

OHSR RESPONSE TO REQUEST FOR REVIEW OF RESEARCH ACTIVITY
INVOLVING HUMAN SUBJECTS

FAX: 301-480-2198
To: Hesse, Bradford
NCI
EPN 4068

Exempt #: 13204

From: Office of Human Subjects Research (OHSR)

Nature of Research Activity:

The purpose of this study is to field Cycle V of the NCI Health Information National Trends (HINTS) survey. HINTS collects nationally representative data routinely about the American public's use of cancer-related information and in its current iteration collects data using a probability-based address sample. The survey is sponsored by NCI staff, and conducted by its contractor (Westat). NCI staff direct the design of the study, including the survey questionnaire and will conduct analysis of aggregate study data but have no contact

Original Request Received in OHSR on: 4/11/2016

Responsible NIH Research Investigator(s): Bradford Hesse, PhD NCI

OHSR review of your request dated Mon, Apr 11, 2016 has determined that:

- Federal regulations for the protection of human subjects do not apply to above named activity. The OHSR determination of Not Human Subjects Research is based on the interpretation of 45 CFR 46 under "Research Involving Coded Private Information or Biological Specimens" (OHRP, Revised October 16, 2008) and Guidance on Engagement of Institutions in Human Subjects Research (October 16, 2008). NOTIFY OHSR VIA AN E-MAIL AMENDMENT OF ANY CHANGES THAT MAY ALTER THIS RESEARCH ACTIVITY.
- The activity is designated **EXEMPT**, and has been entered in the OHSR database. PLEASE NOTIFY OHSR OF ANY SIGNIFICANT CHANGES THAT MAY ALTER THE EXEMPT STATUS OF THIS RESEARCH ACTIVITY.
- NOT EXEMPT.** OHSR recommends IRB review. Please forward your request to the Chair of your IRB, who may ask you to provide additional information in order to determine whether expedited or full review is appropriate.
- Confidentiality Agreement
- Reliance
- Amendment
- Other

Office Person JE

Admin Assist. CB

Note:
4/25/16: Survey research conducted by Westat



Julie M. Eiserman

Policy Analyst, OHSRP

4/25/2016

Signature

Title

Date

Domestic/International:

Domestic

Human Subjects Data: Yes

Biologic Material: No

OHSR Use Only

1 2 3 4 5 6

9-11-2015

OHSRP REQUEST FOR DETERMINATION FORM

II. SHOULD I STOP OR GO FORWARD WITH AN OHSRP SUBMISSION?

1. Have you already started or completed your research activity
 - Yes (**Stop here.** Please consult OHSRP.)
 - No

2. Is the proposed activity a component of a protocol that is under NIH IRB review, e.g. the results of this activity will be used in support of the protocol?
 - Yes (**Stop here.** You will likely need to amend the NIH protocol for the proposed activity. Please consult the IRB if you are unsure. Do not submit this request.)
 - No

3. Is this a research collaboration in which the NIH investigator has access to individually identifiable specimens/data (including coded specimens/data for which the investigator has the code key), and wants to send specimens/data that are either coded or anonymous to collaborators? *If the specimens/data are not individually identifiable, but the identity of the subjects may readily be ascertained by the investigator or associated with the information because of a small sample size or other reason, please answer "Yes" below.*
 - Yes (**Stop here.** You must obtain IRB approval of an amendment to the original protocol or IRB approval of a new protocol. Do not submit this request.)
 - No

4. Does this activity involve prisoners?
 - Yes (**Stop here.** Please consult the IRB. Do not submit this request.)
 - No

5. Please select the type of activity or materials involved in your project. (*Select all that apply.*)
 - 5a. **Single Case Report** that does not contain any identifiable information about the participant; and no changes were made to the participant's care for the sake of reportability
 - 5b. **Program Evaluation**, the results of which will only be shared with the relevant program or institution; and the participants have not been assigned to groups for comparison; and no comparison of a standard versus non-standard intervention is taking place
 - 5c. **Quality Assurance/Quality Improvement activity with a clinical practice focus**, that does not introduce an untested clinical intervention or collect patient outcomes for the purposes of collecting scientific evidence about how well the intervention achieves its intended results, **in which the sole purpose is to**

improve internal practice and not to also conduct research to develop or contribute to generalizable knowledge

- 5d. **Quality Assurance/Quality Improvement activity with a non-clinical practice focus**, e.g. usability testing or evaluation of websites, workshops, conferences, tools, policies, etc., **in which the sole purpose is to improve a product or service and not to also conduct research to develop or contribute to generalizable knowledge**
- 5e. **Clinical Consulting**
- 5f. **Diagnostic Testing for Clinical Purposes** (*Other approvals may be needed if investigational tests are used. Please consult your IC FDA representative or the FDA.*)
- 5g. **Autopsy Materials, Specimens/Data from Deceased Persons** (*Please contact your privacy officer for further guidance.*)
- 5h. Specimens/data purchased from a **commercial repository** which will contain no identifying information
- 5i. **Derivatives** of materials (e.g. DNA, RNA, cell fragments or sub-parts, viruses or parasites) obtained from humans which will contain no identifying information
- 5j. **Established NIH Human Embryonic Stem Cell Lines that are available to qualified investigators and require no ethical review according to the registry.** The cell line must be listed here: http://grants.nih.gov/stem_cells/registry/current.htm and not be identifiable to the NIH researchers.

*If 5a. - 5j. is selected above, and your proposed project involves **ONLY** these activities: **STOP** answering questions here. No submission or determination is required from OHSRP or an IRB. However, other NIH policies or IC requirements apply. Please retain this documentation for your files.*

*If your proposed project involves **any of these activities above and other activities not listed here or involves none of these activities above**, please continue with the request for determination form.*

III. WHAT ADDITIONAL DOCUMENTATION MUST BE SUBMITTED TO OHSRP WITH THE REQUEST FOR DETERMINATION FORM?

There are three categories of research that require additional documentation to be submitted to OHSRP with the request for determination form. The categories are:

PART I: GENERAL INFORMATION

This fillable form must be typed and submitted in pdf format, upon receipt of all required signatures. This form must be completed by NIH staff only.

1. Date of Request: **04/11/2016**
2. Is this a **new** request for determination or an **amendment** to a previously OHSRP-approved project? (**Please note** if this is an amendment, we ask that you use your previously submitted request for determination form to answer the questions on this form.)
 - a. New project
 - b. Amendment

If an amendment, provide the determination number of the original approved project: OHSRP#:

3. Project Name: **Health Information National Trends Survey V (HINTS V) (NCI)**

4. Project Description (*Please describe the research activity that will be performed in lay terms, including its purpose. Explain the roles of the NIH investigator and collaborator(s) on the project; and what each party will contribute to the research. As you type, the box will increase to allow for additional text.*):

The purpose of this study is to field Cycle V of the NCI Health Information National Trends (HINTS) survey. HINTS collects nationally representative data routinely about the American public's use of cancer-related information and in its current iteration collects data using a probability-based address sample. The survey is sponsored by NCI staff, and conducted by its contractor (Westat). NCI staff direct the design of the study, including the survey questionnaire, and will conduct analysis of aggregate study data, but have no contact with survey respondents, and no access to individual identifiers.

5. Proposed Start Date: **09/01/2016**

Proposed Completion Date (**Required**): **09/30/2018**

6. Requestor Details:

Name: **Brad Hesse, PhD** Institute/IC: **NCI**
 Phone Number: **(240)276 - 6721**
 Email Address: **hesseb@mail.nih.gov**

7. Are you the **Senior Investigator (SI)** for this project? (*i.e., the team lead. The term "SI" on this form does not refer to one's official NIH title. The SI must be an NIH FTE.*)

Yes No

- 7.1. If no, what is your role?
- a. Administrative Support
 - b. Other investigator
 - c. Other, *specify:*

8. **If not already included above**, provide SI details (*See instructions in Q. 7.*):

Senior Investigator Name:
 Institute/IC:
 Phone Number: () -
 Email Address:

SI Signature (Required): *Brenda D. Reese* **Date:** 4/11/2013

9. Supervisor Name: **William Klein, PhD**
(Please note the supervisor cannot be a member of the research team for this specific project.)

I (the supervisor) certify that the IC concurs that this project may proceed if it meets regulatory and NIH policy requirements.

