**File name: Sunday discussion 1hr38 5 participants**

## 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

**[participant introductions]**

**I:** So we’ll now move over to the slides. So what we’re going to do is you’ve all had a chance to look at some of the workshop activities that we shared with you and again we’re very, very grateful for your responses to those activities. What we’ll do now is we’re going to be showing you a selection of the activities that we have received. We’re going to be sharing them anonymously, I’ll come back onto that in a moment, but you will get to see how yourselves and others have responded to the activities and we’re hoping to have a chat with you all about how these activities perhaps capture different bits of the experience of tinnitus, what they don’t capture, what worked for you, what didn’t work for you, and what you think about the various things that we’re sharing with you. So Sally, would you mind moving over to the PowerPoint so that we can see those?

So what I’d like to begin with is some ground rules. That sounds very formal but hopefully these will help give you a sense of how we’re hoping the discussion will go and also how you might or might not want to participate today. So the first thing to note, as I’m sure you’re all aware of, is that tinnitus can be a sensitive topic for discussion and you’re very welcome to take some time out or leave if you feel the need to, and I’ll come back to that in a moment again.

So as part of the workshop discussion we’ll be looking at some of the responses that have been created by different people in this group. We’re also including some responses from people who aren’t in this group as well. So our discussions are to be focussed on the process of making, and how the responses relate to different experiences of tinnitus. So please be considerate of others when discussing their work.

We’re going to be sharing the responses anonymously, as I said earlier, however you are very welcome to identify yourself as the creator and comment on the activity response if you wish. So you’re very welcome to say, ‘This is my work, this is what I did, this is how I approached it,’ but equally there is no pressure to identify yourself as the person who has made something. There’s one activity where we can’t share things anonymously, as will become apparent, but for the most part we’ll be sharing things anonymously. But as I said, very welcome to identify yourself as the creator.

So we know that tinnitus can affect people in very different ways so please be mindful that others might have different experiences to your own.

Sally, can I go to the next slide please? Some of us might be using Zoom’s auto-captioning function. This works best when there’s one person speaking at a time and there is limited background noise, so please can you make sure that your microphone is muted when you’re speaking and try to avoid speaking over others. We do know that that’s difficult when you’re having a conversation. If you are finding it difficult to insert yourself into the conversation, or if you feel more comfortable doing this you’re very welcome to either physically raise your hand so that we can see it on screen, or if you go to the reactions button at the bottom of your screen there is an option to raise your hand in Zoom. So if you’re wanting to say something but you’re struggling to get into the conversation, feel free to use that.

We will have a 15-minute break half-way through the session and if you need to take some time away from the discussion you’re very welcome to leave. If you want to re-join, you will be able to use the Zoom link that we have sent to you, to re-join the session. And if you feel that you would like someone to talk to during the session, or if you feel that you could do with some support or advice as to what to do if you need to speak to someone privately, you can use the chat function to contact Sally privately or Patrick privately, or you’re very welcome to email us.

Finally, I think this is always useful to say, silences or relative silences are OK. We know that people might need a bit of time to respond so please don’t worry if nobody is saying anything.

OK, Patrick and Sally, did I miss anything there that’s worth mentioning? Oh, I know something that might be worth mentioning. If you are wanting to see everybody’s faces at the same time as well as the slides, you should be able to put … there’s a couple of different options for viewing videos, there’s a grid icon and that will allow you to see everybody’s faces at the same time; there’s also a show active speaker option, which will just show one person at a time who’s speaking. So if you’re needing to see people’s faces in more detail that’s a good option for you. Does anyone have any questions?

No? Brilliant. OK. Well we’ll move on to sharing the activity responses. Sally, could I get you to … that’s it, you’ve done it already.

So … with the tinnitus maps activity we’ve got a few different responses to show you. We can see lots of different approaches to this activity, which is great, we like different approaches, we purposefully gave you instructions that allow you different ways of doing things. So Sally, could I just get you to tap through the next three slides quite slowly? So we’ve got a couple of options here, which you can hopefully see.

**P1:** I don’t mind telling you the one on the left is mine.

**I:** Thank you P1. So yours is the one that’s typed with the red, yellow and green?

**P1:** Yep.

**I:** Brilliant, thank you P1.

**P3:** And I don’t mind telling you that the appalling artwork on the right is mine! <Laughs>

**I:** I thought this was very interesting, P3, so please do not feel it was appalling. I think far from it. Thank you.

Do we want to go to the next one? So we’ve got quite a different approach taken here. And I can tell you, if you’re struggling to read some of the palest ones, which maybe the point, I think this one says something, if I remember rightly, something like, ‘in noisy places, quietest’. And this says garden – quiet. Sorry, I can see my curser, but you can’t see my curser ‘cause it’s not my screen. The top right-hand corner says ‘garden – quiet’ and then I think if I remember rightly, the furthest to the right says ‘noisy places – quietest’.

And then Sally, could we go to the next one please?

**I:** Again a very different approach taken here.

<Pause>

**P5:** That’s mine.

**I:** Thanks P5.

Since so many people have identified themselves as the creators of these maps, does anyone want to say anything about how they want about this activity or the approach they’ve taken?

**P1:** Well I think it involved thinking much more about it than I would normally do, trying to analyse it. It was, at first I didn’t think I’d be able to do it because I wasn’t conscious of it, but it was interesting.

**I:** Thank you P1.

**P:** I’ve just spotted my typos, sorry about those, but anyway … <laughs> I think what I discovered doing these whole tasks, was that I feel mine is, I don’t know if there’s a difference here but between hearing and consciousness, I don’t know … I mean this is something I’ve said about mine for a while. It’s when I’m conscious of it, which doesn’t necessarily mean I’m … it’s about hearing. I don’t know if those two things make any sense to anybody else, but they make sense to me anyway.

**P:** I noticed the difference between … Sorry, go on.

**P:** It’s about when I’m conscious of it. That’s OK, no, go?

**P:** I was going to say, I really notice a difference between when my eyes were engaged, when I’m watching something, then I don’t seem to hear it but when I’m listening to music, when I’m using my ears, then it becomes more … I’m more aware of it.

**P:** That’s so interesting ‘cause that’s exactly the opposite for me. Watching TV< watching anything like that, I’m aware that it seems to be getting louder, because it’s like it’s fighting with the TV, because I don’t wear them very often, I was given hearing aids to have the tinnitus manager, so you get the sounds of the sea and the television and the tinnitus all fighting together – so I whip out the hearing aids. But listening to my radio, which is one single earphone, is my absolute lifesaver, where-ever I am. Interesting it's so opposite.

**P:** Mm.

**I:** Do you think that this exercise enabled you to capture some of those different experiences of listening with tinnitus, shall we say? Or was it difficult to represent those different encounters or experiences with tinnitus?

**P4:** I found it got easier the more I got into it, if that makes sense. So I think at first it was quite difficult to … relate the concept of a map to the concept of tinnitus, to thing of tinnitus, but … I think once I’d sorted out how that was gonna work I really became quite interested in it as an activity, and my one was the one that was on before this one, with the blue circles and stuff. And you’re right, the paleness of those words was on purpose, but I didn’t know it was going to be used in a group setting so I wouldn’t have done it if I’d known that other people were gonna see it in a setting, but … yeah, it ended up being quite a fun activity towards the end, in some ways <chuckles>.

