OMB No. 0952-0589 Exp. 04/30/2014

HINTS 4, CYCLE 3 DRAFT INSTRUMENT FOR TESTING

STATEMENT OF PRIVACY: Collection of this information is authorized by The Public Health Service Act, Sections 411 (42 USC 285 a) and 412 (42 USC 285a-1.a and 285a-1.3). The purpose of this data collection is to evaluate whether the survey questions are easy to understand. The results of the data collection will be used to improve the survey instrument. Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act and will only be seen by people authorized to work on this project. The report summarizing the findings will not contain any names or identifying information. Identifying information will be destroyed when the project ends.

NOTIFICATION TO RESPONDENT OF ESTIMATED BURDEN: Public reporting burden for this collection of information is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0589). Do not return the completed form to this address.

	A: Looking For Health Information	A6.	Based on the results of your most recent search for information about health or
A1.	Have you ever looked for information about health or medical topics from any source?		medical topics, how much do you agree or disagree with <u>each</u> of the following statements?
	- Yes No → GO TO A7 in the next column		Strongly agreedly Somewhat Somewhat Gomewhat Gomewhat Gomewhat Gomewhat Gomewhat
A2.	The most recent time you looked for information about health or medical topics,	a.	It took a lot of effort to get the information you needed
	where did you go first? Mark only one.	b.	You felt frustrated during your search for the information
	Books	C.	You were concerned about the quality of the information
	□ Brochures, pamphlets, etc.□ Cancer organization□ Family	d.	The information you found was hard to understand
	Friend/Co-worker Doctor or health care provider Internet Library Magazines Newspapers Telephone information number Complementary, alternative, or unconventional practitioner	A7 .	Overall, how confident are you that you could get advice or information about health or medical topics if you needed it? Completely confident Very confident Somewhat confident A little confident
A3.	Did you look or go anywhere else that time?		Not confident at all
	☐ Yes ☐ No	A8.	In general, how much would you trust information about health or medical topics from <u>each</u> of the following?
A4.	The most recent time you looked for information about health or medical topics, who was it for? Myself		wot at all all all all all all all all all
	Someone else Both myself and someone else		bFamily or friends
			cNewspapers or magazines
A5.	Do family members and friends ask you for information or advice on health topics?		fTelevision
	□ No		gGovernment health agencies
			iReligious organizations and leaders

A9.	A9. Imagine that you had a strong need to get information about health or medical topics Where would you go first?	
	Mark one.	
	Books Brochures, pamphlets, etc. Cancer organization Family Friend/Co-worker Doctor or health care provider Internet Library Magazines Newspapers Telephone information number Complementary, alternative, or unconventional practitioner Other-Specify→	
	Otrier-Specify→	
	.Have you ever looked for information about cancer from any source? Yes No .How much attention do you pay to information about health or medical topics from each of the following sources?	
	None Some	
	aIn online newspapers	
	bIn print newspapers	
	cIn special health or medical magazines or newsletters	
	dOn the Internet	
	eOn the radio	
	fOn local television news programs	
	gOn national or cable television news programs	
	hOn social networking sites such as Facebook or Twitter	

E	3: Using the Internet to Find Information	B7.	In the last 12 months, have you us Internet for any of the following rea	
B1.	Do you ever go on-line to access the Internet or World Wide Web, or to send and			es o
	receive e-mail? -\ Yes		aVisited a social networking site, such as Facebook or LinkedIn	
	No → GO TO C1 on the next page		bWrote in an online diary or blog (i.e., Web log)	
♥ B2.	When you use the Internet, do you access it through		cShared photos, videos, or other multimedia content on sites such as YouTube or Instagram	
	es o		dDownloaded to a mobile device, such as an MP3 player, cell phone, tablet computer or electronic book device	
	aA regular dial-up telephone line bBroadband such as DSL, cable or	DΩ	In the last 12 months, have you us	od tho
	cA cellular network (i.e., phone, 3G/4G)	ы.	Internet for any of the following rea	
	dA wireless network (Wi-Fi)			es o
			aLooked for health or medical information for yourself?	
В3.	Do you access the Internet any other way? ☐ Yes – Specify→		bLooked for health or medical information for someone else	
	No		cLooked for information about quitting smoking	
			dBought medicine or vitamins online	
B5.	Is there a specific Internet site you like to go to for health or medical information? — Yes		eParticipated in an online forum or support group for people with a similar health or medical issue	
	No → GO TO B7 on the next page		fUsed a website to help you with your diet, weight, or physical activity	
			gLooked for a health care provider	
В 6.	Specify which Internet site you especially like as a source of health or medical information:		hDownloaded health information to a mobile device, such as an MP3 player, cell phone, tablet computer or electronic book device	
			iShared health information on social media sites, such as Facebook or Twitter	
			jExchanged social support about health	
			concerns with family or friends	
			kKept track of personal health information such as care received, test results, or upcoming medical	
			appointmentsl	
			YouTube	

B9.	Have you done anything else health-related on the Internet?		
	☐ Yes-Specify →		
	No		
B10	. Scientists doing research should be able to review my medical information if the information cannot be linked to me personally.		
	Strongly agreeAgreeDisagreeStrongly disagree		
B11	. Which of the following methods have you used to electronically communicate (send or receive) health or medical information with your doctor or health care provider? Check all that apply.		
	E-mail Text message Secure message Smart phone application Video conference on your mobile phone (e.g., Skype, Facetime, etc.) Social media (e.g., Facebook, Google+, CaringBridge, etc.) Other (please specify):		
B12	.What types of medical or health information would you feel uncomfortable receiving electronically from your doctor or health care provider through your mobile phone due to privacy or security concerns? Check all that apply:		
	 Appointment Reminders General Health Tips Medication Reminders Lab/Test Results Diagnostic Information (i.e., Medical Illnesses or Diseases) None of the above 		

