

2007 CPG Needs Assessment Report

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CPG Needs Assessment Report 2007

A. Introduction

This report summarizes the results of a year-long HIV Prevention Needs Assessment that focuses on the prevention needs of Maine people living with HIV. Beginning in the spring of 2007, the HIV Prevention Program and the HIV Prevention Community Planning Group (CPG) planned and implemented this project.

Background

Public health experts estimate that 1,200 people in Maine are living with a diagnosed HIV infection. Maine CDC estimates that another 500 are infected, but are unaware of their HIV status. The total of Maine people with HIV is probably 1,700.

The Federal CDC has recently named “people living with HIV” as one of the priority populations for HIV prevention programming. Several needs assessments already have been conducted among people living with HIV in Maine. They focused on HIV *care* needs. This is the first to assess HIV *prevention* needs.

This inquiry was conducted between June and December, 2006. Our report documents the *specific aims* of the needs assessment, describes the *methods* that were used to gain information, presents and discusses the key *findings* and makes *recommendations* for future program planning.

B. Specific Aims

The purpose of the needs assessment was to examine HIV related *knowledge, attitudes* and *behavior* among people living with HIV. Information from the needs assessment will support future program planning. The goal of these programs will be to prevent as many new infections as possible. One way of accomplishing this goal could be to help HIV positive people with *disclosure* and *harm reduction* practices. We developed the following research questions to guide our work:

Research Questions:

1. What are people with HIV doing to increase their HIV-related risk?
2. How are they lowering their risk? Does risk reduction have anything to do with how long a person has known he or she is infected with HIV?
3. Do those with HIV know about HIV prevention services that are available especially for them? How are they using them?
4. What responsibility do people with HIV have in not causing others to become infected?
5. What difficulties do people with HIV face in getting risk reduction services?

C. Methods of Data Collection and Analysis

The HIV Prevention Needs Assessment used two methods to address the research questions:

- ⇒ Survey of People Living With HIV (PLWH)
- ⇒ Group discussions with PLWH

1. Survey of People Living with HIV

One method of data collection in the PLWH Needs Assessment was a paper and pencil survey. During the spring of 2007, researchers reviewed other states' needs assessments and developed a survey tool with HIV Program staff and CPG members. (See **Appendix A** for a copy of the survey tool.)

The survey was distributed to five Ryan White Part B case management agencies that then mailed the surveys to their clients. Surveys were also distributed by members of the CPG. Over 600 surveys were distributed; 250 surveys were returned. Cases were examined for missing data. Two cases were excluded because of missing information. Two cases were excluded because they were mailed to children under the age of 5. Seven were incomplete because of a language barrier. A total of 239 surveys are included in the analysis. The data were analyzed using software called **Epi Info 2000**.

2. Group Discussions with PLWH

Ten group discussions were held in the major urban areas of the state. Two were held in Southern Maine (DHHS Region I), four in Central Maine (DHHS Region II), and four in Northern Maine (DHHS Region III). Questions included: **how do individuals use services, how do they perceive barriers to prevention, and how do they negotiate risk**. AIDS Service Organizations, Maine CDC staff and the Community Planning Groups recruited participants through direct invitation. In addition, information was posted on <http://www.positiveme.org>, a website for PLWH in Maine. An incentive of \$50 was offered. The aim was to recruit at least three participants per group.

Late in the spring of 2007, Maine CDC staff notified appropriate vendors as to when the needs assessment would take place. All would be expected to recruit participants for the groups and to distribute surveys.

We developed discussion questions (see **Appendix B**) that would help us explore safer sex practices, concern on the part of PLWH about HIV and HIV prevention programming for PLWH. Groups were expected to last as long as one and a half hours and were to be audio-taped.

D. Survey Results

Over 600 surveys were distributed. Some were mailed by Ryan White Part B case management agencies, and others were distributed by members of the HIV Prevention Community Planning Group (CPG).

Two hundred-fifty surveys were returned.

- Two were returned incomplete because recipients were children under the age of 5.
- Seven were returned incomplete due to language barrier.
- Two were returned incomplete for unknown reasons; they were unusable.

This left 239 usable surveys.

Survey data are divided into five sections.

1. Sample Characteristics
2. Risk Behaviors
3. Attitudes Related to Risk Behaviors
4. Challenges
5. Information and Services

Sample Characteristics

Sex

The majority, almost 80% of respondents, were male. This is a little under the Statewide percentage of 83% among people living in Maine with diagnosed HIV/AIDS.

Table 1: Sex of Respondents compared with the Statewide Demographic

	Survey Respondents		People living in Maine with diagnosed HIV/AIDS*	
	Frequency	Percent	Frequency	Percent
Female	48	20.1%	187	17%
Male	189	79.1%	940	83%
Transgender	2	0.8%	3	<1%
Total	239	100.0%	1,130	100%

*includes people living with AIDS or HIV diagnoses reported to ME CDC as of 12/06 (2007 Epi Info)

Age

Ages ranged from 21 to 71, with the average age of respondent being 47.

Table 2: Age of Respondents

	Frequency	Percent
15 - 24	3	1.3%
25 - 44	89	37.6%
45 - 64	138	58.2%
65 and over	7	3.0%
Total	237	100.0%

Table 3: Age of Respondents by Sex

	Female		Male		Transgender	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
15 - 24	1	2.1%	2	1.1%	0	0.0%
25 - 44	21	44.7%	68	36.2%	0	0.0%
45 - 64	25	53.2%	111	59.0%	2	100.0%
65 and over	0	0.0%	7	3.7%	0	0.0%
Total	47	100.0%	188	100.0%	2	100.0%

Females were between the ages of 21 and 64. The average age for females was 44.

Males were between 22 and 71 years old. The average age for males was 48.

The ages for the two transgendered respondents were 48 and 52.

Race and Ethnicity

- The majority of respondents were White/Caucasian – 84%, which is lower than the statewide rate of 90%.
- 5.4% were African American/Black. Statewide, 9% of people living with diagnosed HIV/AIDS are African American/Black
- 6.7% were Native American. This is higher than the Statewide rate of 1%
- 5.4% reported that they were a race not listed in the table.
- 15 people – 6.6% – reported that they are Hispanic. This is a little higher than the Statewide rate of 5%.

Table 4: Race and Ethnicity of Respondents compared with Statewide rates among PLWH

	Survey Respondents		People Living in Maine with diagnosed HIV/AIDS*	
	Frequency	Percent	Frequency	Percent
African American/Black	13	5.4%	98	9%
Asian	0	--	3	<1%
Native American/Alaskan Native	16	6.7%	9	1%
Native Hawaiian/ Pacific Islander	1	0.4%	0	--
White/Caucasian	201	84%	1,020	90%
Other Race	13	5.4%	0	--
Two or more races	5	2.1%	0	--
Hispanic	15	6.6%	60	5%
Not Hispanic	212	93.4%	1,070	95%

County of Residence

There was at least one respondent from each of Maine's 16 counties.

Most of the respondents - 43.6% - live in Southern Maine – DHHS Region I.

33.3% of respondents live in Central Maine – DHHS Region II.

23.1% live in Northern Maine – DHHS region III.

Table 5: Region of Resident for Respondents and Maine’s HIV Population

	Survey Respondents		People Living with Diagnosed HIV/AIDS in Maine	
	Frequency	Percent	Frequency	Percent
Southern Maine – DHHS Region I	102	43.6%	551	49%
Central Maine – DHHS Region II	78	33.3%	376	33%
Northern Maine – DHHS Region III	54	23.1%	203	18%

*DHHS Region I – York and Cumberland

DHHS Region II – Androscoggin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo

DHHS Region III – Aroostook, Hancock, Penobscot, Piscataquis and Washington

Support Services

Case Management

- Most people – 91.2% or 218 people – have an HIV Case Manager.
- Of those people in case management, 72.5% or 169 people, said their case manager talks with them about safer sex or safer injecting.

Medical Care

- Most people – 98.3% or 235 people – have a doctor that they see for their HIV needs.
- Of those people with doctors, 65.3% or 156 people, said their doctor talks with them about safer sex or safer injecting.

Risk Factors

Sexual Partners

Almost three-fourths of men reported that they only have sex with other men. Five percent reported that they have sex with men and women.

Three-fourths of women reported that they have sex with men.

