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# What Hispanic Youth Know About HIV Testing

## FOCUS GROUP REPORT



**The National Alliance for Hispanic Health**  
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## ABOUT THE NATIONAL ALLIANCE FOR HISPANIC HEALTH ([WWW.HISPANICHEALTH.ORG](http://WWW.HISPANICHEALTH.ORG))

The mission of the Alliance is to improve the health and well-being of Hispanics. Founded in 1973, the Alliance is the nation's oldest and largest network of Hispanic health and human services providers. Alliance members deliver quality services to over 12 million persons annually. As the nation's action forum for Hispanic health and well being, the programs of the Alliance strive to:

- Inform and mobilize consumers;
- Support providers in the delivery of quality care;
- Promote appropriate use of technology;
- Improve the science base for accurate decision making; and,
- Promote philanthropy.

The Alliance provides key leadership and advocacy to ensure accountability in these priority areas with the result of improving health for all throughout the Americas. The constituents of the Alliance are its members, Hispanic consumers, and the greater society that benefits from the health and well being of all its people.

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# EXECUTIVE SUMMARY

The National Alliance for Hispanic Health (the Alliance) received funding from the Office of Minority Health (OMH) in 2004 to implement the Take Control: Know Your Status/*Tome Control: Hágase la Prueba* (KYS) project. The goal of this project is to increase awareness among Hispanic adolescents and young adults about the importance of getting tested for HIV as a way to reduce barriers to early diagnosis of HIV infection and increase access to quality medical care, treatment, and ongoing prevention.

During the initial phase of the project, a series of focus groups were conducted with four KYS community partners in order to assess knowledge and awareness about HIV testing with members of the target population. Focus groups were completed during February and March 2005 in Phoenix, Arizona; Philadelphia, Pennsylvania; St. Paul, Minnesota; and, Watsonville, California. These focus groups were organized by the project's community partner agencies—*Concilio Latino de Salud*, *Congreso de Latinos Unidos*, *La Familia* Guidance Center, and *Salud para la Gente*—and conducted by the KYS project director.

## KEY FINDINGS

Some important conclusions regarding knowledge and attitudes about HIV testing can be drawn from the results of the focus groups.

- All (100%) of the Hispanic adolescent and young adult participants in the KYS focus groups had heard about HIV testing from one source or another.
- Few indicated a clear understanding that the key advantage to getting tested is being able to access early medical care and treatment, and prevention case management.
- Many focus group participants equated an HIV positive diagnosis as a death sentence.
- A majority of focus groups participants felt their counterparts in the community were not as knowledgeable as they were about HIV. Most attributed this knowledge to their participation in one or more programs sponsored by the community-based organization.
- Focus group participants in all four communities stressed that the ability to get tested for HIV without needing their parents' permission (and without the fear of having anyone else find out) was extremely important.
- Many participants expressed surprise upon hearing that an HIV test is currently available that can give results within about a half hour. Most agreed that availability of such a test would make a difference when deciding if they should get tested. Many also said that knowing that the test did not involve a needle or having blood drawn was a major plus.
- Participants expressed a preference for having messages about HIV testing given by people like themselves, "regular kids, just like us".
- The issue of confidentiality emerged as an important component to include in educational messages about HIV testing. Many also agreed that whatever the message, it has to be straightforward, "direct" and "straight out".
- Participants expressed a strong preference for having messages about HIV testing provided in either English, or a combination of English and Spanish. None expressed a preference for messages in Spanish only.

## RECOMMENDATIONS:

- There is a clear need to increase educational messages that make the connection between HIV testing and accessing early medical treatment and prevention case management services.
- More television education spots that link the importance of HIV testing and early treatment targeting this population should be developed. Television is an important source of information for this group of Hispanic adolescents and young adults (radio, newspapers, and magazines less so).
- The Internet is an emerging source of information that should also be used to provide educational messages about HIV testing and early treatment. Some Hispanic adolescents and young adults use the Internet as a regular source of information.
- Making HIV testing accessible in the areas where Hispanic adolescents and young adults are found is essential. Taking HIV testing into the community will also help overcome the obstacles related to fear about having others find out. For example, making the rapid test available in a community setting where those being tested can stay and wait for their results would eliminate several of the barriers that were brought up.

- Persons who are representative of the target population should deliver educational messages about HIV testing.

### TELEVISION IS AN IMPORTANT SOURCE OF INFORMATION FOR THIS GROUP OF HISPANIC ADOLESCENTS AND YOUNG ADULTS

- Any messages that are developed should reinforce the confidential nature of HIV testing.
- Adolescents and young adults who have participated in HIV education and prevention programs (such as the ones who participated in these focus groups) are positioned to provide an important source of peer-to-peer education in their communities. More community-based programs should incorporate youth as peer-to-peer educators in their HIV prevention programs.

### MAKING THE RAPID TEST AVAILABLE IN A COMMUNITY SETTING WHERE THOSE BEING TESTED CAN STAY AND WAIT FOR THEIR RESULTS WOULD ELIMINATE SEVERAL OF THE BARRIERS THAT WERE BROUGHT UP.