**I:** That’s great, thank you P4. Yeah, if we can stay with this, I wonder if you have anything to say about … it was interesting that the quieter options, where you’ve got the garden and the bedroom and noisy places, the image there is more spiky. Was that a conscious choice as well; was that something you chose to do?

**P4:** It’s not representative. I did choose to do it but only in terms of making those things different from the loud things. So not in itself representative.

**I:** Brilliant, thank you. Does anyone have any thoughts about the differences between these maps and the different approaches that people have taken?

**P5:** Did you say we can see them all on the screen at the same time? Or we can’t?

**I:** I don’t think with this one we can, but we can scroll through them again if that would be useful? So we can go through.

<Pause>

**P3:** Can you just go back to that one, it was a bit quick, sorry. The first one. I’m still reading the labels on the first one. Thank you.

<Pause>

OK.

<Pause>

**P3:** If anyone can’t read my writing I’m happy to say what the labels are.

**I:** P3, do you want to say a bit about what’s represented on this map?

**P3:** I guess, ‘cause if nothing’s on and I’ve just been for a walk with partner and son, I still have one earpiece in there, so if nobody was talking it was … I’m still enjoying the outside, but I’ve got something to focus on and I get interested in the programmes. So the computer down there is in the dining room and that’s when I’m working on it, and it does seem to get, this will come on to louder as the day progresses. Bed/bedroom, I think everyone’s saying the same, it’s that head on the pillow, last thing at night, when it’s just been roaring because the TV’s been on and then you’ve cut everything off; the car and the radio, that was interesting the other day, having gone for a walk out in the open, everything’s fine, got into the car, shut the doors and it was suddenly much more noticeable and somebody posited that that was more of a pressured cabin environment so I whack on the radio again. And I usually shower, but if I have a bath that’s quite relaxing and I’ll stick one earpiece in there. Again, it’s taking my mind off anything but it’s also helping me listen to stuff. And the TV, as you can see, is horrendous. But we’re always told not to give up doing what we want to do, and not to do avoidance. And the garden, lovely, you’d think peaceful but I think somebody else had that … oh, not aware of tinnitus during those activities … I’m gardening, I’m still aware of it because it’s quiet outside, so once again in it goes. Is that saying all I need?

**I:** Yeah, thank you so much. Thanks for sharing that. And P3, as you say, the fact that there are, amongst these maps there are the same activities or same places but with very different markings – for some people being in the garden is great, for you it’s not so great in terms of the tinnitus. It’s very interesting how we get these differences and that they’re represented across these maps in different ways, so thank you.

Sally, shall we go through to the next couple? I’d be interested to know what people think is missing from these maps about tinnitus – what can’t these maps capture about the experience of tinnitus or understanding tinnitus?

**P5:** I think because of what I said about being conscious or not conscious, and later in some of the text boxes I speak about mood as well, because mine seems to be … I may be at an early stage of tinnitus, mine may get worse, I don’t know; I have also, just as a side note, need to get hearing aids because my hearing is not as good as it was, and all these things, I think, are linked, so I may be at an earlier stage, but I feel that mine is associated with mood as well, and in a way that’s why I try to talk about when I’m doing certain activities I’m lost in those activities, I’m not conscious of my tinnitus. And then suddenly in stressful moments they come back. And so maybe mine is associated with, I don’t know, with mood or anxiety, stress, if I get upset about something I can suddenly be conscious of it. Maybe for me it doesn’t show that angle, but maybe that’s just because that’s my experience of tinnitus.

**I:** Thank you P5. Does anyone else have any thoughts on that?

**P3:** The maps are great to show locations, and intensity as you said about doing the darker square if it was worse, but it’s also timing, and the fact that it can perhaps, for others, I don’t know, be worse as the day progresses, so it doesn’t show the change of that. So if you wake up in the night and it’s there, there’s always the thing, isn’t there, is it there and you pay attention to it, or is it you’re paying attention to it and therefore it’s there?

**P5:** Yeah! Totally.

**P3:** How many workshops has everybody else done and you learn from that? And then you go back to bed thinking don’t think, don’t think, don’t think about it … and same as what you were saying there P5, working on the computer with whatever I’m doing, I’m involved in it but it’s funny, I’ve noticed later afternoon, four-thirty, five-ish, if I’m doing something and I do a lot of singing with a choir on Zoom, completely unaware of it at that point. And the only other place I noticed the other day where I’m completely unaware of it is I’m very lucky, my partner has a 50-year-old MGB, so when the good weather’s been on a couple of days recently we’ve had the roof down and possibly a very smart Mercedes would be a lot quieter, but the dear old MG, you can’t hear anything else! There’s no point in my having my radio, even. But then I hear … it’s bliss, ‘cause I can’t hear it. So it’s location and time of day I think is a factor for some.

**I:** Thanks so much, P3. That’s really helpful to know, and we know that these activities can never capture everything about tinnitus and what it’s like to experience tinnitus or have tinnitus, so just it’s very useful to hear your thoughts about what it can and can’t get a hold of in relation to tinnitus.

**P1:** I wonder how easy it is for people who don’t have tinnitus to understand what it’s like.

**P1:** It’s not! <Laughs>

**P5:** I often get asked to describe it. Mm.

**I:** Do you think these maps would help explain some of that, or are they not getting … could they explain that or some of that?

**P5:** Yes, I do.

**P1:** Certainly some of it, yes. But it’s also the fact that it’s … relentless, it’s all the time, isn’t it? Well it is for me.

**P5:** Mm.

**P3:** Yeah. And there’s just, I think you’ve hit the nail with that, if people ask you, P5, that’s fabulous. I just think there’s such a lack of awareness or there’s such a lack of awareness or there’s such an acceptance that so many people have it and quote, ‘I have it but I had in my left ear’ or ‘I had it ‘cause I did this’ or whatever. People just don’t get it… for people such as yourself I expect, to the degree and the continual.

**I:** Thanks so much everyone. I’m mindful of time. So one of the things you’ll learn over the course of this workshop is that I’m quite militant about timekeeping, so can I suggest that we move to look at the next exercise, please, but thank you so much for all of your comments there. So this was the tinnitus portrait activity. This is the one that I said, for reasons that will become apparent, this is the one that I can’t quite share fully anonymously, but nonetheless … and we have pulled the responses together, so Sally, could I go to the next slide please? OK … so here are some of the different tinnitus portraits we received and the different approaches that people have taken is hopefully apparent here, and so I would welcome any of your initial thoughts about this activity, about what you’re seeing here, the different approaches that people have taken, how these images do or don’t speak to tinnitus for you; any thoughts would be welcome.

**P5:** These are fascinating.

**P4:** I think it’s quite strange to see my one in the context of everybody else’s one, where I dunno … feels like you’re part of club, obviously you don’t really wanna be in <laughs> but it’s quite … I don’t know, it’s quite oh, wow, OK …

‘cause you’re kind of making it up, aren’t you? My tinnitus has got a lot better over the years and so when I was doing this exercise I was thinking maybe it’s not … it’s not concerning enough to be part of this, but … and so you have a sense of not making it up but knowing that it’s not as bad as it could be, and so therefore … but to see it alongside everybody else’s is quite interesting. And a bit depressing! <Laughs>

**P5:** That’s interesting, ‘cause I feel I manage it more than I used to, so psychologically I can manage it, which is part of that … with the years I know that if I’m feeling it now I won’t hear it in an hour, because I won’t be conscious of it, not that I’m not hearing it. Which is how I explain it to myself. So it’s that as well. I don’t feel it’s debilitating yet.

