





CONSENT FORM

Before you start the HINTS survey, we need to obtain your consent to participate. Please read the statements below and initial at the bottom of the page if you agree to participate.

- HINTS is a study about experiences with cancer, health in general, and how people get health
 information. For example, we will ask how you usually get information about health and what
 sources of information you most trust. We will also ask about your beliefs on what contributes to
 good health, how best to prevent disease, and other health related topics. You can find out more
 about HINTS at hints.cancer.gov.
- Your participation is completely voluntary. You can skip any questions you do not wish to answer.
- The survey will take around 30 minutes to complete.
- Some of the questions ask about topics that may be considered sensitive, such as alcohol use, tobacco use, and mental health, and completing the survey may therefore cause some discomfort and anxiety. You can skip any question or set of questions that you do not feel comfortable answering.
- By completing the survey, there is a small risk to your privacy that may result from linking your survey responses to information from the cancer registry. However, we have taken measures to ensure that your private information will not be disclosed:
 - Once received, your completed survey will be given an anonymous code that will prevent it from being linked to your name, address or other personal information.
 - o Your name will not appear in any written reports or publications stemming from this research.
 - o Your answers will be combined with those of other people who complete the survey.
- There are no direct benefits to you for taking part in this survey, but your answers will help us understand the information needs of people who have had cancer.
- We are including a postage-paid envelope for you to return your completed survey.
- If you have questions about this research, please contact Kelly Blake, the Principal Investigator at 240-281-5934 or kelly.blake@nih.gov.
- If you have questions about your rights and welfare as a research participant, please call the Westat Human Subjects Protections office at 1-888-920-7631. Please leave a message with your full name, the name of the research study that you are calling about (HINTS), and a phone number beginning with the area code. Someone will return your call as soon as possible.

If you have read this consent form and agree to participate in this survey, please initial here:

Be sure to initial here!

Instructions:

Please use a black or blue pen to complete this form.

Mark X to indicate your answer. To change an answer, darken the box s and mark the correct answer.

A: Looking For Health Information

A1. Have you ever looked for information about cancer from any source?

SeekCancerInfo



A2. Based on the results of your most recent search for information about cancer, how much do you agree or disagree with each of the following statements?

- a. It took a lot of effort to get the information you needed.....
- b. You felt frustrated during your search for the information....... CancerFrustrated
- A3. Overall, how confident are you that you could get advice or information about cancer if you needed it?

CancerConfidentGetHealthInf

- 1 Completely confident
- 2 Very confident
- 3 Somewhat confident
- 4 A little confident
- 5 Not confident at all

A4. In general, how much would you trust information about cancer from each of the following?

		Not at all	A little	Some	A10¢
a.	A doctorCancerTrustDoctor	4	3	2	1
b.	Family or friends	4	3	2	1
C.	Government health agencies	4	3	2	1
d.	Charitable organizations	4	3	2	1
e.	CancerTrustCharities Religious organizations and leaders CancerTrustReligiousOrgs	4	3	2	1

A5. If you had a strong need to get information about cancer. Where would you go first?

SEERStrongNeedCancerInfo

Mark only one.

- 1 Books
- 2 Brochures, pamphlets, etc.
- 3 Cancer organization
- 4 Family
- 5 Friend/Co-worker
- 6 Doctor or health care provider
- 7 Internet
- 8 Library
- 9 Magazines
- 10 Newspapers
- 11 Telephone information number
- 12 Complementary, alternative, or unconventional practitioner
- 91 Other Specify→

B: Using the Internet to Find Information

B1. Do you ever go on-line to access the Internet or World Wide Web, or to send and receive e-mail?

UseInternet Yes No → GO TO B5 in the next column

B2. When you use the Internet, do you access it through...

a. A regular dial-up telephone line...... 1 Internet DialUr Broadband such as DSL, cable, or FiOS.... 1 Internet BroadBnd c. A cellular network (i.e., phone, 3G/4G)...... 1 d. A wireless network (Wi-Fi)......1 Internet_WiFi

B3. How often do you access the Internet through each of the following?

a. Computer at home..... WhereUseInternet Home b. Computer at work..... c. Computer in a public place (library, community center, d. On a mobile device (cell phone/smart phone/tablet)...... 1 WhereUseInternet_MobileDevice

B4. To what extent are you satisfied with your Internet speed?

InternetSpeed 1 Not at all satisfied 2 Not very satisfied 3 Somewhat satisfied 4 Very satisfied

5 Extremely satisfied

B5. In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following?

Yes No a. Looked for health or medical information for yourself..... 2 b. Used e-mail or the Internet to communicate with a doctor or a c. Look up medical test results...... 1 d. Made appointments with a health care 2 Electronic MadeAppts

B6. Please indicate if you have each of the following.

Mark all that apply.

- 1 Tablet computer (for example, an iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire) Smartphone (for example, an iPhone, Android, Blackberry, or Windows phone) 1 Basic cell phone only **GO TO B10** aveDevice CellPh on the next 1 I do not have any of page the above HaveDevice None HaveDevice Cat
- B7. On your tablet or smartphone, do you have any "apps" related to health and wellness?

TabletHealthWellnessApps Yes No → GO TO B9 on the next page 3 Don't know → GO TO B9 on the next page

B8. In the past 12 months, have you used any of these health or wellness apps?

UsedHealthWellnessApps 1 Yes

2 No

3 Don't know

B9.	Has v	your	tablet	or	smart	phone
-----	-------	------	--------	----	-------	-------

		Tes	NO
a.	Helped you track progress on a health- related goal such as quitting smoking, losing weight, or increasing physical		
	activity? Tablet AchieveGoal	1	2
b.	Helped you make a decision about how to treat an illness or condition?	1	2
C.	Helped you in discussions with your health care provider?	1	2

B10. In the past 12 months, have you used an electronic wearable device to monitor or track your health or activity? For example, a Fitbit, Apple Watch, or Garmin Vivofit.

