

Tinnitus and the Arts: Workshop Report

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Keeping score

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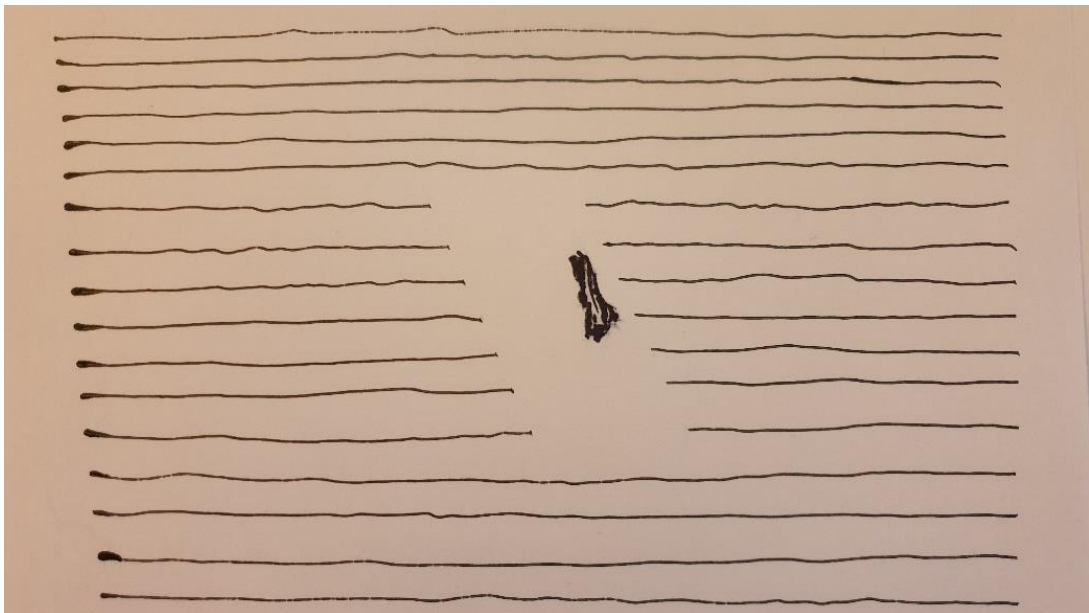
1. Summary

Tinnitus is the perception of sounds that have no external source. According to the British Tinnitus Association, about 30% of people will have tinnitus at some point in their lives. Tinnitus is often thought of as high-pitched ringing sound. However, there is a lot of variation in what tinnitus sounds like and the ways it affects people.

This publication reports on a series of workshops that were held in 2021 as part of the Arts and Humanities Research Council project, *Tinnitus, Auditory Knowledge, and the Arts*. These workshops explored how art activities might be used to share different experiences of tinnitus. A total of 37 people took part.

Data from the workshops suggests that art activities can help people understand, reflect on and think about their tinnitus; share their experiences of tinnitus with others; and allow new ways of representing tinnitus. However, the different ways that tinnitus can affect people means that a variety of activities are needed so that those with tinnitus can choose an approach that suits them best. There is also a risk that, for some people, art activities may cause tinnitus to become more noticeable than usual.

This report outlines what happened during the workshops and some key findings. It also highlights some possible future uses of the workshop materials.



Tinnitus drawing: Silent Pause

2. Introduction to the workshops

In 2021, Marie Thompson (The Open University), Patrick Farmer (Oxford Brookes University) and Sally Blackburn-Daniels (The Open University) ran a series of online workshops exploring how art activities might be used to share different experiences of tinnitus.

The purpose of the workshops was to explore the following questions:

- Can art activities be used by people with tinnitus to share their experiences?
- Can art activities enrich understandings of tinnitus, and the diverse ways it affects listeners?
- How might engaging in art activities about tinnitus be beneficial to members of the tinnitus community?

Participants were given instructions for six art activities and asked to complete at least two. The activities allowed participants to use a range of creative methods, including drawing, map-making, creative writing, and sound recording. No previous experience was needed to take part. Participants were asked to share their responses with the project team, as well as any thoughts they had about the activities. The six activities were:

Tinnitus maps

creating a map of where tinnitus is louder or quieter, or more or less noticeable

Tinnitus portraits

developing a self-portrait that includes tinnitus, showing where the sound travels from and to

Tinnitus drawing

exploring how tinnitus might be depicted without words by making a series of drawings

Putting tinnitus into words

a creative writing exercise, where each person chooses a word or set of words that they associate with tinnitus and provides a definition for them

Keeping score

turning tinnitus into a 'word-sound' that is then used to create a visual score or sound recording

Capturing sounds

finding, making and documenting sounds that relate to each person's tinnitus in some way

Once participants had finished the activities, they took part in a two-hour discussion in groups of four to six. This was an opportunity to talk about the activities as a group and reflect together on some of the submitted responses.

