

VOICES OF EXPERIENCE 2003

Findings

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FEBRUARY 2004

FINAL



SUFFOLK UNIVERSITY

CENTER FOR PUBLIC MANAGEMENT

This project is supported by funding from the Boston Public Health Commission and the Massachusetts Department of Public Health through the Ryan White C.A.R.E. Act Titles I and II.

**VOICES OF EXPERIENCE 2003:
HIV/AIDS Consumer Views on Their Needs for Services
in Massachusetts and the Boston Eligible Metropolitan
Area (EMA)**

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February 2004

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Supplemental publications to be developed include:

- The "Voices 2003 Data Book"
- "Voices 2003: Summary of Open Ended Responses"

Voices of Experience 2003 Highlights

**

These findings are based on self-reported data collected between April and June 2003 from 466 people living with HIV/AIDS who receive services for their HIV disease in Massachusetts and Southern New Hampshire.

- 41% of respondents were residents of the Boston Health Services region and 84% were members of the Boston EMA (Eligible Metropolitan Area).
- 63% were male and 36% female.
- Respondents' average age was 44, with 56% under age 45 and 44% ages 45 and older.
- These HIV/AIDS consumers:
 - have **very low incomes** (ninety percent have \$27,000 or less annual income),
 - **live alone** (47%) and **in subsidized housing** (58%), and
 - have their **healthcare paid for by Medicaid**.

NOTE: There were no significant differences between the Massachusetts sample and the EMA. The major differences appear to be between Central, Southeast and the Western regions as compared to other regions both in Massachusetts and New Hampshire.

- ✓ **Among HIV/AIDS consumers that we surveyed who receive services in Massachusetts and the Boston EMA, most accessed primary care in the past year and therefore are not considered to have “unmet need” according to the Federal definition.**¹
 - Ninety-eight percent of the respondents have a primary care doctor or nurse/physician assistant and 99% have seen their PMC provider within the last year. The median number of visits in the last year was six.
 - Ninety-seven percent of the respondents have had their viral loads measured and 98% have had their CD-4 counts tested within the last year.
 - Seventy-nine percent of the respondents are currently using anti-retroviral therapy (ART).

¹ As described in the “Methodology” section, consumers were recruited for this study through letters sent to clients of HIV/AIDS service provider agencies and thus by design have had at least some contact with a care giver. The Health Resources Services Administration (HRSA) defines “unmet need” as having a primary HIV-care visit in a 12-month time period.

- ✓ While their health needs including accessing primary care, limiting emergency room use, and taking/adhering to medication plans were largely met, most consumers had many **complicated health problems**.

- Forty-six percent have hepatitis C, 18% have Hepatitis B, 37% report mental illness and 30% report a physical disability.

- ✓ **Most (84%) HIV/AIDS consumers have case managers.**² Approximately, one third have two or more case managers. Respondents are evenly divided as to whether they would like to be working with “one” or “more than one” case manager.

- ✓ **More than half of the respondents tested positive 10 or more years ago.**

The majority of respondents (53%) reported that they accessed medical services within the first three months of their diagnosis; 14% accessed medical services within 4-12 months of their diagnosis and 30% waited more than a year after their diagnosis. The length of time that respondents waited to seek medical services was similar regardless of whether they were diagnosed a long time ago or more recently.

- ✓ **Consumers receive their services from a limited (mean = 2.33) number of agencies.** Five percent of the respondents are receiving services from five or more agencies.

- ✓ Consumers reported the **highest need** for:

- dental care (63% of respondents)
- access to benefits and entitlements such as SSI and welfare (49% of respondents)
- help with emotional or mental health issues (46% of respondents).³

With respect to previous VOE studies, employment assistance, pain management, and legal services were new areas of need noted.

² Inconsistencies were found in the responses to the “case manager” questions. Several respondents reported not having a case manager but in follow-up questions reported having one or more case managers.

³ “Highest need” is defined as respondents selecting their top five needs from a provided list.

- ✓ In general, most service needs were being met, but consumers said they **needed but could not get** the following services:

- dental care (25% of respondents)
- complementary therapies (20% of respondents)
- emergency rental/utility housing assistance (14% of respondents)
- legal and financial advocacy services (11% of respondents)
- food vouchers/food bank (11% of respondents).

The main reason that people were not getting dental services was **financial**, and for the other services the main reason was they **did not know where to go for services**.

NOTE: A higher percentage of consumers from the Non EMA (Western Massachusetts and the Cape) reported a need for services that they could not get. These services include drug reimbursement/ADAP HDAP (EMA-5%, Non EMA-12%), legal and financial advocacy (EMA-9%, Non EMA-20%), and complementary therapies (EMA-18%, Non EMA-29%).*

- ✓ Over two-thirds of consumers thought that their service **needs would change in the future**. They were worried about what these changes would be and how they would affect them.⁴
- ✓ **Very few providers of any type (Doctor, Case Manager, Peer Support) are talking to consumers about non-medical issues** -- domestic violence, counseling at-risk partners, safer drug use, or substance abuse treatment.
- Doctors are most likely to talk about adherence to medications, mental health issues, and keeping doctor appointments, but much less so about sexual behavior and HIV transmission or disclosure of HIV status.
 - About a quarter of case managers talk with consumers about any of these issues.
 - These issues were discussed at most in 25% of peer support groups.

