**File name: Thursday workshop 1hr38 5 participants**

## Key

**P:** = Participant

**I:** = Interviewer

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

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

[word] = best guess at word

… = interruption in sentence, trailing off or short pause

**I:** So the purpose of today’s discussion is to discuss with you all, or chat with you all about the various workshop activities that you have taken part in, or that you decided not to take part in as well. We’d welcome some feedback around that as well. And reflecting on the process of taking part in these activities. What was it like to engage with your tinnitus in the various ways that we’ve guided you to do so? We’re also going to be looking at some of the responses that have been created with these activities. I should say that everyone here is going to be represented in the responses but we’re not sharing all of the responses that we got because time limits us from doing that. So I’m going to go through a few ground rules, which sounds very formal but will hopefully give you a sense of some of the more practical aspects of today’s session and what you might be able to expect and how the conversation is going to take place. So Sally, could you go to the next slide please?

So the first thing to note, I’m sure many of you here today are aware, is that tinnitus can be a sensitive topic for discussion. You’re very welcome to take some time out of the session or leave if you feel you need to, and we’ll come back to that again in a moment.

As part of the workshop we’re going to be looking at some responses that have been created by different people in this group. Our discussion should be focussed on the process of making and how these responses reflect different experiences of tinnitus, what they capture about tinnitus. So please be considerate of others when you are 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 of an activity response should you wish to. So if you want to tell us a bit about what you’ve made and why you took the approach that you did, feel free to, but there is no obligation to say, ‘Actually this is mine’. If we can just keep that in mind.

There’s some activities where it’s a little bit more difficult to keep people anonymous. That should become clearer why that is as we go on but nonetheless we’ll, as a principle, not name people who’ve created the different activities.

One of the things that’s really come out clearly over the course of these workshops is that tinnitus can really affect people in different ways, so please keep in mind that others might have experiences that are different to your own.

OK, Sally, can I go to the next slide please? So a couple of practical things. Some of us are using Zoom’s auto-captioning, I’ve mentioned those a few times now, the auto-caption function. This works best when one person is speaking at a time and there is limited background noise, so with this in mind, please can you make sure your microphone is turned off if you’re not speaking and try to avoid talking over others. We know that that can be difficult when you’re having conversations. So with that in mind, if you want to enter into a conversation but are struggling to do that, feel free to wave at us on camera and we’ll try and pick that up, or if not, in the bottom right-hand corner of Zoom there is a reactions button and if you click that there is a raised hand option. So if you are wanting to get into a conversation that’s probably quite a good way of doing it. There might be some times where it’s entirely appropriate to just unmute and speak. We’ll just have to see how things go.

The other side to that is silences, or relative silences, are OK. We know that some people might take a while to think and respond, so please don’t worry if nobody is saying anything.

We’re going to be having a 15-minute break halfway through the discussion, so at five to eight we will have a break for 15 minutes. If you need to take some time out from the discussion before or after that break, you’re very welcome to leave the session and if you would like to re-join you should be able to just re-click the Zoom link that we sent you and that will bring you back into the session. If you are wanting some extra support during the session or if you are needing someone to talk to or if you can’t figure out quite how to step away from the session, please feel free to message Sally using the chat function. The chat function will allow you to send a private message, you just need to change the recipient to Sally from everyone. So if you’re needing that, please do feel free to message Sally.

OK, I think that is the discussion guidelines. Does anyone have any questions relating to those?

<Pause>

No? OK, good. Great. Thank you everyone. And Sally if you wouldn’t mind going to the next slide. The first activity that we’re going to be talking about and looking at responses to is the tinnitus maps. So I’ve got a quick reminder on the next slide of what this activity was. This is a cut-down, edited version of the instructions, but this activity was about getting you to map out the different relationship between places and environments and your tinnitus. So you were asked to identify some different places or environments and represent those on a map, and then place your tinnitus on the map, where your tinnitus was perhaps more noticeable or where your tinnitus was less noticeable, where you might associate your tinnitus more with or less with. That was the kind of approach that we were encouraging you take. So before we look at the responses, I’d welcome any reflections that you have about the approach that you took to this activity if you participated in it, how you approached it or what you thought of this activity, whether or not it was something that made sense to you. So yeah, I’ll hand over to anyone who wants to say anything.

<Pause>

**P1:**  I took it quite literally and drew an actual ordinance survey map, which I like doing anyway, part of my work during lockdown has been drawing maps for some people in America, fantasy maps, so I was on that roll anyway so it kind of fitted in with the whole where my head was at at the time, so it was an interesting way to reflect on the last year-and-a-half as well.

**I:** Thanks P1. Does anyone else have any thoughts?

**P2:** I think maybe my approach was almost the opposite. I found it really difficult to think of specific places that … there’s one place in particular, which is when I’m sitting in bed or lying in bed, even if it’s not night-time, it can be in the daytime, but bed is where it’s loudest. And apart from that it was all very activity-based, so it was like if I’m out with friends I don’t notice it at all but then if maybe a quieter activity then it might … so yeah, for me the mapping aspect was … I was really interested in it to begin with but then I was just like argh, there’s not really that many places that I was able to link it to easily.

**I:** Thanks P2. So for you, mapping out activities rather than places would make more sense?

**P2:** Yeah.

**I:** Thanks.

**P4:** I think I can relate to that as well, ‘cause I never really associate it with places. It’s more the loudness of the environment I’m in and whether I notice it, and that tends to be in quieter places, but it was interesting to think about where those were and it made me realise that there’s certain places where I don’t feel I hear it at all, and I’d just never really noticed that, so it was quite interesting to see how it was associated with certain places.

**I:** Thanks so much, P4.

**P3:** Yeah, I really struggled with this one personally. I thought the idea was originally quite good, but the more I thought about it, the more hung up on it I got, and as P2 said, it’s more activities that I associate tinnitus with. There is not actual set place where it affects me more or affects me less. So yeah, I had to skip this one in the end.

**I:** Thanks P3. So yeah, it’s interesting, for some people the place-based approach does make sense or is something that they could get a hold of, but for others an activity-based approach would make more sense. Yeah, interesting.

OK, does anyone want to say anything about how they went about identifying places, ‘cause we did give you some suggestions of how you might think about this. Or was it something, P4, I think you said that there were some places that you had noticed that you notice it more or less … I’d be interested to know a little bit about the process by which you identified places.