# METHODOLOGY

During the initial phase of the project, a series of focus groups were conducted with KYS community partners in order to assess knowledge and awareness about HIV testing with members of the target population. Focus groups were completed during February and March 2005 in Phoenix, Arizona; Philadelphia, Pennsylvania; St. Paul, Minnesota; and, Watsonville, California. These focus groups were organized by the project’s community partner agencies—*Concilio Latino de Salud*, *Congreso de Latinos Unidos*, *La Familia* Guidance Center, and *Salud para la Gente*—and conducted by the KYS project director.

A focus group protocol was adapted and tailored to the needs of the KYS project. The protocol includes information on the procedures for coordinating and running the focus group. The project coordinator at the community level had responsibility for recruiting participants and coordinating the focus group logistics, including obtaining consent forms from participants (or their parents if they were under 18 years of age). The project coordinator was also in charge of arranging for the location, snacks or meals, and the incentive provided to the focus group participants.

The focus group protocol includes the questions that formed the basis of the guided discussion in all four focus groups. This format was adhered to in all four focus groups conducted by the Alliance’s KYS project director. All focus groups were composed of female and male participants, with the exception of the focus group in Phoenix. Based on previous experience with young focus group participants, *Concilio Latino de Salud* organized two simultaneous focus groups, one with males and the other with females, under the premise that each group would feel more comfortable expressing their views without the presence of the opposite sex. If technical questions arose during the focus group discussion, participants were asked to wait until the focus group ended before discussing the answers. Only requests to clarify a focus group question were provided with a response during the actual discussion.

## DEMOGRAPHIC CHARACTERISTICS OF KYS FOCUS GROUP PARTICIPANTS

Four focus groups were conducted for the KYS project, one each in Phoenix, Arizona (February 22); Philadelphia, Pennsylvania (March 11); St. Paul, Minnesota (March 18); and, Watsonville, California (March 31).

### Gender and Age

The four KYS focus groups included a total of thirty-nine (39) participants, twenty (20) males and nineteen (19) females (see Table 1), ranging from 13 – 25 years of age (see Table 2).

**TABLE 1: GENDER (N=39\*)**

Female	Male
19	20

\* Note that while there were 39 participants, one (1) did not complete the participant survey, so all numbers will add up to 38.

**TABLE 2: AGE**

Age	No. Participants
13	1
14	3
15	9
16	7
17	9
18	5
19	2
20	1
25	1

## Grade in School

The school grades represented went from 7th (1) to college (2), with four (4) no longer attending school. Four (4) participants were in the 12th grade, seven (7) in the 11th grade, twelve (12) in the 10th grade, five (5) in the 9th grade, one (1) in the 8th grade, one (1) stated that her school doesn't have grades, and one (1) did not answer this question (see Table 3).

**TABLE 3: GRADE IN SCHOOL**

Grade	Number
7th	1
8th	1
9th	5
10th	12
11th	7
12th	4
College	2
No grades in my school	1
No longer attend school	4
No answer	1

## Hispanic Subgroup

The majority of participants (25) identified their Hispanic heritage as Mexican-American. Three (3) identified as Central American, two (2) as Mexican, two (2) as Puerto Rican, one (1) as Mexican-American and Puerto Rican, one (1) as Pacific Islander, one (1) as Filipino, one (1) as "Other: Hispanic", one (1) as "Other: African American", and one (1) did not provide a response to this question (see Table 4).

**TABLE 4: HISPANIC SUBGROUP**

Hispanic Origin	Number
Mexican-American	25
Mexican	2
Central American	3
Puerto Rican	2
Mexican-Am./Puerto Rican	1
Pacific Islander	1
Filipino	1
Other: 'Hispanic'	1
Other: "African-American"	1
Did not answer this question	1





## METHODOLOGY (CONTINUED)

### Place of Birth and Length of Time in U.S.

A majority were born in the United States (24), with the remainder in Mexico (10) (see Table 5). Of those not born in the U.S., most have been in the U.S. for many years, with five (5) indicating 6-15 years of residence in the U.S., four (4) indicating 16-25 years, and one (1) indicating 1-5 years (see Table 6).

**TABLE 5: PLACE OF BIRTH**

Place of Birth	Number
United States	28
Mexico	10

**TABLE 6: LENGTH OF TIME IN U.S.**

Length of Time in U.S.	Number
Less than 1 year	0
1 – 6 years	1
6 – 15 years	5
16 – 25 years	4
Born in U.S.	28

While most focus group participants were born in the U.S., their parents are primarily foreign-born, with the majority (21) from Mexico, ten (10) born in the U.S. (includes two (2) sets of parents born in Puerto Rico), four (4) sets of parents born in the U.S. and Mexico, one (1) set of parents born in the Philippines, one (1) set of parents born in El Salvador and Ethiopia, and one (1) set of parents born in Central America (no country specified) and the Philippines.

### Language Spoken at Home

Half (19) of focus group participants stated that both English and Spanish were spoken in their homes, while eight (8) said only Spanish was spoken, and ten (10) said only English was spoken. One (1) respondent checked “Only English” and “Only Spanish”. (See Table 7.)

**TABLE 7: LANGUAGE SPOKEN AT HOME**

Language Spoken at Home	Number*
Only Spanish	8
Only English	10
English and Spanish	19

\* One respondent circled “only English” and “only Spanish”

### Language Preference

Likewise, most of the participants (26) expressed a personal preference for speaking English and Spanish, nine (9) expressed a preference for speaking only English, and one (1) checked all three responses. None of the participants expressed a preference for speaking only Spanish (see Table 8).

