Title of project:
Exploring the use of smartphone monitoring for young adults with Tuberous Sclerosis Complex (TSC): A qualitative analysis.

- We would like to invite you to take part in this research study.
- Before you decide, it is important for you to understand what the study is about and what will happen to you if you take part.
- Please read this information carefully and ask us about anything that you do not understand.

What is the study for?
- This study is trying to see if a new smartphone app can help young adults with TSC to keep track of how they are feeling.
- This study wants to use a new way of recording a person’s emotions and feelings using a smartphone app.
- Using the app, you would answer questions about your feelings a couple of times a day.
- It may also ask you questions such as, ‘what are you doing?’ and ‘who are you with?’.
- It can also ask you to complete short puzzles.
- We hope that this app can help you tell other people about how you are feeling.
- Before we use this smartphone app, we would want to ask you some questions about using apps in your everyday life.

Why have I been chosen to take part?
- You are aged 16-30, have a diagnosis of Tuberous Sclerosis Complex and we think you might be interested in taking part.
- This study will be conducted on a computer and telephone call so there is no need to travel.

What would happen if I agree to take part?
- After you have read this information sheet, you will be asked to complete a contact details form.
- We will then give you a call to discuss the study and answer some questions about yourself.
- You will be asked to complete a consent form.
- You will then complete a questionnaire about yourself. The questionnaire will ask you whether you want to take part in an online focus group or an online individual interview.
● The focus group will have 6 people with TSC (including yourself) who will be asked the same questions by a researcher.

● We know some people find talking in groups hard so if you would like to, you can take part in a one-to-one interview instead.
● If you want to take part in an interview, you can also tell us if you would like a key support person in the interview with you. This person can be a parent, a sibling or someone who you trust. If you do, you will need to give us their contact details too.

● When you have finished the questionnaire, we will give you another call to discuss the rest of the study.

● If you still want to take part, we will organise a time for the online interview or focus group. You will be asked some questions by a researcher for about 1 hour.
● You will be given the option to have 5-10 minutes to chat without your key support person in case you had any sensitive issues that you did not want to speak about in front of your key support person.

● In the interview or focus group, you will be asked questions about if you use smartphones and how you use them.
● You will be asked questions about your life as a person with TSC.
● You will be shown an example of the smartphone app. We will ask you how you feel about the app.

● After the interview you will be asked to complete an online questionnaire about using the smartphone app and an evaluation form.

● If you want, a few weeks after your interview you will be sent a copy of the results to give your feedback via an online questionnaire.
● A few months after this you will be sent a copy of the final results.

**COVID-19 safety procedures**

● The research study will take place only by online video call to reduce the risk of COVID-19.
Do I have to take part?

- No, you will only take part if you want to.
- If you do want to take part, you will need to sign a form to say that you understand what the research study is and what is required of you.

Are there any possible disadvantages of taking part?

- There are no identified disadvantages to taking part in the study.
- If you do find anything difficult to talk about or feel stressed because of the interview and what was talked about you can ask to pause the interview, skip the question or say you do not want to take part in the study anymore.
- Individuals with TSC may also have learning difficulties or experience mental health difficulties so we have put in a safeguard for this and allow participants to attend an interview with a key support person of their choosing.

What are the possible benefits of taking part?

- You will be paid a £25 voucher for taking part in the interview or focus group.

Will people know that I took part in the research study?

- Only the people you tell and the people who are part of the research study will know you have taken part. This includes the researcher, interviewers, their supervisor(s) and examiners.
- What you say in the interview will be anonymised when it is being written up. This means all the information that could let people know who you are will be changed to protect your identity. This includes your name, where you are from, and your friends and family members’ names.
- Everything you say in the interview will be kept confidential unless there are concerns for people’s safety. This means the interviewer won’t tell anyone what you said to anyone other than the researcher and supervisor unless something you say makes the interviewer concerned for you or someone else.
- Only members of the research team at King’s College London University will have access to your information.
What will happen if I change my mind and do not want to take part in the study anymore?

- After completing the first questionnaire, if you change your mind and do not want to be part of the research study anymore, you can ask the researcher to delete all the information they have about you. You have two weeks after completing the questionnaire to do this. You do not need to give a reason why you have changed your mind.
- If you have taken part in an interview, you can change your mind about taking part in the research study up until two weeks after the interview. You do not need to give a reason why you have changed your mind.
- If your key support person does not want to take part, you can pick another person to support you.

Who has approved the research project?

- This project has been looked at by a professional group, called a Research Ethics Committee, to protect participants.
- This study has been reviewed by the Institute of Psychiatry, Psychology & Neuroscience and Florence Nightingale School of Nursing & Midwifery Research Ethics Panel: rec@kcl.ac.uk

What if there is a problem?

- If you are not happy about any part of the research study, you should talk to the researcher’s supervisor Dr Sara Simblett. Email: sara.siblett@kcl.ac.uk
- If you want to make a complaint you can contact King’s College London: The Chair: Institute of Psychiatry, Psychology & Neuroscience and Florence Nightingale School of Nursing & Midwifery Research Ethics Panel: rec@kcl.ac.uk
Who should I contact for further information?

If you have any questions about this study, please contact me using the following contact details:

Kate Fifield  
PhD Researcher  
Henry Wellcome Building for Psychology,  
Institute of Psychiatry, Psychology and Neuroscience,  
King's College London,  
De Crespigny Park,  
London,  
SE5 8AF  
Email: Kate.fifield@kcl.ac.uk

Or you can contact my supervisor:

Dr Sara Simblett  
Henry Wellcome Building for Psychology,  
Institute of Psychiatry, Psychology and Neuroscience,  
King's College London,  
De Crespigny Park,  
London,  
SE5 8AF  
Email: sara.siblett@kcl.ac.uk

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