



## **GENERAL INFORMATION SHEET**

### **Developing Smartphone Apps for Adults with Fetal Alcohol Spectrum Disorder - Survey**

**Principal Investigators:** Christie Petrenko, Ph.D. & Cristiano Tapparello, Ph.D.

#### **Who is conducting this study?**

This form describes a research study being conducted by Drs. Christie Petrenko and Cristiano Tapparello. They are researchers at the University of Rochester in Rochester, NY, USA. Dr. Petrenko is a psychologist. She has been working with people with fetal alcohol spectrum disorder (FASD) since 2003. Dr. Tapparello is in computer engineering.

We are also partnering with members of the Adult Leadership Committee of FASD Change Makers to run this study. We value their motto: "Nothing about us without us."

#### **What is this study about?**

We want to develop smartphone apps for adults with FASD. These apps can help with daily life. The purpose of this study is to get your feedback on an app we are developing for adults with FASD.

#### **What will happen if you do this study?**

Here is what will happen if you choose to do this study:

- You will first complete a short online survey. This is to check that you meet the criteria for this study. We will also ask for your contact information.
- If you meet the study criteria, you will be asked to complete a longer online survey. In this survey, you will watch some short videos that show different parts of the app. After each video, you will be asked if you like that part of the app. You can also share any other feedback or ideas you have to make the app better.

#### **How long will this study take?**

This survey will take anywhere from 20 to 40 minutes to complete.

#### **How many people can do this study?**

Up to 500 people with FASD can do this study.

#### **What are the possible risks or discomforts if you do this study?**

You might get bored or feel uncomfortable completing the survey. You can choose to skip questions you do not want to answer. You can also take a break and come back to the survey. You can also decide to not participate anymore and stop the survey.

**What are the possible benefits from being in this study?**

You will not benefit personally from being in this research study at this time. But in the future, you might be able to use the apps we develop to make life easier.

**What if you don't want to do the study?**

You can choose to not participate or complete the survey at any time.

**Will you get any money or gifts for being in this study?**

You will not receive money or gifts for being in this study.

**How will the researchers keep your information private?**

The University of Rochester makes every effort to keep your information private. Your name and other identifying information will not be released in public about this study. We will keep your information and the survey responses on our secure computer servers.

Sometimes, researchers need to share information that may identify you with people who work for the University. If this does happen, we will make efforts to protect your information. Results of the research may be presented at meetings or in publications, but your name will not be used.

**What if you have questions about this study?**

For more information or questions about this research you may call Christie Petrenko at (001) 585-275-2991, or email: [christie\\_petrenko@urmc.rochester.edu](mailto:christie_petrenko@urmc.rochester.edu).

**What if you have questions about your rights as a research subject?**

Please contact the University of Rochester Research Subjects Review Board at 265 Crittenden Blvd., CU 420628, Rochester, NY 14642, Telephone (001) 585-276-0005 or (001) 877-449-4441 for the following reasons:

- You wish to talk to someone other than the research staff about your rights as a research subject;
- To voice concerns about the research;
- To provide input concerning the research process;
- In the event the study staff could not be reached.

**REMEMBER!**

**Taking part in this study is your choice.** You can choose not to do the study, and no one will be mad at you. You can also choose to stop at any time.