UNIVERSITY OF HAWAI'I SYSTEM ANNUAL REPORT

REPORT TO THE 2009 LEGISLATURE

REPORT ON THE HAWAI'I AIDS RESEARCH PROGRAM

FOR 2008 AND 2009

Act 213, SLH 2007 (Section 87)

November 2008

REPORT ON THE HAWAIʻI AIDS RESEARCH PROGRAM
2008 – 2009
November 4, 2008

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The Hawaiʻi State Legislature appropriated general and revolving funds for the University of Hawaiʻi at Mānoa (UOH 100) in the sums of $800,000 and $400,000 respectively for fiscal year 2007-2009 and similar amounts for fiscal year 2008-2009 to support the Hawaiʻi AIDS Clinical Research Program (HACRP)'s operational costs. This report provides a status report for fiscal year 2008-2009 on the state of the program.

HACRP remains a strong, active and viable program within the Department of Medicine, John A. Burns School of Medicine, University of Hawaiʻi at Mānoa. It's clinical and laboratory research capability remains intact, including its personnel resources and infrastructure for the conduct of HIV clinical trials. The State appropriation has enabled HACRP's Clint Spencer Clinic to expand and provide high quality care to HIV-infected individuals in Hawaii. In addition since State support of our program started in July 2007, grants which HACRP was able to apply for because of its intact infrastructure have brought in over $20 million in new funds into the University of Hawaiʻi system. In future years HACRP has requested that the funds to support the program be part of the University of Hawaiʻi's biennium budgetary request to the legislature. We have also initiated efforts to obtain an official Center designation from

the University Board of Regents to formalize its HIV training, research and care operations.

Fiscal Year 2008-2009 appropriations continue to be used for salaries of programmatic personnel and for operating costs. The funds have enabled HACRP to retain its programmatic personnel and the ability to conduct research, training and medical care activities. Salaries (% FTE) for the following individuals have been supported by these funds: Faculty [C. Shikuma (16.9%), B. Shiramizu (48%), J. Rudnick (25%), A. McMurtray (27%), L. Marten (5%), L. Eron (1%), M. Gerschenson (12%), D. Chow (20%), K. Tata (13%), N. Hu (55%), V. Valcour (27%)]; Administrative/Fiscal Support R. Ichimura (100%), Unit Coordinator D. Ogata-Arakaki (30%), Nurse Practitioner C. Milne (1%), Data Manager R. Visalli (25%), and Clinic Coordinator J Chapman (50%). In addition, funds support research pharmacy services through Queen's Medical Center and approximately $8,000 was expended in operating costs such as copier rental and maintenance, water, pager and physician exchange services.

HACRP continue to focus efforts in two crucial areas – providing ready access to and enhancing care for HIV-infected individuals in Hawai‘i and in developing and maintaining a nationally competitive HIV research program for the University of Hawai‘i:

Access to HIV Care:

Our programmatic goals in this area have not changed. They are to provide high quality HIV medical care to disproportionately affected and underserved populations and to act as a HIV consultative resource for the medical community and related health organizations. State funding continues to enable HACRP to operate its Clint Spencer Clinic which provides HIV specialty consultative care as well as primary care for HIV-infected individuals. Currently 5 faculty MDs, one Nurse Practitioner, and one RN Clinic Coordinator/Patient Advocate devote some time during the week to provide care for approximately 439 HIV-infected individuals on Oahu and on the neighbor islands. A social worker from Oahu's AIDS Service Organization (Life Foundation) is available every other Wednesday to assist patients with social service needs. Clinic is held one-half-day/month each on the Hilo and Kona side of the Big Island as well as on Maui.

The Clint Spencer Clinic acts as a 'safety net' to ensure that quality health care is available to all HIV-infected individuals in Hawai'i regardless of the ability to pay. The clinic serves a relatively poor population with less than 50% of individuals having private insurance and approximately 10% with no insurance.

With support and guidance from the Hawai'i State Department of Health, Dr. Lisa Marten from our program completed a 'needs assessment' study to better understand how we can support HIV medical care in locations with insufficient HIV specialists available. A copy of the report is attached. In short, the study found that the State of Hawai'i faces

particular problems in maintaining an adequate HIV medical care delivery system due to the relatively small HIV infected patient population, the geographic segmentation of that population, aging of the community physicians providing HIV care coupled with the lack of interest in HIV specialization among young physicians. It is suggested that future strategies to provide care focus on two key elements, particularly in rural areas: resilience (system that can recover from or resist being affected by a disturbance, such as the departure of one particular physician) and multiple patient care options. While the majority of HIV-infected individuals currently manage to receive adequate care and are satisfied with the quality of care they received, a small section of the HIV infected population who are disadvantaged in multiple ways (homeless, low levels of education, poor, insured through public assistance) are likely to require outreach and ancillary services beyond the scope of community physicians.

HIV Research

The state funds continue to provide needed stability to HACRP faculty to write for and accept grants from the National Institute of Health (NIH) and other grant agencies, as well as to have the appropriately trained personnel available to conduct such research.

HACRP has now completed the phase-out of HACRP's participation in trials of the national AIDS Clinical Trials Group (ACTG) trials. HACRP hopes to apply for re-entry in the future when the opportunity presents itself. Increased participation in the AIDS Malignancy Consortium, a NIH-funded multi-center network of sites participating

in trials of HIV-related cancers is planned. In an existing new opportunity, HACRP successfully applied to become one of 8 national sites funded to conduct research in cardiovascular risk in HIV-infected individuals. HACRP continues to participate in the Vietnam PEPFAR (President's Emergency Plan for AIDS Relief) program. Participation in this program now not only includes funding to support HIV care and treatment but also for HIV prevention efforts as well.

In our previous fiscal year 2007-2008 report, we reported receiving grants worth $8 million in total funding for the University of Hawai‘i. New since this last report, the following additional grants worth $12.9 million in total funds for the University of Hawai‘i have been awarded to our program.

R01NS063932-01 Shikuma, C (PI) 08/15/08 – 07/31/13 "HIV and Global Drug Therapies: Peripheral Neuropathy Complications and Mechanisms" The major goal of this project is to define the extent and pathophysiologic mechanisms involved in the neuropathy complications seen with common HIV antiretroviral regimens used globally for the treatment of HIV $3,461,838.00 over 5 years.

R01HL095135-01 Shikuma, C (PI) 09/25/08 – 06/30/13 "Role of Oxidative Stress and Inflammation in HIV Cardiovascular Risk" Major goal of this project is to assess the role of oxidative stress and inflammation in cardiovascular risk in the HIV-infected population $4,509,780.00 over 5 years.

R01NS061696-01A1 Valcour, V (PI) 08/15/08 - 07/31/13 "Peripheral Reservoir of HIV DNA I Monocytes Pivotal to Cognition in HIV" Major goal of this project intends to evaluate cognitive, structural, and chemical correlates to HIV DNA in a population initiating HAART for the first time $3,255,961 total funds over 5 years.

1K23HL088981-01A2 Chow, D (PI) 09/19/08 - 06/30/2012 "Cardiovascular Autonomic Function in HIV Virologic Failure" Major goal of this project is to study the effects of HIV viremia on direct and indirect autonomic function and other cardiovascular markers $579,960 total funds over 4 years.

1406-04-06-CT-60058 09/30/08 – 09/29/09 President's Emergency Plans for AIDS Relief, subcontract through the U.S. Department of Defense $230,731.00 total funds.

GS09Q08CZM2019 09/29/08 – 09/28/09 President's Emergency Plans for AIDS Relief, subcontract through the U.S. Department of Defense $597,573.58 total funds.

GS09Q08CZM2020 09/29/08 – 09/28/09 President's Emergency Plans for AIDS Relief, subcontract through the U.S. Department of Defense $229,102.01 total funds.

In summary, with approximately 6 months still left in the 2 year period of funding appropriated for our program, our program has brought into the University of Hawai‘i system total funds (direct and indirect) of over $20 million, a substantial twelve to one return on the state G funds appropriated.

HAWAI'I STATE-WIDE HIV/AIDS MEDICAL CARE NEEDS ASSESSMENT

HACRP

The Hawaii AIDS Clinical Research Program at Leahi

Also available online at www.hawaii.edu/hacrp/HawaiiHIVCare.pdf

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ACKNOWLEDGEMENTS

The assessment was conceived of and supported by Dr. Cecilia Shikuma, director of HACRP. Dr. Lisa Marten headed the project, with collaboration from Nicole Valcour, Dominic Chow, Joel Chapman, Debbie Ogata-Arakaki and other HACRP staff. The Department of Health offered support and guidance from the earliest stages of the project.

MAHALO to the many individuals and organizations that provided data, helped distribute surveys or provided technical assistance for this assessment.

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Peter Whiticar (STD/AIDS Branch)
Tim McCormick (HSPAMM)
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Sandy Qui (HIV/AIDS surveillance)

Insurance Providers (aggregate data only)
Medicaid
Tricare
Kaiser
University Health Alliance
AlohaCare
Hawai'i Medical Service Association

ASOs
Hawai'i AIDS Education and Training Center
Hawai'i Island HIV/AIDS Foundation
Malama Pono
Maui AIDS Foundation
The Life Foundation

Clinics
Clint Spencer Clinic
Ho'ola Lahui
Maui Community Health Center
The Bay Clinic
Waianae Coast Comprehensive Health Center
Waikiki Health Center

Other Service Providers
Fred Cruz (CVS Procare)
Gregory House
Save the Food Basket

HIV Physicians (interviews)
Kay Bauman
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Irving Brown
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JABSOM (review of statistical analysis)
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ABBREVIATIONS

AACTU	Adult AIDS Clinical Trials Unit
AAHIVM	American Association of HIV Medicine
AIDS	Acquired Immunodeficiency Syndrome
API	Asian Pacific Islander
ART	Antiretroviral therapy
ASO	AIDS Service Organization
CCM	Community Clinic of Maui
CHC	Community Health Centre
CSC	Clint Spencer Clinic
DBEDT	Department of Business, Economic Development & Tourism
DOH	Department of Health
GIS	Geographic Information Systems
GPs	General Practitioners
HAART	Highly active antiretroviral therapy
HACRP	Hawai'i AIDS Clinical Research Program
HAETC	Hawai'i AIDS Education and Training Center
H-COBRA	Hawai'i Insurance Continuation Program
HDAP	Hawai'i AIDS Drug Assistance Program
HIHAF	Hawai'i Island HIV/AIDS Foundation
HIV	Human Immunodefiency Virus
HMA	Hawai'i Medical Association
HMSA	Hawai'i Medical Service Association
HRSA	Health Resources and Services Administration
HSPAMM	Hawai'i Seropositivity and Medical Management Program
ID	Infectious Disease
IDU	Injection drug user
JABSOM	John A. Burns School of Medicine
MAF	Maui AIDS Foundation
MD	Medical doctor
MSM	Men who have sex with men
NP	Nurse Practitioner
PEP	Post Exposure Prophylaxis
PLWHA	People living with HIV/AIDS
PA	Physicians Assistant
SPNS	Special Projects of National Significance
STIs	Sexually Transmissible Infections
TA	Technical Assistance
UHA	University Health Alliance
VA	Veterans Affairs
WCCHC	Waianae Coast Comprehensive Health Center
WHC	Waikiki Health Center

1. INTRODUCTION

The State of Hawai'i faces unique challenges to providing quality medical care to over 2,700[1] people confirmed to be living with HIV due to the segmented island geography, combined with general physician shortages (not just for HIV), and sparse HIV-infected populations in rural areas. In areas with sparse HIV-infected populations, few physicians have the critical mass of patients that would engender developing and maintaining expertise in HIV. Of the 9 physicians in Hawai'i with the American Academy of HIV Medicine credential,[a] only one lives on a neighbor island. Studies have found that greater physician experience with HIV is associated with better choices for HIV care and with higher patient survival rates.[2] Patients in Hawai'i tend to concentrate among a few providers on each of the neighbor islands. When one of these retires or leaves, there are sudden access to care problems for their patients. This situation has been experienced over the last five years on Kauai, Hawai'i, Maui and West Oahu. Many community physicians, including ones with HIV expertise, do not take new patients due to overburdened practices.

Even in Honolulu, there are concerns about possible shortages of HIV specialists in the future due to heavy reliance on a handful of community physicians who have developed expertise in HIV over the last 20 years. Five community physicians with the heaviest HIV patient load see about 500 patients. Only eight additional community physicians are known to care 10 or more HIV patients. Many of these highly experienced physicians are approaching ages at which some physicians retire. Some physicians of the same generation see patients through non-profit, government or HMO clinics. However, it is more likely that these clinics will replace staff as needed and continue to serve their patient populations, numbering currently around 800.

The Hawai'i AIDS Clinical Research Program (HACRP) has played a role addressing these concerns in the past and desires to be ready to play a greater role if needed in the future. HACRP staff established the Clint Spencer Clinic (CSC) at the program's Leahi Hospital site in 2002 to meet the needs of patients who finished research protocols and did not have alternative sources of medical care. In response to loss of care providers in rural areas, and at the request of AIDS Services Organizations (ASOs) seeking to meet their client's needs, the CSC has expanded services geographically. At the time of the study the clinic had grown to 117 currently active patients at the main Leahi site, and an additional 69 currently active patients in four satellite locations at various stages of maturity (Hilo, Kona, Maui and Waianae). The clinic has also been pushed to expand the scope of its services from HIV-specialty care to include general primary care as many of the patients do not have a primary care physician. This occurs both in Honolulu and at the satellite clinics.

The CSC is committed to continue this role as a safety net for PLWHA who otherwise would not be able to access quality care because of lack of providers, lack of health insurance, or because their care is particularly complex. In order to better define the

[a] This credential requires the licensed MD to see 20 patients over 2 years, to have 30 credits of HIV continuing medical education, and to pass a test.

role of the CSC and to devise a strategy to fulfill that role, HACRP conducted this State-wide HIV/AIDS Medical Care Needs Assessment. This needs assessment in no way attempted to evaluate the quality of care provided. The focus was on access to care, satisfaction with care, and the problems faced by those providing the care. While this needs assessment is primarily a planning tool for the CSC, it is hoped other programs concerned with the well-being of PLWHA in Hawai'i will also find it useful.

2. METHODS

Several sources of data were used for this report. These include a survey of consumers and of providers, interviews with key informants and use of third party data.

2.1 Consumer survey

An anonymous consumer survey, approved by the University of Hawai'i's Committee on Human Studies (the Institutional Review Board of the University), yielded 362 responses. Of these, three were excluded as duplicates.[b] The remaining 359 responses included in the analysis make up about 13% of the estimated population of people living in Hawai'i with an HIV diagnosis. Respondents were well distributed across the state with a slight overrepresentation from the neighbor islands. A map indicating the number of respondents from each service delivery area and the distribution of respondents within that area can be found in Attachment 7.1. Demographically, respondents were very similar to the State population of PLWHA described by Department of Health data in terms of age, gender, ethnicity, source of infection and island of residence. This can be seen graphically in section 5.1. The survey instrument can be viewed in Attachment 7.5.

Respondents were not selected randomly, but rather a convenience sample was used. Therefore, the survey may not be representative of the general responses of PLWHA in Hawai'i. In particular the survey is biased towards those who access services. This sampling method was necessary due to the small population of PLWHA in Hawai'i and the stigma attached to the disease. The needle exchange program, for example, could not distribute surveys as they do not know the HIV status of their clients.

Therefore, all four ASOs, CVS Procare, the Waikiki Health Center and the Clint Spencer Clinic distributed survey forms which were returned by business reply mail (263). Save the Food Basket allowed Dr. Marten to distribute and collect surveys during their lunches (47), Gregory House distributed surveys among their clients (14), and a receptionist at the Life Foundation distributed and collected surveys of clients visiting their offices (25). These surveys distributed and collected by hand were particularly important in collecting data on disadvantaged individuals who might not have been able to read and fill out surveys independently. CVS Procare generated 65 respondents by sending out surveys with home

[b] The answers, including comments, were identical. It is likely the respondents simply forgot they had already filled out the survey.

delivered HIV prescriptions. CVS Procare patients include individuals who do not access ancillary HIV services.

One outcome of particular interest from the survey was to learn who was not accessing a minimum standard of care. An indicator of receiving a minimum standard of care was constructed from survey responses reporting whether the patient sees an HIV doctor and/or has CD4 and viral load lab tests performed at least every six months. All insurers, including Medicare and Medicaid, will pay for visits and labs of these frequencies. In Hawai'i, PLWHA who are uninsured *and* do not want to go to a clinic which charges for services on a sliding scale, can still receive these services every six months through the HSPAMM program. The HSPAMM program will pay physicians for an office visit and a panel of laboratory tests every six months.[c] Therefore we assume those who do not receive care of this frequency are falling out of care, not because of medical fees, but due to other barriers. This "minimum frequency of care" falls below the current recommended standard of receiving these services every three months.

The outcome variable "Care frequency < 6 months" was based on responses to the questions:

In the last year, how often did you receive the following types of medical care?	never	Less often than every 6 months	At least every 6 months
Visit a doctor / nurse for primary care *(vaccinations, colds, minor injuries)*			
Visit a doctor / nurse for HIV care *(T-cell and viral load monitoring, managing antiretroviral medications)*			
CD4 counts			
Viral load			

The majority (301) of those received the coding "Care frequency $\geq$ 6 months." This means they responded that they saw a primary care provider, an HIV specialist, or both, and they also received laboratory tests at least once every six months. Some of these wrote down their exact CD4 or viral load value rather than checking the box and this was still coded as "Care frequency $\geq$ 6 months." 46 indicated that they did not receive *any* of the services at least every six months and they were coded "Care frequency < 6 months."

There were 11 respondents who had contradictory responses. They reported they saw care provider/s at least every six months (7) or they had CD4 counts and viral loads every six months (4), but not both. After careful review, these were coded as "Care frequency $\geq$ 6 months." All had medical insurance, either private (5) or public (6). All had positive assessments of their care providers. The 9 that chose to report the name of their care providers listed HIV specialists known to be committed and knowledgeable.[d] It is the belief of the investigator that these physicians would not see a patient without ordering labs at least every 6 months and would not receive unsatisfactory laboratory results without following up

[c] The financial incentives for the physician to use HSPAMM or insurance depends on the type of insurance the patient has. All but one physician in private practice with large HIV case loads use HSPAMM for at least some of their patients.

[d] Frank (3), Kovach (2), Kalauawa (2), Goshima (1) and Morrison (1).

with the patient. Combining this group with those who had clearly fallen out of care might obscure the results of the analysis. To see how this decision may have impacted the results, the analysis was run with this group coded as "Care frequency < 6 months." The only significant difference was an association between female gender and care frequency not OK in the *unadjusted* model. When other variables were included, being female lost significance. This effect is due to the unusually high proportion of this group that is female (5 out of 11).

2.2 Provider survey

Data was collected on 89 providers through a brief survey filled out by the following means.

- Mailing with a business reply envelope to all physicians known by the DOH to have diagnosed or treated an HIV patient (81 sent, 19 responses).
- Distribution and collection during an HAETC dinner lecture (16 responses, including 5 non-physicians whose responses were not included in patient counts due to redundancy with physicians). Those that responded were spared the mailing.
- Distribution and collection during Queens Hospital grand rounds and chief resident training (36 responses, but 18 had no HIV patients).
- Phone calls to significant care providers who did not respond to the mailed survey (12 responses).
- Information provided by case managers at the local ASO regarding providers who did not respond to the survey (6 cases).

There are many limitations with the data collected.

- Many provider surveys were incomplete.
- The data only represent the time of the survey, the winter of 2007/2008.
- The quality of the data enumerating patient load is variable. Some providers and clinics furnished precise numbers of patients currently under care, but others merely estimated their HIV patient load. Where possible, physician estimates were refined with HSPAMM, ASO and clinic data.
- There may be multiple counting of the same patients as some patients may see more than one provider.
- Medical residents included in the survey may not stay and practice in Hawai'i.

Data was gathered on almost all providers with significant patient loads. This is verified by a comparison with physician names provided by respondents to the consumer surveys, and with HSPAMM data. No physicians with more than 2 mentions in the consumer survey and 4 physicians with case loads of 5 or more with HSPAMM last year were not interviewed or surveyed. Of these 4, one had retired, and one cares for patients at Kaiser on Maui and his patients are included in the Kaiser data.

2.3 Interviews with key informants

Site visits were made to all the islands and an attempt was made to visit key providers, in particular community clinics and ASOs. Additional service providers were interviewed by phone. These unstructured conversations focused on the issues facing care

providers and their clients, and their opinions on possible solutions. Individual care providers and multiple staff from the organizations provided interviews which informed this study:

Oahu: Erlaine Bello, Willis Chang, Corrections (Kay Bauman, Glen Morrison), Tim Dueller, Jennifer Frank, Cyril Goshima, Hawai'i AIDS Education and Training Center (Chuck Lyden, Kevin Patrick), James Joyner, Drew Kovach, Department of Health (Peter Whiticar, Tim McCormick), The Life Foundation (case managers), Waianae Coast Comprehensive Health Center (Ricardo Custodio), Waikiki Health Center (Elliot Kalauawa, Bryan Talisayan, Lindi Chun), and Veterans Affairs (Arthur Johnson)

Hawai'i: Stefan Harmeling, Hawai'i Island HIV/AIDS Foundation (case managers from Hilo and Kona), and The Bay Clinic (Ralph Brown, Paul Strauss)

Kauai: Ho'ola Lahui (Jason Laird, Salvatore Abbruzzese), Malama Pono (DQ Jackson, Linda Arn), and James Yoon

Maui: Ronald Kwon, Maui AIDS Foundation (Keith Wolter, case managers), and Community Clinic of Maui (Irving Brown, Linda)

2.4 Data from other sources

Insurance carriers: Non –identifying data was provided by Medicaid, Tricare, Kaiser, University Health Alliance, AlohaCare, and Hawai'i Medical Service Association on their clients with HIV/AIDS. They were requested to provide the aggregate number of clients in the State of Hawai'i with an HIV or AIDS diagnosis by zip code. They were also requested to provide the percentage of these clients who had a greater than 6 month period between "billing code 042" visits in the most recent available annual time period. The method for identifying the gap between visits varied by institution as their data are organized differently, and thus these rates may not be perfectly comparable to each other. For security reasons, Tricare was not able to break down their numbers by zip code. Kaiser did not check for gaps between billing periods. Medicare insures numerous PLWHA in this state, and the analysis suffers from its absence, but obtaining Medicare data was prohibitively expensive.

HSPAMM: A state-funded program open to all PLWHA which pays for an office visit with the individual's own physician and laboratory tests twice a year. Laboratory results and forms filled out by the patient and doctor are sent with coded identifiers to the HSPAMM office. Data used for this study include the insurance information available on the 773 clients enrolled and numbers of HSPAMM patients seen by providers from March 2006 to February 2007.

Reggie System: Demographic and service data on clients benefiting from Ryan White Title II funding is inputted by the ASOs and clinics receiving Ryan White funds into a single computer program called the Reggie system. Specific de-identified data was pulled for all of the ASOs and aggregated for use in this study. 1,056 clients were active at the time of the data pull in May 2008.

Department of Health HIV & AIDS Surveillance Program: The Department of Health collects data on people in Hawai'i with AIDS (reportable by name since 1983) and HIV (reportable by unnamed test code but transitioning to a named system since March 2008). It provided information from its surveillance program on all people known to be currently living in Hawai'i with AIDS or HIV, regardless of where they were diagnosed. This is different from available DOH reports which include only AIDS cases diagnosed in Hawai'i. Data not usually released on people with HIV but not AIDS was provided, but this data may not be complete as there are problems with the coded system.