* Statistically significant difference, $p < .05$.

⁴ See supplemental report, "Voices 2003: Summary of Open Ended Questions" for more detailed responses to these questions.

BACKGROUND AND METHODOLOGY

BACKGROUND

Voices of Experience 2003 (VOE 2003) is a follow-up to Voices of Experience (VOE '96) and Voices of Experience 2000 (VOE 2000) which were also peer surveys of persons living with HIV/AIDS, but limited geographically to the Ryan White Title I Boston Eligible Metropolitan Area (EMA). These previous studies were conducted in 1996-1997 and 1999-2000. Like VOE 2003, they were studies of consumer experiences in accessing and using Ryan White and other HIV/AIDS services.

In Fall 2002, the Boston Public Health Commission (BPHC), which administers the Ryan White Title I program for the Boston EMA, and the Massachusetts Department of Public Health (DPH), which administers Title II HIV/AIDS services for Massachusetts agreed to collaborate on a new peer survey encompassing their respective areas. The study was to be conducted by Suffolk University.

Senior staff from the partner organizations (including John Snow Inc. who administers certain HIV/AIDS research contracts for the Department of Public Health) formed a Work Group and met to define parameters of the study and to develop a work plan and a timetable. Members of the Work Group were:

Richard H. Beinecke	Suffolk University Co-Principal Investigator
Nanjui Awunti	Suffolk University Project Coordinator
Michael Goldrosen	BPHC, Client Services Manager, AIDS Program
Sarah Kanner	BPHC, Senior Program Coordinator, AIDS Program
Alicia Turoff	BPHC, Program Coordinator, Quality Management, AIDS Program
Victoria M. Johnson	DPH, Director of Client Services, HIV/AIDS Bureau
Abigail R. Averbach	DPH, Director, Office of Research and Evaluation, HIV/AIDS Bureau
Renee Woliver	DPH, Research Analyst, HIV/AIDS Bureau
Sophie Lewis	DPH, Director of Consumer and Policy Initiatives, HIV/AIDS Bureau
Stewart Landers	John Snow Inc., Senior Consultant

Jorge Sanchez, Director of Health Communications, DPH, Jeremy Holman, Executive Director, Boston AIDS Consortium, and Sandy Matava from Suffolk University also provided support to the project.

METHODOLOGY

Survey Development

The Work Group reviewed previous Suffolk and DPH HIV/AIDS surveys and surveys by other researchers, in particular a survey conducted by the San Diego Eligible Metropolitan Area. Two questionnaires were developed: the base questionnaire which was designed for face-to-face interviews on a broad cross section of needs for the statewide assessment, and a second tool that was a brief version of the base questionnaire designed for local needs assessments and possible follow-up focus groups. DPH and Suffolk also modified the long survey so that it could be used as a mail survey in three Western Massachusetts consortia. The long survey was translated into Spanish and Portuguese, and the Western Massachusetts' mail survey was translated into Spanish.

Consumer Research Associate Team

With the assistance of the Work Group, Suffolk University recruited 46 applicants for 27 Consumer Research Associate (CRAs) positions. CRAs are people living with HIV who were paid to conduct face to face and telephone interviews.

The CRAs formed a diverse team. They were from all regions of the EMA and Massachusetts; included 11 males and 16 females; and were culturally diverse and multi-lingual, with eight who spoke Spanish, two who spoke Portuguese, and two who spoke Haitian-Creole. Six Suffolk University Graduate Research Fellows (GRFs) supported the CRA Team.

Suffolk University and DPH staff developed and conducted intensive training sessions for CRAs in Boston and in Worcester. During the interviewing process, CRAs were in close, weekly contact with Suffolk University Graduate Research Fellows. At the end of the interviewing phase, two focus groups were held with CRAs and GRFs in Boston and in Worcester to review the project process and impressions.

Recruitment Of Participants

The sample goal was 450 consumer interviews. In order to obtain the correct sample distribution, DPH and BPHC clients in the service delivery system were sorted by residence. There are 8,834 BPHC and 8,114 DPH unduplicated clients at 91 provider agencies. There are 4,417 clients in common.

By comparison, VOE '96 and VOE 2000 utilized only the BPHC database of 11,760 clients in 2000 and 9,030 in 1996 from which to sample consumer respondents.

The target was to recruit a pool of at least 600 consumers who were interested in being interviewed from which the sample would be drawn. Suffolk University sent 6,000 letters to providers, and asked them to address and send the letters to a specified sampling of their clients. This consumer mailing represented an increase of 1,000 letters from the original plan and 2,000 more than had been sent for VOE 2000.

Depending on their client count, providers were asked to send letters to every client, every other client, or every second, third, or fourth client to achieve the desired sampling results. Providers were reimbursed \$25-\$200 for their assistance, depending upon the numbers of letters they sent. Eighty-nine out of ninety-one providers sent out the letters, a 97% participation rate.

