

# **Descriptive Epidemiology of Newly Reported Hispanic HIV/AIDS Cases in Oregon**

**Final Report  
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## Introduction

The objectives of this special public health surveillance project examining newly reported HIV/AIDS cases in Oregon listed on the case report as Hispanic<sup>1</sup> were to:

- Describe demographic characteristics of these cases, including nativity and migration patterns, and, where appropriate, match them to demographics collected on the case reports for quality assurance purposes;
- Describe risk behaviors, HIV testing and care patterns, and the social context of HIV among Hispanics living with HIV/AIDS; and
- Pilot test new questions that are under consideration for addition to the HIV/AIDS confidential case reporting forms (the standard form used to report HIV/AIDS cases in Oregon).

More broadly, the results will be used to guide the delivery of resources aimed at expanding testing opportunities and preventing HIV among Hispanic populations in Oregon.

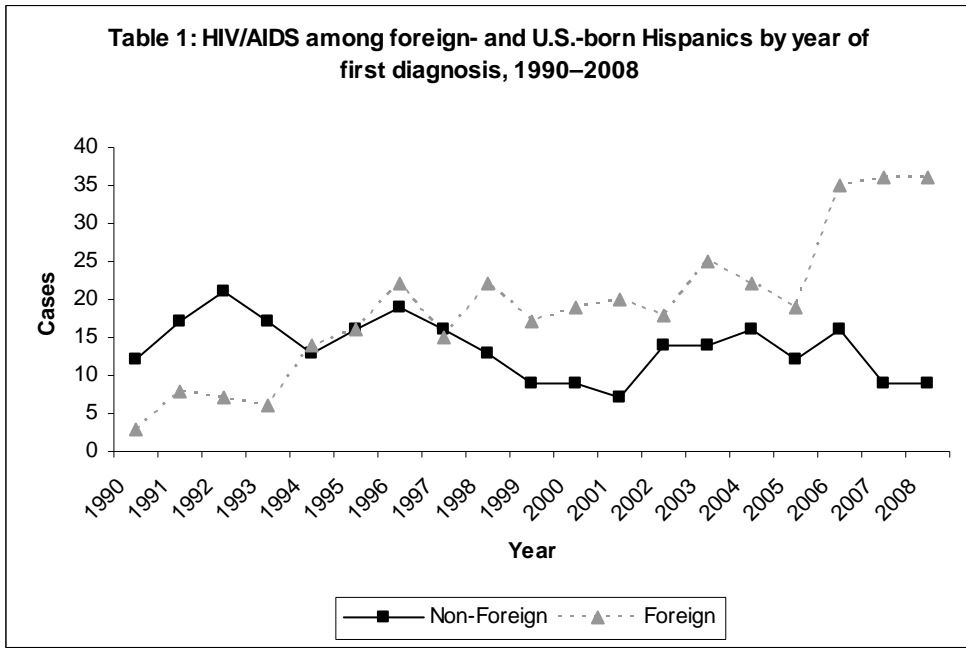
The report is divided into the following sections: 1) Rationale for the project, 2) Methods, 3) Results, and 4) Discussion.

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<sup>1</sup> Hispanic or Latino: a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race.

**Rationale for the Project: HIV/AIDS Prevalence and Prevention among Hispanics**

Hispanics are disproportionately affected by HIV infection and other sexually transmitted infections. HIV incidence estimates for 2006 indicate that Hispanics account for 17% of the 56,300 newly diagnosed HIV infections (CDC, 2008), yet they represent 15% of the total U.S. population. Disparities in Oregon reflect the national trend. While Hispanics comprise 11% of Oregon’s population, they accounted for 15% of all new HIV diagnoses in 2008. In Oregon, the 2007 rate of new HIV/AIDS diagnoses among Latinos was 1.6 times the rate among whites (11.6 vs. 6.2 per 100,000). Since 1998, a majority of Hispanics newly diagnosed with HIV in Oregon have been foreign-born (Table 1).