3. BACKGROUND ON HIV/AIDS MEDICAL CARE

3.1 Who should provide HIV/AIDS medical care?

The type of providers and settings best suited to treat HIV has been a topic of debate. There is concern about lags in adopting complex and changing best practices for HIV treatment, which are often known and available well in advance of their appearance in formalized treatment guidelines or recommendations. These lags are found to be shortest in sites that specialize in HIV care and have high HIV patient volumes[3] and among physicians with high case loads who are infectious disease physicians or general practitioners with self-reported expertise in HIV.[4] Some have argued that due to the complexity and changing nature of HIV treatment regimens, care should ideally be housed in University-based settings.[5]

However, studies indicate that appropriate care can be provided by different types of providers in different settings with the common requirements being a high HIV case load and continued specialty training. One study found that physicians who self-educate and have high case loads (20+ patients), regardless of whether they are ID physicians or generalists, provide better care.[6] Another study looked at patterns of care over time and documented that regardless of calendar year, incremental increase in using recommended treatment regimens as case loads increased from 1 to 5 to 10 to 25. Again, the specialty of the care provider and the setting did not matter.[2] Where experts are not available, as in rural areas, physicians with even small concentrations of patients (4+) have been shown to provide better care than those with fewer patients.[7]

From the sparse data available, it appears that family physicians with low volumes of patients were more active in care earlier in the epidemic.[8,9] Increased referrals by primary physicians to specialists documented in regional studies may be a result of the increasing availability of HIV clinics as well as the growing complexity of management of HIV/AIDS patients.[10,11]

Nurse practitioners (NPs) and physician assistants (PAs) now also provide primary care providers for patients with HIV in many Ryan White CARE Act funded clinics. A study

comparing the quality of care provided by NPs and PAs and physicians at 68 Ryan White funded HIV care sites found the quality of HIV care provided by NPs and PAs was similar to that of physician HIV experts and generally better than physician non-HIV experts. These results are exclusive to NPs and Pas who have high levels of experience, focus on a single condition, and have easy access to physicians with HIV expertise.[12]

3.2 What is the recommended model for HIV/AIDS medical care?

The dominant model advocated for HIV care is quite different than that used to treat other infectious diseases. Rather than a single infectious disease physician, a multidisciplinary team is recommended to provide support services to address the multiple challenges of people living with HIV. Numerous studies have documented how ancillary services are associated with improved use of care which is associated with better health outcomes among people living with HIV. [13,14,15]

This model was first established in urban hospital-based clinics in San Francisco where physicians, nurses and social workers provided a range of inpatient and outpatient services.[16] Others, such as the Whitman-Walker Clinic in Washington DC, have further expanded the constellation of support services to include legal counseling, a food bank, day treatment, transportation as well as a wide range of case management, counseling, and outreach services targeting mental health, substance abuse, adherence and HIV prevention.[17]

The Health Resources and Services Administration (HRSA) has influenced the way care is provided through funding development of "specialized medical care models within the context of a continuum of services in a medical clinic" through the Special Projects of National Significance (SPNS) Program[3] and through funding patterns for ongoing Ryan White programs. HRSA claims that "it is this [service] continuum, nurtured by the CARE Act, that clears away barriers to HIV primary care."[18] The Ryan White HIV/AIDS Treatment Modernization Act of 2006 departed from previous versions of the act by requiring that the core medical services receive 75% of funds allocated to Part A, B and C beneficiaries. Parts A, B and C account for 94% of the over two billion dollar budget. While the new guidelines reduce funding for support services such as housing and food programs, the definition of core medical services is still quite broad. In addition to direct medical care and drugs, 'core medical services' include medical nutrition therapy, mental health services, substance abuse outpatient care, medical case management, and some community-based health services.

The perceived success of the HIV integrated clinic model has inspired HRSA and others to promote additional health programs in these clinics such as counseling for HIV transmission prevention,[19] drug addiction treatment through buprenorphine,[20] and treatment of hepatitis C virus in co-infected patients.[21] This requires a greater concentration of skills and resources in these clinics.

3.3 How is HIV medical care provided in low-incidence areas?

This urban model of care relies on a highly specialized and experienced team of care providers and does not translate easily to geographically remote areas with small and dispersed populations of PLWHA, as found in many parts of Hawai'i. Rural care providers often do not have the critical mass of patients needed to allow them to gain sufficient experience and to merit keeping up on the rapidly changing practice of HIV care. Also, people in small communities may have heightened concerns about confidentiality and stigma.[22] As a result of lack of confidence in local providers or referrals from local providers, almost three quarters of rural HIV patients in a nationally representative sample of the mainland U.S. traveled to metropolitan areas for HIV medical care. Most surveyed found the location inconvenient, had long travel times and one quarter had put off care in the last 6 months because they did not have a way to get to their provider.[23] While patients may travel for care out of need, in rural Vermont 75% of patients surveyed felt it was important to receive care in their own community.[8] The travel distance, cost, or lack of mass transit create additional barriers to care in this situation.[24]

Rural patients are disadvantaged in terms of health outcomes. A recent study in New England found patients with HIV who live in rural areas have higher mortality rates than urban patients with HIV. This was not due to lower rates of antiretroviral treatment or PCP prophylaxis. The study controlled for demographics, year of diagnosis, travel time, and lack of insurance.[25]

Efforts to address these problems in rural communities have taken many forms. Some successful ones include taking a multidisciplinary team to local hospital clinics,[8] taking a support team to complement the services of the local primary care provider,[26] creating networks of care providers to, for example, coordinate care between infectious disease physicians at academic medical centers and locally based case managers,[27] providing psychotherapy interventions not available locally over the phone,[28] developing the HIV care capacity of existing clinics, building local networks of physicians with HIV management experience, and cultivating "shared care" arrangements with urban-based specialists.[28]

4. PROVIDERS OF HIV/AIDS MEDICAL CARE IN HAWAI'I

4.1 HIV/AIDS medical care in Hawai'i

The model of HIV/AIDS medical care which has evolved in Hawai'i is one where the ancillary services are centralized on each island through a single AIDS Service Organization (ASO) working independently on each island but medical care is provided through a broad range of private physicians, community clinics, Kaiser Permanente, a University-based research program and clinic, the military health care system, and the corrections health care system. There is generally close coordination between the ASOs and providers with

significant numbers of patients in the form of mutual referrals, sharing of pre-approved client data, trying to get patients back in care and, in two cases, having an ASO case manager on site during selected clinic hours.[e] Each ASO combines prevention activities, social support, case management to link patients with benefits, and, in Honolulu, psychiatric services as well.

The ASOs have also played a key role in arranging for alternative sources of health care when a key provider left or retired in their service area. Malama Pono on Kauai hosted Dr. Kovach and then Dr. Morrison every few months in their offices for three years when there were no HIV specialists in the late 1990s. HIHAF petitioned the Clint Spencer Clinic to open a satellite clinic in Kona after Dr. Denzer retired there in 2006. MAF requested the same and offered their offices as a site for the Clint Spencer Clinic in anticipation of Dr. Kwon departing in March, 2008. The ASOs are also supportive of developing local HIV medical expertise -- HIHAF provided information and sponsorship to Dr. Harmeling for two mainland trainings and connected Dr. Dueller with Dr. Goshima who provided him with training in Honolulu. When, during this needs assessment, Dr. Laird from the Community Health Center on Kauai indicated a willingness to receive further training in HIV care, Malama Pono offered to help with travel expenses to Oahu. This was not necessary in the end as the HAETC was able to provide the necessary support and training to Dr. Laird.

Additional HIV-specific housing services and nutrition services are available through organizations that coordinate services closely with the ASOs. The Waikiki Health Center, the only Ryan White Part C clinic in the state, provides the broadest array of ancillary services on-site through HIV-specific mental health and nutrition staff.

The State-run HDAP, H-Cobra and HSPAMM programs provided important medical benefits to over 1,000 beneficiaries in 2006[29] by paying for antiretroviral medications, paying premiums to continue insurance under former employers' group health insurance, and paying for a physician office visit and laboratory testing every six months. While these programs do not provide direct services, they provide clients with access to existing medical care and medication. They also benefit private physicians and non-profit clinics providing HIV medical care to uninsured or underinsured patients by reducing financial strain, and time spent trying to find alternative means of providing medication and labs for patients.

While care providers in Hawai'i work in separate clinics, with only a few small clusters of specialists, many collaborate with each other to improve the quality of patient care through informal calls or referrals for consultation. Seventy seven percent of physician respondents in the provider survey said they refer within the state, including very experienced physicians who stated in the provider survey that they "provide all care throughout course of disease." For those working at Queens Hospital (residents and others were surveyed there) they would refer to the ID specialist on call. For community physicians, the most common place of referral was Dr. Shikuma/Clint Spencer Clinic. Some indicated they refer patients to Dr. Shikuma only in cases when a patient is out of options and a clinical trial with new medications might be available.

[e] The Life Foundation sends a case manager once a week to both the Clint Spencer Clinic and the Waikiki Health Center.

The ID specialists and HIV specialist physicians are committed to serving patients and do not mind discussing patient treatment options with colleagues. On the neighbor islands primary care providers reported that the on-island infectious disease specialists (Dr. Yoon on Kauai and Dr. Hoskinson on Maui) welcome calls for advice. Ties have been developed across islands with HACRP physicians due to sharing of patients participating over the years in AIDS clinical trials. These ties facilitate informal consultation on patients with complications, regardless of their involvement in research. HIV physicians are also brought together at pharmaceutical-sponsored HAETC training events (which may provide for travel from neighbor islands), when asked to sit on advisory boards, and at community events relating to HIV. Physicians such as Drs. Goshima and Kovach have been involved in training others in HIV care and may continue these relationships subsequently as mentors. Some physicians turn to mentors out of state or to the UCSF "warm line" which provides consults on the phone. Within state there is no formal network or "warm line" to encourage these interactions among new providers of HIV care in Hawai'i.

The services available and the way HIV medical and ancillary care is provided in Hawai'i has been shaped in part by requirements of federal HIV/AIDS funding sources. In FY2006 a total of $7,954,133 was given to Hawai'i for care, prevention, housing, substance abuse and mental health. The Hawai'i DOH further influences the types of services and which agencies provide them through management of the 41% of these funds received through Ryan White Part B. Of Part B funds the largest portion (66%) was allocated to HDAP and the rest was divided between DOH direct services and services by the various organizations mentioned above.[30] A breakdown of the Ryan White Care Act funding proposed for FY2007 is provided in the table below.

Table 1: Ryan White Care Act funding FY2007 / FY2006

Part B	Life Foundation (ASO Oahu)	169,629
Part B	Hawai'i Island HIV/AIDS Foundation (ASO Hawai'i)	152,596
Part B	Maui AIDS Foundation (ASO Maui)	128,320
Part B	Malama Pono (ASO Kauai)	65,894
Part B	Gregory House Programs (Housing services)	136,800
Part B	Save the Food Basket (Nutrition services Oahu)	70,783
Part B	Waikiki Health Center	59,212
Part B	Clint Spencer Clinic	83,790
Part B	HDAP (FY2006)	2,165,333
Part C	Waikiki Health Center & Community Clinic of Maui sub-site	243,750

Sources: AIDS Community Care Team, www.statehealthfacts.org.

Information on the perspectives of 89 providers relating to the care they provide, their capacity to take on more patients, and types of training or support they would like is available from the provider survey described in the methods section. The survey included most of the significant providers of HIV care, as well as some not providing care. The numbers of responses vary by topic as many surveys were incomplete due to omission or to non-applicability to the respondent (22 physicians had no current HIV patients and 5 were not physicians).

The survey found that most providers caring for significant numbers of HIV patients feel confident in their expertise. 20 providers, who jointly care for most of the patients enumerated in the survey (81%), claim they "provide all care throughout course of disease" and they are "comfortable" doing so.[f] If the estimated combined case load of 1,644 is accurate and not redundant, these confident providers see most of the patients in care in the State. Only 3 respondents, who care for a total estimated 47 patients, stated they provide all care even in complicated cases because "no adequate referral is available locally." One of these was in Kona and one on Maui. An additional 3 provide all care *except* in cases where there are complications such as ART failure, Hepatitis co-infection, etc. 28 responded that they only provide primary care unrelated to HIV and refer out for HIV care. Most of these were recruited at grand rounds and may represent the situation of physicians in Hawai'i who are *not* self-selected HIV experts.

A 2007 survey mailed to *all* physicians in the state (about 2,500) by the HAETC indicates that HIV does not affect the practices of most physicians. The survey yielded 139 responses, presumably biased towards HIV physicians. Respondents cared for a total of 323 patients. Of the 85 who answered the question, "How does HIV affect your practice?," only 19 indicated it was significant or mentioned specific patient problems. Most (65%) indicated it had no or minimal effect. A few indicated they do only prevention or referral (7%), that they have few HIV patients (4%), or they felt lost keeping up (2%). Consistent with this was the selection of topics of interest for training events – 3 of the top 5 apply to MDs who may have initial encounters with HIV infected individuals but will not necessarily continue their treatment. The top ranked topics were: HIV Diagnostic Tests, Antiretroviral Treatment, Early Intervention for HIV, Acute HIV Syndrome, and New Approaches to HIV.

The provider survey for this needs assessment as well as key informant interviews indicated that most private providers are not eager or able to increase their HIV patient load. Even public clinics face constraints on expanding their services. When asked about the types of support they wanted from ASOs, 54 respondents said they wanted them to provide services to their patients but only 9 said they wanted them to refer in new patients. One of these 9 has since left.

Many of the primary care providers have full practices and are not taking new patients, regardless of their HIV status. The Hawai'i Medical Association (HMA) describes the problem of attracting and keeping physicians as a "state of crisis." Despite high levels of insurance coverage, the ability for patients to find physicians is "dangerously limited," especially on neighbor islands and rural Oahu. HMA blames high costs of medical liability and low insurance reimbursements in Hawai'i.[31] A Kona MD who cared for HIV patients in her private practice wrote in an open letter to her patients that she had no choice but to switch to hospitalist work due to this problem. Another HIV care provider who left Maui cited the poor support and conditions in the state hospitals as the reason for leaving. The availability of primary care physicians, even to those with good insurance, has deteriorated in other parts

[f] 2 additional providers also responded they provide all care and are comfortable, but they were both residents with 1 patient each and were not counted in this group as they are not likely to have dealt with complicated cases yet.

of the US as well in recent years. Demand for primary care has increased while the numbers of primary care providers per capita remains the same.[32]

According to case managers and providers themselves, some physicians will not take patients with public insurance, those with substance abuse problems or chronic pain management issues, or those with poor adherence. Unfortunately these attributes describe many PLWHA in Hawai'i. In the survey, almost all physicians indicated they accept public insurance and most also indicated they accept patients who are uninsured. However, based on subsequent conversations, this might better be interpreted as these physicians have patients in these categories and will continue to care for them, but they do not accept them without limits. It seems providers want to help, but they do not want to be overwhelmed with these types of patients.

The shortage of physicians can be illustrated by the current situation in Hilo, which ironically is the only location with the good fortune to have two new primary care physicians with recent training in HIV care, Dr. Harmeling and Dr. Dueller. When Dr. Martell left Hilo in June 2008, he referred to these new MDs not only his 40 patients with HIV, but many more without HIV. Dr. Harmeling is now overwhelmed and cannot take additional patients. Dr. Dueller and his partners have a long waiting list for their new practice and have placed insurance restrictions that exclude most HIV patients. The CSC was considering reducing the frequency of the Hilo satellite clinic visits, so as not to compete with these promising local providers. However, the general shortage of primary care physicians reduces the capacity of local providers to care for all the HIV patients in need.

While community clinics accept all patients, they face varied resource constraints. Some community clinics have long-standing challenges recruiting and keeping physicians. The community clinics in Waianae and Kona were particularly short-staffed at the time of the survey, limiting their ability to treat many types of patients, not just those with HIV. Again, this is part of a bigger problem, especially in rural areas. Community clinics have over 13% vacancy rate for physicians.[41] Other community clinics were in better shape but would like to expand their capacity further. WHC needs more clinic rooms and will expand its physical plant when its lease is renewed. Maui Community Clinic would like to increase its administrative support to follow up on HIV patient paperwork. The Bay Clinic obtained a HIV care capacity building grant and would like to train a mid-level, but finances are so tight they would need to be compensated for income lost while trainee is not generating revenue.

Questions about types of training and support that interest providers indicate that most are content with the current environment. The few non-residents who indicated interest in more intensive types of training or support can be targeted individually. Most experience providers indicated an interest only in occasional lectures (currently available through the HAETC) with a couple individuals interested in distance learning as well. Other more intensive types of training or support (ex. visiting MDs holding a clinic, hot line or telemedicine) generated interest primarily among residents. This group is not a particular target for additional training as they may leave Hawai'i upon completion of their residency. However, WCCC was interested in visiting MDs holding clinic. A physician from Kauai and

a physician and a nurse from different parts of rural Oahu were interested in more intensive forms of training and support.

The HEATC survey mentioned earlier sheds more light on other ways physicians learn about HIV now. Most learn on their own through reading journals, books or internet. About 40% also learn through educational events, and 12% rely on colleagues for information, particularly ID specialists. Seven percent said they do not learn or that they always refer patients.

4.2 Situation Analysis: State-wide and cross-state services

The VA, the corrections system, HACRP and Kaiser have care systems that extend beyond a particular county and may involve travel between islands by patients or providers. The HIV specialists for all these providers are based in the greater Honolulu area where most of the PLWHA live. Therefore, the majority of patients can be seen without travel. Distributions among counties are shown in Table 2.

Table 2: Geographic distribution of all people, PLWA, and selected PLWHA

	PLWA, DoH n=1,259	PLWHA, Insurers* n=1,309	All People Census 2000
Oahu	68%	74%	72%
Hawai'i	15%	13%	12%
Maui	13%	10%	11%
Kauai	4%	3%	5%

*Medicaid, HMSA, Kaiser, UHA, Alohacare

The military medical system works independently of the civilian sector. Active duty Army patients and their families are mostly seen by two military ID physicians on-site at Tripler. Other branches of the service go to local care providers for primary care then to either San Diego (marines) or Wellford Hall, San Antonio (air force) for regular specialist visits. The total number of military beneficiaries identified in the Hawai'i catchment area during FY 2007 was 166 with 42 receiving direct services (at Tripler) and 124 in managed care.

Also at Tripler is Dr. Arthur Johnson who is AAHIVM credentialed civilian and sees around 80 VA patients, including neighbor island VA patients who are flown in for care. To qualify for free VA care, patients must either be a veteran and qualify for social security, or have been diagnosed while on active duty, regardless of financial status. On request, Dr. Johnson also cares for military patients who are active duty, dependents and retirees. If PLWHA in the navy or marines become sick while they are in Hawai'i, he will also see them until they are reabsorbed into their own systems.

The corrections system oversees about 35 HIV-infected inmates, mostly in-house due to recent hires of staff with HIV expertise. Dr. De Witt has an AAHIVM credential and has worked at Halawa Prison (long term inmates) since 2005. Dr. Morrison maintains a part-time HIV-specific private practice and has worked at the Oahu Community Corrections Center (short term inmates) since 2007. A few patients see community physicians due to

preference for a female provider or other reasons. At the time of the interview, 7 inmates were based at a facility in Arizona, but the medical director of Hawai'i corrections, Dr. Kay Bauman, follows their care through chart reviews and communication with attending physicians. Health outcomes have been good with only one death and 2 hospitalizations since 1989, despite high prevalence of Hepatitis C co-infection. The Life Foundation has an outreach program in the corrections system which provides excellent discharge planning for continuation of care (far better than for other chronic diseases).

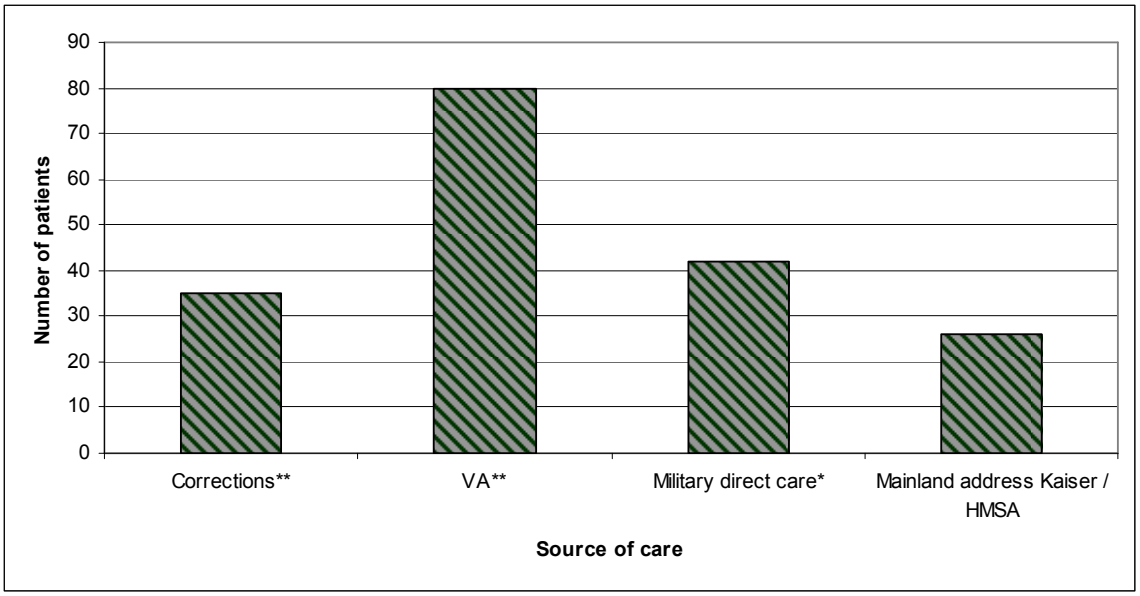
As a site of the Adult AIDS Clinical Trials Unit (AACTU) since 1990, HACRP provided care to research subjects from all the major islands, flying them to Oahu for appointments. This pattern has continued on a smaller scale with local and pharmaceutical research trials since HACRP lost its status as an AACTU site in 2006. HACRP physicians also provide care in Honolulu, Hilo, Kona, on Maui, and Waianae through the CSC. The Honolulu clinic has benefited from staffing changes and increases and has grown dramatically in the last three years. The Hilo and Kona clinics are well established, and are run monthly out of the Queens Specialty Clinics. The Maui clinic was started in response to the departure of Dr. Kwon and the ban on new Medicare/ med quest patients at Kaiser. The numbers of patients at the clinic set up at MAF have been variable, though some were complicated cases in critical need of specialty care. Some patients have indicated they will not seek care at the MAF (including ones that fly to Oahu to come to the CSC) in order to keep their HIV status secret. HACRP is therefore investigating other location options. A clinic was set up at a beach park in Waianae at the request of a case manager from the Life Foundation. While some patients with challenging life circumstances who had fallen out of care were seen, the ability to provide care in that setting is limited. The clinic has been put on hold while other options are considered.

Kaiser is the single largest provider of HIV care in the State with clinic/s on Oahu, Hawai'i and Maui. Dr. Kovach is AAHIVM credentialed and sees the majority of Kaiser patients in his Honolulu clinic which also has a nurse dedicated to HIV care. Neighbor island patients receive primary care at their local clinic and see Dr. Kovach, as needed, during his regularly scheduled visits. The exceptions are on Maui, where some patients see Dr. Hoskinson for HIV specialty care and on Kauai where patients fly to Honolulu for care. Kaiser sees many patients receiving public assistance through the state mandated Medicare/med quest plan. However, Kaiser requested and was granted an exemption from accepting additional Medicare/med quest patients on Maui at this time.

