

Supplementary materials:

Supplementary mat 1: Research Survey

Supplementary mat 2: Tables on Questions/Responses

Pharmacogenetics is the study of how genetic variants may determine the way our body processes certain medications. Pharmacogenetic (PGx) testing looks at these variants to try to determine which medication a patient should take and at what dosage. The goal of PGx testing is to not only increase the effectiveness of a medication, but to decrease the rate of side effects that people may experience.

Abacavir is a medication that is used in the treatment of human immunodeficiency virus (HIV). Those with certain genetic variants who are taking this medication are at an increased risk to develop severe side effects in their first days to weeks of exposure. It is recommended that those who are “positive” for this genetic variant discontinue their use of Abacavir and switch to a different antiretroviral medication.

Below are some examples of PGx test results which we will ask you to interpret.

A doctor ordered PGx testing for the drug Abacavir for a patient. The testing results are below. Based on the test report, answer the following questions to the best of your ability.

Therapeutic	Drug Category	Drug Name	Clinical Interpretation	Gene/
Infectious Diseases	Antiretroviral Drug	Abacavir	Significantly increased risk of Abacavir side effect	"Positive" HLA-B*57

Q1 The patient is at an increased risk to develop a severe side effect from this drug

- True
- False

Q2 The patient is at a decreased risk to develop a severe side effect from this drug

- True
- False

Q3 The patient should share these results with their doctor

- True
- False

Q4 The patient should immediately choose to stop taking this drug before talking to their doctor

True

False

Q5 Their doctor will give them an increased dosing of Abacavir

True

False

Q6 Their doctor will choose to put them on a different drug

True

False

Q7 These results will not affect their continuation of Abacavir

True

False

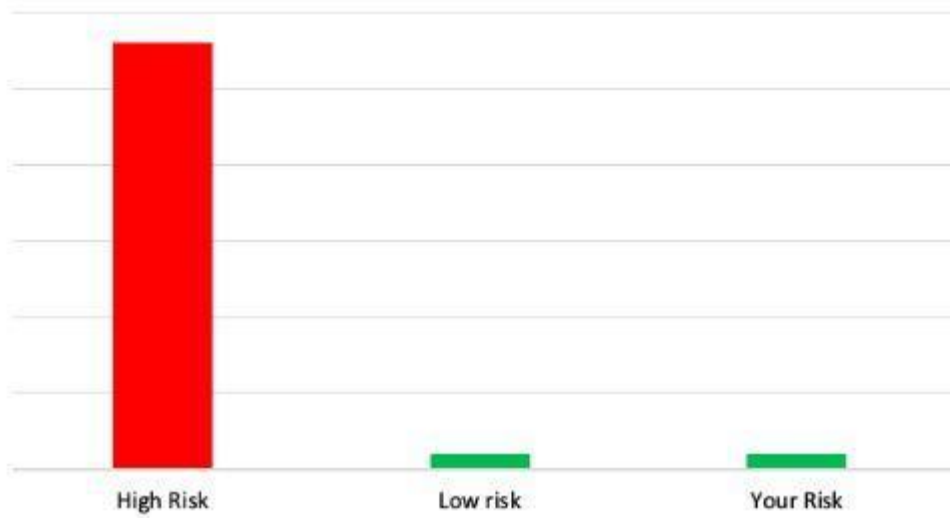
Q8 They should request to be put on a different antiretroviral medication

True

False

Suppose another person decided to get Abacavir PGx testing through a different company. Below are their results:

Risk of developing a severe side effect from Abacavir



Q9 The patient is at a low risk to develop a severe side effect from this drug

- True
- False

Q10 The patient is at a high risk to develop a severe side effect from this drug

- True
- False

Q11 The patient should immediately choose to stop taking this drug before talking to their doctor

- True
- False

Q12 Their doctor will give them a decreased dosing of Abacavir

- True

False

Q13 Their doctor will choose to put them on a different drug

True

False

Q14 These results will not affect their continuation of Abacavir

True

False

Q15 The patient should request to be put on a different antiretroviral medication

True

False

Q16 Which test results were easier to understand?

1st (table)

2nd (graph)

Same

Q17 Why?

The next set of questions will ask your thoughts on PGx testing.

Q18 I believe PGx testing could help decrease bad side effects of certain drugs

Agree

- Neutral
- Disagree

Q19 PGx testing will help my doctor determine the right medication dose for me.

- Agree
- Neutral
- Disagree

Q20 PGx testing will help improve how well my medication works for me.

