**File: OU Marie Thompson – Wednesday workshop 1hr47 6 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:** Hello everyone and thank you so much for joining us on this Wednesday afternoon for the discussion part of our tinnitus and the arts workshop. We’re really grateful for your participation, for the fantastic responses that you sent to the activities, and for the time that you’re giving us today. What we’ll do is we’ll begin by doing some introductions, so I’ll explain who I am and who the rest of the team are and what we’ll be doing today on Zoom. Then if it’s OK with all of you, if you’d be happy to just say who you are and where you’re zooming in from. Then we will get started with discussing the activities that you have participated in and we will be looking at some of the responses to those activities together.

OK, so just to begin the introductions, I’m Marie Thompson, I’m a lecturer at the Open University and I’m the project lead for this project called Tinnitus, Auditory Knowledge and the Arts, and these workshops are part of that project. And I’m currently zooming in from Nottingham. I will be doing much of the talking today, I’ll be leading you through the different activities and the different responses that we’ve had.

If I can now pass over to Patrick, if you’re willing to say hello?

**I2:** Hi everyone, it’s nice to meet you. Yeah, my name’s Patrick, I’m the co-lead on this tinnitus project, I lecture at Oxford Brookes and I’m currently based in Sheffield. And today I’m primarily going to be managing the chat function if anyone wishes to communicate that way, so I’ll just pass over to Sally.

**I3:** Thanks Patrick and Marie, it’s lovely to meet you all, I’m Sally, I’m a researcher at the Open University and I’m zooming in from Warrington. I’m here to look after the tech side and also provide support if you need me, so you can contact me via chat or via email on the tinnitus website and I’ll also add my email address into the chat as well. Thank you.

**[participant introductions]**

**I:** Wow, I think this might be the largest geographic spread that we’ve had for the workshop discussions so far, so thank you everyone, it’s really lovely to meet you all. I’m now going to pass over to Sally briefly to load some slides, so the screen will change and you will start seeing a PowerPoint, hopefully. If you are wanting to be able to see the speaker’s face most clearly, so whoever is talking, if you would like to have the focus on their face, there are lots of different, well I say lots of different options, there are three different options on Zoom to arrange the view of people’s cameras. At the moment you can either have gallery view or speaker view, I currently have you all on gallery view so I can see all of you together, but if you want to change your screen to speaker view so you can see whoever is talking, in the top right hand corner you are able to change that.

So, I’m just going to stop talking momentarily, Sally would you mind sharing the slides please? Brilliant, thank you.

So, today’s session, the discussion part of the workshop, is an opportunity to reflect on the different activities that you’ve taken part in and what it was like to participate in them, and we welcome various bits of feedback, we don’t have any expectation as to what you’re going to say, so all comments are welcome in that regard. And we’re also going to spend a bit of time looking at different people’s responses to the activities. And we’re interested in how these responses relate to, capture or express something about experiences of tinnitus. So, Sally, can I get you to go to the next slide please?

We’ve got a few discussion guidelines that hopefully will help keep us on track, but also give you a sense of how you can participate and what options are available to you in terms of the session and how to interact. So, the first thing that we like to flag up is that tinnitus, as I’m sure many of you are aware, can be a sensitive topic for discussion and you are welcome to take some time out of the session or leave if you need to, and I’ll come onto how you can do that shortly.

As a part of the workshop discussion we’ll be looking at some responses that have been created by different people in this group. Our discussion should be focused on the process of making and how these responses reflect or relate to experiences of tinnitus, so please be considerate of others when discussing their work.

We’re going to be sharing responses to the activities anonymously, but you are very welcome to identify yourself as the creator and comment on your own activity response. So, if you would like to say, ‘This is mine, I did this and this was the approach that I took, this is why this is like this’, then you are more than welcome to do that. However, we are not going to be naming names and saying who has done what unless they want to tell the rest of the group it’s theirs. I should say as well, due to time restrictions we are not going to be sharing every response that we got to each activity, but everyone will be represented at some point within the activity responses that we share.

We know that tinnitus can affect people in different ways and I’m sure that that will be the subject of a lot of our discussions today, so please keep in mind that others might have experiences that are different to your own.

Can I go to the next slide please Sally? Some of us are using Zoom’s auto captioning or live transcript function. This works best when one person is speaking at a time and there is limited background noise. Please can you make sure your microphone is muted when you are not speaking and try to avoid talking over others. We know this is sometimes difficult when you’re having conversations, but if we can try and be conscious of the mute function, that would be great. With that in mind, silences, or relative silences, I should say, are OK. We know that people might need a bit of time to think and respond so please don’t worry if nobody is saying anything. And finally, we’ll be having a 15 minute break halfway through the session, likely at 4:55pm. If you need to take some time out from the session either before or after this, you’re welcome to leave at any time. If you want to re-join, you can click the Zoom link that was shared with you and that will allow you back into the session. If you feel like you need someone to talk to during the session, please send a private message using the chat function to Sally.

OK, so those are the discussion guidelines. I know that’s quite a lot of information to take in. If something is not clear, feel free to ask in the break or feel free to ask now if anyone has any questions? No? One thing I forgot to mention is that should you want to insert yourself into a conversation but are finding it hard to do so, because Zoom can make conversations a bit tricky sometimes, you can either physically wave at us, you can put your hand up and say, ‘I would like to say something now’, or there’s a reaction option in the bottom right hand corner of the screen, there’s a reactions button with a smiley emoji, that allows you to press the raise hand option and that will tell us that you’re wanting to say something in response. So, if you’re finding it difficult to get yourself into that conversation, feel free to either wave or use the reaction function.

OK, thank you everyone for listening. We’ll now pass over to be looking at the activities, so Sally, can I get you to press the slide. So, the first activity that some of you took part in and that all of you will have seen is the tinnitus maps activity which got you to identify different places or spaces and their relationship to your tinnitus.

I’d like to start by just offering you the chance to offer any reflections on this activity, what it was like to do this activity, if you didn’t do this activity, why you didn’t do this activity. Any thoughts you have really about this activity and the process of reflecting or responding to your tinnitus in this way would be great.

**P1:** Is it OK to just speak out? OK, I didn’t take part in this particular activity, although I think I did the rest, because personally for me it didn’t have any real relevance. And for me, tinnitus doesn’t appear in a particular place, for me it appears in a state of mind. And the only rough relevance to mapping would be in a noisy place or a quiet place where a noisy place masks it to an extent and a quiet place allows it to completely come out to the fore. So, apologies for not doing it but it would have been a very artificial activity for me to have conjured up a map when for me it’s meaningless. But I’m very interested to hear from the others who have tinnitus if it is something that is relevant to them. Thank you.

**I:** Yeah, thanks so much, P1. Just to interject there, please don’t feel like you need to apologise for not doing an activity. We know that different activities work better or less well for different people, so there is no obligation to do all of the activities, but I’d be really interested to hear more from you perhaps once we’ve seen other people’s responses as well and how you think about that activity then. So, thank you P1 for your reflections, that’s much appreciated.

**P2:** Hi, I think I agree with P1 to some degree, that I couldn’t really geographically locate except to do with barriers to sound, so my map just became where I typically hear sound and don’t hear sound. So, it sort of reflects what she was saying but I tried to make a map of that but without the real geography there, I think.

**I:** Yeah, so P2, did you find it quite challenging to identify places beyond this is a space where there’s sound or this is a space where it’s quiet?

