



Participant Information Statement and Consent Form (PISCF)

Research Volunteer Registry

1. Invitation

You are invited to join the Research Volunteer Registry at Flinders Health and Medical Research Institute (FHMRI) Sleep Health/Adelaide Institute for Sleep Health. We focus on understanding and improving sleep and common sleep disorders. Some of our research projects also require healthy volunteers without sleep issues as a comparison group.

This form provides you with information to help you decide whether you wish to be included. Please take the time to read the following information carefully and discuss it with others if you wish.

2. What will happen to my data?

By agreeing to participate, you will be added to our Research Volunteer Registry and may be invited to take part in sleep research studies where volunteers are required, and where the information that you provide indicates that you may be eligible.

Access to the information that you provide to the registry is strictly limited to researchers at FHMRI Sleep Health/Adelaide Institute for Sleep Health. The information collected will only be used for the purpose of establishing and maintaining the research registry, and for identifying people who may be eligible to participate in our sleep research projects. You will only receive requests to participate in research projects that have been approved by a Human Research Ethics Committee.

The information you provide will be collected and stored in accordance with Flinders University Privacy Policy. Further information on how the FHMRI Sleep Health/Adelaide Institute for Sleep Health protects personal information is available in the Flinders University Privacy Policy which can be found at www.flinders.edu.au or by emailing privacy@flinders.edu.au.

3. Who will have access to my data?

The data custodian (Research Volunteer Registry Manager) will only share your data with researchers who are conducting relevant research studies, and only once those projects have received separate ethical approval from a Human Research Ethics Committee. For each research study in which we invite you to participate, the researcher co-ordinating the study will supply you with all the relevant information for that project, along with a study specific consent form. Participation is entirely voluntary, and each time you can choose whether to participate, either in that project, or by continuing to be included in this registry for any future opportunities.

4. How long will you store my data for?

We intend to store your data for as long as you are willing to participate in the Research Volunteer Registry.

5. Can I withdraw from the Research Volunteer Registry?

Yes, you are free to withdraw your consent and to discontinue participation at any time by completing the withdrawal of consent form that is attached, or by phoning the Data Custodian. Your decision whether to participate will not prejudice your future relations with FHMRI Sleep Health/Adelaide Institute for Sleep Health, or Flinders University.

6. Contact Details for the Research Volunteer Registry

Name	Dr Kelly Loffler
	Research Volunteer Registry Manager and Data Custodian
Telephone	08 7221 8314
Email	aish.sleep@flinders.edu.au

7. What if I have a complaint or any concerns about this registry?

If you have any complaints about any aspect of the project, or the way it is being conducted, then you may contact:

Position	Human Research Ethics Officer, Flinders University
Telephone	08 8201 3116
Email	human.researchethics@flinders.edu.au
HC Reference Number	2559

Consent:

FHMRI Sleep Health/Adelaide Institute for Sleep Health Research Volunteer Registry

By clicking “yes” to the question

“Do you consent to participate in our Research Volunteer Registry, and to be contacted by researchers from the Adelaide Institute for Sleep Health if you are eligible for participation in research studies?”

which appears at the beginning of this online survey, I am declaring that:

- ☐ I have read this Participant Information Sheet or someone has read it to me in a language that I understand;
- ☐ I understand that I am providing my consent to have my data stored for future research purposes;
- ☐ I understand that I am free to withdraw at any time and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research volunteer registry as described and
- ☐ I will download and keep a copy of this document.

Form for Withdrawal from the Research Volunteer Registry

I wish to **WITHDRAW** from the Research Volunteer Registry at FHMRI Sleep Health/Adelaide Institute for Sleep Health. I understand that such withdrawal **WILL NOT** affect my relationship with Research Volunteer Registry at FHMRI Sleep Health/Adelaide Institute for Sleep Health or Flinders University.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

Name:	Dr Kelly Loffler
	Research Volunteer Registry Manager and Data Custodian
Email:	aish.sleep@flinders.edu.au
Phone:	08 7221 8314
Postal Address:	AISH, Box 6, Mark Oliphant Building, 5 Laffer Drive, Bedford Park SA 5042