



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:

Income	
<\$20,000	47.36%
\$20,000 to 50,000	40.63%
>\$50,000	12.01%

Employment Status	
Not Working	43%
Working	48%
Retired	9%



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.





ABOUT OUR HEALTH

RESULTS FROM THE
HISPANIC COMMUNITY HEALTH
STUDY/STUDY OF LATINOS



RESULTADOS DEL ESTUDIO DE LA
SALUD DE LA COMUNIDAD HISPANA/
ESTUDIO DE LOS LATINOS

SOBRE NUESTRA SALUD

BE INFORMED AND SHARE!

- Get the Bilingual HCHS/SOL Participant Book : About Our Health - Results from HCHS/SOL : <http://www2.csccl.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.csccl.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/>

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 Talavera et al. Levels of Participants Satisfaction with Initial Contact and Examination Visit: The Hispanic Community Health Study/Study of Latinos (HCHS/SOL) Ethn Dis. 2016;26(3):435-442. doi:10.18885/ed.26.3.435

Why the HCHS/SOL Participants are so Important!

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 (U.S).

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. 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, 99% 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/Latino participants 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
- 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

Participants' contribution has made this groundbreaking study a major success, and it has given the research community a perspective that never had been seen before about Hispanics/Latinos in the U.S. Findings from the HCHS/SOL have been published in scientific journals which will 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 high blood pressure treated and 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 Hispanics/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 Book : About Our Health - Results from HCHS/SOL : <http://www2.csc.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.csc.unc.edu/hchsnews/participation-results>.

For More Information on HCHS/SOL Results

- Visit our website: www.saludsol.net
- Download our data booklets for study participants: <http://www.hispanichealth.org/study-of-latinos-sol.html>
- Or our report to the communities: <http://www.nhbi.nih.gov/research/resources/obesity/population/hchs.htm>
- For more resources visit: [List your local blog address here](#)

Sources: Centers for Disease Control and Prevention (CDC). (2011). *National diabetes fact sheet. National estimates and general information on diabetes and prediabetes in the United States, 2011*. Atlanta, GA: United States Department of Health and Human Services Centers for Disease Control and Prevention.



LA CONTRIBUCIÓN DE PARTICIPANTES ADULTOS/HISPANOS/LATINOS

HCHS/SOL Hoja Informativa # 7:

La información de esta hoja está basada en datos presentados en la siguiente publicación científica:

Talavera et al. Levels of Participants Satisfaction with Initial Contact and Examination Visit: The Hispanic Community Health Study/Study of Latinos (HCHS/SOL) Ethn Dis. 2016;26(3):435-442. doi:10.18885/ed.26.3.435

¡PORQUE SON TAN IMPORTANTES LOS PARTICIPANTES del ESTUDIO HCHS/SOL!

16,145 mujeres y hombres hispanos/latinos de las comunidades del Bronx, 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 sin precedentes es importante porque usted, como hispano/latino, está representado al grupo minoritario más grande en estudios de investigación. Históricamente, pocas investigaciones han abordado las barreras de reclutamiento y retención de las minorías en estudios de seguimiento. Algunas de las barreras de participación incluyen la falta de personal bilingüe y bi-cultural, así como también el poco conocimiento y/o desconfiar 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 de: la visita de examen, el protocolo del 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 auto administrado. Los participantes que completaron el cuestionario, el 99% dijeron que les gustó "algo" o "mucho" la visita al estudio. Casi todos dijeron que los exámenes fueron explicados claramente y calificaron al personal como "bueno", en términos de simpatía, respeto y cortesía. De estos el 83% dijeron que el DVD de consentimiento influyó algo o "mucho" en la decisión para participar en el estudio. Los resultados nos informaron que los participantes estaban muy satisfechos con la forma como 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 longitudinales de seguimiento al reclutar y retener hispanos/latinos. Basado en los resultados de la encuesta de satisfacción el estudio HCHS/SOL sugiere el uso de algunas estrategias para ayudar con el reclutamiento y retención de participantes hispanos o latinos:

- Adaptar culturalmente cada fase del estudio, incluyendo personal bilingüe y bicultural representativo de las comunidades que se estudian.
- Obtener 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 representantes de la comunidad para desarrollar y refinar los materiales del estudio

La contribución de los participantes de ha hecho de este estudio innovador un gran éxito, y le ha dado a la comunidad de investigadores una perspectiva nueva acerca de hispanos/latinos en los Estados Unidos. Los hallazgos de HCHS/SOL publicados en revistas científicas tendrían un impacto significativo en políticas de salud pública, por ejemplo, servicios y programas de salud que son necesarios para 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.
- Muchos participantes entre los 45-64 años no sabían que tenían diabetes.

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

¡INFORMESE Y COMPARTE!

Obtenga el libro bilingüe de Participantes: Sobre Nuestra Salud – Resultados del Estudio de la Salud de la Comunidad Hispana/Estudio de los Latinos

<http://www2.csc.unc.edu/hchsnews/sites/default/files/ParticipantBooklet2014.pdf>

Para Mas Información sobre HCHS/SOL, tener acceso a noticias para participantes y la comunidad y obtener materias educativa gratis:

<http://www2.csc.unc.edu/hchsnews/participation-results>.

Para Mas recursos visite: [List your local blog address here](#)

Fuente: Centers for Disease Control and Prevention (CDC). (2011). *National diabetes fact sheet. National estimates and general information on diabetes and prediabetes in the United States, 2011*. Atlanta, GA: United States Department of Health and Human Services Centers for Disease Control and Prevention.



¡GRACIAS!