**P4:** Yeah, I’m the same. I think it’s always there but over the years I’ve come to know when it’s gonna be … I’ve come to recognise that if I’m noticing it more it’s because I’m stressed out and if I’m stressed out and tired then I’m definitely gonna notice it, so I don’t worry about it. And because I don’t worry about it, it doesn’t affect me half as much as it used to. I just know it’s there. So I think that’s a time thing as well.

**P3:** That word, habituate.

**P5:** Mm.

**P3:** I can’t really be anonymous on mine, can I?

<Laughter>

**I:** Sorry P3!

**P3:** That’s fine. If it had worried me I wouldn’t have sent it. I’m just no good at drawing so that was the easy way of doing it! <Laughs>

**P5:** Neither am I! <Laughs>

**P3:** I don’t know which one you are but I think they’re all brilliant!

**I:** So seeing these different portraits of different people’s tinnitus or people with tinnitus, do any of these images speak to you if it’s not your own image, do they speak to your own experience of tinnitus at all; are there things in these images that you can relate to or can’t relate to?

**P1:** I was wondering, do most people have it in both ears?

**P5:** I do, yeah.

**P1:** Yes.Right.

<Pause>

**P4:** I feel pretty sorry for P3, because that looks like real … I mean it’s obviously my interpretation of your picture, but that to me looks like a lot of pressure from all angles and it must be … to me that is a description that seems a bit overwhelming. At least mine is … on the side. I don’t feel it from here. I feel it just here. If I felt it from there as well, that would be pretty bad.

**P5:** So P4, is yours the top one or the bottom on the left?

**P4:** Mine’s the one that’s got the splashy –

**P5:** The stars?

**P4:** Yeah.

**P5:** OK. I mean mine, I keep thinking of cotton wool and static, that’s what I keep thinking about. Mine’s the one on the right. So mine is this, it’s here, I carry it with me. It’s almost like headphones, large headphones made of cottonwool and cottonwool which makes a sound, so it’s there, but it also goes … behind my ears as well. It’s not just sitting on the outside. And it’s there, I carry it with me.

**P1:** So for you, did you become aware when it started, or did it just creep up on you?

**P2:** It’s definitely a specific incident for me, or a series of incidents.

**P4:** Yeah, same for me.

**P2:** As a musician I was just … as a teenager I was completely unaware of protecting my ears when I was an audience member at gigs, and then I had a fulltime job as a touring musician in a band with a record deal and it just … I learnt to protect my ears with hearing protection, but … this is from the mid-late-eighties through the nineties I guess, and it just wasn’t much of a thing, in the music industry or in going to gigs. Now if i went to Rock City you can ask … sorry, Rock City is a music venue in Nottingham, you can ask behind the bar or you can ask a security guard to give you some earplugs, and they will sometimes offer them on the way in. All the staff behind the bar will be wearing them as a matter of course. And when I worked fulltime as a music lecturer in music performance, the colleges would provide really good-quality ear protection and regular hearing tests, so that’s obviously some health and safety issues. But by that time my hearing had been damaged, the tinnitus was just constant and so it was down to a specific incident but then made worse by … me faffing about not quite knowing what to do, and it just not being a thing that was maybe spoken about in the music industry, but then much more music education it became much more recognised thing I suppose. But only from a health and safety point of view. I think colleges were trying to cover their backs and the universities and stuff were providing some decent hearing protection, but … that only … it doesn’t make my tinnitus any better, if you understand, by protecting my ears. It does in the short term obviously, but it doesn’t make my tinnitus go away. For me, once it was damaged when I was about 17, it’s just not really got any better certainly, but it’s certainly got worse.

**P1:** I don’t think you’re the only one.

**P2:** I’m absolutely sure I’m not the only one. Sorry, I’m mumbling a little bit but yeah.

**P3:** Mine started in July and it came from nowhere. July last year. I didn’t tell anybody about it. Just decided –

**P5:** That’s recent.

**P3:** Well, it’s a year, yeah. And when you hear people on some of the workshops and things I’ve been on saying, ‘Oh, I’ve had it for 27 years’ or something, and I think oh gosh! How are you coping? And you hear some horrible stories, but I didn’t tell anybody about it. That diagram – I’d often sit watching television just like this, and you might have thought I had a headache or something, because I wouldn’t tell whoever was around. Until a hearing aid was found on the ground floor five months later and got picked up and, ‘Oh, found this hearing aid but it can’t be yours ‘cause you don’t wear them,’ and then I had to stand in the rain in November and give out my story of what had been happening for four or five months. It was a bit strange.

But yeah, from nowhere.

**P5:** Growing your hair over your ears helps! <Laughs>

**P5:** That’s interesting.

**P3:** But that diagram is very much, I suppose partly influenced because one knows it’s not actually an ear thing and it’s a brain thing so I was also trying to show that it doesn’t actually go … I think I wrote on my piece that it doesn’t travel anywhere. You were asking, Marie, where does it travel? It’s just there. Just walking under a million electricity cables is the most accurate description, and therefore it’s just in the brain.

**I:** So P3, for you this kind of activity that’s trying to capture or is trying to get a hold of the direction that tinnitus is travelling, ‘cause … one of the things I find so interesting about these pictures is firstly the different directions that things are travelling in, so some people are showing their tinnitus as going inwards, some people are showing it as going outwards, some people are showing it as around the head, so there’s all these different movements going on, but that’s interesting to hear, P3; for you, if it actually doesn’t move and where it is and the need to differ from people who might experience tinnitus as movement or as moving, and those who don’t experience tinnitus like that.

**P2:** I’ll just say I didn’t get time or engage with the drawing but I agree with P3. My tinnitus doesn’t move, it just stays there and it’s in my ear, it’s not outside my ear, it’s in my head somewhere. I’m not sure that I’m hearing it, if you understand, from what I know as a musician about how the ear and the brain are connected in that way, but it’s static – so I agree with whoever said it was like TV static; it’s like TV static, it’s in my head and it doesn’t go anywhere. And I can hear different frequencies, it’s not just one frequency of static, it’s like I suppose you’d call it in music white noise, pink noise we talk about, that kind of thing. It’s different frequencies that can come in and out a little bit but there’s definitely one frequency that is just so persistent.

**P1:** Do you still enjoy music? Can you still listen to music?

**P2:** I do music every day. Yeah. I do. I make a lot of music, I listen to a lot of music. This week I’ve been in three schools all day doing music all day with kids between the age of about 8 and 14, and it’s noisy, it’s loud, I know that I’m just aggravating what is a terrible condition … <sighs> and I know that I just get more and more like, ‘Sorry, what’s your name?’ as I go through the day, ‘Sorry, what did you say; can you just repeat that?’ And it’s just self-flagellation … and not denial really, I’m perfectly aware of what’s going on and I love music. It’s a job that I’ve done for maybe 30 years, working in music education that is, but yeah, I do enjoy music. I love music, I love creating music myself and I love creating music with children as well, getting them to write songs and make music. So yeah. Again was it P3, you said you were in a choir?

