



SHARING TINNITUS

A Creative Toolkit for
Tinnitus Support Groups

About this toolkit

Research shows that creative activities can help people to understand, reflect on and talk about their tinnitus in new ways.

Sharing Tinnitus is a collection of creative activities designed for use in tinnitus support group sessions. This toolkit is intended for support group leaders and facilitators, and can be used flexibly in both in-person and online settings.

Toolkit development

This toolkit was funded by The Open University's Open Societal Challenges (OSC153) and was created by Marie Thompson (Music, The Open University) and Georgina Burns-O'Connell (Audiology, Aston University) with input from the following support groups: Brighton Tinnitus Support Group, Bolton Tinnitus Support Group, Bromley Tinnitus Support Group, Chesterfield and Derbyshire Tinnitus Support Group, Cumbria Tinnitus Support Group, Deaf Connect: NE and Swansea Tinnitus Support Group. Toolkit design by Steff Elliott-Sleigh.

The toolkit is based on research from the Arts and Humanities Research Council project, Tinnitus, Auditory Knowledge and the Arts. The activities include examples of work made from previous 'tinnitus and the arts' workshops. For more examples visit: <https://tinnitusarts.co.uk/>

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How to use this toolkit

This toolkit includes instructions for **eight** activities.

They vary in length, the amount of preparation required, and how participants work: some are quick and simple, while others take more time, and some are designed for individual reflection while others are collaborative. We suggest allowing time for discussion as part of each activity, so participants can share and talk together about what they have made.

Each activity description gives:

- suggested **timings**
- a description of **what the activity is for**
- a list of **what you will need** to do the activity
- instructions on **how to run the activity**, and some ideas for talking about the activity together
- a suggestion **of how you might explain the activity** to the group
- options for how activities can be **adapted** for different types of session or groups

Some activities come with an accompanying **worksheet**. All activities can be run without the worksheets, but can be used to help support an activity. These will need to be printed out in advance of an in-person session.

Activities Key

The toolkit uses a key to help you decide on which activities to use.

The categories are:



Collaborative



Individual



Facilitator prep



Participant prep



Longer (30 mins +)



Quickfire



Adaptable for online

Tips & advice

Different groups, different needs

Every tinnitus support group is different. Each of the activities can be modified and we offer some suggestions for how to do so. You may have your own ideas about how to these activities to best suit your group's needs.

“But I’m not really creative...”

The idea of taking part in a creative activity can be intimidating for some people. There may be group members who worry about not being ‘good enough’ or about their artistic skills being judged by others. While doing something new will often be a little nerve-wracking, the following can help:

- Make clear to people taking part that their drawing/writing/artistic skills aren't being judged: the activities are to help people think and talk about their tinnitus in different ways and so the ‘doing’ and ‘discussing’ is what's important.
- Remind the group of the need to be respectful and to avoid criticising the work of others.
- Sharing some of the illustrative examples provided with the group can help build confidence and encourage participation, as can providing options as to how they take part (e.g. people may wish to draw, write or use another way of responding to the activities).
- Remember there isn't a ‘wrong’ way of doing the activities: it is down to each person how they respond, and their response will be personal to them and their tinnitus.

Paying attention to tinnitus

The activities ask people to think about their tinnitus. As a result, the activities may cause people to focus on their tinnitus more than usual. You might want to encourage people to take breaks if they need to, and to step away from an activity if they are finding it difficult. Keeping things informal and chatty can help: there is no need for people to be working in silence for long periods of time.

Mixed feelings

People can sometimes have powerful and very different responses to art. There may be different reactions and responses to the activities within a group, and this can sometimes bring challenges. The activities can also encourage people to talk about the different feelings they have about tinnitus, and this might include negative feelings. It can be helpful to talk about this with the group at the start.

1. QUICKFIRE DOODLE

🕒 10 – 15 mins



Individual



Adaptable for online



Quickfire

What this activity is for

This activity encourages self-reflection and expression and can be effective as an icebreaker. Group members use pen and paper to create a visual representation of their tinnitus.

You'll need:

- Coloured pens
- Paper

Instructions

1. Introduce the activity, then ask group members to draw their doodle
2. Allow 5 minutes to do this
3. Invite group members to share their doodle with the rest of the group and speak briefly about what it represents. Invite thoughts on what it's like to see tinnitus represented in this way

How to introduce the activity

“Tinnitus can be difficult to describe using words, so today we'll try to share it another way. Using just pen and paper, create a doodle that represents your tinnitus. It doesn't have to be anything fancy, it could be lines, shapes, patterns or anything that feels right to you – there's no right or wrong way to do it”.

Optional variations

Online: For online sessions, group members can use pen and paper to draw their doodle and then hold their doodle up to the camera to share with the rest of the group. The group will need to have access to a pen and paper for the activity. Alternatively, online groups might make use of online drawing tools (e.g. sketch.io, Canva), however these require some technical skill and sometimes need users to share their personal details.

