



S-Five Project: Selective Sound Sensitivity Syndrome Study

INFORMATION SHEET FOR PARTICIPANTS

The study is approved by King's College London Psychiatry, Nursing & Midwifery Research Ethics Subcommittee (REC Reference Number: [HR-19/20-17173](#)).

YOU MAY PRINT OFF THIS INFORMATION SHEET, should you wish to keep it

Title of study

S-Five Project: Selective Sound Sensitivity Syndrome Study

Invitation Paragraph

Thank you for taking interest in this research, conducted by researchers at the Psychometrics and Measurement Lab, Department of Biostatistics and Health Informatics, King's College London. Before you decide whether you want to continue, please take some time to read about the **scopes of this research and what it will involve for you**. Please take the time to read the following information carefully. If there is anything that is not clear or if you would like more information, please email psychometrics@kcl.ac.uk.

What is the purpose of the study?

The study investigates sound sensitivities that are characterised by an intolerance to specific everyday noises (e.g. the sound of people eating or repetitive tapping), which result in an extreme physiological and emotional response. When hearing these sounds, some people can have extreme emotional responses that could make it extremely difficult for them to focus. They may also end up doing things to try and cope better, like wearing earplugs or avoiding being in places where they might hear those sounds. This can understandably **cause problems with work and study**, and sometimes causes big **problems in relationships**.

The study is completed online, and it aims to improve on a questionnaire (S-Five) that has been designed to help work out whether someone has those sound sensitivities, how severe they are, and how much their life is affected by them. The S-Five also tries to capture some of the more unusual thoughts and feelings that people with those sensitivities have, which could give therapists the additional information they need to help those people improve their lives and feel less bothered by their symptoms. The researchers will then use scientific techniques to refine the questionnaire and to make sure it does precisely what it is supposed to do, so that it can be used for research around the world. Together with these questionnaires, demographic information are also collected as well as responses to personality questionnaires.

Why have I been invited to take part?

We are looking for **adults**, aged 18 and over, from a wide range of backgrounds to take part, including people with or without any experience of issues relating to sounds sensitivities. Potential participants are required to be adults **fluent in English** and have **no diagnosis of intellectual disability and/or severe learning difficulties**.

What will happen if I take part?

The study involves completion of an online survey. You will be asked to complete questions from our new questionnaire about your experiences of sound sensitivity, potential trigger stimuli, and reaction to triggers. In addition to this, you will be asked to complete questions about you, such as your age and gender, and questionnaires relating to your personality. The online survey should take **no more than 20 minutes to complete**.

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**Do I have to take part?**

Participation is **completely voluntary**. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. **You can stop filling in the questionnaire at any time.**

If you provide a unique participant identifier when asked at the beginning of the survey, you are able to withdraw your data from the study until April 10th 2020, after which withdrawal of your data will no longer be possible due to the start of data analysis. If you wish to do so, please phone the lead researcher (details below), report on your wish to retract your data, use your unique participant identifier but please do not reveal your name (please do not email us the identifier code, to protect the anonymity of your responses).

What are the possible risks of taking part?

The first section of the questionnaire asks you to identify certain sounds other people make which might cause you severe emotional reaction. **Some people have reported that hearing about other people's triggers can affect them negatively and/or make them endorse those triggers.** They can also feel distressed even reading about these and some worry that they can take on new triggers by hearing about them.

If you think this is the case for you, we made this section optional and you can skip ahead to the next part of the questionnaire. However, if you decide to complete this section but you feel discomfort at any point while reading the triggers, please stop answering the questions of this section by selecting 'Please take me out of here, I have had enough' on the bottom of the page, which will take you to another section of the survey, or close the web browser and skip the survey entirely.

What are the possible benefits of taking part?

Participation in this study is not likely to provide any direct benefit to you as an individual at the time of taking the questionnaire. However, if you experience sound sensitivities this project might be significant to you in the long-term, as the study aims to understand this condition better. Ultimately, the project will give the scientific community a measurement tool (i.e., questionnaire) to use for future research, and a better understanding of how sound sensitivities influence the brain and body.

Data handling and confidentiality

All data will be kept entirely confidential and treated in strictest confidence and accessed only by the 5 researchers involved in the study. The data will be stored securely in accordance with the **Data Protection Act (2018)**. Taking part in this study is completely anonymous. We will ask you to provide a unique participant identifier that will be used to match your responses from the first and second part of the study, or to retract your data from the database in case you wish to do so. **Submission of a response to the items implies consent to participate.**

Data Protection Statement

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). If you would like more information about how your data will be processed in accordance with GDPR please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-ofpersonal-data-in-research>

What if I change my mind about taking part?

You are free to withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way. You are able to withdraw your data from the project up until the 10th of April, after which withdrawal of your data will no longer be possible as anonymised data will be used in analysis models. If you choose to withdraw from the project we will not retain the information you have given thus far.

How is the project being funded?

This project is being funded by the Psychology and Systems Sciences division, Institute of Psychiatry, Psychology & Neuroscience, King's College London.

<https://www.kcl.ac.uk/ioppn/divisions/index-1>

What will happen to the results of the study?

Following the study, we plan to publish the findings in a scientific journal and present the findings at talks or conferences. **You will not be personally identifiable in any publication or talk**, as only group summary data will be presented.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the lead researcher:

Dr Silia Vitoratou,
silia.vitoratou@kcl.ac.uk;
Dept. of Biostatistics & Health Informatics, PO20,
Institute of
Psychiatry, Psychology & Neuroscience,
16 De Crespigny Park,
Denmark Hill, London SE5 8AF.
Telephone:+44 (0)20 7848 0304.

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: The Chair, Joint Schools Research Ethics Sub-Committee for the Institute of Psychiatry and the Florence Nightingale School of Nursing and Midwifery (PNM RESC) rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.



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Please read the following statements and indicate if you consent to them to proceed with the study.

	Yes
I confirm that I have read and understood the information sheet dated [version 2 - 10/02/2020] for the above study. I have had the opportunity to consider the information and asked questions which have been answered to my satisfaction.	<input type="radio"/>
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time without having to give a reason, up until the 10th of April 2020.	<input type="radio"/>
I consent to the processing of my personal information for the purposes explained to me in the Information Sheet (anonymously). I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation .	<input type="radio"/>
I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.	<input type="radio"/>
I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any research outputs.	<input type="radio"/>
I agree that the research team may use my data for future research and understand that any such use would be reviewed and approved by a research ethics committee (individual data would not be identifiable in any report).	<input type="radio"/>
I understand that the information I have submitted will be published as a report .	<input type="radio"/>

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