Supervisor Signature (Required): *Ande Hebel for W. Klein* **Date:** 7/11/16
AD BRP

10. Is there someone other than the **SI**, conducting this research (*e.g. a junior investigator, contractor, fellow, student, etc.*)?

- Yes No

10.1. If yes, provide the following information:

| |
|--|
| NIH Investigator Name: Richard Moser, PhD |
| Institute/IC Name: NCI |
| Email Address: moserr@mail.nih.gov |

11. Please provide the name(s) and email(s) of anyone else, who should receive a copy of the OHSRP determination:

| | | |
|-----------------------------|----------------|----------|
| Name: Gordon Wills | Email | Address: |
| Willisg@mail.nih.gov | | |
| Name: | Email Address: | |
| Name: | Email Address: | |

12. What role(s) will the **NIH Investigator(s)** have on this research project? (*Select all that apply.*)

- a. Interacting directly with subjects to collect specimens/data
- b. Receiving specimens/data from a collaborator to conduct research
- c. Analyzing specimens/data

- d. Generating genomic data (e.g. GWAS, WES/WGS; *Additional NIH requirements may apply: <http://qds.nih.gov/03policy2.html>)*
- e. Running laboratory assays for research
- f. Sending specimens/data to a collaborator to conduct research
- g. Interacting directly or indirectly with subjects to recruit for or conduct surveys, interviews/focus groups, observation of public behavior, educational research or tests, or research on public benefit or service programs
- h. Consulting/advising the collaborator(s)
- i. Authoring publication(s)/manuscript(s) pertaining to this research
- j. Other, *specify:*

13. Will the SI be **collaborating on this research project with** any other person (*not on the NIH research team*) outside or inside the NIH?

- Yes No

13.1. If no, will the senior investigator **only be sending** specimens/data to someone not on the research team?

- Yes No (*If yes, please still add these individuals under Q.14 below.*)

14. Please include the details of each collaborator, his or her role, and when applicable, what will be sent or received. For any more than three collaborators, please provide the information requested below in the email request at the time of submission. *Provide the Federalwide Assurance (FWA)* number for each non-NIH collaborating institution (for more information contact OHSRP). Ask your collaborator for the FWA number or use this link to look it up:*

<http://ohrp.cit.nih.gov/search/fwasearch.aspx?styp=bsc>

**A Federalwide Assurance (FWA) is issued by the U.S. Department of Health and Human Services (DHHS)/Office of Human Research Protections (OHRP) to institutions which receive Federal funds/support to conduct non-exempt human subjects research. An FWA is an assurance of compliance with the U.S. Federal Policy for the Protection of Human Subjects, 45 C.F.R. 46.*

| |
|---|
| a. Collaborator Name: Terisa Davis |
| Institution/IC Name: Westat, Inc FWA #: 55551 |
| City/State/Country: Rockville, MD |
| Email Address: TerisaDavis@westat.com |
| Sending specimens/data: <input type="checkbox"/> Receiving specimens/data: <input checked="" type="checkbox"/> Both: <input type="checkbox"/> |
| Describe what will be sent/received: Ms. Davis is the contractor study manager having overall responsible for survey design, conduct, and data file proeduction and delivery to NCI. |

| |
|-----------------------|
| b. Collaborator Name: |
|-----------------------|

| | |
|--|--------|
| Institution/IC Name: | FWA #: |
| City/State/Country: | |
| Email Address: | |
| Sending specimens/data: <input type="checkbox"/> Receiving specimens/data: <input type="checkbox"/> Both: <input type="checkbox"/> | |
| Describe what will be sent/received: | |

| | |
|--|--------|
| c. Collaborator Name: | |
| Institution/IC Name: | FWA #: |
| City/State/Country: | |
| Email Address: | |
| Sending specimens/data: <input type="checkbox"/> Receiving specimens/data: <input type="checkbox"/> Both: <input type="checkbox"/> | |
| Describe what will be sent/received: | |

15. For this project, will NIH be conducting a research activity with de-identified specimens or data **in support of FDA-regulated research** that is currently under IRB review at another institution?

- Yes No

15.1 If yes, has the **collaborator confirmed** that the planned research activity, which will occur at NIH, is included in the IRB/ethics committee-approved *protocol and consent form* at his/her institution?

- a. Yes, the NIH activity is IRB-approved at the collaborating institution
 b. No, the NIH activity has not yet been IRB-approved at the collaborating institution (**Stop here. Do not submit this request until your collaborator has confirmed IRB approval at his or her institution.**)

16. Does this activity include any of the following? (*Select all that apply.*)

- a. **NIH research team is interacting directly with subjects in person or has access to identifiers** to conduct survey, interview/focus group procedures, observation of public behavior, educational tests, educational research, or research on public benefit or service programs (**If a. only, skip to question 25., otherwise continue.**)
 b. Research with Specimens/Data
 c. NIH BTRIS Query
 d. Case Series
 e. Program Evaluation (*not meeting the definition in the Instructions, Part II, Q. 5b.*)
 f. QA/QI (*not meeting the definition in the Instructions Part II, Q. 5c. or 5d.*)
 g. Other, *specify:*

16.1. If e. or f. is selected above, does the activity involve **the NIH research team interacting directly with subjects in person or access to identifiers** to conduct survey, interview, or focus group procedures only?

- Yes (**Skip to question 25.**)

No (*Continue.*)

PART II: RESEARCH WITH SPECIMENS AND DATA

17. Identify the types of specimens/data involved in this project. (*Select all that apply.*)

- a. Medical Records, *specify:*
- b. Specimens, *specify:*
- c. Data, *specify:* **Answers to survey questions**
- d. Imaging, *specify:*
- e. Pathological Waste/Results
- f. Autopsy Materials/Specimens/Data from deceased persons (*Please contact your privacy officer for further guidance.*)
- g. Audio Recording
- h. Video Recording/Conferencing
- i. Fetal Tissue Additional NIH requirements apply:
<https://oir.nih.gov/sourcebook/ethical-conduct/research-ethics/fetal-tissue-research>
- j. iPSC lines (*Additional NIH requirements apply:*
<https://oir.nih.gov/sourcebook/ethical-conduct/research-ethics/use-human-stem-cells/guidelines-human-embryonic-induced-pluripotent-stem-cells>
- k. hESC lines (*Additional NIH requirements apply:*
<https://oir.nih.gov/sourcebook/ethical-conduct/research-ethics/use-human-stem-cells/guidelines-human-embryonic-induced-pluripotent-stem-cells> AND
<https://oir.nih.gov/sourcebook/ethical-conduct/research-ethics/use-human-stem-cells/areas-prohibited-research>
- l. WES/WGS
- m. GWAS
- n. From a repository
If an NIH Repository, *specify:*
- o. From a publicly available source (*meaning unrestricted access by anyone*),
specify:
- p. Other, *specify:*

18. Do all the specimens/data or information already exist?

- a. Yes
- b. No
- c. Some exist, and other specimens/data will be collected in the future

19. The specimens/data in this project were (or will be) originally collected for:

- a. Clinical purposes only
- b. Research purposes (*even if also collected for clinical purposes*)

20. Is there active IRB/ethics committee approval for the use of the specimens/data at your collaborator's site?

- Yes No

21. Can you identify the subjects, who are the source of the specimens or data, directly or through codes linked to individual identifiers? Yes No
22. Please select the response(s) that best describe(s) the specimens/data that will be shared/used for this activity. (*Please confirm this with your collaborator prior to submitting this form.*)
- a. Specimens/data will not contain any identifiable information, and **cannot be linked to individual subjects by you or your collaborators.**
- b. Specimens/data will be coded, however that **code cannot be used by either the sender or the receiver** to identify specific individuals.
- c. Specimens/data will be coded **so that the sender of the samples/data can link them to specific individuals**, but the receiver will not be able to do so.
- d. Specimens/data will contain **individually identifiable information.**
- e. Specimens/data currently contain identifiable information but data will be recorded in such a manner that subjects **cannot be identified directly, or through identifiers linked to subjects (e.g. a retrospective chart review), or an honest broker will be utilized for de-identification.**
23. If existing identifiable specimens/ data will be de-identified (including coded) before the research activity commences, please indicate who will conduct the de-identification:
- a. Collaborator(s)
- b. Senior investigator or a member of the research team at the NIH
- c. Honest broker (*For use only when identified specimens or data are coming from an NIH investigator; must be someone who will not be conducting the research*) (*The agreement can be found here: <https://federation.nih.gov/ohsr/nih/formtmp.php> (NIH Login required)*)
24. Will recipient of specimens/data be returning results to the sender? (*Select all that apply*)
- a. Yes, coded results will be returned to the sender who can link them to individual subjects
- b. Yes, coded results will be returned, but neither the sender nor the recipient will have a link to the code key
- c. Only aggregate results will be returned (e.g. summary statistics, **not individual line-item data**)
- d. No, results will not be returned

- 24.1. If a.- c. is selected above **AND the sender is external to NIH**, is there IRB/ethics committee approval at his or her institution for the planned research activity to be conducted at NIH? Yes No

For all requests, other than those involving survey, interview/focus group procedures, observation of public behavior, educational research or tests, or research on public benefit or service programs, stop here. Otherwise, continue to Part III.