3. Workshop pilot

Two pilot workshops ran in February 2021. Eleven members of the British Tinnitus Association's consultation group took part. The pilot allowed the project team to get feedback on the workshop activities, the recruitment process, and the online discussion format.

In response to the pilot we made some changes to the activity instructions to help make them clearer. We also changed the software we used to host the online discussion from Microsoft Teams to Zoom due to some accessibility issues.

4. Who took part?

An expression of interest survey for prospective participants was circulated on social media and mailing lists in May 2021. Participants needed to be based in the UK, have access to a web-connected computer or smartphone, and have a Tinnitus Functional Index score below 50.¹ 83 people completed the survey. Nineteen respondents were not invited to take part in the workshops due to their Tinnitus Functional Index score. All other respondents were contacted with an invitation to participate.

26 of those who completed the expressions of interest survey participated in the workshops. Everyone who completed the workshop activities took part in a follow-up discussion: one participant took part in a one-to-one interview as they were unable to attend any of the scheduled group discussions. All participants were given a £20 gift voucher after taking part in the workshop.

Of those who took part in the May workshops:

- 16 (62%) were female, 10 (38%) were male
- 4 (15%) were aged 25-39, 7 (27%) aged 40-49, 8 (31%) aged 50-59 and 7 (27%) aged 60+
- 22 (85%) were white, 4 (15%) belonged to multiple ethnic groups or chose to self-describe their ethnicity
- 22 (85%) were based in England, 2 in Wales, 1 in Northern Ireland, and 1 was in Scotland
- 5 had tinnitus for a year or less, 8 for 2-5 years, 2 for 6-10 years, 8 for 11-20 years, 3 for 20+ years.
- 13 (50%) described tinnitus as their only hearing condition, 10 (38%) also had hearing loss/deafness, 1 had hyperacusis, 2 had Ménière's disease.

Of those who completed the workshop evaluation survey (21/26 participants), 85% had never been to a tinnitus support group.

¹ The Tinnitus Functional Index is a series of questions that helps interpret tinnitus severity and impact.

5. Responses to the workshop activities

The number of responses to the activities suggests a high level of engagement amongst the workshop groups: while participants were asked to complete at least two activities, many chose to complete more. the activities received the following number of responses:

- Tinnitus maps - 20 responses
- Tinnitus portraits - 25 responses
- Tinnitus drawings - 18 responses
- Putting tinnitus into words - 24 responses
- Keeping score - 18 responses
- Capturing sounds - 13 responses

Individual responses to the activities varied significantly, making it difficult to draw conclusions about which activities participants preferred. Amongst those who submitted comments with their activity responses, 'tinnitus portraits' and 'tinnitus maps' generated most positive comments, while 'keeping score' and 'capturing sounds' generated the fewest.²

Acceptance	Delight	Intensity	Persistent	Tin
Acute	Depression	Interference	Personal	TinnitUS
Alarm	Different	Intimate	Piercing	Tiredness
Always	Distraction	Invasive	Pitch	Tiring
Annoying	Drilling	Invisible	Positives	Trapped
Anti-silence	Effervescent	Isolating	Present	Tuneable
Anxiety	Electron	Isolation	Pressure	Unalienable
Aura	Everyday	Jarring	Quiet	Unpredictable
Awareness	Exhausting	Learning	Rest	Unremovable
Background	Fatigue	Legacy	Rubbish	Unusual
Barometer	Fire	Life	Sand-blasting	Void
Battles	Fizz	Luck	Scream	Volume
Blame	Foreboding	Madness	Sharp	Wall
Blanket	Forgettable	Me	'Ssh'	Wave
Breakdown	Friend	Musical	Sleep	Weariness
Breathing	Fuzziness	Niggling	Solitude	Weight
Buzzing	Hissing	Noise	Sudden	Whine
Concentration	Incessant	Nuisance	Stress	Whistling
Constant	Infinity	Odd	There	White noise
Damaged	Insidious	Pain	Thief	
	Integrated	Permanent		

Putting tinnitus into words

² These figures are based on participants using the terms 'good', 'enjoyable', and 'interesting' to describe the activities in free-text comments when submitting their responses. Participants were asked to write down their reflections after each activity, using the prompt: "Did you enjoy this activity? Did it make you think about your tinnitus differently? What did you find difficult about this activity." 8 44% of those who completed the activity commented positively on tinnitus portraits, followed by 40% on tinnitus maps, 38% on drawing tinnitus, 37% on putting tinnitus into words and 22% on keeping score. There were no positive comments for capturing sounds. However, some participants used the spaces provided to write about their process or their tinnitus, so their comments cannot be categorised as positive or negative.

