



GENERAL INFORMATION SHEET

Developing Smartphone Apps for Adults with FASD

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

Who is conducting this study?

This form describes a research study that is 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 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 complete a short survey online. 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, we will send you a Zoom link to participate in an online focus group. This focus group will meet one time for 1.5 hours.
- At the online focus group, we will show you what the app looks like. Then you will go into small groups in Zoom with a member of the Adult Leadership Committee and a researcher. They will ask you what you think about the app.
- We will record the discussion and take notes to help us remember what everyone said.

How long will this study take?

This study will last 1.5 hours.

How many people can do this study?

Up to 100 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 talking to other people in this study. You can choose to skip any questions you don't want to answer or not talk in the group. You can also take a

break if you need to. People may also say things about you to other people not at the discussion. We will tell everyone not to do this.

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 that we develop to make life easier.

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

You can choose not to participate.

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

You will receive a gift card worth about US\$25 for participating in this study. There will also be no cost to you to participate 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 focus group recordings on our secure computer servers. We will also delete the recordings after we write them out.

Sometimes, researchers need to share information that may identify you with people that 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 or voice 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.

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.