**File name: Monday workshop 1hr52 4 participants**

## Key

**P:** = Participants

**I, I2, I3:** = Interviewers – Marie, Patrick and Sally

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

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

[word] = best guess at word

… = interruption in sentence, trailing off or short pause

**[participant and team introductions]**

**I: …**Thanks so much P2. And we’re really, really grateful that you’ve decided to participate and artistic talent is something that is very relative, so please don’t feel unwelcome in this space. So Sally, would you mind beginning to share the slides and I’ll explain a bit more about what our workshop today will be focussing on or what our discussion will be focussing on? So as you all know, you have been sent some activities by us and we’re very grateful that you participated in those activities and sent us your responses. What we’re going to do in today’s session is we’re going to show you some of the different responses that we received in relation to these activities. Your own responses will be in amongst them. I will say a bit more about that momentarily so please don’t panic, but what we’re going to do is just spend a bit of time reflecting together on the kinds of responses that we’ve got to the activities, and you’re also very welcome to share your own experiences of participating in the activities as well. So you’ve done the activities, and now you get to see how others have responded to the activities as well.

So we have a few ground rules. That sounds a bit strict, but it hopefully helps give you a sense of how you can participate, how you can engage in the conversation and what we’re aiming for.

So the first thing to flag up, I’m sure many of you are already aware of this, is that tinnitus can be a sensitive topic for discussion, and you’re very welcome to take some time out of the session or leave if you feel the need to. I will come back and say a bit more on the practicalities of that momentarily.

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

We will be sharing these response to the activities anonymously. However, you are very welcome to identify yourself as the creator and comment or share your own thoughts on your own activity response. So there is no pressure – we wont be pointing to something and saying, ‘Who’s work is this, stand up please.’ We’re not going to do anything like that. But you are very welcome to say, ‘Oh, actually, that response is mine. I can tell you a bit about how I approached this or was thinking about it.’ But the option to remain anonymous is there.

We also know that tinnitus can affect people in different ways, so please keep in mind that other people might have experiences that are different to your own. One of the really challenging things about tinnitus and one of the really interesting things about this project is no two people’s tinnitus is the same so if we can just bear that in mind when we’re discussing some of the things that have been created, that would be great.

Can I go to the next slide please, Sally?

Some of us are using Zoom’s auto-captioning function. This works best when one person is speaking at a time and there is minimal background noise, so please can you make sure your microphone is muted when you are not speaking and try to avoid talking over others. We know that this is quite difficult when you’re having a conversation. On that, if you are struggling to find a way into the conversation, on an online platform this can sometimes be difficult, please feel free to stick your hand up and sort of wave at us and wave at the group, or if you go to the bottom right-hand corner in Zoom there should be a reactions button, that allows you to raise your hand. So I’ll just illustrate that – I’m hoping I’m illustrating that now … I seem to have disappeared. So yes, if you want to try and get into the conversation but can’t seem to find a way in, by all means either physically raise your hand or use the reaction button.

Saliences, or relative silences are OK. We know that people might need a bit of time to respond, so please don’t worry if nobody is saying anything. And that’s a reminder to myself as much as everyone else.

We’ll be having a 15-minute break half-way through the session, so about five-to-seven we will have a 15-minute break but if you need to take some time out of the discussion before or after that you’re very welcome to leave at any time and you should be able to re-join the discussion using the Zoom link that we have sent to you. If you’re wanting to leave the discussion but aren’t quite sure how to, or if you have any other concerns, Sally is the person to message on the chat function. You will be able to send a private message to Sally and she will happily advise you about how to step away if you need to or on anything else that you might have concerns with.

OK, so that all sounds very formal. Does anyone have any questions at this stage, before we move over to you speaking and communicating and talking a bit more?

No, good. I can see a few shaking heads. I can’t see everything at the moment so I’m just going to change my screen a bit. OK, Sally, would you mind going to the next slide please? Thank you.

So the tinnitus maps, we’ll looking at the exercise in the order that you received them, so there’s six exercises in total. Hopefully as well we’ll have a bit of time at the end for a more general chat about this kind of approach to tinnitus, what works, what doesn’t, and what you have found in participating in these activities.

So if we can click through, I think there are three tinnitus maps for us to look at. If we just go through them slowly together and you can have a bit of time to look at these … <pause> I should say as well, if there’s anything that you are struggling to read on the screen or if there’s anything you would like me to clarify I can try and help, ‘cause I know that reading text on a screen can be tricky.

**P2:** Sorry, can I just check, is the idea that we take a look at them and then have a general discussion about them at the end, or are we welcome to comment on them?

**I:** If you want to jump in with comments now, you’re very welcome to. If not, we’ll look at all three and have a general discussion, but yeah, feel free to respond as you’re looking as well.

**P2:** It’s just, like you said, everyone’s tinnitus is different, so I’m looking at the rustle-rustle sound and I think ooh, that’s a quite a comforting sound for me, but obviously for certain people that’s going to be quite a distinct thing. But I’ll happily save my comments till we’ve seen them all.

**I:** Thank you but that’s really interesting, P2. So that sound, knowing what that means for different people or how that feels for different people can be challenging.

On that note, could we go to the next one please?

<Pause>

And shall we go over to the third one?

<Pause>

I should say as well, feel free to ask us to go back and forth between different images as well.

So yeah, we’d welcome any thoughts that you have about the different approaches that have been taken here, the different things that are marked on these maps. Any thoughts that you have in general about this activity as well, you’re very welcome to share.

**P3:** I don’t mind going first. The first one was mine, so it’s interesting that you said that with the rustling, because that is one of the most highly irritating sounds for me, but obviously not for you, no?

**P2:** Yeah, so I do understand, but mine was the slightly less artistic middle one, which had a kind of symbol-based approach, and so the triangles are the bad sounds and the circles are the good sounds, and for me I do understand what you mean when you say about the paper, because the sound of cutlery clanging together, when I went through this … this was the one I started on and put probably the most thought into, and just there’s no sound on earth like the sound of cutlery that just bang, that’s it, as soon as I hear that, it hits all those notes.

**P3:** Do you find it worse if, say you’re in a kitchen, and maybe the TV’s on and maybe somebody’s talking and then that noise happens – do you find the noise more irritating?

**P2:** Cuts straight through, just cuts straight through!

**P3:** <Laughs>

**P2:** Sorry, I’m gonna jump in and just add something on this experience, it was really interesting for me as well because thinking about some of them I noticed that on all of them sleep was mentioned, and on certain of the maps sleep was noted as this maybe more negative or more noticeable, but I find times when I expect to hear my tinnitus, so for example when I’m in bed or when I know it’s an actively quiet environment, it doesn’t tend to bother me as much, ‘cause I think well, you’re more aware of it so you will notice it – which I found quite interesting anyway.

**P3:** No, I agree with you there. I expect to hear it when the house is quiet and if I do start to read a book – ‘cause I do tend to read in the evenings, it irritates me maybe for the first few pages but if I get into the story I can blank it out. But sometimes when it’s bad, that’s when I’ll put my Audible on, which is the headphones, but I’ve bought ones that cancel the background noise, to stop me raising the volume, so to keep the volume low so I don’t damage my ears, and it also drowns out my husband snoring so it’s fantastic! ‘cause I’ve got my tinnitus on this side and then if anybody’s on this side … well that’s it, then I just definitely can’t read. But those are the two things that help me in the evening, but if I fall asleep and I get woken in the middle of the night, I find that the tinnitus is really loud then. And that can be difficult to go back to sleep. I feel like … I think I’m irritated anyway because I’ve been woken, and then you’ve got that on top as well. So I dunno how you guys feel but …

**P2:** Yeah, it’s funny that you say about headphones ‘cause again I find with headphones it really makes me notice my tinnitus so even if I’m listening to music I tend to wear … probably for the first couple of years of having tinnitus I’ve just cut headphones out of my life, and it’s only more recently I’ve reintroduced them, but it does … I notice it more when I use them, which is interesting, ‘cause kind of hearing that background noise.

**I:** P4, would you like to chip in?

**P4:** Yeah, I find it interesting ‘cause I think it’s just … as you said it can be just so different for different people and I found especially when I first got it really bad, and it was just raging, I found the headphones were actually the thing that really helped me because I got the myNoise app and I just tuned in sounds, mixed … you can mix all sorts of sounds there and it was like the equivalent of aural scratching really I found with the myNoise app, you could create a sound and it could just kind of counterbalance it. And I found that really helpful, especially at the beginning. But it’s interesting the sound of waves, that’s just –

**P3:** Oh yeah, I love that, that’s my favourite sound.

**P4:** It’s my favourite! And occasionally my tinnitus sounds like that. It doesn’t happen often, it’s one of these rare moments, actually sounds like that and you go, ‘You know what? That’s pretty good! I like that!’