While the geographic isolation of Hawai'i from the other continental states makes accessing care across state lines prohibitive for most, there are some who receive care both here and on the mainland, or even exclusively on the mainland. This may reflect a mobile lifestyle, a desire for complete confidentiality, or loyalty to care providers elsewhere. This pattern is also seen among neighbor island PLWHA who receive all their care on Oahu. While most of these mobile individuals are likely to be financially well off, ASO case managers described clients on public assistance that carefully coordinate regular trips to visit family on the mainland with doctors' appointments. Insurance data indicated that 23 Kaiser patients and 3 HMSA patients have mainland addresses and are likely to receive care in more than one place.

Data on numbers of patients in care from Kaiser and HACRP will be included in the situation analysis of each island. Corrections, military and mainland patients could not be matched with Hawai'i-based zip codes and are included in Figure 1.

Figure 1: Numbers of patients in care by provider, State-wide systems (n=183)



4.2 Situation Analysis: Oahu

Honolulu has 16 health care providers known to provide care to at least 5 patients, seven of whom are currently certified by the American Association of HIV Medicine and an additional six with ID board certification. (This does not include 2 ID physicians who treat only active duty military patients at Tripler.) Ten of these have a private practice, at least part time. Eight work at least part time at clinics with significant HIV-infected populations (Kaiser, CSC, WHC, Queen Emma Clinic (QEC), VA and corrections). Many of these physicians attend continuing HAETC education events regularly and are engaged with the HIV-infected community in a variety of ways (ex. participate on the advisory board of HACRP or Life Foundation).

However, a large proportion of this group of physicians can be expected to retire over the next decade. For 70% of this group, the average time since graduating from medical school was 34 years.[40] The graying of the provider population, with few young replacements stepping forward, has concerned some physicians enough that they are holding meetings to stimulate community discussion on this topic.[41] The one new arrival is an ID physician, Dr. James Joyner, who transferred from Colorado and has a particular interest in HIV care. As he establishes a private practice, he is working at Queens Hospital and sees private patients in Dr. Bello's clinic.

Clinics which are part of larger organizations are perhaps less vulnerable to the retirement of individual physicians as staff can be replaced and will gain experience quickly while working with existing staff on the established HIV case load. Oahu patients,

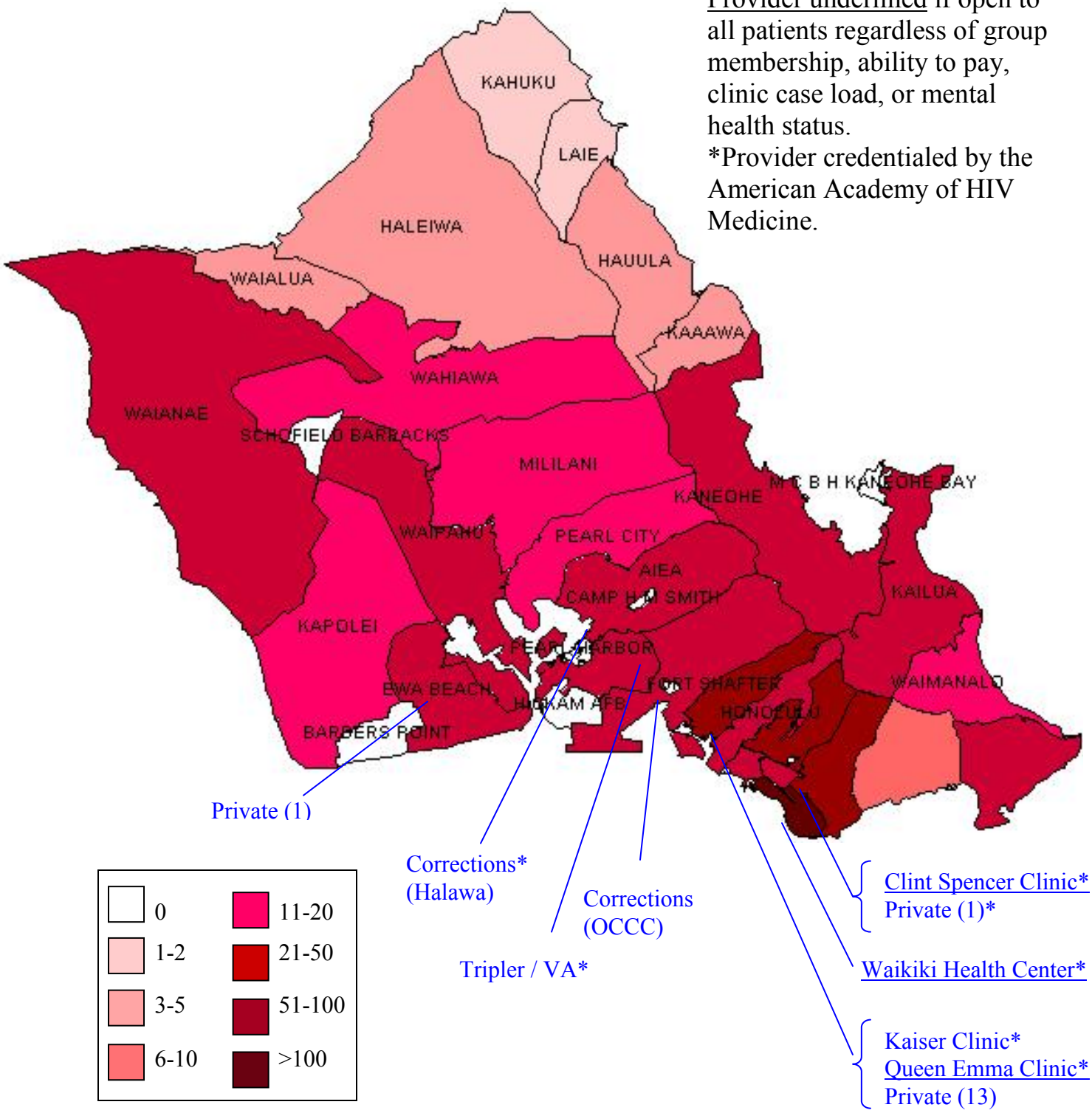


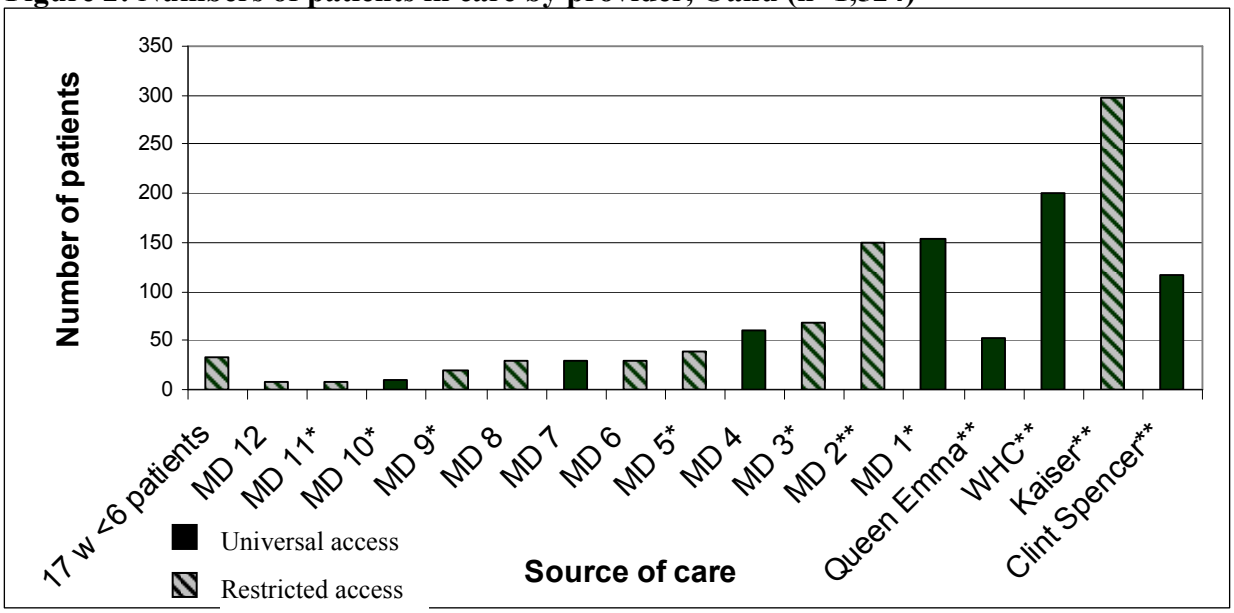
Figure 3: Distribution of HIV clients on Oahu (862) insured by Kaiser (297), Medicaid direct pay (258), HMSA (224), Alohacare (55), UHA (15), or unduplicated client of Life Foundation (13)

Distribution of physicians on Oahu known to have >4 HIV patients (22)

particularly indigent ones, benefit from several of these. Kaiser, CSC, corrections and VA were described in section 4.2. The QEC has three part-time HIV specialists (Drs. Bello, Tice and Chow) who serve indigent patients, including 52 with HIV. These specialists also see patients at the CSC, the WHC and in private practice, but patients may come to QEC for the favorable rates or downtown location.

WHC was the only community clinic to apply for and receive Ryan White Title III funding when the DOH encouraged all community clinics to do so several years ago. WHC has developed a program unique to Hawai'i in that two Physicians Assistants (PAs) have been developed to provide care with support from Dr. Kalauawa in the form of daily chart reviews and weekly discussions. While Dr. Kalauawa finds that PAs operate more similarly to MDs than do nurse practitioners (who he believes spend more time focused on daily living issues), in order to have more than one in his clinic he has needed to assign one to an outside MD for regulatory reasons. All new patients see the PAs first and are transferred to Dr. Kalauawa only if their cases are complicated. WHC would consider being a site to train other midlevel providers. Patients also see a nutritionist, case manager and, if needed, a social worker. The current staff can take on more patients, but there are limited clinic rooms (which are used for all patients, not just HIV). WHC is planning to expand and remodel to address this constraint as soon as a new lease is in place.

Figure 2: Numbers of patients in care by provider, Oahu (n=1,524)



*Infectious Disease **AAHIVM credential

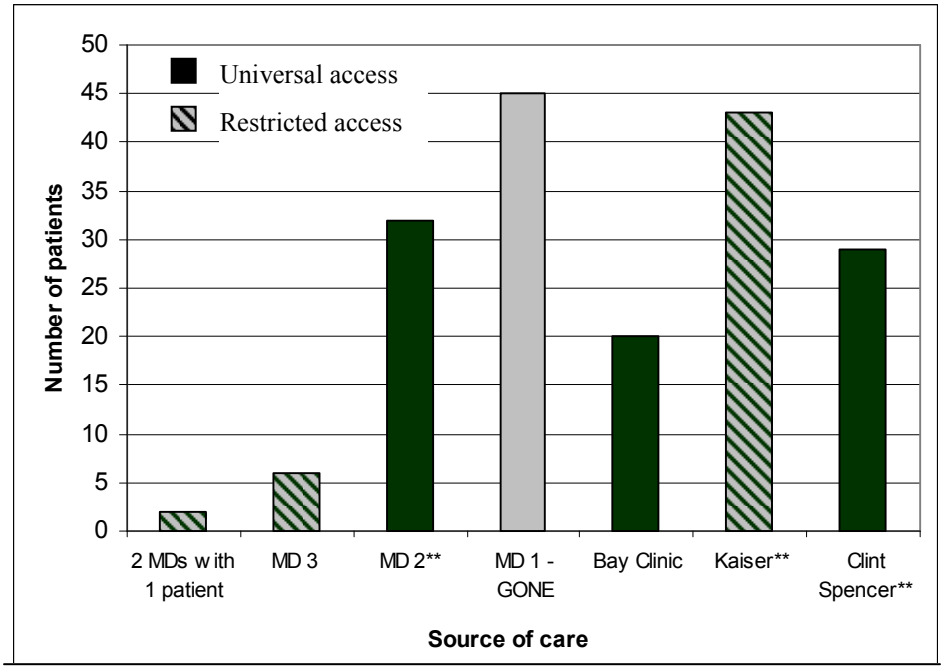
A problem with HIV care on Oahu is that the providers are concentrated in Honolulu, which is a long commute from West Oahu and the North Shore. While there are community health centers in these areas, they serve few HIV-infected clients.[42] West Oahu has the longest commute to Honolulu clinics (up to 2 hours each way by bus) and is home to substantial number PLWHA, many of whom also suffer from poverty and substance abuse problems. At the time of this survey the large and well-established health center, WCCHC, had lost an internist (Dr. Cooke-Palmer) in June 2006 who had seen 10 HIV patients and was

about to lose their only other internist. The HIV patients were lost to follow up. In discussing possible solutions, Dr. Ricardo Custodio ruled out telehealth as it had failed in the past. He was open to hosting an HIV specialty clinic with CSC staff. CSC and Life Foundation staff are reluctant due to potential confidentiality concerns of PLWHA in the area – most of WCCHC's 450 employees are from the surrounding communities. Dr. Willis Chang, an ID physician at St. Francis West Hospital (about ½ hour from Waianae), has about 10 HIV patients. While there is a wait for new patients to get in, he said that the real problem is not access to local physicians, but the patients themselves habitually dropping out of care due to problems such as substance abuse.

4.4 Situation Analysis: Hawai'i Island

Due to the vast distances involved, the two sides of the island are treated separately. In Hilo, care has been and continues to be affected by the general shortage of physicians resulting in large primary care case loads for local providers. Two community physicians, Dr. Martell and Dr. Linden, saw patients for many years, but would occasionally freeze taking new patients due to large general case loads. Since 2001 Dr. Shikuma (and, more recently, Nicole Valcour, ACRN) from the CSC have held a monthly clinic in Hilo at the Queens specialty clinic to supplement local provider capacity. Many of these patients receive primary care at the busy Bay Clinic, which experiences high physician turnover and long waits. In addition to primary care, the Bay Clinic also provides HIV specialty care. Dr. Sonoda-Fogel saw a few patients in the Hawai'ian Health Care system, but she departed in 2008.

Figure 4: Numbers of patients in care by provider, Hilo (n=177)



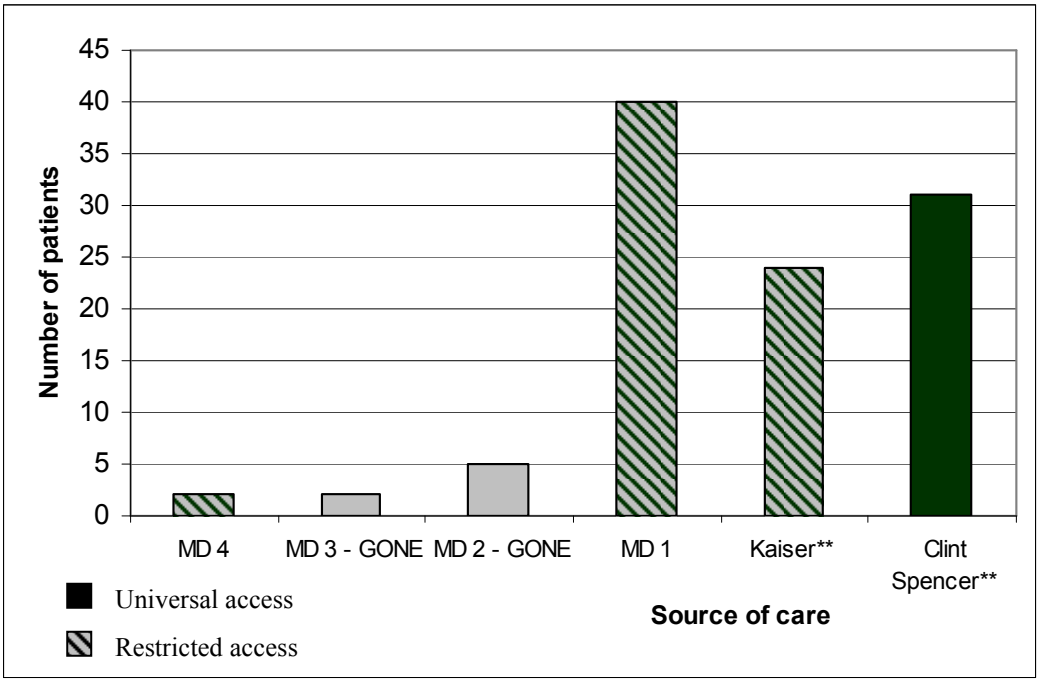
Two new young community physicians with HIV training set up private practices in the last year, but they have not been able to fill the void left by Dr. Martell in June 2008. Dr. Harmeling (AAHIVM credentialed) had worked at the Bay Clinic but departed to open a fee-

for-service HIV specialty practice. Now, he has hired a PA and provides primary care as well as HIV specialty care and accepts insurance. After having both HIV and primary care patients referred by Dr. Martell, he is not accepting new patients. Dr. Dueller underwent some HIV care training on Oahu prior to opening a primary care practice with two partners in July 2008. However, Dr. Dueller is not taking new Medicaid or Medicare patients at this time. HIHAF has asked the CSC to extend their monthly clinic hours in Kona.

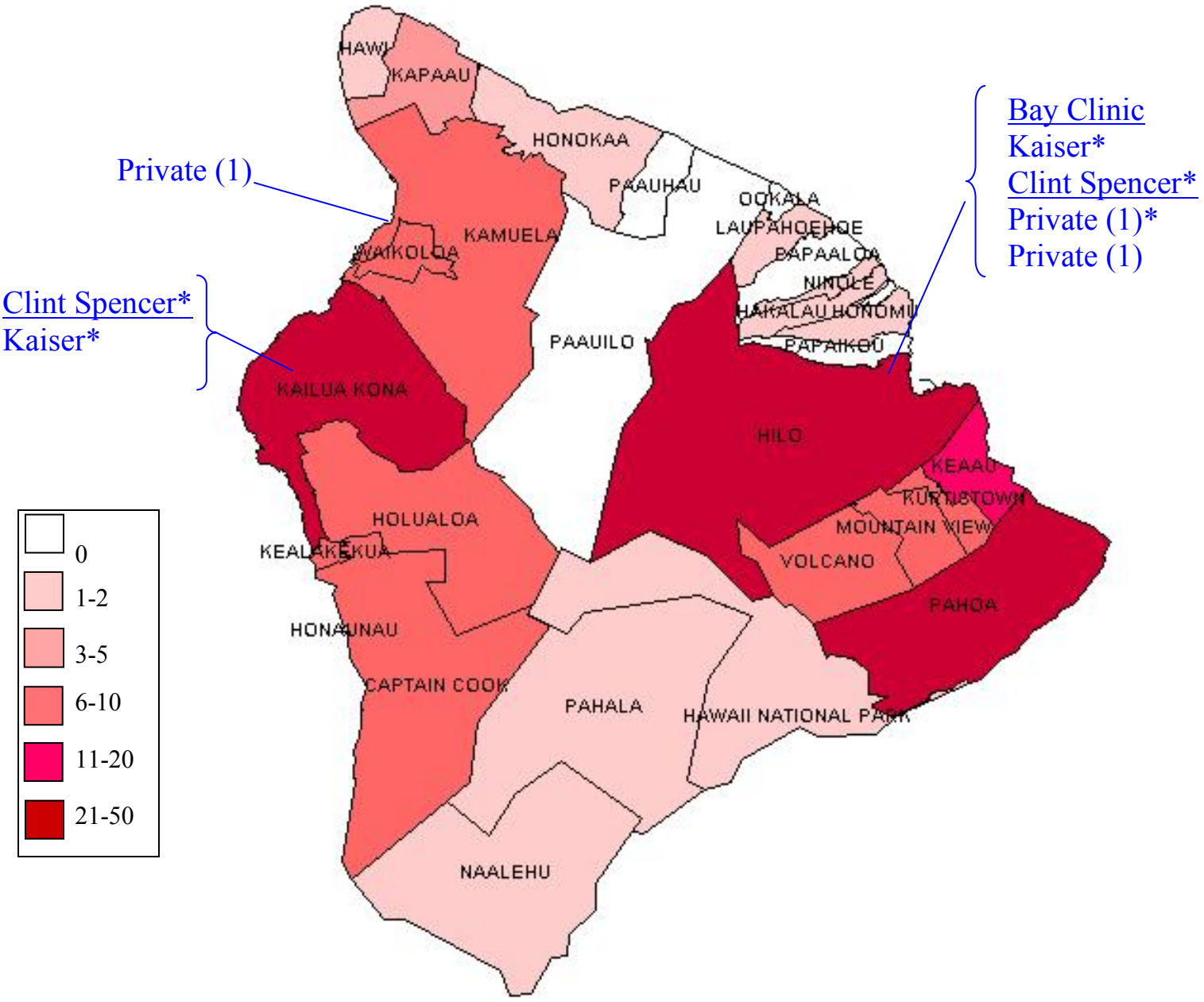
Dr. Tony Brown at the Bay clinic has indicated an interest in HIV for some time and is now actively pursuing opportunities to expand services. The Bay clinic received a capacity building grant and is looking into other types of funding to support HIV services. The new Executive Director, Paul Strauss, transferred over from the WHC and is supportive of setting up a team care approach similar to the one he left. An interested NP has been identified should the appropriate training opportunity and substitute clinic support become available. The Bay Clinic and HIHAF do not currently coordinate services as closely as do the ASOs and community health centers on other islands.

No visits were made to Kona for this needs assessment as there were no promising opportunities to investigate. Dr. Lawrence is a long time provider of HIV care in Waikoloa, a 45 minute drive from Kona. He is comfortable providing care throughout the course of the disease, and consults Dr. Shikuma as needed. The two other significant sources of care are the Kaiser clinic and, since 2007, a monthly CSC clinic manned by Dr. Chow and Nicole Valcour, ACRN. HIHAF has paid Medicare premiums for some clients so they can enroll in Senior Advantage and become eligible for Kaiser.

Figure 5: Numbers of patients in care by provider, Kona (n=104)



*Infectious Disease **AAHIVM credential



Provider underlined if open to all patients regardless of group membership, ability to pay, clinic case load, or mental health status.
*Provider credentialed by the American Academy of HIV Medicine.

Figure 6: Distribution of HIV clients on Hawai'i (223)
insured by Kaiser (67), Medicaid direct pay (54), HMSA (45), UHA (12), Alohacare (6), or unduplicated client of HIHAF (39)

Distribution of physicians known to have >4 HIV patients Hawai'i (9)

The Kona Community Clinic (KCC) lost one of two physicians and a nurse practitioner during this study, so calls made in an effort to support someone in HIV care or to at least coordinate primary care for the CSC patients went unanswered. Since that time another physician has been hired and KCC is again providing primary care to some HIV patients. Another source of primary care is at newly-established Ali'i Health, a Kona hospital initiative which took over the practices of departed primary care providers.