1	WearableDevTrackHealth Yes
2	No → GO TO B13 in the next column

B11. In the past month, how often did you use a

wearable device to track your health? FreqWearDevTrackHealth Every day
2 Almost every day
3 1-2 times per week
4 Less than once per week
5 I did not use a wearable device in the past month

B12. Would you be willing to share health data from your wearable device with...

1	2
1	2
1	2
	1

B13. Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the last 12 months?

Within the last 12 months.
SharedHealthDeviceInfo
1 Yes
2 No
3 Not Applicable

B14. Sometimes people use the Internet to connect with other people online through social networks like Facebook or Twitter. This is often called "social media".

> In the last 12 months, have you used the Internet for any of the following reasons?

		162	INO
a.	To visit a social networking site, such as Facebook or LinkedIn	1	2
b.	To share health information on social networking sites, such as Facebook or Twitter. Intro SharedSocNet	1	2
C.	To participate in an online forum or support group for people with a similar health or medical issue	1	2
d.	To watch a health-related video on YouTube IntRsn_YouTube	1	2

C: Your Health Care

C1. Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often?

	RegularProvider Yes
2	No

Voc No

C2.	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	C5.	In the past 12 months, when getting cancel care or care for other medical problems, was there a time when you	r
	health professional to get care for yourself?		Yes No	-
	FreqGoProvider None → GO TO C6 in the next column 1 time 2 times		Had to bring an X-ray, MRI, or other type of test result with you to the appointment?	
ر	3 3 times		SEER ProbCare BringTest Had to wait for test results longer than you thought reasonable?	
	4 times 5 5-9 times	C.	SEER ProbCare WaitLong Had to redo a test or procedure because the earlier test results were not available?	
	6 10 or more times	d.	SEER ProbCare RedoTest Had to provide your medical history	
C 3.	Overall, how would you rate the quality of health care you received in the past 12		again because your chart could not be found? 1 2 SEER_ProbCare_ProvideHist	
	months? QualityCare 1 Excellent	C6.	In the past 12 months, have you seen or talked to a mental health professional such	1
	Very goodGood		as a psychologist, psychiatrist, psychiatric nurse or clinical social worker about your	
	4 Fair		health? TalkedMentalHealthProf	
	5 Poor		1 Yes 2 No	
C4.	The following questions are about your communication with all doctors, nurses, or other health professionals you saw <u>during</u> the past 12 months.	C7.	Are you <u>currently</u> covered by any of the following types of health insurance or healt	
	\mathcal{L}		coverage plans?	th
	How often did they do			
2	each of the following?	a.	coverage plans? Yes No Insurance through a current or former employer or union	
a.	Give you the chance to ask all the health-related questions		Insurance through a current or former employer or union	
	Give you the chance to ask all the health-related questions you had	b.	Insurance through a current or former employer or union	
b.	Give you the chance to ask all the health-related questions you had	b.	Insurance through a current or former employer or union	
b.	Give you the chance to ask all the health-related questions you had	b. c. d.	Insurance through a current or former employer or union	
b.	Give you the chance to ask all the health-related questions you had	b. c. d.	Insurance through a current or former employer or union	
b. c.	Give you the chance to ask all the health-related questions you had	b. c. d. e.	Insurance through a current or former employer or union	
b. c.	Give you the chance to ask all the health-related questions you had	b. c. d. e. f.	Insurance through a current or former employer or union	
b. c.	Give you the chance to ask all the health-related questions you had	b. c. d. e. f.	Insurance through a current or former employer or union	
b. c. d.	Give you the chance to ask all the health-related questions you had	b. c. d. e. f.	Insurance through a current or former employer or union	

D: Medical Records

Next, we are going to ask you some questions about your medical records. Medical records are defined as medical history, such as laboratory test results, clinical notes, and current list of medications.

D1. Do any of your doctors or other health care providers maintain your medical records in a computerized system?

ProviderMaintainEMR2

1 Yes

2 No

3 Don't know

D2. Have you ever been offered online access to your medical records by your...

		Yes	No	know
a.	health care provider?	1	2	3
b.	health insurer?	1	2	3

D3. Have any of your health care providers, including doctors, nurses, or office staff ever encouraged you to use an online medical record?

HCPEncourageOnlineRec

1 Yes

2 No

D4. How many times did you access your online medical record in the last 12 months?

AccessOnlineRed	cord
<u> </u>	
1 to 2 times	
2 3 to 5 times	GO TO D6
3 6 to 9 times	on the next
4 10 or more times	page
1	

D5. Why have you not accessed your medical records online? Is it because...

		Yes	No
	You prefer to speak to your health care provider directly? NotAccessed_SpeakDirectly	1	2
b.	You do not have a way to access the website? NotAccessed NoInternet	1	2
C.	You did not have a need to use your online medical record?	1	2
d.	You were concerned about the privacy or security of the website that had your medical records?	1	2
e.	You don't have an online medical record	. 1	2
f.	You found it difficult to login (for example, you had trouble remembering your password)? NotAccessed LogInProb	1	2
g.	You are not comfortable or experienced with computers?	1	2
h.	You have more than one online medical record?	1	2



If you have not accessed any medical records in the last 12 months, go to E1 on the next page

Otherwise, go to D6 on the next page

D6. In the past 12 months, have you used your <u>online</u> medical record to...

		res	NO
a.	Look up test results?	1	2
b.	Securely message health care provider and staff (for example, e-mail)?	1	2
C.	Download your health information to your computer or mobile device, such as a cell phone or tablet?		2

D7.	How did you access your online medical
	record?

