

Seattle RARE Project

Rapid Assessment, Response and Evaluation

Final Report and Recommendations

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Executive Summary

Background

In Seattle-King County, as in the U.S. as a whole, epidemiological data indicate that HIV and AIDS are disproportionately affecting African Americans and foreign-born Black immigrants (hereafter referred to as Blacks). Overall, the percent of HIV/AIDS cases among people of color has risen steadily since the early years of the epidemic in King County, going from 13% of cases in 1984-86 to 26% in 1993-95 and 35% in 1999-2001. Blacks, increasing 4.5 times more likely to be infected with HIV than whites, are the most disproportionately impacted racial group. About 2% of Black men and 1% of Black women in King County are currently living with HIV/AIDS. Foreign-born Blacks comprise an increasing share of the infections among Blacks in King County. In light of these data, Public Health—Seattle & King County decided to assess the HIV prevention needs of the Black community in order to provide more effective prevention services.

At the request of Executive Ron Sims, King County applied for and received money from the Department of Health and Human Services to conduct an in-depth HIV prevention needs assessment of the local Black community called the RARE Project (Rapid Assessment, Response, and Evaluation). RARE draws on the resources of both the Public Health agency and the community for an effective data gathering process. The project was overseen by a Community Working Group (CWG) comprised of local service providers, leaders, and community members with unique experience and expertise in HIV prevention. The purpose of the assessment was to gather information from the community about barriers to receiving HIV prevention services, and to find out how to more effectively address these barriers.

RARE Methodology

By design, RARE projects focus on two geographic sites, with each site being no larger than 22 square blocks. A combination of community expertise and analysis of HIV/STD surveillance data for Blacks in King County quickly focused attention on the two sites selected for study: the 23rd Avenue corridor in the Central District of Seattle (CD) and the south end of Rainier Avenue from Orchard to Henderson. These two sites were selected based on community expertise and because they have the highest rates of HIV and STD infections for Blacks. Using the standardized RARE methodology, a team of 6 field investigators undertook mapping and ethnographic observations of the sites and conducted interviews, focus groups, and street intercepts with members of the priority population, service providers, and policy makers.

Barriers to HIV Prevention

The 84 one-to-one interviews and 18 focus groups provided the comprehensive information about the community's current knowledge and perceptions of HIV prevention in their neighborhoods. Street intercept surveys with 109 community members provided additional detail on specific issues raised during the assessment. Overall, community experts, service providers, and community leaders from both sites were cohesive in their assessment of current HIV prevention efforts and suggestions for improvement.

The assessment yielded the following findings:

- 1. People know the basics of HIV transmission, but myths remain:** Although participants expressed a basic knowledge of HIV transmission through unprotected sex and injection drug use, many also related varying levels of transmission myths that kept them from feeling personally at risk for HIV or getting an HIV test.
- 2. Stigma and fear drive community attitudes:** Participants clearly identified the powerful sense of stigma and fear surrounding HIV as the root of HIV prevention barriers for their community. Many cited the church's historically negative stance as both a cause and perpetuating factor of the shame around HIV.
- 3. Distrust and mistrust of HIV prevention work:** Participants expressed a great deal of distrust of HIV information and testing efforts. In particular, they did not trust information distributed by the government or by white people – often citing the belief that HIV was designed as a tool for the “genocide of black people”.

Executive Summary

4. **Invisibility of HIV and lack of services:** The community perceives a distinct lack of accessible HIV prevention information and testing services in their neighborhoods, and cites the invisibility of the HIV as a major factor in the epidemic's growth.
5. **Educate Educate Educate:** The community overwhelmingly supported the need for HIV education "anywhere and everywhere". Specifically, closely matched peer education was seen as the key to effectively promoting HIV prevention.
6. **Confidentiality is essential:** Confidentiality is an overriding concern for the community when considering HIV testing. Because of the stigma associated with HIV, community members do not want to be seen getting tested or, in some cases, actively seeking information about HIV.
7. **The Testing Catch-22:** The counseling and testing aspects of HIV prevention remain the most difficult to provide in the Black community because of prevailing community norms, the lack of accessible and acceptable testing facilities, and fears of confidentiality.
8. **Need for leadership:** Participants described the urgent need for leadership around HIV prevention, so that the issue would move to the forefront and be addressed. They identified two main sources of potential leadership: churches and mosques, and a community-wide effort led by trusted elders and teachers.
9. **Subpopulations present their own barriers:** While several community subpopulations at risk for HIV share the overarching report findings, particularly those related to the need for peer education and outreach, they also presented barriers unique to their background or circumstance. The subpopulations included in RARE were formerly incarcerated men, African immigrants, women, youth, and gay men.

Recommended Action Steps

Based on the findings, the Community Working Group recommends the following action steps. [More detail on these action steps can be found in the body of the report.]

Action Step 1: Incorporate RARE findings in 2004-05 HIV Prevention funding cycle.

- 1.1 Encourage programs funded through Public Health to use the RARE findings to guide program development.
- 1.2 Fund a program that specifically focuses on the HIV prevention needs of African Immigrants.
- 1.3 Ensure that Allocation Panel for 2004-05 HIV Prevention funding considers the RARE Project findings and actions steps in their funding recommendations.

Action Step 2: "Back to Basics" outreach: Increase the presence of one-to-one HIV prevention/ education outreach in each of the RARE Project sites.

- 2.1 Emphasize outreach in the current funding cycle.
- 2.2 Generate additional resources to increase peer outreach.

Action Step 3: Implement a media campaign to increase the visibility of the epidemic.

Action Step 4: Adapt HIV Counseling and Testing to increase availability and enhance confidentiality.

- 4.1 Increase availability of HIV Counseling and Testing (HIV C/T) at multi-use service centers and as part of general health screening services.
- 4.2 Increase availability of HIV C/T in publicly funded clinics that serve the needs assessment sites.
- 4.3 Increase availability of rapid testing in the African American community.

Action Step 5: Increase leadership and clergy involvement in HIV prevention efforts.

Action Step 6: Increase the level of HIV prevention services available in both RARE sites.

I. Introduction

The Rapid Assessment, Response, and Evaluation (RARE) Project was established to provide multidisciplinary technical assistance to cities whose racial and ethnic minority communities are struggling with the devastating effects of AIDS. The RARE project is designed to work in partnership with local community officials, public health personnel, and community leaders. The RARE Project assists communities to identify potential strategies to enhance prevention, to maximize community health services and support networks targeted at HIV/AIDS issues, and to provide access to care for the most vulnerable populations.¹

In Seattle-King County, as in the U.S. as a whole, epidemiologic data indicate that HIV and AIDS are disproportionately affecting African Americans and African-born immigrants. Due to these rising rates, Public Health–Seattle & King County recognized the need to better understand how to provide HIV prevention services to the Black community living in King County.²

At the request of Executive Ron Sims, King County applied for and received money from the Department of Health and Human Services (DHHS) to conduct an in-depth HIV prevention needs assessment of the local Black community called the RARE project (Rapid Assessment, Response, and Evaluation). By design, the project focuses on two geographic sites within the county, with each site being no larger than 22 square blocks. Using the standardized RARE methodology, a team of field investigators undertook mapping and ethnographic observations of the sites and conducted interviews, focus groups, and street intercepts with members of the priority population, service providers, and policy makers. The purpose of the assessment was to gather information from the community about barriers to receiving HIV prevention/education services and HIV counseling and testing, and to find out how to provide these services to the local Black community.

This report begins by briefly presenting the multiple data gathering methods and steps that are part of the RARE methodology, including the number and demographics of community members that participated. It also describes the two neighborhoods chosen for the RARE study, the Central District and Rainier Valley neighborhoods. RARE findings are presented in two sections: observation results and findings from the interviews, focus groups, and surveys. Overall, findings from both sites yielded very similar results and are presented cohesively in both of these sections. The report ends with a set of action steps designed to turn the findings into concrete recommendations for how to effectively address the rising HIV epidemic in King County’s Black Community.

¹ RARE Handbook, Page 3.

² Because Seattle has an increasing population of people of African descent who were not born in the United States, Seattle RARE soon realized that more inclusive terminology than “African American” was needed. Therefore, the term “Black community” is used to describe the population of interest. This includes all people of African descent regardless of where they were born. HIV/AIDS surveillance data refers to this group as “Black, non-Hispanic.” In this project, the term “African American” refers to people of African descent who were born in the U.S. “Foreign-born Blacks” are those not born in the U.S. (e.g., Kenya, Haiti, Cuba, etc.).

II. RARE methodology

*The Rapid Assessment and Response (RAR) model, initially developed as an effective qualitative evaluation tool in the fields of anthropology and public health, has been applied to emergent health crises in primarily developing countries. For over 30 years, the World Health Organization (WHO) and other public health entities have implemented RAR techniques to successfully address a wide range of public health issues . . . The assessment methods used in RARE are drawn from the following key features of the RAR model: epidemiology, ethnography, survey research, and evaluation strategies. . .*³

The RARE methodology uses a combination of observation, interviews, focus groups, and street intercept surveys to determine the barriers to HIV prevention and possible action steps to improve local services. As a site-specific study, RARE fieldwork is limited to two designated RARE sites, each of which cannot be larger than 22 blocks. RARE draws on the resources of both the Public Health agency and the community for an effective data gathering process.

While the overall RARE process was started with an application for funding to DHHS, ongoing direction was provided by a Community Working Group (CWG) comprised of local service providers, leaders, and community members with unique experience and expertise in HIV prevention. The CWG was involved in the full process, beginning with the initial stages of selecting the two RARE sites. Primary data were gathered within each RARE site by a team of six representative community members, which were directed by a Field Team Coordinator. At the end of this participatory evaluation process, the Field Team and Coordinator presented a set of findings to the Community Working Group, and both groups jointly created a set of action steps designed to ensure that the issues identified in data collection are addressed.

While the main RARE methodology is set forth by the Department of Health and Human Services, it is designed to be adapted to the needs of local areas. This section of the report will briefly detail the following steps involved in implementing RARE in Seattle.

Preparation for RARE:

- 1) Selecting a target population: the Black community, including African Americans and African-born immigrants
- 2) Selecting two RARE sites
- 3) Selecting the Community Working Group
- 4) Selecting the Field Team

Data gathering and analysis:

- 5) Observation and mapping
- 6) RARE participants: Community Experts, Service Providers, Community Leaders
- 7) Interviews
- 8) Focus groups
- 9) Street intercept surveys

Finally, the driving characteristic of the RARE project is its “Rapid” nature. The entire Seattle RARE process, from CWG and field team selection to final report presentation, lasted just over 5 months. While this fast timeline does encourage a timely response to important community issues, it also presents severe logistical hurdles to both effective data gathering and a truly participatory process. Although data limitations related to the Rapid nature of the project will not be fully detailed for each of the following

³ RARE Handbook, Origins of RARE methodology section.

methodology steps, members of the Seattle RARE study would caution other cities to consider these potential difficulties when designing future RARE studies.

1. Selecting a target population: Focusing on the Black community

Public Health–Seattle & King County decided to apply for RARE funding to target the Black community for two main reasons: 1) epidemiological data clearly demonstrates dramatic rises in disproportionate HIV rates, and 2) a growing recognition that the department needed more detailed information about the community to provide effective services.

HIV/AIDS Epidemiology in King County

In Seattle-King County, as in the U.S. as a whole, epidemiological data indicate that HIV and AIDS are disproportionately affecting African Americans, American Indians/Alaska Natives, and persons of Hispanic ethnicity compared to Whites or Asian/Pacific Islanders. Of the total of 8,400 estimated King County residents currently living with HIV infection (including those with AIDS), an estimated 2,250 (27%) are people of color. The estimated number of HIV-infected persons includes roughly: 6,150 (73%) non-Hispanic Whites; 1,240 (15%) non-Hispanic African Americans; 690 (8%) persons of Hispanic ethnicity; 180 (2%) Asian/Pacific Islanders; and 140 (2%) American Indian/Alaska Natives. The percent of HIV/AIDS cases among people of color has risen steadily since the early years of the epidemic in King County, going from 13% of cases in 1984-86 to 26% in 1993-95 and 35% in 1999-2001. This trend has been most evident among African Americans and Hispanic persons.

Figure 1: King County HIV/AIDS cases diagnosed

	King County Estimated population (2000)		No. King County HIV/AIDS cases diagnosed (1999-01)		Average. Annualized Rate per 100,000 population	Rate Ratio (Rates compared to White rate)
White, not Hispanic	1,327,891	76.4%	704	64%	17.7	--
African American, not Hispanic	95,597	5.5%	230	21	80.1	4.5
Hispanic	95,242	5.5%	120	11%	42.0	2.4
Asian/Pacific Islander	203,435	11.7%	29	3%	4.8	0.3
Am Indian/ Alaskan Native	14,869	0.9%	13	1%	29.1	1.6
Total	1,737,034	100%	1,104	100%	18.8	--

As shown in the table above, population-based rates in recent years (1999-2001) demonstrate the epidemic's disproportionate impact on persons of color, with rates in African Americans, Hispanics and American Indian/Alaska Natives being two to five times that of Whites in King County. African Americans have the highest rate (80.1 per 100,000) which is 4.5 times that of Whites. About 2% of Black men and 1% of Black women in King County are living with HIV/AIDS.

