



National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

Date: January 12, 2011 (Revised)

To: Office of Management and Budget (OMB)

Through: Seleda Perryman, DHHS Report Clearance Officer
Marilyn Tuttleman, NIH Project Clearance Officer, OPERA
Vivian Horovitch-Kelley, NCI OMB Project Clearance Liaison, OMAA

From: Bradford Hesse, Project Officer
Health Information National Trends Survey (HINTS),
Division of Cancer Control and Population Sciences,
National Cancer Institute/NIH

Subject: Health Information National Trends Survey 4 (HINTS 4) Advance Materials Focus Groups
Generic Sub-Study under “Questionnaire Cognitive Interviewing and Pretesting,” OMB No. 0925-0589-06, Expiration Date: 5/31/2011

The National Cancer Institute’s (NCI) Division of Cancer Control and Population Sciences (DCCPS), Behavior Research Program (BRP) proposes conducting formative research prior to the fourth iteration of the Health Information National Trends Survey (HINTS 4) (OMB No. 0925-0538). Specifically, NCI proposes conducting focus group research for the purpose of obtaining feedback on alternative message content included in the survey mailing materials. Conducting this research is critical to successful recruitment efforts and to gaining the cooperation of thousands of household respondents for HINTS 4. Results will be used to inform the development of the content for the following correspondence with sampled households: the advance letter, the cover letters sent along with the HINTS 4 questionnaires, the reminder postcard sent to households who do not initially respond to the survey request, and the Questions and Answers (Q&A) document included with the questionnaire mailing packages.

Background, Need and Use of Information. The HINTS data collection program addresses many critical health research and programmatic needs. The HINTS program monitors changes in the rapidly evolving field of health communication. Survey researchers are using the data to understand how adults 18 years and older use different communication channels, including the Internet, to obtain vital health information for themselves and their loved ones. Program planners are using the data to understand and address barriers to health information usage across populations, and to create more effective communication strategies. Finally, social scientists are using the data to refine their theories of health communication in the information age and to offer new and better recommendations for reducing the burden of cancer throughout the population. HINTS creates and publishes *HINTS Briefs* showcasing results to ensure that findings from HINTS research can be used to develop evidence-based policies, programs, and practices relevant to health communication at the national, state, and local level.

These important scientific and program functions require that the HINTS program engage in efforts to develop and improve data collection protocols that will result in high data quality. Based on experimentally controlled methods research conducted as part of the previous round of

HINTS, HINTS 4 will use an entirely mail-based data collection procedure that collects data in 4 cycles with 4 independent samples. Thus, the proposed formative research seeks to identify the most effective messages to use with the HINTS 4 mailing materials to encourage the participation of all sampled households, improving overall response rate and diminishing the chances of systematic nonresponse specific to certain subpopulations.

Participants and Recruitment. Focus group participants will be recruited from the non-institutionalized adult household population. Neither Westat nor NCI employees will be eligible to participate in the focus groups. Two of the four focus groups will be conducted with adults who speak primarily Spanish at home. HINTS 4 will include a Spanish-language questionnaire and supporting materials so evaluative information about the effectiveness and clarity of those materials for the Spanish speaking population is needed. The English-speaking focus groups will recruit a racially diverse population. Both the English- and Spanish-speaking focus groups will recruit participation from adults representing a variety of educational attainment levels.

Westat, along with their subcontractor EurekaFacts, will recruit participants for the focus groups. Recruiters will place advertisements on Internet sources such as Craig's List, and will print advertisements in local community papers around the Washington DC metropolitan area. In addition, local adult education programs will be contacted to seek permission to distribute flyers at one or more classes that cater to populations with less than a college education. All advertisements will include a toll-free phone number for those interested in finding out more about participation.

EurekaFacts will handle recruitment of the Spanish-speaking participants. As a professional focus group and market research firm specializing in Spanish-speaking and other hard-to-reach populations, EurekaFacts will advertise for participants in Spanish-market papers and locations for which they have had prior success in recruiting focus group and one-on-one interview participants. Additionally, EurekaFacts may draw from eligible Spanish-speaking respondents within their established recruitment database, providing individuals have not participated in a similar focus group in the last 12 months. All advertisements will include a toll-free number dedicated to Spanish language calls.

When interested individuals call either toll-free number, recruitment staff will explain the purpose of the project, eligibility criteria, and what is involved in participating. Recruitment staff will screen individuals for participation in the focus groups (**see Attachment 6A**). One week before the focus group session, recruitment staff will send individuals who have agreed to participate a reminder letter (**see Attachment 6B**), and directions to the Westat facility. Recruitment staff will attempt to contact all participants by phone 1–2 days prior to the focus group to remind them of their appointment.

Data Collection Methods. The focus groups will be conducted in the focus group facilities at Westat in Rockville, MD. All the focus groups will be conducted by professionally trained moderators. Two of the four total focus groups will be conducted by a bilingual (Spanish/English) moderator and the other two conducted by an English-speaking moderator.

