# PRIORITY SETTING for SLEEP DISORDERS: Towards a national priority setting framework using concept mapping of stakeholder views

## PARTICIPANT INFORMATION SHEET

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| **Short Title** | ***PRIORITY SETTING for SLEEP DISORDERS*** |
| **Protocol Number** | X26-0086 |
| **Project Sponsor** | The Life Course Centre |
| **Principal Investigator** | Dr Aaron Schokman<br>aaron.schokman@sydney.edu.au |

### 1. Introduction

You are invited to take part in a research study looking at developing a national research priority for sleep disorders. The aim of the study is to get your help to understand what you think are the main priorities to improve sleep disorder research and policy.

**We are asking you to be in our study because you have said that you work with those affected by sleep disorder in a research, clinical, or advocacy role** (for example, insomnia, obstructive sleep apnoea, Narcolepsy (Type 1 / Type 2), idiopathic hyposomnia, etc.). You have said that you are over 16 and are able to take part in this research in English.

The study is part of a national collaborative study coordinated by the Australian Research Council Centre of Excellence for Children and Families over the Life Course (the Life Course Centre) and is supported by a Knowledge Transfer Outstanding Leadership grant from the Life Course Centre.

This Participant Information Sheet (PIS) will tell you what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask.

### 2. Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form at the end of this document. On the consent form you will have the opportunity to let us know if you would like to be sent a summary of the results. The summary will be sent to you via the way that you choose (i.e., via email, post, or another way you would like).

If you would like help to complete the tasks in this study, you will be given the option in the consent form to ask for a researcher to contact you to do these tasks online through Zoom, over the phone, or face-to-face at the Royal Prince Alfred Hospital or University of Sydney if possible.

This study involves responding to two separate tasks. You can choose to undertake one or both, depending on which point the study is at when you receive this information. For both tasks, once you have signed the consent form you will be sent a link to an online platform and asked to answer a small number of questions to help us understand who has taken part (i.e., “Were you born in Australia?” and “Which sleep disorder/s do you experience?”). Task A will occur first, and then approximately two months later we will be looking for individuals to take part in Task B.

**Task A** involves thinking of answers to a specific question. In this case, the question will be:

*"What do you think are the main priorities researchers should focus on to improve the lives of Australians living with sleep disorders?*
*(Put simply, what research into sleep disorders should Australia be focusing on)"*

You will be encouraged to think of as many answers as possible (brainstorm) that you feel could answer the question. There are no 'wrong' answers to the question, and the answers can be as long or as short as you think necessary. This task should take approximately **20 minutes**. If you have completed Task A, you will be asked if you are happy to be contacted in approximately two months' time to undertake the second task (Task B).

**Task B** involves two separate activities based on the answers (statements) provided by all the participants who completed Task A. Together they should take approximately **40 minutes**. Again, the tasks can either be completed online using a secure unique weblink or we may be able to offer it to you on Zoom, over the phone, or face-to-face (depending on researcher availability).

**Task B1** involves ranking the importance of each statement on a scale from one-to-five, with 1 representing the 'least important' reasons and 5 being the 'most important' reasons.

**Task B2** involves organising the statements that you think go together into groups (clustering). You are also asked to think of a title name for each of the groups if possible.

Response data (i.e., brainstorming and clustering activities) will be collected and stored using the online system known as Concept Systems™ (which you can see at http://www.conceptsystemsglobal.com). This platform allows the research team to analyse participants responses to determine which priorities for research on sleep disorders are the most important based on ideas from people with lived experience of sleep disorders.

## 3. Risks

Apart from giving up your time, we do not think that there will be any risks to you if you take part in this study. However, in the unlikely event that you do feel distress or become upset during the completion of the concept mapping tasks, the contact details of a health professional will be available for advice and support via phone during office house/email after office hours.

If you want to talk to someone outside of the research team, you can contact any of the following supports:

- Your care-coordinator, doctor, or GP
- NSW Mental Health Line - 1800 011 511
- Lifeline - 13 11 14 or visit their website at www.lifeline.org.au
- beyondblue Infoline - 1300 224 636
- Head to health - 1800 595 212 or visit their website at www.headtohealth.gov.au

## 4. Benefits

We cannot guarantee that you will get any benefits from this research. By being part of this study, you might learn more about the priorities for improving sleep disorders for Australians that might help with your or others health and wellbeing.

If you participate in this study *outside of a paid work role*, you are also eligible to receive an Australia Post Mastercard gift card valued at $25 if you complete Task A and Task B as reimbursement for your time. You can use this gift card at any retailers that accept EFTPOS.

