



INFORMATION SHEET

Development of Provider-Assisted Families Moving Forward Connect

Principal Investigators: Christie L. M. 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. Dr. Petrenko is a psychologist. She has been working with people with fetal alcohol spectrum disorders (FASD) since 2003. Dr. Tapparello is in computer engineering.

What is this study about?

The purpose of this study is to learn about the barriers and facilitators to providing FASD-informed care from the perspective of mental health care providers. We are using this information to develop a provider-assisted version of our Families Moving Forward (FMF) Connect app and training materials for providers to help families raising children with FASD.

What will happen if you do this study?

If you decide to take part in this study, you will be asked to:

- Complete several short surveys online. These will check that you meet study criteria and gather demographic information.
- Participate in one or two 90-minute focus group(s) with other mental health providers. This may occur in person or online over Zoom, depending on your location and preferences. For any in-person groups, current COVID-19 safety guidelines will be followed.
 - You can choose to participate in one or both focus groups, depending on when you join the study.
 - During the first focus group we will tell you what FASD-informed care is and show you what the FMF Connect app looks like. We will ask you if you think providers would be interested in using this with families and what that could look like. This will help us design and develop training materials for mental health providers.
 - During the second focus group, we will show you the materials we developed for providers to use the FMF Connect app with families. We will then ask you what you think the barriers and facilitators would be to implement these and any changes you would make.
- We will record the discussion and take notes to help us remember what everyone said.
- Communicate with you by phone or email to schedule focus groups and process payment. Email communications between you and the study team may be filed in your research record. Messages will be limited to appointment reminders and payment confirmation.

How long will this study take?

Online surveys take about 5-10 minutes. Focus groups last 90 minutes.

How many people can do this study?

We expect about 30-50 mental health providers to participate in focus groups.

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.

Email may be sent or received in an unencrypted (unprotected) manner. Therefore, there is a risk that the content of the communication, including your personal information, could be shared beyond you and the study team. The University of Rochester is not responsible for any interception of messages sent through email/text.

What are the possible benefits from being in this study?

You will not benefit personally from being in this research study at this time.

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

You can choose not to participate.

Who is funding this study?

The University of Rochester is receiving payment from the National Institute on Alcohol Abuse and Alcoholism for conducting this research study.

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

You will receive a gift card worth about US\$25 for each focus group you complete. 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 transcribe them.

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.

Your participation in this study is completely voluntary. You are free not to participate or to withdraw at any time, for whatever reason. No matter what decision you make, there will be no penalty or loss of benefits to which you are otherwise entitled.

Taking part in this research is not a part of your University duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research.