In pairs: If you have a large group and/or people might find it difficult to talk about their doodle with the whole group, you can pair off people so that they each draw a doodle and discuss it together.

Quick(er) version: You can give the group an even shorter amount of time to complete the doodle (e.g. 1 minute): this can help prevent people 'overthinking' the activity.

2. TINNITUS DICTIONARY

🕒 10 minutes (quickfire version) – 40 minutes

 **Individual**  **Collaborative**  **Adaptable for online**  **Quickfire**

What this activity is for

This activity creates a ‘tinnitus dictionary’ made up of words and definitions chosen by the group. Some examples are provided in the instructions below. You might find it helpful to share these examples with the group at the beginning to help get them started. You can encourage the group to ‘get creative’ in their responses: can they provide entries that others are unlikely to think of, and are unique to them? The ‘options’ section provides ideas for turning this into a quickfire/icebreaker activity; and for how it can be adapted for use by online groups.

You’ll need:

- Large post-it notes
- Pens
- A large sheet of paper/wall/table to arrange the post-it notes

Instructions

1. Explain the activity, then give the group a set amount of time (e.g. 10 minutes) to each choose three words for the tinnitus dictionary, using the prompts below. Each word should be added to a post-it note, so that there is one word per post-it-note. If the person feels able to, they should also come up with a definition for each word. They can add this to the post-it note. Each person should choose:
 - a word that relates to how their tinnitus sounds
 - a word that relates to how their tinnitus makes them feel
 - a word you might use to explain your tinnitus to someone else

Examples from previous workshops:

Annoyance – why me?

Barometer – things have changed; up/down good/bad; things change

Electron – tinnitus feels like it has a positive charge

Integrated – it is as much of me as my own hands I think

Whine – like a small child – seeking attention/an overtight fan belt, comes and goes/piercing/metal on-metal – chalk-on-board.

2. Ask the group to arrange the post-it notes alphabetically onto a large surface (e.g. paper/a table/a wall).
3. Take some time to look at the list of words together as a group. Are there words the group are surprised to see? Are there words they find relatable? Are there particular words the group thinks are missing?

What impression of tinnitus does the list of words give? You might want to allow another 5 minutes to add more words to the dictionary that might be inspired by the discussion.

How to introduce the activity

“We’re going to be making a tinnitus dictionary for our group, and we need everyone to come up with some words and some definitions for them. We don’t want everyone to have the same words, so feel free to get creative with your choices. We’re going to start by each choosing three words that capture something about our tinnitus. We’ll share these with one another so we have a list of words. We’ll then spend some time talking about the words we have come up with as a group”.

Optional variations

Quickfire/icebreaker version: Give the group 3 minutes for each person to come up with as many words as possible to describe their tinnitus. You might ask each group member to write each word down on a post-it-note then follow steps 3 and 4 above. To make the activity even shorter, you can ask each group member to write a list of their words (on paper or as a note on their phone). You can then talk about these lists together: e.g. who has the most words? What types of words did they choose? What is the most unusual word on each list? How might these words be grouped together?

Individual version: Ask group members to save the three words they have chosen so that they can return to them at a future date. At a later session (e.g. 3 months after) ask each member to review their words: would they still choose the same words today? This may allow those taking part to track changes in how they experience tinnitus.

Online version: Words and definitions (or if doing the quickfire version, lists of words) might be shared using the chatbox/textbox. If time allows, a group leader or a nominated member might copy and order the words (and definitions, if provided) into a single document (e.g. Word/Powerpoint) so that they can be seen together by the group.

Collaborative version: If the group members might struggle to complete the activity individually or if you want the activity to be more collaborative, you can adapt Step 2 so that people work in pairs or small groups to come up with words together. To do this, you might give the groups e.g. 15 minutes to come up with 10 words.

Revisiting the activity: The tinnitus dictionary can be treated as an ongoing group project. This needs someone from the group to act as notetaker, creating a record of the group’s submitted words (we’d recommend using a word document/spreadsheet so that it’s easier to add to the alphabetical list). New words can be collected every few months, either by repeating steps 1-3 or simply by asking attendees if there are any new words they’d like to add to the group’s dictionary.

3. SELF PORTRAIT

🕒 30 – 45 minutes

 **Individual**  **Collaborative**  **Longer (30 mins +)**

What this activity is for

Tinnitus is often described as ‘ringing in the ears’ but where people hear tinnitus in their head varies: some people hear tinnitus in one ear, others hear it in both ears. Some hear the sound coming from outside their head, some hear it inside. This activity gets people to draw a self-portrait that features their tinnitus, showing where they hear it in relation to their own head. The self-portrait can be as simple or detailed as people wish. Some group members might feel confident drawing a self-portrait from scratch. Others might want to use the template, included in the activity worksheet. The activity ends with displaying the portraits together so attendees can see themselves alongside one another. As a group activity, it can make clear some of the different ways tinnitus is experienced.

