The Hispanic Community Health Study—Study of Latinos (HCHS-SOL)

It has been well documented that most Hispanic/Latino adults are socioeconomically disadvantaged and have a high prevalence of risk factors that may adversely influence their health. Some data support the notion of a “Hispanic paradox”—namely, that despite high rates of obesity, diabetes, poverty, and lack of access to medical care, Hispanics may have relatively lower all-cause mortality, and cardiovascular morbidity and mortality rates. Recently the U.S. Census Bureau reported that Hispanics live two years longer than non-Hispanic whites, and seven years longer than African Americans.

But Hispanics have not been regularly included in research studies, resulting in large gaps in our knowledge about Latino health. These gaps pose a particular challenge given the changing demographics of our country. According to the U.S. Census Bureau, the Hispanic population is expected to nearly triple from 46.7 million in 2008 to 132.8 million—30% of the total U.S. population—in 2050.

Because of this rapid growth, it is more important than ever that we understand the factors and health behaviors that protect Hispanics from or increase their risk for chronic diseases.

That is why in 2006, the NHLBI, along with six other institutes, centers, and offices of the National Institutes of Health (NIH), funded the historic, six-and-a-half-year Hispanic Community Health Study—Study of Latinos (HCHS-SOL). This landmark study is the largest longitudinal epidemiological study of health and disease in Latino populations living in the U.S.

For the first time, Latinos are being studied in depth to answer questions such as:
- Do all Latinos suffer the same risk of heart attack, stroke, asthma and COPD?
- Why is it that some Latinos seem to suffer less from cardiovascular disease despite having multiple risk factors?
- What health care access issues are common among Latinos and are they similar across the nation?
- What can we learn about Latino health that will help us create better guidelines for the prevention of disease as well as medical care tailored for them?
- What is the role of cultural beliefs and practices in Latino health? How does adoption of the U.S. lifestyle affect their health?

The HCHS-SOL study was designed to collect baseline comprehensive health data from 16,000 Hispanics from Mexican, Cuban, Puerto Rican, Dominican, and Central and South American backgrounds, and follow them over time. The study participants, who are between 18 and 74 years of age, live in four cities: the Bronx (New York), Chicago, Miami, and San Diego.

Enthusiastic staff members across the Field Centers have worked over the last three years in the recruitment and examination of study participants.

It’s more important than ever to understand the factors and health behaviors that protect Hispanics from chronic diseases.
"Since the risk of disease in a population can be influenced by different cultural and genetic backgrounds, it was important to have the study include population groups from several geographic areas and countries of origin and with residence in the U.S. for varying lengths of time," said Paul Sorlie, Ph.D., chief of NHLBI's Epidemiology Branch and one of the deputy project officers.

As immigrant Hispanic populations adapt to the lifestyle and culture of the U.S., they will increase their risk of developing some chronic diseases.

Results from the HCHS-SOL study will help determine the role of cultural adaptation and disparities in the prevalence and development of disease. The study will also help us learn a great deal about the segments of the Latino population that are fit and healthy, and what they are doing—or not doing—to stay that way.

There is a good chance that, like other immigrant groups, as immigrant Hispanic populations adapt to the lifestyle and culture of the U.S., they will increase their risk of developing some chronic diseases. "We want to identify the changes in risk associated with immigration and acculturation to living in this country," says Larissa Avilés-Santa, M.D., of NHLBI's Epidemiology Branch and the study's project officer. "At the same time, we want to identify beliefs and behaviors that are beneficial, and that could be encouraged as part of prevention strategies for Hispanics, and the population at large."

Read on to find out more about the exciting work being done at each of the four field centers and the research coordinating center.

HCHS-SOL Field Centers
Research Coordinating Center: University of North Carolina at Chapel Hill
Albert Einstein College of Medicine in the Bronx, New York
Northwestern University in Chicago
University of Miami
San Diego State University

NHLBI Staff
Larissa Avilés-Santa, M.D., M.P.H., HCHS-SOL Project Officer
Paul Sorlie, Ph.D., HCHS-SOL Deputy Project Officer
Lorraine Siisbee, MHS, HCHS-SOL Deputy Project Officer
You are now almost five years into the study. What have been the most interesting and/or surprising findings to come out of the work you have coordinated for the Field Centers?

