An Inside Look at Chronic Disease and Health Care among Hispanics in the United States

NCLR
NATIONAL COUNCIL OF LA RAZA

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IHH INSTITUTE FOR HISPANIC HEALTH

The National Council of La Raza (NCLR)—the largest national Hispanic civil rights and advocacy organization in the United States—works to improve opportunities for Hispanic Americans. Through its network of nearly 300 affiliated community-based organizations, NCLR reaches millions of Hispanics each year in 41 states, Puerto Rico, and the District of Columbia. To achieve its mission, NCLR conducts applied research, policy analysis, and advocacy, providing a Latino perspective in five key areas—assets/investments, civil rights/immigration, education, employment and economic status, and health. In addition, it provides capacity-building assistance to its Affiliates who work at the state and local levels to advance opportunities for individuals and families.

NCLR's health programs are housed in the Institute for Hispanic Health (IHH). IHH is dedicated to reducing the incidence and impact of health problems in the Latino community by designing, implementing, and evaluating science-based health interventions that are culturally competent and linguistically appropriate. IHH works closely with Affiliates, government partners, private funders, and other Hispanic-serving organizations to develop and deliver these quality health interventions. IHH works extensively in the areas of chronic diseases, nutrition and physical activity, maternal and child health, and mental health, among others.

Founded in 1968, NCLR is a private, nonprofit, nonpartisan, tax-exempt organization headquartered in Washington, DC. NCLR serves all Hispanic subgroups in all regions of the country. It has regional offices in Chicago, Los Angeles, Miami, New York, Phoenix, and San Antonio, and state operations throughout the nation.

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JSI
John Snow, Inc.

John Snow, Inc. (JSI) is a public health research and consulting organization with over 30 years of experience providing technical services to local, state, and federal agencies to improve the health of individuals and communities, with a focus on vulnerable and underserved populations. JSI partners with governments, organizations, and experts in the United States and abroad to improve quality, access, and equity of health systems worldwide and collaborates with government agencies, the private sector, and local nonprofit and civil society organizations to achieve change in communities and health systems.

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EXECUTIVE SUMMARY

The health of the United States is closely tied to that of Hispanic* Americans. Approximately 50.6 million people now identify themselves as Hispanic American, and by 2060 that number is expected to double to almost one-third of the U.S. population.[1] As the Latino community grows, so will the prevalence of chronic conditions that Hispanics face, such as diabetes, heart disease, asthma, obesity, and related complications. Addressing chronic diseases among Hispanics is imperative to improving the nation's health and maximizing its resources.

Collaborating with its network of Latino-serving grassroots Affiliate organizations, the National Council of La Raza (NCLR) applies community-based formative research as a key tool in understanding the health issues faced by the Latino community. NCLR, in conjunction with public health consulting firm John Snow, Inc. (JSI), designed and implemented a study called the Hispanic Health and Chronic Disease Survey (HHCDS), which gathered information about the rates of chronic disease among Latino health center users, their barriers to and motivators of chronic disease prevention and management, and the roles of health care providers and community resources in helping Latinos manage their conditions.

This study yielded three major findings:

- There is **high prevalence of chronic disease and multiple chronic diseases** among Hispanic health center users, which is compounded by the pervasiveness of obesity.

- Hispanic health center users often reported **inadequate chronic disease management**, which can be addressed with improved follow-up care and access to affordable medication.

- Respondents reported **many barriers to receiving appropriate care**, including cost in time and money, immigration status, and language.

Based on these findings, NCLR proposes the following programmatic and policy recommendations:

- Create a social and media marketing campaign aimed at raising awareness and educating the Latino community about the importance of prevention and treatment of chronic diseases.

- Ensure that prevention and management efforts—including obesity prevention—are tailored to Latinos and linguistically and culturally appropriate.

- Invest in the capacity of community health centers and community-based organizations to provide self-management training, resources, and support to community members via proven, cost-effective initiatives such as peer support programs.

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* The terms "Hispanic" and "Latino" are used interchangeably by the U.S. Census Bureau and throughout this document to refer to persons of Mexican, Puerto Rican, Cuban, Central and South American, Dominican, Spanish, and other Hispanic descent; they may be of any race.

- Support community-based outreach and enrollment efforts to provide health insurance coverage for the Hispanic population, and when possible, a medical home.

With the future of the nation's health closely linked to Hispanic well-being, it is imperative that leaders at the federal, state, and local levels advance a comprehensive strategic framework to integrate Latinos into a transformed health care system that will promote health, improved care, and longevity for all Americans.

INTRODUCTION

The toll of chronic disease in the United States

The human and financial toll of chronic disease on patients, their families, and society is enormous. Chronic diseases cause seven in ten deaths each year in the United States.[2] About 133 million Americans—nearly half of the adult population—live with at least one chronic illness, and approximately one-quarter of them experience significant limitations in their daily activities due to their illness.[3] The management of these widespread chronic conditions, many of which are largely preventable, consumes more than 75% of American expenditures on health care.[4] If the epidemic of chronic disease continues to grow, some experts have predicted that children born today will be the first generation in two centuries to have a shorter life expectancy than their parents,[5] and that chronic conditions will cost more than $1 trillion annually in direct medical costs and economic productivity within the next ten years.[6] The United States is at a critical juncture in which prompt attention and action can reduce and prevent immense human and economic costs.

The Latino community and chronic disease

Latinos are the largest and one of the fastest growing racial/ethnic minorities in the United States.[7] They currently represent 50.6 million people throughout the country, or approximately 16% of the total population, followed by Blacks (12.2%) and Asians (4.7%).[8] According to U.S. Census projections, by the year 2060, the proportion of the Hispanic population will double to nearly one in three people (31%).[9] This population is not only growing rapidly; it is also aging. In 2060, Hispanics are expected to comprise 38% of the nation's 65-and-older population, up from 24% in 2012.[10] The rates and cost of chronic disease have been rising steadily, and will continue to rise with the aging of the Hispanic and overall U.S. population.[11] This massive demographic shift will have profound repercussions for U.S. society and government, including for important services such as Medicare and Social Security.

