



‘Here’: An Anxiety App

Participant Information Sheet

QMUL Research Ethics Committee Approval ID Number: QMERC22.119

You are invited to participate in a research study. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully. Please ask questions if anything is not clear or you would like more information. You do not need to give a reason if you do not wish to participate.

What is the purpose of the study and what would taking part involve?

My name is Amy Dowse and I am a PhD student at Queen Mary University of London. My research focuses on the use of technology to support people who experience anxiety, either alone or with chronic pain.

The purpose of this study is to explore the effects of an app called 'Here' for people to use when feeling anxious. 'Here' is called an 'ecological momentary anxiety-focused' app. This just means that it helps users during their everyday lives (i.e., in real-time) and in natural settings. Therefore an 'ecological momentary anxiety-focused app' is an app that is designed to help someone with their anxiety in their day to day lives, in the moment that they are experiencing anxiety.

The main focus of the study is on whether such apps can change the levels of anxiety people perceive they are experiencing. The results will help us determine whether and how such apps can help and how to make them more effective. Therefore, the focus is not on 'Here' specifically, but on the class of apps – 'Here' is being used as an example of an ecological momentary anxiety-focused app.

This study, testing 'Here', consists of four parts:

- 1) **Prior Questionnaire**
This is the questionnaire asking questions about your views of ecological momentary anxiety-focused apps in general as well as about your experience of anxiety and chronic pain. It will take approximately 10 minutes to complete.
- 2) **Testing Here**
You will have four weeks to use 'Here' as and when needed – there is no minimum level of engagement needed. When using 'Here' you just complete images gaining 'achievement points' when you do so. During the use of 'Here', the app will collect data about when the app is used, how long it is used for, and when you complete an image to gain an 'achievement point'.

3) Post Questionnaire

This is a questionnaire to be completed at the end of the four weeks asking questions about your views of ecological momentary anxiety-focused apps based on your experience of using 'Here', as well as asking about your experience of anxiety and chronic pain. It will take approximately 10 minutes to complete.

4) Interview

A 30 to 60 minute online interview (either Zoom or Teams will be used) to ask some more detailed questions about your experience of using 'Here'.

Who can take part?

This study is only appropriate for people who experience anxiety of some kind. Participants may or may not also experience chronic pain.

There are certain eligibility criteria that must be met in order for someone to take part in this study. You must be:

- Aged 18+
- Currently living in the UK
- Experience anxiety (either formally diagnosed by a medical professional or self-diagnosed)
- Own an iPhone
- Are stable on any treatments (3+months)
- Are not anticipating any changes to treatment for the duration of the study
- Are not classed as vulnerable – are not 65+, do not have learning difficulties, are not cognitively impaired

In order to take part in later stages of the study you must complete all earlier stages.

Do I have to take part?

It is up to you whether you wish to take part. If you do decide to take part, you will be free to withdraw at any time up until one week after completing the interview. To withdraw, please send an email, stating your name, to a.h.dowse@qmul.ac.uk. You do not need to provide any reason for withdrawing. All of your data from completed parts of the study will be deleted and will not be used in the study.

What are the possible benefits of taking part?

Participants may experience an immediate benefit from taking part in this study as they may find that their levels of anxiety and/or chronic pain reduce. This cannot be guaranteed as the purpose of the study is to determine if there is any perceived improvement on levels of anxiety and/or chronic pain.

There may also be a non-immediate benefit as the results will help to improve the understanding of ecological momentary anxiety-focused apps. This will contribute to later research and the development of apps to support people with anxiety and chronic pain, helping to create solutions that are better suited to people's needs and therefore can offer them more support.

What are the possible risks of taking part?

The questions within both questionnaires are based around the topic of anxiety. You will have to consider your answers to the questions based on your experiences of anxiety which may be upsetting for some people.

The interview questions will probe deeper into your experiences of using 'Here'. They will be more in depth than the questionnaire questions. They will ask you to recall a time when you were anxious in order to discuss the use of the app and this may be upsetting. You are free to take breaks throughout the interview if you feel that you need some time. You can also choose not to answer a question if you do not feel comfortable doing so.

You should not delay seeking help, either through therapy or medication, for your anxiety or chronic pain despite the eligibility criteria for this study that stipulates that these must remain the same for the duration of the study. Please be assured that your health and wellbeing is the top priority and that if you feel that you need to seek additional help that this should always be done. I only ask that you message me to let me know that you will no longer be taking part in the study – I do not require any reason.

What information will you be collecting about me?

There are four parts to this study and different information will be collected during each part.

When you start the study you will be assigned a participant ID – this is a randomly generated two-digit number. This number will be used to link together your responses to the four parts of the study.

1) *Prior Questionnaire*

During the prior questionnaire some demographic information will be collected. This will include your name, age, gender and some health-related information (how long you have experienced anxiety and/or chronic pain).

The demographic information is collected to give an idea of how representative the sample of participants are in relation to the wider population. This will help to establish how generalisable the findings are to the wider population.