**P4:** I think when I knew when I was lining myself up for this, I tried to be a bit more conscious in the runup to the art sessions and the workshops, just to try and notice it a bit more, ‘cause I don’t know how the others feel but I’ve had tinnitus for so long that I just try and ignore it, and I’m so used to just putting it to the back of my mind that I have to think consciously of where it was louder, and I ended up discussing it with my husband quite a lot in the runup to doing this, ‘cause again you just accept it as part of life, don’t you, and you don’t really sit and chat about it, so it shone a light on it really which was dead interesting. So yeah, and then I started just commenting that one evening I could hear it while we were watching TV, and that led me on to thinking well I always hear it when I’m in bed, but at the gym not at all … so it just escalated from there really. More thoughts came as to where it was affecting me most.

**I:** Thanks so much P4. That’s really interesting. P5, were you wanting to say something?

**P5:** Just similar to what everyone else is saying, and I did find … I know this is a mapping thing, but as it went on I found it quite difficult visualising it, and also, sounds a really obvious thing but I got it a few months before the pandemic, so I haven’t had it comparatively for that long, so just less places that I’ve had it in, if that makes any sense. So I did go on a walking holiday last summer and it was quite … I hadn’t got used to it, so I found that difficult in terms of the wind and so forth, so environment I suppose … I don’t really think about it in … my map was really boring, but it was mostly in terms of the house and the local area really, so quite limited places that I used.

**I:** Thank you P5. You’ll have noticed that our own examples were from quite a confined set of spaces, and it was for precisely that reason, that the pandemic is quite the restriction on this activity, isn’t it? It would be interesting to do this … hopefully at a different time. But yeah, thank you P5, that’s really [13:33]… and don’t feel that that’s stating the obvious, it’s really quite an important thing to remember, that mapping out places and environments at this point in time is not an easy thing to do, when a lot of us are spending a lot of time in various rooms in our house, if we’re fortunate enough to have multiple rooms. So yeah, thank you.

Shall we have a look at some of the responses.

Great, OK, so this is the first we’ve got.

<Pause>

What we can do is we can go through all of the responses in one go and then talk about them, but also if anyone wants to say anything as we’re looking at a particular response, feel free. And also I should say if anyone is struggling to read the text, please just let us know and I will try and read it out.

<Pause>

Those are the four examples we’re going to show you.

Feel free to offer any reflections on what you’ve just seen there, or if you want to go back to a particular example we’ll be very happy to move the slides back and forth, but at this stage I’d welcome any thoughts you have on these maps, what they might capture about different experiences of tinnitus, are they a way of sharing different experiences of tinnitus, what do they not capture? Feel free to offer any comment.

**P1:** I think it was possibly fairly obvious that most of us would mention that the bedroom is a place where it’s loudest. For me that’s, I don’t know if any of the rest of you wear hearing aids, I wear them mainly for tinnitus but partially for high-end hearing loss, and of course when I go to bed I take them out, so it becomes that much more noticeable going to sleep and in the morning when I wake up, before I put them in.

**P3:** I find it really interesting that everyone’s mentioned the bedroom. But then everyone’s tinnitus is different. Mine isn’t so constant and it comes in blasts and I don’t really notice it at night or in bed. But it is fascinating that a lot of people do.

**I:** Thanks P3.

It’s quite noticeable, we’ve given you quite an open set of instructions in many ways and we did give you some examples, but it’s really striking the difference in approach that’s been taken here. It’s great!

**P4:** Interesting that lots of people use similar colours as well, so red for loudest and that sort of traffic-light system I guess. I don’t know who did this one, but that map is absolutely amazing. Maybe that’s P1’s artistry.

**P5:** There’s one thing with tinnitus that none of us have drawn and it didn’t occur to me at the time, is you said about a map and things but there’s no silence, so it’s always something. So we identify the sounds around us in relation to tinnitus, so I think that’s probably what I miss most is just some quiet, not having to think of what the other sounds are or the environment even. So I suppose that’s one thing. These pictures are great, and the thing about ‘turn it up please’ and the TV and I can’t tell … I’m not deaf in any way, but I just think I don’t hear sounds in the same way anymore, just because of that distraction.

**I:** Thanks P5. So you can relate to some things that others have –

**P5:** Yeah, definitely.

**I:** - have put on their maps.

**P5:** Yeah.

**I:** P3, I’d be interested to know, ‘cause you said you didn’t do this activity, because for you it’s not space-based. Space-based sounds a bit … that’s hard to say, but this activity didn’t really work for your tinnitus is probably how we might say it. Having seen others’ examples, do you still think that’s the case or do you think if you were to an activity-based map it would make more sense?

**P3:** It’s been fascinating seeing all these answers, they’re all brilliant, but I don’t relate to much of it to be honest. Yeah. I mean actually tinnitus has been on my mind a lot lately because it’s recently come back and in fact it kind of went away before this week and then amazing timing, came back on Monday! So I’ve been thinking a lot about it this week, and a lot of these activities have helped me think more about it and actually when it happens or what causes certain tones or … but none of it is rational. It’s … yeah, I think … if I kind of do a map now I’d still feel I can’t really put it to places. It’s more to activity, if I’m to do some kind of map.

**I:** Thanks P3, yeah, I should say as well, that question wasn’t trying to put pressure on you to do an activity that wasn’t work. I should say for everyone’s benefit that we know that not all of these activities will work for everyone because tinnitus is so different.

**P3:** No pressure, didn’t feel any, so don’t worry about that!

**I:** Right. Thank you. Is there any other final thoughts on these maps and the differences between them or how they express something about tinnitus? Do you think that these … for those of you who did do the maps, do you think that these would be able to show something to someone else who perhaps didn’t have tinnitus, what tinnitus is like? Do you think they’re able to capture that, or are they missing too much in order to really be able to share that experience?

**P1:** I think they certainly give an idea. It’s very hard because it’s … if you’re talking to someone who doesn’t have it, it’s hard for them to appreciate no matter how … you can’t put on a pair of headphones and … well, I suppose you could but it doesn’t quite tell them what it’s like every day. We’ll probably get onto this later but it’s interesting that people experience it in different ways and hear different sounds and sometimes people are less aware of their tinnitus because it manifests itself as a particular noise that they might hear every day anyway. But I think it’s a very good launching point for pointing this conversation forward to people who are worried about it or intrigued by it or … whatever. <Laughs>

**I:** Thank you.

With this activity as well, we’ll come on to some later, we’re not really asking you what your tinnitus sounds like with this activity; we’re taking a slightly different approach and I wondered if that was something you had thought about in this way.

**P5:** Sorry, I missed … which approach did you mean?

**I:** Sorry, I’m mindful that my internet is being a bit glitchy this evening. With this activity, which was the first activity, we weren’t asking you what your tinnitus sounded like, to describe it as it sounds to you. We were asking quite a different question with this activity and I wondered if this is something you’d been asked before, where is your tinnitus, where do you experience tinnitus, whether this approach was something that was surprising to you, not to be talking about it first of as how it sounds but in relation to place.

