introduction

ABOUT THESE ACTIVITES

On these pages you will find some activities that will guide you in thinking about your tinnitus. There are six activities in total.

There are three activity themes: 'where is tinnitus?' (la and lb), 'expressing tinnitus' (2a and 2b) and 'what tinnitus sounds like' (3a and 3b).

We know that tinnitus is different for everyone, so some of these activities might be more or less suitable for you. We would like you to try to do at least 2 activities. You can do more or all of the activities if you would like to.

Please do not include any information that could be used to identify you in your responses. (e.g. your home address, your full name).

We've included some examples to show how you could respond to the activities. You can use these as a guide but please don't feel limited by them: you can approach the activities in a different way.

What you use to respond to these activities is up to you. You can write, draw and sketch your responses by hand using paper and pencil. Or you can use a computer, if you prefer.

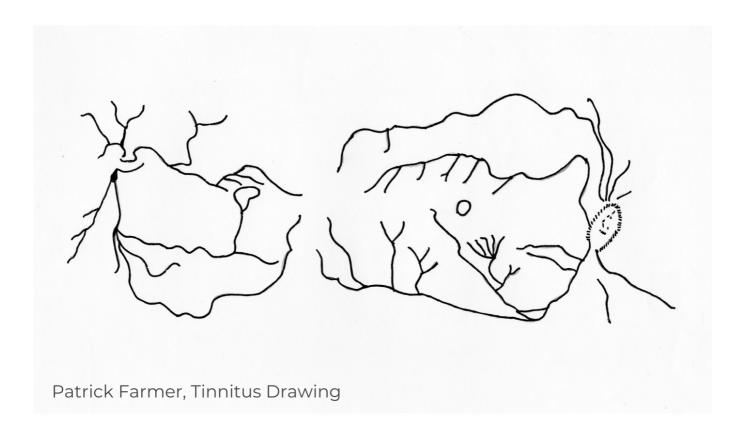
After each activity there is a place for you to enter or upload your response. If you have used pen and paper, you can take a photograph of this using a phone or digital camera and then share the file with us. If you have any issues with this, please contact the project lead: marie.thompson@open.ac.uk.

We will share some of these responses as part of the workshop discussion and on the project website. If you would like to share something with the project team but do not want it to be shared as part of the online discussion, please include the word 'private' in the file name.

After each activity there is a section for you to write down any thoughts to share with the project team.

We know that thinking about tinnitus can sometimes be upsetting. Please feel free to take your time with the activities or take a break when completing them. Details of support services for those with tinnitus are available through the British Tinnitus Association website.

Thankyou for taking part.



details

Your name		
your email address		

1A TINNITUS MAP

1A: TINNITUS MAP

The purpose of this activity is to show about how tinnitus can change in different places and environments.

- 1. First, you'll need to think of some different places that you'll want to put on your map. In order to choose these places, you might ask yourself:
 - Where does my tinnitus seem quiet, or where do I notice it less?
 - Where does my tinnitus seem loud, or where do I notice it more?
 - Where are some of the different places that I go as part of my weekly routine? What is my tinnitus like in these different places?
 - Have any places i've been surprised me in relation to my tinnitus?
 - What places do I associate with my tinnitus being made worse?

You don't need to choose lots of places: it could be 3 or 4. If you want to choose more, that's fine too! These places might be very close together (e.g. different rooms in your home) or they might be far apart (locations in different countries you've been to). You might be very specific in identifying these places (e.g. 'my allotment on

a windy afternoon') or you might want to keep it more general (e.g. 'allotment').

