

**MA and Southern NH
HIV/AIDS Consumer Survey**
Update and Selected Results

**Boston EMA HIV Health Services
Planning Council**

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Objectives

Provide refresher on:

- Survey methods
- Sample characteristics
- Needs and barriers data

Share new data on:

- Access to services
- Service interactions
- Stigma
- Disclosure

Methods

Part 1 (short form)

- Mail-based survey
- Distribution
 - Case management programs
 - HDAP
- \$3 gift card incentive
- June 2009

Part 2 (long form)

- Mail, online, or phone survey
- \$25 gift card incentive
- June thru September 2009

Other

- 4 languages
- Pilot tested
- IRB approval
- Advisory Group



Surveys

Short Form

- Targeted data on large sample
- Focus on:
 - Role of service
 - Need for/use of service
 - Barriers
 - Basic demographics
- Invitation for long form

Long Form

- In-depth data on smaller sample
- Focus on:

Access to care

Aging

Co-morbidities

Education and
employment

Health knowledge

Health status

HIV diagnosis

HIV

medications

Housing

status

Mental

health

Positive

prevention

Primary care

Stigma and



Short Form Survey

Short Form Distribution	
Total Distribution	5,060
Thru HDAP	1,676 (34%)
Thru case management	3,216 (65%)
Thru field methods	168 (1%)
Short Form Responses	
Total received	1,791
EMA Only	1,339
Response rate	35%
Language	
English	1,548 (86%)
Spanish	204 (11%)
Portuguese	16 (1%)
Haitian-Creole	23 (1%)



Long Form Survey

Long Form Distribution	
Total Distribution	1,528
By mail	976 (64%)
By web	263 (17%)
By phone	219 (14%)
By field methods	70 (5%)
Long Form Responses	
Total received	1,066
Response rate	70%
Linked to Short Form	1,029
Linked EMA Only	763
Language	
English	908 (88%)
Spanish	109 (11%)
Portuguese	6 (1%)
Haitian-Creole	6 (1%)



Sample Demographics

	EMA HIV Prevalence ('08)	Long-Short linked EMA Only (n=763)
Age		
<20	1%	0%
20-44	45%	31%
45+	53%	69%
Gender		
Male	71%	65%
Female	29%	35%
Transgender	-	<1%
Place of birth		
US	68%	79%
PR/territories	12%	10%
Non-US	20%	10%
Sexual orientation		
Heterosexual	N/A	51%
Homosexual	N/A	43%
Bisexual	N/A	7%

Sample Demographics

	EMA HIV Prevalence ('08)	Long-Short linked EMA Only (n=763)
Race/ethnicity		
White Non-Hispanic	48%	52%
Black Non-Hispanic	29%	21%
Hispanic	20%	18%
Asian/PI	1%	1%
Other	1%	6%
Transmission risk		
Heterosexual	30%	33%
IDU	22%	16%
MSM	37%	41%
MSM/IDU	3%	2%
Other	8%	3%
Unknown	NA	4%

Sample Demographics

	EMA HIV Prevalence ('08)	Long-Short linked EMA Only (n=763)
Regional geography (EMA counties)		
Bristol, Norfolk, Plymouth	17%	21%
Essex, Middlesex	29%	26%
Suffolk	38%	32%
Worcester	11%	14%
New Hampshire	5%	7%

Sample Demographics

Other

- 99% have health insurance
- 99% “in care”
- 65% living with HIV >10 years
- 45% at or below poverty
- 10% (n=74) non-US born
 - 69% (n=50) of non-US born tested HIV positive after moving to the US
 - 24% (n=18) of non-US born may be undocumented

Selected Short Form Data

**EMA Respondents Only
(n=1,339)**



Needed and Used Services

Rank	EMA Respondents (n=1,339) “needed and used”
1	Primary Care (92%)
2	Drugs (86%)
3	Case Management (77%)
4	Benefits (65%)
5	Dental (63%)
6	Mental Health (52%)
7	Adherence (47%)
8	Food Vouchers/Bank (45%)
9	Peer Support (45%)
10	Nutritional Counseling (39%)
11	Rent (34%)
12	Housing Search (28%)
13	Substance Abuse (26%)
14	Congregate Meals (25%)
15	Legal Assistance (24%)
16	Home-delivered Meals (15%)
17	Respite (12%)
18	Job Help (11%)
19	Immigration Assistance (7%)