You’ll need:

- pens and pencils for drawing
- printed copies of the worksheet and/or sheets of paper
- a wall or pinboard and blu-tack, pins or sellotape that you can use to ‘hang’ the portraits

Instructions

1. Explain the activity
2. Ask the group to draw a picture of their face. This can have as much or as little detail as you like. Some people might want to use the worksheet template.
3. Once the group have drawn their face, get them to think about where they usually hear their tinnitus in their head. The following can work as prompts:
 - a. Do you hear it coming from your left ear, right ear, both ears, or somewhere else?
 - b. Does your tinnitus seem like it is coming from inside or outside your head?
 - c. Does it feel like your tinnitus moves around? Or does it just stay in the same place?

4. Now, get the group to add their tinnitus to the portrait. You can use the following prompts to help with this:
 - a. Are there any types of line or shape that can help you show what your tinnitus is like?
 - b. Are there any colours that can help you show what your tinnitus is like?
 - c. If you have different types of tinnitus in different ears, how might you show this?
5. Once the group have finished their portraits, stick them up on a wall/pinboard so you can look at them together. What do the group notice about the portraits? What was it like to create a self-portrait that includes tinnitus?

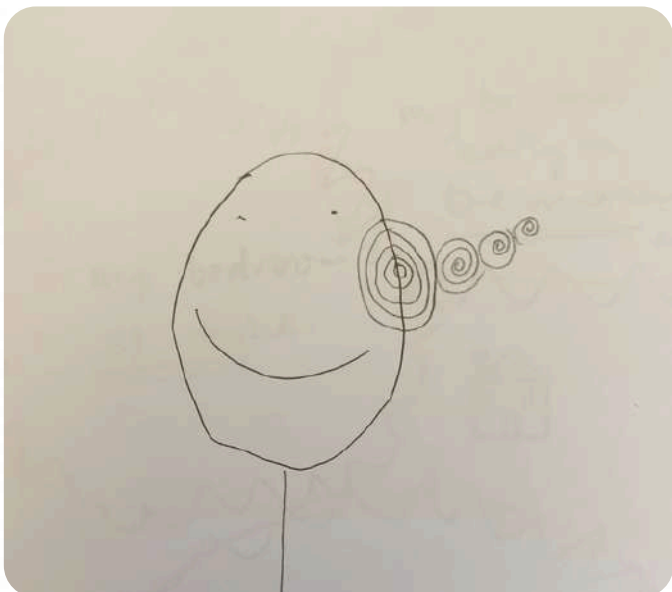
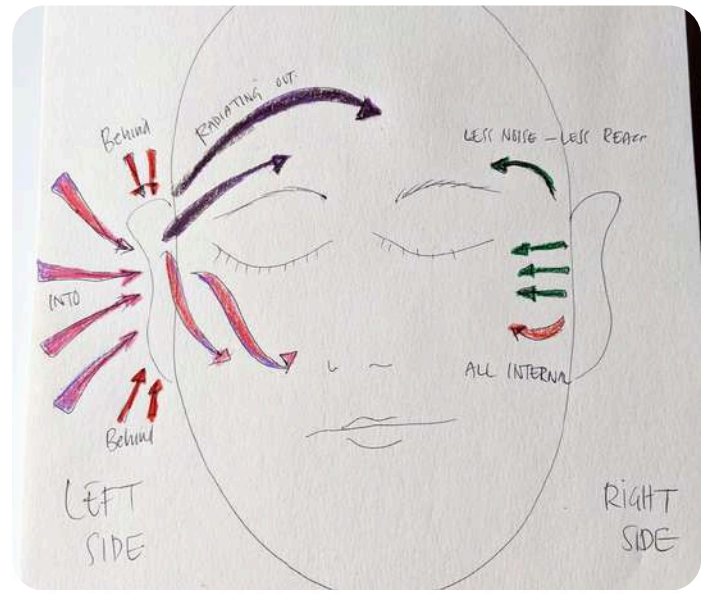
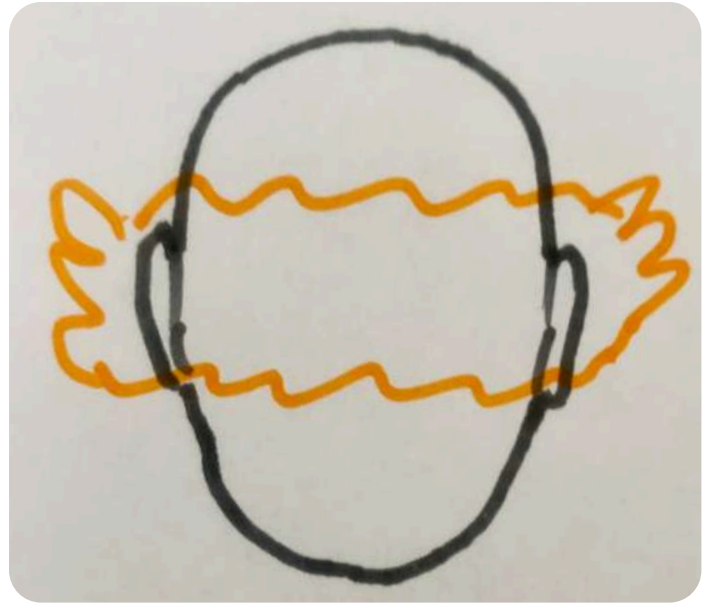
How to introduce the activity

