**File: Saturday workshop 1hr46 5 participants**

#### Key

**I:** = Interviewer

**P:** = Participant

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

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

word = best guess at word

- = interruption

… = trailing off or change of thought, mid-sentence

**I:** Perhaps we’re best starting, I think we’ve now got everyone here, I think perhaps maybe if we start by doing introductions, does that sound OK with you, Patrick and Sally? So, if I go first and then I can pass over to Patrick and Sally and they can say what their role is going to be in today’s session, and I’ll explain what my role is going to be. And then if you each wouldn’t mind going around and saying just briefly who you are, just give your first name, should you wish, and if you could maybe tell us where you’re Zooming in from as well, that would be appreciated. So, I’m Marie Thompson, I’m the lead of the tinnitus, auditory knowledge and the arts project, and I’m zooming in from Nottingham and I’m going to be doing a lot of the talking today and taking you through the different activities and responses that we’ve received. Partick, do you want to say hello?

**I2:** Thanks, Marie. Yeah, hi, my name’s Patrick and I’m the co-investigator with Marie on the tinnitus project. I’m currently based in Sheffield, although not for very long, and today I am primarily going to be monitoring the chat function, so if anyone wants to express any thoughts or reactions through that medium, please feel free and we’ll be able to keep things rolling in a variety of mediums.

**I:** Sally, before you go, if anyone is needing to use live captioning or auto captioning on Zoom, now is probably a good time to mention, I’ll mention it again later, but there is a CC icon at the bottom of the screen which should enable you to switch on auto captioning should you wish to. And if there’s any issues with that just type in the chat and we can try and chat. Sorry, Sally.

**I3:** Hi everyone, my name’s Sally, I’m one of the researchers at the Open University, I’m zooming in from Warrington, I’m here to help Patrick with the chat and also to keep an eye on you, give you any advice if you need it, if you’ve got any problems with Zoom, I’m here.

**[PARTICIPANT INTRODUCTIONS]**

**I:** ….Thank you everyone and again, I will probably say thank you about a hundred times because that’s what I’m like, but I would really like to say thank you so much for taking part and for sharing your responses with us and for your generosity in joining us on a Saturday just about morning, it’s really appreciated. So, what I will do now is we have a few guidelines which will help you get a grasp of what this online discussion is for, and hopefully will give you a sense of some of the things were trying to talk about. We’ll then share some responses with you. We’ll have a 15-minute break starting probably at 11:55 so that you can get any refreshments that you need, have some time away from the screen, should you wish, and then we’ll start the second half, all being well, at 12:10. So, that’s the rough structure. So, I’ll just move on to talking about the discussion guidelines. As I’m sure many of you are aware and don’t need telling, tinnitus can be a sensitive topic for discussion. You’re welcome to take some time out of the session or leave if you feel you need to. And if you need to re-join, you can just click on the Zoom link that we shared with you, that should enable you to re-enter the session if you need to take a break. So, as part of the workshop discussion, we’ll be looking at some of the work that’s been created by different people in this group, and we might also include some responses that haven’t been created by people in this group. Our discussion should be focused on the process of making and how what’s been made helps express experiences of tinnitus or, in your view, doesn’t express experiences of tinnitus. So, please be considerate of others when discussing this work. We’re going to be sharing the responses to the activities anonymously, however if you feel that you would like to, you are very welcome to identify yourself as the creator. We think it’s best to start anonymously and people can say, ‘Well actually, this was mine’, should they wish to rather than naming names. So, if your name doesn’t come up, that’s why. And finally, for this page at least, we know that tinnitus can affect people in different ways, and that’s certainly something that’s been coming out from these workshop activities, so please keep in mind that others might have different experiences to your own. And now I’ll see if I can move to the next slide. Power point is feeling Saturday morning.

OK, some of us are using Zoom’s auto captioning function, that works best if one person is talking at a time. We know this can make conversation feel a bit limited sometimes, but if you can make sure when you’re not speaking, if you can have your microphone switched off, and if we can try and avoid talking over others. If you’re wanting to say something but you are struggling to interject, if you just want to stick your hand up physically or there is an option to do it on Zoom, at the bottom of the screen there is a reactions icon and that will allow you to raise your hand. So, if you’re struggling to put yourself into the conversation, if you’re struggling to find that place, please feel free to just stick your hand up. And we know this can be difficult when people are trying to have conversations.

On the other end of that spectrum, silences are OK. We know that people might need some time to respond and to think about things, so please don’t worry if nobody is saying anything or nobody is typing in the chat box, and we’ll try and remember that as well.

As I said earlier, we’ll be having a 15-minute break halfway through, and if you need to take some time out beyond that, as I said earlier, you’re very welcome to, you can leave the session at any time and re-join using the Zoom link that was sent to you.

If you feel you need some support or are having any issues during the session, you can use the chat function to privately message Sally and she will try and provide you with some guidance or talk through different options with you. So, if you’re needing some support during the session, Sally is the person to contact. And Sally has just very helpfully put her email address there as well if you want to contact her by email as well, we’ll try and keep an eye on multiple things at the same time.

Does anyone have any questions about that? I know those guidelines feel very long. No? Great, OK. So, I will try and move on to look at some of the responses we’ve had to the first activity, which was the tinnitus maps. I should say as well, for the sake of time we’re not sharing every response we had to each activity, so if your response is not there, please don’t feel that it’s because it wasn’t interesting or good enough or anything like that, that’s certainly not the case. It’s that we’ve chosen a selection of things. Everyone here will have something of theirs appearing at some point, so hopefully that doesn’t fill you with nerves. Again, we’ve been really grateful for the responses that we’ve received.

OK, so what I’m going to do is I will show you a few of the different tinnitus maps that we received, and we can just take some time to look through them and then I would open it up to you all for any reflections that you have on these things that have been created. We’re particularly interested in how you think they relate to experiences of tinnitus, or they don’t relate to experiences of tinnitus. We’re interested in what you notice about how people have approached the activity, and any other thoughts that you have on what has been created.

OK, so hopefully you can see, this is the first one that was a lovely hand drawn example. We have different colours representing different states. So, this is two different maps that we received, taking quite different approaches, which is good, we like different approaches. We’ve got this one. This one I really notice that after a long Teams or Zoom call features here, so yes, we’ll try and bear that in mind.

OK, and I’ve gone too far now. So, over to you, we’d welcome any of your thoughts on these responses and also any responses that you have about this activity more generally. Feel free to stick up your hand or switch your mic off or take a moment to gather your thoughts.

**P3:** Can I just say that it’s interesting that it showed a real range of different triggers or different situations, and I’m surprised that some people’s experiences are very different to mine so it was really interesting to see, of those situations that made the tinnitus more noticeable or more disruptive.

**I:** Great, so you got a sense that what was negative or positive in relation to different people’s tinnitus was quite different to your own experiences?

