

Veterans Health Care Survey Main
April 2008
Questionnaire

ASSESSING VETERANS' ATTITUDES ABOUT THE GENOMIC MEDICINE PROGRAM

[SCREENING QUESTION]

S1

Have you ever received health or psychological care through the Department of Veterans Affairs (VA)?

- Yes
- No [end survey]

[END SURVEY SCREEN] We appreciate your response. We are seeking to understand the opinions of veterans who receive health care through the VA. Thank you for your time.

[DISPLAY]

Thank you for agreeing to take this survey. The survey is being done by the Genetics and Public Policy Center at Johns Hopkins University. Funding for the survey comes from the Department of Veterans Affairs (VA). The purpose of the survey is to collect opinions from veterans who get health care through the VA about a research project being considered by the VA.

All of the answers you provide in this survey will be kept confidential. No identifying information will be provided to the Genetics and Public Policy Center or the VA. The survey data will be reported in a summary fashion only and will not identify any individual person.

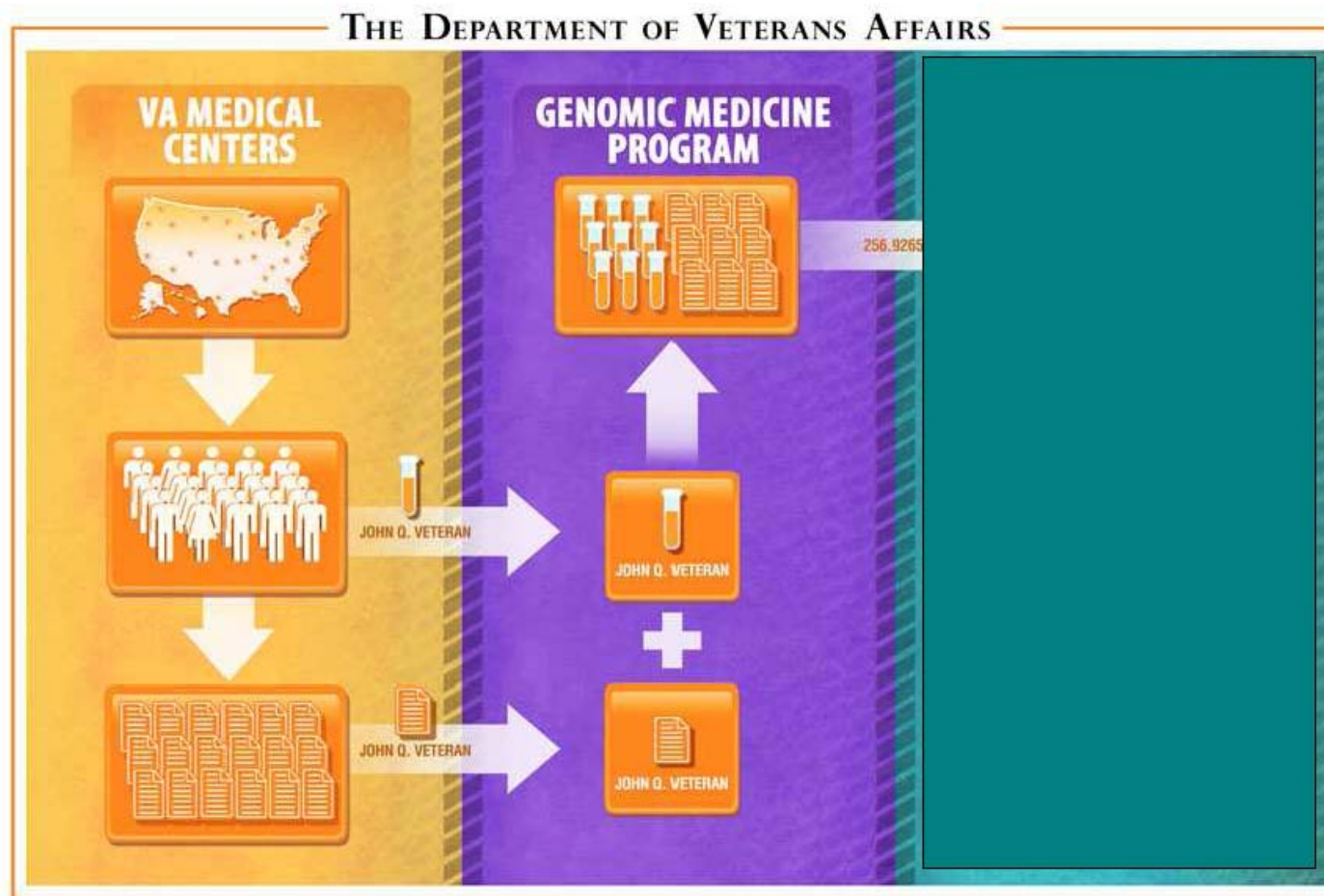
This survey will take about 20 minutes to complete.