“We’re going to make a self-portrait that includes our tinnitus. These portraits will show where you hear your tinnitus in relation to your own head. We’ll display the portraits alongside one another at the end of the activity, and spend some time looking at them together.”

Optional variations

Messy making: We’ve suggested using pens and pencils to create the portraits but a longer (and messier!) session can use painting. You would need washable paints and disposable aprons and/or to advise people to dress appropriately. This would need some forward planning. Using collage to make the portraits is also an option: see activity 7 for what you would need for this.

Examples from previous workshops:

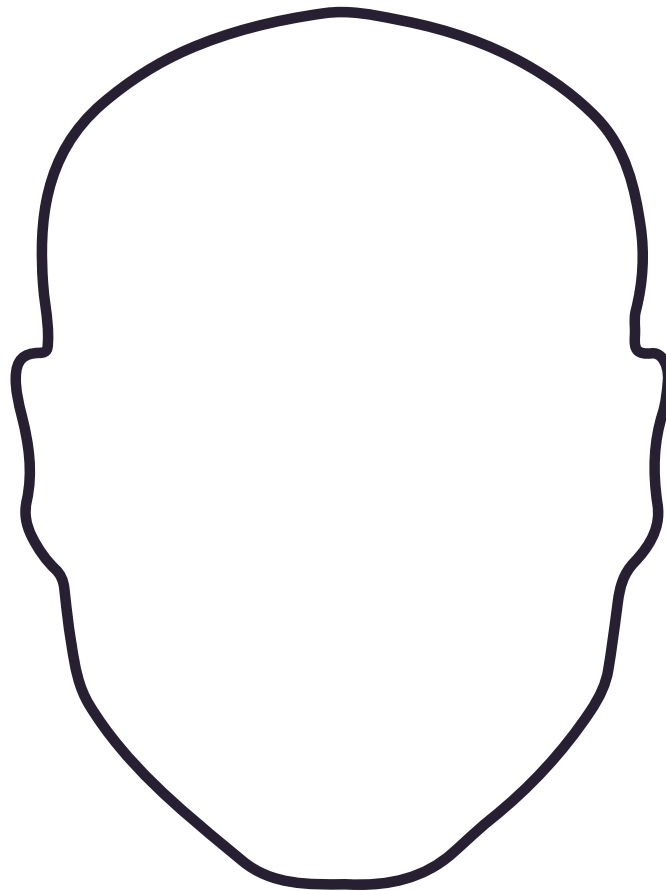


WORKSHEET: SELF PORTRAIT

Add your face to this template. it can be as simple and detailed as you like.

Next, add your tinnitus to this portrait. Use the following questions to help you think about how to represent this:

- Where do you hear your tinnitus: do you hear it coming from your left ear, right ear, both ears, or somewhere else?
- Does your tinnitus seem like it is coming from inside or outside your head?
- Does it feel like your tinnitus moves around or does it stay in the same place?
- Are there any types of line or shape that might help show what my tinnitus is like?
- Are there any colours that might help show what my tinnitus is like?
- If you have different types of tinnitus in different ears, how might you show this?



4. TINNITUS MAPS

🕒 35 – 50 mins



Individual



Longer (30 mins +)

What this activity is for

This activity involves creating a map that shows how people experience tinnitus in different places. This can help people think about where they find their tinnitus to be challenging, as well as the times and places where their tinnitus is less intrusive. Each map will be unique to each person. There is no right or wrong way of making the map: there can be many different types of place included and many different ways of representing them. This is a longer activity, so it can be helpful to break it down into different stages (see below).

You'll need:

- Pens and pencils for writing and drawing
- Paper – A3 paper size is best

Instructions

1. After introducing the activity, the group will need to think of three or four places they want to put on their maps. Ask the group to spend a few minutes thinking about the places they associate with their tinnitus being more noticeable and less noticeable, or louder and quieter. These places might be close together (e.g. different rooms of a house) or far apart (e.g. in different countries). They might be specific (e.g. a particular street in a neighbourhood) or general (e.g. busy cafés with hard surfaces).
2. Get the group to spend a few moments thinking about what the different places they have chosen are like. What do they look and sound like? What happens there? Are they indoors or outdoors? How might you describe this place to someone else?
3. Once the group is prepared, it's time to start making the map. Add the chosen places to the map. These can be shown using words, images or a combination of the two.
4. Next, tinnitus needs to be added to the map, using the symbols and key provided on the worksheet. There is also the option for people to create their own symbols.
5. In pairs, or as a group, talk about what it was like to make a tinnitus map. What types of places did people include? How does seeing the map make them think about their own tinnitus? If there was more time, are there other places they would include?