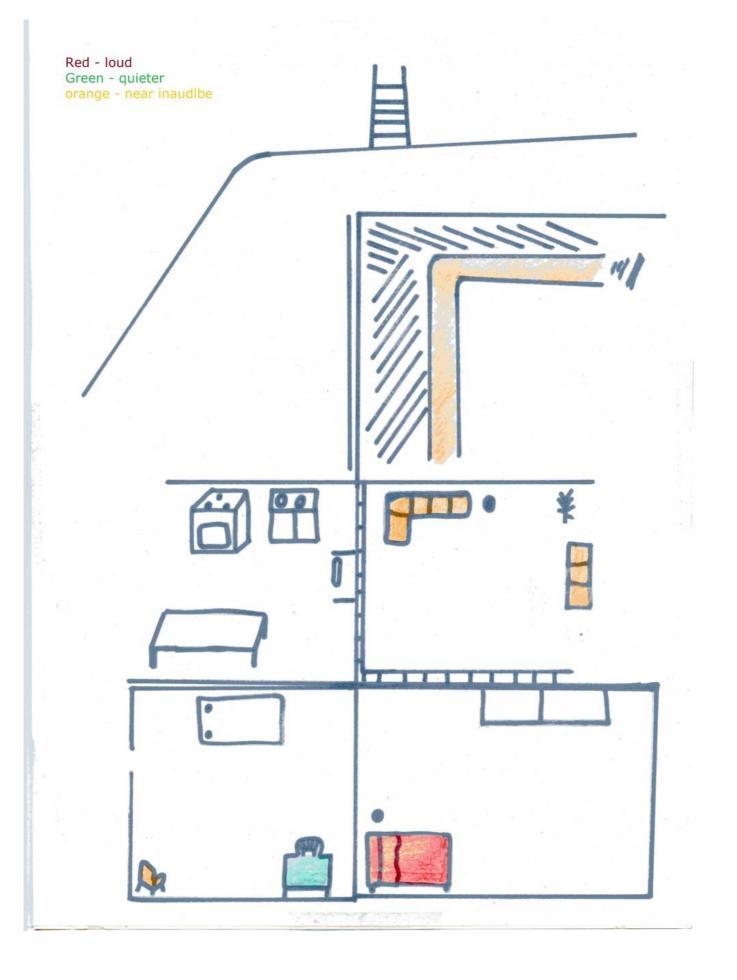
- 2. Spend some time thinking about what these different places are like. How do they look? What do they sound like? Are they open to the weather? Are they predictable? How might you talk about this place to someone else?
- 3. You can now start making your map. You can do this on a computer or using a pen and paper. It can be as simple or elaborate as you like!

These maps are about the relationship between different places and your tinnitus. They don't need to show the distance between places. To start making your map you could:

- Provide a short written description of the places on different parts of a piece of paper (e.g. 'my quiet bedroom at night'; 'the road during rush hour'; 'the hot house of a botanic garden'; 'my kitchen, near the fridge'; 'the garden with friends'; 'the local swimming pool')
- Draw some different illustrations to represent different places
- You can add some 'sounds' to your places (see example below)

- 4. Next, you need to put your tinnitus on the map. Again, there are some different ways to do this. Some options include:
 - Draw a circle around each of the places. Where your tinnitus is louder/more noticeable, you can draw a bigger circle. Where your tinnitus is quieter/less noticeable, you can draw a smaller circle. If there is a place where it's not possible to hear your tinnitus, you can have no circle. (see example above)
 - Use a colour scale: where your tinnitus is louder/more noticeable use a darker colour, and where your tinnitus is quieter/less noticeable use a lighter colour.
 - Make places where your tinnitus is louder/more noticeable bigger and the places where your tinnitus is quieter/less noticeable smaller.
 - Underline places on the map where you find your tinnitus to be aggravated
- 5. Provide a key so that someone else can interpret the map. The key can be as simple as:
 - 'Small circle quiet tinnitus, large circle loud tinnitus'
 - 'Dark red tinnitus most noticeable, light pink, tinnitus least noticeable'
 - 'Size of place shows tinnitus loudness: the smaller the place, the louder the tinnitus.'
 - 'Underlined places = tinnitus hotspot'