HowAccessOn	lineR	ecord

- 1 App
- 2 Website
- 3 Both app and website
- 4 Don't know
- D8. Do any of your online medical records include clinical notes (health provider's notes that describe a visit)?

- 1 Yes
- 2 No
- 3 Don't know
- D9. Have you electronically sent your medical information to....

		Yes	No
a.	Another health care provider?	1	2
b.	A family member or another person involved with your care?	1	2
C.	A service or app that can help manage and store your health information?		
	ESent_HealthApp		

D10. How easy or difficult was it to understand the health information in your online medical record?

UnderstandOnlineMedRec

- 1 Very easy
- 2 Somewhat easy
- 3 Somewhat difficult
- 4 Very difficult

E: Cancer History

E1. What type(s) of cancer have you been diagnosed with?

Mark all that apply.

1 I have never been diagnosed
as having cancer → GO TO E9 on
SEER_CaNone the next page
Bladder cancer
SEER_CaBladder 1 Bone cancer
SEER CaBone
Breast cancer SEER CaBreast
Cervical cancer (cancer of the cervix) SEER_CaCervical
1 Colon cancer
SEER_CaColon
Endometrial cancer (cancer of the uterus) SEER_CaEndometrial
1 Head and neck cancer
SEER_CaHeadNeck Leukemia/Blood cancer
SEER_CaLeukemia
1 Liver cancer SEER CaLiver
1 Lung cancer
SEER CaLung Lymphoma (Hodgkin's)
SEER CaHodgkins
Lymphoma (Non-Hodgkin's) SEER_CaNonHodgkin
1 Melanoma
SEER_CAMelanoma Non-melanoma skin cancer (basal cell
or squamous cell carcinoma)
SEER CANonMelSkin
Oral cancer SEER CaOral
1 Ovarian cancer
SEER_CaOvarian 1 Pancreatic cancer
SEER CaPancreatic
Pharyngeal (throat) cancer SEER CaPharyngeal
Prostate cancer
SEER_CaProstate
Rectal cancer SEER CaRectal
1 Renal (kidney) cancer
SEER CaRenal Stomach cancer
SEER CaStomach
1 Other - Specify -> SEER_CaOther SEER CaOther OS
SEER Cancer Cat
SEEK CAILCEL CAL

E2. At what age were you first told that you had cancer?

WhenDiagnose	rd('ancei
Years old	cacance



tindergoCancerTreatment Yes 2 No → GO TO E6 below E4. About how long ago did you receive your last cancer treatment? HowLongFinishTreatment Cat Silli receiving treatment Less than 1 year ago 1 year ago to less than 5 years ago 1 1 years ago to less than 10 years ago 4 10 or more years ago E5. Overall, how would you rate the quality of the cancer care you received when you were treated for cancer? QualityCancerCare Excellent Very good Good Fair Poor The following questions ask about your knowledge about cancer in your family. By family we mean your first- and second degree biological relatives: your parents, brothers and sisters, children, grandpare aunts and uncles, nieces and nephews. How well do you know your family's cancer diagnosis or cancer treatment?				
2 1 year ago to less than 5 years ago 3 5 years ago to less than 10 years ago 4 10 or more years ago 5 Coverall, how would you rate the quality of the cancer care you received when you were treated for cancer? Oual ityCancerCare 1 Excellent 2 Very good 3 Good 4 Fair 5 Poor 6 Have you ever experienced any of the following conditions as a result of your cancer diagnosis or cancer treatment? Yes No a. Cognitive impairment (for example, having difficulty remembering things, or chemobrain)		your cancer? UndergoCancerTreatment Yes 2 No → GO TO E6 below About how long ago did you receive your last cancer treatment? HowLongFinishTreatment_Cat	E7.	first diagnosed with cancer, how much, if at all, has cancer and its treatment hurt your financial situation? CancerHurtFinances Not at all A little Some
## Fair 5	Ξ5.	 Less than 1 year ago 1 year ago to less than 5 years ago 5 years ago to less than 10 years ago 10 or more years ago Overall, how would you rate the quality of the cancer care you received when you were treated for cancer? QualityCancerCare Excellent Very good 	E8.	with cancer, did any doctor or other health care provider ever discuss with you the impact of cancer or its treatment on your ability to work? CancerAbilityToWork Discussed it with me in detail Briefly discussed it with me Did not discuss it at all I don't remember
a. Cognitive implementation (in example, having difficulty remembering things, or 'chemobrain')	Ξ6.	4 Fair 5 Poor Have you ever experienced any of the following conditions as a result of your cancer diagnosis or cancer treatment?	E9.	knowledge about cancer in your family. By family we mean your first- and second-degree biological relatives: your parents, brothers and sisters, children, grandparents, aunts and uncles, nieces and nephews. How well do you know your family's cancer history, including if you have no history of
d. Nausea	b.	having difficulty remembering things, or 'chemobrain')		FamiliarFamilyCancer2 5 Not at all 4 A little 3 Somewhat 2 Well
e. Something else. Specify 1 2 CancerCond_Other CancerCond_Other_OS E10. Have any of your first- or second-degree biological relatives (parents, brothers and sisters, children, grandparents, aunts and uncles, nieces and nephews) ever had cancer? FamilyEverHadCancer2	d.	Nausea 1 2		
2 No 3 Not sure 18226	e.	Something else. Specify 1 2 CancerCond_Other	E10.	biological relatives (parents, brothers and sisters, children, grandparents, aunts and uncles, nieces and nephews) ever had cancer? FamilyEverHadCancer2 Yes No Not sure

F: Impact of COVID-19

F1. The following questions are related to the coronavirus/COVID-19 pandemic that impacted the United States in 2020.

Has the COVID-19 pandemic affected either your cancer treatment or any follow-up medical appointments related to your cancer? Do not include routine cancer screening or preventive care appointments.

Mark <u>all that apply</u>.