Unmet Needs

Rank	EMA Respondents (n=1,339) “needed but couldn’t get”
1	Rent (25%)
2	Food Vouchers / Food Bank (21%)
3	Dental (19%)
4	Job Help (18%)
5	Housing Search (16%)
6	Legal Assistance (15%)
7	Nutritional Counseling (13%)
8	Home-Delivered Meals (13%)
9	Peer Support (12%)
10	Respite (10%)
11	Congregate Meals (9%)
12	Benefits (8%)
13	Mental Health (7%)
14	Case Management (7%)
15	Immigration Assistance (6%)
16*	Drugs (5%)
16*	Adherence (5%)
17	Substance Abuse (5%)
18	Primary Care (2%)

Barriers

Among services PLWH needed, but could not get

Most Common Barrier

- *Didn't know service existed or how to get*
 - #1 barrier for each of the top 10 services that PLWH needed but could not get
 - Reported by 33% - 50% of those who identified a barrier

Other Common Barriers

- *Transportation Problems*
- *Didn't have enough money*
- *Told not eligible*

Selected Long Form Data

**EMA Respondents Only
(n=763)**



Access to Services

Medical Care

- 77% accessed within 6 months of diagnosis
 - 58% immediately (<30 days)
 - 19% within 6 months
- 9% waited more than 3 years

Other Services

- 57% accessed within 6 months
 - 34% immediately (<30 days)
 - 23% within 6 months
- 21% more than 3 years

Most Helpful Person for Access

- 39% said medical provider
- 15% said case manager



Access to Services

What Would Have Helped You Get <u>HIV Medical Care</u> Sooner? (Among those who waited 1 year or more)	EMA (n=125)
Needed time to deal with diagnosis	28%
Nothing	18%
Help dealing with drug or alcohol issues	10%
More info about what might happen if I did not get it	10%
Other	10%

What Would Have Helped You Get <u>Other HIV Services</u> Sooner?* (Among those who waited 1 year or more)	EMA (n=245)
More info about where to go to get services	38%
Needed time to deal with diagnosis	31%
Information about free or low cost services	27%
Talk or counseling when I got my diagnosis	22%
Someone with HIV to help me talk about or deal with dx	20%
Help dealing with drug or alcohol issues	20%
Nothing	18%
More info about what might happen if I did not get it	17%
Other	11%

* Respondents could select more than one option (bottom table only)
Tables include only those response categories with $\geq 10\%$ of responses.



Care Interaction

My medical provider . . .	Always	EMA n
Seems to understand how to treat HIV/AIDS	93%	747
Treats me with respect	93%	748
Makes sure I get the care I need, including referral	88%	744
Listens to me during visits	87%	748
Offers me testing for other diseases (Hep B/C, STI)	85%	743
Seems to understand the needs of people my age	84%	742
Encourages me to participate in my own care	83%	743
Spends enough time with me during visits	81%	746
Is able to help me with with other health issues	80%	740
Works with me to help me keep my appointments	79%	693
Seems to understand my culture or community	78%	708
Is easy to schedule an appointment with	77%	743
Refers me to MH or SA services if I need them	74%	593
Is easy to reach when I need to	66%	745
Meets w/ my sex & drug-using partners on request	55%	477

Care Interaction

Medical Provider	Agree	EMA n*
My medical provider seems comfortable discussing alcohol or drug use with me.	92%	721
I am comfortable discussing alcohol or drug use with my medical provider .	90%	717
My medical provider seems comfortable discussing sex with me, including ways to keep my partner(s) and me healthy.	91%	736
I am comfortable discussing sex with my medical provider , including ways to keep me and my partner(s) healthy.	88%	734
Case Manager		
My case manager seems comfortable discussing alcohol or drug use with me.	90%	588
I am comfortable discussing alcohol or drug use with my case manager .	89%	579
My case manager seems comfortable discussing sex with me, including ways to keep my partner(s) and me healthy.	87%	600
I am comfortable discussing sex with my case manager , including ways to keep me and my partner(s) healthy.	84%	595

