Assessing Community Readiness for Structural Interventions to Prevent the Spread of HIV:

The Case of the HIV Home Test

Latino Commission on AIDS is a private non-profit organization founded in 1990 in response to the unmet national need for HIV/AIDS prevention and care for Latinos. The Commission’s public health mission is to impact the HIV/AIDS epidemic, in the context of addressing health disparities, by spearheading health advocacy, promoting health education, developing and replicating evidence-based programs for PLWHA and high-risk communities, and by building capacity across the public health sector including community-based organizations, health departments, healthcare organizations, and universities. The Commission’s unique mission and corresponding model encompasses five service divisions: 1) capacity building assistance; 2) disease prevention and health promotion; 3) access to care (HIV and hepatitis testing, linkages); 4) community mobilization; and 5) research and evaluation.

The HEARD Institute (Hispanic Health Equity: Action Driven Research and Development) amplifies the diverse voices of the Hispanic communities to improve health outcomes through research, evaluation, education and promoting community networks. Our goals are to: increase the amount and quality of research that puts the experience of Latinos at the forefront; heighten the use of analytic and evidence-driven policy and programming; and empower the community to use research as an effective mobilization tool.
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Health is rooted not only in the personal choices we make and our genetics, but strongly shaped by the context in which we live. Take eating your vegetables, a typical example of a “healthy choice”. We know that eating vegetables is healthy, so why don’t we all do it? The reasons why we do not make this healthy choice fall under two main categories – environmental reasons and personal reasons. Personal reasons we are very familiar with. I just don’t like broccoli. Greens make me feel sick. I’m allergic to carrots. Environmental reasons (or structural factors), include things like “The grocery store doesn’t carry fresh vegetables,” “I don’t know how to cook vegetables,” “The vegetables I can cook aren’t at the closest store,” “The vegetables I can cook are at the store, but they are just too expensive.” These reasons are called structural because they are all about Acceptability (not part of my diet), Accessibility (just too expensive), and Availability (the store doesn’t carry them).

3A’s, Acceptability, Accessibility, and Availability define what makes something a “structural factor,” and this applies not only to health-related behaviors like eating your vegetables, but also HIV prevention-related behaviors, like wearing a condom, getting tested for HIV, taking HIV treatment medication if needed, and disclosing to your partner that you have a sexually transmitted infection. In 1993, when the FDA approved the first female condom, there was hope that they would fill a gap in the HIV/STI and pregnancy prevention market as the only female-initiated prevention method. Despite this great need, sales have been “disappointing”, particularly in the west. This is often attributed to their higher cost (accessibility), discomfort and challenges negotiating with their male partners (acceptability) and lack of widespread availability. The usage of a once promising intervention is still relatively low. Whenever a new public health intervention or tool is rolled out, we have to assess how Accessible, Acceptable and Affordable that new tool is to different communities in order for the tool to be effective.

In the following sections, we will present a blueprint of how to assess the 3 A’s for a new public health tool and structural intervention – the OraQuick At-Home HIV Test. We will briefly examine the history of HIV testing, our survey methodology for assessing readiness for at-home HIV testing among ethnic minorities living in New York City, findings from the survey, and key recommendations for implementing a formative community readiness assessment for structural interventions.
**History of the HIV Test:**

**Sixteen Years** after the first discussions of an HIV home test, the Food and Drug Administration (FDA) approved the first actual “self testing” home kit for consumer use – the OraQuick In Home HIV Test. For the first time, populations at high risk for HIV infection, as well as the general public, have the option of taking a hands-on approach to their HIV testing-related behaviors. Despite these advancements, the CDC estimates that around 16% of individuals infected with HIV are not aware of their infection and that this is fueling about half of the new infections in the U.S.

Routine HIV testing, as recommended by the CDC, is recognized as an important public health tool for the general public, those at higher risk for HIV infection and all pregnant women. It has been shown that persons aware of their infection are more willing to make changes in their sexual behaviors that hinder transmission of the virus, such as wearing a condom. With many not aware of their HIV infection, getting more people to know their HIV status through testing could have a significant impact on the HIV epidemic today.

Beginning with the first Enzyme-Linked ImmunoSorbant Assay (ELISA) HIV test kit approval in 1985 by the FDA, the detection of HIV was mostly relegated to the hands of laboratories and doctors. At the time, the complexity of performing these tests required, in the benefit of public interest, that individuals be tested in controlled settings; accuracy could not be warranted without the presence of trained professionals. In fact, in 1988 the FDA made public their opinion that “HIV testing should be limited to professionals only.”

**History of HIV Testing at a Glance**

- **1981:** First cases reported of what would later be identified as AIDS
- **1984:** Human immunodeficiency Virus identified
- **1985:** ELISA test for HIV is licenced
- **1987:** Western Blot blood test kit developed
- **1992:** Rapid test licenced by FDA
- **1994:** Oral fluid test approved, first non-blood antibody test
- **1996:** Home collecting kit & urine tests approved
- **2002:** Finger prick rapid testing approved
- **2003:** Rapid finger prick test granted CLIA waiver
- **2004:** First rapid oral fluid test granted CLIA Waiver
- **2005:** Blood Products Advisory Committee directs FDA to start working with companies to bring HIV OTC products to the market
- **2006:** BPAC agrees upon requirements for an OTC HIV test
- **2006:** CDC recommends routine HIV screening in U.S. health care settings
- **2007:** CDC launches Expanded HIV testing initiative in the U.S.
- **2007:** WHO/UNAIDS global guidelines recommend routine HIV screening in health care settings
- **2008:** Completion of observed use trial submitted to FDA
- **2009:** BPAC votes to allow unobserved trials (phase III)
- **2010:** First test approved that detects both antigen and antibodies
- **2012:** First rapid oral fluid home test
- **2013:** USPSTF gives routine HIV screening an “A” rating
- **2013:** First rapid test approved that detects both antigen & antibodies, & distinguishes between acute & established HIV-1 infection

**Where are We Today?**
The year 1996 brought us the first urine-based HIV test and the first FDA approved over the counter home test kit, Confide. At the same time, the Centers for Disease Control and Prevention (CDC) released findings that while only 20% of people at high risk for HIV had made some sort of plan to get tested by a professional within the year, only 42% of these individuals would likely use a home testing and counseling service. These findings, in tandem with the availability of the Confide HIV home test, suggested public health benefits to including a home test as part of the “HIV prevention toolkit”. While the availability of the Confide HIV home test provided a step in the right direction, this test still required a lengthy wait period to get results because the urine sample had to be mailed and results were given by the phone, which technically did not make this test a “self-test”. The Confide HIV home test was taken off the market in 1997.

Since that time, technology in HIV testing has advanced shortening not only the “window period” of testing up to the point where it is possible to detect infections in the Acute Phase, but also making it possible to perform tests in just about any location or time, conducted by any person. In 2002, the FDA approved the first rapid HIV testing kit for use in the U.S. For the first time, non-clinical settings were allowed to utilize this blood test; additionally, tests were now approved for room temperature storage and a drastically reduced “run and read time” allowed a more widespread use of the test. Ten years later, in 2012, OraQuick released the first rapid oral fluid-based in home HIV test, the particular subject of this community readiness assessment. The question now is: how accessible, acceptable and available is this advancement to Latino and ethnic minority communities in New York City?
SURVEY METHODOLOGY

In order to gain insight into how this structural intervention (the rapid HIV home test) might impact ethnic minority communities New York City, we developed a survey using the framework of the 3 A’s of structural interventions.

Acceptability. Questions in this category included: HIV and STD testing history, type of testing used and type of testing facility (private, community based, street), likelihood and comfort using an HIV home test, reasons for testing or not testing, and how often one would use the home test.

Accessibility. Questions in this category included: physically accessibility including closeness to pharmacies, amount willing to purchase the test, likelihood to buy the test via private funds or insurance and knowledge of how to use, read, and confirm the home test.

Availability. Questions in this category included: access to pharmacies that carry the HIV home test and awareness of the test.

Between January and June 2013, the survey was administered to three different cohorts (groups) selected to provide comparison points between segments of the overall population: gay/bisexual men, the religious community and the general public.

Gay & Bisexual Men

As a sub-population with higher risk factors, we recruited Latino gay and bisexual identified men through a community-level intervention called Latinos Diferentes. Members were surveyed prior to one of the weekly workshops offered by the program. This cohort ranged in age between 18 years and their mid 40’s, were mostly first generation immigrants and openly identified themselves as Gay men, both HIV positive and negative. This cohort gave us insight from a population that is both actively and passively in contact with recent HIV information, testing procedures and advancements.

Religious Community

The religious community is a powerful messenger for information in the Latino community, including health information. With more than 80% of Hispanics identifying with a particular religion, religious communities around the nation have the attention of a large majority of the Latino community with the potential to impact various behaviors. Through our Latino Religious Leadership Project, we recruited religious leaders to complete the survey. Respondents ranged in age between 18 years and their mid-70’s, and more often identified as heterosexual. This cohort gave us insight from a population that is connected to both the HIV community, as well as the larger religious community.

General Public

In order to get the general public’s knowledge, attitudes, awareness, and planned behaviors regarding the HIV home test, we utilized a street-intercept approach and recruited residents in the Latino-populated neighborhoods of Jackson Heights (Queens) and Washington Heights (Manhattan). Individuals were intercepted in high traffic areas, such as bus stops, train stations, and commercial avenues. All genders and those 18 years of age or more were targeted for this cohort. This gave us insight from a population that may not necessarily interact with an AIDS service organization regularly.
Surveys were available in both English and Spanish and the respondents were provided with the option to choose the survey language. The survey was self-administered allowing respondents to answer without bias introduced by the surveyors.

We analyzed the data in two ways: first we used descriptive statistics to understand what the common responses were to each question; second, we used inferential statistics, including the t-test, chi-square, ANOVA and correlation (as appropriate) to understand if there were any differences in response based on certain characteristics, i.e. were there differences in how likely to use the test based on if one was born in the US or abroad?

The main responses we examined were: 1) awareness and access to a pharmacy that carries the test (availability); 2) likelihood of using the home test and comfort using the test (acceptability); and 3) knowledge of use, price point, and distance to the nearest pharmacy (accessibility). We assessed differences in these responses based on cohort, gender, sexual orientation, age, place of birth, being sexually active, relationship status, or past use of at-home tests.

### Assessment Findings

#### Who Completed the Survey?

It is crucial as we interpret the findings to understand whom the findings represent. Keep in mind that we utilized a convenience sampling method, thus what we find here does not reflect what you may find in your community. Across the three cohorts described above, we collected 76 surveys (34 from the religious community, 25 from the general public and 17 from the gay/bisexual program).

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mixed or “other” race</td>
<td>30%</td>
</tr>
<tr>
<td>Spanish Speaker</td>
<td>68%</td>
</tr>
<tr>
<td>Average age in years</td>
<td>44.2 years</td>
</tr>
<tr>
<td>Gay or Bisexual</td>
<td>21.2%</td>
</tr>
<tr>
<td>Born Outside U.S. or Territories</td>
<td>62%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>85%</td>
</tr>
<tr>
<td>Female</td>
<td>50%</td>
</tr>
</tbody>
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Across these cohorts, 85% identified as Hispanic or Latino, with about 10% not reporting ethnicity. The majority of respondents listed Spanish as their primary language (68.4%), and 6.6% reported being bilingual in Spanish and English. Overall, 61.8% were born outside the US and its territories, representing 12 Latin American countries, the most common being Dominican Republic.

In terms of race, respondents identified as white/Caucasian (18.4%), “other race” (17.1%), mixed race (13.2%), and African American (5.5%). Only about half of all respondents answered the question of race.

As with race, only about half of all respondents reported their sexual orientation; 34.2% of the entire sample identified as straight and 21.2% as gay or bisexual.

As for gender, 50% of respondents identified as female, 43.4% as male and 1.3% and male-to-female transgender (the remaining did not specify).

There was a wide range of ages represented (18-77 years), averaging at 44.2 years.
Acceptability

The HIV home test appears to be relatively acceptable among our sample, with high levels of previous testing but moderate levels of comfort and likelihood of using the at home HIV test. However, likelihood of using the test is influenced by sexual activity, past experience with home screening and place of birth.

Relative to New York State, this sample reported higher rates of HIV testing with 65.8% reporting having tested before, compared to 43.2% of all New Yorkers. A plurality experienced a blood test (43.4%) with 26.3% using an oral test; only 3.6% reported using a finger stick. There were no differences in history of testing by cohort.

As HIV testing is now “routine” in New York, one might expect that most people are testing in clinic or hospital settings. However, we found in this sample that the majority of respondents who tested were tested in either a community setting (35.6%) or a health department setting (28.8%), suggesting the continued need to have testing available outside of medical settings.

One of the main indicators of acceptability is comfort. We asked respondents how comfortable they were in taking the HIV home test. While about 45% of participants noted feeling at comfortable with taking the home test, almost 25% reported feeling not comfortable. Comfort did not differ by cohort, past HIV testing, whether respondents were sexually active or not, relationship status, past use of home screenings, gender, sexual orientation or place of birth.

How Comfortable Are You With Taking an HIV Test at Home?

In addition to comfort, we directly asked respondents how likely they are to use the HIV home test; we found a fairly even distribution of responses, although a plurality were likely to use the home test.
How Likely Are You To Use the OraQuick In-Home HIV Test?

Sexually active respondents reported significantly higher likelihood of using a home test, compared to those not sexually active. Additionally, if one had used a home screening test before, one is significantly more likely to test as well. Finally, those born outside of the US and its territories were significantly more likely to use the HIV home test.

Who is significantly more likely to use the HIV home test?

* Sexually Active
* Previous use of home screening kits
* Those born outside U.S. and Territories

We also asked respondents why they would take an HIV home test. Largely, respondents wanted to use the home test for speed and privacy. In terms of reasons why they would not use the home test, respondents noted two main reasons: 1) that they did not want to think about HIV testing and 2) that they were not sure what to do if they received a positive result. We would also like to note that very few people indicated discomfort in buying the test at a pharmacy as being a barrier to at-home testing.
Accessibility

In terms of accessibility, the home test seems to be physically accessible, however not financially accessible. Additionally, it appears that knowledge of reading and using the test are quite low.

In terms of physical accessibility, we examined respondents’ distance to local pharmacies. To do this, we asked participants how far their pharmacy is from their homes. After eliminating one outlier, the average distance to their pharmacy was 3.6 blocks, ranging from 1-25 blocks. The most common distance was two blocks. We found that the distance to the pharmacy was not significantly related to comfort, likelihood to use, frequency of using and awareness of the HIV home test; this is possibly due to the finding that the majority of respondents (88.9%) listed a distance between one and three blocks, so there was very little variation.

Another aspect of accessibility involves one’s ability to use the test once acquired – accessing accurate results. We assessed this aspect of accessibility through questions that tested respondents’ knowledge of the valid time to test after potential exposure to HIV, reading the test, and what to do if one tests positive.

As the home test is an anti-body test, it takes at least three months post-exposure for the test to be considered accurate; thus, three months is the valid time to test after potential exposure. We asked respondents how long after exposure would they use the HIV home test. In this case, only 18.4% of respondents answered correctly, with 50% saying they would take the test immediately. There were no significant differences in correctly answering the question based on gender or previous use of home screening kits.

In terms of reading a test result, while 88.6% of those who responded to the question correctly read the result, nearly half of respondents did not complete this question. Being that the survey did not include an “I don’t know” option, it may be that part of the non-response is due to uncertainty. It does seem, however, that those who think that they know how to read the test result actually do so. Of note, both women and respondents who reported using home screening tests in the past were significantly more likely to correctly read the test, possibly due to experience with pregnancy or diabetes tests.

One of the main concerns that HIV providers have regarding the HIV home test is how individuals will respond when they receive a positive result. To examine this concern, we asked participants “if someone you know received a positive HIV test result at home, where would you send them for help?”
As this was an open-ended question, we were able to collect a wide variety of responses, which ultimately described both where one would send a person testing positive and the reasons one would make this recommendation. After coding responses, a plurality of those surveyed affirmed that they would send a person with a positive HIV result to a primary care doctor. The second most common response was to send the person to a community-based organization that is recognized as providers of HIV testing or HIV/AIDS related services. Some of the reasons for recommending seeing a doctor or a community base organization were to get a confirmatory test, to get additional information from a health provider or to get emotional support be it from counselor or religious figures. Overall, this points to participants’ knowledge of the need to follow up with a health professional and finding some form of community support.

The HIV home test does not appear to be affordable to individuals in this sample. At the time of the survey and continuing today, the OraQuick in-home HIV test costs around $40. Respondents were asked how much they would pay for the test. While earlier we noted that nearly 45% were likely to use the HIV home test, only 7.9% of respondents indicated that they would pay within the range of the actual cost ($30-$50). However, 65.8% of respondents reported that they would get the test if their health insurance covered it. Those that would not get the test even if their insurance covered it were significantly more likely to be 1) women, 2) born outside the US, PR or the Virgin Islands and 3) state that they would not buy the home test at any price.

There were several additional factors related to preferred price points. Do note however, that in none of these groups did more than 15% of the group indicate they would pay the $35-$40 for the test.

- First, there was a significant difference by cohort, where those in the gay/bisexual cohort reported a willingness to pay more compared to those in the religious community cohort.

- Second, those who had used a pregnancy home test in the past reported a willingness to pay more compared to those who had never used a home health test.

- Third, age was correlated with willingness to pay, where the younger respondents were willing to pay than older respondents.

- Finally, a higher price point was significantly correlated with increased likelihood of using the test, and increased frequency of using the test.
Availability

Based on our findings, it appears that availability of the HIV home test is variable; there is moderate awareness of the availability of the test, however there is a sizable minority that utilizes small, neighborhood pharmacies, which may or may not have the HIV home test stocked.

Overall, 59.2% of our respondents were aware of the HIV home test. There was no difference in awareness based on cohort, gender, sexual orientation, age, place of birth, being sexually active, relationship status, or past use of at-home tests (such as glucose or pregnancy).

In terms of physical availability, we examined respondents’ use of pharmacies. The OraQuick in-home HIV test launched in October 2012 in about 30,000 stores, including Walgreens, Walmart, CVS, Kroger and Rite Aid. Based on our findings, the majority of our sample utilizes these pharmacies. However, a sizable minority of respondents (about 23%) does not use these pharmacies; instead they list local, neighborhood stores.

CVS - 34.2%, RiteAid - 23.7%, Others - 19.7% Walgreens - 6.6%, None - 3.9%, Walmart - 2.6%

Summary and Recommendations

In assessing the 3 A’s of the HIV home test, a structural public health intervention, we uncovered five key findings that have the potential to impact future campaigns, programming, patient advocacy and financing.

While the home test seems to be generally physically accessible, it appears that knowledge of reading and using the test are quite low. This is a concern that has been voiced from the beginning. Educational materials and posters should have messaging around the “window period” to build people’s sense of efficacy and accuracy in using the HIV home test. As less that 20% showed that they use the test correctly, it is imperative that educational efforts address this knowledge gap in order for the home test to make the greatest impact on diagnosis. Additionally, materials should have examples of positive and negative HIV test results; this messaging should be targeted towards men based on the finding that they were significantly less likely to accurately read the test result.

The HIV Home test does not seem to be affordable at its current price point, however the cost vs. perceived value balance may be tipped by finding ways to subsidize cost through insurance or utilizing home test kits through community based organizations for a discount. This is the main barrier for this structural intervention to be successful among ethnic minority New Yorkers and must be considered simultaneously with the following findings and recommendations.
Overall, respondents showed moderate levels of comfort and likelihood to use the at home HIV test; likelihood to test was related to perceived risk (being currently sexually active), having past experience with home screening, and to those born outside the US and its territories. There will never be an intervention that is 100% acceptable to all people. Home testing should be seen as one tool in the prevention toolkit that may have particular impact on those ethnic minority New Yorkers who feel they are at risk, feel that they know what the test will be like, or were born outside the US and its territories. This includes campaign and educational material messaging and developing procedures among staff working with clients and their partners.

Largely, respondents wanted to use the home test for speed and privacy. This finding resonates with the stigma associated with HIV/AIDS. While New York City has a wide range of places to confidentially test for HIV, privacy does remain a key concern for people. Community based organizations are valuable in this regard where they often offer free, walk-in testing in a safe space. The home test provides an opportunity to reach more individuals who want the utmost privacy of testing in their own homes. There are many avenues to incorporate this finding into an organizations services; this may include training those who come into an organization for testing to discuss and teach their partners how to use the home test, or building non-AIDS service organizations’ (community centers, businesses) awareness of the home test as a health tool for their clients, customers or staff.

Very few people indicated discomfort in buying the test at a pharmacy as being a barrier to at-home testing. This could indicate lower levels of stigma. At the same time, a large minority of respondents mentioned that they primarily go to neighborhood pharmacies. Community advocates should be aware of which pharmacies do not have the HIV test in stock and actively request that the pharmacy begin carrying the test.

Does your pharmacy advertise the test?

Achieving healthy communities requires us to create environments that make it easy and safe for individuals to choose their own path to wellness. This is the role of the structural public health intervention. Whether we are concerned about diabetes, heart disease or HIV/STDs, one size does not fit all when it comes to such interventions, thus it is crucial that we assess potential impact to various communities, especially those that are vulnerable, marginalized or stigmatized.

Acknowledgements

The Latino Commission on AIDS and the HEARD Institute are grateful to all those who participated in this formative community readiness assessment. These data were collected to assess incorporating the HIV home test into our community programs; as data on this level is generally not available to community based organizations, we are pleased to share our process and findings with the broader community.

The Latino Commission on AIDS and the HEARD Institute are eager and available to lend expertise in developing, implementing, analyzing and interpreting findings. Contact us at heard@latinoaids.org.
References


v. Ibid.


xi. Department of Epidemiology, University of Washington, Seattle, WA, USA


xiii. Federal Register, 2/17/89 (54 FR 7279), Blood Collection Kits Labeled for Human Immunodeficiency Virus Type 1 (HIV-1) Antibody Testing; Home Test Kits Designed to Detect HIV-1 Antibody; Open Meeting.


xxiv. One respondent noted a distance of 83 blocks from their pharmacy, which is significantly higher than the next farthest distance, 25 blocks.

xxv. From an October 2012 presentation to the Latino Commission on AIDS by Andrew Thomits of Ora-Sure.