**TABLE 8: LANGUAGE PREFERENCE**

Language Preference of Focus Group Participant	Number*
Spanish	0
English	11
English and Spanish	26

\* One respondent circled all 3 responses



## Preferred Methods for Learning

Participants expressed a wide variety of preferences with regard to how they best learn. The categories of watching television and videos received the highest number of responses (14) followed by “listening to others” (9). Three (3) participants indicated they preferred reading brochures, two (2) preferred reading brochures and watching television/videos, two (2) preferred reading brochures and listening to others, and three (3) checked all 4 options. One (1) expressed a preference for watching television/videos and listening to others, one (1) expressed a preference for listening to others and “hands on”, one (1) preferred listening to others and looking on the Internet. One (1) selected “Other” adding “teaching myself and reading”, and one (1) selected “Other” adding “reality”. One (1) participant listed “looking on the Internet” together with “listening to others”. No participant in any focus group listed looking on the Internet exclusively (see Table 9).



**TABLE 9: PREFERRED METHODS FOR LEARNING**

I learn better by...	Number
Reading brochures	3
Watching television or videos	14
Listening to others	9
Looking on the Internet	0
Reading brochures & watching television or videos	2
Reading brochures & listening to others	2
Watching television or videos & listening to others	1
Listening to others & “hands-on”	1
Listening to others & looking on the Internet	1
All 4 options	3
Other: “Teaching myself and reading”	1
Other: “Reality”	1

## METHODOLOGY (CONTINUED)

### Number of Hours of Television Watched Per Week

There was a fair amount of consistency across focus groups with regard to hours spent watching television, listening to the radio, and reading newspapers or magazines. Eleven (11) participants stated they watch an average of 0-4 hours per week of television, fifteen (15) indicated watching 4-8 hours, six (6) stated watching 8-12 hours, three (3) indicated 12-16 hours, and two (2) said they watched more than 16 hours of television per week. One (1) participant checked both 4-8 hours and 8-12 hours, this response was not included in the analysis). (See Table 10.)

**TABLE 10: NUMBER OF HOURS OF TELEVISION WATCHED PER WEEK**

Hours of Television Viewing Per Week	No. Participants
0 – 4 hours	11
4 – 8 hours	15
8 – 12 hours	6
12 – 16 hours	3
More than 16 hours	2



### Number of Hours Listening to the Radio Per Week

A majority (26) listened to the radio anywhere from 0-4 and 4-8 per week. Fourteen (14) participants stated they listened to 0-4 hours of radio per week, ten (10) stated they listened to the radio 4-8 hours per week, seven (7) indicated 8-12 hours, one (1) stated listening to the radio 12-16 hours, and six (6) said they listened to the radio for more than 16 hours per week (see Table 11.)

**TABLE 11: NUMBER OF HOURS OF LISTENING TO THE RADIO PER WEEK**

Hours of Listening to the Radio Per Week	No. Participants
0 – 4 hours	14
4 – 8 hours	10
8 – 12 hours	7
12 – 16 hours	1
More than 16 hours	6

### Number of Hours Spent on the Internet Per Week

Most participants (24) indicated they spent 0-4 hours per week on the Internet, eleven (11) stated they spent 4-8 hours on the Internet, and two (2) indicated 8-12 hours on the Internet. Only one (1) said that they “don’t use” the Internet (see Table 12.).

**TABLE 12: NUMBER OF HOURS SPENT ON THE INTERNET PER WEEK**

Hours on the Internet Per Week	No. Participants
0 – 4 hours	24
4 – 8 hours	11
8 – 12 hours	2
12 – 16 hours	0
More than 16 hours	0
“Don’t Use”	1



### Number of Hours Reading Newspapers or Magazines Per Week

Newspapers and magazines received the least amount of attention, with twenty-eight (28) participants stating they spent 0-4 hours on this activity, eight (8) indicating they spent 4-8 hours, and two (2) stating they spent 8-12 hours on reading newspapers and magazines per week (see Table 13).

**TABLE 13: NUMBER OF HOURS READING NEWSPAPERS OR MAGAZINES PER WEEK**

Hours Reading Newspapers/Magazines Per Week	No. Participants
0 – 4 hours	28
4 – 8 hours	8
8 – 12 hours	2
12 – 16 hours	0
More than 16 hours	0
“Don’t Use”	0

# SUMMARY OF GUIDED DISCUSSION

All focus group participants stated that they had heard about HIV testing. When asked about the benefits of knowing your HIV status, most responded that it was important in order to avoid infecting someone else, to protect yourself, to make it possible to have sex without worrying about transmission, and to not pass it on to your child. A very small number of participants talked about the importance of early diagnosis of HIV and getting appropriate medical care and prevention case management services.

When asked about the disadvantages of knowing your status, the most typical response was “knowing that you are going to die”. Most focus group participants expressed the feeling that being HIV positive was a sure death sentence.

In general, focus group participants were very confident in their belief that they knew much more about HIV transmission and prevention than their counterparts in the community. They gave credit for this knowledge to educational programs sponsored by the community-based agency, and for the most part expressed respect and appreciation for the programs that were offered to them.