In addition to the moderator, each focus group will include an assistant who will take notes, gather informed consent forms, distribute respondent payments and manage other administrative details. Each focus group will last up-to 90 minutes, and all participants will be asked to arrive a

few minutes early to review and sign the consent form. All focus groups will be video and audio recorded with the consent of participants. Focus group moderators will use the session notes and recordings to summarize the sessions. The Spanish speaking moderator will do the initial summary in Spanish, and then translate to English for NCI and other project staff. Participants of the focus groups will receive \$50.00 as a thank you for their participation. The amount of this incentive is slightly higher than average to account for time spent in screening and reviewing the consent form, travel time (the amount of time required by participants for a 1.5 hour focus group is close to 2 hours when travel is counted), and travel expenses (Westat is not located on the Metro) .

Focus Group Moderator Materials. Westat will test the following materials as part of the focus groups (see **Attachment 6C for the full set of materials**):

- two versions of the cover letter mailed with the questionnaire packets, plus the version used in the 2007 HINTS mail sample,
- two versions of a refusal conversion letter mailed to households who don't initially respond
- a set of Frequently Asked Questions, and
- alternative facts that could replace or add to the relevant content of the letters under consideration.

The Spanish-language materials will reflect the same content as the English language materials, but will be fully translated into Spanish. The moderator will follow a semi-structured moderator guide for the focus groups (see **Attachment 6D**) and consent form (see **Attachment 6E**). The guides address the following research objectives:

- What information about the HINTS program do participants:
 - find most relevant to his/her own life, if any?
 - consider important to them, their families or their community more generally?
 - think really encourage their interest and participation in HINTS 4?
- Are there possible differences between the English and Spanish speaking groups in what messages seem most relevant, important or encouraging?
- Do participants understand the specific language used in the proposed materials in the intended manner? If not, what is the source and impact of the confusion?
- Do participants view any of the content in the proposed materials negatively or think the content is likely to diminish participation in the survey? If so, why?
- Does the format or style of the letter affect the level to which participants read and attend to the content of the letters?

Data Analysis. Westat will analyze the data using qualitative analysis methods. Consistent themes occurring in the focus groups summaries addressing the research questions will guide the development of the final survey letters, reminder postcard and Question & Answer information planned for HINTS 4 data collection.

Other Considerations. The focus group activities and materials outlined in this memo have been approved by Westat's IRB (see **Attachment 6F**) and is currently under review at NCI's IRB. Approval or exemption from both IRBs will be provided to OMB once received and prior to the initiation of any testing.

No personally identifying information (PII) will be retained for this submission, however PII will be collected in the full HINTS questionnaire. Additionally, the advance materials included in this submission are in preparation for fielding the first HINTS questionnaire in 2011 which does include PII. The information collection has been reviewed by the NIH Privacy Act Officer and it was determined that the Privacy Act does apply to the first HINTS questionnaire (see **Attachment 6G**).

Respondent Burden and Costs. The table below displays the burden estimates for this data collection effort. We anticipate screening up to 80 individuals and retaining 40 to participate across both the English- and Spanish-language focus groups. Each focus group session will last up to 90 minutes. The total respondent burden for this effort is estimated to be 67 hours. This effort will account for less than 4 percent of the total burden hours (1800) granted in OMB No. 0925-0589 approved package.

Estimates of Hour Burden and Respondent Cost

Types of Respondents	Instrument	Maximum Number of Respondents	Frequency of Response	Estimated Burden (Min/Hours)	Annual Burden Hours
General Public	Screening Questionnaire (Attach 6A)	80	1	5/60 (0.083)	7
	Focus Group/Moderator Guide (Attach 6C and 6D)	40	1	90/60 (1.5)	60
Total		120			67

Thank you for your consideration of this proposed sub-study.

List of Attachments (Attached Below)

6B: **English and Spanish**¹ Reminder Letter

¹ **SPANISH DOCUMENTS**

For all advance materials and data collection instruments, HINTS is using the TRAPD method of translation (see citation below). This method involves two main steps in order to get the best translation possible:

1. Documents are independently translated by two different translators that are not in contact with each other. In the case of HINTS, there are two separate subcontractors, each doing their own independent translations of the documents. The translators both have been provided with a way to track places where they are unsure of an appropriate translation or where they feel translations are awkward.
2. Both translations and tracking sheets are provided to a third translator who acts as an adjudicator between the two translations. This translator determines the best Spanish version of the document based on the two translations received. Where there are questions or inconsistencies, the adjudicator is in contact with the two translators to discuss the issues and come to a resolution.

Only once all issues have been resolved are the letters and data collection instruments considered final.

This process is time consuming. Two to three weeks are provided to the subcontractors for the initial translations of documents depending on the complexity of the documents (with instruments taking longer than letters). Then, an additional two to three weeks are provided for the adjudication process. It therefore takes approximately four to six weeks from the time that the translators receive the initial English documents to the time that a Spanish translation is finalized. We are currently in the middle of this process for the advance materials.

