



# Understanding and Reimagining Sleep and Its Disorders

## Participant Information Sheet

**Principal Investigator: Dr Diletta De Cristofaro**

You are being invited to take part in this public engagement project. Before you decide it is important for you to read this document so you understand why the project is being carried out and what it will involve.

Reading this document, discussing it with others or asking any questions you might have will help you decide whether or not you would like to take part.

### **What is the Purpose of the Project**

“Understanding and Reimagining Sleep and Its Disorders” consists of a workshop series and an online exhibition. You will be coming together with the researchers and other participants to share your experiences of sleep, explore cultural representations of sleep and sleep and wellbeing knowledge, and express your experiences of sleep issues through art.

This public engagement project aims at facilitating knowledge-sharing around sleep and sleep issues. We believe that lived experience has an important role to play in research around sleep and we would like to learn from you. The project also aims at fostering wellbeing through creative expression and at engaging new audiences with multidisciplinary research about sleep.

### **Why have I been invited?**

You self-identify as somebody who would like to explore their sleep and sleep issues further. You self-identify as somebody who might benefit from the knowledge-sharing and creative expression at the core of the project.

Please note: You cannot take part in this project if you are under 18. To facilitate participation at the in-person workshops, you should also be living in/near Newcastle.

### **Do I have to take part?**

No. It is up to you whether you would like to take part in the project. We are giving you this information sheet to help you make that decision. If you do decide to take part, remember that you can stop being involved in the project whenever you choose, without telling us why. You are completely free to decide whether or not to take part, or to take part and then leave the project before completion.



(NOTE: We may ask your reason for withdrawal for feedback purposes, but you do not have to tell us. We may also ask if we can use the data you have provided thus far; again, you do not have to agree to this).

### **What will happen if I take part?**

You will be taking part in one online workshop and one in-person workshop.

The workshop series is organised around 3 themes:

- Sleep and ageing
- Sleep and parenting
- Sleep and menopause

You are free to choose the theme that is more relevant to your sleep and therefore the workshops you'd like to attend.

In the online workshop, you will be coming together with the researchers and other participants to share your experiences of sleep, and explore cultural representations of sleep and sleep and wellbeing knowledge. The online workshop will last one hour and take place on Microsoft Teams. With your permission, we will record the conversations to make sure we remember everything we talk about.

In the in-person workshop, which will follow the same themes of the online workshops, artist and creative producer Chiara Dellerba will guide you in activities aimed at expressing your experiences of sleep creatively. These activities will include creative writing, drawing, performance, sculpting, sensory mapping, and collage. The in-person workshop will last 2 hours and will take place at the Baltic Centre for Contemporary Art in Newcastle. With your permission, the creative outputs you will produce at the in-person workshop will be collected into an online exhibition.

We want anybody who is interested in the project and lives in Newcastle or within reasonable distance from the city to be able to participate. Therefore, if you think you may need help with expenses connected with your participation at the in-person workshop, please get in touch with the project Research Assistant Dr James Rakoczi (james.rakoczi@northumbria.ac.uk). We have a small budget but are happy to support the participation of those who need it by covering reasonable expenses, such as metro/bus/train tickets and/or dependent-care (please note: you will have to provide receipts).

After the workshops and the exhibition launch, with your permission, you will be contacted to provide feedback on the project. This will take the shape of an online survey and will help us determine your views of the project, with a view to improve future activities of this kind.

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

During our workshop discussions you will be asked to share your experiences of sleep and sleep disorders, which might make you experience some embarrassment.



if you don't want to go into some details just say so, you are only being asked to share what you wish to. At any point in a discussion you can ask for it to end. No reason needs to be given.

Anything we discuss at the workshops will remain confidential and we will ask participants to be respectful of other people's privacy and to support an inclusive and safe space.

The project has been fully risk assessed in order to mitigate any risk/distress to you.

If you have any concerns about your mental health, sources of help include your GP, Samaritans (116 123) or you can self-refer to talking therapies in Newcastle ([talkinghelpsnewcastle.org](http://talkinghelpsnewcastle.org)). The Sleep Charity operates the National Sleep Helpline (03303 530 541) and have a wealth of support material available at <https://thesleepcharity.org.uk/information-support/>.