While Hispanics are a vital and expanding part of the U.S. population, there are troubling trends in their health and well-being. Chronic diseases—such as heart disease, cancer, diabetes, asthma, obesity, hypertension, arthritis, and liver disease—are prevalent and burdensome among this community. For some of these conditions, including diabetes, obesity, and HIV and AIDS, Hispanics face significant health disparities. Despite being younger overall and having lower rates of age-adjusted mortality,[12] Latinos are more likely to report being in poor or fair health than their non-Hispanic White counterparts.[13] Mexican Americans and Puerto Ricans are almost twice as likely as non-Hispanic Whites to be diagnosed with diabetes, and Hispanics are 50% more likely to die from the disease than non-Hispanic Whites.[14] Obesity rates also tend to be higher among Latino adults (39.1%) than among non-Hispanic White adults (34.3%),[15] which puts them at a greater risk of developing diabetes and other chronic health conditions. Moreover, the rate of new HIV infections among Hispanics is more than three times that of non-Hispanic Whites.[16] Addressing these disparities is a matter not only of equity, but also of the future of the nation's health, as we witness a doubling of the Hispanic population within the next fifty years.

An additional and growing concern is the share of people who suffer from multiple chronic conditions, which are associated with poorer day-to-day functioning and increased risk for mortality and which consume about two-thirds of the total health care spending in the United Sates.[17] According to the CDC, 14.2% of Hispanics had two or more concurrent chronic diseases in 2010, up from 11.7% in 2000, while 2.7% of Hispanics had four or more chronic conditions.[18] These high morbidity rates impose enormous costs on Latino families and the economy. Given the high and increasing prevalence of chronic conditions and the aging of the Latino community, it is critical to address the dynamics that can help prevent and treat chronic conditions.

Factors contributing to chronic disease morbidity in the Latino population

Lack of access to affordable, high-quality health care. One of the biggest risk factors for poor health among Latinos is the lack of access to affordable, high-quality health care. More than twice as many (33%) Latinos under age 65 lack health insurance, as compared to non-Hispanics (14%).[19] It is not surprising, therefore, that Latinos are almost twice as likely as non-Hispanic Whites to lack a regular source of health care[20] that includes important screenings and preventive services, making it more difficult to identify and treat potentially serious health conditions at an early stage.

The Patient Protection and Affordable Care Act (ACA) of 2010 can play a critical role in decreasing the high rates of uninsurance among Latinos. Because Latinos are more likely to work in low-paying industries that are less likely to provide employer-sponsored health insurance, the ACA presents an opportunity for Latinos to gain free or low-cost coverage through the health insurance marketplace or Medicaid expansion. In addition, the new health care law focuses on chronic disease management by requiring most health plans to cover recommended preventive services without co-pays. Another valuable ACA initiative is the Medicaid Incentives for the Prevention of Chronic Diseases Model, which authorizes grants to ten states to provide incentives to Medicaid beneficiaries of all ages who participate in prevention programs and demonstrate changes in health risk and outcomes.

Social determinants. Research demonstrates that poverty, income and wealth inequality, racism, sex discrimination, and low socioeconomic conditions are risk factors for poor health.[21] These issues are compounded within the Latino community due to factors such as immigration status, lack of knowledge of available services, prohibitive cost of health services, language/cultural differences, and lack of trust in the health care system. Moreover, the concept of “prevention” implies a sense of control over the future, which many low-income Latinos may lack, and preventive care is less likely to be a priority for people who struggle to meet their families’ basic survival needs.

Inadequate intervention efforts. Hispanics are less likely than non-Hispanics to be reached by mainstream health education, promotion, and disease prevention messages, which tend to reach middle-class, well-insured, English-speaking people.[22] It is imperative that barriers to health care access are understood if Latinos’ health needs are to be met. These issues are among those that this study explored to gain a better understanding of Latino beliefs, attitudes, and behaviors regarding chronic disease and its prevention and management.

METHODOLOGY

Hispanic Health and Chronic Disease Survey

In collaboration with John Snow, Inc. (JSI), the National Council of La Raza (NCLR) developed the Hispanic Health and Chronic Disease Survey (HHCDS), a two-pronged effort that used written surveys and focus group discussions to study how Hispanic Americans understand and manage chronic disease. The population of interest for the HHCDS was Latino adult patients of NCLR Affiliate health centers. The surveys focused on the use of health care access to prevent and manage chronic diseases, the sources Latinos use to seek health information, and the overall community perception of health care services in the United States. Focus groups elicited experiences with the health care system, as well as general health conditions and the prevalence of chronic disease and self-management among Latino health center users. The HHCDS also provided insights into the barriers to accessing health care services in the Latino community.

Written survey

Data collection instrument development. The quantitative survey instrument was developed by JSI in collaboration with NCLR health experts to ensure that its design would capture the range of information desired. The final survey consisted of 61 primarily multiple-choice questions divided into six sections: 1) demographics; 2) health care access and utilization; 3) weight; 4) health information; 5) health status, chronic disease, and self-management; and 6) medications. The majority of questions were adapted from relevant national surveys to ensure reliability and validity.* Question language was adapted for a sixth-grade reading level and cultural competency based on feedback from JSI and NCLR experts as well as two focus groups conducted with Hispanic individuals in Lawrence, MA. Hard copies of the survey in Scantron format in both Spanish and English were sent to the data collection sites that agreed to participate in the project.

*Data collection sites***.** An invitation to participate was sent out through NCLR's Affiliate network targeting community health centers (CHCs). Survey sites were selected for geographic diversity as well as organizational staff capacity to administer a volume of surveys to a wide community base of patients. An hour-long training session was held with a project coordinator at each Affiliate site prior to survey distribution. Based on their response to NCLR's invitation and fulfillment of the above parameters, eight organizations were chosen to participate in data collection for this study. For a full description of the sites, see Appendix A.

*Sample selection***.** Between June and August 2013, more than one thousand Hispanic patients were recruited from eight NCLR Affiliate organizations and partners in California, Washington, Illinois, Florida, and Washington, DC, to complete the survey. Patients were between the ages of 18 and 64 and self-identified as Hispanic/Latino. Participants completed the survey in either English or Spanish, selecting the language with which they were most comfortable. Each survey had a unique identification code, and no

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* The corresponding sources used for the different sections were as follows: 1) U.S. Census; Behavioral Risk Factor Surveillance System (BRFSS); 2) BRFSS; 3) National Health And Nutrition Examination Surveys (NHANES) (2011–2012); 4) modified questions from the Pew Internet Survey; 5) modified questions from the California Health Interview Survey (2009); selected and modified questions from the Chronic Illness Resource Survey (Glasgow et al.); 6) novel questions.

personal information was collected. At the end of the survey data collection period, there were a total of 1,090 completed written surveys.