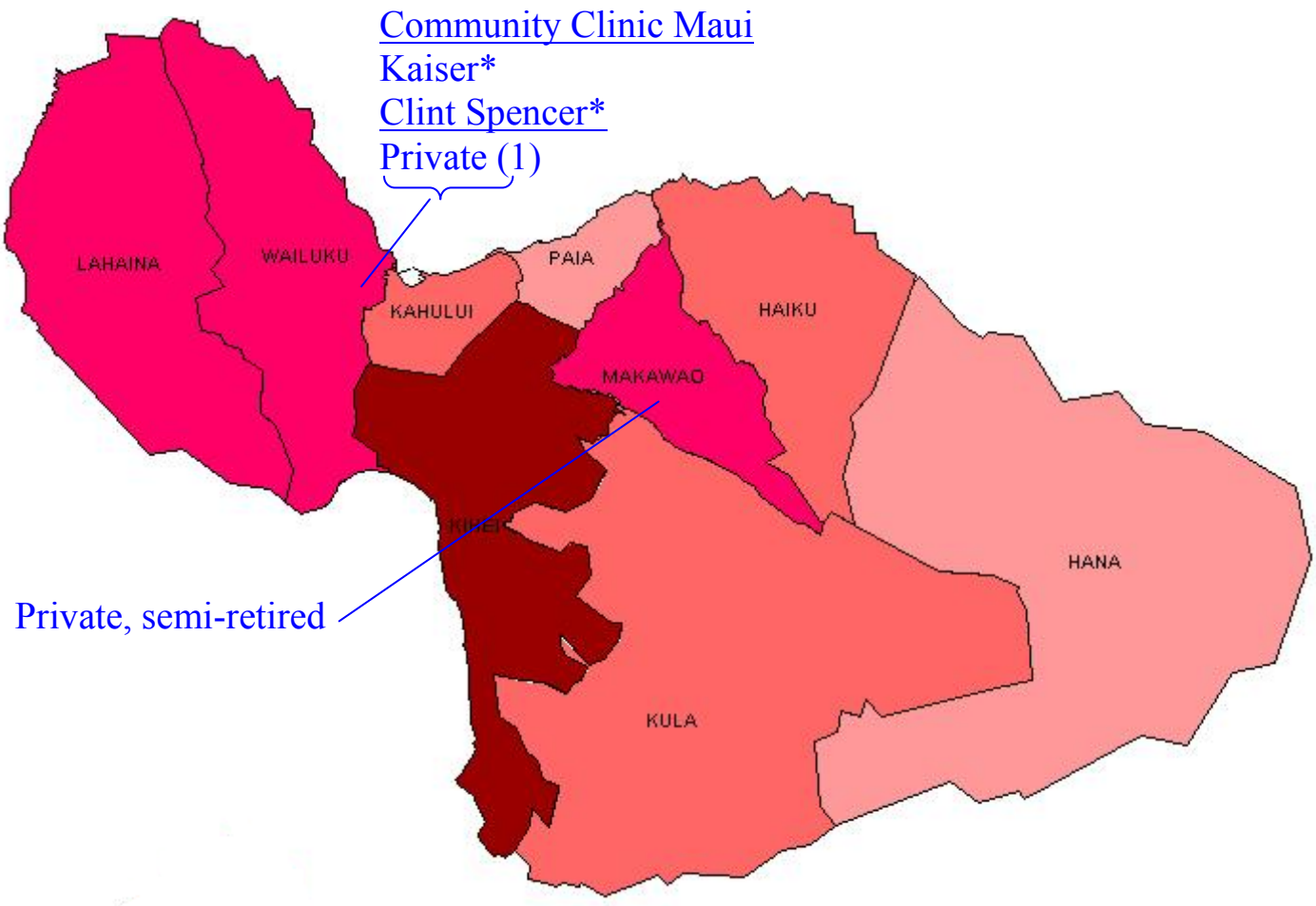
In 2006 Dr. Stephen Denzer reluctantly closed his private practice that provided HIV care for many HIV patients, claiming that Kona "has the lowest reimbursement and highest cost of doing business in North America."[43] HIHAF failed to find alternative care for Dr. Denzer's patients, so CSC responded with an HIV specialty clinic the month after he retired. Following Denzer's retirement, HIHAF sent a faxed survey to all 43 local physicians asking if they would provide HIV care. Of 16 responses, only Hamakua Health center, one hour and 15 minutes away in Honokaa said they would take patients with no restrictions. They do not currently have a significant case load. Dr. Lawrence would accept patients, but with insurance, geographical and behavioral restrictions. Others would not take new patients for general HIV care. Some who said "no" cited they are not up to date on HIV care, but they have insurance restrictions that would rule out most HIV patients anyway. The lack of expertise and the reticence to take on HIV patients among Kona physicians is illustrated in the case of a an HIV-infected couple where the deceased husband was first diagnosed in the hospital with advanced AIDS, and the wife was discharged by community-based care provider when he learned of her HIV status.

4.2 Situation Analysis: Maui County

The situation on Maui was in a state of change during this needs assessment. Care had been provided at Kaiser by both Maui-based ID physician Dr. Scott Hoskinson and Dr. Drew Kovach, by ID physician Dr. Irving Brown at the Community Clinic of Maui (CCM) and by an internist with a private practice and a particular interest in HIV, Dr. Ronald Kwon. Kaiser on Maui stopped taking med quest patients (not just those with HIV), and Dr. Kwon transferred to the mainland, limiting the options for most PLWHA. Dr. Resnick is semi-retired and provides primary care out of a home clinic to a handful of HIV patients, but does not take insurance or have hospital privileges. There is one new community physician who has taken several HIV patients and appears to be well-liked. Her expertise is limited, but she calls Dr. Hoskinson when she needs to consult. She is currently not taking new patients, regardless of HIV status.

At the request of the MAF, the CSC opened a satellite clinic in their offices at the end of 2007. The patient load has been variable, but seems to be increasing as Dr. Kwon's patients become due for a check up. Several patients seen are ones that were not doing well on their prescribed therapy. For these cases, and to provide alternative care options, the CSC will continue to explore the best way to support patient care on Maui.

Dr. Brown works one day a week at CCM with support from a half-time nurse dedicated to HIV. He feels he can accommodate as many patients as needed in his weekly clinic if he has an additional half-time administrative person to do follow up paperwork. Dr.



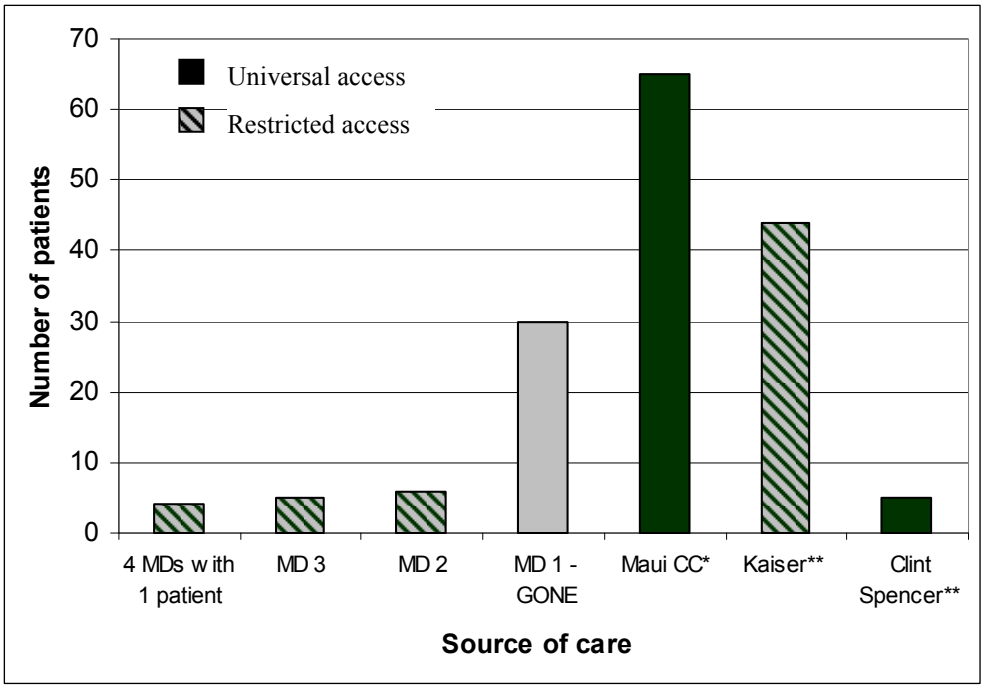
Provider underlined if open to all patients regardless of group membership, ability to pay, clinic case load, or mental health status.
*Provider credentialed by the American Academy of HIV Medicine.

Figure 8: Distribution of HIV clients on Maui (151) insured by Kaiser (44), Medicaid direct pay (42), HMSA (32), UHA (8), Alohacare (5), or unduplicated client of Maui AIDS Foundation (20)

Distribution of physicians on Maui known to have >4 HIV patients (5)

Brown has little tolerance for some behaviors common among PLWHA, such as substance abuse and reliance on pain killers.

Figure 7: Numbers of patients in care by provider, Maui (n=159)



*Infectious Disease **AAHIVM credential

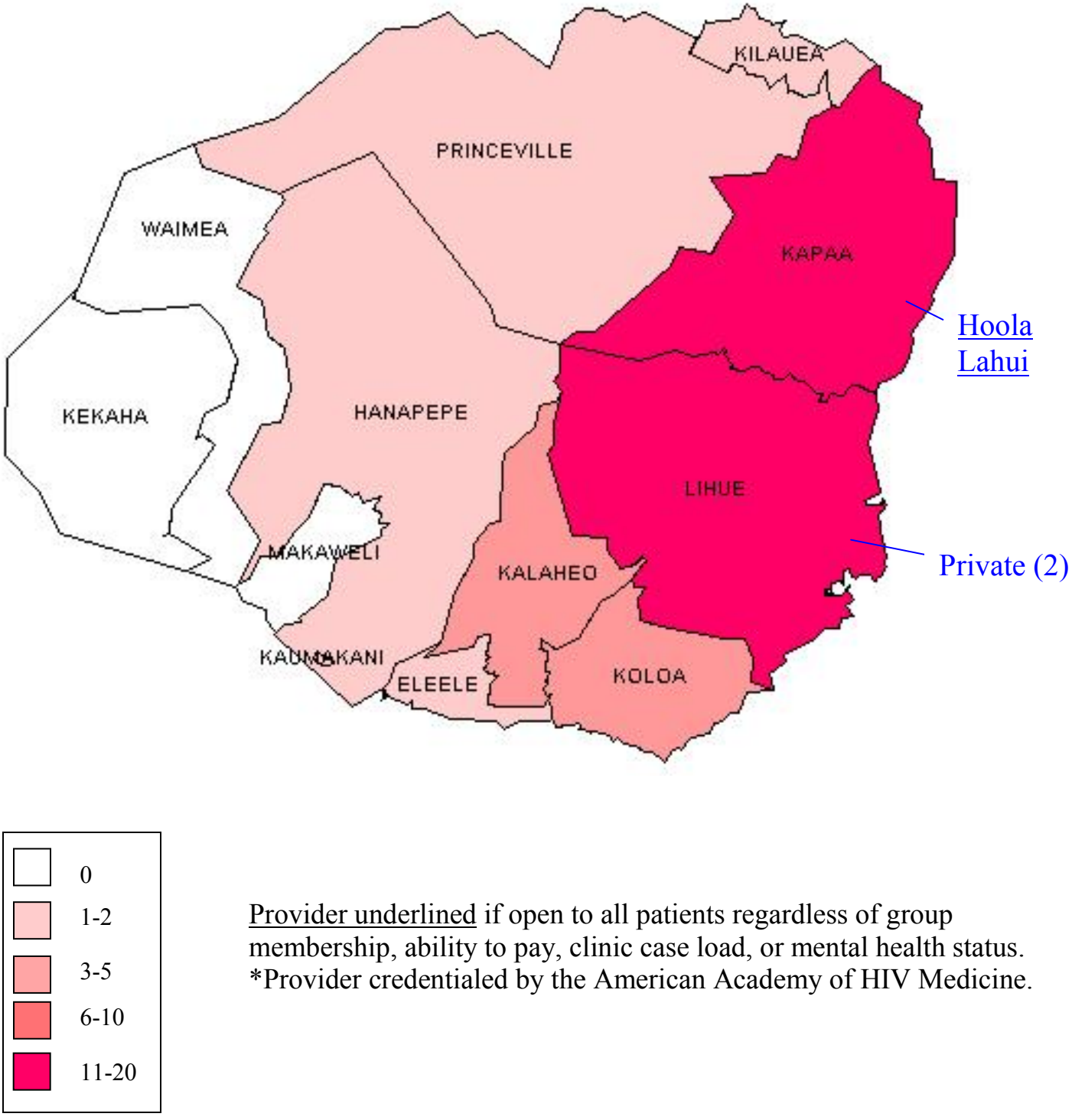
The less populous islands of Lanai and Molokai are close to Maui and many inhabitants go there for specialized medical care. It is assumed that the few PLWHA would do the same.

4.3 Situation Analysis: Kauai County

Kauai's small HIV infected population needs just a couple of good options to keep patients in care. While Kauai has gone for years without a single HIV specialist on island, at the moment they have one and another in training. They also have a community physician (with no known HIV expertise) who sees a handful of HIV patients and is said "not to turn anyone away" despite his busy practice.

Dr. Yoon is an ID physician at Wilcox with HIV experience and a particular interest in Hepatitis C. While some patients want more "hand holding" than he provides, he is committed to HIV (and Hepatitis C) prevention and treatment and serves on the board of Malama Pono, the Kauai ASO.

Dr. Kroon used to care for many HIV patients at Ho'ola Lahui, the community health center. When he left a couple of years ago, some switched providers and some just fell out of care. After much perseverance, access was granted to the new physicians, Dr. Laird and Dr. Abruzesse, to discuss HIV care. Dr. Laird was very interested in providing HIV care and already had a few patients about whom he called Dr. Yoon for advice. Dr. Laird is now



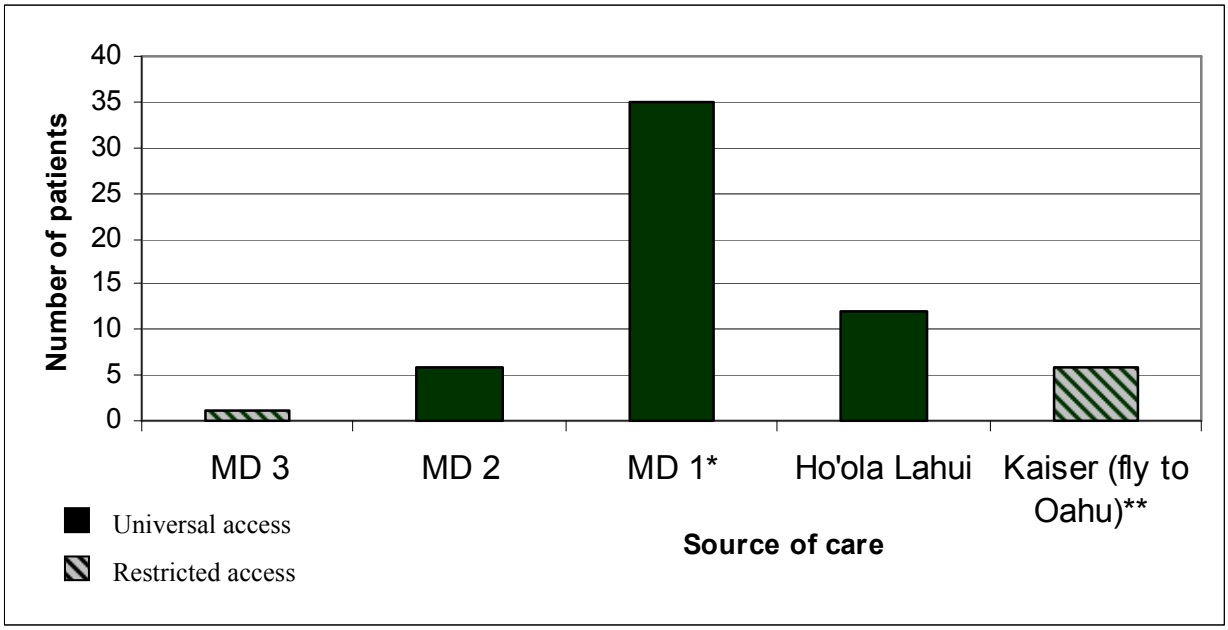
Provider underlined if open to all patients regardless of group membership, ability to pay, clinic case load, or mental health status.
*Provider credentialed by the American Academy of HIV Medicine.

Figure 10: Distribution of HIV clients on Kauai (46) insured by HMSA (19), Medicaid direct pay (10), Kaiser (6), UHA (4), Alohacare (2), or unduplicated client of Malama Pono (5)

Distribution of physicians known to have >4 HIV patients (3)

connected with Malama Pono staff, the CSC, and the HAETC for support and his case load continues to increase. Dr. Goshima of the HAETC has, among other things, provided on-site training with Dr. Laird's patients at Ho'ola Lahui.

Figure 9: Numbers of patients in care by provider, Kauai (n=60)



*Infectious Disease **AAHIVM credential

5. CONSUMERS OF HIV/AIDS MEDICAL CARE IN HAWAI'I

5.1 Demographics and characteristics related to health status

More detailed epidemiologic profiles[29] and analysis of trends over time[44] can be found elsewhere. This section is focused on characteristics of the population as they relate to medical care. To understand the scope of the need for HIV medical care, first we must have some idea how many people need care and how many are actually receiving care. Estimates below are based on best available data from the Department of Health unless an insurance carrier is noted.

Who needs care in Hawai'i?

2,767 PLWHA who know their status, end 2006

- **1,454** with AIDS (AIDS surveillance system)
- **1,313** with HIV (laboratory CD4 reports and government-funded programs)

Who is known to be receiving care in Hawai'i?

1,539 clients with HIV billing code under their medical insurance carrier in 2006/2007

- **1,477** clients reported by HMSA, Kaiser, Medicaid, UHA, Aloha Care, VA and Tricare

- **62** HSPAMM clients insured by other health plans
- Medicare fee-for-service data is missing – 2006 data from agencies receiving Ryan White Part B funds, indicate 153 clients (9.1%) had Medicare as a primary insurance

1,529 PLWHA received at least one viral load or CD4 laboratory test in 2005

- **940** of these had AIDS (76% of the known 1,232 people with AIDS received a test)
- **589** of these had HIV, but not AIDS

1,684 clients enrolled in a subsidized state program providing: drugs, laboratory monitoring, continued health insurance, medical care or social services in 2006

- **1,144** actually received services.

Some part of the over one thousand PLWHA who know of their status and were not receiving care may actually be receiving all their care out of state, or may be long-term non-progressors who are tired of being monitored. Most, however, are likely to be in need of care. The high levels of PLWHA being out of care is consistent with studies elsewhere which found 45% (Louisiana), 33% (Atlanta) and 55% (St. Louis) of PLWHA to be out of care in the year studied.[15]

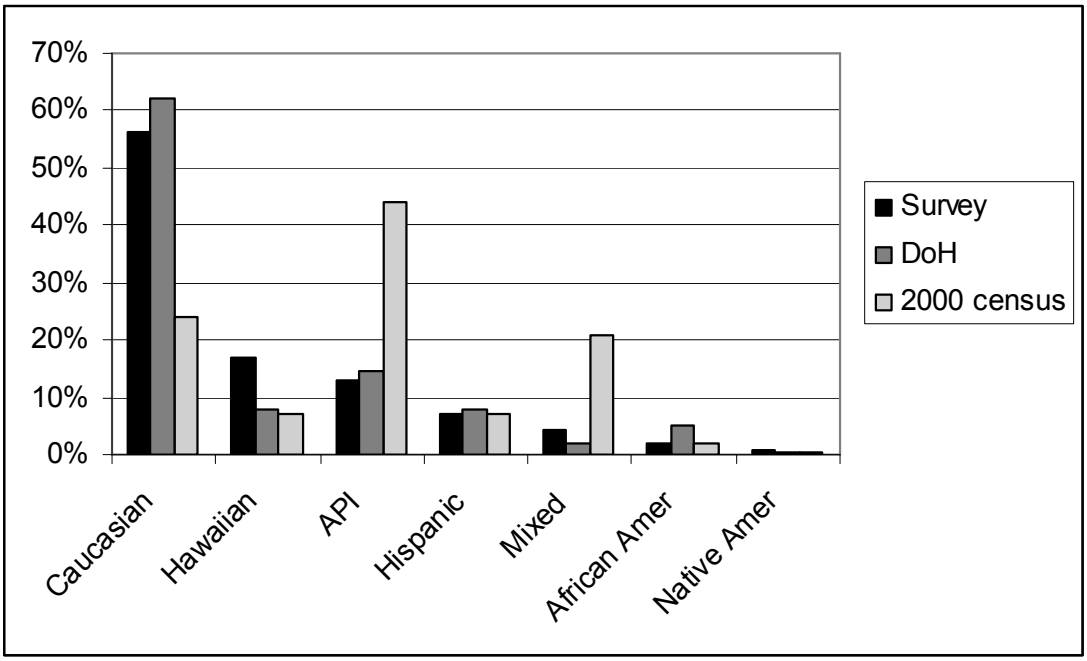
This poor retention in care is common for PLWHA, even when there are few financial barriers to care.[45] Unfortunately poor retention in care predicts poorer survival.[45] Access to medical care is good in Hawai'i relative to other States due to State laws regulating provision of health insurance[7] and 9% of the general population in Hawai'i is uninsured relative to 16% of the US population.[30] For PLWHA, an active and adequately-funded AIDS drug assistance program, and various State and community programs are also available to extend medical care and treatment to the uninsured and underinsured.

The demographics of PLWHA in Hawai'i impact the types of medical care they will need and barriers to providing medical care. Therefore, a quick review of some available data from the DOH[8] is presented graphically. Presented along with this data are the results of the consumer survey, so that the group who responded to the survey may be compared to the general population.

Caucasians accounted for more than half of PLWHA in Hawai'i, followed by Asian/Pacific Islanders (APIs) other than Hawai'ians, and then Hawai'ians. The proportions of PLWHA among other ethnic groups in Hawai'i are small, reflecting small total populations, not low rates of infection. Caucasians and African Americans are over-represented relative to their proportions measured in the total populations in the census. Over time, the AIDS data shows a steady decrease in the proportion of cases that are Caucasian and an increase in APIs, particularly native Hawai'ians. This is of concern as many Asian Pacific Islander groups tend to be socio-economically disadvantaged and to have cultural barriers in accessing HIV services.[44]

[7] Hawai'i is the only state with an ERISA waiver allowing it to require private companies to pay into a state risk pool and provide reasonably affordable insurance to anyone who wants it.

Figure 11: PLWHA and Hawai'i general population by ethnicity



In the census people who are part native Hawai'ian may be classified under "mixed" whereas in the other bars they would be classified as "Native Hawai'ian."

Some of the barriers for APIs experienced in the Clint Spencer clinic and also described by case managers include increased shame and fear of stigma, and greater educational and cultural distance between health care providers and patients. One study of 519 HIV positive people in Hawai'i found lower income levels to be strongly associated with progression to AIDS or death. During the period 1996-2001 APIs comprised 40.3% of persons dying of AIDS though they made up only 23.6% of people living with AIDS.[46] The consumer survey done for this needs assessment also found that APIs are less likely to receive a minimum frequency of care and that Hawai'ians are more likely to skip their medication. Thus the negative health outcomes may be associated with access to care as well as the challenges in adhering to HAART therapy.

Hawai'i is a state with many immigrants in both the general population (43%) and the population of PLWHA. Among those that responded to the consumer survey about 30% were born in state. However, this does not mean that most PLWHA came to Hawai'i after being diagnosed with HIV to live (or die) in paradise. Based on questions about the time of diagnosis and duration of residence in Hawai'i, it is estimated that about 68% of PLWHA in Hawai'i were diagnosed while already living here. Of those likely to be diagnosed elsewhere, 4% were born here and came back home.

Hawai'i has relatively few of the PLWHA who are injection drug users. This group is more difficult to get into care, keep in care and to achieve good adherence to treatment regimens. Men who have sex with men (MSM) who make up the largest number of PLWHA in Hawai'i are relatively easy to target with education and outreach. One study found that MSM were 5 times more likely than other groups to use care in the first year after diagnosis. The same

study found female IDUs were half as likely as others to use care in the first year after diagnosis.[24]

While the proportion of PLWHA in Hawai'i who are IDUs is low, the proportion using other substances that impact their ability to stay in treatment and on treatment is high. As one respondent receiving help filling out his consumer survey replied when asked if he was taking anti-retroviral therapy, "No, it doesn't mix well with drink." Data From the Reggie system on 723 HIV clients for whom a substance abuse assessment had been made indicated that 14% were active substance abusers and an additional 36% had a history of substance abuse.