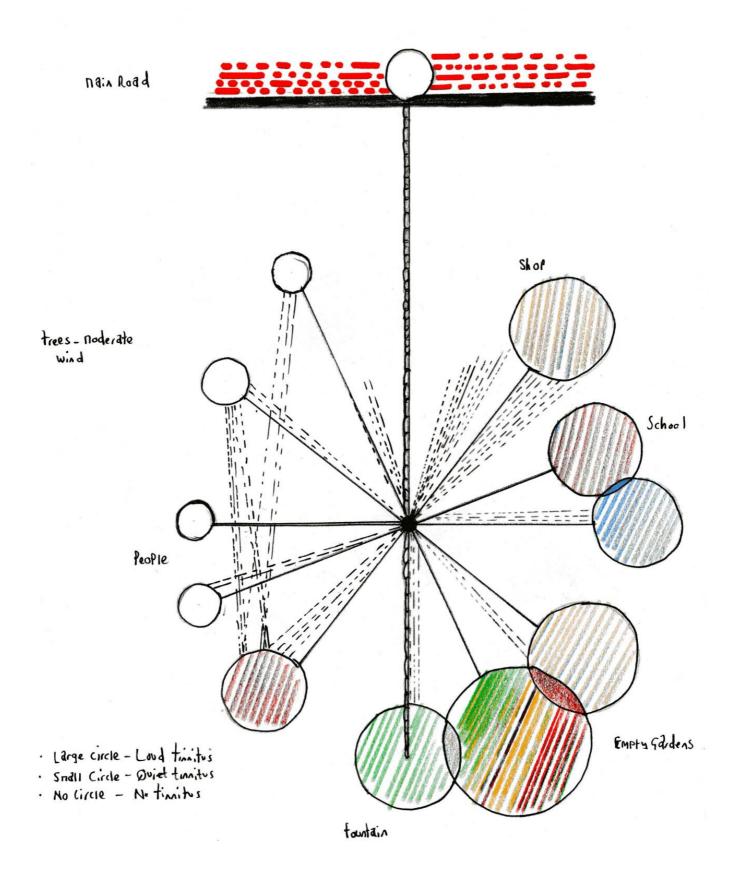
Tinnitus map of home using colour key



A simple tinnitus map made with free drawing software and using a circle key



Tinnitus map of the botanic gardens in the afternoon using circle key



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	it? You can use this space to write down some reflections
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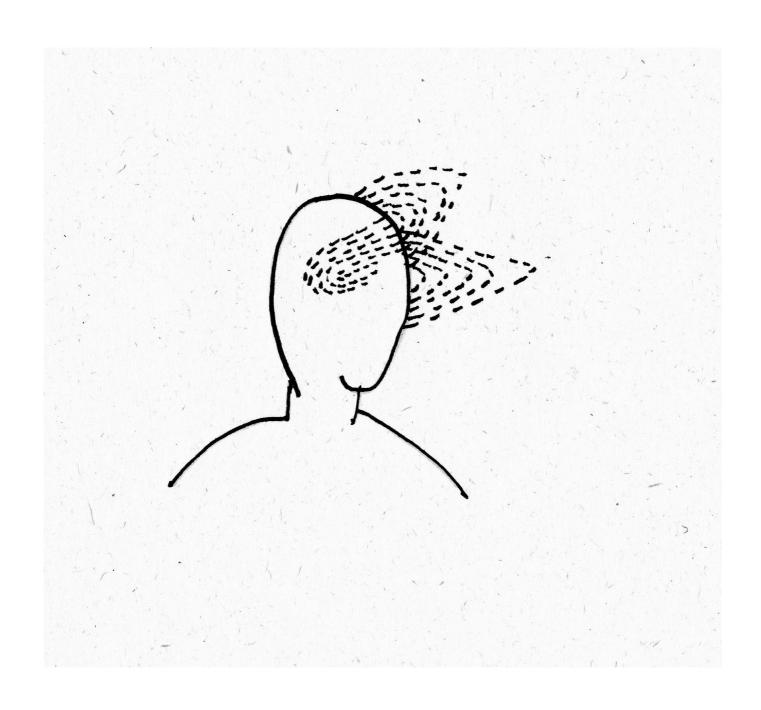
1B TINNITUS PORTRAIT

1B: TINNITUS PORTRAIT

The purpose of this activity is to find out where different people hear tinnitus in their head.

When doing this exercise, try not to focus on the sound of your tinnitus for a long time, as this might make it worse. If you find yourself focusing a lot on your tinnitus, you might want step away and come back to this activity at a different time.