6. Key findings

Data from the submitted activity responses, group discussions and evaluation survey suggests that art activities can help people **reflect on, understand, and think about their tinnitus**; and can be used to **share experiences of tinnitus with others**. Art activities offer **new ways of representing tinnitus**, allowing those with tinnitus to decide how it is portrayed. However, the diverse ways that tinnitus can affect people means that **a variety of artistic approaches are needed**: one type of activity is not suitable for all.

Reflecting, understanding, and thinking about tinnitus

Of those who completed the workshop evaluation survey, 76% of respondents indicated that the art activities made them think about their tinnitus in different ways, and 81% agreed or strongly agreed that the art activities ‘furthered my understanding of tinnitus and how it affects me’. 71% of respondents indicated that taking part in the workshop (i.e. both the activities and online discussion) made them think differently about their own tinnitus. A number of participants suggested that the activities helped them to recognise some of the different ways they experience, respond to and manage their tinnitus.

[The ‘putting tinnitus into words’ activity] made me realise that on good days I can feel more positive about tinnitus. It’s not an option to have it removed, so I have learned to live with it.

[The tinnitus map activity] made me realise that I have different ways of coping for different times, depending on how intrusive my tinnitus is and how I am feeling.

Sharing experiences of tinnitus with others

Many participants suggested that the workshops allowed them to share their experiences of tinnitus. 95% of evaluation survey respondents suggested that the art activities allowed them to communicate something about their tinnitus, while 90% indicated that taking part in the workshop (i.e. the activities and discussion) allowed them to share their experiences of tinnitus with others. Some participants suggested it was important to combine the art activities with a group discussion, as this allowed for different activity responses to be viewed and talked about together. The opportunity to share with others in the workshops was important because, in the words of one participant, tinnitus is an ‘*internalised personal experience*’.

Participants identified different benefits to sharing experiences of tinnitus. For some, it was a valuable opportunity for their experiences to be acknowledged. For others, the workshops allowed them to find out about other people’s tinnitus. As a result, some participants suggested that the workshops gave them a better understanding of tinnitus and the different ways it can affect people. Participants also suggested that the activity responses could potentially help clinicians, friends, and family members without tinnitus to have a greater understanding of its impact on people’s lives.

[The art activities] were challenging, but that was good & sharing responses made me realise the breadth of experiences of tinnitus, but also the points of familiarity.

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

[Tinnitus] is such a internalised personal experience normally that's hard to explain to anyone else, and I think [the tinnitus map activity] is a really good way of visualising it. It might be helpful to show mine to my family and friends actually.

I think [the workshops] would be really good for professionals, audiologists who work with people who have tinnitus because it shows [...] the variety, the inconsistency between people with tinnitus, but also within the person with tinnitus, that it's not just the same sound all the time, there's so much variation [...] to describe is one thing but when you put it in some way pictorially, that might really help professionals to understand exactly what it is that we are hearing and living with day after day after day and for who knows how long.

New ways of representing tinnitus

The workshop activities allowed participants to make decisions about how tinnitus was represented. Some noted that the activity responses were different to how tinnitus tends to be represented in the media. Others highlighted artistic choices they had made that were important for capturing something of their own experience. For many taking part, being able to represent their own tinnitus was important because it allowed them to communicate with others about what they were hearing and experiencing. Some participants also suggested that the activity responses offered a more realistic and diverse portrayal of tinnitus by comparison to those they had come across elsewhere, such as in films and clinical leaflets.

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

In films you quite often have this person looking round in bewilderment and you know that it's only them that's hearing the sound. I don't think you see that represented in any of these pictures.

I don't think I've seen much [representation of tinnitus] 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 [...] it's kind of more meaningful in a way [...] these images, looking at that, they seem to make more sense to me.