**P5:** Yeah, I agree, mostly you think about the sound or the how often it happens or how long you’ve had it. Those are the things I’ve usually discussed.

**P2:** I think for me it took me probably a couple of days to do it, because I had that automatic ‘Oh yeah, this is the one place’ and then I really had to … I think pretty similar to what P4 was saying earlier, actually, just had to think about it a lot more and when I was out and about or doing different things or in different places, try and work out or try to remember to tune in and be like, ‘Right, OK, what’s happening here at this time?’ So yeah, and like what P1 was saying about a kind of launching pad, as an activity it was a good launching pad to start to think about that as well I think.

**P4:** I was just going to add that I did actually go to the hospital in the spring to have my tinnitus investigated after probably two decades of having it, but the doctor was asking about what it sounded like, how frequently I had it, but nothing about the environments I was in at the time or where I was when it occurs or when I notice it. So I think that’s just an area even specialists maybe don’t think about.

**I:** Thank you P4. Thank you all for your generous responses. P2, I’m really struck by you, and Cath was well your description earlier, that you were having to tune in, because obviously that makes things more complicated, doesn’t it, when you’re tuning in to your tinnitus, that can make things a bit more difficult because obviously it might mean that you notice it more. But thank you so much, everyone, for sharing those experiences and your reflections on these maps.

So I’m mindful of time, shall we go [26:25 IA] Oh OK, I can hear that I’m breaking up.

<Pause>

Am I coming through now? OK, I can see some nods, sorry about that. Obviously everyone in Nottingham is on the internet at the same time I think. So hopefully my internet connection will stay with us. So this was the tinnitus portraits activity. If we can go to the next slide, Sally … we should have some instructions. OK, so with this activity you were asked to draw a picture of yourself, and that could be as detailed or as abstract as you wanted it to be, and we then asked you to [28:16 IA] where you heard, up to any reflections that you had on this activity, what it was like to do this activity, whether it was something that you felt easy or difficult to participate it? And then we’ll look at the responses together.

**P2:** I this this one, for me, was another one where I had to tune into, and I think when I sat down to do the activity, it was I guess a more constant tinnitus, the norm or my norm tinnitus … the default I guess, and then I think after I’d done it, I noticed that there were more fluctuations and variations than what I’d done in this. But yeah, even after doing it I was still not sure how I would represent those, but yeah.

**I:** Thanks P2, I’m hoping I’m coming through now. I’m sorry if I was glitching previously. [30:06 IA] Thanks for that.

**P4:** I found it quite interesting thinking about where it is in my head. I’d just had the perception that it’s in my ears, but actually this made me reflect and think it’s almost like it goes across the middle of my head almost, like reverberates inside my skull. And because you don’t think about it or examine it, I’ve just never really thought about that or realised that really.

**P4:** Yeah, like P2, I found it quite hard to make it visual.

**I:** Thanks, yeah. We’re in many ways asking you to do a very difficult thing, which is to put sound into image and yeah, that’s a very, very challenging thing to do. So can totally appreciate if that was difficult, but thanks for sharing that this opened up a different understanding if your tinnitus in that way.

Shall we have a look at the portraits? Sally are you happy to … oh, you’re there already.

So much like the last activity, feel free to take a few moments to look through these and then if anyone has any thoughts on what impression of tinnitus might we get, what understanding of tinnitus might we get from these different portraits. I’d welcome any thoughts that you had.

**P2:** I’m quite interested in the asymmetrical aspect that it looks like a lot of people have a different … a worse ear and a better ear for want of a better way of saying that. ‘cause I definitely … I think that was one of the few things that I had noticed about my tinnitus beforehand, was that there was some sort of difference, but I haven’t really thought about it that much before.

**I:** Thanks P2, so a lot of these pictures [32:48 IA] Sorry, I talked over you.

**P5:** I went to get my ears checked at the hospital last year and when it was explained it could be just something that’s internal that becomes external, and that’s … I found it quite difficult to visualise because part of it is coming to terms with it, so I didn’t actually like thinking about it, if that doesn’t sound too … silly. But … yeah. I did find it interesting but really hard to do or … I don’t know, just even trying to focus on it could make it worse … and it isn’t even that bad in … I don’t know what bad is, but yeah, think it’s … so it was interesting, ‘cause again one of these things is trying to understand it, and I hadn’t done it in this way before.

**I:** Thanks P5. And yeah, this was one of the activities we definitely gave a health warning with, where we said that in drawing where you are experiencing it, [34:01 IA] can draw attention and that’s [34:24 IA] I’m sorry everyone, I think my internet keeps dropping out again. I don’t know how much of that was heard.

**I2:** Are you able to switch your camera off, Marie? Does that make a difference to the bandwidth? I know it’s not ideal.

**I:** Erm … what I’m going to do, I think I’m going to move room. The connection should still hold while I’m moving, so please feel free to talk amongst yourselves while I just go slightly closer to my router.

**P1:** Was it P4 who said that on reflection it was like a line going through her head? Having finished the drawing, a few days later I thought if I’d drawn it again I would have had a line and subsequent little sketches I did did have a line going straight through my head, despite it’s louder on one side than the other. There’s definitely a kind of cut through, when I stop to think about it. And as we were just discussing, I do find, even now because we’re talking about it and reflecting on it, especially my right ear is making it known a lot more than usual!

**P3:** I really enjoyed this activity, especially because I have so many different types of tinnitus, so it’s me, the bottom left – if you can’t read my handwriting that’s fine – the one off to the far left is the more recent one, the most distressing, came out of nowhere, sounded like a sound outside of my head. I even went round the house going, ‘What’s that noise, everyone, what’s that noise?’ And no one knew what I was on about. And it also made me realise I have very different tinnitus in each ear. I don’t ever get tinnitus across ears. It’s always in one ear. And I realise actually that I’ve got a left and right wrong on this one – I think I meant … so the left and the right is the other way around. Yeah, so that first one is this new low groan which I’ve never noticed before, and what was quite interesting about it is that it’s two notes that it kind of oscillates between, almost like someone on a very loud deep organ, switching between the two notes. And that was constant. It just wouldn’t go away. It hasn’t really fully gone away, it’s got quiet so less noticeable, and that’s always in the right ear, never in the left.

The other type of tinnitus, the one in the middle, very rarely have but when it comes it’s always quite loud. It’s this noisy … rustly … it’s quite hard to describe. Describing it as just white noise is kind of a copout but it’s like a kind of wind rushing sound. That tends to fade out quite quickly. And then to the right, perhaps the most common one I think, [38:11] and that loud eeee and a ringing sound. But what I found with that one more recently is that it was like an air pressure change when it happens and it feels like it affects my balance ever so slightly. So there have been times I’ve had some mild vertigo along with this ringing, which is what I tried to convey with the little [38:37] at the head.