**P3:** Yeah, definitely, yeah. It’s really interesting to have that context because it’s such an internalised personal experience normally that’s hard to explain to anyone else, and I think this is a really good way of visualising it. It might be helpful to show mine to my family and friends, actually.

**I:** Thank you, that’s really useful to hear. P2, did you have something you’d like to say?

**P2:** Well, actually, I can’t remember your name, sorry, but I saw a lot of my own experience in other people’s maps, and I think that I saw the resonance in other people’s maps, not the dissonance. So, I saw similar experiences to mine and I ignored or I didn’t focus on those things that were different from mine. I found this exercise probably the most difficult of all of them, because my tinnitus is different almost in every room in the flat, every part of where I go, and therefore there was such a lot to document, I didn’t really know where to start because I hadn’t reflected on it for years, therefore I didn’t have a summary to be able to, like this lovely map we have here, to go, oh yeah, this is intent, this is what I’m looking at. And because I was keen to get going with the exercises, I just took the first example and tried to do that. So, there’s quite a lot to unpick there.

**I:** Thank you, P2. P4, did you want to …?

**P4:** Yes, I just wanted to pick up on P2’s comments about the variability of sensation of tinnitus in different rooms of the flat, and at the same time in very different parts of the day. For example, when you are in bed, for me it’s when you can both have the quiet background making the tinnitus more evident but also I can wake up at night and have no tinnitus at all. Or it may be in, so I had it tonight, normally it’s only on the right, and in my case it’s probably connected to [17:25] disorder, but I had it for once in the left ear and it was like alternating and also with different pitches. But then when I woke up a few hours later it was completely absent. So, even just to capture in space, say in the bedroom it’s necessarily less or more noticeable, it’s not necessarily true, it depends on the time of the night.

**I:** P5, would you like to say something?

**P5:** Thinking back to what, I can’t remember her name and I can’t see her picture at the moment but talking about picking up on the similarities in the tinnitus, I did completely the opposite and I noticed where someone had put something with intents where I feel that I hardly notice it, and so I picked out the differences. And like the gentleman who said that he found it really hard to know where to start, and that’s exactly where I was, I had no idea where to start, and so mine is quite different to what everyone else has done. I drew all the lines where I showed it from where I notice it a lot, that’s the black line, and then the orange line because orange is my favourite colour, to where I hardly notice. Yeah, it’s the one on the left hand there, and I realise now it’s really complicated but to me it makes sense because it starts off with where it’s so noticeable and where it becomes more and more intermittent and more managed, until there are times when it’s not managed at all and I don’t even notice it. And just like what P4’s just said, the variability that comes within different times as well and depending on how you’re feeling, if you’re well or not well. So, yeah, it was an interesting exercise because it really made me focus and think about where the good places are and where the bad places are and how I manage it to make the bad places better, or the bad times, I should say, better.

**I:** Thank you so much for those comments, I think there’s some really interesting themes coming out of this around, I mean, one of the things that I noticed is that when people have represented places on these maps, they’ve tended to also represent different activities, and there’s that challenging thing that others have picked up on of it’s never just about the place, it’s also about what’s going on in those places but also about how you’re feeling at that time of day, other things that have happened as well. So, place is only one factor amongst a whole range of things. So, these representations are necessarily incomplete.

So, P3, you said that you felt this would be something that you would like to potentially show others, and you think it might be useful to show others so that they get a sense of some of what you’re experiencing. Is there a sense that this kind of depiction or representation of different activities and places might be a more effective way of getting others to understand what you’re experiencing than just telling them the different places or activities where your tinnitus is more or less intense?

**P3:** Definitely, and I think P5’s methodology, although it’s initially quite complicated and takes you a moment to understand her system, I actually think it’s a really, really clear way of explaining to people that it’s not, and it’s interesting, isn’t it, a lot of people have some experience of tinnitus, but if you have gone beyond that kind of intermittent tinnitus to tinnitus that’s probably with you nearly constantly, I think at that stage it’s quite hard for people to understand. And I think something like P5’s method would probably be a really great way of trying to say to people, so for instance when I’m tired mine is often worse, personally I’ve noticed if I’ve had a busy day, and I could maybe help explain to people around me, I’m sorry if I’m a bit withdrawn, my tinnitus is worse at the moment and it just would help broker that conversation, I suppose, definitely.

**I:** P5 do you want to come back to that?

**P5:** Picking up what P3 said there, it’s the invisibility of it, because nobody can see what you’re listening to, nobody can see what you’re hearing, and therefore other people, it’s really hard for them to remember that you even have an issue because it’s completely invisible, you don’t have a mark on your head or blood coming out of your arm or have a stick or something, so it’s completely invisible. So, any pictorial thing is going to make it easier for other people to see, and I’m just going to leave my chair for a minute and show you something that makes my people at work know that things are not good.

Oh, I’ve left them downstairs, but I bought myself bone conducting headphones, so I can use my, yeah, so people would know by something they can see that there’s something not right because everything else is the same, I’m sitting at the same computer or I’m in the same meeting, but when I’ve got something they can see, so anything that’s pictorial helps people to know that there’s something going on.

**I:** Thank you. P1, did you want to come in, and then P2, do you want to come in?

**P1:** Yeah, the first thing I wanted to say, it’s just fascinating to see how diverse the experience of tinnitus is, which is something I’ve read about but is interesting to see the evidence of it as well. I started doing this exercise but I didn’t finish it. I think what I started doing ended up being the portrait because generally, location wise I find that if my, most of my tinnitus is located on the left ear, if my left ear is exposed away from any surfaces then it’s not evident at all because it’s being masked. I feel quite fortunate, it’s quite low in frequency, in pitch, my tinnitus, it’s fairly constant so it’s quite easy to mask. So, once I do the location it was just everywhere but depending on where I was facing. And in my office I’ve strategically placed my whole house, my whole office in a way so my left ear is always exposed, just to make sure there is some ambient sound coming in to mask it.

But like P3 said at the beginning, it is interesting how some of the triggers for other people are the exact opposite for me, such as the one being in a loud environment that agitates the tinnitus, which is the exact opposite for me. I should say as well, while I was doing the exercises and doing this conversation, it’s getting louder and louder just because I’m thinking of it, so it’s interesting to see the psychological aspect of it. Yeah, that’s just what I wanted to say for now.

**I:** Yeah, thanks P1, there’s so much in there to respond to, but just quickly, we know that there is a risk here that we are drawing attention to something that a lot of people spend a lot of time trying not to pay attention to, and if there’s anything that you need to do in order to address that, including taking some time out, feel very welcome to. It’s one of the huge challenges that we are facing with this project, as you can imagine.