Figure 12: PLWHA by source of infection

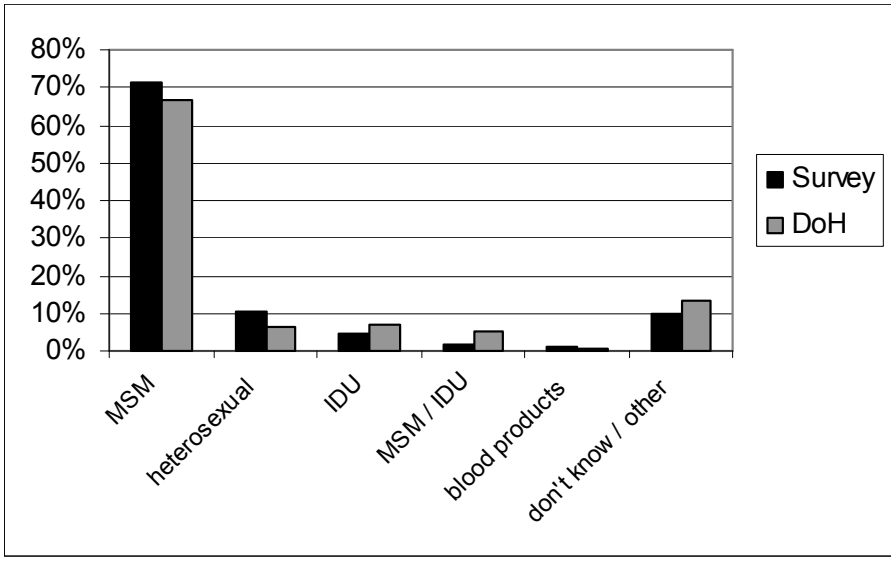
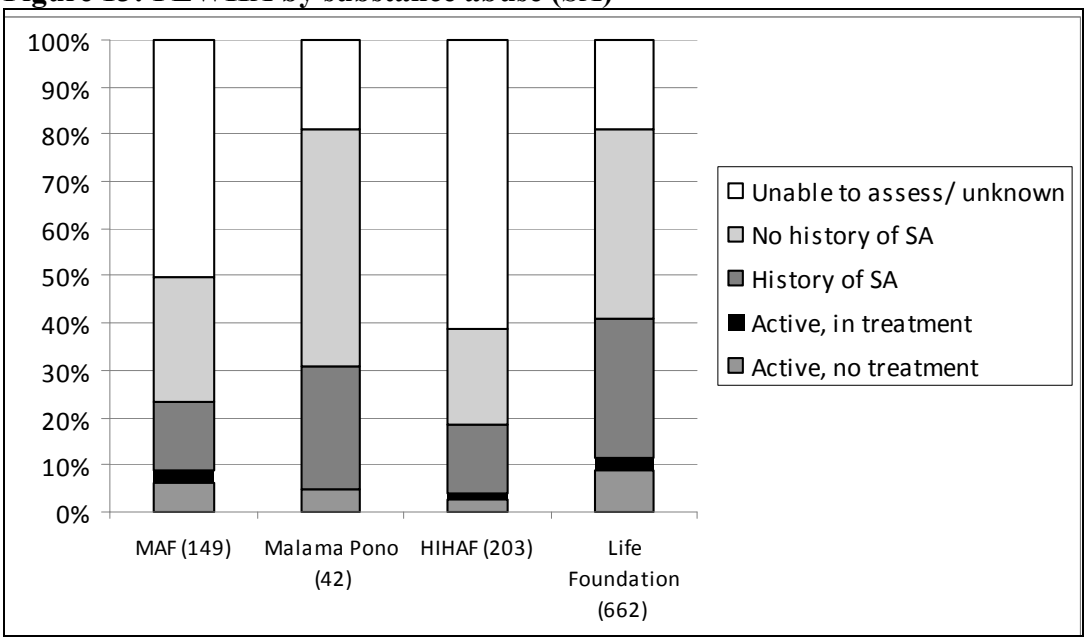
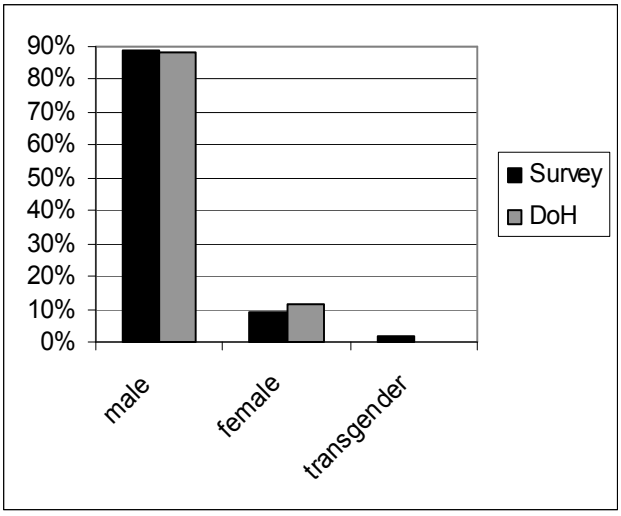


Figure 13: PLWHA by substance abuse (SA)



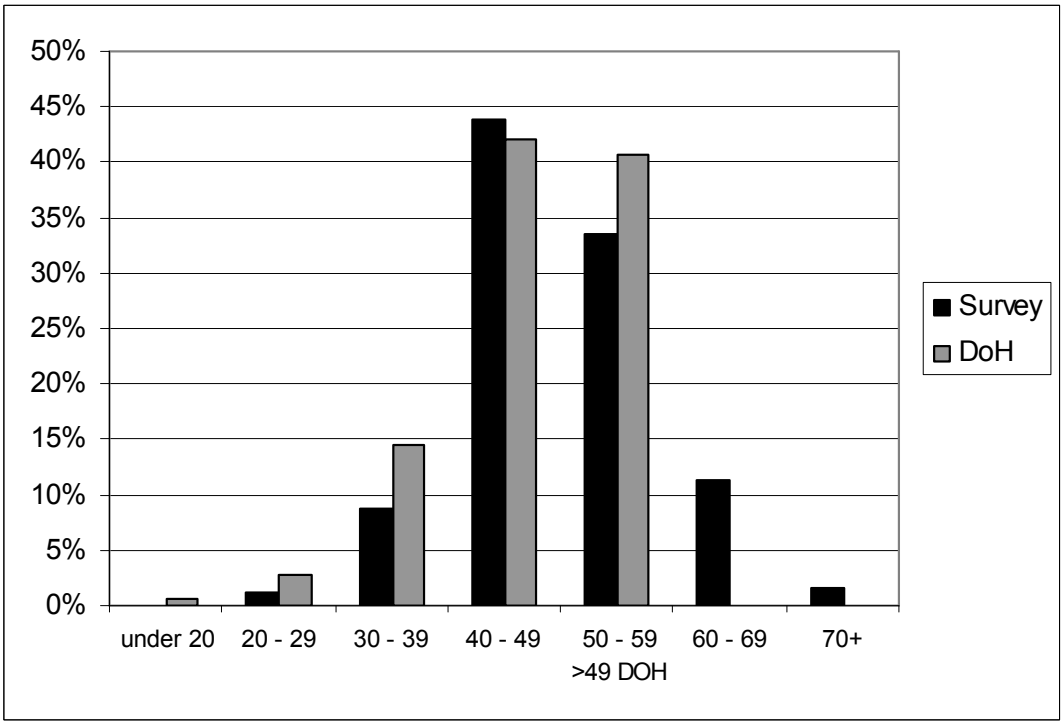
PLWHA in Hawai'i are mostly men, which means there is less need for HIV care specific to women and to prevention of mother to child transmission. The proportion of PLWHA that is women has increased very slowly in Hawai'i relative to the mainland. However, most women are also APIs or Hawai'ians and as such they require services which are sensitive to potential multiple barriers to accessing care stemming from both their ethnicity and their gender. Women often prefer female care providers of which there are few among the State HIV specialists.

Figure 14: PLWHA by gender



The age distribution of PLWHA has a significant impact on their medical care needs. In Hawai'i most known PLWHA are middle aged or elderly. Thus many PLWHA in Hawai'i suffer from HIV itself as well as the myriad of health problems that affects the general population as they age, such as heart disease and cancer. MSM in Hawai'i, as elsewhere,[47] have high rates of cigarette smoking which exacerbates these problems. On the positive side, older people are more likely to seek care and to remain in care.

Figure 15: PLWHA by age



The DOH data is combined for everyone over 49 years of age.

The age distribution suggests that many PLWHA in Hawai'i have been infected for a long time. This also complicates medical care as patients are likely to be sicker from both long-term exposure to HIV and long-term exposure to the medications used to treat it. Seventy five percent of respondents to the consumer survey were diagnosed 8 or more years ago. Many are likely to have been on HAART since it became widely available in the US in 1996. With long term use, and use of some of the earlier drugs which are no longer commonly used, they are more likely to have suffered side-effects with lasting health effects such as metabolic disorders. They are also likely to have developed resistance to some of the medications, limiting their treatment options. Making good decisions under these circumstances requires more experience with HIV care. Finally, they are also more likely to be sicker and to have progressed to AIDS. Indeed, about 30% of respondents in the consumer survey indicated they were diagnosed with HIV when they became sick, presumably with an AIDS-defining illness. Over 62% of the 897 PLWHA for whom information was available in the Reggie data base had progressed to AIDS. Again, sicker patients will require more complex care.

Figure 16: PLWHA by years since diagnosis, consumer survey

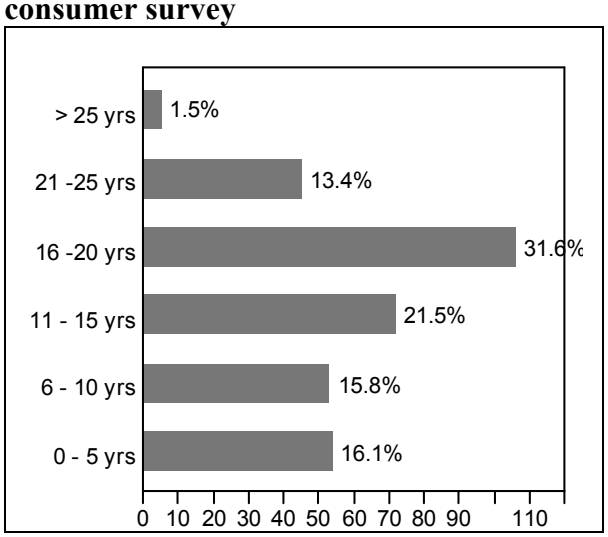
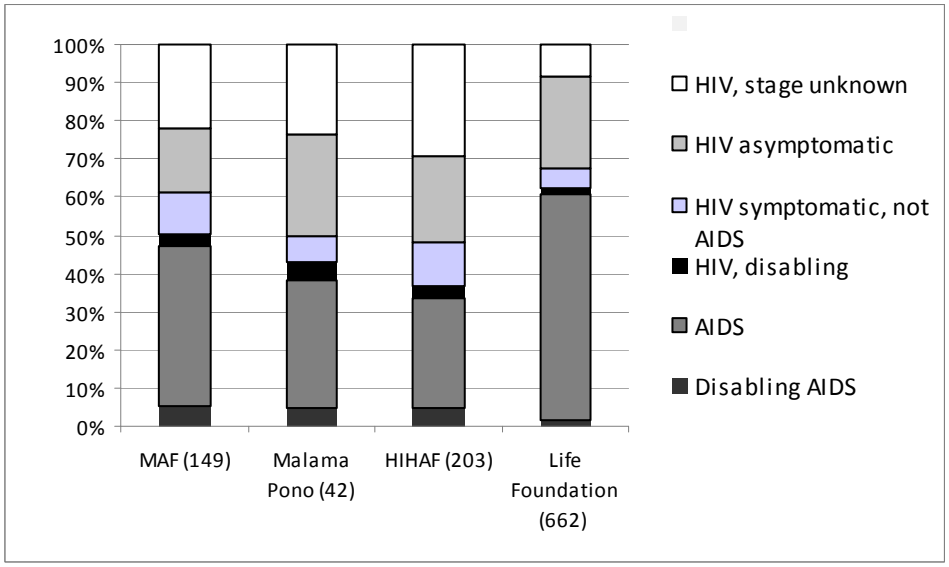


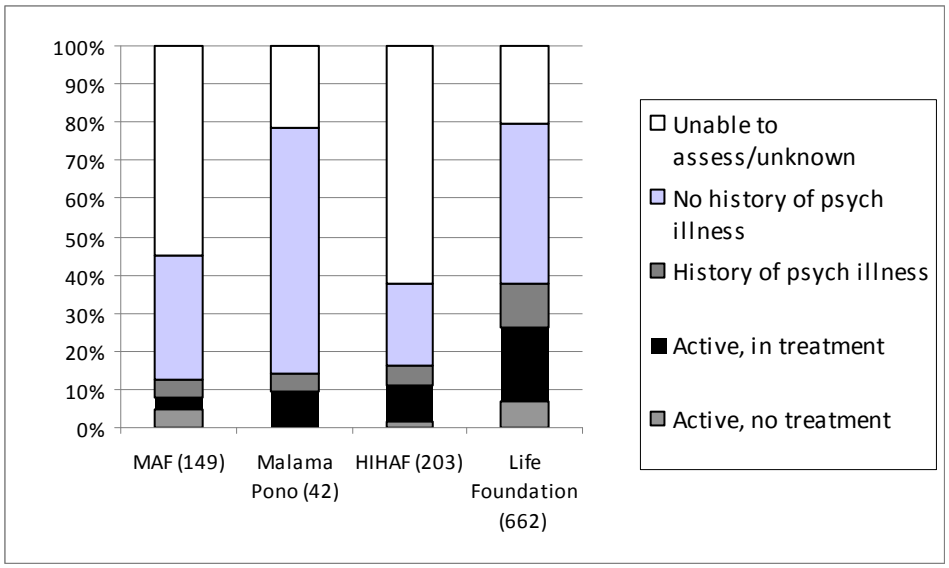
Figure 17: PLWHA by disease stage



Another condition which complicates providing HIV care is psychiatric illness. Of 704 PLWHA assessed, 30% have active psychiatric illness and 14% have a history of psychiatric illness. This high rate can be attributed in part to illnesses caused by AIDS and

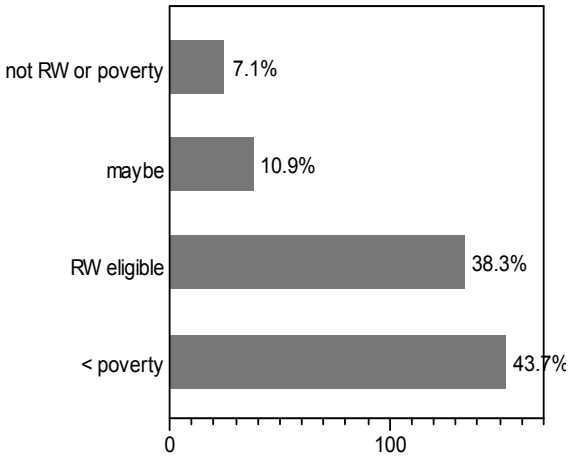
the opportunistic infections that accompany it. These include AIDS defining neurological illnesses such as Toxoplasma Encephalitis or Cryptococcal Meningitis, other CNS disorders, and HIV Associated Dementia. Other psychiatric illnesses such as mood or anxiety disorders

Figure 18: PLWHA by psychiatric illness



may be associated with the stress of having a fatal disease that is highly stigmatized and may lead to economic ruin and loss of loved ones.[48]

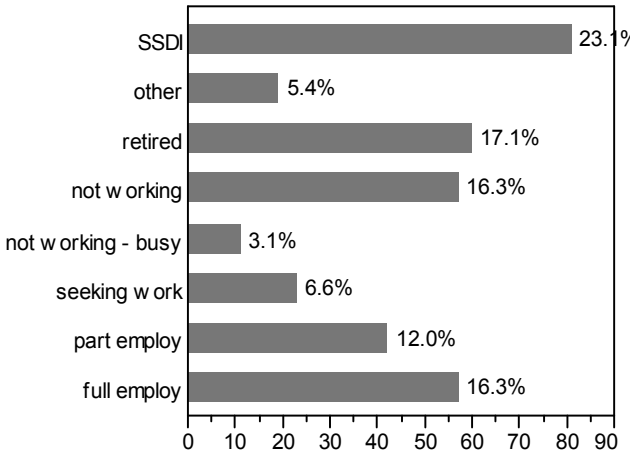
Figure 19: PLWHA by income



Another group difficult to engage and retain in care are PLWHA who are poor.[49] PLWHA in Hawai'i are much poorer than the general population with 44% of respondents of the consumer survey below the poverty line compared to 16% generally in Hawai'i and 17% in the US.[30] The categories are based on the 2007 HHS Poverty Guidelines which set the poverty line at $11,750 for a single person and at $15,750 for a household with 2 people. The Ryan White funded programs are restricted to providing services to PLWHA who are less than 300% of the poverty line. Of survey respondents 82% definitely qualified, 7% did not, and 11% "maybe" qualified as the information was not concise enough to tell for their particular household size. This poverty is surprising given the educational level of this population. 57% finished college, 39% finished high school and only 4% did not finish high school. This is much higher educational achievement than the general population where 25% finished college and 15% did not finish high school. It is explained largely by the fact that only 16% of PLWHA in the survey had full-time jobs. In the general population over the age of 16, 60% of people are employed. The low number that indicated they were seeking work indicates that it is not lack of jobs as much as the

inability to continue to work that is the problem. Most were making do with public assistance, retirement benefits, part-time work or other sources of income.

Figure 20: PLWHA by employment status



People who are homeless are less likely to be in care and more likely to suffer higher morbidity and mortality (even when in care) than other HIV-infected populations.[50] Adherence to complex medical regimens may be more difficult if one does not have stable housing or access to basic subsistence needs. The levels of homelessness are not high among this sample. 4% were homeless, 7% were in transitional or group living situation, 7% were in temporary housing and 83% were in stable living situations. This is in part because the survey is biased towards those who are receiving services (including housing) and thus the homeless are likely under-represented. The 13 homeless represented here were found either through ASO staff giving them the survey at their offices or through Save the Food Basket meals. An additional 7 people who marked other types of living situations put down a location they stay when they are homeless. A study in Los Angeles, for example, found that two thirds of people with AIDS had been homeless. Homeless people often face multiple barriers to care such as lack of health insurance, mental illness, and substance abuse.[51]

5.2 How PLWHA pay for medical care in Hawai'i

Medical care for HIV/AIDS is expensive and life-long. PLWHA often become unable to keep their jobs (and therefore employer-based health insurance) as their disease progresses. PLWHA use varied and multiple sources to pay for their medical care. No complete source of data is available and due to confidentiality concerns, available data can not be combined. Thus data from overlapping populations are presented separately.

Several health insurance organizations provided data for this study. Of the total 1,477 clients, over half receive their health care through a private insurer/HMO. Though the premiums may ultimately be paid through a Medicare or quest contract with the insurer, the care experience and the provider acceptance should not change. The 63% who are not Kaiser, Tricare direct or VA have visited a community provider or public clinic for care. Almost half of these are insured through Medicaid direct pay or AlohaCare which implies restricted access to some community physicians but not to Community Health Centers and other clinics.

All those with the coverage listed here are able to receive care paid by insurers as recommended by the physician (the current CDC recommendation is every three months). PLWHA are known to fail to access care, even when there are no financial barriers.[24] Some

of the insurers checked to see if any of the HIV clients had a gap of greater than 6 months in care during the last year for which data were available. Table 3 indicates that 12% had a gap in care greater than 6 months. Fortunately, this information does not conclusively mean that all these patients did not receive care. It is likely that some of those with AlohaCare and Medicaid are receiving visits billed to HSPAMM (higher reimbursements for MD) between visits billed to the insurer. This is likely to also be the case (though MD reimbursement may be lower) for some patients with HMSA and UHA. Attachment 7.6 displays HSPAMM data by client's type of insurance and enumerates clients with all these types of insurance.

Figure 21: HIV clients by insurance providers, n=1,539

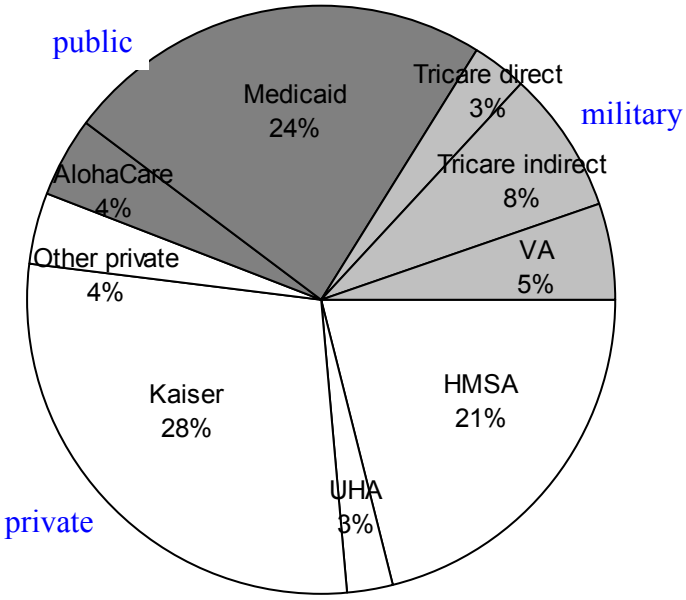
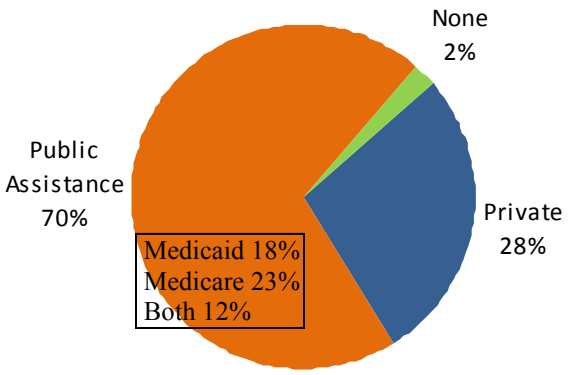


Table 3: HIV clients with gap in billing > 6 months

Insurer	%	#
HMSA	4%	13
UHA	5%	2
AlohaCare	31%	21
Medicaid	26%	96
Tricare direct	20%	9
Tricare indirect	34%	41
Total	**12%**	**182**

The insurance data from the consumer survey is too complex to display graphically, but it illustrates the resourcefulness of many PLWHA in meeting the costs of their medical care. It is difficult to aggregate meaningfully as respondents use varied combinations of up to five different private and public resources. The distribution of responses is summarized in the table 7.1. The chart here aggregates into separate groups those with private sources of insurance (whom may also use public sources) and those with only public sources.

Figure 22: Insurance data from the consumer survey, n=359



This complexity is also evident in HSPAMM data broken down by type of insurance in attachment 7.6. In the graph below, HSPAMM data is grouped into government assistance versus no insurance or private sources. Relative to survey respondents and the ASO client population, a greater percent of this population reports being insured through private means such as employment, self purchase or other (through spouse, as a student, or cobra). HSPAMM is not a needs-based program and thus includes a socio-economically diverse population.

The data aggregated from all the ASOs in the Reggie data base shows the types of insurance by the contribution required from the client in the graph below. Those that have a co-pay or deductible are most likely to have Medicare, though some will have private insurance.