*Prior to submitting, review the instructions to insure that you include **the correct supportive documentation**. All documentation should be submitted in **.pdf format via email** to OHSRP to ohsr_nih_ddir@od.nih.gov. Please write **'Request for Review'** in the subject line of the e-mail.*

PART III: RESEARCH INVOLVING EDUCATIONAL RESEARCH OR TESTING, SURVEY OR INTERVIEW PROCEDURES, OR OBSERVATION OF PUBLIC BEHAVIOR

25. Specify the nature of the data to be collected by: *(Select all that apply)*

- a. Educational Research
 b. Educational Testing
 c. Survey or Interview/Focus Group Procedures
 d. Observation of public behavior
 e. Research on public benefit or service programs
 f. Other, *specify*:

26. How will recruitment and data collection take place? *(Select all that apply)*

- a. In-person at my collaborator's institution(s) or research site(s), *specify*:
 b. In-person at an NIH site
 c. In-person at another site(s), *specify*:
 d. Online
 e. Over the phone
 f. Other, *specify*: **By mail**

27. Who will be conducting the data collection? *(Select all that apply)*

- a. NIH investigator or another member of the research team
 b. Non-NIH collaborator
 c. Off-site contractor, *specify* what company: **Westat**
 d. Online survey tool, *specify*:
 e. Other, *specify*:

28. What is the age range of subjects involved in the research?

- a. Children aged < 18 years
 b. Adults aged ≥18 years

28.1. If a. is selected above, and the project involves observation of public behavior, will the NIH investigator(s) participate in the activities being observed?

Yes No

29. Does your project fall into any of the categories of 'clinical research' as defined by the NIH? (See <http://grants.nih.gov/grants/glossary.htm#ClinicalResearch> for the full NIH definition of 'clinical research'.)

- a. Epidemiological and behavioral studies*
 b. Outcomes research and health services research*
 c. NONE OF THE ABOVE

**If you a. or b. is selected above, please be sure to include the 'Planned Enrollment' Table described in Part II of the instructions.*

*Prior to submitting, review the instructions to insure that you include **the correct supportive documentation**. All documentation should be submitted in **.pdf format via email** to OHSRP to ohsr_nih_ddir@od.nih.gov. Please write **'Request for Review'** in the subject line of the e-mail.*

Eiserman, Julie (NIH/OD) [C]

From: Willis, Gordon (NIH/NCI) [E]
Sent: Monday, April 25, 2016 2:47 PM
To: Eiserman, Julie (NIH/OD) [C]
Cc: Moser, Richard (NIH/NCI) [E]; Terisa Davis (TerisaDavis@westat.com); Hesse, Bradford (NIH/NCI) [E]
Subject: RE: Response Request re: Request for Determination for OHSRP #13204
Attachments: Appendix C - Draft Cycle 1 Instrument.pdf; Appendix H - IRB Approval.pdf; Appendix B - Letters & FAQs.pdf

Hi Julie:

HINTS was Approved by Westat via Expedited Approval (Appendix H – IRB Approval, attached).

The draft questionnaire is Appendix C – Draft Cycle 1 Instrument.

Because this is a mail survey, there isn't a signed consent form, but I have also included the letters that are to be sent with the questionnaire.

The Attachments are selected materials from the OMB package we are putting together – if you would like any other info, please just let me know.

Thanks much, as always –

Gordon

Gordon Willis, PhD
BRP/NCI

From: Eiserman, Julie (NIH/OD) [C]
Sent: Monday, April 25, 2016 1:22 PM
To: Hesse, Bradford (NIH/NCI) [E]
Cc: Moser, Richard (NIH/NCI) [E]; Willis, Gordon (NIH/NCI) [E]
Subject: Response Request re: Request for Determination for OHSRP #13204
Importance: High

Hello Dr. Hesse,

When other sites are conducting research projects for NIH (the research has been designed by NIH), my supervisor has asked me to collect additional information about the project as part of the approval process. Could you find out if Westat has received an exemption, expedited or full committee IRB approval for the project? Could you also please send me a copy of the information sheet/consent form AND the instrument that will be used with the subjects?

Thank you.

Julie M. Eiserman, MA, CCRP [C]
Health Science Policy Analyst
Office of Human Subjects Research Protections

Office of Intramural Research, Office of the Director

National Institutes of Health

10 Center Drive, Bldg. 10, Suite 2C146

Bethesda, MD 20892-1154

Direct Phone: 301-402-8665

Fax: 301-402-3443

Email: julie.eiserman@nih.gov

Site for the request for determination form: <https://federation.nih.gov/ohsr/nih/formtmp.php>

OHSRP website: <https://federation.nih.gov/ohsr/nih/index.php> (NIH login required)

Public site: <http://ohsr.od.nih.gov/>




An Employee-Owned
Research Corporation

Memo

Date: March 28, 2016

To: Marsha Dunn, Project Director

From: Sharon Zack, Primary Reviewer, Westat IRB 
Sharon Zack
I am the author of this document 

Subject: **Expedited Approval of HINTS, Project Number 6048.14**
FWA 00005551

I reviewed the materials submitted for the following: **HINTS, Project Number 6048.14**. The Westat IRB reviews all studies involving research on human subjects. This project is funded by the National Cancer Institute.

The purpose of HINTS is to assess the ways in which the general population uses communication channels to obtain information about health and cancer. The survey monitors the use of information resources while collecting information about respondents' knowledge, attitudes and behaviors related to health and cancer. There have been multiple previous rounds of HINTS data collection since 2003.

Westat will conduct the data collection.

IRB regulations permit expedited review of certain activities involving minimal risk [45 CFR pt. 46.110]. This study can be considered minimal risk and is approved under expedited authority. Per [45 CFR 46.117(c)], a waiver of documentation of informed consent is also approved as the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

As the Project Director, you are responsible for the following:

- You are required to submit this study for a continuing review before March 28, 2017.
- In the interim, notify the IRB Office as soon as possible if there are any injuries to subjects as well as problems or changes with the study that relate to human subjects.

cc: Institutional Review Board
Alicia Sutherland



APPENDIX B: Cover letters and FAQs

FIRST MAILING

Dear {City} Resident:

We are writing to invite you to take part in an important national survey sponsored by the U.S. Department of Health and Human Services, the Health Information National Trends Survey (HINTS). The goal of HINTS is to learn what health information people want to know and where they try to find it. By completing this questionnaire, you will help us learn what health information you need and how to make that information available to you, your family and your community.

In order to make sure we get responses from a random sample of people, we ask that the adult in your household with the next birthday complete and return this questionnaire in the next two weeks.

Your participation is voluntary and your responses will not be linked to your name. We have enclosed \$2 as a token of our appreciation for your participation.

You can find out more about HINTS at hints.cancer.gov. Westat, a research firm, will conduct the survey. If you have any questions about HINTS {or if you need more questionnaires}, or if you would like to complete this survey in a language other than English or Spanish, please call Westat toll-free at 1-888-738-6805.

Thank you in advance for your cooperation.

Sincerely,

Bradford W. Hesse, Ph.D.

HINTS Project Officer

National Institutes of Health

U.S. Dept of Health and Human Services

Si prefiere recibir la encuesta en español, por favor llame al 1-888-738-6812.

The Health Information National Trends Survey is authorized under 42 USC, Section 285A.