**P3:** Yeah.

**P2:** That would be difficult for me. I don’t think I could do it just from the … a practical point of view. I sing a lot and again I sing quite … because I’m a lead singer I sing quite loud and that might have aggravated it as well. I know it does aggravate it. And I do recording sessions and I sing into a microphone and have headphones on, but there’s something in that I don’t think I could bear to hear other people’s voices … close to mine.

**P3:** I’ll point out that actually the choir has been on Zoom since the past 18 months but I personally can still enjoy it. Many others can’t. But P2, are you saying then, when you’re saying you’re asking, ‘What did you say?’ during the day, does it get louder for you during the day or does your hearing get worse during the day or the tinnitus get louder?

**P2:** I think my hearing gets worse during the day but it depends on what I’m exposed to during the day. I think driving is particularly bad for me and it’s not even having the radio on, it’s the noise of the … at the minute I’ve got two cars, like a petrol car, but we’ve just loaned this electric vehicle, which theoretically is silent … it’s a free loan from the council. Anyway, but theoretically it’s silent, there’s no motor, there’s no noise, but the noise is from the road, if you understand. Recently drove it up to Edinburgh and back, and it was just horrendous – it was just absolute … this electric vehicle was just resonating at a frequency that was just so horrible to me, it was like torture almost. So it depends – during the day, I get out of that car and I’m just, ‘What?’ I just can’t hear anything. And especially … and I think it's already been said, being around in social groups with other voices … forget it. I would deliberately avoid such situations because it’s just painful and horrible.

**P4:** Does it affect your appreciation of music as well?

**P2:** No, I don’t know … that’s a good question really. I still can hear … I think I can hear <laughs>. It’s really interesting because obviously there are a lot of deaf musicians and I don’t know, there was a recent film called *Sound of Metal* which I found really, really interesting. It’s about a drummer that goes profoundly deaf, but through a stage of tinnitus I suppose … So I suppose I think I can hear, a bit like Brian Wilson of the Beach Boys was completely profoundly deaf in one ear and so the music that he made was very idiosyncratic to him, and I think that’s probably the same for me, that I probably can’t hear a lot of top end … there’s certain frequencies and certain things that I can’t hear, and on some level of what I do it doesn’t bother me because I think oh, that’s just me, that’s my music; but when I need to … ‘cause I create a lot of songs that go online and go on Spotify and commercial products, I always have to send it to a professional music engineer/producer friend of mine because I don’t trust my ears to … I don’t know how it sounds. I’ve got no concept. ‘cause obviously I record it, I mix it, and then I listen to it back and it sounds a certain way, and then even if I listen to it on Spotify it sounds the same as it was … but I need to just have somebody else’s pair of ears on a professional level, to …

**P5:** I find that really interesting. That discussion is so interesting.

**P2:** Yeah, and I’m suddenly becoming aware that this producer friend of mine, who’s also worked for most of his life as a live sound engineer, also potentially now has some hearing damage which was aggravated during the lockdown actually, because he was asked to work in a certain environment … Anyway … so you’ve got two people with some hearing issues trying to put together pieces of music that … even on YouTube I get a thousand views a day and so there’s thousands of people all over the world listening to my music, and some of it I’ve tried to mix myself, some of it is professionally mixed, and I don’t know … it’s an open-ended question really. I don’t know what they’re hearing, I can’t quite tell what I’m hearing. What I’m hearing is idiosyncratic to me, specific to me and my ears, and I know that my tinnitus is more in this ear,and in the same way that Brian Wilson from the Beach Boys and classical composers, Beethoven, you know … but when you’re recording, if you’ve got stereo you end up compensating, stereo compensating; in other words your mix could end up over here. And the only way I know that that is happening is ‘cause I get a sonic analyser up on my mixing tool and I can see oh my word, look, all the … I’ve just panned everything to the left because that’s what I can hear more and so let’s compensate it back. And yet … I put it back over this side and I … ‘I can’t hear it – it’s gotta be louder!’ <Laughs> So there’s all sorts of technical issues I suppose that go with it from a music point of view.

**P3:** And so hard because this is your working life, this is what you’re doing for a job and you’ve gotta carry on doing it.

**P2:** I’ve just taken a fulltime job as a research fellow and it’s absolutely perfectly suits me in a way that you said, or P1 said that she’d done two degrees … I can do all that job from home, doesn’t involve me listening to anything, I don’t have to be around people, if there’s a meeting it’s in this forum where I can adjust the volume up and down, nobody’s speaking at the same time, I’m not in a reverberant room like an office that might have ten people in a meeting or six people or whatever. And so the job, it’s interesting, I’ve come to that job that I really feel comfortable in, potentially because the hearing is not what it should be.

**P5:** What that makes me think is that it’s almost like you are thinking that there is an ultimate music, that somehow there is a perfection that everybody hears or that we all aspire to or that we should aspire to, and that actually if you’re producing something that’s getting thousands of hits a day or whatever, you’re doing a perfectly good thing and yet you … because of that you’re thinking is the thing that I’m doing not … but it’s not the issue, is it? It’s almost like well you are producing something … and nobody knows. I mean we all hear different things anyway. I don’t believe in perfection anyway.

**P2:** No, I don’t either.

**P5:** But the idea that there is perfection and that we should aspire to it and that because we have tinnitus or hearing issues that we produce is somehow substandard –

**P2:** I completely agree with you. I don’t aim for perfection, but from an audio engineering point of view … there’s a couple of issues I’ll just reflect on, that some upload sites will only take wav, in other words very high end or frequency music, they won’t accept an mp3, in other words a compressed file. And most people will listen to music on tiny either computer speakers or tiny earbuds that just don’t replicate a full frequency sound range anyway. So … there’s issues there that … from an audio production point of view you might just deliberately … I know, produce music for small speakers or for radio, which is massively compressed sound. In other words there’s no loud or quiet; everything’s …

**P5:** [45:43 Wonderful]

**P2:** As a music producer I put compression on it, and then you give it to radio and it puts more compression on it. Nothing is loud. Nothing is quiet. Everything is made … classical radio is really, really noticeable when I put on Radio 3 or Classic FM. They deliberately compress those, because the dynamics are so wide in classical music, in other words you get very loud parts and very quiet parts, they deliberately put loads of compression on so that if you’re driving you don’t get suddenly blasted by a big Wagnerian boom of shocking noise. And so the frequencies are managed in that way. Radio is massively notable for putting loads of compression on everything. And I suppose as a musician I’m technically aware of all these things about how sound can be manipulated and then how sound can be perceived, and then I’ve got to place myself and my, brackets (dis)ability of hearing international that.

**P5:** Sure.

**P2:** And from what I know and what I technically know I suppose.

**I:** Thanks so much for sharing all that P2. There’s so much I want to respond to on loads of different levels, as someone working in music education as well. Some of what you said really resonates. And P5, your comment there about what are the standards that we’re aiming for, and do we get this balance between on the one hand there are engineering standards for music production, but also how do we allow for the fact that everyone’s ears are different? And Patrick’s just posted a link in the chat of a project that’s exploring some of those things as well.

I’m very mindful of time. I told you I was keen on time. Can I suggest that we take a 15-minute break now, and then we’ll come back and look at the remaining four activities together. So if we can come back at ten-past-two, well we’ll start again at ten-past-two, so feel free to take a break.