[DISPLAY]

The Genomic Medicine Program

Many diseases result from a mix of genetics, environment, and lifestyle. To figure out how genes, environment, and lifestyle interact to cause disease, a large number of people need to be studied. The VA would like to do this kind of research and is considering a project called the Genomic Medicine Program. This program would involve developing a database of blood samples, genetic information, and medical information of veterans who get health care through the VA. This database would be used by VA researchers to better understand diseases and disorders affecting veterans.

[DISPLAY] SHOW THE SCHEMA



How the Genomic Medicine Program would work:

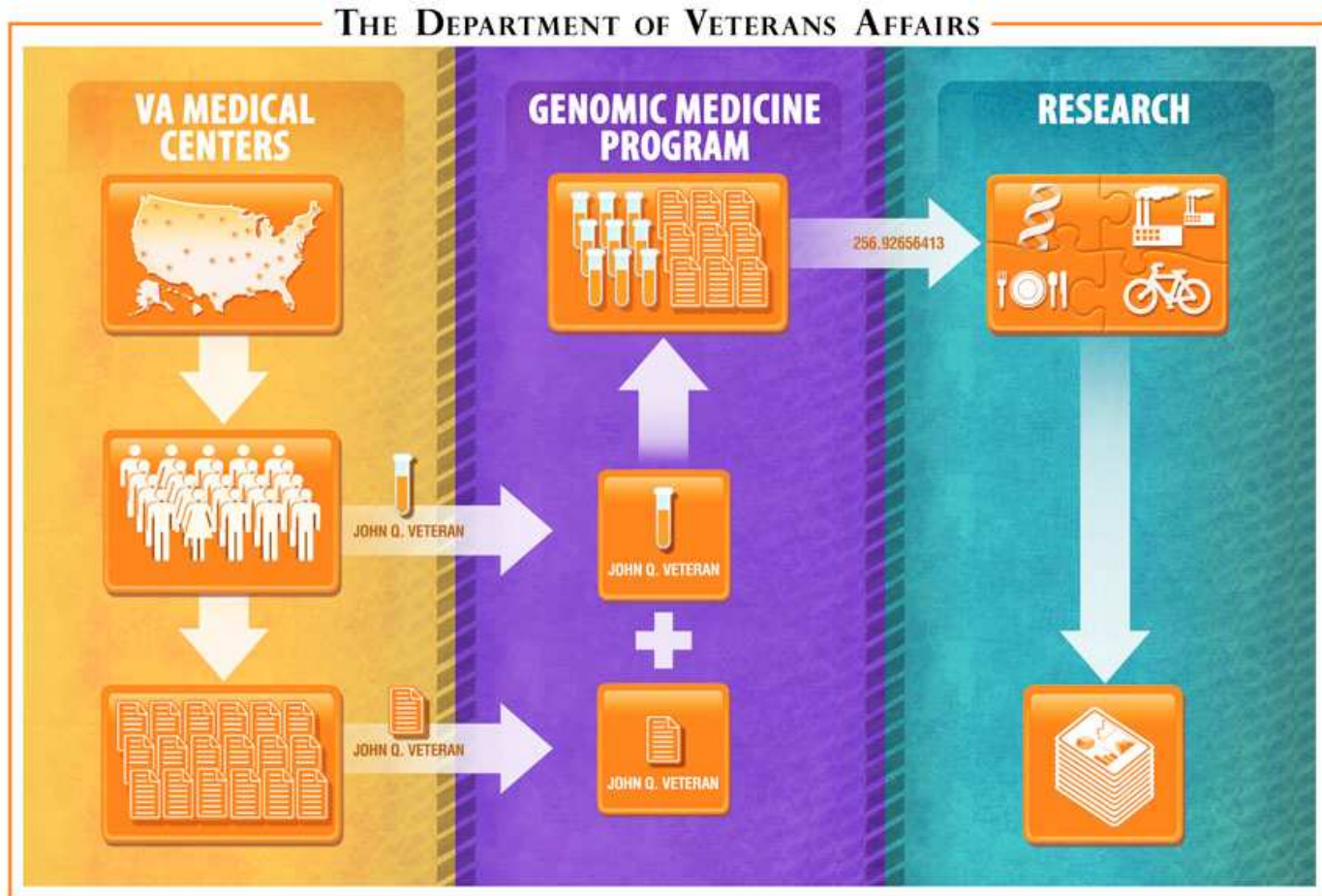
Step One: Who Would Participate Veterans from all over the country who receive health care through the VA would be invited to participate. Participating would be completely voluntary. Whether a person agreed to participate or not would not affect his or her health care in the VA. If an individual agreed to participate, he or she would sign a consent form.

