**File name: Tuesday interview 0hr35**

## Key

**P:** = Participant

**I:** = Interviewer

[time e.g. 5:22] = inaudible word at this time

[IA 5:22] = inaudible section at this time

[word] = best guess at word

… = interruption in sentence, trailing off or short pause

**I:** Great. I’m just going to find some slides that I wanted to share with you, so bear with me for one second.

**P:** Yep, I see them.

**I:** Brilliant. Great. I’m trying to see if it will let me go to … there we are. So what would be really great to do with you, if you’re happy to do so, is it would be great to get any reflections that you have on taking part in the activities, and how you found that process, what was difficult, what was easy, what you think it did and didn’t capture about tinnitus. And I’ll also show you some responses by other people that it would be really great to get your perspective on. I should say what we’ve been saying in the group discussions is obviously talking about tinnitus an be quite difficult, it can draw attention to tinnitus, so if at any point you need a break or you need to step away, please feel free to do so. I’ve scheduled 45 minutes but I’ll try and keep it slightly shorter than that, because obviously this is quite an intense topic.

**P:** No problem.

**I:** But if you do need a break or you need to stop at any point just let me know, or feel free to drop out if you need to.

**P:** Sure. To be honest I’m not bothered about tinnitus in that way. I’ve never been affected that much by it. I’m just aware that it’s there and it’s always been there basically.

**I:** Great. Thank you. That’s useful to know. That’s really helpful. Obviously with this project we’re getting a range of people involved, it’s useful to know where people are coming from.

So thank you so much for sharing your tinnitus map. This activity was about getting you to think about different spaces and places in relation to your tinnitus and where it might be masked, where it might be more noticeable, where you associate with your tinnitus. So yeah, I was wondering how you found completing this activity, and how you decided to approach it?

**P:** OK. This was an interesting one for me ‘cause this was probably the hardest question for me, because in general I’m not too … because I’m not too bothered about tinnitus I tend to ignore it and as I go through my day, so in answering this question I had to actually concentrate and think about actually where it really bothered me, and what I did in general with the entire questionnaire was I ended up working backwards. So I did the last question first and I came back, and this was the last answer that I gave in that sense. And I felt that was easier to explain <laughs> after I got into the flow of things.

**I:** Yeah, that’s really interesting, because obviously we’re constricted with this digital format to have something in an order, but that’s really interesting that you started with the activities towards the end and then worked your way towards this one. That’s really interesting. And I was really struck by your use of colour. I was wondering if you might tell me a little bit about how you’re using colour in this map?

**P:** So for the light-blue it’s the nicest point of the moment, it’s the most comfortable. Red is the most uncomfortable and then the dark, really dark blue is kind of the neutral every-day, this is what happens. So I tend not to think about tinnitus through the blue points. Light blues I really enjoy, so when I wake up I love absolute quiet mornings, even though that means I can hear that it’s more, it’s there. The quietness brings a calm, and I really enjoy that. And when I’m outside, so on the right-hand-side I’ve got nature – neutral, and that for me is also like when you’re sitting out in a park or when you’re within nature, the sounds of nature kind of calms the tinnitus, calms the moment, so I really like that. I absolutely can’t stand music or TV first thing in the morning. I don’t know whether it makes the tinnitus worse but it actually makes my ears get tense in the inside, and I relate that feeling to really bad tinnitus, so that’s how it makes me feel and therefore I don’t like it first thing in the morning. It’s OK through the day. I think it’s the same as well at night. If it’s in the middle of the night and someone puts on loud music it drives me nuts. So yeah.

And with the red one, when I’m out and about, if the police or the ambulance comes by, absolutely hate it! <Laughs> It’s just like [6:09].

**I:** Yeah. Thank you. That’s really useful to hear how you approached it. I was really struck by how, because obviously with a map we’re thinking about different places, but you specified time as well, and that feels really important, the fact that you have music or TV first thing … so it’s not just about the activity or where it’s taking place but also the time at which it’s happening as well. So I thought that was really interesting that you’d included that.