Yeah. I have all sorts of types of tinnitus actually, as I realised this week. Just comes into different activities, some perhaps more embarrassing to talk about, like … intimate situations or … using the bathroom. But I didn’t want to draw those kind of ones, so I spared you all of that!

But yeah, it’s fascinating how two of them are quite similar in that they have something going through the head – I’m not sure I relate to that personally. But yeah.

**I:** Thanks P3, and hi everyone. Hopefully my voice will sound slightly different now. Unfortunately I have relocated to what the cat thinks is his room, so we’re now … I’m sorry if everyone’s bored of Zoom pets but we’re now at risk of a cat taking over this situation, so if you see me moving my arm like I am at the moment it’s because I’m trying to stop a cat climbing on the laptop! But thank you so much for all of your reflections.

I was wondering, P3, you said that you experienced different types of tinnitus and you’ve drawn three different heads – was that to reflect the separation those different types of tinnitus or that they don’t happen at the same time, or is it that you wanted to be able to depict them separately? I guess I’m asking how that experience led to certain choices that you made in this activity.

**P3:** Yeah, they don’t all happen at the same time and they don’t all happen in the same ear. I’m always really noticing [40:46] tinnitus on my left side, my left is my main ear, that’s where I’ve had the ringing, the eee one, even the rustling one. I’ve never really had such issues with the right ear until very recently, where this low groan one has come in. That one I find easy to visualise because it is like two note groan and I tried to convey that the strong tone and this other one that tries to take over … or it feels like … I can’t tell whether I’m doing it myself, listening too hard, or whether it actually oscillates in between these two notes. So that’s why it’s a stronger blue and it’s a constant note of A and the F# is this one that interrupts and comes in. And yeah …

**I:** So for you, this activity needed to be tinnitus portraits rather than tinnitus portrait, because there are different –

**P3:** I think if I’d have put them all in one it wouldn’t have communicated what I experience. And I ended up annotating it quite a lot, which I on reflection thought perhaps not what I was supposed to do, but I felt it was important for getting across what I experience.

**I:** Great. Thanks P3. Before we move onto the next activity, does anyone have any final thoughts on … I’d be particularly if seeing your own portrait in the wider context of other people’s portraits changes how you look at that portrait or if seeing it in this way now or seeing other portraits has made you think about taking a different approach to this activity? Just anything about seeing these portraits together, any thoughts that you might have would be welcome.

**P4:** It’s interesting to me how internalised mine looks. So mine’s the one with the red jagged lines going across my head, and when I was doing it that just felt like the natural way to illustrate my portrait with tinnitus but it’s almost like I’m so conscious of it just being inside my head, and that no one else can hear it, whereas the other portraits it feels more like it’s something that’s being done to them almost, it’s more externalised. So I don’t blame myself for having tinnitus or anything like that; but it’s interesting how I’ve made it really closed and internal and something’s happening to just me and it’s quite isolated.

**I:** Yeah, thanks P4.

**P1:** Yeah, that’s very interesting in that even though I know it’s in my head, it does feel like it’s projecting out for me. It feels like those noises are kind of coming out of my ears <chuckles> even though I know they’re not. That’s how I visualise it.

**I:** So P1, that’s really interesting. So even though you know – there’s that thing of you know that the sound isn’t located there, but at the same time that’s what you experience or that’s what the sensation is, that it’s in a different place; is that correct?

**P1:** Yep.

**I:** Great, thanks.

**P5:** I’m the same as P1 because when it was explained to me by the doctor at the hospital, explained or an explanation, is that it’s noises that are there all the time but you don’t normally hear them, so I always thought them as coming out but I agree with P4 – then it’s confusing because again only you hear it, so if you think about it too much it’s just a bit crazy … so I’ve got no rationality about it, but it is confusing because it’s noise that seems to be coming out but actually is inside.

**I:** Thanks. I’m mindful that we’re at four minutes to eight, so … no, I’m not even reading the time right now! We’re at 19:54, so we’re now at five minutes to eight, so I’m going to suggest that we take a break there. Thank you so much for your contributions so far. If we can take a 15-minute break, please feel free to have a walk around, get any refreshments that you need or just have a break from the screen, should you wish. You’re very welcome to remain logged into Zoom if you want to put your camera off and mute, that’s totally fine, and if we could be ready to start speaking again at ten-past that would be great. But thank you so much for your contributions so far. It’s been really great discussing these activities with you, and we’ll see you again at ten-past.

<Break>

So Sally, would you mind putting the slides up again?

<Pause>

Great, thank you. And Sally, could we go to the next slide? So the activity that we’re going to talk about next is the tinnitus drawing activity, and the purpose of this activity was to consider how tinnitus may be represented without using words, and how drawing might be used to represent tinnitus instead. So the instructions you were given were using whatever materials you wish, try to draw your tinnitus once a day for three days. Consider setting a time limit for your daily drawing, for example five minutes. We gave some examples of drawings, but you were very welcome to draw in any style that you wanted to, and you could have taken a photo of your drawing each day so you could record how it developed over the three days.

So first things first, we’d welcome any thoughts on what it was like to do this activity, how you approached this activity if you did it, if you didn’t do it why that was, any thoughts about this activity to begin with before we look at a couple of responses?

**P1:** I kind of messed up a bit in that even though I read the three-days thing, I couldn’t work out how I could come back to the survey after I’d started it, and I’d started it not long after I got the email, so I thought about … because I’d thought about it over the years anyway I just amalgamated those into one drawing and so apologies, I didn’t get it quite right, but it was interesting.

**I:** That’s absolutely fine. These instructions are only guides anyway and we’ve seen that people have taken different approaches to the activities if they can adapt them for themselves, so please don’t apologise. I’m sorry, you were so quick off the mark P1, you’d got the activities before I’d even had a chance to email you the link out so you were the super-speedy responder and so yeah, that’s why you couldn’t return to the activities without saving the URL. But thank you nonetheless for your drawing.

So P1, you said this was something you had thought about before. Had you tried to draw your tinnitus previously?

**P1:** Sort of … I’ve kind of done doodles and things. Weirdly when years and years ago I was doing a foundation course, god, too many years ago to think about, and one of the best-received pieces of work I did there was when I got conjunctivitis and I did a panel painting about what that felt like for me internally, and everyone said, ‘Oh you’ve got to carry on doing that’ but because I wasn’t then ill with anything <laughs> I didn’t. It was kind of force it and they were just rubbish. So this is probably the first time in a long time when I’ve actually sat down and deliberately do it. Throughout the time I’ve had it, I will sometimes doodle, usually if I’m at a concert I can’t stand seeing people with mobile phones filming and taking photographs, so I whip out a sketchbook, not aggressively <laughs> but sort of passive-aggressively, and do doodles of not just the band and stuff but the whole feel of it. So I do quite like trying to draw sound, but it’s not something I’ve ever really, really focussed on and so this has probably pushed me in that direction.