**P1:** Ten-past-three.

**I:** Did I say ten-past-two? I’m sorry! It’s Sunday! And if you’d like to take a break and then come back ready to start at ten-past-three, that would be great. So feel free to stay logged into Zoom, you can switch off your cameras and microphones, or you can log out and join again with the link that we sent you. But thanks so much for the discussion so far.

See you shortly.

<Break>

Sally, would you mind going back to the slides?

There we go. Brilliant, thank you. And can we go to the next slide please? So we’re going to take a quick look at the tinnitus drawings that people submitted. So this was the third exercise that was available to you. So Sally, can we just do what we did before and if we can toggle through, I think there’s three to look at in total. So this is the first.

<Pause>

This is the second.

<Pause>

And this is the third.

<Pause>

And so we’d welcome any thoughts that you have about these drawings, what they might communicate to you as a viewer, how they might relate to tinnitus. Your thoughts are very much welcome. Sally, maybe if we can just toggle back again so people can see all three?

**P1:** That seems to me quite …violent almost.

<Pause>

**P3:** This is the one where I’m conspicuous by my absence actually ‘cause I found this one hard to do. I omitted this.

**I:** Thanks P3. Do you want to say why you found it difficult to do? We know that different exercises may or may not work for different people so it’s absolutely … you’re very welcome to say why if –

**P3:** I mean your examples in the project were really helpful as guides; I think if you hadn’t done that it would have been different. For me that was helpful. And looking at the one that you gave for that, I thought I couldn’t get from that what somebody might be feeling and actually now I get it a lot better, looking at what people have done with the waves coming in and out and this, as you say, looks pretty extreme, but I would have a hard problem still putting it down into a drawing. Clearly I’m in the minority obviously, everybody did.

**I:** Just to assure you, P3, by no means … in the workshops different people have chosen different activities, so yeah … we know that different activities suit different people better or worse, so yeah.

Any other thoughts on this activity?

<Pause>

Perhaps we can move onto the next activity then and take a look at that one.

**P2:** Yeah, OK.

**I:** Sorry P2, did you want to say anything about the previous one? Oh, you’re muted.

**P2:** When it got to the picture of the sea, that’s the one that I resonated with and I didn’t really recognise the other two. It’s that kind of constant but slightly wavy, I suppose, that kind of white noise aspect of waves on the sea that I would recognise. So there we go. Nice visual representation.

**I:** Thanks P2.

OK, shall we go onto the next one then, the putting tinnitus into words? So this was an activity where we asked you to come up with a word or set of words that you thought captured something about your tinnitus in some way and provide different definitions for that word? So what we’ve done here is we’ve put together all of the different words we’ve had submitted so far. So you are about to be bombarded with a big list of words. They’re in alphabetical order. And I’d welcome you to take a moment, read through those words, if anyone would like me to read the list of words I’m very happy to do that, and then we can perhaps have a discussion about what that list of words says to you: does it capture your experience of tinnitus; does it differ to your experience of tinnitus; what do you think is missing; are there particular words that you’re drawn to? So we’ll just spend a bit of time reflecting on that list of words. So Sally, can I get you to …

So a lot of words, and if anyone’s struggling, as I said, if anyone’s struggling to read all those words I’m very happy to go through them slowly and read them.

<Pause>

**P3:** Really interested in the word ‘delight’.

<Pause>

**I:** Hi P4. We’re just looking at the words that we had submitted for the third exercise, putting tinnitus into words. So these are lots of the different words that we received and you’re very welcome to take a moment to have a look through these and if there’s anything that jumps out at you or if you have any thoughts about this list of words, you’re very welcome to reflect on that.

**P2:** Well after just checking out the link that Patrick put, Aural Diversity website, this list captures some of that diversity; there’s so much difference and difference of experience and difference of perception in this list. Some of it a little bit contradictory I suppose, but that’s the nature of diversity. So it’s very interesting. And obviously a lot of synonyms <laughs> … but interesting things I suppose about perception, like the word ‘invisible’. If you’re synesthetic in any way, just that idea takes on a different sense, if you understand that your senses are not just hearing and site I suppose, and often those two placed at the top of the … what shall we say, the pyramid, the taxonomy? As a sort of ideological pinnacle of our perception of the world.

**I:** Do people feel that their own tinnitus is represented in this list? Or is it missing from this list?

**P5:** I think it’s a really interesting set of words, some interesting ones as well, which … chime with my experience, at different times, not all at the same time obviously, but yeah.

**I:** Great, thank you. Does anyone have any words that they’re particularly drawn to in this? I know that P3 you flagged up delight as a word that stands out to you here. Does anyone else have any thoughts on the words.

**P1:** I like anti-silence.

**P4:** Distraction for me.

**I:** Distraction?

**P2:** Mm.

**P4:** I sort of heard the last bit of what P2 was saying and he mentioned synaesthesia and I’m the same and so I find it super-distracting, ‘cause you can see it as well as hear it so it’s a bit … it’s just if it gets bad I just have to go to bed and block it out, but luckily I don’t seem to have it as constantly as it sounds like some people do.

**I:** So that’s interesting for you, P4, the word ‘constant’ here … which I must say, some of these words we received multiple times from different people but we’ve only listed them once … so the word ‘constant’ for you might not be appropriate or it might be accurate for you, but I’m guessing there are others for whom that word might be appropriate.

**P4:** I think it’s about noticing it in some ways. I mean it must be constant in a way, because it doesn’t go anywhere, but whether I notice it constantly – I definitely don’t. So maybe it’s about the loudness of it and the ability to distract from it, I don’t know.

**P5:** Yeah, I agree, that’s my experience too. Yeah. It’s not constant, but yeah, I’m just going to repeat <laughs> what you just said, yeah. But obviously it’s there.

**I:** Thanks both. Sorry P3, did you want to say something?

**P3:** Sorry, I’d muted myself. I was just going to say could I ask P4 a question there. When you said when it gets so bad you go to bed, can you then block it out, because that would be for me a contradiction. Sometimes I think I really want to get rid of this, if I could just go unconscious asleep or something …

**P4:** Yeah, I think that might be the difference between what my experience and yours, in the sense that I don’t … I think I’ve had it since 2014 and I just have grown so used to it, and so used to specifically not thinking about it, that I don’t have that sense of ‘aargh, this thing’, I just think, if I’m lying in bed at night and I can see it and hear it as well, then I just think OK, I just need to go to sleep – but I don’t tense towards it, if that makes sense. And I don’t know whether that’s what’s helpful for me but yeah – and I do go to sleep, yeah.

**P3:** Right, thank you.

**I:** Thanks so much, both. Shall we have a look at some words, so I’ve picked out some words that I thought were quite interesting in this list and the definitions that people have provided, and I’d be interested to hear what you think of these words and their definitions. So Sally, can we go through – if we go through them all together and then we can go back to any that people pick out and want to return to, if that’s OK. So Sally, do you wanna click next?

So we have ‘blanket’ … and I’m just gonna move my screen around a bit – so it says, ‘a blanket that gets thicker from morning to evening. It muffles the sound of the world outside. It’s not a comfort blanket. More like a thick fog that descends through the course of the day.’

If we can go to the next one? ‘Tuneable: I can imagine my tinnitus saying words and I can make them have a rhythm.’

‘Legacy: It’s all with me. What I was bequeathed by a virus, here to stay.’

‘Aura: It feels like a halo of sparkly sound. It’s there around me, always and invisible. It chose me to host it.’

