

# Patient/Consumer Experience and Interest in Research

You have been selected to complete this research survey regarding your preferences, perspectives and willingness to participate in research. We are conducting this survey from the Vanderbilt University Medical Center to help us understand patient and consumer perspectives on participating in research.

The benefit of completing this survey is to inform researchs of patient and consumer perspectives on research and help identify approaches to research that are important to patients and consumers.

Your participation is strictly voluntary, and your individual responses will be kept anonymous. There is minimal risk, and refusing to participate will not impact your health care or opportunity to participate in future research. The survey will take about 15 minutes to complete.

All participants who complete the survey will receive \$10 for their time and participation. Thank you!

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Please read the above statement.

I have read and understand the above statement, and I am aware that my participation is voluntary and anonymous.

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E-mail. Please include your email address so that you may be contacted to receive your compensation. Your responses will not be identified to your email address.

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**The first set of questions tells us about you and your background.**

What is your year of birth?

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What is your race or ethnicity? (Check all that apply).

- Asian (i.e. Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Hmong, Laotian, Thai, Pakistani, Cambodian, etc.)
- Black, African American, African, or Afro-Caribbean (i.e. African American, Haitian, Nigerian, etc.)
- Hispanic, Latino, or Spanish origin (i.e. Mexican, Mexican American, Puerto Rican, Cuban, Argentinian, Colombian, Dominican, Nicaraguan, Salvadorian, Spaniard, etc.)
- Middle Eastern/North African
- Native American, American Indian, or Alaskan Native (i.e. Navajo, Mayan, Tingt, etc.)
- Native Hawaiian, Guamanian or Chamorro, Samoan, Fijian, Tongan, etc.)
- White (i.e. German, Irish, Lebanese, Egyptian, etc.)
- Some other race or origin (please specify)
- Prefer not to answer

Other, please specify:

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What is your sex?

- Male
- Female
- Other
- Prefer not to answer

If other, please specify:

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What is your marital status?

- Now married
- Living with a partner or significant other
- Widowed
- Divorced
- Separated
- Never married
- Prefer not to answer

What is the highest degree or level of school you have completed?

- 8th grade or less
- Some high school, but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- College graduate
- More than a college degree
- Prefer not to answer

Are you currently:

- Employed Full Time (32+ hours per week)
- Employed Part Time (less than 32 hours per week)
- Unemployed
- Volunteer
- Stay-at-home parent
- Retired
- Receiving disability
- Other

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If other, please describe:

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How many people live in your home (including yourself)?

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Have you visited your doctor in the past year?

- Yes  
 No

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If yes, please select the clinic(s).

- Vanderbilt University Medical Center  
 Vanderbilt University Children's Hospital  
 Vanderbilt University Stallworth Rehabilitation Hospital  
 Vanderbilt University Psychiatric Hospital  
 Vanderbilt University Outpatient Practices  
 Meharry/Metro General Hospital  
 Matthew Walker Community Health Center  
 Prefer not to answer  
 Other

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If other, please list:

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Do you have a cell phone?

- Yes  
 No

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How often do you text?

- Not at all  
 Not often  
 Somewhat often  
 Often  
 Very often

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Can you access the internet using your phone?

- Yes  
 No

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Do you have access to the internet at home?

- Yes  
 No

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How confident are you using computers?

- Very confident  
 Confident  
 Fairly confident  
 Not confident  
 Prefer not to say

**Many patients have trouble understanding the medical information they get at the hospital or doctor's office.**

How confident are you filling out medical forms by yourself?

