

Participant Information Sheet



SubSleep: Understanding multiple subjective experiences of sleep in people with bipolar disorder

You are invited to take part in a research study.

To help you decide whether or not to take part, 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. Talk to others about the study if you wish. Take time to decide whether or not you wish to take part. Please contact us if there is anything that is not clear, or if you would like more information.

What is the purpose of the study?

The SubSleep study is investigating how people with bipolar disorder experience sleep. We know that sleep problems are common in people with serious mental illness (including bipolar disorder) and can have a negative impact on their daily functioning, emotional regulation and wellbeing. However, most of the research to date on this topic is quantitative, using standardised questionnaires and objective physiological measures to describe sleep in people with bipolar. These methods can often miss the wider context of sleep issues.

The SubSleep study will conduct in-depth interviews with people with bipolar ('Experts by Experience') to explore how well they sleep, how they think their bipolar impacts their sleep, and their experiences of addressing any sleep issues with healthcare professionals.

We will also conduct a focus group with people who have experience of working in areas related to sleep or bipolar disorder ('Experts by Profession'). The group discussions will explore the rationale behind commonly-used sleep measures and interventions, as well as the development of sleep interventions for different populations (such as people with severe mental illness). We will additionally explore the experience of engaging with people with bipolar with regards to sleep, whether that is in a research or healthcare context. These discussions will further contextualise the experiences of people with bipolar, and will identify what similarities and differences exist in the priorities and needs of our Experts by Experience and Experts by Profession.

This study will improve understanding of the subjective sleep experience of people with bipolar. In the future, we would like to use the findings from SubSleep to co-design sleep recommendations for people with bipolar.

Why have I been invited to take part?

You have been invited to take part as an Expert by Profession, because you are an adult with professional experience related to bipolar disorder or sleep.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights.

What will happen if I take part?

Overview

Experts by Profession SubSleep study participants are invited to participate in one focus group session which will last for approximately 3 hours. The focus group will be made up of 6-8 participants. The focus group will be facilitated by the SubSleep research team and will be held on Tuesday 8th July 2025 in-person at The Bayes Centre, the University of Edinburgh central campus (time TBC). Reasonable travel expenses and childcare costs will be reimbursed.

Expressing your interest to participate

You can express an interest in study participation by completing the SubSleep Expression of Interest form <https://blogs.ed.ac.uk/subsleep/take-part/> or by contacting the research team directly.

Deciding to take part

If you decide to take part in the study, a member of the research team will check that you have read this Participant Information Sheet and will answer any questions that you might have. They will check that your professional experience matches the study requirements and that you are able to attend the scheduled focus group date and time. They will then send you a Participant Information Pack via email which contains information about the focus group and what to expect.

Attending the focus group session

When you arrive to the focus group session, we will ask you to first sign a consent form to take part. You will then be asked to complete a short demographics questionnaire about your background and work. Once all members of the focus group have completed the consent form and demographics questionnaire, the group discussion will begin.

During the focus group session, the research team members will introduce topics for discussion. These will include topics such as participant's experiences in identifying, managing or treating sleep issues in people with bipolar, and the use of sleep assessment tools and the suitability of these for different populations.

There will be a short comfort break halfway through the session. Light refreshments will be provided.

The focus group discussion will be audio-recorded for the purposes of analysis. The audio recording will be transcribed by the external transcription company 'University Transcriptions' (TP Transcription Limited, UK). One of the researchers will also take notes during the focus group.

After the focus group session

Once the focus group session has ended, your participation in the study will be complete. You will receive a Debrief Pack via email or post after the session, containing a copy of your signed consent form and useful resources.

Once the SubSleep study has finished and the data analysis is complete, all participants will receive a report of the main findings via email or post.

Payment

You will not be paid for the time you spend participating in the focus group. We will reimburse reasonable travel expenses and childcare costs to support your in-person attendance.

Is there anything I need to consider?

You should maintain confidentiality and anonymity of the other focus group attendees. Please do not discuss any sensitive information from the focus group with an external individual/non-attendee

What are the possible benefits of taking part?

You may not get a benefit from taking part in this study.

While there may be no direct benefits to you taking part in this study, the results from this study might help to improve the future understanding and management of sleep in people with bipolar.

What are the possible disadvantages of taking part?