- 1 I have not had any scheduled cancer treatment or any follow-up medical appointments related to my cancer during the pandemic COVIDCA NoAppts
- 1 Yes, some or all of my cancer treatment or follow-up medical appointments related to my cancer were cancelled or delayed COVIDCa ApptsCanceled
- 1 Yes, some or all of my cancer treatment or follow-up medical appointments related to my cancer were done by phone or video conference instead of in-person (telehealth) OVIDCa TelehealthAppts
- No, my cancer treatment or follow-up medical appointments related to my cancer have not been affected by the COVID-19 pandemic COVIDCa ApptsUnaffected COVIDCa Cat
- F2. Has the COVID-19 pandemic affected any of your appointments for routine cancer screening or preventive care (e.g., mammography, colonoscopy, etc.)?

Mark all that apply.

- 1 I have not had any scheduled appointments for routine cancer screening or preventive care during the pandemic
- COVIDRoutine_NoAppts 1 Yes, some or all of my appointments for routine cancer screening or preventive care were cancelled or delayed
- COVIDRoutine ApptsCanceled
 Yes, some or all of my appointments for routine cancer screening or preventive care were done by phone or video conference instead of in-person (telehealth)
- OVIDRoutine_TelehealthAppts 1 No, my appointments for routine cancer screening or preventive care have not been affected by the COVID-19 pandemic COVIDRoutine ApptsUnaffected COVIDRoutine Cat

F3.	Has your cancer treatment plan changed
	as a result of the COVID-19 pandemic?

COVIDChangeCaTreatment 1 Yes, my cancer treatment plan changed because of the COVID-19 pandemic

2 No, my cancer treatment plan has not changed because of the COVID-19 pandemic

3 I have not been undergoing cancer treatment during the COVID-19 pandemic

F4. Have any of your healthcare providers discussed, or provided you with information about your risk for COVID-19 complications due to your cancer history?

COVIDRiskCancerHistory

- 1 Yes
- 2 No
- 3 Don't know



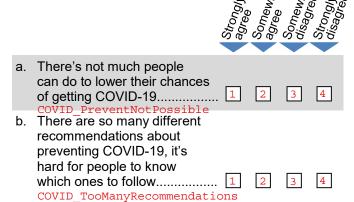
F5. During the COVID-19 pandemic, have you done any of the following things more, less, or about the same as you normally do?

		l've done this MORE	done this the SAME	l've done this LESS	I don't do this at all
a.	Slept COVIDLife Slept	1	2	3	
b.	Ate food in general COVIDLife GenFood	1	2	3	
C.	Ate high fat or sugary foods	1	2	3	4
d.	Ate healthy food	1	2	3	4
e.	COVIDLife_HealthFood Exercised		2	3	4
f.	Drank alcohol	1	2	3	4
g.	Smoked cigarettes or vaped	1	2	3	4
h.	marijuana, or CBD		2	3	4
i.	COVIDLife_Cannabis Used prescription drugs. COVIDLife RxDrugs	1	2	3	4
j.	Used non-prescription drugs	1	2	3	4
k.	Connected with others, including talking with people you trust about your concerns and how				
	you are feelingCOVIDLife_ConnectPeo Contacted a healthcare	nle	2	3	4
I.	Contacted a healthcare provider COVIDLife ContactedH	1	2	3	4
m.	Looked for health information	1	2	3	4
n.	Took breaks from watching, reading, or listening to news stories,				
	including social media COVIDLife NewsBreaks		2	3	4

F6. How much would you trust each of the following for reliable information about COVID-19?

		Notatall	A little	Some	A /ot
a.	CDC – Centers for Disease Control and Prevention	4	3	2	1
b.	NIH – National Institutes of Health COVIDTrust NIH	4	3	2	1
C.	Your state government	4	3	2	1
d.	Your local government	4	3	2	1
e.	COVIDTrust_LocalGov News media COVIDTrust NewsMedia	4	3	2	1
f.	Your healthcare provider	4	3	2	1
g.	COVIDTrust_HCP Your family and friends COVIDTrust FamFr	4	3	2	1
h.		4	3	2	1
i.	WHO – The World Health Organization	4	3	2	1

F7. How much do you agree or disagree with each of the following statements about your feelings towards COVID-19?



G: Genetic Testing

G1. Genes are inherited from your parents and are passed down from one generation to the next. Genetic tests can determine your genetic makeup.

Which of the following types of genetic tests have you heard of?

Mark all that apply.

1 Ancestry to	esting
---------------	--------

To determine the background or geographic/ethnic origin of an individual's ancestors (for example, Ancestry.com and 23andMe)

HeardGenTest Ancestry

Genetic health risk testing:

To determine health risk for a variety of health conditions (for example, 23andMe) IeardGenTest HealthRisk

1 Cancer genetic testing

(for example, testing for inherited cancer syndromes like BRCA1/2 or Lynch Syndrome)

1 Other - Specify HeardGenTest_Other HeardGenTest Other OS

1 Not sure

HeardGenTest NotSure

1 | I have not heard of any of these types of genetic tests → GO TO G8 on the next page HeardGenTest_None HeardGenTest_Cat

G2. From which of the following sources did you read or hear anything about genetic tests?

Mark all that apply.

- Newspaper
- 1 Magazine
- ırce_Mag
- 1 Radio
- ource Radio 1 Your primary health care provider
- 1 Oncologist/cancer surgeon
- 1 Genetic counselor
- 1 Family member
- TestSource_Family
 Friend
- ource_Friend
- Social media ource SocMed
- 1 Television
- 1 Internet
- 1 Internet TestSource WWW
 1 Other Specify → TestSource Other TestSource Other Other TestSource Other TestSource Other TestSource Other TestSource Other O
- 1 Have not heard of such tests → GO TO G8 on estSource_NotHeard the next page
- 1 Not sure

TestSource NotSure TestSource_Cat

G3. Have you ever had any of the following types of genetic tests?