**P2:** Yes, yes, I couldn’t really extract anything more geographical out of it. It was almost more to do with the time of the day, the different tasks that you do at the time of the day mapped onto a cycle rather than a landscape.

**I:** Great, thank you, yeah. Does anyone else have anything they wanted to say in response to this?

**P3:** I didn’t draw a map but I actually put images of places and the effect that tinnitus has on those.

**I:** Great, so P3, you could identify places that had a relationship to your tinnitus in some way, is that correct?

**P3:** Yeah.

**I:** Great, thank you. Maybe if we now move to look at some of the responses that we received. So, there are three responses we’d like to share with you. What we can do is just spend a bit of time not saying anything and just having a look at these together, although feel free if there’s something that jumps out at you, feel free to offer it to the group. But if we have a look at these three and then maybe if we have a chat about the approach that’s been taken, what you notice about these maps, what you think they do and don’t capture about tinnitus, that would be great. So, this is the first. P5?

**P4:** Yes, OK. Again, I had the problem with the space and the time, so this is really a cycle of the day and the places at different times of the day. And probably because my tinnitus is pulsatile, that affects the noise and it mightn’t be the same for other people. But yes, I had this problem with the map, the place, the time, so I’ve done it like a clock.

**I:** Great, thanks P4. So, you found a solution to the limitation of representing things only in terms of place, so you have a map that is both space and time, which is great.

**P4:** Yes, and the time does affect the place and the volume of the tinnitus, the time of the day.

**I:** Thank you. Does anyone want to add any comments on that before we look at the next two? OK, well maybe if we go to the next one, because there’s an interesting similarity with this person’s map as well and that they are combining space and time as well.

**P2:** So, P4, similar, this is my map and the not being able to find the geography, so I’ve sort of mapped it as the cycle of the day that the things that you do and the different things that affect it and what noise that I manage to extract and where it’s good and where it’s bad.

**I:** Great, thank you, thank you P2. And shall we go to the third piece, Sally? So, we’ve got quite a different approach taken here.

**P5:** So, this is mine. I’m not an artist so I relied very much on my computer to do it all, as you can tell by the great clip art. I work with a hearing therapist, have done for a few years now, for my tinnitus, and I’ve identified lots of places there are either triggers or good places, so in the top I’ve got outdoor swimming is a great thing, and then at the bottom road noise is a bad thing, and I’ve kind of done it as an increase in, the yellow arrow represents just the tinnitus getting bigger and growing as negative things happen, so red is in the middle.

**I:** Thanks so much, P5. Can I ask what the birds represent?

**P5:** It is literally birds. I’ve got a small garden but I’ve been feeding the birds for years and nurturing them and I have a rather full garden of birds. But they not only mask my tinnitus in the sounds there but they also calm me, so it’s two sided thing with them.

**I:** Thank you. So, P5, for you, thinking about the relationship between tinnitus and different places is something that you’ve done before, is that correct?

**P5:** Yeah, yeah, I think it’s, so my tinnitus, I use it as kind of a barometer of my stress, so I know that if I’m stressed my tinnitus tells me, it tells me first before I know most of the time. And I’ve identified places where I don’t get so stressed and that’s where I know my tinnitus will be lower as well.

**I:** Great, thank you. I’d like to invite anyone who would like to comment on the different approaches that have been taken here, how tinnitus is represented in these maps, any thoughts that you have about that, and how you are perceiving these maps and how you are thinking about tinnitus through these amps. Any thoughts around that would be very welcome.

**P:** Just to go along with this person’s picture, the other place that I find relief from the tinnitus is also swimming, even though there’s not necessarily much other noise there, for some reason it sort of, yes, it is the distractor, maybe more of a physical distractor.

**I:** Thanks P2, so swimming might be the exception in terms of the noisy and quiet places. Is swimming a place? I guess water is a place or it could be a place.

**P2:** Yes, it seems to make a difference.

**I:** Thank you. P1, were you wanting to say something?

**P1:** Yes, just going back, there were some words at the bottom of the first map about tinnitus being a physical reaction to blood pressure and increased heart rate, and something that I would note is that I do practice yoga a lot, so that can have a very good effect on my whole life and the way that I’m reconciled with my tinnitus. My tinnitus is always there, it’s just the level to which I notice it. And I say it troubles me, it doesn’t trouble me because I’m kind of over it, I’ve lived with it for 15 years and I’ve accepted it and have sort of welcomed it in. But ironically in yoga when you do the breathing, and there’s some particular breathing, I don’t know if you’re familiar with that or not, but there’s one that’s called breath of fire, which is a very vigorous form of breathing where it’s a very strong exhale and a passive inhale, blimey that doesn’t half set it off. And so, when I’ve done that my whole head is really going for it, and yeah, at first I thought, well perhaps I shouldn’t do this anymore because maybe it’s a bad thing, but I’m just reading that thing about blood pressure and increased heart rate and thinking, well maybe the breathing like that is a physical thing that’s making the tinnitus sound louder and maybe it’s that that’s doing it. So, yeah, that’s just an observation really around one activity.

**I:** Yeah, so it’s making you ask questions about your own experiences, seeing someone else’s experiences represented in this way?

**P1:** Yes, because I’ve never really thought about there being a physical cause or an accelerator for it, if you like, I haven’t really thought about that until I read those sentences at the bottom of that particular map, and yeah, that’s just interesting. It kind of fits in with something that more recently I was wondering about. I don’t think for me it’s the cause but I can see how maybe heart rate or blood pressure or something, something that you do that gets it going faster or you know, increases your blood pressure, maybe that intensifies the effect of the tinnitus.

**I:** Thank you. P6, were you wanting to say something?

**P6:** Yeah, I also do yoga, and so obviously when I do meditation it’s really quiet and I don’t even notice my tinnitus then, so I find that if I am concentrating on something else, I can manage to manage it. But my tinnitus is when I’m thinking about it, lying in bed maybe and I just can’t get to sleep or something like that, or I think about it and then I can hear it, and I think, is it bad today or is it quieter today? So, it really is just when I’m thinking about, it’s not a big deal, so I do manage it as well, but it would be quite nice if it wasn’t there, obviously. But yeah, I find the yoga is very helpful.

**I:** Can I just ask, having seen these different maps now and different people’s approaches to this activity, bearing in mind this is a small selection of the responses we received, has anyone thought, oh, I might have approached my map differently having seen these, or there’s things I would want to include in my own map now, or oh, I wonder about doing this, if I was to do this activity again, maybe I’d do this. Yeah, I’d welcome any thoughts around that.

P6?

**P6:** Yeah, when I came across this exercise I really didn’t know what to do, to be honest, because it’s not, I just didn’t know, when it happens, it happens, whether I’m out and it’s quiet or indoors and it’s quiet, so I didn’t really know how to approach it. So, having looked at these now I think I probably would approach it in a different way. But basically, it’s when it’s quiet I hear it, and if I’m concentrating I can manage for it to go away. And if it’s noisy outside or inside, I don’t hear it.

**I:** Thanks P6. Did anyone else have any thoughts on whether they would do this activity the same or differently or if they’d identify different things, or whether they’d want to have a go at it now? P5, hi.

**P5:** I really like the one we’re looking at now, I’d find this to be really useful to do in the future. I just like the idea of working through the day and identifying different bits and pieces because I think I’ve identified big activities in my life but not necessarily everyday things that I do, and so this actually, yeah, this is a great way of doing it and I think this is something I will take from this and go and try and do myself.