Figure 23: Insurance data from HSPAMM, n=773

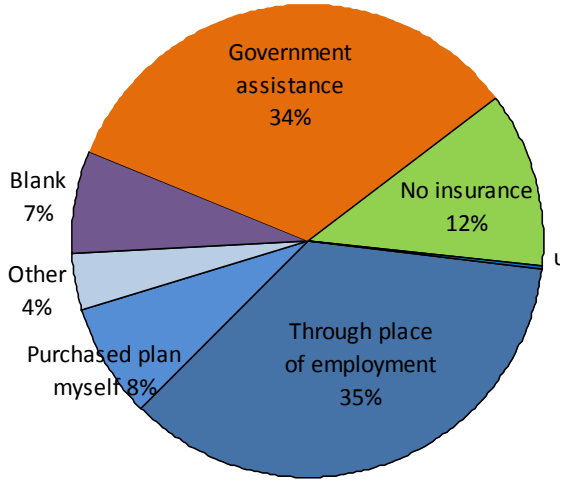
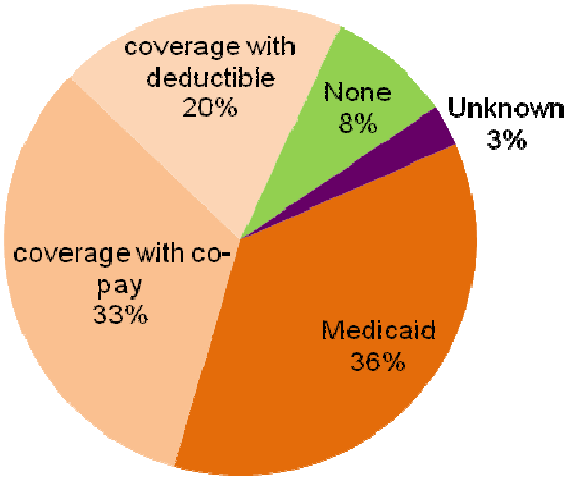


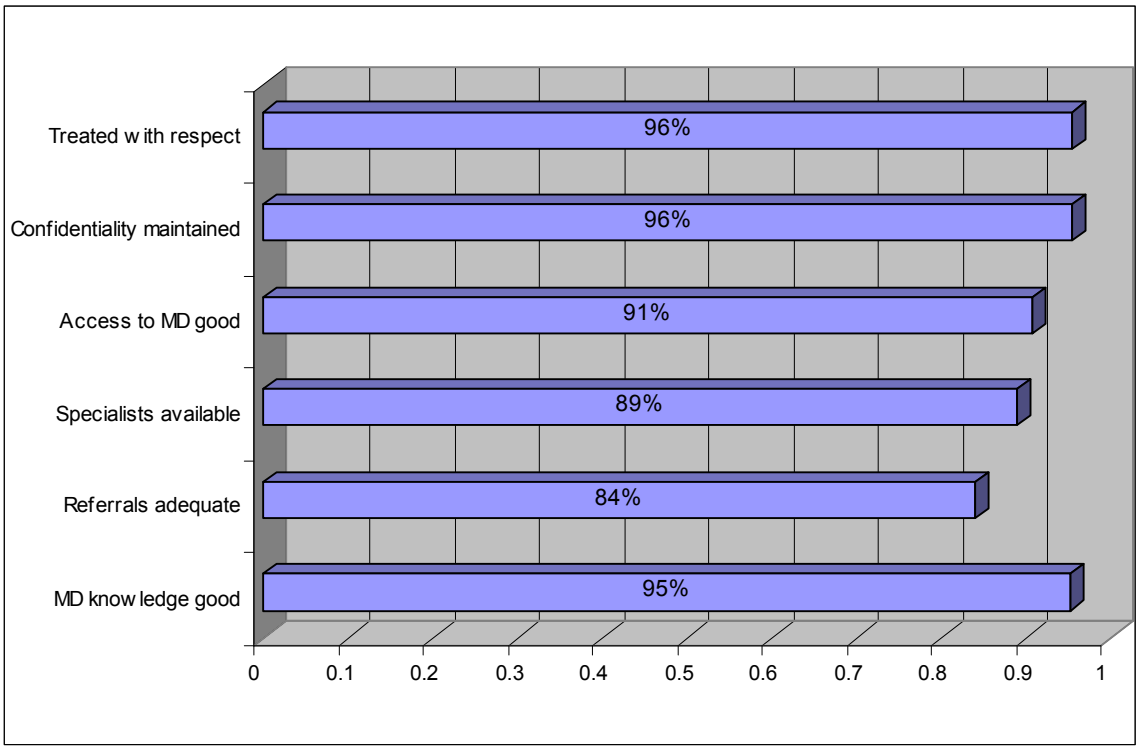
Figure 24: Insurance data Reggie system (ASOs), n=1,056



5.3 Satisfaction with providers

PLWHA report very high levels of satisfaction with their providers in the six aspects quality of care or access to care on which there were "yes / no" questions in the consumer survey. Over 90% responded that they felt confident their care provider knew enough about HIV, that they had access when they needed it, that their confidentiality was protected and that they were treated with respect. Over 80% responded that they received referrals to specialists when needed, and that the specialist was able to see them. Furthermore, as will be discussed in the following section, all of these measures of care were also associated significantly with retention in care at least every 6 months.

Figure 25: Reported satisfaction with providers



In the space made available for comments at the end of the survey, 31 respondents specifically praised their care providers. This high rate of satisfaction is unlikely to be politeness -- 16 respondents specifically expressed dissatisfaction with their ASO staff, though that was not the topic of the survey. Some of the comments were very heartfelt:

While several mentioned the need for more specialists or more locally-based specialists only 6 negative comments were made regarding existing specialists. One claimed that a physician was too busy, one that a physician did not listen to the patient's difficulties, and 4 rather strongly questioned the competence of particular physicians. While some patients may blame their physicians unfairly for poor health outcomes, one study showed that HIV patients may make good assessments of the quality of care they receive. 15% of the patients voluntarily switched physicians and these tended to seek care from providers with more HIV knowledge, experience and patient trust.[52]

5.4 Meeting a minimum frequency of care

All data collected in the survey that might impact retention in care was evaluated. First, chi-square tests were run for each variable to see if the population proportions falling into the categories 'care frequency < 6 months' and 'care frequency > 6 months' were different than would have been expected by random chance. A table with the frequencies, percentages and chi-square values is found in Attachment 7.2. Variables with a statistically significant chi-square probability *and* a potentially relevant relationship with the outcome variable were selected. These were then used as the independent variable in a logistic regression model with the outcome of 'care frequency > 6 months.' The odds ratios were

also calculated and can be understood as the odds that those from a particular category (ex. homeless) will receive care at least every 6 months as compared to the odds that those from a different category (ex. stable housing) will receive care at least every 6 months. The results are displayed in Table 4. Since the variables have categorical values with no numerical relationship to each other, all categories are converted to dummy variables with a value of 1 or 0. The reference category (the one with the lowest frequency of care) to which the others are compared is not coded.

Table 4: Unadjusted sociodemographic and quality of care variables associated with receiving care at least every 6 months

		Odds Ratio	P value
Education	< High school (reference)		
	High school	4.7	0.0130*
	College	6.9	0.0022*
Ethnicity	API (reference)		
	Caucasian	4.0	0.0004*
	Hawai'ian	2.6	0.0431*
	Mixed	2.7	ns
	African American	1.1	ns
	Native American	1.4	ns
Income	< Poverty line (reference)		
	Ryan White eligible (300%)	3.2	0.0029*
	Maybe Ryan White eligible	3.0	ns
	Not Ryan White eligible	6.1	ns
Housing	Homeless (reference)		
	Transitional program	24.7	0.0008*
	Temporary	7.1	0.0100*
	Stable	20.7	0.0001*
Insurance	Govt. assistance (reference)		
	Private insurance	2.8	0.0221*
	No insurance	1.3	ns
MD Knowledge	Inadequate (reference)		
	Adequate	7.0	0.0003*
Referral Available	Not available (reference)		
	Available	3.0	0.0233*
Access to MD	MD not available (reference)		
	MD available	5.1	0.0002*
Confidentiality	Not maintained (reference)		
	Maintained	4.9	0.0063*
Respect shown	Not respected (reference)		
	Respected	8.6	0.0001*
Adherence	Not counseled (reference)		
	Counseled by MD	2.3	0.0097*

The results generally confirmed that those who are socio-economically more privileged are more likely to receive care at least every 6 months. Those with higher levels of education are more likely to be in care than those who did not complete high school and that the benefit is greater for those who completed college than for those that completed high school. For ethnicity, the sample sizes for African Americans, Native Americans and Mixed were not large enough to show significance. However, Caucasians and native Hawai'ians were more likely to be in care than APIs who were not Hawai'ian. This outcome was

expected for Caucasians, but not for Hawai'ians. People at higher income levels are more likely to be in care, though the sample sizes of those in the higher income categories were too small to show statistical significance. People who are not homeless are much more likely to be in care than those that are. Those in transitional programs such as Gregory House have the same elevated odds of being in care as those with stable housing. The services received in transitional programs get people into care despite their complicated life situations. Too few people were uninsured to show statistical significance, but those with private insurance were more likely to be in care than those with government assistance.

The results also confirmed that those that were more satisfied with their access to care and their quality of care were more likely to be in care at least every six months. Those that felt their MD was knowledgeable in HIV care, referred them to specialists as needed, treated them with respect and maintained confidentiality were all more likely to be in care. Those whom were able to access a specialist once referred were also more likely to be in care. Those that recalled receiving adherence counseling from their MD (this is independent of being counseled by other care providers) also were more likely to be in care. On this last variable, 89% to whom this question applied did recall being counseled by their MD, so it was a sign of something out of the ordinary to *not* recall being counseled.

Finally for the significant variables, dummy variables representing the reference category were put together in a multiple logistic regression model. This allows each variable to be adjusted for any possible interactions with the other variables. Because the reference categories are those accessing care least frequently, the odds ratio is a fraction showing how much *less* likely a group with a particular attribute is to be in care. The results are displayed in Table 5. They show that most variables lose their statistical significance when the other variables are adjusted for. The only to maintain significant association with the dependent frequency of care variable are: confidentiality, API ethnicity and homelessness. This is not because the other variables are unimportant, but rather because there are strong associations between the independent variables.

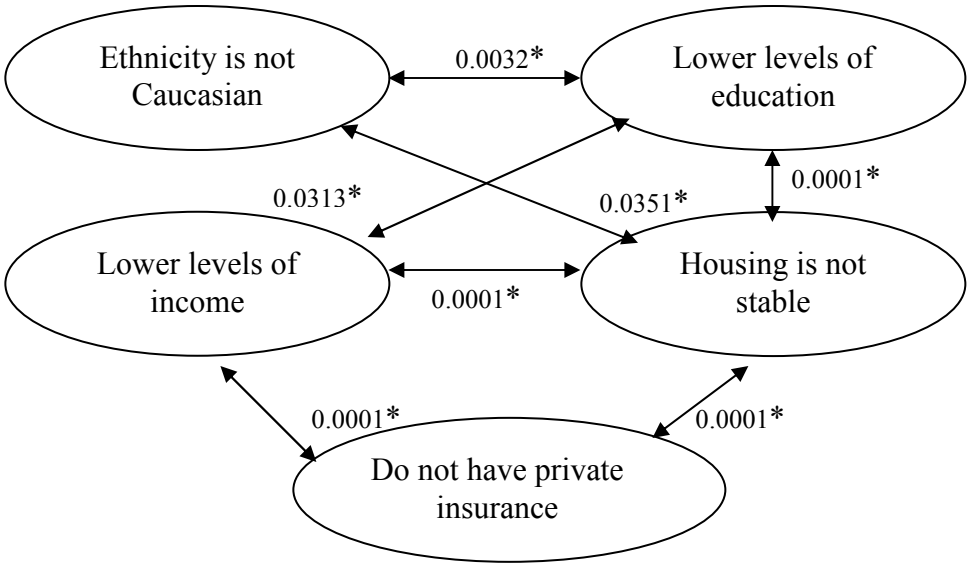
Table 5: Adjusted variables associated with receiving care at least every 6 months

All dummy variables		Odds ratio	P value
Education	< High school	0.24	ns
Ethnicity	API	0.27	0.0121*
Income	< Poverty line	0.60	ns
Housing	Homeless	0.17	0.0454*
Insurance	Govt. assistance	0.57	ns
MD Knowledge	Inadequate	0.55	ns
Referral Available	Not available	0.70	ns
Access to MD	MD not available	0.46	ns
Confidentiality	Not maintained	0.10	0.0374*
Respect shown	Not respected	0.52	ns
Adherence	Not counseled by MD	0.87	ns

Pearson's Chi square significance values indicate strong statistically significant relationships between all sociodemographic variables except: Ethnicity is *not* correlated with

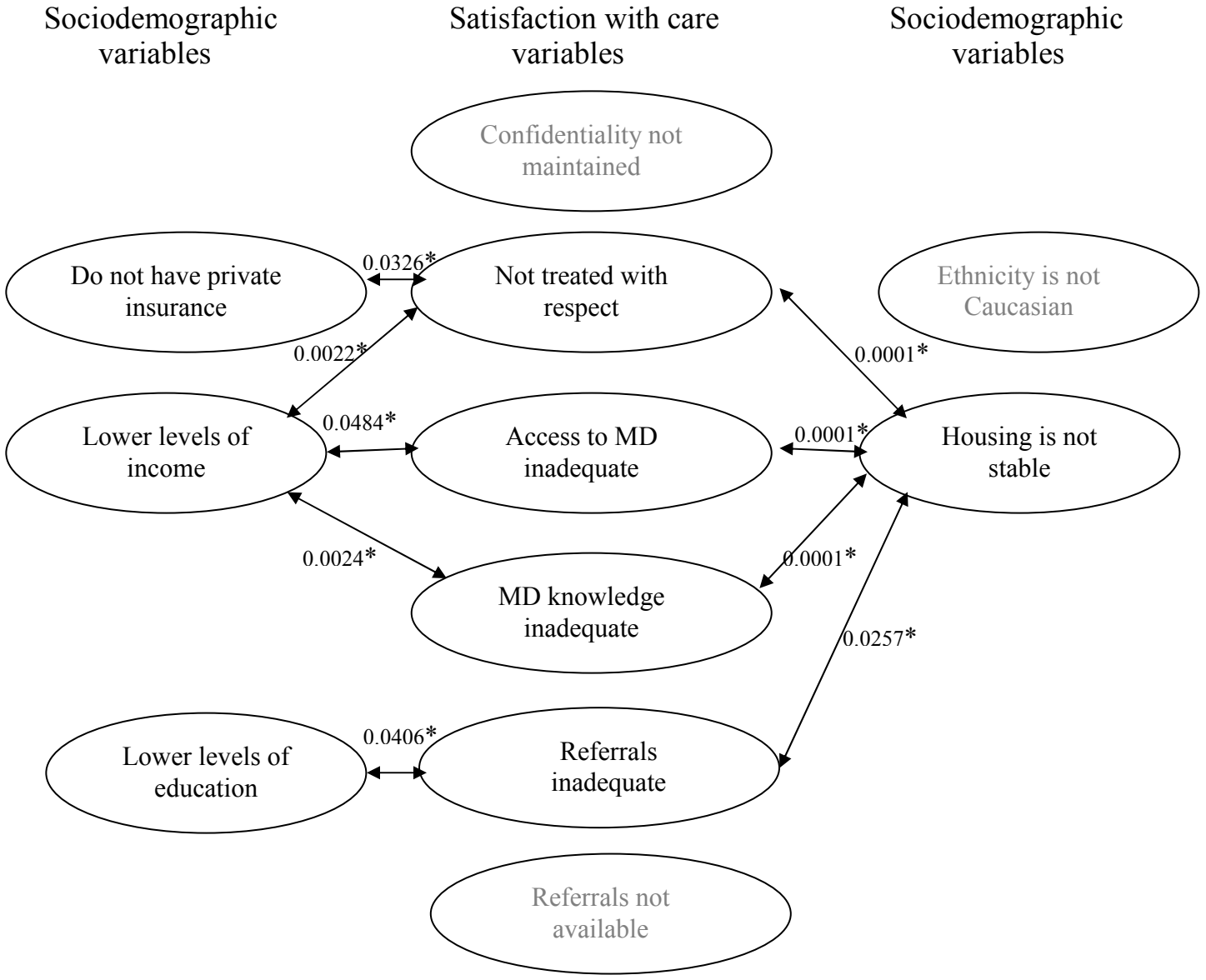
either income or type of insurance, and education is *not* correlated with insurance type. In the multiple regression model, not having stable housing in effect trumps most variables due to its strong relationships with them. The multiple barriers faced by homeless people and the problems they have with enrolment and retention in care is a major challenge of the AIDS epidemic.[53] Ethnicity which is free of association with income, insurance status and satisfaction with care variables (Figure 26) is the only other sociodemographic variable to have a statistically significant effect independent of housing status.

Figure 26: Relationships between sociodemographic variables



The associations between the independent socioeconomic variables and satisfaction with care are described graphically in Figure 27 with Pearsons chi-square probability indicated where significant. Most respondents reported satisfaction with their care across all categories. The minority of respondents who did not (4% - 16% depending on the variable) were more likely to be homeless and/or to be below the poverty line. Type of insurance is associated only with "treated with respect" where all respondents with private insurance or no insurance at all felt they were treated with respect. Education was associated only with the perception of insufficient referrals to specialists. One reason confidentiality remains statistically significant in the multiple regression analysis it that is not associated with any sociodemographic variables.

Figure 27: Relationships between sociodemographic and satisfaction with provider variables



The survey asked about specific reasons for not receiving care in the last year. Due to high use of care among survey respondents, only 28 answered this survey question. They reason given and the frequency are as follows:

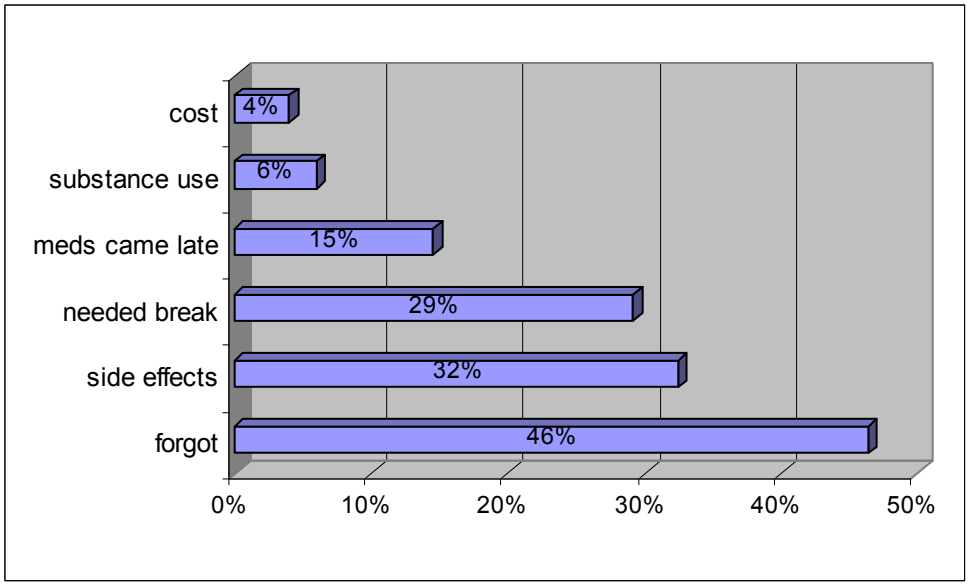
- cost too much 8
- I was too sick 8
- didn't want anyone to know 7
- didn't need care 6
- there was no HIV MD 5
- transportation problem 4
- takes too long 3
- don't know where to go 2
- not eligible for care 1
- fear discrimination 1

5.4 Adherence to antiretroviral therapy (ART)

Highly active antiretroviral therapy is responsible for delaying the onset of AIDS among HIV-infected people, and in reducing morbidity, and increasing life expectancy among those already progressed to AIDS. However, adherence to the therapy must be almost perfect, forever. Failure to take the medicine properly even 5% of the time results in greater morbidity and mortality,[54] and resistance to the class of medication taken.[55] This means that options for future therapies are reduced.

To understand the benefit of HIV medical care to PLWHA in Hawai'i it is important to know how many are on ART and to what extent they are adherent. In the consumer survey, 85% were currently on ART while only 11% were not and 4% did not know. Due to the side effects, it is not advisable to start ART before indicated by immune status, therefore having 11% not yet on medication is not necessarily a problem. 329 of those surveyed responded to the question: Did you ever skip or stop taking your antiretroviral medications? 46% of these said they did and 54% said they did not. In the follow questions regarding reasons for skipping or stopping, some common reasons were unintentional such as "forgot" or "medications came late." Others indicated intention such as "side effects," "needed a break" and "cost." The responses are tabulated in Figure 28.

Figure 28: Reasons for skipping / stopping ART



A logistic regression analysis similar to that done for frequency of care was run with the results that those most likely to skip are those who grew up in Hawai'i (as opposed to the continental US) or are Hawai'ian; those possibly infected through injection drug use; and those that stated a barrier to care in the last year in the consumer survey. Current and ever drug use are associated with poor adherence, and those who did not access care are also likely to have stopped taking their medications. Why growing up in Hawai'i or being Hawai'ian predisposes people to skip is left to conjecture about the relaxed island attitude which does not lend itself to rigid adherence.

Those that were least likely to skip are those who work full time and those who were counseled by a pharmacist. The last of these suggests that the State-funded program with a full-time HIV pharmacist, Fred Cruz, at CVS pro-care which distributes medication and provides follow up to some 800 PLWHA is effective.

Unadjusted variables associated with skipping ART

Dummy variables		Odds ratio	P value
Immigrant status	Grew up in Hawai'i	2.3	0.0008*
Ethnicity	Caucasian (reference)		
	API	1.0	ns
	Hawai'ian	2.9	0.0007*
	Mixed	1.5	ns
	African American	1.1	ns
	Native American	2.2	ns
Infection source	IDU or IDU/MSM	3.6	0.0088*
Barriers to care	Barriers to care stated (any)	2.7	0.0357*
Work	Full employment	0.4	0.0124*
Counseled	By pharmacist	0.5	0.0068*

When multiple regression analysis is repeated adjusting for association between variables, everything is still statistically significant except for "Hawai'ian." "Hawai'ian" is strongly correlated with "grew up in Hawai'i" and if this variable is excluded, Hawai'ian remains significant.

Adjusted variables associated with skipping ART

Dummy variables		Odds ratio	P value
Immigrant status	Grew up in Hawai'i	1.9	0.0421*
Ethnicity	Hawai'ian	1.7	0.2196
Infection source	IDU or IDU/MSM	3.0	0.0322*
Barriers to care	Barriers to care stated (any)	3.0	0.0282*
Work	Full employment	0.4	0.0046*
Counseled	By pharmacist	0.5	0.0421*

5.5 Comments from respondents

Respondents were given the opportunity to write suggestions for improving medical services for PLWHA or any additional comments. While many left this blank, a couple attached an additional page. Many respondents wrote eloquent and thoughtful comments. The comments can be summarized as follows:

- Need more HIV experts locally 34
- Praise for care / service providers 31
- Need more dental care / funds 23

- Concerns about income / access to assistance 21
- Unhappy with ASO 16
- Need more mental health services 7
- Problems with transportation 6
- Problems with confidentiality 5

The most common comment was that there was a need for HIV specialists. Most of these were specific to their own locale, but some were more general about Hawai'i. Some focused on the departure of MDs, echoing HMA concerns: "Find a way to keep and attract doctors to the State of Hawai'i." Some focused on the impending retirement of MDs: "Get new docs, the old guys are going to retire soon." Others indicated that one option wasn't enough: "We need more doctors knowledgeable about HIV/AIDS so we have a choice." The lack of choice was sometimes linked with confidentiality concerns, as a physician might be known as the "AIDS doctor."