How to introduce the activity

“We’re each going to make a map of our tinnitus. This will show some of the places that we associate with our tinnitus being louder and quieter, easier and more difficult. You’ll each come up with ideas for places to put on your map, and come up with a way of representing what your tinnitus is like in each of these places. Your map, and what you put on it, will be personal to you”.

Optional variations

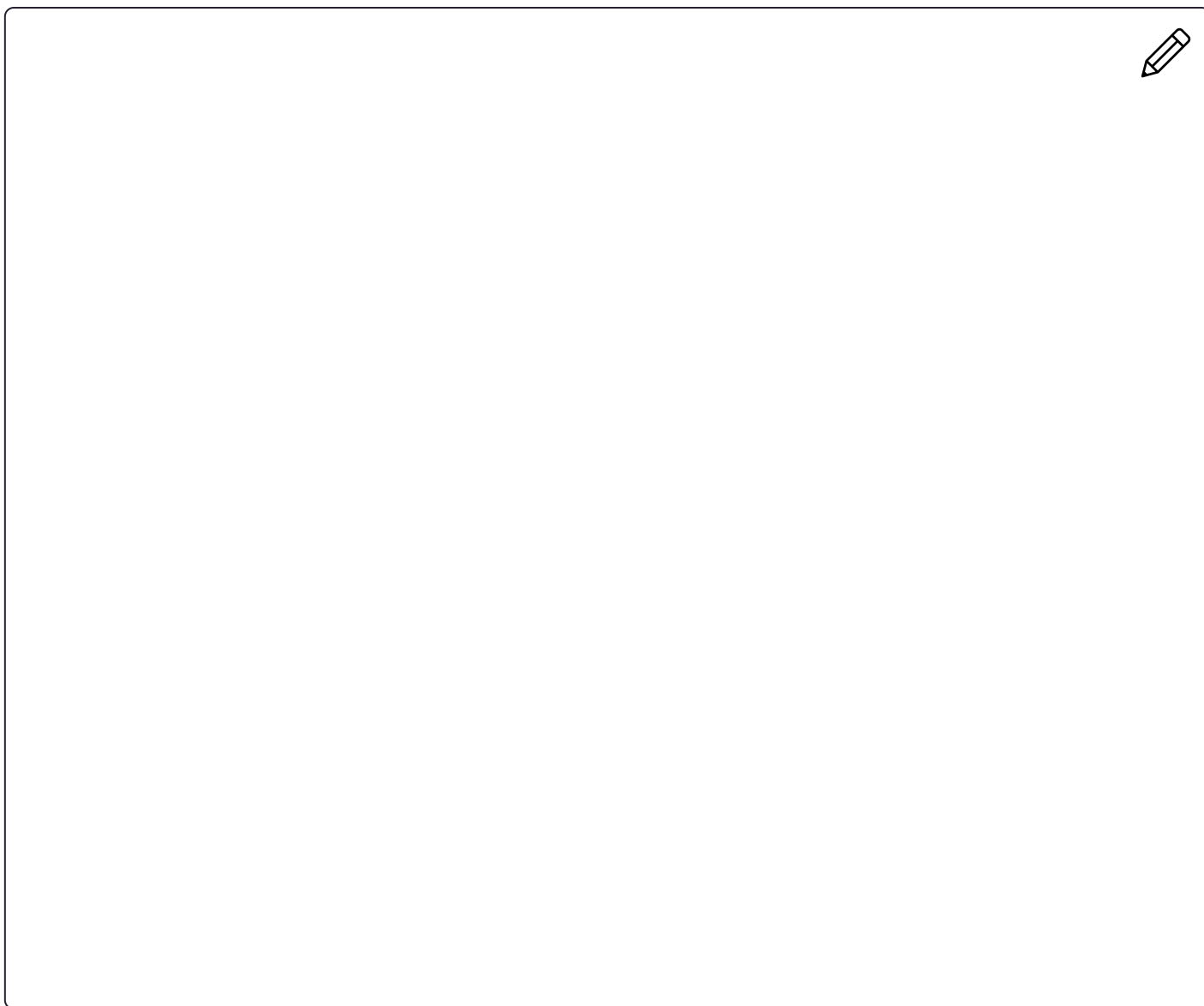
Keeping it simple: The activity can be simplified by the group leader choosing a key for everyone to use (e.g. red places are where tinnitus is loudest, purple places are where tinnitus is quietest).

Including more discussion: While the places identified should be particular to each person, steps 2-3 might be done in pairs. This will allow people to talk through their ideas with someone else.

WORKSHEET: TINNITUS MAPS

Use this space to create your tinnitus map.

