

Participant Information Sheet

Designing adolescent sleep research

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Co-investigators: Dr Bina Ram, Ms Alena Oxenham

You are being invited to take part in a research study about the methods used for sleep monitoring and research. Before you decide 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 and discuss it with others if you wish.

Please ask 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?

Sleep is an important contributor to both physical and mental health. In particular in adolescents, experimental studies find that improving adolescent sleep duration and quality can reduce mental illness and improve cognitive function. Many devices and smartphone applications are available that allow individuals to monitor their sleep. Around one third of young adults now wear a smartwatch, and over 99% own a smartphone, so these technologies could be used to collect sleep data for research. However, although these technologies are available, the best way to collect high-quality data for research is not clear. Data from smartphone apps can be low quality, and research participants may not want to use sleep monitoring devices. Getting comparable data across different devices may not be easy.

In this study we want to work with a group of adolescents to test methods for collection and analysis of sleep data, and develop recommendations for the design of future adolescent sleep research and research questions to be addressed.

Our research will address the following questions:

1. What are adolescents' preferences for sleep monitoring, and how can we maximise participation of adolescents in sleep monitoring for research studies?
2. What research questions should we prioritise in studying the role of sleep in adolescent health?
3. How can we harmonize sleep measurements collected across different devices?

Why have I been invited?

We are inviting individuals in school year 12. We are looking for 30 adolescents to take part, from across several different schools.

Do I have to take part?

It is up to you to decide whether or not you would like to take part. If you do decide to take part you can download a copy of this information sheet and you are asked to fill in the application and consent form which is available on our website. If you decide to take part you are still free to withdraw at any time and without giving a reason. If you withdraw, then we will keep the data that you have contributed to the study up to the point of your withdrawal. These data will only be processed anonymously.

What will happen to me if I take part and what do I have to do?

The study will involve a series of 6 in-person workshops, each 1.5hrs, across a 3-month period (May-July). These workshops will take place either at your school, or at the Mohn Centre, Imperial College London, White City.

We ask that you aim to attend all the workshops.

Across these workshops we will:

- Introduce the topic of sleep measurement and discuss participants own interests in sleep research
- Discuss incentives/barriers for adolescents to take part in sleep monitoring, and any ways that participants currently monitor their sleep
- Between the workshops: test combinations of different sleep devices for tracking sleep, and collect daily data on sleep using sleep devices and in a sleep diary. Devices to test may include Fitbits, Withings sleep mats, Garmin smartwatches, Apple watches, and GENEActiv research accelerometers.
- Discuss experiences with using the devices and perceptions of accuracy of the devices
- Discuss different topics around research design e.g. duration of sleep monitoring, concerns around data sharing, preferences for feedback
- Develop recommendations for future sleep monitoring in research, as well as suggestions for research questions for adolescent sleep research

Notes will be taken in the workshops, demographic data collected by questionnaire, and sleep data collected using sleep devices and a sleep diary. Data will be stored separately from your name and contact details. All personal data will be stored securely within the Imperial College London Certified Secure Research Environment. Data will be held for 10 years after the study has been completed, and then deleted.

What are the possible disadvantages and risks of taking part?

There are very limited disadvantages to taking part in the study aside from the time it to attend workshops and monitor your sleep.

What are the possible benefits of taking part?

Taking part in this study will give you an insight into how research works, and may be something you might like to refer to in a personal statement or job cover letter. Participating in research can be an interesting and novel experience, especially for those interested in higher education or a career in science or healthcare. It can also be incredibly rewarding to know that you are contributing to health research to improve the future health of the population.

As a thank you for your participation in the study, participants will receive £15 for each workshop that they attend, up to a total of £90 across the study.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator (Dr Eleanor Winpenny: e.winpenny@imperial.ac.uk). If you are still not satisfied with the response, you may contact the Imperial College Research Governance Integrity Team (rgitcoordinator@imperial.ac.uk).

What will happen to the results of the research study?

The findings from this research study will be used to inform the development of further research on adolescent sleep. In addition, the findings of this study will be written up for publication in a journal paper. When the paper is published, a link to the publication will be made available on the study website. Study participants will not be name or identified in any publications.

Who is organising and funding the research?

This research is conducted at the School of Public Health, Imperial College London and funded by the Huo Family Foundation.

Who has reviewed the study?

This study was given favourable opinion by The Research Governance and Integrity Team (RGIT) and approval by Prof Paul Elliott, Head of Department, Department of Biostatistics and Epidemiology, Imperial College London.