Table 6: Gender of Sexual Partners

	Male		Female		Transgender	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Men	125	70.2%	34	75.6%	1	50.0%
Women	38	21.3%	6	13.3%	0	0.0%
Both Men & Women	9	5.1%	3	6.7%	0	0.0%
Did not answer	6	3.4%	2	4.4%	1	50.0%
Total	178	100.0%	45	100.0%	2	100.0%

Relationship Status

People were asked to select the description that best describes their sexual relationship over the past year. About half of females reported that they are in a relationship with only one partner, and they agree along with their partner to only have sex with each other. One-quarter of males

reported that they are in a similar relationship, and one-quarter indicated that they are single and have had multiple sex partners in the past year.

Table 7: Relationship Status

	Female		Male		Transgender		MSM	
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
I have a partner, and we agree to only have sex with each other	26	54.2%	50	26.5%	0	--	31	23.1%
I have a partner, and we agree to have sex with other people	1	2.1%	16	8.5%	0	--	16	11.9%
I'm in a relationship, but I have sex with other people that my partner doesn't know about	0	--	4	2.1%	0	--	4	3%
I'm single and have had more than one sex partner during the last year	4	8.3%	48	25.4%	0	--	46	34.3%
I did not have sex during the past year	15	31.3%	64	33.9%	2	100%	33	24.7%
Did not answer	2	4.2%	7	3.7%	0	--	4	3%
Total	48	100%	189	100%	2	100%	134	100%

Number of Sex Partners

Vaginal Sex Partners

Females

- Most women – 91.5% - reported having 0 or 1 vaginal sex partner in the last year.
- One sex partner was the most common answer with 51% of respondents.
- One female reported having 30 vaginal sex partners, the highest number reported among women.

Males

- Most men – 82.4% - reported having no vaginal sex partners.
- One male reported having 48 vaginal sex partners.

Transgender

- Both transgendered respondents reported having no vaginal sex partners.

Anal Sex Partners

Females

- Most women – 82.6% - reported having no anal sex partners in the last year.
- Seven women, 15.2%, reported having one anal sex partner.
- One woman reported having two anal sex partners, the highest number reported.

Males

- About half of the men – 53.7% - reported having no anal sex partners in the last year.
- Thirty-five men reported having one anal sex partner – 20%.
- One man reported having 48 anal sex partners, the highest number reported.

Transgender

- Both transgendered respondents reported having no anal sex partners.

Oral Sex Partners

Females

- About half of the women – 52.2% - reported having no oral sex partners.
- 34.8% reported having one oral sex partner.
- One woman reported having 60 oral sex partners, the highest number reported.

Males

- Among men, 39.2% reported having no oral sex partners.
- 25% reported having one oral sex partner.
- 3% reported having more than 40 oral sex partners.
- One person reported 80, the highest number reported.

Transgender

- Transgendered respondents reported no oral sex partners.

Specific Risk Behaviors

Almost one-fourth of respondents indicated that they have had unprotected sex without disclosing their HIV status since they learned that they were HIV positive. Almost 30% of people have had unprotected sex with someone of unknown status.

Table 8: Disclosure during Sex or Needle Sharing

	All		MSM	
	Frequency	Percent	Frequency	Percent
Protected sex with disclosing HIV status	146	61.1%	91	67.9%
Unprotected sex with disclosing HIV status	106	44.4%	72	53.7%
Protected sex without disclosing HIV status	89	37.2%	70	52.2%
Unprotected sex without disclosing HIV status	54	22.6%	44	32.8%
Unprotected sex with someone of unknown status	71	29.7%	53	39.5%
<hr/>				
Avoided or chose not to have sex since diagnosis	119	49.8%	60	44.8%
<hr/>				
Shared needles or works with disclosing HIV status	7	2.9%	--	--
Shared needles or works without disclosing HIV status	2	0.8%	--	--
Shared needles or works with someone of unknown status	3	1.3%	--	--

Condom/Dental Dam Use

The following tables indicate frequency of condom and/or dental dam use for the various types of risky sexual behaviors. A large percentage of people for males and females indicated that these questions were not applicable to them. This data makes sense when comparing it to the number of sex partners for each behavior as about half of respondents indicated that they had no sex partners in the last year.

Table 9: Condom/Dental Dam Use by Females

	<u>Every Time</u>	<u>Most of the Time</u>	<u>Some times</u>	<u>Rarely</u>	<u>Never</u>	<u>N/A</u>	<u>Did not answer</u>
Anal Sex	2 (4.2%)	3 (6.3%)	1 (2.1%)	1 (2.1%)	6 (12.5%)	32 (66.7%)	3 (6.3%)
Vaginal Sex	9 (18.8%)	7 (14.6%)	3 (6.3%)	2 (4.2%)	9 (18.8%)	16 (33.3%)	2 (4.2%)
Oral sex being performed on me	1 (2.1%)	0 --	0 --	2 (4.2%)	17 (35.4%)	25 (52.1%)	3 (6.3%)
Oral sex that I perform on someone else	1 (2.1%)	0 --	1 (2.1%)	2 (4.2%)	19 (39.6%)	22 (45.8%)	3 (6.3%)

Table 10: Condom/Dental Dam Use by Males

	<u>Every Time</u>	<u>Most of the Time</u>	<u>Some times</u>	<u>Rarely</u>	<u>Never</u>	<u>N/A</u>	<u>Did not answer</u>
Anal Sex	51 (27.1%)	19 (10.1%)	15 (8%)	7 (3.7%)	11 (5.9%)	62 (33%)	23 (12.2%)
Vaginal Sex	26 (13.8%)	0 --	3 (1.6%)	1 (0.5%)	4 (2.1%)	119 (63%)	36 (19%)
Oral sex being performed on me	25 (13.2%)	4 (2.1%)	10 (5.3%)	15 (7.9%)	58 (30.7%)	53 (28%)	24 (12.7%)
Oral sex that I perform on someone else	16 (8.5%)	7 (3.7%)	8 (4.2%)	18 (9.5%)	70 (37%)	47 (24.9%)	23 (12.2%)

Table 10A: Condom/Dental Dam Use by Men who have sex with Men

	<u>Every Time</u>	<u>Most of the Time</u>	<u>Some times</u>	<u>Rarely</u>	<u>Never</u>	<u>N/A</u>	<u>Did not answer</u>
Anal Sex	49 (36.6%)	19 (14.2%)	15 (11.2%)	7 (5.2%)	9 (6.7%)	29 (21.6%)	6 (4.5%)
Vaginal Sex	8 (6%)	0 --	2 (1.5%)	1 (0.7%)	0 --	97 (72.4%)	26 (19.4%)
Oral sex being performed on me	18 (13.4%)	3 (2.2%)	10 (7.5%)	15 (11.2%)	51 (38.1%)	25 (18.7%)	9 (6.7%)
Oral sex that I perform on someone else	11 (8.2%)	6 (4.5%)	8 (6%)	18 (13.4%)	64 (47.8%)	19 (14.2%)	8 (6%)

Table 11: Condom/Dental Dam Use by Transgendered Respondents

	<u>Every Time</u>	<u>Most of the Time</u>	<u>Some times</u>	<u>Rarely</u>	<u>Never</u>	<u>N/A</u>	<u>Did not answer</u>
Anal Sex	0 --	0 --	0 --	0 --	0 --	2 (100%)	0 --

Vaginal Sex	0 --	0 --	0 --	0 --	0 --	2 (100%)	0 --
Oral sex being performed on me	0 --	0 --	0 --	0 --	0 --	2 (100%)	0 --
Oral sex that I perform on someone else	0 --	0 --	0 --	0 --	0 --	2 (100%)	0 --

Table 12 shows the reported condom use among people with more than three anal or vaginal sex partners in the last year. This is broken down by gender of respondent and gender of his/her sex partners. All people with fewer than three sex partners were excluded from this table.

Table 12: Condom Use in Relation to Number of Sex Partners in the Last Year

		Reported Condom Use				
		Every Time	Most Times	Sometimes	Rarely	Never
Men who have sex with men						
<i>Anal Sex</i>						
3-4 partners		4	6	3	1	0
5 or more partners		4	3	2	3	0
<i>Vaginal Sex</i>						
3-4 partners		1	0	0	0	0
5 or more partners		1	0	0	0	0
Men who have sex with men and women						
<i>Anal Sex</i>						
3-4 partners		0	0	0	0	0
5 or more partners		1	1	0	0	0
<i>Vaginal Sex</i>						
3-4 partners		0	0	1	0	0
5 or more partners		1	0	0	0	0
Men who have sex with women						
<i>Vaginal Sex</i>						
3-4 partners		1	0	0	0	0
5 or more partners		1	0	0	0	0
Women who have sex with men						
<i>Vaginal Sex</i>						
3-4 partners		0	0	0	0	0
5 or more partners		0	0	0	0	1

When asked who brings up use of a condom/dental dam,

- About 25% of people said they bring up condom/dental dam use
- About 5% said that their partner brings up condom/dental dam use
- About 30% of people said that they and their partner both bring up condom/dental dam use
- About 15% said that they never use condoms/dental dams

The following table shows who discussion of condom/dental dam use stratified by gender.

