HISPANIC COMMUNITY HEALTH STUDY/
STUDY OF LATINOS (HCHS/SOL)

LEVELS OF PARTICIPANTS SATISFACTION WITH
INITIAL CONTACT AND EXAMINATION
Presentation Outline

• About the Hispanic Community Health Study/Study of Latinos (HCHS/SOL).
• Levels of Participants Satisfaction with Initial Contact and Examination Visit.
• What do the results of HCHS/SOL tell us about Hispanics/Latinos?
• Being informed and sharing it.
About the Hispanic Community Health Study/Study of Latinos (HCHS/SOL)

- HCHS/SOL is a comprehensive, longitudinal (prospective), population based, multicenter, cohort study of Hispanic/Latino heritage groups in the United States.

- The study is sponsored by the National Heart, Lung and Blood Institute; and six other Institutes, Centers and offices within of the National Institutes of Health.

- Four communities participating in this landmark study are:
  - Bronx, New York
  - Chicago, Illinois
  - Miami, Florida
  - San Diego, California
HISPANIC COMMUNITY HEALTH STUDY/ STUDY OF LATINOS (HCHS/SOL)

- To identify the prevalence of cardiovascular, pulmonary disease and related conditions in U.S. Hispanic/Latino groups of diverse backgrounds.

- To identify the prevalence of risk factors.

- To identify causes of mortality, and the prevalence of cardiovascular and pulmonary disease and related events.
Why HCHS/SOL Participants are So Important!

- Participation in this landmark study is important because Hispanics/Latinos are representing the largest minority group in research studies. Historically, few studies have addressed barriers to recruit and retain minority groups in longitudinal research studies.
  - 16,145 Hispanics/Latinos men and women from the communities in Bronx, Chicago, Miami, and San Diego who are participants of the HCHS/SOL are contributing to understand the health of Hispanics/Latinos in the United States.
Levels of Participants Satisfaction with Initial Contact and Examination Visit: Results from the HCHS/SOL Longitudinal Study

• **Aim 1:** To assess perceived satisfaction with study recruitment process and overall visit experience.

• **Aim 2:** To examine the influence of viewing the informational tool (DVD) on decisions to enroll in the study.

• **Aim 3:** To assess the perceived time burden of participating in baseline examination.
METHODS

- HCHS/SOL participants completed a self-administered optional *Participant Feedback Questionnaire* at the end of the baseline examination visit.

- The questionnaire assessed levels of satisfaction with recruitment, the study examination, and staff attention.

- The questionnaire included a series of closed-ended questions with multiple responses and 3 open-ended questions.
Results

- 3,584 (22%) participants completed the Participant Feedback Questionnaire (PFQ)
- Average participant age was 42 years

Participant Characteristic Summary:

<table>
<thead>
<tr>
<th>Income</th>
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<tbody>
<tr>
<td>&lt;$20,000</td>
<td>47.36%</td>
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<tr>
<td>$20,000 to 50,000</td>
<td>40.63%</td>
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<tr>
<td>&gt;$50,000</td>
<td>12.01%</td>
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</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
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</thead>
<tbody>
<tr>
<td>Not Working</td>
<td>43%</td>
</tr>
<tr>
<td>Working</td>
<td>48%</td>
</tr>
<tr>
<td>Retired</td>
<td>9%</td>
</tr>
</tbody>
</table>
Results on aim 1: Participant Satisfaction

Across both language & gender, more than 95% of participants said they:

• Liked their visit to the center somewhat or a lot
• Felt that tests were explained clearly
• Felt like staff were respectful, friendly, and courteous

Aspects of participation that participants liked:

• More Spanish speaking males (91%), compared to English speaking males (78%), said they liked the recruitment process and the location/parking at the field center (84% versus 74%)
• More than 80% of participants were satisfied with:
  • Appointment Scheduling
  • Clinic Visit
  • Instruction on Equipment Use
RESULTS CONTINUED

Results on aim 2: Influence of Informed Consent DVD on decision to participate

- Overall, about 90% of the sample felt that viewing the DVD helped them “somewhat” or “a lot” to understand the study.

- Overall, about 80% of the sample felt that viewing the DVD influenced their decision to participate in the study “somewhat” or a “a lot”

Results on aim 3: Perceived time burden of participating

- Overall, about 80% of the sample felt that the study visit was shorter than expected or what was expected
What does the results from the HCHS/SOL tell us about Hispanics/Latinos?

• One of the most important outcomes of participating in the HCHS/SOL is to better understand what factors may lead to stroke, diabetes, lung, and heart disease.

• Continued participation in the study will help future generations of Hispanics/Latinos to learn how to improve their health, and live longer and healthier lives.