The racial disparities are greatest among women. In 1999-2001, the average annual rate of HIV/AIDS for African American females (53 per 100,000) in King County was 24 times that for White females (2.2 per 100,000). Rates for American Indian / Alaskan Native (13 per 100,000) and Hispanic women (12 per 100,000) were also substantially higher than for White women, but these comparisons must be interpreted with caution due to small numbers of cases in American Indian and Hispanic women.

According to King County HIV/AIDS case data (see table below), just over half of Black men living with HIV/AIDS acquired HIV from sex with another man. However, Black men are more likely than White men to have acquired HIV through injection drug use or heterosexual sex with an at-risk partner. Black women are most likely to have acquired HIV through heterosexual sex with an at-risk partner.

Figure 2: Percent of persons living with HIV/AIDS by race and gender for selected HIV exposure categories
(King County HIV/AIDS case data reported through 6/02)

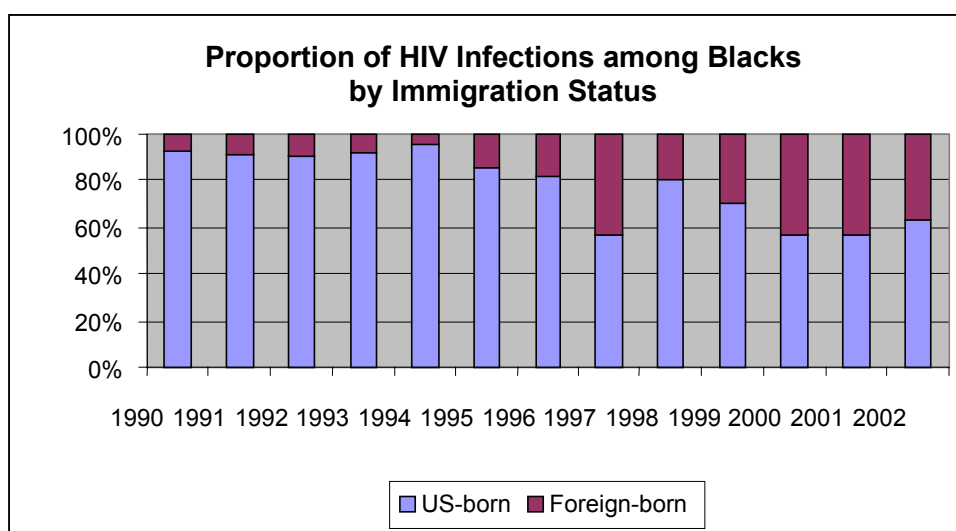
	White	Black, non-Hispanic	Hispanic	Asian	American Indian/Alaska Native
MALES (N = 4,509)					
Gay/bisexual non-injectors	83%	51%	71%	75%	51%
Gay/bisexual drug injectors	10%	7%	6%	4%	33%
Heterosexual drug injectors	3%	14%	10%	4%	13%
Heterosexual at-risk partner, non-injectors	1%	13%	3%	3%	2%
Undetermined or not reported	2%	15%	9%	11%	2%
FEMALES (N =454)					
Drug injectors	29%	21%	5%	0%	67%
Heterosexual at-risk partner, non-injectors	46%	44%	59%	50%	14%
Transfusion/blood product or other known risk	2%	4%	3%	8%	0%
Perinatal exposure	3%	4%	5%	8%	0%
Undetermined or not reported	20%	27%	27%	33%	19%

Seroprevalence data from multiple sources also show the disproportionate impact of the disease on African Americans. In unlinked surveys of King County Harborview Sexually Transmitted Disease (STD) Clinic patients, conducted in 2000-01, 0.2% of heterosexual Whites (n=1504) tested HIV positive compared to 0.7% of African Americans (n=562). Seroprevalence data from unlinked surveys conducted in 1997 to 1999 (when the survey ended) in drug treatment facilities located in King County shows significantly lower HIV prevalence rates among Whites (1.0%) entering drug treatment compared to African Americans (3.2%). In surveys of women giving birth in King County from 1/89 to 5/95 (when the survey ended), the percent of African American women testing HIV positive (0.3%) was 10 times the rate for white women (0.03%).

Information about other STDs is useful in evaluating the risk of HIV transmission because they are an indication of unprotected sexual activity. King County STD data indicate much higher rates of gonorrhea, syphilis, and chlamydia among African Americans compared to Whites. For example, in 1998 the rate of gonorrhea for African American men was nine times higher than the rate for White men, and for African American women 22 times higher than for White women.

Foreign-born Blacks comprise an increasing share of new HIV infections among Blacks. As shown below, until 1995 foreign-born Blacks accounted for only about 10% of new cases among Blacks in King County. Since 2000, foreign-born cases have averaged about 40% of reported cases of HIV/AIDS among Blacks. The transmission risks for foreign-born Blacks differ from those of Blacks born in the U.S. Among Blacks living with HIV/AIDS at the end of 2002, over half (52%) of U.S.-born Blacks indicated either male-to-male sex (MSM) or male-to-male sex and injection drug use (MSM-IDU) as their risk for acquiring HIV. Among foreign-born Blacks, however, the proportion accounted for by either MSM or MSM-IDU risk was nearly 10 times lower (5.8%). Similarly, injection drug use risk is much more common among U.S.-born Blacks with HIV (19%) than among those born outside the U.S. (1%). The main risk categories among foreign-born Blacks were heterosexual sex with someone with HIV (57%) and unknown risk (34%), i.e., no history of known high-risk behavior such as injection drug use, male-to-male sex, or the receipt of blood products.

Figure 3: Recent increase in Foreign-born Cases Among Blacks in King County



2. Selecting two RARE sites

To select the two sites for study, researchers used two methods of data collection. First, the Field Team Coordinator and Public Health Liaison interviewed people knowledgeable about the issue and then looked at HIV/STD data for proposed neighborhoods. The interviews included a wide variety of people familiar with the Black community in Seattle, such as HIV service providers, non-HIV health service providers, clergy, and community leaders. The interviews began with a description of the RARE methodology and then asked participants, based on their personal and professional experience, which three neighborhoods they felt had the highest proportion of Blacks who were engaging in behaviors that put them at risk for contracting HIV. Participants were also asked to explain why they chose those neighborhoods. After they listed their top three selections, the facilitators reviewed some of the other sites that were being mentioned and asked if the participants would change their list. Finally, facilitators explained that each site must be no larger than 22 square blocks and pressed them to put boundaries on their selections.

This process quickly focused attention on the two sites that were eventually selected: the 23rd Avenue corridor in the Central District of Seattle and the south end of Rainier Avenue (See Appendix for maps of each site). All respondents mentioned at least one of these sites in their top two choices, many listed both sites, and almost all put both sites in their top three. Other sites that came up in these conversations were

West Seattle, Kent, and downtown Seattle, although these were not consistently mentioned by all respondents.

A look at the top zip codes for HIV/STD infections in Blacks in King County supports the selection of these sites. The 23rd Avenue and Rainier Avenue sites are in the 98122 and 98118 zip codes, respectively. The table below shows that these sites are consistently in the top three zip codes for HIV/STD infections among King County Blacks.

HIV/AIDS through 2002	Gonorrhea		Chlamydia	
	2000	2002	2000	2002
98104	98118	98118	98118	98118
98122	98101	98122	98122	98122
98118	98122	98101	98178	98031
98144	98144	98144	98101	98101
Homeless	98104	98031	98031	98144

Central District

“The Central District is no longer the center of Black Seattle. The 1960’s prediction of demographers and community activists that Seattle would continue to attract newcomers who would propel the African American population above 100,000 by the mid-1970s was widely off mark.”⁴

As the above quote suggests, the Central District (CD) was a controversial choice for the RARE Project. The gentrification of the historically African American neighborhood in recent years has made the “CD” a sensitive issue with many of its past and present residents. However, it is because of the changing face of the CD that people felt it would be an excellent place to conduct research, in part to determine whether or not the neighborhood is still an effective place to reach Black Seattleites in need of HIV prevention services.

The Central District has indeed changed. Thirty years ago, 16,000 African Americans were residents of the CD. According to 2000 Census data that number has dropped to 7,357, only 25% of the 28,985 Central District residents. In comparison, white residents in the CD now total over 16,500 (57%).

Some see the change as an indication that Black residents of Seattle have come a long way. Historically, racism forced Black people in Seattle to live in either the East Madison or Yesler-Jackson areas. The Black population grew by four times between 1940 and 1950, closing the gap between East Madison and Yesler-Jackson to form what is now known as the Central District.⁵ With recent gentrification, many long-time Black residents of the CD have willingly sold their homes for up to 10 times what they originally paid, financing their retirement, or their children’s college education. But others have been forced to move out due to rising rent and cost of living increases. For example, the median price of a home in the Central District is \$275,000, about \$100,000 more than the median price for a home in the rest of King County.⁶ Two large condominium complexes have recently been erected within the RARE

⁴ The Forging of a Black Community: Seattle’s Central District from 1870 Through the Civil Rights Era by Quintard Taylor

⁵ “Central District: Change is inevitable, but forsaking past is regrettable” by Jerry Lange. *The Seattle Times*, 11/6/2002.

⁶ “Home values rise but black residents are priced out , Influx of whites alters Central District” by Gene Johnson, *The Olympian*, 11/6/2001.

site; both are evidence of the future residents of the CD. Many business owners have also felt “taxed out” of the CD.

Despite it’s changing face, the Central District is still a vital neighborhood for Black Seattleites, and the 22 blocks that comprise the CD RARE site are the heart of this neighborhood. The blocks used for the CD RARE were: both sides of Cherry Street from Martin Luther King Jr. Blvd. to 23rd Avenue; 23rd Avenue from Cherry to Jackson; and 3 blocks bordered by Yesler and Jackson, including Pratt Park.

New businesses offer new opportunities and many old businesses have been able to continue serving the neighborhood. The Starbucks on 23rd and Jackson is more like a community center than a coffee shop; it has established itself as a comfortable hangout spot for African Americans, as well as African-born immigrants. There are established, reputable community centers in the area (The Garfield Community Center, The Garfield Teen Life Center and Langston Hughes Arts Center), a public high school and an alternative high school that both have strong academic records (Garfield High School and Nova High School), a public library and many restaurants, retail stores and beauty shops. There are two clinics in the CD RARE site: Odessa Brown Children’s Clinic and Carolyn Downs Family Medical Clinic. The Central District is also central to other parts of Seattle; it is minutes from downtown and four major hospitals. Many residents utilize the public bus system as their primary mode of transportation.

Poverty in the Central District is common, especially for lower income residents trying to stay in the neighborhood with rising rent costs. The neighborhood is changing economically; there are plenty of older homes in the area, but they are quickly being over shadowed by new condominiums. Depending on the area of the CD, median family income for Black residents in the CD ranges from \$26,831 - \$52,406; in the city of Seattle, the median family income is \$61,162. Much of the poverty in this neighborhood, however, is concentrated among Black residents. Depending on the area of the CD, 27-62% of Black CD families are living below the poverty level, as compared to 6% of all Seattle families.⁷ The average price of rent is \$593; the average price of rent in the city of Seattle is \$749.⁸ As demonstrated in the observation findings section, drugs and prostitution remain part of the neighborhood.

Rainier Valley

Rainier Valley is definitely the most diverse Seattle neighborhood, with 60% of its residents being either African American or Asian American. The community is part of a broader valley that stretches nearly to Renton, an outlying suburb. It is also a neighborhood on the mend after years of economic neglect and white flight.⁹

Historically, immigrants and those looking for cheaper housing prices have populated the Rainier Valley area. In the 1880’s, Seattle’s population boomed with the introduction of the Rainier Avenue Electric Railway. Business developers began to look at Rainier Valley for development because the train ran from Seattle proper into Rainier Valley. Italian immigrants moved into the area in the early 1900s and Japanese immigrants soon followed. During WWII, housing was critically short due to the population boom. The government constructed thousands of low-cost temporary housing units in Rainier Valley. The comfortable neighborhoods became “awash in strangers”. The housing shortage continued for decades. Suburban developments took whites out of the neighborhood, while African Americans moved into Rainier Valley due to discrimination by real estate agents in other areas of the city. The end of the

⁷ The data presented is for Central District RARE Site census tracts 87 – 90 as compared to the Seattle Urban Area. Families living below the poverty level statistics are presented for Black families compared to the general Seattle Urban Area families: 2000 Census. American Fact Finder. www.census.gov.

⁸ Rent averages are from the 2000 Census, and compare zip code 98122 (CD) with the Seattle Urban Area.

⁹ Seattlepi.com “Webtowns”.

