



CHAGAS DISEASE INITIATIVE FOCUS GROUP REPORT

Funded by:

CENTERS FOR DISEASE PREVENTION AND CONTROL (CDC)

Project of:

THE NATIONAL ALLIANCE FOR HISPANIC HEALTH

1501 16th Street, N.W.

Washington, DC 20036

www.hispanichealth.org

Community Partners:

ALIVIO Medical Center (Chicago, IL)

***Concilio Latino de Salud* (Phoenix, AR)**

Community Health of South Dade, Inc. Everglades Health Center (Florida City, FL)

***Salud Para la Gente* (Watsonville, CA)**

Acknowledgements

We wish to acknowledge the collaborative effort of the of the four community partner sites: Alivio Medical Center in Chicago, IL; *Concilio Latino de Salud* in Pheonix, AR; Community Health of South Dade, Inc., Everglades Health Center, in Florida City, FL and, *Salud Para LA Gente* in Watsonville, CA.

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I. Executive Summary

The National Alliance for Hispanic Health (the Alliance) received funding from the Centers for Disease Control and Prevention's (CDC) Parasitic Diseases Branch to assess the level of knowledge and understanding of Chagas disease among foreign-born Hispanics in the United States, and their health care providers. Chagas disease is a disease that is endemic in Central and South America. Chagas disease is caused by *Trypanosoma cruzi*, a parasite transmitted to humans by blood-sucking insects known as triatomines. Although these insects are found in the United States and it is possible to acquire this infection in the U.S., the majority of Chagas disease infections were contracted in endemic areas.

In addition to insect-borne infection, transmission can also occur from blood transfusion, organ transplantation, or congenitally. In 2007 the FDA issued new guidelines regarding the testing donated blood for evidence of *Trypanosoma cruzi* infection. Since that time, CDC's Parasitic Diseases Branch has become aware of an increase in the number of people donating blood who have tested positive for Chagas disease. However, this has not been accompanied by a comparable increase in requests for assistance with the treatment of Chagas disease (CDC is the only agency in the country that has access to and can dispense the treatment for Chagas disease). While blood centers do notify any person who tests positive for Chagas disease about their infection status, it is unclear whether consumers understand the information that is given to them, or if other barriers (such as lack of symptoms, no health insurance, insufficient resources to pay for a doctor's visit, language barriers, documentation status, fear, etc.) are keeping them from seeking the care and guidance of health professionals. CDC estimates there are currently approximately 100,000 or more cases of Chagas disease in the United States.

With CDC's guidance, the Alliance selected four community-based partners in four communities with large Hispanic populations. These communities were primarily rural, and the agencies serve a large number of migrant and seasonal farmworkers from Central and South America. Two discussion groups were conducted at each of the four communities, one group made up of consumers, and the other made up of health care providers. Discussion groups were held in Phoenix, Arizona with Alliance partner Concilio Latino de Salud (June 6, 2008); in Chicago, Illinois with Alliance partner ALIVIO Medical Center (September 10, 2008), and, in Homestead, Florida with Alliance partner Community Health of South Dade (October 22, 2008). (See Appendix 2 for a detailed description of each partner agency.)

Key Findings:

The discussion groups provided valuable information about the level of knowledge and understanding about Chagas disease for both Hispanic consumers and health care providers serving Hispanics. Below are some of the key findings from the discussion groups, all of which are discussed in further detail later in this report.

- Virtually no consumer participants had ever heard of Chagas disease (either by the name Chagas or any of the other terms provided). They had no knowledge of Chagas disease etiology, or health consequences. We suspect that most of the consumer participants formerly lived in areas where Chagas disease is present. When the discussion focused on efforts to

eradicate Chagas disease in Latin America, several individuals remember seeing fumigation in their towns, but did not know if this had to do with Chagas disease.

- No consumer participant was aware that many U.S. blood banks now screen donations for Chagas disease.
- When consumers were provided with information about Chagas disease (after the discussion group), every participant expressed an interest in receiving more information.
- A majority of health care professionals had not heard of Chagas disease (either by this name or any of the other terms provided). Two health care providers who knew about Chagas disease were from South America. One health care provider knew about Chagas disease because she had served in the Peace Corps and learned about the disease and how to prevent infection. Several other health care providers remembered learning about Chagas disease as an infectious disease in medical school, but could not recall more detail.
- A majority of health care providers indicated they were not aware that most U.S. blood banks now screen donations for Chagas disease.
- A majority of health care providers did not know about the treatment for Chagas disease, or the fact that treatment medications are only available through CDC.
- All health care providers expressed an interest in learning more about Chagas disease, its prevention and treatment. A majority of these providers expressed an interest in having further education/training provided on the Internet.

Recommendations:

Given the estimates of Chagas disease in the United States (approximately 100,000 or more cases), a national educational campaign is unwarranted. Based on the discussion group findings, and further discussion with participants, the Alliance puts forth the following recommendations:

- Ensure that blood banks have bilingual staff available to address the needs of persons with Limited English Proficiency (LEP) (this can be achieved by working together with community clinics and agencies working with the target population).
- Work with blood collection agencies to develop effective educational materials to be given to persons with LEP who test positive for Chagas disease.
- Develop an effective bilingual on-line training for health care professionals on Chagas disease, including information about infection, prevention, and treatment of the disease.
- Training on Chagas disease should be targeted to health care providers working in community clinics, Federally Qualified Health Centers, and migrant clinics serving clients of Central and/or South American origin.
- Consumers who test positive for Chagas disease should receive detailed information from their health care providers regarding the risks and benefits of Chagas disease treatment.

- Consumers should make decisions regarding Chagas disease treatment in close consultation with their medical provider, who must also ensure access and continuity of care for the duration of the treatment

II. Methodology

The Chagas Disease Initiative was carried out from June to October 2008. CDC provided guidance with regard to creation of the survey instrument and selection of target communities, and the Alliance proposed community clinics and agencies as partners for this Initiative. In keeping with Alliance policy, each community partner received a small grant to complete the work. The four partners for the Chagas Disease Initiative were: ALIVIO Medical Center in Chicago, Illinois; *Concilio Latino de Salud* in Phoenix, Arizona; Community Health of South Dade, Everglades Health Center in Florida City, Florida; and, *Salud para la Gente* in Watsonville, California. Each of these clinics serves a population primarily comprised of seasonal and migrant farm-workers from countries in Central and South America.

The Alliance adapted its Discussion Group Protocol to reflect the needs of this project, and all materials (including consent forms, participant surveys) were reviewed and approved by CDC. The protocol includes information on coordinating the discussion groups, and clearly states the Alliance's and partner agencies' roles and responsibilities. Each partner site designates a project coordinator who is responsible for recruiting participants and coordinating the discussion group logistics, participant incentives, as well as location, date and time for the discussion groups. The Protocol also includes the specific questions used to guide the discussion with both consumers and health care providers. (See Attachment 1 for Alliance Discussion Group Protocol.)

Each partner agency was asked to recruit 4-9 adult individuals from Mexico, Central America, or South America for the consumer discussion groups, and 4-9 health care professionals (including physicians, nurses, nurse practitioners, social workers, and lay and community health educators) for the health care provider discussion groups. Two focus groups were conducted at each of the four community-based organizations (CBOs) partner sites; eight focus groups were conducted in total. One consumer discussion group and one provider discussion group were conducted in each of the four partner communities.

The Protocol was adhered to in all discussion groups conducted by the Alliance's CDI Project staff. Each focus group lasted approximately one hour. The guided questions focused on knowledge and outreach regarding Chagas disease in the Hispanic community. If a participant asked an informational or clinical question during the discussion group session, they were asked to wait until the end of the open discussion to obtain the answers.

In three out of the four consumer focus groups the guided discussion was carried out primarily in Spanish. In three out of the four provider focus groups the guided discussion was carried out mostly in English (See Table 21 for the languages used at each site).

Table 1: Primary Language Used in Guided Discussion at Each Site

CDI Site	Consumer Focus Groups	Provider Focus Groups
ALIVIO Medical Center	English and Spanish	Primarily English
Concilio Latino de Salud	Spanish	English and Spanish
Comm. Health South Dade Everglades Health Center	Spanish	English and Spanish
Salud Para la Gente	Spanish	Primarily English

The eight CDI discussion groups included a total of 65 participants: 28 health care providers and 37 consumers. Different demographic data was captured for consumers and providers. All participants were asked about their gender, racial/ethnic background, and age, as well as their knowledge level about Chagas disease and treatment options. Consumers were also asked about their place of birth, Hispanic origin, language preferences, and preferred methods for learning. Providers were asked to state their profession, experience diagnosing and reporting Chagas disease cases, and willingness to participate in future Chagas disease educational efforts. Percentages were calculated using SurveyMonkey, an online survey tool used to analyze the responses to questions for both groups. Below is a detailed review of the data.