6C: Test Materials – English and Spanish Letters, FAQs, and Alternative Facts

6E: English and Spanish Consent Form

6F: Westat IRB Approval

6G: Privacy Act Memo

List of Attachments (Attached in a Separate File)

6A: English and Spanish Screening Questionnaire

6D: English and Spanish Moderator Guide

The version of the letters attached here is one copy of an initial translation. They have not yet been through the adjudication process. We anticipate there will be some changes to the translations through adjudication, but these changes should be very minor in nature (selecting one word over a similar word, for example). It should be noted that the attached translations were completed before the addition of the sentence about safeguarding information and the change in wording related to the Privacy Act, so those are not included in this Spanish version but are being added during adjudication.

Items such as moderator guides (for focus groups and cognitive testing) are not undergoing the TRAPD process. Because these items are not seen by respondents and are only used as guides by trained professionals, they are undergoing just one translation and that translation has not yet taken place. The translated moderator guide can be submitted once it is complete.

CITATION:

Harkness, Janet A., Ana Villar and Brad Edwards (2010) "Translation, Adaptation, and Design" in *Survey Methods in Multinational, Multiregional, and Multicultural Contexts* J. Harkness, M. Braun, B. Edwards, T. Johnson, L. Lyberg, P. Mohler, B. Pennell, and T. Smith (eds), Chapter 7, pgs 117-140.

Attachment 6B: English and Spanish Reminder Letter

[Date]

Dear [name],

Thank you for agreeing to participate in our study on health-related topics. Here are details to remind you where and when to appear for the focus group session. The session will take about an hour and a half. You will receive \$50 as a token of gratitude for your participation in the study.

DATE: XX/XX/XXXX

TIME: XX

LOCATION: Westat
Conference Center
1600 Research Boulevard
Rockville, MD 20820

Directions and a map are enclosed.

Kindly allow enough time for travel as we would like to begin on time. There will be parking spaces marked "(Study)" in the Conference Center Parking lot. Someone will meet you in the lobby of the 1600 building.

If you need further information, please call me at the office (301) XXX-XXXX.

We look forward to seeing you and thank you in advance for your assistance.

Sincerely,

[Westat staff]

[Date]

Estimado [name],

Gracias por aceptar participar en nuestro estudio sobre temas relacionados con la salud. Aquí están los detalles para recordarle donde y cuando aparecer para la sesión de grupo de enfoque. La sesión durará aproximadamente una hora y media. Usted recibirá \$50 como muestra de gratitud por su participación en el estudio.

FECHA: XX/XX/XXXX

HORA: XX

LOCALIDAD: EurekaFacts LLC

451 Hungerford Drive (Rockville Pike) Suite 515
Rockville, MD 20850

Direcciones y un mapa está incluido.

Por favor permita el tiempo suficiente para el viaje como nos gustaría comenzar a tiempo.

Si necesita más información, por favor, llámenos a la oficina al (301) XXX-XXXX.

Esperamos su visita y gracias de antemano por su ayuda.

Sinceramente,

[Eureka Facts staff]

Attachment 6C – 1: Cover letter 1 and Frequently Asked Questions – English and Spanish



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

Dear Sir or Madam:

You've been selected 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).

HINTS has interviewed over 10,000 people since 2003. From those interviews we've learned that:

- The number of Americans using email to talk with a doctor or doctor's office doubled between 2003 and 2007.
- In the past several years, as health information becomes more available on-line, American's trust in the health information they get on-line has decreased.
- During the same time period, public trust in doctors as a source of health information increased.

By completing this questionnaire, you can help health professionals use HINTS to find out how you and other Americans get health information now and what needs done to make that information easier to find and understand.

We ask that each adult in this household complete a questionnaire and return it to us in the postage-paid envelope within the next two weeks. We've enclosed \$2 as a token of our appreciation for your participation. Of course, your participation is voluntary. You can keep the money even if you decide not to take part in the survey.

Westat, a research firm under contract with us, is administering the survey. **Your answers will be kept private under the Privacy Act.** More information about the study is provided on the other side of this letter. You can also go to www.HINTS.cancer.gov to find out more about HINTS.

Thank you in advance for your cooperation. If you have any questions about the study or you would like to request more questionnaires, please call Westat toll-free at 1-888-636-6540.

Sincerely,

Bradford W. Hesse, Ph.D.
HINTS Project Officer
Chief, Health Communication and Informatics
Research Branch
National Institutes of Health
U.S. Dept of Health and Human Services
www.HINTS.gov

Si prefiere recibir la encuesta en Español, por favor llame 1-888-636-6536.

**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: Where can I find out more about HINTS?

A: If you have any questions about the study or you would like to request more questionnaires, please call Westat toll-free at 1-888-636-6540, or you can go to www.HINTS.gov

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 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.

Estimado Señor o Señora:

Usted ha sido seleccionado para participar en una importante encuesta nacional patrocinada por el Departamento de Salud y Servicios Humanos de los Estados Unidos, La Encuesta de Tendencias Nacionales de Información Sobre La Salud (HINTS por su siglas en inglés).

