

## **Health and Special Category Privacy Notice for Empathy and Bias Study**

### **Information for Research Participants in Empathy Study**

You have been invited to participate in Empathy and Bias study. Participation in this study is voluntary. You can discontinue your participation in the study at any time. If you discontinue your participation, you will not be subject to any negative consequences, but information gathered from you up until the point of cessation of your participation may be used in the study according to the applicable data protection legislation and this privacy notice.

#### **1. The subject, goal and the possible funder of the research study:**

The aim of the study is to investigate neural mechanisms underlying empathy and bias in humans. Research is funded by the Academy of Finland. The principal investigator is Dr. Yoni Levy, academy research fellow at the Department of Neuroscience and Biomedical Engineering, Aalto University. The coordinating researchers are Niloufar Zebarjadi and Annika Kluge which are responsible for organization and practical implementation.

#### **2. The concrete method by which personal data is collected; for example that data is collected by recording interviews or from the registries of public officials, how much of the participant's time is needed for research study participation, where the study will be conducted:**

In this study, brain function is studied by functional magnetic resonance imaging (fMRI) and magnetoencephalography (MEG) at the AMI Center and at MEG-core at Otaniemi. Each scanning session will take approximately 1 hour, and there will be a break between the two sessions. During each session, the stimuli are presented in two sections of about 20-30 minutes (participants will watch photos and/or listen to some statements or do simple tests). In addition, fMRI measurements include structural scanning during which anatomical images of the brain will be obtained (duration 6 minutes). Additionally, the MEG and fMRI sessions include a resting state measurement during which participant rests in the scanner for about 6 minutes. Furthermore, background information and behavioural measurement are collected from the participant via online form and interview (interview will be video recorded) which lasts in total approximately 1.5 hour.

#### **3. Other possible:**

fMRI and MEG is painless and safe. No drugs or X-rays are used in the study. People suffering from the dread of a cramped place can feel uncomfortable inside the magnet. A potential security risk of MEG and fMRI are a metallic foreign object in the body (eg an artificial joint, post-operative clips in the brain, denture, pacemaker, etc.); the metal object can either move or heat up a magnetic field. Also, clothing and pockets should not contain any metal parts during the study. Jewelry must also be removed during the study. Also inform the researcher of any tattoos, as heat may be felt in their area during the examination.

In this study, participants will be exposed to physical pain pictures and hear short statements and do implicit association test (IAT). In order to mitigate the discomfort which might be experienced while perceiving such stimuli, participants will be informed that they can withdraw from the experiment at any stage. However, it is also noteworthy that in order to study empathy to the physical pain of others, in the past two decades there have been hundreds of studies conducted, including many neuroimaging studies (c.f. a recent meta-analysis Jauniaux et al., 2019 <https://doi.org/10.1093/scan/nsz055>). Although these experiments have been conducted on thousands of people worldwide, it is impossible to rule out that the perception of these stimuli might cause some discomfort. In fact, the experience of empathy often involves feeling discomfort while perceiving vicarious pain, and thus, empathy studies in their nature might involve a certain degree of discomfort. But these experiences are not very strong and they are short-lived and there is no reason to

assume that they would be psychologically harmful.

#### **4. What personal data is processed?**

For the practical arrangements of the study, we need your first and last name, e-mail address and phone number. We also need your name on the consent form. We ask for information about your gender, age, and educational background. In addition, you will be asked to fill out a variety of questionnaires. Besides, We will record your video during the final interview to analyze the answers and body language while answering the question. In addition, we collect health (non-medical) data using fMRI and MEG devices. **Additionally, for conducting the experiment, some data are collected from internet that is publicly available where persons might be identifiable. This data is only used with test setting, and not shared or re-made publicly available.**

#### **5. What special categories of data are processed?**

We use questionnaires about social, political and empathy evaluation self-report because during the experiment we measure empathy and bias toward ingroup and outgroup.

#### **6. Personal data has been collected from the following sources:**

All personal information is collected from the participants themselves. Data are collected through questionnaires, interviews, computer or measured by fMRI and MEG devices.

#### **7. a) How is personal data processed in the study?**

**The concrete method by which personal data is analyzed.**

For the first time that while the data are pseudonymized (by separately and safely maintaining a list where there is subject names contact info matched with the ID code of each subject's data); the code connecting data with the subject will be maintained as incidental clinical findings, the code will be destroyed after initial data analysis has been carried out (where it is seen then that no tumors etc.).