- 1. Draw a picture of your face. This can have as much or as little detail as you like. It can be in any style you want: it can look like you, or it can be more abstract. If you don't want to draw your face, you might want to use a photograph instead.
- 2. Think about where you usually hear your tinnitus as coming from. Do you hear it coming from your left ear? Your right ear? Both ears? Somewhere else in your head? Does it often seem like its coming from outside your head?
- 3. Next, think about what direction your tinnitus travels in. This might be a bit more difficult. Does it feel like your tinnitus moves around? Does it feel like it goes from inside to outside your head? Or does it just stay in the same place?
- 4. Try to add your tinnitus to your portrait. Try to show where your tinnitus comes from and goes to. You might want to think about:
 - 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?



Please upload your tinnitus portrait here

	Did you enjoy this activity? Did it make you think about
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İ	it? You can use this space to write down some reflections
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2A: DRAWING TINNITUS

2A: DRAWING TINNITUS

The purpose of this activity is to consider how tinnitus may be represented without using words.

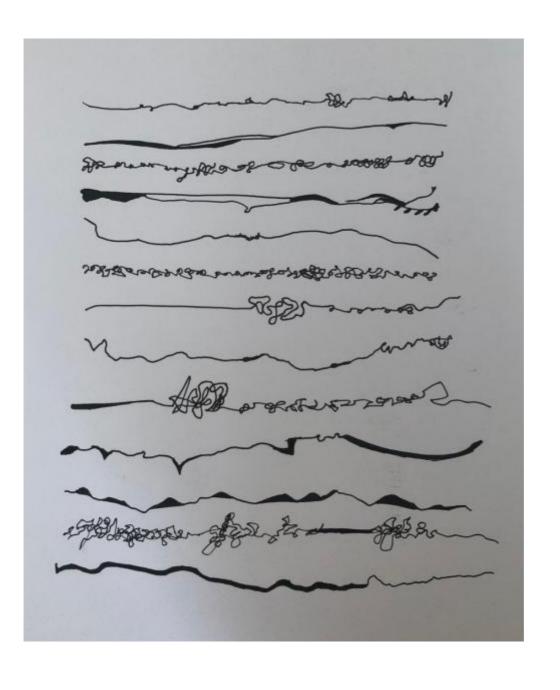
Using whatever materials you wish, whether pencil, charcoal, colouring pens or your computer, try to draw your tinnitus once a day for three days.

Consider setting a time-limit for your daily drawing (e.g. five minutes).

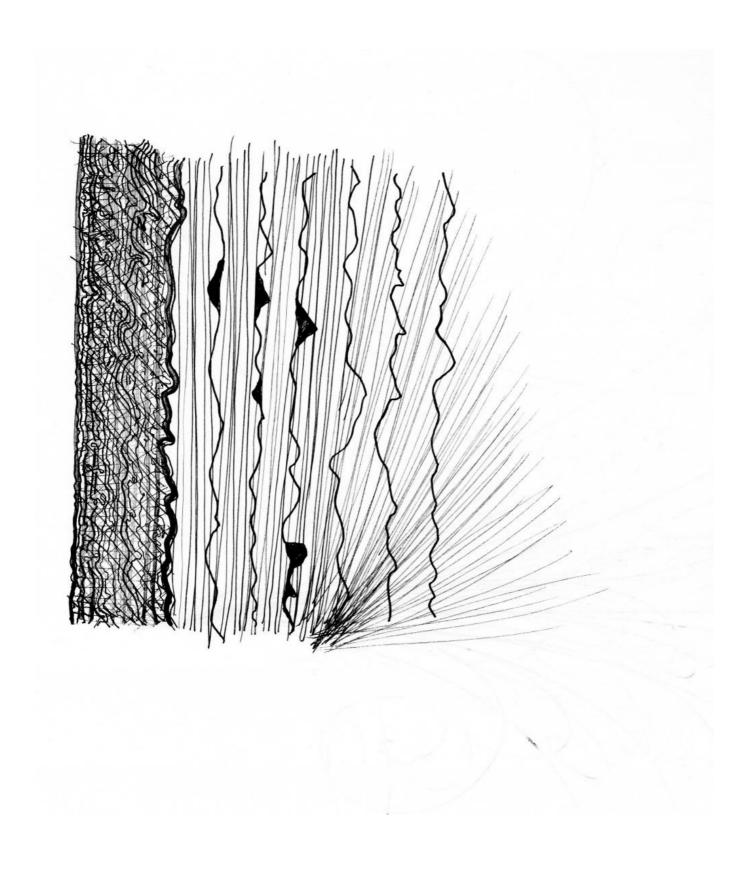
We have included some examples of drawings below but you are welcome to draw in any style you wish. The style of drawing may vary each day.