Mark all that apply.

1 Ancestry testing:

To determine the background or geographic/ethnic origin of an individual's ancestors (for example, Ancestry.com and 23andMe)

HadTest2 Ancestry Genetic health risk testing:

To determine health risk for a variety of health conditions (for example, 23andMe)

HadTest2_HealthRisk
Cancer genetic testing

(for example, testing for inherited cancer syndromes like BRCA1/2 or Lynch Syndrome)

- 1 Other Specify HadTest2_Other_OS
- HadTest2 Other
- Not sure
- HadTest2 NotSure None of the above → GO TO G8 on the next page HadTest2 None HadTest2 Cat
- G4. If you had a cancer genetic test for inherited cancer syndromes, where did you get information about this type of testing?

Mark all that apply.

- 1 I did not have cancer genetic testing → GO TO G6 on the next page
- Your primary health care provider
- 1 Oncologist/cancer surgeon
- Genetic counselor
- Genetic testing companies
- Someplace else. Specify →
 - CaTest Cat

CaTest Other CaTest Other OS

G5. Who ordered your cancer genetic test for inherited cancer syndromes? WhoOrderedCaTest

Mark only one.

- 1 Your primary health care provider
- 2 Oncologist/cancer surgeon
- 3 Genetic counselor
- 4 I ordered it directly from a genetic testing company
- 5 I don't know



G6. If you had any genetic test, who helped you understand the results?

Mark all that apply.

1 Oncologist/cancer surgeon

1 Genetic counselor

1 Spouse/partner

ndGenTest2_Spouse

1 Parents

GenTest2_Parent

1 Siblings

Test2_Sibling

1 Children

dGenTest2 Child 1 Friend

GenTest2 Friend

Other UndGenTest2_Other

1 No one helped me understand the results UndGenTest2_NoOne UndGenTest2_Cat

G7. If you had any genetic test, who did you share the results with?

Mark all that apply.

1	Your	primary	/ health car	e providei

1 Oncologist/cancer surgeon

Genetic counselor

Counselor

1 Spouse/partner

SharedRes3_Spouse Parents

redRes3_Parent

1 Siblings

Res3_Sibling

1 Children aredRes3 Child

1 Friend

aredRes3 Friend 1 Other

redRes3 Other

1 Did not share the results SharedRes3 NotShared

SharedRes3 Cat

G8. How much do you think genes that are inherited determine whether or not a person will develop each of the following conditions?

		Not at all	A little	Somewhai	A10¢
a.	ObesityGenetics2 Obesity	4	3	2	1
b.	CancerGenetics2 Cancer	4	3	2	1
c.	Cardiovascular disease Genetics2 Cardio	4	3	2	1
d.	Diabetes	4	3	2	1

G9. How important is knowing a person's genetic information for...

		Notatall	Alittle	Somewhat	Te. Cel
a.	Preventing cancer?KnowGenes PreventCa	. 4	3	2	1
b.	Detecting cancer early?		3	2	1
C.	KnowGenes TreatCa KnowGenes TreatCa	. 4	3	2	1

G10. "Precision medicine" is an approach for disease treatment and prevention that takes into account individual differences in genes, environment, and lifestyle.

> Before completing this survey, had you ever heard of approaches like precision medicine?

HeardPrecisionMedicine

1 Yes

2 No

G11. Precision medicine in the cancer treatment setting may involve doing genetic testing on the cancer tumor or tissue. This is different from genetic testing to look at genes that are inherited from your parents.

> Was this type of genetic testing on your cancer tumor or tissue ever discussed with vou?

DiscussedCaPrecisionMedicine

1 Yes

2 No

3 I don't know

G12. Was this type of testing done as part of your cancer diagnosis and/or treatment?

TreatedCaPrecisionMedicine

1 Yes

2 No

3 I don't know

H: Clinical Trials

H1. Clinical trials are research studies that involve people. They are designed to compare new kinds of health care with the standard health care people currently get. For example, a new drug or a new way for patients to track their diets.

How would you describe your level of knowledge about clinical trials?

ClinicalTrialKnowledge

- 1 I don't know anything about clinical trials
- 2 I know a little bit about clinical trials
- I know a lot about clinical trials
- H2. Has a doctor or other member of your medical team discussed clinical trials as a possible treatment option for your cancer?

DiscussedClinicalTrial

- 1 Yes
- 2 No
- H3. If you had a need to get information about clinical trials. Which of the following would you go to <u>first</u> to get information about clinical trials?

FirstInfoClinTrials2

Mark only one.

- 1 My health care provider
- 2 My family and friends
- 3 Government health agencies
- Health organizations or groups (for example, the American Cancer Society, American Lung Association)
- Disease-specific patient support groups
- 6 Drug companies
- 7 Internet search

H4. If you had a need to get information about clinical trials. Which of the following would you most trust as a source of information about clinical trials?

TrustInfoClinTrials2

Mark only one.

- 1 My health care provider
- 2 My family and friends
- 3 Government health agencies
- 4 Health organizations or groups (for example, the American Cancer Society, American Lung Association)
- 5 Disease-specific patient support groups
- 6 Drug companies
- H5. Have you ever heard of the website clinicaltrials.gov?

___ HeardClinTrialsWebsite

- 1 Yes
- 2 No
- H6. Have you ever participated in a clinical trial for treatment of your cancer?

ClinicalTrialCancerTx2

- 1 Yes
- No → GO TO J1 on the next page
- 3 Don't know→ GO TO J1 on the next page

H7.	If you participated in a much did each of the your decision to partic	follov	ving			
		Not at all	A little	Somewhat	4/of	No.