Cultural and socioeconomic factors may contribute to the disproportionate rates of HIV among Hispanics (Marin, 2003); examples include poverty, limited education, unemployment, incarceration, inadequate health insurance, language barriers, migration and undocumented status, different levels of acculturation, and limited access to health care (Page, 2005; Akin et al., 2008; Deren et al., 2008). These factors are also barriers to HIV/AIDS prevention and care (Organista et al., 2004; Rajabiun et al., 2008). Research shows that Hispanics, compared to non-Hispanic whites, have higher rates of previously undiagnosed HIV infection, experience delays in obtaining HIV test results, and are more likely to have AIDS-defining conditions at the time of diagnosis (CDC, 2008).

Unprotected intercourse and injection drug use increase the risk of acquiring and transmitting HIV, but these risk behaviors vary according to gender and place of birth (CDC, 2008). Enhanced surveillance data are needed to develop a better understanding of the specific HIV risks and their contexts among Hispanic subgroups and to identify potential prevention strategies (Alvarez, et al., 2009).

## Methods

Two data sources were used in this evaluation: adult HIV/AIDS confidential case reports and telephone interviews with Hispanic adults newly or recently reported as having HIV and/or AIDS.

### *Initial Review of HIV/AIDS Case Reports:*

We reviewed all of the HIV/AIDS Case Reports and, if applicable, Disease Intervention Specialist (DIS) notes on all persons newly diagnosed with HIV between November 1, 2008 and October 31, 2009 whose case report listed them as Hispanic (n=46), and then coded 50% (n = 23) to assess the completeness of the case reports.

### *Interviews with Newly Diagnosed Hispanics:*

A bilingual, bicultural staff member administered a telephone questionnaire with adults newly or recently reported as having HIV in Oregon and identified on the case report as Hispanic. The HIV/AIDS Case Reports for all persons meeting those criteria between October 1, 2009 – March 31, 2010 (n=56) were selected. The interview was primarily quantitative, with 38 close-ended items and 6 brief, open-ended items (Appendix 1). The interviewer explained the study, obtained verbal consent, and administered the questionnaire by phone. Interviews were conducted in March and April 2010. Participants received a \$20 grocery gift card as a thank you for participating in the special surveillance project.

### *Matching Data Sources:*

Relevant data elements (e.g., demographics and HIV risk data) collected in interviews were matched with data elements collected on the HIV/AIDS case report to assess congruity and completeness.

## Results

### *Part I—Initial Review of HIV/AIDS Case Reports:*

There were 46 HIV/AIDS case reports filed for newly reported Hispanics between November 1, 2008 and October 31, 2009 (Table 2).

**Table 2: Oregon Hispanic HIV/AIDS Case Reports, 11/1/08-10/31/09**

	<b>HIV (n=26)</b>	<b>AIDS (n=20)</b>	<b>Total (n=46)</b>
<b>Male</b>	23 (88%)	19 (95%)	42 (91%)
<b>Multnomah County</b>	9 (35%)	2 (10%)	11 (24%)
<b>Marion County</b>	6 (23%)	7 (35%)	13 (28%)
<b>Washington County</b>	4 (15%)	4 (20%)	8 (17%)
<b>Lane County</b>	3 (12%)	--	3 (7%)
<b>Other</b>	4 (15%)	7 (35%)	11 (24%)
<b>Mean Age</b>	32 years	37 years	35 years

We sampled 50% of the HIV (n = 13) and AIDS (n = 10) case reports to determine how thoroughly they were completed and reviewed the accompanying DIS interviews, where available.

Overall, the case reports were adequately complete (Appendix 2). Most were not accompanied by a DIS interview.<sup>2</sup> Patient name, address, and phone number were routinely captured, as was information on the facility of diagnosis. Other than State Patient Number, the other “Health Department Use Only” information was not routinely reported. In terms of demographic information, date of birth, sex, ethnicity and race were always completed. Diagnostic status at report and age at diagnosis were completed for half of the AIDS cases and about three-quarters of HIV cases. Country of birth was recorded for 9 of 10 AIDS cases and 11 of 13 HIV cases. All of the AIDS cases with data were foreign-born; 8 of 9 were from Mexico. Among HIV cases, five were born in Mexico, four were born in the U.S., and two were born in other countries.