Table 13: Discussion of Condom/Dental Dam Use stratified by Gender

	Females		Males		Transgender	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
I bring up using a condom	14	29.2%	44	25.1%	0	0.0%
My sex partner brings up using a condom	1	2.1%	11	6.3%	0	0.0%
We both bring it up equally	10	20.8%	58	33.1%	1	50.0%
Nobody - I never use a condom when having sex	10	20.8%	24	13.7%	0	0.0%
Did not answer	13	27.1%	38	21.7%	1	50.0%
Total	48	100.0%	175	100.0%	2	100.0%

Table 13A: Discussion of Condom/Dental Dam Use among MSM

	Frequency	Percent
I bring up using a condom	38	29.7%
My sex partner brings up using a condom	10	7.8%
We both bring it up equally	47	36.7%
Nobody - I never use a condom when having sex	16	12.5%
Did not answer	17	13.3%
Total	128	100%

Perception of Risk

Among those people who indicate they are sexually active, most people believe their sexual behavior has a low or no risk of transmitting HIV. Only 6.3% of females and 4.2% of males feel that their sexual behavior has a high risk of transmitting HIV.

Table 14: Perception of Level of Risk in Transmitting HIV

	Females		Males		Transgender	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
<i>Overall, I believe my sexual behavior...</i>						
Has a high risk of transmitting HIV	3	6.3%	8	4.2%	0	--
Has a moderate risk of transmitting HIV	0	--	6	3.2%	0	--
Has a low risk of transmitting HIV	13	21.7%	73	38.6%	0	--
Has no risk of transmitting HIV	10	20.8%	37	19.6%	0	--

I am not sexually active	21	43.8%	64	33.9%	2	100.0%
Did not answer	1	2.1%	1	0.5%	0	--
Total	48	100%	189	100%	2	100.0%

Table 14A: Perception of Risk Among MSM

	Frequency	Percent
<i>Overall, I believe my sexual behavior...</i>		
Has a high risk of transmitting HIV	6	4.5%
Has a moderate risk of transmitting HIV	5	3.7%
Has a low risk of transmitting HIV	65	48.6%
Has no risk of transmitting HIV	27	20.1%
I am not sexually active	30	22.4%
Did not answer	1	0.7%
Total	134	

Perception of risk was further stratified by reported condom use during sex and then separated by male and female. Highlighted are the cells indicating when people report that they never use condoms or dental dams during specific sex acts, but still believe that their sexual behavior has low or no risk of transmitting HIV.

Table 15: Perception of Risk among Females stratified by Condom Use during Sex

		Overall, I believe that my sexual behavior...					
		Has a high risk of transmitting HIV	Has a moderate risk of transmitting HIV	Has a low risk of transmitting HIV	Has no risk of transmitting HIV	I am not sexually active	Did not answer
Females							
<i>Anal Sex</i>							
Use Condoms/ Dental Dams...							
	Every Time	0	0	1	1	0	0
	Most of the time	0	0	3	0	0	0
	Some Times	1	0	0	0	0	0
	Rarely	0	0	0	0	1	0
	Never	2	0	1	2	1	0
	N/A	0	0	7	7	17	1
	Did not answer	0	0	1	0	2	0
<i>Vaginal Sex</i>							
Use Condoms/ Dental Dams...							
	Every Time	0	0	2	4	3	0
	Most of the Time	0	0	4	1	2	0
	Some Times	1	0	2	0	0	0
	Rarely	0	0	1	0	1	0
	Never	2	0	4	3	0	0
	N/A	0	0	0	2	13	1
	Did not answer	0	0	0	0	2	0
<i>Oral sex being performed on the respondent</i>							
Use Condoms/ Dental dams....							
	Every Time	0	0	1	0	0	0
	Most of the Time	0	0	0	0	0	0
	Some Times	0	0	0	0	0	0
	Rarely	1	0	1	0	0	0
	Never	2	0	9	4	3	0
	N/A	0	0	2	6	16	1
	Did not answer	0	0	1	0	2	0
<i>Oral Sex that the respondent performs on someone else</i>							
Use Condoms/ Dental Dams...							
	Every Time	0	0	0	1	0	0

Most of the Time	0	0	0	0	0	0
Some Times	0	0	0	0	1	0
Rarely	1	0	1	0	0	0
Never	2	0	9	5	3	0
N/A	0	0	2	4	15	1
Did not answer	0	0	1	0	2	0

Table 16: Perception of Risk among Males stratified by Condom Use during Sex

		Overall, I believe that my sexual behavior...					
		Has a high risk of transmitting HIV	Has a moderate risk of transmitting HIV	Has a low risk of transmitting HIV	Has no risk of transmitting HIV	I am not sexually active	Did not answer
Males							
<i>Anal Sex</i>							
Use Condoms/ Dental Dams...							
	Every Time	2	0	25	15	9	0
	Most of the time	0	0	14	4	1	0
	Some Times	0	3	9	2	0	1
	Rarely	1	1	5	0	0	0
	Never	2	1	5	3	0	0
	N/A	2	0	12	8	40	0
	Did not answer	1	1	2	5	14	0
<i>Vaginal Sex</i>							
Use Condoms/ Dental Dams...							
	Every Time	1	0	11	7	7	0
	Most of the Time	0	0	0	0	0	0
	Some Times	0	0	0	2	0	1
	Rarely	1	0	0	0	0	0
	Never	0	1	2	1	0	0
	N/A	5	4	50	18	42	0
	Did not answer	1	1	10	9	15	0
<i>Oral sex being performed on the respondent</i>							
Use Condoms/ Dental dams....							
	Every Time	3	0	12	5	5	0
	Most of the Time	0	0	5	2	0	0
	Some Times	0	0	6	3	1	0
	Rarely	1	0	7	6	1	0
	Never	2	5	36	11	3	1
	N/A	1	0	7	6	39	0
	Did not answer	1	1	3	4	15	0
<i>Oral Sex that the respondent performs on someone else</i>							
Use Condoms/ Dental Dams...							
	Every	2	0	6	4	4	0

Time						
Most of the Time	1	0	4	2	0	0
Some Times	0	0	4	3	1	0
Rarely	1	0	10	5	2	0
Never	2	5	41	16	5	1
N/A	1	0	5	4	37	0
Did not answer	1	1	3	3	15	0

The following table indicates the reported frequency of people engaging in disclosure and risk reduction behaviors. It should be noted that between one-quarter and one-third of people did not answer any of these questions.

Table 17: Frequency of disclosure and risk reduction

	<u>All the time</u>	<u>Some of the time</u>	<u>Occasionally</u>	<u>Never</u>	<u>Did not answer</u>
I tell all my sex partners my HIV status before I have sex with them.	120 (50.2%)	27 (11.3%)	11 (4.6%)	23 (9.6%)	58 (24.3%)
I tell my HIV status to people I want a relationship with, but not casual sex partners	47 (19.7%)	22 (9.2%)	13 (5.4%)	83 (34.7%)	74 (31%)
I only have sex with people of my own HIV status.	17 (7.1%)	32 (13.4%)	28 (11.7%)	83 (34.7%)	79 (33.1%)
I don't pay much attention to HIV status when deciding to have sex with someone.	46 (19.2%)	21 (8.8%)	15 (6.3%)	86 (36%)	71 (29.7%)
I am in control of whether or not I have protected sex.	142 (59.4%)	17 (7.1%)	4 (1.7%)	15 (6.3%)	61 (25.5%)

Table 17A: Frequency of disclosure and risk reduction among MSM

	<u>All the time</u>	<u>Some of the time</u>	<u>Occasionally</u>	<u>Never</u>	<u>Did not answer</u>
I tell all my sex partners my HIV status before I have sex with them.	71 (53%)	22 (16.4%)	11 (8.2%)	13 (9.7%)	17 (12.7%)
I tell my HIV status to people I want a relationship with, but not casual sex partners	34 (25.4%)	20 (14.9%)	9 (6.7%)	45 (33.6%)	26 (19.4%)
I only have sex with people of my own HIV status.	11 (8.2%)	30 (22.4%)	26 (19.4%)	39 (29.1%)	28 (20.9%)
I don't pay much attention to HIV status when deciding to have sex with someone.	31 (23.1%)	18 (13.4%)	12 (9%)	47 (35.1%)	26 (19.4%)
I am in control of whether or not I have protected sex.	93 (69.4%)	8 (6%)	3 (2.2%)	8 (6%)	21 (15.7%)

Table 18 looks at frequency of disclosure based on gender of respondent and of their sexual partners.