**P1:** I didn’t mention it as a negative, it’s actually interesting because it just gives you an opportunity to study it a bit more, let’s say, and just pay more attention to it. And it’s something that you’ve fought for such a long time to forget about or try to brush on the side, now it’s coming to the foreground, but in the context of research, so it’s for a useful purpose, so you think it’s a worthwhile endeavour. It’s like going to the gym in a way, I hate it but you have to do it because you want to stay healthy and so on. Because like P5 said that it was useful to visualise something so you can tell others what is your experience, I took another route because I’m a composer, I made a piece out of it, and I did it partly for artistic reasons but mainly because my family didn’t believe me when I told them 10 years ago because they’re just not aware, none of them are musicians or anything to do with that. So, I thought, OK, you don’t believe me, here’s what I hear all the time. And they were like, oh OK. They were still a bit dubious but yeah. Anyway, don’t feel bad about it, I think it’s a very interesting exercise, it’s useful as well.

**I:** Thank you, P1. And that’s really interesting about your own experiences of using artistic ways of sharing what you’re experiencing to try and get others to take seriously what’s going on, that seems to be something that’s cropping up a little bit in our conversation.

P2, you had something you wanted to say, didn’t you?

**P2:** Two things, one is I couldn’t remember my tinnitus until I started this and then since then I’ve not slept a whole night, so I am, I’ll get over it, I’ll reduce it. And secondly, the RNIT’s campaign about communication needs has been brilliant for me. I teach and I’m confident and I introduce my deafness to people, I’m not totally deaf but I’m hard of hearing, hearing difficulties, but the campaign earlier this year, introducing your communication needs, has made my life so much easier for strangers because I can introduce it with confidence in a way that is relatable to them.

But P5’s map was really interesting because I was thinking that I could identify when I could manage it and when I couldn’t manage it, and actually my deafness is more difficult with family and people who’ve known me for a long time because it’s crept up and there isn’t a learning about how best to communicate with me, there’s negotiation between their perception of my activity and my reality. So, my communication statements to my partner, he’s heard them all before, and similarly the, yeah, so it’s a something which might be, yeah, there might be an outcome for me to help me explain my tinnitus and how I manage it and what it does when I can’t manage it in my communication with people close to me and people outside. And I find tinnitus doesn’t affect me when I’m on, when I’m performing like this or in workshops, it affects me more in an intimate surrounding and more in a quiet time, but that’s my experience of tinnitus, although I can hear it now, of course I can, of course I can.

**I:** Thank you, P2, that’s so, again, really useful to hear. I probably should say at this moment, this is quite an experimental piece of research and in terms of finding out what these activities might be used for and what they might be able to capture, what they might be able to communicate to others, those are quite open-ended things. So, hearing your suggestions of how these activities might be used in your wider situations is really, really helpful for us.

P5, did you have something you wanted to say?

**P5:** Yeah, I’m sitting here feeling slightly overwhelmed that two people have made comments about my lines and my intermittent things, and I think I just have to share here that I work with children with special needs who have speech and language and communication difficulties and I spend my life sorting out their communication where, like I work with one little girl who only has two sounds and they’re urgh and ergh, and so somehow I’ve worked it on myself as well, and yeah, that was good to hear, that what I did made sense because I was thinking, when I looked at everyone else’s, that mine didn’t make sense to anyone else.

**I:** Yeah, thank you, P5. I’m trying to withhold my comments because you’re all doing a great job of talking and no one needs to hear what I think, I can think about that in my own time, but I just want to say thank you so much for sharing that stuff, and we know this is quite personal stuff to be talking about, so thank you, we really appreciate it.

I feel like we could probably spend the next two hours talking about the maps, but I’m going to try and push on at this point because we’ve got five other activities that people did. But I think there was a lot to talk about tehre, so thank you. I will push on if power point will enable me to, it’s really sleepy. Come on. There we go.

So, tinnitus portraits. So, we’ve included various responses we’ve got here. Hopefully you can all see that. So, feel free to take a moment, have a look, have a browse. Again, we had very different approaches to this exercise, and that’s something we welcome. We gave you some quite vague instructions so we didn’t expect everyone to do the same thing and we kind of wanted people to do different things. So, when you’re ready, feel free to jump in and comment on these responses.

P2, feel free.

**P2:** I found that there was a sense of movement that I wanted to represent in the effects of my tinnitus, and actually, which I’m not very good at expressing, and that’s me with the beard, with the gorgeous white beard down in the bottom right. But actually, the fluidity of the creation was the only way that I found in order to express it, and it resonates with me about, in a different way, with the arrows and the different colours, I think that my lack of self-perception of creativity limits the way that I express it because I’m not used to expressing in this way and therefore, yeah, anyway. But the act of creation, if somebody had filmed me in the way that I drew it then the intensity and the movement would have been more expressed. So, if you watched me do it, it would have been different than the horrible little self-portrait, which is so obviously me, isn’t it?

**I:** Can I just say, I really like your self-portrait, I thought this was wonderful and I really got the sense of movement in it and I was really struck by the almost looking like a halo around your head, and I really got that sense of movement. I thought it was a very striking depiction. But that’s interesting what you say about the relationship between process and outcome, I would maybe phrase it as, that in the drawing you get much more movement.

P1, did you want to come back and say anything?

**P1:** Yeah, just to say on, just in response to P2, I think sometimes this creativity sometimes obscures the point of those exercises, that you’re trying to make something that is aesthetically pleasing and sometimes, especially if you worked professionally or in education or something like that, that you have to make something that you hope people will appreciate, sometimes takes away the true meaning of what you’re trying to make and you get so caught up in trying to make something that looks pretty, then you’re not really expressing what you’re really trying to express. So, yeah, don’t ever call yourself not an artist, everyone’s an artist, you just have to call yourself that.

**I:** P5, did you want to say something?

**P5:** To add onto what P2 said, and it’s all about the process not the product, and I think the more that we could continue to engage in something like this, we would forget about the end result and we’d just do how we’re feeling, how we’re listening, because it’s the end result of the reflection of what’s happening within us, and also the result of helping us to make us feel better about putting what we’re listening to and feeling onto paper, and it doesn’t have to ever be for anyone else anyway, it’s for us to work it, like children or slapping black playdoh around, it doesn’t matter what the end result is, it’s the process of why you’re doing it. And I felt that very much while I was doing mine because it made me focus on what I was hearing and how I sorted it, and you can probably tell, I’m the one that’s all about management, all the eggs, on the left hand side.

**I:** P2, did you want to say something?

**P2:** I’ve started to notice more different people’s approach to the expression of the sound, not quality, of how the sound is. I love the artistic one in the middle and I can resonate with some of the hard shapes and some of the flicky bits, and you see some of my dashy bits were the kind of s-s-s-s-s quality and I like the wavy liney bits, which express something to me as well.

**I:** Thanks P2, yeah, I find there are some really interesting similarities and differences in what’s going on here and the use of lines is something that keeps coming up in the different activities to try and capture what tinnitus is like and what it’s experienced as.

Obviously with all of these activities, they can never capture everything about your tinnitus, they can never get everything. Did anyone have any thoughts about what this couldn’t get a hold of or was there was any frustrations about what the portrait couldn’t take a hold of? If that makes sense?

P3, are you trying to say something? You’re muted.