Step Two: What Participation Would Involve After signing the consent form, a blood sample would be collected. Some of the sample would be sent to a research lab at the VA for genetic testing. The rest of the sample would be stored for

future research. The results of the genetic testing would go into a database along with information from that person’s VA medical record. If a person decided at a later time that they no longer wanted to have their genetic and medical information in the database, they could have them removed.

[INSERT LINKS THROUGHOUT SURVEY TO BELOW IMAGE WHERE NOTED AS “(INSERT LINK TO IMAGE)”]

[DISPLAY] SHOW THE SCHEMA



Step Three: Research Using the Genomic Medicine Database The goal is to have a research database at the VA that contains the genetic and medical information of hundreds of thousands of veterans. Researchers who are interested in studying disorders that affect veterans could apply to use the information in the database. The genetic and medical information would be coded so researchers would not be able to identify individual participants. Researchers would publish findings from their research in medical journals.

NOTE: FOR ALL FOLLOWING QUESTIONS, PLEASE LINK “THIS PROGRAM”, “THE PROGRAM”, “THE GENOMIC MEDICINE PROGRAM”, AND “THE GENOMIC MEDICINE PROGRAM” TO AN HTML PAGE SHOWING THE TEXT ABOVE.

Q1 Based on what you've just learned, do you think the Genomic Medicine Program should be done?

- Definitely yes
- Probably yes
- Probably no
- Definitely no

Q2 When thinking about the Genomic Medicine Program, do you agree or disagree with the following statements?

	Strongly agree	Agree	Disagree	Strongly disagree
--	----------------	-------	----------	-------------------

[RANDOMIZE LIST]

- A research database of genetic and medical information on veterans would lead to improved treatments, cures, or lives saved for veterans.
- I think the program is important to do.
- I suspect that the VA is secretly doing this research already.
- I worry the program would take dollars away from other health care provided at the VA.
- I worry the program would not be able to recruit participants from all segments of the VA population.

[DISPLAY] Assume you were asked to participate in the Genomic Medicine Program. For the next several questions, please answer as if you were thinking about participating.

Q3. When thinking about participating in the program, do you agree or disagree with the following statements?

Strongly agree	Agree	Disagree	Strongly disagree	
----------------	-------	----------	-------------------	--

[RANDOMIZE LIST]

- Participating would make me feel like I was helping veterans.
- Participating in the program would be easy.
- I am curious about the influence of genes on health.
- I would be concerned that information from the program could be used against me.
- Participating in the program would make me feel like a guinea pig.
- I would be concerned about the government having my samples and information.

Q4 In deciding whether or not to participate, how important would the following be to you?

	Very important	Somewhat important	Not very important	Not important at all
--	----------------	--------------------	--------------------	----------------------

[RANDOMIZE LIST]

- Monetary compensation for my time **[IF (1-3) SHOW Q5, ELSE Q6]**
- Receiving information about my health
- Knowing what kind of research is being done using the database
- Knowing who to go to with a question or complaint
- Having my privacy protected
- Having a mechanism to change my mind and withdraw my sample and information at a later time

Q5 What is the lowest amount you would require to participate?

