

**For subjects located in the EU and United Kingdom:  
Notification for Collection and Use of Personal Data**

This research will collect data that can identify you, referred to as Personal Data. The General Data Protection Regulation (“GDPR”) requires researchers to provide this Notice when we collect and use Personal Data about people who are located in a State that belongs to the European Union or in the European Economic Area. Other countries such as the United Kingdom have adopted similar regulations.

We will obtain and create Personal Data from you so that we can conduct the research study entitled “Feasibility Study of the My Health Coach App for Adults with Fetal Alcohol Spectrum Disorders (FASD)”. The lawful bases upon which we process your Personal Data is that processing is necessary for (i) the purposes of the legitimate interests pursued by the University of Rochester, and (ii) archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes.

The research team will collect and use the following types of Personal Data for this research:

- Name
- Email address
- Phone number
- Mail address
- FASD diagnosis
- Demographics such as age, gender, and country of residence
- Your ratings about your well-being, daily activities, and barriers to healthcare
- Opinions about your experiences using the My Health Coach app on your phone
- Information you enter into the My Health Coach app

The research team will collect this information via (1) survey questionnaires that will be distributed via an email link to the questionnaire in University of Rochester’s REDCap database, (2) an interview over Zoom videochat and (3) the My Health Coach app. The survey information will be stored in the REDCap database on a secure server at the University of Rochester and access will be limited to members of the research team. Zoom recordings will be stored on a secure Box platform which will be accessible only by research study staff. The recordings will be transcribed, and spoken identifiers will be removed, then the video recordings will be destroyed. Information you enter into the My Health Coach app will be stored on an Amazon Web Services (AWS) account through the University of Rochester. The University of Rochester will keep your Personal Data indefinitely after this research ends.

If you have a legal guardian, you should first provide this notice to the guardian before you provide any of the guardian’s information to the research team. The research team will collect from you the name, phone number and email address of the guardian, in order to contact the guardian for permission to include you in the research study.

The following categories of individuals may receive Personal Data collected or created about you or your legal guardian:

- Members of the research team so they can properly conduct the research
- The National Institute on Alcohol Abuse and Alcoholism Database (NIAAA<sub>DA</sub>) at the National Institute of Health (NIH); however the data will be pseudonymized, meaning associated with a GUID rather than direct identifiers, as described in the Information Sheet
- Researchers in the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD); however, the data will be pseudonymized and CIFASD will not have access to any data codes or the key that matches data to your identity

When you submit the questionnaires or provide contact information of your guardian, you are transferring your and the guardian's Personal Data to our research site in the United States. The United States does not have the same laws to protect your Personal Data as States in the EU/EEA and United Kingdom. However, the research team is committed to protecting the confidentiality of your Personal Data via the measures described above and in the Information Sheet for the research study.

You and your legal guardian have the following rights relating to Personal Data:

- Access, correct or delete your Personal Data
- Restrict the types of activities the research team can do with your Personal Data
- Object to using your Personal Data for specific types of activities, or request that the University restrict the processing of your data where one of the reasons identified in GDPR or the UK regulations apply
- File a complaint with the applicable EU or UK supervisory authority

Please note that the research team may need to keep your Personal Data as long as it is necessary to preserve the integrity of the research or to achieve the purpose of this research.

The University of Rochester is responsible for the use of your Personal Data for this research. You can contact the University of Rochester Privacy Officer by first contacting the Principal Investigator Christie Petrenko at 585-275-2991 x 241 or by email at [christie.petrenko@rochester.edu](mailto:christie.petrenko@rochester.edu) if you have:

- Questions about this Notice
- Complaints about the use of your Personal Data, or
- If you want to make a request relating to the rights listed above.