**P3:** It’s a very two-dimensional representation of something that for me, so I’m the one with the arrows and I was trying to express that the sound comes from different directions for me. And I think maybe the one in the middle does that much more effectively, that sense of the, for me the one in the middle, which is isn’t my drawing, the very powerfully black and white drawing, that sense that almost the sound isn’t just coming from one direction, it’s almost a 360 degree, maybe if I’d done a picture from the top of my head it would have been more helpful. That sense that some of it is inside, some of it feels like it’s coming in from the outside.

**I:** Yeah, thanks P3. I’m struck by these images of the different directions that tinnitus is shown as going in. So, for some pictures it’s coming from the outside in, and for others it’s shown as going from the inside outwards. And for some people it’s coming in different directions, it’s moving around or it’s moving or it’s a very specific location. So, yeah, I was quite struck by the different directions that things were shown as moving in. So, that’s interesting what you’re saying about the challenges of capturing that.

P5, did you want to say something?

**P5:** My one was the eggs on the left hand side, that’s depicting that it just seems to go straight through and sometimes it’s like dotty and other times it’s undulating, but for a lot of the time it’s just like a high pitched whine. That’s what those lines, they’re not a direction of movement, they’re the undulating of frequencies.

**I:** Thank you, yeah. P2, did you have something to say?

**P2:** One final thing from me, other than being jealous of the one in the middle, it’s the emotion that’s missing from this self-portrait for me because there’s this thing about the noise and the movement and it’s all internal. Well, actually, from a representation of me, obviously I’m quite animated but if it was a portrait of me then you’d see if I was happy, if I was sad, and the violence and the intensity of the emotion is part of what the middle one helps express for me of the artist.

**I:** So, yeah, I think that’s a really interesting point, can this exercise capture the emotional elements of tinnitus or experiences of tinnitus or yourself. And yeah, that’s really challenging so thank you for those responses. Did anyone have any final comments on this or should I move onto the next activity?

**P1:** Just to say I’m interested about the bottom left one with the frequency representation. That’s something I started doing and it was the same question of how do you visually represent timbre, especially something that might be changing all the time as well. So, I was thinking of like a spectral image, one of the spectrograms to begin with, but that wasn’t working. But no, it’s interesting how people take a more scientific approach in representing tinnitus. Three kilohertz, tahat must be really uncomfortable all the time.

**I:** Thank you. Yeah, and again I think with all of these activities we see people taking very different approaches and hopefully now that you’ve seen some of the different approaches that people take, hopefully you can have some more ideas about how others might approach this activity but also see your own work in the context of others as well.

Shall I move on to the next exercise where we’re, I’m just slightly mindful of time so I’m going to skip on. Again, I think we could probably spend ages talking about this, should we wish to. OK, so, tinnitus drawings, we’ve got a couple here that I’m going to show you, so here’s one and here’s another. I always feel a bit like when you’ve been to the opticians and they’re like, ‘Which is clearer, image one or image two?’ So, this is one image and this is titled Silent Pause, and this is another that was titled Tinnitus Drawing. And yeah, I’d be interested to hear your thoughts about these images or this activity. Any thoughts are welcome here.

**P3:** Can you go back to Silent Pause please?

**I:** Yep, I will do. Just give it a minute, it needs to think about this. I don’t know why it’s so slow today. Too much good work in one document. See P3, I said yes, I could go back to Silent Pause and now … There we go, the hamster wheel has finally got up to speed. OK.

**P3:** I think this is just so clever and such a considered response. It’s not mine, I wasn’t able to create anything as powerful as this, but it’s such a good way of representing that moment when you suddenly, you do get that kind of like silence or maybe, and then unfortunately it comes back again. I just think this is just brilliant. It could actually be on the wall of a gallery as well, couldn’t it? I think it’s really, really powerful. But then so is the other piece and the quality of the marks on the Tinnitus Drawing is really interesting, isn’t it, that sense of the bottom image, this again isn’t my drawing, but I can imagine that that might be when it’s almost completely impossible to ignore, and almost feeling that person’s perception and, yeah, I think they’re both incredibly powerful and it just goes to show how a line or a series of lines can really express something that is aural. Mad, isn’t it, but very good. Whoever did these, brilliant.

**I:** Thanks, P3, for those comments. P5, did you have something you wanted to say?

**P5:** Yeah, the Silent Pause I also thought was incredible, showing that moment of peace and quiet in the middle and then that it’s still ever present and going to come back, but for a moment there’s a lack of awareness of what’s happening or that indeed has just switched off completely.

And on the next slide my comments were that I would not want to be, I thought the top box was the one that would be most distressing for me in the way I saw that picture, those hash lines as being an intensity in a different way to the bottom one that would be harder to mask and manage. So, we all approach it so differently and neither of them were my drawings but they speak to me as well.

**I:** Thanks P5. Perhaps I can throw a question out here that perhaps we might return to with some of the other exercises as well. P1, you mentioned that you’d tried depicting your tinnitus before through music, I was wondering if people in the group had encountered representations of tinnitus elsewhere, and it doesn’t have to be artistic representations but have seen tinnitus shown or illustrated or depicted in different ways in different places and times, and how some of these depictions are similar to or different from how you’ve seen tinnitus shown before or shared before.

P1, did you want to say something?

**P1:** Yeah, it might sound a bit facetious but it’s not. Really the only time that I’ve seen, I’ve come across mentions of tinnitus in popular culture is by William Shatner and by Arthur, the animated comic, and they make frequent references to them, but they’re actually very, very accurate, about how it manifests.

Sorry, I’m just getting a little bit self-conscious because people are commenting on my drawing, the Silent Pause is mine, and it was more, I’m not a visual artist by any chance, it’s just a quick biro thing I did. Just these incidentals you get every now and again in your ears, you know, like a loud buzzing or the kind of decompression. I don’t know, I researched it years and years ago and it’s sort of normal, everyone gets it, it’s not just tinnitus sufferers, and sometimes, you know, at the best of times it’s annoying but when it comes to tinnitus sufferers it’s actually a real relief because it just takes it away, it takes your concentration away from the constant, you know, your own thing, and you have something different, and then when it passes you’re back to business as usual. So, perhaps it’s not Silent Pause but just a pause from what’s there all the time. But I may be wrong, I don’t know if there’s any other representations of tinnitus that I’m not aware of, like that’s the only two examples that I’ve come across.