**Dr. LaVange:** During the first year of the study, the Coordinating Center was primarily involved in study design and cohort selection. It was clear once recruitment started, that the composition of the neighborhoods identified for the study had changed substantially between the 2000 Census figures we were using and the start of recruitment in 2008. Some neighborhoods had seen significant migration of Hispanics/Latinos into the area, while others saw the reverse. The countries of origin represented in the study's target neighborhoods also differed from that seen at the time of the 2000 Census. All in all, the recruitment experience reinforces the dynamic nature of new immigrant populations. While this was somewhat expected for HCHS-SOL, I think we were surprised at some of the patterns we observed.

A hard-earned, but pleasant surprise is the willingness of the participants to make a long-standing commitment to study participation, in spite of the somewhat burdensome requirements of the baseline examination, which takes participants from work and families for an entire day. Participants, for the most part, are willing to stay in touch with study personnel for the annual follow-up interviews, and many show a high level of interest in joining one or more ancillary studies being conducted in conjunction with the parent study. Their eagerness to contribute to the overall research effort represented by HCHS-SOL is impressive.

One of the more interesting findings thus far is the degree to which the Hispanic/Latino population appears to be medically underserved. The high degree of diversity and cultural differences across the subgroups being studied is another remarkable finding that emerged early on in these data. Attention to this rich diversity in lifestyles, norms, and behaviors will help us better understand the health needs of these Hispanic populations.

Do you have any anecdotal evidence of how the HCHS research has affected the communities that the Centers serve?

**Dr. LaVange:** Members of the target communities seemed to be somewhat skeptical about the study at first, making recruitment of pre-selected households difficult. As time went on, the communities became more aware of the study's importance to the health of Latino populations and were more engaged in the process. With feedback of study participants reaching other members of the community, recruitment became easier. Awareness of the study through media outlets and community events seemed to have contributed to success in recruitment.

As part of HCHS-SOL, we report findings of medical relevance to study participants based on the clinical exam, and provisions are made by the field centers for access to health care based on these results, even when insurance coverage is lacking. We look forward to the dissemination of study findings in the coming months that will inform communities about their health profile.

**Please share your thoughts about the importance of having a longitudinal study like this when it comes to addressing the issue of health disparities?**

**Dr. LaVange:** The longitudinal study design of HCHS-SOL will enable a better characterization of the health events and health needs of the U.S. Hispanic/Latino population. Most preventable or modifiable conditions that seem to have a high impact on the health of Hispanics in the U.S. develop over time, in response to factors measured earlier in life. This critical information has not been studied in Hispanics/Latinos. The HCHS-SOL will make a contribution by examining relationships between measures of acculturation, health behaviors, occupational exposures, and also factors known to increase the risk of health events in non-Hispanics, by following this unique cohort over time. The long-term effects of the characteristics being measured at this point, particularly among younger members of the population, will emerge as follow-up of the HCHS-SOL cohort continues.
What has been the focus of your Field Center?

Dr. Kaplan: Our group has traditionally been strong in the area of cardiovascular disease. Because the Hispanic Community Health Study is a project that bridges multiple NIH institutes and centers, it has provided an exciting opportunity to build new collaborations in other areas of chronic disease research. For example, we’ve managed to expand our circle of collaborators to include junior and senior investigators from around our institution who bring their interests and expertise in public health, dentistry, infectious diseases, cancer, sleep disorders, the built environment, and other areas. As a public health researcher, the collaborations have been one of the things that make it very exciting and rewarding work.

You are now almost five years into the study. What have been the most interesting and/or surprising findings to come out of the work you have done at your Center?

Dr. Kaplan: More than anything, we have been very pleased at the response of the community members who have participated in the study. The study is very demanding on participants, requiring them to devote a substantial amount of time and effort to the data collection protocol. Nonetheless, at the end of the day, our study participants tend to be very pleased with the experience. All seem very interested to learn about their own health status. But the most rewarding aspect of study participation for most seems to be the personal connection they make with our staff. Especially in today’s health care environment, people really take notice if you spend time with them in the clinic, listen to what they have to say, and treat them with the highest level of respect—I can’t emphasize this enough.

What challenges have you faced (or are you still facing) in recruiting subjects and collecting data?

Dr. Kaplan: For some members of our community, day-to-day work and family obligations make it challenging to find time to participate in the study. Of course, those same pressures and commitments often make it difficult for people to attend to their own health and wellbeing. With this in mind, we are constantly reevaluating our strategies for effective recruitment and retention of participants.