You could take a photo of your drawing each day, so you can record how it develops over the three days.

Below are some examples of tinnitus drawings







please upload your tinnitus drawing here

Does your drawing have a title? if so, please add it here
Did you enjoy this activity? Did it make you think about your tinnitus differently? What did you find difficult about it? You can use this space to write down some reflections about this activity.

Block 4

2B: PUTTING TINNITUS INTO WORDS

- 1. 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.
- 2. Think about how tinnitus can be conveyed in the multiple meanings of a word. Write some of these down.

Alternatively, you can record yourself speaking the word and some of its meanings.

Here are some examples that we came up with:

Excess

I have pushed myself too far An additional sound Beyond what I think of as 'normal'

Everyday

I hear it most days Its part of 'normal' life I carry it with me

Intimate

It's so close to me I can't explain it No one can hear it but me Sometimes it feels like a voice

Interference

It interrupts and distracts
An obstruction and hinderence
it forms patterns

Fatigue

It's worse when I'm tired It takes my energy Rest is my weapon against it

You can submit your own tinnitus words and their meanings here
What do you think a single word can say that a sentence cannot? What do you think are the differences in speaking and writing a word? You can write down any thoughts here

Did you enjoy this activity? Did it make you think about your tinnitus differently? What did you find difficult about it? You can use this space to write down some reflections about this activity.

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Block 5

3A: KEEPING SCORE

The purpose of this exercise is to try to creatively explore what your tinnitus sounds like using written or spoken 'word-sounds'.

- 1. Think about what spoken 'word-sounds' you might use to say your tinnitus out loud. The word-sounds you use can be made up for example, hmmm, woooaaooo, eesh, bombombom. You might want to try out some different options by saying them out loud. You may even just want to experiment with a single letter, e.g. 'eeeeeeeeeee'. Don't worry if your word-sound isn't exactly like your tinnitus: these word-sounds are meant to be a creative interpretation rather than an accurate re-creation of what your tinnitus sounds like.
- 2. There are now two options for sharing your wordsound. You can either write down your word-sound (see

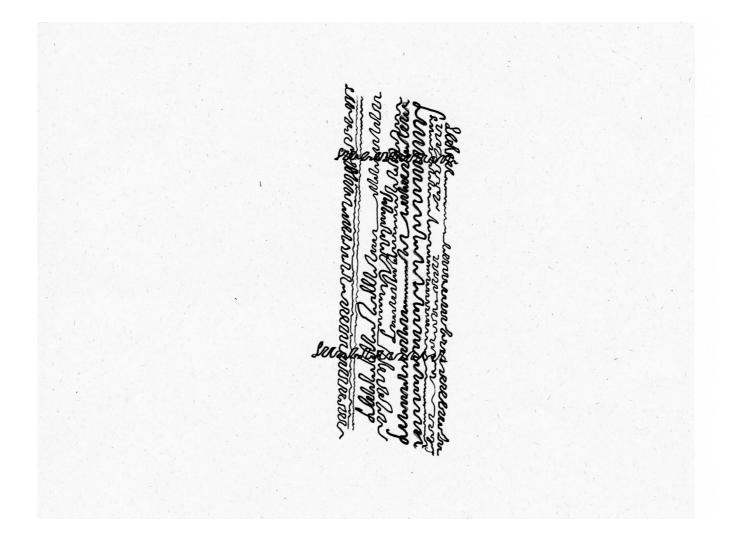
- steps 3-5) or create an audio recording of your wordsound (see steps 6-8).
- 3. If you want to write down your word-sound, think about how this word or words should look on a piece of paper. Should the word be in large letters? Should it be small? Should it change size? Should it be long? Should it be short? Should it be repeated? Should it appear in a pattern? To narrow this down, you might want to think about how your tinnitus tends to sound when you are feeling a particular way, or in a particular time or place (e.g. at night, when feeling stressed, after a good or bad day).
- 4. Think how pitch and/or loudness may be depicted in the words used. Will colour help to represent your tinnitus?
- 5. Once you have decided on how your word or words should look, add them to a page. You might want to provide a title to your piece e.g. 'tinnitus at night', 'after the gig', 'too much on', 'a good day'.
- 6. If you want to create an audio recording of your word-sound or word-sounds, you will need to find a device that is able to record you speaking your word-sound. Most smartphones, tablets and computers will have an sound recorder built in, so if you have one of these devices you could use that to create an audio file.

