

# Focus Group Consent Form

## Views of Pharmacogenetics Among Alaska Native/American Indian People

Denise Dillard, PhD  
Principal Investigator  
Southcentral Foundation Research Department  
Anchorage, Alaska  
(907) 729-8623

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### **Description of the Study:**

We are asking you to join a study and take part in a focus group. A focus group is an interview where 6 to 8 people are asked questions by an interviewer.

DNA is the blueprint of our body. DNA is grouped into clusters called “genes.” Genes are passed on to us by our parents. Some differences between people happen due to differences in genes. For example, genes affect the hair and eye color we are born with. Some research studies have found differences in response to medications according to differences in genes. Pharmacogenetics is the study of how genes affect responses to medications. This study is being done to find out what some Alaska Native people think about pharmacogenetics. When reporting results we will be respectful in noting your responses do not represent responses from Alaska Native people as a whole. We will not be collecting samples during this focus group. We only want your opinions.

Two tape recorders will be used to make sure we get everything people have said in the focus groups. A second person from the research office will take notes.

This group may take about two hours to complete. You will fill out a brief form about yourself at the end of the group. This form asks for your gender, age, your education level, and whether you have participated in research. This will help us see if men and women or people in different age groups share different thoughts. This information will be kept private and not linked to your identity in any way.

### **Risks:**

You may feel uncomfortable about the topic, questions, or what is said in the group. Please feel free to say “pass” or excuse yourself and talk to a research staff member.

Others in the group might share what you said with others after the group. We will try to make this risk small by asking everyone to agree not to do this. There may also be risks to your confidentiality in certain instances described on page two in the Confidentiality section.

There is also a small chance information about you could be found out by others in Anchorage who are not researchers. Forms and audiotapes will be locked in filing cabinets. You will not write your name on the brief form about yourself. A color will be assigned to you when the audiotapes are typed up. All of these efforts will help protect your privacy.

### **Benefits:**

There are no direct benefits to you from this study. You will receive a gift card worth \$50 for participating.

### **Alternative Treatment:**

If you feel uncomfortable during or after the group, please let one of the research staff know. We can help you or give you names of other people who can help if you are in need.

**Confidentiality**

The group will be recorded on audiotape to make sure we get all of what people say. Nobody except research staff will hear it. The audio will be destroyed after it is no longer needed. A color will be used instead of your name when the audiotapes are translated into writing. We will ask for your verbal consent, so your name will not be linked to your participation. When results are shared, your answers will be joined with answers from others so no one will be able to tell which is yours. Results may be shared in different ways. For example, a summary of what we learn may be presented in the Anchorage Native News. Themes identified from your participation in this study may be seen and used by other researchers in the future. Themes are a way of grouping and summarizing answers in a way that does not identify you as an individual. Whenever results are shared, your answers will not be linked back to you. We will keep all research information in locked file cabinets and in computer files that can be opened only with a password. The audiotapes will be kept for 1 year after the study and all written summaries are completed and then destroyed. Written transcriptions and questionnaires will be kept for 10 years for audit purposes and then destroyed.

What you say in this focus group will be kept confidential except in rare instances required by law.

**Withdrawal Privilege:**

Participation in this study is voluntary and you do not have to join this study. You can refuse to join or stop at any time. You will not lose any rights or benefits which you already have such as your medical benefits.

**Funding:**

This research study is being done by the Research Department at Southcentral Foundation and the University of Washington. It is funded by the National Institute of General Medical Science, a part of the National Institutes of Health.

**Research Participant Rights:**

You have the right to be informed fully by a research staff member about the study and your participation. You have the right to ask questions and know the risks of the study. You have the right to end your participation at any time. You have the right to contact Dr. Denise Dillard if you have other questions or concerns.

The results of this study may be published and shared with others as said above. Your answers will be joined with the answers of others. Your personal information will be kept private unless required by law.

You will keep other people's information from the study private by not talking about what others said. You agree to be audio-taped.

**Questions:**

If you have questions about the study, contact Dr. Denise Dillard, Principal Investigator (907) 729-8518 or 1-800-478-3343. She is available during the hours of 8 AM – 5 PM, Monday through Friday. If you have any questions about your rights as a participant in this research study or if you feel you have been harmed by this study, contact Terry J. M. Powell, Alaska Area Institutional Review Board (907) 729-3924. Leave a message with your name and phone number, and tell them you are calling about study # 2010-05-014 and you will be contacted.

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**Summary Report: (Optional)**

If you would like to receive a report of the findings of this study, please include your name and address below. We will send a summary report to you. This summary report will not identify your participation in the study nor give your individual results.

Would you like to receive this summary report?  yes       no

When giving us your name there is an added risk that others may learn you were a part of this study. We will keep this information locked in a locked filing cabinet in the Research Department and then destroy it after sending the report to you. Mail and email are not secure methods of communication and by receiving this report, others in your household or community may learn you participated in this study.

If you would like to receive a summary report, please complete the following.

Name: \_\_\_\_\_

Preferred contact:  mail       email

Address: \_\_\_\_\_

Email: \_\_\_\_\_