Please share your thoughts about the importance of a longitudinal study like this when it comes to addressing the issue of health disparities?

Dr. Kaplan: These types of projects, while quite expensive and labor-intensive, provide gold-standard evidence about disease risk factors, incidence, and prognosis. The methodologies for prospective cohort studies are quite sophisticated at this point, and recent advances in computing and technology have helped make it possible to conduct increasingly complicated study designs. I’m very pleased and impressed by the commitment of the NIH to launch and maintain new longitudinal cohort studies.

What role do you think young clinicians and clinical researchers can play in helping to address—and end—disparities in Hispanic health?

Dr. Kaplan: I’ve observed that epidemiological research has become increasingly collaborative and cross-disciplinary. Projects such as ours provide unlimited opportunities for junior investigators and clinicians to become involved in a meaningful way, make use of the existing data, and then create their own NIH-funded studies. This is how I got my start in epidemiological research, and it’s a very successful model. We hope that our study can do the same for the new generation of researchers interested in Hispanic/Latino health.
Population

The Chicago-Naperville-Joliet Metropolitan Statistical area has over 1.7 million residents of Hispanic/Latino origin, and nearly one in five area residents is of Hispanic/Latino origin, making the area the third largest concentration of Hispanics/Latinos in the U.S. after Los Angeles and New York.

While recent years have seen a trend of urban gentrification in some traditionally Latino neighborhoods in the city and a corresponding trend of Hispanic/Latino out-migration to the suburbs, there remain numerous neighborhoods with substantial concentrations of Hispanics/Latinos. The targeted area for the Chicago site is composed of such ethnically diverse neighborhoods with several that have been majority Hispanic/Latino for decades as well as others that were traditionally White/European immigrants that have experienced Hispanic/Latino immigration only recently.

Q&A with Martha Daviglus, M.D., Ph.D.
» Principal Investigator

You are now almost five years into the study. What have been the most interesting and/or surprising findings to come out of the work you have done at your Center?

Dr. Daviglus: Some of the preliminary findings based on data from all sites that we are now disseminating to study participants include the following:

- Approximately one out of three people living in our SOL communities have unhealthy body weight. SOL participants who were born in the U.S. are more likely to be overweight than those who were born outside of the U.S.
- Cigarette smoking is a risk factor for lung disease, cancer, heart disease and stroke. Data collected reflect that these conditions are more common among Puerto Rican and Cuban SOL participants, than among participants of other Hispanic nationalities.
- High blood pressure, or hypertension, is a widespread problem among our SOL participants. About half of the SOL participants who have high blood pressure are taking medications to control this condition, and less than half have their hypertension under control.
- Hearing loss affects large numbers of both male and female SOL participants over the age of 45, and is especially common among men.
- Sleep apnea, a type of abnormal breathing during sleep, is more common among Hispanic men than Hispanic women. We also found that people with hypertension were more likely to have sleep apnea.

In addition to the above general observations, we are finding that Hispanics/Latinos have less access to medical care due to the high percentage of persons without health insurance coverage (around 50%). Moreover, there appears to be a change in dietary patterns among immigrants from the diet prevailing in their country of origin, to the Western dietary habits seen in the United States.

What challenges have you faced (or are you still facing) in recruiting subjects and collecting data?

Dr. Daviglus: The Coordinating Field Center experienced a number of unique challenges during the recruitment phase. These included:

- Lack of telephone access—more than 95% of the time, recruiters had to visit the household address to screen potential participants for eligibility.
- Gentrification—Chicago had the highest percentage of households selected in the sample that did not qualify because its members were not of Hispanic or Latino origin.
- Age—Chicago has the highest percentage of Hispanic/Latino households who qualified for the study but were rejected because there was no household member age 45 or older.
- Distrustfulness among potential study participants—Many of our participants increasingly do not trust any government funded project, largely due to immigration concerns (among immigrant participants), and negative past experiences with government agencies. In addition, many of our participants have no idea what the word “research” means. More efforts are
needed to clarify many of the stigmas and concerns of these communities towards health studies and medical research.

Weather—The extreme weather conditions in Chicago, especially during the winter months made it difficult for recruiters to be in the field knocking on doors to identify potential study participants. During periods of heavy snowfall, it was difficult for recruiters to find parking spots as the side streets were usually the last ones to be cleared.