Vietnam War in 1975 brought in refugees from Indochina and Latinos began to take advantage of good property values, making Rainier Valley multicultural and multilingual.¹⁰

Today, Rainier Valley is home to 40,409 residents, 29% of whom are African American, and has not yet experienced the gentrification pressure present in the Central District Area. The neighborhood is very ethnically and racially diverse. The number of African immigrants living in King County has been estimated to be 20,000. A Public Health–Seattle & King County survey sent to known African immigrant residents found that most are from Somalia and Ethiopia.¹¹ Businesses that cater specifically to African immigrants can be found lining Rainier Avenue.

The 22 square blocks used for Rainier Valley RARE border both sides of Rainier Avenue from Henderson to Orchard Street. (See Appendix for maps.) Public transportation runs frequently up and down this major thoroughfare, making it fairly easy for residents to access other parts of Seattle, although transportation to downtown employment still takes longer than in the closer Central District neighborhood. It is lined with old and new businesses, advertising billboards, apartment buildings, and many vacant lots and buildings. Many of the neighborhood’s public institutions are located in the RARE site. Rainier Beach High School and South Shore Alternative High School are a vital part of the community, as is the Rainier Beach Community Center. A few small clinics and dental offices can be found there, although there are no public health clinics or HIV prevention agencies in or nearby the RARE site. There are many retail shops, beauty shops, and a few financial institutions in the neighborhood. The south end of the RARE site hosts two large grocery stores, several fast food restaurants, and a public library.

The biggest news in Rainier Valley is the proposed Light Rail system, which will run down Rainier Avenue. There are mixed feelings about this project; some residents welcome the \$50 million in public money to offset the effects of the rail system, while some feel it will only bring gentrification, making it impossible for people to afford to stay in Rainier Valley. Some say that Rainier Valley is heading for the same future as the other Seattle RARE site, the Central District.

Poverty is also a problem in the Rainier Valley RARE site, although surprisingly, median incomes are slightly higher than in the CD, averaging almost \$46,000. These higher median income figures may be influenced by the Rainier Valley’s proximity to Lake Washington, which results in the incomes of residents with desirable lakefront property being included in these calculations. Depending on where families live in the Rainier Valley site, the percentage of Black families living below the poverty level ranges from 16 – 27%, which is slightly lower than the range for CD families, but still much higher than the overall Seattle percentage of 6% families living in poverty.¹² The average rent, however, is slightly higher at \$615, again possibly influenced by included waterfront property.

¹⁰ Historical information provided by www.historylink.org .

¹¹ “African Immigrant Project: Final Report”, March 4, 2003. Dr. Robert Wood with Dr. Das Eteni

¹² The data presented is for Rainier Valley RARE Site census tracts includes census tracts 111.02 and as compared to the Seattle Urban Area. Median income for census tract 111.02 is \$46,863 and for census tract 118 is \$46,111. Families living below the poverty level statistics are presented for Black families compared to the general Seattle Urban Area families: 2000 Census. American Fact Finder. www.census.gov .

3. Selecting the Community Working Group

The Community Working Group (CWG), which acted as an advisory board for the project, consisted of many of the individuals who provided information during the site selection process. Members of the African American Health Leadership group were also invited to participate. A final working group of 12 members convened on March 17, 2003 to gain an overview of the RARE process from the federal Project Officer, and to begin a preliminary discussion of priority sub-populations and list of possible questions. The CWG included officials from Public Health—Seattle & King County, executive directors of health organizations that focus on communities of color, HIV prevention and care providers for the Black community, clergy, and representatives of the African immigrant community. (For a full CWG list, please see the roster listed on the acknowledgements page.)

The Community Working Group remained involved throughout the RARE process, meeting a total of four times. In keeping with the participatory RARE process, however, the Field Team was eager to access the CWG's knowledge, and individual CWG members chose to participate in a variety of additional ways. For example, the main interview questionnaires were emailed to all CWG members prior to use, and many members provided helpful feedback on wording and subject both via email and subgroup meetings. CWG members allowed use of their meeting space for focus group and field team meetings, and also participated as focus group leaders when their expertise was crucial to focus group success. Finally, several CWG members provided access to key community leaders for interviews.

4. Selecting the Field Team

For a successful RARE project, the Field Team must represent the community of interest. As Seattle RARE took a broad focus on the Black Community as a whole, the selected Field Team needed to include a variety of the characteristics of subpopulations that particularly interested the Community Working Group. The selected field team members incorporate the following characteristics:

- People who had both lived and worked in one of the selected sites for many years, and who brought invaluable connections to all aspects of the community from community experts to community leaders
- Mix of gender and ages
- People familiar with HIV prevention work – either through current or former employment
- Formerly incarcerated people
- People in recovery
- African-born immigrant representative
- People with past experience or aptitude for the data gathering methods

Six main field team members and one alternate were selected and attended a weeklong, 30 hour training in RARE methods conducted by a DHHS trainer. At the conclusion of the training, the team was split into two groups, so that each group of three had primary assignment to one site. The only requested characteristic that was not present on the Field Team was the presence of a gay Black man. To ensure the strong presence of this essential part of the community, members of the Community Working Group played key roles in reviewing questionnaires, and suggesting important interview/focus group participants, as well as stepping in to facilitate the focus group for gay-identified men.

The final member of the Field Team, the Field Team Coordinator, was selected because of her extensive experience in primary data collection and assessment – particularly utilizing participatory evaluation methods – and familiarity with the RARE areas. Because she was not Black, the Field Team Coordinator concentrated on behind-the-scenes training, preparation, and analytic tasks including: continuous Field Team training, determining field research schedules, developing questionnaires and written material, coordinating with Public Health–Seattle & King County and the RARE project liaison, managing the payroll and budgets, reviewing all field work notes, maps, and tapes, analyzing the data, preparing oral presentations, and writing the final report.

5. Observation and mapping methods

The Seattle RARE fieldwork began by comprehensively mapping both RARE sites in order to better understand the risk behavior that was present, the composition of the neighborhoods, and references that might be made during other data gathering methods. Observation and mapping were conducted in both the Central District and Rainier Valley sites at all hours of the day and night. The three Field Team members assigned to each site were responsible for observing sections of the site in shifts, with at least two Field Team members present at each shift. All daylight hours were covered through both weekday and weekend shifts. The Field Teams also completed night shifts of 9pm-12am, 12am-3am and 3am-6am. The alternate Field Team member was especially helpful in coordinating these observation shifts.

RARE photo badges identified Field Team members at all times they were working in the field, including their observation shifts. The police in each area were alerted to the night shifts of the Field Teams, and were very helpful in providing important safety information. While observation was conducted in all of the 22 square blocks of each site, the field teams identified several “hot spots”: places where there was a concentration of residents and activity at all hours of the day and night.

6. RARE Participants

RARE methodology designates three groups of community members that should be included in the interview and focus group data gathering:

- **Cultural or community experts:** people from the population who have special awareness of a topic that interests RARE. Cultural experts are not only knowledgeable but are willing and able to share their information. They are able to describe and discuss key issues about their culture and can provide special insights into both the process and the rationale for what people do, why they do it, how they do it, where, when, and with whom they do it.¹³
- **Service providers:** Seattle RARE included both providers of HIV prevention and care services, as well as general health and social service providers. The key selection characteristic was that the service providers worked with community members from one or both of the RARE sites, and could provide a unique perspective for the study.
- **Community leaders:** Seattle RARE chose to broadly define this category, including both traditional leaders such as elected officials, principals, and clergy, but also key community leaders such as elders and business leaders that were seen as leaders by RARE site residents.

Community expert demographics

The Field Team was very successful in reaching a wide variety of community members through interviews and focus groups. Although more information is provided in the following sections about both

¹³ RARE Handbook.

of these methods, here is a demographic snapshot of the community experts that participated in focus groups and interviews:

- *Gender:* 61% male, and 39% female
- *Age:* Overall range from 18 to 71 years; with an average interviewee age of 40¹⁴
- *Ethnic background:* 80% African American, 8% African-born, 3% each American Indian and multi-racial, 4% white, and 1% Latina
- 43% of the interviewees had been formerly incarcerated¹⁵
- Participants were from all parts of the community including: grandmothers, youth, homeless, drug dealers/users, people in recovery, business/apartment owners, sex workers, day care workers, parents, students, gay men, etc.

Participating organizations and institutions:

Service providers and community leaders from the following list of organizations participated in either one-to-one interviews or focus groups. These organizations are either located in one of the RARE sites, or serve people who live in them.

Clergy, Deacons, and Imams

Beacon Hill, Tabernacle, Day Star, Emerald City Outreach Ministries, Martin Luther King Baptist, Immaculate Conception, Somali Mosque, Nigerian Mosque, Union Mosque and School, Cherry Hill Baptist, Goodwill Church, Mt. Calvary, General Truth, New Covenant, To God Be The Glory

HIV Service Providers

Brother To Brother, POCAAN, Street Outreach Services, Lifelong AIDS Alliance, Bailey-Boushay House, Public Health Needle Exchange, Public Health–Seattle & King County Educators, Multifaith Works, Harborview-Madison Clinic, Down Low Barbershop Program

Schools and Youth Service Providers

Garfield Teen Life Center, Nova High School, YouthCare–Orion Center, Juvenile Detention, Garfield High School, AAA Academy, Aki Karouse Middle School, YO! Youth Opportunities, Seattle School District–Health Educators, Rainier View Elementary

Community Organizations and Businesses

Rainier Beach Community Center, Everybody Fitness, Communities Against Rape and Abuse, Masonic Brothers, Urban League, NAACP, CAMP, Cherry Street Association, Seattle Neighborhood Group – Crime Prevention, Cherry Fellowship Hall, Starbucks, Somali Restaurant, Chesterfield Pharmacy, Start Corporation, Nigerian Association, SE Youth and Family Center, Ghanaian Association, Kenyan Association, Mary Mahoney Nurses Association, Delta Sigma Theta Sorority, Adopt-A-Street

Non-HIV Health Service Providers

Center for Multicultural Health, Public Health--Seattle & King County, Carolyn Downs, Rainier Clinic, Columbia Health Center, Swedish Medical Center–Providence Campus, SeaMar Treatment Ctr., Virginia Mason

14 Focus group participants were not asked their age, and so cannot be included in the average.

15 Although there were two focus groups specifically conducted with formerly incarcerated men, members of other focus groups were not asked if they had ever been incarcerated – therefore this statistic represents community expert interviews only

7. Interview methods

Field Team members and Community Working Group members used their connections and knowledge of the community to access key representatives of each interview participant categories. The table below details the number of interviews conducted for Seattle RARE project:

	Community experts	Service Providers	Community Leaders
Central District Team	16	15	11
Rainier Valley Team	16	15	11
Total	32	30	22

A collaboration process developed questionnaires to guide the one-to-one interviews. Although field team members were instructed to cover all of the material in the questionnaire, they were able to adapt their interviews to elicit unique information or to emphasize certain sections of the questionnaire. It was necessary to develop a series of questionnaires to adequately address the unique data that could be gathered from different members of the community. For example, separate questionnaires were developed to interview different types of service providers.

Field team members took notes on both the responses and interactions with each interviewee. In addition, the field team requested permission to tape the interviews, and all but two interviewees agreed. This enabled the Field Team Coordinator to listen to nearly every interview, stay current with the progress of the Field Team, and fully utilize the community's exact words in analysis and presentation. Community experts who agreed to participate received a \$20 voucher to a Safeway grocery store. Community leaders and service providers did not receive incentives for interviewing.

Limitations note: Although Seattle RARE was able to access many important community leaders for interviews, the pace of the project made it difficult to access some of the more traditional or highly visible leaders. This resulted in the inability to access specific people whose input was repeatedly requested by both the Community Working Group members and other community members.

8. Focus group methods

Focus groups were facilitated by members of the Field Team or Community Working Group at locations in or near the RARE sites. Participants in each focus group completed anonymous written questionnaires prior to the group conversation that were designed to elicit demographic or personal/organizational information. Participants were invited using both personal invitations and written fliers.

Community expert focus groups

Given the broad community focus of Seattle RARE, community expert focus groups were designed to bring together members of specific subgroups of the community that were of particular interest to the Field Team and Community Working Group. Representatives from both sites, therefore, were invited to each subpopulation-specific focus group. A Field Team member that represented the characteristic in question facilitated each of the focus groups. As there was not a gay-identified member of the Field Team, a Community Working Group member graciously agreed to facilitate that focus group.