B13	8. What types of medical or health information would you feel uncomfortable sending electronically to your doctor or health care provider through your mobile phone due to	C2.	Do you have any of the following health insurance or health coverage plans: es o
	privacy and security concerns? Check all that apply: Uital signs (e.g., heart rate, blood pressure,		a. Insurance through a current or former employer or union (of you or another family member)
	glucose levels, etc.) Lifestyle behaviors (e.g., physical activity, food intake, sleep patterns, etc.)		b. Insurance purchased directly from an insurance company (by you or another family member)
	Symptoms (e.g., nausea, pain, dizziness, etc.) Digital images/video (e.g., photos of skin lesions) None of the above H. How much do you agree with the following		c. Medicare
B14			Assistance, or any kind of government-assistance plan for those with low incomes or a disability
	statement: "I would be interested in electronically communicating (send or receive) medical or health information with		e. TRICARE or other military health care
	my health care providers and doctors using my mobile phone despite any concerns I		who have ever used or enrolled for VA health care)
	might have about privacy and security". Strongly agree		g. Indian Health Service
	Agree Disagree Strongly disagree	C3.	Do you have any other health care coverage plan for yourself (please do not include dental or vision plans)?
	C: Your Health Care		☐ Yes-Specify → No
C1.	Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often? Yes No	C4.	About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition. Within past year (anytime less than 12 months ago) Within past 2 years (1 year but less than 2 years ago) Within past 5 years (2 years but less than 5 years ago) 5 or more years ago Don't know Never

C5.	In the past 12 months, not counting times you went to an emergency room, how many times did you go to a doctor, nurse, or other health professional to get care for yourself?	C8. Overall, how would you rate the quality of health care you received in the past 12 months?
	 None → GO TO D1 on the next page 1 time 2 times 3 times 4 times 5-9 times 	Excellent Very good Good Fair Poor
C6.	The following questions are about your communication with all doctors, nurses, or other health professionals you saw <u>during</u> the past 12 months	 C9. In the past 12 months, have you talked to a doctor, nurse, or other health professional about any kind of health information you have gotten from the Internet? Yes No→ GO TO D1 in the next column
e.	How often did they do each of the following: aGive you the chance to ask all the health-related questions you had?	C10. In the past 12 months when you talked with a health care professional, how interested were they in hearing about the information you found on-line? Very interested Somewhat interested A little interested Not at all interested Not at all interested study where you got one of two treatments, such as medicines or surgery procedures? Yes No
C7.	In the past 12 months, how often did you feel you could rely on your doctors, nurses, or other health care professionals to take care of your health care needs?	
	☐ Always☐ Usually☐ Sometimes☐ Never	

		∐ Ne	ever	
D1.	D: Your Health, Nutrition and Physical Activity In general, would you say your health is Excellent, Very good, Good, Fair, or	inform order' Alv Off So Ra	nation on ca	ow often do you use menu ories in deciding what to
D2.	Over the past 2 weeks, how often have you been bothered by any of the following problems?	100% each No 1/2 1/2 1 t 2 t	pure fruit ju day?	cups of fruit (including ice) do you eat or drink 1 cup of fruit could be: - 1 small apple - 1 large banana - 1 large orange - 8 large strawberries - 1 medium pear - 2 large plums - 32 seedless grapes - 1 cup (8 oz.) fruit juice - ½ cup dried fruit
D3.	aLittle interest or pleasure in doing things	(inclue) you e No 1/2 1/2 1 t 2 t 3 t	ding 100% p at or drink e	- 1 inch-thick wedge of cups of vegetables oure vegetable juice) do
D4.	How often in the past 12 months would you say you were worried or stressed about having enough money to buy nutritious meals?. Always Usually Sometimes Rarely			

D8.	Not counting any diet soda or pop, about how often do you drink regular soda or pop in a typical week? Every day 5-6 days a week 3-4 days a week 1-2 days a week Less often than 1 day a week I don't drink any regular soda or pop	D11. In a typical week, outside of your job or work around the house, how many days do you do leisure-time physical activities specifically designed to strengthen your muscles such as lifting weights or circuit training (do not include cardio exercise such as walking, biking, or swimming)? None 1 day per week 2 days per week 3 days per week
D9.	In a typical week, how many days do you do any physical activity or exercise of at least moderate intensity, such as brisk walking, bicycling at a regular pace, and swimming at a regular pace?	4 days per week 5 days per week 6 days per week 7 days per week
D10	None → GO TO H3 in the next column 1 day per week 2 days per week 3 days per week 4 days per week 5 days per week 6 days per week 7 days per week 0. On the days that you do any physical activity or exercise of at least moderate intensity, how long do you typically do these activities?	D12. Over the past 30 days, in your leisure time how many hours per day, on average, did you sit and watch TV or movies, surf the web, or play computer games? Do not include "active gaming" such as Wii. Hours per day
	Write a number in one box below. Minutes Hours	D13. About how tall are you without shoes? Feet and Inches
		D14. About how much do you weigh, in pounds, without shoes? Pounds

This information is on the back of a container of a pint of ice cream

Nutrition Facts Serving Size Servings per container	1/2 cup 4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