* “n” includes only respondents with a medical provider or case manager



Substance Use

Diagnosed

- 40% ever diagnosed with drug or alcohol problem
 - 96% of this group has used drug or alcohol services

Possible Problem

- 23% may have recent/current problem with drugs or alcohol (CAGE screen)
- Significantly higher* % of those with possible SA problem than those without said that:
 - SA services were essential (68% vs. 42%)
 - They needed but could not get SA services (15% vs. 3%)
 - They experienced any barrier to SA services (29% vs. 16%)

* $p \leq .05$

Substance Use

Who Talked with Respondents About Alcohol or Drug Use (prior six months)*	% (n=726)
No one	46%
Medical provider	39%
Case manager	25%
Mental health counselor (therapist or psych.)	21%
Family/friends	17%
Support group members	12%
Other HIV services provider	12%
Substance abuse counselor	11%
Other PLWH I know	10%
Table includes only those options with >10%	
*Respondents could select more than one option	

- Of those with possible recent/current problem, 82% said someone had spoken with them about drugs or alcohol in prior 6 mos.
 - % who had drug/alcohol discussion was significantly higher ($p < .0001$) among those with indication of possible SA problem than those without.

Mental Health

Who Talked with Respondents About Mental Health Topics (prior 6 months)*	% (n=737)
Medical provider	47%
Mental health counselor (therapist or psych.)	38%
No one	32%
Case manager	29%
Family/friends	18%
Other HIV services provider	13%
Support group member	10%

Table includes only those options with >10%
*Respondents could select more than one option

- 88% with MH diagnosis said someone had talked to them about MH topics in prior 6 months.
- 75% who reported MH symptoms in prior 30 days said someone had talked to them about MH topics in prior 6 months.

Mental Health

- 47% diagnosed with MH condition in 3 months prior to survey
 - Depression (84%)
 - Anxiety disorder (62%)
- The % with MH condition significantly* higher among those who:
 - Were born in US
 - Experienced a recent change in living situation
 - Were unemployed
 - Were White
- Of those diagnosed, 78% had received professional counseling or treatment in prior 6 months
- Of those diagnosed, 88% said someone had talked to them about MH issues in prior 6 months.

* $p \leq .05$



Mental Health

Data Suggest Impact on HIV Treatment and Adherence

- Among 14% who had stopped taking HIV meds for more than a week (in prior 6 months) . . .
 - the most common reason was **feeling depressed or overwhelmed** (39%)
- PLWH with diagnosed MH condition significantly* more likely than those without a MH condition to report that they:
 - Stopped taking meds for a week or more in prior 6 months (17% vs. 10%)
 - Missed a dose in prior 2 weeks (43% vs. 33%)

* $p \leq .05$



HIV Stigma

Assessed experiences of stigma

- Based on validated scale
- 12 factor items assessed
- Four “clusters” identified:
 1. Negative self-image
 2. Disclosure concerns
 3. Negative perceptions of how others see PLWH
 4. Experiences of discrimination/rejection

HIV Stigma

Factor	Validated Statements	Agree/ strongly agree	N (all)
1	A. I feel set apart or isolated from the rest of the world.	42%	996
1	B. I feel guilty because I have HIV.	36%	1,000
1	C. Having HIV makes me feel like a bad person.	16%	1,007
2	D. I worry that people who know I have HIV will tell others.	55%	1,001
2	E. I work hard to keep my HIV a secret from others.	48%	1,002
2	F. Most people are uncomfortable around PLWH.	53%	1,005
2	G. It is hard for PLWH to have long term relationships.	48%	1,005
3	H. Most people believe PLWH deserve it for how they lived.	41%	1,006
3	I. People's attitudes make me feel worse about myself.	37%	1,003
4	J. PLWH can lose their jobs when employers find out.	54%	1,001
4	K. I have stopped hanging out with some people because of their reaction to my having HIV.	35%	1,002
4	L. I have lost friends of family by telling them I have HIV.	35%	1,006