- Think of 3-4 places that you'd like to add to your tinnitus map. What places do you associate with your tinnitus being loud or quiet, noticeable or not, intrusive or manageable?
- Use the box below to add these places to your map: you can use words or drawings to represent these different places.



Map key:

Use these symbols to show what your tinnitus is like in these different places. You can also add your own symbols.



: Finding things difficult



: Feeling ok



: Feeling good



: Inaudible



: Audible



: Loud

5. SCORING MY TINNITUS SOUND

🕒 15 - 45 mins



Individual



Collaborative



Longer (30 mins +)

What this activity is for

What tinnitus sounds like varies widely between people: some people will have a high pitched ringing in their ear, while others might have rumbling, humming, pulsing sounds in their head. This activity is about creating a 'score' that can be used to share what a person's tinnitus sounds like. In music, a score provides instructions on how to play or perform a piece. Often, music scores use notation, but they can take different forms: words, images, lines, shapes can be used to share musical ideas. Here, we suggest using letters and words to create the score: the activity begins by getting people to think about how they would 'speak' their tinnitus sound, and then write this down using the worksheet. There is also the option (see below) of creating a single, large score for the group. You can also allow some extra time to let people to try to perform each other's scores – if they're feeling brave!

You'll need:

- Paper
- Coloured pens and pencils

Instructions

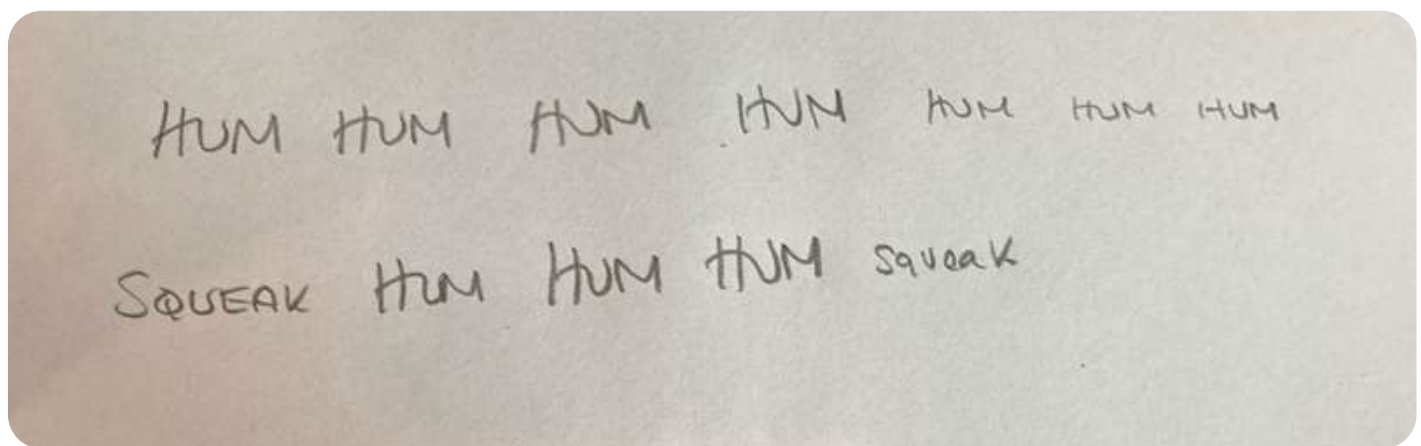
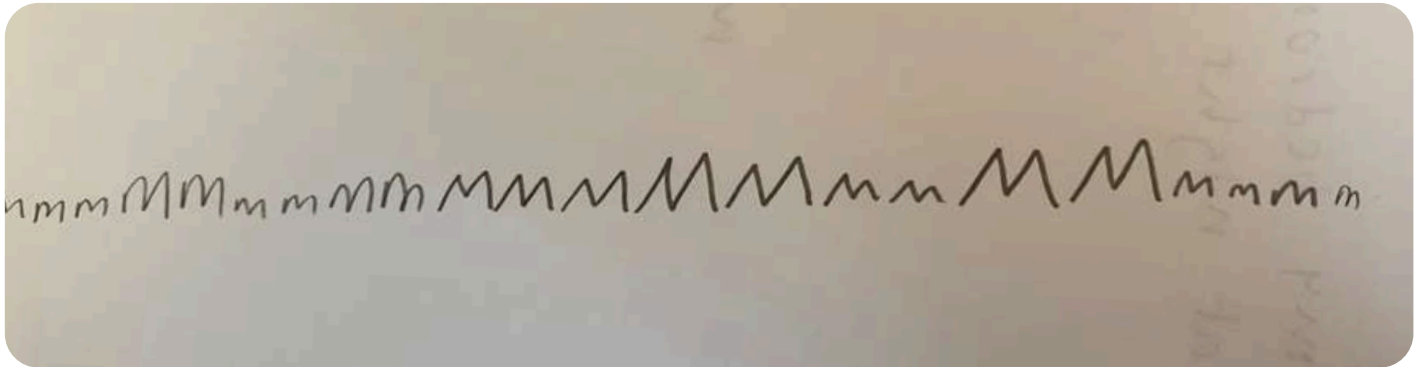
1. Explain the activity, then ask the group to think about how they might use their voice to re-create the sound of their tinnitus. How might they write this sound down using letters or words? (e.g. 'shhh' 'oooh' 'thromb', 'heeee', 'fizzzzzzzz').
2. Use responses to step 1 to create the scores. Encourage the group to think about the use of colour, shapes and size: how can these be used to help communicate to someone else what your tinnitus sounds like? Are there other instructions you might give if someone was to perform this?
3. In pairs or small groups, spend some time looking at each other's scores and talking about the approaches people have taken. If people are feeling brave, they might want to try performing a few of the scores together.