- 7. Aim to create a recording that is around 30 seconds long. Before you press record, think about how you want to say your word-sound: should it be loud? should it be whispered? should it be drawn out? should it be repeated? You might also want to think about where you want to record your word-sound. Would somewhere quiet be best? Or do you want to include some background noise?
- 8. Don't worry if it take a few tries to get a recording that you are happy with. You might need to experiment with where to place the sound recorder so that your voice is picked up in the way you want it to be. Once you have a recording you are happy with, be sure to give it a title and save it.

An example of a word-sound written down: 'tinnitus at night'



A subtler word-sound: 'fizz'



You can upload your image or audio recording for activity 3a here

Did you enjoy this activity? Did it make you think about your tinnitus differently? What did you find difficult about it? You can use this space to write down some reflections about this activity.

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Block 6

3B: CAPTURING SOUNDS

The purpose of this activity is to find and/or make sounds that relate to your tinnitus in some way.

1. Whether at home or elsewhere, try to make and/or identify some sounds that you think express something about your tinnitus. You might want to ask yourself the following questions:

- are there sounds that remind me of how tinnitus feels in different situations?
- are there sounds that help mask or 'soothe' my tinnitus?
- are there sounds I like or dislike being around because of my tinnitus?

As with activity 3A, don't worry about trying to produce a sound that is exactly like your tinnitus: aim for a creative interpretation rather than an accurate imitation of what your tinnitus sounds and feels like.

2. Try to capture some of these sounds. You might want to use a video or audio recording device such as your smart phone. You could take photos of the objects, or write down descriptions of the sounds, and why you have chosen them.

If you associate a sound with your tinnitus being bad you might want to describe this sound from memory, rather than listening to and recording it.

Here are some examples of sounds that we think relate to our experiences of tinnitus:

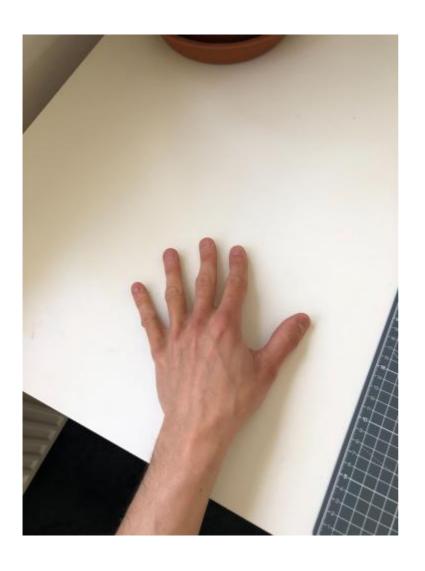
- Standing under a tree on a windy day.
- Rubbing your hands over different surfaces.
- Placing your ear against a fridge.
- Slowly tearing paper.
- The rain from an open window.

- Slowly pouring water from one glass to another.
- The sound of writing and rubbing out.
- The kettle boiling.
- Wind blowing through fence poles.
- Rubbing stones together.

You might want to experiment with making some of these sounds.

Capturing sound example: rubbing hands on the surface of a desk

I spend so much time on Zoom at the moment, and I find that my tinnitus is much more active and present in between sessions. Gently rubbing my hand/s along the surface of my desk often goes some way into focussing my attention on something else.



you can upload any images, audio recordings, or written descriptions from activity 3b here

Did you enjoy this activity? Did it make you think about your tinnitus differently? What did you find difficult about it? You can use this space to write down some reflections about this activity.

Click to write the question text
Block 7
You have now reached the end of the activities. To submit your responses please press the arrow to go to the next page. Please note that once you press this you will not be able to return to the activities.
Is there anything else you would like to tell us?
Is there anything else you would like to share with us?

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