The letters contained a description of the VOE project in English, Spanish, Haitian Creole, and Portuguese; a postage paid postcard with contact and limited demographic information to be returned if the consumer wanted to be interviewed; and a phone number to call with questions. Phone calls were received from 129 consumers; 102 of them asked for more information on how they or their friends could be surveyed, 11 with questions about how confidentiality was assured, and 12 with confusion over a parallel DPH consortia survey. We received 15 calls from providers. Three providers were concerned about the confidentiality of the post cards. In response to that concern, Suffolk University repackaged the letters with postage paid return envelopes for the cards for these three providers. The other calls were asking for more details on the survey process.

Consumers were offered the choice of phone or face to face interviews and preferred language. Clients who were interviewed were paid \$30 for a face to face and \$20 for a phone interview.

Confidentiality was ensured because only provider staff knew to whom the letters were sent and only consumers who wanted to participate in the survey identified themselves to Suffolk University. When this report is completed, all cards and surveys will be shredded so that no identifying information could be released. To Suffolk University's knowledge, there were no violations of confidentiality during the project.

Response: Suffolk University received 985 return postcards (16.5% of the 6000) with representation from all geographic regions. This compares with response rates of 16% in 1997 and 15% in 2000. 158 wrong address letters were returned (2.6%) and 37 blank (unaddressed) envelopes were returned (0.5%).

Western Massachusetts Consortia (Berkshire, Franklin, Hampshire)

In order to gather a sufficient sample in three Western Massachusetts counties where the number of people living with HIV/AIDS is small relative to other areas of the state, a modified sampling methodology was employed. In late May, Suffolk University sent consortia coordinators in each of these regions enough *mail surveys* with postage paid envelopes (to be returned to Suffolk University) to send to all consumers in the consortia (41 Berkshire, 48 Franklin, 62 Hampshire) yielding a total of 151 outbound surveys.

Each survey had an identifying number on it that the consortia coordinators matched to a name. Three weeks later, Suffolk notified the coordinators which surveys had been returned so they could, if they wanted to, encourage non-respondents to complete the surveys. Once surveys were returned to Suffolk, Suffolk notified the coordinators which survey numbers had been returned and sent them a check so that coordinators could mail \$20 to each respondent. This ensured that Suffolk did not know the names of any respondents and preserved client confidentiality.

Responses: At the time of the data analysis, 19 surveys had been received from the Berkshire consortia (46% response rate), 30 from Franklin (63%), and 45 from Hampshire (73%), for a total of 94 (62%). These came from 30 unique zip codes. The surveys were inputted and analyzed separately from the other 454 surveys. These data were merged with the core data in the same proportions as the percent they represented of HIV/AIDS services clients in Massachusetts (1% each, 3% of the total). The surveys were also used by DPH as part of their statewide consortia survey.

SURVEY SAMPLE

The CRA Team completed 454 interviews – 359 face to face (79%) and 95 by phone (21%) during April – June 2003. In addition, twelve surveys were randomly selected from those completed by mail in Berkshire, Franklin, and Hampshire counties yielding a total of ***466 completed surveys in the database***. Of the 454 surveys, responses came from 145 zip codes, compared to 139 zip codes in 2000 and 95 in 1996. In addition, there were 8 unique zip codes from the Western Massachusetts Consortia group represented in the main database of 466 surveys.

The goal of a sample that was geographically similar to that of the population of people receiving services was achieved. In addition to the goal of regional distribution (Figure 1), it was also important to have a representative number of consumers for each of the key cities. The sample that was achieved was on target in terms of representation by region, but the cities of Brockton, Cambridge, Somerville, Springfield, and Lawrence were under-represented to varying degrees (Figure 2).

Geographical Distribution By Region

The table below details the sample goal and frequency of response for each region.

FIGURE 1. SAMPLE RESPONSE BY REGION (GOAL VS. ACTUAL)

Health Service Region	Goal	Actual
Boston	192 (43%)	193 (41%)
Central	25 (6%)	27 (6%)
Metrowest	39 (9%)	36 (8%)
Southeast	40 (9%)	43 (9%)
Southeast-Cape ⁵	22 (5%)	22 (5%)
Northeast	78 (17%)	79 (17%)
Western	38 (8%)	39 (8%)
New Hampshire	16 (3%)	15 (3%)
Sub Total	450 (100%)	454 (97%)
Berkshire	(1% of sample)	4 (1%)
Franklin	(1% of sample)	4 (1%)
Hampshire	(1% of sample)	4 (1%)
Total Sample		466 (100%)

Geographical Distribution *Within* Regions

Within each region, some areas did not reach goal proportion. Of note are non-Boston (within the Boston region), Somerville, Cambridge, Brockton, and Lawrence. Figure 2 (below) shows the goal and percentage of response for target distribution within each region. (Note: Because the actual number of respondents targeted is small within these cities, the percentages are highly variable and should not be over-interpreted. For example, the “actual” number of respondents may be only 1 or 2 fewer than the “goal” but the percentage under-sampled appears large).

⁵ Because the Southeast region has two distinct geographic areas, and part is in the Boston EMA and part is not, the region has been subdivided for purposes of this presentation.