**I:** Thanks P1. I like the idea of passive-aggressive doodling at a gig!

Shall we take a look at a couple of the responses then. Sally, would you mind going to the next slide? So this is one, and this was given the title ‘Inside my head’.

<Pause>

And can we go to the next one please? And I don’t think this one had a title.

<Pause>

And as before, we’d welcome any thoughts you have on these responses, what, if anything, they capture about tinnitus for you, the differences in approach, the similarities in approach, any thoughts that you have on these responses.

<Pause>

**P2:** This one is mine and I think I was trying to capture different aspects or trying to work out different ways of representing it so for each day, and I think the middle one … I wasn’t experiencing this really mad fluctuation one at the time but I think I’d got it the night before or something, so I was trying to remember that and try and represent it. I guess the different swirls was maybe more often it’s more … like a line I guess. So yeah, I think that’s what I was trying to do there.

**I:** Thanks P2. So you weren’t taking the approach of drawing the tinnitus that you were experiencing at the time necessarily; you were thinking about some of the different experiences that you had and trying to capture those, or represent the differences between those experiences?

**P2:** Yeah, I think so. I think the first one is probably my most standard, that was probably what is happening at the moment, and then I think the third one is similar in a lot of ways to the first, but trying to … just trying to work out what is the most accurate representation of how that sound looks, which is I guess pretty much impossible, but …

**I:** So if we got you to do this activity over … this is a hypothetical, over the course of a month or a year and you did this daily, we would be seeing the first and the third most of the time, and then we might have occasional appearances of the second; is that correct?

**P2:** Yeah, I think so.

**I:** We’re not gonna make you do this for a month, don’t worry!

<Laughter>

**P4:** Mine was the first one. I felt like it was always quite linear, similar to P2’s, ‘cause it’s just always there, but I tried to capture different moments of intensity, so that second morning, for some reason, it was really loud, so this was … line is kind of spanning the whole day, and then I think <laughs> I just went over it all together, because it’s there all the time and probably I felt, I’m pretty sure I felt really quite frustrated by the end of this process ‘cause I realised how it is there absolutely all the time, whether I notice it or not. So it kind of made me a bit cross in a way, that putting it down on paper you do realise how much it is in your life and how little you can control it. So I think those scribbles across the middle were my passive-aggressive, maybe, like Adrian, taking it out on paper.

**I:** Thanks P4. So one of the really interesting things I think I find about both of the drawings is how there’s lots of things that look similar in them, so there’s a sense of things being the same or very similar, but then there’s also quite a bit of variation even if that variation is quite subtle. I wonder if that was something you’d consciously … I mean Rowan, you said you had tried to incorporate something that was a different experience within that drawing. Cath, I was wondering if that relates to your drawing as well, whether you’d thought about trying to get … you said variations in intensity but then you wanted the linearity because it’s there all the time?

**P4:** Yeah, and I felt like … so I did the three lines and then I also felt like I needed to fill the paper a bit more because that wasn’t reflective of what was inside my head, and the two at the bottom, the diagonal ones, they’re more about how I can feel it sometimes in my jaw and then these bubbles are … sometimes it feels like it’s just pinging round inside my head as well, so trying to capture that movement inside my head I guess.

**I:** Thanks P4, yeah, so there’s a lot of detail. I hadn’t even seen the bubbles before, so yeah, there’s a lot of detail in there.

<Pause>

Does anyone else have any thoughts – I’d be interested to know, for those of you who these aren’t the drawings of, whether you seen your own experiences of tinnitus in these drawings, or is that an impossible question because, as we know, tinnitus tends to be quite a personal or individualised experience?

**P1:** I think I’m seeing elements … obviously where we’ve got a similar squiggly line, which is obviously quite a common thing, but beyond that I’m seeing similarities that perhaps I didn’t exactly see before, with the first one, with the lines then going up and stuff. That really fascinated me. I can’t quite get my head round how they’ve turned that from an experience into the paper, but that really amazed me ‘cause … yeah … it’s very hard to think of it, and because we’re talking about it, it’s kind of getting louder and louder, but when you do stop to think about it, it’s then, ‘Am I thinking about it too much and therefore overthinking what it’s like?’ and so I try and go away and just … when I catch it again then try and put it down, but it is quite hard. And as Catherine was saying, it’s there all the time and most of the time I can cope with that but there are days where yeah, the squiggly lines there are very much of some moods some days <chuckles>.

**I:** Thanks P1.

<Pause>

If anyone’s got any final thoughts on this activity, please feel free to share them, and if not we’ll go onto the next one, which is we’re moving away from drawing and international words.

OK, shall we go to the next one then please Sally? So this exercise was called Putting Tinnitus into Words, so for this activity you were asked to choose a word or create a list of words, as many or as few as you like, whether written and/or spoken, that you associate with tinnitus. Think about tinnitus can be conveyed in the multiple meanings of the word, write some of these down. Alternatively you can record yourself speaking the word and some of its meanings.

So, I think with this activity we’ll just go straight to looking at the list of words that we received. So what we’ve done is we’ve put together lots and lots of the different words that we’ve received from different workshop participants and we now have a big long list of words, they’re in alphabetical order and we’ve got a few definitions that we’ll focus in on after we’ve spent a bit of time looking at this list, but I’d be interested to know what impression of tinnitus you get from looking at this list, or any other thoughts that you have about this list of words. Oh no, we’ve cut some words off, there was too many words! That’s my fault. Oh …

<Pause>

**P1:** Delight jumps out. I’m very surprised by delight!

**I:** I’ve seen some of the definitions to these words so I’m always torn between explaining the term and just trying to hang fire and just let you have a look at this list of words.

So delight jumps out at you, P1. Are there any other words that jump out at people?

**P1:** When I say jumps out, it’s as a surprise, it’s not something <laughs> I’ve ever felt! Sorry.

<Pause>

**P2:** Just a similar thing. Luck was one that I saw there that, yeah, wouldn’t have necessarily expected.

**P3:** Yeah, a lot of these words are quite negative, and yeah …

**I:** Does the negativity, is that what you were expecting or is that surprising to you?

**P3:** Definitely expected. I don’t think any of us [61:29] the tinnitus. However, those of who have had it all our lives, or a long time, there is a … a familiarity that comes with it as well.