Risk data were completed for all 13 HIV cases and 8 of 10 AIDS cases. The most common risk factor was men having sex with men (MSM) which comprised 62% of HIV cases (8/13) and 60% of AIDS cases (6/10).

With regard to laboratory data, the HIV antibody test at diagnosis was completed on all HIV case reports and all but one AIDS case report. More data were included for AIDS vs. HIV case reports in terms of detectable viral load test and immunologic lab tests, but these fields were incomplete for a majority of both types of case reports.

Most (9/13 HIV and 9/10 AIDS case reports) contained an indication of whether the clinical record was reviewed. Seven of the 13 HIV case reports indicated “asymptomatic,” although only one contained a date. None of the AIDS case reports contained this information. Two AIDS case reports listed AIDS indicator diseases.

<sup>2</sup> The DIS interviews that were reviewed did not provide much descriptive information.

The section of the case reports on treatment services and referrals was usually completed. One HIV case report and one AIDS case report did not have information on whether the patient had been informed of his/her infection. Eleven of thirteen HIV and 6 of 10 AIDS case reports had data on partner notification.

We only reviewed two HIV case reports for women; both contained data on current pregnancy status and whether the patient was receiving or referred for gynecological or obstetrical services. For the one patient who had delivered a live-born infant, the data fields about that child were incomplete.

In summary, reporting facility and patient data, including demographics, risk factors, and treatment services and referrals, were usually complete, while data fields related to laboratory and clinical testing were spotty.

#### *Part II— Interviews with Newly Diagnosed Hispanics:*

In March and April 2010, a bilingual, bicultural interviewer made follow-up telephone calls to 56 individuals who were reported with HIV between October 1, 2009 and March 31, 2010 and listed on the case report as Hispanic. Three individuals were determined to be ineligible because they told the interviewer they were not Hispanic. Of the remaining 53 potential respondents, the interviewer completed 23 interviews (43%), discovered 12 disconnected telephone numbers, and was unable to reach 18 potential interviewees after multiple attempts. There were no refusals. Most interviews (83%, n=19) were conducted in Spanish and took an average of 25 minutes to complete (range: 12-35 minutes).

#### Client Demographics, Nativity and Mobility:

Five respondents identified their race as White, one identified as American Indian, and one identified as both white and American Indian. The remaining 16 identified their race as “Other” and defined it as either Hispanic or Latino. Most respondents were male (87%, n=20). Respondents ranged in age from 21-59 years, with an average age of 37 years.

Five respondents (23%) were born in the United States, all in states other than Oregon. Among foreign-born individuals, the most common country of origin was Mexico (72%, n=13/18). Other countries of origin included Cuba, El Salvador, Guatemala, and the Dominican Republic. Most foreign-born individuals had been in the United States for many years (range: 0-29 years, median: 12 years), and 61% (n=11) first came to Oregon when they arrived in the United States.

Most foreign-born individuals (78%, n=14/18) said they have concerns about their legal status. The most common concern (n=10) was being deported because of a lack of medical care in the country of origin. Other concerns included difficulty getting employment without legal papers, inability to get disability benefits if unable to work, and inability to travel to see children living outside the United States.

Travel between countries was not common. Most (56%, n=10/18) said they never return to their home country; six said they return less than once per year, and two said they return yearly. Only four (22%) said they had plans of returning permanently to their home country.

### Employment and Education:

Most respondents (65%, n=15) reported some kind of employment, including four working full-time, seven working part-time, and four working odd jobs or temporary work. The most common reason for unemployment was lack of available work (n=5); other reasons were poor health (n=2) and legal issues/recent incarceration (n=1).

About half of respondents (52%, n=12) reported having less than a high school education and another 26% (n=6) had a high school education or GED. Three reported some college and two reported having a four-year college degree.