III. Consumer Specific Data and Information

A. Consumer Specific Data

Gender and Age

Of 37 total consumers, 28 (78%) were female and 8 (22%) were male (see Table 2). Of the consumers that indicated their age, 50% were in the age range of 31-40 (see Table 3). Three consumers did not provide their age.

Table 2: Gender (n=37)

Female	Male
28	8

*One consumer did not respond to this question

Table 3: Age of Consumers*

Age	Number of Consumers
18-20	1
21- 30	8
31- 40	17
41-50	4
51-60	1
61-70	3

*Three consumers did not respond to this question

Hispanic Origin

The majority of consumers, 28 (76%) were Mexican American, followed by 6 Central Americans (16%), and two Puerto Ricans (5%). One consumer indicated herself as “Other” (see Table 4).

Table 4: Hispanic Origin of Consumers

Hispanic Origin	Number of Consumers
Mexican American	28
Cuban American	0
Puerto Rican	2
Central American	6
South American	0
“Other”	1
Non-Hispanic Origin	0

Place of Birth

A majority of consumers were born in the Mexico, 24 (66%), 7 (19%) were born in the U.S. and 5 (14%) in Central America (see Table 5).

Table 5: Place of Birth of Consumers

Place of Birth	Number of Consumers
United States	7
Mexico	24
Cuba	0
Puerto Rico	0
Central America	5
South America	0
Other	0

*One consumer did not respond to this question

Length of Time Living in U.S.

The majority of the consumers reported the length of time they have lived in the U.S. as 6-15 years (15 or 40%), with eleven (11) consumers reporting a length of residence of 16-25 years. Six were born in the U.S., two indicated their length of residence as 25 years or more, two indicated a length of 1-5 years, and one consumer reported a length of less than one year (see Table 6).

Table 6: Length of Time in U.S. for Consumers

Length of Time in U.S.	Number of Consumers
More than 25 years	2
Less than one year	1
1-5 years	2
6 to 15 years	15
16 to 25 years	11
Born in U.S.	6

Language Spoken at Home

A large majority of consumers (76%), reported that both English and Spanish were spoken in their homes, followed by 24% indicating they speak only Spanish in their homes (see Table 7).

Table 7: Language Spoken at Home

Language	Number of Consumers
Only Spanish	9
Only English	0
English and Spanish	28

Language Preference

Most of the participants (17 or 47%) reported a personal preference for speaking Spanish, 16 reported a preference for English and Spanish, and 3 reported a preference for only English (see Table 8).

Table 8: Language Preference

Language	Number of Consumers
Only Spanish	17
Only English	3
English and Spanish	16

*One consumer did not respond to this question.

Level of Education

Consumers had a wide variety of education levels. The majority of consumers reported having completed high school (14 or 40%), followed by 12 (34%) consumers who reported not having completed high school (see Table 9).

Table 9: School Year Completed for Consumers

School Year	Number of Consumers
I have not completed high school	12
I have completed high school	14
I have completed some college	7
I have completed college	2
I have completed post-graduate studies	0

*Two consumers did not respond to this question.

Preferred Methods for Learning

The majority of consumers indicated that the category of reading brochures was their preferred method for learning (23 or 62%), followed by watching television or videos (21 or 57%). The Internet (10 or 27%) was the least preferred method for learning. Consumers were asked to check off as many methods as they wanted (see Table 10). During the discussions, consumers generally stated that they liked a combination of all the methods that were mentioned.

Table 10: Preferred Methods for Learning of Consumers

I learn better by...	Number of Consumers
Reading brochures	23
Watching television or videos	21
Listening to others	15
Using the Internet	10
Other	6

Media Use

The majority of consumers stated that they watch 0-4 hours of television per week (18 or 49%). No consumers indicated watching more than twelve hours of television per week (see Table 11). The

majority of consumers listened to the radio 0-4 hours per week (15 or 43%). No consumers reported listening to the radio more than 16 hours (see Table 12). The majority of consumers (71%) reported using the Internet for 0-4 hours a week. Only two participants reported using the Internet 12-16 hours a week (see Table 13). The majority of consumers reported reading newspapers and magazines 0-4 hours a week (73%). Only one consumer reported reading more than sixteen hours a week (see Table 14).

Table 11: Hours Per Week Watching TV

Hours	Number of Consumers
0-4	18
4-8	13
8-12	6
12-16	0
More than 16 hours	0

Table 12: Hours Per Week Listening to Radio

Hours	Number of Consumers
0-4	15
4-8	11
8-12	7
12-16	2
More than 16 hours	0

*Two consumers did not respond to this question.

Table 13: Hours Per Week Using Internet

Hours	Number of Consumers
0-4	20
4-8	3
8-12	1
12-16	2
More than 16 hours	2

*Nine consumers did not respond to this question.

Table 14: Hours Per Week Reading Newspapers/Magazines

Hours	Number of Consumers
0-4	25
4-8	8
8-12	0
12-16	0
More than 16 hours	1

*Three consumers did not respond to this question.

B. Summary of Consumer Knowledge About Chagas Disease

When consumers were asked “Had you heard of Chagas disease before this discussion group?” the majority of consumers (36 or 97%) stated they had never heard of Chagas disease (See Table 15).

Table 15: Consumers’ Awareness of Chagas

Awareness	Number of Consumers
Yes	1
No	36

Awareness of Treatment Options for Chagas Disease

When consumers were asked “Are you aware of treatment options provided for Chagas disease?” 100% of consumers stated they were unaware of the treatment options for Chagas disease (See Table 16).

Table 16: Consumers’ Awareness of Treatment Options

Awareness	Number of Providers
Yes	0
No	37

- Overwhelmingly, knowledge regarding Chagas disease among consumers was low or non-existent. The majority of consumers had never heard of Chagas disease, its etiology or health consequences. No consumer participant was aware of treatment options for Chagas disease.
- All consumers expressed that they would like to receive more information regarding Chagas disease and more specifically, how it can be prevented, and treatment options.

Learning Behaviors:

- The majority of consumers indicated that the most useful ways to receive information include educational sessions and materials, and through TV and radio.
- The majority of consumers indicated that the category of reading brochures was their preferred method for learning (62.2%).
- The majority of consumers indicated watching TV, listening to the radio, using the Internet, and reading newspapers or magazines 0-4 hours a week.
- The majority of consumers felt that the primary sources for health information regarding Chagas would be healthcare providers, followed by friends, schools, mass media, and the Internet.

C. Detailed Review of Consumer Discussions

Knowledge Questions

Have you ever heard about Chagas disease, or “mal de Chagas”? Where did you hear about it? Who do you think is most at risk? Have you ever known anyone who was infected?

The majority of participants had not heard of Chagas disease. Only at one site, a few participants had heard of Chagas disease. The majority of participants did not know of anyone infected with Chagas disease.

Do you know how someone becomes infected with Chagas disease?

The majority of participants did not know about infection or modes of infection.

Are you familiar with any of these bugs?

None of the participants were familiar with the bugs.

Are you familiar with any of these names: Kissing bug, Benchuca, Vinchuca, Chipo/chipon, or Barbeiro?

None of the participants had ever heard of any of the other terms used to identify Chagas disease.

Does anyone know what are the health consequences of having Chagas disease?

None of the participants knew what the health consequences of Chagas disease were.

Have you ever donated, or considered donating blood to a blood bank?

A few participants had indicated that they had donated blood in the past, and others indicated that they were considering it.

Did you know that if you donate blood, it will be tested for Chagas disease?

None of the participants knew that blood donations were screened for Chagas disease.

If you were told that you have been infected with Chagas disease, would you feel the need to go to a healthcare provider to get more information?

Overwhelmingly, participants indicated that if told they were infected with Chagas disease, they would go to a healthcare provider to receive information about Chagas disease and would like to know where they can get more information.

If you were told that you have been infected with Chagas disease, do you have a regular health care provider that you could go see?

The majority of participants indicated that they do have a regular primary healthcare provider. The majority indicated Federally Qualified Health Centers and Migrant Health Center as their primary healthcare provider.