Many participants also felt a great disconnect between what they knew and what their parents knew, and stated that their parents needed to receive HIV testing messages much more than they did. (As one participant stated, rather than having to be so afraid of their parents’ reaction to finding out they wanted to get tested for HIV, wouldn’t it be great if your parents asked, out of concern for you, “when was the last





time you got tested for HIV? Don't you think it's time to go and get tested?") Fear of having parents find out they were tested for HIV was described as a major obstacle, and knowing that their parents would not find out was viewed as a facilitator to getting tested.

**...MESSAGES ABOUT HIV TESTING SHOULD COME FROM PEOPLE LIKE THEM, PEOPLE WHO REFLECT THEIR REALITY.**

Overall, participants felt comfortable telling their friends about getting tested for HIV especially their close friends whom they perceived as trustworthy and supportive. Most participants knew of a place where they could go to get tested for HIV, but gave mixed responses with regard to their comfort levels going to those places. Several expressed concern about being recognized by neighbors, their parents' friends, or being judged by others for their decision to get tested. Ignorance and fear were also mentioned as additional obstacles to getting tested.

With regard to actual tests, there was some confusion about what the test entails, if there were different tests, and the frequency with which one should get tested. However, most participants knew that testing should occur more than once in your lifetime. Most agreed that a test that allowed you to get your results quickly would make a difference in their decision to get tested. Many also expressed that a test that did not involve a needle or having blood drawn was a plus.

**...HIV TESTING SHOULD BE "COMMON SENSE"**

In terms of outreach and messages to convey when conducting outreach, participants expressed that HIV testing should be "common sense", that many people want to know their status. Most suggested that it is

important to emphasize the confidential nature of HIV testing, that they shouldn't be afraid, and also to remind young people that their parents don't need to know. One participant stated that it was important to make the link between HIV and teen pregnancy. Another participant stated that he had seen many messages about drug abuse, but none that connected drug use and HIV infection, and that this was an important connection to make.

Most focus group participants felt strongly that messages about HIV testing should come from people like them, people who reflect their reality. Responses indicated that they would be more prone to listen to a message coming from "real" people, as opposed to celebrities or someone who was paid to give the message. A few stated they would like to hear the message from someone they look up to, "somebody important", "a Hispanic person", "soccer players", "all stars". Some stated that it would be important to use sex in the messages, highlighting that sex is pleasurable, but that you also have to be responsible.

**...THEY WOULD LIKE TO SEE MESSAGES EVERYWHERE, ON THE TELEVISION, ON THE INTERNET, AT BUS STOPS, IN SCHOOL, ON THE RADIO.**

Participants also expressed a preference for messages to be delivered either in English and Spanish together, or just in English. All participants expressed greater comfort speaking in English than Spanish. Responses indicated that they would like to see messages everywhere, on the television, on the Internet, at bus stops, in school, on the radio. However, they felt strongly that messages should not come from parents, "we don't want to hear it from the parents".

# DETAILED SUMMARY OF INDIVIDUAL FOCUS GROUPS

## PHOENIX, ARIZONA

### Demographic Information of Focus Group Participants

(Recruitment and Coordination Conducted by *Concilio Latino de Salud*, February 22, 2005)

The Phoenix focus group was made up of eighteen (18) participants, eleven (11) males and seven (7) females. They ranged in age from 13 to 19 years, with the majority being 15 and older (14). Most of the participants were still in school, most (12) in the 9th, 10th, and 11th grades. A majority (14) was born in the United States and identified themselves as Mexican-American. Of those who were not born in the U.S., all had been in the U.S. for a long time (3 reported 6-15 years, and 1 16-25 years). Most of their parents were born in Mexico (14), a small number had one parent born in the U.S. and another in Mexico (3), and 1 reported being of Salvadoran/Ethiopian heritage. A majority of participants indicated that they spoke both English and Spanish at home (10) and a smaller number reported that only Spanish was spoken at home (6). Only one (1) indicated that only English was spoken at home. The majority of participants expressed a preference for both English and Spanish (17), with only one (1) expressing a preference for Spanish only.

With regard to their preferred method for learning, most indicated a preference for watching television or videos (7) and listening to others (7). One indicated a preference for reading brochures, one (1) chose reading brochures and watching television or videos, and one (1) chose all options (reading brochures, watching television or videos, listening to others, and looking on the Internet). Five (5) participants indicated they watched 0-4 hours of television per week, seven (7) indicated 4-8 hours per week, two (2) indicated 8-12 hours per week, two (2) indicated 12-16 hours per week, and two (2) indicated they watch more than 16 hours of television per week. With regard to how much time was spent per week listening to the radio, five (5) participants indicated 0-4 hours per week, six (6) indicated 4-8 hours per week, five (5) indicated 8-12 hours per week, and two (2) indicated more than 16 hours of listening to

the radio per week. Fourteen (14) of the participants indicated they spent 0-4 hours per week on the Internet, and four (4) reported they spent 4-8 hours on the Internet per week. Fourteen (14) participants indicated that they spent 0-4 hours per week reading newspapers or magazines, two (2) indicated they spend 4-8 hours per week, and two (2) indicated they spend 8-12 hours per week on this activity.