POSTCARD TEXT

A few days ago you should have received a questionnaire packet asking for your household's participation in the Health Information National Trends Survey. By completing the questionnaire, you can help the U.S. Department of Health and Human Services determine the best ways of communicating important health information to members of your community.

We are inviting the adult in the household with the next birthday to complete the questionnaire. If that adult has already completed the questionnaire and returned it to us, please accept my sincere thanks. If that adult has not yet completed and returned the questionnaire, we ask that he or she please do so as soon as possible.

Your household's participation is important to the study's success.

Sincerely,

A handwritten signature in blue ink that reads "Bradford W. Hesse". The signature is written in a cursive style with a large initial 'B'.

Bradford W. Hesse, Ph.D.
HINTS Project Officer
National Institutes of Health
U.S. Dept. of Health and Human Services



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

SECOND AND THIRD MAILINGS

Dear {City} Resident:

We recently invited you to participate in an important national survey sponsored by the U.S. Department of Health and Human Services (HHS). The goal of the Health Information National Trends Survey (HINTS) is to learn what health information people want to know and where they go to find it. Your responses will help us keep you, your family and members of your community better informed on the health issues that matter to you.

We have not yet received your completed questionnaire. To make sure HINTS provides accurate information, we need all the households invited to participate in this year's HINTS to complete the survey. If you did send back your survey and it crossed in the mail with this letter, thank you for the time you took to help make this study a success. In the event that your questionnaire was misplaced, an additional copy is enclosed.

In order to make sure we get responses from a random sample of people, we ask that the adult in your household with the next birthday complete and return this questionnaire in the next two weeks.

Additional information about HINTS is available at: hints.cancer.gov. If you have any questions, or would like to complete this survey in a language other than English or Spanish, please call Westat toll free at 1-888-738-6805.

Thank you in advance for contributing to this important national study.

Sincerely,

Bradford W. Hesse, Ph.D.

HINTS Project Officer

National Institutes of Health

U.S. Dept of Health and Human Services

Si prefiere recibir la encuesta en español, por favor llame al 1-888-738-6812.

The Health Information National Trends Survey is authorized under 42 USC, Section 285A.



FIRST MAILING – SPANISH (sent upon request)

Estimado residente de {City}

Le escribimos para invitarlo a participar en una importante encuesta nacional: Encuesta Nacional de Tendencias de Información sobre la Salud (HINTS, por sus siglas en inglés). Esta encuesta está patrocinada por el Departamento de Salud y Servicios Humanos de Estados Unidos.

El objetivo de HINTS es averiguar qué información sobre la salud les interesa saber a las personas y dónde tratan de buscarla. Complete este cuestionario para ayudar a averiguar la información sobre la salud que usted necesita y cómo ponerla a disposición suya, de su familia y de su comunidad.

Para asegurarnos de obtener respuestas que contengan un muestreo aleatorio de la población, le pedimos que el adulto en su hogar con el próximo cumpleaños, complete y devuelva este cuestionario en las próximas dos semanas.

Su participación es voluntaria y sus respuestas no se asociarán con su nombre. Hemos incluido \$2 dólares como símbolo de nuestro agradecimiento por su participación.

Usted podrá encontrar más información sobre HINTS en el sitio web hints.cancer.gov. La compañía de estudios de investigación Westat está realizando esta encuesta. Si tiene alguna pregunta sobre HINTS o le gustaría completar esta encuesta en otro idioma distinto al inglés o español, llame a Westat al siguiente número de teléfono libre de cargo, 1-888-738-6812.

Gracias de antemano por su cooperación.

Atentamente,

Bradford W. Hesse, Ph. D.

Oficial del Proyecto HINTS
Institutos Nacionales de la Salud
Departamento de Salud y Servicios Humanos de
EE.UU.

La Encuesta Nacional de Tendencias de Información sobre la Salud está autorizada bajo la Sección 285A del USC 42.



SECOND MAILING - Spanish

Estimado residente de {City}:

Recientemente lo invitamos a participar en una importante encuesta nacional patrocinada por el Departamento de Salud y Servicios Humanos de Estados Unidos. El objetivo de la Encuesta Nacional de Tendencias de Información sobre la Salud (HINTS, por sus siglas en inglés) es averiguar cuál es la información sobre la salud que las personas quieren saber y dónde van a buscarla. Sus respuestas nos ayudarán a mantenerlo mejor informado a usted, a sus familiares y a los miembros de la comunidad sobre los temas de salud que les interesan.

Aún no hemos recibido su cuestionario completado. Para poder estar seguros de que HINTS provea información acertada, necesitamos que todos los hogares invitados a participar en la encuesta este año, la completen. Si usted ya nos envió de regreso su encuesta y se cruzó con esta carta en el correo, le agradecemos por el tiempo que se tomó para contribuir al éxito de este estudio. En caso que su cuestionario se haya extraviado, adjuntamos una copia adicional.

Para asegurarnos de obtener respuestas que contengan un muestreo aleatorio de la población, le pedimos que el adulto en su hogar con el próximo cumpleaños, complete y devuelva este cuestionario en las próximas dos semanas.

Usted podrá encontrar más información sobre HINTS en el sitio web hints.cancer.gov. Si usted tiene preguntas o le gustaría completar esta encuesta en otro idioma distinto al inglés o español, llame a Westat al número libre de cargo, 1-888-738-6812.

Gracias de antemano por contribuir al éxito de este importante estudio nacional.

Atentamente,

Bradford W. Hesse, Ph. D.

Oficial del Proyecto HINTS
Institutos Nacionales de la Salud
Departamento de Salud y Servicios Humanos de
EE.UU.

La Encuesta Nacional de Tendencias de Información sobre la Salud está autorizada bajo la Sección 285A del USC 42.



THIRD MAILING - Spanish

Estimado residente de {City}:

Recientemente lo invitamos a participar en una importante encuesta nacional patrocinada por el Departamento de Salud y Servicios Humanos de Estados Unidos, la Encuesta Nacional de Tendencias de Información sobre la Salud (HINTS, por sus siglas en inglés). El completar esta encuesta nos ayudará a mantenerlos mejor informados en asuntos de salud que usted y su familia consideran importantes.

Si usted ya envió de regreso su encuesta y se cruzó con esta carta en el correo, le agradecemos por el tiempo que se tomó para contribuir al éxito de este estudio.

Si aún no ha tenido la oportunidad de completar la encuesta, comprendemos que a veces es difícil encontrar el tiempo para participar en un estudio como HINTS. Para reducir la cantidad de tiempo que va a tomarle, hemos incluido una versión más corta de la encuesta. Esta versión corta se concentra en asuntos que nos informan la manera como personas como usted buscan y utilizan información sobre la salud.

Para asegurarnos de obtener respuestas que contengan un muestreo aleatorio de la población, le pedimos que el adulto en su hogar con el próximo cumpleaños, complete y devuelva este cuestionario en las próximas dos semanas.

Usted podrá encontrar más información sobre HINTS en el sitio web hints.cancer.gov. Si usted tiene preguntas o le gustaría completar esta encuesta en otro idioma distinto al inglés o español, llame a Westat al número libre de cargo, 1-888-738-6812

Gracias de antemano por contribuir con este importante estudio nacional.

Atentamente,

Bradford W. Hesse, PhD.

Oficial del Proyecto HINTS

Institutos Nacionales de la Salud

Departamento de Salud y Servicios Humanos de EE.UU.

La Encuesta de Nacional de Tendencias de Información sobre la Salud está autorizada bajo la Sección 285A del USC 42.

Some Frequently Asked Questions about the Health Information National Trends Survey

Q: What is the study about? What kind of questions do you ask?

A: The study concerns health and how people receive health information. For example, we will ask how you usually get information about how to stay healthy, the sources of information you most trust, and how you might like to get such information in the future. We will also ask about your beliefs on what contributes to good health, how best to prevent cancer, your participation in various health-related activities, and related topics.

Q: How will the study results be used? What will be done with my information?

A: Findings will help the U.S. Department of Health and Human Services promote good health and prevent disease by determining ways of better communicating accurate health information to Americans.

Q: How did you get my address?

A: Your address was randomly selected from among all of the known home addresses in the nation. It was selected using scientific sampling methods.

Q: Why should I take part in this study? Do I have to do this?