- \$0
- \$1-50
- \$51-100
- \$101-250
- \$251-500
- More than \$500

Q6 Participants in the program [insert link to program] would be asked to give a blood sample for genetic research and give permission for their medical records to be put into the database. Assume you agreed to participate. Would you be willing to do the following additional activities?

	Definitely	Probably	Probably not	Definitely not
--	------------	----------	--------------	----------------

[RANDOMIZE ORDER OF SECOND SIX RESPONSES]

- Spend a half-day at a VA facility near you to get a physical examination
- Have follow-up exams over time **[THIS RESPONSE ALWAYS FOLLOWS THE PREVIOUS]**

- Get X-rays
- Agree to have medical records from the health care you get outside of the VA added to the database
- Answer detailed questions about your psychological and emotional health
- Wear an environmental monitoring device such as a pedometer for a week
- Have researchers come to your home to collect information, such as environmental samples
- Keep a diet and exercise journal for one week
- Be contacted by either phone or e-mail periodically to find out about your current health

[Q7 INTRO] HYPERLINK REFERENCES TO LINKING OR A KEY TO THIS SCREEN

When a participant's sample and their genetic and medical information go into the Genomic Medicine Program database, his or her name would be removed and replaced with a number. Researchers using the database would only see the number and would not be able to identify the participant. However, a key could be kept in a secure place linking the name and number. This would allow the participant to be identified and contacted if needed, and would allow new information from a participant's medical record to be added to the database.

Another option is not to keep a key linking the participant's name to their number. In this case the participant could not be identified or contacted. The participant could not be given information about their individual samples, and new medical information from their medical records could not be added to the database.

The next question relates to whether or not a key should be kept linking a participant's name and number.

Q7 Should a key kept linking the participant's name to their number?

- Yes
- No

Q8. Assume you had agreed to participate. Is there information from VA medical records that you think should NOT be included in the Genomic Medicine Program database?

[RANDOMIZE LIST]

- HIV infection or AIDS diagnosis
- Mental illness information
- Cancer diagnosis
- Diagnosis of posttraumatic stress disorder (PTSD)
- Reproductive history
- Sexual behavior
- Social security number
- Sexual trauma
- Drug and alcohol history
- None of the above

NOTE: PLEASE LINK “INDIVIDUAL RESEARCH RESULTS” TO AN HTML SCREEN WITH THE FOLLOWING TEXT.

[DISPLAY]

Individual Research Results

Researchers studying all of the samples and information together may find that a certain genetic, environmental, or lifestyle factor is related to a specific disease. This kind of general study finding would be published in a medical journal.

An individual participant's research result would be the information about whether that person had the specific genetic, environmental, or lifestyle risk factor. Individual research results are generally not returned to research participants, unless the research is conducted in a laboratory certified to give medical results.

Q9 Assume you had agreed to participate and the research is **not** conducted in a certified laboratory so individual research results will **not** be returned to participants. Would you be more or less likely to participate in the Genomic Medicine Program?

- I would be less likely to participate
- It would not make a difference to me
- I would be more likely to participate

Q10 Assume you had agreed to participate, and that the research is done in a certified laboratory. In thinking about individual research results, which would you prefer?

[RANDOMIZE LIST, SELECT ONE]

- I would want to know all of my individual research results.
- I would want to choose which individual research results I would get back.
- I would not want any of my individual research results.
- I do not care if I get any individual research results.

[DISPLAY] If you decided to participate in the Genomic Medicine Program, you would be asked to sign a consent form. Part of the consent form would describe how your samples and information would be used.

Q11 In thinking about the consent you would give, would you prefer to:

- Give your permission at the beginning of the study for all approved research projects
- Select categories of research (for example, cancer or diabetes) up front that you would or would not want your samples and information used for
- Be asked for permission to use your samples and information for each research project as it comes up

Q12 Do you think the following types of researchers outside of the VA should be able to use the Genomic Medicine Program database and samples?

Yes	No	
-----	----	--

[RANDOMIZE LIST]

- Researchers in other health-related government agencies
- Researchers in academic or medical centers in the United States
- Researchers in U.S. pharmaceutical companies
- Researchers in academic or medical centers in other countries

Q13 In thinking about all of the types of research that could be done, do you think research on the following should be allowed or prohibited?