<Laughter>

I remember when it first happened I thought, ‘Well if it’s like that all the time I’m in a good place, aren’t I?’ And then of course …

<Laughter>

**P3:** Do you find them helpful, P1?

**P1:** Yeah, I’m in the second camp with headphones and anything to mask my tinnitus, that’s the direction I take, and my map was third map – a really basic one there – so when I’m out the house or out and about doing things I generally don’t notice it, but when I’m at home it’s like … yeah, if I don’t have things to mask the noise then I notice it all the time. So I have headphones and sound machines in every room and that’s just how it is. And I suppose that this process of thinking about it and looking at the map actually made me a bit sad … well it made me a bit sad in that it’s a constant thing and I don’t think I’d ever thought about it before. I think I just went into autopilot when I realised that I had tinnitus, and just thought right, sound machines, headphones, get it done.

**P3:** Do you feel like it’s sad because it’s worse where you should be safe in your home?

**P1:** It’s sad because it’s a constant thing, that there’s never any silence anywhere.

**P2:** Could I ask, sorry to interrupt, and it might be a personal question, I’m not sure where the boundaries are on that, how long have you noticed it for; is it a more recent development or is it something you’ve had –

**P1:** I think it’s about three years, two or three years, and the reason I knew that masking it and trying to ignore it and come to terms with it was important was because of friend of mine was doing clinical trials on tinnitus way back when, so was just going off on one, talking about tinnitus all the time, and I was like, ‘That sounds awful!’ and then a couple of years later, I got tinnitus. I was like, ‘Right, OK …’ And that’s when I literally just raided Amazon and got a ton of sound machines and stuff like that.

**P2:** It’s funny. Maybe the first six, seven … probably six months to a year, I really found it so much more audible. I used to have to listen to rain noise to sleep and stuff, much to the dissatisfaction of everybody else I lived with, who thought there was a storm every night! But yeah, it’s really interesting. Thank you for sharing that.

**I:** Can I ask, I’m amazed at how quickly the discussion has taken off – this is fantastic – but P1, you said that doing this activity made you feel a bit sad because it made you realise I guess the presence of your own tinnitus in your life. P2 and P3, you identified yourselves as the other authors. What was it like for you, mapping out your tinnitus in this way? Did it make sense to you; was it surprising; were there things that you couldn’t capture through this that were frustrating; was it something that you wanted to share with others or did it feel quite private? I’d be really interested to know what it was like to map out your own tinnitus in this way.

**P3:** It took me a couple of days to think about it before I actually put anything down on paper, but I feel that since lockdown happened, for some reason I’ve just felt more conscious of it and I feel I’ve already started to map it out through the year, so it’s a bit … I dunno, maybe it’s fate, but I think … we had a dog last summer so I’ve been out more, appreciated nature more, and I did start to notice how going to the beach, hearing the waves, definitely relaxed me, made me not worry about the tinnitus. And I feel like this year I’ve sort of made positive steps to try and do something about it, because I don’t feel I had done anything about it really up until now. And that’s why I invested in the headphones. I feel I speak about it more to people to try and make them aware of look, I’m asking you to repeat yourself for a reason – or telling you to turn the TV down for a reason – or when I’m shouting at my kids to come down or they’re shouting me from upstairs and I don’t quite hear ‘cause the cooker’s going and the TV’s on and the dog’s barking outside … but I do find that when I tell people, some people will go, ‘Oh yeah, that’s OK,’ and that’s it, but if you told them you broke your arm then they’d probably ask you about it again, wouldn’t they? It seems even in work I tell people in work about it and it never gets mentioned again. Nobody’s conscious of it at all. So there’s no leeway with it I don’t find.

**P1:** Do you think that sometimes people dismiss it?

**P3:** Completely. I think if you don’t experience tinnitus … I suppose it’s a bit like mental health, isn’t it? If you can’t see it and that person looks OK, then you’re fine. But I’ve even told my manager about it. Really being a teacher, really they should be questioning me about my ability in that class; can I hear, occupational health. I had an operation on my ear in 2000 and I had to go to occupational health then to see if I could hear across that room, but even though I’ve brought tinnitus up several times this year, to different people, not once have they asked, ‘How does that affect you in your work; are you OK teaching online?’ It’s nothing.

**P1:** Has it had a big impact with your teaching then, and teaching online?

**P3:** I will consciously not wear headphones if I’m teaching online, I won’t do it. I do listen to Audible at night but I definitely wouldn’t do it in the day, I do try to limit loud noise. I’m conscious of loud noise. So I think … I dunno, if I went into a nightclub now I think I’d be really, really conscious of it. I’m too old for that now anyway so I’m alright! <Laughs> But I don’t think I’d feel comfortable, I think I’d be really conscious, ‘Oh my god, I hope this doesn’t get worse.’ So I am conscious like that with it. But I am disappointed with other people’s reactions when I finally had … the guts to tell people, ‘Look …’ you know … have you told people as well?

**P1:** I haven’t told anyone really. I don’t think so. But as I said, I just mask it, so I know if I’ve got a task to do, I do lots of quite detailed reading and all that kind of thing, and instead of waiting for me to notice the tinnitus I just start doing that job and the sound machine’s already on, so it’s not as conscious for me I’d say.

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

**P4:** No, I can relate to what P3 saying really. I’m in my … I’m 53, I’ve always had hearing, damaged hearing, but I’m now wearing hearing aids ‘cause I have reverse slope hearing so I hear the high frequencies, so I’ve kind of got away without hearing aids for a long period of time because I can hear the voice element pretty good, but now obviously I need them all the time, and trying to … people can understand the hearing I think, element now. And actually I’ve been impressed with how, especially the younger generation are so kind of … accepting really of hearing. I remember hearing aids, when you were a kid at school, and admittedly they were a lot bigger … you know, it wasn’t a good place to be, a kid with hearing aids, it wasn’t a nice place to be, stood out. And I thought what’s gonna happen when I get my hearing aids in – and admittedly now they’ve got super-tiny, so people don’t really notice them, but the acceptance is completely there.

And you contrast that with tinnitus, and people just don’t get it at all, they really don’t! The tinnitus is a much bigger deal for me than the hearing side of things, and just no one understands it, and I think they think well, it’s a little bit of ringing, but they don’t really get just how … especially when it comes on for the first time, how god-damn scary it is because all of a sudden you’ve got a head full of sound and you can’t get rid of it, and it’s a frightening thing to happen to you. And I just think it’s really misunderstood, and I thought then trying to represent it visually was such an interesting concept because understand things visually I think sometimes more than they do kind of … trying to explain something that no one else can hear. I thought that was just a brilliant concept and then you kind of think well, how do you do it? <Laughs> But yeah, I can completely relate to what you were saying P3. Really can.

I don’t know if any others have had that kind of experience?

**I:** I can see Patrick’s asked a question in the chat here, P4, that builds on some of what you were saying there about…does anyone think that these maps or something similar could help to explain or communicate their experience of tinnitus to others, perhaps in the workplace?

**P3:** I think it could, definitely. Maybe I was at fault as well, even though my husband knew and has known for years, since he’s met me, that I’ve had sounds in my ears, I don’t think I’ve ever actually told him what that sounded like. So I was on the official website for tinnitus, the British Tinnitus site, and there was a study there where they were asking you to fill out a questionnaire and then it led you to a video, and this video gave examples of what do you hear? So I actually played that sound then to my husband, and he was completely shocked. And ever since that I think really he’s more conscious of … my hearing. I don’t get any extra flowers or anything like that <laughs> but I’d say maybe a bit more thoughtful, a bit more aware of if I need that TV turned up or down or him rustling his crisp bag. Now he’ll put them in a bowl. But just little things like that just stops that irritation. But I’ve never really thought of sharing that sound with anybody either. I felt that it does … I dunno, it’s a step forward, isn’t it?