**I:** P5, did you want to say something?

**P5:** Yeah, and this is sort of the opposite end of a visual representation of tinnitus, because I won a competition where I was going to have a piece of music composed for me, and it turned out that the man who was going to do the composing, I didn’t realise when I made the bid, it was a charity thing so I didn’t really mind what I won, he was a binaural musician and he created this piece of music, and because it just happened all at the same time as when my tinnitus was diagnosed, I explained to him how my tinnitus was and what helped my tinnitus, so he created a piece of music, I don’t know how he did it, but there’s bird song and water moving and rustling or crickets and wind and whatever, and he created something that is a really nice mask. So, it’s not tinnitus but it’s something that has helped to mask my tinnitus. So, it’s like the, you know when you get a photo and you have the negative, it’s sort of like that. And I’ve since read that something to do with binaural sound, I don’t know enough about it, P1 I’m sure will know more as he’s a musician, but that seemed to be something that might be reflective of tinnitus. I don’t know, but I just thought I’d share that because it was just a chance encounter and I ended up with this piece of music that I found very soothing, and it helps me drift off to sleep and wake up peacefully in the morning because that’s my alarm clock now. I don’t have an alarm because that’s too intrusive and I wake up thinking about my tinnitus, but when I wake up to this bird song and music that drips and, so it’s like the negative of tinnitus.

**I:** The anti-tinnitus. That’s amazing, thank you for sharing that experience, P5, it’s really interesting hearing people’s different encounters and experiences around I guess the arts, very broadly understood, and tinnitus as well.

I’m very conscious of time, this is something I’m very strict on. It is now five to, can I suggest we take a 15 minute break now, have some time away from the screen if needed, get some water or any other refreshments that are needed, and if we come back at ten past and we’ll have a look at the remaining activities, and then we should have some time at the end to just wrap up, talk more generally about the activities, and also we’ll go through what happens next as well.

So, thank you so much for your contributions so far, I’m personally really enjoying discussing these responses with you so thank you so much, and we’ll see you at ten past. If you want to stay logged into Zoom, you’re welcome to switch off your camera and keep your mic muted, or if you want to log out you can also re-join using the Zoom link that was sent, so it’s up to you how you choose to take your 15 minutes. Thank you.

So, the next activity that we’re going to look at is called putting tinnitus into words. So, I’m about to bombard you with a lot of words. What I’ve done or what we have done is we’ve put together all the words that we got submitted for this exercise so that there is a big list of words, so we can take a moment to have a look at those, and then we can move on and have a look at some of the definitions that people have provided to a selection of words as well.

There we go. A lot of words. If anyone would like me to read out the words, I appreciate this is a lot of text on the screen, if anyone would like me to read them, please let me know.

Now that you’ve started looking at this list of words I’d welcome any thoughts about what you’ve read or what you can see here. Does this depict tinnitus for you, doesn’t it depict tinnitus for you, are there words here you can relate to, are there words you don’t relate to, are there words that you’re surprised to see in this list, are there words that you disagree with? I would be interested to hear your responses to this. P3, feel free to jump in.

**P3:** I think the word thief is really interesting because in a way I think it’s not a word I thought to put down but it’s such an interesting way of describing how it can sometimes feel, that tinnitus has taken something away from you, so yeah, that was one that really stood out for me. Obviously the others were more, I could certainly relate to a lot of the words used to describe the different sound experience as well, and the words tiredness and sleep and stress and pressure. But thief, yeah, brilliant.

**I:** P4, hi, welcome back. Just so you know what’s going on, these are the responses that we got to the exercise about putting tinnitus into words, so these are all the different responses that we got, or I should say that we’ve had so far, I think there’s more coming in, so we’d welcome any thoughts that you have on this list of words and how it does or doesn’t capture experiences of tinnitus, what you’re struck by on this list of words, any thoughts that you have.

P1, do you want to speak?

**P1:** Yeah, it’s like P3 said, I can definitely identify with most of these words but I wonder, delight and legacy, these are the two that pop up as just not, I don’t want to say the odd ones out but I’m just trying to interpret them a little bit, and I’m just wondering if anyone else has any thoughts on those, delight and legacy.

**I:** P5, did you want to say something?

**P5:** As the author of delight, maybe I should explain. I was trying to think positively about the times when I suddenly think, ‘Oh my goodness, I’ve gone a whole day’, or whatever, and I haven’t noticed it at all, or I’ve been out in the park or gone for a walk and all I’ve heard is the insects and I’ve sat and read my book and it’s just been like a relief. So, it’s the opposite of exhaustion, which is the other word that I’m the author of, but I just wanted to think positively as well as, because there are days when I think, I haven’t noticed it at all, I haven’t had to take my headphones out of my bag at work, I haven’t had to put the cricket music on so that I can enjoy reading my book at home. I was also the author of thief because at the very beginning and when I’m tired, I feel that I’ve been robbed of being able to sit in the quiet with a cup of tea and a book. Sometimes I can do it but when I can’t I feel that that’s been stolen from me, so that’s the complete opposite of delight.

**I:** Thanks so much P5 and for identifying yourself there. Yeah, and I’m really interested that you chose words that in many ways are capturing different elements of your tinnitus or the opposites of it. P3 says bitter is probably a word I should have included. P3, would you like me to add bitter to the list? Good, OK. Delight makes sense now, good. Any other thoughts on this list of words or shall I move on to some of the individual words that we’ve picked out for discussion? P2, did you want to say something?

**P2:** Well, for me seeing this list of words, the words exercises seem to be more evocative of the whole me than my inability or my perception of inability with creativity with the drawn line, so seeing other people’s experience with damage, delight, concentration, constant, although they’re not my words I can see them expressing somebody else’s experience and there’s less of a need to connect, to be resonant or non-resonant with the words because I think the words seem to be richer, possibly because there are more of them to see the variability of other people’s experience.

**P4**: I just have a quick comment, although they are not my words, but about two of the words mentioned that are not so easy to interpret, electron and legacy. Electron is in a way can suggest tinnitus as a constant revolution of a particle around the nucleus, which typically happens with sort of like planets around the sun in the old Bradford model of the atom is basically a constant pitch movement, if you want, so it could suggest a sort of whistling sound or other constant pitch.

Legacy, I assume it could be something that we may inherit or it’s something that we find ourself caught in without any agency, maybe.

**I:** Thank you. I know that I have the author’s definition of legacy coming up, so yeah, hopefully you can engage with that. Great, and P1, you’re pointing out that because your experience is different, you wouldn’t have necessarily thought of that word as well. Yeah, thank you for all of those thoughts. I’m going to move on and show you some of the definitions that we received. Again, this could take a while so feel free to take your breath and have a drink. Come on.

OK, so we have one here for acute. What I’ll do is I’ll show you the different definitions and then we can maybe talk about them together. So, strongly felt, pointed, of critical importance and consequence, but also the sufferer is often one with the ability to recognise or draw fine distinctions.

Tuneable. I can imagine my tinnitus saying words and I can make it have a rhythm,

Legacy. It’s always with me, what I was bequeathed by a virus. Here to stay.

Aura was another word that we picked out. It feels like a halo of sparkly sound, it’s there around me, always invisible, it’s chosen me to host it.

So, you can see some different words there and different definitions that people have provided. I would welcome your thoughts on those definitions or those words and what they may or may not capture from your perspective. P5, did you want to say something?

**P5:** The one that’s on the screen now, aura, that seems to me to reflect a bit what I was trying to say with the delight somehow, that it’s thinking of it more positively, but you could also read it, sparkly is not always nice, and it chose me to host it, grr, but to me it reads a little bit positive.