- Extremely
- Quite a bit
- Somewhat
- A little bit
- Not at all

How often do you have someone help you read hospital materials?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

How often do you have problems learning about your medical conditions because of difficulty understanding written information?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

**The next few questions ask about your experience and feelings about working with numbers. For each of the following questions, please check the box that best reflects your answer.**

	Not at all good/ Not at all often	Pretty good / Somewhat often	Good / Often	Very good / Very often	Extremely good/ Extremely often
How good are you at working with fractions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How good are you at figuring out how much a shirt will cost if it is 25% off?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you find numerical information to be useful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**How familiar are you with the following words or phrases?**

	Not at All Familiar	Slightly Familiar	Somewhat Familiar	Moderately Familiar	Extremely Familiar
Genetic Testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Biological Indicators/Biomarkers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Precision Medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pharmacogenetics	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Some new approaches to preventing and treating health conditions will take into account people's individual variations in genes, environment, and lifestyle.**

**To help guide future research and healthcare, how important are the following to you?**

	Not at all Important	Slightly Important	Somewhat Important	Moderately Important	Extremely Important
My healthcare is specific to me. No two cases are the same.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My genes can be used to determine the best treatment for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My genes and other health information can be used to help prevent or treat health conditions in my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health information is kept private and secure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have access to my own health records and can decide which health care providers and researchers have access to them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can add information about my health to my health records	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you have or have you ever had any of the following long-term health conditions? (Please check all that apply).

- No health conditions
- High blood pressure
- Heart disease
- Heart attack
- Overweight or obese
- Diabetes
- Asthma
- Sickle Cell Disease
- Other
- Prefer not to say

If other, please specify: \_\_\_\_\_

Household Income (Optional)

- Less than \$10,000
- \$10,000 - \$14,999
- \$15,000 - \$24,999
- \$25,000 - \$34,999
- \$35,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 - \$99,999
- \$100,000 - \$149,999
- \$150,000 or more

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Health Insurance Category (Optional)

- Insured
- Uninsured (No Insurance)
- Medicaid (TennCare)
- Medicare
- Self Pay
- Other

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If other, please specify:

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**The next set of questions tells us about your experience with research (if any).**

Prior to today, have you ever been asked to participate in research?

- Yes  
 No

Prior to today, have you ever participated in health-related research?

- Yes  
 No

If yes, how would you describe the research? (select all that apply)

- A study comparing treatments or prevention methods (clinical trial)  
 Testing to determine if you are high-risk for a certain disease  
 Testing to determine if a condition has been passed down in your family (inherited)  
 In-person focus group, facilitated discussion or survey of attitudes, beliefs or behaviors  
 An online questionnaire or survey of attitudes, beliefs or behaviors  
 Blood, tissue or other body fluid was collected for use in any current or future research  
 Other

Other, please describe.

In general, what would be the preferred contact methods to learn about potential research studies? Select all that apply. (This is to help us gauge most appropriate methods; you will not be contacted based on your answers to this question).

- E-mail  
 Cell phone text messaging  
 Social media (such as Facebook or Twitter)  
 Letter or postcard in the mail  
 A computer-created phone message  
 Personal phone call from research staff or my doctor  
 Talking face-to-face with research staff or my doctor when I am visiting the clinic  
 Other  
 I am not interested in being contacted about future research studies

Other, please specify.

**If a research was studying a condition or health problem that you care about, would you participate if it required ...**

**(Please pick your level of interest by checking one of the options for each line below.)**

	Not interested	Somewhat interested	Very interested
Completing a survey two or more times	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Giving a blood sample	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in a study that involves talking by phone or over the internet (for example, to get advice about your health)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in a study in which you have to take a medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in a study that involves meeting at a local community center or school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in a study that involves you and other people in your family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking part in a study in which you would stay in the hospital for one or more days	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What sources do you most often use to find information about health or medical topics? Check all that apply.

- Family
- Friend/Co-worker
- Doctor of other healthcare provider
- Internet
- Radio, newspaper or magazines
- Telephone information number of disease-focused group such as the American Cancer Society or the American Heart Association
- Complementary, alternative or unconventional practitioner
- Other
- I have never looked for information about health or medical topics

Other, please describe \_\_\_\_\_

**In general, how much do you TRUST information about health or medical topics from each of the following?**

	Not at all	A little	Some	A lot
Doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other healthcare provider (nurse, pharmacist or other professional who provides care)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family or friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Online community for patients or caregivers dealing with the same health condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disease-focused groups such as the American Cancer Society or the American Heart Association	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your health insurance company (health plan)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Television, radio, newspaper or magazines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Government health agencies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you. Please hit submit below to continue to the next part of the survey.