The concern about dental care is a result of the timing of this survey which coincided with a petition on Oahu circulating about the lack of dental care resources. In actuality, this was a false rumor. Ryan White funds for dental care at the Life Foundation had not run out. The multiple steps involved in approving dental work are a hassle, but providers and case managers are willing to endure them. On Oahu, patients using Ryan White funds are restricted to the Queen Emma Clinic, however there are more options in some other places. On the neighbor islands neither the case managers nor survey respondents identified dental care as a major problem. In fact, finding a dentist is easier than finding a primary care provider in some places.

6.1 CONCLUSIONS AND RECOMMENDATIONS

Because of the relatively small patient population and the geographical segmentation of that population, the State of Hawai'i faces particular problems in maintaining an adequate HIV medical care delivery system. Strategies should focus on maintaining two key elements in the system, particularly in rural areas: resilience and multiple patient care options. The first of these, resilience refers to a system that can recover from or resist being affected by a disturbance, such as the departure of a particular physician. In recent years, the retirement or relocation of a single physician who cared for a significant proportion of the HIV-infected population on an neighbor island or rural Oahu has caused a crisis where patients were at risk of falling out of care. If a lapse in medical care, however brief, causes a lapse in adherence to antiretroviral medication, the result is likely to be drug resistance that limits lifelong medication options for future treatment.

Small numbers of patients do fall out of care when the provider they are accustomed to leaves, as when Dr. Cooke-Palmer left WCCHCC in 2007 or when Dr. Kroon left Ho'ola Lahui in 2006. Some of Dr. Kroon's patients have recently come back into care now that word has spread that Dr. Laird at Ho'ola Lahui has connected with HIV training and support services. However, large scale problems have been averted by the advocacy of the ASO's

who have reacted quickly to these situations and sought alternative means of providing medical services to their clients. One example is the care provided by Oahu-based physicians Dr. Kovach and later Dr. Morrison on-site at the Kauai AIDS Service Organization Malama Pono over a three year period in the late 1990s when there were no HIV specialists on Kauai. Another is the opening of a Clint Spencer Clinic branch in Kona when Dr. Denzer left. That clinic continues to operate with no local alternatives available to those patients.

Community physicians on Oahu who see a large number of patients are approaching ages at which many physicians retire. This trend, and the lack of interest in HIV specialization among young physicians, is of concern to some the physicians themselves, to some of their patients who responded to the consumer survey, and to organizations such as the DOH and HACRP. This trend is not restricted to Hawai'i and may be attributed to the emergence of the AIDS epidemic at a certain point in the training of our current cohort of HIV physicians. At that time HIV was a new, compelling disease affecting groups with whom many young physicians felt connected. Now HIV has become a chronic disease associated increasingly with poverty, ethnic minorities and substance abusers.

While the exact timing of the retirement or change in residence of a particular physician may be a surprise, it is a predictable that such disturbances will happen. Hawai'i needs to plan for these inevitable events. One solution is to support institutions that can provide HIV care alongside or in the absence of community physicians. Institutions can replace staff with another HIV expert or with a physician who will have the opportunity to quickly gain expertise by inheriting a large HIV patient population.

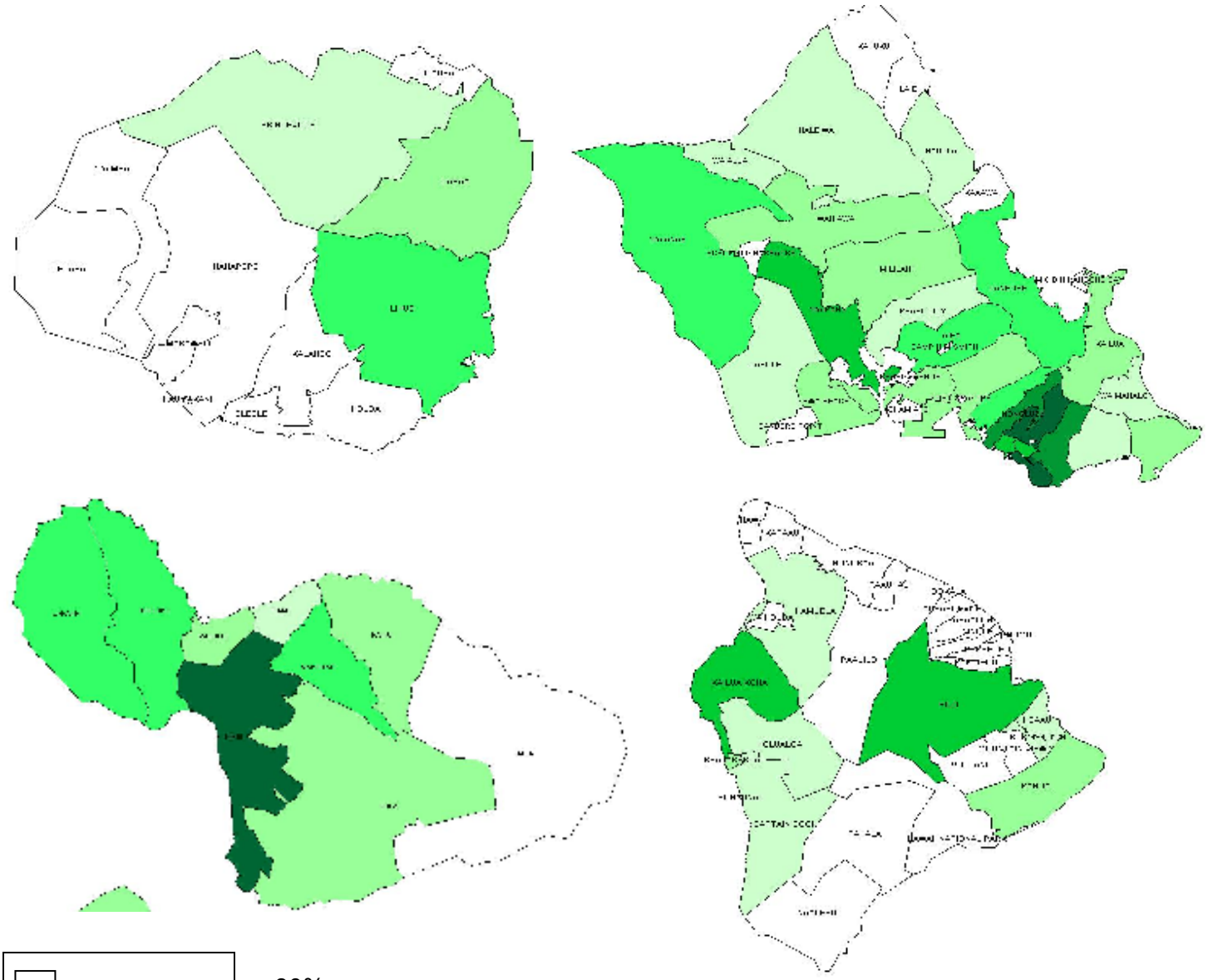
The second element important to the HIV medical care delivery system that may not occur naturally in rural areas of Hawai'i is maintenance of multiple patient care options. Some HIV patients have a variety of mental health and social challenges and they may not feel they receive the help or sensitivity they need in these areas from their physician. Others may not feel their physician is competent in providing the medical care they need. The patient's judgment may or may not be accurate, but that becomes irrelevant when the patient's perception causes him or her to stop seeking care. Having at least one other geographically accessible option to go to when a patient is unhappy with their care provider is important to keeping patients in care.

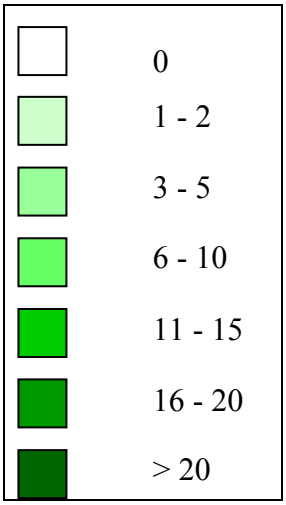
The option of seeing a physician in private practice may be especially important for PLWHA who are high functioning, do not need ancillary services or financial support, and prefer to see a private practice physician in a setting similar to where they have always received health care. Across the US people who are better educated, richer, employed and insured are more likely to choose a clinic that is not funded by the Ryan White Care Act.[56] Therefore community physicians should be encouraged and supported through continuing education such as that they receive now through HAETC and a more formalized outreach to them offering clinical support through telephone consults or other means. Even though some community physicians have restrictions on the types of insurance or types of patients they see, they provide an alternative option for many PLWHA and reduce the case load on public or charitable clinics.

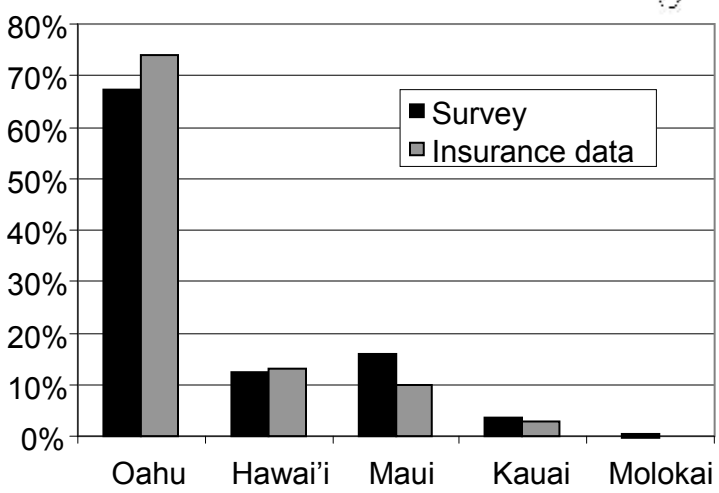
The resilience of the medical care delivery system and the patient choice within that system can be enhanced by supporting institutions that provide HIV care, such as community clinics. In theory, these can provide continuity of care despite changes in particular staff members. The Waikiki Health Center, for example, has built a team with HIV expertise and has enough patients that a new physician could have both the motivation and opportunity to develop HIV experience. Some community health centers, however, have suffered from chronic staff turnover or loss of staff and do not have the luxury at this point to focus on a disease that affects only a small part of their patient population. In these cases, an alternative strategy would be required. Institutions which have a State-wide vision, such as the Clint Spencer Clinic, can provide a safety net and step in with direct patient care or collaboration with locally-based physicians. The AIDS Education Program is also available for tailored training of physicians caring for HIV patients.

Finally, the consumer survey demonstrated that most PLWHA surveyed received care at least every six months (87%) and that most are highly satisfied with measures of access to care and quality of care received (84% - 96%). Those that are *not* receiving care at least every six months are less likely to be taking antiretroviral therapy and can be expected to experience increased morbidity and mortality from HIV. This group is likely to be disadvantaged in multiple ways. They are likely to be homeless, have low levels of education, to be poor, to be insured through public assistance and to be Asian Pacific Islanders (other than Hawai'ians). This group is also less likely to be satisfied with the care they have received. Interestingly, they are seeing the same physicians as those who receive care more frequently. To get this group back in care and to keep them there will require outreach and ancillary services beyond the scope of community physicians.

7.1 CONSUMER SURVEY: DISTRIBUTION OF RESPONDENTS







Distribution of Survey Respondents, n=359

Kauai = 13
Oahu = 230
Maui = 55
Molokai = 2
Hawai'i = 46
(Kona = 26, Hilo = 20)

7.2 CONSUMER SURVEY: FREQUENCY OF RESPONSES

	n	Percent
RESPONSE SOURCE		
Mail (mostly via ASOs)	208	58%
CVS Procare	65	18%
Save food basket	47	13%
Life Found. reception	25	7%
Gregory house	14	4%
Total responses	359	100%
AGE GROUP		
20 - 29	4	1%
30 - 39	30	9%
40 - 49	149	44%
50 - 59	113	33%
60 - 69	38	11%
70+	5	1%
Total responses	339	100%
BIRTH PLACE		
born Hawai'i	104	29%
born elsewhere	253	71%
Total responses	357	100%
IMMIGRATION STATUS		
local (any ethnicity)	121	34%
immigrant	238	66%
Total responses	359	100%
LIKELY DX PLACE (projected)		
Dx likely Hawai'i	242	68%
Dx likely elsewhere	112	32%
Total responses	354	100%
EDUCATION		
< HS	14	4%
high school	138	39%
college	204	57%
Total responses	356	100%
CURRENT WORK		
full employ	57	16%
part employ	42	12%
seeking work	23	7%
not working - busy	11	3%
not working	57	16%
retired	60	17%
other	19	5%
SSDI	81	23%
Total responses	350	100%
YEARS SINCE TEST		
20+	63	19%
10 - 19	174	52%
5 - 9	53	16%
< 5	45	13%
Total responses	335	100%

	n	Percent
GENDER		
male	316	88%
female	35	10%
transgender	7	2%
Total responses	358	100%
ETHNICITY		
Caucasian	208	58%
Hawai'ian	59	17%
Other API	47	13%
Mixed	17	5%
African Amer	7	2%
Native Amer	5	1%
Total responses	343	100%
Total Hispanic	42	12%
HOUSING		
stable	296	83%
temporary	25	7%
Transitl. / group	24	7%
homeless	13	4%
Total responses	358	100%
INCOME		
<12k	153	44%
12k - 25k	104	30%
25k - 35k	30	9%
35+	63	18%
Total responses	350	100%
HOUSEHOLD SIZE		
1	264	75%
2	66	19%
3	11	3%
4+	13	4%
Total responses	354	100%
ECONOMIC STATUS		
< poverty	153	44%
RW eligible	134	38%
maybe RW elig.	38	11%
not RW eligible	25	7%
Total responses	350	100%
INFECTION SOURCE		
MSM	252	71%
heterosexual	39	11%
don't know	34	10%
IDU	17	5%
MSM / IDU	7	2%
blood products	4	1%
other	2	1%
Total responses	355	100%

	n	Percent
WORK INSURANCE		
work	44	66%
Work/VA	3	4%
Work/HSPAMM	4	6%
Work/HSPAMM/HDAP	4	6%
Work/medicare	7	10%
Work/other private	1	1%
Work/state /federal	4	6%
Total responses	67	100%
PRIVATE INSURANCE		
private not work	11	48%
private not work/Medicare	10	43%
private not work/ HDAP/HSPAMM	2	9%
Total responses	23	100%
VETERANS ASSISTANCE		
VA	8	53%
VA & Medicare	6	40%
VA & Quest	1	7%
Total responses	15	100%
COBRA		
cobra	3	33%
Cobra/HDAP/Medicare or HSPAMM	3	33%
Total responses	9	100%
MEDICAID		
Medicaid	38	36%
Medicaid/HSPAMM	6	6%
Medicaid/HDAP/ (some) HSPAMM	3	3%
Medicaid & VA	2	2%
Total responses	57	100%
MEDICARE		
Medicare	44	35%
Medicare/HSPAMM	9	7%
Medicare/HDAP/HSPAMM	17	13%
Medicare/Medicaid	44	35%
Medicare/Medicaid/HSPAMM	8	6%
Medicare/Medicaid/HDAP/ (some) HSPAMM	5	4%
Total responses	127	100%
STATE PROGRAMS ONLY		
HCobra	2	8%
HCobra/HSPAMM/HDAP	1	4%
HSPAMM	7	27%
HDAP	7	27%
HSPAMM/HDAP	9	35%
Total responses	26	100%

	n	Percent
NO INSURANCE		
specifically indicated	8	2%
CARE LAG		
never	2	1%
< 6 months	179	52%
when sick	102	29%
other	63	18%
Total responses	346	100%
ACCESS TO CARE		
Frequency $\geq$ 6 months	313	87%
Frequency < 6 months	46	13%
Total responses	359	100%
CURRENT ARV USE		
currently on ARVs	298	85%
not on ARVs	39	11%
don't know	15	4%
Total responses	352	100%
MD KNOWLEDGE		
adequate knowledge	330	95%
inadequate	16	5%
Total responses	346	100%
REFERRALS		
referred as needed	268	84%
didn't refer as needed	51	16%
Total responses	319	100%
REFERRAL AVAILABLE		
specialist available	265	89%
not available	33	11%
Total responses	298	100%
ACCESS TO MD		
MD available	306	91%
MD not available	31	9%
Total responses	337	100%
CONFIDENTIALITY		
maintained	323	96%
not maintained	15	4%
Total responses	338	100%
RESPECT SHOWN		
respected	324	96%
not respected	15	4%
Total responses	339	100%

	n	Percent		n	Percent
SKIPPED ARVs			**WHY SKIPPED (can be >1)**		
skipped	151	46%	forgot	70	46%
didn't skip	178	54%	side effects	49	32%
Total responses	329	100%	needed a break	44	29%
REASON NO CARE LAST YR (can be >1)			Medications arrived late	22	15%
too sick	8	29%	substance use	9	6%
cost barriers	8	29%	Too expensive	6	4%
HIV status secret	7	25%	MD orders	1	1%
no perceived need	6	21%	Total responses	151	100%
no HIV MD available	5	18%	**ADHERENCE COUNSELING (can be >1)**		
transport barriers	4	14%	from MD	261	89%
takes too long	3	11%	from nurse	97	33%
Didn't know where to go	2	7%	from pharmacist	96	33%
not eligible	1	4%	other (ex, written)	40	14%
fear discrimination	1	4%	from nobody	7	2%
Total responses	28	100%	Total responses	292	100%

If provider is known to provide both specialty and primary care, it was assumed they provided both when one field was left blank. In each category of providers, the percentage of all respondents naming a specific physician is indicated.

	SPECIALTY CARE		PRIMARY CARE	
Clint Spencer Clinic	61	18%	24	7%
Goshima	55	17%	58	18%
Waikiki Health Center (includes Tice)	51	15%	49	15%
Kaiser	46	14%	43	13%
Community Clinic of Maui	22	7%	20	6%
Frank	11	3%	10	3%
Pien	11	3%	10	3%
Martell	10	3%	10	3%
Johnson / VA	10	3%	10	3%
Morrison	6	2%	5	2%
Tice	6	2%	4	1%
Yoon	6	2%	6	2%
Bello	4	1%	4	1%
Dang	3	1%	3	1%
Koo	3	1%	2	1%
Berman	2	1%	2	1%
Harmeling	2	1%	2	1%
Kauai Comm Health Center	2	1%	3	1%
Kwon	2	1%	3	1%
Lawrence	2	1%	2	1%
Palama	2	1%	1	<1%
Chen	1	<1%	1	<1%
Dewitt	1	<1%		
Flora	1	<1%		
Griffin	1	<1%	2	1%

	SPECIALTY CARE		PRIMARY CARE	
Hale Lea Clinic	1	<1%	1	<1%
Linden	1	<1%	1	<1%
Lipetz	1	<1%	2	1%
Ricardo-Dukelow	1	<1%	1	<1%
McEwan	1	<1%	1	<1%
McIntyre	1	<1%	2	1%
Pastrama	1	<1%		
Ummed, Queens	1	<1%		
Waianae Comp	1	<1%	2	1%
Wong	1	<1%		
West Hawai'i CHC (Evans)			8	2%
Queen Emma Clinic			4	1%
Maugauran			2	1%
Aurora Mariani			1	<1%
Bay Clinic			1	<1%
Bernard Chun			1	<1%
Blorden			1	<1%
Craig Kadooka			1	<1%
David Moore, DO			1	<1%
David Saito			1	<1%
DeBoard			1	<1%
Family Medicine Center			1	<1%
Gosmia, Greenly			1	<1%
Hamakua Health Center / Honokaa			1	<1%
HMC			1	<1%
Huber			1	<1%
James			1	<1%
Kalani Bradey			1	<1%
Kalihi			1	<1%
Kato			1	<1%
Maui Medical Group			1	<1%
Pahoa Family Health Center			1	<1%
Queens Medical Center			1	<1%
Sharon Lawler			1	<1%
Till Hanses			1	<1%
Timothy Hiura			1	<1%
Waikoloa Family Clinic			1	<1%
Total	331	100%	328	100%

7.3 CONSUMER SURVEY: CROSS TABULATION WITH FREQUENCY OF CARE

The column "Care frequency <6 months" identifies those failing to receive a minimal standard of care. The Pearson's chi-square probability was included if $p \leq 0.05$. If not $P > 0.05$, it is marked "ns" for "not significant." For those with a significant chi-square and a table with more numerous groupings than 2 X 2 the chi-square for all groups in the variable is indicated in bold at the top of the section. For these, the variables were then converted into dummies and separate chi-square from the 2 X 2 table for each dummy variable is shown, if significant, in that particular line.