**I:** Thanks, and just representing it visually, because obviously you could potentially write it as a list and that would be a reasonable approach to take as well, does representing it visually or spatially on a page, because your map has very much a sense of direction, do you think that’s useful for thinking about your tinnitus and your experience of it?

**P5:** Yeah, I think it is, I think I write about tinnitus a lot so that’s something I do every day but having to visualise my tinnitus and put it into pictures was a very different thing ,and I like the idea of the different colours on this one and the different sizes and yeah, it just brings home different parts of the day. And I like the next one as well with the different, how squiggly the lines were or what the, which I assume is the tinnitus, and the different effects through the day, I think that shows tinnitus more than words can, or to me at least.

**I:** Great, thank you P5. Great, thank you so much everyone for your comments on this first activity. We’ll now move over to the second activity which was the tinnitus portraits. So, we’ll be sharing these in a moment, but much like the first activity, I’d welcome if anyone has any thoughts on what it was like to take part in this activity, this was an activity where we asked you to locate where you heard your tinnitus in your head by drawing yourself and placing your tinnitus on it, or in the different places that your tinnitus appears. Sorry, I’m doing a lot of gestures to try and explain this activity. So, yeah, firstly we’d welcome any thoughts on whether or not this was an activity that you found productive, whether it was easy to participate in, whether it was difficult, what you found difficult about it, yeah, any reflections would be welcome.

**P1:** Yeah, I can say I found, this was obviously the first one I did, from here on in, I decided to do all of the activities in one day, and it was actually, nightmare is a bit strong but I actually had to invite the tinnitus in, and so, like now, talking about it my noise is ringing, hissing, it’s really going for it. And to be able to portray it you had to allow it to come to the fore, so that was challenging but it was also interesting because it makes you actually stop and think. Instead of it just being a noise, to actually think about well, where is it. And for me it was the realisation that the left ear, which is where it all started, where I suddenly lost my hearing, now I’ve got age related hearing loss in my right ear, but it’s got a little friend come to join it, a smaller version, son of tinnitus or whatever you want to call it. But yeah, so it was very interesting because if I hadn’t have done that exercise I wouldn’t really have thought about it as much as I did, because as probably others have already said, you can quell it and so, here we’re actually being asked to do the complete opposite of that, almost to bring up the whole orchestra. So, yeah, pretty challenging.

**I:** Yeah, thanks so much P1. I’d be interested to know if others had similar thoughts. P3, I couldn’t tell if that was an applause or a hands up, so feel free.

**P3:** A hands up really. I found this an easy one to do because my tinnitus is quite well defined, it’s almost entirely in one ear, which I’m quite deaf in as well, but I know that I’ve got problems if I start getting tinnitus in my right ear, because it means that I’m not very far away from an episode of Meniere’s disease, which I suffer from, which for those of you that don’t know it, it’s an inner ear problem which causes nausea, loss of balance and so on. And I control that by drugs, very successfully, I very rarely have an attack. And I fortunately always get warning of the attacks so that it doesn’t affect me with driving or doing anything with machinery. But I do find that I never let tinnitus stop me from doing anything, I’m not going to give into it in any way. It’s not a major issue, I know how to handle it, so it was an easy one to draw, helped by having a very good cartoon portrait of me drawn many, many years ago to save me having to draw myself.

**I:** Thanks so much, P3. Yeah, it’s really useful to hear about your experience and how it might be similar or different to other people’s experience as well. Shall we have a look at the portraits together? So, the way in which I’ve been describing this to other groups, this is not a comment on the quality of the drawings, quite the contrary, but it’s a bit like if you’ve ever seen those school tea towels where everyone’s done their own self portrait, it’s a bit like that, but with tinnitus. So, we’ve got them all on one page, so we’ll allow you to have a few moments just to have a look at these portraits together, and then we can have a conversation about what you notice about them, what you find striking about them, and go from there.

So, Sally, can I get you to go to the next slide. If anyone wants me to try and read out any of the writing, by the way, I’m very happy to do that.

**P1:** Yes please, I’m struggling.

**I:** It’s OK. Is there one in particular that you would like me to read out or just all of them?

**P1:** It’s the one that’s typed, I can’t make that out.

**I:** That’s alright, that’s also a challenge for me. So, it says right ear: if tinnitus is heard it’s a signal that I might be about to have an attack of Meniere’s disease. Time to take anti-nausea drugs and hope that it goes away. Sorry everyone, if you’re looking at me on the camera you get to see me very close up at the moment. And the other side says, left ear, sound varies if it gets very loud, and now the subtitles are over it so I’m just going to move those out the way. I should say as well, if you’re using live transcripts and you’re wanting to arrange your screen you can drag and drop the subtitles. It gets very loud and I lose hearing, there may be problems ahead. Sound is like a ball around the ear and radiating out from it. Hold on. I’m not sure if I read ball or bell.

**P3:** Should be ball.

**I:** Ball, thank you, P3.

**P3:** That portrait was drawn over 35 years ago.

**I:** I’d say it’s still quite recognisable. This is the hard activity to share anonymously, I should have said as well at the start.

**P3:** It was my degree show portrait.

**I:** So P3, if you don’t mind me asking, you’ve taken an older picture of yourself and added tinnitus to it. Was that something that was intentional or was that just a strategic choice because of what was available?

**P3:** It was just an image of me that I knew, I knew where to find it without searching through photographs and the like.

**I:** Thank you. So, yeah, I’d be interested to know now you’ve had a bit of a look at these fantastic tinnitus portraits, what impression of tinnitus you get or what are some of the conclusions about tinnitus you might draw from seeing these portraits together?

**P1:** It looks like a lot of us have got a shared experience of having a louder side of tinnitus and a small amount on the other side. I’m not sure about the one that I’m looking top right on the spiral bound notebook, that looks to have a different sort of pattern to it, but the others seem to be more on one side.

**I:** P4, were you wanting to say something?

**P4:** Yeah, there are two groups, those that have tinnitus defined inside the head and those that have it outside, which is an interesting difference.

**I:** Yeah, thanks P4. So, there are some people who have identified it as being inside themselves and those who position it outside. Yeah, thank you. P2, were you wanting to say something?

**P2:** Yeah, I think I was surprised that it was as much outside as inside, and I’d never really thought about it before because obviously I know it’s not outside but it actually sounds like a sound rather than a figment of the brain’s imagination. So, there wasn’t very much an external resonance there as well, and I’d never even considered that as a thing.

**I:** Thanks P2. If someone didn’t have tinnitus, hypothetically, what impression of tinnitus do you think they might get from these portraits?

**P2:** It’s quite annoying.

**I:** What makes you say that?

**P2:** I think quite a few of us have chosen to use red, which I think is a bit of a warning sign, it’s a high blood pressure sort of tension thing. And it’s inescapable, isn’t it, you can close your eyes and not see something, you can’t close your ears.

**P1:** I think possibly mine is the only one that doesn’t look quite as angry, and mine’s the one with the blue fizz going round it, and I chose that colour because I wouldn’t choose to have it but I’ve learned not to hate it, and it lives outside my head and I just consider almost like an aura that follows me around. And yeah, you could almost put the analogy of when you’ve got a child and they’re a toddler, they can be a bit annoying but you wouldn’t be without them, and they’re there. It’s part of me but I don’t feel it’s living inside my head, I feel it’s just there, on the periphery. But like I say, I prefer not to think of it in a really negative way because otherwise I can’t live with it if I do that, it’s distressing to think of it in a really angry way, for me anyway.