HINTS ha entrevistado más de 10.000 personas desde 2003. De esas entrevistas hemos aprendido que:

- El número de estadounidenses que utilizan correo electrónico para hablar con un médico o un consultorio médico se duplicó entre el 2003 y el 2007.
- En los últimos años a medida que información sobre salud se vuelve más disponible en la internet, la confianza que los estadounidenses tienen sobre la información de salud que reciben en la internet ha disminuido.
- Durante ese mismo periodo de tiempo, la confianza pública en los médicos como fuente de información sobre salud ha incrementado.

Al completar este cuestionario, usted ayudará a que los profesionales de (la) salud usen HINTS para saber como usted y otros estadounidenses reciben y/o obtienen información de salud y qué se necesita hacer para que la información sea más fácil de encontrar y entender.

Pedimos que cada adulto en este hogar complete un cuestionario y lo envíe de regreso en el sobre con franqueo pagado dentro las próximas dos semanas. Hemos incluido dos dólares como agradecimiento por su participación. Por supuesto que su participación es voluntaria. (Usted) puede quedarse con el dinero aún si decide no participar en la encuesta.

Westat, una firma de estudios de investigación, bajo contrato con nosotros, estará administrando esta encuesta. Sus respuestas se mantendrán de forma segura en la medida provista por la ley. Al otro lado de esta página encontrará mas información sobre este estudio. Usted también puede visitar la página www.HINTS.cancer.gov para mayor información sobre HINTS.

Gracias de antemano por su cooperación. Si usted tiene alguna pregunta sobre el estudio o si usted desea solicitar más cuestionarios, por favor llame a Westat al número gratuito 1-888-636-6540.

**Algunas preguntas Frecuentes Acerca de la Encuesta HINTS-
Health Information National Trends Survey**

(Tendencias Nacionales Sobre Información de Salud)

Q: ¿De qué se trata este estudio? ¿Que tipo de preguntas preguntan?

A: El estudio se trata de la salud y de cómo la gente recibe información sobre salud. Por ejemplo, nosotros le haremos preguntas sobre cómo usted por lo general recibe información sobre cómo mantenerse saludable, las fuentes de información en las cuales usted más confía, y cómo a usted desea recibir ese tipo de información en el futuro. También le preguntaremos sobre sus creencias sobre lo que contribuye a la buena salud, de cuales son las mejores formas de prevenir el cáncer, sobre su participación en varias actividades que tienen que ver con la salud, y temas relacionados.

Q: Donde puedo encontrar más información acerca de HINTS?

A: Si tiene alguna pregunta acerca del estudio o si quiere pedir más cuestionarios por favor llame a Westat al número gratuito 1-888-636-6540 o puede visitar la página web www.HINTS.gov

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

A: La información que colectemos ayudara al Departamento de Salud y Servicios Humanos de los Estados Unidos promover la buena salud y prevenir enfermedades mediante la determinación de formas de mejor comunicar información de salud precisa a los estadounidenses.

Q: ¿Cómo consiguió mi dirección?

A: Su dirección fue elegida al azar de todos las direcciones de origen conocido en la nación. Fue elegida mediante métodos de muestras científicas.

Q: ¿Por qué debería participar en este estudio? ¿Tengo que hacer esto?

A: Su participación es voluntaria y usted puede negarse a contestar cualquier pregunta o retirarse del estudio en cualquier momento. Sin embargo, sus respuestas son muy importantes para el éxito de este estudio y se representan a miles de otros. Obtener una respuesta de todos los hogares seleccionados para el estudio es la mejor manera de asegurarse que los resultados del estudio reflejan los pensamientos y las opiniones de todos los estadounidenses.

Q: ¿Se mantendrán privadas mis respuestas a la encuesta?

A: Sí. Sus respuestas no podrán ser conectadas a su nombre o a cualquier otra información que puede identificarle a usted o su hogar hasta el exento previsto por ley.

Q: ¿Cuánto tiempo se tarda en responder a las preguntas?

A: Se tarda como 20 a 30 minutos.

Q: ¿Quién patrocina este estudio? ¿Es este estudio aprobado por el Gobierno Federal?

A: El estudio es patrocinado por el departamento de salud y servicios humanos de los Estados Unidos. El estudio ha sido aprobado por la Oficina de Gerencia y Presupuesto (OMB), la Oficina que revisa todos los estudios patrocinados por el Gobierno Federal. El número de aprobación de la OMB asignado a este estudio es 0925-0538.

Q: ¿Quién es Westat?

A: Westat es una compañía de estudios de investigación ubicada en Rockville, Maryland. Westat está llevando a cabo esta encuesta bajo contrato del Departamento de Salud y Servicios Humanos de los Estados Unidos.

Attachment 6C – 2: Cover letter 2 and Frequently Asked Questions – English and Spanish



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

Dear Sir or Madam:

I'm writing to ask you to take part in a national survey sponsored by the U.S. Department of Health and Human Services. The Health Information National Trends Survey (HINTS) is how policy makers and researchers identify the information that Americans need and want to know about health.

For example, by answering the HINTS survey you can help identify:

- How people find out about food and drug recalls
- The number of Americans who use the internet as their main source of health information
- How people order and receive their prescriptions medicines

By completing this questionnaire, you can help to find ways to get you and all Americans the health information you need, when you need it.