A: Your participation is voluntary, and you may refuse to answer any questions or withdraw from the study at any time. However, your answers are very important to the success of this study and will represent thousands of others. Getting an answer from all the households chosen for the study is the best way to make sure the study results reflect the thoughts and opinions of all Americans.

Q: Will my answers to the survey be kept private?

A: Yes. Your answers will be kept private under the Privacy Act. Your answers cannot be connected to your name or any other information that could identify you or your household, to the extent provided by law. The completed questionnaires will be stored in a separate file with restricted access. Both the paper and electronic versions of the information will be destroyed shortly after the research is finalized.

Q: How long will it take to answer the questions?

A: About 20 to 30 minutes.

Q: Who is sponsoring the study? Is this study approved by the Federal Government?

A: The study is sponsored by the U.S. Department of Health and Human Services. The study has been approved by the Office of Management and Budget (OMB), the office that reviews all federally-sponsored surveys. The OMB approval number assigned to this study is 0925-0538.

Q: Who is Westat?

A: Westat is a research company located in Rockville, Maryland. Westat is conducting this survey under contract to the U.S. Department of Health and Human Services.

Preguntas Frecuentes Encuesta Nacional de Tendencias de Información sobre la Salud

P: ¿De qué se trata el estudio? ¿Qué tipo de preguntas contiene?

R: El estudio trata sobre la salud y la manera en que las personas reciben información sobre la salud. Por ejemplo, le preguntaremos cómo obtiene normalmente información sobre cómo mantenerse saludable, el tipo de información en la que más confía y cómo le gustaría obtener dicha información en el futuro. También le preguntaremos sobre lo que cree que contribuye a la buena salud, cómo prevenir mejor el cáncer y su participación en varias actividades afines.

P: ¿Cómo se utilizarán los resultados del estudio? ¿Qué se hará con mi información?

R: Los hallazgos ayudarán al Departamento de Salud y Servicios Humanos de EE.UU. a fomentar la buena salud y prevenir las enfermedades mediante la determinación de formas de comunicar mejor la información sobre la salud a los estadounidenses.

P: ¿Cómo obtuvieron mi dirección?

R: Su dirección fue seleccionada al azar entre todas las direcciones conocidas en la nación usando métodos científicos de muestreo.

P: ¿Por qué debo participar en este estudio? ¿Es obligatorio hacerlo?

R: Su participación es voluntaria y usted puede rehusarse a contestar cualquiera de las preguntas o retirarse del estudio en cualquier momento. Sin embargo, sus respuestas son muy importantes para el éxito de este estudio y representan a miles de personas. El obtener respuesta de todos los hogares escogidos para este estudio es la mejor manera de asegurar que éste refleje los pensamientos y opiniones de todos los estadounidenses.

P: ¿Se mantendrá la privacidad de mis respuestas a la encuesta?

R: Sí. Se mantendrá la privacidad de sus respuestas en virtud de la Ley de Privacidad. Sus respuestas no pueden asociarse a su nombre ni a ninguna otra información que podría identificarlo a usted o a su hogar en la medida de lo permisible por ley. Los cuestionarios completos se almacenarán en un archivo separado con acceso restringido. Las versiones impresas y electrónicas de la información se destruirán poco después de la finalización de la encuesta.

P: ¿Cuánto tiempo tomará responder las preguntas?

R: Cerca de 20 a 30 minutos.

P: ¿Quién patrocina el estudio? ¿Está este estudio aprobado por el Gobierno Federal?

R: El estudio es patrocinado por el Departamento de Salud y Servicios Humanos de EE.UU. El estudio ha sido aprobado por la Oficina de Administración y Presupuesto (OMB, por sus siglas en inglés). Esta oficina revisa todas las encuestas patrocinadas federalmente. El número de aprobación asignado por la OMB para este estudio es 0925-0538.

P: ¿Quién es Westat?

R: Westat es una compañía de estudios de investigación ubicada en Rockville, Maryland. Westat realiza esta encuesta en virtud de un contrato con el Departamento de Salud y Servicios Humanos de EE.UU.



Health Information

National Trends Survey



National Institutes of Health
U.S. Department of Health and Human Services



START HERE:

1. Is there more than one person age 18 or older living in this household?

Yes
 No → **GO TO A1 on the next page**

2. Including yourself, how many people age 18 or older live in this household?

| | |
|--|--|
| | |
|--|--|

3. **The adult with the next birthday should complete this questionnaire.** This way, across all households, HINTS will include responses from adults of all ages.

4. Please write the first name, nickname or initials of the adult with the next birthday. This is the person who should complete the questionnaire.

| |
|--|
| |
|--|

Si prefiere recibir la encuesta en español, por favor llame 1-888-738-6812

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 285a1.3). 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 30 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 (0920-0538). Do not return the completed form to this address.

A: Looking For Health Information

A1. Have you ever looked for information about health or medical topics from any source?

- Yes
 No → **GO TO A6 in the next column**

A2. The most recent time you looked for information about health or medical topics, where did you go first?

Mark **only 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

A3. The most recent time you looked for information about health or medical topics, who was it for?

- Myself
 Someone else
 Both myself and someone else

A4. Have you ever looked for information about cancer from any source?

- Yes
 No → **GO TO A6 in the next column**

A5. Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with each of the following statements?

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| a. It took a lot of effort to get the information you needed..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. You felt frustrated during your search for the information..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. You were concerned about the quality of the information | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. The information you found was hard to understand | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

A6. 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
 Not confident at all

A7. In general, how much would you trust information about health or medical topics from each of the following?

| | Not at all | A little | Some | A lot |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. A doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Family or friends..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Newspapers or magazines..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Radio | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Internet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Television | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Government health agencies | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Charitable organizations..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Religious organizations and leaders..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

A8. Imagine that you had a strong need to get information about health or medical topics. Where would you go first?

Mark only 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 →

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

| | Daily | Sometimes | Never | N/A |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Computer at home..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Computer at work..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Computer at school..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Computer in a public place (library, community center, other)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. On a mobile device (cell phone/smart phone/tablet)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. On a gaming device/ "Smart TV"..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Other..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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?

- Yes
- No → **GO TO B4 in the next column**

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

| | Yes | No |
|--|--------------------------|--------------------------|
| a. A regular dial-up telephone line..... | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Broadband such as DSL, cable or FiOS.. | <input type="checkbox"/> | <input type="checkbox"/> |
| c. A cellular network (i.e., phone, 3G/4G).... | <input type="checkbox"/> | <input type="checkbox"/> |
| d. A wireless network (Wi-Fi)..... | <input type="checkbox"/> | <input type="checkbox"/> |

B4. Please indicate if you have each of the following.

Mark all that apply.

- Tablet computer like an iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire
- Smartphone, such as an iPhone, Android, Blackberry, or Windows phone
- Basic cell phone only
- I do not have any of the above

B5. On your tablet or smartphone, do you have any software applications or “apps” related to health?

- Yes
- No → **GO TO B7**
- Don't know → **GO TO B7**
- Do not have a tablet or smartphone → **GO TO B7**

B6. Have these apps done any of the following?

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. Helped you achieve a health-related goal such as quitting smoking, losing weight, or increasing physical activity..... | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Helped you make a decision about how to treat an illness or condition | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Led you to ask a health care provider new questions, or to get a second opinion from another health care provider | <input type="checkbox"/> | <input type="checkbox"/> |

B7. Have you used an electronic device or application that monitors or tracks your health within the last year? Examples include electronically tracking your fitness, monitoring your blood glucose levels or blood pressure.

- Yes
- No → **GO TO B9**
- Don't know → **GO TO B9**

B8. Have you shared health information from the monitoring device with a health care provider/professional within the last year?

- Yes
- No
- Don't know

B9. 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?

- | | Yes | No |
|---|--------------------------|--------------------------|
| a. Visited a social networking site, such as Facebook or LinkedIn..... | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Shared health information on social networking sites, such as Facebook or Twitter..... | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Wrote in an online diary or blog (i.e., Web log) | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Participated in an online forum or support group for people with a similar health or medical issue | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Watched a health-related video on YouTube..... | <input type="checkbox"/> | <input type="checkbox"/> |

B10. In the past 12 months, have you used the Internet to look for information about cancer for yourself?