**I:** So, looking at these together, it might be that someone gets these different emotional, because you’ve chosen a different colour, it might be that if we think of the relationship between colour and emotion, some of you have picked up on the relationship between red and irritation or warning, someone without tinnitus might get the sense that there are different ways that people feel towards their tinnitus from these perhaps, do you think?

I was interested, there’s an interesting circular theme going on in a couple of these. So, P3, you described the sound as being like a ball, and you’ll forgive me for the confusion with bell, you can understand why I might have gone for that word given how tinnitus is often spoken about. And then this one in the top right hand corner talks about tinnitus, experiencing it as circulating as well, so there’s something interesting about roundness I guess that I don’t think I’d come across in some of these responses before. I found that quite interesting.

**P4:** Yeah, the spiral one, yeah, for me the tinnitus is almost like electrons sort of firing around and they just circulate around my head just constantly, but they’re inside and it’s that idea that it’s not originating from one ear, I find it’s just in there. They don’t stay still.

**I:** So, for you P4 that movement is really key for it and I imagine you’ve said that you have pulsatile tinnitus so it’s not a constant tone, there is some movement in that sound.

**P4:** There’s some movement, there’s the heartbeat, the pulse is in the tinnitus.

**I:** Right, so yeah, your experience might be different to others in that regard.

**P4:** Yeah.

**I:** Was there anything that you found particularly, P1, you said that letting tinnitus come to the fore was interesting but it’s also something that’s quite challenging about doing this kind of activity, was there anything else that people found challenging in doing this activity? Or having seen other people’s responses and seeing your own response amongst them, does anyone have any thoughts on what it’s like to see yourself as part of a group of portraits? Does that change the way you feel towards your own portrait at all? P6?

**P6:** Yeah, it’s just interesting to see the portraits because I didn’t realise that the tinnitus could buzz around somebody’s head in a circular movement because for me it’s just basically one ear, definitely inside my head, so it’s interesting to see how other people have, what sort of type of noise they have and also where it is, and the fact it can be outside as well as inside is just amazing, I did not realise that.

**I:** Thank you, P6. Patrick has asked a question on the chat and I think this might be something that’s come up previously for us. If anyone had found that on trying to find where their tinnitus is or where they’re hearing it or where they experience that sensation, and trying to draw it, that it seems to shift in location.

**P1:** No, sorry Patrick, not for me. I could move my head and it would be kind of like, if you said like a little swarm of bees, if you imagine they kind of would move with it, but there’s that and there’s a small little cluster here. But for me, it’s not going around the head, it’s not going through it, it’s just always hovering around in the same place. But that’s me and everyone, I think, is different.

**I:** Thanks P1. OK, I’m mindful of time. I’m a bit of a militant timekeeper because I want us to have our 15 minute break and I want to get through everything, so I’m going to suggest we move onto the next activity which was the tinnitus drawing. So, again, to begin with, to get us started I’d welcome any thoughts anyone had about this activity, if its one that you did, what was difficult or challenging and what was enjoyable about this activity, if at all. If you didn’t do it, why did you not do it? Any reflections on that we’d be happy to hear from you about.

**P2:** Is this the one that was meant to be done over a period of days?

**I:** Yeah, so three days of a short time each day drawing your tinnitus.

**P2:** So, I didn’t do this, and I think like another lady had said earlier, I did all of mine literally in one sitting, it was like an immersion event, and I thought I didn’t feel I could just go back to that day after day, it was like I was done. So, I had actually done the first day but I never sent that because I just didn’t do the rest of them. But yes, it was a little bit too much reflection I think.

**I:** Thanks, P2. Yeah, that’s an entirely reasonable response, and we know that different people have different time commitments, people have different capacities in terms of engaging with these kinds of activities, so yeah, thank you for telling us that.

**P1:** I felt P2 pretty much said exactly what I was thinking. Same thing for me. It’s not about not wanting to commit the time, it’s as they said, after going through it with all the other activities, your head’s really going for it, and I also had a bit of a think and thought, well, I looked at the examples and thought, I don’t see that mine is that different on a day by day basis that I could add anything in that way. So, I decided no.

**I:** Thanks P2. I’m wondering hypothetically, because obviously these activities were given to you in quite a compressed amount of time, whether if this was something that you did over a period of a few weeks or a longer period of time, if that might make it easier to participate in that kind of activity, or if it’s just something that because it requires a day by day drawing diary if you will of your tinnitus that it’s not something that works?

**P2:** I think from a really super practical viewpoint, I wasn’t sure that once I’d uploaded something, if I wanted to come back and upload something the next day, whether it would still be there, so I had a little bit of a panic and thought, hell I’m just going to do everything now, just in case once you press go it’s gone.

**I:** Thanks P2. Yeah, that’s one of the challenges of doing this at a distance, and I completely sympathise with you. To be honest, I was also having that worry, despite the fact that I was nominally in charge of the system, and I was hoping that people could return to their activities but you’re never quite sure. So, yeah, you have my sympathy on that but thank you.

P4, were you wanting to say something?

**P4:** Yeah, I found this the most difficult, and again it was like trying to tie down every, for me the tinnitus was very different every day, so trying to tie down, well how does this reflect a time and a period. So, yeah, if you’d specified draw for three minutes every day for four days or whatever, I would have found that easier, or draw at 9am or something, I just found this so open that you’re almost thinking, how can I do this today? What am I going to do? If that makes any sense.

**I:** Yeah, so for you more instruction, more restriction would have been useful here.

**P4:** Yes, more restriction, yeah.

**I:** Thank you. Shall we have a look at a couple of the responses to this activity? So, we’ve got one here, and this person has very helpfully provided us with lots of notes, there’s the time of day that they did the activity, that they spent five minutes on it, or three minutes then, and there’s some notes there about I’m struggling to …

**P4:** OK, so day three was more a blanket noise and that’s more the pulsating thing that I would get, so it’s in and out, that’s what that one’s about.

**I:** Thank you. I’d welcome anyone’s reflections on this, what you learn about tinnitus from this, what you feel is reflected about tinnitus in this drawing, anything else that strikes you about this.

**P5:** I’m just surprised at the variety, I don’t know if that’s a good thing or a bad thing, but mine’s quite consistent.

**I:** Shall we go onto the next drawing and maybe we can think about these side by side. So, we have this lovely drawing that was submitted that says a sound, a modulated wave form varying in intensity, and we’ve got lots of use of colour here as well.

**P6:** I really like this drawing, it almost makes it look like quite a positive experience.

**I:** I’d be interested to know what makes you say that, where that positivity or almost positivity comes from, what do you think?

**P6:** Because it’s flowing, it’s got no sharp edges, and I quite like the colour combination, they feel quite warm and complementary, there’s no spikiness there.

**I:** Yeah, thank you. P4, some of your depictions also didn’t have spikiness did they because there was a kind of whirling?

**P4:** Well, they have things firing, signals firing off, and it’s not as comforting as this. It’s like electrons firing off and there’s a sharpness to that, whereas I don’t get that with this one.

