



## PARTICIPANT INFORMATION SHEET

### Giving a Voice to Parents of Children with FASD – Project 2: Lived Experience Advisory Group

You are being invited to take part in research on how to best engage with Birth Parents when undertaking research. Stewart McDougall, Research Fellow, at the University of Edinburgh is leading this research. We want to hear from parents of children with FASD (Fetal Alcohol Spectrum Disorder) to understand their thoughts and experiences. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

#### What is this research about?

This project seeks to establish a Lived Experience Advisory Group (LEAG) to inform research with birth parents of individuals with FASD. The LEAG will meet three times across the project:

1. Before the project starts – to review the method and change suggestions
2. During the project – to share initial findings, discuss what they mean, and brainstorm solutions to any potential challenges
3. At the end of the project – to discuss the findings, make suggestions for what they mean, and to identify key messages for research, policy makers, and practitioners

Talking about FASD can be tough for parents, so we're inviting you to share what would make it easier for you to talk with us. The findings will help researchers support parents better. It's crucial to share the voices and experiences of birth parents to improve services for them.

#### Who can take part?

Birth parents of individuals diagnosed with Fetal Alcohol Spectrum Disorder who are living in the UK. You **do not** have to have taken part in the earlier phases of this research to be a part of the Lived Experience Advisory Group.

#### Do I have to participate?

No – it is entirely up to you. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your job or healthcare.

#### What will happen if I decide to take part?

If you do decide to take part, please keep this Information Sheet. You will be asked to sign an Informed Consent Form, or complete an online version, to show that you understand your rights in relation to the research, and that you are happy to participate.

You'll join a focus group with other birth parents of children with FASD. These may be held either in person or online, depending on your preferences. In these groups, we'll ask for your opinions on how to do research with birth parents better. The focus group will meet three times, each lasting 1 to 2 hours. We would like to audio record the meetings, and will require your consent for this.

These focus groups will be running concurrently to another study called "*Experiences of Pregnancy and Raising a child with FASD*". In the later meetings of this group, we will share the emerging findings of this study.

If you wish to participate in the "*Experiences of Pregnancy and Raising a child with FASD*" study, please let the research team know and they will provide you with further information.

**Are there any benefits?**

You'll receive a £30 gift voucher for each group meeting you attend.

If you come to face-to-face meetings, we'll pay for your transportation (up to £100), and refreshments will be provided.

This study may also have indirect benefits by making future research more accessible to birth parents of children with FASD.

**Are there any possible risks or disadvantages to taking part?**

There are no significant risks associated with participation. However, we know talking about FASD and alcohol use during pregnancy can be tough. If you feel upset or uncomfortable during the conversation, we'll stop and ask if you want to continue. If you share something indicating future safety concerns for you or others, or talk about criminal activity, the researcher may need to report it to the right authorities for investigation. The researcher will discuss how to handle these concerns with you.

**Can I change my mind?**

Participating is your choice, and you can leave anytime. If you decide to stop, you can choose whether the things you shared up until that point can be used by the research team or deleted.

**Will my participation be kept confidential?**

Yes, your participation will be kept confidential. All the information collected during focus groups will be handled following the General Data Protection Regulations (GDPR). It will be stored securely in a protected data center that meets UK standards.

**How will we use information about you?**

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research.

We will keep all information about you safe and secure.

We'll use a unique participant number, not your name, to identify your data. Electronic data will be on a password-protected computer, and paper records will be locked in a filing cabinet. Your consent information will be separated from your responses to keep your name separate. After the study, we'll keep some data for result verification. We'll make sure no one can tell you took part in the study from the reports. The key linking your identifiable information to your responses will be stored for three months after the transcript has been sent to you, to allow us to identify your data should you wish to withdraw your consent. After this time, your personal information and the key will be permanently deleted.

**What choices do I have about how my information is used?**

You can stop participating anytime without giving a reason, and you can decide what happens to the data you already provided.

**Where can I learn more about how my information is used?**

You can find more information about how we use your data at <https://www.ed.ac.uk/records-management/privacy-notice-research> or by contacting the research team or the University of Edinburgh Data Protection Officer at [dpo@ed.ac.uk](mailto:dpo@ed.ac.uk).

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Edinburgh will keep the anonymised information for 5 years after the study has finished and, with your consent, the data may also be used in future ethically-approved studies. A digital copy of your consent form will be stored for 5 years, with no means of linking this with your de-identified interview transcript.

**What happens after the study?**

Once the study is done, the researchers will write a report summarising the findings. You won't be identifiable in any report or publication. The report may be published in a scientific journal or presented at conferences. We'll talk to the group about other ways to share the research, like with the Scottish Government and third sector organizations. You can request a copy of the study summary or access it on our webpage, likely in Summer 2024. Should you wish to receive a copy of the study findings directly, we will ask you to provide an email or postal address for us to send this to. We will delete this information upon sending the summary to you.

**Who's organizing and funding the research?**

The Fetal Alcohol Advisory, Support, and Training team organized this study, sponsored by the University of Edinburgh, and funded by the Scottish Government.

**Who has reviewed the study?**

This project has been approved by the Ethics Review Committee at School of Health in Social Science at the University of Edinburgh.

If you would like further information, please contact the Chief Investigator:

Dr. Stewart McDougall, University of Edinburgh at [smcdouga@ed.ac.uk](mailto:smcdouga@ed.ac.uk)

If you would like to discuss the project with someone independent of the study, please contact:

Dr. Angus MacBeth, University of Edinburgh at [angus.macbeth@ed.ac.uk](mailto:angus.macbeth@ed.ac.uk)

If you would like to make a complaint about the study, please contact:

Professor Matthias Schwannauer at [headofschool.health@ed.ac.uk](mailto:headofschool.health@ed.ac.uk)

**You can also visit the study's webpage here:** (Webpage to be created and form updated accordingly)