FIGURE 2. REGIONAL SAMPLE RESPONSE BY CITY/TOWN (GOAL VS. ACTUAL)

Health Service Region	Goal	Actual
Boston	80% Boston, 20% non Boston	94% Boston, 6% non Boston
Central	80% Worcester, 20% non Worcester	78% Worcester, 22% non Worcester
Metrowest	30% Somerville, 40% Cambridge, 30% Other	11% Somerville, 19% Cambridge, 76% Other
Northeast	20% Lawrence, 20% Lynn, 20% Lowell, 40% Other	8% Lawrence, 27% Lynn, 23% Lowell, 42% Other
Southeast	30% New Bedford, 20% Brockton, 50% Other	54% New Bedford, 5% Brockton, 41% Other
Southeast (Cape)	30% Provincetown, 70% Other	45% Provincetown, 55% Other
Western	80% Springfield, 20% Other	54% Springfield, 46% Other

FIGURE 3. COMPARISON OF THE GEOGRAPHIC DISTRIBUTION OF VOE 2003 SAMPLE TO DPH/BPHC CLIENTS AND PEOPLE LIVING WITH HIV/AIDS IN MA

Health Service Region	VOE 2003 Sample*	DPH and BPHC Unduplicated Count of Clients in Service Delivery System**	PLWHA in Massachusetts***
Boston	193 (41%)	3,905 (40%)	4,547 (35%)
Northeast	79 (17%)	1,686 (17%)	1,958 (15%)
Southeast	65 (14%)	1,250 (13%)	1,961 (15%)
Central	27 (6%)	659 (7%)	1,204 (9%)
Metrowest	36 (8%)	1,123 (11%)	1,692 (13%)
Western	39 (11%)	1,239 (13%)	1,613 (12%)
New Hampshire	15 (3%)	N/A	N/A
TOTAL	466	9,862	12,975

*Sample was based on consumers in the DPH and BPHC service delivery system, based on zip code of residence.

**There were 2,917 clients whose zip code did not match a health service region.

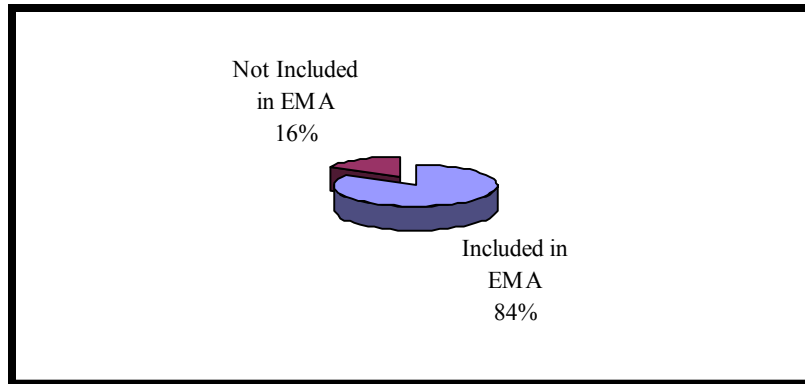
***Persons Living with HIV/AIDS in MA as of 12/31/02, prisoners excluded. Data Source: HIV/AIDS Surveillance Program, MDPH. Residence is at time of diagnosis and may no longer be current.

The sample closely matched the geographic distribution of clients in the service delivery system and the distribution of people living with HIV/AIDS (PLWHA) in Massachusetts.

Eligible Metropolitan Area Vs. Whole Sample Comparison

Ninety-seven (97%) percent of respondents live in Massachusetts. Eighty-four percent (84%) of respondents are included in the Boston Title I Eligible Metropolitan Area (EMA).

FIGURE 4. PERCENTAGE OF RESPONDENTS IN THE ELIGIBLE METROPOLITAN AREA



Geographic Distribution Of Respondents

FIGURE 5. GEOGRAPHIC DISTRIBUTION OF RESPONDENTS



Pushpins Zip code surveyed/Not an indicator of the number of respondents within the zip code
\$

Statistical Analysis

Numerical data was entered into SPSS (a statistical software program) while the open-ended responses were entered as text into MSWord. Descriptive statistics (frequency of response and means) were generated, as appropriate, for all of the variables (survey questions).

Relationships between variables were examined using several methods including *Contingency Tables*, *Correlations* and a *One-Way ANOVA*.

Contingency tables were used to compare categorical data (nominal or ordinal). Statistically significant relationships between variables were measured using the column proportions test (z-test).

The One-Way ANOVA procedure, which produces a one-way analysis of variance for a quantitative dependent variable (interval or ratio) by a single factor (nominal or ordinal), was used to test mean differences between groups. Bonferroni's adjustment, (post hoc analysis test) was used to adjust for differences in the number of respondents within a given group.

For comparisons between quantitative variables (means), correlations yielding the Pearson correlation coefficient, r , a measure of linear association between the variables was used.

Statistically significant relationships with a $p < .05$ are marked with an "*" within the report.

Study Limitations

There are limitations to this study which should be considered when interpreting the results and which have implications for how the findings are used for planning and policy decisions.

Of primary importance is that the sample was not drawn from the entire population of people living with HIV/AIDS in Massachusetts and Southern New Hampshire. The study focused on a stratified sample which included only those individuals enrolled in Title I, Title II, or state funded health and health related support services at the time of recruitment and, to ensure confidentiality, only those who responded to an invitation to participate in the survey. There are many people living with HIV/AIDS in Massachusetts and Southern New Hampshire who either are unaware of their HIV status or are aware of their status but are not enrolled in these services. Therefore, these findings are not generalizable to all people living with HIV/AIDS in Massachusetts and Southern New Hampshire. Furthermore, it is likely that people who are “out of care” may have much greater need for both clinical and non-clinical services and much greater morbidity than those represented in this study.

