

**PARTICIPANT INFORMATION SHEET**UCL Research Ethics Committee Approval ID Number: **2929/002****Responding to Personalised Avatars in Virtual Reality****Department:** Clinical, Educational and Health Psychology, University College London**Researchers:** Prof Chris Brewin, Dr Emma Kilford, Dr Laura Wood**Principal Researcher:** Prof John King

Dear Participant,

We would like to invite you to take part in a research study being conducted by the department of Clinical, Educational and Health Psychology at University College London (UCL). Before you decide to take part, it is important you understand why the research is being done and what taking part will involve. Please take time to read the following information carefully and discuss it with others if you wish. If anything is not clear or if you would like more information, please contact a member of the research team who will be pleased to answer your questions.

What is the study about?

This is the first of several research studies which will help us to develop a virtual reality (VR) based therapy for depression. We have already shown that VR technology can be used to help people with depression be kinder to themselves. We offered people the chance to wear a VR headset and experience what it's like to be in a 'virtual body', known as an avatar. They would comfort a character who appeared upset, and then have their own comforting words played back to them. We found that this helped people to think about themselves more positively and even reduced symptoms of depression. We are now improving this VR therapy and getting it ready to be used in the NHS. We're looking for people who have experienced depression to share their opinions and advice.

What will happen if I take part?

We would like to invite you to attend one of four online consultation groups, each with a maximum of 15 people who have experienced depression, also invited by Mind. A consultation group is a discussion in which you are invited to share your opinions and experiences. The consultation group will take about two hours, with a ten-minute break in the middle, and will take place via video call on Zoom. What you tell us during the group will help us to make the VR therapy as helpful as possible for as many people as possible. We will send you a £20 Amazon voucher afterwards as a thank you for your time.

If you decide to take part, we will first ask you to provide your consent to take part using the form at the end of this **Information Sheet**. We will then ask what times and days you're free to join the groups, and if there's anything we can do to make it easier for you to take part. We will also ask you to choose a non-identifiable name or 'alias' to use for the discussion group, which we will keep a record of so that we know that everyone who signs into the meeting has given their consent to take part.

We will then send you an email with the details of your consultation group, as well as instructions for how to join and to take steps to keep your information private online. The group will be held online via Zoom (www.zoom.us) and will be led by researchers from UCL and Mind who have also experienced depression. Someone will be on hand to provide technical support if you need it. We will tell you more about the VR therapy and show you some videos of what it might look like and then discuss these as a group. We will ask some questions about it, but you do not have to answer any of them if you don't feel comfortable to do so and we will not ask directly about your personal experiences. We will record the consultation groups so that we can type up the discussion later, but we will not type up anything that could be used to identify you personally.

As well as emailing you with the discussion group details, we will also send you a link to an online questionnaire asking you some questions about yourself, such as your age, gender and ethnicity. We are including these questions to help us make sure that the range of people who join these consultation groups reflect as far as possible the range of people who will be using the VR therapy when it's ready. The questionnaire won't ask you for any personally identifiable information and you don't have to answer these questions if you would prefer not to. This information will not be used to describe you individually, and we will make sure that it can't be used to identify you.

You will also have the optional opportunity to give anonymous written individual feedback online after the session if you would like to.

Why have I been invited to take part?

You have been invited to take part in this study because you were selected by Mind (www.mind.org.uk), after you told them that you were interested. Mind are working with us throughout this project to involve a range of different people who have experienced depression. In order to protect your privacy, UCL has no access to any information you may have shared with Mind, and so we apologise if some of the questions we ask seem like a repeat of something you have already been asked.

To be eligible to take part, you need to meet the following inclusion criteria:

- You are over 18 years of age
- You are confident speaking English
- You have experienced depression
- You currently live in the UK

Will I be recorded and how will the recorded media be used?

The discussion will be recorded to a UCL computer using Zoom local recording (<https://support.zoom.us/hc/en-us/articles/201362473-Local-recording>). This creates both a video recording (if you choose to turn your camera on during the session) and voice-only recordings. The video recording will be immediately destroyed in accordance with UCL Information Security Division secure disposal guidelines. The voice-only recordings will be typed up by the research team, at which point any personally identifiable information will be removed. Within 4 weeks of finishing this, the recording will be destroyed in accordance with UCL Information Security Division secure disposal guidelines.

Do I have to take part?

Participation in this study is entirely voluntary - it is up to you to decide whether to take part or not. We will not expect you to take part in any future studies unless you decide that you wish to.

What happens if I change my mind?

If you decide to take part, you are free to change your mind at any time and without giving a reason. If you change your mind before the beginning of the discussion group, please let one of the researchers know so they can offer someone else the opportunity to take part. Unfortunately, we won't be able to offer you an Amazon voucher if you decide not to join the discussion group. However, if you choose to leave during the discussion you will still receive an Amazon voucher as a thank you for your time.

If you choose to leave the study, you will be asked what you wish to happen to any information you have already shared with us. We will keep a record of your name and email address in order to discuss this with you, and then we will quickly destroy it.