*Concilio Latino de Salud* recruited 18 focus group participants. Because of the size and their past experience conducting focus groups on topics related to sexuality, it was agreed that two focus groups would be conducted simultaneously, one with males, and the other with females. The Alliance's KYS project director conducted the focus group with females, and a male staff member trained in conducting focus groups from CLS conducted the focus group with males. Both leaders went over the questionnaire prior to conducting the focus groups in order to ensure that exactly the same questions would be asked. Transcripts of both focus groups were used to summarize the guided discussion.

### Summary of Guided Discussion: Phoenix, Arizona

All participants in the Phoenix focus groups had heard about HIV testing. Among the comments regarding what they had heard were "there is no cure", "you should get yourself tested", "it can be in your body without knowing". When asked if they thought other youth in their community knew what they did, most stated that was not the case. "Others in the community do not have the same knowledge", "parents don't want kids to know", "before coming to the CHIVA<sup>1</sup> program I didn't know a lot".

When asked about the benefits of knowing your HIV status, the general consensus was that knowing meant you could get appropriate treatment, and also

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<sup>1</sup> CHIVA (Creating HIV Awareness) is an HIV prevention program run by *Concilio Latino de Salud*.

gave you the knowledge that you need to be more careful. One participant said it was good because “you start getting treated early”, another “if you know you can be more careful”. As for the disadvantages, “if you know, lots of terrible things can happen to you”, and “what if you don’t get the right treatment?”

Most participants stated they felt comfortable with telling their friends that they want to get tested for HIV. “You can convince them to get tested too”. After a bit more discussion, several participants clarified that they wouldn’t “tell all your friends, just the ones you trust”. With respect to concerns or fears about what others might think if they knew they were getting tested for HIV, participants expressed concern over being judged by others. They might “think bad things about you,” or “mean things” about you, or “that you’re nasty”.



When asked what would facilitate getting tested, confidentiality was a significant issue. Some responses were: “the fact that it’s confidential”, “you don’t have to tell your parents”, “knowing that no one will have access to the information”, “they can’t share the information with anybody”. Not requiring parental consent was brought up several times: “parents think they have innocent little kids”, “they don’t know”. Cost also emerged as a concern, with several participants pointing out that the free testing was a facilitator, “because not many teens have money”.

**...“REMIND PEOPLE THAT WHEN YOU SLEEP WITH SOMEONE, YOU’RE ALSO SLEEPING WITH EVERYONE THEY SLEPT WITH”.**

Mixed responses were given when the participants asked if they knew where to go to get tested, and many expressed feelings of discomfort over the idea of going to a clinic or other location to get tested. “You have to walk in by yourself”, “people will ask why aren’t you with your parents”, “your neighbors might be there, people who know you”, “they know who your parents are”. While there were different responses with regard to how often one should get tested, everyone knew that it was important to get tested more than once: “every few years”, “every 6 months”, “more than once”.

A majority agreed that being able to have the testing come to you, and getting the results quickly, would help in the decision to get tested. One participant added, “Even 20 minutes can be a long time, there’s lots of fear involved”.

The focus group participants expressed strong feelings that they knew much more than their parents, and that it might be important to target parents with HIV testing messages: “in reality, you’re not

gonna wait till you get married”, “you might not think so, but you’re out in a club”, “they would say that’s not my kid”, “parents build their own fantasy world”, “they take their clothes in the backpacks” (to go out later), “your kid is not actually who they think they are”.

With regard to important outreach messages, one participant stated “remind people that when you sleep with someone, you’re also sleeping with everyone they slept with”. Many also agreed that they had seen many more messages about drugs, not about HIV.



## DETAILED SUMMARY OF INDIVIDUAL FOCUS GROUPS (CONTINUED)

They felt there needed to be more messages in the media about HIV, and that these messages need to make a better “connection between drugs and behavior”. Some said they thought that the element of fear worked, and others did not. “There should be some fear to recognize reality, but not enough to become, you know, immobilized”. Once again, several felt that the messages needed to emphasize confidentiality, not be embarrassed, “not to hide”, and “don’t take the chance of not getting tested”. They said that messages should be everywhere, in school, on the radio, on the TV. “But it shouldn’t be people who are getting paid to say get tested,” the message should be given by “regular kids, just like us”, “people our age”. One participant said he had seen so many documentaries, “but I’ve never seen anything on a Mexican channel, or in Spanish, never, never”. They added, “not newspapers or magazines,” “that would only get the attention of adults”. Preference was also expressed for having messages in English and in Spanish. Several participants again stated that it would be important to “have parents’ support”, a message “where parent would be taught to ask you when was the last time you got tested?”



### PHILADELPHIA, PENNSYLVANIA

#### Demographic Information of Focus Group Participants

(Recruitment and Coordination Conducted by  
*Congreso de Latinos Unidos* , March 11, 2005)

The Philadelphia focus group was made up of five (5) participants recruited from *Congreso's* teen pregnancy program. All 5 were female, and ranged in age from 17 (2) to 18 (2). One (1) participant did not complete a participant survey, so demographic data are only reported for 4 participants. All four (4) were in the 12th grade. All four (4) were also born in the U.S., two (2) identified as Puerto Rican, one (1) as African American, and one (1) did not respond to this question. Two sets of parents were born in Puerto Rico, and the other two in the U.S. With regard to language spoken at home, three (3) stated that only English was spoken, and one (1) stated that only Spanish was spoken. In terms of their own language preference, two (2) preferred only English, and two (2) preferred a combination of English and Spanish.