The word that jumps out at me were barometer, and that makes me think what that could mean, from the person who suggested it, and also … <laughs> rubbish, unalienable … I don’t even know what that one means. I think a lot of these do get to what I feel about my own tinnitus. It’s never welcome, but it comes … although there is an odd comfort in it sometimes as well.

**I:** Thanks P3. Do you think if we showed this … there’s always the hypothetical here, but do you think if we showed this list to someone who didn’t have tinnitus, they might get some ideas of what tinnitus is like, or what conclusions about tinnitus do you think they might draw from this list if they hadn’t themselves experienced it?

**P3:** Well they certainly would hate it, like, ‘Oh my lord, this sounds terrible!’ But in terms of describing, to someone who doesn’t have it, I think there’s ideas in these words rather than descriptions. I think they give you an idea of the possibility of having tinnitus and what it might be like.

Aura, aura’s quite…

It’s a great list. Yeah.

**P1:** Fire’s another one that’s quite interesting. I can’t quite get my head round that one!

**I:** So seeing these words without the definitions, some of them it’s quite hard to … certainly for me, some of them I’m like yeah, I was expecting to see that word there in a conversation about tinnitus, but some of them I think oh, they’re quite unusual, aren’t they?

**P4:** I find effervescent really unusual, ‘cause that feels quite … light and fun and not a serious thing at all, whereas that’s not my experience at all. And it’s interesting that acceptance is there, because I think you do get to that point where you just have to accept that you’re living with tinnitus so I can relate to that one.

**I:** Yes, so there’s some words, P4, that you’re like, ‘That’s not my experience,’ but then there’s others that you think, ‘Oh, actually that is’. So yeah, I guess that goes to show that this is definitely something that’s pooled together from different people’s experiences, the fact there is those different relationships, different words.

**P5:** I think it shows the variety of the experience. I don’t know if anybody who hasn’t got it could identify with it from these, but I think they are helpful in terms of the range if nothing else, that it’s not the same thing to everybody and …

<Pause>

**I:** Thanks P5. That probably explains why some of the words seem to be quite contradictory as well.

Shall we have a look at a couple of the definitions? So Sally, if you wouldn’t mind going to the next slide. So the first we’ve got that I chose for us to look at was ‘legacy’. And the definition that we received was, ‘It’s always with me. What I was bequeathed by a virus. Here to stay.’

And if we could go to the next one please … ‘Musical: Despite their often minimalist and noisy forms, there are times I feel like they are a particularly difficult performance or composition that I can meditate with.’

Can we go to the next one please? ‘Interference: Sound waves at me. My insides interrupting me. Misheard embarrassment.’

So yeah, I’d welcome any thoughts that you have on those different definitions. Does seeing the words in relation to the definition change how you view those words? Any thoughts would be welcome?

**P4:** It was interesting hearing the definition of legacy because I assumed that was some sort of more kind of a genetic trait or something. So my dad always suffered with tinnitus as well so I immediately thought something that just continues through families and bad luck if you get it. So I think it’s quite sad that it was brought on by something you couldn’t control and now you’re stuck with it.

**I:** But interesting that you could add another definition of legacy to this person’s definition, potentially, so more than one person could potentially contribute different definitions to a word.

<Pause>

**P3:** Interference is very apt I think. It does almost feel like an interruption into whatever we’re doing. It never seems to have any warning that it’s coming. It just comes. And whether I’m feeling tired or wide awake, and … yeah …

<Sighs> It is like being in the car, listening to the radio and suddenly the station has just been thrown off to this new station that you can’t then tune out of. So yeah.

**I:** I’m really liking this definition of interference, sound waves at me. I like the personification of sound here.

<Pause>

Are there any words that, having seen this list and seen the different definitions that people have provided, are there any words that you would consider adding to that list?

<Pause>

**P5:** I don’t know about the adding to, but the embarrassment word … ‘cause it’s such a weird thing, ‘cause I think that’s one of the things that I’ve read is that if you’ve got an illness or there’s something not working quite well you’ve usually got exterior evidence of that, like conjunctivitis or … any other illness, but with this you do feel like you’re … how do you explain it? It can be … when I first got it, how do you describe it, and it is a bit embarrassing because it’s so altering because it’s there but nobody can see it. So I don’t know what the right word is to add to that but … yeah, there is a … I did feel embarrassed or just uncomfortable. And again you might speak about it at certain times but then most of the time I don’t, and it’s really interesting when people do mention they’ve also got it, because again it's not something people talk about but it does seem relatively common.

**I:** Thanks P5. So for you, you could potentially add in the word ‘uncomfortable’ and I’m sure a lot of people would see that words as describing the sound, but you’re actually getting at in your description there is the difficulty in explaining to others what’s going on.

**P5:** Yeah, and one of the words I added was ‘isolating’ because I just remember early on when I found it really difficult and with family, you can keep … you can talk about it but in essence they can’t hear it or see it, so you look like you’re normal or whatever. So yeah.

**I:** Thanks P5.

I’m very mindful of time, so perhaps if no one’s got any further thoughts on this activity we can move onto the next. So the next activity was called ‘keeping score’ and if we can go to the next slide please, Sally, this was the activity where we asked you to come up with word sounds that were either written or spoken that somehow were related to what your tinnitus sounds like, and we suggested that with this, and also the next activity that is quite similar to this, that you didn’t try and get an exact match for your tinnitus because that would be quite difficult but you tried for a creative interpretation of what your tinnitus sounded like.

So we encouraged you to try out different word sounds out loud. I’m not going to read the word sounds that I wrote down for the moment, and not to worry, as we said here, if it didn’t sound exactly like your tinnitus. They’re meant to be a creative interpretation rather than an accurate recreation. We then suggested you could either write down or draw your tinnitus word or record your tinnitus word. Now I won’t be playing, for this and the next activity, which I’ll explain in a moment, I won’t be playing any of the sound recording submissions that we received. Thank you if you did do that. We are hoping to make some of those more widely available through another means which I’ll mention at the end of today’s session, but for the moment the reason that we’re not playing them on Zoom is because we know that Zoom is not great for sharing audio but also we have groups for different hearing capacities, so it’s best that we stick, for the moment, with the visual representations. But as I said, I’ll talk to you about the possibility of making the sound-based representations more widely available towards the end.

So again as we’ve done with some of the other activities, I’d first like to start by welcoming any reflections that people had on doing this activity or seeing this activity and not doing this activity, and the process that you took in order to participate in this activity.