**P2:** I’m keen to come in off the back of that and just say that I’ve always, I’ve really thought since I first noticed mine, and mine was pretty much self-inflicted through exposure to loud music and at events and things like that, I’ve always thought it would be such an easy way to prevent hearing damage if just at the start of everything that had really loud noises, they just played a soundbite – a minute long – of various tinnitus noises. I think it would make a lot of people reconsider their decisions to wear earplugs and earphones, and it’s a thing that … P4, you were saying that young people are more accepting – actually young people as a demographic are going to be more affected by hearing issues and tinnitus than any other in history. And one of the things I’ve really noticed, again when I first got diagnosed, whatever, it’s very hard to escape loud noises. We live in a very loud world and when you actually actively start trying to avoid loud noises it is very hard to do.

Going back to the map task, one thing I found really comforting about it was actually the places that I didn’t notice my tinnitus and tucked away in the corner of my map, it was food shopping. I dunno, whenever I think about going around, there’s a big Sainsbury’s near where I live and I’ve never ever once noticed my tinnitus in there! <Laughs> And I don’t know why, I’m just quite … you’ve got a nice little task, you can just push around the trolley, I’ve never noticed it. I was just trying to think about that in comparison to other places. So yeah, I think there’s a lot of good that could come from visualising and definitely playing the sounds of tinnitus to raise awareness about it, that hopefully will –

**P1:** Just pop to the Sainsbury’s every time you’re angry with your tinnitus.

**P2:** Yeah, literally!

**P3:** Fantastic. You’ve just given me a fantastic excuse now to go shopping more often!

**P2:** Sometimes notice it in Aldi, but I dunno what they build in those Sainsbury’s!

<Laughter>

**I:** Thanks so much for sharing everyone. I’m very mindful of time. You’ll notice about me that I’m quite militant about timekeeping, so you’ll need to forgive me for this, but I’m hoping we can come back to hopefully some of these discussions at the end, but thank you everyone for sharing so much; you’ve all been so generous in your conversations, we really appreciate it.

So we’re gonna move on to the second activity, which was the tinnitus portrait, so this time we’ve put all the portraits together. It’s a bit like I think of this bit like when you were at school, did you ever get those tea-towels where you drew yourself and there was all the portraits on the tea-towel? It’s a bit like that but with tinnitus. So we’ll skip over to the next slide. There is a couple more in here that aren’t in this workshop, just to give you a sense of what other people have got up to. But yeah, we’ll spend some time just having a quick look at these and then welcome any thoughts that you have about this activity, what you’re seeing here and the approaches that people have taken.

**P4:** I think it goes to show again how there are differences, and there isn’t necessarily consistency, although the approach is very similar on the whole.

**P3:** I feel like I can understand what they’re trying to say, even though the lines are in different places. But mine is the middle one and the reason I did three is ‘cause I feel I have three different sounds, so the first one is the shhhhh sound, which is a good day. And I don’t mind that one, I can put up with it. If I have a cold or anything like that then I can get it in both sides, the side that I have it anyway, the left side, it becomes higher, but then I can faintly – I feel as it if faintly moves over, not completely to the right ear but there’s something there. And then the one I dread is the high pitched ee noise, as if it’s a bleep. And that’s the one I would dread having 24/7. But I have a habit of having to blow my nose or popping my nose like you would on a plane, and that tends to clear it. And it only lasts seconds but out of everything with tinnitus, that’s … I’d be quite happy to live with what I’ve got, as long as I don’t get to that one. That would be the ultimate for me if I had the beep 24/7.

**P1:** Mine’s more of a beep. I’m the top one.

**P3:** I can see why you’ve got all your machines then, P1. Oof.

**P1:** It kind of … I suppose the reason I’ve drawn it with different … what’s the word? Sizes of circle is ‘cause it’s not a constant, same volume. Even when it rings the tone stays the same but the volume goes up and down, it expands and … yeah, it is a bit of an odd one.

**P2:** I’d be quite interested in hearing about the other one in the top corner, the … with orange lines, ‘cause it looks like it’s a sound that envelopes the whole … whereas I’m quite happy to say mine’s the bottom corner, underneath yours, P1; for me it is very much like on one side of my head so to speak, but obviously the other one looks like it encompasses the whole of the headspace, which is interesting to me ‘cause I can really kind of feel it’s that … very directional … is directional a word? I dunno, but yeah. That’s how I’d describe it.

**P4:** My one is the top right, and it’s just there. It’s all around really. It’s like it’s in your head. It’s like normal hearing, that’s the best way to describe it. It’s there all the time, but the sound changes all the time. The one consistent is it’s not consistent. So you know, that’s the only consistency I’ve got. But then it’s just … do you know …

**P3:** Does it get worse for you –

**P4:** … and I thought, ‘Yay, this is great, this is one I actually like’ and then it doesn’t … I think the high-pitched one is always the worst, but you know … one consistent for me, it isn’t consistent, so it’s just about time. Sometimes that could be four days, you know. But eventually it goes and then something else replaces it.

**P3:** Is it worse when you have a cold, P4?

**P4:** Yeah. I think there’s two parts to it P3, if I’m analysing out. There’s parts where the canals get blocked and things like that, physical, and there’s parts are mental. I think most of it is mental for me, it’s the brain thing, but I do occasionally get the hay fevers and stuff that block up ears and that has an impact as well, ‘cause my hearing’s damaged. But most of it I think is brainwave related, yeah.

**I:** What’s it like to see your tinnitus represented or reflected in these images or what’s it like to see other people’s tinnitus reflected in these images? Does it make sense to you.

**P3:** Yeah, very interesting. And it does make sense. You could relate to all of them.

**P2:** Obviously me and P1 have kind of gone obviously different kind of shapes but similar in that direct … I can very much see that on the one side of my head, that’s interesting as well ‘cause I can obviously then see the comparisons between the others which are more all inclusive.

**P3:** P1 is smiling.

**P1:** No, yeah, I’m wondering about that.

**P2:** I’m not sure what the thing I’ve assumed is a drawing of my face is doing, but I don’t think it’s smiling! <Laughs>

**P3:** Your hair looks good anyway!

<Laughter>

**I:** P1, you’re not the only smiling one. We’ve had a few smiling portraits.

**P1:** I think this was quite early on, wasn’t it, in the activity time.

**P2:** I found this was the one that actually, of all the activities, this one made me notice my tinnitus the most because I had to concentrate and draw it. Again, I’m not gonna go on about it but I really don’t feel confident in my drawing abilities and it really did take me a while to draw and that minor irritation did spike my tinnitus, whereas the other ones didn’t as much. I know we need to be commenting on the activities and such, so that was something I noticed, that doing the activity that was more difficult for me, came in that parcel with the experience of tinnitus a bit more.

**P4:** If it’s any consolation, I can’t draw for toffee as well, that’s why I’ve got a camera, but I cheated.

**P2:** I’m impressed with the ears. I’m very impressed with the ears. I thought you’d done a profile excellently!

**I:** P2, having got through the frustration of drawing, ‘cause … I would say that is pretty great self-portrait, you’re very recognisable from it, and you’ve got some great detail there. I know that’s not the point here of how accurate is your portrait in terms of does it look like you, but I think that’s a pretty accomplished drawing.

**P2:** OK.

**I:** Seeing it now, do you maintain those feelings of frustration, do you still have that negativity towards that image, given that you had to put yourself through frustration and your tinnitus got worse in that process, or do you feel differently about it now it’s done?

**P2:** No, it’s funny you mention that. Looking at actually does kind of … it’s interesting to see that I can actually … I never really thought about where I could hear it before. I’ve always kind of been aware but I’ve never tried to put it on. I think more for me, on the picture, it’s kind of lines … the lines of it. I don’t want to go on too much but I have a constant noise but one of the things I noticed throughout the project work that I did for this is that whilst it is a constant noise, it does feel more like there’s dips in and out, and that’s, for me, the more interesting part of it. Whereas again – I keep going on about P1’s, I don’t know why – I can go on about all of them – some of them have … you’ve obviously gone for the swirls, which means a constant sound, whereas for me it’s much more like that if you know what I mean. I don’t know.

**P1:** It’s constant but it’s up and down, and it actually made me quite … between this an the map it made me quite thankful that it … I do have breaks from it. So I do a lot of distance swimming and good lord, if I was to hear it when I was swimming, that would probably just finish the whole swimming thing off to be honest. But it actually made me really fortunate that I don’t notice it when I swim.

**P2:** That’s how I felt about Sainsbury’s!

<Laughter>

**I:** Great, thank you. I’m mindful that we’re ten minutes away, nine minutes away, from our break, so unless anyone has any final thoughts on this activity, shall we move onto the tinnitus drawings? Great, OK, thanks Sally.