Please share your thoughts about the importance of having a longitudinal study like this when it comes to addressing the issue of health disparities?

Dr. Davilgis: One of the obstacles hindering efforts to address health disparities in the Hispanic/Latino population is the lack of research, and the data we are collecting will allow a better understanding of the health problems and better planning of health care programs and services, as well as engagement in advocacy or policy work. The HCHS-SOL is the first large scale study to include representation of diverse Hispanic/Latino populations; traditionally, existing studies on Hispanics/Latinos have mainly included only Mexicans/Mexican Americans (M/MA), primarily from the Southwestern states where the majority of this population resides, or M/MA and Puerto Ricans (PR) primarily from the Northeastern states.

This longitudinal study will increase our understanding about the impact of acculturation on the health and well-being of Hispanics/Latinos. Current research indicates that immigrants are generally healthier. They tend to have lower incidence of chronic diseases or are less likely to die of heart diseases, compared to U.S.-born individuals, despite the fact that when they come to the U.S., the majority of immigrants tend to be the working poor or live below poverty levels and have less access to health and medical care. The literature also indicates that immigrants’ health deteriorates the longer they live in the U.S., and it continues to worsen among the second and third generation. This paradox has been of great interest among researchers. The HCHS-SOL has the potential to help us understand at what point immigrants begin to change lifestyle practices (e.g., changes in diet, physical activity, alcohol and tobacco use) from their country of origin and adopt U.S. habits. It will also help us identify the critical point be for intervention programs and resources that can be allocated to reduce the negative impact of acculturation. The HCHS-SOL will study not only Latinos of diverse age groups and years in the U.S. in terms of acculturation, but also the impact on the children of the 16,000 study participants in a follow-up study. The impact of acculturation on certain health conditions, such as asthma will also be studied.

What role do you think young clinicians and clinical researchers can play in helping to address—and end—disparities in Hispanic health?

Dr. Davilgis: Clinical researchers need to conduct more studies with direct applicability in solving the health, medical, and social needs of Hispanics/Latinos of diverse nationalities or origins. For this to occur, it is critical to translate the research findings into the improvement of medical care.

Clinicians must do their “homework” about the specific Hispanic/Latino group that are being provided the services. Next they need to develop specific social and cultural knowledge of the specific Hispanic group and customize their approach to reflect cultural understanding, sensitivity (empathy), and competency (skills) to engage in cross-cultural communications and culturally appropriate clinical practices. They need to embrace Latino cultural values in service delivery and facilitate the navigation of Hispanics/Latinos into the medical care system. They need to be committed to early prevention, outreach and education, as well as providing the best quality of care. This requires integrating cultural, linguistic, and health literacy-appropriate interventions in the implementation of clinical practices. An example, is providing clinical guidelines for the management and control of chronic diseases such as asthma, diabetes, and hypertension.

Finally, the Institute of Medicine in its 2002 landmark report, Unequal Treatment, documented the prevailing prejudices of physicians and other health care providers toward women, African Americans, Hispanics/Latinos and the poor, and how these prejudices are manifested in provision of differential medical treatment to these groups. Medical students must reflect upon any negative attitudes they may have acquired towards these groups in the process of socialization, and make a conscious effort to work toward changing their attitude, particularly if it is affecting the services they provide in their clinical practice.

One of the obstacles hindering efforts to address health disparities in the Hispanic/Latino population is the lack of research.
Q&A with Neil Schneiderman, Ph.D.

» Principal Investigator

You are now almost five years into the study. What have been the most interesting and/or surprising findings to come out of the work you have done at your Center?

Dr. Schneiderman: Although I am not permitted to release prevalence estimates yet, some of our preliminary observations are of interest. One of the more disquieting observations we have made is that a large percentage of our participants do not ordinarily have access to health care. Fortunately, minority physicians in our community have provided pro bono services and under our Good Samaritan Law have been able to treat people who receive “alerts” from us indicating that they may be diabetic, hypertensive, etc. Our Provost, Dr. Thomas LeBlanc, has generously provided funds to provide some infrastructure for these local minority physicians who have given so generously of their time and expertise.

Another finding of interest is the willingness of the local populace to participate in an arduous examination that requires more than six hours in the clinic, an overnight sleep exam, walking around with an accelerometer for a week, and answering a 24-hour dietary recall from their home phone—all with minimal compensation for time lost from work, telephone expenses, child care, etc. Nevertheless, the participants feel very comfortable at the clinic and are verbally grateful for the medical assessments that they are receiving. Almost all participants prefer to take the examination in Spanish.

