

## CONSENT TO TAKE PART IN A RESEARCH STUDY

**Title of Study:** RAPID: Privacy-Preserving Crowdsensing of COVID-19 and its Sociological and Epidemiological Implications

**Principal Investigator:** Jaideep Vaidya, Ph.D.

This online consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in the study. It is your choice to take part or not. Ask questions if there is anything in the form that is not clear to you. If you decide to take part, instructions at the end of document will tell you what to do next. Your alternative to taking part in the research is not to take part in it.

### Who is conducting this research study and what is it about?

You are being asked to take part in research conducted by Jaideep Vaidya who is a Professor in Rutgers Business School and the Director of the Rutgers Institute for Data Science, Learning, and Applications. The purpose of this study is to track COVID-19 symptoms in a privacy-preserving manner and to understand privacy choices in extreme situations. We anticipate a *large number (>1000)* of subjects will take part in the research.

**Sponsor of the Study:** National Science Foundation.

### What will I be asked to do if I take part?

The questionnaire will take about 5 minutes to complete it.

### What are the risks and/or discomforts I might experience if I take part in the study?

We understand that this questionnaire may ask you for details on sensitive health related topics. We will keep all your data confidential and only report aggregates of the data to others. These aggregates would have mathematical guarantees of privacy. Breach of confidentiality is a risk of harm but a data security plan is in place to minimize such a risk. Also, some questions may make you feel uncomfortable. If that happens, you can skip those questions or withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire your answers will NOT be recorded.

### Are there any benefits to me if I choose to take part in this study?

There no direct benefits to you for taking part in this research. You will be contributing to knowledge about COVID-19 outbreaks and individual's privacy needs in such scenarios. You will also be able to see trends in COVID-19 related information (in an aggregated manner) in real time.

### Will I be paid to take part in this study?

You will not be paid to take part in this study.

### How will information about me be kept private or confidential?

The information provided will be kept confidential. The data from the user to the platform will be transmitted over an encrypted channel. Any personally identifiable information will be encrypted using AES (Advanced Encryption Standard). Online survey data will be stored on secured Amazon Servers which are encrypted and password protected. The bulk of the study information collected will be stored in an encrypted electronic database to which only the research team will have access via a password type

system. The findings will be released only in aggregate terms and any quotes used will not mention the name of the individual.

All efforts will be made to keep your responses confidential, but total confidentiality cannot be guaranteed.

We will use [custom-created website app (name to be decided)] to collect and forward your responses to us. We will know your IP address when you respond to the online research, which we may use to gather location information. You have the option to include your email address or to use a unique code generated by you or by us when you complete the questionnaire. Your IP address and the unique code or email information will be stored with your responses. We will securely store the key code linking your responses to your identifiable information in a separate password protected file which will be destroyed after data analysis is complete and study findings are professionally presented or published.

No information that can identify you will appear in any professional presentation or publication.

### **What will happen to information I provide in the research after the study is over?**

The information collected about you for this research will not be used by or distributed to investigators for other research.

### **What will happen if I do not want to take part or decide later not to stay in the study?**

Your participation is voluntary. If you choose to take part now, you may change your mind and withdraw later. In addition, you can choose to skip questions that you do not wish to answer. If you do not click on the 'submit' button after completing the form, your responses will not be recorded. You may also withdraw your consent for use of data you submit, but for this you must have provided email address at the time of entering your data. You can ask for your data to be removed by writing to the PI Jaideep Vaidya at [jvaidya@business.rutgers.edu](mailto:jvaidya@business.rutgers.edu).

### **Who can I call if I have questions?**

If you have questions about taking part in this study, you can contact the Principal Investigator: Jaideep Vaidya, [jvaidya@business.rutgers.edu](mailto:jvaidya@business.rutgers.edu), Phone: 973-353-1441.

If you have questions about your rights as a research subject, you can contact the IRB Director at: Arts and Sciences IRB (732) 235-2866 or the Rutgers Human Subjects Protection Program at (973) 972-1149 or email us at [humansubjects@ored.rutgers.edu](mailto:humansubjects@ored.rutgers.edu).

Please print out this consent form if you would like a copy of it for your files. Signature of this form constitutes consent and clicking on the "I Agree" button constitutes consent to participate.

If you do not wish to take part in the research, close this website address. If you wish take part in the research, follow the directions below:

By beginning this research, I acknowledge that I am 18 years of age or older and have read and understand the information. I agree to take part in the research, with the knowledge that I am free to withdraw my participation in the research without penalty. Click on the link that will take you to the questionnaire. {LINK here}.