		/ 		Ž	201:	
		Not at all	A little	Somewho	A/0¢	NotA
a.	My participation will help		Г			
	other people SEER ClinTrial Helping	eop	le	4	L	5
b.	I was paid to participate	4	3	2	1	5
_	SEER_ClinTrial_GetPaid					
C.	I was given support to					
	participate such as transportation, childcare,					
	or paid time off from work	4	3	2	1	5
	SEER ClinTrial GetSuppo			ت	الثا	
d.	My doctor encouraged					
	me to participate SEER ClinTrial DocEncor	4	3	2		5
e.	My family and friends	ıray	eu			
	encouraged me to					
	participate	4	3	2	1	5
f.	SEER_ClinTrial_FamEncou I thought that participating	ırag	ed			
١.		4	3	2	1	5
	would help me get better SEER_ClinTrial_GetBette	er				
g.	I wanted the chance to					
	try a new kind of care SEER ClinTrial NewCare	4	3	2		5
h.	The standard care was					
	not covered by my	_	_	_		
	insurance	4	3	2	1	5
	SEER_ClinTrial_StdNotCo	over	ed			

J: Your Overall Health

J1.	In general	, would	you	say you	r health	า is
	Genera	lHealth				

- 1 Excellent,
- 2 Very good,
- Good,
- 4 Fair, or
- 5 Poor?

J2.	Overall, how confident are you about you
	ability to take good care of your health?
	OwnAhilityTakeCareHealth

- 1 Completely confident
- 2 Very confident
- 3 Somewhat confident
- 4 A little confident
- 5 Not confident at all

J3.	Are you deaf or do you have serious
	difficulty hearing?

- Deaf
- 1 Yes
- ² No

J4. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

- Blind
- 1 Yes
- 2 No

J5. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

DecisionMaking

- 1 Yes
- 2 No

J6. Do you have serious difficulty walking or climbing stairs?

- DifficultyWalking
- 1 Yes
- 2 No

J7. Do you have difficulty dressing or bathing?

- DifficultyDressing
- 1 Yes
- 2 No

J8. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

DifficultyErrands

- 1 Yes
- 2 No

J9. Is there anyone you can count on to provide you with emotional support when you need it - such as talking over problems or helping you make difficult decisions?

- EmotionalSupport
- 1 Yes
- 2 No



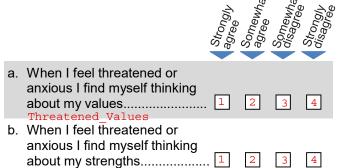
J10. Do you have friends or family members that you talk to about your health? J15. Please respond to each item one box per row.					
	TalkHealthFriends 1 Yes		Sg		
	1 Yes 2 No				
	Z INO		Never Rarely Sometimes Usually		
J11.	If you needed help with your daily chores, is there someone who can help you?	a.	feel left out		
	HelpDailyChores	b.	I feel that people barely		
	1 Yes		know me 1 2 3 4 5 FeelPeopleBarelyKnow		
	2 No	C.	I feel isolated from others 1 2 3 4 5		
		d.	FeelIsolated I feel that people are		
J12.	How often do you feel that you lack		around me but not		
	companionship?		with me 1 2 3 4 5 FeelPeopleNotWithMe		
	LackCompanionship 1 Never		-		
	2 Rarely	J16.	Has a doctor or other health professional		
	3 Sometimes		ever told you that you had any of the		
	4 Always		following medical conditions:		
	- Always		Yes No		
140	How often do you fool that you have a lot	a.	Diabetes or high blood sugar? 1		
JIJ.	How often do you feel that you have a lot in common with the people around you?		MedConditions_Diabetes High blood pressure or hypertension? 1 2		
	LotInCommonPeople		MedConditions HighBP		
	Never	C.	A heart condition such as heart attack, angina, or congestive heart failure? 1		
	Rarely	4	MedConditions_HeartCondition Chronic lung disease, asthma,		
	Sometimes	u.	emphysema, or chronic bronchitis? 1		
	4 Always	e.	MedConditions_LungDisease Depression or anxiety disorder?		
			MedConditions_Depression		
J14.	How often do you feel close to people?				
	FeelClosePeople Never	J17.	About how tall are you without shoes? Height Feet, Height Inches		
	2 Rarely				
	3 Sometimes		Feet and Inches		
	4 Always				
		J18.	About how much do you weigh, in pounds without shoes?		
			Weight		
			Pounds		

J19. Over the past 2 weeks, how often have you been bothered by any of the following problems?

¥/€

		Nearly every	More than h	Several da	Notatall
a.	Little interest or pleasure in doing things	1	2	3	4
b.	Feeling down, depressed, or hopeless	1	2	3	4
C.	Feeling nervous, anxious, or on edge	1	2	3	4
d.	Not being able to stop or control worrying	1	2	3	4

J20. How much do you agree or disagree with the following statements?



J21. How much do you agree or disagree with the following statement?

ExpectWorst

I go to medical appointments expecting the worst.

1 Strongly agree

Threatened Strengths

- 2 Agree
- Neither agree nor disagree
- 4 Disagree
- 5 Strongly disagree

J22. From the set of values below, which ONE is most important to you in your day-to-day

MostImportantValues

Mark only one.

- Making my own decisions
- 2 Being happy
- 3 Helping people
- 4 Being loyal to family and friends
- 5 Having a deep connection to my religion
- 6 Keeping myself in good health
- 7 Assuring my family is safe and secure

K: Health and Nutrition

K1. Thinking about the last time you ordered food in a fast food or sit down restaurant, did you notice calorie information listed next to the food on the menu or menu board?

NoticeCalorieInfoOnMenu

- 1 Yes
- 2 No

K2. To what extent would you support or oppose the following?

> Junk food products, including candy, chips, soda, and flavored sports drinks, should not be advertised to children on social media.