**I:** Yeah, thank you P5. Do you think there’s a need to include some more positive terms in discussions around tinnitus or depictions of tinnitus?

**P5:** Personally I think yes because when you think negatively about things and you label things with negative words, it helps you to think more negatively about it, whereas if you label things more positively, it helps your brain think more positively about it, even though the actual thing itself is the same. But if you think of something as being awful then you sit with it being awful, whereas if you think about it being, I don’t know, a little bit intrusive at the moment, then you think about it as being a bit lighter. Does that make sense?

**I:** It does, yeah, thank you, and I can see P3 put a thumbs up there. P1, did you have something to say about that?

**P1:** Yeah, this discussion on positive outlooks, it actually reminded me of two, maybe I had more occasions but two particular occasions where I had positive experiences of tinnitus. One was a friend suggesting that since your tinnitus is constant, maybe you can use it as a tuning fork to have relative pitch and everything. But I’m nearly tone deaf so it’s not a very good use for me. The other one was when I was in anechoic chamber, and just for those that don’t know, anechoic chamber is a test laboratory essentially where there’s absence of all external sound and there’s no reflections, and generally it feels quite odd and a lot of people feel very uncomfortable in there and there’s actually usually a cord to be used as a panic button if someone feels disoriented. And I actually thought it was a quite interesting experience because I had just a nice drone of my tinnitus accompanying me and sort of reassuring me that everything is normal, everything is OK. So, yeah, it was actually a very positive experience and so this, I’m trying to think of more and hopefully more positive experiences will come up, but I really like P5’s outlook that, yeah, just look at it in a positive way and it shouldn’t be all doom and gloom. That just makes me think that maybe you should look at it positively more.

**I:** P2, did you have something to say?

**P2:** Yes, I can’t remember whether this was my definition or not, but when the tinnitus is tuneable then it makes hearing exams a fucking nightmare because you can tune your tinnitus to the tone that is coming and you have no clue if your head is singing it or it’s the thing that you’re meant to make the button. It’s a nightmare, but I’ve only just remembered that.

**I:** Yeah, thanks P2, so adapting yourself to the test is not an ideal response. But you know, it also shows, I think I found this word so interesting because a lot of the terms that we use to talk about tinnitus suggest it’s something that is happening to us, but there’s something here about being able to have some control or be able to have some ability to modify it that I thought was very, very interesting. And obviously that’s complicated, in the same way that being positive about tinnitus is complicated because sometimes P3, as you said earlier, being able to say to those close to us, ‘Actually, this is where things are really intense for me’, is also important, so yeah. And hopefully these words captured that complexity in some way.

P5, did you have something else to say there, sorry?

**P5:** Something that you said triggered this, somebody told me that I couldn’t have tinnitus because I hadn’t mentioned ringing bells so therefore I couldn’t have it, and it was like, just leave.

**I:** P2, was that sign of agreement there?

**P2:** No, that was that’s really, really funny and I went to a, diagnosed with tinnitus or whatever, but I went to something at the hospital where some person was explaining tinnitus to people who had various different types of tinnitus and saying words that didn’t mean anything to all of us, but some of the words meant some things to some of us. So, the kind of bells, ‘You’ve all got bells, haven’t you, have you got bells?’ No, somebody’s got tuning forks, and you’ve got an aura, have you got an aura? That’s lovely, isn’t it. It’s kind of how difficult for practitioners to help us understand what’s happening and therefore help us understand what’s relevant for us, then just like those with children where they’ve got smiley, where are you on the smiley thing, rather than saying, ‘Is it bad?’, they say, ‘Where are you?’ So, the child can choose an emoji that looks like they feel. That bells thing was quite funny.

**I:** Yes, I don’t know if it helps to know but one of the things that we have found with the various responses is that not everyone is hearing ringing in the ears, or not everyone is experiencing tinnitus like that, and hopefully that’s something that is quite clear from some of the next exercises that we’re going to look at. So, thank you, P5, that gives me a nice segue into …

**P5:** Nobody drew any bells. None of us drew any bells, did we?

**I:** No. No, actually bells have been surprisingly absent, I would say. Right, we’ll see if this can move forward. OK, so there’s a couple of images here for you to have a look at that we got in response to the keeping score activity. So, there’s this one, and again, some of these may or may not be by people in this group.

**P4:** It just reminds me of the word thief that was in the list. So, I sort of assume that is sort of from the same person.

**I:** Yeah, the letters look like an S and maybe a C as well, to me. And there’s a P in there as well. Sorry, you now all get to see my leaning towards my screen while I try and look at the image closer. And then we also had this one which is again quite different in approach. I should say as well, for those who sent in a sonic response to this exercise, thank you so much for those. For various reasons we are not playing the sound responses, you’re very welcome to talk about your experience of recording but there are lots of reasons why we’re not playing the sound responses, one is logistical, because Zoom is not great at playing audio back, but the other is of course we have aural diverse participants in these workshops and so we’ve chosen to go with the visual scores. But hopefully if you did an audio recording and you have some reflections on that, you’re very, very welcome to share those as well. And the same goes for the next exercise.

So, yeah, P3, did you want to say something?

**P3:** I did make a recording and I found it really helpful, I felt in a way it helped me own my tinnitus, trying to replicate it and trying to find a creative way to recreate that sound when I had limited things around me, you know, like a pot of pens or a desk, I didn’t have a lot of equipment around so I was forced to really be quite creative. And when I played it back, I was surprised by how accurately I’d managed to represent what I hear. And again, I think it could be a really useful experience for people who maybe don’t hear it so frequently as the people in this workshop, maybe it’s a very intermittent thing for people, and for them to understand that actually, I could have almost a constant, I tried to make the noise that’s almost constant because that’s the one that is the most probably distracting. So, yeah, I found that really helpful.

**I:** Thank you, P3, and again that’s really useful to hear that that was helpful for you. Did anyone else have anything they wanted to say? P2?

**P:2** I did the recording thing and the thing I found interesting about that is I gave up trying to create all of the tones at one go and gave bits of the recording to parts and types of the sound that came out. And it was quite cathartic to recreate.

**I:** Thank you, P2. P4?

**P4:** Also about the recording process, I also chose to record and by accident the limit of my own breathing capacity forced me to have a stuttering constant speech, which is also the way that maybe half of the time my tinnitus is, so it’s not perfectly constant but it does some micro pauses. It’s like a beeping sound, if you want. And the first thing to hold the constant tone for a while but not being able to because of your breath sort of mimicked also this part.