Table 18: Frequency of disclosure stratified by sex of respondent and sex of their partner(s)

I tell all my sexual partners my HIV status before I have sex with them.

All the Time	Sometimes	Occasionally	Never	Did not answer
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Females

Having sex with both men and women	2	0	0	1	0
Having sex with men	15	3	0	4	12
Having sex with women	4	0	0	0	2
Did not answer	0	0	0	0	2

Males

Having sex with both men and women	3	2	2	0	2
Having sex with men	68	20	9	13	15
Having sex with women	21	2	0	4	11
Did not answer	0	0	0	1	5

Transgender

Having sex with men	1	0	0	0	0
Did not answer	1	0	0	0	0

Co-occurring Disorders

Table 18 indicates diagnoses of co-occurring disorders since HIV diagnosis. The disorders are listed in order of most frequently reported to least frequently reported.

Table 19: Diagnoses of co-occurring disorders since being diagnosed with HIV

	Frequency	Percent
Hepatitis C	32	13.4%
Genital Warts	29	12.1%
Genital Herpes	26	10.9%
Hepatitis B	18	7.5%
Gonorrhea	11	4.6%
HPV	11	4.6%
Hepatitis A	9	3.8%
Chlamydia	8	3.3%
Syphilis	8	3.3%

One person also indicated that he/she had been diagnosed with anal warts since HIV diagnosis.

Substance Use

The two most commonly used substances are alcohol and marijuana/hash. About one-quarter of respondents use alcohol and/or marijuana at least once a week. The most common answer for the reported usage of all of the substances was “Not used in the last year.”

Table 20: Reported usage of substances.

	Not used in the last year	Used in the past 6 months	Used less than once a month	Used at least once a month	Used once a week or more	Did not answer
Alcohol	78 (32.8%)	28 (11.8%)	22 (9.2%)	30 (12.6%)	65 (27.3%)	15 (6.3%)
Marijuana or Hash	107 (45%)	27 (11.3%)	14 (5.9%)	11 (4.6%)	62 (26.1%)	17 (7.1%)
Crack/Cocaine	196 (82.4%)	12 (5%)	2 (0.8%)	3 (1.3%)	2 (0.8%)	23 (9.7%)
Heroin	210 (88.2%)	1 (0.4%)	1 (0.4%)	1 (0.4%)	0	25 (10.5%)
Crystal Meth or Methamphetamines	208 (87.4%)	4 (1.7%)	2 (0.8%)	0	1 (0.4%)	23 (9.7%)
Speedball	212 (89.1%)	1 (0.4%)	0	0	0	25 (10.5%)
GHB	212 (89.1%)	2 (0.8%)	0	0	1 (0.4%)	23 (9.7%)
Poppers	176 (73.9%)	11 (4.6%)	8 (3.4%)	12 (5%)	7 (2.9%)	24 (10.1%)
Ecstasy	209 (87.8%)	5 (2.1%)	0	1 (0.4%)	0	23 (9.7%)
Pills not prescribed by my doctor	191 (80.3%)	12 (5%)	5 (2.1%)	4 (1.7%)	4 (1.7%)	22 (9.2%)

- One person reported using Clonipin
- One person reported using Codeine
- Four people reported using hallucinogens including LSD, acid and mushrooms
- One person reported using ketamine (Special K)

Thirty five people said they have ever injected any substances not prescribed by a medical person.

- 5 people have shared needles within the last year
- 12 people said they do not know how to clean their works (34.3%)

When asked “How likely are you to practice safer sex when you are using,”

- 95 people said they do not use drugs or alcohol (39.9%)
- 76 people said they were **very likely** to practice safer sex (31.9%)
- 24 people said they were **somewhat likely** to practice safer sex (10.1%)
- 25 people said they were **not likely** to practice safer sex (10.5%)

Thirty-four people said they either strongly agreed or agreed some to the statement “When I have sex, I am usually high on alcohol and/or drugs.”

Forty people said they either strongly agreed or agreed some to the statement “When I am high on drugs, I don’t think much about transmission of HIV infection to others.”

Seven people said they always tell their HIV status to their drug using partners before they share needles with them. Conversely, 5 people said they never tell their HIV status to their drug using partners before sharing needles.

Attitudes Related to Risk Behaviors

Most people – 83% - feel that it is their responsibility to disclose their HIV status to their sex partners. Almost half of people also feel that their sex partner has the responsibility of protecting themselves from HIV infection. Six percent of people strongly agreed with the statement that their partner insists on having sex without a condom. Almost 16% of people are not in the habit of using a condom when having sex.

Table 21: Attitudes related to risk behaviors

	<u>Strongly Agree</u>	<u>Agree Some</u>	<u>Disagree Some</u>	<u>Strongly Disagree</u>	<u>Did Not Answer</u>
It is my responsibility to inform my sexual partner(s) that I am HIV positive.	199 (83.3%)	20 (8.4%)	7 (2.9%)	4 (1.7%)	9 (3.8%)
It is the responsibility of the person I am having sex with to protect themselves from HIV infection.	117 (49%)	53 (22.2%)	16 (6.7%)	40 (16.7%)	13 (5.4%)
When I have unprotected sex with another HIV positive person, it presents no health risk for either of us.	22 (9.2%)	17 (7.1%)	38 (15.9%)	141 (59%)	21 (8.8%)
Sex is better without using a condom.	109 (54.6%)	53 (22.2%)	13 (5.4%)	46 (19.2%)	18 (7.5%)
When I am “turned on” putting on a condom ruins the moment.	28 (11.7%)	68 (28.5%)	53 (22.2%)	67 (28%)	23 (9.6%)
I am not in the habit of using a condom when I have sex.	38 (15.9%)	30 (12.6%)	30 (12.6%)	110 (46%)	31 (13%)
I know when my partner is infected	30	25	24	123	37

with HIV.	(12.6%)	(10.5%)	(10%)	(51.5%)	(15.5%)
I am embarrassed to suggest using a condom with a partner.	8 (3.3%)	26 (10.9%)	30 (12.6%)	145 (60.7%)	30 (12.6%)
Sex with a condom isn't real sex.	13 (5.4%)	25 (10.5%)	26 (10.9%)	148 (61.9%)	27 (11.3%)
Using a condom will be interpreted by my partner as me being unfaithful.	11 (4.6%)	11 (4.6%)	28 (11.7%)	162 (67.8%)	27 (11.3%)
I want to have kids and condoms are a form of birth control.	22 (9.2%)	13 (5.5%)	11 (4.6%)	152 (63.6%)	63 (26.5%)
The increased risk of not using condoms makes sex more erotic.	12 (5%)	24 (10%)	23 (9.6%)	152 (63.6%)	28 (11.7%)
My partner insists on having sex without a condom.	15 (6.3%)	27 (11.3%)	21 (8.8%)	133 (55.6%)	43 (18%)

Challenges

Since being diagnosed with HIV, people reported experiencing the following challenges that can affect their relationships and abilities to negotiate safer sex:

Table 22: Challenges

Feeling hopeless about intimate relationships	48.5%
Feeling that I am dirty or contaminated	46%
Feeling that I am trapped or doomed	44.4%
Telling sex partners about my HIV status	43.9%
Having no sex drive	43.1%
Feeling confident that I won't infect others	42.3%
Fear of intimate relationships	40.6%
Feeling unworthy of intimate relationships	39.7%
Telling my friends family about my HIV status	38.5%
Practicing/maintaining safer sex	29.3%
Alcohol and/or other drug use	21.3%
Using clean needles/works	3.8%

People also reported:

- Fear of rejection
- Lack of confidence
- No hope for a relationship
- Rejection after disclosure of status
- Depression

Information and Services

Barriers to Accessing Services

In general, well over half of respondents reported no problems in accessing services. The biggest problems appear to be around fear of community members discovering a person's status.