You will be required to attend one in-person focus group session in central Edinburgh. The focus group will last up to three hours. You may be inconvenienced by the required travel and time spent participating.

What if there are any problems?

If you have a concern about any aspect of this study, please contact the SubSleep study team in the first instance who will do their best to answer your questions. You can contact via email subsleeper@ed.ac.uk or telephone 07884196638 or 07884165917.

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

Participants are free to withdraw from the study at any time and do not need to provide a reason for doing so.

If you decide to withdraw from the study during the focus group session, the data collected up until the point of your withdrawal will be used for subsequent analysis due to the nature of the focus group conversation dynamic. Direct quotes from you would not be used in any published results.

What happens when the study is finished?

Once you have completed the focus group session, your participation in the study will be complete.

The data collected during SubSleep participant interviews and focus group will be stored in the UK by the University of Edinburgh for three years following study completion.

All audio-recordings generated during the study will be securely transferred to the University Transcription Services (UK) for transcription. All data are transferred via a secure file upload service and no data will leave the UK. The University Transcription Services are IASME GDPR Accredited and compliant.

The data and findings from this study may be used in the future to inform funding applications or research to co-design sleep recommendations for people with bipolar.

Will my taking part be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

How will we use information about you?

We will need to use information from you for this research project.

Personal identifiable information collected will include:

- Name
- Email address
- Telephone number
- Age
- Bank details (for reimbursement purposes)
- Address
- Ethnicity
- Sex
- Gender identity
- Details of occupation, education
- An audio-recording of your voice during the focus group

People will use this information to do the research or to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number assigned instead.

We will keep all information about you safe and secure within the University of Edinburgh. Digital data will be held on University of Edinburgh servers and physical data will be stored in a locked filing cabinet on University of Edinburgh premises.

Your participation will be audio-recorded and this will be sent securely to 'University Transcriptions' (TP Transcriptions Limited, UK) for transcription. There will be an appropriate data sharing agreement between organisations to ensure your information is safe.

Once we have finished the study, we will store directly identifiable information such as your name and contact details for one year. We will then delete all identifiable information ensuring you are

not recognisable through any of the data. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. Anonymised direct quotes from you would not be used in any published results.

If you agree to take part in this study, you will also have the option to allow the research team (within the sponsoring organisation) to securely store your contact details and agree to be contacted about other ethically approved research studies. You will only be contacted by a member of this research team to determine if you are interested in taking part in another research study. Your verbal consent may then be sought to pass your contact details to another research team within the University of Edinburgh and/or NHS Lothian. Agreeing to be contacted does not oblige you to participate in further studies.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at <https://blogs.ed.ac.uk/subsleep/>
- at <https://data-protection.ed.ac.uk/privacy-notice-research>
- by asking one of the research team (subsleeper@ed.ac.uk / phone number)
- by sending an email to the University of Edinburgh Data Protection Officer dpo@ed.ac.uk

What will happen to the results of the study?

All study participants will receive a report of the main research findings via email or post. We will publish a summary of the findings on the SubSleep study website: <https://blogs.ed.ac.uk/subsleep>.

This study will be written up for publication as an article in an academic journal. We may publish anonymised direct quotes from you. You will not be identifiable from any published results. The study team will present the study findings at relevant academic conferences.

Who is organising and funding the research?

This study has been organised by **Dr Raahat Manrai and Dr Amber Roguski (University of Edinburgh)** and sponsored by **University of Edinburgh**

The study is being funded by the University of Edinburgh's Edinburgh Mental Health Early Career Researcher Seed Funding Award.

Who has reviewed the study?

The study proposal has been reviewed by the research team. All research is looked at by an independent group of people called a Research Ethics Committee. A favourable ethical opinion has been obtained from **Edinburgh Medical School Research Ethics Committee (EMREC)**.

Researcher Contact Details

If you have any further questions about the study please contact Dr Raahat Manrai or Dr Amber Roguski on 07884196638 or 07884165917 or email on: subsleeper@ed.ac.uk.

Independent Contact Details

If you would like to discuss this study with someone independent of the study please contact Dr. Helen Sharpe at Helen.Sharpe@ed.ac.uk.

Complaints

If you have any concerns or complaint about this research, please contact ACCORD (resgov@accord.scot).