How to introduce the activity

“A score is a way of sharing a musical idea with others, so they might play or perform it, and we're used to seeing scores with lines notes and other

musical symbols. We're going to create a score of our tinnitus, so that others can get an idea of what we each hear, but using words, letters, images or any other shapes, instead of musical notes".

Examples from previous workshops:



Optional variations

A group composition: The activity could be adapted to create a score for the group, which combines the individual responses to step 2. This is likely to work better with smaller group numbers and can be a good option if you want to allow people to engage with the activities in different ways (e.g. some members can 'lead' in creating the score while others offer input and feedback).

WORKSHEET: SCORING MY TINNITUS SOUND

The purpose of this score is to give other people an idea of what your tinnitus sounds like.

A score is a way of sharing a musical idea, often using letters, numbers, signs and symbols.

- Start by thinking about how you might use your voice to re-create the sound of your tinnitus. How might you write this sound down using letters or words? (e.g. 'thromb', 'eeesh', 'shhhh' 'fzzz').
- Use these letters/words to make your score. Think about colour, layout, size and shape: how might these also be used to communicate the sound of your tinnitus? Use the box below to create your score.
- Are there any other instructions you might need to give if someone was going to perform your score? If so, add these in.



6. MY IDEAL SPACE

🕒 15 – 30 mins



Individual



Collaborative



Adaptable for online

What this activity is for

Work together to create the ideal space that provides calmness, peace or a sense of relief for tinnitus. It's a chance to think about what environments are helpful when living with tinnitus and to share ideas with the group. This activity might be used to follow on from the Tinnitus Maps activity. The ideal space might be represented visually or it might be a thought exercise, where people take it in turns to describe their ideal room verbally to one another. If doing the discussion-only version of this activity, leave out step 3. This can be effective as an ice-breaker activity.

You'll need:

For visual representation:

- Paper/worksheets
- Pens, coloured pencils

For discussion only

- No materials needed, just a quiet space for conversation.

Instructions

1. Introduce the activity, then instruct the group to take a moment to think about their ideal space and imagine walking through it – how does it feel?
2. Ask questions to help group members identify their preferences for the space:
 - If you could create a space where you feel calm and relaxed, what would it include?
 - Is the space indoors or outdoors?
 - Would it include any sounds? If so, what would they be?
 - What kind of lighting, colours, or textures would it include? Are there any you'd avoid?
 - Would it include other people? Or any animals/pets?
 - What's essential for making this space an enjoyable/comfortable place for you?
3. If drawing the ideal space: each person draws their idea of their ideal space. They can use the template in the worksheet or create their own. They can use words, colours and images to represent the space. Encourage sharing whilst creating, asking questions like, "why did you choose that colour? How does it make you feel?"

4. Go around the group and ask each person to share one or two details about their ideal space. Are there similarities and differences amongst the group? Ask the group how they might bring something from their ideal space into their daily lives.

How to introduce the activity

“Today we’ll imagine what an ideal space might look or feel like for those of us living with tinnitus. This could be a real place you’ve been to before, or it could be somewhere completely imaginary. It’s a way to explore what brings comfort to you and helps you feel at ease with your tinnitus”.

Optional variations

Online: Individuals can draw their ideal space with pen and paper and hold it up to the camera to show the rest of the group.

Collaborative creation: Collaboratively create a single space on a large piece of paper, whiteboard, or digital tool. Each person adds an element, such as an object or feature to the ideal space.

Digital making: For groups that have access to digital resources and a reasonable level of technical skill, you could use a digital collaboration tool (e.g. Canva, Google docs, Miro) to create the ideal spaces.

Imagining the ideal space: Spend a few minutes as a group imagining that you are in your ideal place. You might use the following script to guide the group in doing this:

I’d like us to take a few moments to use our imaginations to visit our ideal place. I’m going to ask you some questions to help you do this.

First, think about how it would feel to enter this space: how do you feel when you go there? Are you relaxed, calm, happy, excited?

[pause]

What can you see now you are in this place?

[pause]

Are there other people, or animals in this place with you?

[pause]

What does this place sound like?

