UCL Participant Information Sheet - Creative Support Group Study

UCL Research Ethics Committee Approval ID Number: 12611/001

Title of Study: An evaluation of an online creative support group using a mixed methods design

Department: Research Department of Clinical, Educational, and Health Psychology

Name and Contact Details of the Researcher(s): Rachel Tribe, Trainee Clinical Psychologist, 07818 607714, rachel.tribe.16@ucl.ac.uk

Name and Contact Details of the Principal Researcher: Dr Vyv Huddy, Lecturer in clinical psychology, 020 7679 1675, v.huddy@ucl.ac.uk

Invitation Paragraph

You are being invited to take part in a research project that will be investigating the impact of an online 30-day creative support group for people who have been feeling stressed, low in mood or worrying more than usual. Have a read of the following information to find out what is involved and if you have any questions please contact Rachel Tribe on the number listed above. Taking part in this research will be slightly different from taking part in something like the January Challenge, there will be forms to fill in and Rachel will be studying the process, so it’s important you read through this just to make sure you understand.

What is the project's purpose?

An organisation called 64 Million Artists has produced a 30-day online creative support group. Although based on their more public programmes like the January Challenge, this will be a closed group for up to 20 people. This research will run alongside the group to understand the impact on those taking part. To understand this we will measure your mood and wellbeing at the beginning of the 30 days, at the end of the 30 days and two months later. The research also aims to understand how the group is run and what works and doesn’t work, so that it might be possible to roll the groups out more widely.

Why have I been chosen?

If you're reading this you will have responded to an email from 64 Million Artists inviting you to take part in a 30-day online creative support group, for people who self-identified as having low mood and/or anxiety. If you want to take part in this study you need to be aged 18 and over, have a sufficient level of English language and be able to use Whatsapp on your phone. You also need to self-identify as having low mood and/or anxiety. You also need to be based in the UK and have access to a UK telephone number, Internet and a smart phone, with the ability to download Whatsapp. The researchers aim to recruit 60 people in total who will take part in three groups across September, October and November 2018.

Do I have to take part?
Taking part in this study is entirely voluntary and you have the right to leave the group and the study at any time. If you do decide to take part you will be given this information sheet to keep and then be asked to sign a consent form. You can withdraw at any time without giving a reason. If you decide to withdraw any information that you have provided will be destroyed immediately during the duration of the study (March 2018 – March 2019). However, if you have posted in the WhatsApp group before withdrawing, this content will remain in the group and other participants and the researcher will be able to see and access until the group is closed. A copy of the WhatsApp conversation will be downloaded and saved securely by the researchers at the end of the study, and if you withdraw, your posts will not be included in further analysis. The copy will be securely destroyed at the end of the study.

**What will happen to me if I take part?**

Once you have read this information sheet, you will be taken to the next page where you will be asked to sign a consent form. If you consent to take part in this study it will begin on the 3rd September 2018 (unless this group is full, in which case you will be added to the waiting list for October or November 2018). 1 week prior to starting the group you will be sent a link which will include questions about your demographics (age, ethnicity, occupation and gender) and two questionnaires about your mood and wellbeing. Following this you will be added into a WhatsApp group with approximately 19 other participants. The facilitator will post daily challenges in the WhatsApp group, such as “draw the view from your window” or “write a poem about Mondays,” and you will be invited to share and discuss your creative tasks with other group members. We hope this process will be fun and is not intended to feel like a research exercise!

Following the 30-day creative online support group, the researcher will leave the group and formal group will end, although if you want to stay in the WhatsApp group and continue to support each other, this will be up to you. At this point you will be asked to fill in a second online survey, which will include the same questionnaires on mood and wellbeing that you filled out at the beginning of the study. A few people at random will be invited to an interview about their experiences of the group, if you agree to take part in an interview you will be compensated for your time. Two months following the end of the 30 day programme you will be contacted with a link to fill in the mood and wellbeing questionnaires for a final time. This will signal the end of your participation in the study.