We ask that each adult in this household complete a questionnaire and return it to us in the postage-paid envelope within the next two weeks. We've enclosed \$2 as a token of our appreciation for your participation. Of course, your participation is voluntary. You can keep the money even if you decide not to take part in the survey.

Westat, a research firm under contract with us, is administering the survey. Your answers will be kept **private under the Privacy Act.**

More information about the study is provided on the other side of this letter. You can also go to www.HINTS.cancer.gov to find out more about HINTS, or call Westat toll-free at 1-888-636-6540.

Thank you in advance for your cooperation.

Sincerely,

A handwritten signature in blue ink that reads "Bradford W. Hesse".

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

A blue starburst graphic with a white background, containing text about the HINTS website.

Visit the HINTS
website:

www.HINTS.cancer.gov

Si prefiere recibir la encuesta en Español, por favor llame 1-888-636-6536.

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

**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 represent thousands of others and are very important to the success of this study. 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 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 XXXX-XXXX.

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.

Estimado Señor o Señora:

Estoy escribiéndole para pedir que participe en un estudio nacional patrocinado por el Departamento de Salud y Servicios Humanos de los Estados Unidos. La Encuesta Nacional de Tendencias Sobre Salud (HINTS por sus siglas en Inglés) es como los investigadores y políticos encargados de hacer políticas de salud identifican la información que los estadounidenses necesitan y quieren saber sobre la salud.

Por ejemplo, respondiendo a la encuesta HINTS usted puede ayudar a identificar:

- Cómo la gente se entera sobre las retiradas de alimentos y medicinas.
- El número de estadounidenses que utilizan el internet como su principal fuente de información sobre la salud.
- Cómo la gente ordena y recibe sus recetas médicas.

Al completar este cuestionario, usted ayudará a encontrar maneras para que usted y todos los estadounidenses reciban información sobre la salud que necesitan, cuando la necesitan.

Pedimos que cada adulto en este hogar complete un cuestionario y lo envíe de regreso en el sobre con franqueo pagado dentro de las próximas dos semanas. Hemos incluido dos dólares como agradecimiento por su participación. Por supuesto que su participación es voluntaria. (Usted) puede quedarse con el dinero aunque decide no participar en la encuesta.

Westat, una firma de estudios de investigación, bajo contrato con nosotros, estará administrando esta encuesta. Sus respuestas se mantendrán de forma segura en la medida provista por la ley.

Más información sobre este estudio se encuentra al reverso de esta página. Usted también puede visitar la página www.HINTS.cancer.gov para más información sobre HINTS, o puede llamar a Westat al número gratuito 1-888-636-6540.

Gracias de antemano por su cooperación.

Sinceramente,



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

**Algunas preguntas Frecuentes Acerca de la Encuesta HINTS-
Health Information National Trends Survey
(Tendencias Nacionales Sobre Información de Salud)**

Q: ¿De qué se trata este estudio? ¿Qué tipo de preguntas preguntan?

A: El estudio se trata de la salud y de cómo la gente recibe información sobre salud. Por ejemplo, nosotros le haremos preguntas sobre cómo usted por lo general recibe información del cómo mantenerse saludable, las fuentes de información en las cuales usted más confía, y cómo desea recibir ese tipo de información en el futuro. También le preguntaremos sobre sus creencias sobre lo que contribuye a la buena salud, de cuáles son las mejores formas de prevenir el cáncer, sobre su participación en varias actividades que tienen que ver con la salud, y temas relacionados.

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

A: La información que colectemos ayudará al Departamento de Salud y Servicios Humanos de los Estados Unidos promover la buena salud y prevenir enfermedades mediante la determinación de formas de mejor comunicar información de salud precisa a los estadounidenses.

Q: ¿Cómo consiguió mi dirección?

A: Su dirección fue elegida al azar de todas las direcciones de origen conocido en la nación. Fue elegida mediante métodos de muestras científicas.

Q: ¿Por qué debería participar en este estudio? ¿Tengo que hacer esto?

A: Su participación es voluntaria y usted puede negarse a contestar cualquier pregunta o retirarse del estudio en cualquier momento. Sin embargo, sus respuestas son muy importantes para el éxito de este estudio y se representan a miles de otros. Obtener una respuesta de todos los hogares seleccionados para el estudio es la mejor manera de asegurarse que los resultados del estudio reflejan los pensamientos y las opiniones de todos los estadounidenses.

Q: ¿Se mantendrán privadas mis respuestas a la encuesta?

A: Sí. Sus respuestas no podrán ser conectadas a su nombre o a cualquier otra información que puede identificarle a usted o su hogar hasta el exento previsto por ley.

Q: ¿Cuánto tiempo se tarda en responder a las preguntas?

A: Se tarda como 20 a 30 minutos.

Q: ¿Quién patrocina este estudio? ¿Es este estudio aprobado por el Gobierno Federal?