We’ve got the same sort of thing again here, where there’s different slides with different drawings on, so if we maybe take a look at the drawings and then reflect on them together, does that make sense? Great. So I think there’s three. So this is number 1, and this one was called ‘upwards’. <Pause> Shall we go onto number 2? <Pause> And number 3? <Pause>

I should say as well, we haven’t included all responses to each activity, just for time’s sake, so everyone will be represented somewhere, hopefully, but for some activities we haven’t included everything. And some activities we’ve included things from different workshops, just for comparing and contrasting purposes. But yeah, we’d welcome, as we’ve done previously, we’d welcome any thoughts about this activity, what you’ve seen being created in relation to this activity, what about tinnitus do these images capture, what they don’t capture, any thoughts would be welcome.

**P3:** I do like the colours in number 2. It’s quite creative, isn’t it? <Laughs>

**P1:** I was gonna say it’s not very linear, but it actually is, it’s got a linear outline.

**P3:** Yeah, it shows that there’s a peak there, doesn’t it?

**P4:** Yeah, that one’s mine. I can try and explain it if you like? <Laughs>

**P:** I think you could put that on the wall, P4!

<Laughter>

[47:21 IA]

**P2:** I think I do understand, I think you’ve done a really good job there. I wanna hear your explanation but just to say, I think I do understand that so I’d be interested to hear your, how you would explain it.

**P4:** Well the thing in the middle is my brain, that’s kind of like with all the connections going on, and then it’s kind of … it starts at the beginning of the day and ends at the end, and this was a really nice day at the weekend, so there are some days I think where you’ve got jagged red lines … ‘cause mine’s changing all the time, it changes all the time, the yellow is that kind of high-pitched sound that you get, and sometimes that comes and goes during the day, or I notice it more. The green is … it’s there all the time, it never goes away and that’s quite hard to explain to people, it’s there all the time. And then the blue, because it’s a weekend, I mean this nice curvy … that’s actually the nice period where things are going well and I think the green, we were out for dinner, which was very nice, but my brain was being pounded a bit more, and then the blue, coming home and you’re just taking it easy. That’s kind of how it goes, but each day could be completely different for me. It’s not about the rooms, it’s completely different. And the ones, certainly the beginning of it would have been just red lines all the time, it’s kind of … it varies. It’s consistently inconsistent. But that’s where it comes from, so I was trying to visualise it and put it in a way to try and explain it to someone and that’s where it came from really.

**P2:** I thought perhaps the different colours represented the different sounds, just because obviously you’d mentioned that your experience of it is that you do have those different sounds; obviously the colour coding is also something, I didn’t even think about the colour coding, I was just thinking about the different … yeah, so that’s very interesting, and it’s interesting how it’s kind of throughout … you’ve given it that timeframe within the day as well. I think that’s very interesting.

**P4:** To be fair I’ve only got it delivered on Sunday, I was running late, so Marie, I have to apologise!

**P2:** Mine came in at … I emailed Marie today let’s say!

**I:** No, no one needs to apologise for being late. We’re all just very appreciative that you took part, so please don’t apologise. Although I am very, very grateful P4 that you sent this over on a weekend – that’s really kind of you. And thank you so much for sharing your explanation as well.

I’d be really interested, there’s something interesting about this, isn’t there, about seeing an image on its own without explanation, but being told it somehow relates to tinnitus, and having your own interpretation of that image – and then having someone else explain it. And P2, you said you could see, or you thought that there was a connection between colour and sound for example. I was wondering if anyone else had any thoughts about how P4’s explanation related to their own interpretation of this image when they first saw it. Has it changed how you see this image? Has what you saw in this image been confirmed? I’d be really interested to know about that relationship.

**P3:** I didn’t know that that was the brain. I would have put that as the different sounds that he’s heard and that the outer layer would have been maybe the worst-case scenario, the peaks. But after P4 explaining it, I think it’s positive that he’s got so much blue there, and that the red and the yellow don’t spike more often. So I think that’s good to see, isn’t it, from someone that … you know, slightly understands a bit.

But now you’ve said that’s the brain, I look at that picture in a different light and I think fantastic. And the fact that it’s so visual and you know if we see our tinnitus in colour we might look at it in a bit more positive light. Whereas I did the third picture, and I didn’t feel I wanted to use colour on it because I just felt to me it’s grey, it’s … but maybe I should look at it and should use the colour and maybe look at it in a more positive light. For me, when I think of my tinnitus, I visualise my ear canals, so any time I speak about it or someone asks me about it, that’s how I feel. I think it’s because of the operation I had, and I’ve had so many check-ups and I think physically I’ve had so much done, I think I just visual them. So that’s what the lines are, and then the squiggles are the swooshing sounds which are there 24/7, but when I do get the beep I just see that as … somebody pushing that button. But I think again ‘cause I’ve had so many hearing tests, obviously they use the worst sound ever, which is the beep sound, and in the end you feel OK, did I hear that or am I imagining it? So I think that’s where the black dots come from for me. But I do like the way that P4 used the colour in his drawing.

**P2:** So mine was I think the first or the second one, if there was only three, and it’s interesting to me that you have your circular dots with the line running through the middle. I kind of did this over a couple of days and recorded a few different sounds, but I don’t know if everyone can see that, but there’s one that’s kind of numbered 6 and it has that same thing because it is that constant noise but it feels, you know it’s a constant noise but it does have that variation. And again it’s really funny because I guess I pictured it on a horizontal line as if it was my ear canal for the first few, and the reason it’s called ‘Upwards’ is because it kind of then dawned on me that actually I don’t really see it as a horizontal line [54:08], for me it’s a sound that just is constantly on the up because of the tone and stuff. And that felt very interesting to me, to have that realisation that it’s not so much peaks and troughs but it’s just constantly on the up. But without any of the emotional context connected to that phrase! It’s just a statement.

**P3:** Why do you think you’ve got such tight lines at the top but say number 1 and 2, and then numbers 6 and 5 are spaced out?

**P2:** I just thought that maybe it’s just more because it’s just … it is more of those upward sounds and I can’t really explain what I mean more than that, but because of the tone and stuff it just is … I dunno. Once I thought about it like that I couldn’t really go back to thinking about it as in the ups and downs, ‘cause I dunno … I dunno, but yeah, it was interesting. It’s changed how I visualise it for sure.

**I:** Thank you.

**P4:** It’s really interesting ‘cause I hadn’t thought of the ear canal side of things at all. But I can see that, and I can see how you’ve drawn that and actually that’s quite a good way to explain it to people as well. But again we just seem to have … this thing with tinnitus, it’s hard to explain ‘cause there’s so many differences. The more you … but we’ve all got wavy things going on there and lines going on to represent sound in a way or represent feeling. It’s consistency there I think, the approaches.

**I:** I’m going to interject now. Thank you so much for all of your comments there. It is 18:57, which means that were are two minutes late for our break! <Laughs> I told you I was militant about timekeeping. Can I suggest we meet back at 12 minutes past 7 … well OK, can I suggest we are ready to start talking again at 12 minutes past 7 but feel free to take a break, grab some refreshments, should you require, stand up, walk around should you wish to or need to, and we’ll be ready to start talking again at 12 minutes past. But thank you so much for your such insightful comments so far. It’s been a real joy discussing these examples with you so far.

Feel free to stay logged into Zoom if you want to mute yourself and switch your camera off that’s absolutely fine. If you want to close Zoom and come back in the link that we sent you should still enable you to re-join Zoom, but thank you very much and we’ll talking again at 12 minutes past.

<Break>

And Sally, can I get you to share the slides? So we’re gonna look at the final three activities. We’re half-way there. And the next activity is called ‘putting tinnitus into words’. So what we’re going to show you in a moment is a big, long list of words that are in alphabetical order and these are all the different words so far that people have submitted to us in response to this activity. So we’ll start by just looking at this list of words together and then we’ll maybe look at a few different definitions that people have provided of the words. So Sally, can I get you to go to the next slide? I told you there was a lot of words. If anyone would like me to read out these words or read out any words they’re unsure of, please feel free because this is a lot of words on a screen. If not, we’ll give you a few moments to browse through this list of tinnitus words and then welcome any reflections that you have on these.

Any thoughts anyone?