If you don't go to a health care provider, whom would you talk to about it?

Although the majority of participants indicated that they did access a healthcare provider, most indicated that they generally accessed healthcare when they felt their health problem was severe or they had many questions about it. If consumers did not access healthcare, due to work and schedule conflicts, transportation, citizenship status, and cost barriers, sources of health information regarding Chagas disease would be their friends, schools, mass media (TV and Radio), and the Internet.

What kind of information would you like to receive to answer questions you have about Chagas disease?

All consumers indicated that they would like to receive more information on Chagas disease and resources to more information on Chagas disease. Consumers indicated wanting information regarding how Chagas disease can be prevented, how someone knows they have Chagas disease, treatment options, and where they can go to get more information about Chagas disease. Some consumers expressed concern about the topic being “out of the blue,” and “seriousness of the topic.”

What would be the most useful way for you to receive information on Chagas disease?

All consumers indicated that the most useful ways to receive information on Chagas disease include educational sessions and presentations at the clinics, pamphlets and through the TV and radio.

Outreach Questions

All consumers indicated that they would like more information on Chagas disease and informational resources on Chagas disease in Spanish and English. The majority of consumers felt that the best people to deliver messages about Chagas disease are healthcare providers and informed community members who are reliable and trustworthy.

Where do you get your health information? Which method do you use and trust the most?

All participants indicated that the primary source for health information was the clinic’s healthcare providers, services and health fairs. Participants also indicated their friends, schools, mass media (TV and Radio), and the Internet as sources for health information.

What messages do you think are important when talking about Chagas disease? What information would be most important to give?

All consumers felt that resources regarding where consumers can get more information in Spanish on Chagas disease was very important. The majority of consumers indicated that messages about who can be infected, how someone can be diagnosed, how to prevent Chagas disease, and treatment options availability are also important.

Where would be the best places to put these messages?

The majority of consumers felt that these messages should be used in the clinics, in churches or religious organizations, on TV, more specifically on the news, in newspapers, and on the radio.

If information were available on the Internet, would it be a good way for you to learn about Chagas?

A few consumers felt that it is worth putting this information on the Internet, but the majority indicated learning more from the clinic’s educational sessions.

Should the messages be in English, Spanish, or a combination of both?

All consumers felt that all information and messages should be in both Spanish and English. At one site Creole was another language suggested by consumers because of the growing Haitian population within their community. Do we want to delete this, as Haiti is not an endemic area?

Who would be the best person to deliver the message?

The majority of consumers indicated that they felt the best person to deliver information to the community would be a healthcare professional or a person very informed about Chagas disease. The

majority of consumers felt it important that this person should know the community and have its trust; someone that the community recognizes as reliable and trustworthy. A few consumers felt that this information could be delivered in church or on the news.

IV. Provider Specific Data and Information

A. Provider Specific Data

Gender

Of 28 total providers, the majority, 25 or 89% were female and 3 or 11% were male (see Table 17).

Table 17: Gender (n=28)

Female	Male
25	3

Hispanic Origin

The majority of providers (46%) were Mexican American, followed by Non-Hispanic Origin (21%), Central American origin (11%), Puerto Rican (7%), and Cuban (7%). South American and “Other” made up the smallest category for providers (4%) (see Table 18).

Table 18: Hispanic Origin of Consumers and Providers*

Hispanic Origin	Number of Providers
Mexican American	13
Cuban American	2
Puerto Rican	2
Central American	3
South American	1
“Other”	1
Non-Hispanic Origin	6

Professions

Providers were asked to report their profession. The majority of providers reported chose the category “Other”. Physicians made up the largest number of providers (21%), followed by nurses (11%), health educators (11%), case managers (7%) and one social worker (4%) (see Table 19).

Table 19: Professions of Providers

Profession	Number of Providers
Physician/Doctor	6
Nurse	3
Social Worker	1
Health Educator/Promotor(a) de Salud	3
Case Manager	2
Other	13

Perception of Patient Population

Providers were asked to report on the percentage of Hispanics in their patient populations. The percentages in the table below were derived from provider responses. The majority of providers (16)

reported that they felt that anywhere from 80 – 99% of their patients were Hispanic, and the remaining providers (9) stated that 100% of their patients were Hispanic (see Table 20).

Table 20: Patient Populations by Providers

% of Hispanics in Patient Population	Number of Providers
80	4
90	3
95	3
95	1
98	3
99	2
100	9

*Three providers did not respond to this question.

Provider Awareness of Chagas Disease

When providers were asked the question, “Have you heard of Chagas disease before this discussion group?” the majority of providers 61% (17) said that they had never heard of Chagas disease (see Table 21).

Table 21: Providers’ Awareness of Chagas

Heard of Chagas Before	Number of Providers
Yes	11
No	17

Provider Diagnosis of Chagas Disease

When providers were asked the question “Have you diagnosed a case of Chagas disease?” all 28 providers (100%) said that they had never diagnosed a case of Chagas disease (see Table 22).

Table 22: Providers’ Diagnosis of Chagas Disease

Diagnosed Chagas	Number of Providers
Yes	0
No	28

Reported Cases of Chagas Disease

When providers were asked the question “Have you ever referred or reported a case of Chagas disease?” all 27 providers (100%) said that they had never reported a case of Chagas disease (see Table 23).

Table 23: Providers’ Reported Cases of Chagas Disease

Reported Cases	Number of Providers
Yes	0
No	27

*One provider did not respond to this question.

Awareness of Blood Donation Screenings for Chagas Disease

When providers were asked the question “Do you know that according to FDA regulations, blood that tests positive for Chagas must be rejected for donation?” the majority of providers (64%) said that they were unaware that blood donations were screened for Chagas disease (see Table 24). While some providers did indicate on the written survey that they were aware of this regulation, during the verbal discussions no provider ever stated that they were aware of the FDA regulations.

Table 24: Providers’ Awareness of Blood Screenings

Awareness	Number of Providers
Yes	10
No	18

Awareness of Treatment Options for Chagas Disease

When providers were asked the question “Are you aware of treatment options provided by the CDC?” the majority of providers (70%) said that they were unaware of treatment options for Chagas disease (see Table 25). As with the previous question, it is interesting to note that during the verbal discussion, no provider ever stated that they were aware of treatment options, having knowledge about treatment was only stated in the written questionnaire.

Table 25: Providers’ Awareness of Treatment Options

Awareness	Number of Providers
Yes	8
No	19

*One provider did not respond to this question.

Effective Methods for Health Education

Providers were asked to report on the methods they use to inform their patients about health. The majority (48%) of providers reported preferring discussions in groups or one-on-one, followed by education (43%) and use of educational materials (43%) (see Table 26).

Table 26: Methods for health Education by Providers

Methods	Number of Providers
Education	9
Demonstration	3
Discussion (Group or One-on-One)	10
Handouts	4
Outreach	7
Educational Materials	9
Panfletos (Pamphlets)	4
TV and Radio	8

*Seven providers did not respond to this question.

Additional Education on Chagas Disease

When providers were asked the question “If a workshop on Chagas disease were available, would you be interested in attending?” 100% of providers said that they would attend a workshop on Chagas disease (see Table 27).

Table 27: Attend Chagas Workshop

Attendance	Number of Providers
Yes	27
No	0

*One provider did not respond to this question.

Online Education on Chagas Disease

When providers were asked the question “If a workshop were available online, would you be likely to participate?” the majority of providers (94%) said that they would participate (see Table 28).

Table 28: Participate in Online Training

Participation	Number of Providers
Yes	16
No	1

*Eleven providers did not respond to this question.

Interest in Receiving CME Credits for Further Education on Chagas Disease

When providers were asked the question, “If you are a physician or nurse, would you dedicate some of the Continuing Education credits (CMEs) needed yearly to education on Chagas disease?” the majority of providers (19 or 86%) said that they would dedicate credits to Chagas disease training (See Table 29).

Table 29: Willingness to Dedicate Training to Chagas

Willingness	Number of Providers
Yes	19
No	3

*Six providers did not respond to this question.