**I:** Brilliant, thank you. That’s so interesting that by making it with your own voice it perhaps got to something about what your tinnitus sounds like that you might not have been expecting. Yeah, thank you. I’ll talk about this a bit more at the end in terms of what we are hoping to do with these responses, because if people consent and are happy to, it would be really nice to share some of the audio recordings that we’ve got, but I’ll come back to that at the end and we can talk about that. I’m interested, so obviously with both these last two exercises the instructions say, should you have chosen to follow them, that you should aim for a creative interpretation rather than accurate representation of what your tinnitus sounds like, and I’d be interested to know if anyone has any thoughts on that way of approaching tinnitus, rather than we discussed the audiologist experience and P2 discussed the problems of being able to tune yourself to the different frequencies that you are played. So, rather than just playing a set of frequencies or a set of sounds, sign tones or things like that, is there something different about this approach that you think is noticeable, is that a problem, I’d be interested to know your thoughts on that.

**P2:** Making my own sounds, it doesn’t matter whether I can hear them or not, it’s how they feel for me producing them and the tone at which I produce them which is the important thing. I don’t care how you hear it, I care how it feels to be there and creating. Look, that’s better, isn’t it, be there and creating the feeling and the sound. So, the tone for me, I don’t know whether it’s an accurate representation of my tinnitus because my hearing isn’t very good around intensity and depth, certainly in some frequencies, but it’s how it feels which was true for me. But we could do an expressive dance, that was really quite useful for me.

**I:** Thank you, and yeah, I should say as well, at some point it would be really nice to make some of these activities more widely available, but you’re very welcome to use these as a basis for your own experimentations now that we’ve shared them with you, and we’d love to hear how you get on with that as well, so thank you, P2, and that’s really, really useful to hear how you were approaching that exercise and how you were thinking about it.

P5, would you like to say something?

**P5:** Can I explain why I didn’t do it?

**I:** Yes, yeah, of course.

**P5:** Because you said that we could pick and choose and didn’t have to do all of them, and my intention was to do all of them but I didn’t want to make the sound for me to be able to hear it because I hear it already, so I didn’t want to focus on, not to make it perfect but just to hear something back. I’d much rather dance it or draw it, I chose I didn’t want to focus on how I would represent the sound, either on, like I love this one that’s on the screen at the moment and I’ve created the sound by saying it. But having listened to p3 talking about how she used all the different things, maybe I’ll have a go, but I decided to step back from that one.

**I:** Thank you, P5. And I should say the reason that we gave a selection of activities is that we knew that not every activity would be right for everyone, and we knew that there are different ways that people might want to approach this, so that’s very useful to hear why you chose not to do it, and yeah, that’s quite helpful for us to know. It’s interesting to hear as well about now that you’ve seen other people’s responses, you might have a different way of approaching that activity.

I guess one of the things I’d like to flag up for discussing at the end is one of the themes that I’m noticing coming out between your discussion, P5, and P2 what you were saying and P3 what you were saying, is about who these responses are for, because obviously we are sharing things that you have created now with an audience, and are these activities for us, individuals, people with tinnitus? Is the process of making for us or is it about expressing something to someone else? If so, who is that someone else? Or is it both of those things at once? So, I’m just going to flag that as something we might want to come back to at the end because it’s something that keeps cropping up in some of the conversations.

P2, did you want to say something?

**P2:** I was preparing my description but I found these exercises increasingly frustrating because it was resonating, well yeah, it was bringing it bloody back, wasn’t it. And I needed to remember that other people that this might help in the future and therefore I needed to get through it in order to donate my experience to the research. And I realised that if I had reframed that in a way of thinking actually, finding that thing or writing, some of the exercises which I found personally liberating or understanding then yeah, that would have been a different experience for me in taking part in this research, if I had allowed myself to believe that it would be a positive thing for me to do in my experience of tinnitus rather than a research activity. So, that’s just a thought.

**I:** Thank you, P2, that’s really interesting and yeah, it’s really useful to hear how people have come to these activities and what they have been thinking when they have approached them, so yes, thank you.

I’m again very mindful of time so I’m going to push onto the final activity, which again we haven’t shared the sound recordings of this, so this was the capturing sound activity. Please move forward. Right, OK, so I’m going to share some of the written or visual responses that we had to this activity, maybe sometime today. Or maybe not. Come on. OK, so we’ve got a couple of different responses here, on the left we have a description of masking, soothing sounds, sounds that tinnitus is like, sounds that are unlikeable, is that a word, we’ll go for it, unlikeable in relation to tinnitus, and then we have some descriptions of feelings or qualities of sound that are either pleasant or unpleasant. And we’ve got quite a different approach here on the right as well, that hopefully you can see, a more cartoon style drawing. And then we had this submission as well. So yeah, I’d welcome any thoughts that you have on this activity and the responses or your own experiences of participating.

**P: A quick one from me. I really get this one, this one I get it, or it resonates for me.**

**I:** So the image of the lights? P1, what were you going to say?

**P1:** I also identify with this so much and once I tried to make a parallel between my tinnitus with say violin sounds or mosquito buzzing, but I find more and more that sort of industrial noise is something I identify a lot more, because a violin sound is something that can be beautiful within the context of an orchestra, or a mosquito, well it’s just a mosquito, it can’t do anything different. But I think machines, they’re always associated with noise, something unwanted, like a by-product of the operation, and so I always identify with this, with maybe water pipes in an old house or the hum of an engine room in a ship. Yeah, I just really identify with this image.

**I:** Thanks so much, P1, and that description of by product, sound as by-product is really interesting. P5, did you want to say something?

**P5:** This picture that you have up at the moment, for me it resonates either as a masking background sound because the hum of those lights might just be what did it for that moment, if I was busy concentrating, to cancel, that I’d be focusing on that rather than, so that could be pleasant, but equally it could be completely unpleasant if it just happened to hit the tone that brought my tinnitus more out if I was a little bit stressed about the work I was doing. So, it could be either or. And I love the cartoony one, I love the way the bubbles coming out and all part of the man’s head.

**I:** Thanks, P5. Again, I think the point here about we don’t know with this image because I haven’t given it any context, as to whether or not this is an image because it masks tinnitus or if it’s an image that’s like tinnitus. And P5, I think you’ve really captured there the difficulty in knowing the answer to that.

I’m aware that we’ve been talking for quite a long time now and we’ve got just over 10 minutes left, so I’ll invite any final thoughts on this activity, and if not we can just spend a few moments at the end talking more generally about these activities, your experiences and so on, and kind of gathering our thoughts together.

I don’t have a final slide so shall I leave this one on? Great.

**P2:** Can we go to a group view, so lose the slides so that we can see people?

**I:** Yeah, of course, that’s a good idea. There we go, thank you. And if anyone wants me to go back to anything please feel free and we can try and move between. But yeah, oh this is nice, I can now see you all together, I’ve been seeing you all in the corner of my screen.

So, yeah, thank you. You’ve now seen some of the different responses that we received to the activities, and I just welcome any thoughts that you had more generally about this kind of approach to expressing tinnitus. We’ve heard a few things about why this might be useful or different situations in which you could see particular activities being useful, but we’d really welcome any thoughts on how this approach differs to other approaches to tinnitus in explaining or understanding tinnitus, who you think might benefit from seeing or experiencing these responses, and any other thoughts you have about this.