**I:** Do you think it’s worth, how do I put this? If we’re thinking about those different experiences of tinnitus then, is it worth seeing these different kinds of drawings together? Do you think we learn something by seeing them side by side or slide by slide? Or can we think, of course we can think about them individually, but I guess what I’m asking is what do we learn by seeing them together that we perhaps don’t learn from the individual drawing?

**P1:** Do you think it’s possibly people’s emotional response to their tinnitus and how they’re choosing to express it, it possibly gives us a bit of an insight into how that person’s feeling about living with tinnitus. This one, although it’s obviously drawn in a digital way, so just forgetting that for a moment, that for me almost looks like somebody is expressing it in that orchestral form that I mentioned before, where it looks like the different instruments or noises have been depicted in different ways and there’s a pattern to it. Whereas the one before, it seems a much more, I think it’s P4’s, isn’t it, but it felt to me quite painful, how she was experiencing the tinnitus in those drawings, and I could feel that more. This one, as somebody said, it’s a lovely pattern, it’s very flowing and the colours are soothing as well, whereas the one before, although it was drawn in pencil without colour, it did to me, it looked as though somebody was definitely suffering in that one, more so than this one.

**P4:** Yeah, I think we’re also trying to represent something and you sit down with a blank piece of paper and think, how on earth do I put a picture to this tinnitus? So, it’s hard to sum up, I think we need quite a number of pictures to get, as you say, put the pictures together to get more of a feeling of what tinnitus looks like. Does that make sense?

**I:** Yeah, it absolutely does, P4, thank you. So, for you, if I’m understanding correctly, you are agreeing that it’s useful to see multiple drawings together to get a sense of what tinnitus is?

**P4:** Yeah, and think, oh gosh, I could have done that, oh yes, that’s an interesting way to look at tinnitus.

**I:** Yeah, so similar to the portraits where you saw lots of different portraits together?

**P4:** Yeah, yeah.

**I:** Great, thank you. OK, I am mindful of time, we are a couple of minutes after my five to suggestion for a break, so unless anyone has any final thoughts on this, I’m going to suggest that we take a 15 minute break and we join again at 12 minutes past. We’ll be ready to start talking at 5:12pm. You’re very welcome to stay logged into Zoom, if you want to mute your microphone and leave your camera off and go and make a hot drink or get a cold drink, it’s quite warm in Nottingham, so grab some water, do whatever you need to do for the next 15 minutes and then we’ll start talking again at 12 minutes past. But thank you so much for your contributions so far, it’s been really great chatting with you all and we’ll talk about some of the other activities in the second half.

[Break]

There we go. So, Sally, would you mind going back to the slides, we’ve got three more activities to take a look at together and then hopefully we’ll have some time at the end for some more general reflections as well. So, the next activity was putting tinnitus into words. This was where we asked you to come up with some individual words for your tinnitus or related to your tinnitus in some way, and then maybe provide a definition or some definitions for those words. So, much like the previous activities, we’d welcome any thoughts that you have on this activity before we look at the responses that we’ve had.

P4, feel free.

**P4:** Yeah, I find this more difficult, putting into words, and I don’t know if anyone did the recording, I would have found that impossible to actually record the sounds. It would be interesting to know if anyone, maybe other people found that easier. I found it very difficult.

**I:** Yeah, so P4, I think that was probably for the next activity, they’re quite similar, for the keeping score activity where there was the option of recording the sound, the last two activities had the option of recording. But yeah, so this was where we were asking you to come up with individual words but yeah, it’s useful to know that recording was not something that was something that you were wanting to participate in. Maybe it would be useful to have a look at the words as a reminder of what this activity was.

So, what we’ve done is we’ve put together lots of the words that we have received so far, the individual words that people chose, and then we can have a look at a couple of definitions. But this is a big, long list of words, they’re in alphabetical order or mostly alphabetical order I’m hoping at the moment, you can try and spot the ones that I’ve got wrong. I’d invite you to take a minute to have a look at this list of words and offer any thoughts on what these represent about tinnitus, what they reflect about tinnitus, what they express about tinnitus, what you notice about the different kind of words that we’ve got here, and if anyone would like me to read these words out loud, please do just let me know.

P6?

**P6:** Yeah, I mean the word that I really think of is humming, and it’s not on the list, I don’t think. No, it’s not.

**I:** That’s a very good point. Yeah, that’s really interesting, humming is not there.

**P6:** I don’t know if I did this actually, I’m not sure, I don’t remember writing this down, I might have missed this one so sorry.

**I:** That’s OK.

**P6:** But buzzing and humming, the buzzing is there. Delight is an unusual one. And shush, I think that’s one that I would relate to, a sort of shushing noise. I think that’s probably it. Annoying is probably something I would say too.

**P3:** I think we all find it annoying at one time or another. I have a hissing noise that is really high frequency, it’s not far away from the top end of my hearing range, which makes life interesting when you’re trying to have a conversation with somebody who speaks in a high pitched voice because the two start to interfere with each other.

**I:** So, P3, would interference be one for you then on this list? I think interference is there, it certainly was the other day.

**P3:** Yes. I think I summed it all up as one word, hiss.

**I:** Have we forgotten to put hiss in here?

**P3:** No, well, hissing is there. Then nearest I can define it as is the fluorescent tube that’s not working quite right, that’s a really annoying high frequency hiss, buzz, hum, however you want to describe it.

**I:** So, P3, for you, this tinnitus is included in this list potentially, there’s some words that connect to yours?

**P4:** Yeah.

**P2:** I think I might have missed this activity, but it’s interesting because there’s the anticipatory words, then the in the moment experience words that are noise linked, and the consequence words as well, what you feel you get from it, be it the madness or the tiring. So, it’s themed quite interestingly.

**P1:** Yeah, I’ve just scanned down the list and I agree, so some of them are really trying to describe the noise, but there’s some intriguing ones in there which are more about the effect or the mood or the emotion that it invokes in the person. And so, those ones, they can be interpreted in different ways really but those are the ones that for me are the most interesting, more than the ones where you try to pin down exactly what your noise is. So, yeah, I think it’s an interesting list.

**I:** Do you think for you this captures something about tinnitus, do you think for someone who didn’t have tinnitus they might get some idea of what tinnitus is like from this list, could that capture something about the experience for you, do you think? That you is a general you, by the way.

**P5:** I think it would be interesting to put these into, not a timeline, I guess how long people have had tinnitus, I think if some of these words were describing tinnitus four years ago and some of these were describing it now, and that’s very different experiences. Not the ones describing the noise as such, more the emotive words. And I don’t know if other people feel that, it would almost show the journey through from diagnosis through to hopefully getting some help and seeing a doctor, etc.

**I:** Thanks P5, so a bit like the map as well, time is something that perhaps is needed here to interpret these different words.

**P2:** I think if they were presented to someone without the understanding that they’re probably a collection of many people’s experiences, they would be surprised that you even get through the day, because it’s so many experiences wrapped up in this.

**I:** Yeah, so for you P2, this is capturing something about those different experiences, or the multiple experiences, for want of a better way of putting it. Is that useful to have multiple experiences grouped together or do you feel that the individual’s experience needs to be represented by itself in this exercise?

**P2:** I think it might be interesting to see the groups of words captured by different people to see has everyone said something about the actual noise, has everyone said something about the anticipation, has everyone said something about the consequence, or do people frame it differently in their own experiences. So, some people might have just been at a very functional level going, oh, it’s shushy and fuzzy, and other people might have talked about the isolating and the isolation.