- Agree
- Neutral
- Disagree

Q21 I would feel comfortable with my doctor using PGx information to choose which medication I take.

- Agree
- Neutral
- Disagree

Q22 I am concerned that PGx test results could be accessed by unauthorized persons.

- Agree
- Neutral
- Disagree

Q23 I am concerned that insurance companies may use PGx test results to discriminate against me/deny me coverage.

- Agree
- Neutral
- Disagree

Q24 I am concerned about submitting a DNA sample in order to analyze my PGx profile.

- Agree
- Neutral
- Disagree

Q25 Subtle differences in a person's genetic makeup can have major impact on how a person responds to certain medications.

- True
- False

Q26 Genetic determinants of medication response change over a person's lifetime.

- True
- False

Q27 Genetic variations can account for as much as 95% of the variability in a drug disposition and effects.

- True
- False

Direct to consumer testing (DTC; also called at-home genetic testing or home DNA testing) can be done without a healthcare provider. These tests are marketed directly to consumers and

can be bought online or in stores. Customers send in a DNA sample to the company and receive results directly—not through a healthcare provider. These DTC tests can provide information about health, common traits, or ancestry.

Q28 Have you ever heard of direct to consumer genetic testing?

- Yes
- No

Q29 How familiar are you with direct to consumer testing (1=very unfamiliar, 5=very familiar)

- 1
- 2
- 3
- 4
- 5

Q30 Have you ever sent a sample to a direct to consumer company like ancestry.com, 23andMe, etc?

- Yes
- No

The next set of questions will evaluate your personal experience with genetics.

Q31 Have you ever seen a genetic counselor?

- Yes
- No

Display This Question:

If Have you ever seen a genetic counselor? = Yes

Q32 Was the counseling for you or a family member?

- Me
- Family member

Display This Question:

If Have you ever seen a genetic counselor? = Yes

Q33 Was genetic testing done?

- Yes
- No

Display This Question:

If Was genetic testing done? = Yes

Q34 How many years ago?

Display This Question:

If Was genetic testing done? = Yes

Q35 Approximately how old were you?

- <10 years of age
- 11-18 years of age
- 19-40 years of age
- 40-60 years of age
- 61 and older

Display This Question:

If Was genetic testing done? = Yes

Q36 What setting was the testing done in?

- Cancer
- Pediatric
- Prenatal
- Cardiovascular
- Neurology
- Other

Display This Question:

If Was genetic testing done? = Yes

Q37 Was the genetic testing done through a healthcare provider, or DTC testing?

- Healthcare provider
- DTC testing
- Other

The next set of questions are to assess what you know about genetics. Do not worry if you do not know an answer. All questions are True, False, or I don't know

Q38 Some diseases are caused by genes, environment, and lifestyle

- True
- False
- I don't know

Q39 A gene is a disease

- True
- False
- I don't know

Q40 You can see a gene with the naked eye

- True
- False
- I don't know

Q41 Healthy parents can have a child with an inherited disease

- True
- False
- I don't know

Q42 A person with an altered (mutated) gene may be completely healthy

- True
- False
- I don't know

Q43 All serious diseases are inherited

- True
- False
- I don't know

Q44 Genes are instruction for making proteins, which help the body grow and work properly

- True
- False
- I don't know

Q45 The child of a person with an inherited disease will always have the same disease

- True
- False
- I don't know

Q46 A gene is a piece of DNA

- True
- False
- I don't know

Q47 Altered (mutated) genes can cause disease

- True
- False
- I don't know

Q48 Genes are inside of cells

- True
- False
- I don't know

Q49 A chromosome contains many genes

- True
- False
- I don't know

Q50 Genes determine traits such as hair, eye color, and facial appearance

- True
- False
- I don't know

Q51 A person has thousands of genes

- True
- False
- I don't know

Q52 Identical twins have different sets of genes

- True
- False
- I don't know

Q53 Humans have 20 pairs of chromosomes

- True
- False
- I don't know

Q54 Parents pass both copies of each chromosome to their child

- True
- False
- I don't know

Q55 A genetic test can tell you if you have a higher chance to develop a specific disease

- True
- False
- I don't know

Please do not use a calculator or look up answers for any of these questions. We are interested in what you think.

Q56 Imagine that we roll a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up as an even number?

Q57 In the BIG BUCKS LOTTERY, the chances of winning a \$10.00 prize are 1%. What is your best guess about how many people would win a \$10.00 prize if 1,000 people each buy a single ticket from BIG BUCKS?