With regard to their preferred method for learning, one (1) indicated a preference for reading brochures, one (1) for watching television and videos, one (1) for listening to others, and one (1) checked all 4 responses (reading brochures, watching television or videos, listening to others, and looking on the Internet). In terms of time spent watching television, one (1) participant stated they watch 0-4 hours per week, two (2) indicated 4-8 hours, and one (1) indicated 8-12 hours per week. With regard to number of hours spent listening to the radio, two (2) participants stated they listen 0-4 hours per week and another two (2) indicated 4-8 hours. In the area of time spent on the Internet, two (2) participants stated they spent 0-4 hours per week on the Internet, and another two (2) indicated 4-8 hours. All 4 participants stated they spend 0-4 hours per week reading newspapers or magazines.

## Summary of Guided Discussion: Philadelphia, Pennsylvania

All participants stated they had heard about HIV testing, and also indicated that they had all actually been tested. They heard about testing through the HIV project at *Congreso*, in school, or on TV. They were unanimous in thinking that other youth in the community were not as knowledgeable as they were, although people may be hearing some information.

This group was very clear on what they felt were the benefits of knowing your HIV status: “you can’t pass it on to your kids”. They also felt strongly that if you know, “it’s good for your partner”, and it’s important “for you”. When asked about disadvantages of knowing your HIV status, one participant felt that would be very “stressful”, “I wouldn’t want to know”, it would be “scary”, another participant responded “but what if you got cut, and you exposed your son?” “People want to keep their status to themselves”. The hardest part about knowing would be “telling my family”, “having to deal with gossip”. Telling a friend that they were thinking about getting tested for HIV “depends on the friend”, “some people are around you to know your business”, but they don’t really care. However “good friends would be upset” if you tested positive.

When asked what would make it easier for them to get tested, one participant said she “would just go”, another stated she would “be a nervous wreck”, and yet another said “you’ll find out sooner or later, you’ll find out eventually”. Everyone knew of places they could go to get tested, and all expressed they would feel comfortable going to those places. With regard to other barriers to getting tested, one participant said she “would be scared in general”, another added “you have to do it”, and another stated “everyone who has an STD has to be careful”.

When asked about how you get tested for HIV, everyone stated they knew about the blood test, and that everyone had been tested. Overall, not too many volunteered information about the difference between

confidential testing and anonymous testing, one participant stated “confidential means private”. When asked about a test that would allow them to receive their results within a half our, most participants felt this was a positive thing because “you know faster”, and “because you don’t have to be so worried”. Most also felt that having this test available would increase their likelihood of making the decision to get tested.

With regard to outreach, most participants felt that HIV testing is “common sense”, that by not getting tested “you’re not helping yourself”. “A lot of people would want to find out”, “the guys don’t get tested as often as the girls”, “girls go to the doctor more,” girls “have to assume more responsibility”, if girls don’t get tested, “they’re not respecting themselves”. In terms of important information, one participant said “get tested because you have kids”. With regard to the best places to place HIV testing messages, many

**...BY NOT GETTING TESTED “YOU’RE NOT HELPING YOURSELF”.**

expressed a preference for hearing those messages in schools, and also on TV. Messages should be a “combination of both English and Spanish”, “a lot of Puerto Ricans don’t talk in Spanish”. When asked who would be the best person to give these messages, there were quite a few responses, “someone that tests positive”, “not celebrities, regular people”, “if they are older people don’t usually listen to their own age group”, and “I tell myself what to do.” They also expressed that parents should not be involved in giving the message. “Parents don’t care”, “they’re not home”, “parents react badly” to discussions about sex,” “especially HIV”, “kids don’t want their parents involved”, “schools can’t get parents to come to the open house”, parents “would rather not deal with it.” “Schools don’t care”, and one participant added “all parents are different”.

# DETAILED SUMMARY OF INDIVIDUAL FOCUS GROUPS (CONTINUED)

## ST. PAUL, MINNESOTA

### Demographic Information of Focus Group Participants

(Recruitment and Coordination Conducted by *La Familia* Guidance Center, March 18, 2005)

The St. Paul focus group was made up of eight (8) participants, four (4) male and four (4) female. They ranged in age from 14 to 17 years, most were in the 10th grade (6), one (1) was in 9th, and one (1) was in the 11th grade. A majority described their Hispanic heritage as Mexican-American (7) and one identified as Mexican. Most (7) were born in the U.S., and one (1) was born in Mexico. Of those born outside of the U.S., two (2) had been in the U.S. from 6-15 years, and one (1) had been in the U.S. for 16-25 years. A majority of the participants' parents (5) were also born in the U.S., two (2) sets of parents were born in Mexico, and one (1) had one parent born in the U.S. and another in Mexico. Half (4) reported that only English was spoken at home, the other half stated that both English and Spanish were spoken. With regard to the participants' language of preference, five (5) indicated they preferred to speak only in English, and three (3) stated they preferred both English and Spanish.