B. Summary of Provider Knowledge About Chagas Disease

- The majority of providers, 60.7%, had never heard of Chagas disease before the discussion and all providers expressed a need for more information on the subject.
- Several providers who indicated they had knowledge of Chagas disease had misinformation regarding the disease and its transmission.
- No providers reported having ever diagnosed a case of Chagas disease or reporting a case of Chagas disease.
- The majority of providers, 64.3%, reported that they were unaware that since 2007 most blood donations in the U.S. were screened for Chagas disease.
- The majority of providers, 47.6%, reported the best way to deliver health education to their patients was through discussions in groups or one-on-one.
- The majority of providers, 70.4%, reported that they were unaware of treatment options provided by the CDC for Chagas disease.
- All providers felt that learning about Chagas disease would be a service to their patients and indicated they want more information on the subject.
- The majority of providers reported that they would attend a workshop on Chagas disease (100%), access an online training on Chagas disease (94.1%), and dedicate CME credits to Chagas training disease (86.4%).

C. Detailed Review of Provider Discussions

Knowledge Questions

Have you ever heard about Chagas disease, or “mal de Chagas”? Where did you hear about it? Who do you think is most at risk? Have you ever known anyone who was infected?

Only six healthcare providers had ever heard about Chagas disease, the majority of providers had never heard of Chagas disease. Two providers learned about Chagas disease in Medical School, one provided learned through being in the Peace Corps., and the other three providers were originally from Central and South America where Chagas disease is endemic. Two other providers had misinformation, they indicated that Chagas disease existed only in the Caribbean and was a disease transmitted through a mosquito vector.

Are you familiar with any of these names: Kissing bug, Benchuca, Vinchuca, Chipo/chipon, or Barbeiro?

Only one provider had heard of “kissing bug.” The majority of providers were not familiar with any of the names to identify the triatomine bug.

Have you ever diagnosed cases of Chagas disease among the clients you see? If so, have you contacted CDC about your patient?

None of the providers had ever diagnosed cases of Chagas disease. Only at one site, a few providers indicated that rarely patients have come in for follow-up who had been already diagnosed.

Who would you contact to get more information about Chagase disease and its diagnosis?

The majority agreed that the Internet would be the first resource that they would use, followed by the CDC, medical literature “Physician’s Manual,” the Departments of Health, and contacting the Ministry of Salud in Central and South American countries where Chagas disease is endemic.

Are you familiar with the treatment options for Chagas disease? If no, where would you go to find out about treating Chagas disease?

The majority of providers did not know of the treatment options for Chagas disease. Only one provider, originally from South America, knew of the treatment options.

What types of healthcare providers do you think most often treat Hispanics?

All participants felt they reflected the type of health care setting and providers serving Hispanics, and also mentioned the importance of health educators and outreach workers. Providers agreed that they have limited time with each patient, and they rely on nurses, health educators, and outreach workers to provide much of the health education efforts to their patients.

Did you know that blood centers such as the American Red Cross started screening blood donations for Chagas disease in 2007? And that testing positive means the donated blood will be rejected?

The majority of providers were aware of the new FDA regulations pertaining to blood donations and Chagas disease. Only one provider knew that the American Red Cross screened for Chagas disease.

How important do you think information on Chagas disease might be in service to your clients?

All providers felt that “all” information about Chagas disease (the disease, risk factors, transmission, and treatment) would be very important to provide to their clients.

What kind of information would you like to receive to answer questions you have about Chagas disease?

All participants expressed an interest in receiving more about information about Chagas disease. They indicated they would like to receive comprehensive information regarding the disease, symptoms, prevention and treatment options.

What would be the most useful way the CDC could provide more Chagas disease information to you?

The majority of providers indicated that they would like to receive an online training or informational session that they could access at anytime, and any literature and educational materials on Chagas disease. Other providers indicated a presentation on Chagas disease with an informed person present to answer questions.

Outreach Questions

Participants in the provider discussion groups were asked to assess their thoughts on the best way to provide outreach to the community about Chagas disease. Overwhelmingly, providers agreed that community clinics remain the primary source for health information for consumers and the best place to incorporate messages regarding Chagas disease. The majority of providers indicated disseminating information about Chagas disease in a top-down approach, in which community centers and medical professionals should be equipped with information on Chagas disease first, so that they can provide their patients with all information on Chagas disease. The majority of providers indicated that messages about Chagas disease should be in community clinics and in both English and Spanish. All providers agreed that healthcare professionals and health educators would be the best people to deliver health messages about Chagas disease.

What do you think is the best way to educate consumers on Chagas disease? Specifically, what type of media? What literacy level?

The majority of providers indicated that community centers and medical professionals should be equipped with information on Chagas disease first, and then consumers, so that providers could answer any consumers' questions. All health care providers expressed that use of television and videos is preferable for their clients. The majority of providers indicated developing materials in third to sixth grade literacy levels. One provider also indicated that a simple handout with pictures would also be of use.

What information would be most important to give? Would it be information on the disease or what are the risk factors? Or would it be that treatment is available?

All providers indicated that providing consumers with all of information on Chagas disease and its complications would be best to give to patients. Providers indicated that photographs of the insect, the symptoms, prevention and treatment of Chagas disease was most important.

Where would be the best places to put these messages so that your clients would see them?

All providers indicated having messages in the clinics is the best way for clients to see them, followed by the community's churches, schools, and on TV, radio, and the Internet.

Should the messages be in English, Spanish, or a combination of both?

All providers indicated that messages and information on Chagas should be in both English and Spanish. A minority indicated that Spanish would be the preferred language, and one participant stated

that it would depend on the target audience's age, as younger people would probably prefer English. At one site, the majority of providers talked about seeing clients who do not speak Spanish or English, but "Mixteco", the Spanish term for the language known in English as Mixtec. Mixtec is spoken in the Mexican states of Oaxaca, Guerrero, and Puebla.

Who would be the best person to deliver the message?

All providers agreed that healthcare professionals and health educators "promotoras [health promoters]" would be the best people to deliver health messages about Chagas disease. The majority of providers also indicated the importance of disseminating information by word of mouth, through family members, and especially mothers. Other providers indicated that a famous person on TV or radio should deliver the message.

V. Appendices

Appendix 1: Description of Community Based Partner Agencies

ALIVIO Medical Center (Alivio)

Alivio Medical Center is a bilingual, bicultural organization committed to providing access to quality cost-effective health care to the Latino community, the uninsured and underinsured, and not to the exclusion of other cultures and races. This mission is expressed through the provision of services, advocacy, education and research and evaluation provided in an environment of caring and respect.

Support services provided by Alivio include nutrition counseling, OB/GYN, nurse-midwife and nurse practitioner care, pediatrics, family practice services, immunizations, educational services, breast feeding courses, KidCare program information and enrollment, prenatal classes and care, childbirth and parenting classes, adult care, internal medicine, surgery, counseling, WIC services, health education, home visits, as well as overall comprehensive health care services. In addition, Alivio has held the Alivio Y Salud: 5K Run, 5K Kids™ Run, and a two-mile Walk and Kids™ Dash. This event is the largest Hispanic amateur athletic event held in the Chicago area, and seeks to establish role models for young people as well as to educate families about the health benefits of exercise and proper nutrition.

Concilio Latino de Salud (CLS)

CLS was designed to improve the overall well-being of diverse communities, with a focus on the Hispanic/Latino community, through health promotion and disease prevention in partnership with communities and organizations. As dedicated health professionals in a community of diverse cultures, we strive to create an awareness of *bienestar* /well-being as a holistic synthesis of mind, body and spirit, and to establish this awareness as a way of life.

Since 1989, CLS has served the Hispanic/Latino communities by promoting health education and disease prevention. CLS is a nonprofit organization that partners with national and local institutions, neighborhoods, and individuals. CLS actively pursues the goals of “Healthy People 2000” and “Healthy People 2010” by providing cross-cultural and bilingual assistance, advocacy, public policy analysis, workshops, education, service programs, resources, applied research, client referrals, and media links. For almost two decades, CLS has met the needs of the underserved through leadership and partnership with its community.

Community Health of South Dade, Inc (CHI)

CHI was chartered for services in the South Miami-Dade community in 1971. CHI currently operates six community health centers, a behavioral health center, numerous outreach groups, and school health programs. All sites offer comprehensive primary care to patients of all ages and additional specialty services are provided at the main health center including comprehensive behavioral health care services. CHI works to deliver readily accessible, quality health care services to the people of South Miami-Dade in a way that assures their dignity and respect.