Q58 In the ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1,000. What percent of tickets of ACME PUBLISHING SWEEPSTAKES win a car?

Q59 If the chance of getting a disease is 10%, how many people would be expected to get the disease out of 1000?

Q60 If the chance of getting a disease is 20 out of 100, this would be the same as having a ___% chance of getting the disease.

Q61 Suppose you have a close friend who has a lump in her breast and must have a mammogram. Of 100 women like her, 10 of them actually have a malignant tumor and 90 of them do not. Of the 10 women who actually have a tumor, the mammogram indicates correctly that 9 of them have a tumor and indicates incorrectly that 1 of them does not have a tumor. Of the 90 women who do not have a tumor, the mammogram indicates correctly that 80 of them do not have a tumor and indicates incorrectly that 10 of them do have a tumor. The table below summarizes all of this information. Imagine that your friend tests positive (as if she had a tumor), what is the likelihood that she actually has a tumor?

	Tested positive	Tested negative	Totals
Actually has a tumor	9	1	10
Does not have a tumor	10	80	90
Totals	19	81	100

Answer: ___ out of ___

Q62 A bat and a ball cost \$1.10 in total. The bat costs \$1.00 more than the ball. How much does the ball cost?

Q63 In a lake, there is a patch of lily pads. Every day, the patch doubles in size. If it takes 48 days for the patch to cover the entire lake, how long would it take for the patch to cover half of the lake?

Q64 If John can drink one barrel of water in 6 days, and Mary can drink one barrel of water in 12 days, how long would it take them to drink one barrel of water together?

Q65 Jerry received both the 15th highest and the 15th lowest mark in the class. How many students are in the class?

The next section will ask questions about your background.

Q66 Gender

- Male
- Female
- Other

Q67 What is your current age?

- 18-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70+
- Prefer not to answer

Q68 What was your highest level of education?

- Less than high school
- High school graduate
- Some college
- Bachelor's
- Master's
- Professional/Doctorate
- Prefer not to answer

Q69 What race/ethnicity do you identify with?

- Caucasian
- African American/Black
- Asian
- Hispanic/Latino

- Other
- Prefer not to answer

Q70 Did you receive education (past high school) in the healthcare or biological sciences fields?

- Yes
- No

Q71 Do you currently work in the healthcare field?

- Yes
- No

Display This Question:

If Do you currently work in the healthcare field? = Yes

Q72 If yes, for how many years?

- 0-10 years
- 11-20 years
- 20+ years
- Prefer not to answer

Display This Question:

If Do you currently work in the healthcare field? = No

Q73 If no, have you previously worked in the healthcare field?

- Yes
- No

Display This Question:

If no, have you previously worked in the healthcare field? = Yes

Q74 If yes, for how many years?

- 0-10 years
- 11-20 years
- 20+ years
- Prefer not to answer

Q75 If you would like to enter the optional raffle for one of five \$20 Amazon gift cards, please enter your email below:

Supplementary Table 1: List of questions for table representation of test report and number and percentage of participants who answered questions correctly

	Question	n (%)
Question 1	The patient is at an increased risk to develop a severe side effect from this drug	286 (97.6)
Question 2	The patient is at a decreased risk to develop a severe side effect from this drug	288 (98.3)
Question 3	The patient should share these results with their doctor	290 (99.0)
Question 4	The patient should immediately choose to stop taking this drug before talking to their doctor	221 (75.4)
Question 5	Their doctor will give them an increased dosing of Abacavir	289 (98.6)
Question 6	Their doctor will choose to put them on a different drug	272 (92.8)
Question 7	These results will not affect their continuation of Abacavir	278 (94.9)
Question 8	They should request to be put on a different antiretroviral medication	274 (93.5)

n, number correctly answering question; %, percent

Supplemental Table 2: List of questions for graph representation of test report and number and percentage of participants who answered questions correctly

	Question	n (%)
Question 1	The patient is at a low risk to develop a severe side effect from this drug	212 (72.4)
Question 2	The patient is at a high risk to develop a severe side effect from this drug	209 (71.3)
Question 3	The patient should immediately choose to stop taking this drug before talking to their doctor	260 (88.7)
Question 4	Their doctor will give them an increased dosing of Abacavir	252 (86.0)
Question 5	Their doctor will choose to put them on a different drug	210 (71.7)
Question 6	These results will not affect their continuation of Abacavir	183 (62.5)
Question 7	The patient should request to be put on a different antiretroviral medication	205 (70.0)

n, number correctly answering question, %, percent