^{*} Percent Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

D15	. If you eat the entire container, how many calories will you eat?
D16	. If you are allowed to eat 60 g of carbohydrates as a snack, how much ice cream could you have?
D17	. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes 1 serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
	grams
D18	. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
	percent
D19	. Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves and bee stings.
	Is it safe for you to eat this ice cream?
	Yes No

Not sure

D20. How many times in the past 12 months have you used a tanning bed or booth? O times 1 to 2 times 3 to 10 times 11 to 24 times 25 or more times	The following questions are about control over different parts of your life that may be affected by the experience of breast cancer. The questions ask about how much control you <i>personally</i> have over certain aspects of your life. Please read each question carefully and use the following rating scale to select the response that best reflects your current control beliefs. <i>Space is provided to fill in a response to each item</i> .
D21. When you are outside for more than one hour on a warm, sunny day, how often do you wear sunscreen? Never Rarely Sometimes Often Always	No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you
Don't go out on sunny days D22. When you are outside for more than one hour on a warm, sunny day, how often do you	D24. How much <i>personal</i> control do you think you have over your physical symptoms , including No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you
awear long pant\$? bwear a hat that shades your face, ears and neck?	a
D23. How much sleep do you usually get	f
aOn a weekday (e.g., workday or school day)?bOn a weekend (e.g., non-work or non-school day)?	

D25. How much <i>personal</i> control do you think you have over your medical decisions and care , including No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you	D28. How much <i>personal</i> control do you think you have over your relationships with other people in your life, including your No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you
agathering important information and getting your questions answered?	a
D26. How much <i>personal</i> control do you think you have over the outcomes of your breast cance r, including No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you	D29. In general, how much <i>personal</i> control do you think you have over your life , including No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you
arecovering from your breast cancer?	athe events/things that are most important to you?
D27. How much <i>personal</i> control do you think you have over your emotions , including No control A little bit of control A moderate amount of control A great deal of control This item does not apply to you	cchallenges that come your way?
afeeling sad?	

	E: Patient Activation	E5.	In the past 12 months, have you talked to a doctor, nurse, or other health professional about any kind of health information you
E1.	Do you always, usually, sometimes or never bring with you to your doctor visits a list of questions or concerns you want to cover? Always Usually Sometimes Never Don't know		have gotten from es No aThe internet? bMagazines? cNewspapers? dAdvertising? bAdvertising? bFamily or friends cNewspapers or magazines
E2.	Do you always, usually, sometimes or never take a list of all your prescribed medicines to your doctor visits? Always Usually Sometimes Never Not applicable Don't know		de
E3.	The following always, usually, sometimes or never happens: I ask my doctor to explain a test, treatment, or procedure to me in detail. Always Usually Sometimes Never Not applicable		Have you ever checked the medication that a pharmacist gave you with the prescription your doctor wrote? Yes No Does not apply How often do you do your own research on a health or medical topic after seeing your doctor?
E4.	Have you ever asked your doctor questions about any treatment, test or prescription that he or she has recommended? Yes No Does not apply		Very oftenOftenSometimesRarelyNever

y own health care or in determining nction.	E12. Have you ever brought a friend or a relative to a doctor's appointment so that they could help ask questions, understand, or remember what the doctor was telling you?
	☐ Yes☐ No☐ Does not apply
, I am the person naging my health	E13.Have you ever called to check on the results of a medical test you had done? Yes No Does not apply
	E14. Have you ever consulted with your doctor about the hospital you go to? Yes No Does not apply
ometimes or never d the results of any ? (An example ests, or EKG for	E15.Have you ever talked to a surgeon about the details of surgery, such as exactly what they will be doing, how long it will take and the recovery process? Yes No Does not apply
	E16.Please tell me how confident you are that you can identify when it is necessary for you to get medical care.
ometimes or never new prescription, precautions?	 Very confident Confident Somewhat confident Not at all confident Don't know
	or in determining nction. If am the person naging my health ometimes or never d the results of any of the example tests, or EKG for the desire of the results of any of the example tests, or e

E17.The following always, usually, sometimes or never happens: I ask my doctor to explain a test, treatment, or procedure to me in detail. Always Usually Sometimes Never Not applicable	E23.In your opinion, how good is cancer screening at separating people who have cancer from people who don't have cancer? Not good at all Slightly good Pretty good Very good
☐ Don't know	E24.As far as you know, can most cancer screening tests show
E18. The following always, usually, sometimes or never happens: Before I go to a new doctor, I find out as much as I can about his or her qualifications Always Usually Sometimes Never Not applicable Don't know	aWhether a person actually has cancer? bWhat stage of cancer a person has? cWhether a person has precancer? dWhat the chances are that a person might have cancer?
E19.Instead of waiting for them to tell me, I usually ask the doctor or nurse immediately after an exam about my health Strongly agree Somewhat agree Somewhat disagree Strongly disagree	F: Women and Cancer F1. Are you male or female? ☐ Male → GO TO G8 Female F2. Has a doctor ever told you that you could
E20.I usually don't ask the doctor or nurse many questions about what they're doing during a medical exam Strongly agree Somewhat agree Somewhat disagree Strongly disagree	choose whether or not to have the Pap test? Yes No No F3. How long ago did you have your most recent Pap test to check for cervical cancer? A year ago or less
E21.I do what I can to get checked for cancer. Strongly agree Somewhat agree Somewhat disagree Strongly disagree	More than 1, up to 2 years ago More than 2, up to 3 years ago More than 3, up to 5 years ago More than 5 years ago I have never had a Pap test