A: El estudio es patrocinado por el Departamento de Salud y Servicios humanos de los Estados Unidos. El estudio ha sido aprobado por la Oficina de Gerencia y Presupuesto

(OMB), la Oficina que revisa todos los estudios patrocinados por el Gobierno Federal. El número de aprobación de la OMB asignado a este estudio es 0925-0538.

Q: Quien es Westat?

A: Westat es una compañía de estudios de investigación localizada en Rockville, Maryland. Westat está llevando a cabo esta encuesta bajo contrato del Departamento de Salud y Servicios Humanos de los Estados Unidos.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

Dear Resident:

Recently, the U.S. Department of Health and Human Services mailed two questionnaires to your household for the Health Information National Trends Survey (HINTS). As of today we have not received any completed questionnaires from your household.

HINTS has interviewed over 10,000 people since 2003. This year, HINTS is asking you to participate. As health care in America continues to change, we want you to tell us what health topics matter the most to you. Will the ways you communicate with your doctor's change? Can you get current information about medical treatments for you or a family member? Do you have concerns about your ability to take care of your own health needs? HINTS is a way for you to let the government know what people like you do when you need health care information.

We know your time is valuable, but your participation in the study is important to its success. To understand the health topics important to people today, HINTS needs to collect the current views and experiences of all the people we're trying to contact.

Whether or not you or anyone in your family has ever had health problems, your input and opinions are crucial to the success of this study. Your answers, combined with those of other survey respondents, will help us understand what health information you and other Americans want and what needs done to make that information easier to find and understand.

In the event that your questionnaires were misplaced, replacements are enclosed. If you have any questions, please call Westat toll free at 1-888-314-1133 or go to www.HINTS.cancer.gov.

Sincerely,

Bradford W. Hesse, Ph.D
HINTS Project Officer
Behavioral Research Program
National Cancer Institute

Si prefiere recibir la encuesta en Español, por favor llame 1-888-636-6536.

Estimado Residente:

Recientemente, el Departamento de Salud y Servicios Humanos de los Estados Unidos envió por correo a su hogar dos cuestionarios de la encuesta de Tendencias Nacionales de Información Sobre La Salud (HINTS por sus siglas en Inglés). Hasta el día de hoy no hemos recibido cuestionarios completados de su hogar.

HINTS ha entrevistado más de 10.000 personas desde 2003. Este año, HINTS le pide que participe. A medida que el cuidado de salud sigue cambiando en los Estados Unidos, queremos que usted nos diga que temas de salud son más importantes para usted. ¿Cambiará la manera de comunicarse con su médico? ¿Puede usted obtener información actualizada sobre tratamientos médicos para usted o un miembro de la familia? ¿Tiene usted inquietudes acerca de su capacidad para cuidar sus propias necesidades de salud? HINTS es una manera en que usted puede dejarle saber al gobierno lo que personas como usted hacen cuando necesitan información sobre cuidado médico.

Sabemos que su tiempo es valioso, pero su participación en el estudio es importante para su éxito. Para entender los temas de salud importantes para la gente hoy en día, HINTS necesita coleccionar opiniones y experiencias actuales de todas las personas que estamos tratando de contactar.

Ya sea o no que usted o alguien en su familia ha tenido problemas de salud, su opinión es crucial para el éxito de este estudio. Sus repuestas, combinadas con las de otros encuestados nos ayudara entender que tipo de información de salud usted y otros estadounidenses desean y lo que se necesita hacer para que esa información sea más fácil de encontrar y entender.

En el caso que sus cuestionarios han sido extraviados, los reemplazos están incluidos con esta información. Si usted tiene alguna pregunta por favor llame a Westat al número gratuito 1-888-314-1133 o visite la página www.HINTS.cancer.gov.

Sinceramente,



Bradford W. Hesse, Ph.D
HINTS Project Officer
Behavioral Research Program
Instituto Nacional del Cáncer



Dear Sir or Madam:

You've been selected to take part in this year's Health Information National Trends Survey (HINTS). Policy makers and researchers use HINTS to identify the information that Americans need and want to know about health. With your help, we can use HINTS to keep Americans better informed on the health issues important to them.

We recently mailed two HINTS questionnaires to your home. As of today we have not received any back from your address. We know your time is valuable. However, your household is part of a scientific sample representing many other households and it cannot be replaced.

To make sure HINTS provides accurate information we need you and all the household's selected for this year's HINTS to complete the survey. By taking part in this survey, you can help us find ways to get you and all Americans the health information you need, when you need it.

In the event that your questionnaires were misplaced, replacements are enclosed. **We ask that each adult in this household complete a questionnaire and return it to us in the postage-paid envelope within the next two weeks.**

If you have any questions or would like to request additional questionnaires, please call Westat toll free at 1-888-636-6540.

To find out more about
HINTS, go to:
www.HINTS.cancer.gov

Sincerely,

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

Si prefiere recibir la encuesta en Español, por favor llame 1-888-636-6536.