And I think that’s it for the definitions that we’ve got here. I’d be really interested to hear any of your responses to those words that people have submitted and their definitions.

**P3:** Aura is possibly looking at it as – we’re all told, aren’t we, to try and find something positive. I’ve just taken a screenshot of that because I think that might be something to try to think about – it could go anywhere, but it’s come to me, isn’t that nice? Not really but … sparkly sound <laughs> - try and find something good. That’s an interesting one.

**P1:** I thought it was interesting…the one was that able to affect it, I’d not heard that ever.

**I:** Tuneable, the person who’s chosen tuneable?

**P1:** I can make it have a rhythm. Yes, I thought that stuck me.

**P4:** I can quite identify with the fog, becoming more and more dense, or the blanket, yeah. So if I’m having a bad time with it, it does definitely gets worse in the evening, and by the time you go to bed it is like a thick fog, yeah. I get that.

**P5:** The tuneable one is really interesting. It’s almost, I can make it … to me implies that sometimes <laughs>, sometimes I almost talk to it, yeah. It’s that that make it bit, which is interesting for me. I don’t know if I can make it have a rhythm, but I can certainly … I don’t know, not talk to it, you know, but yeah … talk to it, kind of … ‘OK, it’s time for you to go now’ or ‘I know you’re only coming in here because …’ It helps me manage it. I don’t know what the person meant by tuneable, but I can … that’s my relationship with it. It’s a part of me and I can talk to it. Weird, isn’t it? I’ve never said that to anyone before! <Laughs>

**P2:** You’re amongst friends.

**P5:** It’s true!

**P4:** Yeah.

**P2:** I can sort of understand that, even from a very basic music conception exercise that I might do with some of my students, saying, ‘Can you hear the cymbals, can you hear the guitar …’ and you’re listening to the same piece of music maybe over and over again but you’re listening for … you can tune your ear into different parts of it, and reflecting on my tinnitus, yes, I can move up and down the frequency, bandwidths and try and pick out certain ones. Certain ones that just … it’s really hard isn’t it, but like in an audible, human bandwidth that I can hear very strongly all the time … sorry, I’m doing that now aren’t I? It’s like a linear time passing.

**P5:** There wasn’t a project, ‘what movements do you associate with your … what physical movements do you …’

**P2:** Yeah, that’s mine, isn’t it? Like a piece of spaghetti that just goes on.

**P5:** Yeah.

**P2:** Yeah. Well I always think, again, me talking about music teaching but the idea that as you listen to music time passes, so if you look at visual representations like a traditional music score, for example, time passes from left to right, and if you’ve got something that’s completely persistent this is time passing left to right interminably … and incessantly, just time, time … I don’t know, linear, spaghetti, a very long piece, <chuckles> an infinitely long piece of spaghetti. But yeah, I get it. I’m not sure about the rhythm. I can’t perceive rhythm in my tinnitus. I’m sorry but that’s the … the personal experience of this I suppose.

**I:** I’d ask on that, it’s quite interesting here, there’s some words that people are saying yes, I can really relate to that and then there’s some words that people are saying, ‘Ooh no, that’s not what I experience.’ Is it useful or is it revealing to find out what other people with tinnitus are experiencing and how it’s perhaps different to what you are experiencing? ‘cause P2, you said the word ‘diversity’ when you saw that list of words.

**P2:** Yeah, ‘cause Patrick had put in the link to the website Aural Diversity, so I was just picking up on that. But I’m just reflecting on this in terms of having a hearing test that I’ve had regularly and … it doesn’t perceive rhythm, you don’t pick up rhythm. I’m just trying to think, this is potentially why it’s so hard to diagnose or potentially to get treatment for, because of the diversity of perception of it or experience of it, but a traditional hearing test would … you’re not asked to identify rhythm; it’s about frequency and stereo left/right and that’s it really. You’re not asked to find the timing in the sounds that you hear. And there might be completely different types of hearing test that you can do but the standard ones that you get done even in a private hearing clinic, or the ones that you get sent to from work. It’s just frequency. So it’s very interesting. Yes.

**P5:** I would say yes, this is very helpful. I’ve never been in a support group for people with tinnitus but this is a bit like that but does something that I really love, which is around drawing and people’s art and people’s descriptions of things, so as a method I think it’s quite interesting for support group. I find … I’ve never spoken … there’s that instant connection when someone says to you, ‘Yeah, I have tinnitus too!’

**P2:** And you say, ‘Sorry – say that again’!

**P5:** Yeah, or ‘I can’t hear. What?’

So yeah, to answer your question Marie, yes, I do find this quite useful, really helpful, and to hear other people’s experiences.

**I:** I’d be interested to know, was the diversity of tinnitus, the different experiences that people have … was this something you were aware of before this session; is this something you knew about, or this is news to some of you?

**P1:** I think I knew that people could have it a lot worse than I experience it.

**P5:** Only from Googling it, that different people hear clicks, some people hear sou … that was my only knowledge, and speaking to a few people who described their experience to me.

**P3:** For my part, since ‘coming out’ with it in February, which was when I realised it was Tinnitus Week for the BTA, so I decided to take my thumb out of my bum and mind in neutral and do something proactive and run a campaign, and I got some money but it was actually my way of telling friends that this was going on. I really dedicated a lot of time to certainly the BTA seminars and webinars, done loads of those. And I’ve been on a couple of groups, looked at forming a local one myself only to find it actually got formed two days later, complete coincidence in the area. So I’ve listened to a lot of people and heard, yes, that they are very diverse experiences. But I’m still fascinated … Marie, did all these come from just our group now or are these ones from everybody?

**I:** They’re from everybody. So yeah, different groups. (Sorry, I’ve got a bit of an echo here.) They’re from different … same project … so for those of you who might have missed it, we’re running a number of workshops or discussions, I should say, with groups of this size. There’s five in total with five or six people in each group, so those words were sourced … there’s more coming in every day, and this doesn’t include we’d run a pilot session with the BTA Consultancy Group, and this doesn’t include their words, so by the end of these workshops we will have a lot of words and we’ll maybe come back to talk about this at the end but what we might do with some of these responses … and how we preserve them and make them accessible is something that would be useful to talk about at the end of today’s session.

I’m mindful of time, but thank you so much for your responses. That’s been really interesting to hear and listen to and see what words are getting picked up on and picked out here and how different words relate to each of you. So the next exercise that we’re going to look at was called keeping score. I should say if you are someone who did an audio recording for this exercise and the next one, we have those recordings, we’ve very much enjoyed listening to them, but because of Zoom and because of the aural diversity, since we’ve introduced that word earlier, of the different workshop groups, we’ve chosen not to play the sound-based responses, so we’ve only got the visual responses to this exercise. And again, I’ll come back to talking about how we might make those sounds more widely available if people are willing to do so towards the end.

Sally, I think there is three slides with different scores on? So this is number one.

<Pause>

**P3:** That’s me.

**I:** Thanks P3. P3, can I quickly ask, were the red lines intentional?

**P3:** No! <Laughs> I should go into graphic design! How did I do that?! I’ve no idea! <Laughs>

**I:** It was from spellcheck but I thought they might be intentional … so yeah! <Laughs>

**P3:** Not a clue! <Laughs> I hope it gets the point across though.

**P5:** It does.

**P3:** Good.

**I:** Can we go to the next one please?

**P3:** That’s pretty. God, you’re so clever at this, you people! Wow!

**I:** And there’s two here.

<Pause>

**P3:** Ffff…

**I:** So yeah, Sally I think that’s the last one, so again be very interested to hear your reflections on these responses and this exercise and the various images that you’ve just seen there.