**...PARTICIPANTS STATED THEY FELT COMFORTABLE TELLING THEIR FRIENDS THAT THEY WERE GOING TO GET TESTING FOR HIV.**

Most participants (5) stated a preference for learning through watching television or videos, one (1) stated they learned better by reading brochures and listening to others, and one (1) participant indicated that they learned better through "reality". When asked to indicate the average amount of time spent watching television per week, three (3) participants indicated 0-4 hours, two (2) indicated 4-8 hours, one (1) indicated 8-12 hours, and one (1) indicated 12-16 hours. One (1) respondent checked both 4-8 hours and 8-12 hours. In response to the question about how much time they spent listening to the radio, four (4) participants indicated they listened more than 16 hours per week.

One (1) indicated they listened to the radio 12-16 hours per week, one (1) indicated 4-8 hours, and two (2) indicated they listened to the radio from 0-4 hours per week. With regard to the Internet, four (4) indicated 0-4 hours of Internet use, three (3) indicated 4-8 hours, and one (1) indicated no use of the Internet at all. Finally, reported reading of newspapers and magazines was low, with six (6) participants indicating 0-4 hours on this activity per week, and two (2) indicating 4-8 hours.

### Summary of Guided Discussion: St. Paul, Minnesota

All focus group participants stated they had heard about HIV testing. When asked where they had heard about it, a variety of options were offered: "school", "TV", "friends" "magazines", "posters", "hospitals", "Marina" (Marina is a member of the staff, who works with and recruited the participants of this focus group). When asked whether youth in their community knew about HIV testing, responses were mixed. "Most of them", "the ones who are active", "they know but they don't do anything". When asked about the benefits of knowing your HIV status, the overall reaction was positive. "So that you know that you are clean", "so you know that you're sick", "so you can get some". No one thought there were any disadvantages to knowing your HIV status. However, the difficult aspects of knowing would be knowing "you got it, and you can't get rid of it", "your life is going to change," "you'll have it 'till you die", "your life will be shorter".

For the most part, all participants stated they felt comfortable telling their friends that they were going to get testing for HIV. One said, "I don't care what they think". As to how their friends would react, again, "I don't care".

When asked what might make it easier for them to get tested for HIV, the first response was "if they don't take your blood", and another added they want "no test that involves taking your blood". All participants indicated they were knowledgeable about places they could go to get tested, and mentioned schools, clinics,

free clinics, and school clinics. The fact that it is “free” was important, especially because they “don’t tell their parents some things”. For the most part they also felt comfortable with the idea of going to these places, “there is nothing wrong with going”, they should be able to “take time out of class” to get tested, testing should occur “right in school”. In response to the question about other possible barriers to getting tested, the only one that was brought up was cost.

When asked about how you get tested for HIV, most participants stated they “don’t know”. One participant added that it involved “taking blood”. Most did not know the difference between anonymous and confidential testing. When asked their opinions about a test that allowed them to get their results within a half hour, one stated that would be “way better than getting blood taken”, one indicated “there are tests like that”, and another said maybe having more time to wait wasn’t so bad, “if you’re not sure” what the result might be. Most felt that the availability of this test would be a good thing, you “won’t be paranoid”, “wouldn’t worry about needles”. In the discussion about outreach strategies, focus group participants stated that some of the messages that were important to get across included the fact

that “it’s confidential”, “your parents don’t have to know”, and you get “free condoms”. With regard to other important information to provide, they offered “don’t be scared”, “If you don’t want to get tested, then practice abstinence, or masturbate”.

**... “TESTING SHOULD BE GIVEN FOR FREE”  
AND THE MESSAGE SHOULD BE SOMETHING  
LIKE “GO GET TESTED RIGHT NOW!”**

Among the best places to put the message, participants said schools, music videos, cartoons, MTV, BET, “it’s more effective on TV”, and the message “is already there, it needs to be more effective”. The message should be in “all languages”, in English, and “not all Mexicans speak Spanish”. As for who should give the message, suggestions were “Not Bush!” “A Hispanic person”, “Fernando Reyes”, “someone you look up to”, “somebody important”, “Marina”, “role models”. They added “testing should be given for free” and the message should be something like “Go get tested right now!”





# DETAILED SUMMARY OF INDIVIDUAL FOCUS GROUPS (CONTINUED)

## **WATSONVILLE, CALIFORNIA**

### **Demographic Information of Focus Group Participants**

(Recruitment and Coordination Conducted by *Salud para la Gente*, March 31, 2005)

The focus group in Watsonville was comprised of eight (8) participants, five (5) males and three (3) females. A majority ranged in age from 16 to 18 years (2, 16; 2, 17; and, 2 18), one (1) participant was 20 and one (1) was 25. The youngest was in the 9th grade, three (3) were in the 11th grade, two (2) were in college, and two (2) no longer attend school. Most identified their Hispanic heritage as Mexican-American (4), one (1) identified as Mexican, one (1) as Central American, one (1) as Pacific Islander, and one (1) as a Filipino American. Five (5) of the participants were born in Mexico and three (3) were born in the U.S. A majority (5 sets) of their parents were born in Mexico, one (1) set of parents was from the U.S., one (1) had a Central American parent and a parent from the Philippines, and one (1) had a set of parents from the Philippines.