Table 23: Barriers to accessing prevention services

	<u>Big Problem</u>	<u>Moderate Problem</u>	<u>Small Problem</u>	<u>No Problem</u>	<u>Did Not Answer</u>
The HIV prevention programs I need are not available	10 (4.2%)	12 (5%)	19 (7.9%)	180 (75.3%)	18 (7.5%)
I don't have transportation to get from my home to where the program is	14 (5.9%)	14 (5.9%)	16 (6.7%)	181 (75.7%)	14 (5.9%)
I don't know what organizations provide the information or programs I need	9 (3.8%)	19 (8%)	29 (12.2%)	168 (70.6%)	16 (6.7%)
Programs are not available at a time that I can attend	11 (4.6%)	19 (7.9%)	27 (11.3%)	166 (69.5%)	16 (6.7%)
I can't find programs in a language that I speak	2 (0.8%)	0 --	2 (0.8%)	216 (90.4%)	19 (7.9%)
I don't know where to get information	6 (2.5%)	11 (4.6%)	15 (6.3%)	189 (79.1%)	18 (7.5%)
I can't go because there is no one to look after my kids	5 (2.1%)	3 (1.3%)	3 (1.3%)	198 (82.8%)	30 (12.6%)
The people who work at the organization(s) providing the programs are not helpful	7 (2.9%)	9 (3.8%)	18 (7.5%)	187 (78.2%)	18 (7.5%)
The information and programs are too expensive	6 (2.5%)	8 (3.3%)	12 (5%)	192 (80.3%)	21 (8.8%)
The organization providing the program did not answer my questions	4 (1.7%)	10 (4.2%)	20 (8.4%)	186 (77.8%)	19 (7.9%)
I fear that someone I know will see me when I go to get STD or HIV prevention services	25 (10.5%)	15 (6.3%)	27 (11.3%)	154 (64.4%)	18 (7.5%)
I don't know who to ask for help	5	11	19	184	20

	(2.1%)	(4.6%)	(7.9%)	(77%)	(8.4%)
The discrimination I felt from people providing information to me	5 (2.1%)	10 (4.2%)	17 (7.1%)	188 (78.7%)	19 (7.9%)
My community is too small; everyone knows each other	36 (15.1%)	24 (10%)	21 (8.8%)	140 (58.6%)	18 (7.5%)

Table 24 further breaks down the issues of concern for privacy when accessing services by DHHS Region.

Table 24: Concern for privacy stratified by DHHS Regions

I fear that someone I know will see me when I go get HIV or STD prevention Services

	Big Problem	Moderate Problem	Small Problem	No Problem	Did not Answer
DHHS Region I*	11	6	11	64	10
DHHS Region II	9	6	9	51	3
DHHS Region III	5	2	7	37	3

* Region I – Cumberland and York Counties

Region II – Androscoggin, Franklin, Oxford, Knox, Lincoln, Sagadahoc, Waldo, Kennebec and Somerset Counties Region III

– Hancock, Washington, Penobscot, Piscataquis and Aroostook Counties

My community is too small; everyone knows each other.

	Big Problem	Moderate Problem	Small Problem	No Problem	Did not Answer
DHHS Region I*	9	10	7	66	10
DHHS Region II	21	5	4	43	5
DHHS Region III	6	8	10	29	1

*Region I – Cumberland and York Counties

Region II – Androscoggin, Franklin, Oxford, Knox, Lincoln, Sagadahoc, Waldo, Kennebec and Somerset Counties

Region III – Hancock, Washington, Penobscot, Piscataquis and Aroostook Counties

About two-thirds of people – 67.8% – feel that they are getting enough services and info about HIV/AIDS. About one-fourth of people – 27.6% – want more information and services related to HIV prevention.

Ways of Getting More Information

The table below lists the ways that people prefer to get their information about HIV/AIDS.

Table 25: Ways that people like to get their HIV/AIDS info

Their doctor or medical provider	90.4%
From Internet, web or online sources	63.2%

Television, Radio or Newspaper	57.7%
Talking with other HIV positive people in peer group sessions	57.1%
Talking with experts in workshops/group settings	56.5%
From Friends	49.4%

People also reported that they like to get information from

- their case manager,
- books,
- HIV-related mailings/newsletters,
- and family.

One person suggested that a telephone hotline would be helpful.

E. PANEL DISCUSSION RESULTS

Sample information:

Ten discussion groups were held in different parts of the State. **Forty-five** people participated—**32** men, **12** women and **1** transgender person. Ages ranged from **20** to **69**. The greatest number (**38/45**) were between **30** and **59**. Most (**34**) were “white.” There were also **9** “black” and **2** each of “native American,” “biracial,” “Hispanic,” and “other.”

As to sexual orientation, a majority (**29/45**) were gay. **Eleven** individuals were straight.

Ten of the **16** Maine counties were represented: Androscoggin, Aroostook, Cumberland, Hancock, Kennebec, Oxford, Penobscot, Waldo, Washington and York. Department of Health and Human Services (DHHS) Region I had **20** attendees, Region II had **10** and Region III had **15**. Counties by DHHS Region are shown below.

Table 26: Group participants by DHHS Region and sex

Sex	Region I	Region II	Region III
male	16	7	9
female	4	3	5
transgender	0	0	1

Total 45

Table 27: Group participants by DHHS Region and age

Age	Region I	Region II	Region III
0-19	0	0	0
20-29	1	1	1
30-39	5	0	5
40-49	9	3	3
50-59	4	5	4
60-69	1	0	2

Total 45

Table 28: Group participants by DHHS Region and sexual orientation

Sexual Orientation	Region I	Region II	Region III
straight	4	2	5
gay	15	6	8
lesbian	0	0	0
bisexual	1	1	1
other	0	0	1
unknown	0	1	0

Total 45

Region I-Cumberland, York

Region II-Androscoggin, Franklin, Oxford, Knox, Lincoln, Sagadahoc, Waldo, Kennebec, Somerset

Region III-Hancock, Washington, Penobscot, Piscataquis, Aroostook

Recruitment of participants:

Ten groups were held in the major urban areas of the state. Two were held in Southern Maine (DHHS Region I), four were held in Central Maine (DHHS Region II), and four were held in Northern Maine (DHHS Region III.) Topics included: how individuals use services, how they perceive barriers to prevention, and how they negotiate risk. AIDS Service Organizations, Maine CDC staff and the Community Planning Groups recruited participants through direct invitation. Information was also posted on <http://www.positiveme.org>, a website for PLWH in Maine. An incentive of \$50 was offered. The aim was to recruit at least three participants per group.

What Group Participants Said:

It is possible to show the group discussion findings in several ways. We can group the data according to **1.** research questions, **2.** group leader questions and **3.** common areas of concern expressed by attendees. All of this information can be found in this report. (See **Appendix B** for lists of questions).

To make the results as clear and useful as possible, we chose to arrange the discussion results section below by using the research questions. Before we started this investigation, the CPG decided it wanted more information in several prevention areas. These areas led us to ask the following **5** questions:

- 1) **What are people with HIV doing to increase their HIV-related risk?**
- 2) **A. How are they lowering their risk?**
B. Does risk reduction have anything to do with how long a person has known he or she has HIV?
- 3) **Do those with HIV know about HIV prevention services that are available especially for them?**
- 4) **What difficulties do people with HIV face in getting risk reduction services?**
- 5) **What responsibility do people with HIV have for not causing others to become infected?**

- 1) **What are people with HIV doing to increase their HIV-related risk?**

Group participants said that people with HIV are sometimes:

- Not using condoms.
- Not using clean needles.
- Allowing drinking/drugging to interfere with prevention practices.
- Lacking the self-esteem and personal empowerment that help people practice prevention.
- Not able to accept the realities of their HIV status.
- Affected by depression and feel that nothing they do matters.

In their own words:

- ❖ Anything that drops your guard—drink, drug...to some seeding parties, when people are not positive specifically go hoping to be with HIV positive people so they can be positive, too.

- ❖ (A)nything that negatively affects self esteem really has an impact on people and how they choose to act out (*risky behavior*) that negative self esteem.
- ❖ (M)y brother died of AIDS in 1986...I just felt that I was immune to it or something. But I never really heard anything about it anywhere, and I notice back here, too, you really don't hear a lot about it.
- ❖ (T)hey use sex as a means of getting drugs, having a home, a next meal, whatever, and if that has to be without the use of condoms, then so be it....
- ❖ I think the idea that if both people are positive that they don't have to use any protection, because they've both already got it, that's a problem, because you can get infected with a different strain.

2) **A. How are they lowering their risk?**

B. Does risk reduction have anything to do with how long a person has known he/she has had HIV?

A. Group participants said that people with HIV are sometimes:

- Practicing safer sex by using condoms and dental dams.
- Practicing safer sex by using harm reduction practices, such as oral sex rather than anal sex.
- Exchanging used needles for clean ones.
- Getting risk reduction information from many sources:
 - Case managers.
 - Other HIV positive people.
 - Health care providers.
 - Medical journals and websites.
 - STD clinics.
 - Internet.
 - Social contacts/groups.
 - Conferences.
 - Support groups.
 - Magazines (POZ).