I also noticed, so you’ve got the colours, so light blue is positive places that you feel positively towards, red is places that are a bit more aggravating, dark blue is more neutral or where it’s unnoticeable. I noticed as well you’ve got the smiley faces and then I particularly liked the music or TV first thing face – the kind of open-mouthed face. But I noticed that you had super-quiet midnight in red … so I’m assuming this means your tinnitus is bad or more noticeable or aggravated, but then you’ve got a smiley face.

**P:** That’s kind of my favourite time of the day and though it’s quiet and though the tinnitus is loud and all that, it’s all in control, so it’s not an uncomfortable feeling, it’s just more of OK, it’s there but everything’s calm and everything’s happy. So yeah.

I didn’t actually realise I did that!

<Laughter>

That’s quite interesting.

**I:** Oh, how interesting, yeah! I mean I was really struck by how you’d used two different keys and I thought that was really … because obviously tinnitus is something that’s so complicated in terms of how it affects us. I thought that was really fascinating that there’s two sets of scales going on around noticeability but also impact. Is that how you would understand it?

**P:** Yeah, definitely. There’s a sense of me hearing … as you say, noticing, the tinnitus, but there’s also the other sense that I was explaining earlier where I feel like my ears are tense, so the back of my jaw and where my ears start I can feel the muscles just tensing up, and … I think it’s when both are aligned, that’s when I’m unhappy or aggravated, but when it’s just the tinnitus it’s fine, if the area isn’t tense.

**I:** Wow. Did this mapping exercise … did you find it insightful in any way. Did you feel that it enabled you to notice certain things about your tinnitus or do you feel like … we’ve already talked about the time dimension in relation to tinnitus as well and different times of day, or do you think there are things missing from this that don’t really get to your experience? You said this was the last activity you completed as well.

**P:** Yeah. I think it’s made me … putting the two and together of the noticing and the aggravation is new-ish I guess, because in the past I was a musician and I’m around live music a lot and I used to play in orchestras and stuff, so it bothers me at times but it doesn’t bother me at other times and I didn’t quite understand what it was. And I think a lot of it is that feeling of tenseness or aggravation which comes with unease, so if I listen to quiet folk music and I’m happy with it, it’s OK, but if I’m listening to something that I don’t enjoy then it becomes tense and therefore it affects it, kind of thing. So it’s been really interesting being able to put that together. ‘cause I don’t really think too much about tinnitus in general!

<Laughter>

**I:** That’s OK!

**P:** I think that’s normal!

**I:** Yeah, yeah. So I’ve got another person’s map to share with you. I don’t know about you – I’m always fascinated by the approach other people have taken as well to the same activity, and obviously our instructions were quite open to interpretation, so I thought I’d just show you quickly someone else’s map and I’d be interested to see what you notice in comparison to your own, how they’ve approached this activity as well. So I’m hoping … my PowerPoint’s being quite laggy …

<Pause>

Let me just see if manually moving it helps anymore. There we go. So I’m hoping you can see – if you want me to read any of the writing, please let me know.

**P:** No, that looks good. Noticeable, present, very loud …oh, that’s interesting, yeah.

<Pause>

Looking at this, it seems like … they need to be in control of it, just because when you’re practicing yoga you have the self-awareness in place, you can actually control it; it’s present but it’s not loud. Whereas the green activities are all distracting activities I would say, where there’s stuff going on. And obviously when you’re in bed you’ve got nothing to do and unless you’re meditating or something you’re not … you’re fully relaxed. That’s really interesting, yeah.

**I:** There are some similarities with your own map, perhaps in approach rather than topic, although there are some overlaps, aren’t there, in terms of the places or activities that have been marked.

**P:** Especially the morning or night time in bed where I enjoy it but they don’t. It’s the same place and same effect but different reaction I guess.

**I:** Does this make you reflect on your own map differently at all?

**P:** <Pause> I think it kind of validates my map, for me anyway, and … I find it interesting how I think that’s a big connection … I mean this is just me being … I’m a writer so I think a lot of stuff and I come up with stories of my own <laughs> but this is me thinking about the fact that I think there’s a big correlation between us liking or disliking tinnitus. ‘cause I now my mum suffers from it now and she’s a lot older but she says that she has that kind of fighting feeling with it, and when you have that and you are in those really quiet moments, you hate it ‘cause you’re obviously very aware of it. Whereas I don’t have that fighting relationship with the tinnitus so I’m quite alright just letting it be, and it’s probably because I don’t have it as badly as a lot of people as well. But even though right now – especially with headphones you can hear it, it’s just that constant … you know, in the background … but it doesn’t make me angry or stressed.

