

## 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. Contact us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

#### **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, researchers often do not ask people with bipolar about their thoughts, opinions and experiences of their sleep. Instead, most of the research to date uses standardised questionnaires and physiological measures (such as activity tracking) to describe sleep in people with bipolar. These methods can often miss the wider context of sleep issues.

The SubSleep study will conduct 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 with experience of working in areas related to sleep or bipolar disorder ('Experts by Profession'). These discussions will add further information to the experiences of people with bipolar.

This study will improve understanding of the 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 asked to take part as an Expert by Experience as you have been diagnosed with bipolar disorder.

## 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 Experience SubSleep study participants are invited to participate in a one-to-one online interview which will last for approximately 1.5 hours. During the interview, a SubSleep researcher will ask you about your experiences related to sleep. You'll also be asked to discuss three images or photographs which you feel represent your experience of sleep. The interview will be video- and audio-recorded for analysis purposes.

You will be paid £20 for your participation in the study.

At the end of the SubSleep project, the research team will invite you to attend a 'Community Peer Review' meeting where we will present the main findings of the study to our Experts by Experience for your feedback. Attending this meeting is optional. Meeting attendees will be paid £20 for their attendance, plus reasonable travel and childcare costs.

### Expressing interest to participate

You can express an interest in study participation by completing the SubSleep Expression of Interest form on our website (<https://blogs.ed.ac.uk/subsleep/>) or by contacting the research team directly. You do not have to be a 'good' or 'bad' sleeper to take part in the study. We are interested in finding out about sleep from anyone with bipolar.

### 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 you meet the eligibility criteria for study participation. They will then schedule your interview. Once your interview has been scheduled, you will receive a Participant Information Pack via email which contains information about the interview, how to prepare and what to expect.

### Before the interview

We will ask you to send the research team three photographs or images before your scheduled interview. These images should be related to your experience of sleep - for example, a photo of where you normally sleep, or an image that you feel represents how you feel when you wake up. We will provide you with clear instructions for the images and how to send them to us. These images will give us further insights into things like your sleep environment, how well-rested you are in the morning and your feelings related to sleep.

We will reschedule the interview if you are unable to send us the images prior to your interview appointment. This will ensure that the researchers are adequately prepared for your interview.

### Attending the interview

The interview will be held online using Microsoft Teams, a University of Edinburgh-approved video call software. We will send you a link to join the interview video-call via email before your scheduled interview date.

Your interview will be with a member of the SubSleep research team. A second researcher may join the call to provide technical support or take notes. When you first join the video call, we will ask you to sign a consent form to take part. You will then be asked to complete a short questionnaire about your background and identity. After this, the interview will begin. The interview will be relaxed and conversational, and the researcher will ask you several questions about your sleep to shape the discussions. We will discuss broad topics like your general attitudes towards sleep, perceived sleep quality, information about your sleep environment and how your sleep and mood affect one another. There are no right or wrong answers, and you are free to disclose as much or as little personal information as you feel comfortable.

The interview will be audio- and video-recorded for analysis purposes. The audio recording will be transcribed by the external transcription company 'University Transcriptions' (TP Transcription Limited, UK). The researcher will also take notes during the interview.

#### After the interview

Once your interview is finished, your participation in the study will be complete. You will receive a Debrief Pack via email after the session, containing a copy of your signed consent form and support 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.

#### Payment

You will be paid £20 for your participation in the study.

#### After the interview and Community Peer Review meeting

Towards the end of the study (October 2025), we will hold a small 'Community Peer Review' meeting and invite all of our interviewees to attend. At the event, we will present our preliminary findings from the study and will ask you for your feedback on them. We want to ensure that your lived experiences have been accurately reflected in our analysis. We will send you details about the event closer to the date.

You do not have to attend the Community Peer Review - attendance is optional. If you would like to attend, you will be paid £20 for your time and we will reimburse reasonable travel and childcare costs.

### **Is there anything I need to do?**

If you decide to take part, we will ask you to send us three images related to your experience of sleep before your scheduled interview date.

You should make sure that you are in a safe and private space for the interview video-call. This reduces the chances that you will be disturbed during the call.

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

You will be paid for your participation in the study.

You may benefit from knowing that 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 an online interview lasting 1.5 hours. You may be inconvenienced by the required time spent participating.

There is a possibility that the interview discussion may cover some emotionally upsetting topics, as we will be exploring topics such as sleep difficulties and bipolar. You might feel distressed during the interview. If you feel distressed during the call and would like to stop the interview early or take a break, please let the researcher know. If you are concerned about your mood following the interview, we strongly advise that you consult your GP, psychiatrist or Community Mental Health Team.

### 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 the researchers via email: [subsleeper@ed.ac.uk](mailto: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 before your interview data has been analysed by the research team, your interview recording will be deleted and any data collected from you will not be used. However, we would not be able to delete your data once it has been analysed. In that case, we will not be using any direct quotes in any published results.

### What happens when the study is finished?

Once you have completed the interview, your participation in the study will be complete.

The data collected during SubSleep study period will be stored in the UK by the University of Edinburgh for three years following study completion.

All 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 (employment status, most recent job title) and highest level of education
- An audio- and video-recording of your interview with the researcher

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

We will be asking some of the sociodemographic information to understand entire context of your surroundings and how it affects your sleep. This information (e.g. gender identity, details of occupation) will help us to understand your sleep experiences in the wider context of your lifespan.

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- and video-recorded. We will clip the video out and the audio-recording 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 this information. 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](mailto:subsleeper@ed.ac.uk) / 07884196638 or 07884165917)
- by sending an email to the University of Edinburgh Data Protection Officer [dpo@ed.ac.uk](mailto: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](mailto: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](mailto:Helen.Sharpe@ed.ac.uk).

## Complaints

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