In their own words:

- ❖ Well, I think that's why I never forget, is because I don't drink at all so I never forget. I don't drink or use drugs, so I never get an opportunity to forget.
- ❖ (I)t works on prevention through empowerment. Helping people to be happy with who they are, to be safe, to not want to be positive, and if you are positive, to protect other people.

- ❖ I do exchange needles, so I know the people I exchange with are being safe, but I'm not sure if the people around them are, because they don't tell me, you know, because it's, well none of my business.
- ❖ (T)here are ways of playing safe without having, you know, penetration of any kind.
- ❖ Long term dating before you go to that (*sex*).
- ❖ I don't have sex with anybody; I haven't had it in years.
- ❖ Well, they gave me a dental dam, so there's a reason for them. Otherwise, they wouldn't have been invented.

B. Group participants said that:

- In some cases, the longer people have known their HIV status, the more likely they will practice risk reduction. They are more aware of the dangers to themselves and others.
- Some people who have had HIV for a long time, get used to the idea and don't think so much about risks as time passes and they are doing well.

In their own words:

- ❖ Because the younger people now who just get it, it seems like they have no worries in the world. But us old folks...we're more worried about what can happen next, what kind of disease I can get next.
- ❖ (W)hen I first started going to a group in Florida I was like the baby, everybody had had it and had known for like years. And now that it's been four years for me I just, it's easier to talk about it.
- ❖ Brief encounters, it's like aah, you know, I could give a rat's ass, you know, but you know, the longer it goes on, like I said, I get worn down. I get worn down....

3) Do those with HIV know about HIV prevention services that are available especially for them?

Group participants said that sometimes they and other people know about services and sometimes they do not. People find out about services and use them because they get information from:

- Case managers.
- Other HIV positive people
- Support groups.
- Internet.
- Health care providers.
- Conferences.

- Social groups.
- Magazines.

In their own words:

- ❖ No, I'm not aware. Make me aware.
- ❖ Well, I've picked up an awful lot of condoms over at the AIDS Network.
- ❖ I think that one thing that is helpful is the needle exchange program. I mean, I don't use it...But I know a lot of people do go in there and get them.
- ❖ Support groups...That group that ____ mentioned, here in Augusta. It isn't specifically for positive people...but it works on prevention through empowerment.
- ❖ I know there are certain areas of the state that have no prevention. I come from Lewiston, where we don't have prevention. But we have case management....
- ❖ (T)he women's retreats and the groups, the focused workshops, there's more information to be had...*(More)* prevention information has come through ... in the more intimate groups.
- ❖ I do get by with a lot of condoms. I do get clean needles.
- ❖ Like we've got, you know, EMAN.
- ❖ We don't need to hear it from the AIDS service organizations, BOH, CDC ...

4) What difficulties do people with HIV face in getting risk reduction services?

Group participants said the following are barriers:

- Geography/rural areas of Maine.
- Lack of transportation.
- Transportation costs.
- Lack of services in certain parts of the State.
- Health care and other providers who do not offer information.
- Political/social influences.
- Personal factors such as:
 - Embarrassment/self consciousness.
 - Denial.
 - Addictions.
 - Disagreements with or dislike of providers.

In their own words:

- ❖ (T)he support group is very, very important to me but I don't come every week because I live sort of far away. If I lived fairly close to here I would come every single week.
- ❖ HIV (has) been around since the '80s and then possibly even before then, late '70s, there are still so many doctors out there who have very little knowledge about HIV and AIDS and what to do when a patient is diagnosed with it, where to send them, or how to treat them.
- ❖ There are just not enough public resources out there.
- ❖ (P)eople up in the County would like easier access to (*condoms and needles*). (T)here's no real place to go and exchange needles up there, and there's no...place where they can go in and get condoms or get a test.
- ❖ They don't have transportation or, and/or they don't want to use—they don't want to spend the gas money....
- ❖ But just the fact that it was in the building where the AIDS service organization was stopped people from coming to the support group.
- ❖ (I)t's yourself that I believe is preventing you from going to these places, because you don't want people to see you walking in, walking out, you don't want to run into anyone.

5) What responsibility do people with HIV have in not causing others to become infected?

Group participants believe that:

- People with HIV are responsible—no matter what.
- People with HIV and their sex partners, whether they are infected or not, are both responsible for preventing HIV and HIV superinfection.
- Everyone should make his/her own decision, even when knowing partner is HIV positive/negative.
- People with HIV are not responsible for protecting others.

In their own words:

- ❖ ... (I)'ve fallen into that trap before where rather than stand, stand by my own principles, I'll give in and say, okay, and wind up having unprotected sex. And I won't feel okay with that, and yet I do it anyway.
- ❖ I used to be the same way until my husband died. ... I can never get over the guilt I feel that my husband is gone, and we don't know his status before he was with me, and he chose to be unprotected and I chose to allow him because he's a big boy, and now he's dead. So now I will not ever take that guilt on myself again.

- ❖ And it's a moral issue...(W)hy would you want to expose someone else to this unnecessarily?
- ❖ Yeah, because if you're not going to have a certain kind of sex with them, you don't need to tell them anything. Why do you have to tell them?
- ❖ I've been positive for a very long time, and initially I had no concern about having unsafe sex. I practiced unsafe sex regularly. But then when I found a relationship that I was concerned about the health of my partner it became a huge issue, and I have never had unsafe sex since that point in time.

F. Discussion

The key finding from this study is perhaps that very few participants reported risk behaviors that are defined as high risk. Most men and women – 82.4% and 91.5%, respectively – reported having 0 or 1 vaginal sex partner in the last year. Most women and about half of the men – 82.6% and 53.7%, respectively – reported having no anal sex partners in the last year. Seven women and 35 men reported having one anal sex partner. Thirty five people said they have ever injected any substances not prescribed by a medical person, and 5 people reported sharing needles within the last year.

If we break this down even further, of the 26 MSM who reported 3 or more anal sex partners in the last year, 8 reported that they use condoms every time, 9 use them most of the time, 5 sometimes and 4 rarely. No MSM with 3 or more anal sex partners reported never using a condom for anal sex.

During the group interviews, people reported high risk behaviors of people living with HIV, but it is difficult to tell whether some of these reports are theoretical or actual.

It became evident during this process that some people had never heard of the concept of HIV prevention for people living with HIV nor of the services that support HIV prevention among HIV positive people. Many people seemed confused with the difference between prevention and care services, or were focused on case services as that appeared to be where their self-identified area of need was.

At least 25% of respondents reported facing challenges such as feeling hopeless, trapped or doomed that could affect a person's abilities to negotiate safer sex and/or injecting. Challenges were also assessed in the area of service access. Personal challenges included denial, embarrassment and dislike of providers. Issues such as Maine's geography, transportation costs or lack of transportation, and a lack of services in certain areas of the State all affect a person's ability to access HIV prevention services.

Recommendations of Participants

Participants had many suggestions for increased or improved programming. While many of them revolved around opportunities for HIV+ people to become more involved in their communities, few of them truly focused on improving or increasing HIV prevention services for people living with HIV. The complete list is included as an illustration to show that HIV+ people have ideas about how they can be more involved in HIV prevention as a whole, but that they are not identifying HIV prevention as a need for themselves. The CPG's suggestions are separated as their responses were different in variety and quality from the other group interviews. The remaining suggestions are grouped by geographic region, using the DHHS region map.

Southern Maine

- More education targeting:
 - Youth
 - Women at home (The speaker seemed to be referring to refugee/immigrant women)
 - Parents, so they will not interfere with public youth education
 - Health care providers, especially doctors.
 - Programming that supports empowerment, such as HIV Stops with Me.
- PSAs

- Both for general population and people living with HIV

Northern Maine

- More education targeting teens and young adults
- Social and entertaining education opportunities for adults
- Continued and/or increased funding for ASOs
- Organized social/dating opportunities for HIV+ people

Central Maine

- One-stop-shopping HIV health, support and education services
- Improved relationships with bureaucracy, i.e. ASOs and “State”
- Reliable case management, support services and education through ASO
- Education targeting
 - Health care providers
 - General public
 - Teens in high schools
 - Educators
 - Needle users
- Prevention programs with incentives
- PSAs advertising services for HIV+ people.
- Improved access to free condoms
- Increased and/or continued funding for ASO.

CPG

- Increase public presence of HIV among HIV+ people.
- Increase accessibility to all services and information.
- Support projects and opportunities that address community building and skills building.
- Develop prevention programming in areas of the state, such as Lewiston, that don't currently have programs.
- Increase outreach to injection drug users in regard to education.
- Develop needle exchange programs in areas where none exist.
- Increase support group services that are peer run and that focus on self-esteem building.
- Increase support groups that focus on prevention education using empowerment principles.
- Increase support activities that address all addictions.
- Develop education efforts for youth.