The Health Information National Trends Survey is authorized under 42 USC, Section 2

Estimado Señor o Señora:

Usted ha sido seleccionado para participar en La Encuesta de Tendencias Nacionales de Información Sobre La Salud (HINTS por sus siglas en Ingles) de este año. Políticos y investigadores usan HINTS para identificar la información que los estadounidenses necesitan y quieren saber acerca de la salud. Con su ayuda podemos utilizar HINTS para mantener a los estadounidenses mejor informados sobre los temas de salud importantes para ellos.

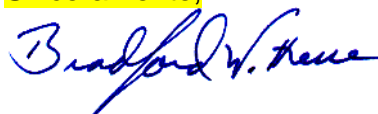
Recientemente le enviamos por correo a su hogar dos cuestionarios de HINTS. Hasta el día de hoy no hemos recibido cuestionarios de regreso de su hogar. Sabemos que su tiempo es valioso. Sin embargo, su hogar es parte de una muestra científica que representa muchos otros hogares y no puede ser reemplazado.

Para asegurar que HINTS proporciona información precisa necesitamos que usted y todos los hogares seleccionados para HINTS de este año completen la encuesta. Al participar en esta encuesta, usted puede ayudarnos encontrar maneras de que usted y todos los estadounidenses obtengan la información de salud que necesita, cuando la necesite.

En el caso que sus cuestionarios han sido extraviados, los reemplazos están incluidos con esta carta. **Pedimos que cada adulto en este hogar complete un cuestionario y lo envíe de regreso en el sobre con franqueo pagado dentro de las próximas dos semanas.**

Si usted tiene alguna pregunta sobre el estudio o si usted desea solicitar más cuestionarios, por favor llame a Westat al número gratuito 1-888-636-6540.

Sinceramente,



Bradford W. Hesse, Ph.D.
HINTS Oficial de Proyectos
Jefe, Comunicación de Salud e Informática
Subdivisión de Investigaciones
Institutos Nacionales de Salud
Departamento de Salud y
Servicios Humanos de los Estados Unidos

Attachment 6C – 5: Alternative Facts – English and Spanish

- About 4 out of 5 adults believe that there are so many recommendations about nutrition that it is hard to know which ones to follow
- Similarly, more than three-quarters (78%) of Americans think there are so many cancer prevention recommendations that it is hard to know which ones to follow.
- Nearly 40% of all Americans have looked for cancer information at some point.
- About 50% of those people are looking for information about a specific type of cancer, but nearly 20% are looking for information about cancer symptoms, early detection or diagnosis.
- About 45% of English speaking households feel their doctors always explain things to them in a way they can understand.
- However, only a little more than 30% of Spanish-speaking households feel their doctors explain things to them in an understandable way.

SET 1.

Usando datos de HINTS, investigadores y oficiales del gobierno pueden identificar los tipos de información que los estadounidenses necesitan para entender los riesgos a la salud correctamente. En 2005, HINTS encontró que:

- Cerca de 4 de cada 5 adultos creen que hay tantas recomendaciones sobre la nutrición que es difícil saber cuáles seguir.
- Del mismo modo, más de tres-cuartos (78%) de los estadounidenses piensan que hay tantas recomendaciones para prevenir el cáncer que es difícil saber cuáles seguir.

SET 2.

Datos de HINTS pueden decirnos de que tipo de información acerca de la salud están interesados los estadounidenses. Por ejemplo –

- Casi 40% de todos los estadounidenses han buscado información sobre el cáncer en algún momento.
- Casi 50% de esa gente está buscando información sobre un tipo específico de cáncer, pero casi 20% están buscando información sobre síntomas del cáncer, detección temprana o diagnóstico.

SET 3.

Datos de HINTS pueden ayudar a médicos y otros profesionales de cuidado de salud mejorar la comunicación que tienen con sus pacientes.

- Cerca de 45% hogares de habla Inglesa sienten que sus médicos siempre le explican las cosas a en una forma que ellos pueden entender.
- Sin embargo, solamente un poco más de 30% de hogares de de habla española sienten que sus médicos le explican las cosas en una manera comprensible.



Attachment 6E: ENGLISH AND SPANISH CONSENT FORM

You have volunteered for a focus group discussion being conducted on behalf of the U.S. Dept. of Health and Human Services (DHHS). The purpose of the study is to improve certain procedures used for a survey that Westat conducts on behalf of DHHS.

- The discussion will be videotaped and notes will be taken. Project researchers may also observe the discussion.
- The discussion should take up to 1½ hours.
- Your participation is completely voluntary. You may stop at any time, and you do not have to answer any questions you do not wish to answer.
- This research does not involve any foreseeable risks.
- All information obtained from 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. We will destroy any identifying information when the project ends.
- There are no direct benefits to participants in this research.
- Participants will receive \$50 in cash for participating.
- If you have questions about this research please contact Brad Hesse, the Principal Investigator at NCI (301-594-9904; hesseb@mail.nih.gov). If you have questions about your role as a research participant, please contact Sharon Zack, the Westat Institutional Review Board Administrator (800-937-8285; sharonzack@westat.com).
- A copy of this consent form has also been provided for your records.

If you agree to participate in this focus group, please read the following statement and sign your name below:

I have read the above information about this project and my rights as a participant. I consent to participate in this research and to have this discussion videotaped.