**I:** Yeah, so you would like to see the different words grouped together by their author in some way? Yeah, that’s interesting. Shall we have a look at a couple of the words and their definitions. So, Sally, if you wouldn’t mind going to the next slide. We have legacy, it’s always with me, what I was bequeathed by a virus, here to stay. And the next one please. Barometer, things have changed, good and bad, up and down, things change. I’d be interested to know what you think of those definitions.

**P2:** I think the legacy one spoke more to me because it’s just sort of this ongoing monotony, whereas this is an entirely different experience, the barometer one, it suggests that there is variation, so to me they’re the polar opposites of each other.

**I:** Thanks p2, does anyone else have any thoughts on these two?

**P3:** I think the barometer one probably can, people would think about it in terms of how the tinnitus is having an effect on their day or their week or even down to the hour at times, I think, because tinnitus comes and goes and depends on what you’re doing how it impinges on life or doesn’t impinge, or if you try not to let it impinge but sometimes it does.

**I:** Thanks P3. So, with this term barometer we could maybe read it two different ways, couldn’t we, that tinnitus might be a barometer of something, or tinnitus can be something that is doing the changing and affecting, I think.

**P5:** I think this one is mine. I use it as part of my acceptance of tinnitus and part of the hearing therapy I have has got me to this point where I wouldn’t call my tinnitus a friend but I find it a useful thing in recognising stress levels. So, that’s how I use it and it is, now that I use it as this tool for identifying stress, I’m much more accepting of my tinnitus and get much less angry at it being there and see the, well as much as you can see positives with tinnitus, there’s the positive side of it.

**I:** Thanks P5. So, for you the meaning of barometer here is that, is tinnitus a barometer for something else, is it that it tells you something about yourself?

**P5:** Yeah, absolutely. If my tinnitus is really going for it then I know, 99% chance that I’m too stressed and I need to stop doing what I’m doing and chill out. And if I can’t hear the tinnitus then that’s a good thing, I’m doing things right that day. And yeah, it’s part of the toolbox for my mental health and my wellbeing.

**I:** Great, thank you. Any other thoughts on this?

**P1:** I’ll put my hand up, I wrote the legacy one, and when I look back at it, it sort of sounds like the voice of doom there, but I’d just like to say that one of the other words that I put down was effervescent, so as I said before, I’m kind of at ease wish the fact that I have got it with me always and it is how it is. But I like the idea of using it as a barometer as well, that does make a lot of sense that you can then recognise your own stress levels maybe by the increasing sound of your tinnitus, maybe it could be used in that way.

**I:** Thanks P1, so for you that idea of tinnitus as barometer is something that makes sense or that’s a word that you can understand. Does having, so we’ve given you two definitions, one of legacy and one of barometer. Does having heard those explanations or seeing the definitions that have been provided, does it change how you look at those words in the list, does it change how you think of them? If we could maybe go back to the long list, Sally. Yeah, so legacy is in the third column, above luck, interestingly enough, about a third of the way down, and we have barometer is about halfway down the first column. Does having heard the explanations of these terms and heard more from their authors in this context, does that change how you think of these words now?

P4?

**P4:** Yeah, definitely. I didn’t understand barometer but when it’s explained, it does make sense. Yeah, most definitely that helps.

**I:** Yeah, so do you think there’s, because I find this list quite, it feels like there’s quite a lot of power to this list in many ways, seeing a long list of words that are quite different to one another in some respects. Do you think that the list on its own and then the definitions combined with it, do you think those are doing different things, do you think they have different kinds of impact?

**P1:** Yeah, I think you definitely need the definitions because on their, some of them I find them really disturbing, the one that says madness, for example, that really bothers me. And so, I would like to know more in terms of reading the definitions that were written with that word, otherwise I do recall there was a question about whether a word on its own can replace a group of words, and I would actually say having seen these here now as a list I would definitely say no, even if I’d said yes in the activity, I would now reverse what I put and say you definitely have to qualify them with some definitions by their author, because when you just take them out of context they’re open to an awful lot of interpretation and misinterpretation.

**I:** Right, thanks P1, that’s really interesting. So, the openness of these words, for some of these words is perhaps something that is difficult and it’s interesting that even reading your own definition of legacy, you said that it might be read in this way, so even with the definition there’s that concern about what we convey with these words. So, thanks everyone, so the definitions are definitely something that’s important here.

Before we go onto the next exercise I’d be interested to know, are there any other words that you really notice are missing from here or you would perhaps want to include in this list? I know P6, you noticed humming was missing.

**P2:** Whining is also missing for me.

**I:** Whining.

**P3:** Pulsating is another one that’s missing.

**I:** So, some of the words that perhaps describe the quality of the auditory sensation or the sound.

**P3:** Yeah.

**I:** I must say, it’s been interesting to see the different ways that people have approached this activity, and you might get a sense from the list, I think P2 or P4, you noticed earlier that you’ve got some words that describe the type of sound or the auditory sensation, you’ve got some that describe the more emotional aspects, or there’s the anticipatory descriptions as well. And yeah, we’ve seen that some people have been very poetic in how they’ve approached this activity and they’ve played with words that might be on the surface read as very negative, or positive, and then have provided a definition that perhaps flips that. So, I remember someone submitted the word, it’s not in this because it was from the pilot, the word breakdown, which on its own you might think, oh gosh, that’s quite a negative word, is breakdown, and then they had this very quite humorous description of faulty equipment and you can’t get the parts, and they’d written this quiet poetic description of this term. So, it’s quite interesting seeing how different people interpret and approach this exercise.

**P1:** Can I just say, I’ve noticed up there on the first column, anti-silence, and for me I just think that’s brilliant because it really brings home the fact that when you’ve got tinnitus you can mask it but you’ll never, sorry that sounds, it makes me feel quite emotional, we will never hear silence again, and I haven’t heard it for many years. So, I can mask the tinnitus but I can’t hear nothing because there is always a sound.

**P2:** Absolutely, P1, I totally agree.

**P3:** But how often are we in somewhere where there is no sound.

**P2:** I used to.

**P3:** Have any of you been in an anechoic chamber, because that is a really weird experience?

**P5:** I’m hoping to later in the year. I’m doing a project on sound and I’ve realised, and this is probably no comfort to anybody, but there is so little silence in our world, especially in this country. Trying to find anywhere that’s silent is nigh on impossible. But an anechoic chamber sounds fun, if that’s the right word, maybe, it would be interesting anyway.

**P3:** It’s very disturbing.

**I:** P6, did you want to say something?

**P6:** What is that chamber?

**I:** P3, do you want to explain, or P5?

**P3:** It’s a chamber where there is no echo, all sound is absorbed as soon as it’s emitted by the fabric of the building. So, no surface reflects sound in any way at all.

**I:** Yeah, they’re very, for external sound they’re very quiet places, they’re sometimes used in industry, I know because in my previous job they had an anechoic chamber and they used it for testing bearing faults in manufacturing, so they could isolate particular frequencies from external sound, so they’re very quiet spaces that any exterior noise is blocked out and, as P3 said, there’s no reverberation. So, if you clap in that space or make any kind of sound, it’s a very, what you would describe as a dead sound, it doesn’t reverberate at all.

**P3:** And you get no external vibration either because they’re isolated as a box, the floor is on springs or rubber mounts so you feel nothing.