	 A mammogram is an x-ray of each breast to look for breast cancer. During the past 12 months, did a doctor, nurse, or other health professional advise you to get a mammogram? Yes No Not sure 		G: Screening for Cancer
		G1.	A vaccine to prevent HPV infection is available and is called the HPV shot, cervical cancer vaccine, GARDASIL®, or Cervarix®.
			Has a doctor or other health care professional ever talked with you about the HPV shot or vaccine?
⊢ 5.	A mammogram is an x-ray of each breast to look for cancer.		☐ Yes ☐ No
	Has a doctor ever told you that you could choose whether or not to have a mammogram?	G2.	Have you ever heard of HPV? HPV stands for Human Papillomavirus
	☐ Yes ☐ No		Yes No Not sure
F6.	When did you have your most recent mammogram to check for breast cancer, if ever? A year ago or less	G3.	Have you ever heard of HPV? HPV stands for Human Papillomavirus. It is not HIV, HSV, or herpes.
	More than 1, up to 2 years ago More than 2, up to 3 years ago More than 3, up to 5 years ago More than 5 years ago		Yes No Not sure
	I have never had a mammogram	G4.	Do you think that HPV causes cervical cancer?
F7.	Is there any particular reason why you haven't had a mammogram {yet}?		Yes No Not sure
		G5.	Do you think HPV can cause cervical cancer?
F8.	Is there any particular reason why you haven't had a mammogram {in the past 2 years}?		Yes No Not sure
		G6.	Do you think that HPV is a sexually transmitted disease?
			☐ Yes ☐ No ☐ Net sure

G7.	Do you think that HPV will often go away on its own without treatment? Yes No Not sure	G10. The following questions are about discussions doctors or other health care professionals may have with their patients about the PSA test that is used to look for prostate cancer.
G8.	There are a few different tests to check for colon cancer. These tests include:	Have you ever had a PSA test? Yes No
	A colonoscopy – For this test, a tube is inserted into your rectum and you are given medication that may make you feel sleepy. After the procedure, you need someone to drive you home.	G11. Has a doctor ever discussed with you whether or not you should have the PSA test?
	A sigmoidoscopy – For this test, you are awake when the tube is inserted into your rectum. After the test you can drive yourself home.	Yes No → GO TO H1 below
	A stool blood test – For this test, you collect a stool sample at home, and then provide it to a doctor or lab for testing.	G12. In that discussion, did the doctor ask you whether or not you <u>wanted</u> to have the PSA test?
	Has a doctor ever told you that you could choose whether or not to have a test for colon cancer?	☐ Yes ☐ No
	Yes No	G13. Did a doctor ever tell you that some experts disagree about whether men should have PSA tests?
G9.	Have you ever had one of these tests to check for colon cancer? Yes	Yes No
<u> </u>	□ No □ No □ No	G14. Has a doctor or other health care professional ever told you that
	en ales, GO TO H1 on the next page.	es o
		aThe PSA test is not always accurate?
		bSome types of prostate cancer are slow-growing and need no treatment?
		cTreating any type of prostate cancer can lead to serious side-effects, such as problems with urination or having sex?

	H: Your Cancer History	H5.	Clinical trials are research studies that involve people. They are designed to test the safety and effectiveness of new
H1.	Have you ever been diagnosed as having cancer?		treatments and to compare new treatments with the standard care that people currently get. Have you ever heard of a clinical trial?
	- Yes No → GO TO H4 on the next page		☐ Yes☐ No☐ Don't know
, H2.	What type of cancer did you have?		
	Mark All that apply.	H6.	Did you hear about clinical trials from
	Bladder cancer Bone cancer Breast cancer Cervical cancer (cancer of the cervix) Colon cancer Endometrial cancer (cancer of the uterus) Head and neck cancer Hodgkin's lymphoma Leukemia/Blood cancer Liver cancer Lung cancer Melanoma Non-Hodgkin lymphoma Oral cancer Ovarian cancer Pancreatic cancer Pharyngeal (throat) cancer		aDoctor, nurse, or other medical professional?
H3.	 □ Prostate cancer □ Rectal cancer □ Renal (kidney) cancer □ Skin cancer, non-melanoma □ Stomach cancer □ Other-Specify At what age were you first told that you had cancer? 		Have you ever participated in a clinical trial for treatment of your cancer? Yes No Don't know Have you ever participated in a clinical trial? Yes
	Age		No Don't know
H4.	Has a doctor or other member of your medical team discussed clinical trials as a treatment option for your cancer? Yes No		

H9.	If you were diagnosed with cancer, how likely is it that you would participate in a research study of a new treatment?	14.	How much do you agree or disagree with each of the following statements?
	☐ Very likely ☐ Somewhat likely		Strongly agree Somewhat Somewhat Somewhat Somewhat Somewhat Somewhat Somewhat Somewhat Somewhat Somewhat
	Equally likely as unlikelySomewhat unlikely	a.	It seems like everything causes cancer
☐ Very unlikely		b.	There's not much you can do to lower your chances of getting cancer
	bu ve been diagnosed with cancer at any time in your please GO TO I4 on the next page.	C.	There are so many different recommendations about preventing cancer, it's hard to know which ones to follow
	I: Beliefs About Cancer	d.	In adults, cancer is more common than heart disease
11.	Think about cancer in general when answering the questions in this section. How likely are you to get cancer in your	15.	As far as you know, who has a <u>greater</u> chance of getting cancer – a person with a 1 in 1,000 chance of getting cancer, or a
	lifetime? Very unlikely Unlikely Neither unlikely nor likely		person with a 1 in 100 chance? 1 in 1,000 is a greater chance of getting cancer 1 in 100 is a greater chance of getting cancer
	Likely Very likely	16.	Have any of your family members ever had cancer?
12.	Compared to other people your age, how likely are you to get cancer in your lifetime? Much less likely		☐ Yes ☐ No ☐ Not sure
	Less likely About the same More likely Much more likely	17.	Which of the following numbers represents the biggest risk of getting a disease?
13.	Select one answer that best represents your opinion about the statement: "I feel like I could easily get cancer in my lifetime." I feel very strongly that this will NOT happen I feel somewhat strongly that this will NOT happen	18.	☐ 1 in 1000 ☐ 1 in 10 ☐ 1 when people tell you the chance of something happening, do you prefer that they use words ("it rarely happens") or numbers ("there's a 1% chance")?
	I feel I am just as likely to get cancer as I am to not get cancer I feel somewhat strongly that this WILL happen I feel very strongly that this WILL happen		☐ 1 - Always Prefer Words ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 - Always Prefer Numbers