**P1:** I had to step away from this one quite few times because … it’s another thing I’ve thought about in the past, where you think there’s a sound or someone tells you there’s a sound and you start to associate that with the sound and then you actually have to stop and think is that what I’m really hearing; am I telling myself I’m hearing it? And of course what tinnitus really is is not accurately heard anyway, and I believe, I dunno if we’re gonna get onto this later but I believe the whooshing sound, which is your internal organs, is the most accurate sound because your ears are struggling and your brain says turn up the volume and all you’re hearing is your insides, not the thing. But then when I was exploring tinnitus when I first saw a specialist about it, they were talking about people of different ages, so older people might hear a steam engine, people about my age, some of them hear the dialup tone of a modem … my wife thinks she’s got it now, we had to move house and there was a lift there in the flat we were staying in and she was amazed how many people were using the lift throughout the night, ‘cause it was mostly old people in the block; then when we moved again and there’s no lift here, she heard a lift at night. So that kind of stuff fascinated me and I had to filter that out to what I hear and not what other people have talked about with it.

**I:** Thanks P1, so for you, concentrating on yourself, despite tinnitus often being something we talk about as quite personal, was actually really challenging.

You’re muted P1.

<Pause>

**P1:** Thought I’d hit the button, sorry!

**I:** That’s OK.

**P1:** No, it’s not challenging – it’s actually the interesting bit for me at the moment, because a lot of people I talk to about it – I write for an Amazon Music Press Association and we’re all getting on a bit, so we’ve all got hearing issues of one sort or another and some of them are starting to realise they’ve probably got it and are trying to work out if what they thought was an extractor fan or something on their computer might not actually be that; that might be internal not external. So all of that has become quite fascinating and … yeah. <Laughs>

**I:** Thanks P1. Did anyone else want to share any thoughts about this activity?

Or do you just want to see the responses?

Shall we take a look then? Sally, if you wouldn’t mind … so this is the first.

<Pause>

And then can we go to the second please?

<Pause>

So yeah, as we’ve done before, open it up to you and your thoughts about these two responses, what they might capture about experiences of tinnitus, what they don’t capture, whether they’re relatable for you or not, any thoughts that you have would be welcome.

**P5:** This one’s mine. My art skills are very limited. The only reason it’s gone down is because early on when I had tinnitus I couldn’t sleep, I found it really distressing not being able to sleep, but now I can sleep so I don’t think the sound necessarily goes away but just my consciousness blocks it out or something, so that’s the only reason … So I found the previous drawing interesting, where it went in a loop, so that’s probably more accurate, but when I go to bed and then it just seems really loud and then I if I can try and not think about it too much then I fall asleep.

**I:** Thanks P5. So this is you experiencing your tinnitus getting quieter or you no longer noticing it or falling off to sleep, is that correct?

**P5:** Yes, so when I go to … so in the evening it may not be that loud, and I just get anxious when I go to sleep ‘cause it’s still relatively new, but now … yeah, I doubt it does reduce but my consciousness of it reduces. ‘cause it isn’t a real sound anyway, so it’s all a bit … you know. Visualising something that is or isn’t there …

**I:** Thanks P5. I think it’s really interesting that you’ve drawn that process of becoming less conscious of it and you’ve represented that with the letters getting smaller.

**P1:** The previous one with all the E’s and the circle of E’s is, if I could only choose one picture to show people, that’s possibly the most accurate I think, and simple to get across, what the general feeling is.

**I:** Thanks P1. P4, did you want to say something, and then I might come back to you on that P1.

**P4:** Yeah, I was gonna say a similar thing actually. I relate most to that first one. Just the mono nature of the noise, it doesn’t change for me, it’s just an alarm, it’s just an E. So that constant … I found this quite tricky and I don’t think I got through to submit mine, but mine would have looked something like that, with all those Es.

**I:** Thanks P4. P1, can I ask why for you this image is the one, as it were? Why is that this one is capturing that experience for you?

**P1:** So my ones I’ve probably over-thought and this one is very simple. It’s also got, apart from the loop thing, which is kind of when you sometimes think about it, it is kind of circling in your head, sometimes it’s coming out either side. Also looks a bit like a tube symbol which <laughs> I don’t live in London anymore but I used to, and that constant noise when you’re on the underground, that’s also … that fits in as well. So I think as a snapshot, poster appeal, if you needed a logo I’d say that was probably it. Whoever did that, well done!

**I:** Thank you P1.

**P2:** Yeah, this was mine and it sounds like it was quite a similar experience I guess to everyone … yeah. It was again I think … I guess the process of doing the activity is starting to recognise those loops that I hadn’t really recognised before and just that whole … I guess it is so weird, ‘cause it is just this one constant but then it can also grow and shrink and then it can just come round from different places and do different things. So yeah, I think this was trying to access that and then also the bit where they kind of come together again as well. ‘cause sometimes then your two ears are doing something and then they start to merge a bit. I was just trying to get those different bits in there I think.

**I:** Thanks so much, P2, and can I ask what it’s like to have … well … does your view of this drawing change at all knowing that others … see their own experiences in it, or when you were drawing it did you think others would share that experience?

**P2:** I had no idea, to be honest. Really didn’t know. I think because … you know how there are examples with the activities, so sometimes … obviously having that string of E’s that was in the example, and I think that’s … I feel like that’s probably one of the most common things that you hear about when people are talking about it, but yeah, because there were different examples given then I was aware that there was probably a lot of different ways that people could be representing it. But yeah, I didn’t realise this was, I guess, a similar thing, but then I suppose from the drawings and all the other things we’ve seen before as well, there are those similarities coming across at various points.

**I:** Thanks P2. I’ve just looked at the time and I’m aware that we are cracking on a bit, so we’re gonna move towards the final activities. There will be a chance at the end to think about everything together, hopefully, so we can come back to anything that people may want to, but thank you so much for your comments so far. So the final activity was quite similar in some ways to the last one. They were grouped together under the heading of what tinnitus sounds like. So this activity we asked you again to find sounds, if we can go to the next page Sally … we asked you to find sounds that relate to tinnitus in some way and document those sounds, be it through a recording or a photograph or a drawing or writing. So it was up to you how you documented these sounds.

Again we advised that you didn’t try and create the complete, accurate recreation of the sound that you hear with tinnitus, but aim for a creative interpretation. So we suggested that you tried making these sounds at home or elsewhere, and we asked whether there were sounds that reminded you of your tinnitus in different situations; are there sounds that help mask or sooth your tinnitus; or are there sounds that you dislike being around because of your tinnitus? And those were the prompts that we gave you.

So just going to share one of the visual submissions that we had to this activity. So if we can go to the next slide please.

<Pause>

**I:** And as before we’d welcome any thoughts you have on taking part in this activity, what your process was, and any thoughts on this response as well.