	Definitely allowed	Probably Allowed	Probably Prohibited	Definitely Prohibited
--	--------------------	------------------	---------------------	-----------------------

[RANDOMIZE LIST]

- Cancer
- Mental illness
- Alcoholism and drug addiction
- Stem cell research
- Cloning
- Athletic ability
- Posttraumatic stress disorder (PTSD)
- Susceptibility to an environmental exposure

Q14 If you were a participant, how important would the following be to you?

	Very important	Somewhat important	Not very important	Not important at all
--	----------------	--------------------	--------------------	----------------------

[RANDOMIZE LIST]

- It would be illegal for insurers and employers to get my information.
- It would be illegal for law enforcement to get my information.
- There would be serious consequences for researchers who violate my research agreement.
- There would be a research agreement signed by researchers and participants.
- VA would develop appropriate safeguards to protect information from misuse and disclosure

Q15 Now that you've had a chance to think more about the Genomic Medicine Program, do you think it should be done?

- Definitely yes
- Probably yes
- Probably no
- Definitely no

Q16 Based on what you know today, would you participate in the Genomic Medicine Program if you were asked?

- Definitely yes
- Probably yes
- Probably no
- Definitely no

[DISPLAY]

The next questions ask about how information from genomic research might be used.

Q17

Imagine that research finds a genetic variant that increases a person’s risk of developing a particular disease in the future. A person has a genetic test and finds out that they have this variant. Do you agree or disagree with the following statements?

	Strongly Agree	Agree	Disagree	Strongly Disagree
--	----------------	-------	----------	-------------------

[RANDOMIZE LIST]

- The VA should be allowed to use this information to determine if a veteran gets particular health care benefits or not.
- The VA should be allowed to use this information to determine if a veteran gets particular disability benefits or not.
- It is important to use genetic information about a person to contain health care costs.

[DISPLAY]

Lastly, we would like to ask a few questions about you, your service in the military, your health and the health care services you receive through the VA.

Q18

Please indicate each of the eras in which you served.

- World War II
- Between WWII and the Korean Conflict
- During the Korean Conflict
- Between the Korean Conflict and the Vietnam Era
- During the Vietnam Era
- Between Vietnam Era and the Gulf War
- During the Gulf War
- Between the Gulf War and Operation Enduring Freedom/Operation Iraqi Freedom
- During Operation Enduring Freedom/Operation Iraqi Freedom

Q19

In total, how many years did you serve on active duty?

Q20

Please tell us about your military experience.

		Yes	No	
--	--	-----	----	--

- Did you ever serve in a combat or war zone?
- Do you believe you were ever exposed to environmental hazards such as Agent Orange, chemical warfare agents, ionizing radiation, or other potentially toxic substances?

Q21

Do you belong to a Veteran Service Organization (VSO)? (For example, Veterans of Foreign Wars, Disabled Veterans of America)

- Yes
- No

Q22

Do you have a service-connected medical condition?

- Yes
- No
- Don't know

[IF "YES" IN Q22 SHOW Q23]

Q23

What is your service-connected rating?

- 50% or higher
- 30-40%
- 10-20%
- 0%
- Don't know

Q24 Not counting prescriptions, about how much of your health care do you currently get through the VA?

- Less than a quarter
- Between a quarter and a half
- More than half, but not all
- I get all of my health care through the VA

Q25

Do you agree or disagree with the following statement:

I am satisfied with the health care that I receive through the VA.

- Strongly agree
- Agree
- Disagree
- Strongly Disagree

Q26 Have you donated blood in the past five years?

- Yes
- No
- I cannot donate blood

Q27

Please answer the following questions.

[RANDOMIZE LIST]

- Have you ever volunteered for a project or activity that benefits veterans?
- Are you registered as an organ donor?
- Have you ever participated in medical research or a clinical trial?

	Yes	No	Not Sure	
--	-----	----	----------	--

[Display]

Thank you very much for taking the time to complete our survey. Your participation will help us to understand the attitudes and opinions of veterans regarding the proposed Genomic Medicine Program **[INSERT LINK TO IMAGE]**.