Written questionnaires for these focus groups also asked subpopulation-specific questions about personal risk behaviors that participants might not feel comfortable sharing in the group interaction. Participants in these focus groups received a \$20 voucher to either Safeway grocery store or Target. Focus groups were held with the following subpopulations:

- Formerly incarcerated men (2 groups)
- Heterosexual women
- People involved with drugs – buying and selling
- Youth (18 year olds)
- African-born immigrants
- Gay-identified men

Community leader focus groups

Focus groups for community leaders were also organized by unifying characteristic instead of by site. Written questionnaires for these groups included questions about their organization’s involvement with HIV prevention, and suggestions for future strategy. The “rapid” pace of RARE made it particularly difficult to convene focus groups for community leaders, who did not have openings in their schedules. Focus groups were held with the following groups of community leaders:

- Clergy – church leaders
- African-born leadership
- Business owners
- Attempted: African-American leadership organizations

Service provider focus groups

The focus groups for service providers included a greater emphasis on affiliation with a particular RARE site. Written questionnaires for these groups were similar to those of community leaders, and included questions about their organization’s involvement with HIV prevention, and suggestions for future strategy. The public safety focus group invited members of the police force, block watch, and involved community members from both sites. Service provider focus groups included:

- General service providers - Rainier Valley
- General service providers - Central District
- HIV service providers – Rainier Valley
- HIV service providers - Central District
- Public Safety

Action step focus groups

Finally, the field team held focus groups specifically related to possible action steps, held in the RARE sites after the mid-point RARE meeting. This allowed the Field Team to invite interested representatives from all three categories of the community to first hear the RARE findings, and then suggest possible action steps. Feedback from these focus groups provided additional input for the Community Working Group to consider in developing the action steps presented at the end of this report.

9. Street Intercept Survey methods

Seattle RARE conducted two sets of street intercept surveys that were designed to provide more detailed information on themes that were emerging from the other data collection methods. Field Team members worked in pairs to randomly solicit responses from passing community members at RARE site hot spots. Both sets began with basic demographic questions. All survey respondents were Black and 52% were male and 48% were female. Twenty percent of respondents were under 20 years old, 25% were 20-29 years old, 19% were 30-39 years old, 17% were 40-49 years old, and 19% were 50 or older.

The first set of street intercept survey questions focused on several issues that were surfacing in the interviews and focus groups. Sixty-nine people responded to this survey. The survey sought information about the following issues:

- finding out whether or not community members could identify locations for HIV education and testing in their neighborhoods,
- who the community considered “leaders”,
- assessing the seriousness of the HIV “problem” – and determining what types of interactions or education would make the HIV epidemic seem like a more serious issue to the community.

The second set focused on more clearly defining possible emerging action steps. 40 people responded to this survey. The survey sought information about the following issues:

- identifying past messages seen by the community member,
- how to increase the visibility of HIV prevention through the media,
- what would make community members feel more comfortable getting tested for HIV, including testing methods, incentives, and locations,
- where the community generally goes for health care, and therefore might access HIV testing services.

III. Observation findings

Overall, the observation findings in each site were very similar, especially given the public perception that these areas have developed very differently in the past several years. This section, therefore, will report the overlapping major observation themes that were present in both areas, highlighting differences when appropriate.

Observation data were analyzed from the perspective of HIV prevention outreach work: how could this data help potential outreach workers both better understand risk behavior in the neighborhood and learn how to access various groups of neighborhood residents. The field team observations in each site, therefore, were broken down into two categories that each had their own set of activities and behavior: *Street Activity* and *General Community Activity*.

Street Activity is defined as what the field teams observed as people “hanging out” in hot spots; some were simply with friends, playing games, talking, etc. Some were involved in illegal activities such as drug using or selling, prostitution, gambling, etc.

General Community Activity was defined as people going about their business; people who were observed coming into the hot spots of each site to shop, eat, get coffee, go to the library, etc. The activities in each site are as varied and diverse as their populations.

Street Activity

Street Activity took place mainly in each site’s hot spots, although some activity was observed in less obvious places. Street activity was observed in these hot spots during day and night hours. The Field Team members took copious notes and made notations of activity on maps of each site.

Street activity hot spots: The hot spots in each site changed depending on the day of the week and month. The hot spots were particularly busy at the end of the week (Fridays). The hot spots also rotated depending on the time of day; there was more activity after school.

As the Rainier Valley site extends along Rainier Avenue, the hot spots in this area were all intersections along this main arterial:

- the Othello intersection at the north end of the site, adjacent to Grubby’s (a deli and mechanic shop) and Shell Gas Station (number 3 on the RV map in Appendix),
- the Rose Street intersection near the middle of the site, with a major bus stop, local African American bookstore, a restaurant and Somalian grocery, and other local businesses (number 2 on the RV map),
- the Henderson Avenue intersection that marks the south end of the RARE site and borders the local high school, community center, library, and several fast food and grocery stores (number 1 on the RV map).

The hot spots in the Central District were more dispersed throughout the irregularly shaped 22 block area:

- the 6 blocks of the Cherry Street corridor that borders both area high schools and includes several restaurants and gas stations, a local clean and sober club, and the community center (adjacent to number 6 on the CD site map in Appendix),
- 23rd and Jackson intersection that is anchored by the neighborhood Starbucks and adjacent to the neighborhood grocery and drug stores, several social service organizations including another clean and sober club (number 4 on the CD map),

- Pratt Park, the largest park in the neighborhood, that borders Yesler Avenue that provides a major pedestrian route to downtown Seattle, includes the neighborhood public health clinic, and a local housing project (number 5 on the CD map).

In general, these hot spots included bus stops and phone booths. These also functioned as pick up spots for sex workers. Both areas contained vacant lots and abandoned buildings that served as places where people buy and use drugs and where sex workers take dates. These were more numerous and prominent in Rainier Valley. Both sites had “party houses” where people were observed buying and using drugs and doing sex work.

Day Street Activity

During the daytime, most of the street activity involved “younger” people, with about 75% of the people observed being 15-22 years old. In general, this age group could be found at bus stops, phone booths, and fast food restaurants by the high schools. Not surprisingly, the numbers of younger people increased dramatically during lunch time and the several hours immediately after school is out for the day. Drug dealers were most likely to be in this age group. While some younger people were also observed using drugs, the age of users in both sites was more varied and slightly older. The younger set in the Rainier Valley area congregated up and down Rainier Avenue, with heavier concentrations from the intersections at Rose St. to the public high school area at Henderson St. In the Central District, the younger set is concentrated on Cherry and 23rd Avenue, near the community center and Garfield High School.

The gender of residents observed participating in daytime street activity was predominately male in both sites. One of the main differences between the sites, however, was the race of those involved in daytime street activity. The Rainier Valley appeared to have a much stronger concentration of African American and African-born people involved in this activity, with levels that averaged close to 95%. Although Black people were still the majority observed in the Central District (about 75%), there was a marked presence in people of other races.

It was more difficult to tell street activity from general community activity during the daylight hours. Both sites’ hot spots are business districts, so there is always a high concentration of people during business hours. As stated above, much of the observed street activity included youth simply “hanging out”, moving between hot spots, interacting with other youth driving through the areas, and playing outdoor games (basketball primarily) at the community centers.

The Field Team also some observed illegal activity in both sites. The drug activity in both sites during the day was active but did not appear to be adversarial. Many local residents described a scene in which most drug sellers would sell in one area for a few days and then moving to another area. Sellers also seemed to “rotate” with each other depending on the day. Residents confirmed that many sellers would either be arrested or move on before long, usually in a matter of weeks or months. Similar to all daytime street activity, much of the overt drug activity in the CD occurred with a several block radius of the 23rd and Cherry Intersection or in the Yesler Corridor. Rainier Valley drug activity moved more easily up and down Rainier Avenue itself, often with dealers using the bus system for transportation. In both sites, the favored drug activity hot spots also were vacant lots and other sites with multiple entrance and exit routes.

The gangs observed in each area behaved more like cliques: they seemed to know each other and interact with each other on a fairly friendly basis. The Field Team also observed prostitution in both sites during daylight hours. Prostitution in Rainier Valley is concentrated at Rose and Henderson; in the Central District, it was observed up and down Yesler. The sex workers in Rainier Valley are mostly women, while in the Central District, there is a mix of females, males and transgendered people.

Night Street Activity

In general, the street activity observed at night followed very similar patterns to that of the daytime, except it was more easy to see and often more intense. This section, therefore, will concentrate on highlighting the differences found during night observation.

There was an increase in drug activity and prostitution at night, and these activities were easier to spot at night. Night street activity shifted in age and location throughout the night hours. From midnight to 2am, there was a higher concentration of youth out on the streets, especially in Rainier Valley. From 2am to approximately 5am, the sites were somewhat “quieter” but activity still occurred. At about 5am, people “pour” back into the streets. Many are looking for their last fix or last date before heading home.

Demographics were similar to daytime activity, with slight variation. As stated above, the crowd began with a majority of youth and gets older as the night goes on. There were more men on the streets in each site at night. There was also a higher number of sex workers in concentrated areas.

Night street activity had a different character in each site, primarily because the activity was more overt in Rainier Valley than in the Central District. Rainier Valley field team members saw large groups gambling, drinking, smoking marijuana, dealing/buying on street corners. The Field Team was able to easily approach people at night on the streets. It was observed that residents appeared to “own the streets” in this site. Rainier Valley gangs are more “territorial” at night than during the day. Rainier Valley police contacts reported several recent night shooting attributed to gang activity, although none were observed by the field team. People did not seem bothered by the Field Teams’ presence.

In the Central District, however, people on the streets tended to scatter when cars passed, although occasionally there were groups gathering at various spots, out in the open. However, there have been several high profile shootings in the last six months at one of the hot spots, 23rd and Cherry.

Police were seen in each site during daylight hours. However, during night observation, neither field team observed police presence. The police appeared to take a “hands-off” approach to the sites when illegal activity is at its peak.

General Community Activity: Day and Night

Both RARE sites are bustling pedestrian areas that remain vibrant throughout the day. Overall, the general community activity was comprised of people coming to and from each area’s busy business/shopping centers, or youth surrounding the local high schools and community centers.

People observed coming into hot spots on business were diverse, with all ages and a mix of male, female and transgendered. Again, there were more African American and African-born people in on average in Rainier Valley than in the CD. While the 75% of the observed general community in Rainier Valley was African American or African-born, the Central District was much more mixed with races, having “every color of the rainbow at Starbucks.” Gender was also more mixed for the general community, and the age range was wider, including people from high school age to their seventies.

Places observed as being heavy traffic spots for potential outreach were coffee shops, laundromats, gas stations, barber shops and nail salons. The hot spots for daytime general community activity, therefore, overlapped with some of the street activity hot spots. Overall, The Central District RARE site has more clinics and services than Rainier Valley RARE site, and therefore offers more opportunities to reach the general public for outreach purposes.

- In Rainier Valley, the main spots of general community activity were the grocery stores, fast food restaurants, and high school at the Henderson end of Rainier Avenue (number 1 on RV site map in Appendix). Near this intersection, there is also a community center, Rainier Beach clinic (private practice), and an office of the Department of Motor Vehicles. The nearest public health clinic is 40 blocks outside the area and the public library is closed indefinitely.
- In the Central District, the 23rd and Jackson intersection is the busiest general community activity area – it has a Starbucks, drug and grocery stores, and several small businesses (number 4 on CD site map in Appendix). Within three blocks, there is also a library, Seattle Vocational Institute, Carolyn Downs/Odessa Brown Clinic (community clinic), several youth organizations, and the 1504 Club, a clean and sober club. Within a mile of the site boundaries, there is also People of Color Against AIDS Network, several social services organizations, and major hospitals like Providence and Harborview.

IV. Barriers to HIV Prevention Findings

The interviews and focus groups provided the most comprehensive information about the community's current knowledge and perceptions of HIV prevention in their neighborhood. Street intercept surveys provided more detailed information about specific issues. Using these three methods, the Field Team met with 278 community members to answer the following main questions:

- What do people know or believe about HIV?
- Do people recognize/perceive/see any HIV prevention or education efforts in their area – and do they perceive them as effective?
- What do people know or believe about getting an HIV test?
- How can access to HIV prevention (education, information, and HIV counseling and testing) be increased?
- Who should be offering these services, and how should they be offered?

Overall, community experts, service providers, and community experts from both sites were very cohesive in their assessment of current HIV prevention efforts and suggestions for improvement. The findings presented in this section, therefore, are equally true for both sites, and include quotes and references from both sites. Sometimes, however, the responses of community experts, service providers, or community leaders did vary, and those differences are highlighted throughout the text where appropriate.

At a base level, members from all parts of the community talked about a strong presence of stigma and fear around HIV that essentially determines perceptions of the disease and affects all efforts to prevent it. They described a lack of HIV prevention information contradicting this stigma – that the very invisibility of HIV prevention information contributed to the spread of the disease and rise in infection rates. Confidentiality was seen as the key to increasing the community's ability and desire to access most HIV prevention services, and testing in particular.

Although the community had a basic knowledge of HIV transmission, they were still dealing with significant myths about the spread of the disease and its origins, many believing that the disease was a purposefully constructed genocide plan for the Black community. This widespread distrust of government and White people impacted the community's acceptance of education and testing efforts.

The distinction between these two types of HIV prevention services – education and testing - was present in every interview. The community embraced the idea of HIV education – as long as it was culturally relevant and presented by peers. The need for extensive education was strongly promoted by most community members. Counseling and testing efforts, however, presented a Catch-22. The community wanted to be tested in local, community settings that were easy to access and where they felt understood. In apparent contradiction, however, they also wanted to be tested where no one could possibly see them accessing services, know them, or report to the community.