**P2:** I like how this is all in the head but also expands outside it. I think that’s probably … one of the key things now that I’m thinking about, about the tinnitus, is it’s … yeah, like what we were talking about with those initial images, where it’s coming from outside but then is actually inside and yeah, I feel like this captures that aspect quite well.

**I:** Thanks P2. So this gets to the place of tinnitus as well in some ways?

**P1:** You can probably guess this was mine. <Laughs> Yeah, it was reflecting on what you were talking about, going to different places and stuff, so I was considering it as a conversation which is why you’ve got the words below, ‘There’s stuff going on in my head.’ Again as I said earlier, sometimes I think these are noises I’m hearing – I don’t think I actually am, and I don’t know if that’s imagination, the tinnitus taking on a different sound, but I don’t think it is; I think it is generally just a continuous sound but my brain may be tricking me, I don’t know. And that’s it.

**I:** Thanks P1. So this is an image about the confusion of what it is that you’re hearing; is that correct?

**P1:** Yes.

**I:** Can I ask what the ‘Just a tone’ means, and you’ve underlined ‘just a tone’.

**P1:** So that’s further to really when I listen to it, it is just a continuous tone, it’s slightly different in that ear to that ear, sometimes, as somebody else was saying, it can almost join up and become a similar noise, but it is really that and so that’s what I was talking about with … is my imagination telling me I’m hearing something else? A good example that happened this week, our fridge/freezer broke down and in doing so started to make some very strange noises. I couldn’t tell if it was my ears or the machine and this morning it went off, my tinnitus was really bad this morning – my wife could hear the machine; I couldn’t hear it at all <laughs> until I got close to it.

**I:** Thanks P1. Does anyone else have any thoughts on this response or this activity?

**P4:** I didn’t do this one but I really like the alarm bell visual element to this, right by the ear. That’s how it feels to me.

**P3:** Yeah, I definitely relate to a lot of these terms and I … this one was interesting for me. I was trying to … not exactly recreate the tone. What I focussed on was the new one, the low groan one, but it [89:34 IA] realised how rich a tone it is, and so I tried to take time away from, just filter it back. I quite capture the fullness of the tone and I’m not sure I want to actually.

When this one came on, in February at the time, it was so loud, and I couldn’t help trying to figure out what pitch it was. So since then I’ve been trying to contextualise it in some kind of musical … or some way to convey it, but it’s not that easy. It’s quite a thick tone … surprisingly warm. So even though it hasn’t fully gone away, it’s this … I don’t notice it today, it’s gone that quiet, but I know it’s there. There is a strange comfort to it as well. So yeah, I did quite enjoy this activity.

**I:** Thank you.

OK, I’m mindful that it’s five to nine. It’s late. So Sally would you mind closing the slides?

Ooh, I can see you all now! Thanks so much everyone for your comments on the activities and for your fantastic responses and for such a rich discussion as well about all of these different activities. I’d just like to take a couple of minutes if anyone had any final thoughts about this kind of approach to sharing experiences of tinnitus, we’d welcome any final thoughts that you have. I’d also be interested just quickly to pose thinking about how some of the images or the responses that you’ve seen today compare to other representations of tinnitus that you’ve seen, maybe in advertising or in medical literature or in films and television and things like that. So I’ll just pose those two big questions to you all, and just offer the space if anyone’s got any final thoughts.

<Paues>

**P5:** Just quickly, I hadn’t really thought of visualising it before and again maybe it’s ‘cause I hadn’t had it for so long, but British Tinnitus Association, they put some pictures up and although … so they had some words and some visuals, so I think it helps, it depends on the picture and it depends how much you relate to it, but I think it is a useful way, for me anyway, of just thinking about it differently. And identifying with some of these pictures, I think that’s helped as well because again it’s one of these things that I’ve personally found isolating, to see it portrayed does help.

**I:** Thanks so much, P5.

**P4:** I thought it was interesting trying to visualise my tinnitus ‘cause I’ve always just thought of it as a flat, ringing, constant sound and that’s all there is to it, but when you start trying to look at the detail of how it affects you and how it makes you feel internally, it wasn’t like a flat line for me, it was kind of intense there and then really big there and so that variety, I just hadn’t really realised was happening to me, so it was quite a rich way to explore it a bit more.

**I:** Thanks P4.

**P1:** Yeah, it’s something that I’ve been meaning to address and visualise, and so this helped me do that. I guess I’m also interested in how the other groups compared. Is it a very similar experience each night you’ve done this, or has it been radically different for people?

**I:** I’m not sure how much I’m allowed to disclose at this stage, but I think it’s fair to say it’s been pretty different. There are some common themes, but what happens in each group is quite different. And the kinds of things that people are sharing, there are again some similarities and some big, big differences as well. So yeah.

On that note, perhaps now is a good time to talk about next steps a little bit. So in a couple of weeks’ time you’ll get another email from me. I’m sure you’re really enjoying getting lots and lots of emails from me, but there’ll be *yet* another email from me asking you to consider filling in an evaluation survey and we’ll also tell you a bit more information about the £20 gift voucher that you shall get for participating in this workshop.

The other thing that we’re hoping to do is, this was something that was mentioned in the information sheet and consent form but we want to mention it again: we would like to make some of the responses to the activities that we’ve received more widely available, and there are two ways that we can do this. We can do it through our project website, so we’d like to develop an archive of responses to the activities, because there are so many different responses and different approaches, it would be really nice to have lots of those responses together. We’re also holding an exhibition at Oxford Visual Arts Development Agency in October; as part of this project we’ve commissioned two artists to create new work responding to the theme of tinnitus, and it would be really great as part of that exhibition to have, in some way, some of the responses available, because they capture such diverse experiences and because, as we know, tinnitus is different for different people, it would great to have as many of those responses available as possible. So what we will do in that email as well is ask you whether you’re happy for us to share your responses more widely; you’ll have the opportunity to say yes, great/no please don’t/maybe you can share these ones but not these ones, and also how you would like to be acknowledged. So do you want us to write your full name and titles, would you like to appear under a nickname, would you like to just have your first name listed, do you not want to be named at all? So we’ll be in touch about that side of things as well. It just seemed that there’s been such a rich set of responses to these activities it would be really nice to make those more widely available if possible.

So yeah, if anyone has any questions about that please feel free to ask as well or send an email.

Great. OK. Well I’m not aware it’s one minute past nine. Thank you so, so much for your participation. Thank you for your generosity in your activity responses and the time that you’ve offered this evening and your comments. We hope that you have a good rest of your evening.

**P1:** Thank you everyone. That was brilliant. Thank you.

**P4:** Yeah, enjoyed that.

**Var:** Thank you.

**Var:** Bye.

**I:** Thanks. Take care. Bye.

**<End of recording>**