In 1998, CHI served approximately 28,000 patients. In the same year, CHI's diverse patient population included more than 8,000 migrant and seasonal farm workers. CHI recently received re-accreditation by the Joint Commission on Accreditation of Health Care Organizations for primary and behavioral health care with outstanding ratings. The culturally diverse and linguistically capable staff represents

more than 30 different cultures. CHI is committed to celebrating cultural diversity and is governed by a community board of directors. In 2000, CHI was recognized in the Health Resources and Services Administration's Cultural Competence Works competition as a Nominated Program of Note.

Salud Para la Gente (SPLG)

SPLG is a non-profit organization comprised of dedicated individuals who are committed to providing a coordinated network of high quality and cost-effective health care services that are responsive to the evolving needs of the Pajaro Valley low-income communities.

SPLG was incorporated in 1980 for the purpose of establishing primary health care services for the medically needy and farm worker families residing in the Pajaro Valley area. SPLG established a small clinic intended to serve the primary health care needs of the children of farm workers living in southern Santa Cruz County and the northern part of Monterey County. SPLG is a Federally Qualified Health Center (FQHC) and receives cost-based reimbursement for services provided to Medi-Cal and Medicare patients. Governed by a 12-member community board of directors, SPLG serves over 8,000 patients per year providing them with over 28,000 patient visits. SPLG has developed over the years to become one of the most important primary health care providers in Pajaro Valley.

Appendix 2: Chagas Disease Initiative Discussion Group Protocol

I. INTRODUCTION

The Chagas Disease Initiative (CDI) is a project of the National Alliance for Hispanic Health (the Alliance) designed to assess the knowledge, attitudes and understanding among Hispanic consumers and healthcare providers about Chagas disease. Once the assessments are complete, the CDI program will actively encourage healthcare providers in the Hispanic community and Hispanic consumers to call the Alliance's *National Hispanic Family Health Helpline (Su Familia Helpline)* to obtain referral information for culturally and linguistically proficient Chagas disease and treatment information, or contact the Centers for Disease Control and Prevention (CDC).

CDI is a one-year project funded by the Centers for Disease Control and Prevention (CDC). During the course of the project, discussion groups will be conducted with healthcare providers in the Hispanic community and Hispanic consumers ages 18 and older. The results of the discussion groups will be used to guide the development of future work in this area that may include educational materials about Chagas disease and treatment options.

Chagas disease is a vector-borne disease, caused by the blood-borne parasite *Trypanosoma cruzi*, and affects an estimated 11 million people in Latin America. Insects that carry the parasites transmit Chagas and these insects are found only in the Americas (mainly in rural areas of Latin America). Chagas disease is not a nationally notifiable disease and is currently reportable in only one state. If left untreated, infection is permanent, can last for decades, can cause severe cardiac or gastrointestinal morbidity, and can be fatal. Chagas disease is now documented in the United States as a result of immigration. It is estimated that at least 100,000 people in the U.S. have Chagas. Many in the chronic stage (which can last for decades) do not know they are infected and can transmit the disease by blood transfusion, organ transplantation, and a pregnant woman can infect her unborn child. Screening for Chagas disease of most of the U.S. blood supply began in January 2007 and blood donations that test positive for Chagas disease are rejected. All of these factors indicate that Hispanics may not be getting early treatment, which can prevent the onset of chronic Chagas disease, its complications, as well as death from the disease.

The following is a discussion group instrument developed to help the Project Coordinator organize the discussion group sessions. The instrument provides a step-by-step protocol for conducting locally based discussion groups. The instrument begins with a brief definition of the discussion group method. This definition is followed by a description of the role and tasks of the Project Coordinator, accompanying surveys and forms for gathering additional demographic information, and a discussion guide to help the Project Coordinator track the group's discussion.

II. THE DISCUSSION GROUP PROCESS

A. What is a discussion group?

A discussion group is defined as a planned or organized discussion with a selected group of individuals on a specific topic or area of interest. Discussion groups are a method for conducting group interviews to elicit the participants' attitudes, feelings, beliefs, experiences, and reactions toward a specific topic. In the case of the CDI project, the topic is knowledge about Chagas disease.

Discussion groups have two main traits: 1) they generate a discussion among individuals participating in the discussion group process, and 2) they require the presence of a moderator who manages the group discussion. Discussion groups are particularly effective for obtaining several perspectives about the same topic. Individuals who opt to participate in the discussion group process can expect to be part of a free-flowing, non-threatening discussion designed to obtain their opinions and experiences, by responding to a series of in-depth questions. The role of the moderator is very significant in facilitating the group discussion. Group leadership and interpersonal skills are required to moderate a group successfully.

B. Advantages of the discussion group method

Discussion groups have many advantages:

- Discussion groups are in harmony with people's social nature.
- Discussion groups are comparatively easy to operate.
- Discussion groups help to generate candid answers and to uncover underlying concerns.
- Discussion groups allow insight into new areas or topics.
- Discussion groups reveal agreements and disagreements within a target group.
- Discussion groups allow for the exploration of unexpected information.
- Discussion groups allow for the identification of why an issue is salient and what is salient about it.
- Discussion groups help build community involvement.

C. Key discussion group personnel

For the purpose of conducting the CDI discussion groups, the Discussion Group Moderator will lead the discussion group process.

The Discussion Group Moderator: The Discussion Group Moderator ("the Moderator") will be an Alliance staff member involved in the development of the main goals and objectives of the discussion group process. The Moderator will facilitate the discussion group. His/her main responsibility is to collect as much useful information to meet the goals of the session. The Moderator is in charge of introducing the project and the staff involved, and explaining the purpose of the discussion groups. The Moderator is also responsible for explaining the means to record the sessions, setting down the ground rules for the group dynamic, carrying out the agenda, carefully wording each question, and ensuring participation of all the members in the group. The Moderator helps to maintain a non-judgmental, non-threatening atmosphere.

The Project Coordinator: The Project Coordinator ("Project Coordinator") represents the community partner and is the principal liaison between the Moderator and the discussion group participants. The

Project Coordinator should have a clear understanding of the main objectives of the discussion groups. The role of the Project Coordinator at each agency is to recruit the consumers and healthcare providers that will participate in the discussion groups. The Project Coordinator is responsible for securing an appropriate venue for the discussion groups, the provision of needed materials, and a healthy snack/meal. The Project Coordinator will distribute the incentives to each discussion group participant after the session. Also, during the session, the Project Coordinator should support the Moderator and reinforce dynamics establishing an open, equal, and unrestricted group process.

D. The goal of the discussion group process

Using a discussion group process, the CDI project aims to gain a better understanding of the knowledge about Chagas disease and treatment options within the Hispanic community and among healthcare providers in the Hispanic community. The project also aims to obtain guidance on culturally and linguistically appropriate outreach and education messages targeting the Hispanic community. Four communities have been selected to conduct discussion groups: Phoenix, Arizona; Watsonville, California; Miami, Florida; and Chicago, Illinois.

III. GUIDELINES FOR THE PROJECT COORDINATOR

The Project Coordinator is a staff member at the selected community based agencies and is therefore familiar with the community and its members. The primary role of the Project Coordinator is to organize the discussion group sessions in his/her community. The Project Coordinator's tasks include: scheduling the discussion group sessions, selecting and recruiting the discussion group participants, identifying the location of the discussion group sessions, selecting the incentives for the participating individuals, setting up the facilities in the location to enhance the participation of the individuals, ensuring that all the necessary materials for the session are available, arranging for childcare (if appropriate), and providing a healthy snack or meal for the participants. The Project Coordinator is also responsible for ensuring that both the Discussion Group Moderator and participants complete the appropriate forms.

A. Scheduling the discussion group sessions

It is the Project Coordinator's role to select the place in which the discussion group sessions will be held and to schedule the sessions. The time should be decided between the Moderator and Project Coordinator, and according to the time and transportation needs of the participants and staff from the Alliance and the project site. The Project Coordinator must keep in mind that if most discussion group candidates work or go to school during the day, the discussion group sessions can be scheduled after school, in the evening, or on a Saturday morning depending on what works best in the particular community. The discussion group sessions should be planned to be a maximum of 1.5 hours. This is inclusive of about half of an hour for the participants to complete necessary forms.