- Yes
- No

B11. Have you sent or received a text message from your healthcare provider within the last year?

- Yes
- No
- Don't know

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?

- Yes
 No

C2. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

- Yes
 No

C3. 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

C4. 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?

- None → **GO TO D1 on the next page**
 1 time
 2 times
 3 times
 4 times
 5-9 times
 10 or more times

C5. The following questions are about your communication with all doctors, nurses, or other health professionals you saw during the past 12 months.

How often did they do each of the following?

Always
▼
Usually
▼
Sometimes
▼
Never
▼

- | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Give you the chance to ask all the health-related questions you had..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Give the attention you needed to your feelings and emotions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Involve you in decisions about your health care as much as you wanted | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Make sure you understood the things you needed to do to take care of your health..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Explain things in a way you could understand | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Spend enough time with you | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Help you deal with feelings of uncertainty about your health or health care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

C6. Overall, how would you rate the quality of health care you received in the past 12 months?

- Excellent
 Very good
 Good
 Fair
 Poor

C7. In the past 12 months, when getting care for a medical problem, was there a time when you...

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. Had to bring an X-ray, MRI, or other type of test result with you to the appointment? | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Had to wait for test results longer than you thought reasonable? | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Had to redo a test or procedure because the earlier test results were not available? | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Had to provide your medical history again because your chart could not be found? | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Had to tell a health care provider about your medical history because they had not gotten your records from another health care provider? | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Have had to put together your medical information across your health care providers? | <input type="checkbox"/> | <input type="checkbox"/> |

D: Medical Records

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

- Yes
- No – **GO TO D5**

D2. Does the doctor, nurse, or other health professional that you see most often maintain your medical information in a computerized system?

- Yes
- No

D3. Within the last 12 months, have you requested that your medical record be sent electronically –that is, by computer or other device - to another health care provider? Electronic does not include telephone, mail or fax.

- Yes
- No – **GO TO D4**

D4. Did the provider agree to send the medical record electronically?

- Yes
- No
- Do not know

D5. During the past 12 months, has a medical laboratory given you direct access to any test results, such as blood test results, in either paper or electronic format?

- Yes
- No – **GO TO D7**

D6. In what format did the medical laboratory provide the test results – paper or electronic?

- Paper
- Electronic
- Both paper and electronic

D7. Have you ever been offered online access to your medical record by your...

- | | Yes | No |
|--------------------------------|--------------------------|--------------------------|
| a. health care provider? | <input type="checkbox"/> | <input type="checkbox"/> |
| b. health insurer? | <input type="checkbox"/> | <input type="checkbox"/> |

[If you answered no to D7a and D7b, go to D18. Otherwise, go to D8]

D8. How many times did you access your online medical record in the last 12 months?

- None
- 1 to 2 times – **GO TO D10**
- 3 to 5 times – **GO TO D10**
- 6 to 9 times – **GO TO D10**
- 10 or more times – **GO TO D10**

D9. Why have you not accessed your medical records online? Is it because...

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. You prefer to speak to your health care provider directly | <input type="checkbox"/> | <input type="checkbox"/> |
| b. You do not have a way to access the website..... | <input type="checkbox"/> | <input type="checkbox"/> |
| c. You did not have a need to use your online medical record..... | <input type="checkbox"/> | <input type="checkbox"/> |
| d. You were concerned about privacy or security of the website that had your medical records | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Was not provided instructions on how to access medical information online..... | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Cost to access medical information electronically | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Process to login to access my record too complicated | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Language barriers (e.g. information not in my first language) | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Other | <input type="checkbox"/> | <input type="checkbox"/> |

[If you have not accessed any medical records, go to D18. Otherwise, go to D10]

D10. How do you view your online medical record?

Mark all that apply

- Smartphone app
- Health provider or health insurer's patient portal or website
- Software that combines medical records from all your health providers (e.g. personal health record)
- Other: _____

D11. How easy or difficult was it to understand the health information in your online medical record?

- Very easy
- Somewhat easy
- Somewhat difficult
- Very difficult

D12. Did any health care provider, including doctors, nurses, or office staff encourage you to use an online medical record?

- Yes
- No
- Do not know

D13. Does your online medical record include the following types of medical information?

- | | Yes | No | Don't Know |
|--|--------------------------|--------------------------|--------------------------|
| a. Laboratory test results | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Current list of medications | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. List of health/medical problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Allergy list | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Summaries of your office visit..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Clinical notes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Immunization history | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

D14. In the past 12 months, have you used your online medical record to...

- | | Yes | No | Don't know |
|--|--------------------------|--------------------------|--------------------------|
| a. Set or track goals related to your health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Made appointments with a health care provider..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Request refill of medications | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Securely message health care provider and staff (e.g. e-mail)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Track health care charges and costs..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Filled out forms or paperwork related to your health care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Look up test results..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Monitor your health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Download your health information to your computer or mobile device, such as a cell phone or tablet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Add health information to share with your health care provider, such as health concerns, symptoms, and side-effects | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Request correction of inaccurate information | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. Help you make a decision about how to treat an illness or condition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. Ask your health care provider new questions, or to get a second opinion from another health care provider | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

D15. Have you electronically sent your medical information to any of the following?

- | | Yes | No | Don't Know |
|--|--------------------------|--------------------------|--------------------------|
| a. Another health care provider | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. A family member or another person involved with your care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. A third party that can help manage and store your health information, such as a personal health record or app on mobile device..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

D16. In general, how useful are your online medical records for monitoring your health?

- Very useful
- Somewhat useful
- Not very useful
- Not at all useful
- Not applicable

D17. 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?

- Very confident
- Somewhat confident
- Not confident

D18. Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record?

- Yes
- No

D19. If your medical information is sent electronically – that is, by computer -- from one health care provider to another, how concerned are you that an unauthorized person would see it?

- Very concerned
- Somewhat concerned
- Not concerned

D20. Are you currently caring for or making health care decisions for a child, a spouse/partner, a parent, or other close family member, friend, or non-relative with a medical/behavioral/disability/other condition? Please check all that apply.

- Yes, a child/children
- Yes, a spouse/partner
- Yes, a parent/parents
- Yes, a close family member, friend, or non-relative (or multiple)
- No – Go to E1

D21. Thinking of all of the kinds of help you provide/provided for this person or persons, about how many hours do you/did you spend in an average week providing care?

| | | |
|--|--|-------|
| | | Hours |
|--|--|-------|

D22. If you selected more than one person in F1, please think about the individual for whom you have provided **the most care**. Please **check all** conditions that your care-recipient has/had, for which they needed your care.

- Cancer
- Alzheimer's, confusion, dementia, forgetfulness
- Orthopedic/Musculoskeletal Issues (examples: back problems, broken bones, arthritis, mobility problems, can't get around, feeble, unsteady, falling)
- Aging
- Mental Health/Behavioral/Substance Abuse Issues (examples: mental illness; emotional problems; depression; anxiety; substance/drug/alcohol abuse)
- Chronic Conditions (examples: high blood pressure/hypertension; diabetes; heart disease; heart attack; lung disease; emphysema; Chronic Obstructive Pulmonary Disease (COPD); Parkinson's)
- Neurological/Developmental Issues (examples: brain damage or injury; developmental or intellectual disorder; mental retardation; Down syndrome; stroke)
- Acute Conditions (examples: surgery, wounds/injuries)
- Other (specify) _____
- Not sure/ Don't know
- None of the above

D23. How many times did you access a family member or close friend's online medical record in the last 12 months?

- None – GO TOE1
- 1 to 2 times
- 3 to 5 times
- 6 to 9 times
- 10 or more times

D24. How did you access a family member or close friend's personal health information?

- | | Yes | No |
|---|--------------------------|--------------------------|
| a. Used family member's login and password | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Used a login and password assigned to me to access their record..... | <input type="checkbox"/> | <input type="checkbox"/> |

E: Medical Research

E1. Doctors use DNA tests to analyze someone's DNA for health reasons. Have you heard or read about this type of genetic test?

- Yes
- No - Go to F1
- Don't know – Go to F1

E2. Which of the following uses of a genetic test have you heard of?

Mark all that apply

- Determining risk or likelihood of getting a particular disease
- Determining how a disease should be treated after diagnosis ("precision medicine")
- Determining which drug(s) may or may not work for an individual
- Determining the likelihood of passing an inherited disease to your children

E3. Have you ever had any of the following type(s) of genetic tests?