### Housing:

Most respondents (70%, n=16) said they currently live in rental housing. Four respondents reported living in a house that they or their partner own and three said they were temporarily staying with friends or family. About half of respondents (n=12) said they had lived in two places in the past 12 months, while the other half reported only living in one place.

### Health Care History and Coverage:

Nine respondents (39%) reported that before they became HIV-infected, they received medical care from a private doctor and five said their usual source of health care had been the health department clinic. However, nine respondents (39%) said they didn't have any health care before HIV "*because I wasn't sick.*"

All but one respondent said they had some type of health care coverage. Thirteen respondents (57%) said they were insured through CAREAssist, three cited private insurance, two cited a public program (i.e., OHP or OMIP), and three said they didn't know what kind of insurance they had. The one uninsured person was newly infected. That respondent reported having information about available medical care and services, and had plans to initiate services soon.

### HIV Testing History:

Newly reported HIV cases were not always new diagnoses. Only 11 of the cases reported during the study time period (9/1/09-3/31/10) were newly diagnosed during that time period (n=7) or one month prior (n=4). Four had been first diagnosed earlier in 2009, five had been diagnosed 2-10 years earlier, and three had been diagnosed more than 15 years earlier. The most common site of initial tests (52%, n=12) was a health department clinic, but seven respondents reported initially testing positive at a hospital, either an emergency department or urgent care center (n=5) or as an inpatient (n=2). Two other respondents first tested positive as part of a medical study and one first tested positive at home: "*my friend is a medical assistant and had some rapid tests. We were basically joking around, but mine came out positive.*" All respondents received their results within two weeks or less, usually from a medical provider (n=18).

About 1 in 3 respondents (35%, n=8) said they had been tested for HIV before they first tested positive. Four had only tested once before and four had tested two to four times before testing positive.

Most (78%, n=18) said that getting tested wasn't difficult for them, including 11 who said that their testing experience was "*fine*" or "*easy*" and seven who said that they never thought about



getting tested (e.g., “they just did it at the emergency room”). Three others said that “fear” was a barrier to testing and two cited provider-level barriers:

*“There are too many questions for two people to be looking at you—the doctor and the interpreter. It’s embarrassing.”*

*“The doctor didn’t provide it. She kept giving me medicine for scabies because I had a bad rash. But it wasn’t until I asked for an HIV test after I broke up with my boyfriend that I got it.”*

Nine respondents reported having basic knowledge of HIV when they first tested positive (e.g., “I knew you could get it through needles, blood, the basic stuff”), while six said they knew quite a bit (e.g., “I knew about it pretty well. I’ve had friends who have been positive for years.”). Six said they knew very little or nothing about HIV when they first tested positive and two said they believed it was immediately deadly:

*“I didn’t know anything. I hadn’t heard anything about it, only what was on TV.”*

*“[I knew] nothing, nothing, nothing.”*

*“I knew what it was, but I thought it was deadly, so when I got diagnosed, I thought I only had a few days left to live.”*

#### Reasons for Getting Tested:

One of the most common reasons respondents gave for getting tested for HIV was that they were sick (43%, n=10):

*“I didn’t ask for it. They asked if they could do it since they couldn’t find out what was wrong with me. I was admitted for two weeks and had a bad stomach ache.”*

*“I had rashes on my face that wouldn’t go away. I had several tests done, including the one for HIV.”*

*“I got really sick, really bad headaches, so I went to the ER. They said I had a virus in my head. They did a bunch of tests, including HIV.”*

Ten other respondents tested because they had a history of some kind of transmission risk, either a HIV-positive partner (n=4) or unprotected sex (n=6):

*“My boyfriend found out at the hospital that he was HIV-positive. He went in for an abscess. So later, I decided to get tested. We didn’t use condoms and we shared needles, but only with each other.”*

*“I didn’t use protection and I went to bars. I was young. I decided to participate in the [HIV MSM] medical study.”*

Three respondents were tested for other reasons, such as part of a routine medical exam.