If you choose to withdraw during or after taking part in the group discussion, the voice recording, including any contributions you made before you decided to withdraw, will be kept until we type them up. We will ask you what you are happy for us to type up and what you would like us to destroy and we will honour your wishes. Please note that if it is over 12 weeks since the consultation group took place, we cannot guarantee that we will be able to

remove everything you have shared with us as once the information has been made anonymous it may be difficult or impossible to do so.

What are the possible disadvantages and risks of taking part?

We do not consider that the study involves any significant risks. We do not expect the discussion to be distressing, and we will not ask any questions that are directly about people's personal experiences of depression. However, it may bring up certain memories or feelings that you may find uncomfortable. If at any stage, you wish to stop the discussion or take a break then you may do so. You will still receive an Amazon voucher as a thank you for your time.

At least one researcher in each group will be responsible for helping to look after your wellbeing. At the start of the discussion we will create a group agreement about confidentiality, respect and listening and at the end of the session there will be a 'check in' with everyone. If you have given us your consent to do so, should you drop off the call or seem upset during the session we will send you a follow-up email to see if everything is OK.

If, during the research study, you have any concerns about your own or someone else's wellbeing, you can discuss these with your doctor, or you can contact one of the organisations listed on the link below to talk in more detail and receive advice. You may also find it helpful to look at Mind's information on [how to deal with pressure](#) or these [booklets about staying mentally well](#). You can also contact the research team should you become distressed or have concerns as a result of participating in this study.

<http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/mental-health-helplines.aspx>

What are the possible benefits of taking part?

While there are no direct benefits to taking part in the study, we hope that this research will help us to develop a VR therapy for depression that is as helpful as possible for as many people as possible. Taking part will therefore be a real opportunity to meaningfully influence what this new VR therapy is like. Some people find that taking part in research gives them a sense of satisfaction they know that they helping to improving services for people like them. We will also send you a £20 Amazon voucher as a thank you for your time.

What if there is a problem?

If you have any concerns about any aspect of this study should speak to a member of the research team (contact details at the bottom of this information sheet). If you feel the research team has not dealt with your concerns to your satisfaction you may contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk.

What will happen to my contact details and other personal information?

Only the researchers will have access to any **personally identifying information** about you (i.e. your name and email address). Your name and email address will be stored separately from your **research data** and will only be used for:

- (i) Sending you the details for the online meeting
- (ii) Sending you a link to some questions about yourself (e.g. your age, gender, ethnicity)
- (iii) Sending you your Amazon voucher and the opportunity to give anonymous online feedback

We may also use it for the following, only if you have specifically given us your consent to do so:

- (i) Checking in with you should you drop off the call or seem upset during the session
- (ii) Sending you a copy of the study report
- (iii) Inviting you to participate in future studies

All information will be held electronically and will be stored securely in compliance with General Data Protection Regulation and the Data Protection Act 2018.

Will my taking part in this project be kept confidential?

Any information you share with us will be stored securely at the Department of Clinical, Educational and Health Psychology, at UCL. The research team will take all reasonable steps to protect your privacy. All **personally identifying information** (e.g. name, email address) you share with us during the course of this research will be kept strictly confidential.

Your **research data**, that is, the other information you share with us, such as answers to online questionnaires and your contributions to the discussion will be **coded** so it is **not associated with your name, email or any other information that could reveal your identity**. After at least 12 weeks has passed since the consultation group took place, this information will be fully anonymised. This means that during those 12 weeks the research team would be able to use their secure codes to look up your data, for example if you wanted to remove it from the study.

We cannot guarantee the information you choose to share in the discussion will be kept confidential by the other members of the discussion group. However, the researchers will remind everyone of the importance of respecting the privacy of other group members and ask them not to repeat what is said in the discussion group to others.

What will happen to the results of the research?

The results of the study will be used to inform the development of the VR therapy. The study results might be published in scientific journals and/or presented at scientific conferences. We will work with Mind to produce a report explaining how your involvement has influenced the development of the therapy. If you consent for us to do so, we will send you a copy of this report by email. You will not be able to be identified in any reports or publications.

Your **fully anonymised research data** will be archived at UCL after the study is completed, where it **can be accessed by other authenticated researchers** on request, providing they consent to adhere to the UK Data Protection Act 1998 and the British Psychological Society Code of Ethics and Conduct.

Who is organising and funding the research?

This research is funded by a National Institute for Health Research (NIHR) award and sponsored by UCL. NIHR is a UK Government agency which funds research into health care.

Contact us:

For further any information, or if you have any questions about the study or your participation in it, please speak to:

Dr Emma Jayne Kilford (Postdoctoral Research Fellow at UCL)

Email: e.kilford@ucl.ac.uk

or

Dr Laura Wood (Lived Experience Research Consultant at Mind and Honorary Research Fellow at UCL)

Email: laura.wood@mind.org.uk/laura.m.wood@ucl.ac.uk

or

Prof John King (Clinical Psychologist and Professor at UCL)

Email: john.king@ucl.ac.uk

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Thank you for reading this information sheet and for considering taking part in this research study.

Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. Personally identifiable information will be stored securely and deleted within one year of the study has ended. Anonymised research data will be stored for up to 10 years after the study has ended, or longer if it is needed to fulfil scientific journal publication requirements.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. **If you remain unsatisfied**, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>