Statistical methods. The data analysis relied largely on descriptive statistics and was stratified by the presence or absence of a chronic condition(s) for many questions. Due to this stratification, the N's for the different analyses vary. Questions related to disease management, resources, and support to deal with the chronic condition and medication were asked only of those who answered "yes" to the question, "Has a doctor or health care professional ever told you that you have a chronic illness?"

Focus group discussions

Data collection instrument development. A research protocol was developed that included a focus group discussion (FGD) guide and participant selection criteria. Both the FGD guide and selection criteria were vetted and approved by NCLR experts to ensure cultural competency and appropriate language level. The FGD guide included a script for the facilitator, guidelines, and 18 questions that were drawn from the written survey. The FGD questions covered the following topics: 1) chronic disease knowledge; 2) health status, chronic disease, and self-management; 3) health care access and utilization; and 4) sources of health information.

Data collection sites. As noted previously, two FGDs were conducted in Lawrence, MA, to inform the development of the written survey tool. During the implementation phase of the study, four additional FGDs were conducted with Latino community members in San Ysidro, CA, and Wimauma, FL, to provide a more in-depth, qualitative perspective on chronic disease management and health service use among Latinos to supplement the information gathered via the quantitative surveys. San Yisdro, CA, is located south of San Diego and just over the border from Tijuana, Mexico. Wimauma, FL, a rural area, is located near Tampa.

Sample selection. Between April and October 2013, a total of six FGDs were conducted with 60 Latino community members recruited by three CHCs. Participants were between the ages of 18 and 70, with the average age being 38.5. All participants identified as Hispanic/Latino and included Dominicans, Puerto Ricans, U.S.-born Latinos, and Mexicans. The sample included 15 men and 45 women. Details on participants at each site can be found in Appendix A.

Data collection and analysis. Each FGD lasted approximately 90 minutes. FGDs were conducted in Spanish and audio recorded to ensure precision in the analysis of the results. Note-takers were also employed for all FGDs. Due to technical problems, there was no audio recording for the second FGD in Lawrence, MA, and therefore notes were used to analyze results. Responses were transcribed, entered into a data spreadsheet, coded, and analyzed for themes.

RESULTS

Taken together, a number of themes emerged from the surveys and focus group discussions, generally falling under one or more of three categories: the prevalence of chronic diseases, experience with medical providers and health services, barriers to health care coverage and utilization, and access to health information. The findings from the quantitative and qualitative data were collected and analyzed in 2013, prior to the implementation of the ACA.

Demographics

A total of 1,090* Latino adults responded to the written survey. Most were female (70.3%), of Mexican origin (65.5%), and spoke Spanish at home (77.6%). More than half (55%) were older than 50. While the majority of respondents (80%) were born outside the United States, most (69.5%) had lived in the United States for at least 15 years. About half (47%) did not have a high school diploma, and 29% had an annual household income of less than $10,000. Survey respondent demographics are presented in Table 1.

Table 1. Demographics (N=1,086)	**Overall**		**Chronic disease**		**No chronic disease**	
	N	**N%**	**N**	**N%**	**N**	**N%**
Sex (N=912)						
Male	271	29.7%	153	30.4%	87	25.7%
Female	641	70.3%	350	69.6%	252	74.3%
Age (N=1,066)						
18–20	26	2.4%	2	0.3%	16	4.2%
20–29	115	10.8%	30	5.1%	74	19.5%
30–39	154	14.4%	44	7.5%	100	26.4%
40–49	180	16.9%	78	13.2%	93	24.5%
50–59	208	19.5%	149	25.3%	40	10.6%
60–69	249	23.4%	192	32.6%	34	9.0%
70+	134	12.6%	94	16.0%	22	5.8%
Hispanic/Latino (N=1,064)						
Yes	1031	96.9%	564	96.4%	375	97.7%
No	33	3.1%	21	3.6%	9	2.3%

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* Four of the surveys were unreadable by the Scantron machine. Therefore, only 1,086 survey responses were analyzed.

Highest degree or level of school completed (N=970)						
Less than high school	458	47.2%	291	54.7%	123	34.6%
High school graduate or equivalent (GED)	273	28.1%	137	25.8%	114	32.0%
Some college (1–4 years) but no degree	123	12.7%	55	10.3%	60	16.9%
Bachelor's degree (BA, BS, AB, etc.)	74	7.6%	38	7.1%	32	9.0%
Graduate degree (master's, doctoral, or other professional degree)	42	4.3%	11	2.1%	27	7.6%
Annual household income (N=1,035)						
Less than $10,000	303	29.3%	195	33.9%	75	20.3%
$10,000–$29,000	381	36.8%	205	35.6%	140	37.8%
$30,000–$49,999	172	16.6%	77	13.4%	85	23.0%
$50,000 or more	53	5.1%	24	4.2%	28	7.6%
I would prefer not to say	126	12.2%	75	13.0%	42	11.4%
Country of birth (N=1,049)						
Mexico	687	65.5%	394	68.2%	235	62.0%
USA	210	20%	101	17.5%	84	22.2%
Other	152	14.5%	83	14.4%	60	15.8%
Number of years living in the U.S. (N=1,059)						
Less than 1 year	17	1.6%	10	1.7%	5	1.3%
1–5 years	54	5.1%	25	4.3%	25	6.5%
6–10 years	118	11.1%	49	8.4%	63	16.4%
11–15 years	134	12.7%	53	9.1%	67	17.5%
15–20 years	135	12.7%	64	11.0%%	58	15.1%
20 or more years	601	56.8%	379	65.3%	165	43.1%
Primary household language (N=1,072)						
English	231	21.5%	119	20.2%	85	22.1%
Spanish	832	77.6%	463	78.7%	297	77.1%
Other	9	.8%	6	1.0%	3	0.8%

Chronic disease burden

Overall, 60.5% (N=595) of survey respondents had been told by a doctor that they had a chronic disease, and comorbidities were highly prevalent. Among respondents who had a chronic condition, 36.6% reported that their health was fair and 9.6% stated that it was poor. More than half (56.2%) had lived with their condition for more than five years.

Table 2 displays the four major chronic diseases experienced by respondents: hypertension (26.8%), diabetes (26.2%), arthritis-related conditions (15.7%), and depressive disorders (10.7%). Respiratory diseases (i.e., combination of asthma, N=72; and COPD, emphysema, or chronic bronchitis, N=34) were experienced by 9.75% of the sample. Heart attacks and kidney diseases also figured prominently. For more information about the most common comorbidities, see Appendix B.