Researcher's Signature

Participant's Signature

Printed Name

Printed Name

Date

Usted se ha ofrecido como voluntario para un grupo de discusión conducido de parte del Departamento de Salud y Servicios Humanos (DHHS por sus siglas en Inglés). El propósito de este estudio es para mejorar ciertos procedimientos usados para una encuesta que Westat lleva a cabo de parte del DHHS.

- La discusión será grabada en video y se tomarán notas. Los investigadores del proyecto también observaran la discusión.
- La discusión puede tardar hasta hora y media.
- Su participación es completamente voluntaria. Usted puede parar en cualquier momento y no tiene que contestar ninguna pregunta que usted no quiere contestar.
- Esta investigación no implica ningún riesgo previsible.
- Toda información de este estudio se mantendrá de manera segura y solo será vista por personas autorizadas para trabajar en este proyecto. El reporte que resume las conclusiones no contendrá nombres o datos de identificación. Vamos a destruir cualquier información que identifique a los participantes cuando termine el proyecto.
- No hay beneficios directos para los participantes en esta investigación.
- Cada participante recibirá \$50 en efectivo por participar.
- Si usted tiene alguna pregunta acerca de este estudio de investigación por favor contacte a Brad Hesse, el Investigador Principal el Investigador Principal en el Instituto Nacional del Cáncer (NCI por sus siglas en Ingles) al 301-594-9904; hesseb@mail.nih.gov). Si usted tiene alguna pregunta acerca de su papel como participante de la investigación por favor contacte a Sharon Zack, Administradora de la Junta de Revisión institucional de Westat (800-937-8285; sharonzack@westat.com).
- Una copia de este formulario de consentimiento también se ha previsto para sus archivos.

Si usted acepta participar en este grupo de discusión, por favor lea la siguiente declaración y firme su nombre abajo:

He leído la información arriba acerca de este proyecto y sobre mis derechos como participante. Doy mi consentimiento para participar en este estudio de investigación y para tener esta conversación grabada en vídeo.

_____	_____
Firma del Investigador	Firma del Participante
_____	_____
Nombre en Letra Imprenta	Nombre en Letra Imprenta

Fecha	

Attachment 6F: Westat IRB approval



An Employee-Owned
Research Corporation

Memo

Date: November 30, 2010
To: Terisa Davis, Project Director
From: Kerry Levin; Chair, Westat IRB
Subject: **Amendment Approval of OMB, Project 8861.01.04
FWA 5551**

Kerry Levin

As Chair of the Westat Institutional Review Board (IRB), I reviewed the materials submitted for the following: **OMB, Project 8861.01.04**. The Westat IRB reviews all studies involving research on human subjects. This project was last approved November 11, 2010.

This request was to approve the following:

1. Focus group research to elicit feedback on alternative message content included in the survey mailing materials.
2. Revise the informed consent form. Replace “confidential” to “secure.” As in: All information obtained from this study will be kept secure.
3. Decrease the incentive amount from \$75 to \$50.

IRB regulations permit expedited review of minor changes to previously approved activities [45 CFR pt. 46.110 (b)]. This study can be considered minimal risk and is approved under expedited authority

As the Project Director you are responsible for the following:

- If you received a conditional approval, project activities (e.g., recruiting, enrolling) may not begin until your responses have been received by the IRB and final approval is granted.
- You are required to submit this study for a continuing review on or before November 11, 2011.
- In the interim, you are responsible for notifying the IRB Office as soon as possible if there are any injuries to the subjects, problems with the study, or changes to the study design that relate to human subjects.

cc: Institutional Review Board
Nancy Weinfield

Attachment 6G: Privacy Act Memo



DATE: January 11, 2011

TO: Bradford Hesse, Ph.D., HINTS Project Officer
Chief, Health Communication and Informatics Research Branch, DCCPS, NCI

FROM: NIH Privacy Act Officer

SUBJECT: Applicability of the Privacy Act: Health Information National Trends Survey 4
(HINTS 4) 2010

I have reviewed the NCI submission to OMB requesting approval for the HINTS 2010 survey to refine theories of health communication in an effort to reduce the burden of cancer.

I have determined that the Privacy Act will apply to this data collection which involves the collection of name and address of potential respondents in order to contact them for participation in a focus group. As part of the recruitment process and survey, additional personally identifiable information will be collected (e.g., age, gender, race, citizenship, height, weight, cancer diagnosis and treatment, occupation, military and marital status, and level of schooling). The mapping and electronic version of recruitment responses and associated ID number will be stored on a restricted-access drive located behind a firewall in the Westat company and will be accessible only to those working on the study. Recruitment information will be destroyed within two weeks of completion of the final report covering the focus group.

The data collection is covered by NIH Privacy Act Systems of Record 09-25-0156, "Records of Participants in Programs and Respondents in Surveys Used to Evaluate Programs of the Public Health Service, HHS/PHS/NIH/OD".

If you have any questions, please contact my office at (301) 496-2832.

Karen M. Plá

Attachment