JunkFoodAdRestrictions

- 1 Strongly oppose
- 2 Oppose
- 3 Neither support nor oppose
- 4 Support
- 5 Strongly support

K3. These are examples of one drink of alcohol:



During the past 30 days, how many days per week did you have at least one drink of any alcoholic beverage?



K4. During the past 30 days, on the days when you drank, about how many drinks did you drink on average?

_	DrinksPerDay
	Average drinks <u>per day</u>

K5. *For males:* During the past 30 days, how many times did you have 5 or more alcoholic drinks on one occasion?

For females: During the past 30 days, how many times did you have 4 or more alcoholic drinks on one occasion?

DrinksOneOccasion

- 1 Never
- 2 1 or 2 times
- 3 to 5 times
- 4 6 to 10 times
- 5 11 or more times

K6. In your opinion, how much does drinking the following types of alcohol affect the risk of getting cancer?

		Decreases rist	Decreases ric.	No effect	Increases rist	Ses	Don't kno
a.	Beer CancerRisk	1	2	3	4	5	6
b.	Wine CancerRisk	1	2	3	4	5	6
C.	Liquor	1	2	3	4	5	6
	Liquor_CancerRisk						

K7. In your opinion, how much does drinking the following types of alcohol affect the risk of getting heart disease?

		Decreases rich	Decreases rist	No effect	Increases rist	ses.	Don't Know
a.	Beer HeartRisk	1	2	3	4	5	6
b.	Wine HeartRisk	1	2	3	4	5	6
C.	Liquor_HeartRisk	1	2	3	4	5	6

K8. To reduce the problems associated with excessive alcohol use, to what extent would you support or oppose...

		Strongly	asoddo)	Neither Sup.	odd Support	Strongly
a.	Banning outdoor advertising of alcohol such as on billboards and bus stops? ExcessiveAlcohol BanAds	1	2	3	4	5
b.	Requiring specific health warnings on alcohol containers?	1	2	3	4	5
C.	Requiring alcohol containers to show the recommended drinking guidelines for keeping health risks low?	1	2	3	4	5

L: Physical Activity and Exercise

L1. 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 (do not include weightlifting)?

TimesModerateExercise

0	None → GO TO L3 below
1	1 day per week
2	2 days per week
3	3 days per week
4	4 days per week
5	5 days per week

6 days per week

7 days per week

L2. On the days that you do any physical activity or exercise of at least moderate intensity, how long do you typically do these activities?

	HowLongModerateExerciseMinutes
	_
	Minutes per day

L3. <u>In a typical week</u>, 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)?

TimesStrengthTraining None

ت	
1	1 day per week
2	2 days per week
3	3 days per week
4	4 days per week

5 | 5 days per week 6 days per week

7 days per week

L4. During the past 7 days, how much time did you spend sitting on a typical day at home or at work? This may include time spent sitting at a desk, visiting friends, reading, driving or riding in a car, or sitting or lying down to watch television.

	AverageTimeSitting
	Hours per day

M: Tobacco Products

M1. Have you smoked at least 100 cigarettes in your entire life?

	Smoke100
	Yes
2	No → GO TO M3 below
₩	

M2. How often do you now smoke cigarettes?

1	SmokeNow Every day
2	Some days
3	Not at all

M3. New types of cigarettes are now available called electronic cigarettes or e-cigarettes (also known as vapes, vape-pens, tanks, mods or pod-mods). These products deliver nicotine through a vapor. Compared to smoking cigarettes, would you say that electronic cigarettes are...

	ElectCigLessHarm
1	Much less harmful,
2	Less harmful,
3	Just as harmful,
4	More harmful,
5	Much more harmful, or
7	I don't know

M4. Have you ever used an e-cigarette, even one or two times? UsedECigEver 1 Yes 2 No → GO TO M6 below M5. Do you now use an e-cigarette every day,	M7. To what extent would you support or oppose the following measures related to cigarettes?
some days, or not at all? UseECigNow Every day Some days Not at all	a. Just like with violence and sex, movies with cigarette smoking should be rated "R" to protect children and youth from seeing cigarette smoking in movies
M6. Heated tobacco products, also known as heat-not-burn tobacco products, use a technology that heats tobacco instead of burning it. These are NOT the same as e-cigarettes. Some brands of heated tobacco products include IQOS and Eclipse.	b. Cigarette packs should be required to have warning labels that use both images and words to show the negative health effects of smoking
Thinking about heated tobacco products, which of the following statements BEST applies to you? HeardHeatedTobacco I have never heard of heated tobacco products I have heard of heated tobacco products but have never tried them I have tried heated tobacco products but do not use them anymore	M8. To what extent would you support or oppose the following measures related to all tobacco products, including cigarettes, e-cigarettes, smokeless tobacco, hookah, and cigars?
4 I currently use heated tobacco products 5 Don't know	a. Stores should be required to keep tobacco products out of customers' view at the checkout counter

N: Cancer Screening and Awareness

N1. For males: GO TO N3 below

For females: How long ago did you have your most recent Pap test to check for cervical cancer?

WhenPapTest

- 1 A year ago or less
- 2 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
- 6 I have never had a Pap test
- N2. When did you have your most recent mammogram to check for breast cancer, if ever?

WhenMammogram

- A year ago or less
- 2 More than 1, up to 2 years ago
- More than 2, up to 3 years ago
- More than 3, up to 5 years ago
- 5 More than 5 years ago
- 6 I have never had a mammogram
- N3. There are a few different tests to check for colon cancer. These tests include:

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.

A sigmoidoscopy - For this test, you are awake when the tube is inserted into your rectum. After the test you can drive yourself home.

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.

Have you ever had one of these tests to check for colon cancer?