 19. People can talk about the chance of something happening using either words like "it rarely happens" or numbers, like "there's a 5% chance. When people tell you the chance of something happening do you prefer that they use words or numbers? Prefer Words Prefer Numbers No preference 	e I13. How likely are you to get heart disease in your lifetime? I have heart disease Very likely Somewhat likely Neither likely or unlikely Somewhat unlikely Very unlikely
I10. In the past 30 days, how often have you felt(5 point scale: very slightly or not at all through extremely)	I14. How much do you agree or disagree with each of the following statements?
All of the time Most of the time Some of the time A little of the time	a. When I feel threatened or
None of the time	anxious I find myself thinking about my strengths
ab	b. When I feel threatened or anxious I find myself thinking about my values
cd	c. When I feel threatened or anxious I find myself thinking about my strengths and values
I11. How likely is it that the average	d. I hardly ever expect things to go my way
<pre>{man/woman} your age will develop cancer in {his/her} lifetime?</pre>	e. I'm always optimistic about my future
Very likelySomewhat likelyNeither likely or unlikelySomewhat unlikelyVery unlikely	f. When I think about cancer, I think about death
I12. How likely are you to get diabetes in your lifetime?	
I have diabetes Very likely Somewhat likely Neither likely or unlikely Somewhat unlikely Very unlikely	

I15. How objective would the following sources be in evaluating new guidelines for how often women should get pap tests (cervical cancer screening)?	I17. How high quality would recommendations be from the following individuals in evaluating new guidelines for how often women should get pap tests (cervical cancer screening)?
Not at all A little Some A lot	Not at all A little Some A lot
a	a
I16. How much would you trust these individuals in evaluating new guidelines for how often women should get pap tests (cervical cancer screening)? Not at all A little Some A lot	K: Medical Research & Medical Records K1. As far as you know, do any of your doctors or other health care providers maintain your medical information in a computerized system? Yes No
in evaluating new guidelines for how often women should get pap tests (cervical cancer screening)? Not at all A little Some	K1. As far as you know, do any of your doctors or other health care providers maintain your medical information in a computerized system?Yes

K3.	How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren't permitted to see them?	K7.	If your medical information is sent electronically from one health care provider to another, how concerned are you that an unauthorized person would see it? (Electronically means from computer to
	Having safeguards (including the use of technology) in place has to do with the security of your medical records. Very confident Somewhat confident Not confident		computer, instead of by telephone, mail, or fax machine). Very concerned Somewhat concerned Not concerned
			L: Tobacco Products
K4.	How confident are you that you have some say in who is allowed to collect, use and share your medical information?	L1.	Have you smoked at least 100 cigarettes in your entire life?
	Having a say in who can collect, use and share your medical information has to do with the <u>privacy</u> of your records	↓	Yes No → GO TO L5
	Very confidentSomewhat confidentNot confident	L2.	How often do you now smoke cigarettes? Everyday Some days Not at all
K5.	Have you ever kept information from your health care provider because you were concerned about the <u>privacy</u> or <u>security</u> of your medical record?	L3.	At any time in the past year, have you stopped smoking for one day or longer because you were trying to quit?
	☐ Yes ☐ No		☐ Yes ☐ No
K6.	If your medical information is sent by fax from one health care provider to another, how concerned are you that an unauthorized person would see it? Ury concerned	L4.	Are you seriously considering quitting smoking in the next six months? Yes No
	Somewhat concerned Not concerned	L5.	How much do you agree or disagree with this statement: "Smoking behavior is something basic about a person that they can't change very much."
			Strongly agreeSomewhat agreeSomewhat disagreeStrongly disagree

L6.	In your opinion, do you think that some types of cigarettes are less harmful to a person's health than other types? Yes Don't know	L10. Do you believe that the United States Food and Drug Administration (FDA) regulates tobacco products in the U.S.? Yes No Don't know
L7.	In your opinion, do you think that some smokeless tobacco products, such as chewing tobacco, snus and snuff are less harmful to a person's health than cigarettes? Yes No Don't know	L11. About how long has it been since you completely quit smoking cigarettes? Less than 1 month ago 3 months to less than 6 months ago 6 months to less than 1 year ago 1 year to less than 5 years ago 5 years to less than 15 years ago 15 years ago
L8.	Compared to people who smoke every day, do you think people who smoke just some days have less or more risk of getting health problems in their lifetime? Much less risk Less risk About the same risk More risk Much more risk	L12. When you last smoked every day, how many cigarettes did you usually smoke each day? 1-9 10-19 20-29 30-39 40+ L13. On the average, how many cigarettes do you now smoke a day?
L9.	New types of cigarettes are now available called electronic cigarettes (also known as e-cigarettes or personal vaporizers). These products deliver nicotine through a vapor. Compared to smoking cigarettes, would you say that electronic cigarettes are	☐ 1-9 ☐ 10-19 ☐ 20-29 ☐ 30-39 ☐ 40+
	 Much less harmful, Less harmful, Just as harmful, More harmful, Much more harmful, or I've never heard of electronic cigarettes 	L14. On the average, when you smoked during the past 30 days, about how many cigarettes did you smoke a day? 1-9 10-19 20-29 30-39 40+