**P2:** Yeah, so there’s a few that I was drawn to them straight away. Acceptance really caught my attention. There was another one, which now I’ve gone word-blind ‘cause I’m looking at a load of words trying to find the one I liked, but there was a few that were quite positive and I really liked that. Acceptance was one. I think ‘me’ is in there somewhere. Let me see … it’s essentially the ones that kind of show … ‘different’, l like different as well ‘cause it’s like … ‘personal’; personal, different, acceptance, me, it’s kind of like it is a debilitating condition if you look at it, but actually it is very personal, it is just me, it’s something that you have to accept, and those really draw my attention. More than some of the other ones I think.

**P3:** I agree with you there P2. I would pick acceptance but I would still pick annoying sometimes, but I definitely wouldn’t have picked acceptance maybe a few years ago. I may have picked damage a few years ago but I wouldn’t pick it now. But I would pick me. So I feel like by accepting that it’s there. It’s not as annoying as it used to be. I feel like I’ve forgotten what quiet is. I don’t feel I can remember that sound of silence. So …

**P2:** Yeah.

**P3:** What does silence sound like now?

**P2:** Do you know, it’s funny ‘cause silence to me is tinnitus. That is my silence and that’s how I try and think about. I just try and think well OK, I know that I’m in silence, this is my silence; this is silence for me and that’s fine – or that’s how I try … obviously everyone has … you have your moments and your good days and bad days but I’m not a total ray of sunshine; I did throw jarring into the mix ‘cause it is jarring. It’s a jarring experience, it can really pull you up when you’re in that kind of place.

**P1:** ‘Delight’ is a bit of an odd one to have there.

**P3:** Are they being sarcastic?

**P1:** That got to me!

**P2:** I like ‘rubbish’ because it feels quite understated. It is rubbish, yeah, that’s a good way of putting it, because it’s …

**P4:** When I look at the words, we’ve got words that describe sounds and we’ve got words that describe feelings, and most of the words that describe feelings are quite negative, aren’t they, really? Particularly some there that … I don’t really wanna think about really. But … on the other hand, you have some positive words in there as well, which is interesting for me. I think I’m definitely drawn to ‘annoying’. You can’t get away from that! <Laughs> Even if you’ve got the ‘acceptance’ one I’m drawn to as well, definitely. Then you’ve got the different sounds and things. Unpredictable – that’s kind of a description of what happens. So as well as feelings and sounds. So there’s a few in there that are doing other things as well, describing the condition as well as sound, which is interesting. It’s an interesting set of words to think about though, isn’t it, and look at?

**P3:** Before this experience, I probably would have thought of it in words, because of my job and I’m a word person, but now I’ve done the drawing side, even though they’re not Picasso drawings, I would say that visually now I think I’d relate to it more as the images and I probably don’t relate to these … I wouldn’t relate it to words anymore, I don’t think, which I don’t think is a bad thing really. Because you’re bringing colour and shape into your brain, aren’t you, rather than just … you know, words, that can be positive or negative. You can interpret a piece of art into anything you want it to be. Like your brain’s full of colour, but to visually look at it, it was something positive.

**P2:** I agree, P3. I’m much more interested in writing, I do quite a lot of writing, but I found it much harder to pinpoint those words than to try and draw it and explain it. So I do agree with you, that was an interesting thing for me.

**P1:** This was the one activity I didn’t do ‘cause I just found it … I would have found it quite difficult. The drawing thing, even though mine were really basic drawings, was much easier I think. And I think if I’d left myself more time I would have liked to have played around with some colour perhaps.

**I:** P1, can I ask, as someone who didn’t participate in this activity, what it’s like to see that list of words; do you feel that that captures tinnitus or something about tinnitus; is it a useful way of explaining tinnitus to others, this list of words; or do you think the other methods, for you, are a better way of capturing?

**P:** I’d say the other … I don’t know. <Pause> It’s interesting to see all the words in front of me, and some of them have quite physical reactions. For some reason the ones with fizz and hissing and … they’re making me feel a bit like…queasy, but that’s not my experience of tinnitus. Mine’s like a ringing sound, rather than a fizzy sound. <Pause> I don’t know. I think it’s probably 50/50.

**P2:** I think the sad words make me feel quite sad, like if I’m looking at that they do make me feel sad, ‘cause it is … there’s some there and you do think well, it is just sad … again you see them and then you try and look for them in the big table and you can’t find them, but …

**P3:** I feel like I don’t want to read them.

**P2:** Mm.

**P3:** I’m like I can feel myself physically avoiding reading them.

**P2:** Pressure, yeah.

**P3:** I dunno why but I really wanna … I don’t mind looking at everyone’s pictures <chuckles>, but I just don’t feel I wanna read them.

**I:** Do you think, P3, for someone who didn’t have tinnitus it would be useful for them to see these words?

**P3:** Definitely. But with the pictures as well.

**I:** Great, thank you.

**P4:** Interesting for me, the words, I think, would be useful for others, but I think it’s probably the visuals that actually relate more to how I feel. Because I don’t think I can put it into words, something that’s almost a little bit abstract really, if that makes sense. Whereas kind of the abstract images … your drawing, P3, and P2 … P2’s self-portrait, things like that actually … they kind of pull into what I feel more than the actual words do and maybe that –

**P3:** I think it makes it more human, doesn’t it?

**P4:** Yeah, maybe that’s what’s so great about art. It can do things that words can’t. And actually when you looked at your portrait, P2, it’s pretty damn good actually when I had another look at it. I think you might be a talent there, you don’t need a camera, mate! You just need to start practicing.

**P3:** Sign the bottom, P2, quick! <Laughs>

**P2:** Do you know, I’ll say one of the words I contributed was tinnit-us, and I’ve had that in my head for such a long time and I’ve really wanted to like try and write … I dunno, like a poem or something about it, ‘cause I really like this idea of it … it’s you and the tinnitus is tinnit-us, it says it in the name. And I just can’t find the words for it because it’s so hard to explain, whereas you could almost describe that through a drawing quite easily, like a drawing project or something. I dunno, it’s a complicated one.

**I:** Speaking of which, Sally … do you want to go to the next slide? Thank you P2. I put this in the wrong way – if you could maybe click on the next one … there we go. So we pulled this one out as one to discuss, so thank you P2 for pre-empting that.

**P2:** I jumped the gun there then, apologies!

**I:** Yeah, so you’ve given us a lovely explanation of that term and why you put it in there. How do others feel about tinnit-us?

**P3:** I think it’d make a fantastic campaign! <Laughs> Raise awareness.

**P4:** It’s really, really quite clever. I kind of see it as me and you, it is us, isn’t it? I see it as part of me. I definitely see that. I think that’s partly the way I deal with it, it’s me. It’s not something I’m gonna fight against ‘cause it’s me. That’s the way I see it. So me and you kind of fits in with that quite nicely.

**P3:** I think also the words P4, ‘fight with it’; I think once you stop fighting with it, mentally –

**P4:** Exhausting, isn’t it?

**P3:** I feel I improved.

**P4:** That’s the benefit when you get in your fifties, P3. You run out of puff. You can’t fight anymore, you just gotta … <laughs>

**P3:** You just get fed up! You just give in, don’t you?!

<Laughter>

**P4:** I’ve also described tinnitus sometimes as my friend. It can be bloomin’ annoying but I do … that me and you thing, it’s a good one P2, it’s good. There you go.

**P2:** I got as far as a second line. ‘It’s Tinnit-us because it’s me and you screaming at each other in a silent room’, and that’s as far as I’ve ever gone with it.

**I:** P4, I think I’ve inadvertently de-anonymised you for the next one, but Sally, would you mind going to the next slide?

So this was a description that was submitted, that we thought would be interesting to share with you and get your thoughts on. So ‘Tinnitus is a part of me, to fight against it is to fight against yourself. I’ve made tinnitus my friend. Sometimes my friend can be annoying but you have to accept them for what they are.’ I’d be interested to know our perspectives on that definition.

**P3:** That’s fantastic, I think. Very true. P4, you’re a mind-reader! <Laughs>

**P2:** I think acceptance is the most important thing and it’s only by accepting it that I think you can really start to … not get better but most of my experience is fighting against it was what was really causing it to be an issue in my life, and now it is that thing of it just is a part of me and there’s nothing I can do except roll with the punches, so to speak. So I think that’s a really good … it was, like I say, in that whole list of words it was the first one I read and it was the first one that I thought wow, yeah, that’s actually got straight to it. It is something you just have to come to terms with in your own way, I think.

