

2024

When You are Asked to Take Part in Research

Information for People with FASD

How Was This Information Developed?

In 2018, about 40 adults with FASD met with researchers to talk about what they needed to be able to participate in FASD research.

We have used the feedback from adults with FASD to develop this information. Below are descriptions of what you can expect and ask for when you are deciding if you want to take part in the research.

What is Research?

Research is all about asking a question, then figuring out a way to answer it. This process usually involves many stages. First comes figuring out what the researcher wants to know (**research question**), then figuring out what kind of information is needed and how to get it (**research design**).

Often, a researcher needs to apply for money to do the research. If they get the money they need, and they get approval by an ethics committee who oversees the study, they can start to collect the information (**data collection**).

After they collect the information, the research team must “interpret and analyze” the data or figure out what the data means (**data analysis**). Researchers do this by answering their research question. After they have finished the analysis, they usually write up papers or present the information at conferences so that other people can learn from what they found (**knowledge translation**).

Types of Research:

Surveys
Interviews
Focus Groups
Medical Treatment



Why Would I Want to be Involved?

It is important that people with FASD and their caregivers participate in research so that more is learned about FASD, including about strengths and needs. This involvement includes participating in research both as a participant and in helping to develop FASD research projects.



How Can You be Involved in Research?

There are two main ways of being involved in research.



1. As a Participant:

- The researcher does all the work setting up the research project. They might ask you to participate in a project as a participant.

2. As a Collaborator:

- The researcher meets with people with FASD and their caregivers to help create the research project. For example, researchers may ask for your help in deciding what topic area to explore, or to ask for your advice on what the research question should be.





IF YOU ARE A RESEARCH PARTICIPANT

There are some things the researcher should do to make you feel comfortable, to help you understand what the research is about, and to make sure your needs are taken care of during the research.

1 Respect and Dignity



The researcher or researchers should always treat you well, with respect and dignity.



The researchers need to provide information to you in a way you can understand.



The researchers need to recognize that you know a lot about FASD and that what you know is important.



The researchers need to understand that your life is complex, that you have responsibilities, and that you might have to change appointments or withdraw from research.



2 Support

The researchers need to understand that your participation can be supported by things like:



Making sure you understand any questions.



Having a trusted person with you to help answer questions and make your participation possible. It is OK to have a trusted person come with you to support you.



Visual cues to go along with written or verbal instructions, so that you are shown, as well as told.



A physical space that is set up for your sensory needs. For example warm temperature, quiet, and not much in the room.



If the research brings up tough emotions, you have the right to ask for counselling or support to manage those emotions.



Having a chance to get used to the surroundings and helpful strategies for dealing with anxiety.



Arranging the timing of appointments to meet your needs, as much as possible, recognizing that your time is valuable.



If you are not sure if the researcher understands and accepts these things, you might not want to participate in the research or sign the consent form until you have discussed your needs with the researcher.

3

Written Description of the Research

The researchers should provide you with a written description of the research. This information should include content about:



Why the research is needed, why they need you, and what they need from you.



You must be able to understand the description or have a trusted person with you to explain it to you.

Written Description Should Tell You:

- What you will be asked to do
- How long it will take
- The risks and benefits involved in taking part in the research. The risks could be physical, psychological, or social. They should tell you how they will try and reduce any risks.
- How the information they collect will benefit others.
- If you will be paid or get any expenses covered for taking part in the research.
- Tell you who to contact with any questions about the research or your rights.
- That you will be asked to sign an informed consent form (see below).

4

Informed Consent

You will be asked to sign an informed consent form that says that you understand what you are going to do and if you agree to be part of the research. The form will:



Explain the research in detail



Ask if you understand what is being asked of you. If you do not understand, do not sign the form. You can ask more questions to clarify.



Ask if you agree to take part in the research. If you do not agree, do not sign the form.



5

Agreeing to take part in the research:



You have the right to say no to doing the research. If you are receiving treatment or support, and you say no to being part of the research, no one can stop the treatment or support.



You can say yes.



If you say yes, you can also change your mind and say no at any time. If you are receiving treatment or support, saying no will not stop the treatment or support.



The researcher must talk to you about how confidential your information will be. If you do not want to be identified in the research, the form you sign must say that you will not be identified.

6

Payment:



You have the right to ask to have any expenses paid for by the researchers. This payment may include getting to the research (gas, bus, taxi, parking costs, or other people's costs to get you there), meals out as a result of the research, photocopying costs, childcare expenses, etc. What you pay for expenses for taking part in the research should be written down.



If you need someone to transport you to the research, they should be paid for their expenses by the researchers.



Some researchers will offer money or give you something (like a gift card) for taking part.

7

Description of the Researcher:



Often researchers work as collaborative teams, meaning there may be multiple researchers and individuals that you have contact with.



You should be told who the researcher is and what their background is.



You should be told who will be in contact with you. Sometimes you will see a student or research associate instead of the main researcher.

If Your Rights Aren't Respected

If you feel like you are not being respected by the researchers, you can contact the **Research Ethics Board**.

In order to do research on people, researchers have to apply for “ethics” for their projects. “Ethics” is a set of rules researchers have to follow to make sure they are keeping you safe, being respectful of your time and input, and protecting you.

Each research project has an REB number, which means was approved by a **Research Ethics Board**. You can usually find this number on the consent form, the project website, or the recruitment materials.

Each project you are part of might have a different ethics board and will have a different REB number.