STRENGTHS AND WEAKNESSES OF RESEARCH

The research methods used in this Needs Assessment are both quantitative (survey) and qualitative (group interviews). (See Glossary, Appendix C for brief definitions of *qualitative* and *quantitative* research.) The most commonly used methods of qualitative research are individual interviews, group interviews, direct observation and written records. Data gathered in these ways can be interpreted and assembled into a document. This useful information can then be used to create or improve programs that affect real people. Qualitative research has a major strength and a major weakness.

Strength:

Qualitative methods can be used by the researcher to study issues or people in *great depth and detail*. It says a *lot* about a *few* issues and people.

Weakness:

It cannot say anything about anyone who was not studied. It cannot be generalized (applied to many other people) as quantitative research can be. It does not represent the views of anyone else.

STRENGTHS AND WEAKNESSES OF GROUP INTERVIEWS**Strengths:**

1. They are comparatively easy to conduct, i.e., quick and inexpensive
2. The researcher has the ability to explore topics and generate ideas and hypotheses. The moderator can probe and follow up on unanticipated issues.
3. The data from group interaction may be more varied and extensive than from an individual interview.
4. Focus groups produce data that has high face validity. Things are as they appear to be. If the data looks believable it probably is and is understandable to the layperson.
5. Sample size can be increased relatively easily if necessary.

Weaknesses:

1. Focus groups are conducted in a somewhat artificial setting in comparison to participant observation.
2. The researcher has less control over data.
3. Would the data mirror that obtained in individual interviews with participants?
4. The data is more difficult to analyze.
5. Groups in the same study can vary enormously.
6. Need carefully trained interviewers.

STRENGTHS AND WEAKNESSES OF MAIL SURVEY**Strengths**

1. Surveys are affordable.
2. The participants are able to work on the surveys when they want.
3. Because the mail survey does not allow for personal contact between the researcher and the respondent, there is little chance for personal bias based on first impressions to alter the responses to the survey.
4. It is possible to reach more people.

Weaknesses

1. One of the biggest drawbacks to written survey, especially as it relates to the mail-in, self-administered method, is the low response rate.
2. Some of those surveyed do not speak English well or at all.
3. They may also be illiterate or have a low reading level.
4. People with conditions that make it hard for them to read, such as dyslexia, visual impairment or old age, may not be able to complete the survey.

CONVENIENCE SAMPLING

Convenience sampling is used when it would otherwise be difficult or impossible to select people in a scientific way. (See Glossary for a definition of *scientific sampling*.) In the case of the CPG Needs Assessment, group interview participants were found through several sources. The only requirement was that they have HIV. They were selected because they were available. This means that the information we get in this way applies only to the person giving it. Other kinds of sampling allow us to apply findings from one group or person to another.

LIMITATIONS OF STUDY

There were people who had a difficult time understanding that this study was asking for *real*, not *theoretical* information. Some seemed to speak as though the questions were asking what people *should* do, not what they were actually doing.

There appeared to be some variation in the definition of “prevention.” For example, one individual tried to interpret medical and dental services as being HIV prevention.

Also, it was clearly very difficult for some to focus on prevention services rather than direct support or medical services. Perhaps because they are HIV+, some individuals are, naturally, more concerned about the availability and quality of direct services, even when they understood the question.

The groups are very small. This limits the value of the information. It is understood that group interviews should have at least 8 people in order to get a variety of opinions and a productive group dynamic.

The survey tool was only created in English, and focus groups were only presented in English. This caused a barrier for people with no or limited English knowledge.

Convenience sampling is probably the most common in group interviewing but is the least desirable. Convenience and cost are important or necessary considerations, but strategic sampling usually produces more useful data. The survey also used convenience sampling.

The data produced by the CPG interview is different in variety and quality from the other group interviews. In extracting the data related to recommendations, there was a quantitative and qualitative difference in suggestions. The CPG commissioned the study. The fact that they participated is not necessarily a conflict of interest, but their data should be separated, as it skews the general data content.

Maine Center for Disease Control Needs Assessment Survey of People Living with HIV and AIDS

INTRODUCTION

*Why fill out **another** survey?*

This survey is important! The info that you give will be used to plan HIV prevention services in Maine. Your answers will help the Maine HIV Community Planning Group and the Maine CDC know what HIV prevention programs best fit your needs.

→ You are making a difference in Maine.

Why survey people already living with HIV about Prevention?

Just because someone is HIV positive doesn't mean that they don't need to help prevent infections. There are other STDs and other strains of HIV. Positive people might also need help disclosing their status or discussing HIV with partners.

→ This survey will help us find out what Maine people need.



For each question, circle or check an answer.



There are no right or wrong answers.

Your answers are completely anonymous. Please do not put your name on this survey.

Thank you in advance for doing this survey.

CIRCLE OR CHECK YOUR ANSWER FOR EACH QUESTION

1. Are you...

Male Female Transgender

2. How old are you? _____

3. Are you: Check all that apply.

African American/Black	<input type="checkbox"/>	Native Hawaiian/ Pacific Islander	<input type="checkbox"/>
Asian	<input type="checkbox"/>	White/Caucasian	<input type="checkbox"/>
Native American/ Alaskan Native	<input type="checkbox"/>	Other _____	<input type="checkbox"/>
Two or more Races	<input type="checkbox"/>		

4. Are you Hispanic/Latino?

Yes No

5. What county do you live in?

Androscoggin	<input type="checkbox"/>	Hancock	<input type="checkbox"/>	Oxford	<input type="checkbox"/>	Somerset	<input type="checkbox"/>
Aroostook	<input type="checkbox"/>	Kennebec	<input type="checkbox"/>	Penobscot	<input type="checkbox"/>	Waldo	<input type="checkbox"/>
Cumberland	<input type="checkbox"/>	Knox	<input type="checkbox"/>	Piscataquis	<input type="checkbox"/>	Washington	<input type="checkbox"/>
Franklin	<input type="checkbox"/>	Lincoln	<input type="checkbox"/>	Sagadahoc	<input type="checkbox"/>	York	<input type="checkbox"/>

6. When did you first test positive for HIV? If you can't remember, estimate.

_____/_____/_____
Month Year

7. How did you find out you were HIV positive?

When you were tested for HIV	<input type="checkbox"/>	As part of a physical exam	<input type="checkbox"/>
When you donated blood	<input type="checkbox"/>	As part of my care while pregnant	<input type="checkbox"/>
When you went to the hospital for something else	<input type="checkbox"/>	Other _____	<input type="checkbox"/>

8. Are you currently taking HIV meds?

Yes No



(Go to #9)

8 a. Which statement best describes your adherence to your med schedule?

I never miss a dose	<input type="checkbox"/>	I miss more than one dose a week	<input type="checkbox"/>
I miss one or two doses a month	<input type="checkbox"/>	I hardly ever take my meds	<input type="checkbox"/>
I miss one dose a week	<input type="checkbox"/>		

CIRCLE OR CHECK YOUR ANSWER FOR EACH QUESTION

9. Do you have an HIV Case manager?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
↓			
9 a. Does your case manager talk with you about safer sex or safer injecting?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
10. Do you currently have a doctor for your HIV needs?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>
↓			
10 a. Does your doctor talk with you about safer sex or safer injecting?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
10 b. When was your last doctor's appointment?	_____ Month and Year		

11. Since the time you were diagnosed with HIV, have you had:

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>		<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
Syphilis				HPV			
Herpes (genital)				Hepatitis A			
Gonorrhea				Hepatitis B			
Chlamydia				Hepatitis C			
Genital Warts				Other (<i>Specify</i>)			

12. Who do you have sex with (anal, vaginal, and/or oral)?

Men Women Both Men and Women

13. Are you currently in a relationship?

Yes



13a.

No



13 b.

	Yes	No	D/K		Yes	No	D/K
Is your partner:				Would you prefer your partner be:			
HIV positive				HIV positive			
HIV negative				HIV negative			
HIV status unknown				HIV status unknown			

*D/K means Don't Know

CIRCLE OR CHECK YOUR ANSWER FOR EACH QUESTION

19. Below are some statements. Do you strongly agree, agree some, disagree some, or strongly disagree with each statement?

