



PARTICIPANT INFORMATION SHEET

Exploring caregiver perceptions and knowledge of sleep quality for people with intellectual/learning disability

You are being invited to take part in research on caregiver knowledge and attitudes towards sleep for supported individuals with intellectual or learning disability. Alison Milne, Trainee Clinical Psychologist at the University of Edinburgh is leading this research. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to better understand what the attitudes and knowledge of caregivers are about sleep for people with intellectual or learning disability. Very little is known about this, and it could be an important area in which NHS psychological therapies services could offer interventions. Understanding what would be useful is very important and this is what the study aims to achieve.

WHY HAVE I BEEN INVITED TO TAKE PART?

You are invited to participate in this study because you are a caregiver to a person with learning disability. You may be an unpaid caregiver, a professional working within a care organisation or directly employed by the person you support.

DO I HAVE TO TAKE PART?

No – it is entirely up to you. If you do 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 you in any way.

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART?

If you do decide to take part, please keep this Information Sheet. You will be asked to complete an Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. This will be indicated by ticking boxes in an online form and clicking submit.



You will be asked a number of questions regarding the person you support and your opinion about the quality of their sleep. The survey will take place online at a time that is convenient to you. The survey should take around 10 minutes to complete. Depending on your answers, you may also be invited to register your interest in taking part in an interview. If this is the case and you would like more information about the interviews, you will be asked to leave your name and email address so that you can be contacted with further information. You will have until the end of July 2025 to leave your details. If you do not wish to be contacted, please just close the window and do not submit your contact information. There are further information sheets and consents that will be required if you wish to participate in the interview stage of this study. The principal investigator will select survey respondents who reported poor sleep for the person they support in the survey and who meet the requirements of the study. If sufficient caregivers in a given category have been interviewed, new participants in that category will not be accepted.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There are no direct benefits, however, by sharing your experiences with us, you will be helping the investigator and the University to better understand what might be useful to caregivers and people with learning disability.

ARE THERE ANY RISKS OR DISADVANTAGES ASSOCIATED WITH TAKING PART?

There are no significant risks associated with participation. However, caregivers face an enormous amount of stress in their endeavours to support people. If answering the questions causes distress, there is information about services that can help you at the end of the survey and at the end of this information sheet.

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?

The answers you give will be kept confidential. You will not be asked for your name or identifying information in order to take part in the survey. However, in answering some of the questions, there is a possibility of leaving identifiable information. Your participation in the survey will be kept confidential. We will record the IP address of the device you use to ensure that large numbers of surveys are not being completed from the same IP address. This is only to try and ensure that genuine caregivers are completing the survey.



Caregiver Views of Sleep for PWID
Participant Information Sheet for Survey DRAFT v5 05/12/2024

Your name and contact details will not be recorded in the survey data and so it will not be possible to trace your individual submission without a code. You will be asked to create your code when you begin to take part in the survey. You will be asked for a memorable number. Your data will only be accessible if you can provide the following information by email to A.Milne-8@sms.ed.ac.uk; your memorable number along with a request to withdraw your data within two weeks of completing the survey. After this time, your memorable number will be deleted and it will be impossible to find your data to remove it.

We will keep all information we hold about you safe and secure.

Your data will be referred to by a unique participant number rather than by name or memorable number. Your data will only be viewed by the researcher.

All electronic data will be stored on a password-protected computer file. Your consent information will be kept separately from your responses in order to minimise risk.

Once we have finished the study, we will keep some of the data so we can check the results. 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.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED?

For further information about data privacy for research participants please refer to:

<https://data-protection.ed.ac.uk/privacy-notice-research>

- by asking one of the research team
- by sending an email to the researcher, Alison Milne (A.Milne-8@sms.ed.ac.uk)

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep identifiable information about you until the study is complete and has been reported and your anonymised data for a minimum of 5 years.

WHAT WILL HAPPEN WITH THE RESULTS OF THIS STUDY?



Caregiver Views of Sleep for PWID
Participant Information Sheet for Survey DRAFT v5 05/12/2024

The results of this study may be summarised in published articles, reports and presentations. You will not be identifiable from any published results. Key findings will always be made anonymous in any formal outputs. With your consent, your anonymised information may also be kept for future research.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

This study has been organised by Alison Milne, Dr Maria Gardani (both University of Edinburgh) and Dr Rowan Reffold (NHS Tayside) and sponsored by the University of Edinburgh.

WHO HAS REVIEWED THE STUDY?

The study proposal has been reviewed by the Health and Social Sciences School Ethics Committee.

WHO CAN I CONTACT?

If you have any further questions about the study, please contact the lead researcher, Alison Milne using the following email address: A.Milne-8@sms.ed.ac.uk

If you would like to discuss this study with someone independent of the study, please contact Dr Tim Bird (timothy.bird@ed.ac.uk)

If you wish to make a complaint about the study, please contact:

Matthias Schwannauer, Head of the School of Health and Social Science
headofschool.health@ed.ac.uk or the Research Governance Team
(cahss.res.ethics@ed.ac.uk)

ADDITIONAL INFORMATION - RECEIVING SUPPORT

You can access support from the following services:

NHS

CALL 111 and select the mental health option

Access longer term support from your GP



Listening Services

Samaritans - Call 116 123, or email: jo@samaritans.org for a reply within 24 hours

Informal or Unpaid caregivers

Carers UK information and support

For information and signposting, our telephone Helpline is available on **0808 808 7777** from **Monday to Friday, 9am – 6pm (including Bank Holidays)**.

If you have a more complex query or would like more detailed guidance, we suggest you contact our **email Helpline** (advice@carersuk.org), as we'll be able to provide more information.

You can also find out about our online support sessions here: [Online meetups | Carers UK](#)

If you have a general enquiry, please email info@carersuk.org

The Carers Trust has a list of support groups, to check if there is one in your area, go to <https://carers.org/help-for-carers/introduction>

Professional Caregivers

If you are a paid caregiver, your organisation may also have service that you seek help from, you may also want to speak to your supervisor if you have one.