Factor 1 = Negative self-image

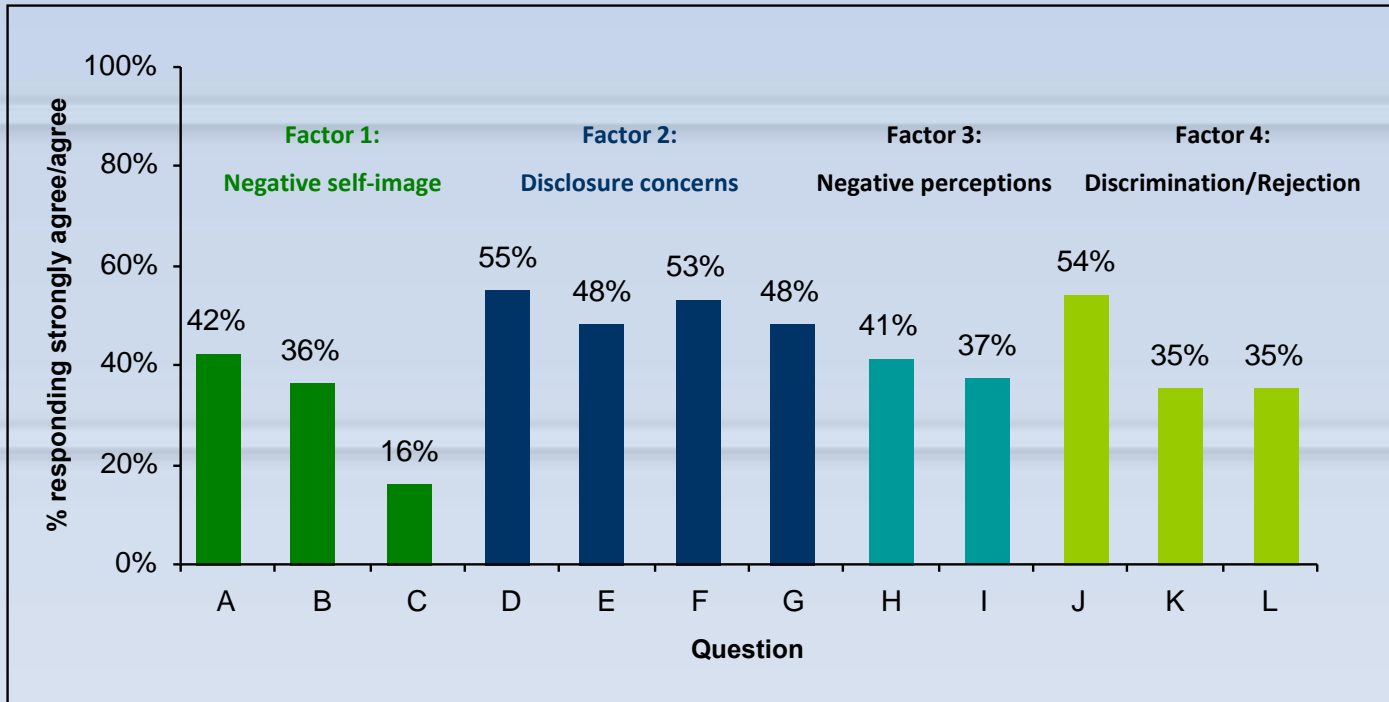
Factor 2 = Disclosure concerns

Factor 3 = Neg. perceptions of how others see PLWH

Factor 4 = Experiences of discrimination/rejection



HIV Stigma



HIV Stigma

Highest prevalence: disclosure concerns

- 79% agreed with one or more disclosure concern items

Lowest prevalence: negative self-image

- 54% agreed with one or more negative self-image items
- Lowest single factor agreement (16%) for “having HIV makes me feel like a bad person”

Experiences with stigma varied by age

- Under 50 more likely to report stigma related to disclosure and negative self-image than respondents 50 and over

HIV Stigma

Additional Stigma Impacts Identified

HIV Services

- 13% of respondents said **I don't want people to see me getting HIV services** when asked what was most difficult for them in using services.