Here are some reasons you might contact the REB:

- The researchers promised to pay you for your time but they haven't;
- The researchers did not update you of any changes or modifications to the project you gave consent to;
- You do not feel respected by the researchers.



Examples of Finding the Research Ethics Board (REB) Number on a Recruitment Poster



CanFASD
CANADA FASD RESEARCH NETWORK

Are you a youth (12-24) with FASD who has had treatment for substance use? Are you a caregiver of a youth (12-24) with FASD who has supported this youth in their substance use treatment?

WE WANT TO TALK WITH YOU!

We would like to do a 30-45 minute phone or Zoom interview with you about your experiences as part of our research study. Recorded with your permission.

If you are interested in participating or would like more information, please e-mail Elizabeth Carlson at emcarlso@ualberta.ca



UNIVERSITY OF ALBERTA

This study has been approved by the University of Alberta Research Ethics Board: Pro00107455

THIS STUDY WAS APPROVED BY THE UNIVERSITY OF ALBERTA ETHICS BOARD - PRO00109341

ARE YOU A CAREGIVER FOR SOMEONE WITH FASD?



SHARE YOUR EXPERIENCES AS A CAREGIVER

- If you take care of someone with fetal alcohol spectrum disorder (FASD), we would like to learn about your lived experiences.

WHAT WOULD YOU DO?

- Complete an anonymous survey about you and the people you take care of.
- There are several sections with breaks in between. The full survey will take approximately 2 hours to complete.

TO LEARN MORE OR PARTICIPATE FOLLOW THIS LINK
[HTTPS://REDCAP.LINK/CAREGIVERFASDSTUDY](https://redcap.link/caregiverfasdstudy)

For questions about this study, please contact
katy.flannigan@canfasd.ca





Inviting Criminal Justice Professionals and Clinicians!

Online survey for:

- Service providers working in criminal justice and forensic contexts
- About identifying and screening for FASD
- Survey will take approx. 30-45 minutes to complete

For more information:

- To participate in the survey please click the link in the description
- Questions? Email us at: planlab@uoguelph.ca

Experience in identification/screening not needed to participate



This project has been reviewed by the Research Ethics Board (#22-09-002) for compliance with federal guidelines for research involving human

Checklist for Participating in Research

- I know what this research is about**
- I know who the researcher(s) is and their background**
 - Name of researcher(s):
- I know how I will participate in this research**
- I know approximately how long the research will take**
 - Timeline:
- I know what the risk are to me if I do this research**
 - Risks:
- I have asked what money I will get for being part of this research**
 - Payment/compensation:
- I know who I can talk to if I have any questions or concerns about my rights**
 - Phone number:
 - Email:
- I know what the Research Ethics Board (REB) Number is**
 - REB Number:
- The researcher discussed how private my information will be**
- I was asked to sign an informed consent form**



COLLABORATIVE RESEARCH

You have been asked to be part of a team to develop the research plan.

So, a researcher asks you if you want to be part of the team to develop a research plan. You might want to ask specifically what part of the research the researcher wants you to be involved with, as there are many parts to a research project.

Usually, you will be asked to participate in some parts, but not all. Some of the things you might be asked to take part in include:

- Being part of the research team.
- Attending meetings.
- Developing research questions. These are questions about what the research team wants to learn about.
- Helping to write the research application (this helps the researcher get the money to do the research).
- Writing letters of support for the research saying why you think the research is important and why the researcher should get money to do it.
- Helping find research participants.
- Assisting with the research. This involvement might include collecting the data, helping to analyze the data, discussing what the results of the study mean, or presenting the study with other members of the research team.
- Reviewing the research findings. This involvement is where you bring your knowledge as a person with FASD to help the researchers understand the answers to the research questions.
- Taking part in writing about the research.
- Presenting at conferences and other meetings.



Your Rights in Research

You have the right to ask the researcher what parts of the research they want you to participate in, and to choose the parts that you feel comfortable with and refuse the parts you don't feel like you want to participate in.

You have the right to ask for payment of expenses you have related to research activities (such as transportation to and from the research), and your name included as a researcher on any documents.

You are a member of the research team and should be treated as such. For example, you have a lot of information about FASD and its effects and that should be recognized by the rest of the research team.

The team members should all be able to talk about the research in a way everyone can understand.

Your Rights in Research Continued.

The researcher should also be aware that there may be things that come up in your life. You may need to change meeting times or you might need reminders about the meeting times. You might need meetings to be short and have a single topic. These are all things that show that you are being treated respectfully as a full member of the team.

Some of the things you might want to suggest to the researcher that can help you be part of the team are:

- Letting the researcher know that you need material ahead of time so you have time to read it and think about it and that there is lots of time to ask questions so you can understand the material. You might want to let the research team know that you will be bringing a trusted person with you to help you.
- Asking for information to be provided to the team in a variety of ways, such as in written form, visual form, or through discussions, so that you get the information in a way that works for everyone on the team.
- If you get distracted easily, asking that the meetings be in a quiet and comfortable space and be held at a time of day that works best for you.
- Sometimes research can bring up strong emotions. It is OK to ask if there is a counsellor available if that happens.
- It is OK to ask that things slow down if it seems like everything is going too fast for you in a research meeting. It is also OK to ask that the meetings be shorter and more frequent if this helps you participate.
- Remember that you have important information to contribute so if something is stopping you from being able to contribute that information, it is in the whole team's best interest to change that.

You might have the opportunity to make a real impact in the lives of people with FASD by participating in a collaborative research project. Keep the things mentioned above in mind so it will be a positive process for everyone on the team.

Research is important!