**I:** Mm. Yeah.

**P:** I think that’s a really big thing with tinnitus relationship in some ways, yeah.

**I:** Thank you. I’m going to move on now and show you, you also participated in the tinnitus portrait, and the way I’ve been describing this to people is a bit like, I don’t know if you’ve ever seen them but the school tea-towels where lots of children draw their own portraits and they’re put together …

**P:** <Laughs>

**I:** That isn’t a comment on people’s artistic ability, but more the approach that I’ve taken.

**P:** <Laughs>

**I:** So I’ve put together some different tinnitus portraits so yours will appear amongst some others, and I wondered if you had any thoughts on this activity as well and how your approach is related to others. So I’ll just show you these now …

**P:** OK … cool.

<Pause>

Wow …

The one with the full body is really … amazing but also you get the feeling that it’s really aggressive.

**I:** Yeah.

And is that aggression something that captures your experience or is that, from what you’ve been saying is that quite different to your experience?

**P:** Yeah, that’s really different. I don’t know what it is, but when I hear my tinnitus I hear it as … a pitch, as a note, as … like you would notice someone playing a flute or something in the background kind of thing, and I notice it that way. It doesn’t … it doesn’t hurt, which I’m superbly grateful for ‘cause I know it’s not the case for a lot of people. The only time it feels stressful is when it’s so high-pitched … like I described it as the … you know the high pitch that people use to test how young you are? That electric high … when it’s like this, it stresses the ear out a little bit, and it’s like your ears just tense up. Then I might feel a little bit stressed. Actually not even stressed, that’s the wrong word; I’ll feel my ears stressing. But it becomes a muscle thing rather than me having an aggression or violent effects to it. Yeah. So I mean it does make me realise how calm my tinnitus is when I look at all these pictures.

**I:** So you feel that yours is quite different to these other visual representations I’m guessing?

**P:** Yeah. I mean the areas where it is is similar, ‘cause it’s obviously around the ears and the back of the eyes, but with … I mean even with the one on the bottom left, that’s quite hard, the scribbles are quite aggressive.

**I:**  I was gonna say, with your drawing as well, there’s quite a different … is this your mouth that you’ve drawn on yours as well … and there’s what I’d interpreted as a little smile.

**P:** It’s just kind of eyes and nose.

**I:** Ah, got you!

**P:** Eyes closed. I put that in purely to have some sort of reference point I guess, but I didn’t realise as well, that’s a subconscious kind of way of not being aggressive, like being quite calm, because it’s actually eyes closed and all that. And when you put it against the others – I don’t know why that really comes across. It’s calming rather than it’s being violent, yeah. ‘cause even the one right in the middle at the bottom, the lines are really … the lines are gentle and it’s quite … a careful drawing, but it’s still a lot of mess … rather than clarity. So you can really feel the person’s discomfort.

**I:** Yeah, that’s so interesting. Thank you.

I thought I’d just, on the drawing theme, I’m mindful of time as well, I thought I’d just quickly share this one. This is an activity that you didn’t do, the tinnitus drawing activity. There’s a lot of lines you’ll notice, but this was someone else’s response to that activity and I just thought I’d give you an opportunity to see this and yeah, see what your response is to their tinnitus drawing, whether this for you captures something about the experience of tinnitus, if it’s quite different, whether this activity made any sense to you at all?

**P:** Yeah. I mean the reason I didn’t do this activity was because it was across three days and I wasn’t able to do that across three days, but I can see how for this person … I’m assuming the top is day 1, the middle is day 2 and the bottom is day 3, or something along those lines, and it looks like day two was a really bad one? Whereas day and day three is quite … kinda organised, you know, it’s there but it’s OK kind of thing. Yeah.