L15	A hookah pipe (or shisha) is a large water pipe. People smoke tobacco using hookah pipes in groups at cafes or bars. Compared to smoking cigarettes, would you say that smoking tobacco using a hookah is	L18. Which statement best describes the rules about smoking inside your home? Smoking is not allowed anywhere inside your home Smoking is allowed some places or at some
	Much less harmful,Less harmful,Just as harmful,More harmful,	times Smoking is allowed anywhere inside your home There are no rules about smoking inside your home
	Much more harmful, orI've never heard of Hookah	L19. Which statement best describes the rules about smoking inside your home?
L16	How much do you think quitting cigarette smoking can help undo the harmful effects of smoking? Not at all A little Some A lot	No one is allowed to smoke anywhere INSIDE YOUR HOME Smoking is allowed in some places or at some times INSIDE YOUR HOME Smoking is permitted anywhere INSIDE YOUR HOME L20. To what extent do you believe the nicotine in
L17	Other than quitting cigarette smoking, how much do you think each of the following might help someone who is currently smoking undo the harmful effects of smoking?	cigarettes to be the chemical that causes most of the cancer caused by smoking? Not at all A little Somewhat Very much Don't know
a.	Exercising	
b.	Eating fruits and vegetables	
C.	Eating no saturated fats	
d.	Eating whole grains	
e.	Feeling guilty when you skip exercising	
f.	Eating organic foods	
g.	Taking vitamins	
h.	Getting screened for lung cancer	
i.	Using moisturizer	
j.	Wearing sunscreen	
k.	Sleeping at least 8 hours per night	
l.	Reducing stress	

	X: Genomics & Family History	X3.	Which of the following type(s) of genetic tests have you had?				
X1. Genetic tests that analyze your DNA, diet,			Please select all that apply				
i	and lifestyle for potential health risks are currently being marketed by companies directly to consumers. Have you heard or		Paternity testing: to determine if a man is the father of a child				
	read about these genetic tests? The very surface of the consumers. The very surface of the consumers of the very surface of the consumers. The very surface of the consumers of the very surface of		Ancestry testing: to determine the background or geographic/ethnic origin of an individual's ancestors				
			DNA fingerprinting: to distinguish between or match individuals using hair, blood, or other biological material				
X2.	From which of the following sources did you read or hear anything about genetic tests?		Cystic Fibrosis (CF) carrier testing: to determine if a person is at risk of having a child with cystic fibrosis;				
	Please select all that Apply Newspaper Magazine. Radio Health professional Family member Social media Television Internet Other Have not heard of such test Not sure		BRCA 1/2 testing: to determine if a person has more than an average chance of developing breast cancer				
			Lynch syndrome testing: to determine if a person has more than an average chance of developing colon cancer				
			None of the above				
			Other-Specify →				
		X4.	Have you ever had a genetic test? Yes No Not sure				
		X5.	Do you have any first-degree relatives (mother, father, sibling, or child) who have been diagnosed with cancer in their lifetime? Yes, specify: No				

X6.	If you had a genetic test, to whom did you communicate the results?	X10.Have you shared the family history information you collected with a health professional?
	Mark all that Apply	Please select only one
	Health professional Family member Friend Other Did not have this type of test Did not communicate the results	 Yes No Not yet, but I plan to in the future I have not collected family history
X7.	In the past year, have you read or heard about the importance of knowing your family's health history for your own health?	X11.How much do you think <u>health behaviors</u> like diet, exercise and smoking determine whether or not a person will develop each of the following conditions?
	YesNo →GO TO X9 below	Not at all Not at all Somewhat
X8.	From which of the following sources have you read or heard anything about the importance of knowing your family's health history?	aDiabetes/High blood sugar
	Please select all that Apply	e
	 Newspaper Magazine. Radio Health professional Family member Social media Friends Television Internet Other Have not heard of Family History 	X12. How much do you think genetics, that is characteristics passed from one generation to the next, determine whether or not a person will develop each of the following conditions?
	☐ Not sure	aDiabetes/High blood sugar
X9.	Have you ever actively collected health information from your relatives for purposes of documenting your family's health history?	cHeart disease dHigh Blood Pressure/Hypertension
	YesNo →GO TO X11 on the next page	e

X13. Health decisions are choices about your health such as which medication to take or whether to have surgery. Have you made a health decision in the last 12 months?

Yes No

I'm not sure

- X14. Think about the last time you made a health decision. Rate your agreement with each statement.
 - 1-Strongly agree,
 - 2-Somewhat agree.
 - 3- Neither agree nor disagree,
 - 4- Somewhat disagree,
 - 5-Strongly disagree,
 - 6- This does not apply to me]
 - a. I knew all of the treatment options that were available to me
 - b. I knew the benefits of each treatment option
 - c. I knew the risks and side effects of each treatment option
 - d. I was adequately informed about the issues important to my decision
 - e. I had information that applied to me, given my personal characteristics
 - f. I had information about health outcomes that matter to me
- X15. In the past 12 months, have you helped the following people make a health decision?