**P3:** I think it’s the only treatment available.

**P4:** I think it’s different for different people. So I can only really speak for myself, and what works for me, and appreciate that there’s people out there with much more severe conditions as well and maybe acceptance may not be possible, but … on the other hand I do find this language of fight and all that just doesn’t work for me. Just doesn’t work for me. You hear about battling, fighting, and I just find it’s counterproductive for me personally, and it might work for other people. We’ve seen it’s very different for different people, but for me that kind of language just doesn’t work at all. And it might be people’s conditions are different as well and I think … just had to kind of find what works for me, and that’s what works for me.

**I:** Thanks P4. Sally, can we go to the next word, just ‘cause I think this will be an interesting one to compare. So some of you might have notice the word ‘aura’. ‘It feels like a halo of sparkly sound, it’s there around me, always and invisible. It chose me to host it.’

**P3:** I wouldn’t view it like that. It’s definitely not a sparkly sound.

**P1:** Makes it sound quite positive, doesn’t it?

**P3:** Yeah. I dunno – it’s just not the right context for me that. Mm.

**P2:** See, for me this one’s more interesting because I didn’t … so when I first noticed mine, obviously it’s something that … I wasn’t born with it essentially, it’s something that came through the environment, whereas I actually had a really insightful and interesting conversation with my boss at the time, and his son actually had been born with tinnitus and they’d gone through a process of him finding out that he had it, basically, through school reports and then it turned out that my boss actually had it as well and he’d never noticed it. And I wonder if perhaps this is something that’s been contributed by somebody who has always had it and hasn’t ever had … ‘cause you would feel like that. And I know that when I have felt kind of negative about my own, that certain people just are born with that condition and it’s … they don’t know any different, and that kind of gives me a bit of … comfort. I dunno why.

**P3:** That’s interesting you’ve said that, P2, ‘cause I’ve never thought of it. It could be normal to somebody outside, but I think when you haven’t had it before … I view it as something inside me.

**P2:** Yeah. I can see why somebody who maybe had been born with it could view it as an aura, because for them it would be an aura, because it’s like it’s …

**P3:** It’s normal.

**P2:** It’s around them and it’s normal, whereas I think if you’ve got it from maybe an environmental reason then it’s more invasive than that.

**P3:** Interesting.

**P4:** Sparkly sound and halo, they’re all really nice, positive words, though, aren’t they? Halo is, sparkly to me is, ‘cause I think of bubbly and champagne and stuff like, all that nice stuff.

**P1:** Apart from host. Host is a bit like a parasite, innit? Don’t know. This isn’t one for me, the acceptance one’s my one probably.

**I:** Thank you. I’m still mindful of time but it’s been really interesting hearing your different responses to these words and their definitions, and the different ways that people are approaching and interpreting them. It’s fascinating how there are different ways of reading these terms. Like you’ve just said, P1, it feels like this definition for me, it sort of changes half-way through when it says ‘it chose me to host it’ and there’s something ambivalent in there about … the positivity, which I think is interesting.

Shall we go onto the keeping score activity? Thanks everyone, and thanks to those of you who identified yourselves as listing certain words. So … I think this one again, if we’ve got a couple of examples to look at that we can go through and get your reflections. So these are different scores, I should say, just on the same slide. <Pause>

And then the next one please?

Yeah, so as before, would welcome your thoughts on this activity, do these images, for you, capture something about tinnitus, don’t they capture something about tinnitus, how do they compare to other activities, what was the process like if you participated? It’s over to you.

**P3:** This one’s actually the one I done but again … what I just see in myself now is the pattern of how I’m constantly looking at two types of tinnitus, the shh one and the bleep. I probably wouldn’t have thought of the bleep as much on a day-to-day basis, but obviously I must be conscious of it somewhere because I keep putting it into everything. And the reason I put the last three at the end is that it does scale up, but then once I pop my nose it goes. But that’s always a frightening thing to pop your nose, because if it doesn’t go when I pop my nose I’m like … <Laughs> It’s a nerve … it does make me nervous doing it, in case it doesn’t go.

**P3:** Now, see the other ones –

**P2:** I like the fact that…I’d like to say on that one, I like that you’ve added it in pencil as well, ‘cause obviously it can rub out so if it’s erased the sounds can go with it.

**P3:** Wouldn’t that be nice! It would probably be weird now<Laughs>

**P2:** You’d have to keep the fan on just to sleep at night again!

**P3:** <Laughs>

**P3:** I think these make sense as well with the up and down pitches, and the whirling as well.

**P2:** I like that this is a very definite mmm kind of noise, you can really see that. I don’t know if that’s the intention – and the way that the eee’s have been drawn as well ‘cause obviously you get that … consistency of the ring but also that it varies as well.

**P1:** So the mmm one is mine and I was trying … not very well, to differentiate between when you draw like a soft and a spikey m, because it is changing. It’s constant but changing. Yeah.

**P3:** ‘cause it looks like you’ve pushed on the pencil a bit harder as you’ve gone as well? The pencil at the beginning is lighter. I wonder if that was conscious? The more you thought about it, the more, harder you were pushing the pencil?

**P2:** Is it a combination of lower case and capital Ms? I just picked up on that ‘cause you said … yeah, I really see what you mean with that ‘cause obviously you do … that’s a really good way of visualising.

**P4:** It really makes you think actually, the way that the changing shapes and the changing letters and changing shapes in the letters, changing, moving around, it’s … it’s something I never would have thought of, but I get it. I can see where … it’s easy to understand as well, but quite abstract, because the shapes can change. It’s … yeah. Really kind of something.

**I:** At this point I’m gonna ask a question that we can return to at the end, but I think I’m asking it for a reason … always, but I’m really struck by how much …when we talk about tinnitus a lot of people describe their tinnitus as constant, but what I find really striking in these images is how … there’s that balance between something being constant and something changing, and I see that across a lot of the activities. There’s this relationship between something that’s very familiar, but also something that is different on a day-to-day basis or in different places and things like that. And on that note, I was wondering how this relates to other representations or depictions of tinnitus that you’ve encountered in your life previously, if at all. Are they similar to how you’ve seen tinnitus represented before; are they different to how you’ve seen tinnitus represented before? Does this remind you of other approaches you’ve seen taken to tinnitus? I’d be interested to know how this compares.

**P3:** The only thing I’ve ever heard about tinnitus is that it’s crippling, high-pitched sounds, and you do not want it. I’ve only ever … and I don’t think I’ve ever seen a poster or watched an advert. I don’t think I’ve seen any media about it to be honest. And I couldn’t actually tell you … other than myself having it, how I know about it. If that makes sense.

**I:** Yeah, P2 I can see your hand is up if you wanted to go.

**P2:** Yeah, I mean I would agree, I think it’s one of those things that unfortunately you’re only really forced to engage with when you develop it, and I think it’s not something anybody who doesn’t have it can ever really understand, because it kind of knocks you for six the first however long you have it, because it’s such an alien experience but it’s so universal as well, so you’ll have it, you think there would be more general awareness around it. Certainly for me … like I said at the start, I’ve tended not to engage with the tinnitus community in that respect, but if I tried to think about it, a lot of what I’ve seen in other people’s art is … I can relate to it. Even looking at these m’s and e’s now I can see … I’ve never drawn or thought what I can see … how it would relate to how I think of my … so it’s interesting, but like you say I’ve never seen those visualisations or anything and it’s certainly not something that just comes up in conversation, or I’ve just seen on like a billboard in town or anything. It’s niche.

**P3:** I’d like to know what people that haven’t got tinnitus would say they see.

**I:** Mm.

**P2:** How would you ask somebody to describe silence? It’s interesting.

**P3:** Yep.

**P4:** I don’t think I’ve seen much in the media. I’ve seen a picture of someone with their head in their hands, kind of thing. That kind of visualisation, but nothing really. Certainly nothing like this ever before. But I find I can relate to this so much more and it’s … it’s something –

**P3:** Therapeutic, isn’t it?

**P4:** Yeah, it’s kind of … more meaningful in a way, but as P2 said, it’s really hard to … if you haven’t got it, to explain it. But almost these kind of pictures that are … these images, looking at that, they seem to make more sense to me. I don’t know if it does to anyone else, but to me they do. And they make more sense as well than the words we saw, or the word charts, as well. It goes to show, I think, there’s a place there for these kind of images and maybe it’s the images and the words, maybe it’s a collection of everything together that then … and the sounds. But it’s fascinating, isn’t it? And helpful as well.