Most (5) stated that both English and Spanish were spoken in the home, two (2) indicated that only English was spoken, one (1) indicated that only Spanish was spoken. When asked about their own language preference, four (4) stated they preferred speaking both English and Spanish, three (3) said only English, one (1) respondent checked "English only", "Spanish only", and "Both English and Spanish". This group had the most variety when expressing their preferred method for learning. This might be because as an older group, they had been exposed to a wider variety of teaching methods. One (1) indicated they preferred watching television or videos, one (1) indicated a preference for listening to others, one (1) stated watching television or videos and listening to others, one (1) stated listening to other and "hands on", one (1) stated listening to others and looking on the Internet, one (1) stated reading brochures and watching television and videos, and one (1) indicated all four methods.

Two (2) participants indicated they watched 0-4 hours of television per week, four (4) indicated 4-8 hours, and two (2) indicated 8-12 hours. With regard to radio, five (5) participants indicated listening to the radio 0-4 hours per week, one (1) indicated 4-8 hours, and two (2) indicated 8-12 hours per week. Four (4) participants stated they used the Internet 0-4 hours per week, two (2) stated 4-8 hours per week, and two (2) indicated more than 16 hours per week. Just like the rest of the focus groups, these participants spent little time reading newspapers or magazines. Four (4) stated they spent 0-4 hours per week on this activity, and four (4) stated they spent 4-8 hours.

### **Summary of Guided Discussion: Watsonville, California**

All focus group participants in Watsonville indicated they had heard about HIV testing. They had heard about it from a variety of sources, including a program conducted by the CBO, in the community, in the media, through pamphlets, and in health class at school. However, most did not think that other youth in their community knew about HIV testing, and felt that further outreach needed to be done.

When asked what might be the benefits of knowing their HIV status, various responses were given: "To not get it", "to protect yourself", "to save others if you have it", "it's confidential", "it's free", "to know to wear a condom", and one participant said "you can use protection but you still might get it". When asked about the disadvantages of knowing your HIV status, responses included "you might have low self-esteem", "you might die soon", "you might not be able to have sex". When asked what would be most difficult about knowing your HIV status, participants responded, "To tell your parents, if you have it", "to accept that you might die", "knowing you'll die soon".

When asked whether they would feel comfortable telling their friends they want to get tested for HIV, and how their friends might react, one participant said "yes, because it would be something positive for

yourself". Another said they would feel uncomfortable, they might feel "dirty", that their friends might not want to "touch" them, to which another participant responded "Yeah, if they were ignorant!" Several others expressed that their friends would be more open about this, and would be there if they were "needed."

The discussion then moved to questions regarding HIV testing. All participants stated that they knew where they could go to get tested for HIV, and they also agreed that they would feel comfortable going to those places in order to get tested. In response to the question about what might make it easier for them if they were contemplating getting tested for HIV, one participant responded "not having to wait" for the result. When asked about other barriers to HIV testing, several mentioned "ignorance" and being "too scared."

Participants were knowledgeable about the topic of how one gets tested for HIV. One talked about Orasure, another said it was "confidential, they put it in a tube with a number on it", that "it takes 30 seconds" that "they have to draw blood," one said they had heard about a test where a swab can be used in your mouth "so you don't have to draw blood", and another responded "but wouldn't drawing your blood be more accurate?" One participant wanted to know if you could get tested for HIV in your urine.

There was a fair amount of confusion about the difference between confidential and anonymous testing, in "confidential they don't say who you are", "they don't tell anyone", and "they use a fake name". With regard to the frequency of HIV testing, everyone knew that it was not a one-time test, but responses to how often one should get tested varied widely: "every 3-6 months", "every time you get involved", "every time you have sex", "every time you have sex with a new partner".

When asked to express their thoughts about a test that would allow them to receive their results within about a half hour, the first response was "that would

be great". Someone else responded "I wouldn't trust it". But when asked if the availability of a test like this would make a difference in their decision to get tested, most said it would. "You wouldn't have to be so concerned". You might not have time to prepare because "you're not expecting to be shocked", and "you really have to be prepared". Someone else added, "I'd be shitting bricks".

From there, the discussion moved to questions regarding outreach. When asked what messages are important to convey in order to encourage young Hispanics to get tested, the responses included: the information should be "direct", "straight out", "something serious". With respect to the type of information that should be given, participants had a wealth of ideas. "Use sex", say "sex is something that can give you pleasure, and can also kill you". Making it so serious is also "a double edged sword", "don't use the HIV part so much", "it's already bad enough". One participant joked, "What's your name again?" One participant expressed that it was important to "make the link with teenage pregnancy".

In terms of where messages should be placed, most participants agreed that it should be "everywhere". In the media, on TV, in pop-up Internet ads, in magazines, in the previews shown in theaters before showing a movie.

There was general agreement that the messages should be in English and in Spanish, "especially here", "because of who lives in the community".

There was great enthusiasm with respect to who should give the message: "young people", "people who have HIV", "friends", "someone who lives a righteous life", "friends", "peers", "basketball players", "soccer players", "porn stars", "Bill Gates", "all stars", "everyone". But "not parents", "teens don't listen to parents", "it's hard for parents to talk about sex", "we'd be disgusted if it comes from the parents", "we don't want to hear it from the parents".









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