	<u>Strongly Agree</u>	<u>Agree Some</u>	<u>Disagree Some</u>	<u>Disagree Strongly</u>
a. It is my responsibility to inform my sexual partner(s) that I am HIV positive.				
b. It is the responsibility of the person I am having sex with to protect themselves from HIV infection.				
c. When I have unprotected sex with another HIV positive person, it presents no health risk for either of us.				
d. Sex is better without using a condom.				
e. When I am "turned on," putting on a condom ruins the moment.				
f. I am not in the habit of using a condom when I have sex.				
g. When I have sex I am usually high on alcohol and/or drugs.				
h. When I am high on drugs I don't think much about transmission of HIV infection to others.				
i. I know when my partner is infected with HIV.				
j. I am embarrassed to suggest using a condom with a partner.				
k. Sex with a condom isn't real sex.				
l. Using a condom will be interpreted by my partner as me being unfaithful.				
m. I want to have kids and condoms are a type of birth control.				
n. The increased risk of not using condoms makes sex more erotic.				
o. My partner insists on having sex without using a condom.				

20. Since you were diagnosed with HIV, what has been a challenge for you?
(Check ALL that apply)

Practicing/maintaining safer sex	<input type="checkbox"/>	Feeling hopeless about intimate relationships	<input type="checkbox"/>
Using clean needles/works	<input type="checkbox"/>	Fear of intimate relationships	<input type="checkbox"/>
Alcohol and/or other drug use	<input type="checkbox"/>	Having no sex drive	<input type="checkbox"/>
Feeling confident that I won't infect others	<input type="checkbox"/>	Feeling unworthy of intimate relationships	<input type="checkbox"/>
Telling sex partners about my HIV status	<input type="checkbox"/>	Feeling that I am dirty or contaminated	<input type="checkbox"/>
Feeling that I am trapped or doomed	<input type="checkbox"/>	Telling my friends/family about my HIV status	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	Other: _____	<input type="checkbox"/>
	<input type="checkbox"/>		<input type="checkbox"/>

CIRCLE OR CHECK YOUR ANSWER FOR EACH QUESTION

21. How often do you do each of the following? (Circle the number that BEST fits your behavior)

	<u>All the time</u>	<u>Some of the time</u>	<u>Occasionally</u>	<u>Never</u>
a. I do not have sex with people who I know are infected with HIV, regardless of condom use.				
b. I tell all my sexual partners my HIV status before I have sex with them.				
c. I tell my HIV status to people I want a relationship with, but not casual sex partners.				
d. I only have sex with people of my own HIV status.				
e. I don't pay much attention to HIV status when deciding to have sex with someone.				
f. I am in control of whether or not I have protected sex.				
g. I have made a commitment to myself to only have safe sex.				
Only Answer These Questions If You Use Or Share Needles				
h. I tell all my drug using partners my HIV status before I share needles with them.				
i. I make the decision about whether or not to share needles.				
j. I don't pay much attention to HIV status when sharing needles with my drug using partners.				

22. Since you learned your HIV status, which of the following have you experienced, **even once?**
(check **ALL** that apply) Please remember that all of your answers are **ANONYMOUS**

- Protected sex (anal, vaginal, oral) with someone who knew I am HIV positive
- Unprotected* sex (anal, vaginal, oral) with someone who knew that I am HIV positive

- Protected sex (anal, vaginal, oral) without disclosing my HIV status
- Unprotected* sex (anal, vaginal, oral) without disclosing my HIV status

- Unprotected* sex (anal, vaginal, oral) with someone whose HIV status I didn't know

- I have avoided sex and/or chose not to have sex.

- Shared needles or works with someone who knew I am HIV positive
- Shared needles or works with someone without disclosing my status

- Shared needles or works with someone whose HIV status I did not know

- I have engaged in other risk activities that could pass on HIV: _____

23. Below is a list of things that can limit people from getting info about HIV or getting HIV prevention services.

Check how big a problem it is for you: a big problem, a moderate problem, a small problem, or no problem at all.

	Big Problem You can't get services or info	<u>Moderate Problem</u> You get limited or delayed services or info	Small Problem You have a small concern or delay in services or info	<u>No Problem</u>
a. The HIV prevention programs I need are not available.				
b. I don't have transportation to get from my home to where the program is.				
c. I don't know what organizations provide the information or programs that I need.				
d. Programs are not available at a time that I can attend.				
e. I can't find programs in a language that I speak.				
f. I don't know where to get information.				
g. I can't go because there is no one to look after my kids.				
h. The people who work at the organization(s) providing programs are not helpful.				
i. The information and programs are too expensive.				
j. The organization providing programs did not answer my questions.				
k. I fear that someone I know will see me when I go get HIV or STD prevention services.				
l. I don't know who to ask for help.				
m. The discrimination I felt from people providing information to me.				
n. My community is too small; everyone knows each other				

24. Do you feel that you...

	<u>Yes</u>	<u>No</u>
Are getting too much info and too many services about HIV prevention		
Have enough info and services about HIV/AIDS		
Need more info and services regarding HIV Prevention		

25. How do you like to get your HIV/AIDS info?

	<u>Like</u>	<u>Don't like</u>
a. Talking with experts in workshops/ group settings		
b. Talking with people like me in peer group sessions		
c. Television, radio, or newspaper		
d. My doctor or medical provider		
e. My Friends		
f. From internet, web, or online sources		
g. Other (specify)		

26. During the past year, how often have you used any of these:

	<u>Not used in last year</u>	<u>Used in the past 6 months</u>	<u>Used less than once a month</u>	<u>Used at least once a month</u>	<u>Used once a week or more</u>
a. Alcohol					
b. Marijuana or hash					
c. Crack/ Cocaine					
d. Heroin					
e. Crystal Meth or Methamphetamines					
f. Speedball					
g. GHB (Gamma Hydroxybutyrate)					
h. Poppers					
i. Ecstasy (X)					
j. Pills not prescribed by my doctor					
k. Other Substances (specify) _____					

27. How likely are you to practice safer sex when you are using?

Not likely

Somewhat likely

Very likely

I do not use
alcohol or drugs

28. Have you ever injected any substances NOT prescribed by a medical person?

Yes

No

28a. How many times have you shared needles with someone in the past year?

Write number of times _____ I don't share needles

28b. Do you know how to clean your works (needles/syringes, cookers)?

Yes

No

THANK YOU!!

You have completed the Maine CDC Needs Assessment Survey for People Living with HIV!

Thank you for your participation in this important project!

Questions for PLWA Focus Group

Risk Behaviors

- What risky behaviors are people with HIV engaging that could transmit HIV?
- How concerned are people with HIV about safer sex and/or safer injecting?
- What is the HIV+ community doing currently to practice safer sex/injecting?

Prevention – Barriers to Prevention and Unmet Need

- What prevention services do people with HIV use most often?
- What prevention services have people wanted or needed and couldn't get? What were the problems in getting those services i.e. distance to travel, unavailable services, cost, etc?

Prevention Services

- What are the top three prevention needs of an HIV+ person?
- Where are people most likely to get info about HIV Prevention?
- What encourages people to attend an HIV prevention program?
- What can doctors, case managers or HIV prevention staff do to help people with HIV tell their sex partners about their HIV status? Practice safer sex/injection?
- What would be the single most important change you would suggest to improve prevention services to people living with HIV?

GLOSSARY

These words are defined as they are used in this needs assessment.

Convenience sample: A group of people who are chosen in a quick, inexpensive “convenient” way to take part in a *study*. This is the kind of sample used in this needs assessment. (See Scientific Sample below.)

Disclosure: Informing sex or needle sharing partners of one’s HIV status.

Face Validity: Whether something seems like it is going to measure what it is supposed to measure

Frequency: The number of times an event *does* occur related to the number of times it *could* occur.

Group Interview: A type of interview with usually 5 to 8 people who come together for a particular purpose. The interviewer asks questions in order to learn participants’ beliefs and knowledge about certain topics.

Harm reduction: A philosophy of public health practice that aims to *lessen* danger rather than *eliminate* it.

Majority: The greater number or part of a whole.

Percentage: A fraction of a whole. For example, 90/100 is 90% or 10/20 is 50%.

Qualitative study: A kind of *study* that uses words to say things about a group of people. This needs assessment uses both *qualitative* and *quantitative* methods.

Quantitative study: A kind of *study* that uses numbers to say things about a group of people. This needs assessment uses both *qualitative* and *quantitative* methods.

Respondent: A person who participates in a *study*.

Risk reduction: The practice of behaviors that lessen the chance of contracting a disease.

Sample: A part of a population that is selected in order to study it and learn something of interest to researchers.

Scientific sample: A group of people who are chosen in a formal, strict way to take part in a *study*.

Study: An effort to investigate something of interest. In this case, the kind of study is a “needs assessment.”

Survey: A gathering of a sample of data or opinions considered to be representative of a whole.

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