What challenges have you faced (or are you still facing) in recruiting subjects and collecting data?

Dr. Schneiderman: The major challenges that we have faced are the lack of access for participants to health care, the financial hardship faced by these people for participating in our study, and the transient nature of some of our population. In part due to the recession and high unemployment rate in Miami-Dade County, a fair number of our participants have found it necessary to return to South/Central America. Nevertheless, they have done a good job of keeping in touch with the HCHS-SOL and providing us with follow-up data.

Young clinicians and clinical researchers are already playing an important role in helping end disparities in Hispanic health.
Please share your thoughts about the importance of having a longitudinal study like this when it comes to addressing the issue of health disparities?

**Dr. Schneiderman:** The importance of having a longitudinal study like this when addressing the issue of health disparities cannot be overemphasized. Although it is still premature to release prevalence estimates, I can report that the proportion of people who first learn that they have diabetes or hypertension when they come to our clinic is quite high. Furthermore, the study will provide important information about the number of participants with chronic diseases whose illnesses are not under control. It is not uncommon for participants to report that they cannot afford to take medication.

**What role do you think young clinicians and clinical researchers can play in helping to address—and end—disparities in Hispanic health?**

**Dr. Schneiderman:** Young clinicians and clinical researchers are already playing an important role in helping end disparities in Hispanic health. Medical students and residents have helped provide some of the pro bono care our participants have received.

Among the researchers at the Miami Field Center are Hispanic graduate students on an NIH training grant, a diversity post-doctoral fellow, and junior and senior faculty members. We have observed that the participants in our study develop empathic relationships with our fully bilingual staff, trainees, and investigators. Having an effective Hispanic Community Advisory Board and cooperation from local Spanish-language media have helped get our message across. I think that the HCHS-SOL and those associated with it have contributed to reducing disparities in Hispanic health.

We have observed that the participants in our study develop empathic relationships with our fully bilingual staff, trainees, and investigators.
You are now almost five years into the study. What have been the most interesting and/or surprising findings to come out of the work you have done at your Center?
Dr. Talavera: There has been overwhelming support from the community, staff, and the participants. There seems to be a strong appreciation for the goals of the project.

What challenges have you faced (or are you still facing) in recruiting subjects and collecting data?
Dr. Talavera: The biggest challenge in recruitment is the fluctuation in the “no-show” rate. Some days 50% of the appointments show up and other days everyone shows up.

Can you talk about the importance of having a longitudinal study like this when it comes to addressing the issue of health disparities?
Dr. Talavera: Over the past few decades, research studies have shown that Hispanics/Latinos are disproportionately affected by cardiovascular risk factors such as obesity, diabetes, uncontrolled hypertension, and high rates of being uninsured. Yet, Hispanics/Latinos seem to have lower rates of death from cardiovascular disease (for example heart attacks and stroke) when compared to the general population.

The reasons for this “paradox” or puzzle between the high number of risk factors and the low rates of cardiovascular disease are not fully understood. One explanation given is that Hispanics/Latinos may return to their country of origin when they become seriously ill and do not show up in US health statistics. Additionally, the health care providers are perhaps not doing a good job of identifying Hispanic/Latino ethnicity when they become ill.

Another explanation is that there is something, not yet detected, about the Hispanic/Latino culture that provides protection or buffering against heart attack and stroke. This buffering capacity is thought to be related to the Hispanic/Latino culture, possibly the diet, lifestyle, or approach to life. If this turns out to be true, then Hispanic/Latinos would have something wonderful to share with all Americans.

The HCHS-SOL is a longitudinal study to explore this paradox and determine what factors are responsible for the differences between cardiovascular risk factors and death from heart attacks and stroke. Hispanics/Latinos represent a large group of people from many different backgrounds. For this reason, it is more likely that multiple factors contribute to the Hispanic Paradox, rather than a single factor. However, the health of Hispanics/Latinos must be accurately profiled before any real inferences can be made about the state of Hispanic/Latino health.

What role do you think young clinicians and clinical researchers can play in helping to address—and end—disparities in Hispanic health?
Dr. Talavera: Clinicians can help by encouraging their patients to stay in touch with our study. Only through good long-term follow-up will we be able to answer the research questions posed by the HCHS-SOL.