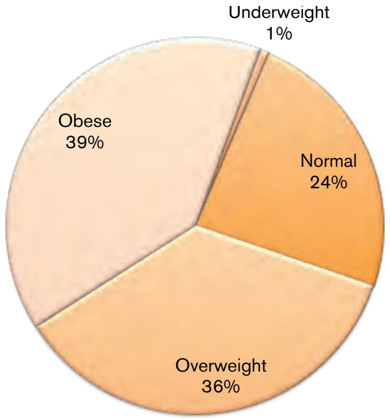
Table 2. Most prevalent chronic conditions experienced by survey respondents (N=1,086)*	**N**	**N%**
Hypertension	291	26.8%
Diabetes	284	26.2%
Some form of arthritis, rheumatoid arthritis, gout, lupus, fibromyalgia	170	15.7%
Depressive disorders (including depression, major depression, dysthymia, or minor depression)	116	10.7%

**Respondents were asked to select all that apply.*

Obesity and body mass index (BMI)

Obesity is a highly prevalent problem among the general Latino population and among health center users. BMI was calculated from the self-reported weight in pounds and height in feet, then categorized into underweight, normal, overweight, or obese, according to international standards established by the World Health Organization.* Figure 1 illustrates the percentage of respondents who fell into each category.

Figure 1. BMI rates of respondents



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* World Health Organization, "Physical Status: The Use and Interpretation of Anthropometry: Report of a WHO Expert Committee," *WHO Technical Report Series* 854 (1995).

About 75% of survey respondents were either overweight or obese, but among them, only about two-thirds (64.3%) had been told by a doctor that they were overweight. Only 42% of respondents who were obese or overweight had discussed their weight with a doctor or other health care professional in the past 12 months. This lack of discussion may be due to the fact that 55% of those who were obese and 67% of those who were overweight felt that their health was "excellent," "very good," or "good." However, about 70% reported trying to lose weight in the past 12 months.

The information from focus groups highlighted respondents' desire to lose weight and their difficulties doing so. Similarly, focus group participants seemed to have a general understanding of how to be healthy, but many reported difficulty in putting that knowledge into practice. Participants mentioned eating healthily, engaging in physical activity, drinking water, knowing one's family health history, getting adequate rest and sleep, taking prescribed medicines, and leading a balanced lifestyle as ways to prevent the development of chronic diseases. However, many respondents reported that some of these guidelines were impractical or difficult to follow.

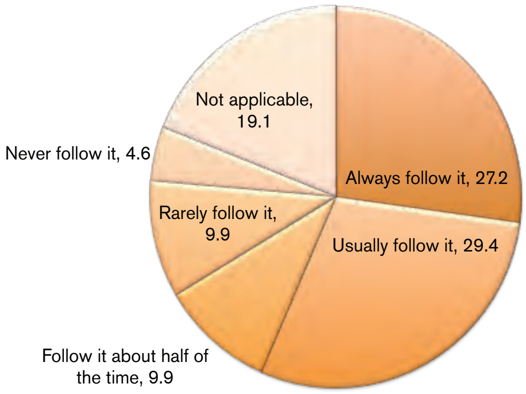
> "The thing is, the harmful food is cheaper, really. Rice, beans, tortillas… It's hard for people who don't have a lot of money. And when you're used to this food, when you've eaten it for years, it's tough."
>
> —Man, Wimauma, FL

Chronic disease management

The focus group participants all suffered from at least one chronic disease—many of them for years or decades—and understood that it is important to control these long-term health conditions. Participants emphasized the importance of getting medical care when one has a chronic disease, following doctor's orders and having healthy habits, and taking prescribed medications. Yet focus group participants, along with survey respondents, revealed that there are significant barriers to getting the care they need.

Of the survey participants living with a chronic condition, a quarter had visited the emergency room and 15% had not seen a doctor for their condition over the past 12 months. Furthermore, 17.4% had not had a doctor explain how to manage their illness at their last visit. About one-third of respondents (29.9%) did not have any care plan. The majority (63.6%) of respondents did not have a written plan to manage their condition, and the existence of a plan did not guarantee adherence to it (see Figure 2).

Figure 2. Adherence to chronic condition care plan



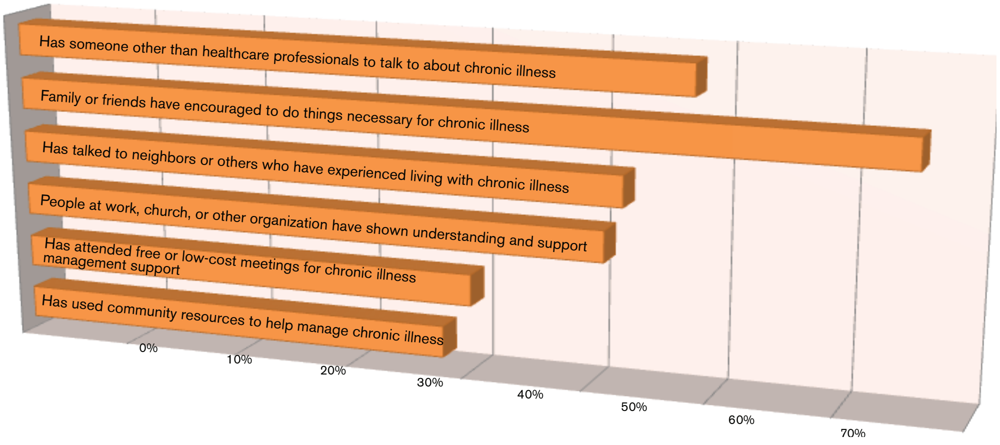
One barrier to adherence is the cost of medication. The majority of respondents (86%) took medications for their chronic disease, yet cost prohibited about one in three of them (32%) from purchasing needed medication in the past 12 months.

> “I have medical check-ups every three months, but there’s no one who takes the time to explain my health status.”
>
> —Man, Wimauma, FL

The absence of and poor adherence to care plans may also be partially due to a lack of adequate medical assistance and explanation during and between health care appointments. For instance, the survey data revealed that about half of respondents did not receive support for managing their chronic illness between visits. Focus group participants reported that they received little or no help between doctor visits, and some said they did not receive instructions from their doctor on how to take care of their illness. Many participants reported only being given prescriptions, with no opportunity to discuss a plan for taking care of their illness with their doctor.