• Other important findings from HCHS/SOL include:
  • Many people did not have their high blood pressure treated and controlled.
  • Many people ages 45-64 did not know they had diabetes.
Improving the recruitment and retention of Hispanics/Latinos into research studies.

- Learning more about participant satisfaction can help us understand how to address the barriers research studies have when recruiting and retaining Hispanic/Latino participants in longitudinal studies.
- Some suggested strategies are:
  - Culturally tailor each phase of the study, including bilingual and bicultural staff who are representative of the community being studied.
  - Gather feedback from participants throughout the study in order to maintain or improve satisfaction.
  - Develop tools that can help participants better understand the study’s purpose, importance, and procedures.
  - Collaborate with community representatives to develop and refine study materials.
FUTURE STEPS

• Incorporate suggestions for improving the HCHS/SOL experience.

• Continue with elements of the study to ensure participant satisfaction as a retention tool.

• Dissemination of results of this study to inform future research.
BE INFORMED AND SHARE!

- Get the Bilingual HCHS/SOL Participant Book: About Our Health - Results from HCHS/SOL: [http://www2.cscc.unc.edu/hchsnews/sites/default/files/ParticipantBooklet2014.pdf](http://www2.cscc.unc.edu/hchsnews/sites/default/files/ParticipantBooklet2014.pdf)

- For more Information about Sol/HCHS and access the participant and community news and get free educational materials: [http://www2.cscc.unc.edu/hchsnews/participation-results](http://www2.cscc.unc.edu/hchsnews/participation-results).

- For more resources visit: List your local blog address here

To download this report visit: [http://www.sol-study.org/](http://www.sol-study.org/)
FACTS ABOUT PARTICIPATION

FACTS ABOUT PARTICIPANT SATISFACTION OF HISPANIC/LATINOS:
HCHS/SOL Factsheet 7: Information in this factsheet is based on data published in research paper

Why the HCHS/SOL Participants are so important!
16,145 Hispanic/Latino men and women from the communities of El Toro, Chicago, Miami, and San Diego who are participants of the HCHS/SOL are contributing to understand the health of Hispanic/Latinos in the United States (U.S.). Participation in this landmark study is important because Hispanic/Latinos are representing the largest minority group in research studies. Historically, few studies have addressed barriers to recruit and retain minority groups in longitudinal research studies. Some of the barriers to participate in research include lack of bilingual and bicultural staff and limited knowledge and/or mistrust of research studies.

In order to better understand these barriers, the HCHS/SOL participants completed a questionnaire that included comments about their experience with the study examination visit, study procedures and whether an informed consent digital video disk (DVD) influenced the decision to participate in the study.

A total of 3,485 participants completed the optional self-administered questionnaire. Of these participants who completed the questionnaire, 95% said that they liked their visit to the study “somewhat” or “a lot.” Almost all participants said that the tests were explained clearly and rated staff as good in terms of friendliness, respect and courtesy. About 83% of participants said that the informed consent DVD influenced the decision to participate in the study “somewhat” or “a lot.” The results showed that participants were very satisfied with how the study components were explained, making language and cultural respect key, and how recruitment materials helped them understand the study and its importance.

What does the results of HCHS/SOL tell us about how Hispanics/Latinos?
Learning more about participant satisfaction can help us understand how to address the barriers research studies have when recruiting and retaining Hispanic/Latinos, who participates in longitudinal studies. Through this study, the HCHS/SOL suggests a few strategies that can help with the recruitment and retention of Hispanic/Latino participants:

- Culturally tailor each phase of the study, including bilingual and bicultural staff who are representative of the community being studied.
- Collect feedback from participants throughout the study in order to maintain or improve satisfaction.
- Develop tools that can help participants better understand the study’s purpose, importance and procedures.
- Collaborate with community representatives to develop and refine study materials.

Participants’ contribution has made this groundbreaking study a major success, and it has given the research community a perspective that is new and has been needed for people of these communities in the U.S. Findings from the HCHS/SOL have been published in scientific journals which have a significant impact on public health policy, for example, what services and health programs are most needed to improve the health of Hispanic/Latinos in the U.S.

Other important findings from HCHS/SOL include:
- Many people did not have their blood pressure treated or controlled.
- Many people ages 45-64 did not know they had diabetes.

One of the most important outcomes of participating in the HCHS/SOL is to better understand what factors may lead to stroke, diabetes, lung, and heart disease. Continued participation in the study will help future generations of Hispanic/Latinos to learn how to improve their health, and live longer and healthier lives.

Be informed and Share It!