[For the 'capturing sounds' activity] I ended up recording the sound of a can of Coke, really cold out of the fridge. [...] when I listened to it, I thought that's as near as I could possibly get to how my tinnitus sounds. And actually having done it, I was really pleased because then I could play it to my husband and say, 'This is what I'm hearing', because as

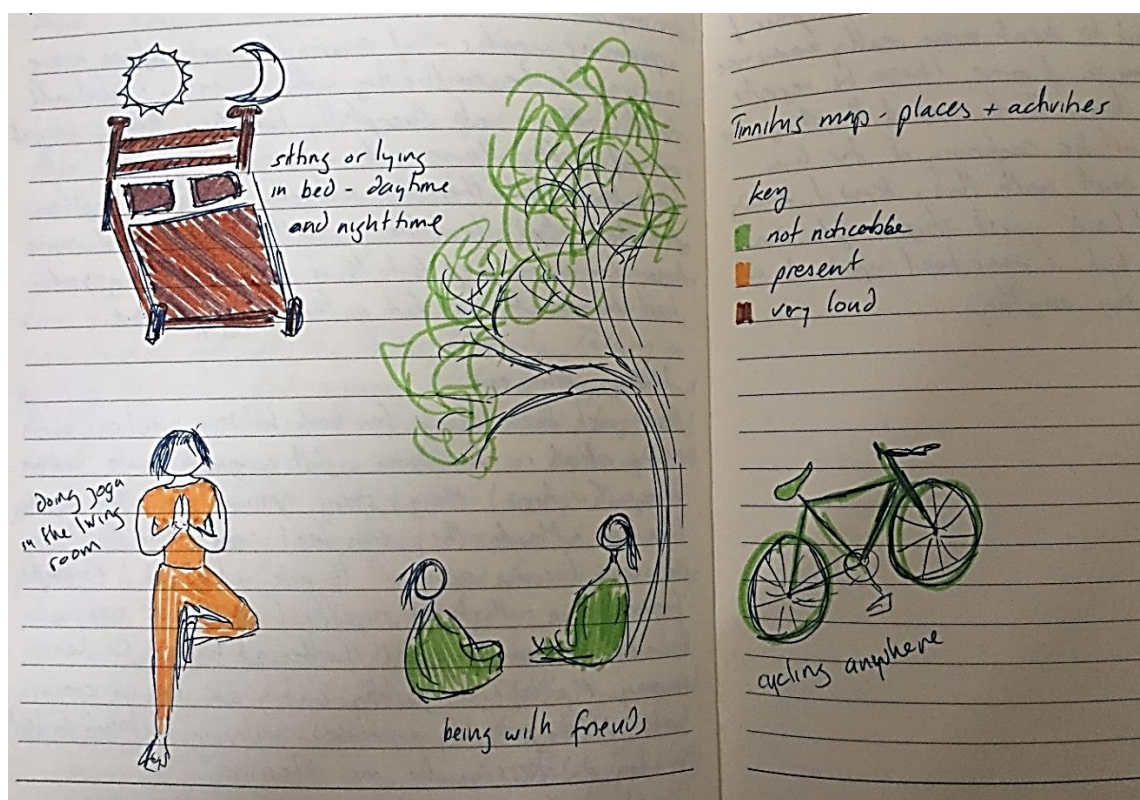
people possibly also experience, when you're trying to describe it someone else, it's such a real sound to you, and they can't hear anything of it, it can be quite frustrating that you can't believe that they can't hear something that is so noisy in your own hearing. Yeah, so I actually found it useful then to be able to communicate it to people who I know and love

The need for a variety of activities

The participant comments made clear the importance of offering a range of art activities. Those taking part in the workshops suggested that different activities were more or less suited to how they experienced tinnitus. Which activities were more or less suitable varied between participants. For example, with the tinnitus map activity, some felt that the task made them realise that there are places that they associate with their tinnitus, while others felt that the activity confirmed that their tinnitus had no relation to place.

I felt that [the workshop] was a very beneficial exercise, especially as you did not need to do all of [the activities] so could focus on the ones that best represented your own experience

Some were not for me and so I didn't do those. One was to create a word form of the sound and I chose not to do that as I thought I might then associate that word or sound with my tinnitus in places when I wasn't thinking about / aware of my tinnitus. Others were really helpful to do as an experience and to help me think about my tinnitus in a different way. I was able to see how far I have come in managing my tinnitus.



Tinnitus map

7. Challenges and limitations

There were challenges that arose with the workshops that need addressing in future work.

