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Article:

Summerfield, Quentin orcid.org/0000-0002-7391-0959, Kitterick, Pádraig and Goman, Adele (2022) Development and critical evaluation of a condition-specific preference-based measure sensitive to binaural hearing in adults:the York Binaural Hearing-related Quality of Life System. *Ear and Hearing*. pp. 379-397. ISSN: 1538-4667

<https://doi.org/10.1097/AUD.0000000000001101>

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Supplementary Digital Content 6

Example of a Response Booklet for the Pilot Experiment

(This document is supplementary to the paper by Summerfield, Kitterick, and Goman entitled 'Development and critical evaluation of a condition-specific preference-based measure sensitive to binaural hearing in adults: the York Binaural Hearing-related Quality of Life System'.)

The Value of Hearing

Thank you for considering whether to take part in this study.

Please read the pages that follow this one.

If anything is not clear, please ask the person who gave you this pack.

Please turn to the next page

Consent Form

Purpose of this study

We are measuring the value of hearing with two ears, rather than one. We hope that the results of this study will help policy makers in the health service make decisions about treatments for people with hearing problems.

Who are the participants?

We are recruiting university undergraduates, clinicians, and adults from the general public.

What is involved?

We would like you to complete a questionnaire in which you will imagine that you are experiencing different combinations of hearing problems. We expect that it will take you approximately 30 minutes to complete the questionnaire. You do not have to take part and have the right to withdraw from the study at any time. Please could you read the attached instructions, examples, and questionnaire. Then, if you would like to take part, please could you sign the consent below.

What should you do with the questionnaire when you have completed it?

Please hand this consent form and the questionnaire back to the person who gave them to you.

About your data

Your consent form will be kept in a secure location to ensure your confidentiality. The personal details you provide will be kept separately from your data. Your data will only be identifiable by a participant number.

Declaration of Consent

I understand the aims and procedures of the experiment I am about to participate in.

I reserve the right to withdraw at any stage in the proceedings. If I do so, I understand that any information that I have provided as part of the study will be destroyed and my identity removed unless I agree otherwise.

Name: _____

Signed: _____

Date: _____

The researchers are Rhian Bardsley (rjb531@york.ac.uk), Sarah-Louise Buggins (sb876@york.ac.uk), Danielle Dickinson (dd576@york.ac.uk) and Rachel Williamson (rjw529@york.ac.uk). Their supervisor is Professor Quentin Summerfield (Quentin.summerfield@york.ac.uk).

Please turn to the next page

Information about You

Please could you provide the following information about yourself:

Your age: _____

Your date of birth: DD/MM/YYYY
Y

Your gender: Male / Female

What is your main occupation (or previous occupation if you are retired or currently not working)?

Have you ever worked with people who have hearing loss or deafness? Yes / No

Do you have any problems with your own hearing? Yes / No

Do any members of your close family have any problems with their hearing? Yes / No

Do you consider yourself to have any other disabilities? Yes / No

If you answered yes, please could you tell us a little about your disability?

Do any members of your close family have any other disabilities? Yes / No

If you answered yes, please could you tell us a little about their disability?

Please turn to the next page

Instructions

While you are completing this questionnaire, we would like you to imagine that you are 30 years old and that you will live for **50 more years**, until you are 80 years old.

The questionnaire consists of 27 'scenarios'. Each scenario is a description of three aspects of a person's ability to **hear**. We want you to imagine that we are describing **you**.

First, we describe your ability to understand speech when there is background noise.

Second, we describe your ability to work out where sounds are coming from; that is, to 'localise' sounds.

Third, we describe the amount of effort that you have to make in order to hear. Also, we describe how tired this makes you feel by the end of the day.

Please read each scenario carefully and imagine that it is describing your own ability to hear. Any difficulties with your hearing are permanent. They are not life-threatening, but there is no cure. Then imagine that you could give up some of your remaining 50 years of life in order to be free of any difficulties with your hearing. You would hear normally now, and for the rest of your life. The years that you would give up would be taken from the **end** of your life.

Remember: you are 30 years old and you can expect to live for 50 more years. **Please read each scenario carefully. Imagine that it is describing your hearing. Then tell us how many of those 50 years you would be willing to give up in order to hear normally now, and for the rest of your life.** Please work your way through all 27 scenarios, one at a time. When you reach the end of the questionnaire, please check that you have answered all of the scenarios.

There are no right or wrong answers. We are simply trying to find out how people value different aspects of the ability to hear.

Please turn to the next page

Examples

Here are two examples of scenarios from a different questionnaire.

In deciding how many years of your life (if any) to give up, you should think about the quality of life that you would have if the description in the scenario applied to you for the remaining 50 years of your life.

Example 1

You have a cut on your hand which is making it difficult to use that hand. You are in a little pain, but have seen a nurse and have had your hand bandaged. You have been told that your hand will heal by itself in a few days and there will be no lasting damage. How many years would you give up (from the end of your life) to restore yourself to perfect health immediately?

I would give up this number of years: 0

In our experience, most people are not willing to give up any years of their life in this scenario. So they would write '0' in the box, as has been done in the example above.