- Get the Bilingual HCHS/SOL Participant Booklet: About Our Health - Results from HCHS/SOL:
http://www.hhs.gov/healthit/research/ohr/hhs_research_participant_booklet.pdf
- For more information about SOL/HCHS and access the participant and community news and get free educational materials:
http://www.solsdhc.gov/healthit/research/ohr/hhs_research_participant_booklet.pdf

For More Information on HCHS/SOL Results
- Visit our website: www.saldosol.net
- Download our data booklets for study participants:
http://www.hhs.gov/healthit/research/ohr/hhs_research_participant_booklet.pdf

For more resources visit: Visit your local blog address here.


FACTS ABOUT PARTICIPATION

LA CONTRIBUCION DE PARTICIPANTES ADULTOS/HISPANOS/LATINOS:
HCHS/SOL Hoja informativa 7:

¿PORQUE SON TAN IMPORTANTES LOS PARTICIPANTES DEL ESTUDIO HCHS/SOL? La información de esta hoja está basada en datos presentados en la siguiente publicación científica:

16,145 mujeres y hombres hispanos/latinos de las comunidades del El Toro, Chicago, Miami y San Diego que participan en el estudio HCHS/SOL están contribuyendo para entender mejor el estado de salud de hispanos/latinos en Estados Unidos.

Su participación en este estudio es muy importante porque, como hispanos/latinos, están representando al grupo minoritario más grande en estudios de investigación. Históricamente, pocas investigaciones han abordado las barreras de reclutamiento y retención de los miembros en estudios de seguimiento. Algunas de las barreras de participación incluyen la falta de personal bilingüe y bicultural, así como también el poco conocimiento y/o desconfianza en los estudios de investigación.

Para entender mejor las barreras que enfrentan los participantes de HCHS/SOL llenaron un cuestionario de satisfacción que incluía comentarios sobre las experiencias con el estudio, el protocolo de estudio y la influencia del video de consentimiento en la decisión de participar en el estudio.

Un total de 3,485 participantes llenaron el cuestionario opcional y autoadministrado. Los participantes que completaron el cuestionario, el 99% dijeron que los guías “algo” o “mucho” les gusta el estudio. Casi todos dijeron que los exámenes fueron explicados claramente y calificaron al personal como “bueno” en términos de amabilidad, respeto y cortesía. De estos, el 83% dijeron que el DVD de consentimiento influyó algo “mucho” en la decisión de participar en el estudio. Los resultados nos informan que los participantes estaban muy satisfechos con la forma en que fueron explicados los componentes del estudio, siendo lo más importante el idioma y el respeto cultural, seguido de cómo los materiales de reclutamiento ayudaron a entender el estudio y su importancia.

¿QUE NOS DICEN LOS RESULTADOS DE HCHS/SOL SOBRE HISPANOS/LATINOS?

El aprender más sobre la satisfacción de los participantes con el estudio, nos ayuda a entender cómo abordar las barreras que enfrentan los estudios de longitud continua de seguir y reforzar las ideas. Basado en los resultados de la encuesta de satisfacción en este estudio HCHS/SOL sugiere el uso de algunas estrategias para ayudar a mejorar el reclutamiento y retención de participantes hispanos/latinos:

- Adaptar estrategias que sean efectivas para el estudio, incluyendo personal bilingüe y bicultural representativo de las comunidades que nos están interesando.
- Entender los comentarios de los participantes durante el estudio para mantener y mejorar la satisfacción con el estudio.
- Desarrollar herramientas que ayuden al participante a entender mejor el propósito del estudio, su importancia y sus procedimientos.
- Colaborar con participantes de la comunidad para desarrollar e influir en los materiales del estudio.

La participación de los participantes ha hecho de este estudio un gran éxito, y el hecho de que la comunidad de investigadores ha hecho una visión de lo que implica ser un estudio de esta magnitud en los Estados Unidos. Los hallazgos de HCHS/SOL, publicados en revistas científicas, tendrán un impacto significativo en políticas de salud pública, especialmente en programas de salud que estén destinados a mejorar la salud de hispanos/latinos en los Estados Unidos.

Otros hallazgos de importancia de HCHS/SOL incluyen:
- Muchos participantes no tenían tratamiento ni control de su hipertensión.
- Uso de los servicios médicos treinta y cuatro años no sabían que tenían diabetes.

Uno de los resultados más importantes en HCHS/SOL es el mejor conocimiento de los factores que podrían contribuir al desarrollo de enfermedades como diabetes, enfermedades del corazón y del pulmón. Su continua participación en el estudio permitirá futuros generaciones de hispanos/latinos a mejorar su salud y vivir una vida más larga y saludable.

INFÓRMESSE Y COMPARE:

Para más información sobre HCHS/SOL, hacer clic en el botón de notificaciones para participantes y su comunidad y obtener más información en nuestra página web:
http://www.saldosol.net/healthit/research/ohr/hhs_research_participant_booklet.pdf

Para más recursos visitar: Visite su local blog address here.

¡GRACIAS!