## 5. Costs

Participation in this study will not cost you anything, nor will you be paid. However, you will receive a $25 Mastercard gift card from Australia Post if you participate in both activities (Task A and Task B) *outside of a paid work role*. Please indicate your eligibility to receive a gift card in the Participant Consent Form.

## 6. Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason by contacting the Principal Investigator (Dr Aaron Schokman) on the email address given at the top of this PIS or by submitting a withdrawal form that will be given to you before you start in the study. Whatever your decision, please be assured that it will not affect your relationship with any member of the research team, or anyone else at the Life Course Centre, or the Sydney Local Health District.

If you decide to withdraw from the study, we will not collect any more study-related information from you.

## 7. Confidentiality

All the information collected from you for the study will be treated confidentially and will be stored on a password-protected research database which is supported by Information Technology services at the University of Sydney. Only the researchers named on this PIS will have access to it and the Chief Investigator (Dr Schokman) will be responsible for upholding its confidentiality. If you give us any information on paper (e.g., completed consent form) it can be mailed to Office 4, Room 156, Level 5, The Professor Marie Bashir Centre, Royal Prince Alfred Hospital, 67-73 Missenden Road Camperdown NSW 2050 where it will be kept in locked filing cabinets in a locked office separately from anonymised (raw) data.

The information you provide will be aggregated (grouped). If you participate in both research activities and wish to receive the $25 gift card you will need to provide your name and preferred contact details (email address, mailing address) and you will be given log in details to the Concept Systems™ software so we can track your participation. At this point your responses are linked to your contact details; however, your confidentiality will be maintained during data analysis. You also have the option to participate anonymously (i.e., your responses will be non-identifiable).

The files will be retained for 7 years from the day the study is completed. Once the retention expires the files will be permanently deleted from the online server and any paper documents will be shredded and disposed of.

By providing your consent, you are agreeing to us collecting information from you for the purposes of this research study. The only circumstances in which we will seek to identify you from your responses is if you discuss something that makes us think you are at risk of harm or harming someone else. In which case we will alert the appropriate authorities. Your personal information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Sharing research data is important for advancing knowledge and innovation. A de-identified set of the data collected in this study may be made available for use in future research. All data for use in journal publications and presentations will be de-identified (de-identified data means that you/your information will not be identifiable).

## 8. Storage of Data

The University of Sydney software licence for REDCap (Research Electronic Data Capture) will be used to manage the collection and storage of identifying research data (i.e., consent form). REDCap is a secure, web-based, non-commercial, data management tool designed for research purposes. Data collected by REDCap is stored on servers in the University of Sydney data centre. Data is secured and regularly backed up to protect privacy and confidentiality.

Concept Mapping projects using this software have been previously undertaken at the University of Sydney and other major universities and published in hundreds of peer-reviewed and other journals. Short-term electronic data storage (i.e., for the period of the study) will occur on the Concept Systems™ platform which is a secure cloud-based infrastructure based in the United States before being transferred to password-protected University of Sydney servers. If you choose to participate in this study, you can engage in the Concept Systems™ platform without providing any identifying information.

## 9. Future use of Data

With your permission, the data collected in this project may also be used in future research studies. The results of this study and non-identified raw data may also be shared in the future with national and international collaborators. If any stored data are used for future research, the research will first be reviewed and approved by an appropriately constituted Ethics Committee.

You can indicate your agreement to this on the Participant Consent Form.

You can request a summary of the research findings once the study is complete. This request can be made on the Participant Consent Form by ticking a box and providing your email address.

## 10. Further Information

When you have read this information, Dr Schokman can discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact him on aaron.schokman@sydney.edu.au.

## 11. Ethics Approval and Complaints

This study has been approved by the Human Research Ethics Committee (RPAH Zone) of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9515 6766 or SLHD-RPAEthics@health.nsw.gov.au and quote protocol number X26-0086.

**Associate Investigator(s)**

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| **University of Sydney** | Prof Nick Glozier<br>Associate Professor Alyssa Milton<br>Dr Elizabeth Stratton<br>Dr Priya Vaughan<br>Dr Sarah Murray |
| **Flinders University** | Associate Professor Andrew Vakulin<br>Dr Jenny Haycock |
| **The University of Melbourne** | Dr Ellie Brown |
| **The University of Queensland** | Dr Shannon Edmed |
| **CQUniversity** | Dr Charlotte Gupta |

This information sheet is for you to keep.