Example 2

You have had a stroke. You have lost the ability to control your hands and to speak clearly. You are regularly forgetting to do things. As a result, you are struggling to cope with day-to-day living. You are very concerned about your future, as you have been told that you will never fully recover. How many years would you give up (from the end of your life) to restore yourself to perfect health immediately?

I would give up this number of years: 25

In our experience, most people are willing to give up 20 or more years from the end of their life in this scenario. If they decided that they would give up 25 years, they would write '25' in the box, as has been done in the example above.

Please turn to the next page

Scenario Questionnaire

Scenario 1

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 1: I would give up this number of years: _____

Please turn to the next page

Scenario 2

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 2: I would give up this number of years: _____

Please turn to the next page

Scenario 3

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 3: I would give up this number of years: _____

Please turn to the next page

Scenario 4

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 4: I would give up this number of years: _____

Please turn to the next page

Scenario 5

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 5: I would give up this number of years: _____

Please turn to the next page

Scenario 6

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 6: I would give up this number of years: _____

Please turn to the next page

Scenario 7

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 7: I would give up this number of years: _____

Please turn to the next page

Scenario 8

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 8: I would give up this number of years: _____

Please turn to the next page

Scenario 9

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 9: I would give up this number of years: _____

Please turn to the next page

Scenario 10

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 10: I would give up this number of years: _____

Please turn to the next page

Scenario 11

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 11: I would give up this number of years: _____

Please turn to the next page

Scenario 12

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 12: I would give up this number of years: _____

Please turn to the next page

Scenario 13

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 13: I would give up this number of years: _____

Please turn to the next page

Scenario 14

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 14: I would give up this number of years: _____

Please turn to the next page

Scenario 15

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 15: I would give up this number of years: _____

Please turn to the next page

Scenario 16

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 16: I would give up this number of years: _____

Please turn to the next page

Scenario 17

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 17: I would give up this number of years: _____

Please turn to the next page

Scenario 18

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 18: I would give up this number of years: _____

Please turn to the next page

Scenario 19

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 19: I would give up this number of years: _____

Please turn to the next page

Scenario 20

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 20: I would give up this number of years: _____

Please turn to the next page

Scenario 21

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 21: I would give up this number of years: _____

Please turn to the next page

Scenario 22

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 22: I would give up this number of years: _____

Please turn to the next page

Scenario 23

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 23: I would give up this number of years: _____

Please turn to the next page

Scenario 24

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You have great difficulty working out where sounds are coming from. You cannot even tell if a sound is coming from the right- or left-hand side without looking around. As a result, you find it very difficult to tell who is speaking when you are in a group with several people. You are also worried about your safety outdoors because of your difficulty working out where sounds are coming from.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 24: I would give up this number of years: _____

Please turn to the next page

Scenario 25

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you find it very difficult to hear your friend speaking. You are usually unable to pick out the words they say. This regularly leads to misunderstanding and confusion. The room needs to be completely quiet for you to understand them.

Localisation

You can work out where sounds are coming from accurately. You can point to where a sound is coming from easily.

Effort and Fatigue

You have to concentrate quite hard when you are trying to hear something or someone. You have to put in some effort to hear what people are saying. By the end of the day, you are moderately mentally and physically tired because of your hearing.

For scenario 25: I would give up this number of years: _____

Please turn to the next page

Scenario 26

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking easily, usually picking up all of the words they say.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate a little when you are trying to hear something or someone. You can hear what people are saying with only a little effort. By the end of the day, you are not mentally or physically tired because of your hearing.

For scenario 26: I would give up this number of years: _____

Please turn to the next page

Scenario 27

Speech Perception in Noise

When a friend speaks to you while the TV is on or other people are chatting in the same room, you can hear your friend speaking, but you can only pick out some of the words they say. This can lead to confusion if you miss an important word. Sometimes you need them to repeat themselves or to turn the volume down for you to understand them.

Localisation

You have some difficulty working out where sounds are coming from. You can usually tell if a sound is coming from the right- or left-hand side, but you cannot be more accurate than that. As a result, you are not always sure who is speaking when you are in a group with several people.

Effort and Fatigue

You have to concentrate very hard when you are trying to hear something or someone. You have to put in a great deal of effort to hear what people are saying. By the end of the day, you are extremely mentally and physically tired because of your hearing.

For scenario 27: I would give up this number of years: _____

Please turn to the next page

That is the end of the questionnaire. Thank you for taking part.

Please make sure you have signed the consent form at the front of this pack and check that you have written a number in all of the scenario boxes.

Once everything is completed, please return the pack to the person who gave it to you.

If you would like a brief summary of the report when the study is complete, please tick the box below and provide your e-mail address in the space provided.

☐

E-mail: _____

If you have any further questions or concerns, please do not hesitate to contact one of the researchers; Rhian Bardsley (rjb531@york.ac.uk), Sarah-Louise Buggins (sb876@york.ac.uk), Danielle Dickinson (dd576@york.ac.uk), Rachel Williamson (rjw529@york.ac.uk), or their supervisor Quentin Summerfield (Quentin.summerfield@york.ac.uk).