B. *Selecting and recruiting the discussion group participants*

The outcome of the discussion group sessions depends on the individuals selected to participate in the discussion group process. To ensure the best results and consistency throughout the implementation of the discussion group sessions, the following criteria to select the participants is highly recommended:

Hispanic Adults: Six (6) to nine (9) individuals from the community should be recruited for the consumer discussion group sessions. However, only 9 participants will be allowed in the session. It is a common occurrence for a few of the respondents who agree to participate to not appear, therefore it is recommended that more individuals be recruited and all those recruited who show up will be compensated. The individuals selected for participation in the CDI discussion groups should:

- be Hispanic adults, ages 18 years or older;
- represent Central and South American countries of origin or heritage, as well as U.S. born Hispanics;
- include male and female Hispanic consumers;
- represent people from American agricultural or rural areas;
- understand the objectives of the discussion group and that the session will be taped; and
- not know each other.

For the provider discussion groups, healthcare providers serving the Hispanic community will be recruited. Individuals selected to participate in the discussion group sessions should be formally invited and offered an incentive for their participation. Individuals should be invited through a letter that clearly identifies the place, the scheduled time, the 1.5 hour duration of the discussion group, the incentive, and if possible a phone number to call and confirm their attendance. The invitation letter should also assure participants that their names and any information they share during the discussion group session will be considered confidential and used only for the purposes of project. This invitation letter should be followed up with a call to each of the invited individuals to enthusiastically reinforce and personalize the invitation. The follow-up call should take into consideration how long it takes for mail to arrive to its designated address.

It is recommended that the Project Coordinator aim to recruit more individuals than are actually needed for the discussion group sessions because it is a common occurrence for a few of the respondents who agree to participate to not appear. A gift or small incentive or stipend (\$20-50) to those recruited will help motivate participation. A healthy meal or appropriate snack should also be offered.

C. Identifying the discussion group location

The Project Coordinator at each agency is responsible for identifying the location of the discussion group sessions. It is expected that the community-based agency will have a space available which accommodates the goals of the discussion group process. The most critical element to keep in mind when selecting a location for the discussion group sessions is the comfort of the participants. If the discussion group participants are comfortable, it is more likely that they will contribute to the discussions by verbalizing their opinions or experiences. The Project Coordinator should plan to hold the discussion group sessions in a conference room, or other setting with adequate seating, airflow and lighting. A place that is inviting and free of distractions is highly recommended. The chairs in the room should be configured to ensure that all the discussion group participants see each other.

Another critical element to keep in mind when selecting the location for the discussion group sessions is the transportation needs of the participating individuals. It may well be that a location outside of the community based agency works better for the Hispanic consumers participating in the discussion group process. If this is the case, a local church or library may be a better location.

In addition to finding the location for the discussion group sessions, the Project Coordinator should gather the necessary equipment to facilitate the flow of the discussion. It is expected that the community based agency will provide the necessary equipment including:

- a flip chart;
- writing tools;
- name tags for each participant;
- copies of the listed forms;
- recording equipment (tape recorder);
- healthy snacks and non-alcoholic beverages; and
- childcare facilities (if necessary and as possible).

D. Taping the discussion group session

The Project Coordinator should plan to record the discussion group sessions with an audio recorder. Counting on one's memory is not a practical option given the duration of the discussion group sessions. Recording the entire sessions will ensure the gathering of as much information as possible. The Project Coordinator is responsible for gathering the recording equipment and ensuring that the equipment is ready for use prior to the session. It is recommended that the Project Coordinator have on hand batteries or the necessary cords for making sure the recording equipment does not run out of energy, sufficient blank tapes, and a small microphone, if necessary, to ensure clear recording of each participant's voice and comments.

It is imperative to inform the discussion group participants about the tape recording of the sessions and to obtain their approval (see Appendix C for *Consent Forms*). The Moderator will explain the importance of conducting the discussion group for the development of educational materials that are appropriate for the local community. The Moderator is also responsible for assuring the participants that the tapes will not be used outside the project and that their anonymity will be maintained at all times.

At the end of each session, the Project Coordinator is in charge of labeling the tapes with the date, location, and language used for conducting the discussion group session. The Project Coordinator will subsequently forward these tapes to the Alliance. The Alliance will transcribe the tapes to document their content. In the transcription process, the Alliance will ensure the elimination of any personal identifiable elements. After the transcript is developed, the tapes will be destroyed to prevent any use foreign to the purposes of the CDI project. It is important for the Moderator to inform the participating individuals about the steps involved in the transcription process as a way of easing any potential discomfort with the recording equipment.

E. Completing the forms

The Project Coordinator is responsible for ensuring that all the forms attached to these guidelines are properly filled out. These forms include the *Sign-up Sheet* (Appendix B), the *Consent Forms* (Appendix C), the *Participant Survey* (Appendix D), and the *Moderator Survey* (Appendix E). The *Sign-up Sheet* should be completed as participants arrive to the session. The *Consent Form* (Appendix C) should be filled out by each participant after they are given an introduction of the format of the discussion group session. The other two forms are to be completed as detailed below.

The Participant Survey (Appendix D) is to be administered after conducting the discussion group session. The *Participant Survey* should be completed by each of the participants. Please keep in mind that:

- If someone is unable to read, please help this person. In order not to embarrass someone who cannot read, it is a good idea to ask, "does anyone need assistance to fill out the form" rather than asking, "is there someone who cannot read the form".
- There should be pens/pencils available for everyone.
- After the participants have completed the survey, please review it to ensure that all the questions have been answered.

The Moderator Survey (see Appendix E) should be completed after each discussion group session to gather the moderator's impression of the group's discussions. The following aspects of the discussion group session should be recorded: how the individuals as a group responded, whether all members participated equally, the moderator's feelings regarding the group dynamics, and any other relevant information.

F. Tracking the discussion

A *Discussion Guide* (next section) is provided to assist the Project Coordinator and the Moderator with the tracking of the group discussions. The format presented in the guide is not intended as a sequence of topics which must be adhered to rigidly. Rather, it is intended as a guiding framework to help simplify the task of directing the discussion to the most relevant topics that will need to be considered by the discussion group.

In addition to keeping track of the group discussion, the Project Coordinator should take notes of the most significant or relevant answers throughout the discussion group sessions. The notes will be an accompanying record of the discussion group proceedings along with the audiotapes. The Project Coordinator is responsible for submitting their discussion group notes along with the audiotapes. The summary should include significant quotes, special vocabulary used by participants, issues most frequently addressed, and participants' comments relevant to the questions asked. Confidentiality should be preserved and no personal information linked to participants' names or other identifiable elements are necessary in the summary to be submitted to the Alliance.

IV. DISCUSSION GUIDE

A. Warm-up and explanations

Introduction

- Good morning (afternoon, evening) and welcome to our discussion. Let me start by introducing myself. My name is [full name] and I work with The National Alliance for Hispanic Health. I may use the terms Hispanics/Latinos interchangeably. Please feel free to use whatever term you prefer.
- This discussion is part of a project coordinated by The National Alliance for Hispanic Health that is being conducted in four states. We are here to ask you some very important questions about a disease that affects Hispanics. Our goal is to learn what you know about Chagas or “mal de Chagas”.
- The National Alliance for Hispanic Health was founded in 1973, and is the only national Hispanic group solely focused on improving the health and human services for Hispanics. It is a private, non-profit organization, which represents all Hispanic subgroups. Specific areas on which the National Alliance for Hispanic Health’s work focuses include immunizations, HIV/AIDS, tobacco control, colorectal cancer, diabetes, prenatal care, and environmental health.
- You have been selected to participate in this discussion because you are Hispanic representatives of your community OR healthcare providers serving the Hispanic community and can help us to learn what type of information we will need to better serve our community.
- During this discussion we will follow a discussion group format. As you may know, a discussion group is like an opinion survey but very general. We will present you with broad questions and let you answer them and express your thoughts and concerns.
- On behalf of [local agency] and the National Alliance for Hispanic Health, I would like to thank each one of you for attending this discussion.

Ground rules

- In the course of our discussion, it is important to remember that there are no right or wrong answers and everyone is encouraged to express their views.
- I am interested in all your ideas, comments and suggestions, but I ask that only one person speak at a time.
- If you feel that some group members are not participating in the discussion, encourage them to do so. And please, give everyone a chance to speak.
- All comments — both positive and negative — are welcome. We would like to have many points of view.

- Please feel free to disagree with one another, but please be respectful of one another.
- Your honest opinion is what we are looking for. Remember, we are not asking you to share parts of your personal or professional life that would make you feel uncomfortable.
- We are interested in what is said here – not necessarily who said it.
- We ask that you please turn off your cell phones at this time or put them on vibrate if necessary.
- Finally, if factual questions come up, I will be happy to answer them after the session is complete. I will share more information about Chagas with you at the end.