#### HIV Risk Factors:

Among the three female respondents, all reported sex with men only; two reported a history of injection drug use. Among the 20 male respondents, seven reported sex with women only, six reported sex with men only, and six reported sex with both; one refused to answer the question. None of the male respondents reported a history of injection drug use.

Three respondents—two males and one female— reported being incarcerated for more than two days at some point in their lives.

#### HIV-Related Medical Care:

Most respondents (74%, n=17) reported receiving medical care within three months of their initial diagnosis. One respondent had been positive for less than three months at the time of the interview and, although not yet in care, reported plans to seek medical care in the near future. The other five who did not initially receive medical care reported various reasons for the delay, including lack of insurance (n=2), inability to make appointment because of work schedule (n=1), “not being ready,” (n=1), and not going because “I didn’t know there was a cure” (n=1). Delays in accessing medical care were not associated with concerns about legal status. All but the one very recently diagnosed respondent reported receiving medical care now.

Thirteen respondents reported no barriers to accessing HIV medical care. Barriers identified by the 10 respondents who encountered them included language difficulties (n=3), embarrassment and/or privacy issues (n=3), lack of information about medical care and other services (n=2), paperwork (n=1), and work schedule conflicting with clinic hours (n=1).

#### HIV Status Disclosure:

Just over half of respondents (52%, n=12) said they have told someone that they have HIV, and about half (n=11) said they know someone else who has HIV. However, there was no correlation between knowing someone else with HIV and disclosure of one’s own status ( $p = 1.0$ ). We asked respondents: “What, if anything, has made it hard to talk with family and friends about having HIV?” The most common factor respondents identified was fear of rejection or being affected by HIV stigma (61%, n=14):

*“My children know that I’m sick, but they don’t know what it is. I don’t know what they will say or how they will react. They’ll think I’ve been bad here, and my wife will probably leave me, and I would end up with nothing.”*

*“No, no one knows. Only my wife knows. Others might think that by touching me or being close to me, I will contaminate them.”*

*“It’s too many changes. I came out when I arrived in the U.S. and my family didn’t accept it. My brothers just accepted it only recently. I couldn’t add this news to that right now.”*

Other factors that made it difficult to disclose status to friends and family included distance (n=3) (e.g., *“My family is in Mexico and I don’t want to tell them over the phone”*) and privacy or the feeling that no one else *“needs to know”* (n=3) (e.g., *“It’s none of their business. I’m an old man, a free man. They don’t need to worry or be burdened by this”*).

#### HIV Prevention Activities:

Participation in available HIV prevention activities in Oregon was far from universal. Most commonly, respondents reported receiving STD testing (65%, n=15). About half of respondents (n=11) had seen billboards addressing HIV prevention among Latinos, 10 had engaged in HIV risk reduction counseling, and 10 had participated in partner notification services after testing HIV positive. Engagement with other prevention activities was rare. Three respondents reported seeing online messages about preventing HIV in Latinos, but none could remember the names of the sites where they encountered the messages. Only one person reported participation in a needle exchange program and none of the respondents had received HIV information or testing at a migrant work camp.

When asked *“What kinds of things are you doing to prevent HIV transmission?”* almost equal numbers of respondents reported using condoms (n=11) or being abstinent (n=9). Three respondents also mentioned keeping their personal hygiene items separate from other household members (e.g., *“I keep all my things separate, my towels, shaving razor, and so on”*).

Only one of the 23 respondents reported participation in a support group or other type of group HIV prevention activities. Some respondents said they didn’t participate because they didn’t know about groups or couldn’t get away from work to attend, while others stated an active disinclination towards participating in a group HIV activity (e.g., *“No way. I will not be involved in any of those groups. They are mostly for homosexuals and that is not me”*).

#### *Part III— Comparison of Data from Case Reports vs. Interviews*

We compared four data elements from the standard HIV case reports with data collected in interviews with the 23 respondents for congruity: gender, race, country of birth, and HIV risk factor. There was a 100% match between data sources on gender, but less congruity on the other three data elements (Table 3).