Interview videos will be watched and analyzed by phenomenologists via a link in Panopto (they are not able to download/copy it). And after they watch and analyze the interviews, they will be anonymized (voices will be distorted and faces will be blurred)

#### **b) What is the purpose of the processing?**

The purpose of this study is to elucidate the brain mechanisms underlying empathy and bias in humans. Contact information is required for practical arrangements, but not for the scientific research itself. Questionnaires information on age, gender and educational background, as well as social, political and empathy evaluation self report are needed in scientific research.

#### **c) Effects to data subjects**

Although it is not a medical examination, it is possible that a surprise finding or an abnormality in the brain image of the healthy volunteer participant would be observed. In this case, a specialist in a suitable field may be consulted. Based on his/her assessment, the participant may be recommended to apply for more detailed studies.

#### **d) Legal basis for processing of personal data**

The processing of personal data, including special category data, is required for the performance of a task carried out in the public interest, scientific research and for academic expression.

## **8. Sharing of Personal Data**

Personal information is not shared with parties outside Aalto University

## **9. Transfer of Personal Data to Non-EU/EEA countries**

Personal information is not transferred to Non-EU/EEA countries

## **10. Storage period of your data and anonymisation**

Data will be stored for a maximum of 5 years after the last publication using the dataset is published and then will be destroyed.

## **11. The rights of the study participant in a scientific study**

According to the General Data Protection Regulation (GDPR), data subjects have the right

- to obtain information on the processing of personal data
- of access to their data
- to request rectification of their data
- to request restricting the processing of their data
- to object to the processing of their data
- right to erasure, if research data have been unlawfully processed and processing is no longer necessary for archiving purposes in the public interest, scientific research purposes or statistical purposes and erasure of research data will not render impossible or seriously impair objectives of scientific research.

If the purposes for which a controller processes personal data do not or do no longer require the identification of a data subject by the controller, the controller shall not be obliged to maintain, acquire or process additional information in order to identify the data or the data subject for the sole purpose of complying with the GDPR. If the controller cannot identify the data related to a data subject, the rights of access, rectification, objection and erasure shall not apply, except if the data subject provides additional information enabling his or her identification and the identification of the research data that relates to data subject.

Data is being processed for the purposes of scientific research, and the data is not used in decision-making related to the participant.

To exercise his or her rights, the data subject should contact the Data Protection Officer, or the research study contact person.

A derogation in the rights of the data subject is necessary and justified, if the research is conducted for the purpose of public interest, and the rights of the research participant would likely prevent reaching these goals or hinder them greatly, and these derogations are necessary to ensure these objectives.

There is no deviation from the rights of the data subjects in this research study

The following protection measures have been enacted in this research

- The processing of personal data is based on a research plan.
- The research has a responsible principle investigator Jonathan Levy
- The personal data is used and disclosed only for the purposes of scientific research or some other compatible purpose and all parties involved in the research agree to ensure that no data pertaining to any specific individuals is disclosed to any third parties.
- The research involves the processing of special categories of research data. An impact assessment on this processing has been made and submitted to the Office of the Data Protection Ombudsman before the processing is set to begin (this is required by law, (Tietosuojalaki/national Data Protection Act 31 §, if there is special category data and deviation from data subject rights )
- There has been an ethical review (date and name of ethical committee)

If, however, it is possible to achieve the aims of the study and the achievement of the purpose is not greatly hindered, Aalto University will actualize your rights as defined in the GDPR. Exercising your rights requires proof of identity.

## 12. More information on the study and the exercising of your rights

The controller in this study is Aalto University.

The contact person in matters related to the research study:

Jonathan Levy, Academy Research Fellow

jonathan.levy@aalto.fi  
Aalto university

The research participant must contact Aalto University's data protection officer if they have questions or demands related to the processing of personal data.

Data Protection Officer

Phone number: 0947001

Email: tietosuojavastaava@aalto.fi

If the research participant sees that their data has been processed in violation of the General Data Protection Regulation or data protection legislation, the participant has the right to lodge a complaint with the supervisory authority, the Data Protection Ombudsman (see more: tietosuoj.fi).