P1?

**P1:** Something I’ve always thought is feeling guilty for my tinnitus because I always thought it was caused by being at raves from a young age and not taking care of my ears a lot. So, I’ve always, it’s just something I’ve always wondered. And I’ve been told by audiologists that no, sometimes it is genetic, and indeed my mother’s side of the family have all gone pretty much deaf after 50 years old, which I’m pretty much approaching, but I guess I don’t ask about the project because obviously it’s an exploration and maybe you don’t know what’s going to come out of it, which is normal for a research project, or maybe you do but that’s a different discussion, but it’s just maybe just more awareness, especially with younger people, about just take care of your ears because it’s something you cannot fix currently. So, maybe this project will be very useful as a platform to bring more awareness on noise induced hearing loss, noise induced tinnitus perhaps, so yeah, I think that would be a very useful social outreach.

**I:** Thanks, P1. P5 and P3, you both put your hands up what looked like at the same time, so I’m going to let you both decide who goes first.

**P3:** You go first, P5.

**P5:** Thank you. Answering that question, who for, I think this would be really good for professionals, audiologists who work with people who have tinnitus because does it not show, even just the bits that we’ve seen, the variety, the inconsistency between people with tinnitus, but also within the person with tinnitus, that it’s not just the same sound all the time, there’s so much variation. So, the more pictorial things, because don’t they say a picture tells a thousand words, because to describe is one thing but when you put it in some way pictorially, that might really help professionals to understand exactly what it is that we are hearing and living with day after day after day and for who knows how long.

I think it could also help us as an artistic, you know like you go and see your audiologist and she sends you off with a little pack that describes about how to do some creative things because that’s meditative and helpful in calming us, but also it’s a way of expressing it, because I’ve learned lots, like we’ve all talked about here, I pick up on what P1 says about educating people who don’t have tinnitus, but who knows, one day they might if X and Y happen, it could be this is what happens to people and this is what you can do to manage it and support it. And for newly diagnosed people with tinnitus, to show that everyone is really different and that what you hear is individual. So, everybody really.

**I:** Thanks P5. P3, did you want to come in?

**P3:** I think P5 has probably said everything I was going to say but much more eloquently than I could have managed. But I’m quite new to tinnitus, it’s only really become a constant companion in 2021, and I’ve had a really poor interaction with professional audiologists, and maybe it’s a personal experience, maybe there are really good audiologists out there, but the person I was referred to was like, ‘Well, we can’t really do anything about it’, they were looking for something they could physically fix, which is why they focused on my hearing loss, which is a different element of my aural experience. And I think it’s really interesting, I’ve kind of got out of this workshop a sense that in the same way there’s a spectrum of so many things we experience as human beings, that maybe if there’s a spectrum of hearing disorder, tinnitus sits upon that, and I suppose it’s that recognition, because lots of things, I think P5 picked up on stress, so stress, tiredness, business, lots of things can be triggers that make it maybe a little bit more invasive or harder to ignore or harder to just cope with, or maybe just sometimes I feel that the tinnitus is a contributing factor to me feeling more tired. And I think if there was more recognition that there is a spectrum of hearing disorder and tinnitus sits upon it, that might help people have a little bit more empathy. So, sometimes I try really hard to limit the amount of time I spend on calls like this because it does come at a cost, and it would be really helpful, I’m imagining an exhibition or something or a TV documentary or something like that might be really powerful to reach a lot of people.

**I:** Well, there’s some good news on the exhibition front. So, as part of this project we will be having an exhibition at Oxfordshire Visual Arts Development Agency, and we’ve commissioned two artists to create work about tinnitus. And it would be, so one of the things you all signed up to when you signed the consent form was that we could share example responses as part of the different parts of this project. Now, obviously these are quite personal things that you have created so we will also perhaps get in touch with you and speak with you about that, but it would be great if people are willing and are happy for us to do so, to share a selection of responses that we’ve had as part of these workshops as part of that exhibition, because I think it’s fantastic to see, certainly from my perspective, it’s fantastic to see the different kinds of responses alongside one another, there’s some really powerful individual responses, but seeing them together as well also has a power. So, yes, we will be in touch about that but just to flag that that is something that we will speak with you about at some point.

P2, feel free to jump in.

**P2:** I’m going to concur with P3 around P5 eloquency. And I would also say just use it like the RNID campaign that I mentioned earlier, seeing how other people express how they experience it helps me express more easily and eloquently with other people how I experience it, which helps them, it enriches their understanding within a broader educational context, yada yada yada, what tinnitus is outside from hearing loss, and P3’s hearing loss, so I think that breadth of something is useful in a way that various different experiences of neuro diversity, certainly within the world’s that I work in, it’s easier to talk about different ways that people perceive things and act and learn within an umbrella of neuro diversities, and similarly within an aural framework, how you pronounce it I never know, thank you very much, I lip read, thank you P5, the place that this creation, which is happening somewhere in here, to me and me only, and the way that that’s expressed was a good thing. I lost it there, sorry.

**P5:**  When you talked about having an artist represent something, there is a pit in the bottom of my stomach because I was thinking, oh, so an artist is going to read about something and decide what they think it is, which is probably not at all what you were saying, but then when you backed it up with some of the representations from your study from people who are experiencing tinnitus, then that stone just pinged away, disappeared.

**I:** Thanks P5, yes, and this is something that Patrick and I have been thinking a lot about. And I don’t know if it helps to know but both the artists that have been commissioned themselves have experiences of tinnitus.

**P5:** OK, the stone is completely not there then. This conversation has gone about how, like if you’ve got two artists, what does the phrase go, if you’ve met one person with tinnitus, you’ve met one person with tinnitus, and this is just so incredibly different.

**I:** Yes, and that’s the huge, the big challenge of this project is that there is such a huge range of experiences of tinnitus, and P2 I’ve just seen you there saying it’s a requirement that they have tinnitus that’s not nice to have, and I guess one of the challenges is how do we include people whose tinnitus is really difficult for them and is intrusive and hard to live with, alongside people whose tinnitus is not something that they experience as particularly impactful on their day to day life. And P5, I think you’ve put it really beautifully, if you meet one person with tinnitus, you’ve met one person with tinnitus, and how do you draw generalisations out from that. So, thank you, that’s really, really useful to hear.

I am mindful that we are now one minute over, so thank you very much for all of your contributions, thank you, it’s been a real pleasure talking with you all. I’m sure you love getting emails from me, big on the emails, you’ll be getting an email from us shortly, there’s an evaluation survey that we will be asking that you consider filling out, and we will also be in touch about the small token of appreciation, the £20 gift card that you’ll be receiving from us. So, yes, please do keep an eye out for that from us. I just laughed and Spotify thought I was playing music, so I don’t know what that says about me. Thank you so much for your time everyone, I hope you have a lovely rest of your Saturday and yes, we’ll be in touch shortly but thank you once again for all of your contributions, it’s hugely appreciated. Bye.

**<End of recording>**