Finally, the community saw the need for clear leadership in the struggle against HIV. Because many perceived a disappointing void in elected or organizational leadership, they instead turned to a wider definition of community leadership meant to engage the entire community in the HIV education process. In particular, participants singled out the need for a stronger leadership role in the religious community, both because of past negative associations and their potential power to change the feelings of stigma and fear surrounding the disease. Participants also focused on the role of elders and teachers as trusted leaders with the ability to engage the community and change the face of HIV in the Black community.

1. People know the basics of HIV transmission, but myths remain

Although participants expressed a basic knowledge of HIV transmission through unprotected sex and injection drug use, many also related varying levels of transmission myths that kept them from feeling personally at risk for HIV or taking preventive actions such as testing.

Most RARE interviews and focus groups began with general questions about HIV to get a sense of the community's base level knowledge of HIV transmission and prevention steps. Overall, community experts did express a basic working knowledge of how HIV is transmitted. When asked how you could get HIV, community experts talked about unprotected sex as a main method of transmission and therefore the need for condoms to prevent the disease. Almost all participants stated that any kind of unprotected sex was risky, including both vaginal and anal sex in that category. A few people, however, didn't realize you could get the disease from vaginal sex with a woman, instead believing that only anal or "gay" sex would transmit the virus. Many participants were unclear about the risk level of oral sex, and tended to either not come to a conclusion or ask the interviewer for their opinion.

Participants also clearly linked drug use with HIV transmission. They knew that HIV was spread "by blood" and talked about the risk of sharing needles. Most also described any drug use as risky, including crack use, both because people are more likely to make poor decisions and because many drugs are an aphrodisiac. People in recovery were particularly clear about the risky sexual behavior they engaged in while they were formerly using substances such as crack.

In addition to any basic knowledge, however, many participants held myths about HIV transmission. Some equated HIV transmission with any type of body fluid exchange, such as playing basketball with someone who was sweating or sharing saliva with someone by sharing a cup. Although very few of the participants made overtly hostile statements about HIV+ people, those who related transmission myths were more likely to express fear about being near HIV+ people and less likely to talk about how the community needed to be inclusive and supportive. Other participants worried about getting HIV from needles in medical settings, either because of sloppy handling or because of a deliberate plot to spread HIV to the Black community. Many related stories about mismanaged medical procedures for members of their community. Also influential were perceptions that HIV was a "white" or "gay" disease, and therefore it was safe to have unprotected sex with someone who was Black, particularly Black women.

Personally I think its a problem – but community at large don't take it as seriously. It may be in our heads but its not in our hearts.

Very few of the people interviewed felt that they were personally at risk for HIV, even if they were sexually active or currently using drugs. The transmission knowledge that they could express at the beginning of the interview did not translate into a sense of personal risk or preventive actions such as testing by the time these questions were reached at the end of the interview. Although many community experts said that "anyone who had sex" or "did injection drugs" could get HIV, most said that gay people, sex workers, people with multiple partners, or people with heavy drug problems, were really the ones at risk. These answers demonstrated how the perception of immoral behavior as a basis for HIV was part of people's basic HIV awareness, and influenced their perception of personal risk: I am not gay, using heavy drugs, a prostitute, or highly promiscuous, therefore I am not really at risk for HIV.

HIV is seen as a gay man's disease – so if I am not gay, I don't have to worry about using a condom. My pastor said it and gave me some scripture to back it up.

2. Stigma and fear drive community attitudes

Participants clearly identify the powerful sense of stigma and fear surrounding HIV as the root of HIV prevention barriers for their community. Many cited the church's historically negative stance as both a cause and perpetuating factor of the shame around HIV.

Over and over, participants stated that the barriers to HIV prevention were a result of the stigma and fear that surrounds HIV in the Black community. Participants often began spontaneously using the words stigma, shame, and fear from the beginning of interviews or focus groups, and later, direct questions about stigma elicited some of the most intense reactions across the realm of participants. Participants talked at length about how these powerful community responses kept people from all types of HIV prevention – from simple steps like talking about HIV in the community, to more overt actions such as choosing to be tested.

Whether or not they agreed with the community norm, almost every community expert, service provider, and community leader described how the general Black community strongly equated HIV with immorality or immoral behavior. The perceived community definition of “immoral” varied across interviews; some participants included promiscuity and drug use, while most included “gay behavior”. This type of stigma also increased the belief that most community members were not at risk because they “didn’t do anything like that”.

Participants said the levels of shame associated with HIV could vary with the transmission method in question. For instance, interviewees described situations where people would rather claim they got HIV from drug use than from “gay sex”.

Because of the links between immorality and transmission, there was also a belief that “if you got HIV you brought it on yourself”. Even deciding to get tested meant that you were admitting to immoral behavior. When asked about this, many participants immediately talked about how “the church” deliberately described HIV as a disease of immorality and would not include HIV+ individuals in the church family. They described sermons that detailed the immorality of HIV+ people and how they were either ostracized from the church, or chose to remain silent about their infection to remain in the church.

If you talk about AIDS it questions their behavior, whether or not you've been using dirty needles, or having sex with men for males, or questioning the male's sexual behavior as far as their preferences or likes or whatever. It brings up a lot of questions dealing with behavior.

The churches are just so judgmental. I always say every church has a few (people who have HIV), but no one wants to fess up – everything is whispered. The churches do have a lot of clout and they are just starting to come around.

Indeed, there was sense of silence about the HIV epidemic throughout much of the community. Participants said they didn't talk about HIV much with their friends or family, except to make jokes about HIV+ people, and they didn't see information about HIV in their community. This silence around HIV contributed to the perception that HIV was not something community members in general were infected with, and therefore there was something shameful about it. This silence appeared to exist even for many who knew someone with HIV. An HIV+ interviewee described how his family still would not discuss his status or his treatments during family gatherings, preferring to believe he is not infected.

A major factor in the community's perpetuation of HIV stigma is that the shame of being HIV positive radiates far beyond the individual. If you have HIV, you not only bring shame on yourself, but also your family, your church, and your community. In fact, participants said

there was much less shame around having family members incarcerated, than having a family member with HIV – particularly if you were an active member of the church. Interviewees described churches that will “pass the hat” for members having trouble with drugs or incarceration, but will not mention families struggling with HIV. This community level shame directly affected HIV service providers’

Yes – of course – because people think it is a death sentence – they don’t have the funding to get the right medications – they are helpless with that – they can kill themselves before that – a lot of people would rather not know.

I know that HIV is a virus that has no cure. It always always develops into AIDS, which is a death warrant.

ability to do HIV prevention work. Many service providers said that when they discussed the growing epidemic as part of their job, they were accused of “contributing to the negative perception of Black people” and “condemning the behavior of African Americans yet again”.

When asked why there was a stigma, many people said that it was because of fear, or started using the words fear and stigma interchangeably in their answer. People were afraid that the community would find out that they were going to get tested and make assumptions about their behavior. They were afraid of how they would cope with HIV if they had it, including how they would pay for expensive medications or deal with the family and community shame. Many participants were also afraid that if they found out that they were positive there would be nothing they could do but die a shameful death.

The words “death sentence” were used repeatedly to talk about the results of HIV testing. Instead, many participants said they would rather not know their status. Service providers recognized the fear of the “death sentence”, and talked about the need to educate the community around the availability of medications and other assistance.

3. Distrust and mistrust of HIV prevention work

Participants expressed a great deal of distrust of HIV information and testing efforts. In particular, they did not trust information distributed by the government or by white people – often citing the belief that HIV was designed as a tool for the “genocide of Black people”.

Although the level of intensity varied, most community experts, and some service providers and community leaders, openly distrusted many aspects of the HIV information they have received. For many participants, this distrust was rooted in the origins of HIV and the belief that the government was covering up the fact that it created HIV by blaming Africa and Black people for its inception. Some participants believed that HIV “got out of the lab” by mistake, and then the government spread a story about HIV originating in Africa to further malign all Black people. Others, however, cited past events such as the Tuskegee Experiment as proof that the government willingly infected the Black community, and had created HIV as a form of genocide or population control for Africans and African Americans.

We are talked to about a weapon of mass destruction in Iraq – and it is (HIV) that was grown in a laboratory. It is very inconclusive that it started in Africa – I have been there before and obviously it would take years to spread. But when it started it didn’t kill people in Africa, it was all over the world – and it was among the drug users and homosexuals. It is the media trying to demonize Africa – the scientists need to tell the truth.

With this as the basis for many people's HIV perceptions, it is not surprising that most of the community said it wouldn't readily believe HIV information if it came from the government or from white people. Instead, people talked about the power of hearing this information from leaders or peers that they trust, or at least from "someone who looks like me." The essential nature of community-led HIV prevention was strong in almost every interview and in all of the focus groups.

This distrust also affected people's attitudes around HIV testing. A few people said they wouldn't get tested because they believed that the government was spreading HIV through the tests themselves, again citing the Tuskegee Experiment. More often, however, participants were extremely wary of giving their names and blood to the government for testing. There was little confidence in the government's ability or desire to keep their status confidential. Participants talked about how testing, "has to be done by Black people, because there is an element of trust - because we know about Tuskegee, Bikini Islands (nuclear testing)."

Yeah – I believe that information is true, that Black people can catch HIV. But I am always wondering in the back of my mind if there is some other way we can catch it that they are not telling us. Its always scary in a way because sometimes I think those scientists don't tell us everything, you know? The real true stuff on everything. Like the SARS disease – they had some shots a while back that only doctors were taking and now there is SARS.

4. Invisibility of HIV and lack of services

The community reports the distinct lack of accessible HIV prevention information and testing services in their neighborhoods, and cites the invisibility of the HIV as a major factor in the epidemic's growth.

If I've never heard about it (the rising HIV epidemic), how can I think it's a problem?



Even though HIV and AIDS disproportionately impacts African Americans and African-born Blacks in King County, members of the community feel they don't see information about the epidemic or HIV prevention education information. Field team members did not find HIV prevention pamphlets, media,

posters, advertisements, or brochures within the two sites during their observation. Information was not readily available at community centers, libraries, or local businesses. During most of field research time, there was little visual information in either neighborhood. The one exception was a mural in a Central District alley that focused on HIV prevention. Its somewhat hidden placement, however, made it obscure enough that even many of the Community Working Group members from that neighborhood were unaware of its existence and its message was lost.

Most community experts, as well as many service providers and community leaders, had no idea that HIV was on the rise in Seattle’s Black community. Many still perceived HIV as a “gay, white disease” that didn’t affect people in their community very much. For some, the rising epidemic strengthened the appearance of HIV as Black genocide.

Personally I don't think that there is enough fear – we think it's someone else's issue. The actual numbers blew me away – we just don't know how big of an issue it is. People who are impacted directly care more – but as a community we just don't care enough.

Although the statistics were alarming, the community was not surprised that an epidemic could develop because “our community is never targeted for HIV prevention.” They cited the lack of organizations, funding, and information as a direct cause of the epidemic and the stigma around HIV. Many drew strong contrasts between the prevalence of negative visuals such as liquor advertising or vacant buildings, and the lack of any educational visuals such as HIV prevention billboards.

Its not like someone is sitting on the street corner selling information about HIV, like they are selling drugs.

In order to validate the finding of HIV invisibility, the second set of street intercept surveys included questions about when people in each neighborhood had last seen or heard information on HIV. Respondents confirmed that they do not see and hear HIV messages that relate to the Black community in general or to their

neighborhoods. Although most people said they had seen or heard something recently about HIV, 56% of this group could not give any indication of where they had seen or heard it, and a third of the group talked about national TV shows.¹⁶ Only five respondents indicated that they had seen information in a local source, either *The Seattle Times* or *The Medium*, a paper published for the local Black community.

About one third of respondents said the message they had seen or heard was about “safe sex” or the “wrap-it-up” campaign, and five people reported messages about getting tested. One of the only local efforts cited through street intercepts was a local billboard and bus campaign in the both areas that began after data collection had begun.



¹⁶ There were forty respondents to the second street intercept survey, 36 (90%) of whom stated they had seen or heard an HIV prevention message recently. Of these 36 people, 20 (55.6) could not state where or how they had seen the message, and 11 (30.3%) listed national TV shows.

When asked what would make media campaigns more effective, 66% talked about locally focused efforts, outreach work, including leaders, and showing Black people in the ads, and 14% talked about more honest portrayals of HIV in the media.¹⁷

In addition, many community experts, non-HIV service providers, and community leaders didn't know where to go for HIV information and testing in their neighborhood if they had wanted to seek it out, and had only guesses about non-neighborhood locations. One local organization, People Of Color Against AIDS Network (POCAAN), was most consistently mentioned as “doing HIV work”, although many interviewees were unclear about exactly what they did or where they were. The Brother to Brother Barbershop program was also mentioned by some interviewees who had attended their workshops.

In one set of street intercept surveys, 69 people were asked to identify two places they could go in the neighborhood for HIV information, and two places for HIV testing. Over 40% of the people who said they knew someplace to go in the neighborhood for information, could only give a generic answer such as a clinic, school, or hospital (even when there was not a clinic or hospital present in the neighborhood.)¹⁸ An even higher number of respondents had only generic knowledge of where to go for testing in their neighborhood, with nearly 60% giving the same non-specific answers.¹⁹ Those who could give a more specific answer to where to find information or testing services gave a wide variety of answers, including their doctor, POCAAN, community centers, and the names of specific hospitals and clinics, with only a few people naming any particular location.

