



Building a Healthy Boston

In 2009 the Boston Public Health Commission (BPHC) and the Massachusetts Department of Public Health (MDPH) collaborated to fund John Snow Inc. (JSI) to conduct a state- and Boston Eligible Metropolitan Area (EMA)-wide consumer needs assessment of persons living with HIV/AIDS. The final report, *Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study* details health status, service needs, and level of connection to medical and social support services of a subgroup of HIV+ residents. The survey engaged over 1,000 consumer respondents, making this the largest local sample of People Living with HIV/AIDS (PLWHA) to date.

The Consumer Study was distributed in four languages, English, Spanish, Haitian-Creole, and Portuguese. Methodologies included strategies to engage hard-to-reach populations, such as homeless individuals and individuals not in care. Survey content addressed a range of issues including connection to health services, service gaps, barriers to care, and stigma in addition to detailed questions about care patterns, co-morbidities, mental health, substance use, disability, aging, and employment.

Key results of the Consumer Study include:

HEALTH STATUS

- Ninety-nine percent (99%) of the sample was currently receiving medical care, and 96% were also receiving other HIV/AIDS services.
- Seventy-two percent (72%) of respondents reported an undetectable HIV viral load—more than three times the rate of viral suppression reported nationally.
- Seventy percent (70%) of respondents reported that their health was good, very good, or excellent.

STIGMA

- Issues related to stigma and disclosure persists in the population. Between 54% and 79% of respondents reported feeling stigmatized by their HIV status according to different scales.
- Fifty-five percent (55%) of respondents said they agreed (or strongly agreed) with the following statements: “I worry that people who know I have HIV will tell others” and “Most people are uncomfortable around someone who has HIV.”
- Additionally, 48% agreed (or strongly agreed) with the statement “I work hard to keep my HIV a secret from others.”

NEEDED AND USED SERVICES

- The top two “needed and used” services were Primary Care (92% in both MA and EMA) and Drug Reimbursement (86% in both MA and EMA) confirming that these services were readily available and accessed with limited barriers.
- Ninety-eight percent (98%) of Massachusetts respondents and 99% of EMA respondents reported visiting their medical provider within the 12 months prior to the survey, and 95% and 94% respectively had done so within the prior six months.
- Ninety-one percent (91%) of respondents indicated they were taking HIV medications, and the majority of the sample relied on one or more forms of public assistance to cover medication costs.

SERVICE GAPS

- The top three service gaps in the state and the EMA (“needed and couldn’t get”) included Rental Assistance (25% in both MA and EMA), Food Bank/Food Vouchers (21% in both EMA and MA), and Dental Services (18% MA and 19% EMA).
- Service gaps were experienced most acutely by HIV+ individuals who were women, people of color, living at or below the federal poverty level, and non-U.S. born.

ESSENTIAL SERVICES

- Survey respondents identified primary care, HIV medications, help with benefits, dental services, and case management as the most essential services.
- These services were even more likely to be identified as essential by HIV+ individuals who were women, people of color, living at or below the poverty level, living with a disability or other chronic condition, and non-U.S.-born.
- Of those services rated “essential,” only dental services was also identified as a service gap.

SUBSTANCE ABUSE

- Thirty-nine percent (39%) of respondents in MA and 40% in the EMA said they had ever been diagnosed with an alcohol or drug abuse problem.
- The vast majority of these respondents (96%) said they had used some form of drug/alcohol services, underscoring the accessibility of substance use treatment services for survey respondents in MA and the EMA.

MENTAL HEALTH

- Forty-seven percent (47%) of respondents in both MA and the EMA reported they had been diagnosed with a mental health condition in the three months prior to the survey, including depression (83% in MA and 84% in the EMA) and an anxiety disorder (61% in MA and 62% in the EMA),
- Of those respondents reporting mental health symptoms in the last thirty days, 75% reported that someone had talked with them about mental health in the prior six months.

The findings from the Consumer Study reinforce that the majority of PLWHA in Massachusetts and the Boston EMA are in good health. Due to the availability of a full range of high-quality clinical and non-clinical support services and progressive public health policies including the implementation of state health care reform, reported access to medical care and engagement and retention in care and treatment is high.

While there have been many successes, some challenges remain. Of particular note is the continued impact of stigma in the lives of PLWHA, and how perceptions of stigma negatively impact the ability of respondents to seek support from family and friends. There remains a small but significant group of PLWHA who waited more than one year after an HIV diagnosis to enter medical care, and another group who experienced barriers to adhere their HIV medications that led to a treatment interruption of a week or more.

The survey findings indicate HIV+ residents in Massachusetts and Boston EMA benefit from the rich health and social services infrastructure in Massachusetts, and that efforts to combat stigma and strengthen advocacy services for the most vulnerable consumers remains needful. The survey findings, in the context of other assessments across the state and the Boston EMA will inform service development and enhancements for people living with HIV/AIDS in 2012.