The interviewers in this study were HIV positive consumers. The “peer-based” research approach has many advantages, and an extensive training was implemented to standardize survey administration techniques. It is possible, however, that standard approaches were not used across all interviewers in all settings making it plausible that some variation in the findings is due to inconsistencies in the interview process. Given the nature of the interview tool and the training of interviewers, it is unlikely that these inconsistencies would introduce any significant bias.

The data collected for this study were based on self-report. The information was not verified with any other source and there is a possibility that the recall of some information was incomplete or incorrect, or questions were misunderstood, or concerns about comfort or confidentiality inhibited full disclosure.

Finally, while substantial effort was made to select a sample of consumers who were demographically (geography, gender, race/ethnicity) representative of the entire pool of clients receiving services, some sub-population groups are under-represented or represented in numbers that are too small to perform detailed sub-population analyses. For example, there were no responses from people of Asian race. A study that targets specific racial, ethnic or linguistic minorities would be required to better describe the service needs of these populations.

RESPONDENT DEMOGRAPHICS

“Who We Are”

Gender: Sixty-three percent of respondents were male, 36% were female, and 1% were transgender.

Age: The average age was 44. Fifty-six percent of respondents were 20-44 and 44% were 45 and older.

Age at Diagnosis: The average age at diagnosis was 33. The incidence data collected is compared to the Boston Eligible Metropolitan Area and Massachusetts HIV/AIDS data in the tables below.

**FIGURE 6. AGE AT TIME OF DIAGNOSIS
 (VOE 2003 VS. BOSTON ELIGIBLE METROPOLITAN AREA)**

Age at time of Diagnosis	Voices 2003 EMA Sample	Boston EMA (alive cases)
		HIV/AIDS Prevalence as of 12/31/02
≤19	1.5%	2.47%
20-44	89.7%	83.72%
45+	8.8%	13.81%

**FIGURE 7. AGE AT TIME OF DIAGNOSIS
 (VOE 2003 VS. MASSACHUSETTS)**

Age at time of Diagnosis	Voices 2003 Massachusetts Sample	Massachusetts (alive cases)
		HIV/AIDS Prevalence as of 12/31/02
≤19	1.5%	2.5%
20-44	89.7%	84.13%
45+	8.8%	13.81%

Race and Ethnicity: Fifty-two percent of respondents identified themselves as White, 26 % Hispanic, and 23% Black. Four percent had moved from another nation within the last three years.

FIGURE 8. RACE/ETHNICITY

Race/Ethnicity ⁶	n	Percentage of Response
Not Reported ⁷	18	3.9%
Hispanic	120	25.8%
Non-Hispanic		
• White	214	45.9%
• Black or African American	95	20.4%
• Native Hawaiian/Pacific Islander	0	0%
• American Indian or Alaska Native	2	.5%
• Asian	0	0%
• Not Reported ⁸	17	3.6%
Total Non-Hispanic	328	70.4%
Total Sample	466	100%

Preferred Language: Eighty-six percent of respondents indicated on the cards they returned that their preferred language was English, 12% Spanish, and 1% or less Haitian Creole and other languages. However, nearly all when contacted spoke English. We conducted 34 interviews in Spanish and 5 in Portuguese.

Sexual Orientation: Thirty-two percent said they were gay/lesbian, 60% straight/heterosexual, and 5% bisexual.

FIGURE 9. SEXUAL ORIENTATION (AND GENDER)

Gender and Sexual Orientation	n	Percentage of Response
Gay Men	140	30.0%
Gay/Lesbian Women	7	1.5%
Straight/Heterosexual Men	129	27.6%
Straight/Heterosexual Women	150	32.2%
Transgender	2	.5%
Bi-Sexual Men	18	3.9%
Bi-Sexual Women	5	1.1%
Missing Information on Sexual Orientation and Gender	15	3.2%
Total Sample	466	100%

⁶ Racial categories based on new Federal Standards effective, Jan 1, 2003.

⁷ Eighteen people did not identify themselves as being Hispanic or Non-Hispanic.

⁸ Seventeen Non-Hispanic respondents did not identify their race.

Paying for Healthcare: Eighty-two percent of the respondents had their healthcare paid for by Medicaid, 16% with Medicare, 10% with private insurance and 7% from another source.⁹

Housing: Forty-seven percent of respondents lived alone, 29% with one other person, and 12% with two, an average of two people per household. Fifty-eight percent lived in subsidized housing, 21% in market rate housing, and 8% with friends and relatives.

Income: Fifty-one percent had incomes under \$9,000, 79% under \$18,000, and 90% under \$27,000.

Poverty Status: Sixty-three percent are considered to be living below poverty level (based on the HHS Poverty Guidelines).

Incarceration: Sixteen percent had been in jail or prison in the last two years.

⁹ Since several respondents chose more than one source of payment the total percent of respondents exceeds 100%. Note: Forty-three respondents (9%) reported that both Medicare and Medicaid paid for their healthcare.