This set of surveys also asked a series of scenarios designed to find out what would make the epidemic more real for them, including “if your pastor/church talked about it” to “if you found out someone close to you has HIV” to “if you saw more information about HIV in posters – radio – tv”. The answers to each question were so strongly positive (each receiving at least 80% positive responses) that no clear winning strategy emerged. This suggests that it is less important to pick the “perfect” information or education strategy, than to realize that any plan that increases discussion or education about HIV would indeed make the epidemic seem more real for people in the community.

Its like its hush hush – nobody talks about it – like its nonexistent.

5. Educate educate educate

The community overwhelmingly supported the need for HIV education “anywhere and everywhere”. Specifically, closely matched peer education was seen as the key to effectively promoting HIV prevention.

Participants consistently and vehemently stated that the way to both prevent HIV, and reduce the stigma and fear around the disease, was effective HIV education in their neighborhoods. The idea of HIV education was seen as positive and non-threatening, in direct contrast to the fears and confidentiality issues surrounding HIV testing. Two main themes emerged around what would make HIV education effective. First, that the education needed to be delivered by peers, and second, that HIV information should be “everywhere” and “anywhere people gather”.

¹⁷ Twenty nine people responded to the question about what would make media campaigns more effective, and 19 (65.5%) talked about locally focused efforts as stated above. Four people talked specifically about honestly portrayed media ads.

¹⁸ Sixty five of the 69 respondents could give a suggestion of a place for information – but 28 of these people (or 43%) could not name a specific place, instead simply saying clinic, hospital, or school.

¹⁹ Sixty five of the 69 respondents could give a suggestion of a place for testing – but 37 of these people (or 57%) could not name a specific place, instead simply saying clinic, hospital, or school.

Peer education

Because of the strong fear and distrust around HIV/AIDS issues, respondents strongly preferred to receive their prevention education information from closely matched peers. At a base level, this meant that it was essential that the education came from a Black person rather than from a white person, and was related in such a way that the individual did not feel judged. Most participants, however, took the match concept further and said that a better guide to finding “someone who looks like me” is to match a variety of personal characteristics, including gender and age, but also including personal background or circumstance when possible. For instance, many different community members talked about being significantly more willing to trust the information if the person talking with them shared similar past experiences, such as being formerly incarcerated. Although this finding is true for most participants we talked to, formerly incarcerated men, African-born immigrants, and youth stated this preference the most strongly.

It depends who they are getting the information from – if I was a white person and I were to hand a Black person messages, there might be some resistance – it’s the whole color thing. But if I as a Black person were to hand information – we know kinda how to lead them in, “I want you to check it out, it ain’t nothing”. But with the white person its how they deal – and it’s the same information.

Service providers also identified peer education as the key method for effectively reaching the community. In their experience, going “back to the basics” with peer outreach and education was necessary to begin building a strong community understanding of the HIV epidemic and to change the culture of stigma and fear surrounding HIV.

Finally, once many interviewees and focus group participants talked about the need for closely matched peer education, they volunteered to become educators in their community. As stated in the following quote from one of the formerly incarcerated men’s focus groups, these community members recognized their ability to reach difficult but essential parts of the community.

So do you have any access to that? To where some of these guys here as well as myself would like to take some of this information back to the community? And share with some of the youngsters within our community? These young brothers that are up on this corner selling their dope?

Information should be everywhere

Interview and focus group participants were asked a series of specific questions about where to provide HIV education. Overall, they were very positive about a range of neighborhood locations for HIV information including community centers, beauty/barber/nail shops, bus stops, community gatherings, and community colleges. Most also talked about how important it was to have HIV information at schools, and to start “young” but “appropriate”. There was a strong feeling that if the community really wants to overcome this epidemic, then everyone should be involved and knowledgeable.

There’s a lot of information that had been passed out – but it has kind of faded away. It would be good to bring it back – to pass out pamphlets and condoms on the corner like they used to. It would help keep the awareness strong – to put it in more areas. It should be everywhere including church – they should pass out information just like they pass out fans in the church.

In addition to the locations they were directly asked about, participants suggested a wide variety of creative ways to access the public from placing information at casinos to highlighting HIV at recovery halls and AA summer picnics. This desire to make the information so visible it becomes unavoidable resulted in creative ideas, such as members of the drug involvement focus group suggesting that public health warnings should be glued to the outside of crack pipes, similar to the warnings on cigarette packages.

Should have (information) available where the people are meeting – where they are at. A big thing with education that we have to have a way to dispel the stigma that is so associated with HIV and AIDS. Then the other piece is that stigma is causing people to not do what they need to do to be safe or to respect someone that is HIV positive. We need information so people can talk about it. HIV would then just be a chronic illness that someone is dealing with cuz there is no cure for it – if the stigma was removed, then it would release a lot of barriers.

There were only a couple negative responses to information and education placement. Participants were divided about education at night clubs, some believing that was the best place to reach people and some thinking it would be a “mood killer” and “simply ignored”. Service providers that had attempted outreach efforts at night clubs echoed the feeling that this is not the most effective place to provide HIV education. There was a negative reaction towards having HIV information around food, some were hesitant to have information at grocery stores and most didn’t want to hear about HIV while at a restaurant.

Many participants also talked about the importance and responsibility of HIV education in the family. They talked about the need to increase parental responsibility and involvement, and to rely on the leadership provided by elders to increase awareness of the rising HIV rates. The underlying message was that everyone needed to be a leader if the community is going to effectively fight the rising HIV rates.

6. Confidentiality is essential

Confidentiality is an overriding concern for the community when considering HIV testing. Because of the stigma associated with HIV, community members do not want to be seen getting tested or, in some cases, actively seeking information about HIV.

The importance of confidentiality around HIV issues was emphasized over and over again in interviews and focus groups with all members of the community. Because of the overwhelming culture of stigma and shame discussed in earlier findings, participants stated that even the idea that the community would know they accessed HIV prevention would keep them from getting the help they might need. Although some people worried about being seen accessing HIV education and information, overall that was less of a concern than being seen having anything to do with HIV testing.

Many participants feared being seen walking into an HIV-identified clinic or van, openly wondering how such an approach could ever be confidential. They did not trust that those doing the testing would keep their names confidential, or that their medical records would remain secure. There also was a belief that if they tested positive, the government or Public Health–Seattle & King County would require them to come downtown and “name

I think what really plagues us in terms of not getting tested is the implications to our family. . . . So, I think for many people the question is “Did anyone see me go in there; if they saw me go in there, then what are the implications when I get home and my mom says ‘Somebody saw you go to the clinic where they treat AIDS patients’.” You know. You don’t want that shame. I think the best thing to do really is to create neutral environments. . . . We’re in a situation where we have a race crisis of a silent nature where people are not sure whether they can trust anyone that’s not Black right now . . . Inform people of what the process is and then assure them of confidentiality. So if when you meet them at the club, you don’t look at them and go “She’s the person I tested and she’s positive.” You know. We need people who really understand confidentiality.

names”, thereby revealing their status and forcing them to compromise their partner’s confidentiality.

Overall, interacting with someone “who looks like me” seemed to be more associated with confidentiality for HIV education issues, than for HIV testing. When asked if race mattered for testing, participants were much more likely to emphasize “professionalism” or “that they can keep it confidential” as prerequisites for the people who may be testing them, and downplay the race of the tester.

7. The testing Catch-22

The counseling and testing aspects of HIV prevention remain the most difficult to provide in the Black community, because of prevailing community norms, the lack of accessible and acceptable testing facilities, and fears of confidentiality.

*(When you go to get tested)
you know you are
advertising to everyone that
you are immoral – just like
when you are a smoker and
you know it is bad, you don't
want to advertise it.*

Although 86% of community experts had been tested at some point in the past²⁰, most of them had not been tested recently or did not “choose” to be tested in the first place. Of the 80% of participants who choose to be tested because of “risky behavior” or “because I wanted to know”, most indicated that they had been tested once and then felt like “they knew” their status. The remaining 20% of those tested did so because of insurance reasons, employment, surgery, or prison time.²¹

Some subgroups of community experts appeared to be more aware of the link between their actions and transmission, and were more likely to choose to be tested on a semi-regular basis. All of the gay men that participated had been tested voluntarily, and either were tested regularly or had deliberately changed their behavior to avoid risky interactions. Formerly incarcerated men also appeared more likely to be tested: 61% of the participants in the formerly incarcerated men focus groups had been tested while in prison, and 84% were tested after leaving prison, although it is not clear how regularly they are being tested. Finally, all of the sex workers and current injection drug users said they were tested on a regular basis.

Although most participants were enthusiastic about the need for HIV education in their neighborhoods, they remained dubious about the viability and accessibility of HIV counseling and testing. The negative community norms described in other findings have the strongest negative consequences when it comes to testing. The stigma and fear associated with HIV is a large barrier to HIV counseling and testing, with

It's a fine line, because how do you have testing be centrally located -- but at the same time it has to make folks comfortable that it can be confidential. I guess there's already a lot of (testing) sites – I mean you can go to the public health clinic and places like that – but most people think you gotta really search out HIV testing. You know its not something in the community . . .

many people saying “I would rather not know”, either because they will be judged immoral or because they see HIV as a death sentence. Also, because many people do not see themselves as at risk for HIV, the need to get tested drops to the bottom of a long list of life issues.

In general, respondents felt that HIV testing is not easily accessible geographically, and most could not name a facility in their neighborhood that offered testing. Many said there was testing

available at large hospitals nearby, while simultaneously talking about the racism they experienced at

²⁰ Although 72 community experts participated in focus groups and interviews, only 63 responded to questions about former HIV testing. 54 participants, or 86% of the respondents, said they had been tested in the past.

²¹ Of the 54 people who said they had been tested, 50 people gave an indication of their reasons for testing. 40 of these people, or 80% of them, said that they had been tested because of their risky behavior or because they “just wanted to know”.

those facilities, as well as the lack of quality care. Most community experts didn't know what was involved in accessing HIV testing, either because they had never sought testing or because their previous HIV test was handled by an insurance or employment agent. Many thought the test would be expensive, some comparing the cost to that of a "DNA test". If they recognized that free testing might be available, they thought accessing it would require an involved process such as that associated with the welfare system and medical coupons. Some participants were aware that local organizations, such as POCAAN, were involved with testing, but very few knew how to access those services.

I think that it being in the community was the premise of people going into a trailer or a van to get tested – but you wouldn't have anybody because you wouldn't want to be seen getting into that van – people would never go.

Questions around what would make people more comfortable being tested revealed a difficult Catch-22. On the one hand, because of overwhelming confidentiality issues, participants did not want to get tested at a location identified in any way with HIV – particularly an HIV mobile van. As mentioned above, many people said they would not

want to be seen getting an HIV test because of the implications about their behavior. Although service providers often recognized the need to normalize testing through the use of vans that would travel to where people were, most community experts interviewed stated that they would never use such a facility.

Often these fears also extended to asking for an HIV test at a local neighborhood or school clinic where another client or a practitioner might know them. Many of these people said they would prefer to go somewhere outside the community, because then there would be less chance of being identified.

On the other hand, however, many respondents insisted that it must be someone from the community performing the HIV test because that would increase their feeling of security and comfort. They didn't want to have to travel very far to get testing, and didn't necessarily trust the government to provide it, thinking that their status and name would be linked and kept on file. Overall people didn't know about anonymous testing, or didn't believe that it would ever actually be anonymous.

Where would a person go? Are there sites available that are kinda – that blend in with the environment and that don't stand out? So people don't say "oh I seen you going into the HIV clinic". And I'm saying I wouldn't mind – but somebody else would say – "oh no man, that wasn't me". But "I see your car over there in the parking lot".

In addition, participants were mixed on the question of whether or not it was important to have a Black person doing the testing, with some strongly supporting the idea and others saying it didn't matter as long as the person was professional. Across the board, professional and non-judgmental behavior on the part of the tester was seen as an important indicator of confidentiality.

I just think in general that if we had a multiuse type room with all kinds of medical information. Then people could go into this place . . . and they could have an HIV test – and then they could have other tests too. That would reduce the stigma because no one would know why they were really over there. There would be some confusion because people like to deny. Could call it the test station – "Oh I'm gonna go up to the test station and get my blood pressure checked" – they wouldn't know what you are there for.

When asked what would resolve this Catch-22 and make them more comfortable being tested, many participants talked about having HIV testing available along with a host of other testing services, so that there was no way for anyone to know exactly what they were being tested for, but they would still have a reason to be accessing the facility. Participants made two suggestions for how this could work: either unobtrusively offering HIV

testing at a multi-use center in the neighborhood that already offered a variety of services, or creating a health screen van that was identified with testing for many diseases including HIV.