Employment

- 13% of unemployed respondents said they were not working because they **worried people would find out their HIV status.**
- 38% of employed respondents said they **cannot be open about their HIV status in the workplace.**

Education

- Among those interested in further education but had not done so, 11% said they **worried people would find out their HIV status.**

Disclosure

- When asked what would help them share their HIV status with others, 14% of the 760 valid responses were related to stigma reduction.



HIV Knowledge/Literacy

Knowledge Question (True or False)	Correct Response	% Correct (n=742)
A T-cell (CD4) test measures the amount of HIV virus in an HIV-positive person's blood.	FALSE	44%
Using a condom is an effective way to prevent HIV transmission during sex.	TRUE	92%
If an HIV-positive person's viral load is "undetectable," it means he/she is cured of HIV.	FALSE	95%
The use of recreational drugs can impact the effectiveness of HIV medications.	TRUE	85%
An HIV-positive woman can give birth to a child without giving HIV to the baby.	TRUE	71%

For respondents who answered all five questions, average number correct was 4.2

Disclosure

96% said someone other than medical provider knows HIV status

Who else knows HIV status?

Family members	80%
Friends	77%
Case manager	75%
Other medical prov.	65%
Dentist	62%
Husband/wife/SO	50%
Other providers	44%
Children	28%
Spiritual leaders	15%



Disclosure

Among women

62% said their OB/GYN knew HIV status

Among those working

37% said co-workers knew HIV status

32% said mgr, supervisor, or HR knew

Small number (n=24) had told no one else; of this group:

75% (n=16) afraid people would judge them

58% (n=14) afraid how others would react

42% (n=10) believed it was their own business

Disclosure Facilitators

Q. *What would help you share your HIV status with others?*

- Open-ended
- 83% of respondents answered
- Qualitative analysis

Most Common Themes	Overall (n=762)
Nothing (no problems or challenges)	16%
Stigma reduction	14%
Education	11%
Support	11%
Don't need or want to tell anyone else	5%
Self-esteem	4%
Trust	3%

Disclosure Facilitators

THEMES

1. Stigma Reduction

48% Concerns with public attitudes

- *“If people would not look at me differently wondering what I did to get that way.”*

24% Fear of rejection

15% Disclosure concerns (keep secret)

6% Negative self-image

2. Education

85% Community/public

- *“For there to be more information and education for the community. This way, there is an education piece for them to learn how to live with people that are HIV+.”*

10% General (non-specific)

6% Self



Disclosure Facilitators

THEMES

3. Support

59% Peer support

- *“Support groups with HIV-positive colleagues who might be more understanding, open mind[ed], the better to support.”*

23% Support from others

17% Professional counseling or advice

4% General (non-specific)



Prevention

Q. *In your opinion, what can be done to help people in your community to stay HIV negative?*

- Open-ended
- 90% of respondents answered
- Qualitative analysis

Most Common Themes	Overall (n=832)
Education	48%
Sexual behaviors	25%
Outreach	21%
Harm reduction/needle exchange	8%
“Not sure” or “nothing”	5%
HIV testing	4%

Prevention

1. Education

49% General (non-specific)

45% Public/community

–“More available HIV education, real life examples of what HIV can do to your life.”

14% Youth focused

2. Sexual Behaviors

93% Safer sex practices

–“Safe sex practices such as always using a condom. It would be nice for people who know they have HIV to practice safe sex with people who don't have HIV. We need to stop the spread of this disease by being smart and exercising control over the decisions we make.”

15% Abstinence



Prevention

3. Outreach

31% General (non-specific)

28% Community

- *“Education in church, community centers, free condoms . . .”*

20% Youth or school focused

- *“Going to schools – Jr. High, High Schools – educating parents, special groups to enforce learning about HIV so children can have HIV prevention.”*

12% PLWH educators/speakers

- *“Possibly having people with HIV speak to groups (especially teens) and give first hand info on how becoming infected has affected their lives.”*

12% Condom access

10% Street activities

Schedule

- Finish draft report (Nov 2010)
- MDPH, BPHC review (Dec 2010)
- Final edits (Jan 2011)
- Presentations (Feb - Apr 2011)
- Additional analyses