FINDINGS

Testing Positive and Initially Receiving Services

Three percent of respondents tested positive prior to 1985, with a respondent average of 10 years ago. Nineteen percent had tested positive in the last five years, 27% in the last 6-10 years, and 54% over 10 years ago.

No significant differences were present in responses, based on *length of time since testing positive*, except that people who had tested positive over ten years ago were more likely to feel that their needs had changed since they first entered care.

Fifty three percent of the respondents began using *medical services* within three months of being tested, while 30% did not use medical services until at least a year after being tested. With regard to *support services*, 31% used services within three months, while 44% waited over a year to use services.

Twenty-eight percent of the respondents were self-referred to their doctor, 15% by a health center, 11% by a case manager, and 9% by family/friends.

Health Status and Problems

Ninety-eight percent of respondents had a T-cell or CD-4 test in the past year and 97% had a viral load test. Ten percent did not know what their T-cell/CD-4 count was and 13% did not know their viral load count.

Fifty percent of respondents had T-cell/CD-4 counts over 351. Fifty-one percent of respondents had viral load counts that were below 50 or undetectable.

The consumers had many other health problems.

- Sixteen percent said that they had injected drugs in the past year and 29% said that they had other substance abuse problems in that year.
- Forty-six percent had Hepatitis C, 18% Hepatitis B, and 3% tuberculosis.
- Nine percent of respondents reported that they had been diagnosed with syphilis, gonorrhea, chlamydia, HPV or any other sexually transmitted disease in the past year.
- Other important health issues included a diagnosed mental illness (37%), being physically disabled (30%), having another chronic disease or impairment (27%), being blind or visually impaired (16%), having a learning disability (16%), being deaf or hard of hearing (9%), and being developmentally disabled or mentally retarded (4%).

Needs

The top needs identified by consumers were getting dental care (63% of cases), access to benefits and entitlements (49%), help with emotional or mental health issues (46%), getting stable and affordable housing (41%), getting a peer support group (35%), getting enough appropriate food (33%), getting transportation assistance (25%), getting employment assistance (23%), help with pain management (20%), and access to legal services (19%).

Differences by Region

Getting dental care, access to benefits (with the exception of the Southeast), and help with emotional needs were the top three needs in every region.

FIGURE 10. TOP 5 NEEDS BY REGION

Need	Boston	Central	Metrowest	Southeast	Southeast-Cape	Northeast	Western ¹⁰	NH
Access to benefits and entitlements such as SSI and welfare	X	X	X		X	X	X	X
Getting dental care	X	X	X	X	X	X	X	X
Help with drug or alcohol problems		X		X				
Help with emotional or mental health issues	X	X	X	X	X	X		X
Getting enough appropriate food				X		X	X	
Finding a support group with other HIV Positive people	X	X	X			X	X	
Getting stable and affordable housing	X		X	X	X		X	X
Getting transportation assistance					X			X

X=Most frequently reported needs (top 5).

¹⁰ Includes the Berkshire, Hampshire and Franklin sample.

Differences by Gender

The only difference in needs by gender were:

- Finding a support group with other HIV positive people was included in the top 5 needs for women and not men.¹¹

***Differences by Race/Ethnicity*¹²:**

- There were no differences in the top 5 needs between Hispanic and Non-Hispanic respondents.
- Black respondents included getting employment assistance in their top 5 needs while other respondents did not.

There were no differences in the top 5 needs based on sexual orientation.

Services

The main services that consumers said they needed were case management, dental, food vouchers, peer support, complementary therapies, mental health treatment, transportation, emergency rental/utility housing assistance, primary care, and housing search and placement. Moderate numbers needed drug reimbursement, substance abuse treatment, substance abuse detoxification, and home health.

They had especially low needs for adoption, day care, hospice, and respite care.

The major services that they said they had used were case management, food vouchers, peer support, mental health services, dental, primary care (the relatively low percent for primary care may not be accurate due to the wording of the question), transportation, housing search and placement, group meals, and complementary therapies.

¹¹ Getting enough appropriate food and finding a support group with other HIV positive people both ranked fifth in frequency of response for female respondents.

¹² Twenty-three percent of respondents did not identify their race.

FIGURE 11. NEEDED AND USED SERVICES

Service	Needed Service ¹³	Used Service
Case Management	86%	83%
Dental Care	81%	57%
Food Vouchers/Food Bank	72%	61%
Group or Individual Peer Support	64%	58%
Complementary Therapies (massage, acupuncture)	64%	44%
Mental Health: Individual and Group Counseling	62%	58%
Transportation	60%	52%
Housing: Emergency Rental/Utility Assistance	55%	42%
Primary Care/OB-GYN	55%	53%
Housing Search and Placement	54%	44%
Group Meals	47%	44%
Drug Reimbursement/ ADAP HDAP	44%	37%
Legal and Financial Advocacy	42%	31%
Substance Abuse Treatment	30%	29%
Home Delivered Meals	37%	32%
Home Health	20%	16%
Substance Abuse Detoxification	21%	20%
Respite Care	14%	12%
Hospice	10%	8%
Day Care/Child Care	9%	5%
Adoption/Foster Care	3%	2%

The main services that they needed but did not get were dental services, complementary therapies, housing emergency rental/utility assistance, legal services and food vouchers.