Nonetheless, only 20.5% of respondents described themselves as *not* confident that they could manage their chronic disease(s). Survey participants did have limited resources and support beyond their doctors, as seen in Figure 3. Classes at the community health center and/or NCLR’s healthy-living projects were noted as sources of information and support between doctor visits for focus groups participants. Also, patients who received reminder calls about their appointments from the health center’s *promotores de salud* (community health workers) or social workers greatly appreciated this service.

Figure 3. Resources and support used to manage chronic illness

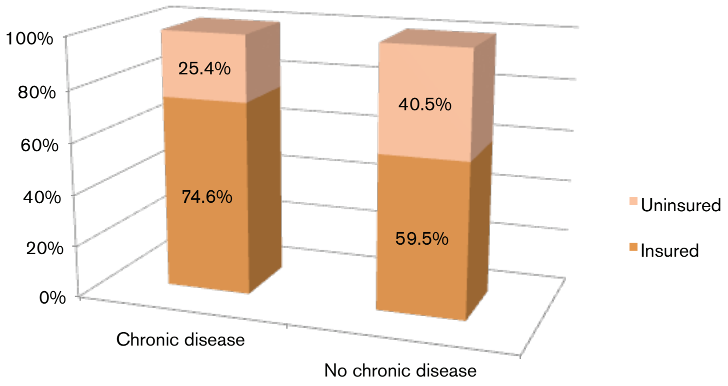


Barriers to health coverage and utilization

Sixty-eight percent of all survey respondents reported having health insurance; 32% did not. Respondents who had one or more chronic conditions were more likely to have health coverage than those who did not have a chronic condition (see Figure 4).

The most common types of health insurance among respondents were employer-sponsored (37%); Medicare (28%); and Medicaid (24.7%). People without a chronic condition were more likely to have insurance through their employer, while people living with a chronic illness were more likely to be Medicare or Medicaid enrollees. About 18% of respondents who currently had insurance reported that there was a period of time in the past 12 months when they did not have coverage.

Figure 4. Percent insured by chronic disease status



The focus group results explain some of the reasons that many Hispanics do not have health insurance. Of the FGD participants who did not have health insurance (roughly half), the main barriers were *affordability* and *immigration status*. These obstacles were both structural, such as eligibility limitations, and perceived, such as a fear of interacting with the health care system or providing information to eligibility workers. Several noncitizen participants said that they were deterred from seeking health care because they believed providers would ask them for proof of citizenship or documentation of legal status. In nearly all the focus groups, participants remarked that fear of unintended immigration consequences was a deterrent to health care access in their communities. Immigration status was more of a concern for participants in Florida than for those in California.

When asked about public options for health insurance, some FGD participants had not heard of the ACA, and others reported general confusion about what it would mean for them. Consistent with the findings of a recent ACA study conducted by NCLR and its Affiliates, most participants had heard varying versions of what the law was about and how it would work, and were unsure what to believe. However, participants were interested in more information.

The three most important factors that prevented survey respondents from seeing a provider were *affordability* (27%); *availability of appointments* (25.1%); and *language* (16.6%). FGD participants reported *time, cost,* and *transportation* as barriers to seeing a health care professional. They prioritized caring for and proving food for their family above worrying about themselves.

"I don't have health insurance. They don't offer it to my husband and it's very expensive. I haven't really needed it… I've felt pretty healthy… And I don't qualify for Medi-Cal."

—Woman, San Ysidro, CA

"The information on TV is really vague; I don't know how [the ACA] will work."

—Man, Wimauma, FL

"Sometimes we give priority to our jobs or other things we have to take care of."

—Woman, Wimauma, FL

Access to health information

Hispanic health center users reported seeking health information from different sources (see Appendix C). About 80% of respondents sought health information at least once every few months, and about 41% sought health information at least once a month. While doctors were clearly their preferred source of health information, about one-third of respondents (30.5%) reported difficulty getting the information they needed in Spanish, the preferred language among 74% of survey respondents. Several focus group participants also reported trouble finding information in Spanish and interacting with non-Spanish-speaking doctors via interpreters. Perhaps unsurprisingly, 70% of survey respondents said they considered language an important factor when selecting a provider (for additional information on provider selection factors, see Appendix D). About one-quarter of the respondents (23%) said they would trust *promotores de salud* for access to specific health information, followed by television (19.3%). Most FGD participants also preferred receiving health information in Spanish, but several said it would be helpful to have information available in both languages.

> "I have difficulty finding [health] information in Spanish."
>
> —Man, Wimauma, FL

Limitations

This study has several limitations. First, because the data are self-reported, certain demographic characteristics (e.g., income level) might have been reported incorrectly. Information recall issues are particularly sensitive in the BMI calculation, which is based on self-reported height and weight. Notably, the consensus among researchers is that people tend to underestimate their weight, so the BMI findings in this study would err on the conservative side. Second, the response rate for the quantitative survey was not collected and thus there is no information on how many health center users declined to participate, and whether their characteristics were significantly different from those who participated in this study. Third, the data was collected from individuals receiving care at CHCs, which suggests that their health outcomes would be better than (Hispanic) individuals who have no access to care.

DISCUSSION

Summary of findings

The NCLR Hispanic Health and Chronic Disease Survey findings reinforce much of what is known about people on the margins of the health care system, while also contributing new information about the experiences and needs of people in the lowest income bracket, who are unemployed, and who are immigrants. The reported findings provide a snapshot of the health statuses and health care services received by a unique sample of Hispanics—clients at CHCs, many of whom have chronic diseases. This snapshot offers opportunities to develop recommendations to improve the health of Hispanics in conjunction with implementation of the ACA, especially for preventive services and patient education.

Three major conclusions emerged from the HHCDS data:

1. There is **high prevalence of chronic disease and multiple chronic diseases** among Hispanic health center users, which is compounded by the pervasiveness of obesity.

2. Hispanic health center users often reported **inadequate chronic disease management** and not receiving the support and resources needed.

3. Respondents reported **many barriers to receiving appropriate care**, including cost in time and money, immigration status, and language.

Implications for Hispanic health

High prevalence of chronic diseases. The results of this study are generally consistent with the rates of chronic disease in the Behavioral Risk Factor Surveillance System (BRFSS), one of the key indicators used by policymakers, researchers, and health care providers to document the health of Americans.* The disease burden experienced by participants in this sample was higher than that of Hispanics participating in the most recent version of BRFSS, but these higher results are expected in a sample of health center patients who are already engaged in care. This sample exhibited much higher morbidity rates for diabetes and obesity, but remained fairly consistent with national standards for hypertension, arthritis, and depression.