[pause]

What can you smell, or taste in this place?

[pause]

It’s time for us to start thinking about leaving our ideal place. Spend these last few moments enjoying it, before joining us back in the room.

WORKSHEET: MY IDEAL SPACE

Use this template to create your ideal space.

You can draw, use words or colours to represent this. The following questions will help you decide what to include:

- If you could create a space where you feel calm and relaxed, what would it include?
- Would it include any sounds? If so, what would they be?
- Is it indoors or outdoors? What kind of lighting, colours, or textures would it include? Are there any you'd avoid?
- Would it include other people? Or any animals/pets?
- What's essential for making this space an enjoyable/comfortable place for you?



7. GROUP COLLAGE

🕒 40 mins – 1 hour



Longer (30 mins +)



Collaborative



Facilitator prep

What this activity is for

Collage involves using different materials (e.g. cut-out image and words, drawings, photographs and objects) to make something new. This activity gets a group to work together to create a collage responding to a theme. You might want to give some ideas about what people might include: pictures, text, colours, doodles, diagrams can all find a place! When creating a collage, things often take shape as you go along: the ‘making’ is often part of the ‘designing’. The collage should represent the group. However, people can take part in this activity in different ways: some people might help select words and images to be included, whereas others might want to take charge of cutting out, gluing and arranging.

You’ll need:

- Large roll of paper that the group can fit around
- Scissors
- Old magazines/newspapers/leaflets (bookshops and supermarkets will sometimes allow you to have old copies of these for free)
- Coloured pens/pencils
- Other collaging materials: coloured/textured paper, string, ribbon, fabric etc.
- Glue

Instructions

1. Introduce the activity, and choose one of the themes listed below (see ‘how to introduce the activity’) for the group to respond to.
2. Give the group a set amount of time (e.g. 40 minutes) to make the collage. Allow time for people to look at what materials are available. Some people may want to get stuck in straight away, while others might take a bit of time to get involved. Try to have the group sat together so that they can talk while they are making the collage.
3. Take some time to look at the collage together. How does it relate to the theme they were given? Why did they include certain images/words/colours in the collage?

How to introduce the activity

“We are going to work together to create a collage. The collage will be based around a theme [pick one]:

- good days/bad days
- what tinnitus means to us
- our week with tinnitus
- what other people should know about tinnitus
- living well with tinnitus
- another theme of your own choosing

A collage brings together different materials to make something new. It can include words, drawings, pictures, photographs, diagrams. So we have some magazines and newspapers that can be cut up, coloured pens and pencils, paper [mention any other resources]”.

Optional variations

Online version: A digital version of the collage could be created using free collaborative design software (e.g. Canva). However, using this software requires some technical skill and sometimes need users to share their personal details to access them.

Sound collage: If you have someone in your group who is confident using audio software, a sound collage can be created using some of the ideas above. Each group member could identify sounds to add to the collage: it might be sounds they like and/or dislike, or sounds that make them feel calm. People can either record and share these sounds themselves (most smartphones have a recording function using voice notes) or use a free sound library (e.g. Freesound.org). Some free audio software (e.g. Audacity, Garageband) can be used to arrange the sounds into a sound collage. You might want to establish some ground rules for this exercise so that some types of sound are avoided. Sounds that sound like some types of tinnitus, for example (e.g. high-pitched sine tones) can be distressing for others to listen to. This is likely to be a more time-consuming version of the activity.

8. SHOW & TELL

🕒 20 – 30 minutes



Individual



Collaborative



Adaptable for online




Participant prep

What this activity is for

Group members bring an object to share with the group that represents or relates to their tinnitus experience. This activity encourages group discussion and personal reflection.

You'll need:

-  **In advance:** ask group members to bring an object that relates to their tinnitus
- A smartphone or camera

Instructions

1. Introduce the activity, Invite group members to take turns showing their object or describing it, explaining what the object is and how it represents or relates to their tinnitus.
2. Ask members to arrange all the objects ready for the group leader to take a photograph of them together. The combined photo showcases the shared but unique experiences of tinnitus. If online, ask members to hold their object to the camera and the group leader will take a screenshot.
3. Reflect on the activity together. Discuss what the objects reflect for the group when brought together. Are there any common themes that are noticeable? What similarities and differences are there in the objects shared? Could group members relate to the objects brought along by other people?

How to introduce the activity

“Today we’re going to share objects that relate to our experience of living with tinnitus. These could be something we use daily or something symbolic”.

Optional variations

Online version: For online groups, ask participants to bring an object they can hold up to the camera or share a picture of it. For a picture of all the objects combined, take a screenshot whilst members hold their object up to the camera.



Toolkit User Feedback Survey

Please **complete our survey** to tell us about how you used this toolkit and to share any feedback or comments. **Click here**, or scan the QR code.



If you'd like a printed version of this resource, or have any questions about it, please contact: Marie Thompson (marie.thompson@open.ac.uk).

