

Part I. Demographic Questionnaire

Part II. History of Side Effects

Key Definitions:

A **prescribed medication or drug** is a medicine that a doctor must order especially for you.

A **side effect** of a medicine refers to an unintended and undesirable consequence of a **prescribed medication or drug**.

- A mild side effect of a medicine could be feeling tired, dizzy, having an upset stomach, or headache. Sometimes a medicine may cause people to be at risk of having a serious side effect.
- A serious side effect of a medicine could be heart or kidney failure, seizures, or having trouble breathing.

1. Have you ever experienced any type of side effect from a prescribed medication?

Yes No

2. Have any members of your family ever experienced a side effect from a prescribed medication?

Yes No Unsure

3. Have you ever stopped taking a prescribed medication because the side effects were too bad?

Yes No

4. Have any members of your family ever stopped taking a prescribed medication because the side effects were too bad?

Yes No Unsure

5. Have you ever stopped taking a prescribed medication early because it was not treating your condition (based on your decision or your doctor's)?

Yes No

6. Have any members of your family ever stopped taking a prescribed medication early because it was not working (based on their decision or their doctor's)?

Yes No Unsure

Part III. Attitudes toward Pharmacogenetic Testing

[Introduction] Everybody responds to medication differently. For example, a medication may work very well to treat a health problem in some people, but not work very well in other people. In addition, some people may experience a mild or serious side effect from medication when other people do not.

These different responses may be partly due to differences in our genes. Special genetic tests known as “pharmaco-genetic” tests look for changes in our genes (genetic make-up) to predict who is at risk to experience side effects from a certain medication.

These tests may be done on either a blood sample or cells collected from the inside of the cheek with a special brush. These tests will only look at genes related to response to medications, and will NOT look for genes related to disease.

These tests could have several benefits and risks.

Benefits: The test result could help doctors prescribe the most effective and safest medicine to treat your condition.

Risks: Other people may have access to your test result and might take action (discriminate) against you based on that information. For example, your employer or your health insurer may cancel your health insurance or other benefits or raise your premiums.

7. There are many reasons why a person might **choose** to have a pharmaco-genetic test. Below is an example of a reason why some people may choose to have a pharmaco-genetic test. Please mark how important this reason would be to YOU:

Answer Choices for Q7-8: Very Important Reason Somewhat Important Reason
 Unsure Not Very Important Reason Not At All Important Reason

- a.) To help your doctor decide which [medicine] would be the safest and have the smallest risk of side effects for you
- b.) To help your doctor decide which medicine is most likely to treat your illness.
- c.) To help your doctor decide what strength or dose would work best or be safest for you
- d.) To learn if you are at risk for mild side effects such as being tired, feeling dizzy, having an upset stomach or headache
- e.) To learn if you are at risk for serious side effects such as heart or kidney failure, seizures, or having trouble breathing
- f.) If your health insurance would pay for it
- g.) To learn why you or some of your family members do not tolerate or respond to certain medicines
- h.) Your doctor recommends that you have the test
- i) Your or your doctor is interested in trying a new medicine.

8. People may also have concerns about having a pharmaco-genetic test. Below is an example

of a reason why some people may **refuse** to take a pharmaco-genetic test. Please mark how important this reason is to YOU when thinking about whether to have a test:

- a.) Because someone outside of your healthcare team would have access to your DNA
- b.) Because you would be worried that the test result would NOT be kept private and could be shared with others without your permission
- c.) Because you do NOT believe it will help your doctor make better decisions about which specific medicine will work best or be safest for you.
- d.) Because your health insurance will NOT pay for the test
- e.) Because you would be worried that your employer might use the test results against you (for example, you might lose your health insurance or the premiums would go up).
- f.) Because you would be worried that a health insurance company might use the test results against you (for example, cancel your health insurance, deny your access to important health services or increase your insurance payments)
- g.) Because you would have to give a blood sample.

Part IV. Summary and Information-Seeking Behaviors

9. Based on the information you've learned about pharmaco-genetic tests in this survey, how likely would you be to agree to take a pharmaco-genetic test?

Very Likely Somewhat Likely Unsure Not Very Likely Not At All Likely

[If respondents answer Unsure, Not Very Likely, or Not at all Likely, please go on to question 9b.]

9b. Based on the information you've learned about pharmaco-genetic tests in this survey, would you be more likely to have a test that could get the same/similar results if it did NOT look at your genes?

Very Likely Somewhat Likely Unsure Not Very Likely Not At All Likely

10. Would you like to learn more about pharmaco-genetics?

Yes No

[If answered No, end of survey. If yes, go on to #11]

11. Several health information sources are listed below. Please mark the two sources you are most likely to use when you want to learn more about a health concern or medical question.

- Medical Doctor, Physician Assistant or Nurse Practitioner
- Nurse
- Pharmacist
- Social Worker
- Family Member
- Friend or Co-Worker
- Public health brochure
- Internet
- Library
- Television

12. Please mark the two sources you are most likely to use when you want to learn more about pharmaco-genetic testing.

- Medical Doctor, Physician Assistant or Nurse Practitioner
- Nurse
- Pharmacist
- Social Worker
- Family Member
- Friend or Co-Worker
- Public health brochure
- Internet
- Library
- Television