The rates of chronic disease among the health center users in this study portend an increase in rates for the national Hispanic population, which for years has largely been disconnected from the health care system. Poor access to health care has reverberating negative effects on wellness, achievement, and productivity. The advancing age of the Hispanic population increases the probability of chronic diseases and the urgency of reducing gaps in health care services for this group.

The epidemic of obesity—which is a risk factor for such diseases as diabetes and hypertension—will also add to the prevalence of chronic disease among this group. Moreover, obesity has itself been recently classified as a chronic disease.[23] Although the partici-

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* This survey is conducted nationally by the CDC every two years and includes a statistically significant proportion of Hispanics.

pants in this study were aware of the risks associated with obesity, they found it hard to change their day-to-day behaviors. It is imperative to promote healthy eating and exercise among this population to combat not only obesity but the problems of diabetes, hypertension, and heart disease, as well.

Insufficient chronic disease management. When asked about the care they received, participants' responses suggest suboptimal care: less than half of overweight respondents reported discussing their weight with their doctor; the majority of respondents did not have a written treatment plan for their chronic disease(s); and many respondents who had a treatment plan did not discuss it with their doctor. Compounding these issues are prohibitive costs of some medications and difficulty getting health information in Spanish. Without appropriate information, support, and encouragement, patients will be ill-equipped to handle the daily decisions and behaviors needed to manage their care and stay out of the emergency room. Self-management training and support will be increasingly critical as the prevalence and complexity of the chronic disease burden grows among the Latino population.

The health center users in this study were aware of the importance of receiving appropriate care for their chronic disease(s), but it was clear that the health system was not fully prepared to meet the increasing burden of chronic disease among Latinos. Health centers and other groups are trying to improve care, but there is variation in provider capacity. Health providers must do more to engage Latino patients in the prevention and self-management of chronic disease now and before the influx of new patients due to the expansion of health care coverage under the ACA. However, the overburdened—and in some cases understaffed—CHCs[24] will be unable to meet this challenge without greater resources and support.

Inadequate health care access and utilization. The lack of health insurance coverage has been a persistent issue for Hispanics, who are significantly more likely to be uninsured in comparison to non-Hispanic Whites.[25] This sample had greater access to health insurance and care than the general Hispanic population, but many experienced barriers to obtaining coverage and using care. Among the obstacles to acquiring health insurance were high prices of coverage, fear of unintended immigration consequences, and lack of knowledge about public health insurance options. Despite potential positive changes by the ACA, the need in the Latino population for health care coverage and chronic disease prevention and management is larger than can be currently met, and this gap will grow larger in subsequent years. The findings from the present study illustrate the significance of the benefits of the ACA and reveal the unmet health care needs of the Latino community.

For those who had coverage, there were difficulties in seeing a doctor due to high costs in time and money, as well as difficulties in getting an appointment with a Spanish-speaking provider. These obstacles can be modified significantly through policies that respond to the needs of the Hispanic population, especially those who are immigrants, low-income, or limited English proficient.

RECOMMENDATIONS

This study's findings foretell a massive human and economic toll on the Hispanic community and on the nation's resources, and underline the need for a major public health initiative devoted to the prevention and management of chronic disease and the reduction of structural barriers to health care. NCLR proposes the design and implementation of a major, sustained, multisite and multidisciplinary demonstration project incorporating the following components:

- **Create a culturally competent and linguistically appropriate obesity and chronic disease prevention and management social marketing campaign targeting Latino families.** A media and communications strategy can play a key role in raising awareness and educating the community about chronic conditions. Due to the popularity of television as a source of health information among Hispanics, the *telenovela* could be an ideal way to promote healthy eating, physical activity, and chronic disease management to the entire family within a culturally and linguistically accessible context. Additional media efforts such as public service announcements should be included and must be tailored specifically to the Latino community. By focusing on the whole family, the stigma associated with obesity and chronic disease can be reduced, and a supportive family environment can be fostered, which encourages the prevention of chronic conditions and adherence to management plans.

- **Ensure the availability of linguistically and culturally appropriate health education materials.** Health education materials should be in basic Spanish, at a literacy level that is accessible to the majority and, due to the range of Latino subpopulations often residing within a given area, avoid colloquial Spanish of any given subgroup or region. Latino-specific art and pictures should be used to reflect the communities targeted, and mere translations of English-language materials should be avoided as much as possible. Educational materials tailored specifically for Latinos will help improve health literacy among this community, help them make informed health decisions, and increase adherence to chronic disease care plans.

- **Invest in the capacity of community health centers and community-based organizations.** CHCs are ideally suited to respond to the needs of people on the margins of the health care system, especially those who are immigrants, low-income, or limited English proficient. Despite receiving federal and ACA funding and providing services to the best of their ability, however, CHCs are often understaffed, under-resourced, and caring for a growing number of Americans. Strengthening the capacity of CBOs to deliver health programs and related activities can help ensure that Latinos not being served by a CHC are nonetheless receiving education and support they need to be healthy. Increasing the capacity of CHCs and CBOs will help many Latino patients receive optimal care and guidance in managing their chronic disease(s).

- **Strengthen linguistically and culturally competent peer support programs such as *promotores de salud*.** One of the biggest challenges for Hispanic chronic disease sufferers is consistent disease self-management. As a member of the clinical care team, a *promotor de salud* is a trusted contact who can follow up with patients between medical visits to encourage adherence to disease management plans and provide social and educational reinforcement as needed. *Promotores de salud* can also link patients to community resources that can assist with day-to-day care and support. Peer support has been shown to be especially effective within the Latino community due to the high cultural value placed on personal and social relationships.

- **Increase cultural competency training for health care professionals.** The ability to respond to the specific health needs of Latinos—the second-largest, and growing, racial/ethnic group in the nation—is an increasingly important asset. Unique training programs and models should be developed to equip physicians, nurses, and other health care professionals with an understanding of the health care needs of diverse Latino populations. At the same time, it is important to increase the diversity of the health care workforce to ensure the availability of Spanish-speaking and culturally sensitive staff.