Your data, including personally identifiable information will be held securely using an encrypted USB stick and will be destroyed securely at the end of the study. WhatsApp uses computer servers that are located in America, therefore the data you share on WhatsApp will be travelling outside of the European Economic Area. The UCL data protection department has assessed this for adequate safeguards of protection for personal data. You can withdraw from the study at any time, the last point at which your personal data can be removed from the study and securely destroyed is 1st March 2019. The data you post within WhatsApp cannot be destroyed by the researchers and will remain visible to other group members until they also ‘exit’ the group. Your telephone number will be visible to other group members, although you can remain anonymous and not give your name.

**Will I be recorded and how will the recorded media be used?**
After your participation in the 30-day program, you may be invited to take part in an interview at UCL. The interview will be audio recorded so that it can be transcribed for analysis. This will be held securely on an encrypted memory stick. During this transcription all identifying material from the interview will be removed, the audio recording will then be destroyed securely and the anonymised transcripts will then be looked at to see if there are any themes among them. No other use will be made of the audio recordings and no one outside the project will be allowed access them.

**What are the possible disadvantages and risks of taking part?**

We hope you will have fun and be engaged by the programme and meet other interesting people who you can connect with.

There is a possibility that you may feel affected by the issues discussed in the WhatsApp group by other members. You can also talk to the researcher (RT) or research programme principle investigator (VH), a qualified clinical psychologist) during participation or afterwards. If you are distressed or upset as a result of participation, the researcher will be able to provide information for accessing resources or services which you may find helpful. If the researcher (who will also be a member of the WhatsApp group) notices that you seem distressed they may contact you via text to offer support and/or signposting. Similarly, during the qualitative interview, there is a possibility that we may discuss issues that you find upsetting. You are able to stop the interview at any time and if you feel you need further support you are able to discuss this will with one of the researchers.

**What are the possible benefits of taking part?**

While there is no guarantee that you will benefit directly from taking part in the study, we anticipate that participants will enjoy and get something out of taking part in the online creative support group. By being part of this research you will be providing information about your experience of the online support group; and depending on what those experiences are, there is the potential for 64 Million Artists to make improvements to the group, which could benefit other people in the long run.

**What if something goes wrong?**

If you are unhappy with any part of your participation in the study you can contact the principle investigator Dr Vyv Huddy on v.huddy@ucl.ac.uk / Rachel.tribe@ucl.ac.uk. If you feel your complaint has not been handled satisfactorily please contact the Chair of the UCL Research Ethics Committee on ethics@ucl.ac.uk.

If content is posted within the WhatsApp group which gives cause for the researchers or 64 millions artists to be concerned, 64 Million artists will contact you directly to signpost you to the relevant organisations.

**Will my taking part in this project be kept confidential?**

The information that we collect about you during the course of the research will be kept strictly confidential, your data will only be available to the researchers Vyv Huddy and Rachel Tribe. The organisation 64 Million Artists will have access to all anonymised data excluding the audio recordings from the interviews with
participants. Transcripts from qualitative interviews will be anonymised by removing all the identifying data and will be available to the research team and 64 Million Artists for the duration of the study. Some anonymised quotes may be used in reports or publications arising from the research. You will not be able to be identified in any ensuing reports or publications.

**Limits to confidentiality**

Confidentiality will be maintained as far as it is possible, unless during the conversations that occur on WhatsApp and the subsequent interviews, the researchers or 64 Million Artists hear anything that suggests someone might be in danger of harm. In such cases 64 Million Artists will contact you in a private message to signpost you to the relevant agencies.

Each participant in the WhatsApp group will be able to see the messages that you post. WhatsApp also allows any group member to save a copy of the conversation history. The researchers will save a copy and keep it for the duration of the study to help us understand what is helpful and less helpful about the groups. Other participants may also download a copy of the conversation.

**What will happen to the results of the research project?**

The results of the research are likely to available by August 2019 in a report format. This report will hopefully be published in a relevant journal. No participants will be identified in this report. Following this all data about individual participants will be destroyed.

**Data Protection Privacy Notice**

**Notice:**

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

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed so long as it is required for the research project and will be destroyed upon study completion (August, 2019). If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

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/](https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/)
Contact for further information

If you require any further information or have any questions please don’t hesitate to contact:

In the first instance: Name: Rachel Tribe, Trainee Clinical Psychologist on 07818 607714, rachel.tribe.16@ucl.ac.uk

Or Name: Dr Vyv Huddy, Lecturer in clinical psychology on 020 7679 1675. v.huddy@ucl.ac.uk