Contact for Further Information

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Thank you for taking the time to consider taking part in this study.

Transparency Notice

How will we use Information about you?

Imperial College London is the sponsor for this study and will act as the Data Controller for this study. Being a Data Controller means that we are responsible for looking after your information and using it appropriately plus are responsible for explaining this to you. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

The study is expected to finish in December 2025.

For more information / confirmation regarding the end date please contact the study team, see **'WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED'** for contact information.

We will need to use information from you (including personal data and data created as part of the study, for example data collected using devices such as smartwatches, Fitbits, sleep mats) for this research project.

This information will include your name, email address, and school. People within the College and study team (see section 'Sharing your information with others') will use this information to do the research or to check your records (see information to be collected) to make sure that the research is being done properly and the information held (such as contact details) is accurate. 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 instead.

Imperial College London is the sponsor of this research and is responsible for looking after your information. We will keep this information about you safe and secure by:

- Data management plans have been created and reviewed in line with Imperial's Information Governance Policy Framework. This covers the collection, movement, processing and storage of the data.
- Data will be stored in a secure ISO 27001 certified environment
- Robust pseudonymisation will be implemented to prevent identification
- Access controls have been implemented to ensure only key personnel can access the data.

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.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Our legal basis for using your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

- Imperial College London - “performance of a task carried out in the public interest”; Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#)

Where special category personal information is involved (most commonly health data, biometric data and genetic data, racial and ethnic data etc.), Imperial College London relies on “scientific or historical research purposes or statistical purposes.

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner, either within the European Economic Area (EEA) or to other countries outside the EEA. Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a UK adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient research partner that incorporates UK approved standard contractual clauses or utilise another transfer mechanism that safeguards how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

We will only share your personal data with certain third parties for the purposes referred to in this participant information sheet and by relying on the legal basis for processing your data as set out above.

- Other Imperial College London employees (including staff involved directly with the research study or as part of certain secondary activities which may include support functions, internal audits, ensuring accuracy of contact details etc.), Imperial College London agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.
- Data will also be shared with third company companies that provide the sleep devices tested in this study:
 - Google – Fitbit data is collected through a Google account and shared with Google. See the Google privacy policy <https://policies.google.com/privacy> and FAQs <https://support.google.com/product-documentation/answer/13532616>
 - Withings – Data collected using the Withings Sleep Analyzer is shared with Withings and subject to the Withings privacy policy <https://www.withings.com/uk/en/legal/privacy->

[policy?srsId=AfmBOopJwfRWovMi0gLshx3r4Obx36p414p18rty37Yg3RCTTVDIwTBJ](https://www.garmin.com/en-GB/privacy/global/policy?srsId=AfmBOopJwfRWovMi0gLshx3r4Obx36p414p18rty37Yg3RCTTVDIwTBJ)

- Garmin – Data collected using the Garmin smartwatch is shared with Garmin, and subject to the Garmin privacy policy <https://www.garmin.com/en-GB/privacy/global/>
- Apple – Data collected using Apple devices is shared with Apple, and subject to the Apple privacy policy <https://www.apple.com/legal/privacy/en-ww/>

POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study (such as contact details) may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you.

COMMERCIALISATION

Data from the study may also be provided to organisations not named in this participant information sheet, e.g. commercial organisations or non-commercial organisations for the purposes of undertaking the current study, future research studies or commercial purposes such as development by a company of a new test, product or treatment. We will ensure your name and any identifying details will NOT be given to these third parties, instead you will be identified by a unique study number with any sample analysis having the potential to generate 'personal data'.

Aggregated (combined) or anonymised data sets (all identifying information is removed) may also be created using your data (in a way which does not identify you individually) and be used for such research or commercial purposes where the purposes align to relevant legislation (including the GDPR) and wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes.

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 because some research using your data may have already taken place and this cannot be undone.

- We need to manage your records in specific ways for the research to be reliable. This means that we may not be able to let you see or change the data we hold about you if this could affect the wider study or the accuracy of data collected.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.
- You will be able to delete any data collected through sleep devices and shared with Google/Withings/Garmin/Apple in accordance with their privacy policies and EU

regulations. We will provide instructions on how to do this at the end of the data collection.

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

You can find out more about how we use your information:

- by asking one of the research team
- by sending an email to e.winpenny@imperial.ac.uk, or
- by ringing us on 02075947520.

COMPLAINT

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to e.winpenny@imperial.ac.uk, or by ringing us on 02075947520.

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)- via www.ico.org.uk. Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.