Procedure

- A tape recorder will be used so that we can write a report. In doing discussion groups in four cities, it is important to know which group said what. However, individual names will never be used in the report.
- All discussions are strictly confidential. Whatever you hear or say will stay only in this room. Before we begin, we ask that you fill out a consent form to indicate that you have been informed of the purpose of the discussion group and stating that you agree to participate.
- I want this to be a group discussion so you don't need to wait for me to call on you. But please speak one at a time, so that the tape recorder can pick up everything.
- We have a lot of ground to cover, so I may need to change the subject at times or move ahead. Please stop me if you want to add something.
- Our session will last about one hour and a half. We will not take a break, but feel free to get up and have refreshments or use the bathroom.
- I will conduct the discussion in English (or Spanish). However, both languages are welcome in your comments.

Self-introductions

- Let's start by introducing ourselves. Once again, my name is [full name], and I was born and raised in [location(s)].
- Others introduce themselves ("name", place of birth, anything else important to you).

B. Semi-structured question and answer session - consumers

The Chagas Disease Initiative (CDI) is a project of the National Alliance for Hispanic Health (the Alliance) designed to evaluate what the Hispanic community knows about Chagas in order to later be able to create appropriate outreach and educational materials. CDI has been funded for one year by the Centers for Disease Control and Prevention (CDC).

Discussion groups will be conducted with healthcare providers serving the Hispanic community and Hispanic consumers ages 18 and older. The results of the discussion groups may be used to guide the development of educational materials about Chagas for the Latino community.

Chagas is a vector-borne disease, caused by the blood-borne parasite *Trypanosoma cruzi*, and affects an estimated 11 million people in Latin America. Insects that carry the parasites transmit Chagas and these insects are found only in the Americas (mainly in rural areas of Latin America). Chagas disease is not a nationally notifiable disease and is currently reportable in only one state. If left untreated, infection is permanent, can last for decades, can cause severe cardiac or gastrointestinal morbidity, and can be fatal. Chagas disease is now documented in the United States as a result of immigration. It is estimated that at least 100,000 people in the U.S. may have Chagas. Many in the chronic stage (which can last for decades) do not know they are infected and can transmit the disease by blood transfusion, organ transplantation, and a pregnant woman can infect her unborn child. Screening for Chagas disease of most of the U.S. blood supply began in January 2007 and blood donations that test positive for Chagas disease are rejected. All of these factors indicate that Hispanics may not be getting early treatment, which can prevent the onset of chronic Chagas disease, its complications, as well as death from the disease.

We have asked you here today to evaluate how we can best serve the Latino community with regards to the disease called Chagas. We're interested in your opinion and thank you for your participation.

Knowledge

- Have you ever heard about Chagas, or “mal de Chagas”?

If yes,

Where did you hear about it?

Who do you think is most at risk?

Have you ever known anyone who was infected?

- Do you know how someone becomes infected with Chagas?
- Are you familiar with any of these bugs [ask and show picture(s) at the same time]?
 - the kissing bug,
 - the benchuca,
 - the vinchuca,
 - the chipo, or
 - the barbeiro.

* IF THE ANSWERS TO THESE THREE QUESTIONS ARE ALL NO, PLEASE SKIP THE NEXT QUESTION AND THE LAST THREE IN THIS SECTION, GOING TO THE OUTREACH SECTION.

- Does anyone know what are the health consequences of having Chagas?
- Have you ever donated, or considered donating blood to a blood bank?

- Did you know that if you donate blood, it will be tested for Chagas?
- If you were told that you have been infected with Chagas, would you feel the need to go to a healthcare provider to get more information? Why or why not?
- If you were told that you have been infected with Chagas, do you have a regular health care provider that you could go see?
- If you don't go to a health care provider, whom would you talk to about it? (Prompt: a family member, a neighbor, someone in the community, your church, etc?)
- What kind of information would you like to receive to answer questions you have about Chagas?
- What would be the most useful way the CDC could provide more Chagas information to you?

Outreach

Part of why we are here is to get your opinion on the best way to reach people like you about the importance of learning about Chagas. We want to create a better understanding among community members about Chagas. So let's imagine we're doing an ad campaign:

- Where do you get your health information? (If need to, prompt: friends, television, Internet?) Which method do you use and trust the most?
- What messages do you think are important when talking about Chagas disease?
- What information would be most important to give?
- Where would be the best places to put these messages? (TV, radio, newspapers, Internet, text messages?)
- If information were available on the Internet, would it be a good way for you to learn about Chagas? Why or why not?
- Should the messages be in English, Spanish, or a combination of both (Spanglish)?
- Who would be the best person to deliver the message? (Community member, celebrity, health professional, parent, someone like you?)

C. Closing

- To reach people with information, we need to know what kinds of things they read, watch and listen to. I am going to give you a very brief form that asks you some basic questions about you, and what you watch, read and listen to. Don't put your names on it. Just check what you believe and hand it back. Feel free to leave once you have completed the form.
- Once again, I want to reassure you that everything you said here is strictly confidential and anonymous. Your names will never be connected to any of it.
- Thank you for coming. The work that we've done here today is very important. You have helped us explore the best ways to reach people like yourselves with information about Chagas.
- If you are interested in finding out about the results of these groups, tell the person who invited you to this session and they will make sure you get some information when we are done. With four groups, it will take a while, but we'd be delighted to share what we learn with anyone who is interested.

D. Semi-structured question and answer session - providers

The Chagas Disease Initiative (CDI) is a project of the National Alliance for Hispanic Health (the Alliance) designed to evaluate what the Hispanic community knows about Chagas in order to later be able to create appropriate outreach and educational materials. CDI has been funded for one year by the Centers for Disease Control and Prevention (CDC).

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Knowledge

- Have you ever heard about Chagas, or “mal de Chagas”?

If yes,

Where did you hear about it?

Who do you think is most at risk?

Have you ever known anyone who was infected?

Can you tell me what you know about Chagas?

- Are you familiar with any of these bugs [ask and show picture(s) at the same time]?
 - the kissing bug,
 - the benchuca,
 - the vinchuca,

 - the chipo, or
 - the barbeiro.
- Have you ever diagnosed cases of Chagas among the clients you see? If so, have you reported this to the CDC?

- Who would you contact to get more information about the disease and diagnosis of Chagas?
- Are you familiar with the treatment options for Chagas disease? (If necessary, prompt about how to obtain the drugs to treat Chagas.)
If no,
Where would you go to find out about treating Chagas?
- What types of healthcare providers do you think most often treat Hispanics? (If necessary, prompt: primary care providers, community clinics, public health departments, Emergency/Urgent Care settings?)
- Did you know that the FDA started screening all blood donations for Chagas in 2007? And that testing positive means the donated blood will be rejected?
- How important do you think Chagas might be in service to your clients? (If necessary, prompt: in comparison to other diseases/conditions like diabetes?)
- Would you be interested in learning more about Chagas for your professional development, in particular to obtain continuing education credits?
- What kind of information would you like to receive to answer questions you have about Chagas?
- What would be the most useful way the CDC could provide more Chagas information to you?

Outreach

Part of why we are here is to get your opinion on the best way to reach the Hispanic community about the importance of learning about Chagas. We want to create a better understanding among community members about Chagas. So let's imagine we're doing an ad campaign:

- What do you think is the best way to educate consumers on Chagas? Specifically, what type of media? English or Spanish? At what literacy level?
- What information would be most important to give? Would it be information on the disease or what are the risk factors? Or would it be that treatment is available?
- Where would be the best places to put these messages so that your clients would see them? (TV, radio, newspapers, Internet, text messages?)
- Should the messages be in English, Spanish, or a combination of both?
- Who would be the best person to deliver the message? (Community member, celebrity, health professional, parent, someone like you?)

E. Closing

- We want to obtain the best possible information on conducting outreach about Chagas in the Hispanic community. I am going to give you a very brief form that asks you some basic questions about your professional experience with Chagas and what you recommend as effective ways to educate your Hispanic clients. Don't put your names on it. Just check off what you believe and hand it back. Feel free to leave once you have completed the form.
- Once again, I want to reassure you that everything you said here is strictly confidential and anonymous. Your names will never be connected to any of it.
- Thank you for coming. The work that we've done here today is very important. You have helped us explore the best ways to reach healthcare providers and Hispanic consumers with information about Chagas.
- If you are interested in finding out about the results of these groups, tell the person who invited you to this session and they will make sure you get some information when we are done. With four groups, it will take a while, but we'd be delighted to share what we learn with anyone who is interested.