The questions from two standard questionnaires widely used in the NHS are included in the questionnaire. One is called GAD-7 and is used to provide a numerical value to represent your levels of anxiety. The second is called a Chronic Pain Grade Scale (CPGS) questionnaire – this is used to provide a number to represent your levels of pain. These values can then be compared to the values at the end of the study to determine if using the app has had any effect on your perceived levels of anxiety and pain.

The questionnaire will ask you about your views on different factors associated with the opportunities, barriers, and motivators when using an ecological momentary anxiety-focused app in general.

Completion of the questions within the questionnaire are not mandatory, you can choose to skip any questions. Most questions within the questionnaire require you to select an answer from a predetermined list and some questions are open ended. Open ended questions are included so that you have the opportunity to provide a fuller, more accurate answer to the question if you do not feel that the pre-provided answers are relevant to you. Please do not include any personal information within these free text answer boxes.

2) App Usage

When using 'Here' information about when you use the app, the length of time you spend interacting with the app, and how many points you collect will be logged. This is so that patterns of usage can be analysed to determine the optimal way to use the app to gain the most benefit. No other data will be collected.

The image below shows an example of the data that will be collected by the app:

Date	Tag	
2022-03-07 11:13:42	Active	
2022-03-07 11:13:48	Active	
2022-03-07 11:14:00	Background	
2022-03-07 11:14:00	End	
2022-03-07 11:14:02	Active	
2022-03-07 11:14:13	Background	
2022-03-07 11:14:19	Active	
2022-03-07 11:14:40	Background	
2022-03-07 11:14:40	End	
2022-03-07 11:14:41	Active	
Date	Colour	Type
07/03/22 11:14:34	White	General
07/03/22 11:14:54	Green	Figure

When you first use the app you will need to agree to this data being collected. Once you have done the data will automatically be recorded. At the end of the four weeks, you will need to send this data to the researcher. You will press a button in the app which will generate a file that contains all of the data which you then email to the researcher. Detailed instructions will be provided when you need to do this.

3) Post Questionnaire

The post questionnaire is very similar to the prior questionnaire apart from two changes. One is that it does not gather the demographic information again. Secondly, the questions ask you about your views on ecological-momentary anxiety-focused apps with respect to your experience using 'Here'.

4) Interview

Participants will take part in a 30 to 60 minute interview which will ask questions about their experience of using 'Here' in more detail. These interviews will be conducted virtually and will be recorded so that a transcript can be produced and analysed.

You do not have to answer all of the questions and can decline to answer any of the questions. You can also take as many breaks as you need to during the interview.

How will my data be stored and how long will it be kept?

Two types of data will be collected during this study – demographic and study data.

Demographic Data

As described above, each participant will be given a unique code. This code will be linked to your responses for each part of the study so that all parts can be linked together. The process of removing the name and replacing it with the code will be done as soon as any data is collected. All other parts of demographic data (i.e. age, ethnicity, gender) will be stored separately to the study data.

Study Data

The study data refers to the answers to each of the part of the study, for example, your responses to the questionnaire, or the interview transcript.

Both demographic and study data will be stored securely. Data will be stored on a password-protected laptop within a password-protected file. The data will be stored in a pseudonymised format. The fully anonymised data (without any links between name and unique code) may be shared with other researchers to support further research in the future.

All data will be handled in accordance with the General Data Protection Regulation 2018, as well as Queen Mary's 'Data Protection Policy' and 'Information/Data Governance Policy – Storage of Information'. You will not be able to be identified in any ensuing reports or publications.

When will my data be destroyed?

Data will be stored for five years before being destroyed in accordance with Queen Mary's Records Retention Schedule. The destruction of the data will be done in accordance with Queen Mary's 'Information/Data Governance Policy – Disposal of Information' policy.

Under what legal basis are you collecting this information?

Queen Mary University of London processes personal data for research purposes in accordance with the lawful basis of 'public task'.

Please read [Queen Mary's privacy notice for research participants](#) containing important information about your personal data and your rights in this respect. If you have any questions relating to data protection, please contact Queen Mary's Data Protection Officer, Queens' Building, Mile End Road, London, E1 4NS or data-protection@qmul.ac.uk or 020 7882 7596.

Who can I contact if I have any questions about this study?

If you have any questions or would like to know more about my research, please email me: a.h.dowse@qmul.ac.uk

What should I do if I have any concerns about this study?

If you have any concerns about the manner in which the study was conducted, in the first instance, please contact the research supervisor, Professor Paul Curzon: p.curzon@qmul.ac.uk.

If you have a complaint that you feel you cannot discuss with the researchers then you should contact the Research Ethics Facilitators by e-mail: research-ethics@qmul.ac.uk. When contacting the Research Ethics Facilitators, please provide details of the study title, description of the study, QMERC reference number (TBC), the researcher(s) involved, and details of the complaint you wish to make.

Where to find help

If you would like further support for anxiety issues, please visit:

<https://www.nhs.uk/mental-health/nhs-voluntary-charity-services/charity-and-voluntary-services/get-help-from-mental-health-helplines/>