[Response scale: 1-Yes, 2-No, 3-I'm not sure]

- a. Spouse or partner
- b. Parent
- c. Child (less than 18 years old)
- d. Child (18 years old or older)
- e. Other family member
- f. Friend or co-worker
- g. Other (option free text: specify other)

X16. For each of the following organizations, please tell us if you had heard of it before being contacted for this study

[Response scale: 1-Yes, 2-No, 3-I'm not sure]

- a. National Institutes of Health (NIH)
- b. Patient Centered Outcomes Research Institute (PCORI)
- c. Agency for Healthcare Research and Quality (AHRQ)
- d. Food and Drug Administration (FDA)
- e. Centers for Disease Control and Prevention (CDC)
- X17. There are many different types of research studies. Which of the following have you heard about? (Check all that apply.)
 - g. Research studies in which patients try an experimental new treatment
 - Research studies that compare two or more treatments that are already used in clinical care to see which treatment works best
 - Research studies based on information from patients' medical records
 - Research studies in which patients help the researchers choose what the study will be about
 - k. Research studies in which patients help researchers decide how to ask patients questions about their health

2-Somewhat disagree, 3- Neither agree nor disagree, 4- Somewhat disagree, 5-Strongly disagree X19. How important are each of the following for improving health decision making? Response scale: 1- Not at all important, 2- Slightly important, 3- Moderately important, 4- Very important] A. Research studies on the best options for diagnosis and treatment b. Coordination between different health providers composed for health care providers on the best options for diagnosis and treatment d. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on the best options for diagnosis and treatment d. More training for place to get medical care in all parts of the country g. Changes in national health policy X20. Some patients work with researchers to plan a study for a medical condition that affects you? Yes No No I'm not sure	X18. More research studies on the best options for diagnosis and treatment are needed in order to improve my health decisions. Response options:	X21. Do you think you would ever be interested in working with researchers to plan a study for a medical condition that affects you? Yes No					
X19. How important are each of the following for improving health decision making? Response scale: 1- Not at all important, 2- Slightly important, 3- Moderately important, 4- Very important a. Research studies on the best options for diagnosis and treatment b. Coordination between different health providers c. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on how to help patients make health decisions e. Patient advocacy for better health information f. Better availability of places to get medical care in all parts of the country g. Changes in national health policy X20. Some patients work with researchers to plan health research studies. X20. Some patients work with researchers to plan health research studies. X20. Some patients work with researchers to plan health research studies. Acker and way of statements: [Response options: 1-Strongly agree, 2-Somewhat disagree, 3- Neither agree and relargree, 4- Somewhat disagree, 6-I'm not sure] a. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. b. Including patients on research teams would improve the value of health research. c. Including patients on research teams would improve	3- Neither agree nor disagree,4- Somewhat disagree,						
a. Research studies on the best options for diagnosis and treatment b. Coordination between different health providers c. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on how to help patients make health decisions e. Patient advocacy for better health information f. Better availability of places to get medical care in all parts of the country g. Changes in national health policy X20. Some patients work with researchers to plan health research studies. X20. Some patients work with researchers to plan health research studies. Have you ever worked with researchers to plan a study for a medical condition that affects you? Yes No No No No Including patients on research teams would impror the value of health research to value of health research to value of health research to value of health research teams would impror the value of health research to value of health research teams would impror the value of health research teams would impror the value of health research to value of health care. 223. How valuable are each of the followin aspects of research to you? [Response options: 1-Very valuable, 2- Moderately valuable, 3- Slightly valuable, 4- Not at all valuable] An	X19. How important are each of the following for improving health decision making? Response scale: 1- Not at all important,	[Response options: 1-Strongly agree, 2-Somewhat agree, 3- Neither agree nor disagree,					
a. Research studies on the best options for diagnosis and treatment b. Coordination between different health providers c. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on how to help patients make health decisions e. Patient advocacy for better health information f. Better availability of places to get medical care in all parts of the country g. Changes in national health policy X20. Some patients work with researchers to plan health research studies. X20. Some patients work with researchers to plan health research studies. Have you ever worked with researchers to plan a study for a medical condition that affects you? Yes No No A. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health research. Including patients on research teams would improve the value of health care. Including patients on research teams would improve the value of health care. Including patients on research teams would improve the value of health care. Including patients on research teams would improve the value of health care. Including patients on research teams vould improve the value of health care.	3- Moderately important,	5-Strongly disagree,					
Have you ever worked with researchers to plan a study for a medical condition that affects you? Yes No Answers questions that patients think are important b. Answers questions that clinicians think are important c. Evaluates outcomes that matter to patients	 a. Research studies on the best options for diagnosis and treatment b. Coordination between different health providers c. More training for health care providers on the best options for diagnosis and treatment d. More training for health care providers on how to help patients make health decisions e. Patient advocacy for better health information f. Better availability of places to get medical care in all parts of the country g. Changes in national health policy 	the value of health research. b. Including patients on research teams would improve health care. X23. How valuable are each of the following aspects of research to you? [Response options: 1-Very valuable, 2- Moderately valuable, 3- Slightly valuable,					
☐ I'm not sure Helps patients make the best health decisions	plan health research studies. Have you ever worked with researchers to plan a study for a medical condition that affects you? Yes	 a. Answers questions that patients think are important b. Answers questions that clinicians think are important c. Evaluates outcomes that matter to patients 					

d
status?
uty in the rves or not r National on, for
ot in the GO TO O5 on the next page
eceived m a VA
L r