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

There is no intended clinical benefit to you. However, we hope that sharing your experiences of sleep through discussion and creativity, and exploring sleep and wellbeing top tips will foster your wellbeing. Also, by taking part and telling us your views of the project you will be helping to improve future initiatives of this kind.

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

Your name will not be written on the recording of the workshops, or on the typed up versions of our discussions from the workshops. The consent forms you will sign, the only documents that contain your name, will be stored separately from your other data. If we publish the results of the project and/or present these results at academic conferences, we will maintain the anonymity of participants and you or the data you have provided will not be personally identifiable.

Only the creative outputs you will produce at the in-person workshop could be associated with you personally, but only if you give us permission to do so in the consent forms.

### **How will my data be stored and how long will it be stored for?**

All electronic data, including the online consent forms and recordings from the workshops, will be stored on the University's OneDrive, which is password protected. The print consent forms will be kept in locked storage. All data will only be accessible to the project team and will be stored in accordance with University guidelines and the Data Protection Act (2018). In accordance with the funder's condition (Wellcome), we may deposit data in a data repository but this will not contain any personally identifiable information. We will store the data for a minimum of 3 years following completion of this project unless the funder or the scientific journal article we publish within requires an extension of this period.

### **What categories of personal data will be collected and processed in this project?**



Through consent forms, we will collect your full name, email address, phone number, age bracket, self-identified gender. At the workshops, we will collect data about your mood, health and wellbeing, and your sleep activity.

### **What is the legal basis for processing personal data?**

The legal basis for processing the personal data required for the purposes of this project is that the research is necessary for scientific research purposes.

### **Who are the recipients or categories of recipients of personal data, if any?**

The funder of the project, Wellcome, our advisory partner, The Sleep Charity, or the journal/s that we may publish with may request access to the project data, but this will not contain any personally identifying information at all.

### **What will happen to the results of the project and could personal data collected be used in future research?**

The general findings might be reported in a scientific journal or other publications and presented at a research conference, however the data will be anonymized and you or the data you have provided will not be personally identifiable, unless we have asked for your specific consent for this beforehand. The findings may also be shared with other organizations/institutions that have been involved with the project. We can provide you with a summary of the findings from the project if you email the researcher at the address listed below.

Any subsequent use of the collected data will be restricted to research projects that have gained ethical approval from Northumbria University.

### **Who is Organizing and Funding the project?**

The organizer is Northumbria University. The Sleep Charity is involved in advisory capacity. The project is funded by the Wellcome Trust.

### **Who has reviewed this project?**

The public engagement project, submission reference 0213, has been approved in Northumbria University's Ethics Online system. It has been reviewed in order to safeguard your interests, and Northumbria University have granted approval to conduct the project.

### **What are my rights as a participant in this project?**

Under the [GDPR legislation](#) you have right of access to your personal data (to do so you should submit a [Subject Access Request](#)); a right in certain circumstances to have inaccurate personal data rectified; and a right to object to decisions being taken by automated means. If you are dissatisfied with the University's processing of personal data, you have the right to complain to the Information Commissioner's Office. For more information see [the ICO website](#).



**Contact for further information:**

Principal investigator email: [diletta.cristofaro@northumbria.ac.uk](mailto:diletta.cristofaro@northumbria.ac.uk)

Name another person who can provide independent information or advice about the project: Prof Jason Ellis – [jason.ellis@northumbria.ac.uk](mailto:jason.ellis@northumbria.ac.uk)

Name and contact details of the Records and Information Officer at Northumbria University: Duncan James ([dp.officer@northumbria.ac.uk](mailto:dp.officer@northumbria.ac.uk)).

***You can find out more about how we use your information at:***  
***[www.northumbria.ac.uk/about-us/leadership-governance/vice-chancellors-office/legal-services-team/gdpr/gdpr---privacy-notice/](http://www.northumbria.ac.uk/about-us/leadership-governance/vice-chancellors-office/legal-services-team/gdpr/gdpr---privacy-notice/)***  
***or by contacting a member of the research team***