	Whole sample		Care frequency < 6 months ☹		Care frequency ≥ 6 months ☺		Chi-Square
	n	Percent	n	Percent	n	Percent	
RESPONSE SOURCE							**0.0295***
Mail (mostly via ASOs)	208	58%	23	50%	185	59%	
CVS Procare	65	18%	4	9%	61	19%	
Save food basket	47	13%	9	20%	38	12%	
Life Found. reception	25	7%	6	13%	19	6%	
Gregory house	14	4%	4	9%	10	3%	
Total responses	359	100%	46	100%	313	100%	
AGE GROUP							**ns**
20 - 29	4	1%	1	3%	3	1%	
30 - 39	30	9%	5	13%	25	8%	
40 - 49	149	44%	15	38%	134	45%	
50 - 59	113	33%	13	33%	100	33%	
60 - 69	38	11%	5	13%	33	11%	
70+	5	1%	1	3%	4	1%	
Total responses	339	100%	40	100%	299	100%	
BIRTH PLACE							**ns**
born Hawai'i	104	29%	13	29%	91	29%	
born elsewhere	253	71%	32	71%	221	71%	
Total responses	357	100%	45	100%	312	100%	
IMMIGRATION STATUS							**ns**
local (any ethnicity)	121	34%	18	39%	103	33%	
immigrant	238	66%	28	61%	210	67%	
Total responses	359	100%	46	100%	313	100%	
LIKELY DX PLACE (projected)							**ns**
Dx likely Hawai'i	242	68%	35	80%	207	67%	
Dx likely elsewhere	112	32%	9	20%	103	33%	
Total responses	354	100%	44	100%	310	100%	
EDUCATION							**0.0082***
< HS	14	4%	6	13%	8	3%	0.0019*
high school	138	39%	19	42%	119	38%	ns
college	204	57%	20	44%	184	59%	ns
Total responses	356	100%	45	100%	311	100%	

	Whole sample		Care frequency < 6 months ☹		Care frequency > 6 months ☺		Chi-Square
	n	Percent	n	Percent	n	Percent	
CURRENT WORK							**ns**
full employ	57	16%	5	11%	52	17%	
part employ	42	12%	8	18%	34	11%	
seeking work	23	7%	5	11%	18	6%	
not working - busy	11	3%	1	2%	10	3%	
not working	57	16%	8	18%	49	16%	
retired	60	17%	10	22%	50	16%	
other	19	5%	2	4%	17	6%	
SSDI	81	23%	6	13%	75	25%	
Total responses	350	100%	45	100%	305	100%	
YEARS SINCE TEST							ns
20+	63	19%	8	20%	55	19%	
10 - 19	174	52%	19	48%	155	53%	
5 - 9	53	16%	5	13%	48	16%	
< 5	45	13%	8	20%	37	13%	
Total responses	335	100%	40	100%	295	100%	
GENDER							**ns**
male	316	88%	39	85%	277	89%	
female	35	10%	6	13%	29	9%	
transgender	7	2%	1	2%	6	2%	
Total responses	358	100%	46	100%	312	100%	
ETHNICITY							**0.0123***
Caucasian	208	58%	17	38%	191	61%	0.0029*
Hawai'ian	59	17%	7	16%	52	17%	ns
Other API	47	13%	13	29%	34	11%	0.0008*
Mixed	17	5%	2	4%	15	5%	ns
African Amer	7	2%	2	4%	5	2%	ns
Native Amer	5	1%	1	2%	4	1%	ns
Total responses	343	100%	45	100%	312	100%	
Total Hispanic	42	12%					ns
HOUSING							**0.0001***
stable	296	83%	29	63%	267	86%	0.0002*
temporary	25	7%	6	13%	19	6%	ns
Transitl. / group	24	7%	2	4%	22	7%	ns
homeless	13	4%	9	20%	4	1%	0.0001*
Total responses	358	100%	46	100%	312	100%	
Homeless location given	20	100%	13	65%	7	35%	0.0001*
INCOME							**0.0030***
<12k	153	44%	31	69%	122	40%	0.0003*
12k - 25k	104	30%	9	20%	95	31%	**ns**
25k - 35k	30	9%	1	2%	29	10%	**ns**
35+	63	18%	4	9%	59	19%	**ns**
Total responses	350	100%	45	100%	305	100%	
HOUSEHOLD SIZE							**ns**
1	264	75%	33	72%	231	75%	
2	66	19%	12	26%	54	18%	
3	11	3%	-	-	11	4%	
4+	13	4%	1	2%	12	4%	
Total responses	354	100%	46	100%	308	100%	

	Whole sample		Care frequency < 6 months ☹		Care frequency ≥ 6 months ☺		Chi-Square
	n	Percent	n	Percent	n	Percent	
ECONOMIC STATUS							**0.0036***
< poverty	153	44%	31	69%	122	40%	0.0003*
RW eligible	134	38%	10	22%	124	41%	0.0176*
maybe RW elig.	38	11%	3	7%	35	11%	ns
not RW eligible	25	7%	1	2%	24	8%	ns
Total responses	350	100%	45	100%	305	100%	
INFECTION SOURCE							
MSM	252	71%	27	60%	225	73%	**ns**
heterosexual	39	11%	5	11%	34	11%	**ns**
don't know	34	10%	8	18%	26	8%	0.0455*
IDU	17	5%	3	7%	14	5%	**ns**
MSM / IDU	7	2%	2	4%	5	2%	**ns**
blood products	4	1%	-	-	4	1%	**ns**
other	2	1%	-	-	2	1%	**ns**
Total responses	355	100%	45	100%	310	100%	
CARE LAG							**ns**
never	2	1%	1	2%	1	0%	
< 6 months	179	52%	24	55%	155	51%	
when sick	102	29%	11	25%	91	30%	
other	63	18%	8	18%	55	18%	
Total responses	346	100%	44	100%	302	100%	
ACCESS TO CARE							**-**
Frequency ≥ 6 months	313	87%			313	100%	
Frequency < 6 months	46	13%	46	100%			
Total responses	359	100%	46	100%	313	100%	
CURRENT ARV USE							**0.0031***
currently on ARVs	298	85%	30	68%	268	87%	0.0012*
not on ARVs	39	11%	9	20%	30	10%	0.0342*
don't know	15	4%	5	11%	10	3%	0.0127*
Total responses	352	100%	44	100%	308	100%	
MD KNOWLEDGE							**0.0001***
adequate knowledge	330	95%	33	83%	297	97%	
inadequate	16	5%	7	18%	9	3%	
Total responses	346	100%	40	100%	306	100%	
REFERRALS							**ns**
referred as needed	268	84%	25	74%	243	85%	
didn't refer as needed	51	16%	9	26%	42	15%	
Total responses	319	100%	34	100%	285	100%	
SPECIALISTS							**0.0183***
referral available	265	89%	22	76%	243	90%	
not available	33	11%	7	24%	26	10%	
Total responses	298	100%	29	100%	269	100%	
ACCESS TO MD							**0.0001***
MD available	306	91%	26	72%	280	93%	
MD not available	31	9%	10	28%	21	7%	
Total responses	337	100%	36	100%	301	100%	
CONFIDENTIALITY							**0.0028***
maintained	323	96%	30	86%	293	97%	
not maintained	15	4%	5	14%	8	3%	
Total responses	338	100%	35	100%	302	100%	

	Whole sample		Care frequency < 6 months ☹		Care frequency ≥ 6 months ☺		Chi-Square
	n	Percent	n	Percent	n	Percent	
RESPECT SHOWN							**0.0001***
respected	324	96%	30	81%	294	97%	
not respected	15	4%	7	19%	8	3%	
Total responses	339	100%	37	100%	302	100%	
SKIPPED ARVs							**ns**
skipped	151	46%	20	50%	131	45%	
didn't skip	178	54%	20	50%	158	55%	
Total responses	329	100%	40	100%	289	100%	
REASON NO CARE LAST YR (can be >1 answer)							**0.0001* (any reason given)**
too sick	8	29%	5	38%	3	20%	
cost barriers	8	29%	5	38%	3	20%	
HIV status secret	7	25%	4	31%	3	20%	
no perceived need	6	21%	3	23%	3	20%	
no HIV MD available	5	18%	2	15%	3	20%	
transport barriers	4	14%	-	-	4	27%	
takes too long	3	11%	2	15%	1	7%	
Didn't know where to go	2	7%	1	8%	1	7%	
not eligible	1	4%	-	-	1	7%	
fear discrimination	1	4%	-	-	1	7%	
Total responses	28	100%	13	100%	15	100%	
WHY SKIPPED (can be >1 answer)							
forgot	70	46%	11	55%	59	49%	ns
side effects	49	32%	7	35%	42	35%	ns
needed a break	44	29%	5	25%	-	-	ns
Medications arrived late	22	15%	5	25%	17	14%	ns
substance use	9	6%	-	-	-	-	ns
Too expensive	6	4%	1	5%	-	-	ns
MD orders	1	1%	-	-	1	1%	ns
Total responses	151	100%	20	100%	120	100%	
ADHERENCE COUNSELING (can be >1 answer)							
from MD	261	89%	26	74%	235	91%	0.0083*
from nurse	97	33%	10	29%	88	34%	ns
from pharmacist	96	33%	9	26%	86	33%	ns
other (ex, written, ASO)	40	14%	6	17%	36	14%	ns
from nobody	7	2%	2	6%	5	2%	ns
Total responses	292	100%	35	100%	258	100%	
INSURANCE TYPE							
Through work	67	21%	5	13%	62	22%	ns
Private, not through work	23	7%	1	3%	22	8%	ns
Cobra	6	2%	-		9	3%	ns
Medicaid	50	16%	9	23%	40	14%	ns
Medicare	127	40%	17	43%	110	39%	ns
VA	15	5%	3	8%	12	4%	ns
H programs	23	7%	4	10%	19	7%	ns
none	8	3%	1	3%	7	2%	ns
Total responses	319	100%	40	100%	281	100%	
INSURANCE TYPE GROUPED							**ns**
Private	99	28%	6	13%	93	30%	0.0182*
Public assistance	252	70%	39	67%	213	55%	0.0117*
None	8	2%	1	2%	7	2%	ns
Total responses	359	100%	46	100%	313	100%	

	Whole sample		Care frequency < 6 months ☹		Care frequency ≥ 6 months ☺	
	n	Percent	n	Percent	n	Percent
WORK INSURANCE						
work	44	66%	4	80%	40	65%
Work/VA	3	4%	-	-	3	5%
Work/HSPAMM	4	6%	-	-	4	6%
Work/HSPAMM/HDAP	4	6%			4	6%
Work/medicare	7	10%	1	20%	6	10%
Work/other private	1	1%	-	-	1	2%
Work/state /federal	4	6%	-	-	4	6%
Total responses	67	100%	5	100%	62	100%
PRIVATE INSURANCE						
private not work	11	48%	-	-	11	50%
private not work/Medicare	10	43%	1	100%	9	41%
private not work/ HDAP/HSPAMM	2	9%	-	-	2	9%
Total responses	23	100%	1	100%	22	100%
VETERANS ASSISTANCE						
VA	8	53%	2	67%	6	50%
VA & Medicare	6	40%	1	33%	5	42%
VA & Quest	1	7%	-	-	1	8%
Total responses	15	100%	3	100%	12	100%
COBRA			-	-	3	33%
cobra	3	33%	-	-	2	22%
Cobra/HDAP/Medicare or HSPAMM	3	33%	-	-	1	11%
Total responses	9	100%	-	-	3	33%
MEDICAID						
Medicaid	38	36%	9	100%	29	32%
Medicaid/HSPAMM	6	6%	-	-	6	7%
Medicaid/HDAP/ (some) HSPAMM	3	3%	-	-	3	3%
Medicaid & VA	2	2%	-	-	2	2%
Total responses	57	100%	9	100%	91	100%
MEDICARE						
Medicare	44	35%	9	53%	35	32%
Medicare/HSPAMM	9	7%	-	-	9	8%
Medicare/HDAP/HSPAMM	17	13%	1	6%	16	15%
Medicare/Medicaid	44	35%	-	-	38	35%
Medicare/Medicaid/HSPAMM	8	6%	6	35%	7	6%
Medicare/Medicaid/HDAP/ (some) HSPAMM	5	4%	1	6%	5	5%
Total responses	127	100%	17	100%	110	100%
STATE PROGRAMS ONLY						
HCobra	2	8%	-	-	2	11%
HCobra/HSPAMM/HDAP	1	4%	-	-	1	5%
HSPAMM	7	27%	2	50%	5	26%
HDAP	7	27%	1	25%	6	32%
HSPAMM/HDAP	9	35%	1	25%	8	42%
Total responses	26	100%	4	100%	19	100%

*If provider is known to provide both specialty and primary care, it was assumed they provided both when one was left blank.

	Whole sample				Care frequency < 6 months ☹			
	SPECIALTY CARE*		PRIMARY CARE*		SPECIALTY CARE*		PRIMARY CARE*	
Waikiki Health Center	51	15%	49	15%	10	26%	9	26%
Clint Spencer Clinic	61	18%	24	7%	5	13%	1	3%
Goshima	55	17%	58	18%	5	13%	5	14%
Morrison	6	2%	5	2%	4	11%	3	9%
Kaiser	46	14%	43	13%	3	8%	3	8%
Community Clinic of Maui	22	7%	20	6%	2	5%	1	3%
Johnson / VA	10	3%	10	3%	2	5%	2	6%
Yoon	6	2%	6	2%	2	5%	1	3%
Frank	11	3%	10	3%	1	3%	1	3%
Tice	6	2%	4	1%	1	3%	1	3%
Palama	2	1%	1	<1%	1	3%		
Flora	1	<1%			1	3%		
Waianae Comp	1	<1%	2	1%	1	3%	1	3%
Kauai Comm Health Center	2	1%	3	1%			1	3%
Queen Emma Clinic			4	1%			2	6%
David Moore, DO			1	<1%			1	3%
Kalihi			1	<1%			1	3%
Till Hanses			1	<1%			1	3%
Total	331	100%	328	100%	38	100%	34	100%

Health Provider Survey –Thank you for your help!

Name (optional)_____

Please check the degrees and certifications below which you have obtained:

☐ DO
☐ Advanced Practice Nurse (NP)
☐ MD
☐ Board certified Family Medicine
☐ Board certified Internal Medicine
☐ Board certified Infectious Disease
☐ Board Certified in other specialty _____
☐ Other _____

Your principal employment setting is:

☐ Private practice
☐ Community clinic
☐ HMO facility
☐ Corrections
☐ Hospital-based clinic
☐ Hospital
☐ School/University

Geographic area of clinic. Zip code _____

Please check if you accept the following forms of insurance.

☐ QUEST
☐ Medicaid
☐ Medicare
☐ Uninsured

Approximately how many HIV-infected patients are currently under your care?

_____

Which of the following best describes your practices regarding treating people with HIV infection?

☐ Refer for all care.
☐ Provide general primary medical care for conditions not related to HIV.
☐ Refer HIV-infected patients when they need antiretroviral treatment.
☐ Refer HIV-infected patients when complications arise such as failing antiretroviral treatment, Hepatitis C co-infections, neurological, metabolic or obstetrical problems associated with their HIV.
☐ Provide all care throughout the course of the disease.

If you refer your patients for HIV care, to whom to you refer them?

Over

_____

What best describes the reason you provide HIV care to your patients rather than referring?

☐ I am comfortable providing their care.
☐ Locally available referral is inadequate.

Which of the following items would help you to provide medical services to HIV-infected people?

Access to further training. ☐ Yes ☐ No .
If yes, what is your preferred format?
☐ Clinical practicum on-site at a specialty clinic
☐ Intense training with comprehensive didactic lectures (one week)
☐ Incremental training with occasional didactic lectures on specific topics outside of office hours
☐ Distance learning (video, teleconference, internet, etc.)
☐ Telephone/fax/email education on topics as needs are identified
☐ Other_____
_____

Access to HIV specialty care support. ☐ Yes ☐ No
If yes, what is your preferred format?
☐ Visiting HIV specialist physicians holding periodic clinics in my area and providing care to my patients.
☐ Telemedicine with specialty care physicians to assist me in jointly providing HIV specialty care to my patients.
☐ Telemedicine with specialty care physicians to assist a local HIV specialty nurse practitioner in providing HIV-specialty care for patients I refer.
☐ Hotline for consultation with specialists on patient care on an as-needed basis.
☐ Other_____
_____

Support from other agencies that help people infected with HIV. ☐ Yes ☐ No
If yes, what type of support?
☐ Referring patients to me.
☐ Providing case management, counseling and other ancillary services to my patients.
☐ Other_____
_____

Do you provide care to patients with Hepatitis C who are NOT HIV-infected?
☐ Yes ☐ No

Would you be willing to do a phone interview to give us a more in-depth understanding of the constraints and possible solutions to providing HIV medical care in Hawai'i?
☐ Yes ☐ No

Phone # _____

Consumer Survey –Thank you for your help!

Age:

Gender: ☐ Male ☐ Female ☐ Transgender

Were you born in Hawai'i? ☐ Yes ☐ No

Origin Hispanic or Latino? ☐ Yes ☐ No

How many years have you lived in Hawai'i?

Zip code of residence _____

If homeless, neighborhood where most often stay
_____

Ethnic background: *Please check all that apply.*
☐ Native Hawai'ian / part Native Hawai'ian
☐ Other Asian or Pacific Islander
☐ Caucasian
☐ African American
☐ American Indian or Alaskan Native

What is the highest level of education you have completed?
☐ Elementary School or Junior High School
☐ High School
☐ College or University

What are your current living arrangements?
☐ Apartment or house – stable situation
☐ Apartment or house – temporary situation
☐ Group home / transitional housing
☐ Homeless
☐ Correctional facility

What is your current work status?
☐ Employed full-time for pay
☐ Employed part-time for pay
☐ Not working – looking for work
☐ Not working – homemaker / student / other
☐ Not working – not looking for work
☐ Retired
☐ Other _____

What is your household (people that combine income) YEARLY income from all sources pre-tax?
☐ Less than $12,000
☐ 12,000 – 25,000
☐ 25,000 – 35,000
☐ More than 35,000

What type of paid work have you done most recently?
_____

How many people are living on that income?
☐ Only me
☐ 2
☐ 3
☐ 4 or more

What kind of health insurance or benefits do you currently have?
Check more than one if they apply.
☐ Medicaid
☐ Medicare
☐ Quest
☐ VA -- Veterans benefits
☐ Insurance through work
☐ COBRA (insurance through my last employer)
☐ Private insurance, not through work
☐ HSPAMM
☐ HDAP
☐ HCobra
☐ None

What was the most likely way you were infected by HIV? *Please check all that apply.*
☐ Having sex with a man
☐ Having sex with a woman
☐ Sharing needles
☐ Blood products or transfusion
☐ Don't know
☐ Other _____

When did you first test positive for HIV?
Month _____ Year _____

How soon after testing positive for HIV did you receive HIV-related medical care?
☐ Never
☐ Within 6 months of being diagnosed
☐ When I got sick
☐ Other _____

Ove

In the last year, how often did you receive the following types of medical care?

	never	Less often than every 6 months	At least every 6 months
Visit a doctor / nurse for primary care *(vaccinations, colds, minor injuries)*			
Visit a doctor / nurse for HIV care *(T-cell and viral load monitoring, managing antiretroviral medications)*			
CD4 counts			
Viral load			

Are you on antiretroviral medication now?

 Yes No Don't know

If you visited a doctor for HIV care in the last year, how did you feel about the care you received?
Please circle yes or no for each statement.

Yes	No	I felt confident that my doctor / nurse practitioner knew enough about HIV care.
Yes	No	I received referrals to other specialists for care when I needed it.
Yes	No	The specialist to whom I was referred was able to see me.
Yes	No	I had access to my doctor / nurse practitioner when I needed it.
Yes	No	I felt my confidentiality was protected.
Yes	No	I was treated with respect.

Did you ever skip or stop taking your antiretroviral medications? Yes No

If so, why? *Please check all that apply.*
- Needed a break.
- Side effects.
- Forgot.
- Received the medication late.
- Couldn't afford them.
- Was drunk or high.

If you did not visit a doctor for HIV care in the last year, what are the reasons?
Please check all that apply.
- I did not know where to get care.
- I was too sick.
- There was no HIV specialist who could provide the care I needed.
- Too expensive.
- I am not eligible for services.
- It took too long to get an appointment.
- I did not have transportation.
- I did not have child care.
- I did not need medical care for my HIV.
- I worried about discrimination from the doctor or staff.
- I didn't want people to know about my HIV status.
- They did not speak my language.
- Other _____

If you have taken antiretroviral medications, who explained how to take your medication, what side effects you might get and why it is important to take them on time? *Please check all that apply.*

 doctor pharmacist
 nurse nobody
 other _____

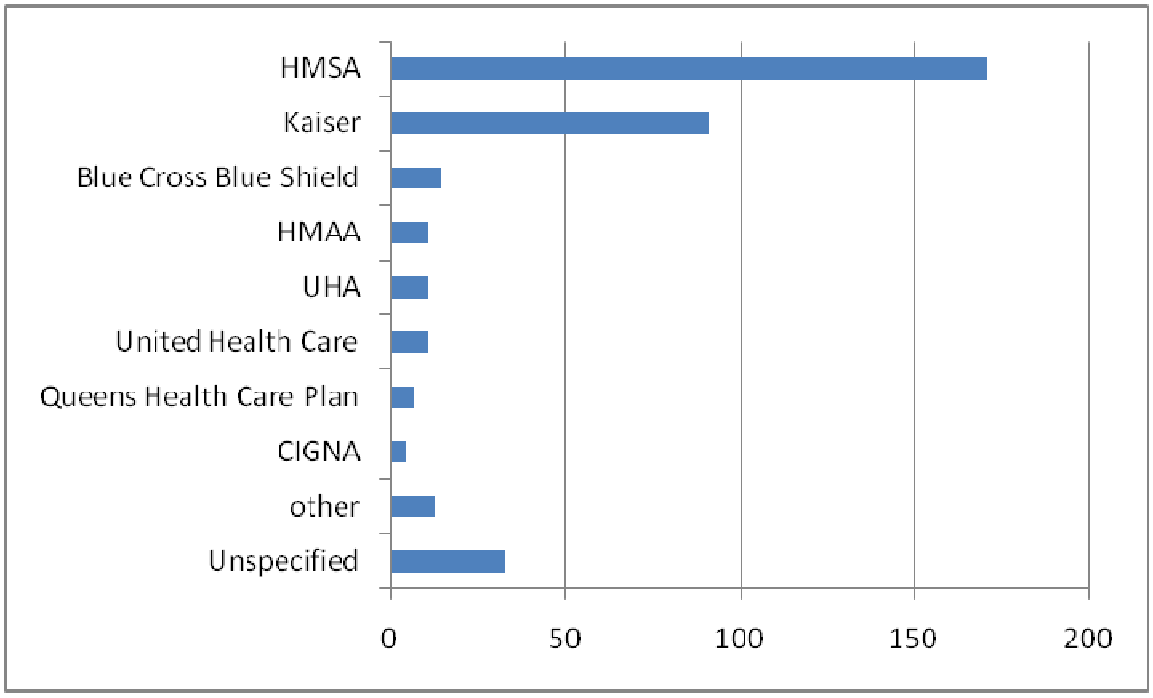
What is the name of the doctor or clinic that you went to most recently for primary care (vaccinations, colds, minor injuries)?

What is the name of the doctor or clinic that you went to most recently for additional HIV specialty care (such as CD4 and viral load monitoring, managing antiretroviral medications)?

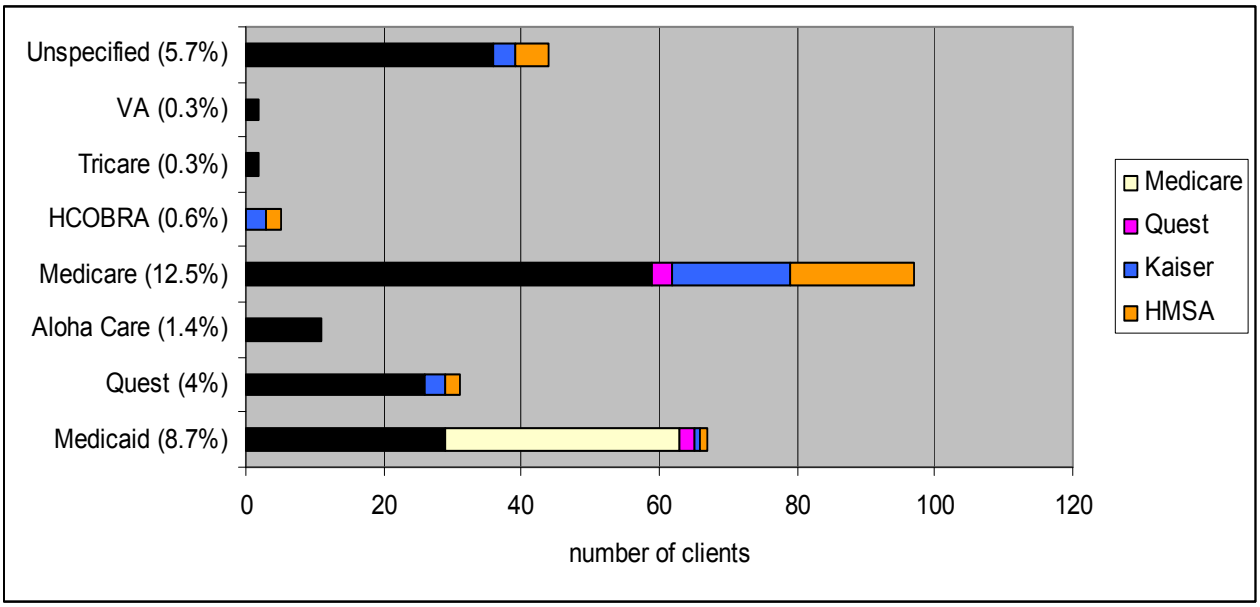
Do you have a suggestion for improving medical services for people living with HIV in your community or any additional comments?

7.5 HSPAMM CLIENTS BY TYPE OF INSURANCE

HSPAMM clients who reported having insurance through work, self-purchase or "other" (spouse, student, cobra) by type of insurance specified, n= 360.



HSPAMM clients who reported having insurance through government assistance by type of insurance specified, n=259



[1] Department of Health data based on AIDS surveillance system, laboratory CD4 reports and government-funded programs.
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