The main reasons that people did not get these services were that they did not know where to go for services, lack of services in their area, difficulty accessing service providers/providers were not helpful, lack of money/insurance to pay for services/medications, told they were not eligible (housing), and difficulty following up with referral (transportation).

¹³ Needed service=the number of respondents who indicated that they used the service plus the number of respondents who reported that they needed but couldn't get the service.

FIGURE 12. SERVICES NEEDED BUT COULDN'T GET AND PRIMARY REASON WHY

Service	Needed Service But Couldn't Get	Primary Reason(s) Why
Dental Care	25%	Lack of money or insurance to pay for services/medications/ Do not know where to go for services
Complementary Therapies (massage, acupuncture)	20%	Lack of services in my area/ Do not know where to go for services
Housing: Emergency Rental/Utility Assistance	14%	Do not know where to go for services/ Difficulty accessing service providers, providers were not helpful/ Lack of services in my area
Legal and Financial Advocacy	11%	Do not know where to go for services/ Lack of services in my area
Food Vouchers/Food Bank	11%	Do not know where to go for services/ Lack of services in my area
Housing Search and Placement	10%	Lack of services in my area/ Do not know where to go for services
Transportation	9%	Do not know where to go for services/ Difficulty accessing service providers, providers were not helpful
Drug Reimbursement/ ADAP HDAP	6%	Do not know where to go for services
Group or Individual Peer Support	6%	Do not know where to go for services/ Lack of services in my area
Home Delivered Meals	5%	Do not know where to go for services
Mental Health: Individual and Group Counseling	4%	Lack of services in my area
Home Health	4%	Do not know where to go for services
Case Management	3%	Difficulty accessing service providers, providers were not helpful
Respite Care	3%	Do not know where to go for services
Group Meals	3%	Lack of services in my area
Day Care/Child Care	3%	Do not know where to go for services
Primary Care/OB-GYN	2%	Difficulty accessing service providers, providers were not helpful/ Do not know where to go for services
Substance Abuse Treatment	1%	Complicated voice mail and delays/ Told I wasn't eligible for services
Hospice	1%	Do not know where to go for services
Substance Abuse Detoxification	1%	Complicated voice mail and delays/ Told I wasn't eligible for services
Adoption/Foster Care	1%	I have other more important priorities

Unmet Need

Although 51% of respondents said they used primary care services, 98% percent said they have a primary care doctor, 97% reported that they had a viral load test and 98% reported that they had a t-cell/CD-4 count done in the past year. Based on the HRSA/HAB definition of unmet need, 3 of the respondents would be considered out of care.¹⁴ Two of these 3 respondents tested positive in the last 1-2 years.

Service Delivery

Eighty-two percent of consumers received services from 1-3 agencies, an average of two agencies. Consumers in Boston were more likely to receive services from more than one agency than those in the Southeast, Western and Central regions.*

Ninety-eight percent had a primary care doctor or nurse/physician assistant. They visited this person an average of nine times per year (median is six visits per year). Thirty-eight percent visited them five times or less, 60% less than 10 times, but 40% 10 or more times. The primary reasons listed by those who had made less than three visits were not feeling sick and transportation.

Fifty-one percent had visited a hospital emergency room in the past year, most for one visit, an average of two visits.

Eighty-four percent had a case manager; they were referred to their case manager by their doctor, themselves, or a health center. Thirty-five percent had more than one case manager, an average of two and seldom more than three. Of those who had more than one, 53% said that they liked having more than one, while 47% would prefer not having more than one.

Among the different cohorts tested (e.g. people who are substance abusers or physically disabled) the group most likely to have multiple case managers included those respondents who had been diagnosed with a mental illness.

Seventy-nine percent were currently on anti-retroviral therapy, but 21% were not. Eighteen percent were having trouble adhering to their medication plans, the main reasons being forgetting sometimes, drug intolerance, difficulty/forgetting to refill prescriptions, and the regimens were too hard or complicated to follow or keep.

¹⁴ As described in the "Methodology" section, consumers were recruited for this study through letters sent to clients of HIV/AIDS service provider agencies and thus have had at least some contact with a care giver. Health Resources Services Administration (HRSA) definition of "unmet need".

* Statistically significant difference, $p < .05$.

USE OF ANTI-RETROVIRAL THERAPY

Of the 21% of respondents not on anti-retroviral therapy, 27% of respondents reported that they were not currently on it because their doctor agreed with them that they should not be on the regimen, 19% reported drug intolerance or side effects and 11% reported that regimens were too hard or complicated to follow.

The following table details CD-4 counts for those respondents whose doctor agreed that they should not be on anti-retroviral therapy.¹⁵

FIGURE 13. CD-4 COUNTS OF RESPONDENTS NOT ON ANTI-RETROVIRAL THERAPY WITH DOCTOR'S AGREEMENT

CD-4 Count	n	Percentage of Respondents
Less than 50	1	3.1%
51-200	1	3.1%
201-350	4	12.5%
351 or Greater	18	56.3%
Don't Know	8	25.0%
Total	32	100.0%

The following table details viral load counts for those respondents whose doctor agreed that they should not be on anti-retroviral therapy.