Mark **all** that apply.

- Paternity testing:** To determine if a man is the father of a child
- 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
- Cystic Fibrosis (CF) carrier testing:** To determine if a person is at risk of having a child with cystic fibrosis
- BRCA 1/2 testing:** To determine if a person has more than an average chance of developing breast cancer or ovarian cancer
- Lynch syndrome testing:** To determine if a person has more than an average chance of developing colon cancer
- None of the above
- Not sure
- Other-Specify →

F: Your Overall Health

F1. In general, would you say your health is...

- Excellent,
- Very good,
- Good,
- Fair, or
- Poor?

F2. Overall, how confident are you about your ability to take good care of your health?

- Completely confident
- Very confident
- Somewhat confident
- A little confident
- Not confident at all

F3. Has a doctor or other health professional ever told you that you had any of the following medical conditions:

- | | Yes | No |
|---|--------------------------|--------------------------|
| a. Diabetes or high blood sugar? | <input type="checkbox"/> | <input type="checkbox"/> |
| b. High blood pressure or hypertension? | <input type="checkbox"/> | <input type="checkbox"/> |
| c. A heart condition such as heart attack, angina, or congestive heart failure? | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Chronic lung disease, asthma, emphysema, or chronic bronchitis? | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Arthritis or rheumatism? | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Depression or anxiety disorder? | <input type="checkbox"/> | <input type="checkbox"/> |

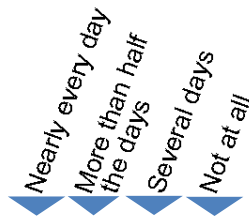
F4. About how tall are you without shoes?

Feet **and** Inches

F5. About how much do you weigh, in pounds, without shoes?

Pounds

F6. Over the past 2 weeks, how often have you been bothered by any of the following problems?



- a. Little interest or pleasure in doing things.....
- b. Feeling down, depressed, or hopeless.....
- c. Feeling nervous, anxious, or on edge.....
- d. Not being able to stop or control worrying.....

F7. 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?

- Yes
- No

F8. Do you have friends or family members that you talk to about your health?

- Yes
- No

F9. If you needed help with your daily chores, is there someone who can help you?

- Yes
- No

G: Health and Nutrition

G1. When available, how often do you use menu information on calories in deciding what to order?

- Always
- Often
- Sometimes
- Rarely
- Never

G2. About how many cups of fruit (including 100% pure fruit juice) do you eat or drink each day?

- None
- ½ cup or less
- ½ cup to 1 cup
- 1 to 2 cups
- 2 to 3 cups
- 3 to 4 cups
- 4 or more cups

- 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
 - 1 inch-thick wedge of watermelon

G3. About how many cups of vegetables (including 100% pure vegetable juice) do you eat or drink each day?

- None
- ½ cup or less
- ½ cup to 1 cup
- 1 to 2 cups
- 2 to 3 cups
- 3 to 4 cups
- 4 or more cups

- 1 cup of vegetables could be:
- 3 broccoli spears
 - 1 cup cooked leafy greens
 - 2 cups lettuce or raw greens
 - 12 baby carrots
 - 1 medium potato
 - 1 large sweet potato
 - 1 large ear of corn
 - 1 large raw tomato
 - 2 large celery sticks
 - 1 cup of cooked beans

G4. How much do you agree or disagree with this statement: "Body weight is something basic about a person that they can't change very much."

- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree

H4. How many times in the past 12 months have you used a tanning bed or booth?

- 0 times
- 1 to 2 times
- 3 to 10 times
- 11 to 24 times
- 25 or more times

H: Physical Activity and Exercise

H1. 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?

- None → **GO TO H3 below**
- 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

H2. On the days that you do any physical activity or exercise of at least moderate intensity, how long do you typically do these activities?

Write a number in one box below.

Minutes Hours

H3. 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

H5. When you are outside for more than one hour on a warm, sunny day, how often do you wear sunscreen?

- Always
- Often
- Sometimes
- Rarely
- Never
- Don't go out on sunny days

I: Tobacco Products

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

- Yes
 No → **GO TO I5**

12. How often do you now smoke cigarettes?

- Everyday
 Some days
 Not at all → **GO TO I5**

13. At any time in the past year, have you stopped smoking for one day or longer because you were trying to quit?

- Yes
 No

14. Are you seriously considering quitting smoking in the next six months?

- Yes
 No

15. At any time in the past year, have you talked with your doctor or other health professional about having a test to check for lung cancer?

- Yes
 No
 Don't know

16. 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 agree
 Somewhat agree
 Somewhat disagree
 Strongly disagree

17. 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

18. 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 ...

- Much less harmful,
 Less harmful,
 Just as harmful,
 More harmful,
 Much more harmful, or
 I've never heard of electronic cigarettes

19. 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...

- Much less harmful,
 Less harmful,
 Just as harmful,
 More harmful,
 Much more harmful, or
 I've never heard of Hookah.

J: Screening for Cancer

J1. Are you male or female?

Male → **GO TO J6**

Female

J2. Has a doctor ever told you that you could choose whether or not to have the Pap test?

Yes

No

J3. How long ago did you have your most recent Pap test to check for cervical cancer?

A year ago or less

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

J4. A mammogram is an x-ray of each breast to look for cancer.

Has a doctor ever told you that you could choose whether or not to have a mammogram?

Yes

No

J5. When did you have your most recent mammogram to check for breast cancer, if ever?

A year ago or less

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 mammogram

J6. 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.

Have you ever had a PSA test?

Yes

No

J7. Has a doctor ever discussed with you whether or not you should have the PSA test?

Yes

No

K: HPV Awareness

K1. Have you ever heard of HPV? HPV stands for Human Papillomavirus. It is not HIV, HSV, or herpes.

Yes

No → **GO TO K5**

K2. Do you think HPV can cause...

| | Yes | No | Not sure |
|---------------------------|--------------------------|--------------------------|--------------------------|
| a. Cervical Cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Penile Cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Anal Cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Oral Cancer? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

K3. Do you think that HPV is a sexually transmitted disease (STD)?

Yes

No

Not sure

K4. Do you think HPV requires medical treatment or will it usually go away on its own without treatment?

- Requires medical treatment
- Will usually go away on its own

K5. A vaccine to prevent HPV infection is available and is called the HPV shot, cervical cancer vaccine, GARDASIL®, or Cervarix®.

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

- Yes
- No

K6. In your opinion, how successful is the HPV vaccine at preventing cervical cancer?

- Not at all successful
- A little successful
- Pretty successful
- Very successful
- Don't know

K7. Including yourself, is anyone in your immediate family between the ages of 9 and 27 years old?

- Yes
- No → **GO TO K10 on the next page**

K8. In the last 12 months, has a doctor or health care professional ever talked with you or an immediate family member about the HPV shot or vaccine?

- Yes
- No
- Don't know

K9. In the last 12 months, has a doctor or health care professional recommended that you or someone in your immediate family get an HPV shot or vaccine?

- Yes
- No
- Don't know

L: Your Cancer History

L1. Have you ever been diagnosed as having cancer?

- Yes
- No → **GO TO M1**

L2. What type of cancer did you have?

Mark **all that apply.**

- 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
- Prostate cancer
- Rectal cancer
- Renal (kidney) cancer
- Skin cancer, non-melanoma
- Stomach cancer
- Other-Specify →

L3. At what age were you first told that you had cancer?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

 Age

L4. Did you ever receive any treatment for your cancer?

- Yes
- No → **GO TO L8 in the next column**

L5. Which of the following cancer treatments have you ever received?

| | Yes | No |
|-------------------------------------|--------------------------|--------------------------|
| a. Chemotherapy (IV or pills) | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Radiation | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Surgery..... | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Other | <input type="checkbox"/> | <input type="checkbox"/> |

L6. About how long ago did you receive your last cancer treatment?

- Still receiving treatment → **GO TO L10 in the next column**
- 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

L7. Did you ever receive a summary document from your doctor or other health care professional that listed all of the treatments you received for your cancer?

- Yes
- No

L8. Were you ever denied health insurance coverage because of your cancer?

- Yes
- No

L9. Looking back, since the time you were first diagnosed with cancer, how much, if at all, has cancer and its treatment hurt your financial situation?