Congruity on race was difficult to assess because so many respondents stated in the interview that they consider their race to be Hispanic, whereas standard data collection protocols classify Hispanic as an ethnicity, not a race. However, one respondent who identified as American Indian was classified on the case report as white.

Country of birth was missing on the HIV case reports for five respondents. Among the remaining 18 respondents, data on country of birth were incongruous for three respondents (17%): one case report listed the respondent as foreign-born, whereas the respondent identified as American; two listed the respondent as born in the United States, whereas the respondents identified as foreign-born.

HIV risk data were missing on the HIV case reports for four respondents. Among the remaining 19 respondents, data were incongruous for one respondent (5%) who was identified on the case

report as MSM, but told the interviewer he had sex with “women only.” Among the four individuals with missing risk data on the case report (all male), three identified their risk as heterosexual and one as MSM during the interview. In addition, one male who was listed as heterosexual transmission risk on the case report refused to answer the question during interview.

As mentioned previously, the interviewer also discovered three individuals among the 56 identified as Hispanic on the HIV case reports who denied Hispanic ethnicity when asked as part of the interview eligibility screening.

**Table 3: Incongruous Data Elements, HIV Case Reports and Interview Data**

<b>Data Element</b>	<b>N incongruous</b>	<b>HIV Case Report</b>	<b>Interview Data</b>
Gender	0 of 23	---	---
Race	1 of ?	White	American Indian
Country of Birth	3 of 18	El Salvador U.S. U.S.	U.S. Guatemala Mexico
HIV Risk	1 of 19	MSM	Sex with women only
Hispanic ethnicity	At least 3 of 56	Hispanic	Not Hispanic

## Discussion

This special surveillance project demonstrated both the feasibility and challenges of interviewing Hispanics newly reported with HIV. Among those reached, all participated and nearly 100% of interview data elements were complete. However, a majority of potential interviewees could not be reached, including about 1 in 4 with telephone numbers that had been disconnected in the weeks or months between case reporting and telephone follow-up.

As would be expected from epidemiologic data, most interviewees were foreign-born, primarily from Mexico. The interviews, however, help enrich our understanding of this group of HIV-infected Hispanics living in Oregon. Most foreign-born respondents have lived in the United States for more than a decade, are working, and plan to stay permanently. However, most have concerns about their legal status, and worry about deportation, primarily because of the lack of medical services that would be available to them in their countries of origin. Travel between countries was uncommon, indicating that international acquisition and/or transmission of HIV is not a likely possibility.

Most respondents did not report barriers to getting HIV tested or to accessing medical care once infected. However, many respondents reflected a social norm of not accessing medical care unless one is sick. About 4 in 10 said they did not receive health care prior to HIV diagnosis because they felt there was no need for it. Likewise, 43% of respondents got HIV tested because they were ill, including seven who were tested at the hospital when their HIV infection was likely very advanced.

On the positive side, the HIV care system in Oregon appears to be working well, since all respondents but one reported current health care coverage and participation in HIV medical care. Most respondents accessed medical care within three months of diagnosis, as recommended, and delays in medical care were not associated with concerns about legal status. In addition, the respondent who was not yet in care reported plans to enter care soon, and the current lack of care was related to recent diagnosis rather than barriers to care.

Social support around HIV appeared to be lacking among this group of interviewees. About half had disclosed their HIV status to at least one person and about half reported knowing someone else with HIV, but there was no correlation between status disclosure and knowing someone with HIV. Respondents commonly identified fear of rejection or HIV stigma as a barrier to status disclosure. In addition, only one respondent reported participation in an HIV support or education group.

Patient data like demographics and HIV risk factors were usually complete on HIV case reports, but were not always accurate. Misclassifications related to race, ethnicity, risk factor, and country of origin occurred among 5-17% of the small numbers of cases with data available from both sources. Evaluation with larger samples of data would be necessary to determine the extent of the misclassification problems.

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### Attachments:

1. Special Surveillance Project Interview Guide (English)
2. Results of HIV Case Report Review from 11/1/08-10/31/09