O5.	What is your marital status?						
	Married	O11. What is your race? One or more categories may be selected.					
	Living as married Divorced		_				
	Widowed		Mark or	ie or more.			
	Separated		White				
			Black or A	African Amer	ican		
	Single, never been married		 American	Indian or Al	aska Native		
			Asian Indi				
06	What is the highest grade or level of		Chinese				
O6.	<u> </u>						
	schooling you completed?		∐ Filipino □ Japanasa				
	Less than 8 years		∐ Japanese				
	8 through 11 years		∐ Korean				
	12 years or completed high school		☐ Vietname:				
	Post high school training other than college		Other Asia				
	(vocational or technical)		Native Ha				
	Some college		Guamania	an or Chamo	orro		
	College graduate		Samoan				
	Postgraduate		Other Pac	ific Islander			
O7.	Were you born in the United States? ☐ Yes → GO TO O10 below		<u>Including yo</u> your housel		w many peo	ople live in	
	- No						
			N	umber of pe	ople		
\							
O8.	In what year did you come to live in the United States?		Starting witl	•	•		
	omica states.		and write in	•			
	Year		each adult 1	•	t age or old	ler living at	
			this address	S.			
O9.	How well do you speak English?			Sex	Age	Month Born (01-12)	
	Very well			Male			
	Well		SEL F				
	Not well		•	Female			
	Not at all			Male			
	Not at all		Adul + 2				
			t 2	Female			
O10	. Are you of Hispanic, Latino/a, or Spanish			Male			
	origin? One or more categories may be		Adul				
	selected.		t 3	Female			
	Mark nore.			Male			
	Mark one or more.		Adul t 4				
	No, not of Hispanic, Latino/a, or Spanish origin		ι 4	Female			
	Yes, Mexican, Mexican American, Chicano/a			Male			
	Yes, Puerto Rican		Adul				
	Yes, Cuban		t 5	Female			
	Yes, another Hispanic, Latino/a, or Spanish origin						

O14. How many children under the age of 18 live in your household?	O20. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
Number of children under 18	☐ Yes ☐ No
O15. Do you currently rent or own your home?	
OwnRentOccupied without paying monetary rent	O21. Because of a physical, mental or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?
O16.Does anyone in your family have a working cell phone?	☐ Yes ☐ No
Yes No	O22.Do you have serious difficulty walking or climbing stairs?
O17. Is there at least one telephone inside your home that is currently working and is not a cell phone?	☐ Yes ☐ No
	O23. Do you have difficulty dressing or bathing?
O18. Thinking about members of your family living in this household, what is your combined annual income, meaning the total pre-tax	☐ Yes ☐ No
income from all sources earned in the past year? \$0 to \$9,999 \$10,000 to \$14,999 \$15,000 to \$19,999 \$20,000 to \$34,999 \$35,000 to \$49,999 \$50,000 to \$74,999 \$75,000 to \$99,999	O24. Because of a physical, mental or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? Yes No
\$100,000 to \$199,999 \$200,000 or more	O25. About how long did it take you to complete the survey?
	Write a number in one box below.
O19. Are you deaf or do you have serious difficulty hearing?	Minutes Hours
☐ Yes ☐ No	

O26. At which of the following types of addresses does your household currently receive residential mail?							
Mark All that apply.							
 A street address with a house or building number An address with a rural route number A U.S. post office box (P.O. Box) 							
 A commercial mail box establishment (such as Mailboxes R Us, and Mailboxes Etc.) 							

Please indicate below how much you think whether behaviors like diet, exercise and smoking as compared to a person's genetic make-up determine whether or not a person will develop each of the following conditions by marking the appropriate box.

Example: In the example below, the respondent believes that behavior is a stronger determinant (but not the strongest) than genetics in developing diabetes and marked the appropriate box. (Note: A value of 3 would indicate that both behavior and genetics equally determine developing the disease).

Please indicate below whether a person's behaviors (like diet, exercise and smoking) or a person's genetic makeup determine whether or not a person will develop each of the following conditions by marking the appropriate box.

Example: In the example below, the respondent believes that behavior is a somewhat stronger determinant than genetics in developing diabetes. (Note: A value of 3 would indicate that both behavior and genetics equally determine developing the disease).

Turne II Dielegtee/Hiele Die ed Curren

Type II Diabetes/High Blood Sugar								
Disease Primarily Determined by Behavior	1	2 2 X	3	2 4	2 5	Disease Primarily Determined by Genetics		
Type II Diabetes/High Blood Sugar								
Disease Primarily Determined by Behavior	1	2	3	2 4	2 5	Disease Primarily Determined by Genetics		

Hypertension (High Blood Pressure)								
Disease Primarily Determined by Behavior	1	2	3	2 4	2 5	Disease Primarily Determined by Genetics		
Obe	sity							
Disease Primarily Determined by Behavior	1	2	3	2 4	2 5	Disease Primarily Determined by Genetics		
Hea	rt Disea	se		_				
Disease Primarily Determined by Behavior	1	2	3	2 4	2 5	Disease Primarily Determined by Genetics		
Cancer								
Disease Primarily Determined by Behavior	1	2	3	2 4	2 5	Disease Primarily Determined by Genetics		

Thank you!

- Please return this questionnaire in the postage-paid envelope within 2 weeks.
- If you have lost the envelope, mail the completed questionnaire to:

HINTS Study, TC 1046F Westat 1600 Research Boulevard Rockville, MD 20850