researcher BN: Yeah.

SU3: I don’t wanna be disrespectful but at the same time, like her view of it, is very narrow.

Researcher BN: Yeah. And is there anything you definitely wouldn't want to talk about with volunteers regarding your health and wellbeing?

SU3: Erm, anything that’s triggering to be I’d avoid. Erm, but again you know, context based. Do I need to talk about it? So other than that I'm not really sure.

Researcher BN: Yeah. And, ultimately, do you think discussing erm, kind of your health and wellbeing and the social determinants with volunteers at these kind of groups like (name of organisation), (name of organisation), do you think that ultimately would affect your health and wellbeing?

SU3: Yeah, I think positively because it's good to get it out, you know if you bottle that stuff up, it just doesn't do you any favours.

Researcher BN: Yeah.

SU3: So, yeah you know, bit of stress relief. Even if it's only a little bit, it also means that I'm not just going to my partner all the time.

Researcher BN: Yeah.

SU3: Erm because that's it, really. It's just me and him. Er, I don't really have friends around here that I can talk to so. I think it is good to sometimes, get it out.

Researcher BN: Yeah. So, so you think yeah it would do (laughs)?

SU3: yeah, yeah. Sorry yeah.

Researcher BN: No it’s alright! Well great that was all the questions I had to ask, is there anything you wanted to add?

SU3: Erm, I'm not sure. I have to say it's been quite useful going to these groups 'cause, we've all shared how shockingly bad the GP's are, and which hospitals to avoid and things like that (laughs). And building a directory of bad health care and how to avoid it, and learning some cheat codes. Like, apparently I've been lied to about there being no pain clinic in Northumberland. There is, erm, the doctor just lied to me, and like specific phrases that you can say to your doctor and then they'll go and do the tests. So it's quite helpful.

Researcher BN: That’s really helpful (laughs)

SU3: Yeah, we're kind of building a list of cheat codes, to actually get some health care, it's so bad that that's necessary, but it's really great that actually we can share that information.

Researcher BN: Yeah.

SU3: And without going to the fibro group, I wouldn't know that there was a pain clinic in Northumberland, actually there's two, apparently. Who knew? Not me.

Researcher BN: Wow.

SU3: Maybe not even the Doctor who told me. Maybe he was mistaken. Unlikely considering he's a specialist, though. And he was so nice in every other way, and then. Barefaced lied straight to my face. Yep.

Researcher BN: Yeah, at least it sounds like you, you’ve got the support if anything from, from the fibro group.

SU3: yeah, and I know that I can go and even if, if I'm having a shitty time I can be like I'm having a really shitty time, and everyone is like we get you (laughs),

Researcher BN: Yeah, yeah.

SU3: ..understandable. Instead of like well have you tried this, we’re just like yeah it sucks I’m like ah that's, that's all I need to hear really. No have you tried this, just yeah it sucks.

Researcher BN: Yeah, yeah, I get it. Well thank you very much I’ll stop recording.

SU3: No problem.