**I:** Yeah, so this discussion of silence, this word silence is obviously something, or anti silence as we’ve got on this list, some people approach this by, you’ll note tinnit-us at the top of the right-hand list, some people were playing with words and putting their own points of emphasis in this list as well. But that idea of silence obviously has a complicated relationship for different people with tinnitus.

P4?

**P4:** Yeah, does tinnitus still exist in the chamber?

**I:** For many people, yes, I think. P3, I don’t know if you …?

**P3:** Yeah, it still exists, you still hear the tinnitus, so you don’t get the total silence that you would expect in this chamber.

**P4:** OK.

**P6:** Just lastly, the word permanent was a bit distressing because I would hope one day there might be some cure.

**I:** Right, so the word permanent for you feels like it’s quite an upsetting word to include?

**P6:** Yeah, absolutely, yeah. I would hope that one day there would be a cure. I don’t know where we are on that at all.

**I:** Shall we look at the next exercise, so this was keeping score and this was the one where you were asked to come up with word sounds that in some way related to the sound of your own tinnitus, and as P4­­­­ noted earlier, this was the one where you could either write or provide a written representation of your tinnitus sound, or you could record it and record yourself trying to make this sound, and I know that for some people the recording wasn’t the chosen option, but I know that for others that was the approach that they took. So, again, would welcome any thoughts on this activity and the process of finding your tinnitus sound through words and capturing those either on paper or through a recording.

P6?

**P6­­­:** So, for me I think I just wrote words actually, I didn’t do a sound recording. For me it’s like the hum of my freezer, which sometime comes on and sometimes goes off. So, I can be in that area and I think, was that the freezer or was that my hearing? So, it’s the only way that I can really describe to other people that don’t have tinnitus what its like. But sometimes it’s also, it pulsates, so sometimes it’s just that hum and then sometimes it pulsates.

**P1:** I took the recording route and to do that I described the sound to my sister, who is probably the person who’s most in tune with me but who doesn’t have tinnitus herself, but obviously because we’ve known each other all our lives, our vocabulary to each other is better understood than to somebody else. And so, having described it to her she suggested to me that did it possibly sound like, because we both like sparkly wine, did it sound like a bottle being opened, like the, not the cork but the sound of the bubbles coming out the top? And I said, actually you’ve got it, and so, I tried to record that and actually, it didn’t sound quite right. So, I ended up recording the sound of a can of Coke, really cold out of the fridge. I thought that the point at which you’re just hearing the bubbles rise to the surface and burst. And when I listened to it, I thought that’s as near as I could possibly get to how my tinnitus sounds. And actually having done it, I was really pleased because then I could play it to my husband and say, ‘This is what I’m hearing’, because as people possibly also experience, when you’re trying to describe it someone else, it’s such a real sound to you, and they can’t hear anything of it, it can be quite frustrating that you can’t believe that they can’t hear something that is so noisy in your own hearing. Yeah, so I actually found it useful then to be able to communicate it to people who I know and love, so yeah, so thank you for that.

**I:** Thanks P1, that’s really useful to hear and it’s also really interesting, on a personal level, really interesting to hear your process of going through different fizzy drinks to find the one that was more closely matched. So you started with the fizzy wine and then went to an ice cold can of Coke and recorded that. So, yeah, thank you for sharing that experience.

I should say at this stage, were not going to share any of the sound responses to the next two activities, playing sound, people on Zoom is tricky at the best of times, and when we have people with different hearing capacities, different relationships to these sounds, we’re not going to play them. But we are hoping to make some of them available after these workshops, and I’ll come onto that towards the end of today’s session because there’s more to say on that.

Sally, would you mind going through, so P1, I suspect that you might be describing the next exercise, which is fine because these two activities are quite similar, the keeping score and capturing sound one. So we’ve got a couple of scores or responses to this activity here, so this is the first, and I think, if I’m reading it correctly, there’s lots of little Ss but there’s also some Ts and As in the mix as well. I spent a really long time looking at this and really enjoyed looking at the different letters. And then we’ve got a second one please, which again, very different in approach.

**P2:** I can relate to that one so much more than the last one. The last one seemed quite pleasant and exciting, whereas this is mine, not mine but that resonates more with me.

**I:** Can I ask P2, what you feel resonates in this for you, what is it about this that you feel relates to your own experience?

**P2:** Just if I made that noise out loud, that’s exactly what’s going on at this very moment, whereas the last one just almost sounds like a, as when P1 was talking about Coca Cola bottles or prosecco or what have you, that sounded really pleasant. This is how it sounds to me, there’s nothing pleasant, it’s just annoying.

I found the recording thing was the most disturbing of all of the activities to do.

**I:** So that didn’t work for you, the recording sounds that are either masking or similar to your tinnitus, or sounds that are like it?

**P2:** I don’t know if it worked for me, I did it and it was, yeah, quite an emotional thing to do.

**I:** I’d welcome any other thoughts on these two pieces and these two scores.

**P5:** I wonder again if it’s different levels of acceptance of tinnitus maybe showing through. Again the first one, which I think is beautiful, and I think that might be the problem, it looks so good it kind of, I don’t know, it’s not happy tinnitus because you can see the letters kind of fizzing out, but the image itself looks more accepting. This one is mine, the other one, the one with, and this is like when we started the workshop today, I had no tinnitus at all until we started talking about tinnitus, and this is pretty much what my tinnitus has done throughout this session, it’s gone, oh hello, you’ve remembered me, I’m back. And yeah, I think this is where my tinnitus is annoying me, whereas actually the picture before is perhaps when it’s not there so much and I can talk to people about it and it’s all OK.

**I:** So, P5, you can see yourself in these two images and the contrasts between them?

**P5:** Yeah, I think the first image is where I hope to be most of the time and this image I did is when it’s annoying me, and perhaps when I just let it come into my head because I’m talking about it or discussing something around it.

**I:** On this note, this is something that I’d like to come back to at the end, but I’m interested to know how, we’ve seen five of the six activities so far and the responses, how the representations or reflections or expressions of tinnitus that we have seen today, how they compare to other representations or depictions of tinnitus you’ve seen elsewhere, be it in medical leaflets or films or television or anywhere else. I’d be interested to know how these compare to what you’ve seen elsewhere or heard or read elsewhere.

**P5:** I think in TV tinnitus to me is always the sound they play when a bomb’s gone off. Why do they do that? It’s some kind of torture for people with tinnitus, but that kind of real high pitched whining, they either use it for bombs or people with hearing issues, and that’s probably the only thing I can think of in an arts form.

**I:** So, yeah, those sounds that are meant to represent hearing trauma are for you not great, as someone who themselves has tinnitus.

**P2:** I don’t think tinnitus is represented in any mainstream media. I can’t imagine anything that I’ve ever seen where it’s ever been presented in any way.

**I:** Yeah, so there’s an absence of representation in your view, P2. OK, perhaps we can come back to that again at the end, I’m mindful that we’re running a bit out of time. So, the final activity was the capturing sounds activity where we asked you to perhaps record or document in some way a sound, an everyday sound that related to your tinnitus in some way. So, it might be a bit like P1’s can of Coke, that it was similar to what your tinnitus sounds like and perhaps captures something about what that sound is like, or it might be a sound that masks or hides your tinnitus, or something else. So, we’ve got a couple more responses here again, so this is the first. And then can we go to the second please, Sally? So, we’ve got a written description of sounds here.