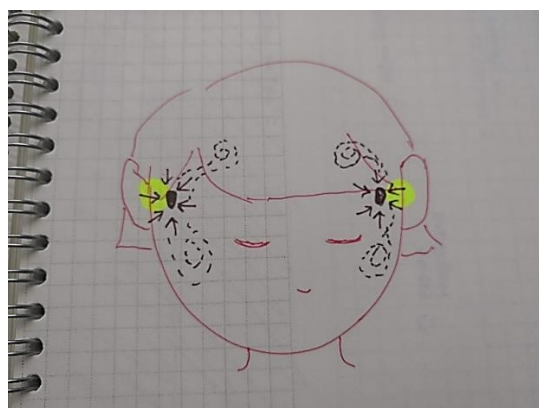
Some participants felt that the art activities drew attention to their tinnitus, making it more noticeable than usual. Guidance was provided on this issue before and during the workshops, including signposting avenues for support. However, we did not ask whether those taking part made use of this guidance.

The activities were met with a mixture of emotional responses. Some responded positively to the activities because they highlighted how their relationship with tinnitus has changed or helped them to recognise their own coping strategies. However, others suggested that reflecting on their tinnitus through the activities made them feel sad or upset, because they made clear how tinnitus shapes their lives. Furthermore, while the group discussions remained respectful, tensions sometimes arose due to the different ways that tinnitus was represented and discussed during the workshops. For example, when sharing some of the activity responses, some participants expressed that tinnitus should not be turned into something beautiful. Others expressed upset at responses that were felt to be particularly negative in their depiction of tinnitus.

As they were open to all, the workshop groups were mixed in terms of artistic skill. A small number of participants suggested they were not confident taking part in the group discussion due to their perceived lack of artistic ability. However, others suggested that they enjoyed the opportunity to try something new despite their limited artistic skills. All participants were able to let the project team know if they did not want their activity responses to be shared as part of the group discussion. No participants opted out of sharing their work.

It is important to note that the workshops excluded those who had a Tinnitus Functional Index score of 50+. Scores in this range would suggest that tinnitus had a significantly negative impact on a person's life and wellbeing. The exclusion of those with higher scores was due to the potential risks of the workshop (i.e. taking part could make tinnitus more noticeable) and the challenges of providing emotional and wellbeing support in an online group setting. The exclusion of those with higher Tinnitus Functional Index scores needs to be taken into consideration in future work using art activities.

Taken together, these issues highlight the importance of providing emotional guidance and support before, during, and after the workshop; and managing participant expectations.



Tinnitus portrait

8. Future directions

Based on the suggestions made by participants, we have identified some ways that the workshop materials could be used in future. These include:

Developing resources for tinnitus support groups

The workshops could be used as a model for tinnitus support groups and could help prompt discussion amongst members. The activities from the workshops could be turned into a printable resource that could be shared with groups. However, it is important to note that many of those taking part in the workshops had never attended a tinnitus support group (see section 4) and some people with tinnitus might prefer to complete the activities alone, rather than in a group. It could therefore be beneficial to make any future resources available through additional avenues (e.g. the project website).

Raising awareness about tinnitus

Responses to the workshop activities could help raise awareness of tinnitus and the diverse ways it affects people's lives. Some of the activity responses have already been shared with the wider public as part of the art exhibition *The Hidden Noise: Tinnitus and Art*. The exhibition was hosted at OVADA, Oxford in October 2021, and was attended by approximately 200 people. Audience feedback suggested the activity responses by workshop participants offered a new perspective on tinnitus:

I knew very little about tinnitus, other than that one day I might develop it. This exhibition has given genuine insight into the condition as experienced. The workshop images in particular have changed the way I will think of it in future.

For those with no experience of tinnitus it [the exhibition] helped give a sense of it.

Really interesting to see other peoples' experiences. I've never seen anyone putting across these perspectives and doing this through art works really well. A fantastic idea, thank you.

These comments suggest that the activity responses could help raise awareness and improve understandings of tinnitus amongst the general public.

Communicating with family members, friends, and health professionals

It can be difficult for people with tinnitus to explain to others what they are experiencing. As discussed in section 6, some participants suggested that the workshop activities helped them to communicate with loved ones about their tinnitus in ways they had not been able to do so before. This suggests that the workshop activities could have future value in helping those with tinnitus to explain to friends and family what they are experiencing; and help friends and family to better understand and support a loved one who has tinnitus.

In providing novel ways to reflect on, represent and communicate about tinnitus, the workshop activities could also have uses for health professionals. Further work would be needed to explore how the activities could be best adapted for use in clinical settings.

9. Acknowledgements

Thankyou to all of those who took part in the project, including members of the British Tinnitus Association's consultation group and all respondents to the expressions of interest survey.

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