

Research funded by:



Participant Information Sheet

“Social context of anomalous experiences in daily life”

Invitation to take part in this study

We'd like to invite you to take part in our research study. Please take time to read the information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

This study aims to explore relationships between social factors and anomalous experiences, like changes in perception, spiritual-type experiences, hearing voices, or extrasensory communications. As we expect these experiences to vary during the day, we are interested to measure feelings and thoughts in the flow of daily life. In practice, this involves using a mobile application ('app') that beeps ten times a day at random moments. After each beep, you will be asked to answer some questions regarding what you are doing and how you are feeling at that moment. These questions will always be the same and completing these will take no longer than two to three minutes. This should be similar to answering a text message on your mobile phone.

Recent research has shown that many people describe having anomalous experiences. For some people these experiences have a negative impact on their life and result in input from mental health services. For others, these experiences have a positive impact and can be life-enriching. This research will attempt to identify what distinguishes between people whose experiences are positive from those whose experiences become distressing. Furthermore, we are interested in the role of your personal environment and the fluctuation of positive and negative feelings during the day. Therefore, capturing a picture of daily life is highly informative and provides individual information that could be used to identify patterns of experiences and feelings in relation to the environment. By providing us with this rich information, you will contribute to increasing our knowledge of how positive and negative feelings are linked to anomalous experiences and the environment.

Why have I been invited to take part?

You have been invited because you have reported you have anomalous experiences which are not distressing for you. These experiences might be described by you or others in mystical / spiritual / religious terms, or in some other way. For this study, it is not important how you describe or explain your experiences, but the fact that they are different to ordinary day-to-day experience makes you a suitable research candidate.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. You may choose to ask for independent information or advice about your rights as a research participant or about being involved in this particular research study by contacting the local Research and Development office (please see below for contact details).

If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time in the process of the study without giving a reason.

What will happen to me if I take part?

Taking part will involve two meetings with 6 days of completing the questions on the app in between. The first meeting will last about 1 hour, including a short interview about your experiences, some questionnaires about, e.g., how you see yourself in relation to others, and an instruction on how to use the app. This app will be installed on your personal smartphone. If you don't own a smartphone, or prefer not to use yours, you will be provided with a device that has the app installed. On the app, we will program part of the questionnaires fit to your personal anomalous experience. The day after the first meeting, the 6 consecutive days will start in which

you will use the app to answer questions throughout the day. On the second day, you will be contacted by telephone to make sure everything works and to solve any questions or difficulties. During the rest of the week, you can contact the researchers when needed, and the researchers will contact you in case of any technological difficulties. The second meeting will be scheduled as soon as possible after 6 days have been completed. This meeting will only last 15 minutes, including getting your feedback about the study, and paying you for your participation. If you have borrowed a device, this will be returned.

What will happen if I start but then don't want to carry on with the study?

You can withdraw from the study at any time without having to justify your decision. If you decide to withdraw from the study you can tell us whether you are happy for us to use the information obtained up to that point. If you are not, any information that you have given will be destroyed and you will not be contacted by us again.

What are the possible risks or is the burden of taking part?

Some of the questionnaires may cover issues that are sensitive and/or distressing for you, such as questions about other people's opinions on anomalous experiences. You may worry that this project involves negative judgements of people whose experiences might be considered unconventional - this is *NOT* the aim of the study. On the contrary, this research hopes to help us understand the range of different experiences people have, and how they relate to other life factors. We hope a better psychological understanding of these types of experiences will, in the long term, help other people to accept and understand them.

Participants may find the number of beeps each day burdensome or distressing. However, answering the questions at each beep will not take longer than two to three minutes. Previous research indicates that participants adapt quickly to this.

The app that will be used will be explained and practiced when we first meet up. This meeting will also address any worries you have about completion of beeps during the day. For instance, you don't have to adapt your life in any way to fit in with the beeps. Furthermore, any difficulties or technological questions can be asked and solved during the 6 days by contacting the researchers. The researchers will contact you during this week in case of any technological difficulties they pick up while receiving the data.

At the end of the study you will have a chance to tell us what your experience of participating in the research and using the app were like, and we will take this into consideration for this and future studies.

What are the possible benefits of taking part?

You may find it helpful to share your anomalous experiences with someone who will not be judgemental. It may also be a positive experience for participants to have an opportunity to contribute to our knowledge of anomalous experiences and related feelings in daily life. In turn, this knowledge could be used to develop and research new interventions to improve wellbeing.

We are able to reimburse any travel expenses that you incur and offer you £70 for your time. This includes £10 for the first meeting, £10 per day for the 6-day measurement period, and travel expenses for the two meetings. Reimbursement payment must be declared for tax or benefit purposes. If you think this may apply for you, please ask the research team for more information, or look at the guidance linked below: <http://www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/sites/21/Benefit-conditions-paid-and-voluntary.pdf>

Will my taking part be kept confidential?

All the information collected during the course of the research will be kept strictly confidential, and will be stored in accordance with the Data Protection Act 1998, secured against unauthorised access. Your personal details will not be seen by anyone other than the primary researchers. Your questionnaire data will be assigned an anonymous code before they are used for supervision purposes with the research supervisors.

How is the project being funded?

The project is funded through a Medical Research Council (MRC) Clinical Research Training Fellowship awarded to Dr Charlie Heriot-Maitland (ref: MR/L01677X/1).

What will happen to the results of the study?

The research should be completed by mid-2016. The results will be written-up as part of an academic PhD and MSc degree, and submitted for a peer-reviewed journal. This will be openly accessible through King's College

London's publications repository. No individual will be identifiable from the published results. A copy of a summary will be sent to participants if they wish.

What if something goes wrong?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you can speak with the Primary Researcher (contact details below) in the first instance or the Research Supervisor (contact details below), who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the Director of Research Quality (below).

Compensation for harm arising from an accidental injury and occurring as a consequence of your participation in the study will be covered by King's College London. In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against King's College London but you may have to pay your legal costs.

Who has reviewed the study?

This research has been reviewed and funded by the Medical Research Council. This research has also been looked at by an independent group of people called a Research Ethics Committee, in order to protect your safety, rights, wellbeing and dignity. This study has been reviewed and approved by the Westminster NRES Committee London (15/LO/2205).

Contact details

If you have any questions relating to this research, or concerns about participation, please contact:

Primary Researchers

Dr Charlie Heriot-Maitland, MRC Clinical Research Training Fellow
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Ms Karlijn Hermans, ResMSc student
King's College London, IoPPN (PO78), De Crespigny Park, London SE5 8AF
Email: karlijn.hermans@kcl.ac.uk / Tel: 0207 848 0022

Research Supervisor

Dr Emmanuelle Peters, Reader in Clinical Psychology
King's College London, IoPPN (PO77), De Crespigny Park, London SE5 8AF
Email: emmanuelle.peters@kcl.ac.uk / Tel: 020 7848 0347

If you would like to speak to someone to get some independent advice about your rights as a research participant, you can contact the local R&D office:

Research Governance Officer

King's College London, IoPPN (PO05), De Crespigny Park, London SE5 8AF
Tel: 020 7848 0251

If you wish to make a complaint about the conduct of this study, you may speak to someone in your NHS clinical team initially, or if you would like to make a formal complaint, you can write to either of the following:

Director of Research Quality

Dr Gill Dale
Joint R&D Office of SLAM NHS Foundation Trust and Institute of Psychiatry, Psychology & Neuroscience
King's College London, IoPPN (PO05), De Crespigny Park, London SE5 8AF
Email: gill.dale@kcl.ac.uk / Tel: 020 7848 0675

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