**I:** Yeah, so day 2 kind of dominates the page doesn’t it?

**P:** Yeah, definitely. And it’s just all over, ‘cause there’s no organisation in it at all.

**I:** Yeah. There’s more variation, isn’t there, in day 2? ‘cause although it’s all over the place, the dots and things like that get smaller …

**P:** And the curves and what look like mini-rainbows, but I’m sure they’re not.

**I:** Ah, thank you. So I’m now bombarding you with a list of words. So these are some of the responses we’ve had to the putting tinnitus into words activity, so these are some of the single words that people have chosen that somehow connect to their tinnitus or their experiences of tinnitus. And yeah, I’d offer you a moment to just feel free to have a look through this very long list of words, and it keeps on getting longer as the week goes on, as the workshops go on. But yeah, I’d just welcome you to take a look at these words and as the responses to the activity, and see what you make of them, whether you think this conveys something about the experience of tinnitus accurately, what might be missing from this list?

**P:** Hmm.

<Pause>

The contradiction is really interesting, isn’t it? There’s so much of that … <pause> And I wouldn’t be surprised if the contradiction is within one person as well, yeah. I think maybe that’s a big thing about tinnitus, is … when we forget then when we remember is two very different experiences.

**I:** Are there any particular terms that you’re thinking about with the contradictions, or any words that you’re noticing really capture that contradiction?

**P:** Because it’s listed in alphabetical, it starts with acceptance, which is really interesting <laughs>, and then you go into things like battles or damaged, and damaged next to delight <laughs> which is … two good words next to each other. Or forgettable and fuzziness, ‘cause if it’s forgettable you wouldn’t think about it, yet it is fuzzy, it is there. Scream and Shhh together, that’s quite interesting.

<Laughter>

**I:** I hadn’t noticed that, yeah. Because this list keeps changing, I hadn’t noticed that one but yeah, well observed!

**P:** I don’t remember the words that I gave in actually.

**I:** You gave a very beautiful summary of the different ways that you experience … you really differentiated between when you were listening to music and other times, when things were more difficult and when things were less difficult as well. We’ve had some really great bits of writing in response to this activity.

Does this trying to put tinnitus into words, does this approach make sense to you, or is this something that doesn’t really get to … the experience?

**P:** Because I’m a writer it does make a lot of sense, yeah. This speaks to me … directly, ‘cause … you could just leave this as this and it’s a brilliant tinnitus poem, you know, <laughs> at the end of the day. Yeah. I have a poem that I wrote about … it’s not quite tinnitus but it’s … you know when you’ve got a really bad cold and everything’s blocked up and you just have this … so I have a poem like that and it just reminds me of this completely.

**I:** Oh amazing!

**P:** ‘cause it’s that same … when it’s there, the persistence of it is all you can think of and overwhelming. As I said before, the relationship doesn’t need to be a horrible one but it all depends on your state of being at that moment.

**I:** Yeah. So are there other words you might put in here?

**P:** Can’t think of any off the top of my head. I mean it’s a big list.

<Laughter>

**I:** I was gonna say, there’s a lot of words. I’m running out of space here! <Laughs>

**P:** I mean electronic would be the one that I always use for describing mine.

**I:** Ah! So we have electron, but not electronic.

**P:** Yeah, electronic, the electronic buzz.

**I:** I’ve got a couple of definitions – I’m very mindful of time so I’m going to do this quite quickly. I’ve got a couple of definitions that I wanted to show you. So they’re both from the As – that’s a coincidence. So we’ve got acute, so someone has written ‘strongly felt, pointed, of critical importance and consequence but also the sufferer is often one with the ability to recognise or draw fine distinctions.’ And then the second definition we got that I wanted to share with you was aura, ‘It feels like a halo of sparkly sound. It’s there around me, always and invisible. It chose me to host it.’

**P:** I love this one. I write science-fiction and this is very fantastical and beautiful in that sense!

**I:** Aah!

**P:** And in some ways it becomes, it separates it from you, yeah. I mean I don’t know whether it helps that person manage it by thinking about it as like a pet or something, that’s just there.

**I:** Sci-fi tinnitus! I guess there is kind of something a bit sci-fi about tinnitus in many ways. But yeah, thank you. So I just thought I would share a couple of definitions with you.

**P:** They’re brilliant.

**I:** Thank you. So I’m very mindful that we have one minute according to my time keeping. Are you OK to hang on for maybe another five minutes?