FIGURE 14. VIRAL LOAD COUNTS OF RESPONDENTS NOT ON ANTI-RETROVIRAL THERAPY WITH DOCTOR'S AGREEMENT

Viral Load	n	Percentage of Respondents
100,000 or higher	1	3.1%
10,000-99,999	9	28.1%
50-9,999	7	21.9%
Below 50, virus undetectable	5	15.6%
Don't Know	10	31.3%
Total	32	100.0%

¹⁵ In most cases respondents noted other reasons in addition to “their doctor agreed” for not being on anti-retroviral therapy. These reasons included current substance abuse, drug intolerance and regimens too hard to follow.

CHANGING SERVICE NEEDS

Fifty-nine percent of respondents said that their service needs had changed since they first entered care, while 69% expected that their service needs would change in the next five years. They described these changes in open-ended questions (See supplemental report, "Voices 2003: Summary of Open Ended Questions").

CONSUMER-PROVIDER CONVERSATIONS

Many providers did not talk with consumers about non-medical health issues (See Figure 15).

- 73% of all interviewed did not talk with any provider about domestic violence, 66% with anyone about partner counseling and referral of their sexual or needle sharing partner, and 42% with anyone about disclosure of HIV status.
- 35% of injection drug users or substance abusers did not talk with anyone about counseling and referral of their sexual or needle sharing partner, and 31% with anyone about substance abuse treatment.
- 27% of injection drug users did not talk with anyone about safer drug use.

Of particular concern, only 79% of doctors talked to consumers who were on anti-retroviral therapies about adherence to medications and 51% about keeping doctor appointments. Case managers and peer support groups were even less likely to talk about these problems.

FIGURE 15. ISSUES DISCUSSED WITH PROVIDERS

Area	Doctor	Case Manager	Peer Support Group	Did Not Talk	Notes
Adherence to medications	79%	26%	14%	15%	Data represents only those respondents who reported that they are currently on Anti-HIV drugs.
Safer drug use	45%	33%	25%	26%	Data represents only those respondents who acknowledged that they injected drugs in the past 12 months.
Sexual behavior and HIV transmission	41%	28%	25%	36%	
Substance abuse treatment	49%	35%	20%	30%	Data represents only those respondents who acknowledged that they injected drugs in the past 12 months and/or had other substance abuse problems.
Keeping doctor appointments	51%	24%	7%	35%	
Disclosure of HIV status	29%	29%	19%	42%	
Mental health including depression	64%	29%	12%	25%	
Domestic violence	8%	11%	11%	73%	
Partner counseling and referral (someone to talk to your sexual or needle sharing partner about their exposure to HIV)	14%	16%	8%	66%	

Statistically Significant Results

Based on cross tabulations of various variables, interesting relationships, which may warrant further consideration are:

- The average respondent in the Western region was diagnosed 8 years ago while the average respondent in the Central region was diagnosed 13 years ago.
- Fifty-eight percent of respondents currently on Anti-HIV drugs reported a viral load below 50 (virus undetectable) compared to 23% of respondents not on Anti-HIV drugs.
- Twenty percent of respondents not on Anti-HIV drugs reported viral loads between 10,000-99,000 compared to 9% of respondents currently on Anti-HIV drugs.
- Respondents were more likely to have viral loads below 50 if they:
 - currently do not have Hepatitis B and/or Hepatitis C
 - are not intravenous drug users
 - do not have any other substance abuse problems
 - are currently on anti-HIV drugs
 - are male.
- Respondents who reported trouble adhering to medication plans can be categorized by one or more of the following:
 - deaf or hard of hearing
 - developmentally disabled or mentally retarded
 - have a learning disability
 - Hispanic
 - live in emergency shelter.
- Although 97% of respondents reportedly had a viral load test in the past year, 13% percent did not remember what it was. Respondents who did not know their Viral Load count as compared to those who did can be categorized by one or more of the following:
 - living in transitional housing
 - female
 - Puerto Rican
 - living under the poverty level
 - not currently on anti-HIV drugs
 - an intravenous drug user
 - has other substance abuse problems.

Voices of Experience 2003 Conclusions

This study is the “voices” of 466 HIV/AIDS consumers in Massachusetts and southern New Hampshire in Spring/Summer 2003. Many of the consumers who participated in this study have very low incomes, live alone, and are on Medicaid. They have complicated health problems including high rates of Hepatitis C and other chronic and acute illnesses. Most are receiving appropriate levels of medical care and have case managers. However, they are often not getting other services that they have a high need for, such as dental care and mental health counseling, primarily because they do not know where to go for services, a lack of services in their area, or difficulty accessing service providers. Many providers do not talk to them about other critical, related issues, such as domestic violence, counseling at-risk partners, safer drug use or substance abuse treatment. Most consumers believe that their service needs will change in the future. They are worried about what these changes will be and how they will be affected by them.

The findings from this study represent a sample of people living with HIV/AIDS who were enrolled in services at the time of recruitment. While it is not generalizable to all people living with HIV/AIDS in Massachusetts or southern New Hampshire, it provides insight into the health status of these consumers and their changing service needs.