- Not at all
- A little
- Some
- A lot

L10. Clinical trials are research studies that involve people. They are designed to test the safety and effectiveness of new treatments and to compare new treatments with the standard care that people currently get. Have you ever participated in a clinical trial for treatment of your cancer?

- Yes
- No → **GO TO L12 on the next page**
- Don't know

L11. Has a doctor or other member of your medical team discussed clinical trials as a treatment option for your cancer?

- Yes
- No

L12. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider ever discuss with you the impact of cancer or its treatment on your ability to work?

- Discussed it with me in detail
- Briefly discussed it with me
- Did not discuss it at all
- I don't remember
- I was not working at the time of my diagnosis.

M3. How much do you agree or disagree with the statement: "I'd rather not know my chance of getting cancer."

- Strongly agree
- Somewhat agree
- Somewhat disagree
- Strongly disagree

M4. How worried are you about getting cancer?

- Not at all
- Slightly
- Somewhat
- Moderately
- Extremely

M: Beliefs About Cancer

Think about cancer in general when answering the questions in this section.

M1. How likely are you to get cancer in your lifetime?

- Very unlikely
- Unlikely
- Neither unlikely nor likely
- Likely
- Very likely

M5. Have any of your family members ever had cancer?

- Yes
- No
- Not sure

M2. How much do you agree or disagree with each of the following statements?

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| a. It seems like everything causes cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. There's not much you can do to lower your chances of getting cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. There are so many different recommendations about preventing cancer, it's hard to know which ones to follow | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. In adults, cancer is more common than heart disease..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. When I think about cancer, I automatically think about death..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

N: You and Your Household

N1. What is your age?

| | | |
|--|--|--|
| | | |
|--|--|--|

 Years old

N2. What is your current occupational status?

Mark **only one.**

- Employed
- Unemployed
- Homemaker
- Student
- Retired
- Disabled
- Other-Specify →

N3. Have you ever served on active duty in the U.S. Armed Forces, military Reserves or National Guard? Active duty does not include training in the Reserves or National Guard, but DOES include activation, for example, for the Persian Gulf War.

- Yes, now on active duty
- Yes, on active duty in the last 12 months but not now
- Yes, on active duty in the past, but not in the last 12 months
- No, training for Reserves or National Guard only
- No, never served in the military

N4. In the past 12 months, have you received some or all of your health care from a VA hospital or clinic?

- Yes, all of my health care
 - Yes, some of my health care
 - No, no VA health care received
- GO TO N5
In the next
column**

N5. What is your marital status?

Mark **only one.**

- Married
- Living as married
- Divorced
- Widowed
- Separated
- Single, never been married

N6. What is the highest grade or level of schooling you completed?

- 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

N7. Were you born in the United States?

- Yes → **GO TO N9 below**
- No

N8. In what year did you come to live in the United States?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

 Year

N9. How well do you speak English?

- Very well
- Well
- Not well
- Not at all

N10. If a person speaks to you in a quiet room, how much can you understand what the person says?

- All of what they said
- Most of what they said
- Some to little of what they said
- Did not understand what they said

N11. Are you of Hispanic, Latino/a, or Spanish origin? One or more categories may be selected.

Mark **all that apply.**

- No, not of Hispanic, Latino/a, or Spanish origin
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino/a, or Spanish origin

N12. Do you think of yourself as...

- Heterosexual, or straight
- Homosexual, or gay or lesbian
- Bisexual
- Something else – Specify

○

N13. What is your race? One or more categories may be selected.

Mark **all that apply.**

- White
- Black or African American
- American Indian or Alaska Native
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander

N14. Including yourself, how many people live in your household?

Number of people

N15. Starting with yourself, please mark the sex, and write in the age and month of birth for each adult 18 years of age or older living at this address.

| | Sex | Age | Month Born (01-12) |
|-------------|--|---|---|
| SELF | <input type="checkbox"/> Male <input type="checkbox"/> Female | <input style="width: 40px; height: 20px;" type="text"/> | <input style="width: 40px; height: 20px;" type="text"/> |
| Adult 2 | <input type="checkbox"/> Male <input type="checkbox"/> Female | <input style="width: 40px; height: 20px;" type="text"/> | <input style="width: 40px; height: 20px;" type="text"/> |
| Adult 3 | <input type="checkbox"/> Male <input type="checkbox"/> Female | <input style="width: 40px; height: 20px;" type="text"/> | <input style="width: 40px; height: 20px;" type="text"/> |
| Adult 4 | <input type="checkbox"/> Male <input type="checkbox"/> Female | <input style="width: 40px; height: 20px;" type="text"/> | <input style="width: 40px; height: 20px;" type="text"/> |
| Adult 5 | <input type="checkbox"/> Male <input type="checkbox"/> Female | <input style="width: 40px; height: 20px;" type="text"/> | <input style="width: 40px; height: 20px;" type="text"/> |

N16. How many children under the age of 18 live in your household?

Number of children under 18

N17. Do you currently rent or own your home?

- Own
- Rent
- Occupied without paying monetary rent

N18. Does anyone in your family have a working cell phone?

- Yes
- No

N19. Is there at least one telephone inside your home that is currently working and is not a cell phone?

- Yes
- No

N20. 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?

- \$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
- \$100,000 to \$199,999
- \$200,000 or more

N22. 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.)

N21. About how long did it take you to complete the survey?

Write a number in one box below.

| | |
|--|--|
| | |
|--|--|

Minutes

| | |
|--|--|
| | |
|--|--|

Hours

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

Brentin, Christine (NIH/OD) [E]

From: Hesse, Bradford (NIH/NCI) [E]
Sent: Monday, April 11, 2016 11:21 AM
To: OHSR (NIH/DDIR)
Cc: Willis, Gordon (NIH/NCI) [E]
Subject: OHSRP Request for Determination
Attachments: Human Subjects HINTS 2016.pdf; HINTS V Intramural_planned_enrollment_report 4-11-2016.pdf

Please find attached our *OHSRP Request for Determination* in preparation for fielding the fifth installment of the [Health Information National Trends Survey \(HINTS\)](#). I have also attached the HINTS V Intramural Planned Enrollment Report.

As always, thank you for your assistance and prompt attention.
-Brad

Bradford W. Hesse, Ph.D.
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National Cancer Institute
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Planned Enrollment Report

This report format should NOT be used for collecting data from study participants.

Is the NIH site responsible for conducting and coordinating the overall clinical study across multiple study sites (i.e. coordinating site)?

- Yes provide the numeric distribution (not percentages) for the total number of participants planned for the study. Provide separate tables for the following: 1) NIH CC Site, 2) All Other Domestic Sites Combined, and 3) Foreign Sites Combined. For additional guidance, see: http://nih-extramural-intranet.od.nih.gov/nih/topics/inclusionwo_main.htm
- No complete the table only for the NIH CC site.

This report format should NOT be used for data collection from study participants

Select Site:

Principal Investigator:

Study Title:

Total Enrollment: _____ **Protocol Number:** _____

| Racial Categories | Ethnic Categories | | | | Total |
|--|------------------------|------|--------------------|------|-------|
| | Not Hispanic or Latino | | Hispanic or Latino | | |
| | Female | Male | Female | Male | |
| American Indian/ Alaska Native | | | | | |
| Asian | | | | | |
| Native Hawaiian or Other Pacific Islander | | | | | |
| Black or African American | | | | | |
| White | | | | | |
| More Than One Race | | | | | |
| Total | | | | | |

Brentin, Christine (NIH/OD) [E]

From: Brentin, Christine (NIH/OD) [E]
Sent: Monday, April 18, 2016 12:59 PM
To: Hesse, Bradford (NIH/NCI) [E]
Subject: Req for Determination Rec'd_OHSRP 13204

Good afternoon Dr. Hesse,

This email is to verify that OHSRP has received your Request for Determination and it is currently being processed as **OHSRP #13204**. Please use this number in any future correspondence regarding this study.

Protocol Title: Health Information National Trends Survey V (HINTS V) (NCI)

Thank you.

Sincerely,
Chris Brentin
Program Specialist
Office of Human Subjects Research Protections (OHSRP)
National Institutes of Health
301-402-3444-Office
301-402-8631-Direct
301-402-3443-Fax



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