**P:** Yeah, that’s not a problem at all.

**I:** Thank you. There’s too much to talk about! So there’s a couple more activities and these were the ‘What tinnitus sounds like’ activities, so one was the tinnitus score, and one was the capturing sound one, and in some ways these are quite similar activities in that they’re trying to get to the sound … what tinnitus sounds like for different people. So I think I’ve got one example of a tinnitus score and one example of the capturing sound activity. I’m not gonna play any of the sound submissions that we had because Zoom is not very good at coping with that, amongst other things, so I just thought I’ll share with you the score, so we have this score.

<Pause>

**P:** Looks about right! <Laughs> Eee.

**I:** And then we have this capturing sound.

**P:** Yeah.

**I:** So do these depictions … do they speak to your own experience, do you think they capture something?

**P:** Yeah, I think they’re exactly what I hear in terms of my tinnitus. In the electronic buzz that I described it as … yeah. And yeah, the eees as well, the picture of the fluorescent light, they’re both … I think they’re both accurate, yeah.

**I:** One of the conversations that we’ve had with one of the groups about this image was they weren’t sure if this was something that the tinnitus … because this exercise was trying to get to sounds that in some way relate to your tinnitus, so it might be that your tinnitus sounds like these things, but it could also be that it’s masked by or hidden.

**P:** Oh, interesting.

**I:** So there’s a difficulty, isn’t there, in interpreting this, I think.

**P:** Yeah.

**I:** Because my first response would be oh, this is what someone’s tinnitus sounds like… but then I think about … hmm, could it also be something that’s hiding their tinnitus or masking their tinnitus?

**P:** For me I think it’s what it sounds like specifically. I think about maybe about eight or nine years ago I was concerned about my hearing because of the tinnitus, so I went for a full hearing test and all that kind of stuff and it’s made me realise that my hearing is actually fine, I’ve no problems with my hearing, and around the house and stuff when there is the sound of electricity I can always hear it, on top of everything else, and there are certain power points that buzz a lot more and … it’s there and I’ve had other people reaffirm that the sound is coming out from it. Sometimes they don’t hear it, I mean it’s like … I guess people who don’t have the same experience as I do will not pick it up, but because I’m aware of it as well … it sounds just like my tinnitus but I can sense … I know that it’s not my tinnitus, if you see what I mean?

**I:** Yeah, so you can differentiate those sounds.

Thank you so much [name]. It would be great to just take a couple of minutes if you’ve any final thoughts on this kind of approach to trying to share experiences of tinnitus, and I’d be particularly interested to know if … I’ve shown you various depictions of tinnitus through drawings, through writing, through photographs; I’d be interested to know how … if you’ve come across other depictions of tinnitus, be they in the arts of elsewhere in the media, on information sheets, how these depictions of tinnitus compare to what you’ve encountered previously in terms of how tinnitus tends to be represented.

**P:** I don’t see much representation of tinnitus, which was why I became interested in participating in this, because I was really surprised to see it and I thought if someone’s doing something about it, we should join up and learn more. So that was interesting. And I don’t think I’ve ever seen anything outside … and I think there’s something that I would like to add, it’s just because my … a lot of I think my tinnitus came from bad practices as a musician when I was younger. One, I think interesting, depiction for me would be imagining sitting … if you imagine a whole orchestra on stage and you’re sat right in the middle of it, but they’re all playing completely different things, rather than in harmony and all that. That mess of a sound I think is … is an interesting depiction for me, just because people always assume that music is music; but actually not all music is pleasant, and a lot of that can actually add to the tinnitus and how we hear and stuff. So I think maybe music might be an interesting bit that could be added to this kind of study.

**I:** Absolutely. Thank you. That’s a really interesting comment. There are a couple of pieces that I’m aware of, that do depict tinnitus but they tend to represent it through a high-pitched violin sound, you can imagine what they get to … but I think your idea there of something much more … where it’s not about necessarily replicating the high-pitched tone but is a much more … I don’t know how we’d describe it –

**P:** I’m slightly claustrophobic as well and I feel the same kind of closeness if there is a lot of noise, then it becomes … you just feel like you’re being bombarded and closed in by sound, and in a claustrophobic kind of way I think. Maybe that could be a description for it. Yeah.

**I:** Yeah. That’s really interesting. Thank you.

**<End of Interview>**