- **Support community-based outreach and enrollment efforts to ensure that eligible Latinos obtain coverage under the ACA or other health coverage programs.** Access to quality and affordable health insurance is critical for low-income Latinos. The ACA, Medicaid, and Medicare all present great new opportunities to gain coverage, but many Latinos are unaware of how these programs work, are unclear about eligibility requirements, and lack trust in the government. Outreach and enrollment efforts should be tailored to Latinos, culturally and linguistically appropriate, and come from a trusted source.

- **Build coalitions with other local, cross-sector organizations to reduce structural barriers that hinder Latinos' ability to prevent and manage chronic disease.** Implementing initiatives focused on reducing or eliminating structural barriers, such as addressing poor transportation or simplifying administrative procedures (scheduling appointments with the same provider, in a timely manner, and during convenient hours, for example) will positively affect community members' ability and willingness to obtain needed care. Coalitions enable groups to pool their resources and work together to gain the power necessary for effective change.

CONCLUSION

As the proportion of Latinos is expected to double from one-sixth to one-third of the U.S. population and to account for a growing share of middle-aged and elderly Americans over the next 50 years, Hispanic health must become a national priority. Through a focused emphasis on the prevention and management of chronic diseases as well as on the reduction of structural barriers to health care, the Hispanic community and the nation at large will benefit from improved quality of care, improved health outcomes, and lower health care costs. NCLR urges leaders at the federal, state, and local levels to advance a comprehensive strategic framework, such as the one proposed, which engages and integrates Latinos into a transforming health care system that promotes health, improved care, and longevity for all Americans.

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APPENDIX A

Data collection sites

Written survey data collection sites

A total of 1,090* written surveys were completed and collected from eight community-based organizations and health centers. Table A1 lists the number of completed surveys submitted by site.

Table A1. Surveys completed by site	**Location**	**N**
AltaMed Health Services Corporation	Los Angeles, CA	192
San Ysidro Health Center	San Diego, CA	177
Sea Mar Community Health Centers	Seattle, WA	163
Eastmont Community Center	Los Angeles, CA	150
Clínicas de Salud del Pueblo	Brawley, CA	132
Alivio Medical Center	Chicago, IL	131
Hispanic Services Council	Tampa, FL	91
Mexican Consulate—Ventanilla de Salud	Washington, DC	54
TOTAL		1,090

Focus group data collection sites

Table A2 displays more information about the focus group sites and the sex and number of Hispanic community members who participated in each group.

Table A2. Focus group discussion sites and participants

Location	**Community type (rural, etc.)**	**Participants recruited by**	**Men/ women**	**N**
Lawrence, MA	Urban	Greater Lawrence Family Health Center	Mixed	10
Lawrence, MA	Urban	Greater Lawrence Family Health Center	Mixed	6
Wimauma, FL	Rural	Hispanic Services Council	Women	10
Wimauma, FL	Rural	Hispanic Services Council	Men	8
San Ysidro, CA	Border town	San Ysidro Health Center	Mixed	11
San Ysidro, CA	Border town	San Ysidro Health Center	Women	15
TOTAL				60

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* Four of the surveys were unreadable by the Scantron machine. Therefore, only 1,086 survey responses were analyzed.

Description of data collection sites

Alivio Medical Center (Chicago, IL) is a bilingual, bicultural organization committed to providing high-quality, culturally sensitive, comprehensive medical care for those whose income, lack of health coverage, or other social and economic vulnerabilities limit their ability to access mainstream medical care. This mission is expressed through the provision of services, advocacy, education, and research and evaluation provided in an environment of caring and respect. Alivio is firmly entrenched as a "safety net" provider for the many low-income and marginalized residents of its nine targeted communities. With an annual budget exceeding $12 million, Alivio meets the primary health care needs of over 20,000 Spanish-speaking, predominantly Mexican immigrants who fall through the cracks of the U.S. health care system.

AltaMed Health Services Corporation (Los Angeles, CA) has delivered quality care to the underserved communities of Southern California for more than 40 years, including primary medical care, dental care, and complete senior long-term care services. AltaMed also delivers disease management programs, health education, youth services, specialty AIDS care, and substance abuse treatment. AltaMed's integrated system emphasizes prevention and healthy living and is designed to reduce health care disparities and avoid unnecessary trips to emergency rooms or other more costly forms of care. AltaMed is the largest independent federally qualified community health center in the U.S., delivering more than 930,000 annual patient visits through its 43 sites in Los Angeles and Orange Counties.

Clínicas de Salud del Pueblo (Brawley, CA) is a private, nonprofit corporation providing comprehensive primary care services to residents throughout Imperial and Riverside Counties. Established in 1970, Clínicas de Salud has expanded from two original clinics to 11 clinics, three dental centers, three Women, Infants, and Children (WIC) nutrition education centers, and six WIC voucher distribution sites. All clinics have bilingual and bicultural staff to assist patients. Clínicas de Salud provides direct access to comprehensive quality primary and preventive health care for high-risk and other underserved valley residents. No one is denied services due to his/her inability to pay.

Eastmont Community Center (Los Angeles, CA) was founded in 1967 to enhance the quality of life of low-income families by providing education, social services, and health and wellness services that promote personal development and self-sufficiency. In addition to providing emergency services such as food and clothing, housing, and job search counseling, Eastmont offers child development services, educational programs for youth, ESL and citizenship classes, adult literacy programs, and senior services including hot meals and low-impact exercise activities.

Greater Lawrence Family Health Center (Lawrence, MA) has been serving the communities of the Merrimack Valley for more than 30 years. With six locations in Lawrence and Methuen, GLFHC is a leader in family medicine in the region, providing high-quality, comprehensive health care services and training health care professionals to respond to the needs of a culturally diverse population. The city of Lawrence comprises a heavily Hispanic and minority, low-income, and limited English proficient population with elevated rates of asthma, diabetes, tuberculosis, teenage pregnancy, lead paint poisoning, and substance abuse.

Hispanic Services Council (Tampa, FL) is a community-based organization working to improve the quality of life of Hillsborough County residents by promoting academic success for children and youth, preparing individuals to excel in today's workforce, supporting the development of healthy communities, and promoting leadership and engagement among Latinos. HSC's health programming currently includes NCLR's

Selección Sana, Vida Saludable (Healthy Choices, Healthy Life) program as well as a three-year initiative, Bridges to Health, which focuses on building the capacity of Latino residents in South County's rural areas to create strategies to close the health disparities gaps where they live and work.