**P5:** I love that one, third slide, I’m actually doing that as I listen to my tinnitus, it’s almost like a score actually, like an actual … there’s a real … that one is really interesting for me personally. I’m doing the whole ‘shhh’ and I can … tune into what I’m hearing here … that’s really interesting.

**P4:** I think they’re quite uncomfortable to look at, somehow. I dunno. I found … so after doing all the activities, I was a bit cross for the rest of the day because I just hadn’t really … I hadn’t thought about my tinnitus for such a long time, and I hadn’t worried about it for such a long time, and then I got a bit annoyed that I still had it, and I think looking at the visual representations definitely brings that feeling of … discomfort back to me, and a sort of like, ‘Ooh yeah, that’s right. That reminds of …’ <Laughs> Yeah.

**P3:** I’d like a bit of an explanation, but completely understand if not wanting to give, of the last one.

**I:** I think this one, I think, is not someone in this group. As I said, we’ve included some that are from different groups. However, I do know that it’s titled ‘Anxiety at Night’.

**P5:** And the previous one, is there any information about that one?

**I:** The one on the left or –

**P5:** The previous slide. That one.

**I:** I think this one was called Fizz. Again this is someone who’s not in the group but we chose it because this shows such different approaches to this exercise.

**P3:** The first word that came into my head when I saw it, it was one of the words in the list, was fizzing. I immediately thought fizz when I saw that.

**I:** So for some of you these images are perhaps uncomfortable to look at and I think that’s very understandable. For others, P5 you were suggesting that one of these was very relatable for you.

**P5:** Mm.

**I:** So with these next two exercises, one of the instructions that we gave was that this shouldn’t be a … or to not aim for an accurate representation or recreation of what your tinnitus sounds like, but more of a creative interpretation. I’d be interested to know, for those of you who did that exercise, whether or not that was something you found difficult to do, or whether that instruction didn’t make any sense for you or whether it was a welcome way of engaging with this theme?

**P3:** What was the next one, I’ve forgotten.

**I:** The capturing sounds exercise. Shall we take a look at that one as well, ‘cause these are quite similar in that they were grouped under ‘what tinnitus sounds like’, as a theme. So Sally, would you mind just toggling through?

**P3:** Ah yes, that’s mine. I think I mentioned the cables before.

**I:** So again, the purpose of this exercise was about thinking about sounds that either relate to or mask your tinnitus in some way. So that relationship didn’t necessarily have to be this is what my tinnitus sounds like, but it could be that the sound hides your tinnitus or has associations with your tinnitus that are other than aggravating or masking. We had this one as well. I can see a lot of nodding.

**P5:** Mm. Mm.

**P2:** Well yeah … you don’t see many of these anymore because not only is it a good representation of tinnitus, but these would give you headaches, that’s what they were known … that’s why you don’t see them anymore, but … yeah. LEDs I suppose is what they’ve been replaced by.

**P5:** They’re good, I like those three, they’re good.

**P2:** Yeah.

**P5:** Those sort of electricity pylons, yeah, that, when you get near them…

**P3:** Exactly what I’m hearing now.

**P5:** Yeah, me too! <Laughs>

**P3:** Noise, mm.

**I:** So one of the things that came up in the previous session that we’ve run is how these images might be quite different to how … members of the other group had seen tinnitus represented elsewhere, and I’d be really interested to know your thoughts on that, how these images are similar or different to other representations of tinnitus that you may have encountered. And I know that we’ve had a couple of films mentioned that depict tinnitus and things like that. So with all of these exercises we’d be really interested to know how these relate to or don’t relate to how tinnitus has been represented elsewhere in your experience.

**P4:** I feel like, you mentioned the films, and I think that’s the only real representation I’ve seen outside of this group of tinnitus. ‘cause I did get a leaflet from the doctor that was all black and white, anciently million-time photocopied black and white stuff, but there wasn’t any representation on it, and what I like about these pictures is that they’re really … identifiable things and they’re really mundane things and they’re just very normal things, so there’s none of this kind of trying to interpret somebody else’s swirls or whatever. You look at that and you get a sense of what that person might be feeling. But … on the other hand, in films I think … what they really depict well is the sense of it being trapped in only your head, and when you look at that, you don’t get a sense of where your place within that picture, and so I think … yeah, so films are … just so yeah, that’s good with films. Sorry, got children running in and out, a bit distracted!

<Laughter>

But yeah, that kind of feeling of enclosure, that P3 did the arrows on the head thing, and that for me is like … in films you quite often have this person looking round in bewilderment and you know that it’s only them that’s hearing the sound. I don’t think you see that represented in any of these pictures.

**I:** So the personalness of tinnitus … personalness isn’t a word, I don’t think, but I’ll go with it … but the individuality of tinnitus, the …

**P4:** Yeah, the feeling that you might be alone with that particular horrible sensation. You get that in films, yeah.

**P5:** It’s interesting, what I like about these is that they’re cross-cultural and that the sound of a running tap is something that probably 99% of people have heard at one stage, and that’s what I like. Words are more difficult especially if they’re in a particular language. But if I think about in the culture, where is tinnitus, if you think about the film, I just thought, wouldn’t it be great to have a film which is like *The Father* but for people suffering from tinnitus, and so if anybody’s seen *The Father,* it’s the experience of Alzheimer’s from a person … so we see that experience, and I think deafness is dealt with quite a lot, years back, deafness is dealt with; I’m not sure where tinnitus is in the culture actually, and is that because it’s so difficult to … or more difficult, maybe artists have not tackled it, I don’t know. It’s an interesting question actually.

**P2:** I’ve posted the link to the trailer of *Sound of Metal* andI’ve just rewatched it, just before I posted it and there was definitely some representation of tinnitus in there, but then I’m just thinking where else is it in popular culture?

**P5:** Yeah.

**P2:** And I’m thinking <laughs> like in cartoons, like I don’t know, like *Roadrunner* or where you’ve got characters battling each other or blowing up dynamite in each other’s faces or getting hit on the head with an anvil and this kind of sound would cut out and then it goes <high pitched tone> ‘doodleoodleoodleooodle’. You know, try and do some almost like comic or exaggerated representation of the sense of your ears ringing, something like that. So even as young children you’re kind of encultured into this idea that having a loud noise go off is gonna make your ears ring or that’s what it looks like, that’s what it sounds like, cut out all the incidental music and <doodleoodleoo>. Anyway …

**P5:** <Chuckles>

**P4:** I was just gonna say that in the … yeah, I feel like if it’s represented anywhere in culture that I can bring to mind, it’s the same kind of thing that P2 was talking about before, where people are starting to give out earplugs at gigs and you go somewhere and you see the bar staff wearing earplugs and you think oh … almost like P3 was saying about hearing aids, where … I don’t know, there’s something a bit hardcore about not wearing earplugs and that still completely persists, but the bar staff are obviously a little bit more educated and a bit more clever and a little bit more accepting of the fact that it does do damage. And I think that we’re seeing … I’m certainly seeing more of that in the places that I go to if I go to gigs and stuff, yeah, at university and whatever.

