

Views of Pharmacogenetics Among Alaska Native/American Indian People Focus Group Guide

Hi, my name is _____. I will be the one asking you questions today.

Because you may not have been in a focus group before, I want to tell you a little about what to expect. I will be asking all of you some questions about pharmacogenetic testing a type of testing that may help to choose the right medication or dose for a particular person. After I ask these questions, anyone is free to answer. Since part of my role is to make sure everyone has a chance to talk, I may call on you, but I am not trying to embarrass you or make you uncomfortable. You can say “pass” if you do not want to answer a question. I might ask you to talk more about your answers to fully understand your point of view. There are no right or wrong answers to these questions. We expect different points of view so please share your point of view even if it is different from what others have said. It is also okay to follow up on something someone has said if it brings up other thoughts for you or you want to agree or disagree. Please state your color when you start to answer a question. It makes it easier for us to transcribe and also makes it easier for other people in the group to maybe comment on what you’ve said or add to it. Also feel free to get up, get refreshments, or use the restroom if you would like.

Are there any questions about what we are doing?

Opening Question

1. What are some words that come to your mind when you think about genetic tests?

Genetic tests may be used in many different ways. In pharmacogenetics, blood is taken to test for a person’s reaction to medication. The test usually cannot give exact information about how each person will react. But, the test may be able to tell who will probably have a bad reaction to a medication, or when the medication may not help at all. The only thing that is tested is how someone’s genes may affect response to medications – no other genetic tests are done. Here is an example of how a pharmacogenetic test might help treatment for blood clots:

A blood clot can sometimes happen in the leg or other parts of the body. The clot may cause pain and sometimes more serious problems like breathing problems. The usual treatment is a medication that thins the blood, called warfarin. The dose of medicine has to be carefully followed because too little medicine may not get rid of the clot but bleeding may occur with too much medicine. Some people need smaller amounts of medicine than others to get to the right level. A genetic test can help to predict the correct dose or amount and help doctors to ensure that the blood clot goes away without bleeding.

2. What do you think about doctors using tests like this before prescribing a medication like warfarin that thins the blood?

PROBE:

- *What are some of the pros to this kind of test?*
- *What are some of the cons to this kind of test?*
- *What else should we be thinking about when we think about using a test for monitoring a medication like warfarin that thins the blood?*

Here is another example: In this example, a pharmacogenetic test might be used to help treatment for breast cancer. One of the common treatments for breast cancer is a medication called tamoxifen. This medication is usually given after surgery and other treatments to help prevent the breast cancer from coming back. However, the body must process the medication before it can be effective – and some people do not process the medication. For those people, tamoxifen appears not to work, and a different medication is recommended. A genetic test can help figure out which women need a different medication than tamoxifen.

3. What do you think about doctors using tests like this before prescribing a medication like tamoxifen as part of the breast cancer treatment?

PROBE:

- *What are some of the pros to this kind of test?*
- *What are some of the cons to this kind of test?*
- *What else should we be thinking about when we think about using a test to figure out if a medication like tamoxifen is likely to work?*

[The next set of question will choose from one of the following scenarios (quit smoking or depression) or questions about both scenarios may be asked.]

Suppose a genetic test can help to figure out the right kind of treatment to help a smoker quit smoking.

4. Do you think this test should be used for smokers trying to quit?

PROBE:

- *What are some of the pros to this kind of test?*
- *What are some of the cons to this kind of test?*
- *What else should we be thinking about when we think about using a test like this?*
- *What do you think about the development of other genetic tests for the treatment of other types of addiction?*

In another example, a genetic test might help to figure out the right amount of medication to help someone who is clinically depressed. However, the test is new and more study would need to be done to see if it will really help.

5. Do you think this test should be developed for people with clinical depression?

PROBE:

- *What are some of the pros to this kind of test?*
- *What are some of the cons to this kind of test?*
- *What else should we be thinking about when we think about using a test like this?*
- *What do you think about the use of genetic tests with the treatment of mental health/illness, as compared to use with monitoring medication that thins the blood?*

Now I'd like to ask you some questions about research which involves pharmacogenetic tests.

Pharmacogenetic tests need to be researched to make sure they work before they can be used in clinical care. Pharmacogenetic research might involve asking a group of people who are on a certain medication to provide a blood or saliva sample. The sample would be used to look at genes involved in how people react to that medication. Researchers may also collect information

about the use of the medication from each person's medical record – for example, what amount they needed, or whether they had any bad reactions to the medication. Then, the researchers would study whether how people respond to medications are related to their genes.

6. What do you think about researchers collecting blood or saliva from you to look at how genes are involved in reactions to medications, and collecting information from your health records?

PROBE:

- *What are some of the pros to this kind of research?*
- *What are some of the cons to this kind of research?*
- *Anything else we should be thinking about?*

Genetic responses to drugs may differ in different populations. As a result, it may not be possible to develop pharmacogenetic tests for Alaska Native people that work without doing research at places like SCF and ANMC where Alaska Native people receive their health care.

7. What do you think about Alaska Native people participating in these kinds of studies?

PROBE:

- *Are there any differences in your mind, about research involving pharmacogenetic tests vs. other kinds of research that we do at SCF and ANMC?*
 - *(if yes): What are those differences? What is important about them, from your point of view?*

So, we've talked about your thoughts about using genetic tests to improve treatment with medications, and your thoughts about doing research with Alaska Native people to develop these types of tests.

Any other thoughts?

Just to keep you informed of what is going to happen next with this study, we will do additional focus groups among people eligible for care at Southcentral Foundation to get as many points of view as possible. Then we will summarize the range of opinions we hear and these results will be shared with your community through your community leaders and community organizations such as your tribal health organizations. If you would like a summary of the results sent to you personally, remember to write your name and address down on this list.