San Ysidro Health Center (San Diego, CA). With a vast network of community clinics and program sites located throughout San Diego, SYHC improves the overall health and well-being of its primarily low-income community by offering comprehensive primary care, dental, counseling, and family support services. SYHC serves over 85,000 patients, of whom nearly half are children and adolescents, and strives to eliminate health disparities and become the connection to a permanent medical home for the most vulnerable families.

Sea Mar Community Health Centers (Seattle, WA), founded in 1978, is a community-based organization committed to providing quality, comprehensive health and human services in Washington State. Sea Mar serves all persons without regard to race, ethnicity, immigration status, gender, sexual preference, or ability to pay for services. Sea Mar's network of services includes more than 50 medical, dental, and behavioral health clinics and centers, and a variety of nutritional, social, and educational services.

APPENDIX B

Prevalence of comorbidities

Comorbidities were examined for written survey respondents for some of the most prevalent conditions, including obesity (as determined from BMI calculations from self-reported height and weight).

a. **Hypertension.** Of those who reported having hypertension (N=291), 13.1% had only hypertension, while 23.7% had one, 27.5% had two, and 35.7% had three or more additional comorbidities. The most common comorbidities associated with hypertension were diabetes (66.5%), arthritis-related conditions (44.5%), obesity (39.2%), depressive disorders (31.1%), heart attack (28.6%), and kidney disease (23.4%).

b. **Diabetes.** Of those who reported having diabetes (N=284), 13.7% had only diabetes, while 24.3% had one, 24.3% had two, and 37.7% had three or more additional comorbidities. The most common comorbidities associated with diabetes were hypertension (68.8%), obesity (46.8%), arthritis-related conditions (37.6%), depressive disorders (32.5%), heart attack (23.7%), and kidney disease (21.9%).

c. **Obesity.** Of those who were calculated to be obese (BMI>30.0) and reported having a chronic condition (N=230), 34.8% had one, 30% had two, and 31.7% had three or more additional comorbidities. The most common comorbidities associated with obesity were diabetes (67.5%), hypertension (60.6%), arthritis-related conditions (37.1%), depressive disorders (27.5%), heart attack (22.2%), and asthma (21.8%).

d. **Arthritis-related conditions.** Of those who reported having arthritis-related conditions (N=170), 11.8% had only arthritis-related conditions, while 23.5% had one, 23.5% had two, and 41.2% had three or more additional comorbidities. The most common comorbidities associated with arthritis-related conditions were hypertension (66.7%), diabetes (54.2%), depressive disorders (40.9%), obesity (36.5%), and heart attack (26%).

e. **Depressive disorders.** Of those who reported having a depressive disorder (N=116), 11.2% had only a depressive disorder, while 13.8% had one, 21.6% had two, and 53.4% had three or more additional comorbidities. The most common comorbidities associated with depressive disorders were hypertension (65.3%), diabetes (65%), arthritis-related conditions (56.8%), obesity (37.9%), heart attack (28.3%), kidney disease (25%), and stroke (22.7%).

f. **Respiratory conditions.** More than six of ten respondents with some kind of respiratory disease presented with three or more additional chronic conditions. Hypertension (42%) and diabetes (40%) were common among this group. Among people with a respiratory condition, 41% had been diagnosed with asthma and were experiencing three or more chronic diseases at the same time.

APPENDIX C

Sources of health information

About 80% of written survey respondents sought health information from different sources at least once every few months, and about 41% sought health information at least once a month. The preferred sources of information are displayed in Table C, with most (85.7%) seeking information from a doctor or health care professional. About 74% of respondents preferred to receive health information in Spanish, and 30.5% stated that they experienced difficulties finding information in their preferred language.

Table C. Sources of information about health*	**Overall (total sample)**		**Chronic disease**		**No chronic disease**	
	N	**N%**	**N**	**N%**	**N**	**N%**
Doctor or health care professional	931	85.7%	522	87.7%	327	84.1%
Friends or family members	142	13.1%	88	14.8%	43	11.1%
Online or other web-based resources	205	18.9%	105	17.6%	90	23.1%
Churches	65	6.0%	37	6.2%	20	5.1%
Books or other printed reference materials	183	16.9%	106	17.8%	70	18.0%
Health fairs	157	14.5%	82	13.8%	64	16.5%
Newsletter or magazines	159	14.6%	97	16.3%	54	13.9%
Promotores de salud or community health workers	249	22.9%	158	26.6%	80	20.6%
Television	210	19.3%	130	21.8%	70	18.0%
Curanderas or *curanderos*	9	0.8%	4	0.7%	5	1.3%
Radio	127	11.7%	83	13.9%	41	10.5%
Other	12	1.1%	5	0.8%	5	1.3%

** Respondents were asked to select all that apply.*

Similarly, focus group participants reported that their most common sources of health information included doctors, CHCs, and *promotores de salud*. Several participants also reported asking friends for help when they had questions about their health or wanted to know where to find information, and one Florida man received considerable information and support from his church. Participants also obtained information from pamphlets at the doctor's office, television commercials, and health- and nutrition-oriented organizations and companies.

APPENDIX D

Factors considered when choosing a health care provider

As shown in Table D, when selecting a new doctor or health care professional, language compatibility was the most important factor considered by all written survey respondents (70.3%), followed by availability of appointments (49.6%), and affordability (37%). These reasons were similar for people both with and without a chronic condition.

Table D. Factors respondents consider when selecting a health care provider*	**Overall (total sample)**		**Chronic disease**		**No chronic disease**	
	N	**N%**	**N**	**N%**	**N**	**N%**
Speaks the same language as I do	763	70.3%	440	73.9%	258	66.3%
Treats other patients with the same health condition	278	25.6%	173	29.1%	89	22.9%
Is available when I need an appointment	539	49.6%	313	52.6%	184	47.3%
A friend or family member recommended this doctor	166	15.3%	105	17.6%	52	13.4%
Appointment costs are affordable	402	37.0%	223	37.5%	149	38.3%
Other	27	2.5%	15	2.5%	10	2.6%

**Respondents were asked to select all that apply.*

Among focus group participants, Spanish language and/or Hispanic cultural competency, consistency, close proximity and affordability, and taking the time to talk to patients were the attributes listed as most important in a health care provider. Other attributes participants looked for included availability, compatibility with insurance, specialization in one's illness, and interpersonal/bedside manner. Participants felt the most comfortable and trusting when their doctors took the time to talk to them and listen to their questions.

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