**I:** Thanks.

**P1:** Oh sorry!

**I:** No, you go P1. It’s fine!

**P1:** I was just gonna say I haven’t seen any visual representation anywhere but when I first got tinnitus, if you get it … I went on a ton of Facebook support groups but I’ve had to snooze them all because it’s just generally people having a kick-off about their tinnitus. Whereas I think if there was to be more of a creative outlook on it, then maybe you would see more positivity around it. So I think something like this has the potential to maybe change people’s focus from it just being … and some of the moans are quite dramatic, of people who really haven’t accepted it or are just nowhere near being able to accept it; like some quite worrying posts that flash up. So yeah, so I just snoozed them all.

**P3:** It does remind me of the Dementia Friends, ‘cause I do a lot with them. It reminds me of their campaign, and their message is that you can live well with dementia, even though it’s perceived that you can’t, and I think that’s … sort of the view of tinnitus is oh, you’ve got tinnitus, you’re not gonna live well. But you can, we’ve proved it today that we can find ways to maybe not eliminate it but … we have got positive things, when we go shopping and we put music on and when we’re in the beach … so I think that’s something really that should be shown as well.

**P2:** Yeah, the lack of awareness is a scary thing I think, and I do think you also do have to be careful with the things you engage with. Certainly for me this is … it’s a unique thing for me to engage with an experience, because it will inevitably lead me to think about my tinnitus more, which is something I think you have to regulate.

I don’t know if we’ve got any more activities to look at, but … going back to the point you just made about the dementia thing, there is that lack of awareness. I remember I was very lucky, I went and saw an ENT and here I was, something like 23, a kid with ringing in his ears just started, and I spoke to the guy and I was like, ‘God, it’s just really getting me down’ and he said something like, ‘Yeah, well it’s only been 6-12 months, it’s a life-long condition,’ and in my head I was like oh my god, I can’t believe what you just said, that’s the worst news I’ve ever heard! But I realise obviously now what he meant was you have so much time to come to terms with it; it just is.

**P3:** But he used negative language with you, didn’t he?

**P2:** I don’t … I’m not sure. I guess he was an ENT so it was kind of like his day job, wasn’t it, whereas here I was having one of the … a little crisis in my young life <laughs>, so …

**P3:** Well that was my experience when they offered me a hearing aid if I wanted the white noise, and I sat there for 40 minutes … and I think she must have looked at me twice, and she’d literally just typed but I wonder, if I’d have gone to that session and she’d have asked me maybe some of the questions I’ve been asked today, if I’d have been asked to maybe take part in some of these activities … I wonder if I’d have come out of that office feeling a little bit more positive or not as worried about it. Something the NHS could look at having.

**P4:** I think just ‘cause of what P3 saying, I just couldn’t agree more with, and P2 really. That kind of initial contact you make, when you need help, it’s just so important. It’s so difficult at the beginning. I was really lucky. Within two weeks I got to see someone who was really good, and I see him every year now, and it just made the world of difference, and I think god, there’s people that don’t get that; I just feel so sorry for them, because it can really … it really makes a difference, it really does, because you can end up with a group perhaps where it becomes very negative and you really … I think there is this kind of thing is much more positive, it’s more educational, it’s helpful, whereas some things I just think aren’t helpful and they’re best avoided. And maybe P1 mentioned about Facebook groups I think you said, P1, and things like that, I just avoided them like the plague, because I thought it could be … it’s really difficult, if you get sucked into something and it’s not particularly positive experience.

But then on the other hand, you do feel pretty isolated with it, don’t you? ‘cause there’s no one out there that really gets it! <Laughs>

**P3:** This is the first time I’ve actually spoken for this long about it, and I didn’t even know half the things that come out of me mouth today, so I’ve found this whole experience completely positive and listening … first time for me to speak to somebody else that actually has tinnitus, so I don’t feel … I’m actually feeling quite good now, to be honest with you! I’m feeling positive because I don’t feel like it’s just me. That there’s other people. Yeah, we’re all different, but … we can relate to each other, can’t we? And I think that’s a really positive thing.

**I:** Thanks so much P3, for saying that, and everyone else for your comments. P2, you can add a new definition to tinnit-us now!

We have got one more activity that we’d like to share with you, but yeah, thank you so much for those reflections. It’s really useful for us to hear how this does and doesn’t relate to other things that you’ve done, other experiences that you’ve had around tinnitus. That’s very helpful for us to know about.

So the final activity was capturing sounds. If you submitted a sound-based response to this activity, we are not going to play those because Zoom isn’t very good at dealing with recorded sound and also there are challenges in playing sound in a group where we’re talking about tinnitus. But we are hoping to make the sound-based responses available at some point, which I’ll come onto later.

So we’ve got a few images to share with you I think. So this was the first.

**P1:** This is mine. This is how I cope with my tinnitus.

**I:** Thank you P1. Do you want to talk through what the images are?

**P1:** It’s basically just how I mask my tinnitus at home. Headphones, sound machines, radio at all times. So I think this … it hasn’t been an overwhelmingly sad experience doing this, but it did make me realise that without these items in my life, I’d … I think I’d have a much poorer quality of life, and especially at the moment, working from home, studying at home and obviously with lockdown you just spend so much time at home, don’t you? So God knows what I’d have been like without these things over the past.

**P3:** What noise do you hear from your sound machines, P1?

**P1:** I like to mix it up a bit <chuckles>, so I’ve got usually birds during the day, and then at night I’ve got just … I think it’s called pink noise actually, it’s just whatever … I just went through it and whatever was closest to … to being able to hide what I was hearing. And so it’s getting to the stage where even if I spend time outside the house, I’m considering just buying a sound machine to take with me ‘cause I don’t like using the one on my phone … but I don’t know why, but yeah, I was on holiday a week before last and I was like, ‘Need to get a wee travel sound machine’.

**P3:** Does it affect you in work?

**P1:** No, because I just lob the sound machine – they’re just always on.

**P3:** On in work as well for you?

**P1:** Yeah.

**P3:** Gosh, it’s loud for you then, isn’t it, really?

**P1:** It’s not loud; it’s just if I don’t have something there to mask it, I’ll notice it and it’ll just piss me off, so just best to just avoid that from the start, just get it switched on straight away.

**P2:** I pretty much always have a podcast or music on, but I just think of it as more that’s just things that I like to do. Maybe part of it is I’m subconsciously masking my tinnitus without really engaging with it, but I think it’s probably quite nice to … I think your quality of life might be lower just ‘cause you haven’t got all those lovely bird sounds in your house all the time! That just sounds like very relaxing sound.

**P1:** Well certainly because I don’t do very well with having the radio on all the time or having voices and things like that, so the birds is something that is just, it feels quite natural.

**P2:** I like birds as well, very nice.

**I:** Shall we compare this to, I think there’s a second image we can compare this to.

**P3:** Is that the buzzing of the lights, is it?

**P2:** That’s a sharp image to look at.

**Various:** Mm.

**I:** I wonder if you have any thoughts about the intent behind this image?

**P3:** That reminds me of a buzzing sound of a light that needs fixing, that would irritate me.

**P2:** Yeah, I’m finding that very intense, that’s … I think that’s very … you know, unpleasant. I don’t really wanna look at it, in this context.

**P1:** Mm.

**I:** We can move off this image if you’d prefer.

**P2:** Oh no, sorry – I’m happy to …

**I:** This is the thing, isn’t it? Some of these images do have that response. Yeah. That’s a very understandable response. This is, as we said at the start, this is quite a difficult subject to work with and talk about so it’s entirely reasonable to say, ‘That’s a bit much!’ We can understand that.

This way of approaching tinnitus as a sound or in relation to sound, was that something that, for those of you who did participate in this activity, was that something that worked for you? Because obviously with other activities we haven’t necessarily thought about tinnitus quite in this way, focussing on sound quite so much. I’d be interested to know your thoughts on that kind of approach?