**CDI Sample Invitation Letter
(English/Spanish)**

Dear **[Name of Invitee]**:

On behalf of **[Name of the Agency]**, I am pleased to invite you to participate in a discussion group to talk about Chagas disease. The discussion has been scheduled for **[date, time]** at **[place]**.

This activity is part of a national effort sponsored by the National Alliance for Hispanic Health and the Centers for Disease Control and Prevention (CDC). **[Name of the Agency]** has been selected to join with three other community-based agencies to participate in this effort to gather information on knowledge about Chagas disease and treatment options. The outcome of these discussions will be the basis for production of educational materials to serve the Hispanic community.

[Name of Site Coordinator] from my staff will be contacting you in the next days to confirm your participation in this event. If you have any questions, please do not hesitate to call me at **[phone number]**. I look forward to your consideration of our request.

Sincerely,

[Name of Head of Agency]

EJEMPLO DE CARTA DE INVITACION

Querido/a **(Nombre del Participante)**:

Es un placer invitarle a nombre de **(Nombre de su agencia)** a participar en un grupo de discusión para discutir el tema “mal de Chagas”. Esta discusión se llevará a cabo **(día, hora)** en **(lugar)**.

Esta actividad forma parte de un programa nacional dirigido por la Alianza Nacional para la Salud de los Hispanos y los Centros para el Control y la Prevención de Enfermedades (CDC por sus siglas en inglés). **(Nombre de su agencia)** ha sido seleccionada como parte del grupo de agencias que participarán en este esfuerzo, diseñado para recopilar información de consumidores hispanos y proveedores de salud a la comunidad hispana sobre conocimiento de “mal de Chagas” y sus tratamientos. Los resultados de estas discusiones van a servir como guía para el desarrollo de materias educacionales para la comunidad hispana.

(Nombre del coordinador del programa) de la **(Nombre de su agencia)** estará en contacto con usted en los próximos días para confirmar su participación en este evento. Si tiene cualquier pregunta, por favor llámeme al (número de teléfono). Será un placer tenerlo/a como participante.

Atentamente,

(Director/a de la agencia)

CDI Sign-Up Sheet

AGENCY/AGENCIA: _____

DATE/FECHA: _____

DISCUSSION GROUP NUMBER/NÚMERO DEL GRUPO DE DISCUSIÓN:

PLEASE WRITE YOUR NAME/POR FAVOR ESCRIBA SU NOMBRE

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

**CDI Discussion Group Consent Form
(English/Spanish)**

This is to certify that I, _____,
(Your Name)

agree to serve as a participant in this discussion group session sponsored by the National Alliance for Hispanic Health's Chagas Disease Initiative project. This discussion group session is being conducted to collect information, which can be helpful in developing educational materials about Chagas disease and treatment options. I understand that this session will be audio-tape recorded to assist in collecting complete information, and that the audio-tapes will not be shared with any person or agency outside of the Alliance. I also understand that when the information collected is used, individual participants will not be identified, and their identities will be considered strictly confidential.

Signature

Date

Con mi firma certifico que yo, _____,
(Su nombre)

voluntariamente participo en esta grupo de discusión del proyecto Iniciativa de la Enfermedad “mal de Chagas” (CDI) de la Alianza Nacional Para la Salud de los Hispanos (la Alianza). Esta sesión se está llevando a cabo para obtener información que será usada para desarrollar mensajes educativos sobre la enfermedad y sus tratamientos. Entiendo que esta sesión se va a grabar con el propósito de obtener una información completa y correcta, pero que las cintas magnetofónicas no se compartirán con nadie fuera de este proyecto, y ninguna organización excepto la Alianza. También entiendo que al usar la información recogida, los participantes no serán identificados y que su identidad será considerada estrictamente confidencial.

Firma

Fecha

I learn better by:

- Reading brochures
- Watching videos or television
- Listening to others
- Looking in the Internet
- Other way _____

On average, I watch ____ number of hours of television per week:

- 0-4 hours
- 4-8 hours
- 8-12 hours
- 12-16 hours
- More than 16 hours

On average, I listen to ____ number of hours of radio per week:

- 0-4 hours
- 4-8 hours
- 8-12 hours
- 12-16 hours
- More than 16 hours

On average, I spend ____ number of hours on the Internet per week:

- 0-4 hours
- 4-8 hours
- 8-12 hours
- 12-16 hours
- More than 16 hours

On average, I spend ____ number of hours reading newspapers or magazines per week:

- 0-4 hours
- 4-8 hours
- 8-12 hours
- 12-16 hours
- More than 16 hours

THANKS FOR YOUR PARTICIPATION!

- Escuchando a otras personas
- Buscando la información por Internet
- De otra manera _____

En promedio, yo veo _____ horas por semana de televisión:

- 0-4 horas
- 4-8 horas
- 8-12 horas
- 12-16 horas
- Más de 16 horas

En promedio, yo escucho la radio _____ horas por semana:

- 0-4 horas
- 4-8 horas
- 8-12 horas
- 12-16 horas
- Más de 16 horas

En promedio, yo estoy en el Internet _____ horas por semana:

- 0-4 horas
- 4-8 horas
- 8-12 horas
- 12-16 horas
- Más de 16 horas

En promedio, yo leo periódicos o revistas _____ horas por semana:

- 0-4 horas
- 4-8 horas
- 8-12 horas
- 12-16 horas
- Más de 16 horas

¡GRACIAS POR SU PARTICIPACIÓN!

The most effective method(s) I have used, to provide health education to my Hispanic clients has been: _____

If a workshop on Chagas were available, would you be interested in attending? Yes No

If the workshop were available online, would you be likely to participate? Why or why not?

THANKS FOR YOUR PARTICIPATION!

CDI Moderator Survey

AGENCY: _____

CITY: _____

DATE: _____

PROJECT COORDINATOR:

BACKGROUND INFORMATION:

1. NUMBER OF DISCUSSION GROUP PARTICIPANTS: _____

2. NUMBER OF MALES: _____

3. NUMBER OF FEMALES: _____

4. AGE RANGE: _____

5. PLACES WHERE PARTICIPANTS WERE RECRUITED:

6. ANY PROBLEMS ENCOUNTERED:

7. WAS THE GROUP CONDUCTED IN:

ENGLISH AND SPANISH _____

ENGLISH ONLY OR MOSTLY _____

SPANISH ONLY OR MOSTLY _____

Appendix 3: Summary of Results of Knowledge Questions

Summary of Results of Knowledge Questions

	Consumers	Healthcare Providers
Awareness of Chagas	Majority had little awareness	Majority had little awareness
Familiarity with Names	100% did not know	Majority did not know
Known Someone with Chagas	Majority did not know	100% did not know
Health Consequences	100% did not know	
Donated to Blood Bank	A few donated, and others considered	
Blood Donations Screening	100% did not know	Majority were aware
Access Healthcare	100% would go to a provider	
Regular Healthcare Provider	Majority have a regular primary provider	
Like to Receive Information	100% want to receive	100% want to receive
How to Receive Information	Clinic-based sessions, pamphlets, TV and radio	
Diagnosed Cases of Chagas		100% had never diagnosed
Access More Information		Internet, CDC, Physician's Manual, and Health Depts.
Knowledge of Treatment Options		Majority did not know
Types of Healthcare Providers		Physicians, nurses, health educators, and outreach workers
Importance of Chagas		Majority stated it was important
Information Like to Receive		Disease, symptoms, prevention and treatments
Way for CDC Provide Information		Online training, educational materials, and presentations

Appendix 4: Summary of Results of Outreach Questions

Summary of Results of Outreach Questions

	Consumers	Healthcare Providers
Sources of Health Information	Clinic, friends, schools, mass media, and Internet	
Important Messages	Resources in English and Spanish, those at-risk, diagnosis, prevention and treatment	All information on Chagas and its complications, photographs of insect, symptoms, prevention, and treatment
Places for Messaging	Clinics, churches TV, radio, and newspapers	Clinics, churches, schools, TV, radio, and Internet
Learn from Internet Information	A few would learn	
English, Spanish or Both	100% both English and Spanish	100% both English and Spanish
Spokespersons	Healthcare provider, informed person, and community member	Healthcare provider/educators, word of mouth, family members, mothers, and celebrities
Best Way to Educate		Top-down approach: medical professionals first, then consumers