Both community experts and service providers did not understand why HIV screening was not just a regular part visits to the doctor, particularly given the increasing number of infections. Although they were careful to say it shouldn't be mandatory, participants said they often aren't offered HIV tests, or they have to say yes to one of several "stigmatizing" questions to be offered a test. This creates a strong barrier to accessing testing, even in the privacy of a doctor's office. Many thought that if everyone was simply offered a test, this would make it more normal and not single out those who were getting tested.

Definitely - definitely – if you could just get a swipe – I know a lot more people would be comfortable getting tested. There's something scary – you know what I'm saying - about when you get your blood taken, and they are testing it. It just seems so scary that way. But when you just look at this little swab it just seems less scary.

Participants also had strong opinions about the type of testing procedure. Most felt they would be more comfortable getting tested if they could avoid the waiting period and get their results in 20 minutes instead. Many also thought that using an oral swab and avoiding the needle altogether would make many people more comfortable.

People's preferences were basically split between these two options, however, when directly asked to choose between these two alternative methods in a street survey. Participants thought that counseling was an essential part of the process, although many stated that there should be flexibility on how best to deliver the counseling.

Many also stated that incentives for testing would encourage many people to get tested. Street surveys demonstrated that while cash was always a good method, other incentives such as movie or bus tickets would also work. On average, people said that they incentive would need to be \$26.

8. Need for leadership

Participants described the desperate need for leadership around HIV prevention, so that the issue would move to the forefront and be addressed. They identified two main sources of potential leadership: churches and mosques, and a community wide effort lead by trusted elders and teachers.

Participants clearly described a lack of leadership around HIV in the Black community. For many, this was a symptom of a larger lack of community leadership from elected officials, traditionally African American organizations, and local and national spokespeople. Indeed, many of these more traditional leadership groups were unwilling or unable to participate in this study. Instead, most participants described the need for HIV leadership to come from a broader definition of community leaders that focused on religious leaders, community involvement, and trusted elders, teachers, and business people.

Tradition and dogma keeps the church inside of four walls. We need to go out into the community. We need elders and deacons to be aware and lead us to implement education. And we need leaders to open their minds. Every church has someone who has died of AIDS – in all denominations.

Religious leaders

Participants were both pessimistic and hopeful about the role of churches and mosques within HIV prevention. As discussed earlier, many said that clergy were mainly to blame for the perpetuation of stigma surrounding HIV, because "whether or not people go to church – we all are basically Christian, or at least brought up that way. And we will listen to our religious leaders – right or wrong we listen to what they say." Many service providers in particular talked bitterly about their experiences trying to reform church attitudes and bring religious leaders into the HIV prevention effort. They talked about the shunning of HIV+ individuals and the preaching about immoral behavior as the only cause for HIV.

The churches have not responded (laughs) – I think there have been some attempts before that have been being made – well now there is this faith based initiative . . . I think that we’re just starting to approach the tip of the iceberg – but just their lack of being able to respond and the stigma and the barriers they have set up to it.

Other community members, however, talked about the change that they see in clergy willingness to participate, citing recent conferences and a current billboard and bus campaign. (See page 24 for this advertisement.) No matter how realistic they felt it was to believe clergy would become involved, the community clearly identified the potential power of their leadership. This was true both for the Christian and Muslim communities.

Most of the church leaders interviewed were open to participating in various types of HIV education. Most, however, described clear limits to acceptable HIV prevention in their churches and identified several main barriers to becoming strong HIV prevention leaders. The most common issue had to do with aspects of their theology that they perceived as contradictory to HIV prevention. For some clergy, this meant that they were willing to participate in education about HIV transmission, but not to espouse condom distribution or the concept of safe sex. For others, HIV prevention only meant abstinence education. Often clergy drew the line at the idea of testing at their churches or mosques, believing this condoned the behavior that transmitted the disease. The following two quotes represent the range of clergy statements both for this assessment and in the community every day.

(Responsibility around HIV) also falls on the faith community – the churches. This is where people go that they have a respect for the leadership. But again knowing the church and the Christian morals and beliefs – they aren’t going to have condoms up there and promote that. But they could have pamphlets and awareness about it – no question.

Tell the people about not fornicating—just going out there and having sex because they’re mad with their spouses. “You have to mind God. And if you don’t mind God the devil is going to make sure you get AIDS.” He’s going to make sure that you get AIDS. Now you can mind God and stay clean and happy like the sunshine or you can mind the devil and suffer in darkness and die a painful death. And hurt all of the people that are around you that really loves you.

Many community members also said that much of the barrier doesn’t necessarily come from the clergy, but instead from the elders in the congregation who set the tone for the community and would be unwilling to include most HIV prevention. Others stated that HIV prevention simply wasn’t a religious issue and therefore had no place in religious settings.

Everyone is a leader: Trust is the key

Due to the perception that there is a traditional leadership void in the Black community, many participants said that the burden of leadership really fell to all community members. Instead of defining a leader by their title, participants described a leader as someone who they trusted or someone who took a stand and helped the community. Most often, participants described elders, teachers and business people as the people with enough trust and influence to provide true leadership for the HIV prevention effort. They talked about how HIV prevention information and changing attitudes from these sources was the key to reducing stigma and spreading an effective message.

We listen to the elders in the community – they hold the knowledge. If they got behind education that would be the key. And parents need to get involved, it needs to start in the home.

Business owners could be considered as community leaders because they bring jobs, money, housing, to the community. We would trust our business leaders to talk to us.

Several participants and focus groups also proposed drug dealers as community leaders, because they clearly fit the description of gatekeepers with money and influence. Members of the drug involvement focus group recognized their position of leadership among particular members of the community and some talked about a commitment to HIV prevention.

9. Subpopulations present their own barriers

While several specific community subpopulations at high risk for HIV share the overarching report findings, particularly those related to the need for peer education and outreach, they also presented HIV prevention barriers unique to their background or circumstance.

In addition to looking at the entire community present in the RARE neighborhood sites, the Seattle RARE study focused in particular on several subpopulations of interest to members of the Community Working Group (CWG). The CWG's interest was generated both through their extensive experience in the field, and the epidemiological data that places many of these groups at high risk for HIV in the community. Members of these subpopulations were able to express their opinions through subpopulation-specific focus groups and multiple individual interviews, which were conducted by a member of the field team or Community Working Group that shared/understood the characteristic in question. There was also special emphasis placed on talking to service providers that work with these subpopulations.

Overall, these subpopulations echoed the same themes as found throughout the community, but spoke even more strongly about the need for closely matched peers for effective outreach and education. The following sections briefly detail the unique aspects of each group of community members that should be taken into account when designing services.

Men on the Down Low (Non-Gay Identified MSM)

Not surprisingly, none of the heterosexually-identified men that participated in this study disclosed any MSM behavior. The larger community, however, recognized the pervasive phenomenon of “men on the down low”, or men who identify as heterosexual but also have sex with men. Many of the community participants perceived men on the down low as a significant source of HIV for their female partners, because of the covert nature of their MSM behavior. There was a belief that, for the most part, these men were not using condoms with their male partners, and were not discussing this behavior with their female partners. A woman who believed herself in an exclusive sexual relationship with a man on the down low, therefore, might not recognize the need to use condoms. This concern was strongly echoed by many HIV and health providers in both areas, and several have designed successful local programs to reach this population.

The community also associated “down low” behavior with formerly incarcerated men. They discussed how the behavior that began during time in prison continues through the transition into the community and sometimes beyond. Providers who work in both neighborhoods also made this connection, and have begun incorporating this knowledge into their work. For example, the community health clinic in the CD has recently included questions about formerly incarcerated partners in their HIV screening questions because of new HIV diagnoses among heterosexual women, with no evident risk factors – except that they all had long-term partners who had been formerly incarcerated.

In a focus group with men who do identify as gay, participants discussed their belief that men on the down low should be viewed as part of their community. They talked about how they often have relationships with men

Non-identified are part of our (the gay) community, but they sometimes interact differently with AIDS. They have less awareness and they don't think of themselves as vulnerable - they think they are immune because they aren't gay.

on the down low that they meet in a variety of community settings, including church and family occasions. They talked about the essential nature of peer education when trying to reach men on the down low, and the ability of gay men to do this work.

I believe the hardest to reach people are people that live in our community that are just regular, run of the mill citizens. Specifically, I'm thinking of women who may have jobs and may not have a background in drugs or alcohol but they might be with a partner that is a drug user or sexually [active] IDU or is a man that has sex with other men. And these particular women are not aware of the risk that their partner may be placing them in and they don't have a good sense of what the disease is and how it affects the community and may even affect them.

Heterosexual women

In addition to agreeing with the main findings presented above, heterosexual women appeared to be more aware of, and more worried about, their past risky behavior. In both heterosexual women-specific focus groups and one-to-one interviews, they were more likely to discuss how they had previously had unprotected sex or shared needles with people that they later learned were HIV positive. This connection increased their sense of past personal risk, although most women stated they no longer engaged in these behaviors and were not currently at risk.

Heterosexual women also talked at length about how the definition of monogamy can differ between men and women, thereby increasing the chance for a woman to think it is safe to have unprotected sex with her exclusive

partner even though in reality it is not safe. Service providers serving heterosexual women talked about the issue of men on the down low as a potential reason that men could be having sex with another partner outside of their “primary relationship”. None of the heterosexual participants talked about this as a significant risk in their own lives, even if they talked about down low behavior in the community. These women also discussed the perception that women are more careful about their health in general, and their sexual health in particular, than their male counterparts. They thought that much of the awareness around the need for safe sex and testing came from women, and that men would not get tested for any health issues, let alone HIV-related issues.

Gay men

Both in focus groups and interviews, Black gay men talked about how they know the community still perceives HIV as a “gay disease” and associates both the disease and being gay with immorality.

I have to say that when I hear that someone has died from AIDS, I always wish that they weren't gay – it just adds to the stigma.

While some gay men felt accepted by their families and the community, others still struggled with the stigma that they felt was perpetuated by churches and some institutions. This sense of stigma that they might feel about their identity increased the difficulty of dealing with stigma surrounding HIV.

People don't know you are gay unless you disclose that you're gay, so that's not how we meet. We meet more often in church. Its surprising who comes on to you – people you thought were straight. I never meet men in clubs in Seattle. There aren't any.

Much of the focus group conversation focused on the need for specific outreach work to Black gay men, by Black gay men. They talked about how few resources are dedicated to this work, and how difficult it is to try to find gathering places to access this part of the community. Participants stated that Black gay men, including both gay and non-gay identified members, don't meet their potential partners at nightclubs or other venues that are generally places to reach the white gay community. Instead, gay men meet through a variety of community settings. This type of interaction necessitates peer education – going back to the basics.

In addition, gay men recognized that there was no HIV prevention or treatment program that could offer a safe and targeted location for services designed to reach Black gay men. This lack was cited as a key issue in reaching the population effectively.

People don't want to call it AIDS. It's just recently... Even our president, our former president, Moi could not say that word. Never spoke about it until about 4 years ago. Now if your own president cannot talk about it, how much more denial will the population be in? So they'll just call it "Oh, it's just a punishment from our ancestors or guardians". You know paying retribution to the people for sin. And what do you say about them? Who's gonna argue about it?

African-born immigrants

Overall, the responses of African-born community members, community leaders, and service providers closely mirrored those of the larger community. The main differences surrounded the increased level of intensity surrounding the findings of stigma, distrust, and confidentiality. Although many of the basic issues were similar, participants made even stronger statements about the lack of acceptance within the community and the belief that HIV was a "death sentence".

Members of the African-born community spoke strongly of the need to return to the "African values" that had been diluted or lost during their time in America. African-born participants talked about stricter moral codes in African society, and the belief the Africans simply did not engage in

behaviors, such as anal sex, that were held responsible for HIV transmission. Indeed, they often cited this return to traditional values as the most basic step in HIV prevention, because the "immoral behaviors" responsible for HIV transmission were antithetical to these African values. This belief reinforced the notion that if someone got HIV, it was through his or her own immoral actions.

Definitely – that is the main reason we are dying – no one wants to say that they have AIDS. . . . So I think that the stigma is because we don't talk about it – we are more ignorant – cuz when you don't talk about the issue the information can't get out – and so when I can't talk about the circumstances I am going to be thinking, "uh oh, if I tell somebody they are going to be thinking less of me". Because they will say my morals are bad. And as you know Africans value morality very greatly – because that is what controls even your profit for marriage and all that stuff. So there definitely is a lot of shame and stigma that can affect even your family. They will say "oh – be careful – in that family this disease is there". The family is judged from that – or you perceive that.

Many African-born participants also, however, were very angry about the theory that HIV and AIDS originated in Africa, instead believing strongly in the HIV as government-sponsored genocide theory. This caused most of this group to be greatly distrustful of the government or white people. African-born participants also discussed the added fear and perceived danger of possible deportation that could come with a positive diagnosis.

Because of the need to recognize separate African experience, values, and trust levels, all African-born participants stressed the need for education of African-born people by African-born people. It is essential that those conducting education and outreach understand the cultural and ethnic differences that provide unique challenges to providing services in this community. In particular, they stated strongly that any effective testing strategy must, at a minimum, include Black testing personnel because the African-born would not trust white people with testing. They also talked about how small their community is and how, again, while they want peer education, they don't want people to find out they are being tested.