EverTestedColonCa

- 1 Yes
- 2 No

N4. Have you ever heard of **HPV**? HPV stands for Human Papillomavirus. It is not HCV, HIV, HSV, or herpes.

HeardHPV 1 Yes 2 No → GO TO N6 below

N5. Do you think **HPV** can cause...

				Not
		Yes	No	sure
			\sim	
a.	Cervical Cancer?	1	2	3
b.	HPVCauseCancer_Cervical Penile Cancer? HPVCauseCancer Penile	1	2	3
C.	Anal Cancer?	. 1	2	3
d.	Oral Cancer?	1	2	3
	HPVCauseCancer_Oral			_

N6. A vaccine to prevent **HPV** infection is available and is called the HPV shot, cervical cancer vaccine, GARDASIL®.

> Before today, have you ever heard of the cervical cancer vaccine or HPV shot?

HeardHPVVaccine2

- 1 Yes
- 2 No

O: Beliefs About Cancer

O1. How worried are you about getting cancer again?

FreqWorryCancerAgain

- 1 Not at all
- 2 Slightly
- 3 Somewhat
- 4 Moderately
- 5 Extremely



			•
O2.	How much do you agree each of the following state	ements?	
		Strongly agreed Somewhat Somewhat sisagree Strongly disagree	
a.	It seems like everything causes cancer	1 2 3 4	
b.	There's not much people can do to lower their chances of	1 2 3 4	P4. In the past 30 days, did you usually work
C.	getting cancer		35 hours or more per week in total at all jobs or businesses? WorkFullTime 1 Yes
	to know which ones to follow	1 2 3 4	2 No
O3.	How much do you think the following can influence when the following can be seen to be a seen as		P5. Which of the following best describe your current occupational status?
	person will develop cance		Mark all that apply.
b.	Being overweight or obese InfluenceCancer_Obesity Gaining weight in adult life InfluenceCancer_AdultWeig Eating too much red meat InfluenceCancer_RedMeat	ght	<pre>1 Employed Occupation Employed 1 Unemployed for 1 year or more Occupation 1YUnEmployed 1 Unemployed for less than 1 year Occupation Less1YUnEmployed 1 Homemaker Occupation_Homemaker 1 Student Occupation_Student 1 Retired Occupation_Retired 1 Disabled Occupation_Disabled 1 Other-Specify Occupation_Other</pre>
	P: You and Your Ho	ousehold	Occupation_Other_OS Occupation Cat
	T. Tod and Todi Tic	deciloid	FullTimeOcc_Cat
P1.	What is your age?		P6. What is your marital status? MaritalStatus
	Age		1 Married
	Years old		Living as married or living with a romantic partner
			3 Divorced
			4 Widowed

5 Separated

6 Single, never been married

P7.	What is the highest grade or level of schooling you completed? Education Less than 8 years 8 through 11 years 12 years or completed high school Post high school training other than college (vocational or technical) Some college College graduate Postgraduate	P10. How much do you agree or disagree with the following statement? I have a strong sense of belonging to my own ethnic group. EthnicGroupBelonging Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree
P8.	Are you of Hispanic, Latino/a, or Spanish origin? One or more categories may be selected. Mark <u>all that apply</u> . 1 No, not of Hispanic, Latino/a, or Spanish origin NotHisp 1 Yes, Mexican, Mexican American, Chicano/a	P11. Do you think of yourself as SexualOrientation Heterosexual, or straight Homosexual, or gay or lesbian Bisexual Something else – Specify
P9.	Mexican Yes, Puerto Rican PuertoRican Yes, Cuban Cuban Yes, another Hispanic, Latino/a, or Spanish origin OthHisp Hisp_Cat What is your race? One or more categories may be selected.	P12. Including yourself, how many people live in your household? TotalHousehold Number of people
	Mark <u>all that apply</u> . 1 White White Black or African American Black American Indian or Alaska Native AmerInd Asian Indian Chinese Chinese Filipino Filipino	P13. How many children under the age of 18 live in your household? ChildrenInhh Number of children under 18 P14. Thinking about politics these days, how would you describe your own political
	1 Japanese Japanese 1 Korean Korean Vietnamese Vietnamese Other Asian OthAsian 1 Native Hawaiian Hawaiian Guamanian or Chamorro Guamanian Samoan Samoan Other Pacific Islander OthPacIsl Race_Cat2	viewpoint? PoliticalViewpoint Very Liberal Liberal Somewhat Liberal Moderate Somewhat Conservative Conservative Very Conservative



P15.	Thinking about members of your family
	living in this household, what is your
	combined annual income, meaning the
	total pre-tax income from all sources
	earned in the past year?

IncomeRanges

- 1 \$0 to \$9,999
- 2 \$10,000 to \$14,999
- 3 \$15,000 to \$19,999
- 4 \$20,000 to \$34,999
- 5 \$35,000 to \$49,999
- 6 \$50,000 to \$74,999
- 7 \$75,000 to \$99,999
- 8 \$100,000 to \$199,999
- 9 \$200,000 or more
- P16. Which one of these comes closest to your own feelings about your household's income?

IncomeFeelings

- 1 Living comfortably on present income
- 2 Getting by on present income
- 3 Finding it difficult on present income
- 4 Finding it very difficult on present income

P17. We invite you to participate in future research studies. These studies are voluntary and will involve answering surveys similar to this one a few times a year.

> Can we send you a request to participate in additional studies?

	Yes
	No → GO TO END
1	_

P18. To make it easier to contact you, could you provide your e-mail address in the box below? This is voluntary and we will follow-up by mail if you do not provide an e-mail address.

E-mail:	

Thank you!

Please remember to sign the consent form on the inside cover of this booklet before returning the survey.

Please return this survey in the postage-paid envelope within 2 weeks.

If you have lost the envelope, mail the completed survey to:

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