**P2:** Yeah, it’s decisions made by management to make sure that their staff are not gonna sue them because they’ve suffered hearing damage as a bar staff in the venue I suppose, but yeah, it’s personal choice as well for them to …

**P4:** Well from my personal point of view, it influences me to think actually maybe I do need to wear my earplugs ‘cause maybe there is actually something to preserve here <laughs>, this is important. And that cultural change where you start to take better care of yourself, and it ties in with selfcare a little bit because it’s not something that you … tinnitus isn’t necessarily something that you have to experience and it’s definitely something that you can accidentally bring upon … because of your own activities. It’s a horrible thing. I got mine because I was on a plane flight and I had that thing where your ears hurt and once all the ear pain from that had gone, which took about a month, by the end of it I had tinnitus and that hasn’t gone away. And I just think if I’d never have got on that flight I never would have had that, it’s really annoying! <Laughs> So anyway – why did I say that? Oh yeah, because it’s not very visible in culture apart from when people acknowledge that it could be a problem.

**P2:** Yeah, but I guess in your case wearing ear protection wouldn’t have prevented it, but it might just prevent it getting worse I suppose.

**P4:** I don’t know. I don’t really know how it works, but yeah, probably something about the whole equalising of pressure and all of that, it’s probably related in some scientific way, but I don’t really know what the causes of tinnitus are exactly, like how does it tie in with biological causes of deafness or something, or how does it tie in with pressure and all that sort of thing? I’m sure it said that on my leaflet which I didn’t read! <Laughs>

**P5:** Whereas I think mine was caused by a stressful time in my life, and I … however, listening to P2 I also relate to a whole load of … I’m old enough to have had a Sony Walkman and I used to have that on too loud. I’m old enough to have been to … we’ve all been to the sort of clubs where you leave with your ears ringing, and you never thought about it when you were 21 or 19, but maybe the cumulative effect is actually that, rather than the stressful period, or maybe it’s both. Just listening to P4 trying to think where did it come from … that’s quite interesting.

**P2:** Yeah, I can certainly relate to that in terms of stress, but also I don’t know whether there’s some genetic factor; my father is also profoundly deaf, probably through gigs, probably through exposure to loud noise at work over a prolonged period. Alcohol is a definite trigger for me. If I get drunk then I get more tinnitus. And I’m not talking about in social situations either really. Again all the … there might be related factors that I’m drunk and the TV’s going up and I’m just watching the football at the minute and I’ve got the subtitles on, the volumes getting louder, I’m having a glass of wine or whatever … there’s this whole cyclical … causes or aggravating factors.

**P5:** Yeah, my father wore hearing aids as well in later life.

**P2:** I can imagine … my father probably wore hearing aids from when he was in his thirties maybe or early forties, and you know … but yeah. But again I’ve worked in factories, it’s that kind of constant … as he did, as a manual worker, just constant noise and completely un-talked about, not talked about, certainly not back in the day anyway.

I was just trying to think … this is a super-duper quite expensive pair of ear defenders, I’ll just … and again just because of a forward-thinking management at the college, we all got these. They’re hundreds of pounds each, but what they do is they can completely block sound, but when you switch them on, ‘cause they’ve got batteries in and a little microphone on the front, you get this compressed sound that I’ve talked about. So you get a very artificial sounding world that you then get exposed to and a sound like this … even 20 yards away, will be as loud as somebody clapping very close to you or shouting. So it’s a very strange … piece of equipment. But anyway.

**P3:** I don’t know whether I can show you this but I was gonna say that I’d not seen any pictorial in the research stuff so what you’ve done has been very interesting, but this is what I used … I hope it’ll just come through when I just sent out an email to people trying to describe it … just taken a quick photograph of it on my camera to see if it’ll come through, see if you can see this. Has anybody seen … that picture before? Can you see the person? And that to me was … have I got it in the screen?

**I:** Just about yeah.

**P3:** That to me was a very representative … somebody who’s like this and there’s these bits going out from her head. And I think I put that on the bottom of an email saying ‘help stop the silence’ … not ‘help find my silence’ or something like that. I think the artwork stuff idea of yours has worked really well. That’s basically it.

**I:** Yeah. I’m very mindful of time again. Thank you P3 and thank you P2 and P4, and thank you all of you for all of your comments. I’d like to move towards drawing this session to a close. Sally, would you mind just closing the slides so we can go back to … there we go. Hopefully we can all see each other’s faces, if you have … if you want to see everyone you can go to the grid view in the top right-hand corner and that should enable you to see everyone. So a couple of things. I’d welcome any final thoughts – I think we’ve moving towards that anyway – about these activities. This is quite an experimental piece of research so what you think these activities might be useful for, what they might not be useful for … anything that you think is beneficial or problematic about them, we’d really welcome your thoughts.

The second thing before I hand over to you all is just to say that we are hoping to make, as part of your consent form we flagged this but we’ll be in touch with you after today’s session to just mention this again; we are looking to make a sample of responses available through the project website and we are holding an exhibition as part of this research project. There are two artists who have been commissioned and we would like to include some examples from the different activities as part of that. We’ll be in touch about that to check in with you about that, so do keep an eye out from us. There’s also an evaluation survey that we’d very much welcome your response to and more information on how you can claim your £20 gift voucher, which is of course very important.

So yeah, just to flag that there will be more. I’m sure you’re all enjoying the many, many emails from me, but there will be one or two more emails from me, that you can look out for, and just to say thank you again for your contributions. So I’ll hand over to you all for any final thoughts that you have about these activities that you might want to share.

**P1:** It’s been really enjoyable. It was very stimulating to try and think of ways of answering your questions, so thank you for that.

**I:** Thank you.

**P2:** I was just gonna say, not only does it open your eyes to the diversity of the actual experience, but to the diversity of the ways that people can communicate it, because me personally, I’m more drawn to writing, as an academic and researcher and song writer, I work with words all the time. But then I fully appreciate others are drawn to visual representations or even sonic representations, which we didn’t get to hear, but we could look at the tap and the fluorescent lights and kind of … imagine a sonic world of representation. So I think that’s really interesting level of diversity as well.

**P3:** Enjoyable thank you. Thank you everybody for sharing what you did too. Not an easy subject.

**P4:** Good luck with your working with the Tinnitus Association as well. I hope that goes well. And I hope it gets better as well, people for whom it can get better, it does get better! Yeah.

**I:** Great, OK. Well we have two minutes to go. Thank you so much for all of your contributions today. As you’ve noticed, this isn’t an easy subject for a lot of people, so thank you so much for your time and your generosity in engaging with this workshop. It’s been really useful to hear your own experiences and also how you’ve approached the activities and your thoughts on other people’s activity responses as well. That’s very, very useful to us. As I said, we’ll be in touch with a follow-on survey and also about that gift voucher and where the project is going on from here, so thank you so much. If you need to get in touch in the meantime, please feel free to drop us a line on the [tinnitusarts@open.ac.uk](mailto:tinnitusarts@open.ac.uk) email address, the one that I’ve been bombarding you from. You’re very welcome to get in touch with us should you wish to. But thanks so much. Have a good rest of your Sunday and yeah, it’s been lovely to meet you all.

**P2:** OK, thank you Marie.

**P4:** Bye.

**P5:** Nice to meet you all. Bye folks.

**P1:** Bye.

**P3:** Bye.

**<End of Interview>**