**P3:** The only thing I thought is the headphones … I had an ear infection a few months ago and I felt that that raised the volume of the tinnitus, even after the infection cleared. And that made me a little bit more paranoid … about putting headphones on. So before that I was using similar headphones to what’s on the screen, but then I realised … I thought oh well, maybe I need to look at … is this level of volume harming my hearing, am I gonna make it worse? Because I’d only really started using the headphones to that extent because of lockdown really. So I decided just to invest in, I researched but then I decided just to invest in noise-cancelling earphones, and maybe ones that didn’t go in the ear, went over the ear, and I’m conscious that I do not put the volume up high as well, because I think I’m just paranoid about that I don’t wanna affect my hearing in any way possible, but I don’t really wanna miss out on ever having to put headphones on again, ‘cause you just feel like oh gosh, come on! <Laughs> Give me something! So yeah. I’d say that’s the only thing. Sometimes in work I’ll go onto YouTube and I will put the white noise on or I will put a rainforest on, so you’ve got a bit of everything. And I have actually been to the beach and recorded the waves. But you can only stand there for so long and do that, can’t you! <Chuckles> But I thought if I’m there, and I can visualise myself being there and I visualise looking at the waves … ‘cause we’re lucky we live in a really lovely spot, we’ve got mountains everywhere, we’ve got the views and everything, so the reason I recorded it, I wanted to feel like I was on that beach, rather than listening to it over YouTube. So I could picture something as well. But I’d say that I haven’t got to the stage of buying the sound equipment yet, but it’s not something I’d rule out if it got any worse.

**P1:** Sorry to interrupt. I’d say that the sound machine was easier than going and recording things. It’s like literally 20 quid, you just put it on in the background, it’s fine.

**P3:** It’s not about that. It’s about … I dunno … ‘cause I listen to it at night, I find that your mind can race, ‘cause of my job, I find that I can go off and think about all these different things, but if I feel like oh, I’ve had a lovely walk, don’t get me wrong, I’m not standing there for an hour … I record it for a minute and then you can just put it on repeat and it’s up to you then how long. God, I’m not that nuts! <Laughs> But I just feel like there’s an extra feeling to the sound … it works for me.

**P4:** What I find interesting about this is that there’s objects, perhaps, that we’ve all got. I’ve got a pair of headphones that work really well for me, they’re Sure headphones, and they work so well I’m terrified they’re gonna go out of production. I’ve got multiple pairs of them! Every time I get a bonus I buy a new pair because they just work so well for me, and I tend to listen to audio books is my thing, but I slow them down. I’m not worried about the volume ‘cause I’ve done a bit of research on that and it depends on what volume level you’re doing it at so I’ve … I’m OK there. But I think going back to P2’s point, I think there’s a need for an education on hearing, and now I go to concerts I’ve got these special plugs I put in, and actually the concert sounds better. I wish I had them when my hearing was better! ‘cause it knocks out the distortion. It’s best sounding concerts I’ve ever been to ‘cause they knock out the distortion and it’s just wow! But there is a need for an education ‘cause there’s gonna be a lot of people getting tinnitus I suspect. Because a lot of people do have their headphones really loud! You’re on the tube, or you’re on the train and you can hear it! So everything must be at levels that are damaging.

**P3:** 90% of my students in class will put their headphones on when they’re doing their work, and I look at them and I cringe.

**P2:** It is hard not to. I get that. You overhear people with loud music, you just wanna shake ‘em and be like, ‘You’ve got no idea what you’re letting yourself in for!’ I just wanted to pick up on something you said, P3, that I thought is so important to me, and it weirdly enough fell into everything everyone’s said, is this idea that for me … I didn’t actually do the sound-related programmes – for me it’s so much more of a mental … mental health I guess, it’s more a mental health thing than a physical sound. And again it’s like you said, I was really worried about using headphones for a long time, and then I realised that actually as long as I’m comfortable and as long as I’m careful it’s OK, and there are certain things that I’m willing to … it’s not even risk. It’s like you say, it’s different for everyone but for me it does make me more aware of my tinnitus, because when you’ve got the headphones on you’ve kind of enclosed that sound, but it’s letting go of that fear of possible damage, which is so minimal, and accepting that OK, I do wanna listen to my … I don’t know, my off-menu podcasts or whatever, and just do that for an hour, and yeah, it might make my tinnitus spike for twenty minutes when I’m in bed tonight, and I might think, ‘Oh, why did I do that?’ But actually the quality you get back from that … it’s difficult, but it’s much more of a mental health thing I think, for me, than an actual physical sound that I feel like I actively need to engage with or mask in that way.

**I:** I’m gonna interrupt now, sorry. We’re at one minute past eight, and I’m very mindful that some people might need to go this evening. If you are someone who needs to go, please feel free to drop out. However, if you’re willing to spare five minutes more we can try and wrap things up a bit if that’s OK. I hate having to do this when we have a chatty bunch of people, and interrupt the conversation, ‘cause it’s so interesting listening to all of you talking about these activities and your experiences, so thank you so much for sharing so much with us, and thank you so much more enabling me to interject. And I’m sorry for not being able to do that in a more gracious way on Zoom.

So yeah, thank you all. Just want to take five minutes to welcome any final reflections now that you’ve seen the activities as a whole. There’s been some fantastic comments throughout, incredibly insightful. We’re not just looking for complements, it’s been really useful to hear the wide ranging responses there’s been, things that people don’t like or find difficult or find quite negative in relation to this as well.

So I just wanna give a couple of minutes, if there’s any final thoughts that any of you wanted to share on these activities and what you’ve experienced, and then I’ll take a bit about the project going forward. P2, I can see your hand is up.

**P2:** Yeah. I think it’s really, really great to have a creative space to actually discuss it. I know that’s something that’s come up and having that creative forum to discuss these things is so important, ‘cause it does…Personally I do find it quite scary in some ways, really engaging with my tinnitus on this kind of level, because you do open yourself up. Certainly it can be really challenging. So whether it’s something that I will do again, I don’t know. I hope so. It’s something I think is really important, but I do have that element of worry inside me around tinnitus, because it can be so … up and down I guess. So yeah, it’s been a really, really good experience, I’ve really enjoyed it, but it does come with that element of fear that is, I think, unavoidable when you’re dealing with something like tinnitus, would be my final remarks.

**I:** Thank you P2. And just to flag up, if you do find that things become difficult over the next few days, the British Tinnitus Association website has quite a lot of avenues of support. They’ve got a helpline and things like that, so just to flag that if anyone does find that their tinnitus is really spiking after participating, that’s a useful resource to go to. But thank you. Very understandable response.

**P4:** I found it really good. Not just the structure that you’ve been doing, Marie, but also the people here, P2, P3 and P1, I think you’ve been a fantastic group to actually … we’ve all been really open, really, haven’t we? Probably a lot more open than we are with <laughs> normal world. And I think that’s been lovely actually ‘cause we’re all … it might be all different for us but we’re all in the same boat and I think we could all appreciate everything that everyone else has said, and it’s been great. Thank you.

**P3:** I completely agree with what you’ve just said, P4, and that’s exactly what I was going to say. I feel really pleased that I’ve met everyone here and I appreciate everything that you’ve shared, and I’m shocked with myself with how much I’ve actually said! <Laughs> I’ll probably go off and think, ‘Did I just say that?’ But I feel really positive. I was worried, like you said, P2, at the beginning, ‘Is this gonna make me more conscious of it now?’ I don’t … at the beginning yeah, doing the sketches, it was, but then it didn’t, and then I’ve definitely … not after this talk, I feel like a little weight has lifted a little bit because it’s the first time hearing about P4, P3 and P2’s experience; everybody’s different, but I can relate to everyone. And yeah, definitely I don’t think I’ve been as open about a thing so personal with anyone really outside the family, definitely not. And I don’t think they’ve understood it, so I’ve quickly moved on. So I do appreciate and … taking part in this project as well has also made me research a bit more, so I have actually applied to be a volunteer for the BTA now. So I feel confident enough to do that, whereas before I would have no way have done that because I would have been scared of spiking it. So thank you everybody for sharing. I think I’ve learnt something off everyone here today. So as we say in Wales, *Diolch yn fawr!* <Laughs>

**I:** Thank you P3!

**P1:** I don’t think I have anything as profound to add really! Sorry. I’d just like to echo everyone else’s sentiments really. But one thing I think … I’m not massively artistic but I do have arty bits as a result of … lockdown, you just go on Amazon and buy loads of tat, don’t you? So what I might do is actually experiment with the pack of parcels that I’ve got sitting on my desk, or just something to do with colour, because I really … P4, your representation was really interesting. So I think that might have inspired me to have a little look at my own creation maybe.

**I:** Thanks all of you. I hope you didn’t feel too put on the spot there, but all of that is so fantastic to hear, and P1, if you do wanna share any future artistic endeavours, please feel free to share them with us. We’d love to see those, and I should say all of the activities should be available to you; should you wish to go and do any of those now that we’ve had this discussion, you’re very welcome to use that activity sheet. So yeah, you should still be able to access that.

**<End of Interview>**