I’d be interested to know from those of you who took part in this activity, what the process was like in terms of identifying sounds. P1, you have already shared very generously your experience of finding sounds, but I’d be interested to know if anyone else had a similar experience to finding sounds or what their approach was in identifying sounds for this exercise.

**P3:** I couldn’t find anything to actually identify and recreate the sound, so I chose the nearest object that I know emits that sound, and couldn’t find a faulty fluorescent tube anywhere, certainly not in the house, and I’m not going round buildings looking for that.

**I:** No.

**P3:** But by my nature I am used to expressing things graphically, so I used the tube as a thing and the size of it’s echoing the intensity of the sound.

**I:** So, P3, forgive me if I’m identifying you and you don’t want to be identified, but there’s multiple tubes here, was that a conscious decision to include multiple fluorescent lights?

**P3:** It’s actually the same one, just duplicated kin different sizes to represent the different volume of interference that I get in sound. I’m a graphic minded person, I’m used to describing things in a pictorial form on paper. I suppose it’s what I do in part for a living, or did do, I’m meant to be retired but I’m not really.

**I:** So, P3, did this activity for you, giving you the opportunity to reflect this graphically, did you feel that that was something that allowed you to reflect something about your own experience then?

**P3:** Yeah, yeah. And the really important thing is I never let the tinnitus take over and stop me from doing anything. Life continues. It’s annoying, it’s a nuisance at times, I’ve found over the years ways of dealing with it. If I’m in a noisy office I use headphones, and invariably I turn to the BBC Gaelic language radio station as a background noise because I don’t really understand the language so the speech doesn’t bother me, the music is smoothing, consequence is I now have a vocabulary of 30 or 40 words of Gaelic, but it’s simply a way of helping cut out background noise and it almost acts as a white noise for me.

**I:** So, maybe for you the counter side of this image would be something to do with the radio or Gaelic radio?

**P3:** Yeah.

**I:** Thanks. I’m very mindful of time, we’ve got a few minutes left, so at this point we’ve gone through the different activities, I’d welcome any of your reflections on I guess the bigger picture, which is this kind of approach to trying to express something about experiences of tinnitus or share experiences of tinnitus, and yeah, whether this is an approach that you feel is effective or if there are things that are missing from these different activities and their approaches that you think are important about the experience of tinnitus, whether or not you think you have been able to share something about your experiences of tinnitus. I just want to hand over to you and offer the opportunity to offer any final reflections.

P6?

**P6:** I think now, having been through the workshop, I would approach the whole exercise completely differently and offer probably more to it. I felt a bit frustrated that I couldn’t really get to grips with what was needed, so that’s been very useful.

**I:** Thanks P6, so just to clarify on that, has it been seeing other people’s responses and talking them through?

**P6:** Absolutely, yeah, really, really useful, and some of the artwork has been incredible, so descriptive, so yes.

**I:** So, for you it would make sense if we had another session?

**P6:** Yes, to have another go.

**I:** Great, thank you. I should say as well, if anyone does want to have another go at the activities, the activities sheet should still be available to you, so if in your spare time you decide that actually, do you know what, I do want to do activity 1a, or I do want to have a go at doing my tinnitus portrait again, you should be able to access the guide that we gave you.

**P1:** If I could just say something slightly opposite to that. I do understand what P6 is saying there but I found with some of the activities there were already too many examples given, which then made it very difficult to think about something in your own way. And so, in the end I was trying not to look at the examples because it’s kind of helpful to have a bit of a steer but sometimes it’s difficult to come up with your own idea when somebody’s already portrayed something seemingly so well, but it’s not your portrayal is it. So, I think it’s a bit chicken and egg, isn’t it, this, I think this sort of discussion is immensely helpful and it probably would be useful to revisit the activities, but just based on having talked about it and having seen other people’s ideas, but without something actually physically in front of me to guide me, if that makes sense. But I did find, just going back to the one before, the use of the language, the three parts there, the third one I thought was wonderful, I’m not sure who wrote that but the language about the water falling on the lake, and I don’t think that anyone could draw something or make a sound that for me resonated any more than that lady’s use, I’m saying lady because I think it was, use of words. I just thought it was absolutely wonderful, so thank you for that.

**I:** Thanks so much, P1. Contradictions are welcome, it’s OK if people want to offer things that are the opposite to one another, it’s useful to hear that, so thanks both of you for offering those perspectives.

**P3:** I think this sort of session would be quite useful for groups in counselling for tinnitus, because it would help them to express their own feelings about it and also to understand how other people understand and address their tinnitus, because tinnitus is an isolating illness and it helps if other people, you know other people suffer from it, because it’s a silent illness in an odd way, because nobody knows you’ve got it unless you say that it’s there, there’s no external physical symptoms, it’s something that’s happening within the brain and in particular the ears that cause the issues, and I think if this whole session was set up for counselling groups, it would be really helpful to them.

**I:** Thanks P3. P5 and P2, did you want to say something?

**P5:** I just wanted to completely agree with P3. I did the BTA group sessions last year where you have the two weeks of group therapy counselling online, and yes, perhaps one of the ones they do as the first week and then here’s some homework, let’s look at this next week, would be amazing and a great way to get people to open up differently. And I also think as a starting point for hearing therapy as well, I have hearing therapy through St. Martin’s hospital in Bath, and they’re fantastic but I think those initial appointments where you’re trying to describe your problem and talk through things, to have done these exercises first and gone in with them, saying this is my issue and my experience, would have made the whole initial process much easier.

**I:** Thanks P5. Can I just ask, I’m mindful of time here, but can I just ask a follow on, do you think there’s something about the different kinds of representation, so it being visual or written or graphic in P3’s case, is there something about that form in particular that’s useful for sharing with others, do you think?

**P5:** Yeah, absolutely, I think the drawing is easier, or the drawing is different for me, I write a lot so the drawing was different for me, and I think it was easy to express some emotions that way and some feelings about the tinnitus, whereas writing it down sometimes is much harder.

**P2:** It’s almost a form of triangulation, isn’t it, bringing it from visual, auditory, verbal, to create a three-dimensional picture.

**I:** Thanks P2, so there’s a sense that actually bringing these things together can give you something a bit more, I don’t want to say rounded because we’ve used rounded quite a lot to describe what tinnitus sounds like, but a fuller picture, as it were. Thanks everyone.

**P1:** Thank you, it’s lovely to meet you all and I look forward to hearing from you.

**I:** Great, thank you.

**P4:** Just one other wee comment, it’s totally unrelated, but misophonia, when I developed tinnitus I no longer am bothered by misophonia. It’s maybe a plus, I don’t know, but the two can’t seem to exist together.

**I:** Right, how interesting. So, I’m guessing you had misophonia to begin with and then you developed tinnitus and the misophonia …?

**P4:** Well yeah, I’ve had misophonia for many, many years, and then developed tinnitus through long covid.

**I:** Right, OK, so the tinnitus is relatively new.

**P4:** Is relatively new, yeah. And I suddenly thought, my misophonia doesn’t bother me. I don’t know if that’s a common thing or it’s just the two sounds, you can’t cope with both or your head can’t cope with both. But anyway, that was just …

**I:** No, that’s really interesting and we know that everyone’s hearing and experience of hearing is quite unique, so yeah, thank you for sharing that with us, P4.

**P4:** OK, thank you. All the best.

**I:** You take care. Bye.

**<End of recording>**