But if you're not legal or if you're just a student and didn't purchase insurance – its very difficult to go in and say test me I am not feeling well – first of all you don't want to be deported, because if you are deported you are a bigger problem to your family at home – you came here wanting to help them – now you bring a bigger problem home to them, a disease they don't know how to handle.

African-born participants also suggested the idea of single-sex or age-divided education as a way to effectively reach both children and older community members, while respecting the cultural differences that could otherwise present a barrier.

Finally, many of the participants maintain strong relationships with their home countries and families, and therefore retain close connections to the growing AIDS crisis in Africa. They described situations in their home countries where AIDS had “wiped out whole families” and left the economy in shambles. This first hand knowledge seems to reinforce the individual and community-level fear that comes with any discussion or testing of HIV.

And you don't bring mothers and daughters to sit in a room and start talking about personal sexual issues. In the same room. I think what you do, you have people in the same age group or peers and teach them separately but you don't mix this whole funky situation where a mom loses her dignity or grandma loses here dignity in the presence of the little ones. So I think you can do the education separately.

Youth

Most of the youth participants, defined as community members aged 18 to 23, were knowledgeable about the basic transmission methods. They talked about learning the basic messages in school. Many also cited a variety of national HIV prevention campaigns, such as the “Wrap It Up” campaign on BET.

As in the larger community, however, this basic knowledge did not translate into a sense of personal risk. The strongest additional theme for youth participants was a strong sense of invincibility – the feeling that although HIV might happen to other people, it could never happen to them. This was particularly true for young Black men, most of whom had not been tested and even though they had multiple sex partners. Young Black women echoed this perception, saying that they were much more aware of their health and utilized the school clinics for regular checkups, birth control, and testing, while they never saw young Black men at the clinics.

In an ideal world, I would like to see testing and counseling be available in the schools so that young people that are sexually active can feel free to go to the nurse at school and get tested.

Youth talked about how having sex is tied to identity. Service providers also talked about the pressure to have sex early, and said the pressure can come from either gender. Many of the youth participants described the role that a “sexed up society” in general plays in their perceptions of what it means to grow up. Service providers talked about how important it is to educate and test sexually active youth.

Peer education was a key issue for youth, with many suggesting paid internships as an effective way to get the message out. Youth also talked about the need to have media campaigns on radio stations that they listened to, which would feature celebrities or rappers that were influential in the community.

Formerly Incarcerated Men

Because the issue of formerly incarcerated men was of particular interest to the Community Working Group, RARE conducted two focus groups with this part of the population. In addition, 43% of the one-to-one interviews were conducted with individuals that had been formerly incarcerated for varying lengths of time, some of whom were now in recovery programs. These community participants talked about HIV prevention issues that affected them both while they were incarcerated, and when they transitioned back into the general community.

I think the big picture of stigma is that they are treated in the institution about the same bad (way) as . . . they're treated out here. It's a disgrace in a big sense for a person to have AIDS/HIV.

One of the biggest issues during incarceration was the increased sense of stigma around HIV and AIDS. Participants talked about how “you could not be seen accessing information or testing” and that this effectively blocked any voluntarily HIV prevention efforts. They also talked about the complete lack of confidentiality that prevented people from joining any programs about HIV education.

And they put us in these programs and speak of confidentiality when there really is no confidentiality around.

In fact, many participants suggested that such programs be mandatory while in prison, so that no one would have to be seen choosing to access services. This idea also appealed because of how common risk behavior was – particularly unprotected sex behavior as condoms are not available in prison. They placed the blame squarely on the prison authorities, and talked about the need to face reality and increase education and testing in the prison system.

So therefore, most of these cats are going to camps [lower security work facilities]. You know what I'm sayin'? In order for them to reach anybody with this, they need to go inside the institutions. . . . You need to make a start. And I believe the prison system is gonna to dodge the bullet. That's not gonna never be addressed. It's already an epidemic, you know what I mean? But it's just not gonna be addressed just like a bunch of things that go on in prison. I think the work . . . would be tryin' to get in to some of them camps and eventually get into the main institutions.

Overall, however, formerly incarcerated men were more hopeful about the effectiveness of providing HIV education that began during the transition back to the community and continued on. They stressed that it must be closely matched peer education – formerly incarcerated men talking with their peers. Formerly incarcerated participants talked about the multiple ways that peer education could address post-incarceration trust issues,

transition issues, and general HIV prevention, while also effectively reaching some men on the down low.

V. Action Steps

The following recommendations respond to the community beliefs, knowledge, and barriers detailed in the RARE findings by determining a concrete action plan to increase and improve the HIV prevention services available both within the RARE sites, and for the larger Black community. These action steps have been agreed upon by the Community Working Group, and will be presented to the community in both RARE sites through public forums in the remainder of 2003.

Action Step 1: Incorporate RARE findings in 2004-05 HIV Prevention funding cycle

1.1 Encourage programs funded through Public Health to use the RARE findings to guide program development.

In July 2003, the RARE findings were presented to the HIV Prevention Planning Committee and they endorsed the inclusion of the RARE findings in the 2004-05 HIV Prevention Request For Proposals (RFP). The RFP now requires applicants that propose to serve African-American and/or foreign-born Blacks to incorporate the RARE findings in the development of their intervention plans.

Based on the 2004-05 Prevention Plan for King County, the following priority sub-populations are most likely to attract proposals that specifically focus on African-American and foreign-born Blacks:

- High-risk heterosexuals: Women and men with, or at highest risk for, STDs; Foreign-born Blacks; HIV+ women and their sexual and needle-sharing partners.
- Men who have sex with men: Non gay-identified Black men, Gay-identified Black men
- Transgender: Male-to-female transgendered people.

1.2 Fund a program that specifically focuses on the HIV prevention needs of African Immigrants.

If Public Health receives no viable proposals for a program serving African Immigrants, the Community Working Groups recommends that the Allocation Panel set aside funds from the 2004-05 funding pool and work with local agencies to develop a program for this population. This could include social service organizations such as Horn of Africa, as well as membership organizations like the Nigerian Association.

1.3 Ensure that the Allocation Panel for 2004-05 HIV Prevention funding considers the RARE Project findings and actions steps in their funding recommendations.

The allocation panel for the RFP should receive a copy of these findings and action steps to inform their decisions.

Action Step 2: "Back to Basics" outreach: Increase the presence of one-to-one HIV prevention/education outreach in each of the RARE Project sites.

Outreach programs should be designed to respond directly to the RARE findings including: 1) the need to utilize closely matched peers and culturally appropriate education and 2) confronting the barriers caused by the stigma, fear, confidentiality, and distrust associated with HIV within the community. The outreach program(s) should train and pay people from the community, even those without prior HIV outreach experience, to conduct the outreach.

2.1 Emphasize outreach in the current funding cycle.

Programs that apply for funding through the 2004-05 RFP should include an outreach component for closely matched peer outreach.

2.2 Generate additional resources to increase peer outreach.

Because much of Public Health's pooled HIV/AIDS funding must conform to the 2004-05 Prevention Plan by targeting prioritized high-risk populations rather than the general community, the department should dedicate extra resources to increase peer outreach in the RARE sites.

- Public Health should hire a health educator, or use an existing health educator, who has the ability to work with this community to coordinate a peer outreach program and/or work closely with agencies coordinating peer outreach and education programs. This person could contribute to the overall visibility campaign through activities such as a regular column in local African American weekly newspapers such as *The Medium* and *The Facts*, participating in local health fairs, visiting schools, etc.

Action Step 3: Implement a targeted media campaign to increase the visibility of the epidemic

As Dr. Alonzo Plough, the Director of Public Health—Seattle & King County said in May 2003 at the King County Leadership Summit for HIV/AIDS and the African American Community, we need a “permanent campaign” against HIV/AIDS in the African American and foreign-born Black community in King County.” Through the Sims Initiative, Dr. Plough and County Executive Ron Sims have indicated their strong support for reducing the rate of HIV/AIDS in the Black community. We call on them to continue this support by increasing the visibility of the HIV epidemic in the African American community. To this end, Dr. Plough and Executive Sims should dedicate additional funds to build on to the recently implemented media campaign that focused on local African American clergy and HIV prevention.

Funding

- At a minimum, the campaign should be funded to run through the remainder of 2003 and all of 2004. Based on the costs of the current campaign that includes design of the campaign, 3 months of bus ads and billboards, and 1 month of radio, the minimum cost for this extended campaign is \$50,000 in 2003 and \$100,000 in 2004.

Campaign messages

- Focus on heightening the visibility of the problem and reducing the stigma, distrust, and fear surrounding HIV.
- Be "in your face" and talk about the disproportionate impact of the disease in the local Black community using blunt statistics about local HIV rates, reminiscent of the recent anti-smoking campaigns.
- A media campaign and other educational efforts must convince people of the benefits of testing (e.g., availability of HIV medical services and effective drug therapy) to combat the perception that a positive test is a “death sentence”.
- Educate about the availability of local HIV prevention services, including their location, cost, level of confidentiality, etc.

Spokespeople

- The media campaign should feature local people, particularly if they are trusted leaders or local celebrities (e.g., owners of barbershops and other local businesses, local rap artists, etc.). If possible, it could also include sports stars, but not to the exclusion of the local people.

Target audience

- Focus first on youth – using targeted messages designed to appeal to this demographic and placed in locations and on radio stations that are frequented by youth
- Secondary audiences can include a variety of community groups – maintaining the targeted approach to the campaign.

Media methods

- Feature radio Public Service Announcements (PSAs) on radio stations listed by the target demographic in question, e.g. placing PSAs on KUBE 93 for youth targets and JWJZ 98.9 for more mature target audiences.
- Can also include busboards, TV PSAs (e.g., BET if possible), billboards, and collaboration with local newspapers that target the Black community.

Outreach component

- The media campaign must be reinforced by one-to-one street and community-based outreach.

Action Step 4:

Adapt HIV Counseling and Testing to increase availability and enhance confidentiality

4.1 Increase availability of HIV Counseling and Testing (HIV C/T) at multi-use service centers and as part of general health screening services.

Public Health should seek additional funding for a comprehensive health screening van that would include not only HIV screening, but also other health screening services. Wherever possible, clients should be offered a choice of testers so they can choose one with whom they feel comfortable. As part of this effort, Public Health should increase internal collaboration among divisions that provide health screening services for African Americans and foreign-born Blacks so that HIV counseling and testing can be included with these services.

4.2 Increase availability of HIV C/T in publicly funded clinics that serve the needs assessment sites.

Public Health should pilot a program to provide intensive technical assistance to help publicly funded clinics serving the Central District and Rainier Valley to incorporate HIV counseling and testing as a routine part of their health screening services.

4.3 Increase availability of rapid testing in the Black community.

Public Health should implement a pilot rapid testing program in at least one of the needs assessment sites. This pilot program should be similar to that implemented in 2003 for gay and bisexual men in the Broadway neighborhood.

Action Step 5: Increase Leadership and Clergy Involvement in HIV Prevention Efforts

Methods for increasing the involvement of Black community leadership and clergy in HIV Prevention efforts remain the most difficult to determine. The Community Working Group, however, has defined several characteristics of this work.

- Utilize a strategic capacity building approach that involves leadership and clergy in the planning and implementation of HIV prevention programs throughout the community.
- Emphasize the utilization of faith-based settings and connections with local congregations for HIV prevention work when possible. Any programs linked to faith based organizations should be offered to all churches and mosques that predominately serve African Americans and foreign-born Blacks.
- Continue existing efforts like the Sims Initiative that have pulled together local Black leaders, especially local clergy, to focus the leadership on the HIV care and prevention needs of their community.
- Support efforts of local organizations that seek to increase the involvement of leadership and clergy in HIV prevention efforts.

Action Step 6: Increase the level of HIV prevention services available in both RARE sites

RARE findings clearly detail the lack of HIV prevention sites and services in both specific RARE sites, and the neighborhoods in which they are located. Increasing the availability of new prevention facilities and targeted services must be a priority.

- Public Health should study the feasibility of locating syringe exchange sites within the needs assessment sites.
- Public Health, through the 2004-05 HIV Prevention funding process, and through other fund sources, should support local programs that provide outreach to these areas – even if their primary location is not within these neighborhoods.
- The HIV Prevention Allocation Panel should recognize the distinct lack of services in the Rainier Valley area, and give special attention to proposals in the 2004-05 HIV Prevention funding cycle that seek to bring services to this area.
- There must be increased collaboration with existing community institutions in the areas, including community centers, schools, and libraries, to ensure that there is adequate printed and visual material available in these areas. Not only would this increase the visibility of the epidemic, but it would also help members of the community find the HIV prevention and care services they need. The Public Health health educator (see above) should provide technical assistance for staff at these organizations to assist in the placement of materials and to facilitate